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# SA NT DataLink

## Access and Pricing Policy

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**Responsible Authority:** SA NT Data Linkage Consortium Steering Committee

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## BACKGROUND

The SA NT DataLink Access and Pricing Policy has been developed in accordance with the SA NT Data Linkage Consortium Agreement and the Population Health Research Network (PHRN) Funding Agreement. These agreements require SA NT DataLink to develop an access and pricing policy consistent with the NCRIS principles and the PHRN Access and Pricing Policy.

### 1. PURPOSE OF SA NT DATALINK

SA NT Data Link was formally established on 5<sup>th</sup> May 2009 in accordance with the direction of the PHRN to develop research infrastructure that will have benefits across Australia by enabling Researchers in universities, research institutes, government agencies and other organisations in South Australia and the Northern Territory to access health, education and other community datasets, ad hoc survey datasets and routine administrative datasets.

The purpose of SA NT DataLink is to provide high quality data linkage services to support research, policy development, service planning and evaluation.

The provision of de-identified linked data will enable a better understanding and monitoring of the population health, education and community wellbeing impacts of policy and investment decisions for South Australians and Northern Territorians.

SA NT DataLink enables the linkage of administrative, government service data and clinical datasets required to provide an evidence base for Researchers and policy makers and is a key source of information to assist the achievement of South Australian and Northern Territory strategic plan targets and meeting COAG goals.

SA NT DataLink's major functions include:

- creating linkages within and between South Australian and Northern Territory administrative, clinical and service delivery data sets;
- providing linkage services for Researchers, planners and policy makers;
- setting up and overseeing processes to produce de-identified linked data sets for approved users;
- contributing to national linkage capacity, in particular through liaison with the PHRN.

As a member of the PHRN, SA NT DataLink works in a strong spirit of collaboration with other organisations undertaking data integration and linkage across Australia and overseas.

### 2. ACCESS TO SA DATALINK SERVICES

#### 2.1 General Data Access Principles

Access to the SA NT DataLink services and data linkage infrastructure is in accordance with the principles outlined in the *2006 NCRIS Roadmap*. These are:

- Australia's investment in research infrastructure should be planned and developed with the aim of maximising the contributions of the research and development system to economic development, social wellbeing and environmental sustainability.
- Major infrastructure should be developed on a collaborative, national, non-exclusive basis. Infrastructure funded through NCRIS should serve the research and innovation system broadly, not just the host/funded institutions. NCRIS funding should encourage collaboration and co-investment amongst universities, government, independent and private sector research organisations. It should not be the function of NCRIS to support institutional level (or small-scale collaborative) infrastructure.
- Access is a critical issue in the drive to optimise Australia's research infrastructure. In

terms of NCRIS funding there should be as few barriers as possible to accessing major infrastructure for those undertaking meritorious research.

- Due regard should be given to the whole-of-life costs of major infrastructure, with funding available for operational costs where appropriate.
- The Access strategy should seek to enable the fuller participation of Australian Researchers in the international research system.

## 2.2 Access to Government and related data

Consistent with the Access and Pricing Policy of the PHRN, access to linked data provided by SA NT DataLink is open to those whose projects comply with the following principles. They are:

- ethically approved by a NHRMC registered human research ethics committee;
- approved of the relevant Data Custodians;
- projects whose results will be available in the public domain;
- projects conducted in accordance with the relevant legislation, regulations and guidelines.

## 2.3 Prioritisation of Researcher Access

Researcher access to the SA NT DataLink infrastructure and services will generally be provided on a first come first served basis. However, the following factors may be taken into consideration when prioritising access:

- data availability
- complexity of project/technical feasibility
- public interest
- research funding time restrictions
- national health priority areas determined by the Australian Health Minister's Conference
- jurisdictional strategic priorities e.g. South Australian or Northern Territory Strategic Plan priorities.

## 2.4 SA NT DataLink project application process

The SA NT DataLink application process is published on the SA NT DataLink website. In summary the process involves:

- an initial in-principle approval for the proposed project from Data Custodians;
- the approval of the appropriate ethics committee;
- a final approval from Data Custodians (subject to the ethics approval).

The SA NT DataLink Statistical Linkage Project application process is compatible with the PHRN application process and complements the National Ethics Application Form.

## 2.5 Terms and Conditions of data release

Researchers must agree to and sign the terms and conditions of use for the data.

The terms and conditions may vary depending on the nature of the individual project and/or the requirements of specific Data Custodians.

The SA NT DataLink Statistical Linkage Project Application provides a template for Data Custodians to specify the terms and conditions governing access to their data. The terms and conditions are based on the legal and regulatory requirements for using the data and are legally enforcement agreements (Deeds) signed by Researchers requiring them to conform to the terms and conditions as well as the security protocols, conditions of use and publication relating to the data.

### 3. ENTITLEMENT OF CONSORTIUM MEMBERS

The members of the SA NT Data Linkage Consortium directly contribute annual funding to SA NT DataLink's Client Service and Linkage functions. This funding is in addition to the funding from the Australian Government's NCRIS to develop the Population Health Research Network.

Under Schedule 2 of the SA NT Data Linkage Consortium Agreement, Consortium Members are entitled to 'linkage credits'.

#### 3.1 Linkage Credits

Linkage Credits are available to Consortium members to offset the cost of SA NT DataLink Services for data linkage research projects they may sponsor.

Linkage credits are available to members for the term of this Consortium Agreement (unless otherwise agreed by the Steering Committee) to offset the cost of accessing SA NT DataLink services. They are not redeemable for cash.

Once a Consortium member's credits are used, the full cost for services based on SA NT DataLink's pricing policy will be charged, less the Member's discount on the Infrastructure Services fee.

To assist organisations making decisions about allocating linkage credits for each project, a preliminary inquiry should be made by the Researcher to SA NT DataLink to seek an indicative cost and an indication of the technical feasibility of the project. The Researcher should provide this and any other information required by the organisation when applying for linkage credits from that body. SA NT DataLink will also provide a copy of this assessment to the person authorised to approve the assigning of linkage credits in their organisation.

This indicative cost will assist member organisations determine the value of linkage credits per project, in the context of its overall cost and any other priorities or criteria the organisation may have. It will also assist Researchers assessing the probable cost of their project. The indicative cost is based on an estimate of the number of individuals and datasets that are required to be linked, based on the information provided to SA NT DataLink by the Researcher. Should there be a subsequent change in number of datasets or total individuals being linked, then the indicative cost is likely to vary from the formal quote from SA NT DataLink.

Researchers should ensure that the member organisation will agree to make linkage credits available for their particular project before SA NT DataLink provides the formal quote that includes the use of an organisation's linkage credits.

Subject to the principles below, the total value of the linkage credits and how they are to be applied is a matter of agreement between the Researcher and the person authorised for approving the assignment of linkage credits within the member organisation.

#### 1. *Authorisation of linkage credits*

- 1.1. Each member organisation must nominate to SA NT DataLink, a person authorised to approve the assigning of linkage credits for a research project sponsored by their organisation.
- 1.2. SA NT DataLink will only consider applications for linkage credits in its formal quotation where it has received written (email) authorisation from the member organisation as to the value of the linkage credits to be assigned for that project.
- 1.3. The authorisation should include any stipulations about what part of the payment schedule the credits are to apply.

## 2. Application and value of linkage credits

- 2.1. 50% of member's annual cash contributions can be used as linkage credits.
- 2.2. Member organisation sponsored linkage research may use linkage credits for up to 100% of the quoted linkage cost.
- 2.3. The value of one linkage credit is equal to the value of one dollar (AU).
- 2.4. Linkage credits are deducted in a manner consistent with SA NT DataLink's pricing policy and in accordance with the payment schedule forming part of the quoted linkage cost.
- 2.5. Linkage credits are applied against the member organisation's balance once written acceptance of the quoted linkage cost is received by SA NT DataLink, and the member organisation's authorised person has been advised by SA NT DataLink of its acceptance.
- 2.6. Member organisation sponsored studies will attract the 50% members discount for the *Infrastructure fee* component only.
- 2.7. Linkage credits cannot be used to cover Data Custodian extraction fees.

## 3. Use and validity of linkage credits

- 3.1. Two or more member organisations may pool linkage credits to fund collaborative linkage research studies. It is up to the organisations to determine the value of the linkage credits to be apportioned to each party and advise SA NT DataLink.
- 3.2. Linkage credits are valid from the 1<sup>st</sup> of January for a period of 12 months. Linkage credits are non-accruing unless otherwise agreed to by the Steering Committee.
- 3.3. Once deducted, linkage credits will not be re-accredited to another project unless agreed to by the Steering Committee.

## 4. SCHEDULE OF PAYMENTS AND DEDUCTION OF LINKAGE CREDITS

Generally payments are due at three key stages in the development of the project. The Schedule of Payments (described below) may be subject to negotiation between SA NT DataLink and the Researcher. Linkage credits can be applied against any stage of the payment schedule as authorised by the member organisation.

- (1) The payment for the *Project Establishment and Coordination Fee* is due within 30 days after the date on which the Data Custodian(s) give their in-principle approval. Note: this payment is a fixed amount to be paid irrespective of the project's final approval from the Data Custodian(s).
- (2) A second payment of 50% of the balance of the quote is due within 30 days after the date on which the project receives final approval of the Data Custodian(s).
- (3) The final payment is due within 30 days of the provision of the final invoice, to be sent after SA NT DataLink provides the Researcher the Statistical Linkage 'Researcher Handover Report'.

## 5. SA NT DATALINK PRICING PRINCIPLES

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

- SA NT DataLink pricing for research projects provides for partial cost recovery to offset operating its costs.

- Charges for research projects will be in accordance with the *PHRN Pricing and Access Policy*, the *SA NT DataLink Access and Pricing Policy* and the schedule of charges as agreed to by the Steering Committee.
- Any amendments or extensions to an approved project where a further HREC is required and for which a formal quote has been previously accepted by an organisation, the amended or extended project may be subject to additional charges or a new quote at the discretion of the Director, SA NT DataLink\*.
- The schedule of charges will be reviewed annually and approved by the Steering Committee.
- The Steering Committee reserves the right to vary access to SA NT DataLink services and the schedule of charges.
- SA NT DataLink may vary the schedule of payments according to the type of service offered and the level of complexity of the project.

\* In determining the prices in the quote, the Director SA NT DataLink will be guided by the number of additional data sets and probable individuals, and the overall work required by SA NT DataLink to establish the amended or extended project and the extraction of the data. The Director may also require that a new application be submitted to SA NT DataLink.

## 6. COST OF LINKAGE PROJECTS

Consistent with SA NT DataLink's principle of partial cost recovery, the cost of a project will vary with the type of service, and the size and complexity of the services required.

**Note:** in some instances the Data Custodian may charge a fee independently of SA NT DataLink. This fee may be included in the final invoice and may be paid directly to SA NT DataLink, or invoiced directly by Data Custodian Organisations.

### 6.1 Types of services

#### *Client Services*

- Pre-project planning and assessment of Expression of Interest, engagement, advice on applications and ongoing liaison with Researchers, Data Custodians and the providers of data.
- Advisory service on data management and metadata practices.
- Co-ordination and follow-up of Statistical Linkage Project outcomes.

#### *Data linkage*

Generally there are four types of data linkage projects, each with varying amounts of work and levels of complexity.

- Linkage of data within SA NT DataLink Master Linkage File (MLF)
- Linking of MLF data to Ad hoc data (Ad hoc datasets are those not within the MLF)
- Ad hoc to Ad hoc Linkage (that is, linking of non MLF data)
- Provision of project specific data linkage keys to Data Custodians enabling the provision of the de-identified data to Researchers.

#### *Project Specific Data Support*

- Statistical Analysis and Analytical services, Data Management and Data Cleaning support (generally provided on a fee for service hourly charge).

#### *Data custodian extraction support*

- Assistance for Data Custodians and data providers with their data extraction and linking of project linkage keys.

#### *Other data analysis and statistical services*

- Statistical analysis and data de-duplication and cleansing services.

## GLOSSARY

**NCRIS** - National Collaborative Research Infrastructure Strategy.

**NCRIS PHRN funding** - project resources outlined in the NCRIS Project Plan which include the NCRIS cash investment, co-investments and in-kind contributions.

**PHRN** - Population Health Research Network.

**PHRN Funding Agreement** – the funding Agreement between the Commonwealth of Australia and the University of Western Australia regarding funding for Implementing an Investment Plan for the National Collaborative Research Infrastructure Strategy’s Research Capability known as Population Health Research Network, originally executed 12 March 2009.

**Researcher** - the Chief or Principal Investigator, a Researcher, Investigator or Analyst

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

**SA NT DataLink** - the operational unit established in 2009 under the governance of the SA NT Data Linkage Consortium Agreement, originally executed 9 May 2009.

**SA NT Data Linkage Consortium Agreement** – signed by the Consortium Members on 9 May 2009, and subsequently extended with Deeds of Variation.

**Schedule of charges** – the prices approved by the Steering Committee annually for the services offered by SA NT DataLink.

**Steering Committee** – the SA NT Data Linkage Consortium Steering Committee is responsible for approving the SA NT DataLink Business Plan, Annual Work Plan, Budget and Finance reports, and SA NT DataLink’s policies and procedure. It is chaired by a SA Minister for Health nominated representative, with representation from each organisation member of the SA NT Data Linkage Consortium Agreement.

**Statistical Linkage ‘Researcher Handover’ Report** - the Report provided by SA NT DataLink to a Researcher detailing the basis of SA NT DataLink’s methods and results for the data linkage sought by the Researcher.