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ReCent medical news

somewhat different

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Personal genomic testing (PGT), the consumer and the life insurance industry

Introduction

The life insurance industry is being challenged to respond to the new reality of democratised access to personal genomic data against the backdrop of consumer and regulatory concerns around data privacy, consumer equity and genetic determinism, on the one hand, and life insurers' concerns about information asymmetry during the underwriting process, on the other.[1]

Given the natural public bias to perceive the life insurance industry's use of personal medical data for risk assessment purposes in a negative light, industry players have their work cut out and will need to offer consumers "upside only" product offerings if they are to persuade consumers to engage with them in regard to undergoing Personal Genomic Testing (PGT) services and sharing their PGT results. Using these results as "just" another underwriting requirement is unlikely to be tolerated, as evidenced by legislative bans in some countries on the use of genetic information for insurance underwriting purposes.[2]

A new technology challenging existing healthcare paradigms

Not only have the means of accessing genetic tests changed but the tests themselves have evolved, with the focus of investigation shifting from the level of the gene down to the level of a Single Nucleotide Polymorphism (SNP for short, pronounced "snip"), which is the commonest type of genetic variation found in a genome. A SNP may reside within a gene or in a regulatory area found near a gene.[3] [4] The current genome sequencing technologies are able to detect these SNPs and companies offering this PGT report the results – which may include an associated disease risk – directly to the consumer undergoing the test. Just as the clinical utility of such reports still remains to be seen, there is not as yet a comprehensive understanding of how consumers will use these data.[5] But how can the life industry engage with and harness the data from these genetic tests in a way that benefits the consumer and the industry in a prudent and ethical manner?

Furthermore, who are the current consumers of PGT services and will consumers of life insurance consider PGT

[1] See Green RC. GINA, Genetic Discrimination and Genomic Medicine. The New England Journal of Medicine, 29 January 2015, Volume 372 Issue 7 PP 397-399

[2] See Green RC. GINA, Genetic Discrimination and Genomic Medicine. The New England Journal of Medicine, 29 January 2015, Volume 372 Issue 7 PP 397-399

[3] See Feero WG et al. Genomic Medicine – An Updated Primer. The New England Journal of Medicine. May 27, 2010, 362: 2001-11

[4] See US National Library of Medicine. Genetics Home Reference. What are Single Nucleotide Polymorphisms? Accessed on 5th May 2017 at https://ghr.nlm.nih.gov/primer/genomicresearch/snp

[5] See Krieger JL et al. The impact of personal genomics on risk perceptions and medical decision-making. Nature Biotechnology, September 2016, Volume 34 Number 9: pp 912-918

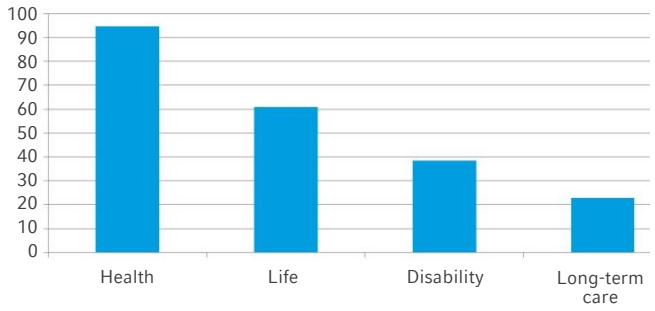
services offered within a life insurance context to be of value and, if so, what would such a value proposition need to look like?

Characteristics of early PGT adopters

Studies have shown that genetic literacy is positively associated with younger ages and higher levels of education and that individuals with high levels of pre-existing genetic knowledge are more likely to purchase PGT services. [6]

The "insurance status" of some of these early adopters of PGT services has also been studied[7] and is shown in graph 1; based on these data, the life insurance industry is right to be concerned about the impact of this technology and potential anti-selective buying behaviour of their target markets given the overlap between PGT buyers and life insurance policyholders. The same statistics could, however, be interpreted as evidence of likely consumer interest in life insurance product innovation that incorporates PGT services.

Graph 1:
The insurance status of early adopters of PGT services[8]
Percentage of early adopters of PGT services with existing health and life insurance



Offering PGT as a preventative health benefit rider on mortality or morbidity products – will it improve personal health outcomes?

It appears reasonable to think that better information regarding genetic disease risk will empower consumers and encourage physicians to embark on rational screening behaviours and the monitoring of disease symptoms, with overall improved health outcomes; this would be good for individuals and also potentially beneficial for the life industry. For this reason, life insurers may be inclined to encourage each existing and prospective policyholder to undergo personal genomic testing. But does this assumption hold true?

Some early studies of the perceived utility of PGT have shown that the majority of participants in these studies perceive the results of these tests as having, at least in the short term, a beneficial impact on their understanding and management of their own personal health[9] – see graph 2. The perceived benefit may, however, be short-lived as there is evidence of a significant reduction in consumers' confidence in their ability to use the genetic information gleaned from PGT six months after testing, compared to their confidence levels immediately following testing.[10]

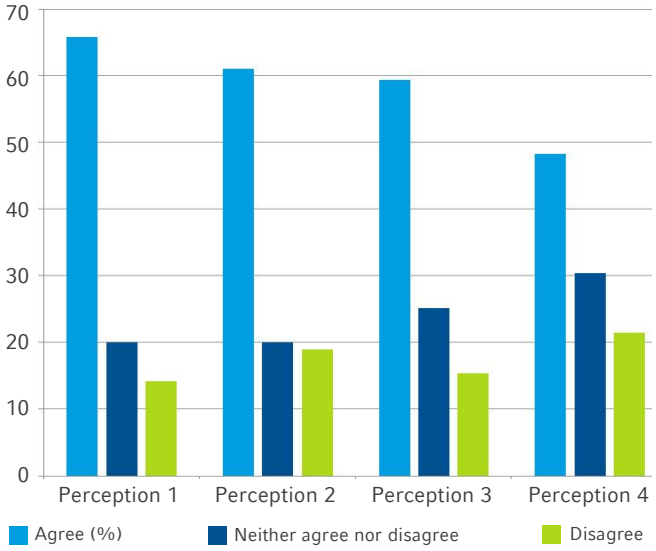
Does the perceived utility of PGT for personal health management result in behavioural change?

A study looking at the impact of PGT for the single nucleotide polymorphism-based cancer risk on health-related behaviours set out to determine whether customers who received increased cancer risk estimates were more likely to change their cancer-screening behaviours compared to customers who received average or reduced PGT cancer risk estimates.[11]

They evaluated the number of mammograms and colonoscopies for breast and colon cancer respectively and the use of Prostate Specific Antigen (PSA) tests for prostate cancer screening at the time of the PGT and again six months later. The results of their analysis are shown in graph 3.

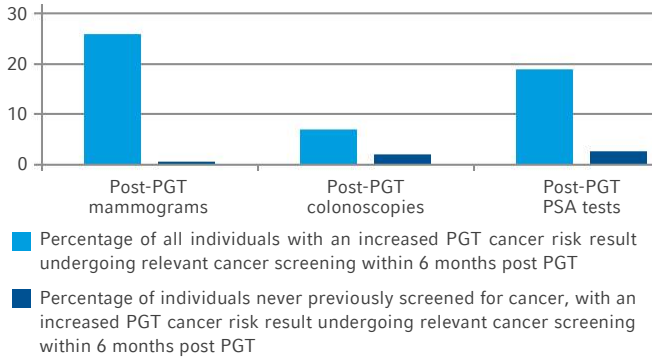
[6] See Carere DA et al. Consumers report lower confidence in their genetics knowledge following direct-to-consumer personal genomic testing. Genetics in Medicine, 26 March 2015, pp 1-8
[7] See Roberts JS et al. Direct-to-Consumer Genetic Testing: User Motivations, Decision Making, and perceived Utility of Results. Public Health Genomics, January 10, 2017
[8] See Roberts JS et al. Direct-to-Consumer Genetic Testing: User Motivations, Decision Making, and perceived Utility of Results. Public Health Genomics, January 10, 2017
[9] See Roberts JS et al. Direct-to-Consumer Genetic Testing: User Motivations, Decision Making, and perceived Utility of Results. Public Health Genomics, January 10, 2017
[10] See Carere DA et al. Consumers report lower confidence in their genetics knowledge following direct-to-consumer personal genomic testing. Genetics in Medicine, 26 March 2015, pp 1-8
[11] See Gray SW et al. Personal Genomic Testing for Cancer Risk: Results From the Impact of Personal Genomics Study. Journal of Clinical Oncology, December 12, 2016, pp 1-9

Graph 2:
Consumers' perceived utility of PGT for personal health[12]



Perception 1: "PGT gives me more control over my health."
Perception 2: "I learnt new info from PGT to improve my health that I did not know before."
Perception 3: "The info from PGT will influence my future health Management."
Perception 4: "The info from PGT will reduce my chances of getting sick."

Graph 3:
Impact of PGT showing an increased cancer risk on cancer screening behaviours[13]



[12] See Roberts JS et al. Direct-to-Consumer Genetic Testing: User Motivations, Decision Making, and perceived Utility of Results. Public Health Genomics, January 10, 2017

[13] See Gray SW et al. Personal Genomic Testing for Cancer Risk: Results From the Impact of Personal Genomics Study. Journal of Clinical Oncology, December 12, 2016, pp 1-9

The findings for individuals undergoing post PGT cancer screening (regardless of whether they were previously screened or not) are modest at best and, interestingly, the participants that were most likely to report screening at 6 months post PGT had previously undergone screening in the year prior to the PGT. For participants who had never undergone any type of cancer screening, the number that reported screening at 6 months post PGT was much smaller. Based on these findings, the authors of the study concluded that screening behaviour for cancer was not significantly impacted by PGT results.

We can currently only speculate as to what the impact of PGT will be on life insurance buying behaviour, although there is evidence showing that genetic test results do motivate individuals to purchase long-term risk products – as in the case of individuals more likely to buy long-term care products after testing positive for an increased risk of developing Alzheimer's disease.[14]

Offering PGT as a potentially curative health benefit rider on mortality or morbidity products – will it improve morbidity and mortality outcomes?

Once a life insurance policyholder manifests with disease, access to PGT should, in theory, offer the possibility of optimised personalised medical care for the affected individual with resultant improved morbidity and mortality outcomes. Whether it comes to offering a targeted biological therapy on the basis of an individual's genetically sequenced cancer, optimising the choice and dose of a medication for treatment of a chronic disease according to an individual's pharmacogenomic profile or finding a cure for an individual with a rare genetic Mendelian disorder, the possibility of PGT delivering on the promise of personalised medicine is without doubt an exciting prospect and an area likely to be scrutinised for innovation by the life industry. What is not yet known is the potential scope of this new applied genomic technology as it pertains to clinical access (meaning both availability and the cost of targeted therapies) and, from an insurance perspective, the timing and magnitude of the effect size of personalised medicine on in-force morbidity and mortality portfolios.

It is, however, becoming increasingly evident that the ability of genomics to deliver on the notion of personalised

[14] See Zick CD et al. Genetic testing for Alzheimer's disease and its impact on insurance purchasing behaviour. Health Affairs, March 2005, Volume 24 Issue 2 pp 483-90

medicine will present an arduous challenge due to the sheer complexity of genomic discoveries. This was highlighted in a recent paper published in The New England Journal of Medicine that examined the limits imposed on personalised cancer medicine by the complex molecular characterisations of tumours.[15]

The authors of this study cite evidence that of all cancer patients referred for genetic analyses only 3 to 13% had treatments selected on the basis of their individual genomic tests. Furthermore, they highlight tumour evolution and intratumour heterogeneity (meaning that cancer cells from different regions from within the same primary tumour and its metastases can show significant variation in their genomic sequencing – the result of tumour evolution) as a significant obstacle to the development of cancer-treating drugs targeting mutated pathways on the basis of molecular analysis of a tumour sample. They conclude with a warning against the direct-to-consumer marketing of the hitherto unproven benefits of personalised cancer medicine.

Conclusion

The important takeaways from a life insurance point of view, based on recent data:

- Purchasers of PGT are likely to own life insurance policies.
- Consumers of PGT perceive the results as having a significant impact on their personal health management, at least in the immediate short term.
- Personal health-related behaviours have not been observed to significantly change following PGT results that show an increased risk of disease.
- The realisation of personalised medicine through PGT will be hard to achieve, with genomic complexity emerging as one of the main obstacles.
- The impact of PGT on buying behaviour of life insurance products by consumers remains unknown.

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[15] See Tannock IF et al. Limits to Personalised Cancer Medicine. The New England Journal of Medicine. September 29, 2016, 375;13 pp 1289-94