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How data linkage can improve the health of older people

Older people, despite bearing the burden of chronic disease and being more likely to take prescription drugs older people are under-represented in clinical trials.

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Studying older people

When pharmaceutical companies do clinical trials, people over the age of 70 are often excluded.

It's partly ageism, says Professor Leon Flicker, a geriatric medicine specialist at The University of Western Australia.

But it's also partly about the practicalities of studying older adults.

"It's because they know that there'll be greater loss to follow up as you get older," Professor Flicker says.

"People get sick with other things or die from other causes. So it makes the trials more difficult."

The result is that older people are under-represented in clinical trials—despite bearing the burden of chronic disease and being more likely to take prescription drugs.

A POWERFUL USE OF LINKED DATA

Professor Flicker says failing to have complete follow up of older people in research can lead to bias in studies.

This happened with case control studies in the 1980s and 1990s that incorrectly suggested smoking could protect against Alzheimer's disease.

Professor Flicker says this was due to an effect known as the 'survivorship bias'.

"The people who smoked, who would have eventually developed dementia, died from other causes before they could," he says.

So when University of Western Australia vascular surgeon Professor Paul Norman and population health researcher Professor Konrad Jamrozik set up a study looking at screening for abdominal aortic aneurysms in older men, they turned instead to linked data.

The researchers started with a data set of 41,000 men, randomly assigning half to receive an invitation to be screened for abdominal aortic aneurysms.

It's a condition that often grows slowly and without noticeable symptoms, but can rupture and cause life-threatening internal bleeding.

In total, 12,203 men turned up for an ultrasound screening of their aorta and filled out a lifestyle questionnaire.

The men were then followed, with their consent, through hospital and mortality data.

"The idea right from the beginning was that the men didn't even have to come back to be assessed again," Professor Flicker says.

"They could be followed from the linked data system to work out the men who had an abdominal aortic aneurysm problem.

"We knew which men came to hospital with a leaking abdominal aortic aneurysm, or who died from one."

Professor Flicker says it was "a very powerful way" of using linked data.

"Effectively, from that point on, we didn't need to see the men again for the purposes of the trial," he says.



CHANGING RISK FACTORS

The abdominal aortic aneurysm research was so effective it morphed into the Health in Men study, Australia's longest-running men's health trial.

The research has followed more than 12,000 men for more than 25 years, and is now exploring 'extreme longevity' in men that live to 100.

Professor Flicker says it's important to include older people in research, rather than assume they will respond in the same way as younger people.

He says one reason is that as we grow older, traditional risk factors for disease may not apply in the same way.

For instance, in young people, those with a normal BMI have the lowest risk of dying.

But in people aged between 70 and 75, people who are overweight have the lowest mortality.

A similar effect occurs in stroke, where Professor Flicker's research has shown that traditional vascular risk factors are poor predictors of stroke risk in older men.

Professor Flicker says linked data also presents an opportunity to study people with dementia or other cognitive impairments.

"The problem with doing community studies now is we really aren't getting very good response fractions," he says.

"And there is definitely a bias towards more disabled and people with cognitive impairment not responding.

"We have a method that doesn't work anymore, at least in high-income countries."

While life expectancy is increasing in most parts of the world, Professor Flicker says we shouldn't take it for granted that it will continue to increase.

"It actually has stalled recently because of Covid," he says

"But even before that period we could see that some countries in the world—including high-income countries like the US—don't do so well.

"In fact, the US has stalled completely and the UK is starting to stall as well as far as life expectancy goes."



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.

