

## Your Health Data: Transforming Our Future

**There is a force for good happening around Australia and the rest of the world. Each of us who is part of the healthcare system is providing vital information to help health researchers and policy makers shed light on health trends and chronic illnesses, which can produce life-saving results.**

**W**hen we interact with the healthcare system in Australia, information about our health and healthcare is recorded in databases owned by hospitals, health departments and other care providers. This information can be securely brought together from different locations and linked, which creates a more complete picture of the health of our population than was previously possible.

Record linkage makes it possible for researchers to construct chronological sequences of health events for individuals and, combined together, these individual 'stories' create a larger report about the health of the population.

The reliability and consistency of modern record-keeping allows researchers to sift through large quantities of data to identify medical patterns and trends. This information can be used to study the safety quality and costs of health care. Record linkage



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provides data for whole populations that would be prohibitively expensive to collect in any other way. It also allows research questions to be tested or developed on already existing data, allowing better targeting of funding for new research.

State and Commonwealth governments in Australia are investing in data linkage, as they recognise the benefits for Australia's research sector: development of priority-driven research that contributes directly, in the short to medium term, to population health and the performance of the health care system.

The ability to use our information more effectively will substantially alter the future of healthcare. Australia is now facing an exciting opportunity to build on its strength in health and medical research to create a healthier and more prosperous nation.

## Protecting your privacy

**A**cross Australia, a small number of dedicated data linkage providers are helping to protect your privacy. The Centre for Health Record Linkage (CHeReL), provides a service linking health-related databases in NSW and the ACT for research that is for the public benefit.

Protection of privacy is a major consideration in record linkage studies; the CHeReL follows a strict privacy preserving protocol. Once ethical approval is obtained, the CHeReL uses personal information such as name, date of birth and address to create links between records for the same person in different health databases. The CHeReL helps to preserve privacy in research by separating the processes of record linkage and data analysis.

Personal information is kept highly secure and confidential, and is used in accordance with privacy laws, and in accordance with any conditions placed on the use of personal information by the database owners and human research ethics committees. Information about people's health does not go to the CHeReL but stays in the original database.

All services provided by the CHeReL have the approval of the database custodians and a human research ethics committee that follows National Health and Medical Research Council guidelines.



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# Size Does Matter

**New data research, undertaken as part of the Sax Institute's 45 and Up study, shows just how important it is for overweight people to keep up their fitness levels in mid to old age to avoid hospital stays.**

**I**t is already known that people who are severely obese are at a higher risk of going to hospital and suffering from a serious illness than people who are at a healthy weight. The research shows that only about a third of people in NSW are in the ideal weight or body mass index (BMI) range. This ongoing study is examining what happens to people who are overweight or just slightly obese, and in fact more people are in that category than in the severely obese category.

Using data linked by the CHeReL, Professor Emily Banks and her team of researchers at Australian National University, are following a quarter of a million individuals around NSW to provide a window on the population's health. Each participant has filled in a questionnaire and given permission to follow their health in the long term through linkage to many different datasets including for hospital admissions and other outcomes. That is one in ten people aged 45 and over in NSW who are

taking part in the study, giving researchers permission to really look in more detail at their lives.

The findings show that small increments in BMI mean there is a concomitant increase in the risk of going to hospital, and that increases steadily from above normal BMI. The more overweight a person is, the more likely they are to go into hospital. For those people just in the overweight category it is about a 20% increase; for those in the slightly obese category it is around a 40% increase; and for those who are severely obese it amounts to a doubling in risk.

The research shows that for anyone who is overweight or obese, those people should be thinking about trying to get themselves back towards an ideal weight range. The study also busted the myth that the risks of being overweight are compensated for by being fit.

## Understanding cervical cancer: using data linkage

**Research reveals disparities in cervical cancer screening uptake in NSW.**

**T**he research study findings show that the incidence of and mortality from cervical cancer has fallen since the introduction of organised cervical screening around NSW in 1991. One of the key questions however, is whether this health gain is equally shared amongst all women, and whether migrant women are participating in screening programs.

Dr Nayyereh Aminisani, an Iranian-born researcher, working with the University of Sydney and the Cancer Council NSW, used the power of data linkage to bring together information about cervical screening and women's country of birth. Using this information, she was able to research cervical screening in NSW and its relationship to country of birth and socioeconomic status.

The key findings show that participation in cervical screening at the recommended interval in women from Asia and the Middle East is less than that in Australian women. The disparity in women from South Central Asia is particularly great.



Photo: Amanda James

"Language and cultural factors may contribute to some of these differences," said Dr Aminisani. "These disparities in cervical screening uptake by country of birth in NSW, particularly in women from South Central Asia, present a challenge to cervical screening services."

The National Cervical Screening Program in Australia is currently undergoing a process of renewal, which will take into account the introduction of the HPV vaccination. Science and technologies related to the program will be reviewed to ensure that all Australian women have access to a cervical screening program that is based on the best available evidence and promotes best clinical practice.

The renewed program aims to continue to improve health outcomes of Australian women. The program recommends two-yearly screening in women aged 18 to 69 years and it is important that all women are aware of the risks of cervical cancer and the need for regular Pap tests to avoid it.