

PEOPLE CENTRED - POPULATION BASED LINKED DATA RESEARCH AND ANALYSIS

RESEARCHING HEALTH AND HUMAN SERVICES DATA THROUGH SA NT DATALINK



Who is SA NT DataLink?

In recognition of the vital importance of collaborative partnerships for sharing data for decision makers, SA NT DataLink was established as research infrastructure in 2009 to provide privacy protecting data access. Organisations collaborating in the SA NT DataLink Joint Venture partnership include:

- The South Australian Government
- The Northern Territory Government
- Cancer Council SA's Beat Cancer Project
- South Australian Health and Medical Research Institute (SAHMRI)
- Flinders University
- University of South Australia
- Health Consumer Alliance (SA)
- The University of Adelaide
- Menzies School of Health Research - Charles Darwin University

SA NT DataLink protected privacy and enables safe sharing of datasets of any size (large or small) for public good policy and research purposes.

As an accredited Commonwealth Data Integrating Authority for South Australia and the Northern Territory it facilitates SA, NT and nationwide linked data analysis and research, collaborating on data projects with members of the NCRIS funded Population Health Research Network (PHRN).

Location: in Adelaide's vibrant Bio Medical precinct at South Australian Health and Medical Research Institute (SAHMRI), SA NT DataLink also has an office in Darwin.

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

Providing high quality linked data to support research and analysis

Through SA NT DataLink's privacy protected record linkage processes, previously unavailable data is able to be connected and made available for statistical research and analysis purposes.

SA NT DataLink links individuals' records relating to the person same across multiple health, education and other human services data sources from SA, NT & other jurisdictions, including Commonwealth & non-government.

Once linked, approved de-identified data for sub-populations or whole population can be facilitated by SA NT DataLink & made available for ethically approved use.

Population-based data linkage cost effectively brings together large volumes of data from multiple sources allowing clinical or population outcomes or interventions to be evaluated and their impacts understood.

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

- Protects individual privacy while providing researchers and analyst access and use.
- Greater opportunity for innovative population wide research and outcome analysis at unit record level.
- Enhanced support for translation of evidence to change practice and policy.
- Improved relevance of research findings to locally collected cohorts through removal of sampling bias.
- Maximise the value and use of existing and routinely collected data sources, researcher cohorts & registries.
- Timely data access via [Custodian Controlled Repository](#)
- Greater opportunity for researchers and government to collaborate and address policy priorities.

The Separation Principle opens doors to data while protecting privacy

1. SA NT DataLink is approved to access personally identifying information from multiple sources.
2. Using the '[Separation Principle](#)' SA NT DataLink substitutes personal information with anonymising keys for each individual, effectively linking records with Researchers only accessing de-identified data.
3. Researchers receive de-identified data along with anonymising keys to then merge & analyse records.
4. The separation of personally identifying information from the clinical/service information protects privacy.
5. Each research study using SA NT DataLink's services must be approved by a NHMRC accredited Human Research Ethics Committee (HREC) & each of the participating data custodians. Specific data access & use conditions can be mandated by the HREC & Data Custodians.
6. **Advanced linkage software and rigorous security and quality protocols have enabled SA NT DataLink to link millions of transactions (unit record level data) between multiple datasets with speed and accuracy.**
7. As a Commonwealth accredited Data Integrating Authority, SA NT DataLink have established strong and trusted relationships with data custodians from SA & NT public, private sectors, and the Australian Government. ie running pilots studies with Govt.
8. Operating as a trusted 3rd party, SA NT DataLink promotes confidence among custodians of previously tightly guarded data & has seen them grant access to sensitive data for researchers through SA NT DataLink.

Research impact using linked data

- In Western Australia, Prof Fiona Stanley proved the link between the lack of folate and birth defects.
- For the first time in South Australia, cancer researchers are able to access Breast Screening records and cancer diagnosis staging, for efficacy of the treatment and patient outcomes.
- Empowers world-class research on children's developmental and educational outcomes [in South Australia](#) and [in the Northern Territory](#).
 - SA NT DataLink provided the most valued data sources for two recent Royal Commissions into Child Abuse in South Australia and the Northern Territory.
 - Agency policy and practice informed by linked data evidence of children's pathways, their home environment and interactions with agencies.
- Australian leading Healthy Ageing research is supported through the integration of data with the establishment of the [Registry of Older South Australians – ROSA](#).

What data is currently available?

SA NT DataLink provides an exceptionally wide range of data for approved research. Please refer below or for more detail, the [online listing of available data sources](#).

A number of nationally relevant registries and consented health cohort studies already linked by SA NT DataLink are available for innovative research. For example, the 20 year longitudinal [North West Adelaide Health Study](#).

Research opportunities using linked data

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

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

SA NT DataLink facilitates cost-effective sophisticated data linkage research, supporting a wide range of interests and jurisdictionally sourced data. Using population wide data is particularly valuable methodology with the ability to examine multi-factorial relationships and pathways of ill-health and disadvantage, including the social and biological determinants of health, education and wellbeing. Smaller linked data research studies and/or consented studies can also be effectively supported.

Cost of SA NT DataLink services

SA NT DataLink is funded by the Australian Government through the NCRIS - PHRN (Population Health Research Network), along with significant cash and in-kind support from its Joint Venture Partners. It provides its 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 may be eligible for funding (linkage credits) to cover the cost of a project.

For more details on accessing [SA NT DataLink's services](#) please [Contact us](#) online or via santdatalink@unisa.edu.au

Health Data

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

Education Data

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

Social Data

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

Registries

- SA and NT Birth Registry
- SA and NT Death Registry
- SA and NT Coronial Codified Cause of Death
- SA and NT Codified Cause of Death
- SA Historic Cause of Death (1989-2006)
- SA and NT Cancer Registry
- 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

Plus access to MBS / PBS records and longitudinal research cohorts.