

Submission to the My Health Records Senate Inquiry

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The Authors

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Introduction

Thank you for the opportunity to contribute to the inquiry into the My Health Records Amendment (Strengthening Privacy) Bill 2018 (the Bill). We welcome the proposed amendments, but note that more needs to be done to protect healthcare recipients and providers under the My Health Records System. In this submission we turn our focus to terms of reference E, F and G.

We put forth the view that My Health Records legislation does not balance adequately the rights of patients and healthcare providers to control medical information. Although there is the argument to say that patients may feel more empowered under My Health due to having additional rights over uses of their health information, it is important to recognise that My Health changes longstanding paradigms of data control held by healthcare providers since the advent of the medical record. The shift in the control paradigm may place additional pressures on healthcare providers without sufficient evidence that using My Health will result in clinical benefits to their patients. We provide here a list of four specific concerns.

Patients can use records “for any purpose”

My Health alters longstanding paradigms relating to the control of data, and the relationship between healthcare providers and their patients. Section 67 of the *My Health Records Act* (2012) states that “a healthcare recipient is authorised to collect, use and disclose, for any purpose, health information included in his or her My Health Record”. We are of the opinion that the words “for any purpose” should be clarified so that patients understand the reasonable limits to their use of My Health data.

The explanatory memorandum to this amending Bill may support a broad reading of “for any purpose,” when it states:

“While individuals can share their personal information as they see appropriate, healthcare providers, the My Health Record System Operator and other participants

in the My Health Record system are restricted in how and when they can use and share information in the My Health Record system.”

Despite this statement, it is still unclear whether a patient would be permitted to post their Record to their social media accounts, or in the public domain. It would be hoped that the details of the practitioner would not be included in any shared posts.

We are of the view that given the casual willingness of many members of society to share their information on social media platforms, this will come to include their personal My Health Records. Patients may share their health records among a circle of friends before or during consultation with healthcare professionals, or even worse, they may Google search using their specific health information to ascertain a plausible diagnosis and treatment. This consumerisation and trivialisation of health data has negative attendant outcomes to the patient in terms of their quality of care, and to the practitioner, in terms of their privacy, respect for their knowledge, and rights over the records they have created.

Patients can easily query the diagnostic process and/or treatment plan

It is unclear whether the *My Health Records Act* would enable a patient to use My Health information for the purposes of querying a diagnostic process or treatment decision made by a practitioner.

In the 2017 Victorian Supreme Court case of *Kitson v Dennerstein*, the patient was interested in what evidence existed in their health record to substantiate the psychiatrist's diagnosis of Narcissistic Personality Disorder. It was decided in that case that the wording of the health record legislation in question prevented the patient from gaining access for the purpose of evaluating or testing the information. However, if the psychiatrist had been using My Health, the patient would have been at liberty to look through their My Health Record and determine what evidence the psychiatrist had to meet the Diagnostic and Statistical Manual of Mental Disorders (DSM) criteria. This would have then given the patient the ability to question the practitioner on their diagnosis, judging their advice to be inappropriate or not.

If a patient were to question their practitioner in this regard, could the practitioner using My Health rightfully refuse to detail the diagnostic process to a My Health recipient? If they did refuse, or provided a vague response, the patient may not feel that they are truly in control over the management of their health information, which is one of the broad objectives of the My Health System.

Patients can limit access to information

The ability of a patient to limit access to information means that the quality of health information may not actually improve under My Health. The Australian Digital Health Agency advises on their website that “consumers can request that a particular document is not uploaded to their record, and healthcare providers must comply with such requests”. However, practitioners can advise patients “about the potential risks of excluding information from their My Health Record and explain the benefits of ensuring all information is included”. The key point here is that what the patient says, goes.

The Australian Commission on Safety and Quality in Health Care discussed these limitations in their [2017 report](#) on My Health:

“Enabling consumer control of their EHR is empowering for the patient; however, limited or inaccessible content by clinicians may be a consequence. Consumer behaviour could be driven by security concerns regarding unauthorised EHR access... Mental health, sexual health or HIV status are examples of sensitive information that consumers are likely to apply access controls on their EHR. This

raises the possibility that less accessible clinical content may produce marginal benefit to clinicians using an EHR.”

In this light, it should be considered whether practitioners can rely on the information stored in a My Health Record for both its accuracy and completeness given that it may not include all of the needed information. Even if a practitioner is confident that their patient is disclosing all of the relevant information, the My Health Record does not contain a complete, retrospective clinical history of the patient. We query how incomplete data could possibly further the *My Health Act* objectives to improve the quality of health information, reduce the occurrence of adverse medical events and the duplication of treatment.

My Health data does not integrate

My Health has been designed to bring together details of an individual’s medical conditions and treatments, medicine details, allergies, and test or scan results, all in one place. However, My Health currently has enabled a system where there is the option to add clinical documents. Summary Medicare data is displayed that, by definition, lacks life-saving details. The individual is to initiate having life-saving data such as allergy details included in their own record. Pre-existing tests and reports will not be stored, and many public hospitals lack the functionality to upload patient discharge summaries. A potentially dangerously incomplete health record may be created even before the individual has exercised their rights to determine what is or isn’t included in My Health.

The lack of real-time integration of existing health systems, be they public or private, appears to render an individual’s My Health Record nothing more than an administrative burden. The consequent time-lags between treatment and inclusion of the relevant data, if included at all, flies in the face of the fact that 25% of all hospital admissions are re-admissions – but not necessarily at the same hospital. The additional effort involved in submitting data may result in the system being shunned by many practitioners who are already time-poor. And due to the absence of key health data, My Health is at risk of being an unreliable source of health information. Searching for data that was never submitted or was blocked by the individual may be more time-consuming than the pre-EHR approach of undertaking independent tests at each health facility due to the lack of access to pre-existing test results. My Health Records can be the life-saving system that was originally envisaged, but this will be very difficult without real-time integration of all Australian health systems to deliver complete health records as and when needed – in particular, when someone’s life is on the line.

The Alternative – the UK Patient Summary

It is worth considering that the primary objective of collecting patient information is first and foremost clinical and not legal. This, we posit, should be the guiding consideration underpinning any proposed amendment – that the regulatory regime to the greatest extent facilitates clinical practice without compromising the known legal imperatives of privacy, data security, civil rights, and confidentiality. The United Kingdom (UK) may provide an example of how a balance of rights may be achieved. The three pieces of legislation governing access to patient health records in the UK are *The Data Protection Act 2018*, *The Access to Health Records Act 1990* and *The Medical Reports Act 1998*. In addition, the UK is also subject to the European gold standard, *The General Data Protection Regulation 2018* (GDPR).

The GDPR (on which the *Data Protection Act* is premised) permits data holders to refuse to comply with data requests “[w]here requests from a data subject are manifestly unfounded or

excessive...”¹The burden of proving the ‘unfounded or excessive’ nature of the request lies with the data controller.² This provision and similar ones in the GDPR serve to guard against an abuse of the power from exclusive control that may be granted to patients without putting in place safeguards. However, data subjects have the option of seeking legal redress if aggrieved by a data controller’s decision. Contrary to the European standard, the *My Health Records Act 2012* seems to suggest that the patient has unfettered control over their records. By this, they fail to recognize, as highlighted earlier, that data subjects can be reckless and/or make unjustifiable requests in respect of their data and this can have adverse implications for clinical care.

Secondly, while the GDPR generally recognizes the right to data portability (rights of access to reuse one’s data for different services), the same is also restricted and may be denied if adjudged as ‘manifestly unfounded or excessive’. Further, the right does “not apply to processing necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller.”³

The approach in the UK makes clear that a central consideration is the public utility of health information. This is easier to justify publicly than the approach taken with My Health, which places an emphasis in Section 67, and in its various marketing materials, that a central consideration is that of ensuring patient control over health information. Whichever policy approach is taken, the application of that policy needs to be consistent, reasonable and supported with evidence before written into law.

My Health has potential, but it needs to change. We hope to see a system that helps bring us into the age of digital health, with the ability to tap into all the wonders of precision medicine. However, we won’t get there unless we place clinical considerations at the forefront, whilst maintaining our respect for the rights of our dedicated healthcare providers. This requires the issues around control of data to be debated and for the rights of health practitioners, patients and the public interest to be balanced.

¹ Article 12(5).

² See Article 57(4).

³ Article 20(3)-(4).