Leading national data linkage development: Innovation and opportunities

Dr Merran Smith, Chief Executive, PHRN
HITWA, Perth, 7 November 2014
Overview

- Health data and data linkage
- Leadership and Innovation
- Challenges and Opportunities
Australia has good health data

This reflects national efforts over many years eg NHIA; NHDD

Reflects efforts by HIMs at all levels across the country
Population data

- Cwlth, state and territory governments hold population-level health data
- Covers most health services incl primary care, prescribing, hospital, aged care
- Also covers public, private and not-for-profit sectors
Health data collection

- **Birth Records**
  - States/Territories

- **Hospital Records**
  - States/Territories

- **Cancer Registries**
  - States/Territories

- **Death Records**
  - States/Territories

**CRADLE**
- GP Records
  - C’wlth

**Hospital Records**
- PBS Records
  - C’wlth

**Cancer Registries**
- Veterans’ Affairs/
  - Ageing
  - C’wlth

**Death Records**
- GRAVE
Data linkage

- Data is fully identified ie name, address, DOB
- These variables are used to link data from a person, within and between data collections
- Linkage is done in designated data linkage units (DLUs) using a two-stage privacy preserving method
Basic linkage model

**Key**
- Demo. data: Demographic data
- RecIDs: Record ID numbers
- PSLKs: Project-specific linkage keys
Data linkage timelines

1995  Systematic population-based health data linkage began in WA

2006  WA helped NSW/ACT set up linkage

2009  PHRN funded to expand data linkage

2014  DLUs operating for each jurisdiction and for cross-jurisdiction linkage
PHRN investment

- PHRN funding from successive Commonwealth programs plus cash and in-kind

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<tr>
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<th>Total ($M)</th>
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<tbody>
<tr>
<td>Australian Government Cash</td>
<td>$33.1</td>
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<tr>
<td>Co-investment Cash</td>
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<tr>
<td>In-kind</td>
<td>$31.6</td>
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<tr>
<td><strong>Total Investment (NCRIS, SSI, CRIS)</strong></td>
<td><strong>$76.7</strong></td>
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Facilities to link and provide access to linked data within and between jurisdictions
Leadership and Innovation
Leadership and innovation: key drivers of success
Leadership

The key to successful leadership is influence, not authority.

Kenneth Blanchard
Network leadership

- UWA is lead agent for PHRN
- Governance is via a Management Council/Board
- Coordination is via PHRN Program Office at TKI
National leadership

- Influence and engagement with
  - Governments and health agencies
  - Data custodians and users
  - Health consumers
  - International groups

- Via common purpose + resource support
Innovation

**PHRN Policies/Processes**

- Information Governance Framework (All)
- Online applications (PO)
- Consumer engagement (All)
Innovation cnt’d

PHRN technologies

✦ Secure **data delivery** (Sax/CDL)
✦ **Production linkage** system (CDL)
✦ Custodian administered **extracts server** (WADLU)
✦ Secure **remote access** to data (Sax)
Challenges and Opportunities
Challenges

- Differences in legislation
- Lead times for project approval
- Create and destroy linkages
A legal framework

Statutory, equitable and privacy considerations, A/Prof Judy Allen
Project approvals

Each project needs approval from:

- **Ethics** committees
- **Data custodians**
- **Data linkage** units

*Cross-jurisdiction projects are complex and it can take months to get approvals*
Approvals for POC#1

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<tr>
<th>Element</th>
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<td>Jurisdictions</td>
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<td>Ethics committees</td>
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<tr>
<td>Data custodians</td>
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<tr>
<td>Data collections</td>
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<tr>
<td>Linkage units</td>
<td>4</td>
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POC#1 involved linkage of 10 years of hospital morbidity and death data from four states.
Opportunities

For data linkage

❖ Clarity in legislation
❖ Faster approvals to access data
❖ Enduring linkage of C’wlth and cross-jurisdiction data
For healthcare

More systematic use of linked data assets for research to:

- inform health policy
- coordinate service delivery
- improve clinical practice
Conclusion

- Health information leadership is complex in Australia
- It takes persistence and perspiration as well as collaboration
- Innovative technologies can be a tool to cement collaboration
Thanks to:

- Australian Government for NCRIS funding
- UWA for acting as Lead Agent
- State/territory governments and academic partners for cash and in-kind support
- PHRN collaborators for providing services
For further information:

www.phrn.org.au