



Privacy Policy

Responsible Officer:	Manager, PHRN Policy and Client Services
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Superseded Documents:	PHRN Privacy Policy v2.0
Review:	To be reviewed in February 2013
Associated PHRN Documents	PHRN Privacy Management Framework (in development) PHRN Ethics and Scientific Review Policy PHRN Consumer and Community Participation Policy PHRN Information Security Policy (in development) PHRN Access and Pricing Policy PHRN Incident and Breach Management Policy (in development)

Version	3.0
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 non-identifiable information from 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. Data linkage infrastructure will be developed using personal health information held in state and territory data collections.

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 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.

The PHRN Privacy Policy aims are to:

- Maximise the protection of people's privacy; and
- Ensure the responsible use of personal information in population health research which will benefit the community.

2. Purpose

The PHRN Privacy Policy is directed at ensuring that the PHRN infrastructure and all research conducted using the PHRN infrastructure adopts best practices for the protection of privacy of personal information and complies with all applicable law.

3. Scope

The PHRN Privacy Policy provides the framework for the development of detailed standards, guidelines, protocols and procedures for the protection of privacy of personal information.

4. Policy Statement

4.1 Commitment to Privacy

The PHRN is committed to the protection of privacy and the support of research in the public interest by providing access to linkable non-identifiable data and reducing the use of personal information in research. The protection of privacy of personal information is integral to all PHRN's activities. The PHRN will ensure that:

- Privacy is integral to the design of its processes and procedures; and
- Its activities comply with all applicable guidelines, codes of conduct and law relating to privacy and confidentiality.

4.2 Community Engagement

The PHRN is committed to meeting the community's expectations about the protection of privacy of personal information. The PHRN will;

- Seek to understand and meet community expectations about privacy in its activities; and
- Include community representatives in the governance of PHRN.

4.3 Maximising the Protection of Privacy

The processes and procedures of the PHRN will be designed to maximise the protection of privacy. The PHRN data linkage protocols will protect privacy by:

- Maintaining separation of linkage variables from content data in establishing linkage keys;
- Maintaining separation of roles between data linkers, data custodians and data users so that only the data custodians will have access to fully identified data ie linkage variables and other data for an individual;
- Providing data users with data that is only identified with a project specific data key;
- Restricting the amount of data used and/or disclosed to the minimum necessary for the purpose; and
- Adopting strict limits on the use, disclosure and retention of personal information.

4.4 Security

PHRN will protect privacy of personal information by requiring strict security of all data held within or accessed via the Network. The PHRN will ensure that data linkage units and data users:

- Adopt strict standards of physical and technological security for information; and
- Adopt strict standards of security of personnel.

4.5 Governance

PHRN governance arrangements will ensure that this Privacy Policy is implemented and that the protection of privacy remains central to the activities of the PHRN. The PHRN will:

- Appoint and maintain the Ethics, Privacy and Community Engagement Advisory Group;
- Develop and maintain policies, procedures and guidelines to protect privacy; and
- Ensure that all individuals and organisations involved in PHRN activities are bound by contract to clearly defined obligations to protect privacy.

4.6 Transparency

The PHRN will ensure that its activities are open and transparent. The PHRN will:

- Promote public awareness and understanding of its activities and ensure that clear information about its activities is readily available;
- Promote open access to information about the projects conducted using PHRN infrastructure and the outcomes of the research;
- Ensure that its policies and procedures are openly available to the public; and
- Maintain transparent and fair procedures for dealing with complaints and breaches.

5. Associated Documents

5.1 Relevant Legislation

The PHRN recognises that this Privacy Policy operates within a legal framework which may impose various restrictions and obligations on those who deliver and access data linkage services. Users of this policy should consider the duty of confidentiality at common law and equity and should refer to relevant legislation applicable in their jurisdiction including:

- State and territory information privacy legislation and principles
- State and territory health information privacy legislation and principles (where information is health information)
- State and territory legislation empowering the collection, use and disclosure of information in each data set
- Privacy Act 1988 (Cth) and the Information Privacy Principles (where the entity is bound by a Participant's Agreement)
- Privacy Act 1988 (Cth) and the National Privacy Principles (when dealing with information held by a private organisation)

5.2 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
- Guidelines under s 95 of the Privacy Act 1988 (Cth)
- Guidelines under s 95A of the Privacy Act 1988 (Cth)

5.3 PHRN Documents

- PHRN Ethics and Scientific Review Policy
- PHRN Consumer and Community Participation Policy
- PHRN Information Security Policy (in development)
- PHRN Access and Pricing Policy
- PHRN Incident and Breach Management Policy (in development)

6. Implementation

6.1 Roles & Responsibilities

6.1.1 PHRN Management Council

The PHRN Management Council has responsibility for the oversight of privacy management and the endorsement of the PHRN Privacy Policy and related procedures and guidelines. The Council will also be responsible for endorsing any amendments to these documents recommended as a result of any review undertaken.

6.1.2 PHRN Program Office for Data Linkage

The PHRN Program Office for Data Linkage has responsibility for;

- Developing and reviewing policies, guidelines and procedures in consultation with participants to protect privacy and confidentiality;
- Providing support for PHRN Project Participants in protecting privacy and confidentiality of information held within or accessed via the PHRN; and
- Ongoing review and development of PHRN privacy management.

6.1.3 PHRN Project Participants

PHRN Participants have responsibility for:

- Protecting the privacy and confidentiality of all information in their custody;
- Ensuring all data users receiving data from the Project Participant are aware of their obligations to protect the privacy and confidentiality of information in their position;
- Ensuring all data users receiving data from the Project Participant are aware of the PHRN Privacy Policy and related policies, guidelines and procedures; and
- Developing and implementing their own privacy policies, procedures and guidelines that are consistent with the PHRN's Privacy Policy, guidelines and procedures.

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@icmr.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

Evaluation of this policy and associated procedures and guidelines is to be undertaken by the PHRN on an annual basis.

8. Definitions

Administrative datasets refers to information including personal information collected by agencies for the administration of programs, policies and services;

Confidentiality refers to the treatment of information that an individual has disclosed in a relationship of trust and with the expectation that it will not be used or divulged to others in ways that are inconsistent with the understanding of the original disclosure, without permission;

Content data is the data in a record that contains health or clinical information and is used for research purposes. In the health context this can also be referred to as 'clinical data';

Custodial approval means approval obtained from data custodians for release of data for PHRN projects;

Data custodian means the organisation or agency which is responsible for the collection, use and disclosure of information in that dataset. The data custodian is responsible for contributing to the guidelines and approval processes on the use of the data, including involvement with ethics committees and input to the protocols surrounding data use;

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;

Ethics approval means a recommendation from an HREC registered with the NH&MRC that a project is acceptable and compliant with the *National Statement on the Ethical Conduct of Research*;

Information privacy is the interest an individual has in controlling the handling of information about themselves, including the collection, use and disclosure of their information to others;

Information Privacy Principles means the base line privacy standards which the Australian and ACT government agencies need to comply with in relation to personal information kept in their records as set out in section 14 of the Privacy Act 1988 (Cth);

Linkage keys means indices created and stored which can be used to group records that refer to the same person or entity (for use in encrypted form in linking related jurisdictional health records);

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 Privacy Principles means the base line privacy standards which some private sector organisations need to comply with in relation to personal information they hold as set out in Schedule 3 of the Privacy Act 1988 (Cth);

Non-identifiable 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 not apparent, or cannot reasonably be ascertained, from the information or opinion;

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

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;

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 activities means the activities to be carried out by the PHRN Project Participants as described in the Project Plans in the PHRN Funding Agreements;

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 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 Participant's Agreement means an agreement between The University of Western Australia and a Project Participant which complies with the PHRN Funding Agreements, in which The University of Western Australia subcontracts some of its obligations under the PHRN Funding Agreements;

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;

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

Privacy is defined as the right or expectation to be let alone or not interfered with and includes information privacy;

Publication refers to the printing and distribution of documents, or publication of a journal article, book, or book chapter.

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 Brendon Kearney	13 May 2011	13 May 2011	Minor changes in sections 1, 6.1.3 and 8.
3.0	Professor Brendon	3 February 2012	3 February 2012	Acknowledgement of PHRN EIF-SSI funding

	Kearney			Minor changes to glossary
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