Government of South Australia
Health Performance Council

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

Dear Dr Butlin

Health and Medical Research Inquiry draft report — response to request for information

On behalf of the Health Performance Council, thank you for this opportunity to respond to your Commission's Inquiry into Health and Medical Research in South Australia draft report that was released on 2 September 2020.

We have reviewed the Commission's information requests in the draft report, and would like to respond to the following specific areas:

Information request 4.4

What empirical evidence is available on the causal relationship between HMR public hospital performance and public health outcomes, particularly at the state level? Please provide details.

While locally there might be an absence of state-wide testing of a relationship between HMR hospital performance monitoring and public health outcomes, there is compelling work from the OECD on strengthening HMR use of data for health quality and outcomes governance. The OECD says "countries that develop a data governance framework that enables privacy-protective data use will not only have the information needed to promote quality, efficiency and performance in their health systems, they will become a more attractive centre for medical research."[1]

The Health Performance Council has, for many years, monitored public health outcomes as a proxy measure of health system performance. One way that we continue to advise the Minister for Health and Wellbeing on the performance of the health system in responding to the health priorities and emerging trends in health outcomes of South Australians is by maintaining our 'State of Our Health' resource.

State of Our Health is published online via our website and maintained as an authoritative source of intelligence on health status and health outcomes in the South Australian population, reporting on over 40 measures, grouped into five domains from the point of view of a person's key life stages. Chapters 3 and 4 of State of Our Health monitor population health status and public health risk indicators by SA Health local health network, over time, by age and sex, and by socioeconomic status using South Australian Population Health Survey data provided by SA Health.

It is the Council's understanding that State of Our Health is the only source of up-to-date publicly available information on public health outcomes for South Australia produced at this level of detail.

State of Our Health is available at: hpcsa.com.au/state_of_our_health

[1] https://www.oecd-ilibrary.org/social-issues-migration-health/health-data-governance_9789264244566-en, viewed 23 September 2020

Information request 7.1

What specific actions are needed to test the opportunity to build big data medical analytics as a strength for the health system and HMR in South Australia? What is the role of the South Australian Government?

Broadly, the Health Performance Council sees the role of the South Australian government in this area as putting renewed emphasis on its own open data principles. As the Department of Premier and Cabinet website states, "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."[2]

The Health Performance Council adheres to open data principles in its own projects—information made publicly available by default (where individuals' privacy is not compromised), transparency in methods for reproducibility, timeliness, relevance, accessibility, comparability, and usability for improved governance and innovation.

We believe these principles scale up to 'big data' analytics as much as they apply to smaller monitoring and evaluation projects.

Information request 7.2

What are the key data gaps, or deficiencies in data quality, which, if addressed, would strengthen performance of HMR in South Australia? Why are they important? What action could be taken by the South Australian Government to address these issues?

In the Health Performance Council's experience, the key data gaps and deficiencies in data quality that need to be addressed concern comprehensiveness data specifically in relation to vulnerable and specific population groups.

Despite the quality assurances of data providers and others, the 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. The Council finds that 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.

[2] https://www.dpc.sa.gov.au/responsibilities/data-sharing/open-data, viewed 7 September 2020.

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

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

The Council provides the following examples of gaps in reporting of specific and vulnerable groups:

- Not all Aboriginal people are correctly identified in government administrative datasets and 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 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.
- Identification of persons from culturally and linguistically diverse (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.
- 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. 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.
- Mental health is another area that can be often excluded in data collection and the Council has found it is another area where data sharing is lacking.

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.

Information request 7.3

The Commission would like to hear views from stakeholders regarding 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.

In the Health Performance Council's view, a whole of state government data strategy to enable interoperability, connectivity and timely access to South Australia's data assets is of the utmost importance. The Council believes that information governance that includes community license for use of administrative government datasets for secondary purposes is vital, including confidence in a system allowing anonymised linked data access for HMR.

In our experience, the main bottleneck that constrains data access and availability concerns timeliness of access to data. The Council has observed varying responsiveness to data requests from custodians and review bodies. In particular, working through the data custodian, ethics and site specific approval processes for statistical linkage datasets 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 became hopelessly bogged in bureaucracy, resulting in key aspects of the data analysis for the project having to be abandoned. This outcome benefits nobody.

We are encouraged that the Commission for Excellence and Innovation in Health is developing a data and analytics plan for SA Health. The Council finds in its reviews that the health system is awash with clinical, administrative and population health data although we find 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. We feel that many that many of the bottlenecks that constrain interoperability, connectivity and timely access to SA Health data would be removed relatively easily and quickly with a change in corporate culture, but the plan is a place to start and we will maintain a watching brief on the plan as it develops.

Information request 7.4

What are the key infrastructure gaps or deficiencies which constrain HMR data management in South Australia? Why are they important? What action could be taken by the South Australian Government to address these gaps and deficiencies?

Lack of access to private hospital inpatient activity data that can be linked to other government datasets to evaluate services, ensure continuous improvement of patient care, and inform policy remains a perennial data blindspot in the system's ability to evaluate performance.

The Health Performance Council continues to prosecute the argument for private and public sector data linkage availability so there is an all-of-South Australia picture from monitoring and analysis. Australia-wide, two-thirds of hospital admissions involving elective surgery occur in private hospitals[3]. People receiving cancer care will dip in and out of the private and public sector. We have a blindspot in managing performance of the whole system and gaps in datasets that would be useful for things like monitoring readmission rates, post-discharge mortality rates, and electronic surveillance of safety of medicines or new therapeutics.

The Council is encouraged by recent indications that legislative changes will soon allow the collection of data from private healthcare providers for the purposes of linking, but this has been a long time coming and we have been frustrated by slow progress and stalled attempts in the past in this area for many years.

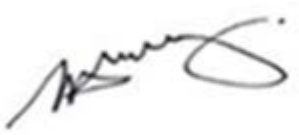
Another perennial data blindspot in the system's ability to evaluate performance is a lack of a centralised unit record outpatient collection. Outpatient reporting has been a significant challenge for South Australia for a long time as different hospitals have various ways of collecting and reporting outpatient information. The Council is encouraged by recent moves by the Department for Health and Wellbeing to work with local health networks, clinicians and data teams to improve the accuracy and availability of outpatient waiting time information to be made available for reporting and analysis. However, we would like SA Health to put renewed emphasis and priority into improving outpatient datasets, including making them available for

[3] https://www.aihw.gov.au/reports/hospitals/hospitals-at-a-glance-2017-18/contents/surgery-in-australias-hospitals, viewed 23 September 2020.

person-level linkage so that health and medical researchers can evaluate the whole hospital patient journey.

The Health Performance Council continues to wish the Commission every success with its inquiry. We look forward to the release of your final report. I hope our response to your request for information is helpful and I welcome an opportunity to meet with you to expand on this letter in more detail, if required.

Yours sincerely



Steve Tully
Chair, Health Performance Council

24 September 2020