## Contents

1. Summary ................................................................................................................................. 3
2. Introduction ............................................................................................................................. 11
   2.1. Context for the Review ..................................................................................................... 11
   2.2. Panel Membership and Declarations of Interest ........................................................... 11
   2.3. Approach Adopted .......................................................................................................... 12
3. The Importance of a National Data Linkage Capability ...................................................... 13
4. Findings Mapped to the Terms of Reference ....................................................................... 15
   4.1. The extent to which the PHRN and its Participants have achieved the Network’s aims and objectives ......................................................................................................................... 15
   4.2. The extent to which expenditure represents value for money relative to the infrastructure and related processes that have been developed ........................................................................ 19
   4.3. The extent to which the new infrastructure has met or will meet the needs of researchers and policy makers for access to linked population level data within and between jurisdictions and sectors .................................................................................................................. 22
   4.4. The significance of the PHRN infrastructure in the national and international context .............................................................................................................................................................. 25
   4.5. The role of the PHRN in the future development of a distributed national data linkage infrastructure in Australia ................................................................................................................................................. 27
      4.5.1. Any changes in structures and processes to assist PHRN Participants to achieve the aims and objectives of current plans and agreements ................................................................................................................................. 27
      4.5.2. Options for further development and maintenance of PHRN and related data linkage infrastructure in the next 5 years, including potential future funding sources ........................................... 29
      4.5.3. The role of the PHRN in the development of Australia’s data linkage infrastructure in the next 5 years .................................................................................................................................................................................. 31
Appendix 1 – Written Submission Origins .................................................................................. 33
Appendix 2 – Additional Reference Resources .......................................................................... 34
Appendix 3 – Public Hearings Participants ................................................................................ 34
1. **Summary**

The Population Health Research Network (PHRN or the Network) was established in 2009 to enhance data linkage capacity, nationally and across jurisdictions, to support the creation of unique research intended to provide valuable information to people who work in and receive care from Australia’s health system.

PHRN was intended to leverage and learn from national data linkage capacity that existed at its inception when, in relation to Western Australia, it was internationally unique and recognised for its leadership and achievements for more than a decade. The Network has received significant funding (approximately $30 million since its inception up to June 2013) from the Commonwealth government through the Department of Industry, Innovation, Climate Change, Science, Research and Tertiary Education (DIICCSRTE) through the National Collaborative Research Infrastructure Strategy (NCRIS), Education Investment Fund Super Science Initiative (EIF-SSI) and Collaborative Research Infrastructure Strategy (CRIS). In addition, State and Territory governments, Commonwealth agencies, universities and research institutes have contributed a further $40 million in cash and in kind over the same period.

The Independent Panel was established in late 2013 to conduct a review of the PHRN on behalf of the Chair of the PHRN Management Council, the Lead Agent (The University of Western Australia), Project Participants and the major funding agency. The review is an independent assessment of progress to date by PHRN in establishing Australia’s national data linkage infrastructure as outlined in the PHRN NCRIS and PHRN SSI Project Plans, including key achievements, challenges and future opportunities. This assessment will also assist PHRN and its supporting agencies and institutions with strategic positioning for further infrastructure development in an uncertain funding environment.

To form its views, the Independent Panel members reviewed PHRN key documents, conducted a web-based survey, sought written submissions and held two full-day public hearings in Sydney and Melbourne. Importantly, the Independent Panel was simultaneously informed by views its members hold regarding: shifts in and current demand for data linkage capacity; the significance of PHRN infrastructure internationally; the perspectives of researchers and policy makers in relation to supply, need and demand for data linkage capacity; and the likely availability of and sources of funding in 2014 and 2015 to support data linkage infrastructure over the next 5 years.

The Terms of Reference of the review and summary comments by the Independent Panel follow:

1. **Term of Reference: Assess the extent to which the PHRN and its participants have achieved the Network’s aims and objectives**

The principal purpose of the PHRN is to build a nationwide data linkage infrastructure capable of securely and safely linking a broad range of population data collections. The infrastructure should enable researchers to access linkable data, in order to carry out nationally and internationally significant population based research to improve health and wellbeing and enhance the

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1 The major funding agency was known by a series of other names since 2009 and is currently the Department of Education.
effectiveness and efficiency of health services. Specifically, the Network and its participants aim to build upon existing data linkage capacity and expertise, focus on data linkage capacity in all Australian jurisdictions, provide technical support and training, facilitate research, enhance collaboration across health systems and consolidate existing collaborations for health data linkage activities. A full assessment of evidence of PHRN’s achievement in relation to its aims and objectives is provided in Section 4.1.

In relation to this Term of Reference, it’s the view of the Independent Panel that:

Today PHRN is a distributed network with national facilities and jurisdictional data linkage services. Many participants in the Network have made impressive improvements in nation-wide, inter-jurisdictional or jurisdiction technical capacity and staffing capability. This capacity is being used to facilitate research. Evidence was provided indicating that data has been provided for over 260 research projects in the four years to June 2013 and initial proof of concept work has been initiated to test and inform improvements to more complex components of the Network.

Therefore, the aim to build on existing data linkage capacity has been achieved, but to date that has not occurred in all jurisdictions. Prior to the establishment of PHRN, some jurisdictions had data linkage activities and others had no or little capabilities. Today, there remain jurisdictional participants in the Network that are either at a very early stage of development or as yet insufficiently developed. This brings into question the sustainability of their participation when current funding is expended.

Therefore, the aim to “consolidate existing collaborations” should be a priority and, given the remaining tenure of funding, might well become an immediate priority.

2. Term of Reference: Note the Network and participant certified statements of income and expenditure to 30 June 2013 (where available). Comment on the extent to which expenditure represents value for money relative to the infrastructure and related processes that have been developed

The Independent Panel found that researchers who participated in a small web-based survey view PHRN services as effective and Data Linkage Units/Services staff hold similar views. While survey participants were generally positive regarding their ratings of efficiency, these ratings were relatively lower than those for effectiveness. A full assessment of evidence of achievements in efficiency of PHRN and participant views of processes in meeting demand for linked data is provided in Section 4.2.

It’s the view of the Independent Panel that:

The extent to which expenditure represents value for money relative to the infrastructure and related processes that have been developed is difficult to ascertain, as the technical capacity and staff capability is now almost complete and researchers are just beginning to make fuller use of the new infrastructure. Accordingly, the benefits realisation phase of this large and important Australian investment has just begun. Full realisation of the benefits will require a national strategy to address issues of privacy and trust in relation to all data.
Efficiency gauged in terms of operational effort versus outputs would suggest that the PHRN has achieved significant technical milestones but has been less successful in resolving barriers to the timeliness of ethics committee approval of research projects and subsequent authorisation from data custodians (mostly governments) who must disclose data on a project-by-project basis before data linkage can occur.

Nevertheless, significant progress has been made and the infrastructure and processes now in place are sufficiently prepared that it is time for the Network to aggressively pursue and optimise return on investment via process improvements. It will be important to make benefits realisation a strategic priority now that infrastructure is in place.

It is the Panel’s view that the Network’s aims of “facilitating research” and “enhancing collaboration across health systems” are now of immediate priority, in order to gain most benefit from the investment so far, and to prepare for any exigency in regard to future funding.

3. Term of Reference: Review the extent to which the new infrastructure has met or will meet the needs of researchers and policy makers for access to linked population level data within and between jurisdictions and sectors

The Independent Panel heard that the extent to which the new infrastructure has met or will meet the needs of researchers and policy makers shows great promise but fundamental hurdles are yet to be overcome if full and timely national data linkage functionality by larger numbers of research teams is to be achieved. Streamlined processes for access to and delivery of data from government custodians on a project-by-project basis for linkage are widely acknowledged as an area of critical need by users and participants in the Network.

While access to linked data from a wide range of data collections has greatly improved since PHRN was established, it varies across the Network and the Panel heard often from researchers that access to Commonwealth data remains very difficult. Cross-border and cross-sectoral data linkage is now possible to some extent (a capacity that is relatively unique internationally) but timeliness is an emerging and pervasive issue. A full assessment of evidence of achievements in meeting demand for linked data is provided in Section 4.3.

It’s the view of the Independent Panel that:

The Network seems on the cusp of potential exponential growth in benefits realisation in relation to having built substantial technical capacity and staffing capability. The extent of collaboration across health systems (an aim of PHRN) has focused on building technical capacity to date. These collaborations across health system stakeholders seem underdeveloped in relation to (1) facilitating improvements in the authorising environments in which data linkage occurs, (2) optimising benefits realisation and (3) ensuring sustainability.
For example, there is a need for a Network-wide or jurisdiction-specific strategy to support establishment or enhancement of positive and productive collaborations with government officials, health system managers, clinicians and/or consumers. This is a major problem and needs to be addressed urgently since these health system managers are key data custodians and represent a key audience likely to benefit from information created by researchers who use linked data.

At the same time, there are impressive role models among Network participants in relation to positive and productive relations with government officials and health system managers. For example, the Independent Panel received written submissions and heard testimony at public hearings from senior health system managers in at least two jurisdictions (outside of WA) who praised and expressed strong support for the benefits of PHRN’s work, particularly in their jurisdiction. The Panel also became aware of impressive consumer engagement activities in at least one region.

The Independent Panel received no evidence that the PHRN had undertaken engagement in national or intergovernmental committees that oversee the creation and use of health information or national or intergovernmental committees most likely to benefit from work undertaken using capacity established by PHRN. It did not receive evidence either of strong linkages with clinical research groups or networks.

Given the multi-jurisdictional nature of the Network, a recent change in Commonwealth government (i.e. source of current funding), the importance of clinical research to patient care and the high importance of engaging consumers in privacy sensitive research, the aim of “collaboration with health systems” should be an immediate priority.

4. Term of Reference: Consider the significance of the PHRN infrastructure in the national and international context

In the international context, Australia has been and remains a leader in producing unique research that relies on data linkage and Western Australia, in particular, has held this reputation for decades. Importantly, these achievements in WA which have undoubtedly impacted health and services in Australia and abroad have accrued over time through continuous investment in technical capacity, staff capability and health system collaborations.

As described in the proceeding pages, the Network has successfully undertaken the first two features (technical capacity and staff capability), and now needs to work on efficiency of production and on the last feature (health system collaborations) to ensure it holds a future prominent position in relevant domestic and international arenas. A full assessment of evidence in relation to national and international significance is provided in Section 4.4.

It’s the view of the Independent Panel that:

Since 2009, Australia has significantly enhanced its technical capacity and staff capability nationally and regionally through the achievements of PHRN. More than one jurisdiction is
now poised to emulate the trajectory of Western Australia and, importantly, set its own unique trajectory both individually and as part of the Network.

More recently, the capacity and productivity of the NSW/ACT and Australian Institute of Health and Welfare (AIHW) participants seems poised for important contributions to Australia’s international recognition. The capacity in SA/NT seems very likely to follow this trajectory, though it is earlier in the process of delivering services to the research community. Both NSW/ACT and SA/NT seem to have pursued important key success factors such as: an appropriate balance of building technical capacity and personnel capability, strong collaborations with government data custodians to ensure the authorising environment remains supportive and does not thwart the efficiency of approval and linkage processes, enactment of strategies to facilitate demand and supply of data to researchers and policy makers and appropriate engagement of consumers to inform and address issues related to privacy.

Importantly, many research questions don’t need to be answered using data in the jurisdiction in which researchers live. This suggests that capacity built in WA, SA/NT, NSW/ACT and AIHW might be best placed to support researchers across the nation and, where appropriate to do so, conduct linkages for other jurisdictions (i.e. like NSW has done with ACT, and SA with the NT).

The technical knowledge among staff at the Centre for Data Linkage (CDL) seems internationally and nationally unique and valuable to future sustainability in relation to research and development on the topic of data linkage. Unfortunately, there remain concerns among some government data custodians regarding disclosure of sensitive data to this university-based participant. The challenge for the Network and this participant in particular, is to define and fund this unique contribution in relation to research and development on linkage issues and to support CDL in conducting linkages using data where it has authority to do so. Building this capacity at CDL will ensure that, for example, AIHW doesn’t remain the only source of supply for multi-jurisdictional data linkage. Alternatively, strengthening the relations between CDL and AIHW might be undertaken to create a single location for supply of multi-jurisdictional data linkage that can’t otherwise be done by other participants.

The engagement of AIHW and the Australian Bureau of Statistics (ABS) as participants in the Network appears to be a strategically wise undertaking, as their establishment as Commonwealth Integrating Authorities should enable researchers across the country to access data for which no other participants are yet able to receive authority (i.e. national survey data and Commonwealth health service data).

AIHW expressed that it was keen to expand its offerings to Network participants and researchers nationally. It seems strategically wise to support AIHW in pursuit of that agenda, given its uniquely placed role to access Commonwealth health service data and these data are deemed high priority by many researchers. Additionally, the AIHW has a long, productive and positive history of collaborative interactions with the health system, government data custodians in particular.
The infrastructure and collaborations established are poised to achieve domestic and international recognition if the PHRN becomes more strategic as it enters the consolidation and operational phase of its establishment. In essence, the next challenge is to consolidate the above-mentioned technical capacity and staff capabilities that are poised for sustainability and more fulsomely embrace the next operational phase of establishment which should involve: (1) clearing gridlock in the authorising environments within relevant governments (work on efficiency of production) to improve the user experience; (2) communicating and collaborating with health systems about the services now available from each participant and (3) nurturing demand.

The international community will recognise Australia’s accomplishments via PHRN only when published high quality research becomes known and is used to improve policy and practice. It would appear there are many participants in the Network who remain predominantly focused on continuing efforts to build technical capacity or on collective efforts to gain access to particular data (e.g. Commonwealth health service files). Given that the value of PHRN work to date is predicated on realising the benefits of current infrastructure, the Network’s aim of “facilitating research” is now an immediate priority. This must include a clear “value proposition” for the potential future funding sources.

5. Term of Reference: Consider the role of the PHRN in the future development of a distributed national data linkage infrastructure in Australia. Issues to be considered include:

5.1. Any changes in structures and processes to assist PHRN Participants to achieve the aims and objectives of current plans and agreements

The majority of interviewees recommend or agree that changes are required in structures and processes to improve the performance of the Network and to optimise benefits to researchers and, ultimately, to Australians.

It’s the view of the Independent Panel that:

In the next phase of establishment, the Independent Panel suggests the Network should take immediate actions to improve the governance, performance and sustainability of the Network. This is needed to increase the likelihood that optimal benefits will accrue to researchers across Australia and, through their work, to the health of Australians.

The opportunity now exists for the Network to consolidate as a national capability and to leverage its considerable expertise across the Network, and this opportunity should include a process of rationalising and potentially reallocating investments into areas where capacity is strongest and most likely to be sustainable, and expected return on investment is the highest.

It is anticipated that some in the PHRN will disagree with this as they are focused to date on building the technical capabilities. However, the Independent Panel feels strongly that changes are needed if the nation is to benefit from the considerable investments already made.
The Management Council was established to oversee the creation and early operations of technical capacity and staffing capability and its composition was well suited to that initial task. This is no longer the case. The Independent Panel concluded that the lack of independence of members in relation to resource allocation decisions makes the current Council composition ill-suited to the above mentioned task of consolidation and strategic development. Moreover, a different composition of members seems appropriate if PHRN shifts its strategic focus now to facilitating research and collaborations across the health system. Decisions of this nature should be made by individuals in independent, impartial governance positions.

If PHRN were to fully shift to a consolidation phase that focused more on efficiency of operations\(^2\) to improve the user experience to facilitate research and support collaborations with health system stakeholders, it may be fruitful to move to an independent board governance arrangement. Membership might include an independent chair, one senior researcher, one health system manager, one consumer, one national and two jurisdictional participants in PHRN. This type of board should be supported by the Program Office and the Management Council’s Terms of Reference should therefore be amended or it might be transformed into a Scientific Advisory Committee or similar.

Strategic leadership from an impartial, invigorated governing body is urgently required if the Network is to pursue consolidation with a focus on realising benefits from the infrastructure and to catalyse the necessary support within government(s) to facilitate data access for research and, potentially, to garner sustainable funding.

Given the length of time it takes for benefits to accrue from shifts in governance and structure and in consideration of the remaining term of PHRN’s existing funding, decisions regarding new governance and management arrangements are clearly an issue for the funding Commonwealth Department (Education), independent Chair and the University of Western Australia to explore urgently.

### 5.2. Options for further development and maintenance of PHRN and related data linkage infrastructure in the next 5 years, including potential future funding sources

Ongoing funding for Australia’s data linkage infrastructure and services is a serious concern among most participants. A full assessment of evidence regarding these concerns is provided in Section 4.5.2.

It’s the view of the Independent Panel that:

The Network participants seem focused, naturally, on completion of funded commitments to technical capacity and staffing capability. This is not surprising given the contractual

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\(^2\) This operational phase of establishment might include a focus on: (1) clearing gridlock in the authorising environments within relevant governments (work on efficiency of production) to improve the user experience; (2) communicating and collaborating with health systems about the services now available from each participant and (3) nurturing demand.
arrangements each participant has with the University of Western Australia and, in turn, the Department of Education.

However, there is now an urgent need for a Network-wide strategy to identify and pursue future sources of sustainable funding from public and/or private sources. The Panel is concerned that members of the Management Council do not appear to have identified this need to develop support for transitioning to a period of consolidation and future growth and sustainability, at completion of funded work.

An important agenda of an independent board would be the identification and pursuit of sustainable funding for the Network. An important agenda for each participant should be to pursue its own sustainable funding strategy to ensure that the unique capacity nationally and in each jurisdiction is sustained as each participant enters its benefits realisation phase.

5.3. The role of the PHRN in the development of Australia’s data linkage infrastructure in the next 5 years

It’s the view of the Independent Panel that:

Different starting points and circumstances for the various facilities and services have led to significant disparity in maturity across the Network. Together with the successive funding arrangements under which the infrastructure has been built, this has largely resulted in the PHRN developing as a loose association of nodes (with inherent governance and standardisation challenges) rather than a close-knit organisation. As the Network moves from an establishment to an operational phase, there does not yet appear to be a shared vision of how Australia’s data linkage capability should best be delivered. Funding, governance and indeed leadership are critical determinants in PHRN’s future.

PHRN’s future role in realising the benefits of population based research using linked data is critically dependent on the development of governance and management that aligns with an increasing need to “facilitate research”, “collaborate with health systems” and identify and pursue a sustainable funding model. The PHRN must evolve and mature to meet the significant challenges that exist as the demand for population based linkage services increases.

There are now broader opportunities for data linkage between policy and program agencies and across sectors and jurisdictions than was envisaged when the PHRN was conceived. However, effective leadership is required to overcome the obstacles that remain and achieve buy-in from all relevant stakeholders. If it can do so, the PHRN will be well placed to coordinate and develop data linkage in Australia for the next 5 years.
2. Introduction

2.1. Context for the Review

The Population Health Research Network (PHRN) was established in 2009 to provide Australian researchers with data linkage facilities of international standard covering a diverse and rich range of health and health-related datasets across jurisdictions and sectors. Today the PHRN is a distributed network with national facilities and regional data linkage services in each Australian State. It has received significant Commonwealth funding ($30 million since its inception in March 2009 to June 2013), a requirement for which included a program review, as well as a further $40 million in cash and in kind over the same period from State and Territory governments, Commonwealth agencies, universities and research institutes. The PHRN has funding for another 15 months with no guarantee of government funding beyond and so the sustainability of this vital data linkage capability is in question.

With the change of Government in late 2013 comes an inevitable re-examination of government priorities. The purpose of the Review is to provide funders and other stakeholders with an independent assessment of progress to date by PHRN in establishing Australia’s national data linkage infrastructure. The Review addresses the Network’s key achievements, challenges and future opportunities according to specified Terms of Reference.

2.2. Independent Panel Membership and Declarations of Interest

Chair:
Prof Warwick Anderson
Chief Executive Officer, National Health and Medical Research Council

- CEO of NHMRC and the Council funds extensive research that requires data linkage
- Member of the NCRIS committee that made the original recommendation to fund a PHRN
- Member of the CRIS Universities Australia-Government Consultative Group that recommended extension funding for the PHRN
- NHMRC’s Principal Committee on Prevention and Community Care is currently developing a principles paper for on data linkage for research

Members:
Prof James Best
Head, Melbourne Medical School, University of Melbourne

- Head of the Medical School at the University of Melbourne, where data linkage is used by academic staff in their research activities
- A tool for secure data collection and linkage, known as GeneRic Health Network Information Technology for the Enterprise (GRHANITE™), has been developed by Dr Douglas Boyle a member of the Medical School’s academic staff
- The University of Melbourne is a member of Biogrid Australia, a company that operates a federated data sharing platform for collaborative translational health and medical research.
Professor Fernando Martin-Sanchez is a director of the company and a member of the academic staff of the Medical School

Dr Diane Watson
Chief Executive Officer, National Health Performance Authority

- CEO of the National Health Performance Authority (NHPA) which monitors and reports on the performance of public and private hospitals and primary health care organisations. NHPA will, on occasion and in the future, rely on linked data to fulfil its statutory functions. NHPA does not seek linked data from PHRN due to the Network's role to support the research community, does not require external sources of funding to access and use linked data to fulfil its statutory functions and does not supply the research community with linked data to conduct their work
- Member of the National Health Information and Performance Principal Committee which is currently developing a Data Linkage Framework at the request of health ministers
- Member of the National Health Information Strategy Committee of the Australian Commission for Safety and Quality in Health Care

2.3. Approach Adopted
Information for the Review was gathered from as many stakeholders as possible using a three phase exercise comprising:

a) Survey of PHRN Stakeholders

Fifty eight responses to a 15 question survey that related to the PHRN Review’s terms of reference were received. Researchers were the largest group represented (55%), followed by Data Linkage Units/Services (33%). Neither Consumer & Community nor Data Custodians were represented in the Survey respondents.

b) Written submissions

Twenty submissions to the Independent Panel were received and are listed in Appendix 1. Additional reference material taken into account by the Panel is listed in Appendix 2.

c) Public Hearings

The Independent Panel conducted public hearings in Sydney on Thursday 6th February 2014 and in Melbourne on Monday 10th February 2014. Fifty eight interviews were conducted with the key stakeholder groups either face-to-face or by teleconference or in combination. A list of the participants in the public hearings is given in Appendix 3.
3. The Importance of a National Data Linkage Capability

We live in the Information Age in which electronic collections of information about every sort of human activity abound. In the public arena, service delivery organisations and agencies, including hospitals (public and private), health departments, schools and other government agencies routinely record data about every individual they come in contact with. The collection of this administrative data is often required under legislation and, in Australia, the information is stored in secure computer databases within the responsible agencies.

It has long been recognised that such data can be mined for useful targeted information, even more so if data collections can be accessed across Government departments and sectors. The process of data linkage makes routinely collected administrative data potentially accessible for research in ways that protect the identification of individuals, while providing a sound evidence base to inform research, and policy development as well as service planning, implementation and evaluation.

The power of data linkage is that it provides clear insight and a completely unbiased picture of an entire population. It makes optimum use of the information currently being collected or which could be collected at modest additional cost. Data linkage can yield larger sample sizes with potentially higher quality data and is more cost-effective than studies which involve direct data collection (e.g. surveys). The large scale of data linkage studies means that events which are relatively unusual can be captured. Data can be re-used and linked in different ways to answer different research questions. They can also be used to enhance data collected by more traditional methods. Data linkage also enables studies to be done that could not otherwise be performed when direct data collection is impossible for technical or ethical reasons.

Governments in the UK, Europe and North America have long recognised the importance of public sector data and linkage and are investing heavily in relevant infrastructure. For example, England, Wales, Scotland and Northern Ireland have recently instigated the development of an Administrative Data Research Network to strengthen the UK’s competitive advantage in Big Data by facilitating linkage of routinely collected administrative data, such as tax, education and health data, thereby stimulating opportunities for innovative research and policy-making.

The Australian Government is also advocating a Big Data agenda and the Productivity Commission has strongly supported the use of publicly funded data for research, health-services provision and evidence-based policy development. Through the establishment of the PHRN, Australia is positioning itself to capture benefits from data linkage and focussing on the health system. Why health? Health care is one of the fastest growing areas of government spending, currently costing Australians an estimated $140 billion a year. Australia also has rich data sources on the health of the population that include outcomes, risk and protective factors for disease (both health and social determinants), and services received (such as drugs, tests, hospitalisations etc.). In the words of Professor Fiona Stanley AC, FAA, FASSA, Australia’s data sources “are of high quality in terms of availability of information, coding of diseases and geocoding – all of which enable excellent capacity to describe

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our disease status in population sub-groups, by areas, look at trends and clusters and to investigate whether risk and occurrence of disease is improving or not and why. This capacity is becoming even more exciting and relevant as genetic information to better classify phenotype and risk is added in to these data sets.”

Analysis and understanding of these data sets can be used to improve the efficiency and performance of health organisations, lead to new treatments or better patient outcomes, or support translation from bench to bedside.

Despite the undisputed benefits offered by data linkage, publically funded administrative data are grossly under-utilised in this country. A root impediment lies in Australia’s federal system which makes it necessary to link data between different legal jurisdictions to achieve the full benefits of population research. Little cross-jurisdictional data linkage is yet undertaken in other countries and it is notoriously difficult to achieve. The problem of cross-jurisdictional data linkage is particularly pertinent for the Australian health system, in which funding is split across both Commonwealth and State agencies, separating highly synergistic datasets into different jurisdictions. Another difficulty Australia faces is the lack of a usable, unique common identifier (such as a social security number) which makes the use of much more sophisticated techniques and specialised software essential to enable effective and accurate data linkage. Finally, a high guarantee of privacy protection is also fundamental in the data linkage process especially across jurisdictions and underpins the third, and perhaps most complex, requirement: the development of trust between data custodians, researchers and other interested parties including the public.

This combination of factors led to the establishment of the PHRN as an overall coordinating body for data linkage in this country. The resultant infrastructure provides a safe and secure system for linking, managing and analysing administrative data. There is now a significant opportunity to increase its efficiency and broaden the way it is used in a health research agenda and beyond into other arenas and across public and private sectors.
4. Findings Mapped to the Terms of Reference

4.1. The extent to which the PHRN and its Participants have achieved the Network’s aims and objectives

a) Survey Findings
The balance of opinion across all respondents to the recent Stakeholder Survey as to the extent to which the PHRN has achieved its purpose tips towards partially achieved (42%) followed by mostly achieved (32%). Data Linkage Units/Services respondents were more positive on this point than either researchers or the remaining grouped respondents. Five (16%) from the researcher group felt the PHRN has not achieved its purpose.

b) Written Submissions Findings
The aims and objectives of the PHRN are encompassed in its Program deliverables as follows.

i. Build upon existing data linkage capacity and expertise in particular jurisdictions and in specific aspects of health data collection and management
The following table from the Program Office shows the infrastructure supported by successive programs.

<table>
<thead>
<tr>
<th></th>
<th>DATA</th>
<th>DATA LINKAGE</th>
<th>ACCESS TO LINKED DATA</th>
<th>ENHANCING LINKAGE/ACCESS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-PHRN</td>
<td>State/Territory data</td>
<td>WA, NSW/ACT</td>
<td>Encrypted physical media</td>
<td>Some State/Territory metadata</td>
</tr>
<tr>
<td></td>
<td>(2 States)</td>
<td></td>
<td></td>
<td>Some training Geocoding</td>
</tr>
<tr>
<td>PHRN (NCRIS)</td>
<td>State/Territory data</td>
<td>WA, NSW/ACT, QLD, SA/NT, TAS, VIC CDL</td>
<td>NSW/ACT SURE Data Delivery System</td>
<td>Enhanced State/Territory metadata National training program Analysis tools Geocoding</td>
</tr>
<tr>
<td></td>
<td>(all States)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PHRN (EIF Super Science)</td>
<td>State/Territory data (all States)</td>
<td>WA, NSW/ACT, QLD, SA/NT, TAS, VIC CDL, AIHW</td>
<td>National SURE AIHW Data Access Lab Extracts Server (CARES)</td>
<td>National metadata repository Web-based applications Data feed automation</td>
</tr>
<tr>
<td></td>
<td>Commonwealth data</td>
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</tr>
</tbody>
</table>

There has been a significant increase in data linkage capacity as a result of the new infrastructure. The approach has been to establish data linkage capability in jurisdictions where none previously existed and build upon existing capacity elsewhere. In addition to the establishment of new regional and national data linkage units the PHRN has also developed policy, frameworks, agreements, a secure laboratory and secure data exchange system, and has ensured linkage is done with privacy preserving methods. As a result, the Network has substantially expanded its overall experience and proficiency at a regional and national level.
The opportunity now exists for the Network to consolidate as a national capability and to leverage its considerable expertise across the Network.

ii. Establish a new focus on data linkage capacity in all Australian jurisdictions

Since the establishment of the PHRN in 2009, four new regional data linkage units have been developed (Queensland Research Linkage Group, South Australia/Northern Territory DataLink (SA NT DataLink), Tasmanian Data Linkage Unit [TDLU] and Victorian Data Linkages [VDL]).

Not all are developed to the same degree. SA NT DataLink was supported by a strong and committed consortium from its inception and has progressed well to now being able to deliver a high quality service. The other three regional units have been slower to attain functional linkage systems for a variety of reasons that have made progress difficult but all have emerging capability.

At a national level, one new national data linkage unit (CDL) has been established and one Commonwealth agency (AIHW) has been accredited as an Integrating Authority. The technical infrastructure to enable cross-jurisdictional linkage has now been built but only the AIHW has the authority to link Commonwealth data and therefore has called into question amongst users CDL’s role as a national data linkage unit. However CDL has clear utility in cross-jurisdictional data linkage that excludes Commonwealth data as was demonstrated in Proof of Concept (PoC) Collaboration #1, one of the largest ever constructed linked datasets linking 45 million records from four States.

iii. Provide ICT support, workforce training and development, data management and custodianship, analytic capacity and coordination among data linkage centres, to support Australian researchers undertaking probabilistic linkage of datasets relevant to the health and wellbeing of the Australian population

The CDL has been integral to, albeit by no means the only contributor to, the technical development and support functions of the PHRN and its technical expertise is widely acknowledged and sought after by Network participants. The unit is renowned in areas including but not limited to linkage software systems, methods and models, development of QA tools, data cleaning and standardization.

It was a requirement that researchers, health consumers and the community have access to information about the national data linkage infrastructure. The PHRN website provides a range of information resources to address these information needs.

Training coordination is under the remit of the national Program Office but limitations within the funding agreements have restricted what could be achieved. The following training programs have been established:

a) for PHRN Participants (on consumer and community participation), workshops in Adelaide, Melbourne, Sydney and Canberra attended by 61 people
b) for ethics committees (on data linkage), workshops in Perth, Adelaide, Sydney, Canberra and Hobart attended by 136 people, and
c) for end-users (SURE training), delivered as an online training package.
iv. **Facilitate research into health determinants, organisation and delivery of health services, health status and health outcomes in the population and non-health fields that impact upon health and vice versa**

This infrastructure has enhanced Australia’s ability to conduct high-quality, internationally competitive research and many significant jurisdictional and, to a lesser extent, cross-jurisdictional projects are now being conducted. From a technical perspective the required systems are in place but the non-physical requirements for data linkage to occur have not kept pace with the physical infrastructure development. The authorising environment for data linkage work in Australia is complex and there are significant jurisdictional differences in governance, policies and priorities across the Network. Nevertheless, since the inception of the PHRN to June 2013, 287 research projects have received ethics and data custodian approvals and data has been provided to 264 projects.

From a practical perspective, data access for research purposes is still limited especially for projects involving data from multiple jurisdictions, with unduly long timeframes and onerous processes to navigate. Data linkage across Commonwealth and State/Territory systems is particularly difficult, if not impossible outside government circles.

From an operational perspective, progress has been made to establish consistent protocols and procedures across the various jurisdictions but more work is needed to standardise application forms and streamline processes to facilitate researcher access to linkable data. To this end the Program Office is developing an online cross-jurisdictional application system and drafting updated information for researchers and data custodians to be provided on the PHRN website.

v. **Enhance collaboration across health systems, public and private health services and agencies that run health systems and provide mainstream health information**

There is little evidence of enhanced collaborations across health systems, let alone with public and private health services and agencies at this stage of the infrastructure’s development. This is probably a function of the highly variable understanding of the data linkage landscape amongst senior government officials and could be expected to develop as the benefits of data linkage become more widely sought after. The Proof of Concept projects are tangible examples of the benefits derived from developing new collaborations between health departments and agencies.

vi. **Consolidate the collaborations that already exist among groups in Australia already engaged in health data linkage activities**

The development of the PHRN infrastructure has inherently consolidated existing collaborations for health data linkage and established new connections as the new regional and national elements of the Network became functional. Some examples are that CDL, AIHW and SURE have actively collaborated to deliver new infrastructure and services and share acquired knowledge, SA NT Datalink and TDLU have forged a new connection and the Program Office has supported the Queensland node in resolving establishment issues.

The PHRN has become actively involved in expanding capacity and benefits from long-term studies such as the Australian Longitudinal Study on Women’s Health but perhaps the most ambitious collaborations for health data linkage activities to date are embodied in the Proof of Concept projects, designed to test different aspects of the Network’s activities. These large and complex
studies have all have experienced delays while the infrastructure was being built (only PoC#1 is largely completed) and, in addition to the anticipated valuable research outcomes, are yielding useful information by revealing areas for improvement in the cross-jurisdictional data linkage process.

c) Public Hearings Findings

Australia has a distributed national health data linkage capability servicing all States and Territories and can also now do cross-jurisdiction linkage of very large datasets. Usage of the PHRN infrastructure has grown in accordance with the availability of service: the more established nodes are participating in cross-jurisdictional projects and are seeing larger, more complex project applications; whereas the newest data linkage unit, in Tasmania, has only recently received the linkage variables it requires enabling provision of data. Different starting points and circumstances for the various facilities and services have led to a large disparity in maturity across the Network. Together with the complex funding arrangements under which the infrastructure has been built, this has largely resulted in the PHRN developing as a loose association of nodes (with inherent problems) rather than a close-knit organisation.

Feedback on the factors inhibiting PHRN from fully achieving its aims points, in the view of interviewees, to:

- jurisdictional differences in governance, policies and priorities obstructing data flow (particularly Commonwealth data)
- potential structural and/or resourcing impediments within the Network
- the need for better engagement at senior levels to resolve issues and enhance collaborations
- a stronger emphasis needed across the Network on consumer and community conversations and spreading the ethos that data linkage is “important for Australians and it’s about Australians”
- the need for greater clarity around the roles, responsibilities and relationships of the national data linkage services
- competing intra-government data linkage systems (examples include the integrating authorities and established relationships such as Queensland Health preference for exclusive use of AIHW for linkage that is cross-jurisdictional or national)
4.2. The extent to which expenditure represents value for money\(^4\) relative to the infrastructure and related processes that have been developed

a) Survey Findings

Stakeholder Survey respondents overall considered PHRN services to be effective. Over 80% of researchers responding to this question reported the services received as very effective (71%) or moderately effective (9.5%). Data Linkage Units/Services respondents agreed (73% very effective, 18% moderately effective).

Efficiency of services, while generally positive, rated slightly lower than effectiveness in that a lower proportion of respondents rated services as very efficient (44%). One third (33%) rated the services received as moderately efficient, 17% as partly efficient and two (from the research category) as not efficient.

b) Written Submissions Findings

i. Effectiveness

The Program Office reports that the outcomes identified in the PHRN NCRIS and EIF-SSI investment plans have largely been achieved and the infrastructure is being used by government and university researchers to address issues of importance to the Australian health and human services systems.

The considerable technical accomplishments in delivering accurate, reliable, load-bearing data linkage infrastructure and services have positioned the PHRN strongly for meeting health data linkage demands. The Secure Unified Research Environment (SURE), a secure remote-access computing environment, is gaining recognition as a preferred process for allowing 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, has been verified through an independent security review and penetration test in 2013.

Many of the written submissions acknowledged the complexities in building such infrastructure however the burden to researchers and custodians in accomplishing data flow is perceived to be an ongoing stumbling block to achieving the Network’s translational research objectives.

ii. Efficiency

Initiatives such as automated data feeds to improve efficiency have been implemented at the Centre for Health Record Linkage (CHeReL), NSW/ACT, and the development of more sophisticated tools for data extraction and transfer elsewhere have made efficiency gains. On the other hand, operational processes are widely reported to be overly onerous (see Section 4.5.1) and streamlining and simplification is required in order to increase ease of data access and timeliness of services and improve researcher experiences using PHRN infrastructure.

\(^4\) The UK National Audit Office defines Value for Money as the optimal use of resources to achieve the intended outcome. It uses three criteria in the assessment: Effectiveness (outcomes achieved), Efficiency (inputs vs. outputs) and Economy (minimising cost of outputs). ([http://www.nao.org.uk/successful-commissioning/successful-commissioning-home/general-principles/value-for-money/assessing-value-for-money/](http://www.nao.org.uk/successful-commissioning/successful-commissioning-home/general-principles/value-for-money/assessing-value-for-money/))
The point has also been made that the data linkage systems in the States and Territories allow enduring linkages that facilitate extraction of high quality, large linked datasets (and related control groups when required) and support monitoring of population trends over a number of decades. Cross-jurisdictional projects and Commonwealth Integrating Authority projects however are subject to a “create and destroy” linkage system which is considered of less value to the nation than ongoing linkage could be.

### iii. Economy

The Program Office has presented data to show that PHRN expenditure (2009-1012) was 0.006% of total Australian Health Expenditure and 0.17% of Australian Health and Medical Research Expenditure. It argues that the expenditure on Australia’s data linkage infrastructure is modest in comparison to the benefits the infrastructure is delivering and has the potential to deliver into the future.

The Commonwealth investment into the PHRN of $30 million since 2009 has been boosted by additional co-investment of $11 million in cash to June 30 2013 plus circa $32 million of in-kind contributions. These significant co-contributions by stakeholders strongly demonstrate the perceived value of the PHRN infrastructure.

The return on investment in PHRN can be summarised in the following:

- New linked data collections in every Australian State and Territory covering decades of health and other human services data
- Research supporting infrastructure, including hardware and software
- Critical mass of skilled personnel focussed on linkage; technical operation and research skills required to run the systems
- Governance structure established across Australia, including principles, policies and processes
- Important outputs from research and related policy outputs using linked data

On a local basis, benefits accruing to hosting organisations include:

- for the government sector, enhanced planning, management and monitoring activities
- for the university sector, opportunities to extend population health research using linked data, to foster new collaborations and to further engage higher degree students

The majority of PHRN NCRIS and EIF-SSI funding went to the State and national data linkage units. While such investment was necessary to achieve the objective of data linkage capacity in all Australian jurisdictions, questions have been raised about State jurisdictions receiving funding for a node with the primary, or at least initial, aim of meeting local needs. In the case of Queensland it appears that PHRN funds were vital in developing data linkage infrastructure and in linking core datasets that would not have otherwise been possible in light of severe State-funding cutbacks.

### c) Public Hearings Findings

Demand for data linkage is growing from both government and the research community in Australia and the return on investment into PHRN can be expected to increase now that the essential building blocks are in place and as researcher and data access is facilitated. There is a strong focus across the Network on linking additional data collections into the infrastructure with linkage to Commonwealth
data perceived to be the most important or valuable goal. The PHRN relied on the Proof of Concept Collaborations to show the benefits of the infrastructure but that outcome has been more drawn out than was hoped for.

While efficient and effective data linkage using both Commonwealth and State and Territory data has yet to be realised, return on investment may be readily demonstrable through:

- availability of new datasets
- much bigger capacity nationally and cross-jurisdictional capability resulting in much bigger and more complex projects being undertaken than pre-PHRN
- SURE providing a secure and trusted environment that facilitates between-State linkages such as hospital files as well as a providing a single place to access data and allow data to be shared by collaborators
- improved timeliness in some areas. For example, in NSW infrastructure development completed in January 2014 has made recent data quickly available (12 weeks compared with 18 months old). Moreover the upgrade has enabled the systems to get both bigger and faster without trade-off enabling double the input of records at the same cost.
4.3. The extent to which the new infrastructure has met or will meet the needs of researchers and policy makers for access to linked population level data within and between jurisdictions and sectors

a) Survey Findings
Stakeholder Survey respondents thought the new infrastructure will meet the needs of researchers and policy makers fully (19%) or mostly (40%). Five percent thought it would not meet their needs or only partially (17%). Respondents from Data Linkage Units/Services were possibly better informed about the new infrastructure than the other categories which contributed to the 17% of respondents with no knowledge of infrastructure plans.

b) Written Submissions Findings

i. Access to linked data from a wide range of data collections
Improved access to linked data through PHRN infrastructure is demonstrated by the number of records linked into master linkage files and for specific projects and by the increasing number of approved projects and data provided for approved projects since 2009. The number of data collections routinely linked at a regional level has increased. Datasets across a wide range of topic areas are now accessible, many of which could not be accessed previously or accessed only with difficulty.

Jurisdictional priorities differ widely and have implications for the support for data linkage systems and activities. While cross-jurisdictional linked data are now available on a project-by-project basis, the process is more complex and lengthy than for intra-jurisdictional projects. The role of data custodians is singled out as one of the most critical barriers to data access particularly for cross-jurisdictional data linkage. Though many data custodians have experience in jurisdictional data linkage projects, few have been involved in cross-jurisdictional data linkage projects and decision-making is consequently adversely affected. Furthermore, the capacity of data custodians to meet the increasing demands for data access per se limits the efficiency of the data linkage process. The national data linkage centre, CDL, being university-based lacks sufficient statutory protections for some State-based data custodians to send their data or for Commonwealth data integration. Access to Commonwealth data can only occur through an Integrating Authority and integration of Commonwealth data with State/Territory datasets is the most problematic of all. The AIHW is the only authorised Integrating Authority in the Network that can access Commonwealth health service files (MBS and PBS).

ii. Information about data collections and how to access them
While information about data collections and how to access them is available on each regional data linkage unit website and also on the PHRN website, more could be done to develop a more coordinated and user-friendly approach to increase awareness of how to access PHRN and best use available resources.

iii. Streamlined processes for access to and delivery of linked data
This is an area has been identified as a critical unmet need. A number of initiatives have begun but the benefits are yet to flow into and across the Network including:

- automated data feeds (implemented for admitted patient data January 2014 in NSW)
iv. Training programs around analysis and secure access to data

The PHRN has developed a mandatory online training program for researchers for access to the SURE and provides information about other training programs (in Australia and overseas) on the PHRN website.

v. Best practice privacy protection

Best practice privacy protection for linked data is of high importance to Commonwealth, State and Territory governments and is an essential pre-requisite to using their substantial data resources to develop services and provide better policy advice.

The PHRN has enabled the establishment of a national system and practices to ensure a consistent approach to the protection of personal information at technical, policy and procedure levels. This is of considerable benefit to researchers whose research focus crosses or will cross jurisdictional boundaries.

The submission from the Information and Privacy Commission (NSW) affirms that the current privacy protection arrangements of the PHRN represent good practice in that state and appear to meet the requirements of the State’s Health Records and Information Privacy Act 2002.

c) Public Hearings Findings

A number of data linkage units report an increase in government use of their services though university research projects are more prevalent. Policy makers are better placed to utilise the data-linkage infrastructure because of their within-government location but researchers are more likely to have the requisite skills. Unfortunately data access for researchers still requires much patience and tenacity. Issues around risk-averse data custodianship and multiple lengthy ethics approvals processes abound. A contributing factor is lack of experience with data-linkage projects particularly cross-jurisdictional and cross-sectoral ones: authorising agents need to learn from scratch where it hasn’t been done before but timeliness of approvals and data extraction improves as experience grows; conversely, frequent turnover of staff hampers the accumulation of knowledge and decision-making confidence. Wider community engagement such as is occurring in WA and SA in particular is perceived to be important to building support for the use of publicly funded data.

A wide-held view is that good ethics review needs specialist data linkage committees. It has been suggested that use of a small number of specialist committees for all data linkage approvals would result in extensive experience that would enable them to get recognition of their expertise (NH&MRC registration) allowing a move to single review.

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5 As assessed from figures for number of approved applications and number of projects where data was provided by year and applicant type.
Researchers have identified the following needs:

- Commonwealth data and cross-border data access for researchers
- change from project-by-project governance; ability to re-link data without approvals
- central agencies and data repositories
- process to report the quality of linked datasets which is critical in understanding the outputs
- standardised and systemised processes and methodologies
4.4. The significance of the PHRN infrastructure in the national and international context

a) Survey Findings
Almost two-thirds of Survey respondents were positive about the significance of the PHRN to addressing the health needs and services of Australians. Data Linkage Units/Services respondents were more positive than the researcher group or other respondents: 92% of Data Linkage respondents thought the PHRN infrastructure very or moderately significant compared with 52% of researcher respondents. There was a similar pattern of responses regarding the international significance of the PHRN infrastructure with a higher proportion (51%) of respondents overall considering it very significant. Three respondents considered the PHRN to be insignificant in both the national and international contexts.

b) Written Submissions Findings
Australia has one of the most comprehensive collections of population-based health and human services data in the world, amassed over decades:

- administrative datasets, disease registers, surveys and other routinely collected data
- an impressive collection of population-based cohort studies, including the Australian Longitudinal Study on Women's Health, the 45 and Up Study, the Longitudinal Study of Australian Children, and the new Ten to Men Study

The PHRN infrastructure is the hub that adds value to these significant assets by enabling such data to be linked together. The challenges to doing so are enormous in Australia because of our federal system in which data collections reside within nine different legal jurisdictions. The aim to achieve cross-jurisdictional linkage makes the PHRN infrastructure unique and a focus of interest by other countries as it navigates the significant technical, legal and political issues involved. Activities have been showcased at international meetings in the UK and USA, with Canada likely in 2014.

In the national context, the PHRN’s linkage system can support a significant role in meeting key components of the National Health Care Agreement 2011 and a number of other intergovernmental agreements related to increased transparency and accountability across the health and aged care system. According to the Australian Bureau of Statistics, the PHRN has provided governments with ideas, such as the separation principle and ways in which it can be applied, which have assisted governments to establish their own arrangements for the integration of data.

The development of PHRN has fostered new collaborations and efforts between government departments and agencies and academic institutions and in doing so it has also assisted in building skills and capabilities within the health research sector which, without a coordinated approach, would have taken considerably more time to develop. An increasing number of international links are evidence of the acknowledged technical expertise within this infrastructure and the emergence of Australia as a world-leader in research using linked data.

Nevertheless in order to maintain Australia’s competitiveness and standing in international research and to obtain greater benefits from the linkage and analysis of multiple data sources across jurisdictions, ongoing investment in the national infrastructure is essential.
c) Public Hearings Findings

To quote Professor Fiona Stanley, leading world expert in data linkage to improve health, Australia’s rich data sources are “grossly under-utilised to monitor and evaluate overall health status and problems and to specifically evaluate services, practices and whether legislation (such as to improve population health) is working. We have data that if used more could prevent death, morbidity and disability but we are not using it fully. Australia was up there with a few other world leaders of population data and record linkage but due to the delayed access and processes to link data, we are falling behind”.

4.5. The role of the PHRN in the future development of a distributed national data linkage infrastructure in Australia

4.5.1. Any changes in structures and processes to assist PHRN Participants to achieve the aims and objectives of current plans and agreements

a) Survey Findings
A majority of respondents (71%) agree that changes are required in structures and processes to improve the PHRN facilities and services. The types of changes suggested include:

- reduced bureaucracy and simplified, uniform processes to increase ease of data access and timeliness of services
- better communication of how to access PHRN and use available resources especially national data linkage services
- improved cross-jurisdictional data linkage
- improved structure to eliminate duplication within the linkage infrastructure
- improved support for researchers including wider access to linked data, access to MBS and PBS data, more focus by PHRN on the scientific aims and output of the research, standardized approach for assessing linkage quality and evaluation studies for research using linked data

b) Written Submissions Findings
While the Program Office would welcome incremental change, it would not recommend major changes that would require variations to the approved Project Plans given the short time frame before the end of the current agreements. However there are clear areas of frustration and need amongst users and would-be users that may necessitate changes to current arrangements or agreements.

i. Structural and governance considerations
Structurally, the distributed PHRN data linkage infrastructure is functional, compliant and load-bearing but more work is now required to optimise its utility. Several submissions call for interoperability, collaboration and shared infrastructure across the Network, and point to duplication of effort in various jurisdictions. In particular there is confusion about the functions and interconnectivity of the national elements of the PHRN and how to access them. The constraints for data access by the university-based CDL are a concern that has led to an apparent supersedence of CDL by the accredited Integration Authority, AIHW, for all Commonwealth health service as well as and some inter-State data linkage. The Program Office, while performing vital administration and governance functions has several additional operational roles that place it in a position seen in some circles as conflicted. Suggestions have been made for some of its functions to be reallocated within the Network.

Strong leadership will be required to effect change within the Network and influence the authorising environment in which the PHRN is operating. The current structure and size of the PHRN Management Council is perceived to be unwieldy for the next stage of development. A more independent governance structure along the lines of a Board is believed to be essential for the sustainability of the Network and a world class data linkage infrastructure.
ii. Reduce bureaucracy and improve processes

Transparent streamlined applications and approvals are called for at all levels to improve timeliness and efficiency for accessing linked data. An overhaul of the human ethics approval process for data linkage projects is an urgent requirement. Data extraction and access could be enhanced with changes in data governance to promote custodian cooperation and routine linkage of certain data, and potentially a move to enduring Master linkage files for Commonwealth and cross-jurisdiction linkage (currently contra to Commonwealth data integration principles) and data repositories. However, differences between the Commonwealth and State data integration/linkage models also need to be accommodated to enable cross-jurisdictional data linkage, perhaps through the function of the Integration Authority.

However, while more structured processes with related indicative timelines may be helpful, the barriers to data flow appear to be as much about attitudes and priorities and the willingness of all jurisdictions to participate in and provide data for jurisdictional and cross-jurisdictional data linkage. Several submissions call for “the development of agreed principles and processes which support the notion of release of data for data linkage under the PHRN framework unless there is a compelling reason not to” with the default position being that publically collected datasets (i.e. funded from public money) ought be made available for public good research.

c) Public Hearings Findings

The structural issues referred to in the written submissions also emerged in feedback from the public hearings. The focus on building capacity is every jurisdiction has, to some extent, fostered preoccupation with building technical infrastructure in all locations rather than operational efficiencies where capacity has been built. The national facilities of CDL and AIHW together with SURE appear to be making a concerted effort to partner for more effective delivery of services. Despite this and efforts to spread expertise throughout the Network, each jurisdiction puts its own interests foremost, hampering true cohesion, coordination and priority setting within the Network.

The public hearings confirmed the belief that the PHRN’s governance needs to be revisited as there are perceived issues with the existing Management Council’s ability to properly and strategically think forward. Specific concerns include:

- ability for proper forthright decision making particularly if challenged by lack of funds
- governance from a conflict of interest viewpoint and independence in decision-making
- insufficient commitment to consultation and promotion of benefits at the community, national and international levels
- PHRN feels like a federation not an organisation; conflict regarding the role of PHRN itself
- insufficient engagement with other stakeholders
- too process driven, suited to building infrastructure but not for using it

Further clarity emerged around data custodial matters. It was reported that the strategic use of datasets has been in place across all Commonwealth players since 2009 and this is not specific to Health or Human Services. So availability of datasets for linkage is less the issue than the issue of maintaining trust with the custodians and the public, as any breach of trust affects all. A further major challenge is the lack of a unique identifier added to data as it is recorded that allow linkage. This is perceived to be critical to national interest but relates to the trust issue (a crucial issue for
most patients and users of our health system, and of particular resonance in Australia following the
controversy around the attempt to introduce an “Australia Card” many years ago). Resourcing and
management of many requests for data access from multiples sources are major issues for many
data custodians who don’t have staff dedicated to this task and available to assist researchers. Some
approaches to streamline access include investment in data warehousing programs that facilitate
data extraction and establishing separate datasets for linkage that are “ready to go”.

4.5.2. Options for further development and maintenance of PHRN and
related data linkage infrastructure in the next 5 years, including potential future
funding sources

a) Survey Findings
Twenty five respondents to the survey offered suggestions which included:
• appropriate Data Governance arrangements and funding to support the establishment and
running of a Data Repository containing linked and anonymised researchable data from
Commonwealth, State/Territory and Private / NGO sectors, maintained for quick release of data
for ethically approved research and policy analysis
• consistent national PHRN-wide standards for: 1) familial linkage of family records, including
Indigenous family / kinship relations 2) geo-spatial (GIS), geo-coding of addresses 3) preserving
privacy
• methods and training programs for cleaning and standardising data, managing large data and
analysing complex and multi-level data
  - centralised detailed information online about the limitations of the various data sets
  - development of a central metadata repository
• engagement with areas outside health to share infrastructure developments and expand data
linkage capabilities e.g. education, crime etc.
  - build mentoring across departments and custodians to help each other as peers
  - support custodians to help them efficiently participate in systemic/ongoing data
provision
• identify legislation obstacles and how that can be improved
• continuance of Government funding of data linkage services across Australia long term
  - sustainable funding for national/cross-jurisdictional projects from NHMRC & ARC
  - funding mechanism to support renewal/replacement of hardware/datalinkage
equipment

b) Written Submissions Findings

i. Funding
It is the Management Council’s view that, for the foreseeable future, the full cost of the
development and operation of the PHRN infrastructure will not be recoverable from researchers.
The PHRN infrastructure needs to be seen as providing a necessary service for public good. A
combination of funding including continuity of funding programs will be required to provide security
for this important national infrastructure and avoid losing the advantage Australia has gained in the
international data linkage arena.
Options include:

- Government funding of data linkage services across Australia, which is ideally not built on one to two year horizon funding programs
  - regional linkage units must find support at State/Territory level, while a national centre might be funded through the NH&MRC Partnership grants or Centre of Excellence Program or direct funding from the Commonwealth
- all services will have to move to a cost-recovery model but this may not be full cost-recovery in short to medium term
  - expanding the client base would lead to economies of scale through improved operational efficiency leading to lower variable cost and income generated from infrastructure utilisation
  - a fee-for-service model will require the research grant funding agencies to be willing to fund the full cost of research but would still not be able to cover capital costs; guidelines and agreements will be needed for how data and technology costs and using data linkage services should be costed and how granting bodies should handle such requests when considering applications
- alternate funding sources
  - engagement of pharmaceutical companies could be considered, but this would depend on availability of PBS data and negotiation of suitable terms of engagement
  - philanthropic support (e.g. linkage analysis by the Wellcome Trust in the UK)

ii. Further development

There will be significant challenges as demand for population based linkage services increases. Many such as governance, harmonising processes and overcoming jurisdictional differences relate to findings already covered in the previous section (Survey Findings) and in Section 4.5.1.

Other specific areas for further development include:

- expansion of data linkage capabilities and methods
  - linkage of a broader range of data collections by the regional data linkage units including health data such as clinical trials, biobanks and pharmaceutical data and data from other sectors such as education, electoral roll and family and community service data
  - service a much wider client base and broader range of issues of interest to governments with concomitant increase in research opportunities (e.g. social and economic research) and potentially link all administrative data (not just health data) that are routinely collected in Australia by the national and State governments
  - preservation of linkage keys
- data repositories and centralised options
  - focus existing Data Linkage Units resources into establishing and operating data repositories
  - legislation (Commonwealth) to safeguard data being provided into a repository to facilitate Data Custodians and data rich organisations to participate in the release of data
The Program Office recommends that an independent facilitator should be appointed to consult widely and develop a Strategic Roadmap for further development of Australia’s data linkage infrastructure after mid-2015.

c) Public Hearings Findings
The objectives of the PHRN must be to deliver value to governments to justify and encourage future funding so that benefit will flow on to the research community. This will entail the PHRN’s focus on strategic issues and ensuring that the development of IT is paralleled by development of transparent data governance processes that will lead to more efficient flows of data. The States/Territories should be encouraged to invest in data linkage and be responsible for the integrity and quality of data at the State level and all nodes should develop plans for ensuring future sustainability that include recovery of at least marginal operating costs. In considering future viability, it is noted that it may not be necessary to have linkage capacity in every State. Just as NT and ACT already effectively outsource their linkage to nodes in adjacent jurisdictions, further consolidation and pooling of resources within the Network could be considered. A scenario has been suggested, for example, where IT infrastructure located and administered within one jurisdiction may be operated remotely by staff of linkage units in other jurisdictions via AARNet high-speed interstate connection.

New opportunities for growth have opened to the Network with the advent of SURE. As more datasets become available, it is envisaged that the “SURE environment” will increasingly become a) a requirement for secure linked data release, and b) preferred by researchers because of the efficiency gains and flexibility it offers such as the ability to run programs overnight and share data with researchers at different institutions, even internationally.

Other suggested areas for funding and further development have already been described earlier in this section.

4.5.3. The role of the PHRN in the development of Australia’s data linkage infrastructure in the next 5 years

a) Survey Findings
Almost two-thirds of Survey respondents considered the PHRN to be very important in the development of Australia’s data linkage infrastructure in the next 5 years (67% of Researchers and 85% of Data Linkage respondents). Only 5 (12%) of the 41 who answered this question thought the PHRN is partially or not important to future development.

b) Written Submissions Findings
Going forward, an extensive advocacy/engagement role for PHRN will be required in order to achieve agreement and cooperation from stakeholders to enable efficient and effective data linkage across all jurisdictions and where health interconnects with other sectors. Many of the legislative, policy and bureaucratic barriers have already been mentioned.

Specific approaches might include:
- advocacy for nationally consistent principles for data custodians and the release of data, especially between the Commonwealth and other jurisdictions
• work cooperatively with the broader data integration community in ensuring a safe and effective environment for the linkage of data within Australia

• brief the Council of Australian Governments (COAG) on the volume of population-based data linkage and its potential to support its business and priorities and seek its support for a position that publicly funded administrative data held by all jurisdictions should, as the default position, be available for public interest research projects approved by a relevant Human Research Ethics Committee

• engage with the community and demonstrate that it is possible to balance concerns about privacy protection with the potential benefits to the community from research

• advocacy for broadening of privacy legislation (Section 95 of the Privacy Act 1988) that allows use of personal information without consent for health research to “research on human development” thereby acknowledging the intersection of health with all human services

c) Public Hearings Findings

The emergence of Commonwealth integrating authority architecture offers established processes and researcher gateways to allow direct access to Commonwealth survey data (ABS) and administrative and/or registry data (AIHW). Therefore the value proposition of PHRN has possibly shifted from a Commonwealth data linkage capability focus to intra and cross-jurisdictional data linkage in that it allows data linkage across all States and Territories. Future development should embrace the changing environment in which PHRN finds itself.

PHRN is beholden to those who were invited into the Network but it is vital to be more involved with the government sector, not just the Commonwealth. The next phase is to get high level and broad political will to commit to data linkage but dialog needs to be at a central agency level. A strong national voice is needed about data linkage and its use, showcasing what can be done. PHRN could also have a significant role in lobbying to get reform in the legal environment that relates to data linkage, which comprises three bodies of law governing privacy, confidentiality and use of data.
Appendix 1 – Written Submission Origins

The following written submissions, with the exception of those that are confidential, may be accessed through the PHRN website at http://www.phrn.org.au/news-events/phrn-review.

<table>
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<tr>
<th>Group</th>
<th>Organisation</th>
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<tbody>
<tr>
<td>PHRN Management Council and advisory groups</td>
<td>PHRN Management Council</td>
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<td></td>
<td>Ethics, Privacy and Consumer Engagement Advisory Group</td>
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<td>PHRN Proof of Concept Collaboration Reference Group</td>
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<td>Funders and funding agents</td>
<td>UWA, lead agent for the PHRN and its partners; contracting party for all</td>
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<td>Researchers</td>
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<tr>
<td></td>
<td>Prof Mark Daniel - University of South Australia, School of Population Health</td>
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<tr>
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<td>individual researcher - affiliation unknown (confidential submission withheld)</td>
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<td>Australian Longitudinal Study on Women’s Health (ALSWH) – National study of</td>
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Appendix 2 – Additional Reference Resources

The following materials were taken into account by the Review Panel and may be accessed through the PHRN website at http://www.phrn.org.au/news--events/phrn-review.

1. PHRN Stakeholder Survey 2013 Results
2. PHRN Overview and Achievements 2009-2013
3. National Collaborative Research Infrastructure Strategy – Summary of Income and Expenditure for each Project Participant and Progress against Milestones for each Project Participant for the Project Period 2008-2014 (Date 24 January 2014)
4. Education Investment Fund Super Science Initiative - Summary of Income and Expenditure for each Project Participant and Progress against Milestones for each Project Participant for the Project Period 2011-2015 (Date 24 January 2014)
5. Summary of Infrastructure Use and Training Activities by PHRN Participants (Date 29 January 2014)
6. PHRN Training Consultation National Scoping Exercise Final Report (Date April 2011)
7. Public Support for Data-based Research To Improve Health - A discussion paper based on the proceedings of a Menzies Foundation Workshop 16th August, 2013
## Appendix 3 – Public Hearings Participants

<table>
<thead>
<tr>
<th>Group</th>
<th>Name</th>
<th>Position</th>
<th>Organisation</th>
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<tr>
<td>PHRN Management Council</td>
<td>Prof Brendon Kearney</td>
<td>Chair, PHRN Management Council</td>
<td>PHRN</td>
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<tr>
<td></td>
<td>Ms Teresa Dickinson</td>
<td>Head, Statistics and Communication Group</td>
<td>Australian Institute of Health and Welfare</td>
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<td>Prof James Semmens</td>
<td>Director of the Centre for Population Health Research</td>
<td>Curtin University</td>
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<td></td>
<td>Dr Merran Smith</td>
<td>Chief Executive, PHRN and Director, Program Office</td>
<td>University of Western Australia</td>
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<td></td>
<td>Mr Andrew Stanley</td>
<td>Director SANT DataLink</td>
<td>University of South Australia</td>
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<tr>
<td></td>
<td>Mr Brian Stokes</td>
<td>Manager, Tasmanian Data Linkage Unit</td>
<td>Menzies Research Institute Tasmania</td>
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<tr>
<td></td>
<td>Dr Campbell Thomson</td>
<td>Director of Research Services</td>
<td>University of Western Australia</td>
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<td>Dr Jeanette Young</td>
<td>Chief Health Officer</td>
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<td>Dr Merran Smith</td>
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<td></td>
<td>Dr Felicity Flack</td>
<td>Manager, Policy and Client Services, Program Office</td>
<td>Telethon Institute for Child Health Research</td>
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<td>Ms Teresa Dickinson</td>
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<td>A/Prof Anna Ferrante</td>
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<td>The Sax Institute</td>
<td>Mr Robert Wells</td>
<td>Policy Head, Research Assets</td>
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<td>Dr Timothy Churches</td>
<td>Epidemiologist, SURE</td>
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<td>Prof Louisa Jorm</td>
<td>Foundation Professor of Public Health; Senior Advisor SURE</td>
<td>University of Western Sydney; The Sax Institute</td>
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<td>Mr James Sloane</td>
<td>Facility Coordinator, SURE</td>
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<td>Ms Katie Irvine</td>
<td>Manager, Centre for Health Record Linkage</td>
<td>NSW Ministry of Health</td>
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<td>Ms Elizabeth Moore</td>
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<td></td>
<td>Dr Lee Taylor</td>
<td>Medical Epidemiologist and Associate Director of Epidemiology and Evidence</td>
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<td>A/Prof Sarah Thackway</td>
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<td><strong>Queensland</strong></td>
<td>Ms Nyree Divitini</td>
<td>Project Coordinator, HealthLinQ</td>
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<td>Dr Tracey Henshaw</td>
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<td>Mr Andrew Stanley</td>
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<td><strong>Tasmanian Data Linkage Unit</strong></td>
<td>Mr Brian Stokes</td>
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<td>Prof Alison Venn</td>
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<td><strong>Victorian Data Linkages</strong></td>
<td>Mr Peter Carver</td>
<td>Project Director, Health Strategy</td>
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<td><strong>Western Australian Data Linkage Branch</strong></td>
<td>Ms Diana Rosman</td>
<td>Program Manager, WA Data Linkage Branch</td>
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<td><strong>Australian Government Department of Education</strong></td>
<td>Mr Tony Rothnie</td>
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<td>Ms Azlina Wilson</td>
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<td><strong>Commonwealth Government Data Custodians</strong></td>
<td>Ms Gemma Van Halderen</td>
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<td>Mr Gary Moorhead</td>
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<td>Mr Paul Basso</td>
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<td>A/Prof Jane Freemantle</td>
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