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Monitoring the Effectiveness of the Australian Genetics and Life Insurance Moratorium: The A-GLIMMER Study Protocol

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Abstract

Around the world, the use of genetic test results in insurance underwriting has raised serious concerns, leading many countries to restrict or ban the practice. In contrast, Australian life insurers are legally permitted to consider genetic information, under rules set by the industry itself through the Financial Services Council (FSC). A 2018 Parliamentary Inquiry recommended prohibiting this practice, and in 2019 the FSC responded with a self-imposed moratorium. Because there is no government regulation, it is vital to independently evaluate how effective and appropriate this moratorium is. This article presents the protocol for a government-funded study designed to provide that evaluation between 2020 and 2023. The project applies a realist evaluation framework, using a context–mechanism–outcome (CMO) approach to examine whether the moratorium meets its intended objectives. Key outcomes were identified, and tailored methods were created to gather evidence from different stakeholders, including consumers, health professionals, the insurance sector, and the genetics research community. Data from these groups will be analysed separately, with findings disseminated through peer-reviewed publications. The A-GLIMMER study offers independent oversight of the industry-led moratorium, assessing both its impact and its effectiveness. At the project's conclusion, a Stakeholder Report will consolidate findings across all study arms, applying the CMO framework to evaluate progress against intended outcomes. The report will also provide evidence-based guidance for policymakers, insurers, and other stakeholders on the future of genetic information in life insurance.

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

Background

Internationally, the use of genetic test results in risk-rated insurance continues to raise ethical, social, and policy challenges [1–4]. A recurring issue in global studies is that individuals may avoid genetic testing or decline participation in genetic research because of concerns about future insurance implications [5–12]. When insurers base underwriting decisions on genetic information, this constitutes genetic discrimination (GD), defined as the unfair treatment of healthy individuals or their relatives due to actual or presumed genetic traits [13, p.64]. To reduce the risk of GD, many countries have enacted restrictions. For instance, Canada's **Genetic Nondiscrimination Act (2017)** prohibits insurers and service providers from accessing genetic test results without explicit consent, while the United States' **Genetic Information Nondiscrimination Act (2008)**

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(GINA) applies only to health insurance and employment, excluding life insurance—though certain states have added their own protections [14].

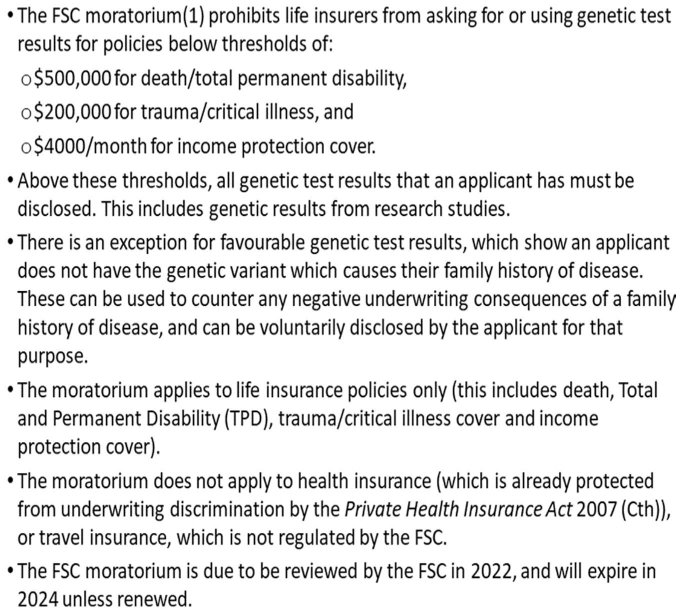
Other regions have adopted voluntary agreements. In the United Kingdom, a government–industry accord was established in 2001, now formalized as the **Code on Genetic Testing and Insurance** [15,16]. Under this arrangement, applicants seeking life policies below £500,000 are not required to disclose genetic test results, except for Huntington's disease in larger policies. The Code is reviewed every three years and remains in effect indefinitely.

Australia

The situation in Australia differs in key respects. Life insurers—not health insurers—offer risk-rated cover, and under the **Disability Discrimination Act 1992 (Cth)**, they are legally permitted to use genetic test results when assessing applicants [1]. Oversight of these practices is delegated to the industry itself, with the **Financial Services Council (FSC)** issuing binding Standards for its members. Despite this self-regulation, Australian studies reveal persistent problems, including non-compliance with both legislative requirements and industry rules [7, 8, 17, 18].

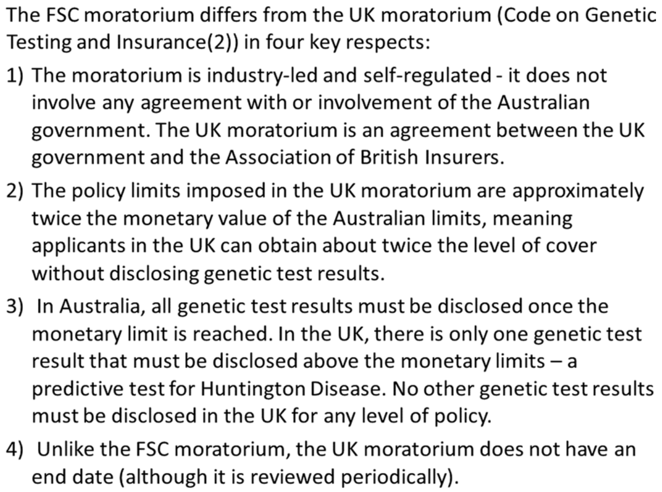
GD in insurance has emerged as one of the most critical ethical, legal, and social issues (ELSI) in Australian genomics, with implications for policy design, clinical uptake, and research participation [19]. In 2018, the **Parliamentary Joint Committee (PJC)** concluded that requiring disclosure of genetic test results in life insurance was inappropriate (s9.84). The Committee judged industry concerns about adverse selection to be overstated (s9.87–88) and considered the risk of deterring individuals from clinically indicated testing or research participation to be a more pressing problem (s9.89). It therefore recommended the introduction of a moratorium, modeled on the UK system, to prevent insurers from using predictive genetic information (s9.93). The Committee also highlighted concerns around self-regulation, pointing to conflicts of interest (s9.94), and suggested government oversight of implementation and compliance, with the possibility of future legislation (s9.96).

Although the federal government has not formally acted on these recommendations, the FSC independently introduced an industry-wide moratorium in July 2019 [19]. This measure restricts how insurers can use genetic test results **(Figure 1)** but differs from the UK model in four key ways **(Figure 2)**. Importantly, it does not alter the legal position under the **Disability Discrimination Act 1992 (Cth)**—insurers remain legally entitled to consider genetic information [1]. Consequently, while FSC members are expected to adhere to the moratorium through its Standards, the arrangement has no statutory force and remains voluntary.



- 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.

Figure 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).

Figure 2. Differences between the Australian and the UK moratoria

The **A-GLIMMER project**, supported by the Australian government through the Genomic Health Futures Mission, has been designed to assess Australia's current approach to genetic discrimination (GD) in life insurance.

Research Question: *To what degree does the FSC's self-regulated moratorium achieve the key policy objectives set out by the Parliamentary Joint Committee (PJC)?*

According to the PJC Report [20], the intended outcomes of reform in this area include:

1. Reducing consumer concerns about insurance that discourage participation in genetic testing or research (s9.98).
2. Eliminating GD within the Australian life insurance industry (ss9.84 & 9.86).
3. Removing barriers that limit the development and success of genetic medicine in Australia (s9.89).
4. Ensuring government oversight and monitoring to address shortcomings and conflicts of interest in industry self-regulation (ss9.94 & 9.96).

This project will determine whether the current moratorium delivers on these aims. By doing so, it will expand the international evidence base and provide Australia with guidance toward sustainable, well-informed regulation that accounts for the perspectives of all relevant stakeholders [21].

Globally, different measures have been introduced to curb GD, and their effectiveness has been evaluated in diverse ways. European studies, for example, have used methods such as ethnographic research within insurance companies [22] and postal surveys of individuals with pathogenic variants [23]. Findings from these studies vary, highlighting the importance of assessing both compliance and effectiveness whenever new policies are introduced. In the United States, while concerns about GD among genetic counsellors decreased after the **Genetic Information Nondiscrimination Act (GINA)** took effect [24], other clinicians remained more apprehensive, suggesting gaps in awareness. Public knowledge of GINA has also been limited; surveys found that fewer than 20% of respondents were aware of its protections [25], and cancer support group members showed limited understanding of the law's scope [26]. Research in the United Kingdom following the introduction of its moratorium similarly revealed ongoing difficulties in accessing insurance [27, 28], reinforcing the need for continued monitoring of how such agreements operate in practice. To date, however, no studies have examined consumer awareness of, or experience with, Canada's **Genetic Nondiscrimination Act** (GNA).

For Australia, we have identified **four key stakeholder groups** whose views are essential for assessing the adequacy of the FSC moratorium as a long-term regulatory approach: consumers, health professionals, the financial services sector, and the genetics research community. International studies have previously explored these groups' experiences of GD, their perspectives on regulation, and their knowledge of local protections. While these studies reflect different times and regulatory environments, they provide valuable context and underscore the importance of evaluating these perspectives within the Australian setting.

Consumers

Since the 1990s, research in North America, the United Kingdom, Europe, and Australia has consistently reported that consumers worry about genetic discrimination (GD). These concerns have been expressed by clinical patients at risk [29–39], advocacy groups [40], and members of the broader public [41]. Some individuals even described feeling pressured to undergo genetic testing in order to qualify for insurance coverage or reduce premiums [42]. Difficulties obtaining health or life insurance have also been documented among unaffected relatives of individuals with genetic conditions [43–45], healthy individuals who tested negative for a familial mutation [44, 45], and asymptomatic carriers who had already reduced their risk through medical surveillance or preventive treatment [27, 32, 45–50]. While legal reforms and other measures have altered the circumstances in which such discrimination occurs, the persistence and breadth of these findings show how strongly GD has shaped consumer experiences, making this group central to ongoing research.

Health professionals

Health professionals (HPs), including both genetic specialists and non-genetic clinicians, play a key role in informing patients about the insurance implications of genetic testing. For example, a Canadian survey conducted before the country's nondiscrimination legislation was introduced found that all genetic counsellors routinely raised insurance issues with clients [51]. In Australia, counsellors are formally required to do so under professional guidelines [52]. Because of this role, HPs often witness firsthand the hesitation patients feel about testing due to GD, and they are also among the first to hear direct reports of discrimination. A comparison of US studies before and after the introduction of nondiscrimination laws illustrates how policy shifts influence professional attitudes: in 2000, genetic counsellors expressed reluctance to undergo personal testing if at risk, but by 2014 they reported greater willingness to share details and pursue testing [53, 54].

Surveys of non-genetics-trained clinicians have also highlighted GD-related concerns. In one large US study, most physicians and nurse practitioners (96%) saw clear benefits of genetic testing, yet three-quarters believed patients would avoid it due to insurance fears, and 11% admitted withholding referrals for this reason [55]. Another study found that 12% of genetics professionals and 14% of primary care physicians had encountered patients denied life insurance because of genetic predisposition [56]. Even in Denmark, where insurers cannot legally ask about genetic risk [57], more than 5% of consultations still involved patient concerns about insurance, and one in 200 tests was not pursued for this reason. Knowledge gaps further complicate the issue: over 90% of US clinicians in one study (n=1110) answered incorrectly about existing protections [58], and in another, fewer than 35% of legal questions were answered correctly [55]. In Canada, a 2018 survey of pharmacists (n=99) found that just 46% were aware of nondiscrimination laws related to pharmacogenetics [59].

Genetic researchers

For researchers, GD has been identified as a significant barrier to participation in genomic studies. Canadian Senate hearings on Bill S-201 (now the **Genetic Non-Discrimination Act**) revealed that more than one-third of families with seriously ill children declined a free research opportunity due to insurance concerns [11]. In the United States, participation rates were similarly affected: fewer than 7% of invited parents joined the **BabySeq** study, with some explicitly citing insurance risks [12], while 25% of those who declined the **MedSeq** study (where genetic results were placed in medical records) identified insurance fears as the main reason for opting out [4]. These findings highlight the chilling effect GD concerns can have on research progress.

The financial industry

Studies have also examined how insurers themselves approach the use of genetic information. Early work in the United States surveyed life insurance medical directors in 1993 [60], using mailed questionnaires to explore company policies and future intentions regarding genetic testing in underwriting. With the introduction of GINA in 2008, which covers health but not life insurance, subsequent research shifted toward health insurers. For example, a 2012 study surveyed medical directors about company policies concerning genetic testing for familial colorectal cancer syndromes [61]. Other US studies [62, 63] asked insurers to assess hypothetical applicants. In one such study (n = 12), only three insurers reported having formal policies in place on how genetic test results would be treated [62]. Together, this body of work shows variation across companies and underscores the importance of directly engaging the insurance sector in ongoing policy discussions.

Project rationale

It is essential to monitor the impact, effectiveness, and appropriateness of the FSC moratorium, particularly from the perspective of the key stakeholder groups: consumers, healthcare professionals, genetic researchers, and the financial services industry. Each group experiences and interprets the effects of genetic discrimination (GD) in different ways, making it critical that the evaluation considers these diverse viewpoints. Such monitoring will provide robust evidence to inform the FSC's planned review in 2022, ensuring that any recommendations or adjustments are grounded in high-quality, empirical data.

Currently, there is no independent mechanism in Australia to assess whether the moratorium is meeting its intended objectives. This project addresses that gap by coordinating a national, multi-stakeholder research effort. Funded by the Australian government, the study will systematically collect and integrate data from all relevant groups to produce a comprehensive picture of how the moratorium functions in practice. The resulting evidence will not only inform domestic policy and regulatory decisions but will also contribute to the international understanding of how self-regulated moratoria impact genetic discrimination in life insurance.

Design and methods

Methodological approach

To evaluate the moratorium rigorously, the project employs a **realist evaluation framework**. Unlike traditional program evaluations that ask whether an intervention "works," realist evaluation seeks to understand *what works, for whom, in what contexts, by which mechanisms, and in what ways* [64, p.2]. This approach is particularly suited to complex policy interventions, such as the FSC moratorium, where multiple stakeholder groups experience the program in different social and professional contexts.

The framework applies a **context–mechanism–outcome (CMO)** model, which enables the systematic mapping of the interplay between stakeholder contexts, the mechanisms introduced by the moratorium, and the outcomes it produces. In this model:

- **Context** refers to the social, professional, and institutional settings in which the moratorium operates, including legal frameworks, organizational practices, and cultural norms.
- **Mechanism** refers to the processes, opportunities, or interventions activated by the moratorium that can influence stakeholder behavior or perceptions.
- **Outcome** represents the measurable or observable effects that indicate whether the moratorium achieves its intended goals.

Pawson and Tilley [65] emphasize that interventions succeed only when appropriate mechanisms are implemented in contexts conducive to generating the desired outcomes. Following this principle, the A-GLIMMER project defines the relevant outcomes for each stakeholder group first. The next step involves specifying the contexts and mechanisms through which these outcomes might be realized and identifying suitable measures to capture them **(Table 1)**. Finally, the project designs evaluation methodologies to test, for each outcome, how, where, and to what extent the moratorium achieves its aims.

This approach allows for a nuanced assessment of the FSC moratorium, recognizing that its effectiveness may vary across stakeholder groups and circumstances. By combining multiple data sources and analytical techniques, the project aims to produce a detailed, evidence-based understanding of the moratorium's impact and to provide actionable insights for policymakers, the life insurance industry, and other relevant stakeholders.

Table 1. Data collection

Intervention: Genetics and Insurance Moratorium					
Actor	**Context**	**Mechanisms**	**Outcome Measures**	**Objectives**	**Data Collection Methods**

1. Consumers	Consumer awareness of the moratorium	Broad public outreach to promote the moratorium	Awareness of the moratorium's existence and correct comprehension of its provisions	1.1	General public survey, genetic testing participants survey, surveys of those considering or declining testing
	Consumer interactions and experiences	Effective safeguards for consumers are in place, compliance with regulations is ensured	Higher participation in genetic testing or shorter delays in testing, reduced anxiety or confusion regarding genetics and insurance, fewer negative insurance outcomes linked to genetic data	1.2, 1.3	
2. Health Professionals (HPs)	HPs' understanding of the moratorium	Targeted education on moratorium details for HPs, provision of guidelines/tools to support patient communication	Thorough knowledge of moratorium terms, confidence in discussing the moratorium with patients	2.1	Survey of health professionals
	HPs' observations of patient attitudes and actions	Robust consumer protections are established, clear communication of moratorium details to patients	HPs note increased genetic testing uptake and fewer testing delays, reduced patient distress or confusion about insurance and genetics	2.2	
	HPs' perspectives on regulatory framework	Sufficient consumer protections are in place	HPs confirm that regulations adequately safeguard patients	2.3	
3. Financial Industry	Financial sector's awareness and comprehension of the moratorium	Engagement with industry and dissemination of moratorium details	Clear and accurate understanding of moratorium provisions	4.1	Surveys of financial advisors and FSC members
	Financial sector's application of the moratorium	Revised industry practices and standards	Complete and accurate logging of genetic information receipt in FSC database, lower rates of receiving genetic test results, fewer adverse insurance outcomes tied to genetic data, industry forms and processes align with moratorium terms	4.2, 4.3	Industry database analysis, application form review, interviews or focus groups with FSC underwriters
4. Genetic Research Community	Awareness among researchers and participants about the moratorium	Updated HREC guidelines and templates for direct participant communication	Greater clarity for researchers and participants, improved ease of communication	3.1, 3.2	Researcher interviews
	Research participants' behaviors	Effective consumer protections are implemented	Fewer concerns about insurance among participants, reduced rates of research participation refusals due to insurance concerns	3.2	

For the moratorium to be effective, several key results must be achieved:

1. People need to clearly understand the moratorium and its rules—this includes consumers, healthcare providers, researchers, ethics committees, insurers, and regulators.

2. All parties—consumers, professionals, researchers, and insurers—must feel confident that the moratorium is being followed and that any breaches are promptly addressed.
3. Policies, procedures, and practices in healthcare, research, and the insurance sector must be updated regularly to reflect the moratorium, such as consent forms for genetic testing and guidelines for genetics services and ethics committees.
4. Insurance companies must actually follow the moratorium's rules when collecting and using genetic test results.

Failing to address any of these areas will weaken the moratorium's impact.

To evaluate the moratorium, a mixed methods approach will be used, combining both qualitative and quantitative data from a variety of stakeholders. This includes comparing data from before and after the moratorium where possible. No single method alone can provide all the information needed. Collecting data on genetic discrimination has historically been challenging, and pre-moratorium information is often incomplete or inconsistent. Existing research and validated measures will guide the study where appropriate.

Figure 3 provides an overview of research already done before the moratorium across different groups and outlines the research planned under the A-GLIMMER project. To assess the outcomes, specific objectives and tailored methods will be applied for each group: Part 1 focuses on consumers, Part 2 on healthcare professionals, Part 3 on researchers, and Part 4 on the insurance sector. The research will also incorporate additional sources of information, such as complaints filed with the Australian Financial Complaints Authority and the Australian Human Rights Commission, to strengthen and supplement the data.

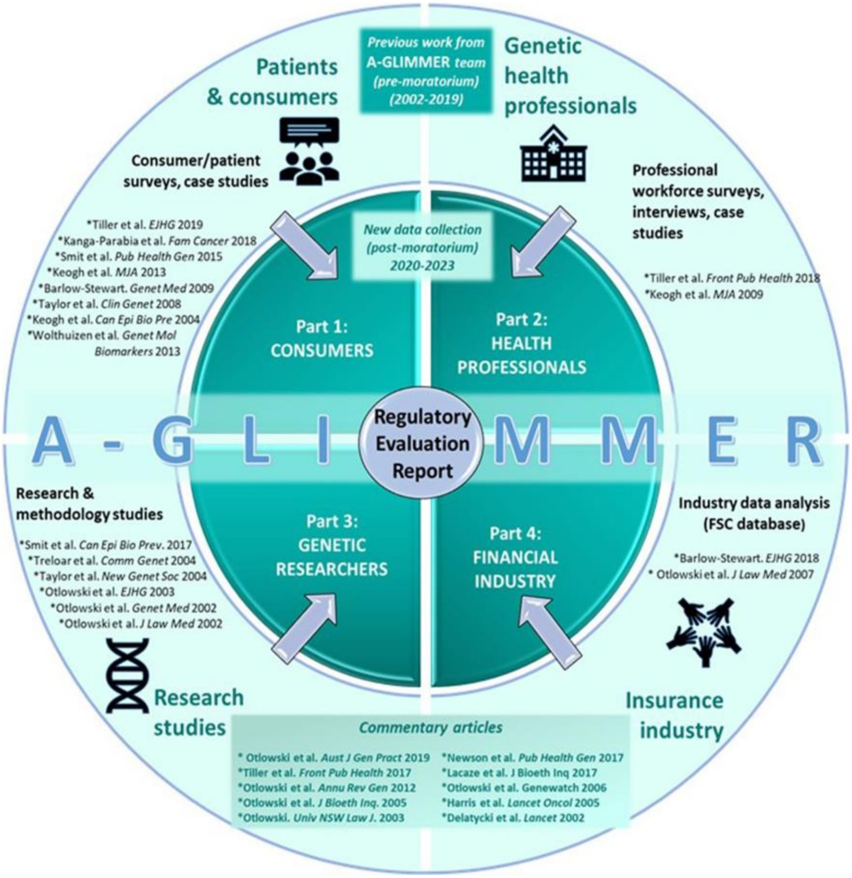
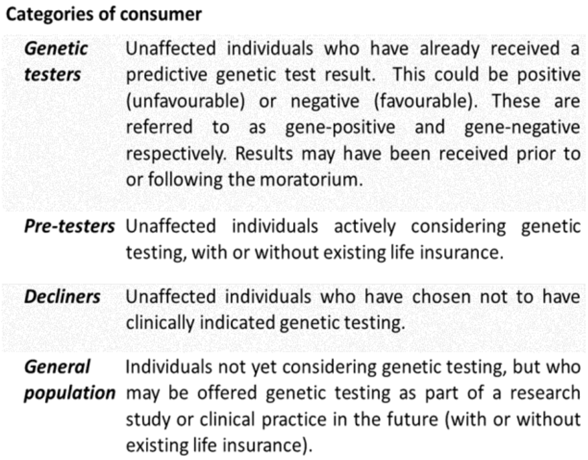


Figure 3. Summary of A-GLIMMER project (image created by authors)

Part 1: Consumers

In the context of genetic testing, a consumer is anyone who has undergone, or might undergo in the future, a genetic test. This includes individuals with a personal or family history of genetic or medical conditions, as well as apparently healthy people who may seek genetic testing for preventive health purposes or be offered testing through population programs or research studies. Regarding genetic testing and life insurance, consumers can be classified into several different groups **(Figure 4)**.



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).

Figure 4. Categories of consumer

Part 1: Consumers

The first part of A-GLIMMER focuses on understanding how consumers experience genetic testing and the moratorium. The main goals are to:

- Find out how much people know and understand about the moratorium.
- See how it affects decisions for those considering or declining genetic tests.
- Explore whether it changes access to life insurance compared to before the moratorium.

Before the study plan was finalized, consumer representatives from disease support groups and the wider community shared their input to ensure the approach would capture real consumer perspectives.

Surveys for genetic testers

Before the moratorium, research with Australian consumers looked at experiences getting life insurance after genetic testing. The study focused on people with positive results and recruited through two support groups: Lynch Syndrome Australia (LSA) and Pink Hope, which supports people with or at risk of breast cancer variants. In total, 174 participants provided baseline information on experiences and opinions.

After the moratorium, the survey will be repeated with a wider group. This includes people with high-risk variants and those whose results rule out family risk. The survey will measure understanding of the moratorium, how it affects decision-making, and experiences with life insurance. Recruitment will include additional groups, such as the Mito Foundation, Familial Hypercholesterolemia Network, Rare Cancers Australia, Genetic Undiagnosed and Rare Disease Network, Rare Voices Australia, and Cancer Council Victoria. With this expanded outreach, more participants are expected than in the previous survey.

Surveys for Pre-Testers and decliners

People thinking about genetic testing will be surveyed to understand their knowledge of the moratorium and how it influences their choices. Those who decide not to test will be asked about their reasons.

Women in the PRiMo trial, offered testing for breast and ovarian cancer-related variants at Familial Cancer Clinics (FCCs), will answer questions on the moratorium, insurance concerns, and life insurance experiences. Follow-ups will occur at six to twelve months after testing.

Men attending FCCs for predictive testing of adult-onset genetic conditions, and women not eligible for PRiMo, will also be invited to answer similar questions.

General population survey

The AuSSA survey, run annually by the Australian Consortium for Social and Political Research, collects data on Australians' social attitudes. Past surveys, including 2003, included questions about genetics and insurance. The 2021 survey will ask about awareness of the moratorium, views on the use of genetic test results by life insurers, and whether these concerns influence interest in future genetic testing. Relevant questions from 2003 will be repeated to allow comparisons, and demographic data will support analysis by factors like income and education.

Part 2: Health professionals

For the A-GLIMMER project, health professionals (HPs) include any qualified practitioners who interact directly with patients considering genetic testing. This group covers those working in genetics services, such as genetic counsellors and clinical geneticists, as well as other clinicians like nurses and oncologists who discuss genetic testing with patients.

The objectives for Part 2 are:

- Objective 2.1: Measure health professionals' understanding of the moratorium.
- Objective 2.2: Document HPs' experiences regarding how the moratorium affects patients.
- Objective 2.3: Explore HPs' perspectives on regulation and the overall effectiveness of the moratorium.

In Australia, some opportunistic interviews with HPs were conducted to verify consumer reports of genetic discrimination [66], but there had been no systematic collection of HP views. Before the moratorium began, the A-GLIMMER team ran the first dedicated survey of Australian health professionals' opinions on the use of genetic test results in life insurance underwriting [67]. This survey focused on 87 HPs working in clinical genetics. Findings indicated that many patients reconsidered testing after learning about insurance implications, and some delayed or opted out entirely. This aligns with previous research showing that insurance concerns can deter both genetic testing and participation in research, even when early interventions can significantly reduce health risks [7–9]. Most Australian genetics professionals report routinely discussing life insurance with patients considering genetic testing [67], highlighting the need for a thorough understanding of these issues.

Before finalizing the follow-up survey, the questions were piloted with several genetics professionals to ensure clarity, relevance, and smooth flow.

Health Professionals Survey – Objectives 2.1 and 2.2

After the moratorium began, HPs who discuss genetic testing with patients will be invited to complete an online survey (see Additional file 1). Recruitment now extends beyond genetics specialists, so a larger sample is expected compared to the previous survey [67]. Outreach will be supported through organizations such as the Human Genetics Society of Australasia and Australian Genomics, plus social media, direct emails, and snowball recruitment. The survey will explore HPs' understanding of the moratorium, experiences with patient impacts, and opinions on regulation of genetic test use in insurance. Results will be compared with earlier data to assess changes over time.

Participants can choose to remain anonymous or consent to a follow-up interview. Those who consent will take part in a 20-minute semi-structured interview, which will be transcribed and analyzed using thematic analysis to gain deeper insights.

Part 3: Genetic researchers

Within A-GLIMMER, genetic research refers to studies in human genetics and genomics where participants provide DNA samples and may receive results.

The objectives for Part 3 are:

- Objective 3.1: Understand how the moratorium affects the conduct of genetic research.
- Objective 3.2: Examine the moratorium's impact on research participants.

Before finalizing the protocol, several leading genetic researchers were consulted about their willingness to participate and the importance of this research. Feedback indicated strong interest and confirmed the relevance of exploring these views.

Researcher Interviews – Objectives 3.1 and 3.2

Previous studies show that insurance considerations influence participants' willingness to engage in genomic research, especially when results of clinical significance are returned [7–9]. In one study, the number of individuals declining predictive testing doubled when they were informed about insurance implications [8]. However, these studies collected the information incidentally, rather than focusing specifically on the impact of insurance and regulatory changes. Part 3 of A-GLIMMER will directly examine how the moratorium affects research participation and conduct, providing dedicated, post-moratorium evidence.

Interviews with genetic researchers

Researchers working in human genetics will be interviewed to understand how the moratorium affects both the conduct of research and participation in genetic studies. Australian researchers leading large-scale genetic projects will be invited via email. Eligible researchers will be identified collaboratively with input from research partners and relevant organizations familiar with ongoing studies. It is expected that at least 10–12 researchers will meet the criteria, with an anticipated response rate of around 80%.

The interviews will collect information on how the moratorium has influenced research activities, including participant recruitment, discussions with participants about life insurance, effects on participation rates and individual participants, ethics committee processes, and researchers' observations of any changes since the moratorium began.

Part 4: Financial industry

While some Australians apply for life insurance directly, many rely on financial advisers or brokers for guidance and assistance. Understanding the perspectives of both insurers and these industry professionals is crucial.

The objectives for Part 4 are:

- Objective 4.1: Assess awareness and understanding of the moratorium among financial industry personnel.
- Objective 4.2: Examine the perceived impact of the moratorium on the financial services industry.
- Objective 4.3: Evaluate life insurance companies' compliance with the moratorium.

Before finalizing the study plan, meetings were held with underwriting representatives from major Australian life insurers to gather feedback on the methodology, target groups, and interview topics.

Telephone Survey of Financial Advisers – Objectives 4.1 and 4.3

A random sample of registered Australian financial advisers (from a list of roughly 18,000) will be invited to complete a brief anonymous phone survey. The survey will assess their knowledge and understanding of the moratorium, focusing on advisers who are not directly employed by life insurance companies.

Analysis of Application Forms – Objective 4.3

Application forms from all risk-rated life insurance underwriters in Australia will be collected (in PDF or online format) and analyzed to determine whether they comply with the moratorium. This includes examining sections that ask about past or future genetic testing and how the moratorium is explained. A 2003 study [68] showed considerable variation in how genetic information was requested across underwriters; post-moratorium forms will be compared with these historical results where possible.

FSC Underwriters Survey/Interview – Objectives 4.1, 4.2, 4.3

Underwriting representatives from FSC-member insurers will be invited to participate in semi-structured interviews or focus groups. Discussions will explore their views on the moratorium, changes in practice, perceived benefits and limitations, and compliance with its terms. Sessions will be conducted via videoconference by the research team. Of the 16 FSC member companies, it is expected that 10–15 underwriters will participate.

FSC Database Analysis – Objective 4.3

The FSC requires member insurers to record de-identified information on all life insurance applications where genetic test results are disclosed, whether voluntarily or inadvertently [19]. Previous analyses have used this database [46, 69]. The FSC has updated its database to capture relevant post-moratorium data. Annual extraction and analysis will track the number of applications disclosing genetic test results and assess compliance with the moratorium, allowing comparison with pre-moratorium trends.

Data analysis and regulatory review

Each part of the A-GLIMMER study will be analyzed individually, and results will be shared in peer-reviewed journals as they become available. At the end of the three-year study, the team will produce a Regulatory Evaluation Report. This report will bring together all the evidence collected and use the Context-Mechanism-Outcome (CMO) framework to assess whether the FSC moratorium is achieving the outcomes recommended by the Parliamentary Joint Committee (PJC).

The report will highlight any objectives that have not been met and explore potential reasons for gaps in implementation. Recommendations will be made to improve how the moratorium operates and address any shortcomings. While the report will provide strong evidence, it does not replace the FSC's formal review of the moratorium [14]. It will also help fulfill the PJC's recommendation to review the moratorium after five years [13].

The completed report will be shared with the Treasurer, the Minister for Health, the heads of the relevant departments, and the PJC Chair. Its findings will inform future decisions on the moratorium, including whether adjustments or additional regulatory measures are needed.

Discussion

The A-GLIMMER project brings together experts from research, clinical practice, patient advocacy, policy, and the life insurance industry. Its central question is whether the FSC moratorium is effectively addressing concerns about genetic discrimination identified by the PJC.

Strengths of the study include a skilled, multi-disciplinary research team with extensive experience in genetics and prior collaborative publications [1, 34, 67, 70–75]. The project builds on more than 20 years of research by some team members [8, 42, 46–48, 74, 76–81]. Support from the Australian government, the Victorian Department of Health & Human Services, the Human Genetics Society of Australasia, and over 20 partner organizations highlights the project's national significance.

The FSC's involvement is crucial, enabling access to industry perspectives and promoting collaboration with Australian life insurers. The project also aligns with Australian Genomics, a national partnership of over 80 organizations integrating genomics into healthcare [82], and benefits from engagement with similar international initiatives in Canada, the USA, and the UK.

There are limitations to note. The variety of data collection methods across stakeholders may make synthesis challenging. The study might capture more input from motivated participants than from a representative sample. Investigator bias is possible, but safeguards have been applied to maintain objectivity.

Time constraints are another challenge. Recruiting participants, obtaining ethics approvals, or disruptions such as COVID-19 could delay milestones. Additionally, while the FSC has agreed to provide industry data, the research team does not control access, which may affect timing and completeness.

Despite these challenges, the findings will provide critical evidence for the FSC review of the moratorium and help shape future policies on the use of genetic information in life insurance.

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