



# Use of genetic testing results in life insurance underwriting

Consultation paper

November 2023

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# Consultation Process

## Request for feedback and comments

Interested stakeholders are invited to comment on the issues raised in this paper by 31 January 2024.

Submissions may be lodged electronically or by post, however electronic lodgement is preferred via email to [genetictestinglifeinsurance@treasury.gov.au](mailto:genetictestinglifeinsurance@treasury.gov.au). For accessibility reasons, please submit responses via email in a Word, RTF or PDF format.

Submissions will be shared with other Commonwealth agencies where necessary for the purposes of this review. All information (including name and address details) contained in submissions may be made publicly available on the Australian Treasury website unless you indicate that you would like all or part of your submission to remain in confidence. Automatically generated confidentiality statements in emails are not sufficient for this purpose.

If you would like only part of your submission to remain confidential, please provide this information clearly marked as such in a separate attachment. Legal requirements, such as those imposed by the *Freedom of Information Act 1982*, may affect the confidentiality of your submission.

### Closing date for submissions: 31 January 2024

Email	<a href="mailto:genetictestinglifeinsurance@treasury.gov.au">genetictestinglifeinsurance@treasury.gov.au</a>
Mail	Insurance Unit Financial System Division The Treasury Langton Crescent PARKES ACT 2600
Enquiries	Enquiries can be initially directed to <a href="mailto:genetictestinglifeinsurance@treasury.gov.au">genetictestinglifeinsurance@treasury.gov.au</a>

The principles outlined in this paper have not received Government approval and are not yet law. As a consequence, this paper is merely a guide as to how the principles might operate.

# Use of genetic testing results in life insurance underwriting

## Introduction

Over recent years, the use of genetic testing results in life insurance has been the subject of significant public debate.

In 2018, a report by the Parliamentary Joint Committee on Corporations and Financial Services expressed concerns that the use of genetic tests in underwriting life insurance was adversely impacting participation in health research projects involving genetic testing.

In 2019, Australia's life insurance industry introduced a partial moratorium on the requirement to disclose genetic test results. The Moratorium was introduced in response to concerns that individuals would not undertake genetic testing for fear of negatively impacting their ability to obtain affordable life insurance.

In June 2020, a \$500,000 grant was awarded to researchers at Monash University to monitor the impact of the Moratorium, its effects on the uptake of genetic testing, and its impacts on genetic discrimination. The subsequent 2023 Australian Genetics & Life Insurance Moratorium: Monitoring the Effectiveness & Response (A-GLIMMER) report documented stakeholder concerns and experiences with genetic test results and life insurance. The report found that the existing moratorium continues to discourage consumers from participating in both established clinical genetic testing, which may identify a need for potentially life-saving treatment, and medical research involving genetic testing.

Addressing these concerns requires review of the regulatory framework for the use of genetic testing in life insurance underwriting. This consultation paper seeks feedback on both the impacts of life insurers using genetic test results in underwriting on genetic testing and research, as well as a range of potential policy responses.

## Life insurance can be individually risk-rated

Life insurance is a mechanism for consumers to aggregate and distribute the costs associated with mortality and morbidity risks. Pooling risk benefits the insured by spreading the significant costs associated with death, illness and injury amongst all the people insured.

There are four main types of life risk insurance products in Australia:

1. Life cover (also known as term life insurance or death cover), which pays a lump sum in the event of the death of the policy holder.
2. Total and permanent disability (TPD) insurance, which pays a lump sum to help with rehabilitation and living costs if the policy holder becomes totally and permanently disabled because of illness or injury.
3. Trauma insurance, which pays a lump sum amount if the policy holder suffers a critical illness or serious injury (e.g., cancer, a heart condition, major head injury or stroke, but not mental health conditions).

4. Income protection insurance (often referred to as individual disability income insurance or IDII), which pays a portion of the policy holders' income if they can't work due to illness or injury.

Life Insurance, like insurance products other than health insurance, is 'risk-rated' not 'community-rated'. Risk-rating gives effect to the principle that insurance premiums should reflect individual risk. By contrast, community rating is the basis of Australia's health insurance system. The *Private Health Insurance Act 2007* requires private health insurers to offer community-rated health insurance, which means all policy holders pay the same premiums for the same policy, regardless of their gender, age or health status. The results of an individual's genetic tests therefore have no direct bearing on their access to or the price of a complying health insurance product.

Underwriting is a process where life insurers individually assess a person's unique risk of illness, injury and death to determine the level of risk to be covered and enable the accurate pricing of premiums. This process ensures that the cost of the cover is proportionate to the risks that the individual concerned presents. Key factors taken into account during the underwriting process include an applicant's personal medical history, age, smoker status, occupation, family history, lifestyle and pursuits.

In Australia, default insurance provided through a superannuation fund or employer is not individually underwritten. However, voluntary insurance, including life insurance purchased from an insurer, via a financial adviser or a voluntary increase in group superannuation will generally be individually underwritten.

As life insurance is a guaranteed renewable product, once a policy has been underwritten and commenced, the life insurer cannot change or cancel a person's cover, provided they pay all future premiums when due. However, life insurers can generally increase premiums across a risk pool if claims are higher than was initially anticipated.

## Genetic testing can indicate potential for individual health risks


Genetic testing investigates a person's genetic variants and changes, some of which may contribute to the risk of developing a health condition<sup>1</sup>. Genetic variants that are disease-causing can be inherited (called germline variants), acquired through the lifespan, or can be found in cancers (called somatic variants). There are over 5000 conditions known to be caused by germline variants, including some conditions which predispose individuals to a higher risk for certain cancers.

The results from genetic testing can be used to identify the genetic origin of a disorder, diagnose rare inherited diseases more efficiently, or predict both the risk of individuals developing a genetic condition and their need for, or likely response to, specific treatments. Medical research involving genetic testing can be used to identify new links between genetic variants and health conditions, as well as develop new treatment methods. Consequently, there are significant medical and public health benefits associated with the use of genetic testing by individuals, as well as ongoing medical research involving genetic testing.

There are various types of genetic test purposes, including diagnostic, predictive (of risk for future disease) and presymptomatic testing.

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<sup>1</sup> A genetic test investigates a person's genetic variants or changes, while a genomic test investigates larger amounts of an individual's genetic sequence or their whole genome. For the purposes of this paper, references to genetic testing will be taken to include genomic testing.



In many cases, genetic testing is used to confirm a diagnosis when a particular condition is suspected based on current physical signs and symptoms. Clinical diagnostic genetic testing is used to identify or rule out a specific genetic or chromosomal condition in an individual with features that may have either a genetic or non-genetic origin. The results of a diagnostic genetic test can also inform the individual's prognosis and influence a person's choices about health care and the management of their disorder. Where a person is experiencing symptoms of a diagnosed condition, they may be required to disclose this to the life insurer, regardless of whether that diagnosis is the result of a genetic test or other medical test.

Predictive and presymptomatic testing is used to detect gene variants associated with heritable disorders that appear after birth, often later in life, but are not clinically detectable at the time of testing. Predictive testing of the general, currently unaffected population can identify variants that increase a person's risk of a developing disorder with a genetic basis. Presymptomatic genetic testing can determine whether or not a person is at risk of a condition that may have already been identified in other family members, or is likely to develop signs and symptoms of the condition in the future. The results of predictive and presymptomatic hereditary disease testing can differentiate between pre-symptomatic genetic diagnosis (which may result in future disease), asymptomatic carrier status (with the majority having no future adverse personal health consequence) or non-carrier status. Depending on the condition identified, a genetic diagnosis may not always result in clinical signs and the degree of severity may vary among those who do develop disease. This variability in risk may not be readily predicted from the genetic test findings alone.

Genetic testing can be used for a range of other purposes, including diagnostic prenatal testing where a fetus is at risk for a heritable genetic condition, newborn screening to determine if a baby has one of a selected number of severe heritable genetic conditions that requires early management, cascade testing of family members once a heritable genetic condition is identified in a family member and carrier testing to determine risk of the condition in offspring. In the context of life insurance, the most relevant uses of clinical genetic testing are for diagnostic, predictive and pre-symptomatic testing, as well as for research purposes, where a genetic condition or risk for a genetic condition is identified in an individual.

Recent Government initiatives in genetic testing and research include a \$500.1 million investment to the Genomics Health Futures Mission, and a \$28.1 million investment to develop a new government body to guide the future translation of genomic research and trials into clinical practice.

## Life insurers can request genetic testing results

Under the *Insurance Contracts Act 1984*, consumers must take reasonable care not to make a misrepresentation to life insurers when entering into contracts, including failing to answer a question or providing an obviously incomplete or irrelevant answer to a question. Consumers have a responsibility to provide information requested by life insurers, including any genetic testing results. Life insurers can subsequently use this information, including, for example, when considering any offer to provide insurance to a consumer.

While the *Disability Discrimination Act 1992* makes discrimination on the grounds of disability (including a disability that may exist in the future because of a genetic predisposition) unlawful in many areas of public life, there are exceptions relating to the provision of insurance. Under section 46 of the *Disability Discrimination Act 1992*, discrimination in insurance and superannuation products (including life insurance) is permitted in the following circumstances:

- where the discrimination is based on actuarial or statistical data on which it is reasonable for the discriminator to rely; and the discrimination is reasonable having regard to the data and other relevant factors; or
- where no such actuarial or statistical data is available and cannot reasonably be obtained – the discrimination is reasonable having regard to any other relevant factors.

Consequently, provided the conditions above are satisfied, life insurers can request details regarding family medical history, and regularly use that information in the same manner. Life insurers are also able to request and use genetic testing results to inform their life insurance underwriting. Consumers can provide favourable genetic test results to life insurers, for example, to demonstrate that they are not at risk of developing certain health conditions despite previous family history.

Consumers who believe they have been unlawfully discriminated against because of a genetic diagnosis, or risk for a heritable genetic condition, can make a complaint to the Australian Human Rights Commission, which has the power to investigate and attempt to conciliate complaints of discrimination. If the conciliation is unsuccessful, in certain circumstances a complainant may commence legal proceedings in the Federal Court of Australia or the Federal Circuit and Family Court of Australia.

## Concerns about the impact on participation in medical research involving genetic testing

In 2016, the Parliamentary Joint Committee on Corporations and Financial Services conducted an inquiry into the life insurance industry. Part of the inquiry focused on use of genetic testing results in life insurance. In its final report, released in 2018, the Committee expressed concerns that the use of genetic tests in underwriting life insurance was adversely impacting the public's willingness to participate in health research projects that involved genetic testing. The Committee made a number of recommendations directed towards the Financial Services Council (FSC), the then peak industry body representing the life insurance sector. These included that the FSC:

- in consultation with the Australian Genetic Non-Discrimination Working Group, assess the consumer impact of imposing a moratorium on life insurers using predictive genetic information, unless the consumer provides genetic information to a life insurer to demonstrate that they are not at risk of developing a disease; and
- make any updates required to the relevant Standards to support the above recommendation.

The Committee further recommended that if the FSC and life insurers adopt a moratorium on the use of predictive genetic information as outlined above, that the Government continue to monitor developments in genetics and genetic testing to determine whether legislation or another form of regulation banning or limiting the use of genetic information by the life insurance industry is required.

## Moratorium on the use of genetic tests in life insurance

Following the inquiry, the FSC introduced a moratorium on the use of genetic testing in life insurance. The updated standard, known as FSC Standard 11: Moratorium on Genetic Tests in Life Insurance, came into force on 1 July 2019. The standard aimed to facilitate an efficient life insurance industry, while also recognising a social responsibility to not hinder the adoption of new medical technologies that could improve health outcomes.



Under the Moratorium, life insurers could only request or use the results of a genetic test if the total amount of cover a person would have – including both the cover being applied for and any existing individual and group insurance cover with any life insurers – was more than:

- \$500,000 of lump sum death cover
- \$500,000 of total permanent disability cover
- \$200,000 of trauma and/or critical illness cover
- \$4,000 a month of any combination of income protection, salary continuance or business expenses cover.

For example, under the Moratorium, a consumer with no existing insurance applying for \$300,000 worth of death cover would not be required to disclose any genetic testing results. Conversely, a consumer with \$300,000 worth of existing death cover, seeking to apply for an additional \$300,000 worth of cover (with either their existing or an alternative insurer), would be required to disclose any genetic testing results if asked.

These limits compare to APRA data that suggests that the average sum insured of individual policies, exclusive of any group cover, is:

- \$713,959 of lump sum death cover
- \$849,128 of total permanent disability cover
- \$207,414 of trauma and/or critical illness cover
- \$7,706 of disability income insurance.<sup>2</sup>

There is currently no data available on the average sum insured via group cover. The extent of cover will generally vary by superannuation fund and the age of the fund member.

The Moratorium also stated that regardless of the amount of cover sought, life insurers would not require or encourage applicants to take a genetic test as part of their life insurance application. Similarly, applicants would not be required to disclose results of genetic tests taken as part of medical research where the applicant would not receive the results.


In February 2022, the FSC released a statement outlining the effectiveness of the Moratorium. Data released alongside the statement indicated that of the 846 applications for cover received by life insurers which included a genetic test result in the six months to 30 June 2021:

- In 653 cases (77 per cent) the genetic test result had no influence.
- 73 cases (9 per cent) were adversely impacted by a genetic test result, all of whom were seeking cover above the FSC Moratorium limits.
- 111 cases (13 per cent) were positively influenced by a genetic test result (i.e., the premium offered was lower than it would have otherwise been).

Importantly, these statistics do not capture instances where consumers may have chosen not to apply for cover above the limit because they were aware that the FSC Moratorium only applies up to certain amounts of cover.

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<sup>2</sup> APRA December 2022 LRS 750 Data



In October 2022, the FSC undertook a review of the Moratorium, and subsequently announced the following changes:

- The removal of the sunset clause (previously the FSC Moratorium was due to sunset in June 2024).
- Immunity for genetic tests taken before, or while, the FSC Moratorium was in place.
- The indefinite extension of the Moratorium, and its incorporation into the Life Insurance Code of Practice (from 1 July 2023).

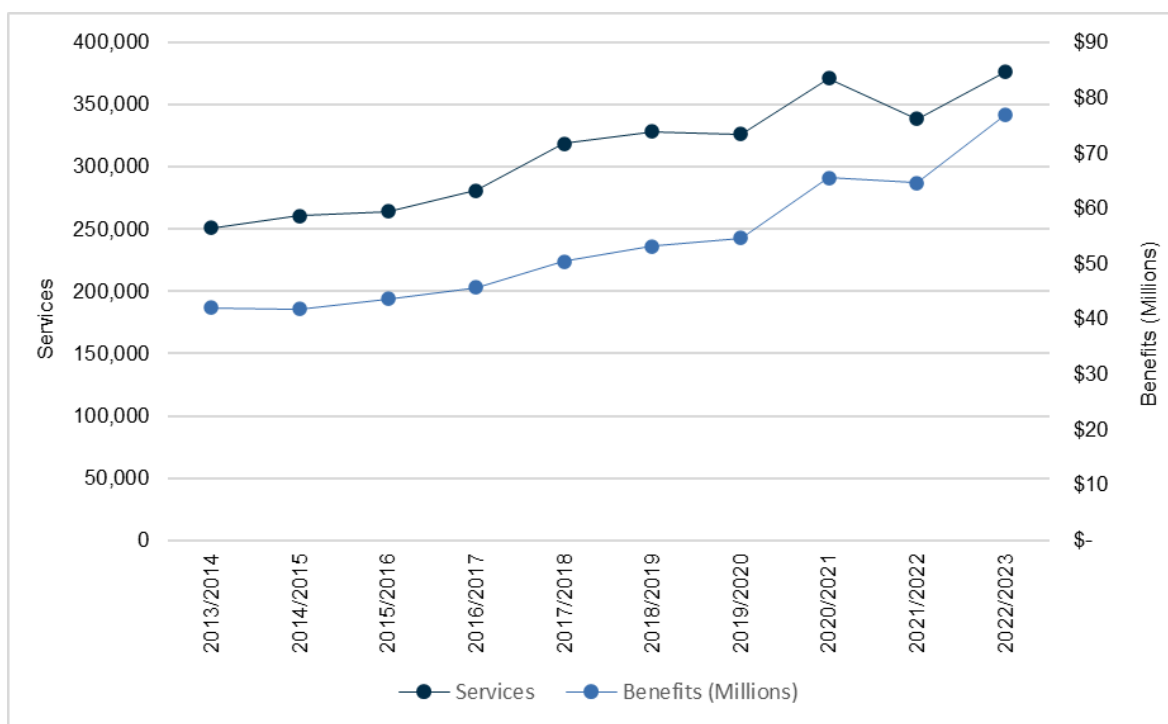
In June 2022, the Council of Australian Life Insurers (CALI) was established as the life insurance industry's new representative body. As of October 2023, CALI's 19 members represent 99 per cent of the life insurance market and all reinsurers in Australia. From 29 September 2023, CALI took over ownership of the Life Insurance Code of Practice from the FSC.

## The prevalence of genetic testing is increasing

Over the last decade, the number of Medicare Benefits Schedule (MBS) genetic and genomic pathology services, as well as the amount of benefits paid, has trended upwards (**Figure 1**). This reflects both advances in genomic medicine and the addition of new genetic and genomic services to the MBS in response to Medical Services Advisory Committee (MSAC) recommendations. With ongoing advances in technology, and associated decreases in cost, the scope and utilisation of genetic testing is expected to increase significantly over the coming years.

Figure 1 reflects genetic and genomic pathology tests eligible for a MBS rebate only, and demonstrates an increase in incidents and investments via the MBS. Figure 1 does not reflect the range of genetic and genomic tests that are available direct to consumers for non-clinical purposes, tests conducted for medical research, or private medical services provided outside the MBS.

Figure 1: Services and benefits for MBS Group P7 – Genetics from financial year 2013-2014 to 2022-2023<sup>3</sup>



## Concerns about effectiveness of Moratorium: The A-GLIMMER report

In June 2020, a Medical Research Future Fund Genomics Health Futures Mission grant was awarded to researchers at Monash University. The researchers sought to monitor the impact of the FSC Moratorium, its effects on the uptake of genetic testing, and its impacts on genetic discrimination (the A-GLIMMER Report).

The A-GLIMMER final report was released in June 2023. The report drew upon consultation with consumers, patients, health professionals and financial advisers to assess views on the effectiveness of the Moratorium.

Key issues raised in the report included that:

- People who have genetic tests that indicate a predisposition to a condition are experiencing difficulties accessing life insurance.
- People are not undertaking genetic tests or participating in scientific research due to concerns about obtaining affordable life insurance.

<sup>3</sup> Services Australia, [Medicare Group Reports](#) (Category 6 – Pathology Services, P7 Genetics data only), Medicare Statistics website, n.d., accessed 1 November 2023.

- Stakeholders have concerns about the life insurance industry's self-regulation of the Moratorium, as well as a low level of confidence in the effectiveness of the Moratorium. Many stakeholders were also concerned about the absence of any Government oversight.
- Life insurers are not complying with the Moratorium, including asking applicants about genetic test results despite applications falling below the financial thresholds.
- The Moratorium's financial limits were too low.
- There was poor awareness and knowledge about the Moratorium amongst some stakeholders.

The A-GLIMMER Project's overall assessment was that the Moratorium is inadequate to address and prevent genetic discrimination in life insurance, and that self-regulation is an ineffective regulatory model to address genetic discrimination. The Final Report recommended that:

- The Government amend the *Disability Discrimination Act 1992* 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.
- The Government allocate responsibility and appropriate resources to the Australian Human Rights Commission ('AHRC') to enforce, promote, educate and support individuals and all relevant stakeholders to understand and meet the new legal obligations under the *Disability Discrimination Act 1992*.

### Questions:

1. Are there particular fields of health care and medical research that are impacted by participant reluctance to take genetic tests due to impacts on life insurance access?
2. Which aspects of the current Moratorium provide inadequate protections for consumers: consumer and industry awareness, financial thresholds, compliance by life insurance industry, or other?
3. As a consumer, has your willingness to undertake genetic testing been impacted by the existing Moratorium?

## Options for regulatory intervention

Genetic testing provides significant public health benefits, both through individual testing and when undertaken as part of medical research. Similarly, life insurance plays an important role in assisting Australians through some of their most challenging moments. Individuals should not be forced to decide between undertaking genetic testing and obtaining life insurance.

However, there are concerns that the current moratorium is deterring individuals from potentially life-saving genetic testing, as well as from participation in genetic research, for fear that it might impact their ability to obtain affordable life insurance. As genomic technologies evolve, there will likely be improvements in the accessibility and affordability of genetic testing. This will lead to more Australians undertaking some form of testing and will likely exacerbate these concerns. As a result, regulatory intervention may be needed to enable consumers to access affordable life insurance, while simultaneously ensuring that the potential benefits of genetic testing are fully realised.

In assessing regulatory interventions, appropriate consideration must be given to potential risks and market consequences. The primary risk of further restrictions on the use of genetic test results is the occurrence of 'adverse selection'. Adverse selection occurs when a consumer, who is aware of a genetic test result indicating that they are at high risk of an early death or disablement, seeks a life insurance policy or level of cover that they otherwise would not have. The issues presented by adverse selection are likely most acute when insurers do not have access to the same information as the consumer (i.e., the genetic test result), as the insurer is unable to accurately assess the risk of a claim. At its most extreme, adverse selection has the potential to threaten the viability of a market, or lead to insurers amending product offerings to moderate any impacts. Where insurer offerings remain unchanged, an increase in coverage attributable to people acting in response to genetic tests may be reflected in increased premiums.

There is mixed evidence on the impact of adverse selection on the behaviour of consumers or the risk exposure of life insurers. A US study found that consumers were up to five times more likely to purchase long-term insurance after a positive test for Huntington's Disease.<sup>4</sup> Conversely, the Canadian Privacy Commissioner commissioned several actuarial reports on the likely impact of a ban on using genetic test results in life insurance underwriting, which concluded that a ban would have negligible market impact at the time.<sup>5</sup> Similarly, a 2022 Report commissioned by the UK Government found no evidence of a current risk to insurers as a result of restricting the use of genetic testing results by life insurers.<sup>6</sup>

A range of options for regulatory intervention are outlined below. For those options involving legislative action, the nature of any amendments or intervention (e.g., the specific Act or Acts to be amended) are not canvassed, as the options focus on the outcome of any proposed intervention. Any approach eventually adopted would be subject to periodic reviews to ensure there is flexibility and

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<sup>4</sup> 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.

<sup>5</sup> 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.

<sup>6</sup> Rodriguez-Rincon, Daniela, Sarah Parkinson, Lucy Hocking, Hamish Evans, Emma Hudson, and Katherine I. Morley, Assessing the impact of developments in genetic testing on insurers' risk exposure. Santa Monica, CA: RAND Corporation, 2022. [https://www.rand.org/pubs/research\\_reports/RRA1209-1.html](https://www.rand.org/pubs/research_reports/RRA1209-1.html).

that the approach remains fit for purpose. Stakeholders are welcome to provide feedback on any implementation considerations that they may wish to raise.

- **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.

This approach would limit the scope for additional adverse selection. Additionally, there would be no further regulatory burden placed on industry, as insurers would not be required to update existing policies or procedures.

Conversely, this approach would fail to address the concerns outlined in the A-GLIMMER report. As outlined above, APRA data suggests that the monetary limits of the Moratorium are below the average sum insured of individual policies.<sup>7</sup> Barring any voluntary action from the life insurance industry, both the disincentives to undertaking genetic testing and impacts on public health would remain as they currently are. Additionally, the Council of Australian Life Insurers has stated that the industry now supports government regulation of the use of genetic tests by life insurers to give Australians peace of mind.

While not a matter for Government, options for industry-led action include increasing or otherwise altering the thresholds within the Moratorium, and submitting the Life Insurance Code of Practice to ASIC for approval as a code of conduct under s1101A of the *Corporations Act 2001*.

- **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. This approach would partially reflect the recommendations of the A-GLIMMER report, and align with the Canadian approach to the use of genetic test results by life insurers, as outlined in the *Genetic Non-Discrimination Act*.

Under a partial ban, life insurers would be prohibited from requesting or utilising any adverse genetic testing results to inform their underwriting decision, subject to certain exemptions. This approach would broadly align with the United Kingdom approach, whereby insurers cannot use predictive genetic test results, except for those for Huntington's disease, and only then in certain applications. A process for determining the nature and extent of any exemptions would need to be delivered to support this approach.

A total or partial ban would provide increased certainty to consumers and medical professionals that undertaking genetic testing, or participating in medical research involving genetic testing, would not impact the ability of consumers to obtain life insurance. These approaches would address many of the concerns raised in the A-GLIMMER report.

Conversely, in the event that a ban on the use of genetic testing is implemented, the information asymmetry between consumers and insurers may give rise to adverse selection. If insurers cannot use adverse genetic tests in any capacity, it is possible for a consumer who has knowledge of a condition to take out a level of cover that they otherwise would not have. Insurers would be unable to accurately assess the risk of a claim by that consumer. There are concerns that this may impact the viability of the life insurance industry, for example due to consumers with adverse test results attempting to take out very large amounts of cover. However, there is limited evidence that such concerns have eventuated in jurisdictions with

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<sup>7</sup>APRA December 2022 LRS 750 Data

similar restrictions. This option would also require life insurers to update relevant policies and procedures.

Additionally, implementing only a partial ban may result in the disincentives to undertaking genetic testing remaining unaddressed. Consumers may not be aware of the existence of any limitations, and may lack clarity as to the exact circumstances in which life insurers may rely on the exceptions. Additionally, genetic test consultations, consent form, and research recruitment process will still have to involve a conversation regarding financial implications and life insurance, which may impact participation rates.

- **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.

Any financial limit developed under this option would exceed the existing thresholds detailed in the Life Insurance Code of Practice, and would be subject to regular and ongoing reviews to ensure they remain at an appropriate level. For example, the limit on death benefit covered could be increased to \$1.5 million.

This approach would ensure that consumers could obtain a certain level of cover, while limiting the scope for additional adverse selection. However, as demonstrated in the A-GLIMMER report, consumers are often unaware of the existence of financial limitations. A prescribed limit may also not reflect the needs or specific circumstances of individual consumers. Additionally, if consumers are aware that the financial limits may be revised in the future, they may continue to avoid genetic testing for fear of what implications might arise in future, once it is too late to choose not to have the genetic test.

### Questions:

4. Of the options outlined above, which do you think is most appropriate to manage concerns about genetic testing and access to life insurance, including those concerns identified in the A-GLIMMER report (see pages 10-11)? Would you change any aspects of that option?
5. What are the key concerns with each option?
6. Is there any evidence to suggest that Government intervention may give rise to adverse selection?
7. Should there be any difference in the treatment of diagnostic and predictive genetic tests?
8. Is there an option not listed that you believe should be considered?

Effective enforcement is vital to ensuring consumer confidence in the protections afforded to them. While the most appropriate enforcement body may ultimately depend on the nature of the limitations adopted, options for enforcing a legislated regime covering the way life insurers utilise adverse genetic test results could include:

- **Option 1: The Australian Human Rights Commission (AHRC):** The A-GLIMMER report recommends that the AHRC be given responsibility to enforce, promote, educate and support individuals and stakeholders to understand and meet any new obligations regarding genetic testing in life insurance. The report notes that the AHRC has extensive experience addressing, resolving, and seeking to prevent significant claims of discrimination in relation to insurance.
- **Option 2: The Australian Securities and Investments Commission (ASIC):** As part of its regulation of life insurers, ASIC could be given responsibility for enforcing any new obligations regarding genetic testing in life insurance. ASIC has extensive experience regulating the conduct of life insurers, and a high level of familiarity with their operations. Under this approach, consumers would have the option of making a complaint to the Australian Financial Complaints Authority (AFCA).

### Questions:

9. Of the options outlined above, which do you think is the most appropriate enforcement body given capacities and enforcement powers?
10. Is there an enforcement option not listed that you believe should be considered?

## Next steps

Feedback is sought on the questions throughout the paper. Your feedback will assist in developing a fit-for-purpose response that aims to ensure consumers are able to access affordable life insurance and the life insurance industry is sustainable, while maximising the potential benefits of genetic testing. The closing date for written submissions is 31 January 2024. Further consultation may be undertaken on an as-needed basis.



## Appendix

### International approaches to the use of genetic testing results in life insurance underwriting

- **United Kingdom:** the UK 'Code on Genetic Testing and Insurance' is a 2018 agreement between the UK Government and the Association of British Insurers (ABI) that imposes restrictions on insurers use of predictive genetic test results.
  - Insurers cannot use predictive genetic test results, with one exception – those for Huntington's disease, used in applications for death cover worth more than £500,000 (AUD 900,000).
  - If a predictive genetic test result is given to an insurer by the applicant, either accidentally or voluntarily, an insurer may take it into account if it is to the applicant's benefit.
  - The limitations in the Code apply only to predictive genetic tests. A diagnostic genetic test result may therefore form part of relevant medical information when making an application for insurance.
  - The UK Code on Genetic Testing and Insurance is indefinite and is reviewed every 3 years.
  - In 2021, the ABI commissioned Cambridge Centre for Health Services Research (CCHSR) to undertake research to identify the current and potential impact of developments in genetics on the UK insurance industry.
    - : The research in 2021 did not show evidence of significant negative impacts on the insurance industry based on current genetic testing across the UK.
    - : The UK Code was deemed effective ("continues to work well").
- **Canada:** Since 2017, the *Genetic Non-Discrimination Act* prohibits any entity (including insurers) from requesting or using genetic test results. It includes an exception to allow individuals to voluntarily disclose a test result to show they do not have a genetic change that runs in the family.
- **Europe:** The Council of Europe's Oviedo Convention on Human Rights and Biomedicine prohibits discrimination on the basis of genetic information. Many European countries have accordingly banned completely or restricted discriminatory use of genetic information in life insurance:
  - Where monetary thresholds exist, they range from amounts broadly similar to the limits under the FSC Moratorium (e.g., in Germany the death cover limit is 300,000 Euros and in Switzerland it is 400,000 Swiss Francs), to amounts much higher such as the UK where the limit, which only applies in relation to Huntington's disease is 500,000 pounds of death cover.
- **United States:** The *Genetic Information Nondiscrimination Act* (GINA), prevents genetic test results being used in health insurance and employment contexts but not life insurance.
  - In 2020, the US state of Florida has introduced a law prohibiting life insurers from using predictive genetic test results in underwriting. Insurers that were exempt from the national protections under GINA (which includes life insurers) are no longer exempt.

- **New Zealand:** The *New Zealand Human Rights Act 1993* (HRA) prohibits discrimination on the grounds of disability, but an exception in section 48 of the HRA allows discrimination in life and health insurance policies, if based on actuarial or other data on which it is reasonable to rely.
- **Singapore:** The Ministry of Health and the Life Insurance Association has developed a moratorium on genetic testing. Insurers cannot take predictive genetic tests into account except:
  - Tests for Huntington’s disease for:
    - : Life insurance over the higher of SGD 2m (AUD 2.2m) or the 99th percentile of all life insurances in Singapore at the time the insurance is underwritten; and
    - : TPD insurance over the higher of SGD 2m (AUD 2.2m) of the 99th percentile of all TPD insurances in Singapore at the time the insurance is underwritten.
  - Tests for Huntington’s disease and breast cancer (BRCA1 and BRCA2) for:
    - : Critical illness (CI) insurance over the higher of SGD 500,000 (AUD 550,000) and the 99th percentile of all CI insurances in Singapore at the time the insurance is underwritten; and
    - : Disability Income Insurance over the higher of SGD 10,000 (AUD 11,000) per month or the 99th percentile of all Disability Income Insurances in Singapore at the time the insurance is underwritten.
  - The monetary limits apply to a monetary cap or the 99th percentile of all life insurance policies, whichever is higher. Insurers are able to use an applicant’s favourable test results or results of a diagnostic test done for clinical care. Insurers cannot ask for a test taken as part of biomedical research.
- **Hong Kong:** Best Practice on the Use of Genetic Test Results was developed by the Hong Kong Federation of Insurers (HKFI) with the Food and Health Bureau (FHB). Any changes to best practice will see HKFI inform FHB. Under Best Practice insurers can only utilise predictive genetic test results if:
  - Life insurance cover exceeds \$950,000 AUD or critical illness insurance is over \$190,000 AUD.
  - The predictive test is for the following:
    - : Early-onset autosomal dominant Alzheimer disease
    - : Hereditary breast and ovarian cancer syndrome
    - : Lynch syndrome/Hereditary non-polyposis colorectal cancer
    - : Autosomal dominant polycystic kidney disease
    - : Huntington’s Disease
    - : Hypertrophic cardiomyopathy
  - Insurers in Hong Kong can use diagnostic genetic tests and favourable genetic tests provided by an applicant. An insurer cannot request a genetic test taken as part of scientific research.



## Attachment A: A-GLIMMER Final Report (2023)

<https://bridges.monash.edu/articles/report/strong-Final-Stakeholder-Report-of-the-strong-em-st-strong-Australian-Genetics-and-Life-Insurance-Moratorium-Monitoring-the-Effectiveness-and-Response-A-GLIMMER-strong-em-strong-Project-strong-/23564538>