



PHRN Population
Health
Research
Network

Annual Review 2011-12



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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.

Australia is a nation that is rich in information resources. Population level data is collected by a range of agencies and institutions to support policy, planning, management, monitoring, evaluation and research. Developments in technology over the last few decades have enabled information from different sources relating to the same person, place or event to be joined together in a privacy-preserving way. This method of combining data, commonly known as 'data linkage', is a powerful tool for exploiting the full potential of the information contained in these collections.

A national approach to data linkage in Australia was identified as a key priority by the Australian Government in its 2006 National Collaborative Research Infrastructure Strategy (NCRIS) Strategic Roadmap and 2008 Strategic Roadmap for Australian Research Infrastructure as it was seen to offer significant opportunities to improve the health and wellbeing and enhance the effectiveness and efficiency of health and related services in Australia. As a result, the Population Health Research Network (PHRN) has received \$30m from the Australian Government Department of Industry, Innovation, Science, Research and Tertiary Education (DIISRTE; formerly Department of Industry, Innovation, Science and Research) via NCRIS and the Education Investment Fund Super Science Initiative (EIF-SSI). Generous cash and in-kind support has also come from every Australian state and territory government as well as key Australian universities and institutions, resulting in a total investment for the 2008-2013 period of over \$70m (see Table 1).

Table 1: PHRN Investment in Data Linkage 2008-13

\$ (GST Exclusive)	PHRN NCRIS	PHRN EIF-SSI	Total
DIISRTE Cash Contribution	\$20,000,000	\$10,000,000	\$30,000,000
Co-investment Funds Cash Contribution	\$10,109,000	\$1,143,000	\$11,252,000
In Kind Contribution	\$21,783,000	\$7,147,000	\$28,930,000
Total Investment	\$51,892,000	\$18,290,000	\$70,182,000

The PHRN is working with states and territories and the Commonwealth to develop safe and secure infrastructure for the linkage of health and related data (including early childhood and education data) contained in statutory and administrative collections and for the provision of this data in non-identified form to data users for approved projects. This infrastructure is world class and internationally recognised.

The PHRN is governed by a Management Council chaired by Professor Brendon Kearney. It has a number of infrastructure elements including:

- Data linkage units in every Australian state.
- An integrating authority being developed at the AIHW to progressing linkage of Australian Government data. The PHRN is providing funding support for AIHW to become an accredited Integrating Authority.

- The Centre for Data Linkage based at Curtin University in Perth. This secure data linkage facility performs cross jurisdictional linkage and has been crucial to the testing and operation of state-of-the-art linkage mechanisms for use within the PHRN.
- The Secure Unified Research Environment (SURE) based at the Sax Institute in Sydney which is a secure access laboratory that allows researchers to remotely access and analyse the approved data extracts provided by data custodians within strict security and privacy protecting parameters.
- A Program Office based at the Telethon Institute for Child Health Research in Perth which is the administrative hub of the PHRN. It is responsible for client services, policy development, contractual and financial management, communications and training support.

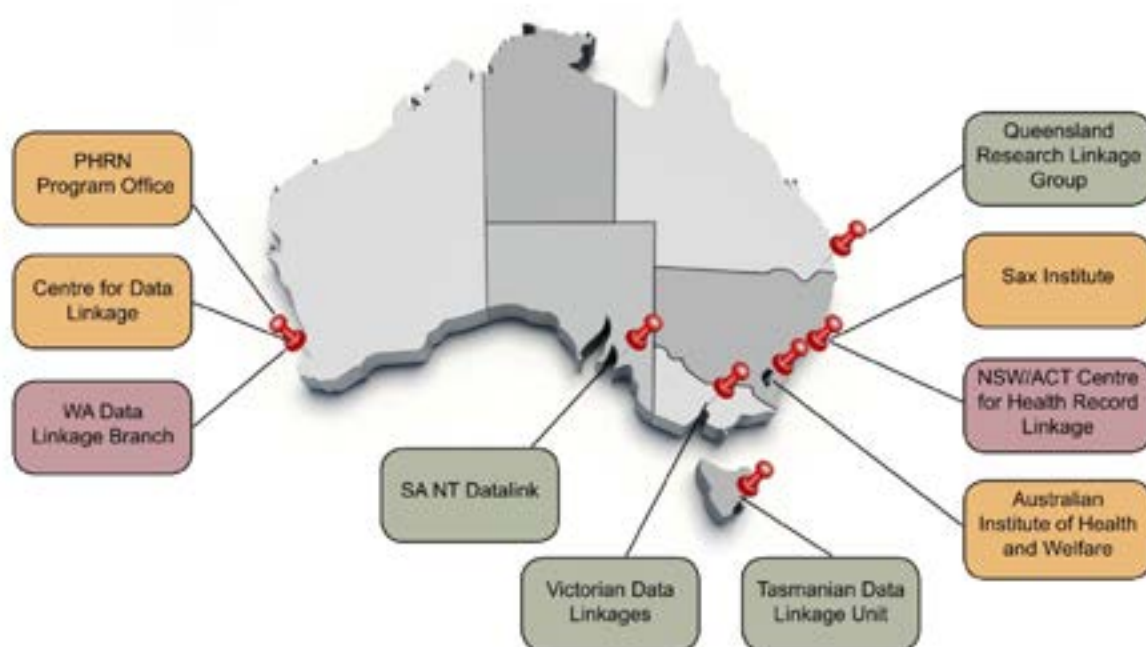


Figure 1: The PHRN data linkage infrastructure network.

Whilst the PHRN is not an organisation, each Participant has signed a contract with the lead agency of the capability, The University of Western Australia, in which each has agreed to:

- Actively participate in PHRN governance processes;
- Abide by agreed PHRN policies and procedures;
- Contribute collaboratively to the ongoing development of Australia’s data linkage capability; and
- Work collaboratively to improve the data linkage capabilities in individual jurisdictions.

PHRN 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.

PHRN 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.

For further information please visit www.phrn.org.au.

CHAIRMAN'S MESSAGE

On behalf of the Management Council, I am pleased to present the PHRN's second annual report, which covers a year of significant development and growth for the network.

The PHRN completed its first year of PHRN EIF-SSI-funded activities with a focus to build on, refine and enhance the national data linkage infrastructure established by PHRN NCRIS investment. Good structures and processes were in place under PHRN NCRIS and this has continued with PHRN EIF-SSI funding. The spirit of collaboration within the network has facilitated strong channels for exchange of information and learnings between Participants, resulting in the significant progress in both the development of the new data linkage units and the elements of national infrastructure.

Three new agencies were welcomed as formal PHRN Participants in 2011-12: the Australian Institute of Health and Welfare (AIHW); the NSW Centre for Health Record Linkage (CHeReL); and the WA Department of Health (WADOH). The addition of these agencies to the PHRN is a crucial step towards establishing the network as a truly national infrastructure and, with the accreditation of the AIHW as a Commonwealth Integrating Authority, facilitating the PHRN's role in the future integration of Commonwealth and jurisdictional data. The Council welcomes the opportunity to work closely with and benefit from the existing expertise within the AIHW, the CHeReL and the WADOH.

Throughout 2011-12, the PHRN has continued to enjoy productive relationships with its funders in the Australian Government and state and territory governments and academic partners. To 30 June 2012, the PHRN has received \$30m from the Commonwealth and over \$13m of co-investment excluding in-kind contributions. Significant return on this investment has already been achieved and can be summarised as follows:

- Over 10 million new records linked into core data linkages in 2011-12 spanning a range of decades and collections
- 75 new data linkage projects approved in 2011-12, an increase of 50% from 2010-11
- Research supporting data linkage infrastructure including studies into hardware and software enabling developing of linkage systems with high efficiency and specificity
- Critical mass of skilled personnel in the areas of linkage, technical operation and research skills required to support the infrastructure
- Robust governance structures across Australia including principles, policies and processes.

Despite these substantial achievements to date, with increased competition for funding and changes in government priorities, the Management Council has recognised the need to build on its relationships with funders and supporters and demonstrate the national and international significance of the infrastructure in order to promote the long-term sustainability of the network.

In February 2012, a Strategic Planning Workshop was held for the Management Council to discuss the objectives of the PHRN and how it can be sustainable in the future. The Workshop included an update from DIISRTE and provided a forum for the Council to reflect on the PHRN's progress and to clearly identify and articulate the key strategic priorities for the network over the next five

years and the activities required to support them. Following very constructive discussion, seven distinct areas were identified as priorities for focus by the network:

1. Proof of Concept Collaborations
2. Development of case studies of relevant policy and practice changes due to data linkage research
3. Collaboration with other sectors beyond health
4. Sustainable finance strategies
5. Continued engagement of Australian Government agencies and committees around data linkage/integration
6. Increased engagement with and provision of information to researchers using linked data
7. Training for researchers.

I believe that underpinning the continued support and success of the PHRN is the need to effectively educate policymakers, the research community and the wider public on the enormous value and potential of research using data linkage and the infrastructure used to support this. Strong leadership and focus from all participating agencies will be instrumental in assisting the Council to achieve this goal.

In closing I would like to sincerely thank members of the Council and its subcommittees and advisory groups, PHRN Chief Executive Dr Merran Smith, staff of each PHRN Participant, funders and all other PHRN supporters for the hard work and commitment shown throughout the year. In my continued role as Chair of Council, I am looking forward to the next 12 months with enthusiasm and great expectation that the substantial progress of the PHRN's national data linkage infrastructure to date will successfully continue.

Professor Brendon Kearney



“The spirit of collaboration within the network has facilitated strong channels for exchange of information and learnings between Participants, resulting in the significant progress in both the development of the new data linkage units and the elements of national infrastructure.”

A MESSAGE FROM THE PHRN CHIEF EXECUTIVE

2011-12 has been an extremely busy year for the PHRN. PHRN Participants have continued to operate and further develop Australia's national data linkage infrastructure under existing PHRN NCRIS funding and the introduction of PHRN EIF-SSI funding from 1 July 2011.

From an administrative perspective, 2011-12 has seen the negotiation and execution of a number of Deeds of Variation between The University of Western Australia as the PHRN's lead agent and the various Project Participants to enable extension of PHRN NCRIS funding through to June 2013 and the reallocation of unspent funds to a number of PHRN projects. Commencement of PHRN EIF-SSI funding has required the development and execution of a second Investment Plan, a head Funding Agreement between the Commonwealth and the UWA and individual Participant Agreements. There has also been a significant increase in administrative and reporting responsibilities that have been required of all Participants in addition to existing NCRIS reporting. I would like to congratulate and thank all staff involved in compilation and submission of these reports. I am also very grateful to the staff at DIISRTE for their assistance in this process.

Notable achievements in the development of PHRN national infrastructure during 2011-12 include the completion of the PHRN Information Governance Framework, the completion of the CDL built baseline production national linkage system for cross jurisdictional linkage and the completion of the Sax Institute's NSW ACT SURE to enable NSW and ACT researchers to access data remotely in a highly secure virtual analysis computing environment. The AIHW's addition to the network should facilitate the opportunity to access Commonwealth data collections and potentially the ability to integrate Commonwealth and state/territory data. The formal accreditation of the AIHW's Data Integration Services Centre as the inaugural Commonwealth Integrating Authority is a major milestone for the AIHW and the PHRN and is testament to the commitment and hard work shown by the AIHW team.

State and territory data linkage units have also made significant progress throughout the year. SA NT DataLink is now operating at full capacity and has already incorporated a range of SA data collections into its Master Linkage Key with several NT collections to follow shortly. The other new linkage units in Queensland, Tasmania and Victoria, despite having encountered a number of legislative, policy and staffing challenges, have made significant progress in the development of their linkage infrastructure. PHRN EIF-SSI funding has also been secured to streamline various aspects of the two existing linkage units in WA and NSW/ACT. The WA Data Linkage Branch has commenced the development of a central data extract server to assist custodians with the resource-intensive task of preparing and supplying extracts to researchers. The CHeReL will use PHRN EIF-SSI funding to develop automated data-feeding mechanisms between custodians and the linkage unit. The initiatives in WA and NSW/ACT will address common bottlenecks in routine data linkage processes and are relevant to linkage units Australia-wide.

2011-12 has also seen significant progress in the PHRN Proof of Concept collaboration initiatives. Queensland and SA have agreed to provide data to the first Proof of Concept collaboration (POC#1) on hospital related mortality. This means that data from four states (WA, NSW Queensland and SA) can be linked and analysed. Proposals from researchers on injury and early childhood development were approved as the PHRN Proof of Concept second (POC#2) and third (POC#3)

collaborations respectively in 2011-12. With co-funding from the Western Australian government for POC#2 secured and resolution of outstanding issues with POC#3, these initiatives are expected to start in the new financial year. Funding for further PHRN system testing in the form of a fourth Proof of Concept collaboration was also secured through PHRN EIF-SSI and will seek to incorporate the linkage of Commonwealth and state/territory data.

The 2012 International Data Linkage Conference held in Perth in May provided an ideal forum for showcasing the PHRN infrastructure to a wide audience. A number of individuals affiliated with the PHRN were involved in the organisational committees of the conference and were instrumental in gaining wide support for the conference which was attended by almost 400 delegates from Australia and around the world. Management and staff of many of the PHRN Participant agencies presented their work which generated a large amount of interest and will pave the way for future collaborations with other data linkage groups in the UK, Canada and Scandinavia in particular.

Reflecting on 2011-12, there are many people that have contributed to the significant progress of the PHRN that I would like to acknowledge. Firstly to Professor Robyn Owens and her team at UWA, whose leadership and efficiency have been instrumental in the negotiation and management of the multitude of contracts involved in disbursement of PHRN funds. My sincere gratitude is extended to Ms Clare McLaughlin and staff of DIISRTE for their continued support, guidance and advocacy of the PHRN, and to the many government and academic institutions around Australia who provide financial and in-kind support. I am also very grateful to Professor Brendan Kearney and to the members of the Management Council and its subcommittees for their generous contribution to the various policy and planning aspects of the network. I would like to thank the management and staff of each of the Participant agencies whose commitment and expertise has been reflected in the quality of the infrastructure developed during this period. Finally, to my colleagues in the PHRN Program Office and at the Telethon Institute for Child Health Research, I am most grateful for your efforts and I look forward to working with you in the coming years.

Dr Merran Smith



CREATING A SUSTAINABLE FUTURE

PHRN NCRIS FUNDING EXTENSION AND DEEDS OF VARIATIONS

Following on from the variation to the PHRN Funding Agreement in 2011 to provide for the PHRN NCRIS program to continue until 30 June 2013, deeds of variation between The University of Western Australia (UWA) and Project Participants were executed during the year for the majority of the Project Participants. Another deed of variation to the PHRN NCRIS Funding Agreement executed on 22 May 2012 provided for variations including extending the project completion date to 30 June 2013 for the Program Office and Queensland, and reallocation of unspent Data Delivery System (DDS) funds for DDS Phase 2 at the Centre for Data Linkage (CDL) and the national Secure Unified Research Environment (SURE) at the Sax Institute.

PHRN EDUCATION INVESTMENT FUND SUPER SCIENCE INITIATIVE

Following the announcement in May 2009 of a further allocation of \$10m over 2011-12 and 2012-13 to the PHRN via the Education Investment Fund Super Science Initiative (EIF-SSI), the PHRN EIF-SSI Investment Plan was submitted to the DIISRTE in May 2011. Receiving formal approval from DIISRTE in July 2011, this document formed the basis of the PHRN EIF-SSI Funding Agreement between UWA (which remained as the lead agency for the capability) and DIISRTE. The Funding Agreement also includes a detailed Project Plan outlining the agreed undertakings of each of the Project Participants.

Subsequent to the execution of the PHRN EIF-SSI Funding Agreement on 30 November 2011, the Program Office commenced facilitation of the negotiation and execution of the PHRN EIF-SSI Participant Agreements. At 30 June 2012, all PHRN EIF-SSI Participant Agreements except for the Department of Health WA, Department of Health Victoria and the Department of Health and Human Services (DHHS) Tasmania agreements had been executed. Despite delays in the execution of Participant Agreements and the related disbursement of EIF-SSI funds, a number of Project Participants managed to draw on support mechanisms including in-kind contributions to start the initial review and testing phase for components of the EIF-SSI funded infrastructure.

PHRN GOVERNANCE: ENHANCEMENT AND PROGRESSION

PHRN MANAGEMENT COUNCIL

The PHRN Management Council provided oversight on the implementation of both the PHRN NCRIS and EIF-SSI Investment Plans. The Council convened at scheduled quarterly meetings in capital cities across Australia to consider and make decisions on key PHRN issues in 2011-12.

During the year new EIF-SSI Project Participants representing the AIHW and the CheReL were formally welcomed as additional members of the Management Council. In addition, the inaugural consumer representative, Ms Stephanie Miller, joined the Council membership. Ms Miller is the Executive Director of the Health Consumers' Alliance of South Australia and currently chairs the SA NT Datalink Consumer Reference Group. She brings with her a wealth of knowledge in consumer and community participation in all aspects of the research and infrastructure building process.

The subcommittees of the Management Council including the PHRN Ethics, Privacy and Consumer Engagement Advisory Group, the PHRN Access Committee, the PHRN Operations Committee and the Data Transfer Working Group have continued to provide advice on the various key policies and other documentation of the network. In addition, the Proof of Concept Reference Group has now become a formal subcommittee of the Management Council and is being chaired by Council member Ms Diana Rosman.

Under PHRN NCRIS the Program Office has acted as the secretariat for the PHRN Management Council and its advisory groups. This role has continued concurrently with PHRN EIF-SSI.

All Project Participants had structured governance processes in place. Some Participants set up additional committees or advisory groups to oversee the PHRN EIF-SSI project developments where required.

PHRN INFORMATION GOVERNANCE FRAMEWORK

Work continued on the development and refinement of the PHRN Information Governance Framework that was commenced in the previous financial year. Under the guidance of CQR Consulting and a Project Control Group containing representation of all of the Project Participants, a final draft of the Framework was completed in late October 2011. This was endorsed in principle by the Management Council at its November 2011 meeting. The Framework outlines a set of controls and procedures to ensure that privacy and confidentiality of data is maintained throughout all PHRN activities and now forms a critical part of the PHRN's mitigation strategy to address possible privacy and security breaches.

Following dissemination of the endorsed PHRN Information Governance Framework throughout the network, all Project Participants have now developed strategies to address identified risks. These include security manuals, security awareness checklists, information security guidelines, confidentiality deeds for staff and researchers, security protocols and incident and breaches investigation processes. In addition, with the encouragement of the Commonwealth Department of Health and Ageing (DOHA), the Framework was provided to the Chair of the National Health Information and Performance Principal Committee (NHIPPC) for consideration in June 2012.

DATA LINKAGE CAPABILITIES AND OPERATIONS: EXPANSION AND TESTING

Good progress has been made by each Project Participant in the development of their infrastructure commenced under PHRN NCRIS funding. Many of the Participants have also commenced new projects or continued to expand existing ones in 2011-12 through the allocation of PHRN EIF-SSI funds.

NATIONAL UNITS

CENTRE FOR DATA LINKAGE (CDL)

In March 2012 the production system environment and components for cross jurisdictional linkage were completed by the CDL and the production national linkage system (NLS) was available and operational. Following its launch, the CDL commenced a review of the NLS to inform the next phase of development and enhancement of the system. The review is critical in providing information on resource use and linkage speeds and for identifying potential bottlenecks in the system. System functionality and linkage quality is also being assessed to ensure that the NLS either maintains or improves upon the quality benchmarks from Proof of Concept linkage activity undertaken by the CDL for PoC#1 (see below).

With Curtin University cash co-investment funding, the CDL dedicated secure office space was extended to house a specialist research and development team to enhance operational linkage services. The facility provides physical and logical separation between the research and development and the operational data linkage teams within the CDL which is critical for the Centre's adherence to the operational governance arrangements agreed as part of the NCRIS Funding Agreement.

The CDL's integral role as the national data linkage unit continued with its ongoing involvement in the Proof of Concept Collaborations. The Centre undertook Proof of Concept linkages of WA and NSW data using the NLS. This testing was crucial for providing information on resource use and performance speeds that allowed fine tuning of the system. Linkage quality was also assessed and refinements made which improved upon the quality benchmarks from the previous Proof of Concept linkage runs.

The relationship between the CDL and the AIHW continued to develop during 2011-12. Director of the CDL, James Boyd, was seconded to the AIHW for a six month period (February to July 2012) to assist with implementation to become an accredited Integrating Authority (see below for further detail). The AIHW and CDL finalised an agreement to undertake linkages for the AIHW Early Childhood Research Project (fully executed in July 2012). The AIHW and CDL also worked together to design a collaborative research project investigating aspects of clerical review (AIHW led; funded under EIF-SSI).



SECURE UNIFIED RESEARCH ENVIRONMENT (SURE)

The Sax Institute continued development of the PHRN's virtual data analysis laboratory known as the Secure Unified Research Environment (SURE) in 2011-12. Work continued on developing related policies and procedures and the progression of end-user training materials and the signing of software licence agreements. In addition, an agreement with the NSW Ministry of Health regarding governance of NSW Health data held in SURE was drafted. This will be used as a template for similar agreements that may be required for other agencies. Separate SURE user agreements for research organisations and researchers were also drafted, reviewed and finalised.

The major breakthrough in 2011-12 was the "go-live" of the initial production SURE facility and its expansion to sufficient capacity for users in NSW and the ACT and some national researchers. The infrastructure for SURE NSW ACT at the GlobalSwitch data centre in Sydney was expanded with the integration of additional servers, firewalls, and network and storage equipment. This site now provides capacity for 120 to 150 researchers. The SURE national expansion project will build on the implementation of the SURE facility for NSW ACT (see below).

The SURE website (www.sure.org.au) went live in November 2011, including the initial version of the SURE knowledgebase, with a restricted access section for registered users that contains discussion forums and a range of research resources. The SURE team held meetings with a range of research teams across Australia who are planning to use SURE. These projects are at various stages of development and about half plan to use data from multiple jurisdictions including Commonwealth data. Initial quotes for access have been provided and work has commenced with the research teams on the process for establishing their projects and gaining requisite approvals from ethics committees and data custodians. SURE researcher training programs were also delivered in NSW, ACT and WA to sixty participants and extremely positive feedback has been received.

The Sax Institute consulted with the Cross Portfolio Data Integration Oversight Board (CPDIOB) regarding the use of SURE by Integrating Authorities for Commonwealth data. The Sax Institute is collaborating with the AIHW to develop a set of arrangements that will allow the AIHW to use SURE to provide a secure data access and analysis environment to researchers under the Integrating Authority model.

AUSTRALIAN INSTITUTE OF HEALTH AND WELFARE (AIHW)

With its extensive track record in the administration and linkage of national datasets, the AIHW was formally welcomed as a PHRN Project Participant at the commencement of the PHRN EIF-SSI funding period on 1 July 2011. The primary role of the AIHW within the PHRN framework is to facilitate access to Commonwealth data in line with the endorsed governance and institutional arrangements for data integration projects involving the use of Commonwealth data for statistical and research purposes. Specifically, the AIHW sought to establish a Data Integration Services Centre (DISC) which could be accredited as a Commonwealth Integrating Authority (IA).

Work commenced on the planning and design phases of the DISC in the latter part of 2011. Associate Professor James Boyd from Curtin University's CDL was seconded to the AIHW between

February and July 2012 to assist AIHW to establish and design testing regimes more quickly and optimally by drawing on experiences from CDL and more broadly. The infrastructure for DISC has required complete IT separation from the mainstream AIHW infrastructure as well as process, policies and security arrangements to meet the stringent Commonwealth requirements for undertaking high risk data integration projects.

The AIHW DISC secure data integration IT environment was commissioned in the first quarter 2012. A comprehensive threat and risk assessment was undertaken which established that all information security risks have been adequately treated. In February 2012 an initial IA accreditation application was submitted to the Commonwealth's CPDIOB following a preliminary audit by the firm Protiviti. The application received a very encouraging response from the Board.

In the second quarter 2012 the DISC hardware was significantly upgraded in processing power and capacity and underwent rigorous acceptance testing. In addition, the AIHW established a secure onsite data laboratory for researchers to perform analysis on de-identified and appropriately confidentialised datasets as well as a Mobile Data Laboratory for data analysis offsite under strictly controlled security arrangements.

With the DISC infrastructure fully operational, the AIHW again engaged Protiviti to independently review the IT and building upgrades in May 2012. Following favourable consideration of DISC processes, policies and infrastructure by the independent auditors, the Final Audit Report indicated AIHW's full compliance against the Commonwealth's IA accreditation criteria. A final application for IA accreditation was submitted in June 2012 to the CPDIOB and the AIHW was formally granted accreditation on 28 June 2012.

Over the first half of 2012, the AIHW undertook productive discussions with the CDL around potential research proposals to demonstrate the capacity of the new infrastructure and collaborations between the two national data linkage units. In addition, the AIHW intends to adopt the SURE system once it becomes generally available and discussions with Data Custodians and the Sax Institute have also been held. A number of DISC staff have now undertaken the SURE training program.

REGIONAL UNITS

SOUTH AUSTRALIA/NORTHERN TERRITORY

Over 2011-12, SA NT DataLink continued to develop a robust and sustainable data linkage unit, with strong support and in collaboration with its numerous consortium partners. Support for the Data Linkage Demonstrations Projects was a high priority and resulted in the linking of thirteen datasets required for the SA Early Childhood Development Project.

Considerable progress was made in the Northern Territory with the NT Early Childhood Development Project linking health and non-health datasets including NT Public Education, Catholic and Independent school data, with NT Immunisation, NT Perinatal and NT Public Hospital data. In June 2012 the NT Department of Justice signed the first NT whole-of-government agreement to transfer data into the Master Linkage File for the NT Births and Death data going

back to 1870. This landmark agreement is part of the 'Enhanced reporting on Closing the Gap targets' initiative that SA NT DataLink is undertaking with the support of PHRN EIF-SSI funding. In addition to NT data, the first Commonwealth Government dataset, Australian Early Development Index (AEDI), was linked by SA NT DataLink in January 2012.

SA NT DataLink continued to progress the development of the Next Generation Linkage System (NGLS). The new system will enhance SA NT DataLink's capability to manage the current and future volume and demand for linked data and includes an online metadata repository component. Stage One development of NGLS was completed during the year. This included technical evaluation and comparative testing of linkage software and testing of storage capabilities. The NGLS Stage One will be implemented in 2012-13.

The development of the Metadata Repository by the UniSA Library Systems team was completed in June 2012. The Repository includes the Linkage Project Application and Online Approvals and the notification and storage of metadata information of use to researchers. Testing and planning for the implementation will take place in 2012-13.

VICTORIA

Victorian Data Linkages' (VDL) activities in 2011-12 were constrained by the state government's staffing freeze impacting on its ability to retain staff and fill vacancies. In July 2011 VDL received legal advice that its ability to link datasets was restricted to the datasets that have been collected by the Victorian Health Department for a departmental purpose, as established in the portfolio Acts. This issue has since been resolved by developing business cases for the required datasets.

VDL has consolidated and improved the existing enduring data linkage for the Victorian hospital datasets and extended the Victorian Data Linkage map to other health related datasets including the Victorian Cancer Register, Victorian Modifiable Infectious Disease Surveillance and Mental Health. Other work undertaken included an ongoing review of linkage methodologies and algorithms to enhance linkage as well as a review of quality assurance processes and storage/security requirements.

One critical aspect of developing enhanced data linkage capability in Victoria is the acquisition and use of full names and addresses in hospital data. Currently, Victorian acute hospital data (including admitted episodes and hospital emergency) do not contain full names and addresses. To address this, EIF-SSI funding was sought by VDL in order to continue to develop Victorian data linkage capacity to support the national effort to build Australia-wide linkable data. The first step of the process was to review the legislative authority for VDL to collect names and addresses. The Department of Health's Legal Branch determined that this could proceed as long as it is necessary for the purposes of one or more of its Secretary's functions. VDL has now embarked on conducting a demonstration project to incorporate names and addresses collected into a new linkage process.

TASMANIA

The Tasmanian Data Linkage Unit (TDLU) has made significant progress over the 2011-12 year and is quickly maturing. A key achievement was the appointment of a full-time Unit Manager, Mr Brian Stokes, in December 2011. Assisted by the TDLU Management Committee, the Manager has provided oversight on the non-technical aspects of the unit and engaged with stakeholders, enabling other resources to concentrate more broadly on technical aspects of data linkage including the transmission and storage of data and the creation of a Master Linkage Map for the population of Tasmania.

Establishment of the TDLU's computing infrastructure to support data-linkage using NCRIS funds was completed in 2011-12. In establishing this infrastructure, expertise from a number of areas was used and the TDLU server architecture features server virtualisation technology providing test, development and production computing equipment housed in fully-secure, standalone facilities.

A data exchange agreement with the Tasmanian Department of Health and Human Services (DHHS) was executed in June 2012 following a lengthy but productive period of negotiation. The TDLU will shortly begin to receive a regular supply of data from the state's main custodian of public health data. Good progress towards signing a deed of agreement with the Department of Education, Employment and Workplace Relations (DEEWR) in support of supplying AEDI data to the TDLU for linkage was also made. A draft security protocol to support the electronic transfer of data to and from data custodians, with emphasis on secure exchange of data between the TDLU and DHHS was developed and will be reviewed and refined over the next financial year.

The TDLU has also commenced the development of a draft workflow process to support applications for linked data comprising forms, flowcharts, checklists, supporting policies and procedures. A draft Publicity, Marketing and Communication Strategy was also developed to support stakeholder and consumer engagement strategies.

QUEENSLAND

In 2011-12, the PHRN Queensland node suffered setbacks due to changed priorities in Queensland Health (QH) which resulted in difficulties with recruitment/retention of staff to carry out data linkage activities. In addition, delays in the contracting process with the Queensland State Government affected the transfer of cash income to Health LinQ (the administrative and client services arm of the Queensland node) from NCRIS and the project partners and delayed the delivery of some project milestones. Despite these challenges, the Queensland Management Committee and staff have continued to work productively with its major stakeholders, the PHRN and the wider research community to move forward with the node's development as efficiently as possible. The contract between the University of Queensland and the Queensland Government's Department of Employment, Economic Development and Innovation (DEEDI) was fully executed on 25 March 2011. Negotiations for extension of the NCRIS completion date to 30 June 2013 are continuing to enable Queensland to successfully achieve its milestones.

In the last year, Health LinQ has provided over 30 researchers with information on linkable datasets and assisted with ethics applications and methodological advice on the use of linked data for multiple projects. Staff also assisted researchers in applying for grants to external agencies. The Health LinQ website has continued to be an important resource for promotion and conveying valuable information to researchers and key health research organisations nationally. Health LinQ

has also maintained its visibility through media appearances including radio interviews and two television appearances on Health LinQ projects in the past year.

Within QH, prior to the receipt of NCRIS funding, a small team consisting of three staff members was created within the Health Statistics Centre (HSC) to undertake linkage of core QH datasets and to respond to ad hoc linkage requests. This process was undertaken on the existing HSC servers and using software purchased by QH (Linkage Wiz) and a freeware product (Link King). By January 2012 this team had linked seven years' of data. This included internal linkage of episodes within admitted patient data and linkage of admitted patient data to death registration data and perinatal data. Linked data in this 'master linkage file' are available from 1 July 2003 to 30 June 2010. Data have now been provided for numerous ad hoc requests from within QH and from external clients both from the master linkage file and based on additional linkage involving non-QH datasets or other QH data not yet included in the master linkage file. The linkage team has also been assessing ChoiceMaker software for suitability to replace use of Linkage Wiz and early indications are that ChoiceMaker will be flexible enough to be used in Queensland's production linkage system.

WESTERN AUSTRALIA

The Data Linkage Branch of the Department of Health WA (WADLB) is set to receive an allocation of funding through the PHRN EIF-SSI investment to establish new infrastructure known as the Custodian Administered Research Extracts Server (CARES). The CARES is a prototype facility being designed and implemented in WA which will acquire, hold and maintain a suite of standardised, enhanced, validated de-identified data extracts for research and other statistical purposes, in close partnership with data custodians. Its main aim will be to provide a systematic and streamlined approach for the linkage and provision of data for approved linkage projects in a way that reduces the burden on custodians whilst maintaining their full control over their data.

The CARES facility will provide data custodian support on dedicated hardware, via database systems augmented with bespoke extraction and risk assessment toolkit(s). The infrastructure is being developed by a small team, comprising a Data Coordinator and a Data Analyst, with Data Linkage systems support. As of 30 June 2012, a PostGres database has been established to hold the core content data, complete core data extracts have been received and loaded from core datasets and a schedule for updates is in place, and data loading and extraction tools and procedures have been created and tested. Presentations on this work have been given to WA stakeholders and local, national and international interest groups, including at the International Data Linkage Conference held in Perth in May 2012.

In addition to its lead role on the CARES infrastructure development, the WADLB continued to lead the PHRN's first Proof of POC Collaboration (POC#1) and coordinated meetings of the PHRN Proof of Concept Reference Group to select POC#2 and #3 (see below). The Program Office PHRN Policy and Client Services Coordinator Dr Angela Rate assisted as the Proof of Concept Coordinator for POC#1 and POC#3. She coordinated the reporting and funding elements of the two initiatives during the year and assisted with development of POC#3.

NEW SOUTH WALES/AUSTRALIAN CAPITAL TERRITORY

The Cancer Institute NSW, which is the host of the Centre for Health Record Linkage (CHeReL), formally joined the PHRN as a Project Participant at the commencement of the PHRN EIF-SSI funding period on 1 July 2011. The primary goal of the project to be funded by the EIF-SSI investment is to enable more timely and efficient access to health and health related data in NSW and the ACT through addressing significant bottlenecks by automation of NSW hospitalisation data feeds, synchronisation of data custodian and linkage unit handling of hospitalisation data, and optimisation of linkage and data management systems.

During 2011-12, PHRN EIF-SSI funded activities did not commence due to the decision of the Cancer Institute NSW to delay the receipt of EIF-SSI funds until after 30 June 2012. Despite this, in kind contributions relating to data linkage systems progressed as planned. CHeReL staff have tested two releases of this system during 2011-12 and it is now being used in production to improve the speed and accuracy of the data linkage process. Early indications are that the modifications have reduced the overall processing time required for data linkage projects. Over the year CHeReL staff have also continued to provide advice to researchers and data custodians on PHRN Proof of Concept Projects as required.

NATIONAL STRATEGIES AND INTERNATIONAL COLLABORATIONS

PROOF OF CONCEPT COLLABORATIONS

Work has continued on the PHRN Proof of Collaboration program which provides a vital opportunity for the Network to develop and test the data transfer and linkage processes required to link and provide researcher access to data from more than one state or territory and to demonstrate the national significance of this infrastructure.

The first PHRN Proof of Collaboration (POC#1) aims to link hospital admissions data with hospital-related deaths data across different states in order to examine the incidence of in-hospital and 30-day post-discharge mortality. Following the successful cross jurisdictional linkage of data from Western Australia and New South Wales by the Centre for Data Linkage in early 2011, agreements with Queensland Health and the Queensland Registrar of Births, Deaths and Marriages have now been negotiated to enable Queensland data to be linked. In addition, ethics approval from SA Health has been granted and an agreement between SA Department of Health and Curtin University is being finalised. Preliminary analysis on the linked NSW and WA data has been undertaken by the senior data analyst and this will be extended to a 4-state analysis following the transfer and linkage of QLD and SA. The original completion date for POC#1 was extended from 31 March 2012 to 31 December 2012 to enable this to occur.

To extend the work of POC#1, the PHRN Management Council approved two new cross-jurisdictional demonstration projects, Proof of Collaboration 2 (POC#2) and Proof of Collaboration 3 (POC#3), respectively.

POC#2 will be led by a research team from the University of NSW and will describe and compare health care utilisation and mortality in injured and non-injured populations in Australia by the analysis of hospital admission, mortality and emergency department data from up to six jurisdictions. The study will also aim to utilise electoral roll data for the selection of a matched control cohort. Co-funding from the Western Australian government for POC#2 was secured and the Program Office commenced negotiations in 2011-12 for the funding contracts associated with the Collaboration which will enable the research team to commence work.

POC#3 on early childhood development will link data from WA, NSW, SA, Northern Territory and Tasmania with data from the national Australian Early Development Index (AEDI) which is held by the Commonwealth Department of Education, Employment and Workplace Relations (DEEWR). The overall objective is to explore the relationship between perinatal factors and developmental and educational outcomes in early school-aged children. Preliminary planning and development of data and ethics applications has commenced and work is continuing on the negotiation of funding contracts for POC#3.

Through the PHRN EIF-SSI funding allocation, a fourth Proof of Concept Collaboration is currently being considered by the PHRN. The aim of this Collaboration would be to link data from multiple jurisdictions with a Commonwealth data collection to research an issue of national health significance. Inclusion of a Commonwealth collection mandates the use of an accredited Commonwealth IA and it is proposed that the AIHW, as the first accredited IA, would take responsibility for the linkage of the data involved in POC#4. It is also anticipated that POC#4 may

provide an opportunity for utilisation of the national SURE facility (see below). Four proposals for POC #4 have now been received by the Proof of Concept Reference Group for consideration and a decision is likely to be made early in the 2012-13 financial year to enable work to commence.

DATA DELIVERY SYSTEM

The PHRN Data Delivery System (DDS) is an ensemble of technology and standards, agreed operational procedures, software and supporting IT infrastructure that will provide harmonised national mechanisms for secure and efficient transfer of data between nodes of the PHRN and from data custodians to linkage units and researchers for approved projects.

Phase 1 of the DDS project, involving the evaluation of a limited set of tools and the development of guidelines for use of the preferred tools, was completed by the Sax Institute during the year. This report was made available to all of the PHRN participants.

Following on from DDS Phase 1, the CDL proposed a second phase of DDS development which was endorsed by the PHRN Management Council in February 2012. DDS Phase 2 will include evaluation of software to manage file transfers and data flows associated with linkage activity between PHRN, data custodians and researchers. Phase 2 is still in its early stages and developments to date include preparation of an architecture and business model and the completion and distribution of the DDS Business Concept and Software Evaluation Reports to the PHRN Operations Committee in April 2012.

A third phase of DDS development was endorsed by the PHRN Management Council in June 2012. The CDL will lead this phase on behalf of PHRN and one of the activities in this phase focuses on technical integration with other PHRN developments.

NATIONAL SURE FACILITY

In April 2012, additional PHRN NCRIS funds from unspent DDS funds were allocated to the Sax Institute to supplement EIF-SSI funds for expanding the NSW ACT SURE into a national facility. The expansion of SURE capacity to support researchers nationally is expected to be completed by 30 June 2013. The membership of the National SURE Advisory Committee has been finalised and the first meeting of the Committee was held in June 2012.

The SURE team has now also commenced discussions regarding the role of SURE as a component of Integrating Authorities for Commonwealth data with other interested PHRN participants, including the AIHW, SA NT Datalink and the CHeReL. A preliminary application for accreditation was submitted at the end of June 2012 to the Commonwealth Data Integration Oversight Board for consideration.

NATIONAL TRAINING AND EDUCATION STRATEGY

Following on from the national training scoping exercise conducted in late 2010, the PHRN national training program developed and coordinated by the PHRN Program Office was rolled out in July 2011 starting with ethics in data linkage training which was identified as a priority by PHRN stakeholders. The response to the training was extremely positive and most of the training

sessions were oversubscribed. The training was conducted in Brisbane, Darwin, Perth, Adelaide and Sydney during the year. Consumer and community participation training was also completed for staff in PHRN data linkage units in Melbourne, Sydney, Canberra and Tasmania.

The Sax Institute has now developed a one day Safe Researcher Training Program for users of SURE incorporating modules on data linkage research in Australia, responsibilities of a researcher, information security and statistical disclosure control. Sixty people attended SURE training workshops in NSW, ACT and WA conducted by the Sax Institute. It is proposed that completion of the SURE training will be a mandatory component of researcher accreditation to use the SURE facility in the future.

NATIONAL CLIENT SERVICES CONSULTATIONS

The quest for the best approach for the delivery of client services for cross-jurisdictional linked data projects continued in 2011-12 with consultations across Australia. Conducted by the PHRN Program Office, consultations in Sydney, Adelaide, Perth and Canberra were completed during the year with representatives from the research and linkage unit communities. Further consultations for Brisbane and Hobart are planned and an online survey has been developed for those researchers who are unable to attend the face-to-face meetings.

The meetings focused on three aspects of PHRN client services that are in development including a centralised metadata database and information portal, an online application and tracking system for cross-jurisdictional linked data projects, and a national researcher training program. Results of the consultations and survey will be summarised in a formal report to be provided to the PHRN Management Council in November 2012. Further work planned to be carried out by the PHRN Program Office includes development of a generic application form for cross-jurisdictional linked data projects and preliminary consultation with data custodians to determine feasibility.

CSIRO/ABS/SAX COLLABORATION ON DATA CONFIDENTIALISATION

Under PHRN EIF-SSI, funding has been provided for a collaborative project between the CSIRO, ABS and the Sax Institute which will aim to review confidentiality issues associated with analysis outputs generated in a secure analysis laboratory such as SURE, and then to examine different approaches to confidentialisation of these outputs for publication. In the context of this project, 'confidentialisation' of an output refers to the application of treatments such as suppression, aggregation or other modification for the purposes of assuring confidentiality protection. Negotiations around the project plan and funding arrangements for the CSIRO/ABS/Sax collaboration were in the final stages at the end of the June 2012 and the project will commence in August 2012. The PHRN Program Office will coordinate and manage the contract for this project.

CONFERENCE PRESENTATIONS AND WORKSHOPS

The PHRN was promoted through conferences, presentations, publications, websites, forums, seminars and workshops by nodes and the Program Office throughout 2011-12.

Staff at the Program Office and nodes attended and presented at national and international conferences on the progress, work, value and impact of PHRN.

The Chair of the PHRN Management Council represented PHRN at the invitation-only meeting of the Wennberg International Collaboration (WIC) in London in September 2011.

In September 2011 a number of PHRN representatives attended and presented at the Scottish Health Informatics Program (SHIP) biennial conference: "Exploiting Existing Data for Health Research" held at the University of St Andrews in Scotland. The conference brought together researchers, administrators, data linkage technicians and practitioners interested in record linkage and the use of routine health data in research.

The PHRN Operations Committee organised a two day technical forum in Canberra in November 2011 for PHRN Project Participants. Day one included an Operations Committee Meeting with updates from each Project Participant. Day two incorporated presentations and discussions on technical issues.

The PHRN Chief Executive accepted an invitation to give the keynote address at a Data Linkage Conference hosted by Population Data British Columbia in Vancouver in February 2012.

A highlight of the year was the very successful International Data Linkage Conference held in Perth from 2-4 May 2012. Over 370 people from Perth, around Australia and internationally attended. PHRN was a joint sponsor of the Conference and staff played an active role in organisation of the conference.

On 19-20 June 2012, a number of representatives from the PHRN attended and presented at a conference in Canberra entitled 'Data Linkage and Integration: Bringing data together to support decision making'. This conference was organised by the ABS to provide a forum for the exchange of ideas between Commonwealth and state government agencies, data linkage units and consumers.

INTERNATIONAL COLLABORATIONS AND RELATIONSHIPS

The PHRN continued to have strong links with data linkage groups in the UK and Canada throughout 2011-12.

In September 2011 PHRN representatives from the Program Office and CDL had a series of meetings across Scotland and Wales with representatives from the Information Services Division Scotland and other Scottish/Welsh university researchers (Dundee, Glasgow, and Swansea) and presented on the functions and activities of the PHRN and the CDL.

Dr Felicity Flack, Manager of Policy and Client Services in the PHRN Program Office, had the opportunity as part of a prestigious Churchill Fellowship to visit a number of data linkage organisations in Canada including the Manitoba Centre for Health Policy Research, Population

Data BC and the Institute for Clinical Evaluative Sciences in Ontario. The visits enabled Dr Flack to gather information regarding the governance structures, data management processes and service delivery activities related to provision of linkable data for research purposes undertaken by each of these organisations which will be invaluable in feeding into the development of the PHRN infrastructure.

SA NT DataLink has been collaborating with the Scottish Health Informatics Program (SHIP), the Scottish Government Health Department and Dr Clive Hertzman from the University of British Columbia, Canada on various matters of mutual interest and benefit.

A strong international contingent was present at the International Data Linkage Conference in Perth in May 2012. This event provided an opportunity for PHRN delegates to network and share information with their international counterparts.

FINANCIAL YEAR IN BRIEF

The following table and diagrams provide a summary of PHRN income and expenditure for 2011-12.

Table 2: Financial Overview 2011-12

	PHRN NCRIS	PHRN EIF SSI	PHRN Total
	\$,000	\$,000	\$,000
BALANCE AS AT 1 JULY 2011	2,676	-	2,676
Income:			
DIIS RTE Cash Contribution	5,645	1,713	7,358
Cash Co-Investments	1,067	138	1,205
In-Kind Contributions	5,111	785	5,896
TOTAL INCOME	12,370	2,636	15,006
Expenditure:			
Salaries	5,291	702	5,993
Hardware and software purchases	92	433	525
Operating Expenses	569	-	569
Contractual & General Expenses	-	229	229
NCRIS expenditure sub-total	5,952	1,364	7,316
Cash Co-Investments Expenditure	1908	138	2,046
In-Kind Expenditure	4134	785	5,896
TOTAL EXPENDITURE	12,997	2,287	15,258
BALANCE AS AT 30 JUNE 2012	2,075	349	2,424

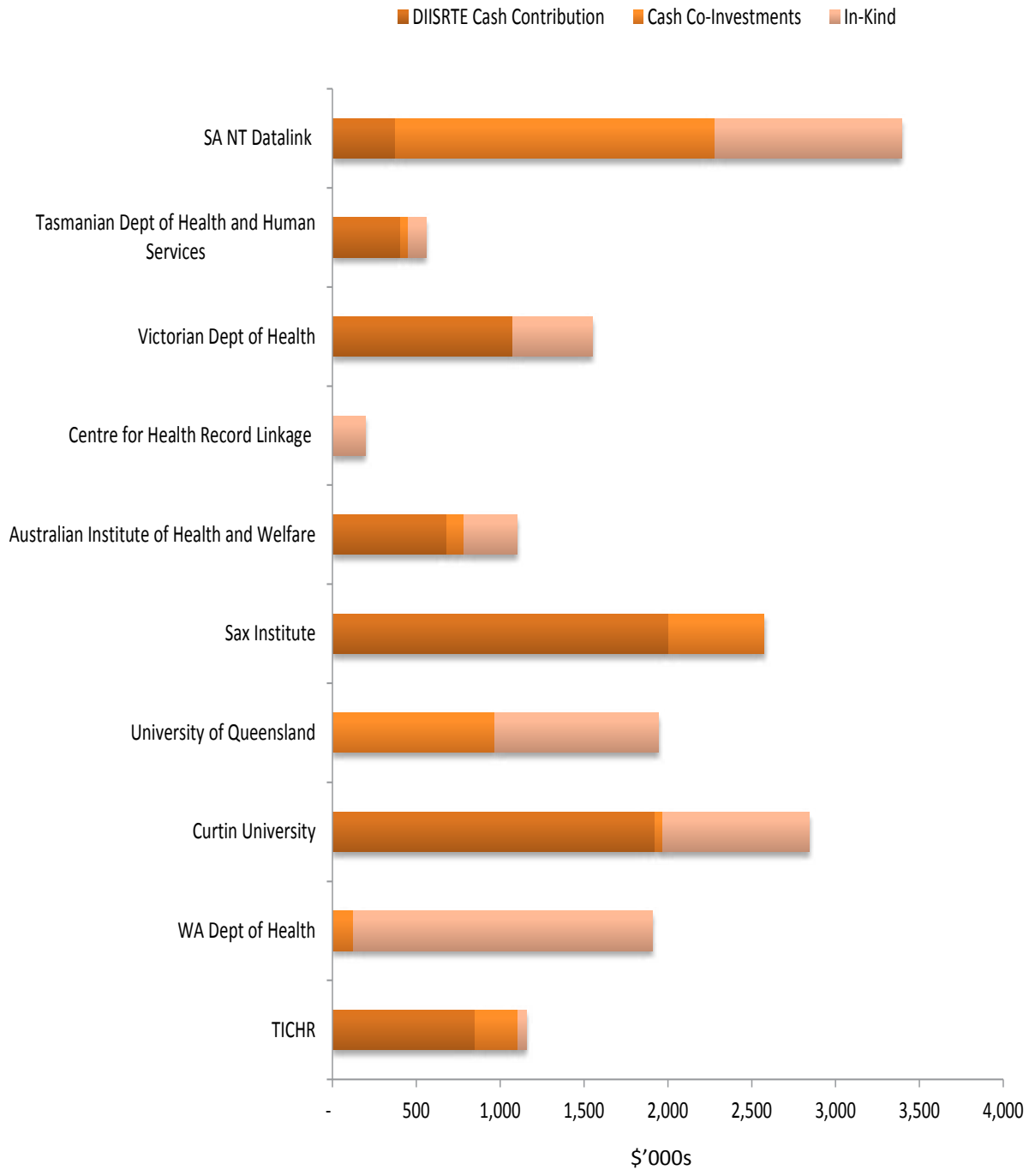


Figure 2: Investment by Project Participant 2011-12

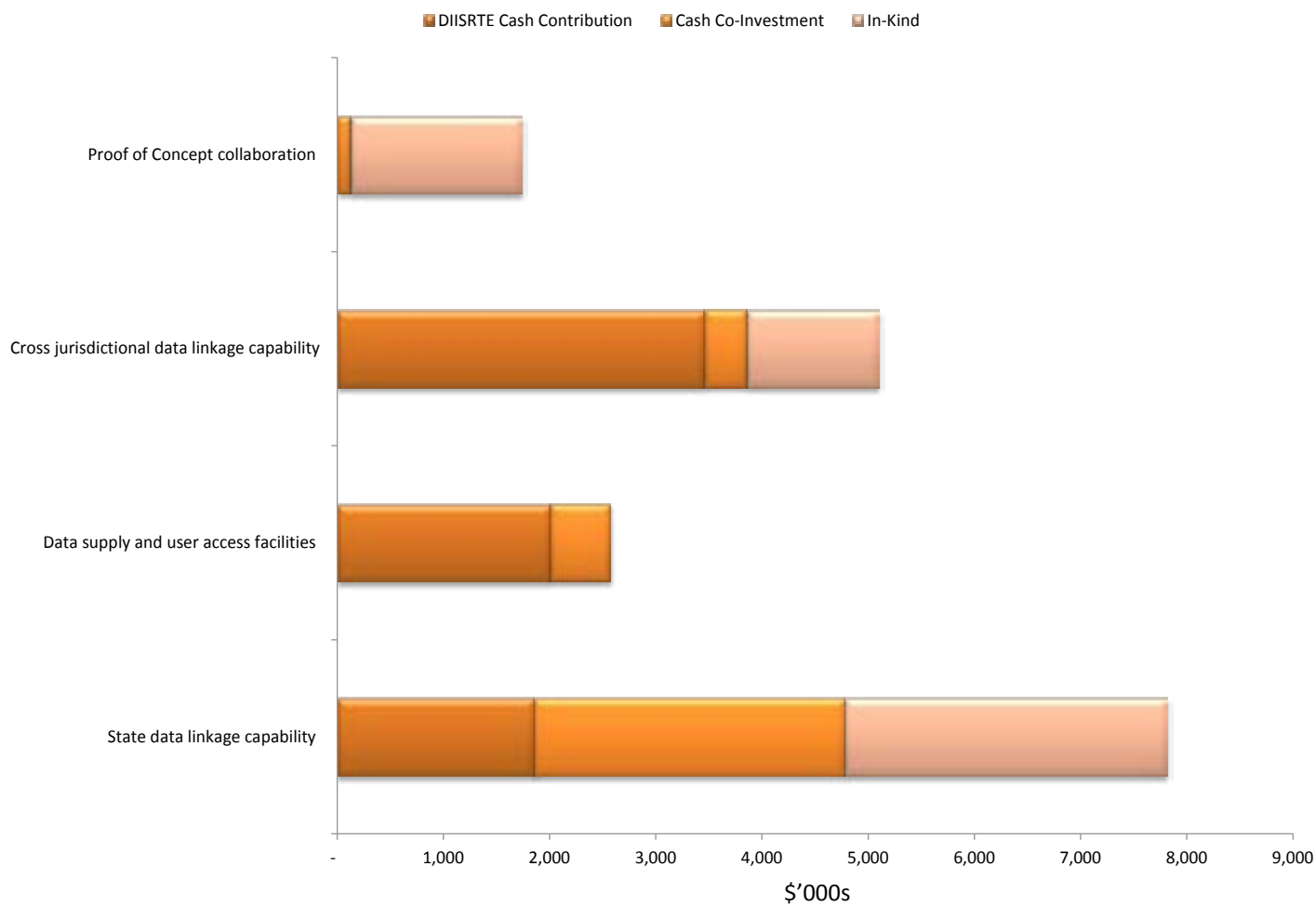


Figure 3: Investment by Kay Activity Area 2011-12.

