Submission by AGenDA to the Finance and Expenditure Select Committee on the Contracts of Insurance Bill.

Preventing genomic discrimination in consumer insurance contracts

Who we are:

Against Genomic Discrimination in Aotearoa (AGenDA), is a group of more than 50 clinicians, researchers, academics, lawyers, and representatives from Māori, Pasific, NGO's and patient groups collaborating with Industry to prevent genomic discrimination whether that relates to insurance or human rights.
(Ref Appendix 2). We wish to speak to our submission.
Professor Andrew Shelling a.shelling@auckland.ac.nz and Fay Sowerby fay.sowerby@xtra.co.nz

AGenDA

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AGenDA welcomes the opportunity to make a submission on the Contracts of Insurance Bill (CIB). We also wish to appear before the Finance and Expenditure Committee to speak to our submission.

1. Executive Summary

New Zealand's Insurance Law framework lacks protection against genomic discrimination, making it the only OECD country without such protection (1) (Appendix 3). The Contracts of Insurance Bill presents a unique opportunity to address this critical issue. This submission seeks to include four clauses in section 65 of the Contracts of Insurance Bill (CIB) to prevent insurers or associated entities from using genomic test results to refuse access to services or charge more for them (2).

This practice is legally acceptable in New Zealand across multiple types of insurance, including health, life (disability, income protection, trauma, and death cover), and travel insurance. Fear of discrimination deters New Zealanders from undergoing potentially life-saving genomic testing. Our submission aims to enable New Zealanders to access modern medical treatment free from the fear of genomic discrimination, aligning this protection with other safeguarded human rights (3).

Genomic testing is an essential diagnostic tool with the potential to optimise treatment pathways and improve health outcomes. It guides screening, prevention strategies, precision medicine treatment selection, and access to clinical trials, ultimately reducing the burden on our healthcare system and benefiting the insurance industry (4).

The Ministry of Health's Long-term Insight Briefing (August 2023) highlights the need for necessary systems, investments, workforce, and regulation to realise the opportunities that precision health offers (5). Canada legislated protection against genomic discrimination in 2017 (6). Australia is moving away from an unsuccessful moratorium towards legislative protection imminently (7) and the UK has had an almost complete ban in place since 2001. Implementing similar protections in New Zealand is crucial for advancing genomic medicine and protecting access to genomic information without fear of discrimination.

Concerns about anti-selection, where individuals at higher genetic risk might seek greater coverage, are often cited against these protections. However, studies and models show that the impact on the insurance industry is minimal compared to the public health benefits of genomic testing. Findings from Canada and Australia indicate that banning the use of genomic information in underwriting has a negligible impact on insurance businesses (1,7,8).

Legal experts Michael Heron KC and Paul Rishworth KC support our submission (2) (Appendix 1), confirming that these protections complement the Bill's goals of modernising and simplifying insurance contracts. They also advise that an amendment to the Human Rights Act 1993 (s48) is not necessary to achieve this protection; a simple insertion into section 65 of the CIB of a prohibition without limits, caps, or exclusions on the use of

genomic testing results, will suffice. We recommend prohibiting insurers from using genomic test results to discriminate, by incorporating Clauses (4) to (7) into section 65 of the CIB.

Furthermore, we support the need for an external monitoring organisation with the power to instruct, govern, educate, promote and enforce these proposed changes. The Financial Markets Authority (FMA) is well-suited for this role.

2. Recommendations

We recommend the inclusion of the following provisions in Section 65 *Certain Provisions of no effect* (additional subsections) of the CIB:

Definition: Genomic testing definition: to be defined as: “a test that analyses or provides interpretation of information about a person’s DNA, RNA or chromosomes” with the addition of other types of molecular testing.

Clause (4): Any requirement to obtain or disclose a genomic test before a consumer insurance contract is entered into or varied, and any refusal to enter into a consumer insurance contract because a policyholder has not obtained or disclosed a genomic test, is prohibited and is of no effect.

Clause (5): Offering of different terms and conditions in a consumer insurance contract by reason of a refusal to take or disclose a genomic test, or by reason of any genomic test that has been disclosed or collected, is prohibited and is of no effect.

Clause (6): The prohibitions in subsections (4) and (5) apply to everyone except health care practitioners, with respect to individuals to whom they are providing health services, and except for persons conducting medical, pharmaceutical, or scientific research, with respect to participants in the research. (Appendix 1 - note1 ref)

Clause (7): For the avoidance of doubt, subsections (4), (5), and (6) are not affected by and do not affect the core prohibitions in section 48 of the Human Rights Act 1993.

Monitoring and Enforcement: Compliance should be monitored, and penalties for noncompliance should be enforced as per the provisions of the Financial Markets (Conduct of Institutions) Amendment Act 2022, effective from 31 March 2025.

The Financial Markets Authority (FMA) is well-suited for this role, given its existing powers under the Financial Markets Conduct Act 2013 to monitor compliance, investigate, and take enforcement action. The introduction of the Financial Markets (Conduct of Institutions) Amendment Act 2022 (CoFI Act), effective from 31 March 2025, further expands the FMA's mandate to ensure financial institutions treat consumers fairly, provide oversight, monitoring, promotion and education in relation to the Contracts of Insurance Act.

This regulatory regimen aligns with the consumer-centric approach of the Contracts of Insurance Bill and the recommendations from the A-GLIMMER report, which criticised the

lack of independent monitoring, education, promotion and enforcement in the Australian Moratorium (7).

3. Our Submission

In this submission, we seek the inclusion of a prohibition similar to the Canadian Genetic Non-Discrimination Act 2017 (4) to prevent insurers, insurance brokers, and other insurance intermediaries from asking for and using genomic test results to refuse access to services and/or charge more for them. This removes impediments to using genomics and/or molecular testing to access modern medical treatments, screening, and prevention programmes, and removes the deterrent from industry for investment (1).

This will align New Zealand with international best practices and the Universal Declaration on the Human Genome and Human Rights. Article 6 of the Declaration states: "No one shall be subjected to discrimination based on genetic characteristics that is intended to infringe or has the effect of infringing human rights, fundamental freedoms, and human dignity" (1). Prohibiting the use of genomic test results in insurance decisions would also align with New Zealand's international human rights obligations. These obligations include the right to health, as stated in the International Covenant on Economic, Social and Cultural Rights (Article 12), the principle of non-discrimination in the Convention on the Rights of Persons with Disabilities, and the protections against discrimination in the Human Rights Act 1993 and the NZ Bill of Rights Act 1990 (1).

Existing legislation through Te Tiriti o Waitangi also requires rights, interests and taonga. Health information is taonga (treasure) that must be cared for, used and treated with respect. Protection through legislation will be well placed to incorporate this aspect (1).

4. Value and Benefits of Genomic Testing

Genomic testing is a transformative tool in modern healthcare, offering significant benefits for individuals, families and the healthcare system as a whole. It enables early detection of illnesses, facilitating preventative interventions and tailored treatment strategies that improve health outcomes and save lives.

Early Detection and Prevention: Genomic testing can identify genetic predispositions to various diseases, allowing for early monitoring and preventative measures. This proactive approach can prevent the onset of diseases or catch them at an early, more treatable stage, significantly improving patient outcomes. For example, identifying BRCA1 and BRCA2 mutations can guide early interventions for breast and ovarian cancer, potentially saving lives through timely preventative measures.

Optimised Treatment Pathways: Genomic information is critical for precision medicine, where treatments are tailored to the genetic makeup of the individual. This approach increases the efficacy of treatments and reduces the risk of adverse effects. For instance, genomic profiling of tumours can identify specific mutations that can be targeted with precision therapies, leading to better outcomes and fewer side effects.

Reduction in Healthcare Costs: By enabling early detection and targeted treatments, genomic testing can reduce the long-term costs associated with chronic and severe illnesses. Early interventions can prevent costly late-stage treatments and hospitalisations. The New Zealand Medical Journal article "Genomic discrimination in New Zealand Health and life insurance" (March 2022) by Shelling *et al.* (4) highlights how genomic testing can lead to cost-effective healthcare by preventing disease progression and optimising treatment. There is a body of evidence demonstrating the clinical and economic benefits of Genomics. The report on success of the 100k Genomes project in the UK reported savings of **87M GBP** in hospital care alone.

Guidance for Screening and Prevention Strategies: Genomic testing can inform screening programmes and prevention strategies for at-risk populations. For example, individuals with a family history of cardiovascular diseases can undergo genomic testing to assess their risk and take preventive measures accordingly. This targeted approach ensures that resources are allocated efficiently, focusing on those who would benefit the most.

Facilitating Access to Clinical Trials: Genomic testing is crucial for enrolling patients in clinical trials, especially for emerging therapies targeting specific genetic mutations. By identifying suitable candidates based on their genomic profiles, researchers can accelerate the development of new treatments and bring them to market faster. This not only benefits current patients but also advances medical knowledge and innovation (9).

Supporting Family Health: Genomic information can provide valuable insights into the health risks for family members. Understanding genetic predispositions allows family members to take proactive steps in managing their health. This is particularly important for hereditary conditions, where early interventions can significantly improve outcomes for future generations.

Enhancing Overall Population Health: The widespread adoption of genomic testing can lead to better health outcomes at the population level. By integrating genomic information into public health strategies, New Zealand can improve its overall health metrics, reduce the incidence of preventable diseases, and enhance the quality of life for its citizens. Genomic testing is now allowing for more informed outcomes for reproduction in families with genetic disease.

Aligning with Global Health Advancements: As genomic testing becomes a standard of care globally; New Zealand must keep pace to ensure its healthcare system remains competitive and capable of offering the best possible care. Many OECD countries have already implemented protections against genetic discrimination, recognising the critical role of genomics in modern healthcare. By adopting similar protections, New Zealand can ensure its citizens are not disadvantaged in accessing cutting-edge medical care.

Impact on Insurance Industry: The benefits of genomic testing extend to the insurance industry. Healthier populations with better-managed diseases lead to fewer and lower-cost claims, improving the overall sustainability of the insurance market. Insurers can also use aggregated genomic data (with appropriate privacy protections) to develop more accurate risk models and product offerings, ultimately benefiting both insurers and policyholders.

In conclusion, the value and benefits of genomic testing are broad and multifaceted. Implementing protections against genomic discrimination will ensure that all New Zealanders can access these benefits without fear, leading to a healthier, more equitable, and economically sustainable healthcare system when complemented by required system, investment and resource changes to ensure improved health outcomes for all.

5. Consequences of Current Absence of Legal Protection

Patient and Consumer Reluctance: Health care and medical research are significantly impacted by participant reluctance to take genomic tests due to a fear of insurance discrimination. This fear is well-founded, as discrimination is legally permissible in New Zealand. A 2023 survey published in the European Journal of Human Genetics by Tiller *et al*. found that a third of consumers who had taken or been offered clinical genetic testing reported difficulties in accessing life insurance (10). These included insurers rejecting applications, financial advisers warning of rejections, and insurers imposing conditions or higher premiums based on disclosed genetic information.

These concerns were amplified in a survey of New Zealand health professionals published in 2023 by Fraser *et al.*, (3) and reported patients declining or delaying genetic testing due to insurance discrimination fears. Clinicians overwhelmingly believe legislation to regulate insurer use of genetic results is necessary.

Impact on Health System and Professionals: Significant pressure is placed on healthcare professionals who handle patients' pre-test consents for genomic testing and must counsel them on financial implications, which falls outside their clinical training and scope. Genomics teams, including genetic counsellors and rare disorder specialists and clinical geneticists, are burdened with advising at-risk patients on the complex financial implications

of testing decisions. This is an unfair burden on genomics teams, risking operating outside their scope of practice and consuming valuable clinical time that should be devoted to medical care. Fraser *et al*.'s research (3) highlighted these concerns – clinicians are very concerned about the impact on their patients and overwhelmingly believe legislation to regulate insurer use of genetic results is necessary.

Although underwriters suggest that the problem lies in the system itself, it is the absence of protection against genomic discrimination that creates disclosure issues, reluctance, uncertainty and an additional burden on the health system.

Deterrence from Medical / Clinical Research: The lack of protection also deters recruitment into genomic research studies, which are critical to understanding disease and developing therapies. New Zealand's ethics 'informed consent process' requires participants to acknowledge that their participation in genomic testing studies may impact their insurance. This often consumes participants' thinking more than the potential opportunities of the research, leading to declined participation.

For people at risk of genetic conditions, choosing not to be tested due to fear of genomic discrimination may have serious health impacts. Evidence of this was found in an Australian survey, with the proportion of participants who declined genetic testing among those informed of insurance implications double the proportion among those without this knowledge, while a New Zealand study revealed a up to a 30% decline (4). Identification of people with specific mutations may be life threatening (11).

Enacting legislation can create an environment where people are encouraged to seek genomic testing, supporting their health, advancing disease understanding, and reducing the overall public health burden.

6. International Comparisons

Canada: A total ban on genetic discrimination in insurance was passed in 2017. This legislation prohibits insurers from requiring or using genetic test results to refuse or vary coverage (5).

Australia: The government has conducted a full community consultation into legislative options to protect consumers against genetic discrimination and is poised to legislate. It has identified that the current moratorium has ultimately failed consumers. The findings of the A-GLIMMER report quantify the adverse effects of genomic discrimination and support the need for comprehensive legislation, including a full ban on non-discrimination to safeguard genetic information (7).

United Kingdom: Genomic testing results are protected, and insurers are prohibited from asking for or using such information in health or life insurance underwriting (with the exception of Huntington's disease results, which also do not have to be disclosed for policies under £500,000 [~1,040,000NZD]) (12).

United States: The Genetic Information Non-discrimination Act (GINA) prohibits discrimination in health insurance and employment based on genetic information and family history. GINA serves as a robust model for legislative protection against genetic discrimination and family history (13).

7. Legal and Ethical Considerations

Legal experts Michael Heron KC and Paul Rishworth KC support the proposed changes to the Contracts of Insurance Bill, asserting that they complement the Bill's goals of modernising and simplifying insurance contracts. The ethical basis for preventing discrimination based on immutable genetic traits is strong, paralleling existing protections against discrimination based on race, gender, and other inherent characteristics (2).

Their legal opinion confirms that the suggested provisions align with and enhance the Bill's intention to modernise, simplify, and make insurance contracts fairer and more easily understood by consumers, and also moving disclosure requirements from consumers to insurers. Additionally, the Human Rights Act 1993 and the New Zealand Bill of Rights Act 1990 enshrine the principles of non-discrimination and the right to health. However, the current legal framework, particularly section 48 of the Human Rights Act, allows for exceptions in insurance based on actuarial data, creating a loophole that permits genomic discrimination. Addressing this gap through explicit legislation is essential to ensuring that genomic information is treated with the same level of protection as other personal characteristics (1).

Furthermore, the Universal Declaration on the Human Genome and Human Rights, adopted unanimously in 1997, explicitly prohibits discrimination based on genetic characteristics. Article 6 of the Declaration states: "No one shall be subjected to discrimination based on genetic characteristics that is intended to infringe or has the effect of infringing human rights, fundamental freedoms, and human dignity."

Prohibiting the use of genomic test results in insurance decisions would also align with New Zealand's international human rights obligations. These obligations include the right to health as stated in the International Covenant on Economic, Social and Cultural Rights (Article 12), the principle of non-discrimination in the Convention on the Rights of Persons

with Disabilities, and the protections against discrimination in the Human Rights Act 1993 and the NZ Bill of Rights Act 1990 (1,2).

The findings of the A-GLIMMER report in Australia and the protections provided by GINA in the United States further underscore the importance of safeguarding individuals from genetic discrimination and family history (7,13). The A-GLIMMER report strongly recommended that a total ban was required, and that introducing exceptions, limits or financial caps would create uncertainty for consumers and fail to address the significant public concerns and deterrence to participating in genetic testing and research. Implementing similar protections in New Zealand will ensure that our legislation is aligned with global standards and provides comprehensive protection against genetic discrimination.

By legislating against genomic discrimination, New Zealand would also foster greater public trust in genomic testing and research. This trust is crucial for the advancement of precision medicine and the broader healthcare system, as it encourages individuals to participate in genomic testing and research without fear of adverse consequences.

In summary, the proposed legal protections are not only aligned with national and international human rights principles but are also crucial for advancing medical research and ensuring equitable access to healthcare. The legal and ethical imperatives for these protections are clear and compelling.

8. Financial and Industry Arguments

Concerns about anti-selection by the insurance industry, where individuals at higher genetic risk might seek greater coverage without insurers being able to assess this risk, are often cited against implementing genomic discrimination protections. However, comprehensive studies and actuarial models indicate that the impact of anti-selection on the insurance industry is negligible compared to the significant public health benefits derived from widespread genomic testing (1,7).

Actuarial and economic models commissioned by the Canadian Privacy Commissioner during the legislative process for their genetic non-discrimination law demonstrated that a total ban on the use of genetic information in insurance underwriting would have a minimal impact on the insurance business. These findings were corroborated by similar studies in other jurisdictions, including submissions to the Australian Treasury, which found no substantial evidence of anti-selection effects in countries with existing genetic discrimination bans (14).

The primary argument from insurers revolves around the fear of financial instability due to inability to price policies accurately without access to genetic information. However, the real-world data from countries like Canada, which has had a total ban since 2017, shows that insurers have continued to operate successfully and profitably. The Australian life insurance industry, during recent consultations, also failed to present concrete evidence of significant anti-selection impacts in markets with similar bans.

Furthermore, the potential health cost savings from early detection and personalised treatment facilitated by genomic testing far outweigh any marginal increase in insurance claims. Early interventions and targeted therapies can prevent more severe health issues, reducing overall healthcare expenditure and leading to healthier, more productive populations. These savings extend to insurers as well, who benefit from reduced claims over time due to better health outcomes in the insured population.

Additionally, the insurance industry's concerns about financial risk are mitigated by the broader societal benefits of genomic testing. By removing barriers to genomic testing, more individuals will undergo testing, leading to earlier and more effective treatments. This, in turn, lowers the long-term costs associated with untreated or late-diagnosed conditions. The insurance industry stands to benefit from a healthier insured population, with fewer large claims and better overall risk management.

Insurers and other key stakeholders will gain benefit from, better understanding the long-term benefits available to all New Zealanders. Risk assessment needs to better account for advancements in genomics and precision medicine and the opportunity it presents New Zealand and the insurance industry.

In summary, the financial arguments against prohibiting genomic discrimination do not hold up under scrutiny. The evidence from other jurisdictions demonstrates that the impact on the insurance industry is minimal, while the public health benefits are substantial. Overtime implementing these protections will lead to better health outcomes, lower healthcare costs, and a more robust and equitable insurance market. It will also lead to increased trust between consumers and the insurance industry.

9. The Future is Now

Healthcare is rapidly transforming, with technological advances enabling the personalisation of medicines and care resulting in significant health system cost savings. Genomic testing allows for a more targeted approach to clinical decision making by providing insights into the molecular basis of a patient’s disease. The importance of this shift cannot be overstated, as it represents a fundamental change in how medical treatments are developed and administered.

A recent study released by Genomics England analysed 13,880 solid tumours from 33 cancer types, integrating genomic data with real-world treatment and outcome data. It found that more than 50 percent of tumours harboured one or more gene mutations indicated for testing in various cancers. This highlights the critical role that genomic information plays in identifying effective treatments and improving patient outcomes (15) and makes clear we are entering a period where the immediacy and importance of genomic technology, and that it should be routine practice, are upon us. Without protection from genomic discrimination, this opportunity will be lost for some. To reinforce this point on 27 May 2024, the European Society of Medical Oncology (ESMO), an important regulatory group in Europe, updated its recommendations for the use of tumour Next Generation Sequencing (NGS) in patients with advanced cancers in routine practice. Cancers such as non-small cell lung cancer, cholangiocarcinoma, prostate and ovarian cancers were expanded to include breast cancer, gastrointestinal stromal tumour,, sarcoma, thyroid cancer, and cancers of unknown primary origin for detecting tumour-agnostic alterations where matched therapies are accessible. More limited testing in well- and moderately differentiated neuroendocrine tumours, cervical, salivary, thyroid and vulvar cancers will also be available (16).

At this crucial juncture, ensuring comprehensive genomic testing results for patients will lead to more accurate and precise diagnoses, providing a pathway to better health outcomes. To achieve this, New Zealand needs to remove the existing barrier of genomic discrimination. Without legal protections, individuals may be deterred from participating in genomic testing due to fears of discrimination, hindering the potential benefits of personalised healthcare.

We acknowledge that New Zealand currently lacks the infrastructure to support these advancements. However, there is significant momentum among key stakeholders, including Health NZ, the Ministry of Health, Pharmac, the Cancer Control Agency, academic institutions, and philanthropists, to address these shortcomings and accelerate the implementation of genomics, paving the way for Precision Health, subject to non-discrimination being resolved.

Additionally, there are substantial opportunities for industry investment and partnership through public-private partnerships. Notably, Australia's Omico founder David Thomas and strategic partners such as Illumina and Roche have highlighted the potential for comprehensive genomic profiling to drive better treatments. Precision oncology trials are needed to achieve these outcomes, and New Zealand has been offered the opportunity to partner with both Illumina and Omico. Focusing on these private partnerships will be faster, more cost-effective and provide better outcomes than attempting to develop these capabilities independently (17).

This collaboration will foster more equitable care and bring economic benefits to New Zealand's health outcomes. Establishing effective mechanisms to prevent genomic

discrimination is essential to fully capitalising on these advancements. By implementing legal protections, New Zealand can ensure that all individuals can participate in genomic testing and benefit from precision medicine without fear of discrimination.

New Zealand cannot afford to miss out on these transformative opportunities due to a lack of necessary protections. The introduction of genomic discrimination protection into the Bill is vital to harnessing the full potential of genomic medicine and ensuring that healthcare advancements benefit all New Zealanders equitably.

10. Conclusion

AGenDA outlines the opportunity the Bill presents to address the lack of protection against genomic discrimination in New Zealand's insurance law framework. We have detailed:

- The unique value of genomic testing for New Zealanders and the healthcare system.
- The importance of genomic research addressing significant health needs for New Zealanders
- The negative consequences of not having protective legislation.
- The moral imperative to prevent discrimination based on genetic traits.
- The inadequacies of the current legal framework and the need for specific legislative protection.
- The alignment with international best practices and human rights declarations.
- The critical importance of legislative change over continued self-regulation, given the lessons from Australia.
- The need for comprehensive protection without exclusions or financial limits.

We recommend prohibiting insurers from using genomic test results to discriminate and incorporating Clauses (4) to (7) into Section 65 of the Contracts of Insurance Bill. Legislative change should include enforceable penalties and appropriate consumer redress through the FMA and CoFI.

For these reasons, we recommend the Finance and Expenditure Committee accept our submission and its recommendation, which is supported by Heron KC and Rishworth KC, that proposed subclauses (4) to (7) be incorporated into Section 65 the Contracts of Insurance Bill tabled by Honourable Andrew Bayly on 3 May 2024.

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Appendix 1 Legal Opinion in Support

MHKC

Michael Heron KC Barrister

To the members of the Finance and Expenditure Select Committee

Paul Rishworth KC and I have reviewed the AGenDA submission and the materials referred to. In our view it merits this Committee's serious consideration for all the reasons outlined.

This Bill is not designed to be the vehicle for a comprehensive solution to the issue but it represents a unique and timely opportunity to deal with one of the more pressing aspects, upon which New Zealand regrettably lags the world.

The core prohibitions in the Canadian legislation relating to genetic tests cover (a) requirements to undergo testing; (b) requirements to disclose the results; and (c) refusal to contract or deal with the person if they refuse.

A possible method of achieving the Canadian result in respect to consumer insurance contracts, would be to add subsections to section 65 of the Act.

> **Section 65 Certain provisions of no effect (additional subsections)**
>
> (4) Any requirement to obtain or disclose a genomic test before a consumer insurance contract is entered into or varied, and any refusal to enter into a consumer insurance contract because a policyholder has not obtained or disclosed a genomic test, is prohibited and is of no effect.
>
> (5) Offering of different terms and conditions in a consumer insurance contract by reason of a refusal to take or disclose a genomic test, or by reason of any genomic test that has been disclosed or collected, is prohibited and is of no effect.
>
> (6) The prohibitions in subsections (4) and (5) apply to everyone except health care practitioners, with respect to individuals to whom they are providing health services, and except for persons conducting medical, pharmaceutical, or scientific research, with respect to participants in the research.[1]
>
> (7) For the avoidance of doubt, subsections (4), (5) and (6) are not affected by and do not affect, section 48 of the Human Rights Act 1993.

[1] Note the question discussed below as to the necessity for this.

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Genomic testing could be defined similarly to the Canadian legislation or simply: "*a test that analyses a person's DNA, RNA or chromosomes*" with the addition of other types of molecular testing (similar to the Australian definition).

The suggested prohibitions meet the recommendations of Laura O'Gorman KC (now Justice O'Gorman) at paragraph 56 (in respect to consumer insurance contracts).

Arguably there is no need to "carve out" research and medical purposes (as these are not captured by this Bill) but if that is required, subsection (6) is directed to that.

The addition regarding section 48 of the Human Rights Act 1993 is out of an abundance of caution.

Laura O'Gorman notes in paragraph 8(d) the interaction between sections 44 and 48 of the HRA. The problem may be more fundamental than is identified. A genetic disorder or predisposition may not be caught by the definition of disability (in s 21(1)(h)) at all, in which case section 44 is not implicated by genomic discrimination and s 48 is not reached. The suggested addition is intended to make it clear that requiring disclosure of genetic information and requiring genomic testing (or refusing insurance on a failure to disclose or undergo testing) is prohibited and of no effect (whether or not it falls within the HRA).

This Committee and Parliamentary Counsel will of course be able to adjust the drafting as they see fit, to accommodate the provisions of the Bill and any other submissions.

In our view, this is a critical step to deal with the issue identified in the AGenDA submission. For reasons set out in the submission and accompanying materials, this is the most effective and simple approach.

Yours sincerely,

Michael Heron KC/Paul Rishworth KC

BRITOMART CHAMBERS

michael@mhkc.co.nz | +64 27 436 7517

Level 15, 152 Quay Street, Auckland 1010

AGenDA Members (Appendix 2)

Andrew N. Shelling, Department of Obstetrics and Gynaecology, Director of Centre for Cancer Research/Te Aka Matauranga Matepukupuku, Faculty of Medical and Health Sciences, University of Auckland, Auckland (AGenDA Leader)

Louise S. Bicknell, Department of Biochemistry, University of Otago, Dunedin

Stefan S. Bohlander, Department of Molecular Medicine and Pathology, University of Auckland, Auckland

Peter J. Browett, Department of Haematology, Auckland City Hospital, Auckland; Department of Molecular Medicine and Pathology, School of Medical Sciences, University of Auckland, Auckland

Libby Burgess, Chair Breast Cancer Aotearoa Coalition

Vicky A. Cameron, Christchurch Heart Institute, University of Otago, Christchurch

Jon Cornwall, Centre for Early Learning in Medicine, University of Otago, Dunedin

Murray P. Cox, School of Natural Sciences, Massey University, Palmerston North

Rob Doughty, Heart Foundation Chair of Heart Health, University of Auckland

Bridget Douglas, Family history

David Downs, Patient advocate, Cancer Survivor and GMO

Emma Felix, Specialist Genetic Counsellor FHGSA, Genetic Health Service NA – Central Hub, Wellington Hospital.

Sara K. Filoche, Department of Obstetrics, Gynaecology and Women's Health, University of Otago Wellington, Wellington

Lisa Foster, Chief Executive, CEO for Home and Community Health Association HCHA.

Harry G. Fraser, Genetic Counsellor, Auckland

Kimberley Gamet, Genetic Counsellor, Auckland

Adele Gautier, Research & Strategic Programmes Manager, Breast Cancer Foundation NZ

Patrick A. Gladding, Department of Cardiology, Waitemata District Health Board, Auckland

Parry J. Guilford, Cancer Genetics Laboratory, Department of Biochemistry, University of Otago, Dunedin

Rachael Hart, Chief Executive, Cancer Society of New Zealand

Mark Henaghan, Faculty of Law, University of Auckland, Auckland

Kimiora Henare, Auckland Cancer Society Research Centre, University of Auckland, Auckland

Chris Higgins, Chief Executive, Rare Disorders New Zealand.

Jessie C. Jacobson, School of Biological Sciences, University of Auckland, Auckland

Rebekah Johnstone, Breast Cancer patient, New Zealand

Sarah Kember, Interested patient skember@xtra.co.nz

Martin A. Kennedy, Department of Pathology and Biomedical Science, University of Otago, Christchurch

Jaime King, Faculty of Law, University of Auckland, Auckland

Paul Lacaze, Department of Epidemiology and Preventive Medicine, School of Public Health and Preventive Medicine, Monash University, Melbourne, Australia

Edward Lee, Patient Advocate, New Zealand

Klaus Lehnert, Centre for Brain Research and School of Biological Sciences, University of Auckland, Auckland

Donia Macartney-Coxson, Human Genomics, Institute of Environmental Science and Research (ESR), Wellington

Kerri Manson, BRCA2 patient.

Jo Martindale, Wellington Regional Genetics Laboratory & Genetic Health, Wellington Jo Martindale [CCDHB]

Lisa Matisoo-Smith, Department of Anatomy, University of Otago, Dunedin

Alison McEwen, President, Human Genetics Society of Australasia (HGSA), Graduate School of Health, University of Technology, Sydney, Australasia

Rinki Murphy, Department of Medicine, School of Medicine, University of Auckland, Auckland

Katherine Neas, Genetic Health Service New Zealand, Wellington

Cristin G. Print, Department of Molecular Medicine and Pathology, School of Medical Sciences, University of Auckland, Auckland

Rachel V. Purcell, Department of Surgery, University of Otago, Christchurch.

Stephen P. Robertson, Department of Women's and Children's Health, University of Otago, Dunedin

Bridget A. Robinson, Mackenzie Cancer Research Group, Department of Pathology and Biomedical Science, University of Otago, Christchurch Bridget Robinson

Irene Kereama-Royal, Senior Research Fellow, University of Waikato.

Andrew N. Shelling, Department of Obstetrics and Gynaecology, Faculty of Medical and Health Sciences, University of Auckland, Auckland

Russell G. Snell, Centre for Brain Research and School of Biological Sciences, University of Auckland, Auckland

Jeanne Snelling, Faculty of Law and Bioethics Centre, University of Otago, Dunedin

Fay Sowerby, Breast Cancer Cure, Breast Cancer Aotearoa Coalition, Auckland.

Andrew Sporle, Department of Statistics, University of Auckland, Auckland

Ben Te Aika, Genomics Aotearoa, University of Otago, Dunedin

Jane M. Tiller, School of Public Health and Preventive Medicine, Monash University, Faculty of Medicine, Nursing and Health Sciences, Melbourne, Australia

Chris Tse, Lynch syndrome NZ group, New Zealand

Logan C. Walker, Department of Pathology and Biomedical Science, University of Otago, Christchurch

Phillip L. Wilcox, Department of Mathematics and Statistics, University of Otago, Dunedin

Michelle Wilson, Medical Oncology, Auckland District Health Board, Auckland

Letters of Support

Cancer Society
Te Kāhui Matepukupuku o Aotearoa

29 May 2024

To whom it may concern

Submission on the Contracts of Insurance Bill by AGenDA

This letter is in support of the recommendations made by AGenDA on the Contracts of Insurance Bill currently before the Finance and Expenditure Committee.

Genetic testing helps identify faulty genes that increase the risk of cancer. Lives can be saved by developing early preventative measures or improved targeted medicines in response. For diseases like inherited breast and ovarian cancer, genomic testing can dramatically reduce cancer risk as people with the faulty gene can opt for early screening and/or prophylactic surgery.

Unfortunately, New Zealand insurance companies can legally ask for a person's genetic test results, which can be used to increase premiums or deny cover.

A recent study has noted this stopped some people from undergoing genomic testing. As one of the Cancer Society's Medical Directors and alongside other staff supporting whanau with cancer, I have observed this in my practice.

Yet, genomic discrimination was identified as a concern by the United Nations in 1999, they declared that: 'No one shall be subjected to discrimination based on genetic characteristics.' While Aotearoa New Zealand is lagging behind Australia, United Kingdom, USA and Canada, this draft Bill offers an opportunity to mitigate this.

Please consider the recommendations made by AGenDA regarding genomic discrimination and its unintended consequences for whanau with cancer.

Nga mihi nui,

Dr Kate Gregory
Medical Director
Cancer Society New Zealand

The Cancer Society of New Zealand
Level 13, Ranchod Tower, 39 The Terrace, Wellington 6011 | PO Box 651, Wellington 6140
04 494 7270 | Cancer Information Helpline 0800 CANCER (226 237)
Major Sponsor ANZ
cancer.org.nz admin@cancer.org.nz

Aotearoa Genomic
Healthcare Alliance

27 May 2024

Professor Andrew Shelling
Spokesman,
Against Genomic Discrimination in Aotearoa

(AGenDA) Dear Andrew

Support for Submission by “Against Genomic Discrimination in Aotearoa” (AGenDA) to the Finance and Expenditure Committee on the Contracts of Insurance Bill.

As you will be aware, over the last four years individuals with expertise in the medical genomics space have formed a group termed the Aotearoa Genomic Healthcare Alliance (AGTA). Its purpose is to prime, inform and advance discussions, policy and decision making to enable the implementation of genomic medicine into mainstream healthcare across New Zealand. Currently AGTA is Chaired by me and Huti Watson (Tainui, Ngāti Porou) and our membership includes individuals from industry, consultancy organisations, clinicians, scientists, and community representatives.

We have watched the activity of AGenDA in promoting a future that features a lack of discrimination for those with genetic conditions with admiration. Recently you have sent us a copy of your submission to the Finance and Expenditure Committee on the Contracts of Insurance Bill that includes recommendations from Michael Heron KC and Paul Rishworth KC, Britomart Chambers. The membership of AGTA has reviewed this submission and we resolved to write to you, making clear our unequivocal support for the recommendations contained within your document.

It is our firm and unstinting viewpoint that New Zealand’s standing as the only OECD country not to have legislation against genomic discrimination in the Insurance arena needs addressing urgently. Your submission offers a simple and readily applicable remedy to this legislative gap and we wish to extend our unequivocal support to your initiative.

Ngā mihi nui

Professor Stephen Robertson FRACP FRSNZ
Curekids Professor of Paediatric Genetics,
Otago University
Alliance Co-Chair Aotearoa Genomic Health Alliance

Huti Watson
Director of Research, Ngāti Porou Organa
Co-Chair Aotearoa Genomic Health

Department of Women’s & Children’s Health, The Laboratory for Genomic Medicine, Dunedin School of Medicine, University of Otago,
PO Box 56, Dunedin 9054, New Zealand

NZFBOC
New Zealand Familial Breast & Ovarian Cancer Trust
Te Pou Manaaki Whānau Mate ā-ira pukupuku o Aotearoa

Dunedin, 21.5.24

The New Zealand Familial Breast and Ovarian Cancer Trust supports the submission by "Against Genomic Discrimination in Aotearoa" (AGenDA) to the Finance and Expenditure Committee on the Contracts of Insurance Bill.

The New Zealand Familial Breast and Ovarian Cancer Trust was established as a charitable trust in July 2021 to encourage and support research for familial breast and ovarian cancers, provide expertise and information in relation to prevention and treatment of familial breast and ovarian cancers, facilitate networks for those working in the field of familial breast and ovarian cancer, seek to reduce the rate of preventable familial breast and ovarian cancers by improving information, care, equity and collaboration.

Dr. Simone Petrich
Chair NZFBOC Trust
waea pūkoro: +64 275698690 | īmēra: simone.petrich@southerndhb.govt.nz

Dr Kate Gregory
Medical Director
Cancer Society New Zealand

Cancer Society
Te Kāhui Matepukupuku o Aotearoa

24 May 2024

Subject: Endorsement and support for the "Against Genomic Discrimination in Aotearoa" (AGenDA) submission to the Finance and Expenditure Committee on the Contracts of Insurance Bill.

One behalf of the following organisations I confirm support of the above mentioned submission:

- Cancer Society Canterbury West-Coast Division
- Cancer Society Otago-Southland Division
- Southern Cancer Research & Innovation Trust
- Canterbury West Coast Cancer Trust

Combined these organisations' make up the Southern Cancer Society and support over 8,500 families who are impacted by cancer and reside in the South Island. The Cancer Society provides support to families impacted by cancer and funds cancer research and innovation to reduce the incidence of cancer.

We support this submission as we believe New Zealanders should be able to access genomic testing without fear of insurance implications.

Yours sincerely,

Nicola Coom Chief Executive

25 May 20204

Re: Submission Against Genomic Discrimination in Aotearoa (AGenDA)

The Gift of Knowledge is a consumer group that exists to provide information and peer support to New Zealanders impacted by familial breast and ovarian cancer. Our goal is that every New Zealander impacted by familial cancer will have access to relevant information and support to aid their decision making and manage or reduce their risk.

The Gift of Knowledge has been established since 2010 and is a registered charity #CC50534.

On behalf of the 2,500 families across New Zealand who we support, we fully support the submission by "Against Genomic Discrimination in Aotearoa" (AGenDA) to the Finance and Expenditure Committee on the Contracts of Insurance Bill.

Yours sincerely

Nicola Coom Trustee

heiahurumowai.org.nz

28 May 2024

Hei Āhuru Mōwai
Māori Cancer Leadership Aotearoa

Tēnā koe

Letter of Support Against Genomic Discrimination in Aotearoa

I am writing to confirm support for the AGenDA submission on the Contracts of Insurance Bill.

Hei Āhuru Mōwai Māori Cancer Leadership Aotearoa is a national network of Māori cancer professionals, clinicians, researchers and whānau who are committed to embedding rangatiratanga into cancer control, eliminating cancer inequities between Māori and non- Māori and accelerating hauora gains for whānau Māori.

We understand the value of genomic testing for whānau to enable early detection of cancer, facilitate preventative interventions and tailored treatment strategies to improve haoura outcomes which can ultimately save lives.

We wholeheartedly support the recommendations to prohibit insurers from using genomic test results to discriminate, by incorporating Clauses (4) to (7) into section 65 of the CIB. In addition, we agree with the need for an external monitoring organisation with the power to instruct, govern, educate, promote and enforce these proposed changes.

Legislating against genomic discrimination in Aotearoa will promote greater trust in genomic testing and research ensuring whānau get the support they need to access timely healthcare.

Ko te matepukupuku ki te pō, ko te whānau Māori ki te whei ao, ki te ao mārama

Cindy Dargaville Tumuaki | CEO

Monday, May 27, 2024

illumina

Illumina Support for Non-Discrimination of Genetic Testing Results in Insurance Underwriting

To the members of the Finance and Expenditure Select Committee,

I am writing to you today to seek your support in ensuring that discrimination based on the results of genetic testing in New Zealand stops. Meaning there is legislation put in place for a complete ban, not a partial ban, on any genetic based insurance discrimination.

Genetic discrimination is impacting the ability of patients to access the benefits of genomics and will make the advancements made in personalizing medicine difficult to realize in this country.

I am particularly passionate about this topic, as while I am a senior leader in global genomics company Illumina, I am also a New Zealand native and passionate about equity of healthcare on-shore in New Zealand. I believe that genomics can make a bit difference here in better treatment options for patients but also in savings to the health system.

Why Genomics Matters

Genomics matters profoundly in the realms of medicine, biology, and beyond, as it unravels the intricate blueprint of life encoded in our DNA. By deciphering the complete set of genes within an organism, genomics empowers scientists and healthcare professionals to understand the genetic basis of diseases, paving the way for more personalized and effective medical interventions. It plays a pivotal role in identifying genetic predispositions, enabling early disease detection, and tailoring treatment strategies to an individual's unique genetic makeup. Moreover, genomics fuels groundbreaking research, offering insights into evolution, biodiversity, and the fundamental mechanisms governing life.

The biggest difference genomic technologies have made to date is in the field of rare genetic conditions and in detecting certain forms of cancer that were previously undiagnosed. This ability to detect and diagnose is helping clinicians better manage conditions and in certain cases even

prevent future complications. The knowledge of personal genetic makeup helps patients, their carers, and doctors to plan and deliver better (individualized) care, support, and services. Genomics also enables applications like disease predisposition screening, population health and prevention, and as such, any introduction of legislation to address genetic discrimination must apply to all genetic tests.

Genomics is a proven technology that consistently demonstrates that extensive screening and predictive analysis, guided by healthcare individuals, empower individuals to manage their risk factors. This proactive approach, including early interventions, when necessary, has the potential to not only decrease overall risk for life insurers but contribute positively to overall health of the New Zealand population, which in turn leads to better economic outcomes for individuals and New Zealand more broadly.

Why Insurance discrimination is a barrier to:

- **Patient access to genomics**

Insurance discrimination poses a significant barrier to patient access to genomics, limiting the full potential of genomic medicine and personalized healthcare. Genomic testing has the potential to revolutionize the diagnosis, prevention, and treatment of various medical conditions by tailoring interventions to an individual's genetic makeup. However, the high cost of genomic testing and the fear of potential discrimination by insurance companies create obstacles for patients seeking these services.

The current state of genetic discrimination underwriting in insurances not only discourages individuals from pursuing genomic testing but also perpetuates inequities in healthcare access, as those with genetic predispositions may face challenges in obtaining affordable and comprehensive insurance coverage. By impeding the integration of genomics into clinical practice, the current lack of prohibitions on discrimination inhibits healthcare providers' ability to deliver truly personalized care. Genomics offers the opportunity to tailor treatment plans and interventions based on an individual's genetic profile, leading to improved diagnostic accuracy, targeted therapies, and better health outcomes.

A recent research poll, conducted by Illumina, demonstrated that genomics usage is low in Australia, with only one in ten surveyed Australians having engaged in some kind of genetic testing or genomic research. The findings underscore a range of concerns and barriers related to access, with 24% of surveyed individuals citing potential discoveries impacting their health or life insurance as their primary concern.

To address this barrier, there is a need for legislation and policies that protect individuals from genetic discrimination in the realm of insurance. Establishing a clear prohibition and safeguards in line with Canada's Genetic Non-Discrimination Act can help ensure that individuals can benefit from genomic advancements without the fear of negative consequences in terms of insurance coverage. This would not only encourage more people to undergo genomic testing, but also promote the integration of genomics into mainstream healthcare, ultimately advancing personalized medicine and improving patient outcomes both in terms of health and their future economic situation.

- ## Investment in genomics in New Zealand

Global innovative technology companies like Illumina need to make decisions on which countries to spend resources on to invest in. Any barriers to uptake of technology in a particular country reduce attractiveness.

We make significant investments into New Zealand medical research; however, we also recognize the importance of maintaining fiscal responsibility to our stakeholders. In line with these commitments, we diligently vet projects and industry partnered grants to ensure their success on completion. A key determinant of project success is effective recruitment of individuals for participation. We understand that the quality and engagement of participants significantly impact the outcomes of medical research initiatives.

We are concerned that insurance discrimination based on results of genetic tests will act as a significant barrier to investment in genomics in New Zealand, as it reduces demand for technologies used in these tests. If individuals fear that undergoing genomic testing may lead to higher insurance premiums or denial of coverage, they may be reluctant to participate in genomics-related initiatives, reducing the potential market size for new technologies. The evidence already shows this deterrent effect, both with respect to clinical testing and engagement in genomic research.

Reduced demand for technologies impacts the success of uptake, creating uncertainties and potential financial risks for both investors and the genomics industry.

Investors like Illumina are concerned that the discriminatory use of genomic information by insurers could limit the market for genomic products and services. This could stifle the growth of genomics- related businesses and startups, hindering home grown innovation and broader adoption of genomics in New Zealand.

To mitigate this barrier, regulatory frameworks and policies are crucial. Clear legislation that prohibits the discriminatory use of genetic information by insurance companies can provide a level playing field for investors and genomics companies. Legislation that safeguards individuals from insurance discrimination based on genetic data fosters a more conducive environment for investment in genomics. By addressing these concerns, New Zealand can encourage the growth of its genomics industry, attract investment, and ultimately accelerate the integration of genomic technologies into mainstream healthcare practices.

Recommendation

Illumina supports the proposed inclusions of Section 65, Clauses (4-7) be incorporated into the Contracts of Insurance Bill to ensure insurers are subject to a positive duty to not discriminate as outlined in Heron KC/Rishworth KC's submission. Illumina agrees this is aligned to the findings of the A-GLIMMER report that a legislated ban that does not contain limits, caps, or exclusions, is the only solution against genetic discrimination by life insurance companies. Illumina believes that adopting the approach in Canada's Genetic Non-Discrimination Act, which legislates a total ban, is the only way to provide consumers and investors alike the certainty and protection required to continue with adoption and innovation practices that genomic testing can provide.

A partial ban will not address consumer uncertainty and therefore will not address the impact on demand for genetic testing. There is significant risk that this will mean the people of New Zealand will not access life- changing genomic testing in a timely or equitable manner or participate in much needed medical research. As a result, we are concerned that investment into genomics technologies in New Zealand could decrease, especially as recruitment into research studies, where access to genetic testing is greatest, becomes increasingly difficult.

Sincerely,

Gretchen Weightman
Senior Vice President Asia Pacific, Middle East & Africa (AMEA)

About Illumina

Illumina is a global genomics and human health company powering the future of personalized medicine. Our industry-leading research and innovation is enabling clinicians to detect and diagnose diseases earlier, opening new, more effective treatment options for patients. Driven by our mission to improve human health by unlocking the power of the human genome, we are committed to making our technology affordable and accessible, realizing health equity for billions around the world.

Our customers include a broad range of academic, government, pharmaceutical, biotechnology, and other leading institutions around the globe. Illumina has been operating in Australia and New Zealand for 18 years. Our office is based in Melbourne, and we have around 80 employees.

NGO's	Logo	Name
The Cancer Society		Rachael Hart Chief Executive
The Breast Cancer Foundation NZ		Ah-Leen Raynor Chief Executive
Breast Cancer Cure		Sonja de Mari Chief Executive
Breast Cancer Aotearoa		Libby Burgess Chair
The Gut Cancer Foundation		Liam Willis Executive Officer
Sweet Louise		Catrin Devonald Chief Executive
Familial Breast & Ovarian Cancer		Simone Petrich Chair
Ovarian Cancer Foundation NZ		Whiteny Grenhoefer General Manager
The Gift of Knowledge		Nicola Coom Trustee
Hei Ahuru Mowai		Cindy Dargaville Chief Executive
Bowel Cancer New Zealand		Rebekah Heal
Head Neck New Zealand		Diana Ayling Excutive officer
Aotearoa Healthcare Alliance		Professor Stephen Robertson and Hui Watson Co Chairs
Rare Disorders NZ		Chris Higgins Chief Executive
22q Foundation Australia and New Zealand		C/- Rare Disorders
The New Zealand Acromegaly Society		C/- Rare Disorders
New Zealand Amyloidosis Patient Association		C/- Rare Disorders
ausEE Inc.		C/- Rare Disorders
Charcot Marie Tooth support group		C/- Rare Disorders
New Zealand Down Syndrome Association		C/- Rare Disorders
The NZ Dystonia Patient Network		C/- Rare Disorders
Ehlers–Danlos Syndromes New Zealand		C/- Rare Disorders
EGPA/Churg Strauss New Zealand		C/- Rare Disorders
FARA - Friedreich's Ataxia Research Association New Zealand		C/- Rare Disorders
Fragile X New Zealand Trust		C/- Rare Disorders

HAE Australasia LTD		C/- Rare Disorders
Haemophilia Foundation of New Zealand		C/- Rare Disorders
Hirschsprung's Disease Support - New Zealand		C/- Rare Disorders
Kiwi CRPS Charitable Trust		C/- Rare Disorders
ANCA Vasculitis NZ support group		C/- Rare Disorders
Muscular Dystrophy Association of NZ		C/- Rare Disorders
Myasthenia Gravis Support Group		C/- Rare Disorders
Motor Neurone Disease NZ		C/- Rare Disorders
New Zealand Pompe Network		C/- Rare Disorders
PNH Support Association of New Zealand		C/- Rare Disorders
New Zealand Prader Willi Association		C/- Rare Disorders
Spinal Muscular Atrophy NZ		C/- Rare Disorders
NZ Stills support group		C/- Rare Disorders
The Arthrogryposis Group New Zealand (TAG-NZ)		C/- Rare Disorders
Tuberous Sclerosis Complex New Zealand (TSCNZ)		C/- Rare Disorders
VHL New Zealand		C/- Rare Disorders
International Waldenströms Macroglobulinemia Federation NZ		C/- Rare Disorders
UNIQUE - Rare Chromosome Disorder Support Group		C/- Rare Disorders
Industry		
Illumina		Gretchen Weightman Senior Vice President Asia Pacific, Middle East & Africa (AMEA)

LAURA O'GORMAN KC

Genomic discrimination — The need for a legislative response

By Laura O'Gorman KC[1] 27 October 2022

Overview

1. This paper addresses the international response to issues of discrimination based on genetic information, particularly for insurance purposes. Following best practice overseas, it recommends the development and introduction of legislation in New Zealand to address the problem of genomic discrimination.

2. There is substantial public benefit from encouraging people to take genetic tests. Broadly speaking, genetic information is used:

   (a) to facilitate the early detection of illnesses and improve the opportunity to achieve better health outcomes, including through earlier preventative interventions and/or targeted therapy;

   (b) to develop more effective, and less harmful, medicine and therapy; and

   (c) to aid research of illnesses.

3. However, without adequate legal protections around use of genetic information, third parties such as employers and insurers can discriminate against those who are, or are seen to be, genetically predisposed to diseases.[2] Studies show that the risk of discrimination deters individuals from taking genomic tests or participating in genomics research,[3] thus denying society of the public benefit of testing.

4. These issues have been managed overseas by specific legislation or self-regulation (industry codes), some of which is summarised below.[4] Despite the issues being identified more than 20 years ago,[5] New Zealand currently lags behind to a significant degree, because it has failed to take any specific responsive measures.

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[1] I wish to acknowledge the valuable assistance of Augustine Choi (barrister at Bankside Chambers) for researching the issues and assisting with the preparation of this paper.

[2] See for example Australian Law Reform Commission *Essentially Yours: The Protection of Human Genetic Information in Australia* (ALRC 96, March 2003) at ch 9; Jane Tiller and others "Genetic discrimination by Australian insurance companies: a survey of consumer experiences" (2020) 28 European Journal of Human Genetics 108-113, available at <www.nature.com>.

[3] LA Keogh and others "Is uptake of genetic testing for colorectal cancer influenced by knowledge of insurance implications?" (2009) 191 Medical Journal of Australia 255, available at <doi.org/10.5694/j.1326-5377.2009.tb02778.x>. [4] See a 2010 paper examining the position taken in 47 different countries: Y Joly, M Braker and M Le Huynh "Genetic discrimination in private insurance: global perspectives" (2010) 29 New Genetics and Society 351, available at <doi.org/10.1080/14636778.2010.528189>. An international comparative analysis is also contained in the report of the Parliamentary Joint Committee on Corporations and Financial Services, Parliament of Australia, *Life Insurance Industry*, Report (2018), Chapter 9 Genetic Information.

[5] See Pamela Jensen "Genetic Privacy: The Potential for Genetic Discrimination in Insurance" [1999] VUWLawRw 21; (1999) 29(2) Victoria University of Wellington Law Review 347. As the author identifies in the conclusion, those interested would

Genetic Testing – Trade-offs and economics

5. The advantages of genomic testing are discussed in the New Zealand Medical Journal article "Genomic discrimination in New Zealand health and life insurance. AGenDA: Against Genomic Discrimination in Aotearoa" (11 March 2022).[6]

   (a) Genomic testing to detect risk conditions can save lives through early preventative interventions and/or improved targeted therapy (which in turn assists more effective and efficient public health spending).

   (b) For people at risk of genetic conditions, choosing not to be tested (for fear of discrimination) may have serious direct health impacts,[7] again impacting adversely on public health burdens.

   (c) Such fear can also deter recruitment into genomic research studies critical to understanding disease, developing prevention/therapies, and improving patient outcomes — another missed opportunity of reducing the overall public health burden.

6. Correspondingly, the moral reasons for addressing genomic discrimination include:[8]

   (a) It is unfair to discriminate against someone based on such an immutable, personal, and uncontrollable trait as one's genetic make-up, in the same way it is unjust to discriminate based on race or gender.[9]

   (b) Discrimination could lead to a so-called genetic underclass—a group of people unable to access insurance or other parts of society because of their genes.[10] The popular film *Gattaca* (1997) explored these issues.

7. Insurers may argue that lack of access to information about genetic risk, or inability to use the information, could lead to unfair pricing constraints and inefficiencies. On the other hand, existing literature indicates that there is little risk of overall detriment to insurers:[11]

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include the Human Rights Commission, the Health and Disability Commissioner, the Privacy Commissioner, the Ministry of Health, geneticists, medical ethicists, lawyers and the insurance industry.

[6] Andrew Shelling and others "Genomic discrimination in New Zealand health and life insurance. AGenDA: Against Genomic Discrimination in Aotearoa" (2022) 135 New Zealand Medical Journal 7, available at <journal.nzma.org.nz> [**Shelling and others "Genomic discrimination in New Zealand"**].

[7] Mark Rothstein "Time to end the use of genetic test results in life insurance underwriting" (2018) 46 J Law Med Ethics 794, available at <doi.org/10.1177%2F1073110518804243> [**Rothstein "Time to end the use of genetic test results"**].

[8] Anya Prince and others "Genetic testing and insurance implications: Surveying the US general population about discrimination concerns and knowledge of the Genetic Information Nondiscrimination Act (GINA)" (15 July 2022) International Insurance Society <www.internationalinsurance.org>.

[9] Anya Prince "Insurance Risk Classification in an Era of Genomics: Is a Rational Discrimination Policy Rational?" (2017) 96 Neb Law Rev 624, available at <www.ncbi.nlm.nih.gov>.

[10] Eric Mills Holmes "Solving the Insurance/Genetic Fair/Unfair Discrimination Dilemma in Light of the Human Genome Project" (1997) 85 Kentucky Law Journal 503, available at <uknowledge.uky.edu>; and Angus Macdonald and Fei Yu "The Impact of Genetic Information on the Insurance Industry: Conclusions from the 'Bottom-Up' Modelling Programme" (2011) 41 Astin Bulletin 343, available at <www.actuaries.org>.

[11] Dexter Golinghorst and others "Anti-selection & Genetic Testing in Insurance: An Interdisciplinary Perspective" (2022) 50 J Law Med Ethics 139, available at <papers.ssrn.com>; and Shelling and others "Genomic discrimination in New Zealand", above n 6, at 8, referring to: Cathleen Zick and others "Genetic testing, adverse selection, and the demand for life insurance" (2000) 93 Am J Med Genet 29; Jane Tiller and Martin Delatycki "Genetic discrimination in life insurance: a human rights issue" (2021) 47 Journal of Medical Ethics 484, available at <dx.doi.org/10.1136/medethics-2021-107645>; Rothstein "Time to end the use of genetic test results", above n 7; Mark Rothstein and Kyle Brothers "Banning Genetic Discrimination in Life Insurance — Time to Follow Florida's Lead" (2020) 383 N Engl J Med 2099, available at <doi.org/10.1056/nejmp2024123>; Angus Macdonald "The Actuarial Relevance of Genetic Information in the Life and

(a) Insurers argue that if applicants are not required to disclose predictive genetic information, those at higher risks could apply for greater policy coverage without insurers being able to assess risk and set appropriately higher premiums, a concept known as "anti-selection" (resulting from information asymmetry).[12] They say that anti-selection may reduce available coverage levels and lead to increased prices for all consumers, even those without genetic predispositions. If they set prices according to the average risk in the population, they could over-attract higher-risk customers, which may create a need to raise premiums. If relatively better risks then drop out of the insurance market, premiums could rise anew, with the potential that in the end only very high-risk types will be insured.[13] If the economic impact is too dire, financial concerns may outweigh genetic privacy and non-discrimination concerns; if it is minimal, regulation may be justifiable to promote human rights and public health.[14]

(b) However, the actuarial and economic models and studies do not suggest wide-spread or material anti-selection effects related to genetic testing.[15] To the contrary, both the insurers and society more generally are likely to benefit from reduced health costs arising from early preventative interventions and/or improved targeted therapy.

New Zealand's current legal framework

8. In the absence of legislation addressing the specific issue of genomic discrimination, existing legislation and the general law will apply to some aspects of how genetic information may be accessed and used:[16]

(a) General legal concepts of confidentiality and the tort of invasion of privacy[17] may apply, to give some protections from disclosure and misuse of private health information.

(b) In addition, New Zealand has legislation regulating the circumstances in which medical or health information can be acquired and disclosed to a third party. This is outlined in the Health Act 1956, which cross-refers to the Privacy Act 2020 and the Health Information Privacy Code 2020. Among other things, health agencies are permitted to disclose genetic information to a third party without consent in circumstances where the information could lessen or prevent a serious threat to the life, health or safety of a person. Section 22C of the Health Act also permits the use of patient information on

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Health Insurance Context" (July 2011) Office of the Privacy Commissioner of Canada <www.priv.gc.ca>; and Michael Hoy and Maureen Durnin "The Potential Economic Impact of a Ban on the Use of Genetic Information for Life and Health Insurance" (March 2012) Office of the Privacy Commissioner of Canada <www.priv.gc.ca>.

[12] Elizabeth Adjin-Tettey "Striking the Right Balance: Does the Genetic Non-Discrimination Act Promote Access to Insurance?" (2021) McGill Journal and Law and Health Vol 14, No 2, 145 at 158, available at <canlii.org>; Dexter Golinghorst and others "Anti-selection & Genetic Testing in Insurance: An Interdisciplinary Perspective" (2022) 50 J Law Med Ethics 139, available at <papers.ssrn.com>.

[13] Dexter Golinghorst and others "Anti-selection & Genetic Testing in Insurance: An Interdisciplinary Perspective" (2022) 50 J Law Med Ethics 139, available at <papers.ssrn.com>.

[14] Dexter Golinghorst and others "Anti-selection & Genetic Testing in Insurance: An Interdisciplinary Perspective" (2022) 50 J Law Med Ethics 139, available at <papers.ssrn.com>.

[15] See for example Elizabeth Adjin-Tettey "Striking the Right Balance: Does the Genetic Non-Discrimination Act Promote Access to Insurance?" (2021) McGill Journal and Law and Health Vol 14, No 2, 145 at 159 and footnote 51, available at <canlii.org>; Dexter Golinghorst and others "Anti-selection & Genetic Testing in Insurance: An Interdisciplinary Perspective" (2022) 50 J Law Med Ethics 139, available at <papers.ssrn.com>; Jane Tiller and others "Genetic discrimination by Australian insurance companies: a survey of consumer experiences" (2020) 28 European Journal of Human Genetics 108-113, available at <www.nature.com>; and other papers referred to above n 11.

[16] See OECD "Regulatory Developments in Genetic Testing in New Zealand" <www.oecd.org>.

[17] See *Peters v Attorney-General* [2021] NZCA 355, [2021] 3 NZLR 191.

public health grounds, in circumstances such as authorised requests by officials, including the police.

(c) Access to one's own health information is covered by Rule 6 of the Health Information Privacy Code 2020 and s 22F of the Health Act 1956. In addition, Right 6(1) of the Code of Health and Disability Services Consumers' Rights 1996, promulgated under the Health and Disability Commissioner Act 1994, gives patients the "right to information that a reasonable consumer, in that consumer's circumstances, would expect to receive", including the results of procedures or tests.

(d) Conduct that may be discriminatory ordinarily falls within the scope of the Human Rights Act 1993 (with freedom from discrimination in turn protected under s 19 of the New Zealand Bill of Rights Act 1990).[18] However, the prohibition in s 44 of the Human Rights Act 1993 against refusing to provide goods or services, or treating any person less favourably in connection with the same, by reason of discrimination does not apply to the provision of insurance policies in circumstances where the conduct is reasonable, having regard to the particular circumstances, and based on reasonably reliable actuarial or statistical data, or medical advice or opinion (s 48).

9. Accordingly, none of the above prevents private service providers, such as insurers, from asking for and using genomic test results and using that information to refuse access to the services, or to charge more for them (e.g. higher insurance premiums).

10. Under Te Tiriti o Waitangi, the New Zealand government must protect the rights, interests and *taonga* of Māori people. Special considerations arise from a *Te Ao* Māori perspective, which existing laws (focussed on individual entitlements) are inadequate to protect:[19]

(a) health information as regarded as a *taonga* (treasure) that must be cared for, used and treated with respect; and

(b) genetic information is viewed as collective (rather than individual) property, since it carries information about whānau, hapū and iwi (both historical and current/predictive).

International approaches to combat genomic discrimination

11. The Universal Declaration on the Human Genome and Human Rights was adopted unanimously and by acclamation at UNESCO's 29th General Conference on 11 November 1997. The following year, the United Nations General Assembly endorsed the Declaration, and Guidelines for the Implementation of the Declaration (1999) were endorsed by the General Conference at its 30th session. Among other things, Article 6 provides:

> No one shall be subjected to discrimination based on genetic characteristics that is intended to infringe or has the effect of infringing human rights, fundamental freedoms and human dignity.

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[18] See a discussion of the issues from a Human Rights perspective in speech notes of Rosslyn Noonan (Chief Commissioner, Human Rights Commission) and Robert Hallowell (Legal Counsel, Human Rights Commission): Rosslyn Noonan and Robert Hallowell "Never make forecasts, especially about the future" (March 2003), available at <privacy.org.nz>.

[19] See Report of the Royal Commission on Genetic Modification (2001) at pp276, 285 and 326-327, available at <https://environment.govt.nz/publications>; OECD "Regulatory Developments in Genetic Testing in New Zealand" <www.oecd.org>; Waitangi Tribunal *Ko Aotearoa Tēnei, Te Taumata Tuatahi: A Report into Claims Concerning New Zealand Law and Policy Affecting Māori Culture and Identity* (Wai 262, 2011) [Wai 262]; and Tai Ahu, Amy Whetu and James Whetu "Mātauranga Māori and New Zealand's intellectual property regime — challenges and opportunities since Wai 262" (2017) 8 NZIPJ 79.

12. Other countries have responded to these commitments and addressed the specific problem of genomic discrimination. The methods used have varied significantly, particularly in the insurance sphere. This section briefly summarises the different approaches.

(i) United Kingdom

13. In the United Kingdom the concern around the impact of genetic information on insurance emerged in the late 1990s.[20] The Association of British Insurers (**ABI**) and the Government adopted a semi-voluntary approach to regulation. A voluntary moratorium (**the Moratorium**) on insurers' use of predictive genetic test results came into effect in 2001. A policy framework agreement (**the Concordat**) on the use of genetic test results in insurance underwriting practices came into effect in 2005.[21] The Concordat and Moratorium were regularly reviewed, updated and extended until their replacement by the voluntary, open-ended, eight-point Code on Genetic Testing and Insurance in 2018 (**the Code**).[22] It is the Code by which members of the ABI have agreed to abide.

14. The Code supplements existing legislation on the use of medical information for insurance (and other purposes), such as the Data Protection Act 2018, which sets out responsibilities of controllers of data, and the Access to Medical Reports Act 1988, which governs how requests for medical information should be made and the need for consent.

15. The Code prohibits insurers from requiring or pressuring an applicant to take a predictive or diagnostic genetic test[23] to obtain insurance.[24] However insurers can ask for diagnostic genetic test results, and the results can be taken into account by insurers.

16. The Code allows insurers to ask for, and take into account, predictive genetic test results **only** for specific conditions[25] and for specific high-value policies, being life insurance for over £500,000, critical illness insurance for over £300,000 and income protection for over £30,000 per annum.[26] This means predictive genetic test results cannot be sought or considered for travel insurance, health insurance, and motor vehicle insurance, for example. Insurers cannot ask for the results of a predictive genetic test results: taken after the insurance cover has started for the duration of that cover, of another person, or obtained exclusively in the context of scientific research.[27]

17. If a predictive genetic test result is provided accidentally or voluntarily, an insurer may take it into account if it is to the applicant's benefit.[28] However if the result is unfavourable then the

[20] SC Davies *Annual Report of the Chief Medical Officer 2016: Generation Genome* (Department of Health, London, 2017) at chapter 15, page 3.
[21] Association of British Insurers and HM Government "Concordat and Moratorium on Genetics and Insurance" (2014) at [37].
[22] Association of British Insurers and HM Government "Code on Genetic Testing and Insurance" (October 2018) at 5 and 7–8 [**2018 UK Code**].
[23] "*Diagnostic genetic tests*" are defined as the kind of genetic tests that "*confirm or rule out a diagnosis based on existing symptoms, signs or abnormal non-genetic test results which indicate that the condition in question may be present*". "*Predictive genetic tests*" are defined as those that "*predict a future risk of disease in individuals without symptoms of a genetic disorder*": 2018 UK Code at 4.
[24] 2018 UK Code at 7 (Commitment 1).
[25] The only one currently being Huntington's disease.
[26] 2018 UK Code at 7 (Commitment 2).
[27] 2018 UK Code at 7 (Commitment 3).
[28] For example if it helps to rule out a risk which was otherwise suggested by family history.

insurer must ignore the result unless the Code otherwise allows the insurer to take it into account.[29]

18. The Code requires relevant insurers to be transparent with applicants and to report their compliance with the Code annually and to maintain a complaints procedure.[30]

(ii) Australia

19. Australia has a mixed legislative and semi-voluntary approach to the regulation of health-related insurers. Legislation governs the position with health insurance while a semi-voluntary model still applies for life insurance products.

20. The Private Health Insurance Act 2017 (Cth) (**PHIA**) prohibits health insurers from using genetic information to discriminate against customers. It does so through its broad definition of "*improper discrimination*", which includes "*discrimination that relates to … (a) the suffering by a person from a chronic disease, illness or other medical condition … (e) any other characteristic of a person … that is likely to result in an increased need for hospital treatment or general treatment*".[31] The Disability Discrimination Act 1992 (Cth) (**DDA**) does something similar. It defines disability to include disabilities that not only presently exist but "*may exist in the future (including because of a genetic predisposition to that disability)*" and sets out an array of areas in which it is not permissible to discriminate, including in work and in the provision of goods, services and facilities.[32]

21. However life insurers are not prohibited by legislation from discriminating using genetic information.[33] The 2018 Parliamentary report on the life insurance industry (**the Australian LII Report**) recommended further consideration of a moratorium on life insurers using predictive genetic information (except where the consumer provides such information to show they are *not* at risk), and implementing an interim moratorium.[34] The Australian LII Report also recommended that if a moratorium goes ahead, the government should consider whether legislation is required.[35]

22. The moratorium bears similarities to the Code in the United Kingdom.

23. In 2019, life insurer members of the Financial Services Council (**FSC**), an Australian industry body to which all life insurers currently belong, agreed to a five-year limited moratorium on the use of genetic test[36] results by life insurers (**the Australian Moratorium**).[37] The Australian Moratorium covers applicants for individually underwritten life insurance with an FSC member.[38] Regardless of the amount of cover, life insurers will not ask or encourage applicants:

    (a) to take a genetic test during the application or underwriting process, or

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[29] 2018 UK Code at 8 (Commitment 6).

[30] 2018 UK Code at 8 (Commitment 7).

[31] Private Health Insurance Act 2017 (Cth), s 55-5.

[32] Disability Discrimination Act 1992 (Cth), s 4 and pt 2.

[33] See for example the exemption under the Disability Discrimination Act 1992 (Cth), s 46.

[34] Parliamentary Joint Committee on Corporations and Financial Services "Life Insurance Industry" (Canberra, March 2018) at [9.98] and [9.100].

[35] Parliamentary Joint Committee on Corporations and Financial Services "Life Insurance Industry" (Canberra, March 2018) at [9.101]

[36] Genetic test is defined as one "*which examines a person's chromosomes or DNA*": Financial Services Council "FSC Standard No 11: Moratorium on Genetic Tests in Life Insurance" (21 June 2019) at [6.1].

[37] Financial Services Council "FSC Standard No 11: Moratorium on Genetic Tests in Life Insurance" (21 June 2019).

[38] Financial Services Council "FSC Standard No 11: Moratorium on Genetic Tests in Life Insurance" (21 June 2019) at [2.1].

(b) to disclose the results of a genetic test taken as part of a medical research study if the results are not provided, or the applicant has asked not to receive the results.[39]

24. However as in the United Kingdom, life insurers may ask for and use the results of a genetic test (during the application process[40]) if the total amounts of cover the applicant seeks is more than $500,000 of death cover, $500,000 of total permanent disability cover, $200,000 for trauma/critical illness cover, and $4,000 a month of income protection cover.[41] Life insurers may also take into account a favourable genetic test that an applicant chooses to disclose and preventive treatment being undertaken to reduce the risk of inherited disease(s).[42]

25. Under the Australian Moratorium, life insurers may still ask applicants to disclose, and take into account, any diagnosis of a condition even if it resulted directly or indirectly from a genetic test.[43]

26. Australia's Financial Services Council recently released its updated life insurance Code of Practice which will come into effect in July 2023.[44] The Australian Moratorium is retained in Appendix A (with the same financial thresholds). It currently has an end date of 30 June 2024,[45] but this will be reviewed during 2022 with a view to extending that date.[46] Relevant to that review is a funded project (yet to be completed) to monitor the impact of the Australian Moratorium on genetic testing and life insurance.[47]

(iii) Canada

27. Canada has opted for a purely legislative approach.

28. In 2017 the federal Parliament enacted the Genetic Non-Discrimination Act. The Act is notable for its brevity and breadth. It has just 11 sections. The Act provides a general prohibition against any person from requiring a person to take a genetic test or to disclose genetic test results as a condition of (a) providing goods or services to, (b) entering into or continuing a contract or agreement with, or (c) offering specific conditions in a contract or agreement with, the person.[48] A person cannot collect, use or disclose the results of a genetic test of someone they are providing goods or services to, or entering or continuing an agreement with, unless they have the latter's written consent.[49] Contravention of the Act's prohibitions are serious offences with maximum penalties of $1,000,000 and five years' imprisonment.[50]

29. The Act's general prohibition does not apply to health care practitioners providing health services, or to medical, pharmaceutical or scientific researchers.[51]

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[39] Financial Services Council "FSC Standard No 11: Moratorium on Genetic Tests in Life Insurance" (21 June 2019) at [3.2].
[40] See also Financial Services Council "FSC Standard No 11: Moratorium on Genetic Tests in Life Insurance" (21 June 2019) at [3.6].
[41] Financial Services Council "FSC Standard No 11: Moratorium on Genetic Tests in Life Insurance" (21 June 2019) at [3.3].
[42] Financial Services Council "FSC Standard No 11: Moratorium on Genetic Tests in Life Insurance" (21 June 2019) at [3.5].
[43] Financial Services Council "FSC Standard No 11: Moratorium on Genetic Tests in Life Insurance" (21 June 2019) at [3.1].
[44] Available at <www.fsc.org.au>.
[45] Financial Services Council *Life Insurance Code of Practice 2023*, Appendix A, A.1(e).
[46] Financial Services Council *Life Insurance Code of Practice 2023*, Appendix A, A.3(a).
[47] The Australian Government's *Genomic Health Futures Mission* has made a $500.1 million investment in genomic medicine research - see <https://www.health.gov.au/initiatives-and-programs/genomics-health-futures-mission>. The monitoring project is listed in Appendix A, Implementation Plan Priority Area 3.1 (AU$500,000, Monash University) – see Jane Tiller, Ingrid Winship, Margaret Otlowski and Paul Lacaze *Monitoring the genetic testing and life insurance moratorium in Australia: a national research project*, available at <https://doi.org/10.5694/mja2.50922>.
[48] Genetic Non-Discrimination Act 2017 (Can), ss 3 and 4.
[49] Genetic Non-Discrimination Act 2017 (Can), s 5.
[50] Genetic Non-Discrimination Act 2017 (Can), s 7.
[51] Genetic Non-Discrimination Act 2017 (Can), s 6.

30. The Act also amends the Canada Labour Code to protect employees from being required to undergo or to disclose the results of a genetic test, and provides employees with other protections related to genetic testing and test results, and the Canadian Human Rights Act to prohibit discrimination on the ground of "*genetic characteristics*". Discrimination on the basis of genetic characteristics includes discrimination on the grounds of a refusal to take or disclose the results of a genetic test.[52]

(iv) United States of America

31. The United States has also opted for a legislative approach in relation to health insurance.

32. Legislative efforts to prohibit genetic discrimination by health insurers (and employers) began in the 1990s. In 2008 and 2010 Congress passed the Genetic Information Nondiscrimination Act 2008 (**GINA**) and the Affordable Care Act 2010 (**ACA**).

33. By amendments to existing legislation,[53] GINA prohibits health insurers from requesting genetic testing or genetic information, and from discriminating based on genetic information, in relation to determining eligibility for benefits, coverage, and premiums/contributions, and any other activity related to the creation, renewal, or replacement of a contract of health insurance or health benefits.[54] The amendment to the Health Insurance Portability and Accountability Act (**HIPAA**) regulations confirms genetic information as health information protected by the HIPAA's Privacy Rule, which protects the privacy of all individually identifiable health information and controls their use and disclosure.[55]

34. "*Genetic information*" includes information about genetic tests of the individual and their family members, as well as manifested diseases in family members. It also includes any request for or receipt of genetic services or participation in clinical research that includes genetic services by the individual or their family members.[56] A "*genetic test*" generally means an analysis of human DNA, RNA, chromosomes, proteins or metabolites, that detects genotypes, mutations, or chromosomal changes.[57]

35. The ACA supplements the GINA regime and requires insurance issuers to provide coverage for all individuals who request it. Insurers cannot refuse coverage for, or increase costs to, individuals because of pre-existing conditions.

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[52] Genetic Non-Discrimination Act 2017 (Can), s 10.

[53] The Employee Retirement Income Security Act 1974, Public Health Service Act, Internal Revenue Code 1986, Social Security Act, and regulations under the Health Insurance Portability and Accountability Act [**HIPAA**].

[54] See for example Genetic Information Nondiscrimination Act 2008, sec 101(d), definition of "underwriting purposes" [**GINA**].

[55] National Human Genome Research Institute "Genetic Discrimination" (retrieved 12 September 2022) <www.genome.gov>; and Department of Health and Human Services "Summary of the HIPAA Privacy Rule" (last revised May 2003) <hhs.gov>.

[56] See for example GINA, sec 101(d), definition of "genetic information".

[57] See for example GINA, sec 101(d), definition of "genetic test". A genetic test does not include however "*an analysis of proteins or metabolites that does not detect genotypes, mutations, or chromosomal changes; or … an analysis of proteins or metabolites that is directly related to a manifested disease, disorder, or pathological condition that could reasonably be detected by a health care professional with appropriate training and expertise in the field of medicine involved.*"

36. GINA protections do not apply to long-term care insurance, life insurance, or disability insurance. A few states extend protections to these areas but there is no federal legislation to prevent genetic discrimination in these areas.[58]

Comparison of the different approaches

37. The different approaches to tackling the problem of genomic discrimination in health and life-related insurance can be compared by considering how they deal with several common issues.

(i) Different types of insurance

38. Only Canada has adopted a uniform approach to genomic discrimination in relation to both health insurance and life insurance (as well as in most other spheres of life). The scheme in the United Kingdom is similar in that it treats health and life insurance essentially the same. With the exception of a few states, the United States has taken no steps towards preventing genomic discrimination in life insurance. And in Australia, a very different approach is taken to life insurance than to other insurances.

39. There is no clear rationale not to have rules against genomic discrimination in relation to both health insurance and life insurance. The concern about deterring what would otherwise be useful testing applies equally whether an applicant or potential applicant is looking at either type of insurance.

(ii) Mandatory legislation or semi-voluntary scheme

40. Canada, in relation to both health and life insurance, and Australian and the United States in relation to health insurance, have adopted legislative schemes. Meanwhile the United Kingdom and the life insurance industry in Australia have adopted semi-voluntary schemes — in the sense of binding, industry-agreed rules.

41. England's Chief Medical Officer's annual report on genomics in 2016 supported the flexible semi-voluntary regulatory structure comprised at the time by the Concordat and Moratorium. In that report writers' view the kind of regulatory structure adopted was better able than legislation to cope with the fast moving technology. It was also better able to adapt to the insurance industry's underwriting principles.[59]

42. On the other hand, competition issues might arise with any attempt to implement a solution via voluntary industry schemes. Section 30 prohibits horizontal contracts or arrangements that contain or give effect to a "cartel provision". That phrase in turn is defined widely in s 30A to include a provision that fixes, controls or maintains the price for services or any discount, allowance, rebate or credit. There is no necessity for there to be an agreement or understanding that an absolute position as to price must be maintained for there to be anti-competitive conduct. All that is required is an agreement that will have an effect on price.[60] Therefore there

[58] National Human Genome Research Institute "Genetic Discrimination" (retrieved 12 September 2022) <www.genome.gov>; and JD Tenenbaum and KW Goodman "Beyond the Genetic Information Nondiscrimination Act: ethical and economic implications of the exclusion of disability, long-term care and life insurance" (2017) 14 Per Med 153. [59] SC Davies *Annual Report of the Chief Medical Officer 2016: Generation Genome* (Department of Health, London, 2017) at chapter 15, page 7.

[60] See *Lodge Real Estate Ltd v Commerce Commission* [2020] NZSC 25, [2020] 1 NZLR 238 at [139]–[146]: "What this means is that the Commission was required to prove only that the arrangement had the purpose or effect of restraining a freedom that would otherwise have existed as to the price to be charged": at [146].

is a risk that insurance industry discussion about the potential price impacts of genetic information (and how that should be addressed) is unsafe territory.

43. Voluntary codes are also subject to criticisms about lack of oversight, compliance monitoring and enforcement.

(iii) Financial limits to application of restrictions

44. The report by England's Chief Medical Officer noted that the different treatment depending on policy limits reflects the different requirements insurers have for underwriting insurance contracts based on the size of the sum insured. On the limits used in the Concordat and Moratorium (which are the same as those in the Code), the estimate was that more than 95% of insurance customers would not need to disclose genetic test results.[61]

45. Similar financial limits apply under the Australian Moratorium. Given the international nature of the insurance industry, it is expected this has been for the same reason.

46. An earlier version of the Canadian bill had exemptions in respect of high-value insurance policies,[62] but these did not remain in the legislation as enacted.

(iv) Amendments to existing rules/legislation or new rules/legislation

47. In Australia the changes to restrictions in relation to health insurance have been achieved through amendments to existing legislation and broadening existing general anti-discrimination rules in the PHIA and DDA. In contrast Canada simply passed a standalone regime within minimal amendments to existing legislation. In doing so it ostensibly left any remaining inconsistencies to be interpreted by the Courts, which is arguably not very efficient.

(v) Test results and family history

48. In Canada, the United Kingdom and Australia, the protected information are the results of genetic tests. In Canada that is defined as "*a test that analyzes DNA, RNA or chromosomes for purposes such as the prediction of disease or vertical transmission risks, or monitoring, diagnosis or prognosis*". The Australian Moratorium uses a simpler definition of "*a test which examines a person's chromosomes or DNA*".

49. Family medical histories, explicitly protected in the United States, appears not to be protected in Canada, the United Kingdom or Australia.[63]

(vi) Research carve-out

50. All the legislation examined have exemptions for use of genetic information for medical and scientific research purposes. Whether this is necessary depends on the breadth and language of the legislation, if legislation is amended or new legislation introduced.

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[61] SC Davies *Annual Report of the Chief Medical Officer 2016: Generation Genome* (Department of Health, London, 2017) at chapter 15, page 7.

[62] *Reference re Genetic Non-Discrimination Act* [2020] SCC 17 at [58] and [61].

[63] Although in Australia, genetic discrimination in health insurance based on family medical history could be in breach of the PHIA and DDA.

(vii) Diagnostic genetic tests and predictive genetic tests

51. In the United Kingdom and Australia, use of diagnostic genetic tests by insurers is distinguished from the use of predictive genetic tests, with the former remaining essentially permissible.[64] In Canada all genetic tests are lumped together in relation to whether they can be used by insurers.

52. Predictive genetic tests may be seen as a greater concern when considering genomic discrimination, due to the uncertainty of whether the diseases the risk of which are predicted would actually appear. It is not clear why diagnostic genetic tests should be less protected. Such tests (conducted when there are symptoms or signs of disease) can help to confirm or rule out a diagnosis, and to help identify the best therapy and medicine.

Legal and other challenges

53. Opponents of the Canadian legislation before it was passed were concerned about the eventual increase in premiums. One group considered that a self-imposed prohibition on use of genetic test information for life insurance applications up to $250,000 would be enough for about 85 per cent of applications not to require disclosure of genetic information.[65]

54. After Canada passed the Genetic Non-Discrimination Act 2017, Quebec made a constitutional challenge, which ultimately failed in the Supreme Court of Canada.[66] The challenge is irrelevant to the situation in New Zealand as it was founded on the Canadian Constitution and its division of law-making powers between the federal and provincial legislatures.

55. It is notable that the United States's GINA was passed 414–1 in the House of Representatives and 95–0 in the Senate.

Recommendation

56. Of the range of options, the general Canadian legislative approach appears the most attractive:

(a) The legislation is comprehensive, accessible and clear. It avoids arbitrary thresholds and distinctions between different types of insurance, and different types of genetic tests. These should be avoided, unless reliable empirical and economic data can be provided to support such distinctions.

(b) Despite action taken in other jurisdictions years ago, New Zealand's insurance industry has not been pro-active with self-regulation. In any event, such action could be problematic on competition law grounds, and voluntary codes are subject to criticisms about lack of oversight, compliance monitoring and enforcement.

(c) Legislation is an appropriate step for New Zealand to take, consistent with the values underlying the *Universal Declaration on the Human Genome and Human Rights*.[67]

(d) The *Te Ao* Māori perspective should be considered, including whether any definitions used in the proposed legislation will be broad enough to protect the collective *taonga* of genetic information.

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Laura O'Gorman KC
BARRISTER
ddi: +64-9-200 1501 | m: +64-21 313 653
e: laura@logorman.com | w: www.logorman.com

[64] 2018 UK Code; and Financial Services Council "FSC Standard No 11: Moratorium on Genetic Tests in Life Insurance" (21 June 2019) at [3.1].

[65] Parliamentary Joint Committee on Corporations and Financial Services "Life Insurance Industry" (Canberra, March 2018) at [9.23].

[66] *Reference re Genetic Non-Discrimination Act* [2020] SCC 17.

[67] *Universal Declaration on the Human Genome and Human Rights* UNESCO Res (11 November 1997).