

International Health Data Linkage Network Meeting

Perth 1st May 2012

MEETING NOTES

Present: James Semmens – Convenor (Australia), Rachael Moorin (Australia), Anna Kemp (Australia), Xinjie Cui (Canada), Jenny Currell (Australia), Todd Owen (Australia), Anthea Springbett (Scotland), Carole Morris (Scotland), David Lawrence (Australia), Michael Goldacre (UK), Fiona Stanley (Australia), Katie Irvine (Australia), Anna Ferrante (Australia), James Boyd (Australia), Morven Ballard (Australia), Margo Gillies (Australia), Diana Rosman (Australia), Sue West (USA), Craig Earle (Canada), Mark Smith (Canada), Pat Martens (Canada), Tenniel Guiver (Australia), Katie Harron (UK), Almond Sparrow (Australia), Stacy Vasquez (Australia), Michael Smith (Australia), Hude Quan (Canada), Merran Smith (Australia), Rose Karmel (Australia), Nancy Meagher (Canada), Lisa Ix (Canada), John Frank (Scotland), Carol Garfield (Australia), Margaret Woon (Australia), Christine Roberts (Australia), Nicky O'Brien (Australia), Davif Ford (Wales), Julie Harris (Australia), Louisa Jorm (Australia), Cath Lawrence (Australia), Rebecca Glauert (Australia), David Preen (Australia), Nick de Klerk (Australia), Natasha Nasser (Australia), Ruth Gilbert (UK), Barbara Chan (Australia), Jane Ford (Australia), Reinier De Vos (UK), Spiros Denaxas (UK), Harry Hemmingway (UK), Apruro Gonzalez-Iquierdo (UK), Teresa Dickinson (Australia), Mark McGilchris (Scotland,UK), Tim Churches (Australia).

1. Welcome + Background to the IHDLN (James Semmens)

James highlighted the purpose of the network stressing its unfunded status and how it has evolved from the first meeting in 2008. The role of D'Arcy Holman was acknowledged together with that of Emma Fuller. James stressed there was a big opportunity to work together share our ideas and work out what we can do to drive data linkage forward in a way that is going to improve health care policy and health care outcomes. James stressed that the IHDLN was an opportunity to come together as an international voice rather than a fragmented voice and talk together to develop our relationships to work together to drive this forward.

2. IHDLN Summary Report 2012 (Rachael Moorin)

2.1. Membership of the network:

Rachael reminded members that membership of the network is open to any group or individual that supports the purpose of the network. Currently the majority of memberships are individual. Group membership allows for the opportunity to “host” the network for which an expression of interest will be called later this year. Rachael encouraged members to contact her to change their membership to group where applicable.

Current membership by country:

Country	Number
Australia	85 (45%)
Canada	43 (23%)
United Kingdom	38 (20%)
United States of America	6
Luxembourg	4
Italy	2
France	2
New Zealand	2
Austria	2
Eire	2
Malaysia	2
Israel	1
Taiwan	1
Total	190
Groups	28
Individuals	162

2.2. IHDLN 1st Proof of Concept Comparative Study: International Meta-Analysis of Vasovasostomy and Prostate Cancer in Vasectomised Men.

The first proof of concept study of the International Health Data Linkage Network is pooling aggregated result data from participating centres in the countries of Australia, Canada, England, Wales and Scotland to show whether vasectomy reversal protects against prostate cancer in vasectomised men. The IHDLN members chose to replicate a WA study performed in 2000 in which the findings were deemed inconclusive and the authors of the study called for other international data linkage centres to pool data to perform a large international meta-analysis.

Linked mortality, hospital separation and cancer data were to be accessed locally by each country's research team and analysed according to the specifications sent out by the WA group (ie specifications for the cohort, exposure, outcome and syntax for cox regression)

Results will be pooled in a meta-analysis will include the age-adjusted rate ratio of prostate cancer in vasectomised men, who did and did not have a subsequent reversal.

This project aims to identify the methodological challenges faced when undertaking comparative studies using international data and provide a proof of concept to undertake such cross-country comparisons.

Current status of project

- Human research ethics approval for the extraction of Western Australian data has been approved and data provided. A/Prof Rachael Moorin has completed the analysis of the Western Australian data and developed a methodological protocol which has been supplied to participating centres.
- Results of data analysis have been received from the following participating centres: Western Australia (The University of Western Australia & Curtin University), UK (Oxford University), Wales (Swansea University) and Canada (Ontario)

Preliminary results

WA results:

Analyses	Number of vasectomies	Number of repairs	Relative risk	95% CI
Unadjusted for Age	55,416	1015	0.34	0.16 - 0.79
Adjusted for Age	55,416	1015	0.57	0.27 - 1.21

Ontario results:

Analyses	Number of vasectomies	Number of repairs	Hazard Ratio	95% CI
Unadjusted for Age	85,846	1,229	0.69	0.34 – 1.38
Adjusted for Age	85,846	1,229	1.19	0.60 – 2.40

Welsh results:

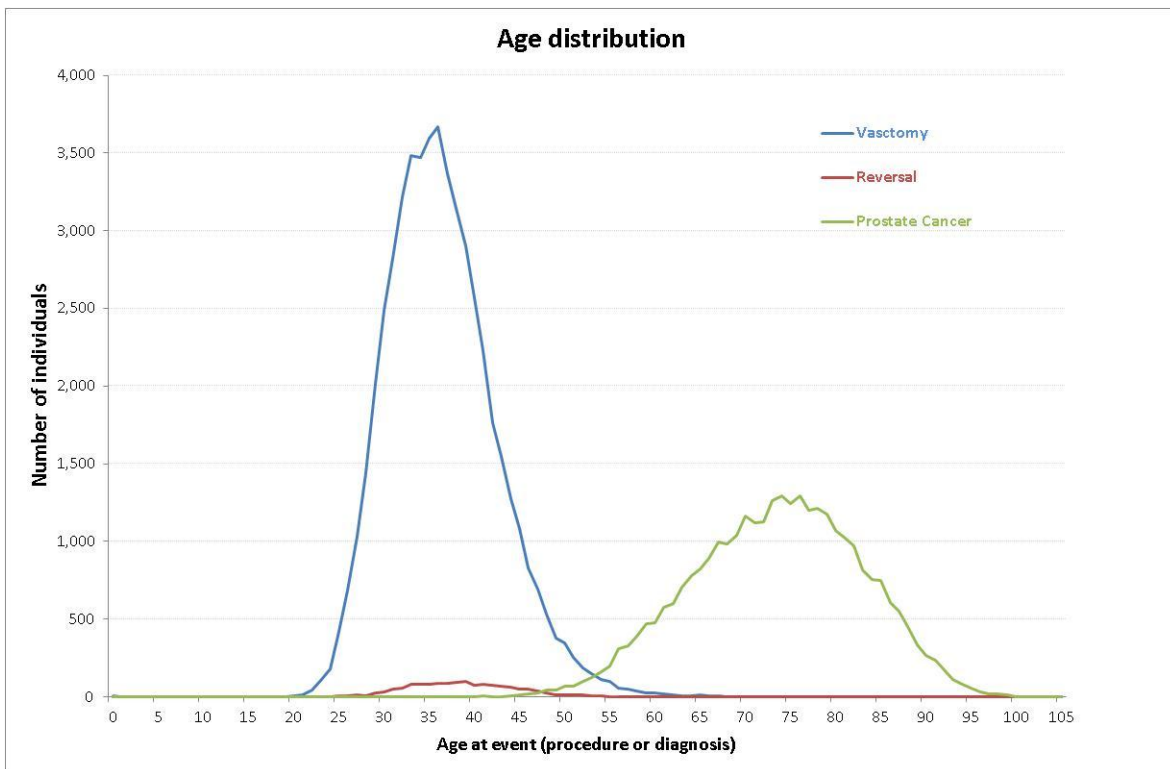
Analyses	Number of vasectomies	Number of repairs	Relative risk	95% CI
Unadjusted for Age	26,858	56	-	-
Adjusted for Age	26,858	56	-	-

NB: Very few cases of prostate cancer in data set – not able to calculate relative risk – due to insufficient follow up time – see below.

	Diagnosed with Prostate Cancer	Total number of individuals
With a reversal	0	56
Without a reversal	19	26,802
Total	19	26,858

Average age at event:

- Vasectomy: 37 years
- Reversal: 39 years
- Diagnosis of prostate cancer: 74 years



Oxford results:

Exposure	Vasectomy and vasovasostomy				
	Observed in reference cohort	Observed number	Expected number	Adjusted rate ratio (95% confidence interval)	p-value
Vasectomy - England	49310	247	262	0.94 (0.83-1.07)	0.38
Vasovasostomy - England	49366	2	7.2	0.28 (0.03-1.00)	0.08

2.3. 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

3. Items for discussion proposed by members (Discussion facilitated by James and Rachael)

3.1. Support and advocacy for the development of data linkage capacity & address issues of standards and methodologies for large database management and analysis.

Significant discussion regarding data quality evaluation and the ability of the network to work together to address issues of standards and methodologies for data linkage. The emerging field of data science was discussed as an area of the network to explore to strengthen collaboration between members.

The potential to undertake evaluation of data quality within and across data linkage systems was discussed including the possibility of evaluating data access timelines across jurisdictions and

models of governance across record linkage centers and how these affect data quality, access, funding for research and translation of findings into policy and practice.

Case studies were suggested as a method of exploring the issues so that there is more awareness of the strengths and weaknesses of each model and that this knowledge could be used. It was also proposed that we develop a typology so that we know exactly what we are referring to with key features of the system. This will facilitate better diagnosis of issues and aid us in exploring the differences.

3.2. A discussion regarding producing a central list of publications and current projects stemming from linked data within and across jurisdictions so that members have access to the list. The outcome of such an initiative driven by the network could be a portfolio of information so that we could put this forward to funding bodies regarding the significance of data linkage and health services research.

3.3. Discussion groups and special interest groups were proposed as a way of moving particular issues that members were interested in forward. It was proposed that a call for special interest groups be made together with a call for champions to take the lead in those groups. Special interest group proposed at the meeting:

- Typology of data linkage, data quality & case studies of models: Proposed Chair: John Frank

3.4. Proof of concept studies for collaborative research by the network: Discussion regarding a “hot topic” to rally around as the next collaborative initiative. It was proposed that we need to find a topic that is both “do-able” and of real public health importance. It was proposed that members construct a menu of really hot topics that would require / significantly benefit from a large multi-national study either to provide a large sample size or because of the difference in variance across countries.

4. Call for expression of interest to host the IHDLN

As stated in the consensus statement of the network, the responsibility for hosting the role of director is to rotate among the members who are participants in the network for a term of two years. Hosting of the Directorship of the IHDLN was handed to Professor James Semmens and Associate Professor Rachael Moorin of the Centre of Population Health Research, Curtin University in 2011. A call for expressions of interest in hosting the network will be made in

August / September 2012. Those interested in applying (hosting is only available to group members).