

Privacy Commissioner's Submission to the Finance and Expenditure Committee on the Contracts of Insurance Bill

Executive Summary

1. I am pleased to provide this written submission to the Finance and Expenditure Committee (the Committee) on the Contracts of Insurance Bill (the Bill).
2. Under the Privacy Act 2020, the functions of the Privacy Commissioner include examining new legislation for possible impacts on individual privacy. It is also part of the Privacy Commissioner's role to monitor emerging privacy issues, and to offer guidance on how people in industry, government agencies, and across broader society can uphold their privacy obligations.
3. The purpose of the Bill is to ensure the effectiveness of insurance contract law and 'to enable consumers and businesses to effectively protect themselves against risk, while minimising costs and impacts on insurers' willingness to provide insurance in New Zealand.'
4. Several submissions on the Bill have addressed the issue of genetic testing and genetic discrimination as it relates to insurance, although the Bill itself does not currently reference genetic testing or genetic information.
5. Some of these submissions have recommended that the Bill be amended to exclude the ability for insurers to require genetic testing to be undertaken or to require existing genetic testing results to be disclosed to insurers. Other submissions have questioned whether the Bill is the best vehicle to address genetic discrimination.
6. The Privacy Commissioner did not initially provide a submission on the Bill given these issues were not explicitly referred to in the scope of the Bill. However, given genetic testing results are highly sensitive personal information, I appreciate being invited by the Committee to provide this written submission with a focus on privacy considerations. This is an important issue which has implications for New Zealanders' privacy and ability to access insurance.
7. I recommend specific protections should be developed to manage the privacy risks presented by the use of genetic tests in the insurance context.
8. If the Committee believes issues relating to genetic information and genetic discrimination are within scope of the Bill, my main recommendation is that a clause, or clauses, be added to the Bill to prohibit insurance companies from requiring an individual to take a genetic test or disclose genetic test results.

Introduction

9. The Privacy Act 2020 is New Zealand's main privacy statute. It governs the collection, use, storage, and disclosure of personal information and provides a mandate for my

Office to consider wider developments that affect personal privacy, including privacy of genetic information.

10. By its nature, genetic information is highly sensitive personal information for both the individual and their wider whānau, as genetic conditions can be hereditary. The collection, use, disclosure and storage of genetic information are subject to the Privacy Act.
11. I am supportive of the safe use of current and emerging technologies, including genetic testing, when it is done safely and ensures adequate protection of personal privacy.
12. Genetic testing provides individuals with knowledge about their risk of developing diseases. People may choose to have genetic tests due to family history of a certain disease. For example, an individual who has a family history of breast cancer may choose to have a genetic test to determine if they have BRCA1 or BRCA2 mutations and are therefore at greater risk of developing breast cancer.
13. The key point here in relation to privacy rights is that it is the choice of the individual to have this testing done and share any information the testing reveals as they choose. The individual will, hopefully, have made an informed decision to be tested in consultation with a health professional.
14. Safeguarding individual choice about whether to be tested and what happens to test results is at the heart of submissions on the Bill which reference genetic testing and genetic discrimination.¹ These submitters support the use of genetic testing. However, they submit that if insurers are able to require people to provide genetic testing results so this highly sensitive personal information can be used to make insurance decisions, individuals are less likely to have genetic testing done.

Status quo in New Zealand

15. Personal health information is protected under the Privacy Act as well as the Health Information Privacy Code 2020.²
16. The Privacy Act does not include specific protections for sensitive personal information such as genetic information, but I consider extra care is needed with sensitive information. My Office has developed guidance for dealing with sensitive personal information and the Privacy Act.³
17. Although genetic information is covered by the Privacy Act, insurance companies are not prevented from collecting people's genetic testing results if they can show that such collection is necessary for a lawful purpose connected to their business activities (Information Privacy Principle 1 (IPP)). Likewise, the Privacy Act would not prevent an insurer from refusing to insure someone who declined to provide the results of a genetic test.
18. I understand there is no current self-regulation of this issue by the insurance industry in New Zealand, but note that the Financial Services Council, when asked by the

¹ For example, the submissions by Against Genomic Discrimination in Aotearoa, Consumer New Zealand, Dr Jane Tiller, and Medicines New Zealand.

² The Health Information Privacy Code is a code of practice made under the Privacy Act. It applies to health information collected, held, used and disclosed by health agencies, including health insurers.

³ <https://privacy.org.nz/assets/New-order/Your-responsibilities/Privacy-resources-for-organisations/Sensitive-Personal-Information-and-the-Privacy-Act-2020.pdf>

Committee, indicated they have been working on issues surrounding genetic testing for the past 12 months.

What have other jurisdictions done in relation to genetic discrimination?

19. This issue is not unique to New Zealand. The use of genetic testing is increasing around the world and some jurisdictions have moved to protect people from genetic discrimination and protect their genetic information.
20. I outline some different approaches other countries have adopted below.

Canada – standalone legislation⁴

21. In 2017, Canada enacted the Genetic Non-Discrimination Act. The Non-Discrimination Act prohibits a person being required to take a genetic test or disclose genetic test results.⁵ Its coverage is not restricted to the insurance industry.
22. The Non-Discrimination Act also prohibits a person from collecting, using or disclosing the results of a genetic test of someone without the written consent of the person who has had genetic testing done.⁶
23. This is an example of a legislative approach with a standalone Act that is focused on genetic discrimination. This Bill, by contrast, could only address genetic privacy and discrimination in relation to insurance.

Australia – self-regulated moratorium⁷

24. Australian **health insurers** are governed by the Private Health Insurance Act 2007, which prohibits health insurers from using genetic information to differentiate against customers through its broad definition of ‘improper discrimination’.⁸
25. However, **life insurers** are not prohibited from similar differentiation using genetic information, or from requiring genetic testing and disclosure of testing results.
26. In 2019, life insurer members of the Financial Services Council (of which all life insurers were members) imposed a five-year limited self-regulated moratorium on genetic tests in life insurance. This moratorium has now been incorporated into the Council of Australian

⁴ https://laws-lois.justice.gc.ca/eng/annualstatutes/2017_3/page-1.html

⁵ Genetic Non-Discrimination Act, section 3, prohibits any person from requiring an individual to undergo a genetic test as a condition of:

- (a) providing goods or services to that individual;
- (b) entering into or continuing a contract or agreement with that individual; or
- (c) offering or continuing specific terms or conditions in a contract or agreement with that individual.

Section 4 prohibits any person from requiring an individual to disclose the results of a genetic test as a condition of engaging in activities (a) to (c) above, and from refusing to engage in such an activity because an individual has refused to disclose the results of a genetic test.

⁶ Genetic Non-Discrimination Act, section 5.

⁷ Council of Australian Life Insurers, *Life Insurance Code of Practice*, December 2023, Appendix A.

⁸ Private Health Insurance Act 2007 (Cth), s 55-5.

Life Insurers Life Insurance Code of Practice and applies indefinitely until further notice following a review.

27. Among other things, the moratorium prohibits life insurers from asking people to take a genetic test as part of the application process. It maintains a life insurer's ability to ask applicants to disclose any diagnosis of a condition, even if it resulted from a genetic test.

United Kingdom – code on genetic testing⁹

28. In 2018, the United Kingdom Government¹⁰ and the Association of British Insurers developed a voluntary eight-point Code on Genetic Testing and Insurance. Members of the Association of British Insurers have agreed to abide by the Code, and other insurance companies can also sign up to it.
29. The Code prohibits insurers from requiring or pressuring an applicant to take a predictive or diagnostic genetic test to obtain insurance. However, insurers can still ask for genetic test results and the results can be considered by insurers.
30. The Code allows insurers to ask for genetic test results for specific conditions. At present the only condition identified is Huntington's disease.
31. The Code also includes a caveat whereby if a genetic test result is provided by the individual to the insurer accidentally or voluntarily, an insurer may take this into account if it is to the applicant's benefit (i.e. if it rules out a risk that is otherwise suggested by family history). However, if the result is unfavourable then the insurer must ignore the result, unless the Code otherwise allows it to be considered.

Privacy considerations of genetic testing

Genetic testing can reveal a lot about an individual and their whānau

32. Genetic testing and its results can reveal a lot about the individual who is tested. Genetics plays an important role in forming individuals' physical characteristics and personalities. This is why information from genetic testing is highly sensitive personal information.
33. Given the nature of genetic testing, it can also provide a lot of personal information about an individual's whānau, their ancestors and possible future children. This is an important point to highlight from a privacy perspective. Genetic testing undertaken by one person could be used to draw assumptions about their near and extended family members.
34. The privacy concern here as it relates to genetic testing and insurance is that an individual's genetic test could be used by an insurer to infer personal information of the tested individual's whānau, potentially affecting the provision of insurance to whānau members.

⁹ <https://www.gov.uk/government/publications/code-on-genetic-testing-and-insurance>

¹⁰ Department of Health & Social Care.

Te Ao Māori perspectives

35. As mentioned above, genetic information can reveal a lot about an individual's whānau and ancestors. For Māori, this is highly sensitive information from both a personal and a collective perspective.¹¹
36. For Māori connection to their tūpuna is an integral part of who they are and where they come from. Genetic information about individuals can also be information about the connections that Māori have with their tūpuna.
37. Such information, because of its association with the tapu of individuals and whānau that derives from their creation stories, is highly restricted. Any breach of the constraints around collection, use, storage and disclosure of Māori genetic information would require restitution to restore balance.
38. If the Committee does not consider the Bill is the appropriate vehicle for addressing genetic discrimination, I strongly recommend insurers work with Māori to build in protections for their genetic information in insurance industry practices and standards.

How is genetic testing different to disclosing personal and family medical history?

39. Disclosure of personal medical history, including information about family medical history, is a well-known part of the process before an insurer will provide either health or life insurance.
40. In addition to the points made above about the nature of genetic information, the main difference between disclosing personal medical history and requiring genetic testing for insurance purposes, is that a person's medical history documents specific current diagnoses and treatments based on assessments by health professionals.
41. Compare this to genetic testing which can tell an insurer what conditions a person may have, but also what their likelihood of developing a condition in the future may be. Tests vary in their accuracy and predictive value. There is a danger that if insurance companies can require genetic testing to be done before they insure an individual, the results could show a greater risk of a condition developing later in life, but that condition may never develop. As a result, the individual could be refused cover, or could be subject to exclusions or higher premiums.
42. IPP 8 of the Privacy Act requires organisations to take reasonable steps to ensure the accuracy of personal information before they use it or disclose it. The question of whether results of genetic testing will be accurate and relevant is a key issue from a privacy perspective, particularly if individuals are required to provide this information to insurers.

Privacy-adjacent issues associated with the use of genetic testing by insurers

43. As noted by submitters, concerns about genetic discrimination by insurers can have a chilling effect on an individual's willingness to undertake genetic testing - for themselves or as part of clinical trials or medical research. This could in turn have negative flow-on effects for both the well-being of the individual and society at large.

¹¹ See the discussion of tikanga Māori and genetic information in Law Commission, *The Use of DNA in Criminal Investigations | Te Whakamahi i te Ira Tangata in ngā Mātai Taihara*, 2020, pp. 59-66.

44. For example, the developing field of precision medicine (the provision of specific individualistic treatment based on a person's genes, environment and lifestyle)¹² is dependent on people being prepared to undergo clinical genetic testing for medical indications and/or participate in medical research. Likewise, research on the impact of specific genes on diagnosed health impacts is dependent on the willingness of those with and without the condition to undergo testing.

Recommendations

I believe the specific issue of genetic discrimination in insurance can be addressed in the Bill, but that genetic testing and privacy rights needs to be considered more broadly

45. While there is concern about the use of genetic testing results in insurance, there are also broader issues relating to genetic testing and genetic discrimination that need to be addressed beyond the insurance sector. These issues are complex and would benefit from careful policy and legal analysis. These are also issues on which it would be desirable to engage with the public.
46. I believe there is merit in exploring amendments to the Privacy Act or the development of new standalone legislation to better protect people's genetic privacy rights and protect against genetic discrimination. However, in the meantime, this Bill provides an opportunity to address these issues in relation to insurance.

If the Committee considers the Bill is appropriate to address genetic information disclosures

47. If the Committee believes the issue of genetic discrimination is within scope of the Bill, I **recommend** a clause, or clauses, be added to the Bill to prohibit insurance contracts from including terms that could allow an insurance company to require a policyholder (as defined in the Bill) to have a genetic test or to provide the results of a genetic test to the insurer.
48. Such a provision could be drafted to be like sections 3 and 4 of Canada's Genetic Non-Discrimination Act 2017,¹³ although this would need to be tailored to be specific to insurance contracts.
49. Such a provision should not preclude individuals who want to or have had a genetic test from voluntarily disclosing the results to an insurer if the results would be favourable to the individual (for example, if they showed that the individual is not at risk from a condition for which they have a family history). This could mirror the example seen in the United Kingdom Code at paragraph 31 above.

If the Committee does not consider the Bill is appropriate to address genetic information disclosures

50. I am aware that some Members of the Committee have raised questions during oral submissions around whether the Bill is the right place to address genetic testing and genetic discrimination in insurance.

¹² See Ministry of Health Long-term Insights Briefing: <https://www.health.govt.nz/publication/precision-health-exploring-opportunities-and-challenges-predict-prevent-diagnose-and-treat-health>

¹³ See discussion of these clauses above.

51. I am also aware that the Financial Services Council has submitted that the Bill is not the right avenue to address genetic testing and genetic discrimination.¹⁴ The Committee may decide to progress the Bill without recommending amendments be made to address genetic privacy and discrimination in insurance.
52. If this is the case, there are several possibilities that the Committee could recommend in place of addressing genetic discrimination in the Bill. These include:
- **Option 1** – the development by government and industry of a voluntary code to set rules for the use of genetic testing and genetic information in the insurance industry. This would be like the United Kingdom; or
 - **Option 2** – self-regulation like the Australian example, where the insurance industry places a moratorium on genetic testing.

Risks of options 1 and 2

53. The options above may provide the Committee with suitable alternatives so the Bill can progress without addressing genetic testing. However, they are not without their risks.
54. For example, option 1 would require significant time and resource from across Government, and would require industry buy-in. There may not be sufficient resource or industry support to implement a code similar to that in the United Kingdom.
55. Self-regulation in option 2 leaves it up to the industry to manage and requires insurers to sign up to self-regulation. Real risks to individuals could remain under this model. It could also risk disparities in insurance cover if it only covers some insurance providers and not others.
56. These risks should be noted by the Committee in their report back on the Bill if genetic information disclosures are not addressed in the Bill.

Conclusion

57. I trust this submission is of use to the Committee. Genetic testing is important for improving the health outcomes of people in New Zealand, but people should not feel that they may find it more difficult or expensive to obtain insurance if they choose to have a genetic test done. This is a highly personal decision made by an individual who may have very serious concerns about their current health and future health risks.
58. I **strongly support** protections being put in place for people's genetic information, whether through this Bill or in some other way.



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Deputy Privacy Commissioner
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¹⁴ https://www.parliament.nz/en/pb/sc/submissions-and-advice/document/54SCFIN_EVI_019dad64-3f9e-46b8-5cd9-08dc67f794e8_FIN2399/financial-services-council-nz-inc-suppl