



Access and Pricing Policy

Responsible Officer:	Manager, PHRN Policy and Client Services
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Superseded Documents:	PHRN Access and Pricing Policy v2.0
Review:	To be reviewed in February 2013
Associated PHRN Documents	PHRN Application Procedure (in development) PHRN Template for Data Provision to Data Users (in development) PHRN Pricing Schedule (in development) PHRN Funding Agreements PHRN Participants' Arrangement

Version	3.0
Authorisation	Authorised by Professor Brendon Kearney [Chair of PHRN Management Council]
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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. The ultimate purpose is to improve health and wellbeing and enhance the effectiveness and efficiency of health services.

The PHRN supports research and related work in the following subject-matter areas:

- health determinants;
- organisation and delivery of health services;
- health status and health outcomes; and
- non-health fields that affect health and vice versa.

The PHRN aims to consolidate the strong spirit of collaboration that already exists among groups interested in data linkage around Australia. Access is a critical issue in the drive to optimise this new research infrastructure and ensure that the research and innovation is served as broadly as possible.

2. Purpose

The PHRN Access and Pricing Policy has been developed to ensure a common approach for access to linkable data available through the PHRN infrastructure, including a common approach to any charging for access.

3. Scope

The policy covers access by data users to facilities, services and material developed as a result of PHRN NCRIS and PHRN EIF-SSI PHRN funding. This includes national health data linkage facilities and services available through the Centre for Data Linkage and the Program Office for Data Linkage as well as facilities and services in NCRIS PHRN and PHRN EIF-SSI funded state/territory data linkage units.

The policy does not apply to access by the Centre for Data Linkage to linkage variables from state and territory health data collections for the purposes of establishing a secure national data linkage facility. The details of these access arrangements are covered by the PHRN Participants' Arrangement.

4. Principles

Access to the PHRN Data Linkage Infrastructure will be consistent with the principles outlined below:

- Australia's investment in research infrastructure should be planned and developed with the aim of maximising the contributions of the research and development system to economic development, social wellbeing and environmental sustainability;
- Major infrastructure should be developed on a collaborative, national, non-exclusive basis. Infrastructure should serve the research and innovation system broadly, not just the host/funded institutions. PHRN NCRIS and PHRN EIF-SSI funding should encourage collaboration and co-investment among universities, government, independent and private sector research organisations. It should not be the function of NCRIS and EIF-SSI to support institutional level (or small-scale collaborative) infrastructure;
- There should be as few barriers as possible to accessing major infrastructure for those undertaking meritorious research;
- Due regard should be given to the whole-of-life costs of major infrastructure; and
- The infrastructure should seek to enable the fuller participation of Australian researchers in the international research system.

In addition access will be open to those whose projects comply with the following principles:

- they are in the public interest i.e. aimed at understanding and/or improving the health and wellbeing of the Australian people;
- they are ethically approved human research projects of scientific merit;
- they have the approval of the relevant data custodians;
- they are projects whose results will be available in the public domain; and
- they are projects conducted in accordance with the relevant legislation, regulations and guidelines.

5. Policy Statement

5.1 Access to linkable health and related data

5.1.1 Purposes for data access

The purposes for which access to linkable health and related data will be provided are:

- To facilitate research which may contribute to the promotion, protection and maintenance of the health of the public;
- To facilitate the planning, evaluation and delivery of health services; and
- To contribute to knowledge regarding research methodologies relating to health data collection, linkage of health-related data and compilation and use of health-related statistics generally.

5.1.2 Data user criteria

Linkable health and related data will be provided to:

- Data users with the appropriate experience, qualifications, facilities and funding to conduct the proposed research; and
- Students and early career data users who are part of a research team with appropriate experience and qualifications.

5.1.3 International data users

Linkable health and related data may be provided to:

- International collaborators, depending on the nature of the project and the form of the data requested.

5.2 Prioritisation of Data User Access

Access by data users for meritorious research will generally be provided on a first come first served basis. However, the following factors may be taken into consideration when prioritising access:

- Data availability;
- Complexity of project/technical feasibility;
- Public interest;
- Resource availability e.g. funding
- National Health Priority Areas determined by the Australian Health Ministers' Conference;
- Strategic priorities.

5.3 Application process

- A standard application process will be advertised on the PHRN website.
- Each PHRN Participant application process will be compatible with the PHRN application process.
- The standard application form will be consistent with the National Ethics Application Form.
- The Program Office for Data Linkage will coordinate the implementation of the access arrangements.
- The PHRN Access Committee will oversee user access to PHRN facilities, including implementation of the Access and Pricing Policy.

5.4 Terms and Conditions of data release

Data will not be released to data users until the terms and conditions have been agreed. A template set of terms and conditions based on the legal and regulatory requirements of using data for research will be available. This may be varied depending on the nature of the individual project and/or the requirements of specific data custodians.

5.5 Pricing

The following pricing principles will apply to access the PHRN Infrastructure:

- Data users will not be charged for funded services as set out in the PHRN NCRIS or PHRN EIF-SSI Project Plans.
- Costs not covered by the PHRN NCRIS or PHRN EIF-SSI Project Plans may be recovered by charging a fee for PHRN data linkage and related services.
- The pricing structure for PHRN data linkage and related services will be:
 - well-defined, readily available and published for the purpose of both users and research funding agencies;
 - transparently based on the cost of data linkage and related services
 - reportable by both operators and users of the PHRN; and
 - reviewed and set periodically by the PHRN Access Committee after due consideration of the costs of provision of data linkage and related services to users, and after consultation with relevant stakeholders, including data custodians and operators of PHRN Participants.
- Additional fees may be charged by data custodians to offset costs.
- Different access and pricing regimes may apply for defined classes of user.

5.6 Access and Pricing Policies of PHRN Participants

Each PHRN Participant will develop an Access and Pricing Policy which will be consistent with NCRIS and EIF-SSI principles and with the PHRN Access and Pricing Policy.

6. Associated Documents

6.1 PHRN Documents

- PHRN Application Procedure (in development)
- PHRN Template for Data Provision to Data Users (in development)
- PHRN Pricing Schedule (in development)
- PHRN Funding Agreement
- PHRN Participants' Arrangement

7. Implementation

7.1 Roles & Responsibilities

7.1.1 PHRN Management Council

The PHRN Management Council has the responsibility to endorse the PHRN Access and Pricing 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 Access Committee.

7.1.2 PHRN Access Committee

The Access Committee is responsible for:

- Advising the PHRN Management Council on the development and implementation of the PHRN Access and Pricing Policy;
- Overseeing user access to PHRN facilities, including implementation of the Access and Pricing Policy, prioritization of use of facilities and monitoring operating costs and access income;
- Ensuring that the Access and Pricing Policy is consistent with:
 - The NCRIS principles set out in Section 1 of the 2006 NCRIS Roadmap;
 - The EIF-SSI principles set out in the Education Investment Fund (EIF) Evaluation Criteria No. 1 of 2011;

- The PHRN Funding Agreements between the Australian Government Department of Innovation, Industry, Science and Research and the University of Western Australia.

7.2 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

7.3 Communication

A hard copy of this policy will be available in the central offices of all PHRN 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.

8. Review

The Access and Pricing Policy will be reviewed annually by the Access Committee.

9. Definitions

Data custodian for a source dataset is 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 data linkage project. This includes investigators, analysts and others who work for a range of organisations including academic institutions and government organisations;

Health data refers to an individual data variable or collection of data variables related to health conditions, reproductive outcomes, causes of death, and quality of life;

Health-related data refers to an individual data variable or collection of data variables that can be connected either logically or causally to health conditions, reproductive outcomes, causes of death or quality of life;

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;

NCRIS Roadmap means the 'Roadmap for the NCRIS' dated April 2006, as described in the PHRN Funding Agreement;

PHRN EIF-SSI funding means the project resources outlined in the EIF-SSI Project Plan and includes the EIF-SSI cash investment, co-investments and in-kind contributions;

PHRN Funding Agreements mean 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 Agreement to oversee the implementation of PHRN infrastructure in accordance with the NCRIS Investment Plan;

PHRN NCRIS funding means the project resources outlined in the NCRIS Project Plan and includes the NCRIS cash investment, co-investments and in-kind contributions;

PHRN Participant encompasses all Project Participants and participant organisations as described in the PHRN Funding Agreements;

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 Participants' Arrangement is the document that sets out the mutual obligations and operational relationships within the PHRN.

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;

Appendix A: History

Version	Authorised by	Approval Date	Effective Date	Sections modified
1.0	Professor Brendon Kearney	30 September 2009	30 September 2009	First endorsed version
2.0	Professor Brendon Kearney	6 November 2010	6 November 2010	Policy reformatted to new template Sections 6, 7 and 8 added Minor re-wording of Section 5.2
3.0	Professor Brendon Kearney	3 February 2012	3 February 2012	Acknowledgement of PHRN EIF-SSI funding Minor changes to glossary