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Using big data to drive big change

From monitoring the effectiveness of surgical interventions to AI-assisted diagnostics, researchers are seeing new ways for data linkage to inform policy and clinical practice.

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New ways for data linkage

In 2019, the Australian Government announced Medicare funding for heart health checks with a GP.

The policy promised free cardiovascular checks for all Australians over the age of 45, and Aboriginal people over the age of 30.

But three years on, few patients are accessing it.

“At the moment, only about one per cent of individuals who are actually eligible are having the new Medicare-funded heart health check,” says Professor Louisa Jorm, the foundation director of the Centre for Big Data Research in Health at UNSW Sydney.

“So just nobody’s getting it, even though there’s a Medicare item for it. There isn’t enough awareness about what your cardiovascular risk might be.”

Linking novel data sets

It’s one of many opportunities Professor Jorm sees for data linkage in Australia.

She points to the potential to monitor the effectiveness of surgical interventions and medical devices.

Professor Jorm and colleagues from Australia’s national joint replacement registry and the University of South Australia recently linked the joint replacement registry to data including hospital admissions, cancer and death records.

It meant being able to study identify adverse outcomes not captured by the registry alone, which only captures joint revision surgery.

Professor Jorm and her colleagues are working on a project they hope can help predict a person’s risk of a cardiovascular event.

The research combines data from hundreds of GP practices in New South Wales with hospital and death records.

The data is fed into a deep learning algorithm designed to estimate an individual’s risk of heart attack or stroke.

Professor Jorm says that risk level can then be delivered back to the GP, prompting a discussion with the patient and a heart health check.

“Potentially, if they need medications or lifestyle advice, those sorts of things can be triggered by this highly-personalised risk approach,” she says.

The research showed that prosthetic joint infections, for instance, occurred in 1.5-2 per cent of cases—ten times the rate identified by the joint registry.

Another of Professor Jorm’s projects, with colleagues from the National Perinatal Epidemiology and Statistics Unit, was the first in Australia to study the proportion of births that are medically assisted, either through reproductive technologies like IVF or other medications.

The research informed a tool for people considering IVF to estimate their chances of success.



“It’s not just a simple checklist it’s actually using individuals’ really detailed data... which hopefully will be more meaningful to them.”



Plug and play data

Professor Jorm advocates for Australia to have a 'core data spine' of routinely-linked information such as Medicare, PBS, hospital and death records.

"Having that puts you immediately in a good position," she says.

Professor Jorm argues a national linked data set for Australia would make it easier to do routine research.

She says it would also speed up bespoke linkage, with a 'plug and play' approach allowing researchers to easily add other novel data sets.

"I think the future in data linkage is actually linking in these extra sources," Professor Jorm says.

"Whether that be survey-based information about health risk factors or demographics, whether it be detailed clinical information... or also more detailed service information so you can actually use data linkage to evaluate programs and services."

Having a core data spine in place would help avoid the "data linkage marathon" Professor Jorm and team faced on the joint replacement research.

That took three years to secure approvals from all nine state, federal and territory health departments.

It would also make it easier to expand research like the IVF study, which initially only used data from NSW and the ACT.



"Even though we had national data... linking that with perinatal data was just not going to be feasible within the funds or time that we had," Professor Jorm says.

Artificial intelligence

Professor Jorm says there has been huge interest in machine learning and artificial intelligence.

But a lack of trust and understanding has made it difficult to implement in the real world.

"The black box nature of many of these analytics means that their safety and effectiveness is hard to determine," Professor Jorm says.

"It's not surprising that in a potentially high-risk environment, such as healthcare, people are not very willing to implement something that they do not understand."

Professor Jorm believes there's a real opportunity for linked data researchers to start to become familiar with these methods.

"But to try to integrate them into approaches that do allow explainability, and will drive potential implementation.

"Because at the moment it's one of the biggest chasms you can imagine between developing lovely algorithms that predict things and actually using them in practical ways to drive either population health planning or clinical care."

Privacy and security

Privacy protection and data security lie at the heart of the Population Health Research Network. The collection, use and disclosure of personal information by government agencies and other agencies are bound by strict legislative and regulatory conditions. Researchers wishing to access linked data must also adhere to stringent conditions, including ethics approval, data custodian approval and the development of a detailed data security plan.

Researchers are typically given access to a linked data set put together to meet the specific needs of their project. This de-identified data includes only the minimum information required for the research, such as age rather than date of birth.

Government agencies handle personal information in highly-secure environments. Data is delivered to researchers through a secure remote access facility, ensuring no information is stored on the researcher's personal computer or their institutional network. Researchers cannot export raw data from this system, only their analyses, and these are checked.

Researchers must only use the data for the approved purpose and are not allowed to link any other information. At the conclusion of the project, all data must be destroyed or returned.

Penalties for researchers and government employees can include criminal conviction, jail time or substantial fines. In the more than ten years since the network began, there has never been a breach.

