Background

– The Commonwealth National Collaborative Research Infrastructure Strategy (NCRIS) identified population health and data linkage as a national priority to build capability, and provided funding to the Population Health Research Network (PHRN)

– In 2009 The Victorian Data Linkage Unit was established under NCRIS funding via PHRN as the key data linkage infrastructure in Victoria, co-funded by the Victorian Government and located in the then Department of Health

– In 2016 the Unit was renamed Centre for Victorian Data Linkage. It is located in the System Intelligence and Analytics Branch, Portfolio Strategy and Reform Division, DHHS
PHRN is a distributed system across Australia:

- Five state data linkage units
- Two national data linkage units
- A remote access laboratory (SURE)
- A coordinating office at UWA
CVDL governance

- DHHS Executives
- IM&ICT sub-committee of Executives and Advisory Committee
- DHHS Business Technology Information Management
- DHHS portfolio Acts and regulations
- Whole of Government Information and Communications Technology policy
- PHRN Board and The Participant Council Board
- Victorian Data Linkage Working Group

Legislative framework governing collection and disclosure of DHHS information held by the Secretary

- Health Services Act 1988
- Public Health and Wellbeing Act 2008
- Mental Health Act 2014
- Ambulance Services Act 1986
- Housing Act (Vic) 1983
- Children, Youth and Families Act (Vic) 2005
- Disability Act (Vic) 2006
- Residential Tenancies (Vic) Act 1997
- Improving Cancer Outcomes Act (Vic) 2014
Privacy and Standards

- WoVG IM GUIDE 01 Information Management Roles and Responsibilities – 2012
- DHHS Data Access and Release Policy
- DHHS Information Asset Governance Policy
- DHHS Information Management Principles
- Privacy and Data Protection Act (Vic) 2014
- Privacy Act (Cth) 1987
- Health Records Act (Vic) 2001
- Charter of Human Rights and Responsibilities Act 2006

CVDL – what we do

- CVDL since its establishment has focused on
  - Creating a data linkage system that will support policy development, planning and research into health and wellbeing
  - Testing linkage concepts and developing data linkage methods
  - Developing privacy policies, protocols and procedures
  - Meeting the demand for data linkage and linked data from government agencies and researchers
- Identified a number of issues for further work in data governance, policy and legislation
What is data linkage?

- Data linkage compares records to identify records believed to belong to the same entity
- It is the method by which information and evidence held within a dataset or in disparate datasets can be integrated to enable new and important questions to be researched and answered by preserving facts, without identifying individuals
- A significant quantity of administrative data is collected that could be a valuable research resource if it were better integrated and linked

Linkage identifiers vary across data collections

- Surname, given name
- Addresses or postcode only
- Service codes/names (eg. hospital code, hospital unique record number)
- Medicare number (for health only), 3 letters of given name
- Gender
- Date of birth
- Key service dates
- SLK-581: 3 letters of surname, 2 letters of given name (5), Date of birth (8), Sex (1) (eg. Dorothy Windsor 08/06/1991 = INSOR08061991F)
- Country of birth, ATSI
Data linkage methods

• **Deterministic** linkage creates a link between records where fields match exactly across records.

• **Probabilistic** linkage assigns a weight to each field that matches. These weights are then aggregated to represent the probability that records belong to the same entity.

Privacy and security principles and best practice protocols

• General confidentialisation rules:
  • DOB is not provided, only 5 year age groups are provided.
  • All other dates are changed into month and year. Dates can be encrypted dates into numeric values to allow calculation between intervals or sequencing.
  • SLAs are provided as the lowest geographic level.
  • Service provider names/codes are not provided:
    • All public hospitals are encrypted as random numbers.
    • Private hospitals encrypted as "0" only.
  • Confidentialisation is often a case by case exercise – different approaches may be applied depending on what data is requested.
1) Data Request — Researcher submits an ethics application to HREC and data linkage application to CVDL.

2) Approval — Ethics & data custodians approve data use & access.

3) Linkage --- CVDL creates linkage map with a common project-specific encrypted ID and pointers to records in relevant datasets.

4) Data Release — Provide the researcher with datasets with project-specific IDs and content data. No identifying information is released.

5) Research — The researcher merges datasets to answer research questions and report to CVDL a list of publications.

CVDL supports data linkage projects that are:

- In the public interest
- Approved by a relevant Human Research Ethics Committee
- Approved by relevant data custodian(s)
- Conducted in accordance with the relevant legislation, regulations and guidelines
- For which researchers undertake to report the results in the public domain

CVDL has provided linked data to around 150 policy/planning and research projects in 2012-2016YTD, 26 in progress currently, 46 being developed.
Examples of publications

- Adverse outcomes associated with elective knee arthroscopy: a population-based cohort study
- Using linked data to more comprehensively measure the quality of care for stroke
- Clinical presentation and patterns of care for short-term survivors of malignant glioma
- Palliative care for patients with chronic obstructive pulmonary disease: Exploring the landscape.
- Emergency department access targets and the older patient: a retrospective cohort study of emergency department presentations by people living in residential aged care facilities.
- Factors involved in intensive care unit mortality following medical retrieval: identifying differences between intensive care unit survivors and non-survivors.

Challenges & new opportunities

- Linkage across Victorian government agencies
- Linkage with Commonwealth data
- National data linkage development
- Cross-jurisdictional data linkage
- Big data awareness
- Legislative changes
To find out more…


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