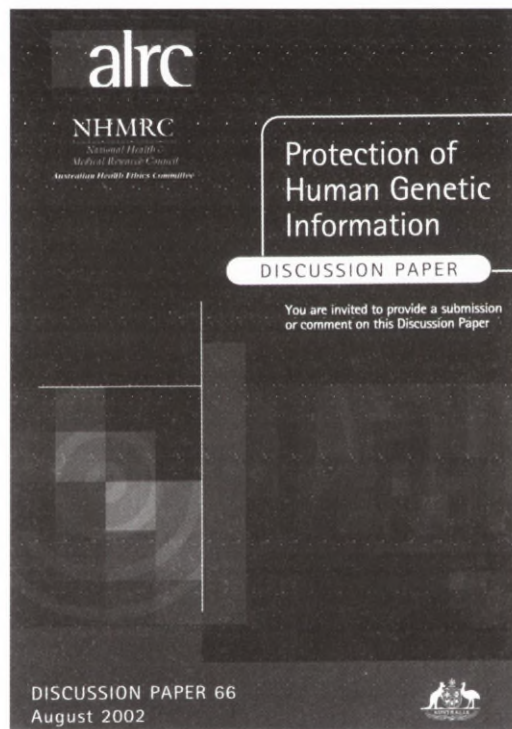


Emerging legal issues in relation to the use of genetic testing:

An examination of the phenomenon of genetic discrimination

This article examines, within the Australian context, the emerging phenomenon of genetic discrimination – that is, the differential treatment of individuals on the basis of their genetic makeup. It focuses on the areas of insurance and employment which are the main areas where discrimination on the basis of genetic status has been reported, and reviews the existing legal framework for the regulation of the use that insurers and employers can make of genetic information.



INTRODUCTION

There have been tremendous advancements arising from the Human Genome Project involving the mapping and sequencing of the entire human genome.¹ As a result of these advancements, the capacity for 'genetic testing' has increased and will inevitably accelerate further in the future as the costs of tests fall. There are, undoubtedly, tremendous advantages flowing from the use of genetic tests and the initiation of wider genetic screening programs,

including the potential to put in place preventative strategies to reduce the risk of disease, the tailoring of drug treatments, and the possibility of gene therapy. There are, however, also attendant risks, such as the impact upon individuals of unwanted genetic information and the potential for discrimination

by third parties on the basis of a person's genetic make-up. This paper seeks to explore the emerging phenomenon of genetic discrimination, examining the use that can presently be made of genetic test information by third parties, such as insurers and employers, with a view to determining whether regulation is necessary. The growing level of concern about these issues is reflected in the fact that there is currently a major national inquiry being

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undertaken jointly by the Australian Law Reform Commission (ALRC) and the Australian Health Ethics Committee of the National Health and Medical Research Council into the Protection of Human Genetic Information.²

GENETIC TESTING

Genetic testing essentially involves analysis of an individual's DNA (from blood, saliva etc) with a view to testing for inherited conditions or predisposition to genetically related disease. The focus of this paper is on *predictive* genetic testing in respect of individuals who are *asymptomatic* and who may never develop the condition in question.

Many people are of the view that genetic information is special, even unique, and thereby distinguishable from other medical information. Genetic information certainly has some distinctive characteristics. It is personal and sensitive information. A person's whole genetic profile, including their risk status in rela-

tion to a range of conditions or disorders, can be determined from a single sample. Genetic information also has familial qualities, in that information collected about one individual can provide information about that person's blood relatives. Genetic information is also special because of the impact that disclosure of this information to others may have for the individual about whom the information relates. This is particularly the case in view of the tendency to treat genetic information as if it were decisive or what is also referred to as 'genetic determinism.' In view of these unique characteristics and in a context where there is growing attention to privacy protection, there are concerns about the use of genetic information particularly with developments in information technology.

GENETIC DISCRIMINATION

'Genetic discrimination' is a newly-emerging phenomenon which can be defined as differential treatment of an

individual by a third party on the basis of genetic factors – real, inferred or wrongly imputed. Discrimination can be positive or negative: the concern in relation to genetic discrimination relates to decisions adverse to the interests of the individuals involved. It is important to recognise, however, that this form of negative discrimination may be justified and lawful so care needs to be taken to avoid interpreting the term as synonymous with illegality.

Instances of genetic discrimination have been documented overseas since the early 1990s³, particularly in the United States in the insurance context. Studies have indicated that genetic discrimination may occur as a result of misinterpretation and misunderstanding of genetic test information and that insurance companies do not always have specific actuarial data to support their rating decisions. As an extreme example, there have been instances of discrimination directed against healthy

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carriers of recessive genetic conditions who will never themselves develop the condition.⁴

There is now emerging evidence that genetic discrimination is also occurring in Australia. There was one early instance reported in 1998 involving discrimination in employment: a person at risk of Huntington's disease had been given an ultimatum that they could only be employed if testing showed that they did not have the gene for this serious late onset condition. This person did not wish to undergo testing but following intervention by a Huntington's disease social worker, was nevertheless employed subject to certain conditions (reduced superannuation benefits if they developed the condition).⁵

Since that time, two further Australian-based studies have been undertaken.⁶ These studies, reported together in the *Journal of Law and Medicine*, have identified a total of 48 cases of alleged genetic discrimination, primarily in the insurance and employment contexts.⁷ All of these cases involved alleged discrimination against individuals who were in good health where the adverse treatment was believed to be a direct result of a genetic test showing predisposition to disease. Genetic discrimination was reported with respect to genetic tests for a wide range of conditions including haemochromatosis, inherited predisposition to cancer (breast, bowel, melanoma), and neurological degenerative disorders such as Huntington's disease and early onset Alzheimer's disease.

In the area of life insurance, which involved by far the majority of cases, discrimination was reported accessing a wide array of insurance packages and types following disclosure of a positive genetic test result. In some cases, it resulted in premiums being loaded when the individuals sought to increase their level of cover. In other instances, applications for increased cover were rejected. There were few outright rejections, but notably, the majority of the respondents (29 out of 48, or 60 per cent) had reported taking out life and

'There have been no reported instances to date of genetic discrimination pursued within the legal system ...'

income protection insurance prior to taking out the genetic test.

In the context of employment, a total of five cases of alleged genetic discrimination were reported. All of these cases had involved asymptomatic individuals who had received positive gene tests for late-onset neurological conditions. Three of these cases involved persons who were already employees who were either demoted or had their position terminated. In a further two cases, it was reported that individuals had been required to undertake genetic testing as part of the employment selection process.

Notably, none of the individuals in this study who had complained of genetic discrimination reported challenging the decision through existing legal avenues (primarily, anti-discrimination tribunals), the majority stating that it was all too hard and stressful and, in some cases, it being reported that they did not know how to seek redress.

A number of conclusions can be drawn from the available data. These studies provide evidence supporting the conclusion that genetic discrimination is occurring in Australia although we cannot presently quantify the precise extent. Genetic discrimination can have significant implications for the individuals affected, and the wider community, particularly as the fear of discrimination undermines public confidence in the use of genetic tests and thereby has ramifications for public health. There have been no reported instances to date of genetic discrimination pursued within the legal system although it is likely that some of these cases have involved unlawful discrimination.

A number of limitations of these

studies should also be noted. These studies are based on anonymous accounts: they are at best 'alleged' or 'reported' cases of genetic discrimination. Concerns have accordingly been expressed, particularly by the insurance industry, about reliance on unverified data. Moreover, in view of the limited information available, there is difficulty in establishing the legal status of the conduct – whether or not it was 'justified' discrimination and therefore lawful.

Steps are currently being taken to fill some of the gaps in current knowledge. A nation-wide empirical study funded by the Australian Research Council⁸ is being undertaken into the extent and nature of genetic discrimination in Australia. This study, by an interdisciplinary, research team⁹, seeks to go further than existing studies through its triangulated design – exploring the situation through the three key sectors: (1) consumers (those considered to be at risk as a result of a genetic test result or because of their family history); (2) insurers and employers (these being the third parties against which allegations of genetic discrimination have most frequently been made); and (3) the legal system to establish what, if any, cases have been pursued involving allegations of genetic discrimination.¹⁰

A further advancement this project makes on existing research is that with the permission of the complainant, individual allegations will be followed up with the relevant third party. This process of verification will hopefully elucidate factors associated with genetic discrimination from both consumer and third party perspectives allowing for objective assessment in relation to the legality of the conduct. This research ►

complements the focus of the concurrent national inquiry into the protection of human genetic information. This project will establish *baseline* data for ongoing assessment of the nature and extent of the problem, as well as for longitudinal evaluation of the impact and effectiveness of any reforms which may be introduced.

USE OF GENETIC TESTING IN THE CONTEXT OF INSURANCE AND EMPLOYMENT

The Insurance Context

As a starting point, it is necessary to distinguish between different categories of insurance: between life insurance and related products (such as sickness and disability insurance) and health insurance. Health insurance is based on a community rated system which requires insurance to be offered on the same terms to everyone, with no risk assessment based on health status.¹¹ For life insurance products, however, there is underwriting on the basis of the applicant's health status, which would include information about genetic testing.

Insurers are entitled, under present laws, to have access to genetic test results and to take these into account for the purposes of underwriting for life and related forms of insurance. It is clear from the industry's own data collection that this information comprises part of the risk assessment process (together with family history) and in some cases has resulted in individuals being denied cover or offered cover on non-standard terms.¹² Contracts of insurance are contracts of the 'utmost good' faith. This reflects the reality that the applicant for insurance is usually in a position to know more about his or her risk factors than the insurance company, and the law (now codified in the *Insurance Contracts Act 1984* (Cth)) therefore imposes an obligation to make full disclosure of all information material to the insurers' assessment of risk at the time of taking out insurance (or increasing level of cover) in order to ensure that there is

symmetry of information between the applicant and the insurer.¹³ Failure to make the required disclosure may result in the contract being invalidated.¹⁴

The important role that voluntary insurance plays in our society is reflected in the fact that insurers are given an exemption from disability discrimination under anti-discrimination legislation. This exemption recognises that the whole notion of insurance is premised on treating individuals differently based on their health status, and that insurers routinely engage in conduct which would otherwise constitute unlawful discrimination.

The relevant Commonwealth legislation is the *Disability Discrimination Act 1992*. This would apply to all insurers operating in Australia, except for those who conduct business solely within a state and therefore would come within the scope of the state and territory legislation. The term 'disability' is defined broadly to cover not only present or future disability but also disability which is imputed to a person.¹⁵ Taken together, with the wide definition of 'discrimination' (less favourable treatment),¹⁶ this legislation would cover discrimination on the basis of genetic test information where that information discloses that the person may in the future develop a particular genetic condition or disorder. The legislation is framed in such a way that *prima facie*, disability discrimination in insurance will be unlawful, and if challenged, the onus lies on the insurer to affirmatively establish that the conduct comes within the insurance exemption.¹⁷ The operation of the exemption is qualified by the requirement that insurers must be able to justify their decisions on the basis of actuarial or statistical data on which it is reasonable for the insurer to rely, or in the absence of such data, the discrimination is reasonable having regard to other relevant factors. The key provision is s 46 covering both discrimination in the form of refusal to offer insurance or discrimination in respect of the terms or conditions on which insurance is offered.

The precise scope of the exemption

in the context of use of genetic test information is presently untested because there have been no cases alleging genetic discrimination under federal or equivalent state and territory anti-discrimination tribunals.¹⁸ Note, however, the case of *D and A Registered Life Insurer* involving interpretation of the equivalent provision in the *Sex Discrimination Act 1984* (Cth) which has highlighted the importance of there being actuarial or statistical data from a source on which it is reasonable for the insurer to rely. Of relevance in interpreting the exemption are the Human Rights and Equal Opportunity 'Disability Standards and Guidelines' which seek to give some general guidance on the operation of the exemption.¹⁹

Real concerns have been raised about the extent and reliability of data in relation to the significance of genetic tests. The process of establishing relationships between genetic test results and the economic costs of the risks identified is one which must be undertaken separately for each genetic condition and it may take many years before an accurate picture emerges. Significantly, in the United Kingdom, these doubts about the actuarial relevance of existing data available to insurers has led to the imposition of a five-year moratorium on the use of genetic test information by insurers.

The Employment Context

Workplace genetic testing could take a number of forms: genetic monitoring of employees for any acquired genetic mutations resulting from exposure to industrial hazards; 'susceptibility screening' of asymptomatic individuals to determine whether they are genetically predisposed to develop occupational diseases due to exposure to workplace hazards; screening for conditions unrelated to workplace hazards which may present a risk of harm to that individual or third parties; or more generally, screening for particular genes to identify 'high risk' individuals. These forms of testing/screening can be distinguished from existing forms of pre-employment

health screening or screening undertaken during employment (for example, drug and alcohol testing) because of its predictive and therefore largely speculative nature.

Employers may seek to obtain genetic information about their employees or prospective employees by initiating their own genetic testing, or inquiring about the health status of employees/applicants including family history and genetic tests undertaken. Factors likely to be motivating employers in the use of genetic testing include concern for the health and safety of employees, co-workers and the public; concern about their legal duty of care and their potential liability to others; and there is also likely to be some economic incentive in being able to screen for workers who are 'low risk', having regard to the cost of sick leave payments, workers' compensation insurance/payments, costs associated with replacing employees etc. Although genetic testing can

clearly have valid occupational health and safety objectives, there are concerns that it will be used to exclude employees/prospective employees from the workforce.

There appears to have been very little use to date of genetic information in Australian workplaces – only a few accounts have emerged from published research into genetic discrimination.²⁰ In contrast, in the United States, where employers are generally responsible for providing health insurance for their workers, workplace genetic testing is already in use as a screening mechanism.²¹ It is not surprising in that light that instances of alleged genetic discrimination by employers are now being litigated in the United States.²²

There is presently no specific regulation of the use of genetic test information in the workplace other than the requirement that testing must be voluntary and that employers must not discriminate against individuals on the

basis of disability (present, future or imputed). These requirements may be in conflict with occupational health and safety legislation which would usually prevail in these circumstances.²³ There are some exemptions available to employers including those relating to 'material differentiation'²⁴ and 'inherent requirements'²⁵, however, it is difficult to envisage circumstances where either of these exemptions would assist an employer who has discriminated against an asymptomatic person on the basis of their genetic status.

IS REGULATION NECESSARY?

In both the insurance and employment contexts there is a need to balance competing interests. In the case of insurers, there is a legitimate need to guard against the problem of 'adverse selection.' Against this is the need to protect individuals from inappropriate use of genetic information, especially given the limited information presently available ►

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about the actuarial relevance of genetic test results. In the employment context, the potentially legitimate uses of genetic test information for occupational health and safety purposes need to be acknowledged, to help screen individuals who may be susceptible to workplace hazards which cannot reasonably be removed, or who may, because of some genetic predisposition, pose a threat to fellow workers or the public at large. Clearly, however, there is plenty of scope for misuse of genetic test information by employers to further their own commercial interests at the expense of the interests of the employee/prospective employee.

Because of the sensitive and personal nature of this information, and the potential for it to be misused against the interests of applicants for insurance or employees/prospective employees, intervention to restrict the use that can be made of genetic test information by insurers and employers is justified. Space does not permit full delineation of what is recommended: this has been done elsewhere²⁶; what is clear is that carefully targeted reforms are required which focus on eliminating 'unfair' or 'unjustified' genetic discrimination. The national inquiry proposes some important advances in its discussion paper²⁷ particularly in the employment context. In the insurance context, the proposals are somewhat disappointing, leaving largely intact the right of insurers to use genetic information for underwriting purposes. The only significant qualification is that the proposed Human Genetics Commission of Australia would have responsibility for determining which genetic tests could be used for underwriting purposes and insurers would only be permitted to use those which have been approved.

CONCLUSION

To date, no cases have been reported in the Australian legal system involving allegations of genetic discrimination in relation to the use of genetic test information. However, this should not give rise to complacency. Indications are

that there are some individuals who feel aggrieved about how their genetic information has been used by insurers and/or employers although they appear to have been reluctant to date to pursue available legal remedies. It seems likely, in the light of the directions set out in the ALRC discussion paper, that reforms will be recommended to better protect the privacy and other interests individuals have in their genetic information. In the meantime, it is helpful to heighten awareness about these issues and ensure that this information is not misinterpreted or misused, or where it is, that available legal remedies are pursued on behalf of the individuals concerned. **PL**

Endnotes:

- ¹ J.Venter *et al.* 'The Sequence of the Human Genome' (2001) 291 *Science* 1304-51; E. Lander, 'Initial Sequencing and Analysis of the Human Genome' (2001) 409 *Nature* 860-921.
- ² This Inquiry which has to date produced an Issues Paper (ALRC *Issues Paper* No 26 (2001)) and a Discussion Paper (ALRC *Discussion Paper* No 66 (2002)) is discussed further below.
- ³ P. Billings *et al.*, 'Discrimination as a Consequence of Genetic Testing' (1992) 50 *American Journal of Human Genetics* 476.
- ⁴ Billings *et al.*, 'Discrimination as a Consequence of Genetic Testing', n 3 above.
- ⁵ S. Taylor, 'A Case Study of Genetic Discrimination: Social Work and Advocacy in a New Context' (1998) 51 *Australian Social Work* 51.
- ⁶ Barlow-Stewart's work had identified 43 cases of alleged discrimination; Keays had identified 5 such cases.
- ⁷ K. Barlow-Stewart and D. Keays, 'Genetic Discrimination in Australia' (2001) 8 *Journal of Law and Medicine* 250. Note also D. Keays, 'Genetic Testing and Insurance: When is Discrimination Justified' (2000) 19 *Monash Bioethics Review* 79.
- ⁸ 2002-2004.
- ⁹ Otlowski, Taylor and Barlow-Stewart.
- ¹⁰ The aims and methodology of this study are outlined in M. Otlowski, S. Taylor and

K. Barlow-Stewart, 'Major Study Commencing into Genetic Discrimination in Australia' (2002) 10 *Journal of Law and Medicine* 41-48.

- ¹¹ *National Health Act* 1953 (Cth) ss 73(2A) and 73(2B).
- ¹² Institute of Actuaries of Australia, 2002.
- ¹³ *Insurance Contracts Act* 1984 (Cth) s 21(1). This requires the insured to disclose all matters which a reasonable person in the circumstances could be expected to know to be a matter which is relevant.
- ¹⁴ See Part IV, Div 3 *Insurance Contracts Act* 1984 (Cth).
- ¹⁵ Section 4.
- ¹⁶ Section 5.
- ¹⁷ This is clear from the High Court decision in *Australian Mutual Provident Society v Goulden and Others* [1986] 160 CLR 330 with regard to the former NSW *Anti-discrimination Act* 1977.
- ¹⁸ 11 February 2000.
- ¹⁹ Disability Standards and Guidelines: Guidance for Providers of Insurance and Superannuation Human Rights and Equal Opportunity Commission (1998).
- ²⁰ K. Barlow-Stewart and D. Keays, 'Genetic Discrimination in Australia', n 7 above.
- ²¹ Congress of the United States Office of Technology Assessment, *Genetic Monitoring and Screening in the Workplace* (1990) US Government Printing Office, Washington DC.
- ²² *Burlington Northern and Sante Fe Railway Company Case*; and *Norman-Bloodsaw v Lawrence Berkeley Laboratory* 135 F.3d 1260 (9th Cir. 1996).
- ²³ see, for example, *Anti-Discrimination Act* 1977 (NSW) s 54; *Equal Opportunity Act* 1995 (Vic) s 69.
- ²⁴ see, for example, *Disability Discrimination Act* 1992 (Cth) ss 4 and 5.
- ²⁵ see, for example, *Disability Discrimination Act* 1992 (Cth) s 15(4)(b).
- ²⁶ M. Otlowski, *Implications of Genetic Testing for Australian Insurance Law and Practice, Occasional Paper No 1*, Centre for Law and Genetics (2001); M. Otlowski, *Implications of Genetic Testing for Australian Employment Law and Practice, Occasional Paper No 2*, Centre for Law and Genetics (2001).
- ²⁷ Australian Law Reform Commission, *Discussion Paper* No 66 (2002).