

# ANNUAL REVIEW

2017-18



**PHRN** Population  
Health  
Research  
Network

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# OVERVIEW

The Population Health Research Network (PHRN) is an Australian Government initiative established as part of the National Collaborative Research Infrastructure Strategy (NCRIS). Our network supports world class research through privacy-preserving linkage of Australia's population data.

Research conducted using linked data generates new knowledge and supports improvements in the delivery of a wide range of human services. Our network includes leading universities, research institutes and government agencies.

The Australian Government provides core funding for the PHRN and the University of Western Australia (UWA) is the lead agent. This allows us to enter into agreements with our Project Participants to develop and operate a data linkage infrastructure for Australia which includes:

- A network of regional data linkage units which service each state and territory
- A national data linkage unit which can perform Commonwealth-Commonwealth, state/territory-state/territory and Commonwealth-state-territory linkages of large data collections
- An online application system
- A secure remote access data laboratory
- A secure file transfer system
- A national coordinating office

# MESSAGE FROM THE CHAIRMAN

It is my privilege to once again report on the progress of the Population Health Research Network (PHRN) during a year that has provided many opportunities in the development of Australia's national data linkage network.

The most significant event for the PHRN during 2017-18 was the Australian Government announcing an additional \$1.9 billion over 12 years from 2017-18 (\$393.3 million over five years) to implement the Research Infrastructure Investment Plan, informed by the 2016 National Research Infrastructure Roadmap.

The Population Health Research Network was awarded \$23.8 million over 6 years 2022-23 to maintain and develop the national infrastructure that enables linked data from around Australia to be made available for research. The funding provided through the National Collaborative Research Infrastructure Strategy, was announced by the Minister for Education and Training, the Hon Simon Birmingham, and will be administered through UWA, as the agency with overall responsibility for PHRN.

I am very pleased that the Australian Government has continued to support this important infrastructure for a further four years. Research has a key role in the management and delivery of health and other human services in Australia and linked data can make a significant contribution to this research. This funding will contribute to improving the health and wellbeing of all Australians. We are very grateful for the ongoing support from the Australian Government.

Australia's administrative data collections are national assets which should be made available to use for high-quality ethical research projects. Throughout this year the PHRN has continued to advocate for improved access to data for research. This has included contributing to a number of public consultations, most notably, the consultation on the Development of a Framework For Secondary Use of My Health Record Data and to the Senate Select Committee on Stillbirth Research and Education. On a personal note, a highlight for me was presenting about the PHRN to the Wennberg International Collaborative Fall Research Meeting 2017 in Oxford in September 2017.

To close, I would like to thank the PHRN Board, Participant Council, Chief Executive and all Participant colleagues for their continued enthusiasm and hard work to progress the objectives of the PHRN. It's an exciting time for the PHRN with next year being our 10 year anniversary so I look forward to 2018-19 with a sense of eagerness, confidence and focus.



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**Professor Brendon Kearney**

Chairman, PHRN Board

# CHIEF EXECUTIVE'S REPORT

This year has seen the PHRN continue to grow at a steady pace with continual improvements being made to the operation of the PHRN national data linkage infrastructure at both regional and national levels.

Our data linkage units have maintained and developed their linked data collections and there has been an increased demand for linked data and for PHRN secure data access services from the Australian research community and government users. Together with the exciting announcement of additional funding from the Australian Government, the PHRN is in an excellent position to further progress Australia's national data linkage infrastructure.

During the year, an analysis of the impact and return on investment of the PHRN national data linkage infrastructure was completed by Lateral Economics. The analysis showed that the net economic benefit to Australian society of continued investment in the PHRN could be as high as \$7.1 billion over the period to 2040, in present value terms. This reflects the contribution of PHRN-related research to policy, practice, technology and health improvements over time and provides confidence that PHRN is a worthy investment for Australia.

As part of our continued commitment to service improvement, we completed a project to identify and prioritise high value data collections for linkage. The study involved an online survey of more than 300 researchers interested in linked data. The results showed there was strong support for linkage of data collections already linked in some jurisdictions to be linked across all jurisdictions. Priorities included private hospital admissions and mental health. Researchers also identified a number of other data collections that they considered to be of high value and should also be made more readily available. Researchers' comments highlighted areas where change is needed and these have helped PHRN to argue for change in our responses to government inquiries and consultations.

The profile of the PHRN continued to develop in 2017-18, with one highlight being presentation of the keynote address to the joint meeting of the Korean Society for Preventative Medicine and National Evidence-based Healthcare Collaborating Agency in October 2017 by video conference with translation. In addition, the network made submissions to a number of public consultations. Our quarterly newsletters have an ever growing circulation of 360 and our website continues to include weekly updates. To make sure we remain connected with all of our stakeholders, we continued throughout the year to host and participate in a range of activities including research symposiums and community conversations. We have also held regular meetings with key stakeholders including the Australian Federal Minister for Education.

In 2017-18, we saw 325 new project applications and 237 projects receiving their linked data which highlights the consistent demand for PHRN-related data linkage services. The number of registered users of the PHRN Online Application System, the SUFEX secure file transfer service and the SURE remote access data laboratory facility have all increased at a steady rate.

In closing, I would like to acknowledge the contribution of the PHRN Board and Participant Council, PHRN Participants and all staff of the PHRN over the year. I look forward to our 10 year celebration in 2019 and the continued development and operation of this important national research infrastructure.



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**Dr Merran Smith**

PHRN Chief Executive

2017-18

# HIGHLIGHTS

PHRN supports world class research through privacy-preserving linkage of Australia's population data. Research done using the linked data generates new knowledge and supports improvements in the delivery of a wide range of human services.



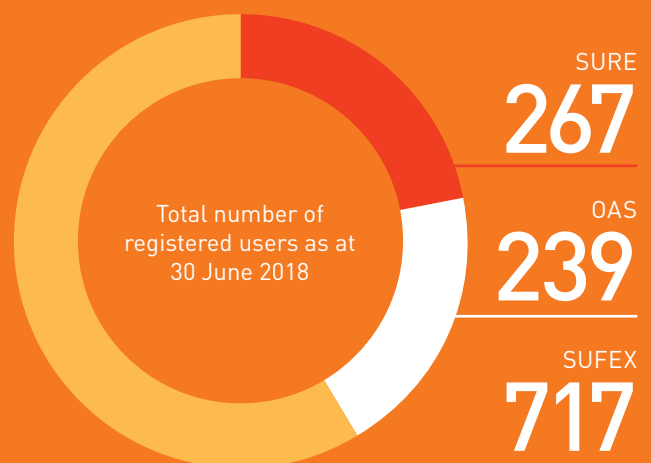
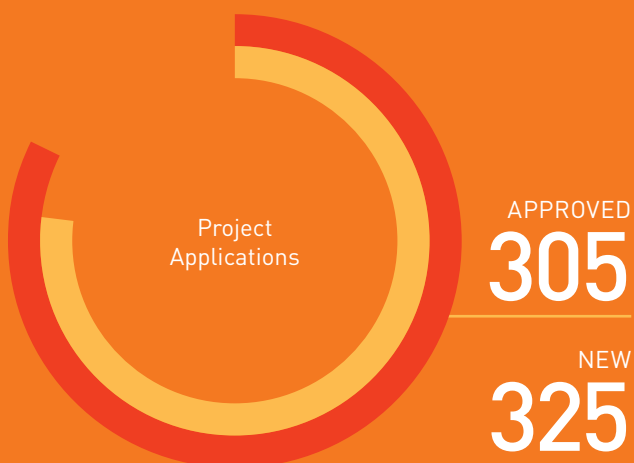
110

Number of researchers that have completed the SURE Training Program in 2017-18



717

Number of publications since 2012-13



## VISION

Linking life data to improve the wellbeing of all Australians.

## MISSION

To lead and enable the linking of data for world class action-oriented research.

# 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 following provides a snapshot of the key achievements of the PHRN Participants for 2017-18.

## NATIONAL DATA LINKAGE INFRASTRUCTURE

### The Australian Institute for Health and Welfare (AIHW)

The Australian Institute for Health and Welfare (AIHW) has worked closely with the Commonwealth Department of Health in 2017-18 to achieve more streamlined access to Medical Benefits Schedule (MBS) and Pharmaceutical Benefits Scheme (PBS) data, leading to efficiencies in completing linkage projects involving those datasets. During the year, arrangements were finalised for linkage of other data to the Department of Social Services DOMINO dataset for approved projects. This has enabled the AIHW to better advise and assist researchers with applications for projects, and to undertake approved linkages more quickly and efficiently (See <https://www.aihw.gov.au/our-services/data-on-request/dss-data> for further information).

AIHW engagement has continued with a wide range of clients from Commonwealth and state governments, universities and other research institutions, including hospitals. Several projects had a therapeutic focus, for example the national linkage of Human Papilloma Virus immunisation records, three cancer screening registries and the Australian Cancer database. Additionally, a number of clinical trials are underway that utilise data linked by AIHW to measure some of the outcomes for participants.

This year, AIHW created a Data Strategies Unit that, among other things, supports the Data Linkage Unit in increasing access to and opportunities for linkage of Commonwealth data. This Unit ensures that the AIHW has a strong input into the Commonwealth initiatives involving data access and linkage.



**Australian Government**

**Australian Institute of  
Health and Welfare**

## REGIONAL DATA LINKAGE INFRASTRUCTURE

### The Centre for Health Record Linkage (CHeReL)

The CHeReL continues to provide high quality data linkage services and infrastructure for NSW and ACT. The CHeReL uses data from the health, education, human services, justice and transport sectors to enable research and evaluation. Services are supported by the CHeReL's core record linkage system (the Master Linkage Key), which currently contains pointers to over 168 million records relating to more than fourteen million people, making it one of the largest systems of linked personal information from health-related databases in Australia. This vast resource is beneficial for researchers, government and health planners.

The newly established Data Integration Unit in the CHeReL has expanded the range of content data sets managed or processed on behalf of data custodians. This has made data delivery to end users faster, more predictable and aligned with Australian government standards. In addition, the CHeReL has been working with the newly opened NSW Statewide Biobank to design and plan a seamless data linkage service for researchers requesting biospecimens and linked data.



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### The Centre for Victorian Data Linkage (CVDL)

Demand for the Centre for Victorian Data Linkage (CVDL) data linkage projects has increased during 2017-18 with more researchers and policy makers looking for evidence based insights to support research evaluation and analytics. To enhance its operating capacity, the CVDL undertook an infrastructure improvement by moving its integrated dataset to a secure cloud platform (Azure) to ensure that it can deliver cutting edge research outcomes.

The year has seen significant progress towards planning and expanding the CVDL's linkage map to facilitate further development across a number of specialty areas of clinical networks. Furthermore, CVDL has been granted Commonwealth Integrating Authority accreditation by the Secretaries Data Group on behalf of the Australian Government.





## REGIONAL DATA LINKAGE INFRASTRUCTURE (CONT.)

### SA NT DataLink

In 2017-18, the Northern Territory's Menzies School of Health Research became a SA NT DataLink Joint Venture Partner, bringing a combined total of eleven government, non-government, university and research organisations and agencies to the Joint Venture agreement under which SA NT DataLink operates.

During this period, SA NT DataLink further expanded its South Australian and Northern Territory data collections for the benefit of research and other data linkage projects. Its Data Linkage Unit now holds approximately 51.4 million records across 50 data collections. Apart from using its data collections to support research projects, SA NT DataLink also supported projects for improvements in the quality of the administrative data held by government agencies such as SA Department of Health and Wellbeing and the SA Registrar of Births, Deaths and Marriages.

SA NT DataLink established the Data Integration Unit (DIU) and employed a Principal Data Analyst to manage the Custodian Controlled Data Repository hosted in SURE to hold the data collections provided by participating data custodians. The DIU operates in partnership with these data custodians in the management, quality control, provision and release of approved de-identified data.

With the support of the South Australian and Commonwealth Governments, SA NT DataLink completed the processes necessary for accreditation as a Commonwealth Integrating Authority, subject to the Data Linkage Unit being prescribed under the Regulations of Commonwealth *Privacy Act 1998* in 2018-19.



## REGIONAL DATA LINKAGE INFRASTRUCTURE (CONT.)

### The Tasmanian Data Linkage Unit (TDLU)

The Tasmanian Data Linkage Unit (TDLU) continued to receive an increasing number of enquiries and expressions of interest for linked data services during 2017-18, and the unit's Master Linkage Map has continued to grow in size. This year, a major focus has been on the quality of links stored with time and resource allocated to the methods, techniques, processes and practices that ensure the links stored and generated are of the highest quality. The TDLU collects and analyses significant amounts of metadata specific to various aspects of its linkage processes in order to continually improve the quality of links stored.

In June 2018, the TDLU completed the release of linkage keys for its most complex linkage project to date. The project entitled "Pathways to better health and education outcomes for Tasmanian's children" (Tassie Kids), involved the linkage of 14 datasets using an innovative linkage design. This was a significant project with the cohort consisting of approximately 24,000 children with the primary cohort being children born in Tasmania between 2008 and 2011. A second stage of this project is planned to commence late in 2018.

Another success for the TDLU during this year has been reaching agreement with the largest provider of private pathology services in the state for the supply of a large dataset to support a major research project. It is hoped that this agreement will pave the way for the routine linkage of this dataset in the future. This dataset will be linked with a number of other datasets to support an innovative research project, which will include linkage of the Australian New Zealand Dialysis and Transplant Registry (ANZDATA) dataset. The TDLU entered into a formal data exchange agreement for the routine linkage of the ANZDATA dataset, with this dataset having been added to the TDLU's Master Linkage Map. The datasets represents records for persons who have received kidney dialysis or transplant across Australia during 2004-2017.



## REGIONAL DATA LINKAGE INFRASTRUCTURE (CONT.)

### Data Linkage Queensland

Throughout 2017-18 Data Linkage Queensland (DLQ) has continued to provide linked data to users with the Queensland Department of Health and for researchers. Additional units within Queensland Health were provided with direct access to linked data to reduce the number of requests being processed by the team. Data Linkage Queensland continued to work with hospital and health services within Queensland Health to support the development of innovative point of care systems based on linked data, including disease specific data warehouses that incorporate clinical data sets.

A new client services team was established within DLQ to work on projects to enhance the process for people requesting linked data. DLQ also collaborated with the University of Queensland to develop and deliver a two-day workshop on using and analysing linked data.

Linkage of data into the Master Linkage File continued to occur in near-real time and several data collections (public admitted patients, emergency department, death registrations and Queensland Ambulance Service data) were linked further back in time. New data collections added to the Master Linkage File were Queensland non-admitted patient and air retrievals data.

During the year, DLQ developed and tested algorithms to enable the use of enduring linkage keys in the Queensland Master Linkage File. This will support the exchange of data with the AIHW for national projects being conducted to establish national enduring linkage keys and better support data quality and longitudinal projects using linked data. This work was completed up to final user acceptance testing stage by 30 June 2018.

Work has also continued on preparing to install the new version of linkage software, ChoiceMaker, on the linkage server. Design specification for a linkage server replacement and upgrade also commenced during this year.



Queensland Government

## SECURE DATA TRANSFER AND ACCESS

### Secure File Transfer Infrastructure – SUFEX

Centre for Data Linkage (CDL) operates SUFEX, a secure file transfer service for PHRN participants and their stakeholders. The SUFEX user base and number of file transfers continued to grow during 2017-18. There are over 700 registered users of the SUFEX service (43% government, 25% universities, 21% industry and 7% from research institutes). SUFEX services supported the Australian research community with over 1,200 secure file transfers last year.



### Remote Data Access Laboratory – Secure Unified Research Environment (SURE)

The demand for SURE services has continued to grow, exceeding expectations for 2017-18 and currently supporting 89 research projects and 267 registered users across Australia and internationally. Users of SURE come from more than 40 different organisations including universities, research institutes, government agencies and non-government organisations.

In 2017-18 SURE attained ISO 27001:2013 certification and completed an Independent Security Assessors Program (IRAP) assessment for a large Commonwealth Government data custodian. The IRAP assessment provides a measure of SURE against IRAP standards that can be used to inform data custodians considering using SURE services.

The SURE Capital Upgrade Program made substantial progress, with both the Server Upgrade Project, supported by a NSW NCRIS Co-Investment Grant, and Citrix Upgrade Project underway. The Capital Upgrade program is being driven by the rapid growth in the use of SURE, and by the need to support researchers with higher levels of computing power for larger datasets and more complex analyses.



APPLICATION FOR DATA

Online Application System

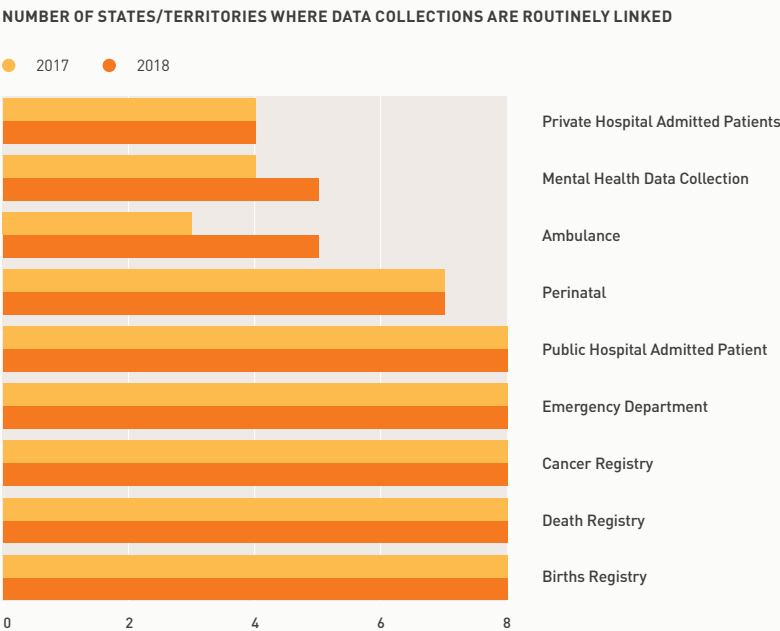
The total number of registered PHRN Online Application System (OAS) users as at the 30 June 2018 was 239 which is an increase of 69 users from the previous year. As in previous years, the majority of OAS applications come from universities and medical research institutes.

Metadata Resource

2017-18 saw the PHRN Metadata Resource being updated and expanded on the basis of additional data/new collections being made available for linkage. The most significant new addition has been the list of data collections which are routinely linked in all states and territories. The PHRN Metadata Resource has proven to be the most frequently accessed section of the PHRN website ([www.phrn.org.au/for-researchers/](http://www.phrn.org.au/for-researchers/)). The catalogue identifies where the data collections are located together with the application and access process. Each data collection in the catalogue contains a description of the content, quality, condition or other characteristics.

Routinely Linked Data Collections

The graph below shows the number of states and territories where selected data collections are routinely linked.



The majority of PHRN Online Application System applications continue to come from universities and medical research institutes.

## STRATEGIC PROJECT

# STANDARDISED BUSINESS PROCESSES – PHASE 2

The Standardised Business Processes (Phase 2) PHRN Strategic Priorities Project started on 1 October 2017. The aim of the project is to improve the customer service experience of researchers applying to conduct a multi- or cross-jurisdictional linked data project. All regional data linkage units and the Australian Institute of Health and Welfare are participating in the project. During 2017-18 the key achievements of the project have included:

- Six-month pilot of the standardised business process for multi- or cross-jurisdictional linked data applications completed.
- Evaluation of the pilot completed. All client service units have agreed to implement the endorsed business process into their jurisdictional work practices. The endorsed business process has:
  1. Substantially improved the response times for provision of quotes and coordinated feedback;
  2. Increased confidence among client service units in the regular monitoring and review of applications; and
  3. Improved transparency of the application and approvals process because this information is communicated to researchers upon lodging a submission to the PHRN Online Application System (OAS).
- Report on the interim evaluation of PHRN Client Services Action Plan Implementation completed.

## STRATEGIC PROJECT

# RETURN ON INVESTMENT

The purpose of this project was to assess the impact of and return on the PHRN investment since 2009. The analysis of the impact and return on investment of the PHRN national data linkage infrastructure was completed by Lateral Economics. Their analysis showed that the net economic benefit to Australian society of continued investment in the PHRN could be as high as \$7.1 billion, in present value terms.

This reflects the contribution of PHRN-related research to policy, practice and technology improvements over time. For example, the analysis suggests that by 2034 over 0.5% of cancer burden reduction in Australia will be attributable to PHRN-related data linkage.

The economic and health benefits of PHRN data linkage and ongoing investment is important for a healthy Australia. One scenario showed that the PHRN infrastructure has a benefit to cost ratio of 16.5, or over \$16 in value for Australia for every \$1 in cost.

# WORLD CLASS RESEARCH AND ANALYSIS

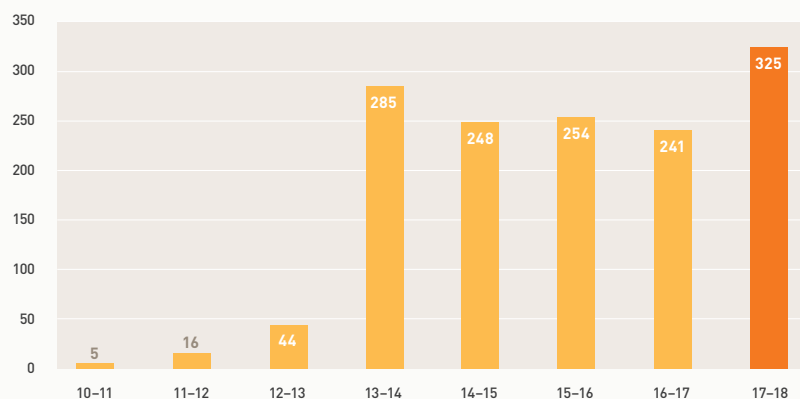
Facilitate and grow the use of linked data for world class, action oriented research. Our objectives are to build and support the development of capacity to analyse and interpret linked population data. To work with researchers and others to identify national priorities for research using linked data.

There has been a solid demand in 2017-18 from researchers for the PHRN linked data infrastructure which is demonstrated in the figures below.

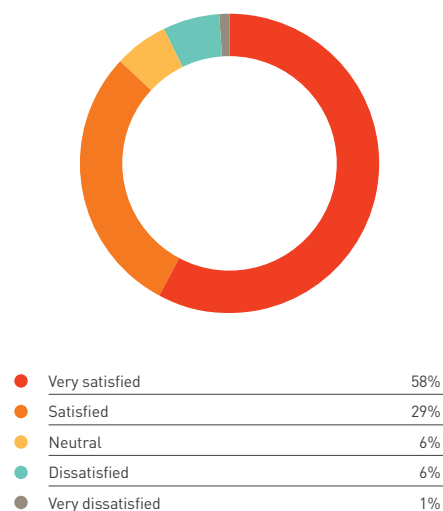
## NEW PROJECTS

There has been a continued increase in demand for PHRN infrastructure. New project applications increased by 35% between 2016-17 (n=241) and 2017-18 (n=325).

NUMBER OF NEW PROJECT APPLICATIONS ONLY 2010-11 TO 2017-18



RESEARCHER OVERALL LEVEL OF SATISFACTION WITH THE SERVICES PROVIDED BY PHRN IN 2017-18



Most researchers were very satisfied or satisfied with services provided by the PHRN in 2017-18.

# WORLD CLASS RESEARCH AND ANALYSIS

## CASE STUDY

# MORTALITY AND CANCER INCIDENCE AMONG MALE VOLUNTEER AUSTRALIAN FIREFIGHTERS

### THE CHALLENGE

In Australia, there are currently an estimated 180,000 volunteer firefighters providing service to rural and some peri-urban areas. This study examined the mortality and cancer incidence of male volunteer firefighters. During firefighting, firefighters are exposed to a number of hazardous materials and there was little or no existing published evidence about the mortality or cancer risk for these types of volunteer firefighters.

### HOW THE PHRN INFRASTRUCTURE HELPED

The Australian Institute of Health and Welfare (AIHW) linked the cohort to the National Death Index (NDI) and the Australian Cancer Database (ACD) to obtain mortality and cancer outcomes. At the time of linkage, the NDI was nationally complete to 30 November 2011 for cause of death coding. The ACD was nationally complete to 31 December 2010, except for one state, which was complete only until the end of 2009.

### THE RESULT

Volunteer firefighters have a reduced risk of mortality and cancer incidence compared with the general population, which is likely to be a result of a 'healthy-volunteer' effect and, perhaps, lower smoking rates. The study did recommend a follow-up of the cohort because the cohort was relatively young, with small numbers of deaths and cancers to date, and further follow-up time will increase statistical power, especially for the type of incident analyses.

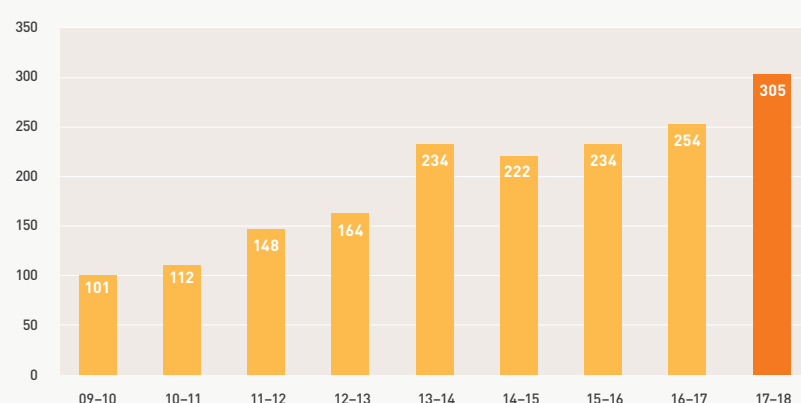
Glass DC, Del Monaco A, Pircher S, et al. Mortality and cancer incidence among male volunteer Australian firefighters. *Occup Environ Med* 2017;74:628-638



## APPROVED PROJECTS

Approved applications increased by 20% between 2016-17 (n=254) and 2017-18 (n=305).

NUMBER OF APPROVED PROJECT APPLICATIONS BY FINANCIAL YEAR 2009-10 TO 2017-18

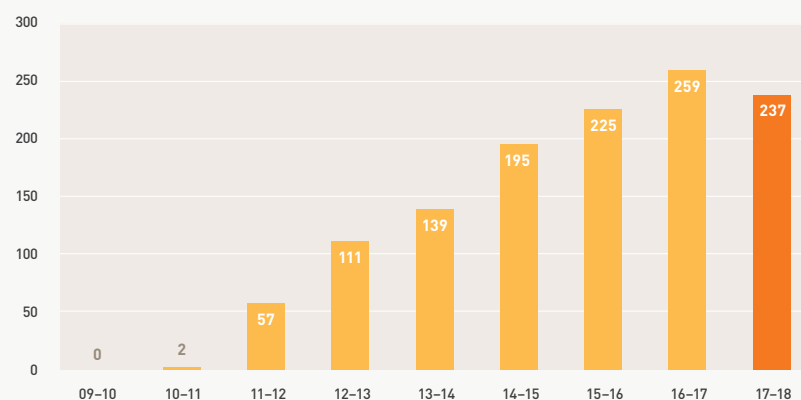


The number of approved project applications increased by 20 per cent.

## APPROVED PROJECTS WITH DATA DELIVERED

In 2017-18 the number of approved projects where all data was provided decreased by approximately 8% (n=22) from the previous reporting period. This is the first year since 2011-12 that the number of approved projects where all data was provided to researchers did not increase.

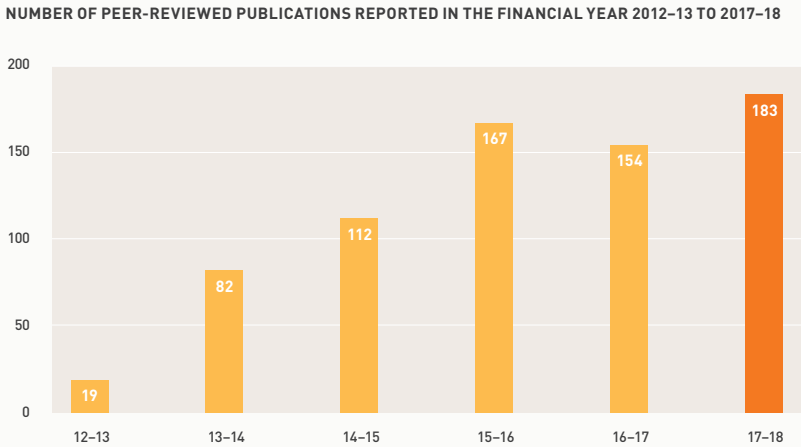
NUMBER OF APPROVED PROJECT APPLICATIONS WHERE ALL DATA WAS PROVIDED 2009-10 TO 2017-18



RESEARCH OUTPUTS

Publications using PHRN infrastructure

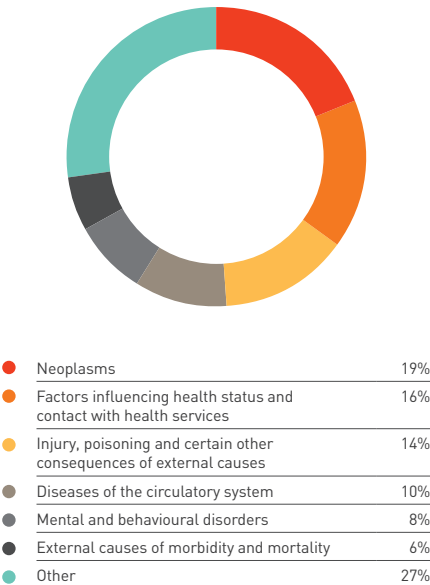
The production of research outputs is the most important part of the research cycle. 2017-18 saw a total of 183 peer-reviewed manuscripts in high quality journals which were a direct result of research undertaken using linked data provided by the PHRN infrastructure.



Focus for Publications

In 2017-18, 174 of the 183 peer-reviewed publications from projects using the PHRN research infrastructure were aligned with the International Statistical Classification of Diseases and Related Health Problem, Tenth Revision, Australian Modification (ICD-10-AM). This shows that researchers' linked data research projects support the evidence base of areas that contribute to the burden of disease in Australia. This year the top three topics covered in the publications were neoplasms (n=35; 19%), factors influencing health status and contact with health services (n=29; 16%), and injury, poisoning and certain other consequences of external causes (n=25; 14%)

CLASSIFICATION OF PEER-REVIEWED PUBLICATIONS BY ICD-10-AM DESCRIPTORS, 2017-18



Policy responsive projects

The PHRN research infrastructure is not only used by researchers but government department and agencies as well. The network has reported that it has become increasingly important for Ministers and governments to respond quickly to important policy questions. During 2017-18, the PHRN data linkage units provided linked data to assist with planning and evaluation and in response to priority issues prompted by government reviews.

High-calibre researchers using data linked through PHRN

The Clarivate Analytics Highly Cited Researchers List of 2018 included a number of high calibre data linkage researchers who have used the PHRN infrastructure and had their findings published in a peer-reviewed publication during 2017-18. Congratulations go to:

- Professor Adrian Bauman (University of Sydney)
- Professor Rinaldo Bellomo (Monash University)
- Professor Louisa Degenhardt (University of New South Wales)
- Professor Graham Giles (University of Melbourne)
- Associate Professor Genevieve Healy (University of Queensland)
- Professor John Lynch (University of Adelaide)
- Professor Nicholas Martin (QIMR Berghofer)
- Professor Paul Mitchell (University of Sydney)
- Professor Jonathan Shaw (La Trobe University)

TRAINING AND EDUCATION INITIATIVES

Leading and participating in the delivery of education and training during 2017-18 for a variety of stakeholder groups has continued to be a priority for the PHRN. Training has included:

Researchers	Consumers
Linked health data workshops	Consumer Training Workshops
Online modules for SURE training	
Secure Data Transfer systems including SUFEX	HRECs
Introductory Analysis of Linked Data Course (USyd and University of New South Wales Masters of Health Data Science)	Human Research Ethics Committee Member Training on Linked Data

The network has reported that it has become increasingly important for Ministers and governments to respond quickly to important policy questions.

# WORLD CLASS RESEARCH AND ANALYSIS

## CASE STUDY

# THE ASSOCIATION OF EMERGENCY DEPARTMENT PRESENTATIONS IN PREGNANCY WITH HOSPITAL ADMISSIONS FOR POST- NATAL DEPRESSION (PND)

### THE CHALLENGE

Depression in the postnatal period is a major public health problem that can significantly impact the health of the whole family. This study investigated the impact of presenting to an Emergency Department during pregnancy on post-natal depression in women in New South Wales.

### HOW THE PHRN INFRASTRUCTURE HELPED

The Centre for Health Record Linkage (CHeReL) linked data from the NSW Emergency Department Data Collection (EDDC), the NSW Perinatal Data Collection (PDC) and the NSW Admitted Patients Data Collection (APDC). The study included all women who gave birth to their first child in NSW between 1 January 2006 and 31 December 2010. Women who had subsequent births in the two years after the first birth were excluded.

### THE RESULT

This study demonstrated that women's hospital admissions for post-natal depression were associated with frequent ED presentations during pregnancy. Additionally, the study concluded that the reasons for this need to be explored further in a future study and that clinicians should consider the association between ED admission and a diagnosis of postnatal depression when planning a woman's care.

Xu, Fenglian et al. "The association of Emergency Department presentations in pregnancy with hospital admissions for postnatal depression (PND): a cohort study based on linked population data" BMC emergency medicine vol. 17,1 12. 23 Mar. 2017, doi:10.1186/s12873-017-0123-8

# ADVOCACY AND COMMUNICATIONS

Advocate for better access to and use of linked data, and communicate research findings. Over time the PHRN has developed a range of communication strategies to successfully connect with and deliver our key messages to all our target groups. These strategies have assisted the PHRN with the communication challenges of reaching our wide range of stakeholders across a vast geographic area.

## NEWSLETTER, WEBSITE, PRESENTATIONS

The PHRN circulated quarterly newsletters throughout the year reaching a continually growing subscription list of 360 researchers and data users.

The website has been the prime mechanism a fundamental port of call for information distribution about the services and facilities provided by the PHRN. A "Latest News" section has been added to the front page of the website which is updated once to twice a week with a new item. All case studies have been printed in colour format and are available for our staff to take to relevant meetings and presentations as examples of how the PHRN infrastructure has assisted research.

## ENGAGEMENT WITH CONSUMERS AND THE WIDER COMMUNITY

Our website continues to be a key tool in communicating with consumers and the general public. The Program Office has also presented at several consumer training workshops conducted in Perth during the year.

## ADVOCACY THROUGH PUBLIC CONSULTATION SUBMISSIONS

During 2017-18, the PHRN and individual PHRN Participants made submissions to a number of public consultations. These included:

- Development of a Framework for Secondary Use of My Health Record Data Submission to the Department of Health from the Population Health Research Network, 17 November 2017
- Stillbirth Research and Education Submission to the Senate Select Committee on Stillbirth Research and Education, 29 June 2018

The PHRN website continues to be a key tool in communicating with consumers and the general public.

# COLLABORATIONS AND PARTNERSHIPS

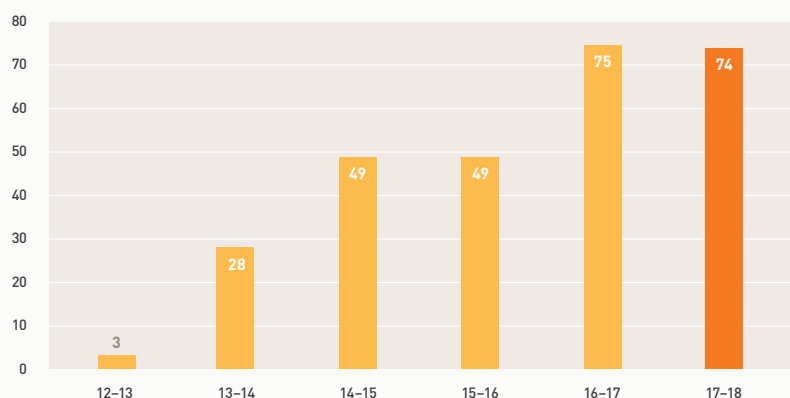
Foster collaborations between researchers, governments and industry partners. We continue to develop new collaborations and partnerships for development and use of linked data.

## NATIONAL COLLABORATIONS

Our PHRN participants have continued to support our researchers through a range of activities such as holding research symposiums and co-ordinating special interest data linkage groups. Through this increased involvement in the research community, the PHRN has seen an increase in the number of research studies using linked data that include researchers from institutions across Australia during 2017-18.

A national collaboration is defined as a peer-reviewed publication which has authors located in more than one jurisdiction in Australia.

NUMBER OF PEER-REVIEWED PUBLICATIONS INVOLVING A NATIONAL COLLABORATION, 2012-2013 TO 2017-2018



Through increased involvement in the research community, PHRN has seen an increase in the number of research studies using linked data that include researchers from institutions across Australia.

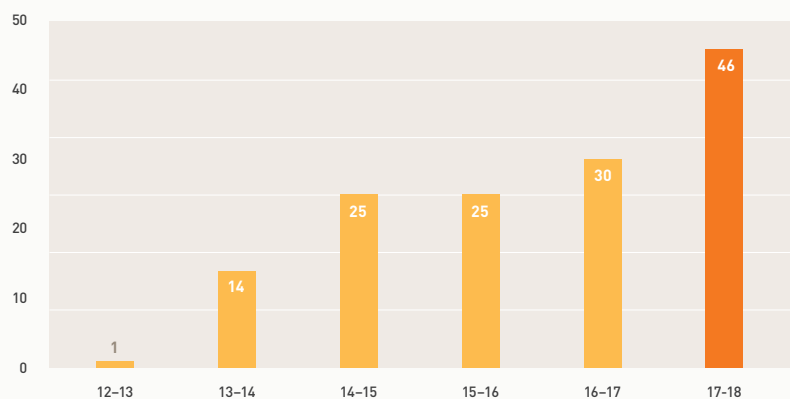
### INTERNATIONAL COLLABORATIONS

There has been a keen interest internationally in the PHRN data linkage infrastructure and the nation's linked data assets. Our Chief Executive, Dr Merran Smith, was an invited keynote speaker to the joint meeting of the Korean Society for Preventative Medicine and the National Evidence-based Healthcare Collaborating Agency on 19 October 2018. The presentation entitled "PHRN Recent Developments and Future Directions" took place via video conference with translation.

In Singapore, the PHRN was represented by our Manager of Policy and Client Services, Dr Felicity Flack, who presented on "The role of data custodians in establishing and maintaining social licence" at the Singapore Symposium on Big Data and Ethics in March 2018. The PHRN was represented by our Board Chairman, Professor Brendan Kearney at the Wennberg International Collaborative Fall meeting in Oxford in September 2017. Professor Kearney presented on "Healthcare variation in oncology – a snapshot of linked data research in Australia".

An international collaboration is defined as a peer-reviewed publication which has a minimum of one author located outside of Australia.

NUMBER OF PEER-REVIEWED PUBLICATIONS INVOLVING AN INTERNATIONAL COLLABORATION, 2012-2013 TO 2017-2018



### CROSS AGENCY AND CROSS SECTOR COLLABORATION

To encourage the linkage of new data collections and the use of the PHRN infrastructure by new groups of researchers, the PHRN has continuously developed collaborations and engagement with various sectors throughout the year.

PHRN Participants have also continued to build cross-agency and cross-sector relationships to improve and expand their services.

There has been a keen interest internationally in the PHRN data linkage infrastructure and the nation's linked data assets.

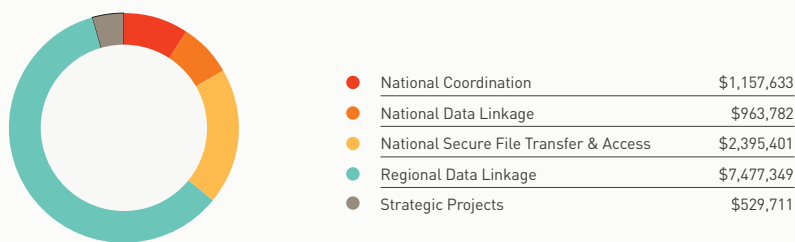
# FINANCIAL SNAPSHOT

The following graphs provides a summary of PHRN income and expenditure for 2017-18.

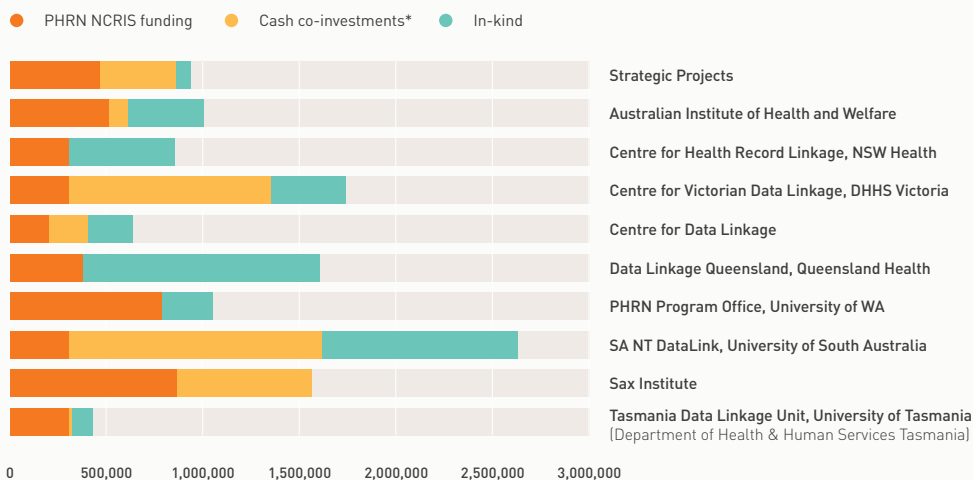
## PHRN NCRIS PROGRAM INCOME 2017-18



## PHRN NCRIS PROGRAM EXPENDITURE BY COMPONENT 2017-18



## INVESTMENT AT PROJECT PARTICIPANT LEVEL 2017-18 (\$)



\*Note cash co-investment includes revenue from user charges



# GOVERNANCE

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

## BOARD MEMBERSHIP

**Professor Brendon Kearney AM**  
(Chairman)

**Ms Lindley Edwards**

**Ms Elizabeth Foley**

**Ms Stephanie Miller**

**Professor Robyn Owens**

**Professor Ian Smith**  
(from 1 October 2017)

**Mr Tim Trumper**

**Associate Professor Sarah Thackway**  
Director, Centre for Epidemiology and Evidence, NSW Ministry of Health

**Dr Jeannette Young**  
Queensland Chief Health Officer, Queensland Government

**Mr Andrew Stanley**  
Director, SA NT DataLink

**Dr Martin McNamara**  
Head, Research Assets Division, Sax Institute

## 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.

**Professor Brendon Kearney AM**  
(Chairman)

**Mr Geoff Neideck**  
Head, IT and Data Strategies Group, Australian Institute of Health and Welfare

**Dr Catherine Gangell**  
(from 7 December 2017 to 26 April 2018)  
Acting Director, Research and Development, Curtin University

**Professor Archie Clements**  
(from 26 April 2018)  
Pro-Vice Chancellor, Health, Curtin University

**Mr Michael Pervan**  
(resigned October 2017)  
Secretary, Tasmanian Department of Health and Human Services

**Dr Jodi Johnson-Glading**  
(from 11 October 2017)  
Deputy Principal Medical Advisor, Acute Planning and Strategy and Principal Medical Advice, Tasmanian Department of Health and Human Services

**Dr Anthony Carpenter**  
(from 29 December 2017)  
Director, System Intelligence and Analytics Branch, Victorian Department of Health and Human Services

**Mr Tim Reid (resigned 4 January 2018)**  
Acting Group Director, Information Data and Standards, WA Department of Health

**Mr Rob Anderson (from 4 January 2018)**  
Executive Director, Information and System Performance, WA Department of Health



PHRN supports world-class research through privacy-preserving linkage of administrative data. PHRN invests in infrastructure that boosts Australia's capacity to link population data.

Our network includes leading universities, research institutes and government agencies. Research done using the linked data generates new knowledge and supports improvements in the delivery of a wide range of human services.

**[phrn.org.au](https://phrn.org.au)**



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