

31/01/2024

## **RE: Use of genetic testing results in life insurance underwriting**

The Public Health Association of Australia (PHAA) is recognised as the principal non-government organisation for public health in Australia working to promote the health and well-being for all. PHAA seeks to drive better health outcomes through increased knowledge, better access and equity, evidence informed policy and effective population-based practice in public health.

These outcomes of knowledge, access, equity and evidence informed policy are inextricably linked to the matter of genetic discrimination in the life insurance industry. For that reason, we are addressing question 4 of the consultation paper, "Of the options outlined above, which do you think is most appropriate to manage concerns about genetic testing and access to life insurance...".

After reviewing the recommendations made in Monash University's Australian Genetics and Life Insurance Moratorium: Monitoring the Effectiveness and Response (A-GLIMMER) report; from a public health perspective, the only acceptable option to address the issue of genetic discrimination is to legislate a complete ban that prevents life insurance companies requiring customers disclose genetic testing results and using these results, without exception. This legislation should also ensure appropriate Government oversight and forego the current industry self-regulation.

Without a complete and permanent ban and proper Government oversight, the implications would be:

- Fewer Australians being tested for genetic conditions.
- Australians who have had genetic testing being deterred from accessing life insurance due to higher premiums or being denied a policy altogether.
- Another industry self-regulation scheme that is a blatant conflict of interest.

As the A-GLIMMER report demonstrated, life insurance companies' ability to request and/or use genetic testing results is a significant deterrent for Australians to undergo genetic testing for diseases.<sup>1</sup> This means that people who may have a genetic predisposition to a preventable disease and are deterred from taking the test could miss out on proactive, preventive interventions, such as early and regular screening, surgeries and lifestyle alterations, resulting in a greater risk of poorer health outcomes due to preventable disease. Removing this barrier to access with a total and permanent ban is likely to result in more Australians accessing preventive healthcare, more Australians who are more informed about their health and ultimately, significant cost savings for the Government.

PHAA is concerned that the introduction of a partial or non-permanent ban could result in higher premiums for people who test positive for genetic conditions, even if preventive measures are taken by those people.<sup>1</sup> This could make attaining life insurance prohibitive for people who have taken proactive steps for their health. Further, a partial ban means that some people will continue to be denied access to life insurance based on their genetic results.<sup>2</sup> This policy is deeply inequitable and will continue to deter many from

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<sup>1</sup> Jane Tiller, et. al. The A-GLIMMER (Australian Genetics & Life Insurance Moratorium: Monitoring the Effectiveness and Response) Project: Final Stakeholder Report (Monash University, 2023) <https://doi.org/10.26180/23564538>

<sup>2</sup> Otlowski, M., Tiller, J., Barlow-Stewart, K., & Lacaze, P. Genetic testing and insurance in Australia. *AJGP*. 2019 Mar; 48(3). Available from: doi: 10.31128/AJGP-10-18-4722

having genetic testing that could save their lives, increase treatment efficacy or provide life-saving information to their relatives.

Further on this point, genetic results are not determinative – that is, although they can alert people to risk, showing a predisposition to a certain condition rarely means that person will definitely develop that condition.<sup>3</sup> Meaning that life insurers can discriminate against a person for the potential of illness, even without any manifestation of illness, although that is the base purpose of life insurance - security for one's family if one potentially dies or becomes permanently disabled.

Industry self-regulation is also a deterrent to Australians looking to access life insurance.<sup>3</sup> The inherent conflict of interest of industry self-regulating its own access to genetic information alone causes distrust of the system.<sup>3</sup> The only meaningful way that trust can be gained is through a complete ban on life insurance companies accessing and/or using genetic testing data, with no exceptions, that is legislated and enforced by Government. Such legislation has been successfully achieved in Canada, which we would strongly encourage the Inquiry to be guided by.<sup>4</sup>

A partial or non-permanent ban will continue to allow insurers access to genetic information in some circumstances (and potentially in circumstances that change over time). This will create uncertainty for consumers, which, combined with ongoing distrust of the insurance industry, will perpetuate the issues already documented with unwillingness to have genetic testing and participate in genomic research. Through prohibiting the attainment and use of genetic testing data by life insurance companies and ensuring greater Government regulation, the Government would be removing a considerable barrier for many Australians to undergo testing for genetic conditions, which in turn, would save lives as people can take proactive measures to prevent the condition.

The PHAA appreciates the opportunity to make this submission and the opportunity to ensure that more Australians have the ability to live healthy lives. Please do not hesitate to contact me should you require additional information or have any queries in relation to this submission.

Yours Sincerely,



Adj. Professor Terry Slevin  
Chief Executive Officer  
Public Health Association of Australia

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<sup>3</sup> Jane Tiller, et. al. The A-GLIMMER (Australian Genetics & Life Insurance Moratorium: Monitoring the Effectiveness and Response) Project: Final Stakeholder Report (Monash University, 2023) <https://doi.org/10.26180/23564538>

<sup>4</sup> Government of Canada, Genetic Non-Discrimination Act (SC 2017, c 3), [https://laws-lois.justice.gc.ca/eng/annualstatutes/2017\\_3/](https://laws-lois.justice.gc.ca/eng/annualstatutes/2017_3/)