

DATA LINKAGE IN THE ACT

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This document describes data linkage and the Preventive and Population Health Division's vision, scope, and intended benefits of ACT population health data linkage. For detailed technical information about how to engage with the data linkage process and outcomes, see the accompanying *ACT Population Health Data Linkage Technical Manual*.

This document outlines the responsible and ethical use of data linkage for the benefit of people across the ACT. The key audiences are:

- People and organisations who are considering making a request for linked data.
- Decision makers and custodians of the data.
- Users of linked data for research, evaluation, performance monitoring and quality improvement – including government epidemiologists and information bureaus, planners and policy makers; researchers; and health care providers such as clinicians.

WHAT IS DATA LINKAGE?

Information about each of us is everywhere

All sorts of information, about each individual in our society, is routinely collected by a wide range of private and public organisations. For example, supermarkets collect data about our grocery shopping habits, phone companies collect data about our phone usage tendencies and dentists keep notes about their patients.

Government departments and agencies – both in the ACT and nationally – also routinely collect data about individuals. This information can range from data about what library books we borrow, to our hospital, education, tax and police records. For example, Governments across Australia are required by law to keep a record of all people who are diagnosed with cancer.

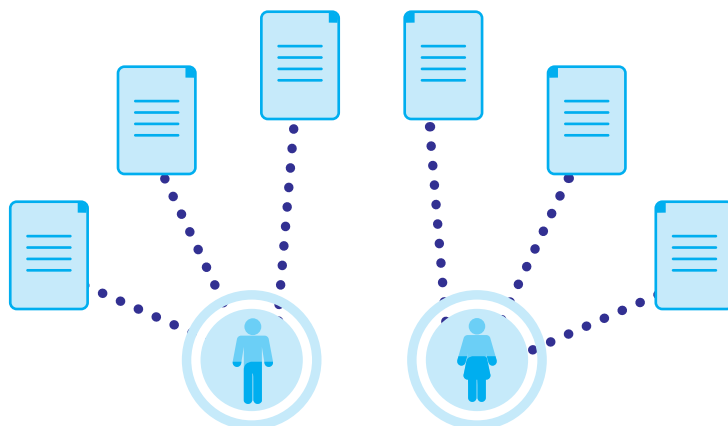
Information is usually kept by the organisation who collects it

Government administrative records tend to stay contained within the organisation which records them: our education information stays with our school or university, our health information stays within the hospital or community health system, and our overdue library fines tend to stay within the library system. Keeping each person's records separate within different government administrative systems happens more often than not – for example in the ACT, there is no automatic link between schools and public libraries about overdue library books and there's no automatic link between someone's hospital records and the National Births and Deaths Register.

Sometimes organisations get together to link up data

There are a few reasons why organisations occasionally get together to link up data.

To ensure a coordinated service: An individual's records might be linked if someone receives support from a range of organisations and this person specifically gives their permission for the organisations to share their personal information. This can help education, health, justice and welfare organisations provide more holistic, "joined-up", "wrap-around" services for their students, clients and consumers, but this is currently only possible for health records in the ACT. This also occurs to assist continuity of care, like when a GP and a hospital share information about a patient. This kind of clinical and personal information sharing can, however, also be experienced by a person as an infringement on their privacy and must only be done with their permission or when permitted by law.



To support administrative accuracy:

From time to time, it is helpful and important for our records to be linked. This may be to help uphold the law, like when the Australian Government links Medicare, Centrelink and Australian Tax Office records to assist people to make accurate claims and statements. Organisations in the private sector often link up our information – for example, a person might accumulate “points” on a bank credit card which are automatically linked with a separate company’s frequent flyer system.

For research purposes:

Data linkage might also occur for research purposes, for example to help improve services. An example of this is when a medical researcher wants to investigate if certain medical treatments work well – perhaps to see if there’s a ten-year relationship between a particular type of hospital treatment and an outcome, like survival (or death).

The term “data linkage” refers specifically to data linked to address questions that researchers and governments may have on the health of patient groups, programs or health care systems. It relates specifically to:

- health and other administrative data collections which are available for linkage; and
- the use of data linkage to provide evidence-base for public health/epidemiological research, health prevention and control efforts, planning, policy, evaluation, performance monitoring and reporting.

Data linkage has huge potential for cost-effective public benefit

Data linkage can help build a more complete picture about what life is really like for people, opening up new possibilities for this data to improve public services. Using this information can give governments more confidence about how to spend public money and plan services for the future.

Research involving linked data can be powerful also because it can cover large sections of the population. Other types of research, such as surveys or focus groups, which involve a sample of a population may inadvertently exclude people experiencing multiple disadvantage, for example if there are language barriers or challenges to being involved in research. “Data that are linked for the entire population are not only more inclusive, representative and unbiased, but are also more just in their distribution of burdens and benefits than conventional studies based on samples”.¹

How does data linkage happen?

Linking data for research purposes involves securely bringing together and de-identifying information from separate databases to one central data repository and then providing specific de-identified information (e.g. length of stay in hospital, cancer type) from the administrative data collection to researchers who have requested and negotiated access to it and who have ethics approval to do so. The many steps in this process are neatly described in this seven minute animation courtesy of *SANT Datalink* found here: www.santdatalink.org.au/animation.

1 Ethics and Data Linkage, Participant Guide. Population Health Research Network 2013. Version 1.2, November 2013, p24.