

**South Australian Productivity Commission**  
*Inquiry into Health and Medical Research  
in South Australia*

**Submission from the Health Performance Council**  
April 2020

Health Performance Council



Government  
of South Australia

Health Performance Council

## Acknowledgement

The Health Performance Council acknowledges the Aboriginal peoples of South Australia and their ongoing contributions to and participation in the life of South Australia. We acknowledge and respect their spiritual relationship with their respective countries.

We also acknowledge the diversity of Aboriginal people in South Australia. Our Australian continent is known to have been inhabited for at least 55,000 years. The first inhabitants comprised over 270 different Aboriginal language/cultural groups across Australia, with 40 independent groups living in South Australia. Each group occupied its own territory and had its own unique culture, beliefs, laws, language, stories, ceremonies and art (Reconciliation SA, 2017). Aboriginal peoples in their diversity have demonstrated resilience and have made significant contributions to South Australia despite the ongoing effects of colonisation and dispossession.

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## The Health Performance Council

The Health Performance Council is the South Australian Government's statutory Ministerial advisory body established under the *Health Care Act 2008*. The Council advises the Minister for Health and Wellbeing on the performance of the health system, health outcomes for South Australians and specific population groups, and the effectiveness of community and individual engagement. The Council does not advocate or advise on behalf of any particular group.

Every four years the Council publishes major reviews of South Australian health system performance that are tabled in the South Australian parliament. In the interim, the Council also produces other reports and statistics.

Output of the Council's activity is available to everyone via our website: [www.hpcs.com.au](http://www.hpcs.com.au)

## The Health Performance Council's submission to this inquiry

The Health Performance Council thanks the South Australian Productivity Commission for this opportunity to make a submission to the Commission's *Inquiry into Health and Medical Research in South Australia*.

The Council has reviewed the Commission's issues paper released on 13 March 2020 pertaining to this inquiry. Specifically, the Council would like to respond to the request for information related to access to data (information request 5.2) with supporting examples and case studies as requested.

### **Information request 5.2: access to data**

- Is the current regulatory environment at the national level conducive to data generation and sharing?
- Is the current regulatory environment at the state level, including the operation of the *Public Sector (Data Sharing) Act 2016*, conducive to data generation and sharing?
- Is there overlap between national and state legislation?
- What types of data are important to share in health and medical research?
- What barriers are there to sharing data for health and medical research?
- What data-related bottlenecks constrain health and medical research and what can be done to remove them?

(SAPC 2019, p. 25)

## Summary of the Health Performance Council's submission to the inquiry

It is the Council's view that access to comprehensive, timely data that can be linked and shared is an important factor affecting South Australia's capacity to secure funding; and identify opportunities to improve South Australia's capability to attract investment in health and medical research. South Australia cannot compete for health and medical research funding without integrated all-of-population data infrastructure that is shared widely and used widely to see the whole.

In summary, the Council's submission to this inquiry responds to the request for information related to access to data:

In the Health Performance Council's experience, the current regulatory environment is not conducive to data generation and sharing.

In the Health Performance Council's experience, any overlap between national and state legislation does not interfere with health and medical research.

The Health Performance Council believes that all types of data are important to share. In the Council's experience, more can be done to improve data sharing, while still meeting legitimate privacy concerns.

In the Health Performance Council's experience, one of the biggest barriers to sharing data lies in the comprehensiveness of the data itself, specifically in relation to vulnerable and specific population groups. When it comes to missing data, you cannot share what you do not have.

In the Health Performance Council's experience, the main bottleneck that constrains health and medical research concerns timeliness of access to data.

The Council wishes the South Australian Productivity Commission every success with its inquiry and welcomes an opportunity to meet to expand on this submission in more detail, if required. Contact details for the Council's Secretariat are located behind the title page of this document.

## The current regulatory environment—national and state

In the Health Performance Council's experience, the current regulatory environment is not conducive to data generation and sharing

Data is an invaluable asset for informing and improving services. The *Public Sector (Data Sharing) Act 2016* makes great strides to enable government agencies to share information and collaborate for better outcomes for South Australians.

However, in health, while there is much to celebrate about state government policy and public hospital clinical performance, there are also issues and unknowns where patient care pathways cross between public and private hospitals. This is not covered by the Data Sharing Act.

Indeed, there is a persistent data blindspot—South Australia does not have access to private hospital inpatient activity data that can be linked to other government datasets to evaluate services, ensure continuous improvement of patient care, or inform policy advice.

A picture of health system performance that only draws on public hospital activity is incomplete, and at worst may be misleading. At present neither South Australian clinicians nor policy makers are able to check on all-of-population health outcomes.

Statistical linkage with private hospital datasets is routine practice in other states and territories in Australia. Structures to make this possible safely have been in place in those jurisdictions for many years.

It can be achieved. However, the Health Performance Council has been frustrated by slow progress and stalled attempts in South Australia in this area for a long time.

Since 2014, the Council has been urging SA Health to provide the private hospital data that it already collects to SA NT DataLink for linkage and use in reviewing the performance of the various health systems within South Australia. SA NT DataLink is part of an Australia-wide national data linkage network—the Population Health Research Network—and provides high quality data linkage services to support research, policy development, service planning and evaluation. The Council has utilised the data repositories maintained by SA NT DataLink in its evaluation and monitoring projects on multiple occasions.

SA Health itself acknowledges that the absence of private hospital data in the SA NT DataLink repositories results in an incomplete picture of the service profile and use of health services in South Australia. In early 2015, the then Minister for Health wrote to the then Chair of the Health Performance Council on the potential to incorporate private hospital data into the SA NT DataLink repositories. In that letter, the Minister committed SA Health to work with SA NT DataLink, the private sector and privacy and ethics committees to build this capability in South Australia.

The Health Performance Council understands that a business case was prepared but little progress otherwise was made on the initiative.

Despite these setbacks in the past, the Council is encouraged for the future by recent statements made by the Governor of South Australia in his opening speech for the second session of the Fifty-Fourth South Australian Parliament. In that speech, the Governor stated that:

“My Government continues to encourage collaboration with the private healthcare sector in health research. To maximise the benefits, legislation will be introduced to allow the

collection of data from private healthcare providers. This will lead to greater research benefits and greater transparency in healthcare reporting.” (Hansard 2020)

The Health Performance Council looks forward to these promised changes in the current regulatory environment, particularly at the state level, that will make private hospital inpatient activity data available for linkage. The Council supports the Birch Review recommendation number 16 that:

“Access to relevant private and public data sets for organisations like SA NT DataLink and other recognised data linking bodies should be permitted. Such data sets can be restricted for use in Human Research Ethics Committee (HREC) approved data-linkage projects that the Department for Health and Wellbeing approves that follow the nationally agreed separation processes to protect privacy.

“Relevant legislation should be reviewed to permit access to relevant public and private data sets that have relevance to population health research. This should happen under strict circumstances and with the expressed permission of the Chief Executive of the Department for Health and Wellbeing following positive consideration from a recognised Human Research Ethics Committee. This is particularly relevant to private hospital data sets which currently are not accessible in South Australia. It is noted that this is not the case in NSW and Victoria.”

(Birch, 2018)

Areas the Council can see immediate benefit from availability of private hospital data for linkage:

- Monitoring unplanned readmissions and potentially preventable hospitalisations. Risk of unplanned readmission of hospital patients and adverse outcomes from potentially preventable hospitalisations cannot be monitored completely if you cannot link private hospital data with public hospital data and other datasets such as deaths data.
- Evaluation for improvement of patient outcomes for people with cancer. Cancer is the leading cause of death in South Australia and a leading cause for people needing palliative care in public hospitals at the end of life (HPC 2019). The omission of being able to link private hospital inpatient activity data with other datasets such as cancer registry information, clinical and screening management data, and national prescription medicines datasets is a major gap in our understanding of the cancer patient journey as people in care transition between public and private systems.

## Overlap between national and state legislation

In the Health Performance Council's experience, any overlap between national and state legislation does not interfere with health and medical research

Research authorised and sponsored by the Health Performance Council is undertaken by its Secretariat who are all South Australian government employees. Analysis of datasets is conducted in accordance with all applicable legislation and code of ethics covering state public servants. Public sector employees are required to maintain the integrity and security of official information for which they are responsible. Employees must also ensure that the privacy of individuals is maintained.

In undertaking its work, the Secretariat also complies with various data custodian deeds of confidentiality and all other data custodian requirements prescribed for securely storing, handling and publishing data.

In the Council's view, any overlap between national and state legislation exists out of an abundance of caution in ensuring the integrity and safety of identifiable personal information collected by government agencies. The Council does not believe the overlap causes conflict or acts as an impediment to health and medical research. In any event, under Chapter 5 of the Australian Constitution, in cases of conflict in areas where the Commonwealth and states have concurrent powers to make laws, Commonwealth law has priority and the state law is invalid to the extent of the inconsistency.

## Types of data that are important to share in health and medical research

The Health Performance Council believes that all types of data are important to share. In the Council's experience, more can be done to improve data sharing, while still meeting legitimate privacy concerns.

South Australia must use its health dollars effectively and efficiently. South Australia cannot compete for health services funding without integrated all-of-population data infrastructure that is shared widely and used widely to see the whole.

The Health Performance Council supports the state government's open data principles.

"The South Australian Government is the custodian of a diverse range of data. Making this available for everyone, unlocks its economic, social and environmental potential. Open Data delivers transparency, supports collaboration between private and public sector and encourages informed participation in government by citizens." (DPC 2019)

In essence, the Council contends that all types of data are important to share—subject to legal, ethical, and privacy conditions that people reasonably expect to secure personal, private, or otherwise sensitive information.

The Council adheres to open data principles in its own work in the following areas:

**Data:** Data must be made publicly available by default, subject to meeting legitimate privacy concerns.

**Methods:** Methods applied in the analysis of the data are made transparent for reproducibility and comparability.

**Results:** Results of the analysis are timely, relevant, accessible, and usable for improved governance and innovation.

The Council finds in its reviews that the health system is awash with clinical, administrative and population health data. However, the Council finds limited evidence that the system is linking and analysing this data or disseminating results to inform decision making across the health system for continuous improvement purposes.

Indeed, the Council would like to use this submission to amplify statements made in the Royal Commission Into Aged Care Quality And Safety that apply—in the Council's opinion—as much to the South Australian health system as they do to aged care:

"We do lots of collection of items of information, but really it doesn't become meaningful information until you start bringing it together in some sort of holistic way, and at the moment we have got lots of different data collections going on, but as a sector we really aren't able to use that data so it's not providing us with any real information about what is going on and I think it's come up time and again that we really don't have good indicators about what is the quality and safety in the sector, and yet that data itself is sitting in these data silos available ready to be used, but it's just not being used and brought together in that way." (Royal Commission into Aged Care Quality and Safety, 2020)

## Barriers to sharing data for health and medical research

In the Health Performance Council's experience, one of the biggest barriers to sharing data lies in the comprehensiveness of the data itself, specifically in relation to vulnerable and specific population groups. When it comes to missing data, you cannot share what you do not have.

Despite the quality assurances of data providers and others, the Health Performance Council recognises that there is data missing, under-reported and misreported in administrative datasets that can and do impact health and medical research. Health and medical researchers can only report self-identified data as-is. Gaps evident in the collection of relevant data for vulnerable populations make it virtually impossible to develop a complete picture of the variations in their health outcomes and makes identification of progress or problems difficult.

Some population groups are not well represented in state level quantitative data. These groups can face particular health challenges and require tailored responses:

- Aboriginal persons
- Persons from culturally and linguistically diverse backgrounds
- Persons living with a disability
- Carers
- Veterans
- Lesbian, gay, bisexual, transgender, intersex and queer persons
- Persons in custody
- Aged persons
- Persons who reside in socioeconomically disadvantaged areas of the state
- Persons who reside in rural and remote areas of the state.

The Health Performance Council finds that specific and vulnerable groups are not well represented in government datasets for three main reasons:

- (i) Low numbers in the community may be missed, undercounted, or incorrectly weighted in government population health surveys. To this end the Health Performance Council encourages an oversampling in government population health surveys to improve representation; and/or
- (ii) Data collections don't ask questions at all to identify the status of persons from some specific population groups; and/or
- (iii) Data collections don't ensure status identification questions of specific population groups are asked consistently.

For example—the Council recognises that not all Aboriginal people are correctly identified in the government administrative datasets and acknowledges that not all Aboriginal people choose to identify themselves or their loved ones every time they interact with government services. Aboriginal leaders have told the Council that many Aboriginal health consumers do not identify as Aboriginal for fear of discrimination. Aboriginal leaders have also told the Council that health service providers frequently fail to ask about the Aboriginal status of health consumers, even where collection of this status field is mandatory. The Council is working to report on systemic racism in the health system as part of its forward review program.

The issue of integrity, variability and quality of self-reported data in administrative datasets applies to other specific population groups as well—often for fear of discrimination—such as persons from culturally and linguistically diverse backgrounds and aged persons.

Expanding on the subject of identification of persons from culturally and linguistically diverse (CALD) backgrounds—identification of CALD persons in the Council’s reports is based only on their country of birth. CALD identification would be improved if preferred language, religious affiliation and interpreter required were also available. These new CALD data elements have been piloted in SA Health’s central hospital inpatient activity data warehouse from 1 July 2017 (an outcome of a Council-led initiative). However, new data elements are not supplied to the data warehouse consistently by the hospitals at a suitable quality. Until there is greater compliance by the hospitals, SA Health won’t make the new CALD elements available for research and monitoring. This gap has been noted in Council reports as a limitation in its analysis of population health outcomes.

In relation to persons in custody—people in prisons experience significant health inequalities, often come from already marginalised populations, and as a group experience a higher burden of chronic illness, mental illness and substance misuse than society at large (HPC 2018). However, the Council finds that the state government is not collecting enough or good enough data to monitor achievements, health outcomes or whether prison health services are achieving value for money. The Council questions what evidence exists to support stated policy objectives when it comes to prisoner health in practice being achieved if they are to be evaluated.

Mental health is another area that can be often excluded in data collection and another area where data sharing is lacking. As the Grattan Institute points out:

“Currently, planning and coordination of mental health services between the Commonwealth and the states is poor. There are no agreed regional plans that establish service models, levels of service to meet needs, resource levels, workforce and service development strategies, data and reporting arrangements, or governance and management accountabilities.” (Grattan Institute, 2020)

Specific and vulnerable population groups may seem invisible to health services. Data gaps need urgent attention before datasets can be shared for the purposes of health and medical research if its results claim to be representative of the population.

## Data-related bottlenecks that constrain health and medical research and what can be done to remove them

In the Health Performance Council's experience, the main bottleneck that constrains health and medical research concerns timeliness of access to data.

The Council has benefited and is grateful for direct access to some of SA Health's major corporate data collections, and indeed could not have functioned effectively over the past twelve years without this. But direct access to a few activity datasets has not been sufficient to complete all reviews. Over this four-year review period, the Council has observed varying responsiveness to data requests from custodians and review bodies.

One example—The Council's application to SA NT DataLink for data in its 2019 end-of-life care case study (HPC 2019) included a request for a linkable dataset of residential aged-care services. However, SA NT DataLink advised that this dataset would not be accessible within project timeframes and so it was excluded from the application. Residential aged-care services were excluded from the Council's 2013 end-of-life care study (HPC 2013) for similar timeliness reasons. The Council recognises this as major gaps in both analyses.

Another example—the Council's research benefits from oversight from the SA Department for Health and Wellbeing Human Research Ethics Committee (HREC) and advice from the Aboriginal Health Research Ethics Committee (AHREC). However, working through the data custodian, ethics and site specific approval processes has proven to be increasingly and frustratingly slow. In 2013, approval processes the Council undertook to receive linked datasets for analysis took, in total, only several weeks. In 2019 the same, repeated, processes took many months. A project requiring the obtaining of linked datasets in 2020 is currently ensnared in bureaucracy with no clear pathway out.

The Council supports Birch Review recommendations numbers 2, 3 and 13 respectively that:

“Agreed average response times for Site Specific Assessment (SSA) approval should be monitored. Where response times for applicants fall short of agreed KPIs by 20% then an applicant should be able to seek a Senior Executive review of the specific process that applies to their application.

“SSA approval should commence either before research ethics application assessment, or at the very least concurrently.

“Contract Bellberry Pty Ltd to undertake training in ethics application assessment in order to achieve standard and consistent responses to applicants during the assessment process and also standard and consistent responses in regard to application risk rating.”

(Birch, 2018)

## Conclusion

The Health Performance Council supports this inquiry's terms of reference that health and medical research is an important part of South Australia's healthcare system. The Council supports the aims of health and medical research to continue to foster innovation and improvements in health service delivery, attract investment and funding to South Australia, and encourage staff development in this state.

The Council notes in the issues paper to this inquiry that "in recent years, South Australia's ability to attract funding in health and medical research has been diminishing. This is demonstrated by a declining percentage of National Health and Medical Research Council (NHMRC) grants being won by South Australian researchers". (SAPC 2019, p. 9)

In closing, it is the Council's view that access to comprehensive, timely data that can be linked and shared is an important factor affecting South Australia's capacity to secure funding; and identify opportunities to improve South Australia's capability to attract investment in health and medical research. South Australia cannot compete for health and medical research funding without integrated all-of-population data infrastructure that is shared widely and used widely to see the whole.

The Council wishes the South Australian Productivity Commission every success with its inquiry.

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