



SACOSS Representative: David Scrimgeour

SA NT DataLink is the operational body of the SA NT Data Linkage Consortium, which is a joint venture entered into by a number of South Australian agencies and ministries, and the Northern Territory Government including:

- The Minister for Health (SA)
- The Minister for Education (SA)
- The Minister for Early Childhood Development (SA)
- The Minister for Families and Communities (SA)
- The Minister for Ageing (SA)
- The Cancer Council of SA
- Flinders University of SA
- Northern Territory of Australia
- The University of South Australia
- The Minister for Mental Health and Substance Abuse (SA)
- The Minister for Aboriginal Affairs and Reconciliation (SA)
- The Minister for Housing (SA)
- The Minister for Disability (SA)
- Motor Accident Commission (SA)
- The University of Adelaide

The main aim of SA NT DataLink is to provide project specific linkage keys across a number of prime databases to enable statistical linkage projects to be undertaken by researchers. Two main demonstration projects are under development dealing with colorectal cancer and early childhood development.

SA NT DataLink has recently up accommodation in its purpose built secure environment located at Level 4, Reid Building in Frome Road, Adelaide, and Prof. Robyn McDermott has been appointed as Director.

A Steering Committee comprised of a representative from each of the Consortium partners, and a non-voting member from SACOSS as a major community body, has been established. The Steering Committee is responsible for the strategic management of SA NT DataLink, and meets monthly.

While this venture should increase opportunities to provide useful data on issues concerning disadvantaged South Australians and Northern Territorians, there are also significant ethical and privacy concerns. By being represented on the Steering Committee, SACOSS has the opportunity to ensure that these concerns are addressed.

will continue in its development and establishment. Protocols and approval processes will be refined and, documentation finalised. The Master Linkage File will be developed and added to as appropriate approvals and access is obtained for new datasets. 2009 – 2010 will be the year in which SA NT DataLink becomes operational.

SA NT DataLink will take up accommodation in its purpose built secure environment located at Level 4, Reid Building in Frome Road, Adelaide around July 2009.

With a new Director employed, staffing will be ramped up anticipating achievement of full staffing levels prior to the end of the financial year.

Two demonstration projects, one dealing with colo-rectal cancer and the other with early childhood development will be further developed, providing priority around the datasets to be added to the Master Linkage File. It is anticipated that project specific linkage keys will be provided to enable investigation of some of the research questions related to these projects. The continued development of these and other projects will enable SA NT DataLink to provide project specific linkage keys to allow research in the areas of:

- early childhood development;
- healthy ageing and chronic disease management;
- Indigenous health and wellbeing; and
- injury.

These are all areas of study proposed in the SA NT Data Linkage Consortium's submission for PHRN funding.

Key risks that have been identified relate to:

- access to data including NT data;
- inability to provide a timely technical solution to data linkage;
- privacy concerns and public awareness; and
- ongoing funding.

Throughout this Plan reference is made to “statistical linkage projects”. These are projects undertaken that use project specific linkage keys provided by SA NT DataLink and include projects with appropriate ethics approvals that have a research, evaluation, monitoring or quality assurance focus.

1 Status of Project

During 2009 – 2010 it is anticipated that SA NT DataLink will commence a number actions with corresponding indicators of achievement:

Action	Indicator of achievement
Documentation refined	Security protocols and documentation completed. Data Linkage Unit, Researcher and Data Custodian Data Linkage Manuals completed. Website developed. Other documentation developed as required.
Linkage, security and administrative systems developed	Linkage, security and administrative systems developed. Appropriate business plans produced.
SA NT DataLink housed in secure accommodation	Stage 1 of Level 4 of the Reid Building occupied. Stage 2 of that development completed and occupied.
Staffing.	Director appointed either late 2008 – 2009 or early 2009 – 2010. Other staffing to take place. Full head count achieved – see 7 below.
Demonstration Projects	Colo-rectal and Early Childhood Development projects developed. Appropriate datasets added to the Master Linkage File. Project specific linkage keys provided for associated statistical linkage/research projects.
Master Linkage File	Access to appropriate datasets to add to the Master Linkage File actively pursued. Master Linkage File developed and added to as new datasets become available.
Capacity Building – increasing the capacity of agencies to provide appropriate data for the Master Linkage File and statistical linkage projects	Employ appropriate staff. Continue to develop innovative and effective ways of improving Data Custodians capacity. This could include the use of consultancies and ABS outposts as in 2008 – 2009.
Communication and community involvement	Refine communication strategies. Develop the web site. Investigate methods of community involvement, at both Consortium and statistical linkage project



Action	Indicator of achievement
	level.
Research	Provide expert advice on the use of linked data and associated research methodologies.

In summary, 2009 – 2010 will be concentrated on the establishment and operationalisation of SA NT DataLink with its associated governance, protocols, processes, technical development and staffing.

Direction for inclusion of initial datasets will be provided largely by the demonstration projects.

2 Research Infrastructure

The main aim of SA NT DataLink is to provide project specific linkage keys across a number of prime databases to enable statistical linkage projects to be undertaken by researchers.

Two main demonstration or proof of concept projects are under development dealing with colo-rectal cancer and early childhood development. In developing these projects, models for future research are being developed with an emphasis on not only research but also communication and meeting State and Territory directions and needs.

The research questions arising from the demonstration projects will prioritise the datasets being added to the Master Linkage File.

The broad nature of the demonstration projects means that research priorities dealing with early childhood development, Indigenous health and wellbeing, healthy ageing and chronic disease management, and injury and trauma, identified in the NCRIS PHRN submission can be met.

Research and Analysis is one of the units in the SA NT DataLink structure, with staff members in that unit being experts in the use of linked datasets for the purposes of research. It is envisaged that members of the Unit will become expert in the datasets included in the Master Linkage File and provide a mentoring, guidance role around analysis and presentation of linked data. These officers will come on-line during 2009 – 2010 when data become available.

3 Governance

3.1 Governance

SA NT DataLink is established under the SA NT Data Linkage Consortium Agreement a joint venture entered into by a number of South Australian agencies and ministries, and the Northern Territory Government including:

- The Minister for Health (SA)
- The Minister for Education (SA)
- The Minister for Early Childhood Development (SA)
- The Minister for Families and Communities (SA)
- The Minister for Ageing (SA)
- The Cancer Council of SA
- Flinders University of SA
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- The University of South Australia
- The Minister for Mental Health and Substance Abuse (SA)
- The Minister for Aboriginal Affairs and Reconciliation (SA)
- The Minister for Housing (SA)
- The Minister for Disability (SA)
- Motor Accident Commission (SA)
- The University of Adelaide

The SA NT Data Linkage Consortium provides the base funding for the Project.

A Steering Committee comprised of a representative from each of the Consortium partners and a non-voting member from a major community body (SA Council Of Social Service (SACOSS)). The Steering Committee is responsible for the strategic management of SA NT DataLink.