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

By email: genetictestinglifeinsurance@treasury.gov.au

13 March 2025

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

Dear Treasury

As the lead and senior author of the Australian Genetics and Life Insurance Moratorium: Monitoring the Effectiveness and Response (A-GLIMMER) report, we attach a submission to the public consultation on the design of the ban on the use of adverse genetic test results in life insurance.

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. The submission represents broad community views, beyond the organisations which contributed to the original A-GLIMMER study.

This submission should be considered as representative of the views of the 107 organisations (as well as many additional individuals) whose names are listed on the pages following, and should be given equal weight as 107 individual submissions.

Please reach out to Dr Jane Tiller at jane.tiller@monash.edu with any queries.

Yours Faithfully

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RESPONSE TO TREASURY CONSULTATION

BAN ON THE USE OF ADVERSE GENETIC TESTING RESULTS IN LIFE INSURANCE

SUMMARY OF KEY POINTS

(SEE END OF DOCUMENT FOR A LIST OF ALL RECOMMENDATIONS)

1. The legislation should ***prohibit*** insurers from
   - asking for, collecting, storing and using genetic results in underwriting (no matter how they are obtained, unless the voluntary exception applies); **[Rec 1.1]**;
   - asking about genetic testing that applicants have considered, planned, or intended [**Rec 1.2]**
   - disclosing genetic test results to any other party without explicit, written consent **[Rec 1.3]**;
   - 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 predictive genetic test results **[Recs 1.4, 1.5, 1.8]**;
   - using voluntarily provided genetic results to provide an adverse outcome **[Rec 6.1]**;
   - applying "checkbox" logic to require every applicant to provide consent to use their genetic results as part of their application for cover **[Rec 6.2]**; and
   - using applicants' favourable genetic results to lower the rates offered to that individual to below the standard rates offered to other applicants **[Rec 6.4].**
2. The legislation should ***require*** that insurers
   - notify applicants of the prohibition on using their genetic test results **[Recs 1.14, 1.15, 2.3, 6.7]**;
   - remove any penalties/loadings applied to existing policies on the basis of genetic test results going forwards **[Rec 10.2]**; and
   - destroy genetic data which no longer has any purpose for underwriting **[Recs 1.19 - 1.22]**; and
3. The definition of "condition" or "diagnosis" should clarify that a genetic predisposition does <u>not</u> amount to a condition **[Recs 1.9-1.12]**.
4. The definition of a genetic test should
   - capture any test which provides predictive genetic information which could be used to discriminate against people based on their potential future health risks **[Rec 3.1 - 3.3]**; and
   - be included in the main legislative instrument, with a clause allowing regulations to be made that prescribe tests to be included in the definition **[Rec 4.1]**.
5. The ban should operate in full from the legislation's commencement date **[Recs 10.1, 12.1, 13.1]**.
6. Any transition period (regarding aspects such as updating application forms and completing data destruction and client notification requirements) should be no more than 6 months **[Rec 13.4]**.
7. A "no wrong door" approach should ensure a clear consumer pathway for complaint resolution, and updates to the Australian Financial Complaints Authority (AFCA) Rules may need to be made to ensure AFCA can consider complaints arising under the new ban **[Recs 9.1-9.5]**.
8. The explanatory materials supporting the Bill should make clear the intention behind the legislation and the legislated requirements, for the benefit of future interpretation **[2.2, 4.4, 11.3]**.
9. ASIC should develop a regulatory guide for life insurers, to inform them of their obligations and requirements under the new legislation **[Recs 1.17, 8.2, 11.4]**.

ANSWERS TO CONSULTATION QUESTIONS

Appropriately targeting the measure

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.***

The prohibition should cover asking for, collecting, storing and using genetic results in underwriting (no matter how the results are obtained, unless the voluntary exception applies) **[Recommendation 1.1].**

The legislation should also prohibit insurers from asking applicants about genetic testing that they have considered, planned, or intended **[Recommendation 1.2].**

Disclosing genetic test results to any other party without explicit, written consent should also be prohibited **[Recommendation 1.3]**, to ensure that results that are provided inadvertently, or obtained through third parties, cannot be used to discriminate.

The prohibition should be framed so as to allow consumers to disclose negative (that is, favourable) genetic results that demonstrate that they do not carry a familial genetic variant that causes a family history of disease. This can be enabled through an exception to the prohibition on collecting, storing and using genetic results where results are voluntarily disclosed (discussed further in the response to **Question 6**).

In addition to prohibiting insurers from requesting, collecting, storing, using or disclosing a genetic test result from an individual, further provisions should be included to strengthen the regulation.

Further prohibitions

The *Canadian Genetic Non-Discrimination Act* (GNDA) contains clauses (at section 3) that:

- prohibit any entity from requiring a person to undergo a genetic test as a condition to providing goods/services or entering into a contract; AND
- prohibit any entity from refusing to provide goods/services or entering into a contract on the grounds that the individual has not undergone a genetic test.

The Australian legislation should include a comparable section. While the current Council of Australian Life Insurers (CALI) Moratorium on Genetic Tests in Life Insurance (Appendix A to the Life Code[1]), states that insurers will not require people to have genetic testing, there have been reports of people being told that their application would only be considered if they had a genetic test for a condition in the family.

As noted, it is important to allow people to disclose negative (favourable) results to insurers to offset the penalising effect of family history caused by a familial variant that an individual does not carry. However, it is also important to ensure that insurers cannot refuse to consider individuals' applications, decline applications outright or indicate that consideration will be delayed until an action is taken, on the basis solely that they have chosen not to have a genetic test, or because they have not provided the result of their test. Otherwise, insurers could seek to avoid any legislative prohibitions by simply refusing to consider (or unreasonably

[1] https://cali.org.au/life-code/

delaying) applications, for example, until applicants with a family history of disease have taken a genetic test, or until those who have had a test have chosen to "voluntarily" provide their test results.

The Australian legislation should prohibit an insurer from requiring a person to undergo a genetic test, or voluntarily disclose the results of a test, as a condition to having their application for insurance considered or being offered a contract of insurance **[Recommendation 1.4].** The legislation should also prohibit an insurer from refusing to consider an application for insurance or refusing to provide a contract of insurance based solely on the fact that an applicant has not undergone or has not chosen to disclose the results of a genetic test **[Recommendation 1.5].**

To ensure this provision operates as intended, the legislation should prohibit life insurers from offering a "discount" below standard rates to applicants who provide favourable genetic results, to avoid a situation where standard rates become a penalty for those who choose not to provide their results (as discussed in the response to **Question 6**).

Currently, the CALI Life Code (at 4.15) states that it only requires that family history of first-degree blood relatives is provided. The legislation should include a provision which mandates that insurers can only ask about and use diagnosed conditions of first-degree blood relatives in underwriting **[Recommendation 1.6]**.

Further, the "Genetic tests and applying for life insurance – Key Facts" fact sheet[2] developed by the Financial Services Council when it was still the life insurance industry body makes it clear that, "*you don't have to disclose the genetic test results of your first-degree blood relatives, only their diagnosed conditions*". We frequently hear that people are worried about having genetic testing because of the possible impact on their children's insurance. The legislation should clearly set out that insurers cannot ask about or use the genetic test results of any relatives of an applicant when underwriting that applicant's insurance policy **[Recommendation 1.7]**.

Inferring genetic test results from ongoing medical care

Insurers should be prohibited from inferring the results of genetic tests from a patient's or family member's ongoing medical care, and using that inference to discriminate against applicants. An issue reported by Canadian colleagues is that Canadian life insurers are asking about future planned investigations, and then declining to consider applications until those investigations have been completed, or using that information to infer risk status. Applicants who are *BRCA1* positive, (a breast cancer susceptibility gene) for example, may be scheduled to have an MRI, or someone with Lynch syndrome may be scheduled to have a colonoscopy, as part of their regular risk-reducing surveillance. This means that even though insurers are not allowed to ask for or use genetic results, they are getting around this by seeing what kind of investigations are being scheduled, and then either inferring their risk status based on the frequency of their surveillance (and then applying penalties based on this perceived higher risk status), or deferring considering applications until they see whether anything comes of the investigations.

Similarly, some medication is only available for individuals who have had a genetic test to determine eligibility, such as the recent expanded PBS listing for Olaparib in certain breast cancer patients. Despite already having a cancer diagnosis, we are told that some patients have held back from testing because of insurance concerns, especially fears for family members. Information that indirectly points to genetic test results (because patients would not have access to that treatment without a positive genetic test) should not be able to be used to infer predictive risk information.

[2] https://fsc.org.au/resources/1785-moratorium-key-facts

This also applies to other information that indirectly discloses predictive risk information, such as participation in clinical trials. Unaffected family members may participate in prevention trials, and participation will depend on having had a positive genetic test. The participation in a clinical trial (or any other indirect method of inferring genetic test results) should not be used to infer genetic risk status and discriminate.

The Australian 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 **[Recommendation 1.8].**

Definition of "diagnosis" or "condition"

The consultation paper has noted that the intention of the legislation is not to remove insurers' ability to discriminate on the basis of an individual's genetic condition. Various terms are used including "condition", "diagnosed condition", "diagnosis" and "disease".

As "condition" is not yet defined under the DDA or any other comparable legislative instruments in Australia, it will be important to define it in the context of the current proposed legislative amendments..

If life insurers took the opportunity to classify a genetic variant as a "diagnosed condition", the intent of the proposed legislation would be completely undermined. Some genetic predispositions have historically been given names, such as Lynch syndrome, which predisposes a person to a significantly increased risk of primarily bowel cancer. A finding that a person has "Lynch syndrome" is not based on a diagnosis of disease, and does not mean a person has cancer, or will necessarily ever have cancer. In fact, regular surveillance through colonoscopy can decrease the risk of developing cancer, or maximise the chances it is caught early at a treatable stage.

There are concerns that a life insurer may use the fact that Lynch Syndrome is a genetic predisposition that has been given a name to label it a "condition" or a "diagnosis", and use this to justify its right to discriminate against a person based on their predictive genetic test results.

The proposed legislative ban should clearly distinguish between a disorder or illness and a predisposition to an illness, whether or not that predisposition has been given a name **[Recommendation 1.9]**. It should stipulate that a genetic predisposition does not amount to a condition (consistent with judicial consideration in *Matthew Hall Pty Ltd v Smart* [2000] NSWCA 284 and the established line of authority following). It should stipulate that a genetic predisposition to disease must fall outside of the definition of condition and cannot be used to discriminate against an applicant. This definition should be applied to any information that is sought about diagnoses or conditions in either applicants or any other person (for example, when applicants are asked about diagnoses in their first-degree relatives) **[Recommendation 1.10].**

Finally, an applicant should not be considered to have a condition or diagnosis merely because they have signs or symptoms which could be associated with that condition, which exist at similar rates in the general population without that condition **[Recommendation 1.11]**. For example, people with Lynch syndrome 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 observation of polyps in a person with Lynch syndrome would not be considered a manifestation of Lynch syndrome – only the development of cancer would be clearly considered clinically as a manifestation of Lynch syndrome. A Lynch syndrome patient with observed polyps, but no cancer, would still be considered as only having a genetic predisposition to disease.

The question of when disease has manifested has been challenging in the United States of America, with respect to their Genetic Information Non-discrimination Act (GINA), which applies in the context of health insurance and employment[3].

We suggest the following definition **[Recommendation 1.12]**:

> *"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."*

For the avoidance of doubt, if a person discloses a diagnosis, condition or signs or symptoms of a condition, then the insurer should be restricted to using only that information in its underwriting – this does not trigger a right to use predictive genetic information based on genetic test results **[Recommendation 1.13]** (see example below).

Worked example: Lynch syndrome

Mary has Lynch syndrome, based on a genetic test result, and during a colonoscopy some bowel polyps are found and removed. These bowel polyps are not cancerous. Mary applies for life insurance and is asked whether she has a diagnosis of disease. Mary discloses that she has Lynch Syndrome (without knowing that she does not have to provide her genetic test results), and that she has had bowel polyps removed.

The insurer determines that because Mary has a "diagnosed condition" (Lynch syndrome) andsbowel polyps, it is allowed to use this information to discriminate, regardless of the fact that the information came from a genetic test. The insurer offers Mary insurance cover with a 50% premium loading and excludes cover for all abdominal cancer, bowel-related disease and all gynaecological cancer.

A correct interpretation in this case should be that the insurer is allowed to use the fact that Mary has bowel polyps in its underwriting, in the same way that it would use the known existence of bowel polyps in the general population, but not have regard to the genetic test or the other predictive information that it provides. This means that the premium loading and exclusions are likely to be disallowed, unless there is evidence that these penalties are applied to all applicants with any evidence of bowel polyps.

Third-party prohibitions

The Canadian GNDA also includes prohibitions against third parties collecting, using or disclosing someone's genetic information without their written consent. While the ambit of financial services regulation may not extend to regulating all third parties' access to information, the Government should consider the potential for insurance companies to obtain genetic information through third parties (such as, for example, data held by direct-to-consumer genetic testing companies), and to prohibit the use of genetic data that is obtained through any source, including third party sources, not just data obtained from an individual directly. This may be addressed by ensuring the prohibition extends to asking for, using, storing and collecting genetic test data from any source (unless the voluntary disclosure exception applies) (see **Recommendation 1.1)**.

Obligations on insurers to communicate

We are often told that consumers are unclear about what information they are required to provide to insurers, and may provide genetic results even when they are not required to, "just in case". Despite the changes to the

[3] https://pubmed.ncbi.nlm.nih.gov/23061591/

Insurance Contracts Act 1984 (Cth) (ICA) to replace the insured's duty of disclosure with the s20B duty to take reasonable care not to make a misrepresentation, many consumers are afraid of being "caught out", and believe that they must provide the insurer with every piece of medical information they have, to minimise their risk of being denied at claim stage for any reason.

Ensuring that consumers are aware of the legislative protections, and of what their obligations are (and are not) regarding disclosing genetic data, is critical. Canadian research[4] shows that some sectors of Canadian society still have limited awareness of the protections afforded by the GNDA, which may limit its impact. On that basis, the Government should consider inserting requirements (with penalties for any breach) that life insurers:

i) Make it clear on their application forms and other documentation (in an easily accessible form, not buried within a lengthy PDS) that there is no obligation to provide any results of genetic tests that have been taken, and that life insurers are legally prohibited from using adverse genetic results to discriminate against applicants **[Recommendation 1.14]**.

ii) Provide information to applicants who voluntarily provide results to insurers, about how their results can and cannot be used. Where adverse results are provided inadvertently, the insurer should provide written information to the applicant about the fact that the results are not legally able to be used, and have not been used, in the underwriting process, confirmation that the data has been destroyed and no records have been kept, and pathways for recourse if they feel their information has not been used appropriately **[Recommendation 1.15]**.

iii) Document any genetic test results that are received, how they are used and evidence that the applicant was provided with clear information (in an easily accessible form, not buried within a lengthy PDS) about their rights, how their genetic results can be used (and not used), and pathways for recourse if they feel their information has not been used appropriately **[Recommendation 1.16]**.

The most effective mechanism to ensure that insurers do not receive or hold genetic test results in contravention with the prohibition will be for them to ensure their application forms and information collection mechanisms limit this as much as possible.

Another way in which insurers regularly receive information is from doctors or healthcare entities when making requests for information. If insurers are under an obligation to take the above steps when they receive genetic test results that they are not legally permitted to collect or use, they will take steps to direct medical professionals to exclude such results from the information sent. Implementing requirements and penalties will encourage insurers to proactively take steps to inform consumers and third parties about these requirements and limit the amount of genetic data that they receive.

To assist with this, ASIC should develop a regulatory guide for life insurers, to inform them of the obligations and requirements and the steps they need to take at each stage of the process. The development of this regulatory guide should be included as a legislative requirement **[Recommendation 1.17]**.

A similar guide should be developed by the Department of Health and Aged Care (or another appropriate agency) for medical professionals and healthcare entities, to ensure that they understand the restrictions on life insurance companies asking for and holding individuals' genetic test results, and their role in not providing copies of genetic test results to insurers when asked for medical records **[Recommendation 1.18]**.

[4] https://karger.com/phg/article/27/1/240/915246/Should-I-Let-Them-Know-I-Have-This-Multifaceted

Information already held by life insurers from past applications

Consistent with the proposals set out above, and the intention behind regulatory changes that were made to protect consumers following the Optus data breach[5], data should only be held while there is a reasonable purpose to hold it, and must be destroyed once it is no longer required for the purpose for which it was collected. In the context of life insurance, the purpose for collection is to guide underwriting decisions. The holding of genetic data for other purposes is of concern generally, but is particularly pertinent for vulnerable populations such as Aboriginal and Torres Strait Islander peoples. Thus, life insurers should destroy any genetic test data that they hold for which there is no longer a purpose for underwriting decisions **[Recommendation 1.19]**. There is no reason to continue to hold genetic test data for individuals who have previously had life insurance underwritten by using genetic test data, unless that data is subject to the voluntary disclosure exemption and is not being used to provide an adverse underwriting outcome. Even in the case of voluntary disclosure, the insurer should only retain the information required to provide reasons for its underwriting decision. Copies of genetic test results which no longer need to be retained should be destroyed once the underwriting has been completed and not kept on file **[Recommendation 1.20]**.

Because underwriting involves an actuarial "black box", it is very difficult for consumers in some circumstances to ascertain whether their genetic test results are being used to discriminate against them. As set out below in the response to **Question 10**, it should be unlawful for insurers to continue to penalise their customers on the basis of genetic test results, once the ban has commenced **(**see **Recommendations 10.1-10.2)**.

For this reason, the legislation should include a requirement that each life insurance provider review its files and identify individuals for whom genetic test data is held. All individuals who are subject to penalties on the basis of genetic test results should have the penalty removed moving forward and should be notified that this has been done and that their genetic test results have been destroyed **[Recommendation 1.21]**. For those whose genetic test results were used to avoid an adverse outcome (favourable genetic test results), the process for ensuring that true voluntary consent to provide access to genetic test results (which will be developed for prospective applications) should be followed for existing customers for whom this type of data will continue to be held (and only to the extent that there is a reason for continuing to hold the data).

If insurers hold genetic data about prospective customers for whom a contract of insurance was declined altogether, that data should be destroyed **[Recommendation 1.22]**. Any other genetic test data that has been collected from applicants and continues to be held, but has not been used in underwriting of the applicant's policy, has no purpose for the insurer in continuing to be held. The insurer should notify each of these individuals that it holds their data, and that in compliance with the new legislation, the data is being destroyed. As discussed in the response to **Question 10**, the insurance industry has indicated that this represents a very small number of individuals (less than 1% of all applications).

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.

In 2021, the ICA was amended to replace the duty of disclosure with a duty to take reasonable care not to make a misrepresentation, for Consumer Insurance Contracts (which are primarily contracts obtained wholly or predominantly for personal, domestic or household purposes). Individual life insurance contracts fall within

[5] https://ministers.treasury.gov.au/ministers/jim-chalmers-2022/media-releases/changes-protect-consumers-following-optus-data-breach

this definition. The duty to take reasonable care not to make a misrepresentation to the insurer also applies to a life insured in a Consumer Insurance Contract provided under a group life contract e.g. a contract of life insurance that is maintained for the purposes of a superannuation or retirement scheme etc: ICA, section 32.

The duty of disclosure in section 21 (including the broad duty to disclose all matters that the insured knows or should reasonably know is relevant to the insurer) only applies to contracts that are not Consumer Insurance Contracts.

Thus, while the duty to take reasonable care not to make a misrepresentation would continue to apply to Consumer Insurance Contracts following the proposed amendments to ban genetic discrimination, the duty of disclosure does not apply to any Consumer Insurance Contracts. The proposed amendments to ban genetic discrimination would not lead to the duty of disclosure applying to these contracts.

We consider that the ban on genetic discrimination will affect the scope and content of the duty to take reasonable care not to make a misrepresentation, so that a failure to disclose otherwise relevant genetic testing information is not a breach of the duty. That is because, inter alia, the ban would constitute a "relevant circumstance" for the purposes of section 20B(2). Nonetheless, there would be value in making this explicit in the legislation. There would be a number of ways of achieving this, for example:

- Inserting a new subsection in section 20B that states expressly that mere non-disclosure of matters the subject of the ban is not capable of constituting a breach of the duty not to take reasonable care to make a misrepresentation (***our preferred approach***) **[Recommendation 2.1]**.
- Inserting a new paragraph in section 20B(3) of the ICA (which sets out matters that may be taken into account in determining whether an insured has taken reasonable care not to make a misrepresentation) referring to the ban.

The proposed ban, coupled with its impact on the duty to take reasonable care not to make a misrepresentation, will represent a statutory modification of the duty of utmost good faith as it applies to consumers. The ban in effect removes a matter consumers might otherwise, consistent with that duty, be required to disclose. We consider any unintended consequences of this modification can be adequately dealt with by (a) making explicit the impact of the ban on the duty to take reasonable care not to make a misrepresentation as outlined above, and (b) the existing provisions of section 12 of the ICA, which relevantly provides:

> *The effect of this Part [i.e. Part II, which imposes the duty of utmost good faith] is not limited or restricted in any way by any other law, including the subsequent provisions of this Act, but this Part does not have the effect of imposing on an insured, in relation to the disclosure of a matter to the insurer, a duty other than:*
>
> *(a) in relation to a consumer insurance contract or proposed consumer insurance contract--the duty to take reasonable care not to make a misrepresentation*
>
> *…*

The explanatory materials supporting the Bill introducing the ban should refer to section 12, to make clear how the ban is intended to interact with the two duties (duty of utmost good faith/duty to take reasonable care not to make a misrepresentation)[6] **[Recommendation 2.2]**.

[6] cf. Explanatory Memorandum, Financial Sector Reform (Hayne Royal Commission Response) Bill 2020 (Cth) [2.97].

The duty to take reasonable care not to make a misrepresentation is predicated on the notion that the burden is on the insurer to elicit the information it needs, and does not require the consumer to surmise or guess what information might be important to an insurer.[7]

Consistent with this notion, and given the level of anxiety amongst consumers regarding "getting in trouble" with an insurer for not providing all of the relevant information, there should be a requirement that insurers notify prospective applicants explicitly about the fact that they are not required to provide information about genetic test results and that insurers are not able to use genetic test results, except in circumstances where the voluntary disclosure exception applies **[Recommendation 2.3]**. A regulatory guide developed by ASIC (see **Recommendation 1.17**) would assist insurers with complying with this.

Examples of content from application forms from Australian life insurers that were updated in compliance with the current moratorium include:

"You do not need to tell us about any genetic test you have previously had, or intend to have unless we specifically ask you. You are obliged to inform us of any diagnosis of a medical condition, even if the diagnosis resulted directly or indirectly from a genetic test. You may volunteer results of genetic tests where the result is favourable"

"If you have a favourable genetic test result, for example, to show that you are not carrying a gene pattern associated with developing an illness that runs in your family, you may choose to disclose the result."

The first of these examples could fairly simply be updated to reflect the proposed ban, for example:

> *"You do not need to tell us about any genetic test you have previously had, or intend to have ~~unless we specifically ask you~~. You are obliged to inform us of any diagnosis of a medical condition, even if the diagnosis resulted directly or indirectly from a genetic test. Having a genetic predisposition to disease does not amount to a diagnosis of a medical condition. You may volunteer results of genetic tests where the result is favourable (for example, to show that you have not inherited a known genetic variant in your family)."*

Defining 'genetic test'

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

The important elements of the statutory definition are that it is:

- Sufficiently precise to be understood and applied by the regulated body (life insurers), with minimal ambiguity, and to be applied by the Australian Financial Complaints Authority or the Courts in the case of disputes;
- Sufficiently robust to protect individuals against the misuse of their predictive genetic information which is derived from testing data; and
- Sufficiently flexible to ensure future-proofing.

[7] Explanatory Memorandum, Financial Sector Reform (Hayne Royal Commission Response) Bill 2020 (Cth) [2.15].

Scientifically speaking, it is necessary to acknowledge that with advancing technology, the ability to use test data to infer predictive genetic information (i.e. to predict, detect or infer an individual's underlying genetic code and thus their likelihood of developing disease in the future) is increasing significantly. Thus, it is essential that the definition of a genetic test captures any use of test data which is used to infer this information. In essence, the definition should capture any test that provides information that predicts the basis of disease based on an individual's genetic profile and protects individuals against life insurance discrimination on the basis of that test data **[Recommendation 3.1]**. This can include tests such as epigenetic tests, which test for the presence of methylation (the binding of methyl groups to the DNA) at certain sites.

Epigenetic/methylation tests are already used to provide important medical information about disease prognosis and staging, and some such tests are listed on the MBS (e.g. MBS item number 73373[8]). Although no currently MBS-listed tests are yet known to provide predictive genetic information about individual genotypes, various research is underway which is investigating relationships between DNA methylation and genetic variants. DNA methylation levels at specific genetic sites correlate strongly with underlying DNA variants at specific parts of the genome, so these could be used to predict genetic information and future disease risk, using tests which may not be referred to as genetic tests under a definition which is not sufficiently robust.

This is exactly the type of predictive genetic information that this legislation intends to prohibit being used by life insurance companies to discriminate against applicants, and so the definition should capture any test which provides predictive genetic information which could be used to discriminate against people based on their potential future health risks **[Recommendation 3.2]**.

On a technical level, the definition should include tests of molecules that directly ***influence the expression of genes***[9] (e.g. epigenetics/methylation) to infer or predict future disease, but **not** include every single thing that is the ***end product of gene expression*** (i.e. not every protein produced by a gene should automatically fall within the definition, as this would include many, many molecules and tests).

The New Zealand definition (as set out in the consultation document) is a good starting point, but requires some refinement to optimally address the points above.

It is important to note that the refinement process and the definition proposed below narrows the scope of the definition, meaning that **fewer tests will fall within the protection** than may otherwise fall within the New Zealand definition. This proposed refinement will make the definition more precise, and limit the number of tests that may inadvertently fall within the definition (for example, tests of proteins and biochemical markers that do not detect, predict or infer genotypes or genetic variants).

There is rightly a concern that a definition that is too broad and not sufficiently precise may end up encompassing all blood tests that test for proteins, including tests such as blood cholesterol. The amendments to the definition tighten it up to reduce this outcome; however, it should be remembered that the right of the insurer to use any diagnosis of disease is already being preserved. This means that even if there is a test that falls within the definition which is in a "grey area", if it in fact can diagnose disease, then that diagnosis will be allowed to be used in any event. Further, the amendments to the definition ensure that tests of proteins/biomarkers, etc. will be protected only in so far as they detect or predict genotypes or genetic variants.

[8] https://www9.health.gov.au/mbs/fullDisplay.cfm?type=item&q=73373&qt=item

[9] https://www.genome.gov/genetics-glossary/Gene-Expression

Finally, feedback from the parties who were responsible for the Canadian legislation has indicated that it would be prudent to include a reference to "a person's DNA..." The Canadian team advised that a case arose in Canada[10] where someone argued that a mandatory vaccination policy was genetic discrimination. The decision-maker had to consider whether to read in "a person's DNA…." rather than just "analyses DNA…" to the definition. The decision-maker did so, but the Canadians indicated that if given the chance they would make it clearer that the definition relates to a particular person's DNA.

The proposed definition, which includes minor tweaks to the New Zealand definition to make it more precise and less ambiguous (as discussed above) is set out below **[Recommendation 3.3]**, followed by some further detailed explanation.

Genetic test means:

a) a test that

i) analyses a person's DNA, RNA, or chromosome, or

ii) interprets information derived from the analysis of a person's 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

i) analyses any molecules or factors that influence or modify the expression of a person's genes (including but not limited to epigenetic tests), to detect, infer or predict genotypes or genetic variants, or predict future risk, or

ii) analyses any product of gene expression (for example, a protein), biomarkers or metabolites, to detect, infer or predict genotypes, or genetic variants,

whether or not there are other purposes for the test; or

c) a test that is prescribed as a genetic test by the regulations.

By way of explanation, a genotype is a person's actual genetic code, whereas a phenotype is the observable characteristics in a person (these can be disease manifestation or just natural variation, like eye or hair colour).

It is appropriate for the part of the definition in (b)(i) to include ***the prediction of future phenotypes***, – for example, doing an epigenetic test to predict whether someone is likely to develop cancer based on their methylation of certain genes. We have replaced the word "phenotype" with "future disease risk" to make the intent clearer and the application more precise.

However, the definition should not include the ***detection of phenotypes***, as this is where a large number of medical tests could end up falling within the definition. The part in (b)(ii) discusses products of gene expression, biomarkers or metabolites, which would include, for example, cholesterol, hormones and other molecules. If these molecules are analysed to ***detect or predict someone's genotype*** (their actual genetic code), that is a genetic test. If they are just used to ***detect a phenotype***, that is not necessarily a genetic test. Thus, "phenotype" has been removed from the definition for (b)(ii).

Any diagnosis of disease will continue to be able to be used by insurers, as set out in the consultation paper.

[10] https://www.hrreporter.com/focus-areas/employment-law/mandatory-vaccination-not-genetic-discrimination-board/387207

For the avoidance of doubt, any genetic test conducted in a research setting should be included within the definition **[Recommendation 3.4]**.

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.

In order to ensure definitions are effectively supporting the consumer protections intended by the legislative provisions, and do not impede their operation in ways that were not anticipated, it may be prudent to include aspects of them in associated regulations or a schedule. However, to provide certainty for consumers, this mechanism should not present an opportunity for wholesale reconsideration of whether the consumer protections contained in the main body of the legislation should be weakened in future years.

The main concern is that any changes to the definition meet the intention of the legislation (to ensure robust protection against discrimination and reduce consumer reluctance to have genetic testing based on insurance fears), and that changes to the definition by future governments do not disadvantage applicants or erode the intended protective effect of the legislation. Without binding future governments' capacity to amend legislative instruments, mechanisms for ensuring that changes to the definition are grounded in scientific and medical evidence, and focussed on consumer protection, should be considered. These should also avoid enabling the definition to be rewritten in its entirety.

On that basis, the best mechanism would be for the definition to be included in the main legislative instrument, with a clause allowing regulations to be made that prescribe tests to be included in the definition (as set out in the definition proposed at **Question 3**) **[Recommendation 4.1]**. This is similar to empowering clauses in Acts such as the *Therapeutic Goods Act 1989* (Cth).

An approach to ensuring that the definition of "genetic test" is maintained and appropriately updated over time would be to establish an independent expert panel to provide advice to the relevant Minister on any changes to the definition. This panel would be made up of experts in the field of genetic testing, and consumer representatives **[Recommendation 4.2]**. This approach has precedent. The 2021 Insolvent trading 'safe harbour' review[11] and the 2016 Review into the financial system's external dispute resolution and complaints framework[12], for example, were undertaken by an independent panel of experts.

Further, given the cross-portfolio nature of this issue, which is a significant health issue but being managed as a regulatory issue through Treasury, the legislation should require that the Minister for Health and Aged Care is consulted and signs off on any changes to the definition which are proposed **[Recommendation 4.3]**. The explanatory materials supporting the Bill should make clear the intention behind these requirements, for the benefit of future interpretation as necessary **[Recommendation 4.4]**.

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.

As technology advances, the capacity for predictive genetic information to be inferred from other test data is likely to increase. Similarly, the ability of insurers to use large amounts of aggregate population data to infer trends and likely risks at the granular level for individuals increases over time, particularly as advanced analytics, artificial intelligence and machine learning are increasingly applied. This phenomenon is already seen in other insurance markets, such as for flood risks in certain areas. While the definition as currently

[11] https://treasury.gov.au/review/review-of-the-insolvent-trading-safe-harbour

[12] https://ministers.treasury.gov.au/ministers/kelly-odwyer-2015/media-releases/new-independent-expert-panel

proposed is intended to remain relevant through some technological advances, it is necessary to have a mechanism to prescribe other tests through the regulations to be included in the definition of genetic test, as unexpected ways to determine individuals' risks emerge, which may in future act to deter people from taking important health tests or being involved in research **[Recommendation 5.1]**.

As discussed in the response to **Question 1**, Canadian colleagues have reported concerns regarding life insurers' use of information about future planned investigations to infer risk and delay considering applications. If Australian life insurers take steps to try to avoid the intent of the legislation, consideration will need to be given to how to ensure the definition of genetic test is sufficiently robust to ensure Australians are adequately protected **[Recommendation 5.2]**.

Consent to the release and use of genetic test results

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.

The main considerations here are that:

a) genetic test results must never be used for the purpose of applying a penalty or providing an unfavourable underwriting outcome, irrespective of whether they are provided voluntarily **[Recommendation 6.1]**; and

b) insurers must not apply "checkbox" logic to require every applicant to provide consent to use their genetic results as part of their application for cover **[Recommendation 6.2]** (see para 8.13-8.99 of the 2018 Parliamentary Joint Committee Report of the Inquiry into the Life Insurance Industry[13] for a discussion of the issue of broad consent to medical record access as a precondition to application or claims assessment).

The situations described in the consultation paper are those in which test results are provided to insurers for the purpose of either removing an already applied penalty, or indicating that a penalty should not be applied. The consideration in a) resolves the issue acknowledged by the Treasury on page 8 of the consultation paper 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".

If the legislation clearly mandates that genetic test results cannot be used to make an unfavourable or adverse offer, the onus need not rest on the consumer to make this determination. The onus will be on the insurer to not make illegal use of that information, even if it is inadvertently or voluntarily supplied by the applicant. To achieve this, an additional requirement should be added to those proposed, to ensure that insurers cannot use genetic test results in a way that adversely impacts the underwriting and offer of insurance **[Recommendation 6.3]**.

Anecdotally, there has been some suggestion that the use of a negative (low risk) result in this way is "reverse discrimination". However, this argument is mischaracterised, because the use of negative (favourable) results occurs in the context of another form of discrimination – usually discrimination against an applicant in the

[13] https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/Corporations_and_Financial_Services/LifeInsurance

form of declining cover or applying a penalty because of a disclosed family history of disease. If an insurer was not planning to apply any penalties due to family history, there would be no need to disclose a negative test result to offset that penalty. Further, the use of the negative result to offset that penalty is not "reverse discrimination"; rather it is the application of evidence to demonstrate that the original discrimination (on the basis of family history) does not have an actuarial basis.

To ensure the intention of the legislation is maintained, it should prohibit the use of an applicant's favourable genetic results to lower the rates offered to that individual to below the standard rates offered to other applicants **[Recommendation 6.4]**. If a "discount" beyond standard underwriting rates is offered to people who have favourable genetic results, this could indirectly penalise individuals who do not provide their genetic results, and the "undiscounted" rate would, in practice, become the penalty applied for choosing not to disclose genetic results. The legislation should mandate that even where an applicant has "voluntarily disclosed" a genetic test result, or consented to its use, it must not be used to provide an offer of insurance that is worse than the offer that would have been made without the use of the genetic test result. That is, voluntarily disclosed genetic test results must only be used to provide an equal or more favourable offer of insurance than would have been made without the test result. As discussed above, however, insurers should not offer a "discount" off standard rates for individuals who voluntarily disclose favourable genetic results. The favourable result should be used only to ensure individuals receive standard rates where they may otherwise have been discriminated against based on factors (such as family history of disease) which the genetic test result shows do not apply.

To assist with this, it may be useful to define a "favourable genetic test result". We propose the following definition **[Recommendation 6.5]**:

> *"a favourable genetic test result is one which shows an individual does not have a genetic variant or condition that is known or suspected to exist within the individual's biological family, or to be causing a family or personal history of disease."*

As addressed in the response to **Question 1,** copies of favourable genetic test results which no longer need to be retained should be destroyed once the underwriting has been completed.

Best practice consent is currently Rule 4.9 of the Consumer Data Right[14] where consent must be: "voluntary, express, informed, specific as to purpose, time limited, and easily withdrawn". We also note that the Privacy Act Review Report[15] has recommended at Proposal 11.1 that the definition of consent under the *Privacy Act 1988* be amended to provide that consent must be "voluntary, informed, current, specific, and unambiguous". These principles should be applied in this context **[Recommendation 6.6]** – noting that some may not necessarily be appropriate here – for example, time limited and easily withdrawn may not necessarily be appropriate in this context.

On this basis, the legislation should contain a requirement that insurers provide written information to consumers who are voluntarily providing genetic test results, to inform them that they are not required to provide the results in order for their application to be considered, and that their result cannot be used to apply a penalty or an adverse underwriting offer **[Recommendation 6.7]**. As addressed in the response to **Question 1**, refusing to consider an application, or declining cover outright, solely on the basis that an applicant has not undertaken a genetic test and/or has not voluntarily disclosed their test results should be prohibited.

[14] https://www.legislation.gov.au/F2020L00094/latest/text

[15] https://www.ag.gov.au/sites/default/files/2023-02/privacy-act-review-report_0.pdf

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.

Please see the response to Question 6, noting the key points that

- genetic test results should never be used to provide adverse or unfavourable offers of insurance, irrespective of whether they were provided voluntarily; and
- broad "checkbox" consent must not be used to convey that a consumer has voluntarily provided results – consumers must provide adequately informed consent that is documented.

Enforcement options

8. Treasury welcomes comments as to the enforcement options available for the ban in the Insurance Contracts Act and the DDA.

Consumer trust in insurers is low[16], and the deterrent effect of genetic discrimination fears on consumer engagement in genetic testing and research cannot be repaired overnight, or through enforcement regimes that are weak or lack regulatory teeth. In order to bolster public trust in genetics, and trust in the regulatory regime intended to protect them against misuse of their genetic information, Australians need to see a pro-consumer approach that is rigorous and proactive. It is vital that breaches of the ICA as they relate to the collection or use of genetic test results to discriminate against applicants are treated seriously and are sanctioned through meaningful penalties.

There should be strict liability and substantial fines payable for any breaches identified, through a simple regulatory process that does not require lengthy and time-consuming prosecution by ASIC **[Recommendation 8.1]**.

In terms of individual avenues to seek remedies for breach of the ban, the legislation or associated regulatory guidance should make clear that non-compliance with the ban has the effect of rendering voidable a decision made by a life insurer not to consider an application, or not to offer life insurance, or to offer it on less favourable terms **[Recommendation 8.2]**. The remedies available through AFCA should include requiring the insurer to retrospectively review the file in compliance with the ban, and offer such cover, backdated as appropriate, as would have been offered had the ban been complied with **[Recommendation 8.3]**.

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

The most important factor to consider is that there is a clear consumer pathway to having complaints resolved. In the past there has been significant confusion for consumers as to how to have a complaint handled – i.e. whether they should complain to the Australian Financial Complaints Authority (AFCA), or the Australian Human Rights Commission (AHRC). The proposed amendment to the DDA will enable a complaint to the AHRC

[16] https://www.pwc.com.au/insurance/future-of-life-insurance-mar17.pdf; https://doi.org/10.26180/23564538

and will allow for proceedings to be issued in the Federal Court, and the inclusion of the ban in the ICA will enable complaints to AFCA.

Most consumers will be able to more easily obtain a resolution through AFCA, and so no matter where a consumer starts their complaints journey, there should be a clear, accessible pathway to the same process **[Recommendation 9.1]**. This could be enabled by an MOU or other understanding between AHRC and AFCA regarding a multiple door (or "no wrong door") approach to consumer complaints, and clear and consistent information provision for consumers **[Recommendation 9.2]**. Further, because there are some restrictions to AFCA's reach (including financial limits), the right to issue proceedings in the Federal Court must be preserved, in case that pathway is preferred or becomes necessary **[Recommendation 9.3]**.

Finally, consequential updates to the AFCA Rules may be required to ensure AFCA can consider complaints arising under the new ban. Under AFCA Rule C.1.4(b)[17], 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 **[Recommendation**

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 **[Recommendation 9.5]**.

Existing policies and tests (prospectivity nature and implementation)

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.

From the date of commencement of the ban, discrimination on the basis of genetic test results should be prohibited, regardless of the date of the test **[Recommendation 10.1]**. The fact that a genetic test was taken before the ban was implemented should not affect the operation of the ban to prospectively protect the individual who took that test against discrimination on the basis of the test results.

Australians with existing policies for which genetic test results have been used to apply penalties, loadings, exclusions or other adverse (non-standard) underwriting outcomes should have their penalties, loadings or exclusions removed, going forward from the date of commencement of the ban **[Recommendation 10.2]**. This would not be a retrospective action (in that they would not receive a refund for the premiums previously paid, or any change to what has occurred in the past including claim declinature), but the calculation of premiums (and applications of exclusions or conditions) going forward would have the impact of the genetic test results removed.

To be maximally financially effective, life insurance is underwritten when the insured is relatively young, and premiums are paid over their (usually working) lifetime. If people are underwritten when older, they likely have more personal and family history of disease, more risk factors (including the simple fact of being older) and premiums are more expensive.

[17] https://www.afca.org.au/about-afca/rules-and-guidelines

If people who have been faithfully paying premiums (sometimes with substantial loadings) for many years are not able to have those loadings/conditions removed after the ban is implemented, they will be faced with a choice between two unfair scenarios:

1) Continue to be discriminated against prospectively for life insurance which is loaded/has conditions placed on it on the basis of genetic test results that life insurers have been legally prohibited from using to discriminate; OR
2) Change providers, or start an entirely new process with their current insurer, to have their whole life insurance re-underwritten – which could disadvantage them significantly and disregard the period during which their premiums were duly paid.

For individuals who took out their life insurance recently, this might not be a significant issue. However, someone who took out life insurance 15 years ago and who has been paying premiums for 15 years will be in a difficult position. They will have to choose between:

(a) Retaining the cover, conditions, and premium loading they were given because of a genetic test result, and
(b) Risk losing that cover and being re-underwritten as someone who is 15 years older (and thus carrying 15 more years of medical history to disclose and have potentially detract from their coverage e.g. through exclusion of pre-existing conditions).

The legislative ban should ensure that people are not unfairly discriminated against by being required to either accept ongoing genetic discrimination or choose to have their years of premiums "ignored" through requiring a new application process.

Although insurers may prefer to require these individuals to be underwritten from scratch (as they will then be able to consider other risk factors, including age and any symptoms experienced since policy inception, to increase the cost of their premiums going forwards), that is not necessary or required, and is not within the spirit of the reform that has been announced. It is a preference aimed at increasing profits rather than an actuarial necessity. If the policy has been underwritten in accordance with the requirements under the DDA (which prohibits discrimination on the basis of future disease risk unless there is actuarial evidence to support the discriminatory underwriting), there should be clear evidence of which part of the policy terms have been adversely affected by the genetic test result, and precisely how that calculation has been made. If an insurer claims that the exact relationship between the genetic test result and the loading/exclusion applied is not easy to delineate, then that underwriting outcome is arguably in breach of the requirements under the DDA and should be scrutinised by the regulator.

It should be a simple matter to remove that penalty and remove exclusions/conditions/loadings. Instances have been reported where applicants have pursued legal avenues to have loadings removed without the insured having to be underwritten again from scratch, which was easily able to be done, even though it was not the preference of the insurer.

In one instance[18] (page 21), "Frank" (a pseudonym) had a 200% loading applied to his premium due to a family history of disease. He paid these increased premiums for several years. When he had genetic testing that showed he did not have the family genetic variant, he asked the insurer to remove the loading. Initially they refused on the basis that he would have to make a full new application and be underwritten from scratch. However, after taking the dispute to the complaints tribunal, the insurer agreed to simply remove the loading and refund the additional premium paid due to the loading from the date he provided the insurer with the

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

genetic test result. This demonstrated that this was a simple exercise and easily able to be done without triggering an entirely new underwriting process. It is worth noting that even in this scenario, the insurer benefited from the increased premiums paid for the years before the test was done and the premium reduced back to standard rates (which were not refunded).

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 **[see Recommendation 10.2]**. It is clear from the industry's own reports that this should be a simple exercise. In CALI's submission to the previous Treasury inquiry into genetic testing in life insurance[19], the industry body highlighted (page 4) how few genetic test results were being disclosed to insurers, and what a tiny fraction of those had resulted in adverse underwriting outcomes. The submission reports that genetic test results were only disclosed in a fraction (<1%) of >200,000 underwriting applications in 2022, and that in only 5% of those (90 cases) the genetic test resulted in an adverse outcome for the consumer. This means that of 200,000 new policies underwritten in 2022, less than 0.05% of them would be subject to adjustment to remove loadings or exclusions following the implementation of the ban.

No data was provided for previous years, but given the increase in genetic testing volume over the last few years, it is expected that the numbers would have been even smaller in previous years. On this basis, and given those insureds are spread across all CALI members in Australia, the impact on life insurers of simply removing loadings and exclusions for those insureds going forwards (which would, at a very conservative estimate, be less than 0.05% of policies held), would be minimal. The work required to initiate entirely new policies and undertake new underwriting from scratch for each of those insureds would be considerably higher.

11. The Treasury welcomes comments as to how (if at all) the ban should affect variations of existing contracts

As discussed in the response to **Question 10** above, any existing contracts of insurance which contain penalties, loadings, or conditions on the basis of genetic test results should have those penalties removed once the ban is implemented, and the data about the genetic information held by the insurer should be destroyed.

If, separate to that process, an insured applies to vary their existing contract, that process should proceed per the usual course **[Recommendation 11.1]**. That is, if the application is to increase the cost of their cover, and in the usual course that increase in cover is within a band for which the insurer would usually not require a full new underwriting, but rather would apply a direct increase in premium, then the application should proceed in that way. If the application is to increase the cost of cover which in the usual course would trigger a new underwriting process, then that underwriting process should proceed without reference to the genetic test results which had previously been disclosed and used.

Any other change of contract terms should proceed accordingly – if the change would not usually trigger the requirement for fresh underwriting (such as a change in beneficiary), the change should be processed in the usual course. If the change would require fresh underwriting, then that underwriting should be undertaken without reference to the genetic test result **[Recommendation 11.2]**.

The legislation and the explanatory materials supporting the Bill should make it clear that this should not be used as an opportunity by insurers to subvert the usual processes and take the opportunity to re-underwrite policies at a higher rate, that would not normally be re-underwritten in such circumstances, in an attempt to

[19] https://cali.org.au/wp-content/uploads/2024/02/CALI-submission-Genetic-Testing-in-life-insurance-underwriting-Jan-2024.pdf

recoup perceived lost profits as a result of having to remove loadings previously applied on the basis of genetic test results **[Recommendation 11.3]**. The ASIC regulatory guide (see **Recommendation 1.17**) should also address this **[Recommendation 11.4]**.

12. The Treasury welcomes comments on how the ban could operate in relation to in-progress applications for life insurance.

The ban should operate in full from the date of commencement, which we submit should be the date of Royal Assent **[Recommendation 12.1]**. This means that any offer of insurance that is made after the date of commencement will be subject to the ban. There should be no reason why applications which are in-progress should not be subject to the ban on the date of commencement, given the extent of notice the industry has had.

Given the Government announced this ban in September 2024, the life insurance industry has been on notice for some time that the ban is coming and should be preparing their processes and systems. Further, by the time legislation is passed, there will have been a public parliamentary process, giving life insurers even more granular information and time to prepare to cease using genetic test results in underwriting.

The industry publicly stated that it welcomes the ban, so it would run counter to their public position to try to use results to discriminate right up until the last possible date. Arguably, insurers should already be putting processes in place, and to avoid any uncertainty for insurers and consumers, should be already altering their systems to stop collecting and using genetic data in the bulk of applications. If insurers instead elect to continue to discriminate until the last possible moment, they should not be given concessions in the legislation to allow them additional time to adjust their processes.

Further, the number of applications that this would affect will likely be minimal – the Moratorium on Genetic Tests in Life Insurance already limits the use of genetic test results to applications for cover above the applicable thresholds, and based on CALI figures, less than 0.05% of their applications are likely to involve an adverse outcome based on a genetic test result (as discussed in the response to **Question 10** above).

13. What, if any, transition period should be provided for implementing the ban and why?

Although some transition period may be necessary to allow for insurance companies to adjust certain systems and practices, the ban on using tests to underwrite policies should commence on the day that the legislation receives Royal Assent **[Recommendation 13.1]**.

The life insurance industry has been on notice that this total ban will be implemented since at least September 2024. The Council of Australian Life Insurers (CALI) indicated their support for the ban at the Assistant Treasurer's press conference on 12 September 2024[20]. Thus, life insurers should have been preparing for the implementation of this ban since that time. Further, the Minister indicated several times that he expected the life insurers to move to voluntarily cease using genetic test results to discriminate (including at the press conference on 12/09/24, linked above). If life insurers have not done so, they should not be afforded further time to continue to discriminate once the legislation receives Royal Assent.

Finally, the life insurance industry is already bound by the Moratorium on Genetic Tests in Life Insurance (Appendix A to the Life Code[21]), which prohibits the use of genetic test results for policies under certain

[20] https://ministers.treasury.gov.au/ministers/stephen-jones-2022/transcripts/doorstop-interview-parliament-house-canberra-8
[21] https://cali.org.au/life-code/

financial limits. For this reason, mechanisms must already be in place to exclude the consideration of genetic results in underwriting processes for policies under certain financial limits, meaning it should be simple to extend this exclusion to every policy underwritten.

Some aspects which **may require** a transition period include updating content on websites, fact sheets, information provided to insurance brokers and in electronic and printed forms. Although insurers should be preparing for these legislative changes, it may require a period of time to ensure that the information provided and available meets the requirements set out in the final form of the legislation.

Another aspect which may require a transition period is the requirement that insurers notify consumers of genetic test results which they hold, destroy genetic data for which they have no ongoing purpose, and remove loadings or penalties applied to ongoing policies going forward. It may take a period of time for these customers to be identified and notified and for records to be destroyed, though the availability of electronic communication and mass mailing software should make this task largely automatable and efficient. The removal of loadings, penalties and conditions should be back-dated to the date of commencement of the ban **[Recommendation 13.2]**. Premiums should be refunded if applicable, and files amended to clarify that any conditions or exclusions did not apply from the ban's commencement date **[Recommendation 13.3]**.

The end date for the transition period should be no later than 6 months following commencement of the ban **[Recommendation 13.4]**. A review of insurer documents undertaken after the transition period ended for the previous FSC genetics and life insurance moratorium[22] showed (at 4.3) that several years later, many application forms had not been updated to reflect the requirements under the moratorium. To ensure that insurers are motivated to provide accurate and transparent information to applicants and consumers receive up-to-date information, these requirements should be subject to penalties for breach if not met after that period, and should be part of the insurers' reporting regime to ASIC **[Recommendation 13.5]**.

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

LIST OF RECOMMENDATIONS

1 Comments on the proposed design option for the ban

1.1 The prohibition should cover asking for, collecting, storing and using genetic results in underwriting (no matter how the results are obtained).

1.2 The legislation should also prohibit insurers from asking applicants about genetic testing that they have considered, planned, or intended.

1.3 Disclosing genetic test results to any other party without explicit, written consent should also be prohibited, to ensure that results that are provided inadvertently, or obtained through third parties, cannot be used to discriminate.

Further prohibitions

1.4 The Australian legislation should prohibit an insurer from requiring a person to undergo a genetic test, or voluntarily disclose the results of a test, as a condition to having their application for insurance considered or being offered a contract of insurance.

1.5 The legislation should also prohibit an insurer from refusing to consider an application for insurance or refusing to provide a contract of insurance based solely on the fact that an applicant has not undergone or has not chosen to disclose the results of a genetic test**.**

1.6 The legislation should include a provision which mandates that insurers can only ask about and use diagnosed conditions of first-degree blood relatives in underwriting.

1.7 The legislation should clearly set out that insurers cannot ask about or use the genetic test results of any relatives of an applicant when underwriting that applicant's insurance policy.

Inferring genetic test results from ongoing medical care

1.8 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**.**

Definition of "diagnosis" or "condition"

1.9 The proposed legislative ban should clearly distinguish between a disorder or illness and a predisposition to an illness, whether or not that predisposition has been given a name.

1.10 This definition should be applied to any information that is sought about diagnoses or conditions in either applicants or any other person (for example, when applicants are asked about diagnoses in their first-degree relatives)**.**

1.11 an applicant should not be considered to have a condition merely because they have signs or symptoms which could be associated with that condition, which exist at similar rates in the general population without that condition.

1.12 We suggest the following definition:

> *"A condition or diagnosis means a disease, injury, illness or disorder, which has been diagnosed by a registered medical professional, and has manifested in a person with 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."

1.13 If a person discloses a diagnosis, condition or signs or symptoms of a condition, then the insurer should be restricted to using only that information in its underwriting – this does not trigger a right to use predictive genetic information based on genetic test results.

Obligations on insurers to communicate

Insurers should be required to:

1.14 Make it clear on their application forms and other documentation (in an easily accessible form, not buried within a lengthy PDS) that there is no obligation to provide any results of genetic tests that have been taken, and that life insurers are legally prohibited from using adverse genetic results to discriminate against applicants.

1.15 Provide information to applicants who voluntarily provide results to insurers, about how their results can and cannot be used. Where adverse results are provided inadvertently, the insurer should provide written information to the applicant about the fact that the results are not legally able to be used, and have not been used, in the underwriting process, confirmation that the data has been destroyed and no records have been kept, and pathways for recourse if they feel their information has not been used appropriately.

1.16 Document any genetic test results that are received, how they are used and evidence that the applicant was provided with clear information (in an easily accessible form, not buried within a lengthy PDS) about their rights, how their genetic results can be used (and not used), and pathways for recourse if they feel their information has not been used appropriately.

1.17 ASIC should develop a regulatory guide for life insurers to inform them of the obligations and requirements and the steps they need to take at each stage of the process. The development of this regulatory guide should be included as a legislative requirement.

1.18 A similar guide should be developed by the Department of Health and Aged Care (or another appropriate agency) for medical professionals and healthcare entities, to ensure that they understand the restrictions on life insurance companies asking for and holding individuals' genetic test results, and their role in not providing copies of genetic test results to insurers when asked for medical records**.**

Information already held by life insurers from past applications

1.19 Life insurers should destroy any genetic test data that they hold for which there is no longer a purpose for underwriting decisions.

1.20 Even in the case of voluntary disclosure, the insurer should only retain the information required to provide reasons for its underwriting decision. Copies of genetic test results which no longer need to be retained should be destroyed once the underwriting has been completed and not kept on file.

1.21 The legislation should include a requirement that each life insurance provider review its files and identify individuals for whom genetic test data is held. All individuals who are subject to penalties on the basis of genetic test results should have the penalty removed moving forward and should be notified that this has been done and that their genetic test results have been destroyed.

1.22 If insurers hold genetic data about prospective customers for whom a contract of insurance was declined altogether, that data should be destroyed.

2 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.

2.1 A new subsection should be inserted into section 20B of the ICA that states expressly that mere non-disclosure of matters the subject of the ban is not capable of constituting a breach of the duty not to take reasonable care to make a misrepresentation.

2.2 The explanatory materials supporting the Bill introducing the ban should refer to section 12, to make clear how the ban is intended to interact with the two duties (duty of utmost good faith/duty to take reasonable care not to make a misrepresentation).

2.3 There should be a requirement that insurers notify prospective applicants explicitly about the fact that they are not required to provide information about genetic test results and that insurers are not able to use genetic test results, except in circumstances where the voluntary disclosure exception applies (to provide a more favourable offer of insurance).

3 How the term 'genetic test' should be defined for the purposes of the ban

3.1 The definition should capture any test that provides information that predicts the basis of disease based on an individual's genetic profile and protects individuals against life insurance discrimination on the basis of that test data.

3.2 The definition should capture any test which provides predictive genetic information which could be used to discriminate against people based on their potential future health risks.

3.3 The proposed definition is:

Genetic test means:

a) a test that

i) analyses a person's DNA, RNA, or chromosome, or

ii) interprets information derived from the analysis of a person's 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

i) analyses any molecules or factors that influence or modify the expression of a person's genes (including but not limited to epigenetic tests), to detect, infer or predict genotypes or genetic variants, or predict future risk, or

ii) analyses any product of gene expression (for example, a protein), biomarkers or metabolites, to detect, infer or predict genotypes, or genetic variants,

whether or not there are other purposes for the test; or

c) a test that is prescribed as a genetic test by the regulations.

3.4 Any genetic test conducted in a research setting should be included within the definition

4 Whether aspects of the definition of 'genetic test' may be placed in subordinate legislation

4.1 The definition should be included in the main legislative instrument, with a clause allowing regulations to be made that prescribe tests to be included in the definition (see Recommenation 3.3).

4.2 An independent expert panel should be established, to provide advice to the Minister on any changes to the definition. This panel would be made up of experts in the field of genetic testing, and consumer representatives.

4.3 The legislation should require that the Minister for Health and Aged Care is consulted and signs off on any changes to the definition which are proposed.

4.4 The explanatory materials supporting the Bill should make clear the intention behind these requirements, for the benefit of future interpretation as necessary.

5 Factors that may require aspects of the definition of 'genetic test' to be flexible

5.1 While the definition as currently proposed is intended to remain relevant through some technological advances, it is necessary to have a mechanism to prescribe other tests through the regulations to be included in the definition of genetic test, as unexpected ways to determine individuals' risks emerge, which may in future act to deter people from taking tests or being involved in research.

5.2 If Australian life insurers take steps to try to avoid the intent of the legislation, consideration will need to be given to how to ensure the definition of genetic test is sufficiently robust to ensure Australians are adequately protected.

6 When/how genetic test results can be considered released under consent to a life insurer

6.1 Genetic test results must never be used for the purpose of applying a penalty or providing an unfavourable underwriting outcome, irrespective of whether they are provided voluntarily.

6.2 Insurers must not apply "checkbox" logic to require every applicant to provide consent to use their genetic results as part of their application for cover.

6.3 An additional requirement should be added to those proposed, to ensure that insurers cannot use genetic test results in a way that adversely impacts the underwriting and offer of insurance.

6.4 The legislation should prohibit the use of an applicant's favourable genetic results to lower the rates offered to that individual to below the standard rates offered to other applicants.

6.5 We propose the following definition of a "favourable genetic test":

> *"a favourable genetic test result is one which shows an individual does not have a genetic variant or condition that is known or suspected to exist within the individual's biological family to be causing a family or personal history of disease."*

6.6 Principles of best practice consent should be applied in this legislation, where appropriate: "voluntary, express, informed, specific as to purpose, time limited, and easily withdrawn", and "voluntary, informed, current, specific, and unambiguous".

6.7 The legislation should contain a requirement that insurers provide written information to consumers who are voluntarily providing genetic test results to inform them that they are not required to provide the results in order for their application to be considered, and that their result cannot be used to apply a penalty or an adverse underwriting offer

7 Other approaches to when/how genetic test results can be considered consented to be released

N/A

8 Enforcement options available for the ban in the Insurance Contracts Act and the DDA

8.1 There should be strict liability and substantial fines payable for any breaches identified, through a simple regulatory process that does not require lengthy and time-consuming prosecution by ASIC.

8.2 The legislation or associated regulatory guidance should make clear that non-compliance with the ban has the effect of rendering voidable a decision made by a life insurer not to consider an application, or not to offer life insurance, or to offer it on less favourable terms.

8.3 The remedies available through AFCA should include requiring the insurer to retrospectively review the file in compliance with the ban, and offer such cover, backdated as appropriate, as would have been offered had the ban been complied with.

9 Interaction between enforcement options under both the DDA and Insurance Contracts Act

9.1 No matter where a consumer starts their complaints journey, there should be a clear, accessible pathway to the same process.

9.2 This could be enabled by an MOU or other understanding between AHRC and AFCA regarding a multiple door (or "no wrong door") approach to consumer complaints, and clear and consistent information provision for consumers.

9.3 Because there are some restrictions to AFCA's reach (including financial limits), the right to issue proceedings in the Federal Court must be preserved, in case that pathway is preferred or becomes necessary.

9.4 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, so the Rules may need to be updated to enable this.

9.5 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.

10 Proposed prospective nature of the ban, and the inclusion of historic (pre-ban) tests

10.1 From the date of commencement of the ban, discrimination on the basis of genetic test results should be prohibited, regardless of the date of the test.

10.2 Australians with existing policies for which genetic test results have been used to apply penalties, loadings, exclusions or other adverse (non-standard) underwriting outcomes should have their penalties, loadings or exclusions removed, going forward from the date of commencement of the ban.

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.

11 How (if at all) the ban should affect variations of existing contracts

11.1 If an insured applies to vary their existing contract, that process should proceed per the usual course. if the application is to increase the cost of their cover, and in the usual course that increase in cover is within a band for which the insurer would usually not require a full new underwriting, but rather would apply a direct increase in premium, then the application should proceed in that way. If the application is to increase the cost of cover which in the usual course would trigger a new underwriting process, then that underwriting process should proceed without reference to the genetic test results which had previously been disclosed and used.

11.2 Any other change of contract terms should proceed accordingly – if the change would not usually trigger the requirement for fresh underwriting (such as a change in beneficiary), the change should be processed in the usual course. If the change would require fresh underwriting, then that underwriting should be undertaken without reference to the genetic test result.

11.3 The legislation and the explanatory materials supporting the Bill should make it clear that this should not be used as an opportunity by insurers to subvert the usual processes and take the opportunity to re-underwrite policies at a higher rate, that would not normally be re-underwritten in such circumstances, in an attempt to recoup perceived lost profits as a result of having to remove loadings previously applied on the basis of genetic test results.

11.4 The ASIC regulatory guide (see **Recommendation 1.17**) should also address the issues raised at Recommendation 11.3.

12 How the ban could operate in relation to in-progress applications for life insurance

12.1 The ban should operate in full from the date of commencement, which we submit should be the date of Royal Assent. This means that any offer of insurance that is made after the date of commencement will be subject to the ban.

13 What, if any, transition period should be provided for implementing the ban and why?

13.1 The ban on using tests to underwrite policies should commence on the day that the legislation receives Royal Assent.

13.2 The removal of loadings, penalties and conditions should be back-dated to the date of commencement of the ban.

13.3 Premiums should be refunded if applicable, and files amended to clarify that any conditions or exclusions did not apply from the ban's commencement date.

13.4 The end date for the transition period should be no later than 6 months following commencement of the ban.

13.5 These requirements should be subject to penalties for breach if not met after that period, and should be part of the insurers' reporting regime to ASIC.