



Cystic Fibrosis Australia
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9th December 2023

Insurance Unit
Financial System Division
Treasury
Langton Cres
Parkes ACT 2600

Via email: genetictestinglifeinsurance@treasury.gov.au

To the Insurance Unit,

RE: Use of genetic testing results in life insurance underwriting

Cystic Fibrosis Australia is the national peak body representing the 3700 Australians living with cystic fibrosis and is deeply committed to advocating for the well-being and fair treatment of individuals with genetic disorders. Cystic Fibrosis is a challenging genetic condition that has no cure. One in 25 people in Australia carries the cystic fibrosis gene yet as carriers they are asymptomatic. Gene testing is important to help diagnose, treat, and in some cases inform fertility.

The critical nature of gene testing for healthcare purposes far outweighs the importance of any benefit there could be in life insurance underwriting. The suggestion of to disclose genetic testing undermines preventive medicine. However, people could be forced to choose between genetic testing and their life insurance policy! This is not acceptable and the health of Australian citizens must be prioritized.

I am greatly concerned about this proposal and urge your office to implement regulations that prohibit the use of genetic testing results in life insurance underwriting. The advent of genetic testing has brought about tremendous advancements in the field of healthcare, providing valuable insights into medical conditions. However, the use of such information by life insurance companies poses ethical and privacy barriers that warrant meticulous consideration.

Firstly, the incorporation of genetic testing results in life insurance underwriting will lead to discrimination against individuals with a genetic predisposition to certain health conditions. Insurance premiums are meant to be based on actuarial risk and shared across a diverse pool of policyholders. The use of genetic information will unfairly target specific groups of individuals, potentially denying them access to affordable life insurance coverage.

Moreover, the rapidly evolving nature of genetic research means that the interpretation of genetic data is subject to change. What may be considered a high-risk genetic marker today may be reclassified as lower risk or even inconclusive in the future. Utilizing such information for underwriting purposes could result in inaccurate risk assessments and unjustifiably high premiums, further exacerbating the potential for discrimination.

Furthermore, the use of genetic information in life insurance underwriting raises significant privacy concerns. Genetic data is highly sensitive and personal, with the potential to reveal not only an individual's health status but also information about their family members. Allowing insurance companies access to this information could jeopardize the privacy and confidentiality of individuals and their families.

In addition, the fear of genetic discrimination may deter individuals from undergoing vital genetic testing, even for medical purposes. This reluctance will hinder advancements in diagnosis, medical research, and impede individuals from making informed decisions about their health and that of their families. Only recently Medicare coverage was expanded to include cystic fibrosis carrier screening, to ease the financial burden of genetic screening and now there is the possibility that this burden could greatly increase.

Considering these ethical and privacy concerns, I strongly urge your office to take measures to protect against genetic discrimination in the context of life insurance underwriting. You must implement clear regulations that prohibit the use of genetic testing results for such purposes would contribute to a fair and inclusive insurance industry while safeguarding the privacy and dignity of individuals.

Thank you for your attention to this critical matter, and I trust you will take the necessary steps to protect individuals from genetic discrimination in the context of life insurance.

Yours sincerely,

A handwritten signature in black ink, appearing to be 'Jo Armstrong', with a stylized, cursive script.

Jo Armstrong
CEO

Cystic Fibrosis Australia