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### **Senate Inquiry on the My Health Record System**

The Health Care Consumers' Association (HCCA) was incorporated in 1978 and is both a health promotion charity and the peak consumer advocacy organisation in the Canberra region. HCCA provides a voice for consumers on health issues and provides opportunities for health care consumers to participate in all levels of health service planning, policy development and decision making.

HCCA involves consumers through:

- consumer representation, and consumer and community consultations,
- training in health rights and navigating the health system,
- community forums and information sessions about health services, and
- research into consumer experience of human services.

HCCA is a member-based organisation and for this submission we consulted broadly. This included input from our members, our Health Policy Advisory Committee, and feedback from consumers more generally through three public information sessions held in July, August and September 2018. These information sessions have been conducted jointly with HCCA and the Capital Health Network (our local Primary Health Network) under their contract with the Australian Digital Health Agency for My Health Record (MHR).

HCCA has a longstanding interest in e-health and the MHR. The MHR is a standing agenda item at our bimonthly meetings of the ACT e-Health Consumer Reference Group. This group regularly discusses the progress of MHR across the ACT, any issues that have arisen, and how to ensure the MHR makes a valuable contribution to health care for consumers and health professionals.

We know that the health literacy level of many Australians does not permit them to easily access, interpret, communicate and use health information. This can affect

their access to effective health care and health improvement activities. It may also impact on their knowledge and awareness about My Health Record.

As a health promotion charity, HCCA

- supports the Australian Commission on Safety and Quality in Health Care (ACSQHC) definition of health literacy<sup>1</sup>,
- acknowledges that some health consumers may need support while they gain the skills and confidence to improve their health literacy, and
- undertakes to become a health literate organisation<sup>2</sup>.

HCCA recognises the importance of health literacy and has developed a position statement on the topic, which can be found here: <http://www.hcca.org.au/about-hcca/position-statements.html>

Contributing to this Inquiry into the My Health Record (MHR) is one of the ways in which HCCA demonstrates its commitment to *improving health literacy and enhancing communication*. Thank you for the opportunity to advocate for consumers and express consumer views on issues around the My Health Record system.

Yours sincerely



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<sup>1</sup> Australian Commission of Quality and Safety in Health Care, 'Health Literacy National Statement | Safety and Quality', <https://www.safetyandquality.gov.au/publications/health-literacy-nationalstatement/>, [Accessed 22 July 2018].

<sup>2</sup> Cindy Brach Benard Dreyer, Paul Schyve, Lyla M. Hernandez, Cynthia Baur, Andrew J. Lemerise, and Ruth Parker, 'Attributes of a Health Literate Organization. Discussion Paper', Institute of Medicine Roundtable on Health Literacy, National Academy of Sciences, 2012.



**HCCA Submission to the Community Affairs  
References Committee**

**Senate Inquiry into the My Health Record System**

**Submitted 14 September 2018**

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## Executive Summary

Under the Australian Charter of Health Care Rights<sup>1</sup>, consumers have rights to *communication* and *participation* – that is,

- to be informed about our health care in a way we can understand, and
- to be included in decisions and choices about our care.

However, communication and participation rest on health literacy. HCCA uses the following definitions<sup>2</sup>:

**Health literacy** is the combined knowledge, skills, confidence and motivation used to make sound decisions about your health in the context of everyday life.

**Individual health literacy** describes how easy it is for people to

- get access to the information they need,
- understand the information they receive, and
- judge if the information is right for them.

**Environmental health literacy** describes the setting in which people seek health information and use health care services.

Our view is that consumers need to have sufficient understanding of the benefits and risks associated with the MHR to make their own, informed decision about whether to opt-out of the system. However, consumer understanding of MHR relies largely on the promotional efforts of the Australian Digital Health Authority (ADHA). Thus, both individual and environmental health literacy are relevant to this discussion.

As a health promoting, consumer advocacy organisation, our work is focused on improving individual health literacy. However, environmental health literacy for this issue rests largely in the hands of the ADHA, particularly, the content of material on MHR and how it is promoted.

Our extensive consultations with consumers suggests uncertainty and distrust about the MHR system. Issues around opting-out and informed consent, more generally, are particularly contentious.

While we have been working closely as an organisation with our local Primary Health Network, the Capital Health Network, we feel that the overall public information campaign nationally has been lacking. There have been errors in communication and the ADHA has not anticipated many predictable questions from consumers about the MHR system. These have subsequently been highlighted in the media coverage as gaps and deficiencies, exacerbating consumer concerns. Furthermore, some consumers may remain unaware of the opportunity to make an informed choice about the MHR, and as of 2019 will have a record created for them, whether records are actively managed or not. We do not think this is in line with the Australian Charter of Health Care Rights and, therefore, it is unacceptable.

Additionally, we would like to see the future functionality of the MHR contribute to improvements in overall health literacy in Australia (we have outlined some suggestions at (g) in this submission).

## Recommendations

HCCA makes the following recommendations to protect the interests of consumers with regard to the My Health Record system:

1. Set each record to default to the most protective options to improve individual control over privacy and security. Consumers who are actively managing their MHR are then in control of their record and able to choose which documents can be accessed by which health professionals in their treating team.
2. The public information campaign must support consumers to gain sufficient knowledge and awareness to make their own informed decision about MHR. This must include comprehensive coverage of issues that are important to consumers, including:
  - the benefits and risks,
  - privacy and security,
  - informed consent,
  - unauthorised access,
  - third party access, and
  - the evidence base underpinning the MHR system.
3. Informed consent and consumer rights to communication and participation, (detailed under the Australian Charter of Health Care Rights), must be considered across all aspects of the My Health Record and its implementation.
4. All health professionals must be strongly encouraged to register to be able to access and upload information to the MHR.

## My Health Record – addressing the Inquiry’s Terms of Reference

### (a) the expected benefits of the My Health Record system;

The main benefit of the My Health Record (MHR) system is that it will allow **both** health practitioners and consumers to access a summary of their diagnosis and treatment information from a range of participating health services. This should also include the results of any diagnostic tests (although at this point in time, not many private pathology and diagnostic imaging services, at least in the ACT, are signed up to provide data to MHR). Access to the MHR can give individuals easy access to health information like never before. For babies and children, if their record is well-maintained, their MHR could provide valuable health information across their lifetime.

The benefits of using MHR to inform and improve individual care include:

- **a shared health summary** which, if kept up to date, provides your current medical conditions and medicines, allergies and immunisations
- **access to your information about prescribed medicines and related diagnoses, as well as dispensing history** – particularly useful if you are seeing a new GP/doctor, or if you are travelling or interstate
- **access to your health information while travelling** – any health professional who has signed up to MHR can access this in Australia, or you can provide access to view your record in Australia or internationally
- ability for consumers to **restrict access to sensitive information**, while also being aware of the option for health professionals to ‘break the glass’ and access all your complete record in an emergency
- as a consumer (particularly those with chronic conditions), **not having to ‘re-tell your story’** because your MHR health summary provides health practitioners with key information and diagnoses
- capacity to **support improved continuity of care** for consumers
- the choice for consumers to **upload an Advance Care Plan** to their MHR
- **visibility of and access to past pathology and diagnostic test results**, which may help prevent duplication and potentially presents both physical and financial advantages
- capacity to **record and access key historical health information**
- option to **print your documents** directly from MHR

However, these benefits rely upon:

- health practitioners signing up to upload data to MHR
- comprehensive and consistent uploading of health information to the MHR
- health professionals accessing MHR information.

Consumers shared these stories with us about the benefits of MHR:

*I joined up some years ago when it was first available; it seemed like a good idea... I've been in it for years and have not had any problems. I am an older person with a number of chronic health conditions, and take a number of different medications. I live alone and it's possible I could find myself at a different doctor's surgery, or in hospital. I don't travel much but it's possible I could be taken ill in NSW or Victoria. I have family in Canberra but I doubt they could tell medical personnel anything [much]... on balance I have decided to keep My Health Record, even though I have some doubts about the online safety. On balance I would prefer to have my information available, and take my chances with my details being accessed.*

*[I was taken to hospital by ambulance]... on that occasion I was able to communicate with doctors and give them my medical details, but it might not*

*always be the case... I can envisage occasions when I am not able to communicate.*

*Recently I updated my Advance Care Plan and Health Direction... these documents can be uploaded to My Health Record, and I have done this. They would be to hand immediately if medical staff need to know.*

### **(b) the decision to shift from opt-in to opt-out;**

The decision to shift the record from being opt-in to opt-out is not in the interest of all consumers. Those with poorer health literacy are at a disadvantage and therefore they are unable to make an informed decision.

Our understanding is that if a consumer has a MHR, either by activating their record, or not opting-out of the MHR system, then health professionals can start to upload information to an individual's MHR. This means that unless you have the knowledge, skills, access and awareness to actively manage your MHR, you could have health information being uploaded to your record. This is then accessible to all health professionals providing care to you, without you necessarily having knowledge of, or easy access to, this information yourself. This is not necessarily in line with the principle of informed consent, and the rights of communication and participation outlined in the Australian Charter of Health Care Rights. A consumer shared with us:

*I am also appalled by the Govt's failure to follow basic principles of informed choice in relation to the opt-out process. At the very least, all Australians should have been sent an easy to understand, balanced and spin-free account of the pros and cons of MHR. We expect that informed choice be applied in clinical settings, we should also expect informed choice in relation to having or not having an electronic health record. The Government has ignored its responsibility to ensure that all Australians can make an informed choice about MHR.*

While we would hope that health professionals would fully inform their patients when uploading information to the MHR, the system is set up to default to open access unless the consumer sets restrictions or security settings on their record. This may leave those more vulnerable Australians, such as those with highly stigmatised chronic conditions, at a disadvantage in the health system if they cannot actively manage the access to information within their MHR. In HCCA's recent information sessions, consumers have voiced their fears around confidentiality and the lack of control of their MHR if they do not have easy access to view and actively manage their record.

Consumers have also told us about their concerns with the length of time it takes to opt-out via phone, as well as the disadvantages faced by those without internet skills or access. There is also confusion about how MHRs have been activated, seemingly without the knowledge or consent of the individual. For example, this consumer story was shared with us:

*She was definitely going to opt-out. However, when she tried to do so, she found that a My Health Record had already been created for her without her knowledge or consent. And it appeared that there was nothing she could do about it. Of course she was not happy and asked her GP how that could have occurred. The GP's practice has done an extensive check and has assured her that they were not responsible. She still is none the wiser how such a thing happened. The only positive thing is that the rules have now changed meaning that a record can be halted, but it is doubtful that the info already in the system can be deleted. We are yet to have this confirmed one way or another.*

**(c) privacy and security, including concerns regarding:**

**i. the vulnerability of the system to unauthorised access**

Consumers continue to express concerns about unauthorised access to MHRs. One element of concern is access to records by staff outside of the treating team, such as non-medical staff in general practice. Another is where access codes could be shared by staff in the hospital setting. Our information sessions with consumers provided some reassurance about the visible audit log in the MHR, and that a process is in place for ADHA to investigate cases of 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**

Consumers we consulted have major concerns about the potential for 'outside' agencies accessing information contained in the MHR. It is not yet clear whether the legislative changes will fully address these concerns. In particular, consumers in our information sessions were apprehensive about future access by insurance companies, banks, potential employers, other government agencies etc. and whether information kept in their MHR could present a future disadvantage.

The Framework to Guide the Secondary Use of My Health Record System Data<sup>3</sup> states that data may be used for research, policy and planning (or 'secondary') purposes. The first release of data to the Australian Institute of Health and Welfare is expected to commence from 2020<sup>4</sup>. Whilst individuals can choose to opt-out of secondary use of data, this process again assumes that consumers have the knowledge and awareness to provide informed consent about the secondary use of data. A consumer suggested:

*I feel quite strongly that this [the secondary use of data] should be an Opt In process – and, at the very least, prior to 2020, information about making the data available to AIHW must be provided to the general public along with information about mechanisms for opting out.*

Some consumers in our information sessions expressed concern about the future use of MHR data, and questions were asked such as 'can the ADHA be sold?' and 'will insurance companies be given access in the future?'. There is uncertainty about



the future directions planned for MHR data, its ongoing privacy and security, and how much control consumers will have over any future changes.

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

- **the public information campaign, and**
- **the prevalence of 'informed consent' amongst users;**

***Public Information Campaign***

A number of consumers told us that they felt the public information campaign for MHR has been "frightening". For example:

*The public information campaign has been frightening, and made many people leave the My Health Record, or not join up. I can see it would be useful to have access to the system tightened up, but it has scared people away, and caused uncertainty and stress.*

This seems to mostly be due to the risks about MHR highlighted in the media. The risks that consumers raised in our information sessions were about MHR data being:

- hacked into,
- shared without a consumer's knowledge or authorisation,
- made public,
- inaccurately recorded, and
- made available to third parties, or for research purposes, without consent.

We do not believe that the public information campaign has been managed well. We suggest there is not widespread knowledge and awareness about MHR. Therefore consumers are unable to make an informed choice about whether to opt-out.

*A more targeted and community focussed marketing campaign is essential. Additional support for GPs, and other private and public service providers is a must. I have a great relationship with my GP, [but] she has never mentioned the MHR to me!!!*

*I was reassured [at the HCCA information session] when I learnt that MHR is a summary of my health issues and not details of my every visit to my practitioner/s and that I could request that information NOT be added. This needs to also be a focus of any later campaigns.*

Many of the issues and risks raised in the media about MHR during the public information campaign to date could have been anticipated and addressed by a solid marketing/communications plan from the ADHA. The result is a perception that the MHR policy has gaps and risks that are un-addressed, leading to distrust and a lack confidence in the system. This is clearly detrimental to the intended outcomes of the campaign, and may result in more Australians deciding to opt-out. A consumer commented:

*“I have opted out because I felt that the system is as bad as the census and ATO”*

### **Informed Consent**

In our consultation with consumers, the issue of ‘informed consent’ appears to be of considerable concern. The following two examples demonstrate instances where informed consent is assumed but does not involve the consumer:

- A consumer has a MHR created for them, as the default of the opt-out process, without making an active choice
- A consumer has a MHR and information is uploaded to that record without their knowledge, and they do not actively manage access to this document in their record. In this situation they have not really provided informed consent for all health professionals in their treating team to access this information.

Those most vulnerable in our community are even less likely to have been given the opportunity to provide informed consent, or to withdraw their consent. These may include:

- those with mental and cognitive impairment,
- people with limited literacy and/or English language ability,
- those with chronic illness, and
- frail elderly, including some consumers residing in residential aged care.

The MHR system and the opt-out process assumes knowledge and awareness about the MHR, as well as sufficient computer literacy and access to suitable information technology in a secure environment. For many people this is just not a reality.

There is certainly a feeling that MHR data is not within consumer control. We know from our evaluation of the information sessions we held that some uncertainty was relieved through discussion and information provision. However, we believe it indicates a potentially low-level of knowledge and awareness in the general public about the MHR.

### **(e) measures that are necessary to address community privacy concerns in the My Health Record system;**

Consumers have continued to express concerns to us about the privacy of their information in MHR. The July 2018 announcement about legislative changes to the MHR<sup>5</sup> has given more certainty to the privacy measures, however there still appears to be some confusion and distrust about how well the MHR data will be protected. For example, consumers told us:

*The biggest risks with MHR are of course the privacy and security issues. I believe that the Govt has not genuinely addressed these concerns. While I’m no IT or security expert, I’ve read what I believe are credible MHR concerns from people who are such experts [such as security experts quoted in*

*CHOICE or articles in the Australian Financial Review]... Yes there are important benefits to having a MHR, but let's not put our head in the sand about the very real risks. Why can't we have action from the Govt and ADHA to mitigate those risks while retaining the benefits?*

*While I can see the potential benefits, I am simply not comfortable in regards to the protection of the data. I believe that the internet is way too difficult to police and there are too many examples of privacy breaches for me to accept all my health records being accessible in that fashion, In addition, there are things I prefer to keep separate For example, I don't feel it is necessary for [all my specialists] to be able to peruse my mental health records.*

One alternative approach to the privacy and security of personal health information in the MHR is to have each record defaulting to the most protective options. Those actively managing their health record could then choose which documents could be accessed by which health professionals in their treating team.

Consumers in our information sessions also expressed a further privacy concern about cancelled records being retained for 30 years after their death. There appeared to uncertainty about how and why this timeframe had been picked, why it was necessary to keep the records for so long, and how the data might be used in this time. A rationale for this could have helped dispel consumer concerns as part of the public information campaign.

#### **(f) how My Health Record compares to alternative systems of digitising health records internationally; and**

Consumers expressed to us interest in the evidence base around MHR, how other such systems are used internationally, and how this might impact on improving the safety and quality of healthcare.

We do not feel that the public information campaign has had sufficient focus on this aspect of the MHR, and it would be valuable to see more about these comparisons, the evidence base and potential future benefits covered in national media.

In terms of digital health records internationally, consumers told us of their concerns raised by news stories about digital health records in other countries and where there have been data breaches or misuse. This has added to the general unease amongst some consumers about MHR, data security, use and access.

#### **(g) any other matters.**

##### **Adding extra functionality to MHR**

In our information sessions, consumers told us that they would like to see improved capacity to be able to enter information themselves into their MHR. They would also like to be able to access information about their health service providers, including maps to services for wayfinding.

The MHR also provides opportunities for improving health literacy, such as being able to access information about medicines, or potentially being able to access other trusted health information, such as the Health Pathways database (see <https://www.healthpathwayscommunity.org/About.aspx>). This kind of functionality is part of helping empower consumers to be active participants in their own health care<sup>6</sup>.

A consumer raised with us how useful it would be for consumers if the MHR could capture in one place the documentation necessary for NDIS applications and ongoing eligibility – even if it just worked as an individual repository for this information for consumers.

### **MHR Registration by Health Professionals**

It is our view that work needs to continue on strongly encouraging all health professionals to register to be able to upload information to the MHR. Otherwise, there will continue to be gaps and omissions in MHRs, and the value of having a relatively complete personal health summary will be partially lost for both consumers and health professionals.

## **Concluding remarks**

HCCA looks forward to seeing how our feedback and comments shape the ongoing communication and development of the My Health Record program in Australia. Please do not hesitate to contact us if you wish to discuss our submission further. HCCA would be happy to clarify any aspect of our response.

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<sup>1</sup> Australian Charter of Health Care Rights, Australian Commission on Safety and Quality in Health Care (2008) <https://www.safetyandquality.gov.au/national-priorities/charter-of-healthcare-rights/> [accessed 13/09/2018]

<sup>2</sup> HCCA recognises the importance of health literacy and has developed a position statement on the topic, which can be found here: <http://www.hcca.org.au/about-hcca/position-statements.html>

<sup>3</sup> Framework to Guide the Secondary Use of My Health Record System Data, Department of Health (2018)

[http://www.health.gov.au/internet/main/publishing.nsf/Content/F98C37D22E65A79BCA2582820006F1CF/\\$File/MHR\\_2nd\\_Use\\_Framework\\_2018\\_ACC\\_AW3.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/F98C37D22E65A79BCA2582820006F1CF/$File/MHR_2nd_Use_Framework_2018_ACC_AW3.pdf) [accessed 13/09/2018]

<sup>4</sup> “The Framework to guide the secondary use of My Health Record system data has been released for implementation”, Department of Health (2018)

<http://www.health.gov.au/internet/main/publishing.nsf/Content/eHealth-framework> [accessed 13/09/2018]

<sup>5</sup> Privacy Policy for My Health Record, <https://www.myhealthrecord.gov.au/about/privacy-policy> [accessed 13/09/2018]

<sup>6</sup> ‘The Future of Health’ CSIRO (2018) <https://www.csiro.au/en/Showcase/futureofhealth> [accessed 13/09/2018]