

# International Health Data Linkage Network

Second Official Meeting of the Network, Manitoba

Tuesday 9th of March 2010

Manitoba Centre for Health Policy 20<sup>th</sup> Anniversary Conference

March 8 & 9 | Fort Garry Hotel | Winnipeg, Manitoba



## International Health Data Linkage Network

Established in December 2008, the International Health Data Linkage Network (IHDLN) facilitates communication between linkage centres and users committed to the systematic application of data linkage to produce community benefit in the health and health-related domains. The purpose of the IHDLN is to provide a clearing house for scientific outputs and community impacts arising from data linkage activities supported by the members; to share information and resources concerning common challenges and solutions, whilst acknowledging the many diverse contexts in which data linkage occurs; to build workforce capacity and other supports for data linkage; to foster collaborative projects that show the value of data linkage applications or improve the quality of data and linkage methods; and to observe and promote high standards of governance and ethical practice in the conduct of data linkage activities.

The IHDLN has over 120 members from Australia, Canada, England, New Zealand, Singapore, Scotland and the United States of America. Membership of the network is open to any group or individual that supports the purpose of the network. Currently work is being undertaken to initiate international comparable data linkage studies in the areas of economic disparity, ambulatory sensitive care conditions, child maltreatment and the pooling of basic international reference tables. The IHDLN website, [www.ihdl.org](http://www.ihdl.org) provides a hub for news contributions, information exchange and clearing house activities, provides links to centres and organisations and lists upcoming events, activities, education and training opportunities. The IHDLN meets biennially and strongly promotes opportunities for staff and student exchange.

### **Director of IHDLN**

Ms Emma Fuller

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Ms Victoria Gray [victoria.gray@uwa.edu.au](mailto:victoria.gray@uwa.edu.au) is working in Emma's role until August 2010.

**A copy of the IHDLN Consensus Statement is located on page 21 of this booklet.**

## International Health Data Linkage Network 2<sup>nd</sup> Official Meeting, Manitoba

**Time/Date:** 1.30 – 4.30pm Tuesday 9<sup>th</sup> March 2010

**Venue:** The Club Room, Fort Garry Hotel, Winnipeg

**Chair:** Professor Les Roos, Manitoba Centre for Health Policy

### PARTICIPANTS

<p><b>Professor Leslie Roos (Chair)</b> Department of Community Health Sciences, Manitoba Centre For Health Policy, University of Manitoba</p>	<p><b>Associate Professor John Bass</b> Menziess Research Institute, University of Tasmania</p>	<p><b>Ruth Bond</b> Manager of Data Repository Access and Documentation, Manitoba Centre for Health Policy, University of Manitoba</p>
<p><b>Dr Xinjie Cui</b> Director, Alberta Child and Youth Data Lab</p>	<p><b>Professor Nicholas de Klerk</b> Head of Biostatistics, Division of Population Science, Telethon Institute for Child Health Research, Western Australia</p>	<p><b>Jane Ford</b> Senior Research Fellow, Clinical and Population Perinatal Health Research, The University of Sydney</p>
<p><b>Associate Prof Jane Freemantle</b> Principal Research Fellow Centre for Health and Society, School of Population Health, The University of Melbourne</p>	<p><b>Victoria Gray</b> Acting Director, International Health Data Linkage Network, The University of Western Australia</p>	<p><b>Professor D’Arcy Holman</b> Chair in Public Health, School of Population Health, The University of Western Australia</p>
<p><b>Dr David Hadorn</b> Director, Centre for the Study of Assessment and Prioritisation in Health Department of Public Health, University Otago, New Zealand</p>	<p><b>Dr David Henry</b> CEO, Institute of Clinical Evaluative Sciences, Toronto</p>	<p><b>Bree Heffernan</b> Centre for Health and Society, Melbourne School of Population Health, The University of Melbourne</p>
<p><b>Dr Phil Hider</b> Senior Lecturer in Clinical Epidemiology, School of Medicine and Health Science, University of Otago, New Zealand</p>	<p><b>Nedeene Hudema</b> Senior Analyst, Health Quality Council, Canada</p>	<p><b>Assistant Prof Douglas Jutte</b> Adjunct Assistant Professor Division of Community Health &amp; Human Development, School of Public Health, University of California, Berkeley</p>

<b>Professor Brendon Kearney</b> Chair, Population Health Research Network, Australia	<b>Professor Milt Kotelchuk</b> Chair of Community Health Sciences, Boston University School of Public Health	<b>Associate Professor Lisa Lix</b> Centennial Chair, School of Public Health, University of Saskatchewan
<b>Dr Pat Martens</b> Director, Manitoba Centre for Health Policy, University of Manitoba	<b>Dr Michael Paterson</b> Institute for Clinical Evaluative Sciences (ICES), Toronto	<b>Chris Radbone</b> Unit Manager: SANT DataLink, Sansom Institute for Health Research, University of South Australia
<b>Glenn Robbins</b> Health Canada	<b>Associate Prof Christine Roberts</b> Kolling Institute of Medical Research, The University of Sydney	<b>Professor Noralou Roos</b> Department of Community Health Sciences, University of Manitoba
<b>Diana Rosman</b> Program Manager, Data Linkage Branch, Public Health Division Department of Health WA	<b>Dr Susan Samuel</b> Paediatric Nephrologist, Alberta Children's Hospital Assistant Professor, University of Calgary	<b>Dr Claudia Sanmartin</b> Senior Researcher, Health Information and Research Group, Statistics Canada, Ottawa
<b>Professor James Semmens</b> Centre for Population Health Research, Curtin University of Technology, Perth, Australia	<b>Mark Smith</b> Associate Director, Repository Manitoba Centre for Health Policy, University of Manitoba	<b>Dr Merran Smith</b> Chief Executive, Population Health Research Network, Australia
<b>Andrew Stanley</b> Director, Strategic Planning Policy and Research Branch, South Australia Health	<b>Professor Fiona Stanley</b> Director, Telethon Institute for Child Health Research, University of Western Australia	<b>Catherine Storey</b> Information Analyst, Healthcare Information Group, NHS National Services Scotland , Information Services Division
<b>Dr Vijaya Sundararajan</b> Director, Victorian Research Data Linkages, Victoria Department of Health, Australia	<b>Dr Lee Taylor</b> New South Wales Health and the Centre for Health Record Linkage, Australia	<b>Professor Ken Turner</b> Respiratory Data Analyst, Manitoba Centre for Health Policy, University of Manitoba
<b>Dr Jacqueline Quail</b> Vice President, Health Quality Council, Canada	<b>Associate Professor Hude Quan</b> Department of Community Health Sciences, The Centre for Health and Policy Studies, University of Calgary Canada	<b>Dr Marcy Winget</b> Leader, Research and Evaluation, Community Oncology, Alberta Health Services - Cancer Care



**Additional participants:**

Alice Chen  
Bosu Seo  
Brenda Elias  
Charlotte King  
Chunli Gu  
Evelyn Forget  
Fei Xu  
Gary Teare  
Gemma Van Halderen  
Helen Coo  
Helen Johansen  
Ingrid Sketris  
Michael Wolfson  
Muhamund Haz  
Sabrina Wong  
Sarath Chandrasekere  
Teresa Mayer

## A G E N D A

### Part 1: Network Business

Concerned with pursuing the stated objectives of the IHDLN

1.30	1.	<b>Welcome</b>	[L Roos]
1.35	2.	<b>IHDLN Summary 2008 – 2010</b> <ul style="list-style-type: none"> <li>- Progress in achieving stated objectives of network</li> <li>- What else would members like from the network?</li> <li>- What projects can the IHDLN embark on together?</li> </ul>	[Gray & Holman]
1.45	3.	<b>International Comparative Studies</b> <ul style="list-style-type: none"> <li>- Vasectomy reversal study</li> <li>- Childhood maltreatment</li> <li>- Ambulatory care sensitive care contributions</li> <li>- Others</li> </ul>	[All members] [Holman] [Stanley] [Quan]
2.00	4.	<b>ESRC Grant – update</b>	[Boyle]
2.05	5.	<b>Other Initiatives</b> <ul style="list-style-type: none"> <li>- International Research Outputs</li> <li>- Dedicated peer-reviewed journal or supplement in 2010 for data linkage</li> </ul>	[All members] [Gray] [Gray]
2.15	6.	<b>Training and Education</b> <ul style="list-style-type: none"> <li>- Upcoming relevant units, courses, and workshops</li> </ul>	[All members]
2.20	7.	<b>Staff Exchange</b> <ul style="list-style-type: none"> <li>- Between which institutions and which levels ie programmers, linkers or researchers</li> </ul>	[All members]
2.30	8.	<b>Website &amp; Membership</b>	[Gray]
2.35	9.	<b>Rotation of Directorship in December 2010</b> <ul style="list-style-type: none"> <li>- To be passed on to another centre for two years</li> </ul>	[Holman]
2.45	10.	<b>Future meetings and conferences</b>	[All members]

- Upcoming conference announcements
- Next IHDLN meeting location

## Part 2: General Communication Briefs

**News items: members can announce and discuss new initiatives or provide short progress items on national developments which are relevant to IHDLN**

### **Instructions: General communications briefs**

We have created a few basic instructions for the general communications section to maximize time at the meeting and give members a chance to announce their ideas/news items as a way to prompt continued communications if interested in the hours/weeks/months after the meeting.

- Create a succinct summary (max one page) of the item/progress you would like mentioned plus your contact details.
- Please send this summary to myself: [victoria.gray@uwa.edu.au](mailto:victoria.gray@uwa.edu.au) by 4<sup>th</sup> March 2010 and I will print and bring a collation of all of the briefs for everyone at the meeting. (Those members not attending are welcome to send an update brief)
- At the meeting members will have 5 minutes each to announce their item and how other members can get in touch if they would like to discuss further.



### **Update: West Australian Developmental Pathways Project**

The Developmental Pathways Project (DPP), commencing in 2004, has taken a multidisciplinary and holistic approach to research into the health, development and wellbeing of children and youth, by initiating and utilising linked, longitudinal population level data.

The DPP pioneered population level data linkage across multiple government service sectors in Western Australia (WA), creating a unique data resource for use by researchers and policy makers.

Success and outputs derived from the initial linkages have encouraged additional government departments to become involved as partner organisations to have their data linked; for existing and new government departments to extend the breadth and depth of their data; and for the linkages to be updated on an ongoing basis.

The project now represents an innovative collaboration between researchers, primarily based at the Telethon Institute for Child Health Research, and 11 government jurisdictions in Western Australia (WA):

Department of the Attorney General	Department for Child Protection
Department for Communities	Department of Corrective Services
Department of Education	Department of Health
Department of Housing	Department of Indigenous Affairs
Department of Treasury and Finance	Disability Services Commission
WA Police	

The WA Data Linkage System, managed by the Western Australian Data Linkage Branch of the Department of Health creates, stores and updates links within and between the Department of Health data collections and the other government agency datasets for individuals, following best practice protocols. Under Memoranda of Understanding, data custodians from within each agency retain control of their data. Researchers conducting approved research receive clinical or service data (no identifying information) from each of the agencies, along with linkage keys to link the cross agency data.

The project has an established governance structure which includes an Advisory Panel, a Research Management Group, a Consumer and Community Reference Group, and a recently initiated Directors General Steering Committee. This governance structure ensures maximum engagement, participation, communication and transparency, as well as appropriate and effective translation of research findings.

The initial five years of the project has been funded through an Australian Research Council (Government) Linkage grant, which included cash and in-kind contributions from partner organisations. To continue the project, State funding is being provided through the Departments involved in the project, and further government funds have been applied for through a competitive grants process.

We anticipate that this collaboration and work will inform whole of government/joined up intervention and prevention strategies to improve outcomes, influence policy frameworks as well as evaluate and monitor existing initiatives and policies that affect the health and well being of children, youth and their families.

#### **Professor Fiona Stanley AC**

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**Update: Noralou Roos and Manitoba Centre for Health Policy**

1. I continue to work with Marni Brownell and others at MCHP merging data from education, child and family services with health data focusing on issues for at-risk/disadvantaged children. I am interested in how the data can be used to understand why some children succeed despite being at risk.

I am also interested in the development of needs driven universal programs (which hospital care in a universal system tends to be – ie the sickest individuals spend more time in hospital) and which education is likely not – (the children from least educated families would seem to have the lowest investment from the education system –they are more likely to drop out, less likely to complete post secondary).

2. I have just received a 3 year grant from the Canadian Institute for Health Research to work with the media around communicating evidence on controversial health policy issues – while it has nothing to do with use of linked data – would like to identify people with similar interests.

**A summary:**

Journalists communicate to the public about a wide range of health policy issues, yet it can be challenging for them to find reliable, evidence-based information. The Best Evidence Network will link journalists with the academics who research and publish reports on these issues, and will create an accessible, credible, evidence-based resource for members of the media that covers topics in health policy, including the most controversial issues.

→ The Best Evidence Network will:

- o Work with journalists to determine the type and format of information that would be useful to them when reporting on health policy issues;
- o Build a research database and a network of researchers prepared to work with the media;
- o Build a media friendly website to allow updates and easy access to the latest reliable health policy evidence and commentary;
- o Become the go-to source for evidence on controversial health policy topics; and
- o Monitor the media and engage the researcher network to respond to breaking news stories across the country where health policy evidence is relevant.

**Professor Noralou Roos, C.M., PhD**

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### Update: Chris Radbone and SA-NT DataLink

I have recently been appointed into a Senior role in the recently established SA NT DataLink Unit, I am working under the Director Robyn McDermott and John Lynch who is the lead researcher in a Early Childhood Development demonstration linkage project.

The other data linkage demonstration project is on Colorectal Cancer, with the lead researcher David Roder and the Cancer Council of South Australia.

I work closely with Andrew Stanley the Chair of the South Australian Northern Territory Consortium – which consists has nine partners from across 3 Universities and the State Governments.

There are excellent relationships and a spirit of trust and collaboration from the Steering Committee members, many of whom have worked for many years to bring the unit into existence.

The unit has only recently become operational – with an official launch in November 2009 attended by 3 Ministers (two from South Australia and the Northern Territory Health Minister). The University of South Australia is the auspicing organisation hosting the Unit on behalf of the Consortium members.

The progress includes:

1. Physical Security and preparation of Security Manual including Policy and Overview.
2. Currently in receipt of Hospital Separations, Emergency Department and the Cancer Registry, with agreement for the Electoral Roll. Work is progressing with the Perinatal data expected in 3 months, and SA Education data and SA Department of Families and Communities awaiting signoff of their MOU.
3. Collaboration across Australian State jurisdictions in the development of a Linkage Management System.
4. Attracting skilled Staff
5. Establishment of the Metadata and Research Advisory Service team
6. Implementation of a standard Project Management approach to activities.

#### **Chris Radbone**

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**Standards for Health Databases in Assessing Treatment Effectiveness:  
A Role for IHDLN?**

Government and professional health bodies around the world are developing and augmenting linked, large-scale observational databases for purposes of assessing treatment effectiveness. These efforts are perhaps most noticeable in the United States, where the U.S. Congress recently allocated US\$1.1 billion dollars for comparative effectiveness research (CER), most of which will be spent on observational databases. Canada is the current world leader in using large population databases to assess treatment effectiveness, primarily through the Institute for Clinical Evaluative Studies (ICES), although New Zealand is gearing up to pose an eventual challenge to this status. The NZ Ministry of Health (MOH) is developing a seamless amalgamation of health databases, including pharmaceutical usage for the entire population – not limited to low-income and elderly people, as in Canada. A recent MOH study on cardiovascular disease incorporated data from more than 4.1 million people – over 99 percent of the NZ population at that time.\*

The ability of observational database research (ODR) to provide valid assessments of treatment effectiveness depends on several factors. Perhaps most importantly, the information in the databases must be relevant, accurate, and reasonably complete. Concerns about data completeness and accuracy can severely limit the acceptance of analyses, and as such they must be tackled head-on, including the regular auditing of accuracy of patient identifiers and coding data. Little has been published concerning these factors for most databases, and no standards (e.g., for checking accuracy) exist. At a minimum, redundant or defunct ID numbers must be reliably culled. Chart-level audits of clinical information (to assess accuracy and completeness of coding) should also be conducted regularly, with results made available and, where found wanting, acted upon. Ideally, IHDLN would develop standards (or guidelines) regarding how -- and how often -- data should be quality checked, including recommendations regarding levels of data completeness and accuracy. Approaches to handling missing data might be put forward, debated, and if agreement is reached, adopted by all (or most) members.

Another major challenge to the acceptance of ODR as a legitimate basis for policy and funding decisions is the lingering concern that observational data are overly susceptible to bias, e.g., selective allocation to treatment and the effects of confounding variables. Here again, IHDLN could play a role by developing guidelines for the analysis and reporting of observational data. For example, approaches to controlling for the effects of measured co-variables (e.g., propensity or prognostic score) and unmeasured confounders (e.g., quantitative bias analysis) could be agreed. Appropriate techniques for statistical significance testing would be identified. Standards on reporting, e.g., Number Needed to Treat, would help make the results of ODR more meaningful. IHDLN might endorse the results of ODR so validated and conducted as sufficiently robust for decision making.

\*Chan WC, Wright C, Riddell T, et al. Ethnic and socioeconomic disparities in the prevalence of cardiovascular disease in New Zealand. *NZMJ* 2008; 121: 11-20.

**David Hadorn, M.D., Ph.D.**

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## **Population Health Research Network (PHRN)**

### **BACKGROUND**

The PHRN has received \$A30 million in funding over four years from 2008-09 from the Australian government to establish data linkage infrastructure across Australia. Australian state and territory governments and their academic partners have contributed a further \$A32 million in cash and in-kind to support the new infrastructure.

Australia already has a well developed population health data linkage capability in Western Australia (since 1994-95) and in New South Wales/Australian Capital Territory since 2006. The PHRN will facilitate development of health and health-related data linkage capability in other Australian states and territories. It will also facilitate development of infrastructure (Centre for Data Linkage at Curtin University in Perth) to link data between states and territories.

The PHRN will use the two-stage data linkage model successfully used in Western Australia since the mid 1990s. This involves use of demographic data (name, date of birth, address, sex) from administrative records to create a high quality, ongoing, dynamic linkage map. Linkable content data without identifying information is then provided by each data custodian to the researcher for an approved project. At this stage the PHRN model does not involve establishing a repository of demographic and/or content data.

### **CURRENT STATUS**

Progress to date includes:

Chief Executive appointed April 2009;

Management Council in place June 2009;

Management Council committees (including Access Committee, Ethics, Privacy and Consumer Engagement Advisory Group and Operations Committee) established;

Good progress with development of key policies and manuals;

Directors in place in all PHRN nodes;

Launch of South Australia/Northern Territory node in November 2009;

Good progress with first Proof of Concept collaboration.

Issues include:

Implementation of Communications Strategy (including possible new name);

Development of secure data exchange systems;

Development of data analysis laboratory capability;

Mechanisms for inclusion of health data held by the Australian government.

#### **Dr Merran Smith**

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### Oxford Record Linkage Group

The main news from us is that we are working on English national linkage of hospital and mortality data. This complements our work on the Oxford record linkage study (ORLS). The English work covers linkage of successive episodes of care for each person, plus death certificate data. We match and link using encrypted identifiers. Our strategy is similar to that used for the ORLS – building comprehensively linked files for the whole dataset, so that, when it comes to analysis for each new topic, the data are already linked. We have built the English linked database to “look like” the ORLS, which means that our investment in analytical software for ORLS can run on the all-England data. We have now built a file covering the ten years from April 1998 to March 2008 and a population of 50 million people. We will add extra years as they become available from the national repository of hospital data (the Health and Social Care Information Centre) and mortality data (the Office for National Statistics). We have permission to add data until (at least) 2012. The Oxford subset of the linked English dataset is used to add to the long historical run of the ORLS. We have not yet linked English national maternity data – linking mothers and their medical histories and babies and their evolving medical records - but we have data protection permission and the data to do so. This will be our next big file-building project (with roughly 500,000 births each year from 1998-2008).

We are using the ORLS (with its long timeframe) and the English linked data (with its national coverage and huge numbers) in combination. Examples of published work using both datasets include studies of mortality from inflammatory bowel disease, risk of lymphoma and other cancers after infectious mononucleosis, risk of pneumococcal disease in people with celiac disease, immune-mediated disease in people who have had meningococcal disease, and trends in retinal surgery and in cataract (respectively, *BMJ* 2007,335,1033; *Epidemiology & Infection* 2009,137,672; *Ep & Inf* 2009,137,681; *BJOphth* 2009 epubaheadofprint; *BJOphth* 2007,91,901). Another example of using both datasets in combination is our recent publication on the risk of breast cancer following benign breast disease. Increasingly, we are likely to place more reliance on the national data (because there is little point in using just the Oxford regional data for studies where the national data cover the same period and have far superior numbers). But there will always be areas of research where the long historical run of the ORLS will be important. I am still treating the English data with some caution because (a) it doesn't have the same degree of quality control as was the case with ORLS, and (b) the English population is incomparably more heterogeneous than that of the Oxford region, and so unmeasured confounding is likely to be a bigger issue than in ORLS analyses.

An early area of work with national linked data has been our production of atlases of hospital care, undertaken with the Public Health Observatories, see <http://www.uhce.ox.ac.uk/Epidembase2/>

We are a small research group, and are not funded to provide data to others (indeed, the conditions for our holding the data would generally preclude that). The official providers of hospital data are the national Information Centre and Northgate Solutions. This said, we are delighted to collaborate on the basis of shared protocols and shared aggregated data. Our particular research interests in the next year or two are likely to focus on basic contemporary profiles of and long-term trends in disease, care and outcomes; geographical variations; disease association studies; perinatal factors and subsequent disease in the child; prior maternal history and perinatal outcomes. It sounds ambitious put like that, but, really, I mean some selected examples within each of these main themes.

**Professor Michael Goldacre, FFPHM FRCP**

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**NEW PROJECT: Evaluating Childhood Risk Factors for Early Onset Hypertension: Using Virtual Birth Cohorts in Information rich environments**

**Principal Investigators:** Susan Samuel, Leslie Roos; **Co-Investigators:** Brenda Hemmelgarn, Marcello Tonelli, Scott Klarenbach, Clare Ramsey, Sheila McDonald

**Background:** Hypertension is a leading risk factor for coronary artery disease, stroke and chronic kidney disease. There are pathological and epidemiological lines of evidence suggesting that the roots of hypertension may be in infancy and childhood. We propose to study the relative contributions of various prenatal/infant, postnatal, genetic and environmental factors to the development of early onset hypertension using population based virtual birth cohorts. **Primary Objective:** 1) To determine the impact of the following variables on development of early onset hypertension (ages 18-40): Infant characteristics (birth weight, gestational age, breastfeeding); Educational attainment; Socioeconomic status; Family history of hypertension; Geographic location of residence in childhood (urban versus rural residence) **Secondary Objectives:** 1) To perform exploratory analyses to determine the role of childhood health conditions (asthma and attention deficit hyperactivity disorder) on development of early onset hypertension. 2) To assess the influence of physician visits on age at diagnosis of hypertension. 3) To calculate incremental health costs incurred by individuals with early onset hypertension. **Methods:** *Data Source* - The Manitoba Research Registry at the Manitoba Centre for Health Policy (MCHP) will be used to study children born in Manitoba during fiscal years 1970-1992. *Independent variables:* The Research Registry will be used to obtain individual level variables birth weight, breast feeding, maternal characteristics (age at first birth, marital status at birth of first child), and educational attainment. Family history of hypertension will be defined as whether mother/father/siblings were diagnosed with hypertension using validated administrative health definitions. Geographic variables (rural vs urban) and socioeconomic variables will be obtained from the Canadian Census and the Research Registry. Other independent variables to be examined are asthma and attention deficit hyperactivity disorder and individuals with these conditions will be identified using Aggregated Diagnostic Groups. Health care utilization variables will include physician visits with diagnosis of hypertension. *Dependent variables:* The outcome to be examined is early onset hypertension (ages 18-40) as defined by validated administrative data definitions. The secondary outcomes will be age at diagnosis of hypertension and healthcare costs associated with diagnosis of hypertension. **Analyses:** Multilevel modeling using simultaneous multiple regressions at different hierarchical levels (neighborhood, family, individual) will be used to examine the effect of each variable on early onset hypertension. Individual (level 1) characteristics to be studied are birth weight, gestational age, breast feeding, educational attainment, asthma, attention deficit hyperactivity disorder. Level 2 variables are family characteristics including family history of hypertension, maternal age at first birth, maternal marital status at birth, household income. Neighborhood (level 3) variables will be neighborhood income and socioeconomic factor index at birth and at 17 years of age of oldest sibling, and urban vs rural area of residence. Cox proportional hazards models will be used to determine the effects of cumulative physician visits on the age at diagnosis of hypertension. Total cumulative and incremental health care costs for those with and without hypertension will be compared. **Power:** Total number of individuals in the Research Registry is approximately 300,000 and 20% leave the Province before age 18. Having over 20,000 cases provides more than adequate power for the modeling proposed. **Relevance:** This study design permits population based longitudinal examination of the determinants of early onset hypertension utilizing information rich virtual birth cohorts available through the Manitoba Center for Health Policy. Findings from this study will help identify at risk children for early-onset hypertension, and help guide strategies to mitigate this risk over life course.

**Susan Samuel**

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**Child and Youth Data Lab**  
**Alberta Center for Child, Family and Community Research**

Alberta Child and Youth Data Lab is a newly established research facility that conducts policy-relevant research with a focus on the wellbeing of children and youth using de-identified and linked administrative data from nine provincial partnering ministries. These ministries include: Health and Wellness, Education, Advanced Education and Technology, Children and Youth Services, Justice and Attorney General, Solicitor General and Public Security, Seniors and Community Support and Aboriginal Relations. Partnering ministries provide funding and data. They are also responsible for building the data linkage mechanism.

Currently the ministries are in the process of developing data sharing agreements, privacy impact assessments, and establishing an Anonymous Identity Resolution System that links data from various government departments. The Lab has built its infrastructure, recruited staff and developed the design for the first two projects.

- ◆ First Project: What are the experiences of youth in Alberta in 2008/2009?
  - Describes the population of youth to better understand the characteristics of youth who received services that were relevant to partnering ministries.
  - Provide an overall picture of how and to what extent Albertan youth receive and utilize services (health, social services) across child serving ministries.
  - Focuses on mental health status, education attainment and social economic status.
  - Identifies and quantifies the pattern of service utilization among youth who for example are with severe mental health problems and/or are with poor school performances.
  - Assesses the degree to which these youth overlap in their service use across ministries so that the most vulnerable youth population can be characterized
  
- ◆ Second Project: What are the longitudinal experiences of youth in Alberta?
  - Describes longitudinal experiences and different trajectories of service use among Alberta youth
  - Identifies factors that influence the pattern of service use over time. These factors may include mental health status, social economic status, school performance, high school graduation, income support, enrollment in post secondary institutions, crime charged, and childhood maltreatment and so on.

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**UPDATE: CFI Leading Edge Competition – successful June 2009 (funding still to come)**

**Title:** The Manitoba Centre or Health Policy’s “LEADERS” Initiative: Leading-Edge Access and Data Enhancement Research Strategy

**1) The Importance of this to Research and Training**

Given the Manitoba Centre for Health Policy’s (MCHP) leadership, reputation, expertise and supportive provincial environment, CFI investment into key database acquisitions, increased accessibility, and increased interdisciplinary collaboration tools are critical to MCHP’s cutting-edge vision. MCHP, through its “Leading-Edge Access & Data Enhancement Research Strategy” Initiative (*LEADERS Initiative*) will enable this exponential leap in cross-sector and cross-institutional research, creating an enhanced and cost-effective data laboratory able to transform scientists’ and graduate students’ ability to understand complex systems of health and social policy. The enhanced Repository along with increased access will create new opportunities and strengthen productive, ongoing collaboration and training, while demonstrating cost-effectiveness and leading-edge data management and security.

**2) The Nature of the Infrastructure Request**

The *LEADERS Initiative* will: 1) Transform the research potential of the Repository housed at MCHP, through 16 key database acquisitions (including justice, provincial laboratory & diagnostics & laboratory tests, in-hospital pharmaceuticals, dentistry, post-secondary education). This will enable world-class cutting-edge research into complex systems of health & social policy. 2) Transform scientist’s access to the Repository by developing and piloting Remote Access Sites (RAS) using innovative, cost-effective, secure database management systems. The pilots will be located across the university and selected external sites, with a vision to an expansion provincially and across Canada. 3) Enhance MCHP’s training environment to facilitate research and its translation into action. MCHP will upgrade 600 sq ft of its current space for additional graduate students, post doctoral fellows, and collaborating local, national and international scientists’ access. 4) Substantially increase opportunities for inter-sectoral collaboration and training. The *LEADERS Initiative* will enable MCHP to be a model of cost-effective accessibility, data management & security through its RASs and restructuring of the Repository.

**3) More details regarding the Specific Data and RAS locations**

By acquiring 16 key databases (justice, housing, emergency services, provincial laboratory & diagnostics tests, in-hospital pharmaceuticals, dentistry, post-secondary education and others), MCHP’s *LEADERS Initiative* will increase scientists’ ability to answer challenging health questions of the 21<sup>st</sup> century – what programs work to reduce disparities in population health? What social and health policies best meet the needs of people with mental illness? What impact do programs such as early childhood, in-school, post-secondary school, public housing, social assistance, youth and adult justice have on short- and long-term outcomes? What are the most effective clinical programs (e.g. cardiac care, emergency services) to enhance outcomes? The enhanced Repository and increased access will create new opportunities and strengthen productive, ongoing collaborations across the world, while demonstrating cost-effectiveness and leading-edge data management and security. Manitoba is home to world-renowned health services and population health scientists. The *LEADERS Initiative* will encourage additional collaborations with social scientists (justice, public housing, post-secondary education) and clinical scientists (cardiac, dentistry, obstetrics, gynaecology, rehabilitation, in-hospital pharmacists, diagnostics and laboratory clinicians). This Initiative will also pilot increased access for scientists to the databases through cost-effective, secure *Repository Access Arms (RAAs)* prior to a potential expansion nationally, with pilots located in: 1) Applied Public Health Epidemiology Unit; 2) Centre for Aboriginal Health Research; 3) Pharmacy (currently the first pilot site); 4) Human Ecology; 5) Health Sciences Centre; and 6) Winnipeg Regional Health Authority (RHA). MCHP is converting its existing Repository to a SAS Scalable Performance Data Server model to provide enhanced security, auditing and access control features. The *LEADERS Initiative* will pilot a web-based training “tool kit” to assist scientists in documenting research concepts and methods, and maximizing translation of evidence into action at planning, clinical and policy levels.

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### Networking and Collaboration – Infrastructure for Sharing Knowledge

On Sept 23rd 17 researchers, analysts and data managers from 7 provinces representing nine data repository centres in Canada along with representatives from the Public Health Agency of Canada and Statistics Canada met in Ottawa to discuss the state of documentation of administrative data in Canada.

While a major theme for the day was documentation, two related and equally important themes that emerged were data quality and communication; in particular communication between programmers and researchers during the execution phase of the project (process flow), but also communication between research centres. Another major area for discussion was the possible development of a multi-centre concept dictionary. Some of the advantages to the latter suggestion included:

- Having definitions from multiple jurisdictions all in one place
- Ability to easily compare definitions and approaches across jurisdictions
- A great opportunity to compare multiple viewpoints on an issue, as well as garner feedback on ones' own approach.

Why have a network of centres discussing these topics?

- It cuts down on duplication of effort; we are 10 provinces and 3 territories all with potentially similar data resources. Discussing and sharing approaches will limit the investment each centre needs to expend in these areas and expand upon the ability to learn from each other as well as develop novel approaches potentially not thought about by any one group.
- Common documentation approaches could help facilitate research collaboration across provinces.
- Value added products like tools for producing data quality reports could be shared rather than reinvented at each location.

The aims of the group are to define best practice(s) in documentation areas, develop common tools for documentation, facilitate communication between centres, develop enhanced data quality practices and to share these tools. Improving data quality and enhancing the ability to collaborate inter-provincially on research projects are related objectives. Finally, advocating for resources to do this kind of work is key, whether internal to each organization, or by means of private or public funding agencies. Through this process it is hoped that the work of this group will help to address some of the documentation concerns raised by earlier groups who have identified as a high priority the development of documentation for administrative data.

In order to maintain contact, group members agreed to establish a Microsoft SharePoint portal site to facilitate online discussion and post group documentation such as PowerPoint presentations, minutes, and agendas. At this initial meeting of the group in Ottawa, plans were made to publish a paper as a way of developing a footprint for the group in the literature and supporting small discussions within each centre. Plans were also made to establish terms of reference for the group and to include discussions of documentation inventories, researcher/analyst communications, and intellectual property in future meetings. The next meeting is scheduled to take place in Winnipeg on Wednesday March 10, 2010.

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## Summary of Two Linkage Projects at Statistics Canada

### 1) Linkage of 1991 Census of Population, Canadian Mortality Database and Canadian Cancer Database Follow-Up Study

**(Partner: Health Canada)**

The new linkage will add 10 years of the Canadian Mortality Database (CMDDB) to the 1991 Census for a total mortality follow-up period of 21 years, extending the current linkage. The linkage will also add 43 years of information from the Canadian Cancer Database (CCDB), information from the 1991 Health and Activity Limitations Survey (HALS) and information from 20 years of the Tax Summary File (which excludes income data), covering a 22-year period that will provide updated immigration and emigration flags. The primary purpose of this expansion and extension is to assess the impact of long-term exposure to air pollution on human health, with the objective of informing the development of Canada-wide standards for key criteria air pollutants. One of the key project objectives is to determine whether mortality from all causes combined, from ischaemic heart disease, from cardiopulmonary disease, from respiratory cancer, and from all cancers combined are associated with *long-term* exposure to ambient air pollutants.

### 2) Population Health Risk Tools: Linkage of 1996-1997 National Population Health Survey to Hospitalization and Mortality Data

**(Partners: CIHR Star Team Grant, Doug Manuel)**

The purpose of this linkage project is to be able to produce risk tools that can be used by policy departments and researchers to estimate the 10-year risk of various health outcomes at the population level including mortality and hospitalizations. Until recently, risk tools used by decision-makers and clinicians in Canada were developed from longitudinal datasets from other countries. This project links the records of respondents to the National Population Health Survey (NPHS), Household component, 1996-1997 to the following databases: Historical Tax Summary File (HTSF), 1996 to 2008; Canadian Mortality Database (CMDDB), 1996 to 2007; and in-patient hospital records from the Health Person-Oriented (HPOI) linked database 1992-1993 to 2006-2007.

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## Ambulatory Care Sensitive Conditions Discussion

Some chronic illnesses can be effectively managed in the community with appropriate medical screening, monitoring and follow-up. Although not all hospitalizations for ACSCs are avoidable, appropriate ambulatory care may prevent or reduce the need for hospitalization.

### Ambulatory care sensitive conditions, ACSCs:

- asthma,
- chronic obstructive pulmonary disease (COPD),
- diabetes without complications,
- epilepsy,
- heart failure and pulmonary edema,
- hypertension without complications
- Pelvic inflammatory disease
- Gastroenteritis
- Severe ENT infections
- Bacterial pneumonia
- Pulmonary/other tuberculosis
- Iron deficiency anemia
- Dental conditions
- Cellulitis
- Drug and alcohol dependency
- Neurotic depressive disorders
- Perforated appendicitis
- Low birth weight
- Dehydration
- Urinary infections
- Lower extremity amputations among patients with diabetes

### Data and Analysis

1. Hospital Discharge Data, Latest year
2. Census

This indicator measures the acute care hospitalization rate for ACSCs in the population younger than 75 per 100,000 population.

### Questions:

1. Are data available?
2. Which ACSCs should be included?
3. Is it feasible to do age and sex stratification and adjustment?
4. Multiple-countries/sites?

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**Professor Milt Kotelchuk**      [mkotelch@bu.edu](mailto:mkotelch@bu.edu)

Chair of Community Health Sciences, Boston University School of Public Health

Founder and leader of the Massachusetts Pregnancy to Early Life Longitudinal (PELL) Data System, a public private linked population data base, with over 800,000 births, 550,000 mothers, linked to hospital discharge records and various other public health data bases - with a capacity to follow the mothers and children longitudinally.

Challenges: don't have an identifier so have to create one based on birth certificates and discharges

Types of studies

- ART, 7 agencies link by cycle (2 years working with lawyers)
- Alcohol and drug use projects → Emergency rooms
- Still births
- Late pre-term births

### POTENTIAL TOPICS OF INTEREST – Leslie Roos

#### **What leads to High Payoff Projects?**

Projects which are valuable in themselves and contribute to future projects

- 1) Take advantage of longitudinal data sets (what are the technical issues?)
- 2) Are data at multiple levels available? (if so, how are they being used?)
- 3) Can we / should we link to survey data?
  - a) Can we get the kind of data used by social scientists?
  - b) Specifically, does such linkage provide an opportunity for looking at wellbeing later in life through different lenses?
- 4) Can we / should we link to clinical data?
- 5) What is the role of sensitivity testing? Some common themes:
  - a) Changes in coding
  - b) Better (or different) measurement for a subsample versus data for a population

How critical is a population registry? To me, this is an underlying question of great importance.

The above questions are very relevant for single-site research. Research across sites raises some additional issues:

- 1) Where are the common data elements permitting meaningful comparison? Are there substantive differences between sites which will affect the results? Or is the emphasis on showing the results hold beyond a single site.
- 2) What is the role of documentation in ensuring appropriate comparison across sites?

## International Health Data Linkage Network Consensus Statement

On the 4th and 5th of December 2008, the inaugural meeting of the International Health Data Linkage Network was convened at the Congress Centre, London, United Kingdom. Thirty three participants from the United Kingdom, New Zealand, Canada and Australia were in attendance.

The purpose of the meeting was to bring together representatives of centres, new initiatives and user groups from different countries to discuss the feasibility of sharing and comparing useful information and to decide upon the future direction of the data linkage network.

We, the participants at the inaugural meeting, express our support for the following principles to guide the development of the network during its formative years:

### 1. Statement of Purpose

The objectives of the network will evolve according to the changing needs and interests of its participants. Initially the objectives include:

- To maintain a useful international network of linkage centres and users committed to the systematic application of data linkage to produce community benefit in the health and health-related domains.
- To provide a clearing house for scientific outputs and community impacts arising from data linkage activities supported by the members.
- To share information and resources concerning common challenges and solutions, whilst acknowledging the many diverse contexts in which data linkage occurs.
- To build workforce capacity and other supports for data linkage.
- To foster collaborative projects that show the value of data linkage applications or improve the quality of data and linkage methods.
- To observe and promote high standards of governance and ethical practice in the conduct of data linkage activities.

### 2. Statement of How the Purposes will be Pursued

The purposes will be pursued initially in the following manner:

- IHDLC Website
  - Provide a hub for news contributions, information exchange and clearing house activities.
  - Provide links to centres and organisations with their permission.
  - Use the website to announce conferences and training opportunities.
- Other Networking
  - Conduct electronic communications directly between network members.
  - Meet at least biennially, commencing in Scotland in 2009 and in Winnipeg in 2010.
  - Promote opportunities for staff and student exchange.

- Impacts and Publications
  - Begin the collection of information on scientific outputs and community impacts from all centres and users.
  - Profile projects that have influenced social and health policy, clinical practice and public health.
- Other Projects
  - Facilitate collaborative projects led by members, such as demonstrations of international comparative data applications, data quality and methods assessments, concept dictionaries and special publishing initiatives.
  - Seek international and national funding support, including parallel application strategies, for projects following successful demonstration or when otherwise justified by a robust rationale.
  - Promote recognition and support of the network by international and national health and health-related bodies.

### **3. Mechanism of How to Work Together**

Membership of the network is open to any group or individual that supports the purpose of the network.

The activities of the network are to be coordinated by a director, who is responsible for pursuing the purpose of the network using strategies consistent with this statement. The director is to keep members well informed of the network's activities and to support participative decision making by consulting widely with members about key decisions affecting the network.

To the extent possible, responsibility for hosting the role of director will rotate among the members who are participants in the network with a term of two years.