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Balancing rights and responsibilities in insurers' access to genetic test results

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Genetic testing is widely used across the developed world in order to diagnose and predict disease. However, along with its usefulness comes concern about how others, such as employers and insurers, can have access to and use its results. This in turn leads to the risk that individuals may avoid medically recommended genetic testing, or participation in genetic research, if they fear that they may be discriminated against based on their results.

At the annual conference of the European Society of Human Genetics tomorrow (Saturday), Anya Prince, JD MPP, a postdoctoral research associate at the Centre for Genomics and Society, University of North Carolina, Chapel Hill, USA, will present results of her study comparing the regulation of life insurers' use of genetic information in the UK, Canada, and Australia.

"Such a study is necessary in order to appreciate the effectiveness and potential downsides of different policy options," says Ms Prince, who hopes to use her results to inform the development of regulations addressing life insurer use of genetic information in the United States. "Understanding which policy options most effectively assuage fear of discrimination has the potential to improve human health by encouraging individuals to undergo testing when medically recommended and to participate in genomics research."

In Australia, private life insurers are permitted to use genetic test results when setting insurance rates and deciding whether or not to accept an

application. Although they are only allowed to use test results based on actuarial or statistical data, they are free to use their own judgements as to which tests meet these requirements.

In Canada, while life insurers are currently allowed to use genetic test results, the Parliament recently passed legislation that would prohibit them from doing so when drawing up insurance contracts. But in Canada insurance regulation comes under the jurisdiction of the provinces, so there is some doubt as to whether this ban is constitutional. The legislation is currently under judicial review.

Of the three countries studied, the United Kingdom had the most comprehensive protection against insurer use of genetic information. Life insurers have agreed to a moratorium on the use of predictive genetic test results for life insurance policies below £500,000 (five hundred thousand pounds). Above this figure, insurers are allowed to use genetic tests sanctioned by a government advisory committee, but to date only Huntington's Disease testing has been permitted.

"The two-tiered UK system is seen by many both within and outside of the country as being an effective way of balancing individual and insurer concerns—on the one hand about genetic discrimination and on the other about the economic viability of the industry. And the flexible nature of the moratorium, which is not permanent legislation, helps insurers feel comfortable that they will be able to react to advances in genomic research if necessary," says Ms Prince.

However, discussions with insurers in Australia and Canada showed that they felt that to lose access to genetic test results would have a drastic effect on their industry, and could threaten financial collapse. Unsurprisingly, individuals in those countries were much more likely to fear discrimination as a result of genetic testing than those interviewed in the UK.

Ms Prince has now widened the scope of her study to include Sweden, where insurers are barred from taking genetic test results into consideration. "I hope this comparative research will help to foster international dialogue about the ethical and legal implications of genetic research and insurance. Personally, I think that a two-tier system, as implemented in the UK, creates an appropriate balance. If insurers are allowed to use test results, I believe their model of an independent committee controlling which test results they may use is necessary," she says.

However, a major question remains. Are genetic test results relevant to insurance underwriting? "While genetic testing may promise to reduce risk, it is important to keep in mind that most genetic information can be affected by so many other factors. These include the environment, the likelihood of developing symptoms if someone has a genetic mutation (called the penetrance), the variation in signs and symptoms that can occur among people with the same condition, and how easy it is to minimise risks in individuals."

"Where there are tests for highly penetrant conditions, it is relatively easy to predict outcomes, but these conditions affect only a very small percentage of the population. It is therefore unsurprising that there is active debate about how loss of access to genetic test results would really affect the economic viability of the insurance industry," Ms Prince will conclude.

Chair of the ESHG conference, Professor Joris Veltman, Director of the Institute of Genetic Medicine at Newcastle University, Newcastle, United Kingdom, said: "Genetic testing is becoming more mainstream and providing an increasing amount of information that can be used to predict disease risks. It is therefore important to evaluate who may or may not have access to these data and for what purpose, and make sure we develop common rules that can be internationally applied and upheld.

This work provides an important analysis of the way different countries deal with this. It points to considerable differences that need to be addressed with all stakeholders involved."

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