



# Ban on the use of adverse genetic testing results in life insurance

Consultation paper

February 2025

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# Consultation Process

## Request for feedback and comments

The purpose of this consultation paper is to seek stakeholder input on issues relevant to the design of the Government's measure to ban the use of adverse genetic testing results in life insurance. Feedback is sought on the proposed design of the ban to ensure that the measure is implemented with clarity, certainty, and without ambiguity. Interested parties are invited to provide responses to one or more of the consultation questions outlined in this paper and comment on implementation considerations more generally.

Interested stakeholders are invited to comment on the issues raised in this paper by 12 March 2025.

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

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

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

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|-----------|---|
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The principles outlined in this paper have not received Government approval and are not law. This paper is merely a guide to support discussion on how the principles might operate.

# Ban on the use of adverse genetic testing results in life insurance

## Background

Genetic and genomic testing (hereafter ‘genetic test/testing’)<sup>1</sup> technology is reshaping clinical practice and the way medical practitioners prevent, diagnose, treat and monitor a range of heritable conditions, cancer predisposition syndromes, and cancers. Genetic testing is a rapidly evolving field, with an abundance of new tests being investigated and developed, and the use of genetic testing is becoming increasingly prevalent.

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, evidence from stakeholder consultation indicates that Australians are 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.

During consultation, stakeholders have attributed this to the current regulatory framework, under which life insurers can request and use consumers’ genetic testing results when considering whether, and on what terms, to offer life insurance policies. This is allowable under section 46 of the *Disability Discrimination Act 1992* (DDA), which provides that it is not unlawful to discriminate against a person on the grounds of a disability by:

- refusing to offer a life insurance policy, or
- offering a life insurance policy under different terms or conditions than would be offered if the person did not have the disability

where the discrimination is reasonable, based upon:


- actuarial or statistical data and other relevant factors, or
- other relevant factors, in the absence of relevant data.

This applies where the person already has, has previously had, may have in the future, or is imputed to have, a disability.

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

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



In response, Australia's life insurance industry introduced a partial moratorium on the requirement to disclose genetic test results in 2019. The moratorium, which is part of the Life Insurance Code of Practice (the Life Code), provides that subscribing insurers can only ask for or use the results of a genetic test where the cover applied for is above certain financial caps (which depends on the type of life insurance sought), and can in no circumstances ask individuals to disclose results of genetic tests taken as part of medical research conducted by an accredited university.

Although this moratorium is in place, stakeholder consultation indicates that there is widespread consumer and medical practitioner confusion and misunderstanding of its operation. This was documented in Monash University's *Australian Genetics & Life Insurance Moratorium: Monitoring the Effectiveness and Response* (A-GLIMMER) report of June 2023. The report found that under the moratorium, there continued to be stakeholder uncertainty and confusion over how the moratorium operates and the impact genetic testing can have on an individual's life insurance. Additionally, the A-GLIMMER report found that the financial limits of the moratorium are likely insufficient, and that stakeholders considered the industry-led model uncertain and had a low level of trust in it. The A-GLIMMER report identified legislation as a preferred alternative.

In late 2023 - early 2024, Treasury undertook public consultation to seek feedback on the impacts of life insurers using genetic test results in underwriting on genetic testing and research, as well as a range of potential policy responses.


On 11 September 2024, the Assistant Treasurer, the Hon Stephen Jones MP, announced the Government's decision to legislate a total ban on the use of adverse genetic testing results by life insurers.

## Policy intent of legislated ban

The Government's objective in introducing a legislative ban is to reduce, to the greatest extent possible, the number of Australians delaying or foregoing genetic testing and/or participating in clinical research involving genetic testing that may indicate their predisposition for future disease due to concerns about the possible impact on their life insurance. The ban is intended to provide certainty that undertaking genetic testing or participating in medical research involving genetic testing (which may, or may not, result in adverse test results), will not impact an individual's life insurance premiums or ability to obtain life insurance cover. This will improve the ability for the significant medical, public health, and scientific benefits offered by genetic testing to be fully realised.

To meet this objective, the Government announced it will introduce a total legislative ban on requesting access to and use of adverse genetic test results in life insurance underwriting. This ban would provide certainty that the results of any genetic testing undertaken by individuals (performed either for personal medical reasons or as participants in clinical research) cannot be requested or used by life insurers when underwriting a life insurance policy.

However, the ban is not intended to remove life insurers' ability to obtain other information necessary for them to be able to risk-assess and underwrite life insurance policies effectively. Life insurers may



refuse to offer life insurance, or offer life insurance on less favourable terms, to individuals that have a genetic condition, or a predisposition to develop to a genetic condition established from non-genetic test result information (e.g. family history), provided that is done in compliance with the DDA.

In addition, the ban is not intended to prohibit life insurers from requesting and using information about a person's diagnosed conditions, even if that diagnosis was made via a genetic test (again, provided this is done in compliance with the DDA).

Further, the ban is not intended to prohibit life insurers from accessing and using genetic tests results consented to be released (volunteered) by an individual applying for life insurance (or their agent). A person may wish to volunteer genetic testing results in various circumstances, such as if there is family history of a genetically linked condition, but a genetic test result demonstrates they do not have the applicable gene(s), or where a person has a condition that has multiple disease-causing variants, and they can demonstrate that they possess a variant that causes less severe features of the condition. Allowing life insurers to consider genetic test results that have been consented to be released would allow individuals to produce those results that may favourably impact the terms and conditions under which they are offered life insurance, if they have such results and choose to disclose them.

It is proposed that the ban will have regulatory oversight from the Australian Securities and Investments Commission (ASIC) and regular five-yearly reviews to monitor the effectiveness of the ban. The ban is proposed to be implemented by amendments to the *Insurance Contracts Act 1984* (Insurance Contracts Act), enabling the necessary regulatory oversight by ASIC and avenues for dispute resolution available under that Act. It is proposed that a corresponding amendment also be made to the DDA to align with the measure.

The ban will operate in conjunction with other existing legislation, including regulations that require insurers to act in utmost good faith regarding any insurance contract, as well as the *Privacy Act 1988* (Privacy Act), which governs the collection, use and disclosure of an individual's personal information. Genetic information is considered sensitive information under the Privacy Act and is therefore generally afforded a higher level of privacy protection than other personal information, including additional protections relating to its collection, use and disclosure.

The following sections include discussion and questions relevant to designing the measure in a way that meets the above policy intent.

## Appropriately targeting the measure

The Government is consulting on the proposed design of the most effective way of targeting the ban to achieve the above-noted policy aims. The approach under consideration involves amendments to both the Insurance Contracts Act and DDA.

It is proposed that the Insurance Contracts Act contain the ban itself. That Act may:

- prohibit life insurers from requesting access to or using genetic testing results, regardless of type of test or the purpose for which the test performed (e.g. diagnostic, indicative of propensity for future disease, clinical research, etc);
- define the term ‘genetic test’ for the purposes of the measure (see below for discussion of the definition of ‘genetic test’); and
- include an exemption to allow life insurers to access and use any genetic test results that are consented to be released by an individual applying for life insurance (or their agent). See below for discussion of when a test would be considered to have this consent and hence be able to be used.

The Insurance Contracts Act may also include a clarifying provision that states that the change does not impact life insurers’ ability to request or use other (non-genetic test-related) relevant information, such as family history information, or information regarding any diagnosed conditions (regardless of whether that diagnosis resulted from a genetic test or not). Further, the ban will seek to ensure that the Insurance Contracts Act’s existing duty to take reasonable care not to make a misrepresentation, the duty of disclosure, and the duty to act in utmost good faith are maintained and apply to the ban (meaning individuals must disclose this information to an insurer).

It is proposed that a corresponding change be made to the DDA to make it unlawful to discriminate by refusing to offer a person life insurance or offering life insurance under different terms and conditions (including the rate of premium charged and coverage available) based on the results of the person’s genetic testing, unless that test result was consented to be released by that person (or their agent).

However, the DDA would continue to operate so that it would not be unlawful for life insurers to discriminate based on a person’s predisposition to develop a future disability, where that information was obtained by information other than a through genetic test results, provided that discrimination is reasonable, based upon actuarial data, statistical data and/or other relevant factors, for example as indicated by family history (in the absence of this data).

### Questions:

1. The Treasury invites comments on the proposed design option for the ban, and whether any modification(s) to the above option should be considered. This includes comments as to the feasibility of the option; whether it is likely to achieve the Government’s policy aims; and whether there are any practical, legal, or administrative considerations.
2. The Treasury invites comments on whether there are any specific implications of the ban for the duty to take reasonable care not to make a misrepresentation, the duty of disclosure, and the duty to act in utmost good faith.



## Defining ‘genetic test’

Regardless of the legislative design option selected for the ban, Treasury considers that it will likely be necessary to define the term ‘genetic test’ for the purposes of the ban. Treasury notes that the approach and way the definition of ‘genetic test’ is incorporated into legislation will be subject to the legislative drafting process.

Treasury understands that there are numerous types of human genetic tests, which examine different elements of an individual’s genetics and gene expression. The various available genetic tests have multiple different uses, with a subset being used to establish when an individual possesses genetic characteristic(s) that are known to establish their predisposition for future disease, while others do not have this use (such as those that inform a diagnosis, identify specific treatment options, examine the characteristics of a disease agent (such as a tumour), map an individual’s genome for examination with other data for clinical research purposes, etc).

There is no settled position or definition of the term ‘genetic test’ either within Australia or international. However, multiple international jurisdictions have defined the term ‘genetic test’ for the purposes of their own regimes, which legislate or codify different matters related to genetic testing and life insurance. These definitions vary in their technical complexity and specificity.

Of these international definitions, New Zealand is one of the most contemporary, and there is value in considering it as a starting point on how the Australian definition can be approached. New Zealand’s *Contracts of Insurance Act* defines ‘genetic test’ as:

- a) *a test that analyses any DNA, RNA, or chromosome for any purpose including the prediction of disease or vertical transmission risks, or monitoring, diagnosis, or prognosis (regardless of the source of the DNA, RNA, or chromosome); or*
- b) *a test that analyses any component of gene expression (for example, a protein) or any metabolite for the purpose of detecting or predicting genotypes, phenotypes, or genetic variants (whether or not there are other purposes for the test).*

Treasury is considering the possible definition, and what technical specificity is necessary for the Australian context as well as the need for a clear and unambiguous definition, considering the policy aims of the ban.

### Questions:

3. Treasury welcomes submissions as to how the term ‘genetic test’ should be defined for the purposes of the ban.

Further to the above, Treasury appreciates that, as the field of genetics and genomics is rapidly evolving, the definition of ‘genetic test’ adopted at the time of making the measure may need future

amendments to ensure the measure remains effective. This will be a focus of the scheduled 5-yearly reviews of the measure. However, amendments to the definition may be necessary more frequently than under the 5-yearly review schedule. Further, amendments may be necessary as quickly as possible to ensure new technologies are captured promptly, and this may need to occur on multiple occasions.

Treasury is therefore considering whether aspects of the definition may be better placed in subordinate legislation (e.g. the *Insurance Contracts Regulations 2017*) than in primary legislation (e.g. both the Insurance Contracts Act and the DDA). This would allow the Government the ability to ensure aspects of the definition can be efficiently kept up to date and reflect changes in technology without undue delay, while also maintaining appropriate parliamentary scrutiny.

#### Question:

4. The Treasury invites views on whether aspects of the definition of 'genetic test' for the purposes of the measure may be suitably placed in subordinate legislation.
5. The Treasury invites views on factors that may require aspects of the definition of 'genetic test' to be flexible and remain fit for purpose.

## Consent to the release and use of genetic test results

As noted above, to ensure individuals can voluntarily provide genetic test results that may be favourable to an individual's underwriting assessment(s), it is proposed the ban include an exemption to allow for individuals to formally and specifically consent to release genetic test results to life insurers. Consequently, and to avoid ambiguity, the ban may need to provide that life insurers can access and use genetic test results released by the effected individual (or their agent) when performing life insurance underwriting.

However, Treasury is alert to stakeholder concerns as to when genetic tests results should be considered as volunteered by the effected person, and hence are able to be used by the life insurer. For example, stakeholders have noted that it is possible that genetic test results that an individual does not wish to be considered as part of life insurance underwriting may be inadvertently forwarded to a life insurer (such as part of an individual's total health record) and that these should not be able to be considered. Stakeholders have submitted that in these cases, a life insurer should not be able to use the genetic test information in their underwriting as formal consent has not been given for this use.

Additionally, concerns have been raised about the use of genetic tests provided by individuals before the ban's implementation. For example, stakeholders have raised that genetic tests provided before the ban's implementation for the purposes of underwriting a policy could be considered consented to be released and/or used in perpetuity and used by a life insurer when underwriting any future policy for that individual.

To ensure genetic tests are only able to be considered by a life insurer when an individual intentionally consents to provide them, and are only considered for the purpose of underwriting the specific policy(ies) that the providing individual intends them to be used for, the Treasury is proposing that the ban's exclusion for tests that are voluntarily provided and consented to be released should require that insurers can only use genetic test results:

- where they were consented to be released in writing by the individual which they relate to, or their authorised agent; and
- for the purpose(s) of underwriting policy(ies) that they were provided in relation to (as specified in writing when supplied).

Where the above requirements are met, the ban may then operate to exclude the requirement that the life insurer cannot have regard to that test (i.e. voiding the ban for the test results and purposes prescribed by the supplying individual).

The Treasury is alert to the fact that this places the onus on the supplying individual to determine whether the test is likely to be favourable or detrimental to the underwriting assessment.

### Questions:

6. The Treasury welcomes submissions as to the above proposed approach to when/how genetic test results can be considered released under consent to a life insurer, and subsequently used in underwriting assessments.
7. Treasury welcomes submissions as to other possible approaches to when/how genetic test results can be considered consented to be released to a life insurer, and subsequently used in underwriting assessments.

## Enforcement options

ASIC is responsible for the general administration of the Insurance Contracts Act. As part of this, ASIC is conferred various enforcement options, including:

- ASIC may commence proceedings to pursue civil penalties for contraventions of prescribed civil penalty provisions. ASIC must make this application within six years of the contravention. If the court has made a declaration that a civil penalty provision has been contravened, the court can order the person who contravened the civil penalty provision to pay a pecuniary penalty to the Commonwealth.
- ASIC may issue infringement notices for alleged contraventions of prescribed provisions. Infringement notices are an administrative tool ASIC can use to deter and punish financial sector misconduct. Infringement notices may be used as an alternative to criminal or civil proceedings. If an infringement notice is complied with, including payment of the penalty, no further action

will be taken against the person and the payment is not considered an admission of guilt. However, if the infringement notice is not complied with, ASIC may pursue criminal or civil penalties.

Treasury is considering the nature of civil penalties and/or infringement notice enforcement options to the ban. This paper seeks feedback on how civil penalties and/or infringement notice enforcement options should apply.

In terms of individual avenues to seek remedies, inclusion of the ban under the Insurance Contracts Act may enable individuals to seek remedies for breach of the ban through the Australian Financial Complaints Authority (AFCA). Further, the DDA contains remedy provisions for where an individual believes that they have been unlawfully discriminated against. These provisions provide for complaints to be made to the Australian Human Rights Commission, for conciliation between parties, and provides for the possibility of court proceedings if conciliation fails.

Treasury is considering how these remedies under the Insurance Contracts Act and DDA would operate and interact (if at all) under the ban.


#### Questions:

8. Treasury welcomes comments as to the enforcement options available for the ban in the Insurance Contracts Act and the DDA.
9. Treasury also welcomes comments as to the interaction between enforcement options under both the DDA and Insurance Contracts Act.

## Existing policies and tests (prospectivity nature and implementation)

Treasury proposes that the measure be prospective in nature, applying to all new applications for life insurance from the date of implementation (factoring in any transition period - see below). Existing life insurance policies would not be impacted (but possibly varied – see below), and life insurers would not be required to reevaluate and/or reprice existing policies as if they had been applied for under the ban.

However, the ban will likely mean that individuals with existing policies that have been underwritten with regard to an adverse genetic test result, that person will be able to have this reconsidered by applying for a new policy. It is proposed that the application for a new policy would fall under the terms of the ban, and the adverse genetic test(s) that were used previously could not be used when underwriting the new policy. However, as discussed above, the person's family medical history and any diagnosed conditions could be accessed and used by the life insurer when underwriting a new policy.



In addition to the above, Treasury is considering how the ban should apply if/when an existing life insurance contract is varied (e.g. amount of cover increases, contract terms are changed, etc). That is, where a person has an existing policy that has been underwritten with reference to a genetic test, but the terms of that policy are varied, Treasury is proposing that whether the ban should operate to require the re-underwriting of the policy without the use of any genetic test.

Further, Treasury proposes that there be no limitation on the date at which an individual took a genetic test in the past. Consequently, genetic tests taken by individuals prior to the ban being implemented would be subject to the ban if the life insurance policy is applied for after the ban's commencement date. However, if a historic genetic test resulted in a diagnosis of a condition, this diagnosis would still need to be disclosed.

Individuals who have life insurance policies that are impacted by historic disclosure of genetic tests, could therefore apply for a new policy and not be required to disclose that test's result.

Additionally, in the case of new regulation, where warranted, the Government may legislate for an appropriate transition period for the regulated population to transition to the new regulatory regime.

### Questions:

10. The Treasury welcomes comments on the proposed prospective nature of the ban, and the inclusion of historic (pre-ban) tests from the ban from the date of implementation.
11. The Treasury welcomes comments as to how (if at all) the ban should affect variations of existing contracts.
12. The Treasury welcomes comments on how the ban could operate in relation to in-progress applications for life insurance.
13. What, if any, transition period should be provided for implementing the ban and why?

## Next steps

Feedback is sought on the questions throughout the paper. Your feedback will assist in the development of exposure draft legislation, which will be subject to public consultation. The Treasury notes that the specifications of the regulatory approach proposed in this paper are subject to change following feedback on this paper and throughout the legislative drafting process in the development of exposure draft legislation. Further consultation may be undertaken on an as-needed basis.