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Health
Research
Network



Improving stroke care

Data linkage is helping researchers learn more about what happens to patients before, during and after hospitalisation for a major stroke, and even how COVID-19 affected stroke care.

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Improving stroke care

Associate Professor Monique Kilkenny first began undertaking data linkage projects more than 25 years ago, painstakingly matching 500 handwritten perinatal forms with death notifications for SIDS cases in Victoria.

Today, the Monash University and Florey Institute stroke researcher uses linked datasets with millions of records.

Through research projects such as Stroke123 and PRECISE, Associate Professor Kilkenny and her colleague Professor Dominique Cadilhac are helping to understand gaps in care and improve outcomes for people who experience a stroke.

They explore the full patient journey through emergency presentations, hospital admissions, prescription data, medical visits and death records.

Associate Professor Kilkenny says their research has found that one in three patients who experience stroke or transient ischemic attack are readmitted to hospital within 12 months.

Another finding is that one in three people who have a stroke stop taking their medication in the first year.

“It tends to happen around six months,” Associate Professor Kilkenny. “But in fact... they need to take them for the rest of their life.”

“So without these data, we would never have known that.”

Professor Cadilhac, also from Monash University and the Florey Institute, is an NHMRC Senior Research Fellow and an expert in health services research for stroke.

Professor Cadilhac’s research team and Ambulance Victoria are using linked ambulance, registry and hospital data to better understand what happens to people with stroke before they arrive at the hospital.

“We can look at health system issues to inform policy, for example, call taker or paramedic recognition of stroke symptoms,” she says.

Other research has looked at sex differences in the quality and outcomes of care in hospital, and the transition to home after a hospital stay.

“We’ve been able to look at things like the influence of frailty among people with stroke, and are currently analysing data on injurious falls and fractures,” Professor Cadilhac says.

“With the linked data, which has enriched the information we have access to in the registry, we’ve been able to look at the impact of diabetes.

“And disability impacts from communication disorders on quality of life or the costs of treating stroke.”



Together, the data are helping researchers, clinicians and policymakers to better understand disability, readmissions and survival after a stroke.

Associate Professor Kilkenny, a National Heart Foundation Future Leader Fellow who also heads Australia’s National Stroke Data Linkage Interest Group, says the linkage is very complex.

“There are 16,000 patients with stroke in the Stroke123 dataset,” she says.

“But the cohort has around 350,000 admissions and emergency presentations because of the five-year ‘look-back’ and up to two-year ‘look-forward’ period.

“PRECISE includes patients linked to data from the Australian Stroke Clinical Registry, PBS/MBS, admissions and emergency, contains around 12 million records.”

Professor Cadilhac also reports to the Victorian Government about the impact of the COVID-19 pandemic on stroke care and stroke services.

“We surveyed all our hospitals... about what’s been happening on the ground,” she says.

“People with stroke weren’t getting the same level of access to the stroke units.

“They were leaving hospital earlier, they weren’t getting some of their discharge care planning to the same standards as pre-COVID.”

Professor Cadilhac, who has been the data custodian for the Australian Stroke Clinical Registry since 2012, says linked data are very important to understanding individual patient journeys.

It also means we do not need to ask clinicians to provide data already in health record systems.

“For the condition of stroke, which is complex and crosses many different parts of the health system, data linkage has been invaluable to filling in gaps,” Professor Cadilhac says.

“You’re able to really unpack some important questions, in particular for subgroups of people, where they might just get lost in the system.”

Associate Professor Kilkenny says data linkage is crucial to her research.

“Some of the best work I’ve done is with the linked data,” she says.



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.

