New Zealand House of Representatives
Te Whare Māngai o Aotearoa

Health Committee
Komiti Whiriwhiri Take Hauora

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Briefing on genetic discrimination in insurance

Presented to the House of Representatives
by Sam Uffindell, Chairperson

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Recommendation

The Health Committee has considered a briefing on genetic discrimination in insurance, and recommends that the House take note of its report.

About this briefing

We sought this briefing after Against Genomic Discrimination Aotearoa (AGenDA) wrote to us in July 2026. In its letter, AGenDA asked to brief us on genetic discrimination in relation to insurance. We held a hearing with AGenDA on 19 August 2026 to hear about its concerns.

It requested that we recommend to the Government that it begin consultation about genetic discrimination in insurance before the end of 2026.[1] This consultation would be under sections 83 to 85 of the Contracts of Insurance Act 2024.

Comments from Against Genomic Discrimination Aotearoa

AGenDA is a coalition of individuals and organisations that advocates limiting insurance companies' access to personal genetic information. Such information can indicate a person's risk of developing illnesses in the future. AGenDA is not suggesting that any changes should be made to insurance provision in relation to already diagnosed illnesses, symptoms, or treatment.

Its overarching concern is that New Zealand insurers could deny or alter insurance coverage based on people's predictive genetic testing results even if they:

- never develop the condition highlighted by testing
- lower their risk of illness through regular monitoring, medication, lifestyle change, or other preventive measures
- get an earlier diagnosis because of testing.

However, AGenDA thinks that insurance applicants should still be able to use favourable genetic testing results to improve an insurance offer, if they wish.

Background

We heard from AGenDA that about one in three New Zealand adults have some form of life insurance, and one in four has private health insurance. Thousands of those insured are likely to carry a rare genetic disorder or have inherited a genetic trait that predisposes them to illness. This is central to the "significant and growing" issue where genetic testing and insurance intersect, it told us.

[1] The Contracts of Insurance Act 2024 is intended to reform and modernise the law relating to insurance contracts. Sections 83 to 85 of the Act relate to regulations about genetic testing. The Act is on the New Zealand Legislation website.

Genetic testing is a medical test which analyses a person's genes and identifies which genes may affect their health. We heard about its benefits, including that it increasingly diagnoses rare disorders, reveals risks of family illnesses, guides cancer treatment, and helps people appropriately monitor their health and take preventative action before disease develops.

Concerns about genetic results adversely affecting insurance

In New Zealand, insurers can request the result of genetic tests and factor it into someone's insurance, AGenDA highlighted. AGenDA believes this conflicts with behaviour that promotes good health. It told us that international and domestic evidence shows about 10 to 30 percent of people may be deterred from having genetic testing due to concerns about what it could mean for their insurance. AGenDA believes this undermines illness prevention and deters family testing, genomic research, and recruitment for clinical trials. Screening for inherited conditions could prevent thousands of cancers and deaths in New Zealand, AGenDA said. It believes that if people fear genetic testing because of the effect it might have on their insurance, the opportunities associated with genetic testing may be lost. If the system creates incentives for people not to have genetic tests, AGenDA said, this creates health and economic costs for families and the public health system.

Examples

AGenDA told us that the issue "is not theoretical". We heard about a woman who has a genetic inherited cancer variant (BRCA2). She reported paying insurance premiums that were subject to a 50 percent loading for 15 years, despite having had risk-reducing surgery. Her daughter was quoted a 75 percent loading by an insurance company, even though she tested negative for the familial variant.

Another woman learned that she carried a pathogenic variant associated with the genetic condition, Lynch syndrome. Having that knowledge helped her monitor the risks associated with the syndrome and she underwent risk-reducing surgery. Although she had never been diagnosed with a Lynch syndrome-related cancer, health and life insurers requested her tests. The insurers imposed loadings of 50 to 150 percent, deferred insurance cover, and reduced her insurance benefits. AGenDA said she was penalised for having knowledge of, and managing, her genetic risk.

AGenDA believes this demonstrates a "one-way ratchet". Adverse genetic testing results can increase people's insurance premiums or restrict the cover they can access. Yet negative results and interventions that reduce people's risk of illness, it told us, "may receive little equivalent favourable weight".

Approaching the issue in other jurisdictions

We heard that New Zealand, Colombia, and Costa Rica are "at the extreme end of the OECD without operative protection governing insurers' use of predictive genetic test results". The other 35 countries in the OECD have legislation, regulation, and industry codes to protect genetic test results from being used by insurers, AGenDA said.

In the United Kingdom, results from predictive genetic tests have been protected since 2001, meaning that insurers cannot ask for or use those tests to underwrite insurance policies.[2] Canada enacted similar legislation in 2017.[3] We also heard that genetic results have been protected from being used adversely in private health insurance in Australia since 2007. Additionally, from October 2026, Australia will prohibit the adverse use in life-insurance underwriting.

Calling for consultation on the Contracts of Insurance Act

The Contracts of Insurance Act 2024 comes into effect in November 2027. It includes clauses that allow regulations to be made relating to insurers' conduct and genetic testing (sections 83 to 85). However, for those regulations to be made, the relevant Minister would need to undertake consultation first.

We heard that consultation documents have been prepared, but consultation has not started. AGenDA wants consultation to begin before the end of 2026 and said that it is where evidence should be tested and appropriate safeguards be designed. Delaying consultation will mean that public health consequences will remain unaddressed, as people put off undergoing genetic testing because they worry about its effects on insurance.

Our comments

We thank Against Genomic Discrimination for briefing us about the matter and for providing real world examples. Some people faced higher insurance premiums, even after taking steps to reduce their risk, or after testing showed they did not have a familial variant of an illness. We agree that there may be benefits and opportunities associated with predictive genetic testing, as well as risks.

We note that, prior to its enactment, the Contracts of Insurance Bill was considered by the Finance and Expenditure Committee. If the adverse use of genetic test results in insurance puts people off getting tested this could have implications for the health system. We consider that timely consultation on possible regulations about insurers' conduct in relation to genetic testing under the Contracts of Insurance Act would benefit the health system and consumers.

2 The *Code on Genetic Testing and Insurance* is available on the Government of the United Kingdom's website.

3 The Genetic Non-Discrimination Act is available on the Government of Canada's website.

Appendix

Committee procedure

We met between 22 July and 16 September 2026 to consider this briefing. We received written evidence from Against Genomic Discrimination Aotearoa. We also heard evidence from Against Genomic Discrimination Aotearoa on 19 August 2026.

Committee members

Sam Uffindell (Chairperson)
Dr Hamish Campbell
Dr Carlos Cheung
Ingrid Leary
Cameron Luxton
Hūhana Lyndon
Jenny Marcroft
Debbie Ngarewa-Packer
Hon Dr Ayesha Verrall

Related resources

The documents we received as evidence for this briefing are available on the Parliament website, along with the recording of our meeting on 19 August 2026.