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Use of genetic testing results in life insurance underwriting

Thank you for the opportunity to comment on the use of genetic testing results in life insurance underwriting consultation paper. The Financial Rights Legal Centre (**Financial Rights**) and Super Consumer Australia have long argued for the need to legislate against the use of genetic tests in life insurance and welcomes the Council of Australian Life Insurers' decision to support government regulation in this space. Designed well, with simplicity at its core, a legislated prohibition on the use of genetic test results will give Australians peace of mind and confidence to undertake testing.

Our comments are confined to those questions where we are able to provide comment.

In summary:

- We are concerned about the ongoing impact of genetic discrimination on consumers.
- The current Moratorium on genetics and life insurance fails to adequately protect consumers against genetic discrimination, and does not meet the recommendations of the 2017 PJC Inquiry into Life insurance for an urgent ban on the practice.
- The Insurance Law Service has received calls from consumers who are concerned about the potential for genetic test results to impact their ability to access life insurance products and manage their and their families' financial risk adequately.
- A total ban on the use of genetic results by life insurance companies, without any limits, caps, or exceptions, is the only appropriate policy reform solution to address the legitimate concerns expressed by consumers in this area.

Question 2. Which aspects of the current Moratorium provide inadequate protections for consumers: consumer and industry awareness, financial thresholds, compliance by life insurance industry, or other?

The current Moratorium on Genetic Test in Life Insurance (**the moratorium**) failed from the very beginning to meet the recommendation of the 2017 PJC Life Insurance Inquiry's recommendations for an urgent ban on the use of genetic test results in life insurance underwriting. This is because of the clear conflict of interest arising out of the industry's desire to gain as much information as possible for legitimate commercial reasons and the subsequent genetic discrimination that may result.

The key failures of the current moratorium are:

The moratorium's financial limits are too low

In 2019, the Financial Services Council (**FSC**) developed a model where the financial limits in place were far lower than the UK's model – the model it was loosely based on. In 2022 when we last undertook an analysis on the difference, the FSC moratorium was approximately \$366,000 lower for life insurance, \$320,000 lower for trauma or critical illness insurance and \$300month lower for income protection or salary continuance policies than the protection in place in the UK. This is stark, considering the limits in place in the UK have not been reviewed for decades and have not themselves kept pace with inflation. We understand the FSC based its figures on the German and Swiss regulations. The use of these figures seemed to be cherry picked on the basis that they are the lower than the UK position. In fact, these two countries are two of the few in the world who have applied financial limits to their prohibitions on genetic discrimination in insurance. Further, both countries have legislative provisions with substantial penalties and strict limitations around how data is accessed. The decision to “benchmark” against these countries was clearly in the sole interest of life insurers not consumers.

We note too that the current levels are well below current average sum-insured levels derived from APRA data.

However, it is important to note that simply raising the financial limits would not resolve the other issues apparent in the current regulatory situation, and would not adequately resolve the issue for consumers.

There is a lack of transparency in whether life insurers are meeting the requirements of the moratorium

The moratorium has always been subject to oversight by the independent Life Insurance Code Compliance Committee (**LCCC**) under clause 5.16 of the first Life Insurance Code of Practice and clause 4.17 of the current Life Insurance Code of Practice. However, no information to date has been provided publicly as to whether life insurers have been meeting the requirements of the moratorium. We note that the LCCC stated in their 2022-23 Annual Report that they intend to run an Own Motion Inquiry (**OMI**) into this area to see how subscribers are meeting these obligations, however given this current consultation, the status of this OMI is not clear.

The FSC itself released a statement outlining the effectiveness of the Moratorium in 2022 – as detailed in the consultation paper.¹ However the Australian Genetics & Life Insurance Moratorium: Monitoring the Effectiveness & Response (**A-GLIMMER project**) final stakeholder report² detailed a significant number of flaws with this review including low quality data, missing data and issues with its approach to collecting and using data – including delays, a refusal to ask insurer members for the data that the moratorium had required it to produce and the self-interested misuse of the data collected.³

The A-GLIMMER Project also found instances of non-compliance with the FSC Moratorium, including where insurance companies have asked insurance applicants about genetic testing, contrary to the terms of the moratorium.⁴

The moratorium is not enforceable

The moratorium is not law and does not legally prevent insurers using genetic test results in underwriting or change the operation of the *Disability Discrimination Act 1992 (Cth)*. The Code of Practice, where the moratorium currently sits, is not a term of the contract with a consumer and is therefore not contractually enforceable. The Code of Practice is not an approved code under the enforceable code regime overseen by ASIC and subsequently has no code commitments enforceable by statute. The LCCC also has very limited sanction powers to enforce the moratorium. Individuals may seek restitution via AFCA but depending on the circumstance and particular wording of the moratorium, enforceability at external dispute resolution is uncertain and unclear.

Lack of awareness

Generally speaking, most clients we speak with on our Insurance Law Service lines are unaware of the specifics of the current moratorium, if they know that one exists at all. This aligns with the findings of A-GLIMMER project final stakeholder report⁵ which found that 84% of those surveyed had never heard of the moratorium. They also found that amongst the general public awareness was even lower at 3%. This is unsurprising. Life insurance is already a complex financial instrument and there is generally limited understanding of the way life insurance works, let alone the complexities of any genetic testing moratorium in place under a self-regulatory regime.

¹ Page 8, Treasury, Use of genetic testing results in life insurance underwriting Consultation paper November 2023

² Tiller, Jane; Gleeson, Penny; McNerney-Leo, Aileen M.; Keogh, Louise; Nowak, Kristen; Barlow-Stewart, Kristine; et al. (2023). Final Stakeholder Report of the Australian Genetics and Life Insurance Moratorium: Monitoring the Effectiveness and Response (A-GLIMMER) Project.. Monash University. Report. <https://doi.org/10.26180/23564538.v1>

³ Pages 25-26 and 33-34, Jane Tiller et al (2023)

⁴ Page 5, Jane Tiller, et al (2023)

⁵ Page 18, Jane Tiller, et al (2023)

Question 3. As a consumer, has your willingness to undertake genetic testing been impacted by the existing Moratorium?

Financial Rights runs the Insurance Law Service, which provides advice nationally to consumers about insurance claims and debts to insurers. From time to time, the Insurance Law Service receives calls from consumers asking for advice with respect to the use and impact of genetic tests in life insurance. Their concerns largely centre on whether a genetic test they are considering having, about to have or have received will impact on their ability to gain life insurance in the future or their current life insurance. It is important to note that these enquires focus on consumers' concerns regarding any loss of coverage or any lost ability to obtain appropriate life insurance to mitigate against financial risks to their family – not on how to game the system.

We also note the findings of the A-GLIMMER project's earlier report that found that there was some reported decrease in patients delaying/declining testing after the moratorium's introduction.⁶ Given the concerns that have been discussed with us through the Insurance Law Service, we can understand how these concerns lead consumers to make the difficult decision not to pursue genetic testing that could be medically important for them or their relatives.

Question 4. Of the options outlined above, which do you think is most appropriate to manage concerns about genetic testing and access to life insurance, including those concerns identified in the A-GLIMMER report (see pages 10-11)? Would you change any aspects of that option?

In line and consistent with the recommendations of the A-GLIMMER Report, we support Option 2 with:

- a total ban without limits, caps or exceptions,
- applying to both asking for and using genetic results,
- allowing consumers to disclose a negative genetic result and
- not refusing to offer insurance coverage on the basis of not choosing to take a genetic test.

Question 5. What are the key concerns with each option?

Our key concern with Option 1 is that it will do nothing to address the concerns raised in the A-GLIMMER report, reflected in the concerns that have been communicated to us through the Insurance Law Service, and will in fact exacerbate uncertainty for consumers and health professionals.

⁶ Tiller JM, Keogh LA, McLnerney-Leo AM, et al. A step forward, but still inadequate: Australian health professionals' views on the genetics and life insurance moratorium, *Med Genet* (2021)

Our key concern with Option 2 relates to the potential for a partial ban, not the total ban for which we advocate. A partial ban:

- maintains and increases complexity for both insurers and consumers;
- enables exceptions to be added over time and financial limits to be changed via industry lobbying;
- provides significant uncertainty into the future and lowers consumer confidence

We hold the same concerns with respect to Option 3 and legislating financial limits on the consumer protections to be introduced.

Question 6. Is there any evidence to suggest that Government intervention may give rise to adverse selection?

We have seen no evidence that intervention will give rise to adverse selection, nor has there been any evidence of adverse selection arising out of the Canadian prohibition.

As we mentioned above, life insurance is a complex financial instrument and there is generally limited understanding of the way life insurance works in the first place, let alone enough knowledge of how to “game the system”. To assume otherwise is to assume a degree of financial literacy and sophistication that simply does not exist.

It also assumes a set of financial motives that are beyond that of the immediate health concerns that a diagnosis can produce and the appropriate desire to ensure the financial security for their family in the event something happens to them. Again, there is no evidence that these cynical motives exist outside of the theoretical.

Further, higher levels of coverage mean higher level of premiums that have to be paid by the consumer – and insurers already take this issue into account in establishing their product designs.

Question 9. Of the options outlined above, which do you think is the most appropriate enforcement body given capacities and enforcement powers?

We strongly support ASIC and AFCA to have a role in the enforcement of a legislated genetic moratorium.

ASIC currently monitors and regulates life insurance behaviour. ASIC is well-placed to oversee any extended regulation over life insurer compliance with any new requirements.

AFCA too is well-experienced in dealing with consumer complaints with respect to life insurers; is effective, independent and fair; and is best placed to take on future complaints. AFCA is also accessible, as a no cost jurisdiction where individuals do not require legal representation.

AFCA’s fairness jurisdiction would also be valuable here to draw upon human rights laws, discrimination etc. to apply to each case, where appropriate.

ASIC and AFCA would however need to be resourced to undertake any additional work.

Concluding Remarks

Thank you again for the opportunity to comment. If you have any questions or concerns regarding this submission please do not hesitate to contact drew.macrae@financialrights.org.au.

Kind Regards,



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