

## **JUST GENETIC DISCRIMINATION?**

### **THE ETHICS OF AUSTRALIAN LAW REFORM PROPOSALS**

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#### **I INTRODUCTION**

Life insurers have used medical information, particularly family histories, for underwriting purposes for more than a century. The practice of using genetic test information began in earnest in the 1990s when DNA diagnostic tests became a more common part of medical records.<sup>1</sup> Since then, the equity of this practice has been a pressing matter of public policy. Recent research has documented a number of instances where individuals have been denied life, disability and travel insurance in Australia,<sup>2</sup> as well as in the United States ('US')<sup>3</sup> and United Kingdom ('UK'),<sup>4</sup> due to genetic test results. Considerable media coverage of this research fuelled agitation about the emergence of a 'genetic underclass'. Partly as a result, the Australian government is considering the need for legislation to prohibit underwriters using genetic tests in this discriminatory way. The Australian Law Reform Commission ('ALRC') and the Australian Health

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1 Select Committee on Science and Technology, *Genetics and Insurance, 5<sup>th</sup> Report*, House of Commons Paper 174, Session 2000–01 (2001) 19.

2 Kristine Barlow-Stewart and David Keays, 'Genetic Discrimination in Australia' (2001) 8 *Journal of Law and Medicine* 250, 251–2.

3 Empirical literature is more extensive in the US. See, eg, Paul R Billings et al, 'Discrimination as a Consequence of Genetic Testing' (1992) 50 *American Journal of Human Genetics* 476; Mark A Hall and Stephen S Rich, 'Laws Restricting Health Insurers' Use of Genetic Information: Impact on Genetic Discrimination' (2000) 66 *American Journal of Human Genetics* 293. For a list of citations and a brief critique of the methodology in these studies, see Tony McGleenan, *Insurance and Genetic Information* (2001) [6.1.6], app A.

4 Genetics Interest Group, *Rare Genetic Disorders and Insurance – An Empirical Study: Report to the Human Genetics Commission* (2001); Lawrence Low, Suzanne King and Tom Wilkie, 'Genetic Discrimination in Life Insurance: Empirical Evidence from a Cross Sectional Survey of Genetic Support Groups in the United Kingdom' (1998) 317 *British Medical Journal* 1632. For further citations and a critique of the methodology of similar studies, see McGleenan, above n 3.

Ethics Council are jointly conducting a National Inquiry into the Protection of Human Genetic Information,<sup>5</sup> and will report to the federal government on this topic by March 2003.<sup>6</sup>

To date, most literature has argued in favour of prohibiting the use of genetic tests (usually defined as DNA or chromosomal tests)<sup>7</sup> in life and disability underwriting.<sup>8</sup> This raises two questions: is this proposal fair and equitable, and should the exclusion apply only to genetic information? The title of this article rephrases these questions: is genetic discrimination just? And if so, should we prohibit just genetic discrimination?

This article suggests that the common proposal of prohibiting the use of genetic tests has a number of shortcomings. It would be fairer to either permit insurers to use genetic information in the same way they use other medical risk information (following the principle of actuarial fairness) or to prohibit insurers from using *all* medical risk information. The common proposal tries to 'split the difference' between these two alternatives. While this may be politically pragmatic, it is arbitrary and ethically unsubstantiated. Instead, it is argued that the first alternative – allowing insurers to use actuarially significant medical risk information (including genetic tests) as a precondition of underwriting – is preferable.

This article describes and analyses the ethics of nine law reform options which emanate from six general approaches to underwriting. Significantly, my argument is not premised on libertarianism and laissez-faire theory, but is rooted firmly in egalitarian traditions. This ethical slant is not a singular view. Ronald Dworkin, one of the most eminent authors of egalitarian theory, has recently

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5 Australian Law Reform Commission ('ALRC') and Australian Health Ethics Committee ('AHEC'), *Protection of Human Genetic Information*, Issues Paper 26 (2001). The law reform proposals discussed in this article are based on academic literature. At the time this article went to print, the ALRC and AHEC had just released a discussion paper. The preliminary view of the National Inquiry into the Protection of Human Genetic Information on the topic of insurance is that there is no demonstrated need, at present, for a radical departure from the mutuality principles that currently apply to genetic information. However, it recommends that only genetic tests that have been approved by a proposed 'Human Genetics Commission of Australia' should be used by insurers: see proposals 24-1 and 24-3. Thus the Inquiry's initial opinion is largely consistent with the primary conclusion of this article, which is based on moral arguments about equity and fairness. It remains to be seen whether the Inquiry will maintain this view in its final report: ALRC and AHEC, *Protection of Human Genetic Information*, Discussion Paper 66 (2002), <<http://www.austlii.edu.au/au/other/alrc/publications/dp/66/>> at 1 September 2002.

6 ALRC, *Protection of Human Genetic Information* (2002) <<http://www.alrc.gov.au/inquiries/current/genetic/index.htm>> at 22 July 2002.

7 Genetic tests and genetic information could be defined more broadly, but this is the definition explicitly or implicitly used in most of the literature. A broader definition would include family history and the results of biochemical tests that reveal information about heritable characteristics. The narrow definition of 'genetic' discrimination is criticised below Part IV(B)(2).

8 See below nn 42–6 and accompanying text.

declared that:

[If we presume that a society guarantees a fair and adequate level of universally-available health and welfare funded out of taxation] should private insurers be permitted to offer extra health and life insurance, at market rates, beyond the basic package? I believe so ... Should insurers be entitled to demand genetic tests in accordance with actuarial and commercial efficiency, in setting discriminatory rates for such additional insurance? I believe so.<sup>9</sup>

While Dworkin did not explain the issue of private life and disability insurance and genetic discrimination in great detail, this paper supports his general contention. Actuarially significant genetic testing should be permitted in underwriting because to do otherwise would unfairly shift the financial burden of insurance from the genetically unfortunate to the medically and economically unfortunate.

## II BACKGROUND

### A Fundamental Concepts of Genetic Testing and Underwriting

The key points of genetic testing and the actuarial science that underlies underwriting have been covered in existing literature.<sup>10</sup> They can be summarised as:

- *Discrimination:* The literature on genetic discrimination generally describes discrimination as ‘the treatment of a person less favourably than another because of different characteristics’.<sup>11</sup> Genetic discrimination is less favourable treatment based on factors related to genetics.
- *Mutuality rating and discrimination:* In Australia, life and disability insurance (the focus of this article) is a private contract between applicant and insurer. Insurers decide what premium to offer once they have evaluated the individual’s risk of making a claim and assigned to them a particular risk stratum. This model of ‘mutuality rating’ relies on three risk classifications – normal, high risk, and uninsurable. The terms and conditions offered to applicants, including the premiums, exclusions and waiting periods, may vary according to their personal risk. Clearly this is inherently discriminatory – some applicants are offered less favourable prices because of their personal risk characteristics, and some will develop impairments that are excluded from cover. Some may even be refused insurance. Whether this sort of discrimination is unfair

<sup>9</sup> Ronald Dworkin, *Sovereign Virtue: The Theory and Practice of Equality* (2000) 435–7, 451.

<sup>10</sup> ALRC and AHEC, *Protection of Human Genetic Information*, Issues Paper 26 (2001) ch 11; Margaret Otowski, *Implications of Genetic Testing for Australian Insurance Law and Practice*, Occasional Paper No 1, Centre for Law and Genetics (2001); McGleenan, above n 3.

<sup>11</sup> See, eg, ALRC and AHEC, *Protection of Human Genetic Information*, Issues Paper 26 (2001) [5.29]–[5.30]; Otowski, above n 10, 16; Trudo Lemmens, ‘Selective Justice, Genetic Discrimination, and Insurance: Should We Single Out Genes in Our Laws?’ (2000) 45 *McGill Law Journal* 347, 355.

depends on whether there is a good justification for the unequal treatment. This is the central issue in this article.

- *Solidarity rating*: Some insurance products are sold according to a different model of underwriting called ‘solidarity rating’. An example is private acute medical insurance.<sup>12</sup> In this case, everyone is offered the same premium, determined according to the group’s overall level of risk. A serious problem with this style of underwriting is that people who judge themselves to be a low risk will often decide that the insurance is too expensive and not purchase it, unlike people in high-risk groups. As a result, the level of insured risks skews upwards, and premiums must be increased to cover the likely number of claims.
- *Adverse selection*: When insurers underwrite risks on a mutuality basis, they attempt to collect sufficient premiums to cover claim payments. ‘Adverse selection’ is the phenomenon where this equilibrium is disrupted. It occurs when people are allowed to conceal personal risk information from their insurer. People who know that they have a high-risk of making a claim (based on, for example, family history or medical tests) will tend to purchase insurance more frequently or for higher amounts, than they would otherwise. This skews the amount of risk the insurer has underwritten without increasing its pool of funds. To avoid losses, insurers increase the standard price of premiums so that everybody pays more for their insurance. Standard or low-risk customers may then decide that the insurance contract is too expensive and drop out of the market, which further skews the risk. Prices are raised again and more people decide against purchasing insurance. Clearly adverse selection can make a product unmarketable.
- *Actuarial significance and actuarial fairness*: To prevent adverse selection, insurers argue that applicants should not be allowed to conceal known personal and material risks. Then, if the insurer determines that the risk would make the person statistically more likely to make a claim, (that is, if it is an ‘actuarially significant’ risk) the applicant is asked to pay a loaded premium to reflect this. Such premiums rely on accurate assessment to be ‘actuarially fair’.
- *Actuarial significance and genetic tests*: Presently, very few genetic tests predict disease in a way that is ‘actuarially significant’, that is, in a way that clearly and reliably indicates that the person is more likely than others to make a claim on the insurance policy.<sup>13</sup> The genetic test for

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12 See below n 19 and accompanying text.

13 Actuarial significance is influenced by the accuracy of the particular test, its precision in predicting likely disease onset, and the impact that knowledge about the test might have on the pool of insurance subscribers. The impact on the pool of subscribers will be influenced by the size of a policy purchased, the size of the insurance market and whether or not family history and other medical information is available.

Huntington's disease is arguably one of these.<sup>14</sup> Most other diseases are caused by a combination of genetic and environmental factors, unlike Huntington's disease which is monogenetic and completely 'penetrant'.<sup>15</sup> The number of 'actuarially significant' genetic tests may increase as genetic technology develops. This depends on whether new genetic tests are clinically accurate and can predict serious illness or death, including age of onset, with reasonable statistical precision.

## B The Current Legal Position

### 1 Insurance Contracts

Section 21(1) of the *Insurance Contracts Act 1984* (Cth) requires an insurance applicant to disclose all matters, before the contract is entered into, that he or she knows are relevant to the insurer's decision whether to accept the risk, or which a reasonable person would think were relevant.<sup>16</sup> The applicant is only required to disclose risks already known.<sup>17</sup> For the purpose of life and disability insurance, a relevant matter is likely to include family history, medical or genetic test results relating to the applicant's health and medical history or prognosis. However, this has not been tested in court. A deliberate failure to disclose allows the insurer to avoid the contract.<sup>18</sup>

The general rule is that insurers may legitimately use the personal information they obtain from applicants to decide what price to offer. One exception is that private acute medical insurers are not permitted to refuse applicants on the grounds of their individual health status.<sup>19</sup> Life and disability insurers are not covered by this restriction, although discrimination legislation is relevant to

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14 The DNA test for Huntington's disease has been approved in the UK as an actuarially significant test: Genetics and Insurance Committee, *Decision of the Genetics and Insurance Committee Concerning the Application for Approval to Use Genetic Test Results for Life Insurance Risk Assessment in Huntington's Disease* GAIC/01.1 (2000), Department of Health <<http://www.doh.gov.uk/genetics/gaichuntington.htm>> at 26 July 2002.

15 Penetrance is a scientific term used to describe the likelihood that an individual with a given genetic mutation will exhibit the physical condition associated with that mutation.

16 *Insurance Contracts Act 1984* (Cth) s 21(1). For an excellent overview of the Commonwealth and State laws that currently apply to insurers, see Otlowski, above n 10, ch 2.

17 This position is also endorsed by Investment Financial Services of Australia ('IFSA'), see IFSA, 'Affordable Life Insurance Assured: IFSA Welcomes ACCC Decision on Genetic Testing Policy' (Press Release, 22 November 2000).

18 *Insurance Contracts Act 1984* (Cth) ss 28, 29. See pt IV, div 3 for other instances when failure to disclose leads to a similar outcome. But note that s 21A provides that an insurer can only take action for failed disclosure if the individual failed to answer a specific question about a particular risk, or a specific question about 'exceptional circumstances' where this request could not have been phrased with greater specificity.

19 *National Health Act 1953* (Cth) s 67(1) provides that the Private Health Insurance Administration Council ('the Council'), established by s 82B must register all health benefit organisations. Section 73(2A) states that the Council must not register a health benefit organisation if, under the rules of the organisation, people may be refused membership of the fund by reason of their state of health. Membership restrictions are only allowed if the health benefit organisation can prove to the Council that the restrictions are not designed to achieve a higher level of health than the level of health in the community generally: s 73(2B).

them.<sup>20</sup> Although all insurers are subject to the *Privacy Act 1988* (Cth), it has little impact on the act of underwriting.<sup>21</sup>

## 2 Discrimination Laws

Commonwealth and State legislation prohibits discrimination on the basis of a person's disability or future disability (that is, progressive or asymptomatic illness), but includes a partial exemption for insurance.<sup>22</sup> Section 46 of the *Disability Discrimination Act 1992* (Cth) ('DDA') permits insurers to discriminate on the basis of a person's disability if it is based on actuarial or statistical data on which it is reasonable for the insurer to rely, and the discrimination is itself reasonable given the data and other relevant factors.<sup>23</sup>

There is very little judicial guidance on the interpretation of this section or comparable sections in State legislation. The few cases in this area suggest that discrimination by life and disability insurers based on medical conditions is lawful if the insurer has up-to-date, direct statistical evidence of actuarial fairness. In *Xiros v Fortis Life Assurance* ('*Xiros*'),<sup>24</sup> the applicant purchased mortgage-linked life and disability insurance (mortgage protection) in 1995. He made a claim in 1997 after he became HIV positive and ceased working. Fortis refused to pay because claims relating to HIV and AIDS were excluded under the policy. The applicant alleged discrimination under the DDA, but the Federal Magistrates Court held that there was sufficient statistical data to demonstrate that the exclusion had a reasonable actuarial basis and was accordingly exempt under s 46.

The judgment in *Xiros* did not describe the kind of documents tendered by the respondent. However, this was the crucial issue in *Opinion re: Elizabeth Kors and AMP Society*.<sup>25</sup> The Queensland Anti-Discrimination Tribunal ('the Tribunal') was asked, pursuant to s 228 of the *Anti-Discrimination Act 1991*

20 See below n 23.

21 Following recent amendment, the *Privacy Act 1988* (Cth) applies to private sector organisations such as insurers. National Privacy Principles constrain the way that insurers collect, use and disclose an applicant's personal information. However, these principles do not limit an insurer's use of personal information in underwriting, since it is lawful to use personal information with an individual's consent. Consent to underwriting will often be express and could be implied from the fact that the applicant has applied for insurance. Insurers are nevertheless prohibited from obtaining information about an applicant surreptitiously or without notification, disclosing the information to unauthorised persons, and using it for illegitimate purposes: see *Privacy Act 1988* (Cth) sch 3, National Privacy Principles 1 and 2.

22 It is a matter of some debate whether all State legislation prohibits discrimination based on a disability that may exist in the future. On balance, it is likely that this is the case since most of the relevant Acts prohibit discrimination on the grounds of an attribute or disability that a person is presumed to have or which is imputed to a person: Otlowski, above n 10, 18–19.

23 If a situation arises where there is no actuarial or statistical data available and it cannot be reasonably obtained, the discrimination must be reasonable having regard to any other reasonable factors: *Disability Discrimination Act 1992* (Cth) s 46. Similar exemptions exist in State and Territory Acts: *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; *Discrimination Act 1991* (ACT) s 28; *Anti-Discrimination Act 1992* (NT) s 49(1)(d), (e).

24 (2001) 162 FLR 433.

25 [1998] QADT 23 (Unreported, Member Dickenson, 24 November 1998).

(Qld), whether it was lawful for AMP to refuse insurance on the grounds of the applicant's psychiatric impairment. AMP claimed that it had actuarial and statistical data to justify treating the applicant in a discriminatory way,<sup>26</sup> and tendered the underwriter's risk manual it had followed as evidence. The Tribunal concluded that this was insufficient. To discharge its burden of proof the insurer needed to show how the relevant classes of risk and the bands within them had been sourced from actuarial and statistical data.<sup>27</sup>

Although no case has yet been heard, discrimination based on genetic information is likely to be judged according to the same standard as medical information. This would mean that life and disability insurers might discriminate on the basis of genetic information if they have evidence of its actuarial significance. The central issue in current debate is whether this is appropriate or whether discrimination based on genetic tests should be prohibited even when it is based on an actuarially sound assessment of risk.

### III OVERVIEW OF LAW REFORM OPTIONS

Apart from allowing insurers to use genetic information, which is the current legal position, or prohibiting its use by insurers, several other policy proposals are open for debate. These include:

- (1) *Deregulated rating*: permits insurers to offer premiums on terms that they choose in line with market forces;
- (2) *Partial solidarity rating*: prohibits insurers using certain kinds of medical risk information, for example genetic tests or family history. They may use other information where it is actuarially significant;
- (3) *Solidarity rating*: prohibits insurers from using all medical risk information in underwriting;
- (4) *Mutuality rating*: allows insurers to use actuarially significant medical risk information (including genetic tests), if it is known to the applicant before entering into the insurance contract;
- (5) *Information-rich mutuality rating*: permits insurers to ask applicants to undergo medical or genetic testing as a precondition of the contract and use actuarially significant results for underwriting; and
- (6) *Capped solidarity rating*: prohibits insurers from using personal risk information for moderate sized policies, but allows them to use it for large insurance policies. This policy could apply to genetic information only<sup>28</sup> or medical information generally.

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26 As permitted by *Anti-Discrimination Act 1991* (Qld) s 74.

27 *Opinion re: Elizabeth Kors and AMP Society* [1998] QADT 23 (Unreported, Member Dickenson, 24 November 1998).

28 See below Part IV(B)(4).

This list is synthesised from a review of the academic literature and European laws.<sup>29</sup> There are two noticeable ways in which these policy options differ. Options (1), (4) and (5) are permissive proposals that endorse a system of mutuality rating, and options (2), (3) and (6) are versions of solidarity rating. The other major demarcation is that options (2), (5) and (6) treat, or tend to treat, genetic information differently from other medical information. In contrast, options (1), (3) and (4) treat all risk information in the same way. Some related issues, not discussed in detail in this paper, are the methods of funding these alternatives,<sup>30</sup> whether legislation or industry self-regulation is preferable,<sup>31</sup> and whether a harmonised national approach is appropriate.<sup>32</sup>

Usually policy makers will rely on an economic cost-benefit analysis to discern which policy option is preferable. However, this is an unsatisfactory methodology because an economically efficient proposal may not effect a fair distribution of costs between policyholders,<sup>33</sup> and may therefore under-determine the 'moral costs' or 'moral harms'. Thus, to arrive at a just policy solution, the ethics of a proposed distribution of costs must be considered separate from mere economic efficiency. One should also resist the temptation to think of 'ethical arguments' as stakeholder interests that can be 'traded' or 'compromised' without losing the special essence of moral authority that makes ethics worth examining in the first place. This article focuses on the morality of the policy options, rather than their economic or political strengths and weaknesses.

This paper ultimately favours the fourth proposal because it is not 'genetically exceptionalist', and there appears to be no good reason to adopt solidarity rating and prohibit medical mutuality rating per se in the life and disability insurance market.

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29 The most informative pieces include: Otlowski, above n 10; McGleenan, above n 3; Lemmens, above n 11. See also art 67 BGB1 510/1994 *Gesetz zur Regelung der Gentechnik (Gentechnikgesetz – GenTC)* [the Genetic Technology Law] (Austria); *Wet 25 Juni op de landsverzekeringsovereenkomst* [Law of 25 June 1992 on Terrestrial Insurance Contracts] BS 20 August 1992, 18 283, arts 5, 95 (Belgium); *Law No 56 of 5 August 1994 on the Medical Use of Biotechnology* (Norway) § 6; *Wet van 5 juli 1997, houdende regels tot versterking van de rechtspositie van hen die een medische keuring ondergaan* [Law of 5 July 1997 Promulgating Provisions Intended to Strengthen the Legal Position of Persons Undergoing Medical Checks (the Medical Checks Law)] Stb 1997/365 (The Netherlands). The terms used to describe the six classifications have been used by some authors, but there is no consistent usage throughout the literature.

30 The moral implications of cross-subsidisation are discussed below in Part IV(D)(2) and reinsurance is also briefly mentioned. See further McGleenan, above n 3, [11.1.2]–[11.1.6].

31 See generally, Ian Ayres and John Braithwaite, *Responsive Regulation: Transcending the Regulation Debate* (1992).

32 This may be a constitutional necessity. If a State law purports to restrict insurers underwriting more or less than Commonwealth legislation, it may be interpreted as a direct inconsistency contrary to the *Australian Constitution* s 109. This issue arose between the *Anti-Discrimination Act 1977* (NSW) and the *Life Insurance Act 1945* (Cth) in *Australian Mutual Provident Society v Goulden* (1986) 160 CLR 330. See further Otlowski, above n 10, 20–1.

33 See below Part IV(B)(4).



## IV ANALYSIS OF LAW REFORM OPTIONS

### A Deregulated Rating

Until discrimination legislation was enacted, insurers were free to decide upon any pricing policy regardless of its arbitrariness. Libertarians prefer this earlier regulatory style and propose that underwriting be deregulated. This view is not widely published,<sup>34</sup> but it underpins the industry's fierce protection of self-regulation. It seems that this critique draws upon Robert Nozick's view that justice is not given by an end-state but rather the freedom to transact one's property autonomously.<sup>35</sup> Theoretically, the claim is that the state departs from a just and good way of life if it imposes restrictions on contractual freedom.<sup>36</sup> Another basis for this view is Epstein's belief that the market is more efficient than state bureaucracy in determining a 'fair' outcome.<sup>37</sup> It is argued that state intervention stifles competition so that consumers cannot pressure insurers to set prices that they consider appropriate. Additionally, it is suggested that the state is likely to overlook transactional costs.<sup>38</sup>

Nozick's theory has been roundly challenged for failing to guarantee basic human rights except as they coincide with people's charity.<sup>39</sup> Its non-distributive nature is problematic because it assumes that each person chooses their wealth status, whereas in fact many people have been disinherited by practices of colonial governments. Perhaps the most dissatisfactory aspect of libertarian theory is that luck lies where it falls regardless of a person's need or merit. If one is born into a wealthy family or with wealth-generating talents, all financial needs are met. If not, life can be a harsh experience regardless of how hard one works. Epstein's efficiency argument largely ignores consumers' powerlessness in the face of large, multinational corporations and their tactical marketing strategies. Laissez-faire theory also privileges wealthy people who exert more pressure on the market. These shortcomings mean that libertarian arguments against regulation are unconvincing.

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34 But see Richard Epstein, 'The Legal Regulation of Genetic Discrimination: Old Responses to New Technology' (1994) 74(1) *Boston University Law Review* 1.

35 Robert Nozick, *Anarchy, State and Utopia* (1974).

36 See, eg, *Australian Mutual Provident Society v Goulden* (1986) 160 CLR 330, 336 (Gibbs CJ, Mason, Brennan, Deane and Dawson JJ):

[T]he [*Life Insurance Act 1945* (Cth)] does not attempt to restrict the business judgment of a registered life insurance company in classifying risks and setting premiums. To the contrary, the Act proceeds on the underlying legislative assumption that ... the life insurance business of such a company is more likely to prosper and the interests of its policy holders are more likely to be protected, if it is permitted to classify risks and fix rates of premium in that business in accordance with its own judgment founded upon the advice of actuaries and the practice of prudent insurers.

37 Epstein, above n 34.

38 *Ibid.*

39 Brian Barry, 'Books in Review: *Anarchy, State and Utopia* by Robert Nozick' (1975) 3 *Political Theory* 331; Peter Singer, 'The Right to be Rich or Poor' in Jeffrey Paul (ed), *Reading Nozick: Essays on Anarchy, State and Utopia* (1982) 37; Bernard Williams, 'The Minimal State' in Jeffrey Paul (ed), *Reading Nozick: Essays on Anarchy, State and Utopia* (1981) 27.

This option has been rightly rejected by s 46 of the *DDA*.<sup>40</sup> Insurers are bound to observe the principle of actuarial fairness, which means that premiums are priced according to mathematical risk assessment. Although we are now more aware that science (particularly risk assessment) is not objective in the sense of having an existence separate from human perception,<sup>41</sup> a statistical approach is nonetheless an impartial and non-arbitrary way of determining premium prices. Each person's information is compared to a standard set of risk indicators prepared by professional actuaries according to the statistical correlation between medical information and the likelihood of illness, disease or death. Actuaries are not concerned with particular people or particular diseases, but rather the statistical properties of clinical and social indicators, disease and insurance claims. All kinds of medical information are subject to the same process of risk analysis. If a risk assessment is challenged, the insurer bears the burden of satisfying the court that it has statistical and actuarial evidence to support its decision. The remaining question is whether impartiality and non-arbitrariness can sufficiently protect equality in the life and disability insurance markets or whether there are other reasons why genetic risk factors should be excluded from underwriting.

## **B Partial Solidarity: Prohibiting the Use of Certain Kinds of Medical Risk Information**

Most authors writing about the genetics and insurance debate have recommended that insurers be prohibited from using *certain kinds* of medical risk information.<sup>42</sup> They propose narrow forms of solidarity rating or what I have called 'partial solidarity rating'. The proposed exclusions all relate to genetic information and vary according to how widely genetic information is defined.

### **1 Partial Solidarity: Prohibiting the Use of DNA Tests**

The most common proposal is that insurers should not be permitted to use genetic tests in the sense of DNA or chromosome tests.<sup>43</sup> This was the

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40 See above n 23.

41 Richard W Miller, *Fact and Method: Explanation, Confirmation and Reality in the Natural and Social Sciences* (1987); Sheila Jasanoff, *The Fifth Branch: Science Advisors as Policymakers* (1990); National Research Council, *Science and Judgement in Risk Assessment* (1994).

42 See the following materials which propose that genetic test results (ie, DNA tests) should be excluded: Otlowski, above n 10; Barlow-Stewart and Keays, above n 2; David Keays, 'Genetic Testing and Insurance: When is Discrimination Justified?' (2000) 19(4) *Monash Bioethics Review* 79; Mathew Stulic, 'Genetic Non-Discrimination, Privacy and Property Rights' (2000) 7(2) *E Law - Murdoch University Electronic Journal of Law* [107] <[http://www.murdoch.edu.au/elaw/issues/v7n2/stulic72\\_text.html](http://www.murdoch.edu.au/elaw/issues/v7n2/stulic72_text.html)> at 26 July 2002; Michael Fotheringham, 'Insurers and Genetic Testing: An Uncertain Future' (1999) 11 *Insurance Law Journal* 2; *Genetic Privacy and Non-Discrimination Bill 1998* (Cth). Similar proposals abound in UK literature as well: Human Genetics Commission, *The Use of Genetic Information in Insurance: Interim Recommendations of the Human Genetics Commission* (2001); Alzheimer's Disease Society, *The Use of Genetics Tests for Alzheimer's Disease by the Insurance Industry* (1999); Per Sandberg, 'Genetic Information and Life Insurance: A Proposal For an Ethical European Policy' (1995) 40 *Social Science and Medicine* 1549.

43 See, eg, Keays, above n 42; Fotheringham, above n 42.

underlying aim in the *Genetic Privacy and Non-Discrimination Bill 1998* (Cth)<sup>44</sup> and the idea discussed in most media debates.<sup>45</sup> This has been adopted in some European countries already.<sup>46</sup> This policy is based on the idea that genetic information is qualitatively different from other medical information, and therefore raises unique social issues and requires special laws. This presumption has been described as 'genetic exceptionalism'.

(a) *The Problem of Genetic Exceptionalism*

The well-documented problem in using genetic exceptionalism as a foundation for legislation<sup>47</sup> is that there is no rationally defensible reason for presuming that genetic illnesses are special and uniquely sensitive. The supposed reasons for taking a genetically exceptionalist approach are that genetic information: is particularly sensitive and private to the individual; reveals much about the individual's future and that of his or her family; and is out of an individual's control. However, each of these points is flawed.

The premise that 'genetic information' is more sensitive than 'medical information' is meaningless as much of what we traditionally call 'medical information' is also information about one's DNA. Consider medical information such as family histories, biochemical and protein assays or tests, ultrasounds and physical examinations.<sup>48</sup> Much of this information tells us something about an individual's DNA. Thus the boundaries between genetic and medical information are blurred, and do not easily support the idea that one is more sensitive to an individual than another.

Even if genetic information is defined as 'information from a DNA analysis', it is still incorrect to generalise that genetic information is more sensitive. Genetic information can be quite insignificant to an individual and his or her family (such as eye colour, blood group, lactose intolerance and height), and often medical or financial information is equally as sensitive as the most sensitive genetic information (for example, information about infectious diseases, infertility, mental illness, abortion, income and past bankruptcy). The

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44 This Bill was modelled on a draft US Bill, see George J Annas, Leonard H Glantz and Patricia A Roche, *The Genetic Privacy Act and Commentary* (1995), Health Law Department: Boston University School of Public Health <<http://www.bumc.bu.edu/www/sph/lw/pvl/act.html>> at 26 July 2002.

45 ABC, 'Genetic Discrimination Starts in Australia', *7.30 Report*, 21 July 2000 <<http://www.abc.net.au/7.30/s154671.htm>> at 3 July 2002; ABC, 'Genetic Discrimination' *The Law Report*, 27 November 2001 <<http://www.abc.net.au/rn/talks/8.30/lawrpt/stories/s426635.htm>> at 3 July 2002.

46 See, eg, Austria, Belgium and Norway: McGleenan, above n 3, [9.1.2], [9.1.6]; Austria and Denmark: Select Committee on Science and Technology, above n 1, [70].

47 Lemmens, above n 11, 369–80; Ron Zimmern, 'What is Genetic Information?' (2001) 1(5) *Genetics Law Monitor* 9; Sonia M Suter, 'The Allure and Peril of Genetic Exceptionalism: Do We Need Special Genetics Legislation?' (2001) 79 *Washington University Law Quarterly* 669, 48–53; Lawrence O Gostin and James G Hodge Jr, 'Genetic Privacy and the Law: An End to Genetics Exceptionalism' (1999) 40 *Jurimetrics* 21, 31; Thomas H Murray, 'Genetic Exceptionalism and "Future Diaries": Is Genetic Information Different from Other Medical Information?' in Mark A Rothstein (ed), *Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era* (1997) 60; Alastair Kent, 'Inheritance, Insurance and Sensationalism', *Science and Public Affairs*, December 2000, 6.

48 Zimmern, above n 47.

same point can be made about the relevance of DNA and medical information to family members. Medical information may also be important because health issues are a potent part of any important relationship. For example, it is significant whether a family member is, or will be, ill and perhaps be unemployed, unable to parent or have special healthcare needs.

The idea that genetic information is a particularly vivid 'future diary' or 'blueprint', and thus has an exceptional impact on discrimination and privacy, is also unsound.<sup>49</sup> Most genetic information is only a mild predictor of one's future health or social status. Complex gene-gene and gene-environment interactions mean that, on the whole, genetic information reveals only probabilities of future illness on par with other medical, financial or socioeconomic data. For example, cholesterol levels, diabetes diagnosis, and living below the poverty line are arguably as predictive as a lot of genetic information. The uncertainty of *genetic or medical* risk information is the reason why it is important that the law requires underwriters to have actuarial and statistical information to establish the suitability of this data as a risk indicator.<sup>50</sup>

In addition, it is misleading to argue that genetic information should be singled out because individuals cannot control it. A genotype may be wholly inherited but its actual effect is to a large extent mediated through one's environment like many other medical conditions. In some instances a person is able to influence whether or not their genotype affects their health by careful management of lifestyle, nutrition and medicine. This power is likely to increase as our understanding of genetic traits improves. In any event, it would be quite radical to suggest that insurance should exclude any factor that is partly or wholly uncontrollable. This would mean that insurers should not be permitted to underwrite on the basis of age, sex, many anticipated illnesses, or possibly even alcohol and nicotine addictions.<sup>51</sup> The suggestion is also impractical because of the difficulties of defining what is and is not controllable.<sup>52</sup>

In short, a medical risk factor may be equally, if not more, predictive, worrying, sensitive, relevant to families, beyond control, and open to discrimination.<sup>53</sup> It would be a very arbitrary law that prohibits the use of DNA tests, and not also the use of other information that is indicative of hereditary risk, such as family histories, certain biochemical assays, ultrasounds, or phenotypic observations. The effect of genetically exceptionalist laws would be that people at risk of equally painful and debilitating illnesses (for example, cancer, coronary heart disease, end-stage renal failure, complications from diabetes) would be disadvantaged.

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49 Murray, above n 47.

50 *Disability Discrimination Act 1992* (Cth) s 46.

51 Evidence is emerging that certain people may be genetically disposed to certain addictions: see, eg, Eoin McKinney et al, 'Association Between Polymorphisms in Dopamine Metabolic Enzymes and Tobacco Consumption in Smokers' (2000) 10 *Pharmacogenetics* 1; Robert Walton et al, 'Genetic Clues to the Molecular Basis of Tobacco Addiction and Progress Towards Personalized Therapy' (2001) 7 *Trends in Molecular Medicine* 70.

52 For example, would a disease risk be considered controllable if a person is too poor or uneducated to take preventative action?

53 Lemmens, above n 11, 369–80 and references above n 47.

The fact that genetic exceptionalism is based on conceptual confusion is not the only problem. It also has consequences for the fairness of premium pricing because it forces a particular pattern of cross-subsidisation on policyholders. Actuaries, independent of the insurance industry, have shown using detailed mathematical modelling that standard life insurance premium prices would rise by at least 5–15 per cent if applicants were permitted to conceal DNA test results.<sup>54</sup> The price increase would be much more for critical illness insurance and other insurance products with small markets. Such an increase could perhaps be more than 30 per cent. The question is whether it is fair that everyone pays this extra price, when only some people stand to benefit – those people whose risk was discovered by a genetic test and not those whose risk was discovered by a medical test. More specifically, the people who would benefit are those who can afford genetic tests and a standard life and disability premium price. The people who are most likely to feel the strain of genetic exceptionalism are the economically disadvantaged people whose prognosis is assessed by conventional medical methods and who may be forced out of the insurance market by even a modest increase in premium price. Sonia Suter writes:

Not only is genetic information like other medical information, but treating the two differently under the law leads to unintended inequities between individuals and classes, which raises serious questions about the propriety of public policy based on genetics exceptionalism ... [C]oncerns about genetic discrimination and privacy are primarily those of the middle to upper classes. Not surprisingly, public policy that focuses solely on those concerns fails to address equally serious concerns about discrimination and privacy regarding medical risks that affect the most disadvantaged in our society.<sup>55</sup>

If this inequity was based on a rational distinction between genetic and medical risk information, it might be acceptable. However, arbitrarily banning the use of DNA tests in underwriting is flawed because it supports people with DNA risks at the expense of other policyholders who may be equally, if not more, vulnerable in the absence of life and disability insurance.

## 2 *Partial Solidarity: Prohibiting the Use of Negative Genetic Tests*

An alternative suggestion is to distinguish between two types of genetic information: information indicating that a person does have a particular trait (ie, a positive genetic test result); and information indicating that a person does not have the trait (ie, a negative genetic test result). The proposal is to prohibit insurers from using genetic information that is unfavourable to an applicant, but to allow them to use favourable information to reduce premiums. Positive discrimination would be permissible, but negative discrimination would not. It would be unfair to charge an individual with a family history of genetic disease a

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54 See, eg, Angus Macdonald, *Moratoria on the Use of Genetic Tests and Family History for Mortgage-Related Life Insurance*, Research Report No 01/3, The Genetics and Insurance Research Centre (2001) 12, 14, Heriot-Watt University <<http://www.ma.hw.ac.uk/~angus/papers/mortgage.pdf>> at 24 July 2002; Angus Macdonald, 'Modeling the Impact of Genetics on Insurance' (1999) 3(1) *North American Actuarial Journal* 83; Angus Macdonald, 'How Will Improved Forecasts of Individual Lifetimes Affect Underwriting?' (1997) 3 (pt V, 15) *British Actuarial Journal* 1009.

55 Suter, above n 47, 671.

loaded premium *as if* he or she was at risk of the family trait even though a genetic test proves that he did not inherit it. Accordingly, the suggestion is that insurers should be banned from using positive DNA tests.

This approach was taken in the *Genetic Privacy and Non-Discrimination Bill 1998* (Cth). It was approved in the UK by the Nuffield Council of Bioethics,<sup>56</sup> and more recently by the UK House of Commons Select Committee.<sup>57</sup> However, some disability advocates have criticised this proposal.<sup>58</sup> They argue that if positive and negative genetic tests are distinguished, insurers will tend to *assume* that a person without a negative test has the genetic trait, especially if their family history indicates this likelihood. They fear this will put pressure on people to have genetic tests and lead indirectly to genetic discrimination. The deeper problem with this policy is that it is a rarefied kind of genetic exceptionalism. It proposes to treat positive DNA tests differently from other medical information that identifies a risk of future impairment. This proposal should be rejected for the reasons given above against genetic exceptionalism.

### ***3 Partial Solidarity: Prohibiting the Use of Genetic Tests and Family History Information***

A further proposal is to prohibit insurers from using both genetic test results and family history information in underwriting.<sup>59</sup> For example, Sweden does not allow insurers to use DNA or family history information.<sup>60</sup> The insurance industry is likely to be highly critical of this proposal because it relies so heavily on family history information for underwriting. It has been argued that this policy would result in severe levels of adverse selection and dramatic premium increases.<sup>61</sup> This is supported by research by Professor Macdonald.<sup>62</sup>

A different concern is that this proposal is yet another genetically exceptionalist policy. Although it gives 'genetic information' a wider definition, it continues to draw an arbitrary distinction between DNA and family history information and other genetic information such as biochemical tests, ultrasounds and physical examinations. Furthermore it arbitrarily distinguishes other medical information which is an indicator of risk, albeit not necessarily inherited risk, such as cardiovascular tests, cholesterol levels and diabetes diagnosis. As discussed above, this other genetic and medical information can be equally predictive, sensitive, relevant to others and beyond control. This policy should be rejected because it will unreasonably disadvantage people with risks detected

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56 Nuffield Council on Bioethics, *Genetic Screening: Ethical Issues* (1993) [7.29].

57 Select Committee on Science and Technology, above n 1, [70]–[71].

58 Harry Cayton, 'Life is "a Genetic Condition"' (Paper presented at the Genetics and Insurance Information-Gathering Meeting, London, 9 February 2001), Human Genetics Commission <<http://www.hgc.gov.uk/harry.pdf>> at 26 July 2002. Cf the view of the Genetics Interests Group reported in Select Committee on Science and Technology, above n 1, [70].

59 The UK Human Genetics Commission plans to consider the merits of this proposal: Human Genetics Commission, *The Use of Genetic Information in Insurance*, above n 42.

60 Human Genetics Commission, *Inside Information: Balancing Interests in the Use of Personal Genetic Information* (2002) [7.11].

61 McGleenan, above n 3, [10.1.5].

62 See above n 54.

by conventional medical tests and people whose risks are not obviously inherited.

#### 4 *Partial Solidarity: Prohibiting the Use of DNA Tests up to a Certain Value*

Support is growing for the idea that insurers should be prohibited from using DNA tests when an applicant seeks insurance up to a certain value. Beyond this level, insurers would be permitted to use the information in accordance with actuarial fairness.<sup>63</sup> This approach has been adopted in the UK and the Netherlands.<sup>64</sup>

The UK moratorium on using genetic testing in insurance began in October 2001 and will run for five years. During this time, genetic tests will only be used in underwriting if they have been authorised by the Genetics and Insurance Committee ('GAIC'). Additionally, they can only be used if the application is for life insurance greater than £500 000 or, in the case of critical illness, income protection and long-term care insurance, £300 000.<sup>65</sup> Presently this means that disclosure of positive Huntington's disease gene test results may be a precondition of life insurance valued at more than £500 000.<sup>66</sup> The moratorium only applies to DNA and chromosome tests, and not to family history information or other medical risk factors.<sup>67</sup>

Again, genetic exceptionalism is the obvious problem.<sup>68</sup> There is no moral reason why persons with a medical risk should be subject to mutuality rating whereas those with a risk detected by a DNA test should have the benefit, subsidised by the others, of a capped level of solidarity. Below, I consider whether the proposal for capped solidarity rating would be more desirable if it also encompassed family history and other medical risk information.

### C Two Minimum Propositions for Just Law

The analysis thus far has considered and rejected the main options advanced in the genetics and insurance debate. The partial solidarity proposals are flawed because they ignore the problems of genetic exceptionalism. Although various justifications have been offered for genetic exceptionalism, none are robust ethical reasons. On the other hand, deregulated rating is problematic because it fails to protect individuals from arbitrary differential treatment.

Two minimum propositions for just law reform can thus be discerned. First, legal policy should not distinguish between genetic risks and other medical risks

63 Sandberg, above n 42, 1557–8; Otlowski, above n 10, 53–6, McGleenan, above n 3, [11.1.5].

64 McGleenan, above n 3, [9.1.7].

65 Association of British Insurers, 'Government Endorses 5 Year Moratorium on Genetic Testing and Insurance: "Opportunity to Develop a Lasting Consensus" Says ABI' (Press Release, 23 October 2001) <<http://www.abi.org.uk/newsreleases/default.asp?display=month&year=2001&month=10>> at 10 August 2002.

66 The GAIC has approved only one genetic test, namely the test for Huntington's disease in life insurance applications: Genetics and Insurance Committee, above n 14.

67 The Human Genetics Commission will consider whether the law should ban the use of DNA tests and family histories during the moratorium: Human Genetics Commission, *Inside Information*, above n 60.

68 See above Part IV(B)(1).

which are similarly predictive, sensitive and uncontrollable. Second, insurers should respect the principle of actuarial fairness and ensure that they only refer to risk factors which have demonstrable relevance according to actuarial data.

A remaining question is whether equality requires more than just actuarial fairness – is there a reason to eschew mutuality rating even though it is not arbitrary? If so, then we ought to consider banning the use of all medical risk information. This would entail a shift from mutuality rating to solidarity rating for all life and disability products.

## **D Solidarity Rating: Prohibiting the Use of Medical Risk Information**

A number of egalitarians in the genetics and insurance debate have argued that we should adopt a system of solidarity rating because charging a few people higher premiums creates a maltreated underclass.<sup>69</sup> They are concerned that at-risk applicants will be deterred from undergoing genetic tests or will be denied the opportunity to purchase insurance, which is considered to be a social good. However these arguments are unconvincing.

### **1 Uptake of Genetic and Medical Services**

If loaded premium prices deter people from undergoing genetic tests,<sup>70</sup> individuals could miss opportunities to take preventative action to avoid genetic disease. David Keays gives the example of an individual who is genetically tested for haemochromatosis and can then initiate regular blood donation to prevent irreversible organ damage due to iron overload.<sup>71</sup> Margaret Otlowski notes that individuals at risk of familial adenomatous polyposis can undergo surveillance to identify polyps at an early stage.<sup>72</sup> A claim that mutuality rating has a chilling effect on genetic tests raises several questions which are yet to be fully addressed. Is there empirical evidence that people are discouraged from genetic testing because of insurance implications? Why is the same point not argued in relation to traditional medical tests and mutuality underwriting? Even if the consequential claim about deterrence is true – that people are turning down useful genetic tests to protect their premium ratings – is this sufficient justification for solidarity rating which would increase the premiums of all policyholders?

The UK Human Genetics Advisory Commission found little empirical evidence of deterrence.<sup>73</sup> Neither Keays nor Otlowski mention further evidence apart from the opinion of the Australian Medical Association and the Human Genetics Society of Australasia.<sup>74</sup> Several studies have been conducted in Europe and the US, but this data falls short of being clear evidence that mutuality rating

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69 See, eg, Keays, above n 42.

70 Ibid.

71 Ibid.

72 Otlowski, above n 10, 43.

73 Human Genetics Advisory Committee, *The Implications of Genetic Testing for Insurance* (1997) [3.18].

74 Keays, above n 42, 85; Otlowski, above n 10, 42–3.



deters genetic testing.<sup>75</sup> Most surveys had small samples, and the US studies dealt mainly with acute medical insurance rather than life and disability insurance. Moreover, the studies indicate that patients are refusing genetic testing for other reasons including the cost of genetic testing, concerns about their employment, their level of education, depression, and their opinions about the invasiveness, inconvenience or futility of preventative action.<sup>76</sup> While some patients may be reluctant to have a genetic test because of their fears regarding future insurance, they have the option to purchase insurance before taking the test. Writing about the largest European patient survey, Tony McGleenan observes that:

The analysis suggests that those who accepted [genetic testing] differed from those who declined in that they had a spouse or partner, were more often employed and had the benefit of a higher education. Of those who took the test only 2% mentioned concerns about insurance as being an argument against testing. After adjusting the results for socio-demographic variables it was found the acceptance was positively related only to employment. Overall uptake of the genetic test was high in this study with 75% of subjects who attended the counselling session going on to take the test.<sup>77</sup>

The fact that there is no conclusive evidence of the detrimental effect of mutuality rating on the uptake of genetic testing does not mean it is non-existent. However, it does mean that we should examine the claim more closely. It would also be useful to investigate whether mutuality rating based on family histories and medical information is having a chilling effect on the uptake of medical tests. If the anxiety is real and rational in the case of genetic tests, it should also apply in a general medical setting. Finally, we should bear in mind that even if patients are discouraged from genetic testing because they want to be eligible for standard premiums, this is not a definitive reason for banning mutuality rating. Some people might conclude that the patient has simply made a poor decision,<sup>78</sup> and that despite their anxiety they should have the test, or purchase insurance before the test. In other words one might conclude that the predicament is unenviable, but not unjust.

## 2 *The 'Social Good' Argument*

A second reason offered by egalitarians for the belief that mutuality rating is inappropriate is that it is uncaring, and thus unfair, to offer more stringent terms and conditions when a genetic test indicates that they are likely to develop a genetic disease.<sup>79</sup> This view is questionable when many people are unable to afford life and disability insurance at market prices yet suffer from terrible illnesses and unexpected death.

To answer the question of fairness we need to consider the effect that a policy of solidarity rating would have on the price of insurance premiums. According to

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75 For a list of such studies and a critique, see McGleenan, above n 3, [6.1.7].

76 *Ibid.*

77 *Ibid.*

78 *Ibid.*

79 Keays, above n 42; Barlow-Stewart and Keays, above n 2.

independent actuarial literature, premium prices are unlikely to spiral out of control or become totally unviable, as insurers once thought. It is estimated that premium prices for mortgage-related life insurance would be likely to increase by 5–15 per cent if the use of DNA test results was banned.<sup>80</sup> However, the increase would be more in small insurance markets like critical illness. If family history information and other medical information were also rated on a solidarity basis, the increases would be even larger.

British insurers took the view that the market could sustain a 5–15 per cent increase in premiums without serious damage, and thus became more willing to contemplate a ban on the use of genetic information.<sup>81</sup> The idea that policyholders should absorb the costs of solidarity rating is deceptively appealing. It is a mistake to assume that solidarity rating solves the equity crisis. Rather, it shifts or accentuates the problems for a different class of people – those who are economically unfortunate.<sup>82</sup> A premium increase of 5–15 per cent might be enough to force some people out of the insurance market, and many more would struggle if solidarity rating were implemented, as it should be, without a genetically exceptionalist footing.

It has been argued that it is particularly important for people who are at risk of genetic disease to have life and disability insurance because of the suffering they might endure in the future.<sup>83</sup> Therefore it might be said that there should be no barrier to purchase and that loaded premiums should be disallowed. This has been widely described as the ‘social good’ argument.<sup>84</sup> The issue in question is whether insurance is the sort of ‘social good’ that the state should guarantee citizens by forcing others to relinquish some of their private wealth.

It is widely accepted that we ought to guarantee people basic liberty, rights and opportunities.<sup>85</sup> As such, we guarantee people ‘primary social goods’ which are essential to basic liberty and opportunity. In contrast, we do not force people to share their wealth in order that other people can purchase ‘secondary social goods’ which are pleasurable, rational, desirable or prudential to have, but which are not essential.<sup>86</sup> ‘Secondary social goods’ are accessible to people with the private resources to afford them.<sup>87</sup>

It is implausible to argue that solidarity rating for life and disability insurance is a ‘primary social good’ when it pushes low income earners out of the market; many people do not or cannot purchase it; and society sees fit to guarantee a much lower level of care in publicly-funded health care systems such as

80 See above n 54.

81 Association of British Insurers, ‘Insurers Confirm Decision to Extend Moratorium on Use of Genetic Test Results’ (Press Release, 1 May 2001) <<http://www.abi.org.uk/newsreleases/default.asp?display=month&year=2001&month=5>> at 10 August 2002.

82 Angus Macdonald, ‘Genetic Information and Insurance’ (2001) 2(1) *Genetics Law Monitor* 1, 4.

83 Keays, above n 42, 84.

84 See, eg, McGleenan, above n 3, [5.1.1].

85 See, eg, John Rawls, *A Theory of Justice* (1971); Dworkin, above n 9; Norman Daniels, *Just Health Care* (1985); Tom Beauchamp and James Childress, *Principles of Biomedical Ethics* (5<sup>th</sup> ed, 2001).

86 On the distinction between primary and secondary social goods, see McGleenan, above n 3, [5.1.1]; Sandberg, above n 42, 1549.

87 McGleenan, above n 3, [5.1.1].

Medicare. On this point Macdonald observes that despite our preoccupation with the genetics and insurance debate 'the largest group excluded from insurance is people who cannot afford it (and wealth is a strongly inherited trait!) ... Only a small minority of people at risk of genetic disorders would benefit [from solidarity rating]'.<sup>88</sup>

Even if it is assumed that life and disability insurance is a primary social good that should be guaranteed by the state, we are yet to have a reason why policyholders should pay for the scheme rather than taxpayers. Moreover, if life and disability is an essential social good, we should ensure that all people have it; not just the moderately wealthy.

It has been argued that life insurance is a special kind of social good because, on occasion, it is a precondition for a house mortgage or business loan.<sup>89</sup> It is arguable, though, that private freehold ownership of property (like life and disability insurance) is not a basic right, liberty or opportunity for which the state should redistribute wealth. It is difficult to see why the interests that genetically unfortunate people have in freehold property would justify excluding more economically unfortunate people from the life and disability market, which is what may happen as a consequence of adverse selection. However, the tension of moral interests might be alleviated if solidarity rating were only applied to mortgage-linked life insurance.<sup>90</sup> That is, we might prohibit underwriting based on an individual's characteristics when they apply for mortgage-linked life insurance, and insist that insurers adopt solidarity rating in these circumstances. The assumption here is that a law that enforces solidarity rating *only* in the mortgage-linked life insurance market would not affect the poor. If they are struggling to afford 5–15 per cent extra on their premiums they are unlikely to be seeking to purchase a house.

If life and disability insurance is not a 'primary social good' there is no immediately obvious reason to shift to a system of solidarity rating. Are there any less obvious reasons to shift to a system of solidarity rating? First, it might be argued that solidarity rating is the most efficient way of improving the care of the most disadvantaged people, if it meant that more resources were freed for the Medicare system.<sup>91</sup> To date, this argument has not been fully developed. Secondly, this policy might be justified if solidarity rating could be implemented without forcing redistribution of wealth. Some researchers have been considering models of reinsurance,<sup>92</sup> where insurers purchase their own insurance for the risks associated with solidarity rating (ie the risks of adverse

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88 Macdonald, 'Genetic Information and Insurance', above n 82, 4.

89 Lemmens, above n 11, 349.

90 Such a system applied in the UK prior to the moratorium of 2001. The code on genetic testing by the Association of British Insurers proposed that insurers should not use DNA tests for underwriting mortgage-linked life insurance policies below £100 000: Association of British Insurers, *Genetic Testing: ABI Code of Practice* (1999).

91 Rawls, above n 85.

92 For further discussion, see McGleenan, above n 3, [11.1.6] and references cited therein; Professor A D Wilkie, *Proposal for a National Genetics Reinsurance Pool* (2001) Human Genetics Commission <[http://www.hgc.gov.uk/insideinformation/iievidence\\_reinsuranceproposal\\_dwilkie.pdf](http://www.hgc.gov.uk/insideinformation/iievidence_reinsuranceproposal_dwilkie.pdf)> at 26 July 2002.

selection). In effect the risks are spread amongst a number of insurers taking the 'sting' out of unusually high levels of adverse selection. However, reinsurance is a complicated area and unlikely to avoid premium increases entirely. It tends to add another layer of transactional costs.<sup>93</sup> Another mechanism to minimise the redistributive burden, (which is the effect of adverse selection) is to compel participation in the life and disability insurance market.<sup>94</sup>

Arguments claiming that solidarity rating is necessary to protect the uptake of genetic tests and to ensure that at-risk applicants have just and equitable access to primary social goods should be viewed with scepticism. Instead it would seem that mutuality rating is preferable. But note the qualifications implied by the analysis. First, it is possible that future research will show more conclusively that patients are refusing medical tests because of mutuality rating. This would improve the case for solidarity rating but not necessarily secure it. Secondly, future research may demonstrate more convincingly that life and disability insurance is an essential part of life in Australia because of its role in long-term care. If this is the case, though, we must simultaneously consider the need to radically improve Medicare services, as implementing solidarity rating will not assist the poor to access life and disability insurance. Thirdly, solidarity underwriting would be less objectionable if it did not increase the cost of premiums for other policyholders. This might be achieved through reinsurance mechanisms or by creating a separate market for life insurance linked to housing mortgages. Fourthly, there would be more reason to support a system of solidarity rating for life and disability insurance if research showed that it freed up similar publicly funded services for the poor.

### **E Mutuality Rating: Permitting Actuarially Fair Underwriting For All Medical Risk Information**

Without evidence to support the qualifications just mentioned, the argument for solidarity rating is weak. At present there is no clear reason to abandon mutuality rating in the context of life and disability insurance. There is little evidence that mutuality rating is discouraging people from seeking the care they need, or that life and disability insurance is a social good essential to wellbeing in a liberal society. If this is correct, insurers should be permitted to underwrite medical risks on a mutuality basis provided they base it on proper risk assessment; that is, if they can show that it is actuarially significant.

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93 On this and other problems see McGleenan, above n 3, [11.1.6].

94 For example, the state might make it mandatory for people to purchase life and disability insurance, subject to a means test. This would keep a larger proportion of 'good risks' in the life and disability insurance market. A less bold form of compulsory participation would be to give people incentives to take out life and disability insurance through, for example, tax rebates. This would be similar to the Commonwealth government's policy of 'Lifetime Health Cover' which gives people incentives to join private health insurance schemes by the age of 30: Commonwealth Department of Health and Aged Care, *Fact Sheet 9 Lifetime Health Cover: Ensuring Australia Has a Balanced Health Care System* (1999) Australian Department of Health and Ageing <<http://www.health.gov.au/pubs/budget99/fact/hfact9.htm>> at 3 July 2002.

This policy is largely reflected by the current legal position. As explained above, s 46 of the *DDA* already requires insurers to prove actuarial significance if challenged.<sup>95</sup> A further issue for consideration is whether there is sufficient accountability and transparency in insurers' risk rating practices. Some authors suggest that insurers are not properly observing the criterion of actuarial fairness.<sup>96</sup>

In response to this concern, a special committee was established in the UK to oversee genetic underwriting.<sup>97</sup> Subsequently British insurers were only permitted to use genetic tests that have been approved as being actuarially significant by this committee – the GAIC.<sup>98</sup> Australia could establish a similar sort of committee to supplement review under s 46 of the *DDA*. A body like the GAIC can pre-empt poor actuarial practices before insurers extract money from consumers. Another advantage of establishing an institutional overseer like the GAIC is that it avoids the shortcomings of adversarial litigation. Few individuals have the data, skills or resources available to mount a serious challenge against an insurer.

Setting up a body like the GAIC is not inexpensive and choosing the members of the committee is a crucial step. The GAIC has encountered problems with apparent conflicts of interests. Although members declared their competing interests, a perception of bias lingered.<sup>99</sup> The method of appointing members led to this conflict. Members were appointed as 'nominees' of particular stakeholders. Although they did not act as 'representatives' in the sense of lobbyists, they were seen as being sympathetic with the nominating stakeholder's interests. A preferable approach is to appoint independent experts who have no prior allegiance to industry or established public views on an issue, similar to the UK Human Genetics Commission. The difficulty lies in finding these people. The scarcity of actuaries outside the insurance industry was a problem in the UK,<sup>100</sup> and could be even more pronounced in Australia.

Furthermore, if an actuarial review body like the GAIC were established in Australia, what would be the proper scope of its remit? The GAIC only reviews the actuarial fairness of underwriting DNA tests. This seems unduly narrow if we reject the idea of genetic exceptionalism. Instead, the actuarial review body should consider the actuarial significance of a wide range of personal risk information including family histories, blood pressure readings and other medical test information.<sup>101</sup> Underwriting other medical risks without clear evidence of actuarial fairness (proper risk assessment) is simply another form of unjust and arbitrary treatment. If there is doubt whether insurers are accurately

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95 See above Part II(B)(2).

96 Otlowski, above n 10, 37–42.

97 Select Committee on Science and Technology, above n 1, [54]–[60].

98 British insurers (who are members of the Association of British Insurers) must also observe a moratorium below a certain level of assurance: see above Part IV(B)(4).

99 Select Committee on Science and Technology, above n 1, [55]–[57].

100 Cayton, above n 58, 9.

101 The Human Genetics Commission has moved towards this view and recently suggested that the GAIC should review the actuarial significance of family histories: Human Genetics Commission, *Inside Information*, above n 60, [7.16].

interpreting DNA data,<sup>102</sup> there is little reason to think that they are accurately rating family histories or other medical risk indicators. This should also be subject to independent, scientific peer review.

### F Information-Rich Mutuality Rating

If mutuality rating is endorsed, a remaining question is whether insurers should be allowed to ask applicants to undergo genetic tests that they have not already had. The risk is that insurers will seek increasing amounts of genetic information about applicants so that they can more accurately assess whether or not a person is likely to make a claim on their insurance. I have called this approach 'information-rich mutuality rating'. A serious ramification would be that applicants would lose the right *not* to know about their genetic predispositions.<sup>103</sup>

Insurers are not currently pursuing an information-rich model for genetic information. The *Insurance Contracts Act 1984* (Cth) does not require a person to disclose information they are unaware of at the time of entering the contract.<sup>104</sup> Likewise the policy of the Investment Financial Services of Australia on genetic testing discourages insurance companies from requesting or requiring applicants to undergo genetic testing.<sup>105</sup> Insurance companies have tried to reassure the public that it has no intention to change this policy by pointing out that adverse selection only occurs when individuals have more knowledge than their insurer about their own personal risk.<sup>106</sup> They argue that since they are only interested in avoiding adverse selection, they only seek the genetic information that the individual knows at the time of entering an insurance contract, and are not planning to implement 'information-rich' mutuality rating.

Scepticism remains as insurers often insist on medical examinations as a precondition of insurance. It is difficult to reconcile this practice with the explanation given about actuarial fairness. Medical examinations may be an attempt to minimise fraudulent nondisclosures. If so, then it is also possible that insurers might one day see mandatory genetic tests as a useful precaution against applicants who deliberately conceal genetic information. This prospect raises concern,<sup>107</sup> although it is arguable that if the practice is morally defensible for medical examinations, it would also be fair for genetic examinations. For present purposes I do not draw a firm conclusion. More information about insurers' reasons for insisting on special medical examinations is required to examine the claim that an individual has a right not to know certain genetic information, and

102 Select Committee on Science and Technology, above n 1, [33]; Otłowski, above n 10, 37–42.

103 See generally, Ruth Chadwick, Mairi Levitt and Darren Shickle (eds), *The Right to Know and the Right Not to Know* (1997).

104 See above Part II(B)(1).

105 IFSA, above n 17. The UK Association of British Insurers has a similar provision in its code on genetic testing: Association of British Insurers, *Genetic Testing*, above n 90.

106 IFSA, above n 17; Stephen Sklaroff, 'Genetic Testing and Insurance' (Paper presented at the Human Genetics Commission Information-Gathering Meeting, London, 9 February 2001), Human Genetics Commission <<http://www.hgc.gov.uk/stephen.pdf>> at 26 July 2002.

107 Otłowski, above n 10, 32–3.

to question whether there is a similar right not to know about medical information.

### **G Capped Solidarity Rating: Prohibiting Use of All Medical Information in Moderate Sized Life and Disability Policies**

The section on partial solidarity rating considers the proposal that the law should ban the use of genetic information when an applicant seeks to purchase insurance of a small or moderate level, but allow mutuality rating when the application is for a large insurance policy. This was rejected for being genetically exceptionalist. It remains to consider whether a similar proposal might nevertheless be desirable if it were applied to all medical risk information.

Capped solidarity is often touted as a response to the perceived inequities of mutuality rating. This was the rationale for the recent moratorium on mutuality rating in the UK. The capped level is £500 000 for life insurance and £300 000 for critical illness insurance.<sup>108</sup> Leaving aside the fact that the moratorium is genetically exceptionalist,<sup>109</sup> it is doubtful that there is a good rationale for such a high cap. If equity is the reason for capped solidarity then the level should reflect what we consider to be a primary social good, and not the level of insurance that we think would be desirable to have or the level above which few people buy insurance.<sup>110</sup> Arguably the UK cap is considerably higher than what should be considered an essential level of insurance, and may well increase premium levels as a result of adverse selection. As such, the policy privileges the genetically unfortunate at the expense of the economically unfortunate and those people with other kinds of medical risks.

An alternative, and preferable, theoretical foundation for capped solidarity is that it provides a mechanism to limit the effects of adverse selection. Macdonald's research shows that adverse selection, due to concealment of genetic risks, is significantly higher when the sums insured are two to four times higher than the average.<sup>111</sup> This supports restricting the concealment of genetic information to moderate levels of insurance, and allowing insurers to underwrite genetic risks in policies with higher values. This prevents people who are fairly certain that they will develop an illness from making large claims after paying relatively small premiums. To implement this kind of policy, more research needs to be conducted to determine which capped level minimises the impact of adverse selection. It may be appropriate to ascertain different levels for different kinds of insurance, for example, life insurance separate from disability or critical illness insurance, or mortgage-linked life insurance separate from other policies. Most importantly, we should carry out this research assuming that genetic and medical information should be treated alike.

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108 See above n 65 and accompanying text.

109 See above Part IV(B)(1)(a).

110 See above Part IV(B)(D)(2).

111 Macdonald, 'Modeling the Impact of Genetics on Insurance', above n 54, 89, 91 (table 3).

## V CONCLUSION: WHICH OPTION FOR AUSTRALIA?

The idea of deregulated rating where insurers set their own terms and conditions should be rejected because of problems with libertarianism and laissez-faire theory. This option is non-distributive and would only enable the economically fortunate to benefit.

A contrasting approach would be to ban the use of DNA tests. Typically this is thought of as the egalitarian response – less heartless, more compassionate to people's needs and vulnerabilities, and opposed to the creation of a genetic underclass. Although the central paradigm of the egalitarians – that we should seek to effect equality, sensitive to people's needs and vulnerabilities – is commendable, there is little evidence to support the idea that life and disability insurers should be banned from using genetic information.

Versions of partial solidarity rating, under which various sorts of genetic information are banned from use, should be rejected because these proposals are genetically exceptionalist. Genetic exceptionalism is an unsatisfactory basis for legal policy because in the context of insurance there is no good reason to think that DNA tests or family histories are different from any other medical risk information. Ironically, in an effort to protect people with genetic risks, genetically exceptionalist proposals unfairly disadvantage people with non-genetic risks. The problem is that egalitarians have overemphasised the interests of genetically unfortunate people whereas they should also take into account the interests of the economically unfortunate and people with medical risks detected by non-genetic tests.

Should we radically overhaul the life and disability insurance market and insist on solidarity rating for all medical risk information? This would mean that no person would be disadvantaged by his or her own personal risk and everyone would pay an equal premium. However, contrary to the two reasons commonly given as justification for solidarity rating, it is questionable whether there is any evidence that mutuality rating is detrimental to the uptake of medical or genetic services, and also whether this argument should determine the debate. It is not fair to expect policyholders to subsidise at-risk applicants if it means they cannot afford their own life and disability insurance or other important goods they desire. Forced redistribution of wealth might be justified if life and disability insurance were a primary social good, but it is difficult to characterise it in this way when so many people lack it and society does not assist them to buy it. It is more plausible to conclude that solidarity rating is not called for. Therefore we should not ban the use of DNA tests, family histories or medical risks in underwriting life and disability insurance.

On the evidence available, mutuality rating is the most ethically astute proposal. Insurers should be allowed to use genetic and medical information provided it is based on solid actuarial science. Section 46 of the *DDA* basically enacts this proposal. Nevertheless, the transparency and accountability of insurers' underwriting could be improved, perhaps by establishing a scientific committee to review the evidence. If this idea is pursued, the committee should have the power to challenge insurers to provide evidence that they are properly



rating family histories and medical information, as well as DNA information. It should not have a genetically exceptionalist remit. However, a full examination of an information-rich mutuality rating whereby insurers could compel applicants to have a genetic test, and not merely reveal information already known to them, is beyond the scope of this paper.

A final option is a capped solidarity rating for all medical risk information. Unlike the option of capped solidarity rating for DNA risk information, this proposal is not genetically exceptionalist. There are two justifications for this policy. Each has implications for the level of the cap. If we accept that the rationale underlying capped solidarity is that it controls adverse selection and pertains to actuarial fairness, then the precise amount of the ceiling should be linked to actuarial data about adverse selection. In this case it is a variation on the theme of mutuality rating. On the other hand, if we take the view that capped solidarity is related to equity, then the ceiling should be linked to the amount of insurance that is a primary social good. If we value consistency and fairness this level of health care should be available to all, regardless of their means, which may mean that further funding of disability and welfare services is required.