

Response to the Strategic Review of Health and Medical Research 2012

The Population Health Research Network (PHRN) welcomes the opportunity to make a submission to the Strategic Review of Health and Medical Research 2012.

Background

The Population Health Research Network (PHRN) is responsible for the creation of a research infrastructure that will enable research using linked data from health 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 services

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 link data across jurisdictional boundaries.

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

Why is it in Australia's interest to have a viable, internationally competitive health and medical research sector? (Terms of Reference 1 and 6)

1. The need for Australia to build and retain internationally competitive capacity across the research spectrum, from basic discovery research through clinical translation to public health and health services research.

- The need to build and retain capacity across the research spectrum is strongly supported. Chronic disease is a major national priority as is the increase in health service demand and costs. Research at the population health and health services end of the research spectrum is essential if the Australian population is to truly benefit from this country's investment in health and medical research. For example, there would be significant health and economic benefits if the release of medications cleared through clinical trials and related processes for use in Australia could systematically monitored at the population level.
- There is continuing strong growth in the demand for and expenditure on health and medical services in Australia. Continued investment in health and medical research including at the population level is essential if this growth is to be properly managed.

6. Strategies to attract, develop and retain a skilled research workforce which is capable of meeting future challenges and opportunities.

- A skilled research workforce will be essential to a successful internationally competitive health and medical research sector. As the depth and breadth of Australia's internationally-recognised, linked population health data expands, there is a growing need for a workforce with skills in data linkage and the analysis of linked data.

How might health and medical research be best managed and funded in Australia? (Terms of Reference 2, 3 and 7)

3. Opportunities to improve coordination and leverage additional national and international support for Australian health and medical research through private sector support and philanthropy, and opportunities for more efficient use, administration and monitoring of investments and the health and economic returns; including relevant comparisons internationally.

- Better coordination between different sources of infrastructure funding e.g. between infrastructure funding available from NHMRC and DIISRTE.
- All infrastructure funding should follow the Principles for Research Infrastructure Investment outlined in the DIISRTE's Strategic Framework for

Research Infrastructure Investment particularly the principle of holistic investment i.e. the inclusion of capital costs, governance, skilled technical support staff and operations and maintenance.

- The ongoing viability of major national research infrastructure that has been built using funds from the National Collaborative Research Infrastructure Strategy (NCRIS) and the Education Investment Fund (EIF) is at risk as these programs draw to an end. The 2011 Strategic Roadmap For Australian Research Infrastructure sets out a way forward.
- An acknowledgement that researchers and research organisations are not necessarily the providers of all research infrastructure. For example the privacy protecting measures taken by data linkage infrastructure providers in Australia means that the data linkage facilities are separated from the researchers i.e. data linkage units are not operated by researchers. Therefore data linkage units are not always eligible for infrastructure funding that is made available to researchers and must be funded in other ways.
- Collaborative mechanisms for development of major Australian research infrastructure are strongly supported.

Mechanisms to measure health and economic returns on investment in health and medical research need further development. Frameworks and related mechanisms for knowledge translation also need further attention. Processes in other countries e.g. Canada are better developed.

7. Examine the institutional arrangements and governance of the health and medical research sector, including strategies to enhance community and consumer participation. This will include comparison of the NHMRC to relevant international jurisdictions.

- There are opportunities for better consumer and community engagement in health and medical research in Australia, including at the governance level. However, effective consumer engagement is generally reliant on capable, representative and appropriately funded health consumer organisations. There is a limited number of such organisations in Australia. In addition, there needs to be a culture of consumer/community engagement in research groups and entities. While there are some good examples of groups with a strong culture of engagement, it is by no means uniform or widespread.

What are the health and medical research strategic directions and priorities and how might we meet them? (Terms of Reference 5, 12 and 13)

5. Likely future developments in health and medical research, both in Australia and internationally.

- Due to the increasing demand for health and medical researchers to analyse vast amounts of information, biostatistics, health informatics and bioinformatics are very important capabilities which will require continuing substantial investment. The current levels of capacity in these areas is low and will require strategic and timely investments in overseas recruitment, and training of new local talent to support the growth of health and medical research in Australia.
- Access to a wide range of data will remain central to answering the important and complex questions which span biomedicine, clinical medicine and public health. Research in these areas will lead to better health services and improvements in the health of Australians. The ageing Australian population along with unhealthy lifestyles and a changing environment means there is a need for the evidence from linked data to enable us to effectively tackle these complex problems through innovation in prevention, management and treatment of chronic conditions. Researchers will require access to linked data from cohort studies, clinical trials and biological data as well as data from non-health areas such as education, family and human services and justice. Such an investment would help provide Australia with a unique international resource platform that would greatly increase our research capacity relative to other countries.
- Legislative changes may be needed to facilitate researcher access to health-related human services data.
- In order for researchers to be able to take full advantage of all the information that could be available more efficient approval and data extraction processes will be required. There are some technical systems that need to be developed in order to achieve this but more difficult is the cultural and potentially legislation changes that may be necessary before different organisations and jurisdictions will be comfortable to make data available.

How can we optimise translation of health and medical research into better health and wellbeing? (Terms of Reference 4, 8, 9, 10 and 11)

8. Opportunities to improve national and international collaboration between education, research, clinical and other public health related sectors to support the rapid translation of research outcomes into improved health policies and practices. This will include relevant international comparisons.

- There are opportunities to improve Australia's research knowledge translation frameworks and processes. Although a considerable body of opinion and experience about how to facilitate the uptake of research findings into policy and practice area exists in Australia and other countries, particularly the UK and Canada, there is a requirement for rigorous research to develop and test interventions in this area.
- Research that is done in partnership with policy agencies, to answer questions that are important for them, is much more likely to be translated rapidly into practice than investigator-initiated research. Schemes such as the NHMRC's Partnerships for Better Health and Partnership Centres present strong potential for such partnership research. However, some health agencies have been reluctant to participate as formal partners in these schemes.

9. Ways in which the broader health reform process can be leveraged to improve research and translation opportunities in preventative health and in the primary, aged and acute care sectors, including through expanded clinical networks, as well as ways in which research can contribute to the design and optimal implementation of these health reforms.

- Good quality linked population health data is considered an essential resource for health reform in Australia. The country has made significant investments in data and information in recent years (including in the development of data linkage capabilities) and is well placed to draw on these data resources to optimise health service delivery and health reform. For example, policy settings may differ in states and territories and differences in policy-related outcomes can be tracked as can the impact of reforms at the national level over time. The development of strong partnership research programs involving both policy agencies and research teams (for example NHMRC Partnership Centres), presents a model to maximise the effective use of population health data to drive health reform.

10. Ways in which health and medical research interacts, and should interact, with other Government health policies and programs; including health technology assessments and the pharmaceutical and medical services assessment processes.

- Government agencies hold data which is the key to health reform in Australia. However there may be legislative and other constraints to accessing that data, including lack of investment in policies, processes and

underlying information management systems. Continued development of mechanisms to facilitate access to government data in safe, secure and privacy-preserving ways is needed. The UK Administrative Data Liaison Service might serve as a useful model.

11. Ways in which the Commonwealth's e-health reforms can be leveraged to improve research and translation opportunities, including the availability, linkage and quality of data.

- The ability for data collected by the e-health system to be used for research should be considered and built into the e-health reforms. This may require consideration of the legal and administrative issues as well as the technical design of the system. Conceptualisation of the research use of e-health data as only a "secondary use" is not helpful, and it is essential that researchers are integrally involved with the design of these systems. Implications for the research utility of e-health data also need to be considered in developing models of consent.
- Linkage of the clinical information captured in e-health records with information in population-based administrative data collections will considerably enrich the potential for large-scale research to investigate the outcomes and costs of clinical interventions.