

Mr Danial Gaudry
Insurance Unit, Financial System Division
Treasury
Langton Cres
Parkes ACT 2600

By email: genetictestinglifeinsurance@treasury.gov.au

31 January 2024

Dear Mr Gaudry,

Use of genetic testing results in life insurance underwriting

The Council of Australian Life Insurers (CALI) is the trusted voice of life insurance in Australia. We support Australians to make informed choices about their future and advocate for national policy settings that expand their access to the life insurance protection that suits them when they need it most over their lifetime.

Life insurers help millions of Australians to live in a healthy, confident and secure way. Our members want to support their customers to proactively manage their health and reduce potential health risks. We recognise that genetic testing plays an important role in empowering people to do this in a preventative and personalised way. This is why we support a ban on life insurers using genetic tests in underwriting, with some limited Government approved exclusions to guarantee fairness for all insured Australians.

Life insurance products and services give people peace of mind when they are making important decisions and provide a financial safety net during life's biggest challenges. Life insurance can reduce a person's reliance on social welfare support and disability schemes, or complement those schemes to help them maintain their lifestyle and financial wellbeing. Life insurers are able to provide this critical financial support by pooling the risks and costs associated with serious illness and injury or death. The underwriting process, which assesses an individual's risk factors, is crucial for insurers to fairly manage premiums across the pool and to continue to offer affordable and accessible life insurance products and services to Australians.

Approximately 15 million people are protected by life insurance in Australia¹. The majority of these Australians obtained their cover without ever having to disclose the results of a genetic test. In more than 80 per cent of cases where a person discloses a genetic test there is no impact on the final underwriting decision. In the remaining cases, it more commonly works in the person's favour by indicating a reduced risk of a certain genetic condition. Our members want to provide protection and certainty to as many Australians as possible. Declining to offer cover is rare and always a last resort for life insurers.

Australia's life insurers have never, and would never, require someone to take a genetic test for underwriting. The Life Insurance Code of Practice (Life Code) clearly states that regardless of the amount of cover, life insurers will not ask or encourage people to take a genetic test as part of their application, or for underwriting². Once a person has obtained life insurance, any future genetic tests do not need to be disclosed to their insurer and will not affect their level of cover or premiums.

As the leading voice of life insurers, we consistently and carefully consider how our industry can continue to meet the evolving expectations of the people we serve. With the uptake of genetic tests becoming more prevalent in the community, we support strict regulation of their use in underwriting to ensure people are not deterred from taking such tests to proactively manage their health.

¹ FSC / NMG, Australia's Life Underinsurance Gap: Research Report, 2022.

² A.2(b)(i), Life Insurance Code of Practice 2023.

Genetic testing technology will rapidly improve over time increasing the predictive certainty of tests and making them vastly more accessible and affordable. The expected trend is for testing to be undertaken by an increasing proportion of Australians.³ The long-term impacts of restricting the use of genetic testing results by life insurers both on the life insurance market and the premiums that insured Australians pay is uncertain and may take many years to fully emerge.

In the underwriting process, each person is priced according to their individual risks. This creates the potential for adverse selection, which is when a person has health information that the insurer does not have and as a result their purchasing behaviour changes. In the insurance context, this means the person is more likely to purchase insurance, insure themselves for larger amounts and to claim but because the insurer is unaware of this, it cannot appropriately price the person's individual risk. If this was to occur, it would increase the level of risk in insurance pools and likely impact the accessibility and affordability of life insurance products. We believe that the risk of adverse selection cannot be dismissed and should be considered in the design of the regulatory model.

CALI supports strict regulation on life insurers using genetic tests in underwriting with limited exclusions approved by the Government. To guarantee fairness for all insured Australians, features should include:

- A flexible approach that provides certainty to people, is reviewed on a regular basis and, if necessary, revised over time to take into account advances in genetic and genomic science and evidence of the impact on the life insurance market and premiums;
- A prohibition on life insurers using predictive genetic tests in life insurance underwriting unless permitted by Government regulation, which would include only allowing permitted tests to be used above prescribed financial limits (similar to the United Kingdom Code on Genetic Testing and Life Insurance). We propose that the Federal Government provide criteria to assess whether a new or specific predictive genetic test should be permitted under the regulations;
- Maintaining the principle that insurers can ask people to disclose, and use as part of the underwriting process, any diagnosis of a condition, even if the diagnosis resulted directly or indirectly from a genetic test (i.e. treats diagnostic genetic tests the same way as other diagnostic medical tests such as a blood test or an ECG, which are already ordinarily disclosable for the purposes of underwriting);
- Allowing a person to voluntarily disclose a genetic test, and permitting an insurer to take it into account if it is to that person's benefit; and
- Enforcement by the Australian Securities and Investments Commission (ASIC) as the key conduct regulator for the life insurance industry, with the Australian Human Rights Commission (AHRC) continuing to be responsible for ensuring and enforcing compliance with the Disability Discrimination Act 1992 (DDA).

More detail on CALI's position is set out in Attachment A.

I look forward to continued engagement as the Government considers this important reform. Please contact Michael Johnston, General Manager, Policy at michael.johnston@cali.org.au for further information.

Kind regards



Christine Cupitt
Chief Executive Officer

³ <https://www.theaustralian.com.au/nation/critically-ill-children-to-become-beneficiaries-of-advances-in-dna-sequencing/news-story/949fa6938cf9d95b02e2bf629c6f9bf8>

Attachment A

The existing use of genetic test results in life insurance underwriting

Under the Life Code, life insurers can currently only ask for and use genetic testing in the individual underwriting process when:

- assessing applications for new life insurance above set financial limits; or
- when increases in insurance cover above set financial limits are requested.

The key commitments on genetic testing already set out in the Life Code ensure that:

- An insurer will never ask or encourage a person to get a genetic test as part of applying for life insurance;
- Up to (and including) the financial limits set in the Moratorium, a life insurance company must not use a person's genetic test results unless they choose to declare them;
- Over the financial limits, a life insurance company can ask a person for genetic test results but must not use them unless the test is relevant to the cover applied for, in accordance with the DDA; and
- Insurers may take into account favourable genetic tests if the person chooses to disclose them (for example, to show that they are not carrying a gene pattern associated with developing a hereditary illness) and any evidence-based preventative treatment they have undertaken that reduces their possibility of developing a hereditary illness.

Life insurance is a product that enables people to pool the risks and costs associated with serious illness and injury or death. It is risk rated, meaning that a life insurer determines which risks it is prepared to cover, the price it charges and the terms on which its products are offered. This differs to community rated insurance, such as private health insurance, where insurers must accept all applicants regardless of age or health issues and offer the same price and terms. The Government uses various incentives to encourage people in good or average health to join the pool. However, to support this model these people will be paying the same cost as those in below average health, despite the fact that they are less likely to claim.

The underwriting process is critical for insurers to manage risks across all the people insured to ensure the costs of contributing (premiums) are kept sustainable and are fairly managed across the insurance pool. Each person's unique risk of illness, injury and death depends on a range of factors that may be taken into account in the underwriting process. This will include their current and historical health including, where permitted, the results of genetic tests, as well as any risks associated with other factors – for example, their age, sex, family medical history, occupation, pastimes and lifestyle choices (such as whether or not they smoke). Insurers are permitted to consider these individual factors, which are indicators of the likelihood of claiming, provided that an evidence base shows that they have relevance to the cover applied for, in line with the DDA.

Where a previously taken genetic test is disclosed, it will be considered as part of the underwriting process alongside any other unique risk factors to determine whether the amount and type of cover is within the life insurer's risk appetite and to set the premium amount that best reflects the person's risk of illness, injury and death.

Life insurers want to provide cover to as many people as possible and will seek to manage increased risks and affordability concerns through modifications to terms rather than refusing to provide cover at all. Declining to offer cover is rare and is always a last resort.

Industry data shows that in the majority of cases when a genetic test has been disclosed it has had no impact on a person's application. In 2022, CALI members reported that out of more than 200,000 underwriting decisions there were only 1,674 instances where a genetic test was disclosed. Of those:

- In 80.8 per cent of cases (1,353), the genetic test had no impact on the final decision;
- In 13.8 per cent of cases (231), the genetic test resulted in a positive outcome for the customer; and
- In 5.3 per cent of cases (90), the genetic test resulted in an adverse outcome for the customer (but in most cases insurance was still offered with a premium loading or policy exclusion rather than declining to offer cover).

The impact of restricting the use of genetic tests

Restricting the information that life insurers can use in the underwriting process increases the risk of adverse selection, which is likely to impact the accessibility and affordability of life insurance products.

We believe that the risk of adverse selection is real and should not be dismissed in the Government's considerations. The longer-term impact on life insurance of restricting access to genetic testing in underwriting is uncertain and claims will typically take many years to emerge following application. This risk will increase as genetic testing becomes more common and as significant new technology and more accurate tests for specific conditions are developed. It is critical that any regulatory model is future proofed through a flexible approach that includes regular review to ensure it keeps pace with emerging information and the changing behaviours of Australians.

It is difficult to obtain reliable empirical data on the impact of restricting life insurers' ability to use genetic tests, particularly due to the relatively short period of time that genetic tests have been available. This should be considered against the length of time insurance contracts are held (sometimes more than 30 years) and data limitations both on technologies for reporting and the sensitive and personal nature of genetic testing. However, there is local and international evidence of the risk. For example:

- US studies have found that a positive genetic test may change purchasing behaviour and, in one study, it was found that people were five times more likely to purchase long-term care insurance after a positive test for Huntington's disease.⁴
- A Swiss Re study found that Australians receiving a high-risk medical genetic test result are twice as likely to take out life insurance than average and low risk consumers⁵; and
- In Canada, the Canadian Privacy Commissioner commissioned several actuarial reports on the likely impact of a ban on using genetic test results in life insurance underwriting.⁶ While these concluded that a ban would have negligible impact at the time, they did note the long-term implications were uncertain.

Importantly, we also expect the increased use of genetic testing within the community will have positive impacts for life insurers and the broader community. It may lead people to take steps to reduce their risk of developing a health condition or proactively manage a health condition they otherwise would not have known they had. Data from genetic tests could also enable insurers to better characterise the individual and population-level risk of morbidity and mortality, and reduce the overall cost of insurance for the population as a result.

⁴ Oster E, Shoulson I, Quaid K, Dorsey E. Genetic Adverse Selection: Evidence from Long-Term Care Insurance and Huntington Disease, National Bureau of Economic Research, 2009

⁵ https://www.swissre.com/dam/jcr:4d7cf5dd-44a1-44ec-9245-636304418c5c/Genetic_testing_publication.pdf

⁶ Hoy M, Durnin M. The Potential Economic Impact of a Ban on the Use of Genetic Information for Life and Health Insurance. Office of the Privacy Commissioner of Canada 2012; Macdonald A. The actuarial relevance of genetic information in the life and health insurance context. Ottawa: Office of the Privacy Commissioner; 2011.

Proposed regulatory approach

The life insurance industry supports a ban on the use of genetic testing in underwriting with limited exclusions approved by the Government to guarantee fairness for all insured Australians. Strict Government regulation should ensure no one is deterred from taking genetic tests to proactively manage their health and reduce potential health risks.

We believe this can be achieved through an approach that would have similar features to the United Kingdom (UK) Code on Genetic Testing and Life Insurance. In particular, the ability to provide approvals, now or in the future, for the use of predictive genetic tests that meet relevant criteria. Under this model life insurers would not be able to use predictive genetic tests in underwriting, except in very limited cases where a specific test has been assessed and approved by the Federal Government. We believe the UK Code is operating effectively and has broad support from stakeholders.

We propose strict regulation with the following features:

- A flexible approach that provides certainty to people, is reviewed on a regular basis and, if necessary, revised over time to take into account advances in genetic and genomic science and evidence of the impact on the life insurance market and premiums;
- A prohibition on life insurers using predictive genetic tests in life insurance underwriting unless permitted by Government regulation, which would include only allowing permitted tests to be used above prescribed financial limits. We propose that the Federal Government provide criteria to assess whether a new or specific predictive genetic test should be permitted under the regulations;
- Maintaining the principle that insurers can ask people to disclose, and use as part of the underwriting process, any diagnosis of a condition, even if the diagnosis resulted directly or indirectly from a genetic test (i.e. treats diagnostic genetic tests the same way as other diagnostic medical tests such as a blood test or an ECG, which are already ordinarily disclosable for the purposes of underwriting);
- Allowing a person to voluntarily disclose a genetic test, and permitting an insurer to take it into account if it is to that person's benefit; and
- Enforcement by the ASIC as the key conduct regulator for the life insurance industry, with the AHRC continuing to be responsible for ensuring and enforcing compliance with the DDA.

Further details on the rationale for these features are set out below.

Definition of a genetic test

It is important that any regulatory model includes a clear definition of a genetic test. This will ensure the regulation applies to genetic tests and achieves the objective that people should not be deterred from taking a genetic test due to concerns about life insurance, without further restricting insurers' ability to underwrite.

The Life Code currently defines a genetic test as “[a] test that examines a person's chromosomes or DNA. It does not include any non-genetic medical tests (such as blood or urine tests for proteins, cholesterol, liver function or diabetes), even if they are to test for a condition that may have a genetic origin”. We believe this is an appropriate definition.

Disclosure of diagnosed conditions

It is essential that Government regulation does not undermine the principle that where a person has been diagnosed with a condition, they should disclose that when making an application for life insurance, regardless of how the condition has been diagnosed. In these circumstances, insurers should be able to ask for and use the

genetic test in underwriting to assess the risk they are being asked to insure. This would mean diagnostic genetic tests would be treated the same as any other diagnostic medical test, such as a blood test or an ECG, which are typically initiated by the treating doctor.

If people were not required to disclose genetic tests that have helped to diagnose a condition, it would result in a situation where someone who is diagnosed from a non-genetic test needs to disclose that condition but a person diagnosed from a genetic test does not. This would create inequality in the risk pool and unfairly benefit those people who receive a diagnosis via a genetic test. The underwriting process relies on people disclosing any diagnosed conditions and is crucial for insurers to fairly manage premiums and to continue to offer affordable and accessible life insurance products and services in Australia.

CALI believes further consideration should be given to the distinction between diagnostic and predictive tests in any regulation. CALI suggests it may be appropriate for any definition to be based on the reason a person has undertaken the genetic testing. For example, if the testing was undertaken because a person is exhibiting symptoms of a possible condition then that would be considered diagnostic, whereas a test taken due to family medical history only (with no personal history of symptoms) would be considered predictive.

Prescribed list of predictive tests

The UK and several other jurisdictions have adopted similar restrictions on the use of genetic test results by life insurers in underwriting and sought to manage the risk of adverse selection by permitting insurers to use prescribed predictive tests subject to financial thresholds. In the UK, the current list of approved relevant predictive genetic tests only includes a predictive genetic test for Huntington's disease, in applications for death cover which totals more than the financial limit of £500,000.

We propose a similar framework be adopted in Australia to permit specific predictive tests (to be determined) to be used by life insurers in underwriting. Insurers would only be permitted to use a test taken after the date the relevant test is added to the regulated list.

Any regulation should include a mechanism to do this, as well as criteria to be considered when determining whether a test should be approved for use by insurers. We note the UdiK Government is currently consulting on a framework including four overarching questions to consider when determining if a predictive genetic test should be included on the approved list. The factors include:

- How useful is the genetic test for characterising the risk of developing a condition?
- How many people take the test?
- What is the impact of the condition in terms of the length and quality of life of people who develop it?
- What is the potential for reducing the risk of developing the condition and managing its effects if it develops?

Further detail on how these proposed questions would be applied is included in the UK Department of Health and Social Care's call for evidence.⁷

We propose that any regulatory model introduced by the Federal Government should be supported by a Government education campaign including simple, easy to understand fact sheets available to anyone undertaking a genetic test to avoid any misinformation in the community. Life insurers feel it is critical that Australians receive accurate information provided by the Government, to ensure people are not deterred from

⁷ <https://www.gov.uk/government/calls-for-evidence/code-on-genetic-testing-and-insurance-call-for-evidence/code-on-genetic-testing-and-insurance-call-for-evidence>

undertaking genetic testing. We would like to work with the Government and other stakeholders to develop this material.

Accurate and independent information, together with a clear and specific list of tests (if any) that may be considered by life insurers should address any lingering uncertainty that could deter people from taking genetic tests to proactively manage their health.

Financial limits

We propose that, as in other international jurisdictions, where insurers are permitted to use a predictive genetic test, this also be subject to financial limits. Insurers would only be able to use approved tests where the total amount of cover to be held is over the prescribed financial limits. The total amount of cover would include the cover being applied for and any existing cover with all insurers. CALI proposes that the financial limits in the regulation be set at a higher level than those currently set in the Moratorium.

In addition to the UK, several other jurisdictions have financial limits as a feature of their regulation of the use of genetic testing in life insurance underwriting. The following table shows the financial limits converted into Australian dollars.

Country	Death insurance limit	TPD insurance limit	Income Protection insurance limit (per annum)	Critical illness insurance limit
UK	965,000	n/a	58,000	579,000
Singapore	2,497,000	2,497,000	136,000	568,000
Germany	494,000	n/a	49,000	n/a
Switzerland	705,000	n/a	71,000	n/a
Netherlands	263,000	n/a	n/a	n/a
Sweden	199,000	n/a	27,000	n/a

We propose that the limits in Australian regulation should be set at the following aggregate cover levels:

- Death - \$1,000,000
- Total and Permanent Disability - \$1,000,000
- Trauma - \$250,000
- Income Protection - \$8,000 per month (\$96,000 per annum)

Based on data from CALI members for the 2022-23 financial year, more than 80 per cent of new underwritten policies in each product would be under these limits. ASIC⁸ recently reported that of the approximately 15 million Australians with accumulation-phase superannuation accounts, about 8 million have some form of insurance through superannuation. Roughly 71 per cent of accounts with insurance have the default insurance cover amount automatically provided by the superannuation trustee and are not underwritten. If this is also taken into account, the proportion of new cover below the financial limits would be much higher. These proposed limits would bring Australia's financial limits broadly in line with the UK.

⁸ [Report REP 760 Insurance in superannuation: Industry progress on delivering better outcomes for members \(asic.gov.au\)](https://asic.gov.au)

Voluntary disclosure of genetic test results

Life insurers want to support Australians to live their most healthy, confident and secure lives. We strongly recommend that any regulation should ensure that a person is always able to voluntarily disclose a predictive genetic test if it may be beneficial for the application for insurance, for example if it shows they do not carry the gene for a condition that runs in their family. We propose that if a predictive genetic test result is given to an insurer by the applicant, either accidentally or voluntarily, an insurer should be able to take it into account if it is to the applicant's benefit. If the result is unfavourable to the applicant, the insurer would need to ignore the result unless it is on the approved list of exceptions as outlined above.

Review

Regardless of the final design of regulation, we believe it needs to be reviewed on a regular basis to ensure it keeps pace as genetic science develops and the take up of genetic testing increases. This would help ensure there are no adverse consequences for Australians as a result of unforeseen impacts on the insurance market. It is critical to the nation's safety net that Australians continue to have access to affordable life insurance protection into the future.

Legislated reviews of new regulations are common and important to assess the operation of legislation, whether it is meeting its objectives and to monitor and respond to any unintended outcomes.

CALI proposes that a review should be built into the legislation and take place five years after regulation commences. The review should consider:

- How effective regulation has been in meeting the objective of not discouraging people from undertaking genetic testing
- Advances in medical science and the use and availability of genetic tests, including population level screening
- Evidence of adverse selection
- Evidence of changes to risk management and pricing and impacts to accessibility, affordability and sustainability.

To support the review, it will be important to improve the availability of high-quality data on the impacts on Australians and the insurance industry. We want to work with the Government to consider how this can be achieved.

Enforcement model

We agree with Treasury's view that ASIC has extensive experience regulating the conduct of life insurers and familiarity with their operations. For this reason we believe ASIC is the most appropriate regulator in this instance. Enforcement of this regulation by ASIC should be limited to considering whether an insurer collected and/or used genetic testing when they were not permitted to do so. Where insurers are permitted to use genetic tests, the AHRC would continue to be responsible for ensuring and enforcing compliance with the DDA.

Under this enforcement model, people would also have the ability to make a complaint to the Australian Financial Complaints Authority (AFCA). Where AFCA or ASIC are considering an issue, it should be clear in regulation that the enforcement or determination should relate to breaches of requirements not to collect or use a genetic test, as opposed to a review of the underwriting decision more generally. Our recommendation is that in the event that AFCA determines an insurer has used a genetic test contrary to the regulation, the appropriate outcome should be that the insurer is required to reconsider the underwriting decision without taking into account the

genetic test. We also recommend that AFCA develop, consult on, and publish a clear document outlining their approach to decision making.

Background: The Genetic Testing Moratorium

In 2019, the life insurance industry through the Financial Services Council (FSC) implemented the Genetic Testing Moratorium to limit how insurers would use genetic tests. The objective of the Moratorium was to ensure Australians could access a suitable level of life insurance, including through their superannuation, without being asked about the result of a previously taken genetic test.

Overall, we believe that the Moratorium has met its objectives according to available data:

- As noted above, the overwhelming majority of people experience no impact on an underwriting decision as a result of disclosing a genetic test;
- Health professionals reported meaningful improvements in people's willingness to take a genetic test as a result of the Moratorium. The A-GLIMMER report found that 61 per cent of health professionals surveyed said people never or rarely declined genetic tests due to concerns about life insurance before the introduction of the Moratorium (with another 38 per cent saying they sometimes saw it). After the introduction of the Moratorium that increased to 82 per cent saying never or rarely after the introduction of the Moratorium (with the remaining 18 per cent saying they sometimes see it); and
- Awareness of the Moratorium among health professionals is high. For example, A-GLIMMER found 86 per cent of health professionals surveyed were aware of the Moratorium⁹, and 66 per cent of genomic researchers were aware of the Moratorium, with 60 per cent feeling they had sufficient knowledge about potential insurance implications.¹⁰

We understand that some concerns have been raised with Treasury about industry compliance with the Moratorium. CALI is not aware of any breaches of the Moratorium. No specific examples have been provided and we are not aware of any complaints that have been made to the Life Code Compliance Committee or AFCA.

However, we note data provided in the A-GLIMMER report shows support for government regulation across all the stakeholder groups surveyed, and anecdotal concerns that people are not getting genetic tests or participating in genetic and genomic research due to concerns about life insurance.

⁹ A-GLIMMER Final Report, p 16

¹⁰ A-GLIMMER Final Report, p 23