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Response from AstraZeneca to Treasury Consultation:

Use of genetic testing results in life insurance underwriting

Executive Summary

AstraZeneca welcomes the opportunity to submit a response to the Treasury Consultation on the use of genetic testing results in life insurance underwriting. Alongside other healthcare organisations, AstraZeneca supports a total ban without any limits, caps or exclusions on the use of adverse genetic testing results by life insurers in Australia.

Genetic testing is a critical diagnostic tool in many patients' treatment journey and has the potential to optimise treatment pathways and health outcomes as well as the health and wellbeing of patients' families, including future generations. Depending on the disease, genetic information can guide screening and prevention strategies as well as precision medicine treatment selection which ultimately reduces the burden on our health care system and health budget.

The implementation of a **total ban** on life insurance discrimination predicated by genetic testing is required to ensure this occurs unconditionally and equitably.

Responses and rationale

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?

Within the next decade, it is believed the future of medical science will require almost every Australian to have some form of genetic test to aid in the early detection, prevention, diagnosis and management of disease.

All fields of health care and medical research are impacted by participant reluctance to take genetic tests due to the impact on access to life insurance. Genetic tests are critical to identify patients who may benefit from lifesaving precision medicines, and has the potential to optimise treatment pathways and health outcomes as well as the health and wellbeing of patients' families, including future generations.

The explanation for patient reluctance to access genetic tests was realised in an Australian survey published in the European Journal of Human Genetics in 2023 by Tiller et al which surveyed consumers who had taken, or been offered, clinical genetic testing for adult-onset conditions, to gather views and experiences about the moratorium and the use of genetic results in life insurance, including its regulation. Results of the survey revealed that a third of these consumers reported difficulties in accessing life insurance, including insurers rejecting applications, financial advisers telling respondents that their applications would be rejected, and insurers placing conditions on insurance policies or charging higher premiums.

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?

All aspects of the current Moratorium – consumer and industry awareness, financial thresholds, compliance by life insurance - provide inadequate protections for consumers. Current restrictions should be removed so that the full potential of genetic testing to positively impact the health and wellbeing of Australians can be realised.

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

While AstraZeneca as an entity is not a consumer of the health care system, we would like to highlight the significant impact of the existing Moratorium that we understand has on healthcare professionals (HCPs).

There is a significant burden placed on oncology HCPs (medical oncologists; surgeons; nurses) who not only conduct patients' pre-test consenting for genetic testing, but also carry the duty of care to counsel patients on the financial implications of their genetic test results. This is outside the scope of their clinical practice and training and places the burden of responsibility upon them to understand the complexities and nuances of insurance law and practice, rather than focusing on health information and the clinical actionability of genetic test results.

Genetics teams including genetic counsellors, clinical geneticists and genetic nurses are also tasked with advising their patients on complex financial implications. This is required to ensure patients have all relevant information to make an informed decision to proceed with genetic testing. This again places undue consideration not only the genetics team but also the patient who must make significant health decisions based on the potential financial impact on future life insurance.

The existing Moratorium discourages participation in guideline-recommended genetic testing in at risk individuals which may firstly, identify a familial risk of disease that may be mitigated through regular screening and/or preventative surgery; and secondly, identify relatives who do not harbour an existing familial mutation who can therefore avoid unnecessary screening and preventive surgery. If genetic testing was used in both situations, health outcomes could be improved, which could contribute to significant benefits to both the health system and economy. Similarly, the current partial Moratorium also serves as a barrier to genetic testing for cancer patients who may forego the opportunity to access life extending or lifesaving precision medicine by not agreeing to genetic testing both in the clinical setting and within clinical trials, due to life insurance concerns. Evidence of this was found in an Australian survey of colorectal cancer patients, where seven out of 33 patients cited fear of insurance discrimination as the key reason for not proceeding to access genetic testing which would aid in the diagnosis, management and familiar impact of the disease.

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? Would you change any aspects of that option?

AstraZeneca supports a total ban without any limits, caps or exclusions on the use of adverse genetic testing results by life insurers. We believe that this is the only solution that will have a positive impact on the lives of patients by improving access to medicines and healthcare, and remove

patients concerns about their life insurance status during a period where they are navigating serious health diagnoses.

Australia should model the approach of the Canadian Government and their *Genetic Non-discrimination Act*, while also acting to ensure a total ban reflects the recommendations of the A-GLIMMER report from Monash University.

A total ban without any limits, caps or exclusions on the use of adverse genetic testing results by life insurers will provide both certainty and confidence to individuals. A total ban will ensure access to adequate life insurance cover is no longer a barrier to genetic testing as either a preventative health measure or to guide treatment decisions.

Further, a total ban without any limits, caps or exclusions will remove the informal requirement for HCPs to have complex financial conversations with their patients about matters relating to life insurance.

5. What are the key concerns with each option?

If a total ban on the use of adverse genetic testing results by life insurers were to come into effect in Australia, additional education for both HCPs and patients would be required to ensure that knowledge of subsequent options of genetic testing are better understood, and to reinforce the role of genetic testing in prevention, diagnosis and management of disease.

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

Following our comprehensive review of the Treasury's Consultation Paper on this matter, the Canadian example cited suggests that there is limited risk of adverse selection if a total ban was to come into effect in Australia.

A total ban has the potential to provide patients with certainty about their health and financial future, by ensuring they have access to genetic testing results without the impact of any life insurance discrimination.

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

AstraZeneca supports no differentiation in the treatment of diagnostic and predictive genetic tests. A total ban without any limits, caps or exclusions on the use of adverse genetic testing results by life insurers – including both diagnostics and predictive genetic tests – will ensure that individuals are provided with the broadest possible access to genetic testing results that may inform a preventative health measure, a diagnosis, or treatment options.

As cited in the Consultation Paper, Canada's *Genetic Non-discrimination Act* does not distinguish between types of tests. The total ban in place in Canada applies to all genetic tests, and we believe that this is the example that Australia should model.

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

AstraZeneca supports a total ban without any limits, caps or exclusions on the use of adverse genetic testing results by life insurers and cites Canada's *Genetic Non-Discrimination Act* as the appropriate approach for Australia to model for local implementation.

We believe that this is the only solution that will have a beneficial impact on the lives of patients. A total ban without any limits, caps or exclusions will improve health care outcomes for Australians by facilitating identification of at-risk individuals to enable cancer prevention, early detection and access to precision medicines, and will remove the need for patients to be concerned about their life insurance status when they are grappling with serious health diagnoses.

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

AstraZeneca is supportive of enforcement bodies being provided with the power to instruct, govern and enforce this change to life insurance in Australia. The Australian Human Rights Commission would have a role to play in advocating and supporting the rights of patients, and the Australian Securities and Investments Commission would continue its regulation across the life insurance industry.

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

AstraZeneca is supportive of both enforcement bodies - the Australian Human Rights Commission and the Australian Securities and Investments Commission being provided with the power to instruct, govern and enforce this change.

Conclusion

Cancer treatment is rapidly transforming, with technological advances enabling the personalisation of medicines and healthcare.

The availability of genetic testing enables a more targeted approach for clinical decision making, by providing insights into the molecular basis of a patient's disease.

A recent study released by Genomics England analysed 13,880 solid tumours from 33 cancer types, integrating genomic data with real-world treatment and outcome data. It found that more than 50 per cent of tumours harboured one or more gene mutations indicated for testing in a host of cancers including brain cancer, melanoma, head and neck cancers, colon and lung cancers. Therefore, comprehensive genetic testing results for patients may provide more concise cancer diagnoses and a pathway to the most appropriate targeted treatment options for their type of cancer.

Australians require genetic testing to enable the personalisation of healthcare including cancer prevention strategies, and to inform cancer management and access to precision medicines. For genetic testing to be successfully and equitably integrated into clinical practice, patients require the certainty and confidence that their genetic test results will not adversely impact their ability to access life insurance. Similarly, HCPs facilitating genetic testing for patients require the same assurance and to be relieved of the burden of advising their patients on complex financial implications.

AstraZeneca supports a total ban without any limits, caps or exclusions on the use of adverse genetic testing results by life insurers and cites Canada's *Genetic Non-Discrimination Act* as the appropriate approach for Australia to model for local implementation.

There are substantial medical and public health benefits associated with the use of genetic testing by individuals. These public health benefits include, but are not limited to, savings to the health care system, which would be enabled by genetic testing through preventative health measures, earlier diagnosis, and use of targeted therapies for diseases with a genetic disposition.

A total ban on the use of adverse genetic testing results, as described above, would ensure that patients can access the life insurance they need for themselves and their families, while also benefitting from the health information that genetic test results can provide for their diagnosis, and the future health and wellbeing of their families.