Consultation Response- Use of genetic testing results in life insurance underwriting

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Via Email genetictestinglifeinsurance@treasury.gov.au

Summary

InGeNA supports **Option 2: Legislating a Ban**.

InGeNA's position on the use of genetic testing results in life insurance underwriting is:

- Legislation should be introduced which bans life insurance companies from requesting genetic test results and using those results in life insurance risk assessment, thus giving consumers confidence that they can have genetic testing and be empowered to manage their health without fear of discrimination.
- There should not be exemptions, caps or limits, giving consumers and healthcare professionals confidence and clarity.
- Oversight should be provided through enforceable legislation with penalties and a clear, easily accessible, pathway for consumer complaints.

Genomics is a rapidly changing field which has the potential to revolutionise prediction, prevention, diagnosis and treatment at individual, family, cohort and population levels over the coming years. Given the complex scientific concepts behind genomics, and the enormous amount that is as yet unknown even at the most advanced level of genomic research, life insurance assessment teams may not have the expertise to understand or incorporate the nuances and variabilities of genetic findings into underwriting. The work by groups such as Australian Genomics[1], Melbourne Genomics Health Alliance[2], Queensland Genomics Health Alliance[3] and others has proven the economic, societal and life changing impacts genomics-informed healthcare can have. Widespread genomics screening and prediction supporting people to manage their risk factors with the assistance of healthcare professionals, with early intervention if required, will ultimately reduce overall risk for life insurers as well as benefit society.

The financial and activity burden on our healthcare system can be significantly reduced through genomics-informed planning and intervention. By preventing disease development and progression through risk stratification and prediction, more precise diagnosis and therefore treatment, and targeted therapies as part of pharmacogenomics, genomics is already revolutionising the potential for precision medicine and disease prevention and treatment.

Australian industry, the Australian Government through the Genomics Health Futures Mission[4], and state and territory governments, invest millions of dollars in genomics research and development. InGeNA is committed to increasing the adoption of and access to genomics to benefit the health and wellbeing of all Australians. Without a clear, enforceable legislated policy position which bans the use of genetic testing results in life insurance underwriting, there is a risk that this investment will slow as Australian researchers, clinicians, industry and investors lose confidence in the potential

[1] Home — Australian Genomics
[2] Melbourne Genomics Health Alliance
[3] Queensland Genomics
[4] Genomics Health Futures Mission | Australian Government Department of Health and Aged Care

uptake by Australians who could benefit from genomics. Indeed, industry investment could flow out of Australia.

Complexity and uncertainty are enemies of good public policy, with the potential to undermine public confidence in government. Exemptions, limits and caps would make legislation more complex, harder to understand and keep up to date with, more costly to maintain, and more difficult to enforce.

Healthcare professionals are required to work within their defined scope of practice under the AHPRA[5] regulations and the registration for their specific profession. Unless there is an unqualified legislative ban, they will continue to have an obligation to ensure that consumers are aware of the financial and life insurance risks of undertaking genetic testing before a test is taken. Healthcare professionals are not trained in financial matters. For the increasing number of practitioners in private practice, financial discussions will be outside the scope of their Professional Indemnity Insurance and could therefore even expose them to additional risk.

InGeNA is committed to the Quintuple Aim of Healthcare[6]. The most recently added, fifth, element is Equity. InGeNA believes that the introduction of a comprehensive legislative ban is an equity issue to ensure that all Australians can confidently choose to participate in the benefits genomics can bring without fearing for their ability to get life insurance.

InGeNA believes the best model for Australia to follow is Canada's Genetic Non-Discrimination Act (GDNA) legislation[7]. This has been in place since 2017. Having lived in Canada and worked in the Canadian health system, InGeNA's Chair can attest to the similarities between our countries – culturally, financially, and socially. Both countries have:

- a commitment to universal healthcare;
- a federated system of government and healthcare governance;
- publicly and privately funded care (noting that Australia's private insurance cover is much broader and more comprehensive than Canada's);
- indigenous populations facing many of the same social, health, equity and access challenges;
- a relatively small population spread over large distances; and
- a culturally, genetically, and linguistically diverse population as a result of generations of immigration from many parts of the world.

Many of the insurance underwriters operate globally and have been able to accommodate legislative bans on the use of genetic information by insurance companies in other countries without apparent disruption or threat to their business or the accessibility of life insurance in those jurisdictions. Therefore, there should be no concern in Australia that an equivalent prohibition would make insurance companies unviable or have such an impact on premiums so as to make life insurance unaffordable.

[5] Australian Health Practitioner Regulation Agency - Home (ahpra.gov.au)
[6] The Evolution of the Quintuple Aim - PMC (nih.gov)
[7] https://laws-lois.justice.gc.ca/eng/acts/G-2.5/index.html

Overview of InGeNA[8]

Making personalised healthcare accessible to all Australians
by harnessing the collective skills and expertise of industry
to accelerate the adoption of genomics

InGeNA Ltd is the industry peak body for organisations working in genomics in Australia. Our members work across areas such as diagnostics, therapeutics, software, data, and analytics. They range from large multi nationals, which bring insights and expertise from their global work and networks, to small innovative Australian startups. We are committed to collaboration, working with other parts of the genomics ecosystem, including patient/consumer groups, to ensure genomics is embedded in our health system in a sustainable way and can achieve clinical and efficiency benefits.

For additional information or to discuss InGeNA's submission, please contact:

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[8] Industry Genomics Network Alliance - InGeNA

Response to Consultation Questions

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?**
   Genomics is already impacting a wide spectrum of diseases and conditions, as evidenced by the range of projects being undertaken in Australia and globally, and the new discoveries regularly announced in the medical literature. Findings related to one disease type can, at times, be found to also relate to other diseases and the traditional boundaries between fields of health care and medical research are becoming less clear.
   There is now publicly funded genetic testing for a range of diseases, and applications for new MBS items are ongoing. As a result of ongoing discoveries, these will continue to expand at a rapid pace.
   Research shows that consumers are reluctant to have predictive or screening tests, reproductive tests, or test their children for rare diseases if they fear discrimination or are unclear about the potential life insurance impacts. Many are also reluctant to participate in research for the same reason. This caution is not limited to a particular type of test, disease or area of medicine, and will only increase as genomics becomes part of mainstream medical care for prevention, diagnosis and treatment across the disease spectrum.
   As the scope of genomics increases, the benefits become more widely understood, and the price of genomic testing continues to fall, we would like to see every Australian have access to such testing to understand their risks and potential impacts for future generations without any fear of discrimination.

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?**
   Awareness – The A-GLIMMER Report[9] found a low level of awareness by both healthcare professionals and consumers.
   Financial thresholds – One of the problems with financial thresholds is that they need to be regularly reviewed, updated and communicated, which adds to the cost of maintaining. This also contributes to uncertainty and confusion. In addition to the findings of the A-GLIMMER Report that the financial limits are inadequate, an important consideration is that the current financial thresholds do not cover paying off a mortgage for many Australians[10]. However, while an increased financial limit may provide better coverage for some consumers, merely increasing the financial limit would not adequately resolve the issues of consumer deterrence and uncertainty that have been demonstrated.
   Self-regulation and Compliance - The A-GLIMMER Report shows that both consumers and healthcare professionals do not trust that self-regulation is effective and there is evidence that consumers are hesitant to have tests undertaken or participate in research as a result.
   The A-GLIMMER report found instances of non-compliance by some insurers.
   The 2023 Edelman Trust Barometer[11] shows that Australian's trust in the Financial Services Sector and, specifically, Insurance Companies is low ("negative"). The Banking Royal

[9] Home - Australian Genetics and Life Insurance Moratorium | Monash University
[10] Lending indicators, November 2023 | Australian Bureau of Statistics (abs.gov.au)
[11] Edelman | 2023 Edelman Trust Barometer

Commission[12] found many governance failures in the Financial Services Sector (includes insurance) which resulted in a tightening of the regulatory framework with greater enforcement and penalties. The need to move away from self-regulation to enforceable controls in key areas was an important part of that.
Enforceable legislation to ban the use of genomics testing in life insurance will provide consumers and healthcare professionals with certainty and confidence that they can access the best possible tools in healthcare without any fear of discrimination.

3. **As a consumer, has your willingness to undertake genetic testing been impacted by the existing Moratorium?**
InGeNA is an industry body. However, we work closely with consumer groups and are aware of consumer concerns about potential discrimination by life insurance companies. Further, we were collaborators on the A-GLIMMER project, which showed that there is patient/consumer unwillingness to undertake genetic testing or participate in research projects due to the uncertainty and fear around genetic discrimination in life insurance, despite the introduction of the self-regulated moratorium.

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?**
InGeNA supports Option 2: Legislating a Ban
InGeNA believes a full ban should be legislated which prevents life insurers requesting, accessing or using genetic testing in assessing risk. There should be no limits, caps or exclusions. It should provide certainty for consumers, healthcare professionals, researchers and industry, and be legally enforceable.
Legislation should allow for consumers to provide a negative test if there is a family history and should they choose to disclose the fact that they have tested negatively to that gene.
It is important that the legislation limits potential loopholes and workarounds that might provide insurers with other ways of either refusing insurance or increasing premiums, for example by requiring that individuals have a genetic test before offering insurance or refusing to offer cover or consider an application for cover on the basis that an individual has chosen not to have a genetic test.
InGeNA believes that the most appropriate model to base Australia's legislation on is the Canadian GNDA legislation. This is also consistent with the findings and recommendations of the A-Glimmer Report.

5. **What are the key concerns with each option?**
Option 1 – No Government Intervention
InGeNA does not support this option.
This option implies the status quo. Whilst this may appear easier for the Insurers (such as not having to update policies), in the long run it is not beneficial for insurers, for healthcare professionals, for consumers, for industry, for researchers, or for the country.
Without intervention and a complete, unqualified ban, consumers could be discouraged from taking out life insurance, thereby increasing the burden on the welfare system; if it means that there is not the expected adoption of genomics at scale or there is a lack of participants for

[12] Final Report | Royal Commissions

research this could result in a slowing of investment by industry and government, and Australia may fall behind the rest of the world; Australians will have suboptimal health outcomes and the greatest impact is likely to be on those already disadvantaged.

With the lack of trust in the financial services sector, lack of awareness and effectiveness of the Moratorium, and the increasing scope and potential benefit of genomics, consumers should not feel like they must choose between life insurance and genetic testing.

Healthcare professionals would have to ensure that consumers understand the potential life insurance implications of undertaking genetic testing. This is outside their scope of practice, diverts the focus from the critical clinical considerations, and may also result in them having to work with patients who are not getting the most targeted and precise diagnosis or care nor the best outcomes.

It is noted that the Australian Council of Life Insurers is supportive of government regulation to give Australians certainty, so they may well have recognised the potential benefits to insurers that will flow from increased access to genetic testing and improved health across the population.

Option 2 – Legislating a Ban

InGeNA supports legislating a complete ban and does not support any partial ban

An unqualified ban, giving consumers and healthcare professionals confidence and certainty, is the only option that will resolve the current issues and ensure that the full potential of genomics is able to be realised to benefit all Australians.

A partial ban with exclusions or other limitations would create uncertainty and a complex system requiring regular updating and communication to consumers and healthcare professionals. Consumers are likely to be concerned about any exclusion list being amended and the potential impact that could have on their situation. It would also lead to a continued lack of willingness to have genetic testing and to participate in important research projects, as consumers would have no confidence that their genetic findings might not in the future end up on a list of exclusions. Genetic information is set from birth and can't be "unknown" in future, so a fear of future changes will continue to deter consumers from having testing.

With a full ban giving certainty, insurers may find that more people take up life insurance and insure to an adequate level. This is beneficial to consumers, insurers and to government with the resultant reduction on the welfare system if people are adequately insured.

As genomics matures and becomes more embedded across our health system, insurers will likely benefit from a reduction in untimely deaths as a result of more precise prediction and earlier interventions.

Option 3 – Legislating a Financial limit

InGeNA does not support any financial limits

A financial limit may work for some consumers , but is unlikely to remove the fear and deterrence currently experienced. Limits would need to be regularly reviewed to ensure appropriateness and any changes would need to be communicated, creating significant and ongoing issues with awareness, which is already low in this area. Financial limits would add complexity and uncertainty, and consumers may not be aware of them. Consumers might also be concerned about potential changes and how those could impact them in future. Further, as discussed above, this option would still require healthcare and research professionals to be aware of and have financial discussions about these implications, limits and risks with their patients and research participants.

6. **Is there any evidence to suggest that Government intervention may give rise to adverse selection?**
   We are not aware of any evidence of adverse selection related to genetic testing and life insurance in other countries with bans. Consumers are interested in genomic testing for their health and wellbeing, managing their risk factors and ensuring they get the best possible diagnosis, treatment and management.

7. **Should there be any difference in the treatment of diagnostic and predictive genetic tests?**
   InGeNA believes that legislation should cover all genetic testing. To do otherwise would create unnecessary complexity and confusion.
   It is difficult to clearly differentiate between predictive and diagnostic tests and, over time, as screening tests become more common this will increasingly be the case.
   The definition of genetic testing in the legislation should be broad to avoid confusion and potential loopholes.
   Consumers should have the confidence to know that they can get access to the best possible tools to manage their long term health whilst also having access to life insurance.

8. **Is there an option not listed that you believe should be considered?**
   No, InGeNA believes there should be a total, unqualified, ban for the reasons outlined above.

9. **Of the options outlined above, which do you think is the most appropriate enforcement body given capacities and enforcement powers?**
   InGeNA believes there is a role for both Australian Securities and Investment Commission (ASIC) and the Australian Human Rights Commission (AHRC).
   ASIC should include legislative compliance as part of its financial services enforcement activities.
   In addition, there should be a clear, independent pathway for consumer complaints. It is most likely that complaints will be regarding genetic discrimination by life insurers. Therefore these would logically fall within the remit of the Australian Human Rights Commission (AHRC) given it is a discrimination issue. While the Australian Financial Complaints Authority (AFCA) may have a role if a matter is related to financial process such as incorrect invoicing or payouts, it is industry funded and therefore may not be trusted by consumers given the sensitive nature of health information related to genomics. Enforcement and consumer complaints pathways must provide for actual and perceived independence.

10. **Is there an enforcement option not listed that you believe should be considered?**
    InGeNA believes that the legislation should be legally enforceable through the courts with criminal penalties as is the case in Canada. This will be a significant compliance incentive. Any action should be funded by the government given the economic disparity between individuals and insurance companies.