

Genetic Discrimination in Life Insurance in Australia: Towards regulatory change

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Life insurance companies in Australia can still use genetic test results to discriminate against applicants, a practice banned or restricted by many comparable countries. This report presents new evidence of genetic discrimination by Australian life insurers, including many breaches of current industry policy.

Cancer support organisations Lynch Syndrome Australia and Pink Hope conducted an online survey (initially devised by LSA), which received responses from 176 individuals, 37% (65) of whom reported difficulties accessing life insurance after genetic testing for cancer risk. Of these, 51% (33/65) had no personal history of cancer and were following regular surveillance regimes, and/or had undertaken preventative surgery to reduce risk.

Risk-reduction was often not taken into account by life insurance companies, as it should be. Less than 10% of those who reported no difficulty obtaining insurance (10/111) were able to obtain life insurance at standard rates after genetic testing. This indicates a widespread, not anecdotal, problem. Regulatory change is urgently needed in Australia.

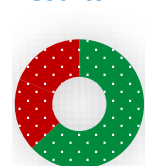
Background

In Australia, there is mounting evidence that individuals are being deterred from predictive genetic testing and participation in research because of insurance fears [1, 2]. The Australian Genetic Non-Discrimination Working Group (AGNDWG) has been lobbying government for a ban on the use of genetic test results in Australian life insurance. The Group made several submissions in 2017 to a Parliamentary Inquiry, which released an official report in March 2018 recommending an immediate ban on the use of predictive genetic test results by life insurers as a matter of urgency [3]. However, to date, no ban has been implemented by the Australian government and life insurers continue to use genetic test results to discriminate against applicants. Here we present new evidence regarding the problem, emphasising the urgent need for regulatory change.

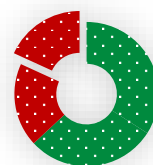
Methods

This study surveyed 176 individuals with genetic mutations that increase the risk of developing cancer. The surveys were distributed through cancer support organisations Lynch Syndrome Australia (LSA) (100 respondents) and Pink Hope (PH) (76 respondents). Respondents were asked about the genetic mutation they had, the surveillance and/or preventative surgery they have undertaken, the insurance products they were able to obtain, and experiences applying for life insurance after having genetic testing. Phone interviews were conducted with a small number of respondents to create case-studies.

Results



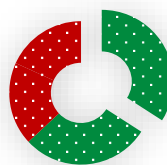
65 people out of 176 reported difficulty accessing risk-rated insurance products at standard rates



33 had no personal history of cancer, were part of a regular high-risk surveillance program and/or had preventative surgery



Only **10** of those who reported no difficulty obtained life insurance products at standard rates after genetic testing



60 people who reported no difficulty already had some sort of life insurance product in place before having genetic testing

Selected case studies

Despite current legal requirements that require life insurance companies to take into account risk-reducing measures, such as preventative surgery and surveillance, in making underwriting decisions, numerous cases demonstrate that this is not always happening. Several case studies set out below – two of which took place in 2018 – demonstrate this problem. In each instance, individuals have proactively taken steps to reduce their cancer risk, often through preventative surgery, and often as part of a rigorous surveillance regime, yet have been unable to obtain cover at standard rates.

Name* and situation <small>*names have been changed for confidentiality</small>	Personal history of cancer	Risk-reducing surgery & surveillance	Life Insurance applications	Appeals
<u>Evelyn</u> 47y/o BRCA mutation detected six years ago	No	Bilateral preventative mastectomy and oophorectomy	Financial advisor unable to secure any cover in 2018. <i>“They tried everywhere, but as soon as they mentioned BRCA1, they could not get me any insurance”</i>	Financial advisor unsuccessful. <i>“They went back to them and said, ‘look, she’s got no breast tissue, she’s got no ovaries’, but apparently it didn’t matter”.</i>
<u>Kayla</u> 31 y/o Lynch mutation detected in early 20s	No	Annual colonoscopy & bi-annual gastroscopy; surgery not recommended until late 30s	Financial adviser advised application rejected because of her “condition”.	No. <i>“They said they’ve tried with other people with that sort of thing and it doesn’t usually get approved, so it wasn’t worth bothering”</i>
<u>Faith</u> 46 y/o Lynch mutation detected in early 30s	No	Hysterectomy, oophorectomy, annual colonoscopy and endoscopy, bi-annual breast screening, regular skin checks	Underwriter at superannuation provider advised that a loading of 100% would be applied to cover (2018)	No. At time of writing Faith was considering options.

Conclusion

We provide new, alarming evidence of both legal and illegal genetic discrimination by life insurance companies in Australia, under current regulations. This indicates current regulations are not adequate to provide safeguards and consumer protections against genetic discrimination in Australia. These results provide added momentum for policy efforts to ban the use of genetic results in life insurance in Australia and to better align with international best practice.

References:

1. Keogh, L.A., et al., *Choosing not to undergo predictive genetic testing for hereditary colorectal cancer syndromes: expanding our understanding of decliners and declining*. Journal of Behavioral Medicine, 2017: p. 1-12.
2. Keogh, L.A., et al., *Is uptake of genetic testing for colorectal cancer influenced by knowledge of insurance implications?* Medical Journal of Australia, 2009. **191**(5): p. 255.
3. Commonwealth of Australia. *Parliamentary Joint Committee on Corporations and Financial services - life insurance industry*. 2018 [30 April 2018]; Available from: https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/Corporations_and_Financial_Services/LifeInsurance/Report.