

SYMPOSIUM ON HEALTH DATA LINKAGE

ITS VALUE FOR AUSTRALIAN HEALTH POLICY DEVELOPMENT AND POLICY RELEVANT RESEARCH
PROCEEDINGS

20-21 MARCH 2002 TUSCULUM HOUSE AUDITORIUM
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SYMPOSIUM *overview*

This Symposium explored the value of linked data for policy development and policy relevant research for Australia. It also provided us the opportunity to review our progress since the earlier symposium, hosted by PHIDU in June 1999, which addressed the theme “Record Linkage for better public health: The state of play”. The goals for this Symposium were:

- To inform participants about the opportunities for data linkage – the practicalities and possibilities;
- To highlight the research outcomes that data linkage (of both administrative and clinical databases) offers in Australia and overseas;
- To encourage discussion and debate about current and future data linkage activities in Australia;
- To develop a possible agenda for further work in the area of data linkage in Australia;
- To discuss a best practice approach to data linkage that fosters the use of linked data for health research but incorporates measures to ensure the optimal protection of individual privacy and restricts nonauthorised use of linked data sets;
- To discuss the need for an approach to coordinate and monitor research projects utilising linked data.

The Program covered two main areas, one looking at the value of data linkage for providing better quality data and the other showcasing national and international research based on data linkage. We were able to secure a number of eminent international keynote speakers to address the Symposium.

The international keynote speakers were:

- Michael Goldacre, Department of Public Health, University of Oxford, United Kingdom
- Leslie Roos, Manitoba Centre for Health Policy, University of Manitoba, Canada
- Nick Andrews, Public Health Laboratory Service, Statistics Unit and Immunisation Division, United Kingdom

Noralou Roos, also of the Manitoba Centre for Health Policy, also presented in the contributed papers sessions.

We also had an impressive list of national keynote speakers including:

- Richard Smallwood, Chief Medical Officer, Department of Health and Ageing
 - Chris Kelman, Medical Advisor, Information and Research Branch, Department of Health and Ageing
- Research findings from studies on linked data were presented in the concurrent sessions for contributed papers under the themes of:

- Health Outcomes
- Surveillance and Adverse Events
- Health Services Research
- Socioeconomic and Environmental Determinants
- Privacy and Process Issues
- Methods

The symposium was thought-provoking and I trust that it advanced our commitment to moving the agenda on health data linkage forward in ways that are valuable for health policy development, strategic planning and clinical practice.

John Glover

Director
PHIDU
University of Adelaide

SYMPOSIUM *acknowledgements*

PROGRAM COMMITTEE

John Glover, PHIDU, University of Adelaide (chair)
Suzie Baker, Health Insurance Commission
Joy Eshpeter, Department of Health and Ageing
John Harding, Australian Institute of Health and Welfare
Diana Hetzel, PHIDU, University of Adelaide
D'Arcy Holman, University of Western Australia
Wilawan Kanjanapan, Department of Health and Ageing
Chris Kelman, Department of Health and Ageing
Jenny Millet, Health Insurance Commission
Marelle Rawson, Australian Bureau of Statistics
Di Rosman, Department of Health, Western Australia

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SYMPOSIUM FACILITATOR

Ian Rouse, Director, Health Policy and Program Research, Division of Health Sciences, Curtin University of Technology, Western Australia
Ian was involved in the initial arrangements which resulted in the establishment of the WA Data Linkage System, a joint venture between the WA Health Department and the University of WA. He is a well recognised health researcher in this field.

SYMPOSIUM ORGANISER

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BACKGROUND *information on international speakers*

RESEARCH INTERESTS OF THE INTERNATIONAL KEYNOTE SPEAKERS

MICHAEL GOLDACRE

Honorary Director, Unit of Health-Care Epidemiology, Public Health and Primary Care Division, University of Oxford, Oxford UK. Also Scientific Director, South East Public Health Observatory. Wide research interests using data linkage, including:

- Oxford record linkage study, which provides an “epidemiological laboratory”, containing information about disease and the use of health services in a large population, which can be used for epidemiological and health services research across a very wide range of topics.
- Use of health services; medical and dental manpower; risk factors for post-hospital deaths etc; prenatal and early life risk factors; natural history of disease and the outcome of medical care; perinatal and child health, National Clinical Standards Advisory Group and outcome indicators.

NORALOU ROOS & LESLIE ROOS

Co-directors, Manitoba Centre for Health Policy, Department of Community Health Sciences, Faculty of Medicine, University of Manitoba, Winnipeg, Manitoba, Canada. Research interests include the use of administrative data for managing the health care system, and the relationship between health care use and population health. For example:

- Conceptual framework for linked population health information system in Manitoba and use in health status, indicators of need for healthcare and needs-based planning;
- Hospital and regional health performance for a population.

NICK ANDREWS

Statistician, Immunisation Division, Communicable Disease Surveillance Centre, Public Health Laboratory Service (PHLS), England and Wales. This Division’s activities cover:

- Carrying out safety and efficacy trials of new vaccines;
- Assessing post-licensure vaccine efficacy and effectiveness;
- Investigation of potential adverse events post-licensure;
- Assessing the impact of vaccination schedules and campaigns using mathematical and economic models;
- Organising enhanced surveillance of vaccine preventable diseases;
- Collating vaccine coverage data.

The PHLS is currently carrying out studies using linked immunisation and hospital admission data using a relatively new statistical method called the self-controlled case-series (SCCS) method that was developed by Dr Paddy Farrington, a statistician formerly in the PHLS. Examples where record linkage and the SCCS method have been used include investigating MMR and convulsions, MMR and autism, MMR and Purpura, Oral Polio Vaccine and Intussusception, and DTP and Convulsions. They are currently looking at possible reactions to the new meningitis C conjugate vaccine. These results should be available for presentation by March 2002.

PROGRAM *at a glance*

DAY 1 20 March 2001

8.45am	Welcome Ian Rouse, Curtin University, Western Australia
9.00am	The value of linked data for policy development, strategic planning, clinical practice and public health: An international perspective Michael Goldacre, Department of Public Health, University of Oxford, UK
9.45am	The value of linked data for policy development, strategic planning, clinical practice and public health: An Australian perspective Richard Smallwood, Department of Health and Ageing
10.15am	Morning tea
10.45am	The value of linked data for research into health outcomes D'Arcy Holman, Centre for Health Services Research, University of Western Australia; and John Bass, Western Australia
11.30am – 1.00pm	CONCURRENT A SESSIONS: CONTRIBUTED PAPERS
1A – HEALTH OUTCOMES	
11.30am – 11.50am	From evidence to practice: Population-based monitoring of the use of breast-conserving surgery for the treatment of breast cancer using record linkage of routinely collected data Presenter: Kim Lim, Epidemiology and Surveillance Branch, NSW Health Department Authors: Kim Lim and Tim Churches
11.50am – 12.10pm	Death subsequent to treatment for heroin and amphetamine use: A record linkage study Presenter: Geoff Gawthorne, Next Step Specialist Drug and Alcohol Services Authors: Geoff Gawthorne, Anne Bartu, Sarah Johnson, Jim Codde, Elizabeth Unwin and D'Arcy Holman
12.10pm – 12.30pm	The use of linked ambulance data to estimate the effect of comorbidity on deternants and outcomes of out-of-hospital cardiac arrest in Perth, Western Australia Presenter: Judith Finn, Department of Public Health, University of Western Australia Authors: Judith Finn, D'Arcy Holman and Ian Jacobs
12.30pm – 12.50pm	Rates and patterns of participation in cardiac rehabilitation in Victoria Presenter: Michael Ackland, Victorian Department of Human Services Authors: Vijaya Sundararajan, Stephen Begg, Michael Ackland, Ric Marshall, Steve Bunker and Helen McBurney

2A – SURVEILLANCE AND ADVERSE EVENTS; AND PRIVACY AND PROCESS ISSUE	
Surveillance and Adverse Events	
11.30am – 11.50am	Trends of Cataract Surgery and Post-Operative Endophthalmitis in Western Australia (1980-1998): A Population-Based Study Presenter: Jianghong Li, Department of Public Health, University of Western Australia Authors: James Semmens, Jianghong Li and Nigel Morlet, on behalf of team EPSWA
11.50am – 12.10pm	Surgical site infections following orthopaedic surgery: Statewide surveillance using linked administrative databases Presenter: Thomas V. Riley, Department of Microbiology, University of Western Australia Authors: Claudia Thomas, Helen Cadwallader and Thomas V. Riley Privacy and Process Issues
12.10pm – 12.30pm	Measuring data and link quality in a dynamic multi-set linkage system Presenter: Diana Rosman, Data Linkage Unit, Department of Health, Western Australia Authors: Diana Rosman, Carol Garfield, Stuart Fuller, Alexia Stoney, Todd Owen and Geoff Gawthorne
12.30pm – 12.50pm	From data linkage to policy and back again Presenter: Christine Stone, Department of Human Services, Victoria Authors: Christine Stone, Jenny Howard, Andrew Ramsden, Maree Roberts, Jane Halliday
3A – HEALTH SERVICES RESEARCH	
11.30am – 11.50am	Linking the prairies to the outback: What can NSW learn from the Manitoba data linkage project? Presenters: Marian Shanahan and Kees van Gool, Centre for Health Economics Research and Evaluation, University of Technology, Sydney. Authors: Marian Shanahan and Kees van Gool
11.50am – 12.10pm	Health Service Use questions addressable by the Queensland Linked Data set Presenter: Rohan Baxter, Commonwealth Scientific and Industrial Research Organisation Authors: Rohan Baxter, Chris Kelman, Richard Solon, Simon Hawkins, Graham Williams, Deanne Vickers, Lifang Gu and Hongxing He
12.10pm – 12.30pm	Applications of record linkage in cardiovascular disease: Monitoring trends and incidence, determinants and outcome of coronary heart disease and stroke Presenter: Michael Hobbs, Department of Public Health, University of Western Australia Authors: Michael Hobbs, Steve Ridout, Konrad Jamrozik and Ian Jacobs
12.30pm – 12.50pm	Applications of record linkage in cardiovascular disease: Establishing illness episodes for planning and evaluation of health services for coronary heart disease and stroke Presenter: Michael Hobbs, Department of Public Health, University of Western Australia Authors: Michael Hobbs, Konrad Jamrozik, Steve Ridout and Robyn Broadhurst

1.00pm	Lunch
2.00pm	Record linkage: Data quality, tool development and substantive research Leslie Roos, Manitoba Centre for Health Policy, University of Manitoba, Canada
2.45pm	The Value of Linked Data for Research into Health Services Use and Expenditure: An Australian Perspective Dr Chris Kelman, Information and Research Branch, Department of Health and Ageing
3.15pm	Afternoon tea
3.45pm – 5.30pm	CONCURRENT B SESSIONS: CONTRIBUTED PAPERS
1B – HEALTH OUTCOMES; AND SOCIOECONOMIC AND ENVIRONMENTAL DETERMINANTS	
Health Outcomes	
3.45pm – 4.05pm	The use of Record Linkage in Epidemiological research into Maternal and Child health Presenters: Gail Reading, Peter Cosgrove and Hoan Nguyen, Telethon Institute for Child Health Research, Perth, Western Australia Authors: Maxine Croft, Hoan Nguyen, Gail Reading, Peter Cosgrove, Melinda Berinson and Gillian Smith
4.05pm – 4.25pm	Ovarian cancer in Western Australia, 1982–98: A population-based review of trends and outcomes Presenter: Crystal Laurvick, Centre for Health Services Research, Department of Public Health, University of Western Australia Authors: Crystal Laurvick, James Semmens, Yee Leung, Anthony McCartney, Ian Hammond and D'Arcy Holman.
4.25pm – 4.45pm	Evolving Treatments for Primary Urolithiasis: Impact on Services and Renal Preservation in 16 679 Patients in Western Australia Presenter: James Semmens, Centre for Health Services Research, Department of Public Health, University of Western Australia Authors: D'Arcy Holman, Stan Wisniewski, James Semmens and John Bass
Socioeconomic and Environmental Determinants	
4.45pm – 5.05pm	Data linkage in the public health assessment of ecosystem change Presenter: Shilu Tong, School of Public Health, Queensland University of Technology Authors: Shilu Tong, Rod Gerber, Rodney Wolff and Ken Verrall
5.05pm – 5.25pm	The potential of linking environmental, socio-economic and health data for health policy development Presenter: Elisabeth Bui, Commonwealth Scientific and Industrial Research Organisation, Land & Water Author: Elisabeth Bui

2B – PRIVACY AND PROCESS ISSUES

3.45pm – 4.05pm **The use of probabilistic record linkage, public key cryptography and trusted third parties to improve the protection of personal privacy and confidentiality in disease registers and tissue banks**

Presenter: Tim Churches, Epidemiology and Surveillance Branch, NSW Health Department

Author: Tim Churches

4.05pm – 4.25pm **Linked health data in the Northern Territory**

Presenter: Stephen Moo, Business Information Management, Northern Territory Department of Health and Community Services

Authors: Cherie Shepherd, Mary-Anne Measey and Stephen Moo

4.25pm – 4.45pm **Consumer Involvement in the Centre for Health Services Research**

Presenter: Rebecca Coghlan, Centre for Health Services Research, Department of Public Health, University of Western Australia

Author: Rebecca Coghlan

4.45pm – 5.05pm **The use of linked data in health surveillance in NSW**

Presenter: Lee Taylor, Epidemiology and Surveillance Branch, NSW Health Department

Authors: Lee Taylor, Kim Lim and Tim Churches

3B – METHODS

3.45pm – 4.05pm **Data linkage and the South Australian Cancer Registry**

Presenter: Wayne Clapton, SA Cancer Registry, Epidemiology Branch, Department of Human Services and Anti-Cancer Foundation of SA

Authors: Wayne Clapton, Colin Luke, Peter Chapman, Kevin Priest, Anh-Minh Thi Nguyen, Graeme Tucker, Maria Cirillo, Mary Merdo, Teresa Molik, Elaine Morton, Chris Scott, Heather Hall, Joanne Bell, Lesley Milliken

4.05pm – 4.25pm **Parallel Computing Techniques for High-Performance Probabilistic Record Linkage**

Presenter: Peter Christen, Department of Computer Science, FEIT, Australian National University

Authors: Peter Christen, Markus Hegland, Stephen Roberts, Ole Nielsen and Tim Churches

4.25pm – 4.45pm **Statistical linkage keys: How effective are they?**

Presenter: John Bass, Western Australia

Authors: John Bass and Carol Garfield

4.45pm – 5.05pm **Inside the Western Australian Data Linkage System**

Presenter: Carol Garfield, Department of Health, Western Australia

Authors: Carol Garfield, Diana Rosman and John Bass

5.05pm – 5.25pm **Linkage of the Victorian admitted episodes dataset**

Presenter: Vijaya Sundararajan, Victorian Department of Human Services

Authors: Vijaya Sundararajan, Toni Henderson, Michael Ackland, Ric Marshall

7.00pm **Conference Dinner Speaker: Robyn Williams**

DAY 2		21 March 2001	
9.00am	Reflections on the previous day Ian Rouse, Curtin University, Western Australia		
9.15am	The value of linked data for research into the social determinants of health Michael Goldacre, Department of Public Health, University of Oxford, UK		
10.00am	Unpacking analyses relying on area-based data: Are the assumptions supportable? John Glover, Public Health Information Development Unit, University of Adelaide		
10.30am	Morning tea		
11.00am	The value of linked data for research into surveillance and adverse events Nick Andrews, Public Health Laboratory Service, Statistics Unit and Immunisation Division, United Kingdom		
11.45am – 1.00pm	CONCURRENT C SESSIONS: CONTRIBUTED PAPERS		
	1C – SOCIOECONOMIC DETERMINANTS		
11.45am – 12.05pm	Inequalities in child health: Bringing together new data sources to assess the roles of family, community, education and health care Presenter: Noralou Roos, Manitoba Centre for Health Policy, University of Manitoba, Canada Authors: Noralou Roos, Marni Brownell and Diane Watson		
12.05pm – 12.25pm	Putting data into context: Findings from linking Medicare health service use and expenditure data with longitudinal health survey data Presenter: Anne Young, Research Centre for Gender and Health, University of Newcastle Author: Anne Young		
12.25pm – 12.45pm	The effect of locational and social disadvantage on utilisation and outcomes of health care: Cardiovascular disease Presenter: Kate Brameld, Centre for Health Services Research, Department of Public Health, University of Western Australia Authors: Kate Brameld, D'Arcy Holman and Todd Owen		
	2C – PRIVACY AND PROCESS ISSUES		
11.45am – 12.05pm	Issues in the use of Unique Patient Identifiers to link Statistical Data Presenter: Ric Marshall, Victorian Department of Human Services Authors: Ric Marshall, Neil Powers and Carmel Heaney		
12.05pm – 12.25pm	Barriers to implementing worthwhile data linkage ideas: Lessons from Queensland Presenter: Magnolia Cardona, Public Health Services, Queensland Health Author: Magnolia Cardona		
12.25pm – 12.45pm	Electronically linked health records: Current proposals in NSW Presenter: Chris Puplick, Privacy NSW Author: Chris Puplick		

3C – METHODS

11.45am – 12.05pm **Data Linkage to Estimate Resource and Service Utilisation for Palliative Care Clients**

Presenter: Andrew McAlindon, Data Linkage Consultant, International Institute of Hospice Studies, Flinders University of South Australia

Authors: Andrew McAlindon and Amy Abernethy

12.05pm – 12.25pm **The sensitivity of probabilistic record linkage: Estimating the number of “false negatives” in a linkage involving client records of a large domiciliary care organization**

Presenter: Luke Marinovich, Silver Chain Nursing Association

Authors: Luke Marinovich, Stuart Fuller, Michael Hobbs and Gill Lewin (WITHDRAWN)

12.25pm – 12.45pm **Estimating the cost of injury using the Western Australia Data Linkage System and Injury Cost Database**

Presenter: Diana Rosman, Data Linkage Unit, Department of Health, Western Australia

Authors: Diana Rosman and Delia Hendrie

1.00pm **Lunch**

2.00 pm **Panel Discussion**

The research use of linked administrative health data – Should consent be an absolute pre-requisite?

D’Arcy Holman, University of Western Australia; Sandra Hacker, Australian Institute of Health and Welfare; Merran Smith, Department of Health, Western Australia; Chris Puplick, Privacy NSW; Anne Young, Research Centre for Gender and Health, University of Newcastle

3.00pm **Afternoon tea**

3.30pm **Where to from here, for Australian data linkage research and practice? Panel discussion with all keynote speakers**

Facilitator: Ian Rouse, Curtin University, Western Australia

4.30 pm **CLOSE**