



**AUSTRALIAN MEDICAL ASSOCIATION
(SOUTH AUSTRALIA) INC.**

ABN 91 028 693 268

23 September 2021

Ms Helen Thomas
Director, Epidemiology
Wellbeing SA
Department for Health and Wellbeing
Government of South Australia
E: helen.thomas2@sa.gov.au

Dear Ms Thomas

**Re: Draft Health Care (Provision of Data and Statistics) Variation Regulations 2021
Draft Health Care (Reporting of Cancer) Variation Regulation 2021**

On behalf of AMA(SA) Council, thank you for the opportunity to provide comments on the draft Health Care (Provision of Data and Statistics) Variation Regulations 2021 and draft Health Care (Reporting of Cancer) Variation Regulation 2021.

As the Regulations were provided to AMA(SA) together, we have chosen to provide feedback on both Regulations in this submission, itemised as necessary below. Much of our feedback relates to both Regulations, so unless otherwise noted we ask that our points be considered in the implementation of both Regulations and the systems and practices that evolve from their implementation.

In general, we welcome the Regulations, which we perceive as aiming to address gaps that AMA(SA) has previously pointed to in the collection and analysis of data from the private health system. As noted on repeated occasions, the collection and availability of private health data is critical in understanding the scale of patient use of and access to private health, and – importantly from a public health and budget perspective – how private patients transfer in and out of the public system. In relation to the draft Regulation regarding the reporting of cancer, we welcome the Regulation as intended to improve existing reporting procedures and so enhance the understanding of the incidence of cancer treatments, prognoses, recurrences and outcomes in South Australia.

In regards to the collection and analysis of data more generally, we have in submissions such as our response to the Health Care (Governance) Amendment Bill 2019 emphasised the need for more data and analysis, including patient-reported outcomes, to capture patients' paths through the entire health system to inform clinical practice, policy making, and the design and delivery of services.

For example, we understand between 50 and 60 per cent of cancer patients are treated in South Australia's private hospitals, moving between private and public hospitals as their needs demand. The collection of data about these patients will help plan services, including new services and technologies, such as 'Car-T' that have implications for ICU bed demand, across the state. It will also be extremely valuable in planning and delivering other services, such as end of life care, across the state.

We are also aware that in regional centres, public funding provides chemotherapy suites in public hospitals, but there is no private access to these suites – unlike other states, where private-public partnerships exist. More data about the demand for and use of such suites would

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support calls from communities and medical practitioners for more services – including private providers – to support regional patients for more equitable care.

The additional burden that the pandemic is placing on the health system means it is more important than ever to understand the many factors at play in managing the capacity and costs of individual services within the system.

Privacy and information security

AMA(SA) Councillors' main concerns relate to what data will be collected, or could be sought, under the terms of this Regulation. We stress the importance of ensuring health data is 'de-identified' and stored in a manner that prevents it being 're-identified' in future. Our AMA members have informed us that the processes involved to ensure these factors are met are complex and very specialised; we strongly recommend that data custodians with deep data set knowledge be engaged to ensure the anonymisation of data is not reversible.

The nature of the data

AMA(SA) Council raises questions about what data will be collected and for what purposes. Beyond the issues of privacy, as noted above, we suggest patients will have legitimate concerns about reasons for the collection of their data.

In particular, Councillors have asked whether the Minister or representative have the authority to seek data such as:

- Intimate details of all care, including self-care where assistance is needed
- The patient notes, including notes by nurses and ancillary staff
- Other information as recorded by the clinician or staff.

AMA(SA) would not support the collection of data that could compromise the confidence a clinician has in the privacy and security of recorded information, and therefore potentially influence important care decisions.

On the other hand, we would hope that one of the outcomes of the Regulation would be more collection, analysis and understanding of the use by self-funding public patients of the private system, and the reasons for doing so.

In addition, Councillors have noted that the Reporting of Cancer Regulation does not appear to cover 'chemotherapy at home'. We recommend that these and similar programs and services are included to ensure data is comprehensive.

The question of the accuracy of data was raised. For example, with hospitals having to provide the data each month, the nature of a condition (such as a specific cancer) may not be confirmed within the reporting period. If the diagnostic reports are provided to the hospital, employees will be needed to manage them, adding costs, technology needs, and possibly layers of bureaucracy.

Methods of collection, storage and transfer

AMA(SA) Council notes that the security of data extends beyond who is collecting it and why, to where and how it is stored and, particularly, how it will be transferred. We ask that consideration be given to these factors to ensure security measures reflect existing and emerging information technologies and how they are governed.

We note that the fact sheet on the Reporting of Cancer Regulation explains that cancer data will be provided using 'existing secure cancer data notification pathways or file notification systems'. However, with the introduction of additional transfer technologies, we ask that these pathways and systems be reviewed by data set experts to eliminate any possibility of hacking or sharing to unauthorised parties, including insurance companies.

In addition, we would seek assurances that the data was not made available to external parties, however well intended the use may be, to prevent the possibility of any such 're-identification' or misuse of the data.

We also note the ethical considerations of collecting and sharing data beyond the hospital's systems, and recommend that careful consideration be given to developing appropriate consent procedures.

Impact on private hospital operations

Council notes that the introduction of this Regulation will increase the workload on individual private hospitals. The larger hospitals and the members of multi-site organisations are less likely to be burdened by this work, but the smaller operations may struggle with the additional financial and staff implications of providing the data. We ask that resources be provided to ensure all hospitals can meet the requirements of the legislation, so the necessary data can be collected from all South Australian private hospitals and accurate perspectives obtained.

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Thank you again for the opportunity to comment on these Regulations. Should you wish to discuss the points raised in this letter, please contact me via EA Mrs Claudia Baccanello on 8361 0109 or at claudia@amasa.org.au.

Yours sincerely



Dr Michelle Atchison
President