

STRICTLY EMBARGOED UNTIL 0830 on Wednesday 11 September 2024

Australian Government bans genetic discrimination in life insurance: A big win for preventive health

Following the recommendations of a <u>report</u> led by Monash University's <u>Dr Jane Tiller</u> and <u>Professor</u> <u>Paul Lacaze</u>, the Australian Government has today announced that it will legislate to completely ban the use of genetic test results in life insurance underwriting.

Consistent with the recommendations, the Government has announced that the Australian ban will not be subject to any financial limits, caps or exceptions, and will be reviewed after five years.

Dr Tiller, who was lead author of the Monash report, said a ban without exceptions was vital to provide consumers with certainty about the protection of their genetic information into the future.

"Our research has shown that the fear of insurance discrimination deters people from having genetic testing that could save their lives, or from participating in important genetic research. Today's announcement marks a decisive step by the Government to ensure Australians can make genetic testing decisions based on health needs, not financial implications," Dr Tiller said.

Dr Tiller, a Monash University Ethical, Legal and Social Adviser in Public Health Genomics, said today's announcement followed extensive stakeholder consultation. She commended Assistant Treasurer Stephen Jones' commitment to consumer-first policy.

"Minister Jones understood the importance of this issue immediately, and we applaud his engagement and dedication to consumer protection," said Dr Tiller. "Drafting of this legislation must now be prioritised to ensure the crucial protection is implemented urgently."

Professor Lacaze, who is Head of Public Health Genomics at Monash University, welcomed the policy shift and the impetus it created for preventive genomics.

"This decision paves the way for increased access to genetic testing and DNA screening for disease prevention", Professor Lacaze. "The Government can now invest in more testing to enable access to preventive genetic information for all Australians, without fear of genetic discrimination."

Kara Ryan found out she had a *BRCA2* variant, which significantly increases her risk of developing breast and ovarian cancer, through her participation in Monash University's DNA Screen study.

"I had to choose between my health or protecting my life financially", Kara said. "Genetic testing has given me the power to take charge of my health, and now others can do the same without the fear of genetic life insurance discrimination."

Health insurance in Australia is community rated, meaning health insurers already cannot legally use genetic results or any other risk factors to deny coverage or change the cost of premiums.

Life insurance companies, however, *can* legally use applicants' genetic test results to deny them cover or increase the cost of premiums in Australia, even if they do not have any symptoms of disease.

The Government's announced reforms will prohibit life insurers from asking for or using applicants' genetic results to discriminate, and bring Australia into line with other countries such as Canada, which introduced a complete legislative ban in 2017.

It will, however, allow applicants to choose to disclose favourable results that show they do not carry a genetic variant that is known to exist in their family.

Dr Tiller emphasised the importance of bipartisan support, both leading up to this announcement and in the next phase of delivery.

"Support for this legislative reform has come from across the political spectrum, including advocacy from independents and members of the opposition," she said. "Ongoing bipartisan support will be essential to ensure its rapid passage, so that community benefit is delivered in a timely manner."

Contacts

Dr Jane Tiller, project lead: jane.tiller@monash.edu or 0413 741 187

Dr Tiller will be in Canberra from 11-12 September and may be available for media on location.

For other media enquiries please contact:

Monash University Cheryl Critchley – Media and Communications Manager (medical) E: <u>cheryl.critchley@monash.edu</u> T: +61 (0) 477 571 442

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