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Mr Stephen Palethorpe
Committee Secretary
Senate Selecte Committee on Health
Via email: health.sen@aph.gov.au

7 December 2015

Dear Mr Palethorpe

Re: Submission to the Senate Select Committee on Health

The Sax Institute welcomes the opportunity to provide a submission to the inquiry of the Senate Select Committee on Health focussed on improving access to and linkage between health data sets held by Commonwealth entities.

Data sets held by Commonwealth entities are an extremely valuable asset informing health policy and administration. Effective use of routinely collected data is a critical part of the solution to address health challenges of our nation. Getting the most out of this national asset depends not only on infrastructure to conduct data linkage but also on data governance systems to allow for secure access and analysis and the skills within the workforce in data analysis, interpretation and research translation. The enclosed submission responds to the specific areas of focus: collection, linkage and access to health data; international policy developments; challenges faced; and reform proposals that may improve overall health outcomes.

I would be happy to provide a response to any questions from the Committee arising from this submission or provide further information. Additionally, I, and Mr Robert Wells, Deputy CEO at the Sax Institute, will be appearing as a witness at the public hearing in Sydney on 11 December 2015.

Yours sincerely

Sally Redman, PhD
Chief Executive Officer

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Sax Institute Submission to the Senate Select Committee on Health

Data, particularly the analysis of routinely collected data, plays a critical role in assessing the impact of changes to funding and other aspects of health policy in Australia. As noted by the 2014 National Commission of Audit, "There is untapped potential to use anonymised data and new data analytic techniques to improve the efficiency and effectiveness of government. The Commission recommends that the Government, recognising the need to safeguard privacy concerns, rapidly improve the use of data in policy development, service delivery and fraud reduction" (Recommendation 10.5).

By analysing individual-level and aggregate linked health, medical, demographic and other social records, there is great capacity to improve our knowledge of health system design, performance and evaluation. There have been great improvements in national health data linkage infrastructure in the last five years through the development of the Population Health Research Network (PHRN) funded by the Australian Government National Collaborative Research Infrastructure Strategy (NCRIS). However, there are still areas for improvement to enhance the enabling environment to allow Australia to get the most from publicly-funded health data.

The Sax Institute is a national leader in promoting the use of research evidence in health policy. One of the functions of the Institute is to build and maintain research assets that enable high-quality research and produce new knowledge for decision making. One of these assets is the Secure Unified Research Environment (SURE), funded as part of the PHRN, which has been designed to facilitate secure access and analysis to large and sensitive datasets, particularly linked data sets.

SURE gives research analysts secure, remote access to the data they require through a secure, encrypted internet connection from their usual working environment, with the data held centrally on servers controlled by the Sax Institute and housed in a top-tier, highly secure data centre. SURE eliminates the need to release data sets to research analysts and thus, eliminates the risks presented by lack of secure storage or data transfer via portable media such as CDs and USB drives. SURE provides state-of-the-art analytical software for analysts to use, high processing speeds and more than sufficient data storage capacity. Importantly, SURE permits widely dispersed investigators to work easily together on complex analytical projects.

SURE has quickly established itself as part of Australia's research fabric since its launch in 2012. As noted by Dr Ron Sandland, Chair of the Commonwealth Research Data Infrastructure Committee and the Australian National Data Service, "SURE is just one excellent example of the type of advantage that Australia has been building through the development of research data infrastructure, which spans data management and reuse, storage, generation and tools for analysis and interpretation. Not only are developments of this kind of national importance, in many cases they are world-leading[1]."

Despite these significant gains in recent years, there are a number of key challenges in increasing access to health data, particularly data from different sources that are linked together:

- First and foremost, is ensuring that data is adequately protected and securely stored when released. There are sophisticated methods employed by data linkage units that exist in various government agencies at a Commonwealth and state/territory level to ensure that an individual's privacy is protected in the linkage process. As the number of data collections linked increases, the information content of each record becomes richer and the risk of inadvertent (or, perhaps, malicious) re-identification of technically non-identifiable records increases. As a result, the importance of secure access to, and storage of, such records increases.

[1] Share: newsletter of the Australian National Data Service. Issue 13: Published July 2012 (accessed: http://ands.org.au/newsletters/share-newsletter-archive.html)

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- An additional barrier faced in access to health data is the Commonwealth and State and Territory divide in the governance of health information. Understanding issues such as integrated care and treatment of chronic conditions that span multiple parts of the health system are only possible through access to data collected from diverse sources. Currently, there is a lack of consistency across Australian jurisdictions in relation to data access, approval and supply which results in lengthy application processes and duplication of paperwork.
- There are circumstances in which data collected for administrative purposes are not easily released for research purposes (as this is a secondary purpose of the collection). The efficient and effective functioning of our health systems heavily relies on making better use of the large volumes of data collected in the provision of health services. The benefit of using these data needs to be carefully considered as part of the data governance environment in the future, taking account of the greatly increased security of data transition, storage and protection of anonymity.
- Building workforce skills and capacity are also critical to realising the benefits of improving data access and linkage. There is not only a need to strengthen skills in the workforce to build capability in analysing large, complex, linked datasets, but also the need to build skills and knowledge of the datasets themselves so that there is a greater awareness of the content and complexity of these datasets and the ability to interpret the results of data analysis. A range of strategies may assist in building skills including training for researchers and public officials and partnerships between government agencies and the academic sector to share information and expertise.

The following reform proposals are suggested to enhance the capacity of data analysis to contribute to improved overall health outcomes. These relate to increased information on available data and new requirements to make publicly funded data available and improve the consistency of the arrangements for data approval and release:

- There is the need for clear communication and detailed information on routinely collected, administrative data that are also valuable research resources. Publicly available information on available datasets, detailed information (metadata) on the contents of the datasets and easily accessible application forms and conditions of release are all components which would facilitate greater access to health data.
- Publicly-funded health and health-related datasets, in non-identifiable form, should be available for research wherever legally and practically possible and should not unreasonably be withheld from research nor delayed by unnecessarily complex or costly processes. This may be facilitated by building in a requirement to make data available for research and analysis in funding agreements as a key performance indicator for government agencies. Increasingly, research funders or publishers require not only that research publications are stored in an open access repository but also that underlying datasets are also made available. While this may not be possible for sensitive, individual-level data sets, this may be appropriate for many forms of data used to assess health outcomes and health system functioning including aggregate information on specific health conditions or health service provision.
- Wherever possible, all levels of government should seek to harmonise access approval and data supply processes with other data custodians responsible for similar or related data sets (particularly data sets that are commonly linked). In addition, these access, supply and data security requirement should be proportional to the re-identification risk in use of de-identified data.
- Publicly-funded data should be viewed from a perspective of stewardship rather than ownership. In a context in which, data volumes are growing exponentially, the need to organise, share, analyse and link datasets will only become more urgent. There are opportunities for clinical data, such as electronic health records, to be linked with routinely collected data through Medicare and other social service information to gain a complete picture about the operations of our

health system and the public's experience to inform public policy development. There are also well-established cohort studies with highly detailed health and demographic information such as the 45 and Up Study and the Australian Longitudinal Study on Women's Health that should be considered as part of the broader, national data 'infrastructure.'

The increasing adoption of eHealth records across the health system is an important development in the context not only of improved and more effective clinical care, but also in the ready availability and capacity for linkage of transactional data for research (both clinical and population health), quality improvement and health system planning and evaluation. In implementing eHealth at jurisdictional and national levels, the opportunities to enhance existing data linkage and analytical approaches should be included in planning and design.

Internationally, there are a range of policy developments that may be of interest to the Committee, particularly related to data governance and the use of linked data in monitoring health system performance. This includes a recently published resource on data governance by the OECD (released in October 2015) titled *Health Data Governance: Privacy, Monitoring and Research* http://www.oecd.org/health/health-systems/Health-Data-Governance-Policy-Brief.pdf. The NSW Bureau of Health Information also recently released a report focusing on using linked data to reflect on health system performance in which the environments in a number of international jurisdictions were compared (including the UK and Canada) http://bhi.nsw.gov.au/publications/data_matters_series.

In summary, there are existing challenges but a great deal of potential to improve access to and linkage between health data sets held by Commonwealth entities. It is encouraging to see the progress that has occurred in recent years, a further demonstration of this has been the release of individual-level, non-identifiable Medicare Benefits Schedule and Pharmaceutical Benefits Scheme to State and Territory health departments and the subsequent training program that has been facilitated by the Sax Institute. There is greater openness in relation to providing access to data for analysis and research, facilitated by improvements to data governance, national and state and territory data linkage infrastructure and data security. For example, the SURE model has been adopted by a number of important custodian groups in Australia such as the Australian Institute of Health and Welfare and is in a position to be implemented more widely. The benefit of the SURE model is that it is not only applicable to academic research. Policy agencies often face barriers in sharing information for the purposes of policy development, monitoring and evaluation. SURE offers a secure and controlled environment to share and analyse information for these purposes.

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SURE: the secure unified research environment

A gateway to better health systems using the power of linked data

Australia has one of the world's most comprehensive collections of population-based health data but its potential is yet to be realised. SURE is a high-powered computing environment developed to help overcome these barriers to making best use of our national knowledge base.

It has been purpose-built as Australia's only remote-access data research laboratory for analysing routinely collected health data. It offers data custodians a secure vehicle for making datasets available to researchers.

HOW DOES SURE WORK?

Each accredited researcher is allocated a virtual computer, which runs entirely on hardware physically located at and controlled by SURE. Researchers see a facsimile of the remote virtual computer screen on their local screen. This eliminates the need for them to use their local computing environments, which may have technical and security limitations. SURE's high-performance computing environment provides enhanced speed, storage and cutting-edge analytic software and tools.

OUR APPROACH TO INFORMATION SECURITY

Our planned, documented and comprehensive approach to managing information security includes:

- Defining requirements for managing information security through exhaustive risk analysis
- Implementing controls in relation to people, technology and processes
- Continuous monitoring and review.

SECURITY FEATURES

Strong access authentication

Users must undertake training in privacy, ethics, statistical disclosure control and information security. Complementary deeds of agreement with individual users, institutions (researchers' employers) and data custodians cover data security and breach management. Third party partners enter into contractual arrangements to ensure compliance with the security standards and procedures required for SURE.

Physical security

SURE is hosted in two physically separate tier-3+ data centres in Sydney (the highest possible level) that also service some of Australia's leading telecommunications, government and financial institutions. The data centres are members of the Australian Government Data Centre Facilities Panel, have strict access controls and continuously staffed surveillance. No data are stored on a researcher's local computer or in their institutional computing environment.

Data security

All files entering or leaving SURE must pass through a purpose-built portal called the Curated Gateway – the control point for all information flow in and out of the facility. Both inbound and outbound files are reviewed to ensure they are consistent with ethics and data custodian approvals and are appropriately anonymised.

The original dataset provided by the custodian is not allowed to leave SURE. Data custodians can request that they prospectively review all or samples of the research output material leaving SURE, to assure compliance with this restriction. Copies of all inbound and outbound files are kept and all file movement activities logged to allow periodic audits to be undertaken.

Within SURE, a user cannot access the internet, email, print or copy data to a USB memory stick or to other removable media.

After a research study is complete, data files are digitally archived in encrypted form and retained in secure storage for the period required by the researchers and data custodians before being destroyed.

Computer and network security

Security is enhanced by rigorous partitioning within SURE of project and study workspaces, ensuring complete separation of each study and its associated data from all others. Three separate firewalls plus VLANS mediate this internal network separation. Intrusion detection and log monitoring systems are in place to detect and prevent potential attacks and maintain data integrity. The entire SURE system runs behind a three-layer firewall with both physical and logical separation of DMZs. Changes to the IT environment are assessed for information security risk before being implemented.

Users are issued with strong, confidential passwords that adhere to SURE guidelines. They are unable to change the passwords themselves. They must also use a physical authentication token for security protection, similar to those used by many banks. Client digital certificates issued by the SURE team must also be installed on each computer used to access SURE.

Incident management

Users must report information security incidents and undertake other actions as directed. SURE staff will investigate information security incidents according to documented protocols and provide timely communication on any security-related service disruptions.

Business continuity

Business continuity and disaster recovery plans are in place and comprehensive backup and restoration processes are in place and regularly tested. All off-site backups and archival data are encrypted before being transferred to secure off-site storage. For users of SURE in academic environments, network access is via the dedicated AARNet research network, rather than the internet.

Breaches and infringements

Breaches or infringements will be investigated as outlined in SURE agreements, which are consistent with the Australian Code for the Responsible Conduct of Research and the Australian Privacy Principles.

WHO IS BEHIND IT?

SURE has been developed by the Sax Institute, a non-profit organisation whose mission is to improve health and wellbeing by driving the use of research in policies, programs and services. The SURE project is part of the Population Health Research Network (PHRN) which is working across the states and territories to develop national health data linkage infrastructure.

FOR MORE INFORMATION

Please contact a member of our team to discuss how SURE can meet your needs as a data custodian.

E sure-admin@saxinstitute.org.au
T 02 9188 9561
W www.sure.org.au

SURE
Secure Unified Research Environment

SURE: the Secure Unified Research Environment

A powerful computing solution bringing researchers together to answer important health questions.

What is SURE?

SURE is a secure computing environment that Australian researchers can log in to remotely to analyse health data from different sources such as hospitals, general practice and cancer registries. These data have been linked together to form records of health events for individuals over time.

SURE is Australia's first and only remote-access data research laboratory for such linked health data, and will promote "Big Science" in health research by boosting our capacity to conduct large-scale collaborative research projects that tackle major health issues.

Who can use it?

Researchers must apply for accreditation to use SURE. They must be part of a research project involving the analysis of linked health-related sets of data, which has approval from a human research ethics committee and the owner of each individual data set. All users must complete training on privacy, ethics, information security and statistical disclosure control and sign a deed that sets out the terms and conditions for using SURE.

What are the benefits?

Research collaboration and capacity

Because SURE can be accessed remotely, researchers from different institutions at different sites across Australia will have new opportunities to collaborate on important, large-scale research projects in the national interest. SURE will allow them to share cutting-edge methods and tools, increasing the quality and efficiency of their research. This will help to boost the international competitiveness of our researchers and attract new research funding.

Getting the best from national and state health information

SURE allows researchers to use anonymised linked data in ways that were previously not possible. This will mean reduced fragmentation and a chance to use the data generated routinely by our health services in ways that will benefit the Australian population.

High performance

The high-performance nature of the SURE computing environment will mean faster analyses and greater storage capacity for researchers dealing with these large research data files. Its leading-edge analytic software and tools will reduce analysis time, allowing research projects to be completed faster.

Security

SURE provides a consistent level of security so that all researchers using it to work with data follow the same security protocols. No data are stored on a researcher's local computer or in their institution's computing environment.

All data accessed in SURE are anonymised by the data owners before they enter the system. Computers used to access SURE must meet certain security requirements. Within SURE, users cannot access the internet, print or use removable media.

A complete audit trail of all information entering or leaving SURE is maintained. The facility is protected by multiple firewalls and data are stored centrally on servers located in a high-level secure data centre with strict access controls and 24-hour security surveillance.

How does it work?

SURE is accessed via AARNET (the Australian Academic and Research Network) or the internet using an encrypted connection from researchers' local computers, which must meet security requirements. Within SURE, users are provided with a remote virtual computer desktop for each research study they are involved in. On their local computer screen, users see a facsimile of their remote virtual desktop, and keystrokes and mouse movements made on the local computer are transmitted to the remote virtual desktop computer in the SURE facility. These remote desktops are highly-specified 64-bit Microsoft Windows 7 systems with a range of proprietary and open-source data analysis software installed.

Inside the facility, each research study is confined within its own security perimeter so there is no possibility of data exchange between studies. Files enter and leave SURE via a portal called the Curated Gateway. They are reviewed before being available to researchers, and research outputs cannot leave the facility without undergoing a confidentiality assessment. The movement of all files is logged to allow for later audit.

After a research study is complete, data files are digitally archived in encrypted form and retained in secure storage for the period required by the researchers and data providers before being destroyed.

Who is behind it?

The SURE project was developed by the Sax Institute, a non-profit organisation whose mission is to improve health services and programs by increasing the use of research evidence in health policy.

SURE has been funded by the Australian Government Department of Industry, Innovation, Science, Research and Tertiary Education, and the NSW Government.

It is part of the Population Health Research Network (PHRN), an initiative that is working across the states and territories to develop national health data linkage infrastructure capable of securely and safely managing health information from around Australia. Developing this infrastructure puts the foundations in place for research to inform better healthcare delivery and improved health outcomes.

The PHRN was established with funding from the Australian Government, state and territory governments and academic partners.

For more information

Information on access charges is available from the SURE team, based at the Sax Institute in Sydney. All users must receive training before accessing SURE.

To contact us:

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T 02 9514 5950
or visit our website at **www.sure.org.au**

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PHRN Population Health Research Network