

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

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Introduction

Data linkage is the bringing together of records from different sources that belong to the same individual or event. Data linkage is an invaluable tool for population health research, it provides a completely unbiased picture of the entire population, is cost-effective and enables studies to be done that could not otherwise be performed.

Since January 2003, I have worked at the Western Australian Data Linkage Unit. Initial work involved linking the Commonwealth aged community care data and the emergency state data to the core health data, which is known as the WA Data Linkage System. In 2005, I moved into a project role and began to collect the research outputs from studies in WA that had used linked data provided by the WA Data Linkage Unit. I also looked at which of these outputs had influenced health policy or clinical practice. This work is detailed in the Summary of the Research Outputs Project 1995 to 2003 available at <http://www.data-linkage-wa.org.au/go/data-linkage/research-outputs> Also in: 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.

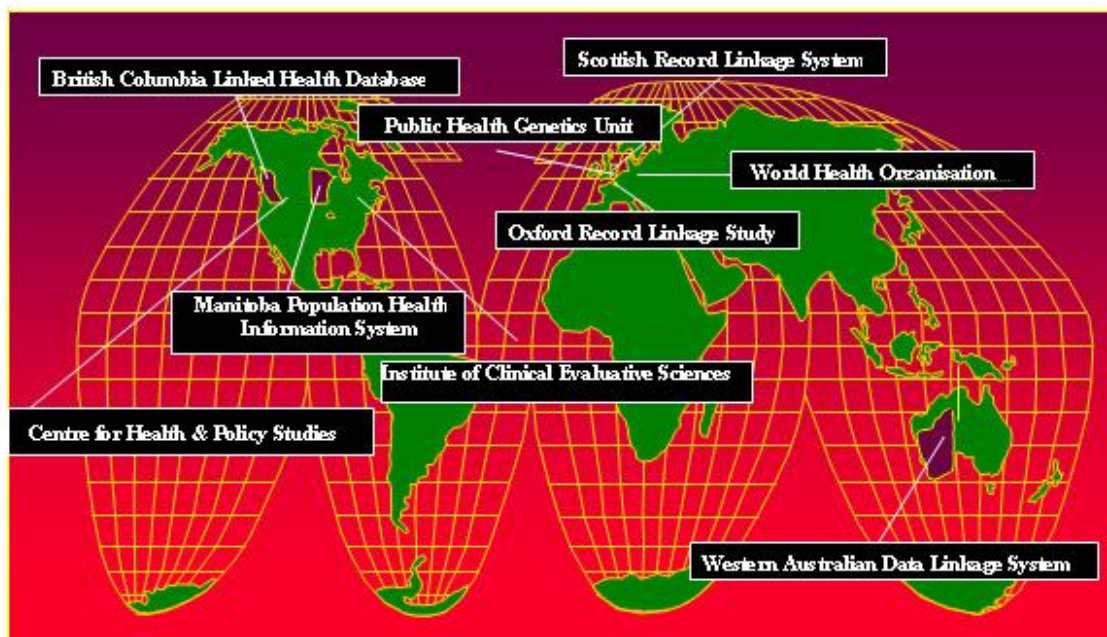
The natural progression of my interest in data linkage began to expand out of Australia. Questions I had included: What were other data linkage centres doing? Where were they? What data did they have access to and how were they allowing researchers to access this information? How many people worked there and what political pressures were they facing? How do they link the data?

The literature searches were not providing me with the information I was seeking.

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
- Population Health Genetics Unit, Cambridge University, United Kingdom
- Scottish Medical Record Linkage System, National Health System, Edinburgh, Scotland



International Data Linkage Centres visited between October 13th 2006 and January 26th 2007

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. I also suggested the ideas of an international consortium of data linkage centres, a staff exchange program and an international data linkage conference.

The centres that are described in this report are by no means the only data linkage centres in the world. They are just the ones I visited. They were chosen as the main existence of these places is to link health data and provide access of the deidentified linked health data to researchers and health policy planners. There is of course the wonderful data linkage work performed by the Scandinavians, Danes & Swedes.

My idea is to establish an international consortium of data linkage centres. To provide a forum in which researchers, policy makers, privacy officers and directors can communicate and disseminate

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information. Essentially I envisage the bringing together of everyone who is involved with data linkage at an international level.

In doing so, I hope that an effective and useful network of international data linkage centres will be created.

Support for the international data linkage consortium was sought in the form of signatures from the Directors and colleagues of the centres. These signatures are attached to this report. This information was taken to the World Health Organisation in Geneva and presented to the Directors of Measurement and Health Information Systems and Research Policy and Cooperation within the branch of Evidence Information and Policy.

It is hoped that many of the other data linkage centres will be happy to participate in the international consortium. I strongly encourage them to contact either myself or the consortium to establish a way to do so.

During my travels, I met many people and organisations that I would not have otherwise planned to meet. A network unfolded.

Thank you very much to the following people for their help, time and hospitality:

Charlyn Black, Kim McGrail, Nancy Hogan, Denise Morettin, Brent Hills, Kerry Kerluke, Harold Yip, Anna Loh, Barbara Weinberg, Sean MacDonald, Chris Balma, David Renardson, Steve Morgan, Hude Quan, Stafford Dean, Andrew Fong, Mingfu Liu, Bing Li, Colleen Maxwell, Lori Cholma, Danielle Southern, Norm Campbell, Jack Tu, Tom Noseworthy, Brenda Lovell, William Ghali, Les Roos, Noralou Roos, Patricia Martens, Paulette Collins, Charles Burchill, Randy Fransoo, Anita K, Pat Nichols, Randy Walld, Shelley Derksen, Rob Santos, Rod McCrae, Ruth Bond, Pam Slaughter, Lisa Lix, Colleen Metge, Louis Barre, John VanWelleghem, Jan Huxtable, Donna Turner, Brenda Ellis, Michael Goldacre, Leicester Gill, Clare Wotten, Susan Flynn, Stavros Petrou, Jane Wolstenholme, Valerie Seagroatt, Ron McCandlish, Janey Read, James Boyd, David Walsh, Kevin McInney, Bill Dunn, Angus K McFadyen, Jim Chalmers, Richard Dobbie, Jim Waldron, Rod Muir, James Boyd, William W Lowrance, Tikki Pang, Tiemas Boema and many others.

Thank you also to Professor D'Arcy Holman, Di Rosman and the staff of WA Data Linkage Unit.

Many thanks to The University of Western Australia for awarding me with the fellowship and providing me with an invaluable opportunity that enabled me to do this work.

User Guide

The “International Health Data Linkage Centres: Findings of a Fay Gale Fellowship” is intended for use by:

- Directors, Managers and staff of Data Linkage Centres
- Affiliated staff of Data Linkage Centres
- Privacy lawyers and those involved in the protection and security of linked data
- Researchers conducting data linkage studies
- Members of ethics boards reviewing data linkage projects
- Those involved in the governance of data linkage centres
- Those involved in the funding of data linkage centres
- Health consumers

How the report can be used:

To learn how major international data linkage centres operate with regards to:

- Funding
- Governance
- Organisation structure
- The application process
- Ethics approvals
- Datasets
- Research, projects and outputs
- Technical aspects of the linkage
- Electronic storage and security
- Teaching and education programs

The report is structured as follows:

- Introduction
- User Guide
- Chapters on each of the main data linkage centres visited
- A overview of the establishment of an international data linkage consortium

- Copies of signatures of support for the international consortium
- A summary of data linkage activities at an international level

Generally only summary information has been provided in this report with markers to websites, the documents or the contacts if further information is to be sought by the reader. This report is by no means intended to be a replication of documented work at each of the centres visited but rather a collation of the information about data linkage at an international level. The information reported here has been ascertained by conversations with people involved with the work of the centres, researchers, policy makers, privacy specialists and government officials. Where information has been taken from documents or websites, the reference is given directly beneath. The information is factual at the time gathered in 2006 and 2007.

For any misrepresentation or errors in the report, the author sincerely apologises. Some sections of this report are not as complete as others. The intention is that this is a document is a starting point for a sharing of knowledge with regards to health data linkage activities. It is anticipated that it can be routinely amended as changes occur to centres, projects are completed and research outputs are produced.

This report only contains information on the data linkage centres visited. To the author's knowledge, whilst this report has been in preparation, New South Wales in Australia has established the Centre for Health Record Linkage (CheReL) and the South Australians are working towards establishing a whole of government data linkage centre. Other centres such as New Foundland & Labrador, in Canada have made themselves known.

This information was gathered in October 2006 and represents the activities of the BCLHD at that time. The operations of the BCLHD, like all organisations, continue to evolve and change.

This chapter has been completed with the editing assistance of Denise Morettin and Dr Kim McGrail of the CHSPR.

British Columbia Linked Health Database

<http://www.chspr.ubc.ca/data>

About

The British Columbia Linked Health Database (BCLHD) is part of the University of British Columbia Centre for Health Services and Policy Research.

“The Centre for Health Services and Policy Research (CHSPR) is an independent research centre based at the University of British Columbia. CHSPR’s mission is to stimulate scientific enquiry into issues of health in population groups, and ways in which health services can be best organised, funded and delivered. Our researchers carry out a diverse program of applied health services and population health research under this agenda.

Much of CHSPR’s research is made possible through BC Linked Health Database, a valuable resource of data relating to the encounters of BC residents with various health care and other systems in the province. These data are used in anonymised form for applied health services and population health research deemed to be in the public interest.

CHSPR has developed strict policies and procedures to protect the confidentiality and security of these data holdings and fully complies with all legislative acts governing the protection and use of sensitive information. CHSPR has over 30 years of experience in handling data from the BC Ministry of Health and other professional bodies, and acts as the access point for researchers wishing to use these data for research in the public interest”

Source: The Centre for Health Services and Policy Research Privacy Policies and Procedures January 2004.

The BCLHD is a valuable resource of data relating to the encounters of BC residents with various health care and other systems in the province.

History

The Centre for Health Services and Policy Research (CHSPR) and its predecessor, UBC's Division of Health Services Research and Development for over 20 years have maintained and provided access to health-related data by agreement with the BC Ministry of Health and other bodies. The linked data project began in 1988 by researchers at UBC, BC Ministry of Health and BC Cancer Agency. Development of the BCLHD began in the early 1990's and it was 'constructed to capture the power of analyses using linkable, longitudinal data, without having to create linkages on a project-by-project basis'. Research use began in 1996, after an access policy was developed by the BC Ministry of Health that complied with the (then new) British Columbia *Freedom of Information and Protection of Privacy Act*. . Since 1996, the BCLHD has provided data for more than 120 health care and health services research projects. CHSPR acts as the custodian of data received from the Ministry and other professional bodies and the BCLHD is responsible for preparing the data for approved research projects.

Source: CHSPR website

Organisation

The BCLHD was established in 1996 and CHSPR was established over 30 years ago.

The Mission Statement of CHSPR is:

“Advance scientific enquiry into issues of health in population groups and ways in which health services can be organized, funded and delivered.”

The BCLHD is located at:

Centre for Health Services and Policy Research
201-2206 East Mall
Vancouver, BC V6T 1Z3 Canada

Phone (604) 822 4969 Fax (604) 822 5690 Email enquire@chspr.ubc.ca

Twelve people work as part of the core BCLHD team and thirty five people work at CHSPR, making for a total of about forty five (when taking into account part-timers)

The BCLHD team is comprised of the following positions:

- Manager
- 5 x Programmer/Analyst
- 2 x Senior Programmer/Analyst
- CHSPR Network and Systems Security Manager/Privacy Officer
- PHLO System Administrator
- Data Liaison Coordinator
- Documentation Specialist

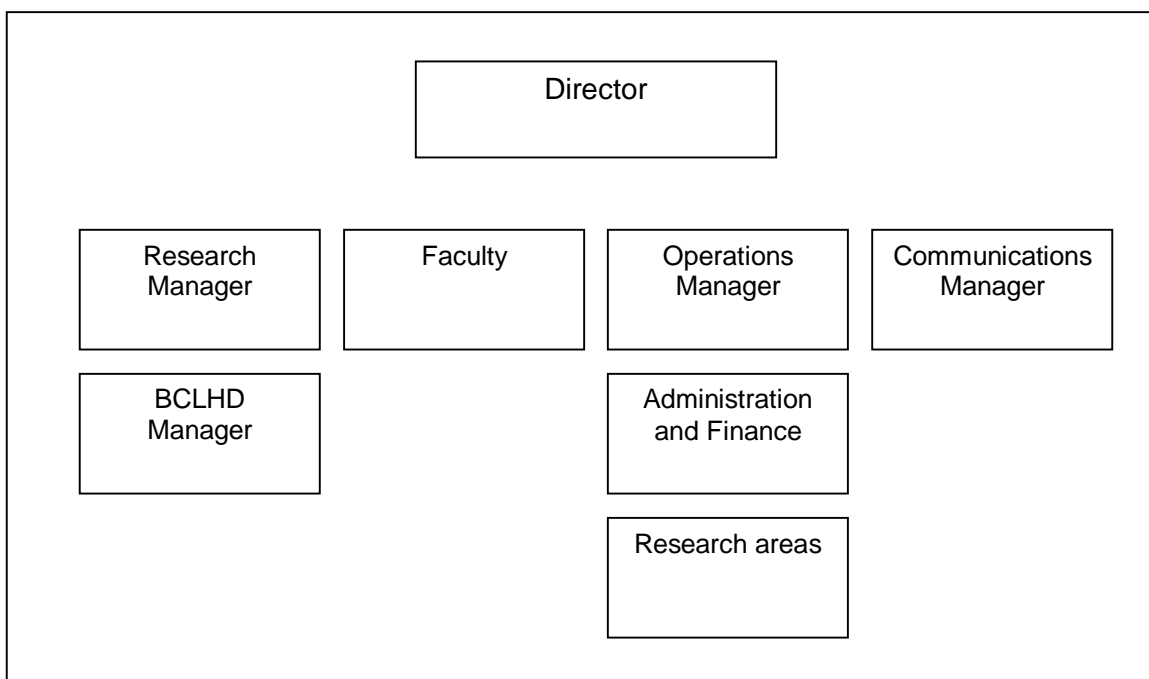
All emails to BCLHD are sent to a Data Help address, datahelp@chspr.ubc.ca The BCLHD Manager and Data Liaison Coordinator jointly respond to these emails. When an email is received to the Data Help address, an auto reply email is sent to the sender that states a response will be received from the BCLHD team in 5 to 7 days. This creates a buffer and enables the BCLHD staff to not be bogged down by emails.

The programmers complete all data cleaning, linkage and extraction operations. There is no such thing as a 'linkage officer'. CHSPR has an operations manager who is responsible for recruitment, maintenance of job descriptions, training and education of staff.

With regards to primary research, a little more than half the funds from the Ministry of Health are dedicated to the BCLHD to provide infrastructure and the remaining funds are used to perform policy work and research. The BC Ministry of Health and CHSPR faculty jointly negotiate research deliverables.

As at October 2006, there is a 3 year contract with the Ministry of Health for \$550,000 CA per annum for the continuing operation of the BCLHD. Lawyers are involved with the development of the contract, and the University is responsible for management of the funds.

The structure of CHSPR:



There are monthly staff meetings and all are expected to attend. New staff are given a training plan which details 4 key competency areas, knowledge and skills, productivity and organisation skills, problem solving and responsiveness and teamwork, interpersonal and communication skills. Employees' progress is reviewed at the 1, 3, 6 month mark and from then on in 1 year reviews. All staff upon commencement of employment are on a one year probation. All positions are sanctioned and advertised by, UBC human resources. Recruitment of new employees is by CHSPR team based interviewing and provision of knowledge tests to the potential applicants. Once employed, all of the CHSPR team assist with training.

To work at CHSPR there is a general requirement of completion of an undergraduate course and a Masters or a combination of training and experience. All jobs are advertised on the UBC website, with contracts and job descriptions.

Before each review, there is a pre-team meeting to discuss the new employee's progress. Any comments are shared with the new employee in their review. During each review the applicant is asked if they have the right equipment to do their job and 'is this the job that you thought it was?' There is funding for professional development and employees are able to take training courses such as online SAS courses when required. Any courses taken at UBC have a tuition waiver.

The operations manager assists with financial support of CHSPR, training courses and strongly encourages professional development. They are also involved in HR administration, strategic planning, hiring and management of staff. In February 2007 the annual CHSPR conference will be held for 250+ people.

Funding

CHSPR receives core funding from the BC Ministry of Health, ongoing support from the University of British Columbia and the UBC College of Health Disciplines. Research is funded by competitive external grants from provincial, national and international funding agencies:

- Canadian Health Services Research Foundation
- Canadian Institute of Health Research
- Commonwealth Fund
- Health Canada
- Michael Smith Foundation for Health Research
- WorkSafeBC

The BCLHD is an independent research organisation funded by the British Columbia Ministry of Health. There is a 3 year financial contract between the BCLHD and the BC Ministry of Health and a 1 year financial contract with CHSPR. As of October 2006 the contract has been undergoing negotiation. There is a contribution from the University of British Columbia to the BCLHD, in terms of accommodation, other infrastructure and a small amount of direct financial support. The research component is split from BCLHD, with the research completed by other parts of CHSPR.

There is a cost recovery/fee for service charge for research projects. The charge is \$550CA a day + \$150CA administration fee. If amendments are made to a project with regards to cohort selection after the contract with CHSPR has been signed, a further \$1000CA is charged. Students are not required to pay for linkage services. However where possible some funds are requested from the grant funder for the student project if they are available. Vital Stats clinical data (e.g. underlying cause of death) is charged at \$500 per year of data requested. Longitudinal studies using the Vital Stats data can work out to be very expensive.

Governance

The Manager of the BCLHD reports to the Director of CHSPR. The Manager liaises with people at the Ministry of Health with regards to the operation of the BCLHD and the review of research projects for which CHSPR prepares data. The work done is influenced by the Ministry of Health in what they approve and what data they choose to release. There is no formal management committee of the BCLHD.

The Privacy Commissioner of British Columbia is aware of and supportive of the work of the BCLHD.

The BCLHD complies with all legislative acts governing the protection and use of sensitive information. CHSPR has also developed its own suite of policies and procedures to ensure high level protection of sensitive data.

Legislative Acts

- The BC Freedom of Information and Protection of Privacy Act, Freedom of Information and Protection of Privacy Act RSBC 1996 Chapter 165
http://www.qp.gov.bc.ca/statreg/stat/F/96165_01.htm

“Part 3 – Protection of Privacy, Division 2 – Use and Disclosure of Personal Information by Public Bodies

Disclosure for research or statistical purposes

35A A public body may disclose personal information or may cause personal information in its custody or under its control to be disclosed for a research purpose, including statistical research, only if

(a) the research purpose cannot reasonably be accomplished unless that information is provided in individually identifiable form or the research purpose has been approved by the commissioner,

(a.1) the information is disclosed on condition that it not be used for the purpose of contacting a person to participate in the research,

(b) any record linkage is not harmful to the individuals that information is about and the benefits to be derived from the record linkage are clearly in the public interest,

(c) the head of the public body concerned has approved conditions relating to the following:

- (i) security and confidentiality*
- (ii) the removal or destruction of individual identifiers at the earliest reasonable time;*
- (iii) the prohibition of any subsequent use or disclosure of that information in individually identifiable form without the express authorization of that public body, and*

(d) the person to whom that information is disclosed has signed an agreement to comply with the approved conditions, this Act and any of the public body's policies and procedures relating to the confidentiality of personal information.

The relevant legislative framework can be found at the front of CHSPR's privacy policy.

The BCLHD abides by the "least amount of data" rule. That is researchers receive the least amount of data sets, years of data and variables of data in order to answer their research questions. "Fishing" of data is not allowed.

Data Steward Review

The Ministry of Health coordinates reviews by the relevant data stewards for data linkage projects to occur. The project is usually given approval for two years, and in most cases access to data for an ongoing project can be renewed annually until completed. Despite the Ministry of Health giving the approval, it is the BCLHD that sets data retention date based on two years from the data release date. This is because the processing of an application, data linkage, data extraction and quality checking takes time, so the retention date for the project is when the data are released from the BCLHD to researchers. Researchers are expected to ensure that ethical certificates of approval are renewed annually for the duration of the BCLHD project.

There are some restrictions on the collection, use and disclosure of linked health data. As per the Terms and Conditions of the Data Access Request / Research Agreement, data are approved only for use to address specified research questions. If new research questions are identified, a separate data access request must be prepared. Researchers must submit journal papers to the Ministry of Health (MoH) prior to publication in a journal. The MoH has 45 days to review the proposed journal

publication for the purposes of risk of re-identification (e.g. cell sizes less than 5) and for any gross misinterpretation in use of the data.

For BCLHD projects, there is a standard confidentiality agreement that must be signed by all members of the project team (e.g., applicant, project manager, and analysts)

All staff of CHSPR must sign a confidentiality statement. It covers both organisation and individual liability. As of October 2006, the statement was being revised.

The community is not involved in governance of the BCLHD and there is no consumer participation in data linkage activities.

CHSPR has a privacy committee with designated individuals. The committee meets up four times a year and sets policy and training for the centre.

In 2001, the United States of America introduced the USA Patriot Act. It was considered by Canadians to be an Act that was rushed in 'broad measures' and there was extreme concern about the USA being able to access health data about Canadian people. The Patriot Act stated that it was able to access any information in the country, including that stored in the country by other countries i.e. if CHSPR had off-site electronic storage back-ups of health data in the USA (which it does not), it would mean that legally, the USA could access the information if it was required.

"The USA Patriot Act became a focus of the B.C. outsourcing debate. That law, enacted shortly after the 9/11 (2001) terrorist attacks, increased the federal government's ability to obtain records from businesses, libraries and others without significant judicial oversight"
Gellman, Robert. May 5th 2005. Outsourcing in Canada Clashes With Patriot Act" DM News.
<http://www.dmnews.com/cms/dm-news/legal-privacy/32075.html>

Subsequent to the introduction of the Patriot Act, BC modified its *Freedom of Information and Protection of Privacy Act* to ensure that personal identifying information is not stored outside of Canada. Data can still be shared across provinces as it is considered to be in the public's interest.

Due to the privacy acts in place, it is not possible for researchers accessing the BCLHD to be able to contact individuals.

If there is a breach with respect to privacy and security of the data or of data released for an approved BCLHD project, there is a duty amongst staff at CHSPR to report suspected breaches to the Ministry of Health.

The website of the Privacy Commissionaire is www.oipc.bc.ca.gov The Office of the Privacy Commissionaire is extremely supportive of the use provincial health data for linkage purposes.

The BCLHD through CHSPR, with the use of software and linkage strategies is able to add significant value to the health data of BC residents by bringing together records from disparate sources.

As detailed in the CHSPR Privacy Policies and Procedures document dated January 2004:

The Centre operates on a Minimum Rights Model. That is only data that are absolutely essential for the conduct of the research project are extracted and provided to a research team. The data is stripped of any personally identifiable information.

The CHSPR Access policy details the conditions that a public body must meet before disclosing personal information for research purposes. They are:

- The research cannot be reasonably accomplished without that information
- Any disclosure is not harmful to the individuals that the information is about
- The research benefits are clearly in the public interest
- The public body has approved conditions relating to such things as security and confidentiality and the removal of individual identifiers

Source: CHSPR website Home>BCLHD>Data Services>Conditions for Access

Intellectual Property

The BCLHD does not decide who may access the linked data. At all times it is the Data Stewards who make decisions about the use and dissemination of the data held in the BCLHD. Authority over the data is with the data stewards and CHSPR is considered the data custodian and responsible for providing protection of data. The word “ownership” of data is avoided as it is really the people of BC, if anyone, who “own” data.

Issues concerning Academic/Public Health System Interface

In 2004 there were significant privacy issues raised in BC and the entire government slowed down release of data. In some cases, data flows stopped entirely. In all cases, access to data became much more difficult and the processes and requirements were much less clear. The impact included an increase in the time taken for research requests to be approved and data to be released to researchers.

As of October 2006, the Ministry of Health had indicated that they would like perform the health data linkage themselves using Automatch. It appears that the MoH no longer will give identifier data to the BCLHD for linkage purposes. This is subject to ongoing negotiation and discussion about activities allowed under the *Freedom of Information and Protection of Privacy Act* as well as legislation specific to the Ministry of Health.

Additionally, there has been a lot of changes and a restructure at the Ministry of Health. At one point, the Data Access Co-ordinator for data release at the Ministry of Health held a full-time job and was coordinating the review of applications in addition to the full-time work. In the past, the Manager of the BCLHD had direct contact with the Co-ordinator and could request status updates. This liaison process is changing as a coordination team has developed at MoH for which the BCLHD manager can contact, and this liaison process will likely continue to evolve.

Future Developments

Population Health Learning Observatory

Future developments with the BCLHD include the Population Health Learning Observatory (PHLO) which began development in 2006/07. The website for PHLO is <http://www.phlo.ubc.ca>

CHSPR is one of the main partners involved with PHLO, and faculty and staff of CHSPR were involved in writing the grant that won the funding to start this initiative. PHLO aims to use and link educational, occupational, environmental and socioeconomic information to 'create the world's most comprehensive data resource on factors that influence health and human development'. PHLO is aiming to establish inter-jurisdictional collaborations.

The Chief Security Officer of CHSPR is involved with the development of PHLO.

PHLO aims to encompass individual clinician data, comparable data from other provinces and international data on the determinants of health.

A few years ago, Ministry of Health data and education data were linked. This was the first linkage to occur between these two jurisdictions. At October 2006, the linked data had never been used because of concerns over authorisation for disclosure of these data.

In the future, it is likely that PHLO and the BCLHD will merge. PHLO is aiming to separate the linkage process from the analysis of data. There will be a linkage team, a client services team and an analysis team. PHLO is negotiating with the Ministry of Health to receive identifier data with names and addresses to increase the accuracy of links and to ensure a complete population health registry. PHLO will have a network and data will be used internally.

As at October 2006, the 3 initiatives of PHLO were to:

- 1/ Establish a data linkage unit (to link the jurisdictional data)
- 2/ Have a data liaison initiative with the involvement of a privacy officer
- 3/ Systems and security

PHLO is funded by a Canada Foundation for Innovation grant, as part of the Canada Funding for Foundation initiative. The funds provided are for infrastructure in the form of people, equipment and space renovation. Matching funds are to be contributed.

PHLO is building on the history of the BCLHD. It is anticipated that other data resources will be routinely sourced from other jurisdictions. It is hoped that after some time private databases will also be linked in as well. PHLO is to be a two phased operation, a place to do linkage (with identifiers only) and a place to serve and support researchers. Funding has been provided for a) developing more documentation on data sets and b) developing more efficient ways of doing extracts. PHLO will receive applications for data and will fulfil two roles: linkage of the data and privacy and security. The funding is \$7.2 million CA over 4 years, with \$1.5 million for construction, \$4 million for personnel and the remaining 20% sourced from matching funding.

There are 10 Investigators involved with PHLO and four are on the Board. Clyde Hertzman is the Principal Investigator.

Initiative Areas of PHLO are:

- System & security

- Data liaison services
- Privacy
- Identifier management
- Operations – collaboration ‘inter-jurisdictional’ overlap.
- Data acquisition

Application

Researchers can apply for data via the DAR – Data Access Request/Research Agreement. This is located on the BCLHD website.

The DAR requires that researchers:

- Become familiar with all material outlining access requirements, data holdings, cohort definitions and privacy considerations
- Ensure that the ethics and peer review requirements of BCLHD data stewards have been met
- Submit a research protocol and completed DAR to BC Ministry of Health

The approval process is co-ordinated by the BC Ministry of Health and is governed by an access policy that is written specifically to comply with the BC Freedom of Information and Protection of Privacy Act. Proof of peer review (e.g. grant funding) and ethics approval are to be provided as part of the application. If not, the CV of the Principal Investigator is needed and the Ministry may perform an ethical review at the researcher’s expense. Ethics approval and peer review needs to be sought for each application.

The BC Ministry of Health reviews the DAR with the designated data stewards. If the DAR is approved, the researcher and CHSPR are notified. Researchers then sign an agreement with CHSPR to reimburse costs and prepare and deliver the data. CHSPR works closely with the researcher to finalise the cohort definition and will then notify the researcher with an estimate of time for data delivery. There is a flow chart of this process and it is on the BCLHD website.

Project application process

Initially, a researcher contacts either CHSPR or the Ministry of Health. Essentially the BCLHD operates a service desk and provides assistance to applicants including completion of the DAR, and especially with defining an operational cohort definition. A completed application form is received by Data Access Services at the Ministry of Health. After a full submission is made, if the data stewards

approve and consent to release of data for the project, CHSPR then receives the application and progresses with the linkage work. (This is repetitive from above) The Manager and Data Liaison Coordinator are involved across all levels of the application process, with the Ministry of Health, the Data Stewards and CHSPR. Researchers may also need help with their proposal and often need to have a quote from CHSPR to attach to their funding application.

If a researcher requests an amendment for more data i.e. an extra year, an extra variable etc, an amendment must be sent to the Ministry of Health for approval. This can take another several weeks to several months. The BCLHD team can strictly only release data that has been approved by the Ministry of Health and other relevant BCLHD data stewards.

There is a process underway to establish an expedited approval process for amendments.

Regarding the latest available data, the BCLHD has steered clear of the terminology 'to the latest available' for practical reasons. Instead they recommend that in applications, researchers state to the end of the current year by inserting the actual year (i.e. Dec 31, 2006) for each data file (page Schedule A -2 of the DAR).

Applicants should be university-affiliated researchers.

The title on the ethics approval form for a project must be the same as that on an application. The application form that researchers fill out (Data Access Request / Research Agreement) becomes a research agreement once approved. Part C of the form contains the Terms and Conditions which researchers are required to adhere.

The BCLHD has a Project Tracker System that has been built in-house. The BCLHD Manager and the Data Liaison Coordinator are able to access and edit the progress of a project. It is hoped that one day the MoH and researchers will be able to login in and see the parts of the Project Tracker System that are relevant to their project.

All researchers must sign a Pledge of Confidentiality.

In the event a project evolves or changes in any way from original design that was approved by the MoH and other bodies, then it must seek new approval in order to continue access to the BCLHD.

The BCLHD team creates the extraction formula and the cohort definition. The time required for programmers, the Manager and the Data Liaison Coordinator on cohort selection, extraction and data documentation is subject to cost recovery charges. .

The BCLHD team generally will not hold any meetings with researchers until they have already been to the BCLHD website and read the information about the application process.

The BCLHD team answers researcher questions directly about data sets and variables, and liaises with data stewards, if necessary, on the researcher's behalf. The BCLHD team assists with justification of variables; often wording such as 'recommend' and 'it is suggested' is used in assisting the researchers with their applications. The researchers generally will not need to meet directly with the Ministry or Data Stewards. Emails sent to the BCLHD are forwarded to the Ministry of Health if necessary.

Regular amendments are made to extracts but not generally to a cohort.

Explicit instructions are being developed with regards to researchers having to return data and destroy the data they have once they have finished with it. The researchers will have to sign a data destruction form. BCLHD is working with MOH on this.

Datasets

The data linked by the BCLHD covers 4 million British Columbia residents from 1985 onwards. The primary purpose of the data collections is for administration purposes however, data are provided to the BCLHD for linkage and research purposes. The data is person-specific, geographic, population-based, longitudinal, policy-relevant and cross-sector. The data includes:

- Medical Service Plan records
- PharmaCare data on drug prescriptions
- Hospital separations on discharges and transfers
- Continuing Care service transactions
- British Columbia Cancer Agency incidence files
- WorkSafeBC (Worker's Compensation Board) injury reports
- Births and deaths registered in BC
- Mental health care episode records

- Ambulance
- Registration & Premium Billing records

The BCLHD website has information about all the different data sets received from the Ministry of Health and other sources.

The BCLHD holds both service and (some) clinical data. This is all kept in flat files. There are some data quality issues, in particular the completeness of the mental health data, coding changes from ICD9 to ICD10 and also policy changes i.e. family deductibles with respect to PharmaCare data. All caveats normal to the use of administrative data for research purposes apply.

Currently, no names or addresses are provided to the BCLHD for linkage purposes. Only demographic information such as sex, date of birth and postal code is received. All records are supplied to CHSPR with an encrypted Personal Health Number (ePHN). No information is gathered about ethical or cultural background in the administrative data sets. There is also no information on newborns or prisoners

Data are received in either fiscal or calendar year format with most data received up to 2004/05. Each year of data is linked individually and stored individually. There is one file for each year. In some cases additional fields need to be requested from the Ministry. The next update of data is due November 2006.

There are multiple data variable names across the Ministry of Health, technical staff at the Ministry of Health, the BCLHD, the data dictionary and programmers. This can sometimes be problematic when referring to a particular data variable.

The Medical Services Plan (MSP) fee for service data set only has information about Doctors that are paid by service. Information about any Doctor who is paid a salary or through other means is not recorded on the MSP. Therefore not all information about all Dr visits in BC are in the MSP data set.

A data dictionary is provided to the researchers upon delivery of data. The Documentation Specialist at BCLHD has completed extensive work on the data dictionary project. There is a considerable amount of time that is spent by researchers cleaning and understanding the data. Often it is recommended to the researcher that they employ a data analyst. Wiki information is soon to be placed on the BCLHD website for researchers.

At the BCLHD, researchers can take the data with them unlike other centres in Canada i.e. Manitoba Centre for Health Policy and Institute of Clinical Evaluative Sciences where data can only be used within the institution on an internal server.

Research

British Columbia, Manitoba and Saskatchewan are all able to perform data linkage/pharmacy work. Topics of interest at CHSPR include:

- Aged care 65+
- BEERS criterion
- Drugs that elderly people shouldn't be on in combination with other drugs or for a certain period of time
- Measures of appropriateness, determinants
- Prescriber details, i.e. age, sex, training – how does that influence what drugs are prescribed?
- Patient adherence to drugs
- Periodicity, appropriateness, persistence work
- Economics, including: trends in drug expenditure, variations in cost, frequency of use
- Variations of high and low use and access to health services
- Impact of differences in use of medicines across time and place
- Population health interests and hospital service use
- Neighbourhoods

PharmaNet is a universal drug dispensing data system and is held by a professional college (not a government or university organisation) with a separate application process for researchers. PharmaCare is a program for which researchers have access to the PharmaCare data as part of the BCLHD, and includes information on publicly-funded drugs and devices. There is information about PharmaCare on the CHSPR website. Linking PharmaNet to data from the BCLHD is possible but can be costly.

There is an Income based program for pharmacy dispensation in Canada. Prior to this, the information that was collected (through PharmaCare) was age-specific, only for individuals 65+. Now an individual's income is used to work out the payment rate.

Technical Linkage Information

A unique identification number called the Personal Health Number, the PHN, is used for linkage. For each individual, the PHN is used in nearly all health datasets in BC. All linkage related data fields are stored in a Linkage Co-ordinating File (LCF). The LCF contains demographic data only, that is the identifying data required for linkage. The LCF cannot be rewound to a point in time.

The PHN is always encrypted and the BCLHD never has the real PHN, as this is scrambled by the MoH. PHN's are always encrypted by the Ministry. When data is given by other sources such as WorksafeBC & BC Cancer, the information goes first to the MoH, for encryption of PHNs and then passed on to the BCLHD. In some cases, one individual may have multiple PHN's. Validation work of the PHN is being carried out at BCLHD.

Sequence numbers (a unique record ID) are assigned to each record in a data file.

For BCLHD projects, project specific study identification numbers are assigned by the Ministry of Health and sequence numbers are encrypted and provided with the data to researchers. These sequence numbers and project IDs may be emailed by the researcher to the BCLHD team in case of specific questions related to the data extracted. In addition to the PHN and sequence numbers, practitioner numbers are also encrypted. The MoH data stewards are extremely cautious about the release of hospital number and practitioner number. However special cases can be made for release of unencrypted hospital numbers.

A metadata extract with fields i.e. layout (start position, end position, length) and dictionary (field descriptions) is given to the researchers. CHSPR only receives data that the MoH will release, no names or addresses are ever released. Data can either be couriered or picked-up.

Matching is both deterministic and probabilistic, depending on the data files and fields available. The linkage strategy is 2 way only and clerical review is performed. The LCF has outcome strings to variables. In-house software is used to link data. Linkage rates vary from 10% to 90%.

A Draft CHSPR Linkage Specifications document details the following regarding linkage:

- Introduction & rationale
- File Pre-processing
- Weight development
- Comparison of records
- Outcome/string analysis/rule development

- Manual review/Resolution
- File post-processing

Programs used are for linkage are **Inkcmp** and **Inkwgt**. Program documentation is as follows:

Inkcmp – compare linkage fields between two files. **Inkcmp** compares records from file1 with records from file2. Only records having the same pocket value are compared. Program writes the outcomes of the comparisons to a file and writes a summary report of the comparison results to **stdout**.

Inkwgt – apply weights to comparison outcomes generated by **Inkcmp**. **Inkwgt** reads records from outcome file and applies weights according to rules set up in program file and writes the resulting weighted outcome records to weighted file. The program writes a summary report of the weighting results to **stdout**.

stdout – a summary report of the weighting results is written to **stdout**. This report includes new weights that were calculated according to the threshold specified in the program file.

At CHSPR, one server is used for research activities and one server is used for storage of raw data files and data sharing. It is isolated. The system is backed up nightly, weekly and monthly. Back-up tapes are stored in a fireproof safe. There is also secure off-site storage of the LCF.

Family Connections

It is possible to work out family relationships in the BCLHD though the Medical Services Plan Registration and Premium Billing File (R&PB) using the MSP contract and dependent numbers. Fathers are typically the primary care holder and the number of dependents is also listed. When a man and woman are married, the woman is usually added to her husband's MSP card. It can be difficult to work out Mother and Baby relationships. This is because when a baby is born, they are often given their Mother's PHN. Pre-1997, this was standard practice. It is also difficult to link newborns as they often have no information to link to, and no names or addresses.

Projects

150 projects have been received since 1996. Some examples of projects include a Fire fighters study which is looking at the occupational risks of the job.

Outputs

Currently there is no collection of research outputs or an annual reporting system by which researchers can detail what their output production is. This is something however that BCLHD would like to do if the funds became available to do so.

Teaching/Education

The British Columbia community is made aware of data linkage activities by the information provided on the BCLHD website and by word of mouth in research and policy circles. There is no advertising about the work of the BCLHD. There are no specific 'introduction to data linkage' or data linkage analysis courses available to researchers, however BCLHD staff do give guest lectures when requested. Individuals, researchers, analysts and policy makers are able to find out further information about the BCLHD via the website. There is no consumer involvement with the operations of the BCLHD.

Data, data everywhere is a document that raises the issue of the erosion of data. More and more data is being accessed and is expected to achieve more than its original purpose. There needs to be significant resources invested in the validation of variables for analysis.

Staff Exchange

BCLHD staff are interested in participating in staff exchange amongst the international centres. The funding to do so would need to be sourced.

WHO

The BCLHD is interested in forwarding research outputs to the WHO, however they do not currently collect them. This is something they would like to do if the funding was available.

Conference Perth 2008/2009

BCLHD staff are interested in attending a data linkage conference in Perth in 2008/2009. Some would present, some would attend. Charlyn Black would be most interested in discussing the themes of: data development, valid and usefulness of data standards and measurement.

Others that would be interested in report/conference:

- Centre Disease Control in USA – involved with population health resources and the National Information System.
- StatsCanada, CIHI

Summary points

- Data from the BCLHD have supported approx 150 internal and external projects since 1996.
- The potential to incorporate more data files to provide even broader understanding of health and health care
- BCLHD is a partner in larger initiative to develop a Population Health Learning Observatory

Source: BC Linked Health Database Expanding the Research Community's Tool Kit Presentation

What other centres can learn from BCLHD

- A one entry point 'helpdesk' email with an automated reply that the query will be dealt with in 5-7 working days.
- Detailed employee training plans with timelines for what skills are needed and what knowledge is required.
- Website is clear, easy to navigate and very functional.
- Research Briefs and Backgrounders – one page documents detailing research projects. Easy to digest and very informative.
- Regular linkage and programmer meetings with well documented agenda and action lists.

Documents

Below is a list of documents collated:

- Employee Training Plan
- Details 1) Knowledge and skills, 2) Productivity and organizational skills, 3) Problem solving and responsiveness and 4) Teamwork, interpersonal and communication skills need to be known at one, three and six months.
- BC Linked Health Database Expanding the Research Community's Tool Kit presentation by Denise Morettin on September 27 2004.
- Alphabetical list of projects
- The BC Linked Health Database – graphic of datasets
- Information from website: data services, about, data etc
- Data Access Procedure – flow diagram of process
- CHSPR, UBC Confidentiality Statement
- CHSPR contact list
- Overview of the BC Linked Health Database presentation by Denise Morettin HCEP Research in Progress January 06 2006
- Research Brief “Primary health care in British Columbia Physician Supply, Distribution and Practice Collocation (1996/97 to 2004/05).
- Research Brief “Mapping Drug Spending A Tale of Two Atlases”
- Research Brief “Big steps, small leaps: Defining and measuring continuity of care”
- Backgrounder “The BC Linked Health Database”
- Backgrounder “About CHSPR”
- CHSPR Confidentiality Statement – document signed by staff.
- Data, data everywhere...Improving access to population health and health services research data in Canada. Exec Summary April 2005.
- Draft CHSPR Linkage Specifications: 1) Introduction and Rationale, 2) File Pre-processing, 3) Weight development, 4) Comparison of records, 5) Outcome String Analysis/Rule Development, 6)Manual Review/Resolution and 7) File Post-Processing (NOTE – this is a draft
- Program documentation detailing Inkcmp and Inkwgt.
- CHSPR – Privacy policies and procedures Jan 2004.
- Privacy and data security – CHSPR website.
- Privacy requirements – CHSPR website.

- Medical Services Plan MSP Publications. www.gov.bc.ca. www.bcstats.gov.ca
- CHSPR staff lists
- Centre for Health Services and Policy Research Privacy Policies and Procedures. Available on the web at www.chspr.ubc.ca

Other useful documentation

- Public Health and Preventative Medicine in Canada. C.P Shah. 3rd Ed 1994.
- The Vancouver Sun Wed March 8th 2006 – Privacy Nightmare
- Sat March 4th 2006 – Thousands of BC Private Health Records Sold at Public Auction
- Tuesday March 7th 2006 Data tapes sold by government show she was accused of embezzlement, recruiting escorts
- Primary Health Care in British Columbia Physician Supply, Distribution and Practice Collocation (1996/97 to 2004/05). UBC Centre for Health Services and Policy Research.
- Mapping Drug Spending A Tale of Two Atlases

Useful Links

FOIPPA http://www.qp.gov.bc.ca/statreg/stat/F/96165_01.htm

Medical Services Plan in BC www.gov.bc.ca www.bcstats.gov.ca

Website has information on Medical Services Plan publications – information brochures, fee-for-service payment statistics, medical services commission financial statement, patient information guides, publications for group plan administrators and publications for physicians and publications for supplementary benefit practitioners.

This information was gathered in October 2006 and represents the activities of CHAPS and HSAU at that time. The operations of these two organisations continue to evolve and change. This chapter has been completed with editing assistance of Dr Hude Quan from the Centre for Health and Policy Studies at the University of Calgary.

Centre for Health and Policy Studies & the Health System Analysis Unit, Calgary Health Region

<http://www.chaps.ucalgary.ca/>

<http://www.calgaryhealthregion.ca>

<http://www.calgaryhealthregion.ca/qshi/hsau/index.htm>

About

Centre for Health and Policy Studies

The Centre for Health and Policy Studies (CHAPS) is within the Department of Community Health Sciences at Faculty of Medicine of the University of Calgary in Alberta, Canada. CHAPS is a research arm of the University of Calgary and provides graduate education. The main areas of study at the Department are Epidemiology, Biostatistics, Health Services Research and Population Health. CHAPS is involved in health service research, population health and intervention, and health economics.

There are currently six centres at the Faculty of Medicine, CHAPS is soon to become the seventh. There is no indigenous or genetic epidemiology work done at the centre.

Institutes in Faculty of Medicine with the University of Calgary include:

- Alberta Bone and Joint Health Institute
- Hotchkiss Brain Institute
- Institute of Infection, Immunity and Inflammation
- Institute of Maternal Child Health
- Libin Cardiovascular Institute of Alberta

- Southern Alberta Cancer Research Institute
- Population Health Institute (potential)

Statistics Canada holds national data and has built Data Access Centres in several locations in Canada. CHAPS is able to value add to health information with labour, finance information and the National population health survey. A unique Personal Health Number (PHN) is used to link administrative datasets. Researchers in Alberta can access data from Statistics Canada at the Data Centre, including the census RRDC data. Currently there is no linkage across multiple sources at the national level but they are linked at the provincial level.

The University of Alberta and the University of Calgary have proposed to build data havens for research purposes. However Alberta Health and Wellness, which holds the provincial administrative data has not released the data for population health and health services studies at this stage

Calgary Health Region

The Calgary Health Region has a research capacity and is involved in operations analysis and decision making. There are nine regions in the province of Alberta and Calgary is one of them. It has a population of 1.2 million. Linkage of data is able to occur under the Health Information Act. The Calgary Health Region hosts regional health information but has to request data periodically from Alberta Health and Wellness. In some instances, Alberta Health and Wellness has not been prompt at responding to data requests.

The Calgary Health Region develops its own research agenda, supports all researchers involved within the region and at the University of Calgary and serves as a host for health research for investigators who need access to patients, providers and system data. The Calgary Health Region ensures that that the research conducted meets ethical, scientific, privacy and resource management standards.

The Research Vision of the Calgary Health Region:

“Excellence in research for the betterment of clinical practice, service delivery and the health of our population.”

The Research Mission of the Calgary Health Region:

“The Calgary Health Region is committed to research excellence and the integration of knowledge that will positively impact clinical care, the delivery of health services and the health of the population through evidence-based decision making.”

“The Calgary Health Region represents one of the largest integrated health systems in Canada”

Priority of the Calgary Health Region is ‘knowledge transfer’. The prerequisites for a strong research program with regards to data (system and patient) are considered to be: data centre, data access, data linkage, data collection and data analysis.

Source: Calgary Health Region Strategic Framework for Research prepared by the Regional Strategic Research and Evaluation Council, April 12 2005.

History

In 1998 at the Calgary Health Region there was a consolidation of health researchers.

Organisation

The address of CHAPS is
Centre for Health and Policy Studies
Department of Community Health Sciences
University of Calgary, Alberta

At the Calgary Health Region, 25 people are involved with the research work with 8 data linkage and analysis specialists. The Head of the Health Systems Analysis Unit (HSAU) manages the unit.

The HSAU builds a Population Registry for the Calgary region. A Personal Health Number (PHN) has been used for many years. In Calgary, families must pay a premium every year in order to be ‘eligible’ for the national health care. A subsidy program is available for low income families or individuals.

The administrative data is used to monitor healthcare utilisation and quantify health status in the region. The data includes diagnostic information, such as radiology in hospitals.

There has been a dramatic increase in the birth rate in the last few years, with 13,000 births a year in Calgary. Planning model and forecasts have been performed and with the predicted ongoing baby boom it is anticipated that many more midwives and schools are needed for the region.

The HSAU receives 20 to 30 applications a year. Many of these are about health service operations and originate from the Calgary Health Region.

There are data access policies and in order to ascertain access to data, the reasons must be justified. There is no consumer representation involvement in the operations of the HSAU. The work of the HSAU is not thought to be widely known about by the people of Calgary. It is assumed that the majority of people are onboard and would approve of the use of administrative health data for research purposes. The cost for work is priced at \$75CA an hour and at approximately \$3000CA for a quick extract.

Funding

CHAPS is funded by the University of Calgary, Calgary Health Region and competitive grants. Funding is related to performance. CHAPS have contracts with the Calgary Health Region and there is a cost recovery/fee for service charge. CHAPS receives external salary support from competitive agencies.

Governance

CHAPS adheres to the Health Information Act of Alberta and the Statistics Act. It is governed by the organisation Alberta Health and Wellness, Evidence & Research.

Application Process

Calgary Health Region

Website: www.ucalgary.ca/md/CAH/research

The Research Administrator at the Calgary Health Region receives all applications. Projects are assessed for whether they are QI or research. QI applications do not need ethics approval.

QSHI, University of Calgary and the Calgary Health Region perform ethics reviews together. There is an Institutional impact review and a scientific review. The two reviews are combined to see how the Calgary Health Region will be impacted by the study.

The Research Administrator reads through the applications and flags concerns in addition to logging all the project information and sponsor information. There is a legal review process with the institutions which assesses the costs, impact of research and information needs for policy. In 2005-06 there were 415 applications to the Calgary Health Region, 140 of which were pharmaceutical related. Ethics approval will not be given for the project until there is institutional approval. There are two committees, one that meets monthly to discuss project applications and one to assess clinical and co-op trials. The committee process has been going since 1988. Ethics approval for a project is on a one year basis only. Larger projects such as the APPROACH study have a blanket ethics approval.

As of Feb 1st 2006, 64 studies of the 320 so far received were for the use of linked data. The linkage can either be performed by the researcher or by the staff of the HSAU at the Calgary Health Region.

Data Access Request Form for the Enterprise Data Warehouse - HSAU

The Data Warehouse can only be used for querying information and not updating existing information. Access must be approved by source owners (where relevant) and the Privacy Information and Access Office. If data from the Enterprise Data Warehouse (EDW) is copied into another application then the EDW team no longer accepts any responsibility for the quality of the data or decisions made about the data. Nor is the EDW team responsible for any breach of the data by the user.

Access to data is limited to 'only the minimum elements' required. Applicants are reminded that they must have a suitable environment in which to store the data, to have appropriate memory and space and ensure that the appropriate rights and security are in place.

The following information is detailed on the EDW request form:

When requesting access to data that is stored within the Enterprise Data Warehouse (EDW) the following steps must be followed:

1. *Data request via change management process or data request form*

2. *State the purpose of the request*
3. *State how long access to EDW is needed and/or end date of project*
4. *Confirmation that this is the minimum information necessary to fulfil the purpose and that aggregate or de-identified information is not sufficient*
5. *Statement that information will be destroyed as soon as the project is finished if project related*
6. *Statement on how the data will be stored (e.g. MS Access, Excel database table)*
7. *Statement on where the data will be stored. All patient identifiable should be stored in one application that can be password protected.*
8. *Statement that users granted access will use reasonable security measures to safeguard the data (including password protections) and will not share the raw data with other individuals.*

Datasets

Alberta, Canada has a population of 3.2 million with 1.2 million living in Calgary. The population health datasets of the HSAU are summarised in the table below.

Health System Analysis Unit Current Population Health Data Sets

Population Registry	Contains dob, gender, pcode. 1992-March 2006, 99% complete. Annual snapshots taken.
ORIS	Operating room information
Inpatient Abstracts	Contains Intensive Care Unit info
Pharmacy	Hospital based only, Bluecross 65+
DI	Diagnostic Imaging only for hospital
Fee for Service Claims	1994-2005, Regional health, Authority Act
Vital Statistics	Births, deaths. Not all data is included
Home Care	Nursing home, home care, utilisation data
RITT data	i.e. # of hours, post surgery information etc
Facility based LTC	Care records
ER Day Surgery	April July 1996 – 2006

Data is collected in fiscal years from April 1st to March 31st of each year. The PHN is used to link the health data. The actual PHN is received by HSAU, not an encrypted version. Data includes the variables of year, names, postcode, sub-region, date of birth and death. All names and addresses are stored with the health information.

Other information:

- Census information is received from Albert Health
- There is no access to the cancer registry
- Laboratory information such as blood tests, pathology, genetic testing etc is expected to be received within 6 months (as of November 2006)
- There has been an 86% linkage of triage data to the population registry (probabilistic linkage with no PHN linkage)
- The estimated money spent on a service is recorded for inpatient abstracts, ER day surgery, Facility based LTC, Home Care and ORIS.
- The actual money spent is recorded in Fee for Service Claims
- Physician data has information about the provider including number and fee costs
- Death data has autopsy information.
- Hospital data has the CDR key, chart number and the unique identifier for the patient at the site. Hospital data includes Clinical Medical Group (CMG)
- Costing data is held by finance divisions at Calgary Health Service.
- ACES is day patient service data

Demographic Data on the Calgary Health Region service population that is currently available from the HSAU on the web include:

Title	Publication Date	Notes
City of Calgary Demographic Data	Ongoing	Social indicators and trends for Calgary
Population by Alberta Regional Health Authorities	March 2006	Alberta Registry population by RHA according to December 2003 RHA boundaries
Calgary Health Region Historical Population by City of Calgary vs. Other	September 2005	Calgary Health Region population according to December 2003 boundaries

		Calgary vs. Rural
Regional Health Authority Net Migration Matrix	May 2005	RHA net migration matrix
Demographic Profile by CHR Health Districts in the City of Calgary, 1998	June 2001	Statistics Canada 1996 Census indicators and relevant maps.
Demographic Profile by CHR Home Care Areas, 1999	June 2001	Statistics Canada 1996 Census indicators and relevant maps.
Demographic Profile by Airdrie, Cochrane and MD of Rockyview, 1999	June 2001	Statistics Canada 1996 Census indicators and relevant maps.
CHR Population by Communities	March 2001	Calgary Health Region Registry Population by Communities based on mailing address.

Technical Linkage Information

A Personal Health Number (PHN) for each individual is on all health records. It is provincially based, therefore a person who moves to another province after being there for three months, will get a new PHN in the province. PHN is useful for provincial linkages since data are mainly hosted in provinces.

The PHN is used to link the health data. If the record does not have a PHN then a combination of personal information and the hospital chart number is used to link records. Each record is assigned a unique number (i.e. representing hospital admission.)

The linkage technique is deterministic based on PHN. When PHN is not available, the client record is used.

The health data is stored in ORACLE. Programmers use whatever programs they like to link the data and all work differently. Microsoft FoxPro, SAS and Access are some of the software programs used. The Data Warehouse is separated from the analysis. Five people in IT work full-time on loading the data.

Projects / Research

The following projects are operating in the Calgary region:

- ACCES – Alberta Continuing Care Epidemiological Studies: Health and quality of Care in Assisted Living and Long-Term Care.
- Calgary Cardiac & Cognition Study
- Canadian Study of Health and Aging 3 CSHA-3

APPROACH study

The APPROACH study started in 1995 and collects data on all patients in the province who have had catheterizations. Additionally the study analyses the health outcomes and health service use of people with Coronary Heart Disease and donors as well. The APPROACH data has been linked to administrative data, including physician's claims, hospital abstracts, vital statistics and population registry. Patients are sent a survey, on the one and third year anniversary of a catheterization. The study is opt in and patients have the option to participate. There is a 50% response rate to survey with some patients taking up to 1-2 years to return the initial survey. After 5 years of follow-up with no feedback from the patient, the researchers give up on recruiting that individual to be in the study. No information is ascertained about the other procedures that happen to these people in British Columbia, or the USA. Postal codes are aggregated and the APPROACH data is linked to census data. From the census data, median income, education and occupation are ascertained for the study participants. Social aspects of the participants are also investigated.

The second initiative of the project is HEART ALERT. This is looking at all patients not just those that are identified when they have a catheterization. Pre-hospital information is gathered for all persons of interest i.e. ECG's taken in an ambulance on the way to hospital.

Data linkage is performed by the APPROACH group, is deterministic in nature and is performed using the PHN and the hospital chart number. The linkage rate is at 95%. Vital Stats information is linked in as well. Only the death information is linked by Vital Stats and this is provided on a 6 monthly basis. All deaths are linked, not just those related to cardiac arrest.

The APPROACH study is administrated by Diane Galbraith and led by Dr Ghali (General Internist) and Dr Knudtson (angioplasty specialist). There is a team working in Calgary in addition to 4-5 IT people and 2-3 physicians in Edmonton. Two analysts are located at CHAPS, Danielle Southern and Fiona Shrive. Some of the research outputs for the APPROACH study are listed in the Outputs paragraph of this chapter.

The website for the APPROACH study is www.approach.org

Hypertension

Dr Norm Campbell of The University of Calgary studies hypertension using national questionnaires and surveys. Research questions are focused on the use of hypertension medication and an estimation of the total number of people using the medication at what time. Dr Campbell is attempting to track the proportion of population using hypertension medication.

Data is utilised from Stats Canada to look at hospital personalised data and mortality. There is no physical measurement surveillance data that is accessible. A new survey is being sent out in February 2007.

A picture of hypertension across Canada is trying to be achieved. An Ontario study has already been completed. Dr Hude Quan is working on validating the Alberta data and this is currently 70-80% linked. Comparisons are being made with the difference in treatment of hypertension in rural and urban areas in British Columbia. Validation of convenience studies are being performed using a diagnostic algorithm validation.

In terms of the bigger picture, ideally all hypertension information will be linked across the provinces. However the difficulty is that the PHN is different in each province, posing problems for the linkage. Dr Hude Quan is investigating how this can be performed and is responsible for all grant information. The National Diabetes Surveillance Study (NDSS) has managed to link data on a nation-wide level therefore it is anticipated that linkage of hypertension data across Canada is feasible.

Outputs

Shrive, F. M., Manns, B. J., Galbraith, P. D., Knudston, M.L., Ghali, W. M.; for the APPROACH Investigators. 2005. Economic evaluation of sirolimus-eluting stents. Canadian Medical Association Journal. Feb 1. 172 (3) 345-351.

Shrive, F. M., Ghali, W. A., Lewis, S., Donaldson, C., Kundston, M. L. and Manns, B. J. 2005. Moving beyond the cost per quality-adjusted life year: Modelling the budgetary impact and clinical

outcomes associated with the use of sirolimus-eluting stents. *Canada Journal of Cardiology*. Volume 21, No 9. 783-787

Southern, D. A., Knudston, M.L., Ghali, W. A. for the APPROACH Investigators. Myocardial Infarction on snow days: Incidence, procedure use and outcomes. *Canada Journal of Cardiology*/ 2006; 22(1):59-61.

Ghali, W. A., Knudston, M.L., on behalf of the APPROACH Investigators. Overview of the Alberta Provincial Project for Outcome Assessment in Coronary Heart Disease. *Canada Journal of Cardiology*. 2000;16 (10):1225-1230.

Southern, D. A., Ghali, W.A., Faris, P. A., Norris, C.M., Galbraith, P. DD., Graham, M. M., Knudston, M. L. for the APPROACH Investigators. Misclassification of Income Quintiles Derived from Area-based Measures. A comparison of enumeration area and forward sortation area. *Canadian Journal of Public Health*; Nov/Dec 2002;93,6;CBCA Complete.

Southern, D. A., McLaren, L., Hawe, P., Knudston, M. L., Ghali, W. A. for the APPROACH Investigators. Individual level and Neighbourhood-level income measures: agreement and association with outcomes in a cardiac disease cohort. *Medical Care*. Vol 43, No 11, November 2005. 1116-1122.

Onysko, J., Maxwell, C., Eliasziw, M., Zhang, J. X., Johansen, H., Campbell, N. R. C. Large Increases in Hypertension Diagnosis and Treatment in Canada After a HealthCare Professional Education Program. *Hypertension Journal of the American Heart Association*. Published online September 18, 2006. <http://hyper.ahajournals.org>

Teaching/Education

Dr Hude Quan, Dr Peter Farris and Dr Stafford Dean are course instructors of MDSC 659.07 Administrative Data Analysis Methodology at the University of Calgary. Prerequisites of the course are completion of Biostatistics and Epidemiology courses, approval by supervisors to participate in the course and submission of a one page outline of a research project. There are 8-10 projects/students a year and they all utilise linked health region data. Each participant must attend a thirty minute interview and are asked what they want to study using administrative data. A student is only selected if they are interested in the use of administrative data for population health or health services studies. By the end of the course, students are expected to be able:

- To understand features of administrative data
- To appropriately analyse the data for health services and population health research
- To write manuscripts suitable for publications at peer reviewed journals

The philosophy behind the course is that:

‘administrative data have been widely used for research purposes and decision making in governments. Analytical skills unique to the data are required to produce valid reports or manuscripts’.

Source: Course Outline of Administrative Data Analysis Methodology.

The course comprises of lectures and students learning SAS software. Students also have the opportunity to analyse administrative data in a protected environment whilst either supervised by their professors or staff of the Calgary Health Region. Small scrambled administrative datasets are provided to the students for practice purposes.

Dr Hude Quan liaises with the Calgary Health Region to establish one manageable research question for each student that can be answered by the linked administrative data. Students are guided through the ethics approval process, educated about analysis software and assisted with publishing their results in a peer-reviewed journal. The course covers all aspects of a data linkage project from a research aspect and teaches students effectively and efficiently how to use linked data.

Other

StatsCan

In Calgary, Statistics Canada data can be accessed at the Regional Data Centre based on the University of Calgary campus. Application to access data and subsequent approval is administered by Statistics Canada. There are nine terminals in a locked area. Marcus is involved with the administration side and setting up the desktops with the requested data. No phones, laptops, pdas, thumbdrives or any electronic equipment is allowed inside the RDC facility. Researchers cannot bring their own data into a RDC to link. All users of the data must sign a declaration of use and during the time spent analysing data, become a temporary employee of StatsCan. Any analysis performed at the RDC is checked by Marcus and is released by email. StatsCan collects information about the outputs from the use of the data they provide. A list of all datasets available for research

is detailed on the StatsCan website as well on the website of the Prairie Health Research Data Centre. Academics affiliated with the University of Calgary are able to access the data for free. Other users have to pay a fee of \$5,000CA a week. Nearly every University in Canada has a RDC.

Centres & Health Information

The Centre for Health Advancement Calgary Health Region

The network of Centre Directors in Health Services and Policy Research is part of the Canadian Health Services Research Foundation and also the Canadian Institutes of Health Research. They last met on September 16th 2006 <http://www.msfr.org/sub-health.htm>

Staff Exchange

The CHAPS and HSAU staff are all very interested in the idea of staff and graduate student exchange.

WHO

CHAPS and HSAU are very keen to forward research outputs to WHO and participate in an international data linkage consortium.

Conference in Perth 2008/2009

Dr Hude Quan, Dr William Ghali and others are all interested in attending a data linkage conference in Perth in 2008/2009. The timing of the conference though would ideally have to fit with the summer break of the Northern Hemisphere Universities.

What other centres can learn from CHAPS & HSAU of the Calgary Health Region

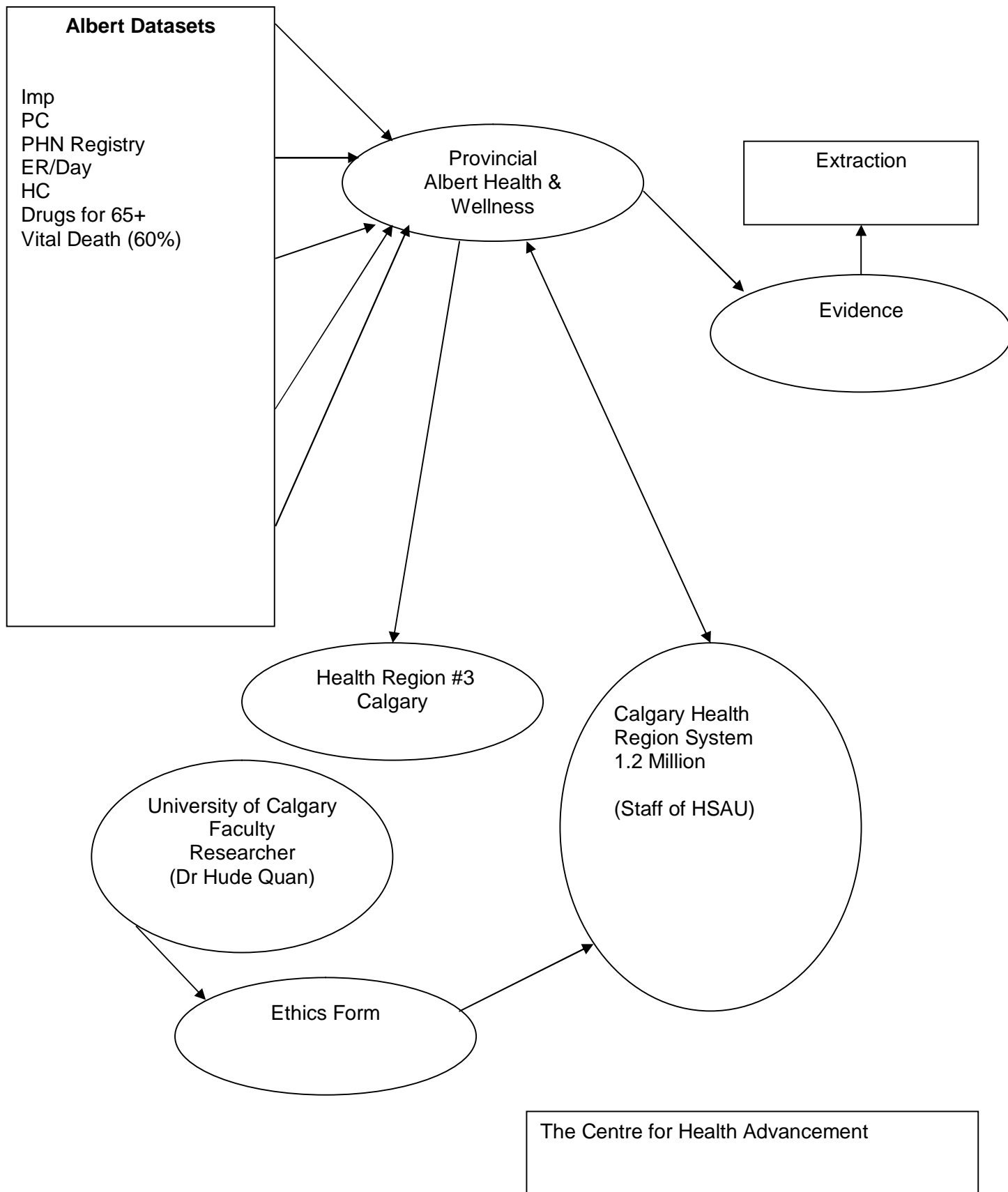
- Excellent education of young researchers in the use and analysis of linked administrative health data via the course Administrative Data Analysis Methodology
- Quick pulls of data for quick questions
- Statistics Canada – data access points at most main Universities across Canada

Documents

- Course Outline - MDSC 659.07 Administrative Data Analysis Methodology, Unit offered by Faculty of Medicine, Department of Community Health Sciences, University of Calgary
- Calgary Health Region Investigation Ethics Screen
- Calgary Health Region Strategic Framework for Research, prepared by the Regional Strategic Research and Evaluation Council, April 12, 2005
- Enterprise Data Warehouse Data Access Request Form
- Calgary Health Region Staff Contact List
- ACCES – Alberta Continuing Care Epidemiological Studies: Health and quality of Care in Assisted Living and Long-Term Care brochure
- Calgary Cardiac & Cognition Study brochure
- Canadian Study of Health and Ageing 3 CSHA-3 brochure
- Canadian Institute of Health Information CIHI Conference 2006 Data Use
- Alberta Health & Wellness Evidence

Books of Interest

- A Telescope on Society – House, Juster, Kahn & Schumar
- Looking at Lives – Phelps, Furstenberg, Colby



This information was gathered in November 2006 and represents the activities of the MCHP at that time. The operations of the MCHP, like all organisations, continue to evolve and change.

This chapter has been completed with the editing assistance of Professor Patricia Martens and Professor Les Roos.

Manitoba Centre for Health Policy

<http://www.umanitoba.ca/centres/mchp/>

About

The Manitoba Centre for Health Policy (MCHP) is based within the Faculty of Medicine at the University of Manitoba. The primary focus of the MCHP is

“What makes people healthy?”

The mission statement of MCHP is:

“To provide accurate and timely information to health care decision-makers, analysts and providers, so they can offer services which are effective and efficient in maintaining and improving the health of Manitobans”

MCHP conducts research on the health of Manitobans, examining patterns of illness and health as well as looking at how people use health care services.

Source: Manitoba Centre for Health Policy – The Manitoba Health Research Data Repository

There are 700,000 people in Winnipeg and 1.2 million in Manitoba.

The MCHP maintains a Population Health Research Data Repository. The repository currently has over 400 million records and spans 20 years. MCHP continually adds more information to the repository.

Data remains the property of Manitoba Health or the providing agency and MCHP acts as steward for the information by accessing and organising files for specific approved research projects.

The MCHP has five year renewable contracts with Manitoba Health to conduct six deliverables per year – five major research studies with the sixth deliverable being knowledge translation of the completed research. The research studies examine patterns of illness and health and look at how people use health services. The studies also involve looking into the broader determinants of health – income, education, employment and social circumstance. The topics of the research studies are jointly decided upon between the Deputy Minister of Health and the Director of MCHP. There is significant involvement between MCHP and government officials, health care administrators, practitioners, decision makers, stakeholders and interested parties in the knowledge translation of the research studies.

Deliverables take about two years to complete. A Project Investigator is assigned by the MCHP to each deliverable and a team is formed, comprising of researchers, programmers and support staff. The team generally meets once a week or once a fortnight. It is possible that individuals may work across several deliverables. MCHP places emphasis on teamwork. There is a working group as well as a research group who meet three to four times a year. This group is not involved in the actual analysis or reporting but is involved in the planning and questions and to provide ‘academic insight’ The role of the working group is to advise on the project in their area of expertise, including: review and suggest improvements to the project methodology; be available for consultation with MCHP researchers on an ad hoc (but limited) basis; provide feedback on the analysis and interpretation of findings; review and comment on draft reports; and provide input to recommendations arising from the study findings.

The contract covers annually 5 new research studies (deliverables), dissemination of the knowledge (deliverable) which includes 3 free workshops held a year, the development, production and dissemination of a comprehensive report, a 4 page user friendly summary of each research study and if applicable a 1 page summary of the research study focused specifically for physicians.

As the contract is ongoing, when there is a change in provincial government, there is a need to re-educate the politicians each time about what the deliverables are and how the data is used. There are two types of government in Manitoba, the provincial Conservatives and the provincial NDP. The NDP does receive labour support. Both governments must honour the Deliverables performed. At times this can be problematic when deliverables are finished and they are answers to questions that a new government does not want answered. Two months before a deliverable report is released, all stakeholders are briefed, including the Deputy Minister and the Minister of Health. There are three

briefings in total and it is not possible for the government to suppress or stop dissemination of the deliverable findings. Both the MCHP and Manitoba government are very focused on truth telling.

MCHP Deliverables

Dissemination of material from MCHP's Deliverables to Manitoba Health includes:

1. publication in journals
2. oral presentation
3. distribution of printed materials at educational or professional conferences or seminars, and
4. publication or oral presentation of thesis material by graduate students

According to agreement, dissemination of the above material other than to MCHP or Manitoba Health is only permissible under following conditions

1. prior written permission is received from Manitoba Health
2. prior notification of at least 30 days provided to Manitoba Health
3. compliance with the Personal Health Information Act

Non-deliverables

Secretary of HIPC needs to be sent a copy of the publication at the time of submission for publication or at least 30 days before publication

Required wording on all documents – all use of material from deliverables should acknowledge MCHP and Manitoba Health and include disclaimer and copyright information.

History

Since 1974, Manitoba Health has provided health care utilisation data to University of Manitoba researchers. In 1991 with the establishment of the MCHP, this information was placed in the MCHP repository. Prior to the information being provided to MCHP, it was processed by Manitoba Health with all identifiers removed whilst keeping the ability to link the records intact.

The renewable contract in place with Manitoba Health for MCHP to conduct Deliverables has been in existence since 1991.

From 1991 to 2004 the number of datasets in the repository has increased from 25 to 60. In 2001, the Canada Foundation for Innovation gave funding to the MCHP to enable the acquisition of large social datasets for linkage purposes. These included Education and Family Services as well as

other additional health datasets. As of 2007 there are 84 datasets and the Manitoba Health five year renewable Contract has increased to \$2.325M per year.

In 2001, the “Need to Know” group was started. It consists of representatives from 11 regional health authorities who meet 3 times a year for 2 days at a time. The idea of the group is that there is a need to get the questions right. The rural days have been hailed a huge success and in 2005, the group was presented a KATY regional impact award for ‘what works’.

The MCHP has been the model on which the establishment of repositories at the University of British Columbia and the Institute of Clinical Evaluative Sciences at Ontario have been based.

Source: Manitoba Centre for Health Policy – The Manitoba Health Research Data Repository

Organisation

The MCHP was established in 1991. It is located at:

Manitoba Centre for Health Policy
Department of Community Health Sciences
Faculty of Medicine, University of Manitoba.
408 – 727 McDermot Ave. Winnipeg, Manitoba R3E 3P5

In 2006/07, over 70 people worked at the MCHP. There are 50 FTE positions, comprising of researchers, co-ordinators, system analysts, programmers, IT and service support. The background of the staff is diverse, with degrees in medicine, psychology, epidemiology, financial planning, statistics, engineering and business administration. Researchers are both tenured University academics and Research Associates of the MCHP. There are also PhD and Masters students who conduct research at MCHP for their thesis work.

The Director of Centre liaises with the Advisory Board of the MCHP and Founding Directors. These two bodies in turn liaise with Administration Support. The Associate Director of the Repository, Associate Director of Research and Chief Administrative Officer all report to the Director and all have their own administration support.

The Associate Director of the Repository is responsible for the following staff:

- Data Acquisition Officer – Acquisition Support
- Manager of Repository Knowledge and Access – Repository Programmer

- Coordinator of External Project Relations – Repository Access Monitor

The researchers are directly responsible to the Director and research assistants are responsible to researchers. They are also responsible to the Associate Director of Research. Research assistants may act in a variety of roles including Research Coordinator, research support and programming

The Associate Director Research is responsible for the:

- Lead Research Coordinator – Research Coordinators
- Programming Supervisor – Programmers
- Communications Officer

The Chief Administrative Officer is responsible for the:

- Office Manager – Research Support and reception
- Information Technology Coordinator – IT support
- Finance Manager – Finance Support
- Communications Officer
- Privacy Officer

The IT staff keep the Repository secure and maintain software and hardware functionality. The Support team assist with all documentation and finances.

The MCHP is comprised of the following positions:

- Director (1)
- Associate Directors (2)
- Researchers and Senior Researchers (11)
- RBC Financial Group Research Fellows (3)
- Research Coordinators (3)
- Systems Development, Programming, Security and Technical Support (20)
- Administration (2)
- Finance & Research Support (10)
- Communication (1)
- Student Research Assistants (17)

New users of the Repository have to read, review and fully understand the following documents in MCHP Documentation Checklist:

1. Orientation policy
2. MCHP Confidential Information Agreement
3. MCHP Card/Access Key Application
4. MCHP Computer Account Application
5. MCHP Pledge of Privacy
6. MCHP Privacy Code
7. The Manitoba Research Data Base
8. Data Access Request Policies and Procedures
9. Protocol for Conducting Administrative Research
10. Policy on Access, Security and Confidentiality
11. Introduction to Computer Resources
12. Policy on Dissemination of Research Findings
13. Guidelines for Deliverable Reports
14. Guidelines for Private Sector Sponsorship
15. Remote Access Policy (where applicable)

Administrative and programming orientation is provided to the new employee.

Communication

The MCHP Communication Plan was created when two independent reviews (beta-test of the Privacy Compliance Tool of the Ombudsman's Office and a Vulnerability Assessment) both noted absence of a communications plan. The objective of the communication plan is to convey to the public and funders, the safeguards in place at MCHP with respect to privacy.

The key messages of the plan are:

- NO names or addresses
- PHIN's are fictitious
- MCHP holds no names, addresses of either patients or physicians
- No real personal health information numbers – real ones are removed by Manitoba Health and are replaced with fictitious (encrypted) ones before received by MCHP
- Results are NEVER at an individual level
- Data is in code and is unusable without knowing file layouts and additional reference material that is kept separately
- Workplace access is controlled by access card + secure front desk for visitors
- Data is PROTECTED by firewalls, encryption, password access, strict monitoring of users

- NO research can be undertaken unless approvals from 3 separate agencies is obtained – The University of Manitoba Ethics Board, the data providers and the Provincial Health Information Privacy Committee
- MCHP undergoes regular security audits and vulnerability assessments AND makes suggested changes
- It is in the best interest of MCHP to always protect privacy
- 30 year incident free track record
- Research using the database contributes knowledge which is in the public good

Communication materials include

1. User-friendly leaflet
2. Card with MCHP Pledge of Privacy
3. Draft news release that could quickly be modified in case of crisis

MCHP have a spokesperson strategy – i.e. who will talk to media regarding MCHP, any data linkage issues arising, health results etc and in their absence, who will take their place. The order of spokespeople for MCHP is as follows:

1. Director, in Director's absence, their delegate
2. Communications co-ordinator
3. Senior administrator
4. Security co-ordinator is resource person but not likely to be speaking to public/media.

Funding

The centre is funded by the Department of Health in the Province of Manitoba and from competitive research grants. These two sources of funds are 50:50.

Manitoba Health Contract Funding has remained the same for the centre since 1994 at \$1.85 million per year. MCHP Researchers are successful in obtaining additional grant funding of between \$1.5 million and \$2 million annually.

Infrastructure in the form of intellect, staff and software capital has been supported by federal and provincial grants and contracts to an amount of \$3 million in 2006

MCHP researchers are reliant on sourcing their own funding. Each researcher is expected to financially support the linkage and extraction processing of their requested data for their grant funded research, through the grant on a cost recovery basis. Research is often sponsored by the

Canadian Population Health Initiative (CPHI), a program of the Canadian Institute of Health Information (CIHI).

Data is not sold. MCHP must cover its operating costs for development, maintenance and protection of the Research Repository. Charges for data access are purely to cover costs.

The MCHP has calculated the cost of obtaining, linking and maintaining a new dataset. It has been costed at \$80,000 in the first year, \$20,000 in the second year and \$5000 for each year after that. As such, MCHP has a committee that annually reviews their cost recovery rate. If a researcher employs the use of a MCHP programmer, they are charged \$85/hour for every hour of work.

If a researcher has a large project it may be cost effective for them to place (imbed) their own programmer in MCHP space full-time. MCHP recovers the cost of an imbedded programmer at a prorated recovery cost of \$25,000 per year. This recovery cost includes the imbedded programmers access and use of the Repository and all its additional resources, i.e. concept dictionary, glossary, programmer's resources, space, equipment, supplies and IT support.

Governance

“MCHP: leading edge research on health and health care issues important to all Manitobans. All undertaken in an environment that protects absolutely the privacy of the individual. That was the promise we made, the promise we’ve kept, the promise we’ll continue to keep.”

Source: MCHP Confidential pamphlet

The Director of the MCHP meets with the Manitoba Privacy Commissionaire, two to three times a year. The purpose of the Information sessions to let the Privacy Commissionaire know what the MCHP is working on. Meetings are also held with the Ombudsman. The MCHP has an advisory board.

The MHCP operates under the legislation of Manitoba's Personal Health Information Act (PHIA). The organisation operates within the National Standard of Canada's Model Code for the Protection of Personal Information.

MCHP's Pledge of Privacy can be viewed at:

www.umanitoba.ca/centres/mchp/policies_external/privacy.htm

It states to

“respect the privacy of all individuals, and furthermore, to protect data against loss, destruction or unauthorized use”

MCHP makes three promises about its work. They are to:

1. Respect privacy: MCHP is a public trustee of sensitive information, bound by legislation, professional ethical standards and moral responsibility
2. Safeguard confidentiality: all staff sign an oath of confidentiality. A break of oath results in immediate loss of access to data and potential dismissal. Records are anonymised before MCHP receives them. All publications are reviewed by Health Information Privacy Committee, the data providers and MCHP management to ensure individual privacy.
3. Provide security: the work environment is controlled, databases are isolated, there is the use of firewalls, encryption, password access and a monitoring of users.

MCHP has a Privacy Code and Principles document and a Pledge of Privacy.

Freedom of Information and Protection of Privacy Act (Manitoba) FIPPA

Purposes of FIPPA

- a. allow any person a right of access to records in the custody or under control of the University
- b. to allow individuals the right of access to records containing personal information about themselves in custody or under the control of the University
- c. to allow individuals a right to request corrections to records containing personal information about themselves in the custody or under control of the university
- d. to control the manner in which the University may collect personal information from individuals and to protect individuals against unauthorized use or disclosure of personal information by the University
- e. to provide for an independent review of certain decisions of the University under FIPPA

The Personal Health Information Act (Manitoba) PHIA

'Personal health information is defined in PHIA as recorded information about an identifiable individual relating to that person's health or health care history, the provision of health care to the individual or payment for health care provided to that individual'

Purposes of PHIA

- a. to provide individuals with a right to examine and receive a copy of personal health information about themselves subject to the limited and specific exceptions set out in PHIA
- b. to provide individuals with a right to request corrections to personal health information about themselves
- c. to control the manner in which the University may collect personal health information
- d. to protect individuals against the unauthorized use, disclosure or destruction of personal health information by the University
- e. to control the collection, use and disclosure of an individual's personal health identification number
- f. to provide for an independent review of certain decisions of the University under PHIA

Privacy, Confidentiality, Security

Research is governed by the Health Research Ethics Board (REB) of the University of Manitoba and by the Health Information Privacy (HIP) committee which approves the use of government based data. The University REB gives 1 year approval for a project. After that time, a continuation of the study must be applied for. Investigators must complete an annual update report for the REB. In addition to this each project must inform MCHP on an annual basis if the project is still active or closed. Currently the HIPC committee approval has no end date. This committee is in the process of changing this process which will result in each project being required to provide an annual update. Research findings must be sent to the provincial HIP and the data provider before publication. Researchers are allowed 'academic freedom' and papers are checked only for the purposes of ensuring that confidentiality has been maintained and that the data has been used appropriately. If the data is about 5 individual events or 5 people, then there are suppression rules. There is a consumer representative on the HIP committee. The regional health authority also has representation.

Both the HIP committee application and other ethics applications are online.

Questions asked in the Health Information Committee (HIC) Request for access to health information held by the government of Manitoba:

1. Date of request
2. Requested by
3. Principal investigators
4. Title of study
5. Study duration
6. Is there more than one phase to the study?
7. Objectives of the study
8. Specific data required
9. Will data held by a department or agency of the government of Manitoba be linked/merged with data from another department or external source(s)?
10. Will the study involve direct access to patients or the public?
- 11. What level of intrusion do you feel your study falls into?**
12. How will the confidentiality of the data be protected by the researcher(s)?
13. Discuss the importance of the research in relation to the level of intrusion
14. Who will be receiving the study results?
15. Will there be any publication of study results?
16. Other information relevant to the submission
17. Please provide a) proof of funding for the project b) proof of ethics committee approval

Declaration

Intrusion

1. Minimal or no intrusion
2. Potential intrusion
3. Moderate intrusion
4. High intrusion
5. Highly sensitive

A MoU exists between government departments to link other data to health information. Manitoba Health, Manitoba Education, Citizenship and Youth, Manitoba Family Services and Housing and Healthy Child Manitoba entered into a Memorandum of Understanding to enable the sharing of data with MCHP in a way that would allow their data within the Population Health Research Data Repository housed and maintained by MCHP to be linked to other data in the Repository.

Under the Federal Privacy Act (FPA), the Health Minister has discretion to link other data as necessary. In the future it is anticipated that community college data (technical/trade schools).

Social services, healthy child and healthy baby data will be linked to the health data in the repository.

The Data Sharing Agreement is an agreement between the data provider and the MCHP, which “constitutes an agreement of the conditions under which anonymised electronic data from a organisation will be disclosed to MCHP in accordance with the provisions stated in The Personal Health Information Act (Manitoba), The Freedom of Information and Protection of Privacy Act (Manitoba) and all other legislative acts governing the use of this data.” There is a new Data Service Agreement with changes to confidentiality.

Definition of “public good” taken from MCHP Privacy Code: the results of linkage are expected to contribute to:

- The identification, prevention or treatment of illness, disease or injury;
- Scientific understanding relating to health;
- The promotion and protection of the health of individuals and communities; or
- Improvements in health system policy and management

The access, use and disclosure of every data set that is housed in the Repository at MCHP is governed by a data sharing agreement with the data provider. Every agreement includes a clause whereby each research project that wants to access/use the specific provider data, must first obtain the Providers approval for the use of their data for that specific project. It is an agreement for each project and it is not given out on a researcher basis. MCHP oversees the process of obtaining the specific provider approval required for each specific project. The Chief Administrative Officer works with the Providers to finalise the Data Sharing Agreement.

MCHP analysts complete the work and abide by the confidentiality rules. There are Confidentiality data agreements for researchers, analysts, linkers, administrators. Anyone who works with or around the data must sign a deed.

For an industry sponsored project, no-one from the sponsoring industry is allowed to be included in the research team for the project, i.e. they are not allowed to be involved in the development of the methodology, analysis, results or publications

MHCP has a tri-policy statement and the Manitoba Ombudsman’s Privacy Compliance Tool was piloted by MCHP.

The privacy commission is at the provincial level and the MCHP meets 2 to 3 times a year with the Provincial Ombudsman. MCHP reviews their privacy policies and procedures and discusses any new initiatives by actively seeking input from the Ombudsman. These information sessions are intended to transfer knowledge.

There are ongoing security audits to test the integrity of MCHP's security procedures and two official audits have been carried out.

It is anticipated that soon, MCHP will offer a virtual private network with data provided by screen shots. Analysts will be able to perform research on the MCHP server, from a remote location. A hardware token, that generates a 6 digit number that changes every 60 seconds will be used to log on to the server. The analyst will need to enter the seed key and time for access. The hardware tokens are RSA and last for 4 years. Further information about RSA can be seen at <http://www.rsa.com/node.aspx?id=1156>

Future Developments

The Winnipeg Regional Health Authority is involved with the development of Repository access arms. This initiative would allow researchers to access project-specific data from anywhere in the world. Access would be via the web and no saving of data or printing of data would be possible. Aggregate data would be checked by a privacy officer in Winnipeg and then emailed to a researcher. This initiative would enable WORLD-WIDE access to health data in Manitoba.

There has been an explosion of interest (in Canada, New Zealand, and Australia) in the multiple-ministry files which MCHP has pioneered. Some of this is noted in Roos et al., *Social Science and Medicine* and there is interesting new data analysis (using multiple outcomes) in Oreopoulos et al., 2008 in *Journal of Human Resources*.

There is some 'convergence' of research possibilities with the Swedish group and American PSID investigators.

Application

Applications must meet with the centre mandate. Researchers are strongly encouraged to discuss their project with MCHP *before* applying for funding and most definitely before applying for ethical approval. Quotes for linkage costs are provided before a formal application is received.

The application process has been formalised and is available at http://www.umanitoba.ca/centres/mchp/protocol_external/

Projects must pass ethical, peer and Provincial Health Information Privacy Committee reviews. Data access is limited to researchers who meet strict protocols, whose research is credible and who will contribute to increased knowledge for public good. As the data repository is legislated, a MCHP researcher must be a co-investigator on a project. Data can only be accessed in a secure environment, however there is a move towards providing direct access for researchers. Researchers are recommended to use the services of an analyst or programmer at MCHP. This is due to the limited scope of access the researchers have to the data (can only access at MCHP) and also the training process, as inexperienced applicants must be taught how to analyse linked data.

Approximately 100 project applications are received a year.

Datasets

All providers are sent a letter when there is a study in order to seek permission from each for use of the data.

Researchers have to work with the data at the centre. The data access room is extremely secure and a security pass is needed to gain access. Researchers are also able to access data directly through Manitoba Health if they are not able to access through MCHP.

The MCHP website contains clear definitions and information about the data in the Population Health Research Data Repository. It holds extensive data dictionaries and concept dictionaries. The Repository contains information about use of physicians, hospitals, home care, nursing homes and prescriptions. It also has information about education and family services. The Registry contains health information about 95% of the Manitoba population. RCMP, military, and inmates are not on the registry. Family connections work can be performed using the family registration number.

Benefits of the Repository include:

1. Entire population is covered
2. Use of identifiers enables history profiles of individuals across files
3. Longitudinal data for hospital & physician claims goes back to 1970
4. Physician claims include diagnostic information
5. Access for many researchers

6. The concept of the repository enables continual upgrading
7. Richness of data is unique as it is derived from multiple unrelated sources
8. Researchers using the data are able to be more productive - \$750,000 to \$1M is awarded annually to grant funded research projects utilizing the repository. Publications in peer reviewed journals + the work supports Manitoba Health in focusing on population-based research and policy analyses
9. MCHP is the steward of the data and monitors use.
10. The data has a high degree of reliability

For individual level administrative data, Manitoba Health scrambles the PHIN. No patient or physician names or addresses are stored in the repository.

Data held includes:

- 1970+ Physician services
 - hospital abstracts
 - Registration Master File
- 1975+ Long term care – pre2003 system
 - long term care – current system
- 1983+ Cadham Provincial Labs (Nov04)
- 1985+ Nursing Home Drug Program
 - MB Immunisation Staff Monitoring System
- 1990+ Mental Health Management Information System
 - MB Support Staff Payroll
- 1992+ Reciprocal Physician Services
- Nonstatistical Physician Services
- Northern Patient Transport (to 1996)
- 1995+ Drug Program Information Network DPIN
- 1997+ Provincial Public Health Stat System
- 2000+ Midwifery Summaries

Manitoba Health Repository De-Identification Support – MH links ScrFileID, scrambles PHIN

Linkage & Scrambling for:

- MFSH – SAMIN, CFSIS, Housing/MHA (Nov04), Child Day Care (Nov04)
- MECY – Enrolment , student tests

- WSD Enrolment
- RRC Enrolment
- Healthy Child Manitoba – Healthy Baby, BabyFirst Screening
- Health Sciences Centre – Maternal Serum, Genetics (pending)
- CCHS 1.1
- CCHS 2.1

Canadian Community Health Survey – MH scrambles PHIN

- CCHS 1.1 2001
- CCHS 2.1 2003
- CCH3 3.1 2005
- NPHS 1996

Manitoba Health Miscellaneous Tables – Reference Only

- Winnipeg Neighbourhood Conversion
- Postal-Municipal Conversion
- Tariff fee schedules
- Drug DIN and DIN category labels
- Bed counts summary

SBGH Magnetic Resonance Imaging – Not Individual Data

- MRI Utilisation Data 1998+

Other Health Agencies – MH scrambled PHIN

- WRHA Emergency Room Data (1999-2006)
- HSC Maternal Serum Screening (1999-2002)
- Bone Marrow Density

Manitoba Health – Non Individual Administrative Data

- 1973-1995 Pharmacare Claims (Families, pre-DPIN)
- 1990+ Physician Master Registry
- MB Support Staff Payroll – Employees
- 1992-1996 Rural Ground Transport (no ID)
- 1995+ Management Information System AKA Annual Hospital Survey
- Facility Locator File
- Electronic User Site Locator

- Population Counts (RETPOPDT)
- DPIN Summaries by Carrier

Vital Statistics Agency –scrPHIN by probabilistic link

- MB Consumer and Corporate Affairs
- Mortality – cause of death 1970+

MB Family Services & Housing scrClientID, scrPHN

- Employment and Income Assistance
- SAMIN 1995+

MB Family Services & Housing scrPersonID, scrPHN

- Child protection and support services
- CFSIS 1992+
- Children with disabilities

Office of Chief Medical Examiner scrPHIN by probabilistic link

- (MB Justice) Under consideration
- Mortality – cause of death

MB Family Services & Housing scrAPPID, scrPHIN

- Manitoba Housing Authority/Housing
- Shelter programs
- Tenant Assistance 1984+
- MB Family Services & Housing scrPartyID, scrPHIN
- Child Day Care Program 2001+
- Submissions and children
- Facilities and spaces

MB Education, Citizenship & Youth scrMET#, scrPHIN

- Systems Technology Services 1995+
- Enrolment, courses and marks
- School and division locator files
- Other de-identification support:
 - scrMET# for WSD
 - scrMET# for Reading Recovery

MB Education, Citizenship & Youth scrMET#, scrPHIN

- Assessment & Evaluation 1995+
- Student testing, absences
- Exams and adaptations

Healthy Child Manitoba Organisation – BFS#, scrPHINMOM, scrPHINKID

- BabyFirst Screening Program 2000+
- BabyFirst Evaluation Survey 2003+

City of Winnipeg – Not individual data

- Winnipeg Police Service – Crime Statistics 2000-03
- Housing
- Neighbourhood Programs

Winnipeg School Division scrWSD#, scrMET#, scrPHIN

- 1990, 1993-2001/2002
- Enrolment and marks

Western Canada Institute of Reading Recovery (2000-2003)

- Student level outcomes
- School level summary statistics

Red River College 1984+

- Enrolment
- Post graduate surveys

Healthy Child Manitoba Organisation scrAppld, scrPHIN

- Healthy Baby Benefit 2000+

Statistics Canada & Data Liberation Initiative (not individual data)

- Census 1986, 1991, 1996, 2001
- Public access census data
- Geographic mapping
- Income quintile resources

Anonymised encounter-based records of individual's interactions with the health care system are derived from information at the Manitoba Health Insurance Registry, health insurance claims routinely filled by physicians, health care facilities with Manitoba Health. Also data from Office of Vital Statistics, Department of Education, Red River College and Family Services and Housing.

1. Hospital file
2. Medical claims file
3. Personal care home database
4. Registration file
5. Mortality file
6. Mental health file
7. Public access census files
8. Hospital statistics part one
9. Financial information system data
10. Management information system data
11. Northern patient and rural ground transport files
12. Manitoba immunization monitoring program files
13. Physician data file
14. Medical nonstatistical file
15. Pharmacare (pre-1995 program)
16. Drug program information network files

Grant funded research special subfiles

- Manitoba Longitudinal Study on Ageing
- The Heart Health Survey
- The National Health Interview Survey
- The Manitoba Health Reform Study
- The Anaesthetic Follow Up Program
- The Statistics Canada/Manitoba Project

Types of data held include:

- Individual level patients data (health)
- Individual level clients data (FS, education etc)
- Aggregate level data

Data Providers to the Repository include:

- Western Region Health Authority
- Manitoba Health
- Regional Health Authority
- Education
- Family Services
- Stats Can
- Vital Stats
- Community Programs
- MIS
- Police
- State Can (census)
- Red River College

MCHP

- Digimon
- Healthsys

Public Domain Aggregate Level Data

- News Letters
- Project Reports
- 4-Pagers
- Media Releases
- Report Briefings
- Concept Dictionary
- Data Dictionary

Manitoba Department of Education Information – Edudata Canada

- **Public and Independent School Enrolment Reporting** – contains info on all students attending public or independent schools in Manitoba, including age, gender, grade level, grade level language information, school they are attending and number of courses enrolled in.
- **BEF Enrolment (Basic French Enrolment Summary)** - number of students enrolled in basic French language program
- **BEF K-8 Classroom** – number of students and their courses for each of the Francais and French immersion language programs

- **Student Course Registration** – contains the courses S1 to S4 that students are registered in on September 30th
- **Student Demographics** – used to share general student information. Can be used to return 'year end' status information.
- **Student Enrolment** - student enrolment information as of September 30th used for grants and funding. Submitted to the department each October from the school division office.
- **Student Health** – student enrolment information in addition to the student's personal health number (PHIN). File submitted to department when requested.
- **Student Marks** – final subject marks achieved by every S1 to S4 student (including failures) during the school year.
- **Student MET** – MET numbers for new students and student with name/birth date changes.
- **Student Personal File** – personal details about a student's mother, father, doctor and medical conditions.
- **TPP Activities** – Information on the subjects and work activities assigned to teachers and professional personnel.
- **Teacher Activity File** – Information on teacher activities, the classes they teach and number of males and females in classroom.
- **Teacher Classroom File** – information on the teacher classroom file.
- **Teacher Employment File** – information on the teacher's position.
- **Teacher Personal File** – contains personal teacher information.

Source: *Edudata Canada* <http://www.edudata.educ.ubc.ca/manitoba/index.htm>

The Education department is working with MCHP to share education data and link with health data for the purposes of studying childhood health and education outcomes.

Education will give health identifiers to MCHP including scrambled Manitoba Education & Training (MET) number, surname, first name, gender, birth date, post code. Education will also give MCHP student enrolment and high school grades data. This is to include data from all years of the Education Information System which have complete records – 1994/95 and subsequent years for seniors 1-4 and 1999-2000 for subsequent years for all grades.

Student enrolment file – scrambled MET, fields that identify school divisions, school, enrolment dates, grades achieved, course loads, program information, indication of special needs, other educational involvements.

Student marks file – scrambled MET, fields that identify the academic year, school, enrolment & leave dates, language of instruction, subjects taken, grades and credits.

Course registration file – scrambled MET, fields will be identified once system is developed.

Standard tests and provincial exams data will be used, data are available for Grade 3, 6 and Senior 1. Also 1991 onward for Senior 4.

Additional information that is deemed useful by MCHP and Education (as agreed by Education) may be given by Education to MCHP.

- information about exams
 - scrambled MET
 - fields identifying subject, exam category & weighting, dates, grades, program, project, language written
- exam adaptations
 - scrambled MET
 - fields identifying exams and adaptations
- completed test results
 - scrambled MET
 - fields that identify exams, schools, marks and completions
- student exemptions
 - scrambled MET
 - fields that identify exams, schools and exemptions

Funding of Schools Program, Categorical Grants Data

- data from Department of Education's Early Intervention Literacy Programs i.e. Reading Recovery. Information on student characteristics, participation and or outcomes will be included. Specific details to be determined by Education and MCHP.
- Scrambled MET
- Fields identifying schools, school divisions, program-specific fields including student characteristics, participation & outcomes

There will be one KEY FILE disclosed by Health to MCHP at the end of the matching and linking process. Key File will contain scrambled MET # and corresponding scrambled PHIN. Key File will include numbers for all clients of all datasets identified by the Standard Tests and Provincial Exams Data.

Healthy Child Manitoba is located at:

Healthy Child Manitoba

Room 219 – 114 Garry Street

Winnipeg, Manitoba R3C 4V6

Tel: (204) 945 2266

Toll-free: 1 888 848 0140

Fax: (204) 948 2585

Email: healthychild@gov.mb.ca

www.gov.mb.ca/hcm

Technical Linkage Information

Linkage is performed at Manitoba Health exclusively by Manitoba Health Staff. MCHP staff help to prepare some of the datasets for linkage.

Non-personalised socioeconomic data containing information about income, education, employment and social circumstance is linked. Information is about groups not individuals.

MCHP receives only the scrambled PHIN, pcode, full dob, gender, service data. The PHIN is 9 characters in length and the Family Registration number is 6 characters. A scrambled ID is received from Manitoba Health. MCHP staff (2 people) go the Manitoba Health to prepare the data for linkage. All linkage is conducted exclusively by Manitoba Health.

Vital Stats provides death data to MCHP and project specific linkage is done at MCHP. Bone density measurement data also given to MCHP.

LinkPro is the software used to link data. The PHIN is used to link records across the different datasets. Linkage is done as needed, sometimes this is only once a year. The records are matched on the PHIN and then manual linkage (clerical review) is performed as needed. Duplications of records are resolved at MCHP. Both deterministic and probabilistic matching techniques are used. A unique number is assigned to all records and the identification numbers are changed to fake ones. Data is stored in a SAS database by year of collection. All information is deidentified before release.

The Registry is the Master file, it contains all people who are eligible for health care. A snapshot of the latest data is received. 97% of the records are linked. A separate linkage is performed for each

file. The PHIN of an individual is added to education data and other datasets records for that individual that do not have a PHIN. Records in the registry that do not have a PHIN are generated a PHIN. MCHP receives scrambled PHIN and service data. MCHP receives most of the health data, except for internal health variables that are created by Manitoba Health for internal use. UNIX and SAS are both used.

The PHIN has been used since 1984 and data files are received from Manitoba Health once a year. Data is in a flat file with a sort merge key and the PHINs provided are encrypted. Linkage is separated from analysis, with linkage performed at Manitoba Health and the analysis at MCHP. Each year of data is stored separately.

There are nightly back-ups of the data. Access to the server room is limited to 4 people.

Projects

A complete list of all the projects using data from the MCHP repository is available. It contains the project reference number, project name, short name, project investigator and status. Information is also collected regarding quotes, ethics approvals and programmer information for all projects.

Outputs

The MCHP collates a list of outputs from research studies. Below are titles of some of the deliverables:

- Defining and Validating Chronic Diseases: An Administrative Data Approach. July 2006.
- Application of Patient Safety Indicators in Manitoba: A First Look. June 2006.
- Primary Prevention: An Examination of Data Capabilities in Manitoba. January 2005.
- High-Cost Users of Pharmaceuticals: Who are They? March 2005.

There are many examples of how MCHP research contributes to public good.

- A MCHP report on Manitoba's children showed that the leading cause of death was injury, with ¾'s of deaths in children aged 15 to 19 is due to injury. Within weeks of the report, Manitoba Health launched an initiative to prevent childhood injuries in the home.

- An MCHP evaluation showed that Manitobans do not use their local hospitals much. These hospitals have low occupancy rates and may keep their patients longer than expected to give them a diagnosis. The Health Minister in July 2002 announced a pilot project with Southeast Manitoba Rural Health Authority to relocate and serve more surgery patients at two local hospitals.
- A 1997 specialist physician report highlighted that Manitobans have the lowest rate of knee and hip replacement surgery in Canada. Within 2 months of the report, funding was transferred (as a result of closure of maternity services at one hospital) to orthopaedic surgery.
- After the death of a child during a routine tonsillectomy, MCHP worked with the College of Physicians and Surgeons to develop a clinical practice guideline. This led to a dramatic decrease in tonsillectomy rates across the province, with children treated for tonsillitis without having to undergo surgery.
- One study showed the impact of flu on hospital overcrowding. Resulted in ad campaign to target groups, 'Get the Shot, Not the Flu'. BC and Ontario both credit the work done by MCHP for expanding their flu immunisation efforts.

Teaching/Education

The Epidemiology of Health Care class is taught by Professor Les Roos.

SAS workshops are run by Charles Burchill, in order to help train new researchers and programmers how to use and analyse the project specific linked data.

Other

“Rules in a box”

This is a checklist for how to set up a data linkage program anywhere.

Manitoba Health

The Director of Health Information Management at Manitoba Health meets with the Health Minister 5-8 times a year to discuss deliverables. The MCHP is protected by format agreements and policies in place for resolution and breaches. At all levels there is integration – from the political aspect down to the programmers. All are involved in the development of the deliverables – not just the top people dictating down. The Director of Health Information Management is answerable to the Chief Financial Officer who is at the executive level of Manitoba Health. They meet every two weeks to discuss 'research that matters'. The deliverables have now been going for 15 years. Data has been given to the Roos since 1970's.

There is a rationale document for the existence of MCHP and the deliverables. There is a constant need to re-educate the people in the government about the existence of the MCHP and what the data is used for. Manitoba Health programmers perform their own validation of the analysis performed by MCHP. There is a sharing of SAS code, coding changes are checked and validated.

Often Manitoba Health and the government asks 'Why are we doing this?' There is a need to constantly focus on the big picture and steer clear of political agendas. Sometimes when a deliverable is completed, the Minister who requested it is no longer in power and the new Minister questions why it was asked for in the first place. It is accepted that the results must be made publically available.

The whole agreement is about relationship building and maintaining relationships. It includes the involvement of senior government, regional health authorities and a government advisory committee. There needs to be commitment at all levels. The right people, with the right personalities in the right places.

A draft report of a deliverable is received by Manitoba Health 2 months before it is released by MCHP. All Manitoba Health staff look at the deliverable, programmers, the policy department, senior officials etc.

The 4 pager is only received 3 days before the release and this is what is consumed by the media. Manitoba Health is interested in receiving this earlier if possible. The staff meet jointly on working groups, which have epidemiologist, statisticians, programmers etc

In 1991 there was an ACTION PLAN and it was about the evolvement of health. It focused on the need for evidence-based policy and NoraLou Roos worked on the very first deliverable. 90% of what is researched shows the quality of Manitoba healthcare, 10% is considered bad i.e. not enough beds, people not receiving health care, mistreatment, misdiagnosis etc.

All research at Manitoba Health is directed through the Health Information Management branch of Manitoba Health. The branch collaborates with StatsCan and CIHI. 16 people work at Health Information Management at Manitoba Health including epidemiologists, statisticians and programmers. Some have a health promotion background, others health information support.

“Health Information Management Branch – provides information management and statistical services in support of the programs of Manitoba Health, the Regional Health Authorities (RHAs), agencies, researchers and the general public. Provides leadership and coordination of health research related activities including support for the Health Information Privacy Committee under the Personal Health Information Act (PHIA)”

Source: Manitoba Health 2003-2004 Annual Report

Objectives of the branch

- To provide the policy and scientific frameworks, standards and processes necessary to ensure the proper use of health data within Manitoba Health, the RHAs and other parties
- To provide the necessary data infrastructure to enable data access, analysis, interpretation and research
- To provide analysis and interpretation of health information to inform and support the strategic functions of Manitoba Health
- To provide leadership and coordination of health research related activities

Expected results

- Departmental policies and standards will be in place for the collection, use and disclosure of health information in accordance with PHIA
- Programs of Manitoba Health, RHAs, researchers and others will have access to health data, interpretation and analysis services to support their needs
- Manitoba Health will have a coordinated approach to health research
- The necessary data infrastructure to enable data access, analysis, interpretation and research will be maintained and developed

Manitoba has a Minister of Health and a Minister of Healthy Living

Manitoba Education, Citizenship and Youth

There is a Memorandum of Understanding between health, family services and housing, health child Manitoba, education and housing. Manitoba Education has no direct questions of the Repository, all the questions and analysis are left to MCHP. The results are used for policy in education. A list of education datasets provided for linkage is available.

CancerCare

CancerCare Manitoba and the Epidemiology Unit collects and provides Manitoban cancer statistics. The Manitoba Cancer Registry dates back to 1930 and has been population based since 1956. There is a legal mandate to collect, classify and maintain health information on all cancer cases in the province of Manitoba. It is a data system that is designed for the collection, management and analysis of data on persons diagnosed with cancer. Is staffed by cancer registrars who are trained and certified health information professionals whose job it is to collect, classify and maintain cancer information.

The Epidemiology Unit researches risk factors, screening patterns, treatment patterns and outcomes such as survival. It is staffed by epidemiologists and data analysts who use information from the Manitoban Cancer Registry as well as from other data sources in order to describe cancer rates and how they vary by age, sex and location.

Cancer and cancer care statistics can be found at the following websites:

CancerCare Manitoba www.cancercare.mb.ca

Statistics Canada www.stanacan.ca

Canadian Cancer Society Website www.cancer.ca

Reports at <http://www.cancer.ca> and <http://www.ncic.cancer.ca>

Staff Exchange

MCHP staff are interested in participating in staff exchange amongst the international centres.

WHO

MCHP is interested in forwarding all research outputs to the WHO on an annual basis. A list of research outputs from each project is collated on a regular basis.

Conference in Perth 2008/2009

Yes interested in attending conference in Perth.

Documents

Deliverables

- High Cost Users of Pharmaceuticals: Who are they? March 2005. Manitoba Centre for Health Policy. Anita Kozyrskyj, Lisa Lix, Matthew Dahl, Ruth-Ann Soodeen.
- Defining and Validating Chronic Diseases: An Administrative Data Approach. July 2006. Manitoba Centre for Health Policy. Lisa Lix, Marina Yogendran, Charles Burchill, Colleen Metge, Nancy McKeen, David Moore, Ruth Bond.
- Primary Prevention: An Examination of Data Capabilities in Manitoba. January 2005. Manitoba Centre for Health Policy. Lisa Lix, Greg Finlayson, Marina Yogendran, Ruth Bond, Jennifer Bodnarchuk, Ruth-Ann Soodeen.
- Application of Patient Safety Indicators in Manitoba: A First Look. June 2006. Manitoba Centre for Health Policy. Sharon Bruce, Heather Prior, Alan Katz, Mark Taylor, Steven Latosinsky, Patricia Martens, Carolyn de Coster, Marni Brownell, Ruth-Ann Soodeen, Carmen Steinbach.

4 pagers

- Manitobans with chronic disease: How Many? How Can We Tell? Summary by Carolyn de Coster and RJ Currie, based on the report: Defining and Validating Chronic Diseases: An Administrative Data Approach by Lisa Lix, Marina Yogendran, Charles Burchill, Colleen Metge, Nancy McKeen, David Moore, Ruth Bond.
- Drug Prescribing in Manitoba: How Appropriate is it? Summary by RJ Currie, based on the report: Pharmaceuticals: Focussing on Appropriate Utilization. Colleen Metge, Anita Kozyrskyj, Matt Dahl, Marina Yogendran and Noralou Roos.

- Hospital Beds in 2020: Will We Have Enough? Summary by Greg Basky, based on the report: Projecting Hospital Bed Needs for 2020 by David Stewart and Robert Tate, Greg Finlayson, Leonard MacWilliam and Noralou Roos.
- On Death and Dying in Manitoba. Summary by Greg Basky and Carolyn De Coster, based on the report: Patterns of Health Care Use and Cost at the End of Life, by Verena Menec, Lisa Lix, Carmen Steinbach, Okechukwu Ekuma, Monica Sirski, Matt Dahl and Ruth-Ann Soodeen.
- Diagnostic Imaging Data: the Good, the Bad, and the Potential. Summary by RJ Currie and Carolyn De Coster based on the report; Diagnostic Imaging Data in Manitoba: Assessment and Applications, by Greg Finlayson, Bill Leslie and Leonard MacWilliam.
- The High Cost of High-Cost Drug Users in Manitoba. Summary by RJ Currie with technical assistance by Carolyn De Coster, based on the report: High Cost Users of Pharmaceuticals: Who Are They? By Anita Kozyrskyj. Lisa Lix, Matthew Dahl and Ruth-Ann Soodeen.
- Assessing Patient Safety in Manitoba Hospitals. Summary by RJ Currie based on the report: Application of Patient Safety Indicators in Manitoba: A First Look by Sharon Bruce, Heather Prior, Alan Katz, Mark Taylor, Steven Latosinsky, Patricia Martens, Carolyn De Coster, Marni Brownell, Ruth-Ann Soodeen and Carmen Steinbach.
- An Apple a Day: Primary Prevention Data in Manitoba. Summary by RJ Currie, based on the report: Primary Prevention: An Examination of Data Capabilities, by Lisa Lix, Greg Finlayson, Marina Yogendran, Ruth Bond, Jennifer Bodnarchuk, and Ruth-Ann Soodeen.

Main documents

- MCHP Privacy Code and Principles http://www.umanitoba.ca/centres/mchp/policies_external/MCHP_privacy_code.pdf
- MCHP Policy on Access, Security and Confidentiality
- Protocol on Conducting Administrative Research
- UoM Policy 238: Use of Computer Facilities
- UoM Policy 216:FIPPA and PIHA <http://www.umanitoba.ca/libraries/units/archives/fippa>
- Provincial Ombudsman's Privacy Compliance tool

Papers

- Bowen, S., Martens, P., The Need to Know Team. 2005. Demystifying knowledge transfer: learning from the community. *Journal of Health Services Research Policy*. Vol 10, No 4, 2005:203-211
- Bowen, S., Martens, P.J. A model for collaborative evaluation of university-community partnerships. *Journal of Epidemiological Community Health* 2006;60:902-907
- Jebamani, L. S., Burchill, C. A., Martens, P.J., 2005. Using Data Linkage to Identify First Nations Manitobans – Technical. Ethical and Political Issues. *Canadian Journal of Public Health*. Vol 96, Supplement 1, S28-S32
- Leslie, W. D., Derkson, S.A., Metge, C., Lix, L.M., Salamon, E.A., Wood Steiman, P., Roos, L.L. Demographic Risk Factors for Fracture in First Nations People. *Canadian Journal of Public Health*. Vol 96, Supplement 1, S45-SMCHP documentation
- Martens, P. J., Sanderson, D., Jebamani, L. S. 2005. Mortality Comparisons of First nations to All Other Manitobans – A Provincial Population-Based Look at Health Inequalities by Region and Gender. *Canadian Journal of Public Health*. Vol 96, Supplement 1, S33-S38
- Martens, P. J., Sanderson, D., Jebamani, L., 2005. Health Services Use of Manitoba First Nations People: Is It Related to Underlying Need? *Canadian Journal of Public Health*. Vol 96, Supplement 1, S39-S44
- Martens, P. J., Roos, N.P. 2005. When Health Service Researchers and Policy Makers Interact: Tales from Tectonic Plates. *HealthCare Policy*. Vol 1. No1. 2005.72-84.
- Mekel, Michele., Shortt, S., E., D. 2005. Coming of Age and Taking Stock: The State of Academic Health Policy Research in Canada

Healthy Child Manitoba documents

- A New Generation of Canadian Families Raising Young Children: A New Look at Data from National Surveys www.manitoba.ca/healthyschools
- A snapshot of early childhood development in Manitoba
- Preparing Manitoba Children for School – Early Development Instrument

- A snapshot of early childhood development in Manitoba – EDI 2003-2004 Results
- Getting ready for school – A parent's guide to helping children learn
- Manitoba Birth Cohort Study: Description and Preliminary Findings
- Child Care Matters
- Growing Minds...Growing Opportunities Consider a career in early childhood education
- Early learning and child care services in Manitoba
- Families First: Program Evaluation Highlights
- Healthy Baby: Healthy Manitoba children get their best start in life
- Families First: For you, your child and family
- Stop FAS: A home visitation program where mentors provide intensive support to pregnant and postnatal women who are struggling with drug and alcohol use
- Spotlight On Manitoba's Parent Child Coalitions
- Leadership: Manitoba's Premier and Healthy Child Committee of Cabinet – established in March 2000 by Premier Gary Doer. Is the only cabinet committee in Canada dedicated to the well being of children and youth.
- Healthy Child Manitoba Office Annual Report 2005-2006
- Healthy Child Manitoba Office Annual Report 2004-2005
- Healthy Child Manitoba Office Annual Report 2003-2004
- Healthy Child Manitoba Office Annual Report 2002-2003
- Investing in Early Childhood Development: 2002 Progress Report to Manitobans
- Supplement to Investing in Early Childhood Development: 2002 Progress Report to Manitobans
- Kids' Health Special Issue 2006 – Published by the hospital for sick children www.sickkids.ca
- Parenting in Motion – National Child Day Forum Nov 6th and 7th 2006 – leaflet
- Child's Play – Rediscovering the joy of play in our families and communities by Silken Laumann www.SilkensActiveKids.ca
- Raising Confident, Competent Children – Discover how the positive parenting program can help you and your children www.manitoba.ca/healthychild
- Manitoba in Motion – Physical Activity – do it for life! www.manitobainmotion.ca
- Healthy Child Manitoba – Ensuring the best possible start for our province's children and youth– Programs and Services
- Investing in Early Childhood Development: 2003 Progress Report to Manitobans – Focusing on Early Learning and ChildCare

Books + Reports

- Centrepiece Winter 2006 Issue No 17.
- Data Flow MCHP document
- “Coming of age and taking stock: the state of academic health policy in Canada” Michele Mekel and Samuel E D Shortt *Healthcare Policy* 1 (1) 2005 140-150
- Looking at Lives American Longitudinal Studies of the Twentieth Century. Erin Phelps, Frank F Furstenberg Jr, Anne Colby, Editors. 2002 Russel Sage Foundation Printed in the USA
- A telescope on society – survey research and social science at the University of Michigan and beyond. James S House, F Thomas Juster, Robert L Kahn, Howard Schuman, Eleanor Singer 2007 USA. The University of Michigan Press.
- CIHR Institute of Health Services & Policy Research – Evidence in Action, Acting on Evidence: A casebook of health services & policy research knowledge translation stories. 2006
- Centre Piece – publication of MCHP, 4-6 issues a year

MCHP reports are available on the website – report summaries or download whole reports at www.umanitoba.ca/centres/mchp or a request can be emailed reports@cpe.umanitoba.ca

Western Regional Training Centre for Health Services Research (WRTC) have an update newsletter. WRTC is a joint graduate training initiative of the University of British Columbia (UBC), University of Manitoba (UM), and affiliated institutions. Update has notes from the Director, information about meetings, training activities, student field placements with health agencies, student awards and conferences, training researcher information, application deadlines. For more details about WRTC, including application materials and current events, visit the website at <http://www.wrtc-hsr.ca>

Institute for Research on Public Policy – Is the class half empty? A population-based perspective on socioeconomic status and educational outcomes. Marni Brownell, Noralou Roos, Randy Fransoo et al. Summary: “Socioeconomic disparities of educational outcomes are far greater than had been previously realized on traditional school based testing. Traditional models of assessing how socioeconomic background is related to educational achievement underestimate the strength of the relationship which in turn contributes to the failure of developing policies that would enable children from socioeconomically deprived backgrounds to overcome disadvantages.”

3 recommendations from the report:

1. Provinces make a priority of developing their capability to track children's progress through the system
2. The design of social programs incorporate a needs-based universal approach
3. Provinces develop policies aimed at changing the trajectories of disadvantaged children within and also outside the school system

2 page report

- Starting Behind, Staying Behind: Low-Income Area Kids and School – summary by R J Currie based on the full report: How Do Educational Outcomes Vary With Socioeconomic Status? Key Findings from the Manitoba Child Health Atlas 2004.
- The MCHP Security Related Responsibilities of MCHP Positions – provides clarification of some duties or responsibilities for MCHP staff within the broader context of the University of Manitoba (UofM) job descriptions related to system and data security – 3 page document.
- University of Manitoba Bannatyne Campus Research Ethics Boards Submission Form
- MCHP Policy on the Dissemination of Research Findings – for all finding which utilize the Population Health Research Data Repository
- University of Manitoba (MCHP) + Manitoba Health Agreement regarding the use of information acquired during the course of producing deliverables for Manitoba Health, agreements with other providers of administrative data such as Manitoba Family Services and Housing, Manitoba Education, Training and Youth, and MCHP's internal historical processes for communicating research findings.
- Confidential Information Agreement – The University of Manitoba and the Researcher of an Institution
- Confidential Information Agreement – The University of Manitoba and the Employee
- University of Manitoba Administrative Bulletin issued Dec 8 1999 and revised June 22 2001 re Freedom of Information and Protection of Privacy Act ('FIPPA' or the 'Act') and Personal Health Information Act ('PHIA' or the 'Act')
- MCHP Data Destruction Policy
 - *"All data deposited in the Repository is retained in accordance with the UofM policy on research materials. The data will be returned to the originating agency if the Repository ceases to exist or destroyed in a secure manner if so directed by the data owner"*
- MCHP Network systems – picture diagram
- Cessation of staff employment/appointment exit form
- MCHP Vulnerability Assessment

- comprehensive network vulnerability and policies/procedures assessment of MCHP information technology infrastructure
 - level of security protecting the target environment is high
 - network vulnerability assessment was conducted from two vectors: externally from Seccuris Labs and internally from the MCHP internal network
 - performed by Seccuris in August 2003
-
- Manitoba Centre for Health Policy secure environment – Research unit strictly safeguards individual privacy – 1 page document ready to go as a media release if needed.
 - Personal Health Information Act and the University of Manitoba

Journal Articles

The following journal articles discuss the use of administrative health data for research.

Roos, L.L., Cageorge, S.M., Austen, E., Lohr, K.N. 1985. Using computers to identify complications after surgery. *American Journal of Public Health*; 75: 1288-1295

Roos, L.L., Nicol, J. P., Johnson, C., Roos, N. P. 1979. Using administrative data banks for research and evaluation: a case study. *Eval Q*; 3:236-255.

Roos, L.L., Roos, N.P. Cageorge, S.M., Nicol, J. P. 1982. How good are the data: Reliability of one health care data bank. *Medical Care*; 20:266-276

Roos, L.L., Nicol, J. P., Roos, N. P. 1984. Using large scale data banks – productivity and quality control: in Bennett EM, Trute, B. (eds): *Mental Health Information Systems: and Prospects*. New York: Edwin Mellen Press, 81-98

This information was gathered in December 2006 and represents the activities of the Unit of Health Care Epidemiology at that time. The operations of the UHCE, like all organisations, continue to evolve and change.

This chapter has been completed with the editing assistance of Professor Michael Goldacre.

Oxford Record Linkage Study

<http://www.uhce.ox.ac.uk/Epidembase2/>

<http://www.uhce.ox.ac.uk/epidem.html>

Overview of History and Organisation

The dataset of the Oxford Record Linkage Study (ORLS) commenced in 1963. It comprises statistical abstracts of hospital admission and hospital day-case records, death certification data, and maternity data. At various times, though not throughout the whole period of its existence, it also included a specialist obstetric and perinatal dataset and it incorporated records of all psychiatric contacts including those made by consultant psychiatrists outside hospital.

From 1963 to 1995, the ORLS was a joint venture between the NHS's Oxford Regional Health Authority and Oxford University's Unit of Clinical Epidemiology (subsequently re-named, and currently named, the University's Unit of Health-Care Epidemiology). The Oxford Regional Health Authority (RHA) was the administrative authority responsible for the provision of health services in its area: it covered the four counties of Oxfordshire, Berkshire, Buckinghamshire and Northamptonshire. At its foundation, data collection for the ORLS originally covered one part of Oxfordshire (population about 350,000) including the city of Oxford. The ORLS subsequently expanded to cover health care in the whole of Oxfordshire and West Berkshire (population 850,000); it then added East Berkshire, Wycombe (part of the county of Buckinghamshire), and the county of Northamptonshire (total ORLS population 1.9 million); and finally it added the health districts of Aylesbury and Milton Keynes in Buckinghamshire (total ORLS population 2.5 million, which was the whole of the population of the former Oxford RHA area).

In 1995, in a major reorganisation of the NHS, the Oxford RHA was abolished. Responsibility for the ORLS dataset passed to the Oxford RHA's successor, the new Anglia and Oxford Regional Office

of the English national Department of Health. A further major reorganisation of the NHS, in 1999, led to the abolition of the Anglia and Oxford Regional Office. The Oxford University Unit of Health-Care Epidemiology then took over sole responsibility for the ORLS. In 1999 there was a further major change of direction for the ORLS. The English national Department of Health advised health authorities to cease collecting data about patients' names and addresses (which, for the ORLS, was previously the mainstay of its record linkage methodology). The Department of Health did, however, promote the universal use of the NHS number. This became the mainstay of the Unit of Health-Care Epidemiology's current approach to record linkage. The Unit is now engaged in the linkage of hospital and mortality data in England nationally. From this, it extracts the data on people who live in the counties of Oxfordshire, Berkshire, Buckinghamshire and Northamptonshire (i.e. the former Oxford RHA/ORLS area) to give an ORLS dataset with continuity from 1963 to the present. The change in linkage methodology means, however, that data on individuals cannot be linked across from the old method, and dataset, to the new.

From the 1960s to the late 1980s, the staff of the ORLS worked in partnership with the statistical staff of the Oxford RHA and provided analytical and statistical service support to the NHS, to researchers, and to anyone with an interest in NHS statistics. Gradually, from the late 1980s, as the processing power of computers increased and costs fell, health authorities provided their own computing and statistical services. NHS staff increasingly looked to their own local health authorities for "data services". The abolition of the Oxford RHA, in 1995, resulted in the abolition of statistical "service" functions at the NHS Regional level. Nowadays, the service provision of NHS statistics is undertaken by the Public Health Observatories (founded in 2000) and, for hospital data including record linkage, by Northgate Solutions. Northgate is the company, with the contract from the NHS Information Centre and Department of Health that is responsible for the national processing of hospital statistical data in England. When the ORLS became the sole responsibility of the University Unit of Health-Care Epidemiology, the ORLS's sole source of funding became its research grants.

The Unit of Health Care Epidemiology is part of the University's Department of Public Health. The site, on which the Department of Public Health and the Unit of Health Care Epidemiology are located, used to be owned by the Oxford Regional Health Authority and was approximately 10 hectares. This area is now entirely populated by Oxford University research departments.

It is important to distinguish that the Oxford Record Linkage Study (ORLS) is not a system and it is not an institution. It is a dataset.

History

The ORLS started in 1962 with Donald Acheson and data linkage began in 1963.

1949: A hospital separation collection started in England nationally (HIPE), It was implemented variably across England at first but was universal by 1955. It was a one-in-ten sample. It was replaced, gradually, in the 1960s by a complete 100% system called Hospital Activity Analysis (HAA).

1963-1994: The data collection system in the Oxford Regional Health Authority, for the national requirement of HAA and for the ORLS, was one and the same. The unlinked version of the data was called HAA, the linked version was called ORLS. The ORLS was headed by Donald Acheson until 1968 and then by Dr John Baldwin until his death in the 1980s.

1963-1979: The principal system was regarded as the ORLS, and subsets of the data were created for NHS “service” uses. The so-called Crockett review in 1979 (named after its chairman) reversed this relationship. The priority for the data collection system, still run by the ORLS, became the provision of NHS service statistics. Research became a secondary, albeit important, function.

1979: This change in operations occurred at the same time that Michael Goldacre was appointed to head up the Oxford RHA’s NHS statistics and information services. This started his long association with, first, NHS “service” statistics and then, later, with record linkage. On the service side, a series of standard reports were prepared for every hospital and every health authority. An “ad hoc” service was provided, for requests for information from individual enquirers and users (including researchers), with an average of 1000 requests a year.

1963-85: Data collection was performed by the ORLS staff, for ORLS and HAA. Staff was trained by the ORLS, and Leicester Gill would go out to see hospitals and make sure that quality assurance was in place. In the pre-electronic data-capture era, Leicester would also collect the data. Data was in paper form and had to be electronically entered. A number of experiments were tried including card punchers, tapes etc to see what was the most efficient method of entering the data. In the late 1970’s to the mid-1980’s, the UHCE also experimented with computerised primary care data systems (the Oxford Community Health Project, and the development of OXMIS).

1985: The national Department of Health asked all health authorities to implement a national minimum dataset on hospital care (the “Korner” dataset”). This impacted on the Oxford ORLS/HAA

dataset, which from then had to conform to the national dataset. This led to a reduction in, for example, the detailed maternity and psychiatry data collection systems. Michael Goldacre, who in principle endorsed the Korner datasets (he was an influential member of the Korner Committee), was nonetheless critical of its rigidity and, in particular, critical of the Department of Health's requirement that all health authorities and hospitals should stop HAA on a single day (December 31 1985) and implement the new Korner systems on a single day a year later (January 1 1987). He persuaded the Oxford RHA to defer the change-over until new systems were fully in place to take over from existing systems. He and his equivalents in all the other English regions – the Regional Specialists in Public Health responsible for information systems – warned that unless a proper transition strategy for HAA/Korner was implemented, English national hospital statistics would collapse.

1985-89: The national datasets collapsed, although the ORLS continued. There are no English national hospital statistics from 1985 to 1989.

1999: The Department of Health decreed that it could not guarantee a legal framework for researchers, cancer registries and others, in processing identifiable data. There was a policy vacuum. Department of Health officials advised custodians of datasets to either get individual-patient consent (impossibility with a historical dataset like ORLS) or delete identifiers. Identifiers in the ORLS were deleted. Hopes turned to the NHS number as a unique identifier and it has been used from 1999 onwards. 1999 was a critical time in ensuring the continuation of collections of health information in England.

2003: The Health and Social Care Act was brought in. The Patient Information Advisory Group was established, by law, to provide a mechanism for authorising the collection of patient data without individual written consent. The cancer registry is still able to access names and addresses. The Department of Health requested the ORLS to host a national linkage project but without the provision of names and addresses for linkage purposes.

About

The Unit of Health-Care Epidemiology, Department of Public Health at the University of Oxford, was established in 1963. The aims of the UHCE are to undertake epidemiological and health services research in particular by using NHS statistical data and using cohort methodologies. The Oxford Record Linkage Study was developed by the Unit of Health-Care Epidemiology with the Statistics

Department of the former Oxford NHS region and contains computerised statistical records of hospital inpatient care, births and deaths in the four counties of the former Oxford Health Region. The collection of statistical records covers the years 1963-1999. It is now an anonymised dataset held by the Unit. It is archived in the sense that, though data in it are analysed, they are not changed with the arrival of new incoming data. However, from the UHCE's national linkage project, linked datasets have been built covering the same geographical areas as the ORLS, from 1999, and the pre- and post-1999 datasets are analysed together for studies that benefit from both (e.g. studies of trends).

Source: Research Protocol: Epidemiology and health services research using routine NHS data: work programme of the Unit of Health-Care Epidemiology, Oxford University, funded by the National Co-ordinating Centre for Research Capacity Development.

The UHCE hosts one of the sites of National Centre for Health Outcomes Development (NCHOD). The other site is at London School of Hygiene. NCHOD produces:

- the national Public Health Common Data Set
- the national Clinical Indicators
- the national Knowledge Base on health outcome measurement
- the database on Patient-Reported Health Outcomes

The work is funded by the Department of Health. Further resources are provided by the UHCE core funding. The funding of the UHCE is from the NHS National Coordinating Centre for Research Capacity Development via the Centre's support for the Oxford Academic Unit for Health Services Research. The South East Public Health Observatory (SEPHO) has also provided resources (Professor Michael Goldacre was one of the founding directors of SEPHO and now fulfils the role of scientific advisor).

The aims of the project are:

- Use linked hospital and mortality data files to
 - Analyse hospital admission rates in each local authority area
 - Study the association between hospital admission rates and the Index of Multiple Deprivation scores for each local authority area
 - Study the outcomes of hospital care
 - Study the association between outcomes

Source: Research Protocol: Development of NHS hospital statistics, using English national linked hospital data, with particular reference to hospital admission rates and outcomes of hospital care: work programme of the Oxford site of the National Centre for Health Outcomes (NCHOD) and of the South East Public Health Observatory (SEPHO)

Organisation

In 2006 there were 6-8 people working with the ORLS. They include a Data Manager/Computer Operator, Computer Programmers and Research Officers. Staff are also involved with governance and teaching.

The ORLS is located at:

Unit of Health Care Epidemiology
Department of Public Health
University of Oxford.

Funding

The sponsoring organisations and funding bodies of the ORLS are detailed in the table below:

Years	Sponsoring Organisations	Funding Bodies	Location
1963-1994	Oxford Regional Health Authority	Department of Health – 5year contracts	Oxford Regional Health Authority/ Oxford University
1995-1999	Anglia & Oxford RO	Anglia & Oxford RO 1 year contract	Oxford University
1999 – 2001	None*	South East England R and D 1 year contracts	Oxford University
2002	None	SE R and D 1 year contract	Oxford University
2003-2004	None	SE R and D 1 year contracts	Oxford University

2005-2010	None	National Coordinating Centre for research Capacity Development 5 years	Oxford University
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Funding for UHCE has been provided from research bodies. From 1963 to 1995 funding was from research and development contracts and the Department of Health. From 1995 onwards funding was provided by the regional office Department of Health, the South East regional office department and the Department of Health South. In 2005, the National Coordinating Centre for Research Capacity Development (NCCRCD) has contributed to 5 years funding for UHCE.

NCCRCD: <http://www.nccrcd.nhs.uk/>

Governance

The Office for National Statistics policy on protecting confidentiality within birth and death statistics explains when disclosure control is necessary for birth and death statistics. The information can be sourced at <http://www.statistics.gov.uk/>

Documents relating to data use and codes of practice:

- ONS - Confidentiality and Data Sharing Protocol
- National Statistics Code of Practice
- Guidance Notes Section 60 of the Health and Social Care Act 2001

Groups involved in approval of data use and linkage:

- Patient Advisory Information Group
- Security Confidentiality Advisory Group (SCAG)
- Multiple Centre Research Ethics Committee.
- Local Oxford Ethics Committee.

Operational Procedures for NHS Research Ethics Committees and guidance for applicants to Research Ethics Committees is available at: www.corec.org.uk email: queries@corec.org.uk The NHS REC application form is also available on the website.

All staff of the UHCE sign a confidentiality agreement also an additional one for the University of Oxford.

Permissions for record linkage by the UHCE, and for studies using linkage, is granted by:

- the Security and Confidentiality Advisory Group (SCAG)

for the hospital data and by:

- the Micro Data Advisory Panel (MDAP) for the death data.

The UHCE also has separate permissions from Research Ethics Committees.

Future Developments

The UHCE has applied for, and has received permission to perform the national maternity linkage.

Application

Data analysis generally performed in-house but there are exceptions. External researchers can apply to use data from the ORLS, despite that the UHCE is not funded to provide data services to others. ORLS records can be provided to researchers outside the UHCE provided that they, and the UHCE, have Ethical Committee permission for the transfer of data. The ORLS is used internally by UHCE staff. There is an application form. Researchers in the National Perinatal Epidemiology Unit have a dataset from the specialised maternity system linked to hospitalisation and mortality. The Childhood Cancer Research Group has files of maternity data linked to cancer data; files of patients with spina bifida; files of twins and their linked records; and files of mothers and babies for pregnancies that followed infertility treatment.

Datasets

Sources of data: synopsis

From its inception in 1963 to the late 1980s, data were collected by staff employed and trained by the ORLS, on behalf of the Oxford Regional Health Authority, in each of the hospitals that were

covered by the NHS data systems that fed the ORLS. From the late 1980s to the early 1990s, responsibility for data collection passed to the local hospitals as part of the localisation of both computing and NHS management. The exact time varied from hospital to hospital. Nowadays, the ORLS gets its data from the national system managed by Northgate Solutions.

English Hospital Trusts now feed their data into a national “clearing centre” which provides data services to the NHS, researchers, and others. In 2003-5, the Unit of Health-Care Epidemiology (UHCE) was commissioned by the Department of Health to pilot English national record linkage of the type previously done by the ORLS on the Oxford data. This was a contract within the UHCE’s work programme for the National Centre for Health Outcomes Development (NCHOD). The UHCE constructed, first a national 5-year file (April 1998 to March 2003) and then a 7-year file (to March 2005). It refined its linkage algorithms and, as part of the contract, provides to Northgate the algorithms for Northgate to do its own national linkages. The UHCE is continuing with national record linkage, under its own agreement with the authorising bodies, and now works with both the historical run of the ORLS, updated from national linkage, and with national linkage itself.

To give some perspective on the size of the population, there are 2.5 million people in the former Oxford RHA area that was covered by the ORLS, 50 million in England and 60 million in the UK. The following datasets are linked in the ORLS:

- Birth
- Death
- Marriages
- Still birth
- Morbidity (over 550,000 years of data based on certificates. It includes all hospital deaths and out of hospital deaths)
- NHS hospitals
- Hospital episode statistics (HES) – 13 million inpatients
- Finished consultant episode (FCE)

There is also the General Physician Research Database (GPRD).

Births, deaths, marriage and still birth data is provided by the Office of National Statistics (ONS).

The general hospital, maternity and psychiatric data all comes in together. Deaths are from all certificates. Birth information is received from public hospitals only. Primary care data has been linked into ORLS.

Records are currently anonymised and encrypted. The NHS number, dob and pcode are all encrypted. Ideally the NHS number means, one number, one person. However there are two problems with this: 1/ it is possible for one person to have two numbers; 2/ an incorrect NHS number can be allocated to a person by a hospital trust

The postcode in England breaks down into approximately 10-15 houses so it is considered extremely identifying. Therefore has to be encrypted. Postcodes can change and this mainly occurs when there is rezoning.

Pre-1999, all clerical review was performed at the Unit. If people are known about in the ORLS, their names are deleted.

Datasets & Management of Them

Years	Datasets
1963-1979	ORLS, feeding HAA (the local + national) hospital statistic system
1979-1985	HAA feeding ORLS
1985	K datasets
1989-1999	Local hospitals/health authorities
1999-present	National datasets → Unit of Health Care Epidemiology

“Hospital Episode Statistics (HES) is the national statistical data warehouse for England of the care provided by NHS hospitals and for NHS hospital patients treated elsewhere. HES is the data source for a wide range of healthcare analysis for the NHS, Government and many other organisations and individuals.

HESonline

The HES database is a record level database of hospital admissions and is currently populated by taking an annual snapshot of a sub-set of the data submitted by NHS Trusts to the NHS-Wide Clearing Service (NWCS). Quarterly information is also collected.

Every year, HES publishes tables of data relating to admitted patient care in NHS hospitals in England. They contain information relating to more than 13 million records and cover a range of topics, including operations and diagnoses.”

Source: <http://www.dh.gov.uk/en/Publicationsandstatistics/Statistics/HospitalEpisodeStatistics/index.htm>

The Hospital Episode Statistics (HES) contains the following information:

- EPIKEY – unique serial issued by the Department of Health UK
- NHS number (downloaded from the National Health Service Central Register)
- Patient details – dob, sex, postcode, NHS Trust Code/local patient identifier
- Admission & discharge details
- Category & classification of the patient
- Intended management
- Diagnosis and surgical procedures
- Dates and order of the episode within the spell
- Purchaser and provider details

It does not include:

- Names of the patient
- Full street address
- Marital status
- Social class
- Occupation
- Drugs or treatment information

The HES has general admissions and Finished Consultant Episodes (FCE). When a baby is born, there is 1 FCE for the mother and 1 FCE for the baby

The National Mortality Data file as supplied by the Office for National Statistics contains

- DTHKEY (assigned by UHCE)
- NHS number (assigned by National Health Service Central Register)
- Patient details – dob, sex, postcode
- Registration details
- Date of death
- Establishment code

- Place of death

Source of data information: "Building a National linked file of Hospital Episodes of treatment (HES) and mortality data (ONS mortality records)". Presentation by Professor Leicester Gill.

Technical linkage information

Linkage is performed once a year. It used to be once a quarter. There was a time when the ORLS had 55 clerical officers working on the study daily.

Calculation of weights and decision tables are the two methods used for linkage of data. Linkage is n-way. UNIX, Fortran, C, Java, IBM UNIX, Windows and FTP platforms are all used. There are 2 UNIX servers and they are used for different projects.

A Master match file is used and a unique system number is given to each record. A lower system number method is carried through for chain information. 7 year data files are used i.e. 1998-2005.

Northgate holds the epikey and all hospital record centres do the coding of the records. The NHS number is kept and used as is. Patient ID, code for general practice, rha, age, pcode, nhs, admdate, sepdate, episode string, death, method of discharge, system numbers are all variables received and used for linkage.

Records are checked for the following:

- Consistent format for each match and statistical file. Then link the two together.
- range check
- standard defaults

A coding frame is calculated with a version number added for codes of the records. The Index of Deprivation is also calculated. Other statistical counts are made.

Using the match file only a selection of blocking factors are chosen i.e. NHS number, dob, sex, postcode, trust code and patient number. Each record gets a unique ACCNUM & SYSNUM from pools of these numbers. A matched file will hold a new sysnum, existing accnum and existing sysnum.

Professor Leicester Gill works on comparison linkages. He looks at encrypted and non-encrypted linkages and then compares linkage rates. Quality checking of the links is also performed.

Information at UHCE is stored on IBM servers, and is backed up 4 times a day and once a week. Back up of the ORLS is performed as needed There is a fireproof safe onsite and additional back-up storage off-site.

Projects

- Abdominal Aortic Aneurysm study from WA has been repeated
- Ophthalmology
- Geographical Mapping
- Long-term trends
- Perinatal studies
- Epidembase
- Geographical profile of whooping cough.
- TURP - Transurethral resection of the prostate
- Gastroectomy & Oosphagusectomy
- Deprivation either by prognostic factor or region
- Heart attack
- Stroke, Cardiovascular Disease, Heart Failure, Subarachnoid haemorrhage,
- Post operational mortality and factors affecting it.
- Incidence of all diseases
- MS and related diseases

Staff Exchange

UHCE staff are interested in participating in staff exchange amongst the international centres.

World Health Organisation

The UHCE is interested in forwarding research outputs to the WHO. Several years ago, Professor Michael Goldacre put the idea to John Fox, when he was the Department of Health's Director of Statistics, and to Sir Muir Gray who is involved with the electronic library for national health, that there could be a Bibliographic database of published uses of routine hospital statistics with the initial focus to be on hospital data but with the idea that it could be applied to any form of health data. The

aim of the proposal is to compile an annotated bibliography of the world literature on uses of routine hospital statistics.

“It is important that people, considering the potential of such systems, know about the considerable body of work that has already been done worldwide using data from routine medical statistical databases”

The aims of Michael’s idea are to:

1. provide information about types of uses, studies, reports & findings
2. key word searches – catalogue by type of application, disease, operation, type of service, client group
3. annotate the references and give a brief paragraph about each

The database would be electronic, user-friendly search wise and available to all via the web.

Conference in Perth 2008/2009

Staff of the UHCE are interested in attending a data linkage conference in Perth in 2008/2009.

Outputs

All publications generated from the ORLS are located on the website. A full list of publications by Professor Michael Goldacre is also available. Below are listed some of the papers by topic. They are a sample of some of the papers produced.

Care of the elderly – health research and health economists

Henderson, J., Goldacre, M.J., Griffith, M. 1990. Hospital care for the elderly in the final year of life: a population based study. *British Medical Journal*, Vol 301, pages 17-19.

Note: WA researchers performed the same study on the WA population: – Brameld, K.J., Holman, C.D. J., Bass, A. J., Codde, J. P. Rouse, I. L. 1998. Hospitalisation of the elderly during the last year of life: an application of record linkage in Western Australia 1985-1994. *Journal of Epidemiology of Community Health* 52:740-744

Himsworth, R. L., Goldacre, M.J. 1993. Does time spent in hospital in the final 15 years of life increase with age at death? A population based study. 1999. British Medical Journal, Vol 319, p 1338-1339.

Time trends NB International comparisons

Roberts, S. E., Goldacre, M. J. 2003. Time trends and demography of mortality after fractured neck of femur in an English population, 1968, 98: database study. British Medical Journal 327

Goldacre, M.J., Roberts, S.E., Yeates, R. 2003. Case fatality rates for meningococcal disease in an English population, 1963-98: database study. British Medical Journal, 327 596-597

Goldacre, M. J., Roberts, S. E. 2004. Hospital admission for acute pancreatitis in an English population, 1963-98: database study of incidence and mortality. British Medical Journal, Vol 328, 19th June 2004.

Roberts, S. E., Goldacre, M. J., Yeates, D. 2005. Trends in mortality after hospital admission for liver cirrhosis in an English population from 1968-99. Gut. <http://gut.bmjournals.com/cgi/content/abstract/gut.2004.058636v1>

Disease Associations

Seagroatt, V. 1995. Mortality after prostatectomy: selection and surgical approach. The Lancet. 346: 1521-24

Seagroatt, V., Goldacre, M. 1994. Measures of early postoperative mortality: beyond hospital fatality rates. British Medical Journal, Vol 309, 361-365

Petrou, S., Mehta, Z., Hockley, C., Cook-Mozaffari, P., Henderson, J., Goldacre, M. 2003. The Impact of Preterm Birth on Hospital Inpatient Admissions and Costs During the First 5 Years of Life. Paediatrics. Vol 112, No 6, 1290-1297

Petrou, S., Kupek, E., Hockley, C., Goldacre, M. 2006. Social Class Inequalities in Childhood Mortality and Morbidity in an English Population. Paediatric and Perinatal Epidemiology. 20, 14-23

Petrou, S., Hockley, C., Mehta, Z., Goldacre, M. 2004. The association between smoking during pregnancy and hospital inpatient costs in childhood. *Social Science & Medicine* 60, 1071-1085.

Henderson, J., Hockley, C., Petrou, S., Goldacre, M., Davidson, L. 2004. Economic Implications of Multiple Births: Inpatient Hospital Costs in the First 5 Years of Life. *Arch Dis Child Fetal Neonatal Ed* 89:F542-F545.

Petrou, S., Kupek, E. 2005. Socioeconomic differences in childhood hospital inpatient service utilisation and costs: prospective cohort study. *Journal of Epidemiology of Community Health* 59:591-597.

Goldacre, M., Kurina, L., Yeates, D., Seagroatt, V. and Gill, L. 2000. Use of large medical databases to study associations between diseases. *Q J Med.* 93: 669-675.

Collaborative Group on Hormonal Factors in Breast Cancer. 2004. Breast Cancer and Abortion: Collaborative Reanalysis of data from 53 Epidemiological Studies, Including 83000 women with breast cancer from 16 countries. *The Lancet.* Vol 363, 1007- 1016.

Goldacre, M.J., Kurina, L. M., Seagroatt, V and Yeates, D. 2001. Abortion and breast cancer: a case-control record linkage study. *Journal of Epidemiology & Community Health.*

Other research outputs

Caesarean delivery and risk of stillbirth in subsequent pregnancy: retrospective cohort study in an English population. Ron Gray, Maria A Quigley, Christine Hockey, Jennifer J Kurinczuk, Michael Goldacre and Peter Brocklehurst Submitted.

Hospital admission for ulcerative colitis and Crohn's disease in England: comparison of prognosis with and without colectomy. Stephen E Roberts, John G Williams, David Yeates, Michael J Goldacre Submitted.

Perinatal factors associated with subsequent diabetes mellitus in the child: record linkage study. R Levins, SE Roberts, MJ Goldacre Submitted.

Elective Surgery for Aortic Abdominal Aneurysm: Comparison of English Outcomes with those elsewhere. Miodrag Filipovic, Michael J Goldacre, Leicester Gill. Submitted to *Journal of Epidemiology and Community Health.*

Research Protocol: Epidemiology and health services research using routine NHS data: work programme of the Unit of Health-Care Epidemiology, Oxford University, funded by the National Co-ordinating Centre for Research Capacity Development

Papers & Books of Interest

- Medical Record Linkage J.A. Baldwin
- Linked Record Health Data Systems J.A. Baldwin
- Frequency of multiple sclerosis in 3 Australian cities – Perth, Newcastle & Hobart McCall et.al.
- Medical Record Linkage – The method and its applications E.D. Acheson
- The structure, function and cost of a file of linked health data E. D.Acheson

Documents

- File Building Processes From HES and ONS supplied data to Linked extract smoothed FCE and CIPS files. Glenys Bettley. Details data preparation, resolving matches, updating and linking files, correcting, generating and extracting files.
- National Record Linkage of Hospital Episode Statistics and Death Registration Records – Report to Department of Health Part 3: Results from matching National HES data with ONS mortality data covering the years 1998 to 2002 (ONS to January 2003). January 2004.
- National Record Linkage of Hospital Episode Statistics and Death Registration Records June 9th 2003 – Report to Department of Health
- Research Protocol “Development of NHS hospital statistics, using English national linked hospital data, with particular reference to hospital admission rates and outcomes of hospital care: work programme of the Oxford site of the National Centre for Health Outcomes (NCHOD) and of the South East Public Health Observatory (SEPHO). – Public health observatory work + “working with clinicians” protocol.
- Example of trend study: mumps – comparison of trends in admission rates for mumps for ORLS episodes and National episodes

Useful Links

Presentation on record linkage by Professor Leicester Gill:

<http://www.ccsr.ac.uk/methods/events/linkage/gill.pdf>

Compendium indicators: www.nchod.nhs.uk

SEPHO: www.sepho.org.uk

GPRD: www.gprd.com/academia - linked data used for general practice.

This information was gathered in December 2006 and represents the activities of ISD Scotland at that time. The operations of the ISD, like all organisations, continue to evolve and change.

This chapter has been completed with no editing assistance.

ISD Scotland

www.isdscotland.org

www.clinicaldatasets.scot.nhs.uk

www.healthscotland.com

About

The Information and Statistics Division (ISD) Scotland is a division of the Common Services Agency (CSA). ISD Scotland, part of NHS National Services Scotland, is responsible for collecting and developing health care information.

The NHS National Insurance Number is collected on all health records. Anyone who visits a Scottish GP practice is given a unique Community Health Index (CHI) number. There is a movement towards using the CHI number for data linkages. It is anticipated that the CHI will be used from April 2007 to link health datasets.

The ISD have health data for 6 million people, with over 26 million records.

Organisation

700 people work in ISD in Edinburgh, another 160 in Glasgow and another 20 in Dunedin. The core business is programme based, the production of publications and provision of an adhoc information service.

Information Services is located at:

NHS National Services Scotland
Gyle Square

1 South Gyle Crescent
Edinburgh EH12 9EB

Funding

Funding for the operations of ISD are provided by the NHS. The Chief Scientist's Office is a major funder for projects.

Intellectual Property

The health data collected, linked and analysed is considered not to be the intellectual property of the NHS Scotland, rather something that is controlled by the NHS.

Privacy and Confidentiality

There is clinical governance and protection of data. Privacy officers are involved with information governance, data protections, confidentiality, and freedom of information, data security and data management. There is a national set of governance standards that are complied with.

There is a Privacy Advisory Committee (PAC) it is comprised of three medical and two lay people. PAC gives 3 to 5 years permission for a study and data is aggregated if necessary.

In January 2005 the Freedom of Information Act was passed in Scotland. This means that information must be released if requested. There is one case where 18 people with leukaemia living near a nuclear power plant were identified.

The Data Protection Act 1998 provides guidance for collection of health data and protection of privacy. There is a Common law of confidentiality. There is uncertainty as to what researchers and the NHS can do with health data. It is anticipated that a future arrangement such as a national committee will be implemented to deal with such issues.

There are sensitivities around who can access the CHI. Currently many people within the NHS have access. There needs to be controlled access to eHealth records, health research, audit, quality and surveillance. There is current uncertainty about legal and ethical processes.

The NHS have standard operating procedures and highly trained staff who sign a confidentiality agreement. Absolute minimal datasets are used and data is held in an encrypted format.

Senior Managers can give approval for named data.

Application

There are 4000 information requests a year to ISD, one third are from Scottish Exec and the Scottish parliament, the other two thirds come from the media and the public.

The application form and information about privacy and confidentiality can be sourced on the website.

The Freedom of Information Act in Scotland decrees that all information has to be given out if requested. There is no barring of health information. The Information Commissionaire had been involved and two cases were overturned in parliament where ISD was forced to release data about surgical mortality rates for individual providers and also information about people who have cancer living near a nuclear power plant in Scotland.

Datasets

NHS both collect and manage health data. There is a data monitoring team and a data quality team.

Data is collected on individuals with an aggregated ISDSI. Data collection is not compulsory for many collections. The only compulsory datasets are for HIV, abortions, and sexually identified diseases.

The prescribing information collected is only from GPs and does not include medications given in hospital. Over 70 million prescriptions are filled a year (approx 6 million a month), this equates to 14 scripts per head of the population. The cost of the script is £6.55, regardless of the item. Children and the elderly are exempt from paying. Data about chemist dispensations is sent to Livingstone, into the Data Capture Validation Pricing (DCVP). The NHS has 6 years of pharmacy data.

There are over 1 million records in the Cancer registry that has been going since 1950. There are an additional 40,000 cases each year.

Readcodes are used by GPs and diagnosis is then mapped to ICD codes.

Datasets collected include: NHS24, ambulance, emergency, out-of-hospital data and cancer. Census, births and deaths data is provided by the Registrar's Office.

The four main datasets used for data linkage are:

- 1968 SMR01 hospital episodes. 1981 linked
- 1900's SMR04 psych 1968 linked
- SMR06 Socrates CDP Cancer 1956, tumour based registry
- GRO Death registrations

There are also

- SMR2 Maternity 1980-2001
- SMR11 Neonatal 1980-2001
- GRO Birth records 1980-2001
- Stillbirth (includes deaths in first year of life) & infant death

- SMR00 Outpatient
- SMR03 Waiting list census – monthly waiting list
- SMR50 Geriatric long stay admission & discharges
- Congenital anomaly register.

- Prescribing information system (PIS)
- Dental
- ACND – access to corporate national data (acute mental health, cancer, deaths)
- Immunisation

The Health and Social Care Data Dictionary is a one stop shop for health and social care data definitions and standards. It is managed by ISD Scotland.

See www.datadictionary.scot.nhs.uk

It includes

1. Data Dictionary: A-Z of NHS and Social Care data definitions
2. SMR Datasets: Online manuals for the Scottish Morbidity Record SMR datasets
3. Clinical Datasets: Information on the National Clinical Datasets Development Programme
4. Social Care Datasets: Social care information developments and data standards.

The website also has data standard developments, the ISD Definitions Archive and the SMR Validation Manual.

Projects

Some of the projects performed include:

- Midspan is a maternity linkage and is joining information about families.
- The NHS survey is used by the ISD and the Scottish Exec utilise ISD linked data.
- Maternal and child health research performed by Jim Chalmers.
- Indicators of surgical mortality, surgical profiles and quality improvement.
- Postgraduate educational data
- Longitudinal health studies in Scotland.
- Better Blood Transfusion- study how blood is being used.
- Scottish Linked Congenital Anomaly Database: includes baby, SMR11, SMR1, stillbirth and infant death survey.
- Laboratory Information Management System – genetics service.

- Family – cancer screening, genetic counselling.

Technical Linkage Information

The Scottish Medical Record (SMR) contains personal identifiers, patient administration information and clinical information. In the early 1960's, datasets were collected, and transferred to electronic format with routine recording of project investigators. Linkage was completed by probability matching and ad hoc methods.

Linkage and analysis is performed at ISD. Probability matching is used for linkage and data is stored in one large catalogue file. Soundex, 1st initial and date of birth are used as blocks. Clericals completed for ad hoc linkages.

There is a one pass linkage system and parallel processing is also used. Cobol, Oracle, PL/SQL, SPSS, Fortran and UNIX are used.

The data is linked and up to date for 2006.

Exact match linkages are performed, using surname, first name, second name, dob, pcode, soundex and nysiis. In-house programming is used to deal with Scottish names. New name programmes are being developed to deal with the influx of Polish immigrants and other Eastern European people to Scotland. Population snapshots are derived.

Suspicious group types, more than one death, an event after death, more than two previous surname soundex codes are all monitored and clerical review is performed.

Staff Exchange

ISD staff are interested in participating in staff exchange amongst the international centres.

WHO

The ISD is interested in forwarding research outputs to the WHO. A list of projects is available to contact researchers and collate their research outputs retrospectively.

Conference Perth 2008/2009

ISD staff are interested in attending a data linkage conference in Perth in 2008/2009.

Documents

- A brief guide to information governance. About information governance September 2005. NHS Scotland.
- A feasibility study of the potential for compiling a health related database. Scottish Needs Assessment Program.
- Assessment of SMR01 and Associated Data. December 2006. Information Services National Services Scotland Data Quality Assurance.
- Bryden JS. Posterity Planting. How ISD has been nurtured over 40 years.
- Information Governance e-Library www.elib.scot.nhs.uk/infogov/
- ISD Scotland Customer Guide. 2005.
- Linking the Scottish Health Survey to hospital discharges & deaths.
- NHS Scotland Data Quality Assurance Report on Acute Inpatient/Day Case Data 2000-2002. ISD. January 2004.
- Posterior Planting. How ISD has been nurtured over 40 years.
- Protecting Personal Health Information: Information guide for patients. Information Services Division part of NHS National Services Scotland.
- Scotland Public Health Observatory. Public health information for Scotland. www.scotpho.org.uk
- Why do you have a CHI number? Community Health Index number.

- Your Emergency Care Summary: What does it mean for you? NHS Scotland.

Midspan

- Hanlon P, Walsh D, Whyte BW, Scott SN, Lightbody P, Gillhooly MLM. Hospital use by an ageing cohort: an investigation into the association between biological, behavioural and social risk markers and subsequent hospital utilization. *The Journal of Public Health Medicine* Vol 20, Iss 4 pp 467-476.
- Hanlon P, Walsh D, Whyte BW, Scott SN, Lightbody P, Gillhooly MLM. The link between major risk factors and important categories of admission in an ageing cohort. *The Journal of Public Health Medicine* Vol 22, Iss 1 pp 81-19.

Books of Interest

Record Linkage and Privacy. Issues in creating new federal research and statistical information. United States General Accounting Office. GAO. April 2001 GAO-01-126SP www.gao.gov/

Useful Links

General – Scottish public health related information www.scotpho.org.uk

Midspan – <http://www.gla.ac.uk/faculties/medicine/midspan>

Linked Scottish Health Survey – summary & technical reports www.scotpho.org.uk

Constituency profiles – <http://www.scotpho.org.uk/constituencyprofiles>

Community profiles – <http://www.scotpho.org.uk/communityprofiles>

“Let Glasgow Flourish” report –

<http://www.gcph.co.uk/background/programmes/strength/strength1.htm>

ISD Scotland Customer Guide www.isdscotland.org

www.indicators.scot.nhs.uk - 6 months updates and funnel plots on SASM, hip, renal registry, STAG – trauma, alcohol, ambulance and emergency and better blood linkages.

Concept of an International Health Data Linkage Consortium

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
- Teaching and education programs
- 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

Signatures of Support for IHDLC

International Consortium of Data Linkage Centres


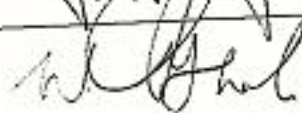

Data linkage is the bringing together of information from two or more records of independent sources that are perceived to belong to the same individual, event or place.

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.

**Department of Community Health Sciences, University of Calgary, Alberta
Canada**

	Signature	Date
Dr Tom Noseworthy, Professor and Head Community Health Sciences		Nov 1, 2006.
Dr William Ghali, Professor Departments of Medicine and Community Health Sciences		Oct 31, 2006
Dr Hude Quan, Assistant Professor, Department of Community Health Sciences AHFMR Population Health Investigator CIHR New Investigator		Oct 31, 2006.

International Consortium of Data Linkage Centres

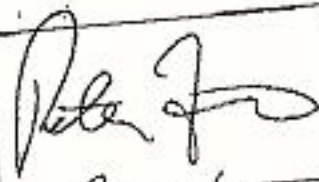



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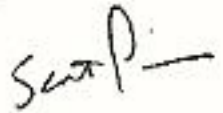
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Department of Community Health Sciences, University of Calgary, Alberta
Canada

	Signature	Date
Mr Stafford Dean, Director System Analysis Unit, Calgary Health Region	SEE ATTACHED	
Dr Peter Faris, Adjunct Assistant Professor, Department of Community Health Sciences		Nov 4/06
Dr Colleen Maxwell, Associate Professor		Nov 2/06
Dr Brenda Hemmelgarn, Assistant Professor		
Dr Norman Campbell, Professor Departments of Medicine and Community Health Sciences		Nov 4 2006
Dr Nathalie Jette, Assistant Professor		Nov. 3, 2006

Dr Cynthia Beck, Assistant Professor Departments of Psychiatry and Community Health Sciences		Nov 3, 2006
Dr Scott Patten, Professor Departments of Community Health Sciences and Psychiatry		November 3 2006

International Consortium of Data Linkage Centres

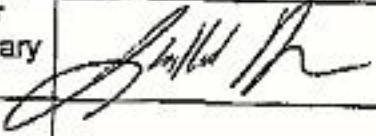
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Dr Brenda Hemmelgarn, Assistant Professor		
Dr Norman Campbell, Professor Departments of Medicine and Community Health Sciences		
Dr Nathalie Jette, Assistant Professor		

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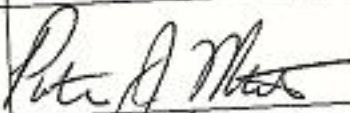



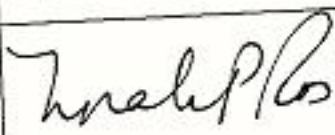
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Manitoba Centre for Health Policy, Winnipeg, Manitoba

	Signature	Date
Dr Patricia Martens , Director, Associate Professor, Senior Researcher		Nov 13/06
Dr Lisa Lix , Associate Director of the Repository, Assistant Professor, Senior Researcher		Nov. 13/06
Dr Carolyn De Coster , Associate Director of Research, Assistant Professor, Senior Researcher		Nov 13, 2006
Dr Leslie Roos , Founding Director, Research Data Repository, Senior Researcher		Nov 13, 2006
Dr Noralou Roos , Founding Director, Manitoba Centre for Health Policy, Senior Researcher		Nov 13, 2006
Dr Evelyn Shapiro , Senior Researcher		

Paulette Collins , Chief Administrative Officer	<i>PK Collins</i>	<i>Nov 16, 2006</i>
Charles Burchill , Data Analyst and Privacy Officer	<i>C Burchill</i>	<i>Nov 17, 2006</i>
Patrick Nicol , Data Acquisition Coordinator	<i>P Nicol</i>	<i>Nov 17, 2006</i>
Dr Colleen Metge , Researcher	<i>C Metge</i>	<i>Nov 16, 2006 -</i>
Dr Anita Kozyrskyj , Researcher	<i>A. Kozyrskyj</i>	<i>Nov 16, 2006.</i>

International Consortium of Data Linkage Centres

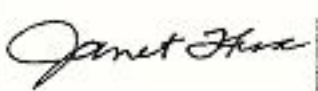
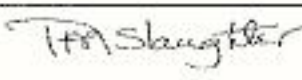
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Institute for Clinical Evaluative Sciences, Toronto, Ontario, Canada

	Signature	Date
Dr Jan Hux, President & CEO (I), ICES		12 January 2007
Pamela Slaughter, Chief Privacy Officer, ICES		8 December 2006

International Consortium of Data Linkage Centres

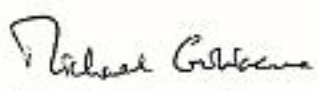
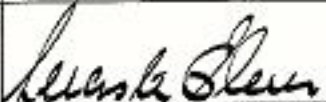
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The following people are interested in participating in an international consortium of data linkage centres. This will enable the data linkage centres and affiliated researchers to share knowledge and expertise with regards to data linkage.

**Oxford Record Linkage Study, Unit of Health-Care Epidemiology,
Department of Public Health, Oxford University, UK**

	Signature	Date
Professor Michael Goldacre , Director of UCHE, Professor of Public Health		7.12.2006
Leicester Gill , Computer Scientist, UCHE		7-DEC-2006

Summary

Purpose of Visit

- 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
- Promote attendance at the data linkage conference in Perth

British Columbia Linked Health Database

University of British Columbia, Vancouver, Canada

- Independent organisation located within the UBC Centre for Health Services & Policy Research
- 4 million British Columbia residents from 1985
- Population Health Number, deterministic linkage
- Population Health Learning Observatory (PHLO)
- <http://www.chspr.ubc.ca/>

Centre for Health and Policy Studies

University of Calgary, Alberta, Canada

- Department of Community Health Sciences, University of Calgary
- Calgary Health Region – 1.2 million
- Contracts with government
- Health Systems Analysis Unit
- PHN, deterministic linkage
- Administrative Data Analysis Methodology
- <http://www.calgaryhealthregion.ca/qshi/hsau/index.htm>

Manitoba Centre for Health Policy

University of Manitoba, Winnipeg, Canada

- “To provide accurate and timely information to health care decision-makers, analysts and providers, so they can offer services which are effective and efficient in maintaining and improving the health of Manitobans”
- Funded by Manitoba Health and competitive research grants
- Deliverables
- 60+ people
- No release of data
- <http://www.umanitoba.ca/centres/mchp/>
(extremely good for data dictionaries & concept dictionaries)

Institute of Clinical Evaluative Sciences

Toronto, Canada

- Autonomous, independent institute

- An agreement with Ministry of Health decrees that NO data can leave ICES. Researchers must become an employee of ICES to use the data.
- 7 ICES satellites – secured rooms in medical schools across the province. Access through DSL servers, with an encryption of data.
- 12 million people in Ontario.
- <http://www.ices.on.ca/>

Public Health Genetics Unit

Cambridge, United Kingdom

- ‘the responsible and effective translation of genome-based knowledge and technologies for the benefit of population health’. Bellagio, Italy 2005
- Cambridge Genetics Knowledge Park
- Privacy
- Website
- <http://www.phgu.org.uk/index.php>

Oxford Record Linkage Study

Oxford University, United Kingdom

- ORLS is not a study and not an institution. It is a dataset.
- 1963
- 2.5 million people (originally 350,000)
- 6-8 people
- 2003/04 commissioned to perform national data linkage for the UK
- Unit of Health Care Epidemiology
 - Funding has been to the unit, NEVER for data linkage or infrastructure
- 1985-89, the national datasets collapsed
- <http://www.uhce.ox.ac.uk/epidem.html>

Scottish Medical Record Linkage System

ISD Scotland, United Kingdom

- ISD Scotland, part of NHS National Services Scotland, is responsible for collecting and developing health care information.
- 4 main datasets are :
 - 1968 SMR01 hospital episodes. 1981 linked
 - 1900’s SMR04 psych 1968 linked
 - SMR06 Socrates CDP Cancer 1956, tumour based registry
 - GRO Death registrations
- Freedom of Information Act, Jan 2005
- <http://www.isdscotland.org>

World Health Organisation

Geneva, Switzerland

- Director of Measurement and Health Information Systems
- Director of Research Policy and Cooperation

Summary Table of Visited International Health Data Linkage Centres

	Data Linkage Branch WA	British Columbia Linked Health Database	Health System Analysis Unit, Calgary Health Region	Manitoba Centre of Health Policy	Institute of Clinical Evaluative Sciences	Oxford Record Linkage Study	Information Statistics Division Scotland
Location	Department of Health WA, 1 st Floor, C Block, 189 Royal Street, Perth, Australia	UBC Centre for Health Services and Policy Research 201-2206 East Mall, Vancouver, BC, V6T 1Z3 Canada	Health Information and System Management Quality, Safety & Health Information Calgary Health Region Northwest II Building 4520 - 16th Ave NW, Calgary, Alberta T3B 0M6	Manitoba Centre for Health Policy Department of Community Health Sciences Faculty of Medicine, University of Manitoba 4th Floor, Room 408, 727 McDermot Ave Winnipeg, Manitoba R3E 3P5	Institute of Clinical Evaluative Sciences G1 06 2075 Bayview Avenue, Toronto, Ontario, Canada M4N 3M5	Unit of Health-Care Epidemiology, Department of Public Health, University of Oxford Old Road Campus, Headington, Oxford OX3 7LF	ISD Scotland, Information Services, NHS National Services Scotland Gyle Square, 1 South Gyle Crescent, Edinburgh EH12 9EB
Established	1995	1996		1991	1992	1962	
Organisation	Department of Health WA, University of Western Australia, Curtin University of Technology and Institute of Child Health Research	Centre for Health Services and Policy Research, University of British Columbia	Calgary Health Region	University of Manitoba	Institute of Clinical Evaluative Sciences. University of Toronto, University of Western Ontario, Laurentian University, York University	University of Oxford	National Health Scotland
Core Focus / Mission Statement		"Advance scientific enquiry into issues of health in population groups	"Supports the monitoring and evaluation of the Region's health	"What makes people healthy?" "To provide accurate and	"The Institute for Clinical Evaluative Sciences (ICES) is an independent,	Assist with the development of health outcome indicators	Programme based, publications to provide an ad hoc

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		and ways in which health services can be organized, funded and delivered.”	requirements and the services provided by the Health Authority”	timely information to health care-decision-makers, analysts and providers, so they can offer services which are effective and efficient in maintaining and improving the health of Manitobans”	non-profit organization, whose core business is to conduct research that contributes to the effectiveness, quality, equity and efficiency of health care and health services in Ontario”		information service.
Key Function	Data Linkage	Data Linkage and Data Repository	Data Linkage, maintenance of Population Registry and Data Warehouse.	Data Repository and Data Analysis	Data Analysis	Data Linkage, Data Repository and Data Analysis	Data Linkage, Data Repository and Data Analysis
Number of people	19 people	7-10 people	25 people	60 people	140+ people	6-8 people	700
Funding	Department of Health WA, University of Western Australia, fee for service	BC Ministry of Health, University of British Columbia, UBC College of Health Disciplines	Calgary Health Region	University of Manitoba, Manitoba Health, federal and provincial grants and contracts.	Ministry of Health, Ontario Medical Association, Competitive grants	National Coordinating Centre for Research Capacity Development, Competitive grants	National Health Scotland
Management	Data Linkage Advisory Board	Manager of BCLHD and Director of CHSPR	Director, Health Systems Analysis Unit	Advisory Board, Manitoba Health, Director MCHP	Research Ethics Board		

Summary Table of Visited International Health Data Linkage Centres

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Governance Arrangements	CHIC	Privacy Commissionaire of BC. BC Freedom of Information and Privacy of Protection Act	Health Information Act	Personal Health Information Act, Federal Privacy Act, Health Information Privacy Committee	Personal Health Protection Act, Confidentiality Committee,		Privacy Advisory Committee Freedom of Information Act Data Protection Act 1998
Data		<ul style="list-style-type: none"> • Medical Service Plan Records • PharmaCare data on drug prescriptions • Hospital separations on discharges and transfers • Continuing Care service transactions • British Columbia Caner Agency incidence files • WorkSafe BC (Worker's compensation board) injury reports • Births • Deaths • Mental health care episode 	<ul style="list-style-type: none"> • Immigration, income and labour files • Population registry • Operating Room Information System (ORIS) • Inpatient abstracts • Pharmacy • Diagnostic imaging data (only from hospitals) • Fee for service claims • Vital statistics (births and deaths) • Home care • RITT data • Facility based care records 	<ul style="list-style-type: none"> • Hospital file • Medical claims file • Personal care home database • Registration file • Mortality file • Cancer registry • Mental health file • Public access census files • Hospital statistics • Financial information system data • Management information system data • Northern patient and rural ground 	<ul style="list-style-type: none"> • Hospital • Ambulatory Care • Mental Health • Emergency • Long term care • Chronic care • Physician data • Health insurance medical claims (fee for service) • Registered persons database • Vital statistics • Road safety data • CancerCare • Motor license information 	<ul style="list-style-type: none"> • Birth • Death • Marriages • Still birth • Mortality • NHS hospitals • Hospital episode statistics • Finished consultant episode • National Centre for Health Outcomes Development 	<ul style="list-style-type: none"> • Hospital episodes • Psychiatry • Cancer tumour based registry • Death registrations • Maternity • Neonatal • Birth • Still birth • Outpatient • Waiting list • Geriatric long stay admission and discharges

Summary Table of Visited International Health Data Linkage Centres

	Data Linkage Branch WA	British Columbia Linked Health Database	Health System Analysis Unit, Calgary Health Region	Manitoba Centre of Health Policy	Institute of Clinical Evaluative Sciences	Oxford Record Linkage Study	Information Statistics Division Scotland
		records	<ul style="list-style-type: none"> Emergency Room Day Surgery 	transport files <ul style="list-style-type: none"> Manitoba immunisation monitoring program files Physician data file Medical nonstatistical file Pharmacare Drug program information network files 			
Population	2.2 million	4 million	1.2 million	1.2 million	12 million	2.5 million	6 million
Linkage system	Best-practice protocol	Linkage Co-ordinating File	Data Warehouse	Population Health Data Repository	Ad hoc	Master match file	One catalogue file.
Data collection	Not involved in data collection	Not involved in data collection	Not involved in data collection.	Not involved in data collection.	Not involved in data collection	Not involved in data collection	Involved in data collection.
Software system	Automatch, in-house programs	Programmers have developed own software.	Programmers create own linkage programs in SAS, FOX, Access etc.	LinkPro	Unix operating system, in-house programs.	In-house programming	In house programming

Summary Table of Visited International Health Data Linkage Centres

	Data Linkage Branch WA	British Columbia Linked Health Database	Health System Analysis Unit, Calgary Health Region	Manitoba Centre of Health Policy	Institute of Clinical Evaluative Sciences	Oxford Record Linkage Study	Information Statistics Division Scotland
Linkage strategy	Probabilistic with clerical review.	Deterministic	Deterministic.	Deterministic and probabilistic with manual review as necessary.	Deterministic, ad hoc as required.	Deterministic and Probabilistic	Probabilistic with clericals completed for ad hoc linkages.
ID number	No. UMRN for hospital records but not reliable as a unique identifier.	Personal Health Number (PHN)	Population Health Number (PHN) (provincially based) Chart number	Population Health Information Number (PHIN)	Health Care Number (HCN) provided as an IKN to ICES.	Hospital Episodes of Treatment Identification (HESDI), Oxford Identification (OXFID)	NHS National Insurance Number, Community Health Index (CHI)
Electronic storage		Isolated server used for storage of raw data files and data sharing. There are back-up tapes that are kept in a fireproof safe. Also off site storage.	ORACLE	SAS database	Isolated LAN. Separate SUN server used for external data.		
Research outputs	Yes	No	No	Yes	No	No	No
List of projects	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Advertising	Website	Website	Website	Pamphlets Website	Website	Website	Website

Summary Table of Visited International Health Data Linkage Centres

	Data Linkage Branch WA	British Columbia Linked Health Database	Health System Analysis Unit, Calgary Health Region	Manitoba Centre of Health Policy	Institute of Clinical Evaluative Sciences	Oxford Record Linkage Study	Information Statistics Division Scotland
Courses	Introductory Analysis of Linked Health Data (UWA) Advanced Analysis of Linked Health Data (UWA)		Administrative Data Analysis Methodology (University of Calgary)	Epidemiology of Health Care (University of Manitoba)	Health Methods Analysis for Health Services Research		
Information	Website	Website	Website	Website	Website	Website	Website
Future directions	NCRIS DLA	PHLO Aiming to increase data and research capabilities. Additions of individual clinical data, comparable data from other Canadian provinces and international data on determinants of health.			Value add to evidence based findings to contribute towards the organisation and delivery of health care in Ontario.		
Website	http://www.data linkage-wa.org.au/	http://www.chspr.bc.ca/data	http://www.calgaryhealthregion.ca/qs/hi/hsau/index.htm	http://www.umanitoba.ca/centres/mc hp/	http://www.ices.on.ca/	http://www.uhce.ox.ac.uk/epidem.html	http://www.statistics.gov.uk/STATBASE/Source.asp?vlnk=1418
Interest in staff exchange	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Summary Table of Visited International Health Data Linkage Centres

	Data Linkage Branch WA	British Columbia Linked Health Database	Health System Analysis Unit, Calgary Health Region	Manitoba Centre of Health Policy	Institute of Clinical Evaluative Sciences	Oxford Record Linkage Study	Information Statistics Division Scotland
Interest in forming international consortium	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Conference attendance in Perth, WA	Yes	Yes	Yes	Yes	Yes	Yes	Yes