

Productivity Commission

Inquiry into Data Availability

and Use

Post- draft Report

Submission

12 December 2016

## Introduction

The Sax Institute welcomes the opportunity to provide further information and input to the Productivity Commission following the release of the Data Availability and Use Draft Report and participation in the public hearings.

### General comments on Draft Report

- The draft report is well-researched and makes a strong case for reform of policies and processes for access to the wealth of government and other data that is generated in the course of day-to-day transactions.
- The draft report strikes a good balance between access to data and the protection of private information and includes proposals that would provide the public much more transparency about what data is held and robust mechanisms to have any errors corrected.
- The draft report recognises that improved data availability and use is dependent upon a complex array of reforms to ensure the integrity, transparency and trust in the collection and use of data, including legislation, enhancement of infrastructure and business and government processes, better use of ICT and education and community awareness raising.
- The choice of the health sector as a case study in the draft report is welcome and highlights the benefits already achieved in the use of data to improve health outcomes, how the health of the population can be maintained and improved and the significant gap that exists between current data access and use in the national health system and best practice internationally in developed countries.
- In order to maximise the gains from enhanced data availability and use in the health sector, it will be important that all government jurisdictions (not just the Australian government) are committed to the process as well as the private insurers and providers. The funding and regulatory arrangements in the health sectors are complex, as highlighted in the case study.

### Draft Findings and Recommendations – Information requested by the Commission

#### **The Commission seeks further views on the most practical ways to ensure improvements to linked datasets are available for subsequent dataset uses.**

Australia has made good progress in the linkage and analysis of population health data; this provides an opportunity to really understand key drivers in the health system and to improve care and efficiencies. Government, at both the national and state and territory levels, is increasingly interested in using this data for research to inform its work; indeed the Senate Select Committee on Health recently published its finding on big data noting that:

*A recent estimate by Lateral Economics suggests that Australian government held health-specific data alone could contribute up to \$5.9 billion per annum across the economy. Data linking is the bringing together of two or more de-identified datasets to create a new, richer dataset. Using data linkage techniques, researchers, clinicians and government administrators can deepen their understandings of the ways people use the healthcare system while maintaining patient privacy. This has the potential to inform government policy making and decisions about improving health service delivery [4]*

The quote above can be extended to many areas of public policy making where data linkage is required to fully understand and analyse the problem. This is of course true in the health sector, with the different Commonwealth and State and Territory responsibilities for health administration, funding and service delivery but is also true of many other areas that have significant impacts and linkages to health outcomes including family and children services, education, housing, transport and the environment.

The health sector has considerable experience in the use of linked data. The Population Health Research

Network (PHRN), a part of the National Collaborative Research Infrastructure Strategy (NCRIS) supports data linkage units covering national data and all states and territories, and a secure data access facility (SURE- see below for more detail) . Several of the initial submissions to the Data Availability and Use Inquiry provide relevant examples of multiple uses and reuses to which linked data have been put (e.g. submissions 13, 21, 46, 56 and 110)

**The Commission seeks more information on the benefits and costs of a legislative presumption in favour of providing data in an application programming interface (API) format, specifically:**

- **In which sectors would consumers benefit from being able to access data in an API format?**
- **What are the main costs and barriers to implementing APIs?**

No comment

**Further views are sought on the effects of providing access to consumer data, as defined. In particular, views are sought on the potential creation of incentives for deliberate de-identification of data holdings to avoid providing access, and whether effective and low cost remedies to such behaviour could be introduced. The Commission seeks views on what methods of disclosure would be most likely to result in consumers making a meaningful choice about how their personal information is being used, and how these disclosure requirements might best be implemented.**

Care needs to be taken in providing incentives across the board for de-identification of data. In the health area de-identification of data would impede very useful data linkages that could considerably enhance the use of the data. This might be a matter usefully to be explored through the proposed Parliamentary oversight committee

**The Commission seeks further views on datasets that are of national interest and that could feasibly be designated as such under the process proposed.**

Presumably all datasets created as part of the business of governments (federal, State/territory and local) should potentially be designated as national interest (with any exceptions to be justified through a transparent process)

**The Commission seeks further views on the establishment of a Parliamentary Committee to take community input on possible National Interest Datasets, to review nominations made, and make proposals for future designations. Views are also sought on practical alternatives.**

We support a Parliamentary Committee process. Alternatively, the office of the proposed National Data Custodian could undertake such a role.

## **The health sector: additional matters for Consideration**

### **1. As pilot for implementation of the Commission's recommended approach**

While strongly supportive of the national Framework proposed in the Draft Report, the task of creating such a comprehensive approach would be extremely challenging, particularly given Australia's federal governmental structures with the added complexity of commercial and other non-government arrangements across the economy.

The Commission might consider recommending using the health sector as demonstration and concept testing first step in the implementation process. . There are a number of considerations that support such an approach:

- The size of the health sector (10% of GDP) and reach (the whole population);
- The importance of the health sector for societal wellbeing The complexity of the health sector that involves national and state and territory governments, the private sector including many small businesses, eg medical practices, and the not-for-profit sector and the impediments to data sharing and access that arise as a consequence of this complexity.
- The evidence is that there is a significant gap between the access to and use of health data as practiced in Australia and the approach that applies in leading developed countries internationally.

This gap does not just adversely impact on the ability to undertake research on health data but also, most importantly, on the ability to manage the health system efficiently and effectively and achieve the best possible health outcomes

- There are already structures within the system that have made considerable progress in the use of data from all parts of the sector to understand better the underlying factors in health risk, more effective means of service delivery and the introduction of new technologies into the system.
- There are effective structures to support consumers in getting access to data and seeking remedy where things go wrong (eg state/territory health complaints commissioners).
- There is strong research and analytical capacity across the health sector, particularly in the use of linked data and assessing value for money in health investments.

Using the health sector as a demonstration project and concept tester will enable the full range of issues to be worked through, accelerating progress in the health sector and ensuring that all the relevant issues have been identified and worked through before being applied across all sectors. Furthermore the complexity of the health sector, with various levels of government having different roles and responsibilities and interacting with both the private sector and not for profit sector does indicate that a nationally coordinated approach does need to be taken to the improving the health sector's access to and use of data, as well as consumer access to health records.

## **2. The use of information technology to provide greater access to sensitive data for public good purposes in a secure environment that protects privacy**

The Secure Unified Research Environment (SURE) provides a model for making sensitive data available to 'trusted users' in a convenient and secure way.

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 has rapidly expanded its number of users, research projects, data collections and fields of research supported.

Due to privacy concerns relating to the types of datasets that users access, SURE has not been established as a data repository. Specific workspaces are set up to accommodate discrete projects or programs of work with users able to access and analyse the data without it been stored on their local computing environment. Only data specific to those projects are stored in SURE. SURE provides a high-security environment, that isn't dependent on a researcher's workplace, which facilitates the use of data from different custodians and also the collaboration of researchers working across multiple institutions, including overseas-based researchers. SURE takes a multi-faceted approach to managing data security including controls related to people, technology and processes including:

- **Curated Gateway** –the control point for the movement of data into or out of the facility. Copies of all files must be approved before they are made available within, or outside the facility. Periodic audits are taken of a sample of these files.
- **User authentication** – multiple authentication measures are in place including unique username, password, token and client digital certificate.
- **Secure data storage** – data is stored in servers located in a high security commercial data centre in which there are strict access controls and continuously staffed surveillance.
- **Breach and incident management** – all users are required to undertake mandatory training on information security and sign agreements that comply with Australian research standards and the Australian Privacy Principles.

SURE currently hosts data for over 60 projects and has more than 300 researchers involved in projects using the facility. Data extracts analysed in SURE come from a wide range of sources including state, territory and national government departments and non-government data sources, including:

- Hospital admissions including emergency departments
- Mortality data

- Births registration
- Electoral roll data
- Cancer registries
- Communicable disease registries
- Perinatal data
- Immunisation registries
- Cohort studies – 45 and Up Study, Australian Longitudinal Study on Women’s Health, Pathways of Care Longitudinal Study
- Clinical registries – Australian and New Zealand Intensive Care Society CORE Data, Australian & New Zealand Society of Cardiac & Thoracic Surgeons
- Medicare Benefits Schedule
- Pharmaceutical Benefits Scheme
- Australian Early Development Census

The technology on which the SURE facility is built is not specific to health data. SURE deals with data from a range of sources (as indicated above) and could in principle be extended to other data from sectors other than health, or indeed from data outside that produced by governments.

### **Conclusion**

The Sax Institute would be very happy to assist the Productivity Commission further on this very important inquiry, particularly in regard to our proposal to have data access and use in the health sector treated as a demonstration project and high priority application of the reform principles and approach set out in the draft report.