

Genomic discrimination in New Zealand health and life insurance.

A GenDA: Against Genomic Discrimination in Aotearoa

Andrew N Shelling, Louise S Bicknell, Stefan S Bohlander, Murray P Cox, Sara K Filoche, Harry G Fraser, Kimberley Gamet, Paul Lacaze, Rinki Murphy, Russell G Snell, Andrew Sporle, Ben Te Aika, Rachel V Purcell, Jane M Tiller

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 cancers, 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, New Zealand insurance companies 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. The professional guidelines applicable to genetic counselors in New Zealand require that, where relevant, insurance implications are included in discussions with individuals considering genetic testing.¹ There is considerable evidence, internationally, that individuals often decline medical genetic testing or participation in genomic research studies because of fears of genomic discrimination.^{2,3} In a US trial of whole-genome sequencing in clinical care, 28% of participants declined involvement due to a concern about insurance discrimination.⁴ 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-sav-

ing genetic tests.⁵ From an ethical perspective, these studies present troubling evidence about the potential harm from the continued legality of genetic discrimination.

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.^{6,7} 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.⁸

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 healthcare 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.⁹ Māori have justifiable mistrust and cynicism of the New Zealand healthcare 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.^{10,11} 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.¹² Although the New Zealand and Australian Standards regarding the use of genetic test results in life insurance underwriting were previously identical, New Zealand did not follow Australia by implementing a moratorium. Accordingly, a significant disparity now exists on this issue between New Zealand and many other first world countries.

The Financial Services Council (FSC) is the industry body for health and life insurance in New Zealand. As discussed, professional guidelines require genetics professionals to discuss relevant insurance implications of genetic testing with patients, meaning that an understanding of how insurers may use results is important. The Australian version of the FSC publishes its Standard on the use of genetic test results in underwriting on its website.¹² The New Zealand FSC’s guidelines for using genetic test results, however, are not available on its website (although they used to be). Members of the author group have made several requests for copies of the guidelines from FSC since 2020. After initially being advised that the guidelines are “for FSC members only”, copies of the guidelines applying to life insurers were provided in late 2021. 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”. The guidelines are still not available on the FSC website at the time of writing, and this lack of transparency continues to be an ethical concern.

Insurers often cite “information asymmetry” (when a customer holds more information about their risk profile than the insurer) as a reason to request genetic test information from applicants. Despite these claims, there is little, if any, peer-reviewed evidence that information asymmetry leads to insurer disadvantage in practice. For example, research has shown women with pathogenic *BRCA1/2* variants do not generally capitalise on their information advantage by purchasing more life insurance than those women who have not undergone genetic testing.¹³ In addition, the availability of risk mitigation strategies for women diagnosed with a *BRCA1/2* variant means that, generally, they undertake risk-reducing behaviours, such as early screening and/or prophylactic surgery, to dramatically reduce their risk of developing or dying from cancer, putting both the woman and life insurer in a better position.^{14–16} The idea that banning the use of genetic test results in insurance underwriting will cause financial harm to insurance companies is not supported by the literature. When asked by an Australian Parliamentary Inquiry regarding this issue to produce evidence of the negative effects of such a ban, the Australian FSC did not produce any such evidence.¹⁷ Several independent experts engaged by the Canadian Government, when its legislation was being considered, concluded that banning the use of genetic test results in insurance underwriting would not threaten the insurance industry’s economic viability in the medium-term future.^{18,19}

In the future, we expect that many 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 clinicians and researchers, and knowledge about genomics is still being uncovered. Issues such as variable penetrance (how often a certain gene change leads to disease in an individual), and “variants of unknown significance” (where it is unknown whether variants are harmless or risk factors for disease) are examples of the continued uncer-

tainty associated with genomic research. Given this uncertainty, it is naïve to expect insurance companies to have a complete understanding of this complex area, and inappropriate for insurers to base underwriting decisions on the results of tests which may still be poorly understood by clinicians. Issues such as “incidental findings” create further ethical challenges when considering the right of insurers to use genetic information, that is, when genomic testing unexpectedly reveals health information that is unrelated to the original purpose of the test.

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, Pasifika, medical charities and patient groups have formed a collaborative alliance, known as “Against Genomic Discrimination Aotearoa”, 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.

COMPETING INTERESTS

Nil.

AUTHOR INFORMATION

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

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

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

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

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

Harry G. Fraser, Genetic Counsellor, Auckland

Kimberley Gamet, Genetic Counsellor, Auckland

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

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

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

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

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

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

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

CORRESPONDING AUTHOR

Andrew N. Shelling, Department of Obstetrics and Gynaecology, Faculty of Medical and Health Sciences, University of Auckland, Auckland, New Zealand.
a.shelling@auckland.ac.nz.

URL

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Members of AGenDA who have approved this editorial

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.

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

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

Ben Curran, Department of Molecular Medicine and Pathology, School of Medical Sciences,
University of Auckland, Auckland.

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

Joep de Ligt, Institute of Environmental Science and Research Limited, Kenepuru Science Centre, Porirua, Wellington.

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

Lisa Foster, Chief Executive, Rare Disorders NZ.

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.

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

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

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.

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.

Jo Martindale: Wellington Regional Genetics Laboratory & Genetic Health, Wellington.

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, Australia.

Susan M Morton: Centre for Longitudinal Research, School of Population Health, University of Auckland, Auckland.

Rinki Murphy: Department of Medicine, School of Medicine, The 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.

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.

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.

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.