PHRN Population Health Research Network

Submission to the National Research Investment Plan Discussion Paper

Population Health Research Network

August 2012

About PHRN

The Population Health Research Network (PHRN) is responsible for the creation of a research infrastructure that will enable research using linked data from health and related data sets across all jurisdictions in Australia. The data linkage infrastructure will support the beneficial use of information held by governments for population based research to improve the health and wellbeing of Australians and enhance the effectiveness and efficiency of health service provision.

The PHRN was established in 2009 with collaboration between Australian, state and territory governments and their academic partners to develop national health data linkage infrastructure. It has received $30 million from the Australian Government Department of Innovation, Industry, Science, Research and Tertiary Education (DIISRTE) through the National Collaborative Research Infrastructure Strategy and the Education Investment Fund – Super Science Initiative. Australian governments and their academic partners have contributed a further $42 million in cash and in-kind.

The PHRN is working with the Commonwealth, states and territories to develop safe and secure infrastructure for the linkage of health and related data contained in statutory and administrative data collections, and for the provision of this data to data users for approved projects. PHRN is also developing the capacity to securely link and analyse data across jurisdictional boundaries, enabling truly 'national' Australian research. PHRN is governed by a Management Council. Details of membership are included at Attachment 1.

The purpose of the PHRN is to support the conduct and quality of population level research which can be conducted without researchers having access to personal information. The protection of privacy is, therefore, central to the rationale and activities of the PHRN.

Response to questions in the National Research Investment Plan Discussion Paper

Q1: Views are sought on this representation of the national research fabric and the notion of focusing on the development of enabling capabilities (domains) in the NRIP.

The National Research Fabric diagram is generally helpful in identifying key research elements and areas, and their relationships and impacts. The PHRN endorses the view that the Fabric must maintain and promote Australia's research competitiveness and that it must be supported by necessary skills, facilities and collaborations. We note, however, that there is no specific mention of the advancement or creation of new knowledge which is fundamental to all research. While this is implicit in the capability areas, incorporation of knowledge creation in the National Research Fabric Diagram should be considered.

The two related but distinct areas of communication and consumer and community participation should also be considered for inclusion in the National Research Fabric. They would fit best as two vertical columns in the diagram. It is very important for these areas to be seen as part of the fabric because they are integral to the translation of research but historically researchers have rarely received specific funding to conduct these activities. Both improve the quality of research considerably but cannot occur without the appropriate expertise and time devoted to them. This is a real cost for the conduct of research.

We note that 'translation' is represented as an arrow outside the square. In our experience, knowledge translation needs to be an active process. Consideration should be given to putting a greater emphasis on knowledge generation/translation both within the diagram and in any accompanying text. The key return on research investment is realised when knowledge it translated into improved policy, process and practice. A number of other countries currently manage this process better than Australia.

The PHRN endorses the view that data is of critical importance across all domains. We note that, in the Human domain, the need for secure access to data is not a future issue but a current one that is driven by growing community concerns over privacy and confidentiality.

Q2: Is the scope of each of the domains appropriate and are they sufficient to cover Australia's needs into the future?

Information Domain

Large volumes of data that is or could be used for research purposes is held by non-research organisations e.g. government departments. This information is not collected specifically for research and its use for research is not necessarily a priority for the organisations responsible for the data. These organisations are not usually specifically funded to enable access to data for research. One way of improving access to this type of data by researchers is to provide a funding stream to non-research organisations to enable investment in systems and staff that will improve access to data for research.

Another gap in the workforce for the Information Domain is the availability of specialist staff with skills and experience in the ethical and legal issues surrounding the use of data for research.

An additional gap in infrastructure in the Information Domain is in the area of secure capabilities. While investment in e-Research infrastructure has been significant, this infrastructure typically does not meet the security requirements necessary for handling sensitive data. Investment in secure research infrastructure (e.g. secure research environments, secure data stores, secure file transfer mechanisms and data integration areas) would address privacy concerns and promote/support research using/analysing sensitive data, particularly in the Human domain.

Q3: What other gaps are there in the current and future capability and what mechanism would be best to address them?

Fundamental Elements of the Research System – Infrastructure
High quality infrastructure is essential to a successful research and innovation sector. Given the PHRN experience in developing high quality research infrastructure over the last four years, the PHRN is very supportive of the Principles for Research Infrastructure Investment outlined in the Strategic Framework for Research Infrastructure Investment. In particular the principles of:

- Continuity of funding;
- Holistic funding; and
- Collaboration.

In addition, coordination between Australian Government and State/Territory Government infrastructure funding programmes should be improved to maximise the benefits of the funding available and encourage collaboration across jurisdictions.

Q4: What will be the impact on the national research fabric and Australia's capacity to increase national wellbeing if the gaps are not addressed?

There will be lost opportunities for productivity growth and national wellbeing.

Q5: What other structural or policy issues could be addressed to further strengthen the research system?

The PHRN is extremely supportive of a collaborative approach to the development of research infrastructure. However, the time required to negotiate collaborative relationships including contractual relationships and recruit specialist staff should not be underestimated. It can be impractical to both negotiate arrangements and complete the significant amount of work needed to complete collaborative projects in short time frames e.g. 3 years or less. It is recommended that funding periods for large infrastructure projects should be at least 5 years.

Q6: What mechanisms would be best to address the structural or policy issues?

In terms of collaboration, some mechanisms are mentioned in the response to Q5 above. In addition, we suggest an ongoing requirement for collaboration in planning for national infrastructure and in funding agreements, as well as continued support for a culture and climate of collaboration across programs and capabilities.

With respect to business research investment, there are opportunities for improved engagement between business and publically funded research in Australia. The Australian government has a key role but state/territory governments may also need to be involved. A number of other countries e.g. UK appear to have good engagement with business and models in such countries could be considered.

Q7: What will be the impact on the national research fabric and Australia's capacity to increase national wellbeing if the structural or policy issues are not addressed?

Again, there will be lost opportunities for productivity growth and national wellbeing.

ATTACHMENT 1

PHRN Management Council

Prof Brendon Kearney
Committee Chair

Ms Diana Rosman
Nominee of the Director General, Western Australian Department of Health

Prof Louisa Jorm
Nominee of the PHRN NSW/ACT Management Committee

Prof Steve Kisely
Nominee of the Management Committee of Queensland HealthLinQ

Mr Peter Carver
Nominee of the Victorian Department of Health

Mr Andrew Stanley
Nominee of the Steering Committee of SA-NT DataLink

Mr Brian Stokes
Nominee of the Tasmanian Department of Health and Human Services

Prof James Semmens
Nominee of Curtin University

Dr Campbell Thomson
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Ms Teresa Dickinson
Nominee of the Australian Institute of Health and Welfare

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Prof John Lynch
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Prof Annette Dobson
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