Submission to the Senate Economics Legislation Committee

Inquiry: *Treasury Laws Amendment (Genetic Testing Protections in Life Insurance and Other Measures) Bill 2025*

Submitted by: *Name withheld* (private individual)
Publication preference: Name withheld

Request for confidentiality:
This submission contains sensitive personal and family health information. I respectfully request that my name be withheld from publication and that identifying details be treated confidentially, in accordance with the Committee's submission guidelines.

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1. Executive summary

I support the passage of Schedule 1 of the *Treasury Laws Amendment (Genetic Testing Protections in Life Insurance and Other Measures) Bill 2025*, which establishes a legislative prohibition on the use of protected genetic information in life insurance underwriting.

The Bill addresses a well-documented policy failure: Australians delaying or avoiding clinically relevant genetic testing and medical research participation due to fear of adverse insurance consequences. This deterrent effect is acknowledged in the Explanatory Memorandum and supported by Australian research and stakeholder evidence.

This submission draws on lived experience. I have actively considered genetic testing but have chosen not to proceed due to the risk that information generated could negatively affect my ability to obtain or maintain life insurance. This decision was not driven by medical reluctance, but by insurance risk.

I support the Bill as drafted and offer a series of recommendations intended to strengthen clarity, enforceability, and public confidence, drawing on implementation lessons from comparable international regimes.

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2. About this submission

I am an Australian resident making this submission in a personal capacity.

I have diagnosed and suspected heritable conditions, as well as a family history of health issues that have not always been clearly communicated across generations. Genetic testing is therefore clinically relevant to my healthcare decisions and preventative planning.

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3. Lived experience: barriers to understanding my own health

In my family, health information has not been consistently or proactively shared. Known conditions and risks were often communicated late, incompletely, or only after symptoms had already emerged.

As a result, I have frequently had to discover — "the hard way" — both:

- what I may be genetically predisposed to; and
- what I actually experience due to inherited or heritable conditions.

Conditions affecting me or my family include:

- **Restless Leg Syndrome (RLS)**;
- **Periodic Limb Movement Disorder (PLMD)**;
- **Psoriasis**; and
- **A family history of heart disease**.

These conditions affect quality of life, sleep, and long-term health, and in some cases carry broader neurological or cardiovascular implications. Improved understanding of genetic predisposition could meaningfully inform prevention, monitoring, and treatment.

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4. Why I have avoided genetic testing

I have actively explored genetic testing to better understand my health risks and guide preventative care. However, I have chosen not to proceed.

The reason is not medical hesitation, but insurance risk.

Under existing arrangements, genetic information generated through testing may be requested, inferred, or used by life insurers in ways that could negatively affect coverage or future insurability.

This creates a problematic incentive structure:

> *Responsibly seeking medically relevant information can itself create financial disadvantage.*

In practice, I have felt compelled to choose between understanding my own biology and protecting my access to fair insurance coverage. This deterrent is real and ongoing.

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5. Research participation deterrence

Two of the conditions I live with — **Restless Leg Syndrome (RLS)** and **Periodic Limb Movement Disorder (PLMD)** — remain under-researched. There is limited evidence,

inconsistent diagnostic pathways, and ongoing uncertainty regarding genetic contributors and long-term management.

Participation in medical and genetic research should be encouraged. However, under current insurance settings, research participation carries perceived and credible risk.

Information generated through research participation, including genetic or genomic data, may later become discoverable, inferred, or used in insurance contexts. This creates a chilling effect on participation in public-interest research.

As a result, I have been reluctant to participate fully in research related to these conditions — not due to lack of willingness, but due to concern about insurance consequences.

This outcome is counterproductive. When individuals avoid research participation due to insurance risk, the costs are borne by medical progress, public health, and future patients.

The Bill's protections directly address this deterrent effect. This lived experience informs several of the recommendations below, particularly those relating to research-derived genetic information, consent, and consumer clarity.

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6. Family context: genetic testing beyond the individual

My wife was born in China at a time when comprehensive medical records were not reliably maintained. As a result, much of her family medical history is incomplete or unavailable.

While we are aware that certain conditions run in her family, the lack of reliable records limits clarity around inheritance patterns and risk.

Access to genetic testing could:

- improve her own healthcare and peace of mind;
- inform our shared health planning; and
- potentially provide valuable insight for her relatives.

Without strong legal protections, however, the decision to pursue testing carries potential financial consequences extending beyond the individual. This discourages shared health knowledge and intergenerational care.

These considerations reinforce the importance of future-proofing protections so that evolving genetic insights do not reintroduce uncertainty or financial risk for families seeking clarity about inherited health conditions.

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7. Why this Bill matters

The Bill resolves a structural conflict between:

- modern genomic medicine, which increasingly relies on predictive information; and

- insurance frameworks not designed for probabilistic genetic risk.

By clearly separating:

- genetic predisposition from diagnosed disease; and
- health-seeking behaviour from underwriting disadvantage,

the Bill enables Australians to pursue medically responsible choices without fear of financial penalty.

While I support the Bill as drafted, lived experience highlights several practical considerations that will determine whether the protections operate effectively in real-world settings. The recommendations below are offered to strengthen clarity, prevent circumvention, and ensure durable public-health outcomes.

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8. Recommendations

I support the Bill as drafted. The recommendations below are intended to strengthen clarity, enforceability, and public confidence, and to ensure the legislation delivers its intended outcomes over time. They draw on implementation lessons from comparable international regimes and are offered in a constructive spirit.

Recommendation 1 — Future-proof the scope of protected genetic information

- **Type:** Bill amendment
- **Recommendation aim:**
  To ensure the protections established by the Bill remain effective as genetic and genomic technologies evolve, and are not undermined by narrow or outdated definitions.
- **Recommendation:**
  Amend or clarify the definition of protected genetic information so that it explicitly encompasses modern and emerging genomic outputs, including whole-genome sequencing, whole-exome sequencing, clinically validated genomic panels, and polygenic risk scores. The definition should be technologically neutral and focused on functional use rather than test modality.
- **Example in practice:**
  Canada's *Genetic Non-Discrimination Act* adopts a broad framing around genetic tests and results, prioritising protective intent over technical specificity.
- **Justification:**
  If statutory protections are tied too closely to current testing models, they risk becoming obsolete as insurers and data providers adopt newer forms of risk scoring that encode genetic information indirectly. Future-proofing the definition supports

the Bill's core objective: ensuring people are not penalised for learning about their biology, regardless of how that information is generated.

- **References:**
  Canada — *Genetic Non-Discrimination Act*

Recommendation 2 — Prohibit indirect or proxy use of genetic information

- **Type:** Bill amendment
- **Recommendation aim:**
  To prevent circumvention of the prohibition through indirect use of genetic information or technically mediated risk proxies.
- **Recommendation:**
  Explicitly prohibit the use of protected genetic information both directly and indirectly, including through derived indicators, third-party analytics, risk scores, or other proxy measures that are substantially informed by genetic data.
- **Example in practice:**
  The United Kingdom's *Code on Genetic Testing and Insurance* operates on a "don't ask / don't use" principle for predictive genetic information.
- **Justification:**
  Where direct use is banned but indirect use is not addressed, enforcement becomes difficult and deterrence persists. Clear statutory language would provide regulators with confidence, insurers with clarity, and consumers with genuine reassurance.
- **References:**
  United Kingdom — *Code on Genetic Testing and Insurance*

Recommendation 3 — Ensure consent exceptions are genuinely voluntary

- **Type:** Bill amendment and implementation guidance
- **Recommendation aim:**
  To ensure that consent-based exceptions do not operate in practice as coerced disclosure or a condition of obtaining cover.
- **Recommendation:**
  Clarify that any consent-based exception must be genuinely voluntary and must not be required, explicitly or implicitly, as a condition of insurance. Consent should be specific, informed, time-limited, and revocable, and refusal to consent must not result in adverse underwriting treatment.

- **Example in practice:**
  Canada's legislative approach prohibits compelled disclosure of genetic information as a condition of accessing goods or services.
- **Justification:**
  Consent frameworks are a common failure point in privacy and discrimination law. Clear guardrails ensure consent supports autonomy rather than eroding it.
- **References:**
  Canada — *Genetic Non-Discrimination Act*

Recommendation 4 — Extend protections across underwriting intermediaries

- **Type:** Bill amendment
- **Recommendation aim:**
  To ensure protections apply consistently across real-world insurance underwriting workflows.
- **Recommendation:**
  Apply prohibitions on requesting, using, or relying on protected genetic information equally to reinsurers, underwriting agents, brokers, advisers, and outsourced service providers.
- **Example in practice:**
  The United Kingdom's framework applies industry-wide and recognises distributed underwriting decision-making.
- **Justification:**
  From a consumer perspective, distinctions between insurers and intermediaries are invisible. Protections must operate across the entire underwriting ecosystem to be effective.
- **References:**
  United Kingdom — *Code on Genetic Testing and Insurance*

Recommendation 5 — Strengthen data handling and retention controls

- **Type:** Implementation guidance
- **Recommendation aim:**
  To minimise the risk of misuse, re-identification, or future repurposing of protected genetic information.
- **Recommendation:**
  Require minimisation, segregation, access control, retention limits, and deletion of

protected genetic information, including prohibitions on retaining such information "just in case".

- **Example in practice:**
  Governance expectations in the United Kingdom emphasise data minimisation and demonstrable compliance.
- **Justification:**
  Even where use is prohibited, retention of genetic data creates latent risk. Strong controls align with modern privacy and risk-management principles.
- **References:**
  United Kingdom — Government oversight of genetics and insurance arrangements

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Recommendation 6 — Mandate clear consumer-facing disclosures

- **Type:** Implementation guidance
- **Recommendation aim:**
  To reduce fear, confusion, and misinformation that discourage genetic testing or research participation.
- **Recommendation:**
  Mandate standardised, plain-English disclosures stating that applicants are not required to disclose protected genetic information and that insurers must not ask for it.
- **Example in practice:**
  Consumer guidance accompanying the United Kingdom's framework.
- **Justification:**
  Clear messaging ensures legislative protections translate into real behavioural change.
- **References:**
  United Kingdom — Consumer guidance on genetics and insurance

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Recommendation 7 — Explicitly protect research-derived genetic information

- **Type:** Bill amendment and implementation guidance
- **Recommendation aim:**
  To ensure participation in medical and genetic research does not create insurance exposure.
- **Recommendation:**
  Reinforce that genetic information generated through research participation must not be used in insurance underwriting or become a pathway to future disadvantage.

- **Example in practice:**
  Advocacy by the Human Genetics Society of Australasia, the peak professional body for clinical genetics and genetic counselling in Australia.
- **Justification:**
  Avoidance of research participation harms public health and slows progress in under-researched conditions.
- **References:**
  Australia — *Human Genetics Society of Australasia*

Recommendation 8 — Require regular independent review and public reporting

- **Type:** Bill amendment
- **Recommendation aim:**
  To maintain accountability, transparency, and policy relevance over time.
- **Recommendation:**
  Mandate regular independent review and publication of aggregate compliance metrics.
- **Example in practice:**
  Periodic review and reporting in the United Kingdom.
- **Justification:**
  Regular review ensures the framework remains aligned with its original policy intent as technologies and practices evolve.
- **References:**
  United Kingdom — Government reporting on genetics and insurance arrangements

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Recommendation 9 — Provide a clear complaints and remedies pathway

- **Type:** Implementation guidance
- **Recommendation aim:**
  To ensure protections are practically enforceable by individuals.
- **Recommendation:**
  Clearly articulate complaint pathways, investigation timelines, and available remedies.
- **Example in practice:**
  Enforceable statutory protections in Canada.
- **Justification:**
  Rights without remedies are unlikely to change behaviour.

- **References:**
  Canada — *Genetic Non-Discrimination Act*

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9. Conclusion

At its core, this Bill reflects a simple and important principle:

> *People should not be penalised for wanting to understand their own bodies or contribute to medical knowledge.*

By removing insurance-based deterrents to genetic testing and research participation, the Bill supports individual health outcomes, strengthens public health, and aligns Australia with international best practice.

I urge the Committee to recommend passage of the Bill, with consideration of the recommendations outlined above.