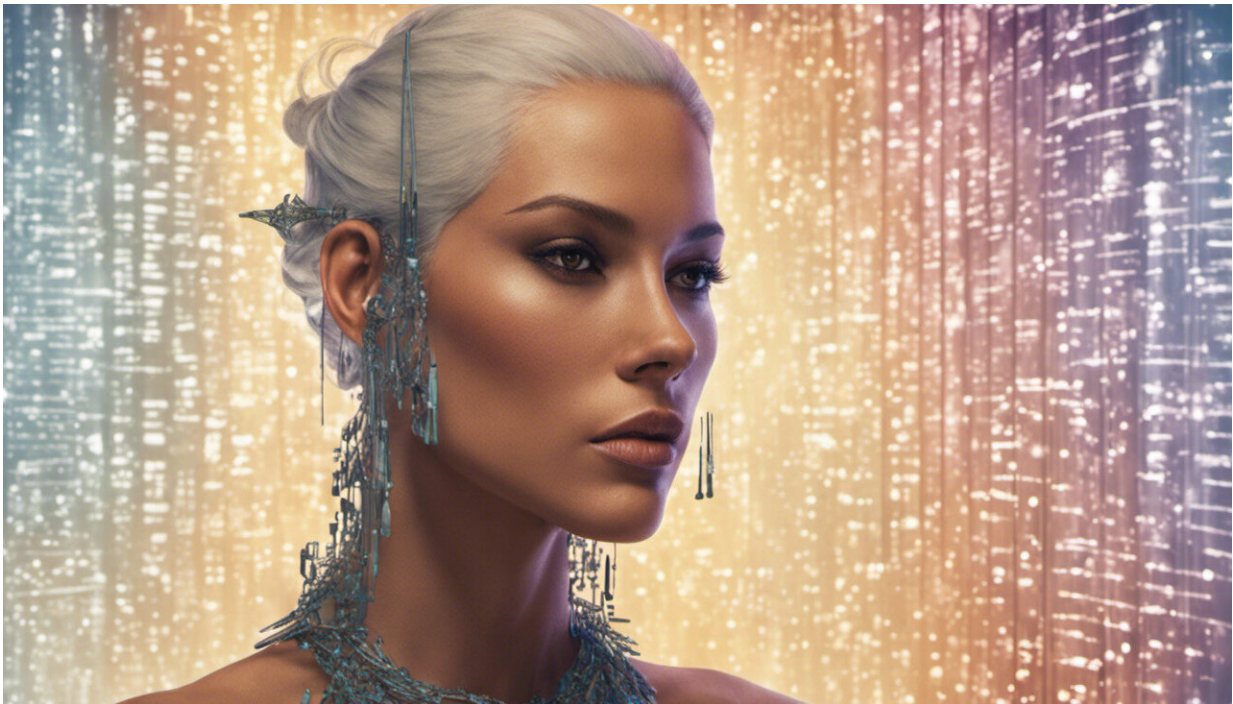


Australians need more protection against genetic discrimination, say health experts

October 5 2021, by Jane Tiller, Paul Lacaze



Credit: AI-generated image ([disclaimer](#))

Genomic testing—the ability to read an individual's genetic code and identify their risk of conditions such as cancer—has opened up huge possibilities in personalized medicine.

But it has also introduced serious ethical challenges. Particularly, there is

the danger of life insurance companies using such information to discriminate against those at higher risk of conditions.

Canada, Britain and most European countries have already banned or restricted life insurers from using genetic test results.

Australia's response so far has been mostly to leave it to industry self-regulation. But our research suggests most [health professionals](#) don't think this is enough. More than 90% [of the experts](#) we surveyed agreed more government oversight is required.

Australia's regulatory approach

Australia's federal Private Health Insurance Act (2017) prohibits health insurers from using [genetic information](#) to discriminate against customers. But there is no legal prohibition against life insurers using results to charge people higher premiums or deny them coverage altogether. This applies to death cover, total and permanent disability, critical illness/trauma and income-protection cover.

In 2018 a [joint parliamentary inquiry](#) recommended a prohibition against life insurers using the outcomes of predictive genetic tests, at least in the medium term. It also recommended the government maintain a watching brief and consider legislation in future.

The federal government did not respond to the inquiry's report, leaving it to the industry to self-regulate.

In 2019 the financial services industry's peak body, the Financial Services Council, introduced a five-year moratorium on insurers using applicants' genetic test results up to certain financial limits.

Life insurers can only ask for or use genetic test results for policies

worth more than A\$500,000 for death cover or total and permanent disability cover, A\$200,000 for critical illness/trauma cover, and \$4,000/month for income protection.

Given the median yearly household income is about [A\\$122,000](#), these thresholds are arguably too low to prevent insurers from using genetic test results in many cases.

Our survey results

With the moratorium now half over (it will end in 2024), we surveyed health professionals to gauge their views about Australia's approach. The survey was part of a [federal government](#)-funded [research project](#) to evaluate the moratorium.

Of 166 respondents, 121 were genetic specialists—geneticists and genetic counselors who help people make sense of and make decisions about genetic testing. There are 480 such specialists in Australia registered with the [Human Genetics Society of Australasia](#). With genetic testing increasingly being offered outside genetics clinics, we also invited specialists such as oncologists to take part.

Not everyone answered every question, so the following percentages are based on those that answered specific questions. While 93% agreed consumers are better protected under the moratorium, 88% remained concerned about genetic discrimination.

The most common complaints were that the financial thresholds were too low, there was no certainty for patients beyond 2024, and the insurance industry couldn't be trusted to regulate itself.

More than 90% said the Australian government should introduce legislation to regulate life insurers.

Canada's [legislation](#), for example, bans insurers and other service providers from using genetic test results to discriminate against applicants.

The British government, meanwhile, has a hybrid regulatory model. This involves a [Code on Genetic Testing and Insurance](#) agreed to between the government and life insurance industry. In our survey, 95% said a similar approach is required for Australia.

Safeguarding Australia's genomic future

Genetic technology is transforming health care. Precision medicine relies on [genomic testing](#) to personalize therapeutic treatments. Genomic research is also critical to understanding disease, improving diagnostic methods and guiding the selection of the most effective drugs for treatment.

To maximize its potential and ensure public trust in genomics, it seems clear more must be done to prevent genetic discrimination and ensure all Australians—particularly those most at risk from genetic conditions—can benefit from the genomics revolution.

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Provided by The Conversation

Citation: Australians need more protection against genetic discrimination, say health experts (2021, October 5) retrieved 12 September 2024 from

<https://medicalxpress.com/news/2021-10-australians-genetic-discrimination-health-experts.html>

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