

National Digital Strategy Consultation Submission from the Sax Institute

The Sax Institute is a not-for-profit organisation that provides a bridge between researchers and health decision-makers giving each the tools to work more closely together to benefit all Australian. In order to do this we:

- Build and retain assets that enable high quality research and produce new knowledge for decision-making;
- Drive research that contribute to policy, program and service delivery options; and
- Give decision-makers access to relevant research funding and research expertise.

Sax Institute organisational priorities in respect to digital health and eHealth

The capacity to link administrative data for services provided across the health system (e.g. MBS, PBS and hospital services) and with other datasets (e.g. clinical and death registers and other relevant datasets such as welfare support) provides an extremely valuable resource for research to understand better patterns of diseases, performance of the health system and opportunities for health improvement through adjustment to policy settings. The availability of health service and clinical information in “real time” through the My Health Record would be a significant boost for health research.

Analysis of linked data from these sources alone can provide significant intelligence for those setting health policies and programs and for service planning and delivery managers.

However, the value of health data can be enhanced by orders of magnitude when administrative data (as discussed above) are linked with survey data from population studies that provide important additional information for a cohort of people over time which is not available from administrative data alone. One example of a cohort study is the Sax Institute 45 and Up Study which follows over a quarter of a million people over 45 from NSW and has been running since 2010. Participants in their Study have consented for this Study data to be linked with health and related administrative data for research purposes. The Study provides a wide range of data provided by the participants, including background, behaviours affecting health including smoking and alcohol consumption, housing, lifestyle and exercise, diet, employment and social and emotional information.

There have been over 200 research papers published using Study and linked data in diverse areas such as obesity, access to services, tobacco consumption and cancer. A list of all publication from the study is at:

www.saxinstitute.org.au/publications/45-and-up-study-research/

Barriers

To gain maximum value from My Health Record data, the current legislative restriction that allows de-identified data only to be released for research would need to be reviewed (My Health Records Act 2012 (Cth), sections 15 and 139). Perhaps it would be desirable for the My Health Records Act to be aligned with the Individual Healthcare Identifiers Act 2010 (Cth), section 24, which allows individual healthcare identifiers to be released by healthcare providers for the purposes of research approved by a Human Ethics Research Committee.

A major gap in the availability of health data has been in the area of services provided outside the Medicare and other publicly funded frameworks. One important gap is in elective surgery admissions to private hospitals, where most elective procedures are provided (AIHW 2016). The My Health record should provide data on these and similar privately provided services. A review by the Productivity Commission of the efficiency of Australia’s health system concluded that greater availability of health service data would provide evidence where the system is inefficient or even failing as well as opportunities through data linkage not only to improve the provision of health research but also to suggest preventive measures in such areas as obesity (PC 2015).

Australia has a strong regulatory framework to protect individual privacy in the use of health data, a national network that provides high quality data linkage and secure access and storage of limited data and world leading research governance to ensure ethical approaches to using personal data for research and analysis.

References

Australian Institute of Health and Welfare, *Australia's Hospitals 2014-15 at a glance*, Canberra, July 2016 (www.aihw.gov.au/australia-hospital-at-a-glance-2014-2015)

Productivity Commission, *Efficiency in Health*, Commission Paper, Canberra, 2015 (www.pc.gov.au/research/completed/efficiency-health)