

INQUIRY INTO THE MY HEALTH RECORDS SYSTEM

**Response to the Senate Community Affairs References
Committee Inquiry**

September 2018

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Our vision: Research Australia envisions a world where Australia unlocks the full potential of its world-leading health and medical research sector to deliver the best possible healthcare and global leadership in health innovation.

Our mission: To use our unique convening power to position health and medical research as a significant driver of a healthy population and contributor to a healthy economy.

Our role:

Engage

Australia in a conversation about the health benefits and economic value of its investment in health and medical research.

Connect

researchers, funders and consumers to increase investment in health and medical research from all sources.

Influence

government policies that support effective health and medical research and its routine translation into evidence-based practices and better health outcomes.

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INQUIRY INTO THE MY HEALTH RECORDS SYSTEM

RESPONSE TO THE SENATE COMMUNITY AFFAIRS REFERENCES COMMITTEE INQUIRY

Introduction

Research Australia is pleased to have the opportunity to make this submission to the Inquiry. A strong supporter of the My Health Records System, we are keen to see it succeed.

Our submission addresses several of the Terms of Reference in turn.

The expected benefits of the MHR system

Benefits for individuals

Research Australia believes that the MHR will facilitate the future delivery of safer, higher quality and more effective care to individuals. This will primarily be achieved through improving the quality, timeliness and completeness of information about a patient that is available to treating health professionals.

During the MHR opt-out period, many voices were those encouraging people to opt out, citing the risk of data breaches. Research Australia acknowledges that those concerns are valid and need to be addressed, which is why we welcomed the proposed privacy amendments to the My Health Record Act¹.

Australians are, for the most part, supportive of the notion of electronic health records. In Research Australia's own national research conducted in June 2018, just before the launch of the MHR Opt Out campaign, we asked people specifically about the use of MHR data for research purposes. 44% of people strongly supported the use of patients' deidentified medical records by health and medical researchers, and a further 46% were somewhat supportive.²

In the roll out of the opt-out period, the expected benefits of the MHR system were conveyed as being around faster diagnosis in emergency scenarios, reduced repeated tests. Anecdotal evidence suggests that while Australians largely accept these benefits, they aren't considered enough to outweigh real or perceived privacy risks.

Research Australia submits that when looking at benefits from personal electronic health records, more needs to be done by the health sector and government to build the narrative around the national-interest case for a My Health Record, with both the risks and the benefits properly discussed and considered.

Broader benefits

Beyond the individual there are benefits to the health system.

The Object of the My Health Records Act is articulated in section 3.

The object of this Act is to enable the establishment and operation of a voluntary national system for the provision of access to health information relating to recipients of healthcare, to:

- (a) help overcome the fragmentation of health information; and*
- (b) improve the availability and quality of health information; and*
- (c) reduce the occurrence of adverse medical events and the duplication of treatment; and*
- (d) improve the coordination and quality of healthcare provided to healthcare recipients by different healthcare providers.*

¹ <https://researchaustralia.org/research-australia-welcomes-my-health-record-reforms/>

² Research Australia, Australia Speaks! 2018 Opinion Polling for health and medical research

Each of the objects stated in the MHR Act have benefits for the individual but also for the health system as a whole. For example, incomplete information about allergies and medical history can be a contributing factor to adverse medical events and to the duplication of diagnostic tests. Not only are these events detrimental for the patient involved but they result in additional costs to the health system.

Australia currently expends around \$170 billion a year on healthcare; approximately 10% of GDP.³ A Strategic Review of Health and Medical Research, commissioned by the Australian Government, reported in 2013 estimated that lost or unnecessary diagnostic tests, adverse drug reactions and preventable surgical complications accounted for 20-30% of health expenditure.⁴ Access to better and more complete information via The My Health Record system has the potential to significantly reduce all three of these factors and the associated expenditure. For example, even a relatively modest 5% reduction in these items would lead to savings of between \$17 billion and \$25 billion per annum.

The My Health Record provides an opportunity to transform our health system and the way we treat patients. Understanding this health system and how it works is the key to making it work better and more efficiently, delivering safer and higher quality care. Data from sources such as hospital records, prescriptions and Medicare is already available but the data from My Health Records will help complete this picture.

The benefits to the broader health system and community of making better use of health data were articulated by the Australian Productivity Commission in a report on an Inquiry it undertook into the health system in 2015.

More generally, administrative data — including performance data, patient health records and government-held datasets on patients' use of medications or procedures — can support development of a more rigorous evidence base on the clinical and cost effectiveness of health interventions. Among other things, these data (subject to appropriate privacy safeguards) enable researchers to investigate the burden of disease, access to health care across the community, and the effectiveness of specific health interventions. This can help health care providers to choose the best treatments for individual patients. It also helps governments and insurers to make better overall funding decisions by directing funding to where the greatest health benefits can be achieved (including to preventive health measures), and away from interventions with low or no clinical value.⁵

³ Australian Institute of Health and Welfare 2017. Health expenditure Australia 2015–16. Health and welfare expenditure series no. 58. Cat. no. HWE 68. Canberra: AIHW.

⁴ Australian Government, Strategic Review of Health and medical Research, Final Report 2013, p. 19

⁵ Productivity Commission 2015, Efficiency in Health, Commission Research Paper, Canberra. p.75

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

Opt out trials

The decision to shift from opt in to opt out was made following a review of the scheme and the legislation undertaken in 2015 and after specific trials of opt out approaches in diverse demographic areas in Queensland, NSW, Victoria and Western Australia from March to October 2016.

The report of the evaluation of the opt out trials (the Evaluation Report) concluded that the opt out approach was the most viable way of proceeding and that most (but not all) people would be supportive of this approach and would find it more convenient than creating the record themselves. Perhaps most tellingly in light of subsequent events,

Once the My Health Record was explained to individuals (briefly during focus groups) all but a very small number of focus group participants in both opt-in and opt-out sites were very positive about the My Health Record and its benefits for them, their families, dependants and the health system.

Once the benefits of the My Health Record system were clear, nearly all focus group participants said that their concerns about security and privacy, or about the fact that a My Health Record had been created, disappeared. They most often said that, while they thought that no computer-based systems were totally safe, on balance they thought that the benefits to them, their families and the health system far outweighed those risks. This attitude held firm across general population, people from culturally and linguistically diverse (CALD) backgrounds, Aboriginal and Torres Strait Islander participants, gender, age groups, varying levels of computer literacy and access to computers or reliable internet. This reinforces the need for national awareness activities which make clear the benefits of the My Health Record system as well as the privacy and security protections.⁶

These responses were from people who participated in focus groups; they were provided with information about the MHR and had the opportunity to consider and discuss this information. Importantly, the risks were recognised and the majority of people (not all) thought the benefits outweighed the risks.

Recent media coverage

One of the key issues raised in the recent media coverage accompanying the commencement of the opt out period was access to records by law enforcement agencies.

There are two references in the Evaluation Report to access to records by law enforcement agencies. The first comes in a report on one of the focus groups.

Concerns about confidentiality and security were expressed more often in the focus group in Mapoon. Many of the participants in this remote NQ community said they were wary of the

⁶ Siggins Miller, Evaluation of the Participation Trials for the My Health Record Final Report November 2016, commissioned by the Australian Government, Department of Health. p.vi

My Health Record as another Government initiative to keep a watchful eye on their community. ... Questions and concerns were also raised by this group regarding law enforcement agencies having access to the My Health Record system. After clarifying that, as a personally-controlled record, they could set their own privacy settings and also access alerts and logs that detailed which healthcare providers had recently accessed the My Health Record, half the participants were satisfied with the level of security and ability of the My Health Record to keep their information confidential, while the other half remained skeptical.⁷

The second reference relates to media coverage during the period of the opt out trials.

During the March to September 2016 period, nine articles discussed privacy at the Government, healthcare provider, and individual level. All these nine articles conveyed a distinctly negative sentiment. On 26 March 2016, four articles published in state and local/regional newspapers detailed the perceived potential risk that having a My Health Record poses on individuals who wish to keep their health information private. All these articles focused on the fact that individuals would be unable to opt out of the My Health Record system until 4 April 2016, after which time a My Health Record would have already been created for them. They raised the possibility that information contained in an individual's My Health Record might be disclosed to lawyers, insurance companies and law enforcement bodies.⁸

There were no specific recommendations in the Evaluation Report proposing that the legislation be amended to address issues of third party access or specifically to address this issue if/when it arose again in the media.

Privacy and security, including concerns regarding:

- i. the vulnerability of the system to unauthorised access,
- ii. the arrangements for third party access by law enforcement, government agencies researchers and commercial interests, and
- iii. arrangements to exclude third party access arrangements to include any other party, including health or life insurers

⁷ Ibid, p.89

⁸ Ibid, p.276

System vulnerability

Technical questions relating to the vulnerability of the My Health Record System to unauthorised access are outside Research Australia's area of expertise and are not addressed in this submission.

Broadly, any system that seeks to limit access to information is vulnerable to the risk of unauthorised access, and the MHR system is no exception although we expect, of course, that all possible measures will be taken to mitigate this risk. It is important to acknowledge that this risk exists despite whatever measures we might take. This risk applies to the MHR as it does to other systems we use every day for our banking, superannuation and insurance. We bank and order our groceries and insure our cars online because, on the whole, we perceive the benefits to outweigh the risks. When it comes to the MHR, a similar assessments of the risks and benefits needs to be made by every individual. Research Australia is not suggesting that the risk associate with unauthorised access of health information are the same as the risks for access to your banking details, but the benefits are also different. Each person needs to make this assessment of the relative risks and benefits for themselves.

Third Party Access

There is currently a Bill before the Parliament to tighten third party access. By requiring a court order before a record can be obtained by a third party such as a law enforcement body, the proposed amendments reflect community expectations about the core purpose for which MHRs exist and how the use of an MHRs beyond the core purposes should be handled.

In respect of access to data for research purposes, section 15(ma) of the My Health Records Act 2012 authorises the System Operator to 'to prepare and provide deidentified data for research or public health purposes'. The requirement to deidentify data provided to researchers and/or used for public health purposes protects the privacy of individuals in relation to the use of My Health Records by researchers. In May 2018 the Government issued a *Framework to guide the Secondary Use of My Health Records System Data*.⁹

More broadly, the Government is creating a new legislative framework to facilitate the development of a national framework for the secure sharing and release of Government datasets containing deidentified data for research purposes. This new framework includes a National Data Commissioner and a process of accreditation of researchers as trusted users. The provision of deidentified My Health Records data for research purposes will be included in this new framework.

These measures are a considered response to the opportunities that exist to make much more effective use of publicly held data in a manner that can advance Australia's health, welfare, society and economy.

⁹ Available at [https://www.health.gov.au/internet/main/publishing.nsf/Content/F98C37D22E65A79BCA2582820006F1CF/\\$File/MHR_2nd_Use_Framework_2018_ACC_AW3.pdf](https://www.health.gov.au/internet/main/publishing.nsf/Content/F98C37D22E65A79BCA2582820006F1CF/$File/MHR_2nd_Use_Framework_2018_ACC_AW3.pdf)

The Government's administration of the MHR system roll-out, including:

- i. the public information campaign, and
- ii. the prevalence of 'informed consent' amongst users

The Government's public information campaign was overwhelmed by the controversy concerning the capacity of public enforcement agencies to access MHR Records without a court order, and examples of errors in the information contained in My Health Records.

The public information campaign should have begun at least 12 months before the opt-out period began. We acknowledge the work done to build awareness amongst the medical community and some targeted stakeholders, but at a population level it is obvious from the reaction to the MHR campaign that much more was needed. In particular, focus should have been paid to the likely concerns evident in the opt out trials and in similar electronic initiatives here in Australia and abroad.

Building a social licence for large-scale reform takes time and money. Communication around key Government policy should not fall solely to a small portfolio agency like the Australian Digital Health Agency without adequate resourcing or experience in campaigns of this nature. Research Australia suggests the public information campaign should have gone beyond targeted communication focused around key communities of interest to include a retail communications plan with television and commercial radio advertising. Clinicians, as the key implementers of this reform, should have been more closely engaged, and this is addressed further in this submission.

As noted above, the Evaluation Report of the opt out trials identified media reports referring to the possibility of disclosure to 'lawyers, insurance companies and law enforcement bodies' but there is no indication that addressing this specific issue was considered as part of the communication or media strategy for the opt out period.¹⁰

The Evaluation Report also identified the importance of communicating the benefits of the MHR system while acknowledging that there are risks. Even in the focus groups for the opt out trials, where people were provided with information about the MHR and had the opportunity to consider and discuss this information, there was still a minority who formed the view that opting out was the right course of action. No public information campaign was ever going to dissuade everyone from opting out.

¹⁰ Siggins Miller, Evaluation of the Participation Trials for the My Health Record Final Report November 2016, commissioned by the Australian Government, Department of Health. P.276

Measures that are necessary to address community privacy concerns in the MHR system

Legislative amendment

The proposed amendments to the MHR Records Act requiring a court order before a record can be obtained by a third party such as a law enforcement body addresses one of the immediate and specific concerns raised at the commencement of the opt out period (and earlier, as the Evaluation Report demonstrates). This closes a ‘loophole’ and is easily achieved with legislation. Addressing the broader issue of trust in the My Health Records System is not as simple, nor as amenable to legislative change; and yet is even more important to the ultimate success of the MHR system.

An informed public

A sustained campaign that addresses public concerns and demonstrates the benefits of the My Health Record is necessary. In many ways the My Health Record is an extension of what we see in society more broadly, where many (but not all) individuals consent to the collection and use of their personal data in exchange for the ability to transact online, to access information and to make and maintain social relationships. In each of these cases individuals consciously or unconsciously evaluate the risks and benefits to them of using a particular application and decide whether or not they will use it. The relative value they assign to the risks and benefits, their assessment of the likelihood of adverse events and the impact it will have are very individual. The experience of a victim of online security theft, for example, is likely make a very different assessment of risks and benefits of being online to someone whose experience has only been positive.

A sustained public information campaign needs to acknowledge that individuals are being asked to provide the MHR system with their personal information, and give them balanced information about this risk; acknowledging that while steps are being taken to mitigate the risk there is no guarantee. The benefits of the MHR should also be presented- both for the individual and for the broader community.

Recognising that the risks and the benefits are perceived and valued differently across the population, as the focus groups for the opt out trials demonstrated, we need many different messages and they need to be delivered through different channels. This includes showing the ways that data from individuals can be used to improve the safety, quality and effectiveness of health care, and better health outcomes for Australians.

Public attitudes to research

Research Australia has had a long interest in the Australians' attitudes to health and medical research, the health system and healthcare, and has been undertaking annual polling since 2003. This polling includes gauging the public's understanding of the role of consumers in health research, and their willingness for personal data to be used for research purposes. Responses have been consistently positive.

In response to our 2017 opinion poll, 48% strongly supported the use of patient's medical records for research purposes and a further 45% somewhat supported this use. In our most recent polling conducted in June 2018, just before the launch of the MHR Opt Out campaign, we asked people specifically about the use of MHR data for research purposes. 44% of people strongly supported the use of patients' deidentified medical records by health and medical researchers, and a further 46% we somewhat supportive. One in ten were somewhat or strongly opposed.¹¹

The use of deidentified MHR data for research purposes, and its ability to contribute to improved health outcomes for Australians in the future through a more effective health system and insights that lead to new therapies and disease prevention will be seen by many (but not all) as a positive, and should be part of a much more considered information campaign.

Health Professionals

While one of the significant benefits of the MHR for health consumers is convenience, it needs to be recognised that for many health professionals the MHR system brings another layer of complexity and yet another computer application to deal with.

It is anticipated that when the MHR is better integrated into GPs' and hospitals' software systems, there will be benefits for healthcare professionals in terms of workflow and access to information, but at the moment for many it is simply an extra burden. This is critical because when it comes to the MHR, health professionals are, and will continue to be, key influencers of health consumers. If the message from health professionals to consumers in their face to face interactions is that the My Health Record is a waste of time and money that puts patients' privacy at risk, and he/she is not using it in their practice, this will be far more influential than any media campaign. Health professionals are a key audience and their concerns and issues with the MHR system need to be understood and addressed.

¹¹ Research Australia, Australia Speaks! 2018 Opinion Polling for health and medical research

Conclusion

Research Australia is supportive of the MHR and is keen to see it succeed.

Data from sources such as hospital records, prescriptions and Medicare is already available but data from MHR can help complete this picture. Beyond the benefit to individuals from participating, the MHR provides the opportunity to transform our health system and the way we treat patients. Understanding the health system and how it works is the key to making it work better and more efficiently, delivering safer and higher quality care.

This opportunity is diminished by people opting out; removing their own experiences from the story of how our health system works, where it fails, and what can be done to make it better. While it is inevitable that some people will choose not to participate, it is in all our interests to strive to ensure that each decision to opt out is a considered response based on an assessment of all the relevant information. Providing this information, and responding to concerns about how the HMR system operates to ensure it is the best system it can be, is the task that remains.

Research Australia is pleased to have had the opportunity to make this submission and is willing to contribute further information and use its convening power in the health and medical research and innovation sectors to respond to any further questions the Committee may have.

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