



**What is SA/NT DataLink and how can it
advance policy-relevant population
health research?**

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HDA Seminar, 14 September 2010

Overview

South Australian and Northern Territory Data Linkage Consortium

- Linkage - what is it?
- Linkage – why do it - potential benefits?
- SA NT DataLink: who is involved & how
- Approval processes
- SA NT DataLink – how are records linked?
- SA NT DataLink - progress to date

What is data linkage?

Bringing together or linkage of records of an individual, household, business unit or other entity from either within or across a number of datasets.

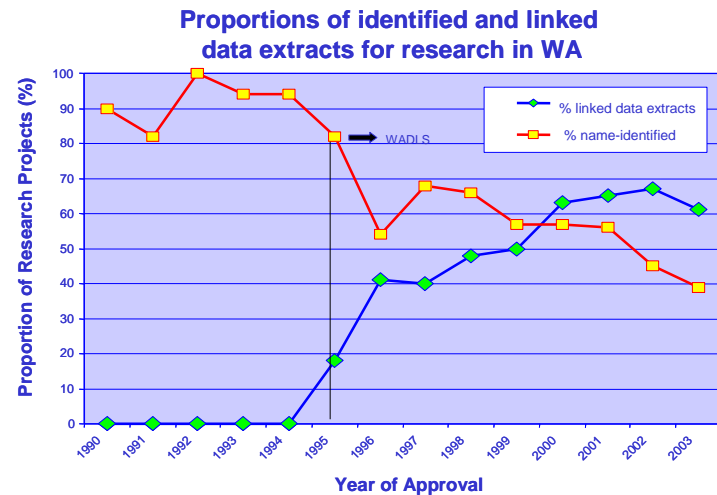
Probabilistic matching: Records are compared and if a number of variables from each record are deemed to be the same then those records are considered to belong to the same person or entity.

Purpose

De-identified, linked data will enable researchers, analysts, evaluators and policy makers to better understand the impact of decision making and the complex interrelations between social, environmental, economic and health factors that impact on individual and community wellbeing.

Benefits

- Compilation of new statistical outputs through effective use of existing data sources
- Reduced use of identified data
- Reduced bias in data
- Work with populations rather than samples
- Reduced respondent burden and costs
- Longitudinal studies become feasible at small marginal cost





**Government
of South Australia**

Department for Families
and Communities



**Government
of South Australia**

SA Health



**Northern
Territory
Government**



**Government
of South Australia**

Department of Education
and Children's Services



SA·NT



DataLink



**The
Cancer
Council**
South Australia



**THE UNIVERSITY
OF ADELAIDE**
AUSTRALIA



UniSA



Flinders
UNIVERSITY

SA·NT



DataLink

Consortium

- Joint Venture Agreement as governance
- SA Health lead Government agency
- UniSA auspicing or host body
- Steering Committee to provide strategic direction
- Director and Executive Committee to provide day to day management and operational direction

Funding and support

- Consortium
 - 9 Parties
 - \$675,000 per year for 4 years
- Consortium and other government agencies
 - estimated \$1.4 million per year in-kind support
- NCRIS – PHRN \$2.6 million over 3 years
 - Early childhood
 - Healthy ageing and chronic disease management
 - Indigenous health and wellbeing
 - Injury

What's different about SA's approach?

- Multi sectoral, interagency and cross jurisdictional approach to data linkage – broader than health
- Joint venture with a range of funders outside of Government who have a material interest in the proposal
- The technical data linkage function is undertaken from within government
- Associate members may bring additional benefits eg BD&M, DFEEEST.

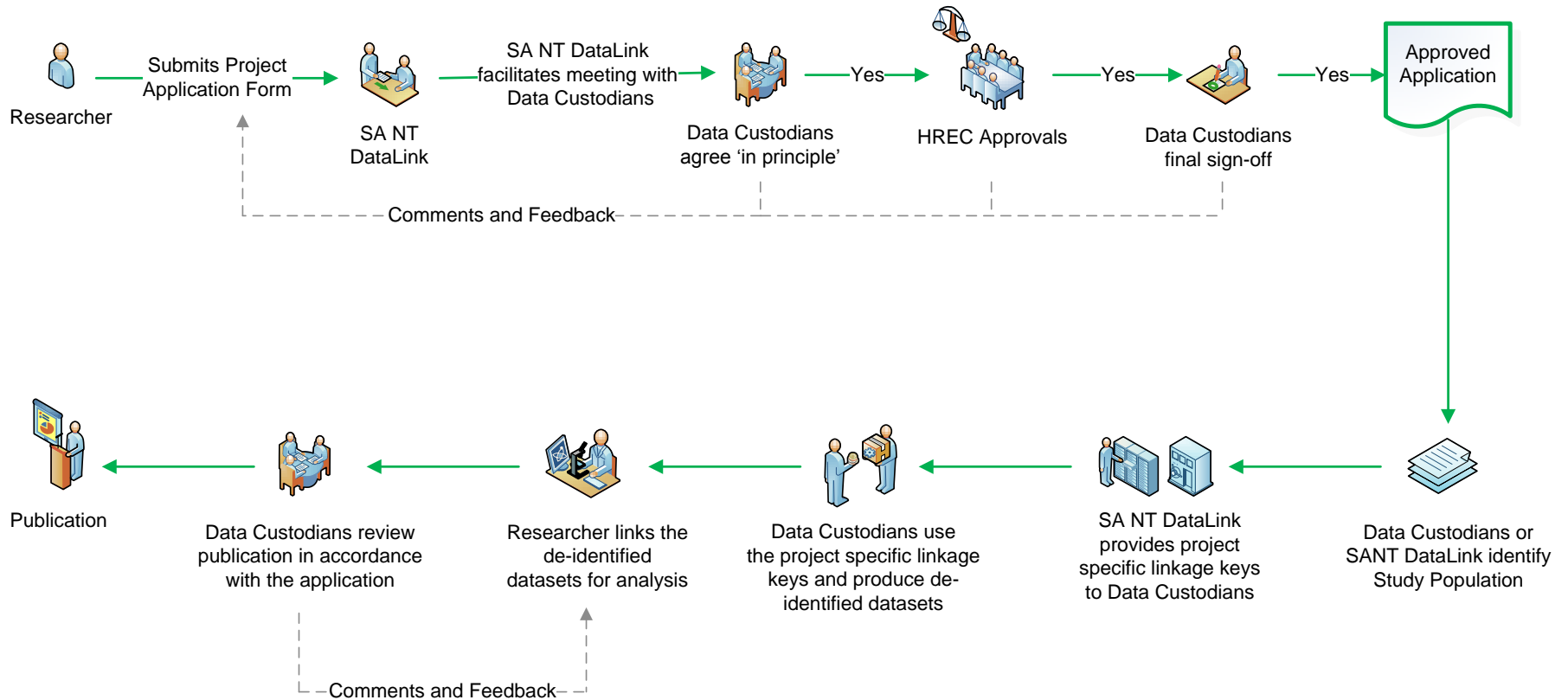
what does SA NT DataLink do?

1. Provides a mechanism for accessing linked data for research, planning and evaluation of health services
2. Under MOUs with custodians and with privacy Committee approval, creates and maintains a Master Linkage File
3. With data custodian and ethical approval, SANTDL creates project specific linkage keys, consisting of 'pointers' to records for specific people in requested data sets

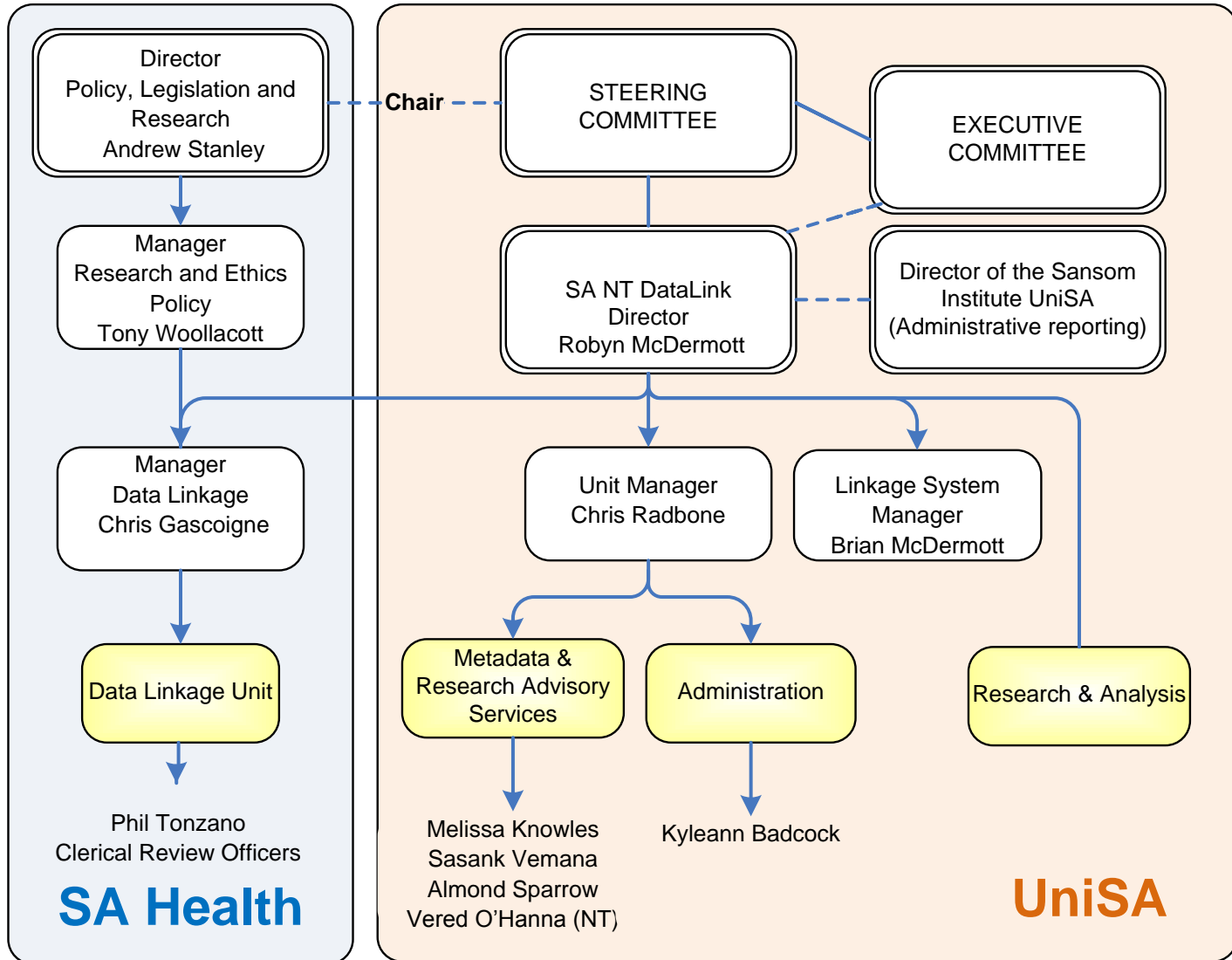
SANDL does not

- track individual patients in the health or community service system
- form part of an electronic health or medical record system
- hold personal information other than that required for the linkage
 - service information stays in the original database
- have a repository of linked health information
- carry out analysis on linked health data
- provide linked data directly to researchers
 - the owners of the data remain responsible for the dissemination and conditions of use of data files

Statistical Linkage Project Application Process



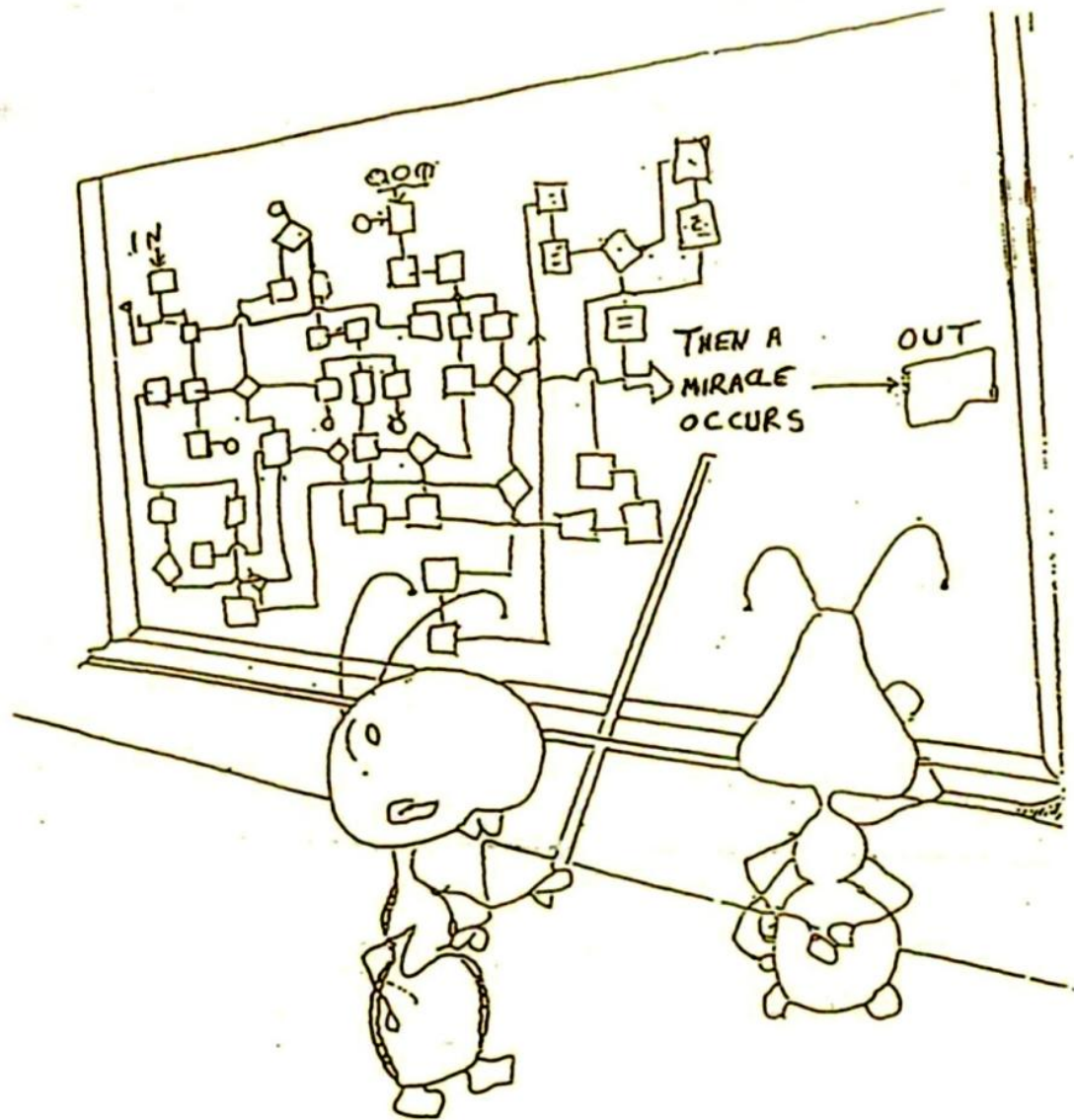
Organisational Structure



Metadata & Research Advisory Services

- Core Responsibilities
 - Data Quality Statements
 - Metadata
 - Support Data Providers
 - Advise Researchers on Statistical Linkage Projects (Application Form – available online at https://www.santdatalink.org.au/application_process)

Record Linkage

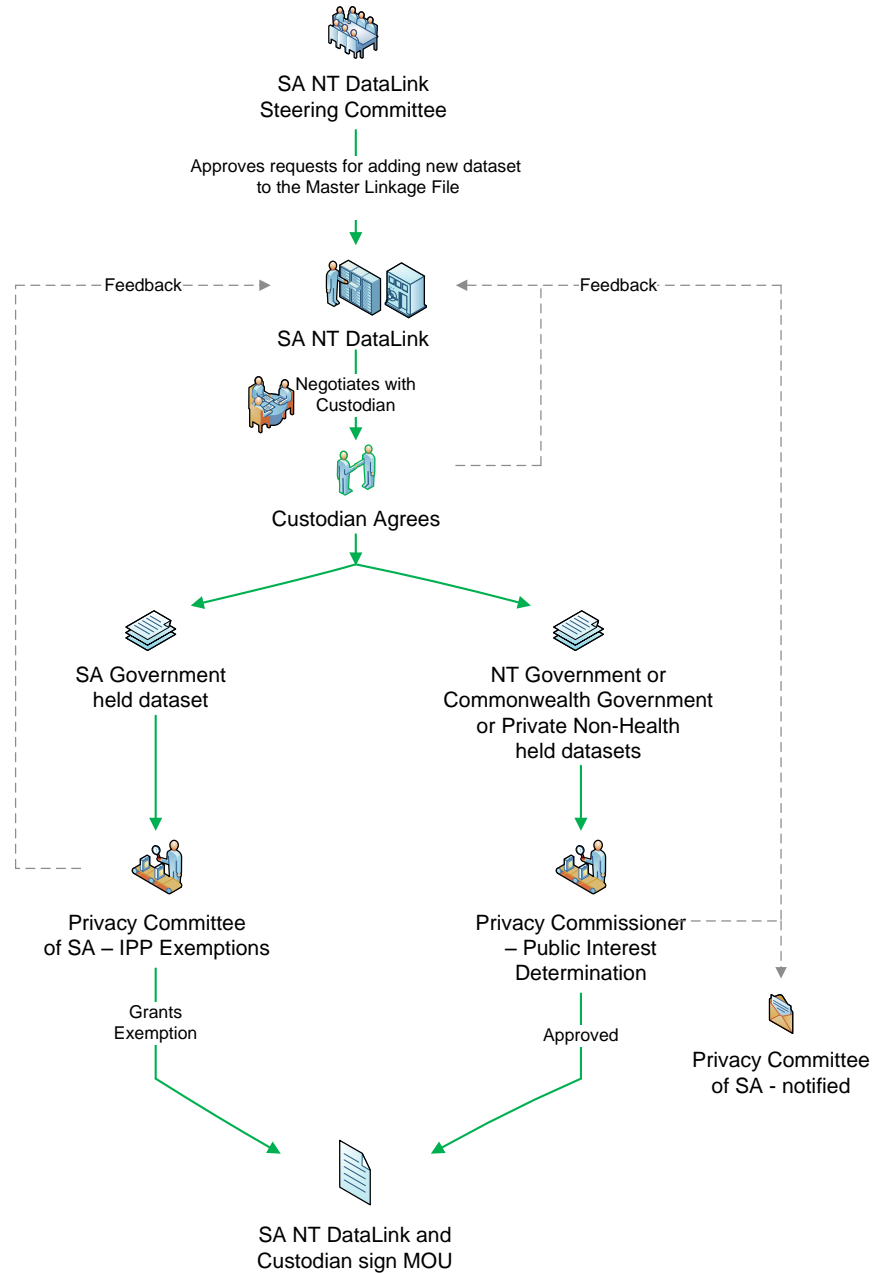


"Good workbut I think we need just a little more detail right here!"

Aim of the Master Linkage File

- link a number of datasets
- manage the links and linkage variables for all of the datasets
- cover as much as the population as possible to maximise the number of links
- provide project specific linkage keys

Adding New Datasets to the Master Linkage File



Summary of security

- Use of WA model
- High levels of physical security (protected level)
- Extensive policy and procedures being developed
- Safe hands delivery of SA data
- Data being delivered is encrypted
- Original data destroyed after successful load to Linkage Management System
- Approval processes agreed
- MOUs and Deeds of Agreement for Custodians
- Confidentiality agreements for staff and researchers

Summary - protection of privacy and confidentiality

- SANTDataLink physical security and protocols
- Privacy Committee SA approval and MOU for datasets to be added to MLF
- Application process and custodian approvals
- Ethics approvals
- Process of separation of data
 - SA NT Data Linkage Unit only has linkage variables
 - Custodian only one with all data
 - Researcher has project-specific de-identified data and project specific linkage keys
- Data Management -

Where are we up to? – September 2010

- SA NT DataLink established and registered in 2009
- Funding obtained – locally and nationally – to end 2012
- Joint Venture Agreement in place
- Auspicing by UniSA, 4th floor Reid Building
- Security audit items identified & audit completed 2010
- Best practices reviewed
- Processes, forms and documentation under development including:
 - MOU, Application Form, Manuals, Security Framework and approval processes
- New website being built santdatalink.org.au
- Staffing complement nearly complete including 1 staff member in Darwin
- Intra and interstate workshops run
- Negotiation underway re access to datasets for 2 Demonstration projects
- Project readiness review (Tom Stubbs) early 2010
- HCA to establish a consumer reference group across SA & the NT, including the non-health sector, on behalf of SANTDL

Data Quality Statements

- DQS required for each Dataset in Master Linkage File
- Based on ABS Data Quality Framework
- Available online at https://www.santdatalink.org.au/available_datasets
- DQS currently available:
 - SA Cancer Registry
 - SA Emergency Department
 - SA Public Hospital Separations

Metadata

- Variable level metadata will be available online (for registered users)
- Questions to be addressed:
 - Which tool to use (METeOR)?
 - How to manage version control (stand alone copy or linked to original)?
 - What if no metadata currently exists?

Questions