

# SUBMISSION

Tuesday, 30 January 2024

## Submission on Treasury Consultation Paper. Use of Genetic Testing in Life Insurance Underwriting

### Online submission

#### Introduction

The Australian Medical Association (AMA) is the peak professional body for doctors in Australia, promoting and protecting the professional interests of doctors and the healthcare needs of patients and communities.

#### Genetic and genomic testing

The AMA believes that genomic testing and research are critical to the future of medicine, and that protecting equitable and discrimination-free access to genomic testing for all Australians is paramount.

New developments in genetic and genomic testing have the capacity to rapidly transform healthcare in Australia, potentially providing more cost-effective treatments and improving patient outcomes; for example, by improving diagnostic accuracy for many conditions, allowing doctors to develop more patient-specific preventive and targeted interventions and allowing patients and their family members to identify both risks and relevant interventions to prevent or reduce the morbidity of a heritable condition.

Attendant with the benefits of genetic testing comes the possibility of genetic discrimination where an individual, their family members or community consider they are being treated unjustly or unfairly by a third party (such as a life insurer or employer) based on their real or perceived genetic status.

#### Genetic discrimination in life insurance

In Australia, genetic discrimination in life insurance is shown to be a clear barrier for many people to undertake clinically indicated genetic testing and to participate in genetic and genomic research for the benefit of future populations. The *2023 Australian Genetics & Life Insurance Moratorium: Monitoring the Effectiveness & Response (A-GLIMMER) Project*<sup>i</sup> comprehensively demonstrated that the use of genetic information by life insurers can lead to discrimination. This research showed that fears of insurance discrimination deters many at-risk people from having potentially life-saving genetic testing that could match them to tailored interventions and treatments, and prevents them from participation in genetic and genomic research.

Currently in Australia, life insurers are able to request and use genetic testing results to inform their life insurance underwriting, in addition to the requirement for disclosure of hereditary conditions in the insuree's family. As of 1 July 2023, the Moratorium on Genetic Tests in Life Insurance contained in Appendix A of the Council of Australian Life Insurers' (CALI) *Life Insurance Code of Practice*<sup>ii</sup> replaced the Financial Services Council's (FSC) *Standard 11: Moratorium on Genetic Tests in Life Insurance*.<sup>iii</sup> Similar to the previous FSC Standard 11, the CALI moratorium allows life insurance providers to ask for or use genetic test results if the total amount of cover in an application exceeds certain monetary thresholds. In addition, the CALI moratorium maintains the position that it does not require or encourage applicants to take a genetic test regardless of the amount of cover sought or disclose results of genetic tests taken as part of medical research where the applicant would not receive the results. The previous FSC moratorium applied for five years, however, the CALI moratorium is not set for a fixed timeframe and applies indefinitely until they give further notice following a review. Effectively, this removes any certainty for consumers about the moratorium's ongoing protections (limited as they are).

The A-GLIMMER Project's extensive research findings clearly demonstrated that the FSC Moratorium – either in its previous form or as now included in the current Life Insurance Code of Conduct – is inadequate to address and prevent current and future genetic discrimination in life insurance.

The Report indicates that industry self-regulation is not an effective regulatory model to address genetic discrimination in relation to life insurance and recommends the moratorium should be replaced with a legislative model of prohibition.

### Regulatory options

The AMA agrees with this position and notes the regulatory options proposed in the Consultation Paper; namely:

**Option 1: No Government intervention:** *Under this option no action would be taken by the Government. Instead, the use of genetic testing results by life insurers would continue to be governed by both the Disability Discrimination Act 1992, and the Life Insurance Code of Practice.*

**Option 2: Legislating a ban:** *Under this option, the Government would legislate a total or partial prohibition on the use of adverse genetic testing results by life insurers. Under a total ban, life insurers would be prohibited from requesting or utilising any adverse genetic testing results to inform their underwriting calculations.*

**Option 3: Legislating a financial limit:** *This option proposes to legislate a financial limit, below which insurers cannot request or utilise adverse genetic testing results in their underwriting. This result broadly reflects the current limitations on the use of adverse genetic testing results by life insurers, as detailed in the Life Insurance Code of Practice. The financial limit may apply to the total cover held by an applicant (in line with Life Insurance Code of Practice), or be restricted to the cover sought under each individual application.*

The AMA strongly advocates that genetic discrimination must be prohibited. In noting the findings and recommendations of the A-Glimmer Report, the AMA supports Option 2 as the most effective option for eliminating genetic discrimination in the life insurance industry. Further, within Option 2, the AMA strongly advocates for a total ban on the use of adverse genetic test results, without financial limits or exclusions.

Considering the potential health benefits of genetic and genomic advances, genetic testing should be incorporated into everyday healthcare. For this to happen, however, the wider community must feel safe and confident that their genetic test results will not result in genetic discrimination. The AMA believes that a total ban is the only way to achieve this safety for the community, and that a partial ban would continue to provide uncertainty and deter patients from having genetic testing and participating in genomic research. It should be noted that, similar to the position taken in countries such as Canada, the prohibition on the use of adverse genetic results (those used to decline cover or apply penalties, conditions or exclusions on applicants' cover) should not affect an individual's ability to voluntarily disclose a negative test result (that is, one that shows they do not carry a familial genetic variant).

In its legislation, the government should also consider incorporating a prohibition on insurers requiring or encouraging consumers to take a genetic test. This would ensure that this aspect of the CALI moratorium is maintained and is consistent with the approach taken in the Canadian *Genetic Non-Discrimination Act*.<sup>iv</sup>

### AMA position statement on genetic testing and genomics in medicine

The AMA's *Position Statement on Genetic Testing and Genomics in Medicine 2020*<sup>v</sup> outlines a range of policy positions to reduce and eliminate genetic discrimination. For example, unless required by law, there should be no compulsion or coercion of any person to undertake a genetic test and a patient's genetic status should never be used to limit their access to medical care. In general, genetic information acquired in the context of the doctor-patient relationship should not be disclosed to a third party without the patient's specific and, where possible, written consent. This not only includes genetic test results but also whether a person has undertaken a genetic test or sought genetic counselling.

The AMA strongly advocates a national approach to the provision and regulation of genetic testing to ensure equitable and efficient access to safe, evidence-based genetic and genomic testing services throughout Australia.

### Contact

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<sup>i</sup> Jane Tiller, Penny Gleeson, Aideen McInerney-Leo, Louise Keogh, Kristen Nowak, Kristine BarlowStewart, Tiffany Boughtwood, Martin Delatycki, Ingrid Winship, Margaret Otlowski and Paul Lacaze. *The AGLIMMER (Australian Genetics & Life Insurance Moratorium: Monitoring the Effectiveness and Response) Project: Final Stakeholder Report (Monash University, 2023)*. <https://doi.org/10.26180/23564538>

<sup>ii</sup> Council of Australian Life Insurers. *Life Insurance Code of Practice*. December 2023. <https://cali.org.au/life-code/>

<sup>iii</sup> Financial Services Council. *FSC Standard No. 11: Moratorium on Genetic Tests in Life Insurance*. 21 June 2019. <https://www.fsc.org.au/resources-category/standard/1779-standard-11-moratorium-on-genetic-tests-in-life-insurance/file>

<sup>iv</sup> *Genetic Non-Discrimination Act* (S.C. 2017, c. 3). <https://laws-lois.justice.gc.ca/eng/acts/G-2.5/page-1.html>

<sup>v</sup> Australian Medical Association. *Position Statement. Genetic Testing and Genomics in Medicine 2020*. <https://www.ama.com.au/articles/genetic-testing-and-genomics-medicine-2020>