Australian data linkage infrastructure

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Overview

- PHRN explained
- Uses of data linkage infrastructure
- Access to data
PHRN explained

- A national collaborative research infrastructure network led by UWA
- Support facilities that link and provide access to linked population data
- Data mainly from Australian, state and territory government agencies
- Focus is on health but other human services data is included
Our beginning

- Australian Government funds 27 national capabilities/facilities via the National Collaborative Research Infrastructure Strategy (NCRIS)

- PHRN is one of these capabilities

- PHRN started in mid-2009

- Tasmania/MRI involved from the start
## Funding to June 2016

<table>
<thead>
<tr>
<th>Source</th>
<th>Total (AUD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australia Government</td>
<td>42,269,000</td>
</tr>
<tr>
<td>Cash Contributions *</td>
<td>19,101,000</td>
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<tr>
<td>In-kind Contributions *</td>
<td>39,725,000</td>
</tr>
<tr>
<td><strong>Total Investment</strong></td>
<td><strong>101,095,000</strong></td>
</tr>
</tbody>
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*Contributions are from state and territory governments, government agencies, universities and institutes*
PHRN facilities

- PHRN is a distributed system
- It currently supports:
  - Five state data linkage units (incl TDLU)
  - Two national data linkage units
  - A remote access laboratory (SURE)
  - A coordinating office at UWA
Service locations

[Map of Australia with service locations marked]

- PHRN Program Office
- Centre for Data Linkage
- WA Data Linkage Branch
- Queensland Research Linkage Group
- Sax Institute
- NSW/ACT Centre for Health Record Linkage
- Australian Institute of Health and Welfare
- SA NT Datalink
- Victorian Data Linkages
- Tasmanian Data Linkage Unit
Current status

- All states and territories now have enduring data linkage keys
- Enduring linkage keys progressing for Australian government data
- Scoping for enduring cross-jurisdiction data linkage keys in progress
Uses of data linkage infrastructure and access to linked data
Hospital-related deaths

- Project linked **10 years** of data from four states (NSW, Qld, SA and WA)
- Included over **44 million records** from almost **12 million people**
- The study showed the extent of **patient movements** across state borders
- It also showed the importance of counting deaths **after** hospital discharge
Note: By definition a mover had at least 2 hospital stays over a 5 year period

Spilsbury et al, MJA 2015, 202 (11): 582-586
Childhood immunisation

- Study linked **16 years** of data from the ACIR and two states (NSW and WA)
- AIHW did the linkage; data accessed via SURE
- Included over **35 million records** from almost **2 million** children
- Showed extent of immunisation in high risk children
Other research

- **Cancer**: High rates of preventable cancer in mental health patients

- **Heart valve surgery**: Excellent outcomes in people over 80 years

- **Prescribing**: 40% of people over 65 years get at least one Potentially Inappropriate Medication

- **Education**: What happens in the perinatal period impacts school achievement
Data access

- **The challenge** for cross-jurisdiction projects:
  - Projects require multiple approvals (ethics, data custodian, DLU)
  - Long delays

- **The approach:**
  - Standardise processes
  - Progress mutual acceptance of approvals
  - Use PHRN Online Application System
The future

- Additional data in linkage systems eg primary care; prescribing; genomics
- Improved access to linked data
- More systematic use of linked data for research and to better inform policy and practice
Conclusion

- All jurisdictions now have significant linked data assets and expertise
- These are being used for a wide range of human services research
- There are opportunities for new uses of linked data in Australia
More about PHRN ..... 
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