International Health Data Linkage Network

Consensus Statement

On the 4th and 5th of December 2008, the inaugural meeting of the International Health Data Linkage Network was convened at the Congress Centre, London, United Kingdom. Thirty three participants from the United Kingdom, New Zealand, Canada and Australia were in attendance.

The purpose of the meeting was to bring together representatives of centres, new initiatives and user groups from different countries to discuss the feasibility of sharing and comparing useful information and to decide upon the future direction of the data linkage network.

We, the participants at the inaugural meeting, express our support for the following principles to guide the development of the network during its formative years:

1. Statement of Purpose

The objectives of the network will evolve according to the changing needs and interests of its participants. Initially the objectives include:

- To maintain a useful international network of linkage centres and users committed to the systematic application of data linkage to produce community benefit in the health and health-related domains.
- To provide a clearing house for scientific outputs and community impacts arising from data linkage activities supported by the members.
- To share information and resources concerning common challenges and solutions, whilst acknowledging the many diverse contexts in which data linkage occurs.
- To build workforce capacity and other supports for data linkage.
- To foster collaborative projects that show the value of data linkage applications or improve the quality of data and linkage methods.
- To observe and promote high standards of governance and ethical practice in the conduct of data linkage activities.

2. Statement of How the Purposes will be Pursued

The purposes will be pursued initially in the following manner:

- IHDLC Website
 - o Provide a hub for news contributions, information exchange and clearing house activities.
 - o Provide links to centres and organisations with their permission.
 - o Use the website to announce conferences and training opportunities.

Other Networking

- o Conduct electronic communications directly between network members.
- o Meet at least biennially, commencing in Scotland in 2009 and in Winnipeg in 2010.
- o Promote opportunities for staff and student exchange.

Impacts and Publications

- 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.

Other Projects

- Facilitate collaborative projects led by members, such as demonstrations of international comparative data applications, data quality and methods assessments, concept dictionaries and special publishing initiatives.
- Seek international and national funding support, including parallel application strategies, for projects following successful demonstration or when otherwise justified by a robust rationale.
- Promote recognition and support of the network by international and national health and health-related bodies.

3. Mechanism of How to Work Together

Membership of the network is open to any group or individual that supports the purpose of the network.

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.

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.