

International Health Data Linkage Network

2nd Official Meeting, Manitoba

1.30 – 4.30pm Tuesday 9th March 2010

Meeting Notes

Present:

Les Roos – Chair (Manitoba), Alice Chen (Canada), Andrew Stanley (South Australia), Bosu Seo (Manitoba), Bree Heffernan (Victoria, Australia), Brenda Elias (Manitoba), Brendon Kearney (South Australia), Catherine Storey (Scotland), Charlotte King (Alberta), Chris Radbone (South Australia), Christine Roberts (New South Wales), Chunli Gu (Canada), Claudia Sanmartin (Canada), D'Arcy Holman (Western Australia), David Hadorn (New Zealand), David Henry (Canada), Diana Rosman (Western Australia), Douglas Jutte (California), Fiona Stanley (Western Australia), Gary Teare (Canada), Gemma van Halderen (Canberra), Glenn Robbins (Canada), Helen Johansen (Canada), Hude Quan (Calgary), Ingrid Sketris (Canada), James Semmens (Western Australia), Jane Ford (New South Wales), Jane Freemantle (Victoria, Australia), John Bass (Tasmania), Ken Turner (Manitoba), Lee Taylor (New South Wales), Lisa Lix (Saskatchewan), Marcy Winget (Alberta), Mark Smith (Manitoba), Merran Smith (Western Australia), Michael Paterson (Canada), Michael Wolfson (Canada), Milt Kotelchuck (Massachusetts), Morris Barer (British Columbia), Muhamund Haz, Nedeene Hudema (Canada), Pat Martens (Manitoba), Phil Hider (New Zealand), Ruth Bond (Manitoba), Sarath Chandrasekera (Canada), Susan Samuel (Alberta), Teresa Mayer (Canada), Victoria Gray (Western Australia), Vijaya Sudararajan (Victoria, Australia), Xinjie Cui (Alberta).

Part 1: Network Business

1. Welcome

The 52 attendees, including new members were welcomed to the second meeting of the International Health Data Linkage Network by the Chair Professor Les Roos. All attendees had the opportunity to introduce themselves to the group.

2. IHDLN Summary 2008 – 2010

The Acting Director of IHDLN Victoria Gray provided a background to the history of the IHDLN and its Statement of Purpose for the benefit of new members. Ultimately the purpose of the Network is focused on working together and learning from each other in the areas of data linkage to better influence health policy and produce community benefit. The Network planned to do this through its website, networking, compiling information on international research outputs, impacts and publications, and generating funding support.

Since the inaugural meeting in London in December 2008 the IHDLN has 120+ members from Australia, Canada, England, Scotland, New Zealand, US and Singapore, and work has focused on:

- Assessing what comparable data linkage studies the Network would like to perform;
- Grant application, ethics and data application for vasectomy reversal study;
- Grant application for ESRC;
- Commencing the collection of international research outputs;
- Establishing the website www.ihdln.org, which contains information about activities & events, training and education, links to data linkage centres;
- Actively working as a network in facilitating contact between members.

Future directions

Members felt the focus of future directions of the IHDLN should include:

- Increasing membership base to include representation from all international data linkage groups

- Exploring fundraising options
- Better utilising the network as an avenue to discuss how other countries deal with data linkage issues and challenges to learn from each other
- Forming sub-groups within the network
- Starting with more basic international comparative studies (ie hospital data) to boost track-record
- Exploring the possibilities of a more formal structure/charter under the new directorship, but ensuring the IHDLN doesn't become overly administrative

3. International Comparative Studies and Future Funding Sources

Vasectomy reversal study

Professor D'Arcy Holman updated members on the progress of the International Meta-Analysis of Vasovasostomy and Prostate Cancer in vasectomised men utilizing linked morbidity, mortality and cancer data. The University of Western Australia has received human research ethics approvals and are ready to submit their application for data to the WA Data Linkage Branch. Oxford University are also contributing to the meta-analysis. Other centres interested in participating in this international meta-analysis should contact Professor Holman. He will provide all of the information and syntax required so it is a very simple and straight forward study, and opportunity to showcase the first collaborative project of the IHDLN.

Action: Other Centre's interested in pooling data for this meta-analysis should contact D'Arcy Holman dholman@meddent.uwa.edu.au

Childhood maltreatment

Fiona Stanley updated members on the work has been undertaken in this area through groups in London and Perth. Prof Ruth Gilbert from the Institute for Child Health in London submitted a grant for treatments in the area of childhood maltreatment. The Lancet commissioned a paper on the topic. Other centres that have agency data from childhood protection are encouraged to collaborate.

Action: Other Centre's interested in pooling data should contact Fiona Stanley fiona@ichr.uwa.edu.au

Ambulatory care sensitive conditions

Hude Quan proposed that the IHDLN collaborate to conduct a study in the special interest topic of ambulatory care sensitive conditions. 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. This study has important potential for international collaboration. It would require pooling of hospital discharge and census data. More information about this project is available in the General Communication Briefs section of the meeting notes.

Action: Other Centre's interested in pooling data for this meta-analysis should contact Hude Quan hquan@ucalgary.ca or Vicky Gray victoria.gray@uwa.edu.au

Future Funding Sources

- Potential opportunities to link with P3G DataSHaPER (Data Schema and Harmonization Platform for Epidemiological Research)
- Canadian Institute for Health Research (CIHR)

- Explore opportunities in international genetic research collaborations as this is a very well funded area
- Bill Gates Foundation
- HPackard
- NYC Commonwealth Fund
- MacArthur Fellowships
- Benign corporate sponsorship opportunities (ie. SAS or Oracle)
- Xinjie Cui has connections at IBM who have bought SPSS
- Members agreed that this is an important area and a Funding Sub-Committee should be formed. Volunteers for this sub-committee include Les Roos, Xinjie Cui, and David Hadorn
- Budgeting: Two types of funding would be required 1) Funding for core infrastructure such as the Directorship role and 2) Funding for specific projects on a project-by-project basis.

Action: Members interested in joining the Funding Sub-Committee (with Les Roos, Xinjie Cui and David Hadorn) or with ideas regarding future funding sources should contact victoria.gray@uwa.edu.au

4. ESRC Grant Update

Late last year a funding application was lead by Paul Boyle from the University of St Andrews, Scotland with the aim to assess and document the comparability of core data sets used in data linkage research across international boundaries and to develop a data dictionary and potential for development of pathways to harmonization for comparative research. It would also look at the effects of economic recessions and how they vary. However, despite excellent referee comments they were not successful. They have spoken to referees and plan to submit a revised version, which they expect will be along very similar lines and will include a similar set of collaborators.

Action: Members requested that Paul Boyle circulate a draft of the revised application for comment by members.

5. Other Initiatives

International Research Outputs

The consensus statement produced in December 2008 by the IHDLN members states that the IHDLN will:

- 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.

Collation of international research outputs has commenced. Thank you to the members and centres who have already provided their outputs.

The information required is as follows and can be sent to victoria.gray@uwa.edu.au:

- Project Lists- A list of the project applications received each year for linked data with the following information:
 - Year applied
 - Investigators
 - Title
 - A short summary of each project and the linked datasets (if possible)
- Output Lists- A list of the following (if applicable) for each project:
 - Published journal articles
 - Reports

- Theses
 - Books or book chapters
 - Presentations
 - Abstractions
 - Media items
- Influence on Health Policy or Clinical Practice- A description of data linkage projects that have changed or influenced health policy or clinical practice in your state, province or country. I.e. public good stories of the use of data linkage.

Action: Members and centres to please send Vicky Gray victoria.gray@uwa.edu.au their international research outputs. Vicky can also assist you in getting started as the Western Australia Data Linkage System has an ongoing process for collating their research outputs.

Dedicated peer-reviewed journal or supplement for data linkage

Members agreed that creating a dedicated peer-reviewed journal would not be feasible for the IHDLN and there would not be enough content for a supplement at this stage. Members agreed that a journal supplement in a relevant journal should be reconsidered in the future once the Network has more content from international collaborative studies.

At this stage, members agreed that journal 'notices' and 'announcements' should be utilised as a means to promote the IHDLN and raise awareness of our existence and seek new members in order to ensure better representation and credibility at an international level.

Action: Vicky Gray will arrange IHDLN journal announcements in key journals to raise awareness of the IHDLN. Members with suggestions for potential relevant journals to please contact victoria.gray@uwa.edu.au.

6. Training and Education

Advanced and Introductory Analysis of Linked Data courses at University of St Andrews, Scotland (6-10 April 2010) and Swansea University, Wales (12-16th April 2010).

Action: If IHDLN members know of any other training and education opportunities please contact Vicky victoria.gray@uwa.edu.au and she will advertise them on the IHDLN website and email Network members with the details.

7. Staff Exchange

James Semmens from Curtin University in Western Australia indicated that they are liaising with groups in Scotland regarding potential for exchange. Members requested a staff exchange EOI form be available on the website for members interested in exchange to provide their skill base and interest to assist in linkage potential exchange centres.

Action: Vicky will update website with Staff Exchange section.

8. Website and Membership

Website

General reminder about the website: www.ihdl.org as a point of contact. Has information about the following:

- The Network
- Data Linkage Operations
- International Studies
- Activities & Events
- Training & Education
- Meetings of the IHDLN
- Members
- Research Outputs
- Job Opportunities
- Health Conferences
- Links
- Contact Details

Action: Please contact Vicky if you have any contact updates for the website.

Membership

Membership of the Network is open to any group or individual that supports the purpose of the Network. Membership is now at 120+. Members noted to need to encourage wider membership to ensure true international representation particularly from groups in Scandinavia, the US and Asia. Members were encouraged to utilize their own networks and encourage others to join or pass on their contact details to Vicky victoria.gray@uwa.edu.au who will invite them to join.

Action: A request was made for members with relevant contacts from other international groups such as Scandinavia, US or China to encourage them to join the Network.

Action: Vicky will contact members asking them to provide information regarding their areas of interest for our membership database to better connect members and promote more collaboration.

9. Rotation of Directorship

In line with Network's consensus statement *"the responsibility for hosting the role of director will rotate among the members who are participants in the network with a term of two years."* This term ends for the University of Western Australia on the 31st of December 2010. Members agreed that the next directorship should be hosted by a membership group rather than an individual member and that only member groups would be eligible to vote through a nominated spokesperson.

Member groups are encouraged to consider hosting the Directorship (0.3-5 FTE) given the potential to expand the IHDLN and opportunity to boost your organisation's international profile. A potential is to involve early career staff or PhD students in the role.

Action: Vicky will contact IHDLN members to determine their membership status (ie as a group or as a member) and if as a group who is the spokesperson for their organisation for voting purposes.

Action: Vicky will call for expressions of interest for the directorship role in July 2010.

10. Future Meetings and Conferences

Early discussions among the Perth, Western Australia data linkage groups are in progress for a data linkage to conference to be held in Perth in November 2011- more information coming soon

Action: Members wishing to advertise future meetings, events and conferences are encouraged to contact Vicky who will forward this information to Network members and the website.

11. Other Business

There is an opportunity for IHDLN to play a role in developing guidelines for the analysis and reporting of observational data. David Hadorn and Lisa Lix will lead a subgroup to develop this administrative data checklist.

Action: Members interested in discussing developing guidelines for the analysis and reporting of observation data or joining this subcommittee can contact David Hadorn david.hadorn@otago.ac.nz

Action: IHDLN members interested in joining the Infrastructure for Sharing Knowledge group should contact Mark Smith Mark_Smith@cpe.umanitoba.ca

Part 2: General Communication Briefs

Detailed Communication Briefs which include news items, new initiatives and progress reports relevant to the IHDLN are available in the meeting booklet. Members are encouraged to contact to the corresponding person/groups to discuss items further.

Included briefs were:

- Western Australian Developmental Pathways Project (Fiona Stanley)
- Noralou Roos and Manitoba Centre for Health Policy (Noralou Roos)
- Chris Radbone and SA-NT DataLink (Chris Radbone)
- Standards for Health Databases in Assessing Treatment Effectiveness: A role for IHDLN? (David Hadorn)
- Population Health Research Network (Merran Smith)
- Oxford Record Linkage Group (Michael Goldacre)
- New project: Evaluating Childhood Risk Factors for Early Onset Hypertension: Using Virtual Birth Cohorts in Information Rich Environments (Susan Samuel and Les Roos)
- Alberta Child and Youth Data Lab (Xinjie Cui)
- Update: CFI Leading-Edge Access and Data Enhancement Research Strategy (Pat Martens)
- Networking and Collaboration – Infrastructure for Sharing Knowledge (Mark Smith)
- Summary of Two Linkage Projects at Statistics Canada
- Ambulatory care sensitive conditions (Hude Quan)
- Massachusetts Pregnancy to Early Life Longitudinal (PELL) Data System (Milt Kotelchuck)