



FINAL STAKEHOLDER REPORT

JUNE 30, 2023

A-GLIMMER

*Australian Genetics & Life Insurance
Moratorium: Monitoring the Effectiveness
and Response*

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

Final Stakeholder Report June 30, 2023

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Acknowledgements

Monash University acknowledges and thanks the Commonwealth Government, Medical Research Futures Fund, Genomic Health Futures Mission for funding the Australian Genetics and Life Insurance Moratorium: Monitoring the Effectiveness and Response (A-GLIMMER) Project (ref. 76721).

The A-GLIMMER Project Team thanks the Project's collaborators, patient/consumer and supporter groups for their assistance and support throughout this Project. Thank you also to the many individuals who participated in the research studies completed as part of the A-GLIMMER Project.

How to cite this Report

Jane Tiller, Penny Gleeson, Aideen McInerney-Leo, Louise Keogh, Kristen Nowak, Kristine Barlow-Stewart, Tiffany Boughtwood, Martin Delatycki, Ingrid Winship, Margaret Otlowski and Paul Lacaze. *The A-GLIMMER (Australian Genetics & Life Insurance Moratorium: Monitoring the Effectiveness and Response) Project: Final Stakeholder Report* (Monash University, 2023) <https://doi.org/10.26180/23564538>

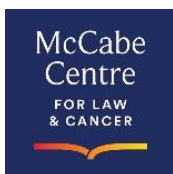
Acknowledgement of Country

Monash University acknowledges and pays respects to the Elders and Traditional Owners of the land on which its Australian campuses stand. Information for Indigenous Australians can be found [here](#).

Collaborators



Patient/Consumer and Supporter Groups



Endorsed By



Recommendations

The A-GLIMMER Project recommends that:

1. **The Australian Government amend the *Disability Discrimination Act 1992* (Cth) ('the Act') to prohibit insurers from using genetic or genomic test results to discriminate between applicants for risk-rated insurance, and consider amendments to the regulation of financial services to ensure insurers are subject to a positive duty to not discriminate.**
2. **The Australian Government allocate responsibility and appropriate resources to the Australian Human Rights Commission ('AHRC') to enforce, promote, educate and support individuals and all relevant stakeholders to understand and meet the new legal obligations under the Act. The AHRC should consult with a range of genetics and genomics experts and stakeholders to achieve this goal.**

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 act as a barrier, by deterring people from having potentially life-saving genetic testing that could match them to tailored interventions and treatments, as well as from participation in genetic research.

In 2018, a Joint Parliamentary Committee Inquiry into the Life Insurance Industry recommended that Australia urgently implement a moratorium (or ban) on the use of genetic test results in life insurance underwriting, similar to the moratorium operating in the United Kingdom (UK) since 2001. In 2019, the life insurance industry peak body, the Financial Services Council (FSC), introduced a partial moratorium 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 investigate effectiveness 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 funding was awarded through the Genomics Mission of the Medical Research Future Fund. This independent project has gathered evidence to assess the effectiveness of the FSC Moratorium, and report findings to Government and other stakeholders. An Interim Stakeholder Report presented the findings of the A-GLIMMER Project's research as at August 2022.

This Final Stakeholder Report sets out the A-GLIMMER Project's findings – published and unpublished – and makes recommendations to the Australian Government (the Project funder). The studies undertaken as part of the Project investigated the views and experiences of health professionals, consumers, researchers, and financial advisors, to assess the impact of the FSC Moratorium.

The purpose of this Final Stakeholder Report is to:

- provide a summary of the A-GLIMMER Project's research findings and an assessment of the FSC Moratorium's self-regulatory model;
- make recommendations based on these research findings and analysis; and

- inform the Australian Government's assessment of the FSC Moratorium and alternative regulatory mechanisms to prevent genetic discrimination.

The A-GLIMMER Project's research findings demonstrate that the FSC Moratorium – either in its current form or as included in the proposed 2023 Life Insurance Code of Conduct – is inadequate to address and prevent genetic discrimination in life insurance. It should be replaced with a legislative model of prohibition. This is supported by the A-GLIMMER Project's findings which show that:

- Key stakeholder groups (health professionals, consumers and researchers) are concerned about the life insurance industry's self-regulation of the FSC Moratorium and express a low level of confidence in the effectiveness of the FSC Moratorium. An overwhelming majority of these stakeholders, as well as many financial advisers that were interviewed, were also concerned about the absence of any Australian Government oversight of the FSC Moratorium.
- A very high proportion of key stakeholders consider that legislation is required to regulate the use of genetic test results in life insurance underwriting (93% of health professionals, 88% of patients with experience of genetic testing, 78% of the general public, and 86% of researchers).
- There are instances of non-compliance with the FSC Moratorium, including where insurance companies have asked insurance applicants about genetic testing, contrary to the terms of the FSC Moratorium. Further, there is a lack of effective mechanisms to enforce the FSC Moratorium or to seek redress.
- Stakeholders are concerned about the uncertainty inherent in the industry-led nature of the FSC Moratorium, and the potential for the use of genetic test results by life insurers in the future.
- Similarly, there is a broad view across stakeholder groups that the FSC Moratorium's financial limits (i.e. life policies <\$500K) are too low to enable individuals to obtain sufficient life insurance.
- Many genomic researchers reported that the potential use of genomic test results by insurers was a barrier to the recruitment of research participants.
- There is poor awareness and knowledge about the FSC Moratorium among stakeholder groups, including differing understandings of how the limits should be applied, even among financial advisers.

Further, industry self-regulation is an ineffective regulatory model to address genetic discrimination in relation to life insurance in Australia. This is in part because of the inherent conflict of interest in industry self-regulation of its own access to genetic information; the risk of harm to individuals through discrimination; and restricted access to preventive healthcare. In addition, there is considerable uncertainty, instability and a lack of cohesion surrounding the current self-regulation of the Australian life insurance industry.

In late 2022, a newly formed body – the Council of Australian Life Insurers ('CALI') – declared that it was now the peak representative body of the Australian life insurance industry. According to CALI and media reports, CALI is backed by a significant proportion of the Australian life insurance industry. To our knowledge, the FSC has not made any public statements about CALI's formation. It is therefore unclear what implications the formation of CALI will have for the self-regulation of the life insurance industry more broadly, or for the FSC Moratorium in particular. This creates further uncertainty for consumers, health professionals and other stakeholders in this area.

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Glossaryⁱ

A-GLIMMER Project

The Australian Genetics and Life Insurance Moratorium: Monitoring the Effectiveness and Response Project (funded by the Commonwealth Government's Medical Research Future Fund, Genomic Health Futures Mission).

Genes

Genes consist of DNA. They are the 'instructions' for building our body and telling it how to work.

Genetic information

For the purposes of this Report, 'genetic information' refers to an individual's genetic or genomic test information and / or that of a relative.

Genetic test*

A genetic test investigates a person's genetic variants or changes. Some of these changes may lead to a genetic condition, which may contribute to the risk of developing a health condition.

Genome

An individual's entire genetic code.

Genomic test*

Investigates larger amounts of an individual's genetic sequence or their whole genome.

Parliamentary Inquiry

Parliamentary Joint Committee on Corporations and Financial Services, *Inquiry into the Life Insurance Industry*,

https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/Corporations_and_Financial_Services/LifeInsurance

Working Group

Australian Genetic Non-Discrimination Working Group. (The Working Group preceded the formation of the A-GLIMMER Project. Key members of the Working Group now lead the A-GLIMMER Project).

ⁱ Unless otherwise stated, these terms are taken directly, or adapted, from 'About Genomics' *Australian Genomics*, (Web Page), <https://www.australiangenomics.org.au/about-genomics/>.

* "Genetic test" and "Genomic test" are sometimes used interchangeably by researchers and clinicians. In this report, both are used to describe tests that investigate a person's DNA.

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, genetic 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 genetic information by life insurers can lead to discrimination. Research shows that fears of insurance discrimination 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 insurers² (see **Appendix I**). In Australia, life insurance companies are still legally permitted to use genetic test results in underwriting. The *Disability Discrimination Act 1992* (Cth) permits insurers to use genetic test results to discriminate in applications for risk-rated insurance (see **Appendix II**).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 the offer of health insurance is not subject to genetic discrimination at this time.⁵

Individuals can often access a level of life insurance cover through their superannuation fund without being subject to underwriting requiring medical information. However, the level of cover offered in these circumstances is generally low. If an individual wants to increase their life insurance cover above this amount they must provide medical (including, if asked, genetic) information.

The use of genetic test results by life insurance companies is self-regulated by the life insurance industry peak body, the Financial Services Council (FSC).⁶ However, there are significant changes anticipated with respect to the body that self-regulates the Australian life insurance industry. This creates considerable uncertainty for those involved in, and affected, by genetic testing. This is discussed further below at **Section A.4**.

2 The FSC Moratorium on Genetic Tests and Life 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 Parliamentary Inquiry') recommended that Australia urgently implement a moratorium (or ban) on the use of genetic test results in life insurance underwriting, similar to the moratorium operating in the UK since 2001.⁷ In making this recommendation, the Parliamentary Inquiry considered:

- evidence that individuals had been denied cover, and charged higher premiums;⁸
- the increasing use and relevance of genetic testing;⁹
- the discouragement of individuals to seek important genetic tests for their health;¹⁰

- reduced participation in research involving genetic tests;¹¹
- the prohibition/restriction on the use of genetic results in underwriting internationally, including in the UK, the US and Canada;¹² and
- the lack of evidence that the life insurance market would be undermined by such a prohibition.¹³

The Australian Government has not responded to these recommendations. In July 2019, however, the FSC introduced a partial and self-regulated voluntary moratorium 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').¹⁴ The FSC Moratorium applies to applications for life insurance received on or after 1 July 2019. At the time of writing, the FSC Moratorium will end on 30 June 2024,¹⁵ although the FSC has announced that from 1 July 2023 it will be made indefinite.¹⁶ However, 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). Additionally, the FSC Moratorium 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 business¹⁷ from asking for or using genetic test results in their underwriting processes (unless a condition has been diagnosed from the result).¹⁸

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.¹⁹

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. For example, if an individual applies for income protection cover of \$5000 per 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.²⁰

The requirement to consider preventative measures is already implicitly required by the current legislative regime (see below and **Appendix II**).²¹ The FSC Moratorium does not, therefore, provide

stronger protections for individuals that take such measures than the *Disability Discrimination Act 1992* (Cth) already provides.

Limited changes to the Moratorium announced by the FSC

The FSC conducted a review of the FSC Moratorium in 2022.²² The terms of the FSC Moratorium required that this review be undertaken with a view to extending the Moratorium's operation beyond 2024, and in consultation with consumer groups and expert stakeholders.²³ The A-GLIMMER Project team made a submission to the FSC's review, which is described in Section D below and attached in full at **Appendix III**. Amongst a range of remarks, including about the inappropriateness of financial limits and the limitations of the self-regulatory model, the submission advocated for the need for Australian Government oversight in this area.²⁴

The FSC subsequently announced that the FSC Moratorium would be extended 'indefinitely' from 1 July 2023 'until the FSC gives further notice following a review'.²⁵ The revised FSC Moratorium will also apply in relation to genetic tests 'taken before it started or during its currency, even if the FSC ends it for subsequently taken Genetic Tests'.²⁶

The FSC also announced that the FSC Moratorium would be included in the new Life Insurance Code of Practice to commence on 1 July 2023 (the '2023 Code').²⁷ The 2023 Code is a set of voluntary self-regulatory standards for the life insurance industry. It replaces the existing 2019 Life Insurance Code of Practice.²⁸ The inclusion of the FSC Moratorium in the 2023 Code would enable industry compliance with the FSC Moratorium 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.²⁹

While the changes announced are positive, they are inadequate to comprehensively address the FSC Moratorium's shortcomings, as identified by the A-GLIMMER Project and discussed in **Section D**.

3 Monitoring by the Australian Government

The Parliamentary Inquiry recommended that the Australian 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'.³⁰ 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 Services Royal Commission, some of which related to recommendations of the Parliamentary Joint Committee's recent inquiries.³¹

4 Uncertainty in Self-Regulation of the Life Insurance Industry

Recent announcements about proposed changes to the life insurance industry body raise significant uncertainty about the future direction, stability and effectiveness of the self-regulation of the industry, including in relation to the FSC Moratorium.

In late 2022 the Council of Australian Life Insurers ('CALI') was formed, driven and backed by significant life insurers which represented 99% of the industry.³² CALI describes itself as the 'newly formed peak body' of the Australian life insurance industry 'to act as the progressive voice of life insurance ... and to represent the interests of the industry and our customers and partners.'³³ CALI describes the impetus for its establishment as the need for a 'dedicated peak body to focus solely on matters affecting the life insurance industry and its customers.'³⁴ CALI has appointed a board, CEO and key staff.³⁵

At the time of writing, it is unclear what implications the formation of CALI will have for the FSC Moratorium. For example, the FSC has stated that the FSC Moratorium would be incorporated in the 2023 Life Insurance Code of Practice [LICOP].³⁶ CALI has announced that it 'will be seeking to take over future responsibility of the LICOP as part of the transition arrangements with the FSC.'³⁷ This will presumably include the FSC Moratorium. However, representatives of the FSC have been reported as 'indicating the FSC was committed to [the 2023 Code's] implementation.'³⁸ It is therefore unclear whether CALI will have responsibility for the 2023 Code, including the Moratorium, or whether the FSC will continue this role. This recent change has caused uncertainty for consumers and stakeholders. Further, even if CALI takes on responsibility for the Code, it is open to CALI to remove or amend the Moratorium at any time, creating additional uncertainty about its future operation.

In further apparent conflict with CALI's announcements, the FSC has stated that it 'would continue to advocate policy relating to life insurance' and that it welcomes CALI as 'a sector specific association that will collaborate with the FSC and compliment the FSC's broader representation and advocacy on behalf of the financial services industry.'³⁹

It is therefore unclear whether, how and when any changes in responsibility for the self-regulation of genetic discrimination by the Australian life insurance industry will occur. It is also uncertain whether CALI will endorse i) the FSC Moratorium in its current form; ii) the FSC's intention that the Moratorium be extended 'indefinitely'; and/or iii) the incorporation of the Moratorium into the 2023 Code.⁴⁰ More broadly, we are not aware whether CALI supports the 2023 Code in its current form.

Beyond historical concerns with the inherently conflicted self-regulatory model,⁴¹ this uncertainty in the self-regulation of the life insurance industry renders unworkable the current regulatory model underpinning the Moratorium. The reasons for this are examined as part of the evaluation of the FSC Moratorium in **Section D**.

Section B: Assessing the Effectiveness of the FSC Moratorium

The A-GLIMMER Project was funded by the Australian 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 designed a number of different research studies to collect a diverse range of evidence from consumers, patients, health professionals, genetic researchers and the financial services industry. Data from these studies was collected and analysed using a mixture of quantitative and qualitative research methodologies. 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 V**).⁴²

An Interim Stakeholder Report for the A-GLIMMER Project, summarising the Project's research findings to date, was published in August 2022.⁴³ It was provided to the FSC to inform its review of the FSC Moratorium. This Final Stakeholder Report provides a comprehensive and updated summary of the A-GLIMMER Project's research findings, conclusions and recommendations. It is intended to inform the Australian Government's assessment of the FSC Moratorium's effectiveness.

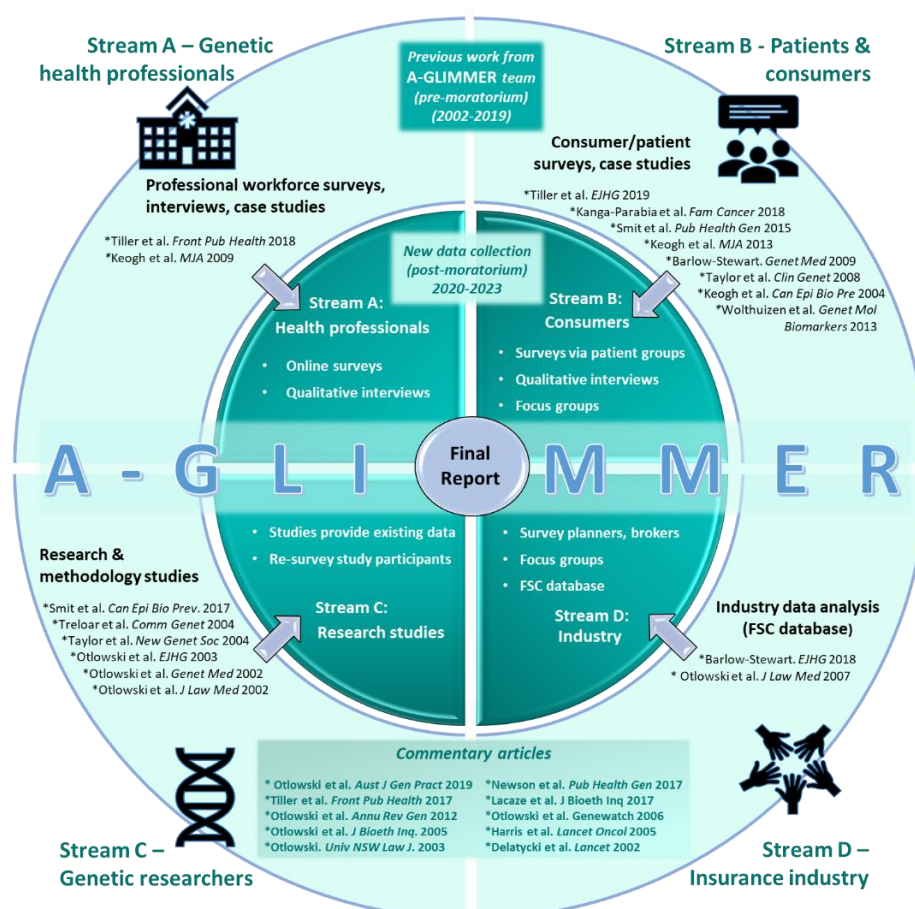


Figure 1 Tiller et al, 'Study Protocol: the Australian Genetics and Life Insurance Moratorium – Monitoring the Effectiveness and Response (A-GLIMMER) Project' (2021) 22(63) BMC Medical Ethics 1, 2

1 Aims of Recommended Prohibition on using Genetic Results in Underwriting

The Parliamentary 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 identified these primary concerns as Aims against which the impact of the FSC Moratorium can be measured.⁴⁴ These Aims, with references to the relevant paragraphs in the Inquiry report, are:⁴⁵

1. to reduce consumer fears related to insurance, which deter the uptake of genetic testing and/or research participation (at [9.89] and [9.90]);
2. to eliminate genetic discrimination in the Australian life insurance industry (at [9.84] and [9.86]);
3. to remove a barrier currently compromising the success of genetic medicine in Australia (at [9.89]); and
4. to ensure Australian Government oversight and monitoring to combat concerns with industry self-regulation (at [9.94] and [9.96]).

To meet these Aims, the FSC Moratorium must achieve certain **Outcomes**, which the A-GLIMMER Project 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:⁴⁶

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: Summary of the A-GLIMMER Project's Research Findings

The A-GLIMMER Project conducted several different research studies to survey the opinions, attitudes and knowledge of Australian stakeholders. These stakeholders included health professionals, patients offered genetic testing, members of the general public, genetic researchers and financial advisers. We have also evaluated the FSC Moratorium against the recommendations of the Parliamentary Inquiry. As at the time of publication of this Final Stakeholder Report, some of the A-GLIMMER Project research studies have been published in peer-reviewed journals. Others are under review by those journals and are yet to be published. Those findings are presented here as preliminary.

1 Health Professionals (HPs)

The A-GLIMMER Project conducted two studies focusing on the opinions, attitudes and knowledge of Australian genetic health professionals (HPs) regarding the FSC Moratorium. The first study surveyed 166 clinical geneticists, genetic counsellors and other HPs who regularly discuss genetic testing with patients. This study was published in the *Journal of Medical Genetics*.⁴⁷ The second study consisted of in-depth follow-up interviews with 23 HPs who had completed the survey. This second study was published in the *European Journal of Human Genetics*.⁴⁸ Copies of these publications can be found in **Appendix VI** and **Appendix VII**, respectively.

1.1 Health professionals' views on the FSC Moratorium and regulation

1.1.1 Online survey of HPs (Appendix VI)

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**).

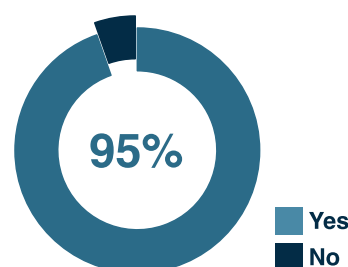


Figure 2 Is a formal agreement between government and industry required in Australia? (n=149)

When asked about how insurers' compliance with the FSC Moratorium should be regulated, 88% (131/149) 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

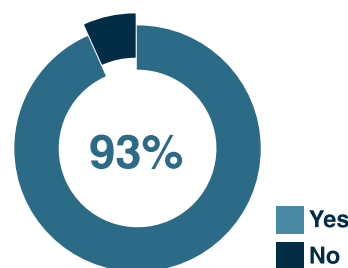


Figure 3 Should the Australian Government introduce legislation to regulate the use of genetic test results in life insurance? (n=149)

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.⁴⁹

Impact of the FSC Moratorium on clinical practice

HPs reported a small improvement in the number of patients who delayed or declined genetic testing because of concerns about insurance since the introduction of the FSC Moratorium. 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.⁵⁰

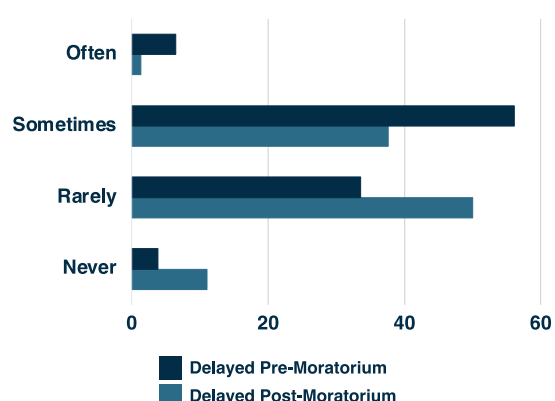


Figure 4 How often did patients *delay* predictive testing due to life insurance concerns? (n=154)

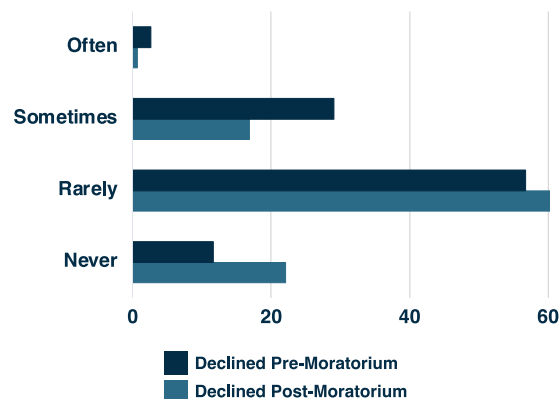


Figure 5 How often did patients *decline* predictive testing due to life insurance concerns? (n=154)

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 (41%; 59/144).

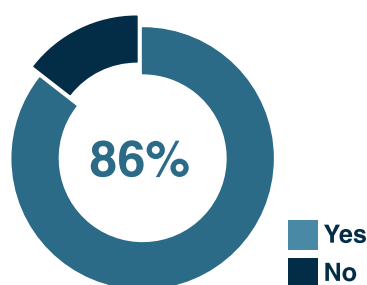


Figure 6 Are HPs aware of the FSC moratorium? (n=166)

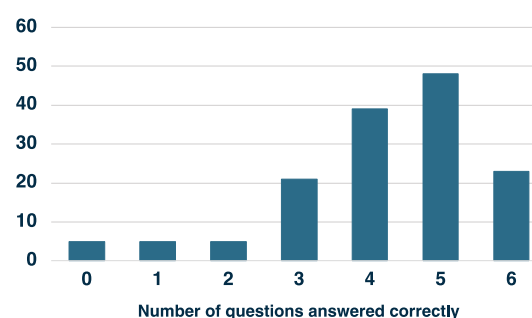


Figure 7 HPs' objective knowledge scores (n=146)

1.1.2 Qualitative HP Study (Appendix VII)

HPs identified some benefits of the FSC Moratorium, including alleviating concerns for some patients.

“Look, I think [the moratorium is] a step in the right direction...patients don’t have to, for low level insurance, disclose genetic test results.”

(genetic counsellor, 6-10 years' experience)

However, interviewed HPs also expressed concerns with the Moratorium and the current regulation. These concerns included self-regulation by the insurance industry, the impact of the financial limits, and the uncertainty associated with the Moratorium.

Many HPs felt insurers' use of genetic information should be regulated by the government through legislation, to hold insurance companies accountable.

“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.”

(genetic counsellor, 0–5 years' experience)

HPs commented that patients often require policies 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.”

(clinical geneticist, 15–20 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.”

(clinical geneticist, >20 years’ experience)

1.2 Survey of dermatologists about genetic testing in relation to melanoma risk

An additional study conducted by members of the A-GLIMMER Project team surveyed Australasian dermatologists about genetic testing (in the context of melanoma risk) and was published in *Frontiers in Genetics*.⁵¹ This study 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.⁵²

2 Consumers

The A-GLIMMER Project completed three research studies involving surveys and interviews with consumers, some of whom had experience of genetic testing and some of whom did not. The first study (the 'Patient Survey Study') has been published by the *European Journal of Human Genetics* and is at **Appendix VIII**. The second (the 'Patient Interview Study') and third (the 'General Public Study') studies are currently unpublished and presented as preliminary findings

2.1 Patients

2.1.1 Patient Survey Study (Appendix VIII – First Consumer Study: Patient Survey Study)

The Patient Survey Study surveyed 367 Australian patients who had, or were eligible for, certain genetic tests.⁵³ 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 in 2019.

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. 82% (288/350) of people believed Australian life insurance companies should not be legally allowed to use genetic test results in underwriting. **Only 4% (14/350) believed this practice should be legally allowed.**

Significantly, participants showed low awareness of the FSC Moratorium: 84% (286/340) had never heard of it.

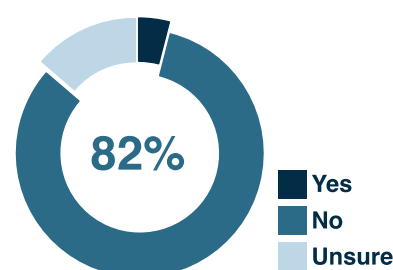


Figure 8 Should Australian life insurance companies be legally allowed to use applicants' genetic test results in underwriting? (n=350)

73% (219/300) of participants believed the fact that compliance with the FSC Moratorium 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 (88%; 298/340; Figure 9);** only 3% (9/340) disagreed. 76% (228/302) of participants believed that the fact that the FSC Moratorium is not permanent was a negative aspect of the FSC Moratorium (only 3% felt it was positive).

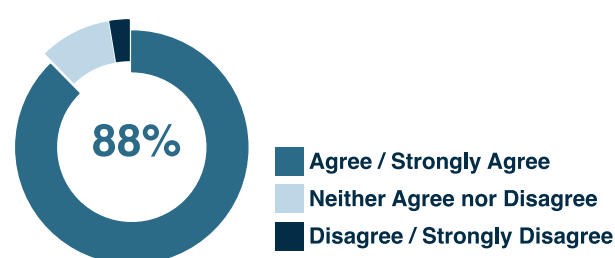


Figure 9 The Australian government should introduce legislation (which is made and enforced by government) to regulate life insurers' use of genetic test results (n=340)

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 was the appropriate amount of life insurance cover that applicants should be allowed to apply for without being required to disclose their genetic results. Most participants (66%; 226/341) considered that the appropriate amount should be more than \$1 million, and the majority of those believed it should be unlimited (64%; 145/266).

Difficulties in obtaining life insurance products were reported by 35% (53/151) of participants who had applied for life insurance products (151/279). These included: insurers rejecting life insurance applications; 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. One participant, a 43 year old woman with a *BRCA2* variant and no personal history of cancer, **was denied life cover outright despite having her ovaries and fallopian tubes removed, and regular intensive breast imaging (mammogram/MRI/ultrasound).**

Half of those who had decided against, or had not yet had, genetic testing⁵⁴ reported that life insurance concerns had a moderate or significant effect on their decision making (50%; 7/14).

2.1.2 Patient Interview Study (*unpublished*)

In this study, 27 patients were interviewed to explore their views and experiences about genetic testing and the FSC Moratorium. The eligibility criteria was the same as for the Patient Survey Study, and almost all participants were recruited from that first study.

Distrust of industry self-regulation

Many participants expressed distrust of the insurance industry, and concerns that industry self-regulation meant that the Moratorium could end at any time and that insurers were inherently focused on their own financial interests, not the best interests of consumers.

“If it’s not really legislated, then they can just pull out of it at any point in time. I don’t trust them to honour it.”

(53 year old female interviewee; high risk result for Lynch Syndrome)

Almost all participants (26/27) stated that the Australian Government should introduce legislation to regulate the use of genetic test results in underwriting life insurance.

Concerns about discrimination affect decisions around genetic testing

Participants reported that concerns about genetic discrimination in life insurance discouraged them from having genetic testing. Further, several participants reported concerns that their genetic test results could affect their children's future access to life insurance. As a result, they did not communicate important information about genetic testing and related medical treatment to their children.

“That was really my primary concern because I’ve got two young kids now too, so I didn’t want to make myself as the primary income earner, uninsurable purely because of a genetic test.”

(41 year old male interviewee; untested, at risk for Lynch syndrome DNA variant)

“Even in my extended family there’s loads – there’s quite a few people who haven’t done genetic testing because they don’t want to be denied insurance cover... They’re not getting regular scans. They’re putting their health on the back foot because of all this. This is ridiculous.”

(34 year old female interviewee; high risk result for Hereditary Breast & Ovarian cancer)

A number of participants were hesitant to apply or reapply for life insurance because of these concerns, despite the protections apparently offered by the FSC Moratorium. Others had decided not to apply for life insurance because they believed or had been advised that they would be unsuccessful.

“I don’t think I was ever rejected life insurance based on an application and disclosure of a genetic test because I think we kind of went there, and the advice was don’t even apply. (...) we didn’t proceed with submitting the application.”

(50 year old male interviewee; high risk result for Mitochondrial disease)

Impact on managing medical risk

The FSC Moratorium requires life insurance companies to consider evidence-based treatment or preventative measures,⁵⁵ which is also reflected in the *Disability Discrimination Act 1992* (Cth).⁵⁶ However, participants perceived that insurers take a ‘blanket approach’ to declining life insurance cover or penalising applicants with genetic results, despite the fact that genetic test results don’t necessarily mean a person will develop disease and may be mitigating their health risks through preventative measures. Several interviewees described experiences of having to go to great lengths to achieve a fair result after an insurer failed to take into account their preventative measures (e.g. see **Case 1** and **Case 2**).

Financial Limits too low

Participants commonly stated that the financial limits of the FSC Moratorium are not high enough to cover their financial needs, in particular to take care of their families if something were to happen to them. Some participants considered that the financial limits should match their current income and the rising cost of living.

“The dollar values need to reflect true dollar costs of the current Australian cost of living. Because I just look at even people my age basically, I don’t know any of us that have got less than a million dollars’ worth of life insurance these days. \$500,000 is two-fifths of stuff all”.

(56 year old female interviewee; high risk result for Hereditary Breast & Ovarian Cancer)

Awareness of the FSC Moratorium

Many participants were previously unaware of the FSC Moratorium and discovered it through this study. Some also expressed concern that insurers and genetic health professionals were also unaware of the FSC Moratorium, limiting its effectiveness.

Case 1 *Ian's storyⁱⁱ: premium loading despite risk management*

Ian has familial hypercholesteremia (FH), which leads to high cholesterol levels and the risk of heart attack at an early age. Ian is on cholesterol-lowering medication, which together with his healthy lifestyle controls his cholesterol levels. When he applied for life insurance, Ian's cholesterol levels were similar or lower than the general population. However, because of his genetic result, Ian had a loading placed on his premium.

Ian challenged the company's decision, referring to his risk management and cholesterol levels. The insurer eventually waived the premium loading. Ian emphasizes the importance of challenging insurers:

"If someone can demonstrate that they're managing it and they're not the risk that the condition would suggest, then it's not fair to say to them, 'You're a higher risk', when you're actually not."

Case 2 *Frank's storyⁱⁱⁱ: premium loading despite a negative test result*

Frank's father had Huntington's disease (HD). Before having genetic testing, Frank obtained life insurance cover, with a 200% premium loading due to his family history of HD. His applications for TPD and IP insurances were declined. Frank subsequently received genetic test results showing he did not inherit the HD variant and was not at risk of HD, and requested that the insurer remove the loading. The insurer refused to do so unless he made a full new application.

"I said, 'Well, no, that's just way too many questions that are irrelevant to why I'm trying to get the loading removed. It just states because of Huntington's disease. I'll tell you about the Huntington's disease. I haven't got it.'"

Frank took the insurance company to the complaints tribunal, which he described as "so stressful and a waste of everyone's time". Eventually, a settlement was reached - the insurer refunded Frank's loading from the date he informed them of his genetic result, on the condition that he withdraw his complaint.

ⁱⁱ Pseudonym used

ⁱⁱⁱ Pseudonym used

2.2 General Public (*unpublished*)

The General Public Study was conducted in partnership with the Australian Survey of Social Attitudes (AuSSA) which surveyed Australian citizens quarterly from May 2021 to February 2022.⁵⁷ The preliminary findings, of 1060 respondents (23% response rate) closely reflect those of the above Patient Studies. **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) of participants 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 FSC Moratorium 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. Only 5% (51/945) disagreed. 55% (498/907) of participants believed that the fact that the arrangement is not permanent was a negative aspect of the FSC Moratorium (only 13% felt it was positive).

2.3 Research Participants (*unpublished*)

Members of the A-GLIMMER Project team conducted a survey of participants in a genetic screening study of individuals from the Jewish community.⁵⁸ Jewish people are ten times more likely than the general population to have a high-risk variant in the BRCA1/2 genes, which significantly increases risk of breast, ovarian and prostate cancers. Participants were given the option of providing a DNA sample immediately or taking a cheek swab home and sending it back at a later date. Of the participants 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.

Members of the A-GLIMMER Project team also lead the *DNA Screen* study, a pilot study of preventive DNA screening for high risk of medically-actionable genetic conditions such as heart disease and some cancers.⁵⁹ *DNA Screen* launched for public registration in August 2022. Within 24 hours, more than 10,000 individuals had registered their interest to participate. Within one week, more than 20,000 individuals had registered their interest. Despite the significant public interest in preventive genetic testing, more than 30% of people who have been invited to participate to date have not accepted the invitation (n=3725/12086). The *DNA Screen* team plans to do more systematic research to understand the reasons for declining participation in the future; however, of 52 people who have written to the study team to volunteer reasons for withdrawing from the study, 29 (56%) have noted the reason as concerns about insurance.

3 Genomic Researchers (*submitted for publication, under peer review*)

The A-GLIMMER Project assessed the FSC Moratorium's impact on the conduct of genomic research and on genomic research participants through surveys and interviews with genomic researchers. This study (the 'Genomic Researchers' Study') is currently under review. The results of this study should therefore be regarded as preliminary.

Preferred regulatory model

This study found that **86% (44/51) of surveyed genomic researchers considered that government should introduce legislation to address genetic discrimination in life insurance.** Almost half of the study participants indicated they were dissatisfied with the FSC Moratorium as a solution (49%; 25/51). Only 4% of participants considered that the FSC Moratorium was the 'ideal' solution (2/51).

Barrier to research

Many genomic researchers (59%; 35/59) reported that the potential use of genomic test results by insurers was a barrier to the recruitment of genomic research participants.

Over half (54%; 21/39) reported that participants in genomic research had expressed concerns about insurance since the FSC Moratorium's introduction. Interviews with genomic researchers revealed instances where insurance companies had asked insurance applicants about genomic testing after the Moratorium's introduction.

Genomic researchers were divided about the perceived impact of the FSC Moratorium on the willingness of individuals to participate in genomic research since the Moratorium's introduction: 23% (9/39) reported a greater likelihood of individuals' willingness to participate; 41% (16/39) reported an equal willingness to participate; and 31% were unsure (12/39). However, comments by researchers consistently reflected the view that some individuals were strongly motivated to participate because of their wish to obtain a clinical diagnosis and that any concerns they had about potential insurance implications were eclipsed by that need.

Financial Limits

A large proportion of genomic researchers (78%; 40/51) considered the FSC Moratorium's financial limits to be too low, with 72% (37/51) reporting that the limit should be \$1,000,000 or that there should be no limit. Only 8% (4/51) reported that the financial limit should be \$500,000. Genomic researchers expressed concern about the uncertainty resulting from the temporary nature of the FSC Moratorium, and **67% (34/51) believed there should be permanent solution to the problem of genetic discrimination in life insurance.**

Awareness of the FSC Moratorium

Awareness of the FSC Moratorium amongst genomic researchers was not comprehensive – only 66% (39/59) were aware of it. Only 60% (27/45) of surveyed genomic researchers who were directly or indirectly involved in consent discussions with their research participants felt they had sufficient knowledge about potential insurance implications to properly carry out their research roles.

4 Financial Services Industry (*submitted for publication, under peer review*)

The A-GLIMMER Project conducted an interview-based research study with 10 participants from the financial advising sector including financial advisers and key informants (the ‘Financial Advisers study’). The study is currently under review with the journal *Public Health Genomics*. The results are therefore presented as preliminary findings. This section summarises that study. We also make some observations about the quality of data collected by the FSC as part of industry self-regulation; and the nature of insurance application forms.

4.1 Financial Advisers Study

The participants interviewed held a range of views on the FSC Moratorium, from positive to more critical.

Financial limits too low

Some participants considered that the FSC Moratorium’s financial limits were too low, particularly given the average Australian salary and mortgage. As of February 2023, the average Australian mortgage was over \$585K, and in Victoria and New South Wales the average mortgage was over \$618K and \$726K respectively.⁶⁰ These figures are well above the FSC Moratorium’s financial limits.

“I think given house prices ... have gone up so much, [\$]500 [k] is better than nothing but it’s not really very much anymore in the capital cities. I think those limits should be increased. And \$4,000 a month income, that’s not very much, like disability support from [the Government is] around about [\$]3,000 a month.”

(Interviewed financial adviser)

Insurance industry compliance

Many participants indicated that they could not comment on whether the industry was complying with the FSC Moratorium because of a lack of experience with its application. However, one financial adviser reported that an insurance company indicated that it would decline trauma cover in circumstances where their client had reported a positive genetic test, even when their application fell within the Moratorium’s financial limits. Some participants suggested that based on their experience, they believed insurance companies would decline cover or increase the premium on another, unrelated, basis if genetic test results were inadvertently disclosed for applications within the FSC Moratorium limits.

“Everything feels like it’s very subjective to whatever the underwriter feels like on the day. Whether you get cover or you don’t. Whether you get loaded or whether you get excluded. You never really get a proper explanation ...I think there’s a real risk in genetic testing that they just turn around and say no to everything.”

(Interviewed financial adviser)

While participants acknowledged the existence of consumer complaint avenues, many were critical of their efficacy. Indeed, many participants suggested that clients had very limited (if any) ability to seek recourse if an adverse decision was made in relation to life insurance underwriting.

Awareness of the FSC Moratorium

Most participants interviewed had some awareness of the FSC Moratorium but, similar to other stakeholder groups, that level of awareness varied. Participants reported that the FSC Moratorium was not highlighted by the financial services industry. Further, study participants had variable understandings about how the FSC Moratorium's financial limits operated. This is concerning given the number of individuals that engage a financial adviser to broker and otherwise assist with applications for life insurance.

Preferred regulatory model

Participants' views varied regarding whether legislation or industry self-regulation was the best way to regulate for genetic discrimination. Participants identified that regardless of the regulatory approach, it should be subject to rigorous external oversight with input from other disciplines (e.g. the health profession), and effective recourse mechanisms for consumers should be in place.

4.2 FSC data

The FSC stated that data was collected from its members 'since the start of 2021' to inform its 2022 review of the Moratorium.⁶¹ 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.'⁶² We raised a number of issues with the FSC regarding missing data.

After cleaning the data, we identified the following problems with it:

- In answer to the question "What genetic conditions did the test seek to identify?" for 511 of 846 responses, the conditions are reported as "other" (486) or "not disclosed" (25). This makes it difficult to analyse the data on types of genetic test information being provided to insurers. It is also difficult to comprehend how an insurer could make an adverse decision without details of the genetic test result.
- Similarly, for data on the "type of genetic test," 540 of 846 are reported as "don't know" and 153 are reported as "other."
- Reports for "results of genetic test" have 72 of 846 as "other" (the other possible responses were carrier, mutation, no mutation and VUS (variants of uncertain significance)).
- It was not possible to ascertain from the data provided how many life insurance companies as a proportion of all total FSC members, had provided data into the database. This means it was therefore not possible to comment on data completeness and representativeness.
- Overall, the dataset is very hard to interpret, as there is inadequate data and no equivalent datasets with which to compare the outcomes for those who provided genetic information.

As an A-GLIMMER Project partner, the FSC had agreed to provide us with information about the database through which it collected information from the life insurance industry. When providing

feedback on the database, members of the A-GLIMMER Project team went to great lengths to explain to the FSC the importance of free text fields to ensure that accurate information was obtained. However, these fields were not included, and no explanation was provided about the reason for this. After subsequent queries from the A-GLIMMER team about missing data, the FSC advised that it would not ask insurers for any of this missing data, despite the requirement that member companies complete the database. No further information was ever provided about this missing data. The delays in receiving promised data from the FSC, and the poor quality of the data, were so serious that we were asked for detailed explanations from the A-GLIMMER Project funder (the Australian Government Medical Research Future Fund, Genomic Health Futures Mission) about the reasons for the delays and the possible risks to the Project outcomes as a result.

4.3 Life Insurance Application Forms

Members of the A-GLIMMER Project team also undertook high-level analysis on life insurance application forms and related documents from 17 insurance companies. We obtained these documents with the assistance of financial advisers and the FSC, as well as through searching individual insurers' websites.

Analysis of the documents revealed a lack of consistency in the way life insurance companies asked about genetic test results. Most contained questions requesting information about 'genetic tests', and did not always make it clear that disclosure of this information was not required if the application fell within the Moratorium's financial limits. It was also unclear how forms (either paper-based or electronic) would have the capacity or functionality to modify questions about genetic testing according to whether the applications were for insurance below or above the limits. Many forms used vague language to request information about the prospect of applicants obtaining genetic tests (e.g. asking if applicants were 'planning', 'considering' or 'intend on' having a genetic test). The use of such language has been criticised by commentators,⁶³ and the FSC itself. During a Parliamentary hearing in 2017, the FSC committed to changing the use of this language.⁶⁴

Moreover, while some application forms referred to the Moratorium's limits (e.g. indicating to applicants that they only need to answer questions relating to genetic tests if they exceeded those limits), there was no explicit reference to the FSC Moratorium, or where to find further information about the Moratorium. Similarly, not all documents explicitly defined favourable genetic test results and distinguished them from unfavourable test results. As a result, applicants may not be aware that they are able to provide favourable genetic test results, in particular when forms instruct applicants to skip the genetic test results section if the life insurance application falls within the financial limits of the FSC Moratorium. Given the limited consumer awareness of the Moratorium, the lack of consistency and limited information about the Moratorium on application forms is concerning.

5 Does the FSC Moratorium Implement the Parliamentary Inquiry's Recommendations?

Research published by members of the A-GLIMMER Project team (**Appendix IX**) identified significant differences between the Parliamentary Inquiry's 2018 recommendations and the subsequently introduced FSC Moratorium.⁶⁵ Australian consumers are more susceptible to genetic discrimination in life insurance than their counterparts in many other countries. This includes the United Kingdom, whose model was the basis for the Parliamentary Inquiry's recommendations.⁶⁶ This remains the case even if the limited changes to the FSC Moratorium, announced by the FSC and described above, are implemented.

A summary of the evaluation of the FSC Moratorium against the Parliamentary Inquiry's key relevant recommendations is set out below, and further detail is included in **Appendix IX**.

Development of policy in discussion with Australian Genetic Non-Discrimination Working Group ('the Working Group'):

"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" (at [9.93])

Key members of the Working Group now lead the A-GLIMMER Project. Prior to the introduction of the FSC Moratorium, the Working Group provided written feedback to the FSC regarding the draft Moratorium document (see **Appendix X**). **A number of matters were not addressed, as set out in Table 1 at Appendix XI.**

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" (at [9.93])

A comparison of key aspects of the UK Code and the FSC Moratorium is at Table 2 (**Appendix XI**).

The UK Code prohibits all use of genetic test results by life insurers, with one exception – applicants for death cover with a Huntington's Disease (HD) predictive result, for policies worth >£500,000 (~AU\$945,000). 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 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.'⁶⁷ 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 (see Figure 1 at **Appendix XI**).⁶⁸

Notably:

- Of 20 countries (other than Australia) listed by the Geneva Institute report, 13 (65%) do not require disclosure of genetic results to insurers in any circumstances (with no limits).
- 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 Parliamentary 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, and only in cases where 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.
- The Netherlands is the only other country listed by the Geneva Institute with financial limits in 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).
- Some countries (like Portugal) completely ban the collection of family history information.

Thus, although the FSC Moratorium adopts lower financial limits (similar to Switzerland), it does so in a context which is entirely different, and subject to radically less regulation and oversight.

Further, all research results are excluded from disclosure in the UK. In Australia, an applicant for life insurance is required to disclose all genetic results (which they know) for applications above the Moratorium's financial limits.

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” (at [9.93])

The introduction to the FSC Moratorium states: ‘[i]t 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 at the time of writing) 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 FSC Moratorium) 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.

As discussed above, in 2022 the A-GLIMMER Project again recommended to the FSC that the Moratorium be made permanent. The FSC subsequently announced that it intends to extend the Moratorium ‘indefinitely until the FSC gives further notice following a review’.⁶⁹ Given there is no legal requirement to continue the FSC Moratorium, and no Australian Government oversight, it is therefore possible that the FSC Moratorium will not apply ‘indefinitely’ if the FSC gives such ‘notice’.

The FSC has announced that it will extend the protection of the FSC Moratorium to tests ‘taken before it started or during its currency, even if the FSC ends it for subsequently taken Genetic tests.’⁷⁰ While this is a positive announcement, it provides little additional certainty for those at risk of genetic discrimination, given the instability of the self-regulated industry (described in **Section A** above).

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” (at [9.94])

The Parliamentary Inquiry acknowledged concerns expressed by the Australian Medical Association, The Royal Australian College of General Practitioners, and others about inherent conflicts of interest in a self-regulatory approach to a ban on the use of genetic testing by the life insurance industry. However, the Inquiry considered that these concerns might 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 Parliamentary Inquiry described this as a ‘co-regulatory’ model. ASIC has not, however, been provided with these powers in relation to the FSC Moratorium. Even if these powers were to be provided to ASIC through registration of the Code, this would likely take some time and would still be subject to the concerns raised in this Final Report regarding the current uncertainty associated with the self-regulation of the life insurance industry.

There are steps that can be taken to improve oversight of compliance with the FSC Moratorium. As noted above, the inclusion of the FSC Moratorium in the proposed 2023 Life Insurance Code of Conduct 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.⁷¹ This is a concern that is reflected in our 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 Parliamentary 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. As concluded below, the research conducted by the A-GLIMMER Project indicates that the FSC Moratorium is not meeting its aims and that this alternative, legislative regulatory model should be implemented.

“The committee recommends that if the Financial Services Council and life insurers have adopted a moratorium on the use of predictive genetic information ... the Australian Government should continue to 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.” (at [9.101])

Section D: Regulatory Analysis and Conclusions

1 The FSC Moratorium is inadequate to address genetic discrimination in life insurance

The research findings of the A-GLIMMER Project demonstrate that the FSC Moratorium has not achieved the Outcomes that we specified early in our research as necessary to achieve the Aims of any effective ban on the use of genetic test results by life insurers.^{iv} Consequently, **the *Disability Discrimination Act 1992 (Cth)* should be amended to make it unlawful, through legislation, for life insurers to use genetic test results to discriminate between applicants for risk-rated insurance.** The Australian Government should also consider whether any additional amendments to the regulation of financial services are required in order to ensure that the legislative prohibition is effective, enforceable and allows for meaningful recourse for affected individuals.

As described above (**Section B**), in order to address and prevent genetic discrimination in relation to life insurance, the FSC Moratorium must achieve the following Outcomes:

1. Widespread and accurate awareness of the existence of the FSC Moratorium.
2. Confidence 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.
4. Adherence to the terms of the FSC Moratorium.⁷²

In contrast, the combined research findings of the A-GLIMMER Project show:

1. Health professionals, consumers and genomic researchers are all concerned about industry self-regulation of the FSC Moratorium. These stakeholders, as well as many financial advisers, are also concerned about the lack of any Australian Government oversight or involvement. These findings indicate a low level of confidence in the FSC Moratorium. This aligns with the finding that decisions by consumers and research participants about whether to undergo genetic testing are impacted by their concerns about life insurance.
2. Difficulties obtaining life insurance products and instances where life insurance companies had asked insurance applicants about genetic testing, including after the introduction of the FSC Moratorium. This shows a failure in adherence to, and enforceability of, the terms of the FSC Moratorium.
3. Concerns around the uncertainty associated with the FSC Moratorium, and possible use of genetic test results in the future.
4. Broad concerns across stakeholder groups about the FSC Moratorium's financial limits being too low to allow individuals to obtain sufficient life insurance cover.

^{iv} As identified earlier, these Aims are derived from the findings and recommendations of the Parliamentary Inquiry's Report.

5. Poor awareness and knowledge about the FSC Moratorium among key stakeholder groups. For some stakeholder groups this was reflected in a failure to update relevant policies and processes.

These findings, and the Outcomes required for a successful moratorium, are set out in further detail at **Appendix XII**.

Further, we sought views from research participants on an optimal model of regulation. A very high proportion of health professionals (93%), patients with experience of genetic testing (88%), the general public (78%) and researchers (86%) consider that legislation is required to regulate the use of genetic test results in life insurance underwriting.

The FSC Moratorium is not therefore meeting the Outcomes identified by the A-GLIMMER Project as being necessary to prevent genetic discrimination in relation to life insurance, and should be replaced with a legislative prohibition. Consequently, **the *Disability Discrimination Act 1992 (Cth)* should be amended to make it unlawful, through legislation, for insurers to use genetic test results to discriminate between applicants for risk-rated insurance.**

The Australian Government should also consider amendments to the regulation of financial services (as discussed further at **section D.2** below) in order to ensure that the legislative prohibition is effective, enforceable and allows for meaningful recourse for affected individuals.

2 Industry self-regulation is inadequate to address genetic discrimination in life insurance and should be replaced with a legislative prohibition

The evidence from the A-GLIMMER Project indicates that industry self-regulation is not an effective regulatory model to address genetic discrimination in relation to life insurance. The FSC Moratorium – either in its current form, or as included in the proposed 2023 Life Insurance Code of Conduct – is inadequate and should be replaced with a legislative model of prohibition.

The *Australian Government Guide to Policy Impact Analysis* states that self-regulation can be an appropriate regulatory model in certain circumstances, namely '[w]here industry participants understand and appreciate the need for self-regulation and there is a low risk to the community in the event of non-compliance.'⁷³ It goes on to state that,

*[s]elf-regulation is not a viable option if any industry has no incentive to comply with its own rules. In some cases, self-regulation may create public concern, where, for example, perceived conflicts of interest could threaten safety, such as in ... healthcare. Self-regulation should be approached carefully where previous attempts to achieve compliance or penalize non-compliance have failed.'*⁷⁴

The A-GLIMMER Project's research findings document instances of non-compliance and highlight inadequate regulatory enforcement and the lack of effective recourse for consumers. This is particularly concerning in a context for which the industry has an inherent conflict of interest, and which has critical importance for preventive healthcare. The FSC Life Code Compliance Committee itself has documented concerns with failures to implement recommendations and its lack of meaningful sanctioning powers.

We also found there was significant public concern, including amongst health professionals, consumers and genomic researchers, about the self-regulatory character of the FSC Moratorium. These stakeholders, as well as many financial advisers, are also worried about the absence of government oversight or involvement. Further, our findings show poor levels of knowledge and understanding amongst key stakeholder groups about the FSC Moratorium. This further indicates failings in the self-regulatory model.

Given that these concerns and findings relate to the uptake of genetic and genomic testing, and participation in related research, this is an untenable situation considering the importance of genetic and genomic medicine to Australian healthcare. **According to the Australian Government regulatory policy referred to above, our research findings present a strong case for the inappropriateness for industry self-regulation to address genetic discrimination in life insurance.**

The Australian Government should instead regulate to make genetic discrimination in life insurance unlawful under the *Disability Discrimination Act 1992 (Cth)*. Consistent with the Act, **the Australian Human Rights Commission ('AHRC') should be given responsibility to enforce, promote, educate and support individuals and stakeholders to understand and meet these new legal obligations. The AHRC is the most appropriate body to undertake these responsibilities.** Unlike bodies such as ASIC or the Australian Financial Complaints Authority (AFCA), the AHRC has extensive experience addressing, resolving, and seeking to prevent significant claims of discrimination in relation to insurance.

In addition, the legislative prohibition should be as effective and enforceable as possible, and allow for meaningful recourse for affected individuals. While the Act provides a legal pathway for redress for discrimination by individuals, it does not ensure that insurers are subject to a positive duty not to discriminate which carries a penalty for breach. The proposed amendment is necessary to implement the prohibition; however, its effectiveness may be limited to circumstances where an individual is able to seek recourse through the AHRC and/or is able to bring an action against an insurer (which can be costly, drawn out, and risky for the individual). It would strengthen the reform if the government also ensured insurers were subject to a positive duty not to discriminate. Without being prescriptive, this positive duty may be best placed within national financial services legislation or the regulation of financial services. As discussed in **Section D.1** above, the Australian Government should also consider amendments to the regulation of financial services, in addition to the amendments to the *Disability Discrimination Act 1992 (Cth)*, to acknowledge this positive duty.

Our position in relation to the inappropriateness of industry self-regulation to address genetic discrimination in life insurance is strengthened by two further factors. First, the A-GLIMMER Project's concerns about the relative ineffectiveness of the FSC's 2022 review of the FSC Moratorium; and second, the current uncertainty, instability and lack of cohesion surrounding the self-regulation of the Australian life insurance industry.

The 2022 FSC Review of the Moratorium

Under the terms of the FSC Moratorium, the FSC was required to conduct a review of the Moratorium in 2022, with a view to extending its operation beyond 2024.⁷⁵ We consider that the review was inadequate, and further indicates that the current self-regulatory model is ineffective.

On FSC's invitation, the A-GLIMMER Project made a submission to the review. We addressed a range of issues regarding the FSC Moratorium, including its temporary nature; financial limits; impact on genetic testing and research; the need to increase awareness and understanding; instances of

non-compliance; and the limitations of a self-regulatory model. We also provided the FSC with the interim research findings of the A-GLIMMER Project. Our submission is attached at **Appendix III**.

Despite the extensive nature of our submission, the FSC's review resulted in only minimal changes to the Moratorium. As described above, the FSC announced that it intends to extend the Moratorium 'indefinitely' from 1 July 2023 'until the FSC gives further notice following a review'.⁷⁶ The FSC will also include the FSC Moratorium in the new Life Insurance Code of Practice to commence on 1 July 2023.⁷⁷ No changes were made to the terms or scope of the FSC Moratorium. We received no communication from the FSC in response to our submission, or engagement regarding the reasons for failing to consider the majority of our submission.

Further, the A- GLIMMER Project has the following significant concerns about the robustness of the FSC review:

- The methodology used to conduct the review was not disclosed or discussed with stakeholders. The questions posed for submissions were narrowly construed.⁷⁸
- It appears that the FSC only encouraged submissions from specific stakeholders, despite our advice that it was important to obtain submissions from a variety of stakeholders, including consumer groups. 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 Forum and FSC members.⁷⁹ No other consumer groups, outside of the FSC, appear to have been invited to make a submission, nor are we aware of any further promotion of the review by the FSC.⁸⁰
- No advance notification was given regarding the timing of the review, and only one month was initially given for submissions to be prepared,⁸¹ (although the A-GLIMMER Project successfully sought an extension of one week).
- As noted earlier, there are problems with the quality of the data that informed the FSC's review, and the timeliness of data which the FSC had agreed to pass on to the A-GLIMMER Project as a Project partner.
- Data timeliness: The data collected under the FSC Moratorium was not ultimately provided to the A-GLIMMER Project until 6 months after the agreed date and numerous requests. The FSC advised members of the A-GLIMMER Project team that it was withholding the data on the basis that it wanted to analyse and publish the findings itself first.
- Data quality: The FSC stated that data was collected from the life insurance industry 'since the start of 2021' to inform the FSC's review.⁸² 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'.⁸³ We raised a number of issues with the FSC regarding missing data.^v When providing feedback on the database, members of the A-GLIMMER Project team went to great lengths to explain to the FSC the importance of free text fields to ensure that accurate information was obtained. However, these fields were not included, and no explanation was provided about the reason for this. After subsequent queries from the A-GLIMMER team about missing data, the FSC advised that it would not ask

^v For the vast majority of instances where genetic results have been used and adverse outcomes reported, both the condition and type of test are merely recorded as "other" or "don't know". This explains nothing about the test undertaken, 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 results of which they did not know the details.

insurers for any of this missing data, despite the requirement that member companies complete the database. No further information was ever provided about this missing data.

- As noted earlier, the FSC's delay in providing data promised to the A-GLIMMER Project, and the poor quality of that data, led to questions from the Project funder (the Commonwealth Government's Medical Research Future Fund, Genomic Health Futures Mission).
- Prior to the review, the FSC issued a media release publishing FSC data about the use of genetic test results by life insurers⁸⁴ (and delayed providing it to the A-GLIMMER Project team, as discussed above). It stated that the data showed genetic test disclosures did not adversely influence life insurance applications. The FSC reached and published (without peer review) 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 noted above in its self-review and publication of its own findings.

The 2023 changes to self-regulation of the life insurance industry

Section A.4 above outlines recent announcements of changes to the self-regulation of the life insurance industry. These changes include the formation of a new industry representative body – CALI – which has stated that it will seek to take over responsibility for the 2023 Code (which proposes to contain the FSC Moratorium).⁸⁵ Simultaneously, the FSC has stated that it will continue its role advocating for the life insurance industry and implementing the 2023 Code.⁸⁶

At minimum, effective self-regulation requires a viable, cohesive and stable industry body.⁸⁷ **In stark contrast, the current regulatory environment surrounding the life insurance industry is unclear, uncertain and apparently divided.** It is not clear whether, how and when any changes in responsibility for the self-regulation of genetic discrimination by the Australian life insurance industry will occur. It is also uncertain what precise form they will take. **This is an untenable regulatory situation for an emerging health technology as important as genetic testing, especially given the significant ethical and public trust issues involved.**

3 Alternative non-legislative regulatory options are not appropriate

Members of the A-GLIMMER Project team with legal and regulatory expertise have considered whether largely non-legislative regulatory models might be effective to prevent and address genetic discrimination in relation to life insurance. Such alternative regulatory approaches include 'quasi-regulation'^{vi} or 'co-regulation'^{vii}. While these approaches may have advantages when compared with

^{vi} Quasi-regulation can be described as 'non-legal rules which have some form of government "halo", including government-endorsed industry codes of practice, government agency guidance notes, industry-government agreements, and national accreditation schemes': Julia Black, 'Decentring Regulation: Understanding the Role of Regulation and Self-Regulation in a "Post-Regulatory" World' (2001) 54 *Current Legal Problems* 103, 117. See also, Department of the Prime Minister and Cabinet, 'Australian Government Guide to Policy Impact Analysis' (March 2023), <https://oia.pmc.gov.au/sites/default/files/2023-02/oia-impact-analysis-guide-nov-22.pdf> 22; Andrew Terry, 'The Unusual Place of Industry Codes of Conduct in the Regulatory Framework' (2022) 45 *UNSW Law Journal* 649, 666-8.

^{vii} Co-regulation has been defined as 'a degree of legislative underpinning of codes or standards, e.g. legislative delegation of power to industry to regulate and enforce codes ... prescribing industry codes as voluntary or mandatory in legislation, legislation setting minimum standards': Black, above vi. See also, Terry, above vi, 672.

the self-regulatory^{viii} model of the FSC Moratorium, we do not consider they are effective regulatory options to address genetic discrimination.

As discussed earlier, the Parliamentary Inquiry supported a co-regulatory approach in which a Life Insurance Code of Conduct (including the FSC Moratorium) was approved and registered by ASIC (as part of its role in overseeing the financial services sector).⁸⁸ Under this ASIC oversight model, the Code would be binding on industry members and would include compliance mechanisms and sanctions.⁸⁹ This approach was not implemented. The A-GLIMMER Project does not consider that this regulatory model is an appropriate one. This is because:

- The entire Life Insurance Code of Conduct, not just the Moratorium, would need to be considered and approved by ASIC. We anticipate that this will be a lengthy process and would fail to address critical genetic discrimination concerns in the short to medium term.
- Regulatory oversight by a body such as ASIC is not an appropriate mechanism to address issues of discrimination and is not designed to address individual circumstances and provide avenues of redress for vulnerable consumers. Similarly, the Australian Financial Complaints Authority (AFCA) is not intended to address egregious discrimination claims, which are best dealt with through non-discrimination legislation and the Australian Human Rights Commission.
- This regulatory approach still requires a strong, stable, cohesive and consultative industry body to fulfil its regulatory responsibilities. As discussed above, we do not consider that the FSC or CALI currently meets these requirements.
- Under this model the existing terms of the FSC Moratorium would be retained. Our research findings shows that these terms (e.g. financial limits) are inadequate to address genetic discrimination.
- This approach does not address low levels of education and understanding of the FSC Moratorium, as reflected in our research findings.

Accordingly, even if the Code was transitioned to CALI, and eventually registered with ASIC, this would take some time and would still offer inadequate protection and reassurance for consumers who are engaging in genetic testing. Far more certainty is required both to protect consumers and ensure that genetic and genomic medicine can reach its potential in Australia. For similar reasons we also do not consider that a 'quasi-regulatory' approach is a viable one to address genetic discrimination in the life insurance industry.

^{viii} Defined as 'industry formulating rules and codes of conduct and being solely responsible for their enforcement.': Black, above vi. See also, Terry, above vi, 659.

Section E: Recommendations

In light of the above research findings, and drawing on the regulatory and legal expertise of team members, the A-GLIMMER Project recommends that:

1. **The Australian Government amend the *Disability Discrimination Act 1992* (Cth) ('the Act') to prohibit insurers from using genetic or genomic test results to discriminate between applicants for risk-rated insurance, and consider amendments to the regulation of financial services to ensure insurers are subject to a positive duty to not discriminate.**

The self-regulatory approach underpinning the FSC Moratorium is inadequate to prevent and address the significant issue of genetic discrimination. The life insurance industry has not exhibited a capacity for effective self-regulation in relation to genetic information, which is a vital pillar of Australians' access to healthcare. A legislative prohibition should therefore be implemented by the Australian Government in its current term.

The Australian Government should also consider whether any additional amendments to the regulation of financial services are required in order to ensure that the legislative prohibition is effective, enforceable and allows for meaningful recourse for affected individuals.

The term 'risk-rated insurance' used in this recommendation covers the broad range of life insurance policies defined in **Section A.1** which were the focus of the A-GLIMMER Project.^{ix} The term may also include other types of risk-rated insurance including travel, mortgage protection and car/vehicle insurance. While these latter types of insurance were not the focus of the A-GLIMMER Project, we recommend that a prohibition on discrimination in relation to the use of genetic or genomic test results extend to all risk-rated insurance. Other research has found consumers experience difficulties obtaining travel insurance after genetic testing;⁹⁰ and some health professionals we surveyed disclosed that patients often or sometimes delay or decline genetic testing because they are concerned about travel insurance.⁹¹ A prohibition on genetic discrimination that covers all risk-rated insurance will also ensure that Australia is further aligned with the UK's approach.^x

Consistently with international approaches discussed at **Appendix I** and the terms of the current FSC Moratorium, the drafting of the legislative prohibition should ensure that insurance applicants may choose to disclose favourable genetic test results and/or information about their adherence to evidence-based preventative measures which reduce the possibility of developing a genetic condition that runs in their family.

^{ix} Encompassing insurance policies covering death; total and permanent disability; trauma and critical illness; and income protection, salary continuation or business expenses: Parliamentary Joint Committee on Corporations and Financial Services, Life Insurance Industry, Final Report, March 2018, [https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/Corporations_and_Financial_Services/LifeInsurance/Report 5](https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/Corporations_and_Financial_Services/LifeInsurance/Report%205).

^x The UK *Code on Genetic Testing and Insurance* also prohibits the use of genetic test results in travel and motor insurance: HM Government and Association of British Insurers, 'Code on Genetic Testing and Insurance' <https://www.abi.org.uk/globalassets/files/publications/public/genetics/code-on-genetic-testing-and-insurance-final.pdf> (October, 2018).

2. **The Australian Government allocate responsibility and appropriate resources to the Australian Human Rights Commission ('AHRC') to enforce, promote, educate and support individuals and all relevant stakeholders to understand and meet the new legal obligations under the Act. The AHRC should consult with a range of genetics and genomics experts and stakeholders to achieve this goal.**

As the body established to carry out functions under the Act, the AHRC is best placed to facilitate the reforms outlined in Recommendation 1 and ensure that aggrieved consumers are provided with accessible and meaningful recourse to remedies.

Further, the Australian Government should ensure that the AHRC is appropriately resourced to enable it, in consultation with appropriate genetics and genomics experts and stakeholders, to carry out appropriate enforcement and educative functions to support these reforms. Stakeholders should include consumer health bodies; patient groups; Aboriginal and Torres Strait Islander peoples and communities; and culturally and linguistically diverse communities. Consultation with stakeholders should identify gaps in knowledge about genetic discrimination and the development of appropriate educational resources.

Section F: Appendices

1 Appendix I – Summary of Treatment of Genetic Information Nationally

In Canada, the *Genetic Non-Discrimination Act*⁹² 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* (GINA)⁹³ prohibits use of genetic information by health insurers and employers. The Council of Europe's *Oviedo Convention on Human Rights and Biomedicine*⁹⁴ prohibits discrimination on the basis of genetic information. Many European countries have accordingly banned or restricted discriminatory use of genetic information.⁹⁵ In the UK, the *Code on Genetic Testing and Insurance* (UK Code),⁹⁶ an agreement between the government and the Association of British Insurers (ABI), 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 more than £500,000 (\$A900,000)....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: Evaluating Policy Compared to Parliamentary Recommendations Regarding Genetic Discrimination'
32(4) *Public Health Research & Practice* 1, 2.

2 Appendix II – 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 III – A-GLIMMER Submission to the FSC’s Review of the Moratorium

Mr Nick Kirwan
Financial Services Council
By email: info@fsc.org.au
cc: nkirwan@fsc.org.au

5 August 2022

Dear Nick

We refer to your email to Margaret Otlowski of 27 June 2022, inviting the Australian Genetic Non-Discrimination Working Group to make a submission to the FSC's review of the Moratorium on the use of genetic tests in life insurance ('the Moratorium').

As you know, the members of the Working Group have established the A-GLIMMER (Australian Genetics and Life Insurance Moratorium: Monitoring the Effectiveness and Response) Project. Please find enclosed the A-GLIMMER Project's submission to the FSC's review.

We also attach the A-GLIMMER Project's Interim Stakeholder Report, which forms part of our submission to the FSC's Review. The Report summarises the A-GLIMMER Project's research findings to-date. Over the next 12 months the A-GLIMMER Project will complete and publish a range of additional research. This research is also relevant to the FSC's review. A Final Stakeholder Report will be completed by the middle of 2023.

Please contact Margaret Otlowski on margaret.otlowski@utas.edu.au if you have any questions. Thank you for the opportunity to contribute to this important work.

Yours sincerely,

Professor Margaret Otlowski
Chair, Australian Genetic Non-Discrimination Working Group
Investigator, A-GLIMMER Project

Jane Tiller
Co-Founder, Australian Genetic Non-Discrimination Working Group
Project Manager, A-GLIMMER Project

Associate Professor Paul Lacaze
Co-Founder, Australian Genetic Non-Discrimination Working Group
Principal Investigator, A-GLIMMER Project



THE A-GLIMMER PROJECT

SUBMISSION TO THE FSC'S REVIEW OF THE MORATORIUM ON THE USE OF GENETIC TESTS IN LIFE INSURANCE

5 August 2022

The A-GLIMMER Project has addressed the FSC's Consultation Questions below and outlined additional substantive issues that the FSC should consider. Our responses are informed by the research led by the A-GLIMMER Project to date. The responses should be read in conjunction with *The A-GLIMMER Project Interim Stakeholder Report* (attached), which contains more detailed data and analysis. The data presented comprises a mixture of published (in peer reviewed journals) and unpublished research, as described in the attached report. Over the next year the A-GLIMMER Project will complete and publish additional research, which will be crucial to further assessing the Moratorium's effectiveness.

We recommend that the FSC:

- 1. consider all of the findings and recommendations in the A-GLIMMER Project's research to-date on the Moratorium's effectiveness, particularly in relation to stakeholders' low confidence in the Moratorium's self-regulatory model;**
- 2. consider supporting an alternative regulatory approach (which involves government oversight) prohibiting the use of genetic information by life insurers; and**
- 3. actively engage a broad range of stakeholders to assess the Moratorium's effectiveness and in relation to any changes to the Moratorium.**

Consultation Question 1.

The FSC is considering extending the Moratorium to 30 June 2027 with a further review in 2025. We invite submissions on whether a 3-year extension draws the appropriate balance between the competing interests of providing certainty and stability to consumers and the genomics community, with the changing landscape of genomics? If not, how long should the extension be? Any supporting evidence would be helpful.

The Moratorium will not achieve its aims unless a ban on the use of genetic test results for life insurance is implemented on an indefinite basis. A temporary ban, irrespective of its duration, contributes to uncertainty about how genetic information will be used in the future. This was the recommendation of the Parliamentary Joint Committee on Corporations and Financial Services in its Final Report on the Inquiry on the Life Insurance Industry ('the Inquiry').¹ Although the Inquiry recommended that the ban should be reviewed after 5 years, it did not recommend that the ban be temporary – it stated that the prohibition should be consistent with the UK moratorium, which is indefinite.²

The Inquiry recommended that the Moratorium be developed in discussion with the Australian Genetic Non-Discrimination Working Group. The Working Group appreciated the opportunity to engage in preliminary dialogue about the Moratorium. One of the primary recommendations made by the Working Group as part of those preliminary discussions was that the Moratorium should be permanent in order to avoid uncertainty about the future use of genetic test results by life insurers.

Recent research by the A-GLIMMER Project found that, of the Australian health professionals surveyed and interviewed, many are concerned about the temporary nature of the Moratorium, and their resulting inability to reassure patients about whether and how the Moratorium will operate in the future. The Moratorium's impermanence exacerbates uncertainty about how genetic information obtained in the short term could be used in the future. This uncertainty contributes to difficulties in explaining the operation of the Moratorium to patients, and to patients understanding of the Moratorium.³ 76% (228/302) of patients and 55% (498/907) of members of the general public believed that the fact that the agreement is not permanent was a negative aspect of the moratorium (only 3% and 13% respectively felt it was positive). The Parliamentary Committee was very concerned about the potential for consumers who took a genetic test with the expectation of having their information protected, having that protection taken away. The Committee recommended that the

¹ Parliamentary Joint Committee on corporations and Financial Services, Life Insurance Industry, Final Report, March 2018

² Ibid.

³ Grace Dowling et al, 'Health Professionals' Views and Experiences of the Australian Moratorium on Genetic Testing and Life Insurance: A Qualitative Study', (2022) *European Journal of Human Genetics*.

arrangements put in place should apply indefinitely to predictive genetic test results obtained before the lifting of the moratorium. The Working Group recommended to the FSC during the preliminary discussions that this protection be included in the moratorium.

Our preliminary research shows that a very large number of surveyed Australians reported that the potential for life insurers to use genetic test results may, or would definitely, decrease the likelihood that participants would undergo genetic testing. This finding is reflected in our research with genetic researchers, of whom 60% (36/60) reported that the potential use of genetic results by insurers is a barrier to recruitment, and almost half (25/53 or 47%) reported that research had directly expressed concerns to them about insurance implications since the Moratorium's introduction.

The majority (34/52 or 65%) of genetic researchers we surveyed believed a permanent (not temporary) prohibition on the use of genetic test information by insurers is required. Notably, genetic researchers report concerns about life insurance as a continuing impediment to their recruitment of research participants. Contrary to Consultation Question 1, consumer interest in 'certainty and stability' is consistent, and not in conflict, with 'the changing landscape of genomics'. The development of genomic medicine and testing requires that consumers feel confident in undertaking genetic testing as recommended by their doctors, and in fully participating in genomic research. This issue has been identified as a priority, unresolved area in numerous Australian genomics policy documents, including the *National Health Genomics Policy Framework Implementation Plan*.⁴ The Commonwealth-commissioned *Essentially Ours* report⁵ identifies genetic discrimination as an ongoing ethical issue of public concern, and "a barrier to the uptake of genomic services", despite recent, industry-led policy changes. Anything less than an indefinite ban will continue to undermine consumer confidence and the success of genomic medicine in Australia.

⁴ Commonwealth of Australia Department of Health AHMAC. National Health Genomics Policy Framework and Implementation Plan 2018-2021 2017 [Available from: <https://www1.health.gov.au/internet/main/publishing.nsf/Content/national-health-genomics-policy-framework-2018-2021>].

⁵ McWhirter R, Eckstein L, Chalmers D, Kaye J, Nielsen J, Otlowski M, et al. *Essentially Ours - Assessing the regulation of the collection and use of health-related genomic information* (Centre for Law and Genetics Occasional Paper No 11). Centre for Law and Genetics, University of Tasmania; 2021.

Consultation Question 2.

Is there evidence to show whether or not the cover limits in the Moratorium appropriately balance the interests of providing a reasonable level of cover, the sustainability of Australia's life insurance industry, minimising cross-subsidies, and the levels of cover people typically take out?

The Inquiry did not recommend that the prohibition on the use of genetic test results by the life insurance industry include financial or 'cover' limits. Instead, the Inquiry recommended a complete ban – the report stated (at 9.93), “as a first step, the committee considers that the FSC, in discussion with the AGND Working Group, should update the Code and Standards 11 and 16 in order to prohibit any life insurers from using the outcomes of predictive genetic tests at least in the medium term. This should be done as a matter of some urgency and take a form similar to the United Kingdom's Moratorium.”.⁶ We also note the Inquiry's conclusion that concerns about the unsustainability of the life insurance sector because of a ban on the use of genetic information were 'overstated'⁷ and that the life insurance industry did not provide strong evidence to the contrary (9.87).

Evidence gathered through the A-GLIMMER Project so far indicates that the Moratorium's financial limits may be too low to provide adequate protection against genetic discrimination given the financial needs of most Australians. As at May 2022, the average Australian mortgage was over \$615K, and in Victoria and NSW the average mortgage was over \$643K and \$780K respectively. These figures are well above the Moratorium's financial limits.⁸

The A-GLIMMER Project's research found that the Moratorium's low financial limits was a strong concern expressed by health professionals in relation to their patients. A significant number of interviewed health professionals stated that the Moratorium's financial limits created a barrier to their patients having genetic testing. They reported that patients often required policies above the financial limits and that consequently the Moratorium provided no reassurance to those patients.⁹ Similarly, a reasonable proportion (40/52 or 77%) of genetic researchers surveyed believed that the Moratorium's financial limits were set too low. Finally, early analysis of our research with financial advisers (8 interviewed) similarly indicates that the Moratorium's financial limits were inadequate given the average Australian salary and mortgage. A number of those financial

⁶ Parliamentary Joint Committee on corporations and Financial Services, *Life Insurance Industry*, Final Report, March 2018, 155 (at para 9.93).

⁷ Ibid 154 (at paras 9.87 – 9.88).

⁸ 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 July 2022.

⁹ Grace Dowling et al, 'Health Professionals' Views and Experiences of the Australian Moratorium on Genetic Testing and Life Insurance: A Qualitative Study' (2022) *European Journal of Human Genetics*.

advisers indicated that the Moratorium offered no protection for clientele who came to see them, as their insurance needs were far higher than the limits set in the moratorium.

Of consumers who we surveyed across different studies, only 16% (54/341) of patients and 22% (209/940) of members of the general public 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.

The Australian Genetic Non-Discrimination Working Group provided feedback to the FSC at the time of the Moratorium's introduction, including about concerns associated with the financial limits. The limits first suggested by the FSC were not amended in the final document after that feedback was given. Beyond concerns about the low limits covered by the moratorium, one of our ongoing concerns is that the financial limits do not operate independently. Consequently, if an individual applies, for example, for income protection cover of \$5000 per month, and also for \$100,000 in trauma/critical illness cover, the Moratorium will not prevent the insurer from requesting and using genetic test results in relation to either insurance product.

When it announced the 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 recent Geneva Institute report.¹⁰ 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). 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 Parliamentary Committee.

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).

¹⁰ The Geneva Association. Genetics and Life Insurance: A View Into the Microscope of Regulation. Zurich, Switzerland; 2017.

Consultation Question 3.

Is there any evidence of changed consumer behaviour when applying for life insurance? If so, what is the evidence, how has people's behaviour changed, and what are the implications of the change?

There are a number of aspects of 'consumer behaviour when applying for life insurance.' Preliminary research findings of the A-GLIMMER Project in relation to patient and consumer experiences with genetic testing and life insurance raise concerns about the Moratorium's effectiveness.¹¹ The preliminary findings of research with patients indicate that concerns about life insurance had a moderate or significant effect on the decision making of half of the respondents who had chosen not to have a genetic test or who were actively considering genetic testing (7/14 or 50%). These results contrast with the data presented by the FSC (discussed below under 'Other Substantive Issues').

Health professionals reported a slight decline in the number of patients who 'often' or 'sometimes' delayed or declined genetic testing because of life insurance concerns since the Moratorium was introduced. However, a number of health professionals also reported patients still delaying or declining genetic testing 'often' or 'sometimes' after the Moratorium's introduction due to concerns about life insurance.¹² Despite the Moratorium, a large proportion of surveyed health professionals still have concerns about genetic discrimination in life insurance.¹³ This is particularly worrying given that health professionals are the primary source of information and advice for patients considering whether to undergo genetic testing.

Further, 60% (23/41) of surveyed participants who delayed testing in a genetic screening study reported that they delayed testing because they wanted to consider their life insurance situation before having testing.

¹¹ Australian Genetics and Life Insurance Moratorium: Monitoring the Effectiveness and Regulation ('A-GLIMMER'), *The A-GLIMMER Project Interim Stakeholder Report*, August 2022 (provided to the FSC with this Submission).

¹² 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.

¹³ *Ibid* 3, 5.

Consultation Question 4.

Is there any evidence about whether or not the Moratorium has changed people's attitude to taking part in genomic research? If so, what is the evidence and how has people's attitude changed?

The A-GLIMMER Project surveyed genetic researchers¹⁴ to capture their perceptions regarding the impact of the Moratorium on research participation. Preliminary analysis of the survey results found that many genetic researchers (36/60 or 60%) reported that the potential use of genetic results by insurers remains a barrier to the recruitment of research participants. Almost half (25/53 or 47%) reported that participants in genetic research had directly expressed concerns to them about insurance since the Moratorium's introduction.

These findings may reflect concerns that have emerged regarding the Moratorium: a large proportion of genetic researchers (77% or 40/52) considered the Moratorium's financial limits were set too low and 65% (34/52) believed a permanent (not temporary) prohibition on the use of genetic test information by insurers is required. A large number of surveyed genetic researchers wanted a legally enforceable prohibition against the use of genetic test results by insurers (37/47 or 79%) and considered legislation to be the appropriate regulatory mechanism (44/52 or 85%).

The temporary and financially limited nature of the protections offered by the Moratorium may explain our additional findings that only a moderate number of genetic researchers had updated their Patient Information and Consent Forms (19/57 or 33%) or revised their consent discussions with patients (16/53 or 30%) since the introduction of the Moratorium.

This preliminary analysis indicates that the Moratorium has not been successful in assuaging people's concerns about participating in genetic research. The A-GLIMMER Project will complete research on the effectiveness of the Moratorium in relation to genomic research by mid-2023. The results of this research will be available online¹⁵ and in a Final Stakeholder Report.

¹⁴ 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.

¹⁵ Monash University, 'The A-GLIMMER Project', <https://www.monash.edu/medicine/a-glimmer/home>.

Consultation Question 5.

Apart from the cover levels and the period of extension, are there other changes that would improve the operation of the Moratorium for all affected people? If so, please describe what these might be.

1. Address the Limitations of the Self-Regulatory Model

Our findings suggest that the self-regulatory model reflected by the Moratorium may be inadequate to support its aims. Research by the A-GLIMMER Project found that the majority of interviewed health professionals expressed strong dissatisfaction with the self-regulatory nature of the Moratorium and reported low trust in the insurance industry. 73% (219/300) of patients and 60% (533/888) of the general public 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 moratorium (only 7% and 10% respectively felt it was positive). Many of the health professionals interviewed considered there was a need for more stringent regulation, both to reassure patients and to ensure compliance by insurance providers.¹⁶ Further, preliminary research found that a high number of health professionals, patients, consumers and genetic researchers surveyed consider that the government should introduce legislation preventing the use of genetic test results by life insurers.

Some interviewed financial advisors 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. Many advisers interviewed so far indicated that they could not comment on whether the industry was complying with the moratorium in absence of evidence. However, we are concerned by reports from a financial adviser 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 moratorium.

These findings should be considered in the context of the recommendations made by the Inquiry. There are numerous discrepancies between the Inquiry's recommendations and the Moratorium which have arguably contributed to a risk that the Moratorium will not achieve its goals. 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

¹⁶ Grace Dowling et al, 'Health Professionals' Views and Experiences of the Australian Moratorium on Genetic Testing and Life Insurance: A Qualitative Study' (2022) *European Journal of Human Genetics*.

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 Moratorium.

There are steps that can be taken to improve oversight of compliance with the Moratorium. The 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.¹⁷ 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 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 Moratorium is not meeting its aims and suggests that an alternative regulatory model should be considered.

2. Implement the Inquiry's Recommendations

The attached Interim Stakeholder Report by the A-GLIMMER Project summarises a number of key differences between the Inquiry's recommendations and the Moratorium. On many bases, the FSC Moratorium falls short of the recommendations made by the Parliamentary Joint Committee in 2018, and provides a poorer level of consumer protection than that contemplated by those recommendations. These differences are notable in light of the significant work undertaken by the Inquiry and its bipartisan nature. Addressing these differences may improve the protection of consumers from genetic discrimination in life insurance.

¹⁷ 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/>>.

3. Increase Awareness and Understanding

The research led by the A-GLIMMER Project also identified that significant improvements needed to be made to the awareness and understanding of the Moratorium by health professionals, patients, consumers, genetic researchers and financial advisers.¹⁸ This is essential to the success of the Moratorium.

4. Increase Support of Genetic Testing and Research Participation

As referred to above, a number of health professionals report patients still delaying or declining genetic testing after the Moratorium's introduction due to concerns about life insurance.¹⁹ The preliminary findings in relation to consumers also show they report being less likely to undertake genetic testing because of concerns about life insurance. Genetic researchers similarly report that life insurance concerns are a continuing impediment to their recruitment of research participants.

¹⁸ 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, 2-3.

¹⁹ 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.

Other Substantive Issues.

There are some key issues outside the scope of the FSC's Consultation Questions which are important for the FSC to consider as part of its review of the Moratorium.

1. Difficulties Obtaining Life Insurance

Preliminary findings from the A-GLIMMER Project's patient-focussed research show that 53 of 149 (or 36%) of patients who had genetic testing and had applied for life insurance products reported difficulties in obtaining cover.²⁰ These difficulties included: insurers rejecting applications for life insurance; financial advisers telling participants that their applications would be rejected; and insurers placing conditions on insurance policies or charging higher premiums. Notably, almost a quarter of the research participants who had difficulties experienced this **after** the Moratorium was introduced.

2. Review Consultation and Scope

We are concerned that only a narrow group of stakeholders has been directly contacted by the FSC to contribute to the review of the Moratorium, and that most of these stakeholders are drawn from the FSC's members and consultative representatives. An effective review of the Moratorium requires contributions from a broad range of stakeholders. The FSC should therefore promote the review more broadly and seek submissions from a wide range of stakeholders in order to assess the Moratorium's effectiveness. Further, stakeholders should be invited to address issues that they identify as relevant to the review. In contrast, the Consultation Questions currently posed by the FSC are limited in scope and focus on the behaviour of consumers and patients, rather than the conduct of the insurance industry. The FSC should also consult broadly with stakeholders about any changes it proposes to make to the Moratorium.

3. Review Data

We are concerned about the limited amount of data which the FSC has collected to inform its review of the Moratorium, in particular the narrow time period evaluated. The FSC has stated that data has been collected from the life insurance industry 'since the start of 2021'.²¹ In contrast, the 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

²⁰ Australian Genetics and Life Insurance Moratorium: Monitoring the Effectiveness and Regulation ('A-GLIMMER'), *The A-GLIMMER Project Interim Stakeholder Report*, August 2022 (provided to the FSC with this Submission).

²¹ FSC, 'Media Release: New Data Shows How Genetics Moratorium for Life Insurance Works for Australians' 24 February 2022, <https://fsc.org.au/news/media-release/genetics-moratorium>.

results.’²² We strongly encourage the FSC to amend its database to make clear to members the level of data that should be included, in order to collect sufficient data in future to allow for thorough analysis.

As described above, the A-GLIMMER Project is well placed to contribute to a meaningful review of the Moratorium. Over the next year additional research findings will be published and made available on the Project’s website,²³ including in relation to patients and consumers, the finance industry and the genetic research community. This research will be summarised in the Final Stakeholder Report in mid-2023 and will be provided to the Commonwealth Government and stakeholders, including the FSC, for their consideration.

²² Moratorium cl 3.9.

²³ Monash University, ‘The A-GLIMMER Project’, <https://www.monash.edu/medicine/a-glimmer/home>.

4 Appendix IV – 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.⁹⁷

The Code states that its members 'will comply with all relevant FSC Standards and Guidance' when assessing an application for life insurance.⁹⁸ 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.⁹⁹

The LCCC Chairperson has expressed concerns about the effectiveness of its oversight role.¹⁰⁰ Further, the LCCC has only imposed one sanction since its inception.¹⁰¹

5 Appendix V – A-GLIMMER Project Study Design

STUDY PROTOCOL

Open Access



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

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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

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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



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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
	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	Genetic testers survey Pre-testers and decliners survey
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	

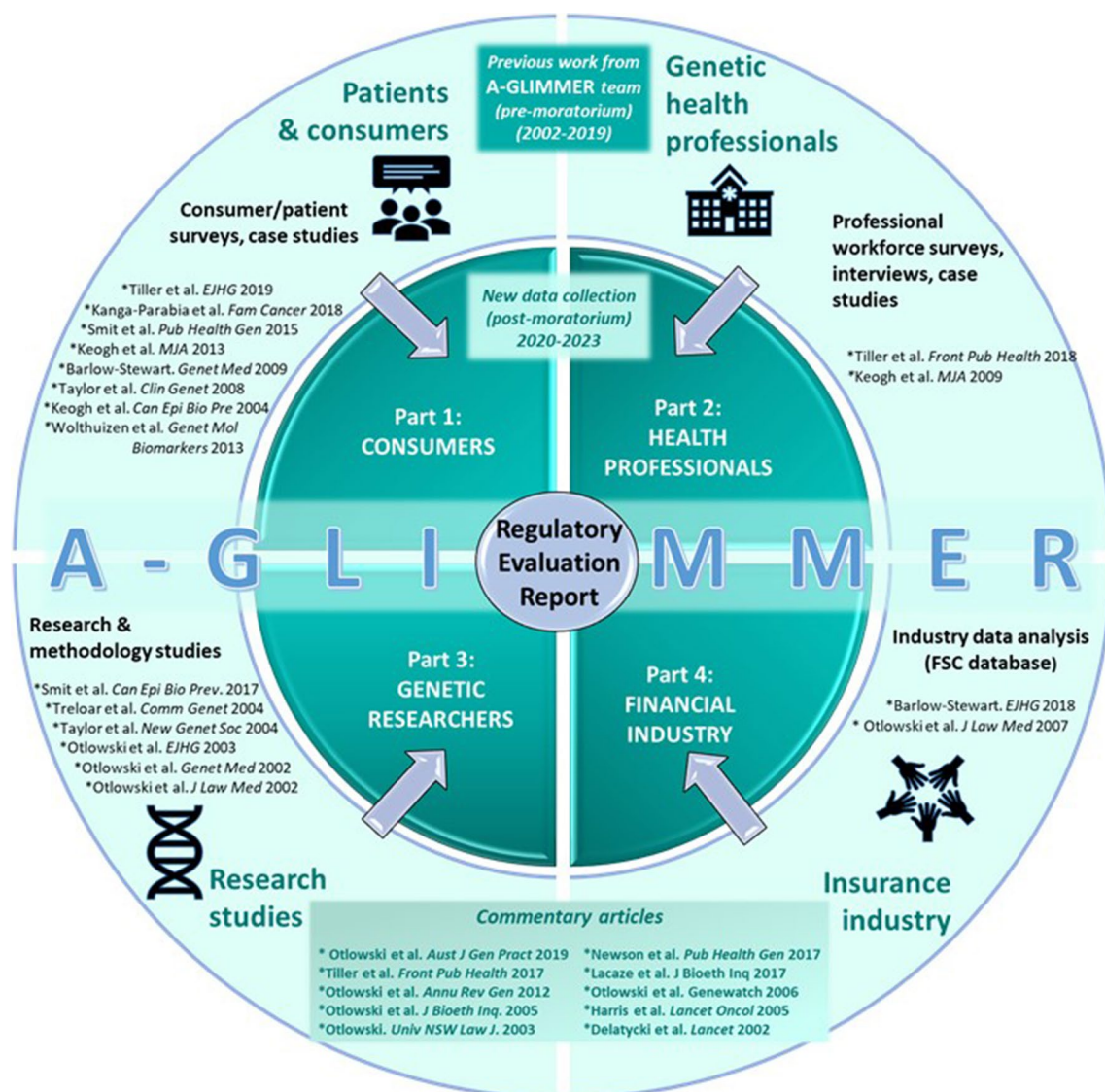


Fig. 3 Summary of A-GLIMMER project (image created by authors)

- **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 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

Acknowledgements

We would like to thank our many project partners, who have provided formal letters of support and otherwise supported our project, including Pink Hope; Lynch Syndrome Australia; Familial Hypercholesterolemia Network Australia; Rare Cancers Australia; Genetic Undiagnosed And Rare Disease Network; Rare Voices; Genetic Support Network of Victoria; Mito Foundation; Cancer Council

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.

Funding

The project is supported by a grant from the Australian government's Medical Research Future Fund (MRFF), ref 76721. The funder is not involved in designing aspects of the study, but the study proposal underwent competitive peer review through a formal tender process with the Australian government and was selected for funding. PL is supported by a National Heart Foundation Future Leader Fellowship. AML is funded by a National Health and Medical Research Council (NHMRC) Early Career Fellowship (ID 1158111).

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.

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Received: 11 February 2021 Accepted: 12 May 2021

Published online: 21 May 2021

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6 Appendix VI – First Health Professionals’ Study

Original research

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

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► Additional supplemental material is published online only. To view, please visit the journal online (<http://dx.doi.org/10.1136/jmedgenet-2021-107989>).

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Received 25 May 2021

Accepted 4 September 2021

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.

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

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



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To cite: Tiller JM, Keogh LA, McInerney-Leo AM, et al. *J Med Genet* Epub ahead of print: [please include Day Month Year]. doi:10.1136/jmedgenet-2021-107989

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 review²¹ 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 20²⁶ and the FSC insurance and genetics moratorium fact sheet²⁷—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 1 July 2019 and a moratorium was introduced on the use of genetic testing in life insurance underwriting? (n=166)	No Yes	3/121 (2) 118/121 (98)	21/45 (47) 24/45 (53)	24/166 (14) 142/166 (86)
(if yes) How did you become aware? (n=142) * more than one option could be selected	My health service A news source HGSA Insurance industry	64/118 (54) 12/118 (10) 96/118 (81) 4/118 (3)	7/24 (29) 10/24 (42) 4/24 (17) 0/24 (0)	71/142 (50) 22/142 (15) 100/142 (70) 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 Yes, information sessions No	7/121 (6) 60/121 (49) 54/121 (45)	0/45 (0) 3/45 (7) 42/45 (93)	7/166 (4) 63/166 (38) 96/166 (58)
How well do you feel you now understand insurance implications for individuals undergoing genetic testing? (n=166)	Extremely well Reasonably well Not particularly well Not well at all	12/121 (10) 89/121 (74) 17/121 (14) 3/121 (2)	0/45 (0) 17/45 (38) 17/45 (38) 11/45 (24)	12/166 (7) 106/166 (64) 34/166 (20) 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 No	98/121 (81) 23/121 (19)	16/45 (36) 29/45 (64)	114/166 (69) 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 I am aware of it, but have not yet read it I am not aware of it	49/117 (42) 42/117 (36) 26/117 (22)	9/42 (21) 13/42 (31) 20/42 (48)	58/158 (37) 55/158 (35) 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 I am aware of it, but have not yet read it I am not aware of it	79/117 (68) 17/117 (15) 21/117 (18)	7/42 (17) 6/42 (14) 28/42 (67)	86/158 (54) 23/158 (15) 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 I am aware of it, but have not yet read it I am not aware of it	29/117 (25) 42/117 (36) 46/117 (39)	6/42 (14) 7/42 (17) 28/42 (67)	35/158 (22) 49/158 (31) 74/158 (47)
	The FSC fact sheet on the life insurance moratorium I am aware of it and I have read it I am aware of it, but have not yet read it I am not aware of it	51/117 (44) 18/117 (15) 48/117 (41)	11/42 (26) 2/42 (5) 28/42 (67)	62/158 (39) 20/158 (13) 76/158 (48)
Number of knowledge questions answered correctly (n=146) (for question-specific data see online supplemental table S2)	0 1 2	1/110 (1) 0/110 (0) 1/110 (1)	4/36 (11) 5/36 (14) 4/36 (11)	5/146 (3) 5/146 (3) 5/146 (3)
Mean score (genetics HPs): 4.5 Mean score (non-genetics HPs): 3.1	3 4 5 6	14/110 (13) 34/110 (31) 41/110 (37) 19/110 (17)	7/36 (19) 5/36 (14) 7/36 (19) 4/36 (11)	21/146 (14) 39/146 (27) 48/146 (33) 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 introduction¹⁸ 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.

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 Non-discrimination Act* (2017) (GNDA), which prevents insurers from using genetic test results, and the US' *Genetic Information Non-discrimination 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 Insurance³¹) 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

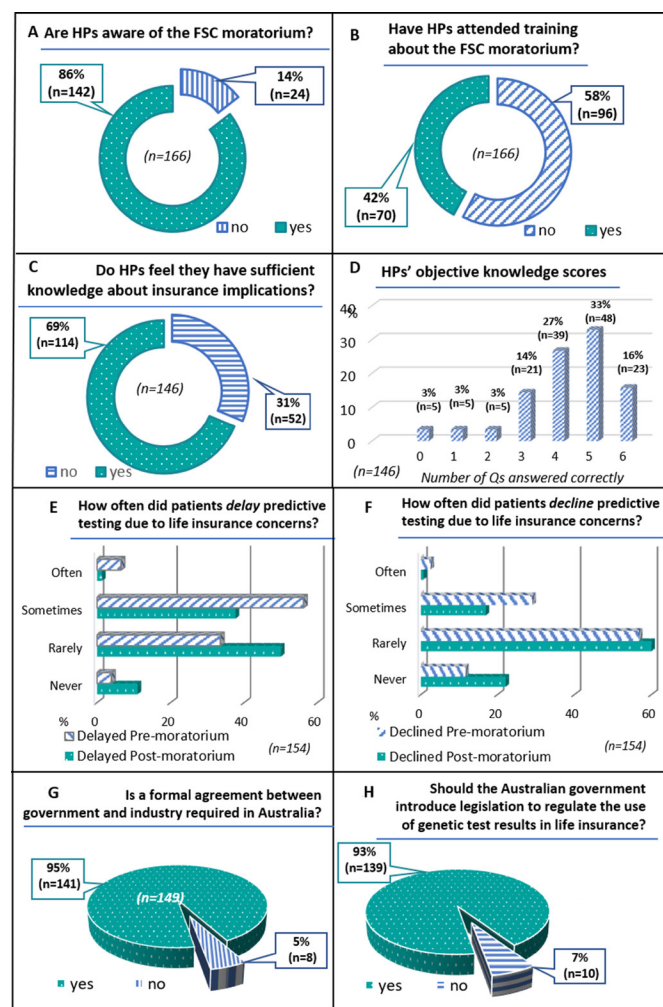


Figure 1 A–H: Awareness, knowledge, training, patient impact and views on regulation. FSC, Financial Services Council; HPs, health professionals.

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)	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)	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)
	Never	1/121 (1)	5/45 (11)	6/154 (4)
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	41/121 (34)	11/45 (24)	52/154 (34)
	Rarely	68/121 (56)	19/45 (42)	87/154 (56)
	Sometimes	5/121 (4)	5/45 (11)	10/154 (6)
	Often	12/121 (10)	5/45 (11)	17/154 (11)
	Never	62/121 (51)	15/45 (33)	77/154 (50)
	Rarely	40/121 (33)	18/45 (40)	58/154 (38)
	Sometimes	0/121 (0)	2/45 (4)	2/154 (1)
	Often	47/121 (39)	14/45 (31)	61/154 (40)
	Never	60/121 (49)	16/45 (36)	76/154 (49)
	Rarely	7/121 (6)	5/45 (11)	12/154 (8)
	Sometimes	0/121 (0)	5/45 (11)	5/154 (3)
	Often	11/121 (9)	7 (16)	17/154 (11)
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	76/121 (63)	12/45 (27)	77/154 (50)
	Rarely	26/121 (21)	19/45 (42)	58/154 (38)
	Sometimes	2/121 (2)	2/45 (4)	2/154 (1)
	Often	28/121 (23)	9/45 (13)	34/154 (22)
	Never	75/121 (62)	18/45 (40)	93/154 (60)
	Rarely	11/121 (9)	15/45 (33)	26/154 (17)
	Sometimes	0/121 (0)	1/45 (2)	1/154 (1)
	Often	56/121 (46)	16/45 (36)	72/154 (47)
	Never	50/121 (41)	14/45 (31)	64/154 (42)
	Rarely	8/121 (7)	8/45 (18)	16/154 (10)
	Sometimes	0/121 (0)	2/45 (4)	2/154 (1)
	Often	3/114 (3)	37/39 (95)	148/153 (97)
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	11/114 (97)	37/39 (95)	148/153 (97)
	No	3/114 (3)	2/45 (4)	5/153 (3)

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 Agree Disagree Strongly disagree	0/113 (0) 89/110 (81) 18/110 (16) 3/110 (3)	0/145 (0) 116/145 (80) 24/145 (17) 5/145 (3)
	The moratorium is easy to explain to patients (n=144)	Strongly agree Agree Disagree Strongly disagree	1/110 (1) 80/109 (73) 25/109 (23) 3/109 (3)	1/144 (1) 108/144 (75) 30/144 (21) 5/144 (3)
	Patients are less confused than they used to be about insurance implications of genetic testing (n=144)	Strongly agree Agree Disagree Strongly disagree	5/109 (5) 51/109 (47) 49/109 (45) 4/109 (4)	5/144 (3) 68/144 (47) 66/144 (46) 5/144 (3)
	Patients are more willing to have predictive genetic testing than they were before the moratorium was introduced (n=144)	Strongly agree Agree Disagree Strongly disagree	6/109 (5) 60/109 (55) 39/109 (36) 4/109 (4)	6/144 (4) 79/144 (55) 54/144 (38) 5/144 (3)
	The moratorium has resolved some concerns I had about insurance discrimination (n=144)	Strongly agree Agree Disagree Strongly disagree	5/109 (5) 82/109 (75) 21/109 (19) 1/109 (1)	7/144 (5) 103/144 (72) 31/144 (22) 3/144 (2)
	After the introduction of the moratorium, I still have concerns about insurance discrimination (n=144)	Strongly agree Agree Disagree Strongly disagree	22/109 (20) 76/109 (70) 9/109 (8) 2/109 (2)	26/144 (18) 101/144 (70) 13/144 (9) 4/144 (3)
	Consumers are better protected post-moratorium than they were before the moratorium was introduced (n=144)	Strongly agree Agree Disagree Strongly disagree	18/109 (16) 84/109 (77) 7/109 (6) 0/109 (0)	20/144 (14) 114/144 (79) 10/144 (7) 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 Somewhat satisfied Somewhat dissatisfied Very dissatisfied	6/113 (5) 52/113 (46) 49/113 (46) 6/113 (5)	6/149 (4) 70/149 (47) 61/149 (41) 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) Regulation through legally enforceable rules Other	16/113 (14) 102/113 (90) 2/113 (2)	20/149 (13) 131/149 (88) 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 No	108/113 (96) 5/113 (4)	141/149 (95) 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)	<i>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.</i> <i>It's a step in the right direction and patients with minor concerns/reliance feel reassured.</i>	P21 (GC, 10–15 y) P108 (GC, 0–5 y)
Some protection provided	19 (31)	<i>Provides at least some level of insurance that may not have been available at all previously.</i> <i>People can access some level of insurance without the threat of discrimination based on their genetic test result.</i>	P42 (GC, 10–15 y) P199 (GC, 0–5 y)
Increased clarity	9 (15)	<i>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.</i>	P129 (GC, 0–5 y)
Family implications	6 (10)	<i>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.</i>	P136 (GC, 0–5 y)
Heightened awareness/ recognition of issue	5 (8)	<i>More awareness of the issue, hopefully future stronger protections for patients depending on how effective the moratorium can be shown to be currently.</i>	P130 (GC, 6–10 y)
'Step in the right direction'	3 (5)	<i>It is a step in the right direction but insurance concerns are still present for many patients and providers.</i>	P108 (GC, 0–5 y)
Provides time	2 (3)	<i>Gives time to find better solution.</i>	P98 (GC, 15–20 y)
Limitation (n=64)	n (%)		
Insurer compliance/self-regulation	29 (45)	<i>It would be better if there was NO discrimination at all, that was made law and insurance companies held accountable (not self-regulated).</i> <i>It is self-regulated and not legally enforceable, so only as good as the trust in the industry generally.</i>	P129 (GC, 0–5 y) P89 (GC, 0–5 y)
Financial limits	28 (44)	<i>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.</i> <i>The amounts are too low and won't give enough reassurance to some.</i>	P229 (CG 15–20 y) P135 (CG >20 y)
Temporary nature of moratorium	17 (27)	<i>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.</i> <i>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.</i>	P149 (GC 15–20 y) P173 (GC, 0–5 y)
Restricted application	8 (13)	<i>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.</i>	P42 (GC, 11–15 y)
Travel insurance not covered	3 (5)	<i>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.</i>	P195 (GC, 15–20 y)
Lack of dissemination	2 (3)	<i>Many financial advisors and workers in the industry seem unaware of the moratorium.</i>	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

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 regulations³⁵ 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

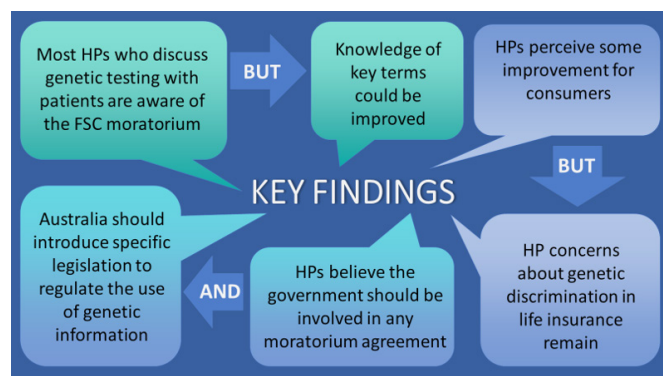


Figure 2 Summary of study findings. FSC, Financial Services Council; HPs, health professionals.

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 testing²⁸ 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 Project²³ 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.

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Funding The project is supported by a grant from the Australian Government's Medical Research Future Fund (MRFF), ref 76 721. AMM-L is funded by a National Health and Medical Research Council (NHMRC) Early Career Fellowship (ID 1158111). PL is supported by a National Heart Foundation Future Leader Fellowship (ID 102604).

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.

Data availability statement Data are available upon reasonable request. All data relevant to the study are included in the article or uploaded as supplementary information.

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7 Appendix VII – Second Health Professionals’ Study

ARTICLE OPEN



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

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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.

European Journal of Human Genetics; <https://doi.org/10.1038/s41431-022-01150-6>

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

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Received: 2 March 2022 Revised: 22 June 2022 Accepted: 4 July 2022

Published online: 28 July 2022

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.

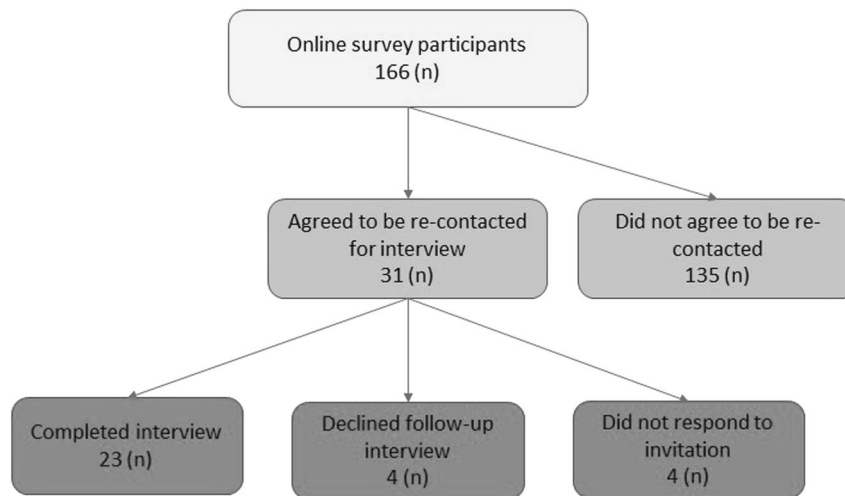


Fig. 1 Recruitment outcomes for qualitative interviews.

Table 1. Participant Demographics.

	Number of participants interviewed <i>n</i> = 23	
	<i>n</i> = 23	<i>n</i> (%)
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

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

genetic test results.” (ID 13, certified genetic counsellor, 6–10 years’ experience)

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 policies 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.

FUNDING

The project is supported by a grant from the Australian Government's Medical Research Future Fund (MRFF), ref 76721. AML is funded by a National Health and Medical Research Council (NHMRC) Early Career Fellowship (ID 1158111). PL is supported by a National Heart Foundation Future Leader Fellowship (ID 102604). Open Access funding enabled and organized by CAUL and its Member Institutions.

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>.

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8 Appendix VIII – First Consumer Study: Patient Survey Study

ARTICLE OPEN



Community concerns about genetic discrimination in life insurance persist in Australia: A survey of consumers offered genetic testing

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Fears of genetic discrimination in life insurance continue to deter some Australians from genetic testing. In July 2019, the life insurance industry introduced a partial, self-regulated moratorium restricting the use of genetic results in underwriting, applicable to policies up to certain limits (eg AUD\$500,000 for death cover).

We administered an online survey to consumers who had taken, or been offered, clinical genetic testing for adult-onset conditions, to gather views and experiences about the moratorium and the use of genetic results in life insurance, including its regulation.

Most respondents ($n = 367$) had undertaken a genetic test (89%), and had a positive test result (76%; $n = 243/321$). Almost 30% ($n = 94/326$) reported testing after 1 July 2019. Relatively few respondents reported knowing about the moratorium (16%; $n = 54/340$) or that use of genetic results in life insurance underwriting is legal (17%; $n = 60/348$). Only 4% ($n = 14/350$) consider this practice should be allowed. Some respondents reported ongoing difficulties accessing life insurance products, even after the moratorium. Further, discrimination concerns continue to affect some consumers' decision-making about having clinical testing and applying for life insurance products, despite the Moratorium being in place. Most respondents (88%; $n = 298/340$) support the introduction of legislation by the Australian government to regulate this issue.

Despite the introduction of a partial moratorium in Australia, fears of genetic discrimination persist, and continue to deter people from genetic testing. Consumers overwhelmingly consider life insurers should not be allowed to use genetic results in underwriting, and that federal legislation is required to regulate this area.

European Journal of Human Genetics; <https://doi.org/10.1038/s41431-023-01373-1>

INTRODUCTION

The use of genetic test results by life insurance companies in underwriting, and the associated impact on clinical and research outcomes, is a long-standing issue of international concern. Studies have described various ethical, medical and societal concerns with this practice, expressed by members of the public, consumers, and disease support groups [1–11].

In Australia, *private health insurance* is community-rated under the *Private Health Insurance Act 2007* (Cth), meaning genetic test results cannot be used by private health insurers to discriminate against applicants. However, for *life insurance* (including death, disability, trauma and income protection cover), an exception under section 46 of the *Disability Discrimination Act 1992* (Cth)

(DDA) permits life insurance companies to use genetic test results in underwriting, if supported by actuarial data or “other relevant factors” on which it is reasonable to rely. Little judicial consideration has been given to the operation of s46 of the DDA, but the Federal Court of Australia has held (in a context outside of genetics) that “other relevant factors” can only be relied upon to justify discrimination if actuarial or statistical data is not available [12].

Research shows that insurance discrimination fears can deter individuals from having genetic testing [13, 14] and participating in genetic research [15]. Internationally, many countries have banned or restricted life insurance companies from using genetic test results in underwriting – to decline an application, restrict

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cover or increase the cost of premiums [16–18]. For example, the Canadian *Genetic Nondiscrimination Act* (2017) (GNA), prohibits the use of genetic test results in all insurance (among other services), and the US *Genetic Information Nondiscrimination Act* (2008) (GINA) bans the use of genetic test results in health insurance and employment contexts. The UK Code on Genetic Testing and Insurance [19], an agreement between the insurance industry and the UK Government introduced in 2001, bans the use of predictive genetic test results with a single exception - predictive genetic tests for Huntington disease, where the life insurance cover is > £500,000 (~ A\$930,000).

In Australia, a Parliamentary Joint Committee hearing into the life insurance industry recommended a ban on this practice in 2018 [20]. The Australian government has not curtailed life insurers' legal entitlement to use genetic test results under the DDA. However, in 2019 the life insurance industry body, the Financial Services Council (FSC) introduced a partial, self-regulated moratorium for applications up to certain limits, including AUD\$500,000 for death and total permanent disability cover, \$200,000 for trauma cover and AUD\$4000/month for income protection [21]. The moratorium, which prohibits insurers from asking for and from using genetic results up to the prescribed limits, is not subject to any government oversight, and was set to expire in 2024 unless renewed. In October 2022, the FSC indicated that the moratorium would become indefinite when it is incorporated into the FSC Life Code (due to take place in July 2023).

Australian health professionals, involved in obtaining informed consent and explaining the implications of genetic testing to patients, have previously [22] reported concerns with life insurance discrimination related to genetic testing. These studies suggest some Australians are still declining or delaying clinical genetic testing, and some may not attend genetics clinics at all, due to fears about potential insurance discrimination. Despite the introduction of the FSC moratorium, health professionals remain concerned about the ongoing deterrent effect of genetic discrimination in Australia, and the lack of government regulation [23].

Genetic discrimination in insurance underwriting has had an impact on consumers internationally [24]. Historical experiences of discrimination reported by consumers include perceived coercion regarding genetic testing in order to obtain insurance [25]; unaffected relatives of individuals with genetic conditions reporting difficulty obtaining insurance, in some cases even with genetic results showing they do not have the familial pathogenic variant [26, 27]; and unaffected individuals with pathogenic variants whose risk-reducing measures are not considered [3, 28–31]. We previously surveyed Australian consumers, before the introduction of the FSC moratorium, to gauge their views about and experiences of genetic discrimination [32]. We found numerous instances of consumers reporting difficulties accessing life insurance products, including thirty-two individuals with no history of the relevant disease, who had undertaken risk-reducing measures.

The Australian Genetics and Life Insurance Moratorium: Monitoring the Effectiveness and Response (A-GLIMMER) study [33] was funded by the Australian Medical Research Future Fund Genomics Health Futures Mission in 2020 to monitor the effectiveness of the FSC moratorium by conducting research with four different stakeholder groups - consumers, health professionals, researchers and the financial services industry [24]. The present study was designed to ascertain updated views and experiences of Australian consumers who have had, or been offered, genetic testing for adult-onset conditions. The study was limited to adult-onset conditions because different considerations arise in the context of *predictive testing* of unaffected individuals for genetic risk of future disease, compared with *diagnostic testing* of individuals who already have symptoms or clinical diagnosis of

disease. The FSC moratorium clearly indicates that it can use disease diagnoses (whether diagnosed through clinical or genotyping testing) as a basis for discrimination, but that the moratorium applies to predictive genetic tests in applications below the financial limits. The moratorium protections do not apply to individuals with childhood-onset disease, who have already received a diagnosis by the time they apply for life insurance in adulthood.

METHODS

Population and recruitment

The A-GLIMMER project protocol has been published previously [24]. This study was part of the consumer arm of the A-GLIMMER project, and its population of interest included Australians, over the age of 18, with or without life insurance products, who met the definition of either a “genetic tester”, “pre-tester” or “decliner”.

Genetic testers	Individuals (affected or unaffected) who have already had a genetic test and received a genetic test result. This could be positive (unfavourable) or negative (favourable). Results may have been received prior to or following the introduction of the moratorium
Pre-testers	Individuals (affected or unaffected) who are eligible for and are actively considering having a genetic test
Decliners	Individuals who are eligible for but have chosen not to have a genetic test

Eligibility was established through screening questions at the beginning of the questionnaire, and defined as “Australians who have had, or are eligible for, a genetic test for a gene change that increases the chance of developing disease (either before or after developing symptoms of disease)”. This included predictive genetic testing, but excluded pre-conception carrier screening or prenatal testing. For the purposes of our study, respondents were included (considered eligible for a genetic test) if they had undertaken or been offered such a test, or their first-degree blood relative (sibling, parent or child) had undertaken such a test.

A range of targeted recruitment strategies were adopted to capture a broad sample, which included:

- Newsletters and email invitations to members of patient support and advocacy groups, including Lynch Syndrome Australia, Pink Hope, Mito Foundation, Breast Cancer Network Australia, Familial Hypercholesterolemia Network Australia, Australian Genetic Heart Disease Registry, Australian Genomics Consumer Advisory Group, and Rare Voices Australia;
- Social media advertisements;
- Newsletters emailed directly to members of the Human Genetics Society of Australasia (HGSA) and the Australian Genomics Health Alliance; and
- Snowball sampling.

Recruitment took place between October 2021 and February 2022. Following the online survey, respondents were invited to consent to future contact. Contact details were not collected if respondents preferred to remain anonymous.

Survey development and data collection

We developed an online survey (see Supplementary Materials S1) using REDCap software [34].

The survey was adapted from our previous survey, that was administered before the introduction of the FSC moratorium [32]. The previous survey had been developed in partnership with consumer groups Lynch Syndrome Australia (LSA) and Pink Hope (PH). It was designed to collect data from respondents who had had genetic testing for genes associated only with Lynch syndrome or Hereditary Breast and Ovarian Cancer (HBOC). The current survey expands beyond this, collecting data from individuals *considering* having genetic testing (*pre-testers*), and who had decided not to have genetic testing (*decliners*), to help identify reasons for declining testing. Further, we broadened the survey's scope to include

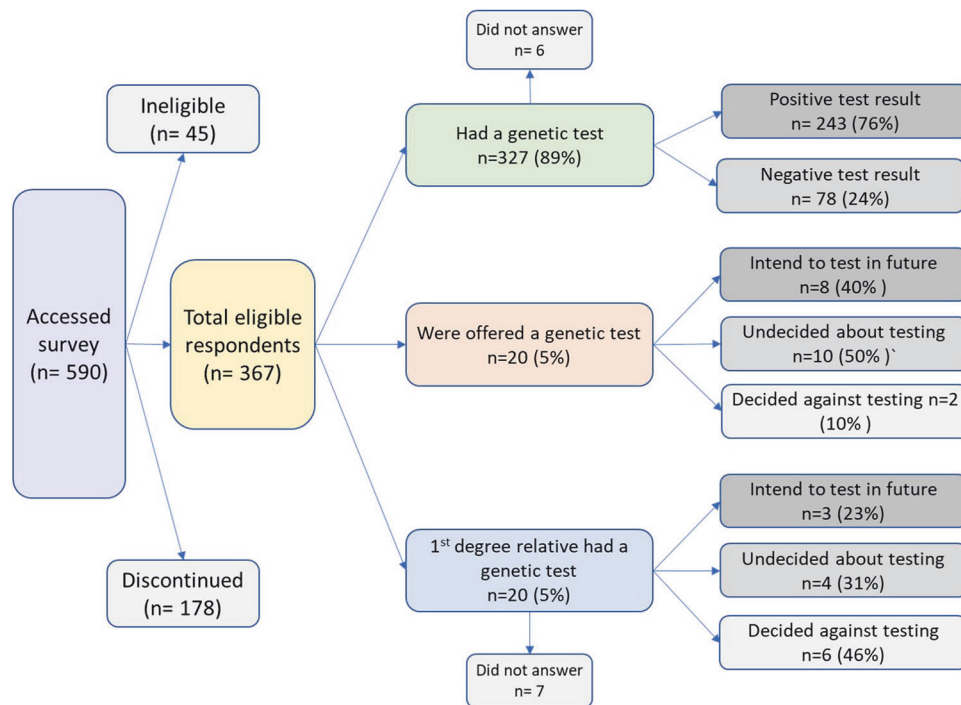


Fig. 1 Characteristics of eligible respondents.

testing for any gene change that increases the chance of developing disease. We also engaged a broader range of project partners (e.g., Rare Voices Australia, Australian Genomics, Familial Hypercholesterolaemia Network Australasia, Mito Foundation, Breast Cancer Network Australia, Rare Cancers Australia and the Australian Genetic Heart Disease Registry), in addition to LSA and PH. These groups helped design the new survey so it was relevant for a range of various conditions.

New questions were also introduced to assess levels of understanding of the moratorium, impact of the moratorium on decision-making and experiences with accessing life insurance products. Information about the terms of the moratorium was provided, before asking participants to rate key aspects as positive, neutral or negative (see Supplementary file S1, p14). We worked with a team of clinical and policy members to develop custom questions as validated scales were not available due to the recency of the FSC moratorium. Data were collected through closed-ended responses using nominal and fixed alternative options, with several open-ended questions where free text was allowed. The survey was piloted by clinicians and representatives from our partner consumer groups, and feedback used to refine survey wording.

Data analysis

Quality control and descriptive analysis of the data were conducted using R 4.0.4 [35], with figures produced using ggplot2 [36]. Participants who provided their year of birth (optional) were divided into three age groups (18–39, 40–65, and 65+), to enable sub-group analysis for certain questions.

For some questions, respondents could use free text to provide further comments. Where applicable, these free-text fields have been categorised and reported, to provide additional richness to the quantitative data.

RESULTS

Overall, 367 individuals progressed through the eligibility questions and answered at least one substantive survey question, of 590 who initially accessed the survey (Fig. 1). The majority (89%; $n = 327/367$) had undertaken genetic testing (*genetic testers*), and of those who answered, 76% ($n = 243/321$) received a positive test result. Demographic characteristics of the respondents are summarised in Table 1. Demographic questions were answered at the end of the survey, and not all respondents answered all questions. Thus, n values are provided for each result reported. A

range of genetic conditions was represented, with ~12–15% of respondents reporting testing associated with each of HBOC, cardiovascular disease, Lynch syndrome, mitochondrial disease, and haemochromatosis. Almost 30% ($n = 94/326$) reported having genetic testing after the moratorium came into effect on 1 July 2019.

Knowledge and awareness

Most respondents (74%; $n = 256/348$) reported not knowing whether Australian life insurance companies are legally allowed to use genetic test results in underwriting, and 9% incorrectly believed they are not allowed to (Table 2). Further, 84% ($n = 286/340$) had never heard of the FSC moratorium.

Use of genetic test results and regulation of insurers

A small number of respondents (4%; $n = 14/350$) said life insurance companies **should** be allowed to use genetic test results to decline an application, restrict cover or increase the cost of premiums. However, the majority (82%; $n = 288/350$) said life insurance companies **should not** be allowed to (Table 2). Further, 73% ($n = 219/300$) rated the fact that *compliance with the agreement is self-regulated by the insurance industry without government oversight* as a negative aspect of the FSC moratorium, and only 7% rated it positive (Fig. 2 and Table S2). The fact that *the agreement is not permanent* was rated as a negative aspect by 76% (228/302) of respondents (only 3% rated it positive). When asked about regulation of the use of genetic test results in life insurance underwriting, 88% of respondents agreed or strongly agreed that government should introduce legislation ($n = 298/340$); only 3% (9/340) disagreed (Table 2).

Financial limits of the FSC moratorium

Overall, 77% of respondents ($n = 234/305$) rated the fact that *people don't have to disclose genetic test results under certain financial limits* as a positive aspect of the FSC moratorium (Fig. 2; Table S2). When asked about what amount of life insurance cover applicants should be allowed to apply for without being required to disclose their genetic results, only 16% ($n = 54/341$) considered \$500,000 or less was appropriate (Table 2). The majority (66%;

Table 1. Demographic characteristics of respondents.

Demographic characteristics	n	%
Sex (n = 300)		
Female	205	68.3
Male	93	31.0
Other/prefer not to say	2	0.7
Age Group (n = 298)		
18–39	66	22.1
40–64	154	51.7
65 +	78	26.2
Timing of test (n = 326)		
Before 1 July 2019	232	71.2
On or after 1 July 2019	94	28.8
State/Territory (n = 301)		
Australian Capital Territory	14	4.7
New South Wales	75	24.9
Northern Territory	1	0.3
Queensland	64	21.3
South Australia	31	10.3
Tasmania	9	3.0
Victoria	74	24.6
Western Australia	33	11.0
Highest level of education attained (n = 300)		
Some high school	26	8.7
Grade 12 equivalent/TAFE	76	25.3
Undergraduate qualification	76	25.3
Post-graduate qualification	111	37.0
Prefer not to say	11	3.7
Conditions represented (n = 367)		
Lynch syndrome (bowel/uterine/other cancer) genes	58	15.8
Inherited cardiovascular disorder genes	57	15.5
Genes related to mitochondrial disease	55	15.0
Hereditary breast/ovarian cancer genes	53	14.4
Haemochromatosis	44	12.0
Genes related to neurodegenerative disease	17	4.6
Genes related to kidney disease	15	4.1
Peutz-Jeghers syndrome	4	1.1
Other	45	12.3
Don't know	19	5.2

$n = 226/341$) considered the amount of cover should be $\geq \$1$ million, with 64% of those ($n = 145/226$) stating the amount should be unlimited. One respondent described the FSC moratorium in free-text comments as a “tokenistic offering” by insurance companies, explaining, “the vast majority of people applying for these insurances will have mortgages above that value. It does not cover basic needs”.

Access to insurance and the FSC moratorium’s influence on decision-making about genetic testing

Table 3 sets out findings relating to what type of life insurance cover respondents hold, when they obtained that cover, and difficulties with accessing cover. We asked respondents to distinguish between cover held within superannuation (either basic cover or extended cover) or outside superannuation, and obtained before or after the genetic test was undertaken. In

Australia, superannuation refers to compulsory employer contributions to employees’ retirement funds. Superannuation funds generally offer a low level of cover for life insurance products without undertaking risk assessment (basic cover), but increasing this cover (extended cover) usually requires risk assessment. The amount of cover offered under “basic cover” varies between superannuation companies. In 2017, the median level of life insurance cover held by working Australians was estimated to be A\$143,000, most of which was held through superannuation accounts [37].

Across each category of cover (death, total and permanent disability (TPD), income protection, and trauma/critical illness) around half of respondents reported that they had no cover. Overall, 42% who answered ($n = 89/212$) reported having **no** cover in any category. Of those who had insurance and reported their type of cover, most reported already having the cover in place before having genetic testing, or only obtaining basic cover within superannuation (70%; $n = 77/110$). Only 11% ($n = 12/110$) of those who reported having insurance obtained cover (other than basic cover within superannuation) after their genetic test.

Of 284 respondents, almost half ($n = 133$) reported they had never tried to apply for, or made enquiries about, life insurance products (Fig. 3). Of those, over a quarter (26%; $n = 34/131$) said genetic discrimination concerns had a moderate or significant influence on their decision not to apply for life insurance. Of those who may have tried to apply for life insurance products (ie they did not report that they had never tried to apply), over a third ($n = 53/151$) reported difficulties, including insurers rejecting applications; financial advisers telling respondents that their applications would be rejected; and insurers placing conditions on insurance policies or charging higher premiums. Types of insurance affected (more than one answer could be selected) were death cover ($n = 38/51$), TPD cover ($n = 21/51$), income protection ($n = 22/51$), and trauma/critical illness cover ($n = 12/51$). Of those who answered, 24% ($n = 12/51$) reported this difficulty happening after the introduction of the FSC moratorium on 1 July 2019. Details of those twelve are provided in Supplementary Table S3.

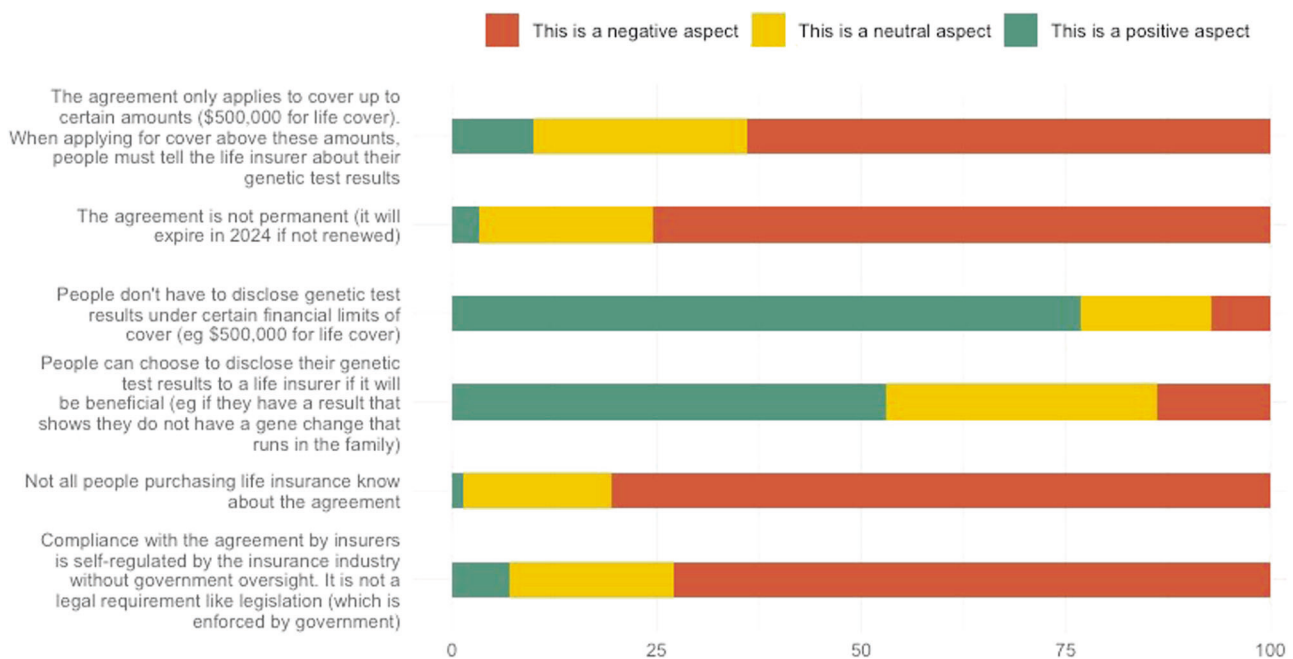
Some respondents reported discrimination even after taking preventive measures, exemplified by “Shona” (a pseudonym), a 43 year old woman with a *BRCA2* variant and family but no personal history of cancer (Table S3). Despite having her ovaries and fallopian tubes removed, and regular intensive breast imaging (mammogram/MRI/ultrasound), she was denied life insurance (death cover) outright with no justification or explanation from the insurer.

When those who had heard about the FSC moratorium were asked to what extent it influenced their decision whether to have a genetic test, the majority stated that it did not have an influence (78%; $n = 42/54$), with the remaining 22% saying it had a moderate/significant influence (Table 2). Half of the respondents who had decided against, or had not yet had, genetic testing reported that concerns about life insurance had a moderate/significant effect on their decision making (50%; $n = 7/14$). One respondent reported in free text that he decided not to have testing because of life insurance issues “such as exclusions or increased premiums that may arise because of the test”. He said, “at the moment it is better to be in the dark”. Two individuals who were undecided about having testing also provided more detail in free text comments – one mentioned the uncertainty about whether the moratorium would continue past 2024, and the other stated they wanted to discuss the life insurance situation with family members before deciding about testing.

Ten individuals provided free-text comments at the end of the survey – seven reported having positive tests for pathogenic variants, two were undecided about testing, and one was intending to have testing. Of those who had positive tests, two mentioned frustration that insurers chose to discriminate rather than encouraging individuals to be proactive or take risk-reducing

Table 2. Awareness of moratorium and opinions about regulation.

Question	Answer options	%	n
Do you know whether Australian life insurance companies are legally allowed to use applicants' genetic test results to decline an application, restrict cover or increase the cost of premiums? (n = 348)	They are allowed to	17.1	60
	They are not allowed to	9.2	32
	I am unsure	73.6	256
<i>[after the moratorium agreement is described]</i> Have you heard about this agreement (called a moratorium)? (n = 340)	No	84.1	286
	Yes, I heard about this through the team that organised my genetic test	5.0	17
	Yes, I heard about this elsewhere	10.9	37
<i>[if yes], To what extent did the agreement described above (the moratorium) influence your decision whether to have a genetic test?</i> (n = 54)	It did not have any influence	77.8	42
	It had moderate influence	9.3	5
	It had significant influence	13.0	7
Do you think life insurance companies should be allowed to use applicants' genetic test results to decline an application, restrict cover or increase the cost of premiums? (n = 350)	Yes	4.0	14
	No	82.3	288
	Unsure	13.7	48
In your opinion, what amount of life insurance cover (death cover) should applicants be allowed to apply for without having to disclose their genetic results? (n = 341)	No cover	0.9	3
	\$250,000	3.2	11
	\$500,000	11.7	40
	\$1,000,000	17.9	61
	Unlimited cover	42.5	145
	Unsure	23.8	81
How much do you agree/disagree with the following statement? The Australian government should introduce legislation (which is made and enforced by government) to regulate life insurers' use of genetic test results (n = 340)	Strongly agree	62.4	212
	Agree	25.3	86
	Neither agree nor disagree	5.6	19
	Disagree	1.2	4
	Strongly disagree	1.5	5
	Can't choose	4.1	14

**Fig. 2** Respondents' rating of aspects of the FSC moratorium.

measures. One participant stated, "if I'm aware of my genetic condition and keep up with my screening, I don't think I should be discriminated against. I should be rewarded for being proactive".

Six respondents outlined concerns about future life insurance discrimination for people who have genetic testing or their family members. One participant stated, "I continue to be worried for my relatives. It has caused family members to hold off on very important

Table 3. Life insurance cover held by respondents and difficulties accessing cover.

Do you hold the following types of cover?			
Life insurance (death cover) (n = 211)		%	n
Yes 46.4% (n = 98)	Basic cover through superannuation	38.0	35/92
	Extended cover through superannuation	22.8	21/92
	Cover outside of super (obtained before genetic test)	29.3	27/92
	Cover outside of super (obtained after genetic test)	9.8	9/92
No cover		48.3	102
Unsure		3.3	7
Prefer not to say		1.9	4
Total and permanent disability (TPD) cover (n = 204)			
Yes 41.7% (n = 85)	Basic cover through superannuation	50.0	40/80
	Extended cover through superannuation	23.8	19/80
	Cover outside of super (obtained before genetic test)	18.8	15/80
	Cover outside of super (obtained after genetic test)	17.5	6/80
No cover		51.5	105
Unsure		4.9	10
Prefer not to say		2.0	4
Income protection/ salary continuance cover (n = 196)			
Yes 33.2% (n = 65)	Basic cover through superannuation	47.5	29/61
	Extended cover through superannuation	21.3	13/61
	Cover outside of super (obtained before genetic test)	24.6	15/61
	Cover outside of super (obtained after genetic test)	6.6	4/61
No cover		63.3	124
Unsure		2.0	4
Prefer not to say		1.5	3
Trauma and/ or critical illness cover (n = 193)			
Yes 21.2% (n = 41)	Basic cover through superannuation	29.7	11/37
	Extended cover through superannuation	16.2	6/37
	Cover outside of super (obtained before genetic test)	45.9	17/37
	Cover outside of super (obtained after genetic test)	8.1	3/37
No cover		67.9	131
Unsure		9.3	18
Prefer not to say		1.6	3
Have you ever had difficulty obtaining life (death cover), TPD, income protection or trauma/critical illness cover, based on your genetic test results? (n = 284)			
Yes* 19.0% (n = 53)	Yes, I have had cover denied	8.1	23
	Yes, I have had a financial adviser tell me that I would not be able to get insurance	4.9	14
	Yes, I have had an increased premium applied	4.6	13
	Yes, I have had certain conditions placed on my cover	6.7	19
No difficulties		35.9	102
I have never tried to apply for, or made enquiries about, life insurance products		46.8	133
<i>If yes to never trying to apply/ Did concerns about genetic discrimination influence your decision not to apply for life insurance products? (n = 131)</i>			
This did not have any influence		74.0	97
This had moderate influence		11.5	15
This had significant influence		15.4	19

Bold values show individuals with no cover.

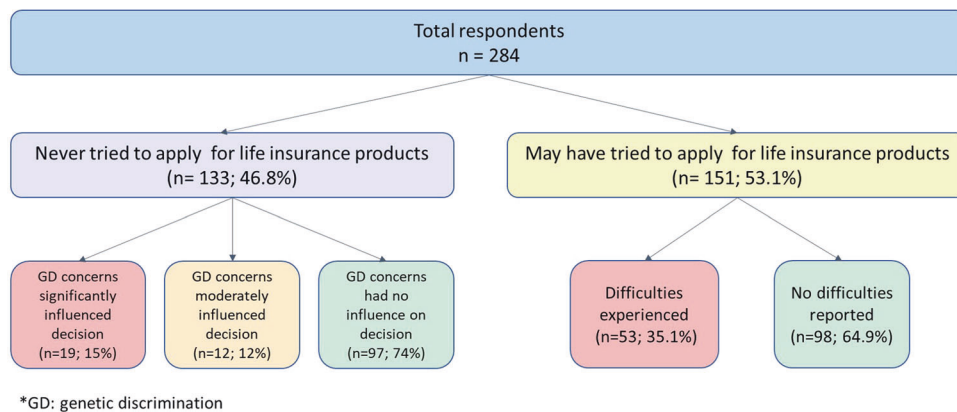


Fig. 3 Decision-making about and difficulties experienced in applying for life insurance products.

gene testing". One respondent with a family history of Lynch syndrome reported that they had been intending to have testing, and although they had trauma cover already, they had not had testing yet because they wanted to obtain new cover with a different insurer before proceeding with testing. They reported that an underwriter informed them that the insurer would not cover them without being told about their genetic test results once they had them, and so this process was continuing to hold up their decision to proceed with testing.

DISCUSSION

Overwhelmingly, our findings demonstrate ongoing consumer concerns about genetic discrimination in life insurance, by people having or considering genetic testing. They also show low awareness about the legality of this practice, or the existence of the FSC moratorium. Our study presents further evidence of ongoing consumer difficulties accessing life insurance products, despite the FSC moratorium being in place. Most respondents (88%) had a strong view that government regulation is required in this area.

Respondents' awareness regarding the use of genetic test results by life insurers was limited, with less than 20% being aware that the practice is legal, or that the FSC moratorium exists. This lack of awareness regarding the legal status of genetic discrimination is reflected internationally [38, 39], and was accompanied by an overwhelming view that using genetic test results in life insurance should not be allowed. Further, when information about the terms of the moratorium were provided (see Supplementary file S1, p14), it became clear that consumers did not consider it to be an adequate mechanism for regulating this issue, with a large majority rating the moratorium's temporary nature, industry self-regulation, and low financial limits as negative aspects. Respondents consider that the moratorium's limits are too low, highlighted by comments that the limit is a "tokenistic offering" by the insurance industry, which "does not cover basic needs".

Our findings suggest that the moratorium has provided some modest benefit to consumers, which should be acknowledged. This includes some aspects rated as positive by the majority of participants, such as the fact that *people don't have to disclose genetic test results under certain financial limits and people can choose to disclose their genetic tests to a life insurer if it will be beneficial*. A small minority of those who had heard of the moratorium (13%) stated that it had a significant influence on their decision to have genetic testing, which is a positive outcome. However, the majority (78%) reported it having no influence on their decision-making about having testing. There is a paucity of international research regarding the impact of moratoria or other regulations on decision-making regarding genetic testing. However, a US study showed that participants' hypothetical interest in

participating in genetic research decreased when they were provided with more detailed information about the limitations in protection offered by US genetic non-discrimination legislation [40].

Further, concerns about genetic discrimination are still influencing consumer decision-making regarding genetic testing in Australia, both with regards to having genetic testing and deciding whether to try to access life insurance products. Half of the respondents who had not had testing, and over a quarter of those who had not tried to apply for life insurance products, reported life insurance concerns as having a moderate or significant effect on their decision-making. Similarly, >two-thirds of US study participants asked about interest in genetic testing (in four states where genetic discrimination legislation does not protect life insurance), had concerns about use of genetic test results by life insurance companies [41].

Of particular concern were reports that consumers continue to have difficulty accessing life insurance products, and still experience discrimination based on genetic test results, even after the introduction of the FSC moratorium. Several respondents commented on the failure of insurers to consider preventive measures, and some respondents reported experiencing discrimination even after taking preventive measures. A 1998 study conducted in the UK before the introduction of its moratorium similarly reported instances of unjustified genetic discrimination of individuals who did not present adverse actuarial risk [27]. No studies have reported whether this unjustified discrimination continued after the introduction of the UK moratorium. The ongoing failure to consider preventive measures is not only frustrating for proactive patients seeking to obtain insurance coverage and contrary to the requirements under section 46 of the DDA, but also inconsistent with the life insurance industry's commitment to evidence-based actuarial practice. Taking breast cancer as an example, survival is very high for women whose breast cancer is detected early. The five-year survival of women with breast cancer is now at least 92% [42], almost as high as for those without breast cancer (98% relative survival rate) for early-stage cancers ≤ 10 mm [43]. In *BRCA1/2* carriers, annual imaging significantly reduces the incidence of later stage breast cancers [44]. Thus, for women like our example, "Shona", who had preventive surgery and is having regular intensive breast screening, their likelihood of survival *even if they do develop breast cancer* is very high. However, our findings show Australian life insurance companies still refuse life cover to some such women, on the basis of their genetic test results. Comparatively, if Shona was not aware of her increased genetic predisposition, and did not take preventive steps, her likelihood both of developing cancer and dying from that cancer would be significantly higher.

Our findings also show that some people at risk of having genetic predisposition to medically-actionable conditions

continue to choose not to have genetic testing because of insurance discrimination fears, despite the introduction of the FSC moratorium. This finding is consistent with reports from health professionals who discuss clinically-indicated genetic testing with at-risk individuals [23], who have reported that people continue to delay and decline testing because of insurance fears. Enabling at-risk individuals to have genetic testing without fear of discrimination will increase risk prevention and ultimately decrease the likelihood of insurance claims [45]. This means anti-discrimination regulation is also in the interests of insurers, despite their frequent opposition, and should be supported.

Many respondents reported having no cover across any life insurance products, including a significant number in the 40–64 year old age group. Anecdotal estimates regarding how many Australians hold life insurance vary, but accurate estimates are difficult to obtain. In 2015, the Australian Securities and Investment Commission reported that there were 21.9 million active policies for life insurance products [46]. Many of those (14 million) were group insurance products within superannuation (and it is likely that some individuals with multiple employers may have multiple superannuation accounts and several low-level insurance product policies).

In our study, the majority of those who reported having cover were fortunate to have obtained it before having genetic testing, or only had basic levels of cover through their superannuation. Although having a low level of cover is better than no cover, the median default level of cover within superannuation funds does not adequately cover Australians' financial needs, especially parents with young children [47]. Very few individuals in this study had successfully obtained cover (outside of basic superannuation cover) after receiving their genetic test results. Some individuals reported that although they had not been declined formally by an insurer, their financial adviser told them that they wouldn't be able to obtain cover, highlighting the critical role played by financial advisers in managing access to insurance for individuals with genetic test results.

Our current study builds upon our previous findings from a survey conducted pre-moratorium [31], in which many individuals reported having difficulties accessing life insurance after genetic testing. In the previous survey, numerous individuals reported genetic discrimination by life insurers even after taking preventive measures for hereditary cancer predisposition. Unfortunately, such instances are unlikely to be mitigated by the introduction of the FSC moratorium, which already requires insurers to consider preventive measures but is not enforceable. Only enforceable regulation by government can meaningfully impact insurers' use of genetic information. The current survey was circulated to consumers less than 18 months after the FSC's introduction, which may have limited the number of new instances of discrimination which it captured. However, this research demonstrates that such discrimination is still occurring and will likely continue to occur in the absence of enforceable regulation.

Limitations of our study include responder bias – it is likely that those who are more interested in this topic would have chosen to complete the survey. However, conversely, individuals who are strongly against testing because of discrimination concerns often won't engage with genetics services or be involved in research, meaning that our survey may also have failed to capture many individuals with strong discrimination concerns. Further, because the survey could be completed anonymously, not all respondents who reported experiences of discrimination could be contacted for more information. A separate qualitative study is now underway, which will interview respondents who have agreed to be contacted. A separate survey of the general public has also been undertaken, which will elucidate any relevant differences between the views of the patient population reported in this paper from those of the general Australian public. Further research

is required to document the views of individuals who have decided against genetic testing (decliners), who are difficult to recruit into research studies.

Our study findings demonstrate that, despite the introduction of the FSC moratorium, fears of genetic discrimination persist in Australia, and continue to deter some individuals from having genetic testing. This suggests that the FSC moratorium is not adequately easing insurance discrimination fears for Australian consumers considering genetic testing. Consumers continue to experience genetic discrimination in life insurance, and overwhelmingly believe that life insurers should not be allowed to use genetic test results in underwriting, and that the Australian government should introduce legislation to regulate this area. This study adds to the growing body of evidence that must be considered by the Australian government in determining whether further regulation is now required. Future research should gather views of the Australian public more broadly about this issue. Our findings to date strongly suggest that the current FSC moratorium is not providing Australian consumers with sufficient reassurance and protection, and that the government should consider the implementation of legislation prohibiting the use of genetic test results in life insurance underwriting.

DATA AVAILABILITY

Numerous data are made available via supplementary materials. Additional data can be made available on reasonable request.

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AUTHOR CONTRIBUTIONS

JT conceived the project, designed the methodology and data collection instrument with consumer group input, analysed the data, and wrote the manuscript. AB assisted with data extraction and analysis. GD assisted with development and testing of the data collection instrument. LK, AML, KBS, TB, PG, MD, IW, and MO assisted with methodology and review of the data collection instrument, and critical review of the manuscript. PL supervised the project, assisted with project conception, methodology, and review of the data collection instrument, and critical review of the manuscript.

FUNDING

The project is supported by a grant from the Australian Government's Medical Research Future Fund (MRFF), ref 76721. AML is funded by a National Health and Medical Research Council (NHMRC) Early Career Fellowship (ID 1158111). PL is supported by a National Heart Foundation Future Leader Fellowship (ID 102604). Open Access funding enabled and organized by CAUL and its Member Institutions.

COMPETING INTERESTS

The authors declare no competing interests.

ETHICAL APPROVAL

This project was granted approval by the Monash University Human Research Ethics Committee on 13 August 2021, ID number 22576, and 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/s41431-023-01373-1>.

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9 Appendix IX – Comparison of Inquiry Recommendations versus FSC Moratorium

Research

The Australian moratorium on genetics and life insurance: evaluating policy compared to Parliamentary recommendations regarding genetic discrimination

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Article history

Publication date: 13 December 2022

Citation: Tiller J, Lacaze P, Otlowski M. The Australian moratorium on genetics and life insurance: evaluating policy compared to Parliamentary recommendations regarding genetic discrimination. *Public Health Res Pract.* 2022;32(4):e3242235. <https://doi.org/10.17061/phrp3242235>

Key points

- In 2018, a Parliamentary Joint Committee recommended a ban on the use of predictive genetic test results in life insurance underwriting in Australia
- In 2019, the national life insurance industry introduced a self-regulated, temporary, partial moratorium on the practice
- Our process evaluation assessed the objectives of the recommendations made by the Parliamentary Committee, and any disparity between the objectives identified and the moratorium that was subsequently introduced
- We found that the Australian moratorium falls short of the Parliamentary recommendations

Abstract

Objectives and importance of study: Genetic discrimination is a health policy issue of international concern to clinicians, patients, researchers, and policy makers, and threatens the success of genomic medicine. In Australia, genetic discrimination in life insurance is legal and leads to public health harms, including deterring at-risk individuals from clinically indicated testing. In 2018, a Parliamentary Joint Committee recommended an urgent ban on the use of predictive genetic test results in life insurance underwriting in Australia, to be implemented in a form similar to the UK Code on genetic testing and life insurance. In 2019, the insurance industry, through the Financial Services Council (FSC), introduced a self-regulated moratorium that applies until 2024, but only to life insurance policies up to certain financial limits. The FSC moratorium will be reviewed in late 2022, but has no government oversight.

Study type: Policy implementation evaluation

Methods: We used policy evaluation methods to 1) summarise the key recommendations of the 2018 Parliamentary Committee that are directed towards practical aspects of policy development and content; and 2) assess the level of disparity between the implemented moratorium and the recommendations of the Committee.

Results: There is a substantial disparity between the Australian moratorium and the Parliamentary Committee recommendations across key areas, including addressing self-regulation, co-development of policy, protection of tests taken during its term, and similarity with the UK Code. The FSC moratorium offers less protection to consumers than the UK Code on a number of measures, including the level of financial coverage, the involvement of government, certainty provided to individuals who have genetic testing, and the treatment of research results.

Conclusions: The FSC moratorium is a step forward for Australia, but falls short of the Parliamentary recommendations. Further regulation by the Australian Government may be required to achieve the aims of the Parliamentary recommendations and ensure the intended level of consumer protection.

Introduction

Genetic discrimination is an issue of international concern to clinicians, patients, researchers, and policy makers, and threatens the success of genomic medicine.¹⁻⁵ Numerous countries have taken steps to ban or restrict the ability of insurance companies to use genetic test results in underwriting^{6,7}, and policy makers and other stakeholders assess the measures taken in other jurisdictions when making recommendations or decisions about regulation.^{8,9} Thus, the implementation and effectiveness of regulatory instruments in individual jurisdictions is of global interest. Here we evaluate the recently introduced Australian moratorium from a policy perspective and compare it to recommendations made by an Australian Parliamentary Joint Committee regarding the practice of insurance companies using genetic tests in underwriting.⁹

International context

In Canada, the *Genetic Non-Discrimination Act*¹⁰ 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* (GINA)¹¹ prohibits use of genetic information by health insurers and employers. The Council of Europe's *Oviedo Convention on Human Rights and Biomedicine*¹² prohibits discrimination on the basis of genetic information. Many European countries have accordingly banned or restricted discriminatory use of genetic information.^{6,7} In the UK, the *Code on Genetic Testing and Insurance*¹³ (UK Code), an agreement between the government and the Association of British Insurers (ABI), has been in effect since 2001. Although it is only mandatory for ABI members, non-members can voluntarily submit to the Code. ABI publishes a list of compliant insurers, which contained more than 200 entries at the time of publication of this manuscript.

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's disease (HD), used in applications for death cover worth more than £500,000 (A\$900,000). Although a mechanism exists in the Code to allow for the use of predictive genetic test results for income

protection and critical illness cover if tests are approved for use, no approval has been given to date for any test. Thus, currently, in the UK, there is no financial limit on the amount of income protection or critical illness cover that can be obtained without disclosing a predictive genetic test result. The UK Code also contains an allowance for disclosure of negative test results as described in the Canadian legislation above.

Australian context

In Australia, the Commonwealth *Disability Discrimination Act 1992* (section 46) allows risk-rated insurers to discriminate on the basis of both predictive and diagnostic genetic test results, if based on actuarial or other evidence.¹⁴ This means genetic discrimination in *life insurance* underwriting is legal.² *Health insurers* in Australia, however, cannot use any genetic test results (or any other risk rating) to discriminate, under the Commonwealth *Private Health Insurance Act 2007*.¹⁵ In 2018, a Parliamentary Joint Committee recommended a ban on the use of predictive genetic test results in Australian life insurance underwriting.⁹ The relevant findings are tabulated in Supplementary Table S1, available from doi.org/10.6084/m9.figshare.21454668.v1.

The recommendations were directed to both the life insurance industry and the Commonwealth Government. In 2019, the Financial Services Council (FSC), the peak body for Australian life insurance companies, introduced the self-regulated *Moratorium on Genetic Tests in Life Insurance*.¹⁶ This may have removed any pressure on the Government to respond to the recommendations, as it still has not done so. Under the partial moratorium, FSC member companies are restricted from asking for or using applicants' genetic test results in underwriting policies up to certain financial limits, until 2024. The FSC moratorium applies to all genetic test results (that is, those categorised as predictive and diagnostic), although its terms clarify that companies may require applicants to disclose any diagnosis of a condition, even if the diagnosis resulted from a genetic test.

FSC review

The moratorium will be reviewed by the FSC in late 2022. The Australian Genetics and Life Insurance Moratorium: Monitoring the Effectiveness and Response (A-GLIMMER) project^{17,18} (of which the authors are part) was funded by the Australian Government to gather evidence from stakeholders about the effectiveness of the FSC

moratorium. Our evaluation may assist with the FSC's review, and also assist the Government in assessing the FSC's adherence to the Parliamentary recommendations.

Methods

We used policy evaluation methods to assess the implementation of the recommendations made by the Parliamentary Committee. While the definition of "implementation" includes numerous stages following initial decision making¹⁹, the current evaluation is limited to the initial stage of implementation: the development of the terms of the policy introduced by the FSC. Numerous other projects being undertaken as part of the broader A-GLIMMER project will contribute to future evaluation of later implementation stages, including outcome-based evaluation.¹⁷

Process evaluation²⁰ was undertaken to assess any disparity between the objectives identified by the Parliamentary Committee and the moratorium which has been introduced. This evaluation was conducted in two stages:

Stage 1: Summarise the key recommendations of the Parliamentary Committee that are directed towards practical aspects of policy development and content, to clearly articulate the objectives against which the FSC moratorium must be measured.

Stage 2: Systematically assess the level of disparity (if any) between the implemented policy and the recommendations which were made, by reference to each objective identified.

This project did not recruit participants or gather participant data so no ethical approval was required.

Results

Stage 1: Summarise key recommendations

The key recommendations of the Parliamentary Committee that are directed towards practical aspects of policy development and content have been summarised below, with words in quotes taken from the section of the Report⁹ as denoted in brackets (also see Table S1, available from: doi.org/10.6084/m9.figshare.21454668.v1).

1. **Development of policy in discussion with Australian Genetic Non-Discrimination Working Group (AGNDWG):** "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).
2. **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).

3. **Protection of tests taken while the 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).
4. **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).

Stage 2: Assess disparity between implemented policy and Parliamentary Committee recommendations

1. Development of policy in discussion with AGNDWG

The Parliamentary Committee recommended that a ban be introduced urgently, to prohibit life insurers from using predictive genetic test results, at least in the medium term. The recommendation specified that this prohibition should be implemented in discussion with the AGNDWG (of which the authors are founding members). Prior to its commencement in July 2019, the FSC sought feedback on the draft moratorium from groups, including the AGNDWG. The AGNDWG provided written feedback (see Supplementary file S2 available from doi.org/10.6084/m9.figshare.21454668.v1) highlighting inconsistencies with the Parliamentary recommendations and issues to be resolved.

FSC incorporated three of the suggestions made by the AGNDWG (see Table 1). The two key issues addressed were:

- i) Removing a question about whether applicants were "planning or considering having a genetic test"; and
- ii) Extending the moratorium to all genetic tests (both diagnostic and predictive), rather than restricting it to predictive tests.

These two key changes were important to the functioning of the moratorium. However, considerable feedback was not incorporated into the final moratorium¹⁶, leaving numerous outstanding concerns (see Table 1).

2. Concordance with UK Code (formerly Moratorium)

The Parliamentary Committee recommended that the moratorium be in a form similar to the UK Code¹³, an ongoing agreement between the UK government and the insurance industry, which has existed since 2001. A

Table 1. Issues raised by AGNDWG and outcome in final moratorium document

Issue raised by AGNDWG in written feedback	Resolved in final moratorium document
Government involvement and oversight is required	X
There should be no limits – or if applied should be consistent with the UK limits	X
Results generated from research studies should be excluded from all disclosure as per the UK policy	X
“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	X
There should be regular compliance reporting, a specific complaints handling process and a Nominated Genetics Underwriter (NGU) role	X
Non-FSC members should be able to opt in to the moratorium	X
All risk-rated policies should be covered by the moratorium	✓
Moratorium should apply to all genetic tests (diagnostic and predictive)	✓

AGNDWG = Australian Genetic Non-Discrimination Working Group; FSC = Financial Services Council

Table 2. 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	Consistency
Financial limits (see Table S3)	The only limits on the moratorium are for life cover applications over £500,000 (approx A\$900,000)	The moratorium only applies up to monetary limits on life cover and total/permanent disability cover (A\$500,000), income protection (A\$4000/month or A\$48,000 pa) and trauma/critical illness cover (A\$200,000)	X
Tests included (see Table S3)	Only Huntington's 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	X
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 of the Australian Government	X
End date	No end date (although it is reviewed periodically)	Currently due to end in 2024 (may be extended following review in 2022)	X
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 results	X
Ability of non-member insurers to opt in	Yes	No	X

FSC = Financial Services Council

Supplementary Table S3 is available from doi.org/10.6084/m9.figshare.21454668.v1

comparison of key aspects of the UK Code and the FSC moratorium is contained in Table 2.

As discussed, 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 (~A\$900,000). Use of any results for other types of insurance is currently prohibited, although the Code includes a mechanism to approve use of results for new conditions (see Supplementary Table S3, available from doi.org/10.6084/m9.figshare.21454668.v1) in the future. Currently, however, UK applicants can obtain unlimited amounts of income protection or critical illness/trauma insurance without disclosing any genetic test results. By comparison, in Australia, there are financial limits on non-disclosure of genetic test results for all these types of insurance (Table S3, available from: doi.org/10.6084/m9.figshare.21454668.v1), for all genetic test results.

Finally, all genetic research results are excluded from disclosure in the UK, allowing consumers to participate in research without concern for how the findings might be used by insurers. In Australia, the FSC declined to follow the UK model in this regard and requires disclosure of all genetic test results once the financial limit is reached.

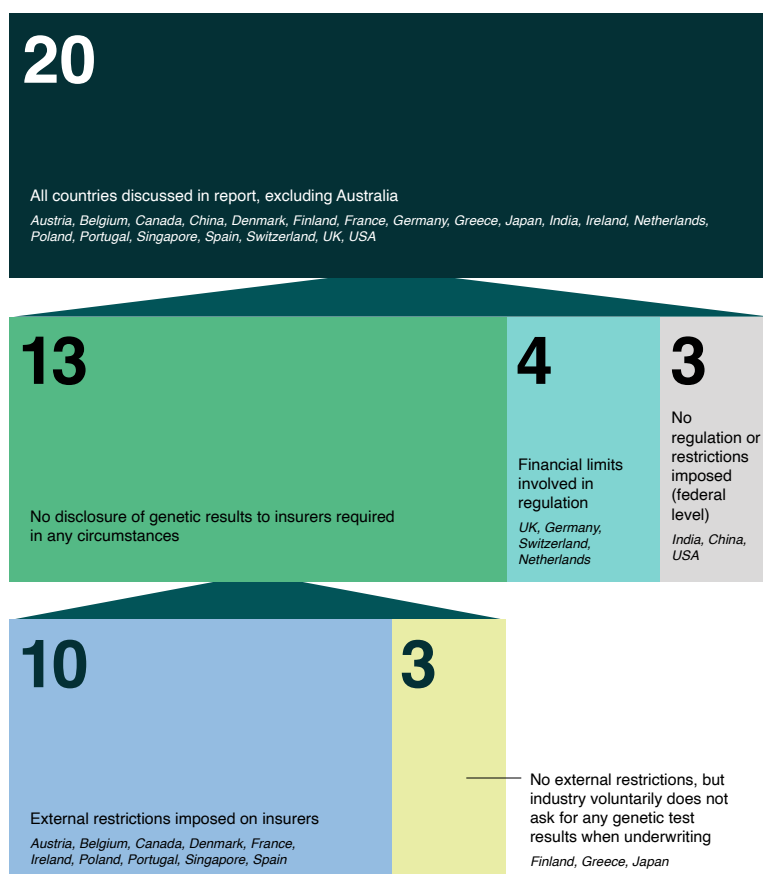
Notably, the FSC moratorium aligns with the UK Code on a key point identified by the Parliamentary

recommendations – the ability to choose to disclose negative genetic test results (see Table 1). Where family history of disease is used to justify adverse underwriting outcomes, individuals can disclose a negative test result to the insurer to nullify the effect of family history on their personal risk profile.

Financial limits

As discussed above, the financial limits in the FSC moratorium are significantly lower than, and affect more types of policies than, those in the UK Code. When it announced the moratorium, the FSC justified these lower limits, stating “the insurance cover limits compare favourably with other countries, being closely aligned to Switzerland and Germany”.⁸ However, the limits are not generally consistent with approaches taken internationally. The Geneva Association document titled, *Genetics and Life Insurance: A View Into the Microscope of Regulation*⁷ shows that most countries where bans exist have no financial limits at all. Of 20 countries it lists (other than Australia), 13 (65%) do not require disclosure of genetic results to insurers in any circumstances (with no limits) (see Figure 1). Some countries (like Portugal) even ban the collection of family history information. Only four (20%) of the 20 countries have financial limits

Figure 1. Restrictions and financial limits on disclosure of genetic results to insurers in different countries



Data source: Geneva Association, *Genetics and Life Insurance: A View Into the Microscope of Regulation*⁷

of any kind. Of those, one is the UK, which is the model recommended by the Parliamentary Committee.

The financial limits in place in Germany and Switzerland, which the FSC have said are comparable to Australia's, are both part of legislation that includes specific criminal penalties applicable for breaches. In Switzerland, genetic test results are not provided to the insurer but to a designated doctor, and only in cases where 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 the insurer with information about the risk group in which the insured person should be placed and no other details. Thus, although the FSC has adopted these lower financial limits, the context is entirely different to Switzerland, and use of test results is subject to far less regulation and oversight under the Australian moratorium. The Netherlands is the only other country with financial limits on its regulations – and it also restricts insurers from asking any hereditary questions for premiums below those limits (including family history questions, not merely the results of genetic tests).

3. Protection of tests undertaken while the moratorium is in place

The FSC moratorium has an end date of 2024, although it may be extended after review in 2022. The Parliamentary recommendations (section 9.93)⁹, propose that 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. As part of feedback provided to the FSC By the AGNDWG, the FSC was provided with the following draft clauses for the moratorium 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.*

However, this protection was not incorporated into the FSC moratorium. As a result, there is no certainty for consumers about the future potential for discrimination on the basis of genetic testing that is undertaken during the term of the moratorium. Research shows that fears about potential impacts on insurance deter individuals from undertaking clinically-indicated genetic testing and from participating in genomic research.^{3,4,21} The introduction to the FSC moratorium states: "Genetic testing has the potential to play an important role in informing people about their health and enabling them to manage their health risks through preventative actions and personalised medicine. 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."¹⁶ However, the moratorium currently fails to ensure certainty for individuals about the future use of their genetic test results.

4. Co-regulatory approach to address concerns with self-regulation

The FSC moratorium is self-regulated, without government involvement or oversight. This is distinct from the UK Code, which is an agreement between industry and government. The Parliamentary Committee made specific references to problems with industry self-regulation, inherent conflicts of interest, and their potential impact on the use of genetic test results in Australian life insurance⁹, in line with concerns raised by submissions by several parties, including the Australian Medical Association and the Royal Australian College of General Practitioners. To assist with safeguarding against the improper use of genetic information by life insurance companies, the Parliamentary Committee supported the co-regulatory approach outlined in the Australian Securities and Investment Commission (ASIC) *Enforcement Review Taskforce Position Paper*.²² This approach includes penalties for corporate misconduct and minimum standards of enforceability/consumer protections. The Committee was especially concerned with the requirements for registration (approval) of codes by ASIC and mandatory applicability for all industry participants, and enforceability of codes and financial remedies for breaches.⁹

The FSC does have a Life Insurance Code of Practice²³, however it has not been approved by ASIC at the time of writing. Further, the FSC moratorium is not yet part of that Code of Practice, despite the FSC stating in its 2018 press release that the moratorium would be "independently overseen by the Life Code Compliance Committee".⁸ It is understood that the moratorium will become part of the new FSC Life Insurance Code of Practice which comes into operation on 1 July 2023.²⁴ This Code of Practice is monitored by the FSC self-constituted Life Code Compliance Committee (LCCC). There are ongoing concerns regarding the LCCC's regulation²⁵, including concerns expressed by the independent LCCC chair in 2020.²⁶ (see Supplementary file S4 for a detailed summary, available from doi.org/10.6084/m9.figshare.21454668.v1). In summary, only one sanction has been imposed (in 2018–19) since the commencement of the LCCC. Despite repeated, published comments from the LCCC about the limitations on its ability to impose sanctions (see S4 and reference list), the LCCC is constrained by the provisions of the Code under which it is constituted.

The LCCC have made numerous recommendations to FSC about the need for amendments to the Life Insurance Code of Practice to incorporate greater sanctioning power and meaningful penalties. These recommendations

have not previously been adopted by the FSC, however, the LCCC notes that the new Code of Practice to be introduced next year will provide “increased powers to determine significant breaches and sanction non-compliant subscribers”.²⁷ On review of the new Code²⁴, it is apparent that the new sanctions are limited to the ability to require a member insurer to make a ‘Community Benefit’ payment to a charity. While the inclusion of a financial sanction is an improvement, it still falls short of enforceable, legislated consumer protections. Further, the ability of individual consumers to obtain remedies in such circumstances will continue to be restricted.

Discussion

This process evaluation assessed the implementation of recommendations about the use of genetic tests by the life insurance industry that were made by the 2018 Parliamentary Joint Committee, through appraisal of the ensuing FSC moratorium against the objectives identified in the Committee report.¹³ While the implementation of the moratorium is a step towards complying with the Parliamentary recommendations, this evaluation demonstrates that the FSC moratorium consistently falls short of the recommendations. When considered systematically, it is apparent that the FSC has, in respect of many of the recommendations made, introduced provisions that provide significantly reduced consumer protection compared with those contemplated by the recommendations.

For example, it is clear on a closer analysis of the international landscape (Figure 1) that international standards favour banning insurers from asking for genetic test results completely, without any limitations. The financial limits applied in Switzerland and Germany are not representative of international standards. Rather, it appears that the FSC has modelled its limits on two countries which, are in the minority, that do have limits (Switzerland and Germany), rather than banning the use of genetic tests altogether or modelling the limits on the UK Code. Further, even 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 moratorium.

In the history of the regulation of genetic discrimination by the insurance industry, it has not been uncommon for the insurance industry to strongly oppose any regulation by governments and resist implementing recommended restrictions.^{28,29} Insurance industries in several jurisdictions, including the UK and Canada, have made arguments that any restriction on their access to genetic test results would lead to significant increases in premiums and potentially the collapse of the insurance industry itself.^{28,30} There is no evidence of this in either jurisdiction following the introduction of non-discrimination instruments. Nor is there evidence, to the authors’ knowledge, of adverse impacts on the industry’s

continuing operation in any of the many international jurisdictions which have restricted or banned the use of genetic test results in insurance underwriting.⁶ However, such arguments against restriction on the use of genetic test results were made by the Australian insurance industry to the Parliamentary Committee.⁹ The Committee report found that no strong evidence had been presented to support the life insurance industry’s claims that adverse selection due to a restriction on insurers’ access to genetic test results would make the life insurance market unsustainable.⁹

In addition to its recommendations regarding co-regulation, the Parliamentary Committee recommended that the Federal Government maintain a watching brief on the field of genetics and consider implementing non-discrimination legislation if necessary (Table S1; ss9.96-97, available from: doi.org/10.6084/m9.figshare.21454668.v1). In such circumstances, the Parliamentary Committee recommended the government should closely consider the approach taken by Canada, which involves a complete legislative ban on access to and use of genetic test results, with accompanying criminal penalties for breach.

Conclusions

The Australian government should consider the failure of the current FSC *Moratorium on Genetic Tests in Life Insurance* to meet the expectations of the Parliamentary recommendations, as detailed in this evaluation. If the Government finds the current moratorium is inadequate, it should implement non-discrimination legislation to adequately protect consumer genetic information, as recommended by the Parliamentary Committee.

Acknowledgements

This work was supported by the Australian Government’s Medical Research Future Fund (number 76721); and a National Heart Foundation Future Leader Fellowship (grant number 102604).

Authors JT, PL and MO are founding members of the AGNDWG and investigators on the Australian Genetics and Life Insurance Moratorium: Monitoring the Effectiveness and Response (A-GLIMMER) research study.

Peer review and provenance

Externally peer reviewed, not commissioned.

Competing interests

None declared.

Author contributions

JT was responsible for the design, drafting, analysis of data, and editing of the manuscript. PL was responsible for reviewing and editing the manuscript. MO was responsible for reviewing and editing the manuscript and overseeing the data analysis.

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

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.

11 Appendix XI – Regulatory evaluation documents

Table 1 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 life insurance policies should be covered by the moratorium	✓
Moratorium should apply to all genetic tests (diagnostic and predictive)	✓

AGND Working Group = Australian Genetic Non-Discrimination Working Group
FSC = Financial Services Council

Table 2 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 (see Table S3)	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 (see Table S3)	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

Supplementary Table S3 is available from doi.org/10.6084/m9.figshare.21454668.v1

Figure 10 Restrictions and financial limits on disclosure of genetic results to insurers in different countries

Data source: Geneva Association,
Genetics and Life Insurance: A View Into the Microscope of Regulation

12 Appendix XII – Does the FSC Moratorium achieve the Outcomes for success?

Table 3 Does the FSC Moratorium achieve the Outcomes for success?

What Outcome is required for a successful moratorium or ban (on the use of genetic test results by life insurers)?	Does the FSC Moratorium achieve this Outcome (according to the A-GLIMMER Project's research findings)?
1. Widespread and accurate awareness of the existence of the FSC Moratorium.	<p>Unsatisfactory levels of awareness and knowledge about the FSC Moratorium:</p> <ul style="list-style-type: none"> • 84% of patients had never heard of the FSC Moratorium • Only 3% of the general public knew about the FSC Moratorium. • Knowledge by genomic researchers about the FSC Moratorium was not comprehensive (66% aware of it). • Most health professionals (86%) were aware of the FSC Moratorium but only half (49%) had a good knowledge about its content. • Varied levels of awareness and knowledge by financial advisers about the FSC Moratorium.
2. Confidence that the FSC Moratorium terms are strictly adhered to, and that breaches are rectified.	<p>Consumers, researchers and health professionals have a low level of confidence in the FSC Moratorium and in self-regulation by the life insurance industry:</p> <ul style="list-style-type: none"> • 88% of health professionals still had concerns about genetic discrimination. • 73% of patients and 60% of the general public believed that self-regulation is a negative aspect of the FSC Moratorium. • 59% of genomic researchers reported that the potential use of genomic test results by life insurers was a barrier to the recruitment of genomic research participants. <p>Decisions by the public and research participants about whether or not to undergo genetic testing are still impacted by their concerns about life insurance:</p> <ul style="list-style-type: none"> • 50% of patients reported that concerns about life insurance had a moderate to significant effect on their decision not to undergo genetic testing or to defer it.

	<ul style="list-style-type: none"> • 41% of health professionals did not think that patients were more willing to have genetic testing because of the FSC Moratorium. • Health professionals reported patients still delaying (39%) or declining (18%) genetic testing because of life insurance concerns. • 54% of genomic researchers reported that participants in genomic research had expressed concerns about life insurance since the FSC Moratorium's introduction.
3. Timely and regular updates to policy, practice and processes in health care, industry and research to reflect the FSC Moratorium	<p>Failures by genomics researchers to update relevant policies and processes to reflect the FSC Moratorium</p> <ul style="list-style-type: none"> • Only 33% of genomic researchers had updated their Patient Information and Consent Forms • Only 41% of genomic researchers had updated their consent discussions with patients to include information about the FSC Moratorium
4. Adherence to the terms of the FSC Moratorium	<p>24% of patients reported problems obtaining life insurance after the introduction of the FSC Moratorium.</p> <p>Financial advisers and other stakeholders report concerns about very limited recourse for consumers if an adverse decision is made.</p>

Section G: Endnotes

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² Joly Y, Dalpé G, Dupras C, et al, 'Establishing the International Genetic Discrimination Observatory' (2020) 52(5) *Nature Genetics* 466. <https://doi.org/10.1038/s41588-020-0606-5>

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, e.g., Parliamentary Joint Committee on Corporations and Financial Services, *Life Insurance Industry*, Final Report, March 2018, https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/Corporations_and_Financial_Services/LifeInsurance/Report 5.

⁵ Jane Tiller, Margaret Otlowski and Paul Lacaze, 'Should Australia Ban the Use of Genetic Test Results in Life Insurance' (2017) *Frontiers in Public Health* 5. <https://doi.org/10.3389/fpubh.2017.00330>

⁶ The FSC Moratorium is currently contained in *FSC Standard No 11: 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> ('FSC Moratorium'). The Standard can be best described as a 'self-regulated voluntary industry code': Andrew Terry, 'The Unusual Place of Industry Codes of Conduct in the Regulatory Framework' (2022) 45 *UNSW Law Journal* 649, 658.

⁷ Parliamentary Joint Committee on Corporations and Financial Services, *Life Insurance Industry*, Final Report, March 2018, https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/Corporations_and_Financial_Services/LifeInsurance/Report.

⁸ Above n 7, 154.

⁹ Above n 7, 154.

¹⁰ Above n 7, 155.

¹¹ Above n 7, 152-3.

¹² Above n 7, 138-144. See also **Appendix I** for a summary of the relevant treatment of genetic information in other countries.

¹³ Above n 7, 154.

¹⁴ Jane Tiller, Aideen McInerney-Leo, Andrea Belcher, 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 <https://doi.org/10.1186/s12910-021-00634-2>; FSC Moratorium.

¹⁵ FSC Moratorium cl 2.2.

¹⁶ FSC, 'Media Release: Additional Consumer Protections to be Included in FSC Life Insurance Code of Practice' 24 October 2022, <https://www.fsc.org.au/news/media-release/additional-consumer-protections-to-be-included-in-fsc-life-insurance-code-of-practice>.

¹⁷ 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: FSC Moratorium 2.3; FSC, *FSC Guidance Note No. 5: Industry Terms and Definitions*, 21 June 2019, 10.

¹⁸ FSC Moratorium cls 2.3, 3.1.

¹⁹ Above n 18, cl 3.3.

²⁰ Above n 18, cl 3.5.

²¹ This is because the *Disability Discrimination Act 1992* (Cth) only permits discrimination on the grounds of a genetic predisposition 'based upon actuarial or statistical data' and certain requirements of reasonableness. We consider that 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. See, e.g., *QBE v Bassanelli* [2004] FCA 396.

²² FSC, 'The Genetics Moratorium Review' <https://www.fsc.org.au/news/genetics-moratorium-review>, 22 June 2022.

²³ FSC Moratorium cl 5.

²⁴ The A-GLIMMER Project, *Submission to the FSC's Review of the Moratorium on the Use of Genetic Tests in Life Insurance*, 5 August 2022 https://www.monash.edu/_data/assets/pdf_file/0004/3058708/2022-08-05-response-to-fsc-review.pdf.

²⁵ FSC, *Life Insurance Code of Practice 2023*, Appendix A, A.1(e), <https://www.fsc.org.au/life-code>; FSC, 'Media Release: Additional Consumer Protections to be Included in FSC Life Insurance Code of Practice' 24 October 2022, <https://www.fsc.org.au/news/media-release/additional-consumer-protections-to-be-included-in-fsc-life-insurance-code-of-practice>.

²⁶ FSC, *Life Insurance Code of Practice 2023*, Appendix A, A.1(f), <https://www.fsc.org.au/life-code>

²⁷ Above n 26.

²⁸ FSC, *Life Insurance Code of Practice 2019* <https://www.fsc.org.au/life-code>.

²⁹ '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/>.

³⁰ Parliamentary Joint Committee on Corporations and Financial Services, *Life Insurance Industry*, Final Report, March 2018, 156 (Recommendation 9.4).

³¹ Email from Secretariat of the Joint Parliamentary Committee on Corporations and Financial Services to Jane Tiller, dated 22 March 2021.

³² CALI, 'Life Insurance Industry Members Back Council of Australian Life Insurers (CALI) as New Peak Body' <https://cali.org.au/media-centre/>, 7 November 2022; Aleks Vlckovick, 'Life Insurers Abandon FSC as Commissions Fight Looms' *Financial Review* <https://www.afr.com/companies/financial-services/life-insurers-abandon-fsc-as-commissions-fight-loom-20220622-p5avnf>, 22 June 2022.

- ³³ CALI, 'Life Insurance Industry Members Back Council of Australian Life Insurers (CALI) as New Peak Body' <https://cali.org.au/media-centre/>, 7 November 2022.
- ³⁴ CALI, 'Australia's Life Insurance Industry Announces Formation of New Dedicated Peak Body, the Council of Australian Life Insurers (CALI)' <https://cali.org.au/media-centre/>, 22 June 2022.
- ³⁵ CALI, 'Life Insurance Industry Members Back Council of Australian Life Insurers (CALI) as New Peak Body' <https://cali.org.au/media-centre/>, 7 November 2022; CALI, 'Board of Directors' <https://cali.org.au/board-of-directors/>, 2023; CALI, LinkedIn <https://www.linkedin.com/feed/update/urn:li:activity:7040789337763942400/>.
- ³⁶ FSC, 'Media Release: Additional Consumer Protections to be Included in FSC Life Insurance Code of Practice' 24 October 2022, <https://www.fsc.org.au/news/media-release/additional-consumer-protections-to-be-included-in-fsc-life-insurance-code-of-practice>.
- ³⁷ CALI, 'Australia's Life Insurance Industry Announces Formation of New Dedicated Peak Body, the Council of Australian Life Insurers (CALI)' <https://cali.org.au/media-centre/>, 22 June 2022.
- ³⁸ Aleks Vlackovick, 'Life Insurers Abandon FSC as Commissions Fight Looms' Financial Review <https://www.afr.com/companies/financial-services/life-insurers-abandon-fsc-as-commissions-fight-looms-20220622-p5avnf>, 22 June 2022.
- ³⁹ Above n 38.
- ⁴⁰ FSC, *Life Insurance Code of Practice 2023*, Appendix A, A.1(e), <https://www.fsc.org.au/life-code>; FSC, 'Media Release: Additional Consumer Protections to be Included in FSC Life Insurance Code of Practice' 24 October 2022, <https://www.fsc.org.au/news/media-release/additional-consumer-protections-to-be-included-in-fsc-life-insurance-code-of-practice>.
- ⁴¹ Ainsley J Newson, Jane Tiller, Louise A Keogh, Margaret Otlowski and Paul Lacaze, 'Genetics and Insurance in Australia: Concerns around a Self-Regulated Industry' (2017) 20 *Public Health Genomics* 247. <https://doi.org/10.1159/000481450>
- ⁴² Jane Tiller, Aideen McInerney-Leo, Andrea Belcher, 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.
- ⁴³ Monash University, *A-GLIMMER: Australian Genetics and Life Insurance Moratorium: Monitoring the Effectiveness & Response* (Web Page) <https://www.monash.edu/medicine/a-glimmer/news>.
- ⁴⁴ Jane Tiller, Aideen McInerney-Leo, Andrea Belcher, 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.
- ⁴⁵ Above n 44, 3.
- ⁴⁶ Above n 44, 5.
- ⁴⁷ Jane M Tiller, Louise A Keogh, Aideen M McInerney-Leo, et al 'A Step Forward, But Still Inadequate: Australian Health Professionals' Views on the Genetics and Life Insurance Moratorium' (2021) 59 *Journal of Medical Genetics* 817. <https://doi.org/10.1136/jmedgenet-2021-107989>
- ⁴⁸ Grace Dowling, Jane Tiller, Aideen McInerney-Leo, et al 'Health Professionals' Views and Experiences of the Australian Moratorium on Genetic Testing and Life Insurance: A Qualitative Study' (2022) 30 *European Journal of Human Genetics* 1262. <https://doi.org/10.1038/s41431-022-01150-6>
- ⁴⁹ Above n 48.
- ⁵⁰ Jane M Tiller, Louise A Keogh, Aideen M McInerney-Leo, et al 'A Step Forward, But Still Inadequate: Australian Health Professionals' Views on the Genetics and Life Insurance Moratorium' (2021) *Journal of Medical Genetics* 817, 819. <https://doi.org/10.1136/jmedgenet-2021-107989>
- ⁵¹ Clare A Primiero, Amy M Baker, Courtney K Wallingford, et al 'Attitudes of Australian Dermatologists on the Use of Genetic Testing: A Cross-Sectional Survey with a Focus on Melanoma' (2022) 13 *Frontiers in Genetics* 1. <https://doi.org/10.3389/fgene.2022.919134>
- ⁵² Above n 51, 5.
- ⁵³ This included predictive genetic testing but not pre-conception carrier screening or prenatal testing.

- ⁵⁴ That is, those participants who had chosen not to have a genetic test or who were actively considering testing.
- ⁵⁵ FSC Moratorium cl 3.5.
- ⁵⁶ Disability Discrimination Act 1992 (Cth) s 46.
- ⁵⁷ Australian Consortium for Social & Political Research Inc, 'The Australian Survey of Social Attitudes', <https://www.acspri.org.au/aussa>.
- ⁵⁸ Jane M Tiller, Nicole E Cousens, Rajneesh Kaur et al 'Population-Based BRCA1/2 Testing Programmes are Highly Acceptable in the Jewish Community: Results of the JeneScreen Study' (2023) 60(3) *Journal of Medical Genetics* 265. <https://doi.org/10.1136/jmedgenet-2022-108519>
- ⁵⁹ Paul A Lacaze, Jane M Tiller and Ingrid Winship. 'Population DNA screening for medically actionable disease risk in adults' (2022) 216 (6) *Medical Journal of Australia* 278. <https://doi.org/10.5694/mja2.51454>
- ⁶⁰ 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>, 3 April 2023.
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- ⁶² FSC Moratorium cl 3.9.
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- ⁶⁴ FSC representatives during the Parliamentary Inquiry hearings indicated that they were "prepared to commit to changing that horrible question... [a]re you *considering* taking a predictive genetics test?": Evidence to Parliamentary Joint Committee on Corporations and Financial Services, Parliament of Australia, Canberra, 1 December 2017, 31 (Nick Kirwan) (emphasis added).
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