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Introduction

25.1 The Australian insurance industry is one of substantial economic importance. Across the full range of products, general insurers collected \$16.5 billion in premiums and paid \$11.4 billion in claims for the year to September 2002.¹ During the same period, life insurers operating in Australia received \$41 billion in premiums and paid \$38.5 billion in claims.² During the 2001–2002 financial year private health insurers collected \$7.2 billion in contribution income and paid over \$6.5 billion in benefits.³

25.2 The purpose of insurance is risk distribution, that is, to spread risk across a large pool of individuals. Insurance provides a mechanism by which individuals who pay an agreed sum, known as a 'premium', can be indemnified against future events that may cause loss. The predictive nature of genetic information means that it is potentially very significant in this context. Insurance companies, especially life insurers, have collected and used family medical histories for well over a century.⁴ More recently, access to information derived from genetic testing has drawn attention

1 Australian Prudential Regulation Authority, *General Insurance Trends September Quarter 2002* (2002), APRA, Sydney.

2 These statistics include life insurance that is provided as a component of superannuation. See Australian Prudential Regulation Authority, *Life Insurance Trends September Quarter 2002* (2002), APRA, Sydney.

3 Private Health Insurance Administration Council, *Industry Performance*, <www.phiac.gov.au/circulars/publications/publications/AR_registered_health/part_a1/index.htm>, 20 February 2003.

4 House of Commons — Select Committee on Science and Technology, *Genetics and Insurance* (2000–1), The Stationery Office Limited, London, 81.

to the potential use of genetic information by the insurance industry in Australia and overseas.⁵

25.3 Concern about the use of human genetic information by the insurance industry was one of the factors that led to the establishment of the present Inquiry. The Terms of Reference expressly require an examination of the use of human genetic information in the insurance sector and ask whether further regulation is necessary to protect the privacy of such information and to prevent inappropriate discriminatory use of the information.

25.4 In response to IP 26⁶ and DP 66⁷, the Inquiry received a large number of submissions that focussed on insurance. The submissions indicated a high level of interest in this area and identified some significant concerns.

25.5 This chapter provides background information about the insurance industry in Australia and about the use of genetic information by the industry. In Chapters 26, 27 and 28 the Inquiry examines the concerns raised in submissions and makes a range of recommendations to address those concerns. The Inquiry is of the view that a shift away from the fundamental principles of voluntary risk-rated insurance, based on parity of information between the applicant and the insurer, is not warranted at the present time. The Inquiry recognises, however, that there are legitimate concerns in the community about the way in which insurers use, or are perceived to use, genetic information. The Inquiry's recommendations are directed toward addressing those concerns by ensuring that the use of genetic information by insurers is fair, transparent, subject to independent oversight, and consistent with anti-discrimination and privacy legislation.

Personal insurance in Australia

25.6 Insurance in Australia is commonly divided into three categories: life, health and general insurance. Life insurance encompasses a variety of products, including policies that provide payment upon death, continuous disability or trauma. Health insurance provides payment for the provision of hospital and ancillary medical and health services. General insurance covers matters not addressed by either life or health

5 A number of national and international inquiries have considered issues arising from the use of genetic information in insurance: A Doble and others, *Genetics in Society 2001* (2001) Institute of Actuaries of Australia; House of Commons — Select Committee on Science and Technology, *Genetics and Insurance* (2000-1), The Stationery Office Limited, London; Human Genetics Commission, *Inside Information: Balancing Interests in the Use of Personal Genetic Data*, Department of Health (UK), <www.hgc.gov.uk/insideinformation/index.htm#report>, 20 February 2003; The Provincial Advisory Committee on New Predictive Genetic Technologies, *Genetic Services in Ontario: Mapping the Future* (2001), Ministry of Health Ontario, Toronto; Human Genetics Advisory Commission, *The Implications of Genetic Testing for Insurance* (1997), Human Genetics Advisory Commission, London; Federal Privacy Commissioner, *The Privacy Implications of Genetic Testing* (1996), OFPC, Sydney; Nuffield Council on Bioethics, *Genetic Screening Ethical Issues* (1993), Nuffield Council on Bioethics, London.

6 Australian Law Reform Commission and Australian Health Ethics Committee, *Protection of Human Genetic Information*, IP 26 (2001), ALRC, Sydney.

7 Australian Law Reform Commission and Australian Health Ethics Committee, *Protection of Human Genetic Information*, DP 66 (2002), ALRC, Sydney.

insurance, such as product liability, travel, professional indemnity, sickness and accident.

25.7 Genetic information is likely to be of greatest significance in relation to insurance policies that rely on the collection and use of health information, require an assessment of an applicant's risk of mortality or morbidity, and are mutually rated.⁸ This Report focuses on these kinds of insurance, which include the following:

- **Term life insurance:** provides for the payment of an agreed lump sum in the event of death of the insured. According to the Investment and Financial Services Association (IFSA), the approximate average level of cover for term life insurance in Australia is \$235,000.⁹
- **Income protection (or disability income) insurance:** provides for regular sums to be paid while an insured is unable to work due to sickness or injury. According to IFSA, the approximate average level of cover for disability income insurance in Australia is \$3,700 per month.¹⁰
- **Trauma (or crisis) insurance:** provides for the payment of an agreed lump sum if the insured person is diagnosed with one of a list of specified conditions such as a heart attack, cancer or stroke within a specified period. The average level of cover for trauma insurance in Australia is \$165,000.¹¹
- **Sickness and accident insurance:** a general insurance product that provides for payment of a lump sum or periodic payments to cover losses or expenses incurred as a result of accidental injury or sickness.
- **Travel insurance:** a general insurance product that provides for the payment of agreed sums to cover losses or expenses incurred in the course of travel, including medical expenses.

25.8 The largest part of personal insurance business in Australia is undertaken by the life insurance industry, either as a component of superannuation or as voluntary mutually rated life insurance. There are currently 42 registered life insurers in Australia, of which six are reinsurance companies.¹² Not all registered life insurers are currently active and several do not operate in the mutually rated market.

25.9 Superannuation funds almost always provide insurance cover for their members against death and disability. Premiums collected for insurance provided as a component of superannuation comprise 87% of total insurance premiums collected by life insurers. Generally, in relation to large superannuation funds, this cover is provided on automatic acceptance terms and is not mutually rated. The only entry requirement is that the person covered be fit enough to attend work on the start date. In its submission to the Inquiry, the Australian Life Underwriters and Claims Association explained:

8 Mutuality is discussed later in this chapter.

9 Investment and Financial Services Association, *Submission G049*, 14 January 2002.

10 Ibid.

11 Ibid. Critical illness insurance does not provide cover for accidental events.

12 Ibid.

In group life insurance, the necessity for underwriting is less strong because of the law of large numbers and the reduced likelihood of adverse selection. With group life insurance, an insurer can take the bad risks, knowing that there will be enough good risks in the entire pool of lives insured to balance the portfolio and allow profitability.¹³

25.10 However, where a person is self-employed, employed by a small business, or wishes to seek a higher level of insurance cover than that offered on automatic acceptance terms, the insurance component of superannuation may be mutually rated. The discussion in Part G of this Report is intended to cover personal, mutually rated insurance products including, for example, those offered as a component of superannuation. Where these products are offered by organisations that are not specifically addressed in this Report (for example, friendly societies or superannuation funds), and are not members of IFSA or the ICA, the recommendations in this Report are intended to set out foundation principles that can be applied to underwriting by those organisations, as appropriate.

Mutually rated and community rated insurance

25.11 It is important to draw a distinction between mutually rated and community rated insurance. Community rating is the basis of Australia's public and private health insurance systems. Under the *National Health Act 1953* (Cth), private health insurance contracts are required to be community rated: in setting premiums, or paying benefits, funds cannot discriminate on the basis of health status, race, sex, sexuality, use of hospital or medical services, or general claiming history. Although this risk is shared collectively across the entire pool of insureds, actuaries and underwriters still collect health information to determine the overall premium that insurers must charge to sustain the pool.¹⁴

25.12 Because insurers in this context are prevented from using health information to assess individual risk, the use of genetic information in relation to health insurance does not raise the same issues as the use of genetic information in relation to other personal insurance products. For this reason, the discussion and recommendations in Part G of this Report focus on those sectors of the insurance industry that offer mutually rated products.

25.13 In mutually rated insurance, the particular characteristics of applicants are taken into account when assessing the risk the applicant will bring to the insurance pool. In its submission, IFSA set out four fundamental principles that underlie the provision of voluntary mutually rated insurance in Australia. These are:

- spreading risks across large groups;
- charging a premium that reflects the risk;

¹³ Australian Life Underwriters and Claims Association Inc, *Submission G300*, 10 January 2003.

¹⁴ For a discussion of the use of genetic information in health insurance, see M Otlowski, *Implications of Genetic Testing for Australian Insurance Law and Practice* (2001) Centre for Law and Genetics, Hobart, 9–13.

- pooling of similar risks; and
- equal access to information.¹⁵

25.14 Characteristics such as an applicant's age and sex will nearly always be considered relevant to assessing risk. Depending on the type of insurance, other factors such as occupation, lifestyle, family medical history, current health condition, and genetic test results may also be relevant. In order to assess fairly the risk that each applicant brings to the pool, insurers require access to all the information known to the applicant that is relevant to the risk. The applicant's duty of disclosure is discussed further below. In mutually rated insurance, insureds with similar risks are treated in a similar way. The price that insureds pay for insurance is thus proportional to the risk they bring to the insurance pool.

Applicant's duty of disclosure

25.15 The contract between the insurer and the applicant for insurance is embodied in an insurance policy. Insurance contracts fall into a special category of contracts that are based on the principle of 'utmost good faith'. One element of this principle is that the applicant has a special duty of disclosure at common law¹⁶ and under legislation.¹⁷ The *Insurance Contracts Act 1984* (Cth) largely replaces the common law on the duty of disclosure in relation to the types of insurance of interest to the Inquiry.

25.16 Section 21 of the *Insurance Contracts Act* requires the applicant to disclose to the insurer all information that is known, or which reasonably ought to be known, to be relevant to the insurer. In practice, disclosure occurs initially when applicants for insurance answer questions posed by insurers in the application form or proposal. The duty may oblige an applicant to give further information to the insurer if the initial answers are insufficient to satisfy the duty. The information disclosed is used for the process of underwriting (or risk rating), in which the insurer assesses whether to accept the insurance application and, if so, on what terms.

25.17 Section 22 of the *Insurance Contracts Act* requires the insurer to inform the applicant clearly and in writing (usually in the insurance brochure and application) about the general nature and effect of the duty of disclosure.

25.18 The general duty of disclosure requires the applicant to disclose relevant information up to, but not beyond, the moment the contract is entered into. This maybe, and usually is, sometime after the application is completed. An insured is required to disclose matters during the course of the contract only if there is a specific provision in the contract to that effect.¹⁸ Because a contract of life insurance is guaranteed renewable, in practice a life insurance application is risk rated only once—before the

15 Investment and Financial Services Association, *Submission G244*, 19 December 2002.

16 *Carter v Boehm* (1766) 3 Burr 1905, 1909 (Mansfield LJ).

17 *Insurance Contracts Act 1984* (Cth) s 21. See also Australian Law Reform Commission, *Review of the Marine Insurance Act 1909*, Report 91 (2001), ALRC, Sydney Ch 10.

18 F Marks and A Balla, *Guidebook to Insurance Law in Australia* (3rd ed, 1998) CCH Australia Limited, Sydney.

contract is entered into. Risk factors, including genetic information, that become known to the insured after the contract has been entered into need not be disclosed. On the other hand, certain insurance policies issued by general insurers, such as sickness and accident policies, must be renewed periodically (usually annually) and there is a duty to disclose relevant information at every renewal.

25.19 Under the *Insurance Contracts Act* an applicant is not required to disclose certain matters such as those that diminish the risk, are of common knowledge, are already known to the insurer, or ought to be known to an insurer in the ordinary course of its business.¹⁹

25.20 The *Insurance Contracts Act* also provides that in some cases the insurer can be held to have waived its right to disclosure from the applicant, for example, where the insurer has not taken steps to investigate obviously incomplete or inaccurate answers provided by the applicant.²⁰

25.21 The insurer may raise non-disclosure as a defence when an insured makes a claim under an insurance policy. In a contract of life insurance, if the insurer can show that the insured failed to disclose relevant information, the insurer may:

- avoid the contract from its inception if the non-disclosure or misrepresentation was made fraudulently;
- avoid the contract within three years if the insurer would not have entered into the contract but for the non-disclosure; or
- vary the contract within three years by substituting the sum insured (including any bonuses) according to a statutory formula.²¹

25.22 For all other personal insurance contracts, if an insurer can establish that the insured failed to disclose relevant information, the insurer may:

- avoid the contract from its inception if the non-disclosure or misrepresentation was made fraudulently; or
- reduce the amount paid to the insured to the amount that would place the insurer in the position it would have been in if there had been no failure to disclose or no misrepresentation.²² This permits the insurer to reduce its liability to zero in appropriate cases.

Insurer's decision

25.23 Insurers classify applicants into four general risk categories—‘standard’, ‘non-standard’, ‘deferred’ or ‘declined’. These categories are described below.

¹⁹ *Insurance Contracts Act 1984* (Cth) s 21(2).

²⁰ *Ibid* s 21(2).

²¹ *Ibid* s 29(4).

²² *Ibid* s 28.

Accepted on standard terms

25.24 'Standard' is the insurance risk benchmark for a policy. Applicants who fall into the standard risk grouping have no particular adverse risk factors that warrant a premium loading.

Accepted on non-standard terms

25.25 This refers to the situation where the application is accepted, but subject to one or more of the following conditions:

- *Premium loading*: the application is accepted but with a higher than standard premium. Premium loadings are imposed as a percentage of the standard premium or as a dollar loading, on a temporary or permanent basis.
- *Exclusion*: the policy includes a term that lists events for which the insurer will not pay. Exclusions may be imposed on a temporary or permanent basis.
- *Restricted period of coverage*: the policy limits the duration of insurance cover, for example, where a person may be at risk for a late-onset disorder.
- *Reduced sum*: the policy reduces the amount that will be paid in the event of a claim.

Deferred

25.26 A deferred decision means that the insurer has declined the insurance proposal at the time of underwriting, but offers the applicant the opportunity to have the application re-rated at a future date. A deferred decision is given where a risk factor is expected to reduce over time, for example, where an applicant is receiving medical treatment for a condition that may stabilise in due course.

Declined

25.27 Insurance is declined when the insurer determines that the risk that the applicant would bring to the pool is too high to accept, at least for a realistically affordable premium. Life insurance is rarely declined but, where it is, it is usually in respect of applicants with serious health impairments or extremely hazardous occupations.

Insurer's duty to provide reasons

25.28 The *Insurance Contracts Act* also regulates the information, notices and reasons that insurers must provide to the applicant in certain circumstances. Upon request, an insurer is required to provide reasons where it:

- does not accept an offer to enter into a contract of insurance;
- cancels a contract of insurance;

- refuses to renew a contract of insurance; or
- offers insurance cover to the applicant on terms that are less advantageous to the applicant than the terms that the insurer would otherwise offer by reason of some special risk relating to the applicant or to the subject matter of the contract.²³

25.29 The redress available to applicants in the event of disagreement about the underwriting decision is limited. An applicant may, in the first instance, make an internal complaint to the insurer concerned. If the matter is not resolved, the applicant may lodge a complaint with a relevant agency, such as the Human Rights and Equal Opportunity Commission. There is currently no independent industry based complaints mechanism in Australia with respect to underwriting. The Financial Industry Complaints Service, which deals with complaints in relation to life insurance, and Insurance Enquiries and Complaints Ltd, which handles complaints about general insurance matters, do not currently have jurisdiction to deal with complaints regarding premiums or underwriting.²⁴ This issue is discussed further in Chapter 27.

Agents and brokers

25.30 The *Financial Services Reform Act 2001* (Cth) (FSRA):

- brings the life, superannuation, general and securities industries under one licensing regime;
- establishes a new disclosure regime for financial products (excluding offers of shares and debentures);
- introduces an amended market regulation regime; and
- imposes standards of conduct for financial service providers dealing with retail clients.

25.31 The FSRA commenced on 11 March 2002, with a two year period for participants in the industry to make the transition from their current regulatory structure to the single licensing and product disclosure regime required under the Act. The Australian Securities and Investment Commission (ASIC) is responsible for the implementation and supervision of the FSRA.²⁵

23 Ibid s 75.

24 Financial Industry Complaints Service, *Rules* (2002), Melbourne, Rule 15; Insurance Enquiries and Complaints Ltd, *The General Insurance Enquiries and Complaints Scheme: Terms of Reference*, <www.iecltd.com.au/index2.html>, 20 February 2003 [4.2].

25 Australian Securities and Investments Commission, *Financial Services Homepage*, ASIC, <www.asic.gov.au/asic/asic_polprac.nsf/byheadline/Financial+Services+home+page?openDocument>, 12 February 2003.

25.32 Insurance agents and brokers act as intermediaries between the insurer and applicant, advising on and selling insurance products on behalf, or independently, of the insurer. Insurance agents and brokers now come within the single licensing framework for all providers of financial services and advice established by the FSRA. Generally, under the FSRA, every person who advises on or sells financial services, including insurance, must:

- hold an Australian Financial Services (AFS) licence; or
- represent an entity that holds an AFS licence.

25.33 Insurance agents and brokers provide advice to applicants on a range of matters, including the type of product needed to cover an identified risk, the choice of insurance policy and the interpretation of questions in the application. They may also assist insurers by providing a report on the applicant to the insurer. When advising applicants, agents and brokers often rely on guidelines, provided by the insurer, about the effect of risk factors on underwriting. As intermediaries between insurers and applicants, agents and brokers may be required to provide advice to applicants on the need to provide, and the implications of, genetic information. The regulation of agents and brokers, including in relation to education and training requirements, is discussed further in Chapter 27.

Actuaries and underwriters

25.34 Actuaries and underwriters act as professional financial advisers to life insurers, including in relation to pricing and policy conditions. Actuaries are also key advisers in general insurance, superannuation and investment.

25.35 As one of their professional roles, actuaries produce ‘standard’ premium rate tables. The rates are based on the best risk statistics available and include loadings for expenses and profit. Informed judgment is required in setting rates as both risk and strategic/competitive factors are involved. The rates set by actuaries for term life insurance are typically a function of age, gender and smoker status. In addition, disability rates are a function of occupational class, for example, ‘white collar’, ‘blue collar’ and so on. The risk characteristics by which premium rate tables vary are called risk classifications. Actuaries rely on various sources of data to determine the pricing appropriate to different risk classifications, including Australian aggregate life insurance industry statistics, a company's own experience, and medical and overseas statistics.

25.36 Underwriters assess individual applications for insurance and provide advice on whether the application should be accepted and, if so, on what terms. The underwriter first confirms the applicant's standard premium rate risk classification, for example, ‘age 25, female, non-smoker, white collar’. An insurance agent may have already quoted a standard rate based on the initial classification. The underwriter then ‘underwrites’ the case by assessing other risk factors. The most important area of assessment for the underwriting process is ‘medical’, that is, current and expected

future state of health. This may include assessment of an applicant's genetic information. The other area is 'non-medical', which includes the risks associated with hazardous occupations, sports and other pastimes.

25.37 Underwriters base their decisions on underwriting manuals, which are usually supplied by reinsurance companies. Underwriters also rely on informed professional judgment and, in some cases, specialist advice from medical officers and reinsurance companies.

25.38 Most Australian insurance companies do not reinsure policies that fall below a certain monetary limit.²⁶ However, above these limits, risk is shared between insurers and reinsurers to guard against large fluctuations when insurers are faced with multiple claims in one area, for example, those caused by a natural disaster.

25.39 The underwriting manuals used by Australian actuaries, underwriters and insurers are developed mainly from those compiled by one of the six large international reinsurance companies operating in Australia—the 'insurers for insurers'. The production and updating of underwriting manuals is a specialist, commercially sensitive and costly task, involving insurance medical specialists, actuaries, underwriters, geneticists and others. Reinsurers play a critical role in formulating basic underwriting manuals because of the large amount of data they obtain through their dealings with many insurance companies globally.²⁷

25.40 While Australian insurance companies do not produce their own underwriting manuals, many may make some adjustments using internal guidelines, and all apply overriding industry codes, such as the IFSA Genetic Testing Policy discussed below.

Genetic information in insurance

25.41 This section examines the use of genetic information in insurance, particularly in relation to the current legal obligations of disclosure and the development of industry policy with respect to the use of genetic test information in underwriting.

Collection of general health information

25.42 An applicant's legal duty of disclosure has an important practical consequence for the underwriting of personal insurance: insurers can and do collect a great deal of information from applicants to determine whether, and on what terms, they will accept the risk. Health information is gathered because research shows that particular characteristics of individuals impact on their likelihood of making a claim in the future.²⁸

26 Investment and Financial Services Association and Institute of Actuaries of Australia, *Consultation*, Sydney, 19 June 2001.

27 J Outreville, *Theory and Practice of Insurance* (1998) Kluwer Academic Publishers, Massachusetts.

28 Investment and Financial Services Association, *Submission G049*, 14 January 2002, 16.

25.43 Insurers collect health information about the applicant from questions posed in the insurance application. Health related questions asked by insurers vary according to the type of policy, but typically they include questions about state of health, physical characteristics, lifestyle, results of medical tests and individual medical history.²⁹

25.44 Further health information may be required in two cases. The first is if the amount of cover sought exceeds the underwriting limit. Insurers generally operate within certain underwriting limits, such as those published by the RGA Reinsurance Company of Australia.³⁰ The underwriting limits take into account a number of variables, including the amount insured, the type of insurance, age, and the additional health information sought (such as an examination by a general practitioner or specialist).

25.45 Second, the applicant may disclose current or past medical conditions that require further investigation through a questionnaire, a report from a current doctor, or a medical examination. Application forms usually include a standard medical authority, which gives the insurer written consent to obtain full particulars of the applicant's medical history, including details of any clinical notes.

Collection of genetic information

25.46 Insurers may also have an interest in using genetic information to underwrite an application for personal insurance. This is because certain kinds of genetic information about an individual, or his or her family, may reveal information about present or future health, which may in turn affect the likelihood of the applicant making a claim under the policy. Insurers may ask applicants to disclose genetic information derived from a genetic test or from family medical history.

Family medical history information

25.47 The IFSA submission noted that:

The use of family medical history is an integral part of the underwriting process. Family medical history has been used for over 100 years within the life insurance industry worldwide ... It is used to identify potential medical risks on the basis of the probability that the insurance applicant may be susceptible to certain risks due to a familial/hereditary link with his or her immediate family.³¹

25.48 Typically, questions about family medical history ask whether immediate family members, that is, parents, brothers and sisters—living or dead—suffered from heart disease, stroke, high blood pressure, diabetes, cancer, or other familial disorders. Family medical history information is used as a means of assessing longevity and the likelihood that an individual will develop a familial or inherited condition in the future.

29 Ibid.

30 RGA Reinsurance Company of Australia, *Medical Underwriting Limits (Life/Crisis/TPD)* (2000).

31 Investment and Financial Services Association, *Submission G244*, 19 December 2002.

25.49 In October 2002, IFSA conducted a survey of its members to determine the significance of family medical history in underwriting. Sixteen insurers and reinsurers participated in the survey. The results of the survey were as follows:

The survey covered 7,949 applications for term life cover, total and permanent disability (TPD) cover, disability insurance, trauma cover or combinations thereof. Family medical history played a part in 558 (7.39%) applications. 349 applications showed a family medical history that was either not significant in the underwriting decision or resulted in a favourable underwriting decision (i.e. accepted at standard rates), when considered with other personal medical information.

The remaining 209 (2.62%) applications had an unfavourable underwriting decision (i.e. resulted in a loading, exclusion, deferral or declinature of insurance), which therefore show that the insured's family history impacts on an extremely small number of underwriting assessments. In 106 of these applications the rating was exclusively attributable to the family medical history, whilst in the remaining 103 applications, the ratings were based on a combination of family medical history and other medical and personal information.³²

Genetic test information

25.50 More recently, the life insurance industry has also been using genetic test information for underwriting where it is disclosed by the applicant. The basis for using genetic test information in underwriting was explained by IFSA in the following terms:

The industry views the use of genetic test results in underwriting as an integral part of the medical information currently used, with the important exception that an insurer will not ask an applicant to undergo a genetic test.

Medical information, including results of medical tests, individual and family medical history, and medical examinations, is used by underwriters to understand an individual's current and likely future health, and thereby to assess their risk of claiming.³³

25.51 In 2001, IFSA initiated a research project to monitor both the volume of genetic tests disclosed in Australian life insurance applications and the progress of these applications through the underwriting process. IFSA commissioned the Institute of Actuaries of Australia to survey, on a six-monthly basis, all life insurance companies that sell term life insurance, total and permanent disability insurance, trauma insurance, disability income insurance, and business expenses insurance in Australia.³⁴

25.52 The number of applications received by Australian life insurers involving genetic test information is currently small. Figure 25-1 shows the genetic disorders for which genetic test results were disclosed during the two year survey period. During the first four reporting periods (ending 31 May 2001, 30 November 2001, 31 May 2002 and 30 November 2002) insurers received a total of 235 applications with a genetic test

³² Ibid.

³³ Investment and Financial Services Association, *Submission G049*, 14 January 2002.

³⁴ The first survey was an exception: the start of the collection period was open-ended to capture as much historical data as possible.

result, of which 211 were assessed. Of these 211 applications, 98 were underwritten on standard terms, 58 were underwritten on non-standard terms, 26 were deferred and 29 were declined. Of the 113 applications that were underwritten adversely—non-standard terms, deferred or declined—the major reason given for the adverse decision was said to be the genetic test result in 27 cases (24% of adverse cases) and some other medical reason in 69 cases (61% of adverse cases).

Figure 25–1 Genetic test results in insurance applications 30 November 2000 to 30 November 2002.

Disease or Disorder Tested For	Number of applications
Hereditary Haemochromatosis	170
Huntington's Disease	22
Breast Cancer	10
Cystic Fibrosis	8
Factor V Leiden	5
Myotonic dystrophy	4
Familial Adenomatous Polyposis	3
Colorectal Cancer	2
Polycystic Kidney Disease	2
Marfans Syndrome	1
Hereditary Non Polyposis Colorectal Cancer	1
Multiple Endocrine Neoplasia	1
Charcot-Marie-Tooth Disease	1
Prothrombin gene mutation	1
Epidermolysis Bullosa	1
Tay Sachs Disease	1
Spinocerebellar ataxia	1
Tuberous Sclerosis Complex	1
Total number of applications	235

Source: Data prepared by the Institute of Actuaries of Australia and provided to the Inquiry by IFSA.

25.53 To place these figures in perspective, according to statistics collected by ASIC, and made available to the Inquiry by IFSA, during the calendar year ended 31 December 2001 approximately 1.23 million new policies were issued by life insurers in Australia (excluding group life products).

Industry policy on the use of genetic information

25.54 Prior to 1995 the life insurance industry in Australia did not have a developed policy with respect to the use of genetic information for underwriting. In the mid 1990s, IFSA's predecessor, the Life Investment and Superannuation Association,

developed a draft policy on genetic testing, which was released to its members for consideration in June 1997.

25.55 In February 1999, IFSA released an agreed draft industry policy, which was lodged with the Australian Consumer and Competition Commission (ACCC). IFSA applied to the ACCC for an authorisation in relation to a number of clauses in the policy which could be construed as anti-competitive.³⁵ This was because the draft policy impeded insurers from competing on the basis of price in so far as it prohibited 'preferred risk underwriting', that is, the practice of discounting premiums to persons who present less than standard risk. In support of its application, IFSA submitted that the primary purpose of the draft policy was to ensure that insurers did not initiate genetic tests. The draft policy had been framed in this way to prevent indirect coercion to undergo a genetic test, and thus to respect an applicant's 'right not to know' about a genetic disorder or predisposition.

25.56 The *Trade Practices Act 1974* (Cth) provides that the ACCC may grant an authorisation if satisfied that any anti-competitive aspect of the arrangements or conduct is outweighed by the public benefits arising from the arrangements or conduct.³⁶ In November 2000 the ACCC granted IFSA a two-year authorisation, noting the establishment of this Inquiry, 'the complex issues involved', and the need to provide a 'breathing space' during which these issues could be debated and government policy developed. The ACCC concluded that:

Ensuring IFSA's members do not require applicants for insurance to undergo genetic testing, and that applicants will not be indirectly influenced into undergoing such tests, is likely to result in benefit to the public. In particular, the Commission considers that there is public benefit in avoiding insurer-initiated coercion to undertake genetic testing.³⁷

25.57 Since the ACCC authorisation, IFSA has further developed the draft policy and formalised it into an industry standard (IFSA Standard 11.00—Genetic Testing Policy). In December 2002, when the initial two-year authorisation expired, the ACCC granted an interim authorisation in relation to the relevant clauses, which will run until the ACCC issues its draft determination for comment. At that time the ACCC will reconsider the interim authorisation.

25.58 The purpose of the IFSA Genetic Testing Policy is to specify standards for handling genetic test results to be adopted by life insurers in the operation of their business.³⁸ There is no equivalent policy in place in relation to the general insurance sector. The IFSA policy does not extend to genetic information obtained from family medical histories. The key elements of the IFSA Genetic Testing Policy are as follows:

35 See *Trade Practices Act 1974* (Cth) s 88(1), concerning arrangements that may have the effect of substantially lessening competition, within the meaning of s 45 of the Act.

36 Ibid ss 90(7), 90(8). While there is some variation in the language of the subsections, the ACCC has adopted the view of the Trade Practices Tribunal that the practical application of the tests is the same: *Re Media Council of Australia* (No. 2) (1987) ATPR 40, 48, 418.

37 Australian Competition and Consumer Commission, *Determination re Applications for Authorisation Lodged by Investment and Financial Services Association (IFSA) in Relation to Clauses 2 and 4 of its Draft Policy on Genetic Testing* (2000), 15.

38 Investment and Financial Services Association, *Submission G049*, 14 January 2002.

- Insurers will not initiate any genetic tests on applicants for insurance.
- Insurers may request that all existing genetic test results be made available to the insurer for the purpose of classifying the risk.
- Insurers will not use genetic tests as the basis of ‘preferred risk underwriting’ (offering individuals insurance at a lower than standard premium rate).
- Members must provide their employees and authorised representatives with sufficient information and training so that they understand the content and meaning of the Standard so far as it relates to their particular jobs and responsibilities.
- Insurers will ensure that results of existing genetic tests are obtained only with the written consent of the tested individual.
- The results of a genetic test will be used only in the assessment of an insurance application in respect of the individual on whom the test was conducted.
- Insurers will ensure that strict standards of confidentiality apply to the handling and storage of the results of genetic tests.
- Insurers will provide reasons for offering modifications or rejections to applicants in relation to either new applications or requests for increases on existing policies.
- Insurers will have a competent and efficient internal dispute resolution system to deal with complaints relating to underwriting decisions involving a genetic test result.³⁹

25.59 The Genetic Testing Policy is an internal industry standard administered by IFSA. Compliance with the policy is the responsibility of each insurance company that is a member of IFSA. Member companies must certify compliance with the policy annually according to the terms of the IFSA Code of Conduct and Code of Ethics.⁴⁰ The Code of Conduct states that, in the event of non-compliance, the IFSA Board may impose a range of disciplinary measures including public or private censure and suspension of, or expulsion from, IFSA membership. However, as IFSA is not a regulator, it has indicated that its monitoring of compliance will be done with a ‘minimum of formality’.⁴¹ The IFSA Genetic Testing Policy is discussed further in Chapters 26, 27 and 28.

39 Investment and Financial Services Association, *IFSA Standard 11.00 ‘Genetic Testing Policy’* (2002), IFSA.

40 Investment & Financial Services Association, *Code of Ethics and Code of Conduct* (2001), Sydney.

41 Investment and Financial Services Association, *Submission G049*, 14 January 2002.

26. Genetic Discrimination in Insurance

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Introduction

26.1 Mutually rated insurance is based on a process of underwriting. As discussed in Chapter 25, this involves differentiating between individuals on the basis of the risk that they would bring to the insurance pool if their application were accepted. The same insurance product may be offered on different terms to different individuals depending on the insurer's assessment of their level of risk. In some cases, insurance may be declined where the insurer determines that the risk the applicant would bring to the pool is too high to accept, at least at commercially plausible premiums.

26.2 The Institute of Actuaries of Australia provided the following example of how this works in practice:

It is well accepted, based on analysis of groups of smokers and non-smokers, that smokers will on average experience heavier mortality than non-smokers. This does not mean that every smoker will die of a smoking related disease. Some will survive to high ages despite the increased mortality risk they have exposed themselves to by smoking. Nevertheless, because their expected or average probability of death is

higher, Australian life insurance companies will almost always charge higher premiums under voluntary life policies for smokers than for non-smokers. It is similar with the predictive nature of medical test results, such as high blood pressure, high cholesterol or a positive test for a genetic disorder. Where the risk is higher in probability terms, then the life insurance company is likely to underwrite a higher than normal rating factor for that risk.¹

26.3 The differentiation between individuals on the basis of their genetic status for the purpose of insurance was a principal factor underlying the establishment of this Inquiry. From one perspective, this process of differentiation constitutes a form of discrimination—it involves treating people differently on account of their genetic status.² However, such discriminatory practices are largely exempt from the provisions of Australian anti-discrimination legislation. The exemptions recognise that differentiating between individuals is fundamental to the market in mutually rated insurance products—at least where the decision making process is based on actuarial and statistical data or is otherwise reasonable.

26.4 A large number of submissions received by the Inquiry expressed a range of concerns about discrimination based on the use of genetic information in insurance. A number of submissions also reported cases of alleged genetic discrimination in insurance, although it was often impossible to assess on the facts provided whether the behaviour complained of amounted to unlawful discrimination. There have been no complaints made to the Human Rights and Equal Opportunity Commission (HREOC) on this issue, although the Inquiry recognises that this may not be an accurate indicator of the extent of the problem.³

26.5 This chapter examines the evidence available and concludes that, at this time, there is insufficient evidence to justify a departure from the fundamental principle underlying the market in voluntary, mutually rated insurance in Australia, namely, equality of information between the applicant and the insurer. However, given developments in other jurisdictions, including the introduction of two-tier systems in some European countries, the Inquiry is of the view that the Human Genetics Commission of Australia (HGCA) should keep this matter under review.

Existing regulatory framework

26.6 The broad framework of privacy and anti-discrimination laws in Australia has been canvassed in Chapters 7 and 9. The exceptions in anti-discrimination legislation in relation to insurance recognise the underlying duty of an applicant, both at common law⁴ and under legislation,⁵ to disclose to the insurer all information that is known, or which reasonably ought to be known, to be relevant to the insurer—

1 Institute of Actuaries of Australia, *Submission G105*, 7 March 2002.

2 M Otlowski, *Implications of Genetic Testing for Australian Insurance Law and Practice* (2001) Centre for Law and Genetics, Hobart, 15.

3 Human Rights and Equal Opportunity Commission, *Complaints of Genetic Discrimination under the Disability Discrimination Act: Case Studies* (2002).

4 *Carter v Boehm* (1766) 3 Burr 1905, 1909 (Mansfield LJ).

5 *Insurance Contracts Act 1984* (Cth) s 21. See also Australian Law Reform Commission, *Review of the Marine Insurance Act 1909*, Report 91 (2001), ALRC, Sydney Ch 10.

including genetic information. This section examines the legislative framework in further detail.⁶

26.7 In addition to legislation, industry standards also play a role in regulating the collection and use of genetic information by the insurance industry. For example, as discussed in Chapter 25, the Investment and Financial Services Association (IFSA) has developed a Genetic Testing Policy to regulate the collection and use of genetic test results (but not family medical history).⁷ Under the policy, applicants must disclose any existing test results, in accordance with their common law and statutory duty of disclosure, and this information can be used in underwriting. However, the policy does impose some constraints. Life insurers cannot require applicants to undergo a genetic test, nor indirectly coerce applicants to take a genetic test by offering ‘preferred risk underwriting’ to those who have favourable genetic status.⁸

Anti-discrimination legislation

26.8 As discussed in Chapter 9, Australia has anti-discrimination legislation at the federal, state and territory levels. Despite differences in detail, all legislation dealing with anti-discrimination embodies the same paradigm for identifying unlawful discrimination. For discrimination to be unlawful, an act or omission must be:

- based on one of the grounds or attributes set out in the legislation, such as sex, race or disability;
- fall within an area of activity set out in the legislation, such as employment or the provision of goods and services;
- result in some harm or less favourable treatment, whether by direct or indirect discrimination; and
- not fall within an exception, exemption or defence.

26.9 At the federal level, the *Sex Discrimination Act 1984* (Cth) (SDA), the *Racial Discrimination Act 1975* (Cth) (RDA) and the *Disability Discrimination Act 1992* (Cth) (DDA) contain provisions relevant to discrimination in insurance. All three Acts make it unlawful to discriminate in the provision of goods and services. Subject to the other requirements identified above, it is generally unlawful to discriminate by refusing to provide a good or service, offering a good or service on altered terms or conditions, or by discriminating in the manner in which the good or service is provided.⁹ ‘Services’ are defined to include insurance services.¹⁰

6 Privacy regulation in the insurance context is discussed in detail in Ch 28.

7 Investment and Financial Services Association, *IFSA Standard 11.00 ‘Genetic Testing Policy’* (2002), IFSA.

8 This element of the policy is the subject of an interim Australian Competition and Consumer Commission (ACCC) authorisation. See Ch 25.

9 *Sex Discrimination Act 1984* (Cth) s 22; *Racial Discrimination Act 1975* (Cth) s 13; *Disability Discrimination Act 1992* (Cth) s 24 which are general provisions applying to the supply of goods and services, including insurance.

10 *Sex Discrimination Act 1984* (Cth) s 4(1); *Racial Discrimination Act 1975* (Cth) s 3(1); *Disability Discrimination Act 1992* (Cth) s 4(1).

26.10 The DDA and SDA both contain exceptions relating to the provision of insurance, which allow insurers to discriminate in certain circumstances.¹¹ Complaints of discrimination on the basis of genetic information in insurance are, however, most likely to be brought under the DDA and this chapter focuses on the provisions of that Act.

26.11 The RDA does not provide an exception for discrimination in insurance based on race. The RDA limits the information that insurers are permitted to use in underwriting applications for insurance, despite the actuarial relevance of the information. For example, insurers may not discriminate between applicants on the basis of race even though the life expectancy of indigenous Australians is known to be markedly lower than for the population at large.

State and territory anti-discrimination legislation

26.12 Each State and Territory in Australia has its own anti-discrimination regime and each Act contains its own insurance exception.¹² The language of the insurance exceptions varies between jurisdictions but most of the provisions contain elements similar to those in s 46 of the DDA.

26.13 There may, however, be problems of overlap or conflict between federal laws, on the one hand, and state and territory laws, on the other. To address this problem, each federal anti-discrimination Act contains a provision expressly indicating that the federal Act is not to be taken to exclude or limit the operation of any state or territory law capable of operating concurrently with the federal Act.¹³ These provisions seek to prevent the paramount operation of federal law over state and territory law by reason of the Constitution.¹⁴ However, in relation to state laws such a provision can only cure one kind of constitutional inconsistency—it cannot cure a direct conflict between the operation of a state law and a federal law.¹⁵

26.14 Following the decision of the High Court in *Australian Mutual Provident v Goulden*,¹⁶ the insurance provisions in state anti-discrimination legislation may be subject to challenge on the basis that they are inconsistent with federal legislation that regulates how life insurers may determine premiums by reference to actuarial advice and prudent insurance practice. In that case the High Court found that the provision

11 *Disability Discrimination Act 1992* (Cth) s 46; *Sex Discrimination Act 1984* (Cth) s 41.

12 *Discrimination Act 1991* (ACT) s 28; *Anti-Discrimination Act 1992* (NT) s 49; *Anti-Discrimination Act 1977* (NSW) s 49Q; *Anti-Discrimination Act 1991* (Qld) ss 74, 75; *Equal Opportunity Act 1984* (SA) s 85; *Anti-discrimination Act 1998* (Tas) s 44; *Equal Opportunity Act 1995* (Vic) s 43; *Equal Opportunity Act 1984* (WA) s 66T.

13 *Sex Discrimination Act 1984* (Cth) s 10; *Racial Discrimination Act 1975* (Cth) s 6A; *Disability Discrimination Act 1992* (Cth) s 13; *Human Rights and Equal Opportunity Commission Act 1986* (Cth) s 4.

14 Section 109 of the *Australian Constitution* provides that where a law of a State is inconsistent with a law of the Commonwealth, the law of the Commonwealth shall prevail to the extent of the inconsistency. Section 122 grants the Commonwealth Parliament a general power to make laws for the government of the Territories.

15 Such provisions can cure only 'cover the field' inconsistency. See *University of Wollongong v Metwally* (1984) 158 CLR 447.

16 *Australian Mutual Provident Society v Goulden* (1986) 160 CLR 330.

prohibiting disability discrimination in the provision of goods and services in the *Anti-Discrimination Act 1977* (NSW) was invalid to the extent that it was inconsistent with the *Life Insurance Act 1945* (Cth).¹⁷ Because of the possibility that state legislation on this issue remains subject to challenge, future complaints of discrimination on the basis of genetic information in insurance are more likely to be brought under the DDA.¹⁸

Disability Discrimination Act

26.15 Section 24 of the DDA provides as follows:

- (1) It is unlawful for a person who, whether for payment or not, provides goods or services, or makes facilities available, to discriminate against another person on the ground of the other person's disability or a disability of any of that other person's associates:
 - (a) by refusing to provide the other person with those goods or services or to make those facilities available to the other person; or
 - (b) in the terms or conditions on which the first-mentioned person provides the other person with those goods or services or makes those facilities available to the other person; or
 - (c) in the manner in which the first-mentioned person provides the other person with those goods or services or makes those facilities available to the other person.
- (2) This section does not render it unlawful to discriminate against a person on the ground of the person's disability if the provision of the goods or services, or making facilities available, would impose unjustifiable hardship on the person who provides the goods or services or makes the facilities available.

26.16 As noted above, the insurance industry operates by making distinctions between risk classifications. To that end, insurers may offer the same insurance product to different individuals on different terms, or may refuse to offer some products to certain individuals. Section 46 of the DDA recognises the nature of mutually rated insurance and provides the following exception:

- (1) This Part does not render it unlawful for a person to discriminate against another person, on the ground of the other person's disability, by refusing to offer the other person:
 - (a) an annuity; or
 - (b) a life insurance policy; or
 - (c) a policy of insurance against accident or any other policy of insurance; or
 - (d) membership of a superannuation or provident fund; or

¹⁷ This Act was repealed and replaced with the *Life Insurance Act 1995* (Cth).

¹⁸ For a detailed discussion of the High Court's decision and its implications see M Otowski, *Implications of Genetic Testing for Australian Insurance Law and Practice* (2001) Centre for Law and Genetics, Hobart, 19–21.

(e) membership of a superannuation or provident scheme;

if:

(f) the discrimination:

(i) is based upon actuarial or statistical data on which it is reasonable for the first-mentioned person to rely; and

(ii) is reasonable having regard to the matter of the data and other relevant factors; or

(g) in a case where no such actuarial or statistical data is available and cannot reasonably be obtained—the discrimination is reasonable having regard to any other relevant factors.

26.17 The same exception applies both to the refusal to offer insurance (s 46(1)) and to the terms or conditions on which it is offered (s 46(2)).

26.18 According to the *Guidelines for Providers of Insurance and Superannuation* issued by HREOC pursuant to the DDA, actuarial or statistical data upon which insurers may reasonably rely include underwriting manuals, local data (for example, census statistics), relevant overseas studies, and relevant domestic and international insurance experience.¹⁹

26.19 Where there are no relevant statistics or actuarial data available, and these cannot reasonably be obtained, insurers are required to show that discrimination is ‘reasonable’ based on other factors. Some genetic disorders are so rare that it might take decades to collect statistically reliable data. HREOC has suggested a number of factors that insurers may seek to rely on, including:

- medical opinion;
- opinions from other professional groups;
- actuarial advice or opinion;
- relevant information about the individual seeking insurance; and
- commercial judgment.²⁰

Evidence of genetic discrimination

26.20 In 2001, Dr Kristine Barlow-Stewart and David Keays published research that identified 48 cases in Australia of alleged discrimination based on genetic information. Most case studies were in the areas of life insurance, income protection insurance and trauma insurance. In these cases, applicants reported their concerns that

19 Human Rights and Equal Opportunity Commission, *Guidelines for Providers of Insurance and Superannuation*, <www.hreoc.gov.au/disability_rights/standards/Insurance/insurance_adv.html>, 19 February 2003.

20 Ibid.

insurers' decisions or actions were inappropriate, based on misinformation or a lack of understanding of genetic information and the nature of genetic disorders.²¹

26.21 The Centre for Law and Genetics noted, however, that:

The Barlow-Stewart and Keays study reported in the *Journal of Law and Medicine* indicates some difficulties in this area, but the limitations of this study, in particular, it being based on unverified consumer accounts, need to be acknowledged. Nevertheless, taken together with anecdotal accounts of clinicians and genetic counsellors, it provides some evidence that there are individuals who are experiencing disadvantage in their dealing with insurance companies as a result of their genetic status.²²

26.22 In its submission, IFSA indicated that the Barlow-Stewart and Keays findings were at odds with the industry's own research, which indicated that life insurers have received no complaints with respect to underwriting decisions involving genetic test results.²³

26.23 David Keays, in his submission to the Inquiry, included an additional three case studies of alleged discrimination in insurance.²⁴ In the first case study the applicant stated that he was refused income protection insurance on the basis of his family medical history of myotonic dystrophy. The insurance company informed him that he would only be considered for insurance if he underwent genetic testing. He did undergo a test, the result was negative and he was able to obtain insurance cover.

26.24 IFSA responded in its submission to the Inquiry that:

This case reported in 1998 could not occur today as members of IFSA are prevented from requiring individuals to undergo genetic testing.²⁵

26.25 The second case study involved an applicant who had undergone a genetic test for Charcot-Marie Tooth disease (CMT) to assist in the diagnosis of a family member. The genetic test showed that he had inherited the genetic mutation that causes CMT. Prior to the genetic test, the applicant had not been diagnosed with CMT because he suffered only very mild symptoms. He was subsequently denied income protection insurance and was told that this was because of his genetic test result.

26.26 In IFSA's view:

The denial of insurance in this case comes within the ambit of the relevant legislative exemptions and therefore is not regarded as unlawful discrimination. If the application was for term life insurance [rather than income protection insurance], then the applicant would be most likely to be accepted at standard rates.²⁶

21 See K Barlow-Stewart and D Keays, 'Genetic Discrimination in Australia' (2001) 8 *Journal of Law and Medicine* 250, 254–256.

22 Centre for Law and Genetics, *Submission G255*, 21 December 2002.

23 Investment and Financial Services Association, *Submission G049*, 14 January 2002.

24 D Keays, *Submission G152*, 14 April 2002.

25 Investment and Financial Services Association, *Submission G244*, 19 December 2002.

26 Ibid.

26.27 The third case study involved an applicant with a family medical history and positive genetic test result for Huntington's disease who was refused life insurance. The applicant had applied for a home loan that was subject to a requirement that she have life insurance. The bank refused her application for a loan, as she did not qualify for life insurance.

26.28 IFSA again commented that the decision appeared to come within the ambit of the relevant legislative exception and did not, therefore, amount to unlawful discrimination.²⁷

26.29 The author of a separate confidential submission to the Inquiry stated that he was denied life insurance, and only provided with disability insurance on unfavourable terms, based on his family medical history of Huntington's disease. The author stated that the insurance companies he approached were provided with a genetic test result indicating that he was not at risk for the disease but refused to take the genetic test result into consideration. The author indicated that this situation had severely affected his ability to obtain loans.²⁸

26.30 The Association of Genetic Support of Australasia briefly referred to two cases of alleged genetic discrimination in its submission to the Inquiry:

There is discrimination occurring in the area of insurance. A family applied for life insurance for their child with Marfan syndrome and was refused. A carrier of Fabry's disease with a specialist report stating normal life expectancy was refused life insurance.²⁹

26.31 These individual case studies and anecdotal accounts, although limited in number, have provided a valuable source of information for the Inquiry about the way in which genetic information is used by insurers. The Inquiry notes that in some of these cases the insurer appears to have acted on the basis of a misunderstanding of the genetic information provided and that some decisions may not have been consistent with anti-discrimination law. In others, however, there appears to have been a lawful decision by the insurer that the risk the applicant would bring to the insurance pool was too high to accept. It is also important to note that some of the examples discussed above pre-dated the adoption of IFSA's Genetic Testing Policy, which is described in Chapter 25 and discussed further below.

26.32 There is still considerable uncertainty about the nature and extent of discrimination in this area and a need for further detailed empirical research. To this end, Associate Professor Margaret Otlowski, Dr Sandra Taylor and Dr Kristine Barlow-Stewart have established the Genetic Discrimination Project Team, funded by the Australian Research Council, and are conducting research into the nature and extent of genetic discrimination in Australia. The project team's work is due to be completed in 2004.

27 Ibid.

28 *Confidential Submission G046CON*, 26 December 2001.

29 Association of Genetic Support of Australasia, *Submission G135*, 19 March 2002.

26.33 Genetic information, whether in the form of genetic test results or family medical history, is currently being used by the insurance industry to assess applications for mutually rated insurance products. The case studies examined by the Inquiry indicate that the use of genetic information in insurance sometimes leaves an applicant with the impression that the underwriting decision was not well informed or fair—even if the insurer's actions are permitted by law. These issues and others raised in submissions are discussed further below.

Issues and problems

26.34 Submissions received by the Inquiry identified a range of issues and problems related to the use of genetic information in underwriting. On the one hand, allowing unlimited use of genetic information in this context gave rise to concerns about the creation of a 'genetic underclass' that would be denied access to insurance and other related benefits. Concern was also expressed about the negative impact that the use of genetic information by insurers may have on individual and public health outcomes. On the other hand, concern was expressed that there was little or no justification for drawing a distinction between genetic and other health information in the voluntary, mutually rated, personal insurance market and that prohibiting the use of genetic information would threaten the viability of that market. Each of these issues is discussed below.

Equitable access to risk rated insurance products

26.35 A number of submissions expressed concern that allowing insurers access to genetic information would limit the availability of insurance based on genetic status, creating a 'genetic underclass'.³⁰ David Keays expressed the view that:

The cascading discrimination that can result from a genetic test has the potential to foster the creation of a genetic underclass. A group of people who already have the misfortune of inheriting genetic mutations, who then suffer discrimination at the hands of insurance companies, which then limits their opportunity and freedom. Furthermore, because genetic characteristics are passed from one generation to the next, so too is the discrimination that accompanies it.³¹

26.36 The Anti-Discrimination Commission of Queensland, however, commented that:

It is acknowledged that the contract of insurance is a private commercial relationship between the insured and an insurer and that insurers should not be expected to provide a social safety net for people.³²

26.37 The IFSA submission made the following observation:

30 See D Keays, *Submission G152*, 14 April 2002; Androgen Insensitivity Syndrome Support Group Australia, *Submission G106*, 26 February 2002; Disability Discrimination Legal Service, *Submission G146*, 28 March 2002.

31 D Keays, *Submission G152*, 14 April 2002.

32 Anti-Discrimination Commission Queensland, *Submission G214*, 2 December 2002.

While insurance is provided by commercial enterprises, there will always be a group of people who cannot be offered insurance. Such a situation currently exists, and is not new with the advent of genetic testing. This occurs because for some individuals the risk of claiming is so high or so difficult to assess, that a reasonable premium either cannot be determined or would be prohibitively high.

The issue of access to insurance for all is an issue of equity and is a matter for government. A socialised insurance system would involve significant cross-subsidies between different groups of policy owners and could risk escalating costs and reductions in participation rates as witnessed in the private health system.³³

26.38 In addition, IFSA expressed the view that the use of genetic test information would not significantly impact on the number of individuals who would be uninsurable:

Various community groups have expressed concern that the use of genetics in underwriting will result in a pool of individuals being unable to secure insurance cover, disadvantaging them financially ...

The introduction of new testing technologies, such as genetic testing, does not in itself impact the underlying health of the population. It does not increase the number of people who are likely to develop severe health conditions in the future, and therefore does not impact the number of people who present such a high risk as to be uninsurable. Therefore, it is not expected to increase the number of people who are declined insurance.³⁴

Impact on individual and public health outcomes

26.39 A number of submissions suggested that the potential for discrimination in insurance deters people from taking health-related genetic tests³⁵—a claim substantiated by the experience of several individuals who made submissions to the Inquiry.³⁶ Health professionals stated that some patients hesitate to consult clinical genetics services due to the fear of negative consequences for insurance.³⁷ As a result, some health professionals counsel patients to seek life insurance prior to undergoing genetic testing.³⁸ Although the Inquiry did not receive submissions from individuals indicating that the fear of genetic discrimination had prevented them from participating in genetic research projects, the Centre for Law and Genetics suggested that this might also be a problem.³⁹

26.40 The Genetic Discrimination Project Team commented:

33 Investment and Financial Services Association, *Submission G049*, 14 January 2002.

34 Ibid.

35 G Suthers, *Submission G026*, 30 November 2001; Human Genetics Society of Australasia, *Submission G050*, 14 January 2002; B Williamson, *Submission G011*, 26 June 2002; Centre for Law and Genetics, *Submission G048*, 14 January 2002; C Roberts, *Submission G072*, 13 January 2002; Cancer Council Victoria Cancer Genetics Advisory Committee, *Submission G195*, 27 November 2002.

36 Melbourne, *Public Meeting*, 22 November 2001; *Confidential Submission G066CON*, 10 January 2002; *Confidential Submission G025CON*, 13 December 2001.

37 J Kirk, *Submission G096*, 30 January 2002; F Macrae, *Submission G069*, 14 January 2002; Familial Cancer Service — Westmead Hospital, *Submission G295*, 6 January 2003.

38 Genetic Support Network of Victoria, *Consultation*, Melbourne, 22 November 2001.

39 Centre for Law and Genetics, *Submission G255*, 21 December 2002.

However, even on the basis of current knowledge, available from existing studies and anecdotal accounts of clinicians and other health care professionals, there are strong indications that genetic discrimination does occur and is certainly *perceived* by many to be a problem. Indeed, the *fear* of discrimination is a significant issue because of the potential impact this may have on people's health care decisions, in particular, whether to undergo genetic testing and also in relation to their willingness to participate in genetic research. These are both areas that will be the subject of inquiry in our study of consumers.⁴⁰

26.41 The Director of the Familial Cancer Service in New South Wales, Associate Professor Judy Kirk, expressed the following concerns based on her experiences in the provision of cancer screening and prevention:

In my experience some people hesitate to even consult and seek advice from such a service for fear that they will have future difficulty with insurance. Insurance companies do ask whether a person has seen a doctor in the last X years, and the consultation at a familial cancer service may be in issue (for themselves and for their family, despite the assurances of the IFSA mandatory standard). Furthermore, it has been reported to me that some insurance companies ask whether one 'intends having' a genetic test. I would also comment that current advice to patients may sometimes infer that they should seek insurance cover before a genetic test is done, and this cannot be of benefit to the system if it becomes a widespread approach.⁴¹

26.42 Margaret Otlowski has noted, however, that:

In this situation, where insurance is secured prior to genetic testing being undertaken, there is no issue in relation to adverse selection on the basis of greater knowledge on the part of the applicant as a result of genetic test information. (As noted above, there may be some relevant family history of genetic disease but this would have to be disclosed in any case in response to specific questions.) In short, it is submitted that there would be no breach of the legal duty of disclosure if insurance is purchased before genetic testing is undertaken, provided any specific questions contained in the policy are answered truthfully.⁴²

26.43 The Human Genetics Society of Australasia (HGSA) submitted that:

It is a relatively common occurrence that we see individuals who decline genetic testing when the potential implications of that test on insurability are raised. These of course are only people who get to the point of seeing a clinical geneticist or genetic counsellor. How many people do not even get to that point because of these concerns is something that we do not, and cannot know. The best way to address this issue is for legislation banning the use of genetic tests in underwriting insurance policies.⁴³

40 Genetic Discrimination Project Team, *Submission G252*, 20 December 2002.

41 J Kirk, *Submission G096*, 30 January 2002.

42 M Otlowski, 'Avoiding genetic discrimination in insurance: An exploration of the legality and ethics of precautionary measures in anticipation of unfavourable test outcomes' (2001) 20 *Monash Bioethics Review* 24, 28.

43 Human Genetics Society of Australasia, *Submission G050*, 14 January 2002.

26.44 In consultations, the Genetic Support Network of Victoria noted that it was aware of at least one incident of a medical practitioner advising a person not to be genetically tested in case they became ineligible for life insurance.⁴⁴

26.45 IFSA expressed a contrary view in its submission, noting that:

IFSA research of consumer perceptions, [found] there was no evidence ... to suggest that people would refuse a genetic test due to fears about adversely affecting their standing with insurers. In fact most people would have any test should that test be recommended by their doctor.⁴⁵

26.46 Members of the Familial Cancer Service at Westmead Hospital, Sydney, commented that patients had difficulty distinguishing between the various types of insurance, including health insurance.⁴⁶ It is possible that the level of concern about potential discrimination in insurance is in part based on the misapprehension that genetic information will impact on access to public or private health insurance.

26.47 The majority of submissions that addressed this issue supported some degree of regulation of genetic test information in insurance to overcome negative consequences for patient health and medical research.

Distinguishing genetic from non-genetic health information

26.48 Although recognising that genetic information has special characteristics, the Inquiry has generally resisted making recommendations in this Report based on the notion of genetic exceptionalism. A number of submissions cautioned against treating genetic test information in an exceptional way in the insurance context.⁴⁷ IFSA submitted that 'treating consumers with access to genetic information differently to the remainder of the insured population would introduce inequities between consumers'. The submission included the following example:

Consumer A—Applies for \$1.0m of life insurance coverage. Due to her age and the amount of cover applied for she is required, as standard practice, to undergo an electro-cardiogram (ECG) which identifies an abnormality. Additional investigations confirm that the applicant has severe coronary artery disease. On the basis of this information the applicant's mortality is classified as being 4 times that of a standard risk.

Consumer B—Applies for \$1.0m of life insurance coverage. This applicant has previously undergone a genetic test which indicates she will develop, with certainty, a specific medical condition which may result in her death within the next 10 years. At present she is asymptomatic. If disclosure of a previous genetic test were excluded from the underwriting process, the applicant would obtain her insurance cover at standard premium rates.

44 Genetic Support Network of Victoria, *Consultation*, Melbourne, 22 November 2001.

45 Investment and Financial Services Association, *Submission G049*, 14 January 2002.

46 Familial Cancer Service — Westmead Hospital, *Consultation*, Sydney, 19 November 2002.

47 Investment and Financial Services Association, *Submission G049*, 14 January 2002; S Raeburn, *Submission G033*, 2 January 2002; G Whittaker, *Submission G085*, 21 January 2002.

Both applicants were asymptomatic at time of applying for insurance cover. Both applicants have a significant likelihood of claiming within the next 10 years. However because one has been diagnosed by ECG and the other by a genetic test their insurance applications are treated completely differently.

The industry believes that this situation is both illogical and inequitable.⁴⁸

26.49 By contrast, the Centre for Law and Genetics submitted that:

Whilst *prima facie*, it may seem inequitable to treat genetic test information differently from other health information, some of which may also be predictive or of a particularly sensitive nature, it is submitted that there are good reasons for differentiating in view of the greater risks associated with this kind of information. Of particular concern is the risk that predictive genetic test information will be misunderstood and misinterpreted, treated as having greater probative value than it deserves, resulting in unfair discrimination against individuals. To single out this form of information as one category of information that insurers should not be entitled to, at least for the time being, would not affect the equitable treatment of all insurance applicants. Although some may perceive it as unfair that genetic conditions are given 'favourable' treatment, in contrast to other health conditions, this can be justified as necessary because of the particular risks presently associated with this category of predictive genetic test information.⁴⁹

Impact on viability of risk rated insurance market

26.50 A number of individuals and organisations expressed concern that prohibiting the use of genetic information in underwriting would give rise to 'adverse selection', which would threaten the viability of the voluntary, mutually rated insurance market.⁵⁰ The Australian Prudential Regulation Authority (APRA) explained the phenomenon of adverse selection as follows:

Genetic information may influence a person's desire to apply for insurance. A person who is aware of their genetic test results indicating that they are at high risk of an early death or disablement might find a life insurance policy an attractive proposition. Conversely, armed with favourable genetic test results, some people might choose not to take out insurance to cover their future risk for developing a particular condition. This is symptomatic of the inherent problem with insurance of adverse selection, where the demand for insurance is largest for individuals who are most likely to have a loss, more generally, or who expect their loss to be larger than average.

The adverse selection problem is especially acute when buyers of insurance can conceal information that the insurer could use to evaluate the likelihood of loss, such as the information available from genetic tests undertaken. In this sense, genetic test information is no different from any other information relevant to an assessment of the insured's health or medical condition. APRA's concern is to ensure that life insurance companies are in a position to assess and accurately price the risks which they underwrite.

48 Investment and Financial Services Association, *Submission G049*, 14 January 2002.

49 Centre for Law and Genetics, *Submission G048*, 14 January 2002.

50 S Raeburn, *Submission G033*, 2 January 2002; Institute of Actuaries of Australia, *Submission G105*, 7 March 2002; Investment and Financial Services Association, *Submission G244*, 19 December 2002; Association of British Insurers, *Submission G053*, 15 January 2002; Australian Prudential Regulation Authority, *Submission G279*, 31 December 2002; Australian Life Underwriters and Claims Association Inc, *Submission G300*, 10 January 2003.

The presence of asymmetric information also raises systemic implications. If more people with knowledge of their higher risk join the risk-sharing pool at too low a price relative to their likelihood of claim, then premiums would rise for all policyholders. This will result in insurance becoming generally less attractive to those who believe themselves to be relatively healthy and therefore less in need of insurance cover. This could lead to a shift in the average risk of people taking out life insurance, causing an upward spiral in premiums and risk across the industry.⁵¹

26.51 IFSA stated that it was

opposed to the placing of restrictions on underwriting such that it undermines the right of access to all information relevant to the underwriting process including human genetic information known to the applicant. The undermining of this fundamental principle could lead to the destabilising of the system and threaten the commercial viability of this form of insurance.⁵²

26.52 However, a number of submissions questioned the severity of the likely impact of denying insurers access to existing genetic information.⁵³ The Centre for Law and Genetics, for example, submitted that:

Although these [adverse selection] arguments have frequently been made of the damaging effect for the industry if insurers are denied access to genetic test information for underwriting purposes, rarely have they been substantiated. There is in fact evidence (largely from the United Kingdom), to suggest that, whilst there are risks to insurers arising from adverse selection in the event that applicants have access to genetic test information that is not available to the insurer, the risks are greatest in respect of large policies. This research indicates that the risks arising from adverse selection in relation to small to average size policies would not be significant and certainly would not undermine the viability of the industry. This points to the desirability of distinguishing between large policies on the one hand, for which some measures to protect against adverse selection may be warranted, and small to average sized policies, in respect of which the industry could reasonably be expected to absorb the risks associated with adverse selection.⁵⁴

26.53 Graham Whittaker, an actuary with expertise in underwriting, suggested that, while the short-term consequences of prohibiting the use of genetic test information may not be significant, it would be important to consider carefully exactly what information was excluded:

In the short term it is unlikely that the viability of the market would be threatened, as the volumes of significant genetic tests are low. However a consequence would be that some individuals would be able to obtain very cheap insurance for a high risk, unfairly, and subsidised by other policyholders. If 'family history' were excluded (which is a type of genetic data) the position would be much more serious.⁵⁵

51 Australian Prudential Regulation Authority, *Submission G279*, 31 December 2002.

52 Investment and Financial Services Association, *Submission G244*, 19 December 2002.

53 Centre for Law and Genetics, *Submission G048*, 14 January 2002; Human Genetics Society of Australasia, *Submission G050*, 14 January 2002; D Keays, *Submission G152*, 14 April 2002; F Richards, *Submission G044*, 14 January 2002; M Otlowski, *Submission G159*, 24 April 2002; Anti-Discrimination Board of NSW, *Submission G157*, 1 May 2002; K Liddell, *Submission G147*, 10 April 2002; Office of the Privacy Commissioner (NSW), *Submission G118*, 18 March 2002; J MacMillan, *Submission G015*, 19 November 2001; *Confidential Submission G066CON*, 10 January 2002.

54 Centre for Law and Genetics, *Submission G048*, 14 January 2002.

55 G Whittaker, *Submission G085*, 21 January 2002.

26.54 A body of expert opinion in other countries suggests that adverse selection is unlikely to be significant in the current climate, at least where genetic test information alone is excluded.⁵⁶ Tony McGleenan, who was commissioned by the Association of British Insurers to conduct research into the impact of genetic information on the insurance industry, notes in his report that:

Actuarial modelling indicates that four factors are crucial in determining whether adverse selection based on genetic information will be damaging to a life insurance company.

- (i) If the results of the genetic test need not be disclosed to the insurer.
- (ii) If the possibility of the condition being present would not have been revealed in any event by other medical information, notably family history.
- (iii) If the additional mortality risk indicated by the genetic test is higher than that in the broad categories already used to classify risk in underwriting.
- (iv) If there is no therapeutic option to improve the healthcare prospects of someone with a positive genetic test.

It must be said that currently, given the costs involved in genetic testing, these diagnostic procedures are usually only performed when clinically indicated for some phenotypic reason other than family history. Therefore, in most cases the condition outlined in (ii) above will not be satisfied. The market for genetic testing for the purposes of satisfying personal curiosity is extremely small and is likely to remain so.⁵⁷

26.55 Angus Macdonald, a United Kingdom actuary, has noted that:

The most striking feature about this, often heated, debate is the almost total absence of numerical estimates of the cost implications. Actuarial modelling is beginning to provide such numerical estimates, in the first instance to the question of the costs of adverse selection if life insurers did not know genetic test results. The answers point to a sharp distinction between dominant single-gene disorders and multifactorial disorders. The former are rare enough that solutions outwith the free market should be sought, and (with some exceptions) the latter probably will not provide clear and reliable estimates of lifetime risk, distinguishable from lifestyle and environmental factors; they might therefore not meet criteria of accuracy and reliability such as those that govern discriminatory pricing in respect of disability.⁵⁸

26.56 In its final report, the United Kingdom Human Genetics Commission (HGC) concluded that

56 P Harper, 'Genetic Testing, Life Insurance, and Adverse Selection' (1997) 352 *Philosophical Transactions of the Royal Society of London (B series)* 1063; A Macdonald, 'Modeling the Impact of Genetics on Insurance' (1999) 3 *North American Actuarial Journal* 83; A MacDonald, 'How Will Improved Forecasts of Individual Lifetimes Affect Underwriting?' (1997) 352 *Philosophical Transactions of the Royal Society of London (B series)* 1067; A Macdonald, *Human Genetics and Insurance Issues*, Genetics and Insurance Research Centre, <www.ma.hw.ac.uk/~angus/papers/aberdeen.pdf>, 18 February 2003; A Macdonald, *Genetics and Insurance: What Have We Learned So Far?* (2002); A MacDonald, 'Genetics and Health Costs: Some Actuarial Models' (2002) 1 *Law, Probability and Risk* 97.

57 T McGleenan, *Insurance and Genetic Information* (2001), Association of British Insurers, London.

58 A MacDonald, 'Genetics and Health Costs: Some Actuarial Models' (2002) 1 *Law, Probability and Risk* 97.

recent [actuarial] modelling has shown that a moratorium that extended to family history (as well as genetic test results) would be likely to have a large impact on insurance premiums and affordable access to ‘essential’ insurance. On the other hand, we have also heard that restricting access to family history information might have only a small impact on insurance premiums in most markets in comparison with the commercial variations that already exist. We do not at present recommend that the insurance moratorium should be extended to the use of family history information.⁵⁹

Options for reform

26.57 The Inquiry received a large number of submissions recommending further regulation of the use of genetic information in underwriting. Suggestions ranged from a complete prohibition on the use of genetic test results and family medical history, to a government subsidised, community rated, universal insurance pool. On the other hand, IFSA, the Insurance Council of Australia, the Institute of Actuaries of Australia and a number of other individuals and organisations did not support a significant change in the collection and use of genetic information for the purposes of underwriting.⁶⁰

26.58 In this section the Inquiry examines the following five options:

- maintaining the status quo;
- prohibiting the use of genetic information in underwriting;
- introducing a two-tier system;
- developing specialised insurance products; and
- cross-subsidising poorer risks through an industry or government scheme.

Maintain the status quo

26.59 A number of submissions expressed the view that there should be no change in Australian law as it relates to the collection and use of genetic test information for underwriting. IFSA noted that the existing system was designed to achieve the following goals:

Ensuring fairness to consumers—namely ensuring the cost of insurance is fair and reasonable relative to an individual’s risk profile, so that lower risk individuals are not required to subsidise higher risk individuals.

Protection of insurer’s financial soundness—ensuring the insurance industry remains viable so that protection is available when it is needed and that, in the event that insurance providers withdraw from the market, individuals interests are protected.

59 Human Genetics Commission, *Inside Information: Balancing Interests in the Use of Personal Genetic Data* (2002), London, 124.

60 Investment and Financial Services Association, *Submission G049*, 14 January 2002; Institute of Actuaries of Australia, *Submission G105*, 7 March 2002; G Whittaker, *Submission G085*, 21 January 2002; S Raeburn, *Submission G033*, 2 January 2002; N Renton, *Submission G038*, 14 January 2002; Insurance Council of Australia, *Submission G010*, 27 June 2001; Australian Life Underwriters and Claims Association Inc, *Submission G300*, 10 January 2003.

Equity between insureds—minimise opportunities for high-risk individuals to adversely select against insurers and be subsidised by low-risk individuals.⁶¹

26.60 IFSA expressed support for the status quo, on the basis that other options would: not be in the best interests of consumers; generate complexity and cost beyond any potential benefits gained; create administrative difficulties; lead to reduction in currently available cover; and create a climate where the viability of the currently available forms of life insurance is placed in doubt.⁶²

Prohibit the use of genetic information

26.61 A general prohibition on the use of genetic test information in insurance received some support in submissions, either on an interim or permanent basis.⁶³ The Centre for Law and Genetics noted that:

One of the key advantages of at least delaying the use of genetic test information for the purposes of insurance underwriting (eg through an industry moratorium) is that it permits time for the scientific and actuarial relevance of genetic tests to be established, thus addressing current concerns about the reliability and relevance of information currently used by the industry for underwriting purposes.⁶⁴

26.62 The Genetic Support Council of Western Australia stated:

The genetic support groups were strongly opposed to the idea that their genetic information could be used by insurance companies for underwriting purposes. The groups felt that insurance companies should not be legally allowed to request or use genetic information. This view stems from the concern that insurance companies may not understand the range of genetic tests available, such that a test for a predisposition to a condition not yet present may be treated in the same manner as a diagnosis of a current debilitating condition.⁶⁵

26.63 The Haemophilia Foundation of Victoria stated:

There was a strong and unanimous feeling that insurance companies should NOT have access to genetic information under ANY circumstance. While it is fair that they know of pre-existing conditions, a predisposition to a condition should not have to be declared, even if tests have been conducted and results known. No one has perfect genes!⁶⁶

61 Investment and Financial Services Association, *Submission G244*, 19 December 2002.

62 Ibid.

63 Queensland Government, *Submission G161*, 16 May 2002; *Confidential Submission G051CON*, 14 January 2002; *Confidential Submission G066CON*, 10 January 2002; C Roberts, *Submission G072*, 13 January 2002; Androgen Insensitivity Syndrome Support Group Australia, *Submission G106*, 26 February 2002; Genetic Support Council WA, *Submission G112*, 13 March 2002; Christian Science Committee on Publication, *Submission G127*, 19 March 2002; *Confidential Submission G133CON*, 17 March 2002; Association of Genetic Support of Australasia, *Submission G135*, 19 March 2002; Haemophilia Foundation Victoria, *Submission G145*, 25 March 2002; Genetic Health Services Victoria, *Submission G211*, 28 November 2002; Australian Medical Association, *Submission G212*, 29 November 2002; Genetic Discrimination Project Team, *Submission G252*, 20 December 2002; Human Genetics Society of Australasia, *Submission G267*, 20 December 2002.

64 Centre for Law and Genetics, *Submission G048*, 14 January 2002.

65 Genetic Support Council WA, *Submission G112*, 13 March 2002.

66 Haemophilia Foundation Victoria, *Submission G145*, 25 March 2002.

26.64 The Genetic Discrimination Project Team summarised as follows:

We agree ... that the dangers associated with insurers' use of predictive genetic information are too great, at least at the present time, to allow the routine use of genetic information in underwriting. We believe that this information should not be used until such time as there is better understanding of its significance, particularly in relation to multi-factorial disorders.⁶⁷

26.65 IFSA did not support a prohibition on the use of genetic information for the following reasons:

The major disadvantage of a complete ban is that it undermines the basic principles of a voluntary, risk-rated insurance system. Such an approach exposes the industry to the risk of adverse selection and potentially destabilises the system. The main advantage of the approach is that it potentially provides greater access to life insurance to those who are aware of an unfavourable genetic test result. However, the industry believes this preferential treatment is inequitable, as other consumers bear the additional cost.⁶⁸

Introduce a two-tier system

26.66 A two-tier system would allow individuals to purchase insurance up to a specified monetary limit without an obligation to disclose genetic information. Once the sum insured exceeded the threshold, full disclosure would be required. Genetic information could be defined to include only genetic test information or extended to include family medical history.

26.67 The two-tier system attracted some support in submissions on the basis that it would go some way to address consumers' concerns by providing access to a basic level of insurance regardless of genetic information. It was also thought to go some way to meet insurers' concerns if the monetary limit was set below the level at which the effects of adverse selection might become apparent.⁶⁹

26.68 The Centre for Law and Genetics recommended that:

A 'ceiling' model along the lines suggested ... is readily applicable to life insurance and could also be adapted to disability and related forms of insurance. Such an approach could be accommodated within existing insurance legislation (*Insurance Contracts Act 1984* (Cth)) as a qualification on the usual disclosure obligations: the alternative, and arguably preferable option, would be for this to be dealt with by way of an industry code or moratorium.⁷⁰

26.69 Some European jurisdictions have adopted various forms of the two-tier system. The type of genetic information protected varies between jurisdictions. In Sweden, the two-tier system applies to the use of genetic test results and family medical history, while in the United Kingdom the system applies only to genetic tests, defined as chromosomal cytogenetic tests and molecular DNA tests.⁷¹

67 Genetic Discrimination Project Team, *Submission G252*, 20 December 2002.

68 Investment and Financial Services Association, *Submission G049*, 14 January 2002.

69 See M Otlowski, *Implications of Genetic Testing for Australian Insurance Law and Practice* (2001) Centre for Law and Genetics, Hobart.

70 Centre for Law and Genetics, *Submission G048*, 14 January 2002.

71 Association of British Insurers, *Submission G053*, 15 January 2002.

26.70 The method of implementation also varies. The United Kingdom insurance industry has opted for a self-imposed industry scheme to run for five years. In Ireland, a Bill that included a moratorium on genetic testing for insurance purposes until 2010 and imposed a two-tier system with respect to the use of family medical history was introduced into Parliament in December 2001 but has now lapsed.⁷²

26.71 The monetary thresholds vary depending on the type of insurance purchased. In the United Kingdom, for example, the limit for term life insurance is set at a higher level than other insurance products (for example, trauma insurance and disability income protection insurance) because these other products are more vulnerable to the effects of adverse selection.⁷³

26.72 The monetary threshold also varies significantly between countries. For example, the threshold for term life policies ranges from €60,000 (approximately AUD \$110,000) in Sweden to £500,000 (approximately AUD \$1.35m) in the United Kingdom. The difference in the threshold appears to reflect differences in the insurance market and the type of genetic information protected under the threshold. In some countries with a two-tier system, the threshold was initially selected by reference to the average cost of housing because life insurance was generally required in order to obtain a mortgage.

26.73 In its submission to the Inquiry, the Association of British Insurers set out the rationale for the five year moratorium and two-tier system adopted by insurers in the United Kingdom:

The purpose of the five year moratorium, as set out in our press release, is to enable there to be a rational and informed discussion about the best way forward for the UK on genetics and insurance in the medium term. It does so by balancing the desire of those faced by genetic disadvantage to be able to access life and health insurance, with the insurance industry's need to protect itself against the highest levels of adverse selection.⁷⁴

26.74 The Inquiry received a number of submissions supporting the adoption of a two-tier approach in Australia.⁷⁵ There are two ways in which a two-tier system could be implemented: through industry codes or standards, or through legislative

72 Disability Bill 2001 (Ireland). See the Irish Parliamentary website: Parliament of Ireland, *Disability Bill 2001*, <www.irlgov.ie/bills28/bills/2001/6801/default.htm>, 18 March 2003.

73 Association of British Insurers, *Submission G053*, 15 January 2002.

74 Ibid.

75 See eg Human Genetics Society of Australasia, *Submission G050*, 14 January 2002; Association of British Insurers, *Submission G053*, 15 January 2002; F Macrae, *Submission G069*, 14 January 2002; Department of Human Services Victoria Genetics Advisory Committee, *Submission G089*, 24 January 2002; F Richards, *Submission G044*, 14 January 2002; New South Wales Health Department, *Submission G092*, 25 January 2002; Office of the Privacy Commissioner (NSW), *Submission G118*, 18 March 2002; Androgen Insensitivity Syndrome Support Group Australia, *Submission G106*, 26 February 2002; Cancer Council Victoria Cancer Genetics Advisory Committee, *Submission G195*, 27 November 2002; N Stott Despoja, *Submission G198*, 27 November 2002; Anti-Discrimination Commission Queensland, *Submission G214*, 2 December 2002; A Dominello and others, *Submission G222*, 3 December 2002; Centre for Genetics Education, *Submission G232*, 18 December 2002; Centre for Law and Genetics, *Submission G255*, 21 December 2002; Australian Huntington's Disease Association (NSW), *Submission G268*, 20 December 2002.

amendment, for example, by altering the applicant's duty of disclosure in the *Insurance Contracts Act 1984* (Cth).

26.75 A number of submissions that addressed this issue favoured implementation through industry codes, coupled with independent government oversight and approval of genetic tests. Submissions noted that industry codes would be an effective strategy in the short-term and would retain sufficient flexibility to develop long-term policy at a time when the number of genetic tests being undertaken is small.⁷⁶

26.76 As discussed in Chapter 25, many superannuation funds provide a certain amount of life insurance to members without requiring the insurance to be fully underwritten. The Anti-Discrimination Commission of Queensland noted that

separate insurance policies have now been replaced by personal insurance benefits attached to superannuation. Presently, most employees (other than those who are self-employed or employed in small businesses) are provided with automatic cover up to an automatic acceptance limit. Where employees require a greater amount of insurance, that extra cover is mutually rated.

In our submission, the system of underwriting presently used for insurance benefits attached to superannuation provides a good example of a working 'two-tier' system of insurance.⁷⁷

26.77 The Queensland Government submitted that, if a two-tier system were recommended, it should apply only to genetic test results, and not family medical history.⁷⁸

26.78 IFSA expressed the view that the introduction of a two-tier system would be impractical in Australia for a number of reasons:

The size of the population in Australia compared to the population overseas where the two-tier system operates is significantly smaller. Thus, the costs of implementing a two tier system in a small voluntary market are not justifiable (given the costs will outweigh any perceived benefits).

The nature of the business sold in the Australian market is more risk focused and therefore the impact on price of any such introduction would be more significant ...

The variable nature of Australian life insurance products compared with those offered in the overseas market, would make it difficult to introduce a common two-tier system (like the overseas models) to apply across diverse and unique products.⁷⁹

26.79 APRA expressed some concern:

Obviously, the potential impact of such a proposal depends on the level of any threshold adopted. However, this has the potential to reintroduce adverse selection problems ... and will lead to cross-subsidisation, in that one group of policyholders

76 Human Genetics Society of Australasia, *Submission G050*, 14 January 2002; Centre for Law and Genetics, *Submission G048*, 14 January 2002; M Otlowski, *Submission G159*, 24 April 2002.

77 Anti-Discrimination Commission Queensland, *Submission G214*, 2 December 2002.

78 Queensland Government, *Submission G161*, 16 May 2002.

79 Investment and Financial Services Association, *Submission G244*, 19 December 2002.

(eg. those who have not undertaken a genetic test) may be subsidising the other group that have undertaken such tests.⁸⁰

Develop specialised insurance products

26.80 A further option raised in submissions is development by the insurance industry of specialised products that cater for the insurance needs of individuals with genetic disorders or predispositions. The Centre for Law and Genetics submitted that:

We believe that there is definitely merit in encouraging insurers, agents and brokers to specialise in designing products and handling coverage for persons with a higher level of risk due to genetic factors. It is important that the legitimate insurance needs of this category of the population are met and that their difficulties are not compounded through insensitive treatment. Development of products with the needs of those at increased risk due to genetic factors in mind and ensuring that those handling coverage for such persons are specialised in the area, would be a way of achieving this objective on terms that are also compatible with the viability of the insurance industry. This strategy could augment the protection provided by a ceiling approach, as recommended above, or possibly be an alternative to it.⁸¹

26.81 The HGSA submitted that:

If the overall decision is that insurers are allowed to use genetic information to underwrite policies, it is vital that they produce products that allow those with a genetic predisposition to disease to avail themselves of insurance, including:

1. Having policies below a certain amount of money for which questions about family history and genetic testing are not asked.
2. Having policies that allow coverage for all eventualities other than the genetic illness for which the person is at risk.
3. Having policies with a time limit may be appropriate in some instances.⁸²

26.82 The New South Wales Branch of the Australian Huntington's Disease Association expressed the concern that:

Although it may be possible to design products for those with positive family histories of genetic conditions or positive genetic test results, the cost could be prohibitive for the average Australian family.⁸³

26.83 IFSA's view was that:

Boutique specialised products require investment of large sums of money to develop and without the market demand to fund potential high risk claims, there is no financial justification for introducing such products.⁸⁴

80 Australian Prudential Regulation Authority, *Submission G279*, 31 December 2002.

81 Centre for Law and Genetics, *Submission G048*, 14 January 2002.

82 Human Genetics Society of Australasia, *Submission G050*, 14 January 2002.

83 Australian Huntington's Disease Association (NSW), *Submission G054*, 14 January 2002.

84 Investment and Financial Services Association, *Submission G244*, 19 December 2002.

26.84 The Institute of Actuaries of Australia submitted that there are a number of alternative products already available to those at higher risk:

Superannuation: The mandatory Superannuation Guarantee Contributions (SGC) provide every employee in Australia with a minimum level of superannuation benefits. These superannuation facilities almost invariably carry a certain amount of life cover. The only entry requirement is that the person covered be fit enough to attend work on the start date. Thus, most people who are fit enough to obtain employment at present have access to some insurance regardless of their predisposition for future health problems. ... Once obtained, superannuation insurance covers can often be maintained even after the employee leaves employment, under continuation cover terms.

Consumer credit insurance: People who buy goods under hire purchase can often obtain insurance to cover the remaining repayment instalments in the event of their prior death. This cover has varying terms from company to company. Sometimes it is offered automatically, without the need to provide evidence of good health.

Credit card offers: Credit card providers, and other organisations including large chains of retail shops, sometimes make offers of simple entry insurance policies. Some of these may have an initial period of accident only cover, say three years, before full cover commences. This prevents a person who may be terminally ill from obtaining cover, while providing insurance to most people, including those who have poor prospects beyond medium term survival.⁸⁵

Cross-subsidise poorer risks

26.85 A final option is the establishment of schemes whereby individuals with poorer risks, who may not otherwise be able to obtain insurance, are subsidised for the purpose of obtaining insurance. Depending on the model chosen, the subsidy might come either from government (with cross-subsidisation from taxpayers) or from the insurance industry (with cross-subsidisation from other insureds).

26.86 A report of the United Kingdom HGC in 2002 noted the development of detailed models for the creation of a re-insurance pool, which would provide insurance to poorer risks through a partnership between insurers and government.⁸⁶

26.87 This sort of scheme operates in the Australian private health insurance industry. As discussed in Chapter 25, private health insurance is community rated:

the premium for an individual is based on the risk for the group (or community) to which the individual belongs, rather than the individual's own risk. Thus private health insurers may not increase premiums for more risky individuals. The highest risk individuals are in general, the oldest individuals. Community rating leads to the problem of adverse selection ... This is mitigated by the operation of a reinsurance

85 Institute of Actuaries of Australia, *Submission G105*, 7 March 2002.

86 Human Genetics Commission, *Inside Information: Balancing Interests in the Use of Personal Genetic Data* (2002), London.

scheme operated by government that requires all insurers to pay into a common pool, and pays out to those insurers with a more risky client profile.⁸⁷

26.88 The reinsurance scheme redistributes the hospital and medical costs of high risk members—those aged over 65 and those with more than 35 days of hospitalisation in any one year—and acts to counter the effects of adverse selection which can follow from community rating:

Funds with a greater proportion of low risk groups (the young) pay contributions to a pool which then distributes the income to funds with a greater proportion of high risk groups (the chronically ill and the aged).⁸⁸

26.89 Another model referred to by the HGC was an industry-funded risk pooling system based on the United Kingdom Motor Insurance Bureau model:

A new “Central Insurance Bureau” (CIB) would underwrite life and health insurance for those who cannot obtain insurance because of an adverse genetic test result. Insurance companies would have to be members of the CIB in order to underwrite life and health insurance in the UK. It would be funded by a levy on all life and health insurance of up to 5% of premiums.⁸⁹

26.90 In its submission, the Institute of Actuaries of Australia noted that:

It would be feasible, at a suitable cost, for the Australian government to provide a base level of life insurance to all Australians, regardless of individual risk factors.⁹⁰

26.91 Although not necessarily supporting such a scheme, the Institute outlined a scheme that could provide a certain level of life insurance for all Australians—a ‘government funded, community, life insurance pool’. One option outlined was a compulsory, universal scheme providing a benefit on death for members between the ages of 18 and 67, covering all Australians of working age.

26.92 The Director of the Queensland Clinical Genetics Service, John MacMillan, submitted that:

In the case of genetic testing and insurance I believe that a basic level of insurance, regulated by the state not the insurers, should be made available to all irrespective of any genetic test result. This would not expose the industry to adverse selection and would spread the risk and cost over the whole population.⁹¹

87 Reform Monitor International, *Thirty percent rebate for private health insurers*, <www.reformmonitor.org/httpd-cache/doc_reports_1-63.html>, 20 February 2003. See also Department of Health and Aged Care, ‘Public and Private — In Partnership for Australia’s Health’ in, *Occasional Papers, Health Financing Services* (1999) Commonwealth of Australia, Canberra, 62.

88 Productivity Commission, *Private Health Insurance*, Commonwealth of Australia, <www.pc.gov.au/ic/inquiry/57privatehealth/finalreport/index.html>, 20 February 2003.

89 Human Genetics Commission, *Inside Information: Balancing Interests in the Use of Personal Genetic Data* (2002), London, 135.

90 Institute of Actuaries of Australia, *Submission G224*, 29 November 2002.

91 J MacMillan, *Submission G015*, 19 November 2001.

26.93 In relation to the idea that government should assume some level of responsibility for providing a basic level of personal insurance cover, the Queensland Government submitted that:

The notion of providing basic cover through government-run programs similar to a national medical/hospital insurance scheme, would require considerable resources and depend on the willingness of society to pay for the premiums through increased taxation. It raises the question of how much compensation and taxation the community would be willing to provide.⁹²

26.94 Dr James Butler, Deputy Director of the National Centre for Epidemiology and Population Health, suggested that

there are important social and ethical issues associated with the use of genetic testing in life insurance (see, for example, Lowden, 1999). However, these issues are better addressed through social policies specifically designed to address those issues rather than regulating the life insurance industry by prohibiting the use of genetic test information. For example, a program of explicit government subsidies to those individuals who face dramatic increases in life insurance premiums as a result of a genetic mutation would provide targeted assistance to those affected. At the same time, this would avoid the adverse selection side-effects of regulations that attempt to avoid such premium increases by prohibiting the use of the information on which they are based.⁹³

Inquiry's views

26.95 The Inquiry recognises the range of genuine concerns raised by the use of genetic information in underwriting mutually rated insurance. However, for the reasons explained below, the Inquiry's view is that a shift away from the fundamental principles of voluntary mutually rated insurance, based on parity of information between the applicant and the insurer, is not warranted at the present time.

26.96 A contract of insurance is a private commercial relationship between an insured and an insurer by which the former agrees to pay a regular premium in exchange for a payout on the occurrence of a defined event. Although insurance can provide insureds and their families with significant financial support in adverse circumstances, private insurers should not be expected to provide a social safety net for Australians regardless of their genetic status—that function is more appropriately performed by the social security system and the public health system.

26.97 Australians do not appear to regard private insurance of the kind presently in question as an essential good. While accurate statistics are not available, it is common knowledge that not all, or even most, adults have voluntary life insurance.⁹⁴ This suggests that most Australians consider life insurance to be an option rather than a necessity. It may also reflect the fact that other investments and financial products, which are not mutually rated by reference to genetic status, are available, including

⁹² Queensland Government, *Submission G161*, 16 May 2002.

⁹³ J Butler, *Submission G299*, 9 January 2003.

⁹⁴ Statistics produced by the Insurance and Superannuation Commission in 1996 suggested that about one-third of Australians had life insurance. However, the reliability of the data has been questioned by IFSA.

group life cover provided as a component of superannuation, to provide individuals with financial security for the future. In addition, Australians generally appear to view such insurance as a personal good rather than a social good. If so, it is difficult to justify the imposition of higher costs on the community at large.

26.98 A departure from a system of equality of information between applicants and insureds raises significant issues of equity. If high-risk individuals can join an insurance pool at standard rates, the increased claims by those individuals must ultimately be borne by others. In the absence of a government subsidy, that cost will be borne by other insureds in the insurance pool in the form of higher premiums. This gives rise to inequities because individuals in the pool do not contribute in accordance with the risk they bring to the pool.⁹⁵

26.99 Although the number of applications for life insurance involving genetic test information is currently quite small, it is important to adopt policies that are sufficiently robust to endure in the longer term. As genetic tests become cheaper and more widely used, and as our knowledge of the genetic basis of common disorders such as asthma, diabetes and depression expands, the relevance of genetic test information is likely to grow. If insurers were denied access to that class of information in underwriting, the disparity in the information known to the applicant and the insurer would grow, enhancing the prospect of adverse selection.

26.100 Giving more favourable underwriting treatment to applicants because of the genetic basis of their disease creates an arbitrary distinction between individuals according to the source of their ill health or disability. It is not clear why a person suffering from a cancer that is not (currently) known to be genetically linked should be treated less favourably than a person suffering from a cancer that is. It is for these reasons that the Inquiry rejects the idea of ‘genetic exceptionalism’—that is, the idea that genetic information is so fundamentally different from, and more powerful than, all other forms of personal health information that it requires different and higher levels of legal protection (see Chapter 3).

26.101 The legal principles upon which personal insurance is currently underwritten do not prevent an individual from obtaining insurance at standard rates merely because of his or her genetic status, so long as that status is unknown to the applicant. The present law targets decision making on the basis of differential information; it does not target decision making on the basis of underlying genetic status as such.

26.102 In light of these considerations, the Inquiry has formed the view that a departure from the fundamental principle underlying the market in voluntary, mutually rated personal insurance in Australia, namely, equality of information between the applicant and the insurer, cannot be justified at this time. The Inquiry notes that many of the concerns raised in submissions relate to the manner in which insurers use, or are

⁹⁵ See comments by L Ralph in Senate Legal and Constitutional Legislation Committee, *Inquiry into the Provisions of the Privacy Amendment (Private Sector) Bill 2000* (2000), The Parliament of Australia, 35. See also R Pokorski quoted in T Lemmens, ‘Selective Justice, Genetic Discrimination, and Insurance: Should We Single Out Genes in Our Laws?’ (2000) 45 *McGill Law Journal* 347, 384.

perceived to use, genetic information in underwriting rather than the underlying duty of disclosure. The Inquiry is of the view that these concerns can be addressed without departing from the existing principle of parity of information between the applicant and the insurer. Chapter 27 includes a range of recommendations (including oversight by the HGCA of genetic tests used in insurance) to ensure that the use of genetic information by insurers is fair and transparent, and that insurers are kept to the terms of the exemption granted to them by anti-discrimination laws.

Adverse impact on health outcomes

26.103 The Inquiry notes the concerns raised in relation to the use of genetic information by insurers and the potential adverse impact on individual or public health outcomes. The Inquiry is of the view that these problems can be addressed in part through better provision of information, for example, by ensuring that individuals are aware that taking a genetic test will not affect their ability to access health insurance but that it might affect their ability to access life insurance products.

26.104 The Inquiry notes that IFSA's Industry Statement on Haemochromatosis and its Genetic Testing Policy include an explanation of the potential impact of test results on access to life insurance products. This information could also be provided through medical practitioners and genetic counsellors. A brochure prepared for genetic counsellors by the Centre for Genetics Education advises pretest patients to consider carefully the implications for insurance of undertaking a genetic test.⁹⁶ Armed with accurate information, individuals will be in a better position to make informed decisions about whether and when to undergo testing and whether and when to take out insurance. In relation to testing for research, potential participants should be informed about the implications of testing and, for example, given the opportunity to participate in the research without being informed of their individual results, as provided by the National Statement on Ethical Conduct in Research Involving Humans.⁹⁷

26.105 As noted above, many of the concerns about the use of genetic information by insurers relate to the way in which insurers use, or are perceived to use, genetic information. The recommendations in Chapter 27—ensuring that genetic information is used for underwriting only when it is reasonable to do so, that applicants may request clear and meaningful reasons for adverse decisions, and that applicants are able to seek effective review of those decisions—should help to allay those concerns.

26.106 The Inquiry also notes that genetic test results are a form of personal health information. Individuals are required to make choices about other forms of medical testing, either for individual health reasons or prior to participating in a research project or other public health initiative. The results of this testing may also have adverse consequences for the individual's ability to access insurance. As noted in Chapter 3, the Inquiry does not generally support approaches based on genetic exceptionalism.

96 Centre for Genetics Education, *Submission G232*, 18 December 2002.

97 National Health and Medical Research Council, *National Statement on Ethical Conduct in Research Involving Humans* (1999), NHMRC, Canberra.

The need for ongoing review

26.107 However, given developments in other jurisdictions, including the introduction of two-tier systems in some European countries, the Inquiry is of the view that the HGCA should keep this matter under review.

26.108 Within the last ten years, many countries have begun to confront the challenges posed by the use of genetic information in underwriting. Different approaches have been taken in different jurisdictions, and some countries have experimented with a number of models within a relatively short period of time. The variety of responses suggests that this shared problem has no universal solution that is likely to commend itself to all. Account must be taken of important differences between insurance markets and between social objectives when comparing jurisdictions.

26.109 The consequences of changing the framework for regulating the use of genetic information in underwriting are likely to take considerable time to manifest themselves. A thorough evaluation of new regulatory structures is thus likely to take some time. In Australia at present, the number of cases in which genetic test information is used to underwrite personal insurance is very small (see Chapter 25). In this environment, much can be gained by monitoring developments in countries that have begun to experiment with alternative approaches.

26.110 To this end, the Inquiry considers that the HGCA should keep under review the experience of the insurance industry in using genetic information in underwriting, both in Australia and overseas, in order make recommendations to government at a later time, if the need arises. The work of the Genetic Discrimination Project Team in providing more detailed information on the nature and extent of genetic discrimination will assist with this process.⁹⁸

26.111 In keeping a watching brief on the experience of the industry, the HGCA should liaise with peak industry bodies, including IFSA and the Insurance Council of Australia, and with industry regulators, including the Australian Competition and Consumer Commission, the Australian Securities and Investments Commission and the Australian Prudential Regulation Authority.

Recommendation 26–1. As a general matter, there should be no departure from the fundamental principle underlying the market in voluntary, mutually rated insurance, namely, equality of information between the applicant and the insurer. However, where the underwriting of insurance involves the use of human genetic information, the insurance process should be subject to the Recommendations in this Report. (See Chapters 27 and 28).

98 Genetic Discrimination Project Team, *Submission G252*, 20 December 2002.

Recommendation 26–2. The Human Genetics Commission of Australia, in consultation with peak industry bodies and regulators, should keep a watching brief on developments in the insurance industry in relation to the use of human genetic information, both in Australia and overseas, with a view to reviewing Australian insurance practices as the need arises.

Testing children and access to insurance

26.112 A further issue raised in public meetings was whether individuals should be obliged to disclose the results of a genetic test conducted on them as a child, as a result of a decision made on their behalf by a parent or guardian, when they seek insurance later in life.⁹⁹ A related issue is whether a parent may be unduly influenced by the potential use of genetic information in insurance when making health related decisions on behalf of a child. This concern was highlighted in the following submission received by the Inquiry:

From a personal point of view, I did not register my son's disability as I didn't want any insurance companies to discriminate against him or in the future any of his children or their children. Even if I wanted to, I would not have a genetic test undertaken on my son due to the same reason—lack of confidentiality and possible future discrimination.¹⁰⁰

26.113 The genetic testing of children, with the exception of DNA parentage testing and testing for law enforcement purposes,¹⁰¹ is not generally regulated by legislation. However, the World Health Organisation,¹⁰¹ the Nuffield Council on Bioethics,¹⁰² the American Society of Human Genetics¹⁰³ and the HGSA¹⁰⁴ have developed guidelines on the genetic testing of children. These guidelines proceed on the basis that predictive testing of minors should be restricted to situations in which the testing provides treatment options that are of direct benefit to the child. Testing for adult onset disease, for which there is no known treatment or preventive strategy, should not be carried out on children. Such testing should be deferred until adulthood, or until individuals are able to appreciate the implications of testing and make informed decisions for themselves.

99 Parramatta Public Meeting, *Consultation*, 13 March 2002.

100 *Confidential Submission G025CON*, 13 December 2001.

101 World Health Organization, *Proposed International Guidelines on Ethical Issues in Medical Genetics and Genetic Services* (1997), WHO, Geneva. This issue is also discussed in National Health and Medical Research Council, *Ethical Aspects of Human Genetic Testing: an Information Paper* (2000), NHMRC, Canberra.

102 Nuffield Council on Bioethics, *Mental disorders and genetics: the ethical context*, <www.nuffieldbioethics.org/publications/pp_0000000004.asp>, 20 February 2003.

103 American Society of Human Genetics and American College of Medical Genetics, *Points to Consider: Ethical, Legal, and Psychosocial Implications of Genetic Testing in Children and Adolescents*, <www.faseb.org/genetics/acmg/pol-13.htm>, 20 February 2003.

104 Human Genetics Society of Australasia, *Predictive Testing in Children and Adolescents*, <www.hgsa.com.au/policy/ptca.html>, 20 February 2003.

26.114 As discussed in Chapter 25, an applicant for insurance is obliged to disclose every matter that is known to be relevant, or which reasonably ought to be known to be relevant, to the insurer. Where an individual is aware that he or she underwent a genetic test as a child, that individual is obliged under the current law to disclose the results for insurance purposes, if relevant to the risk. As a result, while the circumstances in which children undergo predictive genetic testing may be limited in practice, the potential for adverse insurance consequences still exists.

Submissions and consultations

26.115 At a public meeting held in Melbourne, a member of the public explained the choices that parents face when deciding whether to genetically test children for the purpose of clinical management:

I have now submitted my DNA for testing, and it's important from my children's point of view that they know whether they have Marfan Syndrome. If they do then we can treat them early and perhaps prevent a premature death. Who should get the right to that information? My personal view at the moment is that they should not even be told themselves. They're at a young age that they are being genetically tested because they can then answer honestly on a form they have never been genetically tested. If they do say they have Marfan's Syndrome they will be discriminated against quite clearly by companies whose responsibilities are to shareholders and not to the customer.¹⁰⁵

26.116 The Australian Medical Association submitted that:

Individual[s] should be given the option to have their childhood genetic test declared 'null and void' to insurers when that individual reaches the legal age of consent.¹⁰⁶

26.117 Margaret Otłowski has commented that:

In view of the strong terms of the *United Nations Convention on the Rights of the Child*, to which Australia is a party, it is essential that the interests of children are not compromised and that decisions whether to subject a child to genetic testing can freely be made on the basis of medical advice, without fear of later repercussions for the child. Moreover, where genetic testing has been undertaken on a person whilst a minor, (ie at a time that they are not in a position to personally give a full and informed consent to testing), one may question the fairness of requiring that person in later life to disclose to insurers information about the results of those tests. An unqualified obligation to disclose existing genetic test information clearly presents problems for individuals in these circumstances.¹⁰⁷

26.118 However, IFSA was of the view that:

The applicant's knowledge of the test result should be the determining factor for disclosure, rather than the circumstances in which the test was conducted. The question of whether or not, and what genetic tests should be performed on a child,

105 Melbourne, *Public Meeting*, 22 November 2001.

106 Australian Medical Association, *Submission G091*, 29 January 2002.

107 M Otłowski, *Discussion Paper No 1: Implications of the Human Genome Project for Australian Insurance Law and Practice* (1997) Centre for Genetics and the Law, 44.

raises societal and medical issues, which are not appropriately addressed by limiting the utmost good faith principle.¹⁰⁸

26.119 In relation to those tests that have a health benefit for the child, the Human Genetics Society of Australasia stated that:

Such tests may be done for children at risk of an adult-onset condition where there is a direct health benefit to testing in childhood. Testing enables screening strategies to be utilised and so minimise the risk of harm to the individual. It would seem appropriate to disclose the results of such a test when applying for insurance as an adult.¹⁰⁹

Inquiry's views

26.120 The Inquiry is of the view that guidelines, such as those developed by the HGSA,¹¹⁰ provide a valuable ethical framework for the genetic testing of children. Predictive genetic testing should be restricted to situations in which the result is likely to be of direct benefit to the child through medical surveillance or intervention. In particular, the Inquiry agrees that genetic testing for adult onset conditions for which there is no known treatment should be deferred until individuals are capable of making informed decisions for themselves.

26.121 The Inquiry recognises that the obligation to disclose to insurers the results of genetic tests undertaken as a child is a difficult and sensitive issue on which there are differing views. The Inquiry notes, however, that where testing is undertaken in accordance with existing ethical guidelines, the circumstances in which children are tested will be quite limited. In those cases in which testing is conducted, it is likely that there will be other available health information (such as family medical history or a record of clinical treatment), which existing law requires to be disclosed to an insurer, whatever position is taken about the disclosure of a minor's genetic test results.

26.122 The Inquiry supports the principle that, to the greatest extent possible, children should be involved in decision making processes and that both the child and the child's parents or guardians should be counselled on the implications of any proposed genetic test. However, because of their age, children are not always capable of making informed decisions for themselves. In these circumstances parents very often make decisions on behalf of their children, including decisions in relation to health, which have implications for their children in later life.

26.123 As noted above, the Inquiry has generally resisted making recommendations based on genetic exceptionalism. The Inquiry is of the view that providing more favourable treatment to insurance applicants because of the genetic basis of their condition creates an arbitrary distinction between individuals according to the source of their ill-health or disability. Many people undergo medical testing and treatment as children. Where known to the applicant, this information must be disclosed in an

108 Investment and Financial Services Association, *Submission G244*, 19 December 2002.

109 Human Genetics Society of Australasia, *Submission G267*, 20 December 2002.

110 Human Genetics Society of Australasia, *Predictive Testing in Children and Adolescents*, <www.hgsa.com.au/policy/ptca.html>, 20 February 2003.

application for insurance if it is material to the risk insured. In the Inquiry's view there is insufficient justification to draw a distinction between genetic tests undertaken as a child and other medical tests undertaken as a child, particularly where those tests were undertaken for the benefit of the child's health.

26.124 For these reasons, and in conformity with Recommendation 26–1, the Inquiry is of the view that an applicant for insurance should continue to be subject to an obligation to disclose known results of a genetic test undertaken while the applicant was a minor, where those results are material to the risk insured.

27. Improving the Underwriting Process

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Introduction

Gone are the days when applicants had a deferential attitude towards highly respected financial institutions. In these days of openness, transparency and accountability there will be pressure for insurers to develop and to demonstrate the scientific basis for all of their underwriting policies and decisions and to disclose much more to prospective policyholders on how they are viewed by the underwriting process, especially when they are rated up or refused cover.¹

27.1 In Chapter 26 the Inquiry expressed the view that there is currently no demonstrated justification for departing from the fundamental principle underlying the market in voluntary, mutually rated insurance, namely, equality of information between the applicant and the insurer. However, the Inquiry noted that a number of concerns had been raised in submissions about the way in which insurers use, or are perceived to use, genetic information in underwriting.

¹ C Daykin and others, *Genetics and Insurance — Some Social Policy Issues* (2003), Institute of Actuaries and Faculty of Actuaries, UK, 38.

27.2 In response to those concerns, this chapter makes a range of recommendations that are directed toward ensuring that the use of genetic information in insurance is fair and transparent, and that insurers are kept to the terms of the exemption granted to them by anti-discrimination laws. The recommendations are aimed at improving the underwriting process where genetic information is involved, and ensuring that applicants are better informed about the reasons for adverse decisions and the available mechanisms of review. The recommendations also seek to make the review mechanisms more effective.

Scientific reliability and actuarial relevance

27.3 Section 46 of the *Disability Discrimination Act 1992* (Cth) (DDA) provides an exception from the operation of the disability discrimination provisions in relation to insurance. The effect of the exception is to enable insurers to discriminate lawfully where:

- the discrimination is based on actuarial or statistical data and is reasonable, or
- in the absence of actuarial or statistical data, the discrimination is reasonable having regard to any other relevant factors.

27.4 In seeking to rely on genetic information to discriminate between individuals for the purposes of underwriting, insurers must therefore be able to demonstrate either the actuarial or statistical basis of their decisions or the reasonableness of their actions. Where the scientific reliability or actuarial relevance of genetic information is doubtful, its use in underwriting may take insurers outside the scope of the exception and render their discriminatory conduct unlawful.

27.5 Although questions of relevance and reasonableness often arise in relation to genetic information derived from genetic tests, the use of family medical history is also of concern. In its final report, the United Kingdom's Human Genetics Commission recommended that the government continue to monitor the evidence used by the insurance industry to justify its use of family medical history in underwriting.² This chapter also examines the use of family medical history by insurers in Australia and makes recommendations designed to ensure that this use is consistent with anti-discrimination laws.

27.6 In establishing whether it is reasonable for insurers to rely on genetic information in underwriting, two main issues arise—the scientific reliability of the genetic information and its actuarial relevance. The first factor relates to the link between the existence of a genetic mutation and the expression of a particular disorder; the second relates to the link between the expression of disease and increased morbidity or mortality.

2 Human Genetics Commission, *Inside Information: Balancing Interests in the Use of Personal Genetic Data* (2002), London, 124.

27.7 As discussed in Chapters 2 and 3, the existence of a genetic mutation for a disease does not lead inexorably to the development of that disease, except in a number of rare monogenic disorders. Yet, the concern has been expressed that

genetic information is often credited with greater probative value than it deserves, and in many cases it is treated as if it was medical fact rather than mere prediction.³

27.8 For example, a genetic test that indicates a predisposition to a recessive polygenic disorder will not be as scientifically reliable in terms of predicting the occurrence of disease as a genetic test for a dominant monogenic disorder. As Martin Bobrow noted before a House of Commons Select Committee:

[G]enetic tests are very good at distinguishing those who carry a particular gene from those who do not. They are somewhat less accurate at identifying those who will and will not eventually get the disease.⁴

27.9 Moreover, the expression of a genetic disease or disorder may or may not have a bearing on an individual's mortality or morbidity, particularly where the condition may be treated effectively. It is the role of actuaries to determine the actuarial significance of particular genetic information by analysing health data collected from large numbers of individuals. The data enable actuaries to calculate the risk that an applicant with a particular condition will make a claim, if insurance were granted.

27.10 In its submission, the Institute of Actuaries of Australia described the way in which actuarial data is compiled over time whenever a new medical treatment or test is developed.

In the early days statistics will be scanty. The development will be experimental at first. The impact of it on life rating factors will at that stage be based mostly on informed opinion. Only after scientific papers have been published will the development be put into widespread use. With familiarity, the development will be further refined and the results re-evaluated. This will lead to another round of medico-actuarial analysis, this time with a larger pool of statistics to work with. So the new development will work its way through a classic learning curve, with the level of confidence in it steadily growing.

This is the way that life insurers have always assessed new medical information for use in underwriting. IAAust sees no reason why insurers would not follow the same pattern with genetic information.⁵

Genetic test information

27.11 Chapter 25 provided information on the use of genetic test information by Australian life insurers in recent years. As Figure 25–1 indicated, in the two-year period to November 2002, very few applications involving genetic test information

3 M Otowski, *Implications of Genetic Testing for Australian Insurance Law and Practice* (2001) Centre for Law and Genetics, Hobart, 37.

4 House of Commons — Select Committee on Science and Technology, *Genetics and Insurance* (2000–1), The Stationery Office Limited, London, xvi.

5 Institute of Actuaries of Australia, *Submission G105*, 7 March 2002.

were received by life insurers, and those that were received relate to a small range of tests: of the 235 such applications, over 200 involved tests for only five conditions.

Submissions and consultations

27.12 Despite the modest use of genetic test information to date, a large number of submissions expressed unease with the insurance industry's ability to accurately interpret and use genetic test information, both scientifically and actuarially.⁶ Privacy NSW submitted that:

Evidence indicates that the insurance industry generally does not yet have the information which would be needed to make actuarially sound use of genetic test results.⁷

27.13 The Human Genetics Society of Australasia submitted that:

There is inadequate scientific data for interpreting the majority of genetic tests for the purposes of insurance underwriting at this time. The interpretation of data needs to be undertaken by experts in the area, based on published data. It often takes many years following the discovery of a gene to understand the significance of a result, and sometimes even then specific results cannot be interpreted with certainty.⁸

27.14 Fiona Richards submitted that:

I suspect that most insurance companies are not aware of the implications of intermediate range results in [Huntington's disease] testing—this is a complex area which requires highly specialised knowledge. An advisory body would be able to provide this updated information to insurers and assist with interpretation of complex results.⁹

27.15 As discussed in Chapter 26, where the scientific reliability or actuarial relevance of genetic information is uncertain, its use may result in unlawful discrimination. The Centre for Law and Genetics stated in its submission that:

6 F Richards, *Submission G044*, 14 January 2002; Thyroid Australia Ltd, *Submission G045*, 10 January 2002; *Confidential Submission G046CON*, 26 December 2001; Centre for Law and Genetics, *Submission G048*, 14 January 2002; Human Genetics Society of Australasia, *Submission G050*, 14 January 2002; UnitingCare NSW & ACT, *Submission G052*, 14 January 2002; Australian Huntington's Disease Association (NSW), *Submission G054*, 14 January 2002; J Boyle, *Submission G057*, 14 January 2002; D Pawlukowski, *Submission G067*, 15 January 2002; New South Wales Legal Aid Commission, *Submission G087*, 21 January 2002; New South Wales Health Department, *Submission G092*, 25 January 2002; New South Wales Genetics Service Advisory Committee, *Submission G094*, 25 January 2002; National Council of Women Australia, *Submission G095*, 31 January 2002; Androgen Insensitivity Syndrome Support Group Australia, *Submission G106*, 26 February 2002; Genetic Support Council WA, *Submission G112*, 13 March 2002; Neurofibromatosis Association of Australia Inc, *Submission G121*, 18 March 2002; K Liddell, *Submission G147*, 10 April 2002; Commonwealth Department of Health and Ageing, *Submission G150*, 15 April 2002; D Keays, *Submission G152*, 14 April 2002; Anti-Discrimination Board of NSW, *Submission G157*, 1 May 2002; M Otowski, *Submission G159*, 24 April 2002; Queensland Government, *Submission G161*, 16 May 2002.

7 Office of the Privacy Commissioner (NSW), *Submission G118*, 18 March 2002.

8 Human Genetics Society of Australasia, *Submission G050*, 14 January 2002.

9 F Richards, *Submission G044*, 14 January 2002.

In many cases, insurers would probably be able to justify their decisions to load premiums or decline cover on the basis of actuarial or statistical data. But given the broad range of genetic conditions and the increasing number of genetic tests that are available, serious concerns are being raised about the reliability of the actuarial data that is currently being used by insurers to make their underwriting decisions, raising doubts about the lawfulness of their decision-making. Indeed, many have argued that there is presently insufficiently reliable actuarial, statistical or other data available to allow use of genetic test information for underwriting purposes.¹⁰

27.16 In its submission to the Inquiry, however, the Investment and Financial Services Association (IFSA) expressed the view that

the insurance industry's current use of genetic information in underwriting has sufficient actuarial and statistical basis ...

In examining the impact of genetic test results on the level of risk, underwriters generally rely on existing statistical data and research drawn from previous experience; medical research and expert actuarial advice; and in particular underwriting guidelines and ratings manuals of international reinsurance companies. Extensive actuarial and statistical analysis of data over many years is used to formulate such risk ratings and guidelines. The review and modification of these ratings and guidelines is an ongoing process applying actuarial and statistical analysis to the latest published medical research.¹¹

27.17 IFSA drew attention to its industry statement on haemochromatosis as an example of the industry's approach to genetic test results. Of the 235 applications involving a genetic test result received by life insurers in the two-year period to November 2002, 170 involved a test result for haemochromatosis, a life threatening but treatable genetic condition. Working with the Murdoch Childrens Research Institute's HaemScreen program, IFSA has developed an industry statement that makes clear that, for the vast majority of people tested in the HaemScreen program there will be no impact on their life, disability or trauma insurance. For the one in 200 individuals found by HaemScreen to be at high risk of developing haemochromatosis, there will be no impact on their application for life insurance as long as there is no evidence of medical problems caused by the condition.¹²

Independent oversight of genetic tests

27.18 In response to concerns raised in submissions, in DP 66 the Inquiry proposed that the Human Genetics Commission of Australia (HGCA) provide independent oversight of the use of predictive genetic tests in insurance. The majority of submissions that considered this issue expressed support for the proposal,¹³ although

10 Centre for Law and Genetics, *Submission G048*, 14 January 2002.

11 Investment and Financial Services Association, *Submission G244*, 19 December 2002.

12 Investment and Financial Services Association, *Gene Testing for Haemochromatosis: Will it Impact on Your Insurance?* (2001), Sydney.

13 Haemophilia Foundation Victoria, *Submission G201*, 25 November 2002; A Dominello and others, *Submission G222*, 3 December 2002; Institute of Actuaries of Australia, *Submission G224*, 29 November 2002; Centre for Genetics Education, *Submission G232*, 18 December 2002; Genetic Support Council WA, *Submission G243*, 19 December 2002; Human Genetics Society of Australasia, *Submission G267*, 20 December 2002; Department of Health Western Australia, *Submission G271*, 23 December 2002;

some submissions expressed support for HGCA oversight only in the context of a two-tier system.¹⁴

27.19 The Anti-Discrimination Board of NSW expressed a common view in the following passage from its submission:

Without an adequate independent mechanism for evaluating the scientific reliability and actuarial relevance of genetic information, an onerous burden will fall to individuals to lodge complaints under anti-discrimination legislation in order to test the actuarial relevance of the genetic information upon which the insurers seek to rely and the accuracy of the interpretation of that information in the underwriting process. To allow the scientific reliability and actuarial relevance of predictive genetic test information to be determined on a case by case basis is totally inadequate to address the complexities of determining the use of genetic information when applied to risk rating for insurance purposes.¹⁵

27.20 The Centre for Law and Genetics expressed the view that:

The prospects of ensuring that accurate and reliable information is uniformly available to agents and brokers would be greatly enhanced if this responsibility was shared between the insurance industry and government, through the work of an expert committee established for the specific purpose of evaluating the scientific and actuarial relevance of genetic tests proposed for use by the insurance industry in setting insurance premiums, along the lines of the *Genetics and Insurance Committee* (GAIC) established in the United Kingdom.¹⁶

27.21 The Anti-Discrimination Commission of Queensland commented that it would be important to ensure that the process was open and transparent with adequate opportunities for stakeholders to make submissions. The Commission was of the view that this would improve public confidence in the use of genetic test information by insurers and that underwriting decisions would be more likely to be consistent with anti-discrimination legislation.¹⁷

27.22 The Australian Life Underwriters and Claims Association, on the other hand, did not support the proposal. The Association expressed the view that where a genetic test is reliable enough to be used by the medical establishment it should be available for use by insurers. In addition, the Association was concerned that an independent approval process might result in unacceptable delays in the availability of tests to underwriters.¹⁸

Australian Prudential Regulation Authority, *Submission G279*, 31 December 2002; Androgen Insensitivity Syndrome Support Group Australia, *Submission G290*, 5 January 2003; Acting Disability Discrimination Commissioner — Human Rights and Equal Opportunity Commission, *Submission G301*, 16 January 2003.

14 Anti-Discrimination Commission Queensland, *Submission G214*, 2 December 2002; Centre for Law and Genetics, *Submission G255*, 21 December 2002. On two-tier systems, see Ch 26.

15 Anti-Discrimination Board of NSW, *Submission G157*, 1 May 2002.

16 Centre for Law and Genetics, *Submission G048*, 14 January 2002.

17 Anti-Discrimination Commission Queensland, *Submission G214*, 2 December 2002.

18 Australian Life Underwriters and Claims Association Inc, *Submission G300*, 10 January 2003.

27.23 While IFSA was of the view that the insurance industry's current use of genetic test information in underwriting has sufficient actuarial and statistical basis, it was not opposed to involvement of the HGCA. IFSA suggested:

In the case of new genetic tests being developed, IFSA would support the proposed HGCA's role in reviewing and approving tests as being suitable for medical diagnostic, therapeutic or predictive purposes in Australia on the understanding that they can then also be used for underwriting. IFSA believes the authorisation of tests for use in underwriting should stand or fall with the authorisation of tests for use in medical practice in Australia for therapeutic, diagnostic or predictive purposes.¹⁹

27.24 In addition, IFSA made clear that:

IFSA opposes any prohibition on the use of existing predictive genetic test results in underwriting pending specific approval by the proposed HGCA. The industry believes that the inability to continue to use results of *existing* genetic tests—which have been already approved for medical therapeutic, diagnostic or predictive purposes—in underwriting would be inconsistent with the principles of a commercially based mutually rated insurance system. It would effectively create a moratorium on the use of genetic test results by the insurer and, by preventing consideration of relevant genetic test information in assessing an individual's risk, would expose the industry to the risk of adverse selection by those asymptomatic individuals aware of their positive test results who, but for the moratorium, would otherwise be unable to obtain cover at standard rates and inevitably destabilise the system.²⁰

27.25 The Institute of Actuaries of Australia noted that there was likely to be a delay in establishing the HGCA and that there would be a need for transitional arrangements so as not to undermine existing insurance practices. The Institute was of the view that the review process to be adopted should be developed by the HGCA once it was established. There would be a need for two processes, one in relation to genetic tests already in use by insurers and one for new genetic tests. The Institute also emphasised that membership of the HGCA would need to include relevant insurance experts.²¹

27.26 The Centre for Law and Genetics made the following suggestion:

The wording of Proposal 24–3 calls for clarification in relation to the use of negative genetic test results: ie genetic tests which indicate that the person is *not* at risk of the particular genetic disease or disorder tested for. Strictly construed, this Proposal would preclude insurers from having regard to the results of any predictive genetic tests: these would first need to be approved by the HGCA for use by insurers. We believe a distinction needs to be drawn between positive and negative genetic test results. Whilst there is clearly a need to regulate insurers' use of positive genetic test results for the protection of individuals at genetic risk, it would seem that a restriction on the use of negative results of predictive genetic tests would work against the interests of the individuals affected.²²

19 Investment and Financial Services Association, *Submission G244*, 19 December 2002.

20 Ibid.

21 Institute of Actuaries of Australia, *Submission G224*, 29 November 2002. On proposed membership of the HGCA, see Ch 5.

22 Centre for Law and Genetics, *Submission G255*, 21 December 2002.

Industry code or legislation

27.27 DP 66 also asked whether the proposal for oversight by the HGCA would be implemented most effectively through an industry code or legislation. A number of submissions expressed the view that legislation would apply more comprehensively, given, for example, that not all life insurers are members of IFSA.²³ Others were of the view that this proposal could be implemented effectively through industry codes.²⁴ IFSA suggested that its Genetic Testing Policy could be amended to prohibit the use of genetic tests that had been considered and rejected by the HGCA and to prohibit the use of new genetic tests until they had been considered and approved by the HGCA. This would allow insurers to continue to use existing genetic tests until they were considered by the HGCA.

27.28 The Inquiry was informed that the Insurance Council of Australia (ICA) is currently reviewing the General Insurance Code of Practice.²⁵ Amendments to the Code will be submitted to the Australian Securities and Investments Commission (ASIC) for approval. As with the IFSA Genetic Testing Policy, the Code could be amended to implement the recommendations in this Report. Alternatively, the ICA may wish to consider developing a separate genetic testing policy for general insurers.

27.29 DP 66 sought feedback on whether, if the proposal were implemented through legislation, this should be through amendment to the duty of disclosure in the *Insurance Contracts Act 1984* (Cth) (*Insurance Contracts Act*) or the insurance exemption in anti-discrimination legislation. The acting Disability Discrimination Commissioner expressed the following view:

Government, the public and industry should be able to expect insurance to be properly regulated by insurance law and industry mechanisms in the first instance, with discrimination law providing a safety net or check on these mechanisms if necessary rather than needing to be the first resort on any issue.²⁶

27.30 On this basis, he was of the opinion that any changes should be implemented through amendment to insurance industry law and practice, and that a complementary amendment to the DDA would not be needed. The Anti-Discrimination Commission of Queensland noted that, if insurers were limited to relying on those genetic tests approved for use by the HGCA, underwriting decisions would be more likely to be consistent with the provisions of the DDA.²⁷

23 Anti-Discrimination Commission Queensland, *Submission G214*, 2 December 2002; Centre for Genetics Education, *Submission G232*, 18 December 2002; Genetic Support Council WA, *Submission G243*, 19 December 2002; Centre for Law and Genetics, *Submission G255*, 21 December 2002; Human Genetics Society of Australasia, *Submission G267*, 20 December 2002.

24 Institute of Actuaries of Australia, *Submission G224*, 29 November 2002; Investment and Financial Services Association, *Submission G244*, 19 December 2002; G Whittaker, *Submission G298*, 2 January 2003.

25 Insurance Council of Australia, *Consultation*, Sydney, 18 November 2002.

26 Acting Disability Discrimination Commissioner — Human Rights and Equal Opportunity Commission, *Submission G301*, 16 January 2003.

27 Anti-Discrimination Commission Queensland, *Submission G214*, 2 December 2002.

27.31 The acting Disability Discrimination Commissioner also noted that it would be possible to reflect any changes by amending the *Guidelines for Providers of Superannuation and Insurance* issued by the Human Rights and Equal Opportunity Commission (HREOC).²⁸ It would also be possible to recognise the changes through the issue of a temporary exemption under the DDA.

Inquiry's views

27.32 In exempting insurers from the operation of the DDA, the legislature has recognised that differentiation between individuals goes to the very nature of mutually rated insurance. However, the exemption from the general proscriptions of the Act is expressly confined to discrimination based on reasonable actuarial or statistical data, or—where no actuarial or statistical data are available—to discrimination that is otherwise reasonable. If neither test is satisfied, the inherently discriminatory conduct of insurers in underwriting mutually rated insurance will be unlawful.

27.33 The Inquiry notes the concerns expressed in consultations and submissions in relation to the use of genetic test results in underwriting. Society's understanding of the genetic basis of disease is changing rapidly and this presents a serious challenge for underwriters in establishing the necessary links between genetic mutation and disease, on the one hand, and between disease and mortality and morbidity, on the other. Experience with genetic test information is relatively new, so that there has been no deep accumulation of data and precedents upon which to base underwriting decisions in such cases.

27.34 Apart from the HREOC complaint process or formal review by a court, the present system offers no independent oversight of whether the discriminatory use of genetic test information is based on reasonable actuarial or statistical data, or is otherwise reasonable. Insurers themselves determine which genetic test information is considered to be scientifically reliable and actuarially relevant, and then apply this information to underwriting individual applications. From the perspective of an applicant who has received an unfavourable underwriting decision, this practice may give rise to dissatisfaction—even if the decision is sound in fact and falls within the terms of the insurance exemption.

27.35 In the light of these considerations, the Inquiry has formed the view that independent oversight of the use of genetic test information in underwriting is needed and that the HGCA is the appropriate body to undertake that role. The Inquiry does not suggest that insurers routinely use genetic information to underwrite applications in a manner that falls outside the terms of the exception in s 46 of the DDA or equivalent legislation. Rather, the Inquiry believes that independent oversight would help to build public confidence that genetic test information is being used to discriminate only in the limited circumstances permitted by law and that insurers' use of genetic test information is transparent and based on objective information. In this context, the

28 Human Rights and Equal Opportunity Commission, *Guidelines for Providers of Insurance and Superannuation*, <www.hreoc.gov.au/disability_rights/standards/Insurance/insurance_adv.html>, 19 February 2003.

Inquiry recalls the note of caution sounded by the United Kingdom's House of Commons Science and Technology Committee:

We regret that the insurance industry insisted on using genetic tests before their reliability had been fully established. In hindsight it would have been better if the insurance industry had proceeded far more cautiously in this difficult area, which at present can bring them little financial return but a great deal of adverse publicity.²⁹

27.36 The Inquiry recommends that the HGCA should, as a matter of priority, establish procedures to assess and make recommendations in relation to particular genetic tests used in underwriting mutually rated insurance, having regard to their scientific reliability, actuarial relevance and reasonableness. Industry codes should ensure that, once the HGCA has made a recommendation in relation to a particular test, members are required to use that genetic test information only in accordance with the HGCA's recommendation. Under this scheme, the HGCA would not be involved in making or reviewing individual underwriting decisions.

27.37 In DP 66 the Inquiry put forward a similar proposal, although limited to oversight of *predictive* genetic tests. During consultations a number of individuals indicated that diagnostic genetic tests also raise issues of scientific reliability, actuarial relevance and reasonableness. The Inquiry agrees with this view and has cast its present recommendations accordingly.

27.38 The Inquiry does not agree with the view that, where a genetic test is reliable enough to be used by the medical profession, it should necessarily be available for use by insurers. As discussed in Chapter 11, the Therapeutic Goods Administration (TGA) evaluates some goods used in genetic tests for quality, safety and efficacy, among other things. Although the TGA may comment generally on the use of specific tests in clinical settings, this evaluation does not extend to whether the test is appropriate for use in a particular clinical situation. This decision is made on a case-by-case basis by the medical professional arranging the test. The TGA approval process involves an examination of the scientific reliability of a particular test—for example, it examines whether genetic test X gives a reliable result for genetic mutation Y—but it does not consider the actuarial significance of potential test results.

27.39 The only other formal government evaluation of particular genetic tests occurs in relation to listing under the Medicare Benefits Schedule (MBS). As discussed in Chapter 10, the Medical Services Advisory Committee provides advice to the federal Minister for Health and Ageing about tests that are to be subsidised through Medicare. MBS listing requires an appraisal of evidence relating to the safety, clinical effectiveness and cost effectiveness of a particular test. These considerations extend beyond the scientific reliability of a genetic test to matters of cost and public funding. Only four genetic tests are currently listed on the MBS: if MBS listing were to be a precondition for making genetic tests available to insurers, many tests currently used by the industry would be unavailable for the purpose of underwriting.

29 House of Commons — Select Committee on Science and Technology, *Genetics and Insurance* (2000–1), The Stationery Office Limited, London, xxvi.

27.40 IFSA has suggested that the HGCA could make recommendations in relation to whether particular genetic tests are suitable for use for diagnostic, therapeutic or predictive purposes in Australia, and that use in insurance should flow automatically from this. In the Inquiry's view, the use of genetic tests in the medical context, where the health and well being of the individual are the paramount consideration, raises different issues from the use of genetic tests in insurance, where the test result may have adverse consequences for the individual. It is easier to justify the use of new or experimental genetic tests that might benefit the health of an individual in the medical context than the use of such tests in underwriting.

27.41 As discussed in Chapter 5, the Inquiry recommends that the HGCA be established with a balanced and broad-based membership, including both expert and community representation. A body established in accordance with those recommendations, and utilising whatever sub-committees or working parties may be appropriate, will have the level of expertise and authority necessary to provide appropriate oversight of the use of genetic tests in underwriting.

27.42 The Inquiry has refrained from making recommendations about the processes and procedures for the HGCA in considering genetic tests for use in insurance. These should be developed by the HGCA, in consultation with peak industry bodies and other stakeholders. The Inquiry considers that the process should be open and transparent, with adequate opportunity for stakeholders to make submissions.

27.43 As indicated above, the Inquiry is of the view that the recommendations of the HGCA in relation to the use of genetic test information in underwriting should be implemented through the development or amendment of relevant industry codes. This approach allows flexibility in a rapidly developing area. The insurance industry peak bodies have demonstrated a willingness to work with government and stakeholders to improve industry practices through self-regulation. This situation should, however, be kept under review by the HGCA in accordance with Recommendation 26–2.

27.44 Industry codes issued by IFSA and the ICA cover the vast majority of insurers in Australia. Insurers operating outside these codes will remain subject to the provisions of the DDA. Where the HGCA recommends the rejection of a genetic test on the basis that it is not scientifically reliable, actuarially relevant or reasonable, reliance on that test by an insurer may give grounds for complaint under the DDA.

27.45 In implementing the Inquiry's recommendations, it is necessary to establish suitable transitional arrangements. The Inquiry considers that insurers should be permitted to use genetic tests in underwriting in accordance with industry policies (as amended in accordance with this Report), until such time as the HGCA makes a recommendation in relation to a particular test. The HGCA should ensure that tests are considered in a timely fashion and that the process of review is constrained by reasonable time limits built into the HGCA procedures. The HGCA should consider, as a matter of priority, those genetic tests that are in use by the insurance industry and give rise to concern in relation to scientific reliability or actuarial relevance.

27.46 The Inquiry does not recommend an amendment to the duty of disclosure in s 21 of the *Insurance Contracts Act*, nor to the obligation of insurers in s 22 of the Act to inform applicants in writing of the ‘general nature and effect of the duty of disclosure’. The duty of disclosure extends only to information that is known, or which reasonably ought to be known, to be relevant to the decision of the insurer whether to accept the risk and, if so, on what terms (see Chapter 25).

27.47 Despite the qualified nature of the duty of disclosure, in practice applicants may disclose and insurers may collect information that is *not relevant* to the decision of the insurer; for example, in response to general questions about the applicant’s health. In general, it is the insurer who assesses what information is relevant and what is not. Under the proposed arrangements, the HGCA will assess whether a particular genetic test is relevant for use in underwriting. Those tests that are rejected by the HGCA will not be relevant to the decision of the insurer because they will have been found to lack scientific reliability, actuarial relevance or reasonableness. Accordingly, applicants will have no duty to disclose the results of genetic tests that have been considered and rejected by the HGCA.

27.48 However, insurance applicants cannot reasonably be expected to know which genetic tests have been considered, recommended or rejected by the HGCA. Nor should applicants be expected to know, without the provision of additional information, the implications of the HGCA’s decisions for the applicant’s duty of disclosure. The Inquiry is therefore of the view that peak industry bodies should require their members to inform applicants of the nature of their duty of disclosure in relation to genetic test information and to provide applicants, upon request, with information about the relevant recommendations of the HGCA. In particular, insurance application forms that seek to collect health information about applicants should advise applicants that not all genetic test results have to be disclosed and that applicants may obtain further information about this from the insurer. Insurers should ensure that they have access to up-to-date information in relation to those tests that the HGCA has recommended not be used in underwriting, so that they can provide accurate information to applicants.

27.49 The Inquiry’s recommendation that insurers should be able to continue using genetic tests until such time as the HGCA makes an adverse recommendation in relation to a particular test removes much of the pressure, canvassed above, to create an exception for the use of negative test results. Nevertheless, the Inquiry considers that the HGCA should be free to develop recommendations on the use of negative test results in underwriting on a test-by-test basis. It may be that in some circumstances a negative result is more scientifically reliable, actuarially relevant or otherwise reasonable than a positive test result and might be used, for example, to displace a family medical history relating to the particular condition. Since such use does not prejudice the interests of an insurance applicant, the Inquiry leaves it open to the HGCA to recommend that insurers be allowed to use that information in appropriate cases.

Recommendation 27–1. The Human Genetics Commission of Australia (HGCA) should, as a matter of priority, establish procedures to assess and make recommendations on whether particular genetic tests should be used in underwriting mutually rated insurance, having regard to their scientific reliability, actuarial relevance and reasonableness.

Recommendation 27–2. The Investment and Financial Services Association (IFSA) and the Insurance Council of Australia (ICA) should develop mandatory policies for their members to ensure that, once the HGCA has made a recommendation in relation to the use of a particular genetic test in underwriting, that test is used only in conformity with the recommendation. As a transitional arrangement, insurers should be permitted to continue using genetic tests in underwriting in accordance with industry policies, until such time as the HGCA makes a recommendation in relation to those tests.

Recommendation 27–3. IFSA and the ICA should require their members to state, on relevant insurance application forms, that not all genetic test results have to be disclosed and that applicants may obtain further information about this from the insurer. In addition, IFSA and the ICA should require their members to provide, upon request, accurate information to applicants in relation to those genetic tests that the HGCA has recommended not be used in underwriting in accordance with Recommendation 27–1.

Family medical history information

27.50 Although the majority of submissions focussed on the interpretation of genetic test results, the Inquiry also received submissions expressing concern about the use of family medical history in underwriting. Concerns included the unreliable nature of family medical history information and the potential for this information to be misunderstood and misapplied. In its submission to the Inquiry, IFSA described the way in which family medical history is collected and used in life insurance:

The use of family medical history is an integral part of the underwriting process. Family medical history has been used for over 100 years within the life insurance industry worldwide.

Family medical history can be a relevant factor in assessing the likelihood of an individual meeting the policy conditions to substantiate a claim. It is used to identify potential medical risks on the basis of the probability that the insurance applicant may be susceptible to certain risks due to a familial/hereditary link with his or her immediate family.

The majority of insurers in Australia have a section in their standard application forms asking about the applicant's family medical history. The purpose of the question is to identify whether the applicant's immediate family members (limited to biological mother, father, brother(s) or sister(s), known collectively as 1st degree relatives) have been diagnosed with, or have died from a number of medical conditions which

medical research has identified as having a strong familial link or for which there is an identifiable direct genetic link (such as Huntington's disease). The insurer does not ask for family history information relating to the applicant's children or their uncles, aunts, cousins or relatives that are not immediate family.³⁰

27.51 IFSA also included a number of examples of the way in which family medical history impacts on risk rating of applications for insurance. This information is generally drawn from reinsurance manuals. The following information was provided on familial colorectal cancer:

No family history of colorectal cancer equates to a 2% lifetime risk of developing colorectal cancer. That is 2 in 100 people will suffer this condition at some stage of their life.

1 first-degree relative with colorectal cancer translates to a 6% lifetime risk of developing the disease. If an applicant is over 45 years of age and asymptomatic at the time of underwriting they would be assessed as:

- borderline ordinary rates for life insurance;
- up to +50% extra morbidity for trauma insurance;
- borderline ordinary rates for disability insurance.

1 first-degree relative aged < 45 years of age when first diagnosed with colorectal cancer translates to a 10% lifetime risk of an individual developing the disease. If an applicant is under 45 and asymptomatic at time of underwriting they would be assessed as:

- up to +50% extra mortality for life insurance;
- +75% extra morbidity for trauma insurance;
- up to +50% extra morbidity for disability insurance.

2 first-degree relatives with colorectal cancer translate to a 17% lifetime risk of developing the condition. If the applicant is under 45 and asymptomatic at time of underwriting he or she would be assessed as:

- up to +50% extra mortality for life insurance;
- up to +100% extra morbidity for trauma insurance;
- up to +50% extra morbidity for disability insurance.³¹

27.52 Family medical history is one of many factors taken into account in the underwriting process. Other factors include the age of the applicant, past and current medical status and lifestyle including, for example, whether the applicant is a smoker. Insurers rely to a large extent on reinsurance manuals to provide information on how each of these factors affects risk. The extent to which insurers rely on family medical history is discussed in Chapter 25.

30 Investment and Financial Services Association, *Submission G244*, 19 December 2002.

31 Ibid. The source of the risk ratings is the *Gerling Global Reinsurance Manual*.

Submissions and consultations

27.53 A number of submissions expressed support for the inclusion of family medical history information within the oversight functions of the HGCA.³² Privacy NSW submitted that:

Questions have been raised about the accuracy of actuarial decisions based on family history information. Ideally, if a Genetics Advisory Committee is formed, the safest option is to include family history information in the proposed moratorium on the use of genetic testing information. Alternatively, if family history information continues to be used, the Genetics Advisory Committee should assess the way it is used in the light of progress in genetics. Proposers should be provided with appropriate information to assist them to understand how this information may affect their applications.³³

27.54 The New South Wales Anti-Discrimination Board submitted that:

In our view use of family medical history, whether or not such information can amount to genetic information, should be subject to greater scrutiny to determine whether or not the information used in the underwriting process is scientifically reliable and actuarially relevant. The independent body we propose above should play a role in evaluating the scientific reliability and actuarial relevance of both genetic and non-genetic information.³⁴

27.55 The Inquiry was informed that placing limits on insurers' access to family medical history information would have serious consequences for the industry and would be more likely to lead to adverse selection than limits on access to genetic test information.³⁵ In its recent report, the United Kingdom Human Genetics Commission recommended that the voluntary moratorium not be extended to cover family medical history. This recommendation was based on modelling which indicated that the exclusion of family medical history from underwriting was likely to have a significant impact on insurance premiums.³⁶

27.56 A related issue is the way in which insurers deal with the interaction between family medical history information and genetic test information. As noted above, the Inquiry received one submission reporting an incident in which insurers appeared to underwrite on the basis of the applicant's family medical history of Huntington's disease despite the provision of genetic test results showing that the applicant did not have the genetic mutation for that disease.³⁷

27.57 The Human Genetics Society of Australasia (HGSA) made the point that:

32 Including the Anti-Discrimination Commission Queensland, *Submission G214*, 2 December 2002.

33 Office of the Privacy Commissioner (NSW), *Submission G118*, 18 March 2002.

34 Anti-Discrimination Board of NSW, *Submission G157*, 1 May 2002.

35 Association of British Insurers, *Submission G053*, 15 January 2002; C Daykin and others, *Genetics and Insurance — Some Social Policy Issues* (2003), Institute of Actuaries and Faculty of Actuaries, UK.

36 Human Genetics Commission, *Inside Information: Balancing Interests in the Use of Personal Genetic Data* (2002), London.

37 *Confidential Submission G046CON*, 26 December 2001.

In the setting where a person has had a genetic test for a familial condition and they have been shown not to have the mutation, this should negate the effect that their family history has on the loading. The basis for this recommendation is that where a family mutation is not present, the evidence is clear that that individual is either at the same risk of the condition in question as others in the community or not at risk at all.³⁸

27.58 In DP 66, the Inquiry proposed that insurers, through their peak bodies and in consultation with the HGCA, should develop industry policies on the use of family medical history information. A number of submissions expressed support for this proposal.³⁹ The Centre for Law and Genetics noted that this would be an important step towards increasing the transparency and accountability of insurance practice in this area.⁴⁰

27.59 The Australian Life Underwriters and Claims Association was concerned that a binding, industry wide policy on the use of this information by insurers would be an inappropriate fetter on the underwriting freedom of insurers. The Association noted, however, that a high level policy guideline to assist insurers to avoid discrimination would be more acceptable.⁴¹

27.60 IFSA responded to the proposal in the following terms:

IFSA acknowledges that the current published industry policy on the use of genetic tests in underwriting does not cover the use of other forms of genetic information such as family medical history. To ensure industry practice in relation to use of family medical history in underwriting is consistent and properly takes into account all relevant concerns, IFSA agrees with the Inquiry that as a peak body of the insurance industry, IFSA should work in consultation with the proposed HGCA to develop appropriate industry policies that document current practices to address this issue.

IFSA sees the existing Genetic Testing Policy as the appropriate mechanism to incorporate a suitable policy on underwriting practices in respect of family medical history, and will commence discussions with its members in 2003 to give effect to this.

Moreover, IFSA will seek the involvement of the proposed HGCA in its development and maintain its practice of proactively reviewing its standards and policies on a regular basis (including the Genetic Testing Policy) to ensure such standards/policies reflect community attitudes and advances in technology (medical or otherwise).⁴²

38 Human Genetics Society of Australasia, *Submission G050*, 14 January 2002.

39 A Dominello and others, *Submission G222*, 3 December 2002; Institute of Actuaries of Australia, *Submission G224*, 29 November 2002; Centre for Genetics Education, *Submission G232*, 18 December 2002; Genetic Support Council WA, *Submission G243*, 19 December 2002; Investment and Financial Services Association, *Submission G244*, 19 December 2002; Genetic Discrimination Project Team, *Submission G252*, 20 December 2002; Centre for Law and Genetics, *Submission G255*, 21 December 2002; Human Genetics Society of Australasia, *Submission G267*, 20 December 2002; Australian Huntington's Disease Association (NSW), *Submission G268*, 20 December 2002; Department of Health Western Australia, *Submission G271*, 23 December 2002; G Whittaker, *Submission G298*, 2 January 2003; Acting Disability Discrimination Commissioner — Human Rights and Equal Opportunity Commission, *Submission G301*, 16 January 2003.

40 Centre for Law and Genetics, *Submission G255*, 21 December 2002.

41 Australian Life Underwriters and Claims Association Inc, *Submission G300*, 10 January 2003.

42 Investment and Financial Services Association, *Submission G244*, 19 December 2002.

Inquiry's views

27.61 Chapter 25 noted that family medical history information has been used by insurers for the purpose of underwriting for over a century. Consequently, the industry has had a long period in which to collect statistical data and assess its actuarial relevance, particularly when compared with genetic test information. However, the use made of family medical history is in some ways more abstract and subjective than genetic test information. In particular, problems may arise because of the quality of the data collected about genetic relatives or the lack of medical understanding about the genetic influences on common diseases.

27.62 The Inquiry does not propose that the HGCA be asked to consider the use of the family medical history for underwriting purposes in particular circumstances. Such an approach is likely to be impractical, given the variability of circumstances in which family medical history may be relevant. However, the Inquiry is of the view that insurers, through their peak bodies, should develop industry policies on the use of family medical history in underwriting to ensure that where such information is relied on by insurers, it is scientifically reliable, actuarially relevant or otherwise reasonable. Such policies should be developed in consultation with the HGCA and the Institute of Actuaries of Australia.

27.63 Amongst other things, the policies should provide guidance for members on the following matters:

- the relationship between family medical history and other factors used to assess risk, so that the former is only given its due weight;
- the relationship between family medical history and genetic test information, particularly where a genetic test result is negative;
- the proximity of the blood relationship between the applicant and his or her family members that justifies collection of family medical history; and
- the need, if any, for verifying diagnoses of family members and the procedures for doing so.

Recommendation 27–4. IFSA and the ICA, in consultation with the HGCA and the Institute of Actuaries of Australia, should develop and publish policies for their members on the use of family medical history for underwriting mutually rated insurance.

Insurer's duty to provide reasons

27.64 The Inquiry received a number of submissions expressing the view that the reasons provided by insurers for unfavourable underwriting decisions are, from an applicant's point of view, generally inadequate. Moreover, the mechanisms for

obtaining reasons were seen in some circumstances to be unduly onerous. The Anti-Discrimination Board of NSW stated that:

We strongly disagree with the view ... that the current methods of risk assessment using genetic information are sufficiently transparent and accountable to the public because the DDA provides consumers with the capacity to lodge a complaint and this in turn would mean that the insurer may be required to provide evidence in support of their underwriting decision. We do not consider that it is acceptable for insurance companies to require individuals to lodge a complaint before such information is provided to consumers.

In our view, consumers should have the right to access adequate information about the basis for the insurer's decision and the actuarial or statistical evidence on which the insurer has relied in making that decision. It is only with such information that consumers can determine whether to challenge the decision under anti-discrimination legislation.⁴³

Industry regulation

27.65 The extent to which an applicant is given reasons for an adverse underwriting decision is currently regulated in three ways:

- s 75 of the *Insurance Contracts Act* imposes a duty on insurers to give applicants written reasons for an unfavourable underwriting decision, where requested in writing to do so;
- s 107 of the DDA enables the President of HREOC to require an insurer to disclose the source of the actuarial or statistical data on which a discriminatory act was based; and
- IFSA's Genetic Testing Policy requires members to give reasons in a clear and meaningful way in respect of adverse decisions based on genetic test information.

27.66 The first and second methods apply to underwriting decisions irrespective of whether they use genetic information. The third is specific to genetic information, but is confined to genetic test information to the exclusion of family medical history. Each of these provisions is described in more detail below.

27.67 Section 75(1) of the *Insurance Contracts Act* currently provides:

Where an insurer:

- (a) does not accept an offer to enter into a contract of insurance;
- (b) cancels a contract of insurance;
- (c) indicates to the insured that the insurer does not propose to renew the insurance cover provided under a contract of insurance; or

43 Anti-Discrimination Board of NSW, *Submission G157*, 1 May 2002.

(d) by reason of some special risk relating to the insured or to the subject-matter of the contract, offers insurance cover to the insured on terms that are less advantageous to the insured than the terms that the insurer would otherwise offer;

the insurer shall, if the insured so requests in writing given to the insurer, give to the insured a statement in writing setting out the insurer's reasons for not accepting the offer, for cancelling the contract, for not renewing the insurance cover or for offering insurance cover on less advantageous terms, as the case may be.

27.68 Section 107 of the DDA provides a mechanism for HREOC to obtain access to 'the source of the actuarial and statistical data' used in assessing an individual's insurance application. Section 107 provides:

If a person has engaged in an act of discrimination that would, apart from section 46 be unlawful, the President or the Commission may, by notice in writing served on the person as prescribed, require the person within 28 days after service of the notice on the person, to disclose to the President or to the Commission, as the case may be, the source of the actuarial or statistical data on which the act of discrimination was based and, where the President or the Commission, as the case may be, makes such a requirement of a person, the person must not, without reasonable excuse, fail to comply with the requirement.

Penalty: \$1,000.

27.69 IFSA's Genetic Testing Policy addresses the issue of providing reasons to an applicant in the following terms:

11. All underwriting decisions, involving a genetic test, whether or not the test was a significant factor in the decision, should be thoroughly documented, so that adequate information can be provided to the applicant on request. ...

12. Insurers will provide reasons for offering modifications or rejections to applicants in relation to either new applications or requests for increases on existing policies.⁴⁴

27.70 The explanatory notes which accompany the policy state that members will inform applicants 'in a clear and meaningful way' of the reasons for the decision; reasons may be given to the applicant's doctor in appropriate cases; and members will include information on how an applicant can lodge a complaint in relation to the decision.

Submissions and consultations

27.71 A number of submissions were critical of s 75 of the *Insurance Contracts Act*. Margaret Otłowski noted that:

Under the *Insurance Contracts Act* — individuals can request in writing that they be given written reasons. There are, however, questions about the scope of this provision and whether it would entitle an individual to details of the actuarial or statistical data (or other data) relied on by the insurance company in reaching its decision.⁴⁵

44 Investment and Financial Services Association, *IFSA Standard 11.00 'Genetic Testing Policy'* (2002), IFSA.

45 M Otłowski, *Submission G159*, 24 April 2002.

27.72 The Institute of Actuaries of Australia accepted that

the wording of the *Insurance Contracts Act 1984* needs to be addressed. The [*Insurance Contracts Act*] does not adequately convey the nature of the material that an insurer should provide where an unfavourable underwriting decision is questioned.⁴⁶

27.73 The HGSA recommended that the insurance industry be compelled to provide an explanation for loading or refusal of policies in every case:

This explanation should be provided to the individual and any third party nominated by the individual such as their medical practitioner. Any decision to refuse, or to load, an insurance policy based on the genetic test result must be justified by reference to appropriate medical literature, and appropriate peer review studies.⁴⁷

27.74 The Anti-Discrimination Commission of Queensland supported clarification of s 75 on the basis that, if an applicant's rights under the *Insurance Contracts Act* were clearer, there would be less need to proceed under anti-discrimination legislation. The Commission expressed the view that the amendment to s 75 should ensure that the obligation to provide reasons arose automatically and that it was not dependent on the applicant requesting reasons in writing. The Commission was of the view that a statement of reasons should explain the statistical and actuarial or other basis for a decision and that supporting documentation should be available on request.⁴⁸

27.75 IFSA and the Australian Life Underwriters and Claims Association were not opposed in principle to providing clear and meaningful reasons. IFSA, however, expressed a preference for dealing with the issue at industry policy level. IFSA noted that a legal requirement to provide reasons may impose a costly and time consuming burden on insurers and may not necessarily be helpful to consumers. The Australian Life Underwriters and Claims Association noted that, if insurers were required to provide reasons, this may conflict with an applicant's 'right not to know' or may not be of benefit to the applicant in other ways, for example, applicants may be required to disclose this information in subsequent applications for insurance.⁴⁹

27.76 Other submissions directed criticisms toward s 107 of the DDA. The Centre for Law and Genetics noted the practical need to lodge a complaint with HREOC in order to invoke HREOC's power under s 107, with the consequence that the desired information may come too late:

At present, the only sure means by which an individual can gain access to relevant actuarial and/or statistical data is by lodging a complaint with the Human Rights and Equal Opportunity Commission under the *Disability Discrimination Act 1992* (Cth), thereby invoking the power in the Commission under s 107 of the Act to require a person who is *prima facie* in breach of the prohibition against unlawful discrimination

46 Institute of Actuaries of Australia, *Submission G224*, 29 November 2002.

47 Human Genetics Society of Australasia, *Submission G050*, 14 January 2002; Anti-Discrimination Board of NSW, *Submission G157*, 1 May 2002 made a similar point.

48 Anti-Discrimination Commission Queensland, *Submission G214*, 2 December 2002.

49 Investment and Financial Services Association, *Submission G244*, 19 December 2002; Australian Life Underwriters and Claims Association Inc, *Submission G300*, 10 January 2003.

to disclose to the Commission the source of the actuarial or statistical data on which the act of discrimination was based. This seems an unduly onerous and impractical approach, particularly in view of the fact that the availability of this information may well be influential in deciding whether or not to bring proceedings under the *Disability Discrimination Act* (or equivalent state or territory legislation).⁵⁰

27.77 Similarly, the Anti-Discrimination Board of NSW submitted that:

There are some inadequacies with this provision. First, the provision appears to limit disclosure to the *source* of the data, rather than the data itself. Secondly, the provision only refers to 'disclosure to the President or to the Commission'. As far as we are aware, the terms of the provision have not been used to prevent disclosure of the information to the complainant. However, in the interests of clarity, it should be made clear that complainants are entitled to access the information disclosed to the President or the Commission.⁵¹

27.78 IFSA expressed support for amending the DDA to allow the applicant to gain access to the reasons for decision but was of the view that the provision should remain limited to the 'source' of the statistical and actuarial information and not the information itself. IFSA was of the view that the content of the statement of reasons should be regulated by industry policy.⁵²

27.79 The acting Disability Discrimination Commissioner supported clarification of the DDA but noted that s 107

has had limited practical significance in the administration of the DDA to date, and that as indicated above provisions for disclosure of reasons at an earlier stage and not only in the context of a DDA complaint are likely to have greater beneficial effect.⁵³

27.80 There was substantial comment in submissions concerning the content of any statement of reasons provided by insurers. The Centre for Law and Genetics suggested that:

The information provided should include an explanation, in layman's terms, of the reasons for the unfavourable underwriting judgment and the actuarial basis for that decision. To avoid the feedback to the individual being entirely negative, where possible, it would be desirable if information could be provided about alternative insurance products and or options which may be open to the applicant, notwithstanding the genetic information.⁵⁴

50 Centre for Law and Genetics, *Submission G048*, 14 January 2002.

51 Anti-Discrimination Board of NSW, *Submission G157*, 1 May 2002. See also Centre for Law and Genetics, *Submission G255*, 21 December 2002.

52 Investment and Financial Services Association, *Submission G244*, 19 December 2002.

53 Acting Disability Discrimination Commissioner — Human Rights and Equal Opportunity Commission, *Submission G301*, 16 January 2003.

54 Centre for Law and Genetics, *Submission G048*, 14 January 2002. IFSA's Genetics Testing Policy makes provision in this regard. Rule 10.13 states that, if an application is rejected, 'members should endeavour to offer alternative terms (as may be actuarially justifiable) or alternative products': Investment and Financial Services Association, *IFSA Standard 11.00 'Genetic Testing Policy'* (2002), IFSA.

27.81 Other submissions suggested that it might be difficult to disclose the actuarial or statistical data on which an underwriting decision is based for ‘commercial in confidence’ reasons.⁵⁵ IFSA was of the view that:

If insurers were legally required to explain in every instance the actuarial or statistical basis for unfavourable underwriting decisions based on genetic information, this would be an onerous and costly exercise. It would involve compiling and extracting specific information relevant to each particular decision from large volumes of relevant data and explaining and breaking down the derivation of the actuarial or statistical basis, which may be as a result of lengthy research and extensive historical analysis accumulated over time, in each case.⁵⁶

27.82 The Institute of Actuaries of Australia noted that

if all this information were to be provided on every request, the applicant would most often receive an overwhelming quantity of data that is incomprehensible except to an expert. Life companies prefer to start by giving a plain English explanation that is consumer friendly.⁵⁷

27.83 IFSA expressed the view that, in relation to genetic test information, the Genetic Testing Policy makes sufficient provision for clear and meaningful reasons for adverse decisions. In response to the Inquiry’s proposal that reasons should also be provided for decisions based on family medical history information, IFSA remarked:

IFSA is prepared to review current practices in relation to communicating reasons for adverse underwriting decisions based on family medical history with the view to formulating appropriate policies and standards to address relevant concerns. This may involve reviewing IFSA’s existing Genetic Testing Policy and determining the extent to which the provision of reasons model can be expanded to cover unfavourable underwriting decisions based on family medical history. Further, IFSA maintains its commitment to working with the community and relevant bodies such as the proposed HGCA in the development of these policies.⁵⁸

Inquiry’s views

27.84 The Inquiry is of the view that applicants are entitled to know the reasons for an adverse underwriting decision. Transparency and accountability of decision making has the benefit of building public confidence in the way in which insurers use genetic information in underwriting and is likely to generate a better decision-making process. It also creates checks and balances by providing consumers with the means of ensuring that the discriminatory acts of insurers fall within the terms of the exemptions permitted by law.

27.85 The Inquiry considers that the reasons provided must be effective for the purposes of consumer understanding and possible review—and they may fail to be so if an insurer provides either too little information or too much. A bare statement that an applicant has been denied insurance because of his or her family history of a particular

55 M Otlowski, *Submission G159*, 24 April 2002.

56 Investment and Financial Services Association, *Submission G244*, 19 December 2002.

57 Institute of Actuaries of Australia, *Submission G105*, 7 March 2002.

58 Investment and Financial Services Association, *Submission G244*, 19 December 2002.

genetic disorder is unlikely to satisfy a consumer's wish to understand the basis of an adverse decision. On the other hand, the provision of vast quantities of raw statistical or actuarial data is unlikely to offer an applicant any better understanding.

27.86 The Inquiry regards IFSA's Genetic Testing Policy as encapsulating the essence of effective reasons: insurers should inform applicants 'in a clear and meaningful way of the reasons for their decision in relation to the application'.⁵⁹ However, much will depend on how such principles are applied in practice.

27.87 With these considerations in mind, the Inquiry has formed the view that existing legal mechanisms and industry practice fall short of the desired standard in several respects.

- Section 75 of the *Insurance Contracts Act* imposes a duty on insurers to 'give to the insured a statement in writing setting out the insurer's reasons' upon request, but it says nothing of the adequacy of those reasons or the statistical or actuarial basis for the decision.
- Section 107 of the DDA enables HREOC to require an insurer to disclose the source of the actuarial or statistical data on which a discriminatory act was based. However, the section does not indicate that an applicant is entitled to the information so obtained; the section is obscure in so far as it requires only the disclosure of the 'source' of the data; and disclosure may in any case come too late to be effective.
- IFSA's Genetic Testing Policy provides a sound model in relation to the giving of reasons, but the policy applies only to genetic test information, not to family medical history. Moreover, the success of the policy ultimately will depend upon how it is implemented in practice by individual insurers.

27.88 In the Inquiry's view s 75 of the *Insurance Contracts Act* should be amended to clarify the nature of the information that must be provided to applicants on their request. The reasons provided by insurers should be clear and meaningful and explain the actuarial, statistical or other basis for the decision. In order to ensure that applicants are aware of their right to request reasons, the Inquiry also recommends that IFSA and the ICA develop mandatory policies requiring their members to inform applicants of their statutory entitlement to reasons for an adverse underwriting decision.⁶⁰ This will ensure that an applicant's right not to know is respected because reasons will not be given to an applicant unless they have been requested. It will also limit the cost to insurers because it is likely that reasons will not be required in every case.

59 Investment and Financial Services Association, *IFSA Standard 11.00 'Genetic Testing Policy'* (2002), IFSA [10.12.1].

60 The Inquiry notes that an IFSA Fact Sheet already includes information for applicants about their right to request reasons: Investment and Financial Services Association, *Fact Sheet: Life Insurance and Genetic Testing in Australia*, 1 March 2002.

27.89 In relation to the content of statements of reasons, the Inquiry believes that a balance must be found between the provision of adequate information and the provision of too much information. While the level of detail provided in underwriting manuals may not be helpful to an applicant, the Inquiry believes that the insurance industry should develop statements that describe the basis for decisions in a way that is readily understood by applicants.

27.90 The Inquiry notes that, in some cases, the information to be provided to applicants may be sensitive because of the inclusion of data about expected morbidity or mortality. Insurance industry peak bodies should develop policies on appropriate mechanisms for providing reasons to applicants where sensitive information is involved. In some cases it may be appropriate to provide information to the applicant's nominated medical practitioner rather than directly to the applicant, as is already common practice in the industry.

27.91 The Inquiry notes that, if the insurance industry is required to provide better information about reasons for adverse decisions under s 75 of the *Insurance Contracts Act*, there will be less need for applicants to seek redress under the DDA. However, in the Inquiry's view, s 107 of the DDA should also be clarified to ensure that information provided to HREOC is also available to the applicant. The existing requirement to provide the 'source' of statistical and actuarial data is, in the Inquiry's view, too limited. Insurers should be required under the DDA to provide clear and meaningful reasons for their decisions, including the statistical and actuarial data or other information upon which the decision was based. Once a dispute has progressed to the stage of a complaint to HREOC, there is justification for requiring more detailed information to be produced by the insurer to enable HREOC to determine whether the decision was consistent with the terms of the DDA.

27.92 The Inquiry is also of the view that industry policies dealing with the provision of reasons for adverse decisions based on genetic test information should be further developed to cover the provision of reasons for decisions based on family medical history. The Inquiry notes that IFSA has suggested extending the Genetic Testing Policy to cover family medical history and the Inquiry supports this approach. As noted above, the requirements to provide reasons in the *Insurance Contracts Act* and the DDA already extend to decisions based on family medical history information.

27.93 The interest of consumers in obtaining adequate information about adverse underwriting decisions is not, of course, confined to underwriting based on genetic information. The Anti-Discrimination Board of NSW made this point in its submission when referring to the findings of its report into Hepatitis C related discrimination.⁶¹ The Board expressed support for legislative amendments that would compel insurers to provide consumers with access to adequate information in relation to all unfavourable decisions, a view shared by the Institute of Actuaries of Australia.⁶² While there is

61 NSW Anti-Discrimination Board, *C-change: The Report of the Enquiry into Hepatitis C Related Discrimination* (2001), Sydney.

62 Anti-Discrimination Board of NSW, *Submission G157*, 1 May 2002; Institute of Actuaries of Australia, *Submission G224*, 29 November 2002.

merit in such an approach, in conformity with the Terms of Reference, the Inquiry's proposals are confined to the situation in which an application has been assessed using a person's genetic information.

Recommendation 27–5. The Commonwealth should amend the *Insurance Contracts Act 1984* (Cth) to clarify the nature of the obligation of an insurer to provide written reasons for an unfavourable underwriting decision upon the request of an applicant. Where such a decision is based on genetic information, including family medical history, the insurer should be required to give reasons that are clear and meaningful and that explain the actuarial, statistical or other basis for the decision.

Recommendation 27–6. IFSA and the ICA should require their members to inform applicants of their statutory entitlement to reasons for an adverse underwriting decision based on genetic information, including family medical history. IFSA and the ICA should also develop mandatory policies for their members about appropriate mechanisms for providing sensitive information to applicants in response to a request for reasons.

Recommendation 27–7. IFSA and the ICA should develop mandatory policies for their members regarding the provision of reasons by an insurer to an applicant following an unfavourable underwriting decision based on family medical history. These policies should ensure that the reasons given are clear and meaningful and that they explain the actuarial, statistical or other basis for the decision.

Recommendation 27–8. The Commonwealth should amend the *Disability Discrimination Act 1992* (Cth) and related legislation to clarify the nature of the information required to be disclosed by an insurer to the Human Rights and Equal Opportunity Commission in the course of resolving a complaint. The legislation should ensure that the complainant is entitled to access to the information so disclosed.

Review and appeal mechanisms

27.94 The Inquiry received a number of submissions expressing the view that the review and appeal mechanisms available to insurance applicants who received adverse decisions were inadequate.⁶³ At present, applicants are limited to seeking internal

⁶³ Centre for Law and Genetics, *Submission G048*, 14 January 2002; Office of the Privacy Commissioner (NSW), *Submission G118*, 18 March 2002; Equal Opportunity Commission of Victoria, *Submission G151*, 11 April 2002; D Keays, *Submission G152*, 14 April 2002; Centre for Genetics Education, *Submission G232*, 18 December 2002; Genetic Support Council WA, *Submission G243*, 19 December 2002; Anti-Discrimination Commission Queensland, *Submission G214*, 2 December 2002; Androgen Insensitivity Syndrome Support Group Australia, *Submission G290*, 5 January 2003; Commonwealth Department of Health and Ageing, *Submission G313*, 6 February 2003; Human Genetics Society of Australasia, *Submission G267*, 20 December 2002; Institute of Actuaries of Australia, *Submission G224*, 29 November 2002.

review by the insurer, lodging a complaint with IFSA in relation to an alleged breach of the Genetic Testing Policy or lodging a complaint of unlawful discrimination with HREOC. Existing external review processes—the Financial Industry Complaints Service (FICS) and Insurance Enquiries and Complaints Ltd (IEC)—do not have jurisdiction to consider complaints relating to premiums or underwriting decisions.

27.95 To date, HREOC has not received any complaints of discrimination on the basis of genetic information,⁶⁴ nor has IFSA received any complaints from consumers in relation to the application of the Genetic Testing Policy.⁶⁵

Industry regulation

27.96 In its January 2002 submission to the Inquiry, IFSA described the existing review and appeal mechanisms available to unsuccessful applicants for life insurance:

All life insurers have complaints handling processes. With the advent of licensing requirements under the *Financial Services Reform Act 2001*, these processes will be required to meet specified minimum standards approved by ASIC and we should therefore see further consistency across the industry.

Should a customer be dissatisfied with an insurer's response then a complaint can be considered by FICS [Financial Industry Complaints Service] at no charge to the customer. Determinations by FICS are binding on the insurer.

FICS does not consider complaints relating to underwriting, so in the case of dissatisfaction with an underwriting decision, the complaint may be referred to the Human Rights and Equal Opportunity Commission (HREOC).⁶⁶

27.97 As discussed in Chapter 25, the *Financial Services Reform Act 2001* (Cth) (FSRA) commenced in March 2002, with a two-year transition period. Under the new licensing arrangements, holders of an Australian Financial Services (AFS) licence, who provide financial services (including life and general insurance) to retail clients are required to have adequate dispute resolution systems. The Australian Securities and Investments Commission (ASIC) administers the dispute resolution provisions of the *Corporations Act 2001* (Cth) (Corporations Act) as amended by the FSRA.

27.98 According to ASIC Policy Statement 165 Licensing: Internal and External Dispute Resolution (PS 165):

A dispute resolution system must consist of:

(a) internal dispute resolution procedures that comply with standards and requirements made or approved by us and that cover complaints made by retail clients about the financial services provided; and

64 Human Rights and Equal Opportunity Commission, *Complaints of Genetic Discrimination under the Disability Discrimination Act: Case Studies* (2002).

65 Investment and Financial Services Association, *Consultation*, Sydney, 17 February 2003.

66 Investment and Financial Services Association, *Submission G049*, 14 January 2002.

(b) membership of one or more external dispute resolution schemes approved by us that covers, or together cover, complaints made by retail clients in relation to the financial services provided.⁶⁷

Internal dispute resolution

27.99 ASIC requires all internal dispute resolution (IDR) procedures to:

- satisfy the Essential Elements of Effective Complaints Handling in s 2 of Australian Standard 4269–1995;
- provide for appropriate documentation of IDR procedures; and
- have a system for informing complainants about the availability and accessibility of the relevant external dispute resolution (EDR) scheme.⁶⁸

27.100 IFSA informed the Inquiry that all life insurers have internal complaint handling processes.⁶⁹ Clause 10.14 of IFSA’s Genetic Testing Policy requires that:

Insurers will have a competent and efficient internal dispute resolution system to deal with complaints relating to underwriting decisions involving a genetic test result. Responses to any complaints must include a reference to the legal remedies available to the applicant.⁷⁰

27.101 Those processes must now meet the standards set out in PS 165 which in turn adopts the guidelines in Australian Standard 4269–1995 in relation to allocation of resources to IDR procedures, fairness, visibility, access, assistance to complainants, responsiveness and remedies. Insurers’ IDR procedures do not have monetary or other limits on their jurisdiction—as the existing EDR schemes do—and insurers are able to review their own underwriting decisions.

Genetic Testing Policy

27.102 IFSA’s customer brochure on genetic testing in life insurance provides applicants with the following information about monitoring and compliance with the IFSA Genetic Testing Policy:

If you believe that an IFSA member company has breached the provisions of the IFSA Genetic Testing Policy, then contact the IFSA’s Senior Policy Manager (Life Insurance). IFSA will review the matter with a view to liaising with the member company to ensure that the Policy has been followed.

67 Australian Securities and Investments Commission, *Policy Statement 165 Licensing: Internal and External Dispute Resolution*, Australian Securities and Investments Commission, <[www.asic.gov.au/asic/pdf/lib.nsf/LookupByFileName/PS165.pdf/\\$file/PS165.pdf](http://www.asic.gov.au/asic/pdf/lib.nsf/LookupByFileName/PS165.pdf/$file/PS165.pdf)>, 28 November 2001.

68 Ibid.

69 Investment and Financial Services Association, *Submission G244*, 19 December 2002.

70 Investment and Financial Services Association, *IFSA Standard 11.00 ‘Genetic Testing Policy’* (2002), IFSA [10.14].

If after IFSA has liaised on your behalf you are still of the view that you have been subject to discrimination you may take the matter of discrimination up with the Human Rights & Equal Opportunity Commission.⁷¹

27.103 As noted above, IFSA has not received any complaints under the policy to date. The policy is mandatory for members and, as noted in Chapter 25, the IFSA Code of Conduct and Code of Ethics state that, in the event of non-compliance, the IFSA Board may take a range of disciplinary measures, including public or private censure and suspension of, or expulsion from, IFSA membership.⁷²

External dispute resolution

27.104 In considering whether to approve EDR procedures, ASIC is required to take the following matters into account: accessibility, independence, fairness, accountability, efficiency and effectiveness as well as any other matter ASIC considers relevant. The specific guidelines against which ASIC approves EDR schemes are set out in Policy Statement 139 Approval of External Complaints Resolution Schemes (PS 139).⁷³

27.105 FICS is an independent company established to assist consumers in the resolution of complaints relating to members of the financial services industry, including life insurers. FICS is funded by industry members and approved by ASIC in accordance with PS 165 and PS 139. FICS receives complaints directly from insurance applicants and has the authority to make determinations that are binding on participating life insurers. The jurisdiction of FICS is limited in a number of ways, including monetary limits. FICS may only consider complaints about life insurance policies with a value of less than \$250,000.⁷⁴ The reason for the monetary limit is presumably that insurers do not wish to be bound by the external dispute resolution process for large claims, since they may wish to exercise their full legal rights.

27.106 IEC handles complaints about general insurance matters and is also an ASIC approved scheme. IEC determinations are binding on participating general insurers.⁷⁵ FICS, IEC and the Australian Banking Industry Ombudsman operate a common point of access telephone number to assist consumers. Lodging a complaint with FICS or IEC is free of charge to consumers.

71 Investment and Financial Services Association, *Submission G049*, 14 January 2002.

72 Investment & Financial Services Association, *Code of Ethics and Code of Conduct* (2001), Sydney.

73 Australian Securities and Investments Commission, *Policy Statement 139 Approval of External Complaints Resolution Schemes*, Australian Securities and Investments Commission, <www.cpd.com.au/newcorp/asic/ps/ps139.pdf>, 8 July 1999.

74 Financial Industry Complaints Service, *Rules* (2002), Melbourne.

75 Insurance Enquiries and Complaints Ltd, *The General Insurance Enquiries and Complaints Scheme: Terms of Reference*, <www.iecltd.com.au/index2.html>, 20 February 2003.

27.107 As noted above, FICS and IEC do not currently have jurisdiction to deal with complaints regarding premiums or underwriting.⁷⁶ The Inquiry received advice from FICS that there may be scope for it to examine the actuarial basis of decisions when a proposal 'was rejected maliciously, or on the basis of incorrect information', but this possibility does not appear to be utilised in practice.⁷⁷

27.108 PS 139 requires an independent review of EDR schemes every three years. FICS is currently the subject of such a review. The review published an Issues Paper in August 2002, with the Final Report expected in March 2003. The Issues Paper identified a number of problems with the existing FICS scheme, including the monetary limits on jurisdiction and consumer dissatisfaction with the FICS process.⁷⁸

27.109 The Inquiry was informed that the ICA and general insurance industry members are currently engaged in a review of IEC's terms of reference.⁷⁹

Anti-discrimination legislation

27.110 A complaint of unlawful discrimination based on the use of genetic information by an insurer can be brought before HREOC, which has the power to investigate and conciliate complaints under the DDA.⁸⁰ Of the total 452 complaints received by HREOC in relation to alleged unlawful discrimination under the DDA during the period 2001–2002, 15 complaints (3.3%) were received in relation to insurance and superannuation.⁸¹ As noted above, however, to date, HREOC has not received any complaints in relation to the use of genetic information in insurance.

27.111 Once a complaint has been lodged, HREOC has the power to require an insurer to provide actuarial or statistical data in accordance with s 107 of the DDA. As discussed above, a number of submissions raised concerns about the effectiveness of this mechanism. When HREOC terminates a complaint of alleged unlawful discrimination because, for example, it cannot be conciliated, the complainant may apply to have the complaint considered by the Federal Court or the Federal Magistrates Court.

27.112 IFSA expressed the view that the anti-discrimination regime provided an effective mechanism for insurance applicants to pursue their rights:

IFSA believes that existing anti-discrimination laws are adequate. In the past they have allowed people to seek recourse when needed and we see no reason why they should fail where genetic information is concerned. We do not see genetic

76 Financial Industry Complaints Service, *Rules* (2002), Melbourne, Rule 15; Insurance Enquiries and Complaints Ltd, *The General Insurance Enquiries and Complaints Scheme: Terms of Reference*, <www.iecltd.com.au/index2.html>, 20 February 2003 [4.2].

77 W Ribbands, *Correspondence*, 23 July 2002. See also Financial Industry Complaints Service, *Rules* (2002), Melbourne, Rule 15.

78 Community Solutions and La Trobe University and University of Western Sydney, *Review of the Financial Industry Complaints Service 2002 — What are the Issues?* (2002).

79 Insurance Council of Australia, *Consultation*, Sydney, 18 November 2002.

80 *Human Rights and Equal Opportunity Commission Act 1986* (Cth) s 11(1)(aa).

81 Human Rights and Equal Opportunity Commission, *Annual Report 2001–2002* (2002), Sydney.

information as being any different to any other type of information collected for risk assessment.⁸²

27.113 The Anti-Discrimination Board of NSW, however, raised the following concerns in relation to relying on the anti-discrimination regime to address consumer complaints in the insurance context:

IFSA's approach also fails to acknowledge the power inequities which exist between individuals and insurance companies. Where an application for insurance is refused, the onus is on the individual to lodge a complaint under anti-discrimination law. This means people have to understand their experience as discrimination, and have sufficient information and resources to use the complaints mechanisms available.

Even if consumers can do so, there is a significant imbalance of power between consumers and the insurance industry, particularly in relation to their respective capacities to bear the costs involved in pursuing a matter to hearing. This can lead to unsatisfactory settlements at conciliation, while in turn conciliated settlements do not produce binding precedents.⁸³

27.114 The acting Disability Discrimination Commissioner expressed the view that insurance should be properly regulated by insurance law and industry mechanisms in the first instance and that the anti-discrimination regime should be relied on to provide a safety net only where necessary.⁸⁴

Awareness of existing complaint mechanisms

27.115 A number of submissions indicated that consumers are not made sufficiently aware of the complaint mechanisms available to them in the area of insurance. The study conducted by Dr Kristine Barlow-Stewart and David Keays noted that:

None of the cases of reported genetic discrimination indicated that they were followed by an exhaustion of the available appeal mechanisms and three individuals stated they were unaware how to appeal against the decision of an insurance company. It is apparent that consumers are unaware of the mechanisms available for redress following discrimination.⁸⁵

27.116 As noted earlier in this chapter and in Chapter 25, IFSA has taken steps to improve this situation, particularly in relation to the Genetic Testing Policy, which imposes an obligation on members to inform applicants about their legal rights to challenge an unfavourable decision.⁸⁶ In addition PS 165 now requires insurers to have a system for informing complainants about the availability and accessibility of the relevant EDR scheme.

⁸² Investment and Financial Services Association, *Submission G049*, 14 January 2002.

⁸³ Anti-Discrimination Board of NSW, *Submission G157*, 1 May 2002.

⁸⁴ Acting Disability Discrimination Commissioner — Human Rights and Equal Opportunity Commission, *Submission G301*, 16 January 2003.

⁸⁵ K Barlow-Stewart and D Keays, 'Genetic Discrimination in Australia' (2001) 8 *Journal of Law and Medicine* 250, 258.

⁸⁶ Investment and Financial Services Association, *IFSA Standard 11.00 'Genetic Testing Policy'* (2002), IFSA [10.14.2].

27.117 The Anti-Discrimination Board of NSW submitted that government and anti-discrimination agencies also need to be more active in making individuals aware of their right to lodge a complaint of unlawful discrimination in insurance under anti-discrimination law:

People are less likely to be deterred from undertaking genetic testing if they are confident that their human rights will be protected. In order to instil such confidence in the community, not only must privacy and anti-discrimination laws provide adequate protection, people must understand their rights. We refer you to section 3.3.9 above where we emphasise the important role anti-discrimination agencies can play in educating those affected about their rights. As we have discussed, if complaint handling mechanisms are fraught with delays, people are unlikely to feel confident that anti-discrimination legislation will provide effective redress. Community confidence is also likely to be supported where people are assured that they can access information upon which insurance companies base their decision.

So too, anti-discrimination agencies have a critical role to play in working with employers, insurance companies and other service providers to prevent discrimination.⁸⁷

Options for reform

27.118 A number of submissions proposed changes to the existing review and appeal mechanisms available to applicants, drawing particularly on the experience of some overseas jurisdictions.

27.119 In the United Kingdom, the Association of British Insurers (ABI) has established the Genetic Testing—ABI Code of Practice Adjudication Tribunal, which can receive and adjudicate complaints of alleged breaches of the ABI Genetic Testing Code of Practice for life insurance and some forms of general insurance. The Code of Practice states in part:

48. If an applicant has concerns about any aspect of his/her application for insurance and the resulting decision, he/she should contact the company using its complaints procedure. If the company cannot satisfy the applicant within a reasonable period of time, and the complaint is about a breach in the Code of Practice, the applicant has the right to refer the case to the independent Genetic Testing—ABI Code of Practice Adjudication Tribunal to which ABI companies agree to be bound. The Tribunal, like other adjudication services, will consider appeals only if the insurer's own complaints mechanism has not resolved the issue to the complainant's satisfaction. The applicant, of course, is free to apply to another insurance company at any time.

49. The independent Adjudication Tribunal will comprise individuals who have the confidence of both the insurance industry and the public. Amongst them, they will demonstrate a clear understanding of insurance law and underwriting practice and of genetic science and its clinical implications.

50. The Tribunal will consider a complaint from an individual where the insurance company has allegedly breached the Code of Practice when considering his/her application; there will be no cost to the individual whether or not the complaint is

87 Anti-Discrimination Board of NSW, *Submission G157*, 1 May 2002.

upheld. The Tribunal will be funded by the ABI, if necessary by a special levy on its members. They will take evidence from the insurer as well as the applicant. The Tribunal's decision is binding on the insurer but not on the complainant. Decisions will be analysed so that best practice can be adopted across the industry. The Tribunal will work within terms of reference and to service standards. The Tribunal will publish an annual report which will be available to the public.⁸⁸

27.120 The Centre for Law and Genetics supported the establishment of a similar body in Australia:

There should also be a clear avenue of appeal to individuals in circumstances where they disagree with the decision that has been made. ... The creation of a robust, independent appeals mechanism as recommended by the [United Kingdom] Human Genetics Advisory Commission and as now provided for under the Association of British Insurers *Code of Practice* should therefore be a priority.

Such measures would assist in enhancing the accountability of insurers in their use of genetic information and at the same time, would help to promote understanding of the implications of genetic testing in the community.⁸⁹

27.121 The Commonwealth Department of Health and Ageing proposed that serious attention should be given to the framework elements of the ABI Genetic Testing Code of Practice, including a complaint and appeal mechanism such as adjudication by the ABI Code of Practice Adjudication Tribunal.⁹⁰ It was suggested that IFSA's Genetic Testing Policy, which already includes a number of these elements, could form the basis for further developments in both the life and general insurance industries.

27.122 In consultations, the Swedish Insurance Federation reported that a review board had been established by statute in Sweden to investigate complaints with regard to the use of genetic information in underwriting.⁹¹ The body had been established to provide a mechanism of review that was independent of the insurer that made the underwriting decision but by March 2003 it had not received a complaint.

27.123 In response to DP 66, IFSA expressed the view that:

IFSA supports the need to ensure that only acceptable and appropriate uses are made of genetic test results and that the development of an appropriate independent review mechanism is the best way to achieve this. IFSA believes that the Financial Industry Complaints Service Limited (FICS) with an extension of that body's jurisdiction to deal with such matters would be ideally suited to this task ...

IFSA believes that it is feasible for the existing role of the FICS as an EDR scheme to be expanded to cover complaints concerning underwriting decisions based on the use of genetic test information only. IFSA's view is that the position on family medical history requires further research and investigation, as canvassed earlier, before giving consideration to any expansion of the jurisdiction of FICS with respect to family medical history.

88 Association of British Insurers, *Genetic Testing: ABI Code of Practice* (1999), Association of British Insurers, London Pt 5.

89 Centre for Law and Genetics, *Submission G048*, 14 January 2002.

90 Commonwealth Department of Health and Ageing, *Submission G150*, 15 April 2002.

91 Swedish Insurance Federation, *Consultation*, Stockholm, 25 March 2002.

IFSA proposes to seek an in principle agreement with FICS to amend their Rules/Constitution which currently excludes dealing with complaints relating to underwriting decisions leading to an offer or rejection of insurance based on genetic test results.

IFSA will commence liaising with FICS in January 2003 with a view to seeking an extension of FICS' jurisdiction to deal with complaints against life insurers and the establishment of a separate panel. This separate panel would comprise individuals who have the right mix of skills to adjudicate matters relating to genetic information such as a representative from the Human Genetics Society of Australasia.⁹²

27.124 The Centre for Law and Genetics noted in relation to this proposal that a properly constituted industry body could fulfil this role, although the Centre suggested some level of oversight of the industry body by the HGCA.⁹³ The Australian Life Underwriters and Claims Association agreed that FICS could take on this role but suggested that an expert panel within FICS may have to be established to deal with complaints about insurers' use of genetic information.⁹⁴

Inquiry's views

27.125 The Inquiry is of the view that there is a gap in the avenues for review and appeal currently available to applicants for insurance where genetic information has been used in underwriting. An applicant may seek review by the insurer that made the decision, in accordance with the insurer's IDR procedures. If the complaint is not resolved with the insurer, applicants may seek external review through a government agency such as HREOC, and ultimately through the courts. Applicants for life insurance products may also approach IFSA under its Genetic Testing Policy.

27.126 The difficulties with internal review by insurers include that the process lacks independence, and the adequacy of procedures may vary widely among insurers. The mandatory standards established for IDR procedures under the FSRA, discussed above, may lead to a more consistent approach to this issue across the industry in the future. The intercession of IFSA under the Genetic Testing Policy is limited to complaints in relation to applications for life insurance products involving genetic test information.

27.127 The difficulties with HREOC procedures are that applicants may be unaware of their right to seek review; such review may be costly and slow; applicants may have difficulty in ascertaining the information upon which they can base their claim of unlawful discrimination; and the disparity between the capacity of the applicants and insurers to pursue the claim may lead to unsatisfactory settlement outcomes. Many of the difficulties of review by a government agency are systemic: they are not specific to complaints regarding the use of genetic information, nor even to complaints against insurers. If solutions to these problems are to be found, it will be necessary to look beyond the scope of the present Inquiry. As a result, the Inquiry makes no

92 Investment and Financial Services Association, *Submission G244*, 19 December 2002.

93 Centre for Law and Genetics, *Submission G255*, 21 December 2002.

94 Australian Life Underwriters and Claims Association Inc, *Submission G300*, 10 January 2003.

recommendations for the reform of the existing system of merits review by anti-discrimination agencies.

27.128 The Inquiry has formed the view that the external dispute resolution schemes offered by FICS and the IEC should be expanded to provide an industry-based mechanism for investigating and adjudicating disputes about underwriting decisions based on genetic information. This will provide a middle tier of review—one that is independent of the insurer who made the decision but avoids some of the difficulties associated with independent agency review.

27.129 Implementation of this recommendation will require a review of the constitution of each body to enable them to receive complaints about adverse underwriting decisions. It will also require a reconsideration of the monetary limits on their jurisdiction. In Chapter 25 the Inquiry noted that the approximate average level of cover for term life insurance in Australia is \$235,000. If FICS were to maintain its current jurisdictional limit of \$250,000, many life policies would be excluded from the review process. The Inquiry is of the view that any monetary limits on jurisdiction should be adequate to ensure that FICS and IEC have the capacity to deal with a substantial majority of complaints. These issues will need to be addressed in response to the final report of the independent review of FICS, which may provide a starting point for the development of this new role for FICS.

27.130 The Inquiry is of the view that the jurisdiction of FICS and IEC should be expanded to include underwriting decisions involving family medical history as well as genetic test information. This would be consistent with the suggested extension of the Genetic Testing Policy to cover family medical history. Some of the case studies in submissions involved the interaction of genetic test information and family medical history and it is important that industry complaints bodies are able to consider both issues where they arise. Both are of concern to the community and the Inquiry is of the view that the additional transparency and accountability likely to accompany independent review will improve public confidence in the use of this information by insurers.

27.131 Given the complexity of using genetic information in insurance, it is important that review bodies have the expertise to examine both the medical and actuarial dimensions of the underwriting process. One way of achieving this might be to establish expert panels as part of the FICS and IEC processes. As noted above, these EDR processes are subject to independent oversight by ASIC under the FSRA. Any amendment to the rules of FICS or IEC must meet the standards set out in PS 165 and PS 139 and must be submitted to ASIC for approval.

27.132 In relation to the raising of awareness of review procedures, the Inquiry notes that PS 165 imposes an obligation on insurers to inform applicants of available EDR processes. The issue of community education is discussed further below.

Recommendation 27–9. IFSA and the ICA should expand the jurisdiction of the Financial Industry Complaints Service Ltd (FICS) and Insurance Enquiries and Complaints Ltd (IEC) to allow those organisations to review underwriting decisions involving the use of genetic information, including family medical history. The amended rules should ensure that the complaint handling processes are:

- timely and efficient;
- carried out by suitably qualified individuals with a demonstrated understanding of insurance law and anti-discrimination law, underwriting practice, and clinical genetics;
- binding on the insurer but not on the complainant; and
- available in respect of a substantial majority of complaints, having regard to the monetary sum in question.

Education and training

27.133 A number of submissions to the Inquiry expressed concern that participants in the insurance industry, and particularly those providing advice directly to applicants, such as agents and brokers, did not have an adequate understanding of genetic information and its implications for insurance. The Centre for Law and Genetics submitted that:

Anecdotally one hears accounts which suggest that the information available to agents and brokers on this subject may be less than adequate, or even if adequate, is not well understood by the agents and brokers, and that this, in turn, is reflected in the quality and accuracy of the information that they are able to provide. Indeed, it has been suggested that advice given by agents and brokers at the coalface may inappropriately deter individuals who have obtained unfavourable genetic test results or who have a family history of genetic disease from even applying for insurance, on the mistaken belief that their application will not be accepted.⁹⁵

27.134 The Institute of Actuaries of Australia submitted that education is an important consideration for those who work with genetic information. However, the Institute also noted that the degree of understanding and training required depends on the context:

We see a strong need for all people who are going to be dealing with genetics in their day to day work to understand what they are seeing. Sometimes this will require them to undertake detailed continuing professional education on genetics. This will apply, for example, to members of the medical profession ... or to underwriters and actuaries who are making assessment decisions on applications for life insurance policies ... In other cases, it will be enough to obtain a broad understanding, provided that the

95 Centre for Law and Genetics, *Submission G048*, 14 January 2002.

persons concerned know their limitations and seek the help of experts when they reach the boundaries of their own knowledge. This is likely to be the case in the employment field ... or for insurance agents and brokers.⁹⁶

27.135 The HGSA expressed concern about the specificity of advice that agents and brokers might be required to give:

The HGSA believes, given the sensitivity of genetic information and the complexity of interpreting it, that agents and brokers should NOT offer specific advice about the implications of genetic testing. They must be able to offer generic advice about the implications for insurance of having, or not having, a genetic test and where to get further information about genetic testing such as through a medical practitioner.⁹⁷

Industry education

27.136 Under the FSRA all AFS licence holders are required to:

- maintain the competence to provide the financial services covered by the AFS licence; and
- ensure that their representatives are adequately trained and are competent to provide the financial services covered by the AFS licence.⁹⁸

27.137 ASIC Policy Statement 146 Licensing: Training of Financial Product Advisers (PS 146) sets out minimum training standards for those who provide financial product advice to retail clients.⁹⁹ IFSA summarised the application of PS 146 to insurers as follows:

IFSA would like to note that under new licensing requirements, holders of the AFS licence have obligations to ensure their representatives (including employees and authorized representatives) are adequately trained and competent to provide financial services on their behalf. In particular, ASIC's Policy Statement 146 [PS 146] contains minimum training standards for representatives who provide financial product advice to retail clients. For advisers in insurance products, ASIC set out in Appendix A2.6 of [PS 146] the core insurance knowledge and specialist knowledge requirements for all categories of insurance (general, life and broking).¹⁰⁰

27.138 The National Finance Industry Training Advisory Body (NFITAB) was established to act in an advisory and consultative role to assist in improving vocational education and training within the Australian financial services sector. Working with industry and government, NFITAB develops national competency standards, learning strategies and resources, assessment instruments and industry seminars. In particular, NFITAB works with industry to ensure that competency standards comply with PS 146. Standards are defined by industry, nationally recognised by the Australian

96 Institute of Actuaries of Australia, *Submission G105*, 7 March 2002.

97 Human Genetics Society of Australasia, *Submission G050*, 14 January 2002.

98 *Corporations Act 2001* (Cth) s 912A(1).

99 Australian Securities and Investments Commission, *Policy Statement 146 Licensing: Training of financial product advisers*, Australian Securities and Investments Commission, <[www.asic.gov.au/asic/pdflib.nsf/LookupByFileName/PS146.pdf/\\$file/PS146.pdf](http://www.asic.gov.au/asic/pdflib.nsf/LookupByFileName/PS146.pdf/$file/PS146.pdf)>, 22 January 2003.

100 Investment and Financial Services Association, *Submission G244*, 19 December 2002.

National Training Authority (ANTA) and form the basis of training for the industry. NFITAB also develops and regularly updates the Financial Services Training Package based on the relevant competency standards.¹⁰¹

27.139 ASIC maintains a Training Register, administered by NFITAB on ASIC's behalf, which lists training courses that have been approved by ASIC authorised assessors as complying with PS 146. In order to be accredited with ASIC, training courses must supply evidence that they have aligned the course to the Financial Services Training Package using the relevant competency standards.

27.140 A number of training providers are involved in delivering accredited training courses to industry participants, including the Financial Planning Association (FPA), the Association of Financial Advisers (AFA), the National Insurance Brokers Association of Australia (NIBA) and the Australian and New Zealand Institute of Insurance and Finance. IFSA noted, for example, that:

The Australian and New Zealand Institute of Insurance and Finance (ANZIIF) has launched its new Diploma of Financial Services (Life Insurance Stream) for 2003 ... To assist members with their professional development, the ANZIIF will also be establishing an insurance medicine interest group. Through this group the latest medical knowledge will be made available to insurance professionals and assist the insurance industry in dealing with medicine related matters such as genetics.¹⁰²

27.141 IFSA also noted that under its Genetic Testing Policy:

Members must provide their employees and Authorised Representatives who represent them with sufficient information and training so that those employees and Authorised Representatives can reasonably be expected to understand the content and meaning of this Standard so far as it relates to their particular jobs and responsibilities.

Members' Authorised Representatives must be aware of the need to seek specialist advice before responding to applicants' questions, as the types of genetic test and their potential impact on the applicant differ enormously.¹⁰³

Community education

Unfortunately, there is a significant lack of public understanding on all matters genetic, whether GM food or cloning or testing. The mechanics of insurance are also not at all well understood, and when the two topics are linked in the same story, all too frequently the result is heat and no light.¹⁰⁴

101 National Finance Industry Training Advisory Body, *Financial Services Training Package Review* (2002), Sydney.

102 Investment and Financial Services Association, *Submission G244*, 19 December 2002.

103 Investment and Financial Services Association, *IFSA Standard 11.00 'Genetic Testing Policy'* (2002), IFSA [10.4].

104 C Daykin and others, *Genetics and Insurance — Some Social Policy Issues* (2003), Institute of Actuaries and Faculty of Actuaries, UK, 36.

27.142 IFSA and the Institute of Actuaries of Australia both agreed that there was a need to provide more community education about genetics and insurance. The Institute drew attention to its paper, *Genetics in Society 2001*, prepared by its workgroup on genetics as a community service.¹⁰⁵ IFSA drew the following conclusions from a commissioned survey on consumer attitudes to genetic testing and life insurance:

Life insurance is a relatively low involvement product, even for those who have voluntary cover. It is not something that occupies consumers' minds at times other than the time of consideration / purchase. The result of this is a low level of awareness and understanding of life insurance products, and more generally, of the operation of life insurance companies ...

The industry believes it is important to continue its efforts to provide better education on insurance matters to the community at large ...

The research indicates that community attitudes are malleable and that there is a need for communication and education not only by the insurers but also by the government and the wider medical community, and to be effective some of that communication should be done jointly.¹⁰⁶

Submissions and consultations

27.143 The majority of submissions dealing with this matter expressed general support for enhanced training and education, at both the industry and community levels. However, several submissions expressed the view that, due to the complex nature of genetic information, it may be unduly onerous to expect insurance agents and brokers to keep fully abreast of relevant developments.¹⁰⁷ It was suggested that

one possible measure to overcome this difficulty would be the appointment of specialist advisors ... who can be contacted as required by the agents and brokers, or even by the applicants themselves, when they have queries regarding the implications of genetic testing on insurance.¹⁰⁸

27.144 The Anti-Discrimination Board of NSW suggested that the HGCA, in conjunction with the insurance industry, undertake educational activities for agents, brokers and other significant participants in the insurance industry.

27.145 The Institute of Actuaries of Australia expressed the view that

there are adequate rules already in place to ensure that agents and brokers have the necessary knowledge on matters relating to the sales process. This includes knowledge on the correct completion of application forms to meet existing legal requirements for full disclosure of all information relevant to the risk the applicant is asking the insurance company to assume.¹⁰⁹

105 A Doble and others, *Genetics in Society 2001* (2001) Institute of Actuaries of Australia.

106 Investment and Financial Services Association, *Submission G049*, 14 January 2002, 43–44.

107 Institute of Actuaries of Australia, *Submission G105*, 7 March 2002; Investment and Financial Services Association, *Submission G049*, 14 January 2002; Human Genetics Society of Australasia, *Submission G050*, 14 January 2002.

108 Centre for Law and Genetics, *Submission G048*, 14 January 2002.

109 Institute of Actuaries of Australia, *Submission G105*, 7 March 2002.

27.146 The Institute went on to note that it may be timely to consider this issue as ASIC is currently reviewing training and accreditation rules under the FSRA.

27.147 In consultations with the Inquiry, Deen Sanders, National Project Manager at NFITAB, noted that NFITAB is also in the process of reviewing and further developing the competency standards and Training Package discussed above. He indicated that NFITAB, in consultation with industry and the HGCA, could ensure that the competency standards and Training Package incorporate an appropriate level of competence in the use of genetic information in insurance. He also indicated that NFITAB is in the process of developing a community education project on financial services and that it would be possible to include information on the use of genetic information in insurance.¹¹⁰ ASIC could have regard to these amended competency standards in assessing whether a training provider is to be listed as a Registered Training Provider under PS 146.

27.148 The Australian Underwriters and Claims Association expressed the view that, as well as building in appropriate modules to existing training programs delivering PS 146 qualifications, industry should also conduct targeted seminars and conferences.

27.149 IFSA indicated its willingness to

work with the HGCA and other relevant parties to further develop appropriate programs that take into account the legal/licensing requirements regarding education and training that flow from the Financial Services Reform Act.¹¹¹

Inquiry's views

27.150 The Inquiry considers that education and training about the nature and use of genetic information in insurance are vital, both for the insurance industry and the broader community. Community and professional education, and the ready availability of information when needed, can minimise misunderstanding of, and over reaction to, genetic information. The Inquiry recognises that the insurance industry is already active in this area, but there is still work to be done.

27.151 In Chapter 5, the Inquiry recommended that the HGCA assist with the development of community and professional education about human genetics. The establishment of the HGCA will provide an opportunity for a heightened focus on industry and community awareness of the wider issues associated with the use of human genetic information in insurance. The HGCA should also have a role in working with industry in relation to education and training.

27.152 However, responsibility for the training and education of industry representatives falls primarily on the industry itself. The Inquiry proposes an increased focus on training and education of industry members and their representatives, including agents and brokers, in relation to the collection and use of genetic

110 National Finance Industry Training Advisory Body, *Consultation*, Sydney, 13 December 2002.

111 Investment and Financial Services Association, *Submission G244*, 19 December 2002.

information in insurance. This focus should extend to continuing professional education. The Inquiry recommends that peak bodies review their policies and practices in this regard.

27.153 In addition, the Inquiry recommends that NFITAB, in consultation with industry and the HGCA, ensure that the Financial Services Training Package and competency standards incorporate an appropriate level of competence in the use of genetic information in insurance.

Recommendation 27–10. IFSA, the ICA and other relevant bodies should review their policies and practices in relation to training and education of members regarding the collection and use of genetic information in insurance.

Recommendation 27–11. The National Finance Industry Training Advisory Body, in consultation with IFSA, the ICA and the HGCA, should review relevant competency standards and the Financial Services Training Package to incorporate an appropriate level of competence regarding the collection and use of genetic information in insurance.

28. Insurance and Genetic Privacy

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Introduction

28.1 The Terms of Reference require the Inquiry to report on whether, and to what extent, a regulatory framework is needed to protect the privacy of human genetic samples and information in a number of contexts, including insurance. Chapters 7 and 8 examine the legal framework for the protection of genetic privacy generally and make a number of recommendations intended to promote greater harmony across Australian jurisdictions and to ensure that privacy laws apply to both genetic samples and information. This chapter considers whether those privacy laws provide sufficient protection for genetic information in the context of insurance.

28.2 Chapters 25, 26 and 27 discuss what genetic information is collected by insurers, the way in which it is used to underwrite insurance policies, and problems that can arise from that use, including possible unlawful discrimination. That discussion focuses on the underwriting of mutually rated insurance in which health information is collected and used, such as life insurance. Privacy issues can arise, however, in relation to both mutually rated and community rated insurance. Health insurers in both the public and private sectors also collect health information. For example, the Health Insurance Commission collects health data in the course of administering Medicare payments for medical services and private health insurers collect health information in relation to pre-existing conditions.

28.3 The privacy of health information held by health insurers is protected by a number of laws. Public sector organisations that administer programs at the federal level, such as the Health Insurance Commission, are bound by the Information Privacy

Principles under the *Privacy Act 1988* (Cth) (*Privacy Act*), as well as by guidelines issued by the Office of the Federal Privacy Commissioner (OFPC) pursuant to the *National Health Act 1953* (Cth).¹ Private sector health insurers are governed by the private sector provisions of the *Privacy Act*. These are discussed further below.

28.4 Submissions received by the Inquiry did not raise concerns in relation to the privacy of genetic information collected in relation to health insurance. However, while the discussion in this chapter focuses on mutually rated life and general insurance, the recommendations made in this chapter are intended to apply to private sector insurers generally.

28.5 Submissions received by the Inquiry did not indicate the existence of major inadequacies in the regulatory framework for protecting the privacy of genetic information in insurance. The OFPC has received a number of complaints in relation to the information handling practices of private sector insurers but is generally of the view, as noted in DP 66, that there is a developed awareness of privacy principles and appropriate personal information handling practices across the insurance industry in Australia.² It appears that both the Insurance Council of Australia (ICA) and the Investment and Financial Services Association (IFSA) have been active in promoting these principles to their members and in contributing to the development of sound practices in the insurance industry.

Regulatory framework

28.6 As discussed in Chapter 25, a contract of insurance is one of ‘utmost good faith’: an applicant for insurance has a duty at common law³ and under legislation⁴ to disclose to the insurer all information that is known, or which reasonably ought to be known, to be relevant to the insurer. As a result, insurers can and do collect a great deal of health information, including some genetic information, from applicants. The privacy of that information was formerly regulated solely by industry standards; it is now regulated by statute and supplemented by industry standards.

Before 21 December 2001

28.7 Prior to 21 December 2001, when the *Privacy Amendment (Private Sector) Act 2000* (Cth) came into force in relation to the private sector, the insurance industry was essentially self-regulating in relation to the principles governing the collection, storage, use and disclosure of personal information. It appears that self-regulation was generally effective in protecting information privacy. In a 1996 Information Paper on the privacy implications of genetic testing, the then Federal Privacy Commissioner found that:

1 Office of the Federal Privacy Commissioner, *Submission G143*, 22 March 2002.

2 Office of the Federal Privacy Commissioner, *Submission G294*, 6 January 2003.

3 *Carter v Boehm* (1766) 3 Burr 1905, 1909 (Mansfield LJ).

4 *Insurance Contracts Act 1984* (Cth) s 21. See also Australian Law Reform Commission, *Review of the Marine Insurance Act 1909*, Report 91 (2001), ALRC, Sydney Ch 10.

life insurance companies put considerable emphasis on protecting the confidentiality of personal information and complaints about improper handling of information do not appear to be a major focus of dissatisfaction with industry practice.⁵

28.8 More recently, but prior to 21 December 2001, the Financial Industry Complaints Service (FICS) commented on the low number of complaints in the industry with respect to privacy. In a letter to IFSA, FICS stated that:

Complaints about specific breaches of privacy by our life insurance company members are low. However, the Service has received a number of complaints related to disputed claims where the complainant has raised a privacy issue, such as an objection to the insurer seeking information from old medical records. It is not possible to determine the exact number of complaints the Service has received containing such an associated privacy issue. However, I have consulted our long standing staff members who have advised such complaints would only be in the vicinity of 2 to 3 per year.⁶

28.9 IFSA noted in its submission to the Inquiry that:

The life insurance industry has a long history of collecting medical and personal information for use in underwriting whilst at the same time safeguarding the individual's privacy. This has been demonstrated by the way in which the industry has managed the highly sensitive information associated with underwriting for HIV/AIDS.⁷

28.10 The ICA notes on its website that:

[The general insurance industry] was first among private sector groups to adopt the National Principles for the Fair Handling of Personal Information, a voluntary set of information privacy principles for the private sector issued by the federal Privacy Commissioner in February 1998. At the same time the industry set up an independent complaints handling, monitoring and enforcement scheme to support the effective operation of the National Principles. The scheme (called the 'General Insurance Information Privacy Principles') was formally launched by the federal Attorney-General in August 1998.⁸

Since 21 December 2001

28.11 Since 21 December 2001, the collection, use, storage and disclosure of an applicant's or insured's personal information by private sector insurers has been regulated by the *Privacy Act*. Under these provisions, the National Privacy Principles (NPPs) apply to insurers unless they choose to be bound by a privacy code that has been approved by the Privacy Commissioner and provides an equivalent level of protection.

5 Federal Privacy Commissioner, *The Privacy Implications of Genetic Testing* (1996), OFPC, Sydney, 40.

6 Investment and Financial Services Association, *Submission G049*, 14 January 2002.

7 Ibid.

8 Insurance Council of Australia, *Submission G010*, 27 June 2001.

28.12 The ICA was the first private sector organisation to develop a privacy code and to have it approved and listed on the Register of Approved Privacy Codes under s 18BG of the *Privacy Act*. The Code is based on the General Insurance Information Privacy Principles, with some additions and modifications to meet the new legislative requirements. The General Insurance Information Privacy Code was approved on 17 April 2002. It applies to general insurance business, which, as discussed in Chapter 25, includes some insurance products in which an applicant's health information is collected and used for underwriting.⁹

28.13 As discussed in Chapter 7, the NPPs do not apply to certain small business operators.¹⁰ Although insurance companies are unlikely to fall within this exemption (by reason of their high annual turnover), the situation in relation to insurance brokers and agents is not as straightforward. In its submission, the OFPC noted that:

Insurance is now covered by the private sector amendments to the Act, unless some entities within the industry can bring themselves within the small business exemption. For the most part, however, insurance agents and brokers will be either traders in personal information or related bodies in the terms of section 6D of the Act and hence will be subject to the Act.¹¹

28.14 The Inquiry notes, however, that even traders in personal information are exempt from the *Privacy Act* in some circumstances, for example, if they disclose personal information only with the consent of the individual concerned or as required or authorised by legislation.¹²

28.15 In Chapter 7 the Inquiry expressed the view that all small business operators who collect, use or disclose genetic information should be subject to the provisions of the *Privacy Act*. Recommendation 7-7 has been framed to address this gap in the coverage of federal privacy law, and would apply, if adopted, to small business operators in the field of insurance.

28.16 In addition to the role of federal legislation, the privacy of genetic information in underwriting is regulated by industry standards. For example, in 2001 IFSA issued a Genetic Testing Policy for its members, which is described in more detail in Chapter 25. The policy applies to genetic tests, as defined in the policy, but does not extend to genetic information in the form of family medical history. Several provisions in the Genetic Testing Policy are directed to privacy issues, including the following:

- 6 Insurers will ensure that results of existing genetic tests are only obtained with the written consent of the tested individual.

9 See ICA website: Insurance Council of Australia, *Privacy Code*, <www.ica.com.au/privacyprinciples/>, 20 February 2003.

10 *Privacy Act 1988* (Cth) s 6C.

11 Office of the Federal Privacy Commissioner, *Submission G143*, 22 March 2002.

12 *Privacy Act 1988* (Cth) s 6D(7).

- 7 The results of genetic tests will only be used in the assessment of an insurance application in respect of the individual on whom the test was conducted. The result will not be used in the assessment of insurance applications of relatives of the tested individual.
- 8 Insurers will ensure that strict standards of confidentiality apply to the handling and storage of the results of genetic tests.
- 9 Access to the results of genetic tests in a form identifiable to particular individuals will be restricted to the insurer's underwriters and reinsurers. The results will be made available to other third parties only with the written authorisation of the applicant/insured or in the normal course of discovery during legal proceedings.¹³

Adequacy of regulatory framework

28.17 Submissions received by the Inquiry did not identify major problems in the legal framework for protecting genetic information collected by the insurance industry. The OFPC expressed the view that:

As previously argued in this submission, the privacy protection framework for personal information across the private sector, including the insurance industry, is fundamentally sound.¹⁴

28.18 The Centre for Law and Genetics observed:

The new private sector privacy laws and arrangements, although as yet largely untested in view of their recent commencement, appear to provide quite a satisfactory framework for the protection of privacy interests in general. They are, of course, not specially geared to the protection of genetic information, although for most practical purposes, this category of information would be covered within the definition of health information which is recognized under the legislation as being a particularly sensitive form of information ...

Notably, although there have been ongoing concerns about the use by insurers of genetic test information, few, if any, complaints have been heard regarding insurers' failure to adequately protect the privacy of this information.¹⁵

28.19 The Inquiry considers that the basic framework for privacy protection in the insurance context is satisfactory. However, a number of specific issues were raised which require further consideration. These issues are discussed in the following sections and relate to:

- the quality of consent to collection and use of genetic information by insurers;
- the collection of family medical history by insurers; and
- the sharing of information between related insurance organisations.

13 Investment and Financial Services Association, *IFSA Standard 11.00 'Genetic Testing Policy'* (2002), IFSA.

14 Office of the Federal Privacy Commissioner, *Submission G143*, 22 March 2002.

15 Centre for Law and Genetics, *Submission G048*, 14 January 2002.

Consent to collection and use of genetic information

28.20 Concern was expressed in some submissions about the quality of consent required to meet the standards set out in the NPPs. Consent may be required under the NPPs in a range of circumstances such as the collection of sensitive information (including most genetic information); use for any purpose other than the primary purpose of collection; and transfer of personal information out of Australia. The OFPC's *Guidelines to the National Privacy Principles* set out the requirements for valid consent under the *Privacy Act*:

Consent means voluntary agreement to some act, practice or purpose. It has two elements: knowledge of the matter agreed to, and voluntary agreement. Consent can be express or implied. Express consent is given explicitly, either orally or in writing. Implied consent arises where consent may reasonably be inferred in the circumstances from the conduct of the individual and the organisation. Consent is invalid if there is extreme pressure or coercion.¹⁶

28.21 The two elements for valid consent identified in the Guidelines—the informed nature of the consent and its voluntariness—are discussed separately below. This section also considers the related issue of ‘bundled consents’, which goes to the voluntariness of consent.

Informed consent

Submissions and consultations

28.22 A number of submissions raised concerns about whether applicants for insurance are sufficiently well informed about the collection and use of genetic information by insurers to give valid consent. UnitingCare NSW & ACT stated in its submission:

One problem with privacy legislation is that a wide range of things can be done with information provided that the individual gives their consent to a company to disclose the information. This assumes that individuals are aware of the implications, for themselves and others, of information being disclosed. This is likely to be untrue in many situations. People lack the information necessary to give informed consent. This makes legislative requirements hollow.¹⁷

28.23 The Centre for Law and Genetics was of the view that, in relation to genetic information in particular, there were grounds for ensuring that particular care is taken in collecting and using the information:

There are good grounds for suggesting that a heightened level of protection of this form of information is appropriate in some particular areas—not necessarily because genetic information should be regarded as ‘unique’, but because there are a number of factors associated with it, the combined effect of which justifies taking particular care in the collection and use of this information. We would accordingly support an

16 Office of the Federal Privacy Commissioner, *Guidelines to the National Privacy Principles* (2001), OFPC, Sydney.

17 UnitingCare NSW & ACT, *Submission G052*, 14 January 2002.

enhanced level of consent being required from the applicant in relation to genetic information to ensure that it is only collected when necessary, as one measure which would assist in the better protection of genetic information.¹⁸

28.24 Privacy NSW expressed a similar point in relation to medical authority forms used by insurers:

In the case of insurance contracts, it seems that no 'standard' medical authority is in use. If insurance companies are to collect genetic testing information, the consent form should be standardised and include a separate section on genetic testing with precise information as to the exact and specific nature of the test requested, why it is requested, and how it will be used and/or disclosed.¹⁹

28.25 In response to DP 66, IFSA submitted:

IFSA believes that the current consent and medical authority forms fully satisfy National Privacy Principle (NPP) 1 Collection and NPP 10 Sensitive Information with respect to the collection of human genetic test information. However, in the interests of establishing public confidence, IFSA would support a review by insurers of their consent forms and medical authority forms. Such a review would examine what additional information might be provided (e.g. the definition of a 'Genetic Test' based on the IFSA Genetic Testing Policy) so that applicants for insurance are better informed about this issue and its relevance to the assessment of their insurance proposal.²⁰

28.26 A number of submissions suggested that such a review be conducted in consultation with the Human Genetics Commission of Australia (HGCA).²¹

Inquiry's views

28.27 In the Inquiry's view, the collection and use of genetic information by insurers does give rise to the need to ensure that applicants are adequately informed. Genetic information has some special characteristics, such as its predictive and familial nature, which need to be raised with and considered by applicants at the time of collection. While applicants have a duty to disclose relevant information to insurers, that duty only arises if the applicant decides to proceed with the insurance application. An applicant should be given sufficient information to enable the applicant to make an informed decision about whether to proceed.

28.28 The Inquiry recommends, therefore, that insurers review their consent and medical authority forms to ensure that they contain sufficient information about the collection, use and disclosure of genetic information to allow applicants to make an informed decision about whether to proceed with the application and consent to the collection of the information. The review would also provide an opportunity to ensure that consent and medical authority forms are consistent with the NPPs, any approved privacy codes and IFSA's Genetic Testing Policy, where applicable. The Inquiry

18 Centre for Law and Genetics, *Submission G048*, 14 January 2002.

19 Office of the Privacy Commissioner (NSW), *Submission G118*, 18 March 2002.

20 Investment and Financial Services Association, *Submission G244*, 19 December 2002.

21 Human Genetics Society of Australasia, *Submission G267*, 20 December 2002; Centre for Genetics Education, *Submission G232*, 18 December 2002.

considers that the review should be conducted in consultation with the HGCA and the OFPC, and might usefully be streamlined by engaging IFSA and the ICA in the process.

Recommendation 28–1. Insurers should review their consent forms, including medical authority forms, to ensure that they contain sufficient information about the collection, use and disclosure of genetic information to allow applicants to make an informed decision about whether to proceed with their application and consent to the collection of the information. In undertaking this review, insurers should consult with the Human Genetics Commission of Australia and the Office of the Federal Privacy Commissioner.

Voluntary consent

28.29 As noted above, legislation requires an applicant to disclose to the insurer all information that is relevant to underwriting the risk. A number of submissions expressed concern that this obligation may have implications for the voluntariness of an applicant's consent, which is the second element identified by the OFPC as necessary for valid consent under the *Privacy Act*.

Submissions and consultations

28.30 Privacy NSW expressed the concern that, in the insurance context, the voluntariness of consent may be compromised:

In any event, even the full provision of accessible information will not support fully free consent in the insurance and employment context where penalties may apply if an applicant declines to provide information. Applicants may feel unable to refuse where there is a possibility of their application for employment or insurance being rejected if they do not agree to the disclosure of genetic testing information.

It is questionable as to whether this situation of *coerced consent* is adequately addressed in the existing privacy legislation. For instance, the guidelines to the *Privacy Act*, cite 'extreme pressure' as vitiating voluntary consent. This does not equate to the 'take it or leave it' option that is likely to arise when genetic testing information is solicited for insurance and employment purposes.²²

28.31 UnitingCare NSW & ACT was also of the view that:

Reliance on individual consent also ignores the difference in power in the relationship of individuals with organizations. Employers and insurance companies have considerable power compared to individuals, based on their economic power, knowledge power, and coercive power. Individuals can feel powerless to say 'no' to insurance companies or employers. They need the law to protect them from unnecessary invasion of their privacy and erosion of their interests.²³

²² Office of the Privacy Commissioner (NSW), *Submission G118*, 18 March 2002.

²³ UnitingCare NSW & ACT, *Submission G052*, 14 January 2002.

28.32 Margaret Otowski described the interaction between the disclosure obligations in the *Insurance Contracts Act 1984* (Cth) (*Insurance Contracts Act*) and the obligations in the *Privacy Act* in the following terms:

Information disclosed to the insurer pursuant to these disclosure obligations would be regarded as information provided with the consent of the individual even though individuals may feel they have no real choice about this and in that sense one might question the 'voluntary' nature of this disclosure.²⁴

28.33 Kathy Liddell also emphasised that privacy laws are directed towards how information is handled rather than what information is required in particular contexts:

Usually, privacy laws allow information to be used consistent with an individual's consent. The fundamental tenet of these statutory schemes is that an individual ought to have control over their personal information. The response by insurers is simply to refuse to enter into an insurance contract if the individual does not consent to the use of their information. In these circumstances there is no breach of information privacy law.²⁵

Inquiry's views

28.34 The Inquiry is of the view that in a properly regulated environment the duty of 'utmost good faith' of contracting parties is necessary and appropriate in relation to mutually rated insurance products in the private sector. While there may be a tension between an applicant's legal obligation to disclose all relevant information to the insurer and the voluntariness of consent to disclosure for the purposes of the *Privacy Act*, the tension is created by the applicant's desire to enter into a contractual arrangement in which there is an established duty of disclosure.

28.35 Some submissions identified the problem of coerced consent as arising in the contexts of both employment and insurance. The Inquiry considers that a relevant distinction can be drawn between these situations. The right to work has been recognised as a fundamental human right by many countries within the international community.²⁶ A person's ability to work is important to his or her financial security, self-esteem and community involvement. If access to employment were made conditional on the provision of genetic information to an employer, there may be a real sense in which consent to provide that information is coerced—the alternative to the offered employment may be unemployment.

28.36 The inability to access insurance products creates problems of a different order. While some insurance products provide financial support for the insured, or his or her family, on the occurrence of the insurance event, the consequences of being unable to purchase an insurance product are different in degree from the consequences of being unable to sell one's labour to earn a livelihood. In a practical sense, the

24 M Otowski, *Submission G159*, 24 April 2002. The Centre for Law and Genetics also addressed the tension between the need for voluntary consent under the *Privacy Act* and the requirement to disclose all relevant information to insurers. See Centre for Law and Genetics, *Submission G048*, 14 January 2002.

25 K Liddell, *Submission G147*, 10 April 2002.

26 *International Covenant on Economic, Social and Cultural Rights*, opened for signature 19 December 1966, 993 UNTS 3, (entered into force on 10 March 1976), art 6(1).

voluntariness of consent may depend on the nature of the insurance and the circumstances of the insured. To a self-employed individual whose access to a mortgage depends on having income protection insurance, the disclosure of information may not seem entirely free. Yet, in general, consumers do voluntarily choose whether to apply for insurance, and thus enter into a commercial relationship with the insurer. One aspect of that commercial relationship is that the consumer gives up the right to decide what information should be disclosed and what may be withheld.

28.37 In the Inquiry's view, the essence of the problem does not appear to be that consent to providing the information is vitiated by coercion in purchasing the insurance product. The real problems appear to be whether genetic information is scientifically reliable and actuarially relevant to the application for insurance and the extent to which insurers' use of the information is fair and reasonable. The Inquiry considers that these problems are better addressed by examining industry practice and the operation of anti-discrimination laws (see Chapters 26 and 27), than by amending privacy laws.

Bundled consents

28.38 A related issue, which also goes to the voluntariness of consent, is the question of 'bundled consents'. The OFPC set out the problem as follows:

The OFPC's concerns around 'bundled consents' are directed against the practice of financial institutions making it a condition of an individual's access to their services that the individuals agree to a wide range of further uses and disclosures of their information. In other words, the individual's consent to those further uses and disclosures in some circumstances may lack the requisite voluntariness and range of options. In other circumstances, the consents sought from the individual are unduly broad or loosely worded, allowing an organisation to interpret the consents in a manner which is ultimately intrusive or harmful to the individual. While the practice of bundled consents may not be in breach of the Act, it must be regarded as contrary to the spirit of the legislation.²⁷

28.39 The OFPC has received a small number of complaints in relation to bundled consents in insurance claims forms²⁸ and, in a May 2002 Media Release, the Federal Privacy Commissioner made the following comment:

Bundled consents are not good privacy or business practices and are totally contrary to the spirit of the Privacy Act ...

Where the exchange of personal information for a service is necessary, the information collected should be required to undertake that particular service—this is the whole thrust of National Privacy Principle One. If the organisation wants to use that information for a purpose other than that for which it was collected, then the

²⁷ Office of the Federal Privacy Commissioner, *Submission G294*, 6 January 2003.

²⁸ *Ibid.* See *A v Insurer* (2002) PrivCmrA 1: see Office of the Federal Privacy Commissioner, <www.privacy.gov.au/publications/casenotes/ccn1_02.doc>, 18 March 2003.

individual's consent should be sought for the extended use of that information but it should not be made a condition of the original service.²⁹

28.40 DP 66 asked whether the practice of 'bundling consents' undermines the ability of an applicant for insurance to validly consent to the collection of genetic information and, if so, what measures should be taken to address the problem.

Submissions and consultations

28.41 In response to DP 66, a number of submissions expressed the view that provisions seeking consent to the collection of genetic information should be specific to genetic information.³⁰ The Queensland Government commented that

including consent provisions about the use and release of genetic information into bundled consent packages may not be appropriate. There is a need to ensure this difficult subject receives sufficient attention from the applicant to enable informed consent to be given.³¹

28.42 The Androgen Insensitivity Syndrome Support Group expressed the view that:

The practice of blanket or bundled consents should not be applied to genetic information. It should be clear where a person consents to their genetic information being used for any purpose, the purposes for which the information can be used and any other person to whom the information can be disclosed. A person who gives consent for access to their genetic information should also have the option of specifying the purpose or purposes for which the consent is given, not the all or nothing approach offered by blanket consents. They should also be told that they could withdraw their consent at a later date.³²

28.43 In its submission to the Inquiry IFSA stated:

When insurers seek consent from an individual to the provision of health information (including medical, genetic test or family history information) in order to underwrite the relevant life insurance policy, the consent is used for that purpose and that purpose alone.³³

28.44 The submission went on to make clear that:

29 Office of the Federal Privacy Commissioner, *Announcement: Bundled Consents and the Privacy Act*, The Office of the Federal Privacy Commissioner, <www.privacy.gov.au/news/media/02_8.html>, 20 February 2003.

30 Cancer Council Victoria Cancer Genetics Advisory Committee, *Submission G195*, 27 November 2002; Centre for Genetics Education, *Submission G232*, 18 December 2002; Genetic Support Council WA, *Submission G243*, 19 December 2002; Human Genetics Society of Australasia, *Submission G267*, 20 December 2002.

31 Queensland Government, *Submission G274*, 18 December 2002.

32 Androgen Insensitivity Syndrome Support Group Australia, *Submission G290*, 5 January 2003.

33 Investment and Financial Services Association, *Submission G244*, 19 December 2002.

IFSA does not support the bundling of consents not related to the primary purpose of collection as a practice. The issue of bundling consents is irrelevant to the collection of genetic test information, which is for the sole purpose of providing life insurance services in accordance with the *Insurance Contracts Act*.³⁴

28.45 The OFPC noted in its submission that it is continuing to monitor the use of bundled consents and to encourage best practice through consultation with industry members. If this issue continues to be of concern, the OFPC intends to consider bundling of consents in its review of the private sector provisions of the *Privacy Act* to be conducted once the legislation has been in operation for two years.³⁵

Inquiry's views

28.46 The Inquiry recognises that, while the bundling of consents may not be in breach of the *Privacy Act*, the practice has the potential to undermine the voluntariness of the consent of an applicant for insurance. The Inquiry agrees with the OFPC that this is contrary to the spirit of the NPPs and is not good business practice.

28.47 The Inquiry is of the view that, where an insurer seeks consent from an applicant to collect genetic information, the original consent should be limited to collection for the primary purpose of assessing the application for insurance. Consent to collection of genetic information for the purpose of assessing the application should not be bundled together with consents to other, unrelated or secondary uses of the genetic information. Where the insurer wishes to seek consent for other uses, consent should be sought separately and the application for insurance should not be made dependent on the provision of consent to those other uses. This approach is consistent with the ethical principle of respect for persons and their autonomy, discussed in Chapter 6 in relation to the use of genetic information in health care and research. The Inquiry recommends that, in conducting the review of consent forms in accordance with Recommendation 28–1, insurers should ensure that consent provisions in relation to the collection of genetic information are limited in this way.

28.48 In addition, some submissions suggested that provisions seeking consent to the collection of genetic information in insurance applications should be separate to provisions seeking consent to the collection of other health information. While the Inquiry has not formed a view on this matter, insurers should consider this issue in conducting the review of consent forms.

Recommendation 28–2. In reviewing consent and medical authority forms in accordance with Recommendation 28–1, insurers should ensure that consent to collect genetic information for the purpose of assessing an application for insurance is not bundled together with consent for other purposes. The provision of insurance should not be made conditional on the giving of consent to other, unrelated or secondary uses of the genetic information.

³⁴ Ibid.

³⁵ Office of the Federal Privacy Commissioner, *Submission G294*, 6 January 2003.

Collection of family medical history

28.49 As discussed in Chapter 25, insurance companies routinely collect family medical history information and use it in underwriting. The collection and use is based on the long recognised fact that certain diseases have a hereditary component, and that information about the medical history of family members is relevant in assessing the applicant's risk. IFSA's current Genetic Testing Policy does not address the issue of family medical history in underwriting—it is solely focused on genetic test results, which are narrowly defined.³⁶

28.50 The collection and use of family medical history raises two distinct privacy issues. The first is whether it is permissible to use personal information that the insurer has already collected about an insured, X, in assessing the insurance application of a genetic relative, Y. This conduct would be in breach of the NPPs and the Inquiry has been informed that insurers do not engage in this practice. IFSA's Genetic Testing Policy, quoted above, provides that the results of a genetic test on X will not be used in the assessment of insurance applications from his or her relatives (ie Y).

28.51 The second issue is whether it is permissible for insurers, in assessing an insurance application from X, to collect personal information from X about X's genetic relatives (Y, Z and so on), without the knowledge or consent of those relatives. There are grounds for thinking that this widespread practice may not be consistent with NPP 1.5 and NPP 10.

28.52 Similar issues have already been addressed by the OFPC in the context of the provision of health services (see Chapter 21). Medical practitioners regularly take a medical history from patients, which may include the collection of personal information about genetic relatives of the patient. In its submission to the Inquiry, the OFPC identified some of the problems that arise in the application of the NPPs to this common situation:

Problems may arise, however, in circumstances where, in the course of a diagnosis, treatment or care of an individual, an organisation collects a medical history from an individual which also reveals health information about a genetic relative. NPP1.5 would require the organisation to inform the relative of the matters contained in NPP1.3, relating to the circumstances of the collection. NPP10 would also require the organisation to obtain the relative's consent to the collection of the health information about them, except in certain defined situations such as where the collection is required by law.³⁷

28.53 As noted in Chapter 21, this position was remedied in relation to health service providers by a Temporary Public Interest Determination (the Temporary PID), issued by the federal Privacy Commissioner on 21 December 2001,³⁸ and by final

³⁶ Investment and Financial Services Association, *IFSA Standard 11.00 'Genetic Testing Policy'* (2002), IFSA [9.1]. See further Ch 10.

³⁷ Office of the Federal Privacy Commissioner, *Submission G143*, 22 March 2002.

³⁸ The date the NPPs came into force under the *Privacy Amendment (Private Sector) Act 2000* (Cth).

Public Interest Determinations (PIDs) 9 and 9A issued on 15 October 2002.³⁹ The OFPC made the following comments in relation to the Temporary PID:

Since the collection of health information about relatives from an individual forms an integral part of a wide range of health services, the continuation of this practice by providers would have been in breach of NPP1 and NPP10. In order not to unduly impede the provision of health services, a Temporary Public Interest Determination under Section 80B(3) now allows the taking of family histories by health service providers without being in breach of the NPPs (OFPC, 2001e). This would include the collection by an organisation from an individual of genetic information about the individual's relative.⁴⁰

28.54 Unlike the Temporary PID, the final PIDs do not exempt organisations from their obligations to adhere to NPP 1.5. Organisations remain obliged to take reasonable steps to ensure third parties are informed about the collection of information. However, it may not be necessary to take such steps where the third party is already aware of the relevant matters, where there are no steps that are reasonable in the circumstances or steps could be taken but it is unreasonable to do so.⁴¹

Submissions and consultations

28.55 In DP 66 the Inquiry proposed that insurers should seek a PID under the *Privacy Act* in relation to the practice of collecting family medical history from applicants for use in underwriting insurance. The Inquiry had formed the preliminary view that this practice may not be consistent with NPP 1 and NPP 10.

28.56 In relation to NPP 1, IFSA expressed the view that, given the importance of family medical history information to the accurate assessment of an individual's health, it would be preferable to amend the *Privacy Act* to allow the collection of this information rather than requiring the insurance industry to apply for a PID.

28.57 Both IFSA and the Australian Life Underwriters and Claims Association expressed the view that, in the insurance context, the collection of family medical history by insurers was not in breach of NPP 10:

IFSA acknowledges that NPP 10.1 prohibits organisations from collecting sensitive information unless the individual has consented or the collection is required by law. Sensitive information is defined in the *Privacy Act* to include health information. IFSA is of the view that the family medical history collected from an applicant is materially relevant to an insurer's decision of whether to accept the risk.

39 *Privacy Commissioner Public Interest Determination No. 9 2002* (Cth); *Privacy Commissioner Public Interest Determination No. 9A 2002* (Cth). A Public Interest Determination (PID) may be issued by the Privacy Commissioner, on the application of an interested person, where an act or practice may breach the NPPs but the public interest in doing the act, or engaging in the practice, substantially outweighs the public interest in adhering to NPPs. See *Privacy Act 1988* (Cth) Pt VI. PID 9A gives PID 9 a general application to all health service providers.

40 Office of the Federal Privacy Commissioner, *Submission G143*, 22 March 2002. For further information on the PID process and, in particular, the PID in relation to the collection by health service providers of social and medical history information for the diagnosis, treatment or care of an individual, see Office of the Federal Privacy Commissioner, *The Australian Privacy Commissioner's Website*, <www.privacy.gov.au>, 19 February 2003.

41 For a detailed discussion see Ch 21.

Section 21 of the *Insurance Contracts Act* imposes a duty on a person seeking insurance to disclose relevant matters to the insurer. Thus IFSA asserts that in terms of NPP 10.1(b), the collection of family medical history is ‘required by law’. Therefore, an insurer by obtaining and requesting medical history about a family member from the prospective insured in accordance with the *Insurance Contracts Act*, has satisfied NPP 10 Sensitive Information because ‘consent’ is not required from the relevant family member [NPP 10.1(a)] given the collection is ‘required by law’ [NPP 10.1(b)].⁴²

28.58 The Institute of Actuaries of Australia expressed support for the proposal in DP 66 but noted that it would be more efficient to extend the scope of the existing PID rather than developing a separate PID in relation to insurance.

28.59 The OFPC noted that PID 9A was expressed in wide terms and that the collection of family medical history information from applicants for insurance may be covered. The PID allows a ‘health service provider’ to collect family medical history information where the information is relevant and necessary to provide the ‘health service’. While insurance would not fall within the ordinary meaning of a health service, the OFPC noted that:

The definition of ‘health service’ in Section 6(1)(a)(i) of the Act refers to ‘an activity performed in relation to an individual that is intended (expressly or otherwise) ...by the person performing it...to record ...the individual’s health.’ In other words, the activity of *recording* the information is, in itself, the provision of a *health service* directly to the individual/consumer.

Inquiry’s views

28.60 In the Inquiry’s view, while it is possible that the terms of PID 9A might technically extend to the collection of family medical history information by insurers, this is far from clear. The Inquiry notes that the Explanatory Front Sheet to PID 9A states:

The types of health services covered include traditional health service providers such as private hospitals and day surgeries, medical practitioners, pharmacists, and allied health professionals such as counsellors, as well as complementary therapists, gyms, weight loss clinics and many more.⁴³

28.61 The list is inclusive and consistent with the usual meaning of the term ‘health service’. Insurers do not fall within the usual meaning of that term and, in the Inquiry’s opinion, it would be desirable to clarify the position in relation to insurers.

28.62 In considering whether to issue a PID, the Privacy Commissioner is required to consider whether the public interest in allowing, for example, the collection of family medical history information outweighs, to a substantial degree, the public interest in adhering to the NPPs or an approved code. The public interest issues to be considered in relation to the collection of this information by insurers are not the same as those considered in the development of PID 9 and PID 9A, which focused on the

⁴² Investment and Financial Services Association, *Submission G244*, 19 December 2002.

⁴³ *Privacy Commissioner Public Interest Determination No. 9A 2002* (Cth).

health sector, as normally defined. The Inquiry is of the view that it would be appropriate to consider specific issues that arise in the insurance context as part of a separate process involving insurers and other relevant stakeholders. An application for a PID is a public process and would allow further consideration of the issues.

28.63 The Inquiry notes that PID 9 and PID 9A do not exempt the collection of family medical history by health service providers from NPP 1.5. It may be, however, that different issues arise in the insurance context and the Inquiry is of the view that these issue should be raised and considered.

28.64 The Inquiry also notes the argument put forward by IFSA and the Australian Life Underwriters and Claims Association that collection of family medical history information by insurers is ‘required by law’ and is not inconsistent with NPP 10. While an applicant for insurance is required by s 21 of the *Insurance Contracts Act* to *disclose* certain information to the insurer prior to entry into a contract of insurance, it is not clear, in the Inquiry’s view, that insurers are ‘required by law’ to *collect* the information, within the terms of NPP 10. It is possible to argue that, although the disclosure by an applicant is required by law, there is no requirement that the information be collected by the insurer, nor that collection be without the consent of the genetic relatives to whom the information relates. NPP 10 is intended to provide special protection for the privacy of sensitive personal information. It is likely, therefore, that the exceptions to NPP 10 will be given a strict interpretation by the courts.

28.65 The term ‘family medical history’ in this context may include genetic test results of tests undertaken by the genetic relatives of the applicant. For this reason, the recommendation below refers to ‘genetic information’ about the applicant’s genetic relatives. This is intended to include test results from family members as well as other forms of family medical history information.

28.66 The Inquiry is of the view that it would be desirable to clarify the relationship between provisions of the *Insurance Contracts Act* and the requirements of the *Privacy Act*. The PID process would provide an opportunity to have these issues considered and would provide certainty for applicants and insurers in relation to the collection of family medical history information.

<p>Recommendation 28–3. Insurers should seek a Public Interest Determination under the <i>Privacy Act 1988</i> (Cth) in relation to the practice of collecting genetic information from applicants about their genetic relatives for use in underwriting insurance policies in relation to those applicants.</p>

Sharing information between related organisations

28.67 A further issue raised in one submission to the Inquiry was the degree to which various arms of insurance organisations share genetic information. Privacy NSW stated in its submission that:

Existing privacy legislation does not specifically restrict information from being passed from one insurance arm (for example Life) to another (for example General) or to a re-insurer where it can be argued that the purpose is 'directly related' to the primary purpose of collection. General insurers also share details of refused applicants and claims through Insurance Reference Services P/L.

Privacy NSW recommends that the transfer of genetic information from life and associated product areas to general insurance areas should be prohibited or significantly restricted.⁴⁴

28.68 DP 66 asked whether there was evidence that genetic information is shared between various arms of insurance organisations and if so, whether the practice raised privacy concerns. The Inquiry did not receive any submissions indicating that genetic information is shared between various arms of insurance organisations or indicating that this was a matter of concern. IFSA stated that:

IFSA does not have any evidence of human genetic information being shared or transferred by the collecting organisation to another organisation, whether related or not, in the insurance industry without the consent of the applicant.⁴⁵

28.69 The Inquiry does not have sufficient information to make a recommendation in relation to this matter.

44 Office of the Privacy Commissioner (NSW), *Submission G118*, 18 March 2002.

45 Investment and Financial Services Association, *Submission G244*, 19 December 2002.

Part H. Employment

29. The Use of Genetic Information in Employment

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Introduction

29.1 The right to work has been recognised as a fundamental human right by many countries within the international community, including Australia.¹ A person's ability to work is important to his or her financial security, self-esteem and community involvement. On a broader level, a person's ability to work allows him or her to contribute financially to the community through the income tax system, and to avoid dependence on state welfare. The possibility that a person might be excluded from employment as a result of his or her genetic status is therefore a serious concern.

29.2 Australian employers may currently request genetic information from a job applicant or employee, subject to relevant privacy and anti-discrimination legislation. Employers may seek access to such information where, for example, it is relevant to a person's ability to perform the inherent requirements of the job, or where it is relevant to the employer's common law or statutory occupational health and safety obligations. This chapter examines the various contexts in which employers collect health information and the situations in which this might include genetic information. The chapter summarises the evidence received by the Inquiry about the current use of

¹ *International Covenant on Economic, Social and Cultural Rights*, opened for signature 19 December 1966, 993 UNTS 3, (entered into force on 10 March 1976), art 6(1).

genetic information by Australian employers and discusses the possible extent of use in the future. Finally, the chapter discusses the interests of employers, employees and the community, which must be balanced in developing policy in this complex and rapidly developing area.

The use of health information in employment

29.3 The collection of health information by Australian employers is a well established practice in a number of situations including pre-employment medicals, periodic medicals to assess fitness for duty, occupational health and safety assessments, workers' compensation claims and retirement medicals. Of these, pre-employment health screening of job applicants and ongoing health surveillance of employees are amongst the most important.

29.4 Genetic information is a form of health information and it is likely, as clinical genetics develops, that it will become more difficult to distinguish it from other forms of health information. In addition, as the cost of genetic testing falls and the number, accuracy and reliability of available tests increases there is reason to expect an increased use of genetic information in employment.

Health screening

29.5 A large number of Australian employees are required to undergo health screening as a pre-condition of employment. This form of screening can involve a medical examination, a questionnaire, the taking of a medical and/or occupational history, or the use of medical tests or samples.² In certain industries, pre-employment or pre-placement medical examinations are required by occupational health and safety regulations, for example, where the applicant will be employed in activities that may be hazardous, such as operating machinery in mines.³

29.6 Genetic screening—a subset of health screening—involves examining the genetic status of an employee or job applicant for certain inherited traits, disorders or susceptibilities for the purpose of excluding high-risk persons from the workplace or providing alternative work that may present fewer risks.⁴

29.7 Professor Richard Johnstone has commented that employers often see pre-employment screening as part of their 'managerial prerogative' to hire and fire as they choose.⁵ In practice, however, employers' ability to conduct pre-employment health

2 R Johnstone, 'Pre-employment Health Screening: The Legal Framework' (1988) 1 *Australian Journal of Labour Law* 115, 115–116. The Australasian Faculty of Occupational Medicine of the Royal Australasian College of Physicians has issued guidelines for employment health assessments. See Australasian Faculty of Occupational Medicine, *Guidelines for Health Assessment for Work* (1998) Royal Australasian College of Physicians.

3 *Mines Inspection Act 1901* (NSW) s 18A.

4 US Congress — Office of Technology Assessment, *Genetic Monitoring and Screening in the Workplace* (1990), US Government Printing Office, Washington, 5.

5 R Johnstone, 'Pre-employment Health Screening: The Legal Framework' (1988) 1 *Australian Journal of Labour Law* 115, 117.

screening is constrained by Commonwealth, state and territory anti-discrimination legislation. This is discussed further in Chapters 30 and 31.

Health surveillance

29.8 Health surveillance is conducted in industries involving workplace exposure to hazardous substances or agents. The National Occupational Health and Safety Commission has prepared a package of regulations, standards and codes of practice in relation to health surveillance of employees, and each Australian jurisdiction has implemented the package in regulations under their principal occupational health and safety legislation.

29.9 Health surveillance involves monitoring a person's health on an ongoing basis to identify changes in health status as a result of workplace exposure to hazardous substances. Surveillance may involve monitoring individual employees or groups of employees to identify risks to the entire exposed population. Employers *must* conduct health surveillance in industries involving exposure to hazardous substances such as asbestos, carcinogenic substances or inorganic lead.⁶

29.10 Genetic monitoring—a subset of health surveillance—involves the periodic testing of employees to evaluate the genetic damage caused by exposure to a workplace hazard. Genetic damage may take the form of chromosomal damage or genetic alterations or mutations.⁷ This is discussed further in Chapter 32.

Other health assessments

29.11 In addition to pre-employment health screening and health surveillance other forms of health assessment include:

- sick leave examinations conducted to determine whether a person's illness or injury has resulted in a permanent or temporary disability, which may impact on work arrangements;
- workers' compensation examinations required where an employee has claimed compensation for work related injury or disease (see Chapter 33);
- executive health examinations of senior management to provide feedback on current state of health, and information to enable lifestyle and health improvement; and

6 See National Occupational Health and Safety Commission, *National Model Regulations for the Control of Workplace Hazardous Substances [NOHSC: 1005 (1994)] (Updated for Amendments)*, Commonwealth of Australia; National Occupational Health and Safety Commission, *National Standard for the Control of Inorganic Lead at Work [NOHSC: 1012 (1994)]*, Commonwealth of Australia.

7 US Congress — Office of Technology Assessment, *Genetic Monitoring and Screening in the Workplace* (1990), US Government Printing Office, Washington, 4.

- retirement examinations, which may be carried out to advise retiring employees of any health problems or to discuss the need for ongoing medical surveillance.⁸

Drug and alcohol testing

29.12 Drug and alcohol testing also involves the use of applicants' and employees' health information. Testing may be undertaken to detect alcohol, prescription and over-the-counter pharmacy drugs, as well as illicit drugs such as cannabis, cocaine, amphetamines and heroin. Testing is usually conducted by analysing bodily samples such as blood, urine, breath, hair and saliva.⁹

29.13 Some industry-specific legislation provides for drug and alcohol testing.¹⁰ Employers also justify drug and alcohol testing in the workplace by reference to their duty to ensure the health and safety of their employees and third parties.¹¹ Australian employers have conducted alcohol and drug testing on railway employees, prison officers, coal miners, airline workers, law enforcement officers and members of the Australian Defence Force. While the use in Australia of workplace drug and alcohol testing is generally acknowledged to be widespread, the Inquiry is not aware of recent statistics regarding its use.¹²

29.14 Although workplace drug and alcohol testing has been introduced in a number of industries, concerns have been raised about privacy, the accuracy of test results, the ability to measure the impact on an employee's work performance, and the economic costs and benefits associated with testing.¹³

Types of genetic information used in employment

29.15 As noted above, genetic information is a type of health information that is likely to become increasingly significant in assessing the health of job applicants and employees in the future. Both genetic test results and family medical history are relevant in the employment context. In addition, genetic samples are collected by some employers for identification purposes.

Genetic test results

29.16 There are several situations in which an employer might seek to obtain genetic test results from a job applicant or employee. These include requiring diagnostic or predictive genetic testing as part of pre-employment medical

8 See Australasian Faculty of Occupational Medicine, *Guidelines for Health Assessment for Work* (1998) Royal Australasian College of Physicians, 6–10.

9 The Privacy Committee of New South Wales, *Drug Testing in the Workplace*, 64 (1992), Privacy Committee of New South Wales, Sydney, 5.

10 For example, see *Rail Safety Act 1993* (NSW) s 61; *Australian Federal Police Act 1979* (Cth) s 40M.

11 The Privacy Committee of New South Wales, *Drug Testing in the Workplace*, 64 (1992), Privacy Committee of New South Wales, Sydney, 7.

12 In 1991, nine of the top 600 Australian companies (being 1.5%) reported having drug testing procedures for employees. In 1992, a survey found that 11.5% of a range of private and public sector organisations had some form of drug and alcohol testing program: *Ibid*, 9–11.

13 *Ibid*, 19–25.

examinations, or as part of an ongoing health surveillance program. Alternatively, an employer might ask a job applicant to disclose existing results of diagnostic or predictive genetic tests. Such tests may have been undertaken for health related reasons or through participation in a population screening or medical research program.

29.17 The Inquiry is not aware of any routine genetic testing currently conducted by Australian employers, although the Inquiry received some evidence of occasional use, for example, to confirm family medical history. United States employers have conducted genetic testing for various conditions in the past, for example in relation to the sickle cell trait.¹⁴ Until recently, the United Kingdom's Ministry of Defence screened aircrew applicants for the sickle cell trait in the belief that carriers were vulnerable to health risks at high altitudes.¹⁵

29.18 Testing may be offered on a mandatory or voluntary basis. In the United States, for example, genetic tests for beryllium sensitivity have been offered on a voluntary basis to beryllium-exposed workers. Individuals with a particular genetic mutation are at an increased risk of developing chronic beryllium disease when exposed to the chemical. The condition is potentially fatal.¹⁶

Family medical history

29.19 In addition, or as an alternative to requesting genetic test results, an employer might ask a job applicant or employee to disclose information about his or her family medical history, which is a form of genetic information. Family medical history is routinely collected during general medical examinations and the Inquiry received some evidence of this occurring in the employment context.

Genetic samples

29.20 Employers may also seek access to employees' genetic samples. In the United Kingdom, police officers are requested to supply genetic samples for the Police Elimination Database, which is used to eliminate officers' genetic material as contaminants at crime scenes. By May 2002, over 56,000 DNA samples had been provided. It has been proposed to make the supply of a sample a condition of entry to the police force.¹⁷

29.21 The United States Department of Defense also collects genetic samples from every service member on active duty or in the reserve armed forces on a mandatory basis. The samples are collected for the purpose of identifying the remains of personnel

14 See J Crespin, 'Genetic Screening in the Workplace for Sickle Cell Trait: A Dangerous Tool' (1992) 30 *Medical Trial Technique Quarterly* 91; J Seltzer, 'The Cassandra Complex: An Employer's Dilemma in the Genetic Workplace' (1998) 27 *Hofstra Law Review* 411, 418-420; K Brokaw, 'Genetic Screening in the Workplace and Employers' Liability' (1990) 23 *Columbia Journal of Law and Social Problems* 317, 322-326.

15 Human Genetics Commission, *Inside Information: Balancing Interests in the Use of Personal Genetic Data* (2002), London [8.8].

16 G Marchant, 'Genetics and Toxic Torts' (2001) 31 *Seton Hall Law Review* 949.

17 Human Genetics Commission, *Inside Information: Balancing Interests in the Use of Personal Genetic Data* (2002), London [8.9].

who are killed on active duty. The samples are stored in the Department's DNA Repository for a period of 50 years but may be destroyed at the request of the donor when he or she leaves the military.¹⁸

Current use of genetic information by Australian employers

29.22 The Inquiry is not aware of statistical information indicating the extent to which Australian employers make use of genetic test or family medical history information. The Inquiry is not aware of any routine genetic testing by Australian employers, although the Inquiry did receive submissions documenting occasional use of genetic testing and more routine use of family medical history. Much of this information was collected in the context of complaints and studies of discrimination on the basis of genetic status in employment, as discussed in Chapter 30.¹⁹

29.23 Mandatory pre-employment genetic testing has, however, been considered in at least one situation in Australia. In 2001 it was reported that the Professional Boxing and Martial Arts Board of Victoria had proposed the testing of all professional boxers as a condition of their licence to fight in Victoria. The boxers were to be tested for a genetic mutation that made them more susceptible to 'punch drunk syndrome'. The Board was reportedly concerned that it could be held liable for damages if it allowed boxers with a genetic predisposition to this condition to fight.²⁰ This issue is discussed in Chapter 38.

29.24 In consultations, the Department of Defence indicated that family medical history is routinely collected from applicants to establish their fitness to serve in the defence forces and that some applicants are rejected on the basis of that information.²¹ The Department indicated that if an applicant's medical report includes a family medical history of Huntington's disease, the applicant is likely to be rejected unless a genetic test indicates that the applicant does not have the relevant genetic mutation.

29.25 In relation to multifactorial conditions, the Department of Defence indicated that family medical history sometimes prompts follow up investigation but is not used in isolation to exclude applicants. The Department was of the view that a comprehensive assessment of health status and risks is important because all defence force personnel are required to be deployable, including in harsh conditions with limited medical facilities. A high premium was placed on ensuring that missions would not be impaired by the ill-health of defence force personnel. The Department indicated

18 E Reiter, 'The Department of Defense DNA Repository: Practical Analysis of the Government's Interest and the Potential for Genetic Discrimination' (1999) 47 *Buffalo Law Review* 975, 983–984. For more information about the DNA Repository see A Stevens, 'Arresting Crime: Expanding the Scope of DNA Databases in America' (2001) 79 *Texas Law Review* 921.

19 See K Barlow-Stewart and D Keays, 'Genetic Discrimination in Australia' (2001) 8 *Journal of Law and Medicine* 250.

20 J Robotham, 'Pro Boxers Face Going Down for the Gene Count', *The Sydney Morning Herald*, 1 June 2001.

21 Department of Defence, *Consultation*, Canberra, 6 November 2002.

that, while cost and lack of predictive accuracy meant that genetic testing was not widely used at present during recruitment, this might change in the future.²²

29.26 The use of family medical history in this way is not limited to the defence forces. In one reported case, an 18 year old male with a family history of Huntington's disease applied for acceptance into the public sector. His general practitioner noted the family history of Huntington's disease in his medical report. The man was told that he would only be employed if he undertook a genetic test that showed that he did not have the relevant genetic mutation.²³

29.27 The collection of genetic samples for the purposes of identification is also occurring in Australian workplaces. The Tasmanian Police Service, for example, collects genetic samples from police recruits for use in eliminating their genetic material as possible contaminants at crime scenes. The Tasmanian Police Commissioner has proposed to expand the program to all operational police and to establish a DNA database for police profiles. The Commissioner has indicated that if police do not provide samples voluntarily he will ask the Tasmanian government to implement legislation making it compulsory to provide them.

29.28 The Police Association of Tasmania has opposed the plan, expressing the concern that, once obtained, the samples might be used for other purposes, such as predictive health testing. The Police Federation of Australia (PFA) is also opposed to legislation making the provision of a genetic sample compulsory. The PFA is of the view that this is a breach of the civil liberties of police officers and noted in its submission to the Inquiry that police officers are not the only workers who routinely attend crime scenes. The PFA stated that, if police officers regularly contaminate crime scenes, this is a training issue and should be addressed as such.²⁴

29.29 Section 22 of the *Criminal Investigation (Identifying People) Act 2002* (WA) permits the Western Australian Commissioner of Police to require police officers to supply a DNA sample. However, in consultations the Commissioner of Police indicated that this power had not yet been exercised.²⁵

29.30 The Inquiry understands that the Australian Defence Force is currently considering whether to implement a policy of collecting genetic samples from members of the defence force for identification purposes. In consultations, the Department of Defence indicated that mandatory collection of genetic samples is unlikely to be considered without appropriate mechanisms for protecting the privacy of the information held. At present, a pilot program is under development for the collection of samples for identification purposes on a voluntary basis.²⁶

22 Ibid.

23 S Taylor, 'A Case Study of Genetic Discrimination: Social Work and Advocacy Within a New Context' (1998) 51(4) *Australian Social Work* 51, 53.

24 Police Federation of Australia, *Submission G253*, 20 December 2002.

25 Western Australia Police Service, *Consultation*, Perth, 28 October 2002.

26 Department of Defence, *Consultation*, Canberra, 6 November 2002.

29.31 There is still considerable uncertainty about the nature and extent of the use of genetic information in the context of employment and there is a need for further detailed empirical research. Associate Professor Margaret Otlowski, Dr Sandra Taylor and Dr Kristine Barlow-Stewart have established the Genetic Discrimination Project Team, funded by the Australian Research Council, and are conducting research into the nature and extent of genetic discrimination in Australia. The project team's work is due to be completed in 2004 and may provide a more complete picture of the use of genetic information in the workplace.

Future use of genetic information by Australian employers

29.32 It is difficult to predict to what extent Australian employers may seek to obtain and use genetic information about job applicants or employees in the future. Australian employers already undertake a wide range of employee health assessments on a routine basis and may in future make use of genetic information as part of their pre-employment health assessments, or as part of ongoing health surveillance under occupational health and safety regulation.

29.33 As genetic technology advances, the number and accuracy of genetic tests available is likely to increase. They are also likely to become cheaper and faster to perform. Associate Professor Margaret Otlowski has commented:

Concerns about genetic screening are magnified once account is taken of future gene chip analysis and the potential for testing for a range of non-medical traits, such as aggression, alcoholism or criminality; traits that an employer would undoubtedly be keen to screen for.²⁷

29.34 The financial benefits for employers of screening out potentially unhealthy employees, and of limiting potential liability for workplace injury or disease by screening susceptible employees, are significant incentives for employers to seek to adopt more wide-ranging use of genetic information in the future.

29.35 The situation in the United States illustrates the impact that financial incentives can have on the use of genetic information in the workplace. The United States has a relatively long history of using genetic information, including genetic testing and family medical history, in the workplace. One reason for the widespread use of medical testing of all kinds by American employers is that the majority of Americans rely on employer-provided health insurance. As health insurance costs rise, employers are more likely to use health screening, including genetic screening, to reduce those costs.

29.36 A survey by the American Management Association provides some guidance as to the current use of genetic information by United States employers. The Association conducts an annual survey of its 10,000 member companies, representing one quarter of the United States workforce. In its 1999 survey of 1,054 employers, less

27 M Otlowski, *Implications of Genetic Testing for Australian Employment Law and Practice* (2001) Centre for Law and Genetics, Hobart, 9.

than 1% reported genetic testing for pregnancy and sickle cell anaemia; 4.3% reported genetic testing for breast or colon cancer; and 16.7% reported genetic testing for susceptibility to workplace hazards.²⁸ About 20% of employers surveyed obtained family medical history information from job applicants, and 12% obtained family medical history from employees. Five percent of employers surveyed admitted using this information in hiring decisions, and 2% in assigning or reassigning current employees.²⁹

29.37 Most Australian employers do not provide health insurance for their employees, but other factors may influence the extent to which genetic information is used in Australian workplaces. As discussed further below, the differing interests of employers, employees and the community must be considered and appropriately balanced in developing policy about the use of genetic information in employment.

Competing interests

Employers' interests

29.38 There are a number of reasons employers seek to collect and use medical information about employees. Employers have a legitimate interest in ensuring that an applicant or employee is able to perform the inherent requirements of the job. This includes the ability to work safely. For some positions the inherent requirements of the job will include a certain level of fitness, for example, positions in the defence forces.

29.39 Employers also have an interest in ensuring a productive workforce and in limiting unnecessary overheads. An employee with a susceptibility to a genetic disorder—whether workplace related or otherwise—has the potential to give rise to productivity losses and costs associated with sick leave, employing and training temporary or permanent replacements, potentially higher workers' compensation premiums, and potential legal liability for injuries to employees or the public.³⁰

29.40 It has been suggested that employers may come under pressure from insurers to conduct genetic testing on their workforce. In consultations, Comcare indicated that workers' compensation premiums are calculated, under its scheme, on the basis of an agency's claims history over the last four years, ranging from 0.5% to 3.6% of payroll.³¹ Employers may be prompted to use genetic information to reduce the number of employee claims and so keep premiums low.

28 R Jansson and others, *Genetic Testing in the Workplace: Implications for Public Policy* (2000), Institute for Public Health Genetics, Health Policy Analysis Program, Department of Health Services, School of Law, Department of Economics, University of Washington, Seattle, 19. However, misunderstanding of the definition of genetic testing appeared to skew the results.

29 P Miller, 'Is There a Pink Slip in My Genes? Genetic Discrimination in the Workplace' (2000) 3 *Journal of Health Care Law & Policy* 225, 236.

30 M Otlowski, *Implications of Genetic Testing for Australian Employment Law and Practice* (2001) Centre for Law and Genetics, Hobart, 9–10.

31 Comcare, *Consultation*, Canberra, 7 November 2002.

29.41 Employers may also seek to collect and use medical information to comply with their duties under occupational health and safety legislation, namely, to protect the health and safety of their employees and third parties.³²

29.42 Health screening and surveillance also involve cost, however, and these costs must be weighed against any potential benefits. Costs involved in using genetic tests for screening or monitoring are currently relatively high and the predictive value of many tests is low. As a result genetic testing is not widely used in Australian workplaces at present.

29.43 One issue that arises in this context is whether genetic information should be used to 'inform' employees of risks, or to 'protect' them from risks in the workplace.³³ If a susceptible employee chooses to accept an identified occupational health risk, should the employer be liable if the employee subsequently develops the condition about which he or she was warned? According to Roger Jansson and others:

Genetic testing may result in a Catch-22 for employers: greater liability for known harms of exposure to susceptible workers, but claims by workers of discrimination if employers try to protect them from exposures.³⁴

29.44 On the other hand, if employers are allowed to shift the responsibility for workplace hazards to employees, this might increase the incentive for employers to exclude susceptible employees from the workforce, rather than minimise environmental risks for all employees.³⁵ Occupational health and safety issues are discussed in Chapter 32.

Employees' interests

29.45 The collection and use of genetic information by employers raises a number of issues for job applicants and employees, including privacy and discrimination concerns.

29.46 While the collection of genetic information for medical or research purposes is generally based on informed decision making by the person supplying the sample, a number of commentators have indicated that there are difficulties with applying this principle in the employment context. The voluntariness of consent given by a job applicant or employee may be undermined by the unequal bargaining power in the workplace.³⁶ In addition, employment testing has the potential to compromise an

32 See Ch 32 for more detail.

33 R Jansson and others, *Genetic Testing in the Workplace: Implications for Public Policy* (2000), Institute for Public Health Genetics, Health Policy Analysis Program, Department of Health Services, School of Law, Department of Economics, University of Washington, Seattle, 37. This tension is also evident in the debate about the exclusion of pregnant women from positions involving exposure to lead substances.

34 Ibid, 36.

35 Ibid, 38.

36 For example, see E Draper, 'The Screening of America: The Social and Legal Framework of Employers' Use of Genetic Information' (1999) 20 *Berkeley Journal of Employment & Labour Law* 286, 294; M Otlowski, *Implications of Genetic Testing for Australian Employment Law and Practice* (2001) Centre for Law and Genetics, Hobart, 12–13, 39–40.

individual's 'right not to know' whether he or she has a genetic susceptibility or predisposition.

29.47 In these circumstances, it is particularly important that genetic information is collected from job applicants and employees and stored, used and disclosed in appropriate ways. Contractual and equitable principles offer some privacy protection,³⁷ as does the *Privacy Act 1988* (Cth). However, serious concerns have been raised in relation to the exemption from the National Privacy Principles for personal information contained in 'employee records'.³⁸ This issue is discussed further in Chapter 34.

29.48 Given the sensitive nature of genetic information, employees also have an interest in ensuring that requests for genetic information are limited to those situations in which the information is necessary for a legitimate purpose. It is also important that appropriate procedures are put in place for the collection and use of genetic information in the employment context including, for example, the involvement of appropriate medical professionals and counsellors. These issues are discussed further in Chapter 31.

29.49 A further concern of employees is whether employers have sufficient expertise to interpret genetic information appropriately, given its complexity and variable predictive value. A related concern is that employers may rely on genetic information to discriminate unfairly against job applicants and employees. For example, employers might seek to exclude 'high risk' individuals from the workplace on the basis of their susceptibility to workplace related conditions, or because of risks unrelated to workplace exposure. On the other hand, genetic information has the potential to benefit applicants and employees who may be able to use this information to make career choices to avoid exposure to hazardous substances.

29.50 Job applicants or employees may also be concerned about discrimination by third parties, such as other employers or insurers, if the genetic information is disclosed to them. This raises both privacy and discrimination issues, which are discussed further in the following chapters.

The public interest

29.51 Employers, job applicants and employees have an interest in the appropriate regulation and use of genetic information in the employment context. The community also has an interest in reducing the incidence of occupational injury and disease and the resulting burden on the health care, workers' compensation and social welfare systems.³⁹ Appropriate use of genetic information in employment may contribute to these outcomes, although there is a danger that use of genetic information to screen or monitor employees may shift the focus of employers' efforts from minimising exposure to harmful agents in the workplace to the exclusion of high risk individuals

37 M Otlowski, *Implications of Genetic Testing for Australian Employment Law and Practice* (2001) Centre for Law and Genetics, Hobart, 76–77.

38 *Privacy Act 1988* (Cth) s 7B(3).

39 Nuffield Council on Bioethics, *Genetic Screening Ethical Issues* (1993), Nuffield Council on Bioethics, London [6.8].

from the workplace.⁴⁰ As noted above, the community also has an interest in ensuring that individuals are not unfairly excluded from work and from contributing to the community financially and in other ways through their participation in the workforce.

29.52 As discussed in Chapter 26 in relation to insurance, the use of genetic information by third parties such as insurers and employers also has the potential to deter individuals from taking genetic tests. This may impact both on individual health outcomes and on public health outcomes where individuals are deterred from participating in population screening programs or medical research.

29.53 It has also been suggested that there is a public interest in the protection of individual privacy: while privacy is usually defined in individual terms, the cumulative effect of the invasion of individual privacy has an impact on society as a whole.⁴¹

29.54 In the remaining chapters in Part H of this Report, the Inquiry examines these issues and considers whether the existing regulatory framework draws an appropriate balance between the various interests of employers, employees and the community as a whole. Chapters 30 and 31 examine the anti-discrimination framework. Chapter 32 focuses on the occupational health and safety framework. Chapter 33 considers issues associated with workers' compensation and Chapter 34 considers issues associated with the protection of genetic privacy in employment.

40 M Otlowski, *Implications of Genetic Testing for Australian Employment Law and Practice* (2001) Centre for Law and Genetics, Hobart, 45.

41 *Ibid.*

30. Genetic Discrimination in Employment

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Introduction

Why should anybody invest all that money to train me, when there are a thousand other applicants with a far cleaner profile? Of course. It's illegal to discriminate—'genoism' it's called—but no one takes the laws seriously.¹

30.1 The Inquiry's Terms of Reference require an examination of whether, and to what extent, a regulatory framework is needed to provide protection from inappropriate discriminatory use of human genetic information in a number of contexts, including employment. Chapter 29 outlined the various forms of genetic testing and information that are, or may become, available to employers and the ways that these may be used in employment.

30.2 Information received by the Inquiry indicated that the use of genetic testing in the Australian workplace is very limited, although the use of family medical history appears to be more common. However, given the significant use of pre-employment health screening by Australian employers and the requirements for health surveillance in certain industries, there is potential for the use of genetic information to become more widespread. The Inquiry was informed of a number of cases, both in Australia and overseas, in which genetic information has been used inappropriately in the workplace. This chapter examines the framework of anti-discrimination law to ensure

1 From the screenplay of A Niccol, *GATTACA* (1997), Columbia Pictures.

that appropriate safeguards are in place to regulate the collection and use of genetic information in employment.

30.3 As discussed in Chapter 9, Australia has anti-discrimination legislation at the federal, state and territory level. This chapter, and those following, focus on federal legislation but reference is made to state and territory legislation when discussing the need for greater harmonisation and when considering whether such legislation provides alternative models for consideration. Chapter 9 made a number of general recommendations relating to discrimination on the ground of genetic status, which applied to all contexts, including employment. This chapter proceeds on the basis that the recommendations in Chapter 9 are accepted, and considers whether additional reform is necessary in the context of employment.

Existing regulatory framework

30.4 The *Disability Discrimination Act 1992* (Cth) (DDA) and the *Human Rights and Equal Opportunity Commission Act 1984* (Cth) (HREOC Act) are the most relevant pieces of legislation regulating discrimination in employment on the basis of genetic status. The HREOC Act provides that the Human Rights and Equal Opportunity Commission (HREOC) may inquire into any act or practice, including any systemic practice, that has the effect of nullifying or impairing equality of opportunity or treatment in employment on a wide range of grounds. This is one mechanism for reviewing systemic discrimination on the basis of genetic status in the future. The *Sex Discrimination Act 1984* (Cth) (SDA) and the *Racial Discrimination Act 1975* (Cth) (RDA) may also have some application, depending on the nature of the genetic information under consideration (see Chapter 9).

30.5 These Acts prohibit employers from discriminating against job applicants or employees on the basis of the grounds set out in each Act. In general, an employer must not discriminate in:

- the selection process;
- the terms and conditions on which a job is offered;
- the terms and conditions offered during the course of employment;
- the training and promotion opportunities provided; or
- the termination of employment.

30.6 In addition, the *Workplace Relations Act 1996* (Cth) (WRA) prohibits discrimination on a range of grounds in terminating employment.

Disability Discrimination Act

30.7 The DDA prohibits an employer from discriminating against a job applicant or an employee based on his or her disability. There is some doubt about whether the definition of 'disability' in the DDA is currently wide enough to include genetic status. In the Inquiry's view, discrimination on the basis of genetic status should be covered by the DDA, and other relevant legislation, and the recommendations in Chapter 9 are intended to clarify the issue.

30.8 The employment provisions of the DDA attempt to balance the interests of employers, employees and the community. While disability will often have no impact on a person's ability to work, the legislation expressly acknowledges that in some circumstances it may do so. It is not unlawful to discriminate if a person is unable to carry out the 'inherent requirements' of a job because of his or her disability, or if it would impose 'unjustifiable hardship' on the employer to provide services or facilities that would enable the person to do the job. The effect of these provisions is that employers are required to make reasonable accommodation for a person's disability.

30.9 The DDA employment provisions do not apply to employment in the Australian Defence Forces in combat-related positions or the Australian Federal Police as part of a peacekeeping force.² In other respects, the provisions are of wide application and will apply to most private and public sector employment.

30.10 Under s 31 of the DDA, the Attorney-General may formulate Disability Standards which, once tabled before Parliament for a certain period, gain the force of law.³ Currently there are no standards in force in relation to employment. Draft standards have been prepared by HREOC in a process involving representatives of industry, people with disabilities and government. The process is not proceeding, however, as it has not been possible to reach a consensus on the adoption of the standards.⁴

Workplace Relations Act

30.11 The WRA makes it unlawful for an employer to terminate an individual's employment as a result of a range of factors including race, colour, sex, sexual preference, physical or mental disability, national extraction or social origin.⁵ The employer may do so, however, when this factor renders the employee unable to fulfil the 'inherent requirements' of a particular position.⁶

² *Disability Discrimination Act 1992* (Cth) ss 53–54.

³ See Ch 9.

⁴ Disability Standards Sub-Committee of the National Committee on Discrimination in Employment and Occupation, *Disability Standards Under the Disability Discrimination Act Regarding Employment (Revised Draft)*, <www.hreoc.gov.au/disability_rights/standards/Employment_draft/employment_draft.html> 19 February 2003.

⁵ *Workplace Relations Act 1996* (Cth) s 170CK(2)(f). Under s 170CE(1)(a), an employee may also apply to the Commission for relief if his or her termination was harsh, unjust or unreasonable.

⁶ *Ibid* s 170CK(3).

30.12 There are several differences between the protection offered by the DDA and the WRA. The WRA applies only in relation to termination of employment. It also excludes some employees; for example, those still in their probationary period, those employed on a casual basis for a short period or a specific task, and those employed under a traineeship agreement.⁷ In addition, the WRA does not include an ‘unjustifiable hardship’ provision and so does not appear to impose a requirement that the employer attempt to accommodate the employee’s disability. The courts will, however, generally consider whether the employer has acted reasonably in the circumstances and any accommodation made by the employer, or failure to do so, may be considered in this context. Finally, the WRA does not contain a definition of ‘physical or mental disability’ and does not expressly extend to past, imputed or possible future disabilities, as does the DDA.

30.13 In one respect the protection offered by the WRA is more robust than that offered by the DDA. Once discrimination is raised as an issue under the WRA, the onus is on the employer to establish that it had a valid reason for dismissal. By contrast, under the DDA the onus is on the complainant to establish discrimination and this can be difficult in some cases.⁸

Occupational health and safety legislation

30.14 The use of genetic information for the purposes of occupational health and safety is discussed in detail in Chapter 32. It is necessary at this point, however, to consider the role of occupational health and safety legislation and how that legislation intersects with the anti-discrimination regime. Employers may use genetic information to assist them to meet their obligations under occupational health and safety legislation; for example, by monitoring the effect of hazardous substances in the workplace on the health of employees. Action taken as a consequence of monitoring, such as moving an employee to a different position with a lower level of exposure may, however, be discriminatory, or perceived to be so.

30.15 The Commonwealth and all States and Territories have occupational health and safety legislation. Some state and territory anti-discrimination legislation provides that, if an employer does something that is necessary to comply with other legislation, that act is not unlawful.⁹ This suggests that compliance with occupational health and safety legislation might, in some circumstances, justify conduct that would otherwise amount to unlawful discrimination. However, it is unlikely that a discriminatory response would be regarded as ‘necessary’ if the occupational health and safety requirements could be met without acting in a discriminatory way. HREOC states in its guidelines for employers that:

7 *Workplace Relations Regulations 1996* (Cth) r 30B(1).

8 See M Otlowski, *Implications of Genetic Testing for Australian Employment Law and Practice* (2001) Centre for Law and Genetics, Hobart [2.10].

9 See *Anti-Discrimination Act 1977* (NSW) s 54; *Equal Opportunity Act 1995* (Vic) s 69; *Anti-Discrimination Act 1991* (Qld) s 106; *Equal Opportunity Act 1984* (WA) s 69(1)(a); *Discrimination Act 1991* (ACT) s 30; *Anti-Discrimination Act 1992* (NT) s 53.

The Federal Court is unlikely to accept that an exclusion or restriction on health and safety grounds is justified by the inherent requirements of the job where a non-discriminatory solution to the same issue is reasonably available.¹⁰

30.16 The DDA no longer contains a general exemption for acts that are necessary to comply with other legislation. Section 47(3) did provide an exemption of this kind but the provision ceased to have effect on 1 March 1996. Instead, s 47(2) now provides:

This Part does not render unlawful anything done by a person in direct compliance with a prescribed law.

30.17 Commonwealth regulations do prescribe some state and territory laws under s 47(2), but occupational health and safety legislation is not amongst them. It is possible, therefore, that some conduct that is required by state occupational health and safety legislation may contravene the DDA.

30.18 HREOC's stated position on the relationship between occupational health and safety laws and the DDA is that:

The DDA provides that a person who cannot perform the inherent requirements of the job need not be employed and may be dismissed without unlawful discrimination occurring. Meeting reasonable occupational health and safety standards must be accepted as being among the inherent requirements of any job ...¹¹

30.19 The DDA thus appears to have the effect of requiring employers to meet occupational health and safety obligations in ways that are not discriminatory. Section 15(4) of the DDA also requires employers to provide reasonable services and facilities to assist a person with a disability to do a particular job safely.

30.20 It will usually be possible for employers to comply with their obligations under occupational health and safety legislation without bringing them into conflict with the DDA. Where this is not possible, or it would impose unjustifiable hardship on an employer to provide services or facilities that would make it possible for an employee to do the job without posing a risk to themselves or others, the employer is likely to be protected by the 'inherent requirements' defence in s 15(4).

30.21 In addition, an employer can seek a temporary exemption under s 55 of the DDA for acts done in compliance with occupational health and safety legislation, which are possibly inconsistent with the DDA. This would be appropriate where an employer requires a period of time to make adjustments to bring the workplace into line with the DDA. Temporary exemptions from the operation of the SDA have been granted to employers in the lead industry to allow them to lawfully exclude pregnant and breastfeeding women from lead risk jobs.¹²

10 Human Rights and Equal Opportunity Commission, *Frequently Asked Questions: Employment*, <www.hreoc.gov.au/disability_rights/faq/Employment/employment_faq_1.html#questions>, 19 February 2003.

11 Ibid. In *X v Commonwealth* (1999) 200 CLR 177 the High Court expressed the view that the inherent requirements of a job include a duty not to expose others to a real risk of injury.

12 Human Rights and Equal Opportunity Commission, *Pregnant and Productive: It's a Right Not a Privilege to Work While Pregnant* (1999), Human Rights and Equal Opportunity Commission, Sydney [9.51].

Evidence of genetic discrimination in Australia

30.22 Discrimination in employment on the basis of genetic status does not appear to be widespread in Australia at present. Surveys to date have found only a small number of cases in which individuals believe they have been the subject of such discrimination. It is unclear whether the acts in question would have amounted to unlawful discrimination. The submissions received by the Inquiry did not provide evidence of widespread misuse of genetic information by employers.

30.23 To date, HREOC has received only three complaints involving genetic status. Two were in the employment context and one of these did not proceed because it fell within one of the DDA exceptions. The one remaining employment case is described below. It is possible that the number of complaints received by HREOC is not an accurate reflection of the size of the problem in the workplace. Complaints of discrimination are not always raised with HREOC because individuals may not be aware of their rights or may be fearful that lodging a complaint will lead to victimisation.

30.24 A 2001 study of genetic discrimination in Australia by Dr Kristine Barlow-Stewart and David Keays identified two cases in which job applicants were required to undertake genetic testing as part of the employment selection process. They also identified three cases of alleged discrimination by employers against asymptomatic employees.¹³ These cases, discussed further below, indicate that discrimination can arise from the use of genetic test results or family medical history, and at different stages of the employment process. There remains considerable uncertainty about the extent of discrimination in this area. Empirical research being undertaken by the Genetic Discrimination Project Team into the nature and extent of genetic discrimination in Australia may provide a more complete picture of the use of genetic information in the workplace (see Chapter 29).

Job applicants

30.25 The one complaint raised with HREOC in the employment context, which did not fall within the DDA exceptions, involved an applicant for a position as a psychologist with a public employer. The interview process for the position included aptitude tests, a medical examination and an interview with a psychologist. As part of the tests, the applicant told her employer that she had experienced enuresis (bed-wetting) until the age of fourteen, when the condition had ceased. The employer refused to employ her on the basis that enuresis beyond ten years of age was indicative of psychological problems in adult life.

30.26 In response, the applicant produced evidence that there was a history of 'primary nocturnal enuresis' in her family. She claimed that she had inherited the disorder and that, since it was inherited, it was not indicative of any psychological

13 K Barlow-Stewart and D Keays, 'Genetic Discrimination in Australia' (2001) 8 *Journal of Law and Medicine* 250.

disturbance. The complaint was terminated because there was no reasonable prospect of it being conciliated.¹⁴

30.27 The Barlow-Stewart and Keays survey identified two further cases involving the use of genetic information by employers in the selection process. In one case a young woman reported that when she applied for a position with the public service she was told the success of her application depended on a negative genetic test result for familial adenomatous polyposis. The employer knew she was at risk of the disease because she was undergoing regular colonoscopies for early signs of bowel cancer. When her genetic test result was positive she did not continue with her job application.

30.28 In the second case, a young man who applied for a position in the armed forces reported that he was required to provide evidence that he did not have the genetic mutation for a connective tissue disorder called Marfan syndrome, of which he had a family history. As he had participated in medical research overseas he was able to produce documentation indicating that he had not inherited the mutated gene. He was subsequently accepted for the position.¹⁵

30.29 Another documented case involved an individual with a family history of Huntington's disease who was initially rejected for a position with the public service. The man was informed that he would only be employed if he could provide evidence that he did not have the relevant genetic mutation. Following a written appeal to senior management this decision was reversed.¹⁶

Employees

30.30 The Barlow-Stewart and Keays survey identified three cases of alleged discrimination on the basis of genetic status by employers against existing employees. These cases involved individuals with positive genetic tests for familial early-onset Alzheimer's disease or Huntington's disease. In one case, the person's employment was terminated. In the two other cases the employee was demoted after the employer became aware of the genetic test results.¹⁷

Evidence of genetic discrimination overseas

30.31 It appears that little use has been made to date of genetic information in employment in Europe, including the United Kingdom.¹⁸ By contrast, the United States has a relatively long history of using genetic information in the workplace, including several well-publicised and controversial cases of genetic testing by employers.

14 Human Rights and Equal Opportunity Commission, *Complaints of Genetic Discrimination under the Disability Discrimination Act: Case Studies* (2002).

15 K Barlow-Stewart and D Keays, 'Genetic Discrimination in Australia' (2001) 8 *Journal of Law and Medicine* 250, 254.

16 S Taylor, 'A Case Study of Genetic Discrimination: Social Work and Advocacy Within a New Context' (1998) 51(4) *Australian Social Work* 51.

17 K Barlow-Stewart and D Keays, 'Genetic Discrimination in Australia' (2001) 8 *Journal of Law and Medicine* 250, 254, App 1.

18 Human Genetics Commission, *Inside Information: Balancing Interests in the Use of Personal Genetic Data* (2002), London.

30.32 In 2002, the United States Equal Employment Opportunity Commission (EEOC) reached a mediated settlement with Burlington Northern and Santa Fe Railway Company for US\$2.2 million. The EEOC alleged that the company violated the *Americans with Disabilities Act 1990* (US) by genetically testing, or seeking to test, 36 of its employees without their knowledge or consent. The genetic test was part of a comprehensive diagnostic medical examination that the company required of certain employees who had filed claims or internal reports of work-related carpal tunnel syndrome injuries. The case is the first EEOC litigation challenging genetic testing under that Act.¹⁹

30.33 In another case, the Lawrence Berkeley Laboratory, a government-funded research institution, tested clerical and administrative employees for syphilis, pregnancy and the sickle cell trait during routine mandatory medical examinations. Certain employees brought an action against their employer alleging that the genetic testing was conducted without the employees' knowledge or consent and that the testing was not relevant to the jobs the employees had been hired to perform. The practices were successfully challenged under privacy legislation although the complaint under the *Americans with Disabilities Act 1990* (US) was dismissed on a range of grounds, including that no job-related action was taken against the plaintiffs as a result of the test.²⁰

Options for reform

30.34 A number of overseas jurisdictions have moved to regulate the use of genetic information in employment. Some jurisdictions have imposed complete prohibitions on the use of genetic test information in that context; others have implemented partial prohibitions, allowing specified exceptions for the protection of employee or third party safety. These developments are discussed below.

Prohibition on the use of genetic information

30.35 Austria, France and Norway have imposed prohibitions on the use of certain types of genetic information in employment.²¹ These prohibitions focus on the use of genetic test results rather than family medical history. In Norway, for example, employers are prohibited from requesting, receiving, possessing or using information resulting from a genetic test. It is also prohibited to ask whether a test has been carried out previously.²²

19 Equal Employment Opportunity Commission (US), *EEOC and BNSF Settle Genetic Testing Case under Americans with Disabilities Act*, Press Release, <www.eeoc.gov/press>, 29 July 2002.

20 P Miller, 'Is There a Pink Slip in My Genes? Genetic Discrimination in the Workplace' (2000) 3 *Journal of Health Care Law & Policy* 225, 252–253.

21 M Otlowski, *Implications of Genetic Testing for Australian Employment Law and Practice* (2001) Centre for Law and Genetics, Hobart, 52.

22 European Society of Human Genetics Public and Professional Policy Committee, *Genetic Information and Testing in Insurance and Employment: Technical, Social and Ethical Issues* (2001) European Society of Human Genetics, 22.

30.36 A number of United States jurisdictions have also prohibited the use of genetic information in employment. By April 2002, 31 States had enacted legislation on genetic information in employment, although the provisions in each State vary considerably and not all States impose an absolute ban.²³ Some jurisdictions prohibit employers' collection and use of genetic information as well as discrimination on the basis of that information. Other jurisdictions prohibit discrimination only. In addition, a number of federal bills on the subject have been introduced into Congress.²⁴

30.37 Jurisdictions also vary as to the scope of the information protected. Some older legislation focuses on particular genetic traits (for example, the sickle cell trait), while more recent legislation focuses on genetic test results, or test results and family medical history.

Prohibition subject to exceptions

30.38 Some jurisdictions have prohibited the use of genetic information in employment, subject to specified exceptions. The Netherlands, Denmark, Israel and several United States jurisdictions have adopted this approach.²⁵ The models adopted by different jurisdictions vary in a number of respects, including the scope of the genetic information covered and the scope of the permitted exceptions. Exceptions generally involve use for occupational health and safety reasons, including screening for workplace related susceptibilities or for conditions involving risk to the safety of third parties.

30.39 The United Kingdom is yet to implement legislation in this area but several advisory bodies have supported this approach.²⁶ The 2002 Report of the Human Genetics Commission recommended that employers should not require individuals to undertake genetic testing as a condition of employment but that the situation should be kept under review, particularly in relation to occupational health and safety issues.²⁷

23 For a summary of the state legislation see National Human Genome Research Institute, *Genetic Information and the Workplace: Enacted Legislation*, <www.nhgri.nih.gov/Policy_and_public_affairs/Legislation/workplace.htm>, 19 February 2003.

24 For a summary of the bills see National Human Genome Research Institute, *Issue Update: February 2002*, <www.nhgri.nih.gov/Policy_and_public_affairs/Legislation/01UP_INSjan.html>, 20 February 2003.

25 See M Otlowski, *Implications of Genetic Testing for Australian Employment Law and Practice* (2001) Centre for Law and Genetics, Hobart, 57; European Society of Human Genetics Public and Professional Policy Committee, *Genetic Information and Testing in Insurance and Employment: Technical, Social and Ethical Issues* (2001) European Society of Human Genetics, 21–22; National Human Genome Research Institute, *Genetic Information and the Workplace: Enacted Legislation*, <www.nhgri.nih.gov/Policy_and_public_affairs/Legislation/workplace.htm>, 19 February 2003.

26 For example, the Nuffield Council on Bioethics, *Genetic Screening Ethical Issues* (1993), Nuffield Council on Bioethics, London [6.23]; Human Genetics Advisory Committee, *The Implications of Genetic Testing for Employment* (1999), Human Genetics Advisory Committee, London [3.19].

27 Human Genetics Commission, *Inside Information: Balancing Interests in the Use of Personal Genetic Data* (2002), London.

Permission subject to exceptions

30.40 The existing Australian regulatory framework, described above, allows employers to collect and use job applicants' and employees' genetic information subject to the limits imposed by anti-discrimination legislation, occupational health and safety legislation, and privacy legislation. Employers are permitted to collect and use genetic information unless, for example, the information is used to discriminate unlawfully against a job applicant or employee. This is also the case in a number of other jurisdictions, such as the United Kingdom.

30.41 In DP 66 the Inquiry proposed that the status quo be maintained, subject to a number of proposals aimed at improving the protection offered by the anti-discrimination, occupational health and safety, and privacy regimes.²⁸

Submissions and consultations

30.42 A number of individuals and organisations took the view that employers should not be able to request or use genetic information for *any* purpose.²⁹ This was generally put on the basis that the information is rarely relevant, that it is complex and subject to misinterpretation, and that it is subject to misuse by employers seeking to advance their commercial interests. Some submissions supported a partial prohibition, subject to limited occupational health and safety exceptions.³⁰

30.43 However, the majority of submissions received in relation to this issue supported the Inquiry's proposal. There was significant support for the proposition that an employer should be able to ask for and use genetic information in limited circumstances, for example, where the information is reasonably required to:

- determine whether a person is able to perform the inherent requirements of a job;
- decide what reasonable accommodation might be necessary to enable a person to perform the inherent requirements of a job; or
- promote occupational health and safety.³¹

28 Australian Law Reform Commission and Australian Health Ethics Committee, *Protection of Human Genetic Information*, DP 66 (2002), ALRC, Sydney, Proposal 27–1.

29 Androgen Insensitivity Syndrome Support Group Australia, *Submission G106*, 26 February 2002; P Henman, *Submission G055*, 15 January 2002; Human Genetics Society of Australasia, *Submission G050*, 14 January 2002.

30 Genetic Support Council WA, *Submission G243*, 19 December 2002; Australian Council of Trade Unions, *Submission G278*, 20 December 2002; Department of Human Services South Australia, *Submission G288*, 23 December 2002.

31 Institute of Actuaries of Australia, *Submission G105*, 7 March 2002; Centre for Law and Genetics, *Submission G048*, 14 January 2002; Genetic Support Council WA, *Submission G112*, 13 March 2002; Anti-Discrimination Board of NSW, *Submission G157*, 1 May 2002.

30.44 A number of submissions expressed the view that the circumstances in which an employer would be able to justify the collection of genetic information consistently with anti-discrimination and occupational health and safety regimes is likely to be extremely limited. The Australian Medical Association (AMA), for example, commented:

The AMA would have serious concerns in allowing employers to collect and use genetic information in relation to their employees. We would find it very difficult for an employer to justify requesting or requiring genetic test information in order to ensure that the individual is able to perform the inherent requirements of the job.³²

30.45 The Australian Chamber of Commerce and Industry (ACCI) did not support further regulation at this stage and submitted that:

There are three necessary preconditions for regulatory intervention ... with respect to the employment dimensions of the use of human genetic information. They are:

- Demonstrated need for regulation;
- Evidence of regulatory failure, or a lack of appropriate existing regulation;
- Evidence that the benefits of further regulation outweigh the potential costs to employers and employees.

30.46 ACCI went on to express the view that:

There is also the potential for premature or ill-judged regulation to have extremely negative effects in terms of inhibiting employers from hiring or making decisions which are essential with respect to managing their business, or of provoking a reaction and hesitation from employers to avail themselves of emerging technology which can be of assistance to employers, employees and the community.³³

30.47 In its submission to the Inquiry, Privacy NSW set out some of the arguments in support of allowing employers to use genetic testing and information. They included the following:

Within a free market economy it is an article of faith that both firms and individuals should be able to seek and use information that (they believe) will make them economically better off. It follows then that firms should be entitled to use personal information to minimise projected risk and maximise expected profits, and should be entitled to demand this information as one condition of a consensual transaction.³⁴

30.48 However, concern has been expressed about employers' ability to interpret test results accurately and objectively, given the considerable uncertainty about the quantification of risks and how that information should be evaluated.³⁵ It was suggested in a number of submissions that, if employers are able to request or require genetic information, these requests and the interpretation of test results should be

32 Australian Medical Association, *Submission G212*, 29 November 2002.

33 Australian Chamber of Commerce and Industry, *Submission G308*, 24 January 2003.

34 Office of the Privacy Commissioner (NSW), *Submission G118*, 18 March 2002.

35 M Otlowski, *Implications of Genetic Testing for Australian Employment Law and Practice* (2001) Centre for Law and Genetics, Hobart, 4.

subject to independent oversight and that authoritative guidelines should be developed.³⁶ The difficulties associated with the interpretation of genetic tests are considered in more detail in Chapter 3.

Inquiry's views

30.49 From the information provided to this Inquiry it appears that the use of genetic information in the Australian workplace is not widespread. However, complaints of discrimination are beginning to emerge and it is likely that the number of formal complaints received by agencies such as HREOC does not represent the number of disputes or grievances in the community at large. The situation in the United States demonstrates that a shift in economic incentives can encourage more widespread use of genetic information in the workplace. It is probable that, as tests become cheaper and more reliable, Australian employers will seek to make more use of them to attempt to ensure a healthier workforce, lower risk and higher productivity. These changes may occur quickly.

30.50 The Androgen Insensitivity Syndrome Support Group made the following point in its submission to the Inquiry:

Without doubt, the underlying principle of equal opportunity and anti-discrimination legislation is the Australian ideal of a fair go for all. In practice, it is most often the case that equal opportunity legislation is one step behind rapid societal attitude changes. An inevitable by-product of this 'legislation lag' is that some person often has to suffer damage before the law recognises the need for change.³⁷

30.51 For the reason articulated in this submission, it is important to ensure that regulatory structures, and the anti-discrimination framework in particular, are adequate to protect people from inappropriate use of genetic information in employment, both now and in the future. Individuals should not have to suffer harm before the law recognises the need for change. This Inquiry provides an opportunity to develop appropriate policies in a dispassionate environment, free from a sense of crisis or urgency that might attend belated attention to these issues. The Inquiry's recommendations do not involve the imposition of a new regulatory structure; rather, they build on existing legal regimes and seek to improve existing laws and practices.

30.52 On the basis of the evidence available, the Inquiry is of the view that a complete prohibition on the use of genetic information in employment is not justified. As knowledge and understanding of genetic information increases, there will be scope for applying genetic information in employment in ways that draw an appropriate balance between the interests of employers, employees and the public at large. In the Inquiry's view, a more productive approach is to examine carefully the legal framework within which such information may be collected and used, and to ensure that the appropriate safeguards are in place to guide collection and use.

36 Centre for Law and Genetics, *Submission G048*, 14 January 2002; National Council of Women Australia, *Submission G095*, 31 January 2002; Anti-Discrimination Board of NSW, *Submission G157*, 1 May 2002.

37 Androgen Insensitivity Syndrome Support Group Australia, *Submission G106*, 26 February 2002.

30.53 In the following chapters, the Inquiry makes a range of recommendations for amendments to anti-discrimination, occupational health and safety, and privacy laws to ensure that this balance of interests is achieved. In particular, in Chapter 31 the Inquiry recommends that the DDA should be amended to make it clear that an employer is prohibited from requesting or requiring genetic information from a job applicant or employee unless the information is reasonably required for a purpose that does not involve unlawful discrimination, such as ensuring that a person is able to perform the inherent requirements of the job. As noted above, this may include some requests for genetic information in relation to occupational health and safety issues. The recommendations in Chapter 32 seek to ensure that, in the occupational health and safety context, genetic information is used only in limited circumstances and is subject to the oversight of the Human Genetics Commission of Australia.

30.54 In order to affirm the Inquiry's belief that existing legislative frameworks, once adapted, are appropriate vehicles for finding the right balance of interests in the context of employment, the Inquiry recommends that employers should not collect or use genetic information in relation to job applicants or employees, except in the limited circumstances where this is consistent with privacy, anti-discrimination, and occupational health and safety legislation, as amended in accordance with the Recommendations in this Report.

Recommendation 30–1. Employers should not collect or use genetic information in relation to job applicants or employees, except in the limited circumstances where this is consistent with privacy, anti-discrimination, and occupational health and safety legislation, as amended in accordance with the Recommendations in this Report. (See Chapters 31 to 34.)

31. Inherent Requirements of the Job

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Introduction

31.1 Submissions to the Inquiry identified three major concerns in relation to the anti-discrimination legislation that regulates the use of genetic information in employment. These concerns, which are addressed in this chapter, relate to:

- the meaning and scope of the term ‘inherent requirements’;
- requests for genetic testing or information; and
- guidance for employers on the collection and use of genetic information in employment.

The inherent requirements exception

31.2 Under the *Disability Discrimination Act 1992* (Cth) (DDA) it is lawful for an employer to discriminate against a person on the ground of the person's disability if the person is unable to carry out the ‘inherent requirements’ of the particular job or would, in order to do so, require services or facilities that would impose an ‘unjustifiable hardship’ on the employer. This defence is available to an employer only in relation to ‘hire and fire’ decisions, namely, determining who should be offered employment or dismissed as an employee.¹

31.3 The Inquiry has considered two aspects of the inherent requirements exception as it relates to genetic information: how to define the inherent requirements of a particular job; and whether an employer should be able to discriminate against a

1 *Disability Discrimination Act 1992* (Cth) s 15(4).

job applicant or employee on the basis that, while he or she is currently able to perform the inherent requirements, this may not be the case in the future.

Current law

31.4 The term ‘inherent requirements’ is used in the DDA, the *Human Rights and Equal Opportunity Commission Act 1984* (Cth) (HREOC Act) and the *Workplace Relations Act 1996* (Cth) (WRA). The term is also used in New South Wales, Tasmanian and Northern Territory anti-discrimination legislation, while other jurisdictions use terms such as ‘work genuinely and reasonably required’.² The term ‘inherent requirements’ is not defined in the DDA, the HREOC Act or the WRA.

31.5 In HREOC’s view, inherent requirements must be determined in the circumstances of each job and may include:

- the ability to perform the functions that are a necessary part of the job;
- productivity and quality requirements;
- the ability to work effectively in the team or other type of work organisation concerned; and
- the ability to work safely.³

31.6 There has been some judicial consideration of the term ‘inherent requirements’ as it appears in the WRA and other industrial relations legislation. In *Cramer v Smithkline Beecham*,⁴ two employees of a pharmaceutical plant were dismissed because of their sensitivity to penicillin, to which they were exposed at work. The Federal Court decided that penicillin tolerance was an inherent requirement of working in the pharmaceutical plant and therefore the dismissals were lawful.

31.7 In *Qantas Airways Ltd v Christie*,⁵ Qantas had dismissed a 60-year-old international airline pilot on the basis of his age. In deciding whether the pilot could fulfil the inherent requirements of his position, the High Court considered it relevant to look at the surrounding context of his employment, as well as his physical ability to perform the task. As most countries prohibit pilots over 60 years of age from flying in their airspace, the Court decided that the surrounding context meant that he was not able to fulfil the inherent requirements of the job even though he might be physically capable of flying.

31.8 In *X v Commonwealth*,⁶ the High Court considered the dismissal of a soldier from the Australian Defence Force (ADF) because he had tested positive to HIV. The soldier was discharged from the ADF despite being asymptomatic and in excellent

2 *Anti-Discrimination Act 1991* (Qld) s 35(1); *Equal Opportunity Act 1984* (SA) s 71(2).

3 Human Rights and Equal Opportunity Commission, *Frequently Asked Questions: Employment*, <www.hreoc.gov.au/disability_rights/faq/Employment/employment_faq_1.html#questions>, 19 February 2003.

4 *Cramer v Smithkline Beecham* (1997) 73 IR 470.

5 *Qantas Airways Limited v Christie* (1998) 193 CLR 280.

6 *X v Commonwealth* (1999) 200 CLR 177.

physical health at the time. Once again the High Court found that inherent requirements must be assessed in context and include the ability to work in a manner that does not pose a risk to the health or safety of the individual or other employees.⁷ In this case it was argued that the soldier was unable to bleed safely in the field without risking the infection of his fellow soldiers.

31.9 The Full Federal Court also considered these issues in *Commonwealth v Williams*.⁸ In that case a Communications and Information Systems Controller in the Royal Australian Air Force (RAAF) was discharged on medical grounds. He suffered from insulin dependent diabetes and was declared unable to meet the RAAF minimum employment standard, which requires members to be medically fit for long term deployment to a base with limited facilities and to be able to undertake base combatant duties.

31.10 Section 53 of the DDA provides that it is not unlawful to discriminate in relation to employment in the defence forces where the position involves the performance of combat or combat-related duties. The Federal Court held that the respondent was employed in a position involving the performance of combat-related duties because he was likely to be required to work in support of a person, such as a fighter pilot or other aircrew, performing combat duties.

31.11 In the above cases, the disability or other basis of alleged discrimination was a current or existing one: the employee was already intolerant to penicillin, aged 60 or diabetic. In *X v Commonwealth*, where the soldier was asymptomatic, it was argued that he was not able to fulfil the inherent requirements of the job because of the current risk of transmitting the virus. The courts have not yet considered the inherent requirements exception in relation to a disability that might or will arise in the future, for example, discrimination based on a predictive genetic test result. The cases suggest in deciding what amounts to the inherent requirements of a job, the courts will look further than the skills required in a particular position: the inherent requirements include the ability to work without risk to oneself or others.

Future ability to perform inherent requirements

31.12 DP 66 included two proposals in relation to the inherent requirements exception. The first was that, in assessing whether an applicant or employee is able to perform the inherent requirements of a job, only *current* ability to perform the inherent requirements should be relevant. The second proposal, considered later in this chapter, was that peak employer associations should encourage members to produce clearly defined job descriptions that set out the inherent requirements of every position in the workplace.

7 Ibid, 200 (McHugh J). See also M Hirst, 'X v Commonwealth: Inherent Requirements and the HIV Soldier: Casualties of the Anti-discrimination Battlefield' (2000) 21 *University of Queensland Law Journal* 102, 105–109.

8 *Commonwealth v Williams* [2002] FCAFC 435.

Submissions and consultations

31.13 Submissions generally acknowledged that genetic conditions with existing symptoms might have some impact on a person's ability to perform the inherent requirements of a job. In this respect, a genetic condition was seen to be no different to any other medical condition or existing disability. The impact of the condition should be assessed, along with any necessary accommodation by the employer, in order to determine whether a person is able to do a particular job. Concern was expressed, however, in relation to genetic information that indicates that a disability may or will arise in the future.

31.14 In relation to asymptomatic individuals, the Victorian Disability Discrimination Legal Service made the following comment:

Life is complex and changing and an individual's predisposition to certain conditions cannot be said to be sufficiently scientifically and/or medically determinative to exclude that individual on any grounds other than their current capacity to perform the position.⁹

31.15 The Australian Council of Trade Unions (ACTU) expressed the view that the ACTU

cannot see how a predisposition to acquiring a condition in the future could impact on a person's ability to meet the inherent requirements of a job, whether now or in the future.¹⁰

31.16 The acting Disability Discrimination Commissioner commented:

in most instances legitimate assessments by employers should be concerned with a person's ability to perform job requirements at present rather than with what may happen years into the future. This is consistent with the fact that employment in Australia is a relationship terminable by either party on relatively short notice.¹¹

31.17 The Advisory Committee on Health Research to the World Health Organisation has summarised the issue as follows:

Similar ethical concerns apply to the use of genetic testing by employers or potential employers. Current health problems that would prevent a person from carrying out the duties of employment, even when employers have made reasonable accommodations for illness or disabilities, can justifiably be used in employment decisions. But genetic conditions that constitute risks for future health problems should not be used to bar otherwise qualified people from employment. If and when they prevent the individual from continuing in employment, they can be dealt with appropriately.¹²

9 Disability Discrimination Legal Service, *Submission G146*, 28 March 2002.

10 Australian Council of Trade Unions, *Submission G278*, 20 December 2002.

11 Acting Disability Discrimination Commissioner — Human Rights and Equal Opportunity Commission, *Submission G301*, 16 January 2003.

12 Advisory Committee on Health Research, *Genomics and World Health* (2002), World Health Organization, Geneva, 159.

31.18 While these comments reflect the position adopted in most submissions, the Australian Institute of Actuaries expressed the view that:

It is often an inherent requirement of a job that a person being appointed to fill it be expected to remain fit enough to perform the job for a reasonable period of time. This would be the case in any job, for example, where it would take a period of years to gain full proficiency. Disabilities that may exist in the future can affect how long an employee will be able to perform the job to the standards required. It is difficult to see how making an assessment of future ability to work can then be divorced from considering other inherent requirements of the job.¹³

31.19 The Australian Chamber of Commerce and Industry (ACCI) noted that, in those jobs with legitimate health and fitness requirements, some predictive genetic testing may be appropriate.¹⁴ The Commonwealth Department of Employment and Workplace Relations expressed the view that limiting the use of predictive health information by employers may give rise to inconsistencies with occupational health and safety requirements.¹⁵

31.20 The Inquiry notes that the definition of 'disability' in the DDA includes a disability that 'may exist in the future'.¹⁶ The Anti-Discrimination Board of NSW pointed out in its submission that:

A reading of these provisions which would allow an employer to assess an individual's ability to comply with the inherent requirements of a particular position in the future, would be incongruous with this prohibition.¹⁷

31.21 One of the objectives of the DDA, and of anti-discrimination legislation more generally, is to prohibit discrimination on the basis of some factors that may arise in the future. Such factors are not considered to be a relevant or reasonable basis for discrimination in the employment context. The United States Equal Employment Opportunity Commission has echoed these concerns in the following statement:

[E]mployers may only require employees to submit to any medical examination if those examinations are job related and consistent with business necessity. Any test which purports to predict future disabilities, whether or not it is accurate, is unlikely to be relevant to the employee's present ability to perform his or her job.¹⁸

31.22 A number of submissions, while supporting the proposal in DP 66 in principle, sounded a note of caution in relation to its wording, namely, that inherent requirements should be assessed by reference to current ability. The acting Disability Discrimination Commissioner, for example, noted that:

13 Institute of Actuaries of Australia, *Submission G224*, 29 November 2002.

14 Australian Chamber of Commerce and Industry, *Submission G308*, 24 January 2003.

15 Commonwealth Department of Employment & Workplace Relations, *Submission G305*, 22 January 2003.

16 *Disability Discrimination Act 1992* (Cth) s 4(1).

17 Anti-Discrimination Board of NSW, *Submission G157*, 1 May 2002.

18 Equal Employment Opportunity Commission (US), *EEOC and BNSF Settle Genetic Testing Case under Americans with Disabilities Act*, Press Release, <www.eeoc.gov/press>, 29 July 2002.

Such an amendment could restrict entitlements, which in HREOC's view presently exist under the DDA, for people to have a reasonable time to comply with job requirements. For example, a person temporarily incapacitated by illness would expect to have a reasonable time to recover fitness for work even though not 'currently' able to perform job requirements. A person requiring some initial adjustment period while workplace training is undertaken or assistive technology is made operational could likewise be seen as not 'currently' able to perform inherent requirements.¹⁹

31.23 In relation to those exceptional cases where an assessment of an applicant's future health may be justified, the Inquiry suggested in DP 66 that:

If an employer were faced with such a case, there are adequate mechanisms to deal with it, including the possibility of obtaining an exemption by the administering agency from the application of the anti-discrimination legislation.²⁰

31.24 The acting Disability Discrimination Commissioner did not support this approach:

Administratively it would appear feasible to deal with this small number of matters through the exemption process. However, as a matter of law and policy HREOC does not favour approaches that depend on the exemption process to make the law accord with a realistic interpretation of what should or should not be defined as discriminatory, rather than having the law as far as possible make sense as written.

31.25 Instead, the acting Disability Discrimination Commissioner suggested the following:

Except where exceptional circumstances can be demonstrated, reference to a person being unable to perform inherent requirements does not include circumstances where a person is currently able to perform those requirements but may become unable to in future. A person is not to be regarded as unable to perform inherent requirements if the inability is temporary and can be remedied within a reasonable period in the circumstances (for example where it is due to illness or where time is required to implement some reasonable adjustment).²¹

Inquiry's views

31.26 The Inquiry is of the view that, where genetic conditions are manifest they should be assessed in the same way as other medical conditions and disabilities in deciding whether an individual is able to perform the inherent requirements of the job. However, information about genetic predisposition can usually reveal only risks and probabilities and is unlikely to provide an accurate assessment of an individual's future health. Other factors such as environment, lifestyle and chance also have a major impact on a person's health. For these reasons, it remains the Inquiry's view that, in

19 Acting Disability Discrimination Commissioner — Human Rights and Equal Opportunity Commission, *Submission G301*, 16 January 2003.

20 Australian Law Reform Commission and Australian Health Ethics Committee, *Protection of Human Genetic Information*, DP 66 (2002), ALRC, Sydney.

21 Acting Disability Discrimination Commissioner — Human Rights and Equal Opportunity Commission, *Submission G301*, 16 January 2003.

general, it is not reasonable to rely on genetic information to predict a person's future ability to perform the inherent requirements of a job.

31.27 Given the mobility of the Australian workforce, it is unlikely that genetic information will be sufficiently relevant to an applicant or employees' ability to perform the inherent requirements of the job during the probable period of employment. Less than 25% of the working population in 2002 had been in the same job for ten years or more and less than 10% for twenty years or more.²² It has been estimated that Australian workers remain in their jobs for an average of six to seven years,²³ although mobility varies substantially from one industry to another.

31.28 The Inquiry generally supports the policy position of the Victorian Equal Opportunity Commission as expressed in its Employer Guidelines on Pre-Employment Medical Testing. These guidelines acknowledge that future health status will not usually be relevant but that, where an employer wishes to assess this, the employer should be able to demonstrate that this is reasonable.

The main features of a non discriminatory pre-employment medical test are:

- it relates specifically to the genuine and reasonable requirements of the job;
- the specific physical capacities required for the job are accurately identified and are reasonable in all the circumstances;
- reasonable ways of accommodating people with disabilities/impairments have been considered;
- any facilities or services reasonably required by applicants with disabilities/impairments are provided if reasonable;
- any assessment of a person's ability to perform the inherent requirements of the job is made in conjunction with these facilities or services;
- the test only assesses current health status and does not attempt to predict any future deterioration unless the employer can demonstrate that it is reasonable to do so.²⁴

31.29 The Inquiry notes the concern raised in submissions that limiting the assessment of an applicant or employee's ability to perform the inherent requirements of a job to his or her *current* abilities may give rise to a new set of problems. In some situations it may take a period of time before an individual is able to meet the inherent requirements of the job because of training or reasonable accommodation adjustments. The Inquiry recommends that reform be clearly targeted at the dangers of using genetic information in assessing an individual's ability to perform the inherent requirements of a job in the future. The Inquiry accordingly recommends that the Commonwealth

22 Commonwealth Department of Employment & Workplace Relations, *Submission G305*, 22 January 2003.

23 Commonwealth Department of Employment & Workplace Relations, *Correspondence*, 18 March 2003.

24 Equal Opportunity Commission Victoria, *Employer Guidelines: Pre-Employment Medical Testing*, <www.eoc.vic.gov.au/rescentre/publications/emp_guidelines.html>, 23 May 2002.

amend the DDA, the HREOC Act and the *Workplace Relations Act 1996* (Cth) to provide that, except where it is reasonable to do so, the assessment of an applicant or employee's ability to perform the inherent requirements of a job should not include an assessment of whether he or she will be unable to perform the inherent requirements in the future on the basis of his or her genetic status.

31.30 Some jobs may require that an employee remains fit and healthy for some period into the future; for example, armed forces personnel stationed in remote locations, astronauts training for missions years in the future, or scientists stationed in Antarctica for long periods. In jobs that involve placement for long periods in remote locations with limited medical facilities, an inherent requirement of the job may be the ability to work without unreasonable risk to oneself or others at some time in the future. In these circumstances a medical assessment, possibly including predictive genetic testing, may be permissible. However, this would have to be assessed on a case-by-case basis. Such cases, which in the Inquiry's view will be extremely rare, are accommodated in the recommendation by the requirement that any assessment of an individual's prospective capacities be reasonable in all the circumstances.

31.31 The Inquiry is of the view that further guidance on these issues should be included in employer guidelines issued by HREOC and, possibly, in Disability Standards issued under s 31 of the DDA. The development of Disability Standards and guidelines is discussed further, below.

Recommendation 31–1. The Commonwealth should amend the *Disability Discrimination Act 1992* (Cth) (DDA), the *Human Rights and Equal Opportunities Commission Act 1984* (Cth) and the *Workplace Relations Act 1996* (Cth) to provide that, except where it is reasonable to do so, the assessment of an applicant or employee's ability to perform the inherent requirements of a job should not include an assessment of whether he or she will be unable to perform the inherent requirements in the future on the basis of his or her genetic status.

Job descriptions setting out inherent requirements

31.32 In DP 66 the Inquiry proposed that peak employer associations should encourage members to produce clearly defined job descriptions that set out the inherent requirements of every position in the workplace.²⁵

Submissions and consultations

31.33 A number of submissions were critical of this proposal. The Victorian Automobile Chamber of Commerce noted that, while the preparation of job descriptions was prudent business practice, most jobs did not involve health risks or

²⁵ Australian Law Reform Commission and Australian Health Ethics Committee, *Protection of Human Genetic Information*, DP 66 (2002), ALRC, Sydney, Proposal 28–2.

require the use of genetic testing or information. In addition, a requirement to produce written documentation would impose a burden on small business.²⁶

31.34 The Department of Employment and Workplace Relations expressed the view that the proposal would impose unjustifiable costs and was probably unworkable given the constantly changing nature of jobs and job descriptions.²⁷ ACCI noted that the development of job descriptions was a matter for individual employers rather than for peak employer bodies.²⁸

31.35 The acting Disability Discrimination Commissioner commented that:

I agree that re-examination by employers of the inherent requirements of jobs will often be beneficial, in removing restrictions which may have become outdated with changes in working methods and technology and in focusing on results to be achieved rather than on particular methods for achieving those results which might unnecessarily exclude people with disabilities.

Further encouragement in this process from peak industry bodies would be welcome accordingly.

However, it should be noted that the objective of achieving job descriptions setting out the inherent requirements of every position may be unduly ambitious.²⁹

31.36 The Inquiry notes that HREOC's website includes the following guidance for employers on this matter:

the DDA does not require employers to have written duty statements and where a duty statement does exist it will not necessarily be conclusive. A requirement contained in a duty statement might not be found to be an inherent requirement. The Commission and the courts have emphasised that a requirement is not inherent simply because it is stipulated in a duty statement or contract of employment. Equally, a requirement might not appear on a duty statement but still be found to be an inherent requirement.³⁰

Inquiry's views

31.37 The Inquiry agrees that the proposal in DP 66 was overly broad in so far as it sought to encourage the production of job descriptions setting out the inherent requirements for every position in the workplace, even if this is sound business practice. However, the Inquiry is of the view that some reassessment of this issue by employers is required in relation to those positions in which genetic information, including family medical history, is used to assess an applicant or employee's ability to perform the inherent requirements of a job. In relation to those positions, the Inquiry is of the view that employers should develop clearly defined job descriptions that identify

26 Victorian Automobile Chamber of Commerce, *Submission G242*, 19 December 2002.

27 Commonwealth Department of Employment & Workplace Relations, *Submission G305*, 22 January 2003.

28 Australian Chamber of Commerce and Industry, *Submission G308*, 24 January 2003.

29 Acting Disability Discrimination Commissioner — Human Rights and Equal Opportunity Commission, *Submission G301*, 16 January 2003.

30 Human Rights and Equal Opportunity Commission, *Frequently Asked Questions: Employment*, <www.hreoc.gov.au/disability_rights/faq/Employment/employment_faq_1.html#questions>, 19 February 2003.

the inherent requirements of the job. They should also develop policies to ensure that genetic information is used to assess an applicant or employee's ability to meet the inherent requirements only in relevant and reasonable circumstances.

Recommendation 31–2. Where genetic information is used to assess an applicant or employee's ability to perform the inherent requirements of a job, employers should develop clearly defined job descriptions that identify these inherent requirements. Employers should also develop policies to ensure that genetic information is used for these purposes only in relevant and reasonable circumstances.

Requests for genetic information

31.38 Requests for, or requirements to produce, genetic information lie at the heart of concerns about genetic discrimination in employment. Such requests could include a request for information about family medical history, the results of a past genetic test or a request to undertake a new genetic test. Several submissions expressed the view that the circumstances in which employers are able to request or require such information should be very limited. Irrelevant questions about genetic status are unlikely to contribute to fair recruitment and employment processes. This is particularly so in relation to genetic information because of its sometimes predictive nature and the possibility that the information may be misinterpreted or misapplied.

31.39 The DDA and other anti-discrimination laws are, in general, aimed at acts of discrimination such as refusing to employ a person because of that person's disability or perceived disability. However, in order to create an environment in which acts of unlawful discrimination are less likely to occur, some anti-discrimination legislation also prohibits the collection of information upon which those discriminatory acts might be based. Against this background, it is important to ensure that genetic information is requested or required by employers only in appropriate circumstances.

Current law

31.40 As discussed in Chapter 7, the collection of personal information is regulated by privacy laws. However, the DDA, the SDA, and anti-discrimination legislation in Queensland, Victoria, the ACT and the Northern Territory also contain express provisions regulating requests for information in connection with, or for the purposes of, an act of discrimination.³¹

31.41 Section 30 of the DDA currently provides:

31 *Disability Discrimination Act 1992* (Cth) s 30; *Sex Discrimination Act 1984* (Cth) s 27; *Anti-Discrimination Act 1991* (Qld) s 124; *Equal Opportunity Act 1995* (Vic) ss 100, 101; *Discrimination Act 1991* (ACT) s 23; *Anti-Discrimination Act 1992* (NT) s 26.

If, because of another provision of this Part (other than section 32), it would be unlawful, in particular circumstances, for a person to discriminate against another person on the ground of the other person's disability, in doing a particular act, it is unlawful for the first-mentioned person to request or require the other person to provide, in connection with or for the purposes of the doing of the act, information (whether by completing a form or otherwise) that persons who do not have a disability would not, in circumstances that are the same or are not materially different, be requested or required to provide.

31.42 Section 30 is not limited to requests for information by employers. It applies to requests for information in all the areas covered by the DDA.

31.43 Section 27(1) of the SDA is in similar terms. In its report, *Pregnant and Productive: It's a Right not a Privilege to Work while Pregnant*,³² HREOC noted that the meaning of the SDA provision was unclear and recommended that it be amended to simplify and confirm the intent of the section. The Sex Discrimination Amendment (Pregnancy and Work) Bill 2002 (Cth), currently before the Commonwealth Parliament, forms part of the Government's response to the HREOC report and is intended to clarify the meaning of s 27(1).

Submissions and consultations

31.44 The Anti-Discrimination Board of NSW, in its submission to the Inquiry, expressed the view that s 30 of the DDA, like s 27(1) of the SDA, should be clarified. It is not clear, for example, whether the provision prohibits questions asked of all applicants or employees or only questions asked specifically of individuals with a disability. The HREOC guidelines on disability discrimination in employment state that a question asked of all applicants may amount to unlawful indirect discrimination³³ but it remains unclear whether this sort of question would be unlawful under s 30.

31.45 In examining alternative models for a provision of this kind, it is important to consider whether an employer should be able to seek information about genetic status or to request that a person undergo genetic testing. The ACTU made the following recommendation in its submission:

The ACTU recommends that employers be prohibited from requiring, requesting, collecting or disclosing information derived from genetic testing of current or potential employees.³⁴

31.46 HREOC's policy, however, in relation to requests for information about disability is as follows:

32 Human Rights and Equal Opportunity Commission, *Pregnant and Productive: It's a Right Not a Privilege to Work While Pregnant* (1999), HREOC, Sydney.

33 Human Rights and Equal Opportunity Commission, *Frequently Asked Questions: Employment*, <www.hreoc.gov.au/disability_rights/faq/Employment/employment_faq_1.html#questions>, 19 February 2003.

34 Australian Council of Trade Unions, *Submission G037*, 14 January 2002.

The Commission considers that discouraging, or unnecessarily restricting, discussion or inquiries regarding a person's disability in ... legitimate work related respects would be damaging to effective equality of opportunity and thus would be contrary to the objects of the DDA as well as presenting difficulties for employers. The Commission does not interpret the DDA as having this effect.³⁵

31.47 While this policy makes clear that employers should be able to seek some information about disability, those inquiries are limited to 'legitimate work related' issues. The Anti-Discrimination Board of NSW stated:

There are insufficient safeguards in place to ensure that the information sought by employers relates to the inherent requirements of the particular position in issue. ... In order to comply with anti-discrimination legislation, pre-employment medicals *should* only be used to assess a person's capacity to carry out the inherent or essential requirements of a position, once the employer has identified the preferred candidate.³⁶

31.48 The Genetic Support Council of Western Australia expressed the view that employers should be able to collect genetic information only where it is relevant for occupational health and safety purposes.³⁷

31.49 HREOC states in its guidelines for employers that:

The DDA does not set out particular forms of words as permitted or prohibited. Rather, the lawfulness of inquiries or examinations under the DDA depends on whether they are for a legitimate purpose and are a reasonable means for achieving that purpose.

Employers should ensure that

- they know why they are collecting information
- this is a legitimate purpose
- information is only used for the purposes for which it was properly collected and is protected against improper access or disclosure.

Employers are also advised to make clear the purpose for which they request or require disability information, to reduce misunderstandings which might lead to fears of discrimination.³⁸

31.50 The acting Disability Discrimination Commissioner noted in his submission that:

The basis of this advice, however, requires interpretation of several provisions in the DDA rather than emerging clearly from section 30 which deals expressly with requests for information. The drafting of this section, borrowed from the Sex

35 Human Rights and Equal Opportunity Commission, *Frequently Asked Questions: Employment*, <www.hreoc.gov.au/disability_rights/faq/Employment/employment_faq_1.html#questions>, 19 February 2003.

36 Anti-Discrimination Board of NSW, *Submission G157*, 1 May 2002.

37 Genetic Support Council WA, *Submission G112*, 13 March 2002.

38 Human Rights and Equal Opportunity Commission, *Frequently Asked Questions: Employment*, <www.hreoc.gov.au/disability_rights/faq/Employment/employment_faq_1.html#questions>, 19 February 2003.

Discrimination Act, is not easily understood, and may be open to significantly different interpretations.³⁹

Options for reform

31.51 A United States Executive Order of 8 February 2000 provides guidance on employment with US federal departments and agencies. The Order, though not legally binding, seeks to prohibit entirely requests for genetic tests or test results and allows only limited use of family medical history. Genetic monitoring of biological effects of toxic substances in the workplace is permitted, however, subject to certain safeguards.⁴⁰

31.52 The Genetic Information Nondiscrimination Bill 2002 (US), currently before the United States Congress, seeks to extend the policy set out in the Executive Order to the private sector. The Bill makes it unlawful for an employer to request, require or purchase genetic information about an employee.⁴¹ It is not unlawful, however, where the employer is imposing a 'qualification standard, test or other selection criterion', which is shown to be job related and consistent with business necessity. A qualification standard may include a requirement that a person not pose a direct threat to the health or safety of other individuals in the workplace.⁴² Collection of information is allowed for genetic monitoring of biological effects of toxic substances in the workplace.⁴³ Unlike the Executive Order, the Bill does not impose a strict prohibition on requests for genetic tests or test results. Instead, it requires that any test be shown to be job-related and consistent with business necessity.

31.53 Another possible model, currently under consideration in Australia, is the Sex Discrimination Amendment (Pregnancy and Work) Bill 2002 (Cth), which proposes to replace existing s 27(1) of the SDA with the following provision:

It is unlawful for a person (the *first person*) to request or require another person (the *other person*) to provide information (whether by way of completing a form or otherwise) if:

(a) the information is requested or required in connection with, or for the purposes of, the first person doing a particular act; and

(b) under Division 1 or this Division, it would be unlawful in particular circumstances for the first person, in doing that act, to discriminate against the other person on the ground of the other person's sex, marital status, pregnancy or potential pregnancy; and

(c) persons:

39 Acting Disability Discrimination Commissioner - Human Rights and Equal Opportunity Commission, *Submission G301*, 16 January 2003.

40 *Executive Order 13145: To Prohibit Discrimination in Federal Employment Based on Genetic Information 2000* (United States). See also P Miller, 'Is There a Pink Slip in My Genes? Genetic Discrimination in the Workplace' (2000) 3 *Journal of Health Care Law & Policy* 225, 250.

41 Genetic Information Nondiscrimination Bill 2002 (USA) [202(b)].

42 Ibid [202(d)].

43 Ibid [202(b)(1)].

- (i) of the opposite sex; or
- (ii) of a different marital status; or
- (iii) who are not pregnant or potentially pregnant;

as the case requires, would not be requested or required to provide the information in circumstances that are the same or not materially different.

31.54 The language is somewhat clearer than the existing provision and it would be possible to redraft s 30 of the DDA along similar lines. However, the proposed amendment is still unclear in relation to the lawfulness of questions asked of all applicants.

31.55 The Anti-Discrimination Board of NSW has suggested that s 26 of the *Anti-Discrimination Act 1992* (NT) provides a clearer and more appropriate model for reform. Section 26 provides in part:

- (1) A person shall not ask another person, whether orally or in writing, to supply information on which unlawful discrimination might be based ...
- (3) Subsection (1) does not apply if the person proves, on the balance of probabilities, that the information was reasonably required for a purpose that did not involve discrimination.

31.56 Like s 30 of the DDA, this provision does not specifically address genetic information. If a provision modelled on this section were included in the DDA, employers would be prohibited from asking questions about any disability, including genetic status, unless they could prove that the information was reasonably required for a purpose that did not involve discrimination. An employer would have to be able to demonstrate, for example, that the information was reasonably required to ensure that the person was able to perform the inherent requirements of the job, including the ability to work safely.

31.57 Section 26 also includes a range of exceptions where a request for information is necessary to comply with, or specifically authorised by, a law, an order of a court, an award and so on. These exceptions would need careful consideration if the model were adopted at the federal level.

31.58 The Anti-Discrimination Commission Queensland commented in relation to s 124 of the Queensland Act, which is in similar terms to s 26 of the Northern Territory Act:

The ADCQ has found that section 124 is a very useful provision in terms of community education about restrictions on what information can be sought. Our experience is that if a person is directed to this section, they give greater consideration to the relevance of the information they are seeking and are more aware of the need to avoid taking irrelevant, discriminatory matters into account.⁴⁴

44 Anti-Discrimination Commission Queensland, *Submission G214*, 2 December 2002.

31.59 There is an important difference between s 26 of the Northern Territory Act and s 30 of the DDA. Under provisions such as s 30 of the DDA and s 27(1) of the SDA, the onus falls on the employee to show that information was requested in connection with or for the purposes of discrimination. Under s 26 of the Northern Territory Act the onus falls on the employer to prove that information was reasonably required for a non-discriminatory purpose. The onus of proof under the unlawful termination provisions of the WRA also falls on the employer once disability has been raised as an issue.⁴⁵ A reversal of the onus of proof under s 30 of the DDA would provide a higher level of protection for employees than currently exists.

31.60 The acting Disability Discrimination Commissioner stated that:

Section 26 of the Northern Territory Anti-Discrimination Act appears to provide a more suitable starting point as noted by the NSW ADB. This is not, however, to recommend precisely the same drafting, as in HREOC's view the Northern Territory provision may present some of the risks of discouraging appropriate discussion of disability issues previously raised by HREOC and noted by the Inquiry.

In particular, consideration is needed of whether employers requesting information should face a legal onus of proof of the legitimacy of requests for information, or only an evidential burden as applies to issues of unjustifiable hardship under the DDA. HREOC regards imposing an evidential burden only as the preferable implementation of a requirement to 'demonstrate' a legitimate purpose.

Inquiry's views

31.61 The Inquiry is of the view that in relation to genetic information (whether genetic test results or family medical history), the DDA should prohibit an employer from requesting or requiring such information unless the information is reasonably required for a purpose that does not involve unlawful discrimination. An example would be information that is used to assess whether a person is able to perform the inherent requirements of a job.

31.62 Section 30 of the DDA does not make a clear statement of this kind and should be amended. Although the Inquiry is particularly concerned about requests by employers for genetic information, it recognises that there may be sound reasons for a general amendment that would have a wider application, such as an amendment relating to requests for all information in the areas covered by the DDA. However, consistently with the Inquiry's Terms of Reference and the submissions received, the recommendation below is limited to questions in relation to genetic information in the employment context.

31.63 The proposed amendment to s 27(1) of the SDA goes some way towards clarifying that section, but a similar amendment to s 30 of the DDA would not resolve all the difficulties in the interpretation of the latter provision. In the Inquiry's view, s 26 of the *Anti-Discrimination Act 1992* (NT) provides an appropriate starting point for reconsideration of s 30 of the DDA. The Inquiry notes the acting Disability

45 *Workplace Relations Act 1996* (Cth) s 170CQ.

Discrimination Commissioner's concern in relation to reversing the onus of proof in s 30 and that this may run counter to policy considerations underpinning the DDA. It was suggested that it would be preferable to impose an evidential burden on employers. Employers would be required to produce evidence that a question was asked for a reason that did not involve discrimination but would not bear the onus of proving, on the balance of probabilities, that this was the case. In the Inquiry's view a provision that places an evidential burden on employers would draw an appropriate balance between the rights of the parties and is consistent with the principle that a person who alleges that another has engaged in unlawful conduct must prove his or her case.

31.64 In drafting an amendment it will be important to consider what exceptions might be desirable, such as requests for information necessary to comply with, or specifically authorised by, occupational health and safety legislation.

Recommendation 31–3. The Commonwealth should amend the DDA to prohibit an employer from requesting or requiring genetic information from a job applicant or employee except where the information is reasonably required for a purpose that does not involve unlawful discrimination, such as ensuring that a person is able to perform the inherent requirements of the job.

Guidance for employers on the use of genetic information

31.65 The recommendations above are intended to ensure that requests for genetic information by employers are confined to situations in which the information is reasonably required for a purpose that does not involve unlawful discrimination, for example, assessing an applicant's ability to perform the inherent requirements of a job or meeting occupational health and safety concerns. Even in these circumstances, however, submissions raised concerns about procedures for testing in the workplace and employers' ability to interpret and use genetic information in a reasonable manner.

31.66 The Disability Discrimination Legal Service submitted:

In circumstances where [genetic] testing is permitted, a regime needs to be developed to facilitate the rigorous assessment of the reliability, accuracy and proper interpretation of genetic testing results. The uncertainty of such information is such that any definitive decision-making based on such information is currently doubtful and education and awareness addressing these issues needs to occur in the context of a broader community awareness campaign.⁴⁶

31.67 In DP 66 the Inquiry proposed the development of Disability Standards under the DDA dealing with the collection and use of genetic information in employment. Under s 31 of the DDA, the Attorney-General may formulate Disability Standards that, once tabled before Parliament for a certain period, gain the force of law (see Chapter 30). Currently there are no standards in force in relation to employment.

46 Disability Discrimination Legal Service, *Submission G146*, 28 March 2002.

As an interim measure, the Inquiry proposed that HREOC should issue guidelines in this area.

31.68 The acting Disability Discrimination Commissioner and a number of other submissions expressed support for the proposal.⁴⁷ However, the Anti-Discrimination Board of NSW and the Anti-Discrimination Commission of Queensland expressed concern at the development of binding standards in this area. The Anti-Discrimination Board of NSW submitted that the collection and use of genetic information by employers will be very context specific.

Whether it is lawful to collect and use genetic information will be entirely dependent upon the nature of the work undertaken, the relationship of the work environment to particular conditions ...

As the purpose of Standards is to provide greater guidance about what constitutes discrimination in certain circumstances, then Standards would need to be very specific, including identifying specific types of work environments and conditions, or prepositions to particular conditions, which cannot be eliminated by any other means. Anything short of this degree of specificity would be unacceptable, given that compliance with a Standard may prevent a person who might otherwise have had a claim under the DDA from lodging a complaint. In our view it will be extremely difficult to develop Standards with sufficient precision to warrant usurping people's right to lodge a complaint under the DDA, given that the rapid pace at which the science of genetics is evolving.⁴⁸

31.69 The Anti-Discrimination Commission of Queensland was also of the view that the breadth and diversity of the employment context would make the development of appropriate standards very difficult.

It has taken almost 10 years for the Disability Standards for Accessible Public Transport to be implemented. The access issues occurring in the transport industry are extensive. However, they are significantly less than those that would be faced if it was sought to issue standards that covered the entire employment sector.⁴⁹

31.70 In the Inquiry's view, there is a need for detailed guidance for employers on the use of genetic information in the workplace. It is important to ensure that persons are not excluded from employment on the basis of unnecessary or irrelevant tests or on the basis of misinterpretation of test results.

31.71 The Inquiry notes that the development and approval of standards has proved to be difficult and time-consuming. The Inquiry is of the view, however, that the process itself may be beneficial by raising awareness of the issues among stakeholders.

47 Haemophilia Foundation Victoria, *Submission G201*, 25 November 2002; Institute of Actuaries of Australia, *Submission G224*, 29 November 2002; Centre for Genetics Education, *Submission G232*, 18 December 2002; Victorian Automobile Chamber of Commerce, *Submission G242*, 19 December 2002; Genetic Support Council WA, *Submission G243*, 19 December 2002; Centre for Law and Genetics, *Submission G255*, 21 December 2002; Human Genetics Society of Australasia, *Submission G267*, 20 December 2002; Law Institute of Victoria, *Submission G275*, 19 December 2002; Association of Genetic Support of Australasia, *Submission G284*, 25 December 2002; Acting Disability Discrimination Commissioner - Human Rights and Equal Opportunity Commission, *Submission G301*, 16 January 2003.

48 Anti-Discrimination Board of NSW, *Submission G194*, 27 November 2002.

49 Anti-Discrimination Commission Queensland, *Submission G214*, 2 December 2002.

The Inquiry recommends that the Attorney-General consider the development of Disability Standards in this area.

31.72 As an interim measure, the Inquiry recommends that HREOC, in consultation with the Human Genetics Commission of Australia (HGCA) and other stakeholders, should develop guidelines on the collection and use of genetic information in employment. The guidelines could address a range of issues including:

- the meaning of unlawful disability discrimination in the employment context;
- requests for genetic information under s 30 of the DDA;
- the inherent requirements exception and the circumstances in which genetic information may be relevant, for example, in relation to occupational health and safety issues;
- procedures for the collection of genetic information from applicants and employees, including the use of medical practitioners as intermediaries and genetic counsellors; and
- the use of genetic information by employers including interpretation of the information and appropriate responses to information.

31.73 In Chapter 32 the Inquiry recommends that the HGCA in consultation with the National Occupational Health and Safety Commission and other stakeholders, prepare national guidelines dealing with the collection and use of genetic information for occupational health and safety purposes. If the Attorney-General decides to proceed with Disability Standards, it will be important to ensure that the principles and procedures adopted are consistent as far as possible with the guidelines to be developed in the occupational health and safety context.

Recommendation 31–4. The Human Rights and Equal Opportunity Commission, in consultation with the Human Genetics Commission of Australia and other stakeholders, should develop guidelines dealing with the collection and use of genetic information in employment. The Attorney-General should consider the development of Disability Standards in this area pursuant to the DDA.

32. Occupational Health and Safety

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Introduction

32.1 The extent of occupational illness and injury in Australia is difficult to estimate because until recently there were no national statistics in relation to these occurrences. In a 1995 report, the Industry Commission estimated that every year in Australia there are over 500 fatalities as a result of traumatic injury at work; between 650 and 2,200 workers die of occupational cancers (with the majority of cancers resulting from exposure to hazardous substances); and up to 650,000 workers (one in 12) suffer illness or injury at work. A 1993 study found a strong relationship between workplace fatalities and workplace exposure to toxic vapours, dyes, asbestos, pesticides, metals, dusts, petrochemicals, solvents and allergens.¹

32.2 The Australian Manufacturing Workers' Union (AMWU) noted in its submission to the Inquiry that:

The health effects of exposures at the workplace are complex and multifactorial. In fact the disease outcomes of Australian workplace exposures is grossly under-researched and not understood. For example Australia has:

¹ See R Johnstone, *Occupational Health and Safety Law and Policy: Text and Materials* (1997) LBC Information Services, Sydney, 11, 13, 15. See also National Occupational Health and Safety Commission, *Data on OHS in Australia: The Overall Scene* (2000), Commonwealth of Australia, Sydney.

- no systematic collection of information on workplace diseases eg dermatitis, asthma and cancer;
- no reliable estimation of work related deaths ... ;
- at least 40,000 hazardous substances in use in our workplaces but ... exposure standards for less than 1,000 substances;
- no prevalence data on the use of solvents and other chemicals in our workplaces; and
- no exposure information for employees exposed to these hazardous substances.²

32.3 The National Occupational Health and Safety Commission (NOHSC) states in its *National OHS Strategy 2002–2012* that:

Australia's continuing high rates of work-related fatal and non-fatal injury and disease present a significant challenge to us all. Every year significant numbers of people die and many more are severely affected by work-related injuries and disease.³

32.4 In Chapter 30, the Inquiry recommended that human genetic information should not be collected or used by Australian employers except in conformity with anti-discrimination, occupational health and safety, and privacy laws, amended as recommended by this Report. In Chapter 31 the Inquiry made a range of recommendations designed to clarify and strengthen anti-discrimination laws. This chapter examines whether the occupational health and safety regime requires amendment in so far as it relates to the use of human genetic information. The chapter considers three potential uses of genetic information in employment, namely, genetic screening for work-related susceptibilities; genetic monitoring for workplace-induced injury or disease; and the protection of third party safety.

Regulatory framework for occupational health and safety

32.5 Australian occupational health and safety laws seek to prevent workplace injury, disease and death; compensate workers who suffer work-related injury (or their dependents in the case of death); and rehabilitate workers suffering occupational injuries or disease.⁴ The primary focus of the framework is on fostering safe and healthy work environments and safe work systems.⁵ This point was highlighted by the National Research Centre for Occupational Health and Safety Regulation (NRCOHSR) in its submission to the Inquiry:

² Australian Manufacturing Workers' Union, *Submission G269*, 21 December 2002.

³ National Occupational Health and Safety Commission, *National OHS Strategy 2002–2012* (2002), Commonwealth of Australia, Canberra.

⁴ R Johnstone, *Occupational Health and Safety Law and Policy: Text and Materials* (1997) LBC Information Services, Sydney, 36.

⁵ National Occupational Health and Safety Commission, *National OHS Strategy 2002–2012* (2002), Commonwealth of Australia, Canberra.

While the wording of the OHS statutes varies, the principle is the creation of a safe work environment by eliminating or controlling risks rather than selecting workers who are 'more suited' to work in intrinsically unsafe conditions, or selecting out those perceived to be susceptible to hazardous exposures. In other words, preference is given to measures that make the work environment safer (safe place controls) over individual measures (safe person measures). The risk management approach underpins the national standards developed by the National Occupational Health and Safety Commission and adopted by the states and territories under OHS legislation.⁶

Occupational health and safety legislation in Australia

32.6 The Australian Constitution does not contain an express legislative power relating to occupational health and safety or workers' compensation. The Commonwealth, relying on a range of other heads of power, has enacted some legislation in this area; for example, the *Occupational Health and Safety (Commonwealth Employment) Act 1991* (Cth) and the *National Occupational Health and Safety Commission Act 1985* (Cth), which establishes NOHSC.⁷ Principal responsibility for making and enforcing laws about workplace health and safety in Australia remains with the States and Territories. Each State and Territory has occupational health and safety legislation that sets out requirements for ensuring health and safety in the workplace.⁸ In addition, industry-specific legislation applies in some jurisdictions.

Employers' duty of care to employees

32.7 Each occupational health and safety statute imposes a duty on employers to take reasonable care for the health, safety and welfare at work of all employees. Despite differences in wording, the employer's duty is similar in all Australian jurisdictions except New South Wales and Queensland. The employer must take all reasonably practicable steps to protect the health and safety at work of all employees.⁹

32.8 In New South Wales, the employer's duty is not expressly qualified by the practicability of complying with the duty. However, the employer may rely on a defence that it was not reasonably practicable to comply, or that the breach was due to causes over which it had no control and it was impracticable to make provision for

6 National Research Centre for Occupational Health & Safety Regulation, *Submission G186*, 2 November 2002.

7 NOHSC is a tripartite body representing the Commonwealth, state and territory governments; employer organisations; and trade unions.

8 *Occupational Health and Safety Act 2000* (NSW); *Occupational Health and Safety Act 1989* (ACT); *Occupational Health and Safety Act 1985* (Vic); *Occupational Health, Safety and Welfare Act 1986* (SA); *Occupational Safety and Health Act 1984* (WA); *Work Health Act 1986* (NT); *Workplace Health and Safety Act 1995* (Qld); *Workplace Health and Safety Act 1995* (Tas).

9 *Occupational Health and Safety (Commonwealth Employment) Act 1991* (Cth) s 16; *Occupational Health and Safety Act 1989* (ACT) s 27; *Occupational Health, Safety and Welfare Act 1986* (SA) s 19(1); *Workplace Health and Safety Act 1995* (Tas) s 9(1); *Work Health Act 1986* (NT) s 29; *Occupational Health and Safety Act 1985* (Vic) s 21(1). See generally, A Brooks, 'Occupational Health and Safety' in J Golden and D Grozier (eds), *The Laws of Australia: Labour Law* (1998) Law Book Company Limited, Sydney, [73]–[74].

such a happening.¹⁰ In Queensland, the employer must ensure the health and safety of its employees at work, subject to a number of qualifications provided in the statute.¹¹

32.9 Specific duties flow from this duty of care.¹² These include provision and maintenance of safe plant and systems of work; a safe working environment and adequate welfare facilities; information and instruction on workplace hazards and supervision of employees in safe work; monitoring the health of employees; and monitoring conditions at the workplace.

Employers' duty of care to third persons

32.10 In most jurisdictions, occupational health and safety legislation also imposes a duty of care on employers to persons other than employees, including persons not working for the employer but present at the workplace—for example, police, fire fighters, inspectors, clients, visitors and trespassers. The duty also extends to persons outside the workplace who are affected by the conduct of operations at the workplace.¹³

Employees' duties

32.11 In most jurisdictions, employees have a duty to take care for their own health and safety while at work. All jurisdictions impose a general duty on employees to take care for the health and safety of others at the workplace. Some jurisdictions impose a duty on employees to co-operate with the employer in the interests of workplace health and safety. In addition, some jurisdictions impose a duty on persons within workplaces not to wilfully or recklessly place at risk the health or safety of another at the workplace.¹⁴

Regulations, standards and codes of practice

32.12 While occupational health and safety legislation imposes general duties regarding workplace health and safety, regulations, standards and codes of practice provide more detailed regulation and guidance, often in relation to specific hazards.

32.13 NOHSC develops and declares national standards dealing with specific workplace hazards or hazardous environments. These standards set out essential requirements for inclusion in the occupational health and safety legislation in each jurisdiction. NOHSC also declares national codes of practice to advise employers and workers on acceptable ways of meeting the national standards. Commonwealth, state

10 *Occupational Health and Safety Act 2000* (NSW) ss 8(1), 28.

11 *Workplace Health and Safety Act 1995* (Qld) s 28.

12 Commonwealth of Australia, *National Occupational Health and Safety Commission website*, <www.nohsc.gov.au/>, 6 March 2003.

13 See generally, A Brooks, 'Occupational Health and Safety' in J Golden and D Grozier (eds), *The Laws of Australia: Labour Law* (1998) Law Book Company Limited, Sydney, [81]. However, compare New South Wales: *Occupational Health and Safety Act 2000* (NSW) s 8(2).

14 See generally, A Brooks, 'Occupational Health and Safety' in J Golden and D Grozier (eds), *The Laws of Australia: Labour Law* (1998) Law Book Company Limited, Sydney, [90]–[92], [95].

and territory governments also issue codes of practice to advise on acceptable ways of complying with their occupational health and safety legislation.

32.14 Under all NOHSC standards and codes, employers have a duty to impose a systematic process of hazard identification, risk assessment, risk control and review in the workplace; to make sure that employees receive appropriate training, instruction and supervision; to obtain and provide appropriate information; to consult with employees likely to be exposed to risks, and with their health and safety representatives; and to keep appropriate records.¹⁵ Additional or more specific requirements apply in some areas, for example, in relation to particular hazardous substances.

32.15 In addition, NOHSC has developed the *National OHS Strategy 2002–2012* which provides for five national priorities underpinned by action plans.¹⁶ The five national priorities are as follows:

- reduce high-incidence and high-severity risks;
- develop the capacity of business operators and workers to manage occupational health and safety effectively;
- prevent occupational disease more effectively;
- eliminate hazards at the design stage; and
- strengthen the capacity of government to influence occupational health and safety outcomes.

32.16 On 16 October 2002 NOHSC agreed to a set of National Priority Action Plans (NPAPs) for the period 2002–2005 for the five national priorities identified in the Strategy. These NPAPs are the first in a series of three year national action plans to be developed to cover the ten year period of the Strategy. The NPAPs were endorsed by the Workplace Relations Ministers' Council at its 8 November 2002 meeting. NOHSC, in approving the NPAPs, noted that the plans will be regularly updated to reflect any changes in emphasis or direction that are needed to meet the goals of the Strategy.

Common law principles

32.17 While occupational health and safety is primarily regulated by legislation, common law principles continue to have some application in certain jurisdictions. For example, employers may have a duty arising from implied terms in the common law employment contract to take reasonable care for the safety of their employees, breach

15 National Occupational Health and Safety Commission (Worksafe Australia) and Australian Chamber of Commerce and Industry, *The National Standards Guide (Final Draft)* (1997), Commonwealth of Australia.

16 National Occupational Health and Safety Commission, *National OHS Strategy 2002–2012* (2002), Commonwealth of Australia, Canberra.

of which may give rise to a cause of action. Employees may also be able to bring a common law action for damages for negligence where an employer is in breach of its duty to take reasonable care for the health and safety of employees.¹⁷

32.18 Common law actions require the employee to prove fault (for example, negligence) on the part of the employer. This contrasts with claims under workers' compensation legislation, which establish no-fault compensation schemes. These schemes are discussed in Chapter 33.

Genetic screening for work-related susceptibilities

32.19 The first potential use of genetic information in employment is genetic screening for work-related susceptibilities. The NRCOHSR has noted that:

It is common practice in Australia for larger employers to require some form of pre-employment health screening. The general rationale for such screening is to determine a potential employee's fitness for work.¹⁸

32.20 Against this background, employers might seek to use genetic information in order to screen for a genetic susceptibility (or predisposition) to a work-related condition. Family medical history or genetic test results may disclose that a person has an inherited predisposition to a condition that may be triggered by exposure to certain workplace hazards.

32.21 In 1990, the United States Office of Technology Assessment reported that about 50 genetic mutations had been identified as affecting susceptibility to specific environmental agents.¹⁹ For example, individuals with a genetic deficiency in the production of a particular protein—alpha-1 antitrypsin—are more susceptible to lung disease if exposed to dusty work environments.²⁰ It has also been claimed that a genetic mutation may affect susceptibility to a form of occupational overuse syndrome known as 'carpal tunnel syndrome'.²¹ Individuals with a genetic mutation of this kind may be hyper-susceptible to a particular workplace hazard.

17 J Macken and others, *The Law of Employment* (5th ed, 2002) Lawbook Company, Sydney, 118.

18 National Research Centre for Occupational Health & Safety Regulation, *Submission G186*, 2 November 2002.

19 T Lemmens, "'What About Your Genes?'" Ethical, Legal and Policy Dimensions of Genetics in the Workplace' (1997) 16(1) *Politics and Life Sciences* 57, 60; US Congress — Office of Technology Assessment, *Genetic Monitoring and Screening in the Workplace* (1990), US Government Printing Office, Washington, 83.

20 See National Institutes of Health, *Understanding Alpha-1 Antitrypsin Deficiency*, <www.nhlbi.nih.gov/health/public/lung/other/antitryp.htm>, 20 February 2003.

21 The US Equal Employment Opportunity Commission brought proceedings against the Burlington Northern Santa Fe Railroad in 2001 in relation to the company's policy of requiring employees who submitted claims for work-related carpal tunnel syndrome to provide blood samples. It was alleged that these samples were used for a genetic test that is claimed to predict some forms of carpal tunnel syndrome: US Equal Employment Opportunity Commission, *Press Release: EEOC Petitions Court to Ban Genetic Testing of Railroad Workers in First EEOC Case Challenging Genetic Testing under Americans with Disabilities Act*, 9 February 2001.

32.22 Currently, an employer can ask a job applicant or employee to provide family medical history or genetic test information to identify whether the person has a susceptibility to a particular work-related condition, pursuant to the employer's occupational health and safety obligations. In some industries, employers are *required* to conduct pre-placement health assessments. For example, the National Standard for the Control of Inorganic Lead at Work (the Lead Standard) provides that employers must arrange for each employee to be examined by an authorised medical practitioner prior to commencing work in a lead-risk job. The Lead Standard provides that an individual may be excluded from working in a lead-risk job in a number of circumstances, including on the basis of a personal medical condition or medical history.²²

Issues and problems

Relevance of genetic information

32.23 The Inquiry has heard a number of concerns regarding the use of genetic screening for work-related susceptibilities. One concern relates to the accuracy and reliability of predictive genetic tests and family medical history in identifying real risks to an applicant or employee's future health and safety at work. As most genetic conditions are multifactorial in nature, genetic information often indicates no more than a possibility that an individual will suffer a disease or condition in future. The individual may never develop the disease or condition; if they do, its onset might occur late in life. Alternative forms of health assessment, such as regular medical examinations, may be a more useful indicator of risk.

32.24 NRCOHSR stated in its submission that:

It is important to emphasise the misconceptions about the value of genetic screening for preventing occupational injury and disease. Determining the contributors to adverse health outcomes is an evolving and complex area. In regard to work environment exposures, many substances are not well tested and knowledge of health effects is limited, especially in regard to long-term health effects. Moreover, many conditions are multi-factorial and may be caused by a combination of environmental exposures and/or genetic factors. It would be imprudent to place too much emphasis on the 'science' of genetic screening to unravel the causes and prevention of disease when significant gaps exist in understanding the contribution of occupational exposures to disease.²³

32.25 The Australian Council of Trade Unions (ACTU) expressed the concern that employers might misuse genetic screening programs to test for mutations that are unrelated to workplace exposures but which might affect the person's future health and ability to work, potentially impacting on employers' administrative costs through sick

22 National Occupational Health and Safety Commission, *National Standard for the Control of Inorganic Lead at Work [NOHSC: 1012 (1994)]*, Commonwealth of Australia, cl 14 and 15.

23 National Research Centre for Occupational Health & Safety Regulation, *Submission G186*, 2 November 2002.

leave or replacement costs.²⁴ As noted in Chapter 30, there is evidence of this occurring in the United States.

Timing of screening

32.26 A number of submissions expressed the view that genetic screening should only be conducted once a job offer has been made to a job applicant.²⁵ The Anti-Discrimination Board of NSW explained the basis for this approach:

In order to ensure that tests are only carried out where absolutely necessary, we consider that the proposal should reflect the fact that employers should only seek to determine any susceptibility of the applicant once the employer has selected their preferred candidate. This will ensure that employers will not test all applicants or some applicants and reject any applicants where there may be any prospect of susceptibility.

If the latter approach is taken, then it is often more difficult to establish that the test result was the reason that a particular applicant was not selected and hence the employer's discriminatory use of the information is harder to prove.²⁶

Mandatory or voluntary screening?

32.27 If employers are permitted to collect genetic information for the purpose of susceptibility screening, it is necessary to consider whether screening should be conducted on a mandatory or voluntary basis. Refusal to participate in a mandatory screening program might result in adverse impacts on an individual's job application or employment prospects.

32.28 Several international instruments emphasise the need for free and informed consent to medical and other procedures.²⁷ A number of submissions expressed concern about the undermining of free consent in relation to mandatory screening programs and suggested that screening should be conducted only on a voluntary basis.²⁸ The Department of Health and Ageing submitted that mandatory genetic screening has the potential to undermine an individual's 'right not to know' about a possible genetic predisposition or condition.²⁹

24 Australian Council of Trade Unions, *Submission G037*, 14 January 2002.

25 Anti-Discrimination Board of NSW, *Submission G194*, 27 November 2002; Anti-Discrimination Commission Queensland, *Submission G214*, 2 December 2002; Centre for Genetics Education, *Submission G232*, 18 December 2002.

26 Anti-Discrimination Board of NSW, *Submission G194*, 27 November 2002.

27 See eg *Universal Declaration on the Human Genome and Human Rights*, UNESCO, <www.unesco.org/ibc/en/genome/projet/>, 19 February 2003, Art 5.

28 Anti-Discrimination Board of NSW, *Submission G194*, 27 November 2002; Anti-Discrimination Commission Queensland, *Submission G214*, 2 December 2002; Centre for Genetics Education, *Submission G232*, 18 December 2002; Law Institute of Victoria, *Submission G275*, 19 December 2002.

29 Commonwealth Department of Health and Ageing, *Submission G313*, 6 February 2003.

32.29 Some submissions suggested that employers should warn employees about potential workplace hazards and allow them to seek private medical advice about the risks involved.³⁰ The Australian Nursing Federation submitted:

If employers provide all relevant information about the work to be undertaken and its possible effect on the health of all current and potential employees then the employee can, in consultation with their own medical officer, make an informed decision about the suitability of the employment or the need for genetic testing.³¹

32.30 Dr Paul Henman emphasised the need to protect employee autonomy:

If such a link can be made between genetics and the workplace environment, then the appropriate action is for employers to advise employees that X in the workplace environment may bring about Y in people with a genetic predisposition. This allows employees control over their own genetic information and to decide whether to take steps based on the implications of their workplace environment and what steps they may choose to take. Anything else takes control away from the individual.³²

32.31 The Anti-Discrimination Board of NSW and the Law Institute of Victoria were of the view that, where an employee is given adequate information about the risks but elects not to be screened or to continue to work in the environment in question despite an identified susceptibility, this will significantly reduce the likelihood that the employer will be liable for breach of its duty of care.³³

32.32 Associate Professor Margaret Otlowski has commented that the extent of the employer's duty to employees with regard to genetic screening is unclear. She notes that the scope of the duty of care may be that the employer must simply inform applicants or employees of known potential hazards in the workplace and offer them screening where it is available, or at least advise them of its benefits. If the employer meets required safety standards and the applicant chooses to take the risk by declining testing or pursuing employment despite an identified susceptibility, the employer would not be in breach of its duty of care.³⁴

Response to hazards in the workplace

32.33 One of the principal concerns raised in submissions in relation to genetic screening was that employers might seek to comply with their occupational health and safety duties by excluding susceptible employees from the workforce rather than by eliminating workplace hazards.³⁵ Margaret Otlowski has commented:

30 Australian Nursing Federation, *Submission G080*, 10 January 2002; National Council of Women Australia, *Submission G095*, 31 January 2002; Androgen Insensitivity Syndrome Support Group Australia, *Submission G106*, 26 February 2002.

31 Australian Nursing Federation, *Submission G080*, 10 January 2002.

32 P Henman, *Submission G055*, 15 January 2002.

33 Anti-Discrimination Board of NSW, *Submission G157*, 1 May 2002; Law Institute of Victoria, *Submission G275*, 19 December 2002.

34 M Otlowski, *Implications of Genetic Testing for Australian Employment Law and Practice* (2001) Centre for Law and Genetics, Hobart, 26–27.

35 Australian Council of Trade Unions, *Submission G037*, 14 January 2002; Australian Nursing Federation, *Submission G080*, 10 January 2002; Construction Forestry Mining and Energy Union, *Submission G248*, 20 December 2002; Australian Manufacturing Workers' Union, *Submission G269*, 21 December 2002; Commonwealth Department of Health and Ageing, *Submission G313*, 6 February 2003.

While employers' use of genetic screening may be advocated on the basis of enabling job applicants to make 'informed choices' about whether to take up a particular position, the reality is that the job is unlikely to be offered to a person who is identified as at risk. Further, allowing employers to use genetic testing for the purpose of selecting their employees would deflect attention away from their obligation as employers to endeavour to provide a workplace which is safe and without risk to health for all employees.³⁶

32.34 The ACTU submitted that the most effective way for employers to protect the safety of susceptible employees is to provide a safe workplace, free from potential exposure to hazards.

Employers are responsible for providing employees with a safe and healthy workplace, while work-related illnesses and injuries are caused by hazards in the workplace, not by employees' genetic make-up. ... removing workers with a genetic predisposition to some cancers from work environments where they may be exposed to conditions putting them at additional risk is an unacceptable solution to chemical hazards in the workplace. ... While there might be some statistical validity to such an approach, the fact is that many workers not showing some genetic predisposition, either because they don't have one or because of inadequacies in the testing process, will be exposed and will develop cancer. Removal of hazards for *all* workers cannot be substituted by removal of some workers.³⁷

Options for reform

Prohibition on the use of genetic information

32.35 The ACTU and several other individuals and organisations supported a complete prohibition on the collection and use of genetic information to identify an applicant or employee's susceptibilities.³⁸ This approach protects the privacy of employees' genetic information and emphasises the employer's responsibility for providing a safe workplace.

32.36 However, the Inquiry does not consider this approach to be realistic in light of the practical impossibility of completely eliminating all hazards from the workplace. In addition, some genetic testing may be of benefit to employees by permitting the early avoidance of potentially harmful exposure.

36 M Otowski, 'Employers' Use of Genetic Test Information: Is There a Need for Regulation?' (2002) 15 *Australian Journal of Labour Law* 1, 21. See also T Lemmens, "'What About Your Genes?'" Ethical, Legal and Policy Dimensions of Genetics in the Workplace' (1997) 16(1) *Politics and Life Sciences* 57, 70.

37 Australian Council of Trade Unions, *Submission G037*, 14 January 2002.

38 Ibid; P Henman, *Submission G055*, 15 January 2002; Australian Manufacturing Workers' Union, *Submission G269*, 21 December 2002.

Permission to use family medical history

32.37 A second option is to permit the collection and use only of family medical history for the purpose of susceptibility screening. The United States' Executive Order (discussed in Chapter 31) is an example of this model.³⁹ A federal department or agency may request family medical history information but not genetic test results from an applicant or employee. This information may be used to determine whether to conduct further medical evaluation to diagnose a current disease, medical condition or disorder that could prevent that person from performing essential job functions. In relation to an employee, the information may also be requested if the department or agency reasonably believes that the employee will pose a direct threat due to a medical condition.⁴⁰

32.38 However, this model does not appear appropriate in the context of employment involving exposure to hazardous substances. Family medical history information may be insufficient in these circumstances to identify relevant susceptibilities unless other family members have been exposed to similar work environments.

Permission to use genetic information subject to limitations

32.39 A third option is to permit the collection and use of genetic test results and family medical history for the purpose of susceptibility screening, subject to strict limitations. A number of overseas jurisdictions have adopted this approach. In Denmark, for example, employers are permitted to collect health data where it is relevant to the employee's ability to perform the specific work and to determine the employee's risk of developing or contracting illnesses if the conditions of the working environment make it reasonable and appropriate to do so in relation to the individual, or other employees.⁴¹

32.40 The Inquiry received a number of submissions supporting this option, provided strict safeguards are implemented in relation to the collection, use and disclosure of genetic information.⁴² The Centre for Law and Genetics emphasised that the employer's primary focus should be on elimination of hazards in the workplace, but gave limited support to the use of susceptibility screening.

39 *Executive Order 13145: To Prohibit Discrimination in Federal Employment Based on Genetic Information 2000* (United States). US President Clinton signed the Executive Order in February 2000.

40 Equal Employment Opportunity Commission, *Policy Guidance on Executive Order 13145: To Prohibit Discrimination in Federal Employment Based on Genetic Information* (2000) EEOC, 10–13.

41 *Act On the Use of Health Data etc on the Labour Market*, Act No 286 of 24 April 1996, cited in M Otlowski, *Implications of Genetic Testing for Australian Employment Law and Practice* (2001) Centre for Law and Genetics, Hobart, 60–61.

42 Centre for Law and Genetics, *Submission G048*, 14 January 2002; Anti-Discrimination Board of NSW, *Submission G157*, 1 May 2002; Anti-Discrimination Commission Queensland, *Submission G214*, 2 December 2002; Institute of Actuaries of Australia, *Submission G224*, 29 November 2002; Centre for Genetics Education, *Submission G232*, 18 December 2002; Genetic Support Council WA, *Submission G243*, 19 December 2002; Human Genetics Society of Australasia, *Submission G267*, 20 December 2002; Law Institute of Victoria, *Submission G275*, 19 December 2002; Association of Genetic Support of Australasia, *Submission G284*, 25 December 2002.

In some limited circumstances, employers would be justified in having access to an employee or job applicant's genetic information for occupational health and safety reasons such as determination of whether an employee has a genetic susceptibility to a disease that may [be] triggered by substances present in the workplace and there would be general support for such use in the interests of employees/applicants for employment.⁴³

32.41 The Centre cited the United Kingdom's Nuffield Council on Bioethics' guidelines as a starting point for this consideration. The Nuffield Council recommended that genetic screening for increased occupational risks should be considered only where:

- there is strong evidence of a clear connection between the working environment and the development of the condition for which the screening is conducted;
- the condition in question is one which seriously endangers the health of the employee or is one in which an affected employee is likely to present a serious danger to third parties; and
- the condition is one for which the dangers cannot be eliminated or significantly reduced by reasonable measures taken by the employer to modify or respond to the environmental risks.⁴⁴

32.42 In its submission to the Inquiry, the NRCOHSR also recommended that genetic screening be limited to those circumstances where:

- it is reasonable to expect that the work be performed;
- (reasonably) practicable control measures have been implemented to control risks in the work environment;
- taking into account these control measures a person might still endanger him/herself or others, including members of the public, due to a particular genetic characteristic or condition; and
- there is a reliable method of testing or screening that indicates the presence and nature of the genetic characteristic or condition.⁴⁵

32.43 The Centre for Law and Genetics stressed that susceptibility screening should be based on the principle of informed consent. Where an employee withholds consent to screening, or is identified as susceptible but desires to continue working, the Centre did not recommend excluding the person from employment, but suggested:

43 Centre for Law and Genetics, *Submission G048*, 14 January 2002.

44 Nuffield Council on Bioethics, *Genetic Screening Ethical Issues* (1993), Nuffield Council on Bioethics, London [6.23], [6.28].

45 National Research Centre for Occupational Health & Safety Regulation, *Submission G186*, 2 November 2002.

The best way to ensure that the voluntariness of consent is not undermined, is to avoid impediments to such a person being engaged, but then to give some defence against liability to employers who have fully complied with occupational health and safety best practice.⁴⁶

32.44 The Centre recommended that an independent review process should objectively determine those circumstances in which it is appropriate to undertake genetic testing. The Centre also suggested that an independent body should oversee the use of genetic information obtained by employers to ensure it is used only for the limited purpose for which it was obtained.⁴⁷

32.45 The Anti-Discrimination Board of NSW emphasised the need for clear guidelines in relation to genetic testing in employment, and proposed a comprehensive genetic testing code of practice that would provide a general prohibition on requesting genetic information and testing in employment with specific exceptions. The code would include guidelines on employment testing, informed consent, counselling, and rights and obligations under relevant legislation. Sections of the code could be incorporated into industry codes of practice under relevant occupational health and safety legislation.⁴⁸

Inquiry's views

32.46 The Inquiry is of the view that it is not appropriate to impose a complete prohibition on the use of genetic information by employers to screen for work-related susceptibilities. The Inquiry recognises that the elimination of hazards from the workplace is the most effective means of protecting employees from safety risks and that, as technology advances, this may become easier to achieve. However, complete elimination of workplace hazards may not be possible in practice in some workplaces. For example, exposure to heat and dust is unavoidable when fighting fires, and exposure to trace quantities of substances such as beryllium may be unavoidable in some manufacturing processes (see Chapter 29). In addition, family medical history alone may be insufficient to identify relevant susceptibilities unless other family members have been exposed to similar work environments.

32.47 Chapter 29 outlined the interests of employers, employees and the public in relation to the use of genetic information in employment. Arguments in favour of genetic screening for work-related susceptibilities include its potential to protect susceptible employees from avoidable risk to their health and safety, and to protect employers from potential legal liability and financial costs for illness suffered by susceptible employees. Arguments against screening include the potential for unfair discrimination, invasion of privacy and misuse and misinterpretation of genetic test results.

46 Centre for Law and Genetics, *Submission G048*, 14 January 2002. See also House of Commons Science and Technology Committee, *Human Genetics: The Science and its Consequences* (1995), House of Commons, London [233].

47 Centre for Law and Genetics, *Submission G048*, 14 January 2002.

48 Anti-Discrimination Board of NSW, *Submission G157*, 1 May 2002.

32.48 The Inquiry considers that, consistently with the principles underpinning the occupational health and safety regime in Australia, the primary focus should be the elimination of risks from the workplace rather than the exclusion of susceptible applicants and employees. The Inquiry therefore recommends that employers should not conduct genetic screening of employees for susceptibility to work-related conditions if the environmental risks can be eliminated or significantly reduced by reasonable measures. Where this is not possible, genetic screening may be appropriate in certain circumstances to protect the health and safety of individuals with particular work-related susceptibilities.

32.49 The Inquiry considers that a number of safeguards are necessary for the conduct of this form of genetic screening. In particular, the genetic tests used in employment should be subject to independent oversight by the Human Genetics Commission of Australia (HGCA). The Inquiry recommends that the HGCA establish procedures to assess and make recommendations on whether particular genetic tests should be used in employment for occupational health and safety purposes. The Inquiry believes that the HGCA should take the principles set out by the Nuffield Council on Bioethics and the NRCOHSR into consideration in assessing genetic tests for use in employment.

32.50 The Inquiry also considers that the HGCA and NOHSC, in consultation with other stakeholders, should develop national guidelines for the conduct of genetic screening for susceptibility to work-related conditions. The guidelines should indicate that employers should use genetic tests for screening only where they have been recommended for that purpose by the HGCA in accordance with the procedures outlined above. The guidelines should also address a range of other issues including the use of voluntary and mandatory testing, guidance on the interpretation of test results, appropriate responses to positive test results, the use of family medical history, genetic counselling and privacy.

32.51 In relation to job applicants, the Inquiry considers that screening should be conducted only after an applicant has been offered a position. By minimising the number of individuals subject to screening, this approach would reduce the risks to privacy and the potential for unlawful discrimination based on the results of screening. A more targeted approach would also minimise costs to employers. This recommendation is consistent with Recommendation 31–3, namely, that employers should only request genetic information from job applicants where the information is reasonably required for a purpose that does not involve discrimination.

32.52 Generally, screening should be conducted only on a voluntary basis. Employers should continue to work towards satisfying their duty of care to employees and others by offering voluntary genetic screening programs where appropriate and subject to the safeguards discussed above. However, in those rare circumstances in which it is not possible to eliminate the workplace hazard by taking reasonable measures and the danger to employees is very high, it may be reasonable to implement a mandatory screening program. The Inquiry is of the view that the HGCA should

consider and make recommendations on whether mandatory genetic screening can be justified in such circumstances.

32.53 NOHSC should consider adopting the guidelines as a national code of practice so that they become part of the national regulatory framework. In addition, NOHSC should ensure that NPAPs developed under the National Strategy reflect these developments.

Recommendation 32–1. The Human Genetics Commission of Australia (HGCA) should establish procedures to assess and make recommendations on whether particular genetic tests should be used in employment for screening for susceptibility to work-related conditions. In assessing particular genetic tests, the HGCA should consider whether:

- there is strong evidence of a clear connection between the working environment and the development of the condition;
- the condition may seriously endanger the health or safety of employees; and
- the test is a scientifically reliable method of screening for the condition.

Recommendation 32–2. The HGCA and the National Occupational Health and Safety Commission (NOHSC) should collaborate with other stakeholders to develop national guidelines for the conduct of genetic screening for susceptibility to work-related conditions. The guidelines should indicate:

- that genetic screening of job applicants and employees for susceptibility to work-related conditions should not be conducted if the danger can be eliminated or significantly reduced by reasonable measures taken by the employer to reduce the environmental risk;
- that employers should use genetic tests only where they have been recommended for that purpose by the HGCA;
- how genetic test results are to be interpreted;
- that screening should not be conducted on a job applicant until the applicant has been made an offer of employment;
- that screening should be conducted on a voluntary basis except in those rare circumstances in which the HGCA has recommended that screening be mandatory;
- the circumstances in which family medical history may be collected and used;

- what provision should be made for genetic counselling of those undergoing testing;
- appropriate responses by employers where genetic screening reveals relevant susceptibilities; and
- what measures should be taken to ensure the confidentiality of screening results.

Recommendation 32–3. NOHSC should consider adopting the national guidelines on the conduct of genetic screening for susceptibility to work-related conditions as a national code of practice. NOHSC should ensure that the National Priority Action Plans developed under the *National OHS Strategy 2002–2012* reflect these developments.

Genetic monitoring for workplace-induced conditions

32.54 Health surveillance involves the conduct of ongoing health assessments to identify whether an employee's health is being affected by exposure to a hazardous substance in the workplace. Genetic monitoring—one form of health surveillance—involves the periodic testing of employees exposed to workplace hazards such as toxic chemicals or radiation to assess whether there has been any genetic modification as a result of workplace exposure.⁴⁹ Genetic monitoring measures biomarkers of 'biologically effective dose' (for example, DNA adducts) and 'early biological effects' (for example, chromosomal changes) within an exposed person.⁵⁰ The Inquiry understands that the technology associated with genetic monitoring is not currently sophisticated enough for precise and uniformly dependable test results.⁵¹

32.55 Health surveillance in industries involving workplace exposure to hazardous substances is regulated under the framework of the National Hazardous Substances Regulatory Package, which consists of regulations, standards and codes of practice developed by NOHSC. The National Model Regulations for the Control of Workplace Hazardous Substances (the Model Regulations) apply to workplaces in which hazardous substances are used or produced, and to persons with potential exposure to

49 US Congress — Office of Technology Assessment, *Genetic Monitoring and Screening in the Workplace* (1990), US Government Printing Office, Washington, 55–56.

50 K van Damme, 'Genetic Testing in the Workplace: The Scientific Aspects' (Paper presented at Round Table: Genetic Testing in the Workplace, Brussels, 6 March 2000), 8. See also US Congress — Office of Technology Assessment, *Genetic Monitoring and Screening in the Workplace* (1990), US Government Printing Office, Washington Ch 4.

51 L Trettin, C Musham and R Jablonski, 'Genetic Monitoring in the Workplace: A Tool Not a Solution' (1999) 10(1) *Risk: Health, Safety & Environment* 31. See also J Ford and others, 'Genetic Tests in the Workplace: Detecting Past or Current Chemical Toxicity' (1999) 15(2) *Journal of Occupational Health and Safety* 155.

hazardous substances in those workplaces.⁵² Each Australian jurisdiction has implemented the package (with some variations) in regulations under its occupational health and safety legislation.

32.56 The National Code of Practice for the Control of Workplace Hazardous Substances (the National Code), which forms part of the regulatory package, provides a hierarchy of control measures that can be used to eliminate or minimise exposure to hazardous substances. Consistently with occupational health and safety principles, the control measures emphasise elimination of the hazardous substance from the workplace as the top priority. Other control measures such as substitution, isolation, engineering controls, safe work practices and use of personal protective equipment may be considered only if elimination is not practicable.

32.57 The Regulatory Package provides for health surveillance of employees to identify changes in health status due to workplace exposure to hazardous substances. It establishes safeguards for the conduct of health surveillance, including the form of surveillance, the retention and confidentiality of surveillance records, and in some circumstances the appropriate remedial response to identified exposure.⁵³ The National Code states that:

Health surveillance, which includes biological monitoring, can assist in minimising the risk to health from hazardous substances for which there are known and acceptable health surveillance procedures by:

- (a) confirming that the absorbed dose is below the accepted level;
- (b) indicating biological effects requiring cessation or reduction of exposure; or
- (c) collecting data to evaluate the effects of exposure.⁵⁴

32.58 'Biological monitoring' is one component of health surveillance. The Model Regulations define 'biological monitoring' as the measurement and evaluation of hazardous substances or their metabolites in the body tissues, fluids or exhaled air of an exposed person.⁵⁵ It is unclear whether the term 'biological monitoring' as it is currently defined would include genetic monitoring.

52 National Occupational Health and Safety Commission, *National Model Regulations for the Control of Workplace Hazardous Substances [NOHSC: 1005 (1994)] (Updated for Amendments)*, Commonwealth of Australia.

53 For example, the Lead Standard provides for the removal of an employee from a lead-risk job to a job without lead risks, on the basis of his or her personal medical condition, or if she is pregnant or breast feeding: National Occupational Health and Safety Commission, *National Standard for the Control of Inorganic Lead at Work [NOHSC: 1012 (1994)]*, Commonwealth of Australia cl 14.

54 National Occupational Health and Safety Commission, *National Code of Practice for the Control of Workplace Hazardous Substances [NOHSC: 2007 (1994)]*, Commonwealth of Australia.

55 National Occupational Health and Safety Commission, *National Model Regulations for the Control of Workplace Hazardous Substances [NOHSC: 1005 (1994)] (Updated for Amendments)*, Commonwealth of Australia r 4.

Issues and problems

The employer's duty of care

32.59 The employer's duty to provide a safe workplace is of particular importance in industries involving workplace exposure to hazardous substances. Health surveillance programs have been developed for these industries as one means for an employer to comply with its statutory duty to safeguard employees' health and safety; and to allow for early intervention to prevent onset of a disease in employees exposed to workplace hazards.

Mandatory or voluntary monitoring?

32.60 As with genetic susceptibility screening, it is necessary to consider whether employee participation in genetic monitoring programs should be mandatory or voluntary. As noted above, in some jurisdictions employees have a duty to co-operate with employers in the interests of workplace health and safety.⁵⁶ This duty has been incorporated into the Model Regulations in the requirement that employees must comply, to the extent they are capable, with all activities carried out under those regulations.⁵⁷ The National Code states that:

Employees should participate in the health surveillance program unless there is some compelling reason to the contrary, in which case the matter should be discussed with the registered medical practitioner responsible for the health surveillance program.⁵⁸

32.61 Monitoring under the Lead Standard, which forms part of the hazardous substances regulatory package, is conducted on a mandatory basis.

Submissions and consultations

32.62 In its submission to the Inquiry, the AMWU noted that:

In line with the overriding principles of ... health and safety laws, health surveillance is prescribed for a small number of substances where there is a significant risk to health from exposure. NOHSC has also taken the step of prescribing the health surveillance tests required for these scheduled substances.⁵⁹

32.63 The ACTU was of the view that genetic monitoring should only be conducted within the existing Regulatory Package, adding that:

56 See generally, A Brooks, 'Occupational Health and Safety' in J Golden and D Grozier (eds), *The Laws of Australia: Labour Law* (1998) Law Book Company Limited, Sydney, [92].

57 National Occupational Health and Safety Commission, *National Model Regulations for the Control of Workplace Hazardous Substances [NOHSC: 1005 (1994)] (Updated for Amendments)*, Commonwealth of Australia r 16; National Occupational Health and Safety Commission, *National Standard for the Control of Inorganic Lead at Work [NOHSC: 1012 (1994)]*, Commonwealth of Australia cl 17.

58 National Occupational Health and Safety Commission, *National Code of Practice for the Control of Workplace Hazardous Substances [NOHSC: 2007 (1994)]*, Commonwealth of Australia.

59 Australian Manufacturing Workers' Union, *Submission G269*, 21 December 2002.

It must not be assumed that occupational health surveillance is totally benign. Health surveillance involves monitoring the adverse effects of hazardous agents and substances on the health of working people who are exposed to them. The union movement agrees that health surveillance is necessary in order to alert workers, employers and government agencies to potential adverse health outcomes from exposures. However, health surveillance must be conducted under strict provisions of confidentiality of personal health information and with associated obligations on the part of employers to control exposures where a risk is shown.⁶⁰

32.64 Margaret Otlowksi has suggested that in appropriate circumstances genetic monitoring might be conducted on groups of workers rather than individually. The test results would be disclosed to the individual employees but the employers would receive only aggregate results. This would focus employer attention on improving workplace safety rather than identifying and eliminating ‘at-risk’ employees from the workplace.⁶¹

Inquiry’s views

32.65 The Inquiry is of the view that, within the existing framework of the National Hazardous Substances Regulatory Package, genetic information may be useful in health surveillance programs for employees exposed to hazardous substances in the workplace. However, the Inquiry recommends that genetic monitoring of employees should be conducted only where there is strong evidence of a clear connection between the working environment and the development of the condition, the condition may seriously endanger the health or safety of the employee, and there is a scientifically reliable method of screening for the condition.

32.66 In order to ensure that genetic monitoring is conducted in accordance with this recommendation, the Inquiry recommends that NOHSC, in consultation with the HGCA and other stakeholders, develop a national code of practice for the conduct of genetic monitoring of employees exposed to hazardous substances in the workplace. The Inquiry notes that mandatory testing may be appropriate where there is a significant risk to health from exposure. However, this will be the exception rather than the rule and the code of practice should provide for voluntary or group monitoring to protect employee privacy and autonomy to the maximum extent possible.

32.67 In the course of developing this code, NOHSC should consider whether the definition of ‘biological monitoring’ in the Model Regulations is wide enough to include genetic monitoring.

60 Australian Council of Trade Unions, *Submission G278*, 20 December 2002.

61 M Otlowksi, ‘Employers’ Use of Genetic Test Information: Is There a Need for Regulation?’ (2002) 15 *Australian Journal of Labour Law* 1, 34.

Recommendation 32–4. Within the framework of the National Hazardous Substances Regulatory Package, NOHSC, in consultation with the HGCA and other stakeholders, should develop a national code of practice for the conduct of genetic monitoring of employees exposed to hazardous substances in the workplace. Under this code of practice, genetic monitoring of employees should be conducted only where:

- there is strong evidence of a connection between the working environment and the development of the condition;
- the condition may seriously endanger the health or safety of employees; and
- there is a scientifically reliable method of screening for the condition.

Genetic screening for the protection of third party safety

32.68 The third context in which employers might seek access to an applicant or employee's genetic information is to identify whether he or she has a genetic predisposition to a condition that, if it becomes manifest while the person is at work, could pose a significant risk to the health and safety of other employees or the public. This is more likely to occur in 'safety-critical' positions such as public transport (for example, airline and ship pilots and train and bus drivers), emergency services (for example, fire fighters and police officers), and positions involving the storage or transport of dangerous chemicals or products.⁶²

32.69 As discussed above, employers have a statutory duty to protect the health and safety of third persons present at the workplace or otherwise affected by the conduct of operations at the workplace.

32.70 In some industries, specific legislation requires employers to ensure the health and safety of their employees so that they may perform their work without safety risks to other workers or the public. For example, the *Rail Safety Act 1993* (NSW) provides that all railway employees performing railway safety work must be of sufficient good health and fitness to perform the functions for which they are certified.⁶³

32.71 Some industries have developed industry-based policies for meeting occupational health and safety requirements. For example, the Civil Aviation Safety Authority Australia (CASA) has the statutory power to regulate the safety of civil aviation operations in Australia.⁶⁴ Pilots must undergo regular medical assessments as

⁶² See generally Australasian Faculty of Occupational Medicine, *Guidelines for Health Assessment for Work* (1998) Royal Australasian College of Physicians, 22–23.

⁶³ *Rail Safety Act 1993* (NSW) s 61.

⁶⁴ See *Civil Aviation Act 1988* (Cth) s 9.

a condition of their licence rather than as a condition of employment. If a health risk is identified, the medical examiner must notify CASA and the employee but not the employer.⁶⁵

32.72 Some employers implement their own workplace policies for the purpose of satisfying their occupational health and safety duties. For example, a number of Australian employers conduct drug and alcohol testing on employees engaged in inherently dangerous work activities to determine whether they are under the influence of a drug likely to affect their performance or place the safety of others at risk.

Issues and problems

32.73 As discussed in Chapter 29, there are some reported cases of employers collecting genetic information from employees to identify potential safety risks to third parties. In the 1970s the United States armed forces and airline industry screened pilots and aircrew applicants for the sickle cell trait in the belief that carriers might suffer adverse health consequences in certain atmospheric conditions. These policies were subsequently discontinued due to insufficient evidence that carriers were at risk.⁶⁶ The United Kingdom Ministry of Defence also conducted sickle cell screening on aircrew applicants until recently.⁶⁷

32.74 A number of submissions put the view that predictive genetic testing is not yet sufficiently reliable to determine accurately the degree of risk posed by an employee identified with a certain predisposition.⁶⁸ The Disability Discrimination Legal Service submitted:

Until such time as scientific reliability and certainty of genetic test results can be determined and verified, such risk to the public let alone the individual themselves, is unable to be assessed. Given this uncertainty, such testing would constitute a breach of the human rights of individuals and groups within the community with no appreciable benefit to public or individual safety.⁶⁹

32.75 Several submissions suggested that, instead of collecting genetic information, employers could avoid potential safety risks through alternative measures such as regular medical examinations to identify the onset of symptoms, or by providing technological or other measures to assist employees if safety risks arise.⁷⁰ Dr Paul Henman submitted:

65 See generally Civil Aviation Safety Authority, *Designated Aviation Medical Examiner's Handbook* (2001) CASA.

66 J Crespin, 'Genetic Screening in the Workplace for Sickle Cell Trait: A Dangerous Tool' (1992) 30 *Medical Trial Technique Quarterly* 91, 95–96.

67 Human Genetics Commission, *Inside Information: Balancing Interests in the Use of Personal Genetic Data* (2002), London [8.8].

68 Disability Discrimination Legal Service, *Submission G146*, 28 March 2002; Human Genetics Society of Australasia, *Submission G050*, 14 January 2002; P Henman, *Submission G055*, 15 January 2002.

69 Disability Discrimination Legal Service, *Submission G146*, 28 March 2002.

70 See Human Genetics Society of Australasia, *Submission G050*, 14 January 2002; Australian Huntington's Disease Association (NSW), *Submission G054*, 14 January 2002; P Henman, *Submission G055*, 15 January 2002; Australian Nursing Federation, *Submission G080*, 10 January 2002; Australian Council of Trade Unions, *Submission G037*, 14 January 2002.

We have not had aircraft and bus crashes or nuclear generator collapses that have resulted from a person's sudden manifestation of an undiagnosed genetic condition ... In terms of safety critical employment, the key issue pertains to the existence of a genetic condition that has a sudden, unexpected onset. In contrast, most (all?) genetic conditions that impair a person's capabilities are gradual ... Safety critical jobs normally have a range of procedures to ensure safety ... These checks all make genetic information unnecessary and irrelevant to the operation of safety critical functions. In particular, if a genetic condition may lead to a deterioration of a person's capacity to work, such deterioration is likely to be identified at a regular medical examination. It is only at such time that it is appropriate for the condition to affect one's employment.⁷¹

32.76 The Australian Nursing Federation recommended a 'universal precautions' approach, noting that risk identification, reduction and management processes are routinely undertaken in relation to employees. As examples, it cited the current practice of having more than one pilot in most aeroplanes and the requirement that professional drivers take regular rest breaks.⁷²

32.77 By contrast, the Centre for Law and Genetics submitted that there might be limited circumstances in which genetic screening for the protection of third party safety would be justified:

[T]here would need to [be] some quantification of the risk such that it is reasonable to be taking precautions against it ... Amongst other things, there would need to be consideration of the prevalence of the condition and the likelihood of the person actually developing it. The probability of the person developing the condition also has to be weighed against the seriousness of the hazard that this person represents to others should he or she develop the condition: the more serious the consequences for third parties, the more justifiable testing would be.⁷³

32.78 The Anti-Discrimination Board of NSW considered that employers should be permitted to monitor employees' health in cases where public safety is at issue and there is no way of eliminating the risk without knowledge of a person's health.⁷⁴

32.79 The United Kingdom's House of Commons Science and Technology Committee recommended allowing employers to conduct predictive screening for genetic traits that might put the public at direct and substantial risk. While the Committee stressed that it did not know of any genetic diagnosis that should be revealed to the employer when it released the report, it considered that provision should be made for future advancements in science.⁷⁵

71 P Henman, *Submission G055*, 15 January 2002.

72 Australian Nursing Federation, *Submission G080*, 10 January 2002. See also P Henman, *Submission G055*, 15 January 2002.

73 Centre for Law and Genetics, *Submission G048*, 14 January 2002.

74 Anti-Discrimination Board of NSW, *Submission G157*, 1 May 2002.

75 M Otlowski, *Implications of Genetic Testing for Australian Employment Law and Practice* (2001) Centre for Law and Genetics, Hobart, 63, citing House of Commons Science and Technology Committee, *Human Genetics: The Science and its Consequences* (1995), House of Commons, London.

32.80 A number of submissions commented that, where the safety of third parties is at issue, screening should be done on a mandatory basis.⁷⁶

Options for reform

Prohibition on use of genetic information

32.81 Currently most predictive genetic tests cannot accurately predict the time of onset of a disease or, in most cases, whether the disease will manifest at all. A notable exception is the monogenic disorder, Huntington's disease, where the age of onset of the condition depends on the number of repetitions of the DNA sequence 'CAG' in one portion of one gene.⁷⁷ On this basis, it might be argued that employers should be prohibited from relying on genetic information to protect third party safety in the employment context. While this approach seems reasonable in the short term, the Inquiry considers that a framework should be established which is more responsive to the developing science relating to genetic screening, having regard to the likelihood that more accurate and reliable genetic tests will become available in future.

Permission to use family medical history

32.82 A second option is to allow employers access to family medical history but not genetic test information to identify whether employees in safety critical positions have a family medical history of certain 'high-risk' conditions. While family medical history is relevant in this context, the Inquiry is of the view that this form of screening may not be sufficient to identify all relevant susceptibilities.

Permission to use genetic information subject to limitations

32.83 Several overseas jurisdictions have permitted the use of genetic information in employment for the purpose of protecting third party safety. A number of submissions supported the use of genetic screening for this purpose.

32.84 The Centre for Law and Genetics submitted that this form of screening should be permitted only in exceptional circumstances where a case can objectively be made that screening is necessary for the protection of other employees or the public generally. It recommended a number of procedural safeguards, including the need to demonstrate clear scientific evidence of the risk to third parties; that the danger could not be guarded against by less invasive means such as regular performance monitoring; quantification of the risk so that it is reasonable to take precautions against it; evidence as to the probability of the person developing the condition; and oversight by an independent body.⁷⁸

76 Institute of Actuaries of Australia, *Submission G224*, 29 November 2002; Law Institute of Victoria, *Submission G275*, 19 December 2002; Victorian Automobile Chamber of Commerce, *Submission G242*, 19 December 2002.

77 M Ridley, *Genome: The Autobiography of a Species in 23 Chapters* (1999) Fourth Estate, London, 55-56.

78 Centre for Law and Genetics, *Submission G048*, 14 January 2002.

32.85 The Anti-Discrimination Board of NSW also recognised that there may be limited circumstances in which genetic testing may be appropriate where particular positions involve significant safety risks to the public, the employee concerned, or other employees. The Board submitted that genetic testing of applicants or employees should be limited to

positions where the risk to public safety could not be eliminated other than by being aware of a person's condition or predisposition; and conditions which would [affect] a person's capacity to carry out the inherent requirements of the particular job.⁷⁹

32.86 The Haemophilia Foundation Victoria submitted that the only circumstance in which tests should be available in employment is where there is a proven link between the particular genetic condition and the ability to conduct the job safely.

For example, if a person's genetic information shows that they are likely to have a heart attack, and they are at a high-risk age, that person should not fly planes, drive buses or undertake any job in which a sudden heart attack would put the public, or fellow workers, at risk.⁸⁰

Inquiry's views

32.87 The Inquiry is of the view that in restricted circumstances it is reasonable for employers to obtain and use genetic information from individuals working in safety-critical positions to identify relevant risks to third parties.

32.88 At present, it is difficult to find plausible examples of genetic conditions that involve the sudden and unpredictable onset of symptoms that could not have been identified through regular medical examinations. A possible example is the testing of airline pilots or bus drivers for Huntington's disease due to the risk of the sudden onset of irrational behaviour, which is one of the first symptoms of the condition;⁸¹ or for Marfan syndrome, which is difficult to diagnose but may lead to sudden heart failure.

32.89 The Inquiry considers that in the vast majority of cases regular performance monitoring and medical examinations offer a more effective and reliable means of identifying employees who might pose a risk to third party safety. These assessments can identify deterioration of performance or development of symptoms, whether resulting from genetic or other causes.⁸² Therefore, genetic information from an applicant or employee should not be collected and used for the protection of third party safety if the danger can be eliminated or significantly reduced by other reasonable measures taken by the employer. Where this is not possible, genetic information should be collected and used only where the applicant or employee's condition poses a real risk of serious danger to the health or safety of third parties and there is a scientifically reliable method of screening for the condition.

⁷⁹ Anti-Discrimination Board of NSW, *Submission G157*, 1 May 2002.

⁸⁰ Haemophilia Foundation Victoria, *Submission G145*, 25 March 2002.

⁸¹ M Otlowski, 'Employers' Use of Genetic Test Information: Is There a Need for Regulation?' (2002) 15 *Australian Journal of Labour Law* 1, 21–22.

⁸² *Ibid.*, 22.

32.90 More accurate and extensive genetic testing is likely to become available in future and the Inquiry believes that the use of this information should be expressly addressed in guidelines. On this basis, the Inquiry recommends that the HGCA and NOHSC should collaborate with other stakeholders to develop national guidelines on the collection and use of genetic information from job applicants and employees for the protection of third party safety. In developing national guidelines, the HGCA and NOHSC should consider in what circumstances, if any, testing should be mandatory.

32.91 NOHSC should consider adopting the guidelines as a national code of practice so that they become part of the national regulatory framework. In addition, NOHSC should ensure that NPAPs developed under the National Strategy reflect these developments.

Recommendation 32–5. The HGCA and NOHSC should collaborate with other stakeholders to develop national guidelines for the collection and use of genetic information from applicants and employees for the protection of third party safety. The guidelines should indicate that genetic information from an applicant or employee should not be collected or used for the protection of third party safety if the danger can be eliminated or significantly reduced by other reasonable measures taken by the employer. Where this is not possible, genetic information should be collected or used only where:

- the applicant or employee’s condition poses a real risk of serious danger to the health or safety of third parties; and
- there is a scientifically reliable method of screening for the condition.

Recommendation 32–6. NOHSC should consider adopting the national guidelines on the collection and use of genetic information for the protection of third party safety as a national code of practice. NOHSC should ensure that the National Priority Action Plans developed under the *National OHS Strategy 2002–2012* reflect these developments.

33. Workers' Compensation

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Introduction

33.1 This chapter discusses the potential use of genetic information in the context of a workers' compensation claim or a common law claim for damages for work-related injury or death. The Inquiry is not aware of any instances in which Australian employers or insurers have sought to obtain or use genetic test information in this context. However, as the scientific reliability and range of genetic tests increases, and the cost of testing decreases, there will be clear incentives for employers or insurers to seek access to this information.

33.2 There are three ways in which employers or their insurers might in future seek access to such information: first, to calculate an employer's insurance premium for a workers' compensation scheme; second, to determine liability under a workers' compensation scheme or at common law; and third, to calculate the quantum of compensation or damages payable for a work-related injury or death.

Regulatory framework for compensation

Statutory workers' compensation

33.3 Workers' compensation is a system of accident compensation for workers who suffer or contract work-related injuries or disease, and for the dependants of those whose death is attributable to employment.¹

33.4 Each Australian jurisdiction has workers' compensation legislation which requires employers to insure against their statutory and common law liability to compensate workers for work-related injury and disease that results in incapacity or death.² Each jurisdiction provides compensation on a 'no-fault' basis.³ A claimant does not have to show that the employer acted negligently in order to be eligible for compensation. Depending on the legislation, a person might also be able to bring a common law action in negligence against an employer.

33.5 The two federal workers' compensation schemes are the Comcare scheme, for Commonwealth employees and employees in the Australian Capital Territory public sector; and the Seacare scheme, for certain seafarers.⁴ Comcare is a Commonwealth statutory authority responsible for workplace safety, rehabilitation and compensation in the federal sphere.

Common law claims

33.6 Injured workers may be able to claim common law damages from an employer for negligence, or for breach of a statutory duty. There is also an implied term in the common law contract of employment that an employer must take reasonable care not to expose employees to unnecessary risks to their health and safety.⁵ Breach of this term may give rise to a common law claim for breach of contract.

33.7 Originally, all Australian workers' compensation schemes allowed access to the common law actions for damages for workplace injuries and disease, subject to the claimant making an election between the common law action and statutory benefits. Some jurisdictions have since removed access to the common law entirely, while

1 T Paine, 'Workers' Compensation' in J Golden and D Grozier (eds), *The Laws of Australia: Labour Law* (2000) Law Book Company Limited, Sydney, vol 26.5 [1].

2 See *Safety, Rehabilitation and Compensation Act 1988* (Cth); *Seafarers Rehabilitation and Compensation Act 1992* (Cth); *Workers Compensation Act 1987* (NSW); *Workplace Injury Management and Workers Compensation Act 1998* (NSW); *Workers Rehabilitation and Compensation Act 1986* (SA); *Workers Rehabilitation and Compensation Act 1988* (Tas); *Accident Compensation Act 1985* (Vic); *Workers' Compensation Act 1951* (ACT); *Workers' Compensation and Rehabilitation Act 1981* (WA); *Work Health Act 1986* (NT); *WorkCover Queensland Act 1996* (Qld).

3 T Paine, 'Workers' Compensation' in J Golden and D Grozier (eds), *The Laws of Australia: Labour Law* (2000) Law Book Company Limited, Sydney, vol 26.5 [2].

4 *Safety, Rehabilitation and Compensation Act 1988* (Cth); *Seafarers Rehabilitation and Compensation Act 1992* (Cth). See also Commonwealth Department of Employment & Workplace Relations, *Submission G305*, 22 January 2003.

5 Commonwealth Department of Employment & Workplace Relations, *Submission G305*, 22 January 2003.

others have subjected it to heavy restrictions regarding the available heads of damage, and the amount of damages recoverable.⁶

Other inquiries into workers' compensation

33.8 The Inquiry is aware of several inquiries into workers' compensation reform in Australia. The House of Representatives' Standing Committee on Employment and Workplace Relations has been asked to inquire into, and report on, matters relevant and incidental to Australian workers' compensation schemes. The Committee is examining:

- the incidence and costs of fraudulent claims and fraudulent conduct by employees and employers, and any structural factors that may encourage such behaviour;
- the methods used and costs incurred by workers' compensation schemes to detect and eliminate fraudulent claims, and the failure of employers to pay the required workers' compensation premiums or otherwise fail to comply with their obligations; and
- factors that lead to different safety records and claims profiles from industry to industry, and the adequacy, appropriateness and practicability of rehabilitation programs and their benefits.⁷

33.9 In July 2002, the Federal Government announced that, following finalisation of terms of reference, it would ask the Productivity Commission to inquire into establishing nationally consistent arrangements for workers' compensation and occupational health and safety issues.⁸

33.10 During 2002, a committee chaired by Justice David Ipp conducted a review of the law of negligence. The committee examined methods to reform the common law in order to limit liability and the quantum of damages arising from personal injury and death. The committee's final report, titled *Review of the Law of Negligence*, was submitted to the Commonwealth in September 2002.⁹

6 Ibid.

7 House of Representatives' Standing Committee on Employment and Workplace Relations, *Inquiry into Aspects of Australia's Workers' Compensation Schemes: Terms of Reference*, Parliament of Australia, <www.aph.gov.au/house/committee/ewr/wkc/tor.htm>, 10 February 2003.

8 The Hon Tony Abbott MP & Senator The Hon Ian Campbell, *Joint Media Release: Government to Consider Workers' Compensation Reform*, Parliament of Australia, <www.nohsc.gov.au/NewsAndWhatsNew/MediaReleases/MR-240702.htm>, 10 February 2003.

9 D Ipp, D Sheldon, I Macintosh, P Cane, *Review of the Law of Negligence (2002)*, Commonwealth of Australia, <www.revofneg.treasury.gov.au/content/Report2/PDF/Law_Neg_Final.pdf>, 20 February 2003.

General comments on workers' compensation

33.11 The Inquiry received few submissions about the use of genetic information in relation to workers' compensation. The Australian Council of Trade Unions (ACTU) expressed the concern that many employers see employees' use of sick leave or workers' compensation as an indication of their suitability for employment.

Employers could find themselves required by insurers to minimise risk by not employing people with predispositions to disabling conditions, or face higher workers' compensation premiums. Collection of genetic information could also affect general workplace salary continuance insurance arrangements which are currently offered to all employees in some workplaces ... If such testing and data collection became widespread, it could very well lead to the development of an 'underclass', whose employers, assuming they were employed, would be unwilling to invest in their training and development, or to offer them long-term advancement opportunities.¹⁰

33.12 DP 66 asked whether employers or insurers should have access to an employee's genetic information to determine liability, or to assess compensation or damages, in relation to a workers' compensation claim or a common law claim for work-related injury.¹¹ In response, the ACTU commented:

the ACTU is concerned that genetic information about injured employees could be used by employers and insurers to deny or reduce workers' compensation claims on the grounds of a person's alleged genetic predisposition to certain conditions. The provision for the use of family history under some workers' compensation schemes is already problematic as family history is not unequivocally predictive of a person developing any condition or disease. All workers, or their families, should be entitled to compensation for work-related death, or incapacity whatever their family history or genetic make-up.

Society needs to be convinced that there is a significant public interest before agreeing to genetic testing in the occupational environment. The ACTU is not convinced that such a public interest exists at present, or is likely to exist.¹²

33.13 By contrast, the Australian Chamber of Commerce and Industry submitted:

If genetic information is available concerning the employee's health, and as a result fitness to undertake work which the employee is employed to perform, then the employer/insurer is entitled to gain access to that information. The employer/insurer can then assess:

- a) Whether given the genetic evidence in advance, the employer would have offered or assigned that work to be undertaken by that employee;
- b) The level of liability based on that evidence;

10 Australian Council of Trade Unions, *Submission G037*, 14 January 2002.

11 Australian Law Reform Commission and Australian Health Ethics Committee, *Protection of Human Genetic Information*, DP 66 (2002), ALRC, Sydney, Question 39–1.

12 Australian Council of Trade Unions, *Submission G278*, 20 December 2002.

- c) The employee has a 'duty of care' to the employer, to fellow employees, and others and as a result has an obligation to divulge any health problem, which may affect work performance, and or the employee's own safety and the safety of others.

The employer can then also make decisions about the potential suitability of the employee for certain kinds of work—e.g. it may assist the employer in ensuring that employees are not exposed to hazards and situations which they should avoid from a health and safety perspective.¹³

33.14 The Law Institute of Victoria provided a detailed discussion of this issue. After noting their primary concern that genetic information includes information about an enormous number of 'potentials' as well as current realities, they commented:

In the Workers' Compensation context, it would be naive to expect that insurers would (or even could) use this sort of information only to test for conditions relating directly to the injury in question. An insurer has competing interests and obligations. In defending a common law claim for damages for example, an insurer would understandably want to test for any condition which might be held to reduce the life expectancy of the claimant, so as to limit the damages claim. The prejudicial effect of discovering a 'potential' condition or genetic predisposition, and the lack of certainty on the basis of current scientific knowledge, makes this an extremely dangerous exercise. It also takes no account of the 'egg-shell skull' rule that has long formed part of our system of torts law ... There is no reason why a person with a genetic propensity should be discriminated against in the job market or less compensated for the same injuries as a person who does not carry those genes.¹⁴

33.15 The Law Institute commented that granting insurers the right to obtain genetic information runs counter to much of the ethical debate on this issue. They noted that individuals should have a choice whether to undergo genetic testing or not; and where genetic information is disclosed to an uncounselled claimant or an unscrupulous employer this could have far reaching consequences. They outlined the competing interests involved in this area:

Some of our members argue that there is no reason to subject an individual to genetic intrusion simply because they are insured for workplace injuries. Others believe that testing can be in the interests of the worker, as it will sometimes alert employers to environments which may be particularly unsafe for that worker. In a perfect world, the information could then be used to provide the most appropriate employment possible. However it is in fact as likely to be used to keep vulnerable workers out of the work force altogether, particularly given the potential impact on insurance premiums ...

There is also the risk that genetic testing requirements would deter some individuals from applying for particular work, or from taking action to recover compensation or damages for an injury, which they are legitimately entitled to take ...¹⁵

13 Australian Chamber of Commerce and Industry, *Submission G308*, 24 January 2003.

14 Law Institute of Victoria, *Submission G275*, 19 December 2002.

15 Ibid.

Premiums

Calculation of premiums

33.16 The first issue identified above is the use of genetic information to calculate an employer's insurance premium for a workers' compensation scheme. Workers' compensation schemes are funded primarily by compulsory insurance provided by government or private insurers, or through self-insurance.¹⁶

33.17 Comcare determines the annual premiums for employer agencies by obtaining actuarial advice on the 'premium pool' needed each year,¹⁷ and calculating each agency's premium having regard to the development of that agency's claims over a number of years. To reduce its future premiums, an agency must reduce its claims frequency, its average claim cost, or both.¹⁸

33.18 Under other Australian schemes, employers (other than self-insurers) must pay an annual premium as a condition of the issue or renewal of an insurance policy. In New South Wales, Queensland, South Australia, Victoria and Western Australia, a central authority recommends premiums having regard to the employer's risk and industry classification, the number of employees, and their remuneration. Premiums may also be loaded or discounted having regard to a particular employer's circumstances.¹⁹ In the Australian Capital Territory, the premium is subject to limitations imposed by legislation but otherwise left to the insurers.²⁰

Issues and problems

33.19 In future, it is possible that employers might seek to reduce the number of workers' compensation claims lodged by their workers—in order to minimise their annual premiums—by screening out persons with a genetic predisposition to an injury or disease that could arise in the course of, or out of, the particular employment. Depending on the circumstances, such practices may constitute a form of unfair discrimination.

16 T Paine, 'Workers' Compensation' in J Golden and others (ed), *The Laws of Australia: Labour Law* (2000) Law Book Company Limited, Sydney, vol 26.5 [224].

17 A 'premium pool' is the sum of all premium funds collected from agencies in order to fully fund liabilities: Comcare, *Submission to the House of Representatives Standing Committee on Employment and Workplace Relations Inquiry into Aspects of Australian Workers' Compensation Schemes*, 2002, 34.

18 Ibid, 34.

19 T Paine, 'Workers' Compensation' in J Golden and D Grozier (eds), *The Laws of Australia: Labour Law* (2000) Law Book Company Limited, Sydney, vol 26.5 [228]. For example, in NSW a premium discount scheme provides an incentive to employers to implement programs to impose workplace safety and 'return to work' strategies for injured workers. See Workcover NSW, *Outline of the NSW Workers Compensation Premium Scheme 2001/2002* (2001) NSW Government.

20 T Paine, 'Workers' Compensation' in J Golden and D Grozier (eds), *The Laws of Australia: Labour Law* (2000) Law Book Company Limited, Sydney, vol 26.5 [228].

33.20 As discussed in Chapter 31, Australian employers may lawfully request information from a job applicant or employee for the purpose of determining whether a person can perform the inherent requirements of a job—including the ability to work safely; or to identify any reasonable adjustments required in the performance of work.

33.21 The *Disability Discrimination Act 1992* (Cth) (DDA) permits an employer to discriminate against a person only in limited circumstances. The employer may lawfully exclude the person if, because of his or her disability, the person is unable to carry out the 'inherent requirements' of the particular job or would, in order to do so, require services or facilities that would impose an unjustifiable hardship on the employer.²¹ If an employer otherwise wishes to discriminate against a person with a disability, it must obtain a temporary exemption from the operation of the DDA.²²

Submissions and consultations

33.22 In its submission, the Victorian Automobile Chamber of Commerce commented that employers in its industry currently do not appear to be using genetic tests for several reasons, including the fact that workers' compensation insurance premiums presently are not affected by employees' genetic susceptibility to certain workplace health hazards; and insurers providing coverage have not pressured employers to implement genetic screening of future employee.²³

33.23 During consultations the Construction, Forestry, Mining and Energy Union expressed concerns that workers' compensation premiums might, in future, be linked to genetic testing for predisposition. They emphasised the importance of ensuring that premiums are not based on health information because of the potential for discrimination.²⁴ In a subsequent submission they commented:

The Union believes that there is the real capacity for this potentially invasive technology to be used to reduce the cost of premiums for workers compensation insurance, at the expense of workers. It is the Union's view that there is already gross underpayment of workers' compensation insurance premiums, and the capacity for employers to use this type of technology may well aggravate that problem.²⁵

Inquiry's views

33.24 The Inquiry is concerned that in future employers might seek to obtain genetic information from a job applicant, or an existing employee, to screen out persons whose genetic status suggests that he or she might in future suffer an injury, leading to a workers' compensation claim and, potentially, to higher insurance premiums. While there is no existing evidence of such practices, the increased availability of genetic tests might create an impetus for employers to use this technology as a means of minimising administrative costs.

21 *Disability Discrimination Act 1992* (Cth) s 15(4).

22 *Ibid* s 55.

23 Victorian Automobile Chamber of Commerce, *Submission G242*, 19 December 2002.

24 Construction Forestry Mining and Energy Union, *Consultation*, Sydney, 14 November 2002.

25 Construction Forestry Mining and Energy Union, *Submission G248*, 20 December 2002.

33.25 The Inquiry is of the view that this concern is addressed by Recommendation 31–3, which provides that the Commonwealth should amend the DDA to prohibit an employer from requesting or requiring genetic information except where the information is reasonably required for a purpose that does not involve unlawful discrimination.

33.26 In addition, Recommendation 31–1 provides that the Commonwealth should amend the DDA to provide that an applicant or employee's ability to perform the inherent requirements of a job is assessed on the basis of his or her current abilities, or those which he or she has the potential to acquire within a reasonable timeframe. This will strengthen the prohibition on employers discriminating against workers because they might, in future, suffer a work-related injury or death.

Liability for injury or death

Current law and practice

Statutory schemes

33.27 As noted above, each statutory workers' compensation scheme provides 'no fault' compensation for injury or disease arising out of or in the course of employment. In most jurisdictions, an 'injury' is defined as a physical or mental injury, including the aggravation, acceleration or recurrence of an earlier physical or mental injury.²⁶ A disease, and the aggravation, acceleration or recurrence of a pre-existing disease, is included in the statutory definition of an injury.²⁷ A 'disease' is generally defined as a physical or mental ailment, disorder, defect or morbid condition, whether of sudden or gradual onset or development.²⁸

33.28 To come within the coverage of workers' compensation legislation, an injury or disease must arise out of, or in the course of, employment.²⁹ An injury will arise 'out of employment' where the employment contributed to its occurrence. However, an injury or disease that arises 'in the course of employment' need not necessarily have such a direct causal connection.³⁰ All jurisdictions impose an additional requirement of work-relatedness in respect of disease claims that arise 'in the course of employment', but this is not necessarily the case with injury claims. However, in recent years, a number of jurisdictions have moved to impose an additional work-relatedness test for the compensability of injury claims that arise 'in the course of employment'.³¹

26 See generally T Paine, 'Workers' Compensation' in J Golden and D Grozier (eds), *The Laws of Australia: Labour Law* (2000) Law Book Company Limited, Sydney, vol 26.5 [56].

27 See generally Ibid, vol 26.5 [57].

28 See generally Ibid, vol 26.5 [59].

29 Except in Tasmania, where both of these conditions must be satisfied.

30 See *Kavanagh v Commonwealth* (1960) 103 CLR 547, where the High Court held that 'in the course of employment' indicated a purely temporal connection and that the worker need only be engaged in an activity that was part of or incidental to his or her employment.

31 See generally A Clayton, R Johnstone and S Sceats, 'The Legal Concept of Work-Related Injury and Disease in Australian OHS and Workers' Compensation Systems' (2002) 15 *Australian Journal of Labour Law* 105.

33.29 In relation to injury, in both Victoria and Queensland, the worker's employment must be a 'significant contributing factor' to the injury.³² In New South Wales the requirement is similar, but is framed in terms of a 'substantial contributing factor'.³³ In Victoria and New South Wales, whether the employment contribution is 'significant' or 'substantial' is determined by taking into account a range of factors including the duration, nature and tasks of the employment; the probability that the injury would have happened but for the employment; the state of the worker's health before the injury and the existence of any hereditary risks; and the worker's activities outside the workplace.³⁴

33.30 In relation to disease claims, there is a range of additional tests for work-relatedness across the jurisdictions, but the bar is often set quite low. In the Australian Capital Territory, the employment must simply be a 'contributing factor' to the contraction of a disease or the suffering of an aggravation, acceleration or recurrence of a disease.³⁵ Similarly, in South Australia, the employment must have 'contributed' to the disability in the case of diseases and secondary disabilities.³⁶ Under Comcare, the employment must have 'contributed in a material degree' to the contraction of the disease.³⁷ In Tasmania, the employment must have contributed to the disease 'to a substantial degree'.³⁸ In Victoria, New South Wales and Queensland, the employment must be a 'significant' or 'substantial' contribution to the contraction of the disease or the aggravation of a pre-existing disease, respectively. In Western Australia, the employment must be a contributing factor and contribute to a significant degree to the contraction of the disease or the recurrence, aggravation or acceleration of a pre-existing disease.³⁹

33.31 Once a claim has been made, a worker may be required to submit to an examination for the purpose of determining the worker's entitlement to compensation. Under the Comcare and Seacare schemes, and in the Australian Capital Territory, New South Wales, Queensland and Western Australia, the right to request the examination

32 See *Accident Compensation Act 1985* (Vic) s 82(1); *WorkCover Queensland Act 1996* (Qld) s 34(1). This requirement does not apply to recess or journey injuries. See ss 36(2) and 37(2), respectively.

33 *Workers Compensation Act 1987* (NSW) s 9A(1). This requirement does not apply to journey or recess claims or for certain claims made by trade union representatives: s 9A(4).

34 *Accident Compensation Act 1985* (Vic) s 5(1B); *Workers Compensation Act 1987* (NSW) s 9A(2).

35 *Workers Compensation Act 1951* (ACT) s 9(1).

36 *Workers Rehabilitation and Compensation Act 1986* (SA) s 30(2)(b).

37 *Safety, Rehabilitation and Compensation Act 1988* (Cth) s 4(1). This has been interpreted to mean no more than 'pertinent or likely to influence': *Miers v Commonwealth* (1990) 20 ALD 483.

38 *Workers Rehabilitation and Compensation Act 1988* (Tas) s 25(1)(b). The term 'substantial degree' means 'the major or most significant factor'. See s 3(2A).

39 *Workers' Compensation and Rehabilitation Act 1981* (WA) s 5(1). In determining the issue of employment contribution and that of contribution to a significant degree, the following matters shall be taken into account: the duration of the employment; the nature of, and particular tasks involved in, the employment; the likelihood of the contraction, recurrence, etc of the disease occurring despite the employment; the existence of any hereditary factors in relation contraction, recurrence etc of the disease; matters affecting the worker's health generally; and activities of the worker not related to the employment: s 5(5).

arises when notice of injury is given; in other jurisdictions it arises when compensation has been claimed.⁴⁰

Common law

33.32 As noted above, Australian jurisdictions vary regarding access to common law remedies for work-related injury or death. The Comcare and Seacare schemes have retained the right to claim common law damages in respect of a worker's death, but workers have only a limited right to claim damages in relation to an injury. A person must make a formal and irrevocable election to proceed for damages. Once an election is made, damages are limited to non-economic loss and cannot exceed a prescribed maximum amount.⁴¹

33.33 In the Australian Capital Territory, workers' compensation legislation does not affect employers' common law liability for damages for injury or death. In New South Wales, Queensland, Victoria, Tasmania and Western Australia, the right to seek damages under the common law is significantly limited; and in the Northern Territory and South Australia, the right has been abolished.⁴²

33.34 Legislation in each jurisdiction provides that a person cannot retain both common law damages for compensable injury or death, and compensation awarded under a statutory scheme.⁴³

Issues and problems

33.35 In future, employers or their insurers might seek to obtain a worker's genetic information to deny liability for a work-related injury, disease or death that arose in the course of employment. For example, an employer might seek to establish that the employment did not materially, substantially or significantly contribute to the contraction of a disease, but that it arose primarily as a result of the worker's pre-existing genetic status.

33.36 For example, in 2001 the United States' Equal Employment Opportunity Commission instituted proceedings against a company for the alleged non-consensual genetic testing of certain employees' blood after they had filed claims for work-related carpal tunnel syndrome injuries. The company was allegedly seeking to detect whether the employees had a genetic predisposition to that condition.⁴⁴

40 See T Paine, 'Workers' Compensation' in J Golden and D Grozier (eds), *The Laws of Australia: Labour Law* (2000) Law Book Company Limited, Sydney, vol 26.5 [113].

41 Ibid, vol 26.5 [209].

42 Ibid, vol 26.5 [210]–[223].

43 Ibid, vol 26.5 [205].

44 The EEOC reached a mediated settlement with the company in May 2002: *EEOC v. Burlington Northern Santa Fe Railroad*, [Civ No 01-4013 MWB (N.D. Iowa Apr. 23 2001) (Agreed Order)]. See also US Equal Employment Opportunity Commission, *Press Release: EEOC Petitions Court to Ban Genetic Testing of Railroad Workers in First EEOC Case Challenging Genetic Testing under Americans with Disabilities Act*, 9 February 2001.

33.37 While each Australian jurisdiction permits the medical examination of injured workers once they have filed workers' compensation claims, the Inquiry has not been made aware of any ethical guidelines for conducting these examinations. In practice, the collection of genetic information during these examinations (whether through genetic tests or family medical history) appears to be limited only by existing technology, considerations of relevance and reasonableness, and the worker's discretion to withhold consent. As more genetic tests become available, workers could increasingly be asked to undergo genetic tests, or to disclose the results of genetic tests undertaken previously, as part of these examinations.

Submissions and consultations

33.38 The ACTU commented on the prevalence of workplace injury and death in Australia, noting that such occurrences result from workplace hazards and not the individuals' genetic status.

[There] is a total of at least 2,750 work-related deaths each year, or more than 50 deaths every week, which is higher than the national road toll. According to the Australian Bureau of Statistics, 477,800 people experienced a work-related injury or illness *during the twelve months* ending September 2000. More than 15 serious injuries occur every hour.

These deaths and injuries are a result of hazards in the workplace, not the genetic predisposition of workers. These deaths, injury and diseases are preventable—[The National Occupational Health and Safety Commission] claims that 97% of work-related deaths, injuries, and diseases are preventable—by removing the hazards from the working environment. That Australia continues to suffer such high rates of workplace injury and diseases is because not enough is being done by employers to remove hazards or by governments to enforce the health and safety laws. Genetic testing of job applicants and employees will do nothing to alleviate this situation, but will put them at risk of discrimination.⁴⁵

33.39 Dr Paul Henman commented on this potential use of genetic information:

A possible consideration of genetic information by employers relates to claims for workers compensation that may involve a genetic component. This is a more complex matter as a workplace injury may combine with a genetic predisposition to a specific injury. In this scenario, it would only be appropriate (if at all) for the employee's genetic information to be made available when a claim for worker's compensation is made. This will enable a court to assess the extent to which an injury results from a workplace activity or from a pre-existing condition.⁴⁶

33.40 The Australian Manufacturing Workers' Union (AMWU) commented that workers' compensation legislation was introduced as social legislation. In relation to medical examinations, the AMWU commented:

⁴⁵ Australian Council of Trade Unions, *Submission G278*, 20 December 2002.

⁴⁶ P Henman, *Submission G055*, 15 January 2002. Dr Henman is a Research Fellow in the Sociology Department at Macquarie University.

The abuse of third parties gaining access to private medical information, during workers compensation processes, unfortunately is not uncommon. Often injured workers sign off on general medical release forms, that allow a person's complete medical history to be accessible to the insurer or rehabilitation persons. Misuse of this information does occur, for example an individual who had been a victim of sexual assault had this history made known to her employer during a claim for work related post traumatic stress. If such abuses of medical history can occur in such cases, the AMWU sees no reason why breaches of privacy would not happen with genetic information.⁴⁷

33.41 The Law Institute of Victoria commented on the risk that juries might give undue weight to evidence of a worker's genetic predisposition in this context:

There is a risk that genetic testing will confuse the legal issues in a claim. Claims for personal injury include aggravating factors and not just sole causes of an injury. Where an asymptomatic person is injured but is shown to have a genetic predisposition for a particular condition, this could unduly influence a jury about the actual cause of the condition ... Where genetic predisposition is introduced, people are likely to impose a reverse egg shell skull rule. That is, person X was vulnerable, but rather than this increasing the likelihood that employer Y's actions or negligence caused X's injury, X's vulnerability will be interpreted to mean that X would have developed the condition anyway so Y will not be held responsible.⁴⁸

33.42 The Institute of Actuaries of Australia commented that a worker's genetic susceptibility to a certain disease or injury might be treated as a form of 'contributory negligence' in any claim for damages.

In workers' compensation it may be necessary to examine whether there has been 'contributory negligence' by a claimant who has been exposed to a hazard to which he or she knew they had a higher susceptibility due to genetic factors or other factors. IAAust considers that relevant information, including genetic information, that is known to the claimant should be fully disclosed to a workers' compensation insurer according to the doctrine of utmost good faith, as mandated by the *Insurance Contracts Act 1984*.⁴⁹

33.43 Finally, the National Council of Women Australia submitted that employers could obtain a 'waiver' from an employee in relation to workers' compensation:

Employers who ascertain that an employee's or applicant's personal genetic information is potentially a problem in terms of Workers' Compensation could add a waiver clause but still employ the person. This would be fair to both parties ... An employer should not have access to a job applicant's genetic information for occupational health and safety reasons because the concern on the part of the employer that his insurance premiums might rise if he has someone afflicted can be allayed by again putting in a waiver 'if at the time any symptoms develop from the situation of the environment, it is established that the genetic test results prior to employment showed a predisposition, there is no insurance cover'.⁵⁰

47 Australian Manufacturing Workers' Union, *Submission G269*, 21 December 2002.

48 Law Institute of Victoria, *Submission G275*, 19 December 2002.

49 Institute of Actuaries of Australia, *Submission G224*, 29 November 2002.

50 National Council of Women Australia, *Submission G095*, 31 January 2002.

Inquiry's views

33.44 The Inquiry considers that the collection and use of genetic information in this context should be the subject of independent oversight. In particular, oversight is necessary to ensure that injured workers are not subjected to genetic tests unless those tests are objectively considered to be appropriate and necessary, and are appropriately interpreted.

33.45 The Inquiry does not support the approach suggested by the National Council of Women Australia or the Institute of Actuaries of Australia. Workers' compensation is based on the principle of 'no fault' liability to ensure the universal coverage of workers who are injured or killed in the context of their employment. Currently, insurance contracts entered into for the purposes of a law dealing with workers' compensation are expressly excluded from the *Insurance Contracts Act 1984* (Cth).⁵¹ Both the provision of 'waivers' of liability for employers who employ 'susceptible' workers, and the introduction of a duty of 'utmost good faith' in relation to workers' genetic status, would significantly undermine the philosophy underlying the existing framework.

33.46 The Heads of Workplace Safety and Compensation Authorities (HWSCA) is a group comprising the chief executives (or their representatives) of the peak bodies responsible for the regulation of workers compensation and occupational health and safety in Australia and New Zealand. The HWSCA's objectives include: to develop initiatives and promote consistency of scheme design and scheme administration; to coordinate the development and implementation of initiatives of interest or relevance to multiple jurisdictions; and to liaise with other national bodies to progress issues of national significance or priority to workers' compensation authorities.⁵²

33.47 The Inquiry recommends that the Human Genetics Commission of Australia, in consultation with the HWSCA, should review the use of genetic information in relation to workers' compensation claims, and should develop a policy regarding the appropriate use of genetic information in relation to workers' compensation claims. The policy should address the use of family medical history and genetic test information in determining the employment contribution to any injury arising out of or in the course of employment.

Recommendation 33–1. The Human Genetics Commission of Australia, in consultation with the Heads of Workplace Safety and Compensation Authorities, should develop a policy regarding the appropriate use of genetic information in the assessment of workers' compensation claims.

⁵¹ *Insurance Contracts Act 1984* (Cth) s 9(1).

⁵² Heads of Workplace Safety & Compensation Authorities, HWSCA, <www.hwsca.org.au>, 13 March 2003. The HWSCA liaises with the Workplace Relations Ministers' Council, the Departments of Workplace Relations Standing Committee, the National Occupational Health and Safety Commission, and relevant Commonwealth Departments and agencies.

Quantum of compensation

Current law and practice

Statutory provisions

33.48 The benefits payable under the different workers' compensation statutes vary. The Comcare scheme includes payment of the reasonable cost of medical treatment, income replacement for periods of incapacity for work, and payment of lump sums for permanent impairment.

33.49 Under the Comcare scheme, weekly compensation is payable where a worker is partially or totally incapacitated. Generally, for the first 45 weeks of incapacity, the weekly payments represent the worker's normal weekly earnings minus the amount per week that he or she is able to earn in suitable employment. After this period, the amount is reduced to 75% of the worker's normal weekly earnings minus the amount per week the worker is able to earn.⁵³ Entitlement to incapacity payments continues until the age of 65 years.⁵⁴

33.50 Lump sum compensation is payable for death, permanent impairment and other non-economic loss resulting from a work related injury. The degree of permanent impairment and non-economic loss are determined in accordance with Comcare's *Guide to the Assessment of the Degree of Permanent Impairment*.⁵⁵

33.51 Where a pre-existing or underlying condition is aggravated by a work-related injury, only the permanent impairment resulting from the aggravation is compensable. If the employee's impairment is entirely attributable to a pre-existing or underlying condition, or to the natural progression of such a condition, the assessment for permanent impairment is nil.⁵⁶

Common law

33.52 Common law damages for personal injury are divided into economic loss and non-economic loss. Economic loss includes lost earnings and out of pocket expenses (special damages); lost earning capacity (including loss of superannuation entitlements); and reasonable costs for medical, care and other expenses. Assessment of lost earning capacity and future medical costs will sometimes involve consideration of life expectancy, which may be affected by the injury. Non-economic loss includes pain and suffering, loss of enjoyment of life (caused by partial or total invalidity), and shortened life expectancy.⁵⁷

53 *Safety, Rehabilitation and Compensation Act 1988* (Cth) s 19.

54 *Ibid* s 23(1).

55 Comcare, *Guide to the Assessment of the Degree of Permanent Impairment*, <www.comcare.gov.au/pi_guide/principals.htm>, 20 February 2003. See also *Safety, Rehabilitation and Compensation Act 1988* (Cth) s 28(1).

56 Comcare, *Guide to the Assessment of the Degree of Permanent Impairment*, <www.comcare.gov.au/pi_guide/principals.htm>, 20 February 2003.

57 Commonwealth Department of Employment & Workplace Relations, *Submission G305*, 22 January 2003. See also M Noone, 'Damages' in G Masel (ed), *The Laws of Australia: Torts* (1993) Law Book Company Limited, Sydney, vol 33.10 [2].

33.53 When a pre-existing disease is aggravated or accelerated by a workplace incident, compensation at common law is payable only for what is reasonably attributable to that workplace incident.⁵⁸ The 'egg shell skull' rule provides that a wrongdoer must take the victim as he or she finds him or her. Therefore, the employer would be liable for the full extent of injuries caused even though the injuries would not have been as extensive if the worker had not been unusually susceptible.

33.54 As damages are awarded once and for all, in a lump sum, it is often necessary to consider whether the injured worker's life expectancy is likely to be reduced by the injury. This may be done by reference to actuarial life expectancy tables. The courts may also admit other evidence relevant to the worker's life expectancy.⁵⁹

Issues and problems

33.55 In future, employers or their insurers might seek to obtain genetic information from an injured worker for the purpose of assessing the quantum of compensation or damages payable following a work-related injury. For example, where a genetic test discloses that the injured worker has a genetic condition that is likely to lead to a reduced life expectancy, the employer or insurer might seek to have the compensation or damages award reduced accordingly.

Submissions and consultations

33.56 The Inquiry heard few comments about the potential use of genetic information in this context. In consultations, Comcare noted that this would not be an issue under the Comcare scheme because the legislation provides for payments to be made until the age of 65 years.⁶⁰

33.57 In its submission, the Commonwealth Department of Employment and Workplace Relations commented on the use of genetic information in relation to common law damages claims:

For the purposes of the ALRC inquiry, one of the more sensitive issues is the extent to which personal genetic information may be adduced which indicates that, notwithstanding the employer's conduct, the employee's life expectancy is less than the actuarial norm. Presentation of evidence more particular than actuarial tables—for example, the employee's work history, and evidence regarding the employee's past and present health, constitution and habits—may limit employer/insurer liability to only any additional loss in life expectancy caused by the employer's breach of OHS duty.⁶¹

33.58 The Human Genetics Society of Australasia commented that:

58 Commonwealth Department of Employment & Workplace Relations, *Submission G305*, 22 January 2003.

59 Ibid.

60 Comcare, *Submission to the House of Representatives Standing Committee on Employment and Workplace Relations Inquiry into Aspects of Australian Workers' Compensation Schemes*, 2002.

61 Commonwealth Department of Employment & Workplace Relations, *Submission G305*, 22 January 2003.

The HGSA does not endorse employers or insurers being able to access genetic information to determine the liability, or to assess compensation or damages, in relation to a worker's compensation claim or a common law claim for work-related injury. To argue that the defendant's duty of care to the client can be abrogated because of the susceptibility of the plaintiff, or that compensation to the susceptible plaintiff can be reduced, is to defy the established doctrine in tort law—the 'eggshell skull' rule, which provides that a defendant is liable for the full damages to a plaintiff, even if the extent of the damages in a 'susceptible' plaintiff is greater than they would be in a 'normal' plaintiff. The principles underlying the 'eggshell skull' rule should not be eroded.⁶²

Inquiry's views

33.59 There appears to be little scope under various Australian workers' compensation schemes for the use of genetic information in the assessment of compensation payments. Weekly and lump sum payments are paid according to statutory criteria rather than the worker's own life expectancy or other personal circumstances.

33.60 There appears to be more scope for the use of genetic information in the assessment of common law damages. For example, once negligence has been established an employer could argue that the worker had a genetic predisposition to the injury suffered, and that compensation should be reduced accordingly. Alternatively, the employer could argue that compensation should be reduced where the injured worker has a pre-existing genetic condition that is likely to shorten his or her life expectancy. This may appear to be a windfall to a negligent employer, but it would be consistent with the compensatory principle that underlies the award of damages in tort. The plaintiff is to be placed in the same position, so far as money can do so, as if the wrongful conduct had not occurred: in making that assessment, the plaintiff's pre-injury life expectancy is a relevant consideration.

33.61 As with the potential use of genetic information in other civil proceedings, the Inquiry considers there is a need for greater education of judges and legal practitioners in relation to evidence based on genetic information.

33.62 In Chapter 46, the Inquiry recommends that the National Judicial College of Australia and the Law Council of Australia develop continuing legal education programs for judges and legal practitioners, respectively, in relation to the use of genetic information in civil proceedings. The Inquiry recommends that these bodies provide ongoing guidance regarding genetic technology, reliability of genetic testing, interpretation of genetic test results, and presentation of evidence in civil proceedings. The Inquiry considers this recommendation is equally important in relation to the use of genetic information in actions for common law damages for workplace injury or death.

62 Human Genetics Society of Australasia, *Submission G267*, 20 December 2002.

34. Employment and Genetic Privacy

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34.1 The Terms of Reference require the Inquiry to report on whether, and to what extent, a regulatory framework is needed to protect the privacy of human genetic samples and information in a number of contexts, including employment. Previous chapters in Part H have examined the various forms of genetic information that are available to employers, the way in which these may be used in employment, and some of the legal issues that arise from those uses.

34.2 In Chapters 7 and 8 the Inquiry examined the legal framework for the protection of genetic privacy in Australia and made a number of recommendations to promote greater harmony across Australian jurisdictions and to ensure that privacy laws apply to both genetic samples and information. This chapter considers whether federal privacy laws, if amended as proposed, would provide sufficient protection for genetic information in employment.

Current employment practice

34.3 In Chapter 29 the Inquiry indicated that genetic information is used by some employers in Australia, although it is not possible to determine the extent of that use. Federal anti-discrimination laws generally target the unlawful use of information, but it is also important to ensure that the information itself is protected by ensuring that genetic information is collected, used, stored and disclosed by employers only in appropriate ways.

34.4 In an Information Paper prepared in 1996, the then federal Privacy Commissioner expressed the concern that:

While there is no evidence that trade in such information is being conducted to an appreciable extent in Australia, there may be economic incentives for firms to disclose personal genetic information (with or without the consent of the individual concerned).

Industry associations (or wider employer bodies) could wish to maintain shared lists of employees judged to be genetically unsuitable for employment. Especially if the genetic tests to determine health risk were expensive, this would allow a reduction in the cost per employer.¹

34.5 The Australian Council of Trade Unions (ACTU) stated in its submission that:

It appears that there is potentially some trade in such information, as was seen last year when a small company established an internet site and invited employers to submit names and details of employees who took, in their view, excessive sick leave. The plan was to charge potential employers a fee for access to the database so obtained. While this project does seem to involve some breaches of the *Privacy Act* (although there is also an exemption for small business), it does indicate the level of interest in the subject of employee absenteeism. ... There can be little doubt that genetic information, if obtainable by employers, would be circulated to potential employers and others, particularly in the private sector.²

34.6 One current use of genetic information by employers, which highlights the need for appropriate privacy protection, is the collection of genetic samples from classes of employees for the purposes of identification. As noted in Chapter 29, the Tasmanian police service collects genetic samples from new recruits and in Western Australia the Commissioner of Police has the power to require police officers to provide a genetic sample.³ The samples are collected for the purpose of eliminating police officers' genetic material as possible contaminants at crime scenes.

34.7 In the United States, the Department of Defense collects genetic samples from every service member on active duty, or in the reserves, on a mandatory basis for storage in a DNA Repository. The samples are collected for the purpose of identifying the remains of service members. The policy was unsuccessfully challenged in 1995 by two marines who objected to providing a sample on the basis that it was an unreasonable intrusion on their privacy.⁴

34.8 Chapter 29 noted that the Australian Defence Force is considering whether to adopt a similar policy. There are approximately 50,000 permanent defence force personnel in Australia and almost 20,000 reserves who could potentially be required to provide a genetic sample if this policy were implemented in Australia.⁵ With such developments on the horizon it is important to ensure that privacy in employment is given adequate protection.

34.9 The broad-based and systematic collection of genetic information from employees is not currently a widespread practice in Australia. However, employers commonly collect a wide range of health information, including some genetic information, from employees for the purposes of pre-employment health screening,

1 Federal Privacy Commissioner, *The Privacy Implications of Genetic Testing* (1996), OFPC, Sydney.

2 Australian Council of Trade Unions, *Submission G037*, 14 January 2002.

3 *Criminal Investigation (Identifying People) Act 2002* (WA) s 22.

4 E Reiter, 'The Department of Defense DNA Repository: Practical Analysis of the Government's Interest and the Potential for Genetic Discrimination' (1999) 47 *Buffalo Law Review* 975.

5 Department of Defence, *Defence Annual Report 2000-01* (2001), Commonwealth of Australia.

occupational health and safety assessment and monitoring, and so on. Dr Roger Magnusson noted in his submission to the Inquiry that:

[T]here is nothing discrete or self-contained about genetic information as a form of health information. As clinical genetics continues to develop, any attempt to compartmentalise genetic health data from other forms of health information will likely become unworkable. This is because—as the clinical implications of the genetic determinants of disease come to be better understood—genetic testing, and the volume of clinical genetic information, will both increase.⁶

34.10 On this basis, and as noted in a range of other contexts in this Report, the collection and use by employers and others of genetic information, as one element of general health information, is likely to become more common in the future.

Existing regulatory framework

34.11 Existing contractual and equitable principles may offer some level of privacy protection to individuals in a contract of employment. Employers have an implied duty of confidence and trust toward their employees.⁷ This may include a duty to respect the confidentiality of genetic information obtained about an employee. It may preclude the employer from disclosing that information to third parties, such as insurance companies. While contractual duties will not apply to job applicants who do not enter into an employment relationship with the employer, the employer may still have an equitable duty to maintain the confidentiality of genetic information provided by them.⁸

34.12 At the federal level the collection, use, storage and disclosure of employees' personal information is also regulated by the *Privacy Act 1988* (Cth) (the *Privacy Act*). As discussed in Chapter 7, different privacy regimes apply to employment in the Commonwealth public sector, state and territory public sectors, and the private sector. The handling of employees' personal information in the Commonwealth and Australian Capital Territory public sectors is regulated by the Information Privacy Principles set out in the *Privacy Act*. The Act does not apply to other state and territory government bodies, but employees in these organisations will be covered by state or territory privacy legislation where such legislation exists.

34.13 The handling of employees' personal information in the private sector is now regulated under amendments to the *Privacy Act*, which came into force on 21 December 2001. Under the new legislation, private sector employers may choose to be bound by a privacy code approved by the Privacy Commissioner. In the absence of such a code, the National Privacy Principles in the legislation will apply. As discussed in Chapter 7, most small business operators are exempt from the operation of the Act under s 6C, but this does not include small business operators who provide health services and hold health information that is not contained in an employee record.

⁶ R Magnusson, *Submission G039*, 10 January 2002.

⁷ See eg *Blaikie v SA Superannuation Board* (1995) 65 SASR 85.

⁸ M Otlowski, *Implications of Genetic Testing for Australian Employment Law and Practice* (2001) Centre for Law and Genetics, Hobart [4.4.1].

34.14 In relation to private sector employers who do not fall into the small business exemption and are therefore covered by the *Privacy Act*, s 7B(3) states:

An act done, or practice engaged in, by an organisation that is or was an employer of an individual, is **exempt** for the purposes of paragraph 7(1)(ee) if the act or practice is directly related to:

- (a) a current or former employment relationship between the employer and the individual; and
- (b) an employee record held by the organisation and relating to the individual.

34.15 An 'employee record' is defined in s 6(1) of the *Privacy Act* as:

A record of personal information relating to the employment of the employee. Examples of personal information relating to the employment of the employee are health information about the employee and personal information about all or any of the following:

- (a) the engagement, training, disciplining or resignation of the employee;
- (b) the termination of the employment of the employee;
- (c) the terms and conditions of employment of the employee;
- (d) the employee's personal and emergency contact details;
- (e) the employee's performance or conduct;
- (f) the employee's hours of employment;
- (g) the employee's salary or wages;
- (h) the employee's membership of a professional or trade association;
- (i) the employee's trade union membership;
- (j) the employee's recreation, long service, sick, personal, maternity, paternity or other leave;
- (k) the employee's taxation, banking or superannuation affairs.

34.16 The House of Representatives Standing Committee on Legal and Constitutional Affairs delivered an Advisory Report on the Privacy Amendment (Private Sector) Bill 2000, which included the following examples of how the exemption might operate in practice.

As a result of the exemption, an employer would be able to obtain information about sensitive issues such as health, criminal convictions or trade union membership from a previous employer or some other person without the employee being informed. This could also include information about disciplinary matters, financial records or health records ... In the Committee's view it is also important to note that, while the terms of the exemption offer some protection against disclosure by employers of employee information for commercial purposes, employee information may be disclosed to organisations for other reasons. An employer could, for example, provide personal information on all its employees to a superannuation fund for the purposes of securing superannuation benefits for its employees.⁹

⁹ Standing Committee on Legal and Constitutional Affairs, *Advisory Report on the Privacy Amendment (Private Sector) Bill 2000* (2000), House of Representatives, Parliament of the Commonwealth of Australia, Canberra [319].

34.17 The employee records exemption is limited in several ways. For example, it only applies to information held by an employer about its current and former employees, where that information is held in employee records, and its use or disclosure relates to the employment relationship with that employer. The exemption does not cover information held about applicants for employment who were unsuccessful and who, therefore, did not enter into an employment relationship. In addition, there is no exemption for employee records held in the public sector.

34.18 The Attorney-General's Second Reading Speech on the Privacy Amendment (Private Sector) Bill 2000 included the following statement about the employee records exemption:

The bill also includes an exemption for employee records. An 'employee record' is defined to capture the types of personal information about employees typically held by employers on personnel and other similar files.

While this type of personal information is deserving of privacy protection, it is the government's view that such protection is more properly a matter for workplace relations legislation.

It should be noted, however, that the exemption is limited to collection, use or disclosure of employee records where this directly relates to the employment relationship. This is designed to preclude an employer selling personal information contained in an employee record to a direct marketer, for example.¹⁰

34.19 Despite the government's expressed preference for dealing with the privacy of an employee's personal information in workplace relations legislation, the current provisions of the *Workplace Relations Act 1996* (Cth) (WRA) have limited scope to protect the privacy of employee records. While regulations made under s 353A of the WRA,¹¹ permit employees to access, copy and correct employee records, the ACTU has expressed concern that the provisions in the regulations are intended to cover 'time and wages' information and are not wide enough to cover the broad range of information, including health information, that may be collected as an 'employee record' under the *Privacy Act*.¹²

Parliamentary and international consideration

34.20 Both the House of Representatives Standing Committee on Legal and Constitutional Affairs and the Senate Legal and Constitutional Legislation Committee expressed concern about the employee records exemption in their reports on the

10 Commonwealth of Australia, *Parliamentary Debates*, House of Representatives, 12 April 2000, 15749 (The Hon Daryl Williams AM QC MP (Attorney-General)).

11 *Workplace Relations Regulations 1996* (Cth) rr 131K, 131L.

12 Standing Committee on Legal and Constitutional Affairs, *Advisory Report on the Privacy Amendment (Private Sector) Bill 2000* (2000), House of Representatives, Parliament of the Commonwealth of Australia, Canberra, 27.

Privacy Amendment (Private Sector) Bill 2000.¹³ The House of Representatives Committee concluded that:

In the light of the evidence it has received, the Committee is not satisfied that existing workplace relations legislation provides enough protection for the privacy of private sector employee records and has grave concerns about the inclusion of the employee records exemption in the Bill. It has not been persuaded that there is any clear need for employees to be without privacy protection in relation to their workplace records.

The need for protection is particularly evident when the kind of information held by employers is considered. Employers frequently hold more information in relation to their employees than almost anyone else those employees will come into contact with. Further, this information can be extremely sensitive, even intimate. It may include sensitive health information ranging from genetic test results to medical records.¹⁴

34.21 The House of Representatives Committee drew a distinction between information relating to disciplinary matters or career progression, in which a future employer may have a legitimate interest, and other personal information such as health, family or financial information. The Committee was of the view that this latter information should not be provided to anyone without the employee's consent. The Committee recommended that the definition of an employee record be amended to include only those matters covered by paragraphs (a), (b) and (e) of the definition, that is, information about the engagement, training, disciplining or resignation of the employee; information about the termination of the employment of the employee; and information about the employee's performance or conduct.

34.22 The Senate Committee also expressed concern about the exemption and recommended a sunset clause, which would allow the exemption to operate for two years while the relevant agencies examined whether existing workplace relations and state and territory legislation were adequate to protect the privacy of employee records.

34.23 The European Union Data Protection Working Party also commented adversely on the employee records exemption. The Working Party reports to the European Commission, under Article 30 of the *European Union Directive on the Protection of Individuals with Regard to the Processing of Personal Data and the Free Movement of such Data*, on a range of issues including the protection offered to personal information in third countries.¹⁵ The Directive provides that Member States may transfer personal information to third countries only if those countries have adequate privacy protection in place. The Working Party noted in relation to Australia that

13 Ibid; Senate Legal and Constitutional Legislation Committee, *Inquiry into the Provisions of the Privacy Amendment (Private Sector) Bill 2000* (2000), The Parliament of Australia.

14 Standing Committee on Legal and Constitutional Affairs, *Advisory Report on the Privacy Amendment (Private Sector) Bill 2000* (2000), House of Representatives, Parliament of the Commonwealth of Australia, Canberra [3.29]–[3.30].

15 Directive 95/46/EC of the European Parliament and of the Council on the Protection of Individuals with Regard to the Processing of Personal Data and the Free Movement of such Data, (entered into force on 24 October 1995).

employee related data often contains sensitive data and [the Working Party] sees no reason to exclude it at least from the protection given by NPP 10 for sensitive information.¹⁶

34.24 In a joint press release of 29 November 2000, issued during passage of the Privacy Amendment (Private Sector) Bill 2000, the Attorney-General and the then Minister for Employment, Workplace Relations and Small Business announced that:

The Government will review existing Commonwealth, State and Territory laws to consider the extent of privacy protection for employee records and whether there is a need for further measures ...

The review will be carried out by officers of the Attorney-General's Department and the Department of Employment, Workplace Relations and Small Business and will involve consultation with State and Territory Governments, the Privacy Commissioner and other key stakeholders.

The Government will await the outcome of the review before considering what, if any, action should be taken in relation to privacy and employee records. The review will be completed in time to assist the Privacy Commissioner when he conducts the more general review of the legislation two years after it commences operation.¹⁷

34.25 The Attorney-General's Department provided the following update on the review in its submission to the Inquiry:

The review of current privacy protection for employee records by this Department and the Department of Employment and Workplace Relations is under way and is due to be completed before the Privacy Commissioner's review of the operation of the private sector amendments to the Privacy Act (ie, end of 2003).¹⁸

Submissions and consultations

34.26 In DP 66 the Inquiry proposed that the definition of 'employee record' in the *Privacy Act* be amended to exclude genetic information and that the pending inter-departmental review of the employee records exemption consider whether health information generally should be excluded from the ambit of the exemption. The majority of submissions received in response expressed support for these proposals and concern about the lack of privacy protection currently provided for sensitive information held by employers.

34.27 The Australian Chamber of Commerce and Industry (ACCI) expressed general support for the employee records exemption, both before the House of Representatives and Senate Committees, and in consultations with this Inquiry, on the basis that the exemption allows employers to make informed decisions. ACCI did, however, acknowledge in its submission to the Inquiry that there is room for special provision to be made in respect of genetic information held by employers:

16 Article 29 Data Protection Working Party, *Opinion 3/2001 on the Level of Protection of the Australian Privacy Amendment (Private Sector) Act 2000*, (2001), European Commission.

17 The Hon Daryl Williams AM QC MP (Commonwealth Attorney-General) and The Hon Peter Reith (Commonwealth Minister for Employment Workplace Relations and Small Business), *Joint News Release* (29 November 2000).

18 Commonwealth Attorney-General's Department, *Submission G158*, 7 May 2002.

For this reason, there is a sound policy argument for allowing regulation of genetic information collected by employers to mirror regulation imposed on other bodies while leaving the employee records exemption otherwise intact.¹⁹

34.28 The Law Institute of Victoria and the Australian Medical Association noted that job applicants or employees may feel under considerable pressure to provide genetic information on request given the possible consequences of a refusal to their employment prospects.²⁰ The Law Institute expressed the view that, in these circumstances, it is particularly important to ensure that information is adequately protected.

34.29 The Department of Health and Ageing stated:

The Department agrees with the concerns raised ... relating to the exemption of personal health information, including genetic information, that may be held in employee records. This is an issue that also arose in the context of the Privacy Act amendments—and it should be revisited following the current Commonwealth Department of Employment and Workplace Relations (DEWR) inquiry. Given the potential for discrimination in the workplace arising from inappropriate handling and interpretation of genetic information, this is an issue on which the Inquiry could provide valuable advice in the context of the DEWR review.²¹

34.30 The ACTU stated:

The ACTU strongly opposed the exemption for employment records in the amendments to the Privacy Act extending it to the private sector ... Many employers hold a great deal of sensitive information on their employees, including health information. There is nothing in the Privacy Act to prevent an employer passing on this information to a potential employer of a past or current employee.²²

34.31 The Genetic Support Council of Western Australia stated:

The genetic support groups felt that the Privacy Act (1988) was inadequate in covering genetic information in terms of its application to workforce issues. The groups felt that the Privacy Act should be modified to include current and past employee records.²³

34.32 The Office of the Federal Privacy Commissioner also expressed concern about the exemption and reiterated some of the points made before the Senate Committee:

The proposed exemption, as set out in the Bill, is also not consistent with the proposed treatment of sensitive information, including health information, proposed elsewhere in the Bill. This follows from the definition of 'employee record' as including, for example, trade union membership, membership of professional or trade associations and aspects of employee health information.

19 Australian Chamber of Commerce and Industry, *Submission G170*, 2 March 2002.

20 Australian Medical Association, *Submission G212*, 29 November 2002; Law Institute of Victoria, *Submission G275*, 19 December 2002.

21 Commonwealth Department of Health and Ageing, *Submission G150*, 15 April 2002.

22 Australian Council of Trade Unions, *Submission G037*, 14 January 2002.

23 Genetic Support Council WA, *Submission G112*, 13 March 2002.

Sensitive information, and more particularly, health information are given more specific levels of protection in the Bill. I strongly support this approach. I do not support proposals that might then weaken that protection for the many Australians who are employees.²⁴

34.33 The Centre for Law and Genetics made the following comment in relation to the protection provided in the context of employment:

Inclusion of the 'employee records' exemption within the privacy scheme applying to the private sector has been justified on the basis that whilst this type of personal information deserves privacy protection, such protection is more properly a matter for workplace relations legislation. The reality is, however, that workplace relations legislation does not provide such protection, leaving workers in the private sector in a precarious situation.²⁵

34.34 Privacy NSW was also of the view that

the current industrial relations framework has a limited capacity to deal with privacy issues and offers no adequate appeals mechanisms. The Australian Industrial Relations Commission does not have the power to establish provisions for workplace privacy through the award system. Given the inequality of bargaining power between employers and employees, it is unlikely that there would be a genuine capacity to negotiate.²⁶

34.35 Margaret Otowski summarised the arguments as follows:

the current coverage of employee privacy in the workplace relations context is patently inadequate. While there are some statutory protections applying to the public sector, for the majority of workers in Australia there is little tangible protection of the privacy of their employment records ... The protection available through the ordinary courts is also far from satisfactory. Whilst there are some contractual and equitable principles for maintaining confidentiality that offer some protection, these are, in practice, costly to pursue (involving private litigation in the civil courts) and not easy to establish. In short, neither existing legislation in the workplace context nor common law or equitable principles provide adequate protection of the privacy interests of employees.²⁷

34.36 Both the Centre for Law and Genetics and the Office of the Federal Privacy Commissioner expressed the view that the exemption should be repealed entirely.²⁸

Inquiry's views

34.37 The employee records exemption, in conjunction with the lack of comprehensive privacy protection under workplace relations legislation, has been the focus of sustained criticism since the introduction of the Privacy Amendment (Private Sector) Bill into Parliament in 2000. The criticism has highlighted that sensitive

24 Office of the Federal Privacy Commissioner, *Submission G143*, 22 March 2002.

25 Centre for Law and Genetics, *Submission G048*, 14 January 2002.

26 Office of the Privacy Commissioner (NSW), *Submission G118*, 18 March 2002.

27 M Otowski, *Implications of Genetic Testing for Australian Employment Law and Practice* (2001) Centre for Law and Genetics, Hobart [4.4.3].

28 Centre for Law and Genetics, *Submission G255*, 21 December 2002; Office of the Federal Privacy Commissioner, *Submission G294*, 6 January 2003.

information, which is given a high level of privacy protection in other contexts, is without adequate protection in the context of private sector employment. This is a matter of concern because employees may be under considerable economic pressure to provide sensitive information to employers, including genetic information.

34.38 In his Second Reading Speech in Parliament, the Attorney-General acknowledged that the personal information of private sector employees requires privacy protection²⁹ but the Government has not yet moved to ensure that adequate protection is provided by workplace relations legislation.

34.39 The importance of protecting health information was acknowledged in the development of the small business exemption in the *Privacy Act*, which is examined in Chapter 7. The exemption does not apply to small businesses that provide health services and hold health information except in an employee record.³⁰

34.40 There appears to be no reasonable justification for the fact that the health information of public sector employees is protected but the health information of private sector employees is not.

34.41 Against this background, the Inquiry is of the view that the employee records exemption in the *Privacy Act* is too broad and should be amended. Genetic information held by private sector employers about their employees should be given a high level of privacy protection, as it is in other contexts, for example, where such information is held by health service providers and insurance companies.

34.42 In this context there is a fine line between genetic information and health information. In light of the Inquiry's Terms of Reference, the recommendations below are limited to the protection of human genetic information. However, in the Inquiry's view, the Attorney-General's Department and the Department of Employment and Workplace Relations should consider carefully the implications of the exemption in relation to health information other than genetic information when reviewing the employee records exemption for the purpose of the inter-departmental review.

Recommendation 34–1. The Commonwealth should amend the *Privacy Act 1988* (Cth) (*Privacy Act*) to ensure that employee records are subject to the protections of the Act, to the extent that they contain genetic information.

29 Commonwealth of Australia, *Parliamentary Debates*, House of Representatives, 12 April 2000, 15749 (The Hon Daryl Williams AM QC MP (Attorney-General)).

30 *Privacy Act 1988* (Cth) s 6D(4)(b).

Recommendation 34–2. The Commonwealth Attorney-General’s Department and the Department of Employment and Workplace Relations, in their pending inter-departmental review of the employee records exemption, should consider whether the *Privacy Act* should be amended to ensure that employee records are subject to the protections of the Act, to the extent that they contain health information other than genetic information.

Part I. Other Contexts

35. Parentage Testing

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Introduction

35.1 'Parentage testing' refers to testing conducted to confirm or deny the biological parentage of a particular child or person. Testing may be conducted by blood group or DNA analysis. Parentage testing is one form of kinship testing; other forms include twin testing, sibship testing and grandparent testing.

35.2 DNA parentage testing may exclude a person as the biological parent of a child with certainty, but it cannot prove *absolutely* that a person is the child's biological parent.¹ The test result can, however, provide a probability that a person is the biological parent of a child and, if that probability is sufficiently high, an inference of parentage may be confidently drawn.

35.3 As a child's maternity is usually not in question, most parentage testing relates to paternity. However, there are circumstances in which maternity may be misattributed or otherwise unclear; for example, where a child has been separated from its mother, or where maternity is at issue in the context of an immigration application. Accordingly, the generic term 'parentage testing' is used in this chapter, unless the context indicates otherwise.

35.4 There are many reasons why a person may seek parentage testing. A man may seek parentage testing to confirm or deny suspicions that he may not be the biological father of a child who is said to be his own offspring. A woman may seek parentage testing to confirm or deny her suspicions that her child is not the biological child of her husband or partner. A child may seek parentage testing to establish a biological link with a parent for the purposes of identity, child support, family provision or succession to property. A person may seek parentage testing to provide evidence of a family relationship in the context of an Australian visa application.

35.5 The media has shown considerable public interest in the subject of DNA parentage testing throughout the life of this Inquiry. This has been spurred in part by a few well-publicised cases, and in part by controversial comments by public figures, such as the Chief Justice of the Family Court of Australia (Family Court).²

1 C Pearman, 'Parentage Testing' in I Freckelton and H Selby (eds), *Expert Evidence in Family Law* (1999) LBC Information Services, 745.

2 L Schwartz, 'Paternity: Stop DNA by "Stealth"', *The Sunday Age* (Melbourne), 26 May 2002, 1.

Considerations applying to parentage testing

35.6 Other Parts of this Report have emphasised the very high value placed on protecting the integrity of the person, human dignity, autonomy and the individual's right to consent. These ethical concerns apply equally in the context of parentage testing.

35.7 Part C of this Report provides important background to the parentage testing issues raised in this chapter. Chapter 11 addresses a number of general concerns in regulating access to genetic testing, whether for identification purposes or for health or medical purposes, and makes recommendations addressing the regulation of genetic testing generally. When one applies these general considerations to the specific context of parentage testing, there may be reasons to take a different approach on some or all issues. There are several factors that call for special consideration in relation to parentage testing.

35.8 First, parentage testing does not take place in a legal vacuum. Existing laws already set out a regulatory framework for testing, at least where the testing is conducted for the purpose of family law proceedings. Those laws provide a benchmark against which 'unregulated testing' may be measured.

35.9 Second, the information that is revealed by parentage testing is particularly sensitive. Parentage testing goes beyond the common notion of 'familial information'—it not only provides information about related persons, but goes to the very nature and identity of the family itself.

35.10 Third, the context in which parentage information is revealed is often highly emotionally charged. Where parentage has been misattributed, perhaps for many years, there may be issues of 'betrayal, revenge, truth and the search for resolution'.³ Parentage testing is not alone in this respect, but it is a prime example of the desirability of making counselling available before and after testing.

35.11 Fourth, DNA parentage testing differs from many other kinds of genetic testing. For many medical purposes, useful information can be obtained by testing the genetic material of a single person, who may be shown to have (or not to have) a particular genetic mutation with potential clinical consequences. Parentage testing, by contrast, is relationship testing and requires the participation of two or more individuals in order to reveal useful information about the biological relationship between those persons.

35.12 Fifth, in most cases (although not invariably) one of the individuals whose genetic sample is required for testing will be a child. In such instances, who should make an informed decision on behalf of the child about whether the child should submit a genetic sample for testing? This question is particularly difficult when those who have parental responsibility for the child (who in other circumstances would make

3 A Stanley, 'In DNA Tests, TV Finds Elixir to Raise Ratings', *New York Times*, 19 March 2002.

important decisions affecting the child's welfare) are directly affected by the outcome of the testing procedure.

35.13 A sixth and related point is that this is not an area in which it is especially useful to draw on the language of 'rights'—whether that be a child's 'right' to know his or her biological parentage, or a man's 'right' to know who are his biological offspring. This is an area that requires a careful balancing of *interests* of mothers, fathers and children in different biological and social relationships with each other. To privilege the interest of one party by accepting a claim to an absolute right fails to give adequate regard to the interests of others involved in the equation.

35.14 Seventh, the direct accessibility of parentage testing currently surpasses that of many others forms of genetic testing, and this has highlighted practical problems that are yet to be confronted in other fields of genetic testing. Parentage testing does not require the referral of a medical practitioner, and it is often consumer-initiated. Moreover, direct to the public genetic testing kits (or, more accurately, genetic sampling kits) are readily available, and there is widespread advertising of local and offshore testing facilities via the Internet and other media. For these reasons, some of the detriments associated with widespread and unregulated access to genetic testing have become apparent in the particular context of parentage testing. These may provide valuable lessons for other kinds of testing in the future.

35.15 Finally, under existing Australian law, the outcome of parentage testing may have important consequences for the financial obligations of a father or mother to support and maintain a child. In response to financial incentives, fraudulent practices might arise both in seeking to attribute parentage where none exists and in seeking to deny parentage where it does.

Methods of parentage testing

Blood group testing

35.16 Traditionally, parentage testing was conducted by blood group (serological) analysis. Blood group analysis involves the use of scientific principles regarding the inheritance of blood types to establish whether a person is *excluded* as the parent of a child, or whether a person may be the parent of a child—it cannot establish with certainty that a person is the parent of the child.⁴

DNA testing

35.17 DNA parentage testing has developed since the mid-1980s and is generally considered to be a more reliable form of testing than blood group testing. As with serological testing, it cannot definitively prove that a person is the biological parent of

4 See A Dickey, *Family Law* (1997) LBC Information Services, Sydney, 296–297.

a child but instead produces a probability of parentage.⁵ DNA parentage testing is usually conducted using the polymerase chain reaction method (see Chapter 10).

35.18 DNA parentage testing usually involves determining whether the putative parent has a series of DNA markers identified as having been inherited by the child. For example, in paternity testing, it is assumed that the mother is the biological mother of the child, and that half of the child's DNA has been inherited from her. The analyst then identifies a series of DNA markers that must have been inherited from the biological father. If the putative father does not carry all of the required DNA markers, he can be definitively excluded as the biological father of the child. If the putative father does carry all of these paternal markers, either:

- he is the biological father of the child; or
- he is not the biological father but carries the genes by co-incidence.⁶

35.19 As it is not possible to prove paternity absolutely, the scientist then estimates the probability that the putative father is the biological father of the child.

Social consequences of parentage testing

Potential impact on social relationships

35.20 An underlying theme in the discussion of parentage testing is whether the law should emphasise biological parentage over social parentage in matters of parental responsibility, child support, succession and so on.⁷ Before the availability of serological and DNA parentage testing, it was difficult to determine with scientific accuracy the biological parentage of a particular child. In the absence of scientific proof, parentage usually was accepted on the basis of certain social relationships between adult and child. For legal purposes, greater certainty was provided by common law or statutory presumptions of parentage. For example, a presumption of parentage arose from marriage, cohabitation, registration on a birth certificate, and so on.

35.21 The increased availability of scientific methods for determining biological parentage may result in a new emphasis on biological over social relationships. In the Australian context, this issue may arise where:

- a man seeks to avoid paying child support or maintenance for a child whom he discovers is not his biological child;

5 See B Atchison, A Georgalis and O Drummer, 'Disputed Paternity Testing' (1994) October *Law Institute Journal* 947.

6 C Pearman, 'Parentage Testing' in I Freckelton and H Selby (eds), *Expert Evidence in Family Law* (1999) LBC Information Services, 789.

7 This issue has also been considered in other jurisdictions. See eg M Anderlik and M Rothstein, 'DNA-Based Identity Testing and the Future of the Family: A Research Agenda' (2002) 28 *American Journal of Law & Medicine* 215; *Uniform Parentage Act 2000* (US). In his submission to the Inquiry, Colin Andersen emphasised the need to counteract any tendency in Australian family law toward favouring genetic over other social or psychological criteria when making decisions about the legal rights and responsibilities associated with parenthood: C Andersen, *Submission G002*, 14 January 2002.

- a woman seeks to avoid sharing custody of her child with her former husband or partner, whom she knows is not the child's biological father;
- a child or adult seeks a share in the deceased estate of his or her biological parent, rather than social parent; or
- an adopted child, or child born as a result of an artificial reproductive technology procedure involving donated gametes, seeks information about his or her biological parents.

35.22 Difficult policy choices necessarily will be involved in deciding whether and how to regulate DNA parentage testing. Underlying these choices is a broad policy issue of the extent to which parent-child relationships should be seen as socially or biologically constructed. These are matters on which reasonable minds may differ. The remainder of this chapter gives further consideration to a number of specific issues that arise in respect of parentage testing.

General comments in the submissions

35.23 A substantial number of submissions responding to DP 66 commented on DNA parentage testing. Many of these submissions were forwarded by what are commonly known as 'men's rights' or 'fathers' rights' groups. Many submissions reflected a strongly biological determinist view of parental responsibility. These submissions expressed several common themes, including:

- Men have a right to test the paternity of a child presumed to be their own.⁸
- Children have a right to know their biological parents.⁹
- Paternity testing is in the best interests of the child.¹⁰

8 For example, R Thomas, *Submission G173*, 16 September 2002; Family Law Reform Association of NSW, *Submission G205*, 27 November 2002; J Dezordi, *Submission G180*, 4 September 2002; J Baxter, *Submission G280*, 27 December 2002; Reliable Parents Inc, *Submission G204*, 27 November 2002; Men's Confraternity WA Inc, *Submission G234*, 17 December 2002; *Confidential Submission G309CON*, 19 December 2002.

9 For example, Family Law Reform Association of NSW, *Submission G205*, 27 November 2002; DNA Testing Law Reform, *Submission G207*, 27 November 2002; Dad's Landing Pad, *Submission G208*, 25 November 2002; NT Office Status of Family, *Submission G229*, 12 December 2002; Men's Confraternity WA Inc, *Submission G234*, 17 December 2002; Grandpower for Grandkids, *Submission G310*, 28 January 2003; *Confidential Submission G163CON*, 27 May 2002; R Thomas, *Submission G173*, 16 September 2002; A Unger, *Submission G192*, 18 November 2002; Reliable Parents Inc, *Submission G204*, 27 November 2002; *Confidential Submission G309CON*, 19 December 2002.

10 For example, Reliable Parents Inc, *Submission G204*, 27 November 2002; C Nicholson and Others, *Submission G188*, 5 November 2002. Some submissions argued that it is in a child's best interests to know his or her true biological parents from birth; other submissions emphasised the alleged benefits for the child in knowing both his or her biological and social parents.

- Universal paternity testing should be carried out at birth, for example at the time of the newborn screening test.¹¹
- If paternity is not tested at birth, paternity testing should be conducted as a precondition to an application for child support,¹² or when an existing payer of child support requests such testing, or when proceedings involving children are instituted in the Family Court.¹³
- Men should not be financially responsible for children with whom they have no biological relationship.¹⁴
- Women who knowingly misattribute the paternity of their children are committing 'paternity fraud'.¹⁵

35.24 Several submissions expressed concern about the perceived bias against men within family law legislation and practice. For example, a submission in the form of a petition commented that:

For far too long now there has been a blatant bias against fathers in family law decision-making. We feel that men have simply become sperm banks with fat wallets and that has led to decisions that are neither in the best interest of the children nor the fathers ... No man should be forced to pay to rear and educate another man's child. As the law operates now, it happens and that constitutes legal fraud.¹⁶

35.25 Several submissions expressed substantial discontent with the Family Court due to the cost of court proceedings and the Court's perceived bias against men in family law matters. The Australian Law Reform Commission heard similar criticisms during its Inquiry into the federal civil justice system.¹⁷ The Inquiry notes that proceedings in the new Federal Magistrates Service (FMS) are less formal and costly

11 For example, C King, *Submission G176*, 2 September 2002; R McElhinney, *Submission G187*, 28 October 2002; C Nicholson and Others, *Submission G188*, 5 November 2002; A Unger, *Submission G192*, 18 November 2002; DNA Testing Law Reform, *Submission G207*, 27 November 2002; Dad's Landing Pad, *Submission G208*, 25 November 2002; NT Office Status of Family, *Submission G229*, 12 December 2002; Men's Confraternity WA Inc, *Submission G234*, 17 December 2002.

12 For example, C Nicholson and Others, *Submission G188*, 5 November 2002; A Unger, *Submission G192*, 18 November 2002; Reliable Parents Inc, *Submission G204*, 27 November 2002; Dad's Landing Pad, *Submission G208*, 25 November 2002.

13 For example, Reliable Parents Inc, *Submission G204*, 27 November 2002; Dad's Landing Pad, *Submission G208*, 25 November 2002.

14 For example, R McElhinney, *Submission G187*, 28 October 2002; C Nicholson and Others, *Submission G188*, 5 November 2002; United Kingdom Men's Movement, *Submission G193*, 26 November 2002; Reliable Parents Inc, *Submission G204*, 27 November 2002; Family Law Reform Association of NSW, *Submission G205*, 27 November 2002; Dad's Landing Pad, *Submission G208*, 25 November 2002; Men's Confraternity WA Inc, *Submission G234*, 17 December 2002.

15 For example, C King, *Submission G176*, 2 September 2002; A Unger, *Submission G192*, 18 November 2002; United Kingdom Men's Movement, *Submission G193*, 26 November 2002; Reliable Parents Inc, *Submission G204*, 27 November 2002; NT Office Status of Family, *Submission G229*, 12 December 2002; M Yeaman, *Submission G231*, 16 December 2002; Men's Confraternity WA Inc, *Submission G234*, 17 December 2002; *Confidential Submission G237CON*, 19 December 2002.

16 C Nicholson and Others, *Submission G188*, 5 November 2002.

17 See Australian Law Reform Commission, *Managing Justice: A Review of the Federal Civil Justice System*, Report 89 (2000), ALRC, Sydney.

than those in the Family Court, and that the FMS may provide an alternative venue for many proceedings involving parentage testing.

35.26 In addition, several submissions suggested an historic bias of law reform agencies against men in respect of family law matters. For example, the Men's Confraternity WA Inc commented that:

For decades now [Law Reform Commissions] in all States have in our view encouraged the implementation of legislation for the purpose of advancing women's rights and their role in Australia ... This, in theory, would be good for all if the LRC hadn't done it in such a manner as to undermine men and their role in society. The LRC in all States have acted with the designed intent to enact legislation to reduce males to the lowest common denominator and reduce them to a position of powerlessness in Australian society.

Many pieces of legislation recommended by the LRC in all States have inevitably been constructed with radical feminist ideology, by feminists and males of the same ilk within the Commission. The fact that many well known feminists have served time on the various LRC's in the past is not in dispute ...

We ... believe that our submission enclosed will be ignored by this Australian Law Reform Commission. In doing this, the ALRC will be ensuring the breach of many basic human rights, all for the sake of feminist ideology and protecting mothers from the consequences of their fraudulent actions.¹⁸

35.27 Many submissions argued that where a social father discovers he is not the biological father of a child he should never be held financially liable for the child. In addition, several submissions suggested that the *Child Support (Assessment) Act 1989* (Cth) (CSAA) should be amended so that a man should not be liable for child support unless the child's mother produces parentage test results establishing that he is the biological father of the child.

35.28 The CSAA framework is described below. In short, the Act provides that child support is payable by a biological or adoptive parent of a child, and not by a step parent. A man who discovers that he is not the biological father of his social child can apply for a court declaration that he is not liable for child support—but such an action can have significant implications for the child's financial security and sense of identity. The Human Genetics Society of Australasia (HGSA) emphasised that parentage has a social as well as a biological context:

Where parentage is disputed from the outset, biological evidence of non-paternity may well be grounds for a Court finding that an individual has no financial responsibility for the upbringing of a child, but it would be unfortunate if proof of non-paternity following, for example, the breakdown of a long partnership in which a parental role had been fully undertaken, became grounds for abrogation of all responsibility for the support of a child.¹⁹

18 Men's Confraternity WA Inc, *Submission G234*, 17 December 2002.

19 Human Genetics Society of Australasia, *Submission G267*, 20 December 2002. In some cases, while the man might be released from liability for child support on the basis that he is not the biological father, a court could make a child maintenance order against him as a 'step parent'. These orders may be made only in limited circumstances, specified by the *Family Law Act 1975* (Cth) s 66M(3).

35.29 The Inquiry also received a number of submissions expressing concerns about alleged paternity testing fraud, by which men procure false paternity test results to avoid legal responsibility for their children.²⁰

The uses of parentage testing

Family law and child support proceedings

35.30 A party to family law proceedings may seek to rely on parentage test results where the biological parentage of a child is in issue—such as in proceedings relating to child support, child maintenance or parental responsibility.²¹

35.31 The *Family Law Act 1975* (Cth) (FLA) regulates proceedings for child maintenance, however a court cannot make a maintenance order where an application could properly be made under the CSAA for administrative assessment of child support.²² The FLA provides that a child's parents are primarily responsible for his or her maintenance.²³ The Family Court has held that the natural meaning of the word 'parent' in the context of child maintenance orders is 'the biological mother or father of the child and not a person who stands in loco parentis',²⁴ although the definition is extended by statute.²⁵ The court may also make a child maintenance order against a step parent where it is proper for him or her to have a duty to maintain the step child.²⁶

35.32 To determine a child's parentage as a matter of law, rather than science, the FLA contains a number of presumptions of parentage. These presumptions arise from marriage; cohabitation; entry as a parent in a register of births or parentage information; a court finding of parentage; and execution of an instrument acknowledging paternity.²⁷

35.33 Parentage testing may be used to rebut a presumption arising under the Act, or to establish evidence in circumstances where no presumption arises. The court has a discretion whether to order a parentage testing procedure.²⁸ The court generally will not order parentage testing on the basis of a mere suspicion of misattributed parentage;

20 For example, *Confidential Submission G074ACON*, 10 January 2002 to *Confidential Submission G074OCON*, 20 March 2002; *Confidential Submission G175CONA*, 5 September 2002; *Confidential Submission G175CONB*, 20 December 2002; N Turner, *Submission G099*, 22 February 2002; *Confidential Submission G137CON*, 20 March 2002.

21 'Parental responsibility' in relation to a child means all the duties, powers, responsibilities and authority that, by law, parents have in relation to children: *Family Law Act 1975* (Cth) s 61B.

22 Ibid s 66E.

23 Ibid s 66C(1).

24 *In the Marriage of Tobin* (1999) 24 Fam LR 635, 645.

25 *Family Law Act 1975* (Cth) s 60D(1) and s 60H in relation to children born as a result of an artificial conception procedure.

26 Ibid ss 66M(2), 60D(1). In making such an order, the court must have regard to the matters specified in s 66M(3).

27 Ibid ss 69P–69T.

28 Ibid s 69W(1).

the applicant must have an honest, bona fide and reasonable belief that there is a doubt as to the child's parentage before a parentage order will be made.²⁹

35.34 The CSAA provides a framework for administrative assessment of child support in respect of a child whose parents separated on or after 1 October 1989, or who was born after that date, or who was born before that date but has younger siblings born after that date.³⁰ The CSAA provides that a carer may lodge an application for assessment of child support against a child's parent.³¹ Child support is payable by a biological or adoptive parent of a child, or a person deemed to be a parent as a result of an artificial conception procedure;³² it is not payable by a non-adoptive step parent or a foster parent. Where a parent or carer seeks financial support from a step parent, he or she may apply for a child maintenance order under the FLA.³³

35.35 If the Child Support Registrar is satisfied that a person is a parent, and makes an administrative assessment against him or her, the person may apply for a court declaration that the person is not liable on the basis that he or she is not the child's parent.³⁴ The FLA provisions regarding establishing parentage apply to these proceedings. If the court makes a declaration that a person is not a liable parent, the person may apply for recovery of child support moneys paid for the child up to that date.³⁵

Paternity fraud proceedings

35.36 A man might seek DNA parentage testing in order to obtain evidence of non-paternity for the purposes of civil proceedings instituted against the child's mother for what has been termed 'paternity fraud'. Several such actions have been instituted in Australia in recent times.

35.37 In one case, a Victorian man brought civil proceedings in fraud against his ex-wife after discovering that two of the children born during their marriage were not his biological children. The man had paid child support for all three children for several years after the marriage ended. After discovering that he was not their biological father, the man brought proceedings against his ex-wife, alleging fraud and seeking damages for the emotional stress and financial loss he had suffered. In

29 See *In the Marriage of F and R* (1992) 15 Fam LR 533. See also *Duroux and Martin* (1993) 17 Fam LR 130, 135; *OP v HM* [2002] FamCA 454 [28].

30 *Child Support (Assessment) Act 1989* (Cth) ss 18–21. See also H Finlay, R Bailey-Harris and M Otlowski, *Family Law in Australia* (5th ed, 1997) Butterworths, Sydney [5.131].

31 The CSAA applies at the federal level and in each state and territory jurisdiction except Western Australia, which has adopted the administrative scheme of assessment in the *Child Support (Adoption of Laws) Act 1990* (WA).

32 *Child Support (Assessment) Act 1989* (Cth) ss 5, 29(2). See also *In the Marriage of Tobin* (1999) 24 Fam LR 635, 648.

33 *Family Law Act 1975* (Cth) ss 66E, 66M.

34 *Child Support (Assessment) Act 1989* (Cth) s 107(4)(c). Alternatively, if an application is refused, and an objection to the Registrar has failed, a carer applicant may apply for a declaration that he or she is entitled to administrative assessment on the basis that the putative parent is in fact the child's parent: s 106.

35 *Ibid* s 143.

November 2002, the Victorian County Court awarded the man \$70,000 for general damages and economic loss.³⁶

Succession to estates

35.38 A person may seek to rely on parentage testing as evidence that he or she has a biological connection with a deceased person in order to claim a share in the estate. This may occur where:

- the deceased's will provides for general categories of relatives, such as 'children' or 'grandchildren'—and parentage testing may provide evidence that the person falls within such a category;
- the deceased's will does not make provision for the person at all and parentage testing may provide evidence that that person falls within a category of relatives eligible for family provision pursuant to legislation; or
- the deceased has died intestate (ie without having made a will) and parentage testing may provide evidence that the person falls within a category of persons eligible to inherit the estate pursuant to the laws of intestacy.

35.39 Australian courts have heard a number of applications for access to stored tissue and blood samples of deceased persons for parentage testing in respect of succession.³⁷ Under the FLA, a parentage testing order may be made only in relation to procedures and testing of bodily samples taken from living persons, not human remains.³⁸

Immigration applications

35.40 The Department of Immigration and Multicultural and Indigenous Affairs (DIMIA) uses DNA parentage test results as evidence of family relationships for the purposes of assessing immigration applications. DIMIA's *Procedures Advice Manual* outlines the Department's policy regarding the use of such testing.³⁹

36 See G Bearup, 'The Doubt About Dad', *The Good Weekend (The Sydney Morning Herald)*, 3 November 2001, 16; I Munro, 'Ex-Wife Pays the Price for Paternity Lie', *Sydney Morning Herald*, 23 November 2002, 13; I Munro, 'Man Sues Former Wife Over Children', *The Age* (Melbourne), 15 November 2002. Another man has reportedly brought proceedings in the Family Court against his ex-wife to recover all of the money he spent on contact visits with his daughter, after discovering that the girl was not his biological child. The man has reportedly sought a refund of \$18,247, representing the amount he spent on access visits with the child—including visits to Luna Park, the zoo and McDonalds, and the cost of various toys, a car seat, blankets and doonas for the child. The man also sought a refund of all child support payments, and the legal fees he had incurred in custody proceedings over the child: N Protyniak, "'Father" Wants his \$18,247 back', *Daily Telegraph*, 1 November 2002, 2.

37 For example, *Roche v Douglas* [2000] 22 WAR 331; *Pecar v National Australia Trustees Ltd* (Unreported, Supreme Court of NSW, Bryson J, 27 November 1996); *AW v CW* (2002) 191 ALR 392.

38 *McK v O* (2001) FLC 93.

39 Department of Immigration and Multicultural and Indigenous Affairs, *Procedures Advice Manual (PAM3)* (1994–2002), DIMIA, Canberra. See Ch 37 for more detail.

Identification of human remains

35.41 Parentage and kinship testing is used in identifying deceased persons and human remains where, due to the cause of death or delay in locating the body, the deceased cannot be identified by traditional means. This form of testing is increasingly used in identifying the victims of mass disasters and terrorist attacks.⁴⁰

Incidental parentage testing

35.42 Certain types of genetic testing for medical or research purposes may also identify parentage as an incidental effect of the testing. For example, *The New York Times* reported a case in which a man's genetic test results disclosed that he was not a carrier of cystic fibrosis, the disease with which his youngest child had been born. As both parents must be carriers in order for the condition to be passed on to their child, the man's doctor recommended he have a paternity test. The results disclosed that he was not the father of that child.⁴¹

Personal interest

35.43 A person may wish to undergo parentage testing for personal reasons, such as his or her own peace of mind or for family reunion. For example, if a woman had more than one sexual partner around the time her child was conceived, she may seek parentage testing in order to determine her child's paternity for her own peace of mind. Alternatively, a man may seek parentage testing to confirm or deny his suspicions of misattributed paternity.

Regulation of parentage testing

35.44 It has been reported that an estimated 3,000 paternity tests are carried out each year in Australia.⁴² The Family Court has advised the Inquiry that in the 2000–2001 financial year, parentage testing orders were made in a total of 103 matters before the Court.⁴³ These figures suggest that a large number of paternity tests take place under the supervision of other courts, or (as is more likely) outside the court system altogether.

35.45 Parentage testing services may be accessed in Australia in a number of ways. A person wishing to undergo parentage testing may approach a laboratory or company offering these services directly, or may arrange testing through his or her medical practitioner or lawyer. A number of Australian and offshore laboratories advertise their services over the Internet and through the media.

40 See Ch 42 for more detail.

41 T Lewin, 'In Genetic Testing for Paternity, Law Often Lags Behind Science', *The New York Times*, 11 March 2001. See Pt F for more detail.

42 D Smith, 'Mothers Kept in the Dark on Paternity Tests', *The Sydney Morning Herald*, 27 March 2000.

43 Family Court of Australia, *Correspondence*, 22 January 2002.

35.46 Australia has a three-tiered system of DNA parentage testing. Testing may be conducted in accordance with the family law regulatory framework;⁴⁴ in accordance with relevant state and territory legislation;⁴⁵ or outside any regulatory framework. In addition, laboratories follow their own policies regarding certain aspects of parentage testing not covered by these regulatory frameworks. These aspects include the conduct of ‘motherless testing’,⁴⁶ guidelines about which parent may consent on behalf of a child, the provision of counselling, and the persons to whom parentage testing results should be sent.

35.47 The National Association of Testing Authorities, Australia (NATA) operates a national system of accreditation for laboratories conducting parentage testing. The system does not extend to other forms of DNA kinship testing, which are therefore unregulated. The NATA system of laboratory accreditation is outlined in Chapter 11. The purpose of the accreditation system is to ensure the technical proficiency of genetic testing. It is a NATA accreditation requirement that parentage test reports must comply with the requirements of the *Family Law Regulations 1984* (Cth) (FL Regulations), which are discussed below.⁴⁷

35.48 The scientific reliability of parentage testing is of vital importance, whether the testing is conducted by accredited or non-accredited laboratories. In one case, the Family Court ordered a man to undergo DNA parentage testing in relation to a child of whom he claimed to have no knowledge. The test results disclosed a 98.5% probability that he was the father of the child, and he therefore paid maintenance for the child. Years later, the man’s brother admitted having had a relationship with the child’s mother, and parentage testing showed a 99.5% probability that the brother was the child’s father.⁴⁸ The social, psychological and economic consequences of unreliable testing suggests the need to maintain the highest technical and scientific standards in conducting parentage testing.

44 *Family Law Act 1975* (Cth); *Family Law Regulations 1984* (Cth).

45 See the status of children legislation: *Status of Children Act 1974* (Vic); *Status of Children Act 1978* (Qld); *Status of Children Act 1974* (Tas); *Status of Children Act 1996* (NSW); *Birth (Equality of Status) Act 1988* (ACT); *Family Relationships Act 1975* (SA); *Status of Children Act 1978* (NT).

46 This involves testing the putative father and child’s bodily samples only. In the absence of the mother’s bodily sample, the analyst must test more loci on the DNA molecule to reach the level of statistical probability of parentage required by NATA accreditation requirements.

47 National Association of Testing Authorities Australia, *ISO/IEC 17025 Application Document: Supplementary Requirements for Accreditation in the Field of Forensic Science* (2000), National Association of Testing Authorities, Australia Sec 3, Pt B Supplementary Requirements for Accreditation: Parentage Testing [5.10.2(a)].

48 This case was reported in G Bearup, ‘The Doubt About Dad’, *The Good Weekend* (*The Sydney Morning Herald*), 3 November 2001, 16, 20.

Parentage testing under the family law framework

Family Law Act

35.49 Parentage testing conducted under the FLA is regulated by Part VII Division 12 of the Act and by Part IIA of the FL Regulations.⁴⁹ The FLA gives the court a power to order a ‘parentage testing procedure’ where a child’s parentage is in issue in proceedings under the FLA or the CSAA.⁵⁰ The court may make the order in relation to the child, the mother, or any other person who might assist in determining the child’s parentage.⁵¹ If an adult contravenes an order, or withholds consent on behalf of the child, the court may draw such inferences as appear just in the circumstances.⁵²

35.50 A report made in accordance with the provisions of the FL Regulations may be received in evidence in any proceedings under the FLA.⁵³ This is one means of encouraging laboratories to comply with the FL Regulations in conducting parentage tests. Once the court has decided the issue of parentage for the purpose of proceedings under the FLA, it may also issue a ‘declaration of parentage’, which is conclusive evidence of parentage for the purpose of all Commonwealth laws.⁵⁴

Family Law Regulations

35.51 Part IIA of the FL Regulations applies to parentage testing procedures conducted pursuant to a court’s parentage testing order made under the FLA.⁵⁵ Part IIA may also be relevant to parentage testing that has not been ordered by a court under the family law provisions. This is because it is a NATA accreditation requirement that parentage test reports issued by NATA accredited laboratories comply with the FL Regulations. However, NATA also permits accredited laboratories to conduct parentage testing that does not comply with the FL Regulations—provided the laboratories do not hold themselves out as accredited for the purposes of that particular test.⁵⁶

35.52 The FL Regulations address two main aspects of scientific reliability in parentage testing: the protection of the integrity of bodily samples and the technical accuracy of the testing process. The FL Regulations cover the collection of bodily

49 Western Australia, unlike other Australian States, has its own state family court: *Family Court Act 1997* (WA). The courts with jurisdiction to hear matters arising under Pt VII of the FLA in relation to children are the Family Court of Australia, state Family Courts, the Federal Magistrates Court and, in some circumstances, courts of summary jurisdiction: *Family Law Act 1975* (Cth) ss 69H, 69J.

50 See *Family Law Act 1975* (Cth) s 69W(1); *Child Support (Assessment) Act 1989* (Cth) s 100(1). Where a child’s parentage is in issue in proceedings under state and territory status of children legislation, for example, in relation to an application for a declaration of parentage, a court may order a parentage testing procedure pursuant to the relevant legislation.

51 *Family Law Act 1975* (Cth) s 69W(3). The court may make the order on its own initiative or on the application of a party to the proceedings or a person separately representing the child: s 69W(2).

52 Ibid ss 69Y, 69Z.

53 Ibid s 69ZC(1). See *Family Law Regulations 1984* (Cth) Pt IIA—Parentage Testing Procedures and Reports.

54 *Family Law Act 1975* (Cth) s 69VA.

55 *Family Law Regulations 1984* (Cth) r 21A.

56 National Association of Testing Authorities Australia, *Correspondence*, 12 April 2002.

samples; the storage of samples and their transport to the laboratory (that is, chain of custody); the timeframe for testing samples; and the format of the parentage testing report.⁵⁷

35.53 The procedure for taking bodily samples is prescribed in some detail. A person providing a sample must complete a prescribed affidavit and declaration, and sign the label on the sealed container holding the sample.⁵⁸ The donor must also provide a recent photograph of him or herself (or make an arrangement to do so). The sampler must affix the photograph of the donor to the sampler's prescribed statement, and sign over the photograph and statement in a way that, if the photo were later removed, the removal would be evident. There is no requirement, however, that the sample donor provide any personal identification to the sampler for the purpose of verifying that he or she is in fact the person who should be providing the sample.

35.54 The prescribed affidavit and declaration outline aspects of the donor's recent medical history.⁵⁹ They do not refer to consent to the taking of the bodily sample or to the conduct of testing on the sample. Consent is inferred by the person's completion of the forms and provision of the sample, as well as by the completion of any application form that may be provided by the laboratory.

Parentage testing under state and territory legislation

35.55 Each Australian State and Territory (except Western Australia) has enacted status of children legislation in similar terms.⁶⁰ The purpose of the legislation is to give nuptial and ex-nuptial children equal status for the purpose of state or territory law. In Western Australia, the *Family Court Act 1997* (WA) contains similar provisions.

35.56 Each Act includes presumptions of parentage and provisions for establishing parenthood.⁶¹ The legislation in New South Wales, Tasmania, and the Northern Territory closely follows the parentage provisions of the FLA. The provisions of the state and territory legislation have residual operation in relation to proceedings that fall outside the coverage of the FLA, such as in relation to succession.⁶²

⁵⁷ *Family Law Regulations 1984* (Cth) Pt IIA, Div 2, 3.

⁵⁸ In the case of a child or a person suffering a mental disability, the person responsible for his or her long term care, welfare and development must do this.

⁵⁹ *Family Law Regulations 1984* (Cth) r 21F, Form 2. For example, whether the donor has suffered from leukaemia or has received a bone marrow transplant, a transfusion of blood or a blood product within a specified period before providing the bodily sample.

⁶⁰ *Status of Children Act 1974* (Vic); *Status of Children Act 1978* (Qld); *Status of Children Act 1974* (Tas); *Status of Children Act 1978* (NT); *Status of Children Act 1996* (NSW); *Birth (Equality of Status) Act 1988* (ACT); *Family Relationships Act 1975* (SA).

⁶¹ Except in South Australia, where parentage testing is regulated by the *Family and Community Services Act 1972* (SA).

⁶² See the discussion in H Finlay, R Bailey-Harris and M Otlowski, *Family Law in Australia* (5th ed, 1997) Butterworths, Sydney [7.5].

35.57 The status of children legislation generally permits a person to apply to the Supreme Court of the relevant jurisdiction for a declaration of parentage, or an order annulling a declaration of parentage, even if there are no other legal proceedings on foot.⁶³

Unregulated parentage testing

35.58 As noted above, accredited laboratories may conduct parentage testing that does not comply with NATA accreditation requirements or the FL Regulations. Similarly, non-accredited laboratories do not have to comply with these requirements. As a result, both accredited and non-accredited laboratories may offer unregulated parentage testing. Practices and procedures regarding consent, collection of samples, transfer of samples to the laboratory, counselling, quality assurance and technical proficiency can vary depending on individual laboratory policy.

35.59 One of the main differences between regulated and unregulated parentage testing is in the collection of bodily samples. The FL Regulations provide a detailed process for ensuring the integrity of the samples. By contrast, a number of laboratories offer home-based collection of bodily samples (for example, buccal swabs or hair follicles) using mail order sampling kits. This enhances the prospect of non-consensual collection of bodily samples, and exacerbates the risks of sample contamination, error and fraud.

Evaluating the regulatory framework

Issues and problems

35.60 The Inquiry received many submissions expressing concerns about the regulation of parentage testing in Australia. These concerns related both to testing conducted under the family law scheme and to unregulated testing conducted by accredited and non-accredited laboratories. Arlette Mercae suggested:

The availability of mail order paternity tests from unlicensed laboratories can only jeopardise the well being of the child. Careful regulation of the circumstances under which paternity tests can be sought, and adequate counselling for the whole family should be put in place. This is primarily to ensure the security and physical and emotional welfare of the child, whose needs in this situation should be paramount, not those of the parents.⁶⁴

35.61 Colin Andersen submitted that the debate so far has been narrowly focused on the activities of non-accredited, as opposed to accredited laboratories. He emphasised the need for reform not only of the non-accredited sector of the parentage testing industry, but also of the accredited sector.

63 For example, see *Status of Children Act 1996* (NSW) ss 21(1), 22(1). In contrast, the FLA provides that the court may issue a declaration of parentage *after* the issue of a child's parentage has been determined for the purpose of proceedings: *Family Law Act 1975* (Cth) s 69VA.

64 A Mercae, *Submission G031*, 12 January 2002.

Whatever regulatory regime is eventually adopted in Australia it has to be recognised that reining in the non-accredited laboratories alone is not in itself sufficient to clean up the industry—the practice of accredited agencies is also wanting, especially in allowing the unilateral, non-consensual initiation of paternity testing by mothers whose aim is to ensure that ex-husbands also become ex-fathers.⁶⁵

35.62 On the other hand, the Inquiry was informed that one of the benefits of testing outside the family law framework is that it is cheaper. Dr Geoffrey Edelsten, director of Gene-e Pty Ltd, submitted that accredited parentage testing involves high costs because of the legal costs involved in obtaining a parentage testing order and the actual cost of the accredited test.⁶⁶ The Inquiry heard that another benefit of testing outside the family law framework is that it allows parents to conduct ‘peace of mind’ testing without causing potentially unwarranted concern to the child or the family.⁶⁷

35.63 The Inquiry received several submissions addressing concerns about the accuracy and reliability of parentage testing conducted by both accredited and non-accredited laboratories. The author of one submission gave examples of alleged tampering with bodily samples, as well as alleged deliberate false reporting by a number of Australian accredited and non-accredited laboratories. The author raised concerns that current safeguards for protecting the integrity of the samples do not protect against tampering or deliberate fraud.⁶⁸

35.64 Another submission emphasised the opportunity and temptation for parents to obtain falsified results:

There seems to be secrecy about the tests in Family Law cases (the mother, for instance, may not be present during the testing). There are few safeguards, and it would seem that accreditation of testers is haphazard and loose. Moreover ... there are ample opportunities for contamination, mislabelling and degradation of samples ... A man who fathers a child outside marriage can expect to pay child support for at least 18 years. Depending on the relevant factors in the child support legislation and the *Family Law Act*, and inflation, his total liability is likely to be at least \$500,000 ... The temptation to obtain false testing must be great.⁶⁹

35.65 The Inquiry also heard of alleged cases of sample substitution, in which the putative father sent a substitute man, and in another case, the child’s mother sent a substitute woman and child, to provide the bodily samples in order to obtain paternity exclusions.

65 C Andersen, *Submission G002*, 14 January 2002.

66 G Edelsten, *Submission G117*, 14 March 2002.

67 DNA Solutions, *Submission G162*, 30 May 2002. See also Genetic Technologies Corporation Pty Ltd, *Submission G245*, 19 December 2002; A Newson, *Submission G283*, 23 December 2002; Men’s Rights Agency, *Submission G213*, 29 November 2002.

68 *Confidential Submission G074BCON*, 13 January 2002. The media have reported allegations of inaccurate paternity reporting in relation to a testing laboratory in the United States: N Stancill, ‘Paternity Lab May Have Overlooked Real Fathers’, *Houston Chronicle* (Houston), 24 February 1993, 1, quoted in N Turner, *Submission G083*, 14 January 2002.

69 N Turner, *Submission G099*, 22 February 2002.

Options for reform

35.66 There are two different approaches to the regulation of parentage testing. The first involves regulating access to genetic testing by imposing an additional hurdle between the individual seeking the test and the laboratory doing the testing—for example, a court order or the authorisation of a medical practitioner. The second approach preserves the right of individuals to make a direct approach to a laboratory, but seeks to regulate the laboratories themselves—for example, by requiring laboratories to be accredited or comply with an industry code of practice.

Court supervision

35.67 The option of using court supervision would make access to parentage testing subject to a parentage testing order under the FLA, or relevant state and territory legislation. This would enable the courts to provide independent oversight of the testing, including in relation to the validity of consent. Several submissions supported this approach.⁷⁰ The HGSA suggested the courts could ensure both the accuracy and reliability of the evidence admitted and a mechanism to address issues arising from the test results.⁷¹

35.68 However, using a court in every case may be expensive, slow or inconvenient. While Family Court proceedings may be confidential, by necessity they require individuals to place sensitive information in the public arena—at least to the extent of being heard by those present in court. Additionally, there are constitutional difficulties in utilising federal courts to make orders in cases where parentage testing is not related to a legal dispute between parties.

Medical practitioners as gatekeepers

35.69 An alternative would be to make medical practitioners the ‘gatekeepers’ of parentage testing conducted by Australian laboratories by specifying appropriate request pathways. Medical practitioners would be well placed to take a bodily sample from each person involved in the testing procedure, to protect the integrity of the samples, and to ensure informed consent is given by those from whom it is required. However, parentage testing is not inherently related to the health of the parties concerned. Involvement of medical practitioners might be seen as compelling doctors to divert their resources to the provision of a social service that is unrelated to their medical expertise and more appropriately provided by others.

70 Human Genetics Society of Australasia, *Submission G050*, 14 January 2002; Law Society of New South Wales, *Submission G285*, 18 December 2002; Law Institute of Victoria, *Submission G275*, 19 December 2002. *Confidential Submission G022CON*, 3 December 2001 suggested that DNA paternity testing should only be allowed through a Family Court order.

71 Human Genetics Society of Australasia, *Submission G050*, 14 January 2002.

NATA accreditation

35.70 A principal advantage of NATA is that it provides an industry-based mechanism for independent oversight of laboratories that conduct genetic testing. A disadvantage is that current accreditation standards focus mainly on technical proficiency and do not address the ethical issues associated with testing.

35.71 The Inquiry addressed this issue in Chapter 11, where it recommended that National Pathology Accreditation Advisory Council, in consultation with NATA and the Royal College of Pathologists of Australasia (RCPA), should examine how compliance with its accreditation standards in relation to consent, counselling and other ethical considerations in medical genetic testing should be assessed as part of the NATA/RCPA accreditation process.⁷² It should be noted, however, that NATA accreditation standards currently make provision for protecting the integrity of the sample in parentage testing by adopting the requirements of the FL Regulations.

Code of practice

35.72 A final option would be to implement a voluntary code of practice for parentage testing conducted by Australian laboratories. The United Kingdom's Department of Health has implemented such a code, which applies to all organisations advertising and providing genetic paternity testing services direct to the public.⁷³ Several submissions supported this option.⁷⁴ However, the greatest drawback of such a system is that it is not legally enforceable. Concerns about compliance have led the United Kingdom's Human Genetics Commission to recommend a review of the effectiveness and relevance of the Code of Practice.⁷⁵

Submissions and consultations**NATA accreditation**

35.73 In DP 66, the Inquiry noted its preliminary view that DNA parentage testing should be conducted only by NATA accredited laboratories, and only in accordance with NATA accreditation standards.⁷⁶ Adoption of this policy would eliminate DNA parentage testing that is currently performed in Australia by non-accredited laboratories. It would also eliminate the practice of allowing NATA accredited laboratories to conduct non-accredited parentage testing by the expedient of not holding themselves out as being accredited for the purposes of a particular test.

⁷² Recommendation 11–3.

⁷³ Group on Genetic Paternity Testing Services, *Code of Practice and Guidance on Genetic Paternity Testing Services*, (2001) Department of Health, <www.doh.gov.uk/genetics/paternity.htm>, 19 February 2003. The Group comprised representatives from commissioners of genetic paternity testing services, providers of such services, patients' groups, clinicians, academics and scientists.

⁷⁴ The Victoria Police supported this option: Victoria Police, *Submission G086*, 21 January 2002; Genetic Technologies Corporation Pty Ltd, *Submission G245*, 19 December 2002.

⁷⁵ Human Genetics Commission, *Inside Information: Balancing Interests in the Use of Personal Genetic Data* (2002), London, 166.

⁷⁶ Australian Law Reform Commission and Australian Health Ethics Committee, *Protection of Human Genetic Information*, DP 66 (2002), ALRC, Sydney, Proposal 31–1.

35.74 Most of the submissions addressing this proposal expressed their support.⁷⁷ The Reliable Parents (Inc) commented that it

recognises the importance of both scientific and ethical standards to ensure that the results of paternity testing are as accurate as possible. The social implications of an error or substitution in a testing procedure require that the highest standards be maintained.⁷⁸

35.75 Both Sydney IVF Limited and the Genetic Technologies Corporation Pty Ltd (Genetic Technologies)⁷⁹ submitted that only NATA accredited laboratories should be permitted to conduct DNA parentage testing.⁸⁰ However, Genetic Technologies commented that if the NATA guidelines are changed to preclude some kinds of parentage tests, for example 'motherless tests', they would not support the proposal, noting that:

even though we do offer testing outside the NATA guidelines, this is not done in complete ignorance of them. It would be undesirable, for example, to test samples without evidence of consent, and we do not do this. Additionally, we ensure that samples are collected with as high a degree of integrity as possible. Once in the laboratory, the sample is tested to exactly the same technical standards as if it were obtained in accordance with NATA guidelines of testing.⁸¹

35.76 NATA advised the Inquiry that in practice some accredited laboratories offering non-accredited testing do not follow the same standards and procedures in relation to non-accredited tests.⁸²

Review of the ethical and technical requirements

35.77 The consequences of parentage testing can be of profound significance to the persons tested and to others whose parentage status is affected by the test results. DP 66 proposed that both the NATA accreditation requirements for DNA parentage testing, and Part IIA of the FL Regulations, should be reviewed to ensure that they

77 Reliable Parents Inc, *Submission G204*, 27 November 2002; Institute of Actuaries of Australia, *Submission G224*, 29 November 2002; Centre for Genetics Education, *Submission G232*, 18 December 2002; Genetic Support Council WA, *Submission G243*, 19 December 2002; Centre for Law and Genetics, *Submission G255*, 21 December 2002; Human Genetics Society of Australasia, *Submission G267*, 20 December 2002; Department of Health Western Australia, *Submission G271*, 23 December 2002; New South Wales Legal Aid Commission, *Submission G282*, 24 December 2002; Department of Human Services South Australia, *Submission G288*, 23 December 2002; Law Institute of Victoria, *Submission G275*, 19 December 2002; Victorian Bar, *Submission G261*, 20 December 2002; Association of Genetic Support of Australasia, *Submission G284*, 25 December 2002; NSW Health Department, *Submission G303*, 13 January 2003; National Association of Testing Authorities Australia, *Submission G273*, 18 December 2002.

78 Reliable Parents Inc, *Submission G204*, 27 November 2002.

79 Genetic Technologies is the largest provider of DNA parentage testing in Australia and operates the following parentage testing laboratories: Genetic Technologies, Silbase Scientific Services Pty Ltd, Simons GeneType Diagnostics Pty Ltd, DNA-ID Labs and Curtin Genetics: Genetic Technologies Corporation Pty Ltd, *Submission G245*, 19 December 2002.

80 Sydney IVF Limited, *Submission G246*, 19 December 2002; Genetic Technologies Corporation Pty Ltd, *Submission G245*, 19 December 2002.

81 Genetic Technologies Corporation Pty Ltd, *Submission G245*, 19 December 2002.

82 National Association of Testing Authorities Australia, *Consultation*, Melbourne, 21 October 2002.

meet the highest technical and ethical standards, particularly in relation to consent to testing, protecting the integrity of genetic samples, and provision of counselling.⁸³

35.78 Most of the submissions addressing these proposals expressed their support.⁸⁴ NATA supported the proposal, advising that a review of the accreditation criteria is being planned and the issues raised in DP 66 would be considered in that review.

In particular, those requirements currently covered by the Family Law Requirements (for example, requirements for the collection and security of samples) will be incorporated to make the accreditation program applicable to parentage testing outside that performed for Family Law purposes.⁸⁵

35.79 The New South Wales Legal Aid Commission commented that the improvement of identification and security standards to protect the integrity of samples, and the provision of information and counselling, are particularly important.⁸⁶ Sydney IVF Limited commented that:

the exacting requirements necessary to perform genetic testing on humans should adequately cover the collection of specimens, the chain of custody, appropriate laboratory testing protocols, reporting protocols and storage of retained specimens and laboratory records. Given the impact that the results of parentage testing can have on mother, purported father and child, the highest level of sample and testing control should be required.⁸⁷

35.80 Genetic Technologies questioned whether NATA is the most appropriate organisation to determine ethical standards for parentage testing, and requested clarification whether the FL Regulations would be developed separately to the NATA guidelines in relation to this issue. It was suggested that the Inquiry should exercise caution in introducing too much complexity into the regulation of parentage testing.⁸⁸

83 Australian Law Reform Commission and Australian Health Ethics Committee, *Protection of Human Genetic Information*, DP 66 (2002), ALRC, Sydney, Proposals 31–2, 31–3.

84 Reliable Parents Inc, *Submission G204*, 27 November 2002; Institute of Actuaries of Australia, *Submission G224*, 29 November 2002; New South Wales Legal Aid Commission, *Submission G282*, 24 December 2002; Victorian Bar, *Submission G261*, 20 December 2002; Department of Health Western Australia, *Submission G271*, 23 December 2002; Association of Genetic Support of Australasia, *Submission G284*, 25 December 2002; Department of Human Services South Australia, *Submission G288*, 23 December 2002; NSW Health Department, *Submission G303*, 13 January 2003; Centre for Law and Genetics, *Submission G255*, 21 December 2002; Human Genetics Society of Australasia, *Submission G267*, 20 December 2002; Institute of Actuaries of Australia, *Submission G224*, 29 November 2002. However, the Institute of Actuaries of Australia noted that it has no specific comment on Pt IIA of the FL Regulations. The Commonwealth Attorney-General's Department had no objection to the first two proposed areas of review, but considered that further consideration should be given regarding the provision of counselling: Commonwealth Attorney-General's Department, *Submission G228*, 12 December 2002.

85 National Association of Testing Authorities Australia, *Submission G273*, 18 December 2002.

86 New South Wales Legal Aid Commission, *Submission G282*, 24 December 2002.

87 Sydney IVF Limited, *Submission G246*, 19 December 2002.

88 Genetic Technologies Corporation Pty Ltd, *Submission G245*, 19 December 2002.

Inquiry's views

35.81 Despite the support expressed in several submissions for court supervision of parentage testing in every case, the Inquiry considers that this approach would be overly prescriptive. The cost, delay and potential exposure of a court order is likely to act as a deterrent to testing, or to force interested persons 'underground' to unregulated parentage testing available through mail order or over the Internet.⁸⁹ The Inquiry is also of the view that it is not appropriate to expect medical practitioners to provide a range of social services in relation to a genetic testing procedure that is largely unrelated to the present or future health of the sample donors.

35.82 While the introduction of a code of practice has been suggested, the Inquiry is concerned that the voluntary nature of the code would permit laboratories to continue offering non-accredited testing that may not meet minimum technical and ethical requirements. Some laboratories may maintain the high standards required of accredited testing when conducting non-accredited tests but this may not be the case in all laboratories.

35.83 The consequences of parentage testing can be of profound significance to the individuals tested and to others whose parentage status is affected by the results of the test. Test results may lead to the destruction of long-standing social relationships between adults and children, and between partners in a relationship. As noted above, significant financial consequences may turn on the results. It is essential in this context to ensure that parentage testing is performed to the highest standards of technical proficiency and in accordance with sound ethical principles.

35.84 In the Inquiry's view, these objectives can be achieved by requiring all parentage testing in Australia to be performed by NATA accredited laboratories in accordance with NATA standards, provided those standards are upgraded to address the full range of scientific and ethical concerns, such as procedures for protecting the integrity of the sample, consent to testing, and the provision of information about the availability of counselling.

35.85 To that end, the Inquiry recommends that:

- The Commonwealth should enact legislation to provide that DNA parentage testing in Australia is conducted only by laboratories accredited by NATA, and only in accordance with NATA accreditation requirements.
- NATA should review its accreditation requirements for DNA parentage testing to ensure that they meet the highest technical and ethical standards, particularly in relation to consent to testing, protecting the integrity of genetic samples, and providing information about counselling.

⁸⁹ There is merit, however, in using courts to resolve disputes between parents regarding consent to the sampling and testing of a child who lacks the maturity to make a decision on his or her own behalf. See further below.

- The Commonwealth should review Part IIA of the FL Regulations to ensure that the requirements for parentage testing meet the highest technical and ethical standards, particularly in relation to consent to testing, protecting the integrity of genetic samples, and providing information as to counselling.

35.86 To minimise uncertainty or complexity between these two regulatory frameworks, the Inquiry recommends that in reviewing Part IIA of the FL Regulations, the Commonwealth should have regard to the accreditation requirements for DNA parentage testing developed by NATA in accordance with Recommendation 35–2.

Recommendation 35–1. The Commonwealth should enact legislation to provide that DNA parentage testing in Australia is conducted only by laboratories accredited by the National Association of Testing Authorities, Australia (NATA), and only in accordance with NATA accreditation requirements.

Recommendation 35–2. NATA should review its accreditation requirements for DNA parentage testing to ensure that they meet the highest technical and ethical standards, particularly in relation to consent to testing, protecting the integrity of genetic samples, and providing information about counselling.

Recommendation 35–3. The Commonwealth should review Part IIA of the *Family Law Regulations 1984* (Cth) (FL Regulations) to ensure that the requirements for parentage testing meet the highest technical and ethical standards, particularly in relation to consent to testing, protecting the integrity of genetic samples, and providing information as to counselling. In so doing, the Commonwealth should have regard to the accreditation requirements for parentage testing developed by NATA in accordance with Recommendation 35–2.

Direct to the public parentage testing

35.87 As discussed in Chapter 11, direct to the public genetic testing refers to two different forms of genetic testing. One form is akin to home pregnancy testing, in which the test is performed and interpreted by the person at home. At present, this form of genetic testing for parentage is not available in Australia.

35.88 The second form is a test in which the person collects a bodily sample at home and sends it to a laboratory for analysis. Kits for testing may be made available through pharmacists or other retailers, by mail order or over the Internet. The samples are forwarded through the mail to the company offering the services, either in Australia or overseas, and the laboratory testing the samples may or may not be accredited. Home-based sample collection raises a number of concerns, which are discussed in Chapter 11.

Submissions and consultations

35.89 DP 66 proposed that home use parentage test kits should be subject to regulation under the *Therapeutic Goods Act 1989* (Cth) and the *Therapeutic Goods Regulations 1990* (Cth).⁹⁰

35.90 Most of the submissions addressing this proposal expressed support for it.⁹¹ Several submissions opposed the use of direct to the public kits in any circumstances.⁹² For example, Sydney IVF Limited commented that the inappropriate or inadequate use of such kits could lead to incorrect non-consensual sampling, or sample substitution.

Sydney IVF recommends that sample collection should always be supervised, for example in an approved pathology collection centre ... the utilization of home use parentage kits can circumvent the responsibilities associated with the provision and acceptance of informed consent for testing.⁹³

35.91 In contrast, Genetic Technologies noted that home-use kits for DNA parentage testing are not sensitive to heat or aging, and concerns with contamination and 'chain of custody' can be mitigated by limiting the uses to which results from home-use testing can be put. It was noted that home based collection does not preclude a client from obtaining counselling or clinical interaction.⁹⁴

35.92 Dr Geoffrey Edelsten emphasised the potential additional cost to the consumer, which he argued would result from implementation of the proposal.⁹⁵ However, the evidence available to the Inquiry suggests that the cost differential is relatively modest. For example, Genetic Technologies (an accredited laboratory) advised the Inquiry in 2001 that its standard fees for parentage testing were:

- paternity test involving samples from the mother, father and child: \$825;
- home collection paternity test involving samples from the mother, father and child: \$715; and

90 Australian Law Reform Commission and Australian Health Ethics Committee, *Protection of Human Genetic Information*, DP 66 (2002), ALRC, Sydney, Proposal 31–4.

91 Institute of Actuaries of Australia, *Submission G224*, 29 November 2002; Genetic Technologies Corporation Pty Ltd, *Submission G245*, 19 December 2002; Office of the Privacy Commissioner (NSW), *Submission G257*, 20 December 2002; New South Wales Legal Aid Commission, *Submission G282*, 24 December 2002; Department of Health Western Australia, *Submission G271*, 23 December 2002; Association of Genetic Support of Australasia, *Submission G284*, 25 December 2002; NSW Health Department, *Submission G303*, 13 January 2003; Commonwealth Department of Health and Ageing, *Submission G313*, 6 February 2003; Centre for Law and Genetics, *Submission G255*, 21 December 2002; Department of Human Services South Australia, *Submission G288*, 23 December 2002; Human Genetics Society of Australasia, *Submission G267*, 20 December 2002. The Commonwealth Attorney General's Department gave equivocal support, commenting that 'The proposal may be an appropriate method of regulating the availability of do-it-yourself DNA parentage testing': Commonwealth Attorney-General's Department, *Submission G228*, 12 December 2002.

92 Sydney IVF Limited, *Submission G246*, 19 December 2002; New South Wales Legal Aid Commission, *Submission G282*, 24 December 2002; Victorian Bar, *Submission G261*, 20 December 2002.

93 Sydney IVF Limited, *Submission G246*, 19 December 2002.

94 Genetic Technologies Corporation Pty Ltd, *Submission G245*, 19 December 2002.

95 G Edelsten, *Submission G206*, 27 November 2002.

- home collection paternity test involving samples from the father and child ('motherless' testing): \$935.⁹⁶

35.93 The last two listed tests are non-accredited because they are based on home collection of samples, but their costs do not differ substantially from the accredited test. The higher cost of 'motherless testing' is explained in part by the fact that more DNA loci must be tested where samples come from only two individuals.

Inquiry's views

35.94 The availability of direct to the public parentage testing raises a range of concerns, including:

- the possibility of error and fraud where the genetic sample is collected without independent supervision;
- the possibility of sample contamination because the sample may not have been stored correctly or shipped to the laboratory under optimal conditions, or because the chain of custody of the sample cannot be verified;
- the possibility that appropriate informed consent may not have been obtained from the person; and
- the fact that persons are less likely to be referred for genetic counselling.

35.95 In Chapter 11, the Inquiry recommended that the Commonwealth should amend the law to enable the Therapeutic Goods Administration to regulate DNA identification test kits, including for parentage and other kinship testing used in genetic testing provided directly to the public. This recommendation adequately addresses the concerns raised in relation to direct to the public parentage testing, and no further recommendation is required.

Access to offshore parentage testing

35.96 Australian and foreign laboratories market parentage testing services through the media, including the Internet. The availability of offshore testing raises concerns about the ability to regulate ethical, legal and quality assurance standards in the provision of services to Australian consumers. DP 66 asked what steps, if any, should be taken to regulate Internet advertising of home use DNA parentage test kits and testing services.⁹⁷

35.97 Dr Geoffrey Edelsten submitted that his company, Gene-e Pty Ltd, uses an accredited laboratory in the United States to conduct its parentage testing. He suggested that this form of testing is cheaper and more accurate than accredited laboratories in Australia.

⁹⁶ Genetic Technologies Corporation Pty Ltd, *Correspondence*, 15 May 2002.

⁹⁷ Australian Law Reform Commission and Australian Health Ethics Committee, *Protection of Human Genetic Information*, DP 66 (2002), ALRC, Sydney, Question 31–1.

[T]he quality of testing is, it is submitted, of as high a standard as that conducted by laboratories in Australia. The consumer however can obtain this testing at approximately 50% less than that charged by Australian laboratories ... Our testing service provides a higher level of accuracy in paternity as 13 alleles are tested routinely.⁹⁸

35.98 Dr Edelsten stated further that there is no evidence of any detriment caused by current advertising, and noted that Australia is part of the world community. He saw no reason to regulate Internet and other advertising for parentage testing.⁹⁹

35.99 Several submissions emphasised the desirability of regulating Internet advertising of parentage test kits and services,¹⁰⁰ while others noted the difficulty in regulating Internet content.¹⁰¹ Some suggested that if it were not possible to regulate Internet content, there should be greater community and professional education to limit the number of people using the services¹⁰² or to ensure that persons using the services are informed about the desirability of counselling.¹⁰³ By contrast, Privacy NSW suggested that:

the emphasis should be on the proposals to regulate laboratories and the reception of evidence by the courts, rather than attempting to directly influence human behaviour through regulating communication over the Internet. While this does create a risk of driving unprincipled testing practices offshore, it is not clear that imposing restrictions which only extended to Australian based web sites would lead to a significantly different outcome. This is an eventuality that might better be addressed in the future, should the implications of a lack of regulation of on-line advertising become more apparent.¹⁰⁴

35.100 The Inquiry recognises that continued access to offshore parentage testing could undermine the ethical and technical standards recommended in this Report. At the same time, the Inquiry acknowledges the difficulty of regulating Internet content, particularly the services that are provided by foreign companies and are advertised through websites hosted on non-Australian servers. Until such time as 'direct to the public' parentage test kits are regulated by the Therapeutic Goods Administration (see Chapter 11), the Inquiry considers that it would be premature to implement a regime intended to restrict Internet advertising of parentage test kits and testing services.

98 G Edelsten, *Submission G117*, 14 March 2002.

99 G Edelsten, *Submission G206*, 27 November 2002.

100 For example, see New South Wales Legal Aid Commission, *Submission G282*, 24 December 2002; Office of the Privacy Commissioner (NSW), *Submission G257*, 20 December 2002.

101 Centre for Genetics Education, *Submission G232*, 18 December 2002; Human Genetics Society of Australasia, *Submission G267*, 20 December 2002; Institute of Actuaries of Australia, *Submission G224*, 29 November 2002; Office of the Privacy Commissioner (NSW), *Submission G257*, 20 December 2002.

102 Centre for Genetics Education, *Submission G232*, 18 December 2002; NSW Health Department, *Submission G303*, 13 January 2003; Department of Human Services South Australia, *Submission G288*, 23 December 2002; Genetic Technologies Corporation Pty Ltd, *Submission G245*, 19 December 2002; Queensland Government, *Submission G274*, 18 December 2002; A Newson, *Submission G283*, 23 December 2002.

103 NSW Health Department, *Submission G303*, 13 January 2003.

104 Office of the Privacy Commissioner (NSW), *Submission G257*, 20 December 2002.

35.101 In Chapter 12 the Inquiry recommended a new criminal offence where a person submits a sample for genetic testing (including offshore testing) without the consent of the person from whom the sample originated. In addition, in this chapter the Inquiry recommends that non-accredited parentage testing results should not be admissible in legal proceedings in federal, state or territory courts. These recommendations should deter members of the Australian community from using offshore parentage testing services that fail to meet minimum standards of proficiency, reliability and ethics.

Admissibility of parentage test reports

Current law and practice

35.102 DP 66 noted that there is some uncertainty about the admissibility in proceedings under the FLA of a parentage test report that does not comply with the FL Regulations.

35.103 Section 69ZC(1) of the FLA provides that a report made in accordance with the regulations covered by s 69ZB(b) ‘may be received in evidence’ in any proceedings under the Act. Section 69ZB provides that the regulations may make provision about the carrying out of parentage testing procedures under parentage testing orders and about the preparation of reports as a result of carrying out such procedures. Regulation 21M(2) provides that the report must be in accordance with the form prescribed by the FL Regulations, and r 21M(5) provides that the report is taken to be of no effect if completed otherwise than in accordance with r 21M.

Issues and problems

35.104 A question raised during the Inquiry was whether a parentage testing report conducted by a non-accredited laboratory, or by an accredited laboratory that has not adhered to the FL Regulations, might be admissible in proceedings under the FLA.¹⁰⁵ There is little case law on this point.

35.105 In *Re C (No 1)*, the Family Court considered whether the results of parentage testing conducted pursuant to a parentage testing order were admissible despite a failure to comply with regulations regarding the collection, storage and testing of the sample. The court held that the non-compliance rendered the report inadmissible. Fogarty J considered the regulations to be mandatory in their terms and stated that ‘neither the Act nor the regulations seem to provide any discretion or capacity to admit the report notwithstanding non-compliance’.¹⁰⁶

35.106 In *McK v O*, the Family Court considered whether a DNA testing certificate was admissible where testing involved human remains in the absence of a parentage testing order. Mullane J held that the FL Regulations relate to parentage testing

105 This question would not arise if Recommendation 35–1 were adopted, but until such time the issue remains a real one.

106 *Re C (No 1)* (1991) 15 Fam LR 350.

procedures carried out pursuant to parentage testing orders. As the testing was not conducted pursuant to a parentage testing order, s 69ZC(1) did not apply to the testing certificate, which was thus inadmissible in the circumstances.¹⁰⁷

35.107 While the cases referred to above suggest a strict interpretation of the section, the permissive terms in which it is phrased could lead to uncertainty. For example, a party might argue that a non-complying report should be admissible subject to the general rules of evidence.¹⁰⁸

Submissions and consultations

35.108 DP 66 proposed that the FLA should be amended to provide that parentage testing reports are admissible in proceedings under the Act only if made in accordance with the provisions of the FL Regulations.¹⁰⁹

35.109 Several submissions supported the proposal.¹¹⁰ By contrast, the Reliable Parents Inc strongly opposed the proposal. They referred to the Family Court's reluctance to make parentage testing orders and stated that, unless the FLA were amended to provide that orders are made automatically upon application, the proposal could lead to hardship or unfairness for men seeking to rebut the presumption of fatherhood in relation to child support.

Typically, an applicant to the court for paternity testing uses a surreptitious test to demonstrate that he could not be the father. In turn, the court will then order court-supervised testing in order to verify the accuracy of the test submitted by the applicant. Were such surreptitious tests made inadmissible, then it is unlikely that the court would order any testing at all.¹¹¹

Inquiry's views

35.110 The admissibility of reports obtained through unregulated parentage testing is a largely transitional concern. In this chapter, the Inquiry recommends that the Commonwealth should enact legislation to provide that parentage testing may be conducted within Australia only by NATA accredited laboratories, in accordance with NATA accreditation requirements. Once this recommendation has been implemented, unregulated parentage testing would be available only from offshore laboratories.

¹⁰⁷ *McK v O* (2001) FLC 93.

¹⁰⁸ For example, in October 2000 the Chief Justice of the Family Court, Alastair Nicholson, suggested in a TV interview that the Court has a discretion to admit the results of non-accredited parentage testing in certain circumstances subject to the rules of evidence: Lateline, *DNA Testing and the Family Court: Transcript*, ABC TV, <www.abc.net.au/lateline/s200192.htm>, 18 February 2003.

¹⁰⁹ Australian Law Reform Commission and Australian Health Ethics Committee, *Protection of Human Genetic Information*, DP 66 (2002), ALRC, Sydney, Proposal 31–5.

¹¹⁰ Genetic Technologies Corporation Pty Ltd, *Submission G245*, 19 December 2002; Department of Health Western Australia, *Submission G271*, 23 December 2002; Centre for Law and Genetics, *Submission G255*, 21 December 2002; Human Genetics Society of Australasia, *Submission G267*, 20 December 2002; Centre for Genetics Education, *Submission G232*, 18 December 2002.

¹¹¹ Reliable Parents Inc, *Submission G204*, 27 November 2002.

35.111 In the interim, the Inquiry recommends that the Commonwealth should enact legislation to provide that parentage testing reports are not admissible in proceedings under the FLA unless the testing complies with the relevant provisions of the FL Regulations. In practice, this would help to ensure the reliability of parentage test results that are admitted in proceedings, and would deter members of the Australian community from resorting to non-accredited testing by limiting the use to which the test results may be put. Some uses might remain—for example, where a person seeks parentage testing for ‘peace of mind’ reasons only—but in most cases there will be little benefit in seeking non-accredited testing.

35.112 In addition, the States and Territories should consider enacting parallel legislation to ensure that parentage testing reports are not admissible in state or territory proceedings unless the testing complies with NATA accreditation requirements.

Recommendation 35–4. The Commonwealth should enact legislation to provide that parentage testing reports are not admissible in proceedings under the *Family Law Act 1975* (Cth) (FLA) unless the testing complies with the relevant provisions of the FL Regulations. The States and Territories should consider enacting parallel legislation to ensure that parentage testing reports are not admissible in state or territory proceedings unless the testing complies with NATA accreditation requirements.

Consent to parentage testing

35.113 Two types of consent are at issue in the context of parentage testing: consent to taking the genetic sample and consent to performing a genetic test upon that sample. At present, in parentage testing performed under the family law regime, consent appears to be implied from the act of providing the bodily sample and completion of the prescribed affidavit and declaration. In relation to unregulated parentage testing, there appears to be no specific requirement of consent from the person whose bodily sample is taken and tested. Some non-accredited laboratories seek to avoid potential legal liability for testing mail order samples by requiring the customer to warrant that he or she is legally entitled to possession of the samples.¹¹²

35.114 Serious privacy concerns arise from taking a bodily sample from a person, or from his or her personal effects, in order to perform a genetic test on the sample without the person’s knowledge or consent.¹¹³ The following sections consider consent in relation to the testing of adults and children, respectively.

112 For example, DNA Solutions, which markets its parentage testing on the Internet: DNA Solutions Pty Ltd, *DNAnow.com*, <www.dnanow.com/ausssheet.html>, 20 February 2003.

113 See Ch 11 and Ch 12 for more detail.

Decision making by adults

35.115 Depending on the circumstances, parentage testing may be performed using a genetic sample from one or two adults, together with that of a child. When each adult has made an informed and voluntary decision to submit his or her genetic sample for parentage testing, there is no ethical objection to carrying out a genetic test on that person's sample. However, ethical concerns do arise where one adult obtains a genetic sample from another adult and submits it for testing surreptitiously.

35.116 Legal protection against the non-consensual collection and use of an adult's bodily sample for the purpose of parentage testing is currently limited. As discussed in Chapter 12, some protection exists under the common law through the tort of trespass to the person, but this would not apply to the collection of much genetic material—such as hair from combs, saliva from a glass, or cheek cells from a toothbrush.

35.117 Federal privacy legislation also has limited application to the collection of genetic samples by individuals for the purpose of parentage testing.¹¹⁴ First, the collection and use of personal information is exempt under s 16E of the *Privacy Act 1988* (Cth) (*Privacy Act*) where done for the purpose of, or in connection with, a person's personal, family or household affairs. Second, s 7B exempts from the Act acts done by a person other than in the course of a business conducted by the person. While certain aspects of parentage testing might fall outside these exemptions, the majority of contexts would be exempt from the protection of the Act.¹¹⁵

35.118 For the reasons given in Chapter 12, the Inquiry recommends a new criminal offence that would make it unlawful for a person or corporation, without lawful authority, to submit a sample for genetic testing, or conduct genetic testing on a sample, knowing (or recklessly indifferent to the fact) that the person from whom the sample has been taken did not consent to such testing.¹¹⁶ This recommendation would apply to samples taken to determine parentage, as it does in other contexts such as where an employer surreptitiously tests an employee.

35.119 The Inquiry notes that circumstances might also arise in which parentage testing involves a genetic sample obtained from a deceased person—whether taken during his or her lifetime or after death. While it has been held that the FLA does not provide for the making of parentage testing orders in relation to human remains,¹¹⁷ such testing might be conducted pursuant to other lawful authority. In these circumstances, there may be uncertainty as to who has lawful authority to consent to the testing of these human remains.¹¹⁸

114 The question whether genetic samples are 'personal information' for the purposes of the *Privacy Act 1988* (Cth) is discussed in Ch 8.

115 However, once the bodily sample has been forwarded to a private laboratory, the NPPs would apply. See Ch 8 for a full discussion.

116 Recommendation 12–1.

117 *McK v O* (2001) FLC 93.

118 See Sydney IVF Limited, *Submission G246*, 19 December 2002.

Submissions and consultations

35.120 In DP 66, the Inquiry expressed the preliminary view that measures are needed to require laboratories conducting parentage testing to be satisfied that the sample of each adult donor has been supplied for that purpose with appropriate consent.

35.121 DP 66 proposed that NATA should develop accreditation requirements that require laboratories to be satisfied that the sample of each adult donor has been supplied for parentage testing with his or her consent; and that the FL Regulations should be amended to require that the prescribed affidavit and declaration submitted to a laboratory in relation to parentage testing include a signed consent form for each adult donor indicating that the sample has been supplied with his or her consent.¹¹⁹

35.122 Several submissions supported the proposals.¹²⁰ Sydney IVF Limited made a practical suggestion, that:

A signed consent form should require a witness and photographic identification at the time of signing to prevent the likelihood of substitution. The timing of completion of such a consent form, together with the affidavit, requires review ... Sydney IVF recommends the implementation of a consent form, and a time frame of one week prior to provision of the sample for completion of both a consent form and affidavit.¹²¹

35.123 In consultations, NATA expressed general support for the proposal, suggesting that one way to ensure that consent has been given would be through the incorporation of prescribed consent forms into the FL Regulations. NATA could review the content of the consent forms held by laboratories during its periodic reviews, but would not have the capacity to review the validity of the consent given.¹²² In a subsequent submission, NATA emphasised that it does not have expertise in setting requirements for the content of consent forms or the mechanism for obtaining informed consent from individuals. It noted that it may be beyond the expertise of laboratories to 'ensure' that consent had been obtained.¹²³

Inquiry's views

35.124 In order to promote the practice by which laboratories conduct parentage tests only on samples that have been provided with consent, the Inquiry considers that reform of laboratory procedures is warranted. This reform should establish a mechanism by which laboratories can be satisfied that a sample obtained from an adult donor was collected and submitted for testing with the donor's consent.

119 Australian Law Reform Commission and Australian Health Ethics Committee, *Protection of Human Genetic Information*, DP 66 (2002), ALRC, Sydney, Proposals 31–6, 31–7.

120 Centre for Law and Genetics, *Submission G255*, 21 December 2002; Centre for Genetics Education, *Submission G232*, 18 December 2002; Human Genetics Society of Australasia, *Submission G267*, 20 December 2002; Association of Genetic Support of Australasia, *Submission G284*, 25 December 2002; Genetic Technologies generally supported the proposals: Genetic Technologies Corporation Pty Ltd, *Submission G245*, 19 December 2002.

121 Sydney IVF Limited, *Submission G246*, 19 December 2002.

122 National Association of Testing Authorities Australia, *Consultation*, Melbourne, 21 October 2002.

123 National Association of Testing Authorities Australia, *Submission G273*, 18 December 2002.

35.125 The Inquiry recommends that NATA develop accreditation requirements that require laboratories to be satisfied that the sample of each adult donor has been supplied for parentage testing with his or her consent; and the Commonwealth should amend the FL Regulations to insert a prescribed consent form in relation to parentage testing for each adult donor indicating that the sample has been supplied with his or her consent. In developing the prescribed consent form, the Commonwealth should consider the need for the person providing the bodily sample to show photographic identification to confirm that he or she is the person whose name appears on the consent form. This would minimise the opportunity for sample substitution.

35.126 The Inquiry recognises that there might be circumstances in which a person might seek to use the bodily sample of a deceased person in relation to parentage testing. In these circumstances, provision should be made for obtaining consent from the deceased's next-of-kin or other authorised person (such as an executor or legal representative) in relation to the parentage testing.

Recommendation 35–5. NATA should develop accreditation requirements that require laboratories to be satisfied that the sample of each adult donor has been supplied for parentage testing with his or her consent. Provision should also be made for obtaining consent from the deceased's next-of-kin or other authorised person in relation to a sample from a deceased person.

Recommendation 35–6. The Commonwealth should amend the FL Regulations to insert a prescribed consent form in relation to parentage testing for each adult donor indicating that the sample has been supplied with his or her consent. Provision should also be made for obtaining consent from the deceased's next-of-kin or other authorised person in relation to a sample from a deceased person.

Decision making by mature children

35.127 Because parentage testing is a form of kinship testing, it necessarily requires a comparison of genetic samples from at least two persons. In most circumstances, one of those persons will be a child, which is taken here to mean a person under the age of 18 years. Where the offspring in question is 18 years or older, the question of consent to sampling and testing must be answered in the same way as for other adults.

35.128 However, where one of the parties to be tested is a minor, how is the consent of the child to be assessed? In this section, the Inquiry examines the position of 'mature' children; that is, those of a sufficient age and maturity to be able to make an informed decision about parentage testing on their own behalf. In the next section, the Inquiry examines the position of children who, by reason of their age or mental capacity, lack that degree of maturity.

35.129 The current law draws a bright line between individuals of 18 years of age or more, who are treated as adults, and those under 18 years, for whom decisions are generally made by a parent or guardian. The FLA provides that a parentage testing procedure may be conducted on a child under the age of 18 years with the consent of a parent, guardian or person who, under a specific issues order, is responsible for the child's long term or day-to-day care, welfare and development.¹²⁴ There is no provision for children to consent, and a person who carries out a parentage testing procedure with parental consent will not be liable for any civil or criminal action.¹²⁵ Where parentage testing is conducted outside this regulatory framework there is no specific requirement that the child, or his or her parent, consent to the procedure.

35.130 The Inquiry recognises that children develop at different rates in terms of emotional maturity and intellectual understanding. Many children reach a sufficient level of maturity to form their own opinions on important matters affecting their welfare before they reach the age of 18 years.

35.131 Concerns arise where a mature child's wishes do not accord with those of the parent or other person authorised to give or withhold consent on the child's behalf.¹²⁶ The right of a child with sufficient maturity and understanding to form his or her own views has been recognised in the *Convention on the Rights of the Child*, to which Australia is a party. Article 12(1) provides that:

States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.¹²⁷

35.132 This approach is reflected in legislation in several States, and in common law principles regarding a child's consent to medical treatment.¹²⁸ The Inquiry supports the general principle that some minors are capable of making, and should be entitled to make, their own decisions about whether to provide a sample for parentage testing.

Options for reform

35.133 In considering whether children under 18 years of age should be able to make their own decisions regarding parentage testing, two models of reform present themselves:

¹²⁴ *Family Law Act 1975* (Cth) s 69Z(2). See also *Family Law Regulations 1984* (Cth) r 21F(3)(a), which provides that the prescribed donor affidavit and declaration may be completed only by a person responsible for the long term care, welfare and development of the child.

¹²⁵ *Family Law Act 1975* (Cth) s 69ZA(1).

¹²⁶ For example, see *In the Marriage of F and R* (1992) 15 Fam LR 533.

¹²⁷ *Convention on the Rights of the Child*, opened for signature 20 November 1989, UNTS 1588, (entered into force on 16 January 1991).

¹²⁸ See *Secretary, Department of Health & Community Services v JWB (Marion's Case)* (1992) 175 CLR 218. While the *Privacy Act* does not specify an age at which young persons can make their own privacy decisions, the *Guidelines to the National Privacy Principles* reflect a similar approach to that in the *Convention on the Rights of the Child*: Office of the Federal Privacy Commissioner, *Guidelines to the National Privacy Principles* (2001), OFPC, Sydney, 15.

- the consent of mature children should be based on the understanding and maturity of the particular child in question; or
- the consent of mature children should be based them having attained a specified age at which they are presumed to have capacity, subject to the presumption being rebutted in particular cases.

35.134 The first of these options has the advantage of accounting for differing rates of development among children, but the disadvantage of requiring a potentially time-consuming determination of a child's capacity on a case-by-case basis. This approach has been adopted in the common law with respect to a child's consent to medical treatment. Where a child has sufficient understanding and intellectual capacity to enable full comprehension of the nature and purpose of the treatment, he or she may give or withhold consent to that treatment.¹²⁹ If a child has such capacity, parental consent is not required. A similar position is adopted in relation to child consent to participation in medical research.¹³⁰

35.135 The second option has the advantage of simplicity—it avoids the need for minors who have attained the specified age to obtain independent assessments of their capacity, which might be costly and time consuming. This approach has been adopted by several Australian States in legislation relating to consent to medical treatment.¹³¹ It has also been adopted in the United Kingdom's voluntary code of practice on genetic paternity testing services: in England, Wales and Northern Ireland, a child aged 16 years or over may give or withhold consent to paternity testing on his or her own behalf.¹³²

35.136 The FLA previously specified a presumed age of capacity in relation to children's wishes. The now repealed s 64(1)(b) provided that:

where the child has attained the age of 14 years, the Court shall not make an order under this Part contrary to the wishes of the child unless the Court is satisfied that, by reason of special circumstances, it is necessary to do so.

¹²⁹ *Secretary, Department of Health & Community Services v JWB (Marion's Case)* (1992) 175 CLR 218.

¹³⁰ National Health and Medical Research Council, *National Statement on Ethical Conduct in Research Involving Humans* (1999), NHMRC, Canberra cl 4.2. In addition, a Human Research Ethics Committee must not approve, and consent cannot be given for, research which is contrary to the child or young person's best interests: cl 4.3.

¹³¹ *Minors Property and Contracts Act 1970* (NSW) s 49; *Consent to Medical Treatment and Palliative Care Act 1995* (SA) ss 6, 12. See also NSW Commission for Children & Young People, *Consent by Minors to Medical Treatment* (2001) unpublished [19.01], [25.07]. In August 2002 the NSW Law Reform Commission received terms of reference to inquire into the laws relating to the consent of minors to medical treatment.

¹³² Group on Genetic Paternity Testing Services, *Code of Practice and Guidance on Genetic Paternity Testing Services*, (2001) Department of Health, <www.doh.gov.uk/genetics/paternity.htm>, 19 February 2003.

35.137 However, the Family Law Council (FLC) recommended in 1978 that the age requirement be removed.¹³³ In its submission, the FLC explained its reasons, namely, that the presumed age was peremptory and attached too much significance and weight to the wishes of the child; often resulted in parents exerting undue influence on the child; placed the responsibility and burden of an ‘adult’s decision’ onto the shoulders of a child; and legislated for an age of maturity when there appeared to be considerable divergence of opinion on the part of psychiatrists, social workers and psychologists about the age at which a child has the capacity to make such a decision.¹³⁴

Submissions and consultations

35.138 DP 66 proposed a two-tiered approach to the regulation of decision making in relation to children. First, younger children, namely, those under 12 years of age, should be regarded as lacking the capacity to make a free and informed decision in relation to parentage testing. For these children, a decision as to whether they should participate in parentage testing generally should be made by the adults who have parental responsibility in relation to the child, in accordance with the proposals described in the following section. Second, children between the ages of 12 and 18 years should be independently assessed to determine whether they have sufficient maturity to comprehend the nature and purpose of the parentage testing, in order to make a decision on their own behalf.

35.139 In relation to the second tier, DP 66 proposed that the child’s maturity should be assessed by two independent professionals who have known the child for not less than two years. In addition, NATA should develop accreditation requirements to ensure that laboratories conducting DNA parentage tests obtain the required child consent.¹³⁵

35.140 Most of the submissions that addressed these proposals expressed support for them.¹³⁶ The Centre for Genetics Education generally supported the proposals but questioned the age being set at 12 years.¹³⁷ The Queensland Government noted that children at the proposed minimum age of 12 years might be too young and inexperienced to fully comprehend the implications of genetic testing for parentage.¹³⁸

133 Family Law Council, *Children’s Wishes: Section 64(1)(b) of the Family Law Act 1975 — Working Paper No 2* (1978) Commonwealth of Australia, 10–11, 14.

134 Family Law Council, *Submission G202*, 28 November 2002.

135 Australian Law Reform Commission and Australian Health Ethics Committee, *Protection of Human Genetic Information*, DP 66 (2002), ALRC, Sydney, Proposals 31–8, 31–9.

136 Department of Health Western Australia, *Submission G271*, 23 December 2002; Centre for Law and Genetics, *Submission G255*, 21 December 2002; Human Genetics Society of Australasia, *Submission G267*, 20 December 2002; Association of Genetic Support of Australasia, *Submission G284*, 25 December 2002; Centre for Genetics Education, *Submission G232*, 18 December 2002. Privacy NSW commented that it ‘supports the general intent of these recommendations to the extent that they recognise children’s right to privacy and their right to be consulted as far as reasonably practicable’: Office of the Privacy Commissioner (NSW), *Submission G257*, 20 December 2002.

137 Centre for Genetics Education, *Submission G232*, 18 December 2002.

138 Queensland Government, *Submission G274*, 18 December 2002.

Several submissions emphasised the importance of counselling for children during this process.¹³⁹

35.141 Genetic Technologies suggested that the use of independent professionals may not be appropriate for several reasons. First, it is unlikely that professionals such as teachers would wish to be involved in these matters. Second, involving two external professionals who have known the child for two years may exacerbate the already sensitive nature of the situation, and could potentially breach a family's privacy or confidentiality. Third, it would be unreasonable to expect the laboratory to verify the competence of the person providing the reference.¹⁴⁰ The Inquiry notes that it did not intend laboratories to have this role.

35.142 The FLC also expressed concerns about the use of independent professionals to assess a child's maturity:

The strong preference expressed in the [Family Law Council's 1978] Working Paper to ascertain the child's wishes was for the use of a welfare report prepared by a Family Court Counsellor. The rationale for this was that lawyers, including judges, 'do not have the necessary expertise to undertake such a sensitive role'. The Working Paper also urges that steps be taken to ensure that a child, prior to expressing a wish, should understand the meaning and significance of the decision. And this function is seen as being the preserve of lawyers, and complementary to the role of the Court Counsellor.¹⁴¹

35.143 The FLC considered that the proposal contained too many hurdles for a mature child to override parental consent and did not assure that the child's consent was voluntary. The Council suggested that the person conducting the assessment should consider the child's maturity *and* genuineness of consent. The Council also noted that:

the proposed procedure requires disclosure of extremely sensitive material to a professional who must have known the child for at least two years (teacher, social worker, doctor, or minister) and who will, it is presumed, have an on-going relationship with the child. This is seen as inappropriate precisely because of the on-going relationship with the child ... Council also proposes a narrowing of the proposed qualifications required of the professionals.¹⁴²

35.144 The Victorian Bar considered that the proposal gave insufficient weight to the practical difficulties in assessing the child's maturity:

the discussion concentrates on the capacity of the child to make the decision at the expense of the more difficult question, i.e. whether the child has the capacity to deal with the possible outcomes of the testing. It is submitted that children should not be in a position to give consent until age 18.¹⁴³

139 Association of Genetic Support of Australasia, *Submission G284*, 25 December 2002; Sydney IVF Limited, *Submission G246*, 19 December 2002; Centre for Genetics Education, *Submission G232*, 18 December 2002.

140 Genetic Technologies Corporation Pty Ltd, *Submission G245*, 19 December 2002.

141 Family Law Council, *Submission G202*, 28 November 2002.

142 Ibid.

143 Victorian Bar, *Submission G261*, 20 December 2002.

35.145 The Reliable Parents Inc noted the potential for parental pressure to be applied to a child when making his or her decision:

The practical experience of litigants in the Family Court is that in situations where the onus is placed upon the child to express a viewpoint, the child is invariably subjected to pressures from one or both of the parents. Although consent by a child of twelve may seem to be giving the child some responsibility for his or her own genetic information and privacy, this is greatly outweighed by the potential for divisive pressures to be applied to the child. The use of 'Court Experts' to determine whether such permission or refusal is freely given is also fraught and expensive ...¹⁴⁴

35.146 The FLC proposed an alternative framework for regulating mature children's consent to parentage testing, in which every child aged 12 years and over must sign a consent form. Where both parents provide samples and consent forms with the child's sample and consent form, there should be no need for proof of the child's capacity and understanding. However, where only one parent provides a sample and consent form, then the child's consent form must be accompanied by an assessment of maturity and informed consent completed by either a family and child counsellor, a social worker or a psychologist. Where the child withholds consent, the parent or parents must seek a court order that the test is in the child's best interests. Where only one parent's sample and consent are provided and the child does not have capacity, both parents' samples and consent should be required—or alternatively, a court order that parentage testing be carried out.¹⁴⁵

Inquiry's views

35.147 The Inquiry is of the view that the law should recognise a child's right to give or withhold consent to the testing of his or her own genetic sample where the child has sufficient maturity and understanding of the process and its implications to safeguard his or her own interests. However, society also has an underlying responsibility to protect children from their own misjudgement where they do not sufficiently comprehend the implications of the testing.¹⁴⁶

35.148 The Inquiry does not support a presumed age of capacity approach in relation to child consent to parentage testing. In practice, it would be difficult to settle on any particular age at which a child may safely be presumed to have sufficient maturity to make an informed decision in this context. Moreover, this approach appears to be contrary to the family law experience, where an early attempt to use this method was abandoned. On the other hand, no child under the age of 12 years can reasonably be expected to have the capacity to understand the implications of, and make an informed decision about, participation in parentage testing. The Inquiry recommends that all children under 12 years should be dealt with as minors in accordance with the recommendations in the following section of this chapter.

144 Reliable Parents Inc, *Submission G204*, 27 November 2002.

145 Family Law Council, *Submission G202*, 28 November 2002.

146 NSW Commission for Children & Young People, *Consent by Minors to Medical Treatment* (2001) unpublished [15.01].

35.149 In relation to the testing of children between the ages of 12 and 18 years, the Inquiry continues to support the general approach that was canvassed in DP 66, but subject to some modifications. Children within this age band should be assessed by an independent professional for their maturity to make an informed decision about their participation in parentage testing. Several submissions criticised the original proposal regarding independent assessment on the basis that some of the named professionals might not wish to be involved in these matters, and that utilising professionals who have known the child for at least two years could have significant privacy implications for the child and the family. With these considerations in mind, the Inquiry supports the views of the FLC that the persons who are most appropriately qualified to undertake this assessment are family and child counsellors (as defined under the FLA), social workers and psychologists.

35.150 In addition, the Inquiry recognises the importance of ensuring that the child's consent is freely given, particularly within the context of family law matters where undue emotional pressure could be placed on the child by one or both parents. The Inquiry thus recommends that the independent professional who assesses the child must assess not only his or her maturity to consent, but the voluntariness of the child's decision to give or withhold consent in the circumstances of the particular case.

35.151 Where a child between the ages of 12 and 18 years is independently assessed to be sufficiently mature to make a free and informed decision, the child may give or withhold consent to participation. However, in the event that the child withholds consent, there should be a safety valve to avoid an unreasonable veto by the child. For this reason, the Inquiry considers that the person seeking testing should be able to apply to a court for an order granting consent on behalf of the child. Persons seeking such court orders could apply to the Family Court or Federal Magistrates Service (where parentage is an issue in proceedings pursuant to the FLA or CSAA), or to a state or territory Supreme Court in other cases. In deciding whether to grant the order, the court should consider, amongst other things, whether parentage testing would be in the child's interests.

35.152 Where a child between the ages of 12 and 18 years is independently assessed to lack insufficient maturity to make a free and informed decision, consent to the child's participation must be given in accordance with the recommendations in the following section of this chapter.

35.153 The Inquiry notes that the FLC had proposed an alternative model by which parentage testing could proceed where samples of both putative parents and the child were submitted with signed consent forms. On this model, the child's maturity to consent would not be independently assessed unless his or her sample was submitted with the sample of only one parent. However, the Inquiry considers that this model does not adequately protect a child against parental pressure to consent to testing where both parents wish to proceed with it. This additional protection for the child is unlikely to create any difficulties in practice: as the data quoted below indicates, parentage testing of 12–18 year olds is uncommon, and testing of such children where both parents agree is even more so.

35.154 Finally, the Inquiry recommends that NATA develop accreditation requirements to ensure that laboratories conducting DNA parentage tests obtain the written consent of each mature child.

Recommendation 35–7. The Commonwealth should enact legislation to provide that where a child: (a) has attained 12 years of age; and (b) has sufficient maturity to make a free and informed decision, testing of the child’s genetic sample can be performed only with the written consent of the child or pursuant to a court order. The child’s maturity, and the voluntariness of the child’s consent, should be assessed by an independent professional, being a family and child counsellor as defined under the FLA, a social worker or a psychologist.

Recommendation 35–8. NATA should develop accreditation requirements to ensure that laboratories conducting DNA parentage tests obtain the written consent of each mature child in accordance with Recommendation 35–7.

Decision making on behalf of immature children

35.155 Many minors will not have the capacity to make an informed decision on their own behalf about submitting a genetic sample for parentage testing. This may arise because, under the Inquiry’s recommendations, they are under 12 years of age or because they have attained 12 years but lack the maturity necessary to make an informed decision. In these circumstances it is necessary to consider who should be authorised to make a decision on behalf of the child.

35.156 Genetic Technologies advised the Inquiry that the average age of a child undergoing parentage testing at its laboratories is below school age.¹⁴⁷ Sydney IVF Limited provided the Inquiry with statistics regarding parentage testing conducted at its laboratory over a period of 18 months. According to their data, the age of children undergoing paternity testing ranged from birth to 54.5 years; the average age of a child was 6.3 years, and the median age was 2.5 years. Moreover, 84% of children tested were 12 years or younger, while 12% were one year or younger.¹⁴⁸ Extrapolating from the data provided by these two large laboratories, it is safe to assume that the overwhelming majority of children undergoing parentage testing will not have sufficient maturity or understanding to make the decision on their own behalf.

Regulation and practice regarding parental consent

35.157 The FLA currently requires the consent of *only one* parent, guardian or carer in relation to the conduct of a parentage testing procedure on a child under 18 years. There is no specification about which parent must give consent. Where parentage testing is conducted outside the family law framework, there is no formal regulation of parental consent.

147 Genetic Technologies Corporation Pty Ltd, *Consultation*, Melbourne, 21 October 2002.

148 Sydney IVF, *Correspondence*, 12 December 2002.

35.158 In practice, these permissive rules may be supplemented by the ethical policies developed by individual testing laboratories. Current practice reveals widespread variations among laboratories (whether accredited or non-accredited) as to which parents must be tested, and who may give parental consent on behalf of a child. Several laboratories require evidence of the mother's consent in all cases. Some accredited laboratories require the bodily samples of a mother, putative father and child (if under 18 years) for paternity testing. Some accredited laboratories conduct 'motherless' paternity testing provided they receive evidence of the mother's consent; other laboratories conduct 'motherless' testing without requiring evidence of the mother's consent to, or knowledge of, the testing.

35.159 A *Sydney Morning Herald* article in 2000 reported that 'paternity testing laboratories in Australia are routinely analysing children's DNA without their mothers' knowledge or approval'. The article reported that at least 80% of one non-accredited laboratory's paternity tests were requested by the father and conducted without the mother's permission.¹⁴⁹

35.160 Genetic Technologies advised that it currently offers the following types of parentage tests without the consent of all persons with parental responsibility for a child:

- 'motherless' testing, where a father tests only samples from himself and his child, without the mother's involvement;
- 'fatherless' testing, where a mother commissions a test using samples from herself, her child and a man who is not the child's social father; or where a pregnant woman commissions a pre-natal parentage test without informing her partner, instead involving a third party; and
- testing in immigration situations and for other government departments where one parent cannot be located, or due to logistical reasons cannot provide a sample.¹⁵⁰

Issues and problems

35.161 A central question is whether the consent of an immature child may be given on his or her behalf by one parent or carer, or whether the consent of both parents or carers should be required. One of the principles underlying the FLA is that, except when it would be contrary to a child's best interests, parents share duties and responsibilities concerning the care, welfare and development of their children. However, s 61C(1) provides that, subject to a court order, each of the parents of a child under 18 years has parental responsibility for the child. This leads to uncertainty about

149 D Smith, 'Mothers Kept in the Dark on Paternity Tests', *The Sydney Morning Herald*, 27 March 2000.

150 Genetic Technologies Corporation Pty Ltd, *Submission G245*, 19 December 2002.

whether parental responsibilities for children should be exercised jointly or independently.¹⁵¹

35.162 In October 2000, the Chief Justice of the Family Court, Alastair Nicholson, expressed concerns that current practice may not reflect the joint nature of parental responsibility for a child. In an interview on the ABC program *Lateline*, he stated that:

The law is pretty clear that both parents, unless the court otherwise orders, are entitled to take part in decisions relating to children, such as long term decisions such as medical treatment as so on. And it seems to me that for one parent to in effect go off and supply a piece of the child's DNA to a laboratory without regard to the other is probably in breach of the Act, and it's certainly in breach of the other parent's rights in relation to the child, or really the child's rights.¹⁵²

Submissions and consultations

35.163 DP 66 proposed that legislation should require that, where a child does not have sufficient maturity to make a free and informed decision whether to submit a genetic sample for parentage testing, such testing can be performed only with the written consent of *all persons* with parental responsibility for the child, or pursuant to other lawful authority. Where one person with parental responsibility withholds consent or cannot reasonably be contacted, a court should be authorised to make a decision on behalf of the child. In addition, NATA should develop accreditation requirements to ensure that laboratories conducting DNA parentage tests obtain the required parental consents.¹⁵³

35.164 The Inquiry received many submissions that, although not specifically addressing these proposals, strongly asserted a man's right to test the parentage of his presumed child without obtaining the mother or child's consent.¹⁵⁴ These submissions suggested that a man has an inherent right to test the biological paternity of his presumed child, particularly where he is financially liable for the child through child support or other arrangements. A recurrent theme was that in most cases a woman knows that she is the biological mother of her child, while a man cannot be certain that he is the biological father unless this is scientifically confirmed.

151 See generally the discussion in H Finlay, R Bailey-Harris and M Otlowski, *Family Law in Australia* (5th ed, 1997) Butterworths, Sydney [7.58]–[7.60]. The Family Court has provided some guidance on this point. In *B and B*, the Full Court commented that where parents have separated, as a matter of practical necessity either parent will have to make individual decisions when they have sole care of the children. However, both parents should consult in relation to major issues such as major surgery and place of education: *B and B* (1997) 21 Fam LR 676.

152 *Lateline*, *DNA Testing and the Family Court: Transcript*, ABC TV, <www.abc.net.au/lateline/s200192.htm>, 18 February 2003.

153 Australian Law Reform Commission and Australian Health Ethics Committee, *Protection of Human Genetic Information*, DP 66 (2002), ALRC, Sydney, Proposals 31–10, 31–11.

154 For example, DNA Solutions, *Submission G162*, 30 May 2002; G Edelsten, *Submission G117*, 14 March 2002; *Confidential Submission G163CON*, 27 May 2002; C Andersen, *Submission G002*, 14 January 2002; J Baxter, *Submission G280*, 27 December 2002; Men's Rights Agency, *Submission G213*, 29 November 2002; Reliable Parents Inc, *Submission G204*, 27 November 2002; Men's Fraternity WA Inc, *Submission G234*, 17 December 2002; Family Law Reform Association of NSW, *Submission G205*, 27 November 2002.

35.165 Many submissions argued that a woman who knowingly has misattributed her child's paternity would be unwilling to consent to parentage testing; and a man would be unwilling to go to court for an order that the child be tested due to personal reasons, the cost involved, or the Family Court's perceived bias against men in family law matters.¹⁵⁵ DNA Solutions Pty Ltd, a company that offers non-accredited DNA parentage testing, submitted:

We have evidence to illustrate that many people avoid courts due to cost and fear of 'losing' or fear or resentments or humiliation by the opposing party. We know that many persons will avoid DNA testing if forced to move through these channels ... Enforcing fathers to front the court is certainly not always the most sensitive method, and not always in the best interests of the child.¹⁵⁶

35.166 Several submissions suggested that the Inquiry's proposal would encourage consumers to seek offshore parentage testing services.¹⁵⁷ Several submissions suggested that the Inquiry's proposal might lead to an alternative harm, being the potential disruption of family life or relationships where partners must disclose their suspicions about parentage. For example, Genetic Technologies commented that:

Fathers usually undertake testing with the presumption that the child is theirs, and in 9 out of every 10 cases, this presumption is confirmed—notably a much lower rate of non-paternity than we observe with parentage tests where all family members are involved. ... the rates of non-paternity in tests without the involvement of all parties are significantly less (around half) than those observed in testing where both parents have given consent. Our experience has shown that requests for father/child testing are more likely to be used to reassure fathers with nagging doubts, rather than being indicative of families where a relationship has already broken down.¹⁵⁸

35.167 The differential rates of non-paternity were confirmed by a submission received from Ainsley Newson. Her research indicated that a large provider of parentage testing services reported that its rate of non-paternity in motherless tests was 10%, whereas the rate for tests involving all parties was 22%; and a smaller accredited laboratory reported that its rate of non-paternity for motherless tests was 11%, while its rate with traditional testing was 31.6%.¹⁵⁹

35.168 Many submissions supported the Inquiry's proposals.¹⁶⁰ The Centre for Law and Genetics commented that the consent framework is consistent with the current

155 For example, Genetic Technologies Corporation Pty Ltd, *Submission G245*, 19 December 2002; Men's Rights Agency, *Submission G213*, 29 November 2002; NT Office Status of Family, *Submission G229*, 12 December 2002.

156 DNA Solutions, *Submission G162*, 30 May 2002. See also Genetic Technologies Corporation Pty Ltd, *Submission G245*, 19 December 2002; A Newson, *Submission G283*, 23 December 2002.

157 For example, see Genetic Technologies Corporation Pty Ltd, *Submission G245*, 19 December 2002; A Newson, *Submission G283*, 23 December 2002.

158 Genetic Technologies Corporation Pty Ltd, *Submission G245*, 19 December 2002.

159 A Newson, *Submission G283*, 23 December 2002.

160 Centre for Law and Genetics, *Submission G255*, 21 December 2002; Office of the Privacy Commissioner (NSW), *Submission G257*, 20 December 2002; Human Genetics Society of Australasia, *Submission G267*, 20 December 2002; New South Wales Legal Aid Commission, *Submission G282*, 24 December 2002; Association of Genetic Support of Australasia, *Submission G284*, 25 December 2002; NSW Health Department, *Submission G303*, 13 January 2003; Department of Health Western Australia, *Submission G271*, 23 December 2002; Institute of Actuaries of Australia, *Submission G224*, 29 November 2002.

development of family law towards openness, parental responsibility and the interests of the child.¹⁶¹ The Human Genetics Society of Australasia generally supported the proposals but commented that:

With reference to parentage testing involving the collection of a sample from a child, this may present some problems to accredited laboratories. Ascertaining who are ‘all persons with parental responsibilities’ ... should not be the responsibility of the laboratory. Should there be additional criminal liability for falsely representing who are ‘all persons with parental responsibilities’?¹⁶²

35.169 The Commonwealth Attorney-General’s Department commented that it would need to consider in more detail the basis upon which the court might grant an order—that is, whether the ‘best interests of the child’ should be the paramount consideration or whether the court should assess the interests of all the affected parties.¹⁶³ The FLC also commented on the potential application of the ‘best interests’ principle in relation to parentage testing.¹⁶⁴

Inquiry’s views

35.170 The Inquiry is of the view that all those with parental responsibility for a child should be required to give consent to parentage testing on behalf of the child. This recognises that parents share duties and responsibilities concerning the care, welfare and development of children.

35.171 This approach would protect children against testing by one parent, without the knowledge or consent of the other parent. This is particularly important because the implications of parentage testing for the whole family may make it difficult for parents to approach the question of the child’s interests with impartiality. This approach would also eliminate the perceived disparity in access to accredited testing by ensuring that one parent is not favoured as a primary carer, for the purposes of consent, over another parent.¹⁶⁵

35.172 One argument raised against the Inquiry’s proposal was that ‘motherless testing’ allows a man to confirm his child’s paternity for reasons of ‘peace of mind’. If the man were to alert his partner or child to his doubts about paternity, this could create tension, potentially destroying family relationships. According to this argument, it is better for the man to obtain testing without notifying other family members, and in the majority of cases (where paternity is confirmed), no harm would be done.

161 Centre for Law and Genetics, *Submission G255*, 21 December 2002.

162 Human Genetics Society of Australasia, *Submission G267*, 20 December 2002.

163 Commonwealth Attorney-General’s Department, *Submission G228*, 12 December 2002.

164 Family Law Council, *Submission G202*, 28 November 2002.

165 This approach is also consistent with current practice in relation to a child’s participation in medical research. The National Health and Medical Research Council’s National Statement on Ethical Conduct in Research Involving Humans provides that consent to participation in research is necessary from both parents, other than in exceptional circumstances (or any organisation or person required by law): National Health and Medical Research Council, *National Statement on Ethical Conduct in Research Involving Humans* (1999), NHMRC, Canberra cl 4.2. In addition, the consent of the child is required where he or she has sufficient competence to make this decision.

35.173 The Inquiry accepts there is some force to this argument but ultimately cannot accept it as a matter of principle. In essence, the argument suggests that the father's curiosity about biological paternity is a more important interest than the child's right to the integrity of his or her person. A similar argument might be made by an employer wishing to conduct secret genetic testing on its workforce to identify those workers with a susceptibility to a disease that might manifest during their term of employment. The employer might do so due to nagging doubts about the impact of its workers' ill health on their future well being or on the company's future costs. For the great majority of workers who are found to have no relevant genetic susceptibility, the employer might argue that 'no harm was done'.

35.174 This form of non-consensual testing breaches the workers' basic privacy rights and personal autonomy. The same applies to a child in relation to parentage testing, whether or not the child understands these implications at the time. In addition, such testing deprives the other parent of his or her right to make important decisions affecting the child's development.¹⁶⁶

35.175 The Inquiry recognises that in practice situations may arise in which one person with parental responsibility for an immature child will refuse consent to the child's involvement in parentage testing, despite the other parent's consent. Situations may also arise in which one person with parental responsibility cannot be contacted despite reasonable efforts to do so.

35.176 In each of these circumstances, the consenting parent should have the right to apply to a court for determination of the issue through an order granting consent on behalf of the child; and in making this determination, the court should have regard to the interests of the child. One of those interests, as recognised by the FLA, is the child's right to know both parents, except when it would be contrary to a child's best interests.¹⁶⁷ However, consistent with existing family law, the child's interests need not be 'paramount' in the sense of trumping all other considerations in the context of parentage testing.¹⁶⁸

35.177 The requirement of court intervention to resolve a stalemate between parents might be thought by some to be too bureaucratic and to impose unnecessary hurdles in the path of an adult who seeks to have a paternity issue resolved. However, where agreement is not possible, a court provides a neutral arbiter, which is able to assess the interests of all the affected parties.

35.178 Several submissions suggested that the cost of court proceedings would constitute a significant deterrence to obtaining parentage testing. The Australian Law Reform Commission expressed concerns about the Family Court's processes in its

166 See Ch 11 and Ch 12 for more discussion of the implications of nonconsensual genetic testing.

167 *Family Law Act 1975* (Cth) s 60B(2)(a).

168 The 'best interests of the child' principle is the paramount concern in a number of contexts arising under the FLA, but this does not include parentage testing. While the paramount welfare principle did apply to all proceedings under Pt VII of the FLA for several years, the principle has had more limited application since 1991: A Dickey, 'The Paramount Welfare Principle and Parentage Tests' (1993) 67 *Australian Law Journal* 47, 49.

report on the federal civil justice system.¹⁶⁹ However, the establishment of the Federal Magistrates Service in 1999 now provides an alternative forum for cases to proceed with less cost and formality than the Family Court.

35.179 Some submissions suggested that the Family Court has at times exercised its discretion against making parentage testing orders. After reviewing the relevant case law, the Inquiry considers that the test applied by the courts in exercising this discretion is a fair one. If an applicant does not have an 'honest, bona fide and reasonable doubt' as to the child's parentage, the Inquiry believes the test should not be ordered. Indeed, if it is true that only about 10% of 'motherless' tests disclose misattributed paternity, a significant number of men might be seeking such testing without any reasonable grounds to doubt their paternity.

35.180 The Inquiry recommends that the Commonwealth should enact legislation to require that, where a child does not have sufficient maturity to make a free and informed decision whether to submit a genetic sample for parentage testing, such testing can be performed only with the written consent of all persons with parental responsibility for the child, or pursuant to a court order. Where one person with parental responsibility withholds consent or cannot reasonably be contacted, a court should be authorised to make a decision on behalf of the child.

35.181 In addition, the Inquiry recommends that NATA develop accreditation requirements to ensure that laboratories conducting parentage tests obtain, in relation to each child's sample, the written consent of all persons with parental responsibility for the child.

Recommendation 35–9. The Commonwealth should enact legislation to provide that where a child is:

- (a) under 12 years of age; or
- (b) 12 years of age or over but less than 18 years of age and does not have sufficient maturity to make a free and informed decision whether to submit a genetic sample for parentage testing;

such testing can be performed only with the written consent of all persons with parental responsibility for the child, or pursuant to a court order. Where one person with parental responsibility withholds consent or cannot reasonably be contacted, a court should be authorised to make a decision on behalf of the child.

¹⁶⁹ See Australian Law Reform Commission, *Managing Justice: A Review of the Federal Civil Justice System*, Report 89 (2000), ALRC, Sydney.

Recommendation 35–10. NATA should develop accreditation requirements to ensure that laboratories conducting DNA parentage tests obtain, in relation to each child's sample, the written consent of all persons with parental responsibility for the child, in accordance with Recommendation 35–9.

Counselling and disclosure of results

Current law and practice

35.182 The provision of counselling before and after parentage testing is an important means of ameliorating the emotional impact of parentage testing and maintaining existing family relationships. By undergoing counselling before engaging in parentage testing, a child may gain an understanding of the reasons his or her parent is seeking the test and may discuss the possible impact of the test results on any existing relationships with that parent. Similarly, a parent may gain a better understanding of the consequences of the test for his or her relationship with the child or with the other parent.

35.183 At present, the FLA provides for counselling in a number of contexts, such as in proceedings relating to children.¹⁷⁰ Indeed, a court exercising jurisdiction in proceedings relating to children is obliged to consider whether or not to advise the parties about counselling in order to assist family members to adjust to the consequences of a court order.¹⁷¹ In contrast, where parentage testing is conducted outside the family law framework, there is no requirement that those involved obtain counselling before or after testing.

35.184 It is difficult to assess how many persons undergoing parentage testing have an effective opportunity to be counselled. The Inquiry understands that neither accredited nor non-accredited laboratories commonly provide counselling services. Several accredited laboratories have on-site counsellors available, and several laboratories refer clients to other counselling services, or forward the test report to the client's medical or legal practitioner in the expectation that they will provide counselling, if necessary.

35.185 Vern Muir, director of non-accredited DNA Solutions Pty Ltd, advised the Inquiry that his company's policy is to have persons dealing with clients undergo a qualified counselling course.¹⁷² Dr Geoffrey Edelsten, director of non-accredited Gene-e Pty Ltd, advised the Inquiry that all putative fathers who discover that they are not the biological father of their child are offered counselling. He stated:

170 *Family Law Act 1975* (Cth) ss 62C–62E.

171 *Ibid* s 62B(2).

172 DNA Solutions, *Submission G162*, 30 May 2002.

There has not been one case of over 250 clients who have been offered counselling where this has been requested and undertaken. ... They are offered alternatively to have the counselling through their medical practitioner and other health services in their states. But again it is not known of any such cases where this has been undertaken.¹⁷³

35.186 Once a genetic sample has been analysed by a private laboratory,¹⁷⁴ the DNA profile and test results created from the sample would generally be 'personal information' as defined by the *Privacy Act*.¹⁷⁵ The acts and practices of the laboratory in relation to that information are subject to the National Privacy Principles. Laboratories attached to state and territory public hospitals are not bound by the *Privacy Act*, but must comply with similar state or territory privacy legislation, where it exists.¹⁷⁶

35.187 Due to the shared nature of parentage information, it is reasonable to assume that disclosure of the test information to each person providing a bodily sample is either for the primary purpose of collection or for a related secondary purpose. The disclosure of results to each person providing a genetic sample thus appears to comply with the *Privacy Act*. The position is less clear, however, where disclosure is to an individual who has not provided a sample and has not contracted with the laboratory to receive the results of the analysis.¹⁷⁷

Issues and problems

35.188 In his interview with ABC-TV's *Lateline* in October 2000, the Chief Justice of the Family Court, Alastair Nicholson, raised the potential emotional impact of parentage testing on a child:

[O]ne of the problems about these exercises is that a lot of people don't pay sufficient regard to the child, and of course, it's a terrible thing for a child who's been brought up, for example, for 11 or 12 years to believe that a person is their father and for all intents and purposes is their father, to be suddenly told that person is not. ... I've seen cases where it causes enormous resentment, indeed the fact of taking the test can cause a complete rupture in relationships between the child and the father.¹⁷⁸

35.189 Concerns also arise regarding a parent's potential response to discovering, through parentage testing, that he or she is not the biological parent of a child. For example, if an unstable parent receives test results indicating misattributed parentage, in the absence of counselling he or she may in some circumstances become aggressive

173 G Edelsten, *Submission G117*, 14 March 2002.

174 Private sector laboratories generally fall within the definition of an 'organisation' under the *Privacy Act: Privacy Act 1988* (Cth) s 6C.

175 Ibid s 6. The profile is information about an individual whose identity can reasonably be ascertained from it. The parentage test report would likewise contain information about an individual whose identity is apparent. The possible application of the *Privacy Act* to the samples themselves is discussed in Ch 8.

176 *Health Records (Privacy and Access) Act 1997* (ACT); *Health Records Act 2001* (Vic); *Privacy and Personal Information Protection Act 1998* (NSW); *Information Privacy Act 2000* (Vic).

177 For more discussion, see Australian Law Reform Commission and Australian Health Ethics Committee, *Protection of Human Genetic Information*, DP 66 (2002), ALRC, Sydney [31.137]–[31.142].

178 Lateline, *DNA Testing and the Family Court: Transcript*, ABC TV, <www.abc.net.au/lateline/s200192.htm>, 18 February 2003.

or violent toward the child or other family members. Geneticist, Dr Brian McDonald of DNA Consults, has stated:

This is potentially explosive information. A lot of these people are on the edge as it is. Don't you think that a mother might need to know that her former partner has just found out he is not the father of one or more of her children? It is vital that she knows. Even if it is just so she can leave town for a few days while he cools down ...¹⁷⁹

35.190 One further issue raised during the course of the Inquiry was the appropriateness of parentage test results being made available directly to the tested individuals. Some laboratories send the parentage test reports by mail directly to the client or to each person providing a bodily sample for testing. The Inquiry understands that at least one laboratory gives its clients parentage test results over the telephone. Other laboratories forward test results to a nominated medical practitioner or lawyer of each person tested.¹⁸⁰

Submissions and consultations

35.191 DP 66 proposed that NATA should develop accreditation requirements that require laboratories performing DNA parentage tests to inform all persons who provide genetic samples of the availability of counselling, both at the time the samples are submitted for testing and at the time the results are made available. The Inquiry had also proposed that test results be forwarded to an independent person who has the skills to counsel the tested individuals and other relevant family members. Such a person was to be nominated by each individual who has provided a genetic sample, and might be a qualified counsellor, social worker, minister of religion, medical practitioner, lawyer or court officer.¹⁸¹

35.192 Several submissions supported the proposal.¹⁸² NATA expressed support provided that laboratories would only be required to give general advice about the availability of counselling, and provided the person submitting the sample clearly nominated the independent person to whom the test results should be forwarded.¹⁸³

35.193 The FLC recommended that counselling for the child should be required whenever parentage testing is conducted and the test results are different from the child's current understanding of paternity. The Council suggested that resources be developed to accompany test results, for example, a brochure containing information

179 G Bearup, 'The Doubt About Dad', *The Good Weekend (The Sydney Morning Herald)*, 3 November 2001, 16, 19.

180 For example, see DNALABS.SIVF website: Sydney IVF, *DNA Paternity Testing*, <www.sivf.com.au/dna_paternity_testing.htm>, 20 February 2003.

181 Australian Law Reform Commission and Australian Health Ethics Committee, *Protection of Human Genetic Information*, DP 66 (2002), ALRC, Sydney, Proposal 31–12.

182 Genetic Support Council WA, *Submission G243*, 19 December 2002; Family Law Council, *Submission G202*, 28 November 2002; Victorian Bar, *Submission G261*, 20 December 2002; NSW Health Department, *Submission G303*, 13 January 2003; Human Genetics Society of Australasia, *Submission G267*, 20 December 2002. The AGSA agreed, so long as the nominated person is genetically trained: Association of Genetic Support of Australasia, *Submission G284*, 25 December 2002.

183 National Association of Testing Authorities Australia, *Submission G273*, 18 December 2002.

and advice on disclosing the results and listing referral services that could assist.¹⁸⁴ The FLC considered that court ordered test results should not be released to the parties but to a suitable intermediary with the experience and expertise to deal with the issues arising out of parentage testing.¹⁸⁵

35.194 Reliable Parents Inc supported the need for counselling but suggested that the Family Court's counselling services would be more appropriate than the ad hoc framework suggested by the Inquiry.¹⁸⁶ The South Australian Department of Human Services considered that counselling before and after testing should be mandatory for all family members seeking parentage testing; however, the Department suggested that the list of professionals proposed by the Inquiry needed further consideration.¹⁸⁷

35.195 Genetic Technologies argued that counselling should not be mandatory. The submission noted its current practice is to forward results by post directly to the person who has commissioned the test, and suggested that forwarding the results to third parties would generally be inappropriate.

Overall, although counselling may indeed be important, to compel parties to undergo counselling in order to receive their test result effectively fails to respect individuals' rights to autonomously refuse such counselling (and again may provide another incentive to procure testing from overseas providers). On the other hand, we are more than happy to advise of the availability of counselling—in fact we already do so as a matter of course, although this is only *very rarely* taken up.¹⁸⁸

35.196 The Commonwealth Attorney-General's Department noted that the general policy in family law is that counselling should be available, but not compulsory.

While there may be merit in informing persons who undergo parentage testing of the availability of counselling, we think further consideration needs to be given to whether or not it should be a requirement of accreditation that the laboratory forward the test results to a prospective counsellor.¹⁸⁹

Inquiry's views

35.197 The Inquiry considers that access to counselling before and after parentage testing is an important means of minimising the emotional and psychological impact of such testing on the persons involved.

35.198 Although a large number of submissions supported the proposal, other submissions have raised legitimate doubts about the utility of *compulsory* counselling in all cases involving parentage testing. In the majority of cases, where parentage is confirmed, the parties may not consider counselling necessary. Even in those cases in which a parentage exclusion is reported, the parties may be able to deal with the information without the need for third party counselling. Of course, there will be cases

184 Family Law Council, *Submission G202*, 28 November 2002.

185 Ibid.

186 Reliable Parents Inc, *Submission G204*, 27 November 2002.

187 Department of Human Services South Australia, *Submission G288*, 23 December 2002.

188 Genetic Technologies Corporation Pty Ltd, *Submission G245*, 19 December 2002.

189 Commonwealth Attorney-General's Department, *Submission G228*, 12 December 2002.

in which the test results are shattering to those involved and may impact negatively on the social parent's relationship with the child, and potentially with the family.

35.199 The Inquiry accepts the concerns raised in several submissions that counselling should not be forced upon unwilling participants. The law must strike a balance between protecting individuals (especially minors) from harm, and respecting an individual's autonomy to make decisions affecting personal and family life. Consistently with general family law policy, the Inquiry considers that counselling should be available and encouraged, but should not be universally imposed upon all individuals undergoing testing, regardless of their own wishes.

35.200 The Inquiry recommends that NATA should develop accreditation requirements that require laboratories performing DNA parentage tests to inform all persons who provide genetic samples of the availability of counselling, both at the time the samples are submitted for testing and at the time the results are made available. This advice should explain the importance of counselling for that person's ongoing relationship with the child. In addition, laboratories should provide all parties with a list of available counsellors at the time the samples are received, and upon receipt of the results.

Recommendation 35–11. NATA should develop accreditation requirements that require laboratories performing DNA parentage tests to inform all persons who provide genetic samples of the availability of counselling, both at the time the samples are submitted for testing and at the time the results are available.

Other kinship testing

35.201 DNA parentage testing is one form of kinship testing. Other forms of kinship testing may involve identifying or confirming biological relationships between twins, siblings, grandparents or other relatives.¹⁹⁰

35.202 DNA testing for kinship, other than parentage, is not currently regulated within Australia. This form of testing falls outside the FLA, the FL Regulations and the current NATA accreditation requirements. As a result, both accredited and non-accredited laboratories may offer these forms of kinship testing. There is currently no formal oversight of the collection of bodily samples, procedures for maintaining the integrity of the samples, consent to participation in testing, provision of counselling, conduct of testing, or disclosure of test results.

¹⁹⁰ There are various reasons for conducting genetic tests in relation to these forms of kinship. A person might seek testing to establish a biological connection with a deceased person to claim a share in his or her estate; for identification purposes, such as after a mass disaster; for immigration purposes; or to ascertain personal identity, such as where a person has been separated from his or her biological family through adoption, past government policy, or other circumstances.

35.203 The Inquiry has some concerns about the lack of regulation of this form of testing. However, it also recognises that some of the special features of parentage testing, which justified heightened regulatory scrutiny, may be absent in the case of broader kinship testing. For example, kinship testing may be less sensitive because it concerns the identity of the extended family rather than the immediate family; the test outcome may have a lesser capacity to produce emotional or psychological harm; the testing may not involve children; and the financial consequences for the parties may not be as great.

35.204 In DP 66 the Inquiry asked whether DNA kinship testing (other than parentage testing) should be regulated and whether NATA accreditation standards should be extended to cover this form of genetic testing.¹⁹¹

35.205 NATA supported the extension of accreditation requirements to cover kinship testing.¹⁹² The other submissions addressing the question supported the extension of NATA to kinship testing generally.¹⁹³ Sydney IVF Limited commented that the NATA accreditation requirements for parentage testing should be extended to other forms of kinship testing as one way to ensure the accuracy of the results.¹⁹⁴

35.206 The Inquiry agrees with the submissions that these forms of testing should be regulated to ensure that minimum technical and ethical standards are upheld by the laboratories conducting the testing. While parentage testing usually involves more direct relationships than those involved in other kinship testing, both involve questions about family and identity, with potentially serious emotional and other implications for those being tested.

35.207 The Inquiry recommends that NATA should extend its accreditation program to cover DNA kinship testing other than parentage testing. NATA should apply the requirements for parentage testing, as amended by the Recommendations in this Report, to other kinship testing, in so far as they are applicable.

191 Australian Law Reform Commission and Australian Health Ethics Committee, *Protection of Human Genetic Information*, DP 66 (2002), ALRC, Sydney, Question 31–2.

192 National Association of Testing Authorities Australia, *Submission G273*, 18 December 2002.

193 Genetic Support Council WA, *Submission G243*, 19 December 2002; Centre for Genetics Education, *Submission G232*, 18 December 2002; Institute of Actuaries of Australia, *Submission G224*, 29 November 2002; Human Genetics Society of Australasia, *Submission G267*, 20 December 2002; Law Institute of Victoria, *Submission G275*, 19 December 2002; Association of Genetic Support of Australasia, *Submission G284*, 25 December 2002; Department of Human Services South Australia, *Submission G288*, 23 December 2002; NSW Health Department, *Submission G303*, 13 January 2003; Genetic Technologies Corporation Pty Ltd, *Submission G245*, 19 December 2002; Office of the Privacy Commissioner (NSW), *Submission G257*, 20 December 2002; Department of Health Western Australia, *Submission G271*, 23 December 2002.

194 Sydney IVF Limited, *Submission G246*, 19 December 2002.

Recommendation 35–12. NATA should extend its accreditation program to cover DNA kinship testing other than parentage testing (for example, sibling testing). NATA should apply the requirements for parentage testing, as amended by the Recommendations in this Report, to other kinship testing, in so far as they are applicable.

36. Kinship and Identity

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Introduction

36.1 Genetic testing provides a powerful tool for identifying or dispelling biological linkages between individuals, that is, in establishing kinship relations. Chapter 35 considered this matter in the context of parentage testing. Chapter 37 considers this matter in the context of establishing kinship relationships for immigration purposes. In Chapters 2 and 3, the Report noted that genetic information not only has a strong familial dimension, but can also contain links beyond the individual to the broader descent group or community. Chapter 3 also contains the Inquiry’s arguments against accepting the notion of genetic essentialism, that is, the reductionist idea that human beings are no more than the sum of their genes.

36.2 In IP 26, the Inquiry noted that it had heard suggestions that:

in future, there may be arguments that genetic information could or should be used as a means of establishing or proving Aboriginal or Torres Strait Islander identity, for the purposes of determining eligibility for membership or voting rights in Indigenous organisations such as the Aboriginal and Torres Strait Islander Commission (ATSIC); for the purposes of determining eligibility for the provision of entitlements and services reserved for Indigenous people (such as Abstudy); or, perhaps, even in the context of native title determination applications. The push to use genetic information could come from either direction: that is, a person asserting Aboriginal identity which has not been accepted by the community, or a government authority might seek to

offer genetic evidence in support of this claim; conversely, a party might use (or call for) genetic information to dispute someone else's entitlements, voting rights, etc.¹

36.3 However, the Inquiry strongly questioned whether genetic testing is an appropriate means of determining 'Aboriginality', even if there is the technical capacity to do so.

To date, the concept has relied upon a social construct of identity: that a person is a member of an Aboriginal community if he or she identifies as a member of the community, and is accepted by that community as one of its members. There is a real question whether there would be any value in insisting upon evidence of a *genetic* link to that community. This certainly would affect the status of persons adopted into that community, and perhaps persons with mixed Aboriginal and European or Asian (or other) ancestry, among others. As a matter of policy, should genetic science have any role to play in determining personal identity, or in determining racial or ethnic identity and membership?²

36.4 The Inquiry has heard from genetic counsellors and others about positive uses of genetic testing technology in Australia to re-establish links between individuals and their Aboriginal family members—links that were severed by adoption, circumstance, or government policies of a previous era that promoted separation and assimilation (the 'Stolen Generations').³ This exercise involves the use of genetic testing or other genetic information to confirm direct kinship relationships. It does not in itself contain any determination of a person's culture, race or ethnicity—although these things may flow separately from the person's re-integration into their family and community.

36.5 As detailed below, the Inquiry was correct in foreshadowing that arguments might arise about whether genetic information could or should be used as a means of establishing Aboriginal or Torres Strait Islander identity for the purposes of determining eligibility to vote in Aboriginal and Torres Strait Islander Commission (ATSIC) elections—as occurred in Tasmania in 2002.⁴ The Inquiry remains sceptical about whether there is any proper role for genetic testing in determining Aboriginal identity, which is basically a social and cultural matter.

A sensitive area

36.6 In the final report of the Royal Commission into Aboriginal Deaths in Custody (the Royal Commission), Commissioner Elliott Johnston QC commented that:

1 Australian Law Reform Commission and Australian Health Ethics Committee, *Protection of Human Genetic Information*, IP 26 (2001), ALRC, Sydney [12.26].

2 Ibid [12.27].

3 This has parallels in other parts of the world. Professor Jeong-Ro Yoon of the Korea Advanced Institute of Science and Technology informed the Inquiry that similar efforts have been made to re-unite families separated since the 1950s by the border established between North and South Korea.

4 R Guilliatt, 'A Whiter Shade of Black?', *The Good Weekend (The Sydney Morning Herald)*, 15 June 2002, 18, 22.

How 'Aboriginal' has been defined, and the qualities attributed to Aboriginal people, have varied over time and from place to place, in ways that can only be understood in terms of the local, national and international concerns of a European colony of settlement in the South Pacific. Declaring this or that individual person Aboriginal or not Aboriginal has been a political act, prompted often enough by administrative convenience or economic advantage, such as access to land or the control of cheap labour. Correspondingly, Aboriginal people have at times denied Aboriginal identity, as a strategy for evading official harassment or popular discrimination, and at other times claimed it as a means of improving their material or political circumstances.⁵

36.7 The Inquiry acknowledges that Aboriginal communities have good reason to be particularly sensitive about attempts by non-Aboriginal institutions or organisations to define 'Aboriginal identity'. Commissioner Johnston commented:

No area of research and commentary by non-Aboriginal people has such potential to cause offence as does that which attempts to define 'Aboriginality'. This determination of non-Aboriginal people to categorise and divide Aboriginal people is resented for many reasons, but principally, I suspect, because the worst experiences of assimilation policies and the most long term emotional scars of those policies relate directly to non-Aboriginal efforts to define 'Aboriginality' and to deny to those found not to fit the definition, the nurture of family, kin and culture. To Aboriginal people there appears to be a continuing aggression evident in such practices.⁶

36.8 Submissions and consultations following DP 66 emphasised the sensitivity attaching to any attempt to define Aboriginality. The Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) submitted that:

The issue of Aboriginality does not warrant a separate chapter given that 'race' cannot be determined through genetic testing. The report will need to justify why there is a chapter devoted exclusively to questions of Aboriginal identity because it could be perceived to perpetuate unethical and unscientific references to Aboriginal people as a distinct race.⁷

36.9 AIATSIS emphasised that Indigenous people have a right to determine issues of identity and community through their own processes, but suggested that

the ALRC lend expertise to develop, through extensive consultation and negotiation with Indigenous peoples and communities, identity frameworks that are appropriate and relevant for Aboriginal and Torres Strait Islander peoples.⁸

36.10 The Inquiry agrees that these matters should be determined by Aboriginal and Torres Strait Islander people themselves, working through their own communities, institutions and consultation processes. The remainder of this chapter contains research and commentary intended to assist any further consideration of these issues, as well as to promote general community understanding of these matters.

5 Royal Commission into Aboriginal Deaths in Custody, *National Report* (1991), Commonwealth of Australia, Canberra [11.12.20].

6 Ibid [11.12.4].

7 Australian Institute of Aboriginal and Torres Strait Islander Studies, *Submission G286*, 16 December 2002.

8 Ibid.

Legal definitions of Aboriginality

Early definitions

36.11 The legal historian, John McCorquodale, has reported that since the time of white settlement, governments have used no less than 67 classifications, descriptions or definitions to determine who is an Aboriginal person.⁹

36.12 The ALRC discussed the definition of an 'Aborigine' in its 1986 report, *The Recognition of Aboriginal Customary Laws*.¹⁰ The ALRC noted that early attempts at a definition tended to concentrate on descent, without referring to other elements of Aboriginality. Problems arose in deciding whether descendants of unions between Aborigines and settlers were to be regarded as Aboriginal for the purposes of various restrictive or discriminatory laws (for example, disentitling Aborigines from voting or enrolling to vote). In applying these restrictive laws, tests based on 'quantum of blood' were commonly applied.¹¹

36.13 The Commonwealth Parliament obtained the power to legislate with respect to people of 'the aboriginal race in any State' in the 1967 referendum. The Commonwealth subsequently enacted a number of statutes for the purpose of providing certain rights and privileges for the exclusive benefit of Indigenous Australians.¹² These statutes have generally defined an Aboriginal or Indigenous person as 'a person who is a descendant of an indigenous inhabitant of Australia',¹³ or a member or a person 'of the Aboriginal race of Australia'.¹⁴ One commentator has observed in relation to the latter definition:

Though possibly an improvement on 'blood' quantum definitions, the utility of this definition can still be questioned, not least of all on the grounds that there is no such thing as an Aboriginal race. Most scientists long ago stopped using the word 'race'.¹⁵

The three-part definition

36.14 In the early 1980s, the Commonwealth Department of Aboriginal Affairs proposed a new three-part definition of an Aboriginal or Torres Strait Islander person.

9 See Royal Commission into Aboriginal Deaths in Custody, *National Report* (1991), Commonwealth of Australia, Canberra [11.12.5].

10 Australian Law Reform Commission, *The Recognition of Aboriginal Customary Laws*, Report 31 (1986), Australian Government Publishing Service, Canberra [88]–[95].

11 Ibid [89].

12 For example, *Aboriginal and Torres Strait Islander Commission Act 1989* (Cth).

13 For example, *Racial Discrimination Act 1975* (Cth) s 3(1).

14 *Human Rights and Equal Opportunity Commission Act 1986* (Cth) s 3(1); *Indigenous Education (Targeted Assistance) Act 2000* (Cth) s 4; *Indigenous Education (Supplementary Assistance) Act 1989* (Cth) s 3; *Native Title Act 1993* (Cth) s 253; *Aboriginal and Torres Strait Islander Commission Act 1989* (Cth) s 4(1).

15 J Gardiner-Garden, *The Definition of Aboriginality: Research Note 18, 2000–01* (2000) Parliament of Australia, 2.

An Aboriginal or Torres Strait Islander is a person of Aboriginal or Torres Strait Islander descent who identifies as an Aboriginal or Torres Strait Islander and is accepted as such by the community in which he [or she] lives.¹⁶

36.15 Federal government departments adopted the definition as their ‘working definition’ for determining eligibility to certain services and benefits. The definition continues to be applied administratively in relation to programs such as Abstudy funding for tertiary students.

36.16 In *The Recognition of Aboriginal Customary Laws*, the ALRC emphasised the benefits of a flexible definition of Aboriginality:

Experience under Commonwealth and States legislation suggests that it is not necessary to spell out a detailed definition of who is an Aborigine, and that there are distinct advantages in leaving the application of the definition to be worked out, so far as is necessary, on a case by case basis.¹⁷

36.17 Only a small number of judicial decisions in Australia have considered this issue.¹⁸ In *Commonwealth v Tasmania*, the High Court considered the definition of an ‘Aborigine’ for the purpose of s 51(xxvi) of the Constitution, in relation to laws with respect to ‘the people of any race for whom it is deemed necessary to make special laws’. Deane J applied the three-part test, stating:

By ‘Australian Aboriginal’ I mean, in accordance with what I understand to be the conventional meaning of that term, a person of Aboriginal descent, albeit mixed, who identifies himself as such and who is recognised by the Aboriginal community as Aboriginal.¹⁹

36.18 Brennan J supported this approach in his leading judgment in *Mabo v Queensland (No 2)*, in relation to native title:

Membership of the Indigenous people depends on biological descent from the Indigenous people and on mutual recognition of a particular person’s membership by that person and by the elders or other persons enjoying traditional authority among those people.²⁰

36.19 As noted above, the Commonwealth has enacted a number of statutes for the purpose of providing certain rights and privileges for the exclusive benefit of Indigenous Australians. Due to the broad terms in which these statutes define an Aboriginal person, it has been necessary for the courts to interpret these definitions.

16 Department of Aboriginal Affairs, *Report on a Review of the Administration of the Working Definition of Aboriginal and Torres Strait Islanders* (1981), Commonwealth of Australia, Canberra, cited in J Gardiner-Garden, *The Definition of Aboriginality: Research Note 18, 2000–01* (2000) Parliament of Australia, 2.

17 Australian Law Reform Commission, *The Recognition of Aboriginal Customary Laws*, Report 31 (1986), Australian Government Publishing Service, Canberra [95].

18 See *Attorney-General (Cth) v Queensland* (1990) 94 ALR 515; *Gibbs v Capewell* (1995) 128 ALR 577; *Shaw v Wolf* (1998) 163 ALR 205. See also *In the Matter of the Aboriginal Lands Act 1995 and In the Matter of Marianne Watson (No 2)* (Unreported, Supreme Court of Tasmania, Cox CJ, 27 August 2001). The following analysis draws on a discussion in an unpublished paper: L de Plevitz and L Croft, *Proving Aboriginality: Legal and Genetic Constructs of Aboriginal Descent* (2002) unpublished.

19 *Commonwealth v Tasmania* (1983) 158 CLR 1, 274 (Deane J).

20 *Mabo v Queensland (No 2)* (1992) 175 CLR 1, 70 (Brennan J).

36.20 In *Attorney-General (Cth) v Queensland*, the Federal Court considered the meaning of the word 'Aboriginal' in relation to the Letters Patent authorising the Royal Commission to inquire into the deaths in custody of 'Aboriginal and Torres Strait Islanders'. The Queensland government argued that the Royal Commission could not inquire into the death of a 17-year-old boy in custody because he was not Aboriginal. While the boy had some Aboriginal descent, he had not identified as an Aborigine and had not been recognised as such by the Aboriginal community.²¹

36.21 The Federal Court held that Aboriginal descent was, by itself, sufficient proof of Aboriginality for these particular purposes. French J commented that the three-part definition should not be seen as representing the contemporary content of the word 'Aboriginal', irrespective of context or purpose. The better view was that Aboriginal descent alone is a sufficient criterion for classification as Aboriginal for the purposes there in question.²²

36.22 Spender J commented that once it is established that a person is 'non-trivially' of Aboriginal descent, then that person is Aboriginal within the ordinary meaning of that word. Neither self-identification nor community recognition is necessary, and the presence of either factor, or even both, is not sufficient to satisfy the definition of an 'Aboriginal' person.²³ Spender and Jenkinson JJ both commented that where Aboriginal descent is uncertain, or where the extent of Aboriginal descent might be considered insignificant, self-recognition or recognition by other Aboriginal persons may have an evidentiary value in resolving the question.²⁴

36.23 In *Gibbs v Capewell*, the Federal Court discussed the meaning of the statutory definition of an Aboriginal person in the *Aboriginal and Torres Strait Islander Commission Act 1989* (Cth) (ATSIC Act).²⁵ The Act defines an Aboriginal person as 'a member of an Aboriginal race of Australia'. Drummond J concluded that Parliament's intention was 'to refer to the group of persons in the modern Australian population who are descended from the inhabitants of Australia immediately prior to European settlement'.²⁶ For the purposes of the ATSIC Act, an Aboriginal person must be a biological descendant of one of those inhabitants. His Honour stated:

Since the Act itself makes it clear that proof of descent from the pre-European settlement inhabitants of Australia is essential before a person can come within the expression 'Aboriginal person' in the Act, I reject the suggestion ... that a person without any Aboriginal genes but who has identified with an Aboriginal community and who is recognised by that community as one of them can be an 'Aboriginal person' for the purposes of this particular Act. It follows that adoption by Aboriginals of a person without any Aboriginal descent and the raising of that person as an Aboriginal ... will not, because of the statutory requirement for descent, bring that person within the description 'Aboriginal person'.²⁷

21 *Attorney-General (Cth) v Queensland* (1990) 94 ALR 515.

22 *Ibid*, 538–539 (French J).

23 *Ibid*, 523–524 (Spender J).

24 *Ibid*, 516–517.

25 See *Aboriginal and Torres Strait Islander Commission Act 1989* (Cth) s 4(1).

26 *Gibbs v Capewell* (1995) 128 ALR 577, 580.

27 *Ibid*, 580.

36.24 Drummond J commented that Deane J's three-part test should not be regarded as containing an exhaustive description of the meaning in ordinary speech of the term 'Aboriginal'. His Honour held that a person must have some degree of Aboriginal descent to satisfy the definition of an 'Aboriginal person'. A small degree of Aboriginal descent coupled with genuine self-identification or with communal recognition may be sufficient for eligibility; alternatively, a substantial degree of descent may by itself be sufficient.²⁸ Drummond J recognised the probative value of communal recognition as evidence of Aboriginal descent.

Aboriginal communal recognition will always be important, when it exists, as indicating the appropriateness of describing the person in question as an 'Aboriginal person'. Proof of communal recognition as an Aboriginal may, given the difficulties of proof of Aboriginal descent flowing from, among other things, the lack of written family records, be the best evidence available of proof of Aboriginal descent. While it may not be necessary to enable a person to claim the status of an 'Aboriginal person' for the purposes of the Act in a particular case, such recognition may, if it exists, also provide evidence confirmatory of the genuineness of that person's identification as an Aboriginal.²⁹

36.25 In *Shaw v Wolf*, the Federal Court again considered the meaning of an 'Aboriginal person' for the purposes of the ATSIC Act. Merkel J held that if a person has no Aboriginal descent then he or she cannot be an Aboriginal person for the purposes of the Act. However, evidence about the process by which self-identification and communal identification occurs can be probative of descent.³⁰ Merkel J referred to the lack of documentary records and to the reticence of some families of Aboriginal descent to publicly acknowledge that fact due to actual or perceived racism from the rest of the community.

In these circumstances Aboriginal identification often became a matter, at best, of personal or family, rather than public, record. Given the history of the dispossession and disadvantage of the Aboriginal people of Australia, a concealed but nevertheless passed on family oral 'history' of descent may in some instances be the only evidence available to establish Aboriginal descent. Accordingly oral histories and evidence as to the process leading to self-identification may, in a particular case, be sufficient evidence not only of descent but also of Aboriginal identity.³¹

36.26 Merkel J noted that his decision involved the interpretation of a statutory definition only, and did not purport to be a comprehensive definition of Aboriginality. His Honour commented that:

Aboriginality as such is not capable of any single or satisfactory definition ... The present case offers a good example of the difficulties thrown up by issues of Aboriginal identification. That some descent may be an essential legal criterion required by the definition in the Act is to be accepted. However in truth, the notion of 'some' descent is a technical rather than a real criterion for identity, which after all in

28 Ibid, 583–584.

29 Ibid, 585.

30 *Shaw v Wolf* (1998) 163 ALR 205, 211–212.

31 Ibid, 213.

this day and age, is accepted as a social, rather than a genetic, construct. The solution to such problems is a matter for the legislature rather than the courts.³²

36.27 In his concluding observations in *Shaw v Wolf*, Merkel J made the point that since this issue involves an important aspect of Aboriginal self-determination, it is best left for bodies with Aboriginal representation:

It is unfortunate that the determination of a person's Aboriginal identity, a highly personal matter, has been left by a parliament that is not representative of Aboriginal people to be determined by a court which is also not representative of Aboriginal people. Whilst many would say that this is an inevitable incident of political and legal life in Australia, I do not accept that that must always be necessarily so. It is to be hoped that one day if questions such as those that have arisen in the present case are again required to be determined that that determination might be made by independently constituted bodies or tribunals which are representative of Aboriginal people.³³

36.28 In summary, the Commonwealth government appears to apply the three-part test of Aboriginal descent, self-identification and community recognition for determining eligibility for certain programs and benefits. The courts, in interpreting statutory definitions in federal legislation, have emphasised the importance of descent in establishing Aboriginal identity, but have recognised that self-identification and community recognition may be relevant to establishing descent, and hence Aboriginal identity, for the purposes of specific legislation.

International approaches

36.29 Dr William Jonas, the Aboriginal and Torres Strait Islander Social Justice Commissioner of the Human Rights and Equal Opportunity Commission, noted that Indigenous peoples have resisted attempts internationally to prescribe an exhaustive definition of 'Indigenous'.³⁴

36.30 The United Nations Working Group on the Rights of Indigenous Populations has considered the definition of Indigenous peoples, communities and nations but has never adopted a formal definition. In the Working Group's first session, indigenous participants argued against attempts to formulate a definition, in the absence of more broadly representative indigenous participation.³⁵ In its second session, the Working Group considered a definition developed by Martinez Cobo, the Special Rapporteur to the United Nations' Subcommission on Prevention of Discrimination and Protection of Minorities:

Indigenous communities, peoples and nations are those which, having a historical continuity with pre-invasion and pre-colonial societies that developed on their territories, consider themselves distinct from other sectors of the societies now

32 Ibid, 268.

33 Ibid.

34 Aboriginal and Torres Strait Islander Social Justice Commissioner — Human Rights and Equal Opportunity Commission, *Submission G160*, 13 May 2002.

35 R Bartlett, A Brown and G Nettheim, 'Aborigines and Torres Strait Islanders' in Garth Nettheim (ed), *The Laws of Australia: Aborigines* (1992) Law Book Company Limited, Sydney, vol 1.7 [48].

prevailing in those territories, or parts of them ... They form at present non-dominant sectors of society and are determined to preserve, develop, and transmit to future generations their ancestral territories, and their ethnic identity, as the basis of their continued existence as peoples, in accordance with their own cultural patterns, social institutions and legal systems.³⁶

36.31 The importance of self-identification has also been recognised in Article 1.2 of International Labour Organization Convention 169, concerning Indigenous and Tribal Peoples in Independent Countries:

Self-identification as indigenous or tribal shall be regarded as a fundamental criterion for determining the groups to which the provisions of this Convention apply.³⁷

36.32 Dr Larissa Behrendt, Professor of Law and Indigenous Studies at the University of Technology Sydney, has commented:

If we're going to talk about treaties and recognition of rights, the question of who's in and who's out is going to be the most important issue facing indigenous Australians. If that isn't resolved, you run the risk of having the parameters stretched to the ludicrous point where someone can say: 'Seven generations ago there was an Aboriginal person in my family, therefore I am Aboriginal'.³⁸

Concerns about the application of existing law

36.33 A number of submissions commented on the appropriateness, or otherwise, of the existing legal definition of Aboriginality.³⁹ The Commonwealth Attorney-General's Department commented:

The question of whether genetic testing and information should be used to establish Aboriginal identity is an important issue given that it may determine eligibility to Indigenous-specific entitlements. Any departure from the current three-pronged test to determine whether someone is an Aboriginal or a Torres Strait Islander based on descent, self-identification and community recognition requires careful consideration.⁴⁰

36 M Cobo, *Study of the Problem Against Indigenous Populations*, vol 5, Conclusions, Proposals and Recommendations, UN Doc E/CN.4/Sub.2/1986/7 Add.4 [379], [381]: cited in Ibid, [48]. In addition, Cobo defines an Indigenous person as 'One who belongs to these Indigenous populations through self-identification as Indigenous (group consciousness) and is recognised and accepted by these populations as one of its members (acceptance by the group)': cited in S Pritchard, 'Working Group on Indigenous Populations: Mandate, Standard-Setting Activities and Future Perspectives' in S Pritchard (ed), *Indigenous Peoples, the United Nations and Human Rights* (1998) Federation Press, Sydney, 43.

37 *Indigenous and Tribal Peoples Convention*, opened for signature 27 June 1989, 1650 UNTS 383, (entered into force on 5 September 1991). The Commonwealth Attorney-General's Department noted in its submission that this Convention has been ratified only by a minority of states, and Australia is not one of them: Commonwealth Attorney-General's Department, *Submission G228*, 12 December 2002.

38 R Guilliatt, 'A Whiter Shade of Black?', *The Good Weekend* (*The Sydney Morning Herald*), 15 June 2002, 18, 21.

39 See L de Plevitz and L Croft, *Submission G115*, 13 March 2002; Australian Institute of Aboriginal and Torres Strait Islander Studies, *Submission G286*, 16 December 2002; Aboriginal and Torres Strait Islander Social Justice Commissioner — Human Rights and Equal Opportunity Commission, *Submission G160*, 13 May 2002; Anti-Discrimination Board of NSW, *Submission G157*, 1 May 2002.

40 Commonwealth Attorney-General's Department, *Submission G228*, 12 December 2002.

36.34 The Inquiry was told in some consultations that the three-part definition works well enough in most circumstances. However, a number of concerns were expressed about the test. In some cases, the courts have interpreted ‘descent’ in terms of biological descent when interpreting the meaning of an Aboriginal person.⁴¹ This tends to undermine the role of social descent within Aboriginal communities whose traditional laws and customs might provide for adoption or other social forms of inclusion into a family or community. The emphasis on biological descent has led to some anxiety that genetic testing might increasingly be used (or even required) as a means of proving a person’s kinship relationship with another Aboriginal person.

36.35 Several submissions emphasised the difference between Western and Aboriginal definitions of kinship.⁴² The Aboriginal and Torres Strait Islander Social Justice Commissioner commented that:

While Aboriginal people may generally be direct descendants of the original inhabitants of a particular part of Australia, indigenous customary law does not rely on linear proof of descent in the Judeo-Christian genealogical form of ‘Seth begat Enosh begat Kenan’ in order to prove membership of the group. ... A person may have been adopted into a kinship group where there is no direct or suitable offspring to carry out ceremonial obligations. ... Genetic science should have no part to play in determining whether or not a person should be eligible for benefits. If the element of descent is to remain in Australian law as a test of Aboriginality, it should be interpreted in accordance with Indigenous cultural protocols.⁴³

36.36 Professor Larissa Behrendt also expressed concern about the tendency of the courts to distort the three-part test by focussing unduly on descent, however defined. Professor Behrendt noted that self-identification has been recognised as the international standard for establishing indigenous identity, and she emphasised that, in talking about elections and treaties, indigenous people need to talk among themselves about Aboriginality and what makes their Indigenous identity.⁴⁴

36.37 In its submission to the Inquiry, AIATSIS supported the existing definition, commenting that it should be emphasised in legal determinations, but it stressed the need for judicial flexibility to ensure Indigenous peoples were not disadvantaged.

The legal imperative of utilising the three pronged approach to Indigenous identity should be emphasised in legal determinations. There should also be a strengthening of the three pronged test to allow judges to make this test a legal standard. AIATSIS

41 For example, *Mabo v Queensland (No 2)* (1992) 175 CLR 1, 70 (Brennan J). In relation to the ATSIC Act, see *Gibbs v Capewell* (1995) 128 ALR 577; *Shaw v Wolf* (1998) 163 ALR 205.

42 Centre for Genetics Education, *Submission G232*, 18 December 2002; NSW Health Department, *Submission G303*, 13 January 2003; Department of Human Services South Australia, *Submission G288*, 23 December 2002; Law Society of New South Wales, *Submission G285*, 18 December 2002; Aboriginal and Torres Strait Islander Social Justice Commissioner — Human Rights and Equal Opportunity Commission, *Submission G160*, 13 May 2002.

43 Aboriginal and Torres Strait Islander Social Justice Commissioner — Human Rights and Equal Opportunity Commission, *Submission G160*, 13 May 2002.

44 L Behrendt, *Consultation*, Sydney, 3 December 2002.

stresses the need for judicial discretion so that Indigenous people [a]re not further disadvantaged in legal proceedings.⁴⁵

36.38 The difficulties surrounding elements of the three-part test are illustrated by the controversy that arose in 2002 over eligibility to vote in the election for ATSIC councillors representing Tasmania. The ATSIC Act provides that a person is entitled to vote in a Regional Council ward election if he or she is an Aboriginal person or a Torres Strait Islander.⁴⁶

36.39 Some Tasmanian people who identify as Aboriginal, and are acknowledged as such by the relevant Aboriginal community, nevertheless may have difficulty obtaining documentary evidence of their Aboriginal descent. This is due to inadequate colonial record keeping, past policies of removal and other consequences of the historical discrimination against Aboriginal people. These persons assert that self-identification and community acceptance should be sufficient evidence of their Aboriginality for legal purposes. On the other hand, it has been argued that requiring proof of descent is one way to protect against fraudulent or inappropriate claims of Aboriginality by non-Indigenous persons for personal or financial reasons.⁴⁷

36.40 These concerns led ATSIC to trial an Indigenous Electoral Roll for the purpose of the Tasmanian Regional Aboriginal Council Elections.⁴⁸ Individuals could object to an applicant being included on the roll on the basis that he or she was not of Aboriginal or Torres Strait Islander descent. Where an objection was made, the applicant was required to provide documentary evidence addressing his or her Aboriginal ancestry, self-identification and community acceptance. To prove ancestry, the person generally was required to provide a verifiable family tree, or archival or historical documentation that linked the person to a traditional family or person.⁴⁹ The Inquiry understands that several applicants sought genetic testing to produce evidence supporting their claims of Aboriginal descent.⁵⁰

45 Australian Institute of Aboriginal and Torres Strait Islander Studies, *Submission G286*, 16 December 2002.

46 *Aboriginal and Torres Strait Islander Commission Act 1989* (Cth) s 101. In addition, either the person's name must be on the Commonwealth Electoral Roll and the person's place of residence (as shown on the roll) must be within the ward concerned, or the person must be entitled to vote pursuant to rules made under the Act.

47 See R Guilliatt, 'A Whiter Shade of Black?', *The Good Weekend* (*The Sydney Morning Herald*), 15 June 2002, 18.

48 See ATSIC's website: Aboriginal and Torres Strait Islander Commission, *ATSIC Regional Council Elections 2002*, <www.atsic.gov.au/Events/Elections_2002/Tasmania/default.asp>, 22 July 2002.

49 See ATSIC's website: *Ibid*.

50 See 'Aboriginal DNA Testing Stopped After Complaints', *Mercury* (Hobart), 3 September 2002; S Sayer, 'Aboriginal Centre Slams DNA', *Mercury* (Hobart), 4 September 2002.

Genetics and ‘race’

36.41 One of the most interesting outcomes of the Human Genome Project and other current scientific research is that there is no meaningful genetic or biological basis for the concept of ‘race’.⁵¹ As discussed in Chapter 3, any two human beings are 99.9% identical genetically. Within the remaining small band of variation, scientists estimate that there is an average genetic variation of 5% *between* what are called ‘racial groups’—which means that 95% of human genetic variation occurs *within* ‘racial groups’.

36.42 It is now well-accepted among medical scientists, anthropologists and other students of humanity that ‘race’ and ‘ethnicity’ are social, cultural and political constructs, rather than matters of scientific ‘fact’. In 1997, the American Anthropological Association (AAA) recommended that the United States government no longer use the term ‘race’ on census forms or other official data collection documents, because the term has ‘no scientific justification in human biology’. The AAA noted that

ultimately, the effective elimination of discrimination will require an end to such categorization, and a transition toward social and cultural categories that will prove more scientifically useful and personally resonant for the public than are categories of ‘race’.⁵²

Genetics, ancestry and identity

Methods of genetic kinship testing

36.43 Although current scientific knowledge holds that there is no genetic basis for race, there are several forms of genetic kinship testing that might be used to establish that one person is related to a living person who is recognised as belonging to a particular family or group; or that a person is descended from a deceased person who was recognised as belonging to such a family or group.

36.44 The most common form of genetic kinship testing between two living persons involves the comparison of both individuals’ DNA profiles (and potentially those of other putative relatives, as well). These profiles comprise a set of numbers representing the number of short tandem repeats at different loci along a person’s DNA

51 See J Graves, *The Emperor’s New Clothes: Biological Theories of Race at the Millennium* (2001) Rutgers University Press, New Brunswick. See also A Caplan, ‘Handle With Care: Race, Class and Genetics’ in Timothy Murphy and Marc Lappe (ed), *Justice and the Human Genome Project* (1994) University of California Press, 30.

52 American Anthropological Association, *American Anthropological Association Response to OMB Directive 15: Race and Ethnic Standards for Federal Statistics and Administrative Reporting*, <<http://www.aaanet.org/gvt/ombdraft.htm>>, 25 February 2003. Directive 15 designated four races (‘American Indian or Alaskan Native’, ‘Asian or Pacific Islander’, ‘Black’ and ‘White’) and two ethnic backgrounds (‘of Hispanic origin’ and ‘not of Hispanic origin’) for the purposes of government statistical collections.

molecule. If the profiles are sufficiently similar, a forensic scientist may report a probability that the persons are biologically related.⁵³

36.45 Two main techniques are currently used in identifying genetic ancestry: mapping polymorphisms on the Y chromosome to trace paternal ancestry, and on mitochondrial DNA (mtDNA) to trace maternal ancestry. The former technique identifies biological relationships between a father and son, while the latter identifies biological relationships between a mother and her male and female children.⁵⁴

36.46 Using these techniques, some laboratories are marketing genetic tests that purport to identify Jewish ancestry,⁵⁵ Native American ancestry, 'Viking markers',⁵⁶ and even a genetic connection to the so-called 'Daughters of Eve'.⁵⁷ Genetic testing is now also available commercially which purports to help black people in America, England and the Caribbean trace their lineage back to the parts of Africa from which their ancestors originated.⁵⁸

36.47 Dr Martin Richards, a researcher in human evolutionary genetics, has cautioned against investing any spiritual significance in the 'not very meaningful DNA sequences' that emerge from such testing, pointing out that:

Studies of human genetic diversity have barely begun. Yet the fashion for genetic ancestry testing is booming. ... Buoyed by the hype, the private sector has been moving in. ... By tracking the history of genes back through time, geneticists can try to reconstruct the migrations and expansions of the human species. They have no special insight into ethnicity and identity.⁵⁹

53 See Ch 35 for more detail.

54 C Elliott and P Brodwin, 'Identity and Genetic Ancestry Testing' (2002) 325 *British Medical Journal* 1469.

55 Ibid. See also N Wade, 'In DNA, New Clues to Jewish Roots', *New York Times*, 14 May 2002; M Thomas and others, 'Origins of Old Testament Priests' (1998) 394 *Nature* 138.

56 Prompted by BBC2's five-part documentary series 'Blood of the Vikings', first screened in November 2001. See also J Richards, *Blood of the Vikings* (2001) Hodder & Stoughton General, London.

57 See B Sykes, *The Seven Daughters of Eve: The Science That Reveals Our Genetic Ancestry* (2001) WW Norton & Company, New York. Sykes, a professor of genetics at Oxford University, used mtDNA analysis, archaeological and climatic records, and other sources to develop the proposal that nearly all modern Europeans are descendants of one of seven 'clan mothers'—or 'the Seven Daughters of Eve'—who lived 10,000–50,000 years ago. Sykes identifies 33 'Daughters of Eve' worldwide. See S Wells, *The Journey of Man: A Genetic Odyssey* (2003) Princeton University Press, for the male version of this research, utilising Y chromosome analysis.

58 C Elliott and P Brodwin, 'Identity and Genetic Ancestry Testing' (2002) 325 *British Medical Journal* 1469. John Presser's submission noted that mtDNA analysis has been used to reunite the 'stolen' children of Argentina with their grandparents, and has been used by the United States' Armed Forces to identify the remains of US soldiers from World War II, and the Korean and Vietnam wars: J Presser, *Submission G183*, 3 October 2002. See also M Richards, 'Beware the Gene Genies: Lavish but Questionable Promises Have Been Made to Those Who Want to Trace Their Genetic Ancestry', *The Guardian* (London), 21 February 2003.

59 M Richards, 'Beware the Gene Genies: Lavish but Questionable Promises Have Been Made to Those Who Want to Trace Their Genetic Ancestry', *The Guardian* (London), 21 February 2003.

Overseas experiences

36.48 Apart from such fads, there have been a number of circumstances in recent times in which serious consideration has been given to the role (if any) of genetics and genetic testing in determining racial or ethnic identity. The website of the University of Minnesota's Center for Bioethics contains useful case studies and discussion of the issues in this area.⁶⁰

36.49 The Center for Bioethics notes that, to date, there 'are no reports of American Indian tribes requiring or relying on DNA testing for membership'.⁶¹ However, in February 2000, a Bill was introduced into the Vermont state legislature, which proposed that the State Commissioner of Health should establish standards and procedures for DNA-HLA testing to certify that an individual had Native American ancestry.⁶² The Bill failed to become law and has not been reintroduced—after provoking a strong negative reaction to the prospect of using genetic testing to determine racial or ethnic heritage, both as a matter of scientific validity and public policy.⁶³

36.50 There has also been controversy in the United States over the identity of the so-called 'Black Seminoles'.⁶⁴ The Seminoles are an established Native American tribe originating in what is now the southern part of the United States. Over a period of about 200 years, significant numbers of fleeing black slaves found refuge among the Seminoles. In the aftermath of the American Civil War, the Seminoles in Oklahoma signed a treaty with the United States government under which 'Blood Seminoles' and 'Black Seminoles' were accorded equal rights. However, in July 2000, the Seminole Nation of Oklahoma passed a resolution to amend their tribal membership criteria to require possession of 'one-eighth Seminole Indian blood'—in effect, expelling many of the Black Seminoles (also known as 'Freedmen') from the tribe. The Center for Bioethics' commentary notes that:

At a time when using genetics to prove identity is becoming more and more common, the Freedmen are an interesting case primarily because genetics has traditionally taken a back seat in the construction of their 'Indian-ness'. Their membership of an American Indian tribe has for generations been based on a shared history, rather than on shared Indian genetics. However, the Freedmen's membership of the Nation is

60 University of Minnesota Center for Bioethics, *Genetics and Identity*, <www.bioethics.umn.edu/genetics_and_identity/case.html>, 25 February 2003.

61 Ibid.

62 HLA stands for 'Human Lymphocyte Antigen', a more sophisticated form of conventional blood testing developed in the 1970s. HLA blood types are the ones that now must be matched before an organ transplant can proceed.

63 For a further account of this Bill, see N Yona, 'DNA testing in Vermont', *The Abolitionist Examiner*, April/May 2001. See generally K Tallbear, *Genetics, Culture and Identity in Indian Country*, International Institute for Indigenous Resource Management, <www.iiirm.org/publications/Genetics/ISEPaper.pdf>, 25 February 2003.

64 See J Johnston, 'Just your roots are showing' (2002) 32 *The Hastings Center Report* 6. See also J Johnston, 'Resisting a Genetic Identity: The Black Seminoles and Genetics Tests of Ancestry' (2003) *Journal of Law, Medicine and Ethics* (forthcoming).

now under threat as the tribe moves over to an identity system that places genetics above history, that values blood quantum over contribution to tribal affairs.⁶⁵

36.51 In Canada, there has been controversy over indigenous membership rules in Kahnawake, a large Mohawk community near Montreal. In 1981, the membership rules were changed to require 'at least 50 per cent Mohawk blood'—and some residents were then told they could no longer have jobs or homes on the reserve even though their families had lived there for generations. After considerable community disputation and the commencement of some litigation, the community announced in March 2003 that it intended to change the membership rules so that while Mohawk lineage would remain a key factor, other criteria would include residency and the commitment to learn the Mohawk language. Professor Taiaiake Alfred, an adviser to the band council on this issue, noted that the '50% blood rule' rule had been prompted by the Canadian *Indian Act*,⁶⁶ which introduced the idea that a bureaucratic ruling could be made about who is, and who isn't an Indian. Professor Alfred commented that:

The Indian Act took away the fundamental rights of native people in Canada to define who they are. There is no justification outside of colonial control to have one group of people telling another group of people who they are.

The object of this [new] law is to get away from the notion of blood quantum. We moved back to the traditional conception of what it means to be a Mohawk, cultural factors and community integration, as opposed to strict genetic determination.⁶⁷

36.52 There also have been a number of cases in which particular African communities—such as the Falashas of Ethiopia,⁶⁸ the Abayudaya of Uganda,⁶⁹ and the Lemba of Southern Africa—have asserted a Jewish religious identity, based upon ancient oral traditions, or the presence of certain genetic markers said to be associated with persons of Jewish heritage, or both.⁷⁰ In the case of the Lemba, a recent Y-chromosome study found evidence of Semitic origins, although it was not clear whether this involved Jewish or Arabic ancestry, or a mixture of the two. However, the study found that the Lemba carry a particular genetic marker (the Cohen modal haplotype or CMH) at a frequency similar to that found in Jewish populations,

65 University of Minnesota Center for Bioethics, *Genetics and Identity*, <www.bioethics.umn.edu/genetics_and_identity/case.html>, 25 February 2003. See also J Wickliffe-Ary, 'Seminole Nation in Election conflict over Freedmen and their voting rights', *Native American Times*, 19 February 2003.

66 Revised Statutes 1985, ch 1-5, ss 5–14. See *Laws*, Department of Justice Canada, <<http://laws.justice.gc.ca/>>, 11 March 2003.

67 Tu Thanh Ha, 'Mohawk membership no longer blood simple: Quebec reserve to change divisive rule requiring strict 50-per-cent lineage', *The Globe and Mail*, 5 March 2003, A4.

68 *The History of the Ethiopian Jews*, American-Israeli Cooperative Enterprise, <www.us-israel.org/jsource/Judaism/ejhst.html>, 25 February 2003. See also eLandnet, *Links*, <www.elandnet.org/links/en/Africa/Falasha/>, 25 February 2003.

69 M Lacey, '600 Ugandans Struggle for Recognition by Israel as Jews', *New York Times*, 19 February 2003.

70 See generally, T Parfitt, *The Thirteenth Gate: Travels Among the Lost Tribes of Israel* (1987) Adler & Adler, Bethesda; S Cohen, *The Beginnings of Jewishness: Boundaries, Varieties, Uncertainties* (2001) University of California Press.

although this marker was not found among neighbouring African tribes.⁷¹ Apart from any desire to gain broader acknowledgment of their deeply-held religious identity and heritage, recognition of their status as Jews also has potentially significant legal consequences, in so far as the State of Israel's *Law of Return 1950* grants every Jew the right to migrate to Israel and to acquire citizenship automatically.⁷²

36.53 Elliott and Brodwin have attempted to put genetic ancestry testing into context, noting that:

clearly confusion looms when genetic markers conflict with other kinds of markers of group membership, such as a shared culture or historical narrative. Does it make you more English, or Sioux, or [a relative of Thomas] Jefferson if your identity has been corroborated by a genetic marker? ...

Many observers worry that this new genetic information will be given too much authority in deciding questions about identity. Media accounts have often treated tracing of genetic ancestry as the final answer to extremely controversial questions—as if genetic tests had authoritatively settled the question of whether the Lemba are really Jewish or the question of from what African tribe an individual African-American legitimately claim descent.⁷³

36.54 Brodwin has pointed out that, whatever the emerging scientific knowledge of population genetics, the use of such genetic information will often have a sharp political edge:

For example, tracing your ancestry—via a pattern of particular alleles, or mutations on the Y chromosome or in mitochondrial DNA—has become not just a laboratory technique, but a political act. Who in our society requests this sort of DNA analysis, and who provides it? Once people learn the results, who controls what those results mean? It is no longer just geneticists and population biologists, but also political activists, individuals claiming inclusion in a particular ethnic, racial, or national group, and those who must decide to accept or reject their claims.

To interpret the results of research with genetic markers means not just judging whether the laboratory used the right population-specific allele or had a large enough sample size. It also involves judging the worth of genetic knowledge against other kinds of claims to authentic identity and group membership (oral history, written documentation, cultural practices, inner convictions). What is at stake in genetically-based claims of identity or rightful belonging is not just good or bad science. What is at stake is also personal esteem and self-worth, group cohesion, access to resources, and the redressing of historical injustice.⁷⁴

71 T Parfitt, 'Genes, Religion, and History: The Creation of a Discourse of Origin Among a Judaizing African Tribe' (2002) 42 *Jurimetrics* 209. See also M Thomas and others, 'Y Chromosomes Traveling South: The Cohen Modal Haplotype and the Origins of the Lemba — The "Black Jews of Southern Africa"' (2000) 66 *American Journal of Human Genetics* 674.

72 There are now about 36,000 Falashas residing in Israel, having emigrated from Ethiopia in several waves since 1977.

73 C Elliott and P Brodwin, 'Identity and Genetic Ancestry Testing' (2002) 325 *British Medical Journal* 1469, 1470.

74 P Brodwin, *Genetics, Identity, and the Anthropology of Essentialism*, University of Minnesota Center for Bioethics, <www.bioethics.umn.edu/genetics_and_identity/anthro_of_essentialism.html>, 26 February 2003

36.55 Similarly, Professor Tudor Parfitt, who conducted the Lemba study, has noted that perceptions of genetic research may substantially influence aspects of group self-identity. This has the potential to cut both ways by providing

ammunition both for conservative forces in the preservation of their prejudices and for liberal groups who seek the elimination of differences among peoples.⁷⁵

Genetic testing and Aboriginality

36.56 In the Tasmanian ATSIC election controversy discussed above, some disputants talked about using genetic testing as a means of addressing the practical difficulty of proving their Aboriginal descent through direct documentary evidence. The argument goes that such people could instead provide scientific evidence that they are biologically related to a known Aboriginal person.

36.57 As suggested above, however, genetic kinship and ancestry testing has important limitations in practice. First, it relies on the availability of reference samples for comparison. If a living person wishes to establish that he or she is a member of a particular family group, the person must find someone within that group who can provide a genetic sample for the purpose of comparison. This becomes more difficult where a person seeks to establish a biological relationship with a person or family group that has been dead for years, decades or centuries.

36.58 John Presser, a forensic scientist, commented in a submission:

In conjunction with other information, especially lineage or family trees, mtDNA is informative as to aboriginality where an unbroken female lineage exists. But it is imperative to remember that if no 'aboriginal' sequence is found, this result is silent as to aboriginality, all you can say is that there is no direct female line of descent and the result is inconclusive. It does not prove non aboriginal descent.⁷⁶

36.59 Second, mtDNA and Y chromosome analysis are both extremely narrow in their focus when compared with the rich tapestry of a person's genetic ancestry. Elliott and Brodwin have written that:

The problem is that mapping Y chromosome and mitochondrial DNA polymorphisms will trace only two genetic lines on a family tree in which branches double with each preceding generation. For example, Y chromosome tracing will connect a man to his father but not to his mother, and it will connect him to only one of his four grandparents: his paternal grandfather ... Continue back in this manner for 14 generations and the man will still be connected to only one ancestor in that generation. The test will not connect him to any of the other 16,383 ancestors in that generation to which he is also related in equal measure.⁷⁷

75 T Parfitt, 'Genes, Religion, and History: The Creation of a Discourse of Origin Among a Judaizing African Tribe' (2002) 42 *Jurimetrics* 209.

76 J Presser, *Submission G183*, 3 October 2002.

77 C Elliott and P Brodwin, 'Identity and Genetic Ancestry Testing' (2002) 325 *British Medical Journal* 1469, 1469–1470. See also J Presser, *Submission G183*, 3 October 2002. This point was also made by Dr Ian Anderson of Melbourne University: M Langton and I Anderson, *Consultation*, Melbourne, 23 October 2002.

36.60 AIATSIS pointed to the inappropriateness of genetic testing in establishing Aboriginality, submitting that:

Pure scientific analysis of genetic identity cannot take stock of the effects of colonisation and past governmental policies. For example, a history of inter-marriage has resulted in large populations of Indigenous people of mixed descent, ie Indigenous and non-indigenous ancestry. Such ancestry generates extreme social and cultural complexity that has not been raised in this paper.

The inherent right (also contained in international conventions) to determine one's own cultural identity will be seriously eroded by a reliance upon a scientific method that has no capacity to consider cultural and social changes ...

Genetic testing provides no 'pure' point of reference for Aboriginal identity, especially given the history of colonisation in Australia. Scientists cannot now recover the control data that establishes the set of Indigenous genetic traits at contact. This raises the question of why Indigenous peoples have been singled out for particular attention for genetic testing?⁷⁸

36.61 Similarly, the Queensland Government commented that:

Caution should be given against the use of genetic tests as a primary tool of evidence and application should be limited, particularly given that it has only been in the last few years that any serious attempt has been made to collect tissue samples on a regular and systematic basis. It will always be difficult for Aboriginal and Torres Strait Islander people to trace their ancestry, in a physical sense, to some long distant ancestor.⁷⁹

36.62 The Human Genetics Society of Australia agreed that, in the absence of archival genetic material, genetic testing that identifies particular polymorphisms among a group might support the contention of common ancestry, but would not prove it definitively:

The relative isolation and small population base of indigenous peoples of Australia prior to European settlement makes it very likely that the frequency of many genetic polymorphisms in pre-European contact indigenous peoples differed from that of Europeans. Such differences may be expected to vary across the continent. A polymorphism absent or rare in Europeans but common in an ancestral indigenous population is likely to persist at a higher frequency in the descendants of that population than in peoples of European descent. Its presence at an appreciable frequency in a group claiming common ancestry would support the contention of common ancestry but not prove it. Its presence or absence in any given individual would not establish or refute membership of the group. None of the above, in the absence of archival genetic material, could establish association with a geographical location. Cultural and genealogical information is more likely to provide evidence of association between a group of indigenous individuals and a geographical location than genetic information.⁸⁰

78 Australian Institute of Aboriginal and Torres Strait Islander Studies, *Submission G286*, 16 December 2002.

79 Queensland Government, *Submission G274*, 18 December 2002.

80 Human Genetics Society of Australasia, *Submission G267*, 20 December 2002.

36.63 Genetic kinship testing is irrelevant where a person seeks to establish descent based on social or cultural—rather than biological—considerations. The Inquiry heard concerns that the use of genetic testing to establish biological relatedness would ultimately lead to a stronger emphasis on biological descent as an aspect of the legal definition of Aboriginality, and this would be contrary to traditional understandings of Aboriginal identity. AIATSIS challenged

the notion that Aboriginal identity can be determined through a eurocentric model of descent that privileges western familial structures. Indigenous familial structures differ in cultural organisation and historic context. For example adoption of children is a very common practice within extended families and regional clusters of families. It is also common for families to move great distances and be given rights to new territories. Models that identify genetic descent as the key to familial identity and land relations are highly inappropriate in this context.⁸¹

36.64 The South Australian Department of Human Services submitted that:

It is imperative that western notions of ‘biological’ family and kinship should not become the benchmark for the determination of what constitutes family and kin in the Aboriginal context. Aboriginal concepts of kinship should be equally respected in all legal proceedings addressing parenting rights and/or obligations. This is particularly relevant in many Torres Strait Islander communities where ‘traditional adoption’ between families is widely practiced.

Other ‘social’ means of establishing Aboriginality may be more important and it is this part of the identification process, which should be regulated by ATSIC.⁸²

36.65 AIATSIS also suggested that the use of genetic testing could be seen as a return to outmoded and offensive legal classifications of Aboriginality based on ‘strains of blood’, such as the classification of people as being of ‘half’, ‘quarter’ or ‘one-eighth’ Aboriginal descent:

A possible danger of such testing (amongst a range of others), is that testing will result in the exclusion of Indigenous people—in other words create a ‘blood rule’ not dissimilar to previous legislative regimes and the current situation in other jurisdictions. As has been demonstrated in the past, these methods for determining Indigenous identity are destructive, assimilationist and divisive.⁸³

36.66 Dr Loretta de Plevitz and Larry Croft summarised the four major barriers to proving Aboriginality by means of genetics as follows:

Firstly, there is no such thing as a genetically differentiated ‘race’: we are all one species. Secondly ... if race is defined by cultural and genetic context, then there are difficulties in proving membership of the ‘Aboriginal race’ as on this definition there were hundreds of Aboriginal races pre-1788. Thirdly, looking at the polymorphisms in an individual’s DNA shows us who they are related to. But this just defers the problem of whether those people related to the claimant are Aboriginal or not.

81 Australian Institute of Aboriginal and Torres Strait Islander Studies, *Submission G286*, 16 December 2002.

82 Department of Human Services South Australia, *Submission G288*, 23 December 2002.

83 Australian Institute of Aboriginal and Torres Strait Islander Studies, *Submission G286*, 16 December 2002.

Fourthly, who could the claimant's genetic inheritance be tested against? It would be necessary to construct DNA reference groups based on 'pure blood' Aboriginal people covering all geographic groups in Australia. If by chance one of the reference DNA groups was very similar to the claimant's then we can show descent ... as the Australian Aboriginal population is so genetically diverse, there would need to be a large reference set of people for all genetically distinct groups ... Where there has been the wholesale extermination of entire groups of people, claimants attempting to prove their Aboriginality may not be related to any of the reference groups because there is no longer a reference group for them.⁸⁴

36.67 Concern also was expressed in consultations that if genetic kinship testing were used in this context, even on a voluntary basis, this might lead to undue pressure being placed on persons to 'prove' affirmatively their descent through testing. Such pressure might come from government departments or other service providers, or perhaps from people within their own communities. The imperative to submit to genetic testing runs contrary to ethical principles, including the principles of autonomy, informed consent and the individual's 'right not to know'. Further, any requirement that a person must prove his or her descent through genetic testing in order to access goods, services or other facilities may contravene the *Racial Discrimination Act 1975* (Cth).⁸⁵

36.68 In their submission, de Plevitz and Croft commented that compelling persons to undergo any genetic testing in order to confirm their Aboriginal identity would serve to compound their social disadvantage:

Other disadvantaged groups such as the poor, the uneducated or the disabled do not have such requirements of proof to access benefits. ... Aboriginal people will walk away from such humiliation rather than face legal questioning on their identity. An Australian legal test based on cultural difference would fulfil the same purpose as the descent test without its potentially divisive effects.⁸⁶

36.69 Dr Paul Henman also submitted that any shift towards genetic testing to determine eligibility to Indigenous programs, policies and benefits should be resisted because social processes are much more significant than genetic processes in determining identity:

Policy makers should be encouraged to ensure that the eligibility criteria to policies and programs aimed at Aboriginal and Torres Strait Islanders give greater importance to cultural, rather than genetic, identity. Having said this, genetic information may be important in testing claims of genetic identity. Even so, genetic heritage should not necessarily constitute immediate eligibility to such programs. Programs aimed at individuals who have been forcibly removed from their cultural heritage—such as the 'Stolen Generation'—may also find it appropriate to use genetic information.⁸⁷

84 L de Plevitz and L Croft, *Submission G115*, 13 March 2002. Dr de Plevitz is a lecturer in the Faculty of Law, Queensland University of Technology; Mr Croft is employed by the Institute for Molecular Biosciences, University of Queensland.

85 See *Racial Discrimination Act 1975* (Cth) s 9.

86 L de Plevitz and L Croft, *Submission G115*, 13 March 2002.

87 P Henman, *Submission G055*, 15 January 2002. Dr Henman is a Research Fellow in Sociology at Macquarie University.

36.70 The Inquiry considers that under no circumstances should any person be required to undergo genetic testing to establish their Aboriginal descent. As noted above, this would have significant ethical implications, and would arguably constitute racial discrimination against Aboriginal persons.

Identity and self-determination

36.71 While the Inquiry remains sceptical about the wisdom of using genetic kinship testing to establish Aboriginality, the Inquiry agrees unequivocally with the view that matters of Aboriginal identity are primarily for Aboriginal communities to determine.

36.72 The Anti-Discrimination Board of NSW submitted that:

The central issue is ... whether it is appropriate to use genetic information to determine community, racial and ethnic affiliation. This is a question better answered by Indigenous communities themselves. We are concerned that should a purely genetic approach to community, racial and ethnic affiliation be adopted, it is conceivable that people who identify as indigenous and are accepted within Indigenous communities as Indigenous may be refused access to Indigenous services programs and benefits, which were specifically designed to address disadvantage of Indigenous people.⁸⁸

36.73 The Law Institute of Victoria agreed that matters of Aboriginal or Torres Strait Islander identity should be primarily determined by Aboriginal communities.⁸⁹

36.74 The Inquiry agrees that the construction of Indigenous identity is quintessentially a matter for Aboriginal and Torres Strait Islander people themselves, working through their own communities, institutions and consultation processes. As noted at the beginning of this chapter, AIATSIS suggested that the ALRC might have a role to play in this process in lending:

expertise to develop, through extensive consultation and negotiation with Indigenous peoples and communities, identity frameworks that are appropriate and relevant for Aboriginal and Torres Strait Islander peoples.⁹⁰

36.75 It is hoped that the material in this chapter may provide some assistance in this endeavour.

⁸⁸ Anti-Discrimination Board of NSW, *Submission G157*, 1 May 2002.

⁸⁹ Law Institute of Victoria, *Submission G275*, 19 December 2002.

⁹⁰ Australian Institute of Aboriginal and Torres Strait Islander Studies, *Submission G286*, 16 December 2002.

37. Immigration

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Introduction

37.1 This chapter examines the law and practices that regulate the use of genetic testing for migration decision making under the *Migration Act 1958* (Cth) (*Migration Act*), the *Migration Regulations 1994* (Cth) (*Migration Regulations*) and the Department of Immigration and Multicultural and Indigenous Affairs (DIMIA) Procedures Advice Manual.

37.2 Genetic testing has two possible applications in the migration context:

- kinship testing—to confirm family relationships for certain types of visas and to detect fraud (such as sibling marriages and child trafficking) for the purpose of migration applications; and
- health testing—to make determinations on the health status of people applying to migrate.

37.3 The Minister for Immigration and Multicultural and Indigenous Affairs has indicated that, in future, genetic testing might also be used (along with other biometric tests) to identify asylum seekers; to ensure that they do not already have protection elsewhere; and to ensure that they have not previously been refused refugee status by another country.¹ The Inquiry understands that legislation for the use of biometric

¹ L. Porter, 'DNA Tests to Screen Migrants', *Sunday Age* (Melbourne), 5 May 2002, 3; Minister for Immigration and Multicultural and Indigenous Affairs, *Ruddock Announces Tough New Initiatives*, Media Release, 13 October 1999.

identification tests is currently under development. Early draft policies included the possibility of using genetic tests, but these tests have subsequently been excluded because they are slower than other biometric identification, such as photographs, fingerprints, and height and weight data.² If, in the future, DIMIA wished to use genetic tests for identification purposes, it would clearly be desirable to ensure privacy protection for the personal information generated in the process.

37.4 DIMIA is responsible for the use made of genetic test results in migration decision making. DIMIA has developed internal policies and practices on the use of genetic tests for these purposes, which are set out in its Procedures Advice Manual.³ These policies and practices must not be inconsistent with the *Migration Act* and the *Migration Regulations*.⁴

37.5 Genetic test results held by DIMIA are subject to the *Privacy Act 1988* (Cth) (*Privacy Act*) and to the Information Privacy Principles, even where test information is collected by DIMIA officers overseas.⁵ Test results held by private testing laboratories are generally subject to the private sector provisions of the *Privacy Act* and the National Privacy Principles.⁶

37.6 The *Disability Discrimination Act 1992* (Cth) (DDA) contains a specific exemption in relation to migration. Section 52 provides that any discriminatory provisions in the *Migration Act*, any regulation made under the Act, or any act done by a person in relation to the administration of the Act or regulations, are not unlawful under the DDA. As a result, conduct that would otherwise be unlawful under the DDA because it involves discrimination on the basis of genetic status is lawful, provided the conduct complies with the migration legislation.⁷ The framework of Australian anti-discrimination law is outlined in Chapter 9.

Kinship testing

37.7 Australian immigration law and many international instruments recognise the importance of facilitating family reunification for humanitarian and other reasons. The *Convention on the Rights of the Child 1989* stresses the need for governments to process applications involving family reunification in a 'positive, humane and expeditious manner'⁸ where children are involved.

2 Department of Immigration and Multicultural and Indigenous Affairs, *Consultation*, Canberra, 20 November 2002.

3 Department of Immigration and Multicultural and Indigenous Affairs, *Procedures Advice Manual (PAM3)* (1994–2002), DIMIA, Canberra Div 1.2 r 1.12, Member of the Family Unit.

4 *Drake v Minister for Immigration and Ethnic Affairs* (1979) 46 FLR 409, 419–420.

5 *Privacy Act 1988* (Cth) s 8(1). See generally Ch 7.

6 Unless the laboratory is a contracted service provider under a Commonwealth contract: *Ibid* s 6A(2).

7 See further on the reasoning behind this exemption: Department of Immigration and Multicultural and Indigenous Affairs, *Submission G272*, 23 December 2002.

8 *Convention on the Rights of the Child*, opened for signature 20 November 1989, UNTS 1588, (entered into force on 16 January 1991) art 10.

37.8 Some visas granted under the *Migration Act* require an applicant to demonstrate certain familial relationships. These applications fall into one of two programs:

- the Migration Program; or
- the Humanitarian Program.

37.9 The Migration Program comprises two visa streams: the Skilled Stream and the Family Stream. Entry to Australia via the Skilled Stream is open to potential migrants who have skills or abilities that will contribute to the Australian economy. One visa subclass within this stream enables the migration of skilled relatives of Australians.⁹ Family Stream visas are based on an applicant's relationship to an Australian citizen, an Australian permanent resident or an eligible New Zealand citizen. This relationship can include immediate family members, orphaned child relatives, those undertaking care of an Australian relative, and other close relatives.¹⁰

37.10 The Humanitarian Program is divided into offshore and onshore components. Within the offshore component, individuals may apply for visas either under the refugee category or the Special Humanitarian Program. Within the onshore component, individuals may apply for either temporary or permanent protection visas. Under the Special Humanitarian program, individuals can apply for humanitarian entry to Australia where they can show an immediate familial relationship to a person holding a permanent protection visa inside Australia, or to a person holding a permanent entry visa outside Australia.¹¹ In this context, immediate family members include dependent children, spouse and parents.¹²

37.11 In addition, individuals applying for almost any kind of offshore visa may include members of the family unit within the application. The *Migration Regulations* define a 'member of the family unit' to include a spouse, a dependent child of either the head of the family or the spouse and his or her children, and other relatives usually living within the family household who are dependent on the head of the family and are unmarried.¹³

37.12 DIMIA uses genetic test information to help determine the existence of family relationships in a very small proportion of cases that fall within the programs outlined above. The Procedures Advice Manual provides policy and procedural guidance for DIMIA officers regarding the use of genetic parentage and other kinship

9 *Migration Regulations 1994* (Cth) Sch 1, Visa Class 1128B, visa 138. See also Department of Immigration and Multicultural and Indigenous Affairs, *Submission G272*, 23 December 2002.

10 Department of Immigration and Multicultural and Indigenous Affairs, *Submission G272*, 23 December 2002.

11 *Migration Regulations 1994* (Cth) Sch 1, Visa Class 1402; Department of Immigration Multicultural and Indigenous Affairs, *Form 964i — Entry to Australia (Offshore Humanitarian Program)* (2002), Commonwealth of Australia, Canberra; Department of Immigration and Multicultural and Indigenous Affairs, *Form 842 — Application for an Offshore Humanitarian Visa (Refugee and Humanitarian (Class XB) visa)* (2002), Commonwealth of Australia, Canberra.

12 *Migration Regulations 1994* (Cth) r 1.12AA. See also Department of Immigration and Multicultural and Indigenous Affairs, *Submission G272*, 23 December 2002.

13 *Migration Regulations 1994* (Cth) r 1.12.

testing. This advice extends to the standards that testing procedures must meet, the circumstances in which testing should be offered, and how the integrity of the sample is to be protected.¹⁴

37.13 The Procedures Advice Manual notes that officers may only *offer* genetic testing; they do not have power to compel an applicant to undergo genetic testing.¹⁵ Although laboratories send results to applicants in some cases, test results are usually sent to DIMIA, which then informs the applicant of the results in writing, either directly or through an English-speaking sponsor.

37.14 Generally, genetic testing for kinship is used to support applications, but on occasion DIMIA uses genetic testing where fraud is suspected, for example if the applicant and sponsor are thought to be siblings'.¹⁶ Testing may also be used as evidence of child trafficking by demonstrating that a woman who is relinquishing a child to another person is not the biological parent of that child.¹⁷

37.15 Genetic testing is also used to determine family relationships for the purpose of migration in other countries, including Canada, the United Kingdom and a number of European countries, subject to procedures similar to those used in Australia.¹⁸

Family Stream and Skilled Stream

37.16 DIMIA uses about 200 genetic tests per year to help verify claimed relationships in Family Stream cases. For example, in the 2001–2002 program year, 206 tests were used for Family Stream cases, and none for the Skilled Stream.¹⁹ This represents about 0.5% of the overall family migration intake.

37.17 Genetic testing may be required to establish the relationship between the applicant and sponsor, or to establish the applicant's family composition. Generally, genetic testing will involve parentage testing but it might also be used to test extended family connections, such as sibling or grandparent-grandchild relationships. In less straightforward cases, the Procedures Advice Manual suggests that the laboratory may need to analyse samples from relatives who are not directly involved in the migration application. For instance, if it is suspected that either of two brothers may be the father

14 Department of Immigration and Multicultural and Indigenous Affairs, *Procedures Advice Manual (PAM3)* (1994–2002), DIMIA, Canberra Div 1.2 r 1.12, Member of the Family Unit.

15 Ibid, Div 1.2 r 1.12, Member of the Family Unit [43.2].

16 Ibid, Div 1.2 r 1.12, Member of the Family Unit [35.1].

17 Department of Immigration and Multicultural and Indigenous Affairs, *Submission G272*, 23 December 2002.

18 See eg Citizenship and Immigration Canada, *Overseas Processing Manual, Chapter OPI — General Procedural Guidelines* (2000), CIC [5.9], [14], [15]; *Aliens (Consolidation) Act 2001* (Denmark) s 40(c); *The Finnish Aliens Act 1991* (Finland) s 18(c); B Roeper, 'Germany Approves DNA Tests for Visas' (1998) 391 *Nature* 723; International Organization for Migration, *Exploring the Use of DNA Testing for Family Reunification* (2001), IOM, Geneva, 13–22.

19 Department of Immigration and Multicultural and Indigenous Affairs, *Submission G272*, 23 December 2002.

of a child, more extensive testing may be required to exclude individuals who are not the parents.²⁰

37.18 Genetic testing is considered most useful in regions where there is a high incidence of document fraud or in countries where official documentation is unavailable.²¹ The Procedures Advice Manual states that genetic testing should be used as a ‘last resort’ where claims are doubtful or if credible documentation cannot be provided to substantiate the claims. Genetic testing should not be used in cases where:

- without undue deliberation officers would ordinarily approve a case on the available documentation by extending the benefit of the doubt; or
- doubts about a case are such that the decision maker would ordinarily have no hesitation in refusing the case.²²

37.19 In its submission to the Inquiry, DIMIA emphasised that genetic testing is offered only in the most problematic cases, which might otherwise be refused.²³

37.20 DIMIA recognises that applicants may refuse testing for reasons of cost, religion, or practical difficulties such as the inability to locate non-migrating relatives whose samples are needed for testing.²⁴ Consequently, the Procedures Advice Manual suggests that, as the costs of genetic testing may be prohibitive for some applicants, an officer should give little weight to an applicant’s decision not to undergo testing, when making a decision on a case.²⁵ In contrast, Applicants are notified that if they refuse to be tested, DIMIA’s decision on the application will be based on the available evidence and the reasons for refusal will be taken into account.²⁶ The Procedures Advice Manual notes elsewhere that testing is a “‘self-selection” procedure’ as ‘non-genuine applicants tend not to proceed with DNA testing’.²⁷

37.21 Where an applicant undergoes genetic testing but does not authorise the release of the test results to DIMIA, the guidelines suggest this may increase existing doubts about the relationship, but that the person should be given an opportunity to explain.²⁸

20 Department of Immigration and Multicultural and Indigenous Affairs, *Procedures Advice Manual (PAM3)* (1994–2002), DIMIA, Canberra Div 1.2 r 1.12, Member of the Family Unit [40.1].

21 Ibid, Div 1.2 r 1.12, Member of the Family Unit [35.1].

22 Ibid, Div 1.2 r 1.12, Member of the Family Unit [31.2], [34.1].

23 Department of Immigration and Multicultural and Indigenous Affairs, *Submission G272*, 23 December 2002.

24 For example, Jehovah’s Witnesses have refused to undergo testing on religious grounds: *Uyanze v Minister of Citizenship and Immigration* (Immigration and Refugee Board, IAD V98-03773, 4 February 2000).

25 Department of Immigration and Multicultural and Indigenous Affairs, *Procedures Advice Manual (PAM3)* (1994–2002), DIMIA, Canberra Div 1.2 r 1.12, Member of the Family Unit [43.2].

26 Department of Immigration and Multicultural and Indigenous Affairs, *Submission G272*, 23 December 2002.

27 Department of Immigration and Multicultural and Indigenous Affairs, *Procedures Advice Manual (PAM3)* (1994–2002), DIMIA, Canberra Div 1.2 r 1.12, Member of the Family Unit [34.1]. This observation is made in the context of a statement that genetic testing can assist genuine applicants who do not possess official documentation to confirm relationships.

28 Ibid, Div 1.2 r 1.12, Member of the Family Unit [43.4.]

37.22 The Procedures Advice Manual notes that different cultures have different concepts of the family unit and that applicants may not fully appreciate that genetic testing is a test only of biological parentage. The Procedures Advice Manual states that suspected ‘non-birth’ children may still be eligible as ‘members of the family unit’, and advises case officers to consider different concepts of family before offering genetic testing.²⁹ Adopted children may be included as members of the family unit, whether adopted by legal means or through ‘customary adoption’. The *Migration Regulations* acknowledge customary adoptions where:

- the adoption occurred in accordance with usual practice or a recognised custom in the culture of the adoptee and adopter;
- the child-parent relationship between the adopter and adoptee is significantly closer than any such relationship between the adoptee and any other person;
- formal adoption was not available or reasonably practicable; and
- the arrangement has not been contrived to circumvent Australian migration requirements.³⁰

37.23 In Family and Skilled Stream cases, visa applicants must pay the cost of securing any evidence requested by DIMIA as proof of assertions made in the application. This includes the cost of genetic testing.³¹ Testing fees are usually \$1000 for a single parent-child test, and increase by several hundred dollars for each extra person sampled.³² In tests offered by DIMIA, the person tested consents to the laboratory providing the results directly to DIMIA.

Humanitarian Program

37.24 The Procedures Advice Manual notes that although its guidance on genetic kinship testing is primarily directed to Family Stream cases, in certain circumstances it may be applicable in Special Humanitarian Program decision making.³³ Examples are where a child has different physical features to other family members; the claimed date of birth seems improbable; or certain background issues raise questions of bona fides. Testing in these cases is performed in the same way as testing in Family Stream cases and is subject to the same guidelines.

37.25 The Procedures Advice Manual suggests that humanitarian and refugee assessment officers should only offer testing in Humanitarian Program cases as a last resort. This is due to the cost of testing and the sensitivities involved in the assessment

29 Ibid, Div 1.2 r 1.12, Member of the Family Unit [34.2].

30 *Migration Regulations 1994* (Cth) r 1.04(2).

31 Department of Immigration and Multicultural and Indigenous Affairs, *Procedures Advice Manual (PAM3)* (1994–2002), DIMIA, Canberra Div 1.2 r 1.12, Member of the Family Unit [42.1].

32 Ibid, Div 1.2 r 1.12, Member of the Family Unit [42.1].

33 Ibid, Div 1.2 r 1.12, Member of the Family Unit [36.1].

of humanitarian cases.³⁴ In the 2001–2002 program year, genetic tests were used in ten Humanitarian visa applications.³⁵

37.26 As with Family and Skilled Stream cases, the applicant bears the cost of testing, except in special cases—such as refugee applications—where testing may be conducted at the government’s expense.³⁶

Genetic testing laboratories

37.27 The Procedures Advice Manual states that DIMIA adopts the benchmark guidelines established in the *Family Law Regulations 1984* (Cth) (FL Regulations) in relation to the level of accuracy required for genetic parentage testing (see Chapter 35). As a matter of policy, it is recommended that cases be referred to two Australian laboratories that have been accredited by the National Association of Testing Authorities, Australia (NATA) for parentage testing—DNALABS.SIVF and Genetic Technologies.³⁷

37.28 The Procedures Advice Manual specifies circumstances in which it might be appropriate to use different testing laboratories. These include situations where all sample donors are offshore or where clients refuse to use the DIMIA-recommended laboratories. While DIMIA cannot prohibit an applicant from having a test performed at a laboratory of his or her choice, the Manual states that applicants should be counselled about the ‘potential difficulties’ of having tests performed by other laboratories. These difficulties include unexpected costs, administrative difficulties associated with international cases, testing capacity (some laboratories lack the capacity to test a range of racial groups), and the sample types the laboratory is capable of testing.³⁸

The offer of testing

37.29 Once it has been determined that genetic testing is appropriate, the Procedures Advice Manual lays down a suggested checklist of procedures. Officers are directed to check with the laboratory that the required testing is possible and to determine which relatives must be sampled. An offer of genetic testing is then made to the applicant in writing.

37.30 A standard letter is available, which covers most points. However the Procedures Advice Manual indicates that officers should be prepared to offer personal counselling on:

34 Ibid, Div 1.2 r 1.12, Member of the Family Unit [36.2].

35 Department of Immigration and Multicultural and Indigenous Affairs, *Submission G272*, 23 December 2002.

36 Department of Immigration and Multicultural and Indigenous Affairs, *Procedures Advice Manual (PAM3)* (1994–2002), DIMIA, Canberra, Div 1.2 r 1.12, Member of the Family Unit [36.3].

37 Ibid, Div 1.2 r 1.12, Member of the Family Unit [37.1].

38 Ibid, Div 1.2 r 1.12, Member of the Family Unit [38.3], [38.5].

- why genetic testing is being offered;
- the applicant's right of refusal;
- the conclusive nature of results;
- the sampling procedure; and
- costs.

37.31 This letter is sent either to the applicant or, where there are language barriers, to the Australian sponsor. The sponsor is then responsible for explaining the offer to the applicant. If the offer of testing is accepted, the Procedures Advice Manual suggests that case officers first check that the applicant can satisfy any health and character requirements. This is done to spare applicants who will fail these criteria the unnecessary cost of genetic testing.

37.32 At present, testing laboratories use forms tailored to sampling under the FL Regulations. The Inquiry understands that DIMIA is considering the development of migration-specific forms, which will include information about the purpose of testing. The forms will require consent to the release of results directly to DIMIA.³⁹

Identity fraud

37.33 The Procedures Advice Manual notes the possibility of 'identity fraud' in relation to sample collection.

The recommended laboratories have measures in place to minimise the incidence of identity fraud at the time of sample collection. Even so, there are still avenues for fraud through the presentation at sampling of a birth child instead of a non-birth child, exchange of samples or collusion with doctors. In the case of suspected 'sibling' marriages, it would be a simple matter for an applicant to send a completely unrelated person to donate a sample, thereby achieving the desired result.⁴⁰

37.34 DIMIA has procedures to address concerns about identity fraud. In relation to offshore sample collection, the Procedures Advice Manual suggests that a migration officer should be present at the time of collection to verify the donor's identity, witness the test and ensure secure dispatch of the sample.⁴¹ For onshore sample collection, the Manual suggests that sample collectors at pathology outlets should check the donor's identity against photographs, driver's licence, passport and so on. For onshore cases, regional offices are advised to send a migration officer to witness the taking of the sample.⁴²

39 Department of Immigration and Multicultural and Indigenous Affairs, *Submission G272*, 23 December 2002.

40 Department of Immigration and Multicultural and Indigenous Affairs, *Procedures Advice Manual (PAM3)* (1994–2002), DIMIA, Canberra, Div 1.2 r 1.12, Member of the Family Unit [41.2].

41 Ibid, Div 1.2 r 1.12, Member of the Family Unit [41.2].

42 Ibid, Div 1.2 r 1.12, Member of the Family Unit [41.3].

Issues and problems

37.35 A range of concerns arise from the use of genetic testing to establish familial relationships for the purposes of migration decision making. These include:

- the lack of express backing for genetic testing in legislation or regulations;
- the absence of a requirement that applicants be given information about the possible consequences of kinship testing or that they be informed about counselling;
- privacy concerns in relation to the delivery of genetic test results;
- the potential for identity fraud in the collection of samples for testing; and
- the cost of testing for migration applicants.

Lack of legislative backing for testing

37.36 At present, there is no specific backing for genetic kinship testing in migration decision making in either the *Migration Act* or *Migration Regulations* because DNA testing is not a legal requirement for the grant of a visa. The procedures for requesting and administering testing are covered only by departmental guidelines contained in the Procedures Advice Manual. This raises questions about the adequacy of protections afforded to applicants.

37.37 As previously mentioned, Family Stream and Skilled Stream applicants are not compelled to undergo genetic testing. The Inquiry understands that DIMIA has no immediate intention to legislate for the use of genetic testing in Family Stream and Skilled Stream cases. DIMIA stated in its submission that to do so would be

extraordinarily complex given the widely varying probabilities which can be reached according to the type of relationship being tested and the relatives available to be sampled.⁴³

37.38 DIMIA also pointed out that this complex issue is best dealt with in policy documents, and that other safeguards to protect applicants are already in place. These include the inclusion of procedural fairness principles in the Procedures Advice Manual and the operation of the *Privacy Act*. DIMIA highlighted the policy of offering genetic testing only as a last resort as a factor weighing against legislative change. It also noted that in a recent international inquiry its procedures were compared favourably with other countries.⁴⁴

43 Department of Immigration and Multicultural and Indigenous Affairs, *Submission G272*, 23 December 2002.

44 Ibid.

Consent, counselling and the provision of information

37.39 Chapter 35 discussed the emotional impact that parentage testing may have on children and parents. These effects result from the potential of tests to reveal sensitive information about the composition of a family. For example, kinship testing may reveal the unexpected information that a child is not the biological offspring of his or her ‘social’ parent. Such information may have a disruptive or emotionally distressing effect on families.⁴⁵

37.40 While applicants must be made aware that kinship testing is voluntary and not a requirement of a migration application, the Procedures Advice Manual does not require the provision of information about the potential consequences of testing. However, officers are required to advise the applicant of why testing is being offered, the right to refuse testing, the conclusive nature of results, the sampling procedure and its cost.

37.41 Additionally, the Procedures Advice Manual does not require applicants to be informed of the availability or desirability of counselling. In Chapter 35, the Inquiry notes that counselling can be an effective means of ameliorating some of the potentially adverse consequences of parentage testing, especially for children. The same is true of kinship testing in the context of migration.

Privacy concerns

37.42 The potentially sensitive nature of genetic kinship test results raises privacy concerns. At present, test results are often delivered to an applicant’s English-speaking sponsor, who is responsible for translating and delivering the results. In doing so, the sponsor may become aware of information that was previously unknown to the applicant or kept confidential, and which the applicant may not want the sponsor to know.

37.43 For some applicants, this disclosure might be distressing or dangerous. Consider an example raised in one submission of test results that show a female applicant’s child is not the biological offspring of her husband. If these results are delivered to her husband, as her English-speaking sponsor, they may reveal an infidelity. In some countries adultery is punishable by death and revealing the test results could therefore endanger the applicant’s life.⁴⁶

37.44 The Procedures Advice Manual notes that there are significant confidentiality issues associated with genetic kinship testing and suggests ‘test results should be handled accordingly’.⁴⁷ However, the Procedures Advice Manual does not provide guidance on protecting the privacy of genetic test results, nor does it direct

45 J Taitz, J Weekers and D Mosca, ‘DNA and Immigration: the Ethical Ramifications’ (2002) 359 *Lancet* 794, 794; J Taitz, J Weekers and D Mosca, ‘The Last Resort: Exploring the Use of DNA Testing for Family Reunification’ (2002) 6 *Health and Human Rights* 21, 27.

46 Immigration Advice and Rights Centre, *Submission G297*, 3 January 2003.

47 Department of Immigration and Multicultural and Indigenous Affairs, *Procedures Advice Manual (PAM3)* (1994–2002), DIMIA, Canberra [43.1].

officers to warn applicants about the consequences of unexpected results. As noted above, information held by DIMIA in relation the migration applications is covered by the provisions of the *Privacy Act*.

Integrity of the testing process

37.45 The Procedures Advice Manual requires migration officers to be present when samples are collected offshore. In onshore cases, a migration officer need not be present to check the identity of a donor. This could provide an opportunity for applicants to give false samples.

37.46 As discussed in Chapter 35, NATA accredited laboratories generally comply with the FL Regulations in the conduct of parentage testing. However, NATA permits accredited laboratories to conduct testing that does not comply with these requirements in certain circumstances.⁴⁸ The FL Regulations prescribe procedures in relation to the collection, storage and transportation of samples to the laboratory.⁴⁹

37.47 As already noted, the Procedures Advice Manual does not require onshore testing to be undertaken by NATA accredited laboratories, although migration officers should endeavour to ensure testing is carried out at laboratories recommended by DIMIA. The Manual states that laboratories will usually have their own procedures for ensuring the integrity of testing, and these procedures are relied upon as protection against identity fraud. As migration officers do not require applicants to use a particular laboratory to perform the tests, this may allow applicants to have testing carried out at laboratories with less stringent controls.

37.48 When an applicant seeks to have testing performed by a non-accredited or overseas laboratory, applicants are counselled on the potential difficulties of using other laboratories, including costs and inadequate facilities.⁵⁰ DIMIA will also investigate the laboratory's testing standards to ensure that the results will be acceptable evidence of kinship.⁵¹ With the applicant's permission, DIMIA may request evidence of the identity checking measures undertaken by a laboratory, as well as its testing system. If the applicant refuses permission, or if DIMIA is not satisfied of the integrity of the testing procedure, DIMIA may request the applicant to undergo testing through a DIMIA-approved laboratory, or may decide the case on the existing evidence.

Cost of testing

37.49 Because of the high cost of testing, some applicants may choose not to undergo genetic kinship testing to prove a familial relationship. If the application is unsuccessful for that reason, the substantial cost of the migration application will have

48 National Association of Testing Authorities Australia, *Correspondence*, 12 April 2002.

49 *Family Law Regulations 1984* (Cth) Pt IIA, Div 2, 3.

50 Department of Immigration and Multicultural and Indigenous Affairs, *Procedures Advice Manual (PAM3)* (1994–2002), DIMIA, Canberra, Div 1.2 r 1.12, Member of the Family Unit [38.3].

51 Department of Immigration and Multicultural and Indigenous Affairs, *Submission G272*, 23 December 2002.

been incurred in vain. This suggests the importance of applicants having advance notice of the possibility of genetic testing and the cost of doing so.

Submissions and consultations

37.50 In consultations, both the Refugee Advocacy Service of South Australia and the Immigration Advice and Rights Centre (IARC) voiced concern about the adequacy and consistency of information provided to applicants about genetic testing. It was also suggested that the framing of letters offering testing might lead some applicants to regard testing as a requirement, rather than as an opportunity to provide additional evidence.⁵² IARC suggested that some of these problems could be overcome by informing applicants at the start of the application process that they may be requested to undergo genetic testing.⁵³

37.51 DP 66 proposed that DIMIA should review its policies and procedures on the provision of information to applicants about kinship testing, particularly with respect to the implications of testing and the desirability of seeking counselling before or after testing.⁵⁴ Submissions expressed considerable support for this proposal, and many, such as the Migration Institute of Australia, noted the importance of providing sufficient information to applicants about the testing process, its implications, and the benefits of counselling if an unexpected result is produced.⁵⁵ The Centre for Genetics Education suggested that DIMIA officers should be educated about genetic testing to better equip them in advising applicants. The Association of Genetic Support Australasia agreed,⁵⁶ while the Department of Human Services South Australia highlighted the importance of obtaining fully informed consent to testing.⁵⁷

37.52 Concern was also expressed about the current application of DIMIA policy and the Procedures Advice Manual provisions. IARC stated that in its experience 'the practice of offering genetic testing does not always reflect [DIMIA] policy guidelines' and that 'increasingly, genetic testing is *not* only being offered as a last resort'. IARC suggested that at times genetic testing is used as a 'blanket response to problems of, or perceptions of, document fraud in particular countries and regions'. IARC argued that in doing so, DIMIA had placed the burden of proving relationship onto the applicant, disadvantaging those who might wish to use other forms of proof in support.⁵⁸

52 Refugee Advocacy Service of South Australia, *Consultation*, Adelaide, 30 October 2002; Immigration Advice and Rights Centre, *Consultation*, Sydney, 14 November 2002.

53 Immigration Advice and Rights Centre, *Consultation*, Sydney, 14 November 2002.

54 Australian Law Reform Commission and Australian Health Ethics Committee, *Protection of Human Genetic Information*, DP 66 (2002), ALRC, Sydney, Proposal 33–1.

55 Migration Institute of Australia, *Consultation*, Sydney, 14 November 2002; Genetic Support Council WA, *Submission G243*, 19 December 2002; Law Institute of Victoria, *Submission G275*, 19 December 2002; Human Genetics Society of Australasia, *Submission G267*, 20 December 2002; Department of Human Services South Australia, *Submission G288*, 23 December 2002; Centre for Genetics Education, *Submission G232*, 18 December 2002; Association of Genetic Support of Australasia, *Submission G284*, 25 December 2002.

56 Centre for Genetics Education, *Submission G232*, 18 December 2002; Association of Genetic Support of Australasia, *Submission G284*, 25 December 2002.

57 Department of Human Services South Australia, *Submission G288*, 23 December 2002.

58 Immigration Advice and Rights Centre, *Submission G297*, 3 January 2003.

37.53 IARC suggested that one solution to this issue would be for DIMIA to inform applicants of the reason why the documents offered as proof of a relationship have been doubted. This would allow applicants to respond directly to these concerns, which might be resolved without recourse to expensive genetic tests. IARC also pressed for applicants to be notified more fully of the adverse inferences that might be drawn from a refusal to be tested.⁵⁹

37.54 DIMIA, in its submission, stressed that the Procedures Advice Manual guides officers to place little weight on an applicant's decision to refuse testing. DIMIA also noted that officers are expected to take account of the many valid reasons why applicants might refuse testing.⁶⁰ The Inquiry understands that DIMIA intends to develop guidelines on the provision of counselling.⁶¹

37.55 DIMIA also submitted that it might consider widening the number of NATA accredited laboratories available for migration purposes. If so, these laboratories might be listed by gazettal, or employed as service providers under contract to the Commonwealth. In either case, DIMIA suggested that this could provide a statutory basis for the protection of genetic information in the migration context.

37.56 DP 66 also proposed that DIMIA should review the adequacy of its policies and procedures for dealing with identity fraud in relation to kinship testing.⁶² Submissions generally agreed with this proposal. For example, the Institute of Actuaries of Australia stressed that the integrity of the genetic testing process needed to be carefully maintained, and that DIMIA should pay careful attention to this matter.⁶³

37.57 Submissions responded favourably to the suggestion in DP 66 that the procedures for conducting genetic kinship testing be given more formal status in the *Migration Regulations*.⁶⁴ The Association of Genetic Support of Australasia suggested this would increase the transparency of genetic kinship testing procedures.⁶⁵ The Migration Institute of Australia submitted that placing safeguards on genetic testing in legislation, which is subject to parliamentary scrutiny, is preferable to placing such protections in internal policy documents.⁶⁶ Other submissions pointed out that the lack of legal consequences for an officer's failure to follow the Procedures Advice Manual was problematic.⁶⁷

59 Immigration Advice and Rights Centre, *Consultation*, Sydney, 14 November 2002.

60 Department of Immigration and Multicultural and Indigenous Affairs, *Submission G272*, 23 December 2002.

61 Ibid.

62 Australian Law Reform Commission and Australian Health Ethics Committee, *Protection of Human Genetic Information*, DP 66 (2002), ALRC, Sydney, Proposal 33–2.

63 Institute of Actuaries of Australia, *Submission G224*, 29 November 2002.

64 Department of Human Services South Australia, *Submission G288*, 23 December 2002; Centre for Genetics Education, *Submission G232*, 18 December 2002; Association of Genetic Support of Australasia, *Submission G284*, 25 December 2002; Migration Institute of Australia, *Submission G316*, 5 March 2003; Refugee Advocacy Service of South Australia, *Consultation*, Adelaide, 30 October 2002; Migration Institute of Australia, *Consultation*, Sydney, 14 November 2002.

65 Association of Genetic Support of Australasia, *Submission G284*, 25 December 2002.

66 Migration Institute of Australia, *Consultation*, Sydney, 14 November 2002.

67 Immigration Advice and Rights Centre, *Submission G297*, 3 January 2003.

37.58 DIMIA, however, opposed legislating for the use of genetic kinship testing. The Department commented that legislation might ‘bind the decision-maker to accept or reject test results which are scientifically open-ended’. Decision makers should be able to decide cases in the light of all available evidence. Where kinship tests are used to establish more remote relationships, decision makers should also be able to take account of their potentially inconclusive nature.⁶⁸

37.59 More generally, the Androgen Insensitivity Syndrome Support Group Australia recommended the proposed Human Genetics Commission of Australia (HGCA) advise on the development of guidelines for the use of genetic testing in migration decision making.⁶⁹

Inquiry’s views

37.60 The Inquiry considers that the use of genetic kinship testing in migration decision making should be subject to more formal and comprehensive control to protect individual privacy and personal autonomy.

37.61 Due to the high cost of testing, the Inquiry recommends that applicants be informed early in the application process that genetic testing may be offered to establish kinship. Where DIMIA doubts the veracity of evidence supplied to support an asserted kinship relationship, visa applicants should also be advised that additional evidence (apart from genetic test results) can be provided as alternative proof.

37.62 DIMIA should also review its policies and procedures to address the potential social and psychological consequences of kinship testing. Migration officers should inform applicants about these consequences and the desirability of seeking counselling before or after testing. As an additional protection for offshore cases, panel doctors (who are overseas medical practitioners contracted by DIMIA to perform examinations) should offer counselling when samples are taken, or information about the availability of counselling. In reviewing its policies on counselling, DIMIA could draw on its existing approach to positive HIV test results.⁷⁰ It might also draw on its own approach to the delivery of written opinions on why an applicant has failed the health requirement:⁷¹ where a health examination has revealed unexpected and potentially distressing information about an applicant’s health, the information is sometimes sent to the applicant’s nominated doctor, who will deliver the information and provide appropriate counselling.⁷² Privacy concerns about the disclosure of test results should be addressed by obtaining consent to release information to third parties, including an applicant’s sponsor.

68 Department of Immigration and Multicultural and Indigenous Affairs, *Submission G272*, 23 December 2002.

69 Androgen Insensitivity Syndrome Support Group Australia, *Submission G290*, 5 January 2003.

70 Department of Immigration Multicultural and Indigenous Affairs, *Guidelines for medical and radiological examination of Australian visa applicants* (2002), DIMIA, Canberra [8.5].

71 Generally, an applicant must be informed of the reasons DIMIA has refused the grant of a visa: *Migration Act 1958* (Cth) s 57.

72 MOCs make the decision to deliver the written opinion in this way on a case-by-case basis: Department of Immigration and Multicultural and Indigenous Affairs, *Correspondence*, 13 March 2003.

37.63 The Procedures Advice Manual should also be reviewed to ensure the adequacy of procedures to prevent identity fraud. This review should take into account the procedures and protections contained in the FL Regulations, having regard to the Inquiry's recommendations in Chapter 35.

37.64 At present, there are limited formal safeguards for applicants because existing practices in relation to genetic kinship testing are regulated by departmental policy. The Inquiry is of the view that the procedures for conducting genetic kinship testing should be given more formal status in order to better protect the genetic information of migration applicants. A balance should be struck between the flexibility of the current arrangements and the development of formalised protections. The Inquiry considers that this can be done most effectively by formalising the general procedures and policies for genetic kinship testing in a ministerial direction made under the *Migration Act*, while retaining more detailed guidance on their operation in the Procedures Advice Manual. For example, the requirement to obtain consent for the disclosure of results could be placed in a ministerial direction, while the processes for seeking consent, such as the provision of forms, could be contained in the Procedures Advice Manual.

37.65 A ministerial direction has binding force, but can be created and changed with greater expedition than amendments to regulations or legislation. Under s 499 of the *Migration Act*, the Minister may give written directions to DIMIA about the performance of its functions and the exercise of its powers under the Act.⁷³ The direction must be consistent with both the *Migration Act* and its associated regulations⁷⁴ and can only amplify existing law, not substitute it. The direction is tabled in Parliament, and DIMIA officers must comply with these directions,⁷⁵ which are then incorporated into the Procedures Advice Manual.

Recommendation 37–1. The Department of Immigration and Multicultural and Indigenous Affairs (DIMIA) should review its policies and procedures on kinship testing. In particular, the revised policies should ensure that:

- (a) visa applicants are advised at an early stage in the application process that they may be asked to undergo genetic testing to prove an asserted kinship relationship;
- (b) where DIMIA doubts the veracity of documentary evidence submitted to establish the existence of a kinship relationship, visa applicants should be provided with adequate reasons and given an opportunity to address the doubts by undergoing genetic testing or providing other evidence;

⁷³ *Migration Act 1958* (Cth) s 499(1).

⁷⁴ *Ibid* s 499(2).

⁷⁵ *Ibid* s 499(2A).

- (c) information in community languages is disseminated to visa applicants about the potential implications of the test and the desirability of seeking counselling;
- (d) in relation to offshore testing, the panel doctor who takes a sample for kinship testing offers the applicant counselling, or information about the availability of counselling;
- (e) DIMIA has adequate procedures for preventing identity fraud; and
- (f) consent is obtained for the disclosure of genetic test results to third parties, including sponsors.

Recommendation 37–2. In implementing Recommendation 37–1, policies and procedures for conducting genetic kinship testing for the purpose of migration decision making should be formalised through a Minister’s direction made under s 499 of the *Migration Act 1958* (Cth), amendments to the Procedures Advice Manual, or both, as appropriate.

Health testing

37.66 In addition to meeting the specific requirements of different types of migration visa, applicants for most visa classes, with a few exceptions, must meet a general health requirement.⁷⁶ This requirement may result in refusal of applicants who pose a public health risk, such as people who are carrying infectious diseases. Applicants who are likely to need significant access to health care or community services in the future may also be excluded under the health requirement. The standards expressed in the health criteria and migration legislation are established on the advice of the Department of Health and Ageing.

37.67 Because genetic information can reveal important information about an applicant’s current or future health, it may be relevant in making determinations about the health requirement. Genetic information relating to health has two potential applications in migration decision making:

- to provide information about a current medical condition; and
- to make predictions about a future medical condition.

37.68 This raises issues about how that information is collected, used and disclosed.

⁷⁶ Visa classes to which the health requirement applies are listed in *Migration Regulations 1994* (Cth) Sch 1, 2. Further detail is given in the Department of Immigration and Multicultural and Indigenous Affairs, *Procedures Advice Manual (PAM3)* (1994–2002), DIMIA, Canberra Sch 4/4005, Health Requirement, 2.

Current law and practice

37.69 Under the *Migration Regulations*, to meet the health requirement to migrate to Australia, an applicant must:

- be free from tuberculosis; and
- be free from a disease or condition that is, or may result in the applicant being, a threat to public health in Australia or a danger to the Australian community; and
- not have a disease or condition such that he or she would be likely to require health care or community services while in Australia, where the provision of the health care or community services relating to the disease or condition would be likely to:
 - (a) result in a significant cost to the Australian community in the areas of health care or community services; or
 - (b) prejudice the access of an Australian citizen or permanent resident to health care or community services.⁷⁷

37.70 Failure to meet these criteria may cause a migration application to be refused, even if the applicant guarantees not to seek access to services once in Australia.⁷⁸ In some visa classes, the Minister may waive the access to services criterion (namely, the third dot-point above) where:

- an applicant's employer undertakes to cover the costs of health care and community services;⁷⁹ or
- the Minister is satisfied that the granting of the visa would be unlikely to result in undue cost to the Australian community or undue prejudice to the access to health care or community services of an Australian citizen or permanent resident.⁸⁰

37.71 The Procedures Advice Manual outlines detailed policy on the assessment of the health requirement and includes guidelines provided to examining doctors.⁸¹

37.72 To determine whether an applicant meets the health requirement, the migration officer dealing with an application must seek the opinion of a Medical Officer of the Commonwealth (MOC).⁸² There are only a small number of cases in

⁷⁷ *Migration Regulations 1994* (Cth) Sch 4, 4005, 4006A(1), 4007(1).

⁷⁸ Ibid; Department of Immigration and Multicultural and Indigenous Affairs, *Procedures Advice Manual (PAM3)* (1994–2002), DIMIA, Canberra Sch 4/4005, Health Requirement, 116.

⁷⁹ *Migration Regulations 1994* (Cth) Sch 4, 4006A(2).

⁸⁰ Ibid Sch 4, 4007(2).

⁸¹ Department of Immigration and Multicultural and Indigenous Affairs, *Procedures Advice Manual (PAM3)* (1994–2002), DIMIA, Canberra Sch 4/4005, Health Requirement; Department of Immigration Multicultural and Indigenous Affairs, *Guidelines for medical and radiological examination of Australian visa applicants* (2002), DIMIA, Canberra.

⁸² *Migration Regulations 1994* (Cth) r 2.25A.

which an MOC forms an opinion that an applicant does not meet the health requirement—usually less than 1% of all cases considered by an MOC. As MOCs often discuss doubtful cases with each other to form a collegiate opinion, applications are generally refused only when the health criteria are clearly not met. The Inquiry understands that cost estimate guidelines for MOCs are in the course of development, but currently MOCs use data from disparate sources.

Medical examinations

37.73 Under the *Migration Act*, the Minister may require an applicant to be examined by a qualified person to determine the applicant's health, physical condition or mental condition.⁸³ This involves taking a detailed medical history that covers all previous medical conditions, injuries and any treatments received, and performing a physical examination that encompasses all the major bodily systems, evidence of drug-taking, and the senses. A chest x-ray and blood test are standard for adults and older teenagers. A family history may be requested if the examination indicates that the applicant has an hereditary condition. All information and tests required for assessment are set out in forms created by DIMIA and can be changed at any time.⁸⁴ Once the examination and tests are completed, the doctor must recommend whether any significant findings exist. The doctor indicates whether such findings exist by making an 'A' recommendation—no significant findings exist—or a 'B' recommendation—significant findings exist.⁸⁵ Guidelines in the Procedures Advice Manual lists criteria that must be met for an 'A' recommendation to be made. These criteria include a requirement that:

there is no family history of a genetically determined disorder, for example, hereditary anaemias, coagulation disorders, Huntington's disease, and so on.⁸⁶

37.74 MOCs assess whether an applicant meets the health requirement on the basis of this information, but may request further investigation.⁸⁷

37.75 Procedures for performing medical examinations are governed by policies and practices developed by the Department of Health and Ageing in consultation with DIMIA. The *Migration Regulations* do not impose restrictions on the type of tests that may form part of this examination. MOCs may request any test that is relevant to forming an opinion about whether the applicant meets the health requirement, although in practice an invasive or risky procedure would be requested only with circumspection.

⁸³ *Migration Act 1958* (Cth) s 60.

⁸⁴ Department of Immigration and Multicultural and Indigenous Affairs, *Consultation*, Canberra, 20 November 2002.

⁸⁵ See eg Department of Immigration and Multicultural and Indigenous Affairs, *Form 26A — Medical Examination for an Australian Visa: For Use in Australia Only* (2002), Commonwealth of Australia, Canberra.

⁸⁶ Department of Immigration Multicultural and Indigenous Affairs, *Guidelines for medical and radiological examination of Australian visa applicants* (2002), DIMIA, Canberra [6.2].

⁸⁷ Department of Immigration and Multicultural and Indigenous Affairs, *Consultation*, Sydney, 25 October 2002.

37.76 In practice, non-standard tests are requested only where a condition is indicated by physical symptoms or a clear family history. For example, an MOC may order tests where an applicant shows both the physical signs of haemophilia and there is a family history of the condition.⁸⁸

37.77 If an applicant refuses to undergo testing or examination, doctors must make a recommendation based on the information available. Migration officers may assess the application on the information on file.⁸⁹

Determining whether the health requirement is met

37.78 Once the risk of tuberculosis and of any other disease that may threaten public health has been excluded, the MOC must calculate how much access to health and community services an applicant may require while in Australia for any identified condition. The purpose of this calculation is to assess whether a 'significant cost' would be incurred, or whether access by Australians to health care or community services would be prejudiced.

37.79 The *Migration Regulations* are silent on how this is to be determined, except that the MOC must estimate the use of costly treatment or resources, 'regardless of whether the health care or community services will actually be used in connection with the applicant'.⁹⁰ The Inquiry has not been made aware of any official guidelines about how this is to be done because 'Notes for the Guidance of Medical Officers for the Commonwealth' have yet to be finalised. The Procedures Advice Manual provides only minimal guidance⁹¹ but MOCs are expected to be skilled in these assessments.

37.80 As indicated above, the *Migration Regulations* require that an applicant be free from a disease or condition that would be likely to result in a 'significant cost' to the Australian community in the areas of health or community services. A 'significant cost' is not defined, but departmental practice, stemming from Department of Health and Ageing advice (as noted in the Procedures Advice Manual), is to make a monetary allowance over and above a multiple of the average annual cost of health and community services incurred by Australian citizens or permanent residents.⁹² MOCs, in consultation with the Department of Health and Ageing, calculate the cost of health care and community services from Pharmaceutical Benefits Scheme data, hospital costs data, Centrelink benefits data, and other similar sources.

88 Department of Immigration and Multicultural and Indigenous Affairs, *Consultation*, Sydney, 26 July 2002.

89 Department of Immigration and Multicultural and Indigenous Affairs, *Procedures Advice Manual (PAM3)* (1994–2002), DIMIA, Canberra Sch 4/4005, Health Requirement, 155.

90 *Migration Regulations 1994* (Cth) Sch 4, 4005(c); Sch 4, 4006(1)(c); Sch 4, 4007(1)(c).

91 Department of Immigration and Multicultural and Indigenous Affairs, *Procedures Advice Manual (PAM3)* (1994–2002), DIMIA, Canberra Sch 4/4005, Health Requirement, 115–116.

92 Department of Immigration and Multicultural and Indigenous Affairs, *Consultation*, 26 July 2002; Department of Immigration and Multicultural and Indigenous Affairs, *Procedures Advice Manual (PAM3)* (1994–2002), DIMIA, Canberra, Sch 4/4005, Health Requirement, 115.

37.81 The *Migration Regulations* also require that an applicant be free from a disease or condition that will prejudice the access of other Australian citizens or permanent residents to services. This might include access to scarce services such as organs for transplantation, some forms of respite and specialised nursing care, or dialysis. The demand for scarce resources is derived from Department of Health and Ageing advice, as well as individual state or territory health authorities.

37.82 The *Migration Regulations* do not specify a temporal dimension to the health requirement. Thus, the Regulations make no distinction between a significant cost that is likely to be incurred in the near future and one that is likely to be incurred in many years time. DIMIA policy, however, is to look at all significant costs and access to services that may foreseeably be used for that health condition.⁹³

Predicting the need for health care and community services

37.83 Genetic information can reveal a variety of things about an individual's health status, which may have a bearing on his or her need for health care and community services. This information may demonstrate:

- current conditions (for example, cystic fibrosis—a congenital genetic disorder);
- conditions that will definitely develop in the future (for example, Huntington's disease);
- the presence of genetic mutations that are predictive of a person's health in the future (for example, breast cancer); and
- carrier status for a condition that might affect offspring (for example, Tay-Sachs disease).

37.84 The Inquiry understands that predictive genetic tests are not ordered under current DIMIA policy because they are regarded as incapable of predicting, with sufficient certainty, that an applicant will develop a condition requiring access to health services.⁹⁴ MOCs focus on detecting conditions suffered by an applicant at the time of the examination and the likelihood that the condition will require care and treatment later, rather than looking for possible future conditions.⁹⁵ However, the permissive nature of the *Migration Regulations* would allow such testing if it were considered relevant.

37.85 In the past, an applicant could fail the health requirement if he or she had a condition that would be passed on to children. DIMIA has now moved away from this approach, and failure on these grounds is no longer provided for in the *Migration Regulations*.⁹⁶

93 Department of Immigration and Multicultural and Indigenous Affairs, *Consultation*, Sydney, 25 October 2002.

94 Ibid.

95 Ibid.

96 Department of Immigration and Multicultural and Indigenous Affairs, *Consultation*, Sydney, 23 July 2002.

Consent and counselling

37.86 There are no prescribed procedures for dealing with consent or counselling in relation to genetic tests. With regard to consent, applicants are informed that they are not required to undergo tests, but that their application may not be able to be processed unless they do so. In this environment, applicants may feel under some pressure to agree to a requested genetic test and this may have implications for an applicant's 'right not to know' about his or her genetic status.

37.87 In relation to counselling, where potentially distressing results have been returned (whether genetic or otherwise) and are known to MOCs, but possibly not to the applicant, an MOC recommends that the applicant choose a medical practitioner to whom the results can be delivered. This medical practitioner will then deliver the results to the applicant and is requested to provide such counselling as would normally be delivered in the course of medical treatment in that country.

Issues and problems

37.88 At present, DIMIA rarely uses genetic testing for the purpose of assessing compliance with the health requirement in the *Migration Regulations* because it does not regard most current tests as sufficiently accurate.⁹⁷ Yet, as the cost of testing falls and the range and accuracy of available genetic tests improves, there is potential to use genetic testing more widely as an indicator of an applicant's current or future health.

37.89 As noted in this chapter and elsewhere in this Report, the use of genetic testing raises a number of ethical concerns ranging from the scientific reliability of the testing to the need for patient counselling. The link between a genetic mutation and a specific disorder is often complex, and may involve an assessment of multiple genes, the penetration of those genes, and environmental factors. Genetic disorders may manifest differently in different people. For some disorders, early detection and treatment can lessen the health effects of a condition. Given this, test results require appropriate interpretation for the purpose of determining health status.

37.90 The use of genetic testing in this context highlights the need for voluntary and informed consent and consideration of the right not to know. Faced with the decision to undergo a genetic test or possibly be refused a visa, migration applicants might feel they have little choice. Many applicants might not understand the full ramifications of taking the test, such as its relevance for their family members. This is a particular concern in relation to predictive testing because many applicants may not wish to learn that they may suffer a genetic disorder later in life. The Human Genetics Society of Australasia was opposed to the use of predictive genetic tests for immigration purposes for this reason, commenting that:

97 Department of Immigration and Multicultural and Indigenous Affairs, *Consultation*, Sydney, 25 October 2002.

As a matter of principle it seems unacceptable to require an Australian citizen to discover information about future risk of disorder when this information is not wanted. It seems equally unacceptable to make it a requirement that a prospective migrant be burdened with such unwanted personal information.⁹⁸

37.91 Genetic testing for health purposes also raises privacy concerns similar to those associated with kinship testing. An applicant might want the privacy of test results to be maintained, for example to avoid the stigma or discrimination associated with a disorder. Although DIMIA observes an individual's privacy in relation to his or her medical details, if the health requirement is not met the applicant's sponsor may be informed of the reasons for this decision. This may give rise to concerns about the privacy of the applicant's genetic status.

Submissions and consultations

37.92 The Centre for Law and Genetics commented that many of the considerations that apply in relation to discrimination in employment and insurance also apply in the context of migration.⁹⁹ Concern about the possible use of predictive genetic testing was voiced in many submissions and consultations. For example, the Migration Institute of Australia stated:

Overall, the implications of genetic testing in regards to health, are quite daunting. There is potential for prejudice in prohibiting the immigration of certain people based solely on prospective health issues.¹⁰⁰

37.93 The Human Genetics Society of Australasia suggested that:

While DNA profiling is legitimate to establish family relationships upon which applications for immigration may be based, it would be as unacceptable for further genetic information to be used to select against individuals on the basis of projected disorders as it would be to use such information against citizens.¹⁰¹

37.94 The Anti-Discrimination Board of NSW stated:

While we have concerns about the extent to which it is necessary to exempt the [*Migration Act*] from the DDA, we recognise that people's health status is a relevant factor in determining applications under the Migration Act, given that consideration needs to be given to the future burden on the Australian health system.

Nonetheless ... the scientific reliability of genetic information in determining the extent to which people are likely to develop health conditions in future, is far from clear. It is certainly conceivable that people's immigration applications may be refused on the basis of their genetic make up, even where the possibility of developing the condition is remote or where their health is unaffected and therefore there is no likelihood that they present a future burden on the health system. ... There is a need to ensure that immigration department decision makers understand the different types and implications of genetic information.¹⁰²

98 Human Genetics Society of Australasia, *Submission G267*, 20 December 2002.

99 Centre for Law and Genetics, *Submission G048*, 14 January 2002.

100 Migration Institute of Australia, *Submission G316*, 5 March 2003.

101 Human Genetics Society of Australasia, *Submission G050*, 14 January 2002.

102 Anti-Discrimination Board of NSW, *Submission G194*, 27 November 2002.

37.95 Submissions supported a review of DIMIA's policies to address issues raised by genetic testing, with some commenting that extensive consultation and the involvement of the HGCA would be desirable.¹⁰³ DIMIA itself welcomed the development of guidelines on the use of genetic tests and information.¹⁰⁴

Inquiry's views

37.96 While the Inquiry understands that genetic testing is rarely used in assessing the health requirement, the permissive nature of the *Migration Regulations* and the Procedures Advice Manual leaves scope for increased use. An expanded use of genetic testing for migration purposes may be a legitimate tool for assessing whether a migration applicant satisfies the health requirement. However, such use should also be attended by suitable safeguards that extend to the use of family medical history as well as genetic test information.

37.97 In light of these considerations, the Inquiry considers that the Department of Health and Ageing, in consultation with DIMIA and the HGCA, should develop policies on the use of genetic information for the purpose of assessing the health requirements under migration legislation. The development of policies on the use of genetic information will assist MOCs in interpreting test results and applying these results in assessing the health requirement. These guidelines should address the need for consent to be obtained and adequate counselling to be provided, where appropriate. In developing these policies, DIMIA should have regard to its current methods for dealing with HIV testing, which provides an effective model for dealing with sensitive health information. Specific guidance on the use of predictive tests will lay down a framework for new tests as they are developed.

37.98 In particular, DIMIA should finalise its guidelines to MOCs on the assessment of the health requirement. These guidelines should direct MOCs on how the issues raised by genetic information—including the need for consent, confidentiality, counselling, and accurate interpretation and application—are to be addressed.

37.99 Chapter 5 proposed that the HGCA be established to perform a number of functions, including providing expert advice on matters relating to human genetics, upon the request of a responsible minister. The Inquiry considers that departmental policies about the use of genetic information in assessing the health requirement should be developed in consultation with the HGCA.

103 Law Institute of Victoria, *Submission G275*, 19 December 2002; Department of Human Services South Australia, *Submission G288*, 23 December 2002.

104 Department of Immigration and Multicultural and Indigenous Affairs, *Consultation*, Sydney, 25 October 2002.

Recommendation 37–3. The Department of Health and Ageing, in consultation with DIMIA and the Human Genetics Commission of Australia, should develop policies on genetic tests and the use of genetic information (including family medical history) for the purpose of assessing the health requirement under migration legislation. These policies should include detailed guidelines for Medical Officers of the Commonwealth on the use of genetic information.

38. Sport

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Introduction

The Olympic motto 'citius, altius, fortius'—faster, higher, stronger—gives a precise concentrate of the strong belief in eternal progress. To break barriers, to push limits, is very important and central in elite sport.¹

38.1 Individuals engage in sporting activities for a range of reasons: as a form of social interaction, for fun, to keep fit, for the thrill of competition and, in some cases, to earn a living. At the elite or professional level, sport can involve exploring the limits of what is humanly possible in terms of speed, strength and skill. At this end of the sporting spectrum there are powerful incentives, including financial incentives, to use new technologies such as gene therapy and genetic testing to maximise potential and provide a competitive edge. The use of genetic information in elite sports is the focus of this chapter.

38.2 While there is potential for the use of gene therapy to treat sport injuries and to enhance performance, these applications are experimental and the subject of continuing research. Part D of this Report addresses the regulatory framework for the ethical conduct of human genetic research in Australia. That framework, and the recommendations made in Part D, extends to genetic research in the field of sports medicine. The issues raised by the potential application of this research, although of great significance for sport's governing bodies and sport's drug agencies, largely fall outside the terms of reference of this Inquiry. It is of interest to note, however, that the World Anti-Doping Agency and the International Olympic Committee have recently included the non-therapeutic use of genes, genetic elements and/or cells that have the

1 G Breivik, *Limits to Growth in Elite Sport - Some Ethical Considerations*, 16 September 2002.

capacity to enhance athletic performance in their list of proscribed substances and methods.²

38.3 The use of genetic information in sport does, however, fall within the Inquiry's Terms of Reference. The Inquiry received few submissions on the use of genetic information in sport, but this application clearly has the potential to raise ethical, discrimination and privacy issues. Two uses, in particular, are considered in this chapter. These are the use of genetic testing to identify:

- potential elite athletes carrying particular 'performance' genes; and
- individuals with a genetic predisposition to sports-related injury.

Talent identification and performance genes

38.4 The Australian Sports Commission (ASC) administers and funds sport in Australia on behalf of the Federal Government. The ASC supports a wide range of programs to develop elite sport, as well as increase community participation in sport. The ASC includes two units with responsibility for delivering these outcomes. The Australian Institute of Sport (AIS) is responsible for training and developing elite athletes and teams, and the Sport Development Group is responsible for developing the community base of Australian sport through the Active Australia initiative. The ultimate aim of this initiative is to increase the number of Australians involved in sport and physical activity in the long term.³

38.5 The AIS offers scholarships annually to about 700 athletes in 35 separate programs covering 26 sports. Scholarship benefits may include:

- access to world class facilities;
- high performance coaching;
- personal training and competition equipment;
- sports medicine and sport science services;
- travel, accommodation and living allowances for events chosen by the Institute;
- full board at the Institute's residences, or living out allowances, as appropriate;
- reimbursement of education expenses to limits that depend on the type of study undertaken; and
- assistance through the national Athlete Career and Education program.

2 International Olympic Committee, *Press Release: IOC Gene Therapy Working Group — Conclusions*, International Olympic Committee, <www.olympic.org/uk/news/publications/press_uk.asp?release=179>, 20 February 2003.

3 Australian Sports Commission, *Australian Sports Commission Website*, Australian Sports Commission, <www.ausport.gov.au/>, 13 January 2003.

38.6 In relation to track and field athletics, the AIS website states that:

Performance is an important criterion for assessing athletes, with clear performance goals designed to prepare the athlete for the highest level of international competition. Results at major national and international competitions are critical to athlete selection ...

The AIS Track and Field program provides scholarships to both senior and developing athletes with the *potential* to reach the top eight in the world in their event.⁴

38.7 The scholarship program entails a significant investment of resources for those who meet the assessment criteria, namely, those who demonstrate proven ability as well as the potential to perform at a very high level. Genetic information may be relevant to the selection process and to the assessment of the future potential of an athlete.

38.8 The National Talent Identification and Development program, or Talent Search, is a program developed by the AIS, in cooperation with state and territory institutes and academies of sport, and national and state sporting organisations. The program is designed to help identify talented athletes between the ages of 11 and 20 and to prepare them for participation in local, national and international competition. The program utilises information across all disciplines of the sports sciences to identify young athletes with characteristics associated with elite performance. The testing currently involves measuring physiological attributes such as height, body mass, strength, speed, flexibility and aerobic capacity, with additional specific testing in relation to particular sports.⁵

38.9 Other organisations in Australia are also involved in selecting elite athletes for national teams and competitions, for example, the Australian Olympic Committee, the National Australian Football League, the Australian Cricket Board and Netball Australia.

38.10 Talent Search, AIS scholarships and other elite athlete selection processes involve decisions with some predictive element in relation to the potential performance of particular individuals. There is persuasive evidence that genes contribute to athletic performance.⁶ AIS Assistant Director, Peter Fricker, has commented that Australia will fall behind as a sporting nation if it fails to embrace genetic screening of athletes, and that this is likely to become as common as measuring height and weight.⁷ As genetic testing technology and understanding progress, it is likely that the selection of elite athletes will include some genetic tests. In the future, an athlete's genetic profile may be one of a range of factors considered in assessing whether that athlete gains access to the resources provided by institutions like the AIS, or is accepted to participate in elite or professional competitions.

4 Australian Institute of Sport, *Talent Search: About the National Talent Search Program*, Australian Institute of Sport, <www.ais.org.au/talent/>, 20 February 2003, emphasis added.

5 Ibid.

6 T Rankinen and others, 'The human gene map for performance and health-related fitness phenotypes: the 2001 update' (2002) 34(8) *Medicine & Science in Sports & Exercise* 1219.

7 Australian Associated Press, 'Genetic Profiling of Athletes Predicted', *The Age* (Melbourne), 1 February 2003, 7.

38.11 Researchers from the AIS and the Department of Molecular and Clinical Genetics at Royal Prince Alfred Hospital, Sydney, are currently working to identify genes that may be helpful in predicting natural sporting ability. The research is aimed at identifying which genes are involved in elite athletic performance, what contribution those genes make, and how that contribution compares to that made by environmental factors such as training. In consultations with the Inquiry, Professor Ron Trent, Chair of the Department of Molecular and Clinical Genetics, indicated that the contribution of genes might range from 5% to 90%, although he was of the view that it is likely to be toward the lower end of the range.⁸

38.12 Participation in elite sport requires a range of physical and physiological attributes, as well as psychological and decision making abilities. The AIS notes on its website that ‘the key to undertaking successful talent identification is trying to determine how much of the performance you can measure’.⁹ Physical and physiological attributes are generally easier to measure than other elements such as psychological and decision making abilities. Research into performance genes is currently aimed at identifying genes associated with physical and physiological attributes, such as supernormal cardiovascular function.

38.13 Because different sports require a different mix of attributes, the usefulness of genetic information as a predictor of likely performance will vary between sports. Genetic information will be more useful in predicting potential talent in sports such as rowing and athletics, which rely more on physical and physiological characteristics. It will be less useful in relation to team sports, which rely to a significant extent on skills like being able to ‘read the play’ and interact with team members. Genetic information may also be less useful in sports such as archery and table tennis, which rely more on skill and decision making ability and less on physical and physiological attributes.

Submissions and consultations

38.14 As noted above, the Inquiry received few submissions dealing with the use of genetic information in sport. One submission, from an applied ethicist and teaching fellow at the University of Abertay Dundee in the United Kingdom,¹⁰ raised a number of concerns in relation to the use of genetic information to identify potentially elite athletes. These concerns included:

- the ethics of using limited medical resources for non therapeutic research, such as identifying performance genes in athletes;
- the potential to limit the life choices of individuals identified as potentially elite athletes at a very young age and the potential to discourage others from even trying; and

⁸ R Trent, *Consultation*, Sydney, 1 November 2002.

⁹ Australian Institute of Sport, *Talent Search: About the National Talent Search Program*, Australian Institute of Sport, <www.ais.org.au/talent/>, 20 February 2003.

¹⁰ A Miah, *Submission G139*, 15 March 2002.

- the potential for discrimination by sporting organisations against athletes on the basis of their genetic information.¹¹

38.15 In his submission, Mr Miah expressed the view that these issues required further consideration with a view to developing ethical and legal policy on the use of genetic information in sport. While the first point listed is a resource allocation issue for government, and the second point is a policy issue for sporting bodies, the third point falls within the Terms of Reference of this Inquiry and is considered in detail below.

38.16 In consultation, Professor Ron Trent indicated that the joint research project being conducted by the AIS and Department of Molecular and Clinical Genetics, discussed above, had received approval from three human research ethics committees at the AIS, Royal Prince Alfred Hospital and the University of Sydney. He noted that the project had a strong therapeutic element because the examination of heart function in AIS rowers is likely to assist with the treatment of heart disease.

38.17 Professor Trent noted that it would be many years before the project produced results that might be of practical use to the AIS. He also noted that no single gene, or combination of genes, would ensure a gold medal or the development of an elite athlete. He was of the view that coaches were unlikely to risk their careers by relying on genetic profiles alone to select athletes. While genetic makeup may make some contribution to sports performance, an individual's application, response to training and desire to win were also key factors necessary for success. As the AIS notes on its website:

In the future, blood testing will never replace traditional methods of talent identification, but might provide an extra piece of the predictive jigsaw.¹²

38.18 Professor Trent also noted that genetic information might be used in the future to develop individualised training programs for elite athletes.

Existing legal framework

38.19 Access to programs run by the AIS and other sporting organisations in Australia is regulated by anti-discrimination legislation, including the *Disability Discrimination Act 1992* (Cth) (DDA).¹³ Three provisions of the DDA are potentially relevant here. The first is s 28 which provides:

¹¹ Ibid.

¹² Australian Institute of Sport, *Australian Institute of Sport Website*, <www.ais.org.au/>, 13 January 2003.

¹³ This discussion proceeds on the basis that the recommendations made by this Inquiry in Ch 9 are implemented. As discussed in that chapter, state and territory legislation may also be relevant. See, for example, *Anti-Discrimination Act 1977* (NSW) s 49R; *Equal Opportunity Act 1995* (Vic) ss 65–66; *Anti-Discrimination Act 1991* (Qld) s 111; *Equal Opportunity Act 1984* (SA) s 81; *Equal Opportunity Act 1984* (WA) s 66N; *Anti-Discrimination Act 1998* (Tas) s 43; *Anti-Discrimination Act 1992* (NT) s 56 and *Discrimination Act 1991* (ACT) s 57.

- (1) It is unlawful for a person to discriminate against another person on the ground of the other person's disability or a disability of any of the other person's associates by excluding that other person from a sporting activity.
- (2) In subsection (1), a reference to a sporting activity includes a reference to an administrative or coaching activity in relation to any sport.
- (3) Subsection (1) does not render unlawful discrimination against a person:
 - (a) if the person is not reasonably capable of performing the actions reasonably required in relation to the sporting activity; or
 - (b) if the persons who participate or are to participate in the sporting activities are selected by a method which is reasonable on the basis of their skills and abilities relevant to the sporting activity and relative to each other; or
 - (c) if a sporting activity is conducted only for persons who have a particular disability and the first-mentioned person does not have that disability.

38.20 This provision recognises that participation in sporting activity is frequently graded on the basis of skill and ability. Where such discrimination is reasonable, it is not unlawful. Selection of athletes for participation in sporting activities, including the Talent Search program and the AIS scholarship program, is unlikely to contravene this provision so long as the method used to select athletes is reasonable. If the AIS, or other sporting organisation, were to introduce genetic testing as part of the selection process it would be important to ensure that the testing was a reasonable method of selection. Organisations would have to consider issues such as whether the test results were sufficiently reliable and relevant to the skills and abilities required. If not, it would be open to an athlete who was 'reasonably capable of performing the actions reasonably required in relation to the sporting activity' to challenge the decision of the selectors under s 28.

38.21 Section 29 of the DDA is also relevant to AIS programs and provides:

It is unlawful for a person who performs any function or exercises any power under a Commonwealth law or for the purposes of a Commonwealth program or has any other responsibility for the administration of a Commonwealth law or the conduct of a Commonwealth program, to discriminate against another person on the ground of the other person's disability, or a disability of any of the other person's associates in the performance of that function, the exercise of that power or the fulfilment of that responsibility.

38.22 Under the *Australian Sports Commission Act 1989* (Cth), the ASC is given a range of functions including 'to develop and implement programs for the recognition and development of persons who excel, or who have the potential to excel, in sport'.¹⁴ It is also given the power to 'provide scholarships or like benefits'.¹⁵ In fulfilling these functions the ASC and the AIS regularly make decisions that draw a distinction, or discriminate, between individuals on the basis of their skills and abilities, including on the basis of their physical and physiological attributes. Where such discrimination is

¹⁴ *Australian Sports Commission Act 1989* (Cth) s 7(1)(d).

¹⁵ *Ibid* s 8(1)(d).

reasonable for the purpose of implementing a Commonwealth program for the development of elite or potentially elite athletes, it is unlikely to amount to unlawful discrimination under the DDA.

38.23 Once again, however, if the AIS were to use genetic information to select athletes, it would be necessary to ensure that the information was reasonably reliable and relevant. If not, it would be possible to argue that the information was being used to discriminate unlawfully against individuals rather than to genuinely administer a Commonwealth program aimed at identifying and developing elite athletes.

38.24 Finally ss 15–21 of the DDA, which prohibit discrimination in employment, are also relevant where the sporting position is a professional one. These provisions are discussed in detail in Part H of this Report.

38.25 The potential collection of genetic information from athletes also gives rise to privacy considerations. As noted in Chapter 7, privacy protection for personal health information is not comprehensive in Australia. While the ASC, the AIS and many private sector sports organisations are covered by the *Privacy Act 1988* (Cth) (*Privacy Act*), the Act does not extend to state and local government organisations except in the Australian Capital Territory. Privacy legislation in other States and Territories is either absent, incomplete or non-uniform. It is also likely that a range of sports organisations will fall within the small business exemption in the *Privacy Act*. Although small business sports organisations may hold health information about athletes, they are unlikely to fall within the coverage of the Act as ‘health service providers’ or ‘traders in personal information’. In addition, in relation to professional athletes, genetic information will be held in ‘employee records’, which also fall outside the protection of the *Privacy Act*.

Inquiry’s views

38.26 Genetic information is not currently widely used in sport. However, it is likely that financial and other pressures, which operate at the elite end of the sporting spectrum, will mean that genetic testing and genetic information will come to play a role in the early identification and selection of athletes for participation in elite competition, training and scholarship programs. It is less likely that this will become an issue in relation to non-elite sports where there is less competition for places and the financial and other incentives are not as great.

38.27 The issues raised by the use of genetic information to select or identify potentially elite athletes underline the importance of the recommendations made in Chapters 7–9 and Part H of this Report. Many of the recommended changes in these chapters will help to ensure that, in the future, athletes’ genetic information is dealt with in an appropriate manner.

38.28 The Inquiry is of the view that the ASC should keep this issue under review. It would be valuable for the ASC, in consultation with the Human Genetics Commission of Australia (HGCA), the Human Rights and Equal Opportunity Commission (HREOC), the Office of the Federal Privacy Commissioner (OFPC) and

other stakeholders such as Sports Medicine Australia and the Australia and New Zealand Sports Law Association, to develop policies and guidelines on the use of genetic testing and genetic information to identify or select elite athletes, for the guidance of athletes and sporting bodies.

Recommendation 38–1. The Australian Sports Commission (ASC) should monitor the use of genetic testing and genetic information for identifying or selecting athletes with a view to developing policies and guidelines for sports organisations and athletes. The policies and guidelines should be developed in consultation with the Human Genetics Commission of Australia (HGCA), the Human Rights and Equal Opportunity Commission (HREOC), the Office of the Federal Privacy Commissioner (OFPC), and other stakeholders.

Screening for predisposition to injury

There are certain advantages to knowing of a genetic susceptibility to injury. Identifying athletes who are susceptible to a specific injury would give physicians the opportunity to advise them of the potential risk. Such an athlete could elect to participate in a different sport. Other options might include modification of training or playing techniques, use of specialized safety equipment, rule changes, or more rigorous medical surveillance and health status monitoring. Furthermore, the identification of genes for sports injury susceptibility may also provide a basis for novel treatment strategies, such as gene therapy.¹⁶

38.29 The use of genetic information to establish whether an individual has a genetic predisposition to certain sports-related illnesses or injuries is still largely experimental. The Professional Boxing and Combat Sports Board of Victoria has, however, given serious consideration in recent years to making the test for the apolipoprotein E e4 gene compulsory for boxers seeking a licence under the *Professional Boxing Control Act 1985* (Vic).¹⁷ Research suggests that this gene, which is connected with late-onset familial and sporadic Alzheimer's disease, may also be associated with an increased risk of chronic traumatic encephalopathy (CTE), or 'punch drunk' syndrome, in boxers. It has been suggested that a milder form of this condition can occur in players of rugby, soccer and other sports associated with repetitive blows to the head.¹⁸

38.30 Other genetic conditions can also give rise to concern in athletes. Although rare, hypertrophic cardiomyopathy (HCM) has been found to account for a significant number of sudden deaths in athletes during physical activity. One study found that 46%

16 B Jordan, *Genetic Susceptibility to Brain Injury in Sports: A Role for Genetic Testing in Athletes*, *The Physician and Sportsmedicine*, <www.physsportsmed.com/issues/1998/02feb/jordan.htm>, 6 February 2003.

17 J Robotham, 'Pro Boxers Face Going Down for the Gene Count', *The Sydney Morning Herald*, 1 June 2001.

18 B Jordan, *Genetic Susceptibility to Brain Injury in Sports: A Role for Genetic Testing in Athletes*, *The Physician and Sportsmedicine*, <www.physsportsmed.com/issues/1998/02feb/jordan.htm>, 6 February 2003.

of sudden deaths in young athletes were due to HCM or possible HCM. It is thought that mutations in at least eight genes can cause HCM.¹⁹ Individuals with HCM may be advised not to participate in competitive sports or to participate only in low intensity sports.²⁰

38.31 A range of other conditions that are sometimes associated with a genetic mutation, such as deep vein thrombosis and pulmonary embolus, may also be dangerous to athletes. In the United States, the National Collegiate Athletic Association has imposed a mandatory pre-participation evaluation for athletes. This includes assessment for genetic conditions such as Marfan's syndrome, which has been responsible for the deaths of at least two high profile athletes, one an Olympic volleyball player and one a college basketball player, in the United States.²¹

Issues and problems

38.32 Dr Barry Jordan has noted that:

Advances in molecular biology will undoubtedly expand our understanding of the interactions between inherited disease susceptibility and environmental precipitants. Any future application of such scientific knowledge in the domain of sports medicine must be accompanied by scientific validation, ethical responsibility, moral integrity, and appropriate regulatory policies. Genetic testing may be the wave of the future, but because of uncertainty about genetic and environmental interactions, its role remains to be delineated.²²

38.33 The issue for sport organisations, and for athletes, is how to respond to the knowledge that athletes with a predisposition to particular genetic conditions are at increased risk of serious illness or injury, and sometimes death, if they participate in certain sporting activities. While exclusion from a particular sport, or sport generally, may not be a serious imposition for many members of the community, it is much more serious for elite athletes who have invested considerable time and other resources in developing their skills.

38.34 The Professional Boxing and Combat Sports Board of Victoria has not proceeded with its proposal to deny boxers a boxing licence on the basis of their genetic information. The issue was considered, but not resolved, at a Boxing and Martial Arts Industry Symposium held in October 2002 by Sports Medicine Australia (SMA).

19 J Puffer, *The Athletic Heart Syndrome — Ruling Out Cardiac Pathologies*, The Physician and Sports-medicine, <www.physsportsmed.com/issues/2002/07_02/puffer.htm>, 6 February 2003.

20 J Moeller, *Contraindications to Athletic Participation: Cardiac, Respiratory and Central Nervous System Conditions*, The Physician and Sportsmedicine, <www.physsportsmed.com/issues/1996/08_96/moeller.htm>, 6 February 2003.

21 R Ballard, *The Preparticipation Athletic Evaluation*, Journal of the Louisiana State Medical Society, <www.lsms.org/journal/98speval.html>, 6 February 2003.

22 B Jordan, *Genetic Susceptibility to Brain Injury in Sports: A Role for Genetic Testing in Athletes*, The Physician and Sportsmedicine, <www.physsportsmed.com/issues/1998/02feb/jordan.htm>, 6 February 2003.

38.35 The approach of the insurance industry to public liability and other forms of insurance associated with elite athletic competition may have an impact in this area. In March 2002 it was reported that the Australian Football League (AFL) was negotiating with its insurer in relation to public liability insurance cover for games involving Chris Grant. Grant had been diagnosed with a congenital spinal condition and the insurance company initially refused to issue a policy. The AFL reportedly asked Grant to sign an insurance waiver before he was allowed to continue to play. At the time Grant expressed concern about the handling of his case and, in particular, about the fact that his personal health information had been made public. The situation was apparently resolved when the insurer agreed to provide cover on the basis of specialist advice that Grant was at no greater risk of injury than any other player.²³

38.36 As discussed in other chapters of this Report, the uncertain predictive value of genetic information and the issues surrounding the interpretation of test results give rise to concern, particularly in a non-medical environment. As Dr Barry Jordan indicates:

Complicating all of this is uncertainty about the reliability of genetic testing in sports: It may be very difficult to determine the positive predictive value of a genetic test and to quantify the amount of athletic exposure that will trigger a pathobiologic response.²⁴

Submissions and consultations

38.37 SMA is Australia's peak national umbrella body for sports medicine and sports science, with a broad membership of sports medicine and health professionals, sports trainers, sporting clubs and community members. SMA members are involved in every level of sport from elite competition to grass-roots participation. According to SMA:

The safe participation of Australians in sport and healthy physical activity at all stages of life is the primary concern for all involved with Sports Medicine Australia.²⁵

38.38 The Inquiry met with SMA to discuss the implications of the use of genetic information in sport and, in particular, to seek advice on the use of genetic information indicating a predisposition to sports-related illness or injury. In consultations, Gary Moorhead, Chief Executive Officer of SMA, indicated that, because SMA was interested in promoting participation in sport, the organisation would not support policies that excluded people from participation in sport on the basis of their genetic information. SMA would favour the development of policies that made sport safer for participants, including the use of safety equipment and amendments to relevant rules.²⁶

23 Australian Associated Press, 'The wait is over for Grant but his anger may take some time to subside', *Sydney Morning Herald*, 22 March 2002.

24 B Jordan, *Genetic Susceptibility to Brain Injury in Sports: A Role for Genetic Testing in Athletes*, The Physician and Sportsmedicine, <www.physsportsmed.com/issues/1998/02feb/jordan.htm>, 6 February 2003.

25 Sports Medicine Australia, *Who is Sports Medicine Australia?* (2002) Sports Medicine Australia.

26 Sports Medicine Australia, *Consultation*, Canberra, 20 November 2002.

38.39 SMA has, for example, produced a *Policy on the Safety of Boxing* in response to calls from the Australian Medical Association to ban the sport. The policy preamble states that:

There is irrefutable evidence that professional boxing leads to chronic brain injury. The case against amateur boxing is not so clear, but potential for brain injury is there. Potential for similar injuries also exists in kickboxing and full contact martial arts, although research in these sports is currently lacking.²⁷

38.40 The policy makes a range of suggestions designed to make boxing a safer sport, including the education of boxers, referees and trainers on the dangers, a requirement for the informed consent of participants, changes to rules to exclude the head and neck as target areas, and stricter medical supervision of boxers and boxing bouts.

38.41 The approach of SMA to safety in boxing identifies a range of strategies for responding to the risk of illness and injury in sport. These strategies include education of participants, safer rules for all participants, and an increased level of medical supervision. Other strategies might be developed in relation to individual athletes at increased risk of injury or illness. This might involve managing the athlete's participation in sport, for example, by limiting the number of matches played in a particular period or modifying training methods, rather than excluding the athlete from the sport altogether.

Existing legal framework

38.42 As discussed above, the DDA and the *Privacy Act* regulate the use of genetic information in sport. In relation to professional positions, the DDA provisions relating to employment will be relevant. These include s 19, which prohibits disability discrimination by a body or authority responsible for the issue of licences or other authorisations necessary for the practice of a profession or the carrying on of a trade or occupation. Section 19(2) goes on to provide that it is not unlawful for an authority or body to discriminate if the person, because of his or her disability, would be unable to carry out the inherent requirements of the profession, trade or occupation.

38.43 This provision would apply to a decision by the Professional Boxing and Combat Sports Board of Victoria, for example, to deny a professional boxer a licence on the basis of genetic information indicating a predisposition to CTE. As discussed in detail in Chapters 31 and 32, the ability to work safely is one of the inherent requirements of a job, as well as giving rise to occupational health and safety issues. The recommendations made in those chapters in relation to employment and occupational health and safety will assist to ensure that genetic information is treated appropriately in employment in the context of sport. Recommendations 32–1 to 32–3, for example, will ensure that, before a genetic test is used to exclude a professional athlete from participation in that athlete's chosen sport, for occupational health and safety reasons, the test will be approved for that use by the Human Genetics Commission of Australia.

27 Sports Medicine Australia, *Policy on the Safety of Boxing*, Sports Medicine Australia, <www.sma.org.au/images/boxing.pdf>, 16 January 2003.

38.44 The exceptions in s 28(3) of the DDA, set out above, do not address the issue of excluding a person from a sporting activity on the basis of a predisposition to illness or injury expressly. It is unclear, therefore, whether that provision would allow a sporting organisation to exclude an athlete on these grounds. It may be possible to argue that where a genetic condition exposes an athlete to a high degree of risk, that athlete is not ‘reasonably capable of performing the actions reasonably required in relation to the sporting activity’.²⁸

38.45 Section 29, discussed above, would apply to AIS and other Commonwealth sports programs. Once again it would be important to ensure that reliance on particular genetic information indicating a predisposition to illness or injury in the selection process was reasonable in the context of the particular program. It would be necessary to demonstrate, for example, that the genetic predisposition was relevant to, and likely to have an impact on, the athlete’s ability to fulfil his or her potential as an elite athlete.

38.46 Finally, the recommendations made in Chapters 26 and 27 in relation to the use of genetic information by the insurance industry will ensure that there is greater transparency and an increased level of independent oversight in this complex and rapidly developing area.

Inquiry’s views

38.47 The use of genetic information to screen athletes for predisposition to illness or injury is a more pressing issue than the use of genetic information to assess athletic performance potential. Sporting organisations in Australia are already actively considering using this information to exclude athletes from participation in some sports.

38.48 The recommendations made in other parts of this Report in relation to privacy, discrimination, employment and insurance will assist to ensure a more transparent and balanced approach to the use of genetic information in sport, as well as in a range of other contexts. The Inquiry is of the view, however, that sports organisations and authorities should give further consideration to these issues. In particular, the ASC should take the lead in developing policies and guidelines for use by sporting organisations and athletes on the use of genetic information in relation to predisposition to sports-related illness or injury. The elements included in Recommendation 32–1 in relation to genetic screening of applicants or employees for susceptibility to work-related conditions may provide a starting point for the development of these policies and guidelines.

38.49 The policies and guidelines should be developed in consultation with the HGCA, HREOC, the OFPC and other relevant stakeholders such as Sports Medicine Australia and the Australia and New Zealand Sports Law Association.

28 *Disability Discrimination Act 1992* (Cth) s 28(3)(a).

Recommendation 38–2. The ASC should develop policies and guidelines for sports organisations and athletes on the use of genetic information in relation to predisposition to sports-related illness or injury. The policies and guidelines should be developed in consultation with the HGCA, HREOC, OFPC and other stakeholders.

Part J. Law Enforcement and Evidence

39. Forensic Uses of Genetic Information

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Introduction

39.1 This chapter examines the current and potential uses of DNA analysis in the law enforcement context, and provides an overview of the regulatory framework in this area.

Use of genetic information

Forensic DNA analysis

39.2 The forensic analysis of DNA usually involves comparisons between two bodily samples to determine the likelihood that they came from the same person. As discussed in Chapter 2, about 99.9% of the DNA molecule found within human cells is identical between any two persons. The remaining 0.1% is specific to the individual.¹

39.3 Forensic analysis usually involves analysis of nuclear DNA, which is inherited from both parents in random combinations. DNA profiles are created from sections of non-coding DNA found within bodily samples such as blood, semen, hair, skin, urine, bone marrow and cells found in saliva, sweat and tears.²

39.4 Obviously, investigators will utilise any source available to obtain a DNA sample from a crime scene. However, obtaining samples directly from suspects (and convicted serious offenders) is regulated by Part 1D of the *Crimes Act 1914* (Cth) (*Crimes Act*) and equivalent forensic procedures legislation in the States and Territories. In practice, police officers normally obtain a sample through the buccal swab method—which involves lightly scraping the inside of a person's cheek with a swab to collect saliva and cells—or by taking hair samples (including the roots, since these contain the cells required for analysis) or blood samples (by a finger prick).

39.5 All Australian forensic laboratories regularly involved in criminal casework use a profiling kit known as Profiler Plus. This kit uses the polymerase chain reaction method, involving extraction of the DNA from the sample, amplification, and analysis to create the DNA profile. The profile comprises a set of numbers and an indicator of sex. A typical example of a DNA profile looks like this: 'XY 10,12 18,19 14,14 15,16 25,28 16,12 11,10 29,30 17,18'. The numbers indicate the number of short tandem repeats (STRs)³ found at nine sites, or loci, along the DNA molecule. There are two sets of numbers for each loci, one inherited from each parent.⁴

39.6 As a DNA profile represents only a small number of loci along the DNA molecule, it is possible that two persons who are not identical twins might coincidentally have the same profile. However, the chance of such coincidence will decrease inversely as the number of loci examined increases. See Chapter 44 for more detail.

1 With the exception of identical twins. See D Kaye and G Sensabaugh Jr, 'Reference Guide on DNA Evidence' in Federal Judicial Center (ed), *Reference Manual on Scientific Evidence* (2000) Washington DC, 485, 491–492.

2 Legislative Council Standing Committee on Law and Justice, *Review of the Crimes (Forensic Procedures) Act 2000*, Report No 18 (2002), Parliament of NSW, Sydney [2.11], quoting the evidence of Linzi Wilson-Wilde.

3 A short tandem repeat is a locus along the DNA molecule that is composed of a short sequence of between two and seven bases of DNA, which is repeated a number of times in a particular region of DNA.

4 J Gans and G Urbas, 'DNA Identification in the Criminal Justice System' (2002) 226 *Australian Institute of Criminology: Trends & Issues* 1, 2. The Inquiry understands that in some circumstances a number may appear in a DNA profile as an 'NR' (ie not recordable), or may be followed by a 'V' (ie variant): CrimTrac, *Consultation*, Canberra, 23 August 2001.

39.7 Mitochondrial DNA (mtDNA) is found outside the nucleus of a cell. It is less discriminating than nuclear DNA, but can be useful where a sample contains too little nuclear DNA for analysis.⁵ By comparing polymorphisms on two persons' mtDNA or on the Y chromosome, it is possible to identify relationships between a mother and her children, or between a father and son, respectively.⁶ This can be useful in identifying human remains and in certain other investigations.

39.8 An emerging form of DNA analysis involves the identification of single nucleotide polymorphisms (SNPs) within the DNA molecule. SNPs represent alterations in DNA sequence of a single 'letter' in a person's genetic code (eg A, C, T or G), and on average, base variations are observed every 1,000 bases throughout the genome.⁷

Uses for DNA analysis

39.9 DNA analysis is used as an intelligence tool to identify, confirm or eliminate a suspect in a criminal investigation. It may also be used to identify victims of crime or a mass disaster,⁸ or to link crimes by comparing profiles created from DNA samples found at different crime scenes.

39.10 If a suspect's DNA profile matches the DNA found at a crime scene, this match may be used as evidence pointing to the suspect's guilt. However, a DNA match cannot be considered conclusive of guilt for a number of reasons, including the possibility that the match occurred by coincidence, as a result of error, contamination or tampering,⁹ or that the suspect's DNA was innocently left at the crime scene.

39.11 DNA profiling has also become a useful tool in exonerating convicted offenders.¹⁰ Finally, DNA profiling could potentially be used as a form of unique personal identification—for example, in a DNA identity card.¹¹

DNA and conventional fingerprints

39.12 Media and other accounts often suggest that DNA profiles are simply a modern form of fingerprint identification. In fact, DNA profiles differ from conventional fingerprints in several important respects. First, DNA holds vastly more information than fingerprints. A DNA profile can be used in establishing kinship relationships, and the sample from which the profile was obtained may hold predictive health and other information of a sensitive nature. Second, as genetic information is

5 Legislative Council Standing Committee on Law and Justice, *Review of the Crimes (Forensic Procedures) Act 2000*, Report No 18 (2002), Parliament of NSW, Sydney [2.4].

6 See Ch 36 for more detail.

7 See Ch 2 for more detail.

8 See Ch 42 for more detail.

9 Legislative Council Standing Committee on Law and Justice, *Review of the Crimes (Forensic Procedures) Act 2000*, Report No 18 (2002), Parliament of NSW, Sydney [3.22].

10 See Ch 45 for more detail.

11 For example, a 'genotype ID card' has been developed by Zhongnan (Central-South) Hospital Gene Diagnostic Center under Wuhan University in China. The card contains a genetic profile representing 18 loci along the DNA molecule: *China's First Genotype ID Card Comes Out in Wuhan*, People's Daily Online, <www.english.peopledaily.com.cn/200206/20/eng20020620_98228.shtml>, 20 June 2002.

shared with biological relatives, an individual's profile might indirectly implicate a relative in an offence. Third, while it can be difficult to obtain fingerprints of such quality as to be useful in an investigation, DNA can be amplified from tiny and aged samples, and may be recovered from almost any cell or tissue.¹²

Privacy concerns

39.13 It has been suggested that DNA sampling involves intrusion into three forms of individual privacy: bodily privacy, where the sample is taken from a person's body; genetic privacy, where predictive health and other information about the person is obtained from the sample; and behavioural privacy, where the information is used to determine where a person has been and what they have done.¹³ DNA sampling may also impinge on familial privacy where information obtained from one person's sample provides information regarding his or her relatives.

39.14 In a submission to the Inquiry, the Office of the Victorian Privacy Commissioner discussed the balance between individual privacy rights and community safety in this context.

Privacy and respect for human dignity need not be abandoned when balancing civil liberties with community safety. In many ways, privacy principles will enhance the integrity and legitimacy of DNA profiling by limiting collection to the minimum necessary to achieve the legitimate aims of law enforcement agencies, requiring its use to be in accordance with these aims, demanding secure storage of DNA material, and requiring its destruction or de-identification when the information is no longer needed ... Transparency and accountability reassure the community that what is sacrificed for greater safety and security is done so legitimately.¹⁴

Development of the Model Bill

39.15 The Standing Committee of Attorneys-General established the Model Criminal Code Officers Committee (MCCOC) in 1990 to advise on the development of model criminal law for adoption on a national basis. MCCOC was requested to formulate a model forensic procedures bill. The first draft of the model bill was circulated for comment in 1994, redrafted in 1995 and 1999, and finalised in 2000.¹⁵

39.16 The final draft of the Model Forensic Procedures Bill 2000 (Model Bill) provided for: the power to request or require forensic procedures on suspects, convicted offenders and volunteers; a process for carrying out forensic procedures, including safeguards for those undergoing forensic procedures; rules in relation to

12 See the discussion in Human Genetics Commission, *Inside Information: Balancing Interests in the Use of Personal Genetic Data* (2002), London, 145.

13 J Gans, *Submission to the Victorian Parliament Law Reform Committee's Inquiry into Forensic Sampling and the Use of DNA Databases in Criminal Investigations* (2002), 2.

14 Office of the Victorian Privacy Commissioner, *Submission G171*, 8 August 2002.

15 Model Criminal Code Officers Committee, *Final Draft: Model Forensic Procedures Bill and the Proposed National DNA Database* (2000), Standing Committee of Attorneys-General, Canberra. See also the discussion in Legislative Council Standing Committee on Law and Justice, *Review of the Crimes (Forensic Procedures) Act 2000*, Report No 18 (2002), Parliament of NSW, Sydney [2.17]–[2.18].

evidence improperly obtained from forensic procedures; the regulation of DNA database systems; and a scheme for interstate jurisdiction.¹⁶

Commonwealth legislation

39.17 Part 1D of the *Crimes Act* closely follows the Model Bill provisions. Briefly, Part 1D provides for the conduct of intimate forensic procedures¹⁷ and non-intimate forensic procedures¹⁸ on suspects, serious offenders and volunteers; and regulates DNA database systems established for storing and matching DNA profiles.

Suspects

39.18 A ‘suspect’ is a person whom a constable¹⁹ suspects on reasonable grounds has committed an indictable offence; a person charged with an indictable offence; or a person who has been summonsed to appear before a court in relation to an indictable offence. An indictable offence is a Commonwealth offence punishable by imprisonment for a period exceeding 12 months.²⁰ As of August 2002, 34 samples had been collected in the course of a criminal investigation—including 17 samples taken from suspects, nine taken from crime scenes, one from a victim, and three from volunteers.²¹

Forensic procedures by consent

39.19 A constable may ask a suspect (other than a child or incapable person)²² to consent to a forensic procedure if the constable is satisfied on the balance of probabilities that: the person is a suspect; that there are reasonable grounds to believe that the forensic procedure is likely to produce evidence tending to confirm or disprove that the suspect committed a relevant offence; that the request for consent is ‘justified in all the circumstances’; and that the suspect is not a child or an incapable person.²³

16 For a summary of the Model Bill provisions, see Legislative Council Standing Committee on Law and Justice, *Review of the Crimes (Forensic Procedures) Act 2000*, Report No 18 (2002), Parliament of NSW, Sydney [2.20]–[2.37].

17 An ‘intimate forensic procedure’ involves an external examination of, photographing, videotaping etc or taking a sample by specified methods from the genital or anal areas, the buttocks, or breasts (including transgender persons); taking blood, pubic hair, a dental impression, saliva, or a sample by buccal swab: *Crimes Act 1914* (Cth) s 23WA(1).

18 A ‘non-intimate forensic procedure’ involves an examination of, photographing, videotaping etc or taking a sample by specified methods from a part of the body other than the genital or anal area, buttocks, or breasts, that requires touching the body or removing clothing; taking a hair sample other than pubic hair; taking a sample from a nail, or under a nail; or taking a hand, finger, foot or toe print: *Ibid* s 23WA(1).

19 A ‘constable’ means a member or special member of the AFP, or a member of the police force of a State or Territory: Australian Federal Police, *AFP National Guideline for Conducting a Commonwealth Forensic Procedure — Part 1D Crimes Act 1914* (2001), AFP [2.1].

20 *Crimes Act 1914* (Cth) ss 4G, 23WA(1).

21 Australian Federal Police, *Submission to the Independent Review of Part 1D of the Crimes Act 1914 (Cth)*, 10 September 2002. The majority of criminal offences in Australia fall within state and territory jurisdiction, and are therefore investigated by state and territory police.

22 A child or incapable person cannot consent to a forensic procedure: *Crimes Act 1914* (Cth) s 23WE.

23 *Ibid* ss 23WH, 23WI(1).

39.20 The term ‘relevant offence’ is defined broadly. With respect to a suspect, it means: the indictable offence which the person is suspected of having committed; or any other indictable offence arising out of the same circumstances; or any other indictable offence in respect of which the evidence expected to be obtained by the forensic procedure is likely to have probative value.²⁴

39.21 In determining whether a request is justified in all the circumstances, the constable must balance the public interest in obtaining evidence tending to confirm or disprove that the suspect committed the offence concerned against the public interest in upholding the physical integrity of the suspect. In balancing these interests, the constable must have regard to matters specified in the legislation. These matters include the seriousness of the circumstances surrounding the commission of the offence and the gravity of the offence, and the degree of the suspect’s alleged participation.²⁵

39.22 A suspect (other than a child or incapable person) gives informed consent to a forensic procedure if he or she consents after a constable asks the suspect to consent, and gives the suspect a written statement setting out specified information, informs the suspect about the forensic procedure in accordance with s 23WJ, and gives the suspect a reasonable opportunity to communicate, or attempt to do so, with a legal practitioner of the suspect’s choice.²⁶

Forensic procedures without consent

39.23 If a suspect who is in custody withholds consent, a senior constable²⁷ may order the carrying out of non-intimate forensic procedure if satisfied on the balance of probabilities that: the suspect is in lawful custody; there are reasonable grounds to believe the suspect committed a relevant offence, and that the forensic procedure is likely to produce evidence tending to confirm or disprove that he or she committed a relevant offence; and the carrying out of the forensic procedure without consent is ‘justified in all the circumstances’.²⁸

39.24 A magistrate may order the carrying out of a forensic procedure on a suspect who is in or out of police custody, or who is a child or incapable person. The magistrate must consider similar matters as a senior constable before ordering the forensic procedure.²⁹

24 Ibid s 23WA(1). In relation to an offender, a ‘relevant offence’ means the offence for which the offender was convicted and to which an application for an order authorising a forensic procedure relates.

25 Ibid ss 23WI(2), (3).

26 Ibid s 23WF(2). The matters specified in s 23WJ include the purpose for which the forensic procedure is required; the way it will be carried out; that it may produce evidence against the suspect; and that information obtained from analysis of the forensic material obtained may be placed on the DNA database system and the rules that will apply to its disclosure and use.

27 A ‘senior constable’ means a constable of the rank of Sergeant or higher: Australian Federal Police, *AFP National Guideline for Conducting a Commonwealth Forensic Procedure — Part 1D Crimes Act 1914* (2001), AFP [2.1].

28 *Crimes Act 1914* (Cth), ss 23WN, 23WO(1). See ss 23WO(2)–(3) regarding the balancing of interests test to be applied by the senior constable, and the matters to which the senior constable must have regard in applying the test.

29 Ibid ss 23WS, 23WT. However, see Div 5, Subdiv C in relation to interim orders.

Serious offenders

39.25 A ‘serious offender’ is a person under sentence for a Commonwealth offence punishable by a maximum penalty of imprisonment for life or five or more years.³⁰ As of August 2002, 294 offenders had been approached for sampling—of these, 286 gave consent, seven withheld consent and court orders were sought; and one obtained a Federal Court order that placed the sample collection ‘on hold’ until the appeal was heard.³¹

Forensic procedures with consent

39.26 A constable may ask a serious offender (other than a child or incapable person) to consent to a forensic procedure if he or she is satisfied on the balance of probabilities that the request for consent is justified in all the circumstances, and in the case of persons not serving a sentence of imprisonment, that the person is an offender.³²

39.27 A serious offender gives informed consent to a forensic procedure if he or she consents after a constable asks the offender to consent, informs the offender about the forensic procedure in accordance with s 23XWJ, and gives the offender the opportunity to communicate, or attempt to do so, with a legal practitioner of the offender’s choice.³³

Forensic procedures without consent

39.28 If the offender withholds consent, a constable may order the carrying out of a non-intimate forensic procedure if the constable has taken into account: whether Part 1D would authorise the forensic procedure to be carried out in the absence of an order; the seriousness of the circumstances surrounding the offence committed by the offender; whether the carrying out of the forensic procedure ‘could assist law enforcement’ (whether federal or otherwise); and whether the carrying out of the forensic procedure without consent is ‘justified in all the circumstances’.³⁴

39.29 A magistrate or judge may order the carrying out of an intimate forensic procedure on an offender, or a non-intimate forensic procedure in relation to an offender who is a child or incapable person, if the magistrate or judge is satisfied that it is justified in all the circumstances. The magistrate or judge must take into account generally the same matters as a constable when making this determination.³⁵

30 Ibid s 23WA(1).

31 Australian Federal Police, *Submission to the Independent Review of Part 1D of the Crimes Act 1914 (Cth)*, 10 September 2002.

32 *Crimes Act 1914* (Cth) ss 23XWH, 23XWI.

33 Ibid s 23XWG(1). The matters specified in s 23XWJ include the purpose for which the forensic procedure is required; the way it will be carried out; that it may produce evidence against the suspect; and that information obtained from analysis of forensic material obtained may be placed on the DNA database system, and the rules that will apply to its disclosure and use.

34 Ibid ss 23XWK, 23XWL.

35 Ibid s 23XWO.

Volunteers

39.30 A ‘volunteer’ is a person who volunteers to undergo a forensic procedure, or in the case of a child or incapable person, whose parent or guardian volunteers on his or her behalf.³⁶ As of August 2002, one sample had been collected from a victim of crime and three from volunteers.³⁷

Forensic procedures with consent

39.31 A volunteer (or his or her parent or guardian) gives informed consent to a forensic procedure if he or she consents in the presence of an independent person after a constable informs the person of the matters specified in s 23XWR. For example, the constable must advise the person that: he or she may consult a legal practitioner before giving consent; that the forensic procedure might produce evidence that might be used in a court of law; and to the extent relevant, that information obtained from the forensic material may be placed on the DNA database system, and that the person may choose the particular volunteer’s index in which the profile should be stored.³⁸

Forensic procedures without consent

39.32 A magistrate may order the carrying out of a forensic procedure on a volunteer who is a child or incapable person if the consent of the parent or guardian cannot reasonably be obtained; the parent or guardian withholds consent and the magistrate is satisfied there are reasonable grounds to believe the child or incapable person is a suspect and the forensic procedure is likely to produce evidence tending to confirm or disprove that he or she committed the offence; or the parent or guardian consented to the carrying out of the forensic procedure, but subsequently has withdrawn consent. In making this decision, the magistrate must take into account matters specified in the legislation.³⁹

Vulnerable persons

39.33 Part 1D provides procedural safeguards for certain categories of vulnerable persons. As noted above, children and incapable persons cannot consent to a forensic procedure in any context.⁴⁰ In addition, suspects who are Aborigines and Torres Strait Islanders are generally entitled to the presence of an ‘interview friend’ when being asked to consent to a forensic procedure.⁴¹

36 Ibid s 23XWQ(1).

37 Australian Federal Police, *Submission to the Independent Review of Part 1D of the Crimes Act 1914 (Cth)*, 10 September 2002.

38 *Crimes Act 1914* (Cth) s 23XWR.

39 Ibid s 23XWU. The magistrate must consider whether Pt 1D would otherwise authorise the forensic procedure; if the forensic procedure is carried out for the purpose of investigating a particular offence, the seriousness of the circumstances surrounding the commission of the offence; the best interests of the child or incapable person; so far as can be ascertained, the child or incapable person’s wishes; except in certain circumstances, the parent or guardian’s wishes; and whether the forensic procedure is justified in all the circumstances: *Crimes Act 1914* (Cth) s 23XWU(2).

40 *Crimes Act 1914* (Cth) s 23WE.

41 Ibid s 23WG(3).

Carrying out forensic procedures

39.34 Division 6 of Part 1D regulates the carrying out of forensic procedures on suspects, serious offenders and volunteers.⁴² The Division specifies who may carry out different forensic procedures, and provides procedural safeguards including: the provision of reasonable privacy; videotaping the procedure; the presence of an interview friend for certain vulnerable persons; prohibiting cruel, inhuman and degrading treatment; and providing the subject of the procedure with part of the sample for his or her own analysis.

DNA database systems

39.35 Division 8A of Part 1D of the *Crimes Act* regulates DNA databases that fall within the definition of a 'DNA database system'. The division contains rules governing index matching, and criminal offences for certain unauthorised activities in relation to forensic material and information held on a DNA database system.

39.36 By early 2003, the Commonwealth had established the National Criminal Investigation DNA Database (NCIDD system), and a Disaster Victim Identification Database. An executive agency of the Commonwealth government, known as CrimTrac, operates both of these systems. In addition, the AFP operates its own DNA database system.

Inter-jurisdictional sharing

39.37 Division 11 deals with inter-jurisdictional enforcement. The responsible Minister may enter into arrangements with participating jurisdictions for inter-jurisdictional sharing of information held on a DNA database system.

39.38 A new Division 11A was inserted into Part 1D in October 2002. This division was designed to apply to the Bali bombings of 12 October 2002, and other incidents occurring outside Australia in which one or more Australian citizens or residents have died.⁴³

39.39 As of February 2003, CrimTrac had not conducted any inter-jurisdictional information sharing on the NCIDD system. CrimTrac advised the Inquiry that it will not conduct inter-jurisdictional index matching until it finalises agreements with the participating jurisdictions. CrimTrac will enter into a Memorandum of Understanding (MOU) with each participating jurisdiction, which will include permitted index matching protocols between the jurisdictions.⁴⁴ As of February 2003, the MOU was still in draft form.

39.40 The Commonwealth Attorney-General's Department has advised the Inquiry that these protocols will reflect the legislative provisions of each participating jurisdiction, and inter-jurisdictional matching will be conducted on the 'least

42 Ibid Div 6, ss 23XWE, 23XWQ(5).

43 See Ch 42 for more detail.

44 CrimTrac, *Consultation*, Canberra, 7 November 2002.

permissive' terms. However, any inconsistencies between jurisdictions' legislative definitions—for example, the definition of a suspect, an offender and a child—could undermine this principle.

Other Australian jurisdictions

39.41 The Commonwealth, New South Wales and the Australian Capital Territory closely follow the Model Bill, with variations.⁴⁵ Tasmania, Victoria and South Australia have followed the Model Bill in some respects, with more variations.⁴⁶ In 2002, Victoria and South Australia amended their legislation to bring their laws into closer conformity with the Model Bill (however some fairly significant variations remain);⁴⁷ and Western Australia implemented legislation that conforms in some respects with the Model Bill.⁴⁸ Queensland and the Northern Territory have not followed the Model Bill at all.⁴⁹ However, Queensland has indicated a willingness to amend its legislation to facilitate participation in the NCIDD system.⁵⁰

Other forms of regulation

Coronial investigations

39.42 Each Australian State and Territory has legislation governing the powers and duties of the coroner. Generally, the coroner's role is to investigate the circumstances surrounding 'reportable deaths',⁵¹ by providing a written finding to establish the deceased's identity; the circumstances surrounding the death; the cause of death; and the particulars needed to register the death.⁵²

45 *Crimes Act 1914* (Cth) Pt 1D; *Crimes (Forensic Procedures) Act 2000* (NSW); *Crimes (Forensic Procedures) Act 2000* (ACT).

46 *Forensic Procedures Act 2000* (Tas); *Crimes Act 1958* (Vic); *Criminal Law (Forensic Procedures) Act 1998* (SA).

47 See *Crimes (DNA Database) Act 2002* (Vic); *Criminal Law (Forensic Procedures) (Miscellaneous) Amendment Act 2002* (SA).

48 *Criminal Investigation (Identifying People) Act 2002* (WA).

49 *Police Powers and Responsibilities Act 2000* (Qld); *Police Administration Act 1978* (NT); *Juvenile Justice Act 1983* (NT); *Prisons (Correctional Services) Act 1980* (NT). For a summary of the various jurisdictions' legislation, see Legislative Council Standing Committee on Law and Justice, *Review of the Crimes (Forensic Procedures) Act 2000*, Report No 18 (2002), Parliament of NSW, Sydney [2.64]–[2.75]. See also I Freckelton, *DNA Profiling: Collection, Use and Effectiveness — An Issues Paper* (2002), Victorian Parliament.

50 Queensland Government, *Submission G274*, 18 December 2002.

51 The definition of a 'reportable death' varies in each jurisdiction, but generally includes circumstances where the person died unexpectedly and the cause of death is unknown; the person died in a violent or unnatural manner; the person died during or as a result of an anaesthetic; the person was 'held in care' or in custody immediately before they died; a doctor has been unable to sign a death certificate giving the cause of death; or the identity of the person who has died is unknown: Monash University National Centre for Coronal Information, *National Coroners Information System: Coronal Process*, Victorian Institute of Forensic Medicine, <www.vifp.monash.edu.au/ncis/Background/australi.htm>, 1 March 2003.

52 Ibid.

39.43 For example, in New South Wales the coroner may order that a post-mortem examination be conducted on a deceased person who has died a reportable death.⁵³ It may be necessary for the pathologist to retain tissue obtained during the autopsy for further testing and examination. In addition, a coroner's order for a post-mortem examination is sufficient authority for the use of tissue removed from the deceased's body for therapeutic, medical and scientific purposes.⁵⁴

Access to newborn screening cards

39.44 Chapter 19 of this Report discusses Australia's various regulatory frameworks for collecting, storing, accessing and destroying newborn screening cards (often referred to as 'Guthrie cards'),⁵⁵ including access for law enforcement purposes.

39.45 Recommendation 19–1 provides that the Australian Health Ministers' Advisory Council, in consultation with the state and territory Attorney-General's Departments and police services, should develop nationally consistent rules governing disclosure, for law enforcement purposes, of newborn screening cards, pathology samples, banked tissue and other genetic samples.

Overseas jurisdictions

United States of America

39.46 All 50 states in the United States have implemented legislation to create state criminal DNA databases.⁵⁶ The Federal Bureau of Investigation (FBI) operates the Combined DNA Index System (CODIS), which comprises a hierarchy of DNA indexes at the local, state and national levels. Local index laboratories upload profiles to the state indexes, and the state index laboratories upload profiles to the national index. CODIS holds four separate indices: convicted offenders, crime scenes, unidentified human remains and relatives of missing persons.⁵⁷ As of November 2002, CODIS held over 1,224,034 profiles of convicted offenders, and 44,140 crime scene profiles.⁵⁸

England and Wales

39.47 The *Police and Criminal Evidence Act 1984* (UK) regulates the taking of bodily samples in England and Wales. Non-intimate samples (mouth swabs and hair) may be taken without consent from any person suspected of being involved in, charged

53 *Coroners Act 1980* (NSW) ss 48, 49.

54 *Human Tissue Act 1983* (NSW) s 31(3). See also Monash University National Centre for Coronal Information, *National Coroners Information System: Coronal Process*, Victorian Institute of Forensic Medicine, <www.vifp.monash.edu.au/ncis/Background/australi.htm>, 1 March 2003.

55 See [19.14].

56 D Crosby, *Protection of Genetic Information: An International Comparison* (2000), Human Genetics Commission, London [1.73].

57 Office of the Inspector General, *Audit Report: The Combined DNA Index System* (2001), Department of Justice, Washington, i–ii, 9. State law determines the offences for which a convicted offender is required to submit a sample.

58 Federal Bureau of Investigation, *National DNA Index System*, United States, <www.fbi.gov/hq/lab/codis/national.htm>, 1 March 2003.

with or about to be reported for, or convicted of a 'recordable offence'. Intimate samples may be taken provided the appropriate consent is given.⁵⁹

39.48 Although the police initially focussed on taking samples from suspects for the most serious arrestable offences (for example, murder and sexual offences), this has been extended to include a range of less serious offences.⁶⁰ The Forensic Science Service operates the national DNA database, which contains three indexes, for suspects, serious offenders and unknown samples (that is, crime scenes).⁶¹ In May 2002, the database held about 1.5 million profiles.⁶²

39.49 As a result of legislative amendments in 2001, a suspect's sample and profile may be retained even if he or she is acquitted of the crime for which the sample was taken. In addition, volunteers in police 'intelligence screens' can be asked to sign a non-revocable consent form for the permanent retention of their samples and profiles.⁶³ As a result, the database is expected to hold 3.5 million profiles by 2005.⁶⁴

Canada

39.50 Canada authorises the taking of DNA samples from suspects for certain categories of offence pursuant to court warrants. A judge may grant a warrant if satisfied of specified matters, and the sample only may be used to investigate the designated offence for which it was taken. In addition, a judge may order that DNA samples be taken from persons convicted of designated offences, or from persons declared dangerous or who have been convicted of multiple murder or multiple sexual crimes. The judge must consider specified matters before making an order.⁶⁵

39.51 The Royal Canadian Mounted Police operates the national DNA databank, which contains a crime scene index and an offenders index.⁶⁶ As at February 2003, the databank held 35,719 profiles in the offenders index, and 8,144 profiles in the crime scene index.⁶⁷

59 'Recordable offences' include the majority of offences investigated by police, including offences involving violence or dishonesty and that can lead to a prison sentence: Human Genetics Commission, *Inside Information: Balancing Interests in the Use of Personal Genetic Data* (2002), London, 147.

60 Ibid, 149.

61 P Schneider and P Martin, 'Criminal DNA Databases: The European Situation' (2001) 119 *Forensic Science International* 232, 234.

62 Human Genetics Commission, *Inside Information: Balancing Interests in the Use of Personal Genetic Data* (2002), London, 145.

63 See *Criminal Justice and Police Act 2001* (UK) ss 81, 82. See also Human Genetics Commission, *Inside Information: Balancing Interests in the Use of Personal Genetic Data* (2002), London, 148.

64 S Morris, 'Police Allowed to Retain DNA of Ex-Suspects', *The Guardian* (London), 23 March 2002.

65 Legislative Council Standing Committee on Law and Justice, *Review of the Crimes (Forensic Procedures) Act 2000*, Report No 18 (2002), Parliament of NSW, Sydney [2.85]–[2.88].

66 Ibid [2.90].

67 Royal Canadian Mounted Police, *National DNA Data Bank: Statistics*, <www.nddb-bndg.org/stats_e.htm>, 19 February 2003.

New Zealand

39.52 In New Zealand, as of 2002, blood samples can be taken from suspects and certain convicted offenders by consent or by court order. A sample can be taken from a suspect for an indictable offence by consent. If consent is withheld, a court can order the taking of a blood sample if satisfied of specified matters, including that a crime scene sample is available for matching, and that in all the circumstances it is reasonable to make the order. In addition, a court can order a person convicted of specified offences to provide a blood sample for the database.⁶⁸

39.53 The Institute of Environmental Science and Research administers the national DNA databank on behalf of the New Zealand police. The databank contains suspects and offenders profiles, which are matched against a crime sample database.⁶⁹

Germany

39.54 In Germany, as of 1999, DNA samples can be taken from a suspect where there is a justified suspicion that the person has committed an offence 'of some gravity'. DNA samples also can be taken from persons convicted of 'serious crimes'. A court order generally is required if taking the sample involves an invasive procedure, but buccal swabs are not considered invasive.⁷⁰ Initially, each of the 16 German states operated their own DNA databases. However, one national database now contains indexes of suspects, convicted offenders and unknown samples for serious crimes (ie serious crime scenes),⁷¹ and each state provides information directly to the central database.⁷²

Other inquiries and reviews

39.55 There are several inquiries into the various forensic procedures regimes in Australia. For example, in addition to this Inquiry's consideration of Part 1D of the *Crimes Act*, the legislation provides for the following independent reviews:

- an independent review of the operation of Part 1D of the *Crimes Act* to be undertaken as soon as possible after June 2002;⁷³

68 Legislative Council Standing Committee on Law and Justice, *Review of the Crimes (Forensic Procedures) Act 2000*, Report No 18 (2002), Parliament of NSW, Sydney [2.82]–[2.84].

69 Institute of Environmental Science and Research, *The DNA Databank*, ESR, <www.esr.cri.nz/features/esr_and_dna/databank/index.htm>, 20 February 2003.

70 Legislative Council Legislation Committee, *Forensic Procedures and DNA Profiling: The Committee's Investigations in Western Australia, Victoria, South Australia, the United Kingdom, Germany and the United States of America*, Report No 48 (1999), Parliament of Western Australia, Perth [6.33], [6.35].

71 P Schneider and P Martin, 'Criminal DNA Databases: The European Situation' (2001) 119 *Forensic Science International* 232, 234.

72 Legislative Council Legislation Committee, *Forensic Procedures and DNA Profiling: The Committee's Investigations in Western Australia, Victoria, South Australia, the United Kingdom, Germany and the United States of America*, Report No 48 (1999), Parliament of Western Australia, Perth [7.35].

73 *Crimes Act 1914* (Cth) s 23YV. Section 23YV(1) outlines the specific matters that must be reviewed.

- if the report of the independent review identifies inadequacies with the matters covered by the review, a further independent review must be conducted within 2 years of the tabling of the first report to ascertain whether the inadequacies have been effectively dealt with;⁷⁴ and
- an independent review of the operation of Division 11A—in relation to overseas incidents—must be undertaken as soon as possible after 12 October 2003.⁷⁵

39.56 The independent review into Part 1D of the *Crimes Act* (Sherman review) commenced operation in 2002. Mr Tom Sherman AO chairs the review committee, which also includes the federal Privacy Commissioner, representatives from the AFP, the Commonwealth Director of Public Prosecutions and the Commonwealth Ombudsman's Office. At the time of writing the report of the review committee had not yet been tabled.

39.57 The Commonwealth Attorney-General's Department advised the Inquiry that at a meeting of the Australasian Police Ministers Council (APMC) on 5 November 2002, it was resolved that in the longer term, improvements to the Model Bill would be considered by the Joint Standing Committee of Attorneys-General/APMC Working Group. The APMC resolution requires the joint working group to consider 'specific reforms to the Model Bill which are designed to facilitate a more effective approach'.⁷⁶ As of January 2003, the process for review and formal terms of reference had not yet been finalised.

39.58 Various state and territory jurisdictions have conducted reviews of their own forensic procedures legislation. For example, the *Crimes (Forensic Procedures) Act 2000* (NSW) has been reviewed by the New South Wales Legislative Assembly's Standing Committee on Law and Justice,⁷⁷ and is under review by the New South Wales Ombudsman,⁷⁸ and by the Minister.⁷⁹ The Victorian Parliament Law Reform Committee was conducting an inquiry into forensic sampling and the uses of DNA databases in criminal investigations in that jurisdiction, until the inquiry lapsed in November 2002.⁸⁰

74 Ibid s 23YV(5).

75 Ibid s 23YUK.

76 Commonwealth Attorney-General's Department, *Submission G228*, 12 December 2002.

77 See Legislative Council Standing Committee on Law and Justice, *Review of the Crimes (Forensic Procedures) Act 2000*, Report No 18 (2002), Parliament of NSW, Sydney.

78 See NSW Ombudsman, *Discussion Paper: The Forensic DNA Sampling of Serious Indictable Offenders Under Part 7 of the Crimes (Forensic Procedures) Act 2000* (2001) NSW Ombudsman.

79 See *Crimes (Forensic Procedures) Act 2000* (NSW) s 122. At the time of writing, the Minister's report had not yet been tabled.

80 Due to the prorogation of the Legislative Council and dissolution of the Legislative Assembly on 5 November 2002, the Parliamentary Committees ceased to hold office and all uncompleted inquiries lapsed as from that date.

Function creep

39.59 As DNA technology advances, new methods of analysis might allow forensic analysts to access increasing amounts of personal information about a person from a DNA sample. In future, there may be pressure to expand the scope of DNA analysis to include identification of physical and behavioural traits; or to expand the scope of persons subjected to testing to include particular community groups, all arrestees, all persons applying to enter Australia as tourists, immigrants, or asylum seekers, or even all Australians.⁸¹

39.60 The Inquiry believes that any future expansion of the use of this technology would necessitate community debate to strike an effective balance between individual privacy rights and the need for community protection from crime.

81 For example, Peter Lindsay MP suggested in April 2001 that mandatory DNA sampling of all Australians should be introduced to create a comprehensive national DNA database: *MP Calls for DNA Sampling of All Australians*, ABC Online News, <www.abc.gov.au/news/>, 26 April 2001.

40. Harmonisation of Forensic Procedures Legislation

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Introduction

40.1 Chapter 39 examined the current and potential uses of DNA analysis in criminal investigations, and provided an overview of the Australian regulatory framework for the use of genetic information in law enforcement. This chapter discusses issues and concerns arising from the lack of harmonisation between the forensic procedures legislation of the Commonwealth and that of each State and Territory.

Lack of harmonisation

40.2 Every Australian jurisdiction has implemented forensic procedures legislation. As outlined in Chapter 39, some jurisdictions have followed the Model Forensic Procedures Bill 2000 (Model Bill)¹ closely; some have followed the Model Bill with significant variations, while others have not followed the Model Bill provisions at all.

Legislative differences among jurisdictions

40.3 Legislative variations among the jurisdictions gain significance in light of the proposed inter-jurisdictional sharing of information. Examples of jurisdictional variations are the differences in the:

¹ Model Criminal Code Officers Committee, *Final Draft: Model Forensic Procedures Bill and the Proposed National DNA Database* (2000), Standing Committee of Attorneys-General, Canberra.

- classification of certain forensic procedures as ‘intimate’ and ‘non-intimate’;
- seriousness of the offence for which a forensic procedure might be carried out on a suspect or offender;
- treatment of volunteers, children and other vulnerable persons;
- procedure for authorising compulsory forensic procedures;
- index matching rules (or other rules regarding profile matching); and
- requirements for destruction of genetic samples or profiles.

Sharing of forensic material and information

40.4 The Commonwealth has established a National Criminal Investigation DNA Database (NCIDD system) and a Disaster Victim Identification Database, both of which provide for inter-jurisdictional sharing of information held on them.²

40.5 Division 11 of Part 1D of the *Crimes Act 1914* (Cth) (*Crimes Act*) provides for the sharing of information held on a DNA database system between participating jurisdictions. Section 23YUD(1) provides that the Minister may enter into arrangements with participating jurisdictions for the sharing of information held on a DNA database system for the purpose of criminal investigations and prosecutions. This provision does not appear to cover the sharing of forensic material which is not held on a DNA database system.³

40.6 A ‘participating jurisdiction’ is defined as a State or Territory in which there is a corresponding law in force. A ‘corresponding law’ is a law relating to the carrying out of forensic procedures and DNA databases that substantially corresponds to Part 1D of the *Crimes Act* or is prescribed by the regulations for the purpose of the definition.⁴

40.7 It is unclear the extent to which a law must mirror Part 1D to satisfy this ‘substantial correspondence’ requirement. A broad reading of the definition would require substantial compliance in all provisions of the legislation, while a narrow reading would require correspondence only in the provisions relating to the ‘carrying out’ of forensic procedures and the operation of a DNA database system. The Revised Explanatory Memorandum provides some guidance, commenting that a ‘corresponding law’ means ‘another jurisdiction’s law that is in substantially similar terms to this Bill’.⁵ This suggests that the broader approach may have been intended.

2 See Ch 43 for more detail.

3 See Ch 41 for more detail.

4 *Crimes Act 1914* (Cth) s 23YUA.

5 Revised Explanatory Memorandum to the Crimes Amendment (Forensic Procedures) Bill 2001 (Cth) [218].

40.8 Under s 23YP(2)–(3), the Commonwealth may retain or use forensic material or information obtained from another jurisdiction for investigative, evidentiary or statistical purposes, provided the material or information was taken in accordance with a state or territory law.

40.9 Section 23YUD(2) provides that information that is transmitted must not be recorded, or maintained in an identifiable database in the second jurisdiction after the specified destruction date.⁶

Concerns with sharing of information

40.10 The Inquiry has heard concerns that in the absence of real harmonisation among Australian jurisdictions' forensic procedures legislation, a jurisdiction that has loose controls and allows the collection of samples in a wider range of circumstances could undermine appropriate restrictions on the use of a DNA database system in another jurisdiction.⁷ The Model Criminal Code Officers' Committee (MCCOC) provided the following example:

State A may only allow taking samples from serious offenders while State B might allow them to be taken from any offender. A law enforcement officer in State A could then check to see if the suspect had committed an offence in State B through a criminal records check. The officer discovers the person committed a traffic offence after which a person had been required to give a sample for DNA analysis. The law enforcement officer then conducts matching on the DNA database against someone who would not be on the database in the same circumstances under local legislation.⁸

40.11 MCCOC considered it undesirable that jurisdictional variations should be able to undermine the legislative safeguards:

It is not desirable that variations of the nature described ... should be allowed to undermine the DNA databases legislative requirements. The Committee therefore believes that a consistent approach between jurisdictions is very important in combating this type of problem.⁹

40.12 The Senate Legal and Constitutional Legislation Committee expressed a similar concern in its report on the Crimes Amendment (Forensic Procedures) Bill 2000 (Cth). The Committee commented that the provisions for the sharing of data were the most contentious aspect of the Bill, and concluded that uniform adoption of the highest standards in the collection, use and disposal of information was fundamental to the effectiveness of the legislation.¹⁰

6 As determined by Pt 1D, or the corresponding provisions of state or territory law.

7 Model Criminal Code Officers Committee, *Model Forensic Procedures Bill and the Proposed National DNA Database, Discussion Paper* (1999) Standing Committee of Attorneys-General, 87.

8 Ibid.

9 Ibid, 87, 89.

10 Senate Legal and Constitutional Legislation Committee, *Inquiry into Provisions of the Crimes Amendment (Forensic Procedures) Bill 2000* (2000), Canberra [3.63], Rec 3.

40.13 In response to IP 26, several submissions raised concerns about the lack of harmonisation in forensic procedures legislation.¹¹ Most of these concerns focused on the potential undermining of privacy and other legislative safeguards if forensic material or information obtained in one jurisdiction is shared with a jurisdiction that does not have equivalent legislative safeguards.

Harmonisation in practice

Legislative amendment

40.14 In April 2002, the Commonwealth entered into an agreement with State and Territory leaders providing, among other things, for modernisation of the criminal law by legislating in the area of model forensic procedures during 2002; and the enhancement of capacity in each jurisdiction for the collection and processing of samples to create DNA profiles, and the uploading of profiles onto the national DNA database.¹²

40.15 As of February 2003, several state and territory jurisdictions had either amended, or expressed an intention to amend, their forensic procedures legislation to bring them into closer conformity with the Model Bill provisions. For example:

- In March 2002, Victoria enacted the *Crimes (DNA Database) Act 2000* (Vic), which amended the *Crimes Act 1958* (Vic) to 'facilitate Victoria's participation in the national DNA Database system, and to amend procedures for the obtaining, use and retention of forensic samples'.¹³
- In June 2002, the Western Australia Parliament passed the *Criminal Investigation (Identifying People) Act 2002* (WA), which varies significantly from the Model Bill but has been recognised by the Commonwealth as a 'corresponding law'.¹⁴
- In December 2002, the South Australian Parliament passed the *Criminal Law (Forensic Procedures) (Misc) Amendment Act 2002* (SA), which amends the *Criminal Law (Forensic Procedures) Act 1998* (SA) to facilitate participation in the NCIDD system.
- The Queensland government has advised that it intends to amend the *Police Powers and Responsibilities Act 2000* (Qld) to facilitate participation in the NCIDD system. Queensland intends to generally retain its current standards regarding the collection, use, and storage of forensic material and DNA profiles.¹⁵

11 For example, Centre for Law and Genetics, *Submission G048*, 14 January 2002; Office of the Privacy Commissioner (NSW), *Submission G118*, 18 March 2002; Office of the Federal Privacy Commissioner, *Submission G143*, 22 March 2002; New South Wales Legal Aid Commission, *Submission G087*, 21 January 2002.

12 Council of Australian Governments, *Commonwealth and States and Territories Agreement on Terrorism and Multi-Jurisdictional Crime* (2002), Commonwealth of Australia.

13 *Crimes (DNA Database) Act 2000* (Vic) s 1.

14 *Crimes Regulations 1990* (Cth) s 6E.

15 Queensland Government, *Submission G274*, 18 December 2002.

40.16 The Northern Territory remains unwilling to amend its forensic procedures legislation to bring it into greater conformity with the Model Bill. In a press release prior to the Australasian Police Ministers Council (AMPC) conference in November 2002, the Northern Territory's Acting Police Minister, Syd Stirling, commented:

If the NT was to move towards this national 'model', it would significantly reduce the capacity of NT Police to use DNA as a crime fighting tool. I will be taking the Territory's position to the Police Minister's Conference and calling on all jurisdictions to make greater use of DNA as a modern crime fighting tool.¹⁶

40.17 The APMC meeting resolved that, as a matter of priority, the Commonwealth and the Northern Territory would commit to further exploring ways to enable the Northern Territory to participate in the national DNA database.¹⁷

Prescribed jurisdictions

40.18 The Commonwealth has recognised several state and territory jurisdictions as participating jurisdictions by prescribing them in the *Crimes Regulations 1990* (Cth). As of February 2003, the Commonwealth had prescribed the forensic procedures legislation of New South Wales, the Australian Capital Territory, Tasmania, Victoria and Western Australia.¹⁸ Each of these jurisdictions has followed the Model Bill to some extent; however as noted above, some significant variations remain.¹⁹

40.19 In addition, New South Wales and Western Australia have prescribed in regulations the forensic procedures legislation of all other Australian jurisdictions for the purposes of the definition of 'corresponding legislation'—including the Northern Territory and Queensland—despite significant variations between the jurisdictions.²⁰ Dr Jeremy Gans has commented that:

The NSW government has ... taken advantage of the regulatory power under the [*Crimes (Forensic Procedures) Act 2000* (NSW)] to abandon MCCOC's commitment to encouraging similar legislation through the definition of 'corresponding law'. Relying on the pretext of supposed administrative difficulties in transferring a profile from a NSW detainee who was a suspect in the Northern Territory backpacker kidnapping case, the NSW government issued regulations deeming the forensic procedures law of every jurisdiction in Australia to be a 'corresponding law'.²¹

Ministerial arrangements

40.20 The Inquiry understands that the Commonwealth is negotiating ministerial agreements with each of the States and Territories, and the intention is for ministerial

16 Office of the Chief Minister, *DNA and Handgun Issues to be Tackled at Police Ministers' Conference, Press Release*, Northern Territory Government, <www.nt.gov.au/ocm/media_releases/20021104_police.shtml>, 11 March 2003.

17 Commonwealth Attorney-General's Department, *Submission G228*, 12 December 2002.

18 *Crimes Regulations 1990* (Cth) r 6E.

19 See Ch 39 for more detail.

20 See *Crimes (Forensic Procedures) Regulation 2001* (NSW) r 12; *Criminal Investigation (Identifying People) Regulations 2002* (WA) r 6.

21 J Gans, 'The Quiet Devolution: How the Model Criminal Code Officers' Committee Botched New South Wales' DNA Law' (2002) 14(2) *Current Issues in Criminal Justice* 210, 220.

agreements to contain tables specifying the index matching permitted between each participating jurisdiction. As noted above, the wording of s 23YUD(1) suggests that these agreements only would deal with the transfer of profiles, and not with the forensic material from which the profiles are obtained.

40.21 The Inquiry has not been given access to these draft agreements, and therefore cannot comment on their contents. However, the greater the number of variations in the provisions of each jurisdiction's forensic procedures legislation, the greater the complexity of the index matching tables or protocols, and the greater the difficulties of operation in practice.

40.22 New South Wales, Western Australia and South Australia have each entered into ministerial agreements for the sharing of information with the Northern Territory, despite significant variations between them.²² The Inquiry understands that New South Wales and South Australia entered into these agreements in the context of a criminal investigation into the presumed murder of British tourist, Peter Falconio, in the Northern Territory in 2001.

Inquiry's preliminary views

40.23 DP 66 noted the Inquiry's preliminary view that harmonisation of forensic procedures legislation is a necessary precondition for the effective operation of a national DNA database system, or of any inter-jurisdictional information sharing.

40.24 The Inquiry commented that greater harmonisation would avoid complexity in the operation of the NCIDD system. The greater number of variations in index matching rules between the jurisdictions, the greater complexity and difficulty there will be in administering the matching regime, which may create operational problems for police as well as making it more difficult to ensure compliance with all of the legislative safeguards.

40.25 In addition, the Inquiry noted that variations in forensic procedures legislation may tend to result in a 'lowest-common-denominator' approach. Where a sample or profile is transferred from a jurisdiction with strong privacy and civil liberties protections to a jurisdiction with lesser protections, the safeguards applying in the first jurisdiction could be undermined. For example, where a person in the first jurisdiction volunteers for a forensic procedure for 'limited purposes', that persons' sample or profile should not be subjected to use for other purposes in any jurisdiction to which it is legitimately transferred.

Submissions and consultations

40.26 DP 66 proposed that the Commonwealth, States and Territories should work together to achieve harmonisation in Australian forensic procedures legislation, in

22 See R Rose, 'DNA Law Reform to Ease Falconio Inquiry', *The West Australian* (Perth), 13 June 2002, 5; P Toohey, 'Falconio Suspect's DNA Matches', *The Australian*, 10 October 2002; 'Swap Agreement for Crime Suspects' DNA', *West Australian*, 7 November 2002; 'Prisoner Investigated over Falconio Murder', *The Canberra Times*, 12 June 2002.

particular in relation to the collection, use, storage, destruction and index matching of forensic material and the DNA profiles created from such material. Inter-jurisdictional sharing of forensic material and DNA profiles, whether on a bilateral basis or via the national DNA database system, should be permitted only after such harmonisation has been achieved.²³

40.27 Most of the submissions supported the proposal.²⁴ In its initial submission, the Commonwealth Attorney-General's Department commented that:

Consistent legislation between jurisdictions based on the Model Bill is the key to ensuring that information transmitted to another jurisdiction is protected by the same safeguards as those in the originating jurisdiction.²⁵

40.28 In a further submission, the Department commented that the proposal

is consistent with the commitment made by the leaders of the Commonwealth, States and Territories at the 5 April 2002 Leaders' Summit to legislate in the priority areas of model forensic procedures before the end of 2002 ... all jurisdictions are also fast-tracking the preparation of arrangements that will facilitate the inter-jurisdictional matching of DNA profiles. It is important that harmonisation is achieved because inconsistencies in legislation will limit the optimal use of the DNA database and reduce its effectiveness as a crime fighting tool.²⁶

40.29 The Office of the Federal Privacy Commissioner supported the proposal, commenting that:

Lack of legislative uniformity may have the unintended consequence of diminishing the utility of the national DNA database system, as well as compromising an individual's privacy rights. The need for legislative uniformity, however, should not provide an excuse for an extension of the power to collect, use, retain and match DNA profiles, in ways which would have the effect of diminishing the standards of privacy protection ... achieving a high degree of uniformity may be many years away. In the meantime, the means should be found to make the best use of existing transparency and accountability mechanisms.²⁷

40.30 National Legal Aid submitted that in order to have access to a national DNA database system, participating jurisdictions should be required to comply with national standards for the collection, use and destruction of DNA samples.

23 Australian Law Reform Commission and Australian Health Ethics Committee, *Protection of Human Genetic Information*, DP 66 (2002), ALRC, Sydney, Proposal 35–1.

24 Office of the Federal Privacy Commissioner, *Submission G294*, 6 January 2003; Centre for Genetics Education, *Submission G232*, 18 December 2002; Genetic Support Council WA, *Submission G243*, 19 December 2002; Centre for Law and Genetics, *Submission G255*, 21 December 2002; Victorian Bar, *Submission G261*, 20 December 2002; Human Genetics Society of Australasia, *Submission G267*, 20 December 2002; Association of Genetic Support of Australasia, *Submission G284*, 25 December 2002; Department of Human Services South Australia, *Submission G288*, 23 December 2002; Androgen Insensitivity Syndrome Support Group Australia, *Submission G290*, 5 January 2003; New South Wales Legal Aid Commission, *Submission G282*, 24 December 2002; Office of the Victorian Privacy Commissioner, *Submission G266*, 20 December 2002; Law Institute of Victoria, *Submission G275*, 19 December 2002.

25 Commonwealth Attorney-General's Department, *Submission G158*, 7 May 2002.

26 Commonwealth Attorney-General's Department, *Submission G228*, 12 December 2002.

27 Office of the Federal Privacy Commissioner, *Submission G294*, 6 January 2003.

As things currently stand, a law enforcement agency in one State may have access to forensic information obtained in another jurisdiction to which they would not have had access if they were limited to information collected, used and destroyed in accordance with their own State legislation. This may occur because the sample would not have been collected, or because it would have already been destroyed, or because it would have been included on a limited purpose index which could not have been accessed for the relevant purpose ... this situation is unacceptable. It undermines the protections provided by those jurisdictions which have adopted legislation providing appropriate levels of protection to people from whom forensic samples are taken.

One of the areas in which the lack of uniformity in the legislation is most pronounced is the use which can be made of information obtained from the samples taken ... Because of the variations in indexes and permissible matching, there are numerous types of matching which are lawful in some jurisdictions but not in others. With the confusion arising from such a situation there is a real risk that a match will be made which is not permitted under the law of the relevant jurisdiction.²⁸

40.31 In its initial submission, Privacy NSW expressed concerns regarding the lack of uniformity:

A uniform national legislative approach is very important as a means of holding the line against ad hoc and incremental arrangements which would undermine the protective provisions of forensic legislation. I am concerned that Police Services have been exploiting the political appeal of crime control to play off the different jurisdictions so as to weaken the safeguards provided in the *Model Forensic Procedures Bill*. Ministerial agreements would simply promote this process.²⁹

40.32 In its subsequent submission, Privacy NSW noted two recent legislative amendments in relation to forensic procedures legislation. First, New South Wales prescribed all the other jurisdictions' forensic procedures legislation as corresponding laws for the purpose of sharing information. Second, the Commonwealth Parliament amended the *Crimes Act* to authorise the use and disclosure of information on a DNA database system for the purpose of identifying the Bali bombing victims, and informing relatives. Privacy NSW suggested that these amendments 'might be seen to make the goal of uniformity harder to achieve', noting that:

Arguably each of these responses goes further than is necessary in response to the specific events which gave rise to them. We can appreciate the urgency which may inform a desire to share genetic data in some circumstances. However, the hurried passage of sweeping amendments to legislation whose function is essentially one of protecting individual rights does undermine confidence and make the prospect of harmonisation seem somewhat remote. Assuming that such situations are likely to recur there is a case for anticipating a more measured way of responding to them in the legislation itself.³⁰

40.33 Several submissions supported the need for greater harmonisation of forensic procedures legislation but considered that the public interest in resolving crime would

28 National Legal Aid, *Submission G314*, 19 February 2003. See also New South Wales Legal Aid Commission, *Submission G282*, 24 December 2002.

29 Office of the Privacy Commissioner (NSW), *Submission G118*, 18 March 2002.

30 Office of the Privacy Commissioner (NSW), *Submission G257*, 20 December 2002.

justify the sharing of information in the interim.³¹ For example, the Victoria Police noted the desirability of harmonisation, but commented that:

considering the time it will take to achieve harmonisation of the legislation in Australia, and in the interest of public safety, it would be inappropriate to hinder current investigations by disallowing the exchange of information until complete harmony exists. An appropriate interim resolution could be found by agreements of each jurisdiction to use relevant information in compliance with the highest standards of commonality as set by the Commonwealth.³²

40.34 The New South Wales Police Service commented that the process of working to facilitate inter-jurisdictional matching on the NCIDD system has highlighted the differing philosophical and political views on the use of forensic evidence in criminal investigation that are held throughout Australia:

[I]f the exchange of information related to forensic material is only permitted after the harmonisation of the laws of all Australian jurisdictions is achieved then it is highly likely that only a couple of jurisdictions will ever achieve this goal and accordingly the inter-jurisdictional exchange of information will be extremely limited. This will prevent law enforcement agencies from having access to important evidence which in the past has been available to them. It may also result in the ridiculous situation where a criminal may avoid prosecution and conviction by entering a bordering jurisdiction after the commission of an offence.³³

40.35 The Law Institute of Victoria supported the need for uniformity, but stated that this should not be achieved without fully considering the views of each jurisdiction. The Law Institute suggested that there is a risk that a 'lowest common denominator' approach will mean that jurisdictions holding a minority view will be compelled to pass legislation to which there remain strong objections, in order to be eligible to participate in the national DNA database system.³⁴

40.36 The Queensland Government commented that harmonisation would not be achievable if it required conformity with the most restrictive jurisdiction's legislation. Queensland would not support a 'reduction' in its forensic procedures legislation. While Queensland would be willing to amend its legislation in order to participate in the national system, the submission noted that Queensland would continue to operate outside that system—for example, by sharing information with the Northern Territory.³⁵

40.37 Adam Johnston suggested a new approach to the inter-jurisdictional sharing of information, by making sharing of data conditional on a court order:

31 Victoria Police, *Submission G203*, 29 November 2002; NSW Police Service, *Submission G306*, 22 January 2003; Institute of Actuaries of Australia, *Submission G224*, 29 November 2002; Australian Federal Police, *Consultation*, Canberra, 7 November 2002.

32 Victoria Police, *Submission G203*, 29 November 2002.

33 NSW Police Service, *Submission G306*, 22 January 2003.

34 Law Institute of Victoria, *Submission G275*, 19 December 2002.

35 Queensland Government, *Submission G274*, 18 December 2002.

To obtain such an order, authorities should have to show that they were unsuccessful in genuine attempts to obtain a sample from a suspect. As well, they should have to satisfy a judge that on the basis of other evidence collected there is probable cause to believe that a suspect has a case to answer and, that obtaining DNA evidence from another jurisdiction's database is necessary to assist the case. Presuming the court agreed, this would not necessarily make the DNA evidence admissible at trial.³⁶

40.38 Finally, the South Australian Attorney-General's Department commented in a consultation that when MCCOC was developing the Model Bill, DNA testing was very expensive, required a large sample and was not very accurate; therefore, it was only to be used in very serious cases. However, as the technology has changed the key issue has become whether DNA testing should be used more broadly, in the same way as other investigative tools—for example, fingerprinting and photography. The Department suggested that it would be impossible to harmonise legislation if there is no harmony in the policy underlying the use of DNA analysis in law enforcement.³⁷

An alternative approach

40.39 Dr Jeremy Gans has commented that 'the most obvious danger of uniformity is that it will impose on all jurisdictions, not merely the strengths of a particular model, but also its weaknesses'.³⁸ In order to prevent Australian laws from 'sliding further towards the "lowest common denominator" of Queensland and the Northern Territory', he has suggested 'mutual recognition' as an alternative approach.³⁹

40.40 Under this approach, each jurisdiction would be required to enact laws requiring its investigators to obey the matching, destruction, access and disclosure rules of the jurisdiction where those profiles were originally obtained. The administrators of any cross-jurisdictional database—including the NCIDD system—would apply the jurisdictional rules on retention and disclosure applicable to each profile and could only compare profiles from two different jurisdictions if permitted to do so by the laws of both jurisdictions.⁴⁰ Dr Gans suggested that this approach would avoid the 'lowest common denominator' effect without affecting how States and Territories deal with profiles obtained locally.⁴¹

40.41 In order to achieve this result, Dr Gans has suggested that s 23YUD(2) of the *Crimes Act* should be expanded to cover matching, access and disclosure, and the Commonwealth should pass legislation prohibiting the sharing of information with

36 A Johnston, *Submission G042*, 13 January 2002.

37 South Australian Attorney-General's Department, *Consultation*, Adelaide, 30 October 2002.

38 J Gans, 'The Quiet Devolution: How the Model Criminal Code Officers' Committee Botched New South Wales' DNA Law' (2002) 14(2) *Current Issues in Criminal Justice* 210, 219.

39 J Gans, *Submission to the Independent Review of Part 1D (Forensic Procedures) of the Crimes Act 1914 (Cth)*.

40 J Gans, 'The Quiet Devolution: How the Model Criminal Code Officers' Committee Botched New South Wales' DNA Law' (2002) 14(2) *Current Issues in Criminal Justice* 210, 221. See also J Gans, *Submission to the Independent Review of Part 1D (Forensic Procedures) of the Crimes Act 1914 (Cth)*.

41 J Gans, 'The Quiet Devolution: How the Model Criminal Code Officers' Committee Botched New South Wales' DNA Law' (2002) 14(2) *Current Issues in Criminal Justice* 210, 221.

other jurisdictions unless those other jurisdictions enact laws recognising the laws of the jurisdictions from which the profiles were first obtained.⁴²

Inquiry's views

40.42 The need for greater harmonisation in this area has been well recognised. During the course of this Inquiry, several Australian jurisdictions have amended, or have indicated an intention to amend, their forensic procedures legislation to effect greater conformity with the Model Bill.

40.43 DP 66 noted the Inquiry's concerns that efforts at harmonisation could take a 'lowest common denominator' approach. The Inquiry considers that this has occurred at two levels. First, although several jurisdictions have amended their laws to effect greater conformity with the Model Bill, they have done so in a minimal way, leaving significant variations between their own legislation and the Model Bill provisions. Second, several jurisdictions have formally prescribed the forensic procedures laws of other jurisdictions as constituting 'corresponding laws', despite the existence of significant variations between them. The most extreme example of this occurrence was the action by New South Wales and Western Australia in prescribing the forensic procedures legislation of all other jurisdictions—including the Northern Territory and Queensland, whose laws were developed independently of the Model Bill and do not contain the safeguards developed through that process.

40.44 In summary, developments over the course of the Inquiry have suggested a growing pragmatism among the Australian jurisdictions regarding the need for 'corresponding laws' as a precondition to participation in inter-jurisdictional sharing of forensic material and profiles. While each of the Australian jurisdictions participated in the development of the Model Bill, none has been willing to adopt its provisions entirely. As a result, harmonisation in practice has involved a process of negotiation between the Commonwealth and the other jurisdictions to determine the minimum number of amendments required in order for their laws to be considered to 'correspond' with Part 1D of the *Crimes Act*.

40.45 At the same time, the Inquiry recognises that full harmonisation of forensic procedures legislation might require the removal of higher protections from existing state or territory legislation. Legislation in Victoria, Western Australia and South Australia currently contains procedural and other safeguards that are absent from the Model Bill provisions.⁴³

42 J Gans, *Submission to the Independent Review of Part 1D (Forensic Procedures) of the Crimes Act 1914 (Cth)*.

43 For example, the *Crimes Act 1958* (Vic) provides, among other things, that: compulsory orders for a forensic procedure may be made by a magistrate (for an adult) or a Children's Court (for a child) only—and not by a police officer; part of a crime scene sample must be given to a suspect for independent analysis where there is sufficient of the sample to share; and the Chief Commissioner of Police must, upon request, notify a person in writing that his or her sample or related material and information has been destroyed in accordance with the legislation.

40.46 In DP 66, the Inquiry suggested that if it is not possible, or realistic, to achieve fully harmonised forensic procedures legislation, the Commonwealth should specify the critical features of the legislation upon which it would be reasonable for the public to expect commonality. At a minimum, it would be necessary to achieve commonality in relation to the collection, use, storage, destruction and index matching of forensic material and information obtained from it.

40.47 The Inquiry considers that this approach better reflects the current Australian climate in relation to forensic procedures regulation. Achieving commonality in these provisions is especially important in light of the lack of co-ordinated, independent oversight of DNA database systems established for law enforcement.⁴⁴ Where all jurisdictions participating in information sharing have common provisions regarding the handling of that information, the community can have greater confidence that such information will be used only as would be permitted within the jurisdiction in which the information was obtained.

40.48 Consequently, the Inquiry suggests that the Commonwealth, States and Territories should work together to determine a set of national standards for the use, storage, destruction and index matching of forensic material and DNA profiles shared between jurisdictions for law enforcement purposes. The Model Bill provisions could provide a model for these standards. Inter-jurisdictional sharing should be permitted only where both of the jurisdictions involved have inserted a legislative provision into their forensic procedures legislation providing that information transferred to the jurisdiction must be treated in accordance with the national minimum standards. This would avoid the existing difficulties arising from the existing requirement that participating jurisdictions must have ‘corresponding laws’.

40.49 While the mutual recognition approach might be possible in the absence of such common standards—for example, New South Wales could pass information to the Northern Territory provided the latter had a legislative requirement to respect the information handling rules in the former—the Inquiry considers it could be overly confusing for investigators who, depending on the number and source of the information held, could be required to comply with up to nine different legislative regimes.

40.50 The better approach would be to settle on a set of common standards for implementation by each jurisdiction, so that once the information has been transferred, the latter jurisdiction would have a clear understanding of the information handling standards with which it must comply.

40.51 The Inquiry recommends that in order to facilitate an effective national approach to sharing genetic information for law enforcement purposes, the Commonwealth, States and Territories should collaborate to develop adequate national minimum standards in Australian forensic procedures legislation for the use, storage, destruction and index matching of forensic material, and the DNA profiles created from such material. A jurisdiction should not be permitted to engage in the inter-

44 See Ch 43 for more detail.

jurisdictional sharing of genetic information—whether on a bilateral basis or through the national DNA database system—unless there is legislation requiring that any information transferred to that jurisdiction will be treated in accordance with the national minimum standards.

40.52 In order to implement this recommendation, the Inquiry recommends that where applicable, state and territory legislatures should amend their forensic procedures legislation in a manner consistent with the recommendations made in this Report in relation to the *Crimes Act*.

Recommendation 40–1. In order to facilitate an effective national approach to sharing genetic information for law enforcement purposes, the Commonwealth, States and Territories should collaborate to develop adequate national minimum standards in Australian forensic procedures legislation with respect to the collection, use, storage, destruction and index matching of forensic material, and the DNA profiles created from such material.

Recommendation 40–2. The Commonwealth, States and Territories should not engage in inter-jurisdictional sharing of genetic information—whether on a bilateral basis or through a national DNA database system—unless there is legislation requiring that any information transferred to that jurisdiction will be treated in accordance with the national minimum standards developed under Recommendation 40–1.

Recommendation 40–3. In order to facilitate an effective national approach to sharing genetic information the States and Territories should amend their forensic procedures legislation in a manner consistent with the recommendations made in this Report in relation to the *Crimes Act 1914* (Cth).

Ministerial agreements

40.53 As noted above, s 23YUD(1) of the *Crimes Act* provides that the Minister may enter into arrangements with participating jurisdictions for the sharing of information on a DNA database system for the purpose of criminal investigations and prosecutions.⁴⁵ In addition, each participating jurisdiction would need to enter into arrangements with each other jurisdiction for the sharing of information.

40.54 DP 66 noted that while these ministerial agreements are expected to make some provision for privacy and other protections, they do not have the same status as legislation or regulations, and there are sometimes problems with gaining public access to them. The Inquiry considers that in order to afford greater transparency, ministerial

⁴⁵ The form or content of these arrangements is not detailed in the legislation but the Explanatory Memorandum refers to ministerial ‘agreements’: Revised Explanatory Memorandum to the Crimes Amendment (Forensic Procedures) Bill 2001 (Cth) [224].

agreements for the sharing of information and inter-jurisdictional matching protocols should be prescribed in regulations.⁴⁶

40.55 Most of the submissions supported this proposal.⁴⁷ The Commonwealth Attorney-General's Department advised that 'the arrangements will be public documents and will not impact on the safeguards that are in the statute'.⁴⁸

40.56 The New South Wales Police commented that:

there may be a number of practical difficulties. It is unlikely that all the agreements between the jurisdictions will be signed off at the same time [with the proposal]. Accordingly, the agreements may need to be prescribed by the regulations in an ad hoc fashion. Additionally, at least in the initial stages there may be the need to amend the agreements several times at short notice. This process is made far more difficult and time consuming if the agreements are prescribed in the regulation.

However, on a positive note prescribing the agreements in the regulation would add strength to the argument that the agreements are lawful which would provide police with greater certainty when acting under the agreement.⁴⁹

40.57 The Office of the Federal Privacy Commissioner commented that:

Without any experience of the functioning of [the] national DNA database system and of the operation of Part 1D, it may be advisable for this proposal to be evaluated at a later date, with the benefit of experience. In the event of the statutory provisions requiring a further Review of Part 1D being invoked by the current Review, the opportunity will arise for further consideration of this issue.⁵⁰

40.58 The Inquiry considers that for the purpose of achieving greater transparency, Commonwealth, state and territory governments should publish all ministerial agreements for the sharing of information, as well as protocols for inter-jurisdictional matching. In practice, these agreements need not be prescribed in regulations under the relevant forensic procedures legislation but they should be made easily available to the public—for example, by gazettal.

Recommendation 40–4. For the purpose of achieving greater transparency, the Commonwealth, States and Territories should publish all ministerial agreements for sharing genetic information, as well as protocols for inter-jurisdictional matching.

46 Australian Law Reform Commission and Australian Health Ethics Committee, *Protection of Human Genetic Information*, DP 66 (2002), ALRC, Sydney, Proposal 35–2.

47 For example, Victoria Police, *Submission G203*, 29 November 2002; Institute of Actuaries of Australia, *Submission G224*, 29 November 2002; Centre for Law and Genetics, *Submission G255*, 21 December 2002; Office of the Privacy Commissioner (NSW), *Submission G257*, 20 December 2002; Victorian Bar, *Submission G261*, 20 December 2002; Law Institute of Victoria, *Submission G275*, 19 December 2002; Association of Genetic Support of Australasia, *Submission G284*, 25 December 2002; Human Genetics Society of Australasia, *Submission G267*, 20 December 2002.

48 Commonwealth Attorney-General's Department, *Submission G228*, 12 December 2002. See also Centre for Law and Genetics, *Submission G255*, 21 December 2002.

49 NSW Police Service, *Submission G306*, 22 January 2003.

50 Office of the Federal Privacy Commissioner, *Submission G294*, 6 January 2003.

41. Criminal Investigations

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Introduction

41.1 This chapter discusses specific issues arising from the existing regulatory framework for forensic procedures, and contains recommendations to address the privacy, discrimination and ethical concerns identified by the Inquiry in relation to the use of genetic information in criminal investigations.

41.2 In Chapter 40, the Inquiry recommended that, where applicable, state and territory legislatures should amend their forensic procedures legislation in a manner consistent with the recommendations made in this Report in relation to the *Crimes Act 1914* (Cth) (*Crimes Act*). Each specific recommendation discussed below also should be read in light of that general recommendation.

Authorisation of forensic procedures

Crimes Act provisions on consent

41.3 Part 1D of the *Crimes Act* authorises the carrying out of a forensic procedure on a suspect, serious offender or volunteer with the ‘informed consent’ of that person.¹

41.4 The informed consent provisions regarding suspects and serious offenders are similar in nature. An Australian Federal Police (AFP) constable must ask a suspect or a serious offender (who is not a child or incapable person) to consent to a forensic procedure before making an order, or applying to a court for an order for a compulsory forensic procedure. The constable must give the suspect or serious offender the information specified in the legislation about the nature, purpose and consequences of the forensic procedure, and must give the person a reasonable opportunity to communicate (or attempt to do so) with a legal practitioner before consent is given.²

41.5 Where a suspect or serious offender withholds consent to the carrying out of a forensic procedure, a specified decision maker may order that the procedure be carried out without consent, provided that the appropriate legislative test has been satisfied.³ Consistently with other areas of operational policing, these tests give the decision maker a broad discretion in deciding whether or not to order a compulsory forensic procedure.

41.6 The Inquiry heard concerns about the appropriateness of the term ‘informed consent’ in relation to a forensic procedure conducted in the context of a criminal investigation. The Inquiry understands that the consent provisions in forensic procedures legislation were borrowed from the medico-legal area with the intention of providing a procedural safeguard to protect personal autonomy. However, in virtually

1 Except in relation to children and incapable persons.

2 See Ch 39 for more detail. In addition, a volunteer (or his or her parent or guardian) gives informed consent if he or she consents to the forensic procedure in the presence of an independent person after a constable gives the volunteer (or parent or guardian) the information specified in the legislation.

3 See Ch 39 for more detail.

all clinical and medical research contexts, an individual's refusal to (or withdrawal of) consent to a procedure is the end of the matter—individual autonomy is given precedence.⁴ By way of contrast, in the law enforcement context, an individual's refusal of consent may be readily over-ruled by an AFP officer exercising a statutory discretion, or by a court.

41.7 The inherently coercive nature of a criminal investigation also challenges the free nature of any consent given to a forensic procedure. For example, where a suspect consents because he or she believes—correctly or otherwise—that a compulsory procedure will be ordered anyway, this may suggest the consent has not been freely given. Similarly, where a police officer suggests that a suspect should consent to a forensic procedure because this would exclude the person from suspicion, this also undermines the free nature of the consent given.

41.8 Dr Jeremy Gans has stated that some investigators might rely on a refusal to consent to a forensic procedure as a sign that the person has 'something to hide', arguing that this would constitute a breach of the privilege against self-incrimination.⁵

41.9 In its submission to the independent review into Part 1D of the *Crimes Act* (Sherman review), the NSW Legal Aid Commission commented that:

There is some anecdotal evidence to suggest that some police officers are advising suspects that if they do not consent to the taking of a buccal swab, the police have the power to use reasonable force to take a sample of growing hairs. This is a misleading statement of the effect of the NSW Act, which mirrors Part 1D in this respect ... Anecdotal evidence suggests that police officers may be ... proceeding to take DNA samples from suspects on the basis of consent which does not fulfil the requirements of informed consent.⁶

41.10 The Inquiry has not heard any allegations that a federal prisoner has felt pressured to consent to a forensic procedure under the *Crimes Act*.⁷ However, concerns have been raised that state prisoners might have felt such pressure. For example, in its review of the New South Wales forensic procedures legislation the New South Wales Legislative Council Standing Committee on Law and Justice (NSW Standing Committee) heard allegations that some New South Wales prisoners had been pressured into consenting to forensic procedures, and that some prisoners who had withheld consent had subsequently lost privileges or had been reclassified or transferred to higher security prisons. The NSW Standing Committee commented on the New South Wales situation as follows:

4 See Ch 15 for more detail.

5 J Gans, 'Something to Hide: DNA, Surveillance and Self-incrimination' (2001) 13(2) *Current Issues in Criminal Justice* 168, 176–182.

6 NSW Legal Aid Commission, *Submission to the Independent Review into Part 1D of the Crimes Act 1914 (Cth)* (2002), 2.

7 However, the NSW Ombudsman has noted allegations that NSW police may have taken forensic samples from Commonwealth prisoners without authority: NSW Ombudsman, *Discussion Paper: The Forensic DNA Sampling of Serious Indictable Offenders Under Part 7 of the Crimes (Forensic Procedures) Act 2000* (2001) NSW Ombudsman, 11. See also New South Wales Council for Civil Liberties, *Submission G312*, 10 February 2003.

It appears to the Committee that offenders feel pressured to consent, whether or not pressure in fact is placed upon them. The Committee is concerned about the potential for courts to overturn consent given by prisoners in circumstances that could be interpreted to be coercive.⁸

Submissions and consultations

41.11 DP 66 proposed that, in relation to suspects and serious offenders, the consent provisions should be removed from Part 1D of the *Crimes Act*, rendering compulsory procedures the only means by which a forensic procedure may be carried out on a suspect or serious offender.⁹

41.12 The Inquiry received a number of submissions both supportive and critical of this proposal. Several submissions worried that removing the consent provisions would undermine an individual's personal autonomy and human dignity.¹⁰ For example, Privacy NSW submitted:

The concept of the rule of law as it applies to criminal investigation implies that individuals have choices at each stage of the investigation/prosecution as to whether to cooperate or not ... The consent provisions as they apply to taking samples from suspects reflect this process. They represent an important, if in some circumstances symbolic, recognition of the personal autonomy of suspects and convicted offenders ... Requesting consent also serves an important if symbolic role where samples are taken from convicted offenders. It recognises that their rights to bodily integrity are not entirely overborne, and should act as a break on excessive collection of DNA samples where there is no clear probative case to support the practice.¹¹

41.13 Privacy NSW also was concerned that removing the consent provisions in relation to suspects might place pressure on the courts to make compulsory orders for forensic procedures:

If the only way to obtain a DNA sample from a suspect is by court order, there is a risk that courts may be less critical when asked to make orders, especially where they have no indication that the individual concerned has refused to provide a sample voluntarily. This would undermine the assumption inherent in forensic testing legislation that a suspect's bodily integrity could only be interfered with where there was good and sufficient cause.¹²

41.14 The Office of the Federal Privacy Commissioner (OFPC) acknowledged the 'inherently coercive nature of criminal investigations', but submitted that removing the consent provisions would not be the most effective means of remedying any procedural

8 Legislative Council Standing Committee on Law and Justice, *Review of the Crimes (Forensic Procedures) Act 2000*, Report No 18 (2002), Parliament of NSW, Sydney [5.127]. The NSW Council for Civil Liberties noted that it has received a number of complaints from prisoners alleging pressure to consent: New South Wales Council for Civil Liberties, *Submission G312*, 10 February 2003.

9 Australian Law Reform Commission and Australian Health Ethics Committee, *Protection of Human Genetic Information*, DP 66 (2002), ALRC, Sydney, Proposal 36–1.

10 See New South Wales Legal Aid Commission, *Submission G282*, 24 December 2002; Office of the Privacy Commissioner (NSW), *Submission G257*, 20 December 2002; Victoria Police, *Submission G203*, 29 November 2002; National Legal Aid, *Submission G314*, 19 February 2003.

11 Office of the Privacy Commissioner (NSW), *Submission G257*, 20 December 2002.

12 Ibid.

inadequacies. The OFPC noted that the requirement that consent be informed and voluntary provides a measure of restraint or control over the taking of samples and thus could, in practice, provide benchmarks for complaints, audits and other oversight measures. In addition, an emphasis on the voluntary nature of the consent can alleviate the sense of coercion inherent in most investigations.¹³

41.15 The Victorian Bar submitted that the abolition of consent would simply shift the focus of litigation from the issue of ‘voluntariness’ to the issue of whether there was a valid basis to justify the making of an order.¹⁴

41.16 The Commonwealth Attorney-General’s Department considered that the proposal raised a number of difficulties.

First, the ordering of a compulsory procedure under the existing provisions is not automatic. If a person does not consent to a forensic procedure, a senior police officer or a magistrate must still be satisfied of a number of matters before an order can be made. Requiring a magistrate to make an order for a DNA sample in relation to every suspect would involve unnecessary strain on resources of magistrates and increase the time in which a suspect ... may be held in custody. Secondly, there is no evidence that the informed consent provisions are operating ineffectively. While it is too early to make an assessment of the provisions in Part 1D of the *Crimes Act 1914* ... provisions in Victoria have been working without any reports of major difficulties for a number of years.¹⁵

41.17 Finally, the Victoria Police submitted that:

the suggested benefit that this proposal is a better reflection of the coercive nature of these forensic procedures and will result in removal of potential arguments of voluntary consent are far out-weighed by the negative influence in the timely, efficient and effective administration of justice.¹⁶

41.18 By contrast, several submissions supported the proposal,¹⁷ as did the AFP in a consultation meeting.¹⁸ The New South Wales Police Service (NSW Police Service) supported the proposal on the basis that it would streamline the process of carrying out forensic procedures, but only provided that ‘in appropriate cases a New South Wales police officer could issue an order and that judicial officers be available to make orders at short notice if required’.¹⁹

13 Office of the Federal Privacy Commissioner, *Submission G294*, 6 January 2003.

14 Victorian Bar, *Submission G261*, 20 December 2002.

15 Commonwealth Attorney-General’s Department, *Submission G228*, 12 December 2002.

16 Victoria Police, *Submission G203*, 29 November 2002.

17 Centre for Law and Genetics, *Submission G255*, 21 December 2002; Centre for Genetics Education, *Submission G232*, 18 December 2002; Institute of Actuaries of Australia, *Submission G224*, 29 November 2002; Human Genetics Society of Australasia, *Submission G267*, 20 December 2002; Office of the Victorian Privacy Commissioner, *Submission G266*, 20 December 2002; NSW Police Service, *Submission G306*, 22 January 2003; Australian Privacy Charter Council, *Submission G304*, 21 January 2003; Association of Genetic Support of Australasia, *Submission G284*, 25 December 2002.

18 Australian Federal Police, *Consultation*, Canberra, 7 November 2002.

19 NSW Police Service, *Submission G306*, 22 January 2003.

41.19 The Law Institute of Victoria agreed that removing the consent provisions would better reflect the coercive nature of the procedures in these circumstances, and would remove potential arguments that consent given by a suspect or serious offender was not a valid informed consent. In addition, as an unwilling suspect would not have to refuse consent, the suspect would not be subject to the risk of adverse inferences being drawn from such refusal. However, the Law Institute commented that:

while we agree that the carrying out of a forensic procedure on a suspect or serious offender should require an Order, we believe that should come from an appropriate judicial officer ... It is essential that appropriate judicial scrutiny over police investigative activities be maintained. That is the only safeguard currently offered to protect civil liberties. The fact that judicial scrutiny makes it more inconvenient for police to obtain DNA samples simply takes account of the importance of this protective role.

The Law Institute maintains the view that the many competing aims of our criminal justice system must each be taken into account. Efficiency and reliability should not be achieved at the expense of access to justice and the protection of the rights of all individuals, including the accused.²⁰

41.20 The Australian Privacy Charter Council submitted that:

it is entirely inappropriate to pretend that consent is being obtained in situations where suspects or convicts have no real choice. It may however be appropriate for magistrates or judges being asked to issue a warrant in such cases to be informed as to the individual's degree of reluctance.²¹

41.21 The submissions generally agreed that, if the consent provisions were removed, the existing prescribed information nevertheless should be retained in the *Crimes Act*.²²

Removal of consent provisions?

41.22 The 'informed consent' provisions contained in the *Crimes Act* appear to be based on notions of 'policing by consent' and a concern to protect an individual's personal autonomy by allowing the person to give or withhold consent to a procedure involving some invasion of bodily and information privacy.

41.23 Several submissions expressed the concern that removing the consent provisions from the *Crimes Act* would undermine an individual's personal autonomy. The Inquiry recognises the importance of free choice in maintaining human dignity but considers that the coercive nature of a criminal investigation and prison life already seriously weakens an individual's capacity for free choice. In practice, it is likely that a

²⁰ Law Institute of Victoria, *Submission G275*, 19 December 2002.

²¹ Australian Privacy Charter Council, *Submission G304*, 21 January 2003.

²² For example, Commonwealth Attorney-General's Department, *Submission G228*, 12 December 2002; Victoria Police, *Submission G203*, 29 November 2002; Institute of Actuaries of Australia, *Submission G224*, 29 November 2002; Office of the Victorian Privacy Commissioner, *Submission G266*, 20 December 2002; Centre for Law and Genetics, *Submission G255*, 21 December 2002; Centre for Genetics Education, *Submission G232*, 18 December 2002; Human Genetics Society of Australasia, *Submission G267*, 20 December 2002; Law Institute of Victoria, *Submission G275*, 19 December 2002; Association of Genetic Support of Australasia, *Submission G284*, 25 December 2002.

suspect or serious offender would feel considerable pressure to 'consent' to a forensic procedure whether or not a police officer intended to apply such pressure. An individual's consent as a result of such real or perceived pressure does not amount to an exercise of free choice or the preservation of personal autonomy.

41.24 An alternative approach would be to retain the consent provisions in the legislation and improve the safeguard through greater access to legal or other independent advice prior to the giving of consent. However, the NSW Legal Aid Commission has commented that:

There are practical limitations to a suspect's capacity to obtain legal advice. No Australian State or Territory provides a duty solicitor scheme on the model used in the United Kingdom where publicly funded lawyers are available to provide advice to suspects in police custody. In the absence of such a service the right to legal advice before consenting to provide a sample is an illusory right.²³

Compulsory orders

41.25 The Inquiry considers that removing the consent provisions in relation to suspects and serious offenders would better reflect the coercive nature of the procedures in these circumstances, and would remove potential arguments that consent given by a suspect or serious offender was not a valid informed consent. However, due to existing legislative provisions, the removal of the consent provisions from the *Crimes Act* could have significant practical implications for individuals undergoing a forensic procedure.

41.26 The two primary means of conducting a forensic procedure are: (a) the buccal swab method; and (b) removal of hair samples by the root.²⁴ Buccal swabs are defined as an 'intimate' forensic procedure, while the removal of hair samples are defined as a 'non-intimate' procedure.²⁵ While a buccal swab is a relatively simple and painless procedure, and in most cases would be preferable to the removal of hair samples by the roots, the Model Criminal Code Officers Committee (MCCOC) classified the former as an 'intimate' procedure when drafting the Model Forensic Procedures Bill 2000 (Model Bill). MCCOC explained that:

where the person from whom the sample is being taken agrees to the procedure it can be very simple and is not invasive. However, where a person does not consent and resists the procedure, the procedure would not fairly be described as being non-intimate. Placing something inside someone's mouth against the person's consent is invasive.²⁶

23 New South Wales Legal Aid Commission, *Submission G282*, 24 December 2002.

24 Hair samples that are plucked from the root have a greater capacity to produce DNA. The AFP advised the Inquiry in a consultation that a number of hair samples are required to obtain a DNA profile: Australian Federal Police, *Consultation*, Canberra, 7 November 2002.

25 *Crimes Act 1914* (Cth) s 23WA(1). The taking of a blood sample is an alternative form of intimate forensic procedure.

26 Model Criminal Code Officers Committee, *Model Forensic Procedures Bill and the Proposed National DNA Database, Discussion Paper* (1999) Standing Committee of Attorneys-General, 11.

41.27 Where a suspect in custody or a serious offender (who is not a child or incapable person) withholds consent to the conduct of a forensic procedure, an authorised AFP officer can order the conduct of a non-intimate forensic procedure (for example, a hair sample) on that person provided the legislative test for such authorisation is satisfied.²⁷ An AFP officer cannot order an intimate forensic procedure (for example, a buccal swab) in any circumstances.

41.28 A court may order the conduct of a forensic procedure on a suspect who is, or is not, in custody, including a child or incapable person;²⁸ an intimate forensic procedure on a serious offender;²⁹ or a non-intimate forensic procedure on a serious offender who is a child or incapable person.³⁰

41.29 The provision of independent court oversight for children and incapable persons, and for suspects who are not in custody, safeguards the bodily privacy of persons who are considered to be more ‘vulnerable’ in the context of a criminal investigation. In practice, if the consent provisions were removed from the *Crimes Act*, police investigators seeking forensic material from a suspect who is not in custody would need to obtain a court order to do so. This would involve additional time and resources, but may be justified by virtue of the serious nature and implications of taking a genetic sample from a person in the law enforcement context.

41.30 However, for suspects in custody and serious offenders, the safeguard of court oversight would only be triggered if the AFP sought to conduct an intimate forensic procedure on that person. For example, an adult suspect in custody could be subject to either an authorised AFP officer’s order for a non-intimate forensic procedure, or to a court’s order for an intimate forensic procedure. In practice, it would be faster and easier for the AFP officer to order removal of hair samples than to apply for a court order to conduct a buccal swab procedure. Therefore, it could become rare for a court to be asked to consider an application to order a forensic procedure on an adult suspect in custody or serious offender.

Inquiry’s views

41.31 The Inquiry believes the existing legislative provisions are unsatisfactory, particularly in relation to the authorisation of buccal swab procedures. While removing the consent provisions in relation to suspects and serious offenders would better reflect the coercive nature of the procedures in these circumstances—and would remove potential arguments that consent given by a suspect or serious offender was not a valid informed consent—the practical consequence likely would be that more suspects and serious offenders would be subject to a more painful method of forensic procedure, without any additional oversight by the courts.

27 *Crimes Act 1914* (Cth) ss 23WM, 23WN, 23XWC, 23XWK.

28 *Ibid* s 23WR.

29 *Ibid* s 23XWO(1), (6).

30 *Ibid* s 23XWO(2), (6).

41.32 The Inquiry considers that where a suspect is not in custody, or where a suspect or serious offender is a child or incapable person, only a court should be authorised to make a compulsory order. In relation to a suspect in custody, or to a serious offender, an authorised AFP officer should make a compulsory order (provided the legislative test has been satisfied). However, the type of the procedure conducted should not be dependent upon whether it is an AFP officer or a court making the order.

41.33 One option for reform would be to remove the consent provisions from the *Crimes Act* and amend the existing provisions so that once the appropriate authority has made an order for a compulsory ‘forensic procedure’, the person who is the subject of the order should have the right to choose either a buccal swab procedure or the removal of hair samples.³¹

41.34 This could be accomplished in a number of ways. First, the *Crimes Act* could be amended to remove the distinction between an ‘intimate’ and a ‘non-intimate’ forensic procedure, and insert provisions regarding the categories of suspect or serious offender upon whom an authorised AFP officer, or a court, could order a forensic procedure. However, this could have flow-on effects for the other procedures included within these legislative definitions—for example, in relation to the authorisation of fingerprints and other procedures.

41.35 Another approach would be to retain the existing distinction, but insert a legislative provision stating that where a non-intimate forensic procedure has been ordered, the person who is subject to the order has the right to self-administer a buccal swab. This might require some consequential amendments to the legislation in relation to the carrying out of the forensic procedure but otherwise would not undermine the existing legislative framework.

41.36 In any case, the Inquiry considers this matter would benefit from further consideration and practical experience in the conduct of forensic procedures. Therefore, the Inquiry recommends that the Commonwealth Attorney-General should consider amending the *Crimes Act* to: (a) remove the consent provisions in relation to suspects and serious offenders, so that a forensic procedure only may be conducted on these persons pursuant to an order made by a judicial officer or an authorised police officer in accordance with the *Crimes Act*; and (b) provide that, once the appropriate authority has made an order for a compulsory forensic procedure, the person who is the subject of the order should be able to choose the method by which the sample is taken.

31 In normal circumstances it is expected that a buccal swab would be preferred. However, where the person refuses to cooperate, and the sample has to be taken against the person’s will, the removal of hair samples probably would be preferable to a *forced* buccal swab.

Recommendation 41–1. The Commonwealth should consider amending the *Crimes Act 1914* (Cth) (*Crimes Act*) to:

- (a) remove the consent provisions in relation to suspects and serious offenders so that a forensic procedure only can be conducted on these persons pursuant to an order made by a judicial officer or an authorised police officer in accordance with the *Crimes Act*; and
- (b) provide that, once the appropriate authority has made an order for a compulsory forensic procedure, the person who is the subject of the order should be able to choose the method by which the sample is taken.

Provision of prescribed information

41.37 Chapter 39 outlines the prescribed information which must be given to a suspect, serious offender or volunteer before being asked to consent to a forensic procedure. Briefly, this information outlines the nature, purpose and consequences of a forensic procedure.

41.38 A child or incapable person is a volunteer under Part 1D of the *Crimes Act* if his or her parent or guardian volunteers on his or her behalf to the conduct of a forensic procedure. The parent or guardian must be given specified information about the nature, purpose and implications of carrying out the forensic procedure before giving consent to it.³² There is no provision, however, for informing the child or incapable person about these matters, even though the child or incapable person is the subject of the proposed procedure. The Inquiry understands that this resulted from an oversight by MCCOC in drafting the Model Bill rather than a policy decision to exclude these persons from the information-giving process.³³

41.39 In addition, there appears to be no legislative requirement to inform a child or an incapable person who is a suspect or serious offender, and who is subject to a compulsory order for the carrying out of a forensic procedure, about the nature, purpose and implications of that procedure.³⁴

41.40 DP 66 proposed that forensic procedures legislation should provide that volunteers who are children or incapable persons also should be given the prescribed information about the nature, purpose and implications of a forensic procedure prior to it being carried out.³⁵

32 *Crimes Act 1914* (Cth) ss 23XWQ, 23XWR. See Ch 39 for more detail.

33 Evidence and Law Enforcement Working Group, *Meeting*, 5 March 2002.

34 Pt 1D specifies certain information that must be given to a suspect or serious offender before he or she gives or withholds consent to the forensic procedure. However, as children and incapable persons cannot give consent to a forensic procedure, they are not privy to the information-giving process.

35 Australian Law Reform Commission and Australian Health Ethics Committee, *Protection of Human Genetic Information*, DP 66 (2002), ALRC, Sydney, Proposal 36–3.

41.41 The submissions and consultations generally supported this proposal.³⁶ Privacy NSW stated that this proposal (and the proposal in relation to child volunteers' consent) represents:

a sensible and currently appropriate balance between the contrasting views about the privacy status of children referred to in the Discussion Paper. They recognise that the views of children should be given weight even where there may be some doubt as to their capacity for fully informed consent.³⁷

41.42 Several groups emphasised the need for the prescribed information to be given in a form that can be understood by the child or incapable person.³⁸ The Inquiry heard concerns that the prescribed information for adult suspects, serious offenders and volunteers may be overly complicated—and therefore not easily understood.³⁹

41.43 The Inquiry recognises that some children may not fully comprehend the prescribed information due to their youth or immaturity, and that some incapable persons may not fully comprehend this information due to their particular circumstances. However, exclusion from the information-giving process could cause confusion or distress to a child of any age and to some incapable persons.

41.44 As a result, the Inquiry considers that volunteers who are children and incapable persons should be entitled to receive the prescribed information at the same time as the parent or guardian. In addition, although suspects and serious offenders who are children or incapable persons cannot consent to a forensic procedure, they should be given the prescribed information prior to the forensic procedure being carried out. For all children and incapable persons—and, indeed, for all adult suspects, serious offenders and volunteers—this information should be given in a form that is capable of being easily understood.

41.45 The Inquiry recommends that the Commonwealth should amend the *Crimes Act* to provide that: (a) the prescribed information about the nature, purpose and consequences of a forensic procedure should be given to a suspect, serious offender or volunteer in a form that is capable of being easily understood by the person receiving the information; (b) a child or incapable person who is a volunteer, suspect or serious offender should be given the prescribed information in a form that is capable of being

36 Institute of Actuaries of Australia, *Submission G224*, 29 November 2002; Office of the Privacy Commissioner (NSW), *Submission G257*, 20 December 2002; Australian Federal Police, *Consultation*, Canberra, 7 November 2002; Office of the Victorian Privacy Commissioner, *Submission G266*, 20 December 2002; Human Genetics Society of Australasia, *Submission G267*, 20 December 2002; Centre for Law and Genetics, *Submission G255*, 21 December 2002; Centre for Genetics Education, *Submission G232*, 18 December 2002; National Legal Aid, *Submission G314*, 19 February 2003; Office of the Federal Privacy Commissioner, *Submission G294*, 6 January 2003; Law Institute of Victoria, *Submission G275*, 19 December 2002; Australian Privacy Charter Council, *Submission G304*, 21 January 2003; Association of Genetic Support of Australasia, *Submission G284*, 25 December 2002; NSW Police Service, *Submission G306*, 22 January 2003.

37 Office of the Privacy Commissioner (NSW), *Submission G257*, 20 December 2002.

38 For example, Australian Federal Police, *Consultation*, Canberra, 7 November 2002; NSW Police Service, *Submission G306*, 22 January 2003; Law Institute of Victoria, *Submission G275*, 19 December 2002.

39 For example, Australian Federal Police, *Consultation*, Canberra, 7 November 2002; NSW Police Service, *Submission G306*, 22 January 2003. See also Law Institute of Victoria, *Submission G275*, 19 December 2002 in relation to children and incapable persons.

easily understood by that child or incapable person, as far as circumstances permit; and (c) in addition to information provided to a parent or guardian, the prescribed information also should be given to a child or incapable person who is a volunteer.

Recommendation 41–2. The Commonwealth should amend the *Crimes Act* to provide that:

- (a) the prescribed information about the nature, purpose and consequences of a forensic procedure should be given to a suspect, serious offender or volunteer in a form that is capable of being easily understood by the person receiving the information;
- (b) a child or incapable person who is a volunteer, suspect or serious offender should be given the prescribed information in a form that is capable of being easily understood by that child or incapable person, as far as circumstances permit; and
- (c) in addition to information provided to a parent or guardian, the prescribed information also should be given to a child or incapable person who is a volunteer.

Consent by mature child volunteers⁴⁰

41.46 Chapter 39 outlines the consent procedures in relation to children or incapable persons who are volunteers under Part 1D of the *Crimes Act*. A child or incapable person cannot consent to a forensic procedure.⁴¹ Instead, a parent or guardian can give consent on behalf of a child or incapable person in accordance with the volunteer provisions. Where such consent has been given, the forensic procedure may be carried out unless the child or incapable person objects or resists.⁴²

41.47 DP 66 noted that a parent or guardian might not always act in a child's best interests when giving informed consent to a forensic procedure. For example, where a child is a potential suspect in a criminal investigation, the parent or guardian might consent to the carrying out of a forensic procedure on the child as a volunteer in the mistaken belief that this will exclude the child from suspicion. If the forensic procedure incriminates the child in the offence, this may not have been in the child's best interests.⁴³

40 This discussion is limited to child volunteers. Pt 1D of the *Crimes Act* provides that a child suspect or serious offender cannot consent to a forensic procedure and the Inquiry sees no policy reason to alter this procedural safeguard.

41 *Crimes Act 1914* (Cth) s 23WE.

42 See *Ibid* s 23XWQ(4).

43 Australian Law Reform Commission and Australian Health Ethics Committee, *Protection of Human Genetic Information*, DP 66 (2002), ALRC, Sydney [36.22]. While a child volunteer has the ultimate right to object to the conduct of a forensic procedure, in practice a child whose parent or guardian has given consent to the procedure may feel obliged to comply with it.

41.48 In addition, conflicts of interest might arise for parents or guardians where the child is accused of assault in relation to another family member, or theft or destruction of family property, or simply where there is a history of antagonistic relations.⁴⁴

Submissions and consultations

41.49 DP 66 proposed that forensic procedures legislation should provide that a forensic procedure may be carried out on a child volunteer of 12 years or above only with the consent of a parent or guardian *and* the child.⁴⁵

41.50 Most submissions and consultations on this topic supported this proposal.⁴⁶ The OFPC supported the proposal in principle, commenting that:

The over-riding concern should be the protection of children of any age, the promotion of their well-being and respect for their interests ... There should be wide-spread community consultation on this issue. It will be important to take into account the relevant recommendations of the Review and the forthcoming Commonwealth Attorney-General's Department's issues paper on *Protecting children's privacy*.⁴⁷

41.51 Privacy NSW submitted that:

The legal climate in relation to children's rights generally is still in a process of evolution from the traditional view which treated children as the property of their parents to the assumption that parental rights are held in trust to be exercised in the best interests of the child, having regard to his or her growing capacity for personal autonomy. The safeguards for children when DNA is collected should be flexible enough to reflect this evolving approach.⁴⁸

41.52 The Office of the Victorian Privacy Commissioner submitted that:

Any consent provisions allowing for collection of DNA from children must recognise the right of children to participate in decisions that impact on their lives. A decision to take a DNA sample that will become part of a national database has considerable potential impact on a life. Genetic knowledge will grow alongside today's children (and just as fast) so it seems. Forensic procedures ought not be performed on child 'volunteers' without their consent if they have sufficient maturity and understanding to give consent.

44 Ibid [36.23].

45 Ibid, Proposal 36–4.

46 For example, Office of the Victorian Privacy Commissioner, *Submission G266*, 20 December 2002; Office of the Privacy Commissioner (NSW), *Submission G257*, 20 December 2002; Human Genetics Society of Australasia, *Submission G267*, 20 December 2002; Centre for Law and Genetics, *Submission G255*, 21 December 2002; Office of the Federal Privacy Commissioner, *Submission G294*, 6 January 2003; National Legal Aid, *Submission G314*, 19 February 2003; Association of Genetic Support of Australasia, *Submission G284*, 25 December 2002; Law Institute of Victoria, *Submission G275*, 19 December 2002.

47 Office of the Federal Privacy Commissioner, *Submission G294*, 6 January 2003.

48 Office of the Privacy Commissioner (NSW), *Submission G118*, 18 March 2002.

Where a child does not have sufficient capacity to consent, the decision will be for the parent or guardian. But, depending on age, the child should nevertheless be consulted about having the procedure so that their views can be taken into account and they are given the opportunity to object and for that objection to be recorded.⁴⁹

41.53 Finally, the Institute of Actuaries of Australia submitted that the proposal was inconsistent with the Inquiry's proposal in relation to children's consent to participation in DNA parentage testing:

We feel that both circumstances would be equally stressful for the child and could have equally profound implications for the child's future well being. We suggest the Inquiry might care to reconsider if Proposals 31–8 and 36–4 should be brought into line.⁵⁰

Conclusions on child consent

41.54 The Inquiry recognises that circumstances of conflict of interest are not the norm, and the requirement of parental consent is usually an important safeguard of children's rights. However, the current provisions may be out of step with other areas of law that increasingly recognise children's right to participate in decisions that impact on their lives.

41.55 The Inquiry's proposal in this context is consistent with the position in relation to children's consent to participation in research. The National Health and Medical Research Council's *National Statement on Ethical Conduct in Research Involving Humans* provides that consent to a child or young person's participation in research must be obtained from the child or young person where he or she has sufficient competence to make this decision, *and* from the parents or guardian in all but exceptional circumstances (or any organisation or person required by law). Unlike the common law position, where a child has such capacity, the consent of both parents remains necessary (absent exceptional circumstances).⁵¹

41.56 This approach is not entirely consistent with Recommendation 35–7, which provides that where a child of 12 years or over is assessed to have sufficient understanding and maturity to decide whether to participate in DNA parentage, the child may give or withhold valid consent to that procedure—and in these circumstances, parental consent is unnecessary.

41.57 The Inquiry has chosen a different approach in relation to forensic procedures for two reasons. First, while a child might have sufficient understanding and maturity to decide whether to consent to a forensic procedure as a volunteer, the

49 Office of the Victorian Privacy Commissioner, *Submission G266*, 20 December 2002.

50 Institute of Actuaries of Australia, *Submission G224*, 29 November 2002.

51 National Health and Medical Research Council, *National Statement on Ethical Conduct in Research Involving Humans* (1999), NHMRC, Canberra [4.2]. The Australian common law provides that, once a child achieves a sufficient understanding and intelligence to enable full comprehension of a proposed medical treatment and the consequences and risks entailed, the child may give valid consent to that medical treatment. See *Secretary, Department of Health & Community Services v JWB (Marion's Case)* (1992) 175 CLR 218. This reflects art 12(1) of the *Convention on the Rights of the Child*, opened for signature 20 November 1989, UNTS 1588, (entered into force on 16 January 1991).

child might—due to the inherently coercive nature of any criminal investigation⁵²—feel a pressure to consent to the procedure due to his or her youth or inexperience. In these circumstances, the child should have the additional safeguard of parental decision making.

41.58 Second, while it might be preferable to conduct an independent assessment of each child volunteer to determine his or her capacity to consent in each case, this would require substantial additional training and resources. In the absence of such resourcing, and in light of the fact that a parent must also give or withhold consent, the Inquiry considers that the age of 12 years would be an appropriate minimum age at which a child volunteer should be presumed to have such capacity.

41.59 Consequently, it is recommended that the Commonwealth should amend the *Crimes Act* to provide that valid consent to the carrying out of a forensic procedure on a child of 12 years or above may be given only by the child *and* his or her parent or guardian. In the event of a dispute between the parent and child, the forensic procedure should not proceed—unless pursuant to a magistrate’s order under Part 1D of the *Crimes Act*.

Recommendation 41–3. The Commonwealth should amend the *Crimes Act* to provide that a forensic procedure may be carried out on a child volunteer of 12 years or more only: (a) with the consent of the child and his or her parent or guardian; or (b) pursuant to a magistrate’s order under s 23XWU of the *Crimes Act*.

Volunteer provisions

Definition of a ‘volunteer’

41.60 Part 1D of the *Crimes Act* does not specify each of the contexts in which a person might be asked to consent to a forensic procedure as a volunteer. The Model Bill also does not contain a comprehensive definition of volunteers.

41.61 MCCOC’s discussion paper noted that volunteers would include potential suspects (for example, where suspicion is based on a hunch rather than on reasonable grounds), persons in a large pool for comparison purposes (for example, persons involved in mass screening programs); and victims of crime.⁵³ Volunteers might also include people whose DNA profiles were left at the crime scene innocently—for example, the victim’s flatmates in relation to a burglary; the victim’s sexual partner in relation to a sexual assault by another person; police officers and other persons whose DNA samples might have contaminated the crime scene; or relatives of missing or deceased persons.

⁵² Whether the child is a victim of crime, a potential suspect, or a relative of a missing or deceased person.

⁵³ Model Criminal Code Officers Committee, *Model Forensic Procedures Bill and the Proposed National DNA Database, Discussion Paper* (1999) Standing Committee of Attorneys-General, 61.

41.62 DP 66 noted that the volunteers provisions of Part 1D of the *Crimes Act* need clarification. One way to do this would be to deal with each category of volunteer separately. For example, the *Criminal Investigation (Identifying People) Act 2002* (WA) contains separate provisions dealing with volunteers (for example, potential suspects), deceased persons, police officers, victims and witnesses. This approach allows for the development of specific provisions for each particular category of person requested to undergo a forensic procedure.

41.63 In order to clarify which persons fall within the scope of Part 1D of the *Crimes Act*, and to better regulate the use of the forensic material and profiles obtained from each category, the Inquiry recommends that the Commonwealth should make separate provision for the collection, use, storage, index matching and destruction of forensic material, and profiles obtained from that material, for each main category of volunteer, whether by amending Part 1D of the *Crimes Act* or through regulations. These separate categories of volunteers may include potential suspects, victims, relatives of missing or deceased persons, police officers and other persons providing elimination samples for law enforcement purposes.

Recommendation 41–4. The Commonwealth should make separate provision for the collection, use, storage, index matching and destruction of forensic material, and profiles obtained from that material, for each main category of volunteer, whether by amending Part 1D of the *Crimes Act* or through regulations.

Victims of crime

41.64 Police investigators might need to conduct a forensic procedure on a victim of crime where, for example, the offender has left a bodily sample on or in the victim's body during an assault. A DNA sample found at a crime scene might include the DNA of the victim only, or a mixture of samples from the offender and victim.

41.65 DP 66 noted that victims of crime fall within the volunteer provisions of Part 1D of the *Crimes Act*.⁵⁴ Therefore, where a DNA sample is taken from a victim through a forensic procedure, the victim must be dealt with under these provisions. The victim should have a choice whether the resulting DNA profile will be stored in the volunteers (limited purposes) index or the volunteers (unlimited purposes) index of a DNA database system.⁵⁵ If stored in the former index, strict index matching rules apply; if stored in the latter index, more general index matching is permitted.⁵⁶ As a

54 Australian Law Reform Commission and Australian Health Ethics Committee, *Protection of Human Genetic Information*, DP 66 (2002), ALRC, Sydney [36.38].

55 *Crimes Act 1914* (Cth) s 23XWR.

56 *Ibid* s 23YDAF(1).

volunteer, the victim also should have the power to withdraw consent to retention of the forensic material or the DNA profile.⁵⁷

41.66 There is an issue whether, in practice, victims may not always be dealt with as volunteers. To the extent that a victim's DNA cannot be removed from the offender's sample, the victim's profile could be stored in a volunteers index, or in the crime scene index of a DNA database system. In light of the varying index matching rules, there are potentially significant privacy implications for the victim, depending on the respective index in which his or her profile is stored.⁵⁸

Submissions and consultations

41.67 DP 66 proposed that forensic procedures legislation should be amended to specify that identified victims of crime should be treated as 'volunteers'; to insert a new index for 'identified victims' profiles' into the DNA database system, with limited index matching rules that exclude comparisons between this index and the crime scene index; and to provide specified information to be given to victims regarding the storage of their profiles.⁵⁹

41.68 Several submissions and consultations supported the proposal.⁶⁰ The Institute of Actuaries of Australia summarised the divergent views on the issue:

It is possible that the attitudes of some members of the community towards persons who have committed crimes may be hardening. Some Australians might take the view that justice would be served if DNA provided by a victim of a crime also helped to convict that person of a crime they had previously committed. Proposal 36-5 might be seen by those citizens as providing too much protection to criminals. On the other hand, many others in the community are fearful of loss of privacy and of too much power being given to law enforcement agencies. Those citizens might support Proposal 36-5, as setting a desirable balance between police operations and personal privacy.⁶¹

41.69 The Law Institute of Victoria generally endorsed the proposal, including the insertion of a new index in a DNA database system, but emphasised that victims' material should only be stored until closure of the investigation into the relevant crime.

To store a victim's DNA profile on a database for any longer than is necessary in the interests of the specific investigation is unwarranted ... To learn that their genetic profile is to form part of an ongoing database, whether or not in a separate 'victim' index, must produce a sense of invasion and further victimisation in many cases ... However its storage after the relevant investigation has closed serves no legitimate

⁵⁷ Subject to a magistrate's order that it be retained: Ibid, ss 23XWT(2), 23XWV.

⁵⁸ See Australian Law Reform Commission and Australian Health Ethics Committee, *Protection of Human Genetic Information*, DP 66 (2002), ALRC, Sydney [36.36]–[36.45].

⁵⁹ Ibid, Proposal 36-5.

⁶⁰ Office of the Privacy Commissioner (NSW), *Submission G257*, 20 December 2002; Centre for Genetics Education, *Submission G232*, 18 December 2002; Human Genetics Society of Australasia, *Submission G267*, 20 December 2002; Centre for Law and Genetics, *Submission G255*, 21 December 2002; National Legal Aid, *Submission G314*, 19 February 2003; Law Institute of Victoria, *Submission G275*, 19 December 2002; Association of Genetic Support of Australasia, *Submission G284*, 25 December 2002; Liberty Victoria, *Consultation*, Melbourne, 23 October 2003; I Freckelton and J Gans, *Consultation*, Melbourne, 21 October 2002.

⁶¹ Institute of Actuaries of Australia, *Submission G224*, 29 November 2002.

purpose ... The same argument can be extended from victims to other volunteers and to those suspected but not convicted of an offence.⁶²

41.70 The Office of the Victorian Privacy Commissioner submitted that forensic procedures legislation should be reviewed to clarify the application of the volunteer provisions and to ensure that privacy safeguards apply relevantly to all forensic material obtained from volunteers, whenever and however it was obtained. However, the Office did not support the insertion of a new index for identified victims.

There is no clear justification for including innocent persons' DNA profiles on a criminal DNA database that is directed at solving and deterring crime or identifying missing or deceased persons. Where a victim or volunteer's sample contaminates a crime scene sample, the innocent person's DNA ought to be excluded from the sample where practicable. As the Inquiry noted, including victims' and innocent persons' samples on the DNA database system may deter people from reporting crime or assisting in the investigation of crime.⁶³

41.71 The Queensland Government submitted that, according to Queensland Police Service policy:

[A] 'known victim of crime' is provided with the same election as a person involved in a mass screening (volunteer). That is, they are given a choice whether to provide their sample as a 'volunteer-limited purpose' or a 'volunteer-unlimited purpose'. As a result, Queensland does not see the need for the creation of additional indexes.⁶⁴

Other approaches

41.72 As noted above, in Western Australia specific legislative provisions deal with obtaining DNA samples from victims of crime.⁶⁵ The NSW Standing Committee commented on the treatment of victims of crime in its review of the New South Wales forensic procedures legislation as follows:

The Committee notes the need to develop separate provisions to deal with victims' profiles. The Committee considers it to be inappropriate for victims' profiles to be placed on the crime scene index. A victim's profile should be used solely in an attempt to make a link with a suspect for that crime, and should not be more broadly matched.⁶⁶

41.73 The Committee recommended that the New South Wales Attorney-General develop provisions regulating the databasing of victims' DNA profiles that ensure that matches are not attempted between victims' profiles and any other crimes.⁶⁷ The New South Wales Parliament subsequently amended the *Crimes (Forensic Procedures) Act 2000* (NSW) to exclude victims of offences against the person from the operation of

62 Law Institute of Victoria, *Submission G275*, 19 December 2002.

63 Office of the Victorian Privacy Commissioner, *Submission G266*, 20 December 2002.

64 Queensland Government, *Submission G274*, 18 December 2002.

65 *Criminal Investigation (Identifying People) Act 2002* (WA), Pt 5.

66 Legislative Council Standing Committee on Law and Justice, *Review of the Crimes (Forensic Procedures) Act 2000*, Report No 18 (2002), Parliament of NSW, Sydney, [6.22].

67 *Ibid*, Rec 45.

the Act.⁶⁸ The Attorney-General announced that a protocol would be developed to deal with the carrying out of forensic procedures on such victims.⁶⁹ The NSW Police Service submitted that:

A victim's profile will not be placed on any index of the database but will simply be matched within the case itself. In the circumstances, the creation of a new index for 'identified victims' profiles' will have limited, if any application, in the New South Wales context. The treatment of victim profiles is consistent with the treatment to be afforded to DNA samples provided by a volunteer for limited purposes.

The Victims' Protocol will specify the information to be provided to a victim prior to him/her being requested to provide a buccal or hair sample. The information will, inter alia, include details of where the profile and any remaining DNA sample will be stored and when, and under what circumstances, the sample and profile can be destroyed.⁷⁰

Inquiry's views

41.74 There is a public interest in protecting the privacy of victims of crime, but also in ensuring that real victims are not reluctant to report crime through fear of implicating themselves in other unrelated offences.

41.75 The Inquiry does not propose to remove crime victims from the scope of Part 1D of the *Crimes Act*. Instead, the Inquiry considers that it would be better to clarify the provisions in Part 1D of the *Crimes Act* in relation to victims of crime in order to greater protect their genetic privacy. Recommendation 41–4 provides that specific provisions should be inserted into the Act in relation to victims of crime.

41.76 The proposed new database index for 'identified victims' profiles' received some criticism and the Inquiry has decided not to recommend this approach. As the AFP has advised that in practice all reasonable attempts are made to separate a victim from a mixed DNA sample, the Inquiry considers that it would be reasonable to give this practice legislative form.

41.77 The Inquiry recommends that, where a known victim's DNA sample is found at a crime scene or is mixed with an offender's DNA sample, all reasonable measures must be taken to:

- separate the DNA belonging to a victim of crime from a crime scene sample where the latter contains mixed samples;
- ensure that a victim's DNA profile is not stored on the crime scene index of a DNA database system; and

68 *Crimes (Forensic Procedures) Amendment Act 2002* (NSW). The Act received Assent in June 2002, and is due to commence operation on 1 June 2003. The amendments also excluded persons who volunteer to provide a sample of their fingerprints for elimination purposes in relation to property offences.

69 NSW Parliament, *Parliamentary Debates*, Legislative Assembly, 28 May 2002, (The Honourable Bob Debus (Attorney-General)).

70 NSW Police Service, *Submission G306*, 22 January 2003.

- ensure that a victim's DNA profile is not matched against the crime scene index of a DNA database system.

Recommendation 41–5. The Commonwealth should amend the *Crimes Act* to specify that a known victim of crime must be treated as a volunteer, and to require that all reasonable measures be taken to:

- (a) separate the DNA belonging to a victim of crime from a crime scene sample where the latter contains mixed samples;
- (b) ensure that a victim's DNA profile is not stored in the crime scene index of a DNA database system; and
- (c) ensure that a victim's DNA profile is not matched against the crime scene index of a DNA database system.

Potential suspects and mass screenings

41.78 The volunteer provisions of Part 1D of the *Crimes Act* allow police investigators to ask a potential suspect to submit to a forensic procedure for the purpose of eliminating him or herself from suspicion. Police might ask a small number of potential suspects to volunteer in the context of a criminal investigation, or they might conduct a mass screening program in which they ask a section of a workplace, neighbourhood or town to submit to a forensic procedure.

41.79 The world's first mass screening is believed to have occurred in Britain in 1987 in the context of a murder investigation. Four thousand men in Leicestershire were tested before the offender was caught after convincing another man to submit a DNA sample for him. Reportedly the largest mass screening to date occurred in northern Germany in 1998 where 16,400 people were tested in relation to a rape-murder.⁷¹

41.80 The Inquiry has heard that the first Australian mass screening program occurred in Western Australia in 1997, when many of Perth's 3,500 taxi drivers voluntarily provided DNA samples as part of the investigation into the Claremont serial killings. More recently, large mass screenings have been held in Wee Waa, NSW in relation to a sexual assault, and in several Queensland towns in relation to murder and rape investigations.⁷²

41.81 In its submission to the Inquiry, the Office of the Victorian Privacy Commissioner outlined the following concerns in relation to mass screenings:

71 D Halbfinger, 'Police Dragnets for DNA Tests Draw Criticism', *The New York Times*, 4 January 2003.

72 See generally, Office of the Victorian Privacy Commissioner, *Submission G266*, 20 December 2002.

- a. potential for less intrusive methods of investigation to be overlooked, with consequent risk that time will be lost and resources needlessly expended on DNA collection and screening;
- b. social (or police) pressure being exerted to coerce consent;
- c. potential for collection to be excessive (both in the number of persons tested and the possibility for additional personal information to be collected, such as photographs and interview statements); and
- d. potential for the understandable shock and concern felt by any community after a serious crime to be used to obtain from volunteers consents of wider scope than necessary in the circumstances—in particular, consent to retain samples and/or data and/or photographs for any future purpose.⁷³

41.82 The Inquiry has heard concerns that members of the community might feel pressure to submit to a forensic procedure as a volunteer in order to eliminate themselves from potential suspicion in a criminal investigation. It has been suggested that such requests might be used as an intelligence tool known as ‘DNA request surveillance’, where a person requested to submit to a forensic procedure as a volunteer becomes a suspect in the investigation solely as a result of refusing to provide a sample.⁷⁴

41.83 For example, in June 2002, Queensland police investigating the death of an English backpacker who was believed to have fallen, or to have been pushed, from a bridge in the town of Bundaberg announced a mass screening program to identify the male whose DNA sample was found on the bridge. It was reported that close to 2,500 men and boys in north Bundaberg would be asked to submit to DNA testing and that police would record the name of any person who refused to do so.⁷⁵

41.84 The NSW Legal Aid Commission raised the following concerns about the use of mass screening programs in its initial submission to the Inquiry:

This process places great pressure on affected individuals to consent. People who decline to participate may come under unreasonable suspicion. Innocent people may decline to participate for a number of reasons, including a concern to retain the privacy of their genetic information, or concerns about how the samples may be used. There is also a problem associated with the media coverage that such mass screenings receive. This coverage could have a prejudicial effect on any suspect charged following the screening program. The cost and time expended on the screening program could create a strong impression on the public that the person identified through the screening is the offender, even though the DNA evidence is not conclusive evidence of guilt.⁷⁶

73 Ibid.

74 J Gans, ‘Something to Hide: DNA, Surveillance and Self-incrimination’ (2001) 13(2) *Current Issues in Criminal Justice* 168, 170–176.

75 A Wilson, ‘City’s Males Face DNA Testing in Hunt for Killer’, *The Australian*, 10 June 2002, 3.

76 New South Wales Legal Aid Commission, *Submission G087*, 21 January 2002. The NSW Council for Civil Liberties also expressed concerns about pressure to consent to mass screening programs: New South Wales Council for Civil Liberties, *Submission G312*, 10 February 2003.

41.85 In practice, the delineation between a suspect and a potential suspect is often fuzzy. For example, it might be explained to a potential suspect that, if he or she submits to a forensic procedure as a volunteer, the person may decide in which volunteer index the profile will be stored⁷⁷ and the retention period of the forensic material and profile. However, if the person will not consent as a volunteer, he or she may be considered a suspect, in which case the police might seek a compulsory order for a forensic procedure. If the order is given, the resulting profile could be stored in the suspects index for a period of 12 months, during which time it could be matched against all outstanding crime scene profiles.

41.86 The NSW Standing Committee considered the use of mass screening programs in its review of the New South Wales forensic procedures legislation. The Committee recommended that the Attorney-General consider amending the legislation to require a court order before police can undertake a voluntary mass screening.⁷⁸

Submissions and consultations

41.87 DP 66 proposed that regulations or police guidelines should be developed in every jurisdiction on the conduct of mass screening programs, both in relation to the approval process for initiation as well as the manner in which such programs are conducted.⁷⁹

41.88 Many submissions and several consultation meetings supported the proposal.⁸⁰ The Office of the Victorian Privacy Commissioner commented that a clear written protocol on how mass screenings should be conducted would appropriately balance the competing public interests of law enforcement and privacy. The Office emphasised that the guidelines should have legislative force, and also suggested that police should be required to seek a court order before undertaking any mass screening.⁸¹

41.89 The NSW Police Service supported the proposal, but noted that the regulations or guidelines would need to be sufficiently flexible to accommodate the circumstances of individual cases.⁸² The Queensland Government submitted that its Police Service's Operational Procedures Manual already contains a policy for

77 The volunteer has a choice whether the profile will be stored in the volunteers (limited purposes) index, or the volunteers (unlimited purposes) index. The index matching rules vary according to the index: see *Crimes Act 1914* (Cth) s 23YDAF(1).

78 Legislative Council Standing Committee on Law and Justice, *Review of the Crimes (Forensic Procedures) Act 2000*, Report No 18 (2002), Parliament of NSW, Sydney, Rec 23.

79 Australian Law Reform Commission and Australian Health Ethics Committee, *Protection of Human Genetic Information*, DP 66 (2002), ALRC, Sydney, Proposal 36–6.

80 Office of the Privacy Commissioner (NSW), *Submission G257*, 20 December 2002; Department of Human Services South Australia, *Submission G288*, 23 December 2002; Office of the Victorian Privacy Commissioner, *Submission G266*, 20 December 2002; Centre for Genetics Education, *Submission G232*, 18 December 2002; Liberty Victoria, *Consultation*, Melbourne, 23 October 2003; Centre for Law and Genetics, *Submission G255*, 21 December 2002; Office of the Federal Privacy Commissioner, *Submission G294*, 6 January 2003; Law Institute of Victoria, *Submission G275*, 19 December 2002; Association of Genetic Support of Australasia, *Submission G284*, 25 December 2002.

81 For example, Office of the Victorian Privacy Commissioner, *Submission G266*, 20 December 2002.

82 NSW Police Service, *Submission G306*, 22 January 2003.

determining the necessity for, and scope of, a mass screening to assist in an investigation. This policy provides that the investigating officer is to liaise with the DNA Coordination Unit in relation to the management and administration of the mass screening.⁸³

41.90 The Human Genetics Society of Australasia noted that it supported the proposal for police guidelines or regulations, but remained concerned about how these would be monitored to ensure compliance by law enforcement authorities.⁸⁴

41.91 The OFPC supported the proposal in principle, but noted that:

It may prove difficult ... to formulate 'universal' regulations or guidelines with any degree of precision. A screening program and its implementation may be devised to achieve a certain forensic goal. The local circumstances and the nature of the investigation may influence the conduct of the screening processes ... much will often depend upon the maintenance of the integrity of the procedure by the investigating officers and of their respect for the participating subjects. Objective data, obtained by appropriate means of 'field-testing' or monitoring the conduct of the program will be critical. Ultimately, the effectiveness of such programs may depend upon dispelling perceptions that they are privacy-intrusive for the participating individuals.⁸⁵

41.92 Finally, several submissions suggested the use of a GeneTrustee system to protect the privacy of volunteers' genetic information.⁸⁶ The Institute of Actuaries of Australia submitted that:

The guidelines should cover the use of a 'gene trustee' to hold the samples volunteered by the persons screened. The gene trustee will be charged with keeping the samples secure and protecting the privacy of all volunteers, except for that one (or more) volunteer(s) whose DNA is found to match the DNA left at the crime scene by the suspect or suspects.⁸⁷

Inquiry's views

41.93 The Inquiry considers that some form of oversight is important in light of the absence of any legislative guidance regarding the definition of a volunteer, or the circumstances in which a person may be asked to consent to a forensic procedure. The intention is not to inhibit people from volunteering for a forensic procedure where this would be of real value to a criminal investigation. However, the Inquiry considers it necessary to ensure that individuals who would not otherwise be considered suspects in a criminal investigation do not feel undue pressure to 'volunteer' for a forensic procedure in order to eliminate themselves from potential suspicion.

83 Queensland Government, *Submission G274*, 18 December 2002.

84 Human Genetics Society of Australasia, *Submission G267*, 20 December 2002.

85 Office of the Federal Privacy Commissioner, *Submission G294*, 6 January 2003.

86 Centre for Genetics Education, *Submission G232*, 18 December 2002; Institute of Actuaries of Australia, *Submission G224*, 29 November 2002. See Ch 18 for more detail.

87 Institute of Actuaries of Australia, *Submission G224*, 29 November 2002.

41.94 Some form of oversight of police actions is currently provided through existing complaints mechanisms. Complaints can be made about the actions of AFP employees to either the AFP or the Commonwealth Ombudsman.⁸⁸

41.95 The Inquiry has heard the suggestion that mass screenings should be permitted only where police investigators have obtained a court order to do so. This would provide external judicial scrutiny of proposed mass screening programs, and would be consistent with the approach taken by the NSW Standing Committee in its review of the New South Wales forensic procedures legislation.

41.96 The Inquiry has decided against adopting this approach. Instead, the Inquiry recommends the development of guidelines for the conduct of mass screening programs, both in relation to the approval process for initiation as well as the manner in which such programs are conducted. These guidelines could be inserted into Part 1D of the *Crimes Act* or regulations made thereunder, or they could be located within police operational guidelines—provided they are published in the Government Gazette or some other accessible form.

Recommendation 41–6. The Commonwealth should develop and publish guidelines for the conduct of mass screening programs in relation to both the process for approving the initiation of programs and the manner in which they are conducted.

Analysis of forensic material

Limits on analysis

41.97 Australian forensic laboratories currently analyse only the non-coding section of the DNA molecule for law enforcement purposes.⁸⁹ In his Second Reading Speech in relation to the Crimes Amendment (Forensic Procedure) Bill 2001 (Cth), the Commonwealth Attorney-General, the Hon Daryl Williams AM QC MP, commented on the limited information included in a DNA profile:

It is important that we all appreciate the nature of the forensic information that will be stored on the national law enforcement database as a DNA profile. The analysis of the DNA samples will only reveal the sex of the person from whom it is taken. It does not reveal any other personal characteristics.⁹⁰

88 The Ombudsman has oversight of internal investigations conducted by the AFP, and only the Ombudsman can decide that an investigation should not be conducted: see *Complaints (Australian Federal Police) Act 1981* (Cth). See also Australian Law Reform Commission, *Integrity: But Not by Trust Alone*, Report 82 (1996), ALRC, Sydney.

89 Except in so far as the laboratories analyse the chromosomes to determine the person's sex.

90 Commonwealth of Australia, *Parliamentary Debates*, House of Representatives, 26 March 2001, 25635 (The Hon Daryl Williams - Attorney General).

41.98 However, advances in forensic science suggest two potential developments in forensic analysis. First, scientists have suggested that non-coding DNA may contain some information relevant to health.⁹¹ Second, it might be possible in future to obtain some information about physical, and possibly behavioural, traits from the coding section of DNA.⁹²

41.99 For example, the United Kingdom's Forensic Science Service (FSS) is currently conducting research directed toward identifying common characteristics from bodily samples—such as race, skin, hair and eye colour, stature, weight, age and facial characteristics—so that in future crime scene samples could be analysed to create a 'genetic photo-fit' of the offender for use in criminal investigations. This might be extended to behavioural traits and other medical information.⁹³ The Inquiry understands that similar research into physical characteristics is being conducted in Australia.⁹⁴

41.100 The FSS is also working on analysis of markers inherited from father to son on the Y chromosome. This information could be used in sexual assault cases in which the offender's DNA has been contaminated with that of the female victim; it has also been suggested that this analysis might provide information about possible surnames and geographic origin. In addition, the FSS provides a 'race identification service', and a 'red hair service' that detects about 85% of redheads.⁹⁵

41.101 The Inquiry has heard concerns that the Australian community has accepted the forensic use of DNA on the understanding that only non-coding sections would be analysed, and only for the purposes of ascertaining an identification number. The analysis of coding DNA in future for law enforcement purposes to provide information about health and behavioural characteristics would have important privacy and other implications, and would require a fundamental review of the whole system.⁹⁶

Submissions and consultations

41.102 DP 66 proposed that forensic procedures legislation should provide that samples (including crime scene samples) collected or otherwise obtained for use in the law enforcement context may be subject to genetic testing and analysis only with

91 D Concar, *Fingerprint Fear*, New Scientist, <www.newscientist.com/news/news.jsp?id=ns9999694>, 19 February 2003, cited in Office of the Federal Privacy Commissioner, *Submission G143*, 22 March 2002.

92 See R van Oorschot and others, 'Beyond DNA Databases: Physical Identification Using DNA' (Paper presented at DNA Evidence: Prosecuting Under the Microscope International Conference, Adelaide, 10 September 2001).

93 Human Genetics Commission, *Inside Information: Balancing Interests in the Use of Personal Genetic Data* (2002), London, 155.

94 For example, by the Queensland University of Technology's Research Centre for Diagnostics.

95 Human Genetics Commission, *Inside Information: Balancing Interests in the Use of Personal Genetic Data* (2002), London, 156.

96 Advisory Committee members, *Advisory Committee meeting*, 29 November 2001.

respect to the non-coding sections of the DNA, and only for the purposes of creating a DNA profile, quality assurance or equipment validation.⁹⁷

41.103 The submissions generally supported the proposal, as did a number of persons consulted.⁹⁸ In addition, the Commonwealth Attorney-General's Department agreed that the proposal restates the current method of DNA analysis for law enforcement purposes, and stated that any proposed change to this current method would require detailed consideration.⁹⁹

41.104 The OFPC strongly supported the proposal in principle, commenting that:

The relative ease of access by law enforcement agencies to DNA database information is predicated on the understanding that no genotypical information about the subject, other than their sex, will be revealed. This understanding is explicit in the Second Reading Speech of the *Crimes (Forensic Procedures) Bill 2001*.

If, however, DNA-related research is conducted on the subject's sample by the research arms of law enforcement agencies (with a view to developing more sophisticated DNA profiling methods) which involve genotypical information, then urgent consideration should be given to enacting legislation to regulate such activity. This legislation should be directed at limiting DNA collection and analysis for prescribed law-enforcement purposes and/or against the potentially harmful collection of sensitive genetic information for purposes other than that for which the sample was collected. Criminal sanctions may be appropriate in this context.¹⁰⁰

41.105 In his submission to the Victorian Parliament Law Reform Committee's review of that jurisdiction's forensic procedures legislation, Dr Jeremy Gans commented that:

The DNA molecule contains considerable personal information, in the form of the details of a person's genetic make-up. Genetic privacy is an issue of considerable sensitivity to the public. Contemporary DNA identification does not—and ought not—involve any analysis of this information. To be useful to investigators, DNA profiles must be derived from the 'non-coding' portions of the DNA molecule. There is no reason why investigators should be permitted to analyze the coding portions of the molecule. If investigators were explicitly barred from doing so, then much public concern about DNA sampling would be alleviated.¹⁰¹

97 Australian Law Reform Commission and Australian Health Ethics Committee, *Protection of Human Genetic Information*, DP 66 (2002), ALRC, Sydney, Proposal 36–8.

98 Office of the Privacy Commissioner (NSW), *Submission G257*, 20 December 2002; Institute of Actuaries of Australia, *Submission G224*, 29 November 2002; Centre for Genetics Education, *Submission G232*, 18 December 2002; Human Genetics Society of Australasia, *Submission G050*, 14 January 2002; New South Wales Health Department, *Submission G092*, 25 January 2002; Liberty Victoria, *Consultation*, Melbourne, 23 October 2002; Centre for Law and Genetics, *Submission G255*, 21 December 2002; National Legal Aid, *Submission G314*, 19 February 2003; Office of the Federal Privacy Commissioner, *Submission G294*, 6 January 2003; Law Institute of Victoria, *Submission G275*, 19 December 2002; Association of Genetic Support of Australasia, *Submission G284*, 25 December 2002.

99 Commonwealth Attorney-General's Department, *Submission G228*, 12 December 2002.

100 Office of the Federal Privacy Commissioner, *Submission G294*, 6 January 2003.

101 J Gans, *Submission to the Victorian Parliament Law Reform Committee's Inquiry into Forensic Sampling and the Use of DNA Databases in Criminal Investigations* (2002), 5.

41.106 The NSW Police Service submitted that it generally had no disagreement with the proposal, but noted that: the ‘valid purposes’ should cover inclusion in relevant databases (including databases of population statistics and internally maintained databases); some allowance should be made for access to, and comparisons with, DNA samples or information from medical records for the purpose of an investigation; and a sequence thought to be non-coding may be later found to influence a predisposition for a particular condition in a discreet section of the population.¹⁰²

41.107 The Victoria Police opposed the proposal on the basis that it would

restrict the development of new DNA markers such as physical characteristics that are currently subject to increasing research worldwide. Such markers may assist in the early identification of an offender through eyewitness accounts and specifically where no DNA profile matches against the established crime indexes. A more appropriate approach would be to prohibit the use of sample collected for criminal investigations to only criminal investigations.¹⁰³

Inquiry’s views

41.108 The Inquiry is concerned about the potential extension of forensic analysis of DNA samples to physical and behavioural characteristics. While information about an unknown offender’s eye or hair colour or other features might be useful in identifying that individual, this form of analysis represents a fundamentally different use of the DNA molecule from that contemplated when the Model Bill was being developed.

41.109 If sensitive information as to a suspect, offender or volunteer’s behavioural characteristics were to be obtained from a DNA sample and inserted into the DNA database system—for example, where the individual has a predisposition to a particular medical or mental condition—this could undermine the individual’s own (and his or her genetic relatives’) privacy in a way that is not directly necessary for the purpose of physical identification.

41.110 In the United Kingdom, the Human Genetics Commission has commented on this form of research, stating that it foresees a danger that the current DNA profiles will be supplemented on the national DNA database by additional personal genetic information that might be considered to be private and sensitive:

It appears to us that there is a clear distinction between using DNA for comparison or identification purposes (which the public broadly accepts) and using it to predict the characteristics of a person. We take the view that the public might have concerns about such uses and that it should be subject to a wider debate.¹⁰⁴

41.111 The Inquiry has not proceeded to a firm recommendation on the basis that the science in this area is still in an early phase and will develop rapidly in coming years. If in future law enforcement authorities wish to go beyond mere DNA

102 NSW Police Service, *Submission G306*, 22 January 2003.

103 Victoria Police, *Submission G203*, 29 November 2002.

104 Human Genetics Commission, *Inside Information: Balancing Interests in the Use of Personal Genetic Data* (2002), London, 156–157.

identification number construction to utilise genetic technology to determine health status or behavioural traits, this would require considerable public consultation and fresh community agreement.

Security of forensic material

Crimes Act provisions

41.112 Part 1D of the *Crimes Act* defines ‘forensic material’ as samples; hand, finger, foot or toe prints; photographs or video recordings; or casts or impressions taken from or of a person’s body by a forensic procedure.¹⁰⁵ Part 1D regulates the collection and destruction of forensic material obtained through a forensic procedure—but there is some uncertainty as to the extent to which it regulates the use, storage and disclosure of forensic material.

41.113 The legislative provisions relating to the use, storage and disclosure of information on a DNA database system are discussed in Chapter 43. The provisions regarding the use, storage or disclosure of forensic material are less detailed, comprising:

- provisions for providing part of a sample obtained through a forensic procedure, and the copy of any analysis results, to the person from whom it was obtained;¹⁰⁶
- an offence in relation to the inappropriate supply of forensic material to a person for analysis in order to include a DNA profile on an index of a DNA database system;¹⁰⁷
- a provision stating that forensic material (or information obtained from it) that was taken in accordance with a State or Territory law may be retained or used for investigative, evidentiary or statistical purposes of the Commonwealth;¹⁰⁸ and
- provisions specifying the destruction requirements for forensic material obtained from a suspect, serious offender or volunteer.¹⁰⁹

41.114 Further, s 23YO(1) prohibits a person from accessing information stored on a DNA database system ‘or any other information revealed by a forensic procedure’ carried out on a suspect, offender or volunteer, and intentionally or recklessly causing the disclosure of the information other than as permitted by that section. Section 23YO(3) specifies the circumstances in which information revealed by the carrying out

105 *Crimes Act 1914* (Cth) s 23WA(1). The discussion below is generally limited to genetic samples.

106 See generally, *Ibid* ss 23XU, 23XUA (where there is insufficient material to share), 23XW, 23YG.

107 *Ibid* s 23YDAD.

108 *Ibid* s 23YP.

109 See discussion below for more detail.

of a forensic procedure may be disclosed, including ‘for the purpose of the investigation of any offence or offences generally’.¹¹⁰

41.115 As genetic samples are not stored on a DNA database system, this section would apply to forensic material only if it constitutes ‘information revealed by the carrying out of a forensic procedure’. However, while a genetic sample is obtained through a forensic procedure, it appears that it may not be information for the purposes of s 23YO of the *Crimes Act*. As discussed in Chapter 8, the plain and ordinary meaning of the word ‘information’ is unlikely to extend to a genetic sample, as opposed to the information that is derived by sequencing the DNA that the sample contains.¹¹¹

41.116 However, while the legislative wording is ambiguous, it does not appear to have been the Commonwealth Parliament’s intention to exclude forensic material for the scope of this provision. The Revised Explanatory Memorandum to the Crimes Amendment (Forensic Procedures) Bill 2001 (Cth) provides that:

[t]he purpose of proposed section 23YO is to protect the privacy of persons whose DNA profiles are included on the DNA database system or who have undergone a forensic procedure under the Bill. Existing section 23YP, which is to be repealed by this Bill, lists the permitted purposes for which disclosure of forensic material derived from the carrying out of a forensic procedure can be made. These reasons are retained in proposed subsection 23YO.¹¹²

41.117 Finally, s 23YUD(1) provides that the Minister may enter into arrangements with participating jurisdictions for the sharing of information ‘from the DNA database system’ for the purpose of a criminal investigation or proceedings. However, as forensic material is not stored on a DNA database system, the provision does not appear to extend to the sharing of such information.

Privacy Act

41.118 Australian forensic laboratories are generally attached to a police service or a state or territory health department. The AFP operates its own forensic laboratories, which are subject to the Information Privacy Principles (IPPs) in the *Privacy Act 1988* (Cth) (*Privacy Act*). Forensic laboratories in other jurisdictions operate subject to privacy legislation applying in that State or Territory, where it exists. A private laboratory that offered forensic analysis services for law enforcement purposes would operate subject to the National Privacy Principles (NPPs) in the *Privacy Act*.

41.119 DP 66 noted that it is doubtful whether the *Privacy Act* regulates the collection, use, storage, disclosure or destruction of forensic bodily samples because genetic samples currently do not appear to fall within the definition of ‘personal

110 *Crimes Act 1914* (Cth) s 23YO(3)(e). This ground could permit disclosure for a broad range of purposes associated with law enforcement.

111 As discussed in Ch 8, in relation to the meaning of ‘personal information’ in *Privacy Act 1988* (Cth) s 6.

112 Revised Explanatory Memorandum to the Crimes Amendment (Forensic Procedures) Bill 2001 (Cth) [202].

information’ as defined in the *Privacy Act*.¹¹³ In Chapter 8 of this Report, the Inquiry recommends that the Commonwealth amend the *Privacy Act* to extend its coverage to identifiable genetic samples so that the IPPs and NPPs, or similar privacy principles, apply to genetic samples.¹¹⁴

41.120 As a result, a DNA sample taken from a suspect, offender or volunteer—and, potentially, a crime scene sample—could fall within the definition of ‘personal information’ for the purpose of the *Privacy Act* if the person’s identity were apparent, or could reasonably be ascertained, from the sample. Where a sample constitutes personal information, the collection, use, storage and disclosure of the sample would be subject to the IPPs (or in some cases the NPPs), subject to specific law enforcement exceptions.¹¹⁵

NATA accreditation requirements

41.121 The National Association of Testing Authorities, Australia (NATA) accredits laboratories in the field of forensic science in accordance with international standards.¹¹⁶ The accreditation program involves establishing and inspecting protocols and procedures for such areas as documentation, security, methodology, laboratory equipment calibration, evidence management, reporting, validation methods, and training.¹¹⁷ As part of its assessment, NATA also examines each laboratory’s documentation relating to internal audits, peer review checks and court testimony reviews.¹¹⁸ The laboratory accreditation program does not extend to the uploading of DNA profiles onto a DNA database system.¹¹⁹

41.122 Accredited laboratories are reassessed every two years to ensure they have complied with NATA’s accreditation requirements. In addition, each laboratory’s analysts must participate in internal and external proficiency testing during the period between these assessments.

113 Australian Law Reform Commission and Australian Health Ethics Committee, *Protection of Human Genetic Information*, DP 66 (2002), ALRC, Sydney [36.67].

114 Recommendation 8–2.

115 For example, exceptions exist to limit the use and disclosure of personal information where that use or disclosure is reasonably necessary for enforcement of the criminal law.

116 See National Association of Testing Authorities (Australia), *AS ISO/IEC 17025: 1999 Australian Standard: General Requirements for the Competence of Testing and Calibration Laboratories* (1999), NATA, Sydney; National Association of Testing Authorities Australia, *ISO/IEC 17025 Application Document: Supplementary Requirements for Accreditation in the Field of Forensic Science* (2000), National Association of Testing Authorities, Australia.

117 See Legislative Council Standing Committee on Law and Justice, *Review of the Crimes (Forensic Procedures) Act 2000*, Report No 18 (2002), Parliament of NSW, Sydney [3.68].

118 See Ibid [3.69]; National Association of Testing Authorities Australia, *ISO/IEC 17025 Application Document: Supplementary Requirements for Accreditation in the Field of Forensic Science* (2000), National Association of Testing Authorities, Australia.

119 National Association of Testing Authorities Australia, *Consultation*, Melbourne, 21 October 2002.

41.123 Most laboratories used by law enforcement agencies for DNA analysis have obtained NATA accreditation in forensic science. In any case, police services normally forward samples to an accredited laboratory for testing and analysis in order to ensure that any evidence obtained is not later challenged in court.¹²⁰

Issues and problems

41.124 The Model Bill and Part 1D of the *Crimes Act* focus more on the protection of DNA profiles held on the DNA database system than on the forensic material from which the profiles are obtained. This leads to potential concerns about the security of stored forensic material.

41.125 The primary concerns regarding the security of forensic material are to ensure the material is secure against improper use or access (especially in light of the vast amount of health and other information contained within each sample) and to protect against misuse of the material to implicate an innocent person in a criminal offence. DP 66 noted that—at least in theory—a person could seek to obtain stored forensic material to conduct an off-database comparison with another DNA sample or profile; or to plant the sample at a crime scene to falsely implicate an innocent person in an offence.¹²¹

41.126 The relative ease of obtaining DNA samples *directly* from a person's body or personal effects may render the latter concern less serious, given that someone motivated to act improperly probably would seek a DNA sample from a less secure source than an accredited laboratory. However, concerns may arise as to the security of genetic samples remaining on an exhibit after it has been released to the police investigators by the laboratory. For example, where a victim's jumper is smeared with the offender's blood, the laboratory might only need a fraction of that blood for the purpose of DNA analysis. The jumper, and the blood remaining on it, could be released to the police investigators as physical evidence.

Options for reform

41.127 Where forensic material is stored on a long-term basis, the sensitivity of the information stored within the samples inevitably leads to concerns for the security of that information. DP 66 outlined three options for improving the security of these samples.

120 M Parsell (NATA), *Correspondence*, 18 March 2003. The Northern Territory Police Service's forensic laboratory is working towards obtaining NATA accreditation in this field: Northern Territory Police Service, *Consultation*, Darwin, 18 March 2002.

121 Australian Law Reform Commission and Australian Health Ethics Committee, *Protection of Human Genetic Information*, DP 66 (2002), ALRC, Sydney [36.76].

Destruction of forensic material

41.128 One option is to require the destruction of forensic material after a DNA profile has been created.¹²² Possible reasons for the long-term retention of forensic material are: to enable a proportion to be used in quality assurance programs; to allow for retesting if allegations of errors in the analytical process are made; or for re-analysis if, in future, more sophisticated analysis techniques become available.¹²³ For example, forensic scientists might wish to re-analyse stored samples to include additional loci in DNA profiles stored on DNA databases, or to conduct a wholly new form of analysis on the samples when better technology emerges.

41.129 The advantage of destruction is that it minimises public concerns regarding the potential misuse of forensic material. If forensic scientists wish to re-analyse samples using more sophisticated technology, they must request the person's consent, or seek an order for a new forensic procedure. The disadvantage of destruction is the time and cost implications of obtaining new samples for analysis. However, it may be that this would not increase the overall cost significantly, given the costs involved in long term storage of these samples in appropriate atmospheric conditions.¹²⁴

41.130 New Zealand, Germany, Sweden, Denmark and the Netherlands currently require samples to be destroyed after the profile has been created. Canada, the United Kingdom, the United States and France retain samples after analysis.¹²⁵

Independent storage of forensic material

41.131 A second option is to permit the retention of forensic material after analysis but to provide for independent storage of that material to provide security against any allegations of future misuse.

41.132 The Inquiry understands that the NSW government is considering the establishment of a State Institute of Forensic Sciences to oversee the organisation and management of forensic sciences and the use of technology in criminal investigations and prosecutions. This is a joint proposal of the Police Service, the Attorney-General and the Department of Health.¹²⁶ This proposal also includes an independent storage facility for exhibits.

122 Except in relation to crime scenes samples, which are dealt with below.

123 See Legislative Council Legislation Committee, *Forensic Procedures and DNA Profiling: The Committee's Investigations in Western Australia, Victoria, South Australia, the United Kingdom, Germany and the United States of America*, Report No 48 (1999), Parliament of Western Australia, Perth [9.2]; Human Genetics Commission, *Inside Information: Balancing Interests in the Use of Personal Genetic Data* (2002), London, 154.

124 See Human Genetics Commission, *Inside Information: Balancing Interests in the Use of Personal Genetic Data* (2002), London, 155.

125 G Gardiner, *DNA Profiling: Information Paper No 22/01* (2002) Victorian Parliamentary Library, 16.

126 Legislative Council Standing Committee on Law and Justice, *Review of the Crimes (Forensic Procedures) Act 2000*, Report No 18 (2002), Parliament of NSW, Sydney [3.52].

41.133 The advantage of this approach is that it could minimise public concerns regarding potential misuse of stored forensic material; however, this would depend on the nature of the body holding the information—that is, its real and perceived integrity and independence—and its systems for maintaining confidentiality and information security.

Improve existing protections

41.134 A third option is to improve existing protections within Part 1D of the *Crimes Act*, the *Privacy Act* and the NATA accreditation framework in relation to stored genetic samples.

41.135 As noted above, the Model Bill and Part 1D of the *Crimes Act* focus primarily on the protection of DNA profiles on the DNA database system, rather than the forensic material from which the profiles are obtained. At a minimum, Part 1D of the *Crimes Act* could be amended to clarify that the provisions limiting the use and disclosure of information held on the DNA database system also extend to forensic material.

41.136 In addition, existing privacy protection would be improved by extending coverage of the *Privacy Act* to genetic samples.¹²⁷ For example, if the IPPs applied to bodily samples, the storage and security of the samples would be regulated under IPP 4. The laboratory holding the sample would be required to ensure it is protected by such security safeguards as are reasonable to protect against loss, unauthorised access, use, modification or disclosure, and against other misuse. However, the Inquiry notes that law enforcement exceptions apply to these principles.

41.137 Finally, existing protections could be improved by extending the NATA accreditation framework to all forensic laboratories analysing and storing forensic material in the law enforcement context. In addition, NATA has a ‘drug and properties’ accreditation program that provides for the cataloguing and storage of evidence stored in a police environment, such as evidence in a narcotics investigation. This program is designed for evidence that is not in the custody of the testing laboratory and is therefore not covered by the laboratory exhibit management system. Although the program has been designed for drug related exhibits it does not preclude being applied to genetic samples.¹²⁸

Submissions and consultations

41.138 DP 66 proposed that forensic procedures legislation should provide that forensic analysis of genetic samples must be conducted only by laboratories accredited by NATA in the field of forensic science.¹²⁹

127 See Ch 8 for more detail.

128 National Association of Testing Authorities, *Accreditation Requirements for Drug and Property Registries* (2000), NATA, Sydney; M Parsell (NATA), *Correspondence*, 18 March 2003.

129 Australian Law Reform Commission and Australian Health Ethics Committee, *Protection of Human Genetic Information*, DP 66 (2002), ALRC, Sydney, Proposal 36–9.

41.139 Most of the submissions supported this proposal.¹³⁰ The Queensland Government objected to the proposal on the basis that if

Queensland legislation was to provide that the laboratories used for forensic analysis must be accredited by NATA, and the standards set by NATA changed, the laboratories may have to respond immediately to the changing circumstances, which may include the purchase of additional equipment ... Queensland is of the view that the recommendation to make the accreditation mandatory through legislation may not be necessary, as this matter may be adequately dealt with as a matter of government policy.¹³¹

41.140 The NSW Police Service opposed the proposal, commenting that:

Acknowledgement must be given to other methods of accreditation (e.g. American Society of Crime Lab Directors (ASCLD), American Association of Blood Banks, College of American Pathologists, National Pathology Accreditation Advisory Council), and acknowledgement must be given to the probability that work will be sometimes undertaken by overseas laboratories ... there may be times when results of medical testing (by accredited medical labs) or paternity tests (by accredited parentage testing labs) are desirable to be presented as evidence. The admissibility of that evidence should not be denied by legislation. The important point is that their evidence be demonstrated to adhere to the standards appropriate to their field of testing.¹³²

41.141 The Office of the Victorian Privacy Commissioner disagreed with the Inquiry's approach, arguing that it does not strike an appropriate balance between the public interest in solving crime and the public interest in protecting individual privacy.

Consideration should be given to investigating alternative methods for police collection of DNA profiles that do not require collection and retention of body samples. This might, for instance, be achieved by having the sample collected, analysed and held or destroyed by an intermediary that is independent of police.¹³³

Inquiry's views

41.142 The Inquiry recommends that Part 1D of the *Crimes Act*, or regulations thereunder, be amended to provide that forensic analysis of genetic samples for use by law enforcement authorities should be conducted only by laboratories accredited by NATA in the field of forensic science.

130 National Association of Testing Authorities Australia, *Submission G273*, 18 December 2002; Victoria Police, *Submission G203*, 29 November 2002; Institute of Actuaries of Australia, *Submission G224*, 29 November 2002; Commonwealth Attorney-General's Department, *Submission G228*, 12 December 2002; Office of the Privacy Commissioner (NSW), *Submission G257*, 20 December 2002; Human Genetics Society of Australasia, *Submission G267*, 20 December 2002; Centre for Genetics Education, *Submission G232*, 18 December 2002; Centre for Law and Genetics, *Submission G255*, 21 December 2002; National Legal Aid, *Submission G314*, 19 February 2003; Office of the Federal Privacy Commissioner, *Submission G294*, 6 January 2003; Law Institute of Victoria, *Submission G275*, 19 December 2002; Association of Genetic Support of Australasia, *Submission G284*, 25 December 2002; Department of Human Services South Australia, *Submission G288*, 23 December 2002.

131 Queensland Government, *Submission G274*, 18 December 2002.

132 NSW Police Service, *Submission G306*, 22 January 2003.

133 Office of the Victorian Privacy Commissioner, *Submission G266*, 20 December 2002.

41.143 This would ensure standardised forensic laboratory practice across Australia for the effective operation of the DNA database systems—including the National Criminal Investigation DNA Database (NCIDD system)—and would be consistent with the Inquiry’s recommendations in other areas of laboratory practice.¹³⁴ As noted above, the submissions expressed widespread support for this approach.

41.144 The NATA accreditation program does not extend to the uploading of DNA profiles into a DNA database system. Therefore, NATA’s two yearly assessments would not cover this aspect of laboratory practice. In practice, laboratories could make mistakes when uploading profiles into a database system, for example by uploading incorrect or incomplete profiles, or by inserting them into the incorrect index of the database. In Chapter 43, the Inquiry recommends that the Commonwealth should amend the *Crimes Act* to provide for a periodic, independent audit of the operation of DNA database systems operating pursuant to the Act—including the forensic laboratories participating in these DNA database systems.¹³⁵ This should provide an additional level of oversight of laboratory practices to ensure public confidence that the relevant legislative requirements are being satisfied.

41.145 DP 66 noted the importance of ensuring that suspects, offenders and volunteers are protected from perceived or real threats to their genetic privacy through future analysis of their samples for predictive health, behavioural or other information.¹³⁶ A number of submissions suggested that the security of forensic material could be best protected by destroying the material after analysis, or by independent storage of the material. The Inquiry agrees that these measures would ensure greater public confidence in the security of their genetic information.

41.146 Therefore, the Inquiry recommends that the Commonwealth should amend the *Crimes Act* to provide that forensic material obtained pursuant to Part 1D must be destroyed as soon as practicable after a DNA profile has been obtained from the material. In the rare circumstances in which police might later seek access to a suspect, offender or volunteer’s genetic sample, they would need to do so pursuant Part 1D of the *Crimes Act*.

41.147 Implementation of this recommendation should increase public confidence in the use of DNA profiling in law enforcement, and in the operation of the DNA database system. In addition, the destruction of all forensic material other than crime scene samples would greatly reduce the resource burden on forensic laboratories who would otherwise be required to store the samples in appropriate conditions on a long term basis.

41.148 This recommendation would necessitate amendments to the *Crimes Act* so that the destruction requirements currently applying to forensic material would apply to any information obtained from analysis of that material.

134 See Ch 10 for more detail.

135 Recommendation 43–4.

136 Australian Law Reform Commission and Australian Health Ethics Committee, *Protection of Human Genetic Information*, DP 66 (2002), ALRC, Sydney [36.98].

41.149 Finally, the Inquiry recommends the improvement of legislative safeguards for the confidentiality and security of forensic material until it is destroyed. There is no apparent reason why genetic information in the form of a DNA profile should receive greater legislative protection than the forensic material from which it was obtained. At a minimum, the provisions limiting the use and disclosure of information should be extended to cover forensic material. This would ensure the prohibition of any unauthorised use or disclosure of stored samples that were obtained under Part 1D of the *Crimes Act*.

Recommendation 41–7. The Commonwealth should amend the *Crimes Act*, or regulations made thereunder, to provide that forensic analysis of genetic samples for use by law enforcement authorities should be conducted only by laboratories accredited by National Association of Testing Authorities, Australia (NATA) in the field of forensic science.

Recommendation 41–8. The Commonwealth should amend the *Crimes Act* to provide that forensic material obtained pursuant to Part 1D must be destroyed as soon as practicable after a DNA profile has been obtained from the material.

Recommendation 41–9. The Commonwealth should amend the *Crimes Act* so that the provisions limiting use and disclosure of information held on a DNA database system also apply to forensic material.

Destruction of forensic material and DNA profiles

Destruction or de-identification?

41.150 Part 1D of the *Crimes Act* defines destruction of forensic material or any information obtained from it in terms of de-identification rather than physical destruction. Section 23WA(5) provides that:

a person *destroys* forensic material taken from another person by a forensic procedure, the results of the analysis of the material or other information gained from it if the person destroys any means of identifying the forensic material or information with the person from whom it was taken or to whom it relates.

41.151 MCCOC explained the reason for this position in its discussion paper:

Forensic scientists advise that once samples have been subjected to the various processes of analysis in a forensic laboratory it would be extremely difficult to trace all remnants of the samples and destroy them. The same also goes for all the different records of the DNA profile. However, they point out that the material is often labelled with a numerical Code which if destroyed makes it impossible to identify the sample.¹³⁷

¹³⁷ Model Criminal Code Officers Committee, *Model Forensic Procedures Bill and the Proposed National DNA Database, Discussion Paper* (1999) Standing Committee of Attorneys-General, 83.

41.152 The Revised Explanatory Memorandum to the Crimes Amendment (Forensic Procedures) Bill 2001 (Cth) noted that the

definition recognises that it is not feasible to require the destruction of all the microscopic forensic material taken from a person that inevitably remains on a laboratory bench.¹³⁸

41.153 The AFP's guidelines provide that, when material is required to be destroyed, the investigating member must as soon as practicable notify the Forensic Services Biology Team of the requirement (including the date, if required, by which time the material must be destroyed) and ensure that all written records, video and audio tapes relating to the sample that are in the possession of AFP members and the Office of the Director of Public Prosecutions are destroyed. The principle biology forensic reporting officer must then destroy the actual sample and the means of identifying the person to whom the sample (or information derived from it) relates; and forward a report confirming destruction of the material to specified persons.¹³⁹

41.154 In a consultation, the AFP advised that its practice is to physically destroy the DNA sample and de-identify the DNA profile obtained from the sample. The sample is physically destroyed by bio-hazard destruction, while the profile is deleted from the electronic database and all paper references to it are destroyed.¹⁴⁰

41.155 The NSW Police Service advised the Inquiry that it observes the following practice for destroying forensic material and profiles:

[U]pon the issue of a destruction order, the identifier for the sample record to be deleted is entered on to the DNA database. Located records are displayed and are deleted by the authorised system user. All personal details are deleted, including name, date of birth, gender and any records associated with the taking of the DNA sample, eg barcode and sample bag number. In addition, the Division of Analytical Laboratories physically destroys the DNA sample and any aliquots or 'remnants' of that sample. A record of the profile may be retained if it exists in a final results table, as a record of the analysis process, but only if all identifying links to it have been deleted. This would not enable a person to trace the personal details of the profile in the results table. Physically destroying such records would place inordinate demands on the system users and serve no useful or practical purpose.¹⁴¹

Submissions and consultations

41.156 In DP 66, the Inquiry asked whether the balance should be tipped in favour of physical destruction of forensic material and information obtained from it in order to maintain information security and public confidence in the use of DNA profiling for criminal investigations.¹⁴² The Inquiry noted that good laboratory practices should

138 Revised Explanatory Memorandum to the Crimes Amendment (Forensic Procedures) Bill 2001 (Cth) [48].

139 Australian Federal Police, *AFP National Guideline for Conducting a Commonwealth Forensic Procedure — Part 1D Crimes Act 1914* (2001), AFP [23].

140 Australian Federal Police, *Consultation*, Canberra, 7 November 2002.

141 NSW Police Service, *Submission G306*, 22 January 2003.

142 Australian Law Reform Commission and Australian Health Ethics Committee, *Protection of Human Genetic Information*, DP 66 (2002), ALRC, Sydney, Question 36–1.

allow for location of all remnants of a sample after analysis, and the destruction of these remnants; and good record keeping should allow for location of all references to the DNA profile and other identifying information.¹⁴³

41.157 Several submissions supported retention of the existing definition of ‘destruction’.¹⁴⁴ The Victoria Police submitted that de-identification appears sufficient. They suggested that in Victoria, due to issues within the item management system and the software attached to the DNA interpretation phase, it is not possible to fully destroy all records. Instead, they suggested that

it should be legislated that it is an offence to knowingly and deliberately pass on or interrogate data held from samples taken under this Act that should be destroyed rather than it being an offence to not having destroyed the information. Thus if something in the process cannot be adequately destroyed then the onus is now shifted to attempting to make a connection between the DNA profile and the person ...¹⁴⁵

41.158 The Victoria Police submitted that most laboratory databases are commercially purchased and therefore the ability to alter the code to allow for full destruction is not generally available. As a result, the:

Victorian Forensic Science Centre’s preferred position is to reduce the need to destroy to breaking the link and making it an offence to re-establish the link and knowingly pass on that information. Current law prohibits the use of the information in a criminal investigation, as any evidence would be tainted. Passage of any DNA or the original sample to a third body such as a centre for disease testing with linkages to insurance companies should naturally be prohibited.¹⁴⁶

41.159 In its initial submission, the Commonwealth Attorney-General’s Department submitted that the definition of ‘destruction’ reflects the practicalities in that it is extremely difficult to trace and destroy all remnants of the forensic samples after analysis, or all the various records of the DNA profile.

The suggestion that forensic material could be re-identified in the future is an important issue but there are strong incentives to ensure proper destruction occurs. For example, the failure to adequately destroy these identifying links may constitute an offence ... Further, any evidence obtained and subsequently relied upon from a failure to properly destroy the identifying links will be inadmissible evidence ... Even where the profile is on the system, it will not be possible, in practice, for anyone other than authorised officers from the respective jurisdiction from which the DNA profile has been provided to identify the profile.¹⁴⁷

41.160 In a subsequent submission, the Department submitted that an amendment to the current definition of ‘destruction’ would raise a number of practical difficulties.

143 Ibid [36.160].

144 Victoria Police, *Submission G203*, 29 November 2002; Commonwealth Attorney-General’s Department, *Submission G228*, 12 December 2002; NSW Police Service, *Submission G306*, 22 January 2003.

145 Victoria Police, *Submission G203*, 29 November 2002.

146 Ibid.

147 Commonwealth Attorney-General’s Department, *Submission G158*, 7 May 2002.

The current definition recognises that it is not feasible to require the destruction of all the microscopic forensic material taken from a person that inevitably remains on a laboratory bench. That view was overwhelmingly conveyed to MCCOC by the forensic science community during the development of the Model Bill. Although the legislation is in its early days, there has been no evidence to indicate that the current definition of destruction has resulted in any breach of privacy or civil liberties.¹⁴⁸

41.161 The NSW Police Service submitted that:

The practical difficulties in tracing and physically destroying all remnants of a sample do justify confining privacy protection to de-identification rather than physical destruction of all forensic material and information. This is particularly so in respect of information that may be disseminated to a wide range of people and thus almost impossible to trace without a great deal of expense. If the information cannot be identified it would seem to be a waste of resources to trace that information.

There may also be sound reasons for the destruction of samples collected from volunteers, or suspects who are later exonerated, the more important aspect is that the link or identifier between the source and the DNA profile be destroyed. There are sound scientific reasons for a laboratory to maintain and accumulate a bank of anonymous DNA samples for R&D purposes ... it is our view that de-identification, if carried out as described, does protect the privacy of the individual particularly if the original biological sample (the buccal swab say which has a name identifier), is also destroyed.¹⁴⁹

41.162 By contrast, the Inquiry received a number of submissions, and heard views in a number of consultations, supporting a new legislative definition based on physical destruction of the forensic material and information obtained from it.¹⁵⁰ A number of these submissions suggested that de-identification might not sufficiently protect the privacy of the person from whom they were obtained, by allowing for future re-identification of information; therefore physical destruction was the most secure option.

41.163 The Office of the Victorian Privacy Commissioner submitted that ‘destruction’ should mean physical destruction, noting that ‘it is questionable whether a biometric such as DNA can ever be permanently de-identified, given it is essentially comprised of identifiable material’.¹⁵¹

41.164 National Legal Aid submitted that:

148 Commonwealth Attorney-General’s Department, *Submission G228*, 12 December 2002.

149 NSW Police Service, *Submission G306*, 22 January 2003.

150 New South Wales Legal Aid Commission, *Submission G087*, 21 January 2002; Androgen Insensitivity Syndrome Support Group Australia, *Submission G106*, 26 February 2002; Centre for Law and Genetics, *Submission G048*, 14 January 2002; Centre for Genetics Education, *Submission G232*, 18 December 2002; Office of the Victorian Privacy Commissioner, *Submission G266*, 20 December 2002; Centre for Law and Genetics, *Submission G255*, 21 December 2002; National Legal Aid, *Submission G314*, 19 February 2003; Law Institute of Victoria, *Submission G275*, 19 December 2002; I Freckelton and J Gans, *Consultation*, Melbourne, 21 October 2002; New South Wales Council for Civil Liberties, Sydney, 3 December 2002; Liberty Victoria, *Consultation*, Melbourne, 23 October 2003; R Trent, *Consultation*, Sydney, 1 November 2002; Human Genetics Society of Australasia, *Submission G267*, 20 December 2002.

151 Office of the Victorian Privacy Commissioner, *Submission G266*, 20 December 2002.

de-identification might not sufficiently protect the privacy of the person from whom they were obtained and therefore physical destruction was the most secure option ... logic would seem to suggest that if the numerical code is destroyed making it impossible to identify the sample that there is still a sample capable of isolation and therefore destruction. If the MCCOC concern is essentially about traces or remnants that no longer form part of the original 'sample' and can no longer be identified, then perhaps that part of the sample has already been 'destroyed'.¹⁵²

41.165 The NSW Legal Aid Commission submitted that:

De-identification is not sufficient because of widely held fear about the possibility that the person's identity may somehow be reassigned to the sample, and concerns about why the samples are being kept. Many people have strong concerns about government authorities having access to their genetic information, and are entitled to the assurance that the genetic material and any profiles or analysis obtained from the material will be destroyed once they are of no further forensic use.¹⁵³

41.166 Privacy NSW suggested that the

current definition of destruction creates too great an opportunity for abuse. The overwhelmingly probative value ascribed to DNA samples calls for stronger safeguards, for example against the creation of a 'black market' of samples that have never been fully de-identified and which can be planted at crime scenes. While there may be practical difficulties in complying with a regime of comprehensive destruction, it should be possible to draft a requirement which at least minimises this kind of risk.¹⁵⁴

41.167 The Androgen Insensitivity Syndrome Support Group submitted that:

this definition of destruction amounts to a deception by omission and samples subject to destruction should be physically destroyed. Physical destruction is the only way [to] alleviate the temptation to later use human tissue samples for purposes not originally consented to.¹⁵⁵

41.168 Dr Ian Freckelton also raised concerns regarding de-identification of information in relation to the Victorian forensic procedures legislation:

The problematic components of the 'de-identified' database are those consisting of persons who have not been charged, whose charges have not been proceeded with, who have voluntarily supplied samples and who have been found not guilty of criminal offences. The question is whether the de-identification process is meaningful and whether an arm of the state should be permitted to retain such potentially identifying information about members of the community against whom no adverse finding has been made. The issue becomes the more stark in light of situations in which information held by policing authorities has been retained contrary to protocols, the issue being whether compliance with even legislative measures would take place when the temptations to breach them may be very significant.¹⁵⁶

152 National Legal Aid, *Submission G314*, 19 February 2003.

153 New South Wales Legal Aid Commission, *Submission G087*, 21 January 2002.

154 Office of the Privacy Commissioner (NSW), *Submission G257*, 20 December 2002.

155 Androgen Insensitivity Syndrome Support Group Australia, *Submission G106*, 26 February 2002.

156 I Freckelton, *DNA Profiling: Collection, Use and Effectiveness — An Issues Paper* (2002), Victorian Parliament, 31.

41.169 In a consultation, Professor Ron Trent, Chair of the Department of Molecular and Clinical Genetics, Royal Prince Alfred Hospital, commented that in his view it would be possible to physically destroy DNA samples and profiles. He noted that the chain of custody for samples is very detailed in forensic laboratories and therefore it should be possible to track all of the separate parts of a particular sample for the purpose of destruction. While destruction of profiles stored in computer databases might be difficult, he considered it would not be impossible.¹⁵⁷

Inquiry's views

41.170 This issue involves two competing considerations. On the one hand, there is the need to maintain public confidence in the use of DNA profiling generally, and in particular the protection of personal privacy rights to the extent practicable. On the other hand, there are concerns about the practical difficulty of ensuring that all remnants of a sample or profile have been located and destroyed.

41.171 The Inquiry does not find the arguments advanced in favour of de-identification compelling in relation to genetic samples. Good laboratory practice requires that it should be possible to locate every remnant of a sample after analysis, and good record keeping should allow for location of all paper-based references to the DNA profile and other identifying information. Indeed, the AFP has advised the Inquiry that such information is currently physically destroyed.

41.172 In relation to DNA profiles held in computerised database systems, the Inquiry recognises that some practical difficulties might arise. For example, the Inquiry has been advised that a record of a profile might be retained in a computer database's backup system after it has been deleted from the database.

41.173 The Inquiry confirms its preliminary view that the balance should be tipped in favour of physical destruction of forensic material and information obtained from it, in order to maintain information security and public confidence in the use of DNA profiling for criminal investigations. However, in relation to profiles, where there is no capacity for further testing, it would be sufficient protection for these to be permanently and irreversibly de-identified. It should be noted in this context that coded data should not be considered 'de-identified' because coding, by its very nature, is reversible.¹⁵⁸

157 R Trent, *Consultation*, Sydney, 1 November 2002.

158 See National Health and Medical Research Council, *National Statement on Ethical Conduct in Research Involving Humans* (1999), NHMRC, Canberra [15.8], [16.13]. Compare *Privacy Act 1988* (Cth) s 6. The *Privacy Act* does not apply to information unless it is 'about an individual whose identity is apparent, or can reasonably be ascertained, from the information or opinion'. Such a standard, based on reasonableness, means that in some cases it will not be clear whether particular information is identifiable and, therefore, whether or not the IPPs and NPPs apply to how it is handled.

Recommendation 41–10. The Commonwealth should amend the *Crimes Act* to define the destruction of forensic material and information obtained from it in terms of physical destruction of samples and permanent and irreversible de-identification of profiles.

Management of destruction dates

Crimes Act provisions

41.174 The destruction requirements for forensic material and DNA profiles are contained in various places in of Part 1D of the *Crimes Act*, depending on the context in which the information was collected.

41.175 Forensic material obtained from a suspect must generally be destroyed as soon as practicable after:

- an interim order for the carrying out of a forensic procedure is disallowed, or the retention period specified by the court has expired;¹⁵⁹
- 12 months have elapsed since the forensic material was taken and proceedings have not been instituted against the suspect, or have been discontinued, and no warrant for apprehension has been issued;¹⁶⁰ or
- the suspect is convicted but no conviction is recorded, or the suspect is acquitted and no appeal is lodged against the acquittal (or if an appeal is lodged, the acquittal is confirmed or the appeal is withdrawn).¹⁶¹

41.176 Forensic material obtained from a serious offender must be destroyed as soon as practicable after his or her conviction is quashed.¹⁶²

41.177 If a volunteer (or parent or guardian) expressly withdraws consent to the retention of the forensic material taken or of information obtained from the analysis of that material, the forensic material and information must be destroyed as soon as practicable after the consent is withdrawn.¹⁶³ To the extent that it is relevant, the volunteer (or parent or guardian) must also be informed that information placed on a DNA database system will be retained for such period as the Commissioner and the volunteer agree, and must then be removed from the system.¹⁶⁴

¹⁵⁹ *Crimes Act 1914* (Cth) s 23YC.

¹⁶⁰ *Ibid* s 23YD(2), unless the period has been extended by a magistrate.

¹⁶¹ *Ibid* s 23YD(3), unless the period has been extended by a magistrate.

¹⁶² *Ibid* s 23YDAA.

¹⁶³ *Ibid* s 23XWT, subject to a magistrate's order under s 23XWV.

¹⁶⁴ *Ibid* s 23XWR(2).

41.178 Where a magistrate finds that forensic evidence is inadmissible under s 23XX, any forensic material taken from the person by that forensic procedure must be destroyed.¹⁶⁵

41.179 A person is guilty of an offence if he or she knowingly or recklessly causes any identifying information to be recorded or retained on the system after the forensic material is required to be destroyed.¹⁶⁶

Destruction in practice

41.180 DP 66 noted that, with some exceptions Part 1D of the *Crimes Act* does not assign responsibility for notifying the person charged with destroying forensic material (or the information obtained from it) of the required destruction date.¹⁶⁷

41.181 In relation to profiles held on the NCIDD system, CrimTrac advised the Inquiry that the draft Memorandum of Understanding between the agency and each participating jurisdiction provides that the jurisdictions must manage the destruction dates. Once the destruction date has been entered into the system the database will automatically search each night for the profiles that must be destroyed.¹⁶⁸ However, CrimTrac has advised that many of the profiles uploaded onto the NCIDD system do not have specified destruction dates.¹⁶⁹

Issues and problems

41.182 There is a lack of clarity in the legislative provisions for the management of destruction dates for forensic material, and the profiles obtained from such material. As a result, problems may arise in practice in ensuring that notice is given to the laboratory storing the forensic material, and the responsible person for a DNA database system, that the information should be destroyed. In addition, there is currently no legislative basis for persons whose information should be destroyed to confirm that this has been done.

Submissions and consultations

41.183 DP 66 proposed that forensic procedures legislation should be amended to: specify the person responsible for notifying the forensic laboratory and CrimTrac of the destruction date of forensic material and any information obtained from it; establish a process for persons to obtain confirmation that their forensic material, and any information obtained from it, has been destroyed; and provide a standard consent form

165 *Crimes Act 1914* (Cth) s 23YDAB.

166 *Ibid* s 23YDAG(1). See also s 23YDAG(2), (3).

167 Australian Law Reform Commission and Australian Health Ethics Committee, *Protection of Human Genetic Information*, DP 66 (2002), ALRC, Sydney [36.149].

168 CrimTrac, *Consultation*, Canberra, 7 November 2002.

169 *Ibid*.

to enable a volunteer (or parent or guardian) to specify the retention period for both the forensic material and any information obtained from it.¹⁷⁰

41.184 Most of the submissions supported the proposal.¹⁷¹ In a consultation, Liberty Victoria emphasised the need for oversight of the destruction of the material, suggesting that an ombudsman or the person to whom the information relates should have some way to ensure that it has been destroyed.¹⁷²

41.185 The Law Institute of Victoria supported the proposal, expressing support for increased accountability of the staff working in forensic laboratories, whether directly handling forensic sampling, conducting analysis or performing administrative and recording duties.

In addition, the Law Institute believes that any DNA (or extracted information) accessed from a database should then bear the ‘footprint’ of the person and organisation accessing it. Creation of the footprint should ideally require that person to provide their purpose in accessing the information, and they should be open to criminal prosecution for unauthorised access or for subsequent misuse of the information obtained.¹⁷³

41.186 The Victoria Police submitted that:

It should be clarified whether this proposal requires a *person* to be specified, rather than a *position*. As a person occupying a certain position may change within an organisation, Victoria Police suggest it would be more appropriate to specify the position responsible for notifying the forensic laboratory, rather than a person.¹⁷⁴

41.187 The NSW Police Service also submitted that the person responsible should be expressed as a position rather than an individual person, and suggested that the function should be delegable. The Police Service noted that:

Anyone who has provided a forensic sample to NSW Police can write to the Commissioner seeking confirmation that the forensic sample has been destroyed. However, to provide such information routinely to all donors without a written request would, logistically, be very difficult ... It is also considered that many donors would be willing to trust the honesty and integrity of NSW Police to destroy forensic material in accordance with the legislative requirements and would not require written confirmation of this destruction ... It would be difficult for a volunteer, when providing a DNA sample, to specify a retention period as it would be impossible at that time to determine the likely duration of any police investigation.¹⁷⁵

170 Australian Law Reform Commission and Australian Health Ethics Committee, *Protection of Human Genetic Information*, DP 66 (2002), ALRC, Sydney, Proposal 36–14.

171 Centre for Genetics Education, *Submission G232*, 18 December 2002; Centre for Law and Genetics, *Submission G255*, 21 December 2002; Office of the Privacy Commissioner (NSW), *Submission G257*, 20 December 2002; Human Genetics Society of Australasia, *Submission G267*, 20 December 2002; Department of Human Services South Australia, *Submission G288*, 23 December 2002; National Legal Aid, *Submission G314*, 19 February 2003; Law Institute of Victoria, *Submission G275*, 19 December 2002; Association of Genetic Support of Australasia, *Submission G284*, 25 December 2002.

172 Liberty Victoria, *Consultation*, Melbourne, 23 October 2002.

173 Law Institute of Victoria, *Submission G275*, 19 December 2002.

174 Victoria Police, *Submission G203*, 29 November 2002.

175 NSW Police Service, *Submission G306*, 22 January 2003.

41.188 The Queensland Government submitted that the matters dealt with in the proposal were more appropriately located within policy and practice, rather than legislation or regulations.¹⁷⁶

Inquiry's views

41.189 The Inquiry considers that the framework of responsibility for the management of destruction dates requires clarification. For example, Part 1D of the *Crimes Act* currently prohibits a person from causing any identifying information about a person to be recorded or retained in a DNA database system at any time after the forensic material is required to be destroyed, where the person is reckless as to the recording or retention, or as to the destruction requirement.

41.190 As noted above, Part 1D generally does not place responsibility on any person or officer to notify the person administering a DNA database system of the relevant destruction date for profiles held on the system. In practice, a profile (or other information) could be retained on a DNA database system after its destruction date due to an omission to advise the administrator of that date. In this case, it is unlikely that the elements of the offence would be satisfied.

41.191 DP 66 proposed that the legislation should be amended to specify the person responsible for notifying the forensic laboratory and CrimTrac of the destruction date of forensic material and any information obtained from it.¹⁷⁷ Section 71 of the *Criminal Investigation (Identifying People) Act 2002* (WA) could provide a model for legislative amendment. Section 71 ascribes responsibility for destroying 'identifying information'. If information or anything else that must be destroyed under the Act is in:

- the possession of the Western Australian Police, the Commissioner of Police must ensure it is destroyed;
- the possession of a person other than the Western Australian Police, that person must ensure it is destroyed; and
- a forensic database, the person who controls or manages the database must ensure it is destroyed.

41.192 This provision makes clear who has ultimate responsibility for managing destruction. Where forensic material is held by the police or by an independent forensic laboratory, the body holding the material is responsible for its destruction. Where a profile is held on a DNA database system, the system's administrator is responsible for its destruction. Therefore, where the administrator is uncertain as to a destruction date, the administrator must ensure that it is informed of that date by the relevant police service.

¹⁷⁶ Queensland Government, *Submission G274*, 18 December 2002.

¹⁷⁷ Australian Law Reform Commission and Australian Health Ethics Committee, *Protection of Human Genetic Information*, DP 66 (2002), ALRC, Sydney, Proposal 36–14.

41.193 The Inquiry recommends that the Commonwealth amend the *Crimes Act* to assign ultimate responsibility for managing the destruction of forensic material and any information obtained from it.

41.194 In practice, the Inquiry considers that destruction dates should be entered into the NCIDD system, and any other DNA database operating under the *Crimes Act*, at the time the profile is uploaded onto the system.¹⁷⁸ An AFP officer or unit should be given responsibility for managing these destruction dates, and procedures should be developed for a person to obtain written confirmation that his or her forensic material and profile have been destroyed. For example, the Victorian forensic procedures legislation currently provides for the issue of a certificate of destruction, upon request.¹⁷⁹

41.195 In addition, the Commonwealth should develop formal policies and procedures to enable a volunteer (or parent or guardian) to specify, from a range of options, the retention period for his or her forensic material and any information obtained from it; and to establish a process for persons to obtain confirmation that their forensic material, and any information obtained from it, has been destroyed.¹⁸⁰

41.196 In the context of a criminal investigation it might be more practical for a volunteer to consent to a general retention period, such as ‘a period of 30 days’, or ‘until the end of the investigation period’ for that particular offence. This will depend on the context of the investigation, and the reason for providing the genetic sample. However, the Inquiry recognises that the volunteer has the legislative right to withdraw consent to the retention of this information (see above for more detail) and does not suggest that this right be removed for any reason.

Recommendation 41–11. The Commonwealth should amend the *Crimes Act* to assign ultimate responsibility for managing the destruction of forensic material and any information obtained from it.

Recommendation 41–12. The Commonwealth should develop formal policies and procedures to:

- (a) enable a volunteer (or parent or guardian) to specify, from a range of options, the retention period for his or her forensic material and any information obtained from it; and
- (b) establish a process for persons to obtain confirmation that their forensic material, and any information obtained from it, has been destroyed.

¹⁷⁸ However, provision would need to be made for profiles obtained from serious offenders which, unless the conviction is quashed, generally may be held indefinitely.

¹⁷⁹ *Crimes Act 1958* (Vic) s 464ZG(7).

¹⁸⁰ Once Recommendation 41–8 has been implemented, the volunteer need only specify the retention period for the information obtained from the forensic material.

Informal collection of genetic samples

41.197 Given the ubiquity of genetic samples in public and other spaces, the Inquiry has heard that police investigators might seek to use informal procedures to obtain these samples. This would result in a parallel system for the collection and use of genetic samples falling outside the formal regulatory framework established under Part 1D of the *Crimes Act*.

Methods of informal collection

Collection of discarded samples

41.198 If police investigators do not wish to alert a person to the fact that he or she is a suspect in an investigation, or do not have sufficient evidence to obtain an order for a non-consensual forensic procedure, they might seek to obtain the suspect's genetic sample after it has been discarded or otherwise become detached from the suspect's body. For example, in *R v Nicola*, New South Wales police obtained a genetic sample from a suspect's used styrofoam cup after he threw the cup into a bin at the police station.¹⁸¹ In *R v Phuc*, police seized cigarette butts discarded by two suspects in relation to a Victorian offence during police interviews conducted outside Australia.¹⁸²

Non-forensic investigative powers

41.199 Similarly, police investigators might seek to obtain a sample by using non-forensic investigative powers such as search warrants, random breath tests or blood alcohol tests. For example, in *R v Daley*, New South Wales police had identified a suspect in relation to eight sexual assaults. The police sought to obtain the suspect's DNA sample covertly and arranged for him to be stopped for a 'random' breath test. After the suspect exhaled into the tube the container was sealed and forwarded to the laboratory for DNA analysis. The police also searched the suspect's house pursuant to a search warrant, asked him to remove his clothes, and subjected the clothes to DNA analysis.¹⁸³

41.200 Alternatively, police might seek to gain access to a suspect or other person's stored genetic samples for use in law enforcement. For example, police might request access to a person's newborn screening card (ie, Guthrie card) or other pathology samples for identification purposes.¹⁸⁴

181 *R v Nicola* (Unreported, NSW Court of Criminal Appeal, Spigelman CJ; Barr and Bergin JJ, 11 March 2002).

182 *R v Truong Hong Phuc & Truong Thi Van* (Unreported, Victorian Supreme Court, Vincent J, 16 June 2000).

183 *R v Daley* (Unreported, NSW Supreme Court, Simpson J, 14 September 2001).

184 See Ch 19 for more detail.

Close genetic relatives

41.201 In light of the similar genetic makeup of close relatives, it is possible that police might seek to conduct a forensic procedure on a close relative of a suspect where the suspect is not available for testing. For example, if a suspect has left Australia, the police might ask his or her sibling to provide a DNA sample to determine whether the suspect should be excluded from suspicion, or whether there is a probability that the suspect may have left the DNA sample found at a crime scene.¹⁸⁵

41.202 This could have significant privacy implications for the family of any person who is identified as a suspect in an offence. In its submission to the Inquiry, the Office of the Victorian Privacy Commissioner expressed the concern that:

[f]orensic procedures provisions allowing forensic samples to be obtained from suspects and serious offenders (and any safeguards accompanying them) may be circumvented if DNA can be otherwise obtained from a ‘third party’, namely from suspects or serious offenders’ relatives. Consideration should be given to prohibiting the seeking or obtaining, without a court order, of DNA material from volunteers for the purpose of identifying suspects or serious offenders.¹⁸⁶

Limitations on police powers

41.203 Police investigators do not have any specific statutory power to obtain a genetic sample from an item or a public space once it has been discarded or has otherwise become detached from a person’s body; nor is there any specific prohibition on this activity. However, there are a number of possible existing limitations on these powers. First, if Australian law recognises a property right in a genetic sample, the taking of that sample without the consent of the person from the sample originates could constitute theft. However, as noted in Chapter 20, Australian law has not generally recognised this form of property right in genetic samples.

41.204 Second, in Chapter 8 the Inquiry recommends that the Commonwealth should amend the *Privacy Act* to extend the coverage of the IPPs and NPPs (or similar privacy principles) to identifiable genetic samples.¹⁸⁷ Once implemented, the genetic samples collected in these circumstances could fall within the IPPs in the *Privacy Act*—however, the exceptions applying to law enforcement contexts would limit its applicability.

41.205 Third, as Part 1D of the *Crimes Act* provides a formal framework for collecting genetic samples from suspects, it is likely that Parliament intended that this legislation should be the sole authority by which police might collect such samples. Section 23YU(1) provides that Part 1D is not intended to limit or exclude the operation of another law of the Commonwealth or a law of a State or Territory relating to:

185 Alternatively, police investigators could use a DNA database system to identify ‘partial matches’ with a crime scene sample, potentially implicating the genetic relatives of the person whose profile registers the partial match.

186 Office of the Victorian Privacy Commissioner, *Submission G266*, 20 December 2002.

187 Recommendation 8–2.

- the carrying out of forensic procedures, including procedures not referred to in Part 1D;
- the carrying out of breath analysis or a breath test or the production of samples of blood and urine to determine the level of alcohol or drugs present in a person's body;
- the taking of forensic samples, including samples not included in Part 1D;
- the taking of identification evidence;
- the carrying out of searches of the person; or
- the retention or use of forensic material or information obtained as a result of activities described above.

41.206 MCCOC's discussion paper explained the provision as follows:

Clause 87 preserves the right to [sic] for police or other officials to ask people to undergo forensic procedures for other purposes. So, for example, there might be separate legislation dealing with the reception of prisoners into prison where fingerprints are required for identification purposes. Clause 87 makes it clear that the Model Bill is not meant to over-ride legislation which performs other purposes. Another example is the taking of samples for blood alcohol analysis.¹⁸⁸

41.207 The Revised Explanatory Memorandum to the Crimes Amendment (Forensic Procedures) Bill 2001 commented on the section as follows:

This proposed amendment ensures that the operation of any Commonwealth, State or Territory laws allowing the carrying out of breath analysis or a breath test or the production of samples of blood and urine to determine the level of alcohol or drugs, if any, present in a persons blood is not limited or excluded by Part 1D.¹⁸⁹

Issues and problems

41.208 Part 1D of the *Crimes Act* establishes a legislative framework for police investigators to obtain a genetic sample from a suspect, serious offender or volunteer for law enforcement purposes. The intention of MCCOC and the Commonwealth Parliament appears to have been that this framework should provide the sole authority for the collection of genetic samples in these circumstances—however, s 23YU appears to permit police investigators to obtain samples by other lawful means. In addition, in the absence of any specific prohibition on the collection of discarded genetic samples, there currently appears to be no limitation on this practice.

188 Model Criminal Code Officers Committee, *Model Forensic Procedures Bill and the Proposed National DNA Database, Discussion Paper* (1999) Standing Committee of Attorneys-General, 111.

189 Revised Explanatory Memorandum to the Crimes Amendment (Forensic Procedures) Bill 2001 (Cth) [214].

41.209 Dr Jeremy Gans has argued that Part 1D of the *Crimes Act* should require that investigators must rely on ‘forensic procedures’ under the legislation rather than informal techniques, or tricks, to obtain a suspect’s genetic sample.

The use of informal methods for gathering DNA is invasive of people’s legitimate expectations of privacy (such as the freedom to drink, spit or blow their nose without incriminating themselves). Moreover, the continuing non-regulation of these methods is an invitation to investigators to avoid the inconveniences of following the formal procedures set out [in] Divisions 4 and 6. Further, the regular use of these methods will lend plausibility to fears that the police may plant a person’s DNA sample at a crime scene. If investigators have a genuine reason to seek DNA covertly ... then they should have to obtain a warrant, akin to other covert surveillance operations.¹⁹⁰

Inquiry’s views

41.210 Part 1D of the *Crimes Act* provides a detailed regulatory framework for obtaining a genetic sample in this context, and the Inquiry considers that allowing police to obtain a sample outside this framework could significantly undermine not only adherence to the framework but also the procedural and other safeguards existing within it.

41.211 One approach is to rely on the existing provisions regarding admissibility of evidence obtained in Division 7 of Part 1D of the *Crimes Act*, or the *Evidence Act 1995* (Cth). The Inquiry considers this would not provide sufficient safeguard against the informal collection of genetic samples. In practice, the police could obtain a suspect’s cigarette butt and have the sample analysed and compared with a crime scene sample. If the person is excluded as a suspect, or if the person is implicated but a formal sample is subsequently taken pursuant to the *Crimes Act* provisions, the admissibility of the covertly obtained sample would not arise as an issue in court proceedings.

41.212 The Inquiry considers there is a public interest in ensuring that Part 1D of the *Crimes Act* is not undermined by the use of informal means to collect genetic samples for law enforcement purposes. The Australian community has a right to expect that the private and sensitive information contained within their genetic samples is used only as specifically permitted by legislation or other court authority.

41.213 Therefore, the Inquiry recommends that the Commonwealth should amend the *Crimes Act* to provide that, with the exception of crime scene samples, law enforcement officers may collect genetic samples only from: (a) the individual concerned, pursuant to Part 1D; or (b) a stored sample, with the consent of the individual concerned (or someone authorised to consent on his or her behalf), or pursuant to a court order.

190 J Gans, *Submission to the Independent Review of Part 1D (Forensic Procedures) of the Crimes Act 1914 (Cth)*, 10.

Recommendation 41–13. The Commonwealth should amend the *Crimes Act* to provide that, with the exception of crime scene samples, law enforcement officers may collect genetic samples only from: (a) the individual concerned, pursuant to Part 1D; or (b) a stored sample, with the consent of the individual concerned (or someone authorised to consent on his or her behalf), or pursuant to a court order.

Deceased persons

41.214 Part 1D of the *Crimes Act* provides for an index of unknown deceased persons on a DNA database system. This index holds DNA profiles derived from the forensic material of deceased persons whose identities are unknown.¹⁹¹ The index matching table permits broad index matching with most of the other indexes in a DNA database system.¹⁹²

41.215 Part 1D also provides a time period after which a deceased person's profile must be removed from the database system.¹⁹³ The 'identifying period' for a profile derived from forensic material taken from a deceased person whose identity is known is defined as such period as the Commissioner orders the responsible person to retain that information.¹⁹⁴ Therefore, where an unknown deceased person is identified through a DNA database system, or by some other means, the Commissioner appears to retain a discretion as to the destruction of that information.

41.216 It is possible that DNA analysis in this context could be extended in future to include the collection of genetic samples from known deceased persons for the purpose of obtaining 'cold hits' on the DNA database system. For example, in the United Kingdom, the police have the power to seize a dead body or take a sample from it if there is reasonable suspicion that the deceased person may have committed an offence.¹⁹⁵

41.217 There is a public interest in the resolution of outstanding offences; however, some form of regulation or oversight also may be necessary to maintain the dignity of the dead, and to protect the genetic privacy of living close relatives. As this matter has not previously been canvassed, the Inquiry does not feel it can make a recommendation at this stage.

191 *Crimes Act 1914* (Cth) s 23YDAC.

192 Ibid s 23YDAF(1). The unknown deceased persons index can only be matched with the volunteers (limited purposes) index if it is within the purpose for which the volunteer provided his or her forensic material.

193 However, the section is ambiguously drafted as the only use of the term 'identifying period' is in relation to volunteers.

194 *Crimes Act 1914* (Cth) s 23YDAG(4).

195 Human Genetics Commission, *Inside Information: Balancing Interests in the Use of Personal Genetic Data* (2002), London, 147.

42. Identification of Deceased Persons

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Introduction

42.1 DNA identification testing is increasingly used to identify human bodies and remains where the deceased cannot be identified by traditional means. This form of testing involves comparing DNA taken from the body of the deceased with DNA taken from his or her personal items (for example, a comb, hairbrush or toothbrush) or from close biological relatives. Newborn screening cards may be used in some circumstances.¹ Several forms of DNA analysis are used, involving nuclear and mitochondrial DNA.²

42.2 DNA testing has been used to identify the victims of aeroplane crashes, and to resolve historical questions—such as the identity of the American ‘unknown soldier’ from the Vietnam war, and the remains of Tsar Nicholas II of Russia and members of his family, who were executed in 1918. More recently, it has been used to identify the victims of the terrorist attack on the World Trade Center in New York on 11 September 2001; and the nightclub bombings in Bali, Indonesia on 12 October 2002, which killed 88 Australians.³

42.3 While recognising the benefits of this form of testing in identifying bodies and remains for families of the deceased, this form of DNA testing raises certain ethical and other concerns.

1 These are also known as ‘Guthrie cards’. See Ch 19 for more detail.

2 See Ch 39 for more detail on these forms of DNA analysis.

3 See below for more detail.

Identification of missing and deceased persons

Crimes Act provisions

42.4 Part 1D of the *Crimes Act 1914* (Cth) (*Crimes Act*) regulates the conduct of forensic procedures on relatives of missing or deceased persons and the matching of their DNA profiles against the DNA obtained from unidentified human bodies or remains. This facilitates the identification of missing or deceased persons, and mass disaster victims, within the federal jurisdiction.

42.5 Blood relatives of missing or deceased persons fall within the ‘volunteers’ provisions of Part 1D of the *Crimes Act*. As a volunteer, a relative should:

- be given the information prescribed for volunteers prior to giving consent to a forensic procedure;
- have a choice whether his or her DNA profile will be stored in the volunteers (limited purposes) index or the volunteers (unlimited purposes) index of a DNA database system; and
- have the right to withdraw consent to retention of the forensic material or the DNA profile, subject to a magistrate’s order that it be retained.⁴

42.6 In practice, blood relatives of missing or deceased persons are not always dealt with according to these provisions. While they are treated as ‘volunteers’ for the purpose of collecting a DNA sample, the Act provides for their profiles to be stored in the ‘missing persons’ index of a DNA database system rather than in a ‘volunteers’ index,⁵ and their profiles may not be destroyed until all relevant identifications have been made.⁶ For example, the AFP advised that all of the profiles stored on the DVI Database—including the bombing victims’ relatives’ profiles—would remain on the database until all of the matching was complete.⁷

42.7 The index-matching table in Part 1D of the *Crimes Act* permits unrestricted matching between profiles held in the missing persons index and all other indexes on a DNA database system—including the crime scene index.⁸

4 *Crimes Act 1914* (Cth) ss 23XWR, 23XWV.

5 The ‘missing persons index’ means an index of DNA profiles obtained from the forensic material of missing persons and volunteers who are blood relatives of missing persons. The missing person’s forensic material may be obtained from his or her personal effects, such as a hairbrush, comb or toothbrush: *Ibid* s 23YDAC.

6 Australian Federal Police, *Consultation*, Canberra, 7 November 2002.

7 *Ibid*.

8 *Crimes Act 1914* (Cth) s 23YDAF(1).

Other legislation

42.8 Where a mass disaster or other incident occurs outside Australia, the Commonwealth would have primary responsibility for identification of the victims; where an incident occurs within Australia, the matter is more likely to fall within the jurisdiction of the State or Territory in which the incident occurred.

42.9 Each Australian State and Territory has implemented forensic procedures legislation that permits the collection of DNA samples in the context of a criminal investigation.⁹ This legislation generally would extend to the use of DNA in identifying missing persons, and human bodies and remains.

42.10 In addition, each Australian jurisdiction has implemented coronial legislation providing for coronial inquests into 'reportable deaths'. An individual death, or multiple deaths occurring out of a mass disaster or terrorist attack, could therefore be the subject of a coronial inquest.¹⁰

Issues and problems

42.11 The Inquiry has identified two primary concerns with the current legislative framework for obtaining genetic samples from relatives of missing persons.

42.12 First, relatives of missing persons are treated as 'volunteers' for the purpose of collection of genetic samples, but not for the purpose of storage or matching their profiles on a DNA database system. Therefore, the prescribed information given to these persons before they consent to a forensic procedure would be inaccurate in advising them that their profiles will be held in a volunteers index and, perhaps, in relation to withdrawing consent to retention of the forensic material or the DNA profile.

42.13 Second, if relatives' profiles are held in the missing persons index of a DNA database system, they may be lawfully subjected to unrestricted matching against any other index on the system; for example, to obtain 'cold hits' with profiles obtained from unrelated crime scenes. This constitutes a use unrelated to the purpose for which the sample was collected and could, in future, deter relatives of mass disaster victims or other missing or deceased persons from assisting police investigators in their inquiries.

42.14 In practice, the latter concern has not arisen in relation to the DNA database system established to identify the Bali bombing victims (see below for more detail). As this database holds four indexes only, unrestricted matching within the database cannot generate 'cold hits' with unrelated crime scene profiles. During the Parliamentary debate on the Crimes Amendment Bill 2002 (Cth), it was said that the

9 *Crimes (Forensic Procedures) Act 2000* (NSW); *Crimes (Forensic Procedures) Act 2000* (ACT); *Criminal Law (Forensic Procedures) Act 1998* (SA); *Crimes Act 1958* (Vic); *Criminal Investigation (Identifying People) Act 2002* (WA); *Police Powers and Responsibilities Act 2000* (Qld); *Police Administration Act 1978* (NT); *Forensic Procedures Act 2000* (Tas).

10 See Ch 39 for more detail.

new database has been created alongside the national CrimTrac criminal DNA database, but is an entirely separate database. We have been given absolute assurances by the government that the two will be quarantined from each other and that there will be no sharing of information between them.¹¹

42.15 However, as Part 1D of the *Crimes Act* permits unrestricted matching, it is at least technically possible—and lawful—to match a relative’s profile against an unrelated crime scene profile, irrespective of whether the profiles have been uploaded onto a computerised database.

Submissions and consultations

42.16 DP 66 proposed that Part 1D of the *Crimes Act* should be amended to delete reference to the DNA profiles of blood relatives of missing persons from the definition of the ‘missing persons index’.¹²

42.17 Most of the submissions supported this proposal.¹³ The New South Wales Police Service supported the proposal, noting that in New South Wales

the DNA profiles of blood relatives of missing persons will be placed on the Volunteers (Limited Purposes) Index, not the Missing Persons Index. The only DNA profiles that will be placed on the Missing Persons Index are those of the missing persons themselves.¹⁴

42.18 The Law Institute of Victoria commented that

for the reasons set out in the Discussion Paper, we believe there is a public interest in protecting the privacy of individuals who volunteer their bodily samples, for example following mass disasters or the disappearance of a relative. It is vital that relatives are not reluctant to notify police of a disappearance, or to assist in the identification process, due to concern about other uses to which their volunteered genetic information may be put.¹⁵

42.19 The Office of the Federal Privacy Commissioner supported the proposal, commenting that:

The events in Bali in October 2002 have demonstrated the public interest in having access to DNA profiles to identify victims of catastrophic events. In the absence of uniform legislation across all jurisdictions, the Commonwealth Government found it

11 Commonwealth of Australia, *Parliamentary Debates*, House of Representatives, 22 October 2002, 8047 (The Hon Daryl Melham MP).

12 Australian Law Reform Commission and Australian Health Ethics Committee, *Protection of Human Genetic Information*, DP 66 (2002), ALRC, Sydney, Proposal 36–7.

13 Victoria Police, *Submission G203*, 29 November 2002; Office of the Privacy Commissioner (NSW), *Submission G257*, 20 December 2002; Centre for Genetics Education, *Submission G232*, 18 December 2002; Human Genetics Society of Australasia, *Submission G267*, 20 December 2002; Institute of Actuaries of Australia, *Submission G224*, 29 November 2002; Centre for Law and Genetics, *Submission G255*, 21 December 2002; Association of Genetic Support of Australasia, *Submission G284*, 25 December 2002; National Legal Aid, *Submission G314*, 19 February 2003; Office of the Federal Privacy Commissioner, *Submission G294*, 6 January 2003; NSW Police Service, *Submission G306*, 22 January 2003; Law Institute of Victoria, *Submission G275*, 19 December 2002.

14 NSW Police Service, *Submission G306*, 22 January 2003.

15 Law Institute of Victoria, *Submission G275*, 19 December 2002.

necessary to enact urgent legislation providing for access to the national DNA database by law enforcement officers for identification purposes. Federal and state police officers collected DNA samples from the relatives of persons missing in Bali and, together with the victims' samples, they were stored in a separate database to enable profile-matching. These measures demonstrated the importance placed on ensuring that, both legally and technologically, it would be extremely difficult to link this database with any other database. The community has a demonstrable interest in law enforcement agencies maintaining the integrity of these processes.

Careful thought and attention should continue to be given to those legal and technical measures, which will ensure that the DNA profiles of all volunteers collected for this, or any future, catastrophe are not included in an inappropriate index or used for any unrelated forensic purposes.¹⁶

42.20 The Queensland Government suggested that further consideration be given to the adverse effect of the proposal on the ability to locate missing persons.

The deletion of blood relatives of missing persons from the definition of 'missing persons index' in *Crimes Act* (Cth) will adversely affect the Commonwealth's ability to match DNA profiles to locate a missing person. For example, the Commonwealth's Volunteers (unlimited purpose) index does not facilitate a match with suspects and other volunteers.¹⁷

42.21 Finally, the Commonwealth Attorney-General's Department commented that the Sherman review¹⁸ is currently considering this issue; and the Joint Standing Committee of Attorneys-General/Australasian Police Ministers Council Working Group is expected to consider improvements to the Model Forensic Procedures Bill in 2003.¹⁹

New South Wales approach

42.22 The New South Wales Legislative Council's Standing Committee on Law and Justice highlighted this issue in its review of the New South Wales forensic procedures legislation. The Committee recommended that the New South Wales Attorney-General seek to address the problem of matching crime scene and DNA profiles of relatives of missing persons.²⁰

42.23 The New South Wales Parliament subsequently passed the *Crimes (Forensic Procedures) Amendment Act 2002* (NSW),²¹ which provided (among other things) that:

- a person giving a sample for the purposes of the missing persons index must first be told that his or her DNA profile may be matched against all of the other indexes on the database; and

16 Office of the Federal Privacy Commissioner, *Submission G294*, 6 January 2003.

17 Queensland Government, *Submission G274*, 18 December 2002.

18 The Sherman review is the independent review into Pt 1D of the *Crimes Act 1914* (Cth), which is chaired by Mr Tom Sherman. See Ch 39 for more detail.

19 Commonwealth Attorney-General's Department, *Submission G228*, 12 December 2002.

20 Legislative Council Standing Committee on Law and Justice, *Review of the Crimes (Forensic Procedures) Act 2000*, Report No 18 (2002), Parliament of NSW, Sydney [6.18]–[6.20], Rec 44.

21 The Act received Assent in June 2002, and is due to commence operation on 1 June 2003.

- information about a match between the person's profile and any other DNA profile on the database cannot be used in proceedings against that person. If a match implicates the person in the commission of another offence police must carry out a fresh forensic procedure in order to obtain an admissible sample.

Inquiry's views

42.24 The New South Wales approach permits unrestricted matching between profiles on the missing persons index and every other index on a DNA database system, but ensures that relatives of missing or deceased persons must be informed that such matching may be conducted. It appears to provide a safeguard for the relative by providing that evidence of any match is not admissible in proceedings against the person—however, this safeguard is more apparent than real. Having been alerted to the 'cold hit', police investigators need only obtain a second sample from the relative in accordance with the forensic procedures legislation. If evidence of the initial 'cold hit' is considered sufficient grounds to authorise the second sample, the apparent safeguard would have no real effect.

42.25 There is a strong public interest in the resolution of crime. However, this needs to be balanced against the public interest in ensuring that persons are not reluctant to notify the police of a disappearance, or to assist in identifying victims of mass disasters and other missing persons, through fear of implicating themselves in outstanding or future offences. The Inquiry considers that in circumstances where relatives volunteer their forensic material for the specific purpose of identifying a missing or deceased relative, the balance should be tipped in favour of protecting those persons from self-incrimination in outstanding offences.

42.26 Therefore, the Inquiry does not propose to adopt the New South Wales approach but instead recommends that the Commonwealth Parliament should amend Part 1D of the *Crimes Act* to delete reference to the DNA profiles of blood relatives of missing persons from the definition of the 'missing persons index'. As noted above, this proposal was supported by most of the submissions.

42.27 As a result of this recommendation, relatives of missing or deceased persons should be treated as volunteers in relation to the collection, use, storage and destruction of their forensic material and DNA profiles under Part 1D of the *Crimes Act*. The missing persons index of a DNA database system should contain only profiles derived from the forensic material of persons who are missing or presumed dead,²² while their relatives' profiles should be stored in the volunteers (limited purposes) index to restrict the index matching to the specific purpose for which the sample was collected.

42.28 As volunteers, relatives also should have the right to withdraw consent to the retention of their forensic material or any information obtained from it. The Inquiry considers that in most cases a relative would agree to an open-ended retention period—for example, until the human remains found at a mass disaster site have been identified

22 For example, DNA profiles created from bodily samples found on the missing or deceased person's personal effects, such as a toothbrush, hairbrush or other items.

to the extent that it is reasonably possible to do so. However, where a relative requests the destruction of his or her forensic material, investigators would still have the option of requesting the victim's own personal item or newborn screening card (if available) for the purpose of DNA comparison.

42.29 While the Queensland Government expressed concern that this proposal might adversely affect the Commonwealth's ability to match profiles to locate a missing person, the Inquiry does not consider that this is the case. For example, if an unidentified blood sample is found at a crime scene that could belong to an unknown victim of crime, the profile obtained from the sample could be stored in the crime scene index, the missing persons index, or the unknown deceased persons index of a DNA database system.

Recommendation 42–1. The Commonwealth should amend the *Crimes Act 1914* (Cth) (*Crimes Act*) to delete reference to the DNA profiles of genetic relatives of missing persons from the definition of the 'missing persons index'.

Disaster victim identification

Uses of DNA disaster victim identification

World Trade Center

42.30 To date, the largest single use of DNA identification testing has been to identify the victims of the terrorist attack on the World Trade Center in New York City on 11 September 2001.²³

42.31 Some of the victims were identified from dental records, X-rays, fingerprints, scars, rings and other pieces of jewellery—however, most of the remains were not capable of visual or other traditional forms of identification. Therefore, shortly after the attack, police investigators asked the victims' families for personal items belonging to the missing and, in some cases, for DNA samples from the family members themselves.²⁴

42.32 The New York medical examiner's office co-ordinated the DNA identification testing program. Due to the volume of bodily samples found, some of the identification work was contracted out to private laboratories. Generally, the laboratory operated by the examiner's office extracted DNA from the tissue samples found at the site, while the New York State Police Laboratory extracted DNA from the victims' personal effects, and family members' samples. Both laboratories forwarded the DNA

23 On 11 September 2001, terrorists hijacked two commercial aeroplanes and flew them into the two World Trade Center towers in New York City. The towers imploded shortly after impact, resulting in an estimated 2,795 deaths.

24 L. Altman, 'Now, Doctors Must Identify the Dead Among the Trade Center Rubble', *The New York Times*, 25 September 2001. See also D Chen, 'Grim Scavenger Hunt for DNA Drags on for September 11 Families', *The New York Times*, 9 February 2002.

extracts to two private laboratories—Myriad Genetics Laboratories and Celera—for analysis. Three laboratories were chosen to test 5% of all samples as a quality control for the tests performed at the private laboratories.²⁵

42.33 In February 2002, it was reported that—because many of the police officers who initially collected personal items and samples had not been properly trained to do so—many samples were inadequate for identification. Victims' families were asked to provide further tissue samples for identification.²⁶

42.34 By 30 November 2002, 1,439 of the estimated 2,795 victims had been identified, including 709 through DNA analysis alone. At that time, the medical examiner held 19,932 body parts in storage, 5,404 of which had been identified.²⁷

Bali nightclub bombings

42.35 DNA identification testing was also used to identify the victims of the terrorist bombing of two nightclubs in Bali, Indonesia on 12 October 2002. Shortly after the bombings, a Joint Investigation Team consisting of Indonesian, Australian and other law enforcement officials was established. The Australian Federal Police's (AFP) function within the Team included the collection of forensic material from suspects, crime scenes, unknown deceased persons, and from the personal items and blood relatives of the missing persons.²⁸ The Inquiry understands that the AFP co-ordinated the forensic identification of the victims, and this was primarily done in the AFP's forensic laboratory in Canberra.²⁹

42.36 The identification process reportedly involved four stages of examination: first, examination for physical characteristics, such as height, sex, weight, hair and eye colour; second, examination for unnatural markings such as tattoos; third, examination of dental records; and finally, DNA analysis. Due to the nature of the blast, it was estimated that 70% of the victims would need to be identified through DNA analysis.³⁰

42.37 Rather than use the National Criminal Investigation DNA Database system for identification of the bombing victims, the Commonwealth Government established a new DNA database for disaster victim identification (DVI Database).³¹

25 L Altman, 'Now, Doctors Must Identify the Dead Among the Trade Center Rubble', *The New York Times*, 25 September 2001.

26 D Chen, 'Grim Scavenger Hunt for DNA Drags on for September 11 Families', *The New York Times*, 9 February 2002.

27 D Chen, 'New Test for 9/11 ID's Is Moving Much Slower Than Scientists Hoped', *The New York Times*, 30 November 2002.

28 Explanatory Memorandum to the Crimes Amendment Bill 2002 (Cth), 1.

29 S Gibbs and T Allard, 'Coroner Prepares for Role in Identification', *The Sydney Morning Herald*, 23 October 2002.

30 J Watts and J Aglionby, 'Long and Agonising Task to Identify Bodies', *The Guardian* (London), 15 October 2002.

31 CrimTrac, *Consultation*, Canberra, 7 November 2002.

42.38 Out of the 221 missing or deceased in Bali, 182 have been identified—including 88 Australians. DNA identification played an important role in this effort: 43 DNA matches were obtained through the DVI Database, while 67 matches were obtained through a kinship database provided by Queensland Health.³²

Proposed use for military personnel

42.39 The Australian Defence Force (ADF) has advised the Inquiry that it is considering introducing a policy of collecting a DNA sample from each ADF member for the purpose of identification of human remains. It is proposed that DNA samples would be held in a repository for use in identifying members killed in action or otherwise.³³

42.40 The United States' Department of Defense already collects DNA samples from every service member on active duty or in the reserve armed forces on a mandatory basis. The samples are collected for the purpose of identifying the remains of war casualties. The samples are stored in the Department's DNA Repository for a period of 50 years but may be destroyed at the request of the donor when he or she leaves the military.³⁴

General comments

42.41 The Bali bombings in October 2002 represented the first mass disaster requiring the Commonwealth to undertake large scale DNA victim identification testing. Obviously, this was an unforeseen incident necessitating a rapid response by the Commonwealth government and the federal, state and territory police services. It was necessary to identify the victims' remains as quickly as possible so that they could be released to their families for burial. The Inquiry has not heard any significant concerns regarding the operation of the DNA identification program.

42.42 Any future mass disaster—or terrorist attack—whether within or outside Australia, could again result in the need to identify hundreds, or possibly thousands, of victims. While the Commonwealth's legislative and administrative response to the Bali bombing incident was rapid and effective in those circumstances, the Inquiry considers there is a need to adopt a more structured framework for the identification of mass disaster and other victims in the event that such need arises in future.

32 CrimTrac, *Disaster Victim Identification Assistance*, Commonwealth of Australia, <www.crimtrac.gov.au/dnabali.htm>, 14 March 2003.

33 Department of Defence, *Consultation*, Canberra, 6 November 2002.

34 E Reiter, 'The Department of Defense DNA Repository: Practical Analysis of the Government's Interest and the Potential for Genetic Discrimination' (1999) 47 *Buffalo Law Review* 975, 983–984. For more information about the DNA Repository, see A Stevens, 'Arresting Crime: Expanding the Scope of DNA Databases in America' (2001) 79 *Texas Law Review* 921.

Current law and practice

42.43 After the Bali bombings, the Commonwealth Parliament amended the *Crimes Act*, inserting a new Division 11A into Part 1D of the Act.³⁵ The new Division 11A applies in relation to the Bali bombings of 12 October 2002 and any incident occurring outside Australia and Norfolk Island that the Minister determines in writing to be an incident in relation to which the Division applies.³⁶ Before making this determination, the Minister must be satisfied that one or more Australian citizens or residents have died in or as a result of the incident and it is appropriate in the circumstances for the Division to apply in relation to the incident.³⁷

42.44 Division 11A contains a definition of ‘permitted purpose’, meaning the purpose of identifying an unidentified person who died in or as a result of an incident to which Division 11A applies, and/or the purpose of conducting a criminal investigation in relation to such an incident.³⁸

42.45 Where Division 11A applies, it modifies the existing provisions of Part 1D of the *Crimes Act* to permit:

- Commonwealth, State and Territory officials to access a Commonwealth DNA database system for a ‘permitted purpose’;³⁹
- information held on a DNA database system to be disclosed to Australian and foreign law enforcement agencies for a ‘permitted purpose’;⁴⁰
- matching within the unknown deceased persons index to identify all the body parts belonging to each victim;⁴¹ and
- the identification of a victim to relatives and friends.⁴²

42.46 The Commonwealth Government established the DVI Database for the identification of the Bali bombing victims. The DVI Database is operated by the CrimTrac agency on behalf of the AFP, and contains four indexes—an unknown deceased persons index; a missing persons index (containing profiles obtained from missing persons’ personal items and blood relatives); a crime scene index; and a suspects index.⁴³ As the database has only four of the indexes specified in the legislative definition of a ‘DNA database system’, it technically falls outside that definition.⁴⁴

35 The *Crimes Amendment Act 2002* (Cth) received assent on 23 October 2002.

36 *Crimes Act 1914* (Cth) s 23YUF(1).

37 Ibid s 23 YUF(2)–(3). A determination is a disallowable instrument.

38 Ibid s 23YUE.

39 Ibid s 23YUG.

40 Ibid s 23YUI(1).

41 Ibid s 23YUH.

42 Ibid s 23YUI(2).

43 CrimTrac, *Consultation*, Canberra, 7 November 2002.

44 See Ch 43 for more detail.

Collection and use of information

Crimes Act provisions

42.47 Part 1D of the *Crimes Act* provides for the reciprocal enforcement of orders for carrying out forensic procedure between the Commonwealth and participating state and territory jurisdictions.⁴⁵

42.48 The Minister may enter into arrangements with the responsible Ministers of participating jurisdictions for the establishment and maintenance, in one or more of those jurisdictions, of a register of orders for the carrying out of forensic procedures made under Part 1D or corresponding laws of participating jurisdictions.⁴⁶ A person is authorised to carry out the forensic procedure authorised by a registered order anywhere in the Commonwealth. However, a state or territory police officer must comply with Division 6 of Part 1D of the *Crimes Act* when carrying out a forensic procedure on behalf of the Commonwealth.⁴⁷

42.49 The Inquiry understands that the AFP was responsible for collecting DNA samples of the Bali bombing victims from the scene of the incident. State and territory police collected forensic material from the missing persons' personal items and blood relatives from around Australia, and forwarded these to the AFP laboratory for analysis. In some cases, the States and territories may have analysed these samples in their own laboratories before forwarding the sample and profile to the AFP.⁴⁸

42.50 The AFP has advised the Inquiry that the state and territory police acted as agents of the Commonwealth in collecting the forensic material from victims' relatives, however no formal agency agreement was entered into between the jurisdictions. These police complied with the federal *Crimes Act* in collecting the samples, but where state and territory forensic procedures legislation provided higher protections or safeguards, these jurisdictions also complied with their own legislation—thus, state and territory police complied with the requirements of the federal legislation.⁴⁹

Issues and problems

42.51 The Inquiry is concerned about the lack of any formal arrangement between the Commonwealth and state and territory police services for the collection and analysis of DNA samples. This could lead to uncertainty amongst state and territory police services about the scope of their authority to retain or use those samples and profiles within their own jurisdictions.

45 *Crimes Act 1914* (Cth) Div 11. A participating jurisdiction is a State or Territory in which there is a corresponding law in force. A corresponding law means a law relating to the carrying out of forensic procedures and DNA databases that substantially corresponds to Pt 1D of the *Crimes Act* or is prescribed by the regulations: s 23YUA.

46 Ibid s 23YUB(1).

47 Ibid s 23YUC(1).

48 Explanatory Memorandum to the Crimes Amendment Bill 2002 (Cth), 1.

49 Australian Federal Police, *Consultation*, 11 December 2002.

42.52 For example, the Northern Territory forensic procedures legislation permits the Commissioner to maintain databases of any information obtained from carrying out intimate or non-intimate procedures under that Act or any other Act.⁵⁰ Hypothetically, if the Northern Territory police collect and/or analyse a DNA sample from a relative of a mass disaster victim on behalf of the Commonwealth, they could decide to upload the profile into the Northern Territory DNA database before forwarding the sample and profile to the AFP. While this might be lawful within the Northern Territory jurisdiction, it would fall outside the nature of their agency relationship.

42.53 The retention or use of a DNA sample or profile within the state or territory jurisdiction would constitute a secondary use unrelated to the purpose for which the relative provided the sample. This could have significant privacy implications where that jurisdiction does not have the same legislative safeguards as the federal *Crimes Act*.

Inquiry's views

42.54 The Inquiry considers that the arrangements by which the Commonwealth authorises the States and Territories to act on its behalf in collecting, using, storing or destroying genetic samples (or profiles) for the identification of missing and deceased persons require clarification. Formalisation of these arrangements should better protect the genetic privacy of the relatives of missing and deceased persons by ensuring that the State or Territory does not retain their samples or profiles after forwarding the information to the Commonwealth. It also should provide greater transparency regarding the process, in order to ensure public confidence. In particular, the arrangements should clarify the scope of the States' and Territories' authority in acting on behalf of the Commonwealth in these matters.

42.55 One existing means of formalising these arrangements would be through the use of ministerial arrangements pursuant to s 23YUB of the *Crimes Act*. However, there may be concerns about the constitutionality of such arrangements in light of the High Court's decision in *R v Hughes*.⁵¹ Therefore, the Commonwealth should be conscious of the constitutional constraints, if any, of the exercise of functions by the officers of one polity on behalf of another polity.⁵²

Recommendation 42–2. The Commonwealth, States and Territories should clarify the arrangements under which police officers of one jurisdiction are authorised to act on behalf of another jurisdiction in collecting, using, storing or destroying forensic material from a missing or deceased person (or from a genetic relative of a missing or deceased person).

⁵⁰ *Police Administration Act 1978* (NT) s 147(1).

⁵¹ *R v Hughes* (2000) 202 CLR 535.

⁵² See generally, Australian Law Reform Commission, *The Judicial Power of the Commonwealth: A Review of the Judiciary Act 1903 (Cth) and Related Legislation*, Report 92 (2001), ALRC, Sydney.

Sharing information

Crimes Act provisions

42.56 Part 1D of the *Crimes Act* provides that the Minister may enter into agreements with participating jurisdictions for sharing information on a DNA database system for the purpose of criminal investigations or prosecutions. Information from the Commonwealth DNA database system may be transferred to a participating jurisdiction for the purpose of the investigation of, or proceedings in respect of, an offence against the law of that jurisdiction (or vice versa).⁵³ As this provision is limited to the context of criminal investigations, it may not always authorise the transfer of information for the purpose of disaster victim identification.

42.57 Shortly after the Bali bombings, the Commonwealth Government expressed concern at the absence of a legal framework for permitting the States and territories to access the Commonwealth's DVI Database, or for the Commonwealth to disclose the results of forensic comparison to these jurisdictions. The Explanatory Memorandum to the Crimes Amendment Bill 2002 (Cth) commented:

Under the current provisions, and in the absence of arrangements between the jurisdictions, States and Territories cannot access their DNA database system for the purpose of transferring DNA profiles to the Commonwealth and the Commonwealth cannot disclose the information held (eg, the results of a matching) to the States and Territories.⁵⁴

42.58 As noted above, the new Division 11A addresses these concerns through new access and disclosure provisions permitting, among other things:

- Commonwealth, state and territory officials to access information stored on a national DNA database system (or a state or territory DNA database system) for the purpose of forensic comparison under the relevant jurisdiction's forensic procedures legislation, where that comparison is for a 'permitted purpose',⁵⁵ and
- the disclosure of information held on a DNA database system to law enforcement agencies, foreign law enforcement agencies, Interpol or any other agency or body prescribed by the regulations, if the disclosure is for a 'permitted purpose'.⁵⁶

42.59 Division 11A is limited to incidents occurring outside of Australia and Norfolk Island, and the amended access and disclosure provisions are accordingly limited to these contexts.

⁵³ *Crimes Act 1914* (Cth) s 23YUD.

⁵⁴ Explanatory Memorandum to the Crimes Amendment Bill 2002 (Cth).

⁵⁵ *Crimes Act 1914* (Cth) s 23YUG.

⁵⁶ *Ibid* s 23YU.

Issues and problems

42.60 The process of identifying the Bali bombing victims highlighted several problems with the current regulatory framework. First, the lack of harmonisation among the Australian jurisdictions' forensic procedures legislation has slowed the process of negotiating ministerial agreements for the sharing of information between jurisdictions. Second, the legislation permitted the sharing of information for criminal investigations or prosecutions only: it did not necessarily extend to sharing information for the purpose of disaster victim identification.

42.61 The new Division 11A of Part 1D of the *Crimes Act* authorises the transfer of information between the Commonwealth and the States and Territories for a 'permitted purpose', being the identification of a person who died as a result of an incident occurring outside Australia. However, these access and disclosure provisions may not sufficiently safeguard the privacy of that information once it has been transferred.

42.62 For example, information stored on a national DNA database system may be transferred to a State or Territory, regardless of whether the latter jurisdiction is a 'participating jurisdiction' within the meaning of Part 1D of the *Crimes Act*, or whether they have entered into a ministerial agreement for the sharing of information. This is contrary to the policy underlying the Model Bill framework.

42.63 As a result, the Commonwealth could disclose information stored on the DVI Database to a jurisdiction does not correspond with Part 1D of the *Crimes Act* in any way. While the disclosure must be for a 'permitted purpose' there is no legislative or administrative safeguard limiting that jurisdiction's potential secondary or unrelated use of that information.

42.64 While s 23YUD(2) provides that information transferred from one jurisdiction to another must not be recorded, or maintained in any identifiable database after the forensic material must be destroyed in the first jurisdiction, this is limited to information shared for the purpose of a criminal investigation or proceedings.⁵⁷ Therefore, the second jurisdiction technically could place information obtained from the DVI Database on its own database for the purpose of 'cold hit' matching, provided that this is lawful under its own legislation.

42.65 The same concerns arise in relation to disclosing information held on the DVI Database to foreign law enforcement agencies. While the access and disclosure may only be conducted for a 'permitted purpose' as defined by the legislation, there is no safeguard against potential secondary uses of that information by the jurisdiction or law enforcement agency to which access is given, or the information is disclosed.

42.66 In its submission, the New South Wales Council for Civil Liberties (NSWCCL) expressed the concern that DNA taken from individuals within New South Wales could be shared with overseas jurisdictions that have insufficient legislative protections regarding the privacy of the information. The NSWCCL also noted that:

⁵⁷ See Ibid ss 23YUD(1), (2).

Concerns have been raised with our council from some of those people providing DNA samples about the future implications. They are concerned about whether that DNA information can or will be used for any other purpose than the Bali identification process, and what protections, if any, are in place to ensure it is not disclosed or misused by the Indonesian authorities ... The concern of this council is that while consent may have been obtained for this process the consent may not be fully informed consent ... It is difficult to imagine that people desperately trying to recover their loved one's bodies are able to comprehend the negative consequences of providing this information in an uncontrolled manner.⁵⁸

42.67 The *Privacy Act* sets out specific obligations that apply when an organisation transfers personal information outside Australia. Briefly, NPP 9 prohibits the transfer of personal information unless the recipient of the information is subject to a law, binding scheme or contract that upholds principles substantially similar to the NPPs, or the organisation has taken reasonable steps to ensure that the information will not be dealt with inconsistently with the NPPs. However, the AFP is not bound by the NPPs and there is no equivalent IPP regarding the transborder flow of personal information.

Inquiry's views

42.68 The Inquiry recommends that the Commonwealth amend Division 11A of Part 1D of the *Crimes Act* to provide that where information stored on the DNA database system is accessed by, or disclosed to, a person for a 'permitted purpose', this information only may be used for that purpose. This would clarify that the State, Territory or foreign jurisdiction to which the information is disclosed may not use the information for any secondary or unrelated purpose.

42.69 The Inquiry also recommends that s 23YUD of the *Crimes Act* be amended to broaden the scope of ministerial agreements for the sharing of information between participating jurisdictions to include the purpose of identification of missing or deceased persons. This would provide an additional safeguard by ensuring that any safeguards for information shared between jurisdictions would apply equally to information shared in this context. Section 23YUD(2) would also apply. This provides that any information transferred under Division 11A must not be recorded, or maintained in any database of information that may be used to discover the identity of a person or to obtain information about an identifiable person at any time after Part 1D of the *Crimes Act* requires the forensic material to which it relates to be destroyed.

42.70 Finally, where information stored on a DNA database system is disclosed to Interpol or any foreign agency, the Commonwealth must take reasonable steps to ensure that the information transferred will not be held, used or disclosed by the recipient inconsistently with the national minimum standards established in accordance with Recommendation 40–1.

58 New South Wales Council for Civil Liberties, *Submission G312*, 10 February 2003, 10 February 2003.

Recommendation 42–3. The Commonwealth should amend Division 11A of Part 1D of the *Crimes Act* to provide that where information stored on a DNA database system is accessed by, or disclosed to, a person for a ‘permitted purpose’, the information may be used only for that purpose.

Recommendation 42–4. The Commonwealth should amend s 23YUD of the *Crimes Act*, which regulates inter-jurisdictional sharing, to extend its coverage beyond criminal investigations to include the identification of missing or deceased persons.

Recommendation 42–5. Where information stored on a DNA database system is disclosed to Interpol or any foreign agency, the Commonwealth must take reasonable steps to ensure that the information transferred will not be held, used or disclosed by the recipient inconsistently with the national minimum standards established in accordance with Recommendation 40–1.

43. DNA Database Systems

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DNA database systems

National DNA database systems

43.1 As of February 2003, the Commonwealth had established three DNA databases for law enforcement purposes. The National Criminal Investigation DNA Database (NCIDD system) was established in June 2001 to facilitate intra-jurisdictional matching of DNA profiles, and inter-jurisdictional matching of profiles between participating jurisdictions, for law enforcement purposes. The Disaster Victim Identification database (DVI Database) was established in October 2002 to identify the victims of the terrorist bombings in Bali, Indonesia, and other similar overseas incidents. Finally, the Australian Federal Police (AFP) operates its own DNA database for law enforcement purposes.

43.2 The CrimTrac Agency operates the NCIDD system and the DVI Database pursuant to Part 1D of the *Crimes Act 1914* (Cth) (*Crimes Act*). CrimTrac is an executive agency of the Commonwealth Government, established as a national law enforcement information system for Australia's police services. The agency is

underpinned by an inter-governmental agreement, signed by all of the Australian police ministers.¹

Regulation of DNA database systems

Crimes Act provisions

43.3 Part 1D of the *Crimes Act* regulates the use, storage, disclosure and removal of information held on a DNA database system. A 'DNA database system' is a database containing specified indexes of DNA profiles and information that may be used to identify the person from whose forensic material each DNA profile was derived.²

43.4 Part 1D of the *Crimes Act* contains the following provisions for the use, storage and disclosure of information on a DNA database system:

- a list of permitted purposes for which a person may access information stored on the DNA database system, and an offence where a person accesses the information other than as permitted;³
- a list of permitted purposes for which a person may disclose information stored on the DNA database system, and an offence where a person recklessly or intentionally discloses the information other than as permitted;⁴
- a table of permitted index matching, and an offence if a person recklessly or intentionally causes matching that is not permitted;⁵
- offences where a person recklessly or intentionally causes any identifying information about a person obtained from forensic material to be recorded or retained in a DNA database system after the forensic material is required to be destroyed;⁶
- a provision permitting the Minister to enter into arrangements with Ministers of participating jurisdictions for the sharing of information from a DNA database system for the purpose of the investigation of, or proceedings in respect of, an offence;⁷ and
- provisions permitting access to, and disclosure of, information held on a DNA database system in relation to 'incidents' occurring outside Australia.⁸

1 *Agreement for the Establishment and Operation of 'CrimTrac', A National Law Enforcement Information System for Australia's Police Services, 13 July 2000*, <www.crimtrac.gov.au/misc/ct_agreement.PDF>, 20 February 2003.

2 *Crimes Act 1914* (Cth) s 23YDAC.

3 *Ibid* s 23YDAE.

4 *Ibid* s 23YO.

5 *Ibid* s 23YDAF.

6 *Ibid* s 23YDAG.

7 *Ibid* s 23YUD.

8 *Ibid* ss 23YUG, 23YUI. See Ch 42 for more detail.

Other regulation

43.5 The Inquiry considers it likely that DNA profiles are covered by the *Privacy Act 1988* (Cth) (*Privacy Act*). A DNA profile contains a set of numbers and a sex gene which, when combined with information held by the forensic laboratory, is capable of identifying the individual from whom the profile was obtained. As such, the Inquiry considers that DNA profiles fall within the definition of ‘personal information’, being information about an individual whose identity can reasonably be ascertained from the information.⁹

43.6 Therefore, the Information Privacy Principles (IPPs) would apply to those DNA profiles held by AFP forensic laboratories and stored on a DNA database system; and the AFP and CrimTrac generally must comply with the IPPs regarding the storage and security, use and disclosure of, and access to, these profiles.¹⁰ The federal Privacy Commissioner reviews agencies’ compliance with the IPPs. Alternatively, the National Privacy Principles would apply to profiles held by independent forensic laboratories. Relevant state and territory privacy legislation may apply to any profiles held by state and territory health departments or forensic laboratories, or on state or territory operated DNA databases.

43.7 Finally, the National Association of Testing Authorities, Australia (NATA) accreditation requirements for forensic science include provisions addressing the information security of forensic material received and analysed by the laboratory.¹¹ In practice, the confidentiality of information held in computerised files would be protected by the use of security clearances, passwords, and audit trails.

Permitted index matching

43.8 Part 1D of the *Crimes Act* provides an index matching table that specifies which indexes of a DNA database system may be matched against each other.¹² The Inquiry has heard concerns that these index matching provisions may be unduly permissive, contrary to the information privacy rights of those providing forensic material in the context of a criminal investigation.

Issues and concerns

43.9 The main privacy concern expressed with the index matching rules is the provision for unlimited index matching between the suspects index and the crime scene index—to generate ‘cold hits’ that may identify a suspect for an unresolved offence.

9 See *Privacy Act 1988* (Cth) s 6(1).

10 However, the IPPs contain exceptions in relation to law enforcement, and in some circumstances these may apply.

11 See National Association of Testing Authorities (Australia), *AS ISO/IEC 17025: 1999 Australian Standard: General Requirements for the Competence of Testing and Calibration Laboratories* (1999), NATA, Sydney; National Association of Testing Authorities Australia, *ISO/IEC 17025 Application Document: Supplementary Requirements for Accreditation in the Field of Forensic Science* (2000), National Association of Testing Authorities, Australia.

12 *Crimes Act 1914* (Cth) s 23YDAF(1).

43.10 This form of index matching constitutes a use of suspects' genetic information that is different from the purpose for which it was collected. For example, a person may be one of a number of suspects in relation to an offence. The suspect might readily submit to a forensic procedure for the purpose of eliminating him or herself from suspicion in relation to that offence. However, despite being eliminated from suspicion the person's DNA profile currently could remain on the suspects index of the DNA database system for a period of 12 months—during which time it could be subject to unlimited matching against the crime scene index.

43.11 The Model Criminal Code Officers Committee (MCCOC) opposed unrestricted matching between these indexes while it was developing the Model Forensic Procedures Bill 2000 (Model Bill). The MCCOC discussion paper proposed that a suspect's profile should be matched only against the crime scene profiles relating to the particular investigation in which the person is a suspect:

The suspects profile can be matched against anything on the crime scene index but unlike the serious offenders index, should not be available for unrestricted comparison as part of a pool of suspects that can be matched with profiles from any index. For example, it is not intended that the whole index of suspects could be compared with all crime scene profiles. To do so would go far beyond the purpose for which the forensic material was obtained in the first place and may expose suspects to random searchings by police anywhere in the country who are quite separate from the particular investigation and who are just fishing for matches on the crime scene index.¹³

43.12 However, the final draft of the Model Bill permitted unrestricted matching between these indexes.¹⁴ MCCOC did not provide any explanation for this change in approach, but the rationale appears to have been to maximise the resolution of unsolved crimes by increasing the potential for 'cold hits' between suspect and crime scene profiles. Dr Jeremy Gans has commented on this process as follows:

An extreme instance of the doubtful decision-making process underlying the matching provisions is the major policy reversal between May 1999 and February 2000 on the question of whether profiles taken from unconvicted suspects can be compared on mass to crime scene profiles to generate 'cold hits' ... This question is, arguably, the most important policy issue in the contemporary politics of DNA databases.¹⁵

Submissions and consultations

43.13 In DP 66, rather than prohibiting cold hit matching in relation to suspects, the Inquiry proposed that opportunities for such matching should be limited by minimising the period of retention for suspects' genetic information.¹⁶ DP 66 proposed

13 Model Criminal Code Officers Committee, *Model Forensic Procedures Bill and the Proposed National DNA Database, Discussion Paper* (1999) Standing Committee of Attorneys-General, 93.

14 See Model Criminal Code Officers Committee, *Final Draft: Model Forensic Procedures Bill and the Proposed National DNA Database* (2000), Standing Committee of Attorneys-General, Canberra cl 82(1).

15 J Gans, 'The Quiet Devolution: How the Model Criminal Code Officers' Committee Botched New South Wales' DNA Law' (2002) 14(2) *Current Issues in Criminal Justice* 210, 218.

16 Australian Law Reform Commission and Australian Health Ethics Committee, *Protection of Human Genetic Information*, DP 66 (2002), ALRC, Sydney [36.118].

that forensic procedures legislation should provide that forensic material taken from a suspect, and any information obtained from its analysis, must be destroyed as soon as practicable after the person has been eliminated from suspicion, or police investigators have decided not to proceed with a prosecution in relation to that investigation.¹⁷

43.14 A number of the submissions supported the proposal.¹⁸ The Law Institute of Victoria commented that to retain an innocent suspect's profile on a national DNA database in an index that permits comparison with unrelated criminal investigations constitutes 'an unjustifiable double standard'.¹⁹

43.15 Several submissions supported the proposal but raised certain concerns with it. For example, the Commonwealth Attorney-General's Department submitted that the proposal raised a number of practical concerns:

The 12 months period is a guarantee that the material will be destroyed after a set time period. The proposal would allow the police to retain material for an indefinite period provided they were able to establish that an investigation was still on foot or a decision not to prosecute had not been made. In essence, such a proposal means that the decision when to destroy material is left entirely in the hands of the police.²⁰

43.16 The Office of the Federal Privacy Commissioner (OFPC) noted that:

It may not always be possible ... to find and destroy all records relating to that sample and the profile, which are capable of identifying the suspect. Hence it is recommended that, in the case of 'eliminated suspects', the investigative officers and laboratory staff undertake to use their best endeavours to destroy all DNA-related information capable of identifying that suspect. In the event that the personal information of an eliminated suspect is improperly obtained or used or disclosed, that information should remain subject to the laws of evidence relating to improperly obtained evidence. The person mishandling that information should also be the subject of criminal sanctions.²¹

43.17 Dr Jeremy Gans commented that the proposal did not achieve much on its own unless 'cold hit' matching were abolished. He also noted the difficulty in defining the 'end of suspicion' for the purpose of managing destruction of the genetic sample.²²

43.18 The AFP noted that its forensic laboratory already has difficulty managing the destruction dates for the genetic samples it holds. The AFP advised that, in practice, suspects' profiles are entered into the AFP's DNA database system with a default destruction date of 12 months from the date the sample was obtained. Two months before the destruction date, the computer reminds the laboratory of the coming date. The laboratory checks the file and contacts the police investigator, who has two

17 Ibid, Proposal 36–11.

18 Department of Human Services South Australia, *Submission G288*, 23 December 2002; Human Genetics Society of Australasia, *Submission G267*, 20 December 2002; Centre for Genetics Education, *Submission G232*, 18 December 2002; Office of the Victorian Privacy Commissioner, *Submission G266*, 20 December 2002.

19 Law Institute of Victoria, *Submission G275*, 19 December 2002.

20 Commonwealth Attorney-General's Department, *Submission G228*, 12 December 2002.

21 Office of the Federal Privacy Commissioner, *Submission G294*, 6 January 2003.

22 I Freckelton and J Gans, *Consultation*, Melbourne, 21 October 2002.

months to inform them of the status of the sample and profile. If they do not do so the profile will be destroyed on the destruction date. For reasons of workload, the AFP considers it would be easier to manage an automatic destruction date—for example, ‘12 months after the sample is taken’—or at least to monitor destruction dates on a periodic basis.²³

43.19 The New South Wales Police Service (NSW Police Service) opposed the proposal on the basis that monitoring investigations to determine appropriate destruction dates would be extremely time-consuming. The Police also noted that:

In certain cases, investigators may decide not to proceed with a prosecution because of lack of sufficient evidence. However, it is impossible to predict what additional evidence may come to light in subsequent months. It is considered that the retention of forensic material for 12 months is justified in such circumstances as the suspect has not been conclusively eliminated from the investigation and 12 months is sufficient time for additional evidence to come to light or for a matter to be re-opened, if necessary, and further investigated.²⁴

Inquiry’s views

43.20 While the submissions generally supported the Inquiry’s proposal, several submissions raised concerns regarding its practical implementation. The Commonwealth Attorney-General’s Department noted that the proposal appeared to permit the retention of the material for a period longer than the current legislative maximum. In order to clarify this ambiguity, the Inquiry has amended the recommendation to reflect the current maximum retention period. Therefore, a suspect’s profile must be destroyed by the end of 12 months from the date of the forensic procedure, subject to any extension granted by a magistrate under s 23YD of the *Crimes Act*.

43.21 The AFP and the NSW Police Service expressed concerns about the potential increase in workload for laboratories. The Inquiry acknowledges these concerns but considers that the recommendation adequately accommodates them. The Inquiry understands that, at the federal level, computer databases currently alert laboratories of an upcoming deadline for destruction in relation to a suspect’s sample. The investigator must then notify the laboratory whether the destruction date has been extended pursuant to the *Crimes Act*. Under the Inquiry’s recommended approach, a police investigator would instead be required to notify the laboratory when the suspect has been eliminated from suspicion, or the investigator has otherwise decided not to prosecute the person in relation to that offence. As the police investigator would have carriage of the investigation, the Inquiry considers this would not be an onerous responsibility.

23 Australian Federal Police, *Consultation*, Canberra, 7 November 2002. See also Australian Federal Police, *AFP National Guideline for Conducting a Commonwealth Forensic Procedure — Part 1D Crimes Act 1914* (2001), AFP Pt D.

24 NSW Police Service, *Submission G306*, 22 January 2003. See also Victoria Police, *Submission G203*, 29 November 2002.

43.22 Once the laboratory has been notified of the destruction date in relation to a suspect's forensic material and profile, the Inquiry considers that regular dates for destruction of batches of profiles—for example, fortnightly or monthly—would satisfy the requirement that they be destroyed 'as soon as practicable'.

43.23 The Inquiry recommends that the Commonwealth should amend the *Crimes Act* to provide that forensic material taken from a suspect, and any information obtained from its analysis, must be destroyed as soon as practicable after the person has been eliminated from suspicion, or police investigators have decided not to proceed with a prosecution against that person in relation to that investigation. However, in any event, the forensic material and information must be destroyed no later than: (a) 12 months after the material was taken or the information obtained; or (b) the period stipulated in an order made under s 23YD of the *Crimes Act*.

Recommendation 43–1. The Commonwealth should amend the *Crimes Act 1914* (Cth) (*Crimes Act*) to provide that forensic material taken from a suspect, and any information obtained from its analysis, must be destroyed as soon as practicable after the person has been eliminated from suspicion, or police investigators have decided not to proceed with a prosecution against that person in relation to that investigation. However, in any event, the forensic material and information must be destroyed no later than: (a) 12 months after the material was taken or the information obtained; or (b) the period stipulated in an order made under s 23YD of the *Crimes Act*.

Unregulated profile matching

Definition of a DNA database system

43.24 Part 1D of the *Crimes Act* defines a 'DNA database system' as a database (whether in computerised or other form and however described) containing the following indexes of DNA profiles: a crime scene index, a missing persons index, an unknown deceased persons index, a serious offenders index, a volunteers (unlimited purposes) index, a volunteers (limited purposes) index, a suspects index, and information that may be used to identify the person from whose forensic material each DNA profile was derived; and a statistical index; and any other index prescribed by the regulations.²⁵

43.25 To fall within the definition of a 'DNA database system', a DNA database must include *all* listed indexes of profiles. Any database that does not hold all of these indexes appears to fall outside the definition, and therefore outside the legislative framework.

²⁵ *Crimes Act 1914* (Cth) s 23YDAC.

Issues and problems

43.26 DP 66 noted that some DNA databases established for federal law enforcement purposes might fall outside the legislative definition of a DNA database system.²⁶ If this is the case, these databases would not be subject to regulation under Part 1D of the *Crimes Act*, thereby undermining the procedures and safeguards established in this legislation.

43.27 For example, the DVI Database contains four indexes only—an unknown deceased persons index; a missing persons index (containing profiles obtained from missing persons' personal items and blood relatives); a crime scene index; and a suspects index.²⁷ As the database has only four of the specified indexes it technically falls outside the definition of a DNA database system. In addition, the AFP operates its own DNA database for criminal investigation purposes that also might not accord exactly with the definition of a DNA database system.

43.28 Further, while hard copy databases (for example, a manila folder or a ring binder) could come within the legislative definition, this would only be the case where the database holds the prescribed indexes, and separates the profiles into these indexes.

43.29 In its submission, the New South Wales Council for Civil Liberties also expressed concern about the historical establishment and maintenance of unofficial databases in that jurisdiction:

The NSW Police Force has a long history of holding forensic and other information in a variety of formats, databases and sub groupings. It is clear from other forensic information such as fingerprinting that this is rarely destroyed or removed from police databases, even when there is a requirement to do so ... To our knowledge, police operate a myriad different paper databases containing information about criminal suspects ... they continue to keep fingerprint information after it is required to be destroyed and removed from police information databases ... It is our view that DNA profiles and databases will be manipulated in a similar manner.²⁸

43.30 Dr Jeremy Gans also raised concerns about the legislative definition in relation to the New South Wales forensic procedures legislation:

This definition is clumsily drafted and unnecessarily complex. As presently written, a database of DNA profiles that lacked just one of the listed indexes would fall outside of the definition (and, hence, regulation by Part 11) The definition should, at the very least, be modified to ensure that a database is covered if it contains any of the indexes in para (a). Better still, the definition should be framed independently of the individual indexes it contains, eg as a database (however described and formed)

26 Australian Law Reform Commission and Australian Health Ethics Committee, *Protection of Human Genetic Information*, DP 66 (2002), ALRC, Sydney [36.120].

27 CrimTrac, *Consultation*, Canberra, 7 November 2002.

28 New South Wales Council for Civil Liberties, *Submission G312*, 10 February 2003.

containing identifiable DNA profiles maintained for the purposes of criminal investigation and prosecution.²⁹

43.31 In its review of the New South Wales forensic procedures legislation, the New South Wales Legislative Council Standing Committee on Law and Justice suggested that the legislation could be clarified, either by prohibiting any database that does not fit the description of a DNA database system; or by redefining the term to include all databases, however formulated. The Committee recommended the former option, suggesting that this would prevent the proliferation of databases.³⁰

Submissions and consultations

43.32 DP 66 proposed that forensic procedures legislation should be amended to prohibit the establishment or maintenance of any DNA database that does not fit within the legislative definition of a DNA database system.³¹ Most of the submissions and consultations supported the proposal.³² Concerns particularly emphasised the need to eliminate unregulated profile matching. The Commonwealth Attorney-General's Department commented that:

It is correct to say ... that parallel systems with different regulatory frameworks and safeguards are contrary to the intention of creating an integrated national DNA database system. Community confidence in that system will be undermined if unregulated matching is allowed to occur, particularly where it involves profiles obtained from samples taken under legislation with few safeguards.³³

43.33 The Law Institute of Victoria supported the proposal, commenting that:

The resulting risk for unofficial and unregulated databases to be abused must be checked ... The confusion which would inevitably result from multiple databases with non-uniform administration is another reason to prohibit establishment and maintenance other than under s23YDAC.³⁴

43.34 Several police services expressed concern about the potential impact of the proposal on their existing DNA databases. For example, the Victoria Police submitted that:

29 Legislative Council Standing Committee on Law and Justice, *Review of the Crimes (Forensic Procedures) Act 2000*, Report No 18 (2002), Parliament of NSW, Sydney, citing Submission by Dr Jeremy Gans [6.27].

30 Ibid [6.36], Rec 46. The NSW Standing Committee also recommended a more comprehensive approach to database restrictions.

31 Australian Law Reform Commission and Australian Health Ethics Committee, *Protection of Human Genetic Information*, DP 66 (2002), ALRC, Sydney, Proposal 36–12.

32 Office of the Privacy Commissioner (NSW), *Submission G257*, 20 December 2002; Commonwealth Attorney-General's Department, *Submission G228*, 12 December 2002; Institute of Actuaries of Australia, *Submission G224*, 29 November 2002; Office of the Victorian Privacy Commissioner, *Submission G266*, 20 December 2002; Office of the Federal Privacy Commissioner, *Submission G294*, 6 January 2003; Law Institute of Victoria, *Submission G275*, 19 December 2002; Human Genetics Society of Australasia, *Submission G267*, 20 December 2002.

33 Commonwealth Attorney-General's Department, *Submission G228*, 12 December 2002.

34 Law Institute of Victoria, *Submission G275*, 19 December 2002.

This proposal may not have taken into account the need to have another database for local matching based on local legislation (or lack of) that is not consistent to Commonwealth law. It is assumed that this proposal only refers to DNA profiles to be compared on NCIDD but it is not clear. If it is suggested that jurisdictions cannot maintain their own local databases, then Victoria Police disagrees with the proposal.³⁵

43.35 The NSW Police Service opposed the proposal, commenting that it is imperative that laboratories have the ability to create and maintain databases such as: employees' profiles, for reference in cases of suspected laboratory or crime scene contamination; databases created in the validation of new technology, and which are required to be maintained for the scrutiny of the wider scientific community; and databases relating to population genetics. They noted that the latter two databases would be expected to contain anonymised information.³⁶

43.36 Finally, the Queensland Government opposed the proposal, stating that it intends to retain the ability to operate its own DNA database and to operate outside the NCIDD system if required. This would enable Queensland to share information with the Northern Territory if the latter did not participate in the NCIDD system.³⁷

Inquiry's views

43.37 The Inquiry now considers that the better approach would be to amend the legislative definition so as to include all DNA databases used in the law enforcement context. This approach more effectively addresses concerns about unregulated profile matching for several reasons. First, a DNA database system established for a particular purpose might not need all of the indexes specified in the legislative definition. For example, a database established only to identify victims of a mass disaster would not need a crime scenes, suspects, serious offenders, or a statistical index.³⁸

43.38 Second, there may be privacy advantages in establishing separate DNA databases for specialised purposes, such as disaster victim identification, rather than using the established NCIDD system. For example, as the DVI Database is separate to the NCIDD system, this removes the opportunity for matching profiles belonging to relatives of missing and deceased persons with profiles stored on the general crime scene index. While such matching currently is permitted under the *Crimes Act*, the physical separation between the DNA databases would provide an added deterrent to such activity.

43.39 Finally, the approach is more inclusive, ensuring that all law enforcement DNA databases—whether in computerised or hard copy form—would fall within the regulatory framework.

35 Victoria Police, *Submission G203*, 29 November 2002.

36 NSW Police Service, *Submission G306*, 22 January 2003.

37 Queensland Government, *Submission G274*, 18 December 2002.

38 However, the Inquiry understands that a crime scenes and a suspects index were each added to the database for use in identifying the persons responsible for the Bali bombings: CrimTrac, *Consultation*, Canberra, 7 November 2002.

43.40 Therefore, the Inquiry recommends that the Commonwealth should amend the definition of a ‘DNA database system’ in the *Crimes Act* to mean ‘a database (however described and formed) containing identifiable DNA profiles maintained for law enforcement purposes’. The Inquiry emphasises, however, that it does not support a proliferation of DNA databases for law enforcement purposes.

Recommendation 43–2. The Commonwealth should amend the definition of a ‘DNA database system’ in the *Crimes Act* to mean a database (whether in computerised or other form and however described) containing identifiable DNA profiles maintained for law enforcement purposes.

Oversight of DNA database systems

Oversight of the CrimTrac agency

43.41 As noted above, the CrimTrac agency operates the NCIDD system and the DVI Database pursuant to Part 1D of the *Crimes Act*. The Australasian Police Ministers’ Council (APMC) is responsible for defining CrimTrac’s strategic directions and key policies, setting new initiatives, and appointing members to CrimTrac’s Board of Management.

43.42 CrimTrac’s operation of the NCIDD system is overseen by the CrimTrac User Advisory Group (UAG), which reports to the CrimTrac Board of Management. The UAG comprises senior police representatives, senior forensic laboratory managers, a representative from the National Institute of Forensic Science, a user representative representing the Biology Special Advisory Group of SMANZFL,³⁹ and a CrimTrac representative. The CrimTrac Board of Management comprises a representative of the Commonwealth, several State and Territory Police Commissioners and several specialist advisers.⁴⁰ The Chief Executive Officer reports to the federal Minister for Justice and Customs.

Federal Privacy Commissioner

43.43 As a Commonwealth agency, CrimTrac is bound by the IPPs in the *Privacy Act* in relation to any ‘personal information’ that it holds. The federal Privacy Commissioner has the power to investigate acts or practices of an agency that may breach an IPP in relation to personal information; and the Commissioner can also audit CrimTrac’s compliance with the IPPs.⁴¹

39 The Senior Managers of Australian and New Zealand Forensic Laboratories.

40 As of February 2003, the Commonwealth nominee was a senior officer of the Attorney-General’s Department; State and Territory nominees were the Police Commissioners of Tasmania, Western Australia, Victoria and New South Wales: CrimTrac, *CrimTrac: About Us*, <www.crimtrac.gov.au/aboutus.htm>, 19 February 2003.

41 See *Privacy Act 1988* (Cth) s 27(1).

43.44 CrimTrac advised the Inquiry that, in its view, the information held on the NCIDD system does not fall within the definition of ‘personal information’ for the purposes of the *Privacy Act*, because the information is held in a de-identified form.⁴² However, Privacy NSW commented that:

The current position of CrimTrac is that no personal information is held on the National DNA database and, because Crimtrac staff have no access to the identifying links, the database is therefore not subject to Privacy legislation. While this position may be technically correct at a given point in time, it could easily break down if illegitimate use is made of the database, or new uses arise, for instance a matching proposal arising out of a terrorist incident like the Bali bombing.⁴³

43.45 The Inquiry considers that information held on the NCIDD system (and other DNA database systems), would fall within the definition of ‘personal information’ under the *Privacy Act*. CrimTrac has advised the Inquiry that the data uploaded into the system generally consists of a DNA profile, a sample number, a case identifier, and the relevant jurisdiction.⁴⁴ While this information does not directly identify the person to whom the profile belongs, the laboratory that uploaded the profile is able to re-identify it. The information held by CrimTrac is information about an individual whose identity can reasonably be ascertained from it—therefore, it should be regarded as ‘personal information’ for the purposes of the *Privacy Act*.

Commonwealth Ombudsman

43.46 The Commonwealth Ombudsman has the power to investigate complaints about the administrative actions and decisions of Commonwealth departments and authorities. The Ombudsman also can initiate investigations on his or her own motion.⁴⁵ This provides a level of independent oversight of CrimTrac’s activities in operating a DNA database system.

Statutory independent review

43.47 The *Crimes Act* provides for an independent review of the operation of Part 1D as soon as possible after June 2002.⁴⁶ The independent review committee was chaired by Mr Tom Sherman AO (Sherman review), and included nominees of both the Commonwealth Ombudsman and the federal Privacy Commissioner.⁴⁷ As of March 2003, the report had not yet been tabled. If the report identifies inadequacies in respect of its review, a further independent review must be undertaken within two years of the tabling of the first report.⁴⁸

42 CrimTrac, *Consultation*, Canberra, 7 November 2002.

43 Office of the Privacy Commissioner (NSW), *Submission G257*, 20 December 2002.

44 CrimTrac, *Consultation*, Canberra, 23 August 2001. In some cases the destruction date is also included, as well as the minimum and maximum number of loci that must match before a ‘match’ is reported.

45 See *Ombudsman Act 1976* (Cth) s 5(1).

46 In addition, an independent review of the operation of the newly inserted Div 11A must be undertaken as soon as possible after October 2003: *Crimes Act 1914* (Cth) s 23YUK.

47 Ibid s 23YV(4).

48 Ibid s 23YV(5).

Oversight in participating jurisdictions

43.48 As noted in Chapter 7, some States and Territories have implemented information or health privacy legislation applicable to the handling of genetic information. This legislation applies privacy principles similar to those in the *Privacy Act* to ‘personal information’.⁴⁹ Most States and Territories also have established ombudsmen to investigate complaints into the activities of a government department, agency and police service within that jurisdiction.⁵⁰

43.49 In practice, where genetic samples or profiles have been mishandled, the person to whom the information relates could make a complaint to that jurisdiction’s Privacy Commissioner (where one exists), or the Ombudsman. However, that official may only investigate complaints regarding activities within that particular state or territory jurisdiction, rather than complaints crossing jurisdictional boundaries.

Oversight in overseas jurisdictions

43.50 Overseas jurisdictions have approached the operation and oversight of their DNA databases differently. In Britain, the National DNA Database is operated by the Forensic Science Service (FSS) under a Memorandum of Understanding with the Association of Chief Police Officers (ACPO), and with the support of the Home Office. The FSS also supplies profiles for the DNA database. The FSS Chief Executive and the ACPO DNA representative jointly chair the National DNA Database Board.⁵¹

43.51 The United Kingdom’s Human Genetics Commission (HGC) has commented that in order to increase public confidence in the National DNA Database and the sample and profiling operations, there is a need for broader and more independent representation, and more openness about future plans. The HGC suggested several possible ways to achieve this and recommended that, at the very least, the Home Office and the ACPO establish an independent body (which should include lay membership) to oversee the work of the National DNA Database custodian and the profile suppliers.⁵²

43.52 In the United States, the Federal Bureau of Investigations (FBI) operates the national Combined DNA Index Systems (CODIS) database, with an external public advisory committee that includes ethicists and a Supreme Court judge.⁵³ In 2001, the Department of Justice’s Office of the Inspector-General conducted an audit of the CODIS system. This involved reviewing documentation at FBI headquarters and at the National Institute of Justice, and conducting audits at eight CODIS-participating

49 For example, *Privacy and Personal Information Protection Act 1998* (NSW); *Health Records Act 2001* (Vic); *Information Privacy Act 2000* (Vic); *Health Records (Privacy and Access) Act 1997* (ACT).

50 For example, *Ombudsman Act 1989* (ACT); *Ombudsman Act 1974* (NSW); *Ombudsman (Northern Territory) Act*; *Ombudsman Act 2001* (Qld); *Ombudsman Act 1972* (SA); *Ombudsman Act 1978* (Tas); *Ombudsman Act 1973* (Vic).

51 Human Genetics Commission, *Inside Information: Balancing Interests in the Use of Personal Genetic Data* (2002), London, 152.

52 Ibid, 153.

53 Ibid.

laboratories.⁵⁴ Prior to that audit, the CODIS-participating laboratories were required to undergo an annual audit to determine if they were in compliance with the FBI's quality assurance standards, as well as to undergo biennial audits by outside agencies representing an accreditation or certification agency.⁵⁵

43.53 In Canada, the Royal Canadian Mounted Police operates the national DNA Data Bank, with an advisory committee that includes specialists in policing, science, genetics, medical ethics and law, and a representative of the Privacy Commissioner of Canada.⁵⁶ The DNA Data Bank is also subject to external oversight by the Privacy Commissioner.

Issues and problems

43.54 Chapter 40 outlines the privacy concerns regarding the sharing of genetic samples and profiles between the Australian jurisdictions for law enforcement purposes. The primary concern about such sharing of information is that the privacy and other safeguards existing in the jurisdiction in which the information was obtained could be undermined once the information has been transferred to a second jurisdiction.

43.55 Section s 23YUD(2) of the *Crimes Act* provides that, where information is transferred between the Commonwealth and another jurisdiction, the information must not be recorded or maintained in a database in an identifiable form after it is required to be destroyed in the original jurisdiction. However, it would be difficult to determine whether the information has been unlawfully retained if the second jurisdiction has inadequate oversight mechanisms.

43.56 The Commonwealth Ombudsman provides oversight of CrimTrac in its administration of the DNA database systems. As noted above, the federal Privacy Commissioner may have a more limited oversight role. However, once the Commonwealth has transferred information to a state or territory jurisdiction, federal oversight mechanisms generally will not extend to the handling of that information within the second jurisdiction.

The need for independent oversight

43.57 The Senate Legal and Constitutional Legislation Committee commented on the limited provision for independent monitoring of the database, the privacy aspects of the legislation, and the laboratories which process the samples for the NCIDD system,

54 The audit report concluded that the FBI needed to improve its oversight of CODIS-participating laboratories to ensure they were in compliance with the legislation, the FBI's quality assurance standards and the FBI requirements for laboratories participating in the national index; and that the FBI needed to initiate procedures to ensure that DNA profiles in CODIS are complete, accurate, and allowable: Federal Bureau of Investigation, *National DNA Index System*, United States, <www.fbi.gov/hq/lab/codis/national.htm>, 1 March 2003, Executive Summary, iii–iv.

55 Office of the Inspector General, *Audit Report: The Combined DNA Index System* (2001), Department of Justice, Washington, ii.

56 *Solicitor General Lawrence Macaulay Announces DNA Data Bank Advisory Committee*, Press Release, 28 September 2000.

in its report on the Crimes Amendment (Forensic Procedures) Bill 2001 (Cth).⁵⁷ The Committee recommended

an expansion of the role of the Federal Privacy Commissioner to include: oversight of the processes governing the retention of material on the DNA database; provisions for its destruction; oversight of the functioning of the new DNA database within the laboratory; and the operation of the database under the Bill.⁵⁸

43.58 During the second reading debate for the bill, the Minister for Justice and Customs, Senator Chris Ellison, recognised the desirability of ensuring the effective oversight of the overall operation of the NCIDD system:

Some serious issues have been raised in relation to the oversight of the national DNA database system. In addition to extending the legislation to include the Privacy Commission and the statutory review of Commonwealth forensic procedures, I have written to state and territory ministers with a view to getting agreement on cooperation between Commonwealth, state and territory bodies to ensure there is effective oversight of not only the operation of a DNA system within each jurisdiction but also the overall operation of the national system. This is best achieved by including formal independent monitoring mechanisms in the CrimTrac agreement with the states.⁵⁹

43.59 However, the Inquiry understands that APMC subsequently resolved *not* to support the imposition of additional accountability arrangements in relation to the operation of the NCIDD system.

Submissions and consultations

43.60 DP 66 proposed that forensic procedures legislation should be amended to provide for independent, coordinated and nationally consistent monitoring of the operation of the entire national DNA database, and in particular the interaction of the forensic procedures regimes operating in each jurisdiction that participates in the national DNA database system.⁶⁰

43.61 Several submissions and consultations supported the proposal.⁶¹ The Human Genetics Society of Australasia submitted that the proposal would assist in increasing public confidence in the quality of the operation of the database.⁶²

43.62 In its submission to the Sherman review, the Australian Privacy Foundation submitted that

⁵⁷ The Crimes Amendment (Forensic Procedures) Bill 2001 (Cth) was based on the Model Bill provisions.

⁵⁸ Senate Legal and Constitutional Legislation Committee, *Inquiry into Provisions of the Crimes Amendment (Forensic Procedures) Bill 2000* (2000), Canberra, Rec 4.

⁵⁹ Cited in Commonwealth Attorney-General's Department, *Submission G158*, 7 May 2002.

⁶⁰ Australian Law Reform Commission and Australian Health Ethics Committee, *Protection of Human Genetic Information*, DP 66 (2002), ALRC, Sydney, Proposal 36–13.

⁶¹ Institute of Actuaries of Australia, *Submission G224*, 29 November 2002; Office of the Privacy Commissioner (NSW), *Submission G257*, 20 December 2002; Centre for Genetics Education, *Submission G232*, 18 December 2002; Centre for Law and Genetics, *Submission G255*, 21 December 2002; Office of the Federal Privacy Commissioner, *Submission G294*, 6 January 2003.

⁶² Human Genetics Society of Australasia, *Submission G267*, 20 December 2002.

[a]ccountability arrangements featured prominently in the parliamentary debates and committee inquiries on the Bill in 1999. The then Minister gave certain assurances which do not all appear to have been implemented—particularly those involving inter-jurisdictional agreements on oversight and accountability. It is not good enough in matters that impinge on rights and liberties to simply accept the difficulty of achieving inter-governmental co-operation. In our view, until adequate oversight and accountability arrangements were in place, the DNA testing regimes and database should not have been allowed to ‘go live’.⁶³

43.63 The Office of the Victorian Privacy Commissioner urged the Inquiry to address this issue as a priority, commenting that:

The overall effect of the arrangements is that while control of CrimTrac is centralised, accountability for it is dispersed. It is mostly spread among various ombudsmen and privacy commissioners, where they have appropriate jurisdiction ...

In view of the interjurisdictional nature of the scheme it is vital that we have arrangements that ensure that the oversight function is like the system itself: interconnected and properly coordinated. These arrangements must also ensure that complaints can be investigated easily without jurisdictional barriers becoming a problem ...⁶⁴

43.64 The Office of the Victorian Privacy Commissioner noted that neither the Commonwealth nor any one participating State or Territory can adopt and enforce a role as independent auditor of the collection and handling of the data held on the NCIDD system. The submission urged that at a minimum, the accountability measures for the NCIDD system should address:

- a. clear, uniform, purpose-built statutory basis for the broader CrimTrac system, to be adopted by each participating jurisdiction;
- b. independent audit, investigation and complaints-handling mechanisms with appropriate powers and a duty to report directly to Parliaments;
- c. provision for redress;
- d. sanctions against misuse;
- e. provision for mandatory annual reporting, in a uniform fashion, by all participating jurisdictions, and by the National DNA Database administered by CrimTrac, as relevant ...⁶⁵

43.65 The OFPC commented that legislative arrangements for the nationally coordinated, independent and objective monitoring and oversight of the entire DNA forensic procedures system will be fundamental to assuring the public that there are privacy and accountability safeguards for the system.

63 Australian Privacy Foundation, *Submission to the Independent Review of Part 1D (Forensic Procedures) of the Crimes Act 1914 (Cth)*.

64 Office of the Victorian Privacy Commissioner, *Submission G266*, 20 December 2002.

65 Victoria Police, *Submission G203*, 29 November 2002.

No less important will be a seamless, transparent national framework for complaints-handling, audits and investigations. It will be critical that an individual complainant does not ‘slip between the cracks’, simply because their DNA profile has passed from one jurisdiction to another, with the attendant risks of breaches of privacy in the profile’s passage between jurisdictions. The audit and investigation functions should command a high level of independent analytical resources, capable of responding to the development in the forensic applications of DNA technology.

... the goal of complete uniformity of forensic procedures legislation may be some years away. Hence it may be advisable, at this stage, to use the existing mechanisms in a more strategic fashion. For example, the Ombudsman, Privacy Commissioners and auditors in each jurisdiction could work together to develop and agree upon reporting, auditing and complaint-handling mechanisms. The mechanisms can be designed to meet the imperatives of effective oversight and accountability. In the event of any further review of Part 1D, the success or otherwise of these measures could be evaluated. This would ensure that any inadequacies within the system can be identified and remedied by effective measures.⁶⁶

43.66 The OFPC noted that Part VIII of the *Telecommunications (Interception) Act 1979* (Cth) provides for the Commonwealth Ombudsman to inspect the AFP records at least twice a year to ensure compliance with legislative requirements for the retention and destruction of interception records:

The similarities in privacy intrusiveness between the investigative tools for telecommunications interception and the taking of forensic DNA samples, indicates that as independent oversight operates successfully for the former, it is surely similarly appropriate for the latter.⁶⁷

43.67 The Law Institute of Victoria agreed that the operation of the entire national DNA database must be coordinated and monitored independently.

In particular, there must be independent monitoring of the interaction of the forensic procedures regimes operating in each jurisdiction that participates in the national DNA database system. This is particularly important while jurisdictional inconsistencies exist, as seems likely.

The standards to which such monitoring and coordination occur must be open to public scrutiny and must be reviewed and upgraded on a regular basis, to maintain pace with the rapidly developing law and science in relation to DNA testing. We understand that the Federal Privacy Commissioner has oversight of all aspects of the DNA database which fall within that Commissioner’s jurisdiction. It is recommended that similar oversight capacity should be given to State privacy commissioners, either jointly or independently.⁶⁸

43.68 By contrast, several submissions considered that such monitoring should be a matter for each state and territory jurisdiction.⁶⁹ For example, the New South Wales Police Service commented:

66 Office of the Federal Privacy Commissioner, *Submission G294*, 6 January 2003.

67 Office of the Federal Privacy Commissioner, *Submission G143*, 22 March 2002.

68 Law Institute of Victoria, *Submission G275*, 19 December 2002.

69 Victoria Police, *Submission G203*, 29 November 2002; Queensland Government, *Submission G274*, 18 December 2002; NSW Police Service, *Submission G306*, 22 January 2003.

This proposal has already been raised in a number of forums, including the 41st Meeting of the Australasian Police Ministers' Council, and is not supported.

NSW Police believe that within NSW there are already ample monitoring/auditing systems (and complaint handling mechanisms) in place and that such systems are open and transparent. In the circumstances, it is the opinion of NSW Police that no further systems need to be put in place to monitor the operation of the NSW legislation. It is also considered that the standardisation of monitoring/auditing systems across jurisdictions is neither viable nor warranted.⁷⁰

Inquiry's views

43.69 When DP 66 was published, the NCIDD system was the only national DNA database operating pursuant to Part 1D of the *Crimes Act*. As the DVI Database has subsequently been established, the discussion below refers to oversight of these DNA database systems generally, rather than the NCIDD system only.

43.70 Many of the submissions acknowledged the need for greater oversight of the national DNA database system. Several of these highlighted the need for nationally co-ordinated, independent oversight in the form of ongoing monitoring and auditing of the information held by CrimTrac and by each jurisdiction.

43.71 As noted above, the Minister for Justice and Customs has recognised the desirability of ensuring the effective oversight of the national operation of the NCIDD system. The Minister suggested that this would be best achieved by including formal independent monitoring mechanisms in the CrimTrac agreement. CrimTrac has advised the Inquiry that it will enter into a Memorandum of Understanding (MOU) with each jurisdiction participating in the NCIDD system. A standard form has been drafted.

43.72 The Inquiry has not seen an official version of the draft MOU, and therefore cannot comment on its contents. In any case, the Inquiry has some reservations about this approach. First, an MOU is not a legally enforceable agreement. Second, the Inquiry considers that the public interest in ensuring the operation of transparent and accountable DNA database systems requires that any oversight must be independent of the organisations operating or using them, and must be publicly accountable.

43.73 The Inquiry noted above that several comparable overseas jurisdictions have provided for some measure of independent oversight of their DNA databases. For example, the FBI's operation of the CODIS database in the United States is subject to an external advisory committee including ethicists and a Supreme Court judge, and has been subjected to an audit by the independent Inspector-General of the Department of Justice.

43.74 The Inquiry recommends that CrimTrac's board of management should include independent members, such as nominees of the Office of the Federal Privacy Commissioner and the Commonwealth Ombudsman, legal academics and ethicists.

70 NSW Police Service, *Submission G306*, 22 January 2003.

While the operation of DNA database systems is only one of CrimTrac's responsibilities, the Inquiry considers that the public interest in ensuring a transparent, accountable database system requires such representation on its board.

43.75 Second, the operation of DNA database systems should be subject to ongoing monitoring by an independent body. This process should involve the auditing of CrimTrac and the forensic laboratories participating in a DNA database system to ensure that, for example, only permitted DNA profiles are uploaded on to these systems, profiles are uploaded into the correct indexes, and destruction dates are adequately managed in the jurisdiction in which the material was obtained and any jurisdictions to which it has been transferred. The Commonwealth Ombudsman or another independent body could carry out this auditing function. In the interests of transparency, the audit report should be made publicly available—for example, by requiring its tabling in Parliament.

43.76 Finally, the Inquiry recommends that the Australian Federal Police, in its annual report to Parliament, provide information on the number and category of samples obtained pursuant to Part 1D of the *Crimes Act* in that year; the authority under which these samples were obtained; and compliance with the required destruction dates for those samples and profiles.

Recommendation 43–3. The Commonwealth should expand CrimTrac's board of management to include independent members, such as nominees of the Office of the Federal Privacy Commissioner and the Commonwealth Ombudsman, legal academics and ethicists.

Recommendation 43–4. The Commonwealth should amend the *Crimes Act* to provide for a periodic audit, by an independent body, of the operation of all DNA database systems operating pursuant to the Act. The audit should include the forensic laboratories participating in the DNA database system and the audit report should be made publicly available.

Recommendation 43–5. In its annual report to Parliament, the Australian Federal Police should provide information on the number and category of samples obtained pursuant to Part 1D of the *Crimes Act* in that year; the authority under which these samples were obtained; and compliance with the required destruction dates for those samples and profiles.

44. Criminal Proceedings

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Introduction

44.1 DNA evidence may be used in criminal proceedings by either the prosecution or the defence. For example, the prosecution may seek to introduce DNA evidence of a match between a bodily sample found at a crime scene (or on or in the victim), and a sample taken from the defendant, to suggest the likelihood that the defendant committed the offence, or was at least present at the crime scene. The prosecution gives weight to evidence of such a match by offering statistical evidence of the relative probability that the sample found at the crime scene might have come from any person other than the defendant. Alternatively, the defence may seek to rely on DNA evidence to establish that the crime scene sample does not belong to the defendant or otherwise to dispute the prosecution’s evidence. This Chapter considers the particular ethical and privacy issues arising in relation to the use of DNA evidence in criminal proceedings.

44.2 A number of early Australian cases supported the exclusion of DNA evidence on the basis that the probative value of the evidence was, in the circumstances, outweighed by its prejudicial tendencies. More recently, courts have taken the view that conflicting expert opinions regarding the evidence are a factual matter for the jury to determine, subject to appropriate judicial direction.¹ The issues usually raised on appeal concern whether the trial judge properly exercised his or her discretion to admit the DNA evidence; whether the evidence was properly presented and explained by a qualified expert witness; and whether the trial judge gave the proper directions to the jury on the application of the evidence.²

Reliability of DNA evidence

44.3 The technical reliability of DNA evidence depends on a number of factors, including the quantity and quality of the sample analysed and the laboratory equipment or technique in analysing the sample.

Sample quantity and quality

44.4 A DNA sample is capable of analysis if there is sufficient quantity and reasonable quality of DNA present in the sample. polymerase chain reaction (PCR) based testing is relatively insensitive to degradation. However, the analysis of poor quality DNA samples may lead to uncertain results requiring substantial interpretation by the forensic scientist, and the potential for human error or varying opinions in the interpretation of the results.³ For example, where a DNA sample contains a mixture of several persons' DNA, and the forensic scientist does not account for this, the resulting DNA profile may be incorrect.

44.5 In *R v Juric*, the Victorian Court of Appeal highlighted the difference between evidence produced from a DNA sample that is:

- so pure and unadulterated that clear typings can be obtained at a large number of DNA sites, giving rise to statistical improbabilities running into the millions or even billions; and
- so adulterated and so old, and the testing process of amplification so powerful, that the typings produced are affected by complications which preclude an expert from giving an opinion as to the statistical probabilities.⁴

44.6 The Court of Appeal warned that:

1 B Saul, 'Genetic Policing: Forensic DNA Testing in New South Wales' (2001) 13(1) *Current Issues in Criminal Justice* 74, 96.

2 G Urbas, 'DNA Evidence in Criminal Appeals and Post-Conviction Inquiries: Are New Forms of Review Required?' (2002) 2 *Macquarie Law Journal* 141, 154.

3 D Kaye and G Sensabaugh Jr, 'Reference Guide on DNA Evidence' in Federal Judicial Center (ed), *Reference Manual on Scientific Evidence* (2000) Washington DC, 485, 505–506, 508.

4 *R v Juric* (Unreported, Supreme Court of Victoria, Court of Appeal, Winneke P, Charles and Chernov JJA, 29 May 2002) [20].

there are cases where the simplicity with which the [expert] opinion is expressed cannot be permitted to obscure the difficulties which have been encountered in the testing process. As in this case, those difficulties will include the poverty of the sample, its mixture with the bodily fluids of others, the age of the sample, the effect of the re-amplification process or the reliability of results and whether—because of or in spite of the encountering of these difficulties—any statistical probability can be pronounced as to the likelihood of other members of the community producing the same ‘match’.⁵

Laboratory performance

44.7 The accuracy of DNA analysis depends on the quality control and quality assurance procedures in the forensic laboratory. Quality control refers to measures to help ensure that each DNA analysis result (and its interpretation) meets a required standard of quality. Quality assurance refers to monitoring, verifying and documenting laboratory performance.⁶

44.8 Laboratory accreditation programs provide an important means of ensuring quality control and assurance in the DNA analysis process, by setting minimum standards and procedures, and providing external oversight of adherence to them. The National Association of Testing Authorities, Australia (NATA) operates a national system of laboratory accreditation for forensic science. In Chapter 41, the Inquiry recommended that the *Crimes Act 1914* (Cth) (*Crimes Act*) should provide that forensic analysis of genetic samples must be conducted only by laboratories accredited by NATA in the field of forensic science. This recommendation is equally important as a means of protecting the integrity of DNA analysis and results. However, laboratory accreditation alone cannot guarantee the integrity of DNA evidence in every instance.

Sample handling

44.9 It has been suggested that sample mishandling, mislabelling or contamination is more likely to compromise a DNA analysis than an error in the analysis.⁷ Contamination may occur at any stage of the collection, transport or analysis of a DNA sample. A DNA sample may be contaminated with other human DNA in a number of ways, including:

- the crime scene sample may contain a mixture of fluids or tissues from different persons due to the nature of the crime;
- the crime scene sample may be contaminated during sample handling at the crime scene or in the laboratory; or

5 Ibid [20].

6 D Kaye and G Sensabaugh Jr, ‘Reference Guide on DNA Evidence’ in Federal Judicial Center (ed), *Reference Manual on Scientific Evidence* (2000) Washington DC, 485, 509.

7 Ibid, 512.

- carry-over contamination may occur in PCR-based testing if the amplification products of one test are carried over into the mix for a subsequent PCR test.⁸

44.10 One reported example of sample contamination occurred in New Zealand when the DNA profile of an assault victim on the South Island was entered into the DNA data bank and matched the profiles obtained from two separate homicide scenes on the North Island. The DNA samples collected from each crime scene, including the assault, had been analysed in the same forensic laboratory. Police were satisfied the assault victim had not been at either of the homicide scenes at any time, and was not the offender. An independent inquiry could not find any conclusive explanation for the false positive results. The inquiry identified a number of potential sources of contamination, including bench contamination, instrument contamination, failure to observe certain protocols, and deliberate contamination. It concluded that, on the balance of probabilities, the results were caused by accidental contamination of the crime scenes samples during an early stage of processing at the laboratory.⁹

Alternative explanations for a match

44.11 A match between the crime scene profile and a defendant's profile does not prove that the defendant committed the particular offence. There may be several alternative explanations for a match, including the possibility that laboratory error resulted in a false positive; the sample was 'planted' at the crime scene, or was innocently left at the crime scene before, during or immediately after the offence; the sample originated from a close relative of the suspect; or that it originated from an unrelated person who, by coincidence, has the same DNA profile as the suspect.¹⁰

Error

44.12 Laboratory staff could make errors in conducting DNA analysis, in interpreting or reporting the results of the analysis, or in entering the resulting DNA profile into a DNA database system. This might result from a failure to comply with an established procedure, misjudgement by the scientist, or some other mistake.¹¹ While protocols and precautions can be introduced to minimise the opportunity for error during analysis or interpretation, the potential for human error cannot be fully eliminated.

44.13 For example, a clerical error at a Las Vegas forensic laboratory led to an innocent man being charged in relation to two separate sexual assaults in 2001. The man was being held in a detention centre for an immigration law violation when another inmate accused the man of raping him. DNA samples were taken from both

⁸ Ibid, 514–515.

⁹ Rt Hon Sir Thomas Eichelbaum and Sir John Scott, *Report on DNA Anomalies* (1999), Auckland. The report commented that while there was no direct evidence of contamination, they had eliminated all other hypotheses: [8.3].

¹⁰ See generally, D Kaye and G Sensabaugh Jr, 'Reference Guide on DNA Evidence' in Federal Judicial Center (ed), *Reference Manual on Scientific Evidence* (2000) Washington DC, 485, 520. See also Legislative Council Standing Committee on Law and Justice, *Review of the Crimes (Forensic Procedures) Act 2000*, Report No 18 (2002), Parliament of NSW, Sydney [3.54].

¹¹ D Kaye and G Sensabaugh Jr, 'Reference Guide on DNA Evidence' in Federal Judicial Center (ed), *Reference Manual on Scientific Evidence* (2000) Washington DC, 485, 510.

men and their profiles were entered into the state DNA database. The man's profile matched two unsolved sexual assaults, and he was charged with these offences. A DNA expert who examined the laboratory's records found that the man's name had been accidentally switched with his cellmate's name when the profiles were entered into the database, resulting in the false match.¹²

44.14 Misconduct by a forensic scientist could also lead to a false result. In the Queensland case of *R v Fitzherbert*, the appellant argued that he had been convicted as a result of deliberate fraud on the part of staff at the forensic laboratory that had conducted the DNA analysis for the prosecution. The Supreme Court of Queensland dismissed the appeal on the grounds that there was no evidence to support the allegation.¹³

Kinship

44.15 Close genetic relatives have more genes in common than unrelated persons.¹⁴ Therefore, it is possible that an innocent person's DNA profile could match the profile obtained from a crime scene, where the offender was in fact that person's sibling or other close relative.¹⁵ However, the chance of such a coincidence will decrease inversely as the number of loci examined along the DNA molecule increases.

Tampering

44.16 A suspect's DNA profile might match the profile found at a crime scene as a result of tampering with the crime scene, or subsequent substitution of DNA samples. This might occur where the actual offender, a police investigator, or another person deliberately leaves a suspect's genetic sample at the crime scene. Alternatively, it is possible that a suspect's sample might later be substituted for the actual crime scene sample to falsely implicate the suspect in the offence.

44.17 In the New South Wales case of *R v Lisoff*, the defendant alleged that DNA evidence implicating him in an assault had been planted on his clothes by police investigators after they took them into custody. The defence expert witness suggested that the blood found on the clothes appeared to be post-transfusion blood from the victim, which must have been deposited on the clothing *after* it was taken into police custody. The victim's blood sample had been stored in the same police exhibit room as the accused's clothing.¹⁶

12 G Puit, 'DNA Evidence: Officials Admit Error, Dismiss Case', *Las Vegas Review-Journal*, 18 April 2002.

13 *R v Fitzherbert* (Unreported, Supreme Court of Queensland, Pincus, Davies JJA and Moynihan J, 30 June 2000).

14 D Kaye and G Sensabaugh Jr, 'Reference Guide on DNA Evidence' in Federal Judicial Center (ed), *Reference Manual on Scientific Evidence* (2000) Washington DC, 485, 522–523.

15 For example, see *R v Watters*, (Unreported, Court of Appeal Criminal Division, Kay LJ; Silber J; Mellor HHJ, 19 October 2000).

16 *R v Lisoff* (Unreported, NSW Court of Criminal Appeal, Spigelman CJ, Newman and Sully JJ, 22 November 1999) [56]. See also G Urbas, 'DNA Evidence in Criminal Appeals and Post-Conviction Inquiries: Are New Forms of Review Required?' (2002) 2 *Macquarie Law Journal* 141, 156.

44.18 While practices and procedures for the collection of crime scene samples, and the handling of those samples during transfer to the laboratory, and at the laboratory itself, may seek to minimise the opportunity for tampering, it cannot be eliminated altogether.

Coincidence

44.19 As a DNA profile contains only a very small section of a person's DNA, it is possible that two persons might have the same DNA profile, by coincidence. This is particularly the case where the profile represents only a small number of loci along the DNA molecule. A widely reported example of a coincidental match occurred in Britain in 1999. A man was charged with burglary as a result of a 'cold hit' between his DNA profile and a crime scene profile on the United Kingdom's national DNA database. The profiles matched at six loci along the DNA molecule, but there was no match upon subsequent comparison at ten loci. The match probability had been reported as one in 37 million.¹⁷

44.20 At the time this incident was reported, the custodian of the national DNA database admitted that, in light of the number of profiles then stored on the database, testing at six loci would produce several hundred chance matches.¹⁸

Presentation of DNA evidence

Significance of a DNA match

44.21 Once a match has been reported between two profiles it is necessary to interpret the significance of the match in order to give weight to the evidence. Scientists usually present their statistical calculations in one of two ways.

44.22 First, the 'match probability' assesses the probability of the matching having occurred by coincidence. This is the probability that a person other than the suspect, randomly selected from the population, will have the same profile as that found at the crime scene. The smaller the probability, the greater the likelihood that the two samples came from the same person. The forensic scientist needs some knowledge of the frequency with which the alleles occur within a population, and population databases are used for this calculation.¹⁹

44.23 Second, the 'likelihood ratio' (LR) is the ratio of the probability of a match if the DNA in the crime scene sample and that from the suspect came from the same person, to the probability of a match if they came from different persons. For example, a likelihood ratio can be expressed as 'an LR of 1,000'. This means the probability that

17 L Lee, 'England Man to Sue Police Over DNA Mistake', *Newsbytes* (Minneapolis), 18 February 2000. The man had an alibi, lived 200 miles from the crime scene, and was suffering from Parkinson's disease. There was no other evidence linking him to the crime.

18 See M Goode, 'Some Observations on Evidence of DNA Frequency' (2002) 23 *Adelaide Law Review* 45, 57.

19 National Research Council, *The Evaluation of Forensic DNA Evidence* (1996) National Academy Press, Washington, 127.

the profiles are the same is 1,000 times as great if the samples came from the same person as if they came from different persons.²⁰

44.24 It has been suggested that in some circumstances a match probability may be unfairly prejudicial to a suspect because the calculation is based on a match involving a randomly selected, unknown, unrelated person. Where the actual offender and the suspect are members of the same family, or perhaps even from the same ethnic community, this could result in a higher than random probability that their DNA profiles will match.²¹ Justice Action, a prisoners' rights group, has commented:

While the chance that a randomly selected Australian citizen may have a DNA profile matching a Brewarrina Aborigine may be a million to one, a randomly selected Brewarrina Aborigine may be at a much higher chance of matching.²²

44.25 It has also been suggested that match probabilities would be irrelevant, or unfairly prejudicial, where they are far smaller than the probability of tampering,²³ laboratory error, contamination or other causes that might lead to a false positive.²³ Several commentators have suggested that the possibility of error should be incorporated into DNA statistics.²⁴

Small match probabilities

44.26 The use of match probabilities has been criticised on the basis that jurors, as ordinary members of the community, generally do not understand probabilities and infinitesimal match probabilities (eg 'one in 90 billion') will so dazzle jurors that they will not be able to evaluate the evidence fairly and critically.²⁵

44.27 Evett and others have commented that probabilities of the order of one in trillions, following from calculations based on ten locus profiles, require assumptions that cannot be evaluated by statistical experiment in the light of the size of existing databases. Such very small numbers are not necessarily incorrect as a technical matter of mathematics, but are without any real meaning and lack credibility in the context of criminal proceedings.²⁶ They have also cautioned against what they call the widespread misconception that there is a real statistical probability to be assigned to any profile:

20 Ibid, 127–129.

21 See generally, Legislative Council Standing Committee on Law and Justice, *Review of the Crimes (Forensic Procedures) Act 2000*, Report No 18 (2002), Parliament of NSW, Sydney Ch 3.

22 Ibid [3.35], citing submission by Justice Action.

23 D Kaye and G Sensabaugh Jr, 'Reference Guide on DNA Evidence' in Federal Judicial Center (ed), *Reference Manual on Scientific Evidence* (2000) Washington DC, 485, 540.

24 For example, see J Koehler, 'Why DNA Likelihood Ratios Should Account for Error (Even When A National Research Council Report Says They Should Not)' (1997) 37 *Jurimetrics* 425; M Goode, 'Some Observations on Evidence of DNA Frequency' (2002) 23 *Adelaide Law Review* 45, 55–57. Compare National Research Council, *The Evaluation of Forensic DNA Evidence* (1996) National Academy Press, Washington, 87.

25 For example, see D Kaye and G Sensabaugh Jr, 'Reference Guide on DNA Evidence' in Federal Judicial Center (ed), *Reference Manual on Scientific Evidence* (2000) Washington DC, 485, 537–538.

26 I Evett and others, 'DNA Profiling: A Discussion of Issues Relating to the Reporting of Very Small Match Probabilities' (2000) *Criminal Law Review* 341, 347–348.

There appears to be a fairly widespread misconception that there is a real statistical probability to be assigned to a profile but this is not the case. There is an infinite range of ways of carrying out the calculation that underlies the figure given. The method chosen in the individual case must be seen to be as much a matter of opinion as one given in other areas of forensic science. The match probability is 'personal'. It is based on what the scientist considers to be the most appropriate calculation given the circumstances of the case.²⁷

The 'prosecutor's fallacy'

44.28 The 'prosecutor's fallacy' is an error in relation to probabilities that usually favours the prosecution. The forensic scientist could make the error in presenting DNA evidence by misrepresenting its probative value. Alternatively, the evidence initially may be presented correctly but the judge or counsel inadvertently could commit the error in summing up. A third possibility is that the jury could make an error in applying the evidence even though the evidence has been presented and summed up correctly.²⁸

44.29 Two different questions may be asked regarding evidence of a match between a defendant's profile and the profile obtained from a crime scene. First, what is the probability that the defendant's DNA profile matches the crime scene sample profile, given that he or she is innocent? Second, what is the probability that the defendant is innocent, given that his or her DNA profile matches the crime scene sample profile? The first question assumes the innocence of the defendant and asks about the chances of getting a match; the second assumes that the defendant's profile matches and asks about guilt or innocence. The 'prosecutor's fallacy' consists of mistakenly giving the answer to the first question as the answer to the second.²⁹

44.30 In *R v Keir*, the New South Wales Court of Criminal Appeal considered whether the 'prosecutor's fallacy' had arisen during a criminal trial. The case involved the presumed murder of a woman in circumstances in which bone fragments were found buried under her house some years after her disappearance. DNA taken from the fragments was compared with her parents' DNA for the purpose of identification.³⁰

44.31 An expert witness gave evidence that it was 660,000 times more likely to obtain the particular DNA profile found in the bones if it came from a child of the missing woman's parents, rather than from a child of a random mating in the Australian population. However, in his directions, the trial judge (restating the

27 Ibid, 346. See also M Goode, 'Some Observations on Evidence of DNA Frequency' (2002) 23 *Adelaide Law Review* 45, 69.

28 D Balding and P Donnelly, 'The Prosecutor's Fallacy and DNA Evidence' (1994) *Criminal Law Review* 711, 711–712. See *R v Doherty v Adams* [1997] 1 Cr App R 369; *R v Keir* (Unreported, NSW Court of Criminal Appeal, Giles JA; Greg James and McClellan JJ, 28 February 2002); *R v GK* (Unreported, NSW Court of Criminal Appeal, Mason P; Sully and Dowd JJ, 16 October 2001); *R v Galli* (Unreported, NSW Court of Criminal Appeal, Spigelman CJ; Sully and Adams JJ, 12 December 2001); *R v Karger* (Unreported, Supreme Court of South Australia Court of Criminal Appeal, Doyle CJ and Prior & Gray JJ, 30 August 2002).

29 D Balding and P Donnelly, 'The Prosecutor's Fallacy and DNA Evidence' (1994) *Criminal Law Review* 711, 716–717.

30 *R v Keir* (Unreported, NSW Court of Criminal Appeal, Giles JA; Greg James and McClellan JJ, 28 February 2002).

prosecution's submissions) referred to the DNA evidence as providing a '660,000 to one' chance that the bones were those of the missing woman, and therefore a '660,000 to one' chance that alleged visual identifications of the woman after her disappearance were not correct. The Court held that the Crown had fallen into the 'prosecutor's fallacy', and the trial judge had repeated the Crown's submissions. The Court noted that neither defence counsel nor the trial judge had recognised the fallacy at trial.³¹

44.32 Even if the prosecution or the trial judge does not make this error, there is a danger that the jury will fall into this error in its consideration of the evidence.³²

Improving the use of DNA evidence at trial

44.33 DNA technology is an evolving area of science. Different methods of DNA analysis and statistical calculation may be employed by forensic scientists who will then be required to give evidence about these methods and results in criminal proceedings. DP 66 noted that a number of proposals may be necessary to ensure that DNA evidence is used in criminal proceedings in a way that is fair and upholds the ethical standards expected in the use of genetic information. These proposals relate primarily to the presentation of the evidence, and improving the level of understanding of DNA science and evidence by each participant in criminal proceedings.³³

Educating the legal profession

44.34 The way in which DNA evidence is presented in criminal proceedings can be fundamental to the outcome of the proceedings, due to the scientific nature of the evidence and the characteristically large numbers used to estimate the probative value of a DNA match.

44.35 In order to evaluate DNA evidence properly, the jury must have sufficient understanding of DNA analysis and the statistical calculations used to determine its probative value. In most cases, it is the role of the expert scientific witness to explain the science and technology of DNA analysis, the interpretation of the results, and their significance to the jury.³⁴ However, the prosecution and defence counsel must also have sufficient understanding to examine or cross-examine the expert witnesses appropriately. The trial judge must have sufficient understanding to properly direct the jury in its evaluation of the evidence.

31 Ibid [27].

32 For example, see *R v Galli* (Unreported, NSW Court of Criminal Appeal, Spigelman CJ; Sully and Adams JJ, 12 December 2001) [97], in which the Court held that although a direction about the prosecutor's fallacy might not be necessary in all cases where DNA evidence is admitted, a warning would have been desirable in the circumstances.

33 Australian Law Reform Commission and Australian Health Ethics Committee, *Protection of Human Genetic Information*, DP 66 (2002), ALRC, Sydney [37.48].

34 The Hon Justice E Mullighan, 'Presenting DNA Evidence' (Paper presented at DNA Evidence: Prosecuting Under the Microscope International Conference, Adelaide, 11 September 2001), 4–6.

Submissions and consultations

44.36 DP 66 proposed that the National Judicial College of Australia and the Law Council of Australia (through its constituent professional associations) should ensure the availability of continuing legal education programs for judges and legal practitioners, respectively, in relation to DNA evidence.³⁵ Most of the submissions supported the proposal.³⁶ The Law Institute of Victoria ‘strongly endorsed’ the proposal, noting that:

The National Judicial College of Australia and the Law Council of Australia would be appropriate bodies to fulfil this role ... ongoing training is absolutely essential in such a fast-moving and developing area, where training and skills can become redundant very quickly with potentially catastrophic results for the individuals involved.³⁷

44.37 Dr Barbara Hocking of the Queensland University of Technology, expressed support, commenting that:

The questioning of experts undoubtedly influences the knowledge gained by the jury of the science that the expert represents in court. These complex scientific issues are translated to the judge and jury through the lawyers and where they are scientifically ill-equipped they cannot by definition fully illuminate the area for those parties. Cross-examination is intended to elicit all relevant information but only knowledge of scientifically acceptable procedures and scientific methodology and reasoning will fully equip lawyers in these situations to adequately inform the jury ...³⁸

44.38 Dr Hocking also recommended that university law programs be expanded to include scientific disciplines.³⁹

44.39 Wendy Abraham QC, the South Australian Associate Director of Public Prosecutions, told the Inquiry that in criminal proceedings involving DNA evidence the prosecutor must have a good understanding of probabilities so that the jury can be properly led. She noted that education is important and agreed that the nominated organisations would be appropriate to provide such legal education.⁴⁰

44.40 Several submissions suggested that the Human Genetics Commission of Australia (HGCA) should be involved in facilitating genetic education for these professional groups.⁴¹ The Human Genetics Society of Australasia emphasised the

35 Australian Law Reform Commission and Australian Health Ethics Committee, *Protection of Human Genetic Information*, DP 66 (2002), ALRC, Sydney, Proposal 37–1.

36 Human Genetics Society of Australasia, *Submission G267*, 20 December 2002; Australian Privacy Charter Council, *Submission G304*, 21 January 2003; Victoria Police, *Submission G203*, 29 November 2002; Centre for Genetics Education, *Submission G232*, 18 December 2002; Association of Genetic Support of Australasia, *Submission G284*, 25 December 2002; Department of Human Services South Australia, *Submission G288*, 23 December 2002; B Hocking, *Submission G293*, 3 January 2003; National Legal Aid, *Submission G314*, 19 February 2003; Law Institute of Victoria, *Submission G275*, 19 December 2002.

37 Law Institute of Victoria, *Submission G275*, 19 December 2002.

38 B Hocking, *Submission G293*, 3 January 2003.

39 Ibid.

40 W Abraham, *Consultation*, Adelaide, 29 October 2002.

41 Centre for Genetics Education, *Submission G232*, 18 December 2002; Association of Genetic Support of Australasia, *Submission G284*, 25 December 2002.

importance for the proposed bodies to liaise with established genetic education bodies in providing education to these groups:

In order to ensure that the legal profession are appropriately skilled to understand DNA evidence it is important that continuing education is provided to them. It will be important for liaison with the HGSA and other genetics education organisations to ensure that National Judicial College of Australia and the Law Council of Australia access experts from the medical and scientific community to maintain the highest possible standards in this education.⁴²

Inquiry's views

44.41 The Inquiry considers there is a need for greater education in DNA science and evidence among scientific and legal professionals and the judiciary. For example, in *R v Keir* the 'prosecutor's fallacy' was committed by the prosecution and repeated by the trial judge, but was not corrected by the defence counsel. If the conviction had not been appealed, the 'fallacy' might not have become known and might have been continued in future criminal proceedings.

44.42 The proposal was supported by most of the submissions, and was consistent with the Australian Law Reform Commission's recommendations in the *Managing Justice* report, which called for enhanced professional development and continuing education schemes in order to improve the efficiency and effectiveness of the justice system. In particular, the Commission called for greater emphasis on programs for trial lawyers and judges, to familiarise them with DNA science, technology and evidence.⁴³

44.43 Several submissions suggested that the HGCA should play a role in the provision of education to judges and legal practitioners about DNA evidence. As discussed in Chapter 5, the Inquiry intends the HGCA to play a major role in public and professional education. In many cases this will involve assisting or facilitating other bodies in providing the direct educational and training services. The Inquiry suggests that, where requested by the National Judicial College of Australia and the Law Council of Australia to do so, the HGCA should provide guidance in developing these continuing legal education programs.

44.44 The Inquiry also considers that expanding the curriculum in both undergraduate and postgraduate university law programs should be encouraged. For example, some law schools could include elective subjects in the scientific and evidential issues relating to DNA evidence.

44.45 The Inquiry recommends that the National Judicial College of Australia and the Law Council of Australia (through its constituent professional associations) should develop and promote continuing legal education programs for judges and legal practitioners, respectively, in relation to the use of genetic information in criminal proceedings.

42 Human Genetics Society of Australasia, *Submission G267*, 20 December 2002.

43 Australian Law Reform Commission, *Managing Justice: A Review of the Federal Civil Justice System*, Report 89 (2000), ALRC, Sydney.

Recommendation 44–1. The National Judicial College of Australia and the Law Council of Australia (through its constituent professional associations) should develop and promote continuing legal education programs for judges and legal practitioners, respectively, in relation to the use of genetic information in criminal proceedings.

Improving jury understanding

44.46 While defence counsel has the opportunity to test the probative value of evidence through cross examination of an expert witness, the jury might nonetheless be ‘dazzled’ by the statistics presented to them, and fail to consider the DNA evidence in the context of all the other evidence admitted. In addition, a jury might introduce the ‘prosecutor’s fallacy’ even though the evidence is presented and summed up correctly.

44.47 Some commentators have suggested that some descriptions of DNA match statistics may have a larger impact on jurors than others because

the perceived probative value of a statistical DNA match (and, by extension, other forensic match evidence) depends on the ease with which triers of fact can imagine examples of others who would also match the DNA profile. When triers of fact find it hard to imagine examples of others who might match by chance, the evidence will be treated as compelling proof that the matching suspect is the source of the recovered DNA evidence. But when such matches are easier to image, the evidence will seem less compelling.⁴⁴

44.48 The National Institute of Forensic Science and the Australian Institute of Judicial Administration are currently conducting a research project into jury comprehension of DNA evidence. This project should lead in future to more effective communication of DNA evidence and better understanding by juries.⁴⁵

Options for reform

44.49 There are several possible ways to improve jury understanding about the nature of DNA evidence to ensure they are able to properly evaluate the probative value of the evidence. Juries could be given written guidance in the form of booklets that explain DNA evidence generally, for reference during the trial.⁴⁶ For example, Wendy Abraham QC advised the Inquiry that she has used jury books to assist jury members in relation to DNA evidence. The books contain a range of material including a glossary of terms, diagrams of processes, photos of testing equipment, tables of results and so on to assist the jury.⁴⁷ Alternatively, Professor Ron Trent suggested that

44 Cited in J Koehler, ‘The Psychology of Numbers in the Courtroom: How to Make DNA-Match Statistics Seem Impressive or Insufficient’ (2001) 74 *Southern California Law Review* 1275, 1280.

45 National Institute of Forensic Science, *Consultation*, Melbourne, 5 September 2001.

46 See The Hon Justice E Mullighan, ‘Presenting DNA Evidence’ (Paper presented at DNA Evidence: Prosecuting Under the Microscope International Conference, Adelaide, 11 September 2001), 5–6.

47 W Abraham, *Consultation*, Adelaide, 29 October 2002.

a standard educational video about DNA technology could be shown to juries before the trial, and replayed for them later, if required.⁴⁸

44.50 Courts could formulate guidelines for the presentation of DNA evidence. The English Court of Appeal formulated guidelines in the headnote to its judgment in *R v Doheny & Adams*. The guidelines deal with the presentation of DNA statistical evidence to the jury; procedural issues such as service of DNA evidence on the defence and the identification of issues of expert evidence before trial; and judicial instructions about the summing up.⁴⁹ The Northern Territory Court of Appeal formulated a similar set of guidelines in its judgment in *Latcha v R*.⁵⁰ The Supreme Court of British Columbia has formulated the following guideline:

[I]t can be made sufficiently clear to the jury that: 1) the estimates are not intended to be precise; 2) they are the products of mathematical and scientific theory, not concrete facts; 3) they do not purport to define the likelihood of guilt; 4) they should only be used to form a notion of the rarity of the genetic profile of the accused; and 5) the DNA evidence must be considered along with all the other evidence in the case relating to the issue of identification.⁵¹

44.51 A third possibility is the development of a standard judicial direction to juries for use either (a) where requested by the defence; or (b) in all cases in which a party to criminal proceedings seeks to rely on DNA evidence.

44.52 Section 165 of the *Evidence Act 1995* (Cth) (*Evidence Act*) provides for judicial warnings to the jury in relation to evidence of a kind that may be unreliable, including identification evidence. Where a party requests the judge to do so—and unless there are good reasons not to do so—the judge must warn the jury that the evidence may be unreliable; inform the jury of matters that may cause it to be unreliable; and warn the jury of the need for caution in determining whether to accept the evidence and the weight to be given to it.

44.53 Defence counsel currently would need to request a judicial warning under s 165 where they consider that, in the circumstances of a particular case, the DNA evidence is unreliable. Where the defence counsel failed to request the direction, or where the judge determines the evidence is not unreliable, the direction would not be given.

44.54 An alternative approach would be to insert a standard jury direction regarding DNA evidence into the *Evidence Act*. The standard direction would provide that the trial judge must direct the jury on the need for caution in evaluating DNA evidence and the statistical calculations relating to that evidence either in all cases, or where considered appropriate. This approach recognises that DNA evidence is a form of scientific evidence that may, without proper direction, be given more probative

48 R Trent, *Correspondence*, 7 February 2003.

49 *R v Doheny v Adams* [1997] 1 Cr App R 369. See discussion in M Goode, 'Some Observations on Evidence of DNA Frequency' (2002) 23 *Adelaide Law Review* 45, 61–63.

50 *Latcha v R* (1998) 104 A Crim R 390.

51 *R v Singh* (1996) 108 CCC (3d) 244, cited in M Goode, 'Some Observations on Evidence of DNA Frequency' (2002) 23 *Adelaide Law Review* 45, 66–67.

weight by a jury than is warranted, and ensures consistency in the judicial approach to DNA evidence in criminal proceedings.

44.55 Matthew Goode commented on the desirability of jury directions in relation to DNA evidence:

The highly subjective nature of the mathematical processes remains concealed behind the apparent certainty of a bald statistic. It may also be that the larger the number of loci compared, the higher the statistic, the more need there is for an appropriate direction to the jury about what the really impressive statistic really means.⁵²

44.56 Goode emphasised the need to formulate more specific jury directions about the subjective nature of the match probability statistic; the factoring in of the incalculable but real possibilities of laboratory error, depending upon the accreditation and practices of the laboratory concerned; and the limitations on the use of certain types of calculations to produce the statistical result.⁵³

44.57 South Australia's Court of Criminal Appeal recently rejected the submission that a general warning should always be required in relation to statistical DNA evidence. While there might be cases where particular circumstances call for a special direction or warning, the Court considered this would depend on the particular facts and circumstances in any given case.⁵⁴ Chief Justice Doyle commented that:

it is undesirable to impose on trial judges the obligation, as a matter of law, to give warnings to a jury except when that is truly necessary. Any idea that there is no harm in giving a warning, and therefore that it is appropriate to make the warning obligatory, should be rejected. Each warning adds to the length of a summing up, and to the matters that a jury must consider. And there is a danger that the giving of too many warnings will undermine the impact of those warnings that are truly required, or will distract the jury from a straightforward consideration of the material before them.

As long as the judge explains to the jury how the evidence may be used, and how it should not be used, there is no need for warnings against its misuse generally, or for a warning against misuses of the evidence that have not taken place in the trial.⁵⁵

Submissions and consultations

44.58 DP 66 proposed that a standard jury direction should be inserted into the *Evidence Act* for use where DNA evidence has been admitted in criminal proceedings. The Inquiry noted that the direction should outline the warning that a trial judge should give the jury regarding the need for caution in evaluating DNA evidence and the statistical calculations relating to that evidence.⁵⁶

52 Ibid, 61.

53 Ibid, 74–75.

54 *R v Karger* (Unreported, Supreme Court of South Australia Court of Criminal Appeal, Doyle CJ and Prior & Gray JJ, 30 August 2002) [182].

55 Ibid [35]–[36].

56 Australian Law Reform Commission and Australian Health Ethics Committee, *Protection of Human Genetic Information*, DP 66 (2002), ALRC, Sydney, Proposal 37–2.

44.59 Most of the submissions supported the proposal.⁵⁷ The Law Institute of Victoria commented that:

The Law Institute supports the introduction of a standard jury direction, to be inserted into the *Evidence Act 1995* (Cth) for use where DNA evidence has been admitted in criminal proceedings. The direction should outline the warning that a trial judge should give the jury regarding the need for caution in evaluating DNA evidence and the statistical calculations relating to that evidence. We believe this is essential in a climate where scientific evidence, and DNA evidence in particular, is often accorded more weight and probative value by the average layperson than is appropriate.⁵⁸

44.60 The South Australian Attorney-General's Department supported a mandatory jury direction, noting that 'making it up on the spot' can lead to appeals against conviction.⁵⁹ By contrast, Wendy Abraham QC did not agree with the giving of warnings as a matter of course because, in her view, DNA evidence is not inherently unreliable. She commented that judges are generally disinclined to use standard directions.⁶⁰

44.61 Several submissions emphasised the need for flexibility in the form of words used in each case, as did several consultation meetings.⁶¹ For example, the Victorian Bar commented that:

The Victorian Bar agrees that trial judges should be required *in all cases* to warn the jury with respect to DNA evidence. However, rather than enshrining a set formula for the direction within the legislation, it would be preferable to include a 'checklist' indicating the minimum requirements to be included in such a direction. The legislation should emphasise the need to structure the direction to suit the facts and issues in any given case.⁶²

44.62 Liberty Victoria noted that appeal courts develop directions over time and these directions take the form of words that are flexible enough to deal with particular situations. It would be difficult for Parliament to develop a direction that would apply to all possible circumstances—and this would be better done through the courts.⁶³

44.63 Finally, the Centre for Genetics Education submitted that the HGCA could be involved in the development of resources for juries to enable understanding of the DNA evidence.⁶⁴

57 Victoria Police, *Submission G203*, 29 November 2002; Victorian Bar, *Submission G261*, 20 December 2002; Human Genetics Society of Australasia, *Submission G267*, 20 December 2002; Department of Human Services South Australia, *Submission G288*, 23 December 2002; Association of Genetic Support of Australasia, *Submission G284*, 25 December 2002; National Legal Aid, *Submission G314*, 19 February 2003.

58 Law Institute of Victoria, *Submission G275*, 19 December 2002.

59 South Australian Attorney-General's Department, *Consultation*, Adelaide, 30 October 2002.

60 W Abraham, *Consultation*, Adelaide, 29 October 2002.

61 Victorian Bar, *Submission G261*, 20 December 2002. See also Human Genetics Society of Australasia, *Submission G267*, 20 December 2002; W Abraham, *Consultation*, Adelaide, 29 October 2002; NSW Police Service, *Submission G306*, 22 January 2003; Liberty Victoria, *Consultation*, Melbourne, 23 October 2002.

62 Victorian Bar, *Submission G261*, 20 December 2002.

63 Liberty Victoria, *Consultation*, Melbourne, 23 October 2002.

64 Centre for Genetics Education, *Submission G232*, 18 December 2002.

Inquiry's views

44.64 The submissions generally supported the proposal for a standard jury direction but differed in relation to the circumstances in which the direction should be given, and the form the direction should take. Some submissions suggested that the direction should be given only in cases in which the evidence suggests the jury might misunderstand the evidence; others considered that DNA evidence is inherently difficult for juries to understand and the direction should accordingly be given in all cases in which the evidence is admitted. At the same time, some submissions supported a specific direction while others suggested that the trial judge should have some flexibility in its formulation.

44.65 The Inquiry considers that unless the trial judge considers it would be unreasonable in the circumstances of the case to do so, the judge should provide a direction to the jury in all criminal proceedings in which DNA evidence is admitted. This would help ensure that the jury is not confused by, or unduly impressed with, the statistical calculations when evaluating the evidence.

44.66 The Inquiry now considers that it would be more appropriate for a standard direction to be formulated by the judiciary. Therefore, in each jurisdiction a body representing the judiciary should develop a model direction. The model should provide guidance to trial judges in cases in which DNA evidence has been admitted, but should provide sufficient flexibility to be adapted to the circumstances of a particular case. The judicial body in each jurisdiction would differ. For example, in federal jurisdiction, the National Judicial College of Australia might develop the model direction; in New South Wales, the New South Wales Judicial Commission might do so.

Recommendation 44–2. In order to provide better guidance for judges and juries, the judiciary should develop a model jury direction for use where DNA evidence has been admitted in criminal proceedings.

Managing the use of DNA evidence

44.67 The Inquiry recognises that there is ongoing debate within the field of forensic science about the appropriate means of calculating and presenting DNA evidence in court proceedings. In DP 66, the Inquiry commented that some form of independent standard setting should be provided regarding the use of DNA evidence in criminal proceedings.⁶⁵

44.68 The New South Wales Legislative Council Standing Committee on Law and Justice recognised the importance of such standard setting in its review of the NSW forensic procedures legislation. The Committee noted that the New South Wales government had proposed the establishment of a State Institute of Forensic Sciences

⁶⁵ Australian Law Reform Commission and Australian Health Ethics Committee, *Protection of Human Genetic Information*, DP 66 (2002), ALRC, Sydney [37.59].

(SIFS) to oversee the organisation and management of forensic sciences and the use of technology in criminal investigations and prosecutions.⁶⁶ The Committee recommended that priority attention be given to the establishment of the SIFS to manage the use of technology in criminal investigations and prosecutions, and that it be requested to further examine methods of calculating the significance of DNA matches.⁶⁷

44.69 The National Institute of Forensic Science (NIFS) is an existing body with similar functions. NIFS was established under an agreement signed by the Australasian Police Ministers' Council (APMC) in 1991. NIFS is a national body that reports to the APMC, and its board of control comprises three Commissioners of Police and three forensic laboratory directors. The current chair is the Chief Justice of Victoria.⁶⁸

44.70 NIFS' core functions require it to sponsor and support research in forensic science; advise on and assist with the development and co-ordination of forensic science services; gather and exchange forensic information, including through the establishment of a national forensic reference service; support, co-ordinate and conduct training programs in forensic science; and conduct relevant quality assurance programs. It is also charged with raising the profile of forensic science.⁶⁹

Submissions and consultations

44.71 In DP 66, the Inquiry proposed that a body with expertise in forensic science and court proceedings should provide ongoing guidance to forensic scientists and legal practitioners regarding reliable methods of DNA analysis, statistical calculation, and presentation of evidence in criminal proceedings. As NIFS already fulfils these functions, the Inquiry suggested that this would be an appropriate body to take on this role.⁷⁰

44.72 The Inquiry received few responses in respect of this proposal. Those submissions that addressed the issue generally expressed support.⁷¹ Wendy Abraham QC also expressed support in a consultation meeting.⁷² The Law Institute of Victoria commented that it:

66 This was a joint proposal of the NSW Police Service, the Attorney-General and the Department of Health.

67 Legislative Council Standing Committee on Law and Justice, *Review of the Crimes (Forensic Procedures) Act 2000*, Report No 18 (2002), Parliament of NSW, Sydney [3.52]–[3.53], Rec 1.

68 National Institute of Forensic Science website, <www.nifs.com.au/NIFS/NIFS_frame.html?about.asp&l>, 20 February 2003.

69 Ibid.

70 See Australian Law Reform Commission and Australian Health Ethics Committee, *Protection of Human Genetic Information*, DP 66 (2002), ALRC, Sydney, Proposal 37–3.

71 Human Genetics Society of Australasia, *Submission G267*, 20 December 2002; Association of Genetic Support of Australasia, *Submission G284*, 25 December 2002; Victoria Police, *Submission G203*, 29 November 2002; Centre for Genetics Education, *Submission G232*, 18 December 2002; Law Institute of Victoria, *Submission G275*, 19 December 2002; National Legal Aid, *Submission G314*, 19 February 2003; Department of Human Services South Australia, *Submission G288*, 23 December 2002.

72 W Abraham, *Consultation*, Adelaide, 29 October 2002.

generally supports a proposal for provision of ongoing guidance to forensic scientists and legal practitioners regarding reliable methods of DNA analysis, statistical calculation, and presentation of evidence in criminal proceedings ... However we are concerned that this proposal ... refers only to guidance from one body, the National Institute of Forensic Science. Given the enormous debate surrounding appropriate use of DNA testing and the weight and credibility to be given to samples dependant upon a myriad of conditions, we believe that wider consultation and guidance may be appropriate, from a range of suitably screened bodies.⁷³

44.73 The Victoria Police similarly commented that the proposal should also

incorporate the jurisdictions providing advice in addition to NIFS. This could be coordinated through the Specialist Advisory Groups, which provide high level advice on policy issues relating to biological casework including DNA.⁷⁴

Inquiry's views

44.74 There is a clear need for a body to oversee the use of technology in criminal investigations and prosecutions, and the Inquiry recognises that NIFS already conducts these activities. The Inquiry's only concern is that NIFS has been established within the law enforcement community, being subject to the direction of APMC. This may lead to a possible perception that NIFS is a 'police' body—however, the Inquiry has not heard any complaints of this nature.

44.75 The Inquiry recognises that, in practice, it is unlikely the Commonwealth government would establish another forensic science institute to oversee the use of technology in criminal investigations and prosecutions. Therefore, the Inquiry recommends that NIFS, in consultation with members of the criminal justice and science communities (including defence practitioners and forensic scientists conducting defence work), should provide ongoing guidance to forensic scientists and legal practitioners regarding reliable methods of DNA analysis, statistical calculation, and presentation of evidence in criminal proceedings.

Recommendation 44–3. The National Institute of Forensic Science, in consultation with members of the criminal justice and science communities, should provide ongoing guidance to forensic scientists and legal practitioners regarding reliable methods of DNA analysis, statistical calculation, and presentation of evidence in criminal proceedings.

73 Law Institute of Victoria, *Submission G275*, 19 December 2002.

74 Victoria Police, *Submission G203*, 29 November 2002.

Independent analysis of DNA evidence

Access to crime scene samples

44.76 Where the prosecution seeks to rely on DNA evidence in a criminal prosecution, the usual procedure is for the prosecution to give defence counsel access to the crime scene samples, and the analysis results, as part of pre-trial disclosure.

44.77 Where a DNA sample is obtained from a suspect under Part 1D of the *Crimes Act*, the Australian Federal Police (AFP) must make part of the material available to the person as soon as practicable after the procedure has been carried out.⁷⁵ If the material is analysed in the investigation of the offence, the AFP must ensure a copy of the analysis results are made available to the person.⁷⁶

44.78 There is no legislative requirement at the federal level that the prosecution must provide all or any part of a crime scene sample to a defendant. By contrast, the *Crimes Act 1958* (Vic) requires that where there is sufficient material, a part of the crime scene material must be forwarded to the suspect (or any person from whom a sample has been taken in relation to the offence) on request.⁷⁷

Issues and problems

44.79 The Queensland case of *R v Button* provides an example of the potential consequences where the prosecution fails to analyse a crime scene sample prior to trial—or even to notify the defence of its existence so that they may arrange its analysis.⁷⁸ In that case, the Queensland Court of Appeal held that the failure to analyse certain samples led to a miscarriage of justice. If the samples had been analysed before the trial, the defendant would have been excluded as a suspect in the investigation. Instead, the samples were not analysed and the defendant was convicted of the offence. Williams JA commented:

What is of major concern to this Court is the fact that the evidence was not available at the trial ... What is disturbing is that the investigating authorities had also taken possession of bedding from the bed on which the offence occurred, and delivered those exhibits to the John Tonge Centre. No testing of that bedding was carried out prior to trial. The explanation given was that it would not be of material assistance in identifying the appellant as the perpetrator of the crime.⁷⁹

75 *Crimes Act 1914* (Cth) s 23XU. However, if there is insufficient material to be analysed both in the investigation of the offence and on behalf of the suspect, and the material does not need to be analysed immediately after the sample is taken, the suspect can request that a person be present while the material is analysed, or to be present personally during the analysis: *Crimes Act 1914* (Cth) s 23XUA.

76 *Crimes Act 1914* (Cth) s 23XW.

77 *Crimes Act 1958* (Vic) s 464ZC.

78 *R v Button* (Unreported, Queensland Court of Appeal, Williams JA, White and Holmes JJ, 10 April 2001).

79 Ibid.

44.80 Williams JA emphasised that there is a two-fold purpose of DNA testing: being to identify the perpetrator of a crime, and to exclude a possible offender as the perpetrator.⁸⁰

Submissions and consultations

44.81 DP 66 proposed that forensic procedures legislation should be amended to provide that the prosecution has a duty to provide defendants with reasonable pre-trial notice of all DNA samples collected at a crime scene in order to give defendants an opportunity to have this evidence independently analysed.⁸¹

44.82 Most of the submissions supported the proposal.⁸² The Law Institute of Victoria commented that:

It is an important rule of our criminal justice system that allows defendants an opportunity to consider all evidence to be adduced against them. This is even more vital where the evidence carries the potential prejudicial value of DNA evidence, and its technical nature may require time and expert advice to comprehend.⁸³

44.83 The Queensland Government broadly supported the proposal, but noted that:

as the collection of DNA samples becomes an increasingly routine investigative procedure, there will be direct cost implications for the criminal justice system as challenges to the validity of a DNA analysis become more common. It is suggested that in addition to requiring the prosecution to give the defence reasonable pre-trial notice of all samples collected at a crime scene, the prosecution must also give the defence reasonable pre-trial notice of which DNA samples it intends to tender as evidence in a trial.⁸⁴

44.84 The Victoria Police expressed concerns about laboratories' practical ability to meet pre-trial disclosure deadlines:

This proposal must take note that any pre-trial notice is generally already adopted through legislation (eg. *Magistrates' Court Act* [Vic]) and is largely dependent on the ability of the laboratory to meet the imposed deadline. Provided resources meet the output capacity, this should not be an issue. However, if demand rises and ability to complete cases within prescribed timeframes becomes more difficult then the court dates may need to be amended.

80 Ibid.

81 Australian Law Reform Commission and Australian Health Ethics Committee, *Protection of Human Genetic Information*, DP 66 (2002), ALRC, Sydney, Proposal 37–4.

82 Centre for Genetics Education, *Submission G232*, 18 December 2002; Institute of Actuaries of Australia, *Submission G224*, 29 November 2002; Human Genetics Society of Australasia, *Submission G267*, 20 December 2002; Association of Genetic Support of Australasia, *Submission G284*, 25 December 2002; Department of Human Services South Australia, *Submission G288*, 23 December 2002; Law Institute of Victoria, *Submission G275*, 19 December 2002; National Legal Aid, *Submission G314*, 19 February 2003.

83 Law Institute of Victoria, *Submission G275*, 19 December 2002.

84 Queensland Government, *Submission G274*, 18 December 2002.

44.85 The New South Wales Police Service opposed the proposal on the basis that to provide notice of all samples obtained from a crime scene might infringe third party rights.

There may be many samples found at a crime scene that are irrelevant to the investigation of the offence. For example, at a break, enter and steal the DNA profile of the victim found in the house. It may be a breach of those persons' privacy to disclose those details to the defence and allow them access to the profile.⁸⁵

Inquiry's views

44.86 In any criminal proceedings in which the prosecution relies on DNA evidence, it is important that the defence be given notice of, and access to, all genetic material collected from the crime scene. In addition, the defence should have sufficient access to retesting and independent expert advice, and be in a position to evaluate the probative value of the evidence and cross-examine the prosecution's expert witness effectively.

44.87 Access to independent DNA analysis and advice is fundamentally important to ensure that a defendant receives a fair trial. This is particularly true where analysis of a crime scene sample may provide material evidence that would assist the defence in rebutting the prosecution case.

44.88 As discussed above, Part 1D of the *Crimes Act* requires the AFP to provide suspects with a portion of any DNA sample taken from them by way of a forensic procedure—where there is sufficient material to share—and a copy of the analysis of that sample. The Inquiry considers that as a matter of procedural fairness, similar provisions should apply in relation to crime scene samples. The prosecution should have a duty to provide the defendant with reasonable pre-trial notice of all DNA samples collected at a crime scene in order to give the defendant an opportunity to have this evidence independently analysed.

44.89 The Inquiry notes the Queensland Government's suggestion that the prosecution should be required to give the defence pre-trial notice of which DNA samples it intends to tender as evidence in a trial. However, as this reflects the existing legal requirement for pre-trial disclosure of evidence, it is not necessary to incorporate this into the recommendation.

44.90 While some samples found at a crime scene might be irrelevant to the proceedings, it is important to the fairness of the trial that the defence be given pre-trial notice of the existence of such samples. The Inquiry proposes that the defence be given a list and description of all samples found at the crime scene; the defence would then need to request access to the physical samples themselves.

85 NSW Police Service, *Submission G306*, 22 January 2003.

Recommendation 44–4. The Commonwealth should amend the *Crimes Act 1914* (Cth) to specify that the prosecution has a duty to provide defendants with reasonable pre-trial notice of all relevant crime scene samples in order to give them an opportunity to have such samples independently analysed.

Defence access to independent analysis

44.91 As a result of the small number of forensic laboratories conducting DNA analysis for law enforcement purposes, practical difficulties may arise for defendants in obtaining independent analysis of, and expert advice about, the DNA evidence relied on by the prosecution.

44.92 Dr Ian Freckelton has stated that

the reality in Victoria, as in many other jurisdictions, is that the pool of available experts in DNA profiling is shallow and almost exclusively to be found within the state facility (in Victoria part of the police force) that undertakes the overwhelming majority of forensic science work. For defendants who wish to re-analyse they have had little option but to seek assistance from one scientist who formerly worked at the Forensic Science Centre ... or to seek advice interstate ... For a range of reasons, this can be logistically and financially problematic.⁸⁶

44.93 Justice Michael Kirby, of the High Court of Australia, has commented:

Effective facilities [should be] provided to suspects to permit them a secure independent scientific scrutiny of DNA samples alleged to relate to them. It is important that the relevant experts should not be entirely within the employ of the state. Just because a result is produced by an expert or a machine is no reason to accept it without further questioning, or the right to question, the applicability, accuracy and reliability of such a result. An abiding difficulty of the present age is the unwillingness of many to accept that experts and machines sometimes err.⁸⁷

44.94 Several of the submissions received by the Inquiry raised concerns about the impact of the cost of DNA testing and expert advice for the defence. For example, the NSW Legal Aid Commission commented on the cost of obtaining DNA analysis and expert advice:

An increasing emphasis on DNA evidence adds to the cost of criminal trials in circumstances where the Commission's budget is already overstretched. The Commission is a significant participant in the criminal justice system. However, increases in funding to law enforcement agencies are not accompanied by increased Commission funding. An increasing emphasis on expensive DNA evidence in criminal trials will have an impact on the services the Commission can provide to its clients.⁸⁸

86 I Freckelton, *DNA Profiling: Collection, Use and Effectiveness — An Issues Paper* (2002), Victorian Parliament, 33–34.

87 M Kirby, 'DNA Evidence: Proceed With Care' (2000) 12 *Judicial Officers' Bulletin* 57, 59.

88 New South Wales Legal Aid Commission, *Submission G087*, 21 January 2002. See also National Legal Aid, *Submission G314*, 19 February 2003.

44.95 The Inquiry recognises that due to the small number of forensic laboratories currently conducting DNA analysis for law enforcement purposes, practical problems arise for defendants who wish to obtain an independent analysis of, or expert advice on, the DNA evidence sought to be relied on by the prosecution in criminal proceedings. In practice, defendants might need to go to another Australian jurisdiction, or overseas, to obtain these services.

44.96 Access to independent testing and expert advice regarding prosecution evidence goes to the fairness of the trial; lack of access to these services could result in a miscarriage of justice. While this issue falls outside the Inquiry's terms of reference, it is a matter that the Inquiry considers needs urgent attention by the Standing Committee of Attorneys-General.

Admissibility of unlawfully obtained DNA evidence

44.97 DNA evidence is a form of expert opinion evidence. Opinion evidence is admissible if it is wholly or substantially based on a person's specialised knowledge, which in turn is based on the witness' training, study or experience.⁸⁹ DNA evidence that is relevant to a fact in issue is admissible in criminal proceedings unless it is barred under an exclusionary rule, or by judicial discretion.⁹⁰

Crimes Act provisions

44.98 Part 1D of the *Crimes Act* provides that evidence obtained from a forensic procedure is inadmissible if there has been a breach of, or failure to comply with, the provisions of Part 1D in relation to the forensic procedure or in relation to recording or use of information on the DNA database system. However, the court has a discretion to admit the evidence if it is satisfied on the balance of probabilities of matters that justify its admission in spite of the non-compliance; or if the person who is the subject of the forensic evidence does not object to its admission.⁹¹ Section 23XX(5) provides a list of matters that the court may consider in making this decision. The probative value of the evidence will not itself justify the admission of the evidence.⁹² Evidence obtained as a result of a forensic procedure is not admissible in proceedings against a person if it is required to be destroyed under Part 1D.⁹³

89 *Evidence Act 1995* (Cth) s 79.

90 See *Ibid*, s 56. In relation to the exclusionary rules and discretions, see ss 135, 137, 138.

91 *Crimes Act 1914* (Cth) s 23XX.

92 *Ibid*, s 23XX(6). If the judge admits the evidence, he or she must inform the jury of the breach or failure to comply with the legislation, and give whatever warning about the evidence the judge thinks appropriate in the circumstances: *Crimes Act 1914* (Cth) s 23XX(7).

93 *Crimes Act 1914* (Cth) s 23XY.

Evidence law

44.99 The *Crimes Act* provisions do not apply to DNA evidence obtained outside the framework of Part 1D—for example, a crime scene sample, or an informally obtained sample.⁹⁴ The admissibility of such evidence would be subject to the rules of evidence applying in the relevant jurisdiction.

44.100 Under the *Evidence Act*, the court must exclude evidence led by the prosecution if its probative value is outweighed by the danger of unfair prejudice to the defendant.⁹⁵ The court must exclude evidence that has been improperly or unlawfully obtained unless the desirability of admitting the evidence outweighs the undesirability of admitting evidence obtained in this way.⁹⁶ Finally, the court has a discretion to exclude evidence where it considers the probative value is substantially outweighed by the danger that the evidence might be unfairly prejudicial, misleading or confusing, or might result in an undue waste of time.⁹⁷

Admissibility of DNA evidence

44.101 Exclusionary rules of evidence are a primary means of deterring the illegal or improper collection, use or retention of DNA evidence. The *Crimes Act* provides the judge with a balancing test when determining whether to admit DNA evidence obtained in breach of the provisions of Part 1D. A similar approach is taken in the *Evidence Act*, in relation to evidence that is obtained improperly or illegally.⁹⁸

44.102 The Inquiry has heard concerns that due to the highly probative nature of DNA evidence, judges might tend to exercise their discretion in favour of admission rather than properly balancing each of the relevant interests, including the privacy of the accused. This would undermine the value of the protection intended by MCCOC in formulating this provision.⁹⁹

44.103 Chapter 41 discusses concerns arising from the informal collection of genetic samples by police investigators. In that chapter, the Inquiry noted that legislative provisions regarding the inadmissibility of improperly or unlawfully obtained evidence might not provide sufficient safeguard against these practices. For example, police investigators could collect a suspect's sample informally. If the person is excluded from suspicion, or if the person is implicated but a formal sample is subsequently taken pursuant to the *Crimes Act* provisions, the admissibility of the covertly obtained sample would not arise as an issue in proceedings.

94 See Ch 41 for more detail.

95 *Evidence Act 1995* (Cth) s 137.

96 *Ibid* s 138.

97 *Ibid* s 135.

98 *Ibid* s 138. In addition, Pt 1D provides a higher protection for DNA evidence retained after its required destruction date, by providing that such evidence is inadmissible in proceedings against that person.

99 For example, see New South Wales Legal Aid Commission, *Submission G087*, 21 January 2002; Office of the Privacy Commissioner (NSW), *Submission G118*, 18 March 2002.

44.104 Rather than amending the legislative provisions regarding admissibility of DNA evidence, the Inquiry considers it would be more useful to protect against the informal or unlawful collection of the genetic information in the first place. Therefore, Recommendation 41–13 provides that the Commonwealth should amend the *Crimes Act* to provide that, with the exception of crime scene samples, law enforcement officers may lawfully collect a genetic sample for law enforcement purposes only from (a) the individual concerned, pursuant to Part 1D of the *Crimes Act*; or (b) a stored sample, with the consent of the person sampled or a person authorised to consent on his or her behalf, or pursuant to a court order.

Behavioural genetics

44.105 Some scientists are currently undertaking research into whether there is a genetic component to various traits relating to an individual's behaviour and personality, including intelligence, aggression, antisocial behaviour, anxiety, alcoholism and addiction. Research into behavioural genetics has raised concerns of a renewed interest in the notion of 'genetic behavioural determinism'.¹⁰⁰

44.106 If these deterministic theories become widely accepted, defendants in criminal proceedings might seek to rely on these theories to prove that they should not be held responsible for their behaviour. For example, a defendant might admit striking the victim, but argue that his or her responsibility was diminished or eliminated because of a genetic predisposition to aggression and violence. These arguments have been raised in a number of criminal trials to date, without success.¹⁰¹

44.107 The courts have taken a cautious approach to admitting arguments or evidence based on genetic behavioural determinism. The science in this area is still at an early stage of development, and no doubt in future there will be strong arguments about the extent of genetic determinism versus environmental influences and interactions, and about criminal responsibility and free will.

44.108 The Inquiry is not in a position to add anything to this early discussion, much less to propose any changes to the law. However, as discussed in Chapter 5, the Inquiry considers that the HGCA could have a role to play in moderating community debate about these important issues in future.

100 See Nuffield Council on Bioethics, *Genetics and Human Behaviour: The Ethical Context* (2001), Nuffield Council on Bioethics, London, for more information.

101 For example, *Nelio Adelino DaSilva Serra v R* (Unreported, Court of Criminal Appeal of Northern Territory, Kearney, Angel and Priestley JJ, 24 February 1997).

45. Post-Conviction Use of DNA Evidence

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Introduction

45.1 DNA evidence has become a powerful tool in exonerating persons wrongly convicted of criminal offences. Where DNA testing excludes the convicted offender as the source of a DNA sample found at the crime scene, sufficient doubt of guilt may be established to overturn the conviction. For example, in a sexual assault case involving one offender whose DNA sample is found on or in the body of the victim, DNA testing that excludes the person convicted of the offence as the source of the DNA would provide substantial doubt as to guilt. However, where the suspect admits that sexual contact took place, but claims that it was consensual, the presence or absence of DNA will be of little relevance.

45.2 As of 28 February 2003, 123 convicted offenders had been exonerated in the United States as a result of post-conviction DNA testing; a number of these had been on 'death row'.¹ The first Australian post-conviction exoneration occurred in April 2001, when a man's conviction for rape was quashed after DNA testing conclusively eliminated him as the source of seminal fluid stains on the bed sheets found at the crime scene. The evidence had not been DNA tested before the trial.²

1 *Innocence Project Website*, Benjamin N Cardozo School of Law, <www.innocenceproject.org/>, 28 February 2003.

2 *R v Button* (Unreported, Queensland Court of Appeal, Williams JA, White and Holmes JJ, 10 April 2001). See also D Kellie, 'Justice in the Age of Technology: DNA and the Criminal Trial' (2001) 25(4) *Alternative Law Journal* 173, 174.

45.3 DNA testing also can confirm guilt, removing doubt about a prisoner's guilt despite long-running campaigns alleging a miscarriage of justice. For example, in May 2002, the English Court of Appeal held that DNA evidence proved beyond doubt that James Hanratty was guilty of the murder for which he had been hanged 40 years previously.³

Access to crime scene samples

45.4 A person might seek to access the original crime scene sample for analysis to overturn his or her conviction where:

- the person was convicted before DNA technology became available;
- more sophisticated DNA technology subsequently has become available;
- the prosecution omitted to test and analyse, or to introduce as DNA evidence at trial, a sample found at the crime scene for the purpose of the trial; or
- the defence failed to question the nature, quality, probity or presentation of the DNA evidence at trial.

Gaining access to crime scene samples

45.5 Part 1D of the *Crimes Act 1914* (Cth) (*Crimes Act*) does not regulate the collection, use or destruction of forensic material found at a crime scene. Police administrative procedures and the National Association of Testing Authorities, Australia (NATA) accreditation requirements outline procedures for the collection and chain of custody of crime scene material, and the analysis and storage of those samples.

Traditional procedures

45.6 DNA samples are currently stored long term. However, where the offence took place prior to the development of DNA technology, there can be no guarantee that the crime scene exhibit (which might include a bodily sample) has been retained. Generally, prisoners can apply to the Office of the Director of Public Prosecutions in the relevant jurisdiction, or to the relevant police service, for access to a crime scene exhibit or sample.

45.7 Crime scene exhibits are usually the responsibility of the police officer in charge of the investigation. In New South Wales, the Inquiry has been advised that samples are kept in a number of different areas. Sample 'slides' are generally kept by NSW Health. Other exhibits may be held in various locations within the New South Wales Police Service including: local area commands; State Crime Command;

3 *Hanratty v R* [2002] EWCA Crim 1141; N Hopkins and O Bowcott, '40 years After His Execution, Appeal Judges Say DNA is Certain Proof of Hanratty's Guilt', *The Guardian* (London), 11 May 2002.

Taskforces; Forensic Science Group; Sydney Police Centre, Exhibits or Property Section; or Records and Information Process Services.⁴

45.8 If an initial request for access to a crime scene sample is unsuccessful, a prisoner could seek access to the sample through a court order. Where the prisoner has lodged an appeal against conviction, the court may order production of the crime scene sample in relation to those proceedings. Where the prisoner has exhausted all avenues of appeal, he or she may be able to rely on some form of administrative law proceedings to obtain a court order for the production of the sample. However, in some circumstances—for example where the sample was collected before the introduction of DNA technology, or through error—the crime scene sample may not have been preserved.

NSW Innocence Panel

45.9 The New South Wales Police Minister has established an administrative body, known as the NSW Innocence Panel, to facilitate DNA analysis for persons who have been convicted of crimes and believe that DNA evidence may help to establish their innocence.⁵ Panel members include: a retired District Court judge; the NSW Privacy Commissioner; a Public Defender; an academic specialist in criminal law; and representatives of the Director of Public Prosecutions, the New South Wales Police Commissioner, the Director-General of the Ministry of Police, NSW Health, the NSW Legal Aid Commission and the Victims' Advisory Board.

45.10 Access to the Panel is initially limited to persons convicted of serious offences, such as murder, manslaughter and serious sexual assault, and where a person is subject to the Serious Offenders Review Council. In special circumstances, the Panel may accept applications from persons convicted of other offences.⁶

45.11 Under the Panel's procedures, the applicant must specify the items that could assist in establishing his or her innocence. If an application is approved, the Panel asks the New South Wales Police (and NSW Health, if relevant) to conduct a search for the crime scene sample or exhibit. If the item is found, it is forwarded to the Division of Analytical Laboratories for analysis (or to another laboratory where the applicant has queried initial test results). The Panel then forwards the results to the applicant, suggesting that he or she seek legal advice about how to pursue judicial review of the conviction.⁷

4 NSW Innocence Panel, *Correspondence*, 3 February 2003.

5 Innocence Panel, *The Innocence Panel, Brochure* (2002), NSW Government. The Panel was established in October 2001, and began to distribute application forms and brochures to correctional centres and other organisations in October 2002.

6 Ibid.

7 NSW Innocence Panel, *Correspondence*, 3 February 2003.

Issues and problems

45.12 Access to DNA analysis for the purpose of ‘establishing innocence’ depends on the long-term storage of crime scene samples in appropriate conditions. One commentator has noted that in the United States:

In seventy-five percent of cases taken by the Innocence Project, where it had already determined that a DNA test would demonstrate innocence if it were favorable to the inmate, the evidence had been lost or destroyed. In two-thirds of the cases in which the evidence was found and DNA testing conducted, the results have exonerated the inmate.⁸

45.13 The *Crimes Act* does not prescribe a minimum period for retaining crime scene samples. In some cases, a person might seek access to a crime scene sample many years, or decades, after the offence occurred. In the interests of justice, it is important to ensure that crime scene samples are retained for a sufficient period, and in appropriate conditions, to ensure they are available for persons seeking to rely on the samples to establish their innocence.

Submissions and consultations

45.14 DP 66 proposed that forensic procedures legislation should require the permanent retention of forensic material found at crime scenes to ensure the preservation of crime scene material for post-conviction analysis.⁹

45.15 A number of submissions supported the proposal,¹⁰ however several suggested that *permanent* retention might not be necessary or practicable. The Institute of Actuaries of Australia submitted:

IAAust supports the need to retain forensic materials from crime scenes for a period long enough to cover any conceivable need for post-conviction analysis ... In practice, a fixed retention period, such as fifty or a hundred years, might suffice.¹¹

45.16 The Victoria Police raised concerns about the resource implications of the proposal:

Permanent retention also raises issues with the storage, security and preservation of forensic material which incurs substantial cost to the community and law enforcement agencies. It is considered impractical that a requirement to retain forensic material should be indefinite.

8 D De Foore, ‘Postconviction DNA Testing: A Cry for Justice from the Wrongly Convicted’ (2002) 13(2) *Texas Technical Law Review* 491, 526.

9 Australian Law Reform Commission and Australian Health Ethics Committee, *Protection of Human Genetic Information*, DP 66 (2002), ALRC, Sydney, Proposal 36–10.

10 Centre for Genetics Education, *Submission G232*, 18 December 2002; Human Genetics Society of Australasia, *Submission G267*, 20 December 2002; Institute of Actuaries of Australia, *Submission G224*, 29 November 2002; Office of the Privacy Commissioner (NSW), *Submission G257*, 20 December 2002; Victoria Police, *Submission G203*, 29 November 2002; Office of the Victorian Privacy Commissioner, *Submission G266*, 20 December 2002; National Legal Aid, *Submission G314*, 19 February 2003; Office of the Federal Privacy Commissioner, *Submission G294*, 6 January 2003; Association of Genetic Support of Australasia, *Submission G284*, 25 December 2002.

11 Institute of Actuaries of Australia, *Submission G224*, 29 November 2002.

The need to retain exhibits for post conviction analysis should be evaluated in view of the availability of physical evidence for re-testing, the role of that physical evidence in the case against the accused, the probative value of re-testing and defence used at trial. The protection of an accused's access to post trial analysis could be adequately addressed by policy, legislative or regulatory criteria to specify or limit which exhibits are retained.¹²

45.17 The Queensland Government also opposed the proposal on the basis that permanent retention of this forensic material would have significant resource implications.¹³

45.18 In a consultation, the NSW Innocence Panel expressed concerns about the practical implementation of the proposal. It was noted that as DNA technology develops it is becoming increasingly possible to obtain DNA samples from crime scenes and exhibits, for example in the form of trace DNA collected from items the offender has touched. This raises policy questions regarding the types of offences from which crime scene samples should be collected, the types of exhibits and samples that should be subject to long term or indefinite retention, and the practicability of retaining these items.¹⁴

45.19 The New South Wales Police Service made a similar point in its submission:

The retention of all items collected from a crime scene poses problems in relation to storage. In the past in New South Wales, items were generally photographed and, after being analysed, were destroyed although policies in this regard were determined locally. All exhibits relating to sexual assaults and serious indictable offences are currently being retained pending a determination of the requirements of the Innocence Panel. As soon as these requirements have been established and endorsed, a service-wide policy in relation to the retention/destruction of exhibits will be prepared. If all items were to be retained, however, a central repository would need to be considered.

The retention of forensic material retrieved from crime scenes or from items collected at crime scenes would certainly have its advantages in some instances in view of the rapid technological scientific advances that are occurring. However, there would need to be some criteria established in relation [to] what was worthy of being retained and, once again, such a policy would pose problems in relation to storage.¹⁵

45.20 NATA also commented that:

If the intention is to store items of evidence found at crime scenes, then the proposal for permanent retention would pose an enormous burden on either laboratories or police services to store vast numbers of evidence items securely and at appropriate temperatures.

If the intention is to store only swabs and subsamples (ie portions cut out of larger items) or DNA extracts, then storage space and conditions would be less of an issue.

12 Victoria Police, *Submission G203*, 29 November 2002.

13 Queensland Government, *Submission G274*, 18 December 2002.

14 NSW Innocence Panel, *Consultation*, Sydney, 24 January 2003.

15 NSW Police Service, *Submission G306*, 22 January 2003.

Laboratories do not always test every item submitted for a given case. In some cases, a determination is made as to which items are most likely to give an interpretable DNA profile(s) and only those items are tested. In these cases, provision would need to be made for the permanent storage of the items not tested.¹⁶

45.21 The Law Institute of Victoria suggested that material found at a crime scene could be destroyed upon ‘closure’ of an investigation, which should take account of both the potential for appeal and the interests of victim's interests in the early destruction of samples relating to the investigation.¹⁷

45.22 Several other submissions expressed privacy concerns about the implications of the proposal for victims and third parties whose samples are recovered from crime scenes. The Office of the Victorian Privacy Commissioner commented:

Extreme care needs to be exercised where a claim of wrongful conviction involves a request for a DNA sample from a victim or third party associated with the victim. Unreasonable and intrusive collection should be avoided to prevent re-traumatisation and to ensure the privacy of victims and their families. In cases where the possibility of exonerating a wrongfully convicted person outweighs the privacy interest of the victim, DNA collection should proceed only with judicial authority and by the use of the least intrusive method.¹⁸

45.23 Dr Gregor Urbas also raised privacy and ethical concerns in relation to victims and their relatives.

Where the forensic material sought to be tested or re-tested as part of a post-conviction review originates from victims or victims’ relatives, there are serious ethical difficulties in turning such material over without the consent of those involved, or more problematic still, in requiring such persons to provide fresh DNA samples for testing ... it is difficult to see how a full inquiry could proceed without the willing co-operation of the victim’s family, or failing that, the extension of coercive powers in regard to forensic procedures significantly beyond current limits.¹⁹

45.24 Privacy NSW suggested an alternative approach: to remove the identifying links to samples that were not found to identify suspects or offenders, with the option of relinking them in the event of a subsequent innocence hearing.²⁰

45.25 Finally, the New South Wales Council for Civil Liberties suggested the need for a system to protect the integrity of crime scene samples.

We are told that in some cases forensic police are asked to collect DNA from a number of different and varying crime scenes in the same day and that the information, once collected, is sent to laboratories for analysis in bulk. The capacity for mix-up under such a system is great.²¹

16 National Association of Testing Authorities Australia, *Submission G273*, 18 December 2002.

17 Law Institute of Victoria, *Submission G275*, 19 December 2002.

18 Office of the Victorian Privacy Commissioner, *Submission G266*, 20 December 2002.

19 G Urbas, *Submission G131*, 19 March 2002.

20 Office of the Privacy Commissioner (NSW), *Submission G257*, 20 December 2002.

21 New South Wales Council for Civil Liberties, *Submission G312*, 10 February 2003.

Inquiry's views

45.26 The submissions generally supported the Inquiry's proposal, but concerns were expressed about the potential resource implications of permanent retention of samples. The Inquiry has sought to address these concerns in two ways. First, it may not be necessary to retain samples obtained from the scene of minor offences on a long term basis. As most applications for post-conviction review would be limited to persons convicted of serious offences—for which they have been sentenced to imprisonment—the Inquiry considers it would be reasonable to require that only samples relating to serious crimes should be retained.²²

45.27 Second, the Inquiry recognises that the permanent retention of crime scene samples may be impractical. Instead, it would be sufficient for the Commonwealth to identify a retention period long enough to ensure that any person convicted of a criminal offence would have access to the crime scene sample throughout the maximum period of imprisonment for the offence and for some period afterward.

45.28 The Inquiry also heard concerns about the genetic privacy of victims and third parties whose belongings or DNA samples are considered crime scene samples. For example, the NSW Innocence Panel suggested an example of an alleged sexual assault in a car. The Panel asked whether the police should be required to retain the entire car—as the alleged crime scene—on a long term basis, or whether it would be sufficient to inspect sections of the car only for DNA samples before returning it to its owner. If the latter, they asked which surfaces the police should be required to inspect in order to ensure that all relevant samples are obtained.

45.29 In practice, decisions about which exhibits would be inspected for samples would be made with reference to all the evidence available in the investigation, and the nature and course of the proceedings. For example, where the victim alleges the assault took place in the back seat of the car there may be no need to inspect the car boot or other surfaces for samples. Alternatively, where the defendant admits that sexual intercourse took place, but alleges that it was consensual, DNA evidence may have no relevance as to guilt or innocence.

45.30 To maximise the possibility of identifying and retaining all relevant crime scene samples with minimal privacy implications for victims and third parties, the Inquiry suggests that police services should develop guidelines regarding the appropriate collection and retention of crime scene samples and exhibits in so far as they might contain DNA samples relevant to the offence.

45.31 The Inquiry recommends that the *Crimes Act* should be amended to require the long-term retention of forensic material found at the scene of serious crimes to facilitate post-conviction analysis.

22 The *Crimes Act* defines a 'serious offence' as a Commonwealth offence punishable by a maximum penalty of imprisonment for life or five or more years: *Crimes Act 1914* (Cth) s 23WA(1).

Recommendation 45–1. The Commonwealth should amend the *Crimes Act 1914* (Cth) to require the long-term retention of forensic material found at the scene of serious crimes to facilitate post-conviction analysis.

Avenues for obtaining a review of conviction

Existing avenues for review

45.32 Dr Gregor Urbas has commented that:

The promise of DNA evidence in overturning wrongful convictions depends heavily on the capacity of the criminal justice system, through the criminal appeals process and other post-conviction proceedings, to recognise and correct errors. This capacity depends in turn on the criminal justice system's appreciation of its own fallibility, including its capacity to deal with mistakes of fact as well as procedural irregularities or mistakes of law in criminal trials.²³

45.33 Every Australian jurisdiction provides statutory avenues for appeal against conviction. Appeals from verdicts in serious criminal matters are heard in Courts of Criminal Appeal within the Supreme Court of each state and territory jurisdiction.²⁴

Courts of Criminal Appeal

45.34 Courts of Criminal Appeal have the power to overturn convictions on three primary grounds: the verdict was unreasonable or unsupportable having regard to the evidence;²⁵ the verdict was based on an error of law; or a miscarriage of justice occurred. A court may dismiss an appeal against conviction if it considers that no substantial miscarriage of justice has occurred.²⁶

45.35 Courts of Criminal Appeal in Australia have the power to receive additional evidence if this is deemed 'necessary or expedient in the interests of justice'. The Federal Court also has a discretion to receive further evidence where it is 'fresh' and 'cogent'. 'Fresh evidence' is evidence that either did not exist at the time of the trial, or which could not with reasonable diligence have been discovered at that time. In order to be admitted, the evidence must be material, and of such weight that the appellate court considers that if it had been placed before the jury together with the other evidence, a different verdict might reasonably have resulted.²⁷

23 G Urbas, 'DNA Evidence in Criminal Appeals and Post-Conviction Inquiries: Are New Forms of Review Required?' (2002) 2 *Macquarie Law Journal* 141, 143.

24 Ibid, 143.

25 This ground is also referred to as an unsafe or unsatisfactory verdict.

26 G Urbas, 'DNA Evidence in Criminal Appeals and Post-Conviction Inquiries: Are New Forms of Review Required?' (2002) 2 *Macquarie Law Journal* 141, 144.

27 Ibid, 151–152.

High Court of Australia

45.36 The High Court has held that it does not have the power to receive fresh evidence in a criminal appeal.²⁸ Therefore, if an appellant obtains fresh evidence, in the form of DNA evidence, after an unsuccessful appeal to a state or territory Court of Criminal Appeal, the High Court does not appear to have the power to receive that evidence or to hear any appeal based upon it.

Administrative review

45.37 All Australian jurisdictions provide for the Attorney-General to refer particular cases to appellate courts for further review, usually after the individual has sought a petition of mercy. Alternatively, the Executive may order a Royal Commission or similar inquiry into a conviction.²⁹

Innocence projects

45.38 The University of Technology Sydney, and Griffith University each have established Innocence Projects, with the intention that law students may assist prisoners in gaining access to post-conviction review on the basis of DNA and other evidence.³⁰

Issues and concerns

45.39 In his submission to the Inquiry, Dr Urbas outlined the obstacles that might confront an appellant seeking the quashing of a conviction on the basis of DNA evidence. First, appellate courts narrowly interpret the grounds upon which they may overturn a conviction, and are reluctant to ‘usurp the function of the jury’. Second, there is the requirement that new evidence on appeal must be ‘fresh and cogent’, and the High Court’s inability to receive fresh evidence in a criminal appeal. Third, there are costs and difficulties in obtaining access to forensic material and having such material independently examined.³¹

Options for reform

Specific legislation

45.40 Several States in the United States have implemented legislation providing for post-conviction access to DNA testing and review of conviction. Most of these States have followed the Illinois or New York legislative models.³²

28 See *Eastman v The Queen* (2000) 203 CLR 1; *Mickelberg v The Queen* (1989) 167 CLR 259.

29 G Urbas, ‘DNA Evidence in Criminal Appeals and Post-Conviction Inquiries: Are New Forms of Review Required?’ (2002) 2 *Macquarie Law Journal* 141, 159.

30 These projects are based on the Innocence Project founded in 1992 by Professor Barry Scheck and Peter Neufeld at the Benjamin N Cardozo School of Law, Yeshiva University, New York.

31 G Urbas, *Submission G131*, 19 March 2002.

32 K Christian, “‘And the DNA Shall Set You Free’: Issues Surrounding Postconviction DNA Evidence and the Pursuit of Innocence” (2001) 62 *Ohio State Law Journal* 1195, 1200–1208. See also D De Foore, ‘Postconviction DNA Testing: A Cry for Justice from the Wrongly Convicted’ (2002) 13(2) *Texas Technical Law Review* 491, 511–512.

45.41 Illinois provides a number of conditions that must be satisfied for access to post-conviction DNA testing. The evidence must have been secured in relation to the trial; the identity of the offender must have been at issue during the trial; the evidence must have been subject to a proper chain of custody; the results must have the scientific potential to produce ‘new, non-cumulative evidence “materially relevant” to the defendant’s assertion of actual innocence’; and the testing methods must be accepted within the scientific community.³³

45.42 The New York model requires instead that the results must raise a ‘reasonable probability’ that the verdict would have been more favourable to the defendant.³⁴

45.43 The Innocence Protection Bill 2001 was introduced into the United States Congress to permit inmates convicted of federal offences to petition a federal court for post-conviction DNA testing.³⁵ The Bill provides that federal courts must grant a defendant’s request for post-conviction DNA testing if:

- the DNA evidence relates to the federal crime for which the defendant was convicted;
- the evidence is still in existence and in a suitable condition for testing;
- the evidence has not been previously tested, or new DNA testing procedures exist that will resolve an issue not resolved by previous testing;
- the testing procedures are be scientifically valid; and
- the testing must yield ‘new, noncumulative, exculpatory evidence material to the claim’ of the defendant.

45.44 If the DNA testing produces exculpatory results, the federal courts must order a hearing and make appropriate orders.³⁶

Administrative bodies

45.45 As discussed above, the NSW Innocence Panel is an administrative body established for the purpose of arranging analysis of crime scene samples for use in appeals against conviction.

33 K Christian, “‘And the DNA Shall Set You Free’: Issues Surrounding Postconviction DNA Evidence and the Pursuit of Innocence’ (2001) 62 *Ohio State Law Journal* 1195, 1202–1203.

34 Ibid.

35 The Bill was re-introduced into Congress in June 2002: *Innocence Project Website*, Benjamin N Cardozo School of Law, <www.innocenceproject.org/>, 28 February 2003. In addition, several other bills have been proposed as the state and federal level to address post-conviction testing.

36 K Christian, “‘And the DNA Shall Set You Free’: Issues Surrounding Postconviction DNA Evidence and the Pursuit of Innocence’ (2001) 62 *Ohio State Law Journal* 1195, 1229–1230. The Bill encourages state compliance by conditioning federal grant money on compliance with the Bill’s provisions. See also D De Foore, ‘Postconviction DNA Testing: A Cry for Justice from the Wrongly Convicted’ (2002) 13(2) *Texas Technical Law Review* 491, 516–519.

45.46 The Criminal Cases Review Commission (CCRC) is another model for post-conviction review. The CCRC is an independent body responsible for investigating suspected miscarriages of justice in England, Wales and Northern Ireland.³⁷ The CCRC's main responsibilities are to:

- review alleged or suspected miscarriages of justice, and to refer a conviction, verdict, finding or sentence to the appropriate court of appeal when it considers that there is a 'real possibility' that it would not be upheld;
- investigate and report to the Court of Appeal on any matter the Court refers to it; and
- consider and report to the Secretary of State on any matter referred to it regarding whether or not to recommend the exercise of the royal prerogative of mercy in relation to a conviction.³⁸

45.47 Other than in exceptional circumstances, a matter may only be referred to the CCRC if an appeal against the conviction, verdict, finding or sentence has been determined, or leave to appeal has been refused.³⁹ The CCRC can investigate issues itself; appoint an expert to carry out an investigation or prepare a report; request police to carry out work; or require formal appointment of an investigating officer.⁴⁰

Submissions and consultations

45.48 DP 66 proposed that the Commonwealth should legislate to establish an independent body to consider applications for post-conviction review based on DNA evidence where the person provides prima facie evidence that there has been a miscarriage of justice.⁴¹

45.49 Most of the submissions supported this proposal.⁴² The Human Genetic Society of Australasia suggested that the body should have the power to investigate alleged miscarriages of justice, similar to the CCRC.⁴³ Liberty Victoria noted the apparent reluctance of appeal courts to re-open issues, and suggested that if the independent body referred a matter to an appeal court, the court should note that the body had considered there was a matter to be addressed.⁴⁴

37 The CCRC was established under the *Criminal Appeal Act 1995* (UK): see Criminal Cases Review Commission, *Annual Report: 2001-02* (2002), CCRC, London, 6.

38 Ibid, 6.

39 Ibid, 8.

40 Ibid, 15.

41 Australian Law Reform Commission and Australian Health Ethics Committee, *Protection of Human Genetic Information*, DP 66 (2002), ALRC, Sydney, Proposal 38-1.

42 Centre for Genetics Education, *Submission G232*, 18 December 2002; Human Genetics Society of Australasia, *Submission G267*, 20 December 2002; Association of Genetic Support of Australasia, *Submission G284*, 25 December 2002; Victorian Bar, *Submission G261*, 20 December 2002; Institute of Actuaries of Australia, *Submission G224*, 29 November 2002; Department of Human Services South Australia, *Submission G288*, 23 December 2002.

43 Human Genetics Society of Australasia, *Submission G267*, 20 December 2002.

44 Liberty Victoria, *Consultation*, Melbourne, 23 October 2002.

45.50 By contrast, the South Australian Attorney-General's Department considered that there was no need for a special post-conviction procedure for cases involving DNA evidence, on the basis that administrative avenues for review already exist.⁴⁵

45.51 Privacy NSW commented that:

The exercise of creating 'innocence panels' and establishing procedures for post-conviction review needs to be seen as more than a political stunt and a means of soft-selling the more privacy invasive aspects of DNA testing. The potential to provide a credible process of review depends on a clear delineation of the functions, powers and responsibilities of the bodies which conduct the initial assessment and any subsequent judicial review.

It is our experience in New South Wales ... that such schemes need to have precise legislative authorisation and that their procedures, powers and responsibilities should be defined clearly, rather than being left to the panel itself to define. Panels require the resources to independently assess the facts relevant to a particular application, without undue reliance on the views of police and prosecutors.

The subsequent review should be conducted by a judicial officer or officers, also operating within a clearly defined framework which pays specific attention to the issues which are likely to arise in such a specialised inquiry and who are equipped or assisted with the expertise to properly assess relevant evidence.⁴⁶

45.52 The Victorian Bar supported the proposal but expressed concern with the suggested requirement that an applicant must provide *prima facie* evidence of a miscarriage of justice.

The Bar considers that such a test places 'the bar' too high. The reality is that the critical factor that may raise a *prima facie* case that there has been a miscarriage of justice is the subsequent DNA testing. However, this would not be available to prove miscarriage under the proposed scheme. The proposal in effect requires that there be independent evidence of miscarriage, other than such DNA testing. It is the Bar's view that a measure of flexibility is required to ensure that testing is conducted where there is a possibility of wrongful conviction based on DNA evidence. This must necessarily be so in cases where, for example, the only real evidence against the Accused was the 'strength' of the DNA evidence, or in cases where there was no ability to conduct exculpatory testing at time of trial, but subsequent scientific advances have made this possible.⁴⁷

45.53 In consultations, both Dr Ian Freckelton and Dr Jeremy Gans also expressed the view that the requirement for *prima facie* evidence of a miscarriage should be removed. Dr Gans also noted a preference for a more general review body than one dealing with DNA evidence only.⁴⁸

45 South Australian Attorney-General's Department, *Consultation*, Adelaide, 30 October 2002. The Law Institute of Victoria also considered that such a body was unnecessary: Law Institute of Victoria, *Submission G275*, 19 December 2002.

46 Office of the Privacy Commissioner (NSW), *Submission G257*, 20 December 2002.

47 Victorian Bar, *Submission G261*, 20 December 2002.

48 I Freckelton and J Gans, *Consultation*, Melbourne, 21 October 2002.

45.54 Finally, the Commonwealth Attorney-General's Department commented that the Sherman review⁴⁹ is currently considering this issue; and the Joint Standing Committee of Attorneys-General and Australasian Police Ministers' Council Working Group is expected to consider improvements to the Model Forensic Procedures Bill in 2003 once it has been in operation for more time and in more jurisdictions.⁵⁰

Inquiry's views

45.55 As discussed above, the Inquiry has heard concerns that there may be particular obstacles confronting a person seeking post-conviction review on the basis of DNA evidence. The Inquiry recognises these concerns but considers that the established processes for obtaining an appeal against conviction, or administrative or executive relief, are generally adequate. For example, where DNA evidence becomes available subsequent to conviction this evidence could, depending on the circumstances, form the basis of an appeal based on the safety of the original verdict, an error of law (for example in the trial judge's summing up), or the assertion that a miscarriage of justice has occurred. While the High Court could not consider such fresh evidence in an appeal against conviction, an appellant could apply to the Attorney-General or the Governor-General (or the Governor, in state jurisdictions) for further review.

45.56 The Inquiry considers that the principal issue for persons seeking post-conviction review on the basis of DNA evidence is the need to obtain access to the crime scene sample, and to DNA testing of the sample. Therefore, it would be desirable to establish a process to consider allegations of miscarriages of justice due to the use of, or failure to use, DNA evidence in a criminal prosecution.

45.57 In DP 66, the Inquiry proposed the establishment of an independent body by legislation, rather than by administrative means. The CCRC is an example of a legislative body, while the NSW Innocence Panel is an example of an administrative body. DP 66 noted that a legislative basis would ensure public confidence in its independence, and thus in the integrity of the criminal justice system as a whole. However, the submissions did not address this issue and the Inquiry does not hold a firm view on it.

45.58 The proposal in DP 66 required the applicant to provide 'prima facie' evidence that there had been a miscarriage of justice in order to access post-conviction review. This requirement was criticised as setting the bar too high for persons who allege that they did not commit the offence for which they were convicted, but do not yet have access to any evidence that might establish this. The Inquiry recognises these concerns, and instead recommends that applicants need only allege that DNA evidence may exist that calls his or her conviction into question.

49 The Sherman review is the independent review into Pt 1D of the *Crimes Act 1914* (Cth), which is chaired by Mr Tom Sherman. See Ch 39 for more details.

50 Commonwealth Attorney-General's Department, *Submission G228*, 12 December 2002.

45.59 As with the NSW Innocence Panel, the new process at federal level should involve obtaining access to the crime scene sample and arranging DNA testing against the applicant's sample. The applicant could then rely on established avenues to lodge an appeal against conviction or, where these have been exhausted, administrative or executive avenues of review.

45.60 Consequently, the Inquiry recommends that the Commonwealth should establish a process to consider applications for post-conviction review from any person who alleges that DNA evidence may exist that calls his or her conviction into question.

45.61 Recommendation 40–3 provides that where applicable, the States and Territories should amend their forensic procedures legislation in a manner consistent with the recommendations made in this Report in relation to the *Crimes Act*. In this instance, States and Territories should consider implementing a similar process for post-conviction review based on DNA evidence.

<p>Recommendation 45–2. The Commonwealth should establish a process to consider applications for post-conviction review from any person who alleges that DNA evidence may exist that calls his or her conviction into question.</p>
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46. Civil Proceedings

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Introduction

46.1 To date there has been limited use of genetic information in civil proceedings in Australia, with the exception of the use of DNA parentage testing in family law proceedings and in proceedings related to succession to estates (see Chapter 35). However, commentators have suggested that as the predictive nature of genetic tests gains greater acceptance in the scientific and medical communities, this information increasingly could be used.¹

46.2 This chapter discusses the potential use of genetic information that discloses a person's inherited predisposition to, or presymptomatic status for, a disease or condition in the context of civil proceedings.

46.3 Genetic information could be used as evidence in various tort actions, including actions for personal injury, medical negligence or product liability. For example, in the United States, wrongful life and wrongful birth cases have been brought for failure to inform patients of the risks of having children with serious genetic disorders, and for the negligent administration of tests for genetic diseases.² As

1 See G Marchant, 'Genetics and Toxic Torts' (2001) 31 *Seton Hall Law Review* 949; R Weiss and others, 'The Use of Genetic Testing in the Courtroom' (1999) 34 *Wake Forest Law Review* 889; N Kording and J DuMontelle, 'An Overview of Admissibility of Genetic Test Results in Federal Civil Actions: An Uncertain Destiny' (1998) 19 *Whittier Law Review* 681; J Wriggins, 'Genetics, IQ, Determinism and Torts: The Example of Discovery in Lead Exposure Litigation' (1997) 77 *Boston University Law Review* 1025; M Rothstein, 'Preventing the Discovery of Plaintiff Genetic Profiles by Defendants Seeking to Limit Damages in Personal Injury Litigation' (1996) 71 *Indiana Law Journal* 877; R Dreyfuss and D Nelkin, 'The Jurisprudence of Genetics' (1992) 45 *Vanderbilt Law Review* 313.

2 R Weiss and others, 'The Use of Genetic Testing in the Courtroom' (1999) 34 *Wake Forest Law Review* 889, 912.

discussed in Chapter 33, genetic information could also be used in the context of workers' compensation claims or common law actions for damages for work-related injury or death.

46.4 In practice, the relevance of genetic information in civil proceedings may be limited by current scientific knowledge about the predictive nature of the information; the probabilistic, rather than deterministic, nature of the information; and the existence of other environmental causes of disease in the facts in issue.

Potential application in tort actions

46.5 The legal elements of a claim in negligence are that the defendant owed the plaintiff a duty of care; the defendant breached that duty; and the plaintiff suffered damage that was caused by the breach of the duty, and was not too remote from it in law.³ Where negligence is established, the court may award damages to the plaintiff.⁴

46.6 It has been said that the tort system has, in the past, treated all persons as 'identical black boxes' in relation to their risk from exposure to hazardous substances and agents. While there have been some limited exceptions, such as the 'egg-shell skull' rule in relation to highly vulnerable plaintiffs (see below), generally there has been no basis for discerning individual risk factors from the risk posed to the general population.⁵

46.7 There are a number of ways in which genetic information and, in particular, genetic test results could potentially be applied by courts in tort actions.

Causation

46.8 A defendant in a negligence action might seek to use genetic information to disprove the plaintiff's allegation that the defendant caused the plaintiff's injury. For example, where a plaintiff had a genetic predisposition to the same condition that he or she ultimately developed, the defendant could argue that it was the predisposition, rather than the defendant, that caused the injury.⁶ Alternatively, a defendant might argue that the predisposition was a contributing cause of the injury in order to minimise his or her own liability. The strength of this argument may depend on the link between the genetic mutation and the occurrence of the disorder (see Chapter 2).

3 S Berns and G Masel, 'Negligence' in G Masel (ed), *The Laws of Australia: Torts* (1997) Law Book Company Limited, Sydney, vol 33.2, [1].

4 See generally, M Noone, 'Damages' in Geoff Masel (ed), *The Laws of Australia: Torts* (1993) Law Book Company Limited, Sydney, vol 33.10.

5 G Marchant, 'Genetics and Toxic Torts' (2001) 31 *Seton Hall Law Review* 949, 953.

6 *Ibid.*, 963–964.

Susceptible plaintiffs

46.9 A plaintiff might seek to rely on genetic tests that show that he or she has a higher susceptibility to a particular chemical agent than an ordinary person in order to establish that exposure to the chemical caused the particular illness or injury, even though other exposed persons remained healthy.⁷

46.10 Alternatively, defendants might argue that they have no duty to protect genetically ‘hyper-susceptible’ persons from harm or injury, in particular where the defendant can show that its product is safe for the ‘normal’ population. However, this argument is inconsistent with an established doctrine of tort law—the ‘eggshell skull’ rule. This rule provides that a defendant is liable for the full damage caused to an unusually susceptible or fragile plaintiff, even if the extent of damage would be less in a ‘normal’ person.⁸

Duty to warn susceptible persons

46.11 A product manufacturer generally has a duty to warn consumers of potential hazards posed by that product. Failure to provide an adequate warning can result in civil liability. With increasing knowledge of susceptibilities to chemicals, pharmaceuticals and other products, it might become necessary to consider to what extent a manufacturer has a duty to warn persons with specific susceptibilities of potential hazards to them.⁹

Assumption of risk

46.12 As more genetic tests become available, defendants could seek to rely on the ‘voluntary assumption of risk’ or ‘contributory negligence’ defence to a tort claim. A defendant might argue that a plaintiff knew, or should have known, that he or she had a genetic susceptibility to a particular agent and therefore should have taken greater precautions to avoid exposure.¹⁰

46.13 It is unlikely that this argument would be successful in the workplace context because occupational health and safety statutes place a duty on employers to eliminate or minimise workplace hazards. Were it otherwise, employees might be compelled by financial circumstances to accept risks that are considered unacceptable by the general community.

Genetic monitoring

46.14 Chapter 32 discusses the use of genetic monitoring as part of health surveillance of employees exposed to hazardous substances in the workplace. Genetic biomarkers can identify changes in a person’s cells as a result of exposure to toxic substances. These genetic changes could provide a measure of exposure to a substance,

7 Ibid, 954–956.

8 Ibid, 960–963.

9 Ibid, 956–957.

10 Ibid, 965.

or an early diagnostic measure of the development of the disease before the onset of symptoms. Thousands of potential biomarkers have already been identified, most of which had yet to be fully validated scientifically.¹¹

46.15 Plaintiffs could potentially rely on biomarkers as evidence of a plaintiff's exposure to a hazardous agent, and of the harm suffered as a result of exposure. Defendants could rely on the absence of these biomarkers to argue against causation. However, the use of such biomarkers in civil proceedings is likely to be limited until they are fully validated.¹²

Assessment of damages

46.16 Defendants who have been found liable in tort could seek to have the quantum of damages reduced on the basis that the plaintiff has a predisposition to, or is presymptomatic of, a condition that would diminish the plaintiff's quality of life or lead to a shorter life expectancy. For example, where a defendant is found liable but can establish that the plaintiff would have developed the injury at some point in the future regardless of the defendant's action, the defendant might seek to have the damages reduced to compensate the plaintiff only for the period for which the defendant's actions accelerated the development of the injury.¹³

46.17 The defendant might alternatively seek to identify a genetic predisposition, or presymptomatic status, for any disease that could shorten or diminish the quality of the plaintiff's life. For example, the defendant might seek to rely on genetic tests that reveal the plaintiff is presymptomatic of Huntington's disease to argue that, because the plaintiff would not be expected to live beyond middle age, the court should reduce the amount of damages accordingly.¹⁴

Discovery of genetic information

46.18 Professor Mark Rothstein has commented:

Conceivably, in every case in which the plaintiff seeks to recover for permanent or long-term disability or lost future earnings, regardless of the legal theory of the case, the defendant could seek to discover the plaintiff's risk of premature incapacity or mortality by obtaining genetic records or performing genetic testing.¹⁵

46.19 In the United States, negligence suits have been brought in relation to children born with health defects as a result of their parents' exposure to toxic substances. In a number of these cases the courts have ordered the production of

11 Ibid, 972.

12 Ibid, 976.

13 Ibid, 968. The difficulty with this argument is in establishing that a person with a mere predisposition to a multifactorial disease would ultimately have developed the disease.

14 Ibid, 969.

15 M Rothstein, 'Preventing the Discovery of Plaintiff Genetic Profiles by Defendants Seeking to Limit Damages in Personal Injury Litigation' (1996) 71 *Indiana Law Journal* 877, 878.

personal records (such as employment, education and medical records), as well as physical and mental examinations of the person bringing the claim, as well as his or her relatives.¹⁶

46.20 The use of discovery procedures to seek access to a party's genetic test results or other genetic information has important implications. If a court were to order a plaintiff (and potentially, his or her relatives) to submit to genetic testing, this could have significant privacy implications, potentially undermining their 'right not to know' certain genetic information about themselves. Unless properly scrutinised by the courts, requests for discovery of genetic information could amount to a 'fishing expedition'; and the potential impact of discovery on plaintiffs and their relatives could be a significant deterrent to bringing legitimate actions.¹⁷

The need for judicial education

46.21 Evidence based on genetic test results is a form of opinion evidence. Under the *Evidence Act 1995* (Cth), opinion evidence is admissible if it is wholly or substantially based on a person's specialised knowledge, which in turn is based on the witness' training, study or experience.¹⁸ DNA evidence that is relevant to a fact in issue is admissible in civil proceedings unless it is barred under an exclusionary rule, or by judicial discretion.¹⁹

46.22 Chapter 44 discusses the use of DNA evidence in criminal proceedings. The Inquiry considers that a number of the concerns identified in that chapter are also relevant to civil proceedings. For example, in the light of the often highly scientific nature of genetic test results, judges will need to balance the probative value of genetic evidence against its potential prejudicial effect when considering whether to admit such evidence. Once the evidence is admitted, the expert scientific witness must explain the science and technology involved in the genetic test, the interpretation of the results, and their significance to the arbiter of fact, whether judge or jury.²⁰ In addition, each party's counsel must have sufficient understanding to examine or cross-examine the expert witnesses appropriately. The judge must also have sufficient understanding to evaluate the evidence, or to direct the jury in its evaluation of the evidence.

46.23 Justice Ming Chin of the Supreme Court of California has commented on the potential implications where genetic evidence is admitted in court proceedings:

16 J Wiggins, 'Genetics, IQ, Determinism and Torts: The Example of Discovery in Lead Exposure Litigation' (1997) 77 *Boston University Law Review* 1025, 1058. The Australian Law Reform Commission considered the role of discovery as an important aspect of effective case management in its review of the federal civil justice system: Australian Law Reform Commission, *Managing Justice: A Review of the Federal Civil Justice System*, Report 89 (2000), ALRC, Sydney.

17 J Wiggins, 'Genetics, IQ, Determinism and Torts: The Example of Discovery in Lead Exposure Litigation' (1997) 77 *Boston University Law Review* 1025, 1067.

18 *Evidence Act 1995* (Cth) s 79.

19 See *Ibid* s 56. In relation to the exclusionary rules and discretions, see ss 135, 137, 138.

20 The Hon Justice E Mullighan, 'Presenting DNA Evidence' (Paper presented at DNA Evidence: Prosecuting Under the Microscope International Conference, Adelaide, 11 September 2001), 4–6.

The use of genetic information in court raises new evidentiary challenges. DNA evidence is often complicated and laborious to present, and those without a scientific background—including most judges and jurors—often have difficulty understanding it. A courtroom is not an ideal forum for resolving conflicts between scientific theories, yet judges will constantly be asked to referee battles among lawyers and scientific experts over the acceptance of DNA evidence. The complexity and rapid development of genetic science will exacerbate the problem. Scientists need ongoing dialogue and continuous re-examination to test their theories. In courtrooms, decisions must be made at the close of the evidence. This reality creates a natural tension between science and the law.²¹

46.24 In the *Managing Justice* report, the Australian Law Reform Commission called for enhanced professional development and continuing education schemes in order to improve the efficiency and effectiveness of the civil justice system. In particular, the Commission called for greater emphasis on programs for trial lawyers and judges, to familiarise them with science, technology and evidence.²²

46.25 In the United States, an organisation known as the Einstein Institute for Science, Health and the Courts (EINSHAC) provides education to judges, courts and court-related personnel in relation to a number of scientific and technical areas, including genetic evidence.²³ According to its website:

Our calling is to make science accessible to the instruments of justice. Our mission is to provide judges, courts and court-related personnel with knowledge tools related to criminal and civil justice proceedings involving evidence from the genetic sciences—genetics, molecular biology, biotechnology and molecular medicine—and from new discoveries and technologies in the environmental and neuro-sciences. In sum, we emphasize the science and impacts of ... technologies in judicial system proceedings.²⁴

46.26 A small number of Australian judges have already participated in EINSHAC programs, and a round of meetings to be held in Australia in 2003 will further strengthen this connection.

Submissions and consultations

46.27 The Inquiry received only a small number of submissions regarding the use of genetic information in civil proceedings. The Human Genetics Society of Australasia (HGSA) submitted:

There should be no occasion in civil law where there is a compulsion for DNA testing ... In the broad context the adversarial nature of civil proceedings should be reviewed.²⁵

21 M Chin, 'Genetics and Law: A Challenge for Lawyers and Judges in the New Millennium' (2002) 18(65) *Notizie de Politeia* 103, 105.

22 Australian Law Reform Commission, *Managing Justice: A Review of the Federal Civil Justice System*, Report 89 (2000), ALRC, Sydney.

23 Einstein Institute for Science Health and the Courts, *Website*, <www.einshac.org>, 17 March 2003.

24 *Ibid.*

25 Human Genetics Society of Australasia, *Submission G050*, 14 January 2002.

46.28 Privacy NSW commented on the different contexts in which genetic information might be used in civil proceedings and the implications of each one:

Distinct approaches may be required in relation to requiring the production of potential evidence which is already held and requiring parties to submit themselves to the process of creating new evidence. Where evidence already exists there is an understandable tendency for privacy to lose out to relevance. However recent legislation expanding the scope of privilege for confidential professional advice and counselling can be seen to reflect the felt need to impose limits on some of the more intrusive effects of the expanded use of the courts' subpoena powers, in an age where litigation has come to rely on the potential of advanced information processing.

Where evidence will only become available if a party submits to testing other factors need to be considered. Should genetic evidence collected without the knowledge of a party in the course of an independent medical examination be admissible? Should the party who is sought to be tested be involuntarily exposed to the knowledge which testing might disclose? Should courts be entitled to draw adverse inferences from a refusal to submit to voluntary testing?

This is an instance where safeguards relating to genetic information might best be addressed in the context of legislation relating to evidence, rather than in general privacy legislation.²⁶

46.29 The Victoria Police suggested the use of expert panels to advise courts regarding evidence based on genetic information, and commented on the potential unfairness in compelling parties to undergo predictive genetic testing:

Consideration should be given to establishing an expert panel to advise a court on issues relating to the impact of genetic information that reveals that a plaintiff has a predisposition to disease or similar affliction ... It would seem unreasonable, however to allow one party to demand that another party in a civil matter undergo DNA testing to reveal genetic dispositions when the results would reveal just that, a disposition towards a condition, not a guarantee. The probability of developing the condition may be further complicated by environmental factors and the possibility of medical advances in treatment in the future.²⁷

46.30 DP 66 proposed that the National Judicial College of Australia and the Law Council of Australia should ensure the availability of continuing legal education programs for judges and legal practitioners, respectively, in relation to the use in civil proceedings of evidence based on genetic information.²⁸

46.31 All of the submissions that addressed this issue supported the need for greater education of judges and the legal profession in relation to this form of evidence.²⁹ The Centre for Genetics Education suggested that the Human Genetics

26 Office of the Privacy Commissioner (NSW), *Submission G118*, 18 March 2002.

27 Victoria Police, *Submission G086*, 21 January 2002.

28 Australian Law Reform Commission and Australian Health Ethics Committee, *Protection of Human Genetic Information*, DP 66 (2002), ALRC, Sydney, Proposal 39–1.

29 Australian Privacy Charter Council, *Submission G304*, 21 January 2003; Human Genetics Society of Australasia, *Submission G267*, 20 December 2002; Association of Genetic Support of Australasia, *Submission G284*, 25 December 2002; Department of Human Services South Australia, *Submission*

Commission of Australia (HGCA) should also have a role in providing education in this context.³⁰ The HGSA suggested the importance of liaison with other genetics education bodies:

In order to ensure that the legal profession [is] appropriately skilled to understand DNA evidence it is important that continuing education is provided to them. It will be important for liaison with the HGSA and other genetics education organisations to ensure that [the] National Judicial College of Australia and the Law Council of Australia access experts from the medical and scientific community to maintain the highest possible standards in this education.³¹

46.32 The Australian Chamber of Commerce and Industry commented that it

would expect that members of the profession would update their knowledge on all issues, which may guide them in dealing with civil proceedings including genetic testing.

A duty already rests with members of the Australian Industrial Relations Commission, under s 20 of the *Workplace Relations Act 1996*, to keep acquainted with industrial affairs and conditions.³²

46.33 The Law Institute of Victoria provided a detailed discussion of the potential application of genetic information to personal injury litigation. It commented:

The Law Institute supports the proposal for the National Judicial College of Australia and the Law Council of Australia, or other appropriate bodies, to ensure the availability of relevant continuing legal education programs for judges and legal practitioners in the area of Human Genetic Information.

The use of evidence based on genetic information in civil proceedings is complex, for many of the reasons set out already in relation to the criminal justice system. It is a rapidly developing area, where training and skills may become redundant very quickly. It is unreasonable to expect lay people to be able to assess the probative value and the prejudicial effect of genetic information without suitable and continuing education ...³³

46.34 The Law Institute of Victoria noted that a small number of its members had no objection to the use of genetic testing in civil proceedings. These members considered that genetic testing is simply another forensic tool which, if properly supervised, should be available in the conduct and resolution of litigation.³⁴

G288, 23 December 2002; Androgen Insensitivity Syndrome Support Group Australia, *Submission G290*, 5 January 2003; Law Institute of Victoria, *Submission G275*, 19 December 2002.

30 Centre for Genetics Education, *Submission G232*, 18 December 2002.

31 Human Genetics Society of Australasia, *Submission G267*, 20 December 2002.

32 Australian Chamber of Commerce and Industry, *Submission G308*, 24 January 2003.

33 Law Institute of Victoria, *Submission G275*, 19 December 2002.

34 Ibid.

Inquiry's views

46.35 The Inquiry is not aware of Australian civil proceedings in which parties have sought to introduce predictive health information into evidence. Several potential applications of genetic information in civil proceedings have been outlined above, in particular in relation to issues of causation and damages.

46.36 All of the submissions that addressed this issue supported the Inquiry's reform proposal. The Inquiry accordingly recommends that the National Judicial College of Australia and the Law Council of Australia (through its constituent professional associations) should develop and promote continuing legal education programs for judges and legal practitioners, respectively, in relation to the use of genetic information in civil proceedings. These bodies should provide ongoing guidance regarding genetic technology, reliability of genetic testing, interpretation of genetic test results, and presentation of evidence in civil proceedings.

46.37 The Centre for Genetics Education suggested that the HGCA should also have a role in the provision of education to the legal profession. The Inquiry considers this a sensible suggestion. Once established, the HGCA could provide guidance to these nominated bodies, upon request, about the education and training of judges and legal practitioners regarding the use of genetic information in civil proceedings.

Recommendation 46–1. The National Judicial College of Australia and the Law Council of Australia (through its constituent professional associations) should develop and promote continuing legal education programs for judges and legal practitioners, respectively, in relation to the use of genetic information in civil proceedings.

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Only legislation discussed in some detail is listed. Other legislation can be located by using the full text search facility available on the internet and CD versions of this Report.

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