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Professor John McMillan AO
My Health Records Legislation Review
Department of Health

By email MHRlegislationreview@health.gov.au

Dear Professor McMillan

Review of the My Health Records legislation

Thank you for the opportunity to provide input into this review.

Avant is Australia's largest medical defence organisation, providing professional indemnity insurance and legal advice and assistance to more than 78,000 medical practitioners and students around Australia.

Our members have access to medico-legal assistance and advice via our Medico Legal Advisory Service. We have offices throughout Australia and provide risk advisory and education services to our members with the aim of reducing medico-legal risk, including on the My Health Record and its predecessor, the Personally Controlled Electronic Health Record. Avant has participated in various consultations during the development and implementation of the My Health Record system.

General comments

We generally agree with the summary of the different perspectives on the operation of My Health Record outlined in section 3 of the Consultation Paper. Avant supports the aims and potential benefits of the My Health Record, as outlined in our position statement. Our focus has been on identifying potential medico-legal risks associated with the My Health Record and to suggest ways to mitigate those risks. Some of those risks come from the design and implementation of the system, but others come from the way in which the legislation is drafted. We also favour consistency in the law where possible because lack of consistency can cause confusion and increase medico-legal and compliance risk.

Over the past 24 months, our members have been concerned with the practical workings of the My Health Record system, more so than any issues caused by the legislation. The key issues centre around engagement (both practitioner and patient) and utility of the system.

We received increased enquiries around the time the system moved to an 'opt out' model in 2019 about that issue.

Other issues our members enquire about:

- What to do in situations when the patient provides information that is inconsistent with that in their My Health Record (for example, inconsistent description of past medications)
- The interplay between My Health Record and Medicare (for example, can practitioners charge Medicare for the time it takes to use My Health Record; will Medicare data be uploaded into My Health Record?).
- Consent issues (for example, are practitioners liable for inadvertently uploading patient documents; what obligation does the practitioner and practice have in educating the patients on the use of My Health Record; do practitioners need to review the My Health Record at each consultation or seek consent to upload at every consultation?).

We also refer you to the FAQs we put together based on the queries we received.

We have provided answers to selected questions asked in the Consultation Paper below.

Responses to general themes

1. *Is MHR providing important practical healthcare benefits to consumers and providers? Could more be done to improve the benefits that are provided? Could more be done to generate better public understanding of the healthcare benefits of MHR?*

From our members' perspectives, benefits are dependent on uptake by clinicians and the usefulness of the information contained within it. Some of the benefits are starting to be realised: we have heard of instances where practitioners have picked up errors in documents in the MHR which have been able to be corrected.

While there has been a significant increase in use of the MHR since it moved to an opt-out system, there remains a concern about a lack of clinically useful information in the record, and the fact that there is little, if any, use by specialists or allied health practitioners.

There is a fine balance however between having too much information and too little. Whilst it would be beneficial for other registered health practitioners to add to the MHR, one concern expressed by members is that it could become very large and complex with a lot of "noise". Identifying key clinical information may become difficult and there is a risk that a practitioner may miss something important, to the detriment of the patient. This is also a medico-legal risk for the practitioner.

We are not certain that there is a good understanding of how the MHR links in with other digital health initiatives.

Avant supports continued education and communication for practitioners and patients about how to use the MHR and how it links in with other digital health initiatives. Increased use by specialists, allied health practitioners and other registered health practitioners should help. At the moment, because practitioners perceive the system as unhelpful and/or clunky to access, they rely on their current systems. We expect that once engagement and use increases, many of the issues our members experience will become second nature to them. We believe that the benefits will only be realised once practitioners and patients use it far more regularly.

2. *Are there any particular features of MHR that make healthcare recipients or providers reluctant or disinclined to use it? Is there unnecessary complexity in MHR legislation?*

Medical practitioners have long been concerned about the patient-control aspects of the MHR, particularly that patients can hide documents. This brings with it a risk that the practitioner will miss something important, which can impact on patient care and leave the practitioner exposed to liability. This is a consequence of the patient control model rather than particular provisions in the legislation.

This concern is mitigated to a degree by the statements that the MHR is not a complete record and that there is no obligation on practitioners to consult it in any particular circumstances, but it would provide more reassurance from practitioners if this could be enshrined in the legislation.

Responses to specific issues

5. Should the prohibited purpose provision in the MHR Act be amended to reduce the adverse impact on health practitioners? How could this best be done – for example, by excluding specific conduct from the scope of the prohibition, or removing the penalty for a breach of the prohibition?

We agree that the prohibited purpose clause is broadly drafted. We agree with the proposition, noted in the Consultation Paper, that the clause could capture use of information from the MHR by the consumer's usual treating practitioner in a report prepared for the purposes of insurance and employment. It would be preferable to draft the provision in a way that defines the prohibited purpose with more specificity, and that better reflects the intention of the provision.

6. Should the MHR Act provisions relating to managing the health information of minors be revised? For example, should the MHR age category of 14-17 be combined with the age category 18 and above? Have the age settings for information access and control under

MHR that are different to those in Medicare or in state and territory laws given rise to any issues that should be addressed?

Lack of consistency causes confusion, and inconsistency in age settings leads to continuing misunderstandings about the age at which children have decision-making capacity generally.

It is widely assumed, incorrectly, that the age at which a child is legally considered to have medical decision-making capacity is set at 14. This is not correct as there is no specified age at which a child is considered to have capacity to consent; capacity in a child is based on an assessment that they have achieved "a sufficient understanding and intelligence to enable then to understand fully what is proposed" (in accordance with the common law test in *Gillick v West Norfolk AHA* , adopted in Australia in *Department of Health & Community Services v JWB & SMB* ("Marion's Case")).

A person is not presumed to have decision-making capacity until the age of 18 (16 in South Australia). To improve consistency with other laws, consideration should be given to raising the age at which control of the MHR record is removed from parents.

7. Should adjustments be made to how the principle of consumer control is embodied in MHR legislation? Is it appropriate to have a category of hidden documents? Should the emergency override function be reformulated?

The principle of consumer control has long been a concern of the medical profession. Not only does it clash with the "established medical tradition of clinical autonomy" (as noted in the Consultation Paper) it also gives rise to significant medico-legal concerns. This has led practitioners to question the clinical utility of the information in the system if it is not complete and the practitioner cannot tell that it is incomplete. As noted above, this brings with it a risk that the practitioner will miss something important, which can impact on patient care and leave the practitioner exposed to liability. It would be helpful if practitioners could know when looking at a patient's MHR whether documents have been hidden and the category of document that has been hidden.

On the issue of emergency access, while the legislative provision is reasonably clear as to the criteria required to be met to permit access, there has been some confusion over the use of the emergency access provision particularly in emergency departments. Practitioners who we have assisted in responding to audits by the Australian Digital Health Agency have misunderstood the nature of emergency access and the criteria they have needed to fulfil to comply with the legislative provision when using this function.

8. Should the MHR Act contain more comprehensive guidance regarding access to and use of health information in the MHR of a deceased person? What rules would be appropriate?

The questions asked in this section of the Consultation Paper are good ones. These issues have not arisen in queries from our members, but with increased information in and use of the MHR, we could expect these questions to come up more frequently.

It may be appropriate to allow access to the MHR for the purposes of autopsy. On the issue of autopsy reports and death certificates, it is not clear what the benefits would be of uploading these documents to the MHR when they are accessible elsewhere. If this is to be permitted under the legislation, there may need to be some parameters around who can access the documents, for what purpose and within what timeframe (is it for the purposes of research, access by the coroner, access by the deceased person's authorised representative for compassionate reasons etc?).

9. What key factors should be taken into consideration during the development of the Rule that will support implementation of the Framework to guide the secondary use of My Health Record system data, to ensure there is a robust legal framework for that to occur?

There is concern about secondary use of data especially by government. It should be a requirement that the use of any data for research and public health purposes be subject to independent ethical review by a Human Research Ethics Committee, in accordance with the requirements of the NHMRC National Statement on Ethical Conduct in Human Research.

12. Should the data breach notification scheme in the MHR Act be revised and possibly harmonised with the data breach notification scheme in the Privacy Act?

Yes. As noted in the Consultation Paper there is a different regime for data breach notification requirements under the MHR Act and data breach notifications under the Privacy Act. This causes confusion and is administratively burdensome. Practices need to have different processes and procedures depending on whether the notification is under the MHR Act or the Privacy Act.

Reporting obligations under the MHR Act are stricter than those under the Privacy Act. Under the Privacy Act a data breach is notifiable to affected individuals and the Office of the Australian Information Commissioner (OAIC) if the breach is likely to result in serious harm to an individuals or individuals, and remedial action cannot be taken to prevent the likelihood of serious harm.

By contrast, all breaches or potential breaches are notifiable under the MHR Act. There is no need for serious harm, and even a breach that has been rectified or where remedial action has been taken must still be notified.

A potential source of confusion is the difference between the requirements under the MHR and the Privacy Act with regard to notifying healthcare recipients. There is an issue as to whether the MHR legislation permits or prohibits a healthcare provider organisation to

notify healthcare recipients of a MHR notifiable breach, as they are required to do under the Privacy Act in the case of a notifiable data breach under that scheme.

The MHR legislation does not specifically prohibit healthcare provider organisations from notifying affected healthcare recipients of a potential or confirmed breach. However, the guidance from the OAIC is that when there is a notifiable data breach related to the MHR: "[the healthcare provider organisation] *cannot* notify affected healthcare recipients directly about the breach, but must ask the System Operator to do this on their behalf…" [emphasis added]

The OAIC informed us that the clear legislative intent is that only the System Operator should inform healthcare recipients. If this is the case, we believe it should be clear in the legislation.

That said, it would be preferable to align the notification requirements under the MHR scheme with those under the Privacy Act, to avoid confusion and to reduce the risk of non-compliance.

15. Should the MHR Act provisions relating to nominated healthcare providers be revised to make it easier to identify who is the nominated provider?

Yes. We agree with the concerns outlined in the Consultation Paper about the "nominated healthcare provider." The definition does not correlate well with clinical practice, and how this interacts with the shared health summary (SHS) and event summaries can lead to confusion.

The Australian Digital Health Agency says that a patient should only have one nominated provider at a time who creates and updates a SHS. Any other doctor, who is not the patient's regular doctor, should use an event summary to upload relevant clinical information such as an after-hours consultation note, or travel vaccination information. There can only be one nominated health care provider but if a practitioner uploads a shared health summary, they become the nominated healthcare provider.

While this may have limited practical implications, it does not align well with clinical practice, and does cause confusion for doctors, especially when considering whether to upload a SHS or an event summary.

Final comments

The Consultation Paper notes that the review of the technical aspects of the MHR Act are more suited to targeted consultation. We would be grateful for the opportunity to be involved in the targeted consultation to provide input into the potential medico-legal implications of any changes to the legislation.

Please contact me on the details below if you require any further information or clarification of the matters raised in this submission.

Yours sincerely

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