Development and Uses of a Health Data Linkage System in Western Australia

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Definition of Data Linkage

Data linkage = ‘the bringing together, from two or more different sources, data that relate to the same individual, family, place or event’.
Data Linkage as Research Infrastructure

‘Each person in the world creates a Book of Life. This Book starts with birth and ends with death. Its pages are made up of the records of the principal events in life. Record linkage is the name given to the process of assembling the pages of this Book into a volume’

(Dunn HL. Record linkage. Am J Public Health 1946; 36: 1412-1416)

Ad hoc Linkage vs Linkage System

<table>
<thead>
<tr>
<th></th>
<th>Ad hoc Data Linkage</th>
<th>Data Linkage System (broader infrastructure)</th>
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<tbody>
<tr>
<td><strong>Purpose</strong></td>
<td>One project (or a small number) with known objectives.</td>
<td>An indefinite number of mostly unknown future projects.</td>
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<td><strong>Data sets</strong></td>
<td>Limited to those needed for the project (often 2-3 data sets).</td>
<td>Unlimited – the more data sets the more versatile &amp; effective the system.</td>
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<td><strong>Data requirements</strong></td>
<td>Exposure/outcome data and identifiers usually come together.</td>
<td>Only requires identifiers – exposure/outcome data sought later on a project-by-project basis.</td>
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<td><strong>Time of activity</strong></td>
<td>Time-limited - data linkage activity closes once links are in place.</td>
<td>Open-ended - needs continuous updates of links as new data arrive.</td>
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<td><strong>Storage of links</strong></td>
<td>Usually links are stored as part of the research project data.</td>
<td>Requires a dedicated storage mechanism for links = the master linkage key.</td>
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<td><strong>Funding</strong></td>
<td>Usually draws on the research grant used to fund the project.</td>
<td>Requires dedicated infrastructure funding for a central, ongoing unit.</td>
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Comprehensive Population-Based Data Linkage Systems Around the World

Western Australian Data Linkage System - Features

- Established in 1995.
- >30 risk factor, morbidity, health care and vital databases.
- Links created using probabilistic matching of names, etc.
- Geocodes for residence are added for selected databases.
- Family trees for those born since 1950 are being added.
- Jointly managed by the Health Dept and universities.

Western Australian Data Linkage System - Present Scope

www.data linkage-wa.org
Geocoding

Example: Assignment of SES or Remoteness Indices

1. Address matching to locate residence.
2. Assign geocodes (latitudes and longitude).
3. Link geocodes to census districts (CDs).
4. Link CDs to social disadvantage and remoteness indices.
Family Connections Genealogical Database

Example of genealogical linkage based on midwife notifications, birth and death registrations


Benefits of Health Data Linkage in Western Australia
*(in ascending order of importance)*

1. Commercial and competitive benefit.
2. Adding value to existing information systems.
3. Cost-efficiency of research.
5. Community development.
6. Contributions to medical and scientific knowledge.
7. Improvements in population health.

1. Commercial and competitive benefits:
   - Research community endowed with a competitive advantage.
   - Return on investment within first 10 years (1995-2004):
     - Investment = Au$3.4 million.
     - Gross return in grants flowing into the state = Au$58.4 million
     \[ \therefore \text{Return on investment (discounted at 4\% p.a.)} = 1,168\% \]

2. Adding value to existing information assets:
   - Unproductive record systems turned into a high performance planning and research engine.
   - 10's of thousands of duplications and recording errors corrected in WA health data.
3. Cost-efficiency of research:
   - Cheap and fast alternative to *ad hoc* longitudinal studies.
   - Particularly cost-effective in follow-up of mobile populations.

4. Conservation of patient privacy:

   ![Graph showing the proportion of research projects (%) linked and name-identified over the years.]

5. Community development:
- Enhanced interactions between researchers, clinicians, administrators, consumer advocates and the media.
- Led to Australia’s inaugural symposium on ‘Involving People in Research’ and now a national strategy.

Examples of media coverage

6. Contributions to medico-scientific knowledge
708 outputs arose from 258 projects in 1995-2004:
- Including 172 journal articles and 177 conference papers.

Some illustrative areas of research:
- Utilisation and economics of health care (21%).
- Cancer (12%) and cardiovascular disease (11%).
- Social & environmental health (11%) and mental health (9%).
Two Examples of Published Projects Arising from government requests

Benefits of Health Data Linkage ...

Air Traveller’s Thrombosis: Risk Assessment

Estimate in Australia, international flights cause:
250 DVTs per annum.
5 deaths from PE per annum.

This equates with a fatality risk of about 2 in one million per long-haul flight.

BMJ 2003;327:1072 (8 November), doi:10.1136/bmj.327.7423.1072

Paper

Deep vein thrombosis and air travel: record linkage study

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2 National Centre for Epidemiology and Population Health, Australian National University, Canberra, ACT 0200
3 School of Population Health, University of Western Australia, Perth, WA 6009, Australia

<table>
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<tr>
<th>Days from arrival</th>
<th>0-7d</th>
<th>8-14d</th>
<th>15-2d</th>
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<tr>
<td>Relative Risk</td>
<td>5.17</td>
<td>2.42</td>
<td>1.38</td>
</tr>
<tr>
<td>95% CI</td>
<td>3.21-8.31</td>
<td>1.31-8.31</td>
<td>0.64-2.98</td>
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Health Outcomes in Users of Mental Health Services

Suicide Rates in First Year After First Admission

Ischaemic Heart Disease Mortality Rates

Benefits of Health Data Linkage ...

7. Improvements in population health

Examples arising from projects in 1995-2004:

A. Policy Reforms:

- Duty to Care Project:
  - Linked cancer, hospital and death records for 230,000 mental patients.
  - Found evidence of appallingly poor physical disease outcomes.
  - Led to Au$173 million funding package to assist the mentally ill.
  - Also led to a new part in the Mental Health Act on discharge planning.

- National exposure standard for crystalline silica:
  - Linked hospital and death records for gold miners.
  - Found evidence that exposure limits were inadequate.
  - Led the National Occupation Health and Safety Commission of Australia to revise the limit from 0.2 to 0.1 mg/m³.

6. Improvements in population health

*Examples arising from projects in 1995-2004:*

**B. Clinical Practice Reforms:**

- **Cardiac arrest:**
  - Linked ambulance, hospital and death records.
  - Found resuscitation performed in only 41% of all arrests.
  - Led to installation of defibrillators in all ambulances and hospital wards and training of all hospital nurses in their use.

- **Quality of Surgical Care Project:**
  - Many changes in surgical practice to improve safety and improve consumer information based on linked inpatient and death data.
  - Led to national roll-out of Australia’s first 30-day surgical mortality audit. Evaluations of the audit found 70% of surgeons had changed their practice due to feedback from the audit.

International Developments
International Consortium of Health Data Linkage Centres

Thank You

Some of the People who made the WA System happen

John Bass  Anne Reid
Kate Brameld  Diana Rosman
Stuart Fuller  Ian Rouse
Carol Garfield  James Semmens
Vivien Gee  Paul Simmons
Mike Hobbs  Merran Smith
D’Arcy Holman  Richard Solon
Jilda Hyndman  Fiona Stanley
Chris Kelman  Lexie Stoney
David Lawrence  Tim Threlfall