

# Regulatory Approaches to Genetic Testing in Insurance

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## 1. Introduction

Rapid advancements in the field of genetic science have engendered considerable debate, speculation, misinformation and legislative action worldwide. While programs such as the Human Genome Project bring the prospect of seemingly miraculous medical advancements within imminent reach, they also create the potential for significant invasions of traditional areas of privacy and human dignity through laying the potential foundation for new forms of discrimination in insurance, employment and immigration regulation.

The insurance industry, which has, of course, traditionally been premised on discrimination as part of its underwriting process,<sup>1</sup> is proving to be the frontline of this regulatory battle, with extensive legislation, guidelines and debate marking its progress. In the last decade, insurers' access to genetic testing has been addressed by legislation or the adoption of industry codes of conduct in over 44 states in the United States of America,<sup>2</sup> a number of European countries and some Commonwealth countries.<sup>3</sup> Many other countries have endorsed specifically drafted Conventions or charters of rights<sup>4</sup> in anticipation of introducing appropriate governance provisions in the immediate future. At a macro level this regulatory 'frenzy' clearly reflects the deep concern most societies harbour over the rapidly changing capacities of genetic science. At the micro level of insurance industry regulation, however, the overall result in relation to industry practices is probably best embodied by one commentator's characterisation of it as a

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1 Modern insurance is premised upon careful assessment of risks and actuarial calculations to distinguish between good and bad risks. See, eg. George Clayton, *British Insurance* (1971) at 65; *Australian Mutual Provident Society v Goulden* (1986) 160 CLR 330.

2 Starting with Wisconsin in 1992, regulatory regimes of various kinds have been adopted by 44 states. US Federal legislation exists through the *Health Insurance Portability and Accountability Act*, Pub L No 104-191, 110 Stat 1936 (1996) which prohibits group health insurers from applying 'pre-existing condition' exclusions to genetic conditions that are evidenced solely by genetic tests and not by actual symptoms; additional bills such as the *Genetic Privacy and Nondiscrimination Act of 1997* and the *Genetic Confidentiality and Nondiscrimination Act of 1997* have also been (unsuccessfully) introduced. See Jeremy Colby, 'An Analysis of Genetic Discrimination Legislation Proposed by the 105<sup>th</sup> Congress' (1998) 24 *American J of Law & Med* 443. Further Uniform Legislation is expected.

3 The UK and Australia thus far have resolved to rely upon industry undertakings. See, eg. Investment and Financial Services Association (IFSA), *Draft Policy on Genetic Testing* (February 1999) approved by the Australian Competition and Consumer Commission (ACCC). See Margaret Otowski 'Review of the ACCC's Decision on the IFSA Genetic Testing Policy' (2001) 16 *Aust Insurance Law Bull* 9.

'patchwork quilt,'<sup>5</sup> — and certainly one comprised of components of widely varying quality. Indeed, one commentator concludes, on the basis of an extensive study of recent US legislative initiatives to prohibit genetic discrimination in health insurance, that many of the affected parties actually regard such legislation as unnecessary, irrelevant or both. The actual use of such data has been, and shows every sign of continuing to remain, influenced far more substantially by extra-legal norms and self-interest.<sup>6</sup>

In the face of a growing international movement towards uniform codification of insurance laws, which arises substantially out of recognition of the growing impact of technology on world markets and the economic mobility of consumers, such an approach seems myopic as a longer term strategy. To survive as a useful form of regulation, whatever legislative approach is adopted law makers need to give careful consideration to:

- (i) whether the interface between genetic testing and insurance regulation is so critical as to justify the introduction of specialised statutory protection for this area alone within the insurance regulatory framework;
- (ii) whether it is acceptable or desirable absent formal debate and consensus to promulgate legislation that potentially (re)defines the role the state plays in protecting welfare interests of its citizens through delegation of health/life/disability protection responsibilities to the commercial insurance industry on a compulsory basis; and
- (iii) whether the legislative provisions advocated or adopted are sufficiently sensitive to the inherent differences in culture, commercial infrastructure and philosophical vision that already exist in the society considering its entrenchment.

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4 Article 11 ('Any form of discrimination against a person on grounds of his or her genetic heritage is prohibited') Article 12 (prohibiting genetic testing for reasons other than health care and scientific research) Council of Europe, *Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine*, ETS No 164 (1997) that entered into force on December 1, 1999. <<http://www.coe.int>> (website for the Council of Europe). See also the UNESCO approved *Universal Declaration on the Human Genome and Human Rights* prohibiting '... discrimination based on genetic characteristics that is intended to infringe or has the effect of infringing human rights, fundamental freedoms and human dignity.' UNESCO, 29<sup>th</sup> Session 20 C/Resolution 19 (1997) Article 6.

5 See, Trudo Lemmens, 'Selective Justice, Genetic Discrimination, and Insurance: Should We Single Out Genes in Our Laws?' (2000) 45 *McGill LJ* 347 at 350. See also Mark Hall, 'Insurer's Use of Genetic Information' (1996) 37 *Jurimetrics* 13.

6 Mark Hall, 'Legal Rules and Industry Norms: the Impact of Laws Restricting Health Insurers' Use of Genetic Information' (1999) 40 *Jurimetrics*. See also Christopher Keefer, 'Bridging the Gap Between Life Insurer and Consumer in the Genetic Testing Era: The RF Proposal' (1999) 74 *Indiana LJ* 1375.

## 2. Genetic Testing, Genetic Discrimination and the Human Genome Project

Evaluating the role various legislative initiatives may play presupposes recognition of the changes that genetic testing is expected to precipitate. The preponderance of these changes arise from the imminent success of the internationally embraced research undertaking referred to as the Human Genome Project<sup>7</sup> as well as other commercial ventures, such as Celera Genomics, which are pioneering the field of proteomics.<sup>8</sup> The HGP project's objectives includes providing an effective 'blue print' of the human genetic structure by mapping the sequences of chromosomes, their genes and their resulting DNA strands that comprise the human form.<sup>9</sup> In doing so, scientists will, by identifying and analysing the chemically encoded information contained in each gene, be able to decipher the hereditary traits that govern each individual's makeup. Once the human genome is described in molecular detail it will be possible to reveal critical mechanisms of human biology and supply the medical context within which investigations of the molecular pathology of human diseases can most efficiently take place. From this will evolve not only substantially more advanced abilities to enhance therapeutic and preventive treatments (such as through lifestyle modifications) but will also in the longer run spawn new forms of treatment and cure for inherited disease through, for example, replacement, repair, or blocking of defective genes.<sup>10</sup>

It is further anticipated that genetic diagnostic tools will be available for popularly perceived 'non-medical' conditions that have genetic components such as, for example, alcoholism, aggression and sexual orientation.<sup>11</sup> Although outside the scope of this paper, this aspect of genetic testing and the potential ramifications it presents if individuals should, in the future, embark upon replacing random

7 See <<http://www.hugo-international.org/hugo/mission.html>> (4 April 2002).

8 Proteomics is a branch of biotechnology which focuses upon the processes by which genes make and manage proteins. Celera Genomics, which is headed by Dr. Craig Venter, is the private company which, in conjunction with the publicly funded Human Genome Organisation, announced on 26 June 2000 that a 'working draft' of the 3.1 billion biochemical 'letters' of human DNA in their correct sequence will be completed imminently. The project has been undertaken in effectively two steps: 1) actual mapping of the 23 chromosomal pairs in the human body and 2) sequencing the DNA contained within these chromosomes. See Craig Venter, 'Proteomics, Genes and Race, and Much More' <<http://www.genemedia.org/Archive/>> (4 April 2002).

9 For a good overview, see <<http://www.ornl.gov/hgmis/publicat/tko/.html>> (the web site for the US based Lawrence Berkeley National Laboratory); or <<http://www.gene.com/AE/AEPC/NIH/gene01.html>> (20 April 2001).

10 See, eg. Colby, above n2.

11 See, David Keays, 'The Legal Implications of Genetic Testing: Insurance, Employment and Privacy' (1999) 6 *J of Law & Med* 357, citing: K Q uaid, H Dinwiddie, PM Conneally, JI Nurnberger Jr, 'Issues in Genetic Testing for Susceptibility to Alcoholism: Lessons from Alzheimer's Disease' (1996) 20 *Alcohol Clin Exp Res* 1430 at 1431; V Morrel, 'Evidence Found for a Possible "Aggression Gene"' (1993) 260 *Sc* 1722; WE Crusio, 'The Neurobehavioural Genetics of Aggression' (1996) 26 (5) *Behav Genet* 459; D Hamer, S Hu, VL Magnuson, N Hu, AM Pattatucci, 'A Linkage Between DNA Markers on the X Chromosome and Male Sexual Orientation' (1993) 261 *Sc* 321.

selection genes with non-random selection is of significant philosophical concern to many and, as it is subsequently contended, colours aspects of the immediate debate.<sup>12</sup>

Genetic testing is generally defined as the analysis of DNA, RNA or protein sequences for the purpose of determining the existence or predisposition to a particular disease group.<sup>13</sup> In its current form it involves analysis of body tissue or fluid for purposes of identifying what is, at this time, a limited range of genetic abnormalities. Roughly put, such abnormalities can be classified as either multi-factorial (polygenic) disorders or single gene (monogenic) disorders. The latter is relatively rare and involves identification of DNA segments that correlate with those of the disease. They are generally intergenerational although individuals affected may be asymptomatic at various stages or may, in some cases, even be a 'carrier' who, while capable of passing on the disease, will not actually develop its symptoms. There are estimated to be over 8,000 monogenic disorders afflicting at least one percent of the population<sup>14</sup> including, for example, cystic fibrosis, Huntington's disease, sickle-cell anaemia or thalassemia. Testing results for monogenic diseases are, in one sense, extremely accurate.<sup>15</sup> They indicate those who do carry abnormal genes (such as for sickle cell anaemia, for example) and, in relation to some diseases, can predict with certainty that its carrier will at some point manifest symptoms (such as is the case with Huntington's disease). Tests generally cannot, however, predict accurately the stage at which many diseases will present symptoms — if at all — or the likely extent of incapacity that will result.

If such results are therefore used to block an applicant from coverage or increase the premium otherwise payable, treating the presence of monogenetic disease traits that may not end up significantly affecting a prospective applicant's quality of life as a litmus test for insurability would seem open to challenge on fairness grounds. Put alternatively in the vernacular that has arisen from this

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12 Australian High Court Justice Michael Kirby recently grounded the issue of genetic engineering firmly — and chillingly — in the present with his observation in regard to genetic determination of homosexuality that: 'There's no doubt... back in 1939 when I was born, if my parents had had that data, in the light of 1939, in the attitudes of that time, that if they had an option, I would have been eliminated... (however)... people are coming to realise that diversity is a very important aspect of being human.' See, [2000] 38(9) LSJ 56. For additional discussions generally see, eg, Larry Gostin, 'Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests by Employers and Insurers' (1991) 17 *American J of Law and Med* 109. See also a dedicated edition of the *Suffolk University Law Rev* (1993) 27(4).

13 See, for more detailed overview <<http://www.lbl.gov/Publications/TKO/>> (the web site for the US based Lawrence Berkeley National Laboratory) or 'Introduction — The Human Genome Project,' National Center for Human Genome Research, National Institutes of Health, <[http://www.accessexcellence.org/AB/IE/Intro\\_The\\_Human\\_Genome.html](http://www.accessexcellence.org/AB/IE/Intro_The_Human_Genome.html)>. See also, Kristine Barlow-Stewart & David Keays, 'Genetic Discrimination in Australia' (2001) 8 *J of Law & Med* 250.

14 Keays, above n11 at 358.

15 See Paul Billings et al, 'Discrimination as a Consequence of Genetic Testing' (1992) 50 *American J of Human Genetics* 476.

debate, to do so would constitute 'insurance discrimination.' In this vein, the Association of British Insurers, the United Kingdom's self-regulating industry authority, recently recanted its 1998 position regarding the validity of four out of a designated seven conditions which insurers could take into account when setting premiums.<sup>16</sup> Two tests were set aside on irrelevancy grounds as, typically, their early onset was sufficient evidence of their existence;<sup>17</sup> one was held to be in fact not sufficiently predictive;<sup>18</sup> and the last was deemed to have too wide an age of onset to be pertinent.<sup>19</sup>

Multi-factorial diseases are both more common and generally more familiar to the average member of the public. They include, inter alia, most cancers, diabetes, psychotic disorders (such as schizophrenia and Alzheimer's) and heart disease. They differ from monogenic diseases in that how and to what extent their symptoms will manifest themselves in specific individuals can be affected by combinations of factors ranging from genetic inheritance through to environmental influence. So, while a given polygenic disorder may present full blown symptoms in one person who carries the trait, another may, through preventative lifestyle measures or other medical intervention, be substantially less affected. In this sense, test results are substantially more ambiguous: they can identify individuals with predispositions to a disease and hence who, other things being equal, stand higher risks of presenting symptoms, but they are incapable of reflecting more realistically whether such applicants, based on their actual lifestyle, will be substantially affected (for insurance purposes) by their carriage of this mutation. Hence, individuals who are aware of their predisposition and avail themselves of preventative lifestyle modifications and/or appropriate therapeutic intervention, are arguably inappropriately discriminated against by the use of such a 'red line' test for insurability.

The scope of the problem of insurance discrimination on genetic testing grounds is open to some debate. At this time, genetic testing is relatively common in scientific research and medical diagnostic contexts such as, for example, pre-implantation testing of embryos and prenatal screening of fetuses and newborn infants for diseases such as cystic fibrosis.<sup>20</sup> It is not, however, a commonly encountered practice for predictive diagnostic purposes in seemingly healthy individuals due in substantial part to the costs inherent in testing which range

16 The remaining three tests are Huntington's disease, early onset familial Alzheimer's disease and hereditary breast and ovarian cancer. See, Patrick Collinson, 'Ensuring our Genes are a Looser Fit' *The Guardian (UK)* (7 April 2001).

17 Familial adenomatous polyposis (potentially leading to colon cancer) and hereditary motor and sensory neuropathy.

18 Myotonic dystrophy (a form of muscle weakness).

19 Multiple endocrine neoplasia (disease of endocrine glands which can lead to kidney stones, stomach ulcers.)

20 In Australia, infants are routinely screened within the first five days of life for cystic fibrosis, phenylketonuria, and congenital hypothyroidism. See David Keays, above n10, citing Loane Skene, 'Access to and Ownership of Blood Samples for Genetic Tests: Guthrie Spots' (1997) 5 *JLM* 137.

between several hundred and several thousand dollars.<sup>21</sup> Consequently, the direct impact on the insurance industry, which itself has yet to employ this procedure with any frequency,<sup>22</sup> is muted.<sup>23</sup> This is expected to change rapidly in the next decade as more efficient and accurate diagnostic tools such as the development of the DNA chip and micro array technology<sup>24</sup> make it possible to 'scan' entire genes for the detection of different mutations more cost effectively, and as the procedures become more familiar to the public.

Industry inexperience with use of genetic testing may also reflect: (i) concerns over adverse public reaction to its use; and (ii) the lack of a sufficiently developed base of statistical data for actuarial forecasting purposes. As this latter variable is somewhat of the 'chicken and egg' nature, it is unlikely to be a long term problem. Both US and Australian insurers indicate that as actuarial tables are prepared on the basis of existing claims histories and a statistically significant number of years of claims therefore presupposes their development, this is more an issue of time and experience.<sup>25</sup> With the development of and access to sufficient banks of predictive data, underwriting procedures will increasingly integrate these variables as part of the forecasting process.

Public reaction concerns are also likely to wane with time. As new technology makes predictive testing both more common and more cost efficient, the public's level of familiarity with the process will diminish some of the sense of uneasiness that currently surrounds this issue. Moreover, to the extent that negative perceptions remain, its impact will simply be factored in as one component of the cost/benefit equation considered in determining the extent of use. Accordingly,

- 21 See, Jon Beckwith & Joseph Apler, 'Reconsidering Genetic Anti-discrimination Legislation' (1998) 26 *J of Law, Med & Ethics* 205 at 206; Richard Braun, (1999) 53(5) 'Keeping Life Insurance Affordable in the Era of Genetic Medicine' *J Financial Services Prof* 46 at 47.
- 22 For example, in the United Kingdom, at its recent hearings regarding potential legislative action on genetic testing, the Select Committee on Science and Technology reviewed insurance industry submissions which indicated the following industry use of genetic testing in 2000: Prudential handled seven applications involving genetic testing; Norwich Union handled 50 (out of 150,000); CIS had 14 (out of 460,000 over the last three years); Patrick Collinson, above n16, citing results from Industry submissions to the Select Committee on Science and Technology in genetic testing hearings. For Australian usage see, Margaret Otlowski, 'Resolving the Conundrum: Should Insurers be Entitled to Access to Genetic Test Information?' (2000) 11 *Insurance LJ* 1. For the Canadian and US perspective, see Trudo Lemmens, above n5 at 351.
- 23 Statistically, and contrary to most predictions, insurers' reluctance to implement genetic testing procedures for discriminatory policy writing purposes has been borne out in U.S. studies. See Mark Hall & Stephen Rich concluding that '[b]ased on market testing and on extensive interviews in the health insurance industry and with genetic counsellors, we found that there are very few documented cases of health insurers either asking for or using presymptomatic genetic test results in their underwriting decisions, either before or after these laws were enacted, or in states without these laws. We also documented that a person with a serious genetic condition that is presymptomatic faces little or no difficulty obtaining health insurance, and there are few indications that the degree of difficulty varies according to whether a state prohibits the use of genetic information.' Mark Hall & Stephen Rich, 'Genetic Privacy Laws and Patients' Fear of Discrimination by Health Insurers: The View from Genetic Counsellors' (2000) 28 *J of Law, Med & Ethics* 245. For another view in the Australian context, see Barlow-Stewart & Keays, above at n13.

popular press predictions and public concern over substantially increased use of genetic testing is likely to become a growing reality over the next decades, although its use may not be as pronounced as is feared at the present time. Use will inevitably raise directly questions of commercial interest and indirectly questions as to how an individual society's infrastructures weigh key issues.

The most evident question is the extent to which insurance discrimination based on genetic testing constitutes a legitimate activity by insurers in determining which applicants it will accept — and on what terms — or whether it bestows an unfair edge to private enterprise that comes at the expense of those already at high risk of suffering debilitating health problems. Implicit within this issue is the sub-question of the extent insurers should be able to impose affirmative requirements that tests be undertaken or, if already independently taken, to compel disclosure of existing information in this respect. This also requires determining of the extent to which test results from one person can be used in conjunction with consideration of the insurability of others who possess similar genetic traits such as family members and even future descendants. Given the intergenerational nature of genetic testing results, the issue of whether a person several generations in the future may already be barred from acquiring health or life insurance has, in particular, managed to capture the public imagination.<sup>26</sup>

Determination of these types of issues inevitably carries with it significant implications for the societal structure in which such debates must be resolved. Accordingly, a number of social policy questions come into play. Foremost among these is whether, or to what extent, individual countries have either de facto or as a formal policy incorporated commercial insurance practices into their socio-welfare infrastructure. In countries such as the United States, for example, where the present lack of a national health care system is off-set primarily by access to private health insurance, any curtailment of this access will be not only controversial but is likely to carry with it substantial spill over costs for that society's current organisation.<sup>27</sup>

Additional concerns centre on the potential disincentive to undergo testing the prospect of insurance discrimination may create and the consequences this presents both for scientific research and for preventative health treatment. Finally, the fundamental question of the right of each individual to choose to remain unaware of events (potentially) in their future underlies generally all debate.

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24 See, Stanley Watson & Huda Akil, 'Gene Chips and Arrays Revealed: A Primer on Their Power and Their Use' (1999) 45 *Biol Psychi* 533; W Henn, 'Genetic Screening with the DNA Chip: A New Pandora's Box?' (1999) 25 *J of Med Ethics* 200.

25 See Trudo Lemmens, 'Selective Justice, Genetic Discrimination and Insurance: Should We Single Out Genes in Our Laws?' (2000) 45 *McGill LJ* 347 at 377.

26 At a popular press level, see eg. Collinson, above n16.

27 The level of societal unrest caused by such debate in the US is likely to be heightened further by the fact that the types of persons who will be most concerned about the potential for exclusion, are those who are already insured and may risk either direct loss of access to insurance or denial of access to those who are related to them. As only the most extraordinarily wealthy in the US would be financially positioned to take on health care costs associated with significant hospitalisation costs or treatment, significant loss of access to policies will certainly constitute a politically loaded issue.

### 3. *The Insurance Industry*

The interface between the predictive nature of genetic testing and insurance discrimination touches upon the fundamental nature of insurance as a commercial enterprise. The insurance industry by definition is premised on risk. While its occasional characterisation as a form of 'blue chip gambling'<sup>28</sup> may be somewhat overstated, the industry's nature is that it can only remain viable when a lower number of members of a designated risk pool generate claims prematurely than do those who continue to pay premiums.<sup>29</sup> The better an insurer's ability to correctly predict the claims forecast for a risk pool and to allocate new applicants appropriately to it, the more accurately cost-efficient premium levels can be set. Generally insurers will attempt to set premium pricing at the lowest possible rate so as to avoid deterring those critical lower risk members of the pool from seeking alternative cover either through competitors or through alternative risk transfer techniques such as not insuring or investing in other ways.

The predictive certainty of genetic testing therefore is central to risk allocation. Depending upon the legal rules applied to its use in the future, it poses the distinct prospect of tipping this calculus unduly in favour of either the prospective policy holders or the insurers.

From an insurers' perspective, use of increasingly accurate genetic data will inevitably create the ability for insurance underwriters to predict with far greater accuracy an individual's expected health care costs or the stage at which a life or disability policy will have to be paid. This in turn creates the ability of insurers to reject candidates who are likely to prove too cost-ineffective or to charge significantly higher premiums to those with test results indicating a predisposition towards engendering higher costs. If insurers are not able to use this information or access to it is curtailed, consumers who are aware of their heightened need for such services will potentially be able to access these products at a substantially lower rate than would otherwise be the case. Although attractive from such individual consumer's perspective, the economic result in a commercial setting will be that the majority of insureds are forced to pay significantly higher premiums than would otherwise be assessed.

The situation outlined above, whereby insurers are, through access to information, able to contract only with applicants who present attractive risk prospects is what has become known as 'insurance discrimination'. As discrimination has always been part of insurance contracting this term sounds substantially more ominous than it probably should.<sup>30</sup> An insurer's willingness to

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28 See, eg, Robert Merkin, 'Gambling by Insurance — A study of the Life Assurance Act 1774' (1980) 9 *Anglo-American Law Rev* 331.

29 Generally speaking, premiums charged to all members of a designated risk pool reflect the average level of risk of that class with the aggregate premium charged usually being roughly equal to the expected monetary value of the loss. Commercial profit for insurers is not earned simply on the basis of premium income but rather on the investment returns on the monies held.

30 Insurers enjoy exemptions under anti-discrimination legislation in Australia, eg, in recognition of the fact that individual risk assessment necessarily involves some discrimination. See, eg, the *Disability Discrimination Act* 1992 (Cth) s52.



cover an applicant and the price at which it would do so hinges on detailed disclosure of medical history and physical condition of candidates ranging from age and sex factors through to cholesterol readings and family medical backgrounds. This term sounds substantially more ominous than it probably should.

The ramifications of adverse selection varies in relation to different types of insurance offered. Adverse selection is the economic term used to describe the greater tendency of those posing comparatively higher risk to seek insurance than would be the case for those who pose a comparatively lower risk. The danger of adverse selection fluctuates by reference to the size and origin of the risk pool at stake, the amount of coverage offered and the type of the insurance sought. The distinction between health and life insurance, for instance, in this context is significant, as is the difference within life insurance policies themselves between term and annuity cover. Disability or crisis insurance would be more analogous to life cover than health but would also carry distinguishable incentives and disincentives from those present in relation to life policies. The distinctions between health and life can be illustrated by considering some of the following variables.

First, life insurance is not an indemnity-based policy. Unlike health insurance which simply reimburses insureds for amounts actually expended, the amount at stake in life policies is only capped by the insurer's judgement as to the amount of coverage it is willing to sell to any particular applicant. This judgement — and hence the amount of coverage and premium schedule adopted — will be based on the risk profile the candidate appears to present based on variables such as physical examination, health records and family history. If, therefore, key information regarding the candidate's life span is omitted from this actuarial process, the underwriting calculations may be flawed. If too many errors of this nature are made and the premium/payout rate is significantly askew, the risk pool will in the longer term cease to be commercially viable, and, as has been the case for a number of insurers around the world in the last two years, so will the insurer itself. Second, once entered into, life insurance policies generally are renewable on an annual basis at the election of the insured. Although insurers may subsequently be able to avoid a contract if it is found that false information as to health was originally given or omitted, generally no other grounds will enable an insurer to exit the policy. Third, the role played by 'adverse selection' in life, disability and trauma cover worldwide is significantly heightened in contradistinction to most private health insurance.<sup>31</sup>

Put in the context of genetic testing, adverse selection would result if those who, as a result of a test procedure, discovered they carried a life shortening condition and took out insurance for the purpose of providing appropriate financial

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31 An important distinction needs to be drawn in the Australian context between life and disability insurance on the one hand, and health insurance, on the other. Whereas the former are based on individual risk assessment which takes account of the health status of the applicant, health insurance is governed by the principle of community rating which prevents insurers from taking account of the health status of applicants in determining premiums.

cover for this affliction. As the point at which a payout is likely to have to be made is earlier than the normal actuarial life tables being used by the insurer would indicate, the premiums paid as per the normal basis will not be sufficient to cover the risk. Moreover, if significant numbers of policy holders in the same risk pool are doing so on this basis, the inevitable result will be inadequate premium intake overall to finance payouts and, in the longer term, the overall demise of the business. In short, given that the likelihood of a payout is certain, the knowledge of this information radically alters the financial viability of any risk pool into which such applicants are placed. Another arguably more serious aspect of the problem is that applicants may be inclined to take out larger amounts of insurance than they otherwise would purchase.

All risk pooling anticipates a certain level of poor risk choice. Inevitably some participants will be better risks than others but, absent adverse selection problems, results should over time average out for an appropriately constructed risk pool. One method in particular whereby adverse selection issues are controlled is through group underwriting — a practice most commonly associated with health insurance policies. By selling policies as an add-on to existing contracts or as fringe benefits to an already established ‘pool’ of candidates — such as to groups of employees or union members — the costs incurred by payouts to those of its members who may present higher risk are submerged in the averaging of costs for that group overall. As the group was already in existence for other purposes, the issue of individuals subsequently joining this group solely to procure needed cover — adverse selection — is substantially minimised.

Life insurance, however, is generally purchased on an individual basis and insurers therefore lack the cost efficiencies that come with pre-existing pools. Insurers are left to construct pools of ‘similarly’ placed applicants on the basis of the correspondence of their submitted profiles with existing underwriting tables. Generally profile information as to health and family history is obtained either in response to specific questions on the proposal and examination requirements and, in the case of most common law jurisdictions, supplemented through the historical requirement of full disclosure. In this respect insurance contracts differ from most other commercial contracts which, based on *caveat emptor*, require parties only to answer truthfully that which they are asked. Insurance contracts are, instead, contracts of ‘utmost good faith’ and therefore require both parties to disclose fully and accurately not only information sought but also any other information that the party may perceive to be relevant to the insurer’s determination in taking on the risk.<sup>32</sup> This distinction, which arose originally from 17<sup>th</sup> Century maritime law, is how the legal system has traditionally addressed the problem of adverse selection.

In Australia, the duties of utmost good faith and disclosure are contained in the *Insurance Contracts Act 1984* (Cth), sections 13, 14, 21, 22 and 28. These provisions emphasise that each party owes a duty of utmost good faith towards one another and outlines the nature of the disclosure required and the consequences

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32 See, eg, *Banque Kayser Ullman v Skandia Insurance Co* [1991] 2 AC 249; *Manifest Shipping Co Ltd v Uni-Polaris Shipping Co Ltd: The Sea Star* 1 All ER 743.

attendant upon non-disclosure.<sup>33</sup> An insured must disclose matters known to him or her that the insured knows is a matter relevant to the decision of the insurer whether to accept the risk and, if so, on what terms; or any matter that a reasonable person in the circumstances could be expected to know to be a matter so relevant.<sup>34</sup>

Of particular relevance to genetic testing issues is adverse selection's corollary, proverse selection. Proverse selection refers to the tendency of low-risk insureds to depopulate risk pools when the opportunity exists for them to enter another arrangement offering better terms either in the form of expanded coverage or lower premiums. In genetic testing terms, proverse selection is of particular concern in circumstances where insurers offer insureds the opportunity to voluntarily supply testing results that indicate their good health in exchange for lower premium rates. If such a course is widely adopted the result will obviously be, on one hand, that no one is 'compelled' to undergo any testing or to be discriminated against on the basis of negative results, but, on the other, that the risk pool will be rapidly depopulated of its low risk members with the inevitable result that, at a minimum, premiums for remaining members — presumably those with negative or no results — will escalate. While such testing remains cost inefficient for consumers to undertake, this pattern is unlikely to have a dramatic impact. It will, however, arise increasingly as new technology facilitates testing.

Conversely, from the perspective of a prospective applicant aware of a predisposition to genetic disease, procurement of sufficient insurance policies as a means of minimising the potential ramifications of this condition makes sense. The greater the degree of certainty of the disease presenting itself and the more serious its ramifications, the more likely it is that health, disability or life cover will be sought. Under these circumstances the applicant is not simply taking out a policy to hedge his or her exposure to financial loss if such an event happens but is effectively seeking to purchase insurance as a formal financial planning mechanism. Clearly this is a rational course of action but the question of whether it is the type of action that should be underwritten by a commercial operation without the knowledge that this is what is being done is a social policy question. Potentially the response to this would be that to do so is an acceptable weight to place on an insurer, in that the added costs it represents simply constitute an additional 'cost' to an insurer of doing business in that particular market. If this price is unacceptable to the insurer, it retains the option of either not offering that type of insurance product, or, if unduly onerous, not participating in that market at all. What is apparent, however, is that under either scenario, insurers who continue to offer such products will inevitably be forced to pass on the costs to those insureds who continue to purchase the product, with the overall effect being that those who wish to avail themselves of insurance will pay the higher price inherent in protecting those with greater propensities for claiming under the policy.

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33 See, eg, *Advance (NSW) Insurance Agencies Pty Ltd v Matthews* (1989) 166 CLR 606.

34 *Insurance Contracts Act 1984* (Cth) s21(1).

#### 4. *Comparative Regulatory Approaches*

Legal intervention in relation to genetic testing and genetic discrimination at this time effectively falls into three categories. The first category is a legislative approach that is premised on the protection of privacy rights. This approach works indirectly by limiting insurers' access to genetic testing results in the first place, thereby curtailing or extinguishing the opportunity for discriminatory use. The second approach adopted by various jurisdictions rests on anti-discrimination law. Legislation in this category seeks to prohibit insurers from using information that they either possess, or could have access to, as part of its underwriting-process either in the form of blocking the direct rejection of applicants or the charging of higher premiums. The third approach is substantially more limited in that it leaves existing insurance regulatory structures in place but effectively creates an automatic right to insurance below designated limits. Many countries at this time have not formally opted into any of the above approaches but have instead created a moratorium on the use of genetic testing for a designated period during which legislative options will be considered. In Australia, for instance, there is a joint agreement between the insurance industry and the Australian Competition and Consumer Commission (ACCC) in relation to an industry policy that will control the use of testing over the course of the next two years.<sup>35</sup> During this time, groups with vested interests in the outcome of this process will participate in dialogues with the Australian Law Reform Commission and the Australian Health Ethics Committee of the National Health and Medical Research Council, which have been charged with the obligation of preparing a report and final recommendations for this area.<sup>36</sup>

A number of states in the United States of America<sup>37</sup> have sought to sidestep genetic testing regulations through the broader rubric of enhancing privacy legislation. This is superficially logical in that genetic tests results, once disseminated, not only have the potential to form the basis for insurance discrimination against prospective insureds, as discussed above, but also carry ramifications for all others perceived to have overlapping genes. Members of the same family as well as intergenerational descendants therefore are potential targets of discrimination based on access to the same test results. Put alternatively, there is nothing to stop insurers from 'red flagging' entire categories of applicants as problematic once they have procured test information for one asymptomatic applicant. Additionally, absent the introduction of specific legislation, no prohibitions exist on this type of information being pooled with other insurers to create databases of groups of individuals who carry heightened claim risks. Indeed, considerable concern has already been expressed in regard to the databases arising

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35 This agreement reflects compliance with governing Australian unfair trade (anti-trust) provisions as set forth by s45 of the *Trade Practices Act 1974* (Cth), whereby the ACCC may, in response to an application (as per s88(1)) grant an applicant whose conduct might otherwise be challenged as being anticompetitive under this legislation, immunity from court action.

36 See Attorney General/Minister for Health Genetic Privacy: Press release (7 Feb 2001). For a description of the interim position see Otlowski, above n3.

37 See Lemmens, above n5 at 347–366.

out of projects such as the Human Genome Project and Celera to the commercially valuable opportunities such databases present for, amongst others, insurers.<sup>38</sup>

Additional privacy concerns exist for two other reasons. First, information relating to health — such as test results — are frequently contained in the information application forms held by insurance brokers. As brokers may approach a number of insurers to obtain the best cover for a client, this information may be broadly disseminated. Moreover, at this time, no duty of non-disclosure exists in relation to this information on the part of brokers. Second, most insurance policies include a waiver of privacy which allows access to existing medical records of patients. If genetic testing results exist it is rare that they would not have been integrated into these records and would therefore be immediately available to insurers. Failure to have disclosed this information in most common law jurisdictions — those which have preserved the utmost good faith standard as set forth above — would potentially have the short term effect of rendering a contract void *ab initio*. It could have the longer term effect, by extrapolation, of revealing information about genetically related parties who have yet to have had dealings with insurers.

Clearly lack of protection in this context is a ground for concern. It is reasonable to expect personal information disclosed for a specific purpose, such as for the consideration of an insurance application or a job application, to be limited to disclosure and use only within that context, unless otherwise agreed upon. Use at this time of genetic information, in particular, underscores this concern; there is something particularly intrusive about others being aware of the physical weaknesses and genetic fate of an individual who has not chosen to share this information (or who may not even be aware of it in the case of relatives). Kenneth Abraham notes that lack of privacy in relation to genetics carries an additional dimension in that possessing genetic flaws to many at this time in history is stigmatic:

At this relatively early stage in the development of genetic testing, concern about genetic privacy is understandable. The eugenics movement in this country and the Nazis' obsession with racial "purity" are not ancient history. These dark moments in our past heighten fears that genetic information may be misused and fuel the concern for the privacy of genetic information....<sup>39</sup>

Abraham argues, however, that in the future such concerns are likely to abate substantially as the mystique that surrounds this area decreases with enhanced knowledge of the field. 'We all are presymptomatic to something', Abraham argues and, 'at that point, carrying such a gene will not be a distinctive or embarrassing characteristic, and fewer people will consider their genetic makeup deserving of privacy protection. Genetic information will simply be one sub-

38 See, eg. Robert H Jerry II, 'Health Insurers' Use of Genetic Information: A Missouri Perspective on a Changing Regulatory Landscape' (1999) 64 *Missouri Law Rev* 759.

39 Kenneth Abraham, 'Understanding Prohibitions against Genetic Discrimination in Insurance,' (1999) 40 *Jurimetrics Journal* 123 at 125.

category of medical information.<sup>40</sup> Therefore as the stigma fades, so too presumably, will the imprimatur for that aspect of its protection that underpins the genetic privacy statutes.

This is not, however, to take away the need for tightening of privacy in this area. Fundamental steps to remedy these — and similarly related — loopholes would seem to be a logical progression for privacy legislation. Such steps, however, would be enhanced if they were not premised solely upon dissemination of genetic profile information. Surely insurers' and brokers' duties to preserve each applicant's right to privacy and dignity should equally be extended to other forms of health information relating to, for example, post symptomatic illnesses or family histories. Additionally, as definitions of what constitutes genetic testing results vary — and may alter again in the future as technology advances, confusing these premises seems jurisprudentially short sighted, albeit a highly effective short term approach to creating privacy in relation to genetic information in this context.

The second major approach to regulating use of genetic information is that aimed at defining and prohibiting activities which constitute its *unfair* use. As distinct from privacy legislation, which seeks to curtail access to this information, discrimination based statutes aim to make specified uses of that information per se illegal. Within this framework, there are several variations on what insurers may do which obviously reflect different levels of what constitutes 'unfair' behaviour. Additionally, it should be kept in mind that some statutes are an amalgamation of both privacy and discrimination approaches.

The broadest statutes of this kind constitute a complete ban on any use of genetic testing information, regardless of whether it favours or is prejudicial to the interests of a prospective insured.<sup>41</sup> This approach, by definition, prohibits any prospect of an insurer requiring testing as a precondition to coverage and negates the problem of disclosure of negative existing results — either in relation to the applicant or to someone who shares genetic traits. Negative in this context refers to a 'bad' result, as opposed to one where no genetic defect was found. Accordingly, it would also ensure that undergoing genetic testing for scientific research purposes or for broader diagnostic or predictive purposes would not be deterred.

Such an approach does little to mitigate adverse selection problems and eliminates proverse selection in that consumers are equally precluded from voluntarily submitting genetic tests that indicate their good risk status. Presumably if the cost of testing was sufficiently low in an appropriate area and the prospect of being offered lower premiums or broader coverage as a 'reward' for their

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40 *Id* at 125.

41 See, eg, Council of Europe, *Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine* ETS No 164 (1997). This Convention has been widely ratified. See also *Federal Law of 1994* (BGBl No 510/1994 Austria); *Law No 56 of 5 August 1994 on the Medical Use of Biotechnology* (Norway) (1995) 46 *International Digest of Health Legislation* 51, ss6–7; *Wet 25 Juni 1992 op de Landsversekeringsovereenkomst*, BS 20 August 1992 (Belgium).

documentation of their 'preferred' risk status was cost effective, many consumers would opt for this course, thereby depleting existing risk pools and, as a result, pushing up the premium price for the remaining group who did not produce results. This provision therefore effectively ensures that the broader risk pool is retained but at the price of passing on higher premium rates to all participants.

This approach also throws up most clearly the fundamental anomaly genetic testing presents in the context of premium writing. As genetic testing is generally defined carefully to foreclose only results that are proffered on a predictive basis as to future health (as opposed to diagnostic genetic testing), it otherwise leaves intact the right of insurers to continue to discriminate on the basis of observable symptoms, health history and family health history. Given that many insurers will standardly refuse to issue life policies above a certain amount to applicants with abnormal cholesterol readings or blood pressure levels or who may have a family history that includes heart disease or cancer deaths, the somewhat peculiar result emerges whereby those who have 'best evidence' in the form of a test indicating a genetic predisposition to high risk disease can still obtain insurance, while those presenting second best evidence in the form of family history or symptoms but who may not actually have the trait may be uninsurable. Further, they will be unable to present test results to indicate their non-risk status in this respect. What effectively results from this legislative approach therefore is the emergence of a special class of individuals: those who, on the basis of genetic testing, are known carriers of a genetic disease but who are exempted from normal industry underwriting practices. The irony in relation to others against whom insurers may continue to discriminate legally is apparent.

A variant on the above approach is to ban compulsory testing but leave in place the option of submission of tests voluntarily. This approach serves to alleviate the scenario outlined immediately above, in that those with good results would be able to override negative family history concerns through the submission of genetic tests indicating a lack of the diseased gene. It would, however, leave the industry and those within certain risk pools open to the problems associated with proverse selection and the accompanying increases in premiums that would be precipitated.

If provisions of this nature are promulgated in jurisdictions which require full disclosure of material information, such as Australia<sup>42</sup> and the United Kingdom,<sup>43</sup> the results are further complicated for those who are aware of test results that indicate they are at risk or that others who share their gene pool have been found to be at risk. Those who fail to disclose this information would, depending on the circumstances that give rise to a claim, eventually run the risk of having the policy declared void or having a claim rejected or reduced, as failure to declare such information would clearly be relevant to the initial decision making process of the insurer. Followed through, the combination of utmost good faith disclosure and voluntary testing would lead, in all probability, to a diminished willingness to undergo testing (whether for health or scientific purposes), or increased

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42 See, *Insurance Contracts Act 1984* (Cth) s21

43 See, eg, *Pan Atlantic Insurance Co Ltd v Pine Top Insurance Co Ltd* [1995] 1 AC 501.

willingness to misrepresent this information in proposal forms and suffer the consequences if and when they ensue. Conversely, if the disclosure standards were redrafted to exempt genetic testing disclosure of any form, the problems outlined above regarding the creation of special classes of acceptable discrimination re-emerge.

An alternative approach is that contained in the Code of Practice of the Association of British Insurers. Under this Code insurers cannot ask prospective insureds as a pre-condition to cover to undergo genetic tests when they apply for insurance. This does not rule out the use of existing genetic test results in assessing whether, or on what terms, to conclude contracts of insurance. However, there is a moratorium imposed on the use of such information in respect of new applications for life insurance up to a total of £100,000 that are directly linked to a mortgage for a private house.<sup>44</sup>

Such an approach obviously mitigates societal concerns related to discouraging scientific research or seeking diagnostic testing for the purposes of undertaking potentially preventative courses of treatment and life style modification. In the United Kingdom it also circumvents a significant ancillary concern: although about 30 per cent of the UK population have life policies, this is attributed in substantial part to the fact that housing loans generally require life insurance policies of £100,000 as a lending condition.<sup>45</sup> Like the vested societal concerns that arise in conjunction with genetic testing and health care in the United States, the United Kingdom position is difficult to explain without reference to the supplemental key concern of housing being thrown into the legislative equation.

Such regulations therefore move the role of their insurance industries away from being simply commercially driven private enterprises whose products provide financial safety nets for certain members of society, towards being a more formally acknowledged part of the social infrastructure planning process. Provided the determination to do so is made with full acknowledgment of this change and its accompanying ramifications, it would certainly seem to be fully within the ambit of any given society to make these regulations. However, to use genetic testing as the mechanism — either deliberately or by implication — for shifting these lines in a social engineering context does raise precedential concerns. Put alternatively, such provisions are effectively legislatively sanctioned variants of the common practice in many jurisdictions of issuing life or income protection cover above specified levels only after successful completion of a physical examination by the insurer's designated medical specialists. Given that such examinations routinely include, for example, HIV, cholesterol and other blood tests as indicia of overall health — none of which necessarily go immediately to the existing level of health of the patient and which are also capable of being influenced by preventive lifestyle changes as well as potential medical

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44 See, eg. James Davey 'Future Imperfect: Human Genetics and Insurance' [2000] *JBL* 587 at 589; Lemmens, above n5 at 361. See also the position in the Netherlands whereby, under a moratorium, insurers are not allowed to request access to genetic information unless the contracts exceed a 300,000 guilder limit: see, Lemmens, above n5 at 360.

45 See, Davey, above n44 at 589.



advancements — the rationale for allowing such discrimination to continue while prohibiting that related to genetic test results seems somewhat spurious. The same argument would of course be true for information gathered through family history sections. In effect, therefore, such provisions — probably more than any of the other categories above — not only create the legally difficult precedent of a special group of prospective insureds who must legitimately be treated more favourably than others, but also blur traditional lines of private/social responsibility without the benefit of eliciting first the broader discussion such a transition should engender.

## 5. *Conclusions*

Careful consideration of the appropriate course to be adopted should be undertaken. Although concerns exist over the imminent impact of genetic advancements generally at this time and for purposes of the next few years, technology relating to testing is unlikely to become so immediately cost effective as to precipitate a dramatic upswing in its use. Time for serious discussion and reflection both on the type of legal precedent best adopted and on the broader question of how society sees itself in relation to allocation of welfare rights is available and appropriate.

The temptation to adopt short term fixes such as genetic testing bans generally or creating protective rights for those who are found to be at high risk of disease is superficially attractive. It is unlikely however to be productive in the longer term when those who are not privy to this protection but who remain subject to insurance discrimination, are 'victimised' or, when those who would otherwise be the beneficiaries of lower premiums choose to make alternative financial arrangements rather than carry disproportionately heavy premium rates. Additionally, it should be recalled that many options exist rather than simply forcing commercial insurers — and consequently their insureds — into absorbing rate increases. Subsidies for those affected, which would of course inevitably be carried by the broader 'pool' of all tax payers, might be a more logical allocation of responsibility for those who are genetically disadvantaged than by transferring risk to insurers and those who seek insurance.

Another point to consider is the artificial creation of what amounts to a specially protected class. Given that the preponderance of individuals who suffer poor family histories or other forms of symptoms will continue to be either legally excluded from cover or subject to premium loadings, notwithstanding anti-discrimination legislation and other regulatory provisions in the insurance area, it is unlikely that special protection in the area of genetic testing will be tolerated in the long term.

Further, if the artificial distinction is to be drawn between genetic tests for asymptomatic persons giving rise to specific rights on the one hand, and general tests which pick up symptoms which are admissible under current disclosure provisions for insurability purposes on the other, the advancement of technology will inevitably make this distinction increasingly absurd. Already, high cholesterol

readings are being shown in certain cases to be tied to a condition that can be diagnosed through genetic testing. Accordingly, the more advanced testing becomes both for 'existing' symptoms and for the presence of genetic disease, the more indefensible (indistinguishable) the two categories will become. To do so is somewhat analogous to the highly criticised underpinning of *Roe v Wade*<sup>46</sup> in the US, wherein the point of foetus viability was pinned to then existing standards of medical care, without reference to the ability of technology in the future to expand this 'line' backwards to the point at which the argument itself ceased to provide a result. Put alternatively, short term reference to existing technological capacities on both diagnostic and predictive fronts is necessarily short sighted and will be unsupportable.

The more realistic approach is to single out that behaviour which is genuinely perilous to a given society and draft to prevent this broader problem as it exists in all forms. A particular example of this, therefore, could include any undue invasion of privacy, in relation to personal information and records generally when submitted in good faith for a specific purpose and in circumstances where privacy should be expected, and to draft provisions to prevent this broader problem as it exists in all forms. In relation to insurance discrimination, the parallel considerations would be whether and to what extent use of information as regards high risk dispositions is truly unfair. It appears that some genuine grounds exist particularly in situations where the courses of diseases are significantly dependent on extraneous factors such as environment, lifestyle, and so forth. But, to treat all parties by the highest possible standard without recourse to opportunities to lower their risk profile is ill conceived.

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46 410 US 113 (1973), 35 L. Ed 2d 147 (1973), 93 S Ct 705 (1973). See, eg, Nancy K Rhoden, 'Trimesters and Technology: Revamping *Roe v Wade*' (1986) 95 *Yale LJ* 639.