

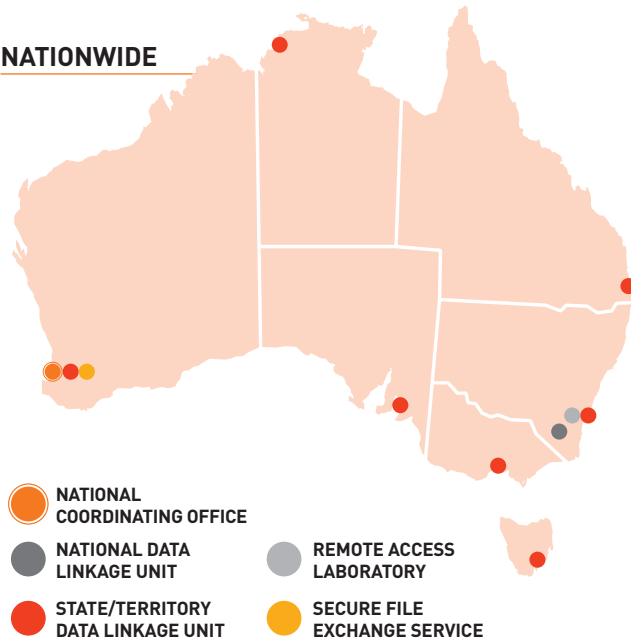
THE PHRN AT A GLANCE

The Population Health Research Network (PHRN) is a ground breaking program which has created Australia's first national data linkage network.

Established with the backing of the Australian Government (as part of the National Collaborative Research Infrastructure Strategy) and supported by every Australian state and territory, the PHRN has built a network that enables existing health data from around the nation to be brought together and made available for vital health and health related research purposes. We use global best practice in maximising the benefits to the Australian community whilst preserving individual privacy.

The PHRN supports six state/territory data linkage units, one national data linkage unit and a secure data laboratory. The PHRN also provides a number of national eResearch tools and services to assist researchers access linked data efficiently and securely.

NATIONWIDE



CONTACT

PHONE: (08) 6488 8600

EMAIL: phrn@uwa.edu.au

ADDRESS:

Population Health Research Network, M320
The University of Western Australia
35 Stirling Highway
Crawley, WA 6009

WWW.PHRN.ORG.AU

PHRN is an initiative of the Australian Government being conducted as part of the National Collaborative Research Infrastructure Strategy.



**LINKED DATA FOR
LONG TERM FOLLOW UP
OF CLINICAL TRIALS
PARTICIPANTS**



BENEFITS OF USING LINKED DATA

Many clinical trials today require long term participant follow up. Longer follow up periods mean that more participants are lost in the process.

Linked administrative data (e.g. hospital admissions, cancer registries and deaths) can be used to follow up clinical trial participants. There are a range of benefits to this approach including:

- Reduction or elimination of the need for follow up visits
- Data collection on participants lost to follow up
- Follow up for very long time periods is possible e.g. decades
- Cost-effectiveness

HOW DO I ACCESS LINKED DATA FOR CLINICAL TRIAL FOLLOW UP?

DATA AVAILABLE

Visit the PHRN website for information on the data collections linked by the PHRN infrastructure including links to data dictionaries.

<http://www.phrn.org.au/for-researchers/data-collections-available/>

CONSENT

Ensure that participants have provided consent for linkage of their clinical trial data to administrative data.

APPLICATIONS

Submit an application for data through the PHRN Online Application System (OAS). A one-stop site for your project application, the OAS enables researchers to submit their application to multiple jurisdictions simultaneously and track their applications online.

<https://oas.phrn.org.au>

APPROVALS

Approvals are required from the data linkage unit/s, data custodians and the relevant Human Research Ethics Committee/s.

ACCESS

The PHRN offers a number of eResearch tools and facilities to assist researchers to access linked data.

Secure File Exchange Service (SUFEX)

SUFEX is one of the options that data custodians can use to send files to the PHRN data linkage units and researchers. SUFEX uses a secure online application that allows users to send and receive files from anywhere at any time.

For more information on SUFEX please visit the SUFEX website or to register email SUFEX directly.

Email: support@sufex.org.au

Website: <https://sufex.org.au>

Secure Unified Research Environment (SURE)

SURE is Australia's first and only remote-access data research laboratory purpose-built for the analysis of linked, routinely collected data. Researchers must use the SURE to access and analyse linked Commonwealth and state/territory data files for approved research projects in Australia.

For more information on the SURE including its design, security features and the process for access, please visit the SURE website and contact the Sax Institute directly.

Phone: (02) 9188 9561

Email: sure-admin@saxinstitute.org.au

Website: <https://www.sure.org.au>