



**Queensland Youth  
Policy Collective**

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Submission to the Senate Standing Committee on Economics

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

11 January 2026

## 1. Introduction

The Queensland Youth Policy Collective (**QYPC**) has prepared this submission to assist the Senate Standing Committee on Economics (**Committee**) in its consideration of Schedule 1, “Limiting the use of genetic information by life insurers”, of the Treasury Laws Amendment (Genetic Testing Protections in Life Insurance and Other Measures) Bill 2025 (**Bill**).

The QYPC was founded in 2021 and has over 40 members across Queensland. We are non-partisan and comprised of young people who want to contribute evidence-based, youth-led perspectives in public debate, particularly in the fields of human rights, climate change and youth justice.

The QYPC is interested in the use of genetic information by life insurers due to its impact on the privacy, health, and financial stability of young Australians. Early adulthood is a period of significant personal decision-making and growth, as young people take their first steps into financial independence. Milestones such as marriage and the birth of children prompt young adults to consider the ways they can financially secure the future of their dependents by taking out life insurance.<sup>1</sup> Lawmakers must protect them from having their genetic information exploited during this process to their financial detriment.

We strongly recommend that the Committee support Schedule 1 of the Bill. The proposed amendments to the *Insurance Contracts Act 1984* (Cth) (**ICA**) will not only help protect the genetic privacy of young people and their relatives but will also promote better health outcomes and long-term economic growth.

## 2. This Bill will safeguard young people’s rights to genetic privacy

Schedule 1 of the Bill will protect the confidentiality of the private medical information of young people seeking insurance coverage and their relatives.

Direct-to-consumer genetic testing blurs the boundary between patient and customer. Under Australian law, patients’ medical information is protected by their doctors’ duty to keep this information confidential and act in their patients’ best interests.<sup>2</sup> By contrast, consumer rights

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<sup>1</sup> Madeline McGrath, ‘Australian Life Insurance Survey and Statistics 2025’, *Budget Direct* (Article, 2 July 2025).

<sup>2</sup> Andelka M Phillips, ‘Genomic Privacy and Direct-to-Consumer Genetics – Big Consumer Genetic Data – What’s in that Contract?’ (presented at GenoPri’15 (The 2nd Workshop on Genome Privacy and Security) and published as part of IEEE Conference Proceedings 2015) Genomic Privacy GenoPri, 1.

prioritise autonomy and customer choice in the free market.<sup>3</sup> Given the personal and unchangeable nature of genetic information and its potential misuse by insurance providers, the Government must take strong action to protect this information.

Protecting the privacy of insurance customers' genetic information also protects the rights of their blood relatives.<sup>4</sup> A person does not require the consent of their relatives to undertake genetic testing. However, one 2018 study found that people of European descent could be identified if their third cousin or closer had their DNA on an open-access or commercial database.<sup>5</sup> Therefore, in the absence of appropriate legal protections, a young person's ability to obtain life insurance, or the conditions upon which they can do so, can be compromised by decisions made by distant relatives they have never even met.

The proposed new section 33H of the ICA will mitigate this risk by making it an offence for insurers to request, incentivise or otherwise induce or encourage a person to provide protected genetic information, including the results of genetic testing.

### **3. The Bill will improve health outcomes for young people**

By making it an offence for insurers to solicit or use customers' genetic information in life insurance underwriting, the proposed amendments to the ICA will encourage more Australians to undergo genetic testing, empowering young people to make more informed decisions about their healthcare.

Genetic testing is a valuable tool in the prevention, early detection and treatment of serious diseases. Test results can inform more effective treatment options for patients already diagnosed with serious health conditions by revealing the influence their genes may have on their response to certain medications.<sup>6</sup> Predictive genetic testing can also identify if a seemingly healthy individual is at an increased risk of developing a serious disease in the future, allowing them to consider preventative measures (such as mastectomies, in the case of

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<sup>3</sup> Ibid; M Neil Browne et al, 'Protecting Consumers From Themselves: Consumer Law And The Vulnerable Consumer' (2015) 63 *Drake Law Review* 157, 159.

<sup>4</sup> Health NSW, Guidance for Health Professionals Obtaining Consent for Clinical Genomic Testing, *The National Model of Consent for Clinical Genetic Testing*, 4, <https://www.health.nsw.gov.au/services/Publications/genomic-testing-consent-guidance.pdf>.

<sup>5</sup> Erlich Yanniv et al, 'Identity inference of genomic data using long-range familial searches' (2018) *Science*

<sup>6</sup> Dianalee McKnight et al, 'Genetic Testing to Inform Epilepsy Treatment Management From an International Study of Clinical Practice' (2022) 79(12) *JAMA Neurology* 1267.

breast cancer) and undergo more regular screenings.<sup>7</sup> This can be a particularly valuable tool for young people, empowering them to take action to secure their long-term health well before symptoms develop.

On a broader scale, de-identified genetic data is a valuable input for scientific and medical research. It can be used to identify populations that are particularly vulnerable to certain diseases to inform public health interventions.<sup>8</sup> Researchers can also use aggregate testing results to identify previously unknown genetic risk factors and develop more effective treatments.<sup>9</sup>

However, Australians are delaying or even completely declining genetic testing due to concerns over the impact it could have on their life insurance. In a 2019 study of nearly 1,500 Australian adults, over 80% of participants expressed high concerns about potential insurance discrimination based on their genetic data.<sup>10</sup> Young people in particular tend to be less willing to share their genetic results than their older counterparts.<sup>11</sup> Another study revealed that the proportion of participants who declined genetic testing in the Victorian Colorectal Concern Family Study more than doubled when participants were informed of the potential impact of genetic testing on their insurance eligibility.<sup>12</sup>

The Bill will remove this powerful disincentive to genetic testing, resulting in improved health outcomes for young Australians.

#### **4. The Bill will contribute to long-term economic growth**

By promoting the prevention and effective treatment of chronic diseases, the proposed amendments to the ICA will also encourage more sustainable, long-term economic growth. Chronic illness is a barrier to employment, reducing productivity through illness-related

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<sup>7</sup> Jacob G Comeaux et al, 'Risk-reducing mastectomy decisions among women with mutations in high- and moderate- penetrance breast cancer susceptibility genes' (2022) 10(10) *Molecular Genetics & Genomic Medicine*.

<sup>8</sup> 'How does genetic sequencing help medical research?', *National Breast Cancer Foundation* (Article, 18 May, 2016).

<sup>9</sup> Hakhamanesh Mostafavi, 'Two Main Gene Discovery Methods Reveal Complementary Aspects of Biology', *NYU Langone Health NewsHub* (Article, 5 November 2025).

<sup>10</sup> McKnight et al (n 6).

<sup>11</sup> Miranda E. Vidgen et al., 'Sharing genomic data from clinical testing with researchers: public survey of expectations of clinical genomic data management in Queensland, Australia' (2020) 21 *BMC Medical Ethics* 119, 6.

<sup>12</sup> Louise A Keogh et al, 'Is uptake of genetic testing for colorectal cancer influenced by knowledge of insurance implications?' (2009) 191(5) *Medical Journal of Australia* 255.

absenteeism and early exits from the workforce due to morbidity and premature mortality.<sup>13</sup> By contrast, a healthier population requires less government expenditure on healthcare, assisted living and income support.<sup>14</sup> By eliminating unnecessary disincentives to genetic testing by passing the Bill, Parliament can build a better financial future for young Australians.

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<sup>13</sup> Jaithri Ananthapavan et al, 'Prevention pays: Investing in Australia's health and economic future' (2025) 49(6) *Australian and New Zealand Journal of Public Health*.

<sup>14</sup> 'Health is the best investment in Australia's economy', *Australian Medical Association* (Media Release, 18 September, 2015); The European House – Ambrosetti, *The Value of Prevention for Economic Growth and the Sustainability of Healthcare, Social Care and Welfare Systems* (White Paper, September 2024).