

International Health Data Linkage Network

Informal Gathering, St Andrews University, Scotland

6.30pm Friday 18th September

MEETING NOTES

Present: Paul Boyle - Convenor (Scotland), James Boyd (Western Australia), David Clark (Scotland), Jane Ford (New South Wales), Rebecca Glauert, D'Arcy Holman (Western Australia), Louisa Jorm (New South Wales), Jo Lamba (Alberta), Amanda Langridge (Western Australia), Geraint Lewis (England), Carole Morris (Scotland), Nick de Klerk (western Australia), Christine Roberts (New South Wales), Claudia Sanmartin (Ontario), Valerie Seagroatt (England), Catherine Storey (Scotland), Jan Van Der Meulen (England), Christine Werk (Alberta),

1. Welcome
2. IHDLN Summary 2009

From the inaugural meeting in December 2008, attended by 33 participants, the IHDLN now has 120+ members from Australia, Canada, England, Scotland, New Zealand and Singapore.

Work has focused on the following:

- Assessing what comparable data linkage studies the network would like to perform
- Grant application for vasectomy reversal study
- Grant application for ESRC
- Grant application for international research outputs
- Establishing the website www.ihdl.org, which contains information about activities & events, training & education, links to data linkage centres

The network is actively working, with members contacting each other regularly. An important objective is to achieve some initial inward funding flow to support collaborative projects.

3. ESRC Grant

A funding application has been led by Paul Boyle 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. The project will then look at the effects of economic recession and how they vary across countries. If successful, the grant will fund a part-time project officer for four years. The grant would start in April 2010 and generate a few thousand pounds per country. Being somewhat methodological, it has at best a moderate prospect of success.

4. MCHP 20th Celebrations

The Manitoba Centre for Health Policy will celebrate its 20th year in 2010. In its short life MCHP has been recognized for numerous groundbreaking achievements in population and public health research leading to evidence-informed health and social policy.

The Repository housed at MCHP is a unique resource that has facilitated research and peer-reviewed publications, placing MCHP at the forefront of the field. To mark this occasion MCHP will be hosting an international conference in March 2010. This conference will bring together leaders in the field as well as highlighting the past and current achievements of the scientists who have helped MCHP set the gold standard in population based research, knowledge translation and data linkage. The founding directors of MCHP will be honored for their vision, leadership, innovation, persistence and remarkable achievements.

The IHDLN will have a breakout session at the conference on Monday 8th, where there will be the opportunity for 3 presentations of research findings. The IHDLN will then hold the second meeting of the network on Tuesday 9th March from 1pm to 5pm, followed by a dinner.

Description of the IHDLN breakout session

One of the purposes of the International Health Data Linkage Network (IHDLN) is to foster collaborative projects that show the value of international comparative data applications, data quality and methods assessments and concept dictionaries. In its first year of operation, the IHDLN has embarked on three collaborative initiatives to show the significance of international comparable data linkage studies.

Like the MCHP, the IHDLN aims to demonstrate the benefits of international collaboration, with ambitions to creatively work together to pool international aggregated deidentified health data to increase the power of knowledge for population based research.

The call for abstracts to present at the IHDLN session of the Manitoba Centre for Health Policy 20th Celebration Conference has been extended to Friday 25th September.

There is the opportunity for 3 presentations, each 20 minutes in length, with 5 minutes for questions.

Presentations are welcomed about the following:

- collaborative initiatives showing the significance of national or international comparable data linkage studies
- national data linkage efforts
- comparison or standardisation of health data from different states/provinces for the purposes of health research
- challenges faced by data linkage centres (those in operation and those being established)

Please email abstracts to Emma.Fuller@health.wa.gov.au

5. International Comparative Studies

Vasectomy reversal study

Oxford University, Manitoba Centre for Health Policy, CancerCare Manitoba, Information Services Division, National Services Scotland and The University of British Columbia submitted a grant application to perform a International Meta-Analysis of Vasovasostomy and Prostate Cancer in Vasectomised Men utilising linked morbidity, mortality and cancer data. The original application was unsuccessful and it is being resubmitted in October for Round 2 of funding at The University of Western Australia. Despite the lack of funding, the centres are progressing with the ethics and data application forms at this time.

Other topics

In developing the ESRC grant, a topic vote was taken for what pilot studies could be performed by the IHDLN. Overwhelmingly, the following two topics polled very highly: childhood maltreatment and ambulatory care sensitive care conditions. Whilst these topics were not chosen for the ESRC study, there seems to be great support for these projects to go ahead. Emma is sourcing potential bodies of funding. **These topic areas (child maltreatment and ambulatory care sensitive conditions) need champions and anyone keen on the topics is strongly encourage to contact Emma to get things moving – also, if anyone knows of suitable international grants, please let Emma know.**

6. 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.

Those present asked if Emma would kindly develop a definition of criteria for inclusion of outputs in the lists – i.e., what outputs are to be considered to result from the use of data linkage systems.

Dedicated peer-reviewed journal for data linkage

The direction of the informal discussion suggested that the best way to pursue this recommendation would be through negotiating an arrangement with an existing journal, such as the IJE, to host a special series on data linkage system infrastructure analogous to the Ice's 'cohort profile' special section. Alternatively, BMC Medical Informatics may be interested.

7. Training & Education

School of Population Health Summer School 2009 – Introductory & Advanced Analysis courses of Linked Health Data, also Consumer & Community Involvement in Research.

Are there any other training and education opportunities that IHDLN members know of? If so, please contact Emma for advertisement on the IHDLN Training & Education page and by email to the network.

8. Membership

Membership of the network is open to any group or individual that supports the purpose of the network. Membership is now at 120+, if anyone would like to join, please contact Emma. The SAILS group from Wales has been encouraged to join.

A request was made for anyone with relevant contacts to encourage some Scandinavian groups to join the Network.

9. Website

General reminder about the website: www.ihdln.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

10. Other

11. Meeting close