

Laws needed to prevent gene-based life insurance discrimination, says report

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Laws are needed to protect Australians from life insurance discrimination based on genetic tests that identify increased risk of certain medical conditions, a [report](#) has found.

Led by Monash University experts, in collaboration with the Universities of Melbourne, Sydney, Queensland, Tasmania, Deakin University and other clinical and consumer partners, the report also found an insurance industry moratorium aimed at preventing this discrimination was inadequate.

The A-GLIMMER (Australian Genetics & Life Insurance Moratorium: Monitoring the Effectiveness and Response) Final Stakeholder Report found that genetic discrimination in [life insurance](#) occurs in Australia, and deters individuals from having [genetic testing](#) and participating in research.

More than 90% of health professionals (93), 88% of patients with experience of genetic testing, 78% of the general public, and 86% of researchers believed legislation was required to regulate the use of genetic test results in life insurance underwriting.

The report follows a 2018 Federal Government Joint Parliamentary Committee Inquiry [report](#) that recommended a ban on genetic discrimination in life insurance underwriting.

In 2019, the life insurance industry's peak body, the Financial Services Council (FSC), introduced a partial moratorium requiring applicants to disclose genetic test results only for policies above certain financial limits. The FSC Moratorium is industry self-regulated, with no government oversight.

Through the Medical Research Future Fund's (MRFF) Genomics Health Futures Mission, the A-GLIMMER coalition of independent experts investigated the moratorium's adequacy from 2020–2023.

Monash University School of Public Health and Preventive Medicine
Public Health Genomics Ethical, Legal & Social Adviser Dr. Jane Tiller,

who gave evidence at the Parliamentary Inquiry and led the research project, said the findings were unequivocal.

"Our research shows, overwhelmingly, that Australian stakeholders believe current protections against genetic discrimination are inadequate, and that legislation is required," she said. "We are calling on the government to legislate to protect consumers from genetic discrimination and remove the barrier to genetic testing and [genomic medicine](#)."

A-GLIMMER conducted research with consumers, health professionals, researchers and the financial industry. It found that genetics had great potential to improve medicine and public health, through enabling diagnosis, prevention and early treatment of disease. However, Australia's life insurance industry was legally permitted to use genetic test results in underwriting, which can lead to discrimination.

"Insurance fears can also act as a barrier, by deterring people from having potentially life-saving genetic testing that could match them to tailored interventions and treatments, as well as from participation in genetic research," the report found.

Among other things, the A-GLIMMER report found:

- Key stakeholders ([health professionals](#), consumers and researchers) are concerned about the life insurance industry's self-regulation and absence of Australian Government oversight of the FSC Moratorium, and express a low level of confidence in its effectiveness
- There are instances of non-compliance, including where insurance companies have asked insurance applicants about genetic testing, contrary to FSC Moratorium terms
- There is a lack of effective mechanisms to enforce the

moratorium or seek redress

- Stakeholders are concerned about the uncertainty inherent in the moratorium's industry-led nature, and the potential for to life insurers to use genetic test results in the future
- Many genomic researchers reported that the potential use of genomic test results by insurers was a barrier to the recruitment of research participants

The report recommended that the Australian Government:

- Amend the Disability Discrimination Act 1992 (Cth) to prohibit insurers from using genetic or genomic test results to discriminate between applicants for risk-rated insurance, and consider amendments to the regulation of financial services to ensure insurers are subject to a positive duty to not discriminate.
- Allocate responsibility and appropriate resources to the Australian Human Rights Commission to enforce, promote, educate and support individuals and all relevant stakeholders to understand and meet the Act's new legal obligations.

Hayley Jones, Director of the McCabe Center for Law and Cancer, welcomed the recommendations. "The report highlights that Australia is lagging behind other countries in dealing with genetic discrimination. The findings of the report clearly show that self-regulation in [insurance](#) is not working, and legislative action is urgently needed" she said.

"The recommendations in this report would help Australians access genetic testing, and participate in important genetic research that can lead to new cancer treatments, without fear of discrimination."

Tiffany Boughtwood, Managing Director of Australian Genomics, said the changes recommended in the report were well overdue. "The issue of genetic [discrimination](#) has stifled clinical and research genomic uptake

for years. The [report](#) makes a clear case for urgent intervention by the Australian Government, to protect consumers and the future of genomic medicine and research, as we're on the brink of realizing population-scale genomic testing in Australia."

Provided by Monash University

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