

**POPULATION HEALTH RESEARCH  
NETWORK  
ETHICS, PRIVACY AND CONSUMER  
ENGAGEMENT ADVISORY GROUP**

**TERMS OF REFERENCE**

August 2010

## 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 **aim to provide policy-makers and healthcare providers with better information for decision-making**, and contribute to improved health care service delivery and health outcomes for Australian communities.

The PHRN will establish nodes that will link data within and between population-based administrative datasets held in Australian states and territories. There are significant ethics and privacy issues that will be addressed as part of this work. The linkage infrastructure that will be established will require approval by relevant Human Research Ethics Committees (HRECs). Each research project that seeks to access linkable data will also require separate HREC approval. Privacy issues are also important as links will be established using demographic data (including name, address and date of birth) held within the administrative collections. States and territories generally have privacy legislation and some also have health records legislation. Legislative provisions related to these matters are generally similar in the states and territories. However they are not identical and the PHRN needs advice to ensure that data linkage models and related matters are developed in a way that meets current and emerging requirements.

Community acceptance of the work of the PHRN and its nodes is important in establishing future engagement and support by Commonwealth, state and territory health agencies and data custodians. It is expected that community participation will be sought and obtained in the planning, governance and operations of the PHRN. This will be achieved through promotion and public outreach activities of the PHRN and through consultations undertaken by the PHRN Ethics, Privacy and Consumer Engagement Advisory Group.

## 2. FUNCTIONS

- 2.1. Development of an Ethics, Privacy and Consumer Engagement Policy for approval by the PHRN Management Council;
- 2.2. The Ethics, Privacy and Consumer Engagement Policy should address:
  - 2.2.1. the ethics and privacy requirements for all applications and projects using the PHRN;
  - 2.2.2. adherence to the principles contained in the *National Statement on Ethical Conduct in Human Research* developed jointly by the National Health and Medical Research Council, the Australian Research Council and Australian Vice-Chancellors' Committee;
  - 2.2.3. adherence to the *Australian Code for the Responsible Conduct of Research* jointly issued by the National Health and Medical Research Council, the Australian Research Council and Universities Australia;
  - 2.2.4. protocols to be followed for the management of health data and linked data both during and after the research project, including:
    - data management and security during the lifetime of a research project;
    - data destruction at the end of a research project;
    - establishment of a verifiable data audit trail;

- 2.2.5. compliance with privacy legislation and regulations both within and across jurisdictions;
- 2.2.6. standards, templates and guidelines on the development and public release of Privacy Impact Assessments at the planning stage of projects that link or use linked health data;
- 2.2.7. consultation with relevant privacy and consumer agencies in each jurisdiction, guided by the *Model Framework for Consumer and Community Participation in Research*, including PHRN requirements for:
  - users of the facilities – provision of evidence of community participation in the development and conduct of research projects using the PHRN;
  - operators of the facilities – provision of evidence of community participation to be included in Annual Progress Reports, Annual Business Plans and performance indicators.
- 2.2.8. The requirements for results of all projects using the PHRN infrastructure to be made publically available.
- 2.3. Oversee and advise the Management Council on the implementation of the Ethics, Privacy and Consumer Engagement Policy across the PHRN. Changes to the Policy must be approved by the Management Council.
- 2.4. Provide ethics, privacy and consumer/community involvement advice to the PHRN Management Council.

### **3. ACCOUNTABILITY OF THE PHRN ETHICS, PRIVACY AND CONSUMER ENGAGEMENT ADVISORY GROUP**

The PHRN Ethics, Privacy and Consumer Engagement Advisory Group is established by and reports to the PHRN Management Council. All recommendations of the PHRN Ethics, Privacy and Consumer Engagement Advisory Group must be tabled at the PHRN Management Council for endorsement.

### **4. MEMBERSHIP OF PHRN ETHICS, PRIVACY AND CONSUMER ENGAGEMENT ADVISORY GROUP**

#### 4.1. Composition

- 4.1.1. The Chair will be nominated by the PHRN Management Council. The Chair will be a member of the Management Council.
- 4.1.2. The Advisory Group will include the following members:
  - At least one member of the Management Council in addition to the Chair;
  - 2 members with expertise in ethical conduct in human research;
  - 2 members with expertise in privacy issues
  - A nominee of the Board of the Consumer's Health Forum of Australia
  - A member with expertise in consumer engagement.

#### 4.2. Appointment Of Members

4.2.1. The Advisory Group may be expanded to include individuals or nominees of other agencies as appropriate and with the 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 Ethics, Privacy and Consumer Engagement Advisory Group 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 eg 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 2011. The appointments of Committee 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. Members who are not nominees of an organisation' as well as consumer/community members may be reimbursed for legitimate expenses incurred in attending the Advisory Group meetings, such as travel and accommodation. Expenses would be reimbursed by application to the PHRN National Program Office.

4.5.2. Membership will lapse if a member fails to attend three consecutive meetings of the Advisory Group without reasonable excuse/apology, unless exceptional circumstances exist. The Chair 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. A member may resign from the Advisory Group at any time upon giving notice in writing to the Chair. Steps shall be taken to fill the vacancy of the former member.

## 5. CONDUCT OF BUSINESS

### 5.1. Meetings

5.1.1. The Advisory Group shall meet at least every 6 months. 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 all meetings of the Ethics, Privacy and Consumer Engagement Advisory Group. All declarations of interest and absence of the member concerned will be minuted.

### 5.2. Decisions

5.2.1. Decision making will generally be by consensus

5.3. Records

5.3.1. The PHRN National Program Office will serve as secretariat for the Advisory Group. The National Program Office will prepare and maintain written records of the Advisory Group's activities, including agendas and minutes of all meetings.

**6. AMENDMENTS TO THE TERMS OF REFERENCE**

6.1. These Terms of Reference may be amended by following the procedure below:

The proposal must be in writing and circulated to all Advisory Group members for their consideration.

The views of the members should be discussed at the next scheduled meeting of the Advisory Group, 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.

The proposal must then be ratified by the PHRN Management Council.

Chairperson \_\_\_\_\_ Date \_\_\_\_\_