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RE: Submission to the Senate Inquiry on My Health Record

Introduction

Thank you for the opportunity to make a submission to the Committee's inquiry on the My Health Record (hereafter "MyHR").

Who we are

This submission has been prepared by: Megan Prictor, Jo-Anne Manski-Nankervis, Jessica Bell, Mark Taylor and Douglas Boyle. We are researchers in general practice, health informatics, health law and regulation at the University of Melbourne. Dr. Manski-Nankervis is also a practising GP. More information about individual authors is available on the University of Melbourne website. The opinions in this submission are those of the named authors, and should not be taken to represent the views of the University of Melbourne. Dr. Megan Prictor (megan.prictor@unimelb.edu.au) and Dr. Jo-Anne Manski-Nankervis (jomn@unimelb.edu.au) are happy to provide further clarification on any area of the submission.

Summary of key points

- The MyHR has the capacity for benefitting both individual patients and the health care system.
- In the shift from opt-in to opt-out, default access settings should have been changed, to protect the privacy of those who do not engage with the system.
- Addressing a number of specific concerns (outlined below) in relation to privacy, security and third-party access will likely improve public trust and confidence in the MyHR.
- There is a need for improved public engagement with MyHR (as well as with the Secondary Use framework) and a governance framework that reflects this.

A. The expected benefits of the My Health Record system

The MyHR has the capacity to result in benefits to both the individual patient and the health care system.

The potential for patient benefits

Currently most health records are not visible to, or accessible by, patients. This means that patients have little access to their own health information. This may be particularly important for people with complex health problems, on multiple medications and who would like to have increased access to their own medical data. Trust that this information is safe, secure, and accessible only to individual patients and those who require the information to provide clinical care may be important to patients in deciding to utilise the MyHR for these indications.

The potential for improved information flow between health professionals and health care settings

The Australian health care system is fragmented and siloed, with a lack of consistent communication between health care professionals and between primary and secondary care. As a result, transfer of information about medical diagnoses, pathology and radiology test results between settings does not always occur. The capacity for recording medical conditions and allergies exists with the MyHR but relies on the record being manually updated by health professionals, rather than being automatically updated when new information is recorded in the electronic medical record.

Whilst mechanisms exist to access this information (for example, phoning a pathology company to access results, or a hospital to access a discharge summary) these often don't occur in a timely manner. In addition, if laboratory results are not easily accessible then additional tests may be ordered, potentially resulting in excess costs. The MyHR may have potential benefits in this regard.

Health summary uploads to MyHR from general practice only happen through an explicit, deliberate action by the GP. Whilst the privacy rationale for this is clear, having incomplete records is a major inhibitor with regard to the clinical utility of MyHR. Ironically, there is a public perception that by not opting-out of MyHR your GP record will be automatically uploaded. A mechanism that has public support to allow more systematic uploading of Health Summaries needs urgent attention if the benefits of MyHR are to be fully realised.

B. The decision to shift from opt-in to opt-out

The fact that 'all documents in My Health Record are set to general access for healthcare providers by default',[1] meaning that everyone involved in a person's health care can, by default, access particularly sensitive information about them (including eg. sexual and reproductive health or illicit drug use) is extremely concerning. In the shift from an opt-in to opt-out system, the default privacy controls should have been tightened to protect the privacy of the many people who will remain disengaged with their MyHR.

C. Privacy and security, including concerns regarding:

i) The vulnerability of the system to unauthorised access

Access logs provide a potential safety mechanism for MyHR. These allow consumers to check who has accessed their record. However only health provider organisations, not the individuals accessing

[1] https://www.myhealthrecord.gov.au/for-you-your-family/howtos/control-access-my-record, accessed 10 Sep. 2018.

a record, are listed.[2] This should be changed so that logs of individual access are visible to consumers, to improve both security and trust in the system.

Promotion of the 'bank strength security' of the system is potentially misleading, given that human error or 'trusted insider' access via the hundreds of thousands of authorised access points is a more likely source of unauthorised access.[3]

ii) The arrangements for third party access by law enforcement, government agencies, researchers and commercial interests

Access by law enforcement, government agencies

The government is rightly acting to restrict access by law enforcement and other government agencies to MyHR through the My Health Records Amendment (Strengthening Privacy) Bill 2018 (Cth) requiring that, to permit health information to be disclosed, a judicial officer must make an order based on certain restrictive criteria. It is still to be the case (under clause 69A(4) of the Bill) that healthcare recipients and record owners will not be informed of the disclosure; rather, ADHA has only to 'make a written note' of the disclosure. A rebuttable presumption that the record owner and/or patient should be informed of the disclosure would strengthen trust in this aspect of the system's operation.

The range of entities ("designated entities") that can apply for an order to obtain information from MyHR is wider under the proposed Bill than under the My Health Records Act 2012 (Cth). As stated in the Bill's Explanatory Memorandum, it is 'no longer limited to enforcement bodies'.[4] The justification for this is unclear.

Secondary use of data by researchers and commercial interests

Numerous concerns have been expressed concerning the secondary use of data framework permitting access to de-identified data for research or public health purposes. These include:

- minimal advertising of the fact that data will be used for secondary purposes and that people can opt-out of this use.[5] The MHR website states "It's your choice to share your information for public health and research purposes".[6] That purported 'choice' has thus far been poorly communicated, and the opt-out option is difficult to locate, within a system that itself is opt-out.
- the preclusion of use '**solely** for commercial' purposes[7] (our emphasis) raising questions about the extent to which it is intended that commercial purposes will be served by secondary use of MHR data. If social licence for purposes with mixed public and commercial benefit is to be promoted, then robust governance against criteria tested for public acceptability will be needed.

[2] https://www.myhealthrecord.gov.au/for-healthcare-professionals/howtos/my-health-record-system-security, accessed 11 Sep. 2018.
[3] https://www.digitalhealth.gov.au/news-and-events/news/fact-check-security-of-my-health-record, accessed 12 Sep. 2018.
[4] Explanatory Memorandum, My Health Records Amendment (Strengthening Privacy) Bill 2018 (Cth) 11.
[5] Australian Government Department of Health, Framework to guide the secondary use of My Health Record system data (May 2018) 4.
[6] https://www.myhealthrecord.gov.au/for-you-your-family/secondary-uses-data, accessed 10 Sep. 2018.
[7] Framework to guide the secondary use of My Health Record system data 7.

- The Framework's failure to adequately address what happens when a person opts out of secondary use, or to make explicit that once data have flowed to external parties a choice to 'opt-out' of MyHR or delete specific documents within it may not have any effect on the data's inclusion in the research or other secondary use.

There is a need for independent and effective systems to challenge uses of data inconsistent with a consumer's reasonable expectations. We endorse the intention to explore implementation of a dynamic consent model to improve consumer control over the secondary use of their data.[8]

iii) Arrangements to exclude third party access arrangements to include any other party, including health or life insurers

While health insurance companies cannot access the MyHR, there is a lack of information around the safeguards in place for the situation whereby such a company also provides healthcare services. For example, HCF and BUPA are among several health insurance providers that also operate dental and optical centres. How will access to MyHR (for the provision of health care) be quarantined within the relevant sections of such companies?

Other privacy and security concerns

Setting "limited document access codes", which is promoted as a way to protect privacy,[9] is cumbersome and time consuming in practice. The document access levels cannot be set globally for a person's whole MyHR, or even for a class of documents such as all diagnostic imaging reports, but instead must be set for each document. This is a tedious process likely to deter people from taking this step.

D. The Government's administration of the My Health Record system roll-out

The government's decision not to run a television advertising campaign on introducing this nation-wide critical infrastructure that potentially affects every Australian's privacy, is questionable. Opacity around its funding arrangements with peak health consumer organisations to promote the MyHR is also of concern.[10]

E. Measures that are necessary to address community privacy concerns in the My Health Record system

While there has been some dedicated consumer and public engagement around the MyHR Secondary Use Framework, this seems premature given the absence of parallel community engagement around the MyHR and the move to an opt-out approach. There is not only a need for a governance framework that relates to the secondary use of the MyHR data, but also a robust and transparent governance framework for the MyHR initiative that makes clear the purposes of the program, the implications of an opt-out approach, and the benefits and risks. A governance framework should outline who the decision-makers are, what processes are in place for decisions to be made, the factors and matters taken into account, and the oversight mechanisms that are in place for accountability of the overall initiative to the proposed benefits of the system, including

[8] Ibid 19.
[9] https://www.myhealthrecord.gov.au/for-you-your-family/howtos/set-privacy-and-security-controls, accessed 12 Sep. 2018.
[10] https://www.dailytelegraph.com.au/news/national/my-health-record-money-trail-questions-raised-over-health-lobby-groups-on-payroll/news-story/32cba5ce3102493dbaab2bd949ffb8d0, accessed 12 Sep. 2018.

how the legislative Privacy Principles are being enacted in the system. There is a clear need for more consumer and public engagement around the MyHR system, and for an effective and independent governance framework that is responsive to the outcomes of such engagement moving forward.

F. How My Health Record compares to alternative systems of digitising health records internationally

In countries such as the UK, a more structured approach to primary care data recording has been taken. Gradual accreditation of the functionality of GP vendors systems allowed for gradual conformance to standards for data collection (coded), interoperability and interfacing. This approach allows for more structured and automatic data communication. In this context, patients are happy – and generally expect data to move between health providers. The GP systems are the key work tool used by general practitioners and yet government investment in this space is almost non-existent. MyHR would benefit greatly from a more balanced investment across the suite of tools utilised nationally and a consideration of international accreditation mechanisms to ensure systems utilised in general practice are fit for purpose.

Thank you for the opportunity to make this submission.

Yours sincerely

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