

**POPULATION HEALTH RESEARCH
NETWORK
MANAGEMENT COUNCIL**

TERMS OF REFERENCE

June 2011

1. PREAMBLE

The Population Health Research Network (PHRN) has been established by the National Collaborative Research Infrastructure Strategy (NCRIS) to provide Australian researchers with access to linkable de-identified data from a diverse and rich range of health datasets, across jurisdictions and sectors. This will support nationally and internationally significant population based research that will improve health and enhance the delivery of health care services in Australia.

The Management Council will oversee the implementation of the NCRIS PHRN Investment Plan, as its primary responsibility.

2. FUNCTIONS

- 2.1. Providing advice to the Director of the Program Office for Data Linkage, who will formulate and give effect to a strategic plan and three-year and annual business plans for the implementation of the Investment Plan, in consultation with Project Participants and participant organisations;
- 2.2. Providing advice on the strategic directions and management of capacity-building for national data linkage;
- 2.3. Facilitating the development and maintenance of relationships with government and other agencies holding datasets that would add value to or be enhanced by data linkage;
- 2.4. Facilitating the development and maintenance of relationships with government and other agencies and consumer organisations with regard to information privacy, confidentiality and ethics;
- 2.5. Promoting and supporting data linkage collaborations throughout Australia and internationally;
- 2.6. Monitoring progress in the implementation of the Investment Plan through the review of reports compiled by the Program Office for Data Linkage, and providing advice on any necessary variations to the Investment Plan or the implementation process;
- 2.7. Reviewing the performance of the PHRN against the agreed performance indicators;
- 2.8. Monitoring and reporting on research outcomes from the PHRN;
- 2.9. Overseeing and reporting the outcomes of an independent review of the implementation of the PHRN and the extent to which it has met the Objectives of the Project; and
- 2.10. Formulating a plan for the continued development and maintenance of data linkage systems and activities beyond the Project Period.
- 2.11. The Management Council will establish a process to ensure that advice is sought from the National Health and Medical Research Council Aboriginal and Torres Strait Islander Health and Research Advisory Committee on issues relating to Indigenous health.
- 2.12. The Management Council will establish a consultation process with the Platforms for Collaboration capability, in particular the Australian Research Collaboration Service.
- 2.13. The Management Council will develop and maintain formal consultation processes with the Australian Health Ministers' Advisory Council (AHMAC) and its committees and other bodies and agencies as appropriate. It will investigate and where appropriate develop processes to support the participation of the private health sector in the PHRN.

3. ACCOUNTABILITY OF THE MANAGEMENT COUNCIL

The PHRN Management Council is established as part of the funding agreement between the Australian Government Department of Innovation, Industry, Science and Research and the University of Western Australia.

4. MEMBERSHIP OF MANAGEMENT COUNCIL

4.1. Composition

4.1.1. The Management Council will have an Independent Chair appointed by the NCRIS Committee. The Chair will be an eminent figure with a knowledge of the Australian health system and related health information systems and a knowledge of the laws relating to health information privacy at Commonwealth and State/Territory levels.

4.1.2. Membership of the Management Council will comprise the following individuals in addition to the Chair:

- One nominee of the Director General, Department of Health WA, being a person with expertise in linkage of health databases;
- One nominee of the PHRN NSW/ACT Management Committee, being a person with expertise in linkage of health databases;
- One nominee of the Management Committee of QCHDS, being a person with expertise in linkage of health databases;
- One nominee of the Victorian Department of Human Services, being a person with expertise in linkage of health databases;
- One nominee of the Steering Committee of the SA NT Data Linkage Consortium, being a person with expertise in linkage of health databases;
- One nominee of the University of Tasmania, being a person with expertise in linkage of health databases;
- One nominee of Curtin University of Technology, being a person with expertise in linkage of health databases;
- One nominee of The University of Western Australia;
- One nominee of the Secretary of the Department of Health and Ageing;
- Two researchers with knowledge of health data linkage systems and methods and the analysis of linked datasets, selected by the Chair in consultation with other members of the Management Council;
- One consumer representative who is a member of a government, professional body, industry or non-governmental organisation committee who voices consumer perspectives, selected by the Chair in consultation with other members of the Management Council.

4.2. Appointment Of Members

4.2.1. The Council may be expanded to include individuals nominated by other agencies who are custodians of population health data as appropriate. Inclusion of any such agencies will be by agreement of the PHRN Management Council.

4.3. Appointment of Proxy Members

4.3.1. In the event that a member is unable to attend a meeting they are required to contact the Chair of the Management Council and discuss whether a proxy is needed and if so, who he/she might be. The Chair will make a decision taking into account a range of issues including:

- the capacity in which the proxy would be attending e.g. as a jurisdictional nominee; as an individual expert;
- the nature of items to be covered in the meeting;
- the need for appropriate representation from all parties.

4.4. Terms of Appointment

4.4.1. The Chair and members will be appointed for terms ending on 30 June 2012. With the exception of the Chair and the two researchers, the appointments of

Council members will be reviewed and may be terminated if the professional responsibilities that formed the basis of their appointments change.

4.5. Conditions of Appointment

- 4.5.1. The Chairperson, Researcher members and the consumer representative will be reimbursed for legitimate expenses incurred in attending PHRN Management Council meetings, such as travel and accommodation. Expenses will be reimbursed by application to the Program Office for Data Linkage.
- 4.5.2. Membership will lapse if a member fails to attend three consecutive meetings of the PHRN Management Council without reasonable excuse/apology, unless exceptional circumstances exist. The Chairperson will notify the member and their sponsor where applicable, of such lapse of membership in writing. Steps shall be taken to fill the vacancy, which may arise.
- 4.5.3. Members will be expected to participate in relevant specialised working groups as required. The Chairperson will be expected to be available between meetings to participate in meetings where required.
- 4.5.4. A member may resign from the PHRN Management Council at any time upon giving notice in writing to the Chairperson. Steps shall be taken to fill the vacancy of the former member.

4.6. Subcommittees, Working Groups and Advisory Groups

- 4.6.1. The PHRN Management Council may establish Committees, Working Groups and Advisory Groups. This will include an Ethics, Privacy and Consumer Engagement Advisory Group and an Access and Pricing Committee.

5. CONDUCT OF BUSINESS

5.1. Meetings

- 5.1.1. The Management Council shall meet on a regular basis, which will normally be four to five meetings per year. Meetings may be conducted face to face or by teleconference
- 5.1.2. Agenda papers will be circulated at least 7 days prior to meetings.
- 5.1.3. A quorum will be five people including the Chair and four other members.
- 5.1.4. Meeting dates and agenda closing dates will be published.
- 5.1.5. A Conflict of Interest Declaration will be a standing item on the agenda for Management Council meetings. All declarations of interest and absence of the member concerned will be minuted.

5.2. Records

- 5.2.1. The Program Office for Data Linkage will serve as secretariat for the Management Council and its Director will serve as the Secretary.
- 5.2.2. The Program Office for Data Linkage will prepare and maintain written records of the PHRN Management Council's activities, including agendas and minutes of all meetings.

6. COMPLAINTS

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7. AMENDMENTS TO THE TERMS OF REFERENCE

- 7.1. These Terms of Reference may be amended by following the procedure below:
The proposal must be in writing and circulated to all PHRN Management Council members for their consideration.

The views of the members should be discussed at the next scheduled meeting of the PHRN Management Council, and a vote taken at that meeting. Any member unable to attend such a meeting may register his or her views in writing.
The proposal shall be ratified if two thirds of the members agree to the amendment.

Chairperson _____ Date _____