Submission to the Public Consultation Paper on the use of Genetic Testing Results in Life Insurance Underwriting

31 January 2024

MITO FOUNDATION
ABN: 84 135 324 391
SUITE 804, LEVEL 8, 28 FOVEAUX STREET, SURRY HILLS, NSW, 2010
PH: (02) 8033 4113

Thank you for the opportunity to respond to the public consultation paper regarding the use of genetic testing results in life insurance underwriting.

Mito Foundation supports legislating a **total ban** on the use of genetic test results in life insurance underwriting as the only **workable** and **fair** approach.

This submission provides a brief background on mitochondrial disease (mito) and Mito Foundation, the importance of genetic testing for the mito community (patients and their families) and provides feedback to the questions in the consultation paper.

Background

Mito is a rare genetic disorder that can cause multiple organ dysfunction or failure and potentially death

Mito is a debilitating genetic disorder that starves the body's cells of energy. Mito is caused by genetic mutations in either mitochondrial or nuclear DNA, which can be inherited from one or both parents or can arise as a spontaneous genetic mistake at conception. Mito can affect both children and adults and can cause multiple organ dysfunction or failure and potentially death. Due to its genetic basis, mito often affects multiple family members.

There is currently no cure for mito, and very few effective treatments exist. It is estimated that approximately 4,500 Australians live with a diagnosis of mito while one in 200 (more than 120,000) carry a gene change that puts them at risk of developing mito in their lifetime.

Mito Foundation supports people with mito and their families and works towards treatments and cures for mito

Mito Foundation supports patients with mito and their families, funds essential research into the prevention, diagnosis, treatment and cures of mito, and increases awareness and education about this devastating disease. Mito Foundation was founded in 2009 by several families personally impacted by mito along with professionals with an interest in mito.

Question 1. Are there particular fields of health care and medical research that are impacted by participant reluctance to take genetic tests due to impacts on life insurance access?

The diagnosis, prevention and treatment of mito are all dependent on genetic testing. Any reluctance from participants or their health professionals to consider genetic testing poses a risk to the health of individuals and progress towards treatments and cures for mito.

Genetic testing can lead to faster and less traumatic diagnosis of mito

Mito is difficult to diagnose because symptoms vary in range, type and severity, and their onset in patients' lives. As a result, patients often undergo multiple clinical tests. These can include invasive muscle biopsies and tissue analysis, which can have a huge mental and physical toll on patients.

> My daughter had a profound hearing loss and then a massive seizure. The doctor suspected mito, but she told us that sadly, we had to go through the whole process of multiple tests to eliminate everything else first.
>
> For our little girl this meant four lumbar punctures, which triggered her to have more seizures. Lumbar punctures also were a source of potential infection and were really distressing for all of us. Our daughter had two muscle biopsies as the first one failed. That meant a second anaesthetic which impacted her physically. This was in addition to other tests - the moment we took her into the pathology room I knew she knew: 'I am going to get poked!' I remember every part of her body having band-aids on it because she was prodded so many times.
>
> Earlier access to whole genome sequencing would have meant less hospital stays, less infections, less anaesthetics. Every admission shortened her lifespan.
>
> Parent of a child who had mito

> I know many people who have spent more than ten years getting a diagnosis. This destroys their lives. I think particularly of one man - the testing they have put him through has risked his health. He completed an exercise stress test that caused him to collapse. This search for a diagnosis through clinical tests has caused people huge emotional and physical stress, wasted a huge amount of health resources and personal finances. If genome testing was available earlier and more easily, this could have been avoided.
>
> Mito Foundation peer support leader who is also an adult living with mito and a parent of children with mito

The important role of genetic testing for the mito community was recognised through the introduction of Medicare funding for whole genome sequencing for mito. We worked with the mito community to understand their views on genetic testing. We found that genetic testing for mito leads to positive health outcomes for patients and their families by:

- Reducing the duration, burden, cost and emotional strain of the diagnostic odyssey
- Improving psychological outcomes through the increased certainty that a genetic test result can provide
- Supporting access to existing pro-active management, early intervention and targeted treatments
- Supporting access to preventative options, including reproductive options such as mitochondrial donation
- Improving access to non-health supports such as disability support and income support.

Cascade genetic testing can improve health and provide access to prevention options

Genetic testing is the key to identifying at-risk family members who may carry the same genetic mutation as someone with mito. For these family members, finding out they are at risk can help them to prevent or minimise symptoms of mito such as through careful management of diet and exercise. Having this genetic testing information can also provide them options to prevent passing on this genetic mutation to any children they may have.

If family members delay or avoid genetic testing due to concerns about life insurance, this can impact their health and their reproductive options.

Increased access to genetic testing is an important foundation for progress on development of treatments and cures for mito

All therapeutic clinical trials for therapeutics for forms of mito involving specific genes require participants to have a confirmed genetic test for mito. Any barrier to access put progress into therapeutic development at risk and can reduce the access that Australians have to these emerging therapies. It is also reasonable to expect some future therapies for mito to aim to delay or prevent symptoms of mito for those that have had a genetic test showing they are at risk.

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 A-GLIMMER project (1) (which included responses from 55 mito community members) found that while the current Moratorium helps protect consumers to some extent, it doesn't cover everything needed for their full protection:

a. Compliance: under the current Moratorium, life insurers are self-regulated, which presents as a major barrier to consumers as public trust in insurance providers is very low.
b. Awareness: uncertainty about how long the Moratorium will last and the limited awareness among both consumers and the industry are discouraging people from getting genetic testing and participating in research.
c. Financial limits: the financial limits set by the Moratorium are lower than what most people require to cover their liabilities. This is particularly worrisome for the mito community: mito impacts adults in the years they most need insurance, and families affected by mito often face substantial out-of-pocket expenses related to both their healthcare needs and non-health support requirements.

It is important, however, to note that dealing with these aspects individually i.e. raising financial limits or increasing awareness is not a long-term solution. **The only appropriate answer to this question is a complete ban on genetic discrimination in life insurance, legislated and regulated by the Government**.

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

Mito Foundation has heard concerns from the Australian mito community about whether they should undergo genetic testing for mito. What we have heard is consistent with the findings of the A-GLIMMER project.(1) These include:

- fear of discrimination; a significant portion reported difficulties in accessing life insurance due to their genetic test results
- concerns about the lack of government regulation of insurance providers
- concerns about the lack of permanency of the Moratorium
- reports of people not getting tested or not wanting to get tested due to these concerns.

We have had reports of health professionals being hesitant to recommend testing due to concerns about life insurance, which often results in patients missing out on important health information.

Question 4. Of the options outlined, 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? Would you change any aspects of that option?

Mito Foundation encourages the Australian Government to legislate for a **total ban on the use of genetic testing in life insurance underwriting, without limits, caps or exceptions**. Legislating this ban will address the issue definitively. Having the ban in place will provide consumers the confidence to make informed, long-term decisions. Additionally, no limits, caps or exceptions to the ban will reduce the burden on consumers and health professionals to understand legal nuances and/or keep up to date on changes. This will mean that consumers will be able to make decisions about genetic testing based on health information.

This approach is consistent with the Genetic Non-discrimination Act (GNA) introduced in Canada in 2017 and the recommendations made in the report from the A-GLIMMER project.(1,2) Similar to the GNA, this ban should additionally:

a. prohibit insurance providers from asking for and/or using genetic test results from consumers, to remove any potential for discrimination
b. allow consumers that have a family history of disease to provide negative genetic test results to demonstrate that they are not at risk of said disease
c. ensure that insurers are not able to exclude people who have a family history of disease from coverage if they have not had a genetic test

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

We have major reservations about any option other than a total ban as described above.

Option 1: Do Nothing

The barrier that genetic discrimination poses to appropriate access to life insurance has been identified as a public health issue, with far-reaching negative implications for medical research and advancement in Australia. For the mito community, doing nothing will allow ongoing discrimination against mito community members with positive genetic testing results and encourage community members at risk to not get tested. This will:

- prolong peoples' diagnostic odysseys unnecessarily, leading to larger health costs and emotional strain,
- limit access to preventative measures, especially reproductive options like mitochondrial donation which require a genetic diagnosis of mito,
- limit access to early intervention, management and targeted treatment options,
- limit access to some non-health supports,

lead to poorer (physical and mental) health outcomes. **Option 2: Total or Partial Ban**

Our view is that these are two very different options:

1. Partial ban: The current Moratorium already enforces this measure, but it has proven ineffective in preventing genetic discrimination, as highlighted in the A-GLIMMER project report.(1) Choosing this option means that consumers will always be left unsure about what getting a genetic test means for their future, leading to hesitancy in getting tested. Additionally, with a partial ban, genetic professionals would have to develop a deeper understanding of the ban to explain the implications of genetic testing to their clients. These responsibilities should not be expected within their professional role.

   Adopting the UK's approach, which prescribes an exclusion list for genetic conditions, is unsuitable. Our knowledge of genetic conditions is constantly changing, which makes regulation complex and updating the exclusion list to reflect research progress burdensome. Australians also have significant concerns about insurers' use of their sensitive data, and introducing this model will incentivise insurance providers to add more genetic conditions to the exclusion list, leading to further genetic discrimination.(3)

2. Total ban: A **total ban, without limits, caps or exceptions is the best solution.** It's the simplest, most consumer-friendly, and ethical solution to the challenge of genetics and insurance. A total ban will:

   - give people absolute certainty by making things straightforward for consumers. They won't have to deal with complicated financial rules, and will not worry about the rules changing, providing clear and unchanging protection against unfair treatment by insurance providers.
   - ensure that decisions about genetic testing are based only on health, and there is no need to worry about risking future access to insurance.
   - keep the genetic workforce focused on providing health advice only, without the need to provide financial advice.
   - prevent stigmatisation by promoting a societal stance against unfairly judging individuals based on their genetic makeup.

Option 3: Legislating Financial Limits

This option faces the same problems as the partial ban discussed above, in that it only provides partial protection to consumers, who will still be hesitant to get genetic tests due to uncertainty and low awareness of financial law. This option will still place an undue burden on health professionals; the issue of genetic information impacting insurance will not be resolved and will remain a part of every conversation about testing and consent forms.

Given the absence of evidence of adverse selection, we advocate for the total ban. If significant adverse selection is identified, then financial limits may be the most appropriate response. The many benefits of a total ban and the current absence of evidence of adverse selection in Canada do not justify the implementation of financial limits at this point in time.

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

We are not aware of any evidence that Government intervention has given rise to adverse selection. We do know that evidence suggests that consumers wait to get their genetic tests until they can afford or access life insurance.(1) This can take a long time for some consumers, further delaying their long and burdensome diagnostic odysseys. Additionally, there is no evidence that consumers are taking out large policies. For someone living with the financial impacts of mito, including the out-of-pocket costs of health care, paying high premiums for a larger life insurance policy is usually out of reach. Consumers would highly benefit from being able to take out the same policies without having to compromise their health and future financial wellbeing.

Question 7. Should there be any difference in the treatment of diagnostic and predictive genetic tests?

Legislation should avoid differentiating between predictive and diagnostic genetic test results. Distinction between the two is challenging; with future advancements in genomic screening and whole genome sequencing, the line between these categories may completely vanish. Mitochondrial disorders provide a good illustration of this challenge for rare genetic diseases. There are over 350 identified genes that are known to cause mito, with patients experiencing varying degrees of severity. It is possible for three different people to have the same gene mutation: one totally asymptomatic, one with only hearing loss and one with multiple life-threatening symptoms of mito. This diversity makes it hard to label tests as predictive or diagnostic.

Genetic testing for families impacted by mito can be both diagnostic and predictive. For example, a person with symptoms of mito can use genetic testing to confirm their diagnosis. This can lead to cascade genetic testing of other family members. For their family members who test positive, the test indicates they are at higher risk of developing symptoms of mito. Some Australian clinicians will actively monitor those with a genetic risk of mito and follow the same surveillance guidelines recommended for those with symptoms of mito.

Attempting to create these distinctions will create confusion for insurers, healthcare professionals and consumers. Additionally, it is crucial to extend this protection to **all types of genetic tests** that analyse or

interpret genetic information, including genomic tests, epigenetic tests, and polygenic risk scores. This will ensure a robust and adaptable policy for future advancements.

Question 8. Is there an option not listed that you believe should be considered?

It is crucial that the government puts in place mechanisms to **enforce** the ban; self- or co-regulated solutions raise concerns about the possibility of insurance providers having increased influence over consumers. The Canadian GNA introduced criminal sanctions to protect individual rights and serve as a disincentive to violations by insurance providers. The Australian government should also consider including a range of criminal penalties along with the total ban.

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

To safeguard consumers, we need strong rules for financial entities and enforcement of financial law. We also need an independent process for reviewing and reconciling any discrimination reported by consumers. Therefore, the ideal scenario involves **both** the Australian Human Rights Commission (AHRC) and the Australian Securities and Investment Commission (ASIC) **working together**. This will ensure good regulation, enforcement, and protection of consumer rights.

Question 10. Is there an enforcement option not listed that you believe should be considered?

We ask the Australian government to consider adding **fines or punishments** for insurance companies that break the rules. This will discourage insurance providers from doing anything wrong and will reduce the burden on individuals to protect themselves from discrimination. The Canadian NGA can be used as a practical model.

Thank you again for the opportunity to provide this input. Mito Foundation is happy to be contacted for further information on this submission.

Contact person:

Clare Stuart
Policy and Advocacy Manager
clare.stuart@mito.org.au
Phone: 0410 685 181.

References

1. Tiller J, Gleeson P, McInerney-Leo AM, Keogh L, Nowak K, Barlow-Stewart K, et al. Final Stakeholder Report of the Australian Genetics and Life Insurance Moratorium: Monitoring the Effectiveness and Response (A-GLIMMER) Project. 2023 Jun; Available from: https://bridges.monash.edu/articles/report/_strong_Final_Stakeholder_Report_of_the_strong_em_strong_Australian_Genetics_and_Life_Insurance_Moratorium_Monitoring_the_Effectiveness_and_Response_A-GLIMMER_strong_em_strong_Project_strong_/23564538

2. Yvonne Bombard, Bev Heim-Myers. The Genetic Non-Discrimination Act: critical for promoting health and science in Canada. Can Med Assoc J. 2018 May 14;190(19):E579.

3. Tiller J, Bakshi A, Dowling G, Keogh L, McInerney-Leo A, Barlow-Stewart K, et al. Community concerns about genetic discrimination in life insurance persist in Australia: A survey of consumers offered genetic testing. Eur J Hum Genet. 2023 May 11; Available from: https://doi.org/10.1038/s41431-023-01373-1