

## NETWORK MEETING MINUTES

August 28, 2013

9am – 12pm

Forbes Room, Irving Building

University of St. Andrews

- Meeting notes
- Action items

### 1. Welcome and Introductions

Attendance of approximately 50. Members introduced themselves and provided short description of role with linked data.

### 2. Director's update

#### a. Website

- New IHDLN website went live January 2013
- It is a challenging balance between making it relevant to members / attractive to potential members, and ensuring the maintenance burden isn't too significant
- Members are asked to communicate training offerings, job postings: [info@ihdln.org](mailto:info@ihdln.org)
- Members are asked to review and update your own membership listings: [http://www.ihdln.org/member\\_directory](http://www.ihdln.org/member_directory)
- IHDLN should remove job postings once expired
- Members are asked to put our IHDLN logo / wordmark on their websites in order to increase cross-promotion

#### b. Membership drive

- One of the goals of this directorship is to broaden and grow membership
- Authors and collaborators who may use linked data were identified through literature and web searching; contacted 357 individuals (as of January 2013)
- Membership has grown from 207 in January to nearly 300 in August
- Have members from 25 countries, 10 new countries since January, including first Nordic country
- The absence of a Nordic presence is still a major gap, given their work in this arena. Need to continue work to network and raise awareness in Nordic countries.
- Consider engaging with non-health specific groups, i.e. historians, who have extensive experience in linkage.

#### c. New business / discussion

- Member suggestion: The Network should consider charging member fees. Challenges: moving funds from one 'directorship' to another; do we have enough to offer yet?; will that dis-incent membership at the same time we are seeking to grow the web of collaborations?
  - Member suggestion: Consider a Network name change in order to be more representative. Recommendation to rename to "population data" rather than "health data." Discussion included: which name is most representative? Are there political concerns about use of term 'population'? We want to ensure the Network remains inclusive.
3. Conference status
- a. Planning update, opportunity for input
    - Conference details were presented, including conference theme, confirmed keynote speakers, the contents of the call (presentations, poster, rapid-fire poster, sub-plenaries and pre-conference workshops) and timelines for abstracts, program and registration. See <http://www.ihdlconference2014.org/>
    - There will also be a significant student / early career focus, with a very active committee already working on programming.
    - Member suggestion that it would be useful to have a speaker on 'how to overcome data protection legislation' – stories of success.
  - b. IHDLN member presentations pre-conference session
    - We would like to have a pre-conference workshop on data access. It should be developed using a common template so that the information can move to our website. Scope could be access only, or include a discussion about access across jurisdictions and / or access outside of jurisdiction. **James Semmens, Australia, has offered to progress the workshop.**
4. Next Directorship timeline and selection
- Recommendation that the next Directorship be chosen by December 2013 for a December 2014 handover in order to support better planning: time to secure resources, initiate conference planning.
  - **Agreement that next directorship will be decided by December 2013.** Processes around selection of directors need to be developed (see working group.)
5. Initiatives:
- a. Classification of Centres (presentation)
    - One of the recommendations from last meeting in Perth, and an objective of the current directorship: move toward common classification and terminology to support comparison among centres
    - Survey instrument developed by Felicity Flack, Emma Brook, Kim McGrail and Nancy Meagher. Goal is to have as much 'close ended' as possible in order to try to classify
    - Web form has been developed, and will be circulated

## BREAK

## b. Timelines for access (discussion)

- Another recommendation from Perth is to gather information on access timelines
- Nancy Meagher and Kim McGrail have completed a study on access in Canada, to be presented at the conference. Bottom line is that there is significant variability in times (1 to 18 mos), and variability in models of access.
- Access timelines were broken down into “application,” “review,” and “data preparation.” Not all processes can fit neatly into these categories.
- Challenge will be finding a way to “count” timelines that is appropriate for the variety of models and countries.
- Recommendation that data preparation be split into two, one for data linkage and the other for the extract itself. Recommendation that the clock stops only when the researcher is content.
- **Decision that this is an important and valuable initiative for IHDLN, and an opportunity for international leveraging. It needs to be framed in a positive light rather than being seen as ‘damning.’ A working group will be struck on the topic. Working group should identify a model for tracking timelines, and clarify the objectives for tracking timelines.**

## 6. Working groups: Choose, define, and identify leaders

- Request that we develop a series of working groups in order to foster collaboration across jurisdictions as well as to expand the content available for Network members. **Agreement that the working group model should be pursued.**
- Groups identified (with lead in **BOLD**):
  - i. Timelines: **Teresa Dickinson (Australia Institute for Health and Wellness)**, Felicity Flack (Australia Population Health Research Network), and Nancy Meagher (Population Data BC)
  - ii. Privacy / ethics / governance / legislation: **Felicity Flack (Australia Population Health Research Network)**, Robyn Blackadar (Alberta Centre for Child, Family and Community Research), Kerina Jones (University of Swansea), Ros Moran (Ireland Health Research Board)
  - iii. Technical: software for research and linkage: **Daniel Thayer (University of Swansea)**, John Bass, James Boyd (Curtin University, WA)
  - iv. Governance: **Nancy Meagher (Population Data BC)**, Merran Smith (Australia Population Health Research Network), David Ford (Swansea University)
  - v. Methodologies: **Joanne Demmler (Swansea University)**
  - vi. Data knowledge / Metadata: **Mark Smith (Manitoba Centre for Health**

**Policy)**

- vii. Student / early career: **Kate Smolina (University of British Columbia), Katie Harron (University College London)**, Michael Falster (University of Western Sydney), Ofer Amram (Simon Fraser University, Canada)
  - viii. Cross country comparative studies: **James Boyd (Curtin University, WA)**, Alison Macfarlane (City University London), Lee Williamson (St. Andrews University), Mark Smith (Manitoba Centre for Health Policy)
    - Cautionary note for this group to not start with too big a scope. Consider something simple such as death rates and comparing with WHO / OECD.
    - Consider a workshop in conjunction with the conference.
- First objectives of groups should include: confirming membership, how you intend to work together, identifying objectives / intended outcomes, intended benefits to network, and preliminary work plan.
7. Training: Identify available training and current gaps: not adequate time to address
8. Member announcement:
- a. Ireland: Ros Moran from the Health Research Board, seeking advice and input into work they are doing regarding access challenges in Ireland.