Public Health Association of Australia submission on the My Health Record system

Contact for recipient:
Committee Secretary,
Senate Standing Committee on Community Affairs
A: PO Box 6100, Parliament House
Canberra ACT 2600
E: community.affairs.sen@aph.gov.au
T: (02) 6277 3515

Contact for PHAA:
Terry Slevin – Chief Executive Officer
A: 20 Napier Close, Deakin ACT 2600
E: phaa@phaa.net.au T: (02) 6285 2373
Contents

Preamble ..................................................................................................................................... 3

The Public Health Association of Australia.............................................................................. 3

Vision for a healthy population ............................................................................................... 3

Mission for the Public Health Association of Australia ........................................................... 3

Introduction ................................................................................................................................. 4

Empowerment of individuals...................................................................................................... 5

‘Opt-in’ or ‘opt-out’? ............................................................................................................... 5

Control of specific sensitive records in an operational MHR .................................................. 5

Privacy concerns .......................................................................................................................... 6

Data security ............................................................................................................................ 6

Risk of commercial misuse of information .............................................................................. 6

Inappropriate demands on individuals .................................................................................... 7

Epidemiological research.............................................................................................................. 7

Conclusions .................................................................................................................................. 8
Preamble

The Public Health Association of Australia

The Public Health Association of Australia (PHAA) is recognised as the principal non-government organisation for public health in Australia working to promote the health and well-being of all Australians. It is the pre-eminent voice for the public’s health in Australia.

The PHAA works to ensure that the public’s health is improved through sustained and determined efforts of the Board, the National Office, the State and Territory Branches, the Special Interest Groups and members.

The efforts of the PHAA are enhanced by our vision for a healthy Australia and by engaging with like-minded stakeholders in order to build coalitions of interest that influence public opinion, the media, political parties and governments.

Health is a human right, a vital resource for everyday life, and key factor in sustainability. Health equity and inequity do not exist in isolation from the conditions that underpin people’s health. The health status of all people is impacted by the social, cultural, political, environmental and economic determinants of health. Specific focus on these determinants is necessary to reduce the unfair and unjust effects of conditions of living that cause poor health and disease. These determinants underpin the strategic direction of the Association.

All members of the Association are committed to better health outcomes based on these principles.

Vision for a healthy population

A healthy region, a healthy nation, healthy people: living in an equitable society underpinned by a well-functioning ecosystem and a healthy environment, improving and promoting health for all.

The reduction of social and health inequities should be an over-arching goal of national policy and recognised as a key measure of our progress as a society. All public health activities and related government policy should be directed towards reducing social and health inequity nationally and, where possible, internationally.

Mission for the Public Health Association of Australia

As the leading national peak body for public health representation and advocacy, to drive better health outcomes through increased knowledge, better access and equity, evidence informed policy and effective population-based practice in public health.
Introduction

PHAA welcomes the opportunity to provide input to the Committee’s inquiry into the My Health Record (MHR) system.

PHAA strongly supports the concept behind the MHR project, for the simple reason that it has the potential to significantly improve the health care of millions of Australians.

PHAA has engaged with the development of Australia’s electronic health record policy over many years. After years of policy examination Australian governments agreed to move forward with such a system in 2009, and the My Health Records Act was eventually enacted in 2012.

More recently PHAA chose to partner with the Australian Digital Health Agency (ADHA) in the extensive task of promoting the existence of MHR, a relationship which includes minor cost-recovery funding from ADHA. PHAA did so in pursuit of its vision and goals for a healthier society. However this relationship does not mean that PHAA will be uncritical of the details of the scheme or of its implementation. In this submission, we make plain our strong support for pursuing the goals of MHR, while also offering constructive criticism of the current state of the project.

Better information flow and record keeping have the potential to prevent a substantial number of adverse incidents and overlooked illness issues, as well as make possible many preventive actions by individuals to improve their health. It may incidentally offer various opportunities and aids to epidemiological research and better population health decision-making.

My Health Record’s launch in mid-2018 was not a sudden or isolated event, but was one step in a process which has been developing for many years, and will continue to develop into the future.

The recent 2018 phase implementation of the My Health Record project received criticism shortly after its implementation, leading to the Committee’s reference. The main thrust of these criticisms related to two topics:

- concerns about empowerment, related to the extent to which individuals could decide for themselves the extent of their involvement in My Health Record, and exercise control over the information recorded about their own health status.
- concerns about privacy, against a background of uncertainty about the security of electronic databases

PHAA believes that the appropriate way to handle this debate is to work on addressing these concerns, while maintaining the overall direction of improving health record keeping while maximising health benefits through appropriate clinical use. My Health Record will improve health and save lives.

My Health Record is one attempt at an integrated platform to yield greater health outcomes for Australian from better use of information about them which already exists.

Health record keeping is a daily reality, with or without MHR’s existence. Vast amounts of data currently exist in the hands of innumerable health care providers. Sound, accurate and well used health records are a fundamental component of an effective health care system. IT security concerns apply to any record-keeping and should be appropriately designed and resourced.

Finally, PHAA places a very high value on population-level epidemiological information in protecting and improving the health of all Australians through better informed public and clinical health policy and practice. MHR may play an important role into the future in generating such information.
Empowerment of individuals

PHAA believes strongly in individual empowerment in regard to health information. The MHR scheme, operating successfully, can clearly increase that empowerment by placing health records at the continual disposal of the individual and their health service providers. With the right policy settings the scheme makes information more available to individuals and places it more under their control.

‘Opt-in’ or ‘opt-out’?

The debate in recent months has turned on the difference between ‘opting in’ or ‘opting out’ of participation in the MHR scheme. The ADHA used this language extensively to explain the capacity of opting out to the community, and it has featured prominently in media discussion and commentary.

The strategic decision was taken to favour an opt-out system over an opt-in one on the basis that take-up would have been far lower, and project expenditure on communications far higher, had opt-in been chosen as the approach. A balance was struck by the Government in deciding that the MHR would proceed at large scale to secure the maximum coverage, with an opt-out option being thought sufficient to ameliorate any public concern.

The initial policy choice was defensible, but it is not impossible to adjust that balance if necessary. The recent extension to the opt-out period is an example of doing just that. Suggestions for further adjustment include making opt-out a permanent right for individuals without any deadline.

In addition it should also be noted that the opt-in/opt-out distinction is not as simple as it seems. Many health records existed prior to, and will be created regardless of, the start of MRH. Participation in MHR does not in itself necessarily create new health records, it simply consolidates into a unified platform the storage and availability of past and future records.

However it is understandable that some people see the negative aspect of a scheme, which alarms people with the thought they will lose control over their health information, and that it might be misused by others. Some are concerned at the possibility for private businesses to somehow come into possession of health information (on individuals or in aggregate) for commercial purposes.

The policy direction here is obvious: MHR should be structured such that individuals retain control. That includes decisions on opting in or out, as well as ongoing control including possible partitioning of records at the individual’s own discretion (see below).

MHRs structure should ensure that this is possible. PHAA understands that there are technical challenges to establishing such a structure, but notes that those challenged are overcome daily in regard to domains such as banking, tax records, driver licensing, and many other fields of government and commercial record keeping. The same should be possible for health records.

Control of specific sensitive records in an operational MHR

The second issue is whether, while a person is ‘in’ the MHR system, they have the capacity to control access to specific components of their health information.

Needless to say, the whole thrust of the record-keeping system is to ensure that information is available to the individual and to every health care provider who might need the information to provide the individual...
with optimal care. In that sense, the system is all about conveying information when and where it is needed.

However it is also obvious that individuals have justifiable sensitivities about some aspects of their health information being available where it is not needed, or even simply where individuals do not wish it to be available.

This applies in particular to health records which relate to an unusual degree to a person’s private life. Records relating to mental illnesses, to family planning matters including dealing with pregnancies, to drug use, or to health issues arising from domestic violence would all raise understandable issues of personal privacy.

The present system has been based largely on record control by each individual’s GP, including partitioning of areas of health information to protect sensitive issues. Alternatives should be explored that allow for even greater control by the individual.

Privacy concerns

Data security

Observers are understandably concerned about the possibility that the database behind the MHR system may be insecure, allowing personal health information to be misused or stolen.

Securing an electronic database is a highly technical and expensive undertaking. High-importance government databases, such as those maintained by defence and tax authorities, understandably attract high levels of spending on security. In addition, levels of security will depend on the range of persons with access to the database and the training and responsibility of those with access.

MHR is, by its nature, a platform which must be accessible at all times to hundreds of thousands of users – GPs, other health professionals, and their staff. This makes it inherently difficult to deliver high degrees of security.

The Government needs to respond to such concerns. Hard platform security measures as well as training of all professionals and office staff which have MHR access involves difficulty and expense. The Government needs to take these concerns on board and adequately resources the system.

Risk of commercial misuse of information

Another concern raised about MHR is the prospect that private corporations will at some point obtain aggregate or individual data out of MHR, either with official permission or illegally.

In some cases this concern is linked to broader concerns about electronic hacking, but there are also concerns that the Government might at some point in the future sell, or otherwise make available, MHR data for commercial uses.

This is not to say that private (as well as public) health care providers would not be able to provide better care over time due to access to quality information about population-level illness (see ‘epidemiological research’ below). But information leading to improved practices should first be filtered by legitimate, accountable public-interest research entities.
PHAA believes that the Government should make very clear that such usages will not be part of the MHR system. Legislative protection against any such commercial usage should be adopted, and any breaches prosecuted with appropriately strong penalties for those proven to infringe.

Inappropriate demands on individuals

Finally, concerns have been raised that employers would make inappropriate demands of individuals to ‘voluntarily’ produce their private health information as a precondition for receiving opportunities such as job interviews. Similar concerns have been raised about the prospect of health insurers demanding MHR information from insurance applicants, and in other contexts.

While recognising that there are legitimate purposes for which employers, health insurers and others may be entitled to expect accurate information from employees, clients and so on regarding relevant aspects of their health, such demands should properly be limited to aspects of a person’s health which are relevant to a particular relationship or transaction.

PHAA believes that for the sake of the public credibility of the MHR, and taking into account other concerns about privacy and MHR, it is desirable that this ‘demand-for-health-records’ concern be addressed. Laws which permit employers, insurers and so on to seek health information from people should be framed in such a way that only relevant and reasonable information may be required, not the whole of an MHR record. On that basis, the Government should ensure that rules relating to release of MHR information to third parties are framed around principles of reasonable and relevant usage and unforced individual consent.

Epidemiological research

Finally, PHAA notes that MHR may potentially provide a highly valuable source of population-level epidemiological information on the Australian community.

In some cases such information could be highly beneficial to the Australian community on immediate issues such as the propagation of disease. In particular, there may be urgent cases where public health authorities can better protect the community overall through the use of aggregate information existing within MHR records.

In broader situations such information could be of high value in tracking the population-level prevalence of diseases and other forms of illness, and assist in prioritising government and health sector attention towards meeting the health needs of the community.

For that reason, the overall societal value of the MHR system (as opposed to its individual-level benefits) should be fully recognised. This aim has already been built into the MHR system. However to maintain the social licence for MHR in the face of community concerns, the Government should ensure that any form of access to aggregate de-identified data and information extracted from the MHR system is limited to legitimate research purposes (or urgent health crisis purposes) in the public interest. Access to such data should not be directly available to commercial interests (see above).

PHAA recognises that there may be an overlap between public concern about commercial misuse of data and concern about public-interest use of MHR data and information. The Government needs to handle communications around such matters appropriately and sensitively, and make the case for public health benefits that MHR might provide.
Conclusions

MHR is overall a very positive initiative for the health and wellbeing of Australians. PHAA supports the broad directions of the MHR system precisely because they are aligned with some of PHAA’s own goals relating to improving public and individual health.

However, PHAA suggests that attention should now be focussed on preventing problems with the current policy design and implementation of MHR, including the following:

1. While the ‘opt-out’ approach was probably the right choice to bring the benefit of MHR to the greatest number of Australians as quickly as possible, in the interests of public confidence in the system at this time, and also to maximise the ongoing degree of individual empowerment relating to My Health Record, the Government should ensure that:
   - opt-out from MHR is a straightforward process for those who wish to take it
   - Individual control over specific health information, including portioning of information relating to personally sensitive topics, is maximised.

2. In regard to the implementation of MHR the Government should adequately resource approaches to protect MHR systems from illegal intrusion.

3. The Government should not permit MHR information to be available, in aggregate or otherwise, for commercial use; this principle should be protected by appropriate legislation and vigorously enforced.

4. Access to MHR-held information for public health response and epidemiological research should be provided for, with appropriate personal privacy safeguards.

Please do not hesitate to contact me should you require additional information or have any queries in relation to this submission.

Terry Slevin
Chief Executive Officer
Public Health Association of Australia

17 September 2018