

My Health Record Consumer Consultation Report

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HCA acknowledges the Traditional Custodians of Country. We pay respect to Elders past and present, and recognise that their cultural heritage, beliefs and relationship to Country are important for sustaining health and wellbeing.

Executive Summary

In 2018, every Australian will get a My Health Record (MHR). People have a four-month period from 16 July to 15 November 2018 to opt out. This is to provide Australians an opportunity to make a decision as to whether to opt out or not. During this period, the government will strengthen the 2012 My Health Record legislation.

There has been concern from community and medical practitioners about the security of MHR, issues relating to consent, third party access to records, and secondary use of information contained in records.

On 15 August 2018, the Senate referred My Health Record to the Senate Community Affairs References Committee for inquiry and report. Submissions are sought by 14 September 2018. The reporting date is 8 October 2018.

Health Consumers Alliance (HCA) sought feedback from consumers via two methods. Firstly, the MHR was placed on the agenda of the quarterly HCA Consumer Advocates Network (CAN) meeting held on 18 August 2018 (18 consumers) and secondly, on 30 August 2018, HCA held a My Health Record Focus Group (9 consumers). Both of these engagement opportunities will be used to inform HCA's submission to the enquiry. The feedback at both engagement sessions about MHR was consistent.

The key messages in the consumer feedback includes:

- My Health Record is a good initiative that should improve information between GPs, consumers and other health professionals and result in improved service coordination and efficiency.
- Security of MHR is paramount. Consumers would like transparency about the security measures that are in place and open disclosure of any security breaches.
- An online tutorial is required to show people how to navigate and manage their record, including how to add information, block documents, change security settings.
- Consideration needs to be given to the needs of vulnerable community members, including people with disabilities, under guardianship, or for whom English is a not their primary language.
- People may need prompts during major life transitions to check and ensure that MHR meets their changing needs. This is particularly relevant when young people turn 16 and become responsible for their own record, and in the case of families fleeing family violence.

Background

Health Consumers Alliance of SA Inc (HCA) was established in 2002 as the peak body for health consumers in South Australia. We are a member-based, independent, not-for-profit organisation, funded by SA Health. We work with our members and supporters to achieve our vision: *Consumers at the centre of health in South Australia*. Our mission is to engage consumers and health services to achieve quality, safe, consumer-centred care for all South Australians.

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Health Consumers Alliance (HCA) sought feedback from consumers via two methods. Firstly, the MHR was placed on the agenda of the quarterly HCA Consumer Advocates Network (CAN) meeting held on 18 August 2018 (18 consumers). This was an informal consultation to identify consumer perspective of MHR given the opt out period had begun and the high level of media attention it had attracted. Secondly, on 30 August 2018, HCA held a My Health Record Focus Group (9 consumers) that was structured directly to the terms of reference of the enquiry. Both of these engagement opportunities inform HCA's submission to the enquiry. The feedback at both engagement sessions about MHR was consistent.

Focus Group Program

The forum program related directly to the terms of reference of the Senate enquiry as below:

- 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.

Attendees were broken into two groups facilitated by Kathy Mickan and Julia Overton, and their responses to the questions were recorded.

At the end of the session, Kathy asked each attendee to identify their most important issue, and these were recorded for them.

Focus Group discussion

Attendees were asked to provide feedback from a consumer's perspective on aspects of MHR:

- a. **the expected benefits of the My Health Record (MHR) system;**

Consumers anticipate many benefits from having an electronic health record – particularly for people with complex or chronic conditions. The sharing of information between the consumer, their GP and other specialists or multi-disciplinary teams is expected to provide improved continuity of care, reduce duplicate testing and improve the prescribing and management of medications. Consumers also anticipate that they will not be required to re-tell their medical history so often. In regard to people with a record identifying them as a person with mental illness, or a history of addiction, MHR can have a positive impact if that information is used in a consumer centred way. In other situations, it could be used to label and discriminate against people, resulting in poorer health outcomes.

Other positives include:

- Repository for their Advance Care Directive

- Emergency department access to vital information in case of emergency – allergies, conditions, medications etc
- Personal access to own health record

b. the decision to shift from opt-in to opt-out;

Many consumers are happy with the decision to move to an opt-out system, as it gives bulk to the system, making it more effective and more likely for medical professionals to participate.

There are still concerns about how vulnerable members of the community will engage with MHR, and whether they are really consenting to participate. Who is making the decision for children and adults under guardianship – and who has access/controls their record? People with poor general or technological literacy are unlikely to have the capacity to manage their account to the level they might prefer. This would impact on some Aboriginal people, people for whom English is not their first language, older Australians and people with disabilities. If these people want to opt out, who will help them. If they want to adjust their security settings, add to their record or block particular documents, who will help them?

c. privacy and security, including concerns regarding:

i. the vulnerability of the system to unauthorised access,

Consumers appreciate the changes that have been made to increase security of MHR and reduce access to non- health professionals such as police and other government agencies. They understand that as we live in a technological society, there is always a risk of cyber breaches, however they would like clearer information on what security measures are in place, public disclosure of any breaches that do take place and what action consumers can take if their record has been illegally accessed. Consumers believe that it is important to ensure that their records are stored in Australia, rather than an offshore repository.

ii. the arrangements for third party access by law enforcement, government agencies, researchers and commercial interests, and

Consumers are clear that MHR should only be about providing comprehensive health care. Consumer information is not to be sold under any circumstance, and should not be available for the purposes of:

- Law enforcement
- Protection of public revenue by Centrelink or Australian Tax Office
- Corporate access or marketing by health insurance providers, drug companies, manufacturers of medical devices etc

Consumers have mixed feelings about use of MHR for research purposes, particularly as there are too many identifiers in the data that can enable the information to be traced back to individuals. They believe that consumers should opt in to making their record available for research purposes, and that any use should be approved via an ethics committee.

iii. arrangements to exclude third party access arrangements to include any other party, including health or life insurers;

Consumers believe it is important that records are not accessible to life or health insurance providers. They questioned the integrity of the system when health insurance companies are also health service providers. Can the health provider arm of the company share the information they have legally accessed with the health insurance arm of the same company? What protections are in place to prevent this from occurring? What sanctions would be imposed on companies who exploit this potential loop hole?

d. the Government's administration of the My Health Record system roll-out, including:

i. the public information campaign, and

Consumers consider that the public information campaign has simply not been good enough. The initial development of MHR should have had broader community/consumer input and an improved process for engaging GPs. When the system changed to an opt out system, there was clear messaging about opting out, but limited information about how to opt out. There was also a time lag between the promotion of the change to opt out, and the time that consumers could practically opt out. For those choosing to not opt out, there is no information about how to actively manage their account – add information, block documents, restrict access etc. There should be an online tutorial about how to actively manage your MHR. There should have been a letterbox drop to all households to ensure that everyone gets access to information about MHR. Television campaigns and print media are not accessed by all Australians.

iv. the prevalence of 'informed consent' amongst users;

The many Australians who have a MHR only because they did not take action to opt out are not participating in any consent process, and no one can tell if those consumers felt informed, or made a choice. Those who chose to opt out also did not participate in an informed consent process. The Australian media ran a negative scare-mongering campaign, and many consumers acted on that basis to opt out. The only indication of consent is consumers engaging with and managing their MHR. Consumers raised concerns about children having an opportunity to consent to retaining a MHR once they turn 16 and become responsible for their own record. Is there a system to prompt young people to consider their record at that time? Who can access a person's MHR after death? If a person restricts access, does that

restriction lift after death? Consumers should consent to any changes, and at no time should any person's data be sold, regardless of whether they are living or deceased.

e. measures that are necessary to address community privacy concerns in the My Health Record system;

Consumers would like full information about the security of MHR. If the system is secure, then make the risk assessment available to the public, so they know they can trust the system. There needs to be public disclosure for any security breaches – including the learnings and solutions to prevent recurrence.

There is concern about the security of MRH for children and adults under guardianship. If parents can access their children's record, can all employees of Dept for Child Protection, foster carers, or the Guardianship board access the records of people under guardianship? Who decides, and who advocates for the rights of the person under guardianship?

In cases of domestic violence or family breakdown where one parent has taken children into hiding, can the other parent use a child's MHR to find new address details, track visits to the GP or pharmacy etc? In the case of domestic violence, there needs to be a systematic response by police or domestic violence support services to prompt parents to block an abusive parent's access the records of other family members in order to keep them safe.

There should an online tutorial to show people how to close an episode of care once they consider the information to not be relevant. This may be relevant for people who were prescribed ADHD medication as a child, past sexually transmitted infections, previous mental health conditions etc.

f. how My Health Record compares to alternative systems of digitising health records internationally; and

Consumer are aware of other electronic health record systems internationally and many of them have failed, such as in the UK, or have flaws such as consumers not having access to their own record as occurs in US. In other jurisdictions, the electronic record has a more limited scope to include allergies or provides access only to GPs and pharmacists. The electronic health record system in NZ is still under development. Estonia seems to have a more comprehensive system that is most similar to MHR.

g. any other matters.

GPs have a pivotal role in informing consumers about MHR. What happens if a consumer wants an MHR, but their GP does not engage with the system?

Actual experience is that specific items cannot be removed from MHR. If a person has a right to not make their record accessible by choosing to opt out, why does a person who chooses to have a MHR not also have a right to make some of their information not accessible?

There is a section under the act that provides an option for records to be hidden from the consumer. Under what circumstances would this be necessary?

If a clinician uploads information that is then found to be inaccurate, it is very difficult to get it removed or corrected.

Stigma associated with mental illness or addictions can lead to poorer treatment and health outcomes.

Can there be an alert to sentinel information so that a GP is made aware of important information relevant to their patients that is added to their record? Can there be a flagging system that indicates that a consumer does not believe a document on their record is accurate, or needs to be understood within a wider context?

Some consumers who self-manage their chronic or complex conditions are frustrated that pathology results are not uploaded for 7 days. Once the GP has reviewed the results, they should be able to authorise immediate availability to the consumer if they believe it is appropriate.

Attendees then had an opportunity to identify the most important thing about MHR for them:

- Protections put in place for vulnerable people and their information. Who manages their account?
- Consumer right to add information to their record, without clinician information be included
- Consumer right to tag information with their own perspective
- Disclosure of any breaches and resolution
- MHR will be good for people with allergies or life-threatening conditions
- Data must not be accessible to insurance companies
- Health records should only be accessed by health providers
- MHR is still an incomplete record of government funded service only. There is still a 7 day lag for pathology results etc.
- Safeguard the accounts of people after death. Who owns or can access the record after death?
- What protection is there for consumers when governments can change policy and legislation?
- Australians do not have a unique identifier. How can we prevent mixing records for people sharing the same name/ date of birth?
- Children need to be informed about MHR and given an opportunity to consent to having MHR when they turn 16 and become responsible for their own account.

Focus Group evaluation

All focus group participants completed a feedback form. The feedback indicated that 100% of attendees felt that their input was valued and were very satisfied with the facilitation of the focus group. Participants appreciated the structure of the session. Many reflected that they appreciated the opportunity to contribute and had also increased their own knowledge of MHR.

Conclusion

HCA facilitated an effective focus group to inform a submission to the Senate Enquiry on My Health Record. HCA's submission will reflect consumer input including:

- My Health Record is a good initiative that should improve information between GPs, consumers and other health professionals and result in improved service coordination and efficiency.
- Security of MHR is paramount. Consumers would like transparency about the security measures that are in place and open disclosure of any security breaches.
- An online tutorial is required to show people how to navigate and manage their record, including how to add information, block documents, change security settings.
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