Dear Sir,

I have made extensive commentary about the Human Tissue Acts and patent legislation. This has included former Senator Bill Heffernan's Patent Amendment (Human Genes and Biological Materials) Bill 2010 at Submissions received by the Committee – Parliament of Australia (submission 3). While appreciating that you do not believe a major part of your inquiry will involve stem cell lines or regenerative medicine, I ask: why? Regenerative medicine could free many from disability and/or chronic illness, as by its very name and nature it restores or replaces damaged tissue. Yet this is never seen as a key part of dignity or equity, as lawyers and ethicists rush to allegedly save 'vulnerable' people from alleged exploitation, harassment, or an early, untimely death. While a lawyer and not a doctor by training, the understanding of risk and reward for all parties is often poorly argued, often constructed in a moral panic about new technology, while failing to consider the actual risk appetites and objectives of clinicians and trial participants. I know – I've participated in many studies as a patient/participant and, would have been happy for the research to be more extensive. Similarly, there have been opportunities to be a consumer advisor to others, though in this submission one writes in a purely personal capacity.

I urge you to pause and consult the Aged Care Royal Commission, the Disability Royal Commission, and the prior McCleland Royal Commission into the Institutional (non) Responses to Child Abuse and Neglect. This is not to mention the likely coming Commission into Child Care. In short, amending the Human Tissue Acts, potentially quite substantially, poses far less risk to me (as someone with a disability) than do many of the current publicly funded care arrangements. There are real potential advances in participants in clinical trials in them receiving more than nominal recompense. Funds could even be placed in a trust and used to fund a participant's immediate medical costs and/or future treatment. This is not to mention the possibility of treatment and cure, obviating the need for much of the care sector, prompting me to make a planned bequest to research several years ago: Macquarie Matters. I am also old enough to remember urgent public campaigns and research in the 1980s about skin cancer, HIV/AIDS, breast cancer and, more recently, COVID-19. All these conditions are now treatable, and I had hoped the Productivity Commission's Disability Care inquiry would consider an element of research and cure. Alas it did not, opting for a lifetime care model instead, the cost of which was grossly underestimated and the efficacy of which is equally debatable today.

Meanwhile, if clinicians and the community are going to benefit from the output of research (financial and otherwise) initial clinical trial participants should as well. In a 1990 Californian Supreme Court, Mosk J gave a compelling and convincing ruling. Sadly, His Honour was in dissent in Moore v. Regents of University of California 15 U.S.P.Q. 2d (BNA) 1753, 16 A.L.R. 5th 903, 793 P.2d 479, 51 Cal. 3d 120, 271 Cal. Rptr. 146, 1990 Cal. LEXIS 2858. However, the judgment still sets out standards of accountability that should apply to researchers. This is further explained in the attachment: a submission to a similar inquiry.

This too is my frustration: the repetition of inquiries and reviews with little action. Injecting the patient and some qualified property rights into the mix may rattle sone researchers but it will also focus their minds. Focus them on the cures I want, if not for me then for those who come after me. Some would say that life itself should be enough and that I should just learn to live with impairment. One took a different view of disability in my 20s than in my 50s. I've have learnt to accept many annoying things (read: medical complexities) coming from disability by middle age, but this doesn't mean one has to like it. Furthermore, it is hard to justify why disability, chronic illness or inherited conditions should be allowed to continue haunting this and future generations, as agencies like the ALRC and governments dither cautiously and repeatedly. Of course, you will be unlikely to hear anything like that from disability or similar advocacy groups, which to me is a sad disservice to us all. So, whether it is human tissue, genes or stem cell line the question should be: what is the benefit to a patient or identifiable patient group? Then, how will the results of research be translated to therapies for patients? Ultimately, the issue is one of intent and context. For example, the Issues Paper highlights concern in terms of tissue, that human breast milk could be considered tissue. This might apply, unless there is an infant needing a feed, so its function as a food takes primacy; surely most would agree. Otherwise, there might be other applications where breast milk (or other tissues) can counteract a harm for which they were not originally intended but are found through research to be an effective measure.

Autonomy, dignity and almost any other principle or value, should be as much related to outcome as it is to process. For example, there is just and reverential treatment of the dead through burial. However, this also comes from respecting their directions. This could be achieved by denying next-of-kin power to veto organ donation for transplant or research, when a duly executed document exists. Similarly, why do few seem to ask whether real dignity, autonomy and freedom from many vulnerabilities comes from the absence of disability and chronic illnesses? Further research on human tissues and what afflicts them will get us to a point where such a freedom from impairment is possible. Yet I find it amazing that a program like the National Disability Insurance Scheme would prohibit funding aimed at functional improvement for people like me: What would Grandma say? - On Line Opinion - 15/5/2020. I recognise that this is potentially a major challenge to providers in the ever-expanding "care economy" but the ALRC needs to take real steps of reform, not just cautious and peripheral actions representing marginal recommendations for reform. For a start, cure and prevention of disease and disability should be central to any debate about human tissue and its inherent value, quite apart from any monetary considerations. Urgency would also be appreciated, just as we saw from the worldwide research community during COVID-19. Finally, as for human rights, when will we start talk debating freedom from impairment and the cure/prevention of disability and chronic illness? The sooner the better, I think.

I hope this submission is of some assistance.

Yours faithfully,

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You can see my paper on the University of New England (UNE), Armidale e-publications at http://e-publications.une.edu.au/1959.11/11369 and the Social Science Research Network (SSRN) at: http://ssrn.com/abstract=1855924

Libertas inaestimabilis res est - Liberty is a thing beyond all price. (Corpus Iuris Civilis: Digesta) (Latin-English Phrase)