



Access and Pricing Policy

Responsible Officer:	Manager, PHRN Policy and Client Services
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Superseded Documents:	PHRN Access and Pricing Policy v1.0 PHRN Access and Pricing Policy v2.0 PHRN Access and Pricing Policy v3.0
Review:	To be reviewed in February 2020
Associated PHRN Documents	PHRN Funding Agreements

Version	4.0
Authorisation	Authorised by Professor Brendon Kearney [Chairman, PHRN Board]
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1. Preamble

The Population Health Research Network (PHRN) is a national collaboration that enables existing data from around Australia to be brought together and made available for important research.

The PHRN supports state/territory data linkage units, a national data linkage unit and a secure data laboratory. The PHRN also provides a number of national eResearch tools and services to assist researchers to access linked data efficiently and securely. The PHRN was conceived and implemented through the National Collaborative Research Infrastructure Strategy framework, an initiative of the Australian Government. State and territory governments and academic institutions have made significant cash and in-kind contributions to PHRN activities.

A condition of the PHRN Funding Agreements is that there must be an access and pricing policy for the funded research infrastructure.

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, PHRN EIF-SSI, PHRN-CRIS and PHRN NCRIS 2013 funding ("PHRN

funding”). This includes national health data linkage facilities and services available through the PHRN Program Office, the Australian Institute for Health and Welfare, the Centre for Data Linkage and The Sax Institute, as well as facilities and services in funded state/territory data linkage units.

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 funding should encourage collaboration and co-investment among universities, government, independent and private sector research organisations. It should not be the function of PHRN funding 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.
- 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, or group of 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.
- 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 human services data will be provided are:

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

5.1.2 Data user criteria

Linkable data will be provided to:

- Data users with the appropriate experience, qualifications, facilities and funding to conduct the proposed research

- 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 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 or impact
- Resource availability e.g. funding
- National Health Priority Areas designated by Australian governments
- 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 Human Research Ethics Application (HREA). For example, if information requested in the standard application form is the same as information requested in the HREA the wording of the question should be the same or similar to the HREA to ensure the applicant is aware that the same information is being requested.

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 from the relevant unit or facility. 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 criteria will apply to access the PHRN Infrastructure:

- Data users will not be charged for funded services as set out in the PHRN NCRIS, PHRN EIF-SSI, PHRN CRIS and PHRN NCRIS 2013 Project Plans.
- Costs not directly covered by PHRN Funding may be recovered by charging a fee for PHRN data linkage and related services. These fees may vary between services due to different cost structures and policies.
- 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
- 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, EIF-SSI, CRIS and NCRIS 2013 principles and with the PHRN Access and Pricing Policy.

6. Associated Documents

6.1 PHRN Documents

- PHRN Funding Agreements

6.2 Other Documents

- Human Research Ethics Application (<https://hrea.gov.au/>)

7. Implementation

7.1 Roles & Responsibilities

7.1.1 PHRN Board

The PHRN Board has the responsibility to endorse the PHRN Access and Pricing Policy and related procedures and guidelines. The Board will also be responsible for endorsing any amendments to these documents recommended as a result of the review of the policy by the PHRN Participant Council.

7.1.2 PHRN Participant Council

The PHRN Participant Council is responsible for reviewing the Access and Pricing Policy on a regular basis.

7.1.3 PHRN Participants

The PHRN Participants are responsible for:

- Ensuring that their Access and Pricing Policies are 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 CRIS Conditions of Grant document
 - The NCRIS principles set out in Section 1 of the 2016 National Research Infrastructure Roadmap
 - The PHRN Funding Agreements between the Commonwealth of Australia and The University of Western Australia
- Ensuring that a copy of their Access and Pricing Policy is available on their website

7.2 Support & Advice

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

- Phone: (08) 6488 8600
- Email: phrn@uwa.edu.au
- Address: M320, 35 Stirling Highway, Crawley, WA 6009

7.3 Communication

An electronic copy of this policy will be available on the PHRN website (www.phrn.org.au) and will be referenced in information available to data users as part of the application process.

8. Review

The Access and Pricing Policy will be reviewed regularly by the PHRN Participant Council.

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.

Human services data refers to an individual data variable or collection of data variables that can be connected either logically or causally to services provided to people in order to help them stabilize their life and find self-sufficiency through guidance, counseling, treatment and the providing for of basic needs.

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 '2016 National Research Infrastructure Roadmap' dated February 2017.

PHRN funding means the project resources, including all associated cash investment, co-investments and in-kind contributions, as outlined in the PHRN NCRIS, EIF-SSI, CRIS and NCRIS 2013 Project Plans and the NCRIS 2013 Annual Business Plans.

PHRN Funding Agreements mean the agreements between the Australian Government and The University of Western Australia regarding funding for NCRIS, EIF-SSI, CRIS and NCRIS 2013 including any variations to these agreements.

PHRN infrastructure means the basic physical and organisational structures needed for the operation of the PHRN and funded through PHRN Funding.

PHRN Board means the group established to independently oversee the implementation of PHRN infrastructure in accordance with the NCRIS, EIF-SSI, CRIS and NCRIS 2013 Investment Plans.

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

PHRN Participant Council means the group established to provide advice to the Board.

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.

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
4.0	Professor Brendon Kearney	27 April 2018	27 April 2018	Significant re-write of policy. Changes to Sections 1, 3, 5, 6, 7 and 8.