The Federal Department of Treasury
Insurance Division
Langton Crescent
PARKES ACT 2600

12 October 2025

RE: Treasury Consultation - Ban on the use of adverse genetic testing results in life insurance

Dear Treasury

I attach a submission to the public consultation on the exposure draft of the *Treasury Laws Amendment Bill 2025: Limiting the use of genetic information by life insurers.*

This submission is the product of wide collaboration, consultation, and consensus between a broad range of stakeholders, including genetic health professionals, researchers, consumer support groups, health and financial services advocacy organisations, professional member organisations and others.

This submission should be considered as representative of the views of more than 60 organisations (as well as many additional individuals) whose names are listed on the pages following.

Please reach out to Dr Jane Tiller at [redacted] with any queries.

Yours Faithfully

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Stakeholder comments in response to Exposure Draft of the *Treasury Laws Amendment Bill 2025: Limiting the use of genetic information by life insurers*

***This document refers to our previous submission to Treasury regarding its technical consultation on the design of the ban, which can be found here:* https://doi.org/10.26180/28551068.v1

The exposure draft (ED) and explanatory memorandum (EM) are well drafted and we commend Treasury and the Australian government on producing what is mostly an excellent legislative framework to give effect to the government's promise. We set out below a few key concerns that should be addressed to ensure the legislation is robust and effective.

Other than these concerns, we believe the ED represents a strong outcome for consumer protection. We recommend that the other provisions in the ED are retained in their current form unless they require strengthening or to harmonise with our recommendations. We would expect that none of the existing protections in the ED are removed or weakened through the consultation process.

SUMMARY OF RECOMMENDATIONS

1. Prospectively removing penalties from contracts of insurance affected by discrimination

1.1 Treasury seek advice from the Australian Government Solicitor regarding how the legislation can give effect to the Government's promise to prevent all discrimination on the basis of genetic results.

1.2 Insertion of a new definition for ***affected policy***

1.3 Insertion of a requirement that insurers remove the penalties, loadings or exclusions applied on the basis of protected genetic information at the time of annual premium adjustment (and an associated offence with penalties).

1.4 Changes to the definition of ***life insurance contract decision*** to include variations of life insurance contracts proposed by insureds with affected policies, and to clarify that premium adjustments are considered 'variations'

1.5 Changes to the EM to clarify the change in Rec 1.4.

1.6 Consequential changes to section 46 of the DDA, to capture the changes in Recs 1.3 and 1.4.

2. Definition of *clinical diagnosis*

2.1 Changes to the definition of ***clinical diagnosis*** to clarify that a diagnosis must be manifested with signs or symptoms of disease.

2.2 and 2.3 Changes to the EM to clarify the changes in Rec 2.1

3. Inferring genetic test results from ongoing medical care

3.1 Expansion of the definition of ***protected genetic information*** to include genetic information inferred from other information collected about an individual.

3.2 Changes to the EM to explain the changes in Rec 3.1

3.3 Restriction of the exclusion of ***protected genetic information*** to first-degree relatives, in accordance with the Council of Life Insurers (CALI) Code of Practice

3.4 Insertion of an additional definition for ***first-degree genetic relative***

3.5 Changes to the EM to clarify the changes in Rec 3.3.

4. Application of penalty provisions

4.1 Changes to the definition of ***life insurance contract decision*** to include decisions whether to consider or delay considering a life insurance application.

4.2 Insertion of a new provision to prohibit solicitation (with associated penalty provisions).

4.3 Insertion of a new section to prohibit insurers from using genetic tests as the basis of preferred risk underwriting.

4.4 Changes to the EM to clarify the changes in Rec 4.3.

5. Additional drafting considerations for the amending legislation

5.1 Changes to the DDA to incorporate changes recommended at Recs 3.1 and 4.1.

5.2 Insertion of a new section to mandate the collection of certain information by life insurance companies to help inform the government's mandatory review of the legislation.

5.3 Consideration of any requirements to ensure AFCA can consider complaints arising under the new legislation.

6. Additional considerations for amendments to the Explanatory Memorandum

6.1 Clarifications to the EM at paragraph 1.8 regarding the terms of the current Moratorium

6.2 Clarifications to the EM at paragraph 1.12 regarding which countries have implemented legislation to ban genetic discrimination

6.3 Clarifications to the EM at paragraph 1.20 (and 1.64) regarding the discretion available ASIC to pursue criminal and civil proceedings.

6.4 Clarifications to the EM at paragraph 1.36 regarding financial advisers discussing the voluntary disclosure exception with clients

6.5 Clarifications to the EM at paragraph 1.52 regarding retained protection for genetic test information after a clinical diagnosis

6.6 Clarifications to the EM at paragraph 1.60 regarding the inclusion of results of direct-to-consumer genetic testing in the definition of genetic test

1. Prospectively removing penalties from contracts of insurance affected by discrimination

In our previous submission, we discussed the importance of prospectively removing penalties from the policies of individuals who are currently discriminated against. This is a critical piece for fairness, justice, consumer certainty and giving effect to the intention of the ban as announced by Government in 2024. Many of the people who were featured in the media in the last 5 years, who wrote to their MPs and shared their stories with the Minister, will not be helped by the legislation as currently proposed.

Under the current drafting in the ED, the ban will apply in relation to life insurance contract decisions made on or after the date of commencement [Item 4; EM 1.98].

A life insurance decision is defined at item 1, section 11 of the ICA to only apply to those decisions an insurer may make in relation to an insured's application for a contract of life insurance. It thus does not capture those insureds who have ongoing long-term coverage whose only interaction is annual premium adjustments.

As set out in our previous submission at pp 16-18, individuals who have been paying premiums for many years, with a loading attached because of legal discrimination on the basis of genetic results, would be faced with an unfair choice of retaining cover with discriminatory penalties or cancelling their current policy and being re-underwritten on very unfavourable terms (due to the passage of time). These are individuals who have done the right thing, have declared their adverse results to insurers, have accepted the discriminatory penalties and in many cases paid additional sums to insurers over a number of years.

During the Assistant Treasurer Stephen Jones' press conference on 12 September 2024 where he announced the total ban, he made the following comment about the intent and effect of the promised reform:

"*Most life insurance contracts are annual contracts, renewed annually. So somebody renewing under the new law, the contract would have to be offered in accordance with the new law.* ***It is the government's very firm belief – and it will be reflected in the law – that the intent of that law is to ensure somebody is not discriminated against because they have had an adverse genetic test. It will be a very firm position, and that will be reflected within the law."***

The Minister was very clear that the intent of the law will be to ensure people are not discriminated against in any way because they have had an adverse genetic test. The clear expectation of the community, confirmed by the Minister's comments, is that the legislation will operate to protect not only people taking out contracts of life insurance for the first time, but also those who currently have life insurance policies which have been negatively affected by their disclosure of genetic information.

In the media release associated with the announcement, Minister Jones stated, "*I have met with countless people affected by this issue and thank them for sharing their stories and helping to drive this important change*". It is clear, based on this statement and his words at the press conference, that he intended that the law would help those people whose stories drove this policy reform.

Further, if the legislation fails to protect people who already have contracts of insurance in place with discriminatory terms applied, this is likely to have negative policy outcomes:

1) The public concern and outcry about the unfairness of this outcome may overshadow what is otherwise an excellent policy reform. The questions from the press at Stephen Jones' 12 September press conference were predominantly related to concerns about the impact of

this reform on people who had already experienced discrimination. It is to be expected that this concern from the press and the community at large will continue to feature in coverage of the policy reform if this issue is not resolved. This is especially so given the policy expectation clearly created by the Minister's comments at the press conference.

2) Public trust in the reform may be damaged by the perception that the law doesn't really protect everyone that it should that is, those who have already provided genetic information to life insurers will be penalised for doing so.. This may interfere with the broader policy aims of the reform, including reducing the deterrence that fears of genetic discrimination have on people's willingness to have genetic testing. A more robust legislative solution, that ensures that people who currently have policies affected by penalties on the basis of genetic test results will benefit as indicated by the Minister, will more effectively ensure public trust is maintained.

Recommendation 1.1. We recommend the Treasury seek advice from the Australian Government Solicitor regarding how the legislation can give effect to the Government's promise. We have made further recommendations about proposed amendments to the ED for consideration below.

In the Council of Australian Life Insurer's previous submission to Treasury, they highlighted the extremely small number of applications that receive adverse underwriting outcomes on the basis of genetic results – reporting that less than 0.05% of their underwriting decisions in 2022 resulted in adverse outcomes for consumers on the basis of genetic test results (a total of 90 cases). On this basis, the impact of removing loadings or exclusions prospectively for insureds who have been discriminated against already should be negligible in the context of the entire insurance market. Given the additional premiums collected from many of these individuals by insurers in the past, it is not unreasonable to ask insurers to apply modest resources to rectify the discrimination applied and cease to discriminate prospectively against current clients in a way that is unlawful for new life insurance applications. There is no suggestion that insurers should retrospectively refund premiums, only that penalties should be removed prospectively.

In our previous submission we recommended insurers should identify which individuals have received adverse underwriting outcomes on the basis of genetic test results, and remove the loadings/exclusions from each of them from the date of the ban's commencement (Recommendation 10.2). This does not require completely new underwriting to be undertaken, merely for adverse terms applied on the basis of genetic results to be removed. As set out in our previous submission, there are numerous cases where loadings or exclusions that have been applied to policies due to genetic results have been subsequently removed.

In Minister Jones' comments at the press conference as set out above, he said that most life insurance contracts are renewed annually and on that annual renewal they would be made in accordance with the new law. Unfortunately, however, most life insurance contracts are not renewed annually, but are guaranteed renewable. This means that the trigger of "annual renewal" is not one that will operate universally to rectify this issue going forwards. It also means that the presence of ongoing "historical" discriminatory contracts will persist for decades, rather than the issue phasing out within 12 months as it would if contracts were renewed annually.

However, we understand that premiums are generally adjusted annually, and other variations are sometimes introduced on this date to comply with regulatory requirements or incorporate other matters. Further, an insured person can at any time propose a variation to a contract to an insurer, and the insurer must consider and decide whether or not to agree to that proposal.

We recommend amendments be made to ensure that when annual premium adjustments are made, or an insured person with a policy that has been affected by discrimination in the past (an ***affected policy***), seeks a variation to remove the penalties, loadings or exclusions applied on the basis of their genetic test results, protected genetic information is not used in ways that contravene the Act.

Recommendation 1.2. We propose the following definition for "affected policy":

Affected policy means a contract of life insurance entered into before the ***commencement day*** where:

a) an insurer has taken into account the results of life insurance underwriting to apply penalties, loadings or exclusions to a life insurance policy; and
b) the penalties, loadings or exclusions were applied partially or fully on the basis of protected genetic information.

Recommendation 1.3 A section should be inserted to require that for each ***affected policy***, at the time of annual premium adjustment an insurer must remove the penalties, loadings or exclusions applied on the basis of protected genetic information. An offence constituting a failure to comply with this requirement may need to be inserted.

Recommendation 1.4 The definition of ***life insurance contract decision*** should be amended to include variations of life insurance contracts proposed by insureds with affected policies, and to clarify that premium adjustments are considered 'variations' as follows:

life insurance contract decision means a decision by an insurer on one or more of the following matters:

(a) whether or not to enter into, or to offer to enter into, a proposed contract of life insurance;

(b) the terms and conditions on which the insurer is to enter into, or to offer to enter into, a proposed contract of life insurance;

(c) whether or not to propose an extension, variation or reinstatement of a contract of life insurance, or to agree to a proposed extension, variation or reinstatement of a contract of life insurance (including a proposal initiated by an insured with an affected policy), where a variation includes an adjustment to the premium payable pursuant to the contract of life insurance;

(d) the terms and conditions on which the insurer is to propose an extension, variation or reinstatement of a contract of life insurance, or to agree to a proposed extension, variation or reinstatement of a contract of life insurance, (including a proposal initiated by an insured with an affected policy), where a variation includes an adjustment to the premium payable pursuant to the contract of life insurance.

* Note Recommendation 4.1 also recommends an addition to the definition of ***life insurance contract decision***.

Recommendation 1.5. The EM should be amended to insert a clarification as follows:

"If an insured proposes a variation of a contract of insurance to remove penalties that were applied (before the legislation commences) on the basis of protected genetic information, the decision of an insurer about whether or not to accept that variation falls within the definition of a life insurance contract decision. In deciding whether to agree to that variation, an insurer may not use protected genetic information in a way that has adverse consequences for the individual. Similarly, when annual premium adjustments are made, insurers must remove penalties in so far as they are based on information that is now protected genetic information."

Recommendation 1.6. This change will also require consequential changes to the proposed amendments to section 46 of the DDA, to capture these circumstances.

Possible Constitutional law issue

We understand that Treasury is concerned about potential drafting challenges associated with these recommendations, in relation to the potential that requiring insurers to modify the terms of contracts prospectively may constitute a breach of the requirement under s51(xxxi) of the Constitution that property must not be acquired other than on just terms.

We consider that there are strong arguments challenging whether such provisions would be disallowed by a Court on this basis, including arguments that this would be more akin to the "adjustments of rights and responsibilities" than the "acquisition of property".[1]

Assumptions about the existence of property rights in a contract notwithstanding, there must be an actual acquisition of property by the Commonwealth or another party[2]. If indeed the insurer is found to have a property interest in the contract, it is likely to be characterised as the right to charge additional premiums over the standard rate for people that the insurer assessed previously as being at higher risk, and the right to exclude coverage for certain conditions or health outcomes. Possibly it could be characterised as the theoretical financial value of a life insurance contract as underwritten, which is a value that is not fixed and changes over time. In these circumstances, it would likely be argued that this is a valuable property right, and reducing this right would detrimentally affect the insurer who entered into the contract on those terms in order to manage its portfolio risk.

However, a readjustment of rights is not necessarily an acquisition of property[3]. That is, just because an insurer is disadvantaged or has its right to continue to collect increased premiums (calculated based on protected genetic information) under an existing contract reduced by way of legislation, does not mean an acquisition has occurred. Further, is very unclear which part of the insurer's putative property right would be "acquired", or by whom, as a result of the proposed changes to the law.

It is highly arguable that there is no acquisition of property in circumstances where an insurer is required to prospectively cease to collect additional premiums on the basis of protected genetic information or to remove exclusions. While an insured may benefit from the legislation's effect of reducing the insurer's rights, this does not automatically mean that the insured has acquired the property interest of the insurer. The insured does not acquire any of the rights held by the insurer in respect of the contract, including the right to set and adjust premiums or the right to make decisions about coverage and exclude certain health outcomes from coverage. Nor does the insured acquire property from the insurer in the form of part of the value of the insurance contract as a profitable contractual agreement between parties. It is unclear what property or property right the insured would be acquiring if the argument is made that there is an acquisition of property under the contract arising from a legislative requirement that discriminatory provisions be varied to comply prospectively with the requirements of this legislation.

However, in the event that the government remains concerned about the risk of potential challenges to this aspect of the law, there are provisions which could be inserted to manage this risk. a

[1] *Nintendo Co Ltd v Centronics Systems Pty Ltd* (1994) 181 CLR 134; *Australian Tape Manufacturers Association Ltd v The Commonwealth* (1993) 176 CLR 480; *Commonwealth v Tasmania* (1983) 158 CLR 1

[2] *Australian Tape Manufacturers Association Ltd v The Commonwealth* (1993) 176 CLR 480; *Commonwealth v Tasmania* (1983) 158 CLR 1

[3] *Nintendo Co Ltd v Centronics Systems Pty Ltd* (1994) 181 CLR 134

provision like s 326A(4) of the *Australian Securities and Investments Commission Act 2001* (Cth) could be inserted to manage this risk. That section reads:

> Despite paragraphs (2)(a) and (b) and subsection (3) of this section, the amendments do not apply to a contract, or a term of a contract, to the extent that the operation of the amendments would result in an acquisition of property (within the meaning of paragraph 51(xxxi) of the Constitution) from a person otherwise than on just terms (within the meaning of that paragraph of the Constitution).

2. Definition of *clinical diagnosis* [item 1, section 11 ICA]

The definition of clinical diagnosis is somewhat circular and does not adequately distinguish between a diagnosis of disease that is symptomatic and predisposition to disease. The ambiguity in this definition is extremely likely to cause confusion and concern for individuals and clinicians, and most likely to result in the need for external determination, legal action and judicial clarification if it is not adequately addressed at this stage.

For the purposes of this legislation, it is critical that clinical diagnosis is defined to include only diagnoses that are made on the basis of medical signs or symptoms, not merely on an understanding that a particular genetic change leads to an increased risk of disease. This legislation explicitly preserves the right of insurers to legally use diagnoses of disease to discriminate. This creates a significant risk that the categorisation of a piece of genetic information as a diagnosis will be used by insurers to undermine the protections of the legislation. Thus, the definition of ***clinical diagnosis*** is a cornerstone of this protective regime, and absolutely critical as the bulwark between the protection intended by this legislation and the ability of insurers to discriminate against consumers. In our previous submission we provided further information about this issue at pp 4-5.

While the EM at 1.50-1.54 attempts to clarify this distinction, the legislation does not provide definitive criteria to ensure that the distinction between genetic information that is protected and a diagnosis that can be used by insurers to discriminate is crystal clear. Most clinicians are not considering implications for life insurance outcomes when making clinical diagnoses, and what amounts to a clinical diagnosis has evolved over time. Syndromes are often so named because they represent a well-understood risk of developing disease in future, with associated surveillance options and preventive measures, not because they are associated with the onset of disease at the time that "diagnosis" is made. While para 1.55 – 1.57 clarifies that regulations may be made to clarify such ambiguities, the legislation as drafted should remove as much ambiguity as possible, leaving the regulations to clarify future unanticipated situations. It should not be required to immediately seek to have regulations made to clarify ambiguities that should have been adequately addressed in the drafting of the legislative instrument.

This clarification is critical to reduce the deterrent effect of life insurance discrimination on Australians' willingness to have genetic testing. The current definition perpetuates and creates further uncertainty regarding whether identification of non-symptomatic "diagnoses" such as syndromes, as set out above, will be captured and used by life insurers. Lack of clarity and uncertainty about such issues will be repeated and amplified amongst groups of consumers and will entrench the current fears and deterrence, as people will continue to fear possible outcomes and advise each other to reconsider testing in case their result is miscategorised as a syndrome. Further, this will further damage consumer trust in the robustness of the legislation and its effectiveness in adequately protecting against discrimination on the basis of genetic results.

A definition for diagnosis was proposed at Recommendation 1.12 of our previous submission: "*A condition or diagnosis means a disease, illness or disorder, which has been diagnosed by a registered medical professional with appropriate training and expertise in the relevant field, and has manifested in a person with medical signs or symptoms that can be objectively measured, and which exist in a clinically significant way, beyond the existence of those signs or symptoms in a person without that condition or diagnosis. A genetic predisposition to disease is not a condition or diagnosis, even if it has been given a name. A genetic variant is not a sign or symptom of a condition.*"

Recommendation 2.1. The definition of diagnosis set out above should be reconsidered in light of the stark ambiguity inherent in the current drafting, and the critical nature of the distinction in terms

of the very intention of the legislation. At the very least, the definition of clinical diagnosis proposed in the ED should incorporate the subsequent proposed definition of "disease" and could be amended as follows:

"***clinical diagnosis***, in relation to an individual, means a clinical diagnosis made by any treating medical practitioner of the individual, with a ***disease*** that has manifested with medical signs or symptoms".

This amendment also requires consideration of the description of "a clinically diagnosed but dormant disease" at 1.54 of the EM. The current description is conceptually difficult to distinguish from a predisposition to disease if the proposed definition of diagnosis is not amended. With the proposed amendment, this explanation would be understood to apply to a disease that had shown symptoms (and been clinically diagnosed) but entered a phase with cessation of symptoms for a period of time. Manifestation of medical signs or symptoms at the point of the clinical diagnosis is critical. Our previous submission contains further discussion of this issue at pp 4-5.

To maximise clarity in this section, paras 1.42 and 1.54 of the EM could be amended as follows:

1.42 **Recommendation 2.2.** We recommend the following amendments:

"Clinical diagnosis' in relation to an individual means a clinical diagnosis made by any treating medical practitioner of the individual, with a ***disease*** that has manifested with medical signs or symptoms. This requirement reflects that such a judgement should only be made by a medical practitioner following their assessment of an individual's medical history, physical examination and results of relevant investigations and testing. To fall within the definition of clinical diagnosis, a disease must have manifested with medical signs or symptoms. This is intended to distinguish between the application of names to genetic predispositions by clinicians, who may label that application a "clinical diagnosis", and the diagnosis of diseases that have manifested with signs or symptoms.

An applicant should not be considered to have clinical diagnosis merely because they have signs or symptoms which could be associated with a disease, which exist at similar rates in the general population without that condition. For example, people with Lynch syndrome (a genetic predisposition to cancer) do not form colon (bowel) polyps at a rate measurably higher than the general population, but the risk of polyps becoming malignant is higher, which is why regular surveillance is so necessary and effective. Thus, the mere observation of polyps in a person with Lynch syndrome would not be considered a manifestation of a disease – only the development of cancer or of polyps with properties consistent with diagnosis of disease would be clearly considered clinically as a manifestation of Lynch syndrome.

1.54 **Recommendation 2.3.** We recommend the following amendments:

"The severity or ongoing manifestation of the disease that has been clinically diagnosed is irrelevant for the purposes of this exception. For example, a disease that has been clinically diagnosed but for which previous symptoms have ceased for a period of time ~~dormant disease~~ is still excepted from the meaning of protected genetic information.

3. Inferring genetic test results from ongoing medical care

The definition of protected genetic information (***item 3, section 33F ICA***) would benefit from an additional sub-clause to address the concerns raised on p3 of our previous submission. See also Recommendation 1.8 of our previous submission: *"The legislation should ensure that insurers are prohibited from using details of applicants' or family members' ongoing medical care (including but not limited to risk surveillance, medication prescription or participation in clinical trials) to refuse to consider applications until completed, inferring predictive genetic risk or discriminating against applicants."*

This is a critical point to address, given reports from Canada that insurers have been trying to avoid (and in some cases reportedly successfully avoiding) their ban through inferring genetic status by considering medical care. Given such "loopholes" or mechanisms used by insurers to attempt to avoid the intent of the legislation have been identified, they should be explicitly included in the body of the legislation and the EM, to send a clear signal that this behaviour by insurers breaches the Act.

As discussed in other sections, if these possible loopholes are not closed and insurers begin to use them, or consumers fear (based on reports from other consumers) they may be used and are uncertain about the status of this behaviour at law, this will perpetuate uncertainty and fear and continue to deter people from having genetic tests due to this fear.

While the definition of genetic test includes information about whether someone has had a genetic test, the inference of genetic risk based on medical care is a step further and is not currently clearly covered in the ED.

Recommendation 3.1. The suggested additional sub-clause is as follows:

33F Meaning of *protected genetic information*

(3) Genetic information is not excluded from being ***protected genetic information*** on the basis that it is inferred through the use of other information collected about an individual, including surveillance type or frequency, or eligibility for clinical trials, medication or other medical care.

Recommendation 3.2. Addition of the following text after para 1.49 in the EM section on "Meaning of protected genetic information" could be bolstered to provide an explanation as follows:

"The definition of protected genetic information is intended to cover the inference of genetic information through other information that may have been legally collected about an individual. For example, individuals with Lynch syndrome may have yearly colonoscopy from age 30 as part of their regular risk-reducing surveillance. An individual may be eligible for a prophylactic cancer drug due to having a *BRCA1* variant, or may be eligible for a clinical trial for cancer prevention. An insurer may receive information about the surveillance type and frequency, or entry to a clinical trial or prescription for a certain medication, and may infer the individual's likely genetic status from this information. This inferred genetic information is not excluded from being protected genetic information merely because it is inferred and not provided directly and cannot be used in any of the ways that protected genetic information are prohibited from being used under the Act."

Recommendation 3.3.

Further, the exclusion in **s33F (meaning of *protected genetic information*)** should be amended to align with the Council of Life Insurers (CALI) Code of Practice (**Code**). Currently, the exclusion in s33F(2)(b) excludes from the meaning of protected genetic information the name of a disease for which a genetic relative has received a clinical diagnosis. This is very broad, and means that disease diagnoses of distant relatives (such as fourth cousins) would also fall within this exclusion.

This is far broader than the information the life insurance industry actually advises consumers it will collect. At 4.15 (b) of the Code, it says "*If we ask you about any family history of illness, we will only ask you to tell us about… your first degree blood relatives (parents, children and siblings) without giving their names or dates of birth.*" It is critical that this Act does not undermine the protections available under the Code, or create a situation that provides less protection than the Code.

Thus, s33F(2)(a) could be amended as follows:

> "(2) However, neither of the following is protected genetic information about an individual (subject to subsection (4)):
>
> (a) the name of a disease for which the individual (or a first-degree genetic relative of the individual) has received a clinical diagnosis, whether or not the clinical diagnosis is based on or informed by genetic testing"

Recommendation 3.4. Clinically, the meaning of "first-degree genetic relative" is relatively clear. However, if deemed necessary, an additional definition could be inserted into s11 to add the following definition and maintain consistency with the Code:

"***first-degree genetic relative*** of an individual means a genetic relative of an individual who is parent, child or sibling of that individual".

This amendment would ensure that information about genetic relatives who are far removed from the insured, whose diagnosis of disease would not be permitted to be collected under the Life Code, would also fall into the definition of protected genetic information (ie would not be excluded).

Recommendation 3.5

The beginning of para 1.51 of the EM could also be amended to clarify this point, as follows:

"The exceptions preserve insurers and underwriters' ability to seek and use certain information about an individual's current state of health (including diagnosis of disease in first degree genetic relatives)."

4. Application of penalty provisions (s33H)

An issue arises around the definition of a ***life insurance contract decision*** and the constraints of the penalty provisions, which do not apply to solicitation alone. We consider the current drafting does not sufficiently capture behaviour by insurers that has been reported to us in the past.

We have set out below some potential scenarios that demonstrate the gaps in the current ED. In our view, the Privacy Act does not assist here, as these scenarios do not relate solely to the actual collection and storage of information by the insurer.

Scenario 1:

- an applicant has a family history of a condition that is known to have an associated genetic test;
- the applicant is working with a broker/financial adviser to canvass options for insurance (rather than applying directly to the insurer); and
- the broker makes initial inquiries, and the insurer tells the broker they will consider an application if the applicant has a genetic test and can show that they don't have the condition that runs in the family.

We have heard multiple stories of versions of this scenario, where brokers make inquiries and advise clients that their application might be considered once they have had a genetic test.

Arguably, this behaviour by the insurer would fall within the definition of ***solicit***. In this scenario, however there has been no ***life insurance contract decision***, as the definition currently only covers decisions whether to offer a contract of insurance, the terms of that contract, or decisions whether to vary and terms of the variation. A decision to delay considering an application does not fall within this definition, and the insurer has not yet declined the application.

Because of this, the penalty provisions would not be activated, because merely soliciting information is not prohibited or the subject of a penalty. Both 33H (1) and (2) require that information was solicited or used **AND** that a life insurance contract decision was made. This means that in this scenario, no prohibition is activated or penalty applicable, even though this should be prohibited under the Act. Whether or not the life insurance industry accepts or denies this occurring to date, it is clear that it is a gap in the legislation that should be closed to ensure it cannot happen.

By contrast with the current ED, the Canadian Genetic Non-Discrimination Act[4] contains prohibitions (with associated penalties) on collecting, using and disclosing the results of a genetic test (without written consent), in addition to the prohibition on requiring individuals to undergo genetic tests or refusing services on the basis of a refusal to undergo testing or disclose results.

Scenario 2:

- DNA screening at the population level becomes much more common, and all adults over a certain age become eligible for DNA testing for disease risk[5].
- Over time, having a DNA Screen result becomes the norm for a large number of people, especially young people applying for life insurance for the first time.
- Insurers start to offer "discounts" to people who voluntarily disclose their DNA Screen results which show low risk.

[4] https://laws-lois.justice.gc.ca/eng/annualstatutes/2017_3/index.html

[5] This is the goal of the Monash University DNA Screen study, and is not a fanciful consideration: https://dnascreen.monash.edu/media-publications.html

This scenario is not one that is currently reported, but one of concern for many stakeholders and frequently raised internationally as an important issue for consideration. Numerous stakeholders immediately raised this concern on review of the current ED. This would create a situation where people with high-risk genetic results are not technically discriminated against under the current terms of the law, but everyone with a low-risk result gets a "discount", which creates an effective penalty for those without a low-risk result. While the offer of "discounts" may not be currently a feature offered by life insurance companies, the legislation should anticipate as far as possible and address the risk of this outcome.

The life insurance industry has been aware for decades of this issue and the potential that insurers could start to offer "discounts" for "good" genetic tests to indirectly coerce the provision of genetic test results. In 1999, the Investment and Financial Services Association (IFSA) (the representative body for life insurance at the time) made an application to the Australian Competition and Consumer Commission (ACCC) for approval of its genetic testing policy.

A key aspect of the policy proposed by IFSA at the time (clause 4) was "***in order to prevent indirect coercion to undergo genetic tests, insurers will not use genetic tests as the basis of preferred risk underwriting (ie offering individuals insurance at a lower than standard premium rate)***".

The policy was considered and approved by the ACCC on 21 November 2000[6]. In its summary and decision, ACCC noted IFSA's submission that that "*insurers may create 'subcategories' of premiums based on genetic tests, with applicants being coerced to undergo genetic tests for insurance purposes*" (5.11, page 9). It also noted "*IFSA considers clause 4 of the policy to be necessary to allay public concern that an 'uninsurable genetic underclass' may develop if insurers were to seek out the 'good' genetic risks by offering them cheaper insurance*" (7.2, page 13).

ACCC further notes, "*ensuring IFSA's life insurer members do not require applicants for insurance to undergo genetic testing, and that applicants will not be indirectly influenced into undergoing such tests, is likely to result in benefit to the public. In particular, the Commission considers that there is public benefit in avoiding insurer-initiated coercion to undertake genetic testing*" (8.9, page 15).

We note that this aspect of the genetic testing policy appeared verbatim at 10.3 of the IFSA Standard 11 approved by the IFSA Board on 26 October 2005 (see Annexure 1). IFSA became the Financial Services Council (FSC) in 2010, and Standard 11 was next updated in December 2016 (see Annexure 2. This version of the Standard no longer contained the undertaking to not use genetic tests as the basis of preferred risk underwriting. There is no explanation in the document as to why this undertaking was removed. It is also absent from the current Council of Life Insurers (CALI) policy on genetics – the Moratorium on Genetic Tests in Life Insurance[7].

There is a clear need, as discussed at length in previous consultations and acknowledged by the life insurance industry, to allow consumers to voluntarily disclose genetic test results to insurers in scenarios where a person will otherwise be unfairly discriminated against on the basis of a family history of disease where the person has not inherited the genetic variant causing that disease. There is a clear distinction between using a favourable genetic test result to offset discrimination applied on the basis of family history of disease, and insurers offering "preferred risk underwriting" or "discounts off insurance premiums" for "good" genetic results.

[6] https://www.accc.gov.au/system/files/public-registers/documents/D00%2B39111.pdf.
[7] Appendix A to the Life Code: https://cali.org.au/life-code/

This issue was raised in our previous submission, at page 14-15 (specifically Recommendation 6.4). We accept that the drafting in the ED is different to that proposed, but conceptually the issue still remains. It is unclear whether the definition of ***solicit*** was intended to capture this behaviour. However, because (as discussed above) there is no penalty for solicitation alone, only where an actual ***life insurance contract decision*** is made, this still falls outside of the prohibitions and penalty regime.

In this scenario, even if solicitation was prohibited, it still may not adequately address this issue. It may go some way towards deterring insurers from subtle solicitation tactics where they advertise the benefit of providing results to gain premium discounts. A clear prohibition on using "good" genetic results for "preferred risk underwriting" should be included.

Recommendation 4.1 The definition of ***life insurance contract decision*** should be expanded to include the following:

(e) whether or not to consider, or to delay considering, an application for insurance that has been provided to, or about which an insured or an agent acting on behalf of the life insured has made inquiries with, the insurer.

Note that Recommendation 1.4 also recommends the addition of a subclause to this definition.

Recommendation 4.2 A new section should be introduced to prohibit solicitation as an activity on its own, and penalty provisions introduced accordingly.

Recommendation 4.3 A section should be inserted at a relevant part of the ED using phrasing similar to the clause approved by ACCC: "*insurers will not use genetic tests as the basis of preferred risk underwriting (ie offering individuals insurance at a lower than standard premium rate).*"

Recommendation 4.4 A sentence should be added to the EM to clarify that this is not intended to interfere with the ability of an insurer to take account of a favourable genetic test to offset penalties applied on the basis of family history of disease, and return the offer to the standard premium rate.

5. Additional drafting considerations for the amending legislation

Recommendation 5.1

Part 2, item 5 of the ED provides for the addition of a section 46(3) to the DDA. An additional sub-section should be included, as follows:

(3) For the purposes of this section, discrimination based on protected genetic information (within the meaning of the *Insurance Contracts Act 1984*) about a person is taken not to be reasonable if it relates to:

(a) a refusal to offer the person a life insurance policy;

(b) refusing to consider, delaying, declining, or penalising applications on the basis that applicants have not taken or not provided genetic test results, based on ongoing medical care information, or any other indirect method of inferring genetic test results; or

~~(b)~~(c) the terms and conditions on which a life insurance policy is offered to, or may be obtained by, the person.

This additional sub-section relates to aspects of the recommendations made above, and ensures that the DDA will have adequate and comparable protections to those introduced into the ICA, to safeguard the avenue of a plaintiff bringing a claim against an insurer under the DDA.

Recommendation 5.2

We recommend a section be inserted which mandates the collection of certain information by life insurance companies to help inform the government's mandatory review of the legislation. The type of data that will be important to benchmark and capture for a review includes the number of genetic results received, the action taken in each instance, and the outcome of underwriting for each, as well as the number of complaints relating to solicitation of or use of genetic results.

In the UK, insurers collect and report data about genetic test results disclosed and complaints received as part of the compliance monitoring for their Code on Genetic Testing and Insurance[8].

The CALI Life Code requires that all life insurers "record anonymous details of all Genetic Test results received as part of the Underwriting process, whether or not we asked for them, on the CALI database of Genetic Test results." (A.2(i)). However, there are real concerns about whether this data is being recorded and whether there is any mechanism to ensure that it is provided to the government to inform its review of the legislation.

Although the FSC Moratorium on Genetic Tests and Life Insurance had since 2019 a requirement identical to the one now contained in the CALI Life Code, FSC advised when it undertook its review of the moratorium in 2022 that it had only collected data from its members "from the start of 2021"[9]. This delay and acknowledgement that it was not collecting data even when required under the Moratorium was concerning and remains a concern.

During the A-GLIMMER study, an agreement was made with the Financial Services Council (FSC) that it would collect and provide data about genetic test results collected and the underwriting outcomes for each. FSC undertook in writing to provide this data to the A-GLIMMER project team within 3 months of the end of each financial year. Partial data for the first year was provided to the research

[8] https://www.gov.uk/government/publications/code-on-genetic-testing-and-insurance-3-year-review-2022/code-on-genetic-testing-and-insurance-3-year-review-2022?ref=ethics-and-insurance.
[9] https://fsc.org.au/news/media-release/genetics-moratorium

team only after a significant delay of many months. Despite numerous requests for the data to be provided in accordance with the research agreement and being advised by FSC that the data was not ready or available as yet, the data was not provided until after FSC had conducted its own analysis and review and posted on its website about what it claimed the data represented. Subsequent data was never provided, despite numerous requests. Numerous problems were identified with the content and completeness of the data provided. More detail about this is reported in the A-GLIMMER final stakeholder report (4.2, page 25)[10]. On this basis, we recommend that the requirement to collect data and provide it to the government to inform its review, and clear requirements regarding the type of data which must be collected, should be included in the legislation (with appropriate penalties applied for non-compliance, as necessary).

If life insurers are able to, or choose to, continue to maintain loadings and exceptions on existing policies – counter to our recommendations outlined above – then data relating to this legacy cohort should be captured.

Recommendation 5.3

In our previous submission at pages 15-16, we mentioned consequential updates to the AFCA Rules may be required to ensure AFCA can consider complaints arising under the new legislation. Under AFCA Rule C.1.4(b), AFCA must exclude a complaint about underwriting or actuarial factors leading to an offer of a Life Insurance Policy on non-standard terms. Given AFCA will apply the law to the consideration of complaints, the "actuarial factors" exclusion may not be operative. The clear intention behind the ban and its inclusion in the ICA is that such complaints will be able to be considered by AFCA, however, so the Rules may need to be updated to enable this.

Should an amendment to the AFCA Rules be required, this should coincide with the commencement of the legislative ban, and ASIC should consider issuing a regulatory requirement under section 1052A of the *Corporation Act 2001* (Cth) to ensure timely implementation.

These aspects have not been covered in the ED or EM. We recommend that these are considered and, if necessary, incorporated into the legislative instrument or EM.

[10] https://doi.org/10.26180/23564538

6. Additional considerations for amendments to the Explanatory Memorandum (by paragraph)

Recommendation 6.1:

1.8 This paragraph is not quite correct. We suggest amending for accuracy as follows:

"..It also provides that insurers cannot ~~in any circumstances~~ ask individuals to disclose results of genetic tests taken as part of medical research conducted by a university or medical research institute, where the test results have not been and will not be provided to the individual, or the individual has specifically asked not to receive them"

Recommendation 6.2:

1.12 For accuracy it should be noted that New Zealand has not yet implemented anti-discrimination measures (although they have recently passed amendments to allow regulations to be made in this regard), and should be removed from this paragraph.

Recommendation 6.3:

1.20 This paragraph implies that ASIC could only pursue criminal or civil proceedings in any given case. While it may be rare that both criminal and civil proceedings would be pursued, nothing in the ED suggests that ASIC would not have the discretion to pursue both. We suggest this paragraph should be amended as follows:

".. to pursue criminal or civil proceedings or both."

Note paragraph 1.64 contains the same language and should be amended in the same manner.

Recommendation 6.4:

1.36 This paragraph leaves open the question whether personnel such as financial advisers or brokers can recommend individuals volunteer favourable genetic test results. It could be bolstered for further clarity, as follows:

"The ban is not intended to operate so that a person cannot notify another person of the existence and operation of this exception. For example, an insurer's 'proposal form' may contain information about the existence of the exception, where that information is compliant with the provisions of the ban, and a financial adviser or broker could discuss the exception and the option of volunteering genetic information with an individual."

Recommendation 6.5:

1.52 This sentence is somewhat ambiguous, as it is unclear whether "that information" relates to the protected genetic information or the information about the clinical diagnosis. It could be clarified by amending as follows:

"However, where an individual has been clinically diagnosed as having breast cancer, then ~~that information~~the clinical diagnosis would not be protected genetic information, regardless of whether that diagnosis was based on or informed by genetic testing. Even in circumstances where the individual was diagnosed with breast cancer, the *BRCA1* result would remain protected genetic information and would not have to be disclosed".

Recommendation 6.6:

1.60 This paragraph could be enhanced to make it clear that results of direct-to-consumer genetic testing are also captured by the definition of genetic test, for the avoidance of doubt. An additional sentence is suggested as follows:

"The definition of genetic test is intended to capture genetic test information that is obtained by an individual through any means, including a medical service, a research study and a direct-to-consumer genetic testing company."