

## Draft 2016 National Research Infrastructure Roadmap

### Submission Template

*Please provide your comments in this word document below, noting that the overall word count should not exceed 1,000 words and any content exceeding this amount may not be counted as part of your submission. If you would like your comments published, please ensure that your submission, including all pictures, diagrams or tables adheres to online accessibility requirements as stated on our [Terms and Conditions](#) page.*

*When your comments are complete, save this document in two of the accepted file types and upload both documents to the Department submissions page in accordance with the instructions.*

### ***Response from the Sax Institute***

The Sax Institute welcomes the opportunity to make a submission on the Draft 2016 National Research Infrastructure Roadmap (Draft Roadmap). As an organisation that supports policy agencies and service providers to use research evidence, the Sax Institute believes that investment in research infrastructure, comprising of assets, facilities and services, is of critical importance to innovative research that is of national and international benefit.

We support the key recommendations of the Draft Roadmap, in particular, considering complementary initiatives such as the Medical Research Future Fund and recognising the importance of a skilled workforce in advanced mathematics and data science. We agree with the Draft Roadmap's focus on a smaller number of priority areas. The Draft Roadmap recognises the broad range of research areas relating directly to health (such as population health) or which have clear connections with health (such as HASS) or where health research shares infrastructure (such as digital data and eResearch platforms). However the nomination of therapeutics as a specific focus area carries a risk of distorting infrastructure investment. While therapeutics will potentially generate health and economic gain, enhancement of infrastructure supporting other areas of health should not be overlooked. Specific comments follow.

#### **Digital data and eResearch Platforms**

This is a very important area that serves data intensive research methods and fosters collaboration and advanced data analytics. While the Draft Roadmap mentions the existence of domain-specific infrastructure, there is no specific description of the rationale or importance of this infrastructure in meeting the unique requirements for storing, accessing and publishing a wide range of human data, particularly that pertaining to individual people. It has been our experience that platforms established for managing large quantities of data such as high performance computing equipment and open research cloud computing facilities are often not appropriate for use in population research as the data is not sufficiently protected from breaches to individual privacy. The health sector is internationally recognised in securely managing and using data to better understand disease risks and opportunities for prevention and improved planning and delivery of health



services. It is important that the research infrastructure underpinning these strengths be maintained and enhanced to meet future demand.

The matching of service data for individuals across a range of government programs also has inherent risks of errors in matching and analysis. As the use of government service data for policy and other purposes increases, more attention to matching and analytical approaches will be required to ensure that the data are of the highest quality and fit for purpose. The health sector, through the Population Health Research Network (PHRN), has considerable strengths in matching and analysis which could be drawn on for other sectors.

### **Platforms for Humanities, Arts and Social Sciences (HASS)**

In order to harmonise platforms for social science research, there is a need to consider the authorising environment for sharing, integrating and accessing data between different disciplines. The population health field, that encompasses areas of health services research and public health, has made great gains in this area through the PHRN and initiatives of the Commonwealth Government in setting up Statistical Integrating Authorities. The health sector has also been a leader in linking health, education, social, economic and geographic data, enabling understanding of complex interactions between social and health factors. Lessons from these initiatives should be considered in developing harmonised and integrated platforms for social science that allows for the collection, integration and re-use of data.

Research data infrastructure that safeguards privacy and is delivered independently of government is critical for timely, policy relevant research.

### **Therapeutic development**

We recognise the development of therapies and medical devices as an important area of health and medical research expanding health care and supporting new technologies and industry. However, this investment should be additional to sustaining and enhancing infrastructure for research into how we can maintain a healthy population and improve the care delivered in our systems. The Draft Roadmap considers the linkage of health and disease registries as necessary to realise best research outcomes but does not consider the non-therapeutic use of routinely collected health (and social) information. The Sax Institute considers this to be a gap in the Draft Roadmap as the improved use of this information in population health planning and delivering health interventions to increase the effectiveness of health care is critical for the sustainability of our health system. This does not only involve new therapeutic development but also the allocation of existing health resources, reducing health services use where possible and using technology to deliver more person-centred care. Like other fields, the increasing capability to routinely collect, store and analyse data opens up new possibilities for research into understanding the operation of our health systems.

We suggest that, without in any way diminishing the importance of research that improves therapeutic capacity, the complexity of maintaining a healthy society requires research infrastructure to support a broad range of research, including health services and public health research as identified in the national research priorities.

Perhaps this focus area might be referred to as 'Healthy Society', or some other title that recognises the complexity of research in the health arena.

