

GENETIC DISCRIMINATION: MEETING THE CHALLENGES OF AN EMERGING ISSUE

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Developments in human genetic technology, including those in the area of predictive genetic testing, hold great potential for improving health and for promoting Australia's economic advancement.¹ However, these developments have also generated concerns about the privacy of genetic information and the potential uses to which such information may be put. One of the emerging issues which has created particular disquiet is that of genetic discrimination; that is, the differential treatment of individuals on the basis of actual or presumed genetic differences.² Whilst this may potentially take the form of positive or negative treatment, fears have focused on the use of genetic information by third parties which is prejudicial to a person's interests, such as the exclusion from insurance or employment.

There has been much debate as to whether genetic information warrants special protection, and considerable resistance to 'genetic exceptionalism'.³ Without disputing that other health information may be equally sensitive, particular attention does appear justified in this area because of the predictive capacity of genetic information and the tendency to treat what is usually only probabilistic information about genetic risk as determinative of a person's future health status. Because of the novelty of these developments, knowledge about the implications of genetic test information is presently incomplete, even in the science and medical community, let alone amongst third parties in the commercial sector who may have an interest in accessing the genetic information of individuals. In these circumstances, there is a real risk that this information may be misinterpreted or misunderstood and there are, therefore, good grounds to

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1 See, eg, the Commonwealth Government's *Innovation Report 2001–2002, Backing Australia's Ability: Real Results, Real Jobs* (2002).

2 Lisa Geller et al, 'Individual, Family, and Societal Dimensions of Genetic Discrimination: A Case Study Analysis' (1996) 1 *Scientific & Engineering Ethics* 71.

3 See Thomas Murray, 'Genetic Exceptionalism and "Future Diaries": Is Genetic Information Different from Other Medical Information?' in Mark Rothstein (ed), *Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era* (1997) 68; Trudo Lemmens, 'Selective Justice, Genetic Discrimination, and Insurance: Should We Single Out Genes in Our Laws?' (2000) 45 *McGill Law Journal* 347, 369.

suggest that caution is needed in determining who should be entitled to obtain such information and the uses to which it can be put.

This stance has received wide support from a range of organisations and individuals, including groups representing consumers, genetic counsellors and health care professionals involved in the genetics field. Not surprisingly, however, third party organisations such as the peak insurance and employment bodies have argued against restrictive regulation in this domain, asserting that it is unwarranted in light of available information. In particular, the life insurance industry, through its peak body the Investment and Financial Services Association ('IFSA'), has vigorously defended the right of insurers to have access to and use of existing genetic test information for underwriting purposes in accordance with standard practices for mutually rated insurance.⁴ These differing viewpoints were well reflected in the range of submissions to the recent national inquiry into the protection of human genetic information discussed below.⁵ The various submissions to the Inquiry underscore the fact that there are competing interests at issue which need to be balanced in coming to any resolution in this area.

There has also been debate about the extent to which genetic discrimination is occurring, with claims from some quarters that the 'problem' is being overstated.⁶ Linked with this is the fact that notwithstanding general protection from disability discrimination under anti-discrimination legislation, not all discrimination on the basis of genetic status will be unlawful, as employers and insurers are exempt from liability in specified circumstances.⁷ There is, at present, no hard data regarding the prevalence of the problem in Australia or other jurisdictions, although there is considerable information from anecdotal sources and case studies of discrimination on the basis of genetic information occurring across a variety of sectors including insurance and employment.⁸ In the United States ('US'), fears of genetic discrimination in insurance have been particularly acute because of the potential for such discrimination to curtail access to health insurance, given the absence of a universal health care system in that country. In Australia, however, where access to health care is guaranteed through the Medicare system and health insurers are legislatively bound by principles of community rating, there is very limited scope for discrimination to occur in this field.⁹

4 The IFSA policy makes clear, however, that insurers will not require that genetic testing be undertaken for the purposes of risk assessment: IFSA Standard No 11.00, *Genetic Testing Policy* (2002).

5 ALRC Final Report, below n 21.

6 See, eg, W Nolan, 'A Scarlet Letter or a Red Herring?' (2003) 421 *Nature* 313 (letter to the editor).

7 See ss 15 and 46 of the *Disability Discrimination Act 1992* (Cth) (and equivalent provisions in State and Territory legislation).

8 E Virginia Lapham et al, 'Genetic Discrimination: Perspectives of Consumers' (1996) 274 *Science* 621; Geller et al, above n 2; Lawrence Low et al, 'Genetic Discrimination in Life Insurance: Empirical Evidence for a Cross Sectional Survey of Genetic Support Groups in the United Kingdom' (1998) 317 *British Medical Journal* 1632; Kristine Barlow-Stewart and David Keays, 'Genetic Discrimination in Australia' (2001) 8 *Journal of Law and Medicine* 250.

9 For discussion of the use of genetic information for the purposes of determining waiting periods in relation to health insurance, see Margaret Otlowski, 'Is There Scope for Lawful Genetic Discrimination in Health Insurance in Australia?' (2001) 8 *Journal of Law and Medicine* 427.

Concerns about the use of this information in the Australian insurance sector have instead focused on life insurance products and some forms of general insurance for which individual risk assessment is undertaken. Research to date supports the view that instances of genetic discrimination are emerging in Australia. A study by Kristine Barlow-Stewart and David Keays identified over 43 alleged cases of genetic discrimination within the Australian insurance sphere – although these were based on anonymous accounts and have not been open to verification.¹⁰ This study also detected a number of instances of alleged genetic discrimination by Australian employers.¹¹ Whilst this research has assisted in drawing attention to the issue, thus contributing to the momentum for reform, its methodology limits its usefulness in evaluating the scope of the problem in Australia.

Because of the limitations of the available data, a major national study funded by the Australian Research Council ('ARC') is presently underway to investigate the extent and implications of this newly emerging phenomenon in Australia. This research, which is being undertaken by an interdisciplinary team,¹² aims to explore the subject through three key sectors: consumers, third parties and the legal system, thus ensuring that the viewpoints of major stakeholders are considered and providing an opportunity for integrated data analysis and verification. Significantly, this study entails the first attempt in Australia to conduct a national quantitative study of individuals with genetic risk in order to examine the actual incidence of genetic discrimination in Australia. Australian insurers and employers are also being surveyed to determine their practices and attitudes to the use of genetic information, as are tribunals within the legal system, to assess the utilisation of available legal remedies. Because of its design and scale, this research has the potential to yield useful information about the nature and prevalence of genetic discrimination in Australia and its legal, social and other ramifications.¹³

Although the extent of the problem is yet to be determined, there is considerable support for steps to be taken to address community concerns. Intervention in this area is justified because even though the incidence of genetic discrimination may not be great, fear of its occurrence appears to be quite pervasive and has the potential to impede beneficial use of genetics services and participation in genetic research. Genetic counsellors in Australia and overseas

10 Barlow-Stewart and Keays, above n 8.

11 A total of five cases of alleged genetic discrimination were reported against employers: three involving existing employees and two involving applicants for employment.

12 The interdisciplinary, cross institutional team for the Genetic Discrimination Project comprises Professor Margaret Otlowski (Faculty of Law, University of Tasmania) and Dr Sandy Taylor (School of Social Work and Social Policy, University of Queensland) as Chief Investigators and Dr Kristine Barlow-Stewart (Director of the NSW Centre for Genetics Education) as Partner Investigator. Dr Mark Stranger (Faculty of Law, University of Tasmania) and Dr Sue Treloar (School of Social Work and Social Policy, University of Queensland) are also contributing to the project as Research Fellows. The website for the project is <<http://www.gdproject.org>> at 20 November 2003.

13 For a more extensive coverage of this research project see Margaret Otlowski, Sandy Taylor and Kristine Barlow-Stewart, 'Major Study Commencing into Genetic Discrimination in Australia' (2002) 10 *Journal of Law and Medicine* 41.

have raised concerns to this effect,¹⁴ and studies have confirmed the reality of these fears and the potential for them to impede engagement with the genetic technologies both in clinical and research contexts.¹⁵ It is, therefore, imperative that appropriate action is taken to allay misgivings about inappropriate use of genetic information so that the benefits of the new genetic technologies can be maximised.

Inevitably, it takes time for a clear political and legislative response to emerge. Despite warnings about the creation of a 'genetic underclass', dating back more than a decade,¹⁶ progress in addressing this problem has been varied. Some European jurisdictions have taken a very protective stance, prohibiting the use of genetic information by third parties. A number of inquiries into the subject have been conducted in the United Kingdom ('UK')¹⁷ and there is presently a moratorium in place on the use of genetic information in insurance. In the US, whilst many states have introduced their own legislation in an attempt to ameliorate the situation, attempts to secure federal legislation have to date been unsuccessful.¹⁸ There are, however, hopes that a current federal Bill which would ban some forms of discrimination based on genetic tests may receive the necessary support.¹⁹

Although legislative measures are yet to be introduced in Australia,²⁰ important initiatives have been underway. In recognition of the sensitivities associated with genetic information and its protection and the potential negative ramifications of public distrust about the use of such information, the Commonwealth Government established a joint inquiry by the Australian Law Reform Commission ('ALRC') and the Australian Health Ethics Committee ('AHEC') of the National Health and Medicine Research Council into the protection of human genetic information ('Inquiry'), with terms of reference specifically directed to examining whether, and to what extent, a regulatory framework is required to provide protection from inappropriate discriminatory use of human genetic samples and information. The Final Report emanating from this Inquiry, *Essentially Yours: The Protection of Human Genetic Information in*

14 Ibid.

15 Donald W Hadley et al, 'Genetic Counseling and Testing in Families with Hereditary Nonpolyposis Colorectal Cancer' (2003) 163 *Archives of Internal Medicine* 573; K Geer et al, 'Factors Influencing Patients' Decisions to Decline Cancer Genetic Counseling Services' (2001) 10 *Journal of Genetic Counselling* 25.

16 P Billings et al, 'Discrimination as a Consequence of Genetic Testing' (1992) 50 *American Journal of Human Genetics* 476.

17 Nuffield Council on Bioethics, *Genetic Screening: Ethical Issues* (1993); House of Commons, Science and Technology Committee, *Human Genetics: The Science and Its Consequence*, Third Report (1995); Human Genetics Advisory Commission, *The Implications of Genetic Testing for Life Insurance* (1997); Human Genetics Advisory Commission, *The Implications of Genetic Testing for Employment* (1999); Human Genetics Commission, *Inside Information: Balancing Interests in the Use of Personal Genetic Data* (2002).

18 In 1996 the *Health Insurance Portability and Accountability Act of 1996* Pub L No 104-191, 110 Stat 1936 was enacted; however, this has a rather limited operation.

19 Genetic Information Nondiscrimination Act of 2003, S 1053, 108th Cong (2003).

20 A private member's Bill (Genetic Privacy and Non-Discrimination Bill) was introduced in 1998 by Senator Stott Despoja. Although this was never passed, it did play a role in fostering debate on this issue.

Australia ('Report'), acknowledges the concerns about genetic discrimination and the reported allegations of its occurrence in Australia.²¹ The Inquiry proceeds from the premise that the development of a response to the problem should not depend on proof of its precise dimensions. Further, the Inquiry recognises the need for timely intervention in anticipation of the inevitable expansion in the use of human genetic technologies and of the availability of genetic information.

The Report accordingly puts forward a raft of recommendations for legislative and other changes to afford greater protection to individuals in respect of their genetic information as well as their genetic samples. In particular, it recommends the establishment of a standing advisory body on human genetics, to be called the Human Genetics Commission of Australia ('HGCA'), based on similar models in other jurisdictions including the UK's Human Genetics Commission. The role of the HGCA would be to provide high-level advice to government, industry and the community about current and emerging issues in human genetics.²² Further, the Report recommends that existing anti-discrimination legislation be strengthened by the express inclusion of genetic discrimination within the framework of disability discrimination.²³

In the insurance sphere, the Inquiry opted not to recommend changes to standard disclosure or underwriting practices in respect of genetic information. This represents a considerable concession to the insurance industry, particularly when contrasted with the position adopted in some European jurisdictions where insurers have been prohibited from accessing this information, or in the UK where the industry has agreed to a moratorium (with the exception of large policies) on the use of such information.²⁴ There was, however, acceptance that more needs to be done to ensure that decisions made by insurers are based on appropriate actuarial, statistical or other data in order to satisfy the terms of the insurance exception under anti-discrimination legislation. To this end, it was recommended that the proposed HGCA should be responsible for determining which genetic tests should be used in underwriting mutually rated insurance, having regard to their scientific reliability, actuarial relevance and reasonableness.²⁵

The Report's recommendations in the employment sphere are more far-reaching. If implemented, employers would be prohibited from seeking or using the genetic information of employees or applicants for employment except in very limited and carefully specified circumstances. These include circumstances where such information is reasonably necessary to determine a person's capacity to perform the job or where such use can be justified on occupational health and safety grounds. As noted earlier, tensions inevitably exist between the interests of

21 Australian Law Reform Commission and Australian Health Ethics Committee, *Essentially Yours: The Protection of Human Genetic Information in Australia*, Report No 96 (2003) ('ALRC Final Report').

22 *Ibid* 211, Recommendations 5.1–5.9.

23 *Ibid* 301–4, Recommendations 9.1–9.2.

24 For life insurance, this threshold for 'large policies' has been set at £500 000. However, before a genetic test result may be used for underwriting 'large policies', the test must first have been approved by the Genetics and Insurance Committee as having sufficient actuarial relevance to justify insurers' reliance on those test results.

25 ALRC Final Report, above n 21, 711, Recommendation 27.1.

individuals and third parties when determining questions of access to and use of genetic information. On balance, it would seem that an approach such as this, which protects the privacy of genetic information except where a compelling case can be made justifying its use, is to be preferred. This is particularly the case as individuals are typically in a weaker position compared to third parties who are generally better placed to absorb the impact of any resulting risk.

It is vital in order to instill public confidence in developments in human genetic technology and to maximise beneficial uptake that we ensure responsible regulation of the use of genetic test information by third parties. Implementation of the recommendations in the Report would represent an important advance in this regard. We should, however, also persevere in our attempts to better understand the newly emerging legal and social issue of genetic discrimination. Clearer insights into the scope of this issue, and the legal and social challenges posed by this phenomenon are necessary to inform the development of effective strategies that can reduce the risk of it occurring and allay fears that the prospect of such discrimination generates. Whilst the ARC funded empirical data collection is expected to shed light on the nature and extent of the problem in Australia, this project is not due for completion until the end of 2004. It remains to be seen what progress will be made in implementing the ALRC/AHEC recommendations in the meantime. In any event, this project will provide benchmark data necessary for the review of existing and proposed protections. In the event that the recommendation for the creation of a HGCA is implemented, the research could conceivably help inform that body in its role of monitoring developments and providing advice to government.