



PHRN Population
Health
Research
Network

Annual Review 2010-2011



CONTENTS

AN OVERVIEW	3
CHAIRMAN'S MESSAGE	4
FROM THE CHIEF EXECUTIVE OFFICER	5
PHRN GOVERNANCE: ENHANCEMENT AND PROGRESSION	6
CREATING A SUSTAINABLE FUTURE	7
DATA LINKAGE CAPABILITIES AND OPERATIONS: EXPANSION AND TESTING	8
NATIONAL STRATEGIES AND INTERNATIONAL COLLABORATIONS	10
FINANCIAL YEAR IN BRIEF	12

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An Australian Government Initiative
National Collaborative Research
Infrastructure Strategy



PHRN Population
Health
Research
Network

The Population Health Research Network is an initiative of the Australian Government conducted as part of the National Collaborative Research Infrastructure Strategy.

AN OVERVIEW

The Population Health Research Network (PHRN) is creating 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 is facilitating development of data linkage capability in nodes around the nation to enable existing population data to be brought together and made available for vital health and health related research.

Conceptualised in 2008 and funded in 2009, the PHRN's data linkage infrastructure is pioneering in its concept and progressive in its implementation. It offers innovative infrastructure capable of linking data across jurisdictions, providing researchers with access to better quality data and policy makers with evidence to support improved services and outcomes.

Prior to the establishment of the PHRN, population-based data linkage capability in Australia was focused on two states with linkage units, Western Australia since 1995 and New South Wales since 2006.

The PHRN has built on these solid foundations by supporting the development of new data linkage groups in other Australian states, a national linkage centre to link data across jurisdictions and a secure data access laboratory to provide remote access for approved researchers. These initiatives are expanding the availability and use of linked administrative data for population health research across Australia.

Additional funding from the Australian Government in 2011-12 and 2012-13 (through the Super Science Initiative) will enable further expansion of the PHRN.

VISION

The vision for the PHRN is significantly improved health and wellbeing for the Australian population resulting from high impact research based on a robust data linkage and integration infrastructure.

MISSION

PHRN's vision will be achieved by facilitating access for data users to a range of high quality, linked population health and human services data in a secure environment for approved purposes.

CHAIRMAN'S MESSAGE

The 2010-11 financial year has been one of great achievement for the Population Health Research Network (PHRN) and as Chair of the Management Council, I am very proud of the dedicated team of Council Members who continue to guide development and provide strategic direction for this progressive data linkage network.

The Management Council met on five occasions in 2010-11 including a meeting in Sydney in April 2011 to discuss the all-important proposals for the PHRN Education Investment Fund Super Science Initiative.

A large number of key policies were developed and debated over the 2010-11 financial period and I am pleased to say a total of eleven policies and procedures were endorsed by the PHRN Management Council and added to the PHRN Policy Framework.

I wish to also acknowledge and thank the members of the PHRN Management Council sub-committees and advisory groups. To all involved in the PHRN Access Committee, PHRN Operations Committee, PHRN Ethics, Privacy and Consumer Engagement Advisory Group and the Data Transfer Working Group, I am most grateful for your efforts, your expertise and your important contribution to the policies and procedures that drive the PHRN.

In this financial period we also completed a Deed of Variation to the PHRN Funding Agreement to allow the inclusion of a Consumer Representative on the PHRN Management Council. This was an important step to ensure that the deliberations and decisions of the Council are informed by a consumer and community perspective. We have since welcomed Ms Stephanie Miller to the position of inaugural PHRN Management Council Consumer Representative.

I would also like to personally thank Professor D'Arcy Holman for his invaluable contribution to the PHRN as an inaugural Researcher Member of the Management Council. Due to increasing commitments Professor Holman resigned from this position in late 2010 and I wish as Chair to acknowledge the expertise and input he provided the PHRN during his time with the Management Council. I would like to warmly welcome Professor John Lynch who joined the Management Council as a replacement for Professor Holman.

2010-11 was a productive and progressive year for the PHRN. I am honoured to have been offered the opportunity to continue as PHRN Management Council Chair during the continued NCRIS funding period and the exciting new phase of Super Science Initiative funding. I have accepted this ongoing role with great enthusiasm and confidence for the years ahead.

PROFESSOR BRENDON KEARNEY



“I am very proud of the dedicated team of Council Members who continue to guide development and provide strategic direction for this progressive data linkage network”.

FROM THE CHIEF EXECUTIVE OFFICER

I am delighted to report on the substantial progress that PHRN has made during 2010-11 in creating data linkage infrastructure across Australia. As we reflect on the second year of our four year program, we do so with a sense of collaborative achievement and commitment to the ongoing development and continued expansion of the PHRN.

There have been many important achievements during the year including progress with development of policy and governance frameworks for the Network including completion of the PHRN Participants' Arrangement which describes how the PHRN Participants will work together. There has also been good progress with development of state data linkage infrastructures as well as infrastructure for undertaking cross-jurisdictional data linkage and providing approved users with secure remote access to research data sets.

I congratulate all involved for their achievements during the year and acknowledge the hard work and dedication that has underpinned the progress. The PHRN by its nature continues to develop at different rates across the country and whilst this can be challenging at times, it is also very rewarding as we witness the continued emergence of a network of nodes and units dedicated to the common cause of improved Australia's data linkage infrastructure.

I wish to make special mention of the funding and guidance provided to the PHRN by the Australian Government Department of Innovation, Industry, Science and Research. Their incredible support via the ongoing National Collaborative Research Infrastructure Strategy (NCRIS) and their additional funding and support through the Education Investment Fund Super Science Initiative 2011-2013 ensures continued expansion and success of the PHRN.

I also would like to acknowledge The University of Western Australia for its ongoing commitment and support as the PHRN Lead Agent and the Telethon Institute for Child Health Research for its invaluable support as host to the PHRN Program Office. In addition thanks go to the many state and territory governments, key universities and major research centres who so wonderfully and generously support the work of the PHRN.

I would also like to personally thank the PHRN Management Council led by Chairman, Professor Brendon Kearney, the PHRN node Directors and staff, the data linkage unit teams and the Program Office staff for their ongoing commitment, support and hard work in ensuring the continued success of the PHRN.

DR MERRAN SMITH



PHRN GOVERNANCE: ENHANCEMENT AND PROGRESSION

PHRN MANAGEMENT COUNCIL

The PHRN Management Council, which oversees the implementation of the national data linkage program in accordance with the NCRIS Investment Plan, met on five occasions in 2010-11.

Key Management Council outcomes included:

- The addition of eleven policies and procedures to the PHRN Policy Framework during the 2010-11 reporting period. These included the key policies of PHRN Access and Pricing, Ethics and Scientific review, Privacy and Consumer and Community Participation. These policies were possible thanks to the efforts of the PHRN sub-committees and Advisory groups.
- The pathway for the appointment of a Consumer representative to the Management Council was made possible through the Deed of Variation to the PHRN Funding Agreement between The University of Western Australia and the Australian Government executed in March 2011.
- The Management Council sub-committees met regularly in 2010-11. These included the PHRN Ethics, Privacy and Consumer Engagement Advisory Group, PHRN Access Committee, PHRN Operations Committee and the Data Transfer Working Group.

PHRN INFORMATION GOVERNANCE FRAMEWORK

A consultancy to develop a framework for PHRN information governance and security was started in 2010-11. This consultancy was aimed at establishing a suitable set of controls and procedures to ensure that privacy and confidentiality of data is maintained. The consultancy involved discussions with all PHRN nodes and data linkage units and included on-site visits, interviews with key staff, review of existing practices and extensive consultation. It was supported by a capable Project Control Group. The framework development continues into 2011-12.

PARTICIPANTS' ARRANGEMENT

The completion of the PHRN Participants' Arrangement marked an important milestone for the Network. The Participants' Arrangement outlines the mutual obligations and operational relationships for all PHRN participants and its finalisation reflects a strong collaborative approach within the PHRN. The Participants' Arrangement ensures agreed parties actively participate in PHRN governance processes, abide by PHRN policies and procedures and continue to contribute and work collaboratively towards the ongoing development of Australia's data linkage capabilities. The Participants' Arrangement was completed in May 2011.

PHRN DATA TRANSFER AGREEMENT TEMPLATE

Another significant national milestone was the finalisation of the PHRN Data Transfer Agreement Template (DTA) by the PHRN Data Transfer Working Group. The DTA template is aimed at assisting nodes and data custodians to negotiate an agreement with Curtin University to transfer

data to the Centre for Data Linkage to enable cross-jurisdictional linkage. It was also designed as a helpful guide for other linkage units wanting to negotiate the transfer of data to build their linkage maps.

CREATING A SUSTAINABLE FUTURE

PHRN NCRIS FUNDING EXTENSION

A major achievement for the PHRN was the execution in March 2011 of a variation to the PHRN National Collaborative Research Infrastructure Strategy (NCRIS) Funding Agreement between the Australian Government and The University of Western Australia. This variation enables the extension of the PHRN NCRIS program until 30 June 2012, ensuring the full three years of operation for PHRN under NCRIS funding.

PHRN EDUCATION INVESTMENT FUND SUPER SCIENCE INITIATIVE

The Australian Government responded to the priorities identified in the 2008 Strategic Roadmap for Australian Research Infrastructure with the announcement in May 2009 of the Super Science Initiative (SSI) which will contribute \$1.1 billion to priority areas of Australian research until 2013. The majority of this funding, \$901 million, is for research infrastructure that will make a lasting contribution to Australian science. These infrastructure investments are being funded from the Education Investment Fund (EIF), which is one of the three Nation-building Funds established by the Nation-building Funds Act 2008. As part of this announcement, a further investment of \$10 million was made available to expand the PHRN.

Consultant Dr Ron Sandland facilitated development of the Investment Plan for this funding with a process that included the development and circulation of a Consultation Paper as well as the co-ordination of workshops and meetings in every Australian mainland state in February 2011. The support and co-operation of all PHRN nodes and linkage units contributed to success of this process. The Investment Plan which covers PHRN development until 30 June 2013 was completed and presented to the Australian Government Department of Innovation, Industry, Science and Research in May 2011. The additional EIF-SSI funding allows the PHRN to welcome two new participants in the upcoming 2011-12 reporting year, with the Australian Institute of Health and Welfare and the NSW/ACT Centre for Health Record Linkage joining the PHRN.

DATA LINKAGE CAPABILITIES AND OPERATIONS: EXPANSION AND TESTING

This financial year has been one of expansion and transformation across the PHRN and is reflective of the collaborative aims and goals of all participants working together to build a significant data linkage Network. As the PHRN continues to evolve, its success is determined and driven by the work and commitment of the Network nodes, data linkage units and support staff working to create an infrastructure with national impact and international influence. There have been many key achievements and milestones around the Network in 2010-11, as we look back on a year that continued to lay the foundations for future growth and success.

CENTRE FOR DATA LINKAGE

Tasked with facilitating cross jurisdictional linkages, the Centre for Data Linkage at Curtin University completed linkages on hospital related mortality with data from Proof of Concept #1 during 2010-11 and supplied national and project linkage keys to data custodians in both NSW and WA (see Proof of Concept outlined previously).

The Centre also completed an operational demonstration linkage system to ensure reliable and secure cross jurisdictional linkages and completed a linkage test and evaluation on behalf of the PHRN. The Centre also organised a number of technical workshops during the reporting year.

SECURE UNIFIED RESEARCH ENVIRONMENT (SURE)

Progress continued in 2010-11 on the development of the Secure Unified Research Environment (SURE) by PHRN participant, the Sax Institute, in Sydney. SURE is aimed at enabling researchers to access data remotely in a highly secure virtual analysis computing environment. A working prototype of SURE was completed and demonstrated to stakeholders in the data linkage community with positive results.

In addition, work continued on developing related policies and procedures and the progression of end-user training materials and the signing of software licence agreements.

Working collaboratively to build a national data linkage infrastructure, each PHRN node and linkage unit progressed their capabilities throughout the 2010-11 reporting period.

SOUTH AUSTRALIA/NORTHERN TERRITORY

SA-NT DataLink established a number of Memorandum of Understandings (MOU's) during the 2010-11 reporting year with the South Australian government and its agencies. These MOUs enabled new datasets to be added to SA-NT's existing Master Linkage File. Work also continued on three demonstration projects to test data linkage processes and build capacity for on-going linkages. SA-NT also engaged an external consultant to complete a second year project review.

VICTORIA

Further development of its data linkage capability was a key focus for Victorian Data Linkages (VDL) in 2010-11. Progress was also made in efforts to update VDL's existing linked datasets to the most up-to-date data provided by Victorian data custodians during 2010-11. Measures were also put in place to improve the quality of its linkages and the refinement of linkage processes.

TASMANIA

The Tasmanian Data Linkage Unit (TDLU) made great progress in negotiating access to patient information from the Tasmanian Department of Health and Human Services in order to begin its work creating a Master Linkage Map. Linkage operations were due to begin early in 2011-12. Progress was also made in the areas of hardware, software and office acquisitions for its linkage operations at the Menzies Research Institute Tasmania (MRIT). The TDLU also began processes to recruit a full time Data Linkage Manager.

QUEENSLAND

HealthLinQ at the University of Queensland continued two on-going demonstration projects using Queensland administrative data during 2010-11. Pilot data from one project (alcohol-related harm in young people) has been analysed and submitted for publication. Data for the second project (mental health co-morbidity) continues to be progressed.

TECHNICAL WORKSHOPS AND FORUMS

A number of workshops, forums and site visits aimed at facilitating PHRN members working together on the technical aspects of data linkage were held in the 2010-11 reporting period. The Centre for Data Linkage at Curtin University hosted the initial PHRN Technical Forum in July 2010, whilst a follow-up site visit to understand the systems and processes of the NSW/ACT Centre for Health Record Linkage took place in September 2011. Following the Technical Forum, the Sax Institute hosted a Functional Requirements Workshop also in September 2011 to further facilitate the development of key Linkage Management System functions and business rules.

NATIONAL STRATEGIES AND INTERNATIONAL COLLABORATIONS

PROOF OF CONCEPT

The Data Linkage Branch at the Department of Health WA continued to build on its history of pioneering work in data linkage by leading the PHRN Proof of Concept collaboration initiative. The Proof of Concept collaborations are testing PHRN data transfer, linkage and access processes as well as the use of linked data for research that will inform issues of national importance.

In addition to managing the first Proof of Concept collaboration, the Data Linkage Branch also coordinated meetings of the PHRN Proof of Concept Reference Group with the aim of selecting additional Proof of Concept collaborations to be considered for 2011-12 and beyond.

Key steps taken in progressing the PHRN Proof of Concept collaboration include linkage completed in May 2011 for the first Proof of Concept collaboration which focuses on deaths that occurred in hospital or within 30 days of hospitalisation. Successful cross jurisdictional linkage of data from Western Australia and New South Wales was carried out by the Centre for Data Linkage with extracts of data containing national linkage keys delivered to the research analyst.

The PHRN Proof of Concept Reference Group also identified a second Proof of Concept collaboration. Proposals were called for in March 2011. Out of six proposals received, two were shortlisted and a proposal aimed at examining and establishing predictive models of health care use and mortality of injured people was selected as the second collaboration.

DATA DELIVERY SYSTEM

The Sax Institute in Sydney coordinated and completed the first phase of development of the PHRN Data Delivery System. This will facilitate the secure delivery of data from custodians to data linkage units and to approved researchers.

NATIONAL TRAINING AND EDUCATION STRATEGY

In October 2010 the PHRN Program Office appointed an experienced training specialist to develop a national training and education strategy and policy. As part of that development, a national training scoping exercise was undertaken to identify Network needs. In response to the scoping exercise, a Consumer and Community Engagement Training workshop was developed and is now being delivered nationally. The workshop is aimed at providing PHRN node staff with improved skills and knowledge for working with consumers and community members. Training for Human Research Ethics Committees was also identified as a priority and a specialised training program has been developed for rollout in 2011-12.

COMMUNICATIONS AND BRANDING

External and internal communications were the focus of a number of new strategies and concepts in the PHRN 2010-11 reporting period. The PHRN underwent an extensive re-branding exercise with the design and build of a new corporate logo and also a major revamp of the existing website. The new website was designed to promote the PHRN's data linkage infrastructure to a range of audiences including data users, researchers, consumers and the community and as a way of promoting the work of the PHRN to an international audience. Additional communications achievements included the development and endorsement of a national communications strategy and guidelines, regular internal e-newsletters, and the design and development of a range of promotional publications and materials.

CONFERENCE PRESENTATIONS AND WORKSHOPS

Throughout the year representatives from nodes, data linkage units and the PHRN Program Office presented at various conferences, seminars and workshops both nationally and internationally. Their efforts are recognised as contributing greatly to the awareness of PHRN services and linkage facilities.

INTERNATIONAL COLLABORATIONS AND RELATIONSHIPS

The PHRN continued to build on its international data linkage relationships throughout 2010-11 with visits and presentations by the PHRN Chief Executive to overseas collaborators in Wales and the United Kingdom. In addition the PHRN co-hosted a visit to Australia by data linkage experts from the Health Information Research Unit, Swansea University Wales, as well as engaging them for a short consultancy which provided an independent, international perspective on the PHRN's planned developments and a review of the PHRN Privacy Management Framework.

The PHRN Centre for Data Linkage in Perth, Western Australia also collaborated with the Information Services Division, NHS Scotland on the PHRN Phase One Linkage Software Test and Evaluation Project.

The PHRN is a joint sponsor of the International Data Linkage Conference to be held in Perth in May 2012. A number of PHRN members are actively engaged with the conference, including as members of the Planning and Scientific Committees.

The new website was designed to promote the PHRN's data linkage infrastructure to a range of audiences

FINANCIAL YEAR IN BRIEF

2010-11

The following table and diagrams provide a PHRN summary for the financial period 2010-11. The fifth and last NCRIS funding instalment for PHRN was received by Funding Agreement Manager the University of Western Australia during the year.

The following charts show the PHRN Project Funding Contributions in 2010-11 as well as Total Project Funding 2008-2012.

TABLE 1: FINANCIAL OVERVIEW 2010-11

	Amount \$'000
Balance as at 1 July 2010	6,321
NCRIS Income	1,817
Cash Co-Investments	2,349
In-Kind Contributions	6,421
Total Funding Received	10,587
Salaries	4,874
Hardware and software purchases	115
Operating	980
NCRIS expenditure sub-total	5,969
Cash Co-Investments Expenditure	1,842
In-Kind Expenditure	6,421
Total Expenditure	14,232
Balance as at 30 June 2011	2,676

Figure 1: Total project funding by funding category, NCRIS and related funds

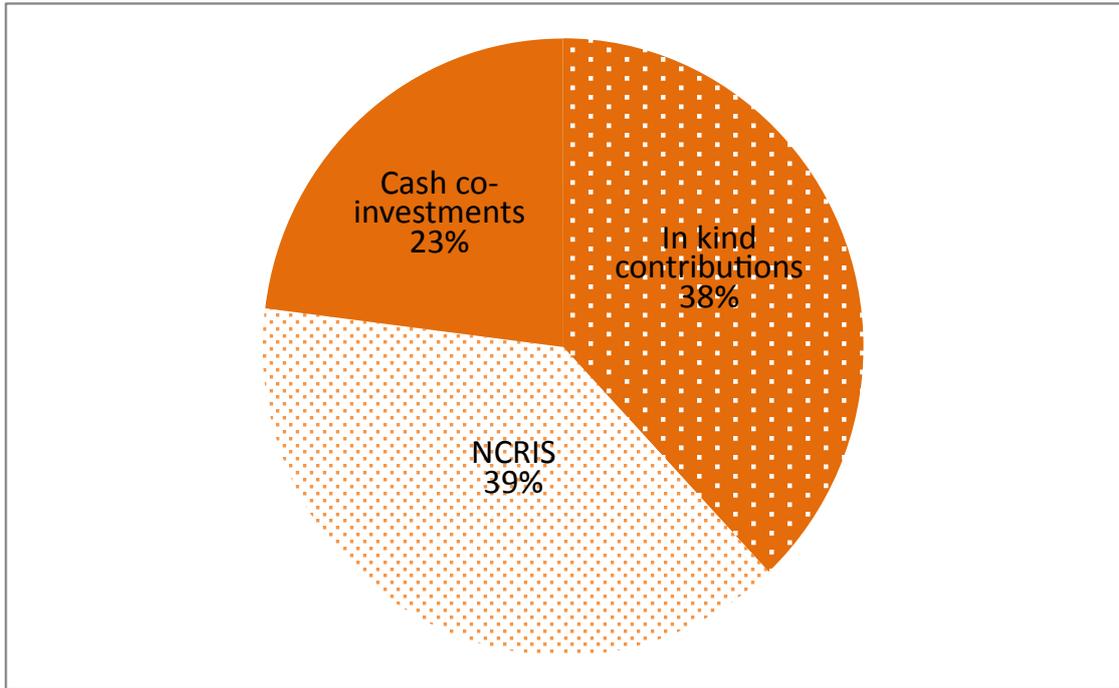


Figure 2: PHRN Funding Contribution by activity area, NCRIS and related funds

