



# POPULATION HEALTH RESEARCH NETWORK

PHRN OVERVIEW AND ACHIEVEMENTS  
2009 - 2013

## Table of Contents

FIGURES AND TABLES.....	i
ACRONYMS .....	ii
EXECUTIVE SUMMARY .....	1
THE PHRN AT A GLANCE .....	3
1.0 INTRODUCTION.....	5
1.1 What is data linkage?.....	5
1.2 History of Data Linkage in Australia.....	5
1.3 Australian Government Investments.....	5
1.4 Population Health Research Network Investment Plans and Related Matters ..	7
2. Description of the PHRN .....	8
2.1 Vision and Mission .....	8
2.2 Governance structures.....	9
2.3 PHRN Investment in Data Linkage .....	9
2.4 PHRN Participants .....	10
2.5 Regional Data Linkage Services.....	11
2.5.1 Centre for Health Record Linkage.....	11
2.5.2 Queensland .....	12
2.5.3 SA NT DataLink.....	14
2.5.4 Tasmanian Data Linkage Unit .....	16
2.5.5 Victorian Data Linkages.....	17
2.5.6 Western Australian Data Linkage Branch (WADLB).....	18
2.6 National Data Linkage Services .....	19
2.6.1 Australian Institute for Health and Welfare .....	19
2.6.2 Centre for Data Linkage .....	20
2.6.3 Secure Unified Research Environment .....	22
2.6.4 Program Office .....	24
2.7 Other .....	26
2.7.1 Data Delivery System .....	26
2.7.2 Proof of Concept Collaboration .....	28
2.7.3 Approaches to confidentialisation of outputs from research using linked data conducted in secure analysis laboratory environments.....	29
2.8 Work in Progress.....	30
2.8.1 Regional Data Linkage Services.....	30
2.8.2 National Data Linkage Services .....	30

2.8.2 Other .....	31
2.9 Measures of PHRN Activity .....	32

## FIGURES AND TABLES

Figure 1 PHRN Investment in Data Linkage Infrastructure .....	11
Figure 2 Location of PHRN Facilities .....	12
Figure 3 Number of Approved Applications by Year.....	32
Figure 4 Number of Projects Where Data Was Provided by Year	
Table 1 PHRN Investment in Data Linkage 2008-2015 .....	11
Table 2 Chief Investigator and Other Information on PoC Collaborations.....	28
Table 3 Number of records linked by linkage units established with PHRN funding between July 2009 and June 2013.....	33

## ACRONYMS

ACT	Australian Capital Territory
AEDI	Australian Early Development Index
AIHW	Australian Institute of Health and Welfare
CARES	Custodian Administered Research Extract Server
CDL	Centre for Data Linkage
CHeReL	Centre for Health Record Linkage
CRIS	Collaborative Research Infrastructure Strategy
CSIRO	Commonwealth Scientific and Industrial Research Organisation
DDS	Data Delivery System
DEEDI	Department of Employment, Economic Development and Innovation
DHHS	Department of Health and Human Services
DIICCSRTE	Department of Industry, Innovation, Climate Change, Science, Research and Tertiary Education
DISC	Data Integration Services Centre
EDDC	Emergency Department Data Collection
HREC	Human Research Ethics Committee
JCU	James Cook University
NAPLAN	National Assessment Program - Literacy and Numeracy
NCRIS	National Collaborative Research Infrastructure Strategy
NGLS	Next Generation Linkage System
NLS	National Linkage System
NSW	New South Wales
NT	Northern Territory
PHRN	Population Health Research Network
PoC	Proof of Concept Collaboration
QCHDS	Queensland Centre for Health Data Services
QUT	Queensland University of Technology
RLG	Research Linkage Group
SA	South Australia
SADS	South Australia Dental Service
SSI	Education Investment Fund Super Science Initiative
SUFEX	Secure Unified File Exchange
SURE	Secure Unified Research Environment
TDLU	Tasmanian Data Linkage Unit
UniSA	University of South Australia
UQ	University of Queensland
UWA	University of Western Australia
VDL	Victorian Data Linkages
WA	Western Australia
WADLB	WA Data Linkage Branch
WADLS	WA Data Linkage System

## EXECUTIVE SUMMARY

### Introduction

This overview document is designed to assist the Population Health Research Network (PHRN) Review Panel members to address the Terms of Reference of the PHRN Review. It has been written to summarise the background to the establishment of the PHRN, the objectives of the PHRN as described in the various funding agreements, the organisation of the PHRN, the roles and responsibilities of each of the Project Participants and the achievements of each of the Participants to date.

### Summary

Data linkage is a technique for creating links between pieces of information that are thought to relate to the same person, family, place or event. Australia has been at the forefront of the development of methods to provide researchers access to linked data whilst preserving privacy since the establishment of the Western Australian Data Linkage System (WADLS) in 1995 and the Centre for Health Records Linkage (CHeReL) in New South Wales (NSW)/Australian Capital Territory (ACT) in 2006. The Australian Government has made substantial investment in building data linkage infrastructure for Australia through the establishment of the PHRN funded by the National Collaborative Infrastructure Scheme, Education Investment Fund-Super Science Initiative and the Collaborative Research Infrastructure Strategy. State and Territory governments and academic partners have also made considerable investment.

The principal purpose of the PHRN is to build a nationwide data linkage infrastructure capable of securely and safely linking data collections from a wide range of sources including within and between jurisdictions and across sectors.

The national lead agency for the PHRN is the University of Western Australia (UWA). The PHRN currently has 10 Participants who are Commonwealth or state-based agencies, universities or institutes.

The activities of the PHRN are divided into Regional Services and National Services.

#### *Regional Services*

The main focus of the PHRN-funded Regional Services has been the expansion of the capacity of existing data linkage units (e.g. WA Data Linkage Branch [WADLB] in WA and CHeReL in NSW/ACT) and the establishment of a data linkage capability in those states that did not have an existing data linkage unit.

#### *National Services*

Prior to the PHRN there was little capacity in Australia to link data collections from different jurisdictions e.g. between two or more States or between the States and the Commonwealth. The main focus of the PHRN National Services is to build a range of facilities and capabilities to enable researchers to access linked cross-jurisdictional data. This includes data linkage units (Centre for Data Linkage [CDL] and Australian Institute for Health and Welfare [AIHW]), secure remote access laboratory (Sax Institute) and national coordination (Telethon Institute for Child Health Research [TICHR]).

### Conclusions

Australia now has the facilities and capabilities to link and provide access to linked data in most States and Territories. 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.

## THE PHRN AT A GLANCE

The principal purpose of the PHRN is to build a nationwide data linkage infrastructure capable of securely and safely linking and integrating data collections from a wide range of sources to enable research.

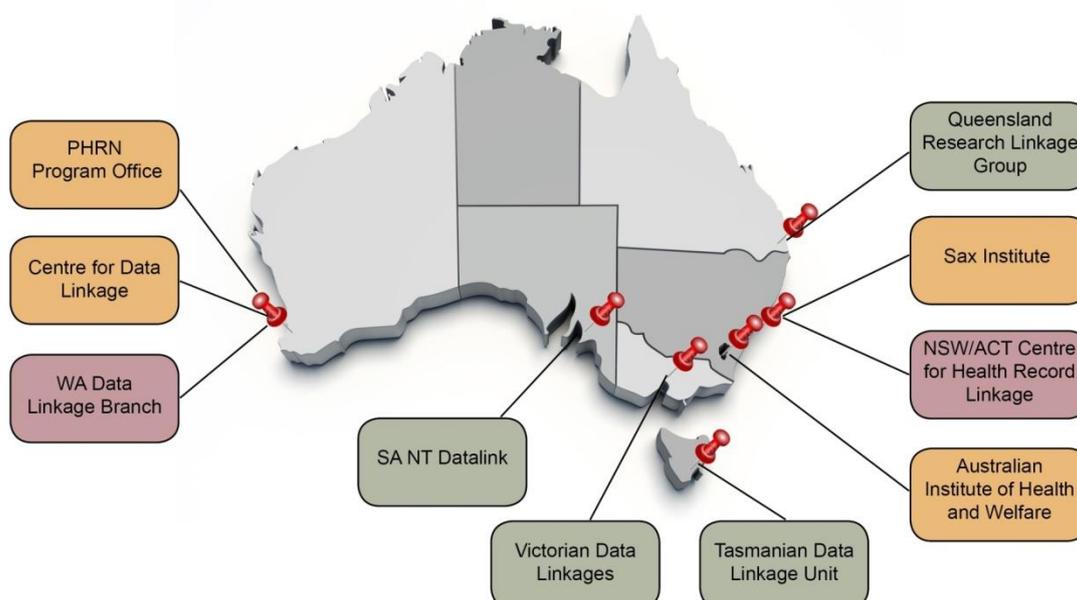
**Vision:** A valued national resource generated from linkage of population data from a broad range of areas such as health, education and community services and used for research to inform policy, planning and management to improve the health and wellbeing of all Australians.

**Mission:** To build a national data linkage infrastructure by working collaboratively with key stakeholders including data custodians, researchers and the community. This will support research of national relevance which results in improved policy making and service delivery and demonstrates global best practice in maximising the benefits to the Australian community whilst preserving individual privacy.

### PHRN Investment in Data Linkage 2008-15

\$ (GST Exclusive)	PHRN NCRIS	PHRN EIF-SSI	PHRN CRIS	Total
DIICCSRTE Cash Contribution	\$20,000,000	\$10,000,000	\$3,085,000	<b>\$33,085,000</b>
Co-investment Funds Cash Contribution	\$10,069,000	\$1,197,000	\$770,000	<b>\$12,036,400</b>
In Kind Contribution	\$23,993,000	\$6,403,000	\$1,174,276	<b>\$31,570,276</b>
<b>Total Investment</b>	<b>\$54,062,000</b>	<b>\$17,600,000</b>	<b>\$5,029,276</b>	<b>\$76,691,276</b>

### PHRN Facilities



## Achievements

Since the establishment of the PHRN in 2009, four new regional data linkage units have been developed (Queensland Research Linkage Group, South Australia (SA)/ Northern Territory (NT) DataLink (SA NT DataLink), Tasmanian Data Linkage Unit [TDLU] and Victorian Data Linkages [VDL]). One new national data linkage unit (CDL) has been established and one Commonwealth agency (AIHW) has been accredited as an Integrating Authority.

In addition to the establishment of new regional and national data linkage units the following national infrastructure has also been built:

- The Secure Unified Research Environment (SURE) - a remote-access computing environment that allows researchers to access and analyse linked health-related data files for approved studies.
- The Secure Unified File Exchange (SUFEX) - a file transfer service for the PHRN and its stakeholders that allows secure, high volume, large-scale transmission of files between parties.
- The Custodian Administered Research Extracts Server (CARES) to create and maintain validated de-identified content data extracts (WA)
- Automated data feeds to enable improve efficiency of data feeds to linkage units (NSW/ACT)
- Training programs for PHRN Participants (on consumer and community participation and on data linkage methods), for ethics committees and for end-users (SURE training).

Linkage Activity from July 2009 to June 2013\*

	Regional	National	TOTAL
Number of approved research projects	253	46	299
Number of research projects where data was provided	184	53	237

Number of records linked into a master linkage file/routine linkages	81,925,792
Number of records linked by national linkage units	76,917,053

*\*Does not include data linkage units in operation prior to 2009.*

## 1.0 INTRODUCTION

### 1.1 What is data linkage?

In Australia, information about an individual's health, education and welfare is recorded throughout their lives as they come in contact with service delivery organisations and agencies, including hospitals (public and private), health departments, schools and other government agencies. The collection of this data is often required under legislation and the information is stored in secure computer databases within the responsible agencies.

Data linkage is a technique for creating links between pieces of information that are thought to relate to the same person, family, place or event. This function is often performed by specialist data linkage units which facilitate access to linked data to enable research for the public benefit.

By their nature, data linkage systems deal with large volumes of data and require complex organisational and technical infrastructure. Bringing together information from different sources often requires many different organisations to collaborate to develop and maintain a data linkage system.

### 1.2 History of Data Linkage in Australia

Professor Michael Hobbs was instrumental in the establishment of population-based data linkage in Australia<sup>1</sup>. His return from Oxford University in the late 1960s saw the routine linkage of numerous data collections (initially records of births, marriages and deaths and hospital morbidity data) in Western Australia (WA), setting the necessary foundations for a data linkage system<sup>2</sup>. A proliferation of record linkage projects over the next two decades led to the idea of a centralised "data linkage project" that would maximise privacy and increase the efficiency and cost effectiveness of population health research.

The WADLB was the first in Australia and came into being in 1995. Located within the WA Department of Health the unit was established to develop and maintain a system of linkages connecting data about health events across all individuals in Western Australia<sup>3</sup>.

The New South Wales (NSW) and-Australian Capital Territory (ACT) data linkage unit, the CHeReL, was established in 2006.

Both the WA and NSW-ACT systems are characterised by the provision of high quality, probabilistic data linkage using fully identified population-based data.

For some years the Australian Institute for Health and Welfare has linked data from a range of administrative data collections including the national death index and Australian Cancer registry for its own work and on behalf of clients.

### 1.3 Australian Government Investments

In recent years, the Australian Government has funded a number of major national research infrastructure initiatives. These include the National Collaborative Research Infrastructure Strategy (NCRIS), the Education Investment Fund Super Science Initiative (SSI) and the Collaborative Research Infrastructure Strategy (CRIS). Each of these programs has been

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<sup>1</sup> Holman CD et al. *Aust Health Rev.* 2008 Nov;32(4):766-77.

<sup>2</sup> Armstrong BK, Krickler A. *Aust N Z J Public Health.* 1999 Oct;23(5):451-2

<sup>3</sup> Kelman CW, Bass AJ, Holman CD. *Aust N Z J Public Health.* 2002;26(3):251-5.

supported by three Strategic Roadmaps for Australian Research Infrastructure released in 2006, 2008 and 2011. All identified population health data linkage as a priority capability area.

### **The National Collaborative Research Infrastructure Strategy**

NCRIS is an Australian Government initiative which is funding the development and implementation of world class national research infrastructure and networks. The NCRIS is intended to promote a sustained cultural shift towards investment attitudes that are national, strategic, collaborative and foster research that is world class.

The underpinning NCRIS principles are:

- Australia's investment in research infrastructure should be planned and developed with the aim of maximising the contributions of the research and development system to economic development, national security, social well-being and environmental sustainability;
- Infrastructure resources should be focused on areas where Australia currently is or has the potential to be world class and provide international leadership;
- Major infrastructure should be developed on a collaborative, national non-exclusive basis. Funding and eligibility rules should encourage collaboration and co-investment;
- There should be as few barriers as possible to accessing major infrastructure for those undertaking meritorious research;
- Due regard be given to whole of life costs of major infrastructure including operational costs where appropriate; and
- Major infrastructure should seek to enable fuller participation of Australian researchers in the international research system.

NCRIS is administered by the Commonwealth Department of Industry, Innovation, Climate Change, Science, Research and Tertiary Education (DIICCSRTE).

In September 2005 the NCRIS Committee was created to oversee the program. In keeping with the collaborative approach, it commissioned independent external facilitators to develop the investment plans for priority capabilities.

The Population Health Research Network (PHRN) was conceived and implemented through the NCRIS framework.

### **Super Science Initiative**

In the May 2009 budget the Australian Government announced a further allocation of \$504 million for the SSI. The initiative targeted key priorities identified in the 2008 Strategic Roadmap for Australian Research Infrastructure, including population health data linkage infrastructure. It was based on the NCRIS principles. The focus of the SSI program was on development of new research infrastructure. The program did not cover the operation of existing infrastructure.

### **Collaborative Research Infrastructure Strategy**

Funding of \$60 million to establish CRIS was redirected from existing research block grants to establish CRIS. The purpose of CRIS is to support the operations of priority projects funded under NCRIS and/or SSI during the 2013 and 2014 calendar years. A Universities Australia-Government Consultative Group was established to oversee the CRIS process and to advise on the prioritisation of funding to eligible facilities. The Consultative Group

conducted a competitive selection process during October and November 2012. The PHRN received funding through CRIS.

#### **1.4 Population Health Research Network Investment Plans and Related Matters**

As part of the collaborative processes undertaken by NCRIS in the development of a national roadmap and investment framework, the need for improved health-related data linkage and integration facilities was recognised. The 2006 Roadmap identified population health and clinical data linkage as a capability and recommended that further work was done to scope issues and options for the capability, with a view to developing a full investment proposal. Professor Michael Frommer, Director Sydney Health Projects Group, was appointed as facilitator for the capability. Professor Frommer undertook extensive stakeholder consultation across Australia and considered a range of investment proposals. He subsequently developed an Investment Plan for PHRN which was accepted by the NCRIS Committee in March 2008.

In late 2010, Dr Ron Sandland was appointed by DIICCSRTE as facilitator to develop an investment plan for a second phase of development of the PHRN. This involved consultation across Australia and the review of investment proposals. The investment plan was submitted to DIICCSRTE in May 2011. The plan was approved and the PHRN SSI Funding Agreement between DIICCSRTE and the University of Western Australia (UWA) was executed in November 2011.

The approach for the CRIS program differed from that for the PHRN NCRIS and PHRN SSI programs. This reflected the different program funding source. The PHRN Program Office developed a proposal for CRIS funding in close consultation with PHRN Management Council and based on submissions from PHRN nodes. The proposal to fund PHRN national components was approved and a Conditions of Grant agreement between DIICCSRTE and UWA was executed in February 2013. A PHRN CRIS Implementation Plan was subsequently developed based on the accepted proposal. The Plan was submitted to and approved by DIICCSRTE in May 2013.

#### **PHRN Funding and Timelines**

The PHRN received a \$20 million allocation from the NCRIS program to fund the network plan from 2008-09 to 2011-12. The project period has since been extended to June 2014. The PHRN NCRIS Participants include State and Territory governments and academic institutions which provided a further \$32 million in cash and in-kind contributions to PHRN activities for the period.

Further funding of \$10 million has since been received from the Australian Government via the SSI for the 2011-12 and 2012-13 periods. In addition \$9 million in cash and in kind contributions has been allocated from Commonwealth, State and Territory governments, research institutions and major universities. The PHRN SSI investment plan included funding to enable a Commonwealth agency to join PHRN as a Participant. The initial project period for PHRN EIF- SSI concluded in June 2013 but this has been extended to December 2014.

Funding of \$3.085 million was received from CRIS for national components of PHRN. This covered the period from 1 July 2013 to December 2014. Cash and in-kind contributions of \$2.044 million were received from CRIS Participants.

### **PHRN Lead Agent and Participants**

The lead agency for the PHRN is UWA. The Funding Agreements for PHRN NCRIS and PHRN SSI are between DIICCSRTE and UWA. This reflects the NCRIS/SSI focus on investment in infrastructure for research institutions and the extensive data linkage expertise in Western Australia

PHRN currently has 10 Participants who are Commonwealth or state-based agencies, universities or institutes. The affiliation of each Participant varies across jurisdictions based on the expertise and relationships that exist in each jurisdiction. In some cases the Participant is a university or research institution. In others it is a government agency. In all cases, Commonwealth, state and territory government agencies are involved because they are custodians of the key health/human services data collections. Each Participant has entered into PHRN Participant Agreement with UWA which provides for activities as specified in the PHRN Investment Plans to be completed.

A full list of Participants can be found at the PHRN website <http://www.phrn.org.au>.

### **Contractual Arrangements**

DIICCSRTE has responsibility for the administration of NCRIS and SSI funds and related Funding Agreements. There is a contractual requirement for a Project Plan to appear at Attachment A of each Funding Agreement.

The Project Plan provides details about project objectives, context, scope, participating organisations, implementation principles, governance and administrative arrangements. It also documents the nodes to be established and their purpose, the new facilities to be installed and the scientific and technical support to be provided. It recognises that contractual agreements will be established between the lead organisation and the individual nodes which will govern:

- The roles of the Participants;
- The disbursement and use of funds;
- The implementation of access and pricing policies; and
- The development of annual business plans and progress reports.

The PHRN CRIS Implementation Plan contains similar details.

UWA has executed or will execute a Participant Agreement with each PHRN NCRIS, SSI and CRIS Participant. This is based on the approved Project or Implementation Plan.

A detailed list of the PHRN Funding and Participant Agreements can be found at <http://www.phrn.org.au/phrn-review/phrn-contracts-and-agreements>.

## **2. Description of the PHRN**

### **2.1 Vision and Mission**

The principal purpose of the PHRN is to build a nationwide data linkage infrastructure capable of securely and safely linking and integrating data collections from a wide range of sources. In turn, this will provide a valuable new capability for monitoring the health of the population and the effectiveness of health services and interventions, as well as increasing the potential for world class research.

**Vision:** A valued national resource generated from linkage of population data from a broad range of areas such as health, education and community services and used for research to inform policy, planning and management to improve the health and wellbeing of all Australians.

**Mission:** To build a national data linkage infrastructure by working collaboratively with key stakeholders including data custodians, researchers and the community. This will support research of national relevance which results in improved policy making and service delivery and demonstrates global best practice in maximising the benefits to the Australian community whilst preserving individual privacy.

## 2.2 Governance structures

### Management Council and Committee Structure

For the PHRN, strategic direction and overview is the responsibility of the Management Council.

The PHRN Management Council has an independent chair appointed by DIICCSRTE, Professor Brendon Kearney. Membership includes nominees of the PHRN Participants and Commonwealth Department of Health and Ageing, as well a consumer representative and two research representatives.

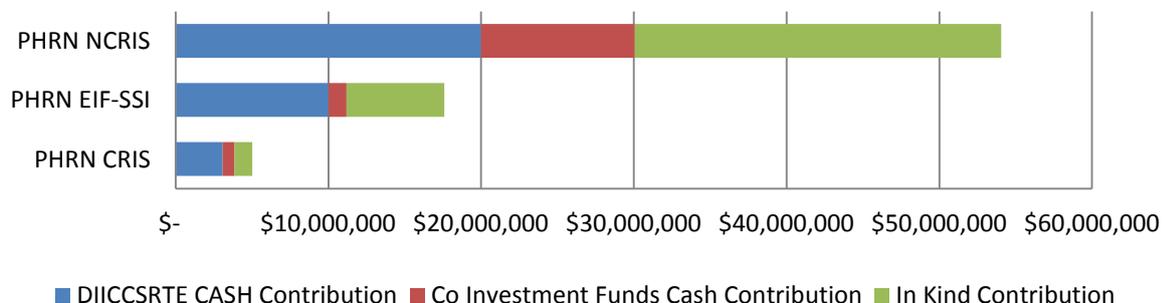
The Management Council has established five sub-committees to provide advice and direction to its members:

- Access Committee;
- Data Transfer Working Group;
- Operations Committee;
- Ethics, Privacy and Consumer Engagement Advisory Group; and
- Proof of Concept Reference Group.

Further details of the PHRN Committee functions and membership can be found at the PHRN website ([www.phrn.org.au/about-us/phrn-management-council](http://www.phrn.org.au/about-us/phrn-management-council)). Each individual PHRN Participant/facility also has its own governance structures.

### 2.3 PHRN Investment in Data Linkage

PHRN investment funding of \$73m consists of three sources of funding. These are the DIICCSRTE cash contributions (\$33m), co-investment funding cash contributions and in kind contributions. The latter two are sourced by Project Participants in each state.



**Figure 1 PHRN Investment in Data Linkage Infrastructure**

Table 1 below shows details of funding provided under each DIICCSRTE funding program. Figures are based on the PHRN NCRIS Project Plan, PHRN EIF-SSI Project Plan and the PHRN

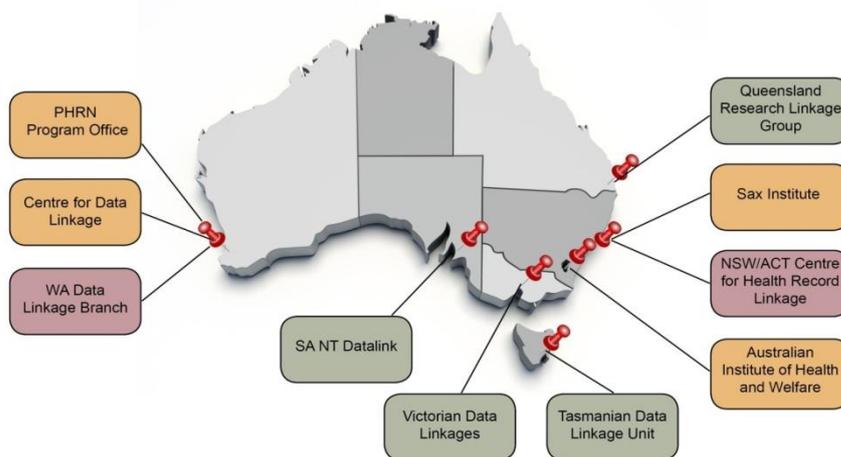
CRIS Implementation Plan. Actuals have remained fairly consistent with some variations in co-investment funding and in-kind contributions. The main variation from the PHRN NCRIS and EIF-SSI Project Plans has been in project duration with the extension of time for implementation of the PHRN programs. The original PHRN NCRIS project period was 2008-?? The current project completion date is 30 June 2014 and no further extensions are anticipated. PHRN EIF-SSI had an original project term of two years to 30 June 2013. However this has been extended to enable completion of infrastructure development by all Project Participants. The current PHRN EIF-SSI Funding Agreement project completion date is 31 December 2014. PHRN CRIS commenced in calendar year 2013 with the first instalment being paid to UWA in May 2013. The project completion date for PHRN CRIS is 31 December 2014. Due to reporting obligations, work for the Program Office on both PHRN EIF-SSI and PHRN CRIS will continue through to the contract completion date of 30 June 2015.

**Table 1 PHRN Investment in Data Linkage 2008-15**

\$ (GST Exclusive)	PHRN NCRIS	PHRN EIF-SSI	PHRN CRIS	Total
DIICCSRTE Cash Contribution	\$20,000,000	\$10,000,000	\$3,085,000	<b>\$33,085,000</b>
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<b>Total Investment</b>	<b>\$54,062,000</b>	<b>\$17,600,000</b>	<b>\$5,029,276</b>	<b>\$76,691,276</b>

## 2.4 PHRN Participants

The PHRN is a distributed network with regional data linkage services in each Australian state. Two states (WA and NSW) have data linkage services that commenced prior to PHRN. Data linkage services for the two Australian mainland territories (ACT and NT) are provided in conjunction with an adjacent state. There are four related national services. Information on PHRN's regional and national services is provided below. Information on related, PHRN-funded initiatives is also provided.



**Figure 2 Location of PHRN Facilities**

## 2.5 Regional Data Linkage Services

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

**Project Participant:** The Cancer Institute of NSW

The CHeReL was established in 2006 to create and sustain record linkage infrastructure for the health and human service sectors in NSW and the ACT that would provide a mechanism to access linked data for bona fide researchers and health planners and policy makers.

#### **Purpose**

*NCRIS*

CHeReL was not a funded Project Participant under NCRIS but was an in-kind contribution to the NSW node. Record linkage services for the research sector were fully operational during the NCRIS period and were operated independently of the PHRN in accordance with the CHeReL's 2006 mission.

*SSI*

CHeReL will:

- expand and refine the design of the automation of NSW hospitalisation data feeds for the CHeReL, synchronisation of data custodian and linkage unit handling of hospitalisation data, and optimisation of linkage and data management systems; and
- support the dissemination of findings from the automation of NSW hospitalisation data feeds initiative to the PHRN through the Program Office in line with the Program Office's communication and governance support roles.

#### **Governance and Organisational Structure**

The CHeReL is hosted by the Cancer Institute NSW and is administered under a memorandum of understanding between the NSW Ministry of Health and the Cancer Institute NSW. The PHRN SSI obligations are managed under the CHeReL's existing governance structure, which comprises an Executive Committee, an Advisory Committee and a Community Advisory Committee.

The CHeReL Executive Committee oversees the operations of the CHeReL and is responsible for approving the CHeReL strategic and business plans, other major projects, fees for the CHeReL's services and matters of valuable consideration. The Committee comprises two persons nominated by the Chief Health Officer of NSW Health, two persons nominated by the Chief Cancer Officer and Chief Executive of the Cancer Institute NSW and the Manager of the CHeReL.

The CHeReL Advisory Committee provides advice to the CHeReL Executive on the CHeReL strategic and business plan, policies and procedures relating to its services, and fees charged by the CHeReL for these services. The Committee comprises two persons nominated by the Chief Health Officer of NSW Health, two persons nominated by the Chief Cancer Officer and Chief Executive of the Cancer Institute NSW and two persons from each CHeReL Member organisation. Members from 1 July 2009 onwards have included ACT Health, University of New South Wales, University of Sydney, University of Technology Sydney and University of Western Sydney.

The CHeReL Community Advisory Committee provides advice to the CHeReL Manager and Executive on issues of community interest in the operation of the CHeReL including: communication strategies for informing the community, procedures for responding to

community complaints or concerns, the CHeReL strategic and business plan, and any other issues of community interest. The Committee comprises six community members recruited following open advertisement.

## **Achievements**

*SSI*

New or upgraded applications are on track to be being delivered by 31 December 2013 at two sites: the NSW Ministry of Health and the CHeReL, Cancer Institute NSW.

- The NSW Ministry of Health has completed Phase 1 of the system build, which synchronises and automates handling of hospitalisation records and will reduce the lag-time by 75%.
- The CHeReL has successfully deployed a new version of software into production in June 2013 which provides a more efficient and sustainable solution for managing the increasingly large and diverse linkage files required by the government and research sector.
- In-kind project contributions are progressing: the CHeReL participated in PHRN Proof of Concept Collaboration #1 and staff of the CHeReL and NSW Ministry of Health have assisted researchers to obtain the necessary state-based approvals for PHRN Proof of Concept Collaborations 2 and 4.

The CHeReL's main linkage system, the Master Linkage Key, has expanded to include 6 new datasets and 43.9 million new records since 2009. Sixty seven other datasets have been linked to parts of this system to support data requests from 555 investigators. From 1 July 2009 to 30 June 2013, 116 new projects and 16 amended projects received ethics and data custodian approval. Of these, 20 involved multiple jurisdictions and 103 have received linked data.

### **2.5.2 Queensland**

**Project Participant:** The University of Queensland (UQ)

#### **Purpose**

*NCRIS*

The Queensland Centre for Health Data Services (QCHDS, now known as Health LinQ) will:

- serve the health data linkage needs of Queensland and contribute to the national capacity through the PHRN.
- enter into a service agreement with the Research Linkage Group (RLG) to provide a data linkage capacity for Queensland and contribute to the national capacity. The primary functions of the RLG will include:
  - Provision of linked datasets for research;
  - Performing all tasks involving the use of named data in the various steps of data linkage;
  - Preparation of linked data for delivery to analysts and researchers, either directly or through the QCHDS or the PHRN Data Delivery System.

The primary functions of Health LinQ will include:

- Facilitation of access to linked datasets involving Queensland Health data, through the RLG;
- Liaison with the national collaboration and data coordination bodies;
- Support of methodological research on data linkage and linked data analysis;
- Human capacity building in data linkage and analysis; and
- Participation in the national coordination of data linkage systems and methods.

## **Governance**

The Queensland node of the PHRN consists of:

- The QCHDS, to be established as an unincorporated joint venture between:
  - UQ;
  - Griffith University;
  - Queensland University of Technology (QUT); and
  - James Cook University (JCU);
- The RLG which is organisationally and physically located within Queensland Health (QH) in accordance with Queensland's privacy policy, which restricts data access to QH employees; and
- The Australian e-Health Research Centre.

UQ is the operator of the QCHDS, which is located at the university

The Queensland node is overseen by a Management Committee with representatives from all the partners as well as a community & consumer representative.

The Director of QCHDS principally reports to the Management Committee of the QLD Data Linkage Consortium. The Director also reports to the Head of the School of Population Health, UQ for administrative purposes.

## **Achievements**

### *NCRIS*

A Joint Venture agreement between UQ and its partners from QUT, Griffith and JCU was fully executed in May 2010. On 19 October 2010 the service provider agreement between Health LinQ, represented by UQ, and QH was fully executed. The contract between the UQ and the Queensland Government's Department of Employment, Economic Development and Innovation (DEEDI) was fully executed on 25 March 2011. Deeds of Variation to these agreements have been executed to extend the project until June 2013. A further extension until June 2014 is currently being negotiated.

The Queensland RLG was formally launched in Brisbane in May 2013.

Queensland RLG's key activities:

- Successful implementation of the 'Interim' Linkage tool using LinkageWiz
- Ongoing expansion of the Master Linkage File. Linked data in this 'master linkage file' are currently available from 01 July 2003 to 30 June 2011. The following data collections are now included in the Master Linkage File:
  - Queensland Health Admitted Patient Data Collection (QHAPDC)
  - Perinatal mothers collection
  - Perinatal babies collection
  - Birth registration
  - Queensland Deaths Registry
- Installation and configuration of ChoiceMaker for routine linkage of core datasets
  - Development of software for grey area checking and management of links
- Ongoing completion of ad hoc linkages
- Completion of two Demonstration Linkage Projects
  - Alcopops
  - Avoidable admissions in psychiatric patients

Health LinQ's key activities:

- Development of a dedicated website to assist researchers in understanding the benefits of using linked data and the processes behind obtaining such data.
- Provision of support and information, including assistance with Public Health Act and Ethics applications, to individual researchers/research teams, many of which are new to using linked administrative data, for over 30 research projects.
- Undertaking of researcher information sessions in access to, and the use of, administrative data.

The Queensland Government provided data for PHRN Proof of Concept Collaboration 1.

### 2.5.3 SA NT DataLink

**Project Participant:** The University of South Australia

SA NT DataLink provides a high quality data linkage service to support research, policy development, service planning and evaluation.

#### **Purpose**

*NCRIS*

The SA NT DataLink will:

- be a multidisciplinary data linkage system that will provide an evidence base to better understand the impact of decision making and the complex interrelations between biological, social environmental and economic factors that impact on individual and community health and wellbeing.
- serve the health and wellbeing data linkage needs of SA and the NT and will contribute to the national capacity through the PHRN.
- contribute to national research capacity in the areas of:
  - Early childhood health and development;
  - Healthy ageing and chronic disease management;
  - Injury; and
  - Indigenous health and wellbeing.
- In addition to health data, the SA NT DataLink will link families, education, housing and justice data as determinants of health or outcomes of health.

*SSI*

- responsible for enhanced reporting on "Closing the Gap" initiatives in the NT including establishing processes for extraction and handling of births and deaths data; and
- responsible for further development and expansion of SA NT DataLink.

#### **Governance**

The SA NT Data Linkage Consortium was established in 2009 with government, non-government and university stakeholders in SA and the NT as a multidisciplinary data linkage system.

The University of South Australia hosts the SA NT Data Linkage Consortium or "SA NT DataLink". The data linkage function is undertaken at SA NT DataLink by staff who are employed by SA Health.

The Director of SA NT DataLink principally reports to the Chair and Steering Committee of the SA NT Data Linkage Consortium. The Director of SA NT DataLink also reports to the

Director, Sansom Institute, Division of Health Sciences, University of South Australia for administrative purposes.

The SA NT DataLink Steering Committee provides strategic direction to the sub-committees, SA NT DataLink and the SA NT DataLink Director.

The SA NT DataLink Executive Committee is appointed by the Steering Committee and is responsible for proposing strategic directions for the Consortium, recommending performance criteria, reviewing the performance of SA NT Data Link and ensuring that SA NT DataLink development, maintenance and management is carried out in accordance with the Consortium (Joint Venture) Agreement.

### **Achievements**

- The Unit was officially launched in November 2009 by the respective NT and SA Health Ministers, the SA Minister for Early Childhood Development and the Executive Director from the SA Department for Education and Children’s Services.
- Implementation of the ‘Interim’ Linkage tool using LinkageWiz
- Development of the Next Generation Linkage System (NGLS)
- Inclusion of the following data collections in the Master Linkage File:
  - South Australia
    - Emergency Department Data Collection (EDDC)
    - Cancer Registry
    - Dental Service (SADS)
    - Inpatient Hospital Separations (ISAAC)
    - Public School Enrolments (Census)
    - Public School Student, Years 1 to 3 Reading Assessments
    - Public School Student English as a Second Language Scale
    - Births Registry
    - Deaths Registry
    - Perinatal Outcomes
    - South Australian Women’s & Children’s Health Network:
      - Midwife Universal Contact Visit
      - Family Home Visiting for Mothers & Infants at Risk
      - New Mother’s Day Service
      - Blue Book” Child Health Checks
      - Childhood Immunisation Registry
      - Universal Neonatal Hearing Screening Program
    - Families SA:
      - Child Protection database
      - Alternative Care database
      - Care and Protection Orders database
  - Northern Territory:
    - Health Department Client Master Index database
    - Births Registry
    - Perinatal Outcomes
    - Immunisation Registry
    - Death Registry
    - Department of Education – School Attendance
  - NAPLAN
  - Australian Early Development Index (AEDI)
- Development of the Metadata Repository completed in June 2012.

- Execution of the data transfer agreement between NT Government and SA NT DataLink.
- Linkage keys were released for the following Statistical Linkage Projects:
  - The South Australian Early Childhood Development Demonstration Project.
  - The Northern Territory Early Childhood Development Demonstration Project.
  - Potentially Preventable Admissions to South Australian Public Hospital Services: analysis using statistically linked administrative data.
  - Enhanced Reporting on “Closing The Gap” Initiatives Project.
  - The South Australian Health Performance Council Quality of End of Life Case Study: Statistical Linkage Project.
  - Colorectal Cancer: early detection, clinical management and survival outcomes at a population level.
  - PHRN Proof of Concept 1: In Hospital and Post Discharge Mortality: Learning of quality of care using data linkages from Australian States.
- Linkage keys are being prepared for
  - Australian Longitudinal Study of Women’s Health (linkage of selected state registries to three survey cohorts).
  - DRUID: Diabetes related urban indigenous diseases, follow-up study.
- SA NT DataLink is currently supporting approximately thirty Statistical Linkage Projects seeking approvals for linkage.

#### 2.5.4 Tasmanian Data Linkage Unit (TDLU)

**Project Participant:** The Department of Health and Human Services (DHHS), Tasmania

The TDLU provides data linkage services to support research, policy development, service planning and evaluation.

##### **Purpose**

*NCRIS*

The TDLU will:

- Create linkages within and between health-related Tasmanian administrative data sets;
- Provide linkage services for researchers, planners and policy-makers;
- Set up and oversee processes to produce de-identified linked data sets for approved users; and
- Contribute to national data linkage capacity, in particular through liaison with the PHRN.

*SSI*

The TDLU will:

- Construct the master linkage map; and
- Enable the extraction and supply of linked de-identified health-related data to researchers.

##### **Governance**

The Menzies Institute, University of Tasmania, hosts the TDLU under an agreement with the Tasmanian DHHS. The TDLU is overseen by the TDLU Management Committee.

##### **Achievements**

- Linkage system computing infrastructure (hardware and software) purchased, commissioned and tested.

- A Data Exchange Agreement between the DHHS and the TDLU has been executed. This provides for transfer of demographic data from core DHHS collections to the TDLU for incorporation into the Master Linkage Map.

### 2.5.5 Victorian Data Linkages (VDL)

**Project Participant:** The Department of Health, Victoria

#### **Purpose**

*NCRIS*

VDL will:

- Create and maintain additional linkages within and between the core population health and health services data collections in Victoria;
- Research and evaluate data linkage opportunities in other portfolio and research sectors;
- Extend the capability for linking State and national datasets;
- Ensure effective and ongoing liaison and contribution to PHRN activities;
- Develop enhanced analytical capabilities to further the most effective usage of linked data;
- Provide data linkage services for researchers;
- Set out glossaries and meta-data standards and protocols for data linkage;
- Set out policies and procedures for the use and disclosure of linked data;
- Develop governance processes for access to linked datasets; and
- Ensure adherence to these processes.

*SSI*

VDL will:

- develop and expand data linkage infrastructure at the VDL, including through the acquisition and use of full names and addresses in hospital and emergency department data.

#### **Governance and Organisational Structure**

VDL is managed as a unit within the Victorian Department of Health. The Department's Information Management and Information Communication Technology Sub-Committee also provides oversight.

VDL also consults and seeks support and advice from the department's Office of the Chief Information Officer, the Victorian Health Services Commissioner and the Privacy Commissioner.

Future governance of VDL will be developed as a part the department's Data and Information Strategy which will be achieved under the broader umbrella of the Victorian Government's Data Vic Access Policy. This will be supported by a number of standards and guidelines to be developed including on areas of data governance and roles and responsibilities.

#### **Achievements**

- Finalisation of the memorandum of understanding between the Victorian Departments of Innovation, Industry and Regional Development and Human Services in June 2009 and the transfer of \$3.2 million to a trust fund. With this funding, the VDL entered its initiation phase, strengthened by the appointment of a Director;

- Commissioning of Convergence Business Solutions Pty Ltd and Dr Bridget Bainbridge to conduct a Privacy Impact Assessment of the VDL and its participation in the PHRN;
- Standardisation of data: Many of the population health datasets which can be linked have variables which have changed over time, in name, category and format. A standardisation process was undertaken with a goal of creating research minimum data where possible.
- Consolidation and improvement of the existing enduring data linkages for the hospital datasets (Victorian Admitted Episode Dataset, Victorian Emergency Minimum Dataset, Elective Surgery Information System, and Victorian Death Index).
- Extension of the Victorian Data Linkage Map by having established enduring linkage between the hospital datasets with the Victorian Radiotherapy Minimum Dataset, Aged Care Assessment, and Victorian Patient Satisfaction Monitor, and having completed data linkage pilots between the hospital datasets with the Victorian Cancer Register, Victorian Modifiable Infectious Disease Surveillance, and Mental Health.
- Data linkage and extraction for over 70 projects.
- Successful negotiation of a business case for obtaining names and addresses for linkage. Negotiation with data custodians to obtain names and addresses for linkage is now underway.
- Review of linkage methodologies and algorithms to enhance linkage has progressed well. Probabilistic data linkage methods have been developed by supplementing the VDL linkage programs with the Manitoba SAS LINKS macros.
- Establishment of a Secure Data Exchange electronic portal with data custodians and researchers.

### 2.5.6 Western Australian Data Linkage Branch (WADLB)

**Project Participant:** The Department of Health Western Australia

The WA Data Linkage System was established in 1995 to connect all available health and related information for the WA population. This information is used for ethically approved research, planning and evaluation projects which aim to improve the health of Western Australians.

#### **Purpose**

##### *NCRIS*

In the NCRIS funding agreement the Western Australian Department of Health were not listed as a Project Participant. However, it was listed as a Participating Organisation and had the responsibility of convening a collaborative process and establishing a Proof of Concept Reference Group which would solicit input from the community of researchers, examine options and advise on the nature, scope, costing and implementation of the Proof of Concept Collaboration. The Proof of Concept Collaboration was required to test the data linkage infrastructure established through the PHRN. Information about the Proof of Concept Collaboration can be found in section 2.7.2

##### *SSI*

The WADLB will:

- create and maintain a suite of standardised, enhanced, validated de-identified extracts via the Custodian Administered Research Extracts Server (CARES) facility; and
- support the dissemination of findings from the creation of CARES to the PHRN through the Program Office in line with the Program Office's communication and governance support roles.

## **Governance**

The WADLB is managed through line management processes within the WA Department of Health.

## **Achievements**

The PHRN Proof of Concept Reference Group has been successfully chaired by the Program Manager of the WADLB. The Program Manager has also been responsible for the first Proof of Concept collaboration which provided its Stage 1 Final Report in June 2013 and related Proof of Concept coordination activities.

The PHRN SSI Participant Agreement with the WA Department of Health has not yet been executed. However there has been significant progress with the CARES initiative.

## **2.6 National Data Linkage Services**

### **2.6.1 Australian Institute for Health and Welfare (AIHW)**

**Project Participant:** The Australian Institute of Health and Welfare

The AIHW is a national agency set up by the Australian Government under the Australian Institute of Health and Welfare Act to provide reliable, regular and relevant information and statistics on Australia's health and welfare.

The AIHW Data Linkage and Data Integration Services Units facilitate the development and analysis of data in order to support whole-of-government and whole-of-life approaches to policy. The AIHW achieves this by investigating data linkage and analytical methods, by undertaking data linkage and analyses of linked data sets, and by providing leadership and assistance to analyses undertaken elsewhere within the AIHW in close collaboration with subject matter staff.

## **Purpose**

### *NCRIS*

The AIHW were not a Project Participant or Participating Organisation in the NCRIS Funding Agreement.

### *SSI*

The AIHW will:

- gain accreditation as an Integrating Authority through the arrangements put in place by the Australian Government;
- design collaboration mechanisms in conjunction with PHRN to create the best possible channels for researchers to access Commonwealth data; and
- provide researcher access to Commonwealth data.

## **Governance**

The AIHW Act 1987 establishes the AIHW Board as the Institute's governing body. The role and composition of the AIHW Board are specified in s. 8(1) of the Act. The Board is accountable to the Parliament of Australia through the Minister for Health and is responsible for setting the overall policy and strategic direction of the Institute. The AIHW's Charter of Corporate Governance adopted by the AIHW Board provides the basis for its operations (see p178 of the 2011-2012 Annual Report. The Director of the AIHW manages the day-to-day affairs of the Institute.

Data integration projects can only be undertaken with the approval of the independent AIHW Ethics Committee.

The AIHW's Data Integration Advisory Committee, with members drawn from the PHRN, a state or territory government agency, a research body and a data custodian, provides advice to the AIHW on establishing and maintaining appropriate governance, administrative and consultative arrangements. Operational processes and project-specific operations and processes are appropriate are managed by the Data Integration Services Centre (DISC) Steering Committee, an AIHW internal committee.

### **Achievements**

- The DISC infrastructure including secure physical space with swipe card controlled access, an onsite data laboratory, a Mobile Data Laboratory (laptop) and development of the policies, procedures and documentation for the operation of the DISC is complete;
- The AIHW has gained accreditation as a Commonwealth accredited Integrating Authority. The AIHW has strengthened its data integration governance and administrative framework and created the DISC. This accreditation places the AIHW in a unique position to play a vital role particularly in bringing together of Commonwealth, state and other data for health and welfare research.

### **2.6.2 Centre for Data Linkage (CDL)**

**Project Participant:** Curtin University

The PHRN CDL was established in 2009 within Curtin University as part of the NCRIS initiative. The focus was to develop and implement secure, state-of-the-art national data linkage infrastructure to enable cross-jurisdictional data linkage for research.

#### **Purpose**

*NCRIS*

The CDL will:

- establish a secure data linkage facility and facilitate linkage between jurisdictional datasets, and between these datasets and research datasets, using demographic data. The CDL will not hold these datasets, but will link the demographic data that has been separated from the remainder of each dataset to create 'linkage keys'. Clinical or service information is not needed by the CDL and will not be provided to it.

The other major functions of the CDL include:

- aggregation of jurisdictional linkages into a national system;
- assistance with the delivery of linkable data to researchers;
- providing technical advice and assistance to jurisdictional data linkage units;
- research and development of data linkage systems and methods;
- evaluation and quality assurance of linkage systems and methods; and
- facilitation of geo-coding of address information.

*SSI*

The CDL will:

- further develop the CDL secure cross jurisdictional data linkage facility in consultation with all PHRN participants;

- provide technical advice and assistance to jurisdictional data linkage units as appropriate;
- continue research and develop of data linkage systems and methods; and
- provide data linkage services for PHRN-EIF system testing initiatives as appropriate.

### **Governance and Organisational Structure**

The CDL is overseen and governed by the PHRN Management Council and the Curtin Steering Committee. The CDL reports directly to the PHRN Management Council. The Council has overseen implementation of all CDL Project Plans and has provided strategic advice and direction to the CDL throughout NCRIS and SSI.

The CDL Curtin Steering Committee was established for the PHRN SSI project to provide broader advice and support the CDL Project Team and to ensure the project objectives and key deliverables are achieved. Oversight and governance by the PHRN Management Council and the Curtin Steering Committee ensure a strong, continuing foundation for future cross-jurisdictional and national linkage by the CDL.

### **Achievements**

The CDL has demonstrated a high level of achievement within the project time-frame. Major achievements include:

- Development and endorsement of the CDL Operational Model for cross-jurisdictional data linkage (subsequently published in a peer reviewed journal);
- Design, build and operation of an innovative, 'baseline' Production NLS for national (cross jurisdictional) linkage;
- Design, build and operation of a secure infrastructure to host the Production NLS system, including the development of policies, procedures and documentation for secure operations;
- Ethics approvals from various jurisdictional human research ethics committees (HRECs) for Proof of Concept linkage activity (WA Health, NSW Health, SA Health, Qld Health, Curtin University) and from Curtin University for Production operations;
- Executed agreements for the transfer of data for Proof of Concept 1 linkage project with data custodians in WA, NSW, SA and Queensland (WA Department of Health, WA Registrar General, NSW Department of Health, NSW Registrar of Births, Deaths and Marriages, Qld Department of Health, Qld Registrar of Births, Deaths and Marriages, SA Health and SA-NT Datalink);
- Completion of Proof of Concept 1 linkages and delivery of national linkage keys. The project is one of the largest linkage projects ever undertaken in Australia, linking over 45 million records of hospital admissions and deaths over a 10 year period across four states (WA, NSW, Qld and SA) ;
- Research leadership and innovation: Completed research in linkage software evaluation/performance, linkage quality improvements, privacy preserving linkage and geocoding systems (results published in various peer reviewed journals);
- Implementation of a secure file transfer system (SUFEX) for the PHRN and its stakeholders (<https://sufex.org.au>);
- Data linkage advisory role within the Network and demonstrating technical leadership (Operations Committee activity; Technical Forums; data linkage training and technical support for VDLU); and
- Collaborative relationship with the AIHW: secondment of Associate Professor Boyd (to help develop an Integrating Authority model at AIHW); executed Agreement between AIHW and Curtin University (to enhance provision of future National Data Linkage Services); and joint research on linkage methodology.

### 2.6.3 Secure Unified Research Environment (SURE)

**Project Participant:** The Sax Institute

The Sax Institute is an independent, not-for-profit organisation that aims to improve health, health services and programs by increasing the use of research in policy making.

#### **Purpose**

*NCRIS*

The Sax Institute will:

- Establish the NSW Secure Data Exchange will comprise systems and support for the exchange of data between custodians, researchers and the CHeReL, and provide a secure repository for storage of current and historical datasets, and secure dataset query, subsetting and selection tools to allow the contents of the repository to be accessed and explored by authorised users. It will relieve much of the burden currently borne by individual data custodians who have a large and growing workload in managing datasets, assessing requests for access to data, providing meta-data for and updates to 'master linkage keys' that form the backbone of data linkage processes, and preparing dataset extracts for release to researchers. The NSW Secure Data Exchange will also improve the speed and efficiency of linkage processes and provide back-up and archiving facilities for other elements of the NSW PHRN Node. It will provide a model for similar facilities that could be set up in other parts of Australia when the PHRN Data Delivery System is fully established.
- Establish the NSW Data Analysis Laboratory which will provide computing and human infrastructure for the management and statistical analysis of linked health datasets.
- develop, use, document and promulgate a set of standardised methods and associated software tools for analysis of linked data. The Data Analysis Laboratory's functions will include an evaluation of currently available analysis tools.
- coordinate the development and implementation of the PHRN Data Delivery System The PHRN Data Delivery System will provide harmonised national mechanisms for secure transfer of data between Nodes of the PHRN and from data custodians to linkage centres and researchers for approved projects.

Its functions will encompass:

- provision of technical assistance to enable jurisdictions to establish complementary data storage systems;
- mechanisms that enable the PHRN Data Delivery System (DDS) to receive information from jurisdictional systems over secure connections in order to facilitate delivery of information that has been approved for release to linkage centres and researchers; and
- tools to assist managing the secure exchange of data between jurisdictional systems.

*SSI*

- expand of the SURE facility beyond NSW/ACT to include data from other jurisdictions; and
- develop policies, procedure manuals and online researcher accreditation for a national SURE facility.

#### **Governance and Organisational Structure**

The development and operations of SURE are managed by the Sax Institute. Program direction was been overseen by the Sax Institute's Principal Scientist with development and

operations of the facility coordinated by a Project Director, SURE Manager and Technical Advisor.

The National SURE Advisory Committee was established in 2012 to provide advice and input into the development of the national SURE facility. Prior to this, a Management Committee and Advisory Group involving stakeholders in the NSW and ACT was convened to guide the facility's first stage of development. The membership of the National SURE Advisory Committee was selected to reflect the stakeholder group that has an interest in the effective operation of SURE and people with relevant expertise.

Members of the National SURE Advisory Committee include nominees of the PHRN Management Council; custodians of health-related data collections; researchers with experience undertaking health-related linked data research; representatives with experience in the linkage of health-related data; a representative of a Commonwealth-accredited Integrating Authority (AIHW); and a representative of DIICCSRTE.

### **Achievements**

The key achievement for the Sax Institute over the period of PHRN funding has been the development of the SURE facility. The facility has progressed from an idea in 2009 to an operational facility in 2012 through processes of functional requirements analysis, extensive stakeholder consultation and prototyping. The SURE facility was officially launched by Senator Matt Thistlethwaite in July 2012. As at 30 June 2013, the SURE facility had 40 active users with established workspaces for 13 different research projects.

Accompanying the facility's technical development has been the development of a policy framework for the use and operations of SURE. Key components of this framework include a user training program (150 participants from over twenty different institutions were trained by 30 June 2013); agreements with data custodians for the use of data in SURE; user agreements; information security and access and pricing policies; and a website ([www.sure.org.au](http://www.sure.org.au)).

In relation to the development of the PHRN DDS, a scoping report and consultation was completed in 2011 that included the evaluation of candidate technical tools. Following completion of the DDS Phase 1 Report, responsibility for implementation of DDS functionality for transfer of files between data custodians and data linkage units was transferred to the CDL at Curtin University (refer Sections 2.6.2 and 2.7.1). Facilities for the exchange of data from data custodians to researchers is provided by the SURE Curated Gateway.

The Sax Institute has collaborated with the Commonwealth Scientific and Industrial Research Organisation (CSIRO) on a project to investigate approaches to confidentialisation of research outputs. The Sax Institute has provided considerable information on the design and operations of the SURE facility and feedback from the SURE User Training Program on researcher perspectives to confidentialisation, participated in two workshops with CSIRO and the Australian Bureau of Statistics and contributed to a review of publications for disclosure risk and the development of a disclosure risk assessment checklist.

## 2.6.4 Program Office

**Project Participant:** The Telethon Institute for Child Health Research (TICHR)

On behalf of the Lead Agent, the University of Western Australia, the Program Office for Data Linkage (Program Office) plays a central role in leading and coordinating the development and implementation of the PHRN data linkage infrastructure.

### **Purpose**

*NCRIS*

The Program Office will:

- lead and champion the development of public health and research data linkage infrastructure in Australia;
- provide executive support to the Management Council including arranging Council meetings, developing agenda papers and taking Minutes of meetings;
- manage and monitor the contracts between UWA and the operational units in WA and elsewhere in Australia, and facilitate the implementation of the Investment Plan;
- coordinate the development of a Participants' Arrangement between the Project Participants setting out their mutual obligations and operational relationship to each other within the PHRN, as described in Attachment A, Section 4.1;
- monitor and report to the Management Council on performance against performance indicators agreed by Us;
- develop and implement the PHRN Access and Pricing Policy, as advised by the PHRN Access Committee and agreed by Us;
- maintain liaison with national health information groups and agencies including the relevant Principal Committees of the Australian Health Ministers' Advisory Council (AHMAC), the Australian Health Ethics Committee of the National Health and Medical Research Council (NHMRC), the Australian Institute of Health and Welfare (AIHW) and the Australian Bureau of Statistics (ABS);
- establish processes to govern provision of demographic data for linkage and release of de-identified data for research, in consultation with custodians of jurisdictional datasets;
- negotiate access to State and Territory Government datasets;
- undertake training coordination; and
- ensure that researchers, health consumers and the community have access to information about the national data linkage infrastructure.

The Program Office will also provide services to researchers using the PHRN. In this role it will:

- foster standard practice and coordinate access by researchers to linked data;
- coordinate development and implementation of standards, procedures and guidelines to support national data linkage activities; and
- facilitate access by researchers to linked, de-identified data for approved projects.

*SSI*

The Program Office will:

- lead and champion the development and use of health and health related data linkage infrastructure in Australia;
- assist UWA to meet reporting and accountability requirements;
- manage agreements between UWA and participating organisations, including delivery of required plans and reports;
- provide executive support for the PHRN Management Council and related groups;

- manage communications with stakeholder groups including health consumer and community groups; and
- complete PHRN EIF-SSI activities including the metadata repository and online application system.

### **Governance and Organisational Structure**

The Program Office is located at TICHR. The Director who is also the Chief Executive of the PHRN is employed by UWA Australia and has an adjunct appointment at TICHR. Program Office staff are employed by TICHR.

The PHRN Management Council has overseen the implementation of both the PHRN NCRIS and SSI Project Plans. It provides advice on strategic direction and management of capacity-building for national data linkage and provided advice to the Program Office during NCRIS and SSI.

### **Achievements**

The main achievements of the Program Office since 2009 include:

- The establishment and administration of the PHRN Management Council and its sub-committees and advisory groups.
- Negotiation, management and monitoring the contractual arrangements for the NCRIS, SSI and CRIS funding programs. This includes 3 separate head agreements and 20 Participant Agreements.
- Negotiation, management and monitoring of contracts for Program Office support, the four Proof of Concept Collaborations and the CSIRO confidentialisation initiative.
- Preparation, submission and receipt of approval of successive Annual Business Plans and Progress Reports for PHRN NCRIS, SSI, and CRIS
- Development and implementation of the PHRN Communications Strategy and Communication Guidelines. A range of communications have been employed to engage with all the PHRN stakeholders e.g.
  - Information newsletters;
  - Promotional and information articles;
  - Face to face meetings with key policy and decision makers;
  - Presentations at relevant local, national and international conferences and meetings;
  - Development of the PHRN website [www.phrn.org.au](http://www.phrn.org.au);
  - Development and distribution of a glossary to enhance understanding and uniformity of message amongst nodes; and
  - Development of case study examples folder for use in promoting the value of data linkage and the PHRN.
- Consultations with the stakeholders to understand their needs and priorities e.g. the researcher consultation conducted in 2012.
- Liaison with national health information committees; engagement with education sector on use of PHRN infrastructure; participation in national innovation activities e.g. Research Data Infrastructure Committee, AUS-EU workshop.
- Development of the PHRN Policy Framework and the PHRN Information Governance Framework to ensure that the PHRN infrastructure is built and operated according to the highest ethical and scientific standards and is compliant with relevant national guidelines, codes of conduct and applicable State/Territory and Commonwealth legislation.
- Review of the legal and legislative environment for data linkage in Australia.

- Conduct of a scoping exercise and needs analysis to the PHRN to identify and prioritise training needs for the Network. As a result training programs for consumer participation and for HREC members were developed and implemented. The HREC training workshop which has been conducted in six states and territories so far aims to improve HREC members' ability and confidence to assess research applications proposing the use of linked data. Significant progress with development of a Metadata Framework for the Network.
- Completion of Business Concept for a central online application system for applications for cross-jurisdictional linked data.

## 2.7 Other

### 2.7.1 Data Delivery System (DDS)

The DDS is an element of the PHRN infrastructure funded through the PHRN NCRIS Agreement. Its purpose is to provide a national mechanism for the secure and efficient transfer of data between Nodes of the PHRN, from data custodians to linkage units, and from data custodians to researchers for approved projects. The DDS is of strategic importance to the PHRN because data flows for the network are heavily reliant on a functional and secure data delivery mechanism.

Phase 1 activities (DDS1) were undertaken by the NSW/ACT node of the PHRN (with support from Intersect Australia, the CDL, CheReL and NSW Ministry of Health. DDS1 comprised an evaluation selected technologies for secure data transfer and the defining of simple but sufficient metadata and data file formats for data being exchanged between PHRN parties.

Phase 2 activities of the DDS project (DDS2) were undertaken by the CDL and delivered a service which provides the PHRN with the ability to transfer data securely and efficiently between stakeholders for the purpose of conducting PHRN projects.

The key delivery outcomes of DDS2 were:

1. A secure data delivery system that meets the requirements of PHRN projects.
2. A user friendly, efficient and trusted mechanism for transferring data between project participants.
3. A system that adheres to PHRN Policies, Principles and Standards (e.g. PHRN Information Governance Framework).
4. A low support and maintenance overhead.
5. A system that is scalable to meet the current and future needs of the PHRN.

The CDL is also responsible for DDS Phase 3 integration activities (DDS3), leveraging off work done in Phase 2. The project is to be undertaken in 2013//14.

### **Governance**

The PHRN Operations Committee acts as the Data Delivery Reference Group, examining options and providing advice on the development of the PHRN DDS. The PHRN Operations Committee is a forum through which network members consider and provide advice to the PHRN Management Council on the technical development of a national infrastructure for data linkage and related research.

### **Status of DDS Project**

The PHRN Secure Data Delivery Service, branded as the Secure Unified File Exchange (or SUFEX; <https://www.sufex.org.au>) went 'live' in July 2013, with first phase users testing management procedures during a short, 'soft launch' period. SUFEX delivers a user-friendly interface for file encryption, transfer and decryption between PHRN participants and stakeholders. Prior to the launch, the SUFEX service and hosting environment were subjected to an audit by external security consultants (CQR) to ensure that the infrastructure met the necessary security standards and objective of the PHRN Information Governance Framework. A wider broadcast of services occurred in September 2013.

### **Challenges**

Two factors impacted on the DDS2 project – delays in agreement/funding and scoping/defining the project. Delays in funding had knock-on effects on the procurement of some resources for the pilot test. In terms of scoping, some areas of the DDS project required further definition and as a result presented as project risks. A number of strategies were employed to mitigate these risks.

### **Outlook**

The CDL is currently operating the SUFEX service and is supporting new users.

The DDS3 project will complement the activities/deliverables from DD2. Planning for the DDS3 project has commenced; with contractual and funding arrangements recently finalized. The DDS3 Project completion date is 30 June 2014.

### **Activities Undertaken**

- Technical report (DDS1) outlining the possible approaches to secure data exchange, metadata and the data file formats for data being exchanged between PHRN parties;
- Evaluation of technologies for secure data transfer and definition of sufficient metadata/data file formats for the data being exchanged between PHRN parties (reports circulated to the PHRN Operations Group and Management Council);
- Operating guide for secure data exchange and secure data storage space;
- Preparation of the DDS2 Business Concept – This document outlined the business concept and requirements of the DDS (the high-level business requirements, milestones and risks). Developed based on feedback from PHRN Operations Committee;
- Solution Evaluation planning - Described the potential solution options and their high level features, costs, usability, support and maintenance needs). Developed based on feedback from PHRN Operations Committee;
- Evaluation of managed file transfer solutions which have the features and demonstrated capability required to deliver a PHRN DDS;
- Completion of a pilot evaluation using Accellion software (involving volunteers from the PHRN who tested functionality and provided comments/observations to the pilot report);
- Completion of a report on DDS2 Project Status and Pilot Evaluation Outcomes;
- Finalised design aspects of the production solution (secure architecture, detailed software configuration, hosting);
- Hosting hardware & related infrastructure were purchased, installed and tested;
- Software and licences acquired;
- An independent security review of design documentation was undertaken by CQR;
- Issues and recommendations from CQR audit were investigated and actioned;
- Domain name and certificates acquired;
- Policies and processes (DDS terms of service, user access, other relevant SOPs) were being established and change control processes were defined & documented;

- Final security review of SUFEX infrastructure undertaken by CQR;
- Soft launch of SUFEX service in July 2013;
- Wider broadcast of services in September 2013; and
- Operation, administration and support of SUFEX service is on-going.

### Promotion

The DDS Project has used the PHRN Operations Committee as an advisory/steering group throughout the process as evidenced in reports to the Management Council and the technical reports distributed across the PHRN.

The DDS Project has also included technical communication within the PHRN, with the technical feasibility, technical evaluation and pilot phases of the project involving various members of the PHRN.

### 2.7.2 Proof of Concept Collaboration

The Proof of Concept (PoC) Collaboration, funded under NCRIS, was designed to assess the ability of the PHRN data linkage infrastructure to perform cross-jurisdictional linkage of data and provide linked de-identified data in a form that can be used for research studies.

The PoC collaboration which was originally envisaged as a single study, has now developed into a set of four carefully selected research studies designed to test different aspects of the diverse network of activities that is the PHRN. The first three studies are funded through PHRN NCRIS. The fourth is funded through PHRN SSI as a system testing initiative. The projects have each been approved by the PHRN Management Council and once commissioned, must also meet the requirements of a range of data provider organisations and government agencies. Each PoC collaboration has been commissioned to test and refine complex data linkage infrastructure processes including data custodian engagement and approval, ethics approval processes as well as jurisdictional and national data linkage and extraction services.

**Table 2 Chief Investigator and other information on PHRN PoC collaborations**

No.	Chief Investigator	Institution	Title
1	Ms Diana Rosman	WADoH	In-hospital and post-discharge mortality: learning about quality of care using data linkages from Australian states
2	Dr Rebecca Mitchell	UNSW	Burden and cost of injury-attributable health care use and mortality in Australia
3	Dr Sally Brinkman	TICHR	Perinatal outcomes and child development (risk and protective factors)
4	Dr Heather Gidding	UNSW	Linkage of the Australian Childhood Immunisation Register (ACIR) and state-based registers to evaluate and inform Australia's immunisation program

## **Governance**

The PoC Collaborations are overseen by the PHRN PoC Reference Group. The Reference Group is appointed by the PHRN Management Council and consists of ten members with a mix of skills and expertise.

## **Achievements**

All of the PoC Collaborations are large and complex projects requiring multiple data custodian and HREC approvals as well as data transfer agreements negotiated with each data custodian. PoC 1 received all its approvals and signed all the necessary agreements. The CDL has recently completed the linkage of all the data collections from WA, SA, NSW and QLD and project specific national linkage keys have been created and delivered to data custodians (using the SUFEX service). The researcher has now received all the data for analysis in the next few months.

The other three PoC Collaborations are at various stages of receiving the necessary approvals and negotiating the data transfer agreements.

### **2.7.3 Approaches to confidentialisation of outputs from research using linked data conducted in secure analysis laboratory environments**

This initiative, funded under SSI, was designed to examine approaches to confidentialisation of data outputs that researchers may wish to remove from the secure analysis laboratory environment during or after a research project.

The CSIRO were contracted to undertake the work with assistance from the Australian Bureau of Statistics and the Sax Institute.

The project is being conducted in the following four stages:

#### **Stage 1: Project Environment**

In this stage an understanding of the applicable legislation, regulation and expectations regarding confidentiality and the SURE secure analysis environment was gained. This included an understanding of the workflows in research projects using linked data in SURE, focussing on potential points to introduce disclosure risk assessment and confidentialisation processes and potential impacts of these processes on research efficiency.

#### **Stage 2: Requirements gathering**

In this stage the requirements of researchers and data custodians were established. This included understanding researchers' needs for access to unit record data and perspectives on disclosure risk assessment as well as data custodians' expectations for confidentiality and perspectives on disclosure risk assessment.

#### **Stage 3: Review of Solution Options**

In this stage the options for approaches to disclosure risk assessment and confidentialisation of data outputs were investigated; a review of guidance (including guidelines and checklists) that can be provided to researchers to allow them to assess and mitigate disclosure risk was undertaken; and a review of available software tools and/or development projects was conducted.

#### **Stage 4: Recommendations**

In stage 4 recommendations about policies, procedures, guidelines, methods and tools for assessing disclosure risks and confidentialisation of outputs that researchers may wish to remove from SURE during or after a research project will be developed??

The initiative is progressing well and will be completed in 2013.

## 2.8 Work in Progress

### 2.8.1 Regional Data Linkage Services

#### **Queensland**

Queensland is currently working on the second demonstration project. The Queensland RLG is also planning to trial the National Linkage Software that CDL have created as another tool for ad hoc request linkage. In addition, trials are planned of quality assurance tools that CDL have developed.

#### **Tasmanian Data Linkage Unit**

The TDLU is still in the process of establishing a master linkage key.

#### **SA NT DataLink**

Work is continuing in the negotiation of the access agreements on researchable datasets in the NT and SA, as well as ensuring appropriate level of information is provided to the researchers on the linkage of project data. There is continued work reviewing options for improving the quality of linkage and the quality of linked data. The piloting, implementation and testing of the Metadata Repository and Next Generation Linkage Management System is continuing.

#### **Victorian Data Linkages**

The initiative to acquire names and addresses for Victoria's hospital and emergency department data is progressing. These characteristics are critical to improving the quality of the data and data linkage; once better patient data has been collected into the department, VDL will re-establish the data linkage algorithm to improve data capability and quality.

#### **Western Australian Data Linkage Branch**

The WADLB is continuing to work toward completion of the CARES design, testing and plan for seamless migration of data and processing. CARES will create and maintain a suite of standardised, validated and de-identified data extracts and forward these to researchers on behalf of data custodians.

### 2.8.2 National Data Linkage Services

#### **Australian Institute for Health and Welfare**

The AIHW is continuing to develop a fully operational secure data integration capability and design collaboration mechanisms across PHRN to enable researchers to access Commonwealth data.

#### **Centre for Data Linkage**

The CDL is continuing to expand the development of the national infrastructure to increase the technical capability and know-how to manage and transform datasets as linkage demand, complexity and size grow. The facility will provide scalable, fast,

efficient, accurate and cost effective infrastructure to support national and international population health research collaboration. Support of PHRN Proof of Concept collaborations is continuing. Operation, administration and support of SUFEX will also continue.

### **Secure Unified Research Environment**

The Sax Institute is progressing the procurement of hardware and software, system integration and testing to expand the NSW/ACT SURE facility built with NCRIS funds to a distributed national facility with servers in two locations.

### **Program Office**

The Program Office is progressing the development of a national web based applications system and the completion of the national metadata framework/repository.

## **2.8.2 Other**

### **Data Delivery System**

A number of elements not included in the phase 2 development were recognised as being critical to a fully integrated and supported implementation of the PHRN DDS. These included:

- Integration capability and roadmap for related PHRN developments;
- Administrative and User support;
- Site implementation/set up assistance;
- extension of functionality to secure project workspaces.

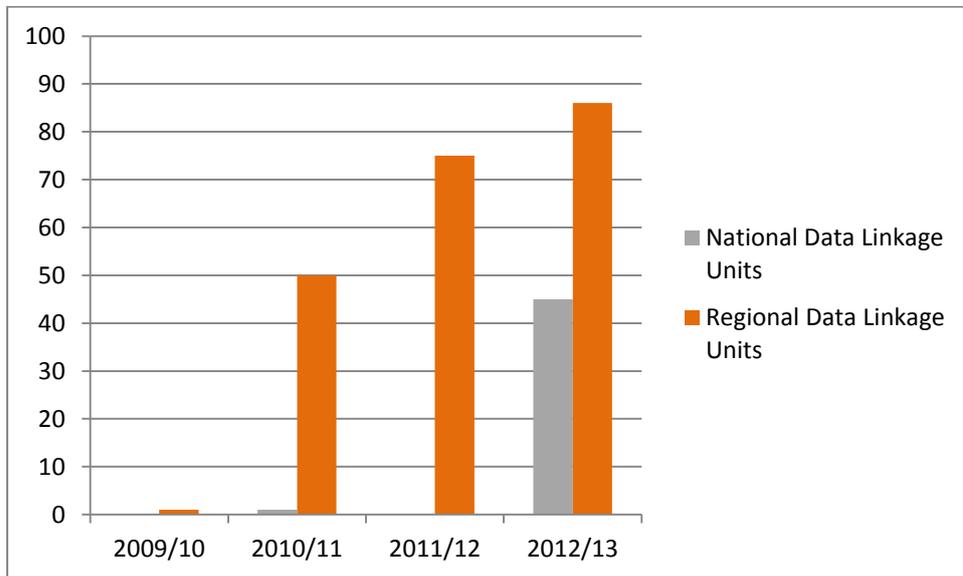
These elements have been packaged into a DDS Phase 3 project which will be undertaken in 2013/14.

### **Proof of Concept Collaboration**

The four Proof of Concept collaborations should all be completed by mid-2014. The final analysis for PoC 1 is in progress and PoCs 2-4 are in the process of receiving all the necessary approvals.

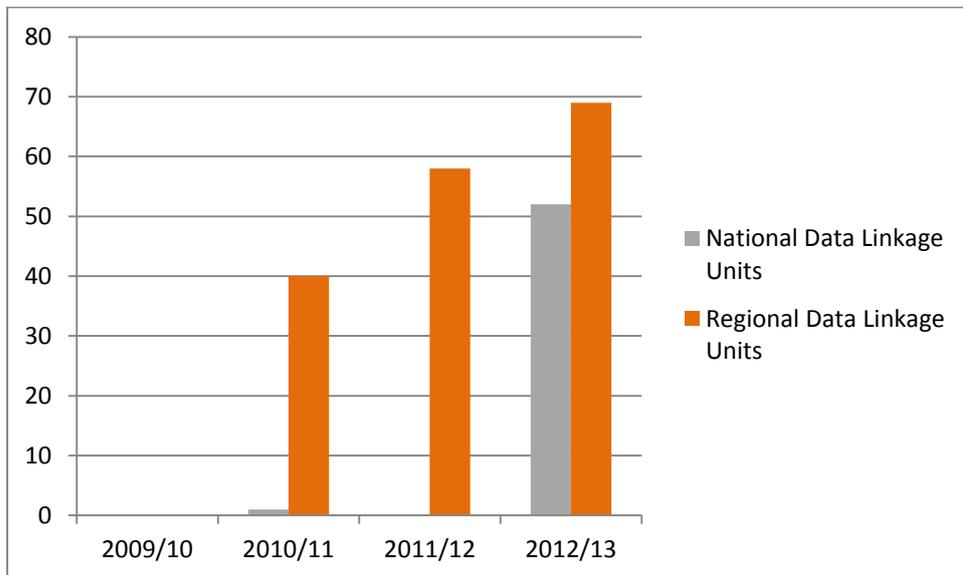
## 2.9 Measures of PHRN Activity

**Figure 3** Number of Approved Applications by Year



\*Does not include data linkage units in operation prior to 2009.

**Figure 4** Number of Projects Where Data Was Provided by Year



\*Does not include data linkage units in operation prior to 2009.

**Table 3**      **Number of records linked by linkage units established with PHRN funding between July 2009 and June 2013.**

<b>Number of records linked into a master linkage file/routine linkages</b>	<b>81,925,792</b>
<b>Number of records linked by national linkage units</b>	<b>76,917,053</b>