

Consumer and Community Participation Policy

Responsible Officer:	Manager, Policy and Client Services
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Superseded Documents:	PHRN Consumer and Community Participation Policy v2.0
Review:	To be reviewed in February 2014
Associated PHRN Documents	PHRN Privacy Policy PHRN Ethics and Scientific Review Policy PHRN Communications Policy PHRN Scientific Research Publications Policy

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1. Preamble

The Population Health Research Network (PHRN) has been funded to provide researchers in Australia with the capability to carry out health data linkage research across jurisdictions and sectors, with the ultimate aim to improve health and wellbeing and enhance the effectiveness and efficiency of health services. In accordance with the *Statement*, the PHRN recognises and supports the central role of consumers and community members in the development, governance and operations of the Network.

The PHRN recognises that privacy is fundamental to the dignity of people in contemporary society and the protection of privacy from unlawful or arbitrary interference is a core human right. The PHRN acknowledges that protecting the privacy of information about their health is very important to people.

The PHRN also recognises that interests in the protection of privacy must be weighed against community interests in improved health and wellbeing and in the effective and efficient delivery of health services. Population health research is important for providing information to help the community make decisions that impact on the health of individuals and the community. That research should be carried out in such a way as to protect people's privacy as much as possible. The public interest in population health research must be balanced against the public interest in the protection of individual privacy.

The *Statement on Consumer and Community Participation in Health and Medical Research*¹ highlights the fact that consumers are placed in an optimal position to provide valuable input

¹ NHMRC/CHF (2001) *Statement on Consumer and Community Participation in Health and Medical Research*. National Health and Medical Research Council/ Consumers' Health Forum of Australia, Canberra, Australia.

to health and medical research as users of health care services. In addition, the *Statement* points out that for high quality research to continue it is imperative that this input is facilitated.

Participation has been defined as ‘where consumers and researchers work in partnership to shape decisions about research priorities, policies and practices which extends further than simply observing or commenting on processes’². To this end, consumer and community participation can be incorporated into all components of research including the development of research goals, questions, strategies, methodologies, information dissemination and advocacy for policy change. In parallel, there is also opportunity for this participation to extend to the planning and decision-making around the infrastructure required to support these important research processes.

The PHRN Funding Agreements detail a number of requirements around consumer and community participation including the establishment of an Ethics, Privacy and Consumer Engagement Advisory Group and the development of a Consumer and Community Participation Policy. In addition, the following key performance indicators are compulsory reporting elements of the Annual Reports of the Network’s participants:

- Level and type of community awareness of the existence, role, impact and value of the PHRN; and
- Level and type of community participation and consultations sought and obtained in facility development and user project planning.

2. Purpose

The Consumer and Community Participation policy is directed at ensuring that the development of the PHRN infrastructure and all research conducted using the PHRN infrastructure includes the appropriate participation of consumers and community members and that this is done in a consistent way across the Network.

3. Scope

The Consumer and Community Participation policy provides the framework for the development of detailed standards, guidelines, protocols and procedures for consumer and community involvement in all components of the PHRN including:

1. Establishment of each new jurisdictional linkage unit (JLU) and the Centre for Data Linkage (CDL) and their corresponding infrastructure;
2. Linkage of new data collections to a jurisdictional linkage map at an individual jurisdictional linkage unit (JLU) or to the national linkage map at the Centre for Data Linkage (CDL);
3. Research applications involving the use of a single jurisdictional linkage map or the national linkage map; and
4. Dissemination of information on current projects and outcomes to the wider community.

4. Policy Statement

- 4.1 The PHRN recognises and supports the important role of health consumers and community members in health and medical research.

² McKenzie A, Hanley B. (2007). *Consumer and Community Participation in Health and Medical Research: A practical guide for health and medical research organisations*. Perth, Australia.

- 4.2 The PHRN supports active partnerships and collaborations between consumers, community members and the PHRN to make decisions about the planning, governance, operations and evaluation of the PHRN.
- 4.3 The PHRN will ensure appropriate resources are provided for education and training of employees and consumers on consumer and community participation.
- 4.4 All projects using the PHRN infrastructure will be aimed at understanding and/or improving the health and wellbeing of the Australian people and will be in the public interest.
- 4.5 Information on current PHRN projects and PHRN project outcomes will be made publicly available and easily accessible in plain language to the wider community.

5. Associated Documents

5.1 National Guidelines

- *Model Framework for Consumer and Community Participation in Research* developed jointly by the National Health and Medical Research Council and the Australian Research Council.
- *Statement on Consumer and Community Participation in Health and Medical Research* developed jointly by the National Health and Medical Research Council and the Consumers' Health Forum of Australia.

5.2 PHRN Documents

- PHRN Scientific Research Publications Policy;
- PHRN Privacy Policy;
- PHRN Ethics and Scientific Review Policy; and
- PHRN Communications Policy.

6. Implementation

6.1 Roles & Responsibilities

6.1.1 PHRN Management Council

The PHRN Management Council has the responsibility to endorse the PHRN Consumer and Community Participation policy and ensure that consumer and community participation occurs across the PHRN in accordance with this policy. The Council will also be responsible for endorsing any amendments to these documents recommended as a result of the annual review of the policy by the PHRN Ethics, Privacy and Consumer Engagement Advisory Group.

6.1.2 PHRN Ethics, Privacy and Consumer Engagement Advisory Group

The Ethics, Privacy and Consumer Engagement Advisory Group is responsible for:

- Advising the PHRN Management Council on the development and implementation of the PHRN Consumer and Community Participation Policy;

- Overseeing the implementation of the Consumer and Community Participation Policy; and
- Providing advice to the PHRN Management Council about consumer and community participation.

6.1.3 PHRN Project Participants

All PHRN Project Participants are required to ensure local processes support the dissemination and implementation of this policy and related guidelines which may include the provision of training for staff and other users of the local and national data linkage infrastructure. Project Participants are also expected to develop and implement their own Consumer and Community Participation policy that is consistent with this document.

6.1.4 Data Users

Data users conducting linkage projects using PHRN infrastructure are required to be aware of and satisfy the requirements of this policy and related guidelines.

6.2 Support & Advice

The PHRN Program Office for Data Linkage will be the central contact point for support and advice relevant to this policy:

- Phone: (08) 6389 7300
- Email: phrn@ichr.uwa.edu.au
- Address: 105 Hay St Subiaco WA 6008

6.3 Communication

A hard copy of this policy will be available in the central offices of all PHRN Project Participants. In addition, an electronic copy will be available on the PHRN website (www.phrn.org.au) and will be referenced in all information available to data users as part of the application process.

7. Review

The Consumer and Community Participation Policy will be reviewed annually by the Ethics, Privacy and Consumer Engagement Advisory Group.

8. Definitions

Centre for Data Linkage refers to the secure data linkage facility hosted by Curtin University of Technology that will facilitate linkage between jurisdictional datasets, and between these datasets and research datasets, using linkage variables;

Community means a group of people sharing a common interest – for example a cultural, social, political, health or economic interest – but not necessarily a particular geographical association;

Consumer representative means a member of a committee, steering group or similar, who voices a consumer perspective and takes part in the decision making process on behalf of consumers. This person is usually nominated by an organisation of consumers and is accountable to them;

Consumers refers to patients and potential patients, carers, organisations representing consumers' interests, members of the public who are targets of health promotion programs and groups asking for research because they believe that they have been exposed to potentially harmful circumstances, products or services;

Data user means a person who performs research using data provided in the course of a PHRN project. This includes investigators, analysts and others who work for a range of organisations including academic institutions and government organisations;

Jurisdiction refers to a territorial jurisdiction which is an authority confined to a bounded space, including all those present therein, and events which occur there. In this context, it refers to an Australian state or territory.

Jurisdictional Linkage Map are the alphanumeric codes created and stored by the jurisdictional linkage units which can be used to group records that refer to the same entity (for use in encrypted form in linking related health records);

Jurisdictional Linkage Unit refers to the secure data linkage facility that will facilitate linkage between administrative datasets pertaining to its own jurisdiction, and between these datasets and research datasets, using linkage variables;

Linkage variables refers to the variables supplied by the data custodians to the data linkage units that are used to match records from different data collections that belong to the same individual, family, place or event. Examples of common linkage variables include name, address and date of birth;

National Linkage Keys are the alphanumeric codes created and stored by the Centre for Data Linkage which can be used to group records that refer to the same entity (for use in encrypted form in linking related jurisdictional health records);

National Linkage Map is a table containing the association between the National Linkage Keys and the encrypted record identifiers as supplied by each jurisdictional linkage unit;

Participant organisation means an organisation that will provide services and functions to the Project Participants but will not be party to a legal contract with The University of Western Australia;

PHRN Funding Agreements means the agreements between the Commonwealth of Australia as represented by the Department of Innovation, Industry, Science and Research and the University of Western Australia regarding funding for implementing the Investment Plans for the research capability known as the Population Health Research Network, under the National Collaborative Research Infrastructure Strategy and the Education Investment Fund Super Science Initiative, respectively;

PHRN Infrastructure means the basic physical and organisational structures needed for the operation of the PHRN;

PHRN Management Council means the group established under the PHRN Funding Agreements to oversee the implementation of PHRN infrastructure in accordance with the PHRN NCRIS and PHRN EIF-SSI Investment Plans;

PHRN Project Participant means a party to a PHRN Participant's Agreement who is approved by the Commonwealth and is directly involved in data linkage activities;

PHRN Projects refer to data linkage projects administered and supported by the PHRN;

Population Health Research Network means the Project Participants listed in the PHRN Funding Agreement and all committees established by the PHRN including the PHRN Management Council.

9. Acknowledgements

- *Model Framework for Consumer and Community Participation in Research* developed jointly by the National Health and Medical Research Council and the Australian Research Council. (2004).
- *Statement on Consumer and Community Participation in Health and Medical Research* developed jointly by the National Health and Medical Research Council and the Consumers' Health Forum of Australia. (2001).
- McKenzie A, Hanley B. *Consumer and Community Participation in Health and Medical Research: A practical guide for health and medical research organisations*. Perth, Australia. (2007).

Appendix A: History

Version	Authorised by	Approval Date	Effective Date	Sections modified
1.0	Authorised by Professor Brendon Kearney	6 November 2010	6 November 2010	First endorsed version
2.0	Professor Brendon Kearney	3 February 2012	3 February 2012	Acknowledgement of PHRN EIF-SSI funding Minor changes to glossary
3.0	Professor Brendon Kearney	11 June 2013	11 June 2013	Minor changes to wording.