

Australians can be denied life insurance based on genetic test results, and there is little protection

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Australia has a lack of regulation to prevent discrimination by life insurance companies based on genetic test results.[from shutterstock.com](#)

A parliamentary inquiry is currently underway into Australia's [life insurance industry](#), which has raised several issues including discrimination by insurers against people with [mental health problems](#)

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[submission to the inquiry](#)

, we argue comparable discrimination is possible based on genetics, with insurers denying applicants life insurance and raising premiums inappropriately based on genetic test results.

There is a concerning lack of regulation over the use of genetic information by the Australian life insurance industry. Insurance companies are allowed to use genetic test results to discriminate against applicants for life, permanent disability, and income protection insurance (which all come under the life-insurance product category), with little independent oversight or consumer transparency.

This discrimination can deter people from getting genetic tests and being involved in medical research that could prove useful for their future health and scientific understanding of diseases.

Read more: [***Brace yourself, genetic testing might give you more than you bargained for***](#)

Genetic discrimination

Australian insurers can increase premiums, exclude insurance cover for certain conditions such as cancer, or refuse insurance cover altogether purely based on your genetic test results.

Genetic tests look at DNA, the material that contains the instructions for our bodies to grow, develop and function. Some DNA changes cause diseases such as cystic fibrosis or Huntington's Disease, while others can make us more susceptible to conditions such as cancer. Doctors can refer patients to a genetics service if they consider such tests might be of value due to family or personal history.

Although cases of genetic discrimination are difficult to identify, they have been documented in Australia. In [one case](#), a woman with a BRCA gene, which is known to [increase breast cancer risk](#), elected to have both breasts removed to reduce her risk. However, the consequent, significant risk reduction wasn't taken into account by the insurer. When she applied for death and critical illness cover, the insurer excluded any cancer cover and imposed a 50% premium loading for death cover.

In [another case](#), a man whose mother had bowel cancer was found to carry a gene increasing his risk of also developing bowel cancer. He was refused cancer cover despite proactively seeking increased surveillance through colonoscopies, which reduced his risk back down to population average. The man eventually obtained cover, but only after taking a complaint to the Human Rights Commission.

Lack of regulation

Under [Australian law](#), life insurance applicants must disclose any known genetic test results if requested by the insurer. This includes results from [approved clinical genetic tests](#), but also less reliable findings from research or [direct-to-consumer \(DTC\) genetic tests](#), if they are known to the applicant.

Direct-to-consumer genetic tests are a new concept whereby consumers have genes tested directly through a private company without medical consultation. Although most of these lack evidence of any predictive medical value, the law does not distinguish between types of genetic tests.

Read more: [Genetic testing isn't a crystal ball for your health](#)

Australian life insurance companies are technically [required by law](#) to justify decisions based on genetic results. In practice, however, consumers have no way of requiring insurers to provide information about how decisions are made.

The Australian government leaves the life insurance industry to self-regulate its policy through the Financial Services Council (FSC). This essentially means the insurance industry writes its own rules on the use of genetic data, raising obvious conflicts of interest. Recently the FSC [updated its genetic testing policy](#) to suggest that insurance companies ask applicants if they are considering having a genetic test. This is a concerning development.

Many other countries have protected consumers by restricting or banning the use of genetic information for insurance altogether. In the UK, a [moratorium](#) established in 2001 sets out an agreement between the government and the insurance industry not to ask for, or use, genetic test results (except for Huntington's Disease for policies worth over £500,000).

Canada has just passed [legislation](#) prohibiting insurance companies from asking for any genetic test results. And many European countries such as Belgium, Austria, Denmark, France, Germany, Lithuania, Norway, Portugal, and Sweden have [implemented outright bans or other regulation](#) in accordance with the Council of Europe's [Oviedo \(human rights and biomedicine\) Convention](#).

Implications

In Australia, the situation is very different. Patients considering predictive or family-based clinical genetic testing are [frequently advised](#) to review their life insurance situation prior to taking the test, due to the obligation to disclose results to insurers.

The fear of unknown insurance implications deters some of these people from having this testing. This can sometimes mean [passing up critical information](#) that can be used to [help prevent cancers](#) and other serious diseases.

For example, [one study](#) looked at patients at risk of bowel cancer due to family history. It found more than double the patients, who had been advised of the possible effect of having a positive test on their insurance claim, declined testing compared with patients who had not been advised of this possible effect.

Read more - [Gene testing for the public: a way to ward off disease, or a useless worry?](#)

Some participants are also being [deterred from involvement](#) in medical research, which can sometimes involve the return of genetic findings. Fortunately, this issue only affects life insurance and related policies in Australia, not private health insurance, which is [treated differently](#). However, this distinction isn't always understood by consumers, who may mistakenly believe that these issues affect all insurance types.

As genetic testing becomes more widespread in our society and offers increased potential to help manage patient risk, we must find a way of regulating the insurance implications.

The Australian government must take action towards an immediate ban (moratorium) on the use of genetic test results in insurance, until adequate long-term regulation is in place. This would bring us in line with other countries.

If you have experienced genetic discrimination by an insurer, or have concerns about this issue and would like to be involved with enacting change, please contact the author.

Paul Lacaze receives funding from NHMRC and NIH.

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