

Response to Government Announcement of Total Ban on Genetic Discrimination in Life Insurance September 11 2024

Pathology Technology Australia and InGeNA welcome the government announcement to support a total ban on the use of genomic data by Life Insurers to discriminate against individuals.

"If Australia is to maintain equitable, timely, and economically sustainable healthcare for all Australians we will need to pivot towards more predictive, preventative, and personalised methods of healthcare delivery. Genetic testing will be foundational in this approach, thus the prevailing infrastructure must also evolve." Dean Whiting, CEO PTA.

Genetic testing underpins early detection and prevention programs, identifies at-risk populations, provides accurate and cost-effective diagnoses, and monitors effectiveness of treatment and intervention approaches connected to all cancers and many other genetic conditions.

"Genomics and precision medicine are at the forefront of transforming healthcare, offering unprecedented opportunities to improve patient outcomes. The removal of genetic discrimination in life insurance is crucial to unlocking these benefits for all Australians. The industry stands united behind the ban to ensure that everyone can confidently access genetic testing without fear of repercussions." Dr Erin Evans, CEO InGeNA.

It's important to understand that in many instances, genetic testing is not a static event. That is, our understanding of, and ultimate clinical utility for the resulting data is ever-evolving. A total ban on insurance discrimination will support a pipeline of genetic tests that can predict risk, support preventative decision-making, accurately diagnose genetic-based conditions, and identify targeted treatment options.

Moreover, the potential to better inform patient care rapidly improves as we expand our understanding of genomics, proteomics, transcriptomics, and other medically-relevant practices associated with the collection of genomic data. It is vital that the evolution of a more predictive, preventative, and personalised healthcare approach is not hampered by individuals and their families opting out of accessing information about their own genetics based on fear of insurance discrimination.

This issue has brought together industry leaders and patient advocacy groups in a collective effort to address the significant barriers facing individuals considering genetic testing. The collaboration between these groups highlights the shared commitment to improving healthcare access and ensuring that Australians are empowered to make informed decisions about their health without fear of discrimination.

We would also like to acknowledge the recommendations report by Dr. Jane Tiller and Professor Paul Lacaze and the tireless advocacy of Dr Tiller on this issue. Their research showed that the fear of insurance discrimination deters people from having genetic testing that could save their lives, or from participating in important genetic research that can positively impact many Australians.

We remain committed to promoting the benefits of genomic medicine and ensuring that this ban is supported by the necessary legislation, so these protections can become a reality.

About Pathology Technology Australia

Pathology Technology Australia (PTA) is the peak industry body representing the manufacturers, distributors, and importers of the technology responsible for more than 95% of pathology testing in Australian laboratories, hospitals and the community. More specifically, PTA represents almost all of the manufacturers and suppliers of genomic testing technology. As such our membership have a clear view

of the technological advancements being developed and their strong impact on patient quality of life. In addition, our members partner with clinical and research institutes to develop the genomic applications that enhance diagnosis and targeted treatment.

About InGeNA

The Industry Genomics Network Alliance (InGeNA) is Australia's peak body for genomics and personalised healthcare, bringing together industry leaders across diagnostics, therapeutics, software, data, and analytics. Our members range from large multinationals to innovative startups, all working to accelerate the adoption of genomics and ensure it is embedded in Australia's health system.

InGeNA collaborates closely with stakeholders, including our own consumer advisory group, to ensure that personalised healthcare benefits all Australians. We advocate for genomics to be embedded in our health system in a sustainable way and can achieve clinical and efficiency benefits that improve prevention, and enhance quality of life.



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Industry Genomics Network Alliance