

Use of genetic testing results in life insurance underwriting

Submission to The Treasury, Australian Government

30 January 2024

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Who we are

The Australian Lawyers Alliance (ALA) is a national association of lawyers, academics and other professionals dedicated to protecting and promoting justice, freedom and the rights of the individual.

We estimate that our 1,500 members represent up to 200,000 people each year in Australia. We promote access to justice and equality before the law for all individuals regardless of their wealth, position, gender, age, race or religious belief.

The ALA is represented in every state and territory in Australia. More information about us is available on our website.¹

The ALA office is located on the land of the Gadigal people of the Eora Nation.

¹ www.lawyersalliance.com.au.

Submission from the Australian Lawyers Alliance

1. The ALA welcomes the opportunity to have input to The Treasury on the use of genetic testing results in life insurance underwriting.
2. ALA members are concerned about the demonstrated impact of genetic testing results on life insurance options – including life cover, total and permanent disability insurance, trauma insurance, and income protection insurance – for those Australians who have undertaken that genetic testing.
3. Genetic testing is undertaken frequently across Australia every year, with an estimated 1.5 million Australians undertaking genetic testing annually.² Genetic testing is being recommended in a variety of contexts within Australia’s healthcare system. For example, guidelines from the Royal Australian and New Zealand College of Obstetricians and Gynaecologists recommend the following:³

Information on carrier screening for other genetic conditions [beyond conditions such as thalassaemia that are screened for by standard haematology laboratory testing] should be offered to all women planning a pregnancy or in the first trimester of pregnancy. Options for carrier screening include screening with a panel for a limited selection of the most frequent conditions (e.g. cystic fibrosis, spinal muscular atrophy and fragile X syndrome³³) or screening with an expanded panel that contains many disorders.

4. **Given this scale, the ALA thus submits that the subsequent use of genetic testing results, including in determining life insurance coverage and the costs for that life insurance coverage, is an area of law and policy which must be urgently addressed.**
5. The ALA is concerned that the impact of genetic testing and the results thereof on life insurance cover options is discouraging Australians from undertaking that genetic testing. Further, as the Consultation Paper for this inquiry notes,⁴ the Parliamentary Joint Committee on Corporations and Financial Services noted in 2018 that “the use of genetic tests in underwriting life insurance was adversely impacting participation in health research projects

² Dana Morse, ‘Genetic testing saves lives but can lead to discrimination when it comes to life insurance’, *ABC News* (online, 23 January 2023) <www.abc.net.au/news/2024-01-23/genetic-testing-can-lead-to-discrimination-in-life-insurance/103379334>.

³ Cited in: Dr Ken Maclean, ‘Genomics: A new frontier in medical negligence’, *Precedent* (174, January/February 2023) 20.

⁴ See: The Treasury, Australian Government, *Use of genetic testing results in life insurance underwriting* (Consultation Paper, November 2023) 4.

involving genetic testing”. This compromises the short- and long-term health outcomes for those Australians who undertake genetic testing and also health outcomes for the wider Australian public.

- a. **The ALA submits that this should be of significant concern to the Federal Government and a priority for reform.**
6. The unfairness inherent in the status quo is of great concern to ALA members. Australians who are undertaking genetic testing are doing so to understand the health risks which may apply to them and usually to also take preventative measures to avoid facing serious health conditions in the future.
 - a. The ALA contends that it is distinctly unfair to financially penalise – through what life insurance options and coverage they do or do not have and/or how much they need to pay for that insurance – those Australians who have made conscientious and responsible decisions.
 7. **The ALA supports regulation and legislative reform in this space. That includes amendments to section 46 of the *Disability Discrimination Act 1992 (Cth)*, such that it would be classified as discrimination if insurers offering life insurance policies amend coverage options or refuse to cover someone altogether based on genetic testing results.**

Conclusion

8. The Australian Lawyers Alliance (ALA) welcomes the opportunity to have input to The Treasury on the use of genetic testing results in life insurance underwriting.
9. The ALA is available to provide further assistance to The Treasury on the issues raised in this submission.



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