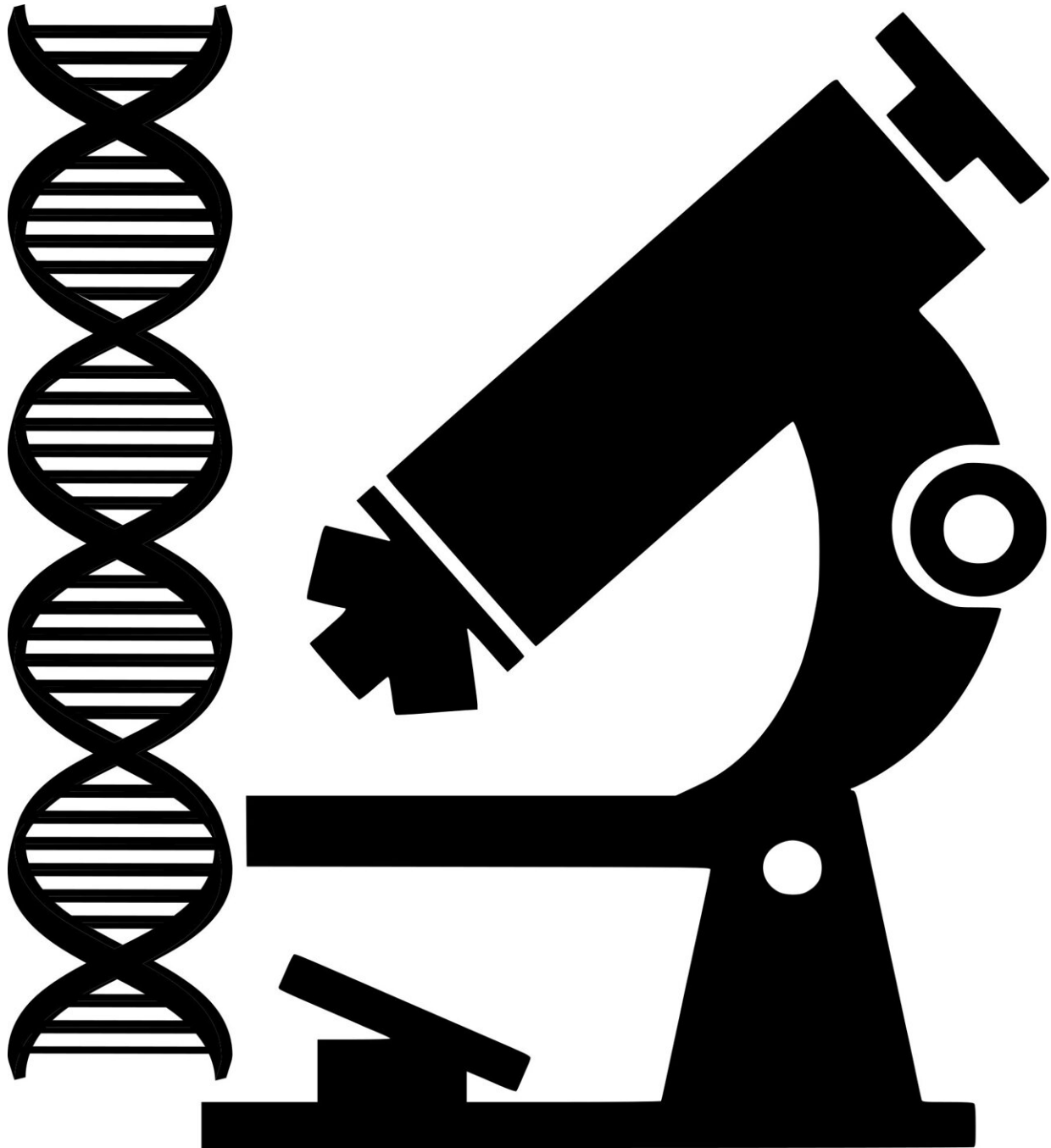


# **Opinion: Life insurers can charge more or decline cover based on your genetic test results. New laws must change this**

September 7 2023, by Jane Tiller and Paul Lacaze

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Genetic tests can provide life-saving information. They can help diagnose disease, enable access to preventive care, prompt early

screening and treatment, and guide patients' therapeutic options.

In Australia, [life insurance companies](#) can legally use the results of genetic tests to discriminate. They can decline to provide life [insurance](#) coverage, increase the cost of premiums, or place exclusions on an individual's cover. This is known as "genetic discrimination."

This week, a number of [federal parliamentarians argued for a ban](#) on genetic discrimination by life insurance companies. This follows [recommendations](#) from our research team for [legislative reform](#) so Australians don't forego important genetic tests for fear of this discrimination.

## **Why would you have a genetic test?**

We don't choose our genetic risk factors. They exist from birth, can't be changed, and are often passed down from parents to children, causing generations of disease.

Genetic testing can, in some cases, stop the generational curse of genetic disease through prevention and early intervention.

One of the most well-known examples is testing for changes in the BRCA1 gene—which significantly increases risks of breast, ovarian and prostate cancer.

[Angelina Jolie](#), who carries the BRCA1 gene mutation, famously wrote in the New York Times in 2013 about her decision to have surgeries to drastically reduce her chance of developing cancer.

## **How is this discrimination currently allowed?**

The Disability Discrimination Act 1992 (Cth) prohibits discrimination on a number of different bases, including genetic risk factors.

However, there is a specific carve-out in the Act that allows life insurers to discriminate in ways other entities are prohibited from doing.

This means companies providing insurance for death, income protection, and disability can discriminate on the basis of genetic risk of disease. Other companies that provide risk-rated insurance (where insurers assess an individual's risk factors and change coverage or premiums based on this risk) can also use genetic test results to discriminate. This includes travel insurance.

Health insurance, however, is not risk-rated. This means a health insurer is not allowed to decline cover or change the cost of premiums based on any risk factors, including genetic risk factors.

## **Protections are needed**

Fears of insurance discrimination [deter many people](#) from having [genetic testing](#) or participating in [genetic research](#). For this reason, numerous other countries [have banned](#) the use of genetic results by insurance companies.

Canada did so in 2017. Its Act prohibits entities (including insurance companies) from collecting or using genetic results to discriminate against individuals.

Insurance industry bodies frequently raise claims that banning the use of genetic results will increase the cost of premiums, making them unaffordable.

Before the Canadian Act was introduced, its Privacy Commissioner

commissioned an [actuarial expert](#) and economic analyst to consider what impact this ban might have on the Canadian insurance industry.

Both experts concluded the impact of Canada's ban would be negligible in the medium term, and the Privacy Commissioner [welcomed the Act](#) as an "important step for privacy and human rights."

## **Genetic testing is likely to expand**

At the moment, only people with a strong personal or family history of certain diseases are eligible for publicly funded genetic testing.

However, research projects such as the [DNA Screen study](#) are piloting [the offer of](#) DNA screening to the whole population.

DNA Screen is offering testing to 10,000 young Australians (18- to 40-year-olds) for [genetic risk factors](#) for cancer and heart disease, which can be prevented or treated early.

However, we have to tell people when they sign up about potential life insurance discrimination, and many of them change their minds about being part of our study.

As genetic testing offers may expand to the whole population in the future, every person being offered genetic testing will have to consider the implications for their life insurance.

## **The long road to legislating protections**

Following [parliamentary recommendations](#) to ban the use of genetic results by life insurers in 2018, the life insurance industry [introduced](#) a partial, self-regulated moratorium on using genetic results in 2019.

We had concerns about its terms and the fact that it was self-regulated, with no government oversight. So we [gathered views](#) from [health professionals](#), [consumers](#), researchers and [financial advisers](#).

We found the the industry moratorium [did not meet](#) the expectations of the parliamentary recommendations. Overwhelmingly, patients, the general public, health professionals and genetic researchers believed legislation on this issue was required. Our [final report](#), released in June, recommends the Australian government introduce a legislative prohibition on the use of genetic test results in insurance underwriting.

This week, federal MP Josh Burns, Chair of the Parliamentary Joint Committee on Human Rights, took the first step by [introducing a motion](#) , for the parliament to consider policy reform on this issue.

This was supported by five other federal MPs, including from the coalition and independents. As Labor MP Louise Miller-Frost explained:

"Australians should be able to make these decisions based on their health needs, not financial ones, and we have the opportunity to make that a reality... self-regulation is clearly not sufficient to protect our interests. I believe legislation is required."

Separate speeches by MP Dr. [Daniel Mulino](#) and Assistant Minister for Health and Aging [Ged Kearney](#) this week also supported the motion.

Ms Kearney spoke about several constituents who have shared their concerns about this issue, and also called for [policy changes](#). She noted the benefits for life insurance companies if people can get genetic testing and are able to take preventive action, to become "better risks."

The Treasury Department, and Stephen Jones MP (Assistant Treasurer and Financial Services Minister) are now considering the appropriate

policy solution, together with the Department of Health and Aging and the Attorney-General's Department. There is no timeline for this legislation to be introduced, but this urgent policy change must be prioritized by the current government.

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