



Ethics and Scientific Review Policy

Responsible Officer:	Manager, PHRN Policy and Client Services
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Superseded Documents:	PHRN Ethics and Scientific Review Policy v1.0
Review:	To be reviewed in February 2013
Associated PHRN Documents	PHRN Access and Pricing Policy PHRN Conflict of Interest Policy PHRN Complaints Policy PHRN Consumer and Community Involvement Policy PHRN Privacy Policy

Version	2.0
Authorisation	Authorised by Professor Brendon Kearney
Approval Date	3 February 2012
Effective Date	3 February 2012

1. Preamble

The Population Health Research Network (PHRN) will develop research infrastructure that will have benefits across Australia. The PHRN will enable data users in universities, research institutes, government agencies and other organisations to access new and existing research datasets, ad hoc survey datasets and routine administrative datasets. 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 recognises that the right to privacy is fundamental to the dignity of people and is a core human right. The PHRN acknowledges that protecting the privacy of their personal information is very important to people and that information about a person's health is sensitive information.

The PHRN also recognises that interests in 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, however, it should be carried out in such a way as protect people's privacy as much as possible. The public interest in population health research must be balanced against the public interest in privacy.

2. Purpose

The Ethics and Scientific Review Policy is directed at ensuring that the PHRN infrastructure and all research conducted using the PHRN infrastructure is of the highest ethical and scientific standard, adopts the best practices for the protection of privacy and confidentiality of personal information, complies with all applicable law and includes the participation of consumers and community members.

3. Scope

The Ethical and Scientific Review Policy provides the framework for the development of detailed standards, guidelines, protocols and procedures for scientific and ethical review of:

- The establishment of the linkage unit/infrastructure
- Linking new data collections to the linkage map
- Research applications using the linkage unit/infrastructure

4. Policy Statement

4.1 The PHRN infrastructure and all projects using the PHRN infrastructure will be undertaken in accordance with the ethical principles articulated in the *National Statement on Ethical Conduct in Human Research 2007* developed jointly by the National Health and Medical Research Council, the Australian Research Council and Australian Vice-Chancellors' Committee; and the *Australian Code for the Responsible Conduct of Research 2007* jointly issued by the National Health and Medical Research Council, the Australian Research Council and Universities Australia.

The ethical principles include respect, research merit and integrity, justice and beneficence.

4.2 The PHRN infrastructure and all projects conducted using the national linkage keys will have undergone ethical and scientific review.

4.3 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.

4.4 Each PHRN Project Participant has the responsibility to adopt a review process that eliminates any unnecessary duplication of ethical review (refer to Chapter 5.3 of the *National Statement on Ethical Conduct in Human Research 2007*).

5. Associated Documents

5.1 National Guidelines

- *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
- *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

5.2 PHRN Documents

- PHRN Access and Pricing Policy
- PHRN Conflict of Interest Policy
- PHRN Complaint Management Policy
- PHRN Consumer and Community Participation Policy

6. Implementation

6.1 Roles & Responsibilities

6.1.1 PHRN Management Council

The PHRN Management Council has the responsibility to endorse the PHRN Ethical and Scientific Review Policy and related procedures and guidelines. 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 Ethical and Scientific Review Policy;
- Overseeing and advising the Management Council on the implementation of the Ethical and Scientific Review Policy.
- Providing advice to the PHRN Management Council about ethical and scientific review of PHRN projects.

6.1.3 Human Research Ethics Committees (HRECs)

Under the National Statement on Ethical Conduct in Human Research, Human Research Ethics Committees are responsible for:

- Reviewing proposals for access to linkable data through the PHRN and determining whether they are ethically acceptable and scientifically valid.
- Ensuring that their members have relevant experience and/or expertise to review applications for data linkage research and providing continuing education.
- Establishing processes to handle complaints by community members, data users and others promptly and sensitively.

6.1.4 PHRN-approved data users

All users of data supplied in the course of PHRN-approved linkage projects are required to obtain ethical approval for each project via the relevant HRECs and conduct their research in accordance with the terms stipulated in the approval documents.

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 Ethical and Scientific Review Policy will be reviewed annually by the Ethics, Privacy and Consumer Engagement Advisory Group.

8. Definitions

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 organizations;

National linkage keys refers to the numbers 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);

Personal information means information or an opinion (including information or an opinion forming part of a database), whether true or not, and whether recorded in a material form or not, about an individual whose identity is apparent, or can reasonably be ascertained, from the information or opinion (Privacy Act 1988);

Personal health information means information or opinions that relate to the health of a person where the identity of a person is apparent or can reasonably be ascertained from the information;

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 facilities, services and installations developed and funded under the NCRIS Initiative;

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;

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

9. Acknowledgements

PHRN Funding Agreement 2009. Commonwealth Department of Innovation, Industry, Science and Research and the University of Western Australia.

Appendix A: History

Version	Authorised by	Approval Date	Effective Date	Sections modified
1.0	Professor Brendon Kearney	6 November 2010	6 November 2010	First endorsed version
2.0	Professor	3 February	3 February	Acknowledgement of PHRN

	Brendon Kearney	2012	2012	EIF-SSI funding Minor changes to glossary
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