

PEOPLE CENTRED - POPULATION BASED LINKED DATA RESEARCH AND ANALYSIS

IMPROVING HEALTH AND HUMAN SERVICES THROUGH SA NT DATALINK

The importance of sharing data to provide an evidence base to improve health and wellbeing is well recognised. Protecting individual privacy when sharing this information is vital, and SA NT DataLink has been doing both successfully for over 10 years.

Who is SA NT DataLink?

SA NT DataLink is a collaborative joint venture including:

- The South Australian Government
- The Northern Territory Government
- South Australian Health and Medical Research Institute (SAHMRI)
- University of South Australia
- Flinders University
- The University of Adelaide
- Menzies School of Health Research, Darwin
- Cancer Council SA

SA NT DataLink is a Commonwealth Accredited Integrating Authority, approved to facilitate SA, NT and nationwide linked data analysis and research projects. DataLink actively collaborates with other jurisdictional members of the Population Health Research Network ([PHRN](#)).

[SA NT DataLink](#) is based in Adelaide's Bio Medical precinct within the SAHMRI building, along with a Darwin office.

[Contact Us](#) via santdatalink@unisa.edu.au

High quality data linkage to support research

- SA NT DataLink is world class research infrastructure enabling safe access to high quality linked data through a privacy protecting framework enabling public good research & policy analysis.
- Governed under legislation and operating under the approval of the Privacy Committee of South Australia, SA NT DataLink operates as a trusted third party, and may access personally identifying information to enable the linking of records from multiple sources, including non-government data sources.
- SA NT DataLink specialises in linking an individual's records across multiple health, education, justice and other human services data sources from SA, NT and nationally including the Commonwealth and non-govt.
- Approval to access linked data for analysis requires appropriate ethical & data custodian approval, including the signing of deeds of confidentiality.
- SA NT DataLink brings together large volumes of unconnected and disparate information sources, allowing activities from targeted or population-based interventions to be evaluated, pathways understood, and impacts and outcomes empirically understood
- Data that is often 'normally' unavailable can be de-identified through SA NT DataLink, with approved access provided for research and innovative analysis.



Key benefits arising from linked data research facilitated by SA NT DataLink include:

- Protecting individual privacy while providing access to data for approved research and analysis.
- Maximising the value and use of routinely collected data sources, researcher cohorts & registries for the benefit of communities.
- Greater opportunity for innovative population wide research and outcome analysis at unit record level.
- Enhanced support for translation of evidence to changes in practice and policy.
- Improved relevance of research finding by removal of sampling bias.
- Greater opportunities for researchers and government to collaborate and address policy priorities.

The Separation Principle opens doors to data while protecting privacy

Under the '[Separation Principle](#)' identifying information is separated from its clinical and service information. SA NT DataLink substitutes identifying information on individual's records with an anonymising key, effectively de-identifying the clinical/service part of the record.

The separation of sensitive clinical/service information and anonymising of identifying information is used to protect individual privacy while giving researchers access who sign deeds of confidentiality for the now de-identified data. Best practice restricts access to personally identifying information, and unless it is a consented study, researchers are prohibited from accessing the identified information.

Research studies must be approved by data custodians & an NHMRC accredited Human Research Ethics Committee.

Advanced linkage software and rigorous security and quality protocols have enabled SA NT DataLink to securely link hundreds of millions of transactional records enabling research analyst access to billions of unit record level data from multiple data sources, with speed and accuracy without breaches of privacy.

Operating as a trusted organisation for over 10 years, SA NT DataLink has established strong relationships and legally binding agreements with data custodians across the SA and NT public and private and non-government sectors, and the Australian Government.

Through the SA NT DataLink system, data custodians have gained the confidence and necessary trust to make their data available more widely for public good evidence based decision making and research.

Research opportunities using linked data

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

DataLink is focussed and committed to facilitating cost-effective data linkage research, supporting a wide range of interests through jurisdictionally sourced data.

By making use of large population wide data linked with smaller cohorts, data linkage is a particularly valuable methodology with the ability to examine multi-factorial relationships and the complex service and health pathways and disadvantage. DataLink's success is the extensive range of datasets available, resulting in analyses of many of the social and biological determinants of health, education and wellbeing.

Smaller population based and/or researcher cohort consented studies can also be effectively supported.

PhD students can use SA NT DataLink's linked data under supervision to support their thesis work.

Research impact using linked data

- In Western Australia, Prof Fiona Stanley proved the link between the lack of folate and birth defects.
- In South Australia, for the first time cancer researchers can access Breast Screening records and cancer diagnosis staging, for improved efficacy of treatment and patient outcomes.
- World-class research on children's developmental and educational outcomes [in SA](#) and [in the NT](#).
- Australian leading Healthy Ageing research has been

enabled through the integration of data for the [Registry of Senior Australians – ROSA](#).

- ROSA's integrated analysis and modelling informed the [Royal Commission in Aged Care Quality & Safety](#).
- SA NT DataLink provided integrated data for the Royal Commissions into Child Abuse in South Australia & Northern Territory.
- Agency policy and practice informed by linked data evidence of children's pathways, their home environment and interactions with agencies.

How much do SA NT DataLink services cost?

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

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 are eligible for a discount of 50% on the cost of the project.

Please [contact us](#) for more details on accessing [SA NT DataLink's services](#) via santdatalink@unisa.edu.au

What data is currently available?

SA NT DataLink provides a wide range of health and human services data sources for approved projects. Please refer below or for more detail, the [online listing of available data sources](#).

Health Data

- SA Public Hospital Separations
- SA Public Hospital Emergency Dept.
- SA Public Dental Service
- 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
- BreastScreen SA and NT
- Drug and Alcohol Services SA
- SA and NT Cervical Screening
- NT Perinatal (Trends)
- NT Public Hospital Inpatient Activity
- NT Public Emergency Department
- NT Primary Health Care Collection
- NT Public Hospital Pharmacy
- NT Hearing Health Data Collection

Access to Commonwealth data, including MBS, PBS, Centrelink, Aged Care, National Death Index records

Education Data

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

Social Data

- SA Child Protection
- SA Electoral Roll
- SA Youth Justice
- SA Public Housing
- SA Homeless Services data
- SA Correctional Services data
- NT Child Protection
- NT Public Housing (Urban)
- NT Integrated Justice Information System including Youth & Adults

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 & NT Cancer Registry
- NT Birth Registry
- NT Death Registry
- NT Codified Cause of Death
- NT Coronial Codified Cause of Death
- NT Immunisation Register
- NT Rheumatic Heart Disease Register

National Registries

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