

BIG DATA POPULATION BASED RESEARCH

ACCESSING HEALTH AND HUMAN SERVICES DATA THROUGH SA NT DATALINK



Who are we

SA NT DataLink is a consortium of Joint Venture Partners from the SA and NT Governments, University of South Australia, Flinders University, The University of Adelaide, Menzies School of Health Research - Charles Darwin University and Health Consumers Alliance (SA).

SA NT DataLink supports population based public good research using linked data in South Australia (SA), the Northern Territory (NT) and across Australia. As a member of the Population Health Research Network (PHRN), it works in collaboration with other Australian linkage units, including the Commonwealth.

SA NT DataLink is located in the South Australian Health and Medical Research Institute (SAHMRI) and also has an office in Darwin. Contact santdatalink@unisa.edu.au or ph 08 8302 1034.

Providing high quality data linkage to support research

Population data held across different health and human services government agencies and private/non-government organisations is most often unavailable to researchers without first seeking the consent of people to use their data.

Through record linkage, this data can be connected and made available for research purposes, while at the same time protecting the privacy of individuals.

SA NT DataLink links records relating to the same individuals across multiple health, education and other human services datasets from SA and NT and from other jurisdictions, including the Commonwealth. Once linked, de-identified data concerning health and other outcomes of whole populations or sub-populations may be made available for ethically approved projects.

Population-based data linkage brings together large volumes of data from a wide range of often unconnected information sources for analysis.

Some of the key benefits arising from linked data research facilitated by SA NT DataLink include:

- Greater opportunity for innovative population wide research.
- Improved relevance of research findings to the local population through removal of sampling bias.

- Maximising the value of existing and routinely collected data.
- Opportunity for enhanced translation of evidence to policy.
- Opportunity for researchers and government to collaborate and address policy and decision-making priorities.
- Protects individual privacy.

The separation principle opens doors to data and protecting privacy

SA NT DataLink uses the identifying information to link the source records and substitutes this information with an anonymising key. The researcher receives the approved de-identified data and the anonymising key from data custodians.

Each record for the same individual can be linked where they have the same key. This separation of the identifying information from the clinical/service information protects privacy while giving researchers access to population level data and maximising the value derived from these often dormant information resources.

Research projects must be approved by data custodians and NHMRC accredited Human Research Ethics Committee(s).

Advanced linkage software and rigorous security protocols have enabled SA NT DataLink to link millions of records between multiple datasets with speed and accuracy, and establish strong and trusted relationships with data custodians from SA and NT public and private sectors and the Commonwealth.

All data provided to SA NT DataLink is located in a separate and secured room at Commonwealth Protected levels of security on air gapped servers.

This best-practice approach to data linkage has promoted confidence among custodians of previously tightly guarded data and seen them grant access to researchers through SA NT DataLink.

Research opportunities using linked data

SA NT DataLink facilitates State, Territory and national linked data research lead by universities, research institutes, governments and clinical practitioners.

PhD students can under supervision use SA NT DataLink's linked data as a key research methodology to support their thesis work.

SA NT DataLink enables researchers to undertake sophisticated, cost-effective and timely research on a wide range of interests and priorities. It is particularly valuable for research considering the social and biological determinants of health and wellbeing using population wide data from multiple sectors and jurisdictions. It also supports research with smaller studies and/or consented studies.

Multi-sectoral linkage can provide unique insights into the complex relationship between determinants and outcomes affecting the population and offer the opportunity for researchers to examine multi-factorial relationships and pathways of ill-health and disadvantage.

How much do SA NT DataLink service cost

SA NT DataLink is funded by the Australian Government from NCRIS (through the PHRN), as well as cash and in-kind support from its Joint Venture Partners. It provides its services on a partial cost recovery principle.

SA NT DataLink costs are generally based on the size of a cohort and the number of datasets to be linked. Where the principal investigator is from one of the SA NT DataLink Joint Venture Partners, they may be eligible for linkage credits to cover the cost of a project. Please contact us for more details.

What data is currently available

SA NT DataLink has the following datasets available for approved research projects (see table below). It is continually adding to these and updates them on a regular basis. We can also add your own dataset. For more details about these please go to the SA NT DataLink website or contact us.

Health Data

SA Public Hospital Separations
SA Public Hospital Emergency Dept.
SA Dental Service (Titanium)
SA Perinatal Statistics Collection
SA Women's and Children's (LHN):
- Child Health Check
- Perinatal Statistics Collection
- Growth and Development Data
- Neonatal Data Collection
SA Public Mental Health Services
SA Cervical Screening
BreastScreen SA
Drug and Alcohol Services SA
NT Perinatal (Trends)
NT Inpatient Activity
NT Emergency Department
NT Primary Health Care Collection
NT Public Hospital Pharmacy
NT Hearing Health Data Collection

Education Data

SA Public School Enrolments Census
SA NAPLAN
SA Running Records
SA English as an Additional Language
Australian Early Development Census
SA Preschool Enrolments
NT Preschool Enrolments
NT Student Activity
NT NAPLAN (Public Schools)
NT NAPLAN (Catholic and Christian)

Social Data

SA Child Protection
SA Electoral Roll
SA Youth Justice
Housing SA
SA Homeless to Home
NT Child Protection
NT Public Housing (Urban)
NT Integrated Justice Information System

Registries

SA Birth Registry
SA Death Registry
SA Codified Cause of Death
SA Coronial Codified Cause of Death
SA Historic Cause of Death (1989-2006)
SA Cancer Registry
NT Birth Registry
NT Death Registry
NT Codified Cause of Death
NT Coronial Codified Cause of Death
NT Immunisation Register
NT Cancer Registry
NT Rheumatic Heart Disease Register

National Registries

Australia and New Zealand Dialysis and Transplant Registry
Australian Orthopaedic Association
National Joint Replacement Registry