



SA NT DataLink

Access and Pricing Policy

Contact: SA NT DataLink

Telephone: 08 8302 1604

Email: santdatalink@unisa.edu.au

Issue Date: January 2020

Version: 4.0

BACKGROUND

The SA NT DataLink Access and Pricing Policy has been developed in accordance with the SA NT Data Linkage Consortium Agreement, the National Collaborative Research Infrastructure Strategy (NCRIS) funding agreement and the Population Health Research Network (PHRN) Access and Pricing Policy.

1. PURPOSE OF SA NT DATALINK

SA NT Data Link was established in 2009 as part of the PHRN national population based data linkage research infrastructure.

SA NT DataLink enables access to a wide range of health, education and other human services and clinical datasets to support research, policy development, service planning and evaluation in South Australia and the Northern Territory. It also supports cross or multi-jurisdictional projects and access to Australian Government data.

In summary, SA NT DataLink's main functions include:

- Ensuring privacy is protected as part of its operations and in the provision of linked data through the separation principle.
- Providing data linkage services for researchers, planners and policy makers.
- Supporting governance processes to make available de-identified linked datasets to approved users.
- Supporting the development of the population data linkage infrastructure capacity at a national level.

2. ACCESS TO SA DATALINK SERVICES

2.1. Data Access Principles

Access to linked data provided by SA NT DataLink is open to projects which:

- Have a public benefit.
- Are approved by a NHRMC registered human research ethics committee (HREC).
- Are supported under legislation where HREC approval is not required.
- Are approved by the relevant data custodians.
- Make results available in the public domain.
- Are conducted in accordance with SA NT DataLink requirements, relevant legislation, and NHMRC and other guidelines.

2.2. Prioritisation of projects

Access to SA NT DataLink services is generally provided on a first come first served basis. However, the Director, SA NT DataLink may also consider the following factors when prioritising projects:

- Data availability.
- Complexity of project/technical feasibility.
- Public interest.
- Research funding time restrictions.
- National and/or jurisdictional (SA and NT) strategic priority areas.

2.3. SA NT DataLink project applications

All SA NT DataLink projects must submit an application through the PHRN on-line application system accessible from the [SA NT DataLink website](#). In summary, once lodged, the application process involves:

- The provision of project quote and letter of feasibility by SA NT DataLink.
- An in-principle approval for the proposed project from data custodians.
- The approval of appropriate ethics committee(s).
- A final approval from data custodians (subject to the ethics approval).
- Signing of deeds of confidentiality.
- Approval of the Director, SA NT DataLink.

2.4. Terms and conditions of data access

- Access to data will only be provided after all approvals are in place and researchers have signed the deeds of confidentiality as required by SA NT DataLink and data custodians.
- The deeds describe the terms and conditions for the receipt, management and use of the data that may be in addition to any conditions that form part of an ethics committee or data custodian approval.
- The terms and conditions may vary depending on the nature of the individual project and/or the requirements of specific data custodians.
- Researchers are required to conform to the terms and conditions in a deed, which are legally enforceable agreements.

3. SA NT DATALINK PRICING PRINCIPLES

The following principles apply to SA NT DataLink prices for its services:

- SA NT DataLink's pricing provides for a partial cost recovery to offset its operating costs, which is consistent with the *PHRN Pricing and Access Policy*.
- Charges for projects will be in accordance with the principles of the *SA NT DataLink Access and Pricing Policy* and the schedule of charges as approved by the Steering Committee.
- An SA NT DataLink quote is usually valid for 18 months. A quote may be amended, or an additional or new quote provided where the period for the quote has expired, and/or a researcher has amended their application to include:
 - additional datasets and/or years for datasets; and/or
 - additional cohort(s); and/or
 - an amendment to the cohort size.
- Where there are significant amendments to a project and/or a new ethics application is required, SA NT DataLink may require a new application to be submitted. SA NT DataLink may issue a new or amended letter of feasibility and/or quote.
- The Director, SA NT DataLink has the discretion to vary a quote.
- The Steering Committee reserves the right to vary the *Access and Pricing Policy* and the schedule of charges at any time.

4. CONSORTIUM MEMBERS ENTITLEMENTS

4.1. Consortium member rebate

The members of the SA NT DataLink Consortium contribute annual funding and/or in-kind support to SA NT DataLink.

Where the principle investigator is in the employ of a Consortium member, the investigator's project is entitled to a 50% rebate. For purposes of a SA NT DataLink and a project application for which a quote is provided, only one person can be designated as the principle investigator.

5. COST OF LINKAGE PROJECTS

The cost of a project will vary with the type of service and the size and complexity of the project. The cost is generally based on the following:

- **Client service project establishment and management fees** – A fixed and variable fee for the cost of SA NT DataLink client services providing support for project management and approval processes, including cross jurisdictional linkage projects.
- **Infrastructure and linkage services fees** – A variable fee based on the work required by the Data Linkage Unit to support the infrastructure and generate the project specific linkage keys. It is based on the number of probable individuals to be linked, whether new datasets are to be added (e.g. a researcher's dataset), the number of datasets.
- **Codified cause of death fee** – A fee to recover (in part) the cost for the provision of the data to SA NT DataLink from the Australian Coordinating Registry.
- **Integrating Authority fee** – An SA NT DataLink fee to recover in part, the cost to SA NT DataLink for providing access to Commonwealth data as part of its Integrating Authority.
- **Data Integration Unit cost** – A cost per project based on the cohort size and number of datasets provided by the DIU to recover the data extraction costs and the infrastructure.
- SA NT DataLink may negotiate fees for other linkage and statistical services. For example:
 - familial links
 - geocoding of datasets
 - statistical analysis and analytical services
 - data cleaning and quality support
- Costs independent of SA NT DataLink - In some instances a project may incur costs independent of SA NT DataLink. These costs may be from:
 - **Data custodian fees** – A data custodian may charge a fee to recover the cost of the provision of the extracted de-identified data. *If applicable, this fee will be included in a quotation and is payable directly to SA NT DataLink. SA NT DataLink will ensure payment to the data custodian.*
 - **Secure Unified Research Environment (SURE)** – SURE has a schedule of fees it charges researchers for the use of the workspace for an approved project. These are independent of SA NT DataLink and available from its website. *These costs are paid directly to SURE as they form part of the Agreement between SURE and the researcher.*
 - **Commonwealth dataset linkage costs** – Researchers should ensure they have a written quote for linkage with Commonwealth datasets. *Commonwealth data linkage costs are paid directly to the Commonwealth linkage unit.*

6. DESCRIPTIONS OF SA NT DATALINK SERVICES

6.1. Client service project establishment and management

- Engaging with researchers to assist in initiating and refining the proposed linkage project application.
- Advisory service on data availability, access and metadata.
- Acquiring new datasets and seeking updates to existing datasets.
- Reviewing and advising on all documentation and applications required.
- Providing estimations of cost and letters of feasibility for a project to support applications.
- Providing advice and liaising with researchers and data custodians on ethics, application processes and deeds of confidentiality.
- Obtaining data custodian in-principle and final project approvals.
- Undertaking due diligence to ensure project applications are consistent with approved ethics applications and deeds of confidentiality.
- Drafting linkage specification to support the extraction of the records and linkage keys.
- Drafting data custodian extract instruction documents to enable the extraction and provision of the approved data to researchers.
- Ongoing liaison with data custodians and researchers regarding the provision of the project data and addressing issues that may arise.
- Managing and supporting amendments or extensions to projects.
- Managing of cross-jurisdictional projects.
- Follow-up of project outcomes.

6.2. Data Linkage Unit services

- Maintaining the MLF.
- Incorporation of new/updated datasets into the MLF.
- Linkage of MLF to datasets external to MLF (e.g. A project specific dataset).
- The generation of Project Specific Linkage Keys (PSLKS).
- Provision of linkage keys to data custodians or the Data Integration Unit (DIU).
- Linkage of Commonwealth data.
- Production of the Researcher Handover Report (describing linkage methodologies and quality statements).
- Identification of project cohorts.
- Undertaking data quality for data custodians on their provided datasets.

6.3. Data Integration Unit (DIU)

- Provision of or providing access to approved de-identified data to researcher(s).
- Support the provision and management of data provided by data custodians to the custodian controlled data repository (CCDR) in the sure environment.
- Data cleaning and quality support.
- Data quality reports for data custodians.
- Identification of project cohorts.
- Provision and management of project workspaces in SURE.

GLOSSARY

Consortium Member - a signatory to the SA NT Data Linkage Consortium Agreement

Custodian Controlled Data Repository (CCDR) – the data repository managed by the DIU holding de-identified data provided by data custodians.

Data Integration Unit (DIU) - that part of SA NT DataLink responsible for the management of the Custodian Controlled Data Repository.

Data Linkage Unit (DLU) - that part of SA NT DataLink responsible for the integration of personally identify information into the SA NT DataLink Master Linkage File.

NCRIS - National Collaborative Research Infrastructure Strategy. NCRIS is funded through the Australian Government providing funding to the PHRN to support population-based data linkage infrastructure across Australia.

PHRN - Population Health Research Network. The PHRN is responsible for the allocation of NCRIS funding to the respective data linkage units and coordinating management for multi and cross jurisdictional projects.

Principal (or Chief) Investigator – the person designated as having primary responsibility for the management of a project and its outcomes in the SA NT DataLink and ethics applications. Note that this must be the same person as described in an ethics application as the principal (or chief) investigator.

Researcher - the chief or principle investigator, a researcher, investigator or analyst

Research project – a project or research study using the services of SA NT DataLink.

Researcher Handover Report - the report provided by SA NT DataLink to a researcher summarising the linkage of the data by SA NT DataLink and the resulting outcomes.

SA NT DataLink - the organisation established in 2009 under the SA NT Data Linkage Consortium Agreement.

SA NT Data Linkage Consortium Agreement – the Agreement signed by the Consortium Members in May 2009 establishing SA NT DataLink, and subsequently extended and/or amended with Deeds of Variation.

Schedule of charges – the prices approved by the Steering Committee for the services offered by SA NT DataLink and as amended from time to time.

Steering Committee – the SA NT Data Linkage Consortium Steering Committee established under the SA NT Data Linkage Consortium Agreement with a representative from each Consortium Member. The Steering Committee is responsible for SA NT DataLink’s strategic directions, its budget, finance and PHRN reports and its policies and procedure, including the *Access and Pricing Policy*.

Secure Unified Research Environment (SURE) - a secure computing environment based in the SAX Institute, Sydney and developed as part of the PHRN for the storage of approved data and to provide a controlled and remotely accessible research facility for researchers to analyse the data.
<http://www.saxinstitute.org.au/our-work/sure/>