Australian Government
The Treasury

Impact analysis

Use of genetic testing information by life insurers

August 2024

treasury.gov.au

© Commonwealth of Australia 2024

This publication is available for your use under a Creative Commons Attribution 3.0 Australia licence, with the exception of the Commonwealth Coat of Arms, the Treasury logo, photographs, images, signatures and where otherwise stated. The full licence terms are available from http://creativecommons.org/licenses/by/3.0/au/legalcode.

Use of Treasury material under a Creative Commons Attribution 3.0 Australia licence requires you to attribute the work (but not in any way that suggests that the Treasury endorses you or your use of the work).

Treasury material used 'as supplied'.

Provided you have not modified or transformed Treasury material in any way including, for example, by changing the Treasury text; calculating percentage changes; graphing or charting data; or deriving new statistics from published Treasury statistics — then Treasury prefers the following attribution:

Source: The Australian Government the Treasury

Derivative material

If you have modified or transformed Treasury material, or derived new material from those of the Treasury in any way, then Treasury prefers the following attribution:

Based on The Australian Government the Treasury data

Use of the Coat of Arms

The terms under which the Coat of Arms can be used are set out on the Department of the Prime Minister and Cabinet website (see https://www.pmc.gov.au/honours-and-symbols/commonwealth-coat-armss).

Other uses

Enquiries regarding this licence and any other use of this document are welcome at:

Manager
Media and Speeches Unit
The Treasury
Langton Crescent
Parkes ACT 2600
Email: media@treasury.gov.au

In the spirit of reconciliation, the Treasury acknowledges the Traditional Custodians of country throughout Australia and their connections to land, sea and community. We pay our respect to their Elders past and present and extend that respect to all Aboriginal and Torres Strait Islander peoples.

Contents

Executive Summary

There are significant individual, public health, and scientific benefits associated with the use of genetic and genomic testing (genetic testing), whether undertaken for individual health reasons or medical research.[1] However, many Australians report delaying or foregoing potentially lifesaving, clinically relevant genetic testing, or not participating in medical research involving genetic testing, for fear that adverse results will affect their ability to obtain affordable life insurance. This is due to the current regulatory framework, under which life insurers are able to request and use consumers' genetic testing results when considering whether, and on what terms, to offer life insurance policies. When these results are requested, consumers must disclose them, due to the existing duty to take reasonable care not to make a misrepresentation, the duty of disclosure, and the duty to act in utmost good faith (contained in the *Insurance Contracts Act 1984* (the Insurance Contracts Act)).

These concerns were noted in a 2018 Parliamentary Joint Committee on Corporations and Financial Services report, in which it suggested that the use of genetic tests in life insurance underwriting was adversely impacting participation in health research projects involving genetic testing.

Subsequently, in 2019, Australia's life insurance industry introduced a partial moratorium on the requirement to disclose genetic test results (the Moratorium). The Moratorium was introduced to address 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 continued 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.

In response to these concerns, Treasury undertook public consultation to examine the nature and extent of the issues caused by the current regime, as well as propose a range of options for reform. These reforms included possible restrictions on the use of adverse genetic testing results by life insurers, as well as potential enforcement bodies to oversee any new obligations. The objective of each option was to reduce, to the greatest extent possible, the number of Australians delaying or foregoing genetic testing due to life insurance-related concerns.

The options consulted on for regulating the use of genetic testing results by life insurers were:

- Option 1A: No Government intervention.
- Option 1B: Legislating a total ban on the use of adverse genetic testing results.
- Option 1C: Legislating a partial ban on the use of adverse genetic testing results.

[1] 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.

- **Option 1D:** Legislating a financial limit, below which life insurers could not utilise adverse genetic testing results.

The options consulted on for potential enforcement bodies included:

- **Option 2A:** The Australian Human Rights Commission (AHRC)
- **Option 2B:** The Australian Securities and Investments Commission (ASIC).

Throughout the consultation period, over 1,000 submissions were received from a range of stakeholders, including individual respondents, industry bodies, parliamentarians and community organisations. In addition to reviewing written submissions, Treasury conducted roundtables with impacted consumers and health care professionals.

Based on the information obtained through the consultation period, Treasury considers the preferred approach to be legislating a total ban on the use of adverse genetic testing results by life insurers **(Option 1B)**, with compliance to be monitored and enforced by ASIC **(Option 2B)**. Importantly, this approach would not impact the existing ability of consumers to volunteer favourable genetic testing results, and for life insurers to use these when conducting individual assessments.

Legislating a total ban on the use of adverse genetic testing results by life insurers would most comprehensively achieve the objective of a reduction in the number of Australians delaying or foregoing genetic testing due to life insurance concerns (coupled with the estimated net benefit detailed below). Of the other options considered, all resulted in a net detriment and lesser impact on consumer behaviour.

ASIC was selected as the most appropriate enforcement body given its current capabilities and expertise. The AHRC acknowledged that such a role was more appropriate for an existing financial system regulator.

A summary of the Impact Analysis is provided below:

Objective: Reduce, to the greatest extent possible, the number of Australians that delay or forego genetic testing due to life insurance related concerns						
	Policy response options				**Enforcement options**	
Option	1A No intervention	**1B** **Total Ban**	1C Partial ban	1D Financial limit	2A AHRC	**2B** **ASIC**
Average Change in Consumers Positively Impacted	Nil	**228**	149	149	Nil	**Nil**
Average Net Benefit	Nil	**$6.6m**	$4.4m	$4.4m	N/A	N/A

Preferred response

1. What is the policy problem you are trying to solve and what data is available?

The problem to be solved

There are significant individual, public health, and scientific benefits associated with the use of genetic testing, whether undertaken for individual health reasons or medical research. However, many Australians report delaying or foregoing potentially lifesaving, clinically relevant genetic testing, or not participating in medical research involving genetic testing, for fear it will affect their ability to obtain affordable life insurance. This is due to the current regulatory framework, under which life insurers are able to request and use consumers' genetic testing results when considering whether, and on what terms, to offer life insurance policies. This ability exists regardless of whether the genetic testing is undertaken as part of an individual's medical treatment, or as part of research.[2]

The Moratorium, introduced by the life insurance industry in 2019, sought to address these concerns by restricting the circumstances in which insurers could require consumers to disclose genetic testing results. The Moratorium acknowledged public concerns surrounding the use of genetic testing results by life insurers may dissuade people from genetic testing, and sought 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. However, the A-GLIMMER report found the Moratorium to be largely ineffective in achieving these objectives.

This Impact Analysis seeks to analyse a range of options to reduce the number of individuals that elect to delay or forego genetic testing due to life insurance related concerns.

The risks or dangers to be mitigated

Genetic testing can be used to inform the early detection, diagnosis, and treatment of a range of conditions, and offers great potential in improving both individual and public health outcomes.[3] However, as noted in the Royal Australian College of General Practitioners submission, 'these gains are at risk if people avoid testing because it may lead to them being denied personal insurance cover'. Amongst other impacts, avoidance of genetic testing may result in delayed or missed diagnoses, as well as inappropriately tailored treatment plans. Two submissions to the Treasury public consultation noted further that pharmaceutical research and the development of new therapies may also be significantly hindered by delayed or avoided genetic testing, although this matter has not been extensively considered by Treasury. [4]

In addition to poorer patient outcomes, there are significant fiscal implications for Government if genetic testing is delayed or avoided by the public. As noted by the Government of Western Australia Department of Health submission, 'being diagnosed at a later stage is associated with additional costs

[2] In Australia, life insurance is primarily provided through either group life policies, which are default products offered through superannuation, or through policies purchased from an insurer, generally via a financial adviser or as a voluntary increase in group cover. Unlike group life insurance or health insurance, life insurance purchased from insurers outside of superannuation is 'risk-rated', not 'community-rated'. Risk-rating gives effect to the principle that insurance premiums should reflect individual risk. As a result, life insurers can adjust their premiums and offerings in accordance with the specific attributes of each individual applicant.

[3] Cancer Australia and Royal Australian College of General Practitioners submissions

[4] Alexion and Medicines Australia submissions

to the healthcare system in terms of treatment and/or care... Additionally, later diagnosis and treatments are often more invasive and mean poorer outcomes for patients. This in turn has economic impacts, as patients are less likely to survive, or survive well, and be able to return to and contribute to the workforce'.

Reduced use of genetic testing and participation in medical research therefore has potentially significant adverse impacts on both individual and public health outcomes.

The magnitude of the problem

There is varying evidence on the extent to which individuals are delaying or foregoing genetic testing due to life insurance related concerns.

Of the consultation responses, 202 (20 per cent) noted instances of individuals delaying or foregoing genetic testing due to life insurance related concerns. Similar concerns were expressed during the roundtables, and were echoed across a range of stakeholder groups, including consumers, researchers, health practitioners, and community organisations. Extracts of consultation submissions are below.

- *'Victorian Clinical Genetics Services has had the experience on a number of occasions of individuals who have come forward for predictive genetic testing for conditions where surveillance improves outcome, such as familial cardiac conditions and familial cancers, where the issue of insurance is raised in the consultation and those individuals are not seen again'* – Victorian Clinical Genetics Services submission.
- *'Health Care Practitioners across the Western Australian healthcare system who facilitate genetic testing have reported consumers regularly delaying or declining genetic testing due to fears of genetic discrimination relating to life insurance'* – Government of Western Australia Department of Health submission.
- *'In 2018, 26% of respondents [to the Ovarian Cancer Australia community survey] who declined genetic testing identified uncertainty regarding impact on life insurance as reason to refuse testing. This halved to 13% in 2022 survey following the partial moratorium but highlights that the partial moratorium wasn't enough to remove this barrier to genetic testing'* – Ovarian Cancer Australia submission.
- *'I have started the genetic counselling process and feel overwhelmed with all the healthcare considerations I may have to have, regarding screening, preventative surgery and decision making around reproductive health. Life insurance limitations are an additional stress that I should not have to be concerned about. My sister, who is 27, has currently decided, after some counselling, to not get tested due to the potential life insurance limitations'* – Submission to Treasury consultation, name withheld.
- *'I recall meeting with the parents of a child who was at risk of a childhood-onset cancer predisposition syndrome. The parents, who were already distressed about the potential impacts of this condition on their child's health, experienced further distress by considering whether their decision to provide consent to testing on their child's behalf would negatively impact their child's insurance prospects in the future. This concern not only resulted in delays to the child's medical treatment, but also created additional stress and anxiety in a family who were already struggling'* – Submission to Treasury consultation, name withheld.

These responses echoed the findings of the A-GLIMMER report, in which 39 per cent of surveyed health practitioners reported patients delaying genetic testing and 18 per cent declining genetic testing due to concerns about life insurance.

The authors of the A-GLIMMER report subsequently provided information regarding a further study, the 'DNA Screen pilot study', which offered preventive DNA screening to 10,000 Australians aged 18–40 years. 7,642 individuals registered interest in the study but ultimately decided not to participate (either through withdrawing, not returning a sample or not responding). 591 individuals subsequently completed a survey and provided reasons for their non-participation, with 338 (57 per cent) reporting concerns about possible insurance implications as a cause of their non-participation.

Conversely, a minority of public consultation submissions (< 1 per cent) challenged the extent of the problem caused by the existing regulatory framework:

- The Actuaries Institute submissions referenced two studies, which found that only a small percentage of individuals (6 per cent and 4 per cent respectively) identified insurance concerns as the primary factor in declining a genetic test.
- Swiss Re cited its own 2019 paper, '*Can life insurance pass the genetic test*', which found that only 4 per cent of people considered life insurance to be the most crucial reason to not take a genetic test.
- The Council of Australian Life Insurers (CALI) submission noted that in 2022, CALI members reported that of more than 200,000 underwriting decisions, only 1,674 instances involved a disclosure of a genetic test. 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).
- GeneEthics noted in its submission that the 'Australian Genomics and the [A-GLIMMER] document fail to produce any convincing independent evidence or arguments to support their claim that life insurance access produce reluctance to take any genetic or genome tests[5].'
- The Financial Advice Association of Australia submission noted that 'very few of our risk specialist members noted any experience or history of their clients ever asking about genetic testing, being asked for genetic testing information or having their premiums affected by either the availability or lack of a genetic test. For example, one member identified 6 instances of providing genetic test results to the life insurer on behalf of the clients of his business related to over 1,290 applications over an 18-month period. Two other members both had only 1 instance each in 20+ years of assisting clients exclusively in life insurance advice.'

Impacted stakeholders

Key stakeholders impacted by this problem include:

[5] GeneEthics submission

- Individuals considering undertaking genetic testing, who may be disincentivised or dissuaded from doing so due to concerns regarding their future ability to obtain affordable life insurance, and subsequently experience adverse health impacts.
- Individuals who have previously undergone genetic testing, who may be unable to obtain adequate or affordable life insurance coverage under the existing regulatory framework.
- Insurers, who are required to consider applications involving genetic testing according to the existing regulatory framework. As outlined above, in 2022, insurers reported 1,674 instances of life insurance applications involving disclosure of a genetic test.
- Health care practitioners and researchers, who are required to counsel patients on the life insurance implications of genetic testing, and may secure less participants in research (and gather less data) where individuals decline participation on life insurance grounds.
- Governments, who may be required to cover the additional cost of treatment for those individuals that delay or forego genetic testing and, as a result, do not access early or preventive treatment.
- The general public, who may be impacted by inferior public health planning due to the underutilisation of genetic testing and screening programs.

Additionally, the Australian Genomics and the Australian Alliance for Indigenous Genomics Joint Consultation Response noted that the current regulatory framework presents a 'high risk of increasing inequities for Aboriginal and Torres Strait Islander peoples, who experience a disproportionate burden of disease but who in many cases feel unable to safely engage in genetic and genomic testing, owing to a history of exploitative research practices and continuing lack of basic protections.'[6]

The Cancer Australia submission expressed similar views, noting that Aboriginal and Torres Strait Islander Australians remain poorly represented in genetic sequencing panels and clinical databases, giving rise to limited evidence of genetic health benefits in First Nations people. The Cancer Australia submission further emphasises that using adverse genetic testing results to assess life insurance may compound this discrimination against First Nations people.

Current regulatory settings

There is no existing legislation that prohibits the use of adverse genetic testing results in determining an individual's access or conditions for life insurance.

On the contrary, while the *Disability Discrimination Act 1992* (DDA) 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, it includes an exception for life insurance policies in certain circumstances (making this type of discrimination lawful). Under the DDA, insurers are able to lawfully discriminate in offering life insurance products, provided there is actuarial or statistical data on which it is reasonable to rely, and the discrimination is reasonable in the circumstances. If there is no actuarial or statistical data available or reasonably attainable, the discrimination must be reasonable having regard to other relevant factors.

[6] Australian Genomics and the Australian Alliance for Indigenous Genomics Joint Consultation Response

This allows life insurers to request, and use, the results of any genetic testing that has been undertaken by an individual, when considering whether and under what conditions the insurer will offer life insurance to that individual.

Other government measures

There are no other Government measures that have been applied to seek to address the problem. However, industry-led measures are currently in place, after Government review of the industry.

Following the 2018 Joint Parliamentary Committee Inquiry into the Life Insurance Industry, the Financial Services Council (FSC), then the peak industry body for life insurers, introduced the Moratorium on the use of genetic testing in life insurance. The standard, *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 can only request or use the results of a genetic test if the total amount of cover a person was seeking – including both the cover being applied for and any existing individual and group insurance cover with any life insurers (including policy(ies) under their superannuation) – 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; or
- $4,000 a month of any combination of income protection, salary continuance and business expenses cover.

Under the Life Insurance Code of Practice, the Life Code Compliance Committee can investigate and respond to potential breaches of the moratorium. This includes issuing a formal warning or requiring an insurer to take steps to rectify identified issues. The Committee can also require a Community Benefit Payment of up to $100,000 to be paid to a registered charity where there are significant breaches. While subscription to the code is voluntary, 99 per cent of the Australian life insurance market, as well as all reinsurers in Australia, have formally agreed to be bound by its standards.

In June 2022, the Council of Australian Life Insurers (CALI) was established as the life insurance industry's new representative body. From 29 September 2023, CALI took over ownership of the Life Insurance Code of Practice, including the Moratorium, from the FSC.

Impact of current measures

Evidence obtained throughout the consultation and via the A-GLIMMER report suggests that the industry-led Moratorium is ineffective for a number of reasons:

- The existing financial limits are too low to enable individuals to obtain adequate life insurance.

  > "Our family is making the decision not to undertake genetic testing despite the recommendations of our doctors and the positive benefits early intervention could achieve. This is because the moratorium limit of $500,000 is inadequate to cover the cost of the loss of a parent in even a low income family" – Submission to Treasury consultation, name withheld.

"Insufficient financial thresholds do not meet the needs of many individuals and their families in providing adequate protection against financial liabilities. This potential exposure exacerbates the psychosocial stress already associated with living with a rare condition" - Genetic Alliance Australia submission.

- There is low stakeholder confidence in the industry self-regulated Moratorium, as consumers do not trust insurers to independently comply with obligations.

  "We also lack faith that the insurance companies will comply with the moratorium without legislative backing" – Submission to Treasury consultation, name withheld.

  "There is no oversight by a regulator or Government. Essentially, life insurance underwriters are self-regulating – which is highly unethical, considering there is money to be made" – Submission to Treasury consultation, name withheld.

  "Industry self-regulation … is out of step with practices across the world, with a growing number of countries … with state-led regulation or co-regulation" - Professor Margaret Otlowski, Dr Robin Banks and Professor Ainsley Newson submission.

  "There is a lack of independent oversight to test the 'robustness of evidence used in underwriting, nor to consider the interests of consumers". "There are problems with accountability, transparency, conflict of interest, and mandating compliance" - Professor Margaret Otlowski, Dr Robin Banks and Professor Ainsley Newson.

- There are lack of effective enforcement and redress mechanisms.

  "The lack of legal remedy for a breach of the Code of Practice (Council of Australian Life Insurers, 2023), which states (at clauses 8.6 & 8.10, on page 34) that the Code: only creates legal or other rights between the entities bound by it and CALI. It does not create rights for any other parties… None of the provisions of the Life Code can be the subject of proceedings in a court or tribunal" - Professor Margaret Otlowski, Dr Robin Banks and Professor Ainsley Newson submission.

- There is poor consumer understanding of how the Moratorium operates.

  "My fear is that Insurance companies report to Superannuation to update with this information for the insurance component" – Submission to Treasury consultation, name withheld.

  "Inadequate knowledge and awareness of the mechanisms and provisions within the existing moratorium, has resulted in members deferring or avoiding testing electively, or in some instances, being declined access to testing by health care professionals due to concerns due to the perception of risk on individuals' behalf. Additionally, uncertainty has acted as a deterrent to clinical research participation where requiring genetic or genomic testing is required as a condition of eligibility" - Genetic Alliance Australia submission.

  "[T]here is often confusion among members of the public as to the types of insurance genetic discrimination may impact. Notwithstanding the clear community rating status of the Australian system of health insurance, there have been reports of consumer concerns about health insurance discrimination even though this is largely unfounded due to the

nature of these products as community risk rated" - Centre for Law and Genetics submission.

"Our consumers report difficulty in understanding the interplay between insurance and the moratorium, their rights and insurance fine print, etc." - Polycystic Kidney Disease Australia Community submission.

Treasury considers that, as a result of these deficiencies, Australians are continuing to delay or forego genetic testing due to life insurance related concerns. Further analysis of the extent of this issue is provided in Section 4 below.

Data supporting this Impact Analysis

Data available to support this analysis includes:

- Submissions provided to the public consultation, including information obtained via the consumer and health practitioner roundtables facilitated by Treasury.
- The A-GLIMMER report.
- Medicare Benefits Schedule genetic and genomic pathology services statistics.

There is currently no readily available additional data that could be used to supplement the Impact Analysis process.

2. What are the objectives, why is government intervention needed to achieve them, and how will success be measured?

Need for government intervention

As detailed above, there are significant individual and public health benefits associated with the use of genetic testing. However, under the current regulatory framework, there is evidence from consumers, health care practitioners and researchers alike, that individuals are delaying or foregoing potentially lifesaving, clinically relevant genetic testing, or not participating in medical research involving genetic testing, for fear it will affect their ability to obtain affordable life insurance.

This is due to the limitations of the current Moratorium, including its inadequate financial limits and limited enforceability, as well as a lack of clarity amongst consumers (see above).

Failure to address these concerns will result in poorer health outcomes for individuals, increased costs to governments through funding eventual treatment (which is often more extensive and expensive than earlier treatment options), and delays to medical and pharmaceutical advancement.

A clear, enforceable, compulsory ban that is regulated by Government is considered necessary to address the issue.

The various approaches taken by overseas jurisdictions (discussed further below) demonstrate that government has the capacity to intervene successfully.

Objective of intervention

The objective of Government intervention is to reduce, to the greatest extent possible, the number of Australians delaying or foregoing genetic testing due to life insurance concerns. This will maximise the possibility that the significant medical, public health, and scientific benefits offered by genetic testing are fully realised.

Constraints/barriers to objective

There are no major constraints or barriers to achieving the goals outlined above.

Determining success

The primary target for measuring the success of this policy change is a reduction in the number of individuals delaying or foregoing genetic testing due to life insurance related concerns.

There are a number of other factors that will impact the success of this policy change.

- Ongoing reviews at scheduled intervals: There is a risk that further restrictions on the ability of life insurers to incorporate genetic testing results may give rise to 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 sought. 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 (including through increasing premiums across the pool). While significant impacts are not anticipated in this instance (due to disclosure requirements surrounding diagnosed conditions and an applicant's relevant personal and family medical history), scheduling regular reviews of the impact of any restrictions will enable Government to promptly identify and address any such concerns.

  The nature and scope of these reviews is considered in further detail in Section 7 below.

- Clarity of framework: The consultation process revealed significant consumer misunderstanding of the current regulatory framework. For this policy change to be successful, it must be easily understood and communicable to both consumers and health care practitioners.
- Effectiveness of communication: The success of this policy change relies on consumers, health care practitioners and researchers being aware of any updates to the regime. As such, the manner in which any changes are communicated will impact the success of this policy change.

Alternatives to Government action

Alternatives to Government intervention include continuing or strengthening the current model of industry self-regulation. Further analysis of this option is provided in sections 3 and 4 below. Notably, 990 submissions (98 per cent), including CALI, supported some form of Government intervention.

3. What policy options are you considering?

A range of policy options were considered, both for regulating the extent to which life insurers should be allowed to utilise adverse genetic testing results in their underwriting, and for allocating enforcement responsibility. Each option that was considered is detailed below.

Use of genetic testing information by life insurers

3.1 Option 1A – Status Quo/No Government Intervention

Currently, for applications above certain financial thresholds, life insurers are able to request and use consumers' genetic testing results when considering whether, and on what terms, to offer life insurance policies. This ability exists regardless of whether the genetic testing is undertaken for individual medical reasons, or as part of research. Under this option, no changes would be made to the existing regulatory settings. Further information on the current regulatory framework can be found in Appendix B – Background Information.

With ongoing advances in technology, and associated decreases in cost, the scope, utility and utilisation of genetic testing is expected to increase significantly over the coming years. However, these expected benefits may be hindered by the reluctance of individuals to undertake genetic testing, whether as part of medical research or for individual health reasons, for fear it will affect their ability to obtain life insurance. As outlined above, this is expected to lead to poorer health outcomes, increased costs to governments, and delayed development of new treatments and technologies.

For example, there is currently work underway considering the impacts of expanding the newborn screening panels to include genomic sequencing techniques.[7] This has the potential for significant individual and population level benefits. At the individual level, such screening could assist in identifying serious genetic conditions that will manifest in childhood and allow for early intervention. At the population level, benefits include reductions in infant mortality and morbidity. A separate benefit is the capacity to identify population-wide trends and conduct population-wide medical research, which could benefit public health planning and provide more comprehensive reference data for analysis.[8]

However, under the current Moratorium, the results of expanded genetic screening of newborns could potentially require disclosure to insurers where an insurance product is being sought that falls outside the limits set out in the Moratorium. There is a risk that permitting life insurers to have to the ability to require individuals provide genomic newborn screening results would undermine future uptake of, and public trust in, any expanded use of genomics in newborn screening.

3.2 Option 1B – Legislating a total ban

Under a total ban, life insurers would be prohibited from requesting or using any adverse genetic testing results to inform their underwriting calculations. This approach would 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 its *Genetic Non-Discrimination Act 2017*. However, insurers would retain the ability to require individuals provide information about personal and family medical histories, and consumers would still be required to disclose any diagnosed condition, regardless of how that diagnosis was obtained (via genetic testing or other diagnostic methods). These disclosure requirements will ensure that the potential impacts of adverse selection are minimised.

3.3 Option 1C – Legislating a partial ban

Under this option, the Government would legislate a partial prohibition on the use of adverse genetic testing results by life insurers. Under a partial ban, life insurers would be prohibited from requesting

[7] MRFF-funded gEnomics4newborns project (gEnomics4newborns, 2023)
[8] Professor Margaret Otlowski, Dr Robin Banks and Professor Ainsley Newson submission

or using any adverse genetic testing results to inform their underwriting decision, subject to certain exemptions (for example, tests for specific genetic conditions). This recognises that for certain genetic tests, an adverse result may indicate, with high levels of certainty, that a person will definitely develop the relevant disorder.

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 be developed to support this approach.

3.4 Option 1D – Legislating a financial limit

Under this option, a financial limit would be legislated, below which insurers could not request or use adverse genetic testing results in their underwriting. This broadly reflects the current limitations on the use of adverse genetic testing results by life insurers under the Moratorium. The financial limit may apply to the total cover held by an applicant (in line with the Moratorium) or be restricted to the cover sought under each individual application.

Any financial limits would exceed the existing thresholds under the Moratorium, and would be subject to regular and ongoing reviews to ensure they remain at an appropriate level.

Enforcement bodies

3.4 Option 2A – The Australian Human Rights Commission (AHRC)

This option proposes that the AHRC be given responsibility to enforce any new obligations regarding genetic testing in life insurance. The AHRC is an independent third party responsible for promoting compliance with the DDA and investigating complaints regarding discrimination and human rights breaches. This option is consistent with the recommendations of the A-GLIMMER report, which notes that the AHRC has extensive experience addressing, resolving, and seeking to prevent significant claims of discrimination in relation to insurance.

3.5 Option 2B – The Australian Securities and Investments Commission (ASIC)

This option proposes that ASIC, as the existing conduct regulator for the life insurance industry, be given responsibility for enforcing any new obligations regarding genetic testing in life insurance. ASIC currently has responsibility for enforcing consumer protections under the Insurance Contracts Act, *Australian Securities and Investments Commission Act 2001* (ASIC Act) and *Corporations Act 2001* (Corporations Act), including the duty to take reasonable care not to make a misrepresentation, the duty of utmost good faith, and unfair contract terms regime.

4. What is the likely net benefit of each option?

This cost-benefit analysis assesses the likely benefits and costs to consumers, insurers, regulators and the wider market. The analysis will look at the 'likely' costs and benefits rather than actual costs and benefits, as many of these effects cannot be accurately calculated. Regulatory costs have been calculated by Treasury and have not been tested with all stakeholders.

Preliminary calculations quantifying the number of impacted consumers, as well as the cost of the current regulatory framework, are detailed below.

Number of impacted consumers:

Estimating the costs and impacts to various stakeholders requires a determination of the number of impacted consumers. As there is no existing data detailing the number of consumers that delay or forego genetic testing due to insurance concerns, an estimate is calculated below using available data sources.

The number of Medicare Benefits Schedule (MBS) genetic and genomic pathology services provided in 2022-23 was 376,140. This figure excludes those 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. It can therefore be taken as a conservative representation of the actual number of genetic tests taken each year.

Based on these figures, a range of estimates for the number of consumers that have delayed or foregone genetic testing annually is provided below. These figures are calculated by estimating the total number of tests that would have been taken if not for life insurance concerns, and then subtracting the actual number of tests taken.

	Rate of non-participation identified during public consultation rate[9]	Low rate of non-participation	Moderate rate of non-participation	High rate of non-participation
Total number of genetic tests actually taken	376, 140			
Percentage of individuals that have delayed or foregone testing due to life insurance concerns	20 per cent	1 per cent	5 per cent	10 per cent
Total number of genetic tests that would have been taken if not for life insurance concerns	470,175	379,939	395,937	417,933
Number of individuals that have delayed or foregone testing due to life	94,035	3,799	19,797	41,793

[9] This rate is calculated by dividing the number of consultation responses identifying nonparticipation by the total number of consultation responses. Treasury notes that the percentage of individuals delaying or foregoing genetic testing identified during the public consultation is likely inflated, given both the self-selecting nature of the responses and the fact that responses were not limited to a particular year.

insurance concerns[10]				

Costs and impacts to consumers:

The primary cost to consumers under the current framework is adverse impacts to their health. As demonstrated by the public consultation extracts below, delayed or foregone genetic testing may result in missed or delayed diagnoses and incorrect or inappropriate treatment plans. This will directly lead to poorer health outcomes.

- *'The consequences of avoiding genetic testing can mean Australians are unable to access potentially lifesaving interventions. For example, bilateral prophylactic mastectomy has been shown to reduce the risk of breast cancer by at least 95 percent in women who have a mutation in the BRCA1 gene or the BRCA2 gene' – Breast Cancer Network Australia.*
- *'The strongest argument in favour of ending the use of genetic test results in life insurance underwriting is that such action will save lives, particularly those of at-risk individuals' – Australian Privacy Foundation.*
- *'Recent State of the Nation 2023 report contains data showing 31 per cent of blood cancer patients who had a genomic test had their diagnosis and treatment plan altered' – Leukemia Foundation.*
- *'Precision oncology has the potential to change the future of cancer care, improve cancer prevention through risk stratified screening, increase survival for people with cancer and reduce the burden of cancer on Australians' – Cancer Australia.*

Based on the calculations above, 3,799 to 41,793 consumers delay or forego genetic testing each year on life insurance grounds. Assuming 1 per cent of tests return a result identifying an increased chance of a future condition, 38 to 418 individuals will be adversely impacted by the current regulations each year.[11] These impacts cannot be readily quantified, and may include decreased quality of life and reduced life spans.

Costs to governments:

Delaying or foregoing genetic testing is likely to lead to poorer health outcomes for consumers, resulting in additional costs for governments. As noted by the Western Australian Department of Health submission, *'being diagnosed at a later stage is associated with additional costs to the healthcare system in terms of treatment and/or care, which is an inefficient use of healthcare resources … Additionally, later diagnosis and treatments are often more invasive and mean poorer outcomes for patients. This in turn has economic impacts, as patients are less likely to survive, or survive well, and be able to return to and contribute to the workforce '*.

Additionally, as outlined in the Australian Genomics and the Australian Alliance for Indigenous Genomics submission, by '*transitioning health care from reactive management of disease to proactive*

[10] This number is calculated by treating the total number of genetic tests as the remainder of 100 per cent minus the percentage of individuals that have delayed or foregone testing. In the example of 20 per cent, this would mean the total number of genetic tests is representative of 80 per cent of potential genetic tests.

[11] The Australian Genomics and the Australian Alliance for Indigenous Genomics submission notes a rate of at least 1 – 2%.

genomic intervention health funders (Governments and insurers alike) will save billions of dollars. However, this transition is unlikely to occur if individuals are unwilling to undertake genetic testing'.

Using the range of 38 to 418 adversely impacted individuals identified above, and the average cost per year for a minor and major health condition, the costs to Government per year by these tests not being undertaken can be estimated as between $1,257,999.50 and $13,837,994.50 annually in health expenditure.[12][13,14] [15,16] This figure does not include the costs of General Practitioner or allied health services, foregone productivity, taxes etc and assumes a diagnostic delay of only one year.

Costs to life insurers:

The unwillingness of consumers to undergo genetic testing under the status quo model similarly adversely impacts life insurers, who may unknowingly carry increased risks which may otherwise have been identified and mitigated.

4.1 Option 1A – Maintaining Status Quo

Under the status quo, and provided the Moratorium remains in force, for applications above certain financial thresholds life insurers are able to request and use consumers' genetic testing results when considering whether, and on what terms, to offer life insurance policies.

Policy benefits

The additional benefits of maintaining the status quo are outlined by stakeholder group below.

Consumers

There are no additional benefits to consumers in maintaining the status quo (other than those already provided under the Moratorium).

Governments

There are no additional benefits to Governments in maintaining the status quo.

Life insurers

There are no additional benefits to Life insurers in maintain the status quo. Relative to other options, maintaining the status quo would not place any additional regulatory or compliance burden on industry, as insurers would not be required to update existing policies or procedures. Additionally, there would be no increased risk of adverse selection beyond current levels.

---

[12] While not all individuals will develop a health condition requiring treatment, this is negated by averaging the cost of major and minor treatment.

[13] Government expenditure for T2DM includes the inflation-adjusted cost of T2DM medications from the Pharmaceutical Benefits Scheme, referred medical services such as pathology, and patients with T2DM in public hospitals, including admissions, emergency department and outpatients.

[14] Australian Institute of Health and Welfare (AIHW), Diabetes: Australian facts, AIHW website, 2024, accessed 2 July 2024.

[15] DE Goldsbury et al, 'Health services costs for cancer care in Australia: Estimates from the 45 and Up Study'. *Public Library of Science One*, 2018, 13(7).

[16] The estimated total cost to government uses the assumed probability of the adversely impacted individuals developing a minor or major condition to estimate the number of cases for each condition. This is then multiplied by the average annual inflation-adjusted cost per case of the respective condition to come to an estimated total cost.

Policy costs and adverse impacts

The additional costs of maintaining the status quo are outlined by stakeholder group below.

Consumers

There are no additional costs or adverse impacts to consumers in maintaining the status quo (beyond those already borne by consumers under the Moratorium).

Governments

There are no additional costs to Governments in maintaining the status quo.

Life insurers

There are no additional costs to insurers in maintaining the status quo, beyond that of the risk they unknowingly cover.

Regulatory Burden Measurement

Administrative Costs: Nil. There are no changes to existing requirements and therefore no additional costs incurred by life insurers to modify their practices or demonstrate compliance.

Substantive compliance costs: Nil. There are no changes to existing requirements and therefore no additional costs incurred to deliver the outcomes being sought under this approach.

Delay costs: Nil. There are no application or approval delays incurred under this approach.

Assessment

There are no additional costs or benefits associated with maintaining the status quo, beyond those already offered by the current regulatory framework.

4.2 Option 1B – Legislating a total ban

Policy benefits

The benefits of legislating a total ban are outlined by stakeholder group below.

Consumers

Legislating a total ban would provide certainty to individuals and medical professionals that undertaking genetic testing, or participating in medical research involving genetic testing, would not impact their ability to obtain life insurance. This would likely reduce to nil the number of individuals delaying or foregoing genetic testing due to life insurance concerns.

Assuming that 3,799 to 41,793 genetic tests, which otherwise would have been delayed, are now taken under a total ban, and that 1 per cent of genetic tests deliver an adverse results, it can be estimated that 38 to 418 individuals per annum will receive an adverse result they otherwise would not have received. While all individuals undertaking testing will receive some benefit, those with adverse results will be able to take proactive health measures to reduce their risk.

Governments

Legislating a total ban would reduce to nil the government costs associated with delayed diagnoses, estimated above to be between $1,257,999.50 and $13,837,994.50 per annum.

Additionally, this approach would realise the recommendations of the Senate Community Affairs Committee, which recently recommended that 'as a matter of priority, the Australian Government legislate a complete ban on genetic discrimination in life insurance' following its recent inquiry into cancer diagnosis and treatment.[17]

This approach would also align the regulatory settings with those adopted in a range of international jurisdictions, including Canada, Ireland, and Poland.[18] Treasury was unable to identify any evidence examining the impacts of such restrictions on the rates of genetic testing in these jurisdictions.

Life insurers

Increasing rates of genetic testing will reduce the risks that life insurers unknowingly carry (as applicants would be required to disclose any diagnoses that resulted from a genetic test). Additionally, those tests results that reveal an increased chance of a future condition but do not result in a diagnosis, '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'.[19] By doing so, the overall risk to life insurers decreases.

Policy costs

Consumers

There are no additional costs to consumers under this option. Under a total ban, consumers would retain the ability to provide favourable genetic testing results to life insurers. These results can be used to negate premium loadings that would otherwise have been incurred due to a consumer's family medical history. While consumers may incur additional costs from seeking preventative treatments following testing, these have not been captured in this analysis.

Governments

There are no additional costs to governments under this option.

Increased rates of testing may result in the Government incurring additional costs to fund MBS pathology services or preventative treatment. These costs have not been captured in the analysis.

Life insurers

In the event of a total ban on the use of genetic testing, the information asymmetry between consumers and insurers may give rise to adverse selection (as detailed in Section 2 above).

Adverse selection concerns primarily relate to conditions that are fully penetrant (i.e., those with the mutation will definitely develop the disease in their lifetime, provided they do not die prematurely of another cause), and currently untreatable. In the United Kingdom, the sole test permitted to be considered by life insurers is Huntington's. As such, Huntington's disease will be used as the basis for adverse selection calculations.

Consultation submissions noted that as Huntington's disease is an inherited disorder with full penetrance and no known treatment, it is highly unlikely that a potential consumer would have no

[17] Equitable access to ...~https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Cancerdiagnosis/Report recommendation 6, para 2.149

[18] Klein, R. (2017) Genetics and Life Insurance – A View into the Microscope of Regulation. The Geneva Association. https://www.genevaassociation.org/publication/health-andageing/genetics-and-life-insurance-view-microscope-regulation.

[19] Council of Australian Life Insurers

family medical history of the condition (as one of the parents must also have Huntington's disease). Under this option, applicants would still be required to disclose their relevant family medical history if requested by insurers, and insurers would be able to adjust their premiums accordingly.

As of 2021, the best available published evidence of relevance to Australia suggests a prevalence rate of 8.4 per 100,000 people.[20] This indicates that with a population of 25.7 million people, there are currently around 2,160 people with a diagnosis of Huntington's Disease in Australia. As such, the cohort of people that may drive the adverse selection concerns flagged by insurers is likely to be very small, and limited to those with a positive genetic test for Huntington's, no personal clinical diagnosis based on symptomatic presentation as and no known family medical history of the disorder yet (both of which would need to be disclosed under the current and proposed regulatory framework).

Using an assumption of 250,000 underwriting decisions annually, a Huntington's prevalence rate of 8.4 per 100,000 suggests that 21 potential applicants may suffer from the disease.[21] Between 1 and 3 per cent of Huntington's cases involve no previous diagnosis or family history, using a conservative assumption of 3 per cent, 0.63 consumers annually would be able to apply for cover without disclosing a result revealing a predisposition to Huntington's.[22] Using APRA data which indicates a median $713,959 of lump sum death cover, and assuming policy holders would seek cover up to double this amount, this would equate to a cost of $899,588.30 per annum.[23]

Of note, Treasury was unable to identify any evidence indicating that such impacts have eventuated in jurisdictions with similar restrictions. Submissions to the consultation did not provide any evidence of negative impacts to the life insurance industries of those jurisdictions that had implemented a total ban. In assessing the likelihood of future impacts, studies have noted that "a ban on such information would likely have no significant negative implications for insurers or for the efficient operation of markets such as life insurance."[24, 25]

Regulatory Burden Measurement

Administrative Costs: Nil. In accordance with the Regulatory Burden Measurement Framework guidance, non-compliance and enforcement costs are excluded, and therefore costs of insurers demonstrating compliance or responding to findings of non-compliance have not been factored here. However, insurers already maintain records of their underwriting of individual policies, as a result no additional administrative costs are expected if they were required to demonstrate compliance.

Substantive compliance costs: $90,384. Life insurers will need to update their policies and underwriting procedures to reflect the total ban on using adverse genetic testing results. These one-off costs can be calculated as follows:

Labour cost = (Time required to update policies/IT systems/conduct training × Labour cost per hour x non-wage labour on-cost multiplier) × (Times policies will need to be updated × Number of life insurers)

---

[20] Australian Institute of Health and Welfare (2024) *Dementia in Australia*, AIHW, Australian Government, accessed 23 July 2024.

[21] CALI submission noted over 200,000 underwriting decisions in 2022.

[22] John Hopkins Medicine (JHM) (2024) *Huntington's disease*, JHM, accessed 23 July 2024

[23] APRA December 2022 LRS 750 Data

[24] Statement on the use of genetic test results by life and health insurance companies (2014). https://www.priv.gc.ca/media/1747/gi_hoy_201203_e.pdf p2

[25] Macdonald, A. S. (2009), "Genetic Factors in Life Insurance: Actuarial Basis," Encyclopedia of Life Sciences (ELS), John Wiley&Sons. 10.1002/9780470015902.a0005207.pub2, pp. 1-5

Labour cost = (40 hours X $53.80 X 1.75 [26]) x (1 x 24[27]) = $90,384

Delay costs: Nil. There are no application or approval delays incurred under this approach.

Average Annual Regulatory costs				
Change in costs ($)	Individuals	Business	Community organisations	Total change in cost
Total, by sector	$0	$9,038.40[28]	$0	$9,038.40

Assessment

The benefits of legislating a total ban can therefore be estimated as between $1,257,999.50 and $13,837,994.50 per annum for the health system, with health benefits for between 38 and 418 individuals. The costs can be estimated as $908,626.70 per annum.

This option therefore provides a net benefit of between $349,372.80 to $12,929,367.80, with health benefits for between 38 and 418 individuals. The average net benefit can therefore be calculated as $6,639,370.30.[29]

4.3 Option 1C – Legislating a partial ban

Policy benefits

The benefits of a partial ban for each stakeholder group are outlined below.

Consumers

Implementing a partial ban will provide increased certainty to individuals considering whether to undergo genetic testing.

Based on the calculations above, 3,799 to 41,793 consumers delay or forego genetic testing each year under the current regulatory settings.

The potential impact of a partial ban is estimated below across a range of effectiveness levels.

	Low impact	Moderate impact	High impact
Individuals delaying or foregoing genetic testing	3,799 to 41,793		
Percentage increase in individuals now willing to undergo genetic testing	10 per cent	40 per cent	70 per cent

[26] This rate is based on Employee Earnings an...~https://www.abs.gov.au/statistics/labour/earnings-and-working-conditions/employee-earnings-and-hours-australia/latest-release#data-downloads Data cube 6. Full-time non-managerial employees paid at the adult rate, average hourly cash earnings for Finance and insurance services

[27] Number of life insurers regulated by APRA in accordance with section 21 of the Life Insurance Act.

[28] In accordance with OIA guidance, costs have been averaged over a 10-year period.

[29] This is calculated as a simple average of the net benefit results, e.g. ($349,372.80 + $12,929,367.80)/2.

Individuals now willing to undergo genetic testing	380 – 4,179	1,520 – 16,717	2,659 – 29,255
Individuals still foregoing genetic testing	3,419 – 37,613	2,279 – 25,076	1,140 – 12,538

As demonstrated above, a partial ban would result in an additional 380 – 29,255 individuals undergoing genetic testing. Assuming 1 per cent of tests return a result identifying an increased chance of a future condition, 4 to 293 individuals will benefit from a test result they otherwise would not have received.

Governments

Based on the calculations above in 4.1, and the number of individuals that will benefit, a partial ban would save governments between $132,421 and $9,699,838.25 for earlier diagnosis and treatment.

Life insurers

A partial ban would limit the scope for adverse selection, although the risk would still exceed current levels (given the restrictions on life insurers would be more stringent than under the current Moratorium).

Policy costs

Consumers

Based on calculations above, the range of individuals that would still forego genetic testing due to insurance related concerns can be estimated as 1,140 – 37,613. Assuming 1 per cent of tests return a result identifying an increased chance of a future condition, 11 to 376 individuals will continue to be adversely impacted by the partial ban each year.

Consumers may incur additional costs from seeking preventative treatments following testing, although these have not been captured in this analysis.

Governments

Increased rates of testing may result in the Government incurring additional costs to fund MBS pathology services or preventative treatment. These costs have not been captured in the analysis.

Life insurers

As outlined above, the cost of adverse selection under a total ban can be estimated as $899,588.30 per annum. Under a partial ban, this cost could be reduced to a range of $269,876.50 (assuming a 70 per cent increase in genetic testing) and $809,629.50 (assuming a 10 per cent increase in genetic testing).

Regulatory Burden Measurement

Administrative Costs: Nil. In accordance with the Regulatory Burden Measurement Framework guidance, non-compliance and enforcement costs are excluded. Insurers already maintain records and there are no additional administrative costs.

Substantive compliance costs: $90,384. Life insurers will need to update their policies and underwriting procedures to reflect the partial ban on using adverse genetic testing results. These one-off costs can be calculated as follows:

Labour cost = ((Time required to update policies/IT systems/conduct training × Labour cost per hour x non-wage labour on-cost multiplier) × (Times policies will need to be updated × Number of life insurers)

Labour cost = (40 hours X $53.80 X 1.75) x (1 x 24) = $90,384

Delay costs: Nil. There are no application or approval delays incurred under this approach.

Average Annual Regulatory costs				
Change in costs ($)	Individuals	Business	Community organisations	Total change in cost
Total, by sector	$0	$9,038.40	$0	$9,038.40

Assessment

The benefits of legislating a partial ban can therefore be estimated as between $132,421 and $9,699,838.25 per annum, with individual health benefits for between 4 and 293 individuals.

The costs can be estimated as between $818,667.90and $278,914.90per annum.

This option therefore provides a net benefit of between -$686,246.90 to $9,420,923.35, with health benefits for between 4 and 293 individuals. The average net benefit can therefore be calculated as $4,367,338.23.

4.4 Option 1D – Legislating a financial limit

Policy benefits

The benefits of this for each stakeholder group are outlined below:

Consumers

Legislating a financial limit would ensure that consumers could obtain a certain level of cover, while limiting the scope for adverse selection

Based on the calculations above, 3,799 to 41,793 consumers delay or forego genetic testing each year under the current regulatory settings.

The potential impact of a financial limit is estimated below across a range of effectiveness levels.

	Low impact	Moderate impact	High impact
Individuals delaying or foregoing genetic testing	3,799 to 41,793		
Percentage increase in individuals now willing to undergo genetic testing	10 per cent	40 per cent	70 per cent
Individuals now willing to undergo genetic testing	380 – 4,179	1,520 – 16,717	2,659 – 29,255
Individuals still foregoing genetic testing	3,419 – 37,613	2,279 – 25,076	1,140 – 12,538

As demonstrated above, a financial limited would result in an additional 380 – 29,255 individuals undergoing genetic testing. Assuming 1 per cent of tests return a result identifying an increased chance of a future condition, 4 to 293 individuals would benefit from a test result they otherwise would not have received.

Governments

Based on calculations in 4.1, and the number of individuals that would benefit, a partial ban would save governments between $132,421 and $9,699,838.25 annually.

Life insurers

A partial ban would limit the scope for further adverse selection, although the risk would still exceed current levels.

Policy costs

Consumers

Based on calculations above, the range of individuals that would still forego genetic testing due to insurance related concerns can be estimated as 1,140 – 37,613. Assuming 1 per cent of tests return a result identifying an increased chance of a future condition, 11 to 376 individuals will continue to be adversely impacted by the financial limit each year.

Consumers may incur additional costs from seeking preventative treatments following testing, although these have not been captured in this analysis.

Governments

Increased rates of testing may result in the Government incurring additional costs to fund MBS pathology services or preventative treatment. These costs have not been captured in the analysis.

Life insurers

As outlined above, the cost of adverse selection under a total ban can be estimated as $899,588.30 per annum. Under a partial ban, this cost could be reduced to a range of $269,876.50 (assuming a 70 per cent decrease in those foregoing genetic testing) and $809,629.50 (assuming a 10 per cent decrease in those foregoing genetic testing).

Regulatory Burden Measurement

Administrative Costs: Nil. Life insurers will only be required to demonstrate compliance in the events of a suspected breach. In accordance with the Regulatory Burden Measurement Framework guidance, non-compliance and enforcement costs are excluded. Insurers already maintain records and there are no additional administrative costs.

Substantive compliance costs: $2,259.60. Life insurers will need to update their policies and underwriting procedures to reflect the updated financial limit. Given a financial limit already exists, there would be minimal effort required to update documentation. These one-off costs can be calculated as follows:

Labour cost = (Time required to update policies × Labour cost per x hour non-wage labour on-cost multiplier) × (Times policies will need to be updated × Number of life insurers)

Labour cost = (1 hour X $53.80 X 1.75) x (1 x 24[30]) = $2,259.60

Delay costs: Nil. There are no application or approval delays incurred under this approach.

Average Annual Regulatory costs				
Change in costs	Individuals	Business	Community organisations	Total change in cost
Total, by sector	$0	$225.96	$0	$225.96

Assessment

The benefits of legislating a financial limit can therefore be estimated as between $132,421 and $9,699,838.25 per annum, with individual health benefits for between 4 and 293 individuals.

The costs can be estimated as between $809,855.46 and $270,102.46 per annum.

This options therefore provides a net benefit of between -$677,434.46to $9,429,735.79, with health benefits for between 4 and 293 individuals. The average net benefit can therefore be calculated as $4,376,150.67.

Enforcement bodies

There was significantly less engagement during the consultation regarding options for enforcement bodies.

4.4 Option 2A – The Australian Human Rights Commission (AHRC)

In its submissions to the public consultation, the AHRC noted that '… enforcement action by an appropriate financial services regulator… is likely to be more effective than seeking to give the Commission a new enforcement role in what is a highly specific and technical area that extends beyond the Commission's usual realm of expertise'.

As identified by the AHRC, its current role and expertise is not that of a government regulator. The AHRC does not have enforcement powers, or any compliance capability. Consequently, if the government were inclined to give this function to the AHRC, it would be necessary for the AHRC to significantly change its mandate and operations (including acquiring new regulatory and compliance skills) to perform as the regulatory body of the ban.

Given the above, as well as the potential lack of familiarity consumers may have with the AHRC, there is limited benefit and significant detriment associated with assigning an enforcement function to the AHRC.

Costs to Government

The AHRC would incur initial and ongoing costs in regulating the conduct of life insurers and conducting supervisory activities to monitor compliance with additional obligations. This includes the cost to upskill staff responsible for monitoring and enforcing new obligations.

These costs can be calculated as follows:

[30] Number of life insurers regulated by APRA in accordance with section 21 of the Life Insurance Act.

Labour cost = (Time required to investigate potential non-compliance × Labour cost per hour x hour non-wage labour on-cost multiplier) × (Times investigations will occur × Number of potential breaches per year + routine compliance checks)

Labour cost = (3 hours X $52.00 [31] X 1.75) x (1 x 12+20[32]) = $8,736.00

Upskilling cost = (Time taken to upskill staff x Labour cost per hour x hour non-wage labour on-cost multiplier x number of staff)

Upskilling cost = (80 hours x $52.00 x 1.75 x 10) = $72,800.00

Total costs to Government: $81,536.00

Regulatory Burden Measurement

Administrative Costs: Nil. All administrative costs are captured in AHRC's ongoing activities.

Substantive compliance costs: Nil. All compliance costs are captured in AHRC's ongoing activities.

Delay costs: Nil. There are no application or approval delays incurred under this approach.

4.5 Option 2B – The Australian Securities and Investments Commission (ASIC)

ASIC currently has responsibility for enforcing consumer protections under the Insurance Contracts Act, ASIC Act and Corporations Act, including the duty to take reasonable care not to make a misrepresentation, the duty of utmost good faith, and unfair contract terms regime. In addition to familiarity with financial services more broadly, ASIC has extensive experience regulating and investigating the conduct and operation of life insurers, rendering it well equipped to enforce any new obligations. ASIC has further indicated that it is able to absorb responsibility for overseeing any new regulations, without adversely impacting current operations.

Costs to Government

ASIC would incur ongoing costs in regulating the conduct of life insurers and conducting supervisory activities to monitor compliance with additional obligations.

These costs can be calculated as follows:

Labour cost = (Time required to investigate potential non-compliance × Labour cost per hour x hour non-wage labour on-cost multiplier) × (Times investigations will occur × Number of potential breaches per year + routine compliance checks)

[31] This rate is based on Employee Earnings an...~https://www.abs.gov.au/statistics/labour/earnings-and-working-conditions/employee-earnings-and-hours-australia/latest-release#data-downloads Data cube 6. Full-time non-managerial employees paid at the adult rate, average hourly cash earnings for Public administration and Safety

[32] Number of potential breaches based on average of FSC and CALI data for annual life insurance applications adversely impacted by genetic test results, in which 10 per cent of cases are estimated to raise non-compliance concerns. Routine compliance checks estimated at 20 application reviews annually.

Labour cost = (3 hours X 52.00 [33] X 1.75) x (1 x 12+20[34]) = $8,736.00

Regulatory Burden Measurement

Administrative Costs: Nil. All administrative costs are captured in ASIC's ongoing activities.

Substantive compliance costs: Nil. All compliance costs are captured in ASIC's ongoing activities.

Delay costs: Nil. There are no application or approval delays incurred under this approach.

5. Who did you consult and how did you incorporate their feedback?

Purpose and objectives of consultation

Treasury consulted on the use of genetic testing results by life insurers over a 9-week period, from 27 November 2023 to 31 January 2024. The consultation sought to better understand how the issue impacted various stakeholders, as well as test the feasibility of a range of policy responses. This information was used to ensure that the selected response adequately considered the views of all relevant stakeholders.

During the consultation period, two stakeholder roundtables were held, one with impacted consumers, and one with genomic health professionals.

1,009 unique written submissions were received in response to the consultation paper, with 945 from individuals, and 64 submissions from various groups, industry associations and organisations.

There was also ongoing engagement with both the Department of Health and Aged Care and the Attorney-General's Department.

This is a broad group of stakeholders that captures the diversity of views and interests related to this topic.

Stakeholder views

The vast majority of submissions (981 or 97 per cent) indicated support for implementing a total ban on the use of adverse genetic testing results by life insurers. This was consistent across all categories of respondents, including health care practitioners and associations.

Many submissions cited personal examples of how the current regulatory framework has impacted decisions regarding genetic testing (for either the respondent, their family members or their patients) and their subsequent ability to access life insurance. Two hundred and two submissions (20 per cent)

[33] This rate is based on Employee Earnings an...~https://www.abs.gov.au/statistics/labour/earnings-and-working-conditions/employee-earnings-and-hours-australia/latest-release#data-downloads Data cube 6. Full-time non-managerial employees paid at the adult rate, average hourly cash earnings for Public administration and Safety

[34] Number of potential breaches based on average of FSC and CALI data for annual life insurance applications adversely impacted by genetic test results, in which 10 per cent of cases are estimated to raise non-compliance concerns. Routine compliance checks estimated at 20 application reviews annually.

noted instances of individuals delaying or foregoing genetic testing due to life insurance related concerns.[35]

There was significantly less engagement from respondents regarding the most appropriate enforcement body.

A summary of responses to the consultation is provided below:

Preferred policy response			
Option	**Individual Submissions**	**Group submissions**	**Total**
Total ban	930	51	981
Partial ban	1	0	1
Financial limit	2	2	4
Partial ban and financial limit	0	4	4
No Government intervention	1	1	2
Other	11	6	17
Total	**945**	**64**	**1,009**

Preferred policy response by respondent type (group submissions only)					
Respondent	**Total ban**	**Financial limit**	**Partial ban and financial limit**	**No Government intervention**	**Other**
Insurer/ reinsurer	0	0	2	0	0
Foundation/ organisation	24	1	0	0	3
Industry association	11	1	2	1	1
Other	16	0	0	0	2
Total	**51**	**2**	**4**	**1**	**6**

[35] Treasury notes that the percentage of individuals delaying or foregoing genetic testing identified during the public consultation is likely inflated, given both the self-selecting nature of the responses and the fact that responses were not limited to a particular year

Preferred policy response by respondent type (individual submissions only)					
Respondent	**Total ban**	**Financial limit**	**Partial ban**	**No Government intervention**	**Other**
Consumer	860	1	0	1	10
Health care practitioners	58	0	1	0	0
Researcher	9	0	0	0	0
Other	3	1	0	0	1
Total	**930**	**2**	**1**	**1**	**11**

Preferred enforcement body			
Option	**Individual Submissions**	**Group submissions**	**Total**
AHRC	3	7	10
ASIC	2	6	8
Combination	0	26	26
Other	2	0	2
N/A	938	25	963
Total	**945**	**64**	**1,009**

Submissions that indicated life insurance concerns has delayed genetic testing			
Delayed testing?	**Individual Submissions**	**Group submissions**	**Combined**
Yes	142	0	142
Others	32	28	60
No	42	0	42
N/A	729	36	765
Total	**945**	**64**	**1,009**

Stakeholder views of preferred option

The overwhelming majority of stakeholders supported the proposed model of a total ban, without any modification to the proposal.

However, a minority of submissions (< 1 per cent) raised concerns regarding the impact of a total ban on the profitability of the life insurance industry. These concerns were primarily expressed in submissions provided by insurers, reinsurers and financial advisers.

- "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" – CALI submission.

- "There is a risk of financial detriment to all stakeholders in the insurance ecosystem as a result of customer behaviour in adverse selection, but this is difficult to quantify currently" – Swiss Re submission.
- "The Australian life insurance market's financial health and sustainability appear precarious, as seen by the recent reductions in life insurers, lives insured, new business, and increases in premiums. Continued significant increases in premiums and the need for APRA regulatory intervention have put further pressure on the industry. Adding policy settings that may adversely affect the financial health of life insurance pools is likely to put additional pressure on their economic viability and lead to premium shocks, resulting over time in fewer Australians being able to afford and maintain coverage" - Financial Advice Association of Australia submission.

Reflecting the concerns articulated above, the impact of adverse selection has been considered and included in the net benefit calculations above. Mitigating factors, including the requirement to disclose both diagnoses and relevant personal and family medical history, have also been considered in the analysis.

Given the concerns regarding longer-term impacts to the profitability and viability of the life insurance market, the preferred option has been modified to include 5-yearly reviews. These reviews will provide a mechanism for Government to assess the effectiveness of the regime, engage with relevant stakeholders, monitor and respond to any impacts on the life insurance market, and consider whether any changes to the ban are required. Should any of the impacts outlined above eventuate, the Government will be well positioned to respond swiftly.

6. What is the best option from those you have considered and how will it be implemented?

Recommended options

Of the options outlined above, Treasury considers implementing a total ban on the use of adverse genetic testing results by life insurers to be the best option **(Option 1B)**, regulated and enforced by ASIC **(Option 2B)**. The entire regime would be subject to regular 5-yearly reviews.

How recommended option was selected

The objective of Government intervention in this instance is to reduce, to the greatest extent possible, the number of Australians delaying or foregoing genetic testing due to life insurance concerns. The Treasury's analysis above has determined that legislating a total ban would have the highest likelihood of comprehensively achieving this objective, with no unacceptable adverse impacts.

A total ban would achieve this objective by providing certainty to consumers and medical professionals that undertaking genetic testing, or participating in medical research involving genetic testing, would not impact their ability to obtain life insurance.

This approach would address all concerns raised in the A-GLIMMER report, reflect the recommendations of the recent Senate Standing Committee on Community Affairs report, and align with the sentiment expressed by the overwhelming majority of submissions.

Under this approach, there would be no life insurance-related reasons for consumers to delay undertaking genetic testing or participating in research involving genetic testing. Additionally, health care practitioners would no longer need to raise life insurance concerns when discussing treatment options with patients, and the simplicity of this approach would make it easily communicable and understandable for all parties.

In conducting the cost benefit analysis, this option offered the highest potential benefit (between $1,257,999.50 and $13,837,994.50 per annum), with a cost ($908,626.70 per annum) similar to other options, leading to an average net benefit of $6.6m. Additionally, of all options considered, this approach would most significantly reduce (likely to zero) the number of individuals delaying or foregoing genetic testing due to life insurance concerns, leading to improved individual and public health outcomes. This demonstrates that option 1B provides the greatest net benefit, and is therefore the preferred option.

Although there is limited evidence to indicate that adverse selection may present a significant issue for the life insurance industry, implementing 5-yearly reviews will enable the Government to monitor this risk. These reviews will provide a mechanism for Government to assess the effectiveness of the regime, monitor and respond to any impacts on the life insurance market, and consider whether any exceptions to the ban are required. These reviews would also reflect recommendations made in a range of submissions, including from CALI and the Actuaries Institute. Further details of the eventual review mechanism will be decided during the legislative design process.

Regarding regulator options, ASIC currently has responsibility for enforcing consumer protections under the Insurance Contracts Act, ASIC Act and Corporations Act, including the duty to take reasonable care not to make a misrepresentation, the duty of utmost good faith, and unfair contract terms regime. ASIC's knowledge and expertise in administering and enforcing financial services, including life insurance regulation involving consumer protections, make it well equipped to enforce new obligations. Conversely, the AHRC is not an established and experienced regulator, and it would require a significant shift in function and uplift of capability for the AHRC to perform this role.

Accordingly, Treasury's analysis supports the preferred option of ASIC being given regulatory authority for the ban.

This is consistent with the AHRC's preference for an existing financial system regulator to oversee any new obligations, this makes 2B the preferred option.

Implementation process

Given the nature of the proposed intervention, ongoing engagement with the Department of Health and Aged Care and the Attorney-General's Department will be undertaken to determine the most appropriate method for implementing the changes. Additionally, sufficient time (to be determined in conjunction with relevant stakeholders) would be provided to enable CALI to update the Life Insurance Code of Practice, life insurers to establish compliant processes and procedures, and ASIC to develop protocols for enforcing any new obligations (it is estimated approximately 3 months would be required by industry).

Treasury will consult with the life insurance industry and relevant advocacy groups on key implementation processes and issues, which will include articulation of all new obligations. Insurers will then be responsible for communicating these changes to applicants. The Department of Health and Aged Care will utilise existing channels and stakeholder engagement forums to communicate changes to the broader medical community. These activities will be supplemented by the Assistant Treasurer, Minister for Health and Aged Care, and Attorney-General.

Risks to implementation

The implementation risks of the proposed reform are below, including possible implementation challenges and subsequent mitigating actions.

Poor compliance: If life insurers consider that the new restrictions impose too heavy a burden, it could lead to non-compliance and render the amendments ineffective.

- ASIC, in its role as the enforcement body, would be responsible for monitoring compliance with any new obligations and taking appropriate enforcement action. However, there is unlikely to be intentional non-compliance, given CALI has already indicated support for some form of Government intervention. ASIC is adequately resourced to respond to this risk and new obligations are not expected to be overly burdensome. Additionally, the simplicity of these reforms will enable consumers to more easily identify potential non-compliance.

Severe financial impacts for life insurance industry: There are concerns a total ban on the use of adverse genetic testing results by life insurers may impact the viability of the life insurance industry, as consumers with adverse test results take out higher amounts of cover than they otherwise would have (adverse selection).

- There are existing mitigants to this risk (for example disclosure requirements) and any unintended financial impact on insurers could be monitored through regular and ongoing engagement with both insurers and peak bodies, as well as evaluation against past financial performance. This impact would also be a key focus of the 5-yearly reviews of the ban.

Lack of consumer awareness: Some consumers may be unaware of changes to the regulatory framework and may therefore continue delaying genetic testing for fear of life insurance implications.

- As outlined above, the Department of Health and Aged Care will communicate changes to the medical community, who will then interact directly with those considering genetic testing. Life insurers will also need to update application documentation to clearly communicate that applicants are no longer required to disclose adverse genetic testing results, as well as implement changes to their practices to support this. Similarly, as part of their enforcement and oversight role, ASIC could consider including information on the new restrictions on the MoneySmart website.

7. How will you evaluate your chosen option against the success metrics?

The objective of the policy intervention is to reduce the number of Australians delaying or foregoing genetic testing due to life insurance concerns.

The performance of the policy will be assessed via ongoing monitoring and 5-yearly reviews, undertaken by the Treasury and supported by a small secretariat. It is expected that the review secretariat will bring the necessary skills and experience to conduct reviews of this nature.

Ongoing reviews are necessary given that impacts to the life insurance industry may take many years to manifest. Noting the range of confounding factors outlined above (for example, the decreasing cost of testing), identifying changes to consumer behavior driven by this intervention will be challenging.

During the reviews, the performance of the policy will be measured through a range of mechanisms. This includes through the collection of statistics of the kind set out in the A-GLIMMER report. For

example, surveys of health care practitioners and individuals engaging or considering engaging in genetic testing will be undertaken, including questions such as 'How often did patients delay predictive testing due to life insurance concerns?', 'How often did patients decline predictive testing due to life insurance concerns?' and 'Would you have proceeded with this genetic testing under the previous regulatory framework?'. The results of these surveys will be tracked over time to determine whether the policy has been effective in eliminating concerns regarding genetic testing and access to life insurance. The Treasury secretariat will be responsible for coordinating and collecting this survey data.

Additionally, interrupted time-series analysis will be used to track the number of MBS genetic and genomic pathology tests provided before and after any Government intervention (noting that this figure would not include 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). Analysis will be undertaken by the secretariat to determine whether any impact can be identified and attributed to the intervention. Services Australia currently records the number of MBS genetic and genomic pathology services provided, and this information is publicly available. No additional resources are required for Services Australia to continue performing this function.

The impact of the policy on the viability of the life insurance industry (which may be impacted due to potential adverse selection) will be monitored through regular and ongoing engagement with both insurers and peak bodies, as well as evaluation against past financial performance.

Treasury regularly engages with the life insurance industry on a range of matters, and no additional resourcing is required to continue this function. APRA currently publishes statistics on the performance of the life insurance industry on a quarterly basis. These statistics contains industry aggregate summaries of financial performance and position, investments, claims, solvency, capital adequacy and management capital, as well as details on the performance of individual product groups. APRA additionally publishes life insurance institution-level statistics, which relate to financial performance, position and capital adequacy, on a biannual basis. This information is publicly available, and no additional resources are required for APRA to continue performing this function.

Given the potential impacts to First Nations people, Treasury will continue to engage with the National Indigenous Australians Agency as part of the evaluation of the efficiency and effectiveness of the policy.

A comprehensive monitoring and evaluation plan will be developed by Treasury post Cabinet decision. This will include identification of required data and allocation of responsibility for collection. Treasury has engaged, and will continue to consult with, the Australian Centre for Evaluation, in order to support the design of the monitoring and evaluation methodology.

Appendix A - IA status at each major decision point

Treasury engaged with the Office of Impact Analysis throughout the policy development process. The status of the Impact Analysis at each major decision point is detailed in the table below:

Decision Point	Timeframe	Status of Impact Analysis
Government decision to investigate nature and extent of problem	August 2023	Undeveloped

Authority provided to undertake consultation	November 2023	Undeveloped
Policy options for consultation developed	November 2023	Undeveloped
Consultation with stakeholders	November 2023 – January 2024	Consultation used to collect data to support IA. Early draft IA not used as basis for consultation.
Internal interim decision	May 2024 – August 2024	Several drafts of IA sent to OIA for informal assessment
OIA 1st Pass Final Assessment	August 2024	IA for first pass assessment presented to OIA.
OIA 2nd Pass Final Assessment	August 2024	IA for second pass assessment presented to OIA. OIA first pass comments addressed in IA and certification letter.
Final policy decision to proceed with proposal	September 2024	To be informed by IA that has been through final assessment by OIA

Appendix B – Background Information

What is life insurance?

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.

What is genetic testing?

Genetic testing investigates a person's genetic variants and changes, some of which may contribute to the risk of developing a health condition. 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 5,000 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 pre-symptomatic 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 pre-symptomatic 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. Pre-symptomatic 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 pre-symptomatic 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.

What is the current legal framework?

Under the Insurance Contracts Act, 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 DDA 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 DDA, 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 AHRC, 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.

When were concerns first raised?

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 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.

How did the industry respond?

Following the inquiry, the FSC introduced the Moratorium on 1 July 2019. The Moratorium 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.[36]

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.

[36] APRA December 2022 LRS 750 data

- 73 cases (9 per cent) were adversely impacted by a genetic test result, all of whom were seeking cover above the 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).

Data provided by CALI members in 2022 indicated that of the 1,674 instances where a genetic test was disclosed in 2022:

- In 1,353 cases (80.8 per cent) the genetic test had no impact on the final decision
- 90 cases (5.3 per cent) were adversely impacted by a genetic test result
- 231 cases (13.8 per cent) were positively influenced by a genetic test results.

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.

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

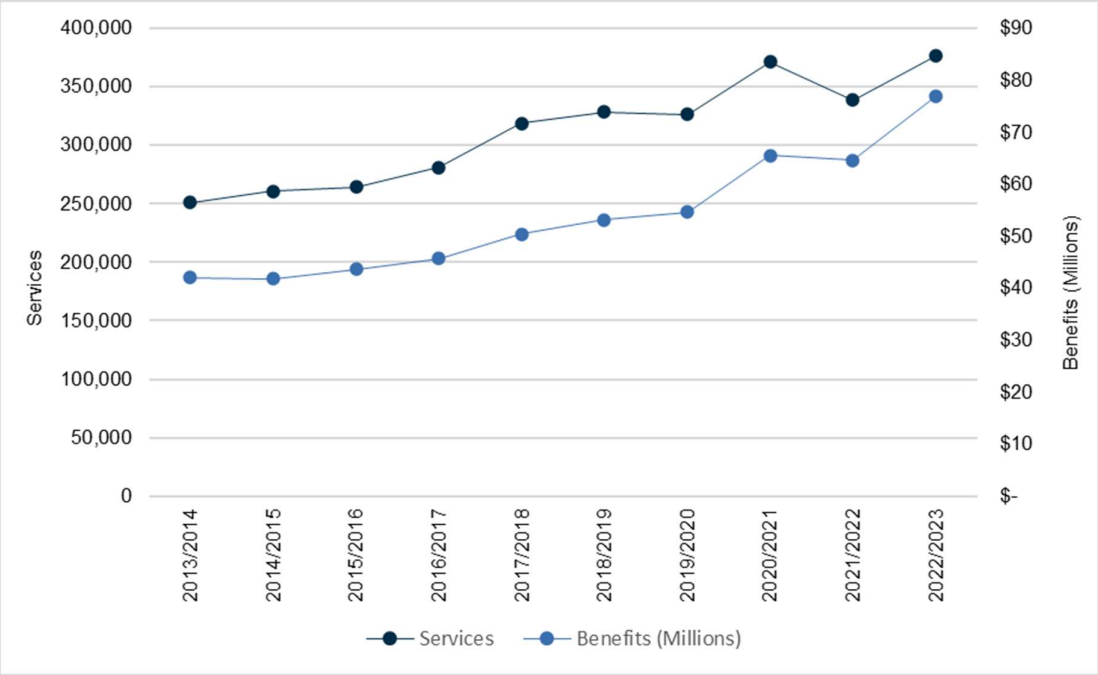
In June 2022, the Council of Australian Life Insurers (CALI) was established as the life insurance industry's new representative body. As of October 2023, CALI's 19 members represent 99 per cent of the life insurance market and all reinsurers in Australia. From 29 September 2023, CALI took over ownership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

How prevalent is genetic testing?

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[37]



[37] Services Australia, *Medicare Group Reports* (Category 6 – Pathology Services, P7 Genetics data only), Medicare Statistics website, n.d., accessed 1 November 2023.