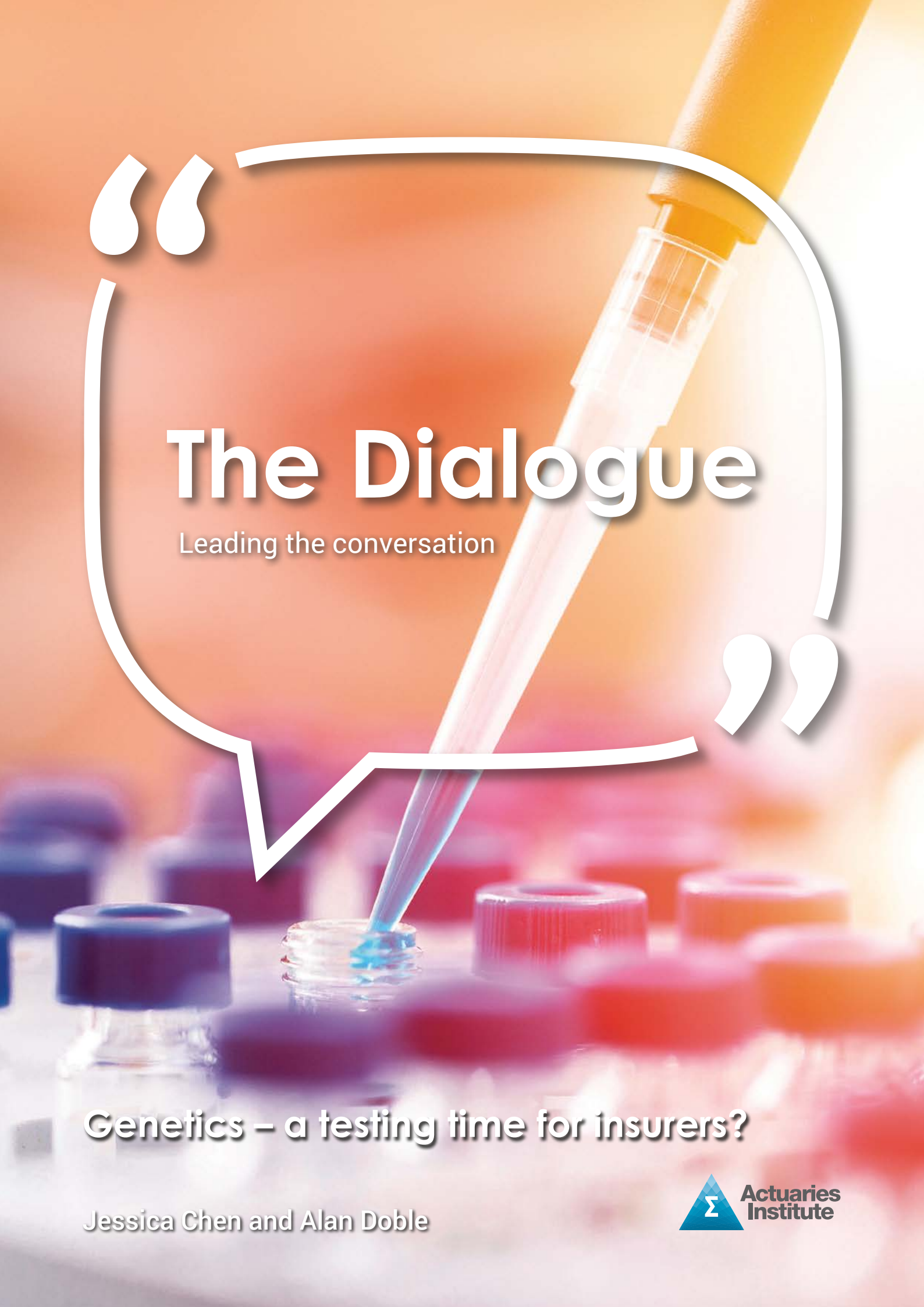

The Dialogue

Leading the conversation

Genetics – a testing time for insurers?

Jessica Chen and Alan Doble

Actuaries Institute

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About the Actuaries Institute

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Genetics – a testing time for insurers?

Jessica Chen and Alan Doble

This paper looks at the broader future implications of genetic testing for society, medical professionals and the insurance industry.

Key points

- Genetic testing has far reaching implications for society, well beyond that of insurance. It creates the potential for affected individuals to mitigate the risk of inherited disease.
- The use of genetic information is likely to increase due to rapidly declining test costs and the increased understanding of genetic research results.
- The genetics community in Australia sees a need to reduce barriers for people who want to understand their genetic make-up, primarily for health or family reasons. The life insurance community has been concerned about the potential for anti-selection by people who do not disclose their test results thus potentially affecting the access to, and cost of, insurance cover.
- The authors of this paper believe the time has come to reconsider these issues. All parties should welcome the chance to join in the discussion. The best solutions are likely to be found if the public are involved in the decision process with input from medical professionals, genetics researchers and insurers.

Genetic Testing and Insurance

Knowledge of the implications of genetics on human health has continued to evolve rapidly since the first mapping of the human genome was completed around the start of this century. The Institute of Actuaries of Australia has long taken an interest in how genetic science may affect Australian society[1]. There are complex issues for life insurance regarding genetic testing, cover availability and affordability. This paper has been prepared in the public interest, to raise awareness of current issues and to aid thinking about how those issues may be managed in the future.[2]

Genetics: evolution or revolution?

Media reports appear frequently on the rapid development of genetic science. A paper with deep implications was published in the scientific journal *Nature*, on 2 August 2017. It reported the first use by scientists in USA, of a laboratory technique called CRISPR, to edit the DNA of human embryos using 'molecular scissors' to replace a faulty section of DNA in a gene known to cause the serious heart condition hypertrophic cardiomyopathy. That is the most common cause of sudden death in otherwise healthy young athletes. The section of DNA inserted has the more commonly occurring gene code that does not cause the disease. The experimental embryos were allowed to grow for only a few days, but in future we could see modification of embryos leading to the birth of babies who carry edited DNA and will later pass on the edited DNA to their own offspring.

While Australian experts have described this as a 'remarkable technical achievement' it raises enormously complex questions. Ultimately the technique could remove the risk of some inherited diseases in the children of affected families. At present, there is a prohibition in the US against considering any clinical trials involving genetic modifications that can be inherited. Any reconsideration of that ban, which would certainly not be finalised for some years, would raise again all the issues about eugenics that have caused concern for over 100 years.

This topic is an example of the controversies that arise at the cutting edge of genetic research and will cause great debate in future years. These issues are likely to be debated first in medical and scientific forums. Their implications are so far reaching that a wider debate may be required to ensure a form of regulation that is acceptable to society. However, the following sections are limited to some questions affecting the present day provision of life insurance in Australia, to applicants who may become aware that their own genetic makeup may have an adverse effect on their future health.

Predictive genetic testing

Genetic research is the study of genetic variation and how it influences biology, including physical traits and propensities to diseases.

In the 1980s, a genetic mapping technique called 'linkage analysis' was developed. This technique combined hereditary patterns from families, together with technology available at the time, to localise single genes that 100% predict the onset of certain diseases, referred to as monogenic diseases. Notable examples include Huntington's disease and cystic fibrosis. Monogenic disease predictions are commonly used for family planning purposes and to confirm medical diagnoses. Whilst useful, application of monogenic disease prediction is limited to the low number of families affected by the uncommon incidence rate of such diseases

In the 2000s, due to advancements in research and technology, genome wide association studies (GWAs) began. This technique compares the genome across many unrelated individuals to identify whether genetic variants are associated with a trait, such as the development of a particular disease. GWAs can be used to aid risk prediction of more common diseases, such as cancer and coronary artery disease. As these illnesses are controlled by many genes, they are referred to as polygenic diseases.

The risk prediction of polygenic diseases is less conclusive than for monogenic diseases. For polygenic diseases, environmental factors such as nutrition, social support, and education, also play an important role in disease manifestation. The impact of genetics versus environmental factors on disease risk varies by disease. The table following illustrates the relative impacts for some common diseases.

Disease[3]	**Heritability** Variance explained by genetic factors
Type 1 diabetes	85%
Alzheimer's disease	80%
Coronary artery disease	50%
Prostate cancer	40%
Parkinson's disease	25%
Breast cancer	25%
Stroke	15%

GWAs have led to the development of predictive genetic testing, which can indicate the propensities for common diseases to manifest later in life, before any onset of symptoms. However, as the probability of disease manifestation is not 100%, there exists a diversity of views on the level of predictive power of these tests. Currently, whilst the technology exists, the uptake of predictive testing

is low. It is generally accepted though, that there is great potential in genetic testing. Despite the debate on the clinical validity of the tests, it is conceivable that they may become commonplace and be considered as part of preventive health screen programs in the future. Such tests may:

1. **More effectively target preventative health screening programs.**
   These tests can identify high-risk individuals who can then be enrolled earlier for medical screening and can be targeted for preventative measures. This allows for a more effective use of medical resources.

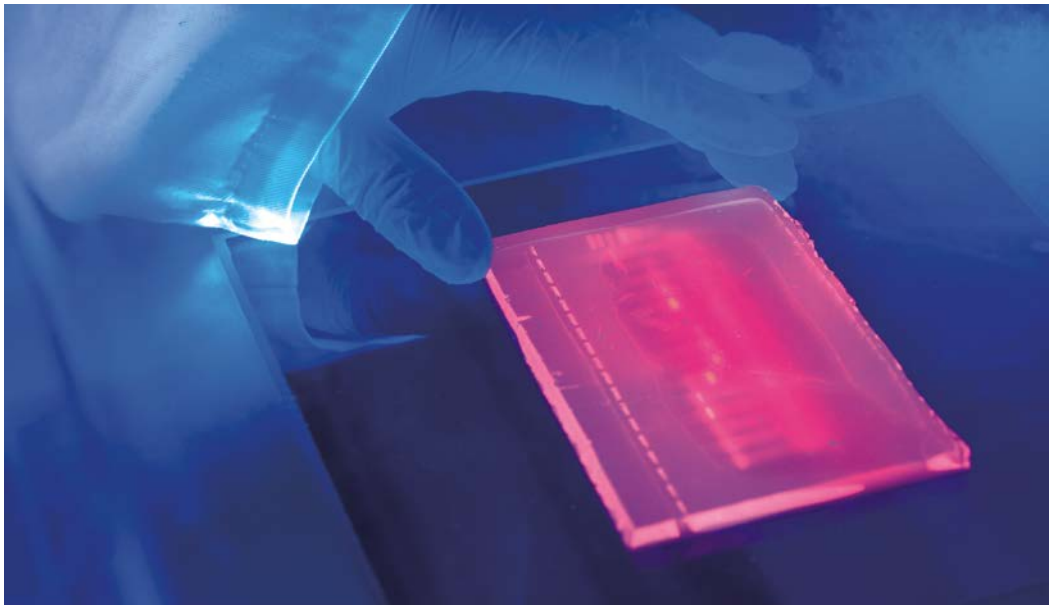
2. **Become easy to obtain and relatively affordable.**
   As an example, the personal genomics company 23andMe offers genetic testing kits online for around $200USD that now can include reports of risks for some diseases[4].

Potential impacts on the individual

One of the major advances in genetics since 2000 has been the development of techniques for examining some, or all, of the genome of individuals and to use the results to test their susceptibility to certain diseases later in life. The use of predictive genetic testing is starting to become a part of health screening, alongside traditional screening measures, such as blood and urine testing and scans. However, there are major differences between the use of genetic test results and the use of non-genetic information. These exceptions are important to the individuals concerned. The following need to be considered.

1. **Persistency of results**
   Traditional medical testing uncovers the situation at a point of time, for example, the patient's blood pressure on the day of the test. The nature of traditional screening is that the test results vary over time. In contrast, the nature of genetic testing is that the results won't change over time, although their interpretation might change in light of any new advances in research. For this reason, some gene testing services provide updated risk reports to customers when they update their predictive models. This means that customers may only need to take a genetic test once in their lifetime. The genetic sequencing identified by that test will always remain valid.

   This raises some considerations. Once an individual's genome has been mapped and recorded, how should that data be used in future? Would a later re-interpretation, based on advances in genetic research, mean that person has pre-emptively consented to future genetic testing? What requirement is there on the testing agency to alert existing clients to new medical insights that could affect them? Does a genetic test create lifetime disclosure obligations for the tester and the client?



The information that can be gleaned from the latest types of predictive genetic testing is wide ranging and may cause unexpected or unwelcome personal ramifications.

2. **Predictability before onset of symptoms**
Many traditional screening tests are designed to either confirm a diagnosis or to provide evidence of onset of symptoms. Geneticists sometimes argue that predictive genetic tests are different because they can also predict the propensity of disease manifestation before any symptoms occur. This is not unique; traditional blood pressure readings or cholesterol test results are often obtained to help predict the onset of more serious medical conditions later in life. The use of smoking status is similarly a predictor of future risk when considering life insurance for a young person without current health issues. The challenge is that the results of all predictive tests are not definitive. They therefore need to be considered together with other information such as one's own environmental factors.

After receiving advice on a test result, the action individuals take to make health and lifestyle changes may vary greatly, as will the resultant future health outcomes.

3. **Information and purpose**
Genetic testing related to a particular monogenic disease is specific to that disease. In contrast, the information that can be gleaned from the latest types of predictive genetic testing, for example from a whole genome mapping of an individual, is wide ranging. Such a test can provide information outside of the original intent of the exercise, which may have been just to find out information on the person's ancestry. This may cause unexpected or unwelcome personal ramifications.

To mitigate this consequence, genetic testing undertaken by Australian based laboratories is generally offered in conjunction with genetic counselling. Genetic counselling is a process which aims to help people understand and adapt to the medical, psychological, familial and reproductive implications of the genetic contribution to specific health conditions[5]. However, genetic counselling may not necessarily be provided to everyone who is advised of a predictive genetic test.

4. **Method of providing cells for a genetic test**
The mechanism by which a predictive genetic test can be obtained may differ to that of traditional screening methods, with key differences being:

- Only a small DNA sample is required.
- The sample can be from past material, from any part of the body.
- While a predictive genetic test can be obtained via a clinical setting, tests are also offered direct-to-consumer (i.e. by mail order).

Insurance and regulatory considerations

The concept of risk pooling across many individuals underpins the tools used to design and price insurance products. As individuals become better informed of their future health prospects, that knowledge may change the mix of individuals taking out insurance within a risk pool and alter the pricing of insurance cover.

For the life insurance industry, if health information known to the insurance applicant is not disclosed, it may be expected to lead to anti-selection[6], increasing premiums and ultimately impacting the financial sustainability of the industry. Conversely, if it is known that genetic test information may need to be disclosed for use in underwriting life insurance policies, that may deter people from undertaking a test that could benefit their wellbeing.

This creates a fundamental tension between the desire for insurance providers to be inclusive and not discriminate between insurance applicants, and the sustainability of insurance companies' business models in the presence of information asymmetry and potential anti-selection. The tension is most prevalent in life insurance. Australian health insurance is community rated, and take-up is encouraged by tax incentives, thereby increasing the size of the risk pool and limiting anti-selection risk. Most lines of general insurance products are not affected by genetic risks.

For life insurance, most Australians can obtain a certain amount of insurance cover without disclosing any medical information, typically through superannuation group insurance plans or the simple insurance products direct marketed through television advertising.

Genetic testing is therefore more likely to impact voluntary retail cover or increased cover sought under group insurance. For these voluntary covers or for higher sums insured, where medical disclosure is required, the Financial Services Council has established a compulsory standard on disclosure requirements for genetic test results[7]. Key items in the guidelines state that:

- Life insurers will not initiate a request for a new genetic test or in any way coerce an applicant for insurance to undertake a new genetic test.
- Where an applicant has already undertaken a genetic test, the results are required to be provided if that is requested by an insurer, unless the test was for scientific research purposes only and the applicant does not know the result.
- The insurer will take account of the benefits of special medical monitoring, early medical treatment, compliance with treatment and the likelihood of successful medical treatment when assessing overall risk.
- The insurer will provide reasons for any adjustment to premiums or policy conditions imposed after their assessment of the application.

These rules are part of a self-imposed industry standard, not enacted by legislation.

Current considerations and international comparison

In December 2016, the Australian Genetic Non-discrimination Working Group provided a submission to the Inquiry on the Life Insurance Industry by the Australian Joint Parliamentary Committee on Corporations and Financial Services, setting out their views on genetic regulation, and making two key recommendations[8]:

- For the Australian government to enact legislation to regulate the use of genetic information.
- Until such legislation is in place, the Australian government to enact a ban or moratorium on the use of genetic data by life insurers.

The recommendations reflect a concern that the potential use of genetic information by life insurers when assessing applications is limiting public participation in genetic research and the uptake of genetic testing.

Similar recommendations were submitted to a very extensive government enquiry into the use of genetic information conducted jointly by the Australian Law Reform Commission and the Australian Health Ethics Committee almost 15 years ago[9]. However, the decision at that time was against proceeding with specific legislation or regulation. Instead, Insurers were permitted to continue treating genetic test information in an equivalent manner to other medical test information, although with certain added safeguards.

That approach, still in place today in Australia, contrasted with the approach that was prevalent in Europe at the time. More recently, other countries have been reconsidering the use that can be made of genetic information. In May 2017, the Canadian Parliament passed the Genetic Non-Discrimination Act which banned the use of genetic test information by providers of goods or services, thereby stopping the use of such information by life insurance companies.

Below is a summary of the life insurance regulations on the use of genetic information in numerous countries[10].

Regulation category	Number of countries	Name of countries
No regulation.	5	China, Finland, India, Spain, United States
No regulation with written or unwritten codes of conduct from insurance industry groups.	2	Greece, Japan,
Prohibitions on insurers requiring applicants to take a genetic test and prohibitions on discrimination if the applicant refuses to take a test.	1	Australia
Prohibitions or moratoriums on using results from existing tests when policies are below certain limits.	4	Germany, Netherlands, Switzerland, United Kingdom
Prohibitions or moratoriums on using results from existing tests at all, sometimes including use of family history information.	9	Austria, Belgium, Canada, Denmark, France, Ireland, Poland, Portugal, Singapore
See source[10] for detailed reference and summary of regulations.		

Of the countries summarised, Australia is shown as having a unique approach. As mentioned above, our approach is primarily governed by the FSC Industry Standard, rather than by government regulation. However, it is important to note that there are differences in the Australian market compared to other countries, which in part have influenced the adoption of our different approach. In particular:

- Life insurance is widely available in Australia as part of superannuation through the Group insurance market, whereby no medical information is required to be disclosed under automatic acceptance limits. Availability of a certain amount of insurance cover through this channel is somewhat similar to availability in countries that make a certain amount of cover available without having to disclose genetic test information, under the operation of a prohibition or moratorium on using genetic test results.
- Commonly, fully voluntary forms of life insurance in Australia are sold with stepped premium rates that may be reviewed in future, depending on the claims experience emerging in the insurance pool. In many other countries, standard practice is to sell level premium policies with premium guarantees. As a result, such life insurance policies in Australia may be priced more dynamically, with finer initial margins, but in the expectation of later repricing, if required.
- Information on the decision of life insurance applications based on the use of genetic test disclosure is provided by insurers to the Financial Services Council. Australia may be the only country in the world where the availability of this information can be used to review the life insurance application assessment process. Whilst this data is provided to the Financial Services Council, it was last published in respect of the period to 2005. However, the authors are aware that more recent data, to 2013, has in one recent case been made available for university research analysis, although the results are as yet unpublished.

The current Australian parliamentary inquiry, advancements in research and media attention have reignited the question of the appropriate use of genetic information in life insurance underwriting. Choosing the best approach remains equally as complex as it was in 2003. Options may include formal regulation, whether it is applied to all or only over certain cover limits, or continuation of the current

self-regulation standards of the FSC, perhaps with further amendments. To assist in choosing and/or in conjunction with the best approach, insurers may consider:

- Establishing an industry data base that could monitor claims where decisions are influenced by illnesses known to be associated with genetic variances.
- Benchmarking the impacts on cover and affordability of life insurance in those jurisdictions that disallow genetic testing by insurers (e.g. Canada).
- To publish the data provided to the Financial Services Council on the decision of life insurance underwriters based on the applicants' genetic information.
- Adopting different approaches to assessing group life sums insured above default levels than for individually underwritten, voluntary life policies.

In addition, one area of fundamental consideration is what is sometimes called 'genetic exceptionalism'. Is genetic information sufficiently different to other medical information that it cannot be encompassed under the existing regulation set? If it is accepted that genetic information is exceptional, then genetic testing may warrant special regulation. Alternatively, if it is accepted that genetic information is fundamentally no different from other predictive medical information, there would not seem to be a good justification for special regulation.

Conclusions for Genetic Testing and Life Insurance in Australia

Genetic testing has far reaching implications to society, well beyond that of insurance. There is the potential to remove the risk of inherited disease and to indicate better treatment or preventative strategies for certain conditions. The use of genetic information is likely to increase due to research developments and the strengthening in the validity of results.

The genetics community in Australia clearly does see a need to reduce barriers for people who want to understand their genetic make-up, primarily for health or family reasons. The life insurance community has not responded publicly (to our knowledge).

The authors of this paper believe the time has come to work though these issues again. All parties should welcome the chance to join in discussion. The best solutions are likely to be found if the public are involved in the decision process, as was the case in 2003. The answers should not just represent the interests of medical professionals, genetics researchers or life insurance companies. ▲

References

1 The Institute's 2001 Biennial Convention discussed the publication *Genetics in Society*, 2001 by Doble, Barlow-Stewart, Ferris, Khor, Stapleton and Whittaker which provided extensive general information on several areas of interest at that time. That publication went on to have quite wide circulation within Australia and internationally.

2 More detail on many of the points discussed in this note may be found in the paper *Thinking about life insurance through a genetic lens*, by Dr Damjan Vukcevic and Jessica Chen, discussed at the Institute of Actuaries of Australia Actuaries Summit in May 2017.

3 Do CB, Hinds DA, Francke U & Eriksson N (2012), *Comparison of Family History and SNPs for Predicting Risk of Complex Disease*, PLOS Genetics 8 (10), e1002973. Results rounded to nearest 5%. Heritability is a measure of the proportion of variation in disease prevalence that is explained by genetic factors. The numbers shown here are estimates of this quantity.

4 FDA news release in April 2017 approving 23andMe to provide information on an individual's genetic propensity to 10 medical diseases or conditions. https://www.fda.gov/newsevents/newsroom/pressannouncements/ucm551185.htm

5 From the Human Genetics Society of Australasia. www.hgsa.org.au/education-training/genetic-counselling/

6 Anti-selection is the name given to the outcome when potential insured lives who know themselves to be worse than average risks are somehow able to obtain insurance at the standard premium rate, thereby obtaining cover at too cheap a price. This creates a moral hazard, by tempting them to take out higher amounts of insurance at a bargain price. Over time, more poor risks may enter the pool to obtain the cheap cover, so worsening the average risk profile in the pool, increasing claim costs and eventually causing the insurer to increase the premium rate to cover its losses. In time, the good risks may be expected to react to paying higher premiums than their own health would require, by cancelling their policies. Removal of the good risks would further worsen the average risk remaining in the pool, causing claim rates and premiums to rise even further, reinforcing the adverse effect.

7 www.fsc.org.au/resources/standards/ Standard No. 11 Genetic Testing Policy.

8 www.aph.gov.au/Parliamentary_Business/Committees/Joint/Corporations_and_Financial_Services inquiry on the Life Insurance Industry, submission number 60.

9 Alrc Report 96 *Essentially Yours – The Protection of Human Genetic Information in Australia*, 2003. A joint report by the alrc and the AHEC of the National Health and Medical Research Council (NHMRC).

10 www.genevaassociation.org Research Reports. June 09, 2017 *Genetics and Life Insurance – A View Into the Microscope of Regulation.*

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