

ANNUAL REVIEW

2015–16



PHRN Population
Health
Research
Network

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OVERVIEW

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 vital health and related research purposes. It was conceived and implemented through the National Collaborative Research Infrastructure Strategy, an initiative of the Australian Government, with significant support from state and territory governments and academic institutions.

The PHRN supports five state/territory data linkage units, national data linkage capability 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.

Australia now has the facilities and capabilities to link and provide access to linked data in all jurisdictions. It also has the facilities and capability to link data from different jurisdictions, to transfer data securely via a data delivery system and to provide remote access to linked datasets in a secure environment. These facilities are of national and international significance. They support research that was not previously possible in Australia and few other countries have the population-based data linkage capability that Australia now has.

CHAIRMAN'S REPORT

2015–16 has been a year of significant achievements for the PHRN in delivering data linkage infrastructure to Australia. The highlight was the development and endorsement of a comprehensive 10-year Strategic Plan for the network.

The PHRN Board led the strategic planning process which provided an opportunity to reflect on the PHRN's achievements and determine how it might position itself to embrace the opportunities and challenges ahead. The Board's goal was for widespread stakeholder ownership of the strategic plan and a rich program of stakeholder engagement was developed. It was very encouraging to see the interest and enthusiasm amongst all groups and a desire for the PHRN to grow and adapt with the changing data sharing environment. The feedback received fed into the development of a bold Strategic Plan that clearly defines the PHRN's vision and mission, its goals and the objectives and activities that will enable their achievement. I thank everyone involved.

Endorsement of the PHRN Strategic Plan preceded the announcement of the Prime Minister's Innovation Statement in early December 2015. The Statement includes \$1.5bn over 10 years for the National Collaborative Research Infrastructure Strategy. The Strategic Plan has now given the PHRN a clear path forward to capitalise on its unique position, to support the national research agenda and develop a strong presence in the National Research Infrastructure Roadmap to be released later in 2016.

The PHRN has continued to promote Australia's rich data collections as a national asset which should be made available to use for high-quality ethical projects through the linkage infrastructure. Advocacy activities have included participation in public hearings and submissions, most notably a presentation by myself and our Chief Executive, Dr Merran Smith to the Senate Select Committee on Health as part of its Inquiry into health policy, administration and expenditure.

There is no doubt that high quality, nationally linked data is essential to the future of health and medical research in Australia. It will underpin innovation over the next 10 years and enable a better understanding of health and disease, improved health and a better health system. 2015-16 has been a productive year for the network, consolidating our position as leaders in provision of state-of-the-art linkage infrastructure and as strong advocates for better access to a wider range of valuable data collections. I am very pleased to announce that the PHRN has been allocated \$4.355m through NCRIS funding for the 2016–17 financial year which will enable this work to continue.

I would like to thank the PHRN Board, Participant Council, the PHRN Chief Executive, Dr Merran Smith and all PHRN Participants colleagues for their hard work and unwavering commitment that continues to drive the network's success. It's an exciting time for the PHRN and I look forward to a productive year ahead.



A handwritten signature in black ink that reads "Brendon Kearney".

Professor Brendon Kearney
Chair, PHRN Board

CHIEF EXECUTIVE'S REPORT

2015–16 has been a year of reflection and preparation for the PHRN: reflection on the network's infrastructure developments and important research outputs, and preparation for the PHRN to position itself as a critical player in the future of research infrastructure in Australia.

The PHRN infrastructure continues to support high quality research of national and international significance. Usage of the infrastructure continues to rise with a record 225 projects receiving data in 2015-16 and over 160 researchers currently registered to use the SURE facility for data access and analysis. Data collected on the outputs of this research shows a 50% increase in the number of peer-reviewed papers published compared to last year. Many of these projects track to the nine National Health Priority Areas targeting the diseases or conditions placing the greatest health and financial burden on Australians.

Development of the PHRN Strategic Plan was a focus for the network and in particular the Program Office during the year. This involved a huge body of work and collaboration between the Board, Participant Council, PHRN Participants and other key stakeholders. The process yielded a comprehensive framework that will be central to all facets of the future operations of the PHRN, including the development of a robust business case for secure future funding.

On that note, the Program Office has also dedicated a large amount of time and resources to participation in the development of the 2016 National Research Infrastructure Roadmap which will frame the allocation of the promised \$1.5bn investment in national research infrastructure. The draft National Research Infrastructure Roadmap is due to be released by the end of 2016.

The Program Office has continued to raise the profile of the PHRN and worked to expand our user base. Communicating to a wider audience about the network and its activities has also been a strong focus during 2015-16. Meetings with researchers, policy-makers, members of the private and not-for-profit sectors and consumers as well as hosting/participating in research symposiums and community conversations have allowed us to connect with all of our key stakeholder groups.

Day-to-day management of the funding contracts and reporting requirements has continued to be coordinated and managed by the Program Office. NCRIS 2015 funding involved preparation and execution of deeds of variation for each of the PHRN Participants and submission of progress reports. Following the provision of a further \$4.355m in NCRIS funding for 2016-17, an allocation process was overseen by the PHRN Board and annual business plans from each PHRN Participant were required. This was a time-intensive process and I thank everyone involved for their patience and willingness to assist.

To close, I would like to thank members of the PHRN Board, Participant Council, PHRN Participants and Program Office staff for their continued commitment and support of the network throughout the year. I look forward to 2016-17 with a sense of enthusiasm, optimism and focus.



A handwritten signature in black ink that reads "Merran B Smith".

Dr Merran Smith
PHRN Chief Executive

STRATEGIC PLAN 2017–2026

Following an external review of the PHRN in 2014, the need for the role and value of the PHRN to be clearly articulated and a clear vision for the future was identified as a high priority for the network.

In response, the PHRN Board engaged Bluegrass Consulting in 2015 to develop a Roadmap for a PHRN strategic planning process, conduct a strategic planning consultation and draft a strategic plan in time of the 2016–17 funding process.

The consultation process included all PHRN stakeholders. Workshops and interviews were held across Australia between October to November 2015, with over 140 people attending these forums including State and Commonwealth Government Department representatives, PHRN Board and Participant Council members, PHRN Participant staff members and some private sector players. Twenty-five online survey responses and five written submissions were also received.

Based on the stakeholder and Board feedback, there was strong support for a bold strategic change for the PHRN to meet and take advantage of the future opportunities and data environment dynamics. This will involve a planned, supported and collaborative change to expand PHRN's current focus as a data linkage network to include more robust and direct contributions to nationally significant issues and initiatives. Importantly, most stakeholders saw this as extending PHRN's current focus to include wider wellbeing services and issues.

The Board endorsed the PHRN Strategic Plan at its June 2016 meeting. Implementation of the Strategic Plan has now commenced in collaboration with the Participant Council, Executive and PHRN Participants. A one-page PHRN Strategic Directions (2017–2026) summary is shown in Fig. 1.

This will involve a planned, supported and collaborative change to expand PHRN's current focus as a data linkage network to include more robust and direct contributions to nationally significant issues and initiatives.

FIG 1: PHRN STRATEGIC DIRECTIONS (2017–2026)



INNOVATIVE INFRASTRUCTURE

Lead and invest in national collaborative, innovative data linkage infrastructure. The network of organisations that form the PHRN have continued to develop and refine their infrastructure in response to the increasing demand for access to high quality linked data by the research community.

The collaborative nature of the PHRN has enabled the newer linkage units to leverage the knowledge and experience of the more mature ones and incorporate the latest in linkage and data delivery technologies. The following provides a snapshot of the key achievements of the PHRN Participants for 2015-16.

NATIONAL DATA LINKAGE INFRASTRUCTURE

The Australian Institute for Health and Welfare (AIHW)

The Department of Human Services and the Department of Health now have provided the Medicare Enrolment File, Medicare Benefits Scheme (MBS) claims and Pharmaceutical Benefits Schedule (PBS) claims data to the AIHW. This supply will allow the AIHW to create and maintain an enduring data resource to support a wide range of data linkage and analytical work.

As part of these developments, the AIHW has commenced the development of a National Master Linkage Key. The National Master Linkage Key will allow efficient and timely national and cross-jurisdictional linkages. It will allow the existing demand for data linkage services to be met and for the growth of future demand.



Australian Government

**Australian Institute of
Health and Welfare**

Centre for Data Linkage (CDL)

In 2015-16 the CDL undertook further enhancements and a full security review of its LinXmart data linkage production system for cross-jurisdictional linkage. The latest version of LinXmart was provided to Queensland Treasury, Tasmanian Data Linkage Unit and AIHW for evaluation in refining their respective data linkage functionality.

The CDL also lead a project on linkage quality during the year. The project involved an assessment of linkage quality benchmarks and practices around the network and the identification of specific techniques and/or tools that yield measurable improvement in linkage quality.



INNOVATIVE INFRASTRUCTURE

REGIONAL DATA LINKAGE INFRASTRUCTURE

The Centre for Health Record Linkage (CHeReL)

As the data linkage unit for NSW and ACT, the CHeReL oversaw delivery of data to 48 approved projects and was involved in the projects for which 90 publications were generated in 2015-16.

More than 100 additional datasets that are not routinely contained within the Master Linkage Key have been linked to the system for specific projects, with data ranging from public laboratory, toxicology and screening data, to administrative data from other sectors such as transport, justice, community services and primary research data collections of cohort or trial participants.

A long historical series of ambulance data is currently being added to the Master Linkage Key to support significant interest by the research and government sectors in pre-hospital care and outcomes.



The Centre for Victorian Data Linkage (CVDL)

The absence of full identifiers from records including full names has posed a major challenge for data linkage in Victoria. In 2015-16, CVDL linked the Patient Master Index (which contains full names, Medicare and hospital reference numbers) to the Victorian Admitted Episodes Dataset (VAED), Victorian Emergency Minimum Dataset (VEMD), Elective Surgery Information System (ESIS) and Victorian Integrated Non-Admitted Health Dataset (VINAH).

The CVDL are now progressing with a linkage map that includes human services datasets with a goal to expand the map to contain all of the Victorian Department of Health and Human Services' major datasets.



SA NT DataLink

2015-16 saw SA NT DataLink continue to expand its Master Linkage File, with the inclusion of additional years' of data of its core collections and the negotiation of supply of other key collections including NT Immunisation, Child Protection and NAPLAN data for Catholic/Independent schools.

SA Mental Health data from 2006 has been approved for inclusion in the SA Master Linkage File and there has been agreement to include the NT Cancer Registry data from 1990 and an additional ten years of SA Cancer Registry data from 1990.

In other technical developments, SA NT DataLink has now established geocoding services for approved data linkage projects. This service is being piloted on a project requiring SA1 level geocoded data with four years of SA public hospital inpatient, Emergency Department and deaths data.



INNOVATIVE INFRASTRUCTURE

REGIONAL DATA LINKAGE INFRASTRUCTURE (cont.)

The Tasmanian Data Linkage Unit (TDLU)

The TDLU's Master Linkage Map (MLM) has continued to grow over the past 12 months, and now contains almost six million individual links, representing over 1,260,000 individuals in the Tasmanian and Australian population. Core datasets comprise birth and death registrations, public hospital admitted patient episodes and emergency department presentations and perinatal events covering both public and private hospitals.

In total, the TDLU has linked either as part of routine operations or ad-hoc projects 33 different datasets. Maintaining high linkage quality and streamlining applications and data access processes have also been key priorities for the unit over 2015-16.



Queensland Record Linkage Group (QRLG)

A key focus of QRLG during 2015-16 was on essential infrastructure enhancements to deal with increasing linkage requests from within and external to Government. This included refactoring scripts for real-time data linkage to increase efficiency, development of links to improve the flows of data in and out of the linkage databases, review and enhancement of grey area and quality checking software, modifications of processes to deal with server capacity issues, migration to a new server environment and preparation for implementation of a new version of ChoiceMaker.

The unit's core collections within its Master Linkage File have been expanded to include additional years. Activities to increase the profile of the data linkage service in Queensland included several invited presentations, a data linkage symposium and a new data linkage website were also undertaken during the year.



SECURE DATA TRANSFER AND ACCESS

Secure File Transfer Infrastructure

The CDL continued to operate and further refine the PHRN's SUFEX, a secure file transfer service enabling large-scale data transmission between PHRN participants, and between PHRN participants and their stakeholders (data custodians and researchers in all states/territories). The SUFEX service supported the Australian research community with 21 new registered users and over 800 secure file transfers in the year 2015-16.

INNOVATIVE INFRASTRUCTURE

SECURE DATA TRANSFER AND ACCESS (cont.)

Remote Data Access Laboratory

Almost 60 research projects involving almost 300 researchers are now being supported by the Secure Unified Research Environment (SURE), Australia's first remote-access data research laboratory that opens the way for more researchers to analyse routinely collected data. This includes five active projects using linked Commonwealth data in SURE through arrangements with the AIHW as an integrating authority. The consolidation of SURE infrastructure to one physical site was also completed during 2015-16 resulting in cost savings and user efficiencies.



APPLICATION FOR DATA

Online Application System

The PHRN Online Application System (OAS) has been developed to improve the efficiency of the application process for cross-jurisdictional linked data projects. The unified online form reduces the number of application forms required and enables researchers to submit their applications simultaneously and track their applications online. The OAS went live in early 2014 and user numbers have been steadily increasing. In 2015-16, the number of new registered users was 75 and the total number of registered users at 30 June 2016 was 112. Led by the Program Office, rolling improvements to the system have continued throughout the year based on feedback to optimise its functionality and user experience.

Metadata Resource

The PHRN Metadata Resource is an online catalogue of data collections which are routinely linked by data linkage units in Australia. The resource was developed by the Program Office in consultation with the Australian data linkage units and relevant custodians and is located on the PHRN website (www.phrn.org.au/for-researchers/). It contains descriptions of the content, quality, condition or other characteristics of the data collections as well as information on where they are located and application and access processes for each.

2015-16 saw the Metadata Resource being updated and expanded on the basis of additional data/new collections being made available for linkage and has proven to be the most accessed section on the PHRN website.

WORLD CLASS RESEARCH AND ANALYSIS

The unique combination of the infrastructure developed by the PHRN, high quality population data collections and recent developments in related infrastructure (e.g. genomics and clinical trials infrastructure) provide new opportunities for Australia to conduct world leading research. There has been a strong increase in demand for linked data in Australia by a large researcher base from a range of academic, government and private industry backgrounds.

APPROVED PROJECTS

Demand for the PHRN infrastructure in terms of number of approved projects receiving linked data has increased over successive years reaching a peak of 225 studies in 2015-16 (Fig. 2). This upwards trajectory is expected to continue as Australia's linked data assets are enriched with the inclusion of additional types of data and the pool of well-trained researchers in statistical linked data analysis increases.

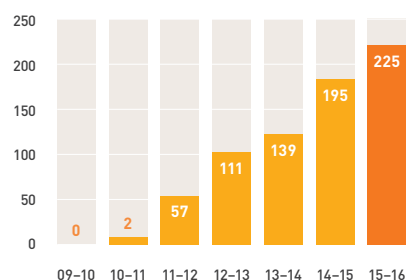


FIG 2: NUMBER OF APPROVED PROJECTS WHERE ALL DATA WAS PROVIDED 2009-10 TO 2015-16

SURE USAGE

The number of accredited users of the Secure Unified Research Environment (SURE) located at the Sax Institute has continued to rise consistently since its launch in 2012 with 160 users now registered including 46 new users during 2015-16 (Fig. 3). SURE users represent over 40 different organisations including universities, research institutes, government agencies or non-government organisations.

A total of 58 active workspaces now exist on the SURE infrastructure to support a range of studies. SURE is now host to some new collections including data from the Centre of Cardiovascular Research and Education in Therapeutics (CCRET) and the Capital Markets CRC (CMCRC) Health Program.

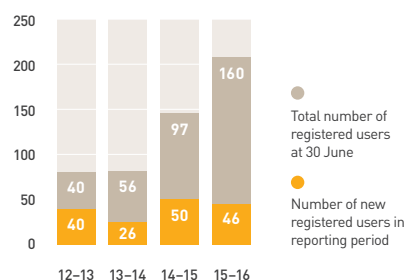


FIG 3: NUMBER OF SURE USERS 2009-10 TO 2015-16

Facilitate and grow the use of linked data for world class, action-oriented research.

WORLD CLASS RESEARCH AND ANALYSIS

RESEARCH OUTPUTS

Publications using PHRN infrastructure

The culmination of the extensive manipulation and analysis of linked data, and arguably the most important phase of the research cycle, is the production of research outputs. 2015-16 saw a total of 167 peer-reviewed manuscripts published in high quality journals which were a direct result of research undertaken using linked data provided by the PHRN infrastructure. This represents a 50% increase in the number of publications for the 2014-15 reporting period (Fig. 4).

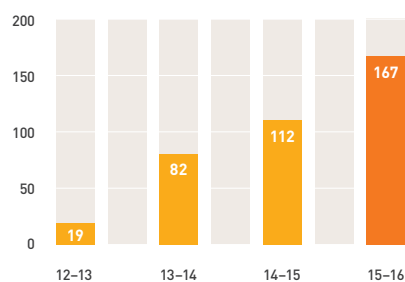


FIG 4: NUMBER OF PEER-REVIEWED PUBLICATIONS USING PHRN INFRASTRUCTURE 2009-10 TO 2015-16

National Health Priority Areas

Data linkage projects supported by the PHRN infrastructure continue to contribute to the evidence base of the areas that contribute the most significantly to the burden of illness and injury in the Australian community. In 2015-16, a total of 77 publications from studies using the PHRN infrastructure were aligned to the nine National Health Priority Areas¹ (Fig. 5).

Policy-responsive projects

One of the main advantages of the use of linked data is the ability to respond quickly to important policy questions due to the availability of high quality population-wide data sources. During 2015-16, the PHRN data linkage units have supported requests for supply of linked data by government agencies and policymakers for a number of studies prompted by parliamentary or media enquiry.

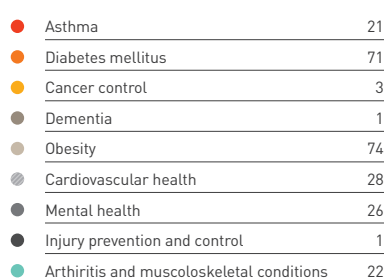


FIG 5: PUBLICATIONS INVOLVING ONE OR MORE NATIONAL HEALTH PRIORITY AREAS¹ 2009-10 TO 2015-16

¹ www.aihw.gov.au/national-health-priority-areas/

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WORLD CLASS RESEARCH AND ANALYSIS

CASE STUDY:

ACT ASBESTOS HEALTH STUDY: THE MR FLUFFY CASE

THE ISSUE

Between the late 1960s and 1979, houses in the ACT and southern NSW were insulated with loose-fill asbestos. Despite remediation, asbestos was still found in many of the 'Mr Fluffy' houses years later. In recent years, the number of people reporting exposure to asbestos, and subsequent health complications has risen.

EXPECTED PROJECT OUTCOMES

The study team will estimate the prevalence of mesothelioma among individuals who have lived in houses containing loose-fill asbestos and compare these to the relative rates of mesothelioma in the general ACT population. They will also calculate the rates of other types of cancers associated with long-term exposure to asbestos. These findings should provide much needed information about health complications arising from exposure to loose-fill asbestos which will be an integral part of the larger body of work being undertaken by the ACT Government's Asbestos Response Taskforce.

www.asbestostaskforce.act.gov.au

HOW DATA LINKAGE WILL HELP

A team from the National Centre for Epidemiology and Population Health (NCEPH) will use data from the cohort of ACT residents living in the affected houses and link it to the National Death Index and the Australian Cancer Database. They will also have a comparison group of non-exposed controls from the general ACT population. The AIHW Data Integration Unit will conduct the linkage.

RESEARCH OUTPUTS (CONT.)

High-calibre researchers using data linked through the PHRN

The PHRN infrastructure is also attracting a high calibre of data linkage researchers. In 2015-16, four of the world's most highly cited scientific researchers were members of Australian research teams that accessed linked data through the PHRN infrastructure². Congratulations go to:

- Professor Bruce Armstrong (University of Sydney)
- Professor Adrian Bauman (University of Sydney)
- Professor John Lynch (University of Adelaide)
- Professor Paul Zimmet (Monash University)

TRAINING AND EDUCATION INITIATIVES

The PHRN has continued to lead or participate in the delivery of a number of training and education initiatives during 2015-16 targeted at a range of stakeholder groups including researchers and ethics committees. Training included:

- SURE training
- PHRN HREC training
- Introductory Analysis of Linked Data Course (USyd)
- Case/Control Workshop (CHeReL/CDL)

² According to the Highly Cited Researchers from Clarivate Analytics (formerly the Intellectual Property (IP) and Science business of Thomson Reuters). This is an annual list recognising leading researchers in the sciences and social sciences from around the world (hcr.stateofinnovation.thomsonreuters.com).

ADVOCACY AND COMMUNICATIONS

Good communication and advocacy is central to the achievement of the PHRN's strategic priorities. There are communication challenges for the PHRN as it has a wide range of stakeholders across a vast geographic area. To address these challenges the PHRN has developed a range of strategies to effectively connect with and deliver key messages to all target groups.

COMMUNICATIONS ACTIVITIES 2015–16

PHRN Video

In early 2016 the PHRN Program Office commissioned Clarity Consulting to develop a short video presentation providing an overview of the PHRN in lay terms and includes a few important case studies demonstrating how it supports valuable research with tangible health benefits. The video has been successfully used by PHRN staff at a number of meetings and conferences and is available to view on the PHRN website (www.phrn.org.au).

PHRN Researcher Newsletter

Clearly communicating the opportunities and benefits to researchers of making use of Australia's wealth of linkable data through the PHRN's infrastructure is of prime importance to the network. The first issue of the PHRN researcher newsletter, a quarterly electronic newsletter for researchers and data users who want to be informed about the services and facilities provided by the PHRN, was circulated in March 2016.

PHRN Website / PHRN Participant Websites

The PHRN website continues to be a key tool in marketing the PHRN infrastructure to its stakeholders (www.phrn.org.au). During the year the website content was regularly updated including the addition of the PHRN video and a new mobile-friendly version of the site was released. Numbers of unique users to visit the site have also increased from previous years.

The websites of the PHRN Participants have also been important avenues of communication to the network's stakeholders and information is regularly revised and updated. Of note in 2015-16:

- Online content for SURE was integrated into new pages on the Sax Institute website and new media content was added including a video (www.saxinstitute.org.au/our-work/sure).
- QLD RLG launched a new data linkage website to assist researchers and government staff in requesting linkage services (www.health.qld.gov.au/hsu/link/datalink).
- TDLU has extensively developed its website including the addition of a list of Tasmanian datasets available for linkage and a comprehensive section on how to apply for linked data (www.menzies.utas.edu.au/research/research-centres/data-linkage-unit).

Advocate for better access to and use of linked data, and communicate research findings.

ADVOCACY AND COMMUNICATIONS

Presentations at national and international meetings and conferences

During the year members of the PHRN Participants and the PHRN Chair presented on the PHRN infrastructure and the research that it supports at a range of other national and international seminars, conferences and workshops throughout the year that were well attended by the research community and other PHRN stakeholders. A sample of these events is provided below:

- Griffith University / Menzies Health Institute Queensland Seminar Series
- University of Queensland Diamantina Institute Trauma Network Meeting
- Big Data-SAHMRI Scientific Symposium
- ACTA 2015 International Clinical Trials Symposium
- University of Sydney Health Data Linkage Research Showcase
- 45 and Up Collaborators meeting
- First International Workshop on Population Informatics for Big Data – 21st ACM SIGKDD Conference on Knowledge Discovery and Data Mining
- ANDS Workshop: Sharing Health-y Data: Challenges and Solutions
- Universities Australia Conference
- Population Health Congress 2015
- Royal Australasian College of Physicians Conference 2015
- Meeting of the National Health Information Principle Performance Committee (NHIPPC)
- Wennberg International Collaborative (UK)
- Digital Health: Neue Optionen für die Versorgungsforschung? (Germany)

Hosted Symposiums

A number of researcher-targeted events were hosted by PHRN Participants. These included:

- ACT Data Linkage Symposium held in Canberra in November 2015 (co-hosted by CHeReL and the ACT Health Improvement Board).
- QLD Health Data Linkage Symposium held in Brisbane in November 2015 (hosted by the QLD RLG)
- Tasmanian Data Linkage Symposium held in Hobart in June 2016 (hosted by TDLU)

ENGAGEMENT WITH CONSUMERS AND THE WIDER COMMUNITY

The involvement of consumers and community members in the development, operations and governance of the PHRN infrastructure continues to be an important part of the success of the network. The PHRN Board and senior governance bodies of all PHRN Participants include membership of at least one consumer representative whose role is to have direct input into how the data linkage infrastructure is run and managed.

The PHRN website also continues to be a key tool in communicating with consumers and the general public. The 'For the Community' section of the site has been boosted by the addition of the PHRN video and new case studies highlighting valuable research that has been supported by the PHRN (www.phrn.org.au/for-the-community/).

The involvement of consumers and community members in the development, operations and governance of the PHRN infrastructure continues to be an important part of the success of the network.

ADVOCACY AND COMMUNICATIONS

ENGAGEMENT WITH CONSUMERS AND THE WIDER COMMUNITY (CONT.)

In addition, a number of other initiatives targeted at this group of stakeholders have been undertaken in 2015–16 including:

- Community and Consumer Conversation Event held in Adelaide in November 2015, in partnership with the Health Consumer Alliance of South Australia (HCASA)
- Presentation by Dr Felicity Flack of the PHRN Program Office to attendees of two Health Consumer Workshops held in Perth in November 2015 and March 2016
- Meeting of the PHRN Chief Executive and the CEO of the national consumer advisory group Consumers' Health Forum of Australia

ADVOCACY THROUGH PUBLIC CONSULTATION SUBMISSIONS

Throughout 2015–16, the PHRN and individual PHRN Participants made submissions to a number of public consultations. These included:

- Senate Select Committee on Health – Inquiry into health policy, administration and expenditure (December 2015): Written submission and presentation to Senate Select Committee on 11 December 2015 by Dr Merran Smith. The Committee's Sixth Interim Report entitled 'Big health data: Australia's big potential' was released in May 2016 and the PHRN's input regarding linkage of Commonwealth and state health datasets featured prominently.
- Productivity Commission National Education Evidence Base Inquiry (May 2016) – written submission
- Review of data linkage capabilities in Western Australia to enhance the next generation of whole-of-Government data linkage (June 2016) – written submission
- Medical Research Future Fund – Australian Medical Research and Innovation Five Year
- Strategy (June 2016) – written submission
- Medical Research Future Fund – Australian Medical Research and Innovation Two Year Priorities (June 2016) – written submission



COLLABORATIONS AND PARTNERSHIPS

The PHRN is currently a collaboration of universities, research institutes and Commonwealth and state departments and agencies. This collaborative network approach enables a wide range of linked data to be made available for research and access to linked data to be provided to researchers across Australia on a non-exclusive basis. An expansion of Australia's data linkage infrastructure will involve nurturing these existing collaborations and actively establishing new ones with a range of research, government and industry partners.

GOVERNMENT COLLABORATIONS – ACCESS TO COMMONWEALTH DATA

On 7 December 2015, the Australian Government released its Public Data Policy Statement which commits Commonwealth Government entities to, amongst other things, collaborate with the private and research sectors to extend the value of public data for the benefit of the Australian public. Following this announcement, the PHRN and its Participants have continued to actively engage with the Australian Government to facilitate researcher access to valuable Commonwealth data collections. The key development of 2015-16 was the agreement by the Commonwealth to provide MBS and PBS data to the AIHW.

Discussions to facilitate access to other Commonwealth-held collections both within and external to the health sphere through the PHRN infrastructure have continued throughout the year. New engagement opportunities with government partners in 2015-16 include proposals to host data of the Australian Taxation Office and the Department of Social Services for researcher access within the SURE facility. Contract negotiations for these proposals were finalised by 30 June 2016 and operations will commence in full from the first quarter of the 2016-17 financial year.

Several regional data linkage units have now also negotiated access to the Australian Early Development Census through the Australian Government's Social Research Centre. This is a full-population census of children's health

and development in their first year of full-time school and has already been linked to other data collections such as health, education and justice to facilitate important research.

STATE/TERRITORY GOVERNMENT COLLABORATIONS

PHRN Participants have engaged with state government agencies to develop and execute policy and practice relevant to use of linked data has assisted in the routine supply of updated data for existing collections and the negotiation of access to new collections. This has also been important in raising the profile of data linkage as an attractive and cost-effective way for government departments to undertake research to inform policy and practice.

For example, the CHeReL have developed new approaches to briefing the NSW Ministry of Health on high profile policy relevant data linkage projects. In Victoria, the CVDL held a large Department of Health-wide forum to promote the unit and increase awareness of data linkage, with a focus on some of the major priority projects for the Department to which CVDL is contributing data linkage work. QLD RLG have developed automated linked data feeds to approved users within the Queensland Department of Health working on patient safety, service planning, waiting list management, mental health reporting and cancer reporting. This initiative has increased the visibility of this service and value of its product within government.

Foster collaborations between researchers, governments and industry partners.

COLLABORATIONS AND PARTNERSHIPS

CASE STUDY:

THE QUEENSLAND LINKAGE PROJECT: DEVELOPMENT AND LIFE-COURSE CRIMINOLOGY

THE ISSUE

Exploring patterns of offending over the life-course and examining risk and protective factors associated with offending careers is dependent on having high quality longitudinal data. However, establishing longitudinal studies of offending have been problematic due to their expense, low sample numbers, high rates of attrition and a bias towards males from low income areas.

THE SOLUTION

Linking population-wide cohorts of administrative data from 13 Queensland Government databases across health (mental health data, emergency and hospital admissions, trauma data, perinatal data and deaths data), justice (police cautions and conferences for youths, adult and youth court finalisations, adult and youth orders and detention/prison data), child protection (child maltreatment victimisations and perpetrations), births (births into the cohort and births from parents in the cohort), deaths and marriages. Data will be available for approximately 190,000 individuals (50.8% male; 4.6% Indigenous Australian) and will include more than 2000 variables.

HOW PHRN WILL PLAY A ROLE

This is a collaborative project involving Queensland Government Agencies. The QLD Record Linkage Group based within QLD Health will manage the health data application, linkage and delivery process for the project.

Reference: Stewart, A., Dennison, S., Allard, T., Thompson, C.M., Broidy, L. & Chrzanowski, A. (2015). Administrative data linkage as a tool for developmental and life-course criminology: The Queensland Linkage Project. *Australia and New Zealand Journal of Criminology*, 48: 409-428.

CROSS-AGENCY ENGAGEMENT

PHRN Participant staff have participated in advisory committees and working groups to foster cross-agency engagement and data sharing. Linking data across agencies and sectors is critical in overcoming the functional 'information silos' that exist and to promote a whole-of-government approach to investigating complex problems.

QLD RLG staff are members of the Queensland Cross Agency Data Sharing Working Group which brings together Departments of Communities, Health, Justice, Police, Education, Transport and Main Roads.

In Victoria, CVDL is a key member of the Victorian Data Linkage Working Group, with representatives from Department of Justice, Department of Education and Training, Department of Premier and Cabinet and the Australian Bureau of Statistics.

The TDLU has also been instrumental in the planning of a large 'Conception to Community' study which will involve population-wide linkage of Tasmanian Government data held including health, justice and child protection.

At SA NT DataLink, new data transfer agreements were negotiated in 2015-16 with the SA Department of Housing and agreements with NT Department of Attorney General and Justice, NT Department of Health, NT Department of Children and Families, NT Department of Education were renewed.

COLLABORATIONS AND PARTNERSHIPS

NATIONAL COLLABORATIONS

In 2015-16, the PHRN has supported a growing number of research studies using linked data that include investigators from multiple institutions across Australia. Various initiatives undertaken by the PHRN Participants such as coordination of special interest data linkage groups or hosting of research symposiums have assisted to facilitate these collaborations. Figure 6 shows the number of publications arising from studies using data linked and/or accessed through the PHRN infrastructure that contained investigators from more than one institution over the past six years.

The three PHRN Proof of Concept Collaborations completed over the last five years have played a key role in developing the partnerships, processes and mechanisms to enable data from across jurisdictions to be linked and analysed on a national basis. There are now a range of other cross-jurisdictional linkage studies that are in the planning or execution stages around the country that involve a number of PHRN-supported facilities.

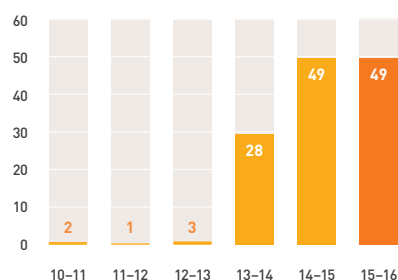


FIG 6: PUBLICATIONS INVOLVING NATIONAL COLLABORATIONS 2010-11 TO 2015-16

INTERNATIONAL COLLABORATIONS

An increased amount of interest in the PHRN data linkage infrastructure and the nation's rich linked data assets has been shown by the international research community. This can be demonstrated by the number of with an international affiliation involved in PHRN peer-reviewed research outputs (Fig. 7).

Productive discussions have also been held with a number of potential international collaborators of the PHRN over 2015-16. These included the European Molecular Biology Laboratory (EMBL) and ELIXIR, the European infrastructure for biological information, and the University of Melbourne's European Research Development Manager (based in Germany). In addition, PHRN Board Chair Professor Brendon Kearney, met with Dr Sue Hill, Head of the World Health Organisation's Medical and Technology Division to discuss opportunities for cooperation and partnership.

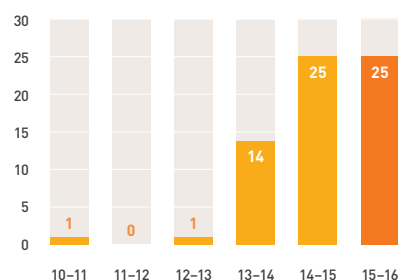


FIG 7: PUBLICATIONS INVOLVING INTERNATIONAL COLLABORATIONS 2010-11 TO 2015-16

PRIVATE AND NOT-FOR-PROFIT SECTOR ENGAGEMENT

During 2015-16 the PHRN has continued to strategically engage with the private and not-for-profit sector as part of implementation of its Industry Engagement Plan. Productive meetings have been held with a range of organisations. Opportunities for linkage of private sector information with data currently linked by the regional/national data linkage units as well as the potential for the PHRN infrastructure to support private sector commissioned research were discussed.

The SURE facility has continued to host data on behalf of the Capital Markets Cooperative Research Centre (CMCRC) Health Program. The aim of the CMCRC is to assist industry partners to explore their data with tools developed by academics and turn that data into information. In addition, a national private health insurance cohort has commissioned a research group to develop a cohort of private insurance members which will be held and accessed in SURE.

During 2015-16, the CVDL has established partnerships between industry and the non-government sector for research projects that are currently underway, involving organisations such as MediBank Private and Sacred Heart Mission.

GOVERNANCE

The PHRN Board is an independent body consisting of five members plus a Chair. Its primary role is to provide oversight and strategic direction for the PHRN. Other responsibilities also include monitoring contractual compliance and performance against key performance indicators, oversight of financial and risk management and facilitation of relationships with PHRN stakeholders.

BOARD MEMBERSHIP

Professor Brendon Kearney AM (Chair)

Ms Lindley Edwards

Ms Elizabeth Foley

Dr Diane Watson

Ms Stephanie Miller

Professor Robyn Owens

PHRN PARTICIPANT COUNCIL

The PHRN Board is supported by the Participant Council which provides advice on strategy, policy, funding priorities, stakeholder engagement, performance and accountability. All PHRN Participant organisations are represented on the Participant Council.

COUNCIL MEMBERSHIP

Professor Brendon Kearney AM (Chair)

Mr Jim Round

Director, System Intelligence and Analytics, Victorian Department of Health and Human Services

Mr Charlie Thorn

Director, Research and Development, Curtin University

Associate Professor Sarah Thackway

Director, Centre for Epidemiology and Evidence, NSW Ministry of Health

Dr Jeannette Young

Queensland Chief Health Officer

Mr Robert Wells

Deputy Chief Executive Officer, Sax Institute

Mr Michael Pervan

Secretary, Tasmanian Department of Health and Human Services

Mr Andrew Stanley

Director, SA NT DataLink

Professor Tarun Weeramanthri

Assistant Director General, Public Health, WA Department of Health

Mr Geoff Neideck

Head, IT and Data Strategies Group, Australian Institute of Health and Welfare

FINANCIAL SNAPSHOT 2015–16

The following table provides a summary of PHRN income and expenditure for 2015–16.

(Excluding GST)	NCRIS 2013 \$,000	NCRIS 2015 \$,000	TOTAL
Balance at the start of the year	1,414	-	1,414
Income			
DET Cash Contribution	977	4,269	5,246
Cash Co-Investments Income		2,878	2,878
In-Kind Contributions		4,108	4,108
Total Funding Received	977	11,255	12,232
Expenditure			
Salaries and On-costs	724	2,069	2,793
Operation, Management and Governance costs	273	780	1,053
Infrastructure maintenance	128	363	491
Operating Expenses	168	481	649
NCRIS expenditure sub-total	1,293	3,693	4,986
Cash Co-Investment Expenditure	1,098	1,277	2,375
In-Kind Expenditure		4,108	4,108
Total Expenditure	2,391	9,078	11,469
Balance at the end of the year	-	2,177	2,177

FINANCIAL SNAPSHOT 2015-16

The following diagrams provide a summary of PHRN income and expenditure for 2015-16.

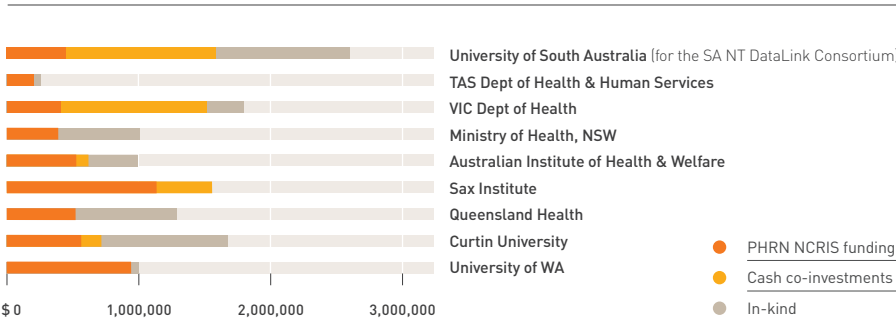


FIG 8: INVESTMENT BY PROJECT PARTICIPANT 2015-16 (\$)

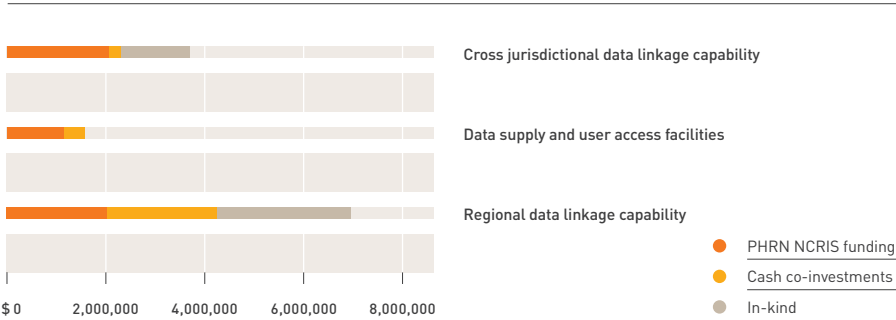


FIG 9: INVESTMENT BY KEY ACTIVITY AREA 2015-16 (\$)



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