

Article type : Perspective (2-pp)

Article begins on page three of this document.

Title	Monitoring the genetic testing and life insurance moratorium in Australia: a national research project
--------------	--

Authors:

	Title	First name	Mid inits	Last name	Postnom (eg, PhD)	Position1	Address1	Position2	Address2	Tel	Email
1	Ms.	Jane		Tiller	LLB(Hons), BSc, MGenCouns	Ethical, Legal & Social Adviser - Public Health Genomics	1				jane.tiller@ monash.edu
2	Prof.	Ingrid		Winship	MBChB, MD, FRACP, FACD	Executive Director	2			0400 989 917 / 03 9342 8593	Ingrid.Winshi p@mh.org.a u
3	Prof.	Margaret	FA	Otlowski	LLB(Hons), PhD	Law Faculty Dean	3			03 6226 7569	Margaret.Otl owski@utas. edu.au
4	Dr.	Paul	A	Lacaze	PhD	Head - Public Health Genomics	1				paul.lacaze @monash.e du
5											

Number of corresponding author:	1
---------------------------------	---

Number of alternative corresponding author:	
---	--

Addresses:

	Institution	City	State		
1	Monash University	Melbourne	VIC		
2	Melbourne Health	Melbourne	VIC		
3	University of Tasmania	Hobart	TAS		
4					
5					

This is the author manuscript accepted for publication and has undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the [Version of Record](#). Please cite this article as [doi: 10.1002/MJA2.50922](https://doi.org/10.1002/MJA2.50922)

Postal address of first corresponding author (if different from the institutional address given above)	
--	--

Primary Keywords [Office use only]	Medical genetics; Ethics and law; Statistics, epidemiology and research design
Secondary keywords [Office use only]	Ethics; Research design
Notes:	

Article details (press ctrl – 9 to enter details):

Article type	Perspective
Blurb	<i>Is the current genetics and insurance moratorium an effective long term regulatory solution for Australia?</i>

Office use

<i>Ms. Number</i>	mja20.01109. R2
<i>Medical editor</i>	Robyn Godding
<i>Medical editor email</i>	rgodding@mja.com.au
<i>Structural editor</i>	Graeme Prince
<i>Structural editor email</i>	gprince@mja.com.au
<i>Section/Category</i>	Perspective (2-pp)
<i>Strapheading</i>	Perspective
<i>Substrap</i>	

Wiley – file data:

Filename for copyediting	til_mja20.01109_ms
Accompanying graphics	
Stock images	til_mja20.01109_im
Appendices	

Office use – history:

Event	Date
Original submission received	22/06/2020

Event	Date
Accept	12/08/2020

Proof sent to author	
Proof returned by author	
Published (date format xx/xx/xx)	01/03/21
Issue	4
Vol	214
DOI	10.5694/mja2 0.01109
Journal	The Medical Journal of Australia
Original article DOI (for response)	

Author Manuscript

Monitoring the genetic testing and life insurance moratorium in Australia: a national research project

Is the current genetics and insurance moratorium an effective long term regulatory solution for Australia?

Genetic discrimination in life insurance is a longstanding issue in Australia,^{1,2} and has been the subject of two government inquiries.^{3,4} The use of genetic test results in underwriting continues to be self-regulated by the life insurance industry.⁵ In 2019, following Parliamentary Joint Committee recommendations,⁴ the industry voluntarily introduced a moratorium restricting the use of genetic test results in life insurance underwriting for policies worth up to AU\$500 000. Although the moratorium is an important step, concerns remain around the financial limits, public awareness, lack of government oversight and compliance monitoring. The impact and effectiveness of the moratorium needs evaluation to inform the planned 2022 review. A new research project has been funded by the Australian government's Genomic Health Futures Mission to serve that important function.

Genomic testing has the potential to improve disease prevention and public health. For example, predictive testing of *BRCA1/2* genes can identify women at high risk of developing breast and ovarian cancer, where risk can be mitigated through preventive surgery and/or screening. As genomic testing becomes more widespread, patients, general practitioners and other health professionals will increasingly be required to address issues related to privacy, data security, genetic discrimination and insurance.^{2,6}

Although health insurance is community-rated in Australia and therefore not subject to genetic discrimination,¹ the use of genetic test results in life insurance is allowed under the *Disability Discrimination Act 1992* (Cth). This means that life insurance companies can legally refuse coverage or increase premiums based on genetic test results. A number of ethical, social and medical implications arise when genetic test results are permitted to be used in insurance underwriting, especially predictive testing in otherwise healthy people.^{1,7}

Previous studies show that fear of insurance discrimination deters individuals from taking clinically indicated genetic tests and participating in genetic research.¹ In a study where predictive genetic testing for Lynch syndrome (which causes an increased risk of colorectal and other cancers) was offered, the proportion of people who declined testing when informed of the insurance implications was more than double the proportion who

declined without knowledge of insurance implications.⁸ There are different concerns from the insurance industry perspective, including the possible actuarial implications of adding genomic information to risk models. Genomic test results can not only reveal risk (positive results), but also indicate reduced risk (negative results), potentially changing the dynamics of actuarial calculations. The notion of adverse selection, whereby individuals at high genetic risk may be more likely to take out insurance policies, is also raised by insurers.

It is critical for the optimisation of genomic medicine that individuals can make informed choices about genetic testing and research participation without fear of insurance implications. Further, moral implications regarding the use of genetic information for insurance underwriting extend beyond actuarial fairness to include consideration of public interests such as justice, beneficence, autonomy and public health.⁷ Several governments internationally have therefore banned or restricted the use of genetic test results in risk-rated insurance, including Canada, the United Kingdom and Europe, using various legal mechanisms.⁹

The National Health Genomics Policy Framework and Implementation Plan 2018–2021⁶ is a strategic policy of the Council of Australian Governments, which recognises the potential of genomics for public health while acknowledging the need for ethical mechanisms for its delivery. Developing a national approach to issues including genetic discrimination was listed as a strategic priority for action in the Framework and listed as the first short term national priority in the implementation plan,⁶ making it one of the most significant ethical, legal and social issues facing genomic medicine in Australia. However, debate remains regarding the most effective mechanism of regulation.

Following previous examination of these issues by the Australian Law Reform Commission and Australian Health Ethics Committee,³ a recent inquiry of the Parliamentary Joint Committee on Corporations and Financial Services into the life insurance industry considered the use of genetic test results in life insurance.⁴ The report expressed strong concerns about insurer access to genetic information and recommended that:

- a moratorium be implemented to “prohibit any life insurers from using the outcomes of predictive genetic tests at least in the medium term ... as a matter of some urgency and [in] a form similar to the United Kingdom’s Moratorium”;⁴
- the Financial Services Council (FSC), together with the Australian Genetic Non-Discrimination Working Group (of which the authors are members), assess the consumer impact of a moratorium; and
- the federal government monitor the implementation of, and adherence to, such a moratorium, and if needed, implement legislation on the issue.

The Australian government has not yet responded to the Parliamentary Joint Committee recommendations. However, the FSC, Australia’s peak national body for life insurers, introduced an industry-led moratorium in July 2019. Under the moratorium, Australian consumers need no longer disclose their genetic test results when applying for policies up to \$500 000 for death/total permanent disability, \$200 000 for trauma/critical illness, and

\$4000/month for income protection cover.¹⁰ The moratorium applies to all genetic test results, including research results and results obtained from internet-based direct-to-consumer tests, which are increasingly resulting in clinical referrals.¹¹

Above these financial limits (which are cumulative across multiple policies), life insurers can still ask for, and use, any existing genetic test result, which can lead to refused or delayed cover, exclusions or increased premiums. However, insurers must not require applicants to undergo a genetic test. Applicants can choose to disclose a favourable genetic test result (showing that an individual with a family history of a genetic condition does not have the familial genetic variant) to offset the effects on underwriting of an adverse family history.

The FSC moratorium is a self-regulated industry standard which is not legally enforceable — insurance companies' legal right to discriminate on the basis of genetic test results remains. By contrast, the UK moratorium (which commenced in 2001) is an agreement between the UK government and the Association of British Insurers. It applies to all life insurance policies without any financial limits, with only one exception for Huntington disease, a progressive, neurodegenerative genetic disorder. Predictive genetic test results for Huntington disease must be disclosed by individuals in the UK only when applying for cover worth over £500 000 (about AU\$900 000).¹² All other individuals can make informed decisions about whether to have genetic testing or participate in genomic research without concerns about insurance implications.

The FSC moratorium is an important step towards consumer protection, but concerns remain around its financial limits, interpretation of its terms, and lack of compliance monitoring. The FSC moratorium has no government or independent regulatory oversight, and as recommended by the Parliamentary Joint Committee, there is a critical need to monitor its implementation and effectiveness. The FSC will review the moratorium and its terms in 2022, to consider amendment and/or extension beyond its current 2024 end date.¹⁰ Currently, there are no mechanisms in place to collect independent evidence from different stakeholder perspectives to inform this review and the Australian government has not indicated any intention to do so directly. A new research project, funded by the first competitive round of the Genomic Health Futures Mission, part of the Australian Government's Medical Research Future Fund,¹³ has now commenced to serve that critical function until 2023.

The A-GLIMMER (Australian Genetics and Life Insurance Moratorium: Monitoring the Effectiveness and Response) project brings together leading researchers, clinicians, patient groups, and policy experts in Australia to answer the question of whether the FSC moratorium is an adequate and effective long term regulatory solution for Australia.

The project aims to address this question by collecting a range of quantitative and qualitative data after the implementation of the moratorium, from different stakeholders including consumers, health care professionals, researchers and the insurance industry. In some cases, the data collected will be directly comparable to similar data collected and published before the moratorium.^{14,15} The project has widespread support across the community. More than 20 project partners, including the FSC, and other supporting

bodies have provided written support and pledged resources towards the study. The project is endorsed by the Victorian Department of Health and Human Services, the Human Genetics Society of Australasia and Australian Genomics, a collaborative national network of clinical, research, academic and community organisations dedicated to implementation of genomics for health and the development of appropriate genomics policy.

A-GLIMMER's overarching aim is to ensure sufficient evidence is collected in the coming years to inform government and the 2022 FSC review, to help determine the effectiveness of the FSC moratorium as a long term regulatory solution in Australia. See the Box for a summary of project aims. A-GLIMMER is divided into four work streams, which will collect data from consumers, health professionals, research studies and the insurance industry.

A final report will be compiled at the conclusion of the project, and will be provided to the federal government to assist with future policy decisions. Although the project will not conclude until 2023, its findings will help inform the proposed FSC review in 2022. Achieving an adequate policy solution to this issue in Australia is essential for ensuring optimal integration of genomics into Australian health care, engendering public trust and consumer participation in genomics, and paving the way to realise the many benefits of genomic medicine for Australia.

Acknowledgements: We are members of the A-GLIMMER project team. A-GLIMMER is funded by the first competitive round of the Genomic Health Futures Mission, part of the Australian Government's Medical Research Future Fund (grant no. 76721). We thank the other members of the A-GLIMMER investigative team — Dr Aideen McInerney-Leo, A/Prof Louise Keogh, Dr Andrea Belcher, Ms Tiffany Boughtwood, A/Prof Kristine Barlow-Stewart and Prof Martin Delatycki — for their crucial and ongoing contribution to the project. We would also like to thank our project partners — consumer groups, research studies, clinical services, and industry groups — for their ongoing support.

Competing interests: No relevant disclosures.

Provenance: Not commissioned; externally peer reviewed.

Author details

Jane Tiller¹

Ingrid Winship²

Margaret FA Otlowski³

Paul A Lacaze¹

¹ Monash University, Melbourne, VIC.

² Melbourne Health, Melbourne, VIC.

³ University of Tasmania, Hobart, TAS.

jane.tiller@monash.edu

doi: 10.5694/mja20.01109

References

- 1 Tiller J, Otlowski M, Lacaze P. Should Australia ban the use of genetic test results in life insurance? *Front Public*

Health 2017; 5: 330.

- 2 Otlowski M, Tiller J, Barlow-Stewart K, Lacaze P. Genetic testing and insurance in Australia. *Aust J Gen Pract* 2019; 48: 96-99.
- 3 Australian Law Reform Commission. Essentially yours: the protection of human genetic information in Australia. Sydney: ALRC, 2003. <http://www.alrc.gov.au/publications/report-96> (viewed June 2020).
- 4 Parliamentary Joint Committee on Corporations and Financial Services. Report: life insurance industry. Canberra: Commonwealth of Australia, 2018. https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/Corporations_and_Financial_Services/LifeInsurance/Report (viewed June 2020).
- 5 Newson AJ, Tiller J, Keogh LA, et al. Genetics and insurance in Australia: concerns around a self-regulated industry. *Public Health Genomics* 2017; 20: 247-256.
- 6 Commonwealth Department of Health; Australian Health Ministers' Advisory Council. National Health Genomics Policy Framework and Implementation Plan 2018-2021. Canberra: Commonwealth of Australia, 2017. <https://www1.health.gov.au/internet/main/publishing.nsf/Content/national-health-genomics-policy-framework-2018-2021> (viewed July 2020).
- 7 Rothstein MA. Time to end the use of genetic test results in life insurance underwriting. *J Law Med Ethics* 2018; 46: 794-801.
- 8 Keogh LA, Niven H, Rutstein A, et al. Choosing not to undergo predictive genetic testing for hereditary colorectal cancer syndromes: expanding our understanding of decliners and declining. *J Behav Med* 2017: 1-12.
- 9 Otlowski M, Taylor S, Bombard Y. Genetic discrimination: international perspectives. *Annu Rev Genomics Hum Genet* 2012; 13: 433-454.
- 10 Financial Services Council. FSC Standard No. 11: Moratorium on Genetic Tests in Life Insurance. Sydney: FSC, 2019. <https://www.fsc.org.au/resources-category/standard/1779-standard-11-moratorium-on-genetic-tests-in-life-insurance/file> (viewed July 2020).
- 11 Millward M, Tiller J, Bogwitz M, et al. Impact of direct-to-consumer genetic testing on Australian clinical genetics services. *Eur J Med Genet* 2020; 63: 103968.
- 12 HM Government and Association of British Insurers. Code on Genetic Testing and Insurance. UK: HM Government and ABI, 2018. <https://www.abi.org.uk/globalassets/files/publications/public/genetics/code-on-genetic-testing-and-insurance-final.pdf> (viewed July 2020).
- 13 Hon Greg Hunt MP. Over \$33 million to boost genomics research into cancers and to combat children's diseases [media release]. 6 May 2020. <https://www.health.gov.au/ministers/the-hon-greg-hunt-mp/media/over-33-million-to-boost-genomics-research-into-cancers-and-to-combat-childrens-diseases> (viewed June 2020).
- 14 Tiller J, Keogh L, Wake S, et al. Genetics, insurance and professional practice: survey of the Australasian clinical genetics workforce. *Front Public Health* 2018; 6: 333.
- 15 Tiller J, Morris S, Rice T, et al. Genetic discrimination by Australian insurance companies: a survey of consumer experiences. *Eur J Hum Genet* 2019; 28: 108-113.

[Box]

Aims of A-GLIMMER (Australian Genetics and Life Insurance Moratorium: Monitoring the Effectiveness and Response)

A-GLIMMER will:

- assess dissemination and awareness of the Financial Services Council moratorium following its implementation
- describe the impact of the moratorium on consumers, health care, research and financial services
- evaluate the effectiveness of the self-regulated Financial Services Council moratorium as a long term regulatory solution