



australian healthcare &
hospitals association

the voice of public healthcare®



Senate Standing Committee on Community Affairs: Inquiry into the My Health Record System

Opening Statement
11 September 2018



OUR VISION

A healthy Australia, supported by the best possible healthcare system.

OUR MISSION

To conduct research, educate and influence the healthcare system to achieve better health outcomes, improved patient and provider experience, greater equity and sustainability.

OUR GUIDING PRINCIPLES

Healthcare in Australia should be:

- Effective
- Accessible
- Equitable
- Sustainable
- Outcomes-focused.

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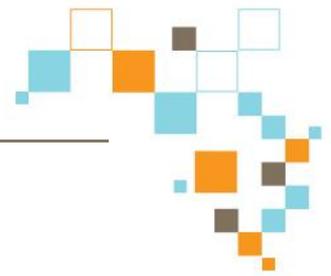
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Inquiry into the My Health Record System

On 15 August 2018, the Senate referred the above matter to the Community Affairs References Committee for inquiry and report by 8 October 2018. The full terms of reference are:

- (a) The expected benefits of the My Health Record system;
- (b) The decision to shift from opt-in to opt-out;
- (c) 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;
- (d) The Government's administration of the My Health Record system roll-out, including:
 - (i) The public information campaign, and
 - (ii) The prevalence of 'informed consent' amongst users;
- (e) Measures that are necessary to address community privacy concerns in the My Health Record system;
- (f) How My Health Record compares to alternative systems of digitising health records internationally; and
- (g) Any other matters.



Opening Statement by the Australian Healthcare and Hospitals Association

I would first like to acknowledge the traditional custodians of the lands on which we meet, and acknowledge elders past, present and emerging.

The Australian Healthcare and Hospitals Association (AHHA) welcomes the opportunity to appear today before this Senate Standing Committee hearing on the Inquiry into the My Health Record system.

The Australian Healthcare and Hospitals Association is Australia's national peak body for public hospitals and health care providers. Our membership includes state health departments, Local Hospital Networks and public hospitals, community health services, Primary Health Networks and primary healthcare providers, aged care providers, universities, individual health professionals and academics. As such, we are ideally placed to be an independent, national voice for universal high-quality healthcare to benefit the whole community.

Our Association's guiding principles are that healthcare in Australia should be accessible, equitable, sustainable, effective and outcomes focussed.

As we say: AHHA is the voice of public healthcare.

As a general comment on the My Health Record system being considered here today, the Australian Healthcare and Hospitals Association supports the development of a comprehensive personal electronic health record for all Australians that chose to participate.

My Health Record, with its inbuilt privacy and security controls set by the consumer, together with the legislative amendments relating to access by law enforcement bodies to My Health Record data, balances the need for better information and coordination of healthcare with the right to privacy.

My Health Record has the potential to realise improved patient care, improved patient convenience, improved safety and quality, and improved system efficiencies.

AHHA believes that a comprehensive personal electronic health record such as My Health Record, is an essential component of a larger whole-of-system health performance information and reporting framework that is focussed on health outcomes, and that can facilitate achieving value in healthcare and transparency in outcomes.



But while there are significant potential gains associated with a comprehensive personal electronic health record, AHHA also believes that the creation and deployment of the My Health Record system must be managed in a manner that ensures the trust of the Australian community.

That their personal healthcare information will only be used in ways that they are comfortable with.

In short, that their personal information will be safe.

I will be addressing the issue of public trust in My Health Record in relation to community expectations, public information and understanding, and the secondary use of My Health Record data.

The Committee will be aware of the evaluation report conducted by consultants Siggins Miller on the participation trials for the My Health Record. This evaluation was on the My Health Record two opt-in and two opt-out trial sites.

There are many recommendations and observations contained in this report. But one comment that is of particular relevance to the Committee's deliberations is that, "many participants were surprised that they had to prompt their healthcare provider to use the My Health Record system, expecting this to be part of standard practice." (Siggins Miller, 2016, Evaluation of the Participation Trials for the My Health Record – Final Report, pg 219).

This is telling.

For this small cross-section of the Australian population, there was an unrecognised belief that their healthcare data was already being managed in the manner intended with My Health Record. For at least part of the community, it seems that My Health Record is in fact playing catch-up with what is already believed to be in place.

But for the Australian community to have confidence in the My Health Record system, they need to be confident in the security and privacy of the information being collected, how this information can be accessed and what control they have over their own personal health information.



This points to the importance of public information and understanding, realised through an effective communications campaign. And an important element of this must be respectful engagement with those that raise legitimate concerns with the My Health Record system.

And one point I would ask the Committee to be particularly mindful of as you engage with various stakeholders, is that awareness of My Health Record is not enough. It is vital that the public understands the My Health Record system to the greatest extent this is possible.

Two areas where I think understanding has been overshadowed, if not lost, is, first, the individual control people have over their own My Health Record, and second, the current risks with the status quo. And these risks relate not only to privacy, but also risks around patient safety and quality of care, risks with incomplete medical records, and risks to system inefficiencies resulting from the absence of comprehensive information on an individual's health care.

AHHA has previously called for comprehensive training and a strong communications strategy, for both consumers and healthcare providers, around the implementation of the My Health Record system. The evaluation of the opt-out trials found that there was very low awareness in the community of the My Health Record arrangements, and very low awareness among all types of healthcare providers of the online training available to them.

The Committee would be aware that the Australian Digital Health Agency began a public awareness campaign with the commencement of the opt-out period on 16 July 2018.

One area where we think the strategy is lacking is that a letter has not, and we understand will not, be sent to all Australians explaining the benefits and relative risks of the My Health Record system, including information on the personal control that individuals will have over the contents of their My Health Record, and what can be seen within their My Health Record by providers and other third parties.

While the evaluation of the opt-out trials noted shortcomings with the mailouts conducted there, we would suggest that the lessons be learned from those trials on how to create a more effective and sustained range of communication messages on the My Health Record system.



There is also considerable latent value to researchers in the information that will accumulate within the My Health Record system. The Committee will be aware of the work being done to develop the *Framework to guide the secondary use of My Health Record system data*. While this remains a work in progress, I understand that it will only allow de-identified data to be released for research proposals that are in the public interest. Furthermore, de-identified data will only be released from My Health Records where the individual has consented to the release of their personal information for research purposes.

This has the potential to provide unique insights to population health issues and service utilisation patterns to the benefit of the public, providers and to governments. Longer term, it also has the potential to provide longitudinal insights into how an individual's health evolves over time and how their interactions with the health system change in response.

I emphasise once again, this would only be with de-identified data.

Such secondary use of My Health Record data can be of legitimate concern for some in the community. I think this comes back to the issues I have raised in relation to community trust, community education, explaining the benefits and relative risks of the My Health Record system and the many controls being put in place to ensure this happens in a manner that the public would be comfortable with.

The final point I make relates to third party access to My Health Records by, for example, insurers. This should not be permitted, as it does not relate to an individual's health care, does not represent a public interest, and could jeopardise the public's confidence in how their personal health information might be used.

But not allowing third parties such as insurers access to My Health Data is not enough. There should also be consumer protections to prevent third parties from discriminating against individuals that do not agree to the release of their My Health Record data. We note that this discrimination could take the form of not selling a product or service unless an individual provides access to their My Health Record data, or differentially pricing a product or service on the basis of one's My Health Record disclosure.

In closing, there are numerous advantages for consumers and healthcare providers to have medical histories consolidated in the one place.



AHHA believes that a comprehensive personal electronic health record such as My Health Record, is a critical part of the future health infrastructure for Australia. It has the potential to make Australia a leader in providing Australians with access to their own health information and contributes to portability of patient data between providers.

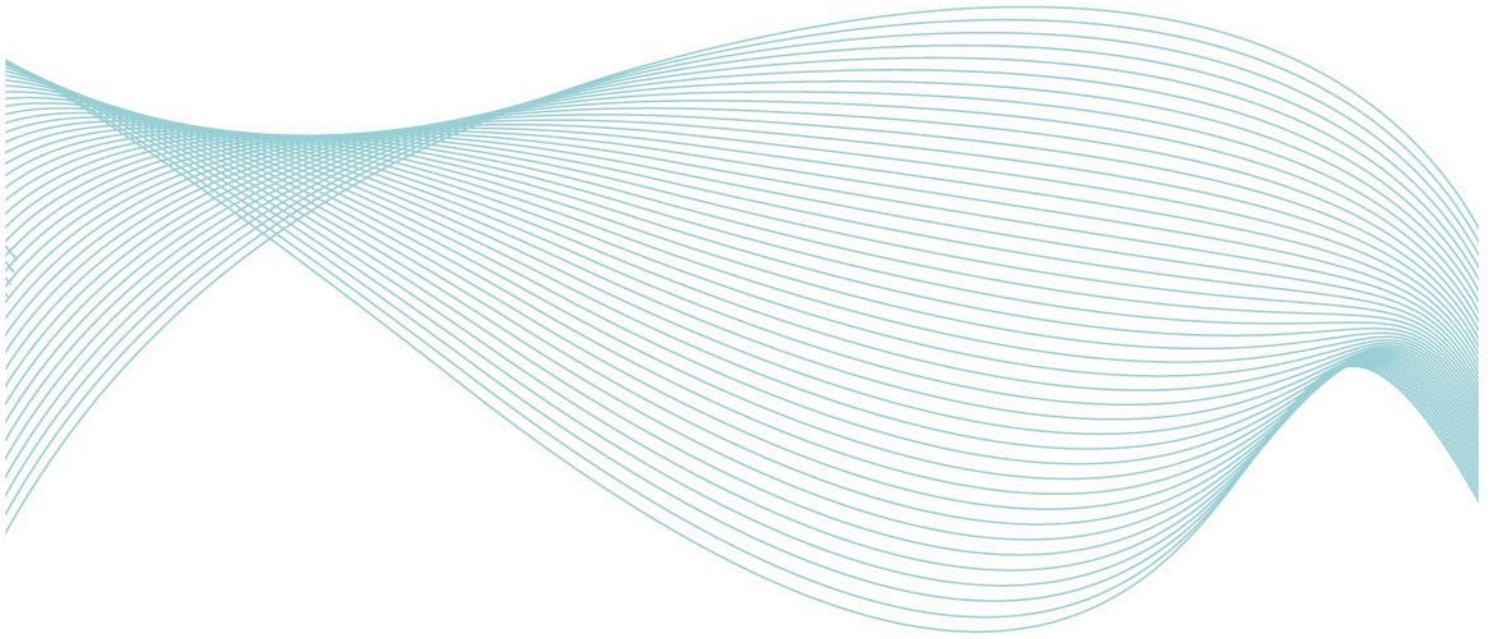
The evaluation of the opt-in and opt-out trials was overwhelmingly in favour of the opt-out approach.

The Australian Digital Health Agency must ensure that the benefits and relative risks of the My Health Record system are understood by all segments of the Australian population to the greatest extent possible.

The ADHA should also proactively engage with individuals or groups that raise legitimate concerns about the My Health Record system. These should not be dismissed, but rather be accepted as valid concerns that either have already been addressed in the design of the My Health Record system and explained as such, or need to be contextualised in terms of the benefits and risks of the My Health Record system and discussed in the context of the benefits and risks of the current environment for managing personal health data.

Overall, My Health Record, with its inbuilt privacy and security controls set by the consumer, together with the legislative amendments that law enforcement bodies can only access My Health Record with a court order, balances the need for better information and coordination of healthcare with the right to privacy.

Thank you and I am happy to take any questions you may have.



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