

Coalition Senators' Dissenting Report

Recommendation 1

The committee recommends that record access codes should be applied to each My Health Record as a default and that individuals should be required to choose to remove the code. The committee further recommends that the ability to override access codes in the case of an emergency should only be available to registered healthcare providers for use in extraordinary and urgent situations.

1.1 This recommendation is not supported as there are concerns with this proposal. In order for all Australians to set access controls, they would need to be provided their access code securely. Those Australians who did not (or could not) want to receive their PIN online, would need their access code to be sent to their postal address.

1.2 This represents a serious implementation challenge for many Australians. The health system does not have an accurate and current address for all Australians, which would result in a large number of Australians not being able to receive their PIN in order to provide it to their clinician. Furthermore, it would not be possible to guarantee that an individual's PIN would be protected from a third party, creating a privacy and security risk for the individual.

1.3 The evidence heard by the committee during the public hearings indicated that to realise the full benefits of the My Health Record system, an individual's multiple healthcare providers need to have timely and comprehensive access to their patients' medical history in which to better make a diagnoses and provide treatments.

1.4 Asking for a PIN, and requiring consumers to remember their PIN, will interrupt the clinical workflow and impede use of the record. Clinicians treating people who are unable to recall their PINs will not be able to view their patient's record. Both the clinician's and the consumer's time will be wasted while the consumer attempts to remember or locate their PIN.

1.5 In addition much valuable clinical work is undertaken for patients when they are not directly in the presence of their treating clinicians. For example, a general practitioner may receive important updated information from a specialist by letter such as a medication change or new investigation being required. Unless the patient was present to provide their record access control, the GP would be unable to check their MHR at that moment for important medication interaction information, or whether or not various investigations had already been done by another clinician. This would represent a great barrier to the realisation of benefits from the MHR system associated with medication safety and reducing unnecessary test duplication.

1.6 The proposal would also in practical terms effectively return the My Health Record to an opt-in participation model. This was noted by the AMA's Dr Chris Moy during the Senate hearings:

Basically, what happens then is the personal access code means that the only way anybody can access it in a reasonable situation, generally, is if the PIN is actually given to the individual, and it basically becomes opt-in then. The person has to go in there to change those details or actually has to be there every single time to be able to provide that information, so it makes it much more difficult.¹

1.7 Information on the My Health Record website provides clear concise information on how an individual can set a record access code and provide it to the healthcare providers they choose.

1.8 We therefore believe the current process is appropriate.

Recommendation 4

The committee recommends that data which is likely to be identifiable from an individual's My Health Record not be made available for secondary use without the individual's explicit consent.

1.9 We do not support this recommendation as this would be inconsistent with the Government's general opt-out approach to My Health Record.

1.10 The Australian Government has developed a framework to guide the secondary use of My Health Record system data for research, policy and planning purposes. This framework was developed in consultation with consumers, clinicians, medical researchers and industry experts.

1.11 The aim of the Framework is to be clear and open about the potential use of data.

1.12 The committee heard from organisations that appeared before the committee such as the Australian Health and Hospitals Association there is also considerable latent value to researchers in the information that will accumulate within the My Health Record system.

This has the potential to provide unique insights into population health issues and service utilisation patterns to the benefit of public providers and governments. Longer term, it also has the potential to gain longitudinal insights into how individuals' health evolves over time and how their interactions with the health system change in response.²

1.13 Coalition senators are therefore concerned that making the system 'opt-in' for research purposes would greatly diminish the potential data pool and limit the potential benefits highlighted above. It could also lead to distortions in data sets and individuals who chose to opt-in under this approach may not be a representative sample of the wider Australian public.

1 Dr Chris Moy, Member, AMA Federal Council, Chair, Federal Ethics and Medico-Legal Committee, AMA, *Committee Hansard*, 11 September 2018, p. 39.

2 Dr Linc Thurecht, Senior Research Director, Australian Healthcare and Hospitals Association, *Committee Hansard*, 11 September 2018, p. 8.

Recommendation 13

The committee further recommends that the Australian Government extend the opt-out period for the My Health Record system for a further 12 months.

1.14 Coalition Senators do not support this recommendation.

1.15 The program to create a My Health Record for all Australians by the end of 2018, unless individuals choose not to have one, is the culmination of ten years of planning, design and development carried out under several Health Ministers, current and former federal governments.

1.16 The legislation and program have been scrutinised by several independent enquiries, and shaped by national and international experience on the most appropriate national system for Australia with regard to our federated health system, mix of public and private healthcare, and sentiment of the Australian community.

1.17 The legislation to enable My Health Record to become an opt-out system passed the Parliament **unanimously** in 2015 and has received bipartisan support over this period. As recently as May this year, the Shadow Minister for Health Catherine King indicated support for an opt-out approach.

1.18 The opt-out approach has the support of every major health peak body including the AMA, RACGP and CHF, several of whom reaffirmed their support for an opt-out approach in their appearance before the committee. In addition all State and Territory Health Ministers unanimously reaffirmed their support for an opt-out approach as recently as the August COAG Health Council Meeting.

1.19 More than 6.1 million Australians already have a My Health Record and over 13,000 healthcare professional organisations are connected, including general practices, hospitals, pharmacies, diagnostic imaging and pathology practices.

1.20 The system has been in operation for over 6 years (commencing under the previous Labor Government with support of Liberals and Nationals), with My Health Record already improving the safety and healthcare management for individuals and healthcare providers.

1.21 The Government has also extended the opt-out period by one month to 15 November 2018 to provide additional time to educate consumers and healthcare providers about the benefits of having a My Health Record.

1.22 The Committee heard evidence provided by the Australian Digital Health Agency that it has implemented comprehensive multi-channelled campaign to reach all Australians through trusted clinical and community networks, that recognise the complexity of the messages and allows the opportunity to answer detailed questions. The ADHA also has plans in place to engage with vulnerable groups and those living in remote areas.

1.23 We therefore consider that a 12 month extension recommended by the Committee to be excessive and unnecessary.

1.24 It should also be noted the proposed legislative amendments announced by Minister Hunt to Section 17 of the My Health Record Act would require the System

Operator (ADHA) to permanently delete health information it holds for any consumer who has cancelled their My Health Record. This makes it clear that the Government will not retain any health information if a person chooses to cancel at any time. The record will be deleted forever.

1.25 This 'hard deletion' effectively means an individual's right to opt-out remains constant, even after the after the conclusion of a formal opt-out period. This was noted by Dr Chris Moy of the AMA when he appeared before the committee.

The other thing is I think the importance of the ability to hard delete the file on patient request is underestimated. I think it basically negates the need to extend the opt-out period, because, in effect, individuals can hop on and off the My Health Record based on their comfort level with privacy. That will vary over time. So, basically, the AMA's position is the amendments appear robust.³

Additional Comments by Coalition Senators

Recommendation 2

The committee recommends that the Australian Government amend the My Health Records Act 2012 to protect the privacy of children aged 14 to 17 years unless they expressly request that a parent be a nominated representative.

1.26 This is a sensitive policy issue and we believe it is premature to suggest specific recommendations on this matter at the present time.

1.27 There is likely to be a divergence of views within the community balancing the rights of minors with the view and expectations of parents and carers. It is also important to ensure such a change would not cause any unintended consequences resulting from this change.

1.28 We also consider it is important that there is consistency in the way policy is handled between My Health Record, Medicare and the State and Territories where possible.

1.29 Therefore, further engagement with all stakeholders is suggested before any changes should be considered.

Senator Lucy Gichuhi

3 Dr Moy, *Committee Hansard*, 11 September 2018, p. 32.