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Research

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

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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 making[19], 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 evaluation[20] 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 Report[9] 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 moratorium[16], 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 Code[13], 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.

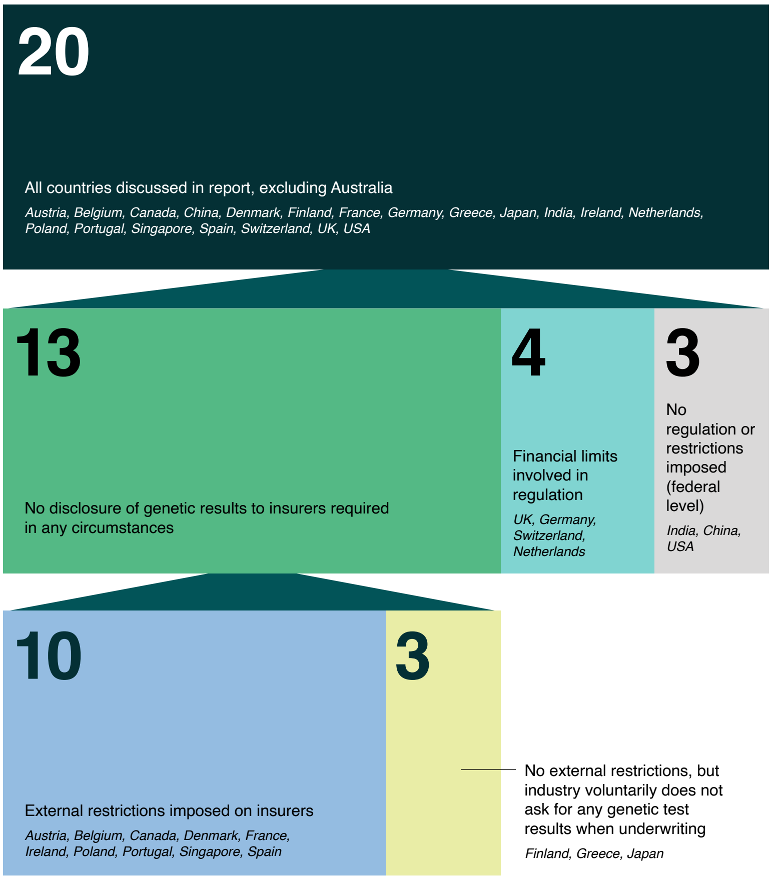
Finally, all genetic research results are excluded from disclosure in the UK, allowing consumers to participate in research without concern for how the findings might be used by insurers. In Australia, the FSC declined to follow the UK model in this regard and requires disclosure of all genetic test 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 LifeInsurance: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 insurance[9], 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 Practice[23], 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 regulation[25], 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 Code[24], 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.

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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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