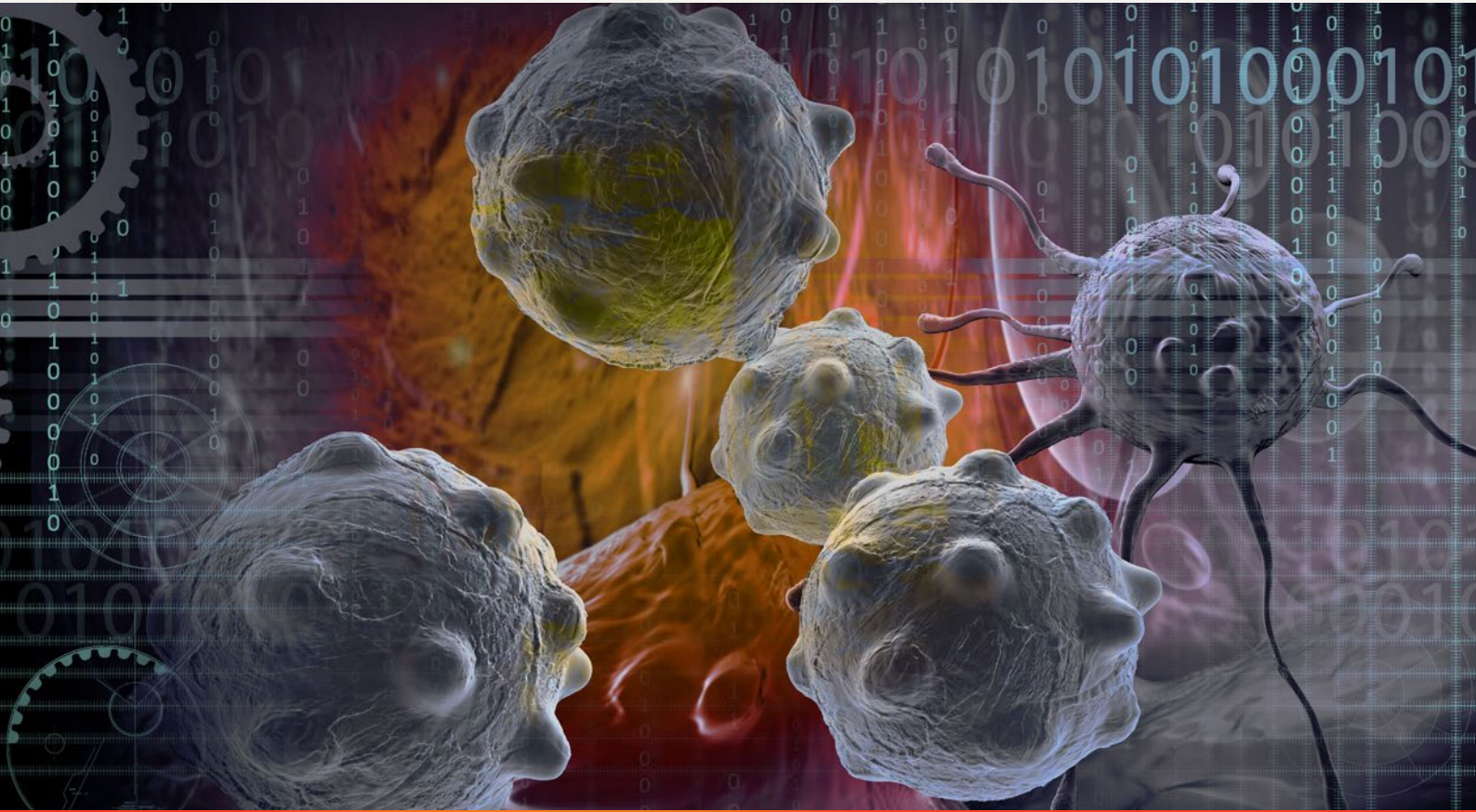




PHRN Population
Health
Research
Network



Bridging the gap in cancer care

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The Research

Living in Australia, there is about a one in two chance you will be diagnosed with cancer before the age of 85.

But not all Australians have the same chance of survival. Who you are and where you live can influence how likely you are to die.

It's something University of South Australia epidemiologist Professor David Roder is hoping to change using linked data.

Professor Roder, a research chair with the Beat Cancer Project, has been studying cancer for more than forty years.

He says Australia is unusual in having cancer data that cover the whole country.

Until recently, cancer registries in the US only included about a quarter of the population.

"We have cancer data in our registries for every person who gets a reportable cancer throughout Australia," Professor Roder says.

"That allows us to look at remote areas and those at increased risk, such as Aboriginal people, low socioeconomic areas and so on, to see if there are disparities that need to be addressed."

Cancer incidence data have been available in Australia since 1982.

But generally, they only contain a limited amount of data, such as the location and type of cancer diagnosed.

It's by combining the cancer registry with other data that Professor Roder sees real potential.



SCREENING AND TREATMENT

By linking cancer data to immunisation records, for instance, Professor Roder and his colleagues can study how HPV vaccines affect cervical cancer rates.

They can see the difference made by screening programs.

"We've got breast screening, cervical screening and bowel screening data that show participation in screening across the country," Professor Roder says.

"This answers the question [of] whether there are some groups in the population who aren't getting their screening."

Last year, the Australian Government introduced the option of self-collection for cervical tests.

Professor Roder is currently researching whether self-collection improves screening coverage, such as in women who previously found the test too intrusive.

This includes some women from diverse cultural backgrounds.

"Will self-collection increase screening coverage of the population?" Professor Roder says.

"This needs monitoring if we are to reach the target of cervical cancer elimination by 2035."

Professor Roder also uses linked data to study whether people are getting timely and effective cancer treatment.

He's looking at whether there are treatment delays in country areas and if people are receiving the best care.

"There are optimal care pathways and best practice guidelines for particular cancers, in terms of whether they get surgery, or radiotherapy, or chemotherapy, or new targeted therapies that are very expensive but very effective," Professor Roder says.

"You can't tell that from just a cancer registry that looks at incidence without treatment data.

"You need to have data on the clinical pathway. So we're pursuing that now."

IMPROVING ABORIGINAL HEALTH

After years of research, one study that stands out for Professor Roder is a project looking at cancer in Aboriginal people.

“We were able to show the differences in outcomes in Aboriginal people compared to other people by stage of cancer,” he says.

“Also how quickly they got care, and how their care measured up compared with non-Aboriginal people.”

The project was driven by a community reference group of Indigenous Australians.

“Even when we did this, which was back in 2010, there was a very strong position that Aboriginal people needed to participate in the collection of their own data,” Professor Roder says.

“And now that’s even stronger.”

“We’re talking about data sovereignty—that Aboriginal people should have much greater control of their data and data presentation.

Professor Roder says the community group also interpreted the data to bring about change.

“They were very strongly linked up with Aboriginal organisations across the population, to spread the word on what needed to be done,” he 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.

