Genetic discrimination by insurance companies in Aotearoa New Zealand: experiences and views of health professionals

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ABSTRACT

AIMS: Genetic discrimination in insurance is a significant clinical, research and consumer issue. Recently, the Australian life insurance industry introduced a partial moratorium on the use of genetic test results. However, in Aotearoa New Zealand, both life and health insurers can still use genetic results legally to discriminate against applicants. We aimed to document experiences and concerns of New Zealand-based health professionals (HPs) around the potential misuse of genetic test results for insurance purposes.

METHODS: We administered an online survey to New Zealand HPs who discuss genetic testing with patients, their experiences regarding the use of genetic test results in insurance and views on regulation.

RESULTS: Twenty-three New Zealand HPs responded, 15 of whom worked in genetics clinics, representing >60% of the total New Zealand clinical genetics workforce. Eleven respondents reported having patients who experienced adverse outcomes related to insurance based on genetic results. Respondents reported patients sometimes/often delayed (n=11) or refused (n=4) genetic testing due to insurance concerns. Over 80% of those who answered (n=17/21) believe insurers' use of genetic results should be legally regulated.

CONCLUSION: New Zealand HPs have concerns about insurance companies using genetic test results in underwriting, including the effect on patients, and strongly believe government legislation is required.

Genetic discrimination (GD) is defined as "*differential treatment of asymptomatic individuals or their relatives on the basis of real or assumed genetic differences or characteristics*".[1] GD in insurance underwriting is a significant clinical, research and consumer issue. International research has demonstrated that concerns regarding insurance implications deter people from clinically indicated genetic testing and involvement in research.[2–6] Health professionals (HPs) also express concerns regarding the impact of GD on patients.[7–10]

Many countries have banned or restricted the use of genetic test results in insurance through various policy mechanisms.[11–12] Canada's *Genetic Non-Discrimination Act (2017)* bans the use of genetic test results by any entity providing goods or services,[12] meaning the use of genetic test results is prohibited for both health insurance and life insurance underwriting (except where results that are favourable to the applicant are disclosed voluntarily—for example, where a patient has *not* inherited a disease-causing familial DNA variant). In the USA, the *Genetic Information Non-Discrimination Act (2008)* prohibits health insurers from using genetic test results (with some exclusions), though it does not apply to life insurance. Recently, the US state of Florida has introduced a law prohibiting life insurers from using predictive genetic test results in underwriting.[13] Since 1997, Europe's Convention on Human Rights and Biomedicine has banned discrimination on the basis of genetic test results, and in 2016, the Council of Europe adopted Recommendation CM/Rec(2016)8, which requires Member States to take steps to prevent discrimination in insurance contracts, including on grounds of genetics.[14] Since 2001, an agreement between the Association of British Insurers and the UK government has banned health and life insurers from using genetic results in underwriting, with one exception—predictive genetic test results for Huntington disease for death cover policies worth over £500,000 (~$950,000 NZD). The UK Code on Genetic Testing and Insurance[15] is indefinite and is reviewed every 3 years.

In Australia, health insurers cannot use genetic results (or other risk information) to deny cover

under the *Private Health Insurance Act 2007* (Cth).[14] However, life insurers can legally discriminate on the basis of genetic test results under section 46 of the *Disability Discrimination Act 1992* (Cth). Following a 2017 Australian Parliamentary Joint Committee (PJC) inquiry into the life insurance industry, the PJC recommended that a moratorium be implemented in Australia (similar to the UK moratorium), and if necessary, legislation may follow.[16] Although the Australian Government has not responded to the PJC recommendations, in July 2019 the life insurance industry introduced a partial moratorium on the use of genetic results in life insurance.[17] The moratorium is self-regulated by the Financial Services Council (FSC), the regulatory body for Australian life insurers,[18] is not legally enforceable and applies only to life insurance policies up to certain financial limits.

In Aotearoa New Zealand, both life and health insurance companies can still use genetic test results in underwriting, which can lead to GD. The *New Zealand Human Rights Act 1993* (HRA) prohibits discrimination on the grounds of disability, but an exception in s48 of the HRA allows discrimination in both life and health insurance policies, if based on actuarial or other data on which it is reasonable to rely.

New Zealand has a small population (~5.1 million in 2021[19]) and clinical genetics workforce. Although New Zealand HPs who discuss genetic testing with patients must discuss potential risks including insurance implications,[20] little research has been conducted into the experiences or views of New Zealand HPs regarding GD in insurance. A survey conducted in 2017,[7] which included New Zealand HPs, was not tailored to New Zealand, and New Zealand data were not published separately. With Australia and many other countries revisiting this issue recently,[21–22] it is critical for New Zealand to now consider its position. In 2021, a group of clinicians, academics, ethics and law experts, patients, and representatives from Indigenous communities formed a collaboration called Against Genomic Discrimination Aotearoa; AGenDA. This group (of which the authors of this paper are members) has documented anecdotal experiences and views of New Zealand HPs,[23,24] however, there is a paucity of published data. This study represents the first dedicated study of the views and experiences of New Zealand HPs about the use of genetic test results in insurance underwriting.

Methods

HPs in Australia and New Zealand were surveyed together as part of a combined study, with slight differences in the survey accessed by each. The results from the Australian survey have been published previously, and the methods of survey development and recruitment are described in that publication.[25] The survey addressed participant demographics, knowledge and training associated with insurance and genetics, general views regarding regulation of the insurance industry, and experience of patient attitudes and behaviours in response to perceived GD. The survey was developed following consultation with clinical and research professionals, as previously validated scales did not exist. A blank copy of the survey is included as Appendix 1.

Sampling and recruitment

The eligible population was qualified HPs working in a New Zealand health service who discuss genetic testing with patients. This encompassed clinical geneticists and genetic counsellors, as well as other health professionals working outside clinical genetics services who organise genetic testing (including but not limited to nurses, cardiologists and oncologists). Recruitment strategies utilised included newsletters emailed via the Human Genetics Society of Australasia (HGSA) and Australasian Society of Genetic Counsellors (ASGC), social media advertisements and snowballing via direct emails to professional contacts to assist with dissemination.

Survey development and data collection

We conducted an online survey using REDCap software,[26] adapted from the Australian survey[25] to account for differences in regulation of this issue. Most questions used closed-ended Likert scales, although several open-ended questions allowed for additional information via free text. The survey was open from April–June 2020.

Data analysis

We used descriptive analysis to report aggregate responses to closed-ended questions, grouped by profession. Statistical analysis of differences between groups was not possible due to the small sample size. Responses to open-ended questions were grouped into key thematic categories and reported using representative quotes.

Ethics approval

This project was granted approval by the Monash University Human Research Ethics Committee on 11 March 2020, ID number 22576, and was performed in accordance with the ethical standards as laid down in the 1964 Declaration of Helsinki.

Results

Respondents

Overall, 23 New Zealand health professionals (HPs) who discuss genetic testing with patients responded to the survey (Table 1). The survey was completed online, and some respondents did not complete all questions—"n" values are provided to clarify the number of respondents for each question.

Given the diverse methods of recruitment, a response rate is difficult to estimate. However, the respondents are grouped into two categories—genetic HPs and non-genetic HPs. Genetic HPs include genetic counsellors (GCs) and clinical geneticists (CGs). Non-genetic HPs include other qualified HPs who discuss genetic testing with patients, such as oncologists. At the time of data collection, there were 9 CGs and 17 GCs (26 total) employed by Genetic Health Services New Zealand (GHSNZ), meaning the respondents to this survey represented more than half of the known clinical genetics workforce in New Zealand (n=15/26) and can be considered representative of that group. Further, when the minimum years of experiences across the respondents are added up, the genetics HPs who responded cumulatively represent a minimum of 243 years of professional experience. The non-genetics HPs are likely a small fraction of HPs who discuss genetic testing with patients in New Zealand.

Three main themes are presented from the data: potential barriers to genetic testing due to insurance discrimination fears; a need for greater regulation of the use of genetic test results in insurance underwriting; and concerns about professional training and awareness.

Barriers to genetic testing and surveillance

Over half of the HPs surveyed (n=11/21) reported that they had observed patients *delaying* genetic testing "often or sometimes" due to life, income or trauma/critical illness insurance concerns. Further, 4/21 participants reported that they had observed patients *refusing* genetic testing sometimes for this reason (Table 2).

Over half of participants (n=11/21) also reported patient/s telling them about an adverse insurance outcome based on genetic test results (Table 3). They report applications for both health and life insurance that were denied, had premiums increased, and/or had exclusions applied. Further, HPs report applicants being required to take a genetic test before being offered insurance policies, and even insurers refusing to pay out claims to family members due to genetic testing carried out on asymptomatic individuals after their death.

When asked "*what, if any, would be the benefits of a moratorium on genetic testing and life insurance in New Zealand?*" some participants considered this would provide reassurance to people considering genetic testing and reduce the potential for discrimination against patients and families.

> *"More people would be comfortable coming forward for medically necessary genetic testing." [CGC, 6–10 years of experience]*

> *"Reassurance for patients that genetic testing that would allow lifesaving intervention for the wider family will not open them up to discrimination. With genetic testing in place, many of their clients will be healthier than if genetic testing isn't possible. Knowing about a genetic condition may allow surveillance, or planning." [CGC, >20 years of experience]*

Participants were also able to provide additional comments in free text. In these comments, further concerns were expressed about GD and reduced access to genetic testing (because of GD fears) that could provide important health information.

> *"I think there should be a certain amount of cover people can get regardless of their genetics. People should not be discriminated against because of their genetic status, which they had no control over." [AGC, 0–5 years of experience]*

> *"Patients decline testing that can potentially save lives in the wider family, around concerns for insurance coverage. Because genetic testing in an affected individual is needed to provide predictive testing to unaffected relatives, this concern is detrimental to the health of the wider family."*

Table 1: Participant demographics (n=23).

Demographic	Category	Number (%)
Location	New Zealand	23 (100)
	Australia	0 (0)
Profession	Associate genetic counsellor (AGC)	5 (22)
	Certified genetic counsellor (CGC)	8 (35)
	Clinical geneticist (CG)	2 (9)
	Non-genetic HP	7 (30)
	Not stated	1 (4)
Years of experience	0–5 years	5 (22)
	6–10 years	5 (22)
	11–15 years	4 (17)
	16–20 years	4 (17)
	>20 years	5 (22)
Average number of appointments with patients considering testing (per fortnight)	0–5	7 (30)
	6–10	10 (43)
	11–20	5 (22)
	No answer	1 (4)
Area of practice	Public only	18 (78)
	Private only	0 (0)
	Public and private	4 (17)
	No answer	1 (4)
Area of genetic testing*	Diagnostic testing—adults	19 (83)
	Diagnostic testing—children	12 (52)
	Predictive testing—adults	19 (83)
	Predictive testing—children	12 (52)
	Carrier testing	14 (61)
	Prenatal testing	15 (65)
	Secondary findings—clinical	15 (65)
	Secondary findings—clinical	3 (13)

* More than one area could be selected.

Table 2: Patient attitudes, behaviours and reported experiences.

Domain	Question	Responses	Genetics HPs (%)	Non-genetics HPs (%)	Total (%)*
How often do you estimate patients delayed predictive testing (n=21)	Due to life, income, or trauma/critical illness insurance concerns?	Never	0/15 (0)	0/6 (0)	0/21 (0)
		Rarely	6/15 (40)	4/6 (67)	10/21 (48)
		Sometimes	8/15 (53)	0/6 (0)	8/21 (38)
		Often	1/15 (7)	2/6 (33)	3/21 (14)
	Due to travel insurance concerns?	Never	4/15 (27)	3/6 (50)	7/21 (33)
		Rarely	10/15 (67)	3/6 (50)	13/21 (62)
		Sometimes	0/15 (0)	0/6 (0)	0/21 (0)
		Often	1/15 (7)	0/6 (0)	1/21 (5)
How often do you estimate patients refused predictive testing (n=21)	Due to life, income, or trauma/critical illness insurance concerns?	Never	2/15 (13)	0/6 (0)	2/21 (10)
		Rarely	10/15 (67)	5/6 (83)	15/21 (71)
		Sometimes	3/15 (20)	1/6 (17)	4/21 (19)
		Often	0/15 (0)	0/6 (0)	0/21 (0)
	Due to travel insurance concerns?	Never	5/15 (33)	4/6 (67)	9/21 (43)
		Rarely	10/15 (67)	2/6 (33)	12/21 (57)
		Sometimes	0/15 (0)	0/6 (0)	0/21 (0)
		Often	0/15 (0)	0/6 (0)	0/21 (0)
Have patient/s told you about having had an adverse insurance outcome on the basis of genetic test results? (For example, having difficulty obtaining a policy, having an increased premium or having a policy application denied)? (n=22)		Yes	9/15 (60)	3/7 (43)	12/22 (55)
		No	6/15 (30)	4/7 (57)	10/12(45)

* The survey was completed online and some respondents did not complete all questions—"n" values are provided to clarify the number of respondents for each question.

Table 3: Reported adverse outcomes of testing on insurance: participant quotes.

Quotation	Participant
"They have had difficulty obtaining policies. Difficulty accessing cover because of the ambiguous language in policies or policies not covering preventative measures. Applications being denied because no testing has been completed."	ID1, AGC, 0–5 years of experience
"Denied health or life insurance."	ID6, CGC, >20 years of experience
"Application denied, exclusions and increased premiums."	ID7, CGC, 16–50 years of experience
"Many people have reported problems with accessing health insurance or increased premiums."	ID8, CGC, 6–10 years of experience
"Individuals have contacted our service prior to having genetic testing, saying that their insurance company is asking them to have a genetic test prior to obtaining a policy."	ID9, CGC, 6–10 years of experience
"Patients have tried to obtain insurance policies prior to genetic testing and was declined. Others have tried after testing and have experienced a higher premium or have been declined."	ID10, CGC, 0–5 years of experience
"Risk reducing refused, cover refused, increased premiums."	ID11, CGC, 16–50 years of experience
"BRCA1 carrier who was declined coverage for any cancer diagnosis, not just BRCA1 related cancers. Patients have chosen to go without insurance due to cost of premiums."	ID13, CGC, >20 years of experience
"Multiple family member of a LQT pedigree screened and DNA tested that owned farms had increased premiums."	ID18, non-genetics HP, >20 years of experience
Advised that life insurance wasn't going to pay out on a death because of post-mortem genetic testing (no pre-existing illness)."	ID20, non-genetics HP, 11–15 years of experience

Table 4: Regulation and moratorium.

Question	Responses	Genetics HPs (%)	Non-genetics HPs (%)	Total (%)*
Based on your professional experience, how do you feel about a moratorium with these terms as a solution to genetic discrimination in life insurance? (n=21)	Very satisfied—this is the ideal solution	1/15 (7)	0/6 (0)	1/21 (5)
	Somewhat satisfied—this is a pretty good solution	10/15 (67)	4/6 (67)	14/21 (67)
	Somewhat dissatisfied—the solution could be better	4/15 (27)	1/6 (17)	5/21 (24)
	Very dissatisfied—the solution should be much better	0/15 (0)	1/6 (17)	1/21 (5)
In your opinion, how should insurers' compliance with such a moratorium on using genetic test results in life insurance be regulated? (n=21)	Self-regulation by the life insurance industry (FSC)	2/15 (13)	2/6 (33)	4/21 (19)
	Regulation through legally enforceable rules	13/15 (87)	4/6 (67)	17/21 (81)
	Other	0/15 (0)	0/6 (0)	0/21 (0)
In the UK, there is a moratorium that involves a formal agreement between the UK government and the life insurance industry. Do you think a formal agreement between the New Zealand Government and industry (Financial Services Council) is required on this issue in New Zealand? (n=21)	Yes	13/15 (87)	5/6 (83)	18/21 (86)
	No	2/15 (13)	1/6 (17)	3/21 (14)
Do you think the New Zealand government should introduce legislation to regulate the use of genetic test results in life insurance? (n=21)	Yes	14/15 (93)	3/6 (50)	17/21 (81)
	No	1/15 (7)	3/6 (50)	4/21 (19)

* The survey was completed online and some respondents did not complete all questions—"n" values are provided to clarify the number of respondents for each question.

Table 5: Awareness, training, knowledge, professional practice.

Question	Responses		Genetics HPs (%)	Non-genetics HPs (%)	Total (%)*
Has your health service provided, or have you attended, any training or information sessions regarding the moratorium and insurance implications of genetic testing? (n=23)	Yes, formal training		0/15 (0)	0/8 (0)	0/23 (0)
	Yes, information sessions		4/15 (27)	1/8 (13)	5/23 (22)
	No		11/15 (73)	7/8 (87)	18/23 (78)
How well do you feel you now understand insurance implications for individuals undergoing genetic testing? (n=22)	Extremely well		0/15 (0)	1/7 (14)	1/22 (5)
	Reasonably well		10/15 (67)	2/7 (29)	12/22 (55)
	Not particularly well		5/15 (33)	3/7 (43)	8/22 (36)
	Not well at all		0/15 (0)	1/7 (14)	1/22 (5)
Do you feel you have sufficient knowledge about the current insurance implications of genetic testing to properly advise patients? (n=22)	Yes		7/15 (47)	2/7 (29)	9/22 (41)
	No		8/15 (53)	5/7 (71)	13/22 (59)
Number of knowledge questions answered correctly (n=21) (for question-specific data see Appendix 2)	0	"Poor knowledge"	0/15 (0)	1/6 (17)	1/21 (5)
	1		1/15 (7)	1/6 (17)	2/21 (10)
	2	"Average knowledge"	3/15 (20)	1/6 (17)	4/21 (19)
	3		5/15 (33)	3/6 (50)	8/21 (38)
	4	"Good knowledge"	4/15 (27)	0/6 (0)	4/21 (19)
	5		2/15 (13)	0/6 (0)	2/21 (10)

Table 5 (continued): Awareness, training, knowledge, professional practice.

Question		Responses	Genetics HPs (%)	Non-genetics HPs (%)	Total (%)*
Is there a statement about insurance implications... (n=22)	On your consent form, where you have a specific form for predictive genetic testing in adults? (n=7)	Yes	3/4 (75)	2/3 (67)	5/7 (71)
		No	1/4 (25)	1/3 (33)	2/7 (29)
	On your consent form, where you have a standard form for all genetic testing? (n=15)	Yes	11/11 (100)	2/4 (50)	13/15 (87)
		No	0/11 (0)	2/4 (50)	2/15 (13)

* The survey was completed online and some respondents did not complete all questions—"n" values are provided to clarify the number of respondents for each question.

[CGC, >20 years of experience]

Need for increased regulation

Over 80% (n=17/21) of HPs considered the New Zealand Government should introduce legislation to regulate use of genetic results in life insurance underwriting (Table 4). In free-text comments, some HPs specifically mentioned this should also extend to health insurance regulation.

> *"…my main concern is access to health insurance, but protection against insurance discrimination for all insurance types would be important." [CGC, 6–10 years of experience]*

Similar concerns about applicability to health insurance arose when asking about the introduction of a moratorium in New Zealand similar to that in Australia.

> *"This is a great solution for life insurance, however for New Zealand main concerns I hear from patients are around health insurance access. This is a good solution for Australia but would not address the issues here in NZ." [CGC, 6–10 years of experience]*

When asked about introduction of a moratorium in New Zealand, over 85% (n=18/21) of HPs agreed New Zealand should introduce a formal agreement between the New Zealand Government and the insurance industry against genetic discrimination in insurance as a regulatory option (Table 4). For some, the recent introduction of a moratorium in Australia was seen as progress that should be followed in New Zealand:

> *"I think it is something that urgently needs to be reviewed in New Zealand and hopefully we can use the example Australia has set." [AGC, 0–5 years of experience]*

Of 13 HPs who answered a question regarding what, if any, would be the benefits of a moratorium on genetic testing and life insurance in New Zealand, most noted either reducing barriers to testing or reducing discrimination.

> *"More people would be comfortable coming forward for medically necessary genetic testing." [CGC, 6–10 years of experience].*

> *"Huge benefits and protection for our New Zealand patients. At the moment it is unclear how exactly genetic results are being used and I think there is massive scope for discrimination that is not recognised. Insurance companies are also using a lot of misinformation and unfairly penalising families." [AGC, 0–5 years of experience]*

Of 8 HPs who answered a question about the limitations of a moratorium, issues mentioned included the lack of health insurance coverage (as noted above), the financial limits applied, lack of regulation and continued discrimination on other grounds.

Although a minority (n=4/21) felt self-regulation by the life insurance industry (FSC) was appropriate, most (n=17/21) thought insurers' compliance should be regulated through legally enforceable rules (Table 4). In free-text comments, a view was frequently expressed that self-regulated restrictions would be an improvement on the status quo, rather than the ideal solution.

> *"Government regulation would be good, but self-regulation would be better than the current [situation]." [CGC, >20 years of experience]*

A minority of HPs (n=4/21) did not support the introduction of legislation—some expressed a view that genetic information should be treated the same as other types of medical information.

> *"Genetic tests should be treated just like any other test." [Non-genetics HP, 6–10 years of experience]*

Training and awareness

An additional issue that arose was a lack of professional training and awareness around the potential insurance implications of genetic testing. No respondents reported attending formal training about this issue (Table 4). Although a minority (n=5/23) attended informal sessions on the subject, 3/5 of those indicated that these sessions did not provide adequate training.

Although all HPs (n=18) who saw adults considering predictive testing reported always discussing insurance implications with those patients, over half of respondents (n=13/22) felt they did not have sufficient knowledge to properly advise clients, and 41% (n=9/22) reported they understood the insurance implications of genetic testing

either *not particularly well* or *not well at all.* Less than 30% (n=6/21) had "good" knowledge (four or five correct answers to knowledge questions) (Table 5 and Appendix 2).

Discussion

To our knowledge, this is the first study to systematically document the views and experiences of New Zealand HPs about the use of genetic test results in insurance underwriting, including its impact on patients and its regulation.

Notably, over half of the surveyed HPs reported patients delaying genetic testing "often or sometimes" because of concerns about insurance discrimination. Concerningly, a number of respondents also reported patients refused testing altogether for this reason. Our findings highlight the urgency of the problem of GD occurring in the New Zealand insurance industry, and suggest that far stronger regulatory protections are required.

More than half of the surveyed HPs also reported patients being denied insurance policies and, in some cases where policies were already in place, denied cover for certain treatments relating to their genetic risk factors. Research in Australia similarly describes direct consumer reports of GD in life insurance, sometimes even when surgery or other preventive measures have virtually removed any disease risk.[22,25] Our findings indicate similar trends in New Zealand—future research in New Zealand should survey consumers to capture their views and experiences directly.

New Zealand HPs expressed a clear preference for increased regulation of the insurance industry. Most HPs agreed that a moratorium, similar to the UK and Australian approach, should be put in place as a temporary measure, but a strong majority also stated that the New Zealand government should introduce legislation to regulate the use of genetic results in insurance underwriting. These findings mirror the larger Australian study,[25] which shows that even after the self-regulated moratorium was introduced in Australia, an overwhelming majority of HPs believed self-regulation by life insurers was insufficient and that government regulation and legislation were required.

All HPs with adult patients considering predictive testing reported always discussing insurance implications with those patients, demonstrating that HPs recognise the importance of addressing this topic during pre-test genetic counselling. Given the role of HPs in obtaining informed consent for genetic testing, the self-identified deficits in HPs' understanding, and lack of training about the potential insurance implications of genetic testing, the current situation is concerning.

New Zealand HPs' limited awareness in this area may be exacerbated by the industry's lack of transparency and reluctance to share any information about their internal policies about use of genetic test results. New Zealand, like Australia, has a Financial Services Council (NZ FSC). While New Zealand FSC guidelines about insurers' use of genetic results were previously published online, they are no longer publicly available. Although the New Zealand FSC provided our research team in 2021 with a copy of the member guideline on genetic testing for *life insurers*, they advised no guidelines existed at the time for *health insurers*. They further advised that there is currently no standard documentation for how genetic testing information is used by the New Zealand life or health insurance industry, prompting concerns regarding how individuals or clinicians can access information about how genetic information may be used. Comments made by HPs in free text similarly raise issues regarding industry transparency and lack of information regarding how genetic test results are used. This further highlights issues with self-regulation that were raised by respondent HPs, and the need for government oversight and regulation to ensure transparency and consumer protection.

One limitation of our study is the small sample size. Given the size of the profession, however, the sample does represent a high proportion of eligible genetics HPs in New Zealand and substantial cumulative years of professional experience (over 240 years). The study also reflects similar results in a larger Australian study.[25] For non-genetics HPs, the sample size substantially limits the generalisability of the findings. Another limitation is that reports of patient experiences are second-hand, which could impact the accuracy of HPs' recollections. Future research should focus on gathering the experiences of New Zealand patients directly.

Our findings demonstrate evidence of New Zealand consumers being deterred from clinical genetic testing because of GD fears, and concerns from HPs about industry self-regulation. New Zealand HPs strongly believe government regulation of GD through national legislation is required. In order for the many benefits of genomic medicine to be realised in New Zealand, far stronger consumer protections against GD occurring in the insurance industry are required. Future research should focus on documenting experiences and views about this issue from the New Zealand public directly.

COMPETING INTERESTS
Nil.

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Appendices

Appendix 1

Demographic information	
Sex	○Male
	○Female
	○Prefer not to say
Profession	○Clinical geneticist
	○Genetics fellow
	○Associate genetic counsellor
	○Certified genetic counsellor
	○Oncologist
	○Genetic pathologist
	○Other
Profession	_____
I have been practising as a [profqualnz] for	○0–5 years
	○6–10 years
	○11–15 years
	○15–20 years
	○more than 20 years
I have been practising as a [profqualnz] for	○0–5 years
	○6–10 years
	○11–15 years
	○15–20 years
	○more than 20 years
I have been practising as a [profothernz] for	○0–5 years
	○6–10 years
	○11–15 years
	○15–20 years
	○more than 20 years
On average, the number of formal appointments I take with patients who are considering genetic testing, by phone or in person, per fortnight, is	○0–5
	○6–10
	○11–20
	○more than 20

Demographic information	
The health service where I primarily work is in the	○Private sector
	○Public sector
	○Both
The health service where I primarily work is	○Urban
	○Regional/rural
I see/speak with patients who are considering testing in the following scenarios [tick all that apply]	□Diagnostic testing in adults
	□Diagnostic testing in children
	□Predictive testing in unaffected adults
	□Predictive testing in unaffected children
	□Carrier testing for recessive conditions in adults
	□Prenatal testing
	□The return of secondary findings from clinical testing
	□The return of secondary findings from research
	□Other
Other	_____

Training and education	
Did you participate in the previous survey on genetics and insurance in 2017?	○Yes
	○No
	○I do not remember
Has your health service provided, or have you attended, any training or information sessions regarding the insurance implications of genetic testing? [select all that apply]	□Yes, formal training
	□Yes, information sessions
	□No
Do you feel this training has been adequate?	○Yes
	○No
How well do you feel you now understand insurance implications for individuals undergoing genetic testing	○Extremely well
	○Reasonably well
	○ Not particularly well
	○ Not well at all
Do you feel you have sufficient knowledge about the current insurance implications of genetic testing to properly advise patients?	○Yes
	○No

How often do you estimate patients delay or refus predictive genetic testing because of life, income or trauma/critical illness insurance concerns?				
	Often	Sometimes	Rarely	Never
Delay	○	○	○	○
Refuse	○	○	○	○

How often do you estimate patients delay or refuse genetic testing because of travel insurance concerns?				
	Often	Sometimes	Rarely	Never
Delay	○	○	○	○
Refuse	○	○	○	○
Are you, or have you been, involved in recruiting participants into research studies?	○Yes			
	○No			
How often do you estimate participants refuse or are concerned about being involved with genetic RESEARCH because of life, income or disability insurance concerns?				
	Often	Sometimes	Rarely	Never
Refuse	○	○	○	○
Concerned	○	○	○	○
Have patient/s told you about having had an adverse insurance outcome on the basis of genetic test results? (for example, having difficulty obtaining a policy, having an increased premium, or having a policy application denied)?	○Yes			
	○No			
Please provide further details (if applicable):	_____			
Does your health service have an agreed policy regarding communicating with patients about insurance that has been discussed with implications of genetic testing?	○Yes, a written policy			
	○Yes – a verbal policy that has been discussed with me or at meetings at which I was present			
	○No			
	○I don't know			

I discuss insurance implications with clients in the following scenarios: (only those which you previously selected will appear here)			
	always	sometimes	never
Diagnostic testing in adults	○	○	○
Diagnostic testing in children	○	○	○
Predictive testing in unaffected adults	○	○	○
Predictive testing in unaffected children	○	○	○
Carrier testing for recessive conditions in adults	○	○	○
Prenatal testing	○	○	○
The return of secondary findings from clinical testing	○	○	○
The return of secondary findings from research	○	○	○
[testtypeothernz]	○	○	○
You indicated that you [predadultnz:checked] discuss insurance implications for predictive testing in adults. Why is this?	_____		

Consent	
When obtaining consent for genetic testing, does your health service have a specific form for predictive testing in adults?	○Yes
	○ No, there is one standard consent form used for all testing
Does the standard consent form include a statement about insurance implications?	○Yes
	○No
Does the form contain a statement about insurance implications?	○Yes
	○No
Further details (if applicable):	_____

Personal views	
We understand that you are a health professional and not a legal or insurance professional. However, we are interested in your personal views on the following matters, based on your experience as a health professional.	
In Australia and New Zealand, life insurance companies are legally allowed to ask for and use genetic test results when underwriting policies, and can refuse cover or increase the cost of premiums on the basis of those results. Do you have concerns regarding this situation in New Zealand?	○Yes ○No
[Optional text]	_____
Are you aware that there was a change in policy on 1 July 2019 in Australia, and a moratorium was introduced on the use of genetic testing in life insurance underwriting in Australia?	○Yes ○No
How did you become aware? [select all that apply]	□Through my health service □Through a news source or social media □Through the HGSA or another professional body □Through the insurance industry directly □Other

The Australian moratorium is a self-regulated (regulated by the insurance industry, not by government) policy change. From 1 July 2019, Australian life insurers have agreed not to ask for or use applicants' genetic test results when underwriting policies worth up to **• $500,000 for life cover,** **• $200,000 for trauma/critical illness cover, and** **• $4000/month for income protection.** **For policies worth over this amount, Australian life insurers will still be able to use genetic test results when underwriting.**	
Based on your professional experience, how do you feel about a moratorium with these terms as a solution to genetic discrimination in life insurance?	○Very satisfied – this is the ideal solution
	○ Somewhat satisfied – this is a pretty good solution
	○Somewhat dissatisfied – the solution could be better
	○Very dissatisfied – the solution should be much better
[Optional text]	_____
In your opinion, how should insurers' compliance with such a moratorium on using genetic test results in life insurance be regulated? [select all that apply]	□Self-regulation by the life insurance industry (FSC) [this is the current situation in Aust]
	□Regulation through legally enforceable rules
	□Other
In the UK, there is a moratorium that involves a formal agreement between the UK government and the Life Insurance Industry. Do you think a formal agreement between the New Zealand government and industry (Financial Services Council) is required on this issue in New Zealand	○Yes
	○No
[optional comment]	_____ (Optional field)
Do you think the New Zealand government should introduce legislation to regulate the use of genetic test results in life insurance?	○Yes
	○No
[optional comment]	_____ (Optional field)

Please answer the following questions to the best of your knowledge. **In New Zealand:**			
	True	False	I don't know
If a patient has an unfavourable genetic test result, their adult child must advise a life insurance company of the parent's genetic results when applying for a new insurance policy	○	○	○
Individuals with a current life insurance policy must notify their existing insurer if they get an unfavourable genetic test result	○	○	○
Life insurance companies are allowed to discriminate based on genetic test results, but health insurance companies are not	○	○	○
If a patient with an unfavourable genetic test result undertakes risk-reducing measures such as surveillance or surgery, an insurer must take this into account when assessing their risk	○	○	○
Travel insuers are also allowed to use genetic test results when underwriting policies	○	○	○

Final comments	
In your opinion, what, if any, would be the benefits of a moratorium on genetic testing and life insurance in New Zealand? [optional]	_____ (Optional field)
In your opinion, what, if any, would be the limitations of such a moratorium in New Zealand? [optional]	_____ (Optional field)
Do you have any final comments about this issue? [optional]	_____ (Optional field)

Further contact	
As part of this research project, we may want to contact you to discuss the matters raised in this survey further. Any data collected in this follow-up interview will be de-identified before being published or shared. If you consent to being contacted for a follow-up interview, please provide your contact details below.	○I prefer to remain anonymous ○I am happy to be contacted in the future
Name	_____
Email address	_____
Best telephone contact number	_____

Appendix 2

Knowledge questions					
Question (Genetics HPs n=15; non-genetics HPs n=6)	**True/ false (correct answer)**	**Group (n=21)**	**Correct answer**	**Incorrect answer**	**Unsure**
If a patient has an unfavourable genetic test result, their adult child must advise a life insurance company of the parent's genetic results when applying for a new insurance policy.	False	Total	13/21 (62)	6/21 (29)	2/21 (10)
		Genetics HPs	10/15 (67)	4/15 (27)	1/15 (7)
		Non-genetics HPs	3/6 (50)	2/6 (33)	1/6 (17)
Individuals with a current life insurance policy must notify their existing insurer if they get an unfavourable genetic test result.	False	Total	15/21 (71)	5/21 (24)	1/21 (5)
		Genetics HPs	13/15 (87)	2/15 (13)	0/15 (0)
		Non-genetics HPs	2/6 (33)	3/6 (50)	1/6 (17)
Life insurance companies are allowed to discriminate based on genetic test results, but health insurance companies are not.	False	Total	15/21 (71)	0/21 (0)	6/21 (29)
		Genetics HPs	12/15 (80)	0/15 (0)	3/15 (20)
		Non-genetics HPs	3/6 (50)	0/6 (0)	3/6 (50)
Travel insurers are also allowed to use genetic test results when underwriting policies.	True	Total	9/21 (43)	3/21 (14)	9/21 (43)
		Genetics HPs	7/15 (47)	1/15 (7)	7/15 (47)
		Non-genetics HPs	2/6 (33)	2/6 (33)	2/6 (33)
If a patient with an unfavourable genetic test result undertakes risk-reducing measures such as surveillance or surgery, an insurer must take this into account when assessing their risk	True	Total	8/21 (38)	6/21 (29)	7/21 (33)
		Genetics HPs	6/15 (40)	5/15 (33)	4/15 (27)
		Non-genetics HPs	2/6 (33)	1/6 (17)	3/6 (50)