



HUMAN GENETICS SOCIETY OF AUSTRALASIA

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PO Box 6012, Alexandria, NSW 2015
ABN No. 17 076 130 937
Telephone: 02 9669 6602 Fax: 02 9669 6607
Email: secretariat@hgsa.org.au

Position Statement

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Article

Human Genetics Society of Australasia Position Statement: Genetic Testing and Personal Insurance Products in Australia

Aideen M. McInerney-Leo¹, Samantha Ayres^{2,3}, Jackie Boyle⁴, Chris Jacobs⁵, Ainsley J. Newson⁶ and on behalf of the Education, Ethics and Social Issues Committee of the Human Genetics Society of Australasia

¹Frazer Institute, The University of Queensland, Dermatology Research Centre, Brisbane, Queensland, Australia, ²Victorian Clinical Genetics Services, Murdoch Children's Research Institute, Melbourne, Victoria, Australia, ³Department of Paediatrics, The University of Melbourne, Melbourne, Victoria, Australia, ⁴Genetics of Learning Disability Service, Waratah, New South Wales, Australia, ⁵Graduate School of Health, University of Technology Sydney, NSW, Australia and ⁶The University of Sydney, Faculty of Medicine and Health, Sydney School of Public Health, Sydney Health Ethics, Sydney, New South Wales, Australia

Abstract

The expansion of genetic and genomic testing in clinical practice and research, and the growing market for direct-to-consumer genomic testing has led to increased awareness about the impact of this form of testing on insurance. Genetic or genomic information can be requested by providers of mutually rated insurance products, who may then use it when setting premiums or determining eligibility for cover under a particular product. Australian insurers are subject to relevant legislation and an industry led standard that was updated in 2019 to introduce a moratorium on the use of genetic test results in life insurance underwriting for policies <AU\$500K. The Human Genetics Society of Australasia has updated its position statement on genetic testing and life insurance to account for these changes and to increase the scope of the statement to include a wider range of personally-rated insurance products, such as life, critical care, and income protection products. Recommendations include that: providers of professional education involving genetics should include ethical, legal, and social aspects of insurance discrimination in their curricula; the Australian Government take a more active role in regulating use of genetic information in personal insurance; that information obtained in the course of a research project be excluded; insurers seek expert advice when making underwriting decisions regarding genetic testing; and engagement between the insurance industry, regulators, and the genetics profession be improved.

Keywords: Genetic testing; genomics; insurance; discrimination; regulation; Australia

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Background

This position statement provides the stance of the Human Genetics Society of Australasia (HGSA) on the use of information obtained from genetic or genomic testing in the underwriting process for life, critical illness, and income protection insurance products (referred to herein as personal insurance products). Relevant definitions are as follows:

- *Genetic testing* involves testing single genes and may result in the diagnosis of a genetic condition or provide information about the chance of an asymptomatic person developing a genetic condition in the future.
- *Genomic testing* involves testing multiple genes simultaneously and can generate a large amount of data that needs to be interpreted by experts.
- *Genetic information* includes personal medical history information, family medical history information, and the results of individual or familial genetic or genomic tests.

Author for correspondence: Aideen M. McInerney-Leo, Email: a.mcinerney@uq.edu.au

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- *Genetic discrimination* is 'the differential treatment of asymptomatic individuals or their relatives on the basis of their real or assumed genetic characteristics' (Otlowski et al., 2012, p. 433).

In this position statement, 'genetic testing' refers to both genetic and genomic testing. Similarly, 'genetic information' refers to information gained from genetic or genomic testing.

Genetic Testing

Genetic tests can be accessed through both publicly funded health-care services and commercial providers. The latter may supply tests without involving a health professional. Genetic test results may have medical and/or social implications for the individual being tested and their family members.

Current knowledge is used to interpret test findings. As knowledge develops over time, interpretation can change, potentially altering whether a finding is considered to be clinically significant or not. All these factors can add complexity to underwriting (discussed further below).

Personal Insurance Products

The provision of personal insurance products usually involves an assessment of the applicant's individual risk factors, including their

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family history and personal health status. This process is known as ‘underwriting’ and premiums are determined by the profile of that individual (*mutually rated*). It is thought that less than 40% of Australians hold personal life insurance products and less than 20% hold other personal insurance products (Canstar, 2016). Other insurance products, such as private health insurance and some forms of personal insurance provided by superannuation funds, are *community rated*. This means that policyholders pay the same premium regardless of their individual health status or risk factors.

The Insurance Contracts Act 1984 (Cth) is relevant for all applicants for personal insurance products. Recent changes to the Act (in 2021) replaced the previous duty to disclose all matters known to the applicant that are relevant to the insurer’s decision, with a new duty (for consumer contracts) to take reasonable care not to make a misrepresentation (s20B). The intention of this change was to shift the onus onto insurers to elicit the information they need, rather than requiring applicants to guess what is important to the insurer and volunteer all information which might be relevant. This means that insurers must ask specific questions and the applicant’s duty is limited to not making misrepresentations in their answers.

Genetic Information and Insurance in Australia

In Australia, genetic information may impact an individual’s ability to obtain personal insurance products or increase the premium paid. The request for, and use of, genetic information by insurers is governed by legislation and an industry policy. The *Disability Discrimination Act 1992 (Cth)* prevents discrimination based on genetic status. However, there is a wide exemption under section 46, which means that insurers are exempt from the prohibition on discrimination if they can substantiate an underwriting decision with reasonable data. Note that an applicant’s family medical history can also lead to an increase in premiums for personal insurance products.

Australia’s Financial Services Council (FSC) has published two voluntary industry standards: FSC Standard No. 11 Moratorium on Genetic Tests in Life Insurance (FSC, 2019) and FSC Standard No. 16 Family History Policy (FSC, 2016). The former standard, introduced in June 2019, replaced the FSC Standard No. 11 Genetic Testing Policy and from July 2023 will be extended indefinitely (FSC, 2022). The Standard No. 16 Family History Policy was updated in 2016. These standards are not binding and do not apply to insurers who are not members of the FSC. The key points of the 2019 Moratorium (Standard 11) are summarised in Box 1. Additional relevant points from Standard 16, not addressed in Standard 11, include the fact that clear reasons for underwriting decisions should be provided and, if an application is rejected, alternative terms or products should be considered for offer instead.

Genetic Information and Insurance in New Zealand

New Zealand residents do not have any legal protections against genetic discrimination. Both health and life insurance companies can request and use genetic test results in the underwriting process (Tiller & Shelling, 2021). The FSC is the industry body for health and life insurance companies in New Zealand but a corresponding moratorium has yet to be introduced there.

The HGSA’s Position on Using Genetic Information in Insurance

General Considerations

The usual aim of genetic testing is to obtain genetic information to inform the health and wellbeing of the individual being tested, or (in the context of research) to benefit the future health of the population. Genetic testing can also be undertaken to benefit another family member, such as testing to clarify a diagnosis or determine the significance of a gene change, known as a ‘genetic variant’, in the other family member. Long-term benefits to individuals, their families, the community, and insurers occur when genetic testing and subsequent risk-reducing behaviours or interventions can mitigate or ameliorate the consequences of inherited disorders.

While genetic testing may reveal an increase in an individual’s risk of developing a genetic condition, it can also serve to reduce or negate an individual’s risk compared to family history alone. This occurs when testing shows that the individual has not inherited a genetic variant present in other family members. Even if genetic testing confirms an individual has inherited the familial genetic variant, it will usually be impossible to predict accurately the age of onset of the condition, its rate of progression, its severity, life expectancy, or whether the person will ever develop the condition. The onset or severity of symptoms of many genetic conditions can also be avoided or mitigated by changing health or lifestyle behaviors. Some individuals choose to undergo genetic testing primarily for the benefit of other family members, electing not to receive results themselves.

Genetic discrimination has occurred in Australia and remains a significant concern for those seeking testing (Kanga-Parabia *et al.*, 2018; Keogh & Otlowski, 2013). Fears of insurance discrimination should not prevent individuals from accessing clinically-indicated genetic testing.

Recommendations

1. The HGSA is concerned that the 2019 FSC Moratorium on the use of genetic test results is industry-led and not legally enforceable. The HGSA notes that researchers are evaluating the implementation and adherence to the Moratorium (Tiller *et al.*, 2021) and requests that regulators and insurers do the same. This will inform future long-term regulatory solutions.
2. The HGSA recommends that those developing curricula and other professional education materials involving genetic testing incorporate content relating to the ethical, legal, and policy considerations associated with the use of genetic information in assessments for personal insurance products.
3. The HGSA urges the Australian Federal Government to take a more active role in regulating the use of genetic information in insurance; for example, to ensure that any discrimination that does occur adheres to the relevant provisions of the *Disability Discrimination Act 1992 (Cth)*. The wide exemption granted by this Act should also be reconsidered.
4. The HGSA urges regulators and insurers not to require disclosure of genetic testing undertaken as part of a research project. Research studies are often exploratory, and findings may not be validated or replicated. There is also evidence that fear of insurance ramifications negatively impacts rates of research participation (Keogh *et al.*, 2009), which may impede implementation of genomics in the future.

Key points of Financial Services Council (FSC) Moratorium on Genetic Tests in Life Insurance, July 2019

Regardless of the policy value, life insurance applicants:

- Must disclose their own medical history and that of their first-degree relatives.
- Cannot be asked to reveal family health history beyond first-degree relatives.
- Cannot be asked to disclose genetic test results of first-degree relatives.
- Cannot be asked to undergo genetic testing.
- Can request favourable policy revision when results demonstrate that a variant has not been found i.e., receipt of a negative test result.
- Can request that the benefits of screening, early diagnosis, or treatment be considered in underwriting where there is a pathogenic variant identified.

For policies <\$500,000 (death cover/total permanent disability cover) life insurance applicants:

- Cannot be asked to disclose their personal genetic test results.

For policies >\$500,000 (death cover/total permanent disability cover) life insurance applicants:

- Can be asked for genetic test results but can only be used if relevant to type of cover.
- There is no distinction between clinical, research or direct-to-consumer genetic test results.

5. Until genetic information gleaned from research is excluded, researchers and human research ethics committees should ensure that the potential implications of research participation for obtaining personal insurance products in the future are clearly explained to participants.
6. If an individual chooses to undergo genetic testing and receives a result that returns the individual to population-level risk then, as per the Moratorium, this result should be used to negate relevant family history information.
7. The HGSA advocates for close liaison between regulators, the insurance industry, and the genetics profession to more accurately interpret genetic information and consider its implications for the overall health of individuals. This is particularly relevant, but not limited to, emerging testing types such as polygenic scores, and the potential for risk-mitigating interventions considering all genetic and genomic test information.
8. The HGSA encourages insurers to continue to review actuarial modelling of the impact of predictive genetic test results. The HGSA wishes to promote trust and confidence between genetic health professionals and insurers and encourages the industry to seek statistical, molecular, and epidemiological information from geneticists and bioinformaticians who have relevant expertise. This will be increasingly relevant in the future as genetic testing evolves to include predisposition to common conditions in the general population.

The HGSA acknowledges the concern that genetic information could potentially be used to engage in adverse selection against insurance companies, that is, individuals at high risk being more likely to purchase insurance products than those at low risk (Vukcevic & Chen, 2017). However, the HGSA also notes that there is limited evidence to support this claim (Newson et al., 2017). Further, the HGSA asserts that the number of highly heritable conditions to which adverse selection can currently apply is very small, with low population prevalence.

Counselling Considerations

An individual's decision to undertake a genetic test should include time to consider the implications of having the test. The HGSA encourages all genetic health professionals to understand the potential implications of genetic testing for individuals considering purchasing personal insurance products. Genetic health professionals should raise the potential insurance implications of genetic information with those seeking genetic testing when, in their professional judgment, it is appropriate to do so (Centre for Genetics Education, 2017). This may include (but is not limited to):

1. For individuals with a family history of a genetic condition, family history alone is likely to impact an application for personal insurance products.
2. Genetic testing can either confirm an individual's family history or return the individual to population-level risk.
3. For individuals with no family history of a genetic condition, there is a possibility that testing may reveal a previously unknown genetic variant, which may impact any applications for personal insurance products.
4. Individuals have an obligation to disclose genetic test results to insurers when applying for life insurance products, if the terms of the policy exceed the Moratorium thresholds.

Companies based in Australia offering genetic testing directly to consumers should also ensure that potential insurance implications, such as those outlined above, are clearly explained to consumers as part of the information provided with the test.

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References

- Canstar. (2016). Life insurance — Are you underinsured? <https://www.canstar.com.au/life-insurance/life-insurance-are-we-underinsured/>
- Centre for Genetics Education. (2017). Fact sheet 20: life insurance products and genetic testing. <http://www.genetics.edu.au/publications-and-resources/facts-sheets/fact-sheet-20-life-insurance-products-and-genetic-testing-in-australia>
- Disability Discrimination Act 1992 (Cth). <https://www.legislation.gov.au/Details/C2018C00125>
- Insurance Contracts Act 1984 (Cth). <https://www.legislation.gov.au/Details/C2022C00015>
- Financial Services Council (FSC). (2016). FSC Standard No 16 Family Medical History Policy. <https://fsc.org.au/resources-category/standard/372-16s-family-history-pdf/file>
- Financial Services Council (FSC). (2019). FSC Standard No 11 Moratorium on Genetic Tests in Life Insurance. <https://www.fsc.org.au/resources-category/standard/1779-standard-11-moratorium-on-genetic-tests-in-life-insurance/file>

- Financial Services Council (FSC).** (2022). FSC Life Insurance Code of Practice 2023. Appendix A. <https://fsc.org.au/resources/2488-fsc-code-of-practice-2022-final/file>
- Kanga-Parabia, A., Gaff, C., Flander, L., Jenkins, M., & Keogh, L. A.** (2018). Discussions about predictive genetic testing for Lynch syndrome: The role of health professionals and families in decisions to decline. *Familial Cancer*, *17*, 547–555. <https://doi.org/10.1007/s10689-018-0078-2>
- Keogh, L. A., & Otlowski, M. F.** (2013). Life insurance and genetic test results: A mutation carrier's fight to achieve full cover. *Medical Journal of Australia*, *199*, 363–366. <https://doi.org/10.5694/mja13.10202>
- Keogh, L. A., van Vliet, C. M., Studdert, D. M., Maskiell, J. A., Macrae, F. A., St John, D. J., Gaff, C. L., Young, M. A., Southey, M. C., Giles, G. G., Rosenthal, D. A., Hopper, J. L., & Jenkins, M. A.** (2009). Is uptake of genetic testing for colorectal cancer influenced by knowledge of insurance implications? *Medical Journal of Australia*, *191*, 255–258. <https://doi.org/10.5694/j.1326-5377.2009.tb02778.x>
- Newson, A. J., Tiller, J., Keogh, L. A., Otlowski, M., & Lacaze, P.** (2017). Genetics and insurance in Australia: Concerns around a self-regulated industry. *Public Health Genomics*, *20*, 247–256. <https://doi.org/10.1159/000481450>
- Otlowski, M., Taylor, S., & Bombard, Y.** (2012). Genetic discrimination: International perspectives. *Annual Review of Genomics and Human Genetics*, *13*, 433–454. <https://doi.org/10.1146/annurev-genom-090711-163800>
- Tiller, J., McInerney-Leo, A., Belcher, A., Boughtwood, T., Gleeson, P., Delatycki, M., Barlow-Stewart, K., Winship, I., Otlowski, M., Keogh, L., & Lacaze, P.** (2021). Study protocol: The Australian genetics and life insurance moratorium-monitoring the effectiveness and response (A-GLIMMER) project. *BMC Medical Ethics*, *22*, 63. <https://doi.org/10.1186/s12910-021-00634-2>
- Tiller, J., & Shelling, A.** (2021) Why New Zealanders are vulnerable to genetic discrimination in health and life insurance. *The Conversation*. <https://theconversation.com/why-new-zealanders-are-vulnerable-to-genetic-discrimination-in-health-and-life-insurance-167783>
- Vukcevic, D., & Chen, J.** (2017, May). *Thinking about life insurance through a genetic lens* [Paper presentation]. Actuaries Summit, Melbourne, Australia. <https://www.actuaries.asn.au/Library/Events/SUM/2017/SUM17VukcevicCHenPaper.pdf>