Rare Voices Australia Submission: Consultation on the use of genetic testing results in life insurance underwriting

Executive Summary

Rare Voices Australia (RVA) welcomes the opportunity to provide a submission to The Treasury consultation on the use of genetic testing results in life insurance underwriting.

RVA's position is informed by the foundation principles in the Australian Government's National Strategic Action Plan for Rare Diseases (the Action Plan)[1], 'person-centred' and 'equity of access'. RVA's position also aligns with Action 2.4.1 in the Action Plan, 'Develop policy that supports people living with a rare disease to have timely and equitable access to new and emerging health technologies'.

RVA is the national peak body for the estimated 2 million Australians living with a rare disease. RVA provides a strong, unified voice to advocate for policy as well as health, disability and other systems that work for people living with a rare disease.

RVA led the collaborative development of the Action Plan, which was informed by extensive multistakeholder consultation. The Action Plan was launched in February 2020 with bipartisan support, and RVA is now leading its collaborative implementation. The Action Plan provides guidance and direction around key goals and priorities of the rare disease sector in Australia and includes a strong patient voice.

About Rare Disease: Relevance to this consultation

Collectively common, rare disease affects approximately 2 million Australians. There are over 7000 known rare diseases and 80 per cent have genetic origins.

Rare diseases, like many other chronic diseases, are often serious and progressive. They typically display a high level of symptom complexity and thus are a significant cause of ongoing health and psycho-social challenges. There is no cure for many rare diseases, and so improving quality of life and extending life expectancy of people living with a rare disease relies on appropriate treatment and care.

With at least 80% of rare diseases having genetic origins, the implications of genetic discrimination for people living with a rare disease, their families and future generations are far reaching. In line with Canada's recent approach to this issue, RVA recommends legislating a total ban without any limits, caps or exclusions to prohibit life insurers from requesting or utilising any adverse genetic testing results to inform their underwriting calculations. Without this change for strong protections, including government oversight and the implementation of enforcement pathways to prevent genetic discrimination, RVA is concerned that Australians living with a rare disease will continue to face high levels of uncertainty around genetic discrimination.

Disclosures

As a partner organisation on the A-GLIMMER study, RVA contributed rare disease policy expertise, including feedback on survey design, dissemination of surveys and feedback on the final stakeholder report.

Rare Voices Australia's Responses to Consultation Questions

RVA's responses to the consultation questions are based on peak body expertise and knowledge of the broader rare disease community and guided by the Action Plan.

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?

Over 80% of rare diseases have genetic causes. This puts rare disease health care and medical research in Australia at risk from participant reluctance to take genetic tests due to concerns around the impact on access to life insurance.

Rare diseases are often difficult for health professionals to diagnose, not only due to rarity but also high levels of symptom complexity. Early diagnosis enables the best clinical care, treatment options, access to services, peer support, increased reproductive confidence and access to participation in clinical trials.

For people living with rare or undiagnosed rare diseases, anything that fuels unnecessary hesitation, causes delays, or is an obstruction to undergoing a diagnostic test, including genetic testing, could cause serious, irreversible, and even life-threatening consequences as a result of delays in access to potentially life changing or lifesaving treatment.

Barriers to diagnostic testing, in particular genetic testing, are contrary to Australian government policy, including the Action Plan. Specifically, they are direct impediments to the implementation of several key priorities and actions in Action Plan including:

> **Priority 2.2.** Ensure diagnosis of a rare disease is timely and accurate.
>
> **Action 2.2.1.** Ensure all Australians have equitable access to a range of diagnostic tools and tests, providing the best chance of early and accurate diagnosis.
>
> **Action 2.4.1.** Develop policy that supports people living with a rare disease to have timely and equitable access to new and emerging health technologies.

The Action Plan further highlights several negative consequences of diagnostic delay and misdiagnosis:

> 'Both diagnostic delay and misdiagnosis are common features of rare diseases and can negatively impact the level of care and support received by individuals. Without a diagnosis, Australians living with an undiagnosed rare disease cannot be provided with an accurate prognosis and have no access to evidence-based treatment. Moreover, a lack of diagnosis is reported as a roadblock to obtaining adequate funding from the National Disability and Insurance Scheme (NDIS).'

Barriers to effective research are also commonplace in rare disease. These barriers include a lack of data due to inherently small patient numbers, and limited interest in, and funding for, rare disease research. Anything that further hampers rare disease research efforts should be prevented. In a space where numbers are inherently small, and complexity and heterogeneity are high, genetic discrimination by life Insurers has the potential to impede recruitment into rare disease research programs further.

RVA recommends a strict ban of genetic discrimination to reduce reluctance of individuals who may otherwise participate in these important research programs, which are vital to improving outcomes for Australians living with a rare disease. This ban is immediately pertinent to preserving the success of several Australian rare disease research programs focused on genetics and genomics in rare disease, particularly around diagnostic testing, including undiagnosed programs.

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?

Understanding the complex implications, including the financial impacts, of genetic testing for people living with rare disease and their families requires specialist rare disease knowledge. From RVA's perspective, a commercially motivated Moratorium, developed and approved by the insurance sector for the insurance sector, is not person-centred, nor can it adequately capture, or respond to, the complexities of rare disease.

RVA is concerned about the lack of government oversight and enforcement pathways to prevent uncertainty related to genetic discrimination by life insurers. Since the Moratorium is not binding for life insurers who are not Financial Services Council (FSC) members, consumers, including 80% of Australians living with a rare disease are vulnerable to genetic discrimination, by non-FSC members. The lack of consistency around compliance and accountability of life insurers with the Moratorium increases uncertainty, and risks inequities in access to life insurance for consumers, particularly those living with genetic rare diseases. In addition, flexibility in the implementation of the Moratorium leaves a lot open to interpretation by life insurers who do not have specialist rare disease expertise.

Raising the awareness of life insurers around the complexities of rare disease or setting financial parameters on life insurers will not solve the problem and may lead to more uncertainty, confusion and distrust. A total ban with without any limits, caps or exclusions that is legislated and enforced by government to prohibit all life insurers from genetic discrimination, is the only way to increase transparency, accountability and enable equity of access to life insurance for all Australians.

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

RVA's position on this consultation is based on peak body understanding of the rare disease sector. RVA is aware of concerns in the rare disease community, from both individuals and families, around the implications of genetic testing on access to life insurance. With 80% of rare diseases having genetic origins, any genetic discrimination by life insurers would disproportionately affect the willingness of this group of Australians to undertake genetic testing. As highlighted in RVA's response to Question 1 above, there can be serious and potentially life-long health-related impacts for some individuals making a conscious choice against genetic testing. From a rare disease perspective, allowing genetic discrimination by life insurers does not only raise issues of equity. It is also irresponsible to impose on the decisions of people living with a rare disease, who require genetic testing for better health and wellbeing outcomes, the need to weigh choices between health and financial security for themselves or their families.

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?

Consistent with Canadian legislation and the recommendations made in Monash University's A-GLIMMER report, RVA recommends Option 2: Legislating a total ban, without any limits, caps or exclusions, to prohibit life insurers from requesting or utilising any adverse genetic testing results to inform their underwriting calculations.

A total ban is the best protection for the over 6 million Australians and their families living with genetic rare diseases or undiagnosed genetic rare diseases. It is vital to preventing the far-reaching harms that result from any further impediments to the timely and accurate diagnosis of a rare disease.

At the time of writing the Action Plan, 'thirty per cent of Australian adults living with a rare disease are impacted by a diagnostic delay of more than five years, while almost half have received at least one misdiagnosis. This has physical, psychological, emotional and financial costs for the person and family living with a rare disease.'[1] Therefore, every effort must be made to prevent further delays to diagnosis, including a total ban on genetic discrimination by life insurers.

The Action Plan also highlights that to respond effectively to rare diseases, Australia needs to reduce uncertainty through policy. One of the steps to this end, is a total ban against using genetic testing results in life insurance underwriting. RVA strongly agrees with the issues raised in the Consultation Paper that will remain problematic in the case of partial ban. For Australians living with rare disease, a total ban is vital to increasing clarity and certainty around access to potentially life changing genetic testing both through routine health care and as part of research.

5. What are the key concerns with each option?

Discrimination by life insurers adds greater complexity to the numerous challenging decisions and inequity that Australians living with a rare disease already face. Without regulatory intervention (as outlined in Option 1: No Government intervention), RVA is concerned that Australians living with genetic rare diseases, by no fault of their own, will face disproportionate consequences compared with the general population. These consequences extend beyond barriers to accessing life insurance. The possibility that some individuals may choose to avoid a diagnosis through genetic testing due to concerns over access to life insurance could prevent their access to life changing or lifesaving treatments and lead to, avoidable, serious progression of disease. This will lead to a greater burden on health, disability and other government systems, which already struggle to effectively respond to rare disease.

Limited data and knowledge are inherent features in rare disease. Option 1, do nothing, will not only contribute to ongoing deterrence of Australians living with a rare disease to access genetic testing but also impede their choice to participate in genetic and genomic research to advance understanding of, and vital new treatments for, rare disease.

Option 2, Legislating a partial ban, and Option 3, Legislating a financial limit, also leave Australians living with a genetic rare disease open to discrimination by life insurers. A partial ban will be insufficient to reduce uncertainty for people living with a rare disease and may still result in a decline in participation in research programs related to genetics and genomics.

RVA is concerned that a partial ban will leave too much to the discretion of life insurers, cause ongoing confusion among consumers and leave Australia's already stretched genetics workforce with the burdensome task of maintaining a current understanding of the these financial laws in order to educate patients. Furthermore, new knowledge in rare disease, thanks to genetic and genomic medicine, is growing rapidly and often leads to nuances and complexities, which cannot be addressed with a partial solution.

To mitigate uncertainty, increase clarity, protect the interests of people living with genetic rare diseases and their families, prevent negative consequences on the health care system and other systems and enable research into genetic rare disease, RVA strongly recommends **Option 2: Legislating a total ban, without any limits, caps or exclusions.**

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

There is no evidence, including internationally, to suggest that Government intervention leads to adverse selection for the rare disease community.

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

It is very difficult to distinguish between predictive and diagnostic genetic tests. From a rare disease perspective, the differences are an important consideration and the complexities around the two require extensive deliberation by an interdisciplinary team of experts, including lived experience. An attempt to categorise these tests will contribute further uncertainty and confusion for insurers, health professionals and Australians living with rare disease. It may even have negative consequences on the future implementation of genomics in government population screening programs such as newborn bloodspot screening.

In line with RVA's position to strongly support **legislating a total ban, without any limits, caps or exclusions,** such deliberations about the implications of these tests by life insurers would become outside scope/irrelevant, but this does not affect the life insurers right to require that a person disclose their diagnosis.

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

As highlighted previously, no self-regulated or co-regulated solutions are adequate as they do not address the high levels of uncertainty for people living with a rare disease and their health professionals, nor do they ensure the transparency and accountability of life insurers to the public.

In line with the Canadian Genetic Nondiscrimination Act, to protect the rights of every Australian to access life insurance, including those living with a rare disease and their families, RVA recommends a range of penalties, including criminal penalties, are considered against life insurers who do not comply with the requirements of the enforcement body, and compliance should not be dependent on any membership or alliance with another entity.

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

RVA recommends both the Australian Human Rights Commission (AHRC) and Australian Securities and Investment Commission (ASIC) should have a role to play in enforcement and pathways for people living with a rare disease who are affected by genetic discrimination.

RVA agrees with the evidence-based position of the A-GLIMMER Report highlighting the Australian Human Rights Commission (AHRC) as the most appropriate enforcement body to provide person-centred and independent education and support to individuals who experience genetic discrimination that is free and accessible.

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

Australians living with a rare disease experience a range of common barriers and challenges across their diagnosis and treatment journey, including profound psychosocial and economic hardships. Preventing any additional challenges and stressors on this group of Australians is vital. To this end, RVA strongly recommends that people living with a rare disease and their families are protected and defended, by law, through a total ban against genetic discrimination by life insurers, without any limits, caps or exclusions, that is enforced through a range of penalties, including criminal sanctions.

References

1. Australian Government. Department of Health. National Strategic Action Plan for Rare Diseases. Canberra; 2020. 63 p. https://www.health.gov.au/sites/default/files/documents/2020/03/national-strategic-action-plan-for-rare-diseases.pdf