

## **International Health Data Linkage Network – Update November 2010**

Dear IHDLN Members,

I hope all is well with you in your part of the world.

Here is the latest IHDLN Update for November 2010. Reading time is 10 minutes and a PDF version is attached for your preference.

### **Rotation of IHDLN Directorship – Centre for Population Health at Curtin University, Perth, WA**

The expressions of interest from centres interested in hosting the next International Health Data Linkage Network Directorship closed on the 31<sup>st</sup> of August 2010. I received only one EOI to host the Directorship through to November 2011 from the Centre for Population Health Research at Curtin University, Perth, Western Australia.

Unless there is an objection, and as this position is currently a non-paid position with no funding, I am happy to hand this Directorship over to Curtin University as of January 2011.

As I am based in Perth, I will be able to assist with the development of the IHDLN in 2011 and to continue working on many initiatives of the IHDLN.

As a member of the network, please indicate if you are in agreement with the Directorship role being handed to Curtin University by emailing [Emma.Fuller@health.wa.gov.au](mailto:Emma.Fuller@health.wa.gov.au) I am sure that you will all agree that the network is in its infancy and the most important matter at this stage is to ensure its ongoing development.

*As a reminder, the consensus statement of the IHDLN states that '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. 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.'*

### **Raising Awareness of the IHDLN & Expanding Membership**

As Director of the IHDLN I am dedicated to raising the awareness of the networks existence and to seek new members in order to ensure that we have excellent representation and credibility at an international level.

Thank you to the members who responded to my request for relevant contacts of other international groups or individuals who you think should be part of our network. Direct invitations have been issued in order to expand our membership.

Membership now stands at 139 and is growing! Please find attached an excel document of the IHDLN Member List as of November 2011. A reminder that if you can see fields of information are blank for you, please email me with the details.

Again, can you please send to me relevant contacts of other international groups or individuals in Scandinavia, the US, China or other that you think should be part of our network? I will then contact the groups or individuals on behalf of the network, introducing who we are, what we do and inviting them to join.

Let's see if we can have 200 members by the end of the year!

## **1<sup>st</sup> Proof of Concept Study of the IHDLN – Progress**

The first proof of concept study of the IHDLN is underway. We are aiming to pool aggregated result data from participating centres (at this stage, UWA, MCHP and Oxford) to show whether vasectomy reversal protects against prostate cancer.

The basic result data should include:

1. the number of men who had a vasectomy in the time period
2. the number of men who have had a reversal
3. the number of incident cases of prostate cancer following vasectomy and the time interval
4. the relative risk of prostate cancer in both groups (vasectomised men and vasectomised men who have had a reversal)

To overcome survival bias and to ensure comparable lengths of follow-up, we will randomly and uniformly allocate the elapsed time between vasectomy and vasovasostomy in vasectomised men who underwent a reversal to those in the same five-year age groups who did not.

Follow-up of prostate cancer will commence either from actual vasovasostomy or, in those with no reversal, from a comparable point in time.

Age will be adjusted.

Cox regression will be performed with vasovasostomy and five year age groups as covariates, incident prostate cancer as the outcome and with survival time in those without cancer censored at death or at the end of the study period.

We are anticipating that each centre will be able to access linked hospital, cancer and death data. The results will then be pooled and a meta-analysis performed on the Australian, Canadian and UK data with the findings hopefully published in an international health journal.

I have begun analysis of the linked data and aim to have this complete by January/February 2011. Once finished, I will send details of the analysis method to each of the centres along with syntax.

## **Visit to Perth by Korean Researchers**

Kisoo Park, Jongmyon Bae and Youngbok Byun from the National Evidence-based Healthcare Collaborating Agency (NECA) in Korea recently visited Perth for 3 days to learn about data linkage activities in WA. They met with people from the WA Data Linkage Unit, Centre for Data Linkage, Population Health Research Network and population health researchers from The University of Western Australia and Curtin University. If you or your colleagues are interested in visiting data linkage centres around the world, please contact me at [Emma.Fuller@health.wa.gov.au](mailto:Emma.Fuller@health.wa.gov.au) to assist.

## **Centre for Data Linkage (CDL) Australia Consultancy Project**

The Information Service Division (ISD) within National Service Scotland (NSS) of NHS Scotland operate a production linkage system which functions on a monthly cycle linking all available validated records submitted in the time period. These linked databases contains information on Scotland's acute hospital day case and inpatient discharges, cancer registrations, General Register Office for Scotland (GROS) death registrations, mental health admissions.

During the Y2K developments, the NSS production linkage system was enhanced to incorporate a number of techniques which increased the speed and efficiency of the linkage systems.

With significant expertise in building a secure production linkage facility, NSS were happy to collaborate with the CDL and saw the benefit of sharing skills and knowledge. This also fits closely with the aims of the International Health Data Linkage Network (IHDLN) to foster collaboration and exchange programs between data linkage centres.

Kevin McInnery is a linkage system expert who was involved in the development and maintenance of the NSS production linkage systems for over fifteen years. Kevin is working with the Centre for Data Linkage (CDL) in Perth, Western Australia for nine weeks to

- review proposed linkage models;
- identify alternative linkage strategies;
- help develop a robust linkage framework to facilitate health research.

During this period, Kevin will be involved in the development and refinement of the national linkage model. This will involve careful consideration of the possible options and identification of the implications for the PHRN in terms of privacy, linkage quality and the services that CDL can provide.

### **3<sup>rd</sup> Call for Information about IHDLN Research Partnerships**

One of the aims of the IHDLN has been to foster collaborative projects that show the value of data linkage applications or improve the quality of data and linkage methods. To date there have been several collaborative projects undertaken that unfortunately have failed to secure funding.

I am very interested to know of any other collaborative research partnerships that you may have set up or are in the process of setting up due to meeting colleagues through the IHDLN. These partnerships can be at any stage, informal or formal and any information about them would be greatly appreciated i.e. the centres involved, topic of research, what data you are planning to use.

Please email me with any news of such collaborations as I am gathering information to demonstrate the effectiveness of the network.

### **2011 International Data Linkage Conference, Perth Western Australia**

Save the date! The 2011 International Data Linkage Conference will be held in Perth Western Australia in November. Dates are soon to be confirmed and more information is forthcoming. It is anticipated the IHDLN will hold a formal meeting at this time. I will keep you posted.

### **ESRC Comparative Cross-National Study**

Some of you may remember that the IHDLN members submitted an application for an ESRC grant in 2009. There is interest in a rebid. I will have more news for you by next week.

### **IHDLN Website**

I had grand plans to update the IHDLN website in the last couple of months but unfortunately other work matters presided. I am currently working with Kelly from [Swish Design](#) to update our website. New to the site will be a search directory for members and an archive of all past IHDLN updates and initiatives.

And that is all for this month. As always if you would like anything circulated to the network or would like to include an item in an update, please contact me. I promise to be in touch more regularly over the coming weeks.

Best wishes,

Emma

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If you would like to unsubscribe to receiving emails about the International Health Data Linkage Network, please email [Emma.Fuller@health.wa.gov.au](mailto:Emma.Fuller@health.wa.gov.au) for removal from the mailing list.