Justice for Our Genes

The Consequentialist Case for Genetic Non-discrimination Regulations in the New Zealand Life Insurance Industry

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Introduction

Genetic testing can predict risk of future disease, an advancement that has had life changing medical benefits. For all its benefits, however, the predictive capacity of genetic testing has allowed insurers to increase premiums to unaffordable levels, or to exclude cover for applicants with genetic susceptibilities, even those showing no signs of disease. The result is that New Zealanders who discover disease susceptibility through genetic testing may simultaneously lose their ability to obtain the life insurance they may greatly need down the line. Those who fail to disclose genetic test results to insurers suffer an equivalent fate, risking avoidance of their insurance policy.[1]

Although there has been previous writing on this issue, very little has focused on the New Zealand policy context. There is an urgent need to fill this gap by critiquing the New Zealand sit-and-wait approach, which is now an outlier from most comparable jurisdictions. Canada, the USA, much of Europe, and most recently Australia in 2019, have all introduced policy limiting insurer access to predictive genetic information. New Zealanders do not enjoy the same protections, and the issue is set to be escalated by impending developments in the field of genomics like personalised medicine.[2]

The New Zealand approach, which allows insurer access to predictive genetic information, has a number of adverse consequences. It disincentivises potentially lifesaving genetic testing and research, risks irrational discrimination and eugenic-like threats, and may contribute to health inequities by inhibiting research necessary to ensure Māori and Pasifika are no longer underrepresented in the Eurocentric field of genomic medicine. Evidently, the approach taken in New Zealand will have life altering consequences, and getting policy right is imperative.

Concerningly, the issue of genetic discrimination in insurance does not seem to be on the radar of those responsible for policy change. Industry body the Financial Services Council has shown no inclination towards significant change, and the Human Rights Commission last reviewed

[1] See Chapter 1 at [IV].
[2] Personalised medicine is targeted medical treatment based on an individual's genetic makeup.

the area in 2007.[3] Despite receiving several public submissions on the subject during the current insurance contract law review, the Ministry of Business, Innovation and Employment (MBIE) has also failed to initiate any work in this area.[4]

This dissertation aims to fill these gaps by asking what the law should be in New Zealand. It will analyse opposing arguments put forward by the industry, before arguing regulatory intervention to prevent insurer access to predictive genetic test results is necessary under a consequentialist utilitarian approach.

While writing this dissertation, a multidisciplinary group of clinicians, researchers, and academics came together to form the Against Genomic Discrimination Aotearoa (AGenDA) group, to lobby for change in New Zealand.[5] I am hopeful that this emerging appetite and pressure for change indicates we sit at the precipice of reform in this area.

[3] Email from Jaimee Paenga (Legal Advisor at Kaitohu Ture New Zealand Human Rights Commission, Govt entity) to Emily Boyle regarding OIA request made to the Human Rights Commission regarding genetic testing and insurance (29 September 2021).
[4] Letter from Tom Simcock (Acting Manager at Ministry of Business, Innovation and Employment, Govt entity) to Emily Boyle regarding OIA request made to MBIE regarding genetic testing and insurance (23 September 2021).
[5] See Jane Tiller and Andrew Shelling "Why New Zealanders are vulnerable to genetic discrimination in health and life insurance" *The Conversation* (online ed, New Zealand, 28 September 2021).

CHAPTER ONE

An Introduction to Genetics and Life Insurance

To set the scene, this preliminary chapter aims to provide the necessary background to genetics, the New Zealand life insurance industry, and insurance law.

I Background to Genetics

Before engaging in the debate surrounding the use of genetic information in insurance, a cursory explanation of the science on which it is predicated is necessary.[6]

The genome is an organism's entire set of DNA,[7] a double stranded molecule which holds the genetic code. Both DNA strands comprise a sequence of nucleotides: adenine (A), thymine (T), guanine (G), and cytosine (C). The strands join to form nucleotide base pairs, A pairing with T, and G with C. In total, the human genome is around 3 billion base pairs in length.[8]

In the cell nucleus, DNA coils around proteins to form structures called chromosomes.[9] Apart from reproductive cells, human cells contain 23 pairs of chromosomes, one set inherited from the paternal line, and one from the maternal line.

Genes are units of DNA containing functional information.[10] Usually, they contribute to cellular and organism function by encoding proteins, molecules that perform structural, functional, and regulatory roles in the body.[11]

Notably, each human genome is unique. Genetic variation includes common single base pair variants known as single nucleotide polymorphisms (SNPs),[12] and structural variants whereby

[6] This short explanation is supplemented by the table of definitions in Appendix 1.
[7] David Chin and others "The human genome and gene expression profiling" (2006) 59 Journal of Plastic, Reconstructive & Aesthetic Surgery 902 at 904.
[8] Mark P Sawicki and others "Human Genome Project" (1993) 165 The American Journal of Surgery 258 at 258.
[9] Nikki Kuhar, Sanchita Sil and Siva Umapathy "Potential of Raman spectroscopic techniques to study proteins" (2021) 258 Spectrochimica Acta Part A: Molecular and Biomolecular Spectroscopy 1 at 1.
[10] See generally Graziano Pesole "What is a gene? An updated operational definition" (2008) 417 Gene 1.
[11] The cellular machinery reads the nucleotide sequence of a gene and translates it into amino-acid chains.
[12] Anthony J Brookes "The essence of SNPs" (1999) 234 Gene 177 at 177.

sections of DNA are deleted, duplicated, or relocated.[13] Rare variants are called mutations. Much variation is non-pathogenic, either neutral or accounting for inter-individual differences.[14] However, some is associated with genetic disease and can be revealed through genetic testing.

A Types of Genetic Disorders

Genetic disorders can be broadly placed into three categories:

(1) Single gene/monogenic disorders – disorders caused by variation in a single gene. For example, Cystic fibrosis, caused by mutations in both copies of *CFTR*.[15]

(2) Complex/polygenic disorders – disorders caused by the combined effects of multiple genetic variants across the genome as well as the environment. For example, abdominal aortic aneurysm.[16]

(3) Chromosomal abnormalities – disorders caused by chromosomes or parts of chromosomes which are missing, present in extra copies, or positionally changed. For example, Trisomy 21 (Down syndrome), caused by a third copy or partial third copy of chromosome 21.[17]

B Genetic Testing

Genetic testing reveals the nucleotide sequence of an individual's genome, or targeted sections of it. The sequence is analysed based on knowledge from prior research to rule out, diagnose, or predict risk of genetic disease.

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[13] Malte Spielmann, Darío G Lupiáñez and Stefan Mundlos "Structural variation in the 3D genome" (2018) 19 Nature Reviews Genetics 453 at 453.
[14] Laurence Loewe and William G Hill "The population genetics of mutations: good, bad and indifferent" (2010) 365 Philosophical Transactions of the Royal Society 1153 at 1153.
[15] Marcus A Mall and Dominik Hartl "CFTR: cystic fibrosis and beyond" (2014) 44 European Respiratory Journal 1042 at 1043.
[16] Gregory T Jones and others "Meta-analysis of Genome-Wide Association Studies for Abdominal Aortic Aneurysm Identifies Four New Disease-Specific Risk Loci." 120 Circulation Research 341.
[17] Maj A Hultén and others "On the origin of trisomy 21 Down syndrome" (2008) 1 Molecular Cytogenetics 1 at 1.

This dissertation will distinguish two types of genetic tests:

(1) Diagnostic – genetic tests which confirm or rule out diagnosis in symptomatic patients.[18]

(2) Predictive – pre-symptomatic genetic tests which identify future onset or susceptibility to disease.[19]

Because diagnosis of manifest disease through genetic testing is indistinguishable from diagnosis using other clinical tests, in most jurisdictions disclosure of diagnostic genetic information to insurers is not challenged.[20] This dissertation will focus on predictive genetic test results, which identify future risk in healthy individuals, giving rise to unique concerns.

C The Role of the Environment

Clearly, the predictive capacity of genetics has great utility, including in insurance risk assessment. However, to formulate good policy it is important not to overestimate the role of genetics in determining disease. Most genetic diseases do not result solely from our genetics, but by a nuanced interaction between our genome and environment.[21] Factors like diet, drugs, or hormone levels can influence how, when, where, and to what extent genes are expressed.[22] It is only in a minority of monogenic disorders like Tay-Sachs or Huntington's that the environment plays little to no role in modulating whether disease manifests.

It is important to recognise the significance of genetics, but to avoid being misled by the genetic determinism, which is "... the impulse to treat DNA as destiny, discounting the possibility of deviating from one's genetic predisposition".[23]

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[18] Best Practice Advocacy Centre New Zealand *The New Zealand Laboratory Schedule Test Guidelines: genetic tests* (Best Tests, November 2014) at 3.
[19] James P Evans, Cécile Skrzynia and Wylie Burke "The complexities of predictive genetic testing" (2001) 322 British Medical Journal 1052 at 1052.
[20] Swiss Re Institute *Seeing the future? How genetic testing will impact life insurance* (Swiss Re Centre for Global Dialogue, 2017) at 8.
[21] Muin J Khoury "Genetics and genomics in practice: The continuum from genetic disease to genetic information in health and disease" (2003) 5 Genetics in Medicine 261 at 266.
[22] Gene expression refers to the process whereby genes are translated into their functional product.
[23] Karen Rothenberg and Alice Wang "The Scarlet Gene: Behavioral Genetics, Criminal law, and Racial and Ethnic Stigma" (2006) 69 Law and Contemporary Problems 343 at 356; and Nathaniel Comfort "Genetic determinism rides again" (2018) 561 Nature 461 at 461.

D The Present and Future of Clinical Genetics

Already, the use of genetics has become integrated in New Zealand society. Genetic tests like preimplantation genetic diagnosis,[24] prenatal screening,[25] the newborn "heel prick",[26] predictive or diagnostic testing,[27] and direct to consumer genealogy and ancestry tests have become relatively common.

Furthermore, declining sequencing costs have made genomic research more accessible than ever,[28] meaning genetics may be on an upward trajectory towards revolutionising medicine. For example, the near future will likely see clinical use of polygenic risk scores (PRS), and 'personalised' medicine. PRS allow statistical prediction of an individual's genetic risk of complex disease by assaying for many disease-associated variants.[29] Personalised medicine allows targeted medical treatment based on an individual's genetic makeup.[30] For example, pharmacogenetics is the identification of variants influencing susceptibility to drugs, allowing for optimal prescription and dosage.[31] It will transform the use of drugs like antidepressants, anticoagulants, and cancer treatments.[32] With genetic testing on the rise, it is imperative New Zealand sets policy allowing the public to reap the benefits of genetics, while protecting from abuse.

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[24] National Ethics Committee on Assisted Human Reproduction *Guidelines on Preimplantation Genetic Diagnosis* (Ministry of Health, March 2005).
[25] National Screening Unit *Antenatal Screening for Down Syndrome and Other Conditions: Guidelines for health practitioners* (Ministry of Health, February 2013).
[26] National Screening Unit *Newborn Metabolic Screening Programme Annual Report 2018* (Ministry of Health, December 2019).
[27] Best Practice Advocacy Centre New Zealand, above n 18, at 3.
[28] Richard T Corlett "A Bigger Toolbox: Biotechnology in Biodiversity Conservation" (2017) 35 Trends in Biotechnology 55 at 55.
[29] Samuel A Lambert, Gad Abraham and Michael Inouye "Towards clinical utility of polygenic risk scores" (2019) 28 Human Molecular Genetics R133 at R133.
[30] Alison Harvey and others "The future of technologies for personalised medicine" (2012) 29 New Biotechnology 625 at 625.
[31] Mary V Relling and William E Evans "Pharmacogenomics in the clinic" (2015) 526 Nature 343 at 343.
[32] John S Mattick and others "The impact of genomics on the future of medicine and health" (2014) 201 Medical Journal of Australia 17 at 17.

II Background to Life Insurance

Insurance is a mechanism of spreading the financial loss resulting from risk events among a pool of people.[33] Insurers collect and pool small, regular premiums from consumers and pay out claims from the pool.[34] In New Zealand, private insurance is voluntary, meaning individuals choose whether and when to obtain insurance, as well as their extent of cover.[35] Private insurance products can be broadly classed as life, health, or general insurance.[36] The disclosure of genetic information is potentially relevant to health and life insurance.

To limit scope, this dissertation will focus on life insurance, which gives rise to separate and significant issues. The use of genetic information in life insurance has already raised eyebrows in New Zealand,[37] including when Cigna introduced a life policy excluding breast cancer cover for applicants with *BRCA1/2* mutations.[38] However, much of the discussion will also be broadly applicable to health insurance.

A Life Insurance in New Zealand

Life insurance is a form of insurance where premiums are paid in exchange for a lump sum payout in the event of death or diagnosis of terminal illness.[39] Its purpose is to secure financial stability of the surviving family, and to ease financial hardships associated with death, such as funeral costs.[40]

Life insurance can be term or whole life. Whole life policies extend for the consumer's entire life on agreed terms so long as premiums are paid, but are usually more expensive.[41] In contrast, term policies cover consumers for a specified period or until a specified age, after which they

[33] Reserve Bank of New Zealand Te Pūtea Matua *Bulletin: An overview of the life insurance sector in New Zealand* (Vol 83 No 1, January 2020) at iii.
[34] Investment Savings and Insurance Association of New Zealand Incorporated *ISI Underwriting Guide* (March 2000) at 5.
[35] Investment Savings and Insurance Association of New Zealand, above n 34, at 5.
[36] I refer to general insurance as a broad category including, for example, car, contents, home, and business insurance.
[37] Rob Stock "Insurers face the genetic test" *Stuff* (online ed, New Zealand, 18 June 2015).
[38] Cigna Life Insurance "Cancer Cover: Policy Wording" Cigna <https://www.cigna.co.nz/assets/documents/cigna-cancer-cover-policy-wording.pdf> at [7].
[39] Reserve Bank of New Zealand Te Pūtea Matua, above n 33, at 3.
[40] Reserve Bank of New Zealand Te Pūtea Matua, above n 33, at iii.
[41] Consumer NZ *Life insurance buying guide* (December 2019).

must be renewed.[42] However, term policies are usually guaranteed renewable,[43] meaning the same cover can be renewed for another term notwithstanding changes in health or new genetic test results that have arisen.[44]

"Life policy" is defined in the Insurance (Prudential Supervision) Act 2010 (IPSA) as an insurance contract providing for the payment of money, premiums, or annuity for a term dependent on the "… death of a person or on the happening of a contingency dependent on the termination or continuance of human life";[45] or

> (d) a contract of insurance that is … more than 1 year's duration and under which a benefit (other than a health insurance benefit) is payable in the event of—
>
> (i) the death, by accident or by some other cause stated in the contract, of the person whose life is insured…; or
>
> (ii) injury to, or a disability of, the insured person as a result of accident or sickness; or
>
> (iii) the insured person being found to have a stated condition or disease.[46]

The definition encompasses several related products which fall under the umbrella of life insurance. These include:[47]

(i) Income protection insurance – policies which pay a proportion of income in the event of illness or injury resulting in inability to work.

(ii) Trauma insurance – policies providing a lump sum payout after occurrence of specified accidents or medical conditions (policies differ but usually cover events like cancers and heart attacks).

(iii) Total permanent disablement insurance – policies providing a lump sum payout in the event of permanent disability from illness or injury causing inability to work.

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[42] Reserve Bank of New Zealand Te Pūtea Matua, above n 33, at 1.
[43] See J Holmes *Mutuality and Solidarity – is it possible to solve the crisis in private health insurance in New Zealand?* (MJW Consulting Actuaries, November 2016) at [3.1].
[44] Margaret Otlowski and others "Genetic testing and insurance in Australia" (2019) 48 Australian Journal of General Practice 96 at 97.
[45] Section 84(1)(a)-(c).
[46] Section 84(1)(d).
[47] References to 'life insurance' made throughout this dissertation refer broadly to all of these products.

1 Regulation of the life insurance Industry

In 2011 the Reserve Bank (RBNZ) became the regulator and supervisor of the New Zealand insurance industry, empowered by IPSA. The purposes of IPSA are to "promote the maintenance of a sound and efficient insurance sector… and promote public confidence in the insurance sector."[48]

IPSA requires each person carrying on insurance business in New Zealand to hold a license.[49] The RBNZ is responsible for licensing decisions,[50] and has powers in relation to insurer solvency, as well as monitoring compliance with IPSA.[51]

In addition, internal regulation is provided by the Financial Services Council (FSC), an industry body representing the financial services sector including life insurers. The FSC produces industry guidelines which its members agree to comply with.

B Underwriting

Private insurance can either be community rated or risk rated. For community rated insurance, premiums are standardised based on population risk.[52] In contrast, for risk rated insurance, premiums are calibrated based on the risk an individual is predicted to bring to the pool.[53] This process is called 'underwriting'.[54]

Life insurance is risk rated in New Zealand,[55] and underwriters assess factors like age, family history, lifestyle risk, and medical history. Applicants assessed to bring heightened risk to the pool may be offered insurance at a higher cost.[56] For example, a person who discloses a *BRCA1*

[48] Insurance (Prudential Supervision) Act 2010, s 3(1).
[49] Section 15.
[50] Section 19.
[51] Insurance (Prudential Supervision) Act, pt 3.
[52] Walther Neuhaus "Community Rating and Equalisation" (1995) 25 The Journal of the IAA 95 at 95.
[53] Risk describes the probability of an insured event occurring. See Investment Savings and Insurance Association of New Zealand Incorporated, above n 34, at 5.
[54] Investment Savings and Insurance Association of New Zealand, above n 34, at 6.
[55] Investment Savings and Insurance Association of New Zealand, above n 34, at 6.
[56] Investment Savings and Insurance Association of New Zealand, above n 34, at 6.

mutation strongly associated with breast cancer will likely be charged higher than standard premiums to reflect their increased risk.

Appraising individualised terms would be impractical, so applicants are grouped into risk pools, and those in the same risk pool are offered insurance on the same terms.[57] Skilful underwriting is central to the solvency and success of insurance companies.[58]

1 The Current New Zealand position

In 2000, the Investment Savings and Insurance Association (now the FSC) introduced an Underwriting Guide to assist members,[59] appended to which was a voluntary Genetic Testing Policy.[60] Recently, the FSC withdrew many of its guidelines including the Genetic Testing Policy for review. A new policy which essentially maintains the previous position has been formed, but it is yet to be published on the website,[61] leaving a concerning absence of consumer guidance. Researchers and clinicians also face uncertainty advising patients of insurance consequences when obtaining informed consent.[62]

Under both policies, FSC members agree not to initiate genetic testing of insurance applicants but retain the ability to request disclosure of existing genetic tests results.[63] This position was reiterated by the Human Rights Commission (HRC) in its Insurance Guidelines.[64] Given the voluntary nature of the policy, and an absence of reporting, it is unclear whether it has been complied with.

2 The Human Rights Act 1993

[57] Investment Savings and Insurance Association of New Zealand, above n 34, at 6.
[58] Investment Savings and Insurance Association of New Zealand, above n 34, at 6.
[59] Investment Savings and Insurance Association of New Zealand, above n 34.
[60] Investment Savings and Insurance Association of New Zealand Incorporated *Genetic Testing Policy* (March 2000).
[61] Letter from the Financial Services Council of New Zealand (Industry Organisation) to Emily Boyle regarding the FSC position on genetic testing and life insurance (24 September 2021).
[62] Personal Communications.
[63] Investment Savings and Insurance Association of New Zealand Incorporated, above n 60, at [2]-[3]; and Financial Services Council *Guidelines: Genetic Tests and Life Insurance* (version 1, October 2020) at [5]-[6].
[64] Human Rights Commission Te Kāhu Tika Tangata *Guidelines: Insurance and the Human Rights Act* 1993 (November 2007) at [5.2].

The lawful limits of discrimination in underwriting are governed by the Human Rights Act 1993 (HRA). Section 44 deems it unlawful for suppliers to the public of "… goods, facilities, or services" to fail to provide or to treat any person less favourably in connection with the provision of goods or services by reason of any of the prohibited grounds of discrimination.

While 'genetic information' is not a prohibited ground of discrimination, diagnosed genetic disease is captured by the protected ground of "disability", defined as follows:[65]

> (h) disability, which means—
>
> (i) physical disability or impairment:
>
> (ii) physical illness:
>
> (iii) psychiatric illness:
>
> (iv) intellectual or psychological disability or impairment:
>
> (v) any other loss or abnormality of psychological, physiological, or anatomical structure or function:
>
> (vi) reliance on a guide dog, wheelchair, or other remedial means:
>
> (vii) the presence in the body of organisms capable of causing illness:

It is less clear whether genetic susceptibilities are captured by this definition, and no case law has determined the matter. However, human rights law is to be broadly interpreted,[66] so susceptibilities are likely captured by s 21(1)(h)(v), any "abnormality of … physiological, or anatomical structure or function".

However, even if genetic susceptibilities are captured by "disability", the protection conferred by the HRA is limited by an insurance exception.

3 The insurance exception

To an extent, discrimination based on prohibited grounds is inherent in risk rated insurance underwriting. Therefore, s 48 of the HRA carves out the following exception:

[65] Section 21(h).
[66] Human Rights Commission Te Kāhu Tika Tangata, above n 64, at 9.

(1) It shall not be a breach of section 44 to offer … life insurance policies … or other policies of insurance … on different terms or conditions for each sex or for persons with a disability or for persons of different ages if the different treatment—

(a) is based on—

(i) actuarial or statistical data, upon which it is reasonable to rely, relating to life-expectancy, accidents, or sickness; or

(ii) where no such data is available in respect of persons with a disability, reputable medical or actuarial advice or opinion, upon which it is reasonable to rely, whether or not contained in an underwriting manual; and

(b) is reasonable having regard to the applicability of the data or advice or opinion, and of any other relevant factors, to the particular circumstances.

Insurers can therefore offer differential conditions based on disability where that decision is based upon actuarial or statistical data, or in its absence, reputable medical advice. Therefore, while unjustified use of genetic information is unlawful, evidence-based use remains fair game for New Zealand life insurers. Individuals carrying well characterised genetic susceptibilities may legitimately be charged higher premiums.

C Complaints Mechanisms

Aggrieved consumers have two avenues of complaint outside their insurance company. Complaints relating to unlawful discrimination can be brought to the HRC through an informal, consumer friendly process.[67] Alternatively, complaints may be made to the Insurance and Financial Services Ombudsman (IFSO).

The IFSO is a free scheme which investigates complaints relating to financial service providers, including life insurers.[68] It is semi-independent, external to each insurance company but nonetheless industry established.[69]

However, the IFSO only covers member companies, and investigates a limited range of complaints. Importantly, it cannot consider complaints about underwriting decisions,

[67] Human Rights Commission Te Kāhu Tika Tangata, above n 64, at 20.
[68] Human Rights Commission Te Kāhu Tika Tangata, above n 64, at 20.
[69] See Insurance & Financial Services Ombudsman "Insurance & Financial Services Ombudsman Scheme" <https://www.ifso.nz>.

premiums, or charges,[70] meaning individuals subjected to adverse underwriting decisions based on genetic test results may not seek redress through the IFSO. The only option for complaints of this nature is the HRC if the insurer has breached the HRA.

III International Law

A triad of international declarations may be influential on the New Zealand position. The UNESCO Universal Declaration on the Human Genome and Human Rights sets out that states must protect from "… discrimination based on genetic characteristics that is intended to infringe or has the effect of infringing human rights, fundamental freedoms and human dignity."[71] The UNESCO International Declaration on Human Genetic Data followed suit in 2003, reinforcing this position and adding the need to protect from stigmatisation.[72] The UNESCO Universal Declaration on Bioethics and Human Rights has a similar ethos, acknowledging the importance of non-discrimination and non-stigmatisation in the bioethics context.[73]

Significantly, in declining protection from genetic discrimination in insurance, the New Zealand position fails to align with these declarations. This may influence the adoption of genetic non-discrimination policy in New Zealand to protect human rights.

IV Background to Insurance Law

Contracts for insurance are largely subject to ordinary principles of contract law but have some distinguishing legal features. A contract for insurance is broadly defined as:[74]

> … a contract for the payment of a sum of money, or for some corresponding benefit …. to become due on the happening of an event, which event must have some amount of uncertainty about it, and must be of a character more or less adverse to the interest of the person effecting the insurance.

[70] Human Rights Commission Te Kāhu Tika Tangata, above n 64, at 21.
[71] UNESCO *Universal Declaration on the Human Genome and Human Rights* (adopted 11 November 1997, endorsed by the General Assembly in Resolution AIRES/53/152, 9 December 1998), art 6.
[72] UNESCO *International Declaration on Human Genetic Data* (C/RES/23, adopted 16 October 2003).
[73] UNESCO *Universal Declaration on Bioethics and Human Rights* (23 C/RES/24, adopted 10 January 2005).
[74] *Prudential Insurance Co v Inland Revenue Commissioners* [1904] 2 KB 658 at 664 per Justice Channell.

The requisite "uncertainty" may regard either whether the event will happen, or as is the case for life insurance, when it will happen.[75]

Importantly, the common law distinguishes indemnity insurance from contingency insurance. Life insurance falls into the latter category, under which the suffering of loss is not required.[76] The contract is seen as an agreement to pay out a predetermined sum on the occurrence of a risk event, whether or not that event is injurious to the assured.[77] Life policies do not indemnify because the value of life cannot be quantified.[78]

A The Doctrine of Uberrimae Fidei and Disclosure Obligations

According to the doctrine of *uberrimae fidei,* insurance contracts are special contracts of upmost good faith.[79] Unlike general contract law, both parties to an insurance contract are under an active duty of disclosure pursuant to this good faith duty, requiring that any and all material facts which may affect risk to the other party are disclosed prior to completion of formation.[80] This leads to symmetry of material information between the applicant and insurer.

Where there has been non-disclosure of material facts, like relevant genetic test results, the contract may be void *ab initio,* meaning non-disclosure "terminates the contract… and restores things, as between [the parties], to the position in which they stood before the contract was entered into".[81]

The duty of disclosure is rather onerous on applicants. Even non-deliberate concealment of material facts, or circumstances where the undisclosed information is unrelated to the claim at hand may void the contract for lack of good faith.[82] Unless the contract stipulates otherwise, in

[75] Robert Merkin and Chris Nicoll "The Contract of Insurance" in *Colinvaux's Law of Insurance in New Zealand* (2nd ed, Thomson Reuters, Wellington, 2017) at 7.
[76] *Gould v Curtis* [1913] 3 KB 84 at 95; and *Feasey v Sun Life Assurance Co of Canada* [2003] EWCA Civ 885 at [154].
[77] *Gould v Curtis*, above n 76, at 95.
[78] Robert Merkin and Chris Nicoll "The Contract of Insurance" in C*olinvaux's Law of Insurance in New Zealand* (2nd ed, Thomson Reuters, Wellington, 2017) at 8.
[79] *FAME Insurance Company Limited v McFadyen* [1961] NZLR 1070 at 1074.
[80] *Carter v Boehm* (1766) 3 Burr 1905 at 189.
[81] *Abram v Westville* [1923] AC 773 at 781 per Lord Atkinson.
[82] *Joel v Law Union and Crown Insurance Co* [1908] 2 KB 863.

the case of avoidance the insurer is entitled to repayment of any previous payouts, and the consumer to repayment of premiums.[83] Because non-disclosure is often revealed in the wake of a claim, the consumer may be left with an uninsured loss.

B Insurance Contract Law Reforms

MBIE is currently reviewing insurance contract law, aiming to ensure it "… is facilitating well-functioning insurance markets that enable individuals and businesses to effectively protect themselves against risk."[84]

Certain proposals will alleviate the harsh nature of insurance law for consumers. This includes a proposal to limit the duty of disclosure, so applicants are only required to accurately answer questions posed by insurers.[85] It is based on concerns the current position is unreasonable, because it expects consumers to know what constitutes material information.[86] Codification of the mutual duty of utmost good faith has also been proposed, to promote awareness of its existence to policyholders.[87]

Disappointingly, the review has failed to examine the issue of genetic discrimination in insurance,[88] despite several public submissions relating to the issue.[89]

V Why Does Access to Life Insurance Matter?

To orient the arguments for and against genetic non-discrimination policy, it is useful to consider the importance and distribution of life insurance.

Life insurance is a commercial product not everyone can afford, distributed pursuant to market principles under a risk rated approach. In New Zealand, those who cannot, or do not access life

[83] *Black King Shipping Corp v Massie* [1985] 1 Lloyd's Rep 437.
[84] Ministry of Business Innovation and Employment *Review of insurance contract law: Terms of Reference* (March 2018) at 1.
[85] Office of the Minister of Commerce and Consumer Affairs *Insurance Contract Law Reforms* (Ministry of Business Innovation and Employment, November 2019) at [4].
[86] Office of the Minister of Commerce and Consumer Affairs, above n 85, at [5].
[87] Office of the Minister of Commerce and Consumer Affairs, above n 85, at [50].
[88] Letter from Tom Simcock to Emily Boyle, above n 4.
[89] Letter from Tom Simcock to Emily Boyle, above n 4.

insurance have some safeguards. Social welfare entitlements, ACC, and the superannuation scheme mitigate at least the worst disadvantages life insurance products address. This may in part explain why New Zealanders have low amounts of life insurance cover compared to other OECD countries.[90] Furthermore, unlike some other countries, life insurance not an integral part of retirement savings in New Zealand.[91]

However, life insurance can be described as a "gateway social good", meaning it is not intrinsically essential the way food or housing is, but can be a gateway to accessing certain goods of basic importance.[92] For example, obtaining life insurance can help provide economic stability for one's family, through benefits well in excess of social welfare entitlements.[93] Furthermore, while life insurance is no longer a prerequisite to obtaining a mortgage in New Zealand,[94] it can be important to ensure that in the event of death, or injury or illness causing inability to work, families do not lose their homes by defaulting on the mortgage.

Additionally, life insurance may be of greater importance for people with genetic susceptibilities. For some families, the hereditary nature of genetic disease may lead to intergenerational reduction in wealth because of medical expenses and premature death or disablement of income earners, occurring in successive generations.[95] Life insurance provides an opportunity to front-foot that wealth spiral.[96]

Therefore, notwithstanding government safety nets, life insurance has important socio-economic implications, and policy affecting access must be carefully considered.

[90] Reserve Bank of New Zealand Te Pūtea, above n 33, iii.
[91] Annalise Vucetich, Roger Perry and Richard Dean *Bulletin: The insurance sector and economic stability* (Reserve Bank of New Zealand Te Pūtea Matua, vol 77 no 3, September 2014) at 3.
[92] Martin O'Neill "Genetic Information, Life Insurance, and Social Justice" (2006) 89 The Monist 567 at 578.
[93] O'Neill, above n 92, at 579.
[94] Personal communications with Tony Mounce (Tony Mounce Mortgages & Insurance, private Co) (1 October 2021).
[95] Personal communications with Stephen Robertson (Professor of Paediatric Genetics, University of Otago) (27 July 2021).
[96] Personal communications with Stephen Robertson (Professor of Paediatric Genetics, University of Otago) (27 July 2021).

CHAPTER TWO

The Consequences of Intervention: An Industry Perspective

To establish whether genetic non-discrimination policy should be introduced, it is important to analyse common opposing arguments. Often, these arguments are raised by the industry itself,[97] which tends to favour a symmetry of information approach. While in some cases the industry has adopted voluntary restrictions on the use of genetic information,[98] usually this is brought about by governmental pressures incentivising measures within the industry in order to avoid legislative intervention.[99]

Arguments against genetic non-discrimination policy tend to fall into three categories:

(1) Genetic non-discrimination policy is unjust because it violates actuarial fairness.

(2) Genetic non-discrimination policy results in negative economic outcomes because it causes adverse selection.

(3) Genetic information is not unique, so non-discrimination policy would be a form of unjustified genetic exceptionalism.[100]

This chapter will analyse categories one and two which are arguments often raised by the industry.[101] The third category goes to the nature of genetic information and tends to instead be raised by the science community, so it will be addressed separately in chapter three.

[97] References to "the industry" in this chapter include other jurisdictions.
[98] This includes Australia and the UK.
[99] Trudo Lemmens, Yann Joly and Bartha Maria Knoppers. "Genetics and life insurance: a comparative analysis" (2004) 11 GenEdit 1 at 10.
[100] Genetic exceptionalism describes the tendency to treat genetic information as inherently different to other medical information. Chapter 3 offers a full explanation.
[101] Investment Savings and Insurance Association of New Zealand, above n 34, at 18.

I Genetic Non-discrimination Policy Would Violate Actuarial Fairness

The first opposing argument relates to injustice. While the concept of justice has been theorised in a variety of ways, life insurance is premised on one theory of justice, 'actuarial fairness'.[102]

In life insurance, 'actuarial fairness' holds that justice is achieved when individuals pay premiums commensurate to the level of risk they bring to the pool.[103] Actuarial fairness therefore endorses 'risk rating', and is reliant on informational symmetry, consistent with the onerous disclosure obligations tied to life insurance.[104]

When actuarial fairness is violated, for example through genetic non-discrimination policy, low-risk individuals subsidise high-risk individuals in the insurance pool.[105] This consequence is inequitable according to an actuarial fairness approach to justice, which instead requires high-risk individuals to carry their greater burden.[106] Therefore, arguably through an industry lens, the current symmetry of information approach is just and equitable for consumers, whereas the introduction of genetic non-discrimination policy would not be.

However, the fact actuarial fairness is the central understanding of justice in life insurance does not barricade it from critique. Actuarial fairness may be a suitable approach to general risk factors disclosed to life insurers like smoking status, high-risk professions, and pre-existing illnesses, which are all easily identifiable. However, arguably it is an unsuitable basis for rating predictive genetic information, because family history or correctly targeted genetic testing is required to become aware of genetic risk, meaning of the proportion of the population with high genetic risk, only some are aware of it.[107]

This distortion in the ascertainment of genetic risk information skews the principle of actuarial fairness. Only those individuals who happen to become aware of their genetic susceptibility

[102] Jonathan Pugh "Genetic information, insurance and a pluralistic approach to justice" (2021) 47 Journal of Medical Ethics 473.
[103] Pugh, above n 102, at 475.
[104] See Chapter 1 at [IV].
[105] Pugh, above n 102, at 475.
[106] Pugh, above n 102, at 475.
[107] Béatrice Godard and others "Genetic information and testing in insurance and employment: technical, social and ethical issues" (2003) 11 European Journal of Human Genetics S123 at S129.

will pay premiums commensurate to their genetic risk.[108] The only way to remedy this distortion would be to subject all applicants to genetic testing, which would be both impractical and an impediment on the right of individuals not to know their genetic risk.[109]

Therefore, a different approach to genetic risk information would arguably be more appropriate given the concept of actuarial fairness is undermined even when that information is accessible to insurers. Actuarial fairness could, however, remain the basis for assessing other risk factors.

A The Concept of "Genomic Subsidising Solidarity" as an Alternative Theory of Justice

The principle of solidarity is arguably more suitable in the limited context of predictive genetic information. Solidarity has a variety of meanings, but generally refers to a social agreement for the equal sharing of risk amongst a group.[110] It is usually associated with social insurance,[111] but is to an extent part of the ethos of all insurance, including private insurance.[112]

An important distinction must be drawn between two types of solidarity. The first is "chance solidarity", a more attenuated account which describes the nature of all insurance as a social, risk sharing activity.[113] Chance solidarity is consistent with the risk rating practices of actuarial fairness.[114] In the context of predictive genetic information, I advocate instead for the second form of solidarity, known as "subsidising solidarity".[115] Under this approach, risk factors are not assessed, meaning risk is shared equally across the pool.[116] The result is that low-risk individuals subsidise high-risk individuals, as is the case in community rated insurance schemes.[117] This approach would represent a shift from an equity-based approach to one of equality, whereby the group takes on risk as a collective to avoid the alternative where the costs of insuring genetic risk fall unfairly on those who happen to become aware of it.

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[108] Godard and others, above n 107, at S129.
[109] See UNESCO, above n 71, art 5(c).
[110] Hans Maarse and Aggie Paulus "Has Solidarity Survived? A Comparative Analysis of the Effect of Social Health Insurance Reform in Four European Countries" (2003) 28 Journal of Health Politics, Policy and Law 585 at 588.
[111] Social insurance is insurance provided by government. For example, the public welfare system.
[112] Turo-Kimmo Lehtonen and Jyri Liukko "The Forms and Limits of Insurance Solidarity" (2011) 103 Journal of Business Ethics 33 at 33.
[113] Lehtonen and Liukko, above n 112, at 38.
[114] Lehtonen and Liukko, above n 112, at 39.
[115] Yves Thiery and Caroline Van Schoubroeck "Fairness and Equality in Insurance Classification" (2006) 31 The Geneva Papers 190 at 196; and Lehtonen and Liukko, above n 112, at 39.
[116] Thiery and Van Schoubroeck, above n 115, at 196.
[117] Thiery and Van Schoubroeck, above n 115, at 196

Because actuarial fairness would remain the basis for rating all other risk factors, I will refer to this concept as "genomic subsidising solidarity" to demarcate its limited scope. It would arguably not be a radical departure to adopt solidarity as an alternative to actuarial fairness in this limited context given actuarial fairness is not an absolute concept. Risk rating only goes so far, meaning mutually rated insurance schemes are already an amalgam of actuarial fairness and solidarity.[118] Insurers do not know every risk characteristic of applicants, and pool risk rather than using it as an exact actuarial measure.[119]

Importantly, I do not draw on genomic subsidising solidarity as an argument in favour of genetic non-discrimination policy. Instead, I raise it to refute claims genetic non-discrimination policy would be an unjust departure from actuarial fairness. The plausibility of a solidarity approach shows removing insurer access to genetic risk information is not necessarily unjust, and could quite legitimately align with an altered conceptualisation of justice required by unique circumstances.

II Adverse Selection Opposes Intervention

Life insurance serves social purposes but is nonetheless a commercial product.[120] Accordingly, the industry's central argument opposing genetic non-discrimination policy is based on economic consequences of market intervention. The concern is that genetic non-discrimination policy will result in adverse selection (AS),[121] which may destabilise the insurance market, or even lead to market failure.[122]

In this context, AS describes the tendency of individuals with higher genetic risk to purchase life insurance, or to purchase larger quantities of it, without having to disclose risk to the

[118] Angus MacDonald *The Actuarial Relevance of Genetic Information in the Life and Health Insurance Context* (Office of the Privacy Commissioner of Canada, July 2011) at 5.
[119] Michael Hoy and Maureen Durnin *The Potential Economic Impact of a Ban on the Use of Genetic Information for Life and Health Insurance* (Office of the Privacy Commissioner of Canada, March 2012) at 1.
[120] Yvonne Bombard "The nature and extent of genetic discrimination among persons at risk for Huntington disease" (Doctor of Philosophy Thesis, University of British Columbia, 2008) at 21.
[121] Jane Tiller, Margaret Otlowski and Paul Lacaze "Should Australia Ban the Use of Genetic Test Results in Life Insurance?" 5 (2017) Frontiers in Public Health 330.
[122] Lan Nguyen and Andrew C Worthington *Adverse Selection in Australian Private Health Insurance* (Reserve Bank of New Zealand Te Pūtea Matua, July 2021) at 1.

insurer, in light of their increased chance of needing to rely on a future claim.[123] This creates informational asymmetry, meaning insurance can be obtained at low rates, not representative of risk. Over time, AS can lead to an increased rate of pay-outs from the risk pool, leading to greater than anticipated costs, destabilising the market.[124] To compensate for increased costs, insurers tend to increase premium prices, which may drive low-risk individuals out of the life insurance market.[125] This effect may also be compounded by proverse selection, whereby individuals who discover they are low-risk for genetic disease become less likely to insure themselves.[126]

From a simplified view, insurance is financially viable when premiums collected are equivalent, or greater than claims paid out.[127] The following example does not relate to genetic information, but demonstrates how AS can theoretically destabilise this balance.

Imagine a law is suddenly introduced preventing life insurers from accessing any risk information from applicants. An applicant who knows she has one month to live buys $100,000 of life cover. She pays the first $20 premium before dying, securing a rate return of ~24,400,000,000,000,000,000,000,000,000,000,000,000,000,000,000% per annum.[128] This example is extreme, and unrepresentative of the effects of non-disclosure of predictive genetic information. I simply draw on it as a theoretical example to demonstrate the financial pressures AS can place on the insurance market.

AS may disadvantage two groups: insurance companies who may face reduced profitability or insolvency, and members of the risk pool who may not be paid out for claims if insolvency occurs. Given these undesirable outcomes, a real risk of AS may be an important factor in determining whether to introduce genetic non-discrimination policy in New Zealand.

[123] Investment Savings and Insurance Association of New Zealand, above n 34, at 5.
[124] Bombard, above n 120, at 23.
[125] Bombard, above n 120, at 23.
[126] Julie-Anne Tarr "Regulatory Approaches to Genetic Testing in Insurance" (2002) 24 Sydney Law Review 189 at 199.
[127] MacDonald, above n 118, at 2.
[128] Angus Macdonald "Genetics and insurance management" in *The Swedish Society of Actuaries: One Hundred Years* (Svenska Aktuarieföreningen, Sweden, 2004) at [2.3].

However, many authors and policymakers now dismiss industry concerns relating to AS as exaggerated.[129] Life insurers in a number of jurisdictions have now been subject to genetic non-discrimination rules long enough to gather empirical data about its effects on the stability of insurance markets, yet there is no evidence AS has occurred.[130] In fact, expert opinion given in the lead up to the Canadian Genetic Non-Discrimination Act 2017 revealed a negligible risk of AS in the near future.[131] The industry can no longer rely on speculation of AS to oppose policy.

In practice, AS may not be actualising for several reasons. Firstly, genetics is not as determinative as it is often perceived to be.[132] The effects of AS will be most severe in relation to individuals carrying variants strongly associated with severe, untreatable, late onset genetic disorders, which predict with high certainty the need to make a future claim.[133] These variants constitute only a small proportion of all predictive genetic information,[134] and usually relate to rare diseases.[135] Robust statistical modelling surrounding these diseases has shown the cost of AS is "very small" when genetic non-discrimination policy is in place, approximately 0.1% of premium income if family history information can be disclosed.[136] Even if the worst-case assumptions are adopted, including a small insurance market and prohibitions on disclosure of family history, the figure rises to just 3%.[137] Research also indicates no real risk of AS resulting from non-disclosure of complex disease risk.[138]

Relatedly, many genetic non-discrimination policies do not prevent insurer access to family history information.[139] This mitigates AS because some individuals will have family history of disease sufficient to justify increased premiums, even in the absence of access to genetic test results. For example, even if a person who has tested positive for an *HTT* mutation is not

[129] Jane Tiller and Martin B Delatycki "Genetic discrimination in life insurance: a human rights issue" (2021) 47 J Med Ethics 484; Pugh, above n 102; Hoy and Durnin, above n 119; MacDonald, above n 118; and Angus Macdonald and Pradip Tapadar "Multifactorial Genetic Disorders and Adverse Selection: Epidemiology Meets Economics" (2010) 77 Journal of Risk and Insurance 155.
[130] Tiller and Delatycki, above n 129, at 484; and Pugh, above n 102, at 475.
[131] Hoy and Durnin, above n 119; and MacDonald, above n 118.
[132] See Chapter 1 at [I].
[133] 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: The Journal of the IAA 342 at 345.
[134] Bombard, above n 120, at 24.
[135] MacDonald, above n 118, at 10.
[136] Macdonald and Yu, above n 133, at 361.
[137] Macdonald and Yu, above n 133, at 361.
[138] Macdonald and Tapadar, above n 129.
[139] Swiss Re Institute, above n 20, at 12.

required to disclose that fact to life insurers, disclosure of their recent family history of Huntington's disease will likely lead to a degree of premium loading.

Insurance markets may also be more resilient than predicted. A useful insight can be gained from the Australian health insurance market, which was able to withstand the imposition of legislation requiring health insurance to be mutually underwritten.[140] This intervention removed the ability to underwrite based on any risk factors,[141] creating more severe parameters for AS than simply barring the use of genetic information would.[142] In part, this resilience may derive from the fact that as long as premiums are not pushed so high as to drive low-risk individuals out of the market, the costs of AS can be swallowed by cross subsidy from low-risk individuals.[143] The effects of AS are therefore borne by members of the pool following premium increases, as opposed to the insurer.

It is worth considering the possibility AS may become a bigger issue in the future with scientific developments and more genetic testing.[144] However, given the effects of AS are predicted to be very small,[145] there is likely significant wiggle room before AS comes close to having significant effects on the market. If necessary, genetic non-discrimination policy can also be crafted in ways to mitigate the effects of AS. For example, some jurisdictions have introduced monetary caps, allowing insurance access without disclosure of predictive test results up to a predetermined level of cover.[146] This prevents individuals with susceptibilities capitalising in bad faith on very large amounts of life insurance, while still securing insurance access.

Furthermore, the arguments discrediting claims of AS are even more convincing when situated in the New Zealand context. Here, the life insurance market is likely to be particularly resilient given it is highly profitable, has a low claims ratio, and is not highly condensed compared to other OECD countries.[147] Evidently, concerns relating to AS do not convincingly oppose genetic non-discrimination policy.

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[140] Nguyen and Worthington, above n 122, at 1.
[141] Hoy and Durnin, above n 119, at 1.
[142] Hoy and Durnin, above n 119, at 1.
[143] MacDonald, above n 118, at 9.
[144] Hoy and Durnin, above n 119.
[145] Macdonald and Yu, above n 133.
[146] This includes Australia, the UK, and Switzerland.
[147] Reserve Bank of New Zealand Te Pūtea, above n 33, at 4.

III Conclusion

The industry's reluctance to depart from symmetry of genetic information is premised on either injustice-based, or market-based concerns. Neither appear to carry convincing weight in opposing genetic non-discrimination policy. The injustice argument can be alleviated by reapproaching the concern from the perspective of solidarity, and AS is unlikely to result in market failure.

At best, the industry could perhaps argue there may be small effects on market profitability and a risk AS will increase with time. These arguments may weigh into policy considerations, but certainly do not hold much weight in opposing genetic non-discrimination policy.

CHAPTER THREE

Is Genetic Information Exceptional?

The third category of counterargument suggests genetic non-discrimination policy would be a form of unjustified genetic exceptionalism, the tendency to treat genetic information as though it is intrinsically different from other medical information and requires special treatment.[148] Genetic exceptionalism is a common misconception that has been zealously rejected in the scientific literature.[149]

Life insurers routinely discriminate based on non-genetic medical information, so it could be questioned whether policy only protecting genetic information is justified. For example, people with high blood pressure predictive of cardiovascular disease, non-genetic disorders like cerebral palsy, or infections like HIV may suffer the same fate as those with genetic susceptibilities; increased premiums leading to inability to access insurance. Is this type of discrimination any different?

This chapter will critically analyse whether there are material factors distinguishing genetic information from other medical information. In the absence of such factors, genetic non-discrimination policy risks perpetuating unjustified genetic exceptionalism by drawing an arbitrary, or even unjust distinction between the type of information it protects, and the type it does not. It will begin by analysing genetic information in the abstract, rejecting common factors raised to argue genetic information is intrinsically unique. Then, it will consider the distinction in the life insurance context, revealing that although genetic information is not inherently different, context-specific factors may warrant unique treatment.

I Is Genetic Information Intrinsically Unique?

Genetic information has been referred to as distinct for the following reasons:

[148] Ilhan Ilkilic "Coming to Grips with Genetic Exceptionalism: Roots and Reach of an Explanatory Model" (2009) 1 Medicine Studies 131 at 131.
[149] Mark A Rothstein "Genetic Exceptionalism and Legislative Pragmatism" (2007) 35 The Journal of Law, Medicine & Ethics 59; James P Evans and Wylie Burke "Genetic exceptionalism. Too much of a good thing?" (2008) 10 Genetics in Medicine 500; and William Bains "Genetic exceptionalism" (2010) 28 Nature Biotechnology 212.

A Genetic Information is Predictive

The predictive capacity of genetic information has been cited as unique.[150] Genetic information has the capacity to inform accurate pre-symptomatic predictions of the likelihood of developing genetic disease, a quality best demonstrated by highly penetrant monogenic diseases.[151] For example, a genetic test revealing an *HTT* mutation in a healthy individual indicates Huntington's disease will almost certainly be developed.

For complex genetic disorders and those which display incomplete penetrance,[152] the predictive power of genetic information is less striking, but still informative. For example, women with a mutation in the *BRCA1* gene have a 57-65% risk of developing complex disease breast cancer by the age of 70.[153] Similarly, PRS can establish genetic risk, as opposed to absolute risk, of complex disease. It could be argued that medical information predicting illness that has not yet manifested, and in some cases may never manifest, is different in nature than information relating to manifest symptoms.

However, pre-symptomatic prediction is not limited to genetic information. For example, DEXA bone scans are a form of non-genetic medical imaging which can determine future risk of certain fractures.[154] Similarly, a quantifiable prediction can be provided by the 5-year cardiovascular risk assessment, a non-genetic test applied in New Zealand general practice.[155] Based on clinical risk indicators, the assessment predicts the percentage chance of an individual developing cardiovascular disease in the next five years.[156] This is not dissimilar to the

[150] Deborah Hellman "What Makes Genetic Discrimination Exceptional?" (2003) 29 American Journal of Law & Medicine 77 at 81.
[151] Penetrance refers to the chance that disease will manifest in the presence of a certain genotype.
[152] Incomplete penetrance is when a genotype does not always manifest into clinical symptoms of disease.
[153] Lu Yao and others "Breast cancer risk in Chinese women with BRCA1 or BRCA2 mutations" (2016) 156 Breast Cancer Research and Treatment 441 at 441.
[154] Jennifer Flynn, Stella Foley and Graeme Jones "Can BMD Assessed by DXA at Age 8 Predict Fracture Risk in Boys and Girls During Puberty?: An Eight-Year Prospective Study" (2009) 22 Journal of Bone and Mineral Research 1463; and G Isanne Schacter and William D Leslie "DXA-Based Measurements in Diabetes: Can They Predict Fracture Risk?" (2017) 100 Calcified Tissue International 150 at 150.
[155] Ministry of Health *Cardiovascular Disease Risk Assessment and Management for Primary Care* (February 2018) at iii.
[156] Ministry of Health, above n 155, at iii.
Heart Foundation, Stroke Foundation of New Zealand Inc, Ministry of Health and New Zealand *Guidelines Group The Assessment and Management of Cardiovascular Risk* (December 2003).

probabilities of disease onset predictive genetic tests may reveal. Furthermore, even routine medical information like high blood pressure is predictive of cardiovascular disease.[157]

Evidently, general medical information can be predictive, even quantifiably so. Conversely, not all genetic information is predictive given much of the genome is yet to be characterised or is thought to be non-functional.[158] Of course, on a sliding scale, the predictive capacity of certain genetic information, like mutations in the *HTT* gene, exceeds that of other predictive medical tests. Nonetheless, the comparison shows predictive capacity cannot unequivocally distinguish genetic information. In particular, it is questionable whether genetic susceptibilities to complex diseases, where genetic factors are one of many risk factors at play, are qualitatively distinct from other medical risk factors, simply because they derive from a genetic test.[159]

B Genetic Information is Hereditary

Another feature of genetic information that has been identified as distinctive is its hereditary nature. Genetic disease runs in families, and often cannot be distilled to only affecting one individual.

However, heritability in the congenital sense is not limited to genetic disorders. A multitude of viral or bacterial infections including congenital HIV,[160] syphilis,[161] hepatitis b,[162] and cytomegalovirus,[163] are transmitted mother-to-child, and left untreated can cause severe health problems. In fact, congenital transmission of infections is relatively common, and cytomegalovirus has a 0.6-0.7% incidence in live births in developed countries.[164] Therefore, heritability cannot alone distinguish genetic information.

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[157] Flávio D Fuchs and Paul K Whelton "High Blood Pressure and Cardiovascular Disease" (2020) 75 Hypertension 285.
[158] See generally Michael Y Galperin and Eugene V Koonin "From complete genome sequence to "complete" understanding?" (2010) 28 Trends Biotechnology 398.
[159] Evans and Burke, above n 149, at 500.
[160] Bonnie R Joubert and others "A whole genome association study of mother-to-child transmission of HIV in Malawi" (2010) 2 Genome Medicine 1.
[161] Serena Braccio, Mike Sharland and Shamez N Ladhani "Prevention and treatment of mother-to-child transmission of syphilis" (2016) 29 Current Opinion in Infectious Diseases 268.
[162] Sylvie Ranger-Rogez and Fran¸ois Denis "Hepatitis B mother-to-child transmission" (2004) 2 Expert Review of Anti-Infective Therapy 133.
[163] Regine Barlinn and others "Maternal and congenital cytomegalovirus infections in a population-based pregnancy cohort study" (2018) 126 Apmis 899.
[164] Concetta Marsico and David W Kimberlin "Congenital Cytomegalovirus infection: advances and challenges in diagnosis, prevention and treatment" (2017) 43 Italian Journal of Pediatrics 1 at 2.

C Genes are Beyond Our Control

The immutability of genetic information has also been invoked as a distinctive factor that justifies treating genetic information differently.[165] The argument that follows is that no-one should be discriminated against based on genetics, a factor beyond their control.[166]

The premise of the argument, that genetics is unchangeable, is sound. Individuals cannot change their genome sequence, or that they have been born with genetic variants associated with disease. However, the argument is arguably unpersuasive because although the genetic sequence itself cannot be changed, in many cases the manifestation of the disease associated with the variant can be changed by altered lifestyle or medical intervention.

Furthermore, even if you accept it is relevant that the genome sequence cannot be changed, it is not clear that unchangeability is a criterion relevant to whether discrimination is unjust. Despite the moral appeal of the philosophy individuals should only be judged for things they can control, it is antithetical to the way society is structured. Individuals are routinely discriminated against or advantaged based on factors beyond their control. A professional basketball player for example, is rewarded not just for her commitment and experience, but also her height, a factor largely beyond her control.[167] Similarly, a person born blind cannot change their visual impairment, but will not be hired as a bus driver. A person born with cerebral palsy cannot change that fact either, but may struggle to access life insurance.

The HRA prohibited grounds of discrimination confirm mutability is not a criterion determining whether forms of discrimination are unlawful in New Zealand.[168] While some of the prohibited grounds of discrimination like race and age are highly immutable, many others are not, including political opinion, employment status, ethical belief, and religious belief.[169] It is therefore not clear that immutability is a material distinguishing feature of genetic information.

[165] Evans and Burke, above n 149, at 500; and Hellman, above n 150, at 87.
[166] Hellman, above n 150, at 87.
[167] Hellman, above n 150, at 87.
[168] Human Rights Act 1993.
[169] Human Rights Act, s 21.

D Genetic Information is Particularly Private

This fourth feature proposed as distinguishing genetic information relates more to socio-cultural perceptions of genetic information than its inherent features. At least in Western society, there is a seemingly widely held belief that genetic information is unique and more private, because it is perceived to be the fundamental instructions for dictating human traits.[170] For example, genetic information has been described as "unique, personal and private" and "much more than a standard medical test".[171] These attitudes give rise to concerns about the use of genetic information by third parties like insurers.

Public attitudes are an important factor in formulating policy. However, perceptions of genetic information may be a problematic basis for policy if informed by the misunderstandings of genetic determinism.[172] Science now recognises the role of non-genetic factors in determining human traits, and metaphors describing the genome as the "holy grail" or "blueprint for life" which were once perpetuated by the scientific community are now perceived as overstatements.[173] Instead our current understanding recognises the importance of environmental factors and other cellular mechanisms, meaning the genome is more accurately described as:[174]

> … at best an overlapping and potentially scrambled list of ingredients … used differently by different cells to make different ingredients at different times, resulting in cells with different phenotypes that host the same genome.

Nonetheless, public attitudes may legitimately inform policy surrounding the use of genetic information by insurers, but this will need to be balanced with the need to avoid reinforcing inaccurate views of genetic determinism and associated stigma which could prevent the

[170] Joseph S Alper and Jon Beckwith "Distinguishing Genetic from Nongenetic Medical Tests: Some Implications for Antidiscrimination Legislation" (1998) 4 Science and Engineering Ethics 141 at 143; Douglas H Ginsburg "Genetics and privacy" (1999) 4 Texas Review of Law & Politics 17; Pamela Sankar "Genetic Privacy" (2003) 54 Annual Review of Medicine 393; and Ellen W Clayton "A systematic literature review of individuals' perspectives on privacy and genetic information in the United States" (2018) 13 PLoS One 1.
[171] Canadian Coalition for Genetic Fairness "Proposal to Protect Canadians from Genetic Discrimination" <http://ccgf-cceg.ca/wp-content/uploads/2015/07/CCGF-Genetics-Proposal.pdf>.
[172] See Chapter 1 at [I].
[173] Alper and Beckwith, above n 170, at 143.
[174] Antony M Jose "Heritable Epigenetic Changes Alter Transgenerational Waveforms Maintained by Cycling Stores of Information" (2020) 42 BioEssays 1 at 7.

progression of clinical genetics.[175] After all, it is perhaps cyclical to treat genetic information as unique on the basis of inaccurate genetic exceptionalist views, when doing so would reinforce those views.

Furthermore, arguably when scrutinised, genetic information is not always seen as more private than other health information, which is also highly identifying and personal.[176] For example, Evans and Burke speculate that "most people would feel more comfortable sharing their *CYP2C9* alleles with a third party than … previous hospitalizations, or history of testing for sexually transmitted diseases."[177]

There is, however, an additional significance to the public perception of genetics in New Zealand to be recognised. Within te ao Māori, DNA and genetic data are taonga linked to whakapapa and are tapu.[178] This may influence specialised policy surrounding the handling of genetic information by third parties.

II Genomic Contextualism, a Non-Binary Approach

Evidently, most features proposed as unique to genetic information overlap significantly with other medical information. It follows that special policy preventing disclosure of genetic information to life insurers would arguably represent unwarranted genetic exceptionalism.

However, there may be flaws in this binary approach which assumes genetic information is *either* the same as other medical information *or* unique. Genetic information is not inherently or entirely unique as genetic exceptionalist views suggest, but it can still give rise to unique consequences in certain contexts.

In recent years the literature has strongly condemned genetic exceptionalism and determinism with good reason.[179] However, perhaps the tendency to label any special consideration of

[175] National Academy of Sciences "Can We - and Should We - Ensure Genetic Privacy?" in *Privacy Issues in Biomedical and Clinical Research* (National Academy Press, Washington DC, 1998) at 9.
[176] Evans and Burke, above n 149, at 500.
[177] Evans and Burke, above n 149, at 500.
[178] Angela Beaton and others "Engaging Māori in biobanking and genomic research: a model for biobanks to guide culturally informed governance, operational, and community engagement activities" (2017) 19 Genetics in Medicine 345 at 346.
[179] Evans and Burke, above n 149; Rothstein, above n 149; Bains, above n 149; and Ilkilic, above n 148.

genetic information as genetic exceptionalism is not conducive to important policy debate, quelling it before it can be engaged. In 2019 a group of authors recognised this, advocating a shift from the rhetoric of exceptionalism towards "genomic contextualism".[180] This approach recognises the "fundamental duality" that "genomic tests both share characteristics with other types of medical tests and represent a combination of features that make them distinct" in certain contexts, and these features are often relevant to forming policy.[181]

Therefore, notwithstanding that genetic information is not intrinsically exceptional, in the insurance context some features of genetic information may justify differential treatment. For example, genetic information is not the only heritable medical information, but infections like cytomegalovirus are far less likely to lead to pre-symptomatic life insurance discrimination.

Similarly, the hereditary nature of genetics gives rise to much more complex ethical issues surrounding consent and disclosure that are relevant to insurance, and inapplicable to congenital transmission of viruses. Specifically, genetic information pertaining to one individual can sometimes be used to infer the genetic status of other family members. For example, in a family with a history of Huntington's disease, a genetic test finding a mutation in the *HTT* gene also reveals that a parent of the tested individual, who may not have wanted to know their status, very likely has the mutation too.[182] Therefore, disclosure of genetic information to a life insurer may lead to discrimination against whole families, or other family members, even those who are healthy or unaware of their susceptibility.[183]

The most convincing distinguishing features of genetic information in the insurance context are the factors proposed in favour of genetic non-discrimination policy in the next chapter.[184] While these factors are posed as consequentialist utilitarian arguments supporting genetic non-discrimination policy to increase overall wellbeing, they can simultaneously be viewed as factors that justify distinguishing genetic information in the specific context of insurance.

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[180] Nanibaa' A Garrison and others "Genomic Contextualism: Shifting the Rhetoric of Genetic Exceptionalism" (2019) 19 The American Journal of Bioethics 51.
[181] Garrison and others, above n 180, at 52.
[182] See generally James F Gusella and others "Molecular Genetics of Huntington's Disease" (1993) 50 Archives of Neurology 1157.
[183] Tarr, above n 126, at 200; and Andru Isac "Genetic Testing and Insurance: The Role of the Industry and the Welfare State" in Duncan Webb and David Rowe (eds) *Insurance Law: Practice, Policy and Principles* (The Centre for Commercial & Corporate Law Inc, Christchurch, 2004) at 5.
[184] The eugenics argument, the disincentive argument, the irrational discrimination argument, and the contribution to health inequity argument.

The genomic contextualism approach therefore establishes that the distinction between genetic and other information may be meaningful in the insurance context, and not simply a deferral to exceptionalism. However, it cannot justify overly broad genetic non-discrimination policy that mystifies genetic information as intrinsically different and always needing protection. Instead, genomic contextualism supports policy tailored to address specific concerns applicable only to genetic information in particular contexts.

CHAPTER FOUR

Justifying Policy Change: A Consequentialist Utilitarian Approach

The analysis so far has assessed opposing arguments, determining that AS; actuarial fairness; and the avoiding genetic exceptionalism argument, as long as any approach taken is consistent with genomic contextualism; are all unpersuasive grounds to oppose genetic non-discrimination policy. Notwithstanding this, the introduction of genetic non-discrimination policy must be substantively justified because discrimination is not *per se* unjust,[185] and the use of genetic information is not *per se* bad.[186]

Several approaches to this task are possible. For example, some approaches advocate for genetic non-discrimination policy on human rights grounds.[187] Alternatively, justice-based approaches can be taken.[188] This chapter instead adopts a consequentialist utilitarian approach. It will assess the outcomes of the current policy in terms of overall utility, defined in terms of wellbeing.[189] Under a consequentialist utilitarianism approach, the policy which should be adopted is the one which "… maximise[s] wellbeing for the greatest number".[190]

Arguably this approach is most convincing because utilitarianism does not judge morality based on motive or intrinsic features.[191] It is therefore an approach which strips any preconceptions or stigma surrounding genetics, instead extracting tangible harms that flow from the current approach.

Importantly, the current symmetry of information approach leads to four adverse outcomes that reduce overall wellbeing. This chapter will analyse these consequences, before arguing genetic non-discrimination policy is necessary to remediate them, increasing overall wellbeing.

[185] Discrimination is common and not always wrongful. For example, selecting the most qualified applicant to for a job.
[186] See Chapter 3.
[187] See Tiller and Delatycki, above n 129.
[188] See Pugh, above n 102.
[189] Jeremy Bentham Utilitarianism (Progressive Publishing Company, London, 1890) at 7-8; and Pugh, above n 102, at 476.
[190] Pugh, above n 102, at 476.
[191] Samuel Brittan *Capitalism with a Human Face* (Cambridge, Harvard University Press, 1995) at 68.

I The Current Approach Disincentivises Healthcare and Innovation

Perhaps the most concerning consequence that flows from the current symmetry of information approach is that it disincentivises genetic testing. This has bifurcating outcomes, affecting both healthcare and research discoveries.

A The Current Approach has Negative Healthcare Outcomes

There is mounting empirical evidence that genetic discrimination, including by life insurers, drives a reluctance to undertake clinical genetic testing.[192] Clear negative outcomes result from this, as failure to test may lead to missed opportunities for healthcare or lifestyle intervention to prevent death or mitigate illness. For example, a person with susceptibility to cardiovascular disease may eat more healthily and become more active, a person found to have a *BRCA1* mutation may have a prophylactic mastectomy, and a person aware of increased risk of colorectal cancer may undertake frequent colonoscopies to detect precancerous lesions.

Furthermore, emerging approaches like personalised medicine may be rejected by patients for fear of secondary findings of genetic susceptibilities leading to inability to access insurance.[193] Given such approaches optimise medical treatment for individuals, policy that reduces uptake detracts from collective welfare and wellbeing.

The familial nature of genetic information also bolsters the disincentive from testing. A finding of genetic susceptibility not only puts oneself at risk of genetic discrimination, but also whānau and future generations. Interpersonal and intergenerational concerns may therefore feed into the decision of whether to test.[194]

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[192] Louise A Keogh and others "Choosing not to undergo predictive genetic testing for hereditary colorectal cancer syndromes: expanding our understanding of decliners and declining" (2017) 40 Journal of Behavioural Medicine 583; Louise A Keogh and others "Is uptake of genetic testing for colorectal cancer influenced by knowledge of insurance implications?" (2009) 191 Medical Journal of Australia 255; Béatrice Godard and others "Factors Associated with an Individual's Decision to Withdraw from Genetic Testing for Breast And Ovarian Cancer Susceptibility: Implications for Counseling" (2007) 11 Genetic Testing 45; and Katrina J Lowstuter and others "Influence of genetic discrimination perceptions and knowledge on cancer genetics referral practice among clinicians" (2008) 10 Genetics in Medicine 691.

[193] Secondary findings are medically relevant findings that are not the target of a genetic test but are happened upon. See Marlies Saelaert and others "Incidental or secondary findings: an integrative and patient- inclusive approach to the current debate" (2018) 26 European Journal of Human Genetics 1424 at 1424.

[194] Tarr, above n 126, at 200.

Although no local studies have identified that New Zealanders are dissuaded from genetic testing for fear of insurance discrimination, the evidence is highly replicated across numerous jurisdictions and likely represents the New Zealand position.[195] During my research, various clinicians and researchers expressed to me that their patients or participants often convey concerns relating to life insurance implications during the consent process.[196] It would be useful to formally gather his kind of evidence from clinicians, researchers, and affected families to support changes in New Zealand.

I am lucky to have had the opportunity to discuss this issue with a woman named Mary,[197] who explained how real the concern can be for New Zealand families. Mary's family carries a heritable blood disorder displaying autosomal dominant expression with variable age of onset.[198] It has caused the death of three members of her extended family, and she has tested positive for the variant but not yet developed the disorder.

Three of Mary's four children expressed a desire to be tested for the variant, but Mary persuaded them against it purely because of concerns relating to accessing life insurance later in life. She strongly believes that reluctance to test is "…purely for life insurance, because as soon as you have families you actually do have to have that safeguard because of financial support and mortgages."[199]

Evidently, negative healthcare outcomes result from the disincentive generated by the current policy, which reduce overall wellbeing. It is difficult to reconcile the current economic centred policy with the consequence of unnecessary illness or loss of life.

Furthermore, even if economic consequences are relevant, it is significant that early intervention enabled by predictive testing can reduce healthcare costs on the state,[200] and may

[195] Keogh and others "Choosing not to undergo predictive genetic testing for hereditary colorectal cancer syndromes", above n 192; Keogh and others "Is uptake of genetic testing for colorectal cancer influenced by knowledge of insurance implications?", above n 192; Godard and others, above n 192; and Lowstuter and others, above n 192.
[196] Personal Communications.
[197] 'Mary' is a pseudonym to protect anonymity.
[198] This means only one copy of the variant needs to be inherited in order to develop disease, but disease onset occurs at different stages of life for different people.
[199] Personal communications with Mary (12 August 2021).
[200] Alexander Nill, Gene Laczniak and Paul Thistle "The Use of Genetic Testing Information in the Insurance Industry: An Ethical and Societal Analysis of Public Policy Options" (2019) 156 Journal of Business Ethics 105 at 112.

reduce the chance of life insurance claims when individuals become aware of risk and take steps to address it.

B Policy Change Would Facilitate Freedom of Choice Whether to Test

It could be argued that because some predictive genetic tests reveal non-actionable information, dissuasion from testing does not always lead to adverse medical outcomes. For example, even when a mutation in the *HTT* gene is detected pre-symptomatically, there is no way to prevent the onset of Huntington's disease. However, it is reasonable to argue that even if only a proportion of those who are disincentivised from testing die or become ill unnecessarily, the overall wellbeing of society is reduced, and the current approach is unacceptable.

Even if this proposition is rejected, there remains a plausible argument that policy dissuading genetic testing reduces overall wellbeing, even when testing cannot change health outcomes. For example, policy that obstructs willingness to test may limit the ability to make informed reproductive choices,[201] which can be important for families carrying heritable disorders, particularly non-actionable ones.

More generally, research has associated both negative and positive psychosocial outcomes with the decision to test; including stress, depression, and anxiety; or reassurance, relief, satisfaction of curiosity, and improved family support.[202] A major reason Mary wanted to know for the purpose of "living … life to the fullest".[203] The decision of whether to undertake a predictive genetic test, particularly when genetic disease runs in the family, is a complex and highly personal one, involving weighing the risks and benefits of testing. Evidently, the current policy may reduce wellbeing for those who want to test to achieve positive psychosocial outcomes, but are dissuaded by fears of losing insurance access.

[201] Marleen Decruyenaere and others "The complexity of reproductive decision-making in asymptomatic carriers of the Huntington mutation" (2007) 15 European Journal of Human Genetics 453 at 453; and Federica Cariati, Valeria D'Argenio and Rossella Tomaiuolo "The evolving role of genetic tests in reproductive medicine" (2019) 17 Journal of Translational Medicine 1.
[202] Christopher H Wade "What Is the Psychosocial Impact of Providing Genetic and Genomic Health Information to Individuals? An Overview of Systematic Reviews" (2019) 49 Hastings Center Report S88 at S88.
[203] Personal communications with Mary (12 August 2021).

C The Current Approach Disincentivises Research Participation

Through tools like PRS and personalised medicine, genetics and genomics have the capacity to revolutionise clinical medicine.[204] However, these innovations are contingent on sufficient voluntary participation in research. During genetic research, incidental findings of medically relevant genetic susceptibilities may be reported to participants.[205] Concerningly, the fear of such findings resulting in life insurance discrimination is discouraging individuals from research participation.[206]

The disincentive from participation is particularly concerning in the genomics research space, where robust studies often require a very large number of participants. For example, genome wide association studies (GWAS) are the central research strategy for identifying SNPs statistically associated with complex genetic disease. Genetic contribution to complex genetic disease often comes from many SNPs with small effect size,[207] which can be lost in the statistical noise without sufficient power from a large sample size. To be effective, GWAS require thousands if not hundreds of thousands of genomes.[208]

Therefore, an adverse consequence of the current approach may be the loss of potential research discoveries rendering better medical testing, treatments, and precision medicine, which would have contributed to overall societal wellbeing. Not only is this an adverse consequence, but it is also arguably ethically problematic to ask people to volunteer for research for the greater social good when an increased risk of discrimination is attached to participation.[209]

1 An additional concern for family studies

[204] See Sophie Visvikis-Siest, Vesna Gorenjak and Maria G Stathopoulou "Personalised Medicine: The Odyssey from Hope to Practice" (2018) 8 Journal of personalized medicine 31.
[205] See Sarah S Kalia and others "Recommendations for reporting of secondary findings in clinical exome and genome sequencing, 2016 update (ACMG SF v2.0): a policy statement of the American College of Medical Genetics and Genomics" (2016) 19 Genetics in Medicine 249.
[206] Robert C Green, Denise Lautenbach and Amy L McGuire "GINA, Genetic Discrimination, and Genomic Medicine" (2015) 372 The New England Journal of Medicine 397.
[207] Meiyue Wang and Shizhong Xu "Statistical power in genome-wide association studies and quantitative trait locus mapping" (2019) 123 Heredity 287.
[208] Krina T Zondervan and Lon R Cardon "Designing candidate gene and genome-wide case-control association studies" (2007) 2 Nature Protocols 2492.
[209] Jean-Christophe Bélisle-Pipon and others "Genetic testing, insurance discrimination and medical research: what the United States can learn from peer countries" (2019) 25 Nature Medicine 1198 at 1198.

A related concern seemingly overlooked in the literature is that the current approach may also disincentivise research which attempts to characterise unknown genetic disorders effecting individual families.

Researchers are often willing to attempt to identify the underlying genetic cause of disease in families affected by hereditary disorders. Characterising the causal variant can provide both answers and the possibility of predictive genetic testing for family members. It may even reveal possible drug targets. However, this type of research is a double-edged sword because when published, those studies can form the actuarial data on which insurers may lawfully discriminate against family members under the HRA s 48 exception. This was an issue brought to my attention by Mary, who for this reason was extremely reluctant to participate when her family was approached by researchers.[210]

Mary had disclosed the unusually high number of family members who had died from a blood disorder when she applied for life insurance in the past.[211] At that time it was not material to the insurer because there was no evidence in the literature suggesting the disorder was genetic. Mary therefore describes the decision to participate in the study as a "Pandora's box".[212] Once the genetic basis for the disease is published in a medical journal, even anonymously, life insurers will have the actuarial grounds to discriminate against her family.

This is another consequence of the current policy which results in tangible harms, this time for individual families.

II The Current Approach Contributes to Health Inequities for Māori and Pasifika

In the New Zealand context, the symmetry of information approach may lead to a further adverse consequence, obstructing research necessary to address health inequities associated with the emergence of genomic medicine.

[210] Personal communications with Mary (12 August 2021).
[211] Personal communications with Mary (12 August 2021).
[212] Personal communications with Mary (12 August 2021).

Māori and Pasifika populations face deeply entrenched health inequities, experiencing the highest disease burden in New Zealand.[213] Alarmingly, in the absence of robust research, the development of genomic medicine is set to compound these inequities.[214]

Western hegemony in science has meant genetic and genomic research is usually centred on the Western European genome, illustrated by a 2009 finding that 96% of participants of GWAS studies were European.[215] By 2016 this figure had reduced to around 80%, but the increase in diversity came mainly from studies relating to populations of Asian descent, with a lack of significant increase in representation of other ancestral groups.[216]

Disease associated variants identified from samples of European descent often do not replicate well in other ancestral groups, meaning a discrepancy has arisen between the level of genomic knowledge benefiting populations of European descent, and other ancestral groups including Māori and Pasifika.[217] This discrepancy will translate into healthcare outcomes if embedded in emerging tools like PRS and precision medicine. If based on this Eurocentric data, these tools will be less effective and potentially harmful for patients of other ethnicities.

Recently, the science community has recognised this issue,[218] calling for a culture shift in genetic research including a focus on studying underrepresented populations.[219] New Zealand researchers have recognised that gathering Māori and Pasifika genomic information is essential to ensure genomic medicine reduces rather than reinforces extant health disparities in Aotearoa New Zealand.[220] The Rakeiora project has been developed in response to this need, co-led by

[213] Heather Came and others "Māori and Pasifika leaders' experiences of government health advisory groups in New Zealand" (2019) 14 Kōtuitui: New Zealand Journal of Social Sciences Online 126 at 126; and Lisa Marriott and Dalice Sim "Indicators of inequality for Maori and Pacific people" (2015) Journal of New Zealand Studies 24.
[214] Stephen P Robertson and others "Genomic medicine must reduce, not compound, health inequities: the case for hauora-enhancing genomic resources for New Zealand" (2018) 131 The New Zealand Medical Journal 81.
[215] Anna C Need and David B Goldstsein "Next generation disparities in human genomics: concerns and remedies" (2009) 25 Trends in Genetics 489.
[216] Alice B Popejoy and Stephanie M Fullerton "Genomics is failing on diversity" (2016) 538 Nature 161.
[217] Popejoy and Fullerton, above n 216, at 163.
[218] Giorgio Sirugo, Scott M Williams and Sarah A Tishkoff "The Missing Diversity in Human Genetic Studies" (2019) 177 Cell 26; Amy R Bentley, Shawneequa Callier and Charles N Rotimi "Diversity and inclusion in genomic research: why the uneven progress?" (2017) 8 Journal of Community Genetics 255; and Popejoy and Fullerton, above n 216.
[219] Popejoy and Fullerton, above n 216, at 164.
[220] Robertson and others, above n 214, at 84.

Māori and funded by MBIE.[221] It aims to acquire and store hundreds of Māori and Pasifika genome sequences made accessible for research.[222]

The evolving research focus on Māori and Pasifika genomes is an urgent and imperative step towards equity as genomic medicine emerges. However, its intentions may be stunted by the current life insurance genetic testing policy in two ways:

(1) Māori and Pasifika may be disincentivised from participating in genomic research for fear of insurance discrimination, leading to collective disadvantage in healthcare; or

(2) The research focus on Māori and Pasifika genomes may lead to secondary findings of predictive genetic information among participants, leading to insurance discrimination disproportionately affecting Māori and Pasifika individuals.

The former will lead to adverse outcomes in healthcare, and the latter in insurance access.

Māori are perhaps particularly vulnerable to these concerns. Distrust of researchers is common amongst indigenous peoples, arising from a troubling history of research that has belittled, and failed to benefit indigenous groups.[223] Apprehension surrounding research can exist amongst Māori, particularly where methodologies do not resonate with te ao Māori.[224] Eliminating adverse outcomes will be important to ensure research is truly beneficial, and does not repeat past abuses or lead to discrimination that may re-entrench distrust.

[221] Sara K Filoche and Jon Cornwall "DNA information: access, use and implications for healthcare in Aotearoa New Zealand" (2021) 134 The New Zealand Medical Journal 107 at 108; and Jamie Morton "$5m project to begin building NZ's first 'gene bank'" *The NZ Herald* (online ed, New Zealand, 2 December 2019).
[222] Filoche and Cornwall, above n 221, at 108; and Morton, above n 221.
[223] Shane Edwards, Verne McManus and Tim McCreanor "Collaborative Research with Māori on Sensitive Issues: The Application of Tikanga and Kaupapa in Research on Māori Sudden Infant Death Syndrome" (2005) 25 Social Policy Journal of New Zealand 88 at 89; see also Carla Wilson "Decolonizing Methodologies: Research and Indigenous Peoples" (2001) Social Policy Journal of New Zealand 214.
[224] Helen Moewaka Barnes "Arguing for the spirit in the language of the mind: a Māori practitioner's view of research and science" (Doctor of Philosophy, Massy University, 2008); and Jacquie Kidd and others "Hā Ora: Reflecting on a Kaupapa Māori Community-Engaged Co-design Approach to Lung Cancer Research" (2021) 16 International Journal of Indigenous Health 192 at 194.

A Crown Treaty Obligations

As a partner to Te Tiriti o Waitangi,[225] the Crown may even be obliged to intervene to prevent disparities in genomic medicine disadvantaging Māori hauora. Health inequities between Māori and non-Māori New Zealanders are influenced by a range of factors including the effects of colonisation,[226] and the Crown has obligations under Te Tiriti to attain health equity for Māori.[227] The nature of those obligations was clarified by the Waitangi Tribunal in stage one of the Wai 2575 inquiry, which discussed systemic problems in the health system which disadvantage Māori in breach of Crown Treaty obligations.[228]

Importantly, the Tribunal criticised the distillment of Treaty principles to partnership, participation, and protection (the three Ps), in the Treaty section of the New Zealand Public Health and Disability Act 2000.[229] The three Ps, which had dominated health discourse, were outdated and reductionist.[230] The Tribunal instead endorsed the following Treaty principles to outline the Crown's duty to achieve Māori health equity: guarantee of tino rangatiratanga, the principle of equity, the principle of active protection, the principle of options, and the principle of partnership.[231] In doing so the Tribunal affirmed the breadth and strength of the Crown's obligations relating to health equity, which may be extrapolated to the impending disparity in genomic medicine.

The Crown is arguably under a Treaty obligation to investigate and safeguard from the possibility that the current approach may discourage research participation, contributing to Māori health inequities. In particular, the related principles of equity and active protection may compel the Crown to act.

The principle of equity stems from Article 3 of Te Tiriti, which guarantees Māori the rights and privileges of British subjects.[232] It places an active duty on the Crown to positively promote

[225] Te Tiriti o Waitangi 1840.
[226] Waitangi Tribunal *Hauora: Report on Stage One of the Health Services and Outcomes Kaupapa Inquiry* (Wai 2575, 2019) at [2.3].
[227] Waitangi Tribunal, above n 226, at [2.3].
[228] Waitangi Tribunal, above n 226.
[229] Waitangi Tribunal, above n 226, at [5.6].
[230] Waitangi Tribunal, above n 226, at [5.6].
[231] Waitangi Tribunal, above n 226, at [9.3.1].
[232] Waitangi Tribunal, above n 226, at [3.4].

equity,[233] and is a broad guarantee of freedom from both unconscious and conscious discrimination, including in health outcomes.[234] The principle of active protection reinforces this, requiring the Government to take steps to ensure Māori have at least the equivalent level of health as non-Māori.[235]

Crown intervention to prevent genetic discrimination in life insurance would be a small step towards achieving health equity. Nonetheless, it is an important one, and is arguably required of the Crown in good faith as a Treaty partner, particularly in light of previous breaches in the health context.

Therefore, the adverse consequences relating to Māori genomic research not only support the introduction of genetic non-discrimination policy under a consequentialist utilitarian approach, but may even represent a breach of Crown Treaty obligations.

III The Non-interventionist Approach may be Reminiscent of Eugenics

Another concern is that the current approach may result in a future eerily reminiscent of eugenics, by facilitating subtle or insidious eugenic-like threats.[236] This arises out of the troubling history of eugenics in Western society, which "casts a long shadow" over contemporary attitudes towards genetic information.[237] During the early 1900s the eugenics movement took hold in New Zealand with reprehensible consequences including a number of eugenic sterilisations.[238]

Clearly, allowing insurers to discriminate against consumers based on their genetics is not equivalent to the state-based restrictions on reproductive autonomy that eugenics entailed. However, it has been argued that policies allowing genetic discrimination, like the current New

[233] Waitangi Tribunal *The Napier Hospital and Health Services Report* (Wai 692, 2001) at 62; Waitangi Tribunal *Report on the Crown's Foreshore and Seabed Policy* (Wai 1071, 2004) at 133; and Waitangi Tribunal The Te Arawa Mandate Report (Wai 1150, 2005) at 94.
[234] Waitangi Tribunal, above n 226, at [3.4].
[235] Ministry of Health Manatū Hauora *The Guide to He Korowai Oranga Māori Health Strategy* (June 2014) at 12.
[236] Bombard, above n 120, at 16.
[237] Aviam Soifer and Miriam Wugmeister "Mapping and Matching DNA: Several Legal Complications of Accurate Classifications" (1995) 22 Hastings Constitutional Law Quarterly 1 at 25.
[238] Hamish G Spencer "Eugenic Sterilization in New Zealand: The Story of the Mental Defectives Amendment Act of 1928" in Diane B Paul, John Stenhouse and Hamish G Spencer (eds) *Eugenics at the Edges of Empire: New Zealand, Australia, Canada and South Africa* (eBook ed, Palgrave Macmillan, 2018) at 86.

Zealand approach, may lead to the adverse outcome of certain individuals being prevented from participating in key aspects of social life, becoming uninsurable, and perhaps even unemployable or unable to adopt children, all based on genetic susceptibilities which may not even manifest.[239] This would establish a "genetic underclass" disadvantaged from conception based on their genetics.[240]

This argument holds some weight in supporting genetic non-discrimination policy. A future where a category of people born with innate, unchangeable genetic differences are oppressed and prevented from participating in important facets of society would reduce collective wellbeing. However, it is the weakest of the four consequentialist utilitarian arguments because it is a prospective argument and is somewhat speculative, relying on a prediction of future outcomes.

IV The Current Approach Leads to Irrational Discrimination

'Irrational' discrimination occurs in insurance underwriting when risk is assessed based on faulty, incomplete, or misunderstood data, including when genetic risk information is misinterpreted.[241] This is opposed to evidence based 'rational' discrimination, covered by the insurance exception in the HRA.[242] Irrational discrimination can lead to unjustified premium increases or exclusions from cover. It often occurs when insurers take an absolutist approach, ignoring the possibility of medical intervention, monitoring, or lifestyle changes in mitigating certain genetic risks.

Most irrational discrimination in insurance is unlawful because the HRA exception only allows discrimination based on actuarial data or reputable advice on which it is reasonable to rely.[243] However, in practice the protection provided by the HRA is limited because of a lack of monitoring for compliance. Consumers must first recognise irrational discrimination has

[239] Ine Van Hoyweghen, Klasien Horstman and Rita Schepers "Genetic 'Risk Carriers' and Lifestyle 'Risk Takers'. Which Risks Deserve our Legal Protection in Insurance?" (2007) 15 Health Care Analysis 179 at 180; see also Hellman, above n 150, at 100.
[240] Elizabeth Adjin-Tettey "Potential for Genetic Discrimination in Access to Insurance: Is There a Dark Side to Increased Availability of Genetic Information." 50 Alberta Law Review 577; and Hoyweghen, Horstman and Schepers, above n 239, at 180.
[241] Bombard, above n 120, at 27.
[242] Section 48.
[243] Section 48(1).

occurred, and then bring a complaint to the HRC in order to achieve redress. Furthermore, the phrase "reputable medical or actuarial advice or opinion" is relatively loose and leaves some scope for lawful irrational discrimination where a reasonable supporting opinion can be found, perhaps even if there is conflicting data relating to a genetic variant.[244]

In theory irrational discrimination could relate to any health information, so one might question whether it is an adverse outcome flowing from underwriting generally, rather than simply the genetic testing policy. However, predictive genetic information is more susceptible to irrational discrimination because of the complexity of the genome, the role of non-genetic factors, and the tendency to assign excessive probative value to genetics.[245] The insurance industry has also underwritten based on general medical information since its inception, but predictive genetic test results are a complex and newer phenomenon which insurers are less experienced in dealing with. As a result, policy conditions surrounding genetic information may be unfair, inconsistent, and lacking transparent reasoning.

These concerns are not merely speculative, and evidence has been gathered of irrational genetic discrimination taking place in life insurance.[246] One published example involves a healthy Australian man who tested positive for a mutation associated with Lynch Syndrome.[247] He was subjected to irrational discrimination after disclosing this susceptibility when applying for life insurance with two companies.[248] Both insurers were only willing to offer cover that excluded cancer, despite evidence yearly colonoscopies reduced his colorectal cancer risk to population level.[249] Even after collating and presenting this risk data to one insurer he was still denied cancer cover. It took enduring efforts including filing a complaint with the Australian Human Rights Commission to obtain cancer cover.[250]

[244] Human Rights Act, s 48(1)(a)(ii).
[245] Otlowski and others, above n 44, at 97.
[246] Louise A Keogh and Margaret F A Otlowski "Life insurance and genetic test results: a mutation carrier's fight to achieve full cover" (2013) 199 Medical Journal of Australia 363; Kristine Barlow-Stewart and others "Verification of consumers' experiences and perceptions of genetic discrimination and its impact on utilization of genetic testing" (2009) 11 Genetics in Medicine 193; and K Barlow-Stewart and others "How are genetic test results being used by Australian life insurers?" (2018) 26 European Journal of Human Genetics 1248.
[247] Keogh and Otlowski, above n 246, at 364.
[248] Keogh and Otlowski, above n 246, at 364.
[249] Keogh and Otlowski, above n 246, at 364.
[250] Keogh and Otlowski, above n 246, at 364.

Furthermore, concerns surrounding irrational discrimination extend beyond poorly understood or misinterpreted genetic information. Even good faith risk estimates based on well-studied genetic variants may be inaccurate because of factors like ascertainment bias in research methodology.

Ascertainment bias arises because studies relating to disease associated genetic variants often only focus on individuals with family history of the relevant disease or symptomology, despite the possibility that disease associated variants may be present in individuals in the general population who never develop disease for reasons like protective variants or environmental factors.[251] The result is that published estimates of penetrance can be overestimated, in particular when disease associated variants are used to predict disease onset in healthy individuals without family history.[252] This type of irrational discrimination is not outlawed by the HRA because it is based on published evidence.

Irrational discrimination has tangible negative outcomes by unjustifiably preventing access to life insurance, leaving individuals without the protections they sought in case of future death, injury, or illness.[253]

It is worth noting that while introducing genetic non-discrimination policy is not the only way to avoid irrational discrimination, the imbalance of power between insurers and consumers means alternative options may be ineffective. For example, a potential solution would be to introduce a more independent and consumer friendly complaint system where adverse underwriting decisions could be challenged. However, this would place an unreasonable onus to pursue fair treatment on consumers, who depending on their knowledge of genetics and the transparency of the insurer, may not recognise irrational discrimination has taken place. Alternatively, the industry could be limited to the use of certain genetic test results approved for underwriting by an external body with scientific expertise. However, without mechanisms for close monitoring of compliance, this too may be ineffective, particularly considering the

[251] Sebastian Zöllnera and Jonathan K Pritchard "Overcoming the Winner's Curse: Estimating Penetrance Parameters from Case-Control Data" (2007) 80 The American Journal of Human Genetics 605 at 605.
[252] Steven Sorscher "Ascertainment Bias and Estimating Penetrance" (2018) 4 JAMA oncology 587; Elias I Obeid, Michael J Hall and Mary B Daly (2017) "Multigene Panel Testing and Breast Cancer Risk: Is It Time to Scale Down?" (2017) 3 JAMA Oncology 1176; and John Michael O Ranola, Ginger J Tsai and Brian H Shirts "Exploring the effect of ascertainment bias on genetic studies that use clinical pedigrees" (2019) 27 European Journal of Human Genetics 1800.
[253] For an explanation of the importance of obtaining life insurance see Chapter 1 at [V].

findings of the Financial Markets Authority (FMA) and RBNZ Life Insurer Conduct and Culture Review reported in 2019, which revealed a consistent lack of transparency in the industry and poor consumer outcomes.[254] Furthermore, these approaches would fail to mitigate the other consequences raised in *I-III* above.

A Irrational Discrimination and Equity Conceived as Actuarial Fairness

Interestingly, the occurrence of irrational genetic discrimination also adds a further justification for the genomic subsidising solidarity approach discussed in chapter two.[255]

The industry suggests genetic non-discrimination policy is inappropriate because it would violate the principle of actuarial fairness, which requires that individuals pay premiums commensurate to their risk.[256] However, this is arguably unpersuasive because the status quo violates actuarial fairness anyway, by facilitating irrational genetic discrimination leading consumers to pay premiums (likely) higher than their risk.

Furthermore, the current approach is arguably a more unjust violation of actuarial fairness because the brunt is borne by the more vulnerable consumer, as opposed to insurance companies which would bear the inequity in the case of genetic non-discrimination policy.

V Conclusion

Four categories of adverse consequences flow from the current policy: the disincentive from clinical and research testing, the compounding of existing health inequities, the occurrence of irrational discrimination, and the possibility of a eugenics-like future. In particular, the former three consequences result in tangible, evidence-based harms.

The introduction of policy which prevents life insurer access to predictive genetic information would alleviate disincentives from genetic testing, removing adverse consequences relating to

[254] Financial Markets Authority Te Mana Tatai Hokohoko and Reserve Bank of New Zealand Te Pūtea Matua *Life Insurer Conduct and Culture: Findings from an FMA and RBNZ review of conduct and culture in New Zealand life insurers* (January 2019).
[255] See Chapter 2 at [I].
[256] Pugh, above n 102, at 475.

health outcomes, research, and healthcare inequity. It would also prevent irrational genetic discrimination and mitigate concerns of an uninsurable genetic underclass emerging.

The only negative consequences that may flow from genetic non-discrimination policy in life insurance are slightly reduced industry profits, and a potential increase in life insurance premiums for low-risk individuals.[257] These financial outcomes clearly pale in comparison to the consequences of the current approach, which include the potential for unnecessary loss of life or illness. A consequentialist utilitarian approach therefore justifies the adoption of genetic non-discrimination policy to increase overall societal wellbeing.

This approach will also bring New Zealand closer to conforming with international law standards,[258] and is consistent with the genomic contextualism approach. It avoids genetic exceptionalism because policy is warranted by these context specific, tangible harms relating only to genetic information.

[257] See Chapter 2.
[258] See Chapter 1 at [III].

CHAPTER FIVE

The Definitional Challenge

The analysis so far has established the need for specialised genetic non-discrimination policy in life insurance. However, the challenge of defining genetic information remains. Chapter three revealed genetic information is not a discrete category, and the line between genetic and non-genetic medical information is more elusive than one might think.[259]

Broadly interpreted, "genetic information" could encompass most of an individual's health information, given the onset or manifestation of most medical events, excluding things like accidents and certain infections, are modulated by genetic factors.[260] This means translating the distinction drawn in principle into a concrete definition of "genetic information" or "genetic test" is difficult.

This chapter addresses the definitional challenge, justifying the exclusion of family history from the definition before analysing the current FSC definition and proposing a better alternative.

I Should Genetic Non-discrimination Policy Encompass Family History?

Some extreme approaches to genetic non-discrimination policy also prevent disclosure of family history information,[261] an approach New Zealand should arguably avoid.

Family history can be viewed as a type of genetic information,[262] but this does not justify equal protection. The arguments justifying policy are not based on anything innately special about the category "genetic information", as expressly rejected in chapter three.[263] Rather, genetic-specific policy is demanded because of context specific consequences, which do not apply to family history information.

[259] National Academy of Sciences, above n 175, at 7.
[260] Hellman, above n 150, at 80.
[261] Swiss Re Institute, above n 20, at 12.
[262] Godard and others, above n 107, at S130.
[263] See Chapter 3.

Importantly, the central arguments in favour of policy do not concern disclosure of family history information. Firstly, there is no evidence allowing insurer access to family history gives rise to the disincentive concern. This is because as long as predictive genetic test results are inaccessible to insurers, taking a predictive genetic test will not disadvantage the individual or their family. Sure, if that disease manifests someday, it will need to be disclosed to insurers as family history by future generations, and may disadvantage them, but the onset of disease would be unrelated to the earlier decision of whether to take the predictive genetic test. Therefore, allowing family history disclosure should not disincentivise testing or research participation. It may even encourage predictive testing to avoid future discrimination based on family history, by possibly reducing the chance of disease onset by enabling preventative or treatment options.

Secondly, the risk of irrational discrimination based on family history is greatly reduced. Unlike predictive genetic test results, the industry has 150 years of experience and a good record of managing and risk rating with family history data.[264] Family history information is also less direct and usually will not reveal information about specific variants carried by applicants, which can lend to miscalculations based on factors like inaccurate penetrance estimates.

Therefore, the definition New Zealand adopts should exclude family history information.

II The Current Definition

It is useful to assess the merits of the current FSC definition if it were to be retained in any future policy adopted to prevent insurer access to predictive genetic test results. The current FSC Policy takes a narrow approach, defining "genetic test" as:[265]

> … a test which examines a person's chromosomes or DNA. It does not include any non-genetic medical tests (for example, blood or urine tests for proteins, cholesterol, liver function or diabetes), even if they are to test for a condition that may have a genetic origin.

[264] Swiss Re Institute, above n 20, at 12.
[265] Financial Services Council, above n 63, at [4].

The benefit of this narrow approach is that it clearly delimits scope.[266] However, it may cause problems, demonstrated by Mary's family.

Mary's children each have a 50% chance they have inherited the disease variant.[267] They have two options to determine their status:[268]

(1) a genetic test for the variant; or
(2) a blood test measuring foetal haemoglobin count.

Both tests reveal the same genetic information, the presence or absence of the disease variant. However, while the former is captured because it "examines" DNA, the latter is a blood test falling outside the definition. Therefore, those who took the blood test would still have to disclose their results to insurers and may be unable to access life insurance purely based on the approach taken to testing.

Therefore, the current definition draws an arbitrary or even unjust line between those protected by the policy, and those not. The definition should be widened, but care must be taken not to overcompensate as broader definitions can lead to overreach or uncertain scope.[269]

III A Proposed Definition

The following definition has carefully extended scope. Instead of "genetic test", the phrase "predictive genetic information" should be adopted, defined as:

> Information obtained through any manner, excluding inference from medically significant symptoms or family history, which confirms the presence or absence of inherited genetic variants or chromosomal abnormalities associated with genetic disease that has not yet manifested. To avoid doubt, predictive genetic information includes polygenic risk scores.

[266] Henry T Greely "Genotype Discrimination: The Complex Case for Some Legislative Protection" (2000) 149 University of Pennsylvania Law Review 1489.
[267] See Chapter 4 at [I].
[268] Personal communications with Mary (12 August 2021).
[269] Bombard, above n 120; and Lemmens, Joly and Knoppers, above n 99, at 8.

Importantly, this definition is broad enough to capture non-genetic tests like foetal haemoglobin, which directly reveal the presence or absence of genetic variants. Equally, it is not broad enough to capture diagnostic genetic information or family history. By requiring insight into the presence or absence of specific variants it excludes medical information that is peripherally "genetic", like blood pressure or cholesterol levels.

Given genetic information is a slippery category and science develops fast, it will be important to have an easily adjustable form of policy to prevent definitional disconnect.

CHAPTER SIX

International Approaches

Genetic non-discrimination policy introduced in other jurisdictions has taken a variety of forms, including legislative and self-regulatory approaches. This chapter will analyse common forms and features of overseas approaches, before recommending the introduction of genetic non-discrimination policy in New Zealand through regulations.

I Common Features of Policy

Ceiling systems, time limits, broad or narrow scope, and the approval body approach are all common features of genetic non-discrimination policy.[270]

A Ceiling Systems

Ceiling systems allow access to life insurance without disclosure of genetic information up to a certain threshold of cover, over which disclosure obligations return. They are a common feature of both legislative and voluntary moratoria approaches.[271]

Ceiling systems represent a sufficientarian approach to justice, whereby a just distribution is one where people can access enough of a good to surpass a certain threshold, rather than one which eliminates all inequality.[272] They mitigate industry economic concerns by preventing individuals who discover genetic susceptibilities from capitalising on very large amounts of life insurance to generate an estate. The underlying assumption, which seems reasonable, is that adverse selection risks are only consequential for large capital amounts.[273]

[270] Lemmens, Joly and Knoppers, above n 99.
[271] For example, the Australian and UK moratoria and the Swiss legislative approach.
[272] Paula Casal "Why Sufficiency Is Not Enough" (2007) 117 Ethics 296 at 297.
[273] Godard and others, above n 107, at S128.

B Time Limits

Voluntary industry-initiated moratoria often only apply for a limited period, after which they are reassessed.[274] Time limits reduce the industry's commitment and provide time to assess the actuarial relevance of genetic information.[275]

However, time limits can be problematic because concerns relating to discrimination are not necessarily immediate.[276] Hesitancy to test may be influenced by concerns for the wider whānau and generations to come, meaning time limited policies may not adequately remedy the disincentive concern.

C Variation of Scope

Approaches to genetic non-discrimination policy may broadly prohibit all genetic discrimination,[277] or specifically target the insurance industry.[278] It may seem favourable to make policy as broad as possible for protection; however, genetic information is not *per se* unique or dangerous.[279] Policy should arguably avoid genetic exceptionalism to ensure New Zealand's legal framework and social attitudes are open to embracing the emerging benefits of genetic technologies.

From a utilitarian perspective, the greatest benefits will arguably come from policy at an equilibrium that strongly protects consumers from tangible harms, but does not overcompensate in a way which interferes with the beneficial acceptance or use of genetic information in cases where harms do not arise. An example which demonstrates the need to carefully balance genetic-specific policy to optimise good outcomes is the medical record. It has been argued that genetic exceptionalism leading to extra protection of genetic information in the medical record may have negative healthcare consequences by sequestering relevant genetic information from medical providers.[280]

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[274] Lemmens, Joly and Knoppers, above n 99, at 10.
[275] Lemmens, Joly and Knoppers, above n 99, at 10.
[276] Tarr, above n 126, at 200.
[277] For example, Canada.
[278] For example, Australia and the UK.
[279] See Chapter 3.
[280] Evans and Burke, above n 149.

That is not to say life insurance is the only social context where genetic non-discrimination policy is justified, and similar analyses may reveal protection is important in other contexts. However, extension to other contexts should arguably be reasoned rather than adopting a one-size-fits-all approach.

D Approval Body

Some approaches simply address irrational discrimination, requiring insurers only access predictive genetic tests approved as actuarially relevant by an external body.[281] This may be a useful approach when paired with other interventions, but adopting this approach alone would be insufficient to remove the disincentive concern associated with genetic discrimination.

II Legislation or Moratorium?

In most instances, genetic non-discrimination policy is introduced either through legislation or industry self-regulation.

A Moratoria

Under the moratoria approach, the industry voluntarily agrees to limit its use of genetic information. The Australian and UK approaches provide useful examples.

1 Australia – self regulation

In 2019 the Australian FSC entered a voluntary five-year moratorium limiting the use of predictive genetic information by life insurers.[282] It followed lobbying from academics and pressure from a government review.[283]

[281] Lemmens, Joly and Knoppers, above n 99, at 5.
[282] Financial Services Council *FSC Standard No. 11: Moratorium on Genetic Tests in Life Insurance* (June 2019) at [2.2].
[283] Parliamentary Joint Committee on Corporations and Financial Services *Life Insurance Industry* (March 2018). Lobbying included advocacy from the Australian Genetic Non-Discrimination Working Group.

The moratorium adopts the ceiling system, meaning insurers can only request disclosure of predictive genetic test results if aggregate cover would exceed any of the following thresholds:[284]

- $500,000 lump sum death Cover.
- $500,000 total permanent disability Cover (TPD).
- $200,000 trauma and/or critical illness Cover.
- $4,000 a month in total of any combination of income protection, salary continuance or business expenses Cover.

Above these thresholds usual disclosure obligations apply. At any level of cover, consumers retain the ability to disclose a favourable genetic test result, like a negative test for a mutation that runs in the family.[285]

One limitation of the moratorium is that it lacks mechanisms for monitoring compliance. A group of academics concerned by this loophole have taken matters into their hands, securing government funding to monitor and report on the moratorium.[286]

2 United Kingdom – agreement between government and industry

Since 1997 the UK has had various forms of moratoria in place to protect from genetic discrimination in life insurance. The current iteration is a voluntary Code negotiated between the Government and the Association of British Insurers, a more rigorous approach than Australia's.[287] The Code is open ended, but reviewed every three years.[288] It too adopts the ceiling system, meaning life insurers will not request disclosure of predictive genetic test results up to the following limits:[289]

[284] Financial Services Council, above n 282, at [3.3]. Note, values given in AUD.
[285] Financial Services Council, above n 282, at [3.5].
[286] Jane Tiller and others "Monitoring the genetic testing and life insurance moratorium in Australia: a national research project" (2021) 214 Medical Journal of Australia 157; and Jane Tiller and others "Study protocol: the Australian genetics and life insurance moratorium - monitoring the effectiveness and response (A-GLIMMER) project" (2021) 22 BMC Medical Ethics 1.
[287] HM Government and Association of British Insurers *Code on Genetic Testing and Insurance: A voluntary code of practice agreed between HM Government and the Association of British Insurers on the role of genetic testing in insurance* (October 2018).
[288] HM Government and Association of British Insurers, above n 287, at 6.
[289] HM Government and Association of British Insurers, above n 287, at 5.

- Life insurance £500,000 (per person).
- Critical illness insurance £300,000 (per person).
- Income protection £30,000 (per annum).

As an additional protection, the approval body approach is taken above these limits, meaning only predictive genetic tests for Government approved conditions must be disclosed.[290] Currently only Huntington's has been approved.[291] Notably, like in Australia, favourable results may be considered for any level of cover.[292]

Government involvement in negotiations helped secure more onerous obligations through the threat of legislative intervention if voluntary restrictions fail to alleviate concerns.[293] In fact, it was the ultimatum of legislative intervention that led to the formation of the initial Code in 1997.[294]

B Legislation

Legislative approaches can also take a range of forms. Canada provides an example of a broad approach, and Switzerland a narrower approach.

1 Canada

Canada recently introduced the Genetic Non-Discrimination Act 2017 (GNDA) which makes it an offence to require a person to undergo a genetic test, or to disclose prior genetic test results as a condition of providing goods or entering a contract.[295] Therefore, its scope extends well beyond insurers. Interestingly, GNDA and some other legislative approaches extend to diagnostic genetic tests.[296] However, this likely has little effect on underwriting because it

[290] HM Government and Association of British Insurers, above n 287, at 7.
[291] HM Government and Association of British Insurers, above n 287, at 7.
[292] HM Government and Association of British Insurers, above n 287, at 8.
[293] House of Commons Science and Technology Committee *Genomics and genome editing in the NHS* (Third Report of Session 2017–19, April 2018) at 4.
[294] E David Cook "Genetics and the British insurance industry" (1999) 25 Journal of Medical Ethics 157 at 158.
[295] Genetic Non-Discrimination Act 2017 (Canada), ss 3-5.
[296] Section 2.

would presumably not prevent the actual diagnosis being disclosed, even in the absence of the genetic test result that revealed the condition.

One benefit of the legislative approach is the inclusion of penalties. Breaches of GNDA may be penalised by fines or imprisonment, increasing compliance incentives.[297]

2 Switzerland

Many European countries have introduced genetic non-discrimination policy pursuant to the Council of Europe Oviedo Convention,[298] which prohibits discrimination based on genetic heritage.[299] Switzerland's response is the Federal Act on Human Genetic Testing 2004, which protects genetic information in specific contexts, including insurance, employment, and certain clinical contexts.[300]

Chapter 5 prohibits insurers from requiring disclosure of predictive genetic information,[301] adopting the ceiling system for certain forms insurance with the following thresholds:[302]

- CHF 400,000 life insurance.
- CHF 40,000 total permanent disability cover.

The Swiss legislative approach is therefore narrower in scope than Canada's.

III Comparing Legislation and Self-Regulation

To inform New Zealand's approach, it is useful to compare the strengths and weaknesses of the moratoria and legislative approaches. Two key categories for comparison are flexibility and compliance.

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[297] Section 7.
[298] M Otlowski, S Taylor and Y Bombard "Genetic Discrimination: International Perspectives" (2012) 13 Annual Review of Genomics and Human Genetics 433 at 442.
[299] Council of Europe Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine (ETS 164, opened for signature 4 April 1997, entered into force 1 December 1999), art 11.
[300] Federal Act on Human Genetic Testing 2004 (Switzerland).
[301] Article 27.
[302] Article 27.

A Flexibility

Genetic non-discrimination policy should be easily updateable given the challenge of defining genetic information, and the unpredictability of the future of genetics. Flexibility helps avoid regulatory disconnect, where the original purposes of policy no longer adequately address modern uses of technology, or policy wording no longer captures the form technology now takes.[303] The moratoria approach clearly has greater flexibility, avoiding onerous processes involved in amending legislation.

An example of the importance of flexibility comes from Switzerland, where genetic non-discrimination legislation had to be reviewed in 2017 after it became out of touch with new analytical techniques and the financial limits of the ceiling approach became outdated.[304]

B Compliance

Clearly, industry compliance is essential for genetic non-discrimination policy to work. Legislation is effective in ensuring compliance, having legal force including penalties for breach and external monitoring. Self-regulation on the other hand simply relies on the agreement's moral force and the good faith of the industry.[305] Self-regulation also gives rise to a conflict of interest in compliance monitoring, as reporting breaches and holding insurers accountable may damage the industry's image.

Government involvement in negotiating the UK Code helped to mitigate these issues through the incentive of avoiding legislative intervention, which increased the Code's strength.[306] Despite this improvement, the UK moratorium still has weaknesses. The Code has no provision of penalties for breach, and compliance and reporting obligations lie in the industry's hands, despite their inherent conflict of interest.

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[303] Roger Brownsword and Morag Goodwin "Four key regulatory challenges" in William Twining, Christopher McCrudden and Bronwen Morgan (eds) *Law and the technologies of the twenty-first century: text and materials* (Cambridge University Press, Cambridge, 2012) 47 at 65.
[304] House of Commons Science and Technology Committee, above n 293, at [81]; and Doris Leuthard and Walter Thurnherr "Message concernant la loi fédérale sur l'analyse génétique humaine" (press release, 5 July 2017).
[305] Lemmens, Joly and Knoppers, above n 99, at 11; and Patricia Kosseim, Martin Letendre and Bartha Maria Knoppers "Protecting genetic information: a comparison of normative approaches." (2004) 2 GenEdit 1 at [B(i)].
[306] See Chapter 6 at [II].

IV The Best Approach for New Zealand

As an alternative solution, arguably the best approach for New Zealand is the provision of genetic non-discrimination regulations by a suitable regulator, empowered by an appropriate parent Act. This intermediate approach would capture the benefits of both the legislative and moratoria approaches, while avoiding their pitfalls.

Foremost, the New Zealand life insurance industry cannot be trusted to self-regulate given compliance concerns are amplified by their particularly poor consumer culture.[307] The industry has systemic problems to address, so the formulation and enforcement of policy should be carried out externally. This would be possible through regulations or legislation, but only the former would balance this with the need for flexibility, given regulations are more easily adjustable.

Furthermore, there is a clear power imbalance between consumers and large insurers, which has perhaps allowed the industry to harbour its poor culture and treatment of consumers.[308] External regulations would arguably facilitate a more equal partnership, intervening to place obligations on insurers.

Regulations would also be consistent with the arguments raised to justify policy. Importantly, regulations would likely effectively address the disincentive argument because consumers would be reassured that non-discrimination policy is enshrined in a format not subject to time limits, and not relying simply on the good faith of the industry.

Regulations would also arguably strike an effective balance between the eugenics argument and avoiding exceptionalism. Empowered through legislation and regularly reviewed, regulations would show government commitment to prohibiting misuse of genetic information, allaying the eugenics argument. However, regulations would be tailored to address particular harms arising in the insurance context, which avoids unduly perpetuating the fallacy of genetic exceptionalism.

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[307] Financial Markets Authority Te Mana Tatai Hokohoko and Reserve Bank of New Zealand Te Pūtea Matua, above n 254, at 6.
[308] Financial Markets Authority Te Mana Tatai Hokohoko and Reserve Bank of New Zealand Te Pūtea Matua, above n 254, at 6.

A Should the Ceiling System be Adopted?

Although adverse selection is unlikely to be a major threat to the insurance industry,[309] the ceiling system is likely appropriate, following the UK and Australia.

Ceiling systems help modulate the effects of genomic subsidising solidarity. Firstly, they ensure high-risk individuals can access a reasonable threshold of cover, avoiding undue disadvantage. As long as the threshold is set high enough, this can be considered fair under a sufficientarian approach to justice.[310] Secondly, they ensure costs borne by low-risk individuals in subsidising high-risk individuals are not unduly high, which could impede their access to insurance and destabilise the pool.[311]

To ensure thresholds do not undermine the crucial goal of addressing genetic testing disincentives they will need to be carefully calibrated for the New Zealand context and set in the higher range of cover. They will also need to be regularly reviewed to account for changes like inflation.

Notably, adopting the ceiling system may reintroduce concerns of irrational discrimination occurring above the threshold. Should this occur, an approval body approach aligning with the UK Code could be adopted.[312]

B Parent Act and Regulator

Regulations will need to be tied to an existing empowering Act and regulator. Perhaps the most obvious choice is to amend IPSA, empowering the Governor-General to make regulations relating to the use of genetic information in insurance on the advice of the Minister, given in accordance with a recommendation of the RBNZ.[313]

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[309] See Chapter 2 at [II].
[310] Casal, above n 272, at 297.
[311] See Chapter 2 at [II].
[312] HM Government and Association of British Insurers, above n 287, at 7.
[313] See Insurance (Prudential Supervision) Act, s 237.

The RBNZ is well established in administering regulations and supervising insurer conduct,[314] responsible for the recent review into life insurer conduct alongside the FMA.[315] A purpose of the supervisory role of the RBNZ in insurance is to "promote public confidence in the insurance sector",[316] which aligns nicely with administering genetic non-discrimination policy.

Of course, this is just one of many possible avenues that may be equally effective, including issuing a Code of Practice under s 33 of the Privacy Act 2020 supervised by the Privacy Commissioner.

C Objectives

Another benefit of regulations is that their content and application could be guided by objectives included either in the regulations or parent Act, to ensure concerns are appropriately addressed. The following objectives may be suitable, aligning with the arguments made in this dissertation:

> The purposes of these regulations are:
>
> (a) To protect consumers from adverse consequences flowing from life insurer use of predictive genetic information. In particular, to resolve the chilling effect it may have on genetic testing and research participation.
>
> (b) To provide mechanisms for regular review and compliance monitoring of insurer use of genetic information.
>
> (c) To respond proportionately to issues arising from genetic information, avoiding unjustified genetic exceptionalism.

[314] See Chapter 1 at [II].
[315] Financial Markets Authority Te Mana Tatai Hokohoko and Reserve Bank of New Zealand Te Pūtea Matua, above n 254.
[316] Insurance (Prudential Supervision) Act, s 3(1)(b).

V Summary

After analysing approaches to genetic non-discrimination policy, I have advocated for New Zealand to introduce a regulatory approach. The regulations will need to prevent insurers from requesting disclosure of predictive genetic test results, and requiring applicants to undertake genetic tests. However, consumers should retain the ability to disclose favourable genetic test results. Furthermore, regulations will need to include mechanisms for regular review and close monitoring.

CHAPTER SEVEN

Recommendations for New Zealand

This chapter summarises recommendations for New Zealand to adopt moving forward. To achieve these recommendations, which significantly depart from the current position, the industry and Government will no longer be able to be complacent, and momentum from consumers, clinicians, researchers, and academics will likely be necessary.

I Recommendations so Far

The analysis so far has recommended:

(1) Regulations prohibiting life insurers requesting applicants undertake genetic tests, and from requesting disclosure of predictive genetic test results up to a threshold.[317]

(2) A new definition for "predictive genetic information" detailed in chapter five.[318]

II Government Led Review

Initiating change in this area will require Government involvement. As a starting point, the Government should undertake a review including a focus on policy implications for Māori, pursuant to Treaty obligations. This would generate the missing data and insight into how genetic discrimination is affecting patients, clinicians, and researchers in New Zealand, to inform policy change. Now is an appropriate time to begin given the review could be pinned onto the current MBIE Insurance Contract Law Review, or could follow suit using its momentum and resources.

[317] See Chapter 6.
[318] See Chapter 5 at [III].

III Independent Complaints Scheme

Arguably, the current IFSO scheme is an insufficient source of redress for aggrieved consumers given it is established by the industry and hears a limited range of complaints.[319] To remedy this, an insurance ombudsman should be established that is independent from the industry, unlike the current ombudsman, and able to hear a broader range of complaints including appealed underwriting decisions. Given a history of poor industry conduct towards consumers, this move will be important for all life insurance consumers, not just those with complaints relating to genetic discrimination.[320]

IV Effort to Normalise Genetic Information

Finally, it will be important to address attitudes of genetic determinism and exceptionalism which exist among the public,[321] as well as the stigma that tends to attach to genetics.[322] The discovery and uptake of emerging genetic tools are contingent on openminded and informed social attitudes, which will allow society to embrace their benefits. For example, New Zealanders embracing approaches like personalised medicine will help maximise health and wellbeing.

As the complexities of this dissertation have highlighted, this stigma and confusion can also interfere with effective policymaking by obscuring the real mischief and harms which must be extricated from the peripheral noise.[323]

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[319] See Chapter 1 at [II].
[320] Financial Markets Authority Te Mana Tatai Hokohoko and Reserve Bank of New Zealand Te Pūtea Matua, above n 254, at 6.
[321] Jérémy Castéra and Pierre Clément "Teachers' Conceptions About the Genetic Determinism of Human Behaviour: A Survey in 23 Countries" (2014) 23 Science & Education 417; Celeste M Condit, Nneka Ofulue and Kristine M Sheedy "Determinism and Mass-Media Portrayals of Genetics" (1998) 62 The American Journal of Human Genetics 979; and Raphael Falk "The Allusion of the Gene: Misunderstandings of the Concepts Heredity and Gene" (2014) 23 Science & Education 273.
[322] Kosseim, Letendre and Knoppers, above n 305, at [B(iii)].
[323] Kosseim, Letendre and Knoppers, above n 305, at [B(iii)].

Conclusion

This dissertation has demonstrated the need to introduce genetic non-discrimination policy in New Zealand through a consequentialist utilitarian lens. It has shown genetic information is not inherently unique or mystical, but may give rise to unique concerns when embedded in particular contexts. In the life insurance context, those concerns are that allowing access to predictive genetic information disincentivises potentially lifesaving genetic testing and research, risks irrational discrimination, may lead to eugenic-like threats, and contributes to health inequities. These adverse outcomes demand policy change, particularly in the absence of evidence of a real risk of adverse selection. The proposed regulatory approach will provide both flexibility and strong enforcement, while avoiding reinforcing attitudes of genetic exceptionalism that may impede on society embracing the benefits genetic advancements will offer.

Over the past two weeks, the media has picked up on the inadequacies of the New Zealand approach following an article published by members of AGenDA.[324] Evidently, public momentum for reform is strengthening, and I am hopeful that with this pressure the Government and industry will take notice, and take steps towards long overdue change.

[324] Tiller and Shelling, above n 5; Chelsea Daniels "Genetic discrimination: The next great health battle likely to wash up on NZ shores" *NewstalkZB* (online ed, New Zealand, 6 October 2021); and Chelsea Daniels "Growing concern over genetic discrimination in New Zealand" *NZ Herald* (online ed, New Zealand, 5 October 2021).

Appendix I: Table of Definitions

Term	Definition
Alleles	Variations of the same gene.
Autosome	All chromosomes except the sex chromosomes (humans have 22 autosome pairs).
Base pairs	Pairs of complementary nucleotides formed between the two strands of DNA: A pairs with T, and G with C.
Chromosomal abnormalities	Disorders caused by chromosomes or parts of chromosomes which are missing, present in extra copies, or positionally changed.
Chromosome	Structures in the cell nucleus consisting of DNA coiled around proteins.
Complex disorders	Genetic disorders caused by the combined effects (independent or interacting) of multiple genetic variants and well the environment.
DNA	A double helix shaped molecule which holds the genetic code: DNA molecules are double stranded, each strand comprising a sequence of nucleotides.
Dominant	Diseases which only require one copy of the disease allele to manifest. Inheriting a single copy from either the father or mother will lead to disease manifestation in offspring.
Effect size	Effect size is a numerical indication of the strength of the association between a genetic variant and a trait.
Gene	Units of DNA that contain functional information and perform specific roles.
Gene expression	The process of constructing proteins by cellular machinery reading the nucleotide sequence of a gene and translating it into amino-acid chains (simplified definition for the purposes of this dissertation).
Genetic non-discrimination policy	Used to refer to any form of policy which places restrictions on life insurer access to predictive genetic test results.
Genetic variant	One 'form' of a region of DNA that exists in multiple forms in the population.
Genome	An organism's entire set of DNA including its genes.

Genome wide association studies (GWAS)	A research strategy for identifying SNPs statistically associated with complex genetic traits. It is carried out by comparing the frequency of SNPs between a sample with a genetic disease and an unaffected control sample.
Genotype	The set of alleles an individual possesses.
Huntington's disease	A monogenic neurodegenerative disease which begins around the ages of 30-50.
Incomplete penetrance	A disease associated genotype that does not always manifest into clinical symptoms of disease.
Monogenic disorders	Genetic disorders caused by variation in a single gene.
Nucleotide	'Bases' which join to form DNA; the four nucleotides are adenine (A), thymine (T), guanine (G), and cytosine (C).
Phenotype	The physical trait that results from a genotype.
Polygenic risk score (PRS)	Scores which predict an individual's genetic risk of developing a complex genetic disease, constructed using disease associated variants identified by GWAS.
Recessive	Diseases which require two copies of the disease allele (one on each chromosome) to manifest. One functional copy of the allele will compensate, allowing the gene to perform its usual function. Individuals with just one copy of the disease allele are carriers, and may pass the allele to their offspring but will not develop disease.
Sex chromosome	The single pair of chromosomes which determine sex (female XX, male XY).
Variable expressivity	A disease associated genotype that can manifest in a range of manners i.e. differing age of onset, symptoms, or severity.
X-linked	Genetic disease caused by variants on the X-chromosome. X-linked disorders are more common in males due to lack of a redundant copy of the X chromosome.

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Privacy Act 2020.

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