REGULATING THE USE OF GENETIC INFORMATION IN THE LIFE INSURANCE INDUSTRY

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I INTRODUCTION

The Australian life insurance industry has been the subject of extensive media and academic criticism due to their treatment of genetic information in the underwriting process. As the field of genetics advances, the potential for genetic discrimination also increases. The nature of this discrimination can be crudely summarised in the statement of a member of the Australian insurance industry, who informed a carrier of the *BRCA1* gene mutation that 'if you were a horse, we wouldn't bet on you because we know you wouldn't finish the race'.[1] The insurer dismissed the relevance of the carrier's significant efforts to reduce her risk by undergoing preventative surgery, in the form of a double mastectomy as well as the removal of her fallopian tubes and one of her ovaries.[2]

Similarly, a life insurance applicant who tested positive for Lynch syndrome was consistently denied coverage, despite undergoing regular colonoscopies and preventative surgery.[3] Federal Labor MP Matt Keogh noted that an oncologist informed him that he spent more time discussing the insurance ramifications of genetic tests with his patients than the health ramifications.[4] These cases have prompted politicians, medical and legal professionals as well as academics to call for greater claims process transparency and government oversight of the life insurance industry.

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[1] Krystal Barter, 'Genetic Testing and Insurance: I Was Destined to Get Cancer, but I Don't Deserve Discrimination', *ABC News* (online, 9 November 2017) <https://www.abc.net.au/news/2017-11-09/genetic-testing-discrimination-from-life-and-health-insurers/9133878>.

[2] Ibid.

[3] Kate Aubusson, 'Insurers Discriminating against People Who Get Genetic Test Results Could Hobble Research, Bioethicists Warn', *The Sydney Morning Herald* (online, 8 November 2017) <https://www.smh.com.au/healthcare/insurers-discriminating-against-people-who-get-genetic-test-results-could-hobble-research-bioethicists-warn-20171102-gzd7vu.html>.

[4] 'Call for Life Insurance Genetic Test Ban', *SBS News* (online, 27 March 2018) <https://www.sbs.com.au/news/call-for-life-insurance-genetic-test-ban>.

Genetic test results cannot affect private health insurance in Australia, as it is community risk rated under the *Private Health Insurance Act 2007* (Cth).[5] Consequently, private health insurers are required to offer the same premiums to all applicants for equivalent policies and are prohibited from discriminating on the basis of health or other information.[6] However, life insurance is mutually rated so insurers classify individuals according to their personal risk.[7] This regime inevitably creates great potential for genetic discrimination, as genetic results can be used for underwriting life insurance in Australia, with little consumer transparency or government oversight. It is true that the use of genetic information has been relatively rare in Australian life insurance.[8] However, it must also be acknowledged that genetic advancements are occurring at a rapid rate and genetic testing is becoming increasingly common.[9] In order to harness the true potential of genomics in healthcare, we need to avoid impediments to the uptake of genetic testing and participation in genetic research.

From 2016 to 2018, the Australian Parliamentary Joint Committee on Corporations and Financial Services conducted an inquiry into the life insurance industry.[10] Following 77 submissions and seven hearings, the Committee made a number of recommendations including: strengthening consumer protections and regulatory oversight of the industry; greater transparency of remuneration, commissions, payments and fees; appropriate access to personal medical and genetic information and; fairer claims handling practices.[11] In particular, Recommendation 9.1 suggested that

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[5] Jane Tiller, Margaret Otlowski and Paul Lacaze, 'Should Australia Ban the Use of Genetic Test Results in Life Insurance?' (2017) 5(330) *Frontiers in Public Health* 1, 1.

[6] Ibid.

[7] Ibid.

[8] See Parliamentary Joint Committee on Corporations and Financial Services, Parliament of Australia, *Life Insurance Industry* (Report, 27 March 2018) 148 (citations omitted) ('*Life Insurance Industry*'):

> Mr Brett Clark, Chief Executive Officer and Managing Director of TAL, stated that out of 33,000 applications for retail insurance, only 750 applications contained genetic information. Likewise, Mr Tim Bailey, Chief Executive Officer of Zurich, commented that it would be extremely rare for genetic information to be disclosed at the time of underwriting.

See also Evidence to Joint Committee on Corporations and Financial Services, Parliament of Australia, Canberra, 18 August 2017, 12 (Brett Clark, Chief Executive Officer and Managing Director, TAL); Zurich Financial Service Australia Limited, Answers to Questions on Notice to Joint Committee on Corporations and Financial Services, Parliament of Australia, *Inquiry into the Life Insurance Industry* (9 June 2017); MLC Life Insurance, Answers to Questions on Notice to Joint Committee on Corporations and Financial Services, Parliament of Australia, *Inquiry into the Life Insurance Industry* (9 June 2017).

[9] See, eg, Australian Health Ministers' Advisory Council, 'National Health Genomics Policy Framework: 2018–2021' (Policy Paper, August 2017) which aims to integrate genomics into national healthcare through significant government investment. This signals a clear expectation that issues generated by genetic testing will increasingly arise in healthcare.

[10] See *Life Insurance Industry* (n 8) 137–56.

[11] Ibid xv–xxv.

> the Financial Services Council, in consultation with the Australian Genetic Non-Discrimination Working Group, assess the consumer impact of imposing a moratorium on life insurers using predictive genetic information, unless the consumer provides genetic information to a life insurer to demonstrate that they are not at risk of developing a disease.[12]

As a result of this recommendation, the Financial Services Council ('FSC') imposed a moratorium on genetic tests in life insurance from 1 July 2019.[13] Parts II and III of this article will review the current Australian and international legal frameworks governing the use of genetic information in life insurance. Part IV will highlight policy concerns and Part V will provide recommendations for reform.

II CURRENT LEGAL FRAMEWORK

The current legal framework consists of a mixture of legislative provisions imposing duties of disclosure, 'utmost good faith' and non-discrimination as well as industry self-regulation of life insurers by the FSC.

A *Disability Discrimination Act 1992* (Cth)

Section 46 of the *Disability Discrimination Act 1992* (Cth) ('*DDA*') allows life insurers to discriminate on the basis of genetic test results, only where they have actuarial or statistical data to justify their decisions.[14]

B *Insurance Contracts Act 1984* (Cth)

Section 13(1) of the *Insurance Contracts Act 1984* (Cth) ('*ICA*') provides that there is a reciprocal duty of 'utmost good faith' implied in all contracts of insurance. The common law principle of utmost good faith was famously established in the case of *Carter v Boehm* where Lord Mansfield observed that '[g]ood faith forbids either party by concealing what he privately knows, to draw the other into a bargain, from

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[12] Ibid 156.

[13] Financial Services Council, *FSC Standard No 11: Moratorium on Genetic Tests in Life Insurance* (at 21 June 2019) ('*FSC Standard No 11: Moratorium*').

[14] *Disability Discrimination Act 1992* (Cth) ss 46(1)(b), (f)–(g), (2)(b), (f)–(g) where it states that it is not unlawful for life insurers to discriminate on the basis of another person's disability if:

> (f) the discrimination:
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> > (i) is based upon actuarial or statistical data on which it is reasonable for the first-mentioned person to rely; and
> >
> > (ii) is reasonable having regard to the matter of the data and other relevant factors; or
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> (g) in a case where no such actuarial or statistical data is available and cannot reasonably be obtained–the discrimination is reasonable having regard to any other relevant factors.

his ignorance of that fact, and his believing the contrary'.[15] This principle allows insurance companies to charge premiums commensurate to an applicant's risk status.

Section 21 of the *ICA* imposes a duty on an insured to disclose any matter that the insured knows to be of relevance to the insurer. This includes an obligation to provide full disclosure of all information material to the insurer's assessment of risk, which a reasonable person in the circumstances could be expected to know to be a matter that is relevant. The central issue is whether genetic test results constitute information that would have a material effect on the judgment of a reasonable person in determining the terms of the insurance contract.[16] The onus is on the insurer to prove materiality as a question of fact.[17] In the context of life insurance, material information includes information within the applicant's knowledge that may affect their mortality or morbidity. Therefore, an applicant will breach their duty of disclosure if they fail to disclose the results of a genetic test when they have full knowledge of the results. An insured's failure to fully disclose this information may have severe repercussions, including avoidance of the insurance contract for misrepresentation or non-disclosure.[18] The requirement to disclose this information is also subject to other policy documents, including FSC Industry Standards on Genetic Testing ('Standards').[19]

C Self-Regulation Standards

The FSC is the peak industry body in Australia for life insurers and establishes the Standards. Compliance with the Standards is mandatory for FSC members, which includes a number of life insurers, and full FSC members must produce annual compliance statements.[20] Breach of a Standard can lead to disciplinary action, including suspension or even expulsion from the FSC.[21]

1 Standard No 11: Genetic Testing Policy (2016)

The FSC's 2016 Standard prohibited life insurers from asking applicants to undergo genetic testing to support an application for insurance.[22] In addition, the Standards stipulated that insurers could not request an applicant to undergo genetic testing on the basis of an adverse underwriting assessment as a result of their family history.[23] Insurers could only obtain genetic test results with the informed written

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[15] (1766) 97 ER 1162, 1164 [1910].

[16] *Barclay Holdings (Aust) Pty Ltd v British National Insurance Co Ltd* (1987) 8 NSWLR 514, 517 (Kirby P).

[17] *Western Australian Insurance Co Ltd v Dayton* (1924) 35 CLR 355, 379 (Isaacs ACJ).

[18] *Insurance Contracts Act 1984* (Cth) pt IV div 3.

[19] Financial Services Council, 'FSC Standards' (Web Page) <https://www.fsc.org.au/resources/standards>.

[20] Financial Services Council, *FSC Standard No 1: Code of Ethics & Code of Conduct* (at 4 May 2018) app B.2.

[21] Ibid app C.5.

[22] Financial Services Council, *FSC Standard No 11 Genetic Testing Policy* (at 7 December 2016) 5 [10.1] ('*FSC Standard No 11*').

[23] Financial Services Council, *FSC Standard No 16 Family Medical History Policy* (at 7 December 2016) 5 [10.1].

consent of the tested applicant and those results could not be used for the underwriting assessment of a relative of the tested applicant.[24]

However, insurers were able to ask applicants to disclose existing genetic test results that were within the applicant's knowledge.[25] The FSC also allowed life insurers to ask applicants if they were even considering having a genetic test.[26] The FSC maintained that the requirement to disclose existing medical information was consistent with the duty of disclosure required by *ICA*.[27] They assumed that genetic information satisfied the test for materiality, as 'like other personal medical information, [genetic information] may influence a person's decision to seek life insurance'.[28] They justified their position by arguing that deliberately withholding genetic information results in inequality of access to material information and has the potential to 'significantly increase the cost of claims, eventually leading to premium rate increases for all costumers'.[29]

The FSC established an important caveat that insurers could not request disclosure of genetic tests used solely for the purpose of a medical research study where the results were unknown to the applicant.[30] The reasoning behind this exception was to uphold the significance of ongoing scientific research.[31] The FSC also encouraged life insurers to 'consider the potentially-beneficial effects of medical screening, early diagnosis and treatment on the Applicant's long-term health outlook' in their assessment of the applicant's risk rating.[32]

2 Standard No 11: Moratorium on Genetic Tests in Life Insurance (2019) ('Moratorium')

Following the recommendations of the Parliamentary Inquiry into the Life Insurance Industry ('Parliamentary Inquiry'), *FSC Standard No 11* was amended to exclude genetic research findings from insurance underwriting.[33] The FSC states that the primary purpose of the revised Standard is 'to ensure people can access a level of life insurance without being asked about the result of a previously taken Genetic Test'.[34] The Moratorium only applies to life insurance applications received on or after 1 July 2019 until 30 June 2024.[35]

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[24] *FSC Standard No 11* (n 22) 7 [10.6]–[10.7].

[25] Ibid 5 [10.2].

[26] Ibid 8 [10.11].

[27] Ibid 5 [10.2.1].

[28] Ibid 5 [10.2.2].

[29] Ibid 5 [10.2.3].

[30] Ibid 6 [10.3].

[31] Ibid 6 [10.3.1].

[32] Ibid 7 [10.5].

[33] *Life Insurance Industry* (n 8) 156 [9.98]–[9.101]; *FSC Standard No 11: Moratorium* (n 13).

[34] *FSC Standard No 11: Moratorium* (n 13) 3 [1.3].

[35] Ibid 3 [2.2].

Most importantly, life insurance providers are no longer able to request or use genetic test results for applications under:

- $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.[36]

Life insurance providers are still entitled to request applicants to disclose the diagnosis of a condition, 'even if the diagnosis resulted directly or indirectly from a Genetic Test'.[37] The diagnosis may also be used as part of the underwriting process.[38] Moreover, where an applicant's total amount of cover exceeds any of the above limits, 'a Life Insurance Provider may ask for and use the result of a previously taken or planned Genetic Test (where planned means the Applicant has consented to have a Genetic Test)', provided that there is evidence of the test's relevance to the cover.[39]

Life insurers are still unable to ask applicants to undergo genetic testing or to disclose results obtained from a medical research study where the results are unknown to the applicant.[40] The revised Standard provides additional consumer protections by allowing applicants to disclose favourable genetic test results and taking into account '[e]vidence based preventative treatment, or adherence to evidence based preventative measures, which reduce the possibility of developing an illness that runs in their family'.[41]

The FSC have declared their intention to undertake a review of the Moratorium, in consultation with stakeholders, in 2022.[42] The review will consider feedback from consumer groups and expert stakeholders, the appropriateness of the limits of Cover, rates of participation in genetic research, advances in the field of genomics and impacts on the sustainability of the life insurance industry.[43]

III INTERNATIONAL CONTEXT

A United Nations

Article 1 of the *Universal Declaration on the Human Genome and Human Rights* describes the human genome as the 'heritage of humanity' and article 6 stipulates that

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[36] Ibid 4 [3.3].

[37] Ibid 3 [3.1].

[38] Ibid.

[39] Ibid 4 [3.4].

[40] Ibid 3 [3.2].

[41] Ibid 4 [3.5].

[42] Ibid 5 [5].

[43] Ibid.

'[n]o one shall be subjected to discrimination based on genetic characteristics'.[44] This Declaration aims to protect the confidentiality of genetic information and prevent genetic discrimination.

B United Kingdom ('UK')

In 2001, the British government and the Association of British Insurers agreed upon a moratorium and concordat allowing consumers to withhold the results of genetic tests and still obtain significant levels of life insurance.[45] It also prevents insurance companies from using the results of such tests unless pre-approved by the government following independent expert consultation.[46] It excludes results for Huntington's Disease for policies above £500,000 as well as allows consumers to disclose negative test results in order to demonstrate that they are not at risk of an inherited disease.[47] The Concordat involves an agreement that insurers should have access to relevant information in order to fairly price risk for the broader benefit of consumers.[48] In October 2018, this regime was replaced by the Code on Genetic Testing and Insurers, with the same parties and effect as the moratorium.[49] It is important to note that there may be some compliance issues, as insurers in the UK are not required to be members of the Association of British Insurers.[50]

C United States

The United States has a number of state laws that govern genetic discrimination for a variety of contexts and diseases. The American federal congress has imposed a common minimal level of protection that states across the country must provide.[51] The

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[44] GA Res 53/152, UN GAOR, 53rd sess, UN Doc A/RES/53/152 (1998). See also *International Declaration on Human Genetic Data*, Records of the General Conference, UNESCO, 32nd sess, 32 C/Resolutions, 39 (16 October 2003) art 1(a) where it states the aim of the Declaration:

> [T]o ensure the respect of human dignity and protection of human rights and fundamental freedoms in the collection, processing, use and storage of human genetic data … in keeping with the requirements of equality, justice and solidarity;

Universal Declaration on Bioethics and Human Rights, Records of the General Conference, UNESCO, 33rd sess, 33 C/Resolutions, 74 (19 October 2005) art 16 which acknowledges the importance of protecting 'future generations, including … their genetic constitution'.

[45] HM Government and Association of British Insurers, 'Concordat and Moratorium on Genetics and Insurance' (Concordat, 2014).

[46] Ibid 9 [35].

[47] Ibid 5 [21(d)(ii)], 7 [24(d)].

[48] Ibid 1 [1], 2 [6].

[49] HM Government and Association of British Insurers, 'Code on Genetic Testing and Insurance' (Code, October 2018).

[50] Ainsley J Newson et al, 'Genetics and Insurance in Australia: Concerns around a Self-Regulated Industry' (2017) 20(4) *Public Health Genomics* 247, 254 ('Genetics and Insurance in Australia').

[51] *Americans with Disabilities Act of 1990*, 42 USC (1990); *Patient Protection and Affordable Care Act*, Pub L 111-148, 124 Stat 119 (2010); *Health Insurance Portability and Accountability Act of 1996*, Pub L 104-191,

absence of a universal health care system means that access to personal insurance is usually linked to employment.[52] Importantly, the current American federal framework does not encompass life insurance and the only relevant legal protection is at the state level, if any.[53]

D Canada

In May 2017, the Canadian Parliament passed the *Genetic Non-Discrimination Act* (‘*GNDA*’) into federal law.[54] The *GNDA* prevents insurers from requesting individuals to undergo genetic tests or requiring disclosure of any previous or future genetic test results.[55] It extends to predictive and diagnostic genetic tests as well as information obtained in clinical and research settings. However, insurers maintain their access to family medical history, such that family members of applicants are required to disclose their medical conditions but not their genetic test results. The *GNDA* fails to stipulate whether individuals are required to inform insurers that they have had a genetic test.

The Canadian Life and Health Insurance Association strongly opposes the *GNDA* and argues that legislative regulation is unnecessary following an update in January 2017 of the Industry Code to include a stipulation that insurers would not request or use genetic test results for life insurance coverage of $250,000 or less.[56] This means that approximately 85% of life insurance applications would not require any disclosure of genetic information.[57] It is worth noting that compliance may be an issue because, similar to the UK, the Industry Code is voluntary for members of the Canadian Life and Health Insurance Association.

The Canadian Institute of Actuaries predicted that the *GNDA* would have a substantial impact on insurance companies with the potential for premiums to increase from between 30–50%.[58] However, the Office of the Privacy Commissioner of Canada found that the *GNDA*’s ban on the use of genetic information would not have any significant impact on the Canadian insurance industry or insurance markets.[59] The key

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110 Stat 1936 (1996); *Genetic Information Nondiscrimination Act of 2008*, Pub L 110-233, 122 Stat 881 (2008).

[52] *Genetic Information Nondiscrimination Act of 2008*, Pub L 110-233, 122 Stat 881 (2008).

[53] See, eg, California prevents life insurers from using predictive genetic testing as a condition for coverage: *Underwriting on the Basis of Test of Genetic Characteristics*, 761 Cal Ins Code §§ 10146–9 (1994).

[54] *Genetic Non-Discrimination Act*, SC 2017, c 3.

[55] Ibid ss 3–5.

[56] Canadian Life and Health Insurance Association Inc, ‘Canada’s Life and Health Insurers Announce Commitment of Use of Genetic Testing Information’, *Cision* (online, 11 January 2017) <https://www.newswire.ca/news-releases/canadas-life-and-health-insurers-announce-commitment-on-use-of-genetic-testing-information-610363125.html#>.

[57] Ibid.

[58] Canadian Institute of Actuaries, *Canadian Institute of Actuaries’ Proposed Amendment to Bill S-201: An Act to Prohibit and Prevent Genetic Discrimination* (Report, 21 November 2016) 2.

[59] Michael Hoy and Maureen Durnin, *The Potential Economic Impact of a Ban on the Use of Genetic Information for Life and Health Insurance* (Report, March 2012) 2.

reasoning for this finding was that severe single gene mutations certain to cause early death and necessitating a high level of expensive coverage, such as Huntington's disease, occur so rarely as to have little impact on the insurance markets and the notion of pooled risk.[60] However, it was acknowledged that this position is subject to change as a result of continuing technological advancements and the increasing reliability, predictability and scope of genetic testing.[61]

The *GNDA* was subject to constitutional challenge, as there was some dispute about whether the *GNDA* is a legitimate exercise of federal power because it seeks to legislate matters that are within the jurisdiction of Canadian provinces. However, the Supreme Court of Canada on 10 July 2020 resolved this dispute, ruling that the *GNDA* is a constitutional exercise of federal powers.[62]

E Europe

The Council of Europe's *Convention on Human Rights and Biomedicine* prohibits genetic discrimination in countries in the European Union.[63] In addition, a recommendation of the Council of Europe in 2016 proposed that insurers should provide reasons for the processing of all health related personal information and should not require the taking of genetic tests, or use test results, for insurance purposes.[64] Consequently, legislative reforms and moratoria have been enacted in many European countries that prevent insurers from using genetic data when setting premiums.[65]

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[60] Angus MacDonald, *The Actuarial Relevance of Genetic Information in the Life and Health Insurance Context* (Report, July 2011) 2.

[61] Hoy and Durnin (n 59) 2–3.

[62] *Canadian Coalition for Genetic Fairness v Attorney General of Canada* [2020] SCC 17.

[63] *Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine*, opened for signature 4 April 1997, ETS No 164 (entered into force 1 December 1999). See also *Additional Protocol to the Convention on Human Rights and Biomedicine concerning Genetic Testing for Health Purposes*, opened for signature 27 November 2008, CETS No 203 (entered into force 1 July 2018); *Charter of Fundamental Rights of the European Union* [2000] OJ C 364/1, art 21(1) which expressly provides that '[a]ny discrimination based on any ground such as … genetic features … shall be prohibited'.

[64] Committee of Ministers, Council of Europe, 'Recommendation CM/Rec(2016)8 of the Committee of Ministers to the Member States on the Processing of Personal Health-Related Data for Insurance Purposes, Including Data Resulting from Genetic Tests' (26 October 2016).

[65] For example, Germany's *Human Genetic Examination Act* prevents insurers from requesting any genetic data for policies valued under a specified financial limit, such as lump sum policies valued under €300,000: *Gesetz über genetische Untersuchungen bei Menschen* [Human Genetic Examination Act] (Germany) 24 April 2009, § 4. For a table summarising European approaches to the use of genetic information by life insurance companies, see *Life Insurance Industry* (n 8) 141.

IV CURRENT ISSUES

Prior to June 2019, the FSC's Standards required insurers to provide the FSC with de-identified data on applications involving genetic testing.[66] However, the FSC has not been able to determine the total number of applications for life insurance that involved genetic information.[67] Therefore, the precise prevalence of the use of genetic data in the life insurance industry remains unclear. Nevertheless, ongoing medical and technological advances signal the increasing importance of genetic testing, fuelling the debate surrounding genetic discrimination in life insurance and highlighting the issues with the current legal framework.

The implementation of a voluntary moratorium is certainly a positive step towards achieving greater consumer protections but it also arguably fails to address broader concerns relating to self-regulation, accuracy of genetic testing, adverse selection and participation in medical research.

A Self-Regulation

The current legal framework lacks independent regulatory oversight of the use of genetic information by the life insurance industry. In their submission to the Parliamentary Inquiry, the FSC asserted that such independent oversight is unnecessary due to Australia's 'strong self-regulation regime'.[68] They also maintained that their regime of self-regulation allows the insurance industry to rapidly respond to any technological and research advancements in genetic testing, unlike legislation which 'could take years before a law is amended'.[69]

However, self-regulation has proven ineffective in ensuring the implementation of, and adherence to, the non-binding recommendations of the Australian Law Reform Commission's ('ALRC') Report on the Protection of Human Genetic Information in Australia.[70] The ALRC recommended that the reasoning provided to an applicant for an adverse underwriting decision based on genetic data should clearly explain the actuarial, statistical or other basis for the conclusion.[71] The ALRC also recommended that access be provided to reviews of underwriting decisions involving the use of genetic data.[72] The failure to implement these recommendations has resulted in

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[66] *FSC Standard No 11* (n 22) 8 [10.16].

[67] See Financial Services Council, Supplementary Submission No 26.2 to Parliamentary Joint Committee on Corporations and Financial Services, Parliament of Australia, *Inquiry into the Life Insurance Industry* (5 September 2017) 5, where it merely states that '[t]he FSC Genetic Testing database was recently independently scrutinised by the University of Sydney, which found there were "no widespread, or systemic issues identified"' ('Supplementary Submission No 26.2'). See also *Life Insurance Industry* (n 8) 147 [9.48].

[68] Supplementary Submission No 26.2 (n 67) 9.

[69] Ibid.

[70] Australian Law Reform Commission, *Essentially Yours: The Protection of Human Genetic Information in Australia* (Report No 96, 30 May 2003).

[71] Ibid vol 2, 723.

[72] Ibid vol 2, 733.

situations where life insurance policies have been denied or premiums increased without sufficient supporting data or explanation.[73] The FSC's Standards also previously contained clauses that could be considered to conflict with the ALRC's recommendations, such as the FSC's policy requiring applicants to disclose even a consideration of genetic testing where the insurer requests such information.[74] This conflict, coupled with a lack of regulatory oversight, created great potential for the industry standards to diminish consumer rights.

For example, an applicant in his early 20s was denied full life insurance cover when he disclosed that he had discussed genetic testing with a genetic counsellor.[75] He later underwent genetic testing and discovered he carried a mutation in the *MSH6* gene. After he disclosed these results, two other life insurance companies denied him coverage for cancer. He presented the insurance companies with extensive research supporting his claim that an annual colonoscopy would reduce his risk of cancer to the same as the population risk but he was still denied coverage and denied his request for actuarial evidence supporting the insurer's risk assessment. He was later offered full coverage by the latter of these insurance companies only after he lodged a complaint to the Australian Human Rights Commission.

The case ultimately demonstrates the high level of initiative and proactivity, in the form of extensive research and advocacy, required for an applicant to achieve a fair result. The denial of full coverage to the applicant was plainly unjustified, as the FSC's Standards and section 46 of *DDA* require insurers to take into account the benefits of special medical surveillance and to have actuarial, statistical or other data on which it is reasonable to rely on in justifying their decisions.[76] Self-regulation clearly failed to assist the applicant in these circumstances, as it was only the threat of legal action that prompted the insurer's change of position. Such cases have prompted medical and legal professionals to conclude that '[a]ny model of industry self-regulation for the use of genetic information by life insurers, who are inherently motivated by commercial gain, represents a conflict of interest'.[77]

B Accuracy of Genetic Testing and Underwriting

As the Moratorium only applies to life insurance applications under a certain limit, the accuracy of genetic test results and underwriting remains a valid concern for life

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[73] Tiller, Otlowski and Lacaze (n 5) 1.

[74] See *FSC Standard No 11* (n 22) 8 [10.11].

[75] Louise A Keogh and Margaret F A Otlowski, 'Life Insurance and Genetic Test Results: A Mutation Carrier's Fight to Achieve Full Cover' (2013) 199(5) *Medical Journal of Australia* 363, 364.

[76] *FSC Standard No 11* (n 22) 7 [10.5].

[77] Tiller, Otlowski and Lacaze (n 5) 2. A recent study completed by Tiller et al reveals the high incidence of genetic discrimination by Australian insurance companies, with the authors concluding that the high 'number of cases reflects a systemic problem with the Australian life insurance industry': see Jane Tiller et al, 'Genetic Discrimination by Australian Insurance Companies: A Survey of Consumer Experiences' (2020) 28(1) *European Journal of Human Genetics* 108, 108.

insurance applications falling outside the scope of the Moratorium. Dr Veikko Launis succinctly stated that 'the more accurate (reliable, predictive) the information, the more morally legitimate it is to incorporate it into actuarial calculations'.[78] This reasoning is reflected in the ALRC's recommendation to establish a process for ascertaining which genetic tests are sufficiently accurate, reasonable, actuarially relevant and scientifically reliable for the purposes of use in life insurance underwriting.[79] However, this recommendation about vetting of genetic tests to determine which are suitable to insurance underwriting was not implemented by the government.[80] Instead, the government left this recommendation as a matter for the industry to implement. This government response was contrary to the terms of some of the recommendations themselves, which would have seen more direct government involvement through a national committee.[81]

In the course of giving evidence to the Parliamentary Inquiry, the Australian Medical Association pointed out that 'many genetic tests are predictive in nature and the results do not necessarily guarantee a person will develop the condition that is being tested'.[82] For example, tests for single gene disorders may only predict that a disease will probably manifest at some time in the future but that time cannot be accurately predicted nor can the test predict the severity with which the person will be affected by the disease.[83] Tests for the more common complex or multifactorial disorders are even more uncertain as they can only identify predisposition to disease and cannot determine whether the person will ever in fact develop that condition.[84] Genetic test results therefore only suggest a probability of developing a given disease for one individual, whereas another individual who has not undergone testing, or who may not have a predisposition to a disease, might fall ill and die before the individual who disclosed the result of a genetic test. Genetic test results have consequently been described as 'fallible regarding future mortality' and therefore insufficiently accurate and inappropriate for use in the underwriting process, either 'as evidence in assessing insurability or, indeed, in deciding the premium to be charged'.[85]

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[78] Veikko Launis, 'The Use of Genetic Test Information in Insurance: The Argument from Indistinguishability Reconsidered' (2000) 6(3) *Science and Engineering Ethics* 299, 302 quoted in Joseph S Alper and Jon Beckwith, 'On the Philosophical Analysis of Genetic Essentialism' (2000) 6(3) *Science and Engineering Ethics* 311, 312.

[79] Australian Law Reform Commission (n 70) vol 2, 711.

[80] Australian Government, *Full Australian Government Response to ALRC Report 96* (9 December 2005) Recommendation 27-1.

[81] Australian Law Reform Commission (n 70) vol 1, 211.

[82] Chris Moy, 'Ethics and Medico-Legal: AMA Evidence to the Inquiry into the Life Insurance Industry' (2017) 29(19) *Australian Medicine* 26, 26.

[83] Margaret Otlowski, 'Genetic Testing and Insurance: The Case for Regulation' (2002) 9(4) *Agenda: A Journal of Policy Analysis and Reform* 335, 345.

[84] Ibid.

[85] Louise A Morris, 'Life Insurance and Genetic Tests: Risks for Insurers and Society' (2010) 12(3) *Health, Risk & Society* 251, 259.

The uncertainty of genetic test results has led to concerns that insurers conducting risk assessments may credit genetic information 'with greater probative value than it warrants'.[86] Medical professionals and academics have suggested that the information currently 'obtained from genetic testing is not sufficiently robust to justify its use in actuarial modelling'.[87] Each genetic condition requires a separate assessment of the relationship between genetic indicators and the economic costs of the identified risks.[88] The increasing complexity of genetic tests demands increasingly specialised knowledge to deduce accurate and reliable statistics and probabilities related to the results.[89] It is also highly difficult or even impossible to adjust statistical risk depending on an individual's actions to address their predisposition to a specific disease.[90] These difficulties increase the likelihood that insurance brokers or underwriters may be unnecessarily cautious in their use of genetic data, or misinterpret this data, resulting in the overcharging, or denial, of applicants for a life insurance policy.[91] Ultimately, it appears that insurance underwriters do not have adequate guidance and lack sufficient expertise or resources to understand and interpret genetic data.[92] The lack of transparency associated with underwriting exacerbates the problem, as applicants are unable to confirm whether the actuarial tables and/or the calculations of the underwriter accurately reflect the correct calculation for their risk.[93]

C Adverse Selection

The FSC maintains that they require access to genetic test results in order to avoid the ramifications of adverse selection.[94] Adverse selection arises where applicants do not fully disclose all material information within their knowledge and are subsequently not charged a premium commensurate to their risk status. This presents a major obstacle to insurers who will struggle to maintain profitability when lower premiums are charged to applicants with a higher risk grade. Adverse selection also arises where applicants with a higher mortality or morbidity risk take advantage of that knowledge

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[86] Otlowski (n 83) 345.

[87] *Life Insurance Industry* (n 8) 152; Evidence to Joint Committee on Corporations and Financial Services, Parliament of Australia, Canberra, 26 May 2017, 61, 63 (Paul Lacaze); Evidence to Joint Committee on Corporations and Financial Services, Parliament of Australia, Canberra, 8 September 2017, 31 (Kate Stockhausen).

[88] Otlowski (n 83) 345.

[89] Morris (n 85) 262.

[90] Ibid.

[91] See, eg, *J v London Life Insurance Company* [1999] BCHRT 36 where 'an insurance applicant was refused insurance due to a lack of statistical data on the part of the insurer': Morris (n 85) 262; Trudo Lemmens, 'Selective Justice, Genetic Discrimination, and Insurance: Should We Single Out Genes in Our Laws?' (2000) 45(2) *McGill Law Journal* 347, 371.

[92] Newson et al, 'Genetics and Insurance in Australia' (n 50) 253.

[93] Ibid.

[94] This is implied in *FSC Standard No 11* (n 22) 5 [10.2.2] where it states that '[g]enetic information, like other personal medical information, may influence a person's decision to seek life insurance'. See ibid.

by applying for one or multiple insurance policies or additional coverage, which they would not have otherwise sought.[95] If applicants are not required to disclose genetic test results to insurers, the concern is that they will have a stronger economic incentive to purchase insurance at underpriced premiums relative to actuarially fair premiums.[96]

At its worst, this information asymmetry can lead to market failure or low profitability and losses where only those applicants most likely to require a payout purchase insurance.[97] These dire financial implications are more likely to arise where applicants with a positive genetic test result present an increased probability of purchasing insurance and requesting significantly higher levels of coverage.[98] If the applicant deliberately conceals genetic information or provides misleading information, the insurer may undergo the significant financial and time expenses of investigating any claims made and/or paying out the insured sum under fraudulent terms.[99] It should be noted that purchasing insurance, or larger sums of insurance, on the basis of a genetic test result 'is not a crime and cannot, therefore, be considered fraudulent as such'.[100] Nevertheless, it may have considerable impacts upon the insurance industry by disrupting the symmetry of information and potentially also the market equilibrium.

The Parliamentary Inquiry found that the insurance industry's fears of market unsustainability as a result of adverse selection arising from non-disclosure of genetic test results 'may be overstated'.[101] There is certainly great concern for consumers that information asymmetry may lead to increased premiums to compensate for the industry's financial costs arising from adverse selection. However, the Parliamentary Inquiry found that 'there is presently greater benefit to consumers in preventing a duty of disclosure from arising in respect of predictive genetic tests' due to a number of reasons, including to encourage greater participation in genetic testing and research.[102]

D Participation in Genetic Testing and Research

Genetic testing could be highly beneficial to an individual's health, as well as that of their biological family members, by allowing them to improve their chances of early detection and survival by instituting preventative health measures, screening and lifestyle alterations. However, a study found that knowledge of insurance implications

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[95] James Butler, 'Adverse Selection, Genetic Testing and Life Insurance: Lessons from Health Insurance in Australia' (2003) 10(1) *Agenda: A Journal of Policy Analysis and Reform* 73, 85.

[96] Ibid 84.

[97] Richard Heaney and David Pitt, 'Impact of Genetic Testing on Life Insurance' (2003) 10(1) *Agenda: A Journal of Policy Analysis and Reform* 61, 61–2.

[98] Ibid 71.

[99] Morris (n 85) 254.

[100] Ibid.

[101] *Life Insurance Industry* (n 8) 154.

[102] Ibid.

influenced the uptake of genetic testing by participants.[103] The study involved 106 people from 25 families believed to be at risk of bowel cancer.[104] It found that participants informed of the prospect of increased premiums, or even refusal of coverage, were 2.6 times more likely to decline genetic testing compared to participants without this knowledge.[105] These results are particularly concerning because genetic testing for colorectal cancer is potentially lifesaving. It can lead to screening and regular colonoscopies, which are proven strategies for detection and prevention among carriers of genetic mutations.[106] This testing is a potentially highly cost-effective way of reducing the burden of bowel cancer on the public health system.[107]

In Australia, genetic counsellors 'commonly recommend clients organize life insurance policies before undertaking genetic testing'.[108] This practice is designed to protect clients from denial of coverage due to genetic test results but it can also encourage them to decline genetic testing altogether due to insurance fears.[109] These concerns have prompted medical and legal practitioners to recommend that the Australian insurance industry reconsider how genetic information is used in circumstances where the information can potentially reduce morbidity and mortality.[110] The new Moratorium goes some way towards addressing these concerns[111] but, as highlighted by the recent Royal Commission into Financial Services, industry self-regulation without adequate oversight continues to be problematic.[112]

V REFORM

Having regard to the international context, scientific advancements and domestic regulatory issues, Australia's current legal framework is unsustainable. Australia requires independent oversight of the insurance industry and amendment of the FSC Standards to enhance the sustainability of the life insurance industry. The new industry-led Moratorium is insufficient to protect consumers.

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[103] Louise A Keogh et al, 'Is Uptake of Genetic Testing for Colorectal Cancer Influenced by Knowledge of Insurance Implications?' (2009) 191(5) *Medical Journal of Australia* 255.

[104] Ibid 256–7.

[105] Ibid 257.

[106] Ibid 255.

[107] Ibid.

[108] Tiller, Otlowski and Lacaze (n 5) 2.

[109] Ibid.

[110] Keogh et al (n 103) 258.

[111] See *FSC Standard No 11: Moratorium* (n 13).

[112] See *Royal Commission into Misconduct in the Banking, Superannuation and Financial Services Industry* (Final Report, 1 February 2019) vol 1, 310–15.

A Independent Oversight

In line with the ALRC's recommendations, the federal government should establish an independent body to oversee the use of genetic information in the Australian insurance industry.[113] An independent government body would be better suited to ensure increased transparency of the underwriting process and to avoid any potential for a conflict of interest. The government did establish the Human Genetics Advisory Committee in 2009 but it lacked a clear mandate, could not compete with industry bodies and was subsequently disbanded in 2015.[114]

The Parliamentary Inquiry recommended the Industry Code be registered with the Australian Securities and Investments Commission ('ASIC') and ASIC be endowed with the requisite enforcement powers to implement a co-regulatory approach between ASIC and the FSC.[115] This approach is less appealing following the recent findings by the Royal Commission into Financial Services revealing 'ASIC's ineffective enforcement culture' including 'a deeply entrenched culture of negotiating outcomes rather than insisting upon public denunciation of, and punishment for, wrongdoing'.[116] However, the Royal Commission also suggested that ASIC 'should be given time to demonstrate that changes can be made and to demonstrate that, once made, the changes are durable'.[117]

Following the revelations of their apparent reluctance to litigate against larger financial institutions, ASIC accepted that when considering enforcement measures, it should start with the question '[w]hy not litigate?'[118] ASIC has also since renewed their enforcement approach by establishing an Office of Enforcement within ASIC, accelerating enforcement outcomes and strengthening penalties available to them.[119] ASIC has therefore demonstrated that 'changes can be made' but only the passage of time will determine whether 'once made, the changes are durable'.

If the changes prove to be short-lived, ASIC would not be well suited to regulate the use of genetic information by life insurers and an entirely new government body would be more suitable as the regulator for this purpose. The new body should be a government entity provided with clear terms of reference and the requisite authority to implement robust regulation.[120] It should be responsible for conducting regular

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[113] Australian Law Reform Commission (n 70) vol 1, 211, vol 2, 711.

[114] Newson et al, 'Genetics and Insurance in Australia' (n 50) 249.

[115] *Life Insurance Industry* (n 8) 155.

[116] See *Royal Commission into Misconduct in the Banking, Superannuation and Financial Services Industry* (n 112) 430, 425.

[117] Ibid 431.

[118] Ibid 427; Australian Securities and Investments Commission, Submission to Royal Commission into Misconduct in the Banking, Superannuation and Financial Services Industry (2 November 2018) 9 [45].

[119] Sean Hughes, 'ASIC's Approach to Enforcement after the Royal Commission' (Speech, Annual Conference of the Banking and Financial Services Law Association, 30 August 2019) <https://asic.gov.au/about-asic/news-centre/speeches/asic-s-approach-to-enforcement-after-the-royal-commission/>.

[120] Newson et al, 'Genetics and Insurance in Australia' (n 50) 254.

audits on the use of genetic data by insurers.[121] It should also have the power to mandate and enforce the compliance of all insurers with its decisions and it should provide an accessible avenue for independent dispute resolution in cases where an adverse insurance decision occurs.[122]

B Amendment of FSC Standards

The 2016 FSC Standards were particularly problematic and a number of their clauses required extensive alteration or deletion. In June 2019, the Standards were amended to exclude genetic research findings, up to certain limits, from insurance underwriting.[123] This alleviates any lingering fears that consumers may have about participating in genetic research and also ensures the unhindered progression of the Australian research industry and the identification of emerging health issues.[124]

The Standards should also be amended to include a detailed guide of how underwriters should assess genetic information in cases of cover excluded from the Moratorium. This guide should highlight the current limitations in the interpretation of genetic data and clarify what level of evidence is required before an underwriter can reach a conclusion about the use of the genetic test results. It should also stress the significance of underwriters recognising in the risk-stratification process an individual's lifestyle and health changes to mitigate their risk. Finally, it should assist insurers to understand that genetic test results are not always entirely accurate and the source of the genetic data should be considered before underwriters reach any conclusions. Importantly, the Standards should address the fact that direct-to-consumer testing is becoming increasingly common and the results are sometimes of questionable quality.[125]

C Government Intervention

Even though a moratorium has been implemented, it is important that the government keep abreast of advancements in the field of genetics in order to ascertain the suitability of enacting legislation or other regulation prohibiting or restricting the use of genetic information by the life insurance industry.[126]

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[121] Ibid.

[122] Ibid.

[123] *FSC Standard No 11: Moratorium* (n 13).

[124] The exclusion of all research findings reflects international practice, such as arrangements for participants in the British 100,000 Genomes Project, and is also supported by the Human Genetics Society of Australasia and an international body of experts: Ainsley J Newson et al, 'Human Genetics Society of Australasia Position Statement: Genetic Testing and Personal Insurance Products in Australia' (2018) 21(6) *Twin Research and Human Genetics* 533; K Barlow-Stewart et al, 'How Are Genetic Test Results Being Used by Australian Life Insurers?' (2018) 26(9) *European Journal of Human Genetics* 1248, 1255.

[125] Newson et al, 'Genetics and Insurance in Australia' (n 50) 252.

[126] *Life Insurance Industry* (n 8) 156.

It is important to also briefly note the argument that ethical issues associated with the use of genetic information in life insurance should be addressed through social policies, rather than a moratorium or increased regulation. For example, it has been argued that the government should provide targeted assistance in the form of subsidies to individuals who are subject to dramatic increases in life insurance premiums as a result of genetic mutation.[127] However, with continuing genetic advancements, such legislation could prove to be a great burden on the Australian economy and the taxpayer. It should be kept in mind that 'hurried and premature legislation in the rapidly evolving field of human genetics can be counterproductive'.[128]

VI CONCLUSION

The Australian life insurance industry has struggled to keep up with scientific and international legal advancements. The duty of disclosure enshrined in section 21 of *ICA* inherently conflicts with the principle of non-discrimination pursuant to section 46 of *DDA*. The concerning lack of transparency in the insurance claims process denies applicants the ability to determine why their claim was denied, their coverage diminished or their premiums increased. This lack of transparency, coupled with the complexity of actuarial calculations based on genetic test results and the potential inaccuracy of such results, has led to significant unfairness. It has also discouraged individuals from participating in potentially lifesaving genetic testing or research due to fears of the insurance ramifications.

The implementation of the voluntary Moratorium is a significant first step towards ensuring greater consumer protections in the life insurance industry. However, the country's current legal framework still requires extensive reform by establishing an independent government body to oversee the use of genetic information in life insurance, as well as significant amendment of the Industry Standards and potential legislative intervention.

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[127] Butler (n 95) 88.

[128] Abdullah Daar and Jean-François Mattei, 'Draft World Health Organization (WHO) Guidelines on Bioethics', *nature* (online, May 1999) <https://www.nature.com/wcs/b23a.html>.