Response to the Big Data Strategy - Issues Paper March 2013

Introduction

The Population Health Research Network (PHRN) welcomes the opportunity to respond to the Big Data Strategy – Issues Paper.   The Strategy recognises the importance of big data to Australia's future prosperity and complements other Australian Government data initiatives eg the Response to the Report of the Government 2.0 Taskforce. It is also very relevant to PHRN's vision:

A valued national resource generated from the linkage of routinely collected and other population data from a broad range of areas such as health, education and justice and used for research to inform policy, planning and management to improve the health and wellbeing of all Australians.

Background information on the PHRN is shown below. Some specific comments on aspects of the Strategy are also provided.

Background

The Population Health Research Network (PHRN) is responsible for the creation of a research infrastructure that will enable research using linked data from population data collections 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 $33 million from the Australian Government Department of Innovation, Industry, Science, Research and Tertiary Education (DIISRTE) through the National Collaborative Research Infrastructure Strategy, the Education Investment Fund – Super Science Initiative and the Collaborative Research Infrastructure Scheme. 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.

Further information about the PHRN including contact details may be found at www.phrn.org.au

Response

Opportunities for Australian Government Agencies

The PHRN is very supportive of the greater use of government data for policy and service improvement. The Big Data Strategy – Issues Paper highlights the increasing volumes and types of data being collected. While new forms of data are being produced, Australia is still not leveraging existing forms of data e.g. administrative data held by health and human services agencies for evidence based policy and better service delivery.

The paper highlights the importance of agency use of data. Consideration should be given to including reference to researcher use. In health in particular, institute and university based researchers are important users of data and often have strong knowledge transfer links to government e.g. the Developmental Pathways Project in Western Australia. Research using linked population health/human services data has already demonstrated/continues to demonstrate important insights into key areas of society.

Challenges

Privacy, Security and Trust

The PHRN agrees that it is essential for all activities to align with the relevant privacy and other laws. In our experience this is a specialised area and ongoing access to expert advice is needed.

There may be concerns about use of big data and these need to be addressed. Based on our experience, active consumer and community participation in the development, implementation and oversight of the Big Data Strategy will be essential to building and maintaining community trust and reaching successful outcomes. Engaging with consumer groups such as the Consumers' Health Forum of Australia should be an important part of the Big Data Strategy.

Currently in the health/human services area, approval for analysis is generally obtained on a project by project basis to meet ethics and privacy requirements and this is likely to continue. Data mining is rare. In other words, a one size approach may not fit all circumstances and this could be recognised in any updated Issues Paper.

Data Management and Sharing

In our experience, a cross agency analytical capacity is very important. We agree that for this to work, there needs to be more standardised data management practice including metadata management. Data quality and information assets registers are also issues (as described in Section 3.2 of the Issues Paper). We note that there are already some national initiatives in this area that could be leveraged e.g. The Australian National Data Service.

Skills

The PHRN agrees that there is a need for ongoing investment in development of a skilled data management workforce. In addition to building the skills and expertise of government agency staff, collaborations should be formed with the academic sector including research institutes and universities in order to leverage the skills in this sector particularly around the analysis of "big data" and translation of results into practice.

The Way Forward

The Australian Government, state and territory governments and academic institutions have already invested significantly in a range of initiatives that could be leveraged or contribute to the Big Data Strategy in all areas including:

- Privacy, security and trust
- Data management and sharing
- Technology and analytical systems
- Skills.

Commonwealth agencies such as the Australian Bureau of Statistics, the Commonwealth Scientific and Industrial Research Organisation and the Australian Institute of Health and Welfare along with a range of initiatives funded by DIISRTE (e.g. Australian National Data Service, Population Health Research Network, the National eResearch Collaboration Tools and Resources project and the National Computational Infrastructure) should be approached to contribute to the Big Data Strategy.

Finally, the Issues Paper makes reference to Gartner's definition of big data in terms of 'three Vs'. In our experience, management of big health and human services data can be distilled into 'three Cs': collaboration, coordination and consumer engagement. A focus on the 'three Cs' will be important to the success of the Big Data Strategy.