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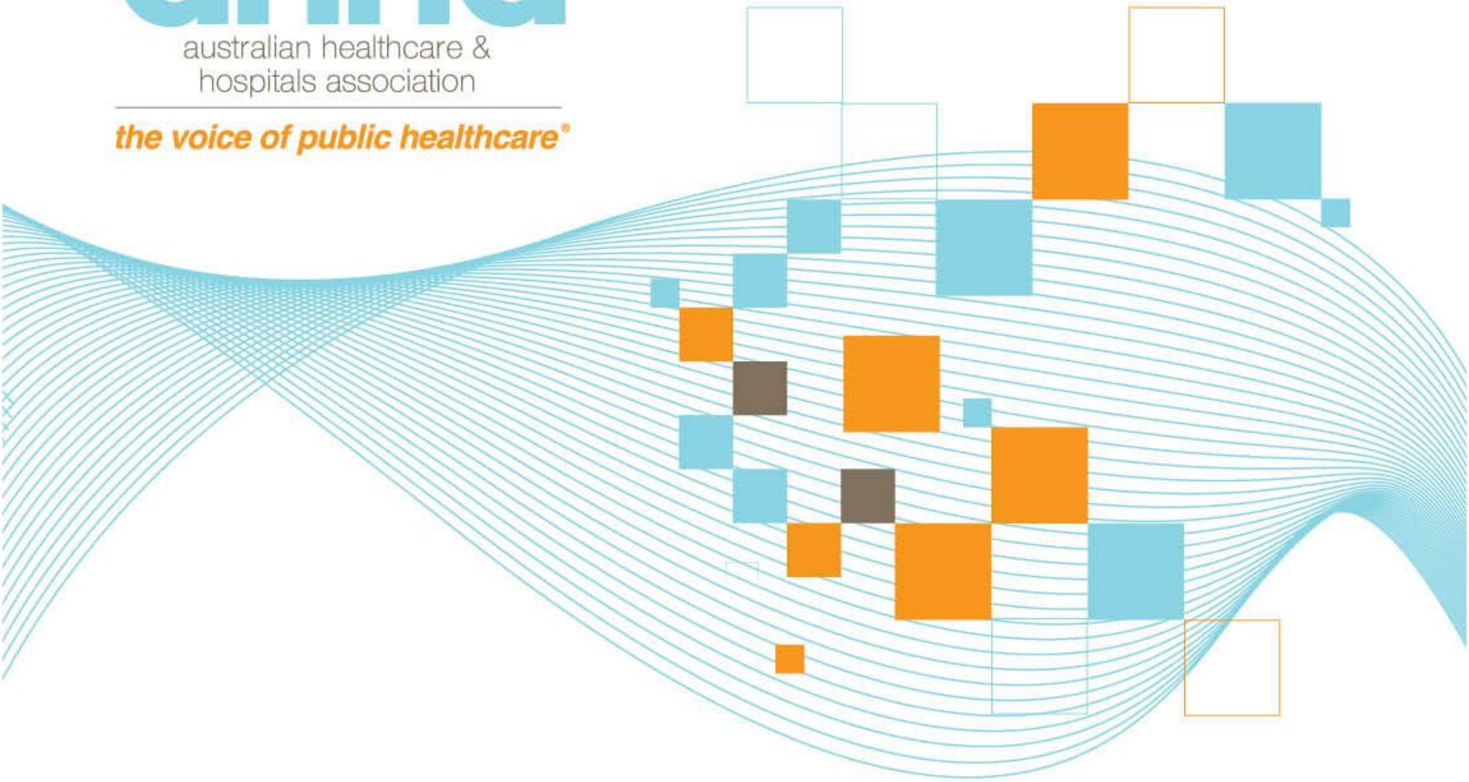

Senate Standing Committee on Community Affairs References Committee

Submission to the Inquiry Into the My Health Record System

14 September 2018

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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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INTRODUCTION

The Australian Healthcare and Hospitals Association (AHHA) is pleased to provide this submission to the consultation into the new Australian Government Data Sharing and Release legislation.

WHO WE ARE

AHHA 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 uniquely placed to be an independent, national voice for universal high-quality healthcare to benefit the whole community.

OVERARCHING VIEW

AHHA 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.

The advantages of having individuals' medical history in the one place, both for consumers and healthcare providers, are numerous. Apart from convenience, the potential benefits include better coordination of care among multiple healthcare providers, better informed decisions on healthcare that involve both the patient and the healthcare provider, reduced duplication of diagnostic tests, fewer adverse drug events and reduced hospital admissions.

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. This can enable a focus on health outcomes and facilitate achieving value in healthcare and transparency in outcomes.

The deployment of My Health Record on an opt-out basis with a properly informed Australian public is consistent with the AHHA proposal for reform of the Australian health system, *Healthy people, healthy systems: A blueprint for a post-2020 national health agreement* (AHHA 2017). A comprehensive personal electronic health record is an essential component of a health system that has performance information and reporting that is fit for purpose at its core.

SUBMISSION BACKGROUND

On 17 August 2018, the Senate Community Affairs Reference Committee invited submissions to the inquiry into the My Health Record System. The 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.

A. THE EXPECTED BENEFITS OF THE MY HEALTH RECORD SYSTEM

An electronic personal health record is an online collection of a patient's medical history in digital format, which includes information such as personal characteristics, diagnosed medical conditions, laboratory results, current and past medications and immunisation history. A person-controlled electronic health record is a special class of electronic personal health record where a consumer controls his or her record content and record access, which means only nominated health practitioners are able to access nominated information in the record (McMahon 2013, p. 112).

Australia chose to pursue a person-controlled electronic health record system following a 2009 recommendation from the National Health and Hospital Reform Commission, which recommended that as part of a transforming e-health agenda:

> The introduction of a person-controlled electronic health record for each Australian is one of the most important systemic opportunities to improve the quality and safety of healthcare, reduce waste and inefficiency, and improve continuity and health outcomes for patients. Giving people better access to their own health information through a person-controlled electronic health record is also essential to promoting consumer participation, and supporting self-management and informed decision-making (NHHRC 2009, p. 8).

An external review of implementation and uptake of the person-controlled electronic health record, commissioned by the Australian Government and publicly released on 19 May 2014, stated that 'overwhelming support was found for continuing the path of implementing a consistent electronic health record for all Australians' (Royle et al. 2013, p. 13), and found that 'an electronic health record remains a critical part of the future health infrastructure for Australia' (p. 12). The expert panel added 'a change in approach however is needed to correct early implementation issues and to review the strategy and role that a shared electronic health record plays in the broader system of healthcare' (p. 13).

In response to the review, the Australian Government's 2015–16 Budget re-committed to a national shared electronic health record system—rebranded My Health Record with a trial opt-out, rather than opt-in, option (Ley 2015). As part of this process My Health Record was to be redeveloped to improve its usability and clinical utility, strengthen e-health governance and operations. (Australian Government 2015, p. 113).

A review of Australia's efforts to introduce a person-controlled electronic health record noted it is an opportunity to improve the quality and safety, to improve continuity and health outcomes for patients and to reduce waste and inefficiency in the health system (McMahon 2013, p. 112). A review of similar electronic personal health record systems in the United States and the United Kingdom support this assertion (Reeves et al. 2013, pp. 71–2).

My Health Record has the potential to make Australia a leader in providing Australians with access to their own health records (Nøhr et al. 2017).

The advantages of having your medical history in the one place, both for consumers and healthcare providers, are numerous. Apart from convenience, the potential benefits include better coordination of care among multiple healthcare providers, better informed decisions on healthcare that involve both the patient and the healthcare provider, reduced duplication of diagnostic tests, fewer adverse drug events and reduced hospital admissions.

A financial incentive also exists for a well-implemented and functioning system. On 10 May 2015, when announcing the system overhaul and rebranding to My Health Record, then-federal Minister for Health Sussan Ley stated ‘a fully-functioning national e-health system could save taxpayers $2.5 billion per year within a decade by reducing inefficiencies, with an additional $1.6 billion in annual savings also delivered to the states’ (Ley 2015). In a 2010 report by consultancy Booz & Company, it estimated that fully digitising the healthcare sector would realise AUD 7.6 billion in annual savings by 2020 and that this figure only reflects direct savings and does not include savings through economic flow-on effect (Booz & Company 2010, p. 2).

AHHA acknowledges My Health Record will not be an overnight success because the usefulness of each person’s record will depend on the amount of information put there by individual healthcare providers and consumers. But with active use and updating, My Health Record has the potential to be very empowering for both clinicians and patients.

Australian consumers are generally supportive of the move toward greater engagement and control. In a 2014 study examining how Australians perceive the promoted idea of having a person-controlled electronic health record, in a sample of 750 participants 34 per cent were interested and 33 per cent were very interested in managing their personal health (Andrews et al., p. 894).

AHHA acknowledges public debate over whether Australians should remain part of the My Health Record system roll-out or to opt-out (Kemp et al. 2018 & Gillespie 2018). The ADHA should proactively engage with individuals or groups that raise legitimate concerns about the My Health Record system. These should 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, including the benefits and risks of the current environment for managing personal health data.

There is also considerable latent value to researchers in the information that will accumulate within the My Health Record system. De-identified data should only be released for research purposes where there is a potential public benefit and only for those individuals who have opted-in for their personal medical data to be used in this way. This should only occur in compliance with the *Framework for Secondary Use of My Health Record System Data* currently under development (DoH 2018). 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.

Overall, My Health Record, with its inbuilt privacy and security controls set by the consumer and the proposed amendments by the Australian Government to Section 70 of the *My Health Records Act 2012*, balances the need for better information and coordination of care, with the right to privacy.

AHHA submits that:

- An electronic health record, such as My Health Record, is a critical part of the future health infrastructure for Australia and has the potential to make Australia a leader in providing Australians with access to their own health records and ensuring portability of patient data between providers.
- There are numerous advantages for consumers and healthcare providers to have medical histories in the one place, which include: convenience; better coordination of care among multiple healthcare providers; better informed decisions on healthcare that involve both the patient and the healthcare provider; the capacity to record details such as allergies, organ donor decisions and advanced care planning information; reduced duplication of diagnostic tests; fewer adverse drug events; and reduced hospital admissions.
- My Health Record has the potential to be very empowering for both clinicians and patients with active use and updating.
- Potential financial incentives and system-wide savings exist for a well-implemented and functioning My Health Record.
- There are potentially valuable population health and health service utilisation insights to be gained from the secondary use of My Health Record data accessed in compliance with the *Framework for Secondary Use of My Health Record System Data* currently under development (DoH 2018).
- My Health Record, with its inbuilt privacy and security controls set by the consumer and the recent amendments to the *My Health Records Act 2012* relating to access to My Health Record data by law enforcement bodies, balances the need for better information and coordination of care with the right to privacy.

B. THE DECISION TO SHIFT FROM OPT-IN TO OPT-OUT

The Australian Government agreed with the external review of implementation and uptake of Australia's person-controlled electronic health record that a key challenge was the opt-in nature of the system. The Australian Government stated health service providers were more likely to use the system if all patients had a record, and announced the trial of system participation and use in both opt-out and opt-in models (Ley 2015).

The evaluation of the My Health Record system participation and use trials was commissioned by the Australian Government in late 2015 and commenced in January 2016. Based on a range of selection criteria, the federal Minister for Health identified sites based generally on Primary Health Network (PHN) boundaries. Two opt-out trial sites were identified, the Northern Queensland PHN and the Nepean Blue Mountains PHN. Two opt-in trial sites were also identified to trial methods of innovative opt-in participation in two different healthcare settings. One opt-in site was in the Ballarat Hospital, Victoria and one covered a number of private general practices in Perth, Western Australia that used a software product designed to facilitate multi-disciplinary team care of people with an identified chronic illness. (Siggins Miller 2016)

Publicly released by the Australian Government Department of Health on 4 May 2017, the evaluation concluded that (Siggins Miller 2016):

1. the opt-out approach to increase both individual and healthcare provider participation and use is the preferred option
2. continuation of current or accelerated opt-in approaches is considered to be unsustainable
3. the opt-out trial sites achieved better outcomes, in terms of participation, understanding and some aspects of use of the My Health Record system
4. key lessons were learned to inform Government's understanding of the effectiveness of different approaches for driving participation and use of the My Health Record system

Commenting on the public release of the evaluation, AHHA supported the opt-out model for My Health Record, but with some important provisos, noting that the report came down overwhelmingly in favour of the opt-out method (AHHA 2017).

Under the opt-out model, a My Health Record is automatically created for individuals. This was assessed as being vital for a broad population uptake of My Health Record. For healthcare providers, assisting in creating My Health Records, which would have been needed for some patients under the opt-in model, was assessed as being impractical without additional funding and would ultimately be unsustainable.

The evaluation found that once the system and its benefits were explained, individuals had minimal confidentiality or security concerns with the My Health Record system. Furthermore, most consumers were strongly of the view that healthcare providers should not be able to opt out of the system. This reflects a broader view of the healthcare system and the importance of healthcare data portability both for individuals and for providers.

AHHA raised concerns that the existing infrastructure may not have the appropriate capacity to support the recommended change.

AHHA called for:

- PHNs to be afforded adequate time to undertake collaborative planning, local mapping of digital capacity and capability and the flexibility to respond to local issues and contexts noting that a national rollout was likely to require support by the PHNs.
- Comprehensive training and a very strong communications strategy—both to consumers and healthcare providers.

Communications cannot be emphasised strongly enough. The evaluation 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 for the current My Health Record system.

AHHA submits that:

- The evaluation of the My Health Record system participation and use trials, commissioned by the Australian Government, came down overwhelmingly in favour of the opt-out approach to deploying the My Health Record system across Australia.
- Comprehensive training and a very strong communications strategy targeting both consumers and healthcare providers is critical to the successful deployment of the My Health Record system. This should include a letter mailed to all Australians explaining the benefits and relative risks of the My Health Record system.
- 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, including the benefits and relative risks of the current environment for managing personal health data.
- The Australian Digital Health Agency should proactively engage with individuals or groups that raise concerns about the My Health Record system, with these concerns meaningfully considered either in the context of security features already built into 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, including the benefits and risks of the current environment for managing personal health data.
- To contribute to the public’s trust in the My Health Record system, the Australian Digital Health Agency must communicate how an individual’s information accessed by healthcare providers will be kept secure, including how this relates to the current relative risk of disclosure of patient information.
- A loss of public trust in the My Health Record system would be a major impediment to the uptake of My Health Record by a significant majority of Australians.

C. PRIVACY AND SECURITY

(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;

My Health Record will only succeed if concerns about protection of confidentiality are respected. Most of the criticisms of My Health Record relate to the potential for inappropriate use or hacking of data.

The vulnerability of the system to unauthorised access

The My Health Records Amendment (Strengthening Privacy) Bill 2018 appears to address community privacy concerns around the need for an appropriate judicial process to access information contained in an individual's My Health Record.

In its six years of operation, first as the Personally Controlled Electronic Health Record and now as My Health Record, there has not been a security or privacy breach, meaning that there has been no unauthorised viewing of any individual's health information (ADHA 2018c). As such, critics have not pointed to any breach, but rather, examples from commercial operations, which are offences that could lead to prison under My Health Record (Hendry 2018).

During the opt-out trials, concerns were mainly focused on individuals' lack of computer skills. However, the evaluation report from the trials noted almost all health consumers thought the benefits greatly outweighed any potential privacy risks (Siggins Miller 2016).

A large amount of health data exists, which are increasingly linked together with great potential benefits – for example Medicare Benefits Schedule (MBS) and Pharmaceutical Benefits Scheme (PBS) data, hospital and immunisation records etc. Extensive governance and management system, and ongoing privacy impact assessments are critical (ADHA 2018b & Bogle 2018). This linked data can be used to improve our knowledge of causes of diseases and risk factors, and the best forms of intervention. This information can also provide insights to health system utilisation patterns to potentially improve patient treatment pathways and to identify system efficiencies.

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

The *My Health Records Amendment (Strengthening Privacy) Bill 2018* appears to address community privacy concerns around the need for an appropriate judicial process to access information contained in an individual's My Health Record.

With regards to third party apps, according to the Australian Digital Health Agency (2018a):

> *"Only you can agree to an app connecting to your My Health Record. These apps are 'view only' and can't store your My Health Record information on their systems. You can cancel access at any time, and they are prohibited from using My Health Record for secondary purposes, like passing on information to third parties such as compensation lawyers." (ADHA 2018a).*

As a further safety precaution, Australians are able to create an access code, like a PIN, so only healthcare providers with the code can access an individual's My Health Record. Australians are also able to see at any time every healthcare provider organisation who has viewed their record in an audit history (ADHA 2018a).

While the Australian Digital Health Agency has put in place many safeguards to protect personal information held within the My Health Record system (ADHA 2018d), the Agency should also advise the procedures and policies that have been developed to protect individual's My Health Record data associated with providers interacting with their record. This is perhaps the area where patient privacy is most at risk and relates to the significantly larger attack surface of the My Health Record system beyond that which the Agency has direct control over (DoD 2014).

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

Only registered clinicians directly caring for you can access your record. Doctors being paid by employers and life insurance companies are not allowed to access an individual's My Health Record for this purpose (ADHA 2018a).

Third parties such as insurers should not be allowed access to any My Health Records. This is because such access would not relate to an individual's health care or represent a public interest. Furthermore, if third parties such as insurers did have access to My Health Records, this could jeopardise the public's confidence in how their personal health information might be used. To further protect privacy, there should also be consumer protections to prevent discrimination against individuals that do not agree to provide access to their My Health Record data. 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 based on an individual's My Health Record disclosure.

AHHA submits that:

- My Health Record, with its inbuilt privacy and security controls set by the consumer and the proposed amendments to the *My Health Records Act 2012* relating to law enforcement bodies access to My Health Record data, balances the need for better information and coordination of care with the right to privacy.
- The Australian Digital Health Agency should provide public information on how the My Health Record system is kept secure, including any policies and procedures developed for ensure providers maintain appropriate security of My Health Record data.

- The Australian Digital Health Agency should communicate how an individual's My Health Record that is accessed by healthcare providers will be kept secure, including how this relates to the current relative risk of disclosure of patient information.
- There must be a legislated requirement that law enforcement bodies and other government agencies cannot access an individual's My Health Record without a court order.
- Researchers should only be able to have access to My Health Record data from the records of individuals that have agreed to allow their data to be accessed for research purposes. This agreement should be in the form of an opt-in process, including the capacity for an individual to not consent for particular entries to be available to researchers.
- Access to My Health Record data should be conducted in accordance with the proposed *Framework for the Secondary Use of My Health Record Data* (DoH 2018), including that data requests should only be considered if there is a public benefit associated with the proposed research.
- Any data released to researchers must be securely de-identified.
- Other third parties should not be able to gain access to My Health Record data.
- There should be consumer protections against third parties that discriminate against individuals that do not agree to the release of their My Health Record data. This discrimination could take the form of not selling a product or service unless an individual provides access to their My Health Record or differentially pricing a product or service on the basis of My Health Record disclosure.

D. THE GOVERNMENT'S ADMINISTRATION OF THE MY HEALTH RECORD SYSTEM ROLL-OUT

(iv) the public information campaign, and
(v) the prevalence of 'informed consent' amongst users;

'WHAT NOT TO DO' LEARNED; 'WHAT TO DO' IGNORED

AHHA understands that the government has claimed that its administration of the My Health Record system roll-out was informed by the participation and use trials conducted in 2016, in particular the evaluation of the activities in the opt-out trial sites (Northern Queensland PHN and Nepean Blue Mountains PHN).

The evaluation of these trials identified that overall the level of awareness and understanding of the My Health Record was low, and that national adoption strategy would need to include a much bigger emphasis on awareness and education. This includes:

- 'putting the My Health Record system on peoples' radar in a positive way
- alerting people to the existence of the My Health Record system and what they need to do under any participation arrangements (be that opt-in or opt-out)
- informing people that they should not assume that the health system already shares information from one part of it to another
- making clear the benefits of the My Health Record system and the privacy and security protections built into the system' (Siggins Miller 2016).

While the 2016 evaluation reported that the data suggested that the mail out of a letter and brochure at the beginning of the opt-out trial period had not worked well, the recommendations were for 'a general population communication strategy, appropriately targeted for each audience segment and using multiple channels of communication (including social media)', that was 'nationally driven but locally supported' (Siggins Miller 2016).

This is consistent with the 2014 consultation on the personally controlled electronic health record that identified that a 'single, high level approach will not work for all stakeholder groups'. It found that the communication approach required high level messaging with more localised support for change management to drive adoption (Deloitte 2014).

Media reports at the time of the introduction of the national roll out of the opt out period, which commenced 16 July 2018, identified that a number of people with a My Health Record did not believe they had ever opted in (ABC 2018). Responses from the Australian Digital Health Authority suggested these people may have opted in when the record was under another name, or had been part of the opt-out trials. Regardless, it reinforces that communication strategies have not been sufficient.

The 2016 evaluation also made recommendations about the range of activities that should be included in the change and adoption strategy, addressing:

- ‘Agenda setting: getting the public/target audience segments thinking about the issue
- Information: education that makes the issue interesting, understandable, personally meaningful
- Incentive: elaboration of the positive personal and social benefits
- Skills: providing step by step instruction and resources
- Action: education to trigger the trial adoption of the new behaviour/s
- Maintenance: developing social and other support for continuation of the changed behaviour’ (Siggins Miller 2016).

COMMUNICATION STRATEGY NOT SUPPORTED BY ADEQUATE EVIDENCE

The 2016 evaluation reported that the timeframe for the evaluation meant that a number of communication activities across the trial sites could not be included in the measurement period. This included:

- work by the Australian College of Rural and Remote Medicine (ACRRM)
- a Facebook public education campaign
- the evaluation results of kiosks in general practices
- work with medical specialists, residential aged care facilities and allied healthcare providers
- work in the ACCHS sector and in Aboriginal communities (in the case of North Queensland PHN) (Siggins Miller 2016).

Recommendations included that there is audience segmentation; that channels of communication be matched to each audience segment’s known sources of credible information; that messages and resources be tested and trialled with each audience segment; that messages are delivered by sources that are credible to each audience segment; and that audiences are encouraged to seek more detailed information. Mass media strategies taking into account the media habits of each audience segment were also recommended (Siggins Miller 2016).

INDIVIDUALISED SUPPORT INSUFFICIENT

The 2016 evaluation identified that individuals reported difficulties with the myGov website and in getting assistance from call centre helplines (e.g. long wait times) and staff who cannot answer their questions when the do get through (Siggins Miller 2016).

Recommendations included that adequate capacity be ensured to meet demand in call centres and service centres, including having enough staff and training to adequately answer questions. (Siggins Miller 2016).

Media reports at the time of the introduction of the national roll out of the opt out period, which commenced 16 July 2018, suggest that capacity was not adequate. Long wait times were reported for those calling the opt out phone line, as well as technical problems with the myGov and My Health Record portals (Healthcare IT 2018).

AHHA submits that:

- The 2016 evaluation of the participation trials for the My Health Record did not include measurement of a range of communication activities, neither those that were nationally driven nor those that were locally supported, to adequately inform the national roll-out.
- While the decision not to do a mail out of a letter could be supported from the 2016 evaluation data, the communication strategy has not been sufficiently informed nor comprehensive to ensure the population is informed of the existence of the system, its benefits, privacy and security protections and participation arrangements.
- Call centre and online portal support was inadequate to support national roll out of My Health Record system as opt out was introduced.

E. MEASURES THAT ARE NECESSARY TO ADDRESS COMMUNITY PRIVACY CONCERNS IN THE MY HEALTH RECORD SYSTEM

The My Health Records Amendment (Strengthening Privacy) Bill 2018 appears to address community privacy concerns around the need for an appropriate judicial process to access information contained in an individual's My Health Record.

Concerns about when a person requests their My Health Record to be cancelled, and whether it is subsequently 'fully deleted' or not, appear to have been addressed by the new section 17(3) of the *My Health Records Act 2012*. However, it does not appear that this 'destruction' of information extends to items deleted from ongoing records.

The proposed review of the *Framework for the Secondary Use of My Health Record Data* within two years of the first dataset being released is supported (DoH 2018). As noted in the Framework, this will provide the opportunity to identify further possible beneficial opportunities for the secondary use of My Health Record data. However, the overriding principle that must be adhered to in such a review is that the existing security and privacy of individual's My Health Record must be maintained.

AHHA submits that:

- The My Health Records Amendment (Strengthening Privacy) Bill 2018 appears to address community privacy concerns around the need for an appropriate judicial process to access information contained in an individual's My Health Record.
- Further clarification is needed to address community privacy concerns about the deletion/destruction of items from an individual's ongoing My Health Record.
- Any review of the *Framework for the Secondary Use of My Health Record Data* should only be conducted with the overriding principle that the existing security and privacy of individual's My Health Record must be maintained.

F. HOW MY HEALTH RECORD COMPARES TO ALTERNATIVE SYSTEMS OF DIGITISING HEALTH RECORDS INTERNATIONALLY

Australia chose to pursue a personally controlled electronic health record (PCEHR) system following a 2009 recommendation from the National Health and Hospital Reform Commission, which recommended that as part of a transforming e-health agenda:

> 'The introduction of a person-controlled electronic health record for each Australian is one of the most important systemic opportunities to improve the quality and safety of healthcare, reduce waste and inefficiency, and improve continuity and health outcomes for patients. Giving people better access to their own health information through a person-controlled electronic health record is also essential to promoting consumer participation, and supporting self-management and informed decision-making' (NHHRC 2009).

The substantial research and consultation that has occurred to implement what is now the My Health Record system must be recognised, particularly that led by the National E-Health Transition Authority (NEHTA). This includes the analyses of international experiences implementing digital health policy, which have been considered in the context of the type of governance structures and policy frameworks of each country, as well as local health, social welfare, telecommunications needs, and variety of stakeholders. It is important to recognise that:

- 'Even the most advanced countries face challenges relating to interoperability, uniform coding of patient information, and dealing with privacy and security concerns'.
- Implementation of Australia's national electronic record is still in its early stages, relatively. For example, some countries had foundational work in place in the 1990s (NEHTA 2016).

AHHA submits that:

- Despite the challenges currently faced in Australia in implementing the My Health Record system, the foundation work is in place, and we should be focusing on ensuring privacy and confidentiality of patient information, with continuing incremental improvements to refine the system to maximise useability and benefits.

CONCLUSION

AHHA 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.

The advantages of having individuals' medical history in the one place, both for consumers and healthcare providers, are numerous. Apart from convenience, the potential benefits include better coordination of care among multiple healthcare providers, better informed decisions on healthcare that involve both the patient and the healthcare provider, reduced duplication of diagnostic tests, fewer adverse drug events and reduced hospital admissions.

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. This can enable a focus on health outcomes and facilitate achieving value in healthcare and transparency in outcomes.

The deployment of My Health Record on an opt-out basis with a properly informed Australian public is consistent with the AHHA proposal for reform of the Australian health system, *Healthy people, healthy systems: A blueprint for a post-2020 national health agreement* (AHHA, 2017). A comprehensive personal electronic health record is an essential component of a health system that has performance information and reporting that is fit for purpose at its core.

The Australian Digital Health Agency should proactively engage with individuals or groups that raise concerns about the My Health Record system, with these concerns meaningfully considered either in the context of security features already built into 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, including the benefits and risks of the current environment for managing personal health data. The Australian Digital Health Agency should also send a letter to all Australian adults to explain the My Health Record system, the control they have over their own information, and the benefits and relative risks associated with both the My Health Record and the current environment for handling personal medical information.

The Australian Digital Health Agency should provide public information on how the My Health Record system is kept secure, including any policies and procedures developed to ensure providers maintain appropriate security of My Health Record data.

AHHA supports the secondary use of de-identified My Health Record data where the research will be in the public interest and where data is only used from individuals that have opted-in to having their My Health Record used for research purposes. However, other third parties such as insurers should not have access to My Health Record data.

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