

# **Data linkage – building the national infrastructure in Australia**

**Dr Merran Smith  
Department of Health Western Australia**

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# Overview

- ❖ **Australia and its health system**
- ❖ **Health information in Australia**
- ❖ **Data linkage in Australia**
- ❖ **Population Health Research Network (PHeRN)**



# Australia

- ❖ **Australia is a federation**
- ❖ **Australian government in Canberra**
- ❖ **Six states and two territories**
- ❖ **Population over 21.5 million**
- ❖ **2.5% of population are Indigenous**





**Western  
Australia**

**Northern  
Territory**

**Queensland**

**South  
Australia**

**New  
South Wales**

**Victoria**

**Tasmania**

# Australian health system

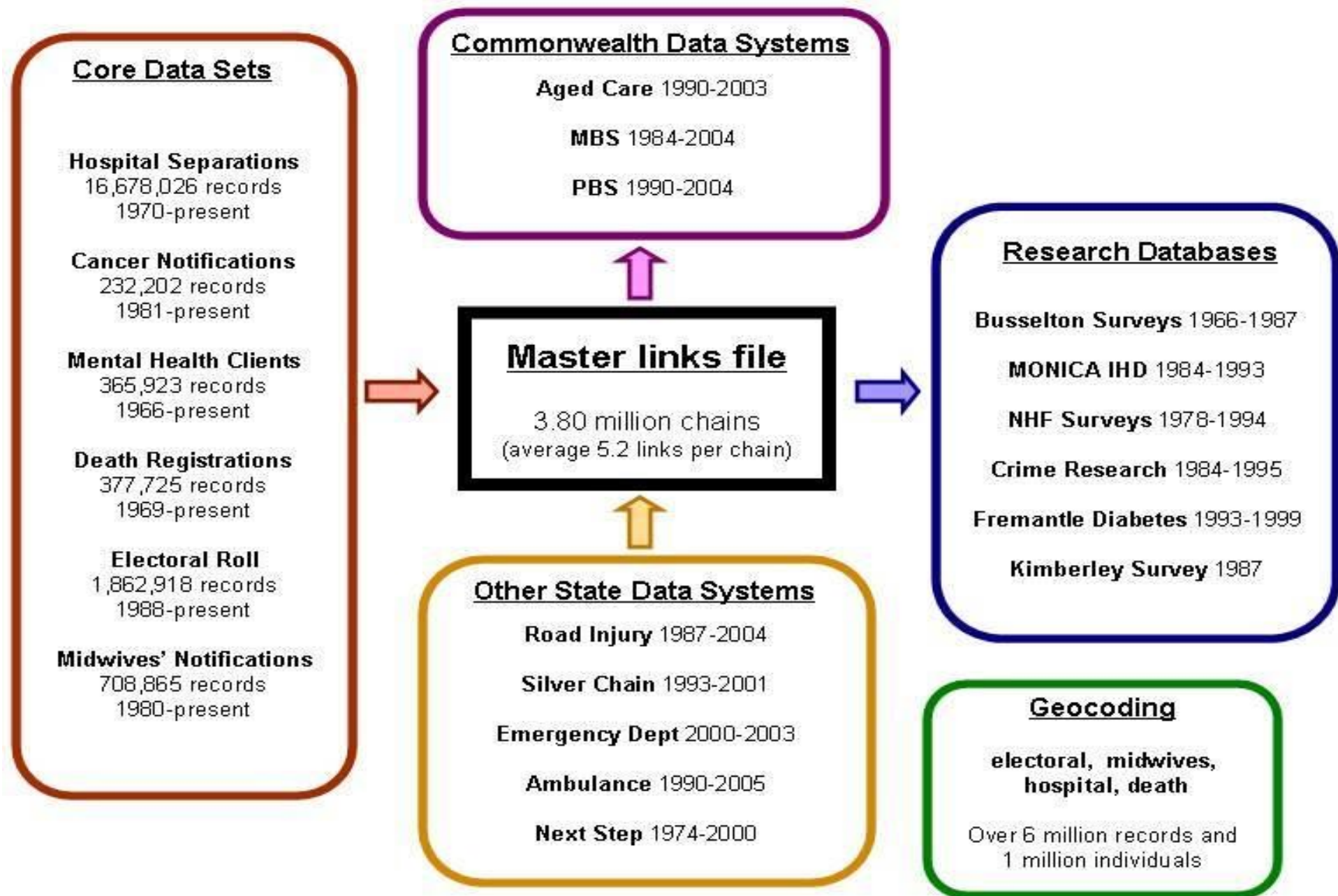
- ❖ **Australian Government (43%)**
  - funds primary care and aged care
  - funds/subsidises pharmaceuticals and hospital care
- ❖ **States/territories (25%)**
  - fund/provide public health, community health and public hospital care
- ❖ **Private and non-government (32%)**
  - fund/provide primary care and private hospital care
  - includes out of pocket payments

# Health information in Australia

- ❖ **Australia has good state and national health information**
- ❖ **Governments collect patient level information on the services they fund/provide**
- ❖ **The National Health Information Agreement requires standardised data to be collected/shared**
- ❖ **The National Health Data Dictionary specifies data standards**

# Data linkage in Australia

- ❖ **Australia has considerable data linkage experience**
- ❖ **Western Australia started statewide health data linkage in 1994**
- ❖ **New South Wales implemented a similar capability in 2006**
- ❖ **Data linkage in other states and territories has started**



**Core Data Sets**

**Hospital Separations**

16,678,026 records  
1970-present

**Cancer Notifications**

232,202 records  
1981-present

**Mental Health Clients**

365,923 records  
1966-present

**Death Registrations**

377,725 records  
1969-present

**Electoral Roll**

1,862,918 records  
1988-present

**Midwives' Notifications**

708,865 records  
1980-present

**Commonwealth Data Systems**

**Aged Care** 1990-2003

**MBS** 1984-2004

**PBS** 1990-2004

**Master links file**

3.80 million chains  
(average 5.2 links per chain)

**Other State Data Systems**

**Road Injury** 1987-2004

**Silver Chain** 1993-2001

**Emergency Dept** 2000-2003

**Ambulance** 1990-2005

**Next Step** 1974-2000

**Research Databases**

**Busselton Surveys** 1966-1987

**MONICA IHD** 1984-1993

**NHF Surveys** 1978-1994

**Crime Research** 1984-1995

**Fremantle Diabetes** 1993-1999

**Kimberley Survey** 1987

**Geocoding**

**electoral, midwives,  
hospital, death**

Over 6 million records and  
1 million individuals

**WA DATA LINKAGE SYSTEM**

August 2008

# Population Health Research Network (PHeRN)

- 2006** Funding of \$A 20m through the National Collaborative Research Infrastructure Strategy for population health data linkage
- 2007** Investment Plan for PHeRN
- 2008** Funding Agreement
- 2009** Building the infrastructure

# PHeRN vision

Improved population health  
through seamless supply of linked  
de-identified data for approved  
research



# PHeRN focus

- ❖ **Current focus on state and territory datasets**
- ❖ **Commonwealth datasets could be considered in future**
- ❖ **Mainly health but also human services data**



# PHeRN elements

- ❖ **Total budget of \$A 51.4m over three years including \$A 31.4m from states and territories**
- ❖ **Management Council**
- ❖ **Program Office**
- ❖ **Six state-based nodes**
- ❖ **Network Linkage Centre**



A photograph of the red sandstone monolith Uluru (Ayers Rock) in the Northern Territory of Australia, set against a clear blue sky.



# PHeRN priorities

- ❖ **Governance processes**
  - access policies
  - privacy, ethics and consumer engagement
- ❖ **Establishing nodes**
- ❖ **Cross-node linkage**
- ❖ **Data supply system**
- ❖ **Proof of Concept collaboration(s)**



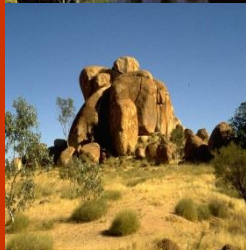
# Privacy preserving protocols

- ❖ Data custodians provide demographic data from each record to linkers
- ❖ Linkage based on demographic data
- ❖ Linkers supply project-specific keys to custodians
- ❖ Custodians supply de-identified linkable data to researchers



# Data linkage preserves privacy



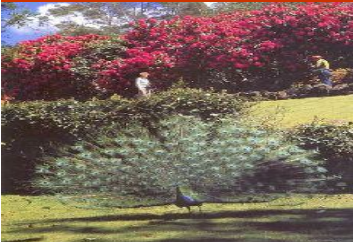


# Data access processes

- ❖ **Application specifying data**  
(year; dataset; data items)
- ❖ **HREC approval**
- ❖ **Analyst undertakings**
- ❖ **Data release**
- ❖ **Project completion processes**

# PHeRN benefits

- ❖ Expanded linked data resources
- ❖ Large de-identified datasets
- ❖ Cost-effective research
- ❖ Improved evidence-based care
- ❖ Opportunities for international collaboration



# Summary

- ❖ **Australia has good state and national health information**
- ❖ **PHeRN will deliver a major expansion in linked health and human services data resources**
- ❖ **New opportunities for research and collaboration**

