

Purpose of the International Health Data Linkage Consortium

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Scope

- Data Linkage Centres
 - Directors, Managers, Linkage Officers, Programmers, Project Officers, Analysts
- Affiliates of Data Linkage Centres
 - Data Custodians/Stewards, Policy Makers, Health Consumers, Privacy Officers
- Researchers

Purpose

- Bring together everyone who is involved with health data linkage at an international level
 - Link the centres
 - Link the affiliated centres
 - Link the researchers
- Learn from each other

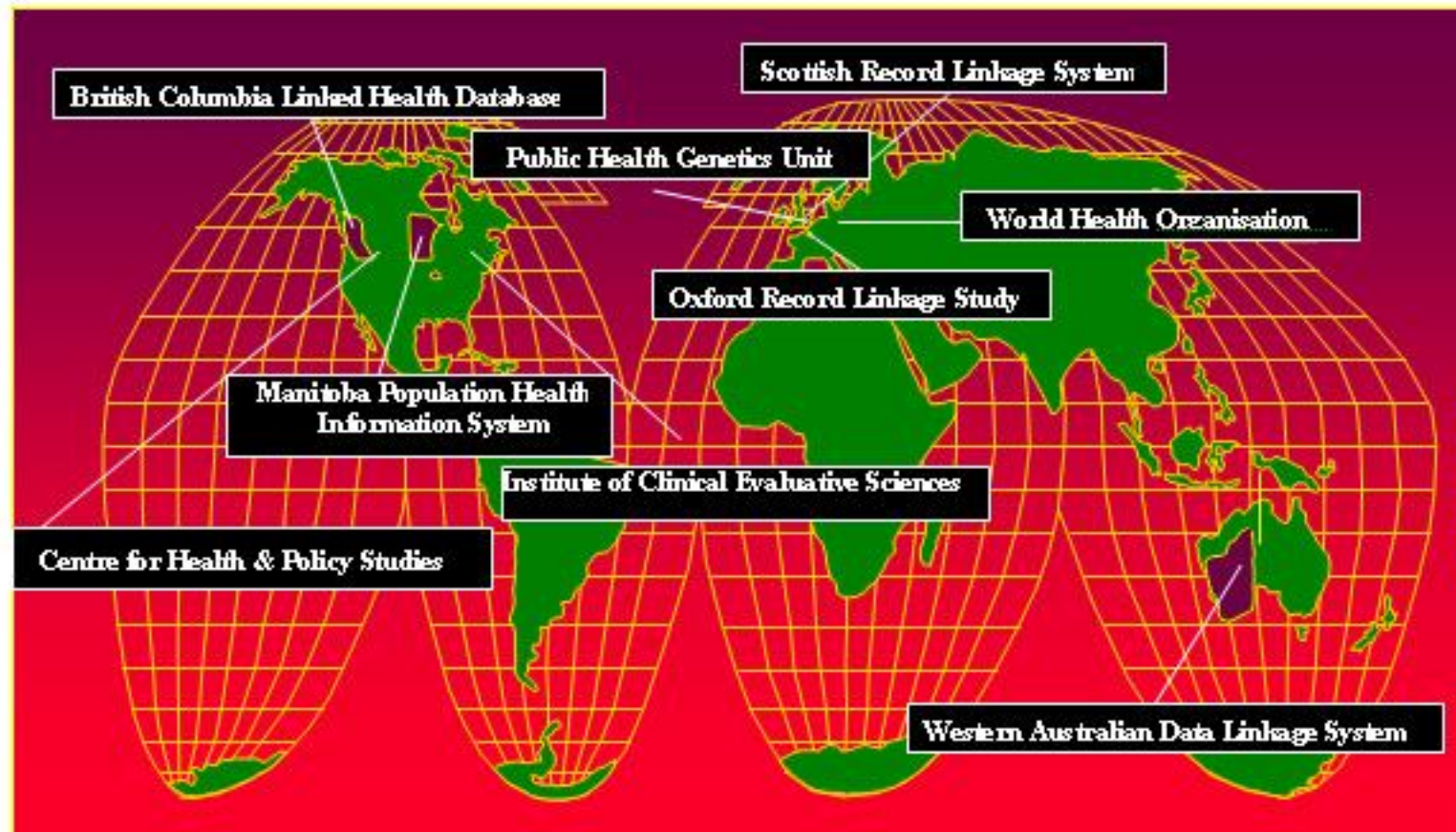
Fay Gale Fellowship 2006-2007

- Visit 7 international data linkage centres
- Establish an international consortium of data linkage centres
- Create a reporting system at the WHO for international data linkage outputs
- Staff exchange program

Fay Gale Fellowship 2006-2007

- The British Columbia Linked Health Database, Centre for Health Services and Policy Research, University of British Columbia, British Columbia, Canada
- Centre for Health and Policy Studies, Department of Community Health Sciences, University of Calgary, Alberta, Canada
- Manitoba Centre for Health Policy, Winnipeg, Manitoba, Canada
- Institute of Clinical Evaluative Sciences, Toronto, Ontario, Canada
- Oxford Record Linkage Study, Oxford, United Kingdom
- Scottish Medical Record Linkage System, National Health System, Edinburgh, Scotland
- Data Linkage Branch WA, Health Department WA

Data Linkage Centres



Core Focus

- Population Health Research
- Health Policy
- Issues of health in population groups
- Epidemiology
- Biostatistics
- What makes people healthy?
- Examining of patterns of illness and health
- How people use health care services
- How health services can be best organised, funded and delivered

Size

Name	Population	Years of Data
British Columbia Linked Health Database	4 million BC residents	1985 - onwards
Calgary Health Region	1.2 million Calgary (3.2 million in Alberta)	1992 - onwards
Manitoba Center for Health Policy	1.2 million	1970 - onwards
Institute of Clinical Evaluative Sciences	12 million Ontario residents	1990 - onwards
Oxford Record Linkage Study	2.5 million (originally 350,000)	1963 - onwards
Scottish Medical Record Linkage System	6 million	1900 - onwards
WA Data Linkage System	2.1 million	1969 - onwards

Fay Gale Fellowship 2006-2007

- About
- History
- Organisation structure
- Funding
- Governance
- Datasets
- Technical aspects of the linkage
- Electronic storage and security
- The application and approval process
- Projects
- Research outputs
- Teaching and education programs

Fay Gale Fellowship

Report located at

www.ihdlc.org

International Health Data Linkage Centres: Findings of a Fay Gale Fellowship

Emma L Brook
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December 2008



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Fay Gale Fellowship 2006-2007

- World Health Organisation, Geneva
 - Measurement and Health Information Systems
 - Research Policy and Cooperation

Objectives

- To establish and maintain an effective and useful network of health data linkage centres
 - Meeting
 - Website
 - Activities
 - Mailing list

Objectives

- To foster collaboration and exchange programs between data linkage centres
 - sharing of knowledge
 - staff exchange

Objectives

- To produce a compendium of measurements based on linkage of health data and health related data across Australia, Canada, New Zealand and the United Kingdom
 - Incidence & prevalence of diseases
 - Morbidity & mortality
 - Health service usage

Objectives

- To foster international comparable health and health related data linkage studies
- Perform 2-3 'proof of concept' studies

Objectives

- To record the outputs from health data linkage activities and programs across the globe

Meeting of IHDLC

- Meet on a 2 yearly basis
- Host 2-3 teleconferences a year
- Discuss work as needed

www.ihdlc.org

- Details of the international data linkage centres and affiliated organisations
 - Australia
 - Canada
 - New Zealand
 - United Kingdom

Fay Gale Fellowship

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- Upload information
- International paper

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- International contact list
 - researchers, analysts, data linkage staff in a directory
- International project list
 - annual list of received applications at each of the centres
- An annotated international research outputs library

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- List datasets & sources
- Data and concept dictionaries
- Relevant SAS/SPSS syntax
- New data linkages, committees, funding and changes in staff
- Helpful hints for students, researchers and policy makers
- Education tool kit
- Privacy tool kit

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- International conferences
- Local activities at each of the centres
- List of current activities with regards to the international consortium

Education & Training

Australia

- Introduction Analysis of Linked Health Data
- Advanced Analysis of Linked Health Data

Canada

- Administrative Data Analysis Methodology
- The Epidemiology of Health Care

Activities

- 7th December
 - Scottish Executive and ISD Scotland
- 8th December
 - Unit Health Care Epidemiology, Oxford

World Health Organisation

- Collaborating Centre
 - activities
 - programs

IHDLC - Actions

- Expansion of website
- Review of report
- Joint international paper about the IHDLC and centres
- Discussion about # of meetings

IHDLC

- Not an exclusive club
- Open to all data linkage centres, operations and affiliated groups

Thank You

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