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Privacy, data science and personalised medicine. Time for a balanced discussion

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Privacy, data science and personalised medicine. Time for a balanced discussion

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There are several fundamental truths that those of us working at the intersection of data science, ethics and medical research have recognised for some time. Firstly that 'anonymised' and 'pseudonymised' data can potentially be re-identified through the convergence of related variables, coupled with clever inference methods (although this is by no means easy). Secondly that genetic data is not just about individuals but also about families and generations, past and future. Thirdly, as we enter an increasingly digitized society where transactional, personal and behavioural data from public bodies, businesses, social media, mobile devices and IoT are potentially linkable, the capacity of data to tell meaningful stories about us is becoming constrained only by the questions we ask and the tools we are able to deploy to get the answers. Some would say that privacy is an outdated concept, and control and transparency are the new by-words. Others either disagree or are increasingly confused and disenfranchised.

Some of the quotes from the top brass of Iceland's DeCODE Genetics, appearing in today's BBC's News, neatly illustrate why we need to remain vigilant to the ethical dilemmas presented by the use of data sciences for personalised medicine. For those of you who are not aware, this company has been at the centre of innovation in population genomics since its inception in the 1990s and overcame a state outcry over privacy and consent, which led to its temporary bankruptcy, before rising phoenix-like from the ashes. The fact that its work has been able to continue in an era of increasing privacy legislation and regulation shows just how far the promise of personalized medicine has skewed the policy narrative and the business agenda in recent years. What is great about Iceland, in terms of medical research, is that it is a relatively small country that has been subjected to historically low levels of immigration and has a unique family naming

system and good national record keeping, which means that the pedigree of most of its citizens is easy to trace. This makes it an ideal Petri dish for genetic researchers. And here's where the rub is. In short, by fully genotyping only 10,000 people from this small country, with its relatively stable gene pool, and integrating this with data on their family trees - and doubtless a whole heap of questionnaires and medical records - the company has, with the consent of a few, effectively seized the data of the "entire population". The reference to "these tricks" by the CEO in this interview pretty much sums it up and gives rise to a feeling of deep unease on the part of this reader. Of course, one can't rule out some mischief making by the BBC in including these quotes - the robustness of the science is demonstrated by its publication in the prestigious Nature Genetics and its potential value for personalised and preventive medicine cannot be disputed. This is important stuff for global health, and one only has to look at the media frenzy over President Obama's precision medicine initiative to see how much optimism the topic is generating. However such progress demands a hand-in-glove relationship with citizens and utter transparency of purpose. Dropping the societal and privacy implications into the narrative only *after* the work has taken place is disingenuous in the extreme. We must be careful not to make the same mistakes ourselves and we are doing our best to engage the public in shaping the governance of the UK's national medical and administrative data research enterprises, constantly balancing the need for science against the need for public trustworthiness and assent, mindful of the challenges involved. www.adrn.ac.uk; www.farrinstitute.org

My red flags were raised closer to home this month at a promotional event for a Scottish project which is seeking to pre-consent members of the public into data sharing for medical research. Some of this is fairly non-contentious; it makes sense to skip a time-consuming research stage by having a representative population of medical records to access when seeking eligible patients for new studies, and engaging people as partners in research must be a good thing. However a request for people's "spare blood" has unexpectedly worked its way into the recruitment drive, with a somewhat ambiguous message implying that blood is merely a waste product and emphasizing that no effort is required to donate it apart from a signature. In fact the researchers are planning to Hoover up some of our most valuable data assets in the form of our genes and then reuse them for as-yet unspecified research. Concern has been noted and should hopefully lead to a more balanced set of messages. <http://www.registerforshare.org/index.php>

This sort of thing is going on worldwide, often in countries where information governance policies and penalties for data misuse are weak or non-existent, while the lines between identifiable vs. non-identifiable, and public vs. commercial interest are continually blurring. Becoming attuned to public sensitivities and engaging citizens and patients is vital for keeping a clean house and preventing potential Snowdenesque trouble later on.

It is not insignificant that DeCODE Genetics now belongs to a Chinese company. http://en.wikipedia.org/wiki/DeCODE_genetics I shall leave it to others to dissect the power implications of this, and will not pre-judge the views of the Icelandic population, whose social contract with the researchers is not clear. Perhaps others will enlighten me. Either way it's worth an open debate.



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