

# Population Health Research Network

**Collaboration to establish  
data linkage infrastructure  
across Australia**

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# Outline of presentation

- ❖ Population Health Research Network overview  
*Merran Smith, PHRN Chief Executive*
- ❖ Curtin University Centre for Data Linkage  
*James Semmens, Chair of Population Health Research, CHIRI, Curtin University of Technology*
- ❖ WA Health Proof of Concept collaboration  
*Diana Rosman, Program Manager, WA Data Linkage Branch, WA Department of Health*

# Australia: some context

- ❖ 22 million population incl 2.5% indigenous
- ❖ Federal government plus six state and two territory governments
- ❖ States provide hospital, public health and community health services
- ❖ Federal government funds GPs, community prescribing and aged care
- ❖ Information quality is good



# State health data

- ❖ The main data collections held by Australian states and territories are:
  - Perinatal/births data
  - Hospital morbidity/discharge data
  - Emergency attendances data
  - Cancer registry data
  - Births, deaths and marriages data
  
- ❖ Data collections generally hold decades of identified data for the whole state/ territory population

# Health information over the lifespan

*Birth Records*  
States/Territories

*Hospital Records*  
States/Territories

*Cancer Registries*  
States/Territories

*Death Records*  
States/Territories



**CRADLE**

**GRAVE**

*GP Records*  
Commonwealth

*PBS Records*  
Commonwealth

*Veterans' Affairs/  
Ageing*  
Commonwealth



# Two-stage model

*PHRN uses the two-stage data linkage model that has been successfully used in Australia since 1995. This does not involve a content data repository.*

## Stage 1: Data Linkage

- ❖ Data custodians provide linkers with **demographic** data
- ❖ Linkers use the data to develop a high quality, dynamic, ongoing linkage map

## Stage 2: Data Delivery

- ❖ Linkers use the map to provide project-specific linkage keys to data custodians for approved projects
- ❖ Data custodians supply non identified **content** data to researchers with project-specific linkage keys

# PHRN funding

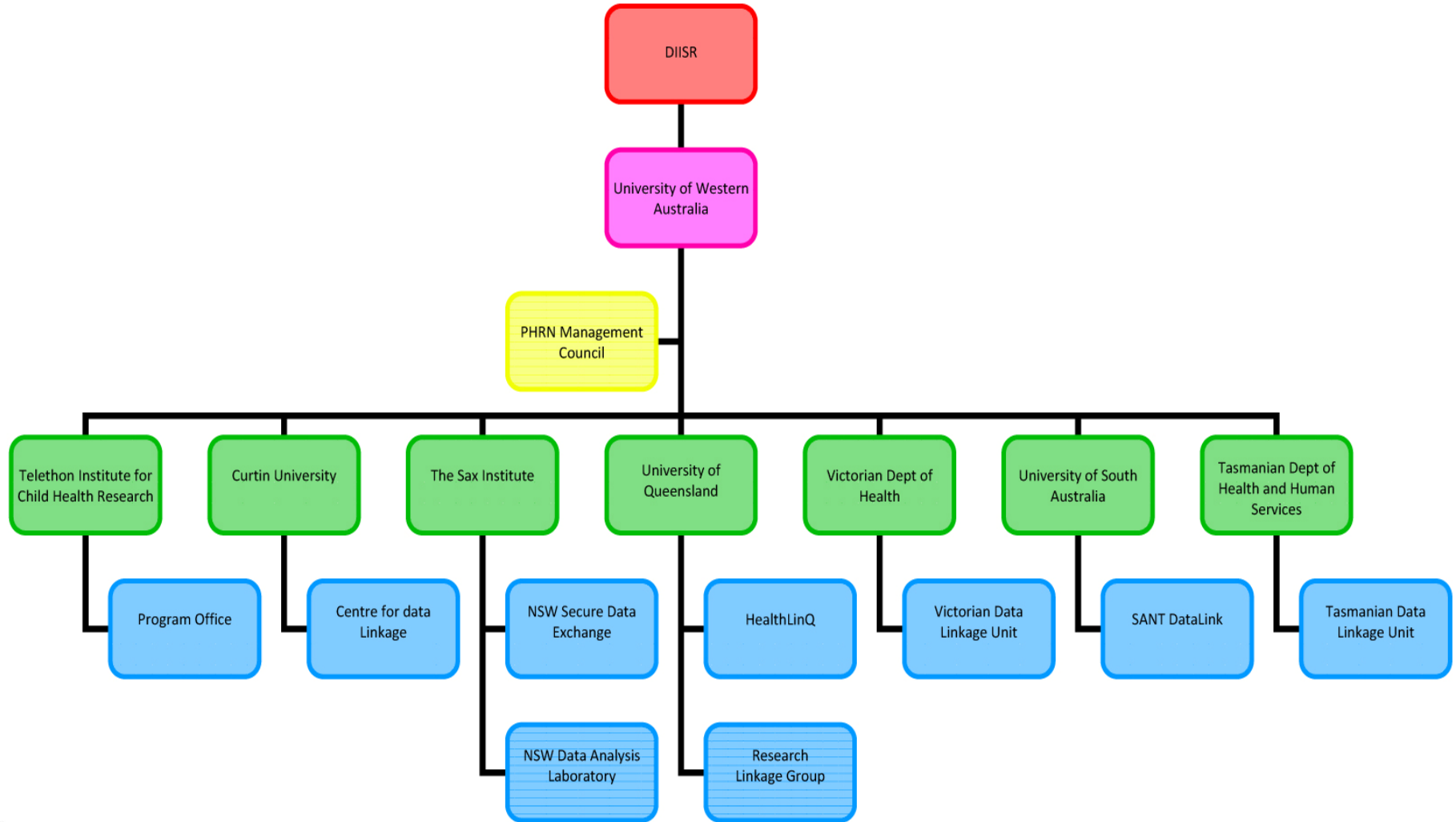
<b>Funding</b>	<b>Source</b>
\$A20m	Australian Government's National Collaborative Research Infrastructure Strategy (NCRIS) program (2008-2011)
\$A10m	Australian Government's Education Investment Fund (2011-2013)
\$A32m	Australian state and territory governments and PHRN academic partners

# PHRN elements

- ❖ **Management Council** with independent chair
- ❖ Six state/territory **linkage units** including the two existing units and four new units (in Queensland, Victoria, Tasmania and South Australia/Northern Territory)
- ❖ Cross-jurisdictional **linkage centre** (Centre for Data Linkage at Curtin University)
- ❖ Program Office in Perth providing **coordination** and client services



# PHRN structure



# PHRN timeline

2006	<ul style="list-style-type: none"><li>• Recognition of need to invest in national health data linkage infrastructure</li></ul>
2007	<ul style="list-style-type: none"><li>• Facilitated consultation and development of investment plan</li></ul>
2008	<ul style="list-style-type: none"><li>• Investment Plan approved by NCRIS</li></ul>
2009	<ul style="list-style-type: none"><li>• Funding Agreement signed</li><li>• First meeting of PHRN Management Council</li><li>• Key staff in place in all nodes</li><li>• First Proof of Concept collaboration in progress</li></ul>



# PHRN priorities

Current priorities for the Network include:

- ❖ Establishing linkage units in Queensland, Victoria and Tasmania
- ❖ Progressing linkages for Proof of Concept collaboration
- ❖ Developing a communications strategy (with possible name change)

# PHRN

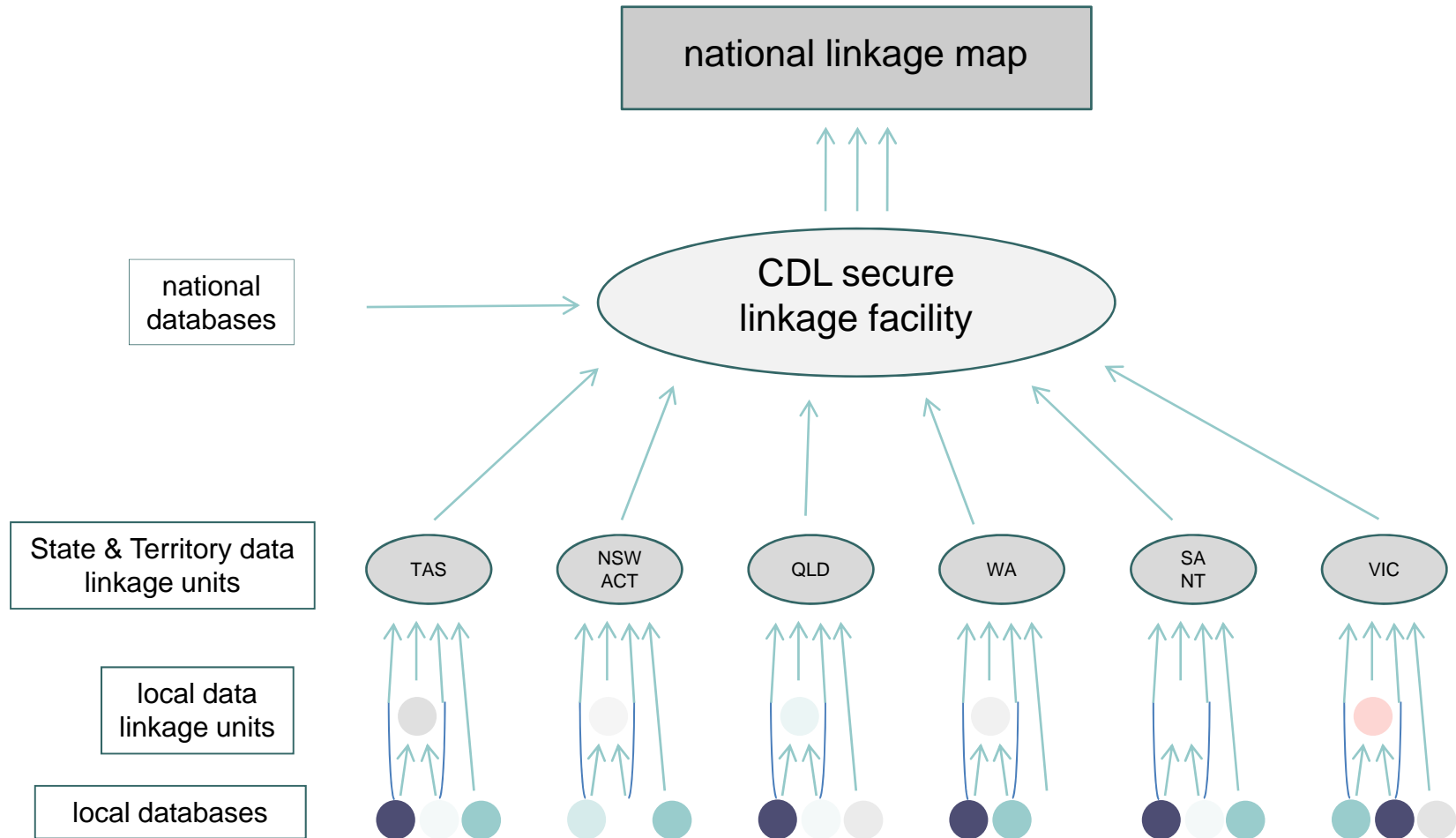
# Centre for Data Linkage



# Centre for Data Linkage

- ❖ Located in CHIRI at Curtin University
- ❖ Budget of \$3.5 million
  - additional in-kind support from Curtin
- ❖ Nine members of staff (as project progresses)
  - includes Linkage, IT and Research Staff

# Linkage across Australian States and Territories



# Centre for Data Linkage – Current focus

Phased implementation of linkage across states and territories:

- Environmental scan of linkage initiatives
- Linkage software testing and development
- Proof of concept collaboration project
- Production data linkage facility

# Centre for Data Linkage – Recent work

- ❖ CDL Operational Model
  - Data flows and data structures
  - Aggregation of linkages into a national map
- ❖ Infrastructure
  - Physical and IT
  - Security Plan and Operational Policies
- ❖ Governance
  - Access Policy
  - Data Ownership (consultation)

# PHRN

# Proof of Concept



# Possible POC topics

- ❖ In hospital and post discharge mortality: **WA, NSW, Qld**
- ❖ Immunisation efficacy: **SA, Vic, NSW**
- ❖ Environmental mobility and chronic disease: **WA, SA/NT, Qld**
- ❖ Surgery and blood products: **WA, NSW, Qld**
- ❖ Life expectancy of mental health clients: **WA, Qld**
- ❖ Cancer staging and treatment: **WA, SA, Vic**

# Collaborative process

## Management Council:

- ❖ agree and endorse selection criteria
- ❖ provide nominations for a Reference Group

## Reference Group:

- ❖ scope and cost up to three candidate projects
- ❖ liaise with PHRN elements (PO, CDL, SDE and nodes)
- ❖ liaise with one or more national sponsors
- ❖ submit proposal to MC for endorsement

# PoC selection criteria

- ✓ Focus on an issue of national importance
- ✓ Ability to demonstrate linkage of data between PHRN nodes
- ✓ Ability to provide research datasets combining data from PHRN nodes
- ✓ Demonstrated ability to deliver research outputs based on “linked” datasets
- ✓ Ability to complete the project on time and on budget



# 1<sup>st</sup> PoC: Hospital-related mortality

- ❖ CDL to undertake linkage of demographic data from **WA, NSW, Qld**
- ❖ Provide linkable research datasets to dedicated PoC Analyst
- ❖ Complete the project on time (2 years) and on budget (\$A452,000)
- ❖ Deliver research outputs for publication



# Progress with 1<sup>st</sup> PoC

- ✓ Experienced data analyst appointed (Aug 2009)
- ✓ Research plan and data protocols submitted (Oct 2009)
- ✓ WA Department of Health ethics approval (Dec 2009)
- ✓ Curtin University ethics approval (Feb 2010)
- ✓ QLD ethics application submitted (Feb 2010)
- ✓ NSW ethics application in preparation (Jan 2010)

# Further information:

[www.phrn.org.au](http://www.phrn.org.au)

# or contact us directly:

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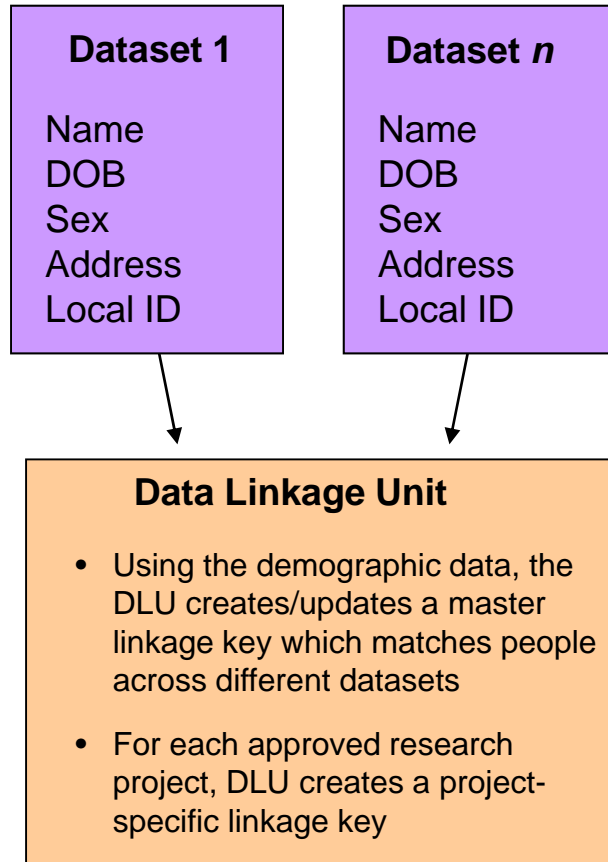




# Stage 1

## Stage 1: Creation of linkage keys by the Data Linkage Unit (DLU)

### Data custodians



- State/territory data custodians provide **demographic** data and a Local ID to DLU
- Linkers in DLU use demographic data to update linkage map
- Linkers create project-specific linkage keys for each approved project
- Content data remains with data custodians.

# Stage 2

## Stage 2: Extraction/merging of content data for approved data linkage projects

