

Genetic testing and insurance: where to now?

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Is 'genetic discrimination' taking place against people seeking life, disability or superannuation insurance? Is it illegal, unfair or simply a legitimate part of the business of life insurance? Professor Skene comments on current laws and the Genetic Privacy and Non-Discrimination Bill currently before the Senate. Series Editor Dr Nisselle warns doctors against deliberately withholding information in reports written for insurers – they could be accused of taking part in a conspiracy to defraud.

Concerns have been expressed in lay newspapers recently about insurance companies' use of genetic test results in deciding whether to issue policies and in setting premiums. An example of 'genetic discrimination' is given in the box on this page. There have been calls for new laws to restrict the use of genetic information, at least when the sum insured is relatively small. I believe the current law is generally adequate to protect applicants for insurance from unfair discrimination. The main issue for the medical profession, as I see it, is whether people will be deterred from seeking lifesaving or health-enhancing testing and treatment by the risk that the test results will

affect their prospects for life, disability and superannuation insurance.

The current law

Australian law prohibits discrimination on health grounds in health insurance. Until recently, all premiums were set at the same rate regardless of risk;¹ now, age is taken into account in setting premiums but with that exception, other health factors may not be considered. On the other hand, for life, superannuation and disability insurance, insurers are allowed by law to base their premiums on the perceived risk of each applicant, and to refuse cover on the basis of risk. However, they must be able to justify that discrimination on health grounds.

The federal *Disability Discrimination Act 1992* makes it unlawful to discriminate in various activities.² 'Discriminate' means to treat less favourably. 'Disability' includes 'malfunction...of a part of the person's body'. Although a genetic mutation in the presymptomatic stage may not be a 'malfunction', the definition

includes a disability that may exist in the future or is imputed to a person. The Act is intended to prevent discrimination on physical grounds, so a broad interpretation would probably be adopted. Even presymptomatic discrimination would then be covered.

Insurers are permitted to discriminate, however, under both the *Disability Discrimination Act 1992* (Cwlth) and similar equal opportunity legislation at state level, if they can show that either:

- their decision was 'based upon actuarial or statistical data on which it is reasonable for [them] to rely; and [was] reasonable having regard to the matter of the data and other relevant factors'.²
- 'if no such actuarial or statistical data is available and cannot reasonably be obtained – the discrimination [was] reasonable having regard to any other relevant factors'.³

The onus is on the insurer to justify its decisions and it is an offence under the relevant Act not to disclose the source of the actuarial or statistical data when it is requested by the Equal Opportunity and Human Rights Commission.³ Insurance

Genetic discrimination in insurance – an example*

A 37-year-old quality manager was refused an increase in a pre-existing income insurance policy after a test in a research project revealed he had Charcot-Marie-Tooth disease. Although severe cases of this disease may cause sufferers to be wheelchair-bound, the condition would not affect this man's ability to earn income in his desk-bound job, even if it progressed from its current mild form. He learnt of his condition when taking part in a research project – not as a result of diagnostic testing.

*Revealed in a research study by David Keays, LLM student at The University of Melbourne, Vic.

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contracts are not subject to judicial review under the *Trade Practices Act 1974* (Cwlth).

There is at present no legislation preventing insurers from requiring genetic tests specifically for insurance. However, the Investment and Financial Services Association (IFSA), the industry association representing Australia's largest fund management firms, has published a policy stating that its members will not require that genetic testing be undertaken by applicants for insurance.⁴

If a person has not been tested, the premium will be set on the basis of risks assessed from family history, physical examination and any other available investigations. But if the person has already had a genetic test, the result must be disclosed to the insurer under both the *Insurance Contracts Act 1984* (Cwlth) and the common law principle that insurance contracts are *uberrimae fides* (in utmost good faith). Fraudulent failure to disclose entitles the insurer to avoid the contract or to reduce its liability under the contract.

If a person takes out life insurance and then has a genetic test, the contract remains on the initial terms; it can only be cancelled for nonpayment of premiums or fraud. This may advantage the insured person. A person who is tested after entering an insurance contract and has no genetic condition may contract on better terms with another insurance company – or the same company, if the company is prepared to alter the premium when the risk is shown to be reduced.

In summary, health insurers are not allowed to discriminate on health grounds in issuing policies. Life, disability and superannuation insurers may discriminate by refusing cover or setting higher premiums, provided that they can produce actuarial or statistical data to show that it was reasonable for them to rely on that risk. By a voluntary policy (not law), the insurance industry has stated that it will not require applicants to undergo genetic tests specifically for insurance

purposes.⁴ But if applicants have already taken a test, they must reveal the results to the insurer and failure to do so may cause the policy to be legally invalid (vitiated).

Where to next?

In my view, the current legislative scheme outlined above covers the field quite effectively and would not be greatly changed if legislation such as the Genetic Privacy and Non-Discrimination Bill 1998 (Cwlth) was passed.⁵ This Bill, introduced in the Senate by Senator Stott-Despoja, has not yet been voted on and is unlikely to proceed in its current form. But if it were passed, it would in effect give statutory force to the voluntary agreement of insurance companies not to require genetic tests before insurance; however, it would not prevent insurance companies taking account of genetic tests that have already been undertaken, provided it is reasonable in the circumstances. Discrimination against and requirements for testing of family members before insuring would be specifically prohibited.

Would this Bill be sufficient? Imagine a young woman who believes that she may be at risk of familial breast cancer. If she is tested for the BRCA1 and BRCA2 genes and found to be affected, she may choose to take prophylactic measures. But she will have to tell the insurance company the results of this genetic testing if she applies for life, disability or superannuation insurance. I have argued that the young woman could apply for the policy and *then* take the test so that a poor result would not increase the premium. But what if she does not wish to incur the cost of ongoing premiums at this stage of her life? She may decide to defer a health-enhancing test for economic reasons.

With the risk of this and similar situations, the medical profession may choose to lobby for insurers to be limited in the use they can make of genetic information, so that risk-based insurance is permitted

only if the sum insured is above a certain limit. Below that limit, everyone could be entitled to insurance at the same rate regardless of risk. This would, of course, increase everyone's premiums as risks would be shared across the whole of the insured population; however, this approach has been adopted successfully in the Netherlands and the UK.

Getting it right

Although there have been calls in Australia for specific legislation banning discrimination on the grounds of genetic tests, I am not convinced that present legislation is inadequate in preventing or addressing unfair discrimination – or could not be made so with relatively minor amendments. Before rushing into a new legislative regime, there should be a closer examination of the provisions that already exist and their practical operation. There have been relatively few cases of apparent genetic discrimination to date and the existing mechanisms have not been tested. If they do not work when tried, it may be more cost-effective to amend the relevant provisions and procedures – within the context of anti-discrimination laws – than to establish new ones.

There are, however, legitimate concerns about people delaying genetic tests for economic reasons. Consideration should be given to requiring insurers to cover all applicants at the same rate regardless of risk if the sum insured is relatively small.

Series Editor's comment Life at the track

As chief executive of a medical defence organisation, I make 'risk selecting' decisions every day. What insurers call 'underwriting decisions' are all about assessing and costing the 'risk' an applicant will bring to the 'risk carrier'. There is no magic to it, despite the arcane language used. The only difference between bookmakers and us is that a bookie looks at the horses running in a race and assesses the risk or chance of each horse winning whereas we

assess the chance of you losing! The odds you are offered by your bookie, and the subscriptions we charge, represent the best, and in our case actuarially-advised, estimate of that risk.

When you apply to join a medical defence organisation, you are asked some questions about the nature of your practice and past litigation track record. That helps us decide into which category of membership you should be placed so that your subscription, when added to the subscriptions paid by all others in that category and then added to all other members' subscriptions, will fully fund the risk of the entire membership.

If you tell us you are a GP, that's one level of risk. If you are a GP doing, say, liposuction, that's another. If you are a liposuctioning GP who has had 10 negligence claims brought against you over the last three years, that's yet another risk. The point is that other GPs do not feel all that happy about subsidising the risk of, say, GPs who do a lot of cosmetic work. Hence we charge that latter group a subscription sufficient to fund its own risk.

What's fair?

Translate these principles to life insurance. Most nonsmokers are pleased that smokers pay more to fund their own higher risk. There is an element of 'victim blaming' in that attitude – smokers choose to smoke and 'if they choose to smoke, they should pay for their foolishness'. But who chooses to be BRCA1 or 2 positive, or apoE4 homo- or heterozygous, or to have an inherited hyperlipidaemia? Is it fair to have to pay more for an 'involuntary' added risk? Conversely, is it fair that your premiums subsidise the risk of another person with a known greater risk than you?

Health insurance still insists on using 'community rating' albeit that this is now 'lifetime community rating'. The young and healthy subsidise the health care costs of the older and infirm. Is that fair? Financially, probably not; but, private

health insurance simply would not work without that cross subsidy.

If patients know their cholesterol or PSA level or their BRCA or apoE status and fail to declare it in an insurance application, that nondisclosure could void their insurance. They may feel they are being penalised for prudence if they accept your recommendations for screening and then find their insurance company applies a loading on their policy because of the results. However, 'once

the information-genie is out of the bottle, it can't be pushed back in'. The insurer is entitled to all known information and is entitled to make responsible underwriting decisions based on that information. For example, while antidiscrimination legislation generally protects HIV positive people from discrimination in a range of areas, it is not necessarily 'discrimination' if the known HIV status of insurance applicants is used for risk assessment purposes.

If the community agrees or seeks legislation to allow insurance applicants to lawfully not reveal information obtained from genetic testing, then the community agrees that most of us will pay a bit more in insurance premiums to subsidise the risk of those with genetic markers

of predisposition to various diseases. In the absence of such legislation, insurers who do not take genetic information into account when making their underwriting decisions will be at the mercy of insurers who do. Insurers try to cherry pick 'good risks' and either refuse or heavily load the premiums of 'bad risks'.

Practice tips

Patients may choose to defer screening until they have completed their insurance arrangements, in the knowledge that once obtained such information cannot be suppressed. This should not alter your advice to patients about such screening. Further, no matter how sympathetic you feel to your patient, you should never deliberately withhold information. A patient might say 'Be a good sport, Doc, don't mention the cholesterol' but if they have signed a blanket consent-for-disclosure form and you omit a material fact, you could end up being liable to the insurer for any loss the insurer suffers as a result of that nondisclosure. If the patient directly instructs you not to mention a particular fact, they have that right – but then you *must* write on the form wording such as, 'This report has been written subject to restrictions on disclosure imposed by the applicant'.

Genetic testing and insurance is a matter of public policy. Until limitations to disclosure are introduced by statute, doctors must not be party to what may be, in effect, conspiracy to defraud by deliberately withholding information. **MT**

References

1. *National Health Act 1953* (Cwlth), ss. 73(2A), (2B).
2. *Disability Discrimination Act 1992* (Cwlth), ss. 4, 5(1).
3. *Disability Discrimination Act 1984* (Cwlth), ss. 46(1), 107(1).
4. Underwriting and Genetic Testing – Draft LISA [now IFSA] Policy on Genetic Testing, June 1997; IFSA: www.ifsa.com.au
5. www.aph.gov.au/senate/committee/legcon_ctte/genetic/contents.htm