

# POSITION STATEMENT



Australian  
Academy of  
Health & Medical  
Sciences

## POSITION STATEMENT ON THE USE OF GENETIC TESTING RESULTS IN LIFE INSURANCE UNDERWRITING

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**05 September 2024**

This position statement outlines the Academy of Health and Medical Sciences' stance on the use of genetic test results in life insurance underwriting<sup>1</sup>.

It aims to:

- Inform the Government's approach to addressing life insurers' use of genetic testing results.
- Protect and nurture participation in medical research.
- Ensure that the benefits of genetic testing are provided for patients.
- Strengthen public trust in the health and medical sciences.

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<sup>1</sup> Life insurance in Australia encompasses insurance policies covering death; total and permanent disability; trauma and critical illness; and income protection, salary continuation or business expenses.

## The Academy of Health and Medical Sciences Position

Genetic testing saves lives. In clinical settings, it identifies the need for crucial treatments, while in medical research, it drives scientific breakthroughs essential for the future of precision medicine and personalised healthcare. However, the lack of a legislated ban preventing the life insurance industry's use of genetic testing results in underwriting is causing concern for patients and eroding trust in this critical technology.

**It is the position of the Australian Academy of Health and Medical Sciences that the Federal Government acts decisively by implementing a total ban on the use of genetic testing results in life insurance underwriting, without any limits, caps, or exclusions.**

A 2023 multi-institutional project led by researchers at Monash University demonstrated that concerns about genetic discrimination are deterring some Australians from undergoing genetic testing or participating in research. This reluctance is fuelled by fears about potentially punitive premiums or even future access to life insurance.<sup>1</sup>

Academy Fellows, who are at the forefront of clinical practice and research, have witnessed firsthand how these concerns are impacting patient decisions. Many patients and potential research participants are opting out of genetic testing due to worries about their ability to secure affordable life insurance. There have been multiple cases where individuals have refused participation in both research and clinical testing, and some have even requested that all records and samples related to genetic testing be destroyed to avoid potential genetic discrimination.

The Academy joins Australian Genomics and the broader genomics sector in advocating for the introduction of robust legislation to protect consumers, eliminate the fear of genetic discrimination by banning its use by insurers, and ensure rigorous government oversight of insurers' compliance with these protections.<sup>2 3</sup>

## Freedom from discrimination

The Academy acknowledges the need for an insurance industry that delivers fair and affordable products while allowing insurers to make a sustainable profit. However, in delivering those outcomes, the insurance industry should not discriminate against those who carry genetic risk. Instead, any financial burden of genetic risks - i.e. heritable, unmodifiable traits over which individuals have no control - should continue to be shared by the community as a whole.

The primary risk of discrimination stems from the life insurance industry's potential use of genetic information. This practice can result in individuals being denied coverage or facing higher premiums solely based on their genetic test results. Such discriminatory actions not only erode trust in genetic testing but also deter individuals from participating in valuable genetic research or seeking necessary medical treatments, ultimately hindering advancements in health and medicine.

Aboriginal and Torres Strait Islander people are particularly at risk due to existing health disparities, limited access to healthcare, and historical injustices that have fostered mistrust in medical institutions. The use of genetic information by insurers could further exacerbate these vulnerabilities, increasing discrimination, deepening existing inequalities

within First Nations communities, and compounding existing hesitations to engage with genetic research.

The Academy believes it is important to recognise that an individual's genetic makeup and inherited risk factors are not within their control. These genetic traits are simply a part of the diverse fabric of our society. No one should be financially penalised for the genes they have inherited. While certain genetic conditions may already impact an individual's health, quality of life, and survival, the focus should be on optimising health outcomes through personalised medicine and healthcare, rather than exacerbating their challenges through financial discrimination.

### Trust in health and medical science

The Academy strongly affirms that building and maintaining trust in health and medical science is essential to ensuring Australians' willingness to participate in research (which increasingly uses genetic data) and to utilise the diagnostic tools and treatments that arise from it.

Public confidence is undermined by the perception that life insurers do not act in the best interests of individuals. The partial moratorium introduced by the life insurance industry in 2019, which limits the requirement to disclose genetic test results, has not provided sufficient reassurance. The limit of insurance on the moratorium is lower than that required for many commonplace forms of coverage such as mortgage protection.

To fully address this issue and safeguard trust in health and medical sciences, a complete ban on the use of genetic testing results by life insurers is necessary. This is the position in a number of countries, with Canada the latest to introduce such legislation. This measure would eliminate the current uncertainty surrounding genetic testing and prevent further erosion of public trust in the scientific and medical community.

### Authorisation

This statement was endorsed by the Australian Academy of Health and Medical Science's Council on 27 August 2024.

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<sup>1</sup> Tiller J, Gleeson P, McInerney-Leo AM, Keogh L, Nowak K, Barlow-Stewart K, Boughtwood T, Delatycki MB, Winship I, Otlowski M, Lacaze P, [Final Stakeholder Report of the Australian Genetics and Life Insurance Moratorium: Monitoring the Effectiveness and Response \(A-GLIMMER\) Project](#). 2023.

<sup>2</sup> [Australian Genomics and the Australian Alliance for Indigenous Genomics Joint Consultation Response on the use of genetic testing results in life insurance underwriting](#). 2024.

<sup>3</sup> McInerney-Leo AM, Ayres S, Boyle J, Jacobs C, Newson AJ. [Human Genetics Society of Australasia Position Statement: Genetic Testing and Personal Insurance Products in Australia](#). Twin Research and Human Genetics. 2023.