Tēnā koutou

Thank you for the opportunity to provide feedback on the Exposure Draft of the Insurance Contracts Bill.

This submission is by the Cancer Society of New Zealand. We are a registered charity focused on reducing the impact and incidence of cancer in New Zealand. As cancer is a significant health burden in New Zealand and New Zealand's leading cause of death, we have an interest in insurance law (particular for health and life insurance).

We wanted to raise an aspect of insurance law practice that we think is unfair and inappropriate – the potential for genomic discrimination in New Zealand health and life insurance policies.

As well as being unfair, allowing insurers to discriminate based on genomic tests would have adverse policy consequences. Policy settings in New Zealand should encourage people to undertake medical tests (as this leads to better health outcomes e.g. through early diagnosis, better preventative measures and more targeted treatments).

We encourage New Zealand to follow Canada's lead and ban the use of genetic tests by life and health insurers, as there are good public health reasons for this.

A group of New Zealand clinicians, academics, scientists, lawyers, and representatives from Māori, Pacifica, medical charities and patient groups have formed a collaborative alliance known as "Against Genomic Discrimination Aoteoroa", or AGenDA, to highlight this issue. AGenDA recommends that a complete ban on the use of genomic information by insurance companies is necessary for the advancement of genomic medicine and the protection of all New Zealanders. We have attached a NZ Medical Journal article by AGenDA that describes the concerns in more detail. While the Cancer Society is not formally a member of this group, we support their mahi.

In addition, a 2021 article by Professor Andrew Shelling of the University of Auckland also highlights the issue (see attached) https://www.auckland.ac.nz/en/news/2021/10/05/genetic-discrimination.html#:~:text=A%20ban%20on%20insurers'%20use,expire%20in%202024%20unless%20renewed).

The Cancer Society hopes that including protections in the Insurance Contracts Bill against genomic discrimination would fall under a broad interpretation of the Government' policy decisions from November 2019 (i.e. to strengthen protections for unfair terms in insurance contracts).

Because genomic discrimination is a discrete issue, we think the clearest way to regulate for a ban by insurers on the use of genetic tests would be a clause within the Bill, e.g. perhaps through a new section in Part 3, subpart 1.

In addition, we also support Option A in clause 171 of the Bill as exclusion clauses should be subject to challenge as unfair terms.

We understand that the Official Information Act applies to this submission and that it may be disclosed, e.g. on your website. This submission is not confidential.

Thanks again for the opportunity to comment on this Exposure Draft.

Ngā mihi nui
Lucy

Editorial

Genomic discrimination in New Zealand health and life insurance.

AGenDA: Against Genomic Discrimination in Aotearoa

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Genetic testing to detect risk for conditions like certain cancers, and cardiac or neurological conditions, can save lives through early preventative interventions and/or improved targeted therapy. For diseases like inherited breast and ovarian cancer, a single mutation in a *BRCA1/2* gene can run within families and predispose individuals to a high likelihood of developing cancer at a young age. Early screening and detection, and prophylactic surgery, can dramatically reduce cancer risk. As genetic testing becomes more complex, it is often referred to as genomic testing, as we move from testing single genes to include all genes and other types of molecular testing.

Currently, within the insurance and financial services sector in New Zealand, they are legally allowed to ask for and use applicants' genetic test results in underwriting decisions. This often leads to genomic discrimination, where insurers increase premiums or deny cover to applicants on the basis of these results. There is considerable evidence, internationally, that individuals often decline medical genetic testing or participation in genomic research studies because of fears of genomic discrimination. In a US trial of whole-genome sequencing in clinical care, 28% of participants declined involvement due to a concern about insurance discrimination.[1] A recent Australian study also reported that concerns about genetic results being provided to life insurance companies deterred up to 10% of people from undergoing potentially life-saving genetic tests.[2]

Anecdotal evidence from clinicians, researchers and consumers in New Zealand indicates that this is an ongoing and significant problem, often leading to withdrawal of individuals and whole families from genomic testing and research. For people who are at risk of genetic conditions, choosing not to be tested may have serious health impacts. The fear of genomic discrimination can also hamper recruitment into genomic research studies.[3] Genomic research is critical to understanding disease, developing preventions/therapies and improving patient outcomes. If people are afraid to be involved in genomic research because of a lack of protection from genomic discrimination, this will undermine the potential that research offers.[4]

Although insurance providers in New Zealand cannot require individuals to undergo genetic testing, both health and life insurance companies can legally ask for and use previous genetic/genomic test results to discriminate against applicants. The obligation is on the person applying for insurance to provide the genetic test result, not on the medical professional or health service. If an applicant doesn't disclose the result or even the fact that a test was taken, the insurer could void the policy for non-disclosure when a claim is later assessed. New Zealanders who are proactive about their health by having genomic testing, or partaking in genomic research, are at risk of themselves or even their relatives being penalised both financially and medically.

The New Zealand Government has an obligation under Te Tiriti o Waitangi to achieve equitable health outcomes for Māori.[5] Māori have justifiable mistrust and cynicism of the New Zealand health system, and historical concerns around race-based discrimination of indigenous peoples have the potential to become amplified, as innovative technology, including genomic analysis, enables greater levels of inequity and discrimination.

The Universal Declaration on the Human Genome and Human Rights (UNESCO 1997) states that "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." Following the ratification of this declaration, many countries have implemented legislation to safeguard people from genomic discrimination in insurance and in the workplace.[6,7] In 2017, Canada introduced a complete ban on the use of genetic test results to discriminate in any area, including insurance and employment. Despite insurer resistance to this legislation, it has withstood a Supreme Court appeal and is now fully implemented. In 2019, the Australian life insurance industry introduced a five-year self-regulated moratorium on the use of genetic tests. New Zealand did not copy this move, however, and a significant disparity now exists between the two countries.

The Financial Services Council (FSC) is the industry body for health and life insurance in New Zealand. Their guidelines for using gentic test results have not been available on their websites. Our group and others have made several requests for the guidelines since 2020, and have only recently (September 2021) received copies of the guidelines applying to life insurers. These guidelines confirmed that life insurance companies can use applicants' genetic test results in underwriting. Of note, the accompanying letter advised that "there is no standard documentation for how genetic testing information is currently used by the New Zealand life or health insurance industry".

Insurers often cite "information asymmetry" as a reason to request genetic test information from applicants. "Information asymmetry" is when a customer holds more information about their risk profile than the insurer, but there is little, if any evidence that people actually capitalise on this in real life. For example, research has shown that *BRCA1/2* positive women do not capitalise on their information advantage by purchasing more life insurance than those women who have not undergone genetic testing.[8] In addition, risk mitigation by women diagnosed with a *BRCA1/2* gene mutation means that, generally, they undertake risk-reducing behaviours, such as early screening and/or prophylactic surgery, to dramatically reduce their risk of dying from cancer, putting both the woman and life insurer in a better position.[9-11] The idea that insurance companies are at significant disadvantage through the denial of access to genetic test results is not supported by the relevant literature. Several renowned experts engaged by the Canadian government, when its legislation was being considered, concluded that this phenomenon will not threaten the insurance industry's economic viability in the medium-term future.[12,13]

In the future, we expect that all types of genomic data will contribute to improved diagnosis and prognosis for a range of disease. Genomic profiling is increasingly used to optimise the efficiency and benefit of therapeutic interventions in a precision or personalised medicine approach. However, analysing and translating genomic data is an ongoing challenge for clinical and academic researchers. Issues such as "incidental findings" need to be considered - that is, when genomic data uncovers findings about a condition that are unrelated to the original purpose of the test. Another common and complex issue is finding "variants of unknown significance", whereby it is unknown if the variant is a harmless change or a risk factor for disease. Variants of unknown significance often stay on watch lists while researchers gather more information to confirm their potential role in disease. There are doubts about whether insurance companies have the expertise on hand to understand these and other complex aspects of genomic information.

By failing to address genomic discrimination in insurance, New Zealand is falling behind a host of countries against which it would normally benchmark its policy approaches. As a result, a group of New Zealand clinicians, academics, scientists, lawyers, and representatives from Māori, Pacifica, medical charities and patient groups have formed a collaborative alliance, known as "Against Genomic Discrimination Aoteoroa", or AGenDA (current members are attached), to address these issues. AGenDA recommends that a complete ban on the use of genomic information by insurance companies is necessary for the advancement of genomic medicine and the protection of all New Zealanders.

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