

2017 ALUCA TurksLegal Scholarship Winner's Paper

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"Genetic testing leaves some excluded from Life Insurance" ...or does it?

On 2 June 2017, an article was published in The Sydney Morning Herald under this headline bringing into question what the writer saw as the Australian life insurance industry's unhelpful position on the disclosure of genetic testing results.

In particular, the author pointed to recent changes introduced in the UK loosening the obligation to give disclosure of genetic testing results and some remarks by local genetic testing expert Associate Professor Kristine Barlow-Stewart, who has asked the industry not to require disclosure of genetic tests conducted for the purpose of scientific research.

With what appears to be a tidal wave of genetic information becoming increasingly available, please outline the strengths and weaknesses of the Australian industry's current approach. What do you think of the critic's arguments? How can we address their concerns while maintaining the viability of the industry?

The judges will be particularly impressed by evidence of research showing how other comparable countries are choosing to handle this issue.

[Question link](#)

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Acronyms

ABI	Association of British Insurers
AGN WG	Australian Genetic Non-Discrimination Working Group
AHEC	Australian Health Ethics Committee
ALRC	Australian Law Reform Commission
CAD	Coronary Artery Disease
CLHIA	Canadian Life and Health Insurance Association
CMO	Chief Medical Officer
DNA	Deoxyribonucleic acid
FSC	Financial Services Council
GINA	Genetic Non-Discrimination Act
HREC	Human Research Ethics Committee
IAA	Institute of Actuaries of Australia
IP	Income Protection
NATA	National Association of Testing Authorities
PJC	Parliamentary Joint Committee
UK	United Kingdom
US	United States

... **Who are you?** What makes you different and unique from others? **Are you who and what you want to be?** If altering something inherent about your nature improved your future, would you embrace it?...

Introduction

While Gregor Mendel was cross-breeding pea plants in the 1850s, he could not have foreseen his posthumous recognition as the founder of a scientific field that over 150 years later made editing a human embryo's DNA possible. Rapid advancements in genetic research have informed scientific understanding of how uniquely inherited traits explain individual differences between and within species. The relevance of genetic science is broad. Arguably, its most profound and promising application is the prediction of disease and alteration of future disease prevalence, incidence, morbidity and mortality.

Genomic research has sought to identify genetic variants and mutations associated with specific disease. The Holy Grail for medical genomics is to reliably predict disease onset so tailored lifestyle and medical interventions can be implemented to prevent disease onset or minimize its impact; thereby altering the future life course nature had in store.

Despite impressive advancement, the science remains in its infancy relative to its anticipated potential. For rare, monogenic diseases with full penetrance, like cystic fibrosis and Huntington's chorea, genetic testing yields definitive results. For polygenic, multifactorial diseases including cancer, CAD, diabetes and depression, the reliability and validity of genetics predictive power remains questionable^{1,2}.

For 30 years international commentary has scrutinized the perceived exploitation of predictive genetic testing by insurers. Opponents proclaim incorporation of unreliable and invalid data into risk stratification, actuarial modelling and underwriting practices leads to unfair discrimination through unjustified premium loadings, exclusions and denials. Insurers meanwhile raise concerns about anti-selection and selective lapsation stemming from greater awareness of personal health risks³. For three decades the same concerns have been raised on both sides. While the science has progressed, arguments around genetics and insurance have not.

Current position

The FSC's genetic testing policy outlines the Australian Life Insurance Industry's current position⁴. The policy stipulates insurers:

- cannot request an applicant undergo genetic testing;
- may request disclosure of previous genetic test results;
- cannot request disclosure of genetic tests undertaken for research where results are unknown to the applicant;
- should consider how screening, early diagnosis and treatment alters risk-rating;
- cannot use genetic test results to assess a relative's risk;
- may ask applicants if they are considering having a genetic test.

The FSC's policy on Family Medical History makes one reference to genetic testing⁵; that insurers:

- cannot use an adverse underwriting assessment based on family history to request an applicant undergo genetic testing.

Strengths

The FSC's position maintains parity of information, a fundamental principle of mutually-rated insurance. The Insurance Contracts Act infers a reciprocal relationship based on "utmost good faith" and a "duty of disclosure"⁶. The Life Code of Practice outlines principles of conduct such as honesty, openness and transparency⁷. While the Code is the industry's commitment to customers, in the context of an equitable and

mutual affiliation, these principles apply equally to the conduct of insurers and customers. The FSC's policy protects both parties' right to information influencing decisions to seek or offer insurance.

The FSC's position upholds customer equity by rejecting the notion of 'genetic exceptionalism', a view supported by the ALRC and AHEC's joint enquiry into protecting human genetic information⁸. Treating genetic information similarly to other forms of personal health data ensures customers with genetic-based risks are not treated more favourably than those with non-genetic risks by avoidance of the duty of disclosure. Indiscriminate disclosure of medical information which reliably and validly informs risk promotes customer equity in the context of a mutually-rated insurance arrangement.

The policy acknowledges the impact of predictive, preventative and personalised medicine in altering risk. Insurers are encouraged to downgrade risk-ratings if engaging in preventative interventions developed within this emerging model of healthcare indicates reduced risk. The FSC's stance recognises that health risks are amenable and a customer's insurability should be advantaged accordingly.

Concerns

Despite the FSC's consultation with geneticists during policy development⁹, commentary from physicians, researchers and community on insurers using genetic information continues.

The AGNWG propose the exemption under the Disability Discrimination Act cannot apply to genetic information in the absence of statistically robust epidemiological data^{10,11}; thereby making it unlawful to discriminate on genetic grounds. Actuarial modelling and underwriting decisions must be evidence-based and cannot incorporate unreliable and invalid data.

The FSC's policy is silent on the source of genetic information. Genetic testing is becoming increasingly available from various sources including clinical laboratories accredited by NATA, research laboratories and online direct-to-consumer testing. The reliability and interpretation across sources is variable and different companies report different health risks for the same individual¹². Indiscriminate access to genetic information may provide inaccurate data that has not been interpreted within validated clinical guidelines¹³.

Use of genetic information is self-regulated by industry, a model supported by the 2003 AHEC and ALRC joint enquiry⁸. Concerns remain however that without independent regulatory oversight, there is a conflict of interest and diminished transparency¹⁴. Recent commentary deemed self-regulation ineffective due to a perception of no progress, no requirement to justify underwriting decisions and no accessible appeals process¹⁴. However, section 10 of the FSC's policy requires insurers to provide underwriting rationales and supporting evidence and clearly outline appeals processes and legal remedies⁴.

Genetic counsellors discuss adverse insurance decisions pre-testing as standard practice¹⁵. Evidence shows fear of insurance consequences deters participation in genetic testing for clinical and research purposes^{16,17}. When considering approval of genetic research proposals, the HREC raise concerns about damaging participants' insurance prospects¹⁰. The AGNWG propose known genetic test results from research participation should be exempt from disclosure¹⁰. However, when such results influence a decision to seek insurance, treating this information uniquely violates principles of utmost good faith, duty of disclosure, information parity and customer equity.

There are calls for Australia to consider international positions and implement a moratorium on genetic information¹⁰. Internationally, positions vary and though some regions have adopted legislation or moratoriums, others have not.

International positions

The UK government and ABI have a voluntary moratorium for predictive genetic tests¹⁸, established in 2001 and due for review in 2019. Known genetic test results do not need to be provided for policies with a value up to £500,000 (Life), £300,000 (Trauma) and £30,000 annually (IP). Above these limits, insurers may request predictive genetic test results for approved genetic tests. Currently only one test is approved; for Huntington's disease. Applicants are not required to disclose predictive or diagnostic test results obtained through research projects. Negative predictive results can be provided to counter an adverse family history. The ABI state this approach is sustainable while genetic testing is rare and the number of policies affected by genetic non-disclosure remains low.

The Council of Europe's Convention on Human Rights and Biomedicine prohibits genetic discrimination and specifies predictive tests may only be used in medicine and research¹⁹. European countries implemented this prohibition variably, though there was overarching consensus that genetic information should be prohibited or restricted in private insurance. Some countries have enacted legislation for complete bans while others have applied restrictions. For example, Germany's Human Genetic Examination Act²⁰ prohibits insurers requesting any genetic information for policies valued under €300,000 (Lump Sum) and €30,000 annually (IP).

Life insurers in the US may request genetic information largely without restriction. GINA passed federally in 2008 and prohibits health insurers and employers accessing predictive genetic results²¹. Initial bills proposed prohibitions apply to life insurers, however resistance was fierce and life insurance was subsequently removed to ensure the bill passed as law²². Three US states enacted legislation to ensure broad regulation for genetics in life insurance. Oregon's Genetic Privacy Act²³ stipulates life insurers cannot use genetic test results of a relative to deny insurance, though the applicant's may be used. Vermont's Insurance Division²⁴ and California's Insurance Code²⁵ prohibits the use of predictive genetic testing as a condition of insurance coverage. California allows requests for diagnostic genetic testing at application for policies contingent on testing for specific diseases.

In March 2017, Bill S-201 passed in Canada, now referred to as the Genetic Non-Discrimination Act²⁶. It prohibits requesting genetic testing or requiring disclosure of test results if "entering into a contract or agreement" or "offering terms or conditions in a contract" but does not reference a specific industry or contract type²⁶. The CLHIA was criticised for taking a position on genetics at "the 11th hour"²⁷. In January 2017, while the bill was being debated, the CLHIA introduced an Insurance Code on genetic testing which stated from January 2018 Life Insurers will not use pre-existing genetic results known to the applicant for life policies valued under \$250,000²⁸. The implications for Canadian Life Insurers remain unclear as a Supreme Court challenge is prepared to test the law's constitutionality; the law was passed federally but insurance is governed provincially. The CLHIA have not removed the code from their website.

Position vs. Approach

Debate continues internationally on the best approach to genetics and insurance. Formal positions differ, however evidence suggests approaches are broadly similar. Though life insurers in countries with no prohibitions may request genetic information, it seems they rarely do.

Reviews conclude genetic discrimination is rare and the fear of discrimination is disproportionate to its actual occurrence^{29,30}. The IAA analysed data from 2000 to 2002, revealing 27 of 1.23million retail policies (0.0002%) had an adverse decision related to genetic information³¹. Recent interviews with Australian underwriters and CMOs indicated requests for genetic information are rare³. One insurer advised 750 of 33,000 applications (2%) in 2016 included genetic information³². During public PJC hearings in May, August

and September 2017, senior industry leaders advised a) they were unaware how genetic information was used in their business, b) genetic information was not used in their business or c) genetic information was used rarely and only if sources are credible, tests scientifically reliable and other risk factors support risk-rating^{14,32,33}. The Chair of the AGNWG expressed interest at these unexpected revelations¹⁴. Therefore while countries like Australia and the US do not have formal moratoriums in place, they appear to operate similarly to those that do. Life insurers rarely use genetic information to make decisions on risk and policy terms.

Countries with moratoriums report no notable material impact on the industry due to genetic non-disclosure and a recent report concluded a similar finding for Australia³. Though as genetic testing becomes more prevalent, the impact of anti-selection and selective lapsation may be more apparent therefore preparation is required now.

Recommendations

1. Three amendments to the FSC's policy are proposed:
 - include a required standard on the source of genetic testing (i.e. NATA accreditation);
 - limit use of genetic information only to tests supported by reliable and valid scientific research (similar to clause 10.3 in the FSC's Standard No.16⁵);
 - remove questioning an applicant on future plans to undergo genetic testing. If plans are for medical reasons, robust underwriting questions will identify this. If plans are curiosity-driven, anti-selection has not occurred.
2. Establish an independent regulatory panel. After three decades of controversy, resolution will not occur under a self-regulated model. The small number of policies impacted make it viable for every adverse genetic-based decision to be reviewed by the panel.
3. The FSC to make data it requires individual insurers to report on genetic information publically available so industry trends and practices are transparent. This may encourage health practitioners to reconsider discussions on insurance and genetics with patients, allowing provision of reassurance based on facts rather than fostering fear based on the unknown.
4. A moratorium is not recommended. It would have limited material impact on the current approach. A 'ban' implies the presumption of guilt and evidence suggests the industry is broadly innocent. Maintaining oversight while collaborating with a regulatory panel will allow the industry to remain part of the solution.
5. Product design will be central to managing anti-selection and selective lapsation when genetic testing becomes widespread. Trauma products will be most impacted by anti-selection³. Industry is currently debating the viability and utility of lump sum products. The impact of genetics should form part of these considerations. Choice-driven IP products that allow customers to self-exclude specific diseases or opt for injury and accident only products may combat selective lapsation.
6. Insurers must consider the benefits of improved customer awareness of individual health risks. Engagement in preventative lifestyle and medical interventions specific to their known risk factors must be acknowledged in risk-stratification processes. Prospective occupational interventions designed to maximize function and partial capacity should disease manifest should also be a future consideration.

Conclusion

Genetic testing does not leave the vast majority of Australians excluded from life insurance. Nevertheless, in times of unprecedented scrutiny, industry must reflect on the cause of widespread fear on genetics in the relative absence of wrongdoing.

The core of the issue is not the science. The core of the issue is trust. For the lay person, the approach of life insurance is puzzling. An industry promises to protect customers when 'the worst' happens, but first seeks to determine what that 'worst' might be so an insurance offer can be carefully tailored not to reflect their future.

Genetic science has revolutionized medical models from reactive, diagnostic and retrospective to predictive, prospective and preventative. Insurance risk-rating models have not kept pace. The concerns of geneticists are not unique to genetics. They echo those of mental health professionals who claim insurance models discourage accessing psychological treatment that would prevent or minimize future illness. They echo those of GPs who report reduced standards of practice for fear of including information in clinical notes that may disadvantage a patient's insurance prospects.

There is significant growth potential for Australian life insurance in an underinsured market. Such growth first requires restoration of community confidence. Risk-pooling management must be reconsidered, equally balancing industry viability and customer outcomes. Greatest resistance will come from within the industry - "It will never work", "It cannot be done", "This is how we've always done it".

It will take cross-industry collaboration with creative actuaries, radical underwriters, revolutionary product designers, forward-thinking rehabilitation professionals and open-minded executives to alter the course of the industry, ensuring it maintains its important societal role long-term. An insurance model which creates community fear, discourages proactive health management and disrupts physician-patient relationships cannot continue.

While the DNA of Australian life insurance is placed firmly under the microscope of the PJC, it is an opportunity for industry to consider what mutations may have inadvertently manifested over the years, what mindsets need to be genetically edited out and how the genome of life insurance can be re-engineered to ensure a healthier future that builds trust, meets community expectations and keeps pace with medical advancement. It is time as an industry to ask...

...Who are we? What makes us different and unique from others? **Are we who and what we want to be?** If altering something inherent about our nature improved our future, would we embrace it?...

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