

Submission

2016 National Research Infrastructure Roadmap Capability Issues Paper

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The Sax Institute welcomes the opportunity to contribute to the 2016 National Research Infrastructure Capability Issues Paper. The purpose of this submission is to make sure that the capability areas for future development in the Issues Paper are the right ones.

The Sax Institute is an organisation that assists policy agencies and service providers to use research evidence and expertise. Accordingly, it strongly endorses the priority given to big health data in the Issues Paper and supports any investment in infrastructure that will facilitate the secure and appropriate use of big data and improve access to data holdings, both public and private, with a primary purpose of using the research findings to improve the health, quality of life and wellbeing of all Australians.

The Sax Institute houses the Secure Unified Research Environment (SURE) which was purpose-built to facilitate access to large, sensitive, human datasets to support better use of our national knowledge base. Funded through the National Collaborative Research Infrastructure Strategy as part of the Population Health Research Network, SURE has been providing services to researchers and data custodians nationally since 2012 and continues to increase its number of users, research projects, data collections and fields of research.

In this submission, we propose an expansion to the 'Health and Medical Sciences' and the 'Culture and Communities' capacity areas, which could be more inclusive of a number of issues important to Australians for which our nation's research community has played a part and is well positioned to play an even larger, more valuable role in the future. We provide our comments in this regard under questions 15 and 24 and, for each, international examples (questions 16 and 25, respectively).

Health and Medical Sciences

[Question 15: Are the identified emerging directions and research infrastructure capabilities for Health and Medical Sciences right?](#)

The first of the five emerging directions and research infrastructure capabilities for Health and Medical Sciences is big health data. Importantly, this recognises the emerging importance of big health data collections and the value of linking them together with patient-level holdings (i.e. electronic medical records and survey data) and patient-level data derived from biological samples. The opportunities identified, however, focus primarily on biological determinants of "disease" and the "design and clinical trialling of treatments". There are broader opportunities for big health data that are missing that likely offer high value to Australians.

In the future, big health data also provide the opportunity to identify non-biological determinants of illness and disease and non-medical interventions designed to prevent illness and disease and protect the health of Australians resulting from, for example, the rising prevalence of chronic conditions and multi-morbidity. In the last few years, for example, big health data have been used to elucidate reasons for variation in preventable use of hospitals, in particular geographical regions

with unusually high complications from chronic conditions such as diabetes. While we know that smoking is associated with increased risk of preventable hospitalisation for chronic conditions in older adults, big health data have shown that smoking cessation, even at older ages, reduces this risk. We have learnt from big health data that even a small drop in BMI will reduce hospitalisations for people with above normal BMI, potentially reducing annual health care costs.

In Australia big health data have been used to identify factors that protect people from disease such as people living in greener communities having a reduced incidence of type two diabetes, and the beneficial impact of social cohesion among elderly people who most strongly identified with, and felt connected to their neighbours and communities.

In Australia big health data have shown that increased walking and cycling have positive health-related benefits. More specifically, there is compelling evidence now which links attributes of urban design with physical activity among adults. Attributes of urban design such as the number of destinations within walking or cycling distance, greater diversity in land use, shorter distance to transit, and neighbourhood walkability have shown to increase physical activity among adults. In addition to the health benefits, health-related economic benefits of changes in urban form have also been shown to be significant at a population level.

In the future, big health data provide the opportunity to identify the impact of risk factors for illness and disease health that are rapidly changing in prevalence, as well as interventions that reduce risk or mediate impact. In the last few years, for example, big health data have examined why some local areas lead the nation and outperform other similar communities in relation to infant and child health, healthy body weights and low smoking rates. Researcher analyses of big health data have identified low income, regional communities where infant and child mortality rates are better than big city, high income areas. And while we know that smoking is associated with increased risk of preventable hospitalisation for chronic conditions in older adults, big data have shown that smoking cessation, even at older ages, reduces this risk. In the future, Australian researchers using big data should be able to offer more insights as to what factors, programs or interventions underlie these success stories.

In the future, big health data provide the opportunity to better describe unwarranted variation in use of medical care and better design interventions that improve the appropriateness of health services. In the last few years, for example, big health data have been used to research why there are geographical variations for diabetic patients experiencing life-altering complications, and very high prescribing rates of antidepressants, anxiolytics and antibiotics. Specifically, linked data have been analysed to identify high-risk-prescribing in people subsequently hospitalized for diabetes, and have shown strong correlations of high rates of use of anti-depressant medications in people with poor physical ill-health and lower socio-economic status. In the future, Australia researchers should quantify the impact of medicines (positive or negative) across populations and identify where to focus their research and development of new medicines. This will enable governments to identify where interventions are needed to reduce inappropriate use of medications.

[Question 16: Are there any international research infrastructure collaborations or emerging projects that Australia should engage in over the next ten years and beyond?](#)

In terms of the emerging directions described in Question 15, there are a number of international initiatives where Australia's research community could collaborate or could learn from (i.e. "streamlined approval process, without requiring interaction with multiple data custodians, ethics committees and data linkage units").

Understanding Cultures and Communities

Question 24: Are the identified emerging directions and research infrastructure capabilities for Understanding Cultures and Communities right? Are there any missing or additional needed?

The Issues paper highlights three emerging directions – innovation and translation, digital humanities and digital repatriation and future role of culture and data institutions. Importantly, these three emerging directions, as well as current capabilities and emerging capability needs (section 8.2) and desirable capacities (8.3), miss broader and bolder research opportunities for big health data that likely offer high value to Australians.

In the future, big health data should provide the opportunity to better understand and evaluate interventions designed to improve complex social, culture and community issues such as domestic violence, teenage pregnancy, disengaged youth, multi-cultural integration, mental health and addictions, persistent unemployment, healthy aging and fiscal independence in retirement. In Australia research is desperately needed to improve our understanding of the pathways that lead towards or prevent the prevalence or impact of these circumstances on individuals, families and communities.

None of these issues are identified as emerging issues or capacity gaps, and in recent years there is rapid growth in supply and demand for research, based on big health and linked data, to shed new light on policy levers, programs and interventions to address these contemporary threats to the vitality of families and the security of communities.

In the last few years, for example, big health linked data research initiatives have commenced in Western Australia and New South Wales to explore the relationship between maternal and child health, educational attainment and child protection involvement. What might the future for this type of research hold for Australians? By linking health, human services and education data between 2001 and 2016 in Manitoba Canada, researchers have shed light on the impact of teenage pregnancy¹ and the impact of interventions designed to improve health and educational outcomes among teens and their offspring. These data have been used, for example, to estimate that children in care are three times as likely to commit suicide and twice as likely to attempt suicide than children who have not had contact with family services. It has also been used to evaluate programs to improve mental health and suicide risk among children and teens, and has been used to show the impact of a social media campaign on sexual assault crimes. In the future, this is the type of research that should be underway in Australia to influence interventions and health locally.

Population ageing in Australia presents challenges which have not been fully explored through big health linked data research initiatives have recently commenced. These are not only health based challenges, but social and community based challenges involved in transitioning out of the workforce with people now having considerably longer life expectancies following retirement. In recent years, research with big health data in Australia have shown that retirees are more likely to increase their physical activity, and among women, have smoking cessation rates double following retirement compared to their same-age, working peers. It has shown the relative risk of early dementia and death among older adults with a history of mental illness, that higher fruit intake is associated with

¹ For example, in Manitoba (population 1.3 million) only 16.5% of all children are born to adolescents and mothers who had their first child as a teen. However, these children account for 27% of first-year hospitalizations, 34% of deaths (birth to 17 years), 30% of failures to graduate high school, 51% in foster care, 44% on welfare as young adults, and 56% of next-generation young teen mothers.

lower relative risk of all-cause and disease specific mortality among elderly women and the amount of recreational physical activity that is needed for elderly men to reduce the risk of major vascular events. In the future, this is the type of research that should be accelerated in Australia to influence interventions and health more broadly.

Question 25: Are there any international research infrastructure collaborations or emerging projects that Australia should engage in over the next ten years and beyond?

In this area of culture and community there are international assets available for Australian researchers to access if they are involved in a national research network which can facilitate collaborations. For example, researchers affiliated with the Population Health Research Network have opportunities to learn about international research data assets. That said, most Australian policy and practice community favour health services research conducted within our nation due to the relevance of research context as a determinant of adoption and use of research findings locally.

At the same time, however, there are international research assets that offer examples about what might be done with Australian big data and linked data to make it more useful to researchers or research users in our nation. There is one international example of linked health, human services and education linked data in Manitoba Canada (PATHS) that is responsible for some of the culture and community research examples outlined. It might provide one example about how Australia might improve access to population-based, multi-agency, multi-jurisdiction linked data.

The PATHS Data Resource is a unique database comprising data that follow an entire geographic population of all children from the prenatal period to adulthood. It was developed for conducting longitudinal research into child health, health care and equity and contains individual-level data on health, socioeconomic status, health care, social services and education. Individuals' data are linkable across these domains, allowing researchers to follow children through childhood and across a variety of sectors. PATHS includes nearly all individuals born between 1984 and 2012 and registered with Manitoba's universal health insurance program at some point during childhood. All PATHS data are anonymized. Key concepts, definitions and algorithms necessary to work with the PATHS Resource are freely accessible online and an interactive forum is available to new researchers working with these data.

The PATHS Resource is currently being used to evaluate interventions, program or policies such as the impact of the location of social housing on the health and educational outcomes of residents; a prenatal benefit for low-income pregnant women on birth outcomes and infant health; and a pay-for-performance physician-funding model on immunization and vaccination rates.