



Consumers Health
Forum OF Australia

SUBMISSION

Senate Inquiry: My Health Record System

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About CHF

The Consumers Health Forum of Australia (CHF) is the national peak body representing the interests of Australian healthcare consumers and those with an interest in health consumer affairs. We have over 160 members reflecting a broad spectrum of organisations including state-based consumer peaks, condition-specific groups, volunteer patient groups, professional associations, PHNs and the research community. CHF works to achieve safe, quality, timely and affordable healthcare for all Australians, supported by accessible health information and systems. We support the principles of consumer centred care, a key tenet of which is that consumers must have choice and control over their own health and care¹.

CHF is a primarily government funded organisation with core funding provided under the Department of Health's Health Peak and Advisory Bodies Programme. Other funding is sourced from government and other agencies seeking to engage CHF's expertise and advice, and membership fees. CHF has received funding from the Australian Digital Health Agency (ADHA) for:

- the engagement of a digital health adviser to support CHF's engagement in digital health policy and national development (\$105,600);
- the design and delivery of an independent roundtable to consider key elements for the successful implementation of digitally enabled models of care under the National Digital Health Strategy and its Framework for Action, and an associated report, (\$57,750); and
- the design and delivery of six webinars on a range of issues in relation to My Health Record (MHR) and its opt-out period (\$64,600).

CHF and the ADHA also signed a Memorandum of Understanding² in relation to support of consumer and community engagement in furthering a digitally enabled healthcare system. This includes recognition of CHF's independent status.

CHF is pleased to make this submission to the Senate Inquiry into the My Health Record system. This submission provides some general comments about My Health Record and digital health, and addresses each of the terms of reference in order.

General comments

An online platform to facilitate sharing of consumers' health information is an important investment in the national health architecture required to modernise our health care system and to improve consumers' experiences of care. Federal and State level government and bipartisan support for the development of a consumer accessible electronic health record has been strong for many years, starting with the endorsement of National Health and Hospital

¹ Consumers Health Forum of Australia. 2018-2022 Strategic Plan: <https://chf.org.au/2018-2022-strategic-plan>, accessed 5 September 2018.

² Available at <https://www.digitalhealth.gov.au/news-and-events/news/consumers-voice-drives-digital-health/CHF%20-%20Memorandum%20of%20Understanding.pdf>

Reform Commission's 2009 recommendation³ for the creation of a personally controlled electronic health record, and more recently through a positive response by government to the Primary Health Care Advisory Group (PHCAG) call for greater use of MHR⁴ and supported at the highest level through Council of Australian Government (COAG) agreements.

Consumer access to their own health records through My Health Record (MHR) is a key step in the shift from health consumers as passive patients, to consumers as active partners in their own care, exercising choice and control. It is vital that the goal of putting consumers at the centre of their health care remains, regardless of the future of MHR.

It is important to note that presently public opinion about the merits of MHR varies and is influenced by factors such as stage of life, the number and complexity of their health conditions, their health literacy and personal attitudes and beliefs, particularly trust in authority.

On the whole, there are several benefits for consumers in having a record. These include the increased availability of key health information such as medications, immunisation status and allergies in a single repository, better coordinated and integrated care, better consumer engagement with their own care and more responsive and efficient delivery of health care services. Many of these have been affirmed by consumers who have already opted in and have been using their record, many of whom typically have several chronic conditions with care pathways that not only require coordinated multidisciplinary team care but also takes them across services settings such as hospital to home. Families with children and older Australians are also among the key beneficiaries of a MHR.

Through our broad constituency, CHF has insights into the views of consumers from across the spectrum. We understand that many consumers with conditions such as HIV and other sexually transmitted diseases, young people or those with mental health-related conditions may be more cautious and more inclined to want additional assurance about both the benefits and privacy protections in making their decision about whether to opt out. This requires nuanced, targeted, respectful and appropriate communication to these parts of the community over and above the general community-level communication effort.

In supporting the move to opt-out CHF has always been clear that it is important that all Australians are given the ability to make an informed choice after considering the relative risks and benefits MHR would present in the context of their own lives.

MHR is a major piece of health infrastructure. In our view it is comparable in scale to Medicare in terms of ultimate impact. Any health reform needs careful change management and implementation, and in this case the creation and retention of a social licence to operate.

³ National Health and Hospitals Reform Commission, *A healthier future for all Australians: final report*, Commonwealth of Australia, Canberra, 2009, accessed 10 September 2018 at <https://catalogue.nla.gov.au/Record/4807046>

⁴ Department of Health (31 March 2016) *My Health Record & Improved Health Data to better coordinate care* [Media Release]. Retrieved from <http://www.health.gov.au/internet/ministers/publishing.nsf/Content/health-mediarel-yr2016-ley022.htm>

Gaining and maintaining MHR's social licence requires widespread community trust in the effectiveness and integrity of MHR and, over time, visible demonstrable benefits so that its utility will strengthen over time.

Healthcare has lagged behind other sectors in exploiting the clear benefits of information technology to provide prompt, secure, and precise patient information. The clinical benefits of My Health Record for patients are significant and compelling and include avoided hospital admissions, fewer adverse drug events, reduced duplication of tests (and hence costs for consumers and the system), better coordination of care for people with chronic and complex conditions, and better-informed treatment decisions.

Consumer trust and confidence in MHR is essential for its success, and an effective and accurate awareness and education campaign that reaches all Australians is necessary to allow the community to make an informed decision about whether or not to opt-out. Consumer fears about privacy and security and, importantly, any misinformation in this regard, could lead to consumers avoiding doctors and disclosing less when they do see them. This would be counter to the intent of the reform and be a significant set-back. This is especially important for any marginalised, stigmatised, or discriminated against group – such as many who are Aboriginal or Torres Strait Islander peoples, mental health consumers, sex workers, drug users, or people living with HIV. The valid concerns of these and other communities must be addressed adequately for MHR to be successful.

It should also be noted that the public's attitude towards My Health Record is also affected by several other contextual factors. These include news-making cyber incidents such as the Cambridge Analytica scandal or the unauthorised access of health information in Singapore's hospital system; broader government use of and plans for big data and data linkage; the wider cyber-climate and the community's own attitudes to health data, who owns it and how it should be used. Any well-conceived communications and issues management strategy needs to take such context into account and respond with timely and appropriate messages.

Another contextual factor is that the community is becoming more data aware and commanding access to their data and engagement on the terms of its use. Research CHF conducted with NPS Medicinewise on engaging consumers in their health data journey⁵ showed clearly that Australians want ownership and control of their own health data and want to be asked for consent when their data is used by either government, private companies or researchers. 96% of respondents believed they should have access to their own health data and 90% of respondents agreed they should be asked for permission if either a government department or a private organisation wants to use the data. The research also found that consumers are more likely to give permission to share their data if they understand how their data will be used and any benefits that will come from its use. Two thirds (62.5%) of survey respondents said they would be comfortable with the Government using their data to support health care providers to improve the care of others in the community. The report also revealed that consumers are more willing to share their data when it is for public or individual good, and

⁵ Consumers Health Forum of Australia and NPS MedicineWise. *Engaging consumers in their health data journey*. Canberra: CHF and NPS MedicineWise, 2018. Accessed on 5 September 2018 at https://chf.org.au/sites/default/files/engaging_consumers_health_data_report_updated.pdf

are significantly less likely to share it if the use is for commercial gain. However, privacy is a real issue with over two thirds (64.8%) of respondents stating they believe sharing their data is acceptable if they are not identified and just one in five (21.8%) were comfortable with their data being shared if they are identified.

In considering the next stage MHR's implementation, CHF supports keeping the focus on why it is that Australia has moved to implement this major transformation in our health system. The Australian people have a system in My Health Record that puts information in people's hands from multiple disparate sources and that is a significant improvement to the status quo, so it is important to look and move forward. Due to the nature and scale of the public response in the early days of the opt-out period, the context and environment that My Health Record exists in has changed; lessons must be learned and changes implemented, but forward motion should continue.

Communication about benefits and assurances about safeguards and risk mitigation strategies must go beyond what is required or even expected to ensure trust is not just maintained but built. This challenge is made more difficult by the low level of community trust in institutions in general, and government in particular⁶.

CHF hears a diversity of opinion about My Health Record and the implementation of opt-out across our membership and our approach has been to respond in a balanced way. We have not implored all Australians to have a record but have instead, in all our communications, advised consumers to appraise themselves of the facts and to make an informed decision about My Health Record after considering the relative benefits and risks in the context of their own lives. It is unrealistic to assume 100% of the community will choose to have a My Health Record however what is possible is to develop and continue to evolve a system that benefits as many consumers as possible, has built in mitigations and protections that are monitored and continually improved, and for the Government to communicate about both benefits and protections effectively, clearly and widely.

Digital is not a synonym for magic and we must be wary of hoping for too much from one project. Healthcare will always be primarily about people, not computers – and there is significant work to be done on the people and processes side of health care before a digital health future becomes a reality. My Health Record has an important role to play as a catalyst for public engagement with and consumer facing element of the much larger project of reinventing health care in the digital age.

Summary of Recommendations

In making these recommendations, CHF's focus is on what needs to happen to improve MHR's social licence to operate such that Australian's can justifiably feel safe and secure in the use of My Health Record. It is important to note that My Health Record reaching a critical

⁶ Edelman. 2018 Edelman Trust Barometer – Global Report:
<https://cms.edelman.com/sites/default/files/2018-01/2018%20Edelman%20Trust%20Barometer%20Global%20Report.pdf> accessed 13 August 2018

mass of users would be the beginning of a process, not the end state. Further improvements will always be needed in a changing world and health system.

a) The expected benefits of the My Health Record system

1: CHF recommends that first and foremost MHR is a tool for improving the efficiency and effectiveness of person-centred care. MHR must be for consumers first, and health professionals second with the core aim of facilitating consumer centred care.

2: CHF calls for the System Operator to commit to publishing the results of all benefits measurement projects, and as soon as possible share information on which academic and industry partners are involved in those projects and what access they have to MHR data.

b) the decision to shift from opt-in to opt-out

3: CHF recommends that the Government and System Operator continue to evolve and improve the system to increase its value proposition and utility to health professionals, creating an environment whereby health professionals have a clear business case and widespread desire to use it in clinical settings as part of standard workflow and business as usual in order to deliver patient-centred care.

c) Privacy and Security

4: CHF recommends that the Government engage the public in an ongoing conversation about Government data use, and set up and maintain a website that focusses on government use of health data, similar to the NHS's '[Understanding Patient Data](#)'.

5: CHF recommends that information about further improvements to the privacy and security settings is made available in easy to find and understand formats and that there is dedicated user education about how to deploy existing privacy and security settings.

6: CHF calls for the capability to enable full deletion of individual items or a whole record on a record to be implemented as soon as practicable.

i) The vulnerability of the system to unauthorised access

7: CHF recommends that the System Operator better inform consumers about the measures in place to detect, prosecute and react to any unauthorised access.

8: CHF recommends an ongoing nationwide education campaign for all health professionals on their digital rights and responsibilities, and IT best practices, to be

developed and delivered in partnership with state level health departments and health professional bodies.

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

9: CHF recommends that the current amendments to the legislation must be passed before the opt-out period ends, and that ideally the requisite technical and policy level changes needed to reflect the changed legislation must be in place before records are created.

10: CHF recommends consideration be given to the key features of the *Framework to Guide the Secondary Use of My health Record System Data* to be put into legislation before any secondary use of that data becomes possible.

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

11: CHF calls for insurer and employer access to MHR to be explicitly ruled out in legislation, with consent only possible to be given in very specific circumstances and for protections against being coerced into providing consent for access introduced.

d) Government's administration of the My Health Record system roll-out
i) The public information campaign

12: CHF recommends that improvements to the public information campaign be extended to include mainstream media and a focus on other strategies to more effectively engage and educate consumers about opt out and the benefits of the MHR. This is most likely to be at the point of care delivery such as in the GP waiting room and on discharge from hospital.

ii) The prevalence of 'informed consent' amongst users

13: CHF calls for significant ongoing work by Government to engage with consumers, especially those with low digital and/or health literacy, to assist understanding and use of MHR.

14: CHF calls for the awareness and understanding rates of MHR as measured by the ADHA to be publicly reported information as part of an annual report on MHR. Consideration could be given to this being tabled to Parliament.

15: CHF calls for a household letter outlining the benefits, risks and how and why to set privacy and security settings available in MHR once the next steps for the MHR project are decided on by Government and prior to the close of the opt-out period.

e) Measures that are necessary to address community privacy concerns in the My Health Record system

16: CHF calls for further funding to be made available to the Office of the Australian Information Commissioner (OAIC) to manage complaints and prosecute where required, and to undertake education and outreach to consumers on their rights, how to make an MHR related complaint and what protections are available to them.

17: CHF calls for clarification of the current legislative and regulatory protections against discrimination for not disclosing health information, and that appropriate action to rectify any deficiencies found is undertaken.

18: CHF calls for the concerns raised by CREATE⁷ about issues for under 18s and National Council of Single Mothers and their Children⁸ (NCSMC) about risks to victims of domestic violence to be resolved before records are created after the opt-out period.

19: CHF calls for the creation of a publicly available development timeline for ongoing improvements to MHR to assist public engagement with and understanding of MHR.

20: CHF recommends that notifications of changes to a records Audit Log are sent to their MyGov account by default.

21: CHF calls on the Government to consider whether a phased approach to the creation of records following the opt-out period should be taken, with records first created for those most likely to benefit from them.

f) Any other matters

22: CHF supports the call from Carers Australia⁹ to develop and implement a feature that allows carers to include information about the people they care for in

⁷ CREATE Foundation (2018) *Submission to Senate Inquiry – My Health Record System* Available at https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/MyHealthRecordsystem/Public_Hearings

⁸ National Council of Single Mothers and their Children (2018) *Submission to Senate Inquiry – My Health Record System* Available at https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/MyHealthRecordsystem/Public_Hearings

⁹ Cth Senate Inquiry – My Health Record System, Senate Community Affairs Reference Committee. 11 September 2018

the carer's record such that if the carer is incapacitated then appropriate assistance can be rendered to the person requiring care.

23: CHF recommends that the Government deliver enhancements to consumer entered information in MHR by implementing changes that make it possible for:

- consumer entered notes to be visible to clinicians if requested by the record holder,
- consumers to add notes to any item in their record and for those notes to be visible to clinicians if requested by the record holder, and
- improvements continue to be made to the types of information that a consumer can upload to the system.

a) The expected benefits of the My Health Record system

There are significant benefits to a national scale, consumer-controlled e-health record system, and the expected clinical benefits of My Health Record for patients are significant and compelling. These includes hospital admissions avoided, fewer adverse drug events, reduced duplication of tests, better coordination of care for people with chronic and complex conditions, and better-informed treatment decisions¹⁰. In this submission we will focus on the benefits to consumers from a consumer centred care and out of pocket costs perspective and leave others with more direct expertise to speak to other benefits that MHR is likely to bring.

In My Health Record, the Australian public has a system that puts information in people's hands from multiple disparate sources, and that is a significant improvement on the current situation. Having access to up-to-date medical information that keeps track of people's medication, allergies, immunisations, end of life wishes, test results and disease status are of great value to the millions of Australians with chronic and complex conditions and to their doctors who need to keep abreast of their patients' care.

In discussing benefits, two key facts should be accepted: that any benefits will only be realised if health providers use the system, and that the benefits will not all be there on day one, with most coming down the track once the system is used widely by consumers and health providers. It is also important to communicate both the benefits to the community and the benefits to the individual, as to an extent that separation is artificial and providing the 'big picture' view of MHR promotes understanding of the value of the reform.

CHF views MHR as benefitting the shift to a health system with shared decision making and the consumer in the centre: without consumer access to health information and measures to overcome the information asymmetry that often exists between consumers and healthcare providers, it is much more difficult for consumers to be part of the conversation about their care. Shared decision making requires shared information. MHR provides the consumer with access to this information, as well as some methods for consumers to communicate back with health professionals. Many of the other clinical hopes for what MHR could do are possibly achievable through other means, such as better interoperability standards or a widely used secure messaging system, however only My Health Record or something like it gives consumers access to their own health information.

The battles to get consumer access to their health information and exercise a degree of control over it has been a hard fought one, with many in the health profession at different times calling for a system without such access. When a possible change or improvement to MHR is being considered, its effect on utility to clinicians and utility to consumers must be

¹⁰ Consumers Health Forum of Australia (14 May 2018) *Decision time approaches on My Health Record* [Media Release]. Retrieved from <https://chf.org.au/media-releases/decision-time-approaches-my-health-record>

weighed up. In cases where it is difficult to separate the two, CHF calls for the decision to err on the side of the consumer.

1: CHF recommends that first and foremost MHR is a tool for improving the efficiency and effectiveness of person-centred care. MHR must be for consumers first, and health professionals second with the core aim of facilitating consumer centred care.

A further key benefit for consumers as both health consumers and taxpayers is the expected reduction in duplicated tests that comes from having previous tests results more readily available and shared with a care team. Out of pocket costs are a significant issue for consumers, and any reduction in unnecessary tests that does not negatively impact care is a welcome improvement on the status quo.

Accurately quantifying the benefits of MHR is vital to its ongoing success, and the System Operator (currently the ADHA) is conducting research into the benefits of My Health Record, such as reductions in unnecessary testing, through a number of benefits measurement projects and the Digital Health Test beds program¹¹. To date, it is not clear whether the results to all of these projects will be published publicly when available. Further, these projects are undertaken by the System Operator with a number of academic and industry partners, however there is a lack of publicly available information on who those partners are and what access (or as is likely the case, lack of access) they have to MHR data. Given public interest in data use by government and secondary access to MHR data, significant improvements to transparency about and accountability for these projects should occur.

2: CHF calls for the System Operator to commit to publishing the results of all benefits measurement projects, and as soon as possible share information on which academic and industry partners are involved in those projects and what access they have to MHR data.

b) The decision to shift from opt-in to opt-out

CHF has long supported the decision to shift from opt-in to opt-out as a way of ensuring there is the critical mass of records essential for the MHR system to have utility.

In CHF's 2013 response¹² to the *Review of the Personally Controlled Electronic Health Record* (PCEHR) among other recommendations CHF called for the, "adoption of an 'opt-out' model in

¹¹ <https://conversation.digitalhealth.gov.au/digital-health-test-beds-program>

¹² Consumers Health Forum of Australia. Submission to the Review of the Personally Controlled eHealth Record, https://chf.org.au/sites/default/files/1129_review-of-pcehr_nov-2013.pdf accessed on 3 September 2018

light of the overwhelming evidence and in the interests of genuine consumer control of their health information.” Vital to the success of the then called PCEHR was that consumer “access and control would remain fundamental to the acceptance of any ‘opt-out’ model”, and that ongoing improvements to those measures would be needed. CHF also called for the system to be made opt-out for health professionals if it was to be made opt-out for consumers, though CHF recognises doing so through legislative means would, among other difficulties, face legislative and constitutional challenges.

The most important factor in the success of MHR is whether health providers, and most importantly among health professionals given the high rate of public trust in them, General Practitioners, support and use MHR and counsel their patients as to how it could help in their health care. Consumers trust their GP and rightly look to them for what they should do about My Health Record.

3: CHF recommends that the Government and System Operator continue to evolve and improve the system to increase its value proposition and utility to health professionals, creating an environment whereby health professionals have a clear business case and widespread desire to use it in clinical settings as part of standard workflow and business as usual in order to deliver patient-centred care.

c) Privacy and Security

Shifting MHR from opt-in to opt-out required that the Government and System Operator take a closer look at legislation and internal policies to ensure that the increased height of the bar that must be reached for a system that will include most Australians is met.

It is important to note that MHR could be the most secure system in the world but that does not necessarily mean privacy is protected by those security measures, as privacy and security are distinct but intertwined subjects. A common analogy is the example of a window on a home; drawing the curtains shut greatly increases the privacy of the homeowner but also increases security by making it more difficult for someone outside to see if what the homeowner is up to. Installing security bars outside the window is a much more effective security measure than curtains, but without the curtains those bars would not improve privacy. Consumers require both security and privacy, and while one does not equal the other, each must be addressed simultaneously.

Some believe that no access to MHR for purposes other than the direct provision of health care is warranted. The proposed amendments to section 70 of the My Health Record Act 2012 are designed to ensure that access for non-health purposes will only be granted under an appropriate judicial instrument. CHF advocated strongly for this strengthening and has submitted separately on the *My Health Records Amendment (Strengthening Privacy) Bill 2018*.

Further, while there are clear benefits to policy planning and academic research that come from the secondary use of de-identified MHR data, the key is bringing the public along with the

reform and earning consent for those uses. The findings of our joint research with NPS MedicineWise mentioned previously suggest the opportunity to establish a social licence for the secondary use of MHR data provided there is informed consent, the right communication and sound data governance.

4: CHF recommends that the Government engage the public in an ongoing conversation about Government data use, and set up and maintain a website that focusses on government use of health data, similar to the NHS's '[Understanding Patient Data](#)'.

It is also vital that the average consumer has the capacity to set appropriate privacy and security settings inside MHR and know when and why they might wish to do so. The low numbers of records with any controls set so far¹³ and the high level of consumer engagement with privacy and security controls when able and motivated to do so¹⁴ indicates that improvements to the MHR privacy and security settings could and should occur. These low numbers could indicate that few want to set privacy and security controls, but it is likely that, for many people who currently have a record, they simply don't yet know that they can exercise this level of control over their record or, if they do, don't have the digital literacy skills to make it happen.

For a consumer that wishes to not have their MHR reflect a diagnosis, a challenge arises when other data sources are connected, for example the PBS data that automatically flows into a new record that has been activated by a health professional uploading something to it, rather than a consumer navigating through MyGov and activating it themselves. There is significant benefit in PBS data being included in their MHR, however if someone wishes to not have a prescription record that may give away a particular diagnosis included, they must either ensure that the pharmacist each and every time follows their instruction to not upload it, or personally disconnect their record from PBS data. This leads to an all-or-nothing type approach, which is insufficient.

In making improvements to My Health Record, the System Operator must conduct robust testing of any changes to the MHR system of its settings with consumers in as close to real life conditions as possible.

5: CHF recommends that information about further improvements to the privacy and security settings is made available in easy to find and understand formats and that there is dedicated user education about how to deploy existing privacy and security settings.

¹³ Chris Duckett (5 September 2018) *My Health Record access controls used only 214 times in million record trial*. ZDNet. accessed on 3 Sep 2018 at <https://www.zdnet.com/article/my-health-record-access-controls-used-only-214-times-in-million-record-trial/>

¹⁴ Andrew Perrin (2018) *Americans are changing their relationship with Facebook*. Pew Research. Accessed on 3 Sep 2018 at <http://www.pewresearch.org/fact-tank/2018/09/05/americans-are-changing-their-relationship-with-facebook/>

The all-or-nothing approach is also an issue in terms of being able to fully delete an entire record, but only hide individual items in it. Hiding an individual item on a record does not protect it from access through appropriate judicial means, leading to a situation where a consumer may choose to fully delete their entire record in order to prevent law enforcement access to a single item from their record. Full deletion of individual items in a record is an improvement that must be considered for development in the near future, else more complete records will be deleted than necessary thus decreasing the overall utility of MHR.

6: CHF calls for the capability to enable full deletion of individual items or a whole record to be implemented as soon as practicable.

i) The vulnerability of the system to unauthorised access

There are many possible vectors through which a digital system can fall victim to unauthorised access, and the risk of unauthorised access can never be reduced to zero. CHF expect that the Government and System operator have appropriate cybersecurity measures in place to protect from external intrusion, and that those measures are under constant testing, revision and improvement. As was seen with the leaking of Medicare details to the 'dark web', a far more likely vector for successful unauthorised access to someone's MHR is by someone who has authorised access to the system, either knowingly when not involved in providing health care to the individual whose record is being accessed or unknowingly by having their identification credentials used by a third party.

Defence to this type of access relies on health providers having appropriate IT policies and procedures and all staff fulfilling their responsibilities adequately. As digital health is still nascent, this is not likely to be the situation in all cases. MHR could be considered a vital step in changing this – without consumers holding health providers and professionals to account, there is less motivation to improve. This is a difficult change management challenge but one that must be tackled.

CHF understands that legally only health professionals involved in a person's direct care can access that person's record. We expect ADHA to be actively monitoring this, have methods and processes in place to detect and investigate it, and that sufficient resources are available to it and other government agencies to prosecute offenders as required. To improve public trust, more transparency about how Australian's are protected by the behind the scenes cybersecurity work of the Government is required, balanced against providing too much detail and making it easier for those measures to be overcome.

7: CHF recommends that the System Operator better inform consumers about the measures in place to detect, prosecute and react to any unauthorised access.

A further concern raised by some is that with private hospitals largely not yet connected to MHR, and responsibility for education public hospital staff not lying with the Federal Government or System Operator but instead State Governments, that there has not yet been consistent and effective education on staff responsibilities when managing health data.

8: CHF recommends an ongoing nationwide education campaign for all health professionals on their digital rights and responsibilities, and IT best practices, to be developed and delivered in partnership with state level health departments and health professional bodies.

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

CHF strongly supports and advocated for the Government's planned amendments to the legislation to ensure no MHR record can be released to police or government agencies, for any purpose, without a court order and to ensure that if any Australian wished to cancel their record, they could do so permanently, with their record fully deleted from the system and no longer accessible to law enforcement or government. To meet the intent of the legislative amendments, it is CHF's view that ideally no records should be created following the opt-out period until it is possible for a consumer to fully delete a record.

9: CHF recommends that the current amendments to the legislation must be passed before the opt-out period ends, and that ideally the requisite technical and policy level changes needed to reflect the changed legislation must be in place before records are created.

Some consumers have expressed concern about access to MHR data by commercial interests, by government for policy planning purposes and even academics for research purposes. In general, CHF supported the *Framework to guide the secondary use of My Health Record system data*^{15,16} and found the Department of Health to be responsive and attentive to concerns during its development. However, the framework is a guideline and not enforceable, and was developed prior to the shift in public attitudes evidenced at the start of the opt-out period.

10: CHF recommends consideration be given to the key features of the *Framework to Guide the Secondary Use of My health Record System Data* to be put into legislation before any secondary use of that data becomes possible.

¹⁵ Consumers Health Forum of Australia (2017) *Submission to Development of a Framework for Secondary Use of My Health Record Data consultation*. Canberra, Australia. Available at https://chf.org.au/sites/default/files/secondary_use_of_data_consultation_submission.pdf

¹⁶ Consumers Health Forum of Australia (2018) *Follow-up to the 23 February 2018 Workshop on the Development of a Framework for the Secondary Uses of My Health Record Systems Data*. Canberra, Australia. Available at https://chf.org.au/sites/default/files/followup_on_the_23_feb_workshop_on_the_framework_for_the_secondary_use_of_mhr_data.pdf

Dr Kerryn Phelps called¹⁷ for changes to section 98 based on concerns that it could allow MHR to be privatised, or the data it holds to be monetised. While CHF believes any attempt at privatising MHR by Government is highly unlikely, if that is a measurable concern of members of the public or the legal fraternity then it should be addressed. CHF do not have the legal expertise required to make a judgment on whether the legislation allows this.

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

A core concern for many consumers since the early days of PCEHR has been possible access by insurers with a common refrain being that insurers should never be able to access this type health record. It is CHF's view that any access by insurers to MHR could spell the end of public support of the project.

While a stronger case can be made for health insurance access to MHR data than other insurers, a key threat to the viability of MHR is the public perception of 'scope creep' in terms of who can access MHR and for what purposes and health insurers should not have access to MHR data. Community rating offers consumers strong protection against being charged different prices for the same insurance, however community concerns such as that the information in a My Health Record could be used to unfairly deny the payment of benefits or erode community rating must be considered.

11: CHF calls for insurer and employer access to MHR to be explicitly ruled out in legislation, with consent only possible to be given in very specific circumstances and for protections against being coerced into providing consent for access introduced.

d) Government's administration of the My Health Record system roll-out

Progress with MHR development and implementation has made significant inroads into improving the state of digital health in Australia. With the recent pledges to strengthen the legislation and enhance the public communication campaign and a commitment to act quickly and appropriately as other needs to strength the system, improve its utility and further

¹⁷ Cth Senate Inquiry – My Health Record System, Senate Community Affairs Reference Committee. 11 September 2018

assure protections and safeguards are identified, it should deserve the public's trust and be of significant benefit to consumers and clinicians over time.

i) The public information campaign

As part of CHF's support for changing My Health Record to opt-out we have stressed the need for both the Government and System Operator to deliver an effective awareness and education campaign that adequately informs the public of the benefits of having an MHR, of the risks and how they are mitigated, and of the protections afforded to consumers by legislation, regulation and policy. The public information campaign about opt-out needed to allay fundamental fears and concerns about government retention of and access to health information. Most importantly, communications need to explain in meaningful terms what MHR is and isn't. Conveying it as a personally controlled online health information "drop box", the use of real patient experience of MHR, and overcoming the misconception that an MHR record is not a patient's full clinical all need to be considered as key messages. CHF has not set thresholds on what level of awareness and understanding of My Health Record by the end of the opt-out period must be met to fulfil this obligation: it is data we don't have access to.

It was unfortunate that public attention and media commentary on the risks of MHR in the first fortnight of the opt-out period overshadowed a robust narrative about the benefits. This should not be taken lightly or dismissed as the concerns about privacy and safeguards was clearly a reflection sentiment in the wider community.

It is important to note that while CHF has provided some advice and feedback to the System Operator on their communications and collateral, CHF has not been closely involved in developing or suggesting detailed improvements to ADHA communications, either in terms of strategy or on individual pieces of collateral. We have, however, taken our obligation to put balanced and informative material out through our constituency about the pros and cons of MHR and have done this primarily through social media, email communications and our webinar series.

CHF believes that the pushback against My Health Record by some quarters of the community at the start of the opt-out period would not have been as strong if all of the policies, processes and communication methods and materials to effectively answer consumer and health provider questions were in place and easily accessible by consumers. Like many consumers, CHF was in the position at the start of opt-out of not knowing exactly which consumer questions there would be answers available to, and which would require further interrogation.

The opt-out period has run for nearly two months, yet still there is a lack of clarity around some major issues. Some examples of issues unaddressed in public information at the start of the opt-out period were how and why a consumer might find they held an MHR but did not recall creating one, how victims of domestic violence should protect themselves from their abusers, who has the responsibility of informing 14-year-old teens of their rights to control their own record, or the risks presented by the inclusion of a record holder's address on some items that can be uploaded to MHR.

The communication challenges early in the opt-out period were compounded when the technical systems responsible for the management of opting out did not perform optimally on the first day of the opt-out period. CHF raised this issue specifically during an MHR Expansion Steering Group meeting in May 2018, cautioning that a collapse of the opt-out website could set the entire project back significantly. While the technical infrastructure required for managing opt-out is not the same as the infrastructure that MHR runs on and hence its initial failure presented no risk to MHR data, that incident affected public confidence at the outset. The consequence arguably was that effort was diverted from communicating the benefits to the need for the System Operator to respond, issues manage and defuse this scenario.

In the weeks following the start of the opt-out period, CHF provided the System Operator with a letter outlining recommendations for further changes to the public information campaign. While not all recommendations were taken on board, a significant number were and are in the process of being implemented. This indicates that the Australian public should reasonably expect that the System Operator will continue to make improvements and respond to constructive feedback.

12: CHF recommends that improvements to the public information campaign be extended to include mainstream media and a focus on other strategies to more effectively engage and educate consumers about opt out and the benefits of the MHR. This is most likely to be at the point of care delivery such as in the GP waiting room and on discharge from hospital.

ii) The prevalence of 'informed consent' amongst users

CHF does not have figures on the prevalence of informed consent among consumers but expect that the System Operator has been doing the measurement, segmentation and analysis work required to answer this question. We do know from our research that informed consent is important and expected.

Healthdirect defines informed consent means that; "you will be given understandable and clear information about your choices so you can make the right decisions about your health and healthcare"¹⁸, and that consent is, "your agreement for a healthcare professional to provide you with treatment and care, including any tests, medicines, treatments or procedures you agree to"¹⁹.

Fully informed consent for the entire population is not possible as not all people have the digital and/or health literacy required to understand all the complexities of MHR and how it

¹⁸ healthdirect. Informed consent. (2018). Retrieved from <https://www.healthdirect.gov.au/informed-consent>

¹⁹ healthdirect. Informed consent. (2018). Retrieved from <https://www.healthdirect.gov.au/informed-consent>

interacts with their care and the wider health system. With the introduction of the ability to fully delete a record, the consent issues opt-out raises are largely mitigated, as it will be possible to opt-out of having a record at any time by deleting it.

13: CHF calls for significant ongoing work by Government to engage with consumers, especially those with low digital and/or health literacy, to assist understanding and use of MHR.

An important issue is that there has been a justified focus on measuring and raising awareness levels, but not as much on the level of understanding among both consumers and health practitioners of what MHR means for them, how it works, and how to use it safely. CHF expects that the System Operator has processes in place to measure understanding of MHR.

14: CHF calls for the awareness and understanding rates of MHR as measured by the ADHA to be publicly reported information as part of an annual report on MHR. Consideration could be given to this being tabled to Parliament.

The issues raised in this section underscore the need CHF's consistent recommendation for a letter detailing MHR to be sent to all households to be heeded. MHR is an important and far reaching reform that must be promoted in a way that is fitting of that level of importance. A well-produced letter to all Australian households that frankly discusses the benefits and explains the privacy measures and how they safeguard people would go a long way to helping build community trust in MHR and the asset it represents to our health system and to improving patient care.

15: CHF calls for a household letter outlining the benefits, risks and how and why to set privacy and security settings available in MHR once the next steps for the MHR project are decided on by Government and prior to the close of the opt-out period.

e) Measures that are necessary to address community privacy concerns in the My Health Record system

My Health Record should never be considered 'complete' and will always require further improvements to how it works, the legislation and policies that govern it, and the communication measures that inform and engage the public about it. Some of these improvements must be implemented before records are created following the opt-out period, however others can be met as the project continues.

What is most important is working towards a system that in terms of rights, ownership and patient confidentiality does not erode current standards or be out of line community expectations for the treatment health information.

Legislative and regulatory changes

Trust in MHR requires effective complaints processes from regulators with the teeth necessary to prosecute when necessary. The Office of the Australian Information Commissioner (OAIC) is charged with this task, however has a number of competing priorities and a pool of funding that has not been expanded for MHR related work.

16: CHF calls for further funding to be made available to the Office of the Australian Information Commissioner (OAIC) to manage complaints and prosecute where required, and to undertake education and outreach to consumers on their rights, how to make an MHR related complaint and what protections are available to them.

Consumers are protected against discrimination in health care received based on whether they do or do not have a My Health Record by section 44 of the *My Health Records Rule 2016*, however it is not as clear whether consumers are protected in legislation against discrimination by others, such as insurers or employers, whether they allow access to their MHR or hand over their health information in another form.

17: CHF calls for clarification of the current legislative and regulatory protections against discrimination for not disclosing health information, and that appropriate action to rectify any deficiencies found is undertaken.

MHR improvements

There are a number of improvements that can be made to how MHR effects privacy that can be achieved with little technical difficulty, and others that would take more time to implement.

Transparency by government is vital to public trust in the digital age but is not just about broadcasting information; it can also be used to engage the public and increase opportunities for open innovation to occur.

In submissions to this inquiry, some other organisations have raised concerns that CHF believes must be addressed adequately by Government.

The Royal Australian College of General Practitioners (RACGP) called for²⁰ the automatic uploading of information to a teenager's MHR to cease when they turn 14. CHF supports this in principle but further consideration of the impacts and whether other measures are also required needs to be done.

For any potentially discriminated against, marginalised or vulnerable section of the population, MHR can present greater risks than for the population in general.

²⁰ Cth Senate Inquiry – My Health Record System, Senate Community Affairs Reference Committee. 11 September 2018

18: CHF calls for the concerns raised by CREATE²¹ about issues for under 18s and National Council of Single Mothers and their Children²² (NCSMC) about risks to victims of domestic violence to be resolved before records are created after the opt-out period.

For MHR to succeed, consumers must be engaged in its ongoing improvement and engagement with communities who raise concerns about MHR must be undertaken. While being aware of and having input into possible future improvements to MHR is not something that would interest all consumers, it would be an effective method of engagement for those who wish to suggest improvements or understand what future changes to MHR are likely. This is especially true for communities with a strong focus on digital rights and privacy and would help allay that community's valid concerns.

19: CHF calls for the creation of a publicly available development timeline for ongoing improvements to MHR to assist public engagement with and understanding of MHR.

To maintain the security of a record, a consumer needs to be aware of who is accessing their record, and when. It is already possible for a consumer to be notified of access to their MHR, however by default none of those options are turned on. Automatically sending an SMS or email raises issues of security and information gathering and the decision to turn that on is best made by the individual consumer, however providing as default an as-it-happens notification or digest of changes made over a certain period of time to a record holder's secure and private MyGov inbox is a change that might be possible to implement relatively simply.

20: CHF recommends that notifications of changes to a records Audit Log are sent to their MyGov account by default.

A consumer can choose to add a Record Access Code (RAC) or PIN to their MHR, however not all consumers will be able to access this setting, be aware it is available, or understand why the ADHA's cybersecurity team recommends all consumers protect their records with one²³. This means that anyone with authority to access that patient's record will need to be given the code set by the patient. Further, it is also likely that whatever the default setting is when a person's record is activated for the first time, will be the setting that remains. Given the relative benefits and risks of MHR are different for each person and different groups in

²¹ CREATE Foundation (2018) *Submission to Senate Inquiry – My Health Record System* Available at https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/MyHealthRecordsystem/Public_Hearings

²² National Council of Single Mothers and their Children (2018) *Submission to Senate Inquiry – My Health Record System* Available at https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/MyHealthRecordsystem/Public_Hearings

²³ Australian Digital Health Agency. (undated) *Empowering healthcare consumers to manage their information* [Blog post] accessed 9 September 2018 at <https://www.digitalhealth.gov.au/about-the-agency/digital-health-space/empowering-healthcare-consumers-to-manage-their-information>

society, some have proposed that it may help public trust in some quarters of the community to apply a RAC by default to some or all records.

For example, the RAC could be turned on by default for all records held by someone under a certain age but left off the records of an older person who is more likely to have multiple chronic conditions and hence likely to derive greater benefit from having an MHR, or an RAC could be applied to all records when the holder turns 14 that only the 14-year-old can get from the System Operator themselves.

CHF does not necessarily advocate this approach, as it is our understanding that to date there has not been an unauthorised breach of MHR information and adding another layer of authentication would decrease the clinical utility of MHR by creating another step authorised clinicians in a patient's care team would need to take in order to view their health information.

We have noted comments from both the RACGP and AMA on the suggestion that a RAC or PIN for all records should be the automatic default in the evidence they have provided to the Inquiry. We concur with their views. RACS would have to be requested from patients, some may not recall them and the risk would be that clinicians may default back to faxing, sending letters and phone calls rather than taking advantage of the MHR portal.

Changing the default setting for the RAC for some or all record holders would be a significant change and should only be considered if measurements of public trust and confidence in MHR present a grave risk to the ongoing success of MHR.

Another similar proposal that may allay community privacy concerns would be to consider creating records following the opt-out period in a phased manner, with records created for some segments of the community before others. This would mean records could be available for those who stand to benefit the most in the short term, such as those over a certain age, while giving time for the concerns of other segments of the community to be adequately addressed.

21: CHF calls for consideration to be given to whether a phased approach to the creation of records following the opt-out period should be taken, with records first created for those likely to benefit most from them.

The RACGP called for the automatic uploading of health information to a record to not occur at all without direct consumer input and consent, and for evidence of that consent to be stored. CHF in principle supports this position.

f) Any other matters

There are further matters CHF asks the committee to consider when making recommendations about My Health Record.

Improvements to consumers' ability to upload information to their MHR

Consumers are able to upload some information to their MHRs, including personal notes. However, the range of information that can be uploaded, who that information can be shared with and types of document that can be uploaded will benefit from ongoing improvement.

CHF recommends the below consumer facing improvements that should be implemented as My Health Record continues to mature that aren't covered in previous sections of this submission.

22: CHF supports the call from Carers Australia²⁴ to develop and implement a feature that allows carers to include information about the people they care for in the carer's record such that if the carer is incapacitated then appropriate assistance can be rendered to the person requiring care.

23: CHF recommends that the Government deliver enhancements to consumer entered information in MHR by implementing changes that make it possible for;

- consumer entered notes to be visible to clinicians if requested by the record holder,
- consumers to add notes to any item in their record and for those notes to be visible to clinicians if requested by the record holder, and
- improvements continue to be made to the types of information that a consumer can upload to the system.

²⁴ Cth Senate Inquiry – My Health Record System, Senate Community Affairs Reference Committee. 11 September 2018