

International Research Outputs of Health Data Linkage Studies

Emma L Fuller

Data Linkage Australia

The University of Western Australia



THE UNIVERSITY OF
WESTERN AUSTRALIA

Proposal

- The international data linkage centres could retrospectively collate research outputs from health data linkage studies in the form of journal articles, reports, presentations, theses and media items.
- Outputs that have influenced health policy or clinical practice could be identified.

Western Australian Data Linkage Research Outputs Project

- Audit the 258 projects of the Data Linkage Unit 1995-2003
- Quantify and document the number of publications & presentations arising from linked data studies
- Identify linked data studies that have altered health policy and or clinical practice

Western Australian Data Linkage Research Outputs Project

- Identify all research outputs from Western Australian data linkage studies and to use this as an indicator of the public good generated by the WA Data Linkage System.
- Produce a handbook of outputs that will be available for health consumers, policy analysts, health service planners, researchers and students.
- Further establish the foundation of the usefulness of linked data for health related research
- Evidence for further funding of data linkage activities

WA Research projects that have used linked data

- Busselton health study 1970-present
- Road injury database
- Attempted suicide in WA
- Comorbidity scoring system
- MONICA
- WA Aboriginal Coordinated Care Trial
- Fibrosing alveolitis
- Stroke and carotid artery disease
- Next Step – illicit drug use
- Dukes C colon cancer
- Staphylococcus aureus bacteraemia
- Fremantle diabetes study
- Prostate cancer and vasectomy
- Hip replacements
- Perth elderly cohort study
- SQSCP: ovarian cancer, hysterectomy, endoluminal stent graphs, gestational breast cancer, spondylosis, endophthalmitis etc
- Cholecystectomy
- Breastscreen WA survey
- SCNA death linkage
- DVT air travel linkage
- Country health services review
- Palliative care constituency
- Alcohol problems and mental health
- Management of major burns
- WA Aboriginal Child Health Survey
- Post partum hypothyroidism
- Rates of migration following illness
- IRC injury cost database
- Adolescent heart defects

Methods

Collection of Papers

- Initial email was sent to all researchers
- Follow up emails and phone calls
- Literature searches
- Outputs allocated to projects

Interviewing of Researchers

- Data
- Ethics
- Attributes of the Researcher
- Progress of the Study
- Outputs

Definitions

Project

A single application for linkage, extraction and or geocoding of data

Output

Any medium by which results from a study utilising linked data are presented

- Peer reviewed journal articles
- Reports
- Abstracts
- Conference presentations
- Theses (PhD, Masters, Honors)
- Posters
- Media (Newspaper, Radio, TV)
- Letters to the editor

Outputs

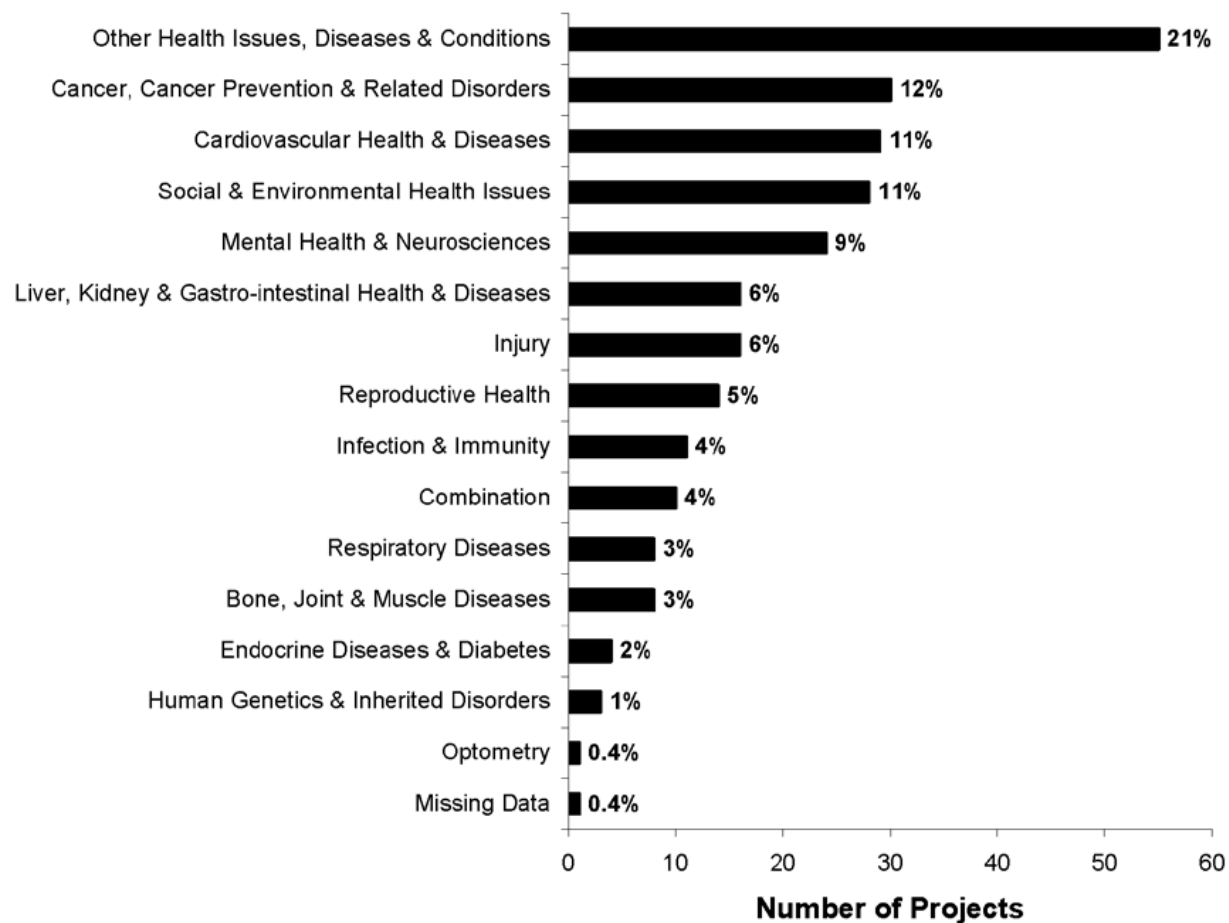
258 projects 708 outputs

- 177 (25.0%) presentations
- 172 (24.3%) journal articles
- 159 (22.4%) media items
- 96 (13.6%) reports
- 104 (14.7%) outputs comprised conference abstracts, posters, theses, book chapters, letters to the editor and journal articles that were submitted or in press.

Type of analysis

- Outputs by type
- Outputs by project
- Organisations performing projects
- Projects by area of health research

Distribution of projects, 1995 to 2003, by National Health & Medical Research Council broad health area



5 examples of projects that influenced health policy and or clinical practice

- Duty to Care
- National exposure standard of crystalline silica
- Cardiac Arrest
- Safety and Quality of Surgical Care Project (SQSCP): Operative procedures for treatment of renal stones and cholecystectomy
- Attempted suicide in WA

Results published

- Brook EL, Rosman DL & Holman CDJ. 2008. Public good through data linkage: measuring research outputs from the Western Australian Data Linkage System. *Australian and New Zealand Journal of Public Health* 32:19-23.
- Summary Report available at <http://www.datalinkage-wa.org.au/go/data-linkage/research-outputs>

International Collection

- Centres are encouraged to contact all users of provided linked data and collate research findings and outputs.
- This information can then be filed by authors, project name and type of data used.
- Reporting of research findings and outputs could be suggested as a mandatory requirement to all users of linked data.

International Collection

- Identify studies that have influenced health policy and or clinical practice
 - Contact researchers
 - Literature reviews
 - Already know

www.ihdlc.org

- Sourced outputs entered into an electronic library.
- Outputs could be annotated.
- Access to be universal.

www.ihdlc.org

- Programmer to create search facility.
- Key word searches of the outputs by study type, data used, authors etc should be possible.

International Research Outputs Paper

- A joint paper could be constructed on the international research outputs of linked data to show the public good of data linkage.

Proposed Plan

- Collate project lists and output lists
- Annual reports
- Contact researchers
- Gather information
- 6-12 months to produce paper
- Collection could then be ongoing and information entered into library as collected

World Health Organisation

- WHO is interested in receiving information about health data linkage outputs
- Outputs could be forwarded to WHO on a annual or 6 monthly basis or direct access to library



Questions?