The Protection of Human Genetic Information

Implications for Insurers

IFSA Lunch
1July 2003

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Terms of reference

In relation to human genetic information and samples, how can we best:

- protect privacy
- protect against *unfair* discrimination
- ensure highest ethical standards

Application to many different contexts

- Medical research
- Clinical practice
- Systemic health care issues
- Genetic databases, tissue banks, registers
- Employment
- Insurance

- Law enforcement
- Kinship & Identity (immigration; parentage; Aboriginality?)
- Other contexts (eg sport)

Inquiry Processes

- ALRC-AHEC received ToR (Feb 2001)
- Advisory committee (geneticists, doctors, bio-ethicists, insurers, actuaries, lawyers)
- Research – national, international
- Public consultation docs (IP 26, DP 66)
- 15 public forums around Australia
- >200 meetings, consultations
- Written submissions (>300)

Final Report – March 2003

- Essentially Yours: The Protection of Human Genetic Information in Australia (ALRC 96) (launched 29 May)
- 144 recommendations
- Directed at 31 bodies: federal and state governments – health, OH&S, police, privacy, immigration; NHMRC; NATA; TGA and other regulators; IFSA and ICA; employers; educational authorities, etc

Implementation rates

- Substantial Implementation [n37-56%]
- Partial Implementation [n15-23%]
- Nil Implementation [n10-15%]
- Proposals under consideration [n4-6%]

A Human Genetics Commission

- **Centerpiece:** Recommended establishment of an independent, statutory advisory body: a **Human Genetics Commission of Australia** (HGCA)
- Recognises rapid change, need for continuing high level advice to government/industry and to maintain public confidence
- Broad-based membership (technical/expert, but also ELSI/community)
- Specific responsibilities:
- advice to insurers, employers, regulators (eg TGA); promote genetics education; provide national leadership and coordination

Is genetic information special?

- Unique (although 99.9% Ξ !)•Ubiquitous
- Powerful – one cell tells all
- Stable – dinosaurs to disasters
- Familial dimension
- Predictive – but interactive, contingent and complex!
- Dynamic technology

On the other hand …

- Family history of hereditable diseases has been used for >100 years by researchers, doctors, and insurers
- Other medical tests/info also very sensitive (eg Hep B/C, HIV-AIDS, STDs, cancers, depression, psychiatric illness, brain injury)
- Artificial and unfair to separate 'genetic' and 'non-genetic' information for policy-making purposes

Employment

- Very few industrial disputes *yet* (police?) – but employer incentives for genetic screening
- direct economic incentives (reduce insurance premiums, sick leave, staff turnover)
- OH&S duties;
- public health and safety (eg pilots, drivers)
- So we can anticipate increased pressure for testing as costs decrease, availability increases
- Cf drug and alcohol testing, psychometric testing, workplace surveillance
- Clear public policy: everyone has right to work; part of human dignity; even work for the dole
- Fear of the creation of a 'genetic underclass' – currently fit and able, but with a *predisposition* to a genetic disease/disorder
- This justifies an interventionist approach:
    - **General rule: no use of predictive genetic testing/information …**
    - **Except** in limited cases where necessary to discharge OH&S or public safety obligations
    - **And** the test/interpretation has been approved for this purpose by the HGCA and NOHSC

Insurance fundamentals are sound

- Mutual insurance is a voluntary private market,
- It's not publicly subsidised (cf community-rated health insurance) and it's not social security
- Risk-rated life insurance is not an *essential* good (c30% take-up in Australia)
- Risk-rating based upon full disclosure – drawing distinctions among individuals – is central
- Need to preserve equity among pooled insureds
- Real risk of adverse selection – perhaps not on GT alone, in short term, but …
- No arbitrary distinctions according to source of actual or predicted ill-health
- Need robust policies for the long-term, **therefore,** "no justification at present for departing from fundamental principles of full disclosure and equality of

information"; b**ut**, still a need for a range of improvements in interests of consumers

1. Oversight by HGCA

- Anti-discrimination law exemptions (sex, disability, age; but not race) must be based upon reasonable actuarial or statistical data
- Insurers currently self-assess the actuarial relevance of genetic information

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- HGCA to advise on the use of specific genetic tests for underwriting, and IFSA, ICA to ensure all members conform (R27-2).
- HGCA to keep a watching brief on relevant international initiatives (eg 2-tier approaches)

Other approaches?

- GTI banned in underwriting
    - eg Denmark (test results; but FMH is OK)
- Two-tier systems
    - eg UK, Holland, Sweden
    - below $ threshold, GT results banned; only above threshold can GT results be used;
    - BUT raises many questions:
        - setting $ threshold – link to mortgages?; index?;
        - why privilege **genetic** information?

2. Use of family medical history

- IFSA policy applies to 'genetic test information' but not to family medical history (FMH) – which is much more widely used.
- Long industry use of FMH, but application and interpretation less certain than GT info?

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- Insurance industry should develop and publish policies on the use of FMH in underwriting (R27-4).

3. Assuring genetic privacy

- Consent forms (including medical authority forms) should provide sufficient information for applicants to make an informed decision about consent to the collection and use of GI (R28-1)
- Applicants should not be asked for 'bundled consents' (R28-2)
- Insurers should seek a PID to collect information about genetic relatives (FMHs) (R28-3)

4. Reasons for adverse U/W decisions

- Currently required under s75 ICA, s107 DDA, and IFSA policy – BUT problems of scope and adequacy.

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- Insurers must inform applicants of statutory right to reasons for adverse decisions (R27-6)
- IFSA to develop mandatory policies on providing clear and meaningful reasons for adverse U/W decisions based on GT information or FMH – explaining the actuarial, statistical /or scientific basis (R27-7)

5. External review

- Review now available through insurer or HREOC – but problems of accessibility, impartiality and formality.

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- FICS' jurisdiction should be expanded to review adverse U/W decisions based on GT or FMH (R27-9):
    - in a timely and efficient manner;
    - conducted by suitably qualified individuals;
    - binding on the insurer but not the complainant; and
    - $ cap set to cover the substantial majority of cases.

6. Industry education

- Industry should review education and training of brokers and agents regarding the collection and use of genetic information in insurance (R27-10).
- NFITAB, in association with the industry, to review competency standards and the Financial Services Training Package, to incorporate appropriate competency standards regarding the collection and use of genetic information (R27-11)

For further information

- ALRC 96 is available free online at: www.alrc.gov.au
- To purchase in hard copy or CD format,
  or for further information –

- Email: genetic@alrc.gov.au
- Tel: 8238 6333
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