



SUBMISSION TO THE SENATE FINANCE AND PUBLIC ADMINISTRATION REFERENCES COMMITTEE

The circumstances in which Australians' personal Medicare information has been compromised and made available for sale illegally on the 'dark web.'¹

This submission deals with the term of reference

'Circumstances in which Australians' personal Medicare information has been compromised and made available for sale illegally on the 'dark web':

c. the implications of this breach for the roll out of the opt-out My Health Record system'

Introduction

The My Health Record (MyHR) is a free online electronic health record service provided by the Commonwealth Government to consumers to store information about their health and future healthcare wishes in an Advance Care Planning Document². It is a secure online summary of a healthcare recipient's health information with the healthcare recipient able to control what goes into the record and who is allowed to access it. A primary aim of MyHR is to increase the exchange of health information between patients and their approved healthcare providers, creating health benefits and efficiencies in terms of costs associated with healthcare, and also reducing adverse events related to the poor exchange of health information at the point of care. MyHR is designed to capture information from different parts of the health system, such as general practice and Medicare, pharmacy, hospitals, and radiology, and present this information online to healthcare recipients and authorised healthcare providers. This enables better decision making about the healthcare recipient's health and service delivery.

Research

The authors of this submission are funded by the National Health and Medical Research Council of Australia to investigate the use of the My Health Record by adolescents and young adults with severe communication disability (NHMRC Project Grant, 2014-2017). Recent statistics show the MyHR is used by only a relatively small percentage of consumers, and even then, not to its fullest possibilities.³ It is estimated that the government has invested

¹ This submission is the work of the authors named at the conclusion of the document. It should not be taken as the position of the University of Newcastle or Deakin University. Author for correspondence: Mr Shaun McCarthy, Director of the University of Newcastle Legal Centre, Australia.

² McCarthy, S., Meredith, J., Bryant, L., & Hemsley, B. (In press, accepted 7 Jun 2017). Legal and Ethical Issues Surrounding Advance Care Directives in Australia: Implications for the Advance Care Planning Document in the Australian My Health Record *Journal of Law and Medicine*.

³ <https://myhealthrecord.gov.au/internet/mhr/publishing.nsf/Content/news-002>

A\$1.2 billion taxpayer dollars in the MyHR system (March 2017⁴). Research has indicated that people may not know what MyHR provides in terms of privacy and confidentiality or the security risks and available protections. Lack of knowledge will contribute to misconceptions and misunderstandings that negatively influence Australians' decisions about their uptake and use of the MyHR.⁵

Discussion

Since the compromise of some Australians' personal Medicare information in an on-line web forum, there is a need to review the effectiveness of the safeguards which exist to protect personal and private information in the MyHR. Although some of this information is available on the MyHR and Privacy Commissioner websites, there is a need to disseminate this material more widely and effectively to healthcare recipients and their health providers alike. Further information about data security should also be provided to legal service providers. The urgent need for community confidence in the security and privacy of the documents contained in the MyHR is critical as MyHR will be rolled out on an opt out basis from 2018.

Information about MyHR has high health literacy demands⁶, and the general population struggle to understand the new concepts associated with sharing online e-health records⁷. The written information about MyHR available on the My Health Record website⁸, and within the MyHR itself, is complex so readers may find it hard to understand. As yet, most Australians have little experience of using the MyHR system. At the same time, their healthcare providers are not yet using the system with high enough frequency to support healthcare recipients effectively in using the system. Both health care recipients' and service providers' concerns about privacy and security of e-health record systems are relevant and pertinent to how the Australian Government departments respond to the Medicare data breach. This breach is likely to erode the confidence of current users of MyHR, and may influence the decisions of healthcare consumers both now and in the future to 'opt out' of the system. It could also impact future registration of healthcare providers and organisations in the system, who may feel they cannot guarantee confidentiality. Mutual trust of all parties in the exchange of health information online, and trust that the information is indeed private and accessed only by authorised individuals, is critical to the roll-out and long-term usage of MyHR. It is also critical that systems for alerting consumers, and for responding to data breaches, are seen as robust and that appropriate responses are taken in the event of any breach of MyHR data, whether intentional or unintentional.

As a result of the intentional breach of Medicare data, healthcare recipients may rely substantially on mainstream or social media reports and discussion to obtain information about MyHR without knowing how to locate credible sources of information that are

⁴ <https://docs.google.com/spreadsheets/d/1iTpjGuOYXJChHFAyqhdHTnrgwJwfvLnwJtNpsjqrB2c/pubhtml#>

⁵ Hemsley BA, McCarthy S, Adams N, Georgiou A, Hill S, Balandin S, 'Legal, ethical, and rights issues in the adoption and use of the My Health Record by people with communication disability in Australia', *Journal of Intellectual and Developmental Disability*, (2016).

⁶ Walsh, L., Hill, S., Allan, M., Balandin, S., Georgiou, A., Higgins, I., Krall, B., McCarthy, S., & Hemsley, B. (2017). A content and quality analysis of the consumer-facing online information about My Health Record: Implications for increasing knowledge and awareness to facilitate uptake and use. *Health Information Management Journal*. <http://journals.sagepub.com/doi/full/10.1177/1833358317712200>

⁷ Hemsley, B., Rollo, M., Georgiou, A., Balandin, S., & Hill, S. (Accepted 9th July 2017). The health literacy demands of electronic personal health records (e-PHRs): an integrative review to inform future inclusive research. *Patient Education and Counseling*.

⁸ www.myhealthrecord.gov.au

accurate. It is vital that the Australian Government Department of Health and Digital Health Agency provide readily available information in a range of formats, including formats that are easily understood by people with a low reading grade or those for whom English is not a first language. This information should be online and distributed through social media channels (Twitter, Facebook, YouTube, websites). It is also important that pictures, graphics, and video or audio materials (e.g., podcasts) are provided to supplement written information. Furthermore, if misinformation or disinformation about data breaches or data privacy and security appear in the mainstream or social media, it is important that accurate information is provided to counter this incorrect or deliberately deceptive information and that the public can feel confident that these measures are introduced quickly.

There are several legal and ethical issues that arise in the use of MyHR for people with communication difficulties. Their needs must also be considered in relation to informing the public about data privacy and security. These individuals rely on third parties (family members, carers) for information access and use of the MyHR. It is important to direct information about MyHR and data security to disability organisations and support networks of individuals with a disability to ensure that nobody misses out on important information. Information about any data breaches, for any Australian MyGov service, whether intentional or unintentional, should be provided on the My Health Record website, and not require substantial 'online searches' for concerned Australians to access. As people currently register for MyHR through MyGov, and information can be linked in MyGov, it is important that Australians can access accurate information about any breaches, the impact of these breaches, including if no harm resulted, and any measures that the government is taking to ameliorate the damage.

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