THE UNIVERSITY OF WESTERN AUSTRALIA
Achieving International Excellence

data linkage australia

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

Professor C. D'Arcy J. Holman
School of Population Health
The University of Western Australia

Data Linkage Australia Centre of Excellence in Science and Innovation

THE UNIVERSITY OF WESTERN AUSTRALIA
Achieving International Excellence

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'.

THE UNIVERSITY OF WESTERN AUSTRALIA
Achieving International Excellence

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)

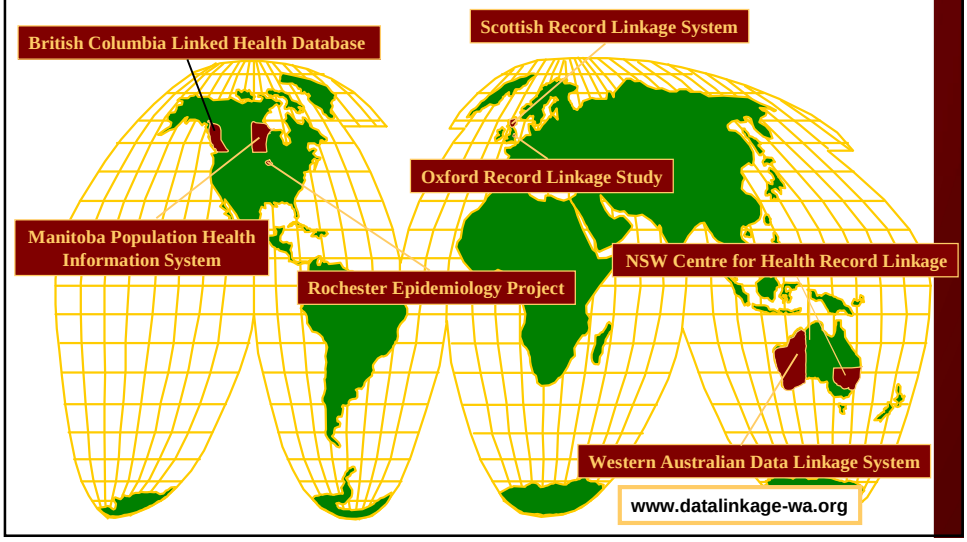
THE UNIVERSITY OF WESTERN AUSTRALIA
Achieving International Excellence

Ad hoc Linkage vs Linkage System

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

THE UNIVERSITY OF WESTERN AUSTRALIA
Achieving International Excellence

Comprehensive Population-Based Data Linkage Systems Around the World



THE UNIVERSITY OF WESTERN AUSTRALIA
Achieving International Excellence

Western Australian Data Linkage System - Features

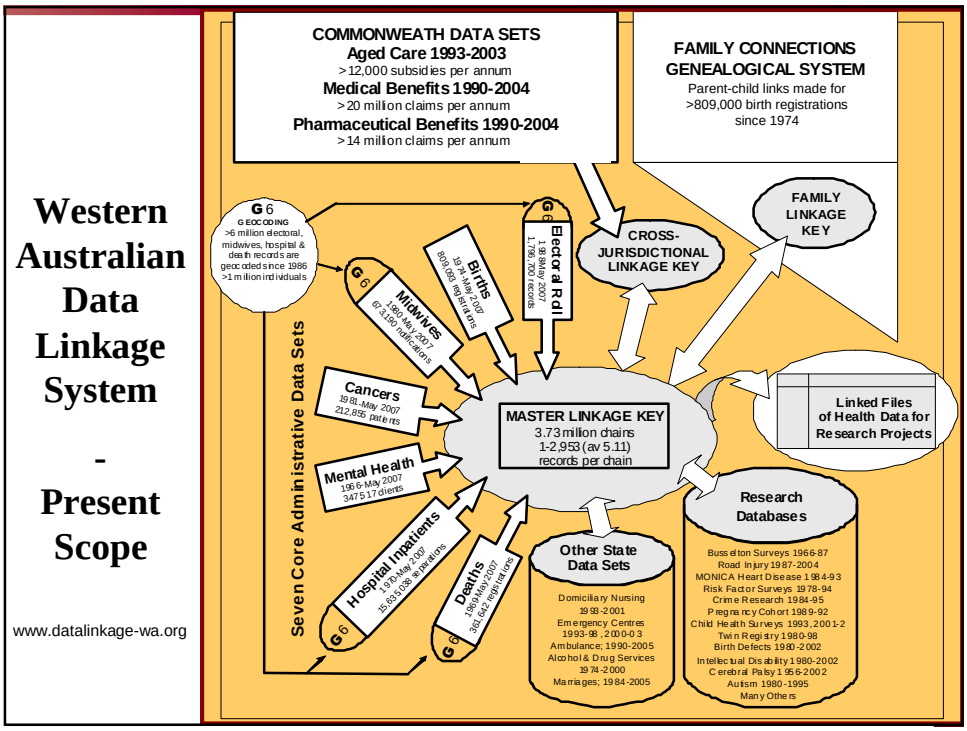
www.datalinkage-wa.org

- **Established in 1995.**
- **Population-based: 2.1 million people in 2008.**
- **>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.**

Holman CDJ, Bass AJ, Rouse IR, Hobbs MST. **Population-based linkage of health records in Western Australia: development of a health services research linked database.** *ANZ J Public Health* 1999; 23: 453-459

Western Australian Data Linkage System - Present Scope

www.datalinkage-wa.org



THE UNIVERSITY OF WESTERN AUSTRALIA
Achieving International Excellence

Chain of Links

Cancer record(s)
Hospital 1 Mar 2005
Hospital 20 Mar 2005
Hospital 31 Mar 2005
Death 31 Mar 2005

Contains no clinical information

Health Databases

Cancer Register
Hospital Morbidity System
Death Register

81	h2
81	h5
82	h3
82	h6
82	h1
82	b2
83	h4
83	B2

Stands alone

Cannot alter any other databases

Contains no intelligible information from other databases

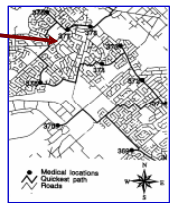
linkage key

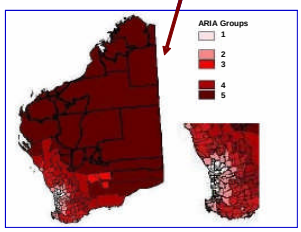
THE UNIVERSITY OF WESTERN AUSTRALIA
Achieving International Excellence

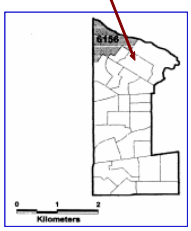
Geocoding

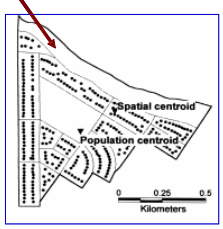
Example: Assignment of SES or Remoteness Indices

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.



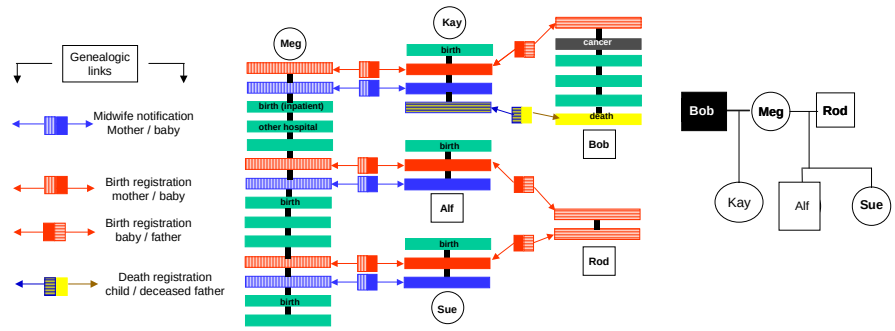






THE UNIVERSITY OF WESTERN AUSTRALIA
Achieving International Excellence

Family Connections Genealogical Database



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

Glasson EJ, de Klerk NH, Bass AJ, Rosman DL, Palmer LJ, Holman CDJ.
Cohort profile: The Western Australian genealogical project. *Int J Epidemiol* 2008; 37: 30-35.

THE UNIVERSITY OF WESTERN AUSTRALIA
Achieving International Excellence

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.**
4. **Conservation of patient privacy.**
5. **Community development.**
6. **Contributions to medical and scientific knowledge.**
7. **Improvements in population health.**

Holman CD, Bass AJ, Rosman D, Smith M, Semmens J, Glasson E, Brook E, Trutwein B, Rouse I, Watson C, de Klerk N, Stanley F. **A decade of data linkage in Western Australia: Strategic design, applications and benefits of the WA Data Linkage System.** *Aust Health Rev* 2008; 32: 766-777.

THE UNIVERSITY OF WESTERN AUSTRALIA
Achieving International Excellence

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**

  ∴ Return on investment (discounted at 4% p.a.) = 1,168%

Benefits of Health Data Linkage ...

THE UNIVERSITY OF WESTERN AUSTRALIA
Achieving International Excellence

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.**

THE UNIVERSITY OF WESTERN AUSTRALIA
Achieving International Excellence

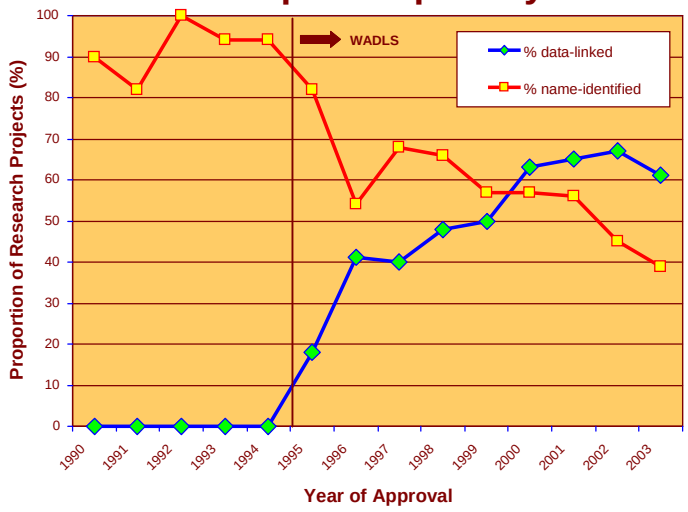
3. Cost-efficiency of research:

- **Cheap and fast alternative to *ad hoc* longitudinal studies.**
- **Particularly cost-effective in follow-up of mobile populations.**

Benefits of Health Data Linkage ...

THE UNIVERSITY OF WESTERN AUSTRALIA
Achieving International Excellence

4. Conservation of patient privacy:



Trutwein B, Holman CDJ, Rosman DL. **Health data linkage conserves privacy in a research-rich environment.** *Ann Epidemiol* 2006; 16: 279 280.

THE UNIVERSITY OF WESTERN AUSTRALIA
Achieving International Excellence

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

Benefits of Health Data Linkage ...

THE UNIVERSITY OF WESTERN AUSTRALIA
Achieving International Excellence

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%).**

Brook EL, Rosman DL, Holman CDJ. **Public good through data linkage: measuring research outputs from the Western Australia Data Linkage System.** *ANZ J Public Health* 2008; 32:19-23.

THE UNIVERSITY OF WESTERN AUSTRALIA
Achieving International Excellence

Two Examples of Published Projects Arising from government requests

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

Paper

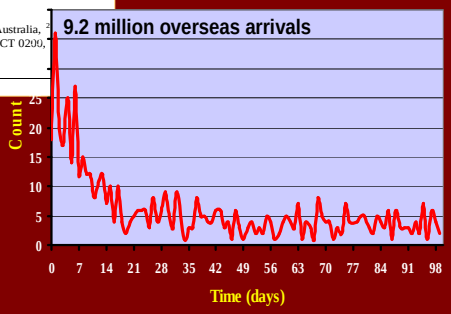
Deep vein thrombosis and air travel: record linkage study

C W Kelman, *medical adviser*[1], **M A Kortt**, *assistant director*[1], **N G Becker**, *professor of biostatistics*[2], **Z Li**, *postdoctoral fellow*[2], **J D Mathews**, *deputy chief medical officer*[1], **C S Guest**, *visiting fellow*[2], **C D J Holman**, *chair in public health*[3]

[1] Commonwealth Department of Health and Ageing, GPO Box 9848, Canberra, ACT 2601, Australia, [2] Centre for Epidemiology and Population Health, Australian National University, Canberra, ACT 0200, [3]

Air Traveller's Thrombosis: Risk Assessment

Days from arrival	0-7d	8-14d	15-2d
Relative Risk	5.17	2.42	1.38
95% CI	3.21-8.31	1.31-8.31	0.64-2.98



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

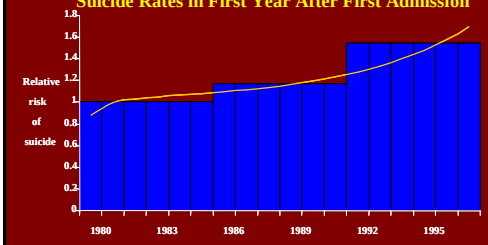
This equates with a fatality risk of about 2 in one million per long-haul flight.

Health Outcomes in Users of Mental Health Services

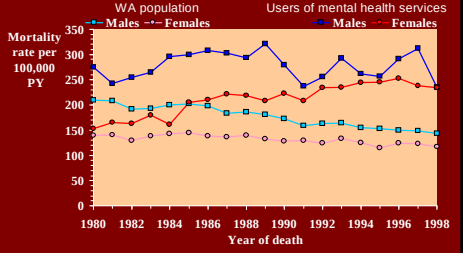
Br J Psych 2003; 182: 31-36

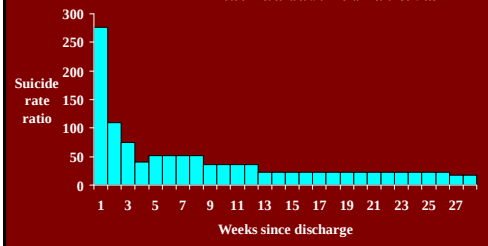
231,311 users (8% of population)

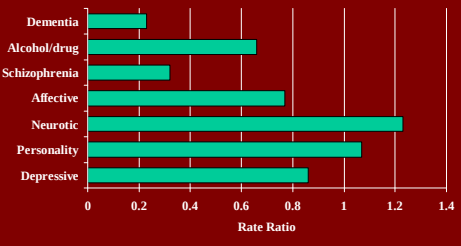
Suicide Rates in First Year After First Admission



Ischaemic Heart Disease Mortality Rates







Benefits of Health Data Linkage ...

THE UNIVERSITY OF WESTERN AUSTRALIA
Achieving International Excellence

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/m^3.**

Brook EL, Rosman DL, Holman CDJ. **Public good through data linkage: measuring research outputs from the Western Australia Data Linkage System.** *ANZ J Public Health* 2008; 32:19-23.

THE UNIVERSITY OF WESTERN AUSTRALIA
Achieving International Excellence

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.**

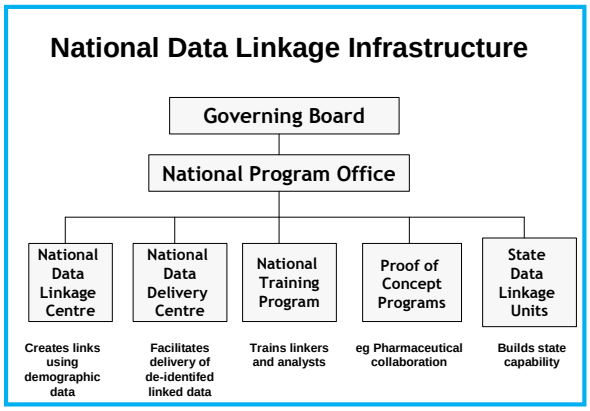
Brook EL, Rosman DL, Holman CDJ. **Public good through data linkage: measuring research outputs from the Western Australia Data Linkage System.** *ANZ J Public Health* 2008; 32:19-23.

THE UNIVERSITY OF WESTERN AUSTRALIA
Achieving International Excellence

Future of Data Linkage in Australia

National Collaborative Research Infrastructure Strategy

The Australian Government has approved a Au$20 million roll out of a national 'hub & spoke' system of health data linkage.



THE UNIVERSITY OF WESTERN AUSTRALIA
Achieving International Excellence

International Developments

International Consortium of Health Data Linkage Centres

Inaugurated in London, December 2008.

data linkage australia

THE UNIVERSITY OF WESTERN AUSTRALIA
Achieving International Excellence

Thank You

Some of the People who made the WA System happen

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

Centre for Health Services Research
School of Population Health
The University of Western Australia

Data Linkage Unit
Health Information Centre
Western Australia Department of Health

Population Health Sciences
TVW Telethon Institute
for Child Health Research

Centre for Health Informatics
Division of Health Sciences
Curtin University of Technology