Australian Genetics and Life Insurance Moratorium: Monitoring the Effectiveness and Response (A-GLIMMER)

INTERIM STAKEHOLDER REPORT

AUGUST 5, 2022

A-GLIMMER

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Interim Stakeholder Report

5 August 2022

Endorsed by

Collaborators

Patient/Consumer Groups

Executive Summary

The field of genetics has great potential to improve medicine and public health, through enabling diagnosis, prevention and early treatment of disease. However, currently in Australia the life insurance industry is legally permitted to use genetic test results in underwriting, which can lead to discrimination. Insurance fears can also deter people from having potentially life-saving genetic testing and participating in genetic research.

In 2018, a Joint Parliamentary Committee Inquiry into the Life Insurance Industry recommended that Australia urgently implement a Mortarium (or ban) on the use of genetic test results in life insurance underwriting, similar to the moratorium operating in the UK since 2001. In 2019, the life insurance industry body, the Financial Services Council (FSC), introduced a temporary moratorium (1 July 2019 to 30 June 2024) requiring applicants to disclose genetic test results only for policies above certain financial limits. The FSC Moratorium is industry self-regulated, with no government oversight.

To monitor the impact of the FSC Moratorium as a regulatory solution to genetic discrimination in Australian life insurance, the Commonwealth government funded the Australian Genetics and Life Insurance Moratorium: Monitoring the Effectiveness and Response (A-GLIMMER) Project from 2020-2023. This independent project aims to gather evidence to assess the effectiveness of the FSC Moratorium, and report findings to government and other stakeholders. The project team has undertaken several research studies, including with health professionals, consumers, researchers, and financial advisors, to assess the impact of the FSC Moratorium from the perspective of those groups.

As at the date of publication of this interim report, some of the A-GLIMMER research studies have been published in peer-reviewed journals. Others are underway but yet unpublished, and are presented here as preliminary findings. At the conclusion of the A-GLIMMER project (in July 2023), all of the project's final research findings will be synthesised into a Final Stakeholder Report. The final report will aim to inform the Commonwealth government's assessment of the FSC Moratorium and consideration of further regulation, and make recommendations based on the findings.

The following concerns are raised by the interim project findings, regarding the FSC's Moratorium:

- although the introduction of the current FSC Moratorium is seen as a positive step forward, there is uncertainty about whether it is achieving its intended goals, especially with regards to protecting consumers and enabling research participation;
- the self-regulatory nature of the FSC Moratorium does not involve any government oversight;
- the temporary time period of the FSC Moratorium causes uncertainty regarding the use of genetic test results obtained now, beyond the current end date (30 June 2024);
- the FSC Moratorium's financial limits (e.g. life insurance policies <$500K) do not align with current average mortgages and costs of living; and
- there is poor awareness and knowledge about the FSC Moratorium among some stakeholders.

Several noteworthy research findings have emerged from the A-GLIMMER project thus far:

- Among surveyed members of the general public, 86% (823/957) said the potential for life insurance companies to use results may or definitely would decrease their likelihood of having genetic testing. 80% (773/963) had the opinion that life insurers should not be allowed to use genetic results in underwriting, and 78% (741/945) had the opinion that the government should introduce legislation to regulate this issue. Only 22% (209/940) considered ≤$500,000 to be the appropriate financial cover limit in the FSC Moratorium [unpublished findings].
- Surveyed patients who had, or were eligible for, certain genetic tests continue to report difficulties obtaining life insurance cover post-FSC Moratorium. 82% (288/350) believe life insurers should not be allowed to use genetic test results in underwriting and 91% (333/367) agreed with a statement that the government should introduce legislation on this issue. 74%; (256/348) didn't know whether life insurers are legally allowed to use genetic test results in underwriting; only 4% (14/350) believed this practice should be legal. Only 16% (54/341) felt ≤$500,000 was the appropriate financial limit [unpublished findings].
- There is a lack of awareness regarding the FSC Moratorium among financial advisors (8 interviewed). Some indicated that the FSC Moratorium limits were inadequate given the average Australian salary and mortgage, and many commented on clients' limited ability to seek recourse if an adverse decision was made [unpublished findings].
- 88% (127/144) of surveyed health professionals (HPs) who discuss genetic testing with patients reported ongoing concerns about insurance discrimination post-FSC Moratorium. 93% (139/149) thought the government should introduce legislation on this issue. Most HPs (86%; 142/166) were aware of the FSC Moratorium, but not all had good knowledge of its terms [published findings].
- 60% (36/60) of surveyed genetics researchers reported potential use of genetic results by insurers is a barrier to study recruitment, and 47% (25/53) said insurance concerns had been raised by research participants since the introduction of the FSC Moratorium. Researchers reported concerns about the uncertainty involved in the temporary nature of the FSC Moratorium. 85% (44/52) believed the government should introduce legislation to regulate insurer use of genetic results. 77% (40/52) believe the financial limits are too low [unpublished findings].

Conclusion

The interim A-GLIMMER Project findings suggest that from the perspective of varied stakeholder groups, the FSC Moratorium may not be an adequate, long-term regulatory solution for Australia, and may not meet the 2018 Joint Parliamentary Committee Inquiry recommendations.

Contents

Section A: Background

1. Genetic Discrimination in Life Insurance

The use of genetic test results in life insurance underwriting is an ethical and legal issue of international concern. Increasingly, genomic information is used in routine patient care to identify individuals at risk for medically actionable conditions. Knowing of this risk early can allow at-risk individuals to take preventive steps to reduce their risk or, in some cases, avoid developing the associated disease altogether. However, the use of genomic information by life insurers can lead to discrimination and research shows that insurance fears deter many at-risk people from having genetic tests and being involved in genomic research[1]. Many countries have accordingly banned or restricted the use of genetic test results by life insurers.[2] (see Appendix 1). In Australia, life insurance companies are still legally permitted to use genetic test results in underwriting. This practice is self-regulated by the life insurance industry body, the Financial Services Council (FSC). The *Disability Discrimination Act 1992* (Cth) (the Act) permits insurers to use genetic test results to discriminate between applicants for risk-rated insurance (see Appendix 2).[3]

Life Insurance in Australia encompasses insurance policies covering death; total and permanent disability; trauma and critical illness; and income protection, salary continuation or business expenses.[4] Life insurance policies are risk-rated, meaning individual risk factors can be considered by insurance providers when deciding whether to cover an applicant. In comparison, health insurance in Australia is community-rated and individual risk factors cannot be considered, meaning health insurance policies are not subject to genetic discrimination at this time.[5]

2. The FSC Moratorium on genetics and insurance

Recommendations of Joint Parliamentary Committee Inquiry into the Life Insurance Industry

In 2018, a Joint Parliamentary Committee Inquiry into the Life Insurance Industry ("the Inquiry") recommended that Australia urgently implement a Mortarium (or ban) on the use of genetic test results in life insurance underwriting, similar to the moratorium operating in the UK since 2001[6]. In making this recommendation, the Inquiry considered:

- evidence that individuals had been denied cover, and charged higher premiums;[7]
- the increasing use and relevance of genetic testing;[8]
- the discouragement of individuals to seek important genetic tests for their health;[9]
- reduced participation in research involving genetic tests;[10]
- the prohibition/restriction on the use of genetic results in underwriting internationally, including in the UK, the US and Canada;[11] and
- the lack of evidence that the life insurance market would be undermined by such a prohibition.[12]

The Australian government has not responded to these recommendations. In July 2019, however, the FSC introduced a partial and self-regulated moratorium (or ban) which limits the requirement for consumers to disclose genetic test results in life insurance applications, applying only to policies up to certain financial limits ('the FSC Moratorium').[13] The FSC Moratorium applies to applications for life insurance received on or after 1 July 2019. Unless extended, the FSC Moratorium ends on 30 June 2024.[14] The FSC Moratorium is not law and does not legally prevent insurers using genetic test

results in underwriting, or change the operation of the *Disability Discrimination Act 1992* (Cth). It cannot be legally enforced.

What does the FSC Moratorium cover?

Up to certain financial limits, the FSC Moratorium prohibits FSC members who carry on life insurance business[15] from asking for or using genetic test results in their underwriting processes (unless a condition has been diagnosed from the result);[16]

The FSC Moratorium only applies in relation to applications for cover below certain financial amounts. It **does not** apply where an individual is applying for, or will hold in total, life insurance above:

- AUD$500,000 for lump sum death cover;
- AUD$500,000 for total permanent disability cover;
- AUD$200,000 for trauma and/ or critical illness cover; or
- AUD$4000 per month for income protection, salary continuance or business expenses cover.[17]

Importantly, the financial limits apply cumulatively across policies – applicants who already hold some cover are only protected if all policies they hold (including with different insurers) total less than the above amounts. Further, the limits do not operate independently - if an individual applies, for eg, for income protection cover of $5000/month, and also for $100,000 in trauma/critical illness cover, the FSC Moratorium will not prevent the insurer from using genetic test results to underwrite either product. This is because applying for a level of cover above the financial limits in any category means that the FSC Moratorium's protection will not apply to any aspect of an individual's application. The insurer may consequently reject, impose exclusions or charge higher insurance premiums for each or both applications for insurance, on the basis of the genetic test information.

Under the FSC Moratorium, life insurance providers **are** required to consider:

- a favourable genetic test result that an applicant chooses to disclose;
- preventative treatment or adherence to preventative measures to reduce the risk of the development of an illness that runs in an applicant's family.[18]

The requirement to consider preventative measures is already implicitly required by the current legislative regime (see below and Appendix 1).[19]

The FSC Moratorium does not, therefore, provide stronger protections for individuals that take such measures than the Act already provides.

3. Monitoring by Government

The Inquiry also recommended that the Commonwealth government 'monitor developments in genetics and predictive genetic testing to determine whether legislation or another form of regulation banning or limiting the use of predictive genetic information by the life insurance industry is required.'[20] We are not aware of any active steps to implement this recommendation. In March 2021, in response to our query about the lack of government response on this issue, the Secretariat of the Parliamentary Joint Committee informed us that the Treasurer had advised that the then-Government had committed to implementing reforms in response to the Financial Service Royal Commission, some of which related to recommendations of the Parliamentary Joint Committee's recent inquiries[21].

Section B: Assessing the Impact of the FSC Moratorium

The A-GLIMMER Project is funded by the Commonwealth government to gather evidence from Australian stakeholders about the impact and effectiveness of the FSC Moratorium (see **https://www.monash.edu/medicine/a-glimmer/home**). The project has designed a number of different research studies specifically to collect a diverse range of evidence from consumers, patients, health professionals, genetic researchers and the financial services industry. Data from these studies is being collected and analysed using a mixture of quantitative and qualitative research methodologies. The evidence gathered will be synthesised into a Final Stakeholder Report at the conclusion of the Project in mid-2023. The Final Stakeholder Report is intended to inform the Commonwealth government's assessment of the FSC Moratorium's effectiveness. The A-GLIMMER Project's study design is outlined in Figure 1 below. A detailed study protocol, including information on project methodology, has been published (see Appendix 4).

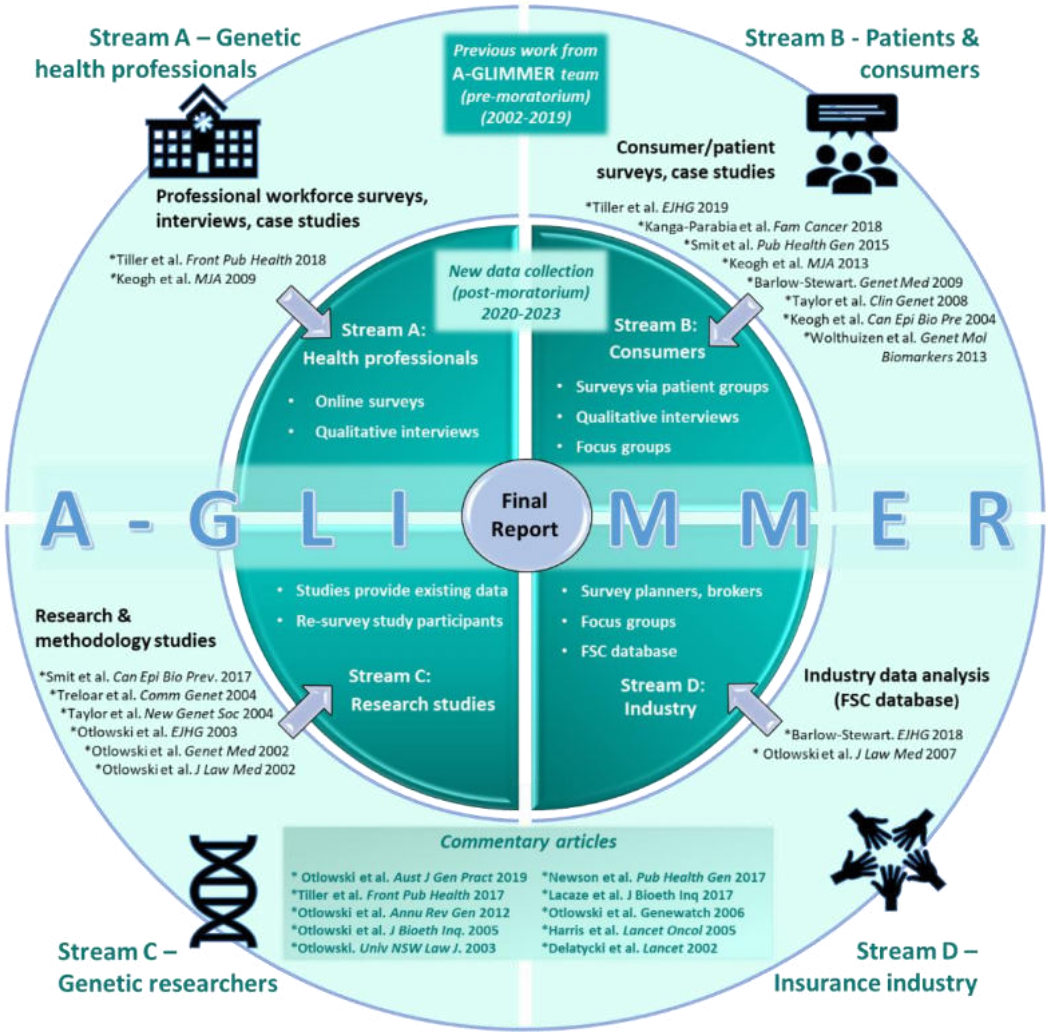


Figure 1 *Tiller et al, 'Study Protocol: the Australian Genetics and Life Insurance Moratorium – Monitoring the Effectiveness and Response (A-GLIMMER) Project' (2021) 22(63) BMC Medical Ethics 1, 2*

1. Aims of prohibition on use of genetic test results in underwriting

The Inquiry report discussed a number of concerns with the use of genetic test results by insurers, and recommended an urgent ban to address these concerns. The A-GLIMMER project has identified these primary concerns as **Aims** against which the impact of the FSC Moratorium can be measured[22]. These aims, with references to the relevant paragraphs in the Inquiry report, are:[23]

1. To reduce consumer fears related to insurance, which deter the uptake of clinical genetic testing and/or research participation (ss 9.89 & 9.90)
2. To eliminate genetic discrimination in the Australian life insurance industry (ss9.84 &9.86)
3. To remove a barrier currently compromising the success of genetic medicine in Australia (s9.89)
4. To ensure Australian government oversight and monitoring to combat concerns with industry self-regulation (ss 9.94 & 9.96)

To meet these Aims, the FSC Moratorium must achieve certain **Outcomes**, which the A-GLIMMER Project has identified as part of its methodology to assess the effectiveness of the FSC Moratorium. The **Outcomes** that must be achieved by the FSC Moratorium (in order to meet its Aims) are:[24]

1. widespread and accurate awareness of the existence of the FSC Moratorium and its terms among consumer and patient groups, health professionals, genetic researchers and research participants, ethics committees, financial industry members and regulators;
2. confidence among consumers, patients, health professionals, researchers and the insurance industry that the FSC Moratorium terms are strictly adhered to, and that breaches are rectified;
3. timely and regular updates to policy, practice and processes in health care, industry and research to reflect the FSC Moratorium (e.g. industry practices, policy and processes, consent forms for genetic testing, policy and practice in genetics services and human research ethics committee (HREC) guidelines); and
4. adherence to the terms of the FSC Moratorium in the collection and use of genetic test results by all insurance companies, in practice.

Section C: Overview of A-GLIMMER Interim Research Findings

To date, the A-GLIMMER Project has undertaken several different research studies to survey the opinions, attitudes and knowledge of Australian stakeholders. These include health professionals, patients with experience of genetic testing, members of the Australian general public, and genetic researchers. We have also conducted interviews with financial advisors and undertaken an evaluation of the FSC Moratorium against the recommendations of the Inquiry.

1. Health Professionals (HPs)

The A-GLIMMER Project has completed two studies focusing on the opinions, attitudes and knowledge of Australian genetic health professionals' ('HPs') regarding the FSC Moratorium. This includes a survey completed by 166 clinical geneticists, genetic counsellors and other HPs who regularly discuss genetic testing with patients, published in the *Journal of Medical Genetics*[25]. Secondly, a follow-up study of qualitative interviews has been published in the *European Journal of Human Genetics*[26], with a select number of HPs who had previously completed the first survey. Copies of these published studies can be found in Appendix 5.

Health professionals' views on the FSC Moratorium and regulation

Many surveyed HPs (76%; 110/144) felt that the FSC Moratorium resolved some of their concerns about the protection of patients from genetic discrimination. However most (88%; 127/144) still had concerns about genetic discrimination following the introduction of the FSC Moratorium. A vast majority of HPs consider that a formal agreement between the Australian government and the life insurance industry was needed (95%; 141/149, ***Figure 2***).

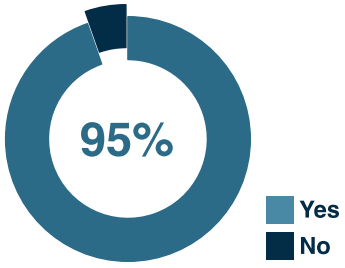


Figure 2 *Is a formal agreement between government and industry required in Australia? (n=149)*

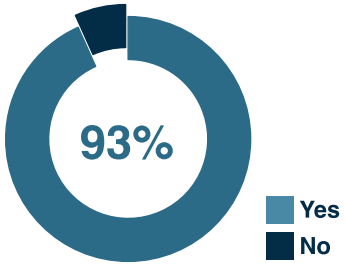


Figure 3 *Should the Australian Government introduce legislation to regulate the use of genetic test results in life insurance? (n=149)*

When asked about how insurers' compliance with the FSC Moratorium should be regulated, 88% (131/139) of HPs chose 'regulation through legally-enforceable rules'. Further, 93% (139/149, ***Figure 3***) said that legislation should be introduced to regulate life insurers' use of genetic test results. The findings of the second HP study mirror those expressed in the first HP study. Participants in the second study generally considered the introduction of the FSC Moratorium as an important first step towards addressing genetic discrimination in life insurance. However, most HPs expressed ongoing concerns about the temporary nature of the FSC Moratorium and their resulting inability to reassure patients about whether and how the FSC Moratorium will operate in the future. Surveyed HPs were also concerned that the FSC Moratorium's financial limits were too low for the needs of their patients, with 44% (28/64) of surveyed participants noting concerns about the financial limits in free text comments.

HPs expressed strong dissatisfaction with the self-regulatory nature of the FSC Moratorium, and, in addition, reported low trust in the insurance industry. 45% (29/64) of surveyed participants noted concerns in free text comments about insurer compliance and self-regulation. HPs in the qualitative study frequently emphasised the need for more stringent regulation, both to reassure patients and to ensure compliance by insurance providers.[27]

Impact of the FSC Moratorium on Clinical Practice

HPs reported a small improvement in the number of patients who delayed or declined genetic testing since the introduction of the FSC Moratorium because of concerns about insurance. However, a number of HPs reported patients still delaying (39%; 60/154, ***Figure 4***) or declining (18%; 27/154, ***Figure 5***) genetic testing after the FSC Moratorium due to their concerns about life insurance.[28]

Figure 4 *How often did patients* ***delay*** *predictive testing due to life insurance concerns? (n=154)*

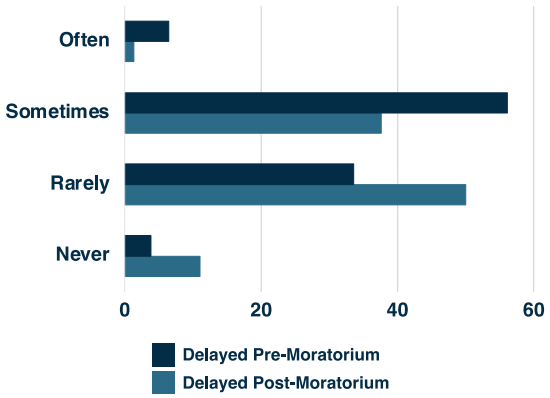
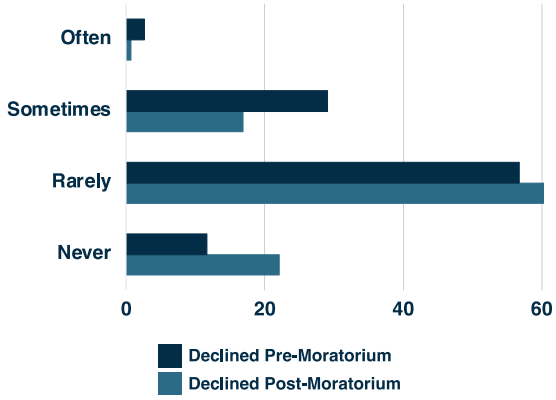


Figure 5 *How often did patients* ***decline*** *predictive testing due to life insurance concerns? (n=154)*



FSC Moratorium Awareness, Knowledge and Training

The first HP study found that most HPs (86%; 142/166, ***Figure 6***) were aware of the FSC Moratorium. However, awareness was much lower (53%; 24/45) amongst non-genetic HPs. Further, only half (49%; 71/146, ***Figure 7***) of HPs displayed good knowledge (5-6 correct questions) about the FSC Moratorium. A large proportion of HPs considered that the FSC Moratorium was easy to understand and explain to patients (80% [116/145] and 76% [109/144] respectively). Nevertheless, a significant number did not think that patients were less confused about the implications of genetic tests for life insurance (49%; 71/144) or more willing to have genetic testing because of the FSC Moratorium (42%; 59/144).

Figure 6 *Are HPs aware of the FSC moratorium? (n=166)*

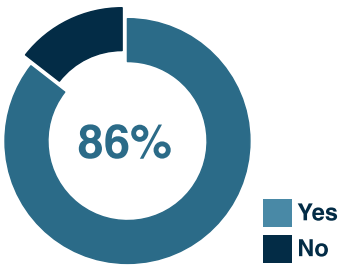
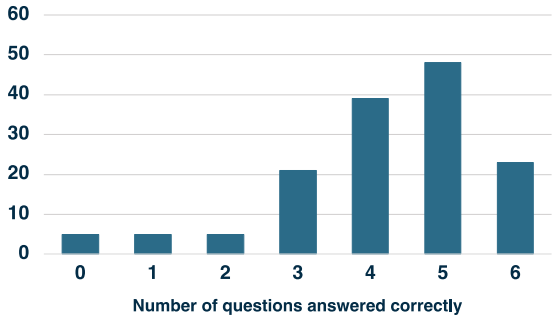


Figure 7 *HPs' objective knowledge scores (n=146)*



Dermatologists' survey

We surveyed Australasian dermatologists about genomics, and found that while over 90% of respondents agreed that genetic testing for melanoma could be of value to patients, 84% believed that genetic testing could negatively impact access to life insurance.

2. Consumers (*unpublished*)

The A-GLIMMER Project has undertaken two research studies focused on surveys of consumers with and without experience of genetic testing. Both are currently unpublished and presented as preliminary findings.

The Patient Study

The first study surveyed 341 Australian patients who had, or were eligible for, certain genetic tests.[29] Individuals were eligible to participate if they were over the age of 18 years and had been tested, offered testing, or who had a first-degree blood relative that had been tested. Notably, 29% (94/326) of participants had testing after the FSC Moratorium was introduced.

A large number of all participants (74%; 256/348) didn't know whether Australian life insurance companies are legally allowed to use genetic test results in underwriting or not, and 9% incorrectly believed they are not allowed to. Only 4% (14/350, ***Figure 8***) believed this practice should be legally allowed. 73% (219/300) of participants believed that the fact that compliance with the agreement by insurers is self-regulated by the insurance industry without government oversight is a negative aspect of the FSC Moratorium (only 7% felt it was positive). A very high number agreed or strongly agreed that government should introduce legislation to regulate this area (91%; 298/340, ***Figure 9***); only 3% (9/340) disagreed.

Figure 8 *Should Australian life insurance companies be legally allowed to use applicants' genetic test results in underwriting? (n=350)*

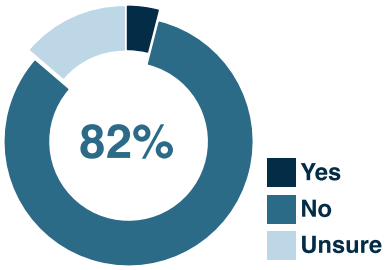
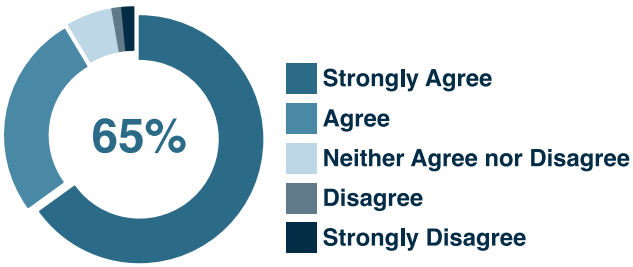


Figure 9 *The Australian government should introduce legislation (which is made and enforced by government) to regulate life insurers' use of genetic test results (n=340)*



While 77% (234/305) said the fact that people don't have to disclose genetic test results under certain financial limits is a positive aspect, only 16% (54/341)) felt that $500,000 or less was the amount of life insurance cover that applicants should be allowed to apply for without being required to disclose their genetic results.

Difficulties in obtaining life insurance products were reported by 36% (53/149) of participants who had applied for life insurance products (149/279). These difficulties included: insurers rejecting applications for life insurance; financial advisers telling participants that their applications would be rejected; insurers placing conditions on insurance policies or charging higher premiums. Of those who answered, 24% (12/51) reported this happening after the introduction of the FSC Moratorium on 1 July 2019.

Half of the participants who had decided against, or had not yet had, genetic testing[30] reported that concerns about life insurance had a moderate or significant effect on their decision making (50%; 7/14).[31] Further, participants showed low awareness and understanding of the FSC Moratorium: 84% (286/340) had never heard of the FSC Moratorium. Few participants (15%; 51/341) felt that $500,000 or less was an appropriate amount of life cover for applicants to be able to apply for without having to disclose their genetic results. 76% (228/302) of participants believed that the fact that the agreement is not permanent was a negative aspect of the FSC Moratorium (only 3% felt it was positive).

The General Public Study

The second study was conducted in partnership with the Australian Survey of Social Attitudes (AuSSA), which surveyed Australian citizens quarterly from May 2021 to February 2022.[32] The preliminary findings, of 1060 respondents (23% response rate) closely reflect those of the above Patient Study. A very low proportion (3%; 25/962) of participants knew about the FSC Moratorium, and only 14% (136/963) knew that it is legal for life insurance companies to use genetic test results in underwriting. Very few respondents (7%; 67/963) believed this practice should be legal. An overwhelming number (86%; 823/957) reported that the potential for life insurers to use genetic test results may, or would definitely, decrease the likelihood that they would undergo genetic testing. While 68% (620/912) said the fact that people don't have to disclose genetic test results under certain financial limits is a positive aspect, only 22% (209/940) felt that $500,000 or less was the amount of life insurance cover that applicants should be allowed to apply for without being required to disclose their genetic results. 60% (533/888) of participants believed that the fact that compliance with the agreement by insurers is self-regulated by the insurance industry without government oversight is a negative aspect of the FSC Moratorium (only 10% felt it was positive). Further, a large majority (78%; 741/945) agreed or strongly agreed that government should legislate to regulate the use by insurers of genetic test results, and only 5% (51/945) disagreed. 55% (498/907) of participants believed that the fact that the agreement is not permanent was a negative aspect of the FSC Moratorium (only 13% felt it was positive).

The research participants study

We surveyed participants in a genetic screening study who were provided with information about testing and were able to provide a DNA sample immediately or take a cheek swab home and send it back at a later date. Of the respondents who answered the survey, 7% (41/575) took the swab home and sent it back at a later date. Of those, 60% (23/41) reported that they delayed testing because they wanted to consider their life insurance situation before doing the testing.

3. Genetic Researchers (*unpublished*)

The A-GLIMMER Project is assessing the FSC Moratorium's impact on the conduct of genetic research and on genetic research participants. Preliminary results (unpublished) have found that a large number of surveyed genetic researchers are of the opinion that there should be a formal agreement between government and industry (81%; 42/52) and/or that the government should introduce legislation on this issue (85%; 44/52).

Many genetic researchers (60%; 36/60) reported that the potential use of genetic results by insurers is a barrier to the recruitment of genetic research participants. Almost half (47%; 25/53) of surveyed researchers reported that participants in genetic research had expressed concerns about insurance since the FSC Moratorium's introduction. A large proportion of genetic researchers (77%; 40/52) considered the FSC Moratorium's financial limits to be too low, with 71% (37/52) reporting that it should be $1,000,000 or unlimited, and only 10% (5/52) reporting that it should be $500,000.

Researchers made comments about the uncertainty involved in the temporary nature of the FSC Moratorium, and 65% (34/52) believed it should be permanent. Some comments noted that although a permanent solution is preferred, the FSC Moratorium needs to be improved to further protect consumers first.

A low number of genetic researchers had updated their Patient Information and Consent Forms (33%; 19/57) or their consent discussions with patients (30%; 16/53) following the introduction of the FSC Moratorium. Finally, awareness of the FSC Moratorium amongst genetic researchers was not comprehensive – only 67% (40/60) were aware of it and only 52% (31/60) felt they knew enough to carry out their current research roles.

4. Financial Advisers (*unpublished*)

To date, the A-GLIMMER project has conducted 8 research interviews with Australian financial advisors, each of which comprises a recorded telephone interview for 30-60 minutes. Preliminary analysis of these interviews suggests that some financial advisers are of the opinion that the FSC Moratorium's financial limits are too low, particularly given the average Australian salary and mortgage. As of May 2022, the average Australian mortgage was over $615K, and in Victoria and NSW the average mortgage was over $643K and $780K respectively.[33] These figures are well above the FSC Moratorium's financial limits.

Advisers also suggested that generally their clientele require a level of cover that does not fall within the FSC Moratorium's limits, meaning the FSC Moratorium confers no real protection for the majority of clients they see. It was suggested that generally the clientele which seek assistance from a financial advisor tend to be higher-income earners who are unlikely to fall within the FSC Moratorium's limits. Many advisers commented on the fact that clients had very limited (if any) ability to seek recourse if an adverse decision is made. Many participants indicated that they could not comment on whether the industry was complying with the FSC Moratorium in absence of evidence. However, a participant indicated that some life insurance companies have indicated that they would decline cover for a client with a genetic test result even when their application fell within the financial limits set out in the FSC Moratorium. Some participants suggested that based on their experience, they believed insurance companies would attempt to decline cover or increase the premium on another, unrelated basis if there was an inadvertent disclosure of a genetic test result for an application that fell within the FSC Moratorium limits. These claims need to be substantiated by further research and documentation.

Our research with financial advisers shows, similarly to other stakeholder groups, a general lack of awareness of the FSC Moratorium. There was some suggestion that advisers were likely to only find out about the FSC Moratorium if they had a client who had undertaken genetic testing. This is concerning because most individuals engage a financial adviser to broker and otherwise assist with applications for life insurance. In many respects, financial advisers are conduits for communication between individual applicants and life insurers.

Section D: Regulatory Evaluation

1. Does the FSC Moratorium Implement the Inquiry's Recommendations?

There are significant differences between the 2018 recommendations of the Parliamentary Joint Committee Inquiry into the Life Insurance Industry and the Moratorium which has now been introduced by the FSC. Australian consumers are more susceptible to genetic discrimination in life insurance than their counterparts in many other countries worldwide. This includes the United Kingdom, whose model was the basis for the Inquiry's recommendations.[34]

An evaluation of the FSC Moratorium against the Inquiry's key relevant recommendations is set out below, and further detail is included in Table 2, Appendix 7.

Development of policy in discussion with AGNDWD:

> *"The FSC, in discussion with the AGND Working Group, should prohibit any life insurers from using the outcomes of predictive genetic tests at least in the medium term" (s9.93).*

Prior to its introduction, the Working Group provided written feedback to the FSC regarding the draft FSC Moratorium document (see Appendix 8). A number of matters were not addressed, as set out in Table 3 (Appendix 9).

Concordance with UK Code (formerly Moratorium)

> *"This should be done as a matter of some urgency and take a form similar to the United Kingdom's Moratorium. However, similar to the United Kingdom's Moratorium, this prohibition should not prevent a consumer from being able to provide genetic information to a life insurer in order to demonstrate that they are not at risk of developing an inherited condition" (s9.93).*

A comparison of key aspects of the UK Code and the FSC Moratorium is at Table 4 (Appendix 9).

The UK Code prohibits all use of genetic test results by life insurers, with one exception – applicants for death cover with a HD predictive result, for policies worth >£500,000 (~AU$900,000). Use of any results for other types of insurance is currently prohibited. By comparison, in Australia there are financial limits (as discussed above) on all of these types of insurance for all genetic test results.

When it announced the FSC Moratorium, the FSC stated that "the insurance cover limits compare favourably with other countries, being closely aligned to Switzerland and Germany". However, the limits are not generally consistent with approaches taken internationally. Most countries where bans exist have no financial limits at all, according to a 2017 Geneva Institute report.[35] Of 20 countries (other than Australia) it lists, 13 (65%) do not require disclosure of genetic results to insurers in any circumstances (with no limits) (see Figure 2, Appendix 9). Some countries (like Portugal) even ban the collection of family history information. Only 4 (20%) of the 20 countries have financial limits of any kind. Of those, one is the UK, which is the model recommended by the Inquiry report.

The limits in place in Germany and Switzerland are both part of legislation, with criminal penalties applicable for breach. In Switzerland, genetic test results are not provided to the insurer but to a designated doctor, only if the results of the test are reliable both technically and in medical practice, and for which the scientific value of the test for the calculation of premiums has been demonstrated.

The doctor can only provide to the insurer the risk group the insured should be in and no other details. Thus, although the FSC have adopted these lower limits, they have done so in a context which is entirely different, and subject to far less regulation and oversight. The Netherlands is the only other country listed with financial limits on its regulations – and it also limits the asking of all hereditary questions below those limits (including family history questions, not merely the results of genetic tests).

Further, all research results are excluded from disclosure in the UK. In Australia, disclosure of all genetic results which an applicant knows is required once the financial limit is reached.

Protection of tests taken while the FSC Moratorium is in place:

> *"Any moratorium arrangements should apply indefinitely to predictive genetic test results obtained before the lifting of the moratorium, if it is lifted, to avoid sharp jumps in premiums for existing insureds" (s9.93).*

The introduction to the FSC Moratorium states, "It is important that public concerns about the use of Genetic Test results in life insurance do not dissuade people from taking Genetic Tests or taking part in genetic research." However, the FSC Moratorium as drafted fails to ensure certainty for individuals about the future use of their genetic test results. During preliminary discussions, the Working group provided the FSC with the following draft clauses (which were not included in the final document) to achieve this aim:

a) Customers who have taken a Genomic Test before the date of this Moratorium will be treated in the same way as Customers taking tests under the terms of the Moratorium.

b) The terms of this moratorium will apply indefinitely to Customers who take a Genomic Test under the terms of this moratorium, even if it is subsequently lifted, amended, or curtailed, to ensure consistency and predictability for individuals.

Co-regulatory approach to address concerns with self-regulation:

> *"The committee acknowledges the significant concerns raised during this inquiry about the conflicts of interest inherent in the FSC's self-regulatory regime… the committee supports the co-regulatory approach outlined in the ASIC Enforcement Review Taskforce Position Paper, particularly the requirements for industry codes to be registered" (s9.94).*

The Inquiry acknowledged concerns expressed by the AMA, RACGP and others about inherent conflicts of interest in a self-regulatory approach to a ban on the use of genetic testing by the insurance industry. However, the Inquiry considered that these concerns could be alleviated if ASIC was granted certain enforcement powers, including the approval (via registration) of the moratorium; the moratorium's mandatory application to all industry participants; and the application of financial penalties for breaches of the moratorium. The Inquiry described this as a 'co-regulatory' model. ASIC has not, however, been provided with these powers in relation to the FSC Moratorium.

There are steps that can be taken to improve oversight of compliance with the FSC Moratorium. The FSC Moratorium has not yet been included in the Life Insurance Code of Conduct. This would enable compliance to be overseen to some extent by the Life Code Compliance Committee. Even if this were to occur, however, the sanctioning powers of the Committee are extremely limited, and the Committee

itself has expressed concerns about compliance with, and enforcement of, the Code.[i] This is a concern that is reflected in our preliminary research with financial advisers, many of whom commented on the very limited recourse that individual insurance policy applicants have to enforce the terms of the FSC Moratorium.

The Inquiry recommended that legislative prohibition on the use of genetic information by life insurers should be implemented if there were failures in compliance, or if it were otherwise appropriate in light of developments in genetics and genetic medicine. The A-GLIMMER Project has emerging and increasing concerns that the FSC Moratorium is not meeting its aims and suggests that an alternative regulatory model should be considered.

The FSC Review

Under the FSC Moratorium terms, the FSC is required to conduct a review in 2022, with a view to extending its operation beyond 2024. The review must be undertaken in consultation with consumer groups and expert stakeholders and consider a range of issues including the financial limits described above.[36] The FSC has invited the Australian Genetic Non-Discrimination Working Group (many members of which lead the A-GLIMMER Project) to make a submission to the review. The A-GLIMMER Project has significant concerns about the robustness of the FSC review because:

- The methodology to be used to conduct the review has not been disclosed or discussed with stakeholders. The questions posed for submission are narrowly construed.[37]
- We have previously advised the FSC that it will be important for them to obtain feedback and submissions from a broad variety of stakeholders, including consumer groups. However, it appears that the FSC has only encouraged submissions to the review from specific stakeholders. In correspondence, the FSC stated that the invitation to make a submission would be extended to the Actuaries Institute, members of the FSC's own Consumer Advocates Form and FSC members.[38] No other consumer groups, outside of the FSC, appear to have been invited to make a submission, nor have we been aware of any further promotion of the review by the FSC.[39]
- No advance notification was given regarding the timing of the review, and only one month was initially given for submissions to be prepared[40], although we successfully sought an extension of one week to finalise our submissions.
- There are problems with the data that will inform the FSC's review. The FSC has stated that data has been collected from the life insurance industry 'since the start of 2021' to inform the review.[41] In contrast, the FSC Moratorium requires, since 2019, that all life insurers 'record anonymous details of all Genetic Test results received as part of the Underwriting process, whether or not the Life Insurance Provider asked for them, on the FSC database of Genetic Test results.'[42] We raised a number of issues with the FSC regarding missing data. For the vast majority of instances where genetic results have been used and adverse outcomes were reported, both the condition and type of test are merely recorded as "other" or "don't know". This tells us nothing about the test that was done, the type of condition, whether it was diagnostic or predictive, etc. It is difficult to comprehend how an insurer could make an adverse decision on the basis of genetic test

[i] Code Committee Raises Concern Over Drop in Significant Breach Reporting', *Insurance News* (online, 4 October 2021) <https://www.insurancenews.com.au/life-insurance/code-committee-raises-concern-over-drop-in-significant-breach-reporting>; 'Insurers Criticised Over Life Code Obligations', *RiskInfo*, (online, 29 June 2020) < https://riskinfo.com.au/news/2020/06/29/insurers-criticised-over-life-code-obligations/>.

results that they did not know the details of. Despite the requirement that member companies complete the database, the FSC advised that they would not be asking insurers for any of this missing data. Further, when providing feedback on the database, the Working Group went to great lengths to explain the importance of free text to ensure that accurate information was obtained. However, this was not included.

- Prior to the review, the FSC issued a media release publishing FSC data about the use of genetic test results by life insurers,[43] and stated that the data showed genetic test disclosures did not adversely influence life insurance applications. The FSC reached and published this conclusion before its review had commenced and before submissions from stakeholders (including on the robustness of the FSC's data) had been requested or received. Further, it did not acknowledge any of the missing data that we noted above.

Section E: What Conclusions do the Interim Findings Support?

The evidence collected thus far by the A-GLIMMER project raises several concerns about the FSC Moratorium, that require further examination and consideration:

1. Concerns regarding industry self-regulation of the FSC Moratorium, and the lack of any government oversight or involvement.
2. Concerns around the temporary nature of the FSC Moratorium, creating uncertainty about how genetic test results will be used in the future.
3. Concerns around the FSC Moratorium's financial limits being too low to allow individuals to obtain sufficient life insurance cover.
4. Poor awareness and knowledge about the FSC Moratorium, among key stakeholder groups.

In addition, a very high proportion of surveyed stakeholders are of the opinion that legislation is required to regulate the use of genetic test results in life insurance underwriting (93% of health professionals, 91% of patients with experience of genetic testing, 78% of the general public, and 85% of researchers).

The findings of the A-GLIMMER Project currently suggest that the FSC Moratorium may not be meeting its intended aims and may not be meeting the recommendations of the Parliamentary Inquiry.

Section F: Next Steps

The A-GLIMMER Project is progressing several research studies intended for publication in 2023, involving consumers, patients, genetic researchers and the financial services industry. Those additional research findings will be published and made available on the Project's website (**https://www.monash.edu/medicine/a-glimmer/home**). The Final A-GLIMMER Stakeholder Report will incorporate all findings into a comprehensive analysis and make recommendations. The Final Stakeholder Report will be provided in June 2023 to the Commonwealth Government and other relevant stakeholders for their consideration.

Section G: Appendices

1. Appendix 1 – Summary of Treatment of Genetic Information Internationally

In Canada, the *Genetic Non-Discrimination Act 2017* prohibits any entity (including insurers) from requesting or using genomic test results – except that individuals can volunteer to disclose a negative test result (to show they do not have a genetic change that runs in the family). The US *Genetic Information Non-Discrimination Act 2008* (GINA) prohibits use of genetic information by health insurers and employers. The *Oviedo Convention on Human Rights and Biomedicine* (1997) prohibits discrimination on the basis of genetic information. Many European countries have accordingly banned or restricted discriminatory use of genetic information.[44] In the UK, the Code on Genetic Testing and Insurance (UK Code),[45] an agreement between the government and the Association of British Insurers, has been in effect since 2001. Under the UK Code, the use of predictive genetic test results is prohibited for policies such as travel insurance, motor insurance and private medical insurance. For life insurance applications (including life, income protection, and critical illness insurance), insurers cannot use genetic test results, with one exception – predictive genetic test results for Huntington disease (HD), used in applications for death cover worth over £500,000. The UK Code also contains an allowance for disclosure of negative test results as described in the Canadian legislation above.

[Excerpt from: Jane Tiller, Paul Lacaze and Margaret Otlowski, 'The Australian Moratorium on Genetics and Life Insurance Fails to Meet Parliamentary Recommendations Against Genetic Discrimination' (Working Paper, July 2022)].

2. Appendix 2 – Excerpt of the Disability Discrimination Act 1992 (Cth)

(Emphasis added)

4 Interpretation

(1) In this Act, unless the contrary intention appears: …

disability, in relation to a person, means:

(a) total or partial loss of the person's bodily or mental functions; or
(b) total or partial loss of a part of the body; or
(c) the presence in the body of organisms causing disease or illness; or
(d) the presence in the body of organisms capable of causing disease or illness; or
(e) the malfunction, malformation or disfigurement of a part of the person's body; or
(f) a disorder or malfunction that results in the person learning differently from a person without the disorder or malfunction; or
(g) a disorder, illness or disease that affects a person's thought processes, perception of reality, emotions or judgment or that results in disturbed behaviour;

and includes a disability that:

(h) presently exists; or
(i) previously existed but no longer exists; or
(j) **may exist in the future (including because of a genetic predisposition to that disability);** or
(k) is imputed to a person.

Part 2 – Prohibition of disability discrimination….

46 Superannuation and insurance

(1) This Part **does not render it unlawful for a person to discriminate against another person, on the ground of the other person's disability, by refusing to offer** the other person:
(a) an annuity; or
(b) a life insurance policy; or
(c) a policy of insurance against accident or any other policy of insurance; or
(d) membership of a superannuation or provident fund; or
(e) membership of a superannuation or provident scheme;

if:

(f) **the discrimination:**
  (i) **is based upon actuarial or statistical data on which it is reasonable for the first mentioned person to rely; and**
  (ii) **is reasonable having regard to the matter of the data and other relevant factors; or**
(g) **in a case where no such actuarial or statistical data is available and cannot reasonably be obtained—the discrimination is reasonable having regard to any other relevant factors.**

(2) This Part **does not render it unlawful for a person to discriminate against another person, on the ground of the other person's disability, in respect of the terms or conditions on which:**

(a) an annuity; or
(b) a life insurance policy; or
(c) a policy of insurance against accident or any other policy of insurance; or
(d) membership of a superannuation or provident fund; or
(e) membership of a superannuation or provident scheme;

is offered to, or may be obtained by, the other person, if:

(f) **the discrimination:**
  (i) **is based upon actuarial or statistical data on which it is reasonable for the first mentioned person to rely; and**
  (ii) **is reasonable having regard to the matter of the data and other relevant factors; or**
(g) **in a case where no such actuarial or statistical data is available and cannot reasonably be obtained—the discrimination is reasonable having regard to any other relevant factors.**

3. Appendix 3 – The Life Code Compliance Committee

The Life Code Compliance Committee ('LCCC') is established by, and operates in accordance with, the Life Insurance Code of Practice. The Code sets out the industry's own customer service standards. Life insurers that are members of the FSC are required to adopt the Code.

The LCCC is funded by the FSC. The LCCC comprises three members: an industry representative appointed by the FSC; a consumer representative appointed by the Australian Financial Complaints Authority (AFCA); and a chairperson appointed jointly by the FSC and the AFCA.[46]

The Code states that its members 'will comply with all relevant FSC Standards and Guidance' when assessing an application for life insurance.[47] These standards include the FSC Moratorium (FSC Standard No 11). The FSC has stated that it plans to include the FSC Moratorium in the next iteration of the Code. Only then will the FSC Moratorium be overseen by the LCCC.[48]

The LCCC Chairperson has expressed concerns about the effectiveness of its oversight role.[49] Further, the LCCC has only imposed one sanction since its inception.[50]

4. Appendix 4 – A-GLIMMER Project Study Design

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BMC Medical Ethics

STUDY PROTOCOL Open Access

Study protocol: the Australian genetics and life insurance moratorium—monitoring the effectiveness and response (A-GLIMMER) project

Jane Tiller[1,2,3*], Aideen McInerney-Leo[4], Andrea Belcher[5,6], Tiffany Boughtwood[2,5], Penny Gleeson[7], Martin Delatycki[2,3], Kristine Barlow-Stewart[8], Ingrid Winship[9,10], Margaret Otlowski[11], Louise Keogh[12†] and Paul Lacaze[1†]

Abstract

Background: The use of genetic test results in risk-rated insurance is a significant concern internationally, with many countries banning or restricting the use of genetic test results in underwriting. In Australia, life insurers' use of genetic test results is legal and self-regulated by the insurance industry (Financial Services Council (FSC)). In 2018, an Australian Parliamentary Inquiry recommended that insurers' use of genetic test results in underwriting should be prohibited. In 2019, the FSC introduced an industry self-regulated moratorium on the use of genetic test results. In the absence of government oversight, it is critical that the impact, effectiveness and appropriateness of the moratorium is monitored. Here we describe the protocol of our government-funded research project, which will serve that critical function between 2020 and 2023.

Methods: A realist evaluation framework was developed for the project, using a context-mechanism-outcome (CMO) approach, to systematically assess the impact of the moratorium for a range of stakeholders. Outcomes which need to be achieved for the moratorium to accomplish its intended aims were identified, and specific data collection measures methods were developed to gather the evidence from relevant stakeholder groups (consumers, health professionals, financial industry and genetic research community) to determine if aims are achieved. Results from each arm of the study will be analysed and published in peer-reviewed journals as they become available.

Discussion: The A-GLIMMER project will provide essential monitoring of the impact and effectiveness of the self-regulated insurance moratorium. On completion of the study (3 years) a Stakeholder Report will be compiled. The Stakeholder Report will synthesise the evidence gathered in each arm of the study and use the CMO framework to evaluate the extent to which each of the outcomes have been achieved, and make evidence-based recommendations to the Australian federal government, life insurance industry and other stakeholders.

Keywords: Genetics, Life insurance, Genetic discrimination, Moratorium, Australia, A-GLIMMER, Realist evaluation, Stakeholder engagement

*Correspondence: jane.tiller@monash.edu
†Louise Keogh and Paul Lacaze have contributed equally to this work.
[1] Public Health Genomics, Department of Epidemiology and Preventive Medicine, Monash University, Melbourne, VIC, Australia
Full list of author information is available at the end of the article

Background

The use of genetic test results in risk-rated insurance is a significant concern internationally [1–4]. A major concern, based on international literature, is the deterrence

of consumers from pursuing clinical genetic testing and being involved in genetic research due to insurance fears [5–12]. The use of genetic test results to discriminate against insurance applicants is a form of genetic discrimination (GD), defined as "differential treatment of asymptomatic individuals or their relatives on the basis of real or assumed genetic differences or characteristics" [13, p.64]. In response to the need to address the social and financial impacts of GD in life insurance, many countries have banned or restricted the use of genetic test results in underwriting [2]. Legislation such as Canada's *Genetic Nondiscrimination Act* (2017) prohibits insurers (and all other entities offering goods and services) from using genetic test results without an individual's express consent. In the US, the *Genetic Information Nondiscrimination Act* (2008) (GINA) limits the use of genetic information only in health insurance underwriting (and employment contexts). It does not apply to life insurance, although some individual states have legislated to limit genetic discrimination in life insurance [14].

Other jurisdictions have implemented alternative mechanisms, such as a moratorium in the UK (now the Code on Genetic Testing and Insurance [15]) which was introduced in 2001 as an agreement between the UK government and the Association of British Insurers [16]. Under the UK moratorium, which has no end date but is reviewed every three years, individuals applying for life policies < £500,000 are not required to disclose any genetic test results. For policies exceeding that amount, only test results pertaining to Huntington disease must be disclosed.

Australia

In Australia, risk-rated insurance is provided by life insurers, not health insurers. Under the *Disability Discrimination Act* 1992 (Cth), life insurers are legally permitted to use genetic test results to discriminate against all applicants [1]. Use of genetic test results in life insurance underwriting is self-regulated by the insurance industry, through mandatory Standards published by the Financial Services Council (FSC), the peak body that represents the majority of life insurers in Australia. Recent Australian research highlights ongoing issues with GD in life insurance, including lack of adherence to legal requirements and industry self-regulated policies [7, 8, 17, 18].

Additionally, GD in this context has been identified as one of the most significant ethical, legal and social issues (ELSI) in genomics currently facing Australia, both in terms of policy development and its impact on genetic research and clinical services [19]. In 2018, a Parliamentary Joint Committee (PJC) recommended that the use of genetic test results in life insurance be banned in Australia [20]. The Committee's report affirmed that GD is a problem of increasing significance (s9.86), and that based on current evidence, a duty to disclose genetic test results to life insurance companies is not appropriate (s9.84). Preventing such a duty of disclosure was considered to be more important for consumers than any concerns regarding adverse selection (which, in the Committee's view, were overstated by the insurance industry) (s9.87–88). The Committee was concerned about at-risk individuals choosing to not have clinically-indicated genetic testing because of insurance discrimination fears, and the impact of reduced genetic research participation on Australia's international research success (s9.89). To address these concerns, the Committee recommended that a moratorium should be urgently implemented to prohibit life insurers from using genetic test results that may predict future health concerns, and that it should take a form similar to the moratorium in the UK (s9.93). The Committee also recognised substantial concerns regarding self-regulation and its inherent conflicts of interest (s9.94), and considered that the federal government should monitor the FSC's implementation of, and insurers' compliance with, the moratorium, and consider implementing non-discrimination legislation if necessary (s9.96).

Although the federal government has not yet responded to the recommendations, in July 2019 the FSC independently introduced an industry-led moratorium [19] restricting insurers' use of genetic test results (see Fig. 1). This moratorium differs in four key respects from the UK moratorium (see Fig. 2). It does not change the legal position applicable to insurers under the *Disability Discrimination Act* 1992 (Cth)—that is, insurers are still legally allowed to use genetic test results to discriminate against all applicants [1]. This means that although the FSC expects its member companies to comply with the

- The FSC moratorium(1) prohibits life insurers from asking for or using genetic test results for policies below thresholds of:
  - $500,000 for death/total permanent disability,
  - $200,000 for trauma/critical illness, and
  - $4000/month for income protection cover.
- Above these thresholds, all genetic test results that an applicant has must be disclosed. This includes genetic results from research studies.
- There is an exception for favourable genetic test results, which show an applicant does not have the genetic variant which causes their family history of disease. These can be used to counter any negative underwriting consequences of a family history of disease, and can be voluntarily disclosed by the applicant for that purpose.
- The moratorium applies to life insurance policies only (this includes death, Total and Permanent Disability (TPD), trauma/critical illness cover and income protection cover).
- The moratorium does not apply to health insurance (which is already protected from underwriting discrimination by the *Private Health Insurance Act* 2007 (Cth)), or travel insurance, which is not regulated by the FSC.
- The FSC moratorium is due to be reviewed by the FSC in 2022, and will expire in 2024 unless renewed.

Fig. 1 Summary of the Australian (FSC) moratorium

The FSC moratorium differs from the UK moratorium (Code on Genetic Testing and Insurance(2)) in four key respects:

1) The moratorium is industry-led and self-regulated - it does not involve any agreement with or involvement of the Australian government. The UK moratorium is an agreement between the UK government and the Association of British Insurers.
2) The policy limits imposed in the UK moratorium are approximately twice the monetary value of the Australian limits, meaning applicants in the UK can obtain about twice the level of cover without disclosing genetic test results.
3) In Australia, all genetic test results must be disclosed once the monetary limit is reached. In the UK, there is only one genetic test result that must be disclosed above the monetary limits – a predictive test for Huntington Disease. No other genetic test results must be disclosed in the UK for any level of policy.
4) Unlike the FSC moratorium, the UK moratorium does not have an end date (although it is reviewed periodically).

Fig. 2 Differences between the Australian and the UK moratoria

Standard containing the moratorium, it is not a legally enforceable document.

The A-GLIMMER study, funded by the Australian government's Genomic Health Futures Mission, will evaluate the current Australian response to GD in life insurance:

> *RESEARCH QUESTION: To what extent does the self-regulated FSC moratorium achieve the critical policy aims identified by the Parliamentary Joint Committee (PJC)?*

The aims of the recommended policy change in this area, as discussed in the PJC Report [20] are:

1. To reduce consumer fears related to insurance, which deter the uptake of clinical genetic testing and/or research participation (s9.98)
2. To eliminate genetic discrimination in the Australian life insurance industry (ss9.84 &9.86)
3. To remove a barrier currently compromising the success of genetic medicine in Australia (s9.89)
4. To ensure Australian government oversight and monitoring to combat concerns with industry self-regulation (ss 9.94 & 9.96)

Our research project will assess whether the moratorium is effective in achieving these aims. This research will serve a critical role in increasing the evidence base internationally and helping Australia achieve appropriate long-term regulation for this important issue, taking into consideration the perspective of all key stakeholders [21].

Internationally, various measures have been introduced to address GD. Research has been conducted into the effectiveness of the regulatory mechanisms used in European countries, such as ethnographic fieldwork within insurance companies [22] and postal questionnaires to individuals with a pathogenic variant [23]. Varying levels of effectiveness are reported, demonstrating the need to monitor compliance with and effectiveness of recently implemented policy changes. Although genetic discrimination concerns among genetic counsellors decreased following the US GINA's commencement [24], non-genetic clinicians held considerably greater concerns, suggesting lower awareness in that group. A survey of cancer support group members [25] demonstrated limited understanding of GINA's non-discrimination protections, and <20% of the general public who were surveyed were aware of GINA [26], suggesting a need for a concerted effort to educate patient populations and the general public about policy changes. Research following the UK moratorium's introduction found that some individuals still reported difficulties obtaining insurance [27, 28], also demonstrating the need for continued research into the implementation and effectiveness of such policy changes following their introduction. No research to date has tested consumer knowledge of, or insurance experiences following the Canadian GNA's commencement.

We have identified four major stakeholder groups, whose perspectives must be considered in order to rigorously assess whether the current Australian moratorium is an appropriate and effective long-term regulatory solution. Some research has previously been conducted internationally on these stakeholder groups to gauge experiences and perceptions of genetic discrimination, views on regulation of genetic discrimination and knowledge of relevant local non-discrimination instruments, as set out below. While these studies represent findings at various timepoints across a variety of regulatory contexts, which may differ from those currently in Australia, they demonstrate the research which has been conducted in this area.

Consumers

Since the 1990s, numerous studies in North America, the United Kingdom, Europe and Australia have described concerns regarding GD. These concerns were voiced by at-risk clinical patients [29–39], support groups [40], and the general public [41]. Some consumers reported feeling coerced into having genetic testing to make themselves eligible for insurance or reduce premiums [42]. Several studies reported difficulty in obtaining health and/or life insurance experienced by unaffected relatives of individuals with genetic conditions [43–45], healthy adults who had tested negative for a familial pathogenic variant [44, 45], and asymptomatic individuals with a pathogenic variant who had mitigated their risk through treatment interventions and/or surveillance [27, 32, 45–50]. Although more recent legislative and other changes mean that some of the circumstances allowing these

instances of GD no longer exist, these studies demonstrate the impact GD has had on consumers over a long period of time, making them a critical stakeholder group for continued research.

Health professionals

Health professionals (HPs) —both genetic and non-genetic clinicians—are key to ensuring adequate communication of information about GD to patients. In a survey undertaken before the recent introduction of Canadian non-discrimination legislation [51], all Canadian genetic counsellors surveyed reported that they discuss insurance implications with clients. In Australia, genetic counsellors are required under the applicable professional guideline to discuss insurance implications with clients considering genetic testing where relevant [52]. Accordingly, HPs often experience firsthand the deterrent effects of GD fears on genetic testing decisions, and are often the first to hear reports of GD from patients. A US study conducted in 2000 [53], which asked genetic counsellors how they would behave if they were personally at risk of inheriting a cancer-predisposing genetic variant, was repeated in 2014 after the introduction of non-discrimination legislation [54]. It showed marked changes in perspectives following the policy change, including greater comfort with providing personal details when undergoing a test.

Various studies have also surveyed health professionals without a genetics qualification about their views and experiences regarding genetic testing and insurance discrimination. In one US study of over 1000 physicians and nurse practitioners [55], 96% of participants considered their patients would benefit from genetic testing, but 75% believed patients would not pursue testing due to GD fears. GD concerns were reported by 11% to justify non-referral of patients to genetics services. In another US study [56], 12% of genetics professionals and 14% of primary care physicians reported instances where asymptomatic patients had been denied life insurance on the basis of a genetic predisposition to disease. In Denmark, where insurers are prohibited from asking applicants about genetically determined risk of disease [57], health professionals reported that insurance concerns arose in > 5% of consultations, and led to genetic testing not proceeding in 1 in 200 cases.

Studies have also tested health professionals' knowledge and understanding of legal non-discrimination provisions. In one US study, > 90% of participants (n = 1110) had an inaccurate knowledge of current legal protections [58], and in another, less than 35% of questions about legal non-discrimination protections were answered correctly [55]. Only 46% of Canadian pharmacists surveyed in 2018 regarding pharmacogenetics (n = 99) were aware of existing non-discrimination legislation [59].

Genetic researchers

International researchers have described the deterrent effect of GD fears on research participation [10]. Evidence in the Canadian Senate proceedings which considered Bill S-201 (now the *Genetic Non-Discrimination Act*) showed that more than a third of families with "very sick children", declined to participate in a free research study because of such fears [11]. Less than 7% of invited parents of sick newborn babies participated in the US BabySeq study, with some decliners citing insurance discrimination concerns as a contributing factor [12]. Similarly, 25% of decliners in the US MedSeq study (in which genetic results are stored in participants' medical records) cited fear of insurance discrimination as the primary reason for declining [4].

The financial industry

Research has been conducted internationally (primarily in the USA) directly with insurance companies to understand their practices and perspectives regarding the use of genetic test results in underwriting. This research includes both life and health insurance providers, but more recently has been focused on health insurers with the introduction of GINA legislation (which applies to health but not life insurers) in 2008. In 1993, medical directors of US life insurance companies were surveyed [60] using a mailed questionnaire about current practices and policies, and future perspectives, around collecting and using genetic information in underwriting. A 2012 US study [61] used online and mail-based methods to survey health insurance plan medical directors about their companies' policies regarding, among, other things, genetic testing for individuals at risk of familial colorectal cancer syndromes. Other US studies [62, 63] asked health insurers to underwrite hypothetical insurance applicants. In one study [62] (n = 12), only three insurers had an underwriting policy related to genetic testing.

Project rationale

It is critical that the impact, effectiveness and appropriateness of the FSC moratorium is monitored, taking into account these different stakeholder perspectives (consumers, healthcare providers, researchers and the financial services industry), to ensure that the proposed FSC review in 2022 is informed by rigorous and evidence-based submissions. Currently, there are no other mechanisms in place to do this, and this project addresses that critical gap. Our project, funded by an Australian government grant, will utilise a nationally coordinated effort to

collect data from different stakeholder perspectives, to build a complete picture of the impact of the moratorium.

Design and methods

Methodological approach

To systematically assess the impact of the moratorium, a realist evaluation paradigm was employed in constructing the evaluation framework. "Realist evaluations asks not, 'What works?' or, 'Does this program work?' but asks instead, 'What works for whom in what circumstances and in what respects, and how?'" [64, p.2]. The realist evaluation, which adopts a context-mechanism-outcome (CMO) approach to conceptualise interventions, is appropriate for this project, as there are multiple contexts pertaining to a range of stakeholders. By defining the specific context, mechanism and outcomes for each of the stakeholder groups, an evaluation can be designed to determine how and how well the intervention (i.e. moratorium) achieves its stated objectives. Pawson and Tilley [65] say that 'programs work [have successful 'Outcomes'] only in so far as they introduce the appropriate ideas and opportunities ['mechanisms'] to groups in the appropriate social and cultural conditions ['contexts'].' The realist evaluation follows from this premise. The first step is to define the relevant outcomes (see below). The second step is to determine the relevant contexts, mechanisms and measures of these outcomes (see Table 1). Step three is to design an evaluation methodology that can test whether, how, where and to what extent each of the outcome measures represent achievement of the moratorium aims.

Outcomes

For the moratorium to accomplish its intended aims (see above), the following outcomes must be achieved:

1. Widespread and accurate awareness of the existence of the moratorium and its terms among consumer groups, health professionals, genetic researchers and research participants, ethics committees, financial industry members and regulators.
2. Confidence among consumers, health professionals, researchers and the insurance industry that the moratorium terms are strictly adhered to, and that breaches are rectified.
3. Timely and regular updates to policy, practice and processes in health care, industry and research to reflect the moratorium (e.g. industry practices, policy and processes, consent forms for genetic testing, policy and practice in genetics services and human research ethics committee (HREC) guidelines).
4. Adherence to the terms of the moratorium in the collection and use of genetic test results by all insurance companies, in practice.

Inattention to any of these areas will reduce the ability of the moratorium to achieve its intended outcomes.

Mixed methods data collection

As indicated in Table 1, a mixed methods design using both qualitative and quantitative data collection from a range of stakeholders will be used, incorporating pre- and post-moratorium comparisons where possible. No single methodological approach is capable of capturing all the data needed to evaluate the impact of this moratorium. Historically, data collection in the area of GD has proven challenging. Therefore, baseline or pre-moratorium data is incomplete and of varying quality. Where possible, relevant pre-existing research will be used to guide our methods and pre-existing measures will be used where possible to determine if the moratorium goals have been achieved. Figure 3 sets out a summary of the pre-moratorium research which has previously been conducted across the different stakeholder groups, and the research which will be conducted through the A-GLIMMER project.

In order to assess the outcome measures in Table 1, a number of objectives have been developed and a methodological approach to collect data to measure these objectives will be outlined for each stakeholder group. In part 1, we describe the research that will take place with consumers, in part 2, the research with health care professionals, in part 3, the approach we will take with researchers, and in part 4, our research program for working with the financial industry. In addition to the data collected through these mechanisms, the research team will seek out complementary data from other sources such as complaints to the Australian Financial Complaints Authority and the Australian Human Rights Commission, to enrich the data where possible.

Part 1: consumers

When considering genetic testing, a consumer is any individual who has had, or may have in the future, a genetic test. Consumers include those with a personal and family history of genetic or medical conditions, as well as ostensibly healthy individuals who may consider genetic testing for potential preventative health benefit or may be offered population genetic testing or genetic testing as part of a research study. With respect to genetic testing and life insurance, individuals fall into a range of different categories (see Fig. 4).

Part 1 of A-GLIMMER is designed to address the following objectives (see Fig. 4 for definitions):

Table 1 Data collection

Intervention: genetics and insurance moratorium					
Actor	**Context**	**Mechanisms**	**Outcome measures**	**Objectives**	**Data collection methods**
1. Consumers	Consumer knowledge of moratorium	Widespread community promotion of the moratorium	Knowledge of existence of moratorium and accurate understanding of its terms	1.1	General population survey Genetic testers survey Pre-testers and decliners survey
	Consumer experiences	Adequate consumer protection is implemented Regulations are complied with	Increased uptake of genetic testing or reduction in delay Less distress/confusion about insurance and genetics for those testing and tested Fewer reports of adverse insurance events based on genetic data	1.2, 1.3	
2. Health Professionals (HPs)	HPs' knowledge of moratorium	Promotion of the features of the moratorium to HPs Guidelines/processes to assist HPs to communicate with patients	Accurate knowledge of moratorium terms Confidence with explaining moratorium to patients	2.1	Health professionals survey
	HPs' experience of patient attitudes and behaviours	Adequate consumer protection is implemented Dissemination of existence and terms of moratorium to patients	HP reports of increased uptake of genetic testing and reduced delays to testing Less distress/confusion about insurance and genetics for these testing and tested	2.2	
	HPs' views on regulation	Adequate consumer protection is implemented	HP reports that regulation is adequate to protect patients	2.3	
3. Financial industry	Financial industry knowledge/understanding of moratorium	Industry engagement and dissemination	Accurate understanding of moratorium terms	4.1	Financial advisor survey FSC member survey
	Financial industry implementation	Adjusted industry standards and processes	Accurate and complete recording of all instances of receiving genetic information into FSC database Reduced rate of receipt of genetic test results Reduced occurrences of adverse insurance events based on genetic test results Industry forms and processes reflect the terms of moratorium	4.2, 4.3	Analysis of industry database Application form analysis FSC Underwriters interviews or focus groups
4. Genetic research community	Researchers' and research participants' awareness of moratorium	Updated HREC guidelines, templates for direct communication to research participants	Increased clarity for researchers and participants, easier communication	3.1, 3.2	Researcher interviews
	Research participants' behaviour	Adequate consumer protection is implemented	Reduced number of insurance concerns Reduced rate of research decliners due to insurance concerns	3.2	

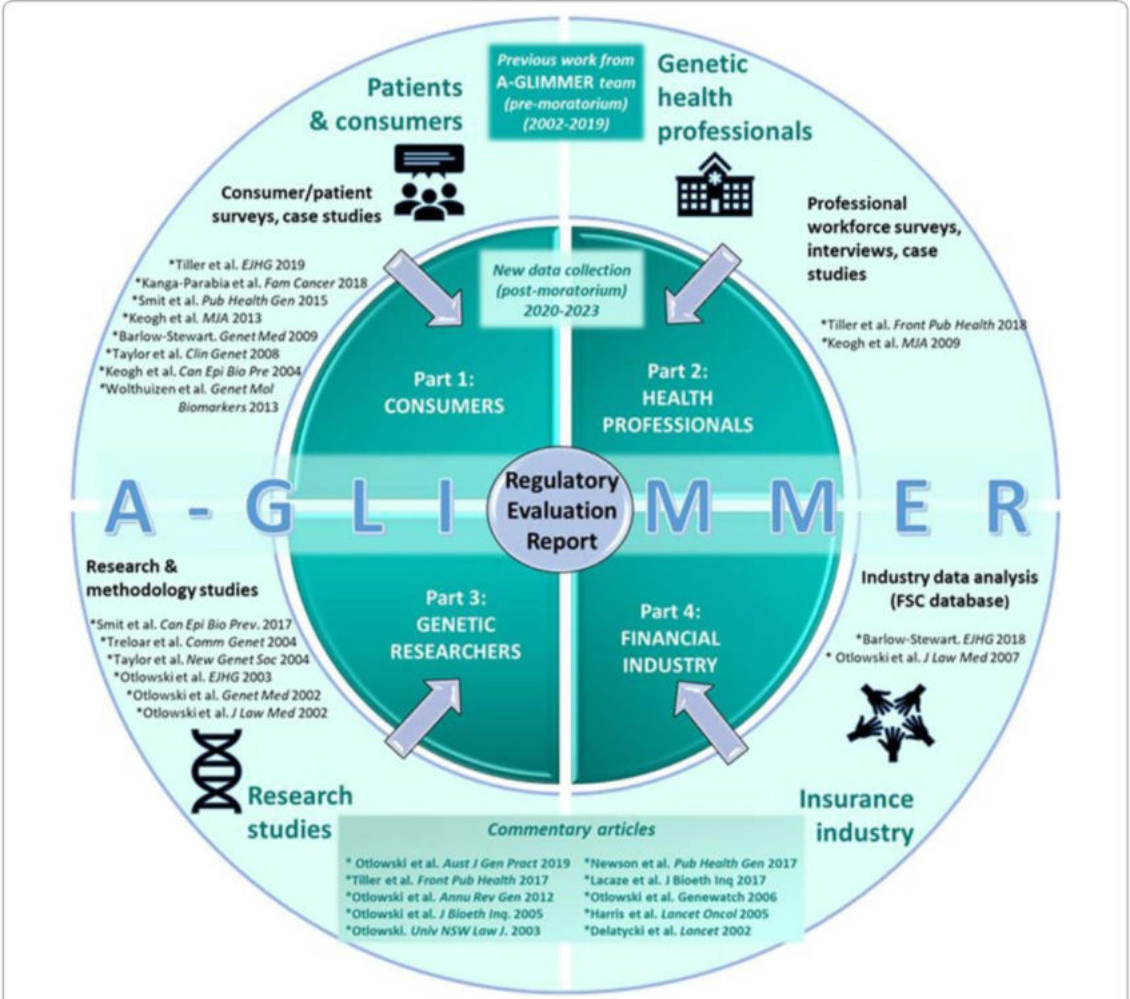

Fig. 3 Summary of A-GLIMMER project (image created by authors)

- **OBJECTIVE 1.1** Assess levels of awareness and understanding of the moratorium in the *general population, genetic testers, pre-testers and decliners*
- **OBJECTIVE 1.2** Assess the self-described impact of the moratorium on the decision-making of *pre-testers and decliners*
- **OBJECTIVE 1.3** Assess the impact of the moratorium on *genetic testers'* ability to access insurance products compared to pre-moratorium

Prior to finalising the protocol, a meeting of consumer representatives (from disease support groups and the general community) was held to seek input regarding the proposed methodology for gathering consumer views.

Genetic testers survey—Objectives 1.1 and 1.3 Prior to the commencement of the moratorium, research was conducted with Australian consumers to assist with identifying experiences in access to life insurance products following genetic testing [66]. This research focussed on consumers with positive genetic test results and was limited to consumers associated with two consumer support groups—Lynch Syndrome Australia (LSA) and Pink Hope, a support organisation for people with or at risk of breast cancer-predisposing pathogenic variants. Through

Categories of consumer	
Genetic testers	Unaffected individuals who have already received a predictive genetic test result. This could be positive (unfavourable) or negative (favourable). These are referred to as gene-positive and gene-negative respectively. Results may have been received prior to or following the moratorium.
Pre-testers	Unaffected individuals actively considering genetic testing, with or without existing life insurance.
Decliners	Unaffected individuals who have chosen not to have clinically indicated genetic testing.
General population	Individuals not yet considering genetic testing, but who may be offered genetic testing as part of a research study or clinical practice in the future (with or without existing life insurance).

Fig. 4 Categories of consumer

these groups, 174 consumers with cancer-predisposing variants were surveyed, providing baseline data on consumers' views and experiences.

Post-moratorium, this research methodology will be repeated and expanded. Individuals with variants that increase their risk of disease, as well as favourable results that negate a family history of disease, will be surveyed to capture levels of understanding of the moratorium, impact of the moratorium on decision-making and experiences with accessing life insurance products. Recruitment will be through support groups and other consumer groups, but the reach will be expanded considerably to groups supporting consumers with a range of genetic conditions, including but not limited to LSA, Pink Hope, Mito Foundation, Familial Hypercholesterolemia Network Australia, Rare Cancers Australia, Genetic Undiagnosed and Rare Disease Network, Rare Voices Australia, and Cancer Council Victoria. With an expanded reach, we expect that the number of participants will exceed the number from the previous survey.

Pre-testers and decliners survey—Objectives 1.1 and 1.2 Unaffected individuals who are considering having predictive genetic testing will be surveyed to capture levels of understanding of the moratorium and the impact of the moratorium on decision-making. Decliners will be surveyed to understand reasons for their decision to not have testing.

The PRiMo (using Polygenic Risk Modification to improve breast cancer prevention) trial is recruiting female participants who will be offered genetic testing through Australian Familial Cancer Clinics (FCCs) for breast and ovarian cancer-predisposing genetic variants. Questions regarding knowledge of the moratorium, influence of insurance implications on decisions regarding genetic testing, and experiences with accessing life insurance will be included in the questionnaires received by participants soon after receiving results. Follow-up questions about experiences with accessing life insurance will be included in questionnaires administered at subsequent 6-12 month intervals.

Males attending an FCC and considering predictive genetic testing for adult-onset autosomal dominant conditions, and females considering predictive genetic testing for adult-onset autosomal dominant conditions who are not eligible for PRiMo, will be invited separately to answer questions regarding knowledge of the moratorium, influence of insurance implications on decisions regarding genetic testing, and experiences with accessing life insurance.

General population survey—Objectives 1.1 and 1.2 Each year, the Australian Consortium for Social and Political Research Incorporated administers the Australian Survey of Social Attitudes (AuSSA) to representative sections of the general public. The AuSSA is "Australia's main source of data for the scientific study of the social attitudes, beliefs and opinions of Australians, how they change over time, and how they compare with other societies" [67]. We previously included questions in the 2003 AuSSA [68] regarding Australians' knowledge of and views about genetics and the use of genetic information in insurance. A module of questions will be included in the 2021 AuSSA to assess participants' awareness and understanding of the moratorium; views regarding the use of genetic test results by life insurance companies; and the effect of insurance implications and the impact of the moratorium on their desire to undergo genetic testing in future. Questions included in the 2003 survey which remain relevant will be included again to allow for comparison. The demographic data collected by the AuSSA will enable comparisons based on income, education and other pertinent factors.

Part 2: health professionals

For the purposes of the A-GLIMMER project, health professionals (HPs) include any qualified health professional who has direct contact with patients who are considering genetic testing. This includes HPs working in genetics services, such as genetic counsellors and clinical geneticists, as well as other non-genetic HPs who discuss genetic testing with patients, such as nurses and oncologists.

Part 2 is designed to address the following objectives:

- **OBJECTIVE 2.1** Assess the level of understanding of the moratorium by health professionals.

- **OBJECTIVE 2.2** Describe experiences of health professionals regarding the impact of the moratorium on patients.
- **OBJECTIVE 2.3** Describe health professionals' views on regulation and the moratorium's effectiveness

In Australia, some opportunistic data collection from interviewing health professionals occurred as part of a project which aimed to verify reports of GD by consumers [69], but did not systemically collect views and experiences of health professionals. Prior to the commencement of the moratorium, members of the A-GLIMMER research team conducted the first dedicated survey of Australian health professionals to understand their views and experiences regarding the use of genetic test results in life insurance underwriting [70]. This research focussed on health professionals working in a clinical genetics context (n=87), who observed that many patients needed time to reconsider testing once insurance implications are raised, and some subsequently chose to delay testing or never return. This is consistent with research showing fear of insurance consequences can deter pursuit of genetic testing and participation in genetic research, even where interventions following a positive result can significantly reduce morbidity and mortality [7–9]. In line with the relevant professional guideline [52], genetic professionals in Australia reported almost always discussing life insurance with individuals who are considering genetic testing [70], making an adequate understanding of these issues critical.

During the data collection period for the pre-moratorium survey, some feedback was obtained regarding the questions asked and the process of completing the survey. Prior to finalising this protocol, the proposed follow-up survey questions were piloted on several genetics professionals in different roles, who provided feedback about content, clarity and flow.

Health professionals survey—Objectives 2.1 and 2.2 Following commencement of the moratorium, health professionals who discuss genetic testing with patients will be invited to participate in an online survey (see Additional file 1). Because the recruitment criteria has been extended beyond only genetics professionals working in genetics services, we expect that the number of participants will exceed that of the previous survey [70]. Recruitment will be supported by partner organisations including the Human Genetics Society of Australasia, Australian Genomics, and other groups with links to HPs, as well as social media advertisements, direct email to professional contacts of the research team, and snowballing. Questions will be asked regarding HPs' level of understanding of the moratorium, experiences regarding the impact of the moratorium on patients, and views on regulation of use of genetic test results in underwriting. Results will be compared with the previous research described above [70] to capture changes over time. Participants who complete the online survey will be given the choice to remain anonymous or to provide their details and consent to being contacted for a follow-up interview. Those who provide consent will participate in a semi-structured interview of approximately 20 minutes' duration, to explore in greater depth their responses to the survey questions. These interviews will be transcribed and analysed qualitatively using thematic analysis.

Part 3: genetic researchers

For the purposes of A-GLIMMER, genetic research is research that is done with respect to human genetics and genomics. This refers to research projects in which individuals sign up as research participants, provide samples for DNA analysis and receive a result.

Part 3 is designed to address the following objectives:

- **OBJECTIVE 3.1** Assess the impact of the moratorium on the conduct of genetic research
- **OBJECTIVE 3.2** Assess the impact of the moratorium on genetic research participants

Prior to finalising the protocol, feedback was sought from several prominent genetic researchers regarding their potential willingness to be involved in, and the perceived value of, this research. Genetic researchers indicated through this process that this was an area of concern, that gathering these views would be beneficial, and that there was strong interest in being interviewed for this purpose.

Researcher interviews—Objectives 3.1 and 3.2 Previous research has demonstrated the impact of insurance implications on research participants' willingness to be involved in genomic research, especially where results of clinical significance may be returned to participants [7–9]. In one study, the number of people who declined predictive testing when informed of the insurance implications was more than double the number who declined without knowledge of the insurance implications [8]. Each of these studies collected this data as part of a broader research study, rather than designing the study for the purpose of considering the impact on research of insurance implications and regulatory change. Part 3 of A-GLIMMER's post-moratorium study will focus on this impact on research studies.

Researchers who conduct research related to human genetics will be interviewed to explore the impact of the moratorium on conducting genetic research and

participation in genetic research. Australian researchers who have significant responsibility in leading large genetic research studies will be invited by email to take part in the study. A list of eligible researchers will be identified collaboratively through input from research partners and partner organisations who are aware of research being conducted in this space. We estimate that we will be able to identify at least 10-12 researchers who fit the criteria and expect a response rate of 80%. Data will be captured on the impact of the moratorium on conducting genetic research, including questions about the experience of recruiting; of informing participants about life insurance; the impact that this had on participation rates and individual participants; ethics committee processes; and their views on any changes that they have seen post-moratorium.

Part 4: financial industry

Although some individuals apply directly to life insurance companies either by filling out a paper application form or online, many Australians engage a financial adviser/financial broker for advice on and practical assistance with applying for life insurance coverage. It is important to gauge not only the perspectives of the life insurance companies themselves, but also to assess the level of awareness and understanding of the industry professionals who are providing advice to consumers.

Part 4 is designed to address the following objectives:

- **OBJECTIVE 4.1** Assess awareness and levels of understanding of the moratorium by financial industry personnel
- **OBJECTIVE 4.2** Assess the (industry perceived) impact of the moratorium on the Financial Services Industry
- **OBJECTIVE 4.3** Assess the level of adherence to the moratorium by life insurance companies

Before the protocol was finalised, a meeting was held with key underwriting representatives from several of the large Australian life insurance providers to seek feedback regarding the proposed methodology, target groups, and subject matter of interviews.

Telephone survey of financial advisors—Objective 4.1 and 4.3 The Australian government publishes a list (n ~ 18,000) of registered Australian financial advisers. Financial advisers will be randomly selected (ensuring a spread across different states of Australia) and invited to complete a short anonymous telephone survey, to assess the understanding of financial industry personnel who are not part of a life insurance company. Participants will be asked questions relating to their knowledge and understanding of the existence and terms of the moratorium.

Application form analysis—Objective 4.3 Application forms (pdf or online, depending on availability) will be collected from all underwriters offering risk-rated life insurance in Australia. Content analysis will be conducted to determine whether the forms comply with the terms of the moratorium. Specifically, fields considered will include those seeking information from applicants about past or future genetic testing, and explanation (if any) of the terms of the moratorium. Previous research conducted in 2003 [71] collected and analysed application and personal statement forms from 21 life insurance underwriters. This analysis revealed considerable variation in the genetic information requested by different underwriters in the different forms, and will be compared with the post-moratorium analysis where possible.

FSC Underwriters survey/interview—Objective 4.1, 4.2, and 4.3 Underwriting representatives from FSC member life insurance companies will be invited to participate in semi-structured interviews or focus groups to explore their views on the moratorium, changes to practice, benefits and limitations, and adherence to terms. Focus groups and interviews will be conducted by videoconference and facilitated by members of the research team. Sixteen life insurance companies are currently members of FSC and it is expected that approximately 10–15 underwriters will attend either a focus group or take part in an interview.

FSC database analysis—Objective 4.3 The FSC requires its member companies to record in a dedicated database de-identified information regarding all applications for a life insurance product where a genetic test result has been disclosed, either voluntarily or inadvertently [19]. Previous analyses have been conducted on data collected in this database [46, 72]. The FSC, as a study partner, has made changes to the database fields to take into account the different data collection required following the commencement of the moratorium. Data will be extracted annually following the end of financial year, and analysed to assess the volume of applications where genetic test results are disclosed and adherence to the moratorium by insurance companies, and compared with pre-moratorium data where possible.

Data analysis, regulatory evaluation report and recommendations

Results from each arm of the study will be analysed and published in peer-reviewed journals as they become available.

At the end of the study term (3 years) a Regulatory Evaluation Report will be prepared. The Regulatory Evaluation Report will synthesise the evidence gathered in each arm of the study and use the CMO framework to evaluate the extent to which the moratorium, as implemented by the FSC Standard, has achieved the outcomes intended by the PJC recommendations. The Regulatory Evaluation Report will identify any outcomes that have not been achieved and will draw on the collected data to provide possible reasons why this has occurred. The Report will make recommendations to rectify any failings in relation to the moratorium and to enhance its operation in the future. Consequently, this research project and the Regulatory Evaluation Report will provide valuable evidence toward, although it will not replace, the FSC's review of the moratorium [14]. The report will also to contribute to fulfilling the PJC's recommendation that the moratorium be reviewed after five years [13]. The Regulatory Evaluation Report will be provided to the Treasurer and the Minister for Health, the Secretaries of their respective Departments, and the Chair of the PJC. The Report's recommendations will provide the basis on which future arrangements for the moratorium, or requirements for further regulatory intervention, can be determined and implemented with all relevant decision-makers and stakeholders.

Discussion

Our project brings together Australia's leading researchers, clinicians, patient groups, policy experts and industry representatives to answer an over-arching research question—*to what extent does the self-regulated FSC moratorium achieve the aims of addressing concerns with GD as identified by the Parliamentary Joint Committee?*

Strengths of the study include an experienced and diverse investigator group from across Australia that has published extensively together in the area [1, 34, 70, 73–78], and built upon previous research over two decades from some of the group members [8, 42, 46–48, 77, 79–84]. The project was made possible by an Australian government grant which was endorsed by the Victorian Department of Health & Human Services, Human Genetics Society of Australasia and over 20 other project partners, reflecting its widespread support and significance. A key partner is the Financial Services Council (FSC), which represents and facilitates collaboration with members of the Australian life insurance industry. FSC's willingness to partner with the project and provide collaborative input strengthens the research potential and signifies FSC's commitment to this important issue. The project is aligned with Australian Genomics, a national collaborative research partnership of more than 80 organizations piloting a whole-of-system approach to integrating genomics into healthcare [85]. The project is also aligned with international efforts, with engagement from several comparable groups in Canada, USA and UK.

The study has limitations and risks which must be acknowledged. The diverse methods of data collection being undertaken across the four stakeholder groups could be challenging to synthesise in a final report. The study may be more likely to collect data from highly motivated or vocal stakeholders, rather than a truly representative cross-section of the community. Further, there is a risk of investigator team bias, given individual views on the issue of GD. We have taken deliberate steps to mitigate against these risks, to ensure rigour and objectivity in our study.

The study's limited timeline presents another challenge, given the broad and diverse scope of work to be completed. Various challenges or delays could prevent key milestones from being achieved. For example, difficulties in recruiting participants, or obtaining necessary ethics approvals, could influence the planned timeline and milestones. Further disruptions caused by the Covid-19 pandemic may also create challenges for recruitment and data collection. Other risks for the study include the availability of industry-collected data. As study partners, FSC has pledged to provide access to certain industry data, but the research team does not have primary access to this data, and so it is possible that access to this data could be delayed or inconsistent.

In conclusion, the findings of this study will provide valuable evidence to inform the FSC review of the moratorium in 2022, and future policy regarding the use of genetic information in life insurance.

Abbreviations

A-GLIMMER: The Australian Genetics and Life Insurance Moratorium—Monitoring the Effectiveness and Response; CMO: Context-mechanism-outcome; ELSI: Ethical, legal and social issues; FSC: Financial Services Council; GD: Genetic Discrimination; GINA: Genetic Information Nondiscrimination Act (US); GNA: Genetic Nondiscrimination Act (Canada); HP: Health professional; PJC: Parliamentary Joint Committee.

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12910-021-00634-2.

Additional file 1. Title of data: Health professional questionnaire. Description of data: questionnaire to be administered to health professionals after the introduction of the moratorium

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Victoria; Australian Genetic Heart Disease Registry; Melanoma Genomics Managing Your Risk Study; JeneScreen, CRISP-SNP (Cancer RISk Prediction), SCRIPT (Snp Cancer RIsk Prediction Trial), Variants in Practice (ViP) and Lifepool research studies; the University of Melbourne; University of Queensland; University of Tasmania; Sydney University; University of Technology Sydney; Murdoch Children's Research Institute (Victorian Clinical Genetics Service); Melbourne Health (Adult Clinical Genetics); Kinghorn Cancer Centre; Australian Genomics; Melbourne Genomics Health Alliance; Queensland Genomics Health Alliance; Human Genetics Society of Australasia; Canadian Coalition for Genetic Fairness; the Financial Services Council; and Illumina. We are also very grateful for the support, input and feedback provided by leading international researchers, including, Prof Mark Rothstein, Prof Yann Joly, A/Prof Anya Prince, A/Prof Yvonne Bombard, Prof Robert Green, Prof Angus Macdonald and Prof Sir John Burn.

Authors' contributions

JT and PL initially conceived the project. All authors contributed to the conception and design of the project. JT drafted the manuscript, with input from AML, PL and LK. KBS, MO, IW, AB, PG, MD and TB substantially revised the manuscript. All authors have read and approved the manuscript for submission.

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Availability of data and materials

No data is included in the manuscript.

Declarations

Ethics approval and consent to participate

Ethics approval for aspects of the project (Part 2: Health Professionals) has been received by the Monash University Human Ethics Research Committee, Project ID no 22576. Participants who have been recruited for this aspect have provided consent in writing. Approval for the balance of the project will be finalised, and informed consent to participate obtained from all research participants prior to data collection.

Consent for publication

Not applicable.

Competing interests

Many of the authors of this manuscript (JT, AML, AB, PG, MD, KBS, IW, MO, LK, PL) are also members of the Australian Genetic Non-Discrimination Working Group (AGNDWG), a multi-disciplinary group of professionals encompassing fields of genetics, medicine, research, law, bioethics, social science and actuarial science, which was formed in 2016 to explore issues around the use of genetic information. The AGNDWG made submissions to and was called upon to provide evidence to the Parliamentary Inquiry into the Life Insurance industry in 2017.

Author details

[1]Public Health Genomics, Department of Epidemiology and Preventive Medicine, Monash University, Melbourne, VIC, Australia. [2]Murdoch Children's Research Institute, Parkville, VIC, Australia. [3]Victorian Clinical Genetics Services, Parkville, VIC, Australia. [4]The University of Queensland Diamantina Institute, The University of Queensland Dermatology Research Centre, Brisbane, QLD, Australia. [5]Australian Genomics, Parkville, VIC, Australia. [6]Faculty of Medicine, The University of Queensland, Brisbane, QLD, Australia. [7]Deakin Law School, Melbourne, VIC, Australia. [8]Northern Clinical School, Faculty of Medicine and Health, University of Sydney, Sydney, NSW, Australia. [9]Department of Medicine, University of Melbourne, The Royal Melbourne Hospital, Parkville, VIC, Australia. [10]Genomic Medicine and Family Cancer Clinic, Royal Melbourne Hospital, Parkville, VIC, Australia. [11]Faculty of Law and Centre for Law and Genetics, University of Tasmania, Hobart, TAS, Australia. [12]Centre for Health Equity, Melbourne School of Population and Global Health, The University of Melbourne, Carlton, VIC, Australia.

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Publisher's Note

5. Appendix 5 – First Health Professional's Study

Ethics and policy

Original research

A step forward, but still inadequate: Australian health professionals' views on the genetics and life insurance moratorium

Jane M Tiller ,[1,2] Louise A Keogh,[3] Aideen M McInerney-Leo,[4] Andrea Belcher,[5,6] Kristine Barlow-Stewart,[7] Tiffany Boughtwood,[2,6] Penny Gleeson,[8] Grace Dowling,[1] Anya Prince,[9] Yvonne Bombard ,[10,11] Yann Joly,[12] Martin Delatycki,[13,14] Ingrid M Winship,[15,16] Margaret Otlowski,[17] Paul Lacaze[1]

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For numbered affiliations see end of article.

Correspondence to
Jane M Tiller, School of Public Health and Preventive Medicine, Monash University Faculty of Medicine Nursing and Health Sciences, Melbourne, VIC 3004, Australia;
jane.tiller@monash.edu

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ABSTRACT

Background In 2019, the Australian life insurance industry introduced a partial moratorium (ban) limiting the use of genetic test results in life insurance underwriting. The moratorium is industry self-regulated and applies only to policies below certain financial limits (eg, $500 000 of death cover).

Methods We surveyed Australian health professionals (HPs) who discuss genetic testing with patients, to assess knowledge of the moratorium; reported patient experiences since its commencement; and HP views regarding regulation of genetic discrimination (GD) in Australia.

Results Between April and June 2020, 166 eligible HPs responded to the online survey. Of these, 86% were aware of the moratorium, but <50% had attended related training/information sessions. Only 16% answered all knowledge questions correctly, yet 69% believed they had sufficient knowledge to advise patients. Genetics HPs' awareness and knowledge were better than non-genetics HPs' ($p<0.05$). There was some reported decrease in patients delaying/declining testing after the moratorium's introduction, however, 42% of HPs disagreed that patients were more willing to have testing post-moratorium. Although many (76%) felt the moratorium resolved some GD concerns, most (88%) still have concerns, primarily around self-regulation, financial limits and the moratorium's temporary nature. Almost half (49%) of HPs reported being dissatisfied with the moratorium as a solution to GD. The majority (95%) felt government oversight is required, and 93% felt specific Australian legislation regarding GD is required.

Conclusion While the current Australian moratorium is considered a step forward, most HPs believe it falls short of an adequate long-term regulatory solution to GD in life insurance.

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INTRODUCTION

Genetic discrimination (GD) is an area of international concern.[1–4] In the context of life insurance underwriting, GD can lead to increased premiums or denial of insurance applications. Predictive genetic testing (where testing can reveal a higher risk of developing disease, before symptom onset) can save lives, by encouraging patients to make informed decisions regarding the uptake of preventative interventions or early treatment of disease. In Australia and internationally, research shows that fear of insurance implications deters some high-risk individuals from having clinically-indicated predictive genetic testing or participating in research.[5–10]

In Australia, the issue of GD in health insurance does not arise, because health insurance premiums are community rated rather than risk rated.[4] However, life insurers can legally ask for and use applicants' genetic test results in the underwriting of life insurance (death cover), permanent disability, trauma/critical illness and income protection cover policies, under s46 of the *Disability Discrimination Act* 1992 (Cth) (DDA). The Australian government allows the life insurance industry to self-regulate their own policy around the use of applicants' genetic information, which raises numerous ethical and societal concerns.[11] These concerns have been reflected in government inquiries in recent years.[12 13]

In 2018, the Australian Parliamentary Joint Committee on Corporations and Financial Services released recommendations after its inquiry into the life insurance industry.[14] Recommendations included a ban (moratorium) on life insurers' use of predictive genetic test results for underwriting and introduction of legislation if necessary. The Australian government has not yet responded to these recommendations. However, in 2019, the Financial Services Council (FSC), the peak industry body for Australian life insurers, voluntarily introduced an industry self-regulated partial moratorium on member organisations' use of genetic test results.[15 16] The FSC moratorium restricts access to and use of genetic test results for applications for death cover ≤$500 000 only (as well as trauma and/or critical illness cover ≤$200 000, total permanent disability cover ≤$500 000, and income protection cover ≤$4000/month). Because travel insurance falls within general insurance, as distinct from life insurance, restriction of the use of genetic test results in travel insurance underwriting is not included in the moratorium.

As a self-regulated industry standard, the FSC moratorium is not enforceable or subject to government oversight. The insurance industry's legal right

to use genetic test results in underwriting is not affected by the implementation of the moratorium, which will end in 2024 if not renewed. The FSC have a Code of Practice (Code), compliance with which is monitored by an external committee of three persons.[17] At the time of publication, the FSC moratorium has not been incorporated into the Code, although we understand that this is FSC's future intention.

Health professionals (HPs) are key to ensuring that patients considering genetic testing are adequately advised of potential insurance implications before testing is undertaken. Further, they often directly witness the deterrent effects of patient fears related to insurance implications.[18] Under Australian professional guidelines, each genetic counselling session should include a discussion of insurance implications where relevant.[19] With the progressive mainstreaming of genetic testing in Australia, a greater proportion of clinicians without genetics training are now discussing genetic testing with patients.[20] A recent systematic review[21] found that non-genetics HPs (nurses and physicians) had limited genetics knowledge and were unprepared for integrating genomics into clinical care. However, little is known about non-genetics HPs' knowledge regarding life insurance discrimination and the moratorium.

Prior to the introduction of the FSC moratorium, we surveyed genetics professionals in Australia about patient experiences of life insurance discrimination, and HP views on GD regulation.[18] That study demonstrated some deficits both in knowledge of current regulations and confidence in advising patients about insurance implications. It also captured widespread concerns regarding GD regulation, with the vast majority of HPs stating that current Australian regulations were inadequate to protect consumers.

To our knowledge, there has been no survey of HPs since the introduction of the FSC moratorium. This study forms a key part of the Australian Genetics and Life Insurance Moratorium: Monitoring the Effectiveness and Response (A-GLIMMER) project—funded by the Australian government.[22 23] The project's purpose is to assess whether the FSC moratorium achieves the policy aims identified by the Parliamentary Inquiry.[14] This particular study contributes to that project by analysing the effectiveness of the FSC moratorium in the clinical context. This study aims to describe the knowledge, experiences and perspectives of HPs who discuss genetic testing with patients, following the commencement of the FSC moratorium. Where possible, it will also compare those findings with pre-moratorium research findings.[18]

METHODS

Population, sampling and recruitment

The A-GLIMMER project protocol has been published previously.[23] The population of interest was qualified HPs, working in an Australian health service, who discuss genetic testing with patients. Eligibility was established through screening questions at the beginning of the questionnaire. A range of targeted recruitment strategies were adopted to capture a broad sample:

- Newsletters emailed directly to members of the Human Genetics Society of Australasia (HGSA), Australasian Society of Genetic Counsellors, Royal Australasian College of Physicians, and the Australian Genomics Health Alliance
- Social media advertisements (Twitter and Facebook)
- Direct email to authors' colleagues and personal contacts
- Snowball sampling (requesting contacts forward an email invitation to their professional networks)

Survey development and data collection

We conducted an online survey (see online supplemental materials for a copy) using REDCap software.[24] The survey was adapted from our previous pre-moratorium survey of genetics HPs.[18] Relevant questions were preserved for comparison, and new questions were introduced to assess the effectiveness of the moratorium through surveying HPs' knowledge, experience and views. The adapted survey included sections relating to demographics; awareness, knowledge and training; patient attitudes, behaviours and reported experiences; and views regarding GD regulation. Validated scales were unavailable for moratorium-specific questions; however, the survey was developed in consultation with a number of clinical and research partners and was pre-tested with a clinical geneticist (CG), a genetic counsellor (GC) and a lay person without health qualifications. Data were mostly collected through closed-ended responses using Likert scales and fixed alternative options, with a small number of open-ended questions where free text was allowed. The survey was open from April to June 2020.

Data analysis

Descriptive analysis was conducted for closed-ended questions, using STATA V.14.[25] Descriptive statistics were reported for each question included in the results, broken down by total number of HPs, as well as separately by genetics HPs and non-genetics HPs. Six questions evaluated knowledge (true/false/unsure) about aspects of the FSC moratorium and current insurance implications. HPs received a point for every correct answer (range 0–6). A mean knowledge score was calculated for comparison between groups. Knowledge scores were categorised into 'good knowledge' (5–6 questions answered correctly), 'average knowledge' (3–4 correct) and 'poor knowledge' (0–2 correct). Z-tests were used to test for significance of differences between groups, with p values (two-sided) <0.05 considered significant.

Responses to open-ended questions were sorted into common categories, which are reported in detail in the online supplemental materials and in summary form with example quotes in the manuscript.

RESULTS

Overall, 166 eligible HPs participated. As some HPs discontinued the survey part-way through, the number of HPs who answered each question varied (range n=144–166). To aid readability, the 'n' for every reported question is not given in the text, but is included in the accompanying figures/tables. Given the diverse recruitment strategies, a total response rate relative to all eligible participants is difficult to estimate. However, at the time of recruitment, the HGSA distribution list included a total of 484 clinical geneticists (CGs) and genetic counsellors (GCs). Of the 166 HPs who participated, 111 were CGs/GCs, making the estimated response rate for those professions 23%.

Table 1 shows HP characteristics. The 'Other' category under the profession field is comprised of HPs representing more than 15 different fields (see online supplemental table S1 for a list), who were eligible for the study as they reported regularly discussing genetic testing with patients. These HPs are referred to as 'non-genetics HPs', as distinguished from 'genetics HPs' (GCs, CGs and genetics fellows).

Awareness, knowledge and training

Most HPs overall (86%), but just over half of non-genetics HPs (53%), were aware of the FSC moratorium. Over half of genetics HPs (55%) reported attending training or information sessions

Table 1 Characteristics of the surveyed population (n=166)

Demographic	Category	Number (%)
Sex	Female	124 (75)
	Male	40 (24)
	Other	2 (1)
Location	Australian Capital Territory	4 (2)
	New South Wales	41 (25)
	Northern Territory	1 (1)
	Queensland	17 (10)
	South Australia	6 (4)
	Tasmania	4 (2)
	Victoria	65 (40)
	Western Australia	28 (17)
Profession	Associate genetic counsellor	59 (36)
	Certified genetic counsellor	38 (23)
	Clinical geneticist	14 (8)
	Genetics fellow	10 (6)
	Other	45 (27)
Years of experience	0–5 years	60 (36)
	6–10 years	33 (20)
	11–15 years	21 (13)
	15–20 years	21 (13)
	>20 years	31 (18)
Average number of appointments with patients considering testing (per fortnight)	0–5	68 (40)
	6–10	70 (41)
	11–20	24 (14)
	>20	8 (5)

regarding the moratorium and insurance implications of genetic testing, while few non-genetics HPs did so (7%). Of the two well-known fact sheets on the moratorium—the Centre for Genetics Education (CGE) Fact Sheet 20[26] and the FSC insurance and genetics moratorium fact sheet[27]—a majority of HPs (65%) had read at least one. However, only a third (n=14) of non-genetics HPs had read one compared with 76% (n=89) of genetics HPs (z=5; p<0.05) (table 2; figure 1A–D).

Many HPs (69%) felt they had sufficient knowledge about insurance implications to properly advise clients. On the objective knowledge test, about half (49%) had good knowledge (5–6 questions answered correctly) (see online supplemental table S2 for question-specific data). More genetics HPs answered questions correctly (mean 4.5/6) than non-genetics HPs (mean 3.1/6) (z=7.3; p<0.05). Of 50 genetics HPs with two or more incorrect questions (average/poor knowledge), almost two-thirds (n=30) felt they had sufficient knowledge. However, of 25 non-genetics HPs who answered two/more incorrectly, only a fifth (n=5) felt they had sufficient knowledge. These differences between genetics and non-genetics HPs were significant (z=4.3 (understanding) z=3.3 (knowledge), p<0.05).

Impact on practice and testing

HPs were asked about how often patients either delayed or declined predictive genetic testing due to life insurance concerns, both before and then after the moratorium was introduced. Overall, 63% of HPs said patients delayed testing because of life insurance concerns often/sometimes before the moratorium and 39% said they delayed often/sometimes post-moratorium (z=4.15; p<0.05). Similarly, 39% said patients declined testing due to life insurance concerns often/sometimes pre-moratorium compared with 18% post-moratorium (z=4.18; p<0.05) (table 3; figure 1E,F).

Although the FSC moratorium does not apply to travel insurance, this creates some confusion for both patients and HPs. GD in travel insurance was raised as an issue by several HPs in free-text responses (see below). When asked about how often patients delay/decline predictive testing due to travel insurance concerns, 11% of HPs said patients delay often/sometimes and 12% said patients decline often/sometimes.

Views on the FSC moratorium's effectiveness and regulation

Almost all HPs (93%) agreed/strongly agreed that consumers are better protected post-moratorium. Although 76% felt the FSC moratorium resolved some of their concerns about GD, 88% still had GD concerns after its introduction (table 3; figure 1G,H)

Most HPs agreed/strongly agreed that the FSC moratorium is easy to understand (80%) and easy to explain to patients (76%); however, a number (20%/24% respectively), disagreed/strongly disagreed, showing some HPs find it difficult to understand and/or explain. HPs were split almost evenly in their views regarding questions about decreased patient confusion (51% agreed/strongly agreed; 49% disagreed/strongly disagreed) and increased willingness to have testing (59% agreed/strongly agreed; 41% disagreed/strongly disagreed).

The vast majority (95%) of HPs (no significant difference between genetics/non-genetics HPs (z=0.2; p=0.83)) felt a formal agreement between the Australian government and life insurance industry is required. In optional free-text answers to this question (see online supplemental table S3 for all responses), 22/149 HPs elected to elaborate (21 who said yes, 1 who said no). Of those who said yes, one-third expressed concerns with industry self-regulation. For example, Participant 129 stated, 'I think that the industry needs to be held accountable; I don't trust that the self-governing model is enough'.

Two HPs felt further regulation may be needed, but the decision should depend on the outcomes of the FSC moratorium, with Participant 127 stating, 'We need an evidence-based approach. We should wait for results to emerge from the current moratorium'. The HP who said no (Participant 109) stated, 'Insurance companies currently load premiums or withhold cover on much less scientific premises than genetic test results. By making these 'special' we do more harm than good by making people afraid of genetic testing and complicating the process'.

The vast majority (93%) of HPs also felt the Australian government should introduce legislation to regulate life insurers' use of genetic test results (no significant difference between genetics/non-genetics HPs (z=−0.1; p=0.94)). Of 149 HPs, 15 elaborated (13 'yes'; 3 'no') (online supplemental table S3). Four HPs expressed mistrust of insurers, with Participant 207 stating, 'if it is not in law, why would an insurance company do it?'. Four HPs commented that legally enforceable/legislation-based regulation is required to ensure consumer protection; for example, Participant 135 noted, 'this is the only way to protect people properly and not have the highly undesirable situation where people don't have genetic testing because of insurance concerns and die of preventable disease'.

One HP's reason (Participant 256) for answering 'no' to the government introducing such legislation appeared to be that insurer use should not be allowed at all, stating, 'Sorry, too many instances where insurance companies look to preserving their cash and not interested in helping people with genuine need'. Participant 229 answered no 'with the caveat that self-regulation is effective and sufficient monitoring is in place' along with two others who felt any regulation should be evidence-based. The other 'no' HP (Participant 109) stated, 'People accept that

Table 2 Awareness, knowledge, training

Question		Responses		Genetics HPs (%)	Non-genetics HPs (%)	Total (%)
Are you aware that there was a change in policy on 1July 2019 and a moratorium was introduced on the use of genetic testing in life insurance underwriting? (n=166)		No		3/121 (2)	21/45 (47)	24/166 (14)
		Yes		118/121 (98)	24/45 (53)	142/166 (86)
(if yes) How did you become aware? (n=142) * more than one option could be selected		My health service		64/118 (54)	7/24 (29)	71/142 (50)
		A news source		12/118 (10)	10/24 (42)	22/142 (15)
		HGSA		96/118 (81)	4/24 (17)	100/142 (70)
		Insurance industry		4/118 (3)	0/24 (0)	4/142 (3)
Has your health service provided, or have you attended, any training or information sessions regarding the moratorium and insurance implications of genetic testing? (n=166)		Yes, formal training		7/121 (6)	0/45 (0)	7/166 (4)
		Yes, information sessions		60/121 (49)	3/45 (7)	63/166 (38)
		No		54/121 (45)	42/45 (93)	96/166 (58)
How well do you feel you now understand insurance implications for individuals undergoing genetic testing? (n=166)		Extremely well		12/121 (10)	0/45 (0)	12/166 (7)
		Reasonably well		89/121 (74)	17/45 (38)	106/166 (64)
		Not particularly well		17/121 (14)	17/45 (38)	34/166 (20)
		Not well at all		3/121 (2)	11/45 (24)	14/166 (8)
Do you feel you have sufficient knowledge about the current insurance implications of genetic testing to properly advise patients? (n=166)		Yes		98/121 (81)	16/45 (36)	114/166 (69)
		No		23/121 (19)	29/45 (64)	52/166 (31)
Are you aware of, and have you read, these fact sheets? (n=158)	The updated HGSA position statement on Genetic Testing and Life Insurance (updated after announcement of moratorium)	I am aware of it and I have read it		49/117 (42)	9/42 (21)	58/158 (37)
		I am aware of it, but have not yet read it		42/117 (36)	13/42 (31)	55/158 (35)
		I am not aware of it		26/117 (22)	20/42 (48)	46/158 (29)
	Fact Sheet 20 published by the Centre for Genetics Education (updated mid-2019)	I am aware of it and I have read it		79/117 (68)	7/42 (17)	86/158 (54)
		I am aware of it, but have not yet read it		17/117 (15)	6/42 (14)	23/158 (15)
		I am not aware of it		21/117 (18)	28/42 (67)	49/158 (31)
	The Financial Services Council (FSC) Standard No 11 on Genetic testing (updated to include the moratorium in mid-2019)	I am aware of it and I have read it		29/117 (25)	6/42 (14)	35/158 (22)
		I am aware of it, but have not yet read it		42/117 (36)	7/42 (17)	49/158 (31)
		I am not aware of it		46/117 (39)	28/42 (67)	74/158 (47)
	The FSC fact sheet on the life insurance moratorium	I am aware of it and I have read it		51/117 (44)	11/42 (26)	62/158 (39)
		I am aware of it, but have not yet read it		18/117 (15)	2/42 (5)	20/158 (13)
		I am not aware of it		48/117 (41)	28/42 (67)	76/158 (48)
Number of knowledge questions answered correctly (n=146) (for question-specific data see online supplemental table S2) Mean score (genetics HPs): 4.5 Mean score (non-genetics HPs): 3.1		0	'Poor knowledge'	1/110 (1)	4/36 (11)	5/146 (3)
		1		0/110 (0)	5/36 (14)	5/146 (3)
		2		1/110 (1)	4/36 (11)	5/146 (3)
		3	'Average knowledge'	14/110 (13)	7/36 (19)	21/146 (14)
		4		34/110 (31)	5/36 (14)	39/146 (27)
		5	"Good knowledge"	41/110 (37)	7/36 (19)	48/146 (33)
		6		19/110 (17)	4/36 (11)	23/146 (16)

HGSA, Human Genetics Society of Australasia; HPs, health professionals.

information available will be used by insurance companies. They don't generally have a problem with this'.

When asked about how insurers' compliance with the FSC moratorium should be regulated, 88% of HPs chose 'regulation through legally-enforceable rules'. Thirteen per cent (n=20) chose self-regulation by the FSC, though 7 of these also chose 'legally-enforceable rules' indicating a preference for a blended regulatory approach. Overall, 49% of HPs felt very/somewhat dissatisfied with the moratorium as a solution to GD. Only 4% felt 'very satisfied'.

Benefits and limitations of the moratorium

Sixty-two HPs responded to the optional free-text question about benefits of the moratorium (see table 4 for categories of benefits expressed, with example quotes, and online supplemental table S4 for full responses). The most common responses were 'increased reassurance' (34%) and 'some protection provided' (31%). Sixty-four HPs provided optional feedback to the question about the moratorium's limitations (table 4; online supplemental table S4). The most common responses were 'insurer compliance/self-regulation' (46%), 'financial limits' (44%) and 'temporary nature of moratorium' (31%). Similar issues arose in responses to the question inviting final comments (online supplemental table S5). Of 21 HPs with comments about the FSC moratorium, a third (n=7) raised issues around the need for legislation/enforceability; two each expressed concerns with the moratorium's temporary nature and the unjustness of discrimination based on uncontrollable factors; one reiterated the inadequacy of the financial limits; five reported difficulty with understanding/explaining the moratorium and three expressed concerns regarding travel insurance. No HPs made positive comments about the moratorium in this section (table 4).

DISCUSSION

We surveyed Australian HPs' knowledge, experiences and opinions regarding the current industry self-regulated partial moratorium

on genetic testing and life insurance. We found most HPs who discuss genetic testing with clients are aware of the FSC moratorium, though knowledge of key aspects could be improved. Genetics HPs have superior awareness of and knowledge about the moratorium compared with non-genetics HPs. Many HPs felt the moratorium had resolved some of their GD concerns. However, the majority of HPs still have concerns regarding GD in life insurance, which are not adequately addressed by the FSC moratorium. Specifically, the majority of HPs feel more stringent consumer protections are required, especially in the form of stronger government regulation or legislation. Key findings of our study are summarised in figure 2.

Our previous survey of Australian genetics HPs conducted before the FSC moratorium's introduction[18] showed only 9% (n=6/69) of HPs felt regulation at the time was adequate. After the moratorium's introduction, we still found that >90% of HPs believe government regulation and legislation are required. Although the moratorium is seen as a step forward by some HPs, most remain concerned about the potential for GD and its impact on patients in Australia. We found many HPs recognised improved consumer protections compared with the pre-moratorium situation, and some HPs cited increased willingness of patients to have genetic testing as a benefit of the moratorium. However, despite some reported reduction in patients delaying/declining testing for insurance reasons, more than 40% of HPs still disagreed that patients are more willing to have testing post-moratorium, suggesting that the moratorium's desired impact has not been fully achieved.

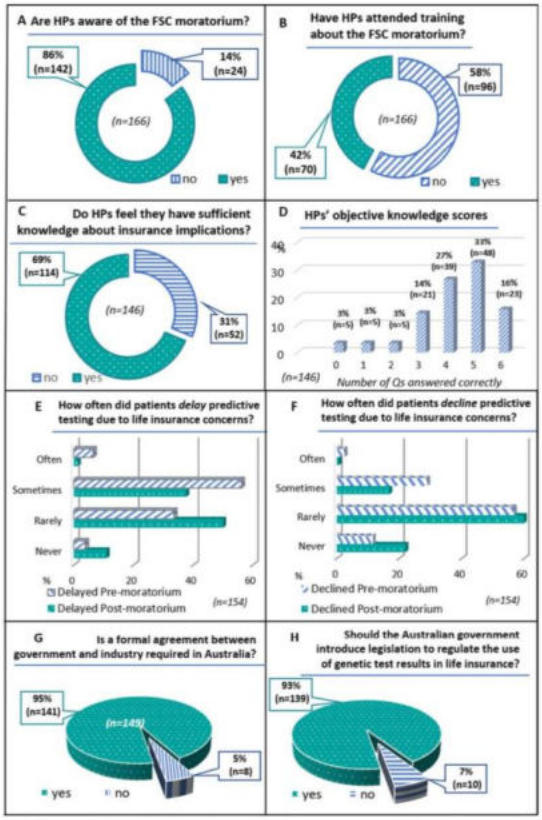

Figure 1 A–H: Awareness, knowledge, training, patient impact and views on regulation. FSC, Financial Services Council; HPs, health professionals.

Although about half of HPs surveyed expressed some satisfaction with the FSC moratorium as a solution to GD in life insurance, various HP responses highlighted the perceived shortcomings of the moratorium in practice. About half were either somewhat or very dissatisfied with the moratorium, and a vast majority still had GD concerns post-moratorium. Primary concerns centred around industry self-regulation, lack of government oversight, the moratorium's financial limits and its temporary nature. HPs' comments showed negative opinions—including distrust of insurers, the conflicted nature of industry self-regulation, the need for more stringent government regulation, the inadequacy of financial limits and the temporary nature of the moratorium (and the uncertainty this creates for patients). A small minority of HPs felt that government regulation was not required, as either the moratorium was adequate or the government should wait and see whether it is effective before introducing further regulation. One participant expressed concern with treating genetic information as 'special', demonstrating a minority view against the notion of genetic exceptionalism in the context of life insurance underwriting. However, the majority view was that genetic test results should be granted specific protection against life insurance discrimination.

Many countries have banned or restricted life insurers' access to genetic test results for underwriting purposes.[28–30] For example, Canada has implemented the *Genetic Nondiscrimination Act* (2017) (GNDA), which prevents insurers from using genetic test results, and the US' *Genetic Information Nondiscrimination Act* (2008) (GINA) bans the use of genetic test results in health insurance and employment contexts. The UK's moratorium (now the Code on Genetic Testing and Insurance[31]) was established in 2001 as an agreement between the insurance industry and the UK Government to ban the use of predictive genetic test results. A single exception applies to predictive genetic tests for Huntington disease, where the life insurance cover is >£500 000 (~$910 000).

Almost all HPs surveyed believe a formal agreement between government and industry is required in Australia rather than industry self-regulation. Further, most HPs feel that any moratorium should be regulated through legally enforceable rules, including specific legislation to regulate life insurers' use of genetic test results. Our findings demonstrate that HPs who offer genetic testing to patients in Australia believe the current policy situation is still inadequate and lacks sufficient consumer protections. Given that in our previous study, 62% of HPs considered the Australian government should introduce such legislation, and 93% of current HPs consider that legislation is needed, it appears the current FSC moratorium has not altered that perception for the majority of HPs.

Although the FSC moratorium may soon be included in the FSC Code,[17] compliance is monitored by a committee of three individuals and is not subject to any legal or regulatory government oversight. The sanctions which can be imposed lack any legal weight or punitive power. Thus, future inclusion of the moratorium in the Code is unlikely to alleviate HPs' concerns regarding lack of government oversight.

The demographics of HPs in this study are similar to those of our previous study.[18] However, the current cohort is larger (n=166, compared with n=87 previously) and more diverse due to the expanded recruitment strategy. This survey has highlighted the diversity of HPs who are discussing genetic testing

Table 3 Impact on practice and clients, and views on regulation

Question		Responses	Genetics HPs (%)	Non-genetics HPs (%)	Total (%)
Is there a statement about insurance implications?	On your consent form, where you have a specific form for predictive genetic testing in adults (n=51)	Yes	34/38 (89)	9/13 (69)	43/51 (84)
		No	4/38 (11)	4/13 (31)	8/51 (16)
	On your consent form, where you have a standard form for all genetic testing (n=99)	Yes	60/75 (80)	6/24 (25)	66/99 (67)
		No	15/75 (20)	18/24 (75)	33/99 (33)
Has your consent form been updated following the introduction of the moratorium on 1 July 2019? (n=151)		Yes	24/113 (21)	4/38 (11)	28/151 (18)
		No	67/113 (59)	8/38 (21)	75/154 (50)
		I don't know	22/113 (19)	26/38 (68)	48/154 (32)
How often do you estimate patients delayed predictive testing? (n=154)	Due to life, income or trauma/critical illness insurance concerns, before the moratorium was introduced	Never	1/121 (1)	5/45 (11)	6/154 (4)
		Rarely	41/121 (34)	11/45 (24)	52/154 (34)
		Sometimes	68/121 (56)	19/45 (42)	87/154 (56)
		Often	5/121 (4)	5/45 (11)	10/154 (6)
	Due to life, income or trauma/critical illness insurance concerns, after the moratorium was introduced	Never	12/121 (10)	5/45 (11)	17/154 (11)
		Rarely	62/121 (51)	15/45 (33)	77/154 (50)
		Sometimes	40/121 (33)	18/45 (40)	58/154 (38)
		Often	0/121 (0)	2/45 (4)	2/154 (1)
	Due to travel insurance concerns	Never	47/121 (39)	14/45 (31)	61/154 (40)
		Rarely	60/121 (49)	16/45 (36)	76/154 (49)
		Sometimes	7/121 (6)	5/45 (11)	12/154 (8)
		Often	0/121 (0)	5/45 (11)	5/154 (3)
How often do you estimate patients refused predictive testing? (n=154)	Due to life, income or trauma/critical illness insurance concerns, before the moratorium was introduced	Never	11/121 (9)	7 (16)	17/154 (11)
		Rarely	76/121 (63)	12/45 (27)	77/154 (50)
		Sometimes	26/121 (21)	19/45 (42)	58/154 (38)
		Often	2/121 (2)	2/45 (4)	2/154 (1)
	Due to life, income or trauma/critical illness insurance concerns, after the moratorium was introduced	Never	28/121 (23)	6/45 (13)	34/154 (22)
		Rarely	75/121 (62)	18/45 (40)	93/154 (60)
		Sometimes	11/121 (9)	15/45 (33)	26/154 (17)
		Often	0/121 (0)	1/45 (2)	1/154 (1)
	Due to travel insurance concerns	Never	56/121 (46)	16/45 (36)	72/154 (47)
		Rarely	50/121 (41)	14/45 (31)	64/154 (42)
		Sometimes	8/121 (7)	8/45 (18)	16/154 (10)
		Often	0/121 (0)	2/45 (4)	2/154 (1)
Since the introduction of the moratorium, have patient/s told you about having had an adverse insurance outcome on the basis of genetic test results? (eg, having difficulty obtaining a policy, having an increased premium or having a policy application denied)? (n=153)		Yes	3/114 (3)	2/39 (5)	5/153 (3)
		No	111/114 (97)	37/39 (95)	148/153 (97)

Continued

Table 3 Continued

Question		Responses	Genetics HPs (%)	Non-genetics HPs (%)	Total (%)
Please indicate the degree to which you agree with the following statements	The moratorium is easy to understand (n=145)	Strongly agree	0/113 (0)	0/35 (0)	0/145 (0)
		Agree	89/110 (81)	27/35 (77)	116/145 (80)
		Disagree	18/110 (16)	6/35 (17)	24/145 (17)
		Strongly disagree	3/110 (3)	2/35 (6)	5/145 (3)
	The moratorium is easy to explain to patients (n=144)	Strongly agree	1/110 (1)	0/35 (0)	1/144 (1)
		Agree	80/109 (73)	28/35 (80)	108/144 (75)
		Disagree	25/109 (23)	5/35 (14)	30/144 (21)
		Strongly disagree	3/109 (3)	2/35 (6)	5/144 (3)
	Patients are less confused than they used to be about insurance implications of genetic testing (n=144)	Strongly agree	5/109 (5)	0/35 (0)	5/144 (3)
		Agree	51/109 (47)	17/35 (49)	68/144 (47)
		Disagree	49/109 (45)	17/35 (49)	66/144 (46)
		Strongly disagree	4/109 (4)	1/35 (3)	5/144 (3)
	Patients are more willing to have predictive genetic testing than they were before the moratorium was introduced (n=144)	Strongly agree	6/109 (5)	0/35 (0)	6/144 (4)
		Agree	60/109 (55)	19/35 (54)	79/144 (55)
		Disagree	39/109 (36)	15/35 (43)	54/144 (38)
		Strongly disagree	4/109 (4)	1/35 (3)	5/144 (3)
	The moratorium has resolved some concerns I had about insurance discrimination (n=144)	Strongly agree	5/109 (5)	2/35 (6)	7/144 (5)
		Agree	82/109 (75)	21/35 (60)	103/144 (72)
		Disagree	21/109 (19)	10/35 (29)	31/144 (22)
		Strongly disagree	1/109 (1)	2/35 (6)	3/144 (2)
	After the introduction of the moratorium, I still have concerns about insurance discrimination (n=144)	Strongly agree	22/109 (20)	4/35 (11)	26/144 (18)
		Agree	76/109 (70)	25/35 (71)	101/144 (70)
		Disagree	9/109 (8)	4/35 (11)	13/144 (9)
		Strongly disagree	2/109 (2)	2/35 (6)	4/144 (3)
	Consumers are better protected post-moratorium than they were before the moratorium was introduced (n=144)	Strongly agree	18/109 (16)	2/35 (6)	20/144 (14)
		Agree	84/109 (77)	30/35 (86)	114/144 (79)
		Disagree	7/109 (6)	3/35 (9)	10/144 (7)
		Strongly disagree	0/109 (0)	0/35 (0)	0/144 (0)
Based on your professional experience, how do you feel about the moratorium as a solution to genetic discrimination in life insurance? (n=149)		Very satisfied	6/113 (5)	0/36 (0)	6/149 (4)
		Somewhat satisfied	52/113 (46)	18/36 (13)	70/149 (47)
		Somewhat dissatisfied	49/113 (46)	12/36 (9)	61/149 (41)
		Very dissatisfied	6/113 (5)	6/36 (4)	12/149 (8)
In your opinion, how should insurers' compliance with the moratorium on using genetic test results in life insurance be regulated? (n=149) * more than one option could be selected		Self-regulation by the life insurance industry (FSC)	16/113 (14)	4/36 (11)	20/149 (13)
		Regulation through legally enforceable rules	102/113 (90)	29/36 (81)	131/149 (88)
		Other	2/113 (2)	3/36 (8)	5/149 (3)
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 Australian government and industry (Financial Services Council) is required on this issue in Australia? (n=149)		Yes	108/113 (96)	33/36 (92)	141/149 (95)
		No	5/113 (4)	3/36 (8)	8/149 (5)
Do you think the Australian government should introduce legislation to regulate the use of genetic test results in life insurance? (n=149)		Yes	105/113 (93)	34/36 (94)	139/149 (93)
		No	8/113 (7)	2/36 (6)	10/149 (7)

FSC, Financial Services Council; HPs, health professionals.

Table 4 Perceived benefits and limitations of the FSC moratorium (free-text responses)

Benefit (n=62)	n (%)*	Example quote(s)	Participant # (qualification, years' experience)
Increased reassurance	21 (34)	*Easing concerns for patients who may now have some level of cover if at high genetic risk. By doing this it lessens the potential negative implications of predictive testing and therefore decision making can be focused more on the health implications.*	P21 (GC, 10–15 y)
		It's a step in the right direction and patients with minor concerns/reluctance feel reassured.	P108 (GC, 0–5 y)
Some protection provided	19 (31)	*Provides at least some level of insurance that may not have been available at all previously.*	P42 (GC, 10–15 y)
		People can access some level of insurance without the threat of discrimination based on their genetic test result.	P199 (GC, 0–5 y)
Increased clarity	9 (15)	*From my practice point of view, having some clear guidelines to present to clients/patients, rather than it all being very dependent on the individual insurer.*	P129 (GC, 0–5 y)
Family implications	6 (10)	*Most people are concerned about what the insurance implications are for their children. It is helpful to be able to let them know that their children only need to disclose their parent's health conditions not their genetic test result.*	P136 (GC, 0–5 y)
Heightened awareness/ recognition of issue	5 (8)	*More awareness of the issue, hopefully future stronger protections for patients depending on how effective the moratorium can be shown to be currently.*	P130 (GC, 6–10 y)
'Step in the right direction'	3 (5)	*It is a step in the right direction but insurance concerns are still present for many patients and providers.*	P108 (GC, 0–5 y)
Provides time	2 (3)	*Gives time to find better solution.*	P98 (GC, 15–20 y)
Limitation (n=64)	**n (%)***		
Insurer compliance/self-regulation	29 (45)	*It would be better if there was NO discrimination at all, that was made law and insurance companies held accountable (not self-regulated).*	P129 (GC, 0–5 y)
		It is self-regulated and not legally enforceable, so only as good as the trust in the industry generally.	P89 (GC, 0–5 y)
Financial limits	28 (44)	*The limit on cover is relatively low. Despite industry assurance that most policies fall below this threshold a significant number of patients see this as limiting.*	P229 (CG 15–20 y)
		The amounts are too low and won't give enough reassurance to some.	P135 (CG >20 y)
Temporary nature of moratorium	17 (27)	*The uncertainty about how long it will be in place—we need this to be PERMANENT to enable patients not to fear having genetic testing because of insurance concerns as genetic testing can really influence their physical AND psychological health.*	P149 (GC 15–20 y)
		The uncertainty of how this will apply in the future if someone wants to take out a policy in a few years and the moratorium no longer applies.	P173 (GC, 0–5 y)
Restricted application	8 (13)	*Not all insurers are FSC Members. It doesn't apply to all life insurance policies, only those under certain amounts. Only applies to policies from 1 July 2019, that is, not pre-existing too.*	P42 (GC, 11–15 y)
Travel insurance not covered	3 (5)	*Travel insurance is a major exclusion. Many patients are concerned about implications for travel insurance especially when their work or family takes them to high cost medical care in countries such as USA.*	P195 (GC, 15–20 y)
Lack of dissemination	2 (3)	*Many financial advisors and workers in the industry seem unaware of the moratorium.*	P207 (CG, >20 y)

*Participants may have listed multiple limitations in their free-text response.
CG, Clinical Geneticist; FSC, Financial Services Council; GC, Genetic Counsellor.

with patients, consistent with the mainstreaming of genetic testing noted earlier. This has also captured, for the first time in Australia, the perceptions of non-genetics HPs on this issue.

Although there was consensus among most genetics and non-genetics HPs on key issues, including regulation, there was divergence between the groups in some areas. Areas of divergence include awareness of the FSC moratorium, with only about half of non-genetics HPs being aware of the moratorium. These findings are consistent with other studies that report poor awareness of local non-discrimination laws/policies by HPs.[32–34] However, given the importance of considering insurance issues where relevant before deciding about genetic testing, this lack of awareness is somewhat concerning and raises questions about how to more

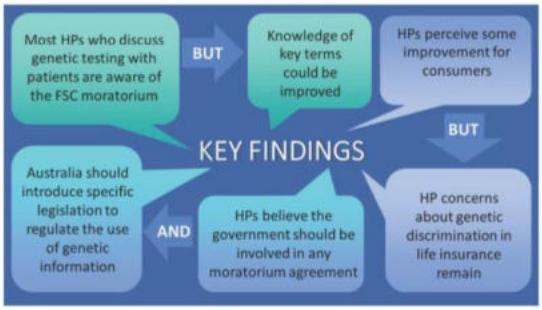

Figure 2 Summary of study findings. FSC, Financial Services Council; HPs, health professionals.

effectively raise awareness, particularly among non-genetics HPs. The numbers of HPs who had read either the CGE or FSC fact sheets indicate that these are a reasonable method of disseminating information to genetics HPs but less effective for non-genetics HPs. Future consideration should be given to effective ways of ensuring non-genetics HPs have adequate information and education regarding aspects of genetics and insurance, including the potential use of decision support tools.

Objective knowledge also varied between genetics and non-genetics HPs. Of genetics HPs, 81% felt they had sufficient knowledge of insurance implications to properly advise patients—an increase from our previous research (61%; n=53/87).[18] However, only a small fraction of both genetics and non-genetics HPs answered all six questions about key aspects of the FSC moratorium correctly and about half had average or poor knowledge. There was a reasonable match between non-genetics HPs' subjective and objective lack of knowledge, consistent with international studies of non-genetics HPs, which found a correlation between subjective and objective knowledge regarding genetic non-discrimination regulations[35] and genetics generally.[36] However, although genetics HPs were more knowledgeable than non-genetics HPs, they appeared to overestimate their knowledge more than non-genetics HPs, indicating some mismatch between subjective and objective knowledge.

An area of historical misinformation is that of the impact of GD on health insurance. In our previous survey,[18] 15% of HPs stated that genetic test results could be used for health insurance policies in Australia, which is incorrect. In the current survey, a similar number (17%) of genetics HPs were still incorrectly under the impression that genetic results could be used in health

insurance. In addition, 50% of non-genetics HPs were either incorrect or unsure about this question.

The knowledge gap between genetic and non-genetic HPs overall was sizeable, highlighting the need to train a wider range of HPs with the mainstreaming of genetic testing. Surprisingly, given the recent policy changes and need for dissemination and education around these changes, similar numbers of genetics HPs reported attending training in our previous survey (51%) as this survey (55%). Further, a smaller percentage of genetics HPs reported having read the CGE fact sheet (68%) than previously (85%).[18] This may explain the knowledge gaps despite clinician confidence (HPs who feel they have sufficient knowledge may be less likely to seek out additional resources).

A significant finding of the study is that many HPs (50%) believe the FSC moratorium applies to travel insurance or are unsure. In the UK, the new Code on Genetic Testing, which commenced in 2018, included travel insurance in its protection.[31] As discussed, however, Australian travel insurers are not restricted by the FSC moratorium. Other research has reported stakeholder concerns with travel insurance implications of genetic testing[28] and consumer experiences of difficulty accessing travel insurance after genetic testing.[37 38] Several HPs raised concerns about insurance implications for travel insurance in free-text comments, providing further support for the contention that broader government regulation and oversight of the use of genetic test results in insurance underwriting are required to adequately protect consumers.

Strengths of the current study include being the first of its kind to report HP views and experiences since the FSC moratorium's introduction. To our knowledge, it also provides the first example of a survey of HPs conducted both before and after the introduction of a major policy change regarding GD and life insurance. By preserving questions from our pre-moratorium survey, we could undertake comparative pre-moratorium and post-moratorium analysis. Our survey reached a wide range of Australian HPs, covering traditional genetics HPs as well as non-genetics clinicians who discuss genetic testing with patients.

Limitations of our study include the relatively small number of non-genetics HPs surveyed, which may limit the generalisability to this group. HPs were asked questions about patient experiences, yielding arguably secondhand information. Other studies, which will seek firsthand experiences/perceptions of consumers, are being developed as part of the A-GLIMMER Project[23] to address this limitation. Given the rising awareness of the issue of GD in Australia, response bias is a potential limitation. We attempted to address this by allowing HPs to remain anonymous if preferred. Further, views of HPs who agreed to be contacted (~20%) will be explored further through qualitative interviews in a subsequent study. Our survey was conducted less than a year after the FSC moratorium's introduction (9 months). Although this was intentional to ensure data collection and analysis could take place to inform the review of the moratorium in 2022, waiting longer could have resulted in different responses and experiences. As the survey was conducted online and in early 2020, it is not expected that COVID-19 restrictions significantly affected participation.

CONCLUSION

Many Australian genetic HPs are aware of the FSC moratorium and have knowledge of its specifics; however, some genetic HPs and many non-genetics HPs do not. Australian HPs report some improvement for consumers as a result of the moratorium's introduction, but concerns about GD in life insurance remain. HPs describe strong views about perceived limitations of the moratorium, including industry self-regulation and lack of government oversight, as well as the inadequacy of the current financial limits and the uncertainty around the moratorium's temporary nature. A majority of Australian HPs believe government oversight of the FSC moratorium is required and that legislation regarding genetic testing and life insurance should also be considered in Australia. Our findings will assist with developing recommendations for the Australian government to consider future policy and regulatory changes in this area, and will be of interest to other jurisdictions internationally who are grappling with similar issues around the regulation of GD in life insurance.

Author affiliations
[1]School of Public Health and Preventive Medicine, Monash University, Faculty of Medicine, Nursing and Health Sciences, Melbourne, Victoria, Australia
[2]Murdoch Childrens Research Institute, Parkville, Victoria, Australia
[3]Centre for Health Equity, Melbourne School of Population and Global Health, The University of Melbourne, Melbourne, Victoria, Australia
[4]Human Genomics Group, University of Queensland Diamantina Institute, Woolloongabba, Queensland, Australia
[5]The University of Queensland, Faculty of Medicine, Herston, Queensland, Australia
[6]Australian Genomics, Melbourne, Victoria, Australia
[7]The University of Sydney, Sydney Medical School, Sydney, New South Wales, Australia
[8]School of Law, Deakin University, Burwood, Victoria, Australia
[9]The University of Iowa College of Law, Iowa City, Iowa, USA
[10]University of Toronto, Institute of Health Policy, Management and Evaluation, Toronto, Ontario, Canada
[11]Li Ka Shing Knowledge Institute, Toronto, Ontario, Canada
[12]Department of Human Genetics, McGill University, Montreal, Québec, Canada
[13]Murdoch Childrens Research Institute, Melbourne, Victoria, Australia
[14]Victorian Clinical Genetics Services Ltd, Parkville, Victoria, Australia
[15]Clinical Genetics, Royal Melbourne Hospital, Parkville, Victoria, Australia
[16]Department of Medicine, The University of Melbourne, Melbourne, Victoria, Australia
[17]University of Tasmania, Faculty of Law, Hobart, Tasmania, Australia

Twitter Jane M Tiller @JaneMTiller and Andrea Belcher @AndreaBelcher6

Contributors JMT conceived the project and designed the survey with assistance from PL, LAK, AMM-L, AB, KB-S, TB, MD, IMW and MO. PG and GD assisted with interpretation of data. AP, YB and YJ assisted with providing international perspectives on the project and interpretation of data. JMT wrote the first draft of the manuscript with input from PL. All authors critically reviewed and provided comments on the second and subsequent drafts of the manuscript.

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Competing interests None declared.

Patient consent for publication Not required.

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.

Provenance and peer review Not commissioned; externally peer reviewed.

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ORCID iDs
Jane M Tiller http://orcid.org/0000-0003-3906-6632
Yvonne Bombard http://orcid.org/0000-0002-9516-4539

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6. Appendix 6 – Second Health Professional's Study

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Health professionals' views and experiences of the Australian moratorium on genetic testing and life insurance: A qualitative study

Grace Dowling[1,14], Jane Tiller[1,2,14✉], Aideen McInerney-Leo[3], Andrea Belcher[4,5], Casey Haining[6], Kristine Barlow-Stewart[7], Tiffany Boughtwood[2,5], Penny Gleeson[8], Martin B. Delatycki[2,9], Ingrid Winship[10,11], Margaret Otlowski[12], Chris Jacobs[13], Louise Keogh[6,15] and Paul Lacaze[1,15]

Australian life insurance companies can legally use genetic test results in underwriting, which can lead to genetic discrimination. In 2019, the Financial Services Council (Australian life insurance industry governing body) introduced a partial moratorium restricting the use of genetic testing in underwriting policies ≤ $500,000 (active 2019–2024). Health professionals (HPs), especially clinical geneticists and genetic counsellors, often discuss the implications of genetic testing with patients, and provide critical insights into the effectiveness of the moratorium. Using a sequential explanatory mixed methods design, we interviewed 23 Australian HPs, who regularly discuss genetic testing with patients and had previously completed an online survey about genetic testing and life insurance. Interviews explored views and experiences about the moratorium, and regulation, in greater depth. Interview transcripts were analysed using thematic analysis. Two key themes emerged from views expressed by HPs during interviews (about matters reported to or observed by them): 1) benefits of the moratorium, and 2) concerns about the moratorium. While HPs reported that the moratorium reassures some consumers, concerns include industry self-regulation, uncertainty created by the temporary time period, and the inadequacy of the moratorium's financial limits for patients' financial needs. Although a minority of HPs felt the current industry self-regulated moratorium is an adequate solution to genetic discrimination, the vast majority (19/23) expressed concern with industry self-regulation and most felt government regulation is required to adequately protect consumers. HPs in Australia are concerned about the adequacy of the FSC moratorium with regards to consumer protections, and suggest government regulation is required.

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INTRODUCTION

Genetic testing can help identify individuals' risk of developing future disease, including some cancers [1], and can effect positive health outcomes through prevention or early detection and treatment where available. In Australia, genetic test results can also lead to genetic discrimination in life insurance, including increased premiums or denial of cover on the basis of genetic test results [2]. Fear of life insurance discrimination has been shown to deter individuals from undergoing predictive genetic testing [3] and participating in genomic research [4].

Debate exists regarding whether the use of genetic test results by life insurers should be restricted [5]. Some contend that the use of genetic information is a necessary and accepted principle of life insurance underwriting. Others, including many governments internationally [6, 7], have accepted that curtailment of this is necessary for the protection of certain human rights, including those protected by Article 6 of the United Nations Universal Declaration on the Human Genome and Human Rights (unanimously adopted by 77 countries, including Australia), and Article 25 of the UN Convention on the Rights of Persons with Disabilities (which Australia has confirmed) [8]. Many countries, including the United Kingdom, Canada, and many European nations, have restricted or banned the use of genetic test results in life insurance underwriting [6, 7, 9]. Private life insurance in those countries has not become unviable so far, suggesting that this debate is not determined, but rather an issue on which there are various points of view.

In Australia, under the *Disability Discrimination Act 1992* (Cth) [10], insurance companies can legally use an individual's genetic status to discriminate against them in underwriting risk-rated

[1]Public Health Genomics, School of Public Health and Preventive Medicine, Monash University, Melbourne, Australia. [2]Murdoch Children's Research Institute, Parkville, Australia. [3]The University of Queensland Diamantina Institute, University of Queensland, Dermatology Research Centre, Brisbane, Australia. [4]Faculty of Medicine, University of Queensland, Brisbane, Australia. [5]Australian Genomics, Melbourne, Australia. [6]Centre for Health Equity, Melbourne School of Population and Global Health, The University of Melbourne, Melbourne, Australia. [7]Sydney Medical School, University of Sydney, Sydney, Australia. [8]Deakin Law School, Melbourne, Australia. [9]Victorian Clinical Genetics Services, Parkville, Australia. [10]Department of Medicine, The University of Melbourne, Melbourne, Australia. [11]Genomic Medicine and Family Cancer Clinic, Royal Melbourne Hospital, Parkville, Australia. [12]Faculty of Law and Centre for Law and Genetics, University of Tasmania, Hobart, Australia. [13]Graduate School of Health, University of Technology Sydney, Sydney, Australia. [14]These authors contributed equally: Grace Dowling, Jane Tiller. [15]These authors jointly supervised this work: Louise Keogh, Paul Lacaze. ✉email: jane.tiller@monash.edu

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insurance, if the company can justify its reasoning with actuarial or statistical data [1]. This allowance does not apply to health insurance, which must be community-rated under separate legislation [11] and is thus protected from genetic discrimination. Risk-rated insurance cover underwritten by life insurance companies in Australia includes life (death) cover, income protection, total and permanent disability, and critical illness/trauma cover.

Australian life insurance companies are self-regulated by the industry governing body, the Financial Services Council (FSC). The FSC self-regulates its own access to, and use of, genetic test results through mandatory practice standards, without government oversight [12]. Despite previous efforts [13, 14], the Australian government has not taken steps to limit insurance companies' use of genetic test results. Following recommendations from a Parliamentary Joint Committee into the life insurance industry that this practice should be banned [13], however, the FSC introduced an industry-led, partial moratorium (ban) on use of genetic test results for life insurance products applied for after July 1 2019 [15]. The FSC moratorium is not a complete ban – protection is only offered for policies ≤ $500,000 for life (death) cover, ≤ $4000/month for income protection, ≤ $500,000 for total and permanent disability, and ≤ $200,000 for critical illness/trauma cover. The self-regulated moratorium will expire in 2024 unless renewed, and is not legally enforceable nor subject to government oversight.

In recognition of the importance of this issue, the Australian government has funded a three-year project to monitor the effectiveness of the FSC moratorium: the Australian Genetics and Life Insurance Moratorium: Monitoring the Effectiveness and Response (A-GLIMMER) [16]. The project is a national study, collecting views and evidence from multiple stakeholders (health professionals, consumers, researchers/research participants, and the financial services industry) [17].

Health professionals (HPs), including clinical geneticists and genetic counsellors, play an essential role in assisting patients with making informed choices about genetic testing [18]. HPs must, where relevant, discuss the implications of genetic testing on life insurance, as required by the Australian professional guidelines for genetic counselling [19]. There is little literature regarding HPs' views and experiences regarding the current FSC moratorium. Understanding these views is an important component for informing its future appropriateness. In this study, we interviewed Australian HPs who had previously responded to an online survey about the moratorium [20], to further explore their views and experiences, adopting a sequential explanatory mixed methods design. The research question addressed was "what are the views and experiences of Australian healthcare professionals regarding the genetics and insurance moratorium?".

METHODS

This study forms part of the A-GLIMMER project [21]. The first element of this study consisted of an online survey distributed to HPs in 2020, to gather evidence regarding their views and experiences of the moratorium. The results of that survey ($n = 166$) have been published [22]. Here, we undertook follow-up interviews with survey participants who agreed to be contacted in order to expand on and explore the quantitative responses. The interviews allowed for a greater in-depth understanding of individual participants' views and experiences.

Genetic testing can occur in different contexts, including research, clinical testing, and direct-to-consumer testing, conducted online without the involvement of a health professional. In a clinical context, health professionals facilitate both diagnostic and predictive testing. Given disease diagnoses can be used by underwriters in any event, predictive genetic test results are more relevant for discussions about the impact of life insurance underwriting. Questions in the survey were framed in the context of unaffected adult patients accessing predictive genetic testing in a clinical context.

Recruitment

Recruitment for the online survey has been described previously [22]. Individuals were eligible for the survey if they were qualified HPs working in Australia who discuss genetic testing with patients. The majority of respondents (73%) were clinical geneticists/genetics fellows and genetic counsellors, with a minority representation from other, non-genetics HPs. At the conclusion of the online survey, participants were asked whether they consented to be contacted for a follow-up interview. No contact details were collected from participants who preferred to remain anonymous. All HPs who consented were contacted via email, approximately 10 months after their initial survey completion, to invite their participation in a follow-up interview.

Interviews

Semi-structured interviews taking up to 30 min were held by teleconference and carried out by GD and CH between January and April 2021. Participants consented to audio recording and were advised that the recording would be de-identified and transcribed for analysis and publication. The interview schedule (Supplementary File S1) was designed to explore the responses given in the online survey and was tailored to each interview participant, using their survey responses as a starting point. The schedule was developed iteratively –new topics that arose regularly in interviews were incorporated for future interviews.

Analysis

The audio files were de-identified and transcribed verbatim to allow for thematic analysis. Inductive thematic analysis [23] involves familiarisation with the data, followed by identification of themes in order to determine patterns of meaning in the data. This enabled the research team to present the collective meanings and experiences from the data set [24, 25]. Five transcripts were read by GD to develop an initial coding framework. These five transcripts and the coding framework were reviewed by CJ to confirm full capture of the main themes present in the data. One full transcript was independently coded by CJ to ensure coding consistency. The coding framework was used to determine when the main themes were saturated and no new themes were emerging during the interviews. Once data collection was completed, all transcripts were read by GD and the coding framework revised to incorporate all data. GD, JT and LK collaboratively refined the final coding framework to capture the main themes (Supplementary File S2). The coding of transcripts was performed by GD, and then each code was further analysed collaboratively by GD, JT and LK.

RESULTS

Sample

Thirty-one survey participants agreed to be contacted and were invited for follow-up interviews – of these, four declined to participate and four did not respond to the invitation. Twenty-three participants took part in an interview (Fig. 1). Data saturation occurred at interview 17, and the final six interviews were conducted to confirm saturation on key themes.

The demographics for the 23 interviewed participants are set out in Table 1. The sample had a reasonable spread of sex (48% males), years of experience (43% with at least 15 years' experience) and location within Australia.

Interviews explored the views and experiences of Australian HPs regarding the genetics and insurance moratorium. Many HPs reflected on how the moratorium has been received by their patients, and the opinions they have formed, based on their experiences as HPs and their interactions with patients. Table 2 sets out the main themes and subthemes identified, which are discussed in more detail below.

Theme 1: The benefits of the moratorium

A number of HPs mentioned some patients telling them that the moratorium provided some reassurance, and made it easier for them to have genetic testing without worrying about implications for their life insurance.

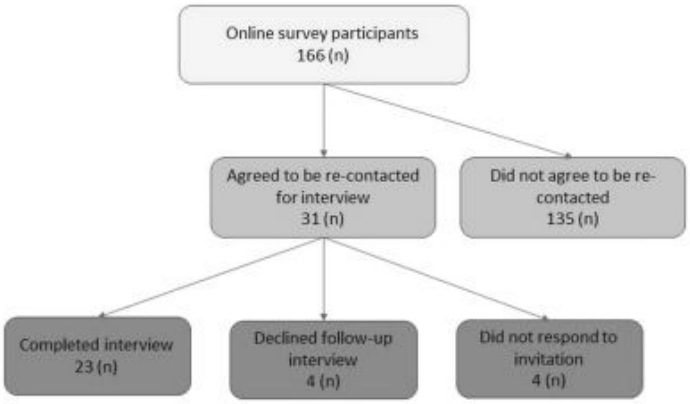

Fig. 1 Recruitment outcomes for qualitative interviews.

Table 1. Participant Demographics.

	Number of participants interviewed $n = 23$	
	$n = 23$	n(%)
Gender		
Male	11	48%
Female	12	52%
Profession		
Associate Genetic Counsellor	7	30%
Certified Genetic Counsellor*	7	30%
Clinical Geneticist	5	22%
Other**	4	18%
Years of experience		
0–5 years	8	35%
6–10 years	3	13%
11–15 years	2	9%
15–20 years	3	13%
> 20 years	7	30%
State		
Victoria	5	22%
New South Wales	9	39%
Queensland	3	13%
Northern Territory	0	0%
South Australia	1	4%
Western Australia	3	13%
Tasmania	2	9%

*In Australia, qualified genetic counsellors are titled "Associate" until they have completed a certification pathway, after which time they are titled "Certified".
**Other included: Genetic pathologist, cardiologist, metabolic clinician, chemical pathologist.

Alleviating patient concerns. Several interviewed HPs expressed a view that the moratorium is a step in the right direction and provides benefits for some patients.

> *"Look, I think [the moratorium is] a step in the right direction … patients don't have to even, for low level insurance, disclose genetic test results."* (ID 13, certified genetic counsellor, 6-10 years' experience)

Table 2. Main themes identified through thematic analysis.

Theme	Subtheme
The benefits of the moratorium	Alleviating patient concerns
	Removing perceived barriers for patients
Concerns about the moratorium	Self-regulation by the insurance industry
	Impact of the financial limits
	The uncertainty created by the moratorium's temporary nature

HPs also reported comments from patients that the moratorium had reassured them about possible adverse insurance outcomes for their family members, if they choose to have genetic testing.

> *"People are more comfortable with any form of genetic testing knowing that there's a moratorium. Both knowing it for themselves and knowing that if they have it, if something's found, it won't impact on their family members."* (ID 8, certified genetic counsellor, 0-5 years' experience)

According to some HPs, a handful of patients expressed concern about the implications of genetic testing on their children, including impacting their eligibility to access insurance products if there is a known family genetic condition. HPs reported that the moratorium helped to alleviate this worry for some patients.

Removing perceived barriers for patients. HPs reported that with the introduction of the moratorium, some patients felt more secure, as they would be able to access some life insurance cover, which may not have been possible pre-moratorium.

> *"I have had positive feedback from patients who have been relieved that if they go ahead with the genetic testing, they can still get a reasonable amount of life insurance cover." (ID 11, certified genetic counsellor, 15-20 years' experience)*

Some HPs also commented that not needing to have insurance in place prior to genetic testing removed pressure

from some patients, who may otherwise have delayed or declined genetic testing.

> *"Now that the moratorium is here it just takes away that added stress of, do I need to get [life insurance] sorted out before I have a genetic test?"* (ID 10, certified genetic counsellor, 11–15 years' experience)

Theme 2: Concerns about the moratorium

Self-regulation by the insurance industry. The vast majority of interviewed HPs (19/23) expressed concerns about the FSC's self-regulation of the industry's adherence to the moratorium, making it the most frequently expressed concern. HPs viewed self-regulation by the insurance industry as inadequate, due to a lack of trust in life insurance companies to abide by the moratorium without any government regulation.

> *"I don't have much trust in the insurance industry as a whole so I guess anything to regulate* [the industry] *that's from an external body* [would be better] *- government would be the best, because that is our structure of the law… to keep things in check and make it fairer for people."* (ID 4, associate genetic counsellor, 0–5 years' experience)

Concerns from HPs included the potential for non-compliance with the moratorium by insurance companies due to lack of government regulation, and lack of penalties for non-compliance. HPs also described their distrust in insurance companies to self-regulate properly because their commercial interests are in direct conflict with patient interests.

> *"I think there should be somebody overseeing it rather than just the life insurance companies. It doesn't make sense because they are – I mean they have a commercial interest in what they're doing so why should we trust them to do the right thing really?" (ID 10, certified genetic counsellor, 11–15 years' experience)*

Many HPs felt that insurers' use of genetic information should be regulated by the government through legislation. HPs expressed a view that legislation would hold insurance companies accountable to limitations on their use of patients' genetic information, helping to ensuring fair treatment of all patients applying for insurance.

> *"This is self-monitored, there is no set legislative regulations that the insurance companies, by the law, have to abide by. Or there is no check, per se, on it, and having legislation would make that happen. There is a bit more responsibility." (ID 1, associate genetic counsellor, 0–5 years' experience)*

> *"If it's law,* [insurance companies] *have to follow it and then if they choose not to, then there are the repercussions of that. They can be liable to criminal charges, I guess. So, yeah, I like that idea in that it holds them accountable for their actions."* (ID 13, certified genetic counsellor, 6–10 years' experience)

A minority of HPs (4/23) expressed a view that government regulation is not needed at this time, as there is no evidence that the self-regulated moratorium is inadequate. Several HPs cited the lack of discrimination witnessed by them personally since the moratorium started as the reason why further regulation was currently unnecessary.

> "[Self-regulation] *has been working well, in that I'm not aware of any discriminatory cases that have come up … I guess the guidelines* [insurance industries] *are guided by with their current regulatory bodies have worked."* (ID 11, certified genetic counsellor, 15-20 years' experience)

Impact of the financial limits. Another significant concern reported by HPs is the effect on their patients of the moratorium's financial limits. Of the 23 HPs interviewed, 18 discussed concerns with the financial limits, with 13 HPs expressing that such limits create a barrier for their patients in accessing testing.

> *"So, whenever you raise the insurance question, I know* [patients say]*,'It's only helpful up to half a million.' And half a million isn't as much as you used to think it was."* (ID 14, certified genetic counsellor, >20 years' experience)

HPs commented that patients often require polices worth more than $500,000, and that the current financial limit provides no reassurance to these patients.

> *"There's lots of people out there who mentioned that, if they were insuring their current income and there was a complete loss of income from this point onwards, that $500,000 [would not be sufficient] - they'd be looking at a much larger policy."* (ID 15, clinical geneticist, 15–20 years' experience)

Several HPs mentioned that the financial limit does not reflect the current cost of living. Particular references were made to the current property prices, and maintaining a mortgage and/or a personal business.

> *"I've had a few people say it's a bit low, this $500,000. Particularly I guess if you were someone who had your own business, or even a mortgage, and you wanted to make sure you were covered for that … So, it does seem a bit low when you consider what things cost."* (ID 9, certified genetic counsellor, 11–15 years' experience)

Uncertainty created by the temporary nature of the moratorium. Many HPs expressed concerns about the temporary nature of the moratorium, and how the uncertainty of its duration leaves HPs unable to advise or reassure clients with confidence. Many HPs mentioned that they are unable to provide patients with clarity around what will happen after the moratorium ends.

> *"It's very difficult to know because I think the term* [of the] *moratorium means that they're building something that's temporary … If someone gets insurance through the moratorium and then the moratorium ends, what does all of that mean?"* (ID 21, "other" HP, > 20 years' experience)

Many HPs commented that they could not provide patients with any information or reassurance relating to how insurance companies will use patients' information in the future.

> *"We really don't know what's going to happen after 2024 … and nobody really knows what the impact's going to be – what the insurance industry or anybody else is doing with that information in those years to come."* (ID 19, clinical geneticist, >20 years' experience)

The temporary nature of the moratorium featured in a number of HPs' descriptions of the difficulty of explaining the moratorium to patients, and its effect on the reassurance they can provide to patients, as well as their own uncertainty about whether the moratorium will continue to apply in the future.

> *"So some [counsellors] are saying, 'So I don't know what will happen after that, it might be wiped.' And so I think for some,*

that's a reason to say, 'Look, this protection may not apply soon.' So there's a little uncertainty there, and a little less, I guess, reassurance that we can provide." (ID 5, associate genetic counsellor, 0–5 years' experience)

Some HPs said that the temporary nature of the moratorium created further complexities, not only for their own understanding about how the moratorium is applied, but also difficulties explaining this limitation to patients.

"It's a short-term thing and it's not entirely clear what it means. So I think that makes it difficult to explain." (ID 18, clinical geneticist, >20 years' experience)

DISCUSSION

Our study provides an in-depth assessment of Australian HPs' views and experiences regarding the current FSC moratorium on genetic testing and life insurance.

Interviews with 23 of the 166 previous participants of our published online survey [22], allowed us to obtain a more in-depth understanding of HPs' views and experiences. Capturing these views and experiences is an important part of adequately informing future policy. The findings emerged within two major themes – HPs' views on the benefits of the moratorium, and their concerns. Although some perceived benefits of the current moratorium were articulated by HPs, the major finding of our study was the consistent concerns raised, especially regarding the temporary nature of the moratorium (creating uncertainty for patients and HPs), the financial limits - which in the assessment of HPs are too low – and the issues with self-regulation by the insurance industry. The majority of interviewed HPs felt that the best solution to genetic discrimination in life insurance in Australia is government regulation or legislation.

While HPs generally consider that the moratorium is an important first step in reducing genetic discrimination in life insurance, most HPs expressed continuing concerns about the temporary nature of the moratorium, its financial limits and industry self-regulation. These concerns mirror those expressed by HPs in the previous online survey [22], where >90% of HPs expressed views that government regulation and legislation regarding the use of genetic test results in underwriting are required. In our qualitative follow-up interviews, Australian HPs again frequently highlighted the need for more stringent regulation, both to reassure patients and to ensure compliance by insurance companies.

Temporary nature of the moratorium

Many HPs expressed discomfort with their inability to reassure patients due to the temporary nature of the moratorium. Despite a recommendation from the Parliamentary Joint Committee (PJC) in 2018 that any ban should apply indefinitely to genetic tests taken before the moratorium is lifted, to ensure certainty for consumers [13], this protection was not incorporated into the FSC moratorium. As anticipated by the Parliamentary Joint Committee, this uncertainty is now impacting patients and their HPs' ability to provide them with adequate information. The temporary nature leaves HPs unsure of how the moratorium will be applied in the future, therefore increasing the complexity of the insurance and genetic testing conversations they have with patients. Furthermore, HPs cannot reassure patients that they will remain protected in the future, creating uncertainty for both patients and HPs.

HPs who are involved in organising genetic testing must provide patients with information regarding the medical and familial implications of a genetic condition, while working collaboratively to plan the next healthcare steps [26]. This role includes helping patients decide whether to have genetic testing. Obtaining informed consent for genetic testing requires HPs to provide information regarding the risks and benefits of undergoing such a test, which includes a discussion around insurance implications [27]. More specifically, in Australia the professional guidelines for genetic counsellors (who comprised ~60% of the online survey participants and 60% of our interview participants) require a discussion of the insurance implications to be included in consultations where relevant [28].

Our interview data demonstrates that many Australian HPs are now unsure how to have conversations about genetic testing and life insurance with patients, given the uncertainty around the future of the moratorium, and the possible future insurance implications of having genetic testing at this time. Given the possibility that the moratorium may not be continued beyond 2024, it is indeed impossible for HPs or any person to provide reliable or guaranteed information about the future insurance risks of genetic testing.

Financial limits

Pre-moratorium, Australian life insurance companies could ask applicants about genetic test results regardless of the amount of cover being applied for. Under the partial current moratorium, patients can apply for life insurance policies up to $ 500,000 without disclosing genetic test results [16]. As indicated by some of the interviewed HPs, this has allowed patients access to a baseline level of insurance cover which was not previously possible. However, the majority of HPs indicated that a proportion of their patients perceived the current financial limits as a significant restriction, with some patients finding the limits too low to adequately cover their financial needs. According to the Australian Bureau of Statistics, as at December 2021 the average loan size for owner-occupier dwellings was $ 602,000 [29].

Concerns with the moratorium's financial limits were similarly reflected in our previously published survey, where almost half of the responding HPs made comments in the optional comments section regarding the moratorium's financial limits being too low [22]. These concerns were echoed in the qualitative HP interviews, highlighting HPs' widespread concerns that the moratorium's financial limits are inadequate to protect patients. Despite the FSC's public statement announcing the moratorium that "the insurance cover limits compare favourably with other countries" [30], analysis shows that countries which have such financial limits, let alone still allow the use of genetic data in life insurance underwriting, are in the minority [7].

Concerns regarding self-regulation

When exploring HPs' views on the moratorium's regulation, a majority of participants voiced the need for life insurers' use of genetic test results to be regulated by government. This result was consistent with our previous online survey, in which 95% ($n = 166$) felt that government oversight of the moratorium is required [22]. In both analyses, we observed strong dissatisfaction with self-regulation by the insurance industry, paired with HP distrust in insurance companies' compliance with the moratorium terms. While a minority of HPs considered that the self-regulated nature of the moratorium is an adequate solution to address genetic discrimination, the majority felt that government regulation is needed to ensure compliance by insurance companies, and to provide a long-term regulatory solution.

Self-regulation in the Australian financial services industry has been criticised repeatedly in recent years, including for lack of transparency and compliance without external regulation [12, 13]. In 2019, an Australian Royal Commission was conducted to assess the misconduct in the banking, superannuation and the financial services industries. The findings reflected various issues that are inherent with industry self-regulation, including conflicts of interest and the industry's failure to monitor and enforce compliance with their codes [31].

For some HPs, the solution to the issue of non-compliance by the insurance industry is to move from self-regulation to government regulation. The introduction of legislation was expressed by many HPs as a necessary intervention to ensure compliance with regulations, and provide consequences for non-compliance. Our findings suggest that the majority of Australian HPs who discuss genetic testing with patients perceive industry self-regulation of the moratorium to be inadequate, and consider government regulation necessary.

Discussions about regulation in this area sometimes raise queries about consequences of restricting insurers' access to genetic information. Some insurers and authors have raised concerns that the restriction on the use of genetic test results by insurers may lead to "adverse selection", whereby the purchase of insurance by individuals with genetic predisposition to disease could lead to unsustainability of the insurance sector [32]. This issue has been raised internationally, including recently when the Canadian regulation on this issue was being considered. The Canadian Privacy Commissioner commissioned several actuarial experts to undertake modelling to assess the impact of a ban on using genetic test results in life insurance underwriting [33]. Each of these experts concluded that a ban would have negligible market impact at the time [34, 35], and were relied on by the Privacy Commissioner in assessing the appropriateness of regulation [36]. Canada eventually passed the *Genetic Non-Discrimination Act* in 2017, which bans the use of genetic test results in the provision of any goods or services (including insurance), with criminal penalties. This issue was also raised by the Australian life insurance industry in the recent Australian Parliamentary Joint Committee inquiry [13]. The Committee commented in its report that, "the committee notes the reasoning underlying the insurance industry's need for genetic information. However, fears that adverse selection as a consequence of consumers not having to disclose predictive genetic testing results would make the life insurance market unsustainable may be overstated. In addition, the Canadian Office of the Privacy Commissioner found that the sustainability of the Canadian insurance industry is not likely to be affected at this time by a ban on the use of genetic information. Life insurers did not provide strong evidence to the contrary… Though the committee considers the fears overstated, the committee acknowledges adverse selection as a phenomenon in insurance. The committee's primary concern in that regard is the potential for higher costs for consumers if information asymmetry between insurers and insureds causes insurers to seek to put up premiums to compensate. However, on balance, the committee believes there is presently greater benefit to consumers in preventing a duty of disclosure from arising in respect of predictive genetic tests for the reasons referred to above".

Limitations of this study include the relatively small number of interviewed participants, and the potential for self-selection bias that may have influenced participation (e.g. HPs who volunteered to participate may be more likely to be engaged and have strong views about the topic, compared to other HPs). Nonetheless, we interviewed all HPs who consented to an interview, and continued interviewing participants until after data saturation was reached, to capture as many viewpoints as possible. A further limitation of our study is the secondary nature of reports by HPs about patient views and experiences. Some of our findings are therefore limited to HPs' understanding and experience of patient views, rather than the collection of direct evidence. Past research by this group has demonstrated significant consumer concerns regarding the use of genetic test results by consumers existed before the implementation of the moratorium [37]. Further studies have been designed to gather updated views from Australian consumers and patients directly about this issue [17] and will be reported separately.

Strengths of the study include the sequential, explanatory mixed method design, which allows for both quantitative analysis of survey data (previously published) and in-depth exploration of the previous survey responses to obtain a more complete picture of HPs' views and opinions.

In conclusion, our study demonstrates that although Australian HPs consider the FSC moratorium to be a positive step that provides benefits for some patients, ultimately the majority of HPs remain concerned about the overall adequacy of the current moratorium as a long-term regulatory solution. Major concerns raised with the moratorium include its industry self-regulation; low financial limits; and temporary nature, resulting in uncertainty of future applicability. Most HPs consider that government regulation and intervention is required to adequately protect Australian consumers long-term. The findings of this study indicate the need for a more stable, independent and long-term policy solution for the regulation of genetic testing and life insurance in Australia.

DATA AVAILABILITY

Some data is made available via supplementary materials. Additional data can be made available on reasonable request.

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AUTHOR CONTRIBUTIONS

JT and PL conceived the study. JT, PL, GD, AML, AB, KBS, TB, PG, MD, IW, MO and LK contributed to and reviewed the study design. GD and CH collected the data with supervision from JT and CJ, and GD and CJ analysed the data. GD and JT wrote the first draft of the manuscript with LK and PL. All authors critically reviewed and revised subsequent drafts of the manuscript.

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COMPETING INTERESTS

The authors declare no competing interests.

ETHICS APPROVAL

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

ADDITIONAL INFORMATION

Supplementary information The online version contains supplementary material available at https://doi.org/10.1038/s41431-022-01150-6.

Correspondence and requests for materials should be addressed to Jane Tiller.

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7. Appendix 7 – Comparison of Inquiry Recommendations versus FSC Moratorium

Table 1 *Comparison of Inquiry Recommendations vs FSC Moratorium*

Issue	Inquiry Recommendations	FSC Moratorium
Content of regulation	Urgent prohibition on life insurers from using the outcomes of predictive genetic tests 'at least in the medium term.'[51]	FSC members cannot ask for or use genetic test results of applicants for life insurance, up to certain financial limits until 2024.
Type of regulation	Co-regulatory approach as a 'first step'.[52] Inquiry acknowledged concerns expressed by AMA, RACGP and others about conflicts of interest inherent in an FSC-led self-regulatory regime. Inquiry considered these concerns could be alleviated if ASIC was given certain enforcement powers (see below).[53] Legislative (or similar) prohibition should be implemented if: life insurers failed to comply with moratorium or if otherwise appropriate in light of developments in genetics and genetic testing.[54] These developments to be monitored by the Commonwealth government.	FSC-led self-regulation. No oversight (ASIC not given recommended enforcement powers.) No monitoring of developments in genetics or genetic testing by the Commonwealth government.
'Vehicle' for regulation	Moratorium should be introduced via amendments to FSC standards.[55] Amended FSC standards (and therefore the moratorium) should be incorporated into the *Life Insurance Code of Practice*. [56]	Relevant FSC standards amended to introduce moratorium. In the four years since the Inquiry the FSC Moratorium has not been incorporated into the *Life Insurance Code of Practice*. The FSC says that it intends to do so.[57]
Enforcement of regulation	ASIC should be provided with enforcement powers to implement a co-regulatory approach.[58] These powers include registration (approval) of industry codes (incl moratorium) by ASIC; mandatory application to all industry participants; enforcement and financial penalties.[59]	ASIC has not been provided with these powers. Very limited oversight of compliance with the FSC Moratorium may be provided by the Life Code Compliance Committee (LCCC) if the FSC Moratorium is included in the *Life Insurance Code of Practice*, which has not yet occurred (see also Appendix 3).

		LCCC recommendations for improvements to enforcement of the Code have not been adopted.[60]
Financial Limits	No financial limits recommended. Inquiry recommended consistency with UK moratorium which does not include financial limits (except in relation to Huntington's Disease).[61]	Financial limits imposed (see above). FSC Moratorium does not apply if consumer / patient applies for insurance above these limits.
Duration	Moratorium should apply indefinitely to predictive genetic test results[62]	FSC Moratorium applies until 2024, unless extended. If FSC Moratorium is not extended (or it is weakened) then life insurers can consider results of genetic tests undertaken before and since the FSC Moratorium.
International Comparison	Moratorium should be consistent with UK moratorium[63]	FSC Moratorium is inconsistent with other countries including UK and Canada. No 'end date' in other jurisdictions (eg. UK). Most jurisdictions do not include financial limits on the use of genetic tests by life insurers. Only four out of 20 countries with prohibitions include financial limits. Other jurisdictions have legislative prohibitions with criminal penalties (eg. Germany, Switzerland).
Process	Moratorium should be developed in discussion with the Australian Genetic Non-Discrimination Working Group[64]	Significant feedback provided by the Working Group was not incorporated into the FSC Moratorium including: • Removal of financial limits. • FSC Moratorium should be permanent, not temporary. • Any genetic research results should be excluded from disclosure, not just those results which the insurance applicant does not receive. • Government should be part of regulatory model. • Compliance mechanisms required.

8. Appendix 8 – Written feedback from the Australian Genetic Non-Discrimination Working Group to the FSC regarding the draft moratorium document

Australian Genetic Non-Discrimination Working Group
Consultation feedback - FSC-proposed Moratorium **2 January 2019**

We are concerned that the current FSC-proposed solution will not achieve the intended benefits of a moratorium on the use of genetic test results in life insurance.

The goals of such a moratorium should be;

a) To remove a current barrier compromising the success of genomic medicine in Australia,
b) To reduce consumer fears related to insurance, which deter the uptake of clinical genetic testing and research participation
c) To minimize or eliminate genetic discrimination in the Australian life insurance industry
d) To achieve a transparent agreement, in good faith, between industry and government.

We outline 8 major concerns below.

1. **Government involvement and oversight is required**

- The FSC has proposed an industry self-regulated moratorium, which is unlike the UK moratorium (now the Code on Genetic Testing and Insurance), which is an agreement between industry and government.
- The PJC made specific and repeated criticisms of problems related to industry self-regulation around the use of genetic test results in Australian life insurance. Issues related to the conflicted nature of industry self-regulation were also made apparent by the Banking Royal Commission.
- The Human Genetics Society of Australasia, Australian Genomics and the AGNDWG Group are aligned in their public position statements regarding the need for government involvement (see attachments).
- We have ongoing concerns regarding industry self-regulation, particularly regarding the operation of the Life Code Compliance Committee (see endnote 1).
- Regulatory oversight must include meaningful penalties for insurers, to ensure compliance

2. **There should be no limits – or limits, if applied, should be consistent with the UK limits**

- The inclusion of limits is not necessarily consistent with bans that have been implemented internationally (see 2017 Geneva Association document and endnote 2).
- The majority of countries where bans or moratoria have been implemented have included no financial limits at all – FSC has chosen to model limits on 2 of the countries which (in the minority) have financial limits.A moratorium with limits as proposed by FSC is unlikely to achieve the aim of removing the deterrent effect generally, although the moratorium is an important first step.
- If any limits are to be applied, the UK model should be followed, as recommended by the PJC.
- Not only does the UK model have much higher limits (close to twice the ceiling amounts) than those proposed by FSC, **those limits apply to only one genetic condition** - Huntington's Disease. HD is one of the very few known adult-onset genetic conditions which have 100% penetrance.

3. **Results generated from research studies should be excluded from all disclosure as per the UK policy**

- If disclosure is required above a certain level, only results generated by clinically accredited laboratories should be considered.

4. **Planning or considering having a genetic test needs to be removed from clause 9**

- Despite acknowledging almost a year ago (1 December 2017) that the recommended question in FSC';s genetic testing policy about whether an applicant was "considering" a genetic test was "horrible", and explicitly undertaking to a Parliamentary Committee to removing that question, the draft moratorium expressly incorporates that language again at clause 9, allowing insurers to ask for and use the results of previously taken, ***planned or considered*** genetic tests. The

"planned or considered" needs to be removed, and insurers advised to change their standard questionnaires, to cease asking about "planned or considered" tests.

5. Any moratorium should apply to genetic tests taken under its current terms

- Consistently with the PJC's recommendations, the terms of the moratorium should apply indefinitely to genetic tests taken before the moratorium is lifted, to ensure certainty for consumers who are making decisions about testing under the current terms.
- See draft Moratorium on Genomic Tests and Personal Insurance Products in Australia for a proposed clause in this regard.

6. There should be regular compliance reporting, a specific complaints handling process and a Nominated Genetics Underwriter (NGU) role

- Reporting to the government should be a requirement of the moratorium
- There should be a specific process for addressing complaints and appeals regarding the use of genetic test results.
- Requiring member insurers to have a Nominated Genetics Underwriter (NGU) (as in the UK) would provide an immediate group of contact points for reporting, reviews etc
- See draft Moratorium on Genomic Tests and Personal Insurance Products in Australia for proposed clauses addressing each of these aspects.

7. Non-FSC members should be able to opt in to the Moratorium

- The moratorium should formally allow non FSC-member Insurers to voluntarily opt in to the obligations (or allow government to require non-FSC insurers offering risk-rated insurance to abide by the moratorium) including having their data included in the government reporting.
- See draft Moratorium on Genomic Tests and Personal Insurance Products in Australia for proposed clauses in this regard.

8. All risk-rated policies should be covered by the moratorium

- The scope doesn't adequately explain what policy types are covered – for clarity, it should be made clear that all types of risk-rated policies sold by FSC insurers are covered (rather than only "life insurance").

End notes

1 Concerns regarding LCCC

Source: LCCC charter

- The LCCC is established by and funded through the FSC
- The LCCC is comprised of only 3 members
  - One industry representative, appointed by the FSC, and considered independent if he/she has not been employed by FSC or an FSC insurer within the last 12 months
  - One consumer representative, appointed by the FOS
  - One chairperson, appointed jointly by the FSC and FOS
- The members can be terminated on 7 days' notice by the appointor
- There is no requirement on the LCCC to investigate any allegation made
- There is no requirement on the LCCC to impose any sanction, regardless of the results of an investigation
- The sanctions to be imposed have little or no punitive value – the worst being the ability to publicly name the insurer as non-compliant with the Code (removing an insurer from membership of FSC is not an available sanction)

- Complaints concerning the LCCC will be determined by a party jointly appointed by the FSC and the FOS – not independently appointed by the FOS to investigate
- There is no mechanism if FSC and FOS cannot agree on the appointment of the independent party

Source: 2017 LCCC Annual report:

- The LCCC states that it should be able to determine whether breaches are significant (currently an insurer who self-reports decides whether the breach is significant or not) as well as other changes that should be made to the Code, yet these changes have not been made in the current draft
- The inaugural chair resigned, and the LCCC was unable to convene from Nov 2017 to Feb 2018, demonstrating the inherent issues in of the appointing parties to prevent the LCCC from carrying out its proposed functions by delaying appointment of representatives
- The LCCC states that it lacked resources to investigate all of the breaches notified to it
- Only 56 investigation files were opened from 747 referrals received.
- Only 2 investigations were completed within the financial year. One identified a breach, and the LCCC is "working with" the insurer
- No sanctions were imposed in the financial year

2 2017 Geneva Association document: "Genetics and Life Insurance – A View Into the Microscope of Regulation"

- Of 21 countries listed in that document,
  - 13 do not require disclosure of genetic results to insurers in any circumstances, (no limits)
    - 10 have an imposed restriction without limits (Austria, Belgium, Canada, Denmark, France, Ireland, Poland, Portugal, Singapore, Spain) – some even ban the collection of family history information.
    - A further 3 do not have an imposed or formal agreed ban, but the insurance industry voluntarily does not ask for any genetic test results when underwriting.
  - 4 have financial limits of any kind (UK, Germany, Switzerland, Netherlands – see below for further detail)
  - We know there are other countries (such as Sweden and others) which also have legislation regulating this issue, that didn't make it into the summary document
- Remaining countries are Australia, India/China (no regulation), and the US (focussed on health insurance, now looking at life insurance)
- Of those that have limits:
    - The UK, which is the model the Parliamentary Inquiry recommended, has limits of £500,000 for life policies, ONLY for specific genetic tests (the only test being for Huntington Disease).
    - **Further, research results are excluded from disclosure altogether**.
    - Germany and Switzerland – both subject of legislation, with specific penalties applicable for breach. In Switzerland, genetic test results are not provided to the insurer but to a designated doctor, only if the results of the test are reliable both technically and in medical practice, and for which the scientific value of the test for the calculation of premiums has been demonstrated. The doctor can only provide to the insurer the risk group the insured should be in – no other details.
  - Netherlands has lower limits but it also limits the asking of **all** hereditary questions below those limits to certain circumstances.
  - By number, international standards actually favour banning insurers from asking for genetic test results, without any limitation. It is not correct to say that the approaches in Switzerland and Germany are representative of international standards.
  - Further, those limits are applied in the context of legislative frameworks with criminal penalties for breach, which are not similar in any way to the FSC's proposed moratorium.

9. Appendix 9 – Regulatory evaluation documents

Table 2 *Status of issues raised by AGNDWD in final FSC Moratorium*

Issue raised by AGNDWD in written feedback	Resolved in final FSC Moratorium document?
Government involvement and oversight is required	✗
There should be no limits – or if applied, should be consistent with the UK limits	✗
Results generated from research studies should be excluded from all disclosure as per the UK policy	✗
"Planning or considering" having a genetic test needs to be removed from clause 9	✔
Any moratorium should apply to genetic tests taken under its current terms	✗
There should be regular compliance reporting, a specific complaints-handling process and a Nominated Genetics Underwriter (NGU) role	✗
Non-FSC members should be able to opt-in to the moratorium	✗
All risk-rated policies should be covered by the moratorium	✔
Moratorium should apply to all genetic tests (diagnostic and predictive)	✔

FSC = Financial Services Council

AGND Working Group = Australian Genetic Non-Discrimination Working Group

Figure 2 *Comparison of Jurisdictions with restrictions on the use of genetic test results in underwriting Created from data contained in "Genetics and Life Insurance – A view into the Microscope of Regulation" (13)*

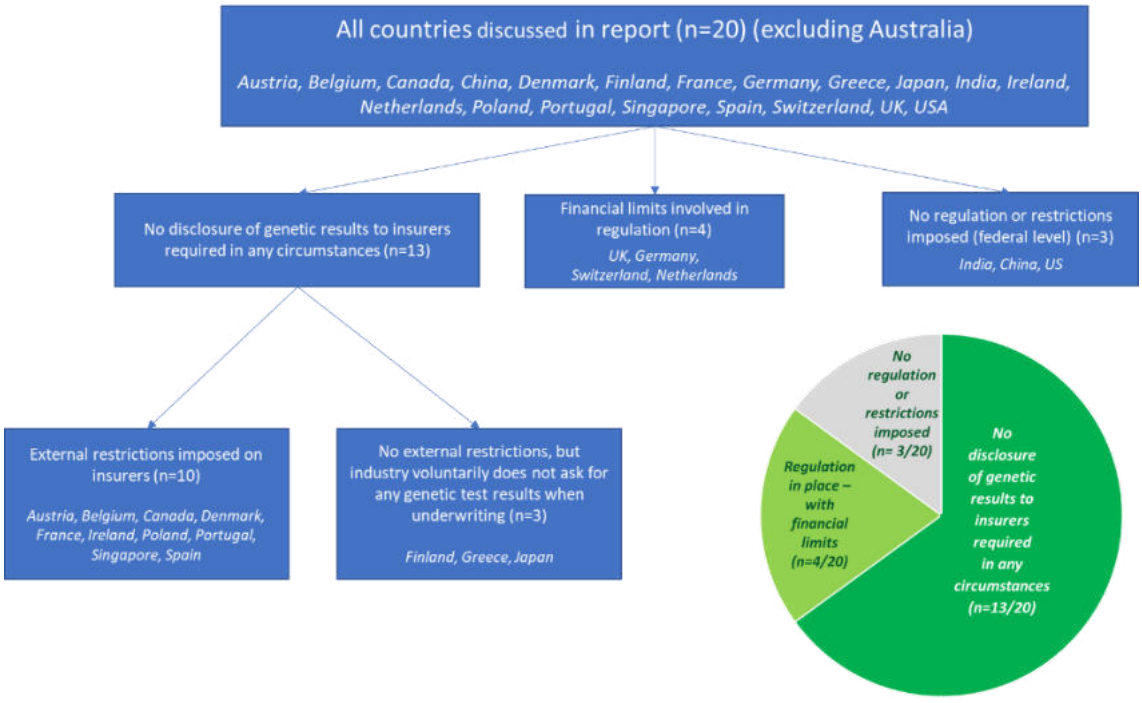

Table 3 *Comparison of key aspects of the UK Code and the FSC Moratorium*

	UK Code on genetic testing and insurance	FSC Moratorium on insurance and genetics	Consistent?
Financial limits	The only limits on the moratorium are for life cover applications over £500,000 (approx. $935,000)	The FSC Moratorium only applies up to the monetary limits on life cover and total/permanent disability cover ($500,000), income protection ($4000/month or $48,000pa), and trauma/critical illness cover ($200,000)	✕
Tests included	Only Huntington disease predictive results must be disclosed above the monetary limits for life cover. Currently, no genetic test results must be disclosed for any other type of policy	All genetic test results must be disclosed once the monetary limit is reached for all types of life insurance policies	✕
Regulation/ government involvement	A formal agreement between the UK government and the Association of British Insurers.	Industry-led and self-regulated, without any agreement or involvement with the Australian government	✕
End date	No end date (although it is reviewed periodically)	Currently due to end in 2024 (may be extended following review in 2022)	✕
Ability to choose to disclose negative genetic test results	Yes	Yes	✔
Research results excluded from disclosure	Yes	No, unless the applicant does not receive the result	✕
Ability of non-member insurers to opt in	Yes	No	✕

FSC = Financial Services Council

Section H: Endnotes

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[3] Parliamentary Joint Committee on Corporations and Financial Services, *Life Insurance Industry*, Final Report, March 2018, 144. An exception in the *Disability Discrimination Act 1992* (Cth) permits discrimination in granting life insurance because of a disability based on actuarial or statistical data. Disability is defined to include a genetic predisposition to a disability: *Disability Discrimination Act 1992* (Cth) ss 4, 46.

[4] See, eg, Parliamentary Joint Committee on Corporations and Financial Services, *Life Insurance Industry*, Final Report, March 2018, 5.

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[6] Parliamentary Joint Committee on Corporations and Financial Services, *Life Insurance Industry*, Final Report, March 2018, available from: https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/Corporations_and_Financial_Services/LifeInsurance/Report

[7] Ibid 154.

[8] Ibid 154.

[9] Ibid 155.

[10] Ibid 152-3.

[11] Ibid 138-144. See also Appendix 1 for a summary of the relevant treatment of genetic information in other countries.

[12] Ibid 154.

[13] Jane Tiller et al, 'Study Protocol: the Australian Genetics and Life Insurance Moratorium – Monitoring the Effectiveness and Response (A-GLIMMER) Project' (2021) 22(63) *BMC Medical Ethics* 1, 2; FSC, *FSC Standard No. 11: Moratorium on Genetic Tests in Life Insurance*, June 2019,

https://www.fsc.org.au/resources/fsc-standards-and-guidance-notes/standards ('the FSC Moratorium').
[14] FSC Moratorium cl 2.2.
[15] The FSC Moratorium is binding on 'Life Insurance Providers', which is defined as all FSC Members who are authorised by the Australian Prudential Regulation Authority to carry on life insurance business: Moratorium 2.3; FSC, *FSC Guidance Note No. 5: Industry Terms and Definitions*, 21 June 2019, 10.
[16] FSC Moratorium cls 2.3, 3.1.
[17] FSC Moratorium cl 3.3.
[18] FSC Moratorium cl 3.5.
[19] This is because the *Disability Discrimination Act* only permits discrimination on the grounds of a genetic predisposition 'based upon actuarial or statistical data' and certain requirements of reasonableness. It would not be 'reasonable', for example, for insurance providers to discriminate against an individual on the basis of 'actuarial or statistical data' – such as it was – that did not take into account preventative measures.
[20] Parliamentary Joint Committee on Corporations and Financial Services, *Life Insurance Industry*, Final Report, March 2018, 156 (Recommendation 9.4).
[21] Email from Secretariat of the Joint Parliamentary Committee on Corporations and Financial Services to Jane Tiller, dated 22 March 2021
[22] Jane Tiller et al, 'Study Protocol: the Australian Genetics and Life Insurance Moratorium – Monitoring the Effectiveness and Response (A-GLIMMER) Project' (2021) 22(63) *BMC Medical Ethics* 1, 5.
[23] Ibid 3.
[24] Ibid 5
[25] Jane Tiller et al, 'A Step Forward, But Still Inadequate: Australian Health Professionals' Views on the Genetics and Life Insurance Moratorium' (2021) *Journal of Medical Genetics* 1.
[26] Grace Dowling et al, 'Health Professionals' Views and Experiences of the Australian Moratorium on Genetic Testing and Life Insurance: A Qualitative Study' *European Journal of Human Genetics* doi: 10.1038/s41431-022-01150-6.
[27] Ibid
[28] Jane Tiller et al, 'A Step Forward, But Still Inadequate: Australian Health Professionals' Views on the Genetics and Life Insurance Moratorium' (2021) *Journal of Medical Genetics* 1, 3.
[29] This included predictive genetic testing but not pre-conception carrier screening or prenatal testing
[30] That is, those participants who had chosen not to have a genetic test or who were actively considering testing
[31] For the purposes of the A-GLIMMER Project, genetic research is research with respect to human genetics and genomics: Jane Tiller et al, 'Study Protocol: the Australian Genetics and Life Insurance Moratorium – Monitoring the Effectiveness and Response (A-GLIMMER) Project' (2021) 22(63) *BMC Medical Ethics* 1, 9.
[32] https://www.acspri.org.au/aussa
[33] Australian Bureau of Statistics, 'Average Loan Sizes for Owner-Occupier Dwellings (Original), By State', https://www.abs.gov.au/statistics/economy/finance/lending-indicators/latest-release, 4/7/22.
[34] Jane Tiller, Paul Lacaze and Margaret Otlowski, 'The Australian Moratorium on Genetics and Life Insurance Fails to Meet Parliamentary Recommendations Against Genetic Discrimination' (Working Paper, July 2022).
[35] The Geneva Association. Genetics and Life Insurance: A View Into the Microscope of Regulation. Zurich, Switzerland; 2017
[36] Moratorium cl 5.1.
[37] FSC, *Genetics Moratorium Review*, available at https://www.fsc.org.au/news/genetics-moratorium-review.
[38] Email from Nick Kirwan, Policy Director (Life Insurance), Financial Services Council to Margaret Otlowski, Chair, Australian Genetic Non-Discrimination Working Group, 27 June 2022.

[39] See eg, FSC, 'Media Release: New Data Shows How Genetics Moratorium for Lie Insurance Works for Australians' 24 February 2022, https://fsc.org.au/news/media-release/genetics-moratorium; FSC, 'Why Taking A Genetic Test Won't Stop You Getting Life Insurance', 4 March 2022, https://fsc.org.au/news/genetic-test-life-insurance; FSC, 'The Genetics Moratorium Review' <https://www.fsc.org.au/news/genetics-moratorium-review>, 22 June 2022.
[40] Email from Nick Kirwan, Policy Director (Life Insurance), Financial Services Council to Margaret Otlowski, Chair, Australian Genetic Non-Discrimination Working Group, 27 June 2022
[41] FSC, 'Media Release: New Data Shows How Genetics Moratorium for Lie Insurance Works for Australians' 24 February 2022, https://fsc.org.au/news/media-release/genetics-moratorium.
[42] Moratorium cl 3.9.
[43] Grace Dowling et al, 'Health Professionals' Views and Experiences of the Australian Moratorium on Genetic Testing and Life Insurance: A Qualitative Study' *European Journal of Human Genetics;* 2022.
[44] Otlowski M, Taylor S, Bombard Y. Genetic discrimination: international perspectives. Annual review of genomics and human genetics. 2012;13:433-54; The Geneva Association. Genetics and Life Insurance: A View Into the Microscope of Regulation. Zurich, Switzerland; 2017.
[45] HM Government and Association of British Insurers. Code on Genetic Testing and Insurance 2018 [Available from: https://www.abi.org.uk/globalassets/files/publications/public/genetics/code-on-genetic-testing-and-insurance-final.pdf.]
[46] Life CCC Charter cl 3.1.
[47] FSC, *Life Insurance Code of Practice*, cl 5.16, <https://fsc.org.au/policy/life-insurance/code-of-practice>
[48] FSC, 'Why Taking a Genetic Test Won't Stop You Getting Life Insurance' 4 March 2022 < https://fsc.org.au/news/genetic-test-life-insurance>.
[49] 'Code Committee Raises Concern Over Drop in Significant Breach Reporting', *Insurance News* (online, 4 October 2021) <https://www.insurancenews.com.au/life-insurance/code-committee-raises-concern-over-drop-in-significant-breach-reporting>; 'Insurers Criticised Over Life Code Obligations', *RiskInfo*, (online, 29 June 2020) <https://riskinfo.com.au/news/2020/06/29/insurers-criticised-over-life-code-obligations/>.
[50] Life Code Compliance Committee, 'Notice of Sanction – OnePath Limited' < https://lifeccc.org.au/app/uploads/2019/07/Notice-of-Sanction.pdf>
[51] Parliamentary Joint Committee on Corporations and Financial Services, *Life Insurance Industry*, Final Report, March 2018, 155 (at para 9.93).
[52] Ibid.
[53] Ibid (at paras 9.94-9.95).
[54] Ibid 155-6 (at paras 9.96-9.97, 9.101).
[55] Ibid (at paras 9.93, 9.99.).
[56] Ibid (at para 9.99).
[57] FSC, *Genetics Moratorium Review*, 2 , available at < https://www.fsc.org.au/news/genetics-moratorium-review>.
[58] Parliamentary Joint Committee on Corporations and Financial Services, *Life Insurance Industry*, Final Report, March 2018, 155 (at paras 9.94-9.95).
[59] Ibid (at para 9.94).
[60] 'Code Committee Raises Concern Over Drop in Significant Breach Reporting', *Insurance News* (online, 4 October 2021) <https://www.insurancenews.com.au/life-insurance/code-committee-raises-concern-over-drop-in-significant-breach-reporting>; 'Insurers Criticised Over Life Code Obligations', *RiskInfo*, (online, 29 June 2020) < https://riskinfo.com.au/news/2020/06/29/insurers-criticised-over-life-code-obligations/>.
[61] Parliamentary Joint Committee on Corporations and Financial Services, *Life Insurance Industry*, Final Report, March 2018, 155 (at para 9.93).
[62] Ibid.
[63] Ibid.
[64] Ibid 155-6 (at paras 9.93, 9.98).