

Purpose of the International Health Data Linkage Consortium

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Background

Preamble signed by members of international data linkage centres in 2006/07:

“Data linkage is the bringing together of information from two or more records of independent sources that are perceived to belong to the same individual, event or place.

Data linkage enables research questions to be addressed without the use of patient identifying information, thereby augmenting the use of existing data while maintaining privacy and the veracity of data sources.

The findings of population based data linkage studies have important implications for health policy and clinical practice. Data linkage centres provide an invaluable health infrastructure to support aetiologic, utilisation and outcomes research.

The following people are interested in participating in an international consortium of data linkage centres. This will enable the data linkage centres and affiliated researchers to share knowledge and expertise with regards to data linkage.”

Faye Gale Fellowship

In April 2006, I was awarded by the University of Western Australia the Fay Gale Fellowship to visit and work with international data linkage centres. From October 2006 to January 2007, I visited:

- 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

The visits varied from several days to two weeks. At each of the centres, I gathered information about the funding, governance, organisation structure, the application process, approvals, datasets, technical aspects of the linkage, electronic storage and security, research outputs and teaching and education programs.

At each of the centres I suggested the ideas of international staff exchange and an international consortium of data linkage centres.

Objectives

The International Health Data Linkage Consortium (IHDLC) will not only link the **centres** but will also link the **affiliates of the centres** and link the **researchers**. The IHDLC will provide a forum in which researchers, policy makers, privacy officers, linkage staff, managers, and directors can communicate and disseminate information. Essentially the idea is to bring together everyone who is involved with data linkage at an international level.

The objectives of the International Health Data Linkage Consortium are:

- To establish and maintain an effective and useful network of health data linkage centres
- To foster collaboration and exchange programs between data linkage centres
- To produce a compendium of measurements based on linkage of health data and health related data across Australia, Canada and the United Kingdom
- To foster international comparable health and health related data linkage studies
- To record the outputs from health data linkage activities and programs across the globe

It is intended that the IHDLC will become a World Health Organisation collaborating research centre.

IHDLC Website

The IHDLC website is located at www.ihldc.org

It is intended that the website could contain information about:

- The international data linkage centres and affiliated organisations
- An annotated international research outputs library

- International contact list: researchers, analysts, data linkage staff in a directory.
- International project list: annual list of received applications at each of the centers.
- 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

The website will have a comprehensive search facility, enabling users to enter key words to find contacts, projects and research outputs.

It is envisaged that the website will detail information about international conferences, local activities at each of the centers and a list of current activities with regards to the international consortium.

As the international data linkage consortium is developed the following initiatives could also be developed on the website:

- A online secure password protected chat forum, in which researchers, policy makers, people interested in data linkage can easily converse and share knowledge
- For each of the centres, list the linked datasets, years and variables with the view to one day enabling comparison studies i.e. sharing of linked data, international comparison studies.
- Sharing of software, linkage and analysis tools, ideas