

Dr Matthew Butlin
Presiding Commissioner
South Australian Productivity Commission
GPO Box 2343ADELAIDE SA 5001
Via e-mail to: sapc@sa.gov.au

Dear Dr Butlin

Please find attached SA NT DataLink's responses to the Draft Report from the South Australian Productivity Commissions Inquiry into Health and Medical Research in South Australia.

SA NT DataLink's responses are limited to those most closely related to its business and concerns.

If you have any further queries, please do not hesitate to contact me.

Yours sincerely



Andrew Stanley (on behalf SA NT DataLink Steering Committee)
Director
SA NT DataLink

09/10/2020

SA NT DataLink response to South Australian Productivity Commission, Inquiry into Health and Medical Research in South Australia, Draft Report, September 2020.

General comments

SA NT DataLink considers that the Draft Report has drawn together the key issues impacting on Health and Medical Research (HMR) in South Australia

SA NT DataLink was pleased to see that its data capabilities (current and future) are seen by the Commission as part of an essential component supporting HMR as well as part of an HMR strategy for SA. This is consistent with unequivocal statements from the research sector supporting SA NT DataLink's development and better integration/collaboration within the health and research sectors to improve research productivity and excellence. These are supported by SA NT DataLink.

Ethics approval in South Australia

In relation to data linkage projects, SA NT DataLink agrees that there is a need to improve the efficiency and timeliness of HREC approval processes.

The section in Draft Report discussing ethics approval does not distinguish differing NHMRC accreditation requirements for an HREC. To approve a data linkage project, an HREC must be accredited by the NHMRC as competent to review data linkage projects.

Until this year, national and/or multiple jurisdictional data linkage projects must have the approval of the HREC accredited committee for each jurisdiction. However, from May 2020 a National Mutual Acceptance (NMA) Agreement specifically relating to data linkage project was established. This enabled a project approved in a participating jurisdiction by an accredited ethics committee automatic approval in another jurisdiction. It is expected that the NMA will considerably reduce the burden on researchers for national and/or multiple jurisdictional data linkage projects, including for research projects based in SA.

Currently jurisdictions not participating under this NMA are the Commonwealth, the Northern Territory and Western Australia. In SA, only the DHW HREC is accredited under the NMA.

The NMA for data linkage research is only newly established and is likely to be carefully monitored to ensure that there is a shared and equal level of competence among the accredited HRECs in assessing data linkage projects.

Note that where there are specific cultural or population-based considerations relating to the population being studied, the ethical review from another HREC with expertise in the specific population group is still needed.

Information request 7.3

SA NT DataLink supports the *"importance of a whole of state government data strategy to enable interoperability, connectivity and timely access to South Australia's data assets and underpin individual agency plans such as the SA Health Data and Analytics Plan."*

Given SA NT DataLink's expertise, significant data assets and capabilities in SA and nationally, SA NT DataLink could provide significant technical, ethical and legal insights for the development and implementation of the *SA Health Data and Analytics Plan*.

7.2.2 Data registries

The Draft Report states “SA NT DataLink houses several core health and social data registries as shown in Figure 7.2. The Commission understands there are several further health datasets awaiting provision from a range of hospital and government sources. These include the SA Cancer Registry, SA Ambulance Service dataset, SA Perinatal Statistics Collection and several datasets from the Women’s and Children’s Hospital.”

SA NT DataLink would like to clarify the Commission’s understanding of the availability of the above mentioned datasets. SA NT DataLink has been provided with these datasets for linkage, noting that the SA Ambulance Service data was provided after the provision of SA NT DataLink’s submission to the inquiry.

RECOMMENDATIONS

Draft recommendation 7.1

To ensure the ongoing security and stability of SA NT DataLink, the South Australian Government, as a matter of some urgency:

- *identify options for securing stable, multi-year funding of SA NT DataLink, including its own contribution and the performance outcomes it expects.*
- *work with SA NT DataLink’s other funders to secure appropriate core funding from the SA and NT Governments together with a simplified joint venture partner funding model in line with other successful Australian data linkage programs.*

SA NT DataLink strongly supports this recommendation and the reasons supporting it which are well outlined in the draft report.

Draft recommendation 7.2

The South Australian Government, through the Attorney-General’s Department, develop and introduce privacy legislation to streamline the current regulatory environment as it relates to data access and privacy protection in order to provide greater transparency and certainty for the South Australian public, researchers and public sector agencies.

SA NT DataLink strongly supports this recommendation for the reasons outlined in the draft report. It has a strong interest in supporting the proposed legislation and considers itself to be a key stakeholder who should be consulted in the construction of a draft Bill.

Sound privacy legislation should provide strong support for the use of personal information in health and medical research as well as providing the assurances needed by the public about its ethical use, protection for their privacy and public accountability in its use.

Over the years, it has been SA NT DataLink’s experience that most consumers are supportive of their health information being used for a public good purpose and were often been surprised to learn of the barriers that inhibit researchers to make better use of their information.

While at the Commonwealth level, the *Privacy Act 1988* sets out the way personal information may be handled by Commonwealth Government agencies and many private organisations, it leaves the States and Territories to regulate the use of personal information in their own public services.

South Australia government agencies operate under Information Privacy Principles (IPPs) for SA Government agencies established by Cabinet. While these IPPs are identical to those established under the *Privacy Act 1988* (Cwth), there is no legislative force behind them.

The SA *Public Sector (Data Sharing) Act 2016 (the DS Act)* enables the sharing of personally identifying information and associated clinical and/or service information between Government agencies. Under the Act, data sharing is only subject to the approval of the respective Chief Executives of the agencies and on condition that data is shared in manner consistent with the DS Act's 'Trusted Access Principle'.

The DS Act provides a limited legislative framework for adherence to these Principles and in the sharing of data within the SA Government and with some "Relevant Entities" (the public universities). Public transparency and accountability is limited to annual reports to the SA Parliament.

The limited legislation and reliance on Principles are not regarded as robust mechanisms for supporting access to data or privacy protection and accountability. For this, and to be consistent with all other jurisdictions, there is a need for a statewide legislative framework and a body independent of Government acting to support access to personal and sensitive information as well as protect privacy and ensure transparency and accountability in its use inside or outside of government.

Draft recommendation 7.3

To improve access to patient related data South Australian Government, through DHW:

- *in conjunction with LHNs, develop and implement a standardized system-wide pre-consent process to assist in the recruitment of research participants.*
- *build online capability to facilitate access to patient groups and individual patient records for HMR purposes.*
- *work with LHNs, the university sector and SAHMRI to resolve the issue of access to health system data for those researchers who are not employed directly by SA Health.*
- ***give effect to the state government commitment to ensure the necessary legislative or regulatory changes to allow the collection and use of data from private health care providers without further delay.***

Most relevant to SA NT DataLink in this recommendation is the last dot point concerning private health care providers, which is also supported by SA NT DataLink.

On this point, SA NT DataLink would like to emphasise that potential legislative or regulatory changes consider the full range of health services provided by the private sector. That is, not just hospital services but services inclusive of emergency department, day surgery, pathology, medical imaging, primary (GP and allied) health care and specialist services.

It is important to distinguish primary health care provided by medical practitioners (primary medical care) and primary health care provided by a range of nursing and allied health practitioners, for example, physiotherapists, occupational therapists, optometrists, psychologists and podiatrists. Access to information from the allied health sector may be difficult because of localised data collections consistent with the nature of the small business arrangements for many allied health practices.

Nevertheless, the addition of such data, as well as data from the private education and non-government sectors, is important to developing more comprehensive evidence based understanding of health and wellbeing outcomes.