Submission from Industry Genomics Network Alliance (InGeNA) on the Treasury Laws Amendment Bill 2025: Limiting the use of genetic information by life insurers

To: Treasury **From:** InGeNA Ltd, the Industry Genomics Network Alliance

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InGeNA Position Statement on Key Issues in the Treasury Laws Amendment Bill 2025

The Industry Genomics Network Alliance (InGeNA), is Australia's peak body for genomics and personalised healthcare, bringing together industry leaders across diagnostics, therapeutics, software, service delivery, data, and analytics. Our members range from large multinationals to innovative startups; all working to accelerate the adoption of genomics and ensure it is embedded in Australia's health system. InGeNA collaborates closely with stakeholders, including clinicians and our own consumer advisory group, to ensure that personalised healthcare benefits all Australians. We are committed to ensuring that all Australians can benefit from advances in genomic medicine without fear of discrimination. The legislation is important for industry members we represent from a precision medicine perspective as a critical enabler to ensure effective clinical management of patients with genomic based diagnosis, as the key enabler to access to life saving treatment options.

We support the Government's commitment to legislating a ban on the use of genetic test results in life insurance underwriting.

We provide our submission and highlight our strong support of the submission made by Monash University concerning the exposure draft of the Treasury Laws Amendment Bill 2025.

While we commend the introduction of the exposure draft Bill as a critical step forward, we believe several key amendments are necessary to ensure the legislation is robust, fair, and achieves the Government's stated policy aims. This is a critical reform that will empower Australians to proactively manage their health without fear of discrimination. However, to achieve the Government's stated policy aims and build public trust, the legislation must be comprehensive, robust, and address key areas of concern highlighted in the Monash submission. InGeNA wishes to emphasise the industry's perspective on the following critical points in the draft legislation is as follows:

1. Removing Penalties from contracts of insurance affected by discrimination

A fundamental flaw in the current draft is that it fails to protect individuals who have already been penalised for disclosing adverse genetic test results. Under the draft, the ban only applies to life insurance decisions made after commencement, excluding those with ongoing policies who will continue to pay discriminatory loadings or be subject to exclusions. We support the Monash recommendations.

- **InGeNA's Position:** We strongly advocate for the legislation to require insurers to proactively remove all penalties, loadings, and exclusions that were applied to existing policies on the basis of protected genetic information. These individuals, whose lived experiences helped drive this important reform, face an unfair choice between continuing to pay discriminatory premiums or undergoing a new underwriting process at an older age, which could lead to even less favourable terms. Given the insurance industry's own data showing a very small number of policies are affected (less than 0.05% of new policies in 2022), this is a manageable and necessary adjustment to ensure fairness and maintain public trust in the reform.

2. The Definition of "Clinical Diagnosis" Must Be Unambiguous to Prevent Loopholes

The distinction between a genetic predisposition and a clinical diagnosis of a disease is a cornerstone of this legislation. The draft definition is ambiguous and creates a significant risk that insurers could classify a genetic variant itself as a "diagnosed condition," which would completely undermine the ban's protections. This concern is validated by instances where health insurers have attempted to classify the presence of a BRCA1 variant as a pre-existing condition in an asymptomatic person.

- **InGeNA's Position:** The legislation must clearly state that a "clinical diagnosis" requires the manifestation of medical signs or symptoms. A genetic predisposition, even if given a name like a "syndrome," must not be classified as a condition or diagnosis. Without this clarity, the ongoing uncertainty will continue to deter Australians from having genetic tests and will damage consumer trust in the effectiveness of the legislation. The Explanatory Memorandum should also be amended to clarify this distinction and support the Monash submission that this 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".

3. Loopholes for Inferring Genetic Risk Must Be Explicitly Closed

International experience, particularly from Canada, has shown that insurers may try to circumvent a ban by inferring a person's genetic risk from other legally collected information. This can include using information about an applicant's schedule of medical surveillance (e.g., frequent colonoscopies or MRIs) or their eligibility for preventative medications or clinical trials. If these loopholes are not closed this will perpetuate consumer uncertainty and fear that will deter clinicians offering or people having genetic tests. Ultimately the legislation must be strengthened to ensure that all Australians can access genetic testing and precision medicine to access life saving treatments.

- **InGeNA's Position:** The legislation must explicitly state that insurers are prohibited from using information about an applicant's ongoing medical care to infer predictive genetic risk and discriminate on that basis. The definition of "protected genetic information" must be strengthened to cover genetic information that is inferred, not just directly provided. Proactively closing this identified loophole is critical to ensuring the ban is effective and that its protections cannot be eroded by alternative underwriting tactics.

4. The Use of Family History Must Align with the Industry's Own Code

The draft Bill proposes to exclude the diagnosis of a disease in any "genetic relative" from the definition of protected information. This is overly broad and inconsistent with the industry's own Code of Practice, which limits family history questions to first-degree relatives (parents, children, and siblings).

- **InGeNA's Position:** The legislation should not create a standard that is less protective for consumers than the industry's existing code. We recommend amending the Bill to limit the family history exception to first-degree genetic relatives only. This ensures that information about distant relatives, which insurers state they do not collect, is protected under the ban.

Summary statement

In summary, InGeNA supports a complete, unqualified legislative ban that provides certainty and confidence for all Australians. By adopting these critical amendments, the Government can deliver a robust, world-class reform that closes loopholes, ensures fairness for all, and secures the future of genomic healthcare in our nation.

InGeNA and its members are committed to realising the profound health and economic benefits of genomics for all Australians. We are concerned that patients are currently missing out on the life-changing benefits that genomics brings to human health through prevention, prediction, and precision medicine. The critical issue for industry is that we have the technology and capability to deliver life-saving outcomes, and we need to ensure that the legislation provides certainty, protection, and fairness for all Australians who may benefit from these advances.

A robust, clear, and comprehensive legislative ban on genetic discrimination is an essential foundation for achieving this vision. We support the extensive advocacy led by Monash University in urging the Government to adopt the proposed amendments. By doing so, the Government will deliver a world-class reform that truly protects Australians, builds public trust, and secures the place of genomic healthcare in our nation to enable improved prevention, early detection, and access to life-saving genomic precision medicine.

For additional information, please contact:
Dr Erin Evans,
CEO, InGeNA