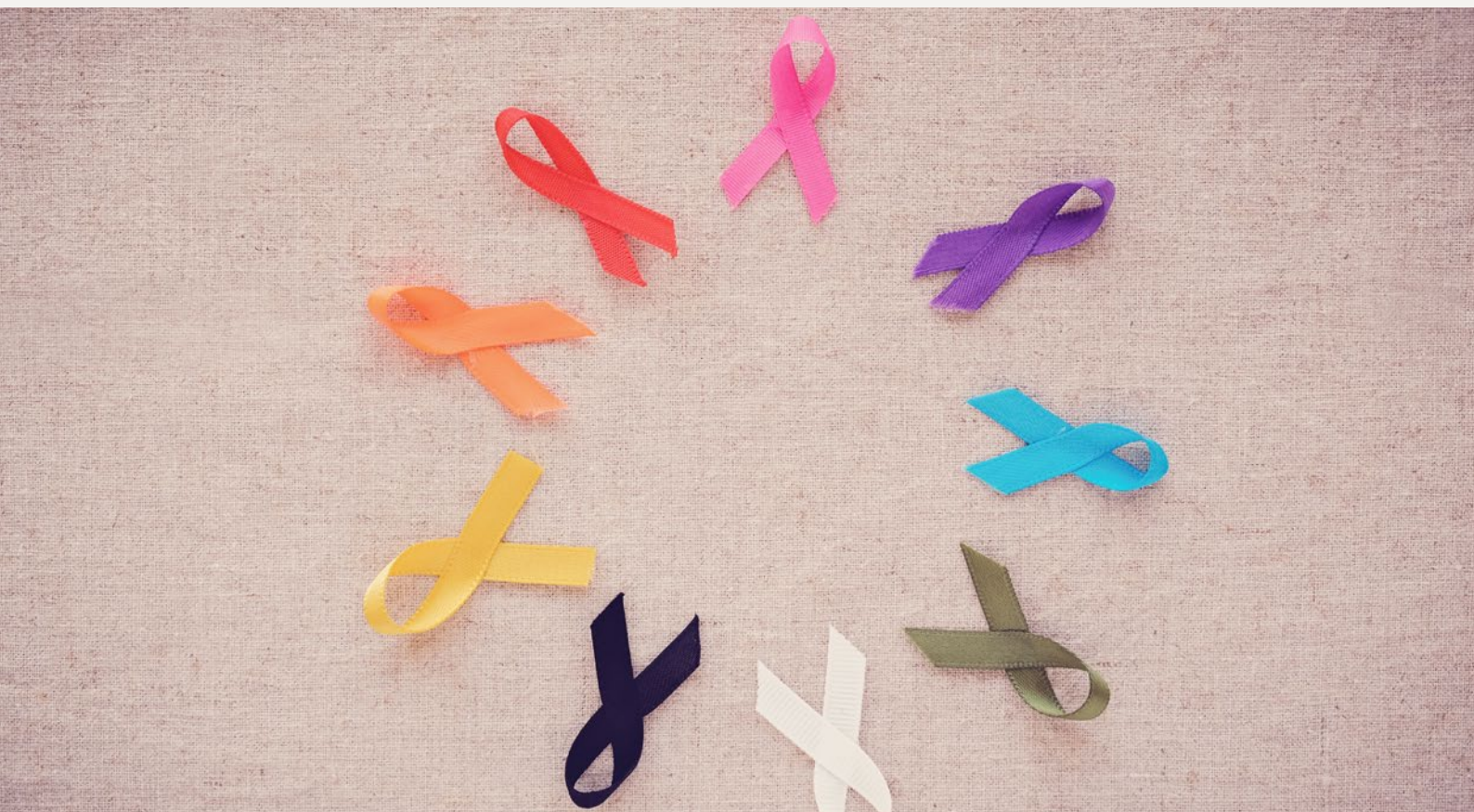




PHRN Population
Health
Research
Network



Using data linkage to battle cancer

Over the last decade, almost 200 peer-reviewed publications have used linked data to study cancer in Australia.

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NCRIS
National Research
Infrastructure for Australia

An Australian Government Initiative

Using data linkage to battle cancer

If you get cancer in Australia, when you're diagnosed, how you're treated, and your chances of survival can depend on where you live.

People in regional areas are 20-30 per cent more likely to die within five years of a cancer diagnosis than people in the city.

Professor David Preen, the Chair in Public Health at The University of Western Australia, is trying to change that.

He was an investigator on a UWA and University of Melbourne study that used a randomised control trial and linked data to address outcomes for cancer patients in rural areas.

IMPROVING SURVIVAL RATES FOR REGIONAL PATIENTS

The study looked at delays in the diagnosis and treatment of the five most common cancers in Australia— bowel, breast, lung, prostate and skin cancer.

"There were poorer outcomes for those that were diagnosed in the country, and also those that were treated in rural hospitals," Professor Preen says.

The research contributed to the establishment of the [Find Cancer Early](#) program—a Cancer Council

WA and Department of Health initiative for West Australians in regional areas.

"The program is now operating in the regions... trying to better inform patients but also general practitioners as well," Professor Preen says.

PUTTING CANCER TREATMENTS TO THE TEST

Professor Preen has been using data linkage to study cancer for almost two decades.

"Linked data are a vital resource, not just for my research but for research around the country," he says.

"In the cancer space, and more broadly across pretty much all priority health areas."

Professor Preen was also involved in a study of endocrine therapy— medication taken by women following treatment for breast cancer.

The medication reduces the amount or uptake of estrogen in the body and reduces the chance of the cancer reoccurring.

Clinical trials suggest endocrine therapy should be continued for at least five years after breast cancer treatment for women who are

hormone receptor-positive (around 80% of all breast cancer patients).

But adherence to the medication in real world practice is low.

To find out why, Professor Preen and his colleagues used linked NSW Cancer Registry, hospital data, death records, PBS medicines data, Medicare data and Australia's largest ongoing study of health and ageing—the 45 and Up Study.

They found about 91% of women commenced endocrine therapy as recommended by the clinical guidelines.

However, 58% stopped before the five-year mark.

"It's about identifying early signs that might indicate somebody has either bowel, breast, lung, prostate or skin cancer to reduce the time between the onset of symptoms and diagnosis."

The research found women were more likely to stop endocrine therapy if they didn't have chemotherapy, didn't have major surgery like a mastectomy, or suffered serious hot flushes (a side effect of the therapy) that required medication to treat.

The work was used to tailor messages promoted through places like the national breast cancer foundation, and advice for GPs.



WHEN MEDICATIONS INCREASE CANCER RISK

Linked data can also identify where medications can increase the risk of cancer.

Professor Preen points to a study led by the University of New South Wales, which found a diuretic medicine used for hypertension was associated with an increased risk of skin cancer.

“That was actually picked up by the Therapeutic Goods Administration and led to a TGA warning being provided to consumers and doctors,” he says.

Another study led by one of Professor Preen’s PhD students, Louise Stewart, used linked data to study the long-term impacts for women who undergo IVF.

The research used linked assisted reproductive technology records in Western Australia with cancer registry, hospital, death and mental health data.

Professor Preen says it showed IVF increased the risk of breast and ovarian cancer.

Surprisingly, women who had IVF and were successful in having a child were more than three times more likely to develop melanoma.

“It’s certainly not suggesting that women should not undergo IVF by any means,” Professor Preen says.

“What it’s saying is, if you do that, these are the long-term outcomes you need to be mindful of.

“So if you do identify a change in your skin... and you’ve had IVF that’s been successful, then that’s something you should get to your doctor asap.”

ENTERING THE AGE OF DATA SCIENCE

Professor Preen says a robust and effective data linkage platform across Australia is essential for important research to help inform health policy and practice.

“Even more so as we move into the newer, next-generation of analytics and the age of data science,” he says.

“Looking at things like AI, machine learning and signal detection... those types of methods rely on having sufficient amounts of data but also quality data.

“Unless [data scientists] have the foundational data to actually apply those methods to, they won’t be as effective to produce the evidence that people need.”

An economic analysis conducted in 2017 found that by 2034, more than 0.5% of the reduction in cancer burden in Australia would be attributable to PHRN-related data linkage.

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.

