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My Health fears on genomics

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The federal government's digital health record system, My Health Record, has been a magnet for security and privacy-related criticisms and there are growing concerns the platform may at some point host genetic profiles of Australian citizens.

Elizabeth Sigston, one of Australia's leading head and neck surgeons, told The Australian the idea of adding genetic information to the My Health system continues to gain currency locally, especially on the back of the work being carried out in the US and China.

The $1.45 billion All of Us project, formerly known as the Precision Medicine Initiative, which aims to collect genetic and health data from one million US citizens by 2022, is continuing to grow from strength to strength. Meanwhile, similar work is under way in China, with the authorities in the city of Nanjing, the capital of Jiangsu province, working on a genetic database of residents.

In November last year, the Council of Australian Governments Health Council released Australia's first National Health Genomics Policy Framework, which is focused on integrating genomics into our health system.

With the workings of the My Health system, which will collect and share information such as GP health summaries, pathology results, prescription and discharge reports, largely a mystery to most Australians, Dr Sigston said many in the medical community have concerns about the federal government potentially opening the door for genomic data to be integrated into the platform.

"People need to be aware of what happens to the information and what type of information is put on the platform," Dr Sigston said.

"There is a lack of education and legislation that protects us. If you look at the terms and conditions of the My Health system it actually allows a patient's data to be used for research and public health purposes.

"Normally that should be fine because this data can be anonymous, but the problem with genomic profiling is that it's someone's identity, it just can't be anonymous."

According to Dr Sigston, any move to integrate genomic data into the platform needs to be treated with caution, despite the purported medical benefits such a move might bring.

“Our privacy principles currently state that anything that’s used for medical research needs to be de-identified and anonymous, so genomic data doesn’t fit the bill,” she said.

“The principles also state that the only genetic information that’s considered sensitive is data that’s not related to health, so when you start looking at genetic profiling for health outcomes the data isn’t deemed to be sensitive.

“We don’t have specific legislation to counter that and it’s important that this data is not used to discriminate when it comes to insurance and employment.”

The local health insurance industry already requires consumers to offer all genetic information, such as profiling done over platforms like Ancestry.com and while insurance companies will not be allowed to access personal information, Dr Sigston said there was still a need for greater public education.

All Australians will have a My Health Record in 2018 unless they opt out of the system during a three-month period from July 15 to October 15, 2018. The public will be automatically signed up for their data to be shared to third parties for secondary use.

Consumers do have the ability to limit access to their data and the Office of the Australian Information Commissioner will regulate the handling of personal information.

Information security consultancy Security in Depth chief executive Michael Connory said there were doubts that the My Health platform was adequately geared technologically to store genomic information should its addition ever become a reality.

The governance framework of the system is yet to be fully formalised and for a platform hosting sensitive citizen data it doesn’t have two-factor authentication protocols.

“From a security perspective My Health is a work in progress,” he said.

“And while there is some built-in security, a compromised PC of a GP can be used to gain access to the system.

“The Ponemon Institute states that 50 per cent of data breaches occur through third-party suppliers so there are no guarantees the research and drug companies - accessing data from My Health will be fully secure.

"The information is de-identified and masked but there is still some uncertainty around who gets to see it.

"Is it just the GP or could it be someone else in a practice?"

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