

15/10/2019

Office of the National Data Commissioner

PO Box 6500

Canberra ACT 2600

Re: Data Sharing and Release Legislative Reforms Discussion Paper

Thank you for the opportunity to comment on the *Data Sharing and Release Legislative Reforms Discussion Paper*. This submission has been prepared by Professor Helena Teede and Mrs Alison Johnson, on behalf of Monash Partners Academic Health Science Centre, an [NHMRC](#) accredited Advanced Health Translation Centre and member of the Australian Health Research Alliance ([AHRA](#)). AHRA facilitates the integration of healthcare, health and medical research, and health professional education to deliver better health outcomes for all Australians. Our member organisations cover 95% of Australia's academic and research teams, and; 78% of its acute health services.

Monash Partners would like to endorse the submission letter provided by Monash University – one of our partner organisations.

We also wish to comment on the following areas:

Data Sharing principles

The Data Sharing principles currently under development by the Office of the National Data Commissioner (pg 30) are of particular interest as Monash Partners is in the process of developing Principles for Sharing of Data across Monash Partners. Another AHRA centre has developed, and has a signed agreement for, a de-identified Data Sharing Accord across its member organisations. Monash Partners is planning to get partner endorsement for the sharing of identifiable data.

It is worth noting that the current process for sharing of health data in Victoria is complex. Consideration of eighteen sources relating to relevant legislation and guidelines, is required when sharing health related data, in Victoria.

This number increases considerably when considering the sharing of data across State and Territory borders.

The provision of a list of State legislation that has been incorporated into this new legislation, and thus replaces it, would be useful. This would reduce the complexity of compliance with relevant legislation, when sharing health data, rather than increase it.

The barriers that exist when attempting to link Commonwealth and State government data are extensive and we would recommend that these barriers be considered as a priority.

Consent

Monash Partners supports the position adopted by the proposed legislation, of not requiring consent in all instances of data sharing. Further input as related to consent are contained in the Monash University submission.

How can I safely share?

In regards to the issue of sharing data safely, and the cultural changes required to shift the thinking from “Can I share” to “how can I safely share?” data.

The aspect of *risk* that a data custodian (a hospital, for example) presently accepts when sharing their data, is a major barrier, within the health sector.

‘Data Custodians’ are defined (pg 55) as Commonwealth entities and companies as defined under the *Public Governance, Performance and Accountability Act 2013*, such as agencies and departments. However, it is not clear how this applies to Electronic Medical Record data that may be used for research purposes and particularly in situations where it will involve linkages with data held by Commonwealth entities. In this situation the data custodian would be Health Service and the organisation or user would be Monash University rather than the user being the health service.

Monash Partners supports the development of both Accredited Data Users and Accredited Data Service Providers, as described in the proposed legislation. It is understood that accreditation would indicate the organisation and individual meet the standards required by the legislation. We would envisage that this would streamline approval processes for the sharing of data.

It should be noted, though, that there are already extensive workforce development programs under development in the use of health data. This is occurring throughout AHRA, The Digital Health CRC and My Health Record initiative.

Monash University is in the process of developing a community of practice in data linkage and are looking at developing minimal training and accreditation standards for managing and analysing linked data. Given that the discussion paper uses SURE training as an example, Monash University’s training requirements are likely to be more stringent than those imposed by the government. We would recommend that duplication in training the health and health related research workforce, should be avoided in any accreditation process.

Finally, we would also support the concept of the (Government) Data Custodian and Accredited Data Service Provider having joint legal responsibility for managing the sharing of data and monitoring of compliance.



Monash Partners

ACADEMIC HEALTH SCIENCE CENTRE

Connecting researchers, clinicians and the community to innovate for better health

Further feedback from Monash Partners has been covered in the submission provided by Monash University.

Thank you for the opportunity to provide feedback on the *Data Sharing and Release Legislative Reforms Discussion Paper*. We look forward to hearing of the outcomes of the consultation and would welcome the opportunity to work with the interim National Data Commissioner on the next stages of the Legislation's development.

Should you require more information, please contact Mrs Alison Johnson or Professor Helena Teede using the details provided below,

Yours sincerely,

Helena Teede

Executive Director Monash Partners Academic Health Research Translation Centre

[Redacted] W: <https://monashpartners.org.au>

And

Alison Johnson

Project Manager – Data-driven Healthcare Improvement

Ph: [Redacted] W: <https://monashpartners.org.au>

AlfredHealth



Cabrini

easternhealth



HUDSON
INSTITUTE OF MEDICAL RESEARCH



Postal: Locked Bag 29, Clayton VIC 3168 • Site: 43-51 Kanooka Grove, Clayton VIC 3168