



NATIONAL RURAL
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14th September 2018

Committee Secretary
Senate Standing Committees on Community Affairs
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Letter of Transmittal

Dear Standing Committee on Community Affairs,

Please accept this submission in response to the inquiry into the My Health Record from the National Rural Health Alliance.

The submission features feedback from the Alliances' 37 member organisations about their views on the My Health Record and implications for health care in rural, regional and remote Australia.

All terms of reference are addressed. The Alliance has also provided recommendations for the committee to consider.

We will gladly answer any questions you have regarding this submission.

My regards

Mark Diamond
Chief Executive Officer
National Rural Health Alliance



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Inquiry into the My Health Record System

Senate Committee on Community Affairs

14 September 2018

National Rural Health Alliance
10 Campion St, Deakin, ACT, 2600

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Introduction

The National Rural Health Alliance (the Alliance) welcomes the opportunity to provide this submission to the Senate Committee Community Affairs into the My Health Record (MHR) System.

The Alliance is Australia's peak body for rural and remote health. It represents 37 national organisations working to improve the health and wellbeing of 7 million people living in rural, regional and remote Australia.¹ Our members include consumer groups, the Aboriginal and Torres Strait Islander health sector, health professional organisations, educators, and service providers. This large and diverse membership gives the Alliance a comprehensive and authentic view of the health interests across country Australia. For a full list of our members see Attachment 1.

This submission is a distillation of contributions from Alliance members. It is informed by the members' experience and in-depth understanding of rural and remote Australian communities' health care needs, in particular the barriers they face in accessing health care.

The Alliance supports the MHR and the benefits that it can provide to informing the provision of timely, accessible and appropriate health care to the 7 million people living in rural, regional and remote areas of Australia. This support is conditional on the acceptance of the following recommendations:

1. **Data Security** – That government commit to ensuring that worlds best practice encryption and data security mechanisms are implemented, maintained, monitored and improved to prevent cyber- attack and other illegitimate access mechanisms to personal health information.
2. **Privacy** – That government commit to ensuring that the necessary legislative changes are made to ensure access to personally identifiable health information is restricted to prescribed circumstances by the named relevant authority. Legislative provisions in other Acts may need to be amended to reflect the changes required. Consistency needs to be established with the Australian Privacy Principles (Privacy Act 1988 and Privacy Amendment (Enhancing Privacy Protection) Act 2012) in particular.
3. **Health Equity and the Digital Divide** – That government commit to ensuring that all Australians have access to the benefits afforded by the introduction of My Health Record. This will require an analysis of what action is required to enable fixed and mobile communications infrastructure with sufficient bandwidth and connectivity to enable all Australians to benefit from the availability of personal health information at the point of care regardless of location and treatment environment. If not addressed the system has the potential to increase health inequities that people in rural and remote Australia already experience.
4. **Whole of Government Approach** – The government must ensure that agencies with a role in implementing the telecommunications universal service guarantee act in collaboration and partnership. Specifically, the Australian Digital Health Agency (ADHA) must work with the Department of Communications and the Arts to ensure that the necessary infrastructure is in place to enable the full functionality of My Health Record and other digital applications that have potential to enhance health outcomes for people in rural, regional and remote Australia.

¹ Throughout this submission references to remoteness areas are based on ASGC-RA, in which category 1 is Major cities, 2 is Inner regional areas, 3 Outer regional, 4 Remote and 5 Very remote. Because of small numbers, Remote and Very remote are often reported jointly. In the submission, references to 'regional areas' mean Inner plus Outer regional; and references to 'remote areas' mean Remote plus Very remote.

5. **Public Communication and Engagement Strategy** - A new public communication and engagement strategy needs to be developed to educate and inform the population about My Health Record. The campaign needs to have a longer lead-in time (at least 12 months) and pay specific attention to vulnerable groups, those with lower literacy levels and those non-English speaking backgrounds.
6. **Training and support for health professionals in rural and remote areas** - The ADHA must should invest in training and support for allied health professionals building on the service model that Primary Health Networks use to engage and support General Practitioners. Health professionals in rural and remote areas must be made a priority.

The National Rural Health Alliance Response to the Inquiry Terms of Reference

a. The expected benefits of the My Health Record system

Overall, the Alliance believes that digital health technologies, such as the My Health Record (MHR) system are a vital element in building the required infrastructure for a better healthcare system in Australia. They have great potential to improve quality of healthcare through better information sharing between health care service providers and health care consumers resulting in consumer empowerment, engagement, and improved self-management.

The MHR, as a personal electronic health record, also aims to improve health care system performance and delivery by minimising duplication of diagnostics tests, improving medication management and continuity of care. System improvement, data sharing and communication is of course dependent on health practitioners and consumers receiving high quality, current and accurate information². Alliance members suggest that allied Health professionals need to access the full functionality of the system with their client's permission, or it will have limitations. Particularly for those who may choose to case manage their own care needs and predominantly use allied health professionals in the early stages of the management of their chronic condition(s).

Alliance members providing services in the Northern Territory tell us they have been working with electronic health record systems for over a decade. They report that this is now business as usual. However, it did require a long lead in time for the innovation to be adopted. The delay in adoption from the health practitioner end was largely due to how the system was integrated into everyday practice. It is notable that the early implementation in the Northern Territory has demonstrated substantial benefits to Aboriginal and Torres Strait Islander people living in very remote, isolated communities.

The MHR has the potential to enhance communication and improve accountability for health professionals to ensure they gain informed consent, educate consumers about their conditions and provide different treatment options with pros/cons for each.

Access to services is a major impediment for people living in rural, regional and remote Australia. A critical advantage of MHR is that information provided by the full range of health professionals

² Robertson-Dunn, B (2018) My Health Record: on a path to nowhere? MJA Issue 25 / 2 July 2018 from: <https://www.doctorportal.com.au/mjainsight/2018/25/my-health-record-on-a-path-to-nowhere/>

involved in a person's care is immediately available at the point of care, regardless where that may be.

In addition, the secondary use of MHR data in aggregated, non-personally identified form, has significant potential for insights into population health and health service delivery issues. While the sensitivity of access to this level of information for commercial purposes should be legislated against there is no doubt about the potential of this data to assist in planning and health needs identification.

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

There was no clear-cut response to this question. Some alliance members see the opt-in approach as a more democratic and libertarian position and "less big-brother-like".

However, many Alliance members agree that it is reasonable for government to have initiated the opt-out method to address the shortfall in enrolments that have occurred to date.

There is a concern that government has not demonstrated its credentials in how it has managed the implementation process to date. Serious concerns remain about the need for the Australian Digital Health Agency (ADHA) to manage the public communication process effectively and ensure that people are informed about the advantages of participating in MHR and the actions being taken to protect privacy and unauthorised access to personal information.

A further concern about the opt-out approach is that people who choose not to actively opt out will not be adequately informed about the access provisions applying to their information. This is particularly the case for people that choose not to actively manage their account – expected to be the majority of the enrolled population. Similarly, for those that do choose to opt out, what provisions are in place to share their information between providers if any.

Despite the high level of support for the MHR, Alliance members do have serious concerns about the ability of government to protect security and privacy. The proposed legislative changes will need to meet the level of concern about this in the general community.

I. The vulnerability of the system to unauthorised access

All systems are vulnerable to unauthorised access. Recent high-profile electronic system failures such as that involving the Australian census and similar failures in the private sector have sharpened awareness in the community of the need to protect personal information. The confidentiality of consumer records in the health sector is sacrosanct and it is essential that consumers can believe that a government sanctioned system will adhere to the highest levels of confidentiality. At the present time confidence levels do not meet this necessary standard.

There is some confusion in the public arena about a general concern about cyber-attack (to which all internet-based systems are vulnerable), authorised access by relevant authorities as permitted in the relevant legislation, and the risks relevant to each. There is an obligation on government to clarify the levels of risk protection that is available and to be clear about what is ultimately controllable and what is not. Consumers need to be encouraged to weigh the risk accordingly compared with the advantages of point of care access to personal health information.

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

ADHA has given unequivocal assurances about authorised access to the MHR system by relevant authorities. The legislative amendments to be put before Parliament will need to provide

appropriate protections that ensure a proper process is in place to enable access to an individual's MHR under prescribed circumstances and by the relevant authorities.

Arguably, the weakest part of the MHR system with respect to security/privacy is with provider's, or indeed individual's, data management practises. ADHA cannot vouch for this, although they still have the responsibility for ensuring that providers (and individuals) have a clear understanding of their significant responsibilities in ensuring the privacy of information held.

The potential to store genetic information on an individual's MHR is of concern to some members. The Alliance supports the need for this to be more fully and publicly explored by the ADHA.

Some Alliance members are concerned about access to the MHR. There is a perception that if police had easy access to the MHR this could discourage open disclosure of information to health practitioners for a range of clinical reasons. Importantly though, it is acknowledged (and supported) that in instances where the life of the consumer or another person is threatened there is actually a requirement (Privacy Amendment (Enhancing Privacy Protection) Act 2012; Privacy Act 1988) for health practitioners to disclose information to the relevant investigative authority. Although this is a mandatory obligation on health practitioners it is surprising that it has not been recognised in the public commentary and debate that has occurred regarding MHR (consider notifications of child abuse for instance).

The potential of a spill over of information is of concern (genetic information on one individual can be relevant to blood related individuals).

Alliance members support the use of de-identified data for research purposes provided the motivation for the research is identified and approval provided by a relevant ethics group. Government agencies already have access to a large amount of personal information on us what is missing is a legislative framework that makes it clear that this information will not be used for the wrong purpose.

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

Alliance members do not support the concept that third parties such as insurers can directly access MHR information. There is a perception that they will refuse to provide a product/service or differentially price a product/service if an individual does not acquiesce to a MHR request. This is unacceptable and there should be legislative measures to protect individuals from such conduct.

Third party agencies such as law enforcement, government agencies, researchers and commercial interests should only be able to access information in prescribed circumstances and those circumstances need to be reflected in legislation.

There does seem to be confusion about the various pieces of legislation and the hierarchy of precedence. The Alliance supports this being part of the disclosure to facilitate public understanding. For example, the provisions in the Current MHR Act compared to the Privacy Principles contained within the Privacy Act 1988 and Privacy Amendment (Enhancing Privacy Protection) Act 2012 seem to be at variance with the former not identifying a requirement for a 'prescribed circumstance' to be met.

c. The Government's administration of the My Health Record system roll-out

Overall, Alliance members believe that the roll-out of MHR could have been handled a lot better with more consumer involvement and participation. Member feedback shows that the public information campaign has been limited in its visibility and relied on support from within the health care sector (eg GP's or other service providers) to support informed consent. In some situations, this has meant that the health provider has recommended against remaining within the system. This

undermines the usefulness of the MHR – its ultimate benefit will only be realised if the vast majority of people have a MHR.

Alliance members are not aware of campaigns that have been aimed at vulnerable or hard to reach groups and there is concern that these groups have not received the information required in order to make an informed consent-based decision to remain in the system.

There also seems to be a perception that the roll-out that the benefits of the My Health Record were self-evident. In hindsight, this has certainly been a naïve view. The experience of what occurred in the Northern Territory should have been used to more accurately inform the communication strategy for MHR. It is clear that leadership is required to ensure that the lessons learnt from the first few weeks of the opt out period are used to better inform the approach from here.

d. Measures that are necessary to address community privacy concerns in the My Health Record

Alliance members provide these suggestions:

- The Government needs to build consumer confidence and demonstrate its credentials in managing electronic information systems and responding to cyber-attack.
- Clearer communication on what it means, in practical terms, for an individual to have complete control of their MHR.
- Clearer instructions on how this complete control is exercised.
- Credible assurances from ADHA of stringent provider data management practices.
- Regular and timely reporting of any breaches, the circumstances of the breach and the action taken in response.
- Passing the proposed legislation on law enforcement access (along with others) to an individuals' MHR.
- Regular and transparent public advice on the development, implementation and use of the secondary use of MHR data framework.
- Show people how the system works and provide more information available online, e-learning modules and hotlines.
- Consistent and clear privacy frameworks that can be communicated to the community and health professionals.
- The consumer must be able to control what information is uploaded to their record and who can have access to what types of information is contained on their record. The principles of enhancing consumer choice and control must be the basis from which we develop the MHR system.

e. How My Health Record compares to alternative systems of digitising health records internationally

Alliance member's feedback showed that they did not have enough detail about overseas systems to make an informed comment. In the event that there are international examples that are definitive and instructive then this information be shared to inform the level of public understanding of the issue.

f. Any other matters

The Australian government has invested heavily in digital health technology, recognising the importance for consumers and the broader health system in using technology to improve efficiency and access to information. Very significant public funding has been invested in supporting general practice to access and use the MHR and related systems such as secure messaging. This support includes funding general practice software development, providing financial practice incentives for the uptake of digital health technology, funding training and support by the Royal Australian College of General Practitioners (RACGP) and others, and funding Primary Health Networks to provide intensive hands-on support and training. This support has been vital to increasing the use and value of My Health Record and other digital health technologies. Allied health practitioners play a crucial role in contributing to the care of people with a range of health issues including chronic conditions and would benefit enormously from full access to digital health technology. Yet until now, the Australian government has not provided support to assist the allied health sector to engage with digital health technology. Without that support, the allied health sector will not be able to contribute meaningfully and consumers will not benefit from the information about them being accessible.

Navigating the health record system requires a level of literacy (health and computer) to be able to navigate and use digital health platforms appropriately. Given that there is a lower level of health literacy in rural and remote Australia, the Alliance is keen to establish how the MHR will address the health literacy gap. Lessons may well exist from the implementation of the Personally Controlled Electronic Health Record in the Northern Territory – particularly relating to Indigenous communities.

Poor internet connectivity is an ongoing issue for many people living in rural and remote Australia and successful adoption of the MHR will be heavily reliant on addressing the digital divide that exists between major cities and rural and remote areas.

The Alliance believes that the roll-out of the MHR and public acceptance of it will take longer to implement than hoped. Positive engaging stories of how the proposed system can improve the health of individual consumers, particularly those from vulnerable and at-risk backgrounds needs to form part of the dialogue as well as assurances that privacy issues will be comprehensively addressed.

Attachment 1: Membership of the National Rural Health Alliance

Australasian College for Emergency Medicine (Rural, Regional and Remote Committee)
Australasian College of Health Service Management (rural members)
Australian College of Midwives (Rural and Remote Advisory Committee)
Australian College of Nursing - Rural Nursing and Midwifery Community of Interest
Australian College of Rural and Remote Medicine
Australian Healthcare and Hospitals Association
Allied Health Professions Australia Rural and Remote
Australian Indigenous Doctors' Association
Australian Nursing and Midwifery Federation (rural nursing and midwifery members)
Australian Physiotherapy Association (Rural Members Network)
Australian Paediatric Society
Australian Psychological Society (Rural and Remote Psychology Interest Group)
Australian Rural Health Education Network
Congress of Aboriginal and Torres Strait Islander Nurses and Midwives (CATSINaM)
Council of Ambulance Authorities (Rural and Remote Group)
CRANApus
Country Women's Association of Australia
Exercise and Sports Science Australia (Rural and Remote Interest Group)
Federation of Rural Australian Medical Educators
Isolated Children's Parents' Association
National Aboriginal and Torres Strait Islander Health Worker Association
National Aboriginal Community Controlled Health Organisation
National Rural Health Student Network
Paramedics Australasia (Rural and Remote Special Interest Group)
Rural Special Interest Group of Pharmaceutical Society of Australia
RACGP Rural: The Royal Australian College of General Practitioners
Rural Doctors Association of Australia
Rural Dentists' Network of the Australian Dental Association
The Royal Australasian College of Surgeons – Rural Surgery Section
Royal Far West
Royal Flying Doctor Service
Rural Health Workforce Australia
Rural and Indigenous Health-interest Group of the Chiropractors' Association of Australia
Rural Optometry Group of Optometry Australia
Rural Pharmacists Australia
Services for Australian Rural and Remote Allied Health
Speech Pathology Australia (Rural and Remote Member Community)