Welcome!

Here at the Digital Death Council we’re going to be all about personalised medicine for the next few weeks as our latest cutting-edge webinar series starts in October. As regular readers will know, it is also a favourite topic of mine. For all intents and purposes the terms personalised and precision medicine can be used interchangeably; personalised medicine seems to be the preferred UK term, whereas precision medicine is ubiquitous in North America medical discourse.

Both terms refer to an approach to patient care which takes into account individual variation across multiple areas-genetic, physiological, environmental and lifestyle. Related subjects include the “-omics”-genomics, metabolomics, transcriptomics, proteomics and, my personal favourite, exposomics- better known as environmental factors. Data from emerging technologies including Internet of Things devices favoured by the cult-like-sounding Quantified Self movement can also be incorporated into personalised medicine analyses, where they are known as digital biomarkers. Its even becoming possible to electronically reproduce a human being’s digital twin, in order to virtually simulate treatment effectiveness before trying in in the flesh, so to speak.

Here in the US, the drive for personalised medicine was given a financial and publicity boost in 2015 by then-President Obama, who launched the $215 million Precision Medicine Initiative in partnership with the National Institutes of Health and many other research centres. The project aims to bring about large-scale implementation of personalised health and personalised healthcare. It includes funding to create a pool of DNA, digital biomarkers and other health information for one million people through the All of Us research program.

Although most treatment guidelines are still currently one-size-fits-all, many clinicians will undoubtedly be thinking that they have been practicing personalised medicine for years, way before Obama made it cool. An easy example would be blood transfusion, where extensive cross-matching and blood typing must be performed to safely provide the best treatment for each patient. A failure to accommodate individual’s needs in transfusion medicine was recognized to lead to severe complications over 100 years ago. Some people therefore consider personalised medicine an evolution, rather than an innovative revolution in healthcare. The new push reflects a desire for availability at the point of care for a wider range of information than that currently relied upon by clinicians, enabling them to better predict which treatments will work for individual patients.

Other early precision medicine successes that are now routine include the BRCA gene and HER-2 receptor in breast cancer. We are now able to offer patients with these clinical features a completely different set of treatments, such as Herceptin (trastuzumab), that massively increases their chances of beating cancer. Healthcare costs may decrease and life expectancy increase as we are better able to predict which treatments will be effective and which would be wasted. The current one-size-fits-all reimbursement tariff could also be superseded by a personalised and more accurate payment model.

There is a flip side to the unprecedented availability of predictive information. Insurers or employers could demand access to this data lake of information about clients, to generate more tailored estimates of health risk. This is already off-putting to some potential donors of information for medical research in the US, who are fearful of being denied healthcare coverage as a result of what might be discovered. Conversely, the information asymmetry produced when individuals know their predicted risks but
insurance companies do not may also lead to higher risk individuals seeking cover and making claims with increased frequency, eventually pushing up premiums across the board, a phenomenon known as adverse selection.

Discrimination, including by insurance companies, on the basis of apparent or perceived genetic variation from a “normal” genotype is currently illegal in the US, Canada and many European countries, but the UK takes a moratorium approach with an agreement between the government and the insurance industry to block access to genetic test results in most, but not all, instances. The risk estimates that precision medicine could produce are not necessarily covered by this existing legislation. They therefore may be used as part of a growing trend in “lifestyle underwriting,” to tailor premiums based on personal habits and to offer discounts to policyholders who regularly attend a gym, or who share their fitness tracker data with their insurance company. It is politically unfavourable, but not impossible to see how insurance companies would make permission to access this data a necessary requirement for providing cover, in the same way that they currently require access to medical records.

Clear safeguards to limit access to predictive information are one of several forthcoming challenges as personalised medicine advances. Healthcare professionals will need reliable data pipelines and new ways to easily integrate and visualise the flood of personalised medicine data sources during patient-facing appointments. Finally, the currently very limited evidence base must be expanded. For most commonly occurring, multifactorial and polygenetic diseases this will require population-sized big data investigation. The future is bright but there is much legislative, informatic and investigative work still to be done. Tune in to the new RSM digital health section webinars to find out more.

Catch you next month!