



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

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,

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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 The data presented comprises a mixture of published (in peer reviewed journals) and unpublished research, as described in the attached report.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 Lie 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>.