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**Interviewer:** Stephen Dixon

**Guest:** Jessica Chen

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**Stephen:** Hello and welcome to the Actuaries Institute's Dialogue podcast. I'm Stephen Dixon. This podcast aims to give you an overview of the actuaries thought leadership series, "The Dialogue – leading the conversation". The Dialogue papers cover a wide range of topical issues from climate risk to health insurance affordability. Today we're talking genetics. Genetic testing is set to increase due to declining test costs and the genetics community being keen to reduce barriers for people wanting to understand the genetic makeup for health or family reasons. The life insurance community on the other hand is concerned about the potential for anti-selection by people who do not disclose their test results, which will affect access to and the cost of insurance cover. Now senior actuaries Alan Doble and Jessica Chen think it's time to reconsider these issues.

Their dialogue paper "Genetics - a testing time for insurers?" explores the future implications of genetic testing for society, medical professionals and the insurance industry. I'm joined today by co-author, Jessica Chen, Director of Insurance, Finance at BT Financial Group. Welcome Jessica.

**Jessica:** Hi Stephen, thanks for having me here. I'm excited to talk about genetics today.

**Stephen:** Genetic testing has far-reaching implications for society well beyond that of insurance. It will potentially allow us to mitigate risk of inherited disease. Jessica what are the implications of genetic research and predictive data for the life insurance industry?

**Jessica:** Steve, as you said the implications are far-reaching for society and it's well beyond insurance. The dialogue paper here considers firstly, the impacts to an individual and then it extends and explores the current regulatory framework and compares how Australia is compared to the other countries.

**Stephen:** The Dialogue paper discusses predictive genetic testing. Can you explain this further for us?

**Jessica:** Sure, the field of genetics has developed quite rapidly over the last couple of decades, so in the early 2000s it was the first time that the human genome was completely mapped. Prior to that, the genetic test used to focus on what we call monogenetic diseases so these are typically single gene mutations that 100% predict the onset of certain diseases. So, examples are Down syndrome or Huntington's. This is typically used for family planning purposes. But since then, the technology's moved and now we have what we call predictive genetic testing. This uses a technology called genome-wide association studies where by diseases that are caused by a number of gene mutations are researched what we call polygenetic diseases and then we use that technology to predict more common diseases such as cancer and heart disease. But the key differential here is this is not a 100% guarantee of the disease onset and hence we call this predictive testing.

**Stephen: The paper mentions new interpretations from older tests. What does this mean?**

**Jessica:** Well this is very interesting. So, one of the key aspects that's different for genetic testing as it is for more traditional methods such as blood or urine test is the results of genetic tests are persistent over time. That's because your genes don't change however over time the interpretation of these results may change as the technology develops, so therefore what we see is as the predictive power of these tests increase, the results become more informative but a major ethical consideration though is how do we store this result and how do we use it in the future? For example, would a later interpretation mean that a person has pre-emptively consented to all future genetic tests? Now there's no easy answer to this question but we do need to consider it.

**Stephen: We certainly appreciate there's no easy answer but what are the implications perhaps unexpected or unwelcome for individuals undertaking genetic testing?**

**Jessica:** Yeah so again this is a complex issue. Now the implications of genetic tests can be quite ranging so for example someone may go in and take a genetic test to understand their heritage, except they may find out that they are at high risk of a genetic disease which they don't expect. Now to mitigate this, we have what we call genetic counsellors to help people to understand, interpret and also action the knowledge that's gained from a genetic test. Importantly though, this is not always available. It is usually available for Australian based labs but where you get tests for example over the internet, genetic counselling is not typically offered.

**Stephen: Jessica we've been discussing how genetic testing has been developing but what challenges does this present to the general life insurance industry?**

**Jessica:** So, this is most challenging for the life insurance industry. General insurance is typically for non-medical risks and also health insurance is more community rated. Now for the life insurance industry, it's commonly viewed that this is an emerging threat, so that therefore it's not a current threat. The biggest factor that would impact the industry, I believe, is the number of people that take these tests. Currently this number is very small because the technology is very new so therefore not very many people have the knowledge to anti-select against insurers, but over time if this does become more prevalent, then people may for example who are of high genetic risk take out insurance which could increase the cost of claims or people who believe that they are at low genetic risk may decide to lapse their policy. So therefore, over time we might get anti-selection and an overall decrease in the quality of lives that are insured. But that said ultimately the aim of genetic tests is to improve people's lives so we do hope that people will use this information to better manage their health and improve the quality of their life.

**Stephen: Jessica, you talk about our hope that genetics will improve the quality of our lives. Can you take us through how the Financial Services Council is looking to ensure disclosure to the industry?**

**Jessica:** Sure, Steve. That's a good question because the Financial Services Council is the industry body that represents the life insurance industry. So currently they have a self-imposing standard which was recently updated in 2016. Now in that standard they have a few key guidelines. The ones of interest are; 1. In Australia, we cannot compel people who haven't taken a genetic test to do so but if they have, we do have the right to ask for their result and then 2. Is when we then get that information, we have to take into account other lifestyle choices or medical treatments that they've taken, to provide an overall assessment and if we do then decide to either increase premiums or to cancel the applicant then we do have to provide a written reason to justify the decision.

**Stephen: And is this standard law?**

**Jessica:** No not at the moment. This is quite unique for Australia. We have a self-imposing standard that is not enacted by law but is followed by the industry.

**Stephen: Okay I've also read about how our standard might be compared to other countries and I've read about some developments in other countries over the last year or two. Can you explain some of these to us**

**Jessica:** Yeah sure, so currently there's a wide ranging of different regulations across the world. So, we've got some countries whereby there's an absolute ban on the use of genetic information. Now these countries are for example Canada and Denmark and Ireland. Canada recently moved to this position but then others that have no regulation at all. So, these are for example Finland or Spain or the United States. We're probably about the middle of the pack, where we have a self-imposing regulation and we're unique in that we cannot ask for people to take genetic tests but we can get them to disclose their results to us.

**Stephen: Concerning regulation, The Australian Genetic Non-Discrimination Working Group made two key recommendations to Government in 2016 around banning the use of genetic data by life insurance. Can you tell us about those and what the state of play on regulation is in Australia?**

**Jessica:** Their recommendations were firstly for the Australian Government to enact legislation to govern the use of genetic information. So, this is taking us from a self-regulatory perspective to something that is governed by law and then the second one is whilst this legislation is still to be put in place, the Australian Government to enact a ban for the use of this information in the meantime.

**Stephen: Then why is the Genetics industry worried about the public limiting their participation in genetic research and testing?**

**Jessica:** The reason I believe those recommendations were made could be on a few issues. The first one is that they are worried that people may feel that they cannot take out insurance for the fear of having their genetic tests done and then finding that they are high risk of a certain disease. Also, they feel that perhaps people are less likely to participate in research, because again they may have to disclose that information at a later stage.

**Stephen: In your paper, you recommend insurers do improve knowledge around the best approach to this issue. Can you take us through those recommendations?**

**Jessica:** Yeah, we came up with a few recommendations. Now this is still up for debate and for consideration. Our suggestions are firstly, there could be some work to analyse and understand the cost and affordability of life insurance across countries where there are different regulations. So for example, to understand is there a cost, whereby the government has banned the use of genetic disclosure information? Also, we think that it might be good if there is a database set up whereby where claim outcomes relate to high genetic information, then we keep track and see how that goes over time and then finally, currently Australia is quite different in that our insurers provide information on how they make decisions on applicants if genetic test disclosure information is used.

Now we encourage the FSC to actually publish that information to understand how we're tracking, but overall this is a very complex issue so our overarching recommendation is for more people to participate in this debate. We'd really like to hear from the public. Also, I think we should have the medical profession, the genetic researchers and also the insurance industry come together and come up with a solution that takes into account everybody's views.

**Stephen: Thank you for taking us through those recommendations Jessica. They are certainly very sound but that's about all we have time for. It will be interesting to see what happens in this space with genetic testing. Thank you for joining us Jessica, your insights have been excellent.**

**Jessica:** Thanks Steve, it's been great.

**Stephen: And thank you for listening. Listen out for other episodes and papers in our Dialogue thought leadership series, including on climate risk, social risks and private health insurance affordability, and head to the public policy and media section of our website for more latest research from actuaries. I'm Stephen Dixon bye for now.**