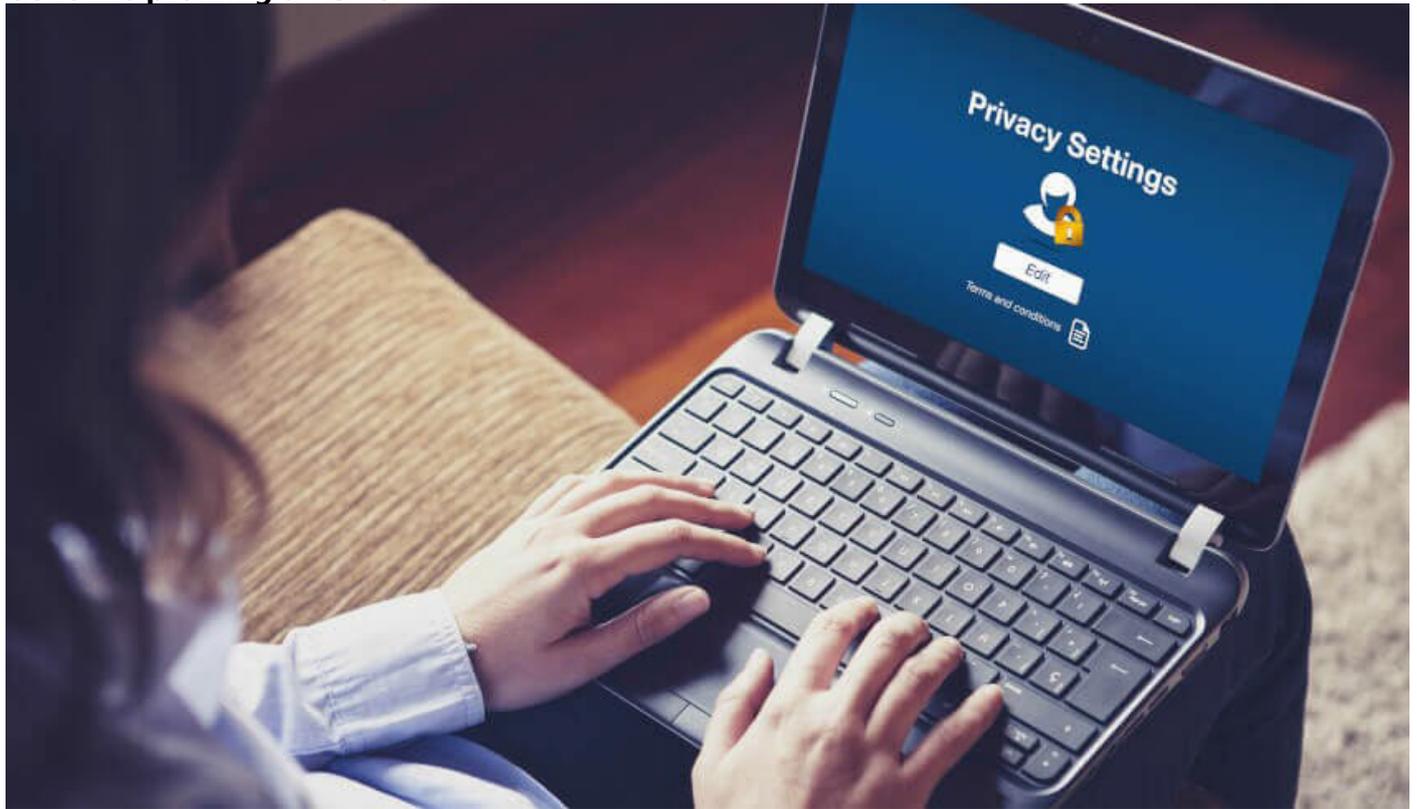


Genomic profiling a risk of



POLITICS | 25 JUNE 2018 | DR ELIZABETH SIGSTON

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Australians have always held a stoic view around the protection of their privacy, writes **Dr Elizabeth Sigston**.

The move to introduce the Australia Card, in the Hawke/Keating years, serves as a stark reminder of how, as a nation, we are guarded about who holds our private information and in what capacity it can be used.

Sabres rattled, and a resounding rejection was delivered.

The completion of the Human Genome Project in 2003 saw the establishment of the Human Genetics Advisory Committee. The committee produced 144 recommendations and led to a change in our Privacy Act in 2009 to define non-health genetic information as 'sensitive' information.

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The rapid evolution of technology and efforts to bring this into the health sector brings with it a different landscape with different rules.

There are without doubt huge potential benefits for the Australian public through electronic health records, wearable devices and other health technologies, but privacy and non-discrimination legislation is being left behind.

The recent revelations by Facebook should alert everyone to the risk to privacy when technology and genomic profiling merge.

Whole genome profiling is different to specific genetic testing for hereditary disease and various cancers or molecular profiling of tumours to assist in targeting treatment. It is as yet not validated as a predictor of health. It is also not anonymous.

You can be identified by your genetic profile. DNA data used by law enforcement agencies currently use only non-coding genes and none that determine physical characteristics. Whole genome profiling potentially enables not only identification by your DNA but also a picture of your physical characteristics, including ethnicity.

My Health Record, while it has many benefits, specifically allows under its terms and conditions of use for de-identified information to be used for research and public health reasons. Whole genome profiling, by definition, is identifiable. Various legislative bodies can also compel the passing over of information.

In the US and in Scotland, major projects have been launched to sequence a million genomes and 100,000 genomes respectively with electronic health records being a key in collecting the data. This essentially breaks the assumption made by our Privacy Laws that there is a clear difference between health related genes and non-health related genes. All genes become health related and are therefore not considered to be sensitive information and no longer protected

In Australia, any genetic information, regardless of where it is obtained or for what purpose must be disclosed to insurance companies. This interpretation of what this means is up to the insurance companies; it could lead to premiums being adjusted based on genes not disease.

Coverage could be refused for specific conditions based on genetic profile. Failure to disclose any genetic testing, including those done for 'fun' through sites like Ancestry[.]com, could result in non-payment.

Under current Australia class law, you cannot own tissue or body parts. Once you have given it away, it is no longer yours. If you have provided tissue or a swab for a whole genome profile to one of many direct-to-consumer services, once they have done something to it, they own the information.

Review of Australian Privacy and anti-discrimination laws is required.

Europe is leading the way, with legislation that prevents insurance companies asking for genetic information as an example. My Health Record makes this matter urgent. Apathy is not the answer.

Just like the sabre rattling that took place in the 80s around the introduction of the Australia Card, the same sabres must rattle again with even greater vigilance around what is at stake and what we will condemn ourselves to should the appropriate safeguards and measures not be put in place to protect our very own human rights.

Dr Elizabeth Sigston is an Australian head and neck surgeon, author and public speaker. She has a PhD in genomic profiling and research.

