Medicines Australia's Submission:
Use of genetic testing results in life insurance underwriting.

January 2024

Medicines Australia welcomes the opportunity to respond to the Treasury's consultation paper on the *Use of genetic testing results in life insurance underwriting*.

Medicines Australia supports Option 2: Legislating a ban, without limits, caps or exceptions for the use of genetic testing results in life insurance underwriting, a regulatory intervention similarly in place in Canada. Anything less will create uncertainty for consumers and prevent patients from accessing critical healthcare and participating in life-changing research.

Uncertainty that genetic testing data may impact a person's ability to apply for life insurance may prevent people from seeking a medical diagnosis and accessing treatments. Individuals should be incentivised to actively investigate and understand their own health, rather than facing penalties for exploring health information that could lead to the identification of new medical conditions.

Keeping people healthy by undergoing genetic testing can also lead to improved productivity outcomes by enabling screening, fostering early diagnosis, and promoting timely intervention. This, in turn, helps individuals maintain their well-being, stay in the workforce, contribute to tax revenue, and continue paying their insurance premiums.

Participants are also key to the research and development of new medicines and therapies. However, fear associated with inability to receive life insurance can mean people choose not to participate in vital research, impeding medical progress.

Medicines Australia is the peak body representing the innovative, research-based, medicines industry in Australia. This submission will focus on the regulatory intervention required to ensure patients access healthcare and contribute to medical research without fear of impacting their ability to apply for life insurance.

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?

Genetic testing is a rapidly evolving field that has the potential to transform healthcare and provide more cost-effective treatments to improve patient outcomes. It can provide early diagnosis for illnesses allowing for more effective interventions and contribute to the development of new medicines, both for treatment and prevention. [1]

Fear of life insurance limitations can deter or delay genetic testing, impacting access to crucial screening programs. Diagnosed genetic conditions grant access to specialised screenings, like Medicare-funded breast MRIs for those with BRCA1/2 mutations. [2] Without genetic testing, delayed screenings increase the risk of late cancer detection, straining both the healthcare system and individual survival prospects.

Implications of genetic testing results can extend beyond the individual being tested to their family members. Parents of sick children may hesitate to have their children genetically tested as it may reveal predispositions to illnesses of other family members, which in turn may affect their ability to qualify for life insurance. [3]

Additionally, avoiding or delaying testing due to concerns about life insurance implications can also disqualify individuals from research where genetic information is required. In an Australian clinical trial exploring a new use for an existing medicine in preventing breast cancer among BRCA1 mutation carriers,[4] patients who forego genetic testing will miss out on the potential benefit of access to a clinical trial. The lack of genetic testing also means potential trial participants are unavailable for involvement in crucial research studies.

Pharmaceutical research and development will also be hindered by genetic testing hesitancy. The reluctance of participants hinders progress by limiting genetic data availability, slowing down advancements in treatments, and affecting the diversity and size of participant pools in research studies, [5] particularly in rare diseases where patient numbers are inherently limited. [6] Ultimately, patients will miss out on access to free cutting-edge medical innovations through clinical trials, and the new treatments they are developing.

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's findings highlight several inadequacies in the current Financial Services Council (FSC) Moratorium, posing insufficient protections for consumers. These include:

- Poor awareness and understanding of the moratorium among consumers, health professionals, and financial advisers, contributing to a lack of informed decision-making.
- The financial thresholds set by the moratorium, limiting disclosure requirements for life policies under $500,000, deemed too low by stakeholders, impeding individuals from obtaining adequate life insurance coverage.
- Instances of non-compliance by life insurance companies, including inappropriate inquiries about genetic testing, raise concerns about the effectiveness of the moratorium.

These shortcomings underscore the need for more robust legislative measures to address genetic discrimination in the Australian life insurance industry.

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

N/A. Medicines Australia is not a direct consumer.

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?

Medicines Australia supports a total ban, without limits, caps, or exceptions rather than a partial prohibition as the only appropriate option. This would be consistent with the recommendations in the A-GLIMMER report and international approaches including *The Genetic Non-discrimination Act* introduced in Canada in 2017. [7]

A legislated ban on genetic discrimination, covering both requesting and using genetic data, is crucial to prevent discrimination. This approach eliminates uncertainty inherent in self-regulation and

provides clarity to consumers, researchers, and health practitioners. It ensures the protection of public health interests and can be effectively enforced by regulators.

5. What are the key concerns with each option?

Option 1: No Government intervention: This option is unacceptable as it perpetuates discrimination, erodes public trust, impedes progress in genomic medicine and research, and reduces access to potentially life-saving diagnosis and treatments. This approach would fail to address the concerns outlined in the A-GLIMMER report.

Option 2: Legislating a ban: A total, permanent ban will provide certainty to consumers when having genetic tests that the results, life insurers would be prohibited from requesting or utilising any adverse genetic testing results to inform their underwriting calculations.

A partial ban in *Option 2*, as used in the UK, [8] still creates uncertainty and fails to instil confidence in consumers. The UK's partial ban example has been in place for 2 decades, and the public has become comfortable with an expected level of protection. However, no such expectation exists in Australia, and the A-GLIMMER report found that Australians do have significant fears about insurer use of their data.

Option 3: *Legislating a financial limit:* This option faces similar issues as a partial ban, providing only partial protection and introducing complexity and uncertainty. Both *Option 3* and a partial ban in *Option 2* still require consumers and healthcare professionals to navigate intricate financial laws, which may lead to misinformation and confusion. The preference is for a total ban to ensure clarity, confidence, and focus on health information in genetic testing decisions.

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

Medicines Australia cannot provide a specific assessment of the impact of a legislated ban on the insurance market. However, it acknowledges the mixed and sometimes contradictory evidence from other jurisdictions, as outlined in the consultation paper.

Prioritising public health interests should be the top priority. Any system that deters consumers from undergoing genetic testing could result in delayed diagnosis and treatment, potentially affecting both quality of life and life expectancy. Moreover, hesitancy towards genetic testing will impact medical research and development, as previously discussed.

Ensuring access to genetic testing without fear of insurance repercussions is crucial for advancing healthcare outcomes and innovation.

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

With the advent of whole genome sequencing, it is increasingly difficult to distinguish between predictive and diagnostic tests. The challenge arises because both types of tests can involve sequencing much or all of the genome. The crucial difference lies in the test's purpose—diagnosing a suspected condition versus predicting susceptibility to a condition—rather than the methodology used. [9]

The Canadian *Genetic Non-discrimination Act* did not distinguish between types of tests, but rather applied the protection to all genetic tests. [10]

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

Medicines Australia reiterates that a total ban, without limits, caps, or exceptions rather than a partial prohibition as the only appropriate option and would address the issues raised in the A-GLIMMER report.

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

Both the Australian Human Rights Commission (AHRC) and the Australian Securities and Investment Commission (ASIC) have essential roles to play.

ASIC is tasked with regulating financial entities and enforcing financial services laws, making it appropriate for overseeing legislation that mandates insurers to refrain from discrimination.[11] However, while ASIC can enforce these laws, individual consumers cannot directly seek recourse through ASIC.

The AHRC, which investigates and resolves discrimination complaints, can in turn serve as a vital resource for individuals experiencing discrimination. The AHRC provides free, accessible information and independent review services, though it lacks enforcement powers. [12]

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

The Australian government should consider including a range of appropriate penalties for breaches by life insurance providers, similar to those established in Canada. The Canadian *Genetic Non-discrimination Act* features criminal penalties, aiming to enable the state to defend individuals' rights without relying on individual funding. This approach serves as a robust deterrent against violations by insurance companies, emphasising the seriousness of the consequences for non-compliance.[13]

Should you have any questions about Medicines Australia's submission, please do not hesitate to contact me.

Yours sincerely,

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