

Australian Genomics Position Statement on the use of Genomic Information in Life Insurance and related policies

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EXECUTIVE SUMMARY

Australian Genomics supports a nationally consistent approach to the use of genomic information by the insurance industry: one that ensures those undertaking clinical testing and/or participating in research are not subject to inappropriate discrimination in life insurance and related policies.

We believe the Australian Government should take a leadership role in regulating the use of genomic information by the insurance industry.

Australian Genomics acknowledges the industry-led Moratorium that limits the use of genetic test results (up to set financial limits) when assessing applications for individually assessed life insurance which took effect from 1 July 2019 and lasts until at least 30 June 2024.

Australian Genomics recognises the need for clear patient and consumer advice on this matter and recommends the development of educational material for health professionals and consumers on the potential insurance implications of genomic testing.

POSITION STATEMENT

Australian Genomics is a national research collaboration of clinicians, researchers, geneticists, counsellors and patient advocates working together to provide evidence for the equitable, effective and sustainable delivery of genomic medicine in healthcare.

Australian Genomics notes the following general considerations on the use of genomic information:

- the use of genomic medicine has the potential to provide better patient outcomes and a more efficient health system through rapid diagnosis, early intervention, prevention and targeted therapy
- there are potential benefits to all - individuals, families, populations, the health service and insurers
- the use of genomic testing can be diagnostic (used to confirm a person's diagnosis when a condition is suspected based on symptoms) or predictive (testing of a person who does not present any signs or symptoms of a condition but whose family history places them at a higher risk)

- genomic testing may reveal either an increased or decreased risk of an inherited condition for an individual
- where an increased risk is confirmed, risk-reducing behaviours or interventions may be able to mitigate the consequences of the condition
- however, even if an increased risk is confirmed, currently for most conditions, it is not possible to accurately determine whether the person will ever develop it; or if they do, the age of onset, severity or rate of progression
- clinical genomic testing and research testing are different with the main differences being the clinical actionability of the results and the purpose of testing

On the use of genomic information by the insurance industry, Australian Genomics would like to see:

- a permanent and nationally consistent approach
- confidence for everyone that undertaking clinical testing and/or participating in research will not lead to inappropriate discrimination in life insurance and related policies

Therefore, Australian Genomics echoes the views of the Human Genetics Society of Australasia (HGSA) and the Australian Genetic Non-Discrimination Working Group (AGNDWG) and calls for:

- the Australian Government to take a leadership role in regulating the use of genomic information by the insurance industry
- an ongoing Moratorium on the use of genetic test results, pending adoption of a national regulatory approach which:
 - has a process that involves regulators, the insurance industry and genomics professionals in determining whether particular genetic tests should be used in underwriting mutually rated insurance, having regard to scientific reliability, actuarial relevance and reasonableness (as recommended in the 2003 *Essentially Yours* Report)
 - includes a regular review mechanism to update standards for genomic data as the technology and scientific/clinical knowledge advances
 - excludes the disclosure of results from direct-to-consumer testing where the quality of testing and interpretation cannot be proven
 - excludes the disclosure of results from projects undertaken with human research ethics committee approval (research projects)
 - is adaptive and flexible to accommodate the fast-moving technology and changing evidence-base
 - ensures that all insurance companies in the market are required to comply
 - is enforceable with mechanisms to monitor compliance, identify breaches and impose penalties, where appropriate
 - has clear channels for consumers to seek review of unfavourable decisions by insurers
- development and promotion of clear patient and consumer advice on the use of genomic information in relation to mutually-rated insurance products
- identification of lead organisations and funding support for the development of educational material for health professionals on the potential insurance implications of genomic testing

CURRENT SITUATION

Currently in Australia, genetic information can impact premiums or eligibility to purchase life insurance and related policies (hereinafter referred to as 'life insurance') but not health insurance.

Under the *Insurance Contracts Act 1984 (Cth)*, applicants for new life insurance policies are required (when asked) to disclose all information that is relevant to the insurer's decision (such as personal and family medical history and results of genetic tests) but applicants are not required to undergo a predictive genetic test (testing of an individual who does not have signs or symptoms of a condition but might have a family history that suggests an increased risk).

The Financial Services Council (FSC) is responsible for a national, insurance industry self-regulatory regime that consists of commitments presented in the Life Insurance Code of Practice (Code) and a series of standards (Genetic Testing (Standard No. 11) and Family Medical History (Standard No. 16)). The Code and standards are mandatory for FSC members to adhere to and a current list of FSC Members is available at fsc.org.au/about/membership

In June 2019, the FSC updated its [Standard No. 11](#) to implement a Moratorium on genetic tests in life insurance. The Moratorium covers an applicant for individually underwritten life insurance (including individually underwritten life insurance in group insurance) with an FSC member. The Moratorium started for applications received on or after 1 July 2019 and applies until 30 June 2024.

Under the terms of the Moratorium, Life Insurance Providers may only ask for or use the results of a genetic test if the total amounts of cover the applicant would have, including both the cover being applied for and any existing individual and group insurance cover with all life insurers in aggregate, is more than any of the following:

- ▪ \$500,000 of lump sum death cover
- ▪ \$500,000 of total permanent disability cover (TPD)
- ▪ \$200,000 of trauma and/or critical illness cover
- ▪ \$4,000 a month in total of any combination of income protection, salary continuance or business expenses cover

Other key features of the Moratorium are:

- allowing people to choose to disclose a favourable genetic test result
- life insurers must take into account evidence based preventative treatment, or adherence to evidence based preventative measures, which reduce the possibility of developing an illness that runs in their family
- a review in 2022 to consider its objectives and the impact on policyholders and the industry
- to be overseen by the Life Code Compliance Committee

Australian Genomics acknowledges the interim Moratorium as a step towards ensuring those undertaking clinical testing and/or participating in research are not subject to inappropriate discrimination. However, some concerns remain around the financial limits, the use of research results and the self-regulated nature of the Moratorium.

BACKGROUND

As the use of genetic and genomic testing is increasing, the potential for genetic discrimination has been raised as a concern by the general public and the medical and scientific community including peak professional organisations. Genetic discrimination has been defined as ‘discrimination against an individual or against members of that individual’s family solely because of real or perceived difference from the ‘normal’ genome of that individual.¹ This insurance discrimination may manifest in a number of ways: higher premiums; a reduced period of coverage; exclusions for specific medical conditions; offers of alternative insurance products; financial coverage limitations or refusal to offer an insurance product.²

There are known instances of Australians choosing not to participate in genomic research due to fears that such testing will have a negative impact on their ability to obtain life insurance.³ This is contrary to the aims of Australian Genomics, which is a national research collaboration of clinicians, researchers and diagnostic geneticists, working to provide evidence for the equitable, effective and sustainable delivery of genomic medicine in healthcare. In order to gather such evidence, it is critical that patients are willing to engage in genomics research. In the UK, individuals who participate in the 100,000 Genomes research project are not required to disclose that they have participated in the project and do not have to disclose any genetic test result received through the project. In comparison, in Australia, if a person obtains a personal result during participation in a research project—such as an Australian Genomics flagship— this would be treated no differently to having the test conducted in a clinical setting. The person must disclose the test result if asked and the insurer may take that into account in the assessment of the person’s risk.² This remains the case under the current FSC Moratorium which applies equally to research and other genetic tests, unless the applicant is not receiving the research test result.

The Australian public’s concerns, coupled with the increasing use of genetic and genomic testing, means that particular health professionals (like general practitioners) may need to consider their increasing role in the provision of information and counselling on genetic testing and insurance. A guideline on Genomics in General Practice developed by the Royal Australian College of General Practitioners advocates that general practitioners are well placed to advise patients to consider the implications around health and life insurance before embarking on genetic testing.⁴

The use of genetic information by the insurance industry in Australia has been the subject of a number of reviews including the 2016-18 Joint Parliamentary Committee on Corporations and Financial Services Inquiry into the Life Insurance Industry⁵ and the extensive review in 2001-2003 by the Australian Law Reform Commission (ALRC) and the Australian Health Ethics Committee of the National Health and Medical Research Council (AHEC).⁶ Newson *et al*⁷ provided a review of progress implementing the recommendations from the ALRC review.

In its submission to a 2016-2018 Joint Parliamentary Inquiry into the Life Insurance Industry, the FSC indicated their view that self-regulation via the FSC Standards is most appropriate in this field, because it ensures the industry is able to respond in a timely manner as the field of genetics evolves.

The Australian Genetic Non-Discrimination Working Group (AGNDWG), which is a self-formed, independent group comprised of genetic and medical professionals, research scientists, lawyers, genetic counsellors, law and bioethics academics, policy experts, social scientists and a senior actuary with experience in the area, held a different view. In an appearance during

the Parliamentary Inquiry's public hearings, three members of the AGNDWG provided two recommendations that represented the majority view of the Working Group:

- 1) the Australian Government should enact legislation to regulate the use of genetic information (predictive genetic test information regarding individuals who are not presently affected by a condition) ideally through flexible legislative instruments;
- 2) until such legislation is in place, the Australian Government should enact a ban or Moratorium on the use of genetic data by life insurers.

The AGNDWG also provided a written submission to the Parliamentary Inquiry, which offered a number of examples of Australian and international research demonstrating that a fear of adverse determinations by life insurers acts as a deterrent to obtaining genetic testing. In one study, the number of people who declined predictive testing when informed of the insurance implications was more than double the number who declined without knowledge of the insurance implications.⁸

The Human Genetics Society of Australasia (HGSA) also has a position statement on Genetic Testing and Personal Insurance Products in Australia⁹ which is available at hgsa.org.au/documents/item/20.

At the conclusion of the 2016-18 review, the Parliamentary Committee recommended the FSC adopt a Moratorium on life insurers using predictive genetic information similar to the Moratorium and concordat in place in the United Kingdom. Subsequently, in October 2018, the FSC announced a self-imposed Moratorium on genetic test results for life insurance to begin in July 2019.¹⁰

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