



# **Australian Government**

Australian Government response to the  
Senate Community Affairs References Committee  
report:

My Health Record System

November 2020

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## Introduction

The Australian Government (the Government) welcomes the opportunity to respond to the findings and recommendations of the Senate Community Affairs References Committee report on the My Health Record (MHR) system.

MHR is Australia's national digital health record system. It is an electronic summary of an individual's key health information that can be shared securely online between the individual and their healthcare providers to support improved clinical decision making and continuity of care. The system has been operating without incident since July 2012.

The Australian Digital Health Agency (the Agency) is the System Operator of the MHR system.

The Government is committed to the MHR system because it is delivering better health outcomes for patients and their treating healthcare practitioners by making it easier to co-ordinate their care and measure their progress. MHR also enables greater participation by consumers in self-management and decision-making for their healthcare.

The National opt-out period concluded on 31 January 2019. A MHR has been created for every eligible Australian who did not opt out. The consumer participation rate for the MHR as at 31 January 2019 is 90.1 per cent. More than 15,000 healthcare provider organisations are participating in the system. The majority of these healthcare providers are general practices (6,902) and pharmacies (4,609), but also include 1,013 hospitals, and 198 residential aged care services.

Since 2012, the Government has worked closely with consumers, privacy advocates and experts, health sector representatives, health software providers, medical indemnity insurers, Commonwealth, state and territory government agencies, to ensure the system remains safe, secure and enables better connected healthcare to all Australians.

On 26 November 2018, the Australian Parliament passed the *My Health Records Amendment (Strengthening Privacy) Act 2018*. The amendments made by this Act further strengthened the already robust privacy and safety framework for the MHR system. These amendments:

- allow people to permanently delete their records, and any backups, at any time;
- prohibit by law access to MHRs by anyone for insurance or employment purposes;
- strengthen privacy for teenagers 14 years and over;
- strengthen protections for people at risk of family and domestic violence;
- make clear that the System Operator cannot delegate functions to an entity other than an employee of the Department of Health or the Chief Executive of Medicare;
- require law enforcement and other government agencies to produce an order from a judicial officer to access information in a MHR;
- establish the governance for the use of MHR information for research and public health purposes; and
- make clear that the system cannot be privatised or commercialised.

The amendments came into effect on 11 December 2018.

The Government continues to engage with stakeholders to ensure the system remains safe and secure for users into the future.

The Government thanks the Committee and the wide range of organisations and people who contributed to this inquiry.

## Recommendations and Australian Government Responses

### Recommendation 1

5.12 The committee recommends that record access codes should be applied to each My Health Record as a default and that individuals should be required to choose to remove the code. The committee further recommends that the ability to override access codes in the case of an emergency should only be available to registered healthcare providers for use in extraordinary and urgent situations.

The Government does not support this recommendation.

The MHR system has a range of mechanisms that support consumers to protect their privacy, and control who has access to their healthcare information. Healthcare providers require timely access to their patients' key health information.

There would be significant implementation challenges to provide all Australians with access codes. To realise the full benefits of the My Health Record system, an individual's multiple healthcare providers need to have timely and comprehensive access to their patients' medical history to better make a diagnoses and provide treatments.

Asking for a PIN, and requiring consumers to remember their PIN, will interrupt the clinical workflow and impede use of the record. Clinicians treating people who are unable to recall their PINs will not be able to view their patient's record. Both the clinician's and the consumer's time will be wasted while the consumer attempts to locate their PIN.

In addition, much valuable clinical work is undertaken for patients when they are not directly in the presence of their treating clinicians. For example, a general practitioner may receive important updated information from a specialist by letter such as a medication change or a new review being required. Unless the patient was present to provide their record access control, the GP would be unable to check their MHR at that moment for important medication interaction information, or whether or not various reviews or investigations had already been done by another clinician. This would represent a barrier to the realisation of benefits from the MHR system associated with medication safety and reducing unnecessary test duplication.

The *My Health Records Act 2012* (MHR Act) makes clear that only registered participants in the MHR system are authorised to access health information in a consumer's MHR for the purpose of providing healthcare and only in accordance with any access controls established by the healthcare recipient.

In the case of a serious threat to life, health or safety, provisions exist for access controls to be bypassed but only in specific circumstances, where information in the MHR system is needed to provide emergency healthcare to a consumer, or to mitigate a serious threat to public health or safety.

All emergency access is logged and subject to audit in accordance with the MHR Act. To date, there have been no purposeful or malicious attacks compromising the integrity or security of the MHR system.

#### Recommendation 2

5.15 The committee recommends that the Australian Government amend the My Health Records Act 2012 to protect the privacy of children aged 14 to 17 years unless they expressly request that a parent be a nominated representative.

The Government supports this recommendation.

The amendments to the MHR Act passed in November 2018 provide greater privacy for teenagers aged 14 to 17 years. Under these measures, parents no longer have authority to access a MHR of a young person aged 14 years or older unless permitted by the young person.

Minors aged 14 to 17 years with limited or no capacity to make decisions are unable to have an authorised representative recognised unless their parent/guardian can provide evidence of express legal authority to act on the minor's behalf. This issue will be considered as part of a review into the privacy settings for minors announced on 7 November 2018.

#### Recommendation 3

5.16 The committee recommends that the Minister for Health amend the My Health Record Rule 2016 to extend the period for which a My Health Record can be suspended in the case of serious risk to the healthcare recipient, such as in a domestic violence incident.

The Government notes this recommendation.

Recent amendments to the MHR Act ensure that a person cannot be the authorised representative of a minor if they have restricted access to a minor or may pose a risk to the minor or a person associated with the minor, regardless of parental responsibility.

The System Operator can suspend or cancel access by one or all authorised representatives where an authorised representative may pose a risk to a minor or a person associated with a minor, the System Operator can suspend or cancel access by one or all representatives while it investigates the dispute and a solution is identified.

When the record is suspended, no representatives can access the child's health information in their My Health Record. The Australian Digital Health Agency continues to engage with stakeholders to ensure system settings are appropriate.

#### Recommendation 4

5.19 The committee recommends that data which is likely to be identifiable from an individual's My Health Record not be made available for secondary use without the individual's explicit consent.

The Government notes this recommendation.

The *Framework to guide the secondary use of My Health Record system data* (the Framework) was released on 11 May 2018. Elements of the Framework were legislated as part of the Government's *My Health Records Amendment (Strengthening Privacy) Act 2018*.

Under these changes, personally identifiable information may only be used for public health or research purposes with the individual's consent.

The Framework specifies the requirements for the provision of de-identified data for research and public health purposes, including the requirement that contemporary de-identification methods and techniques are applied and an expert provides assurance that the risk of re-identification is very low prior to any data being made available.

Consumers retain control over whether their MHR data can be used for research and public health purposes at all times.

#### **Recommendation 5**

5.21 The committee recommends that the current prohibition on secondary access to My Health Record data for commercial purposes be strengthened to ensure that My Health Record data cannot be used for commercial purposes.

The Government notes this recommendation.

The Framework does not permit the use of MHR system data for solely commercial and non-health related purposes. The Framework does acknowledge that MHR system data that is utilised for beneficial research and public health purposes in some instances may also be of commercial benefit, for example, technological and service innovation.

Elements of the Framework were legislated as part of the *My Health Records Amendment (Strengthening Privacy) Act 2018*. These include:

- a Data Governance Board to consider applications for data;
- the Australian Institute of Health and Welfare (AIHW) will be the data custodian; and
- enabling the Minister to make rules to apply to persons handling the data.

The Data Governance Board will include representatives from the Australian Institute of Health and Welfare, the Australian Digital Health Agency, and a range of independent experts on matters including population health, research, data science, data governance, privacy and consumer advocacy.

It will assess applications to use MHR system data for research and public health purposes on a case-by-case basis, and in accordance with the conditions outlined in the framework. This will provide an extra layer of protection, transparency and accountability for the privacy of individuals' MHR system data where that data is to be made available for research and public health purposes.

Successful applicants will also be required to adhere to strict conditions of use agreements to ensure appropriate use of data, and will be subject to criminal penalties for misuse of MHR system information. These penalties include up to five years in jail and up to \$63,000 in fines. Civil penalties can incur up to \$315,000 in fines.

#### **Recommendation 6**

5.23 The committee recommends that no third-party access to an individual's My Health Record be permissible, without the explicit permission of the patient, except to maintain accurate contact information.

The Government notes this recommendation.

The MHR Act makes clear that only registered participants in the MHR system are authorised to access health information in a consumer's MHR.

The regime for collecting, using and disclosing MHR information in the MHR Act, largely reflects the existing privacy framework set out in the *Privacy Act 1988* (although the MHR regime is more restrictive in some cases).

The regime also provides authority for other circumstances in which the information is needed for particular purposes and these are consistent with permissions afforded by the *Privacy Act 1988*, for example, to provide emergency care to an individual, in response to a court order about a MHR-specific matter, or in operating the system where the individual would reasonably expect it to occur (i.e. if a breach is being investigated by the System Operator).

The 2018 Strengthening Privacy amendments offered further protections to individuals by prohibiting the release of My Health Records to a law enforcement agency or government body without a court order or an order by a judicial officer, other than the Commonwealth Auditor General, Commonwealth Ombudsman and Information Commissioner.

All access to MHRs is logged and subject to audit in accordance with the MHR Act.

#### Recommendation 7

5.25 The committee recommends that the Australian Government amend the My Health Records Act 2012 and the Healthcare Identifiers Act 2010 to ensure that it is clear that an individual's My Health Record cannot be accessed for employment or insurance purposes.

The Government supports this recommendation.

The Government's recent amendments to the MHR Act, which were passed by Parliament on 26 November 2018, prohibit insurers and employers from requesting, or coercing a healthcare recipient to disclose MHR information to them.

In addition, the *Healthcare Identifiers Act 2010* specifically prohibits the collection, use or disclosure of the healthcare identifier of a healthcare recipient for the purpose of communicating or managing health information for insurance or employment purposes.

Organisations that use MHR information for such purposes will be subject to penalties of up to \$1,575,000 or imprisonment for up to five years.

#### Recommendation 8

5.26 The committee recommends that access to My Health Records for the purposes of data matching between government departments be explicitly limited only to a person's name, address, date of birth and contact information, and that no other information contained in a person's My Health Record be made available.

The Government notes this recommendation.

Information required for data matching purposes is dependent on the outcomes being sought through the matching.

The data required to undertake matching for the purpose of authenticating a person's identity in the MHR are governed by the Trusted Digital Identity Framework, which sets the rules and standards for how personal information is handled by participating government

agencies and organisations. The data required to undertake matching for the purpose of authenticating a persons' identity in the MHR are set out in the Trusted Digital Identity Framework. The data items set out in this Framework are the same as those contained in this recommendation.

However, MHR system data matching performed for broader purposes, for example for medical and public health research purposes (not identity authentication), often requires other data attributes to validate and perform data linkage. Limiting the data attributes that may be utilised for data matching purposes may significantly constrain future potential benefits from the secondary use of MHR information system.

The *Framework for the secondary use of My Health Record system data* will govern the use of MHR information for research and public health purposes.

The Government's recent amendments to the MHR Act provided a legislative basis for a number of critical governance structures required to support the appropriate use of MHR data. These included the establishment and functions of a Data Governance Board that will play a fundamental oversight role in the use of MHR information for research and public health purposes, and naming the Australian Institute of Health and Welfare – a trusted expert in handling sensitive data – as the data custodian under this framework.

#### **Recommendation 9**

5.28 The committee recommends that the legislation be amended to make explicit that a request for record deletion is to be interpreted as a right to be unlisted, and as such, that every record is protected from third-party access even after it is deleted, and that no cached or back-up version of a record can be accessed after a patient has requested its destruction.

The Government supports this recommendation.

Amendments to the MHR Act that came in to effect on 11 December 2018, require the Australian Digital Health Agency (as the System Operator) to delete any health information from the National Repositories Service, including back-ups and copies that it holds about a healthcare recipient who has requested that their MHR be cancelled.

#### **Recommendation 10**

5.32 The committee recommends that the Australian Digital Health Agency revise its media strategy to provide more targeted comprehensive education about My Health Record.

The Government supports this recommendation.

Please refer to the response provided for Recommendation 11 for further information.

#### **Recommendation 11**

5.36 The committee recommends that the Australian Digital Health Agency identify, engage with and provide additional support to vulnerable groups to ensure that they have the means to decide whether to opt out, whether to adjust the access controls within their My Health Record and how to do this.

The Government supports this recommendation.



Determination of the groups considered 'hard to reach' or vulnerable for the purposes of the MHR Expansion Program was through size of the group based on Census data (or other credible data available through desktop research), the likely challenge for the group to come into contact with national communications being planned, and any issues they may face in regards to literacy, privacy or access.

The Agency engaged with over 45 national and state-based peak advocacy and other organisations which represent or support a wide range of 'hard to reach' and vulnerable groups including the Australian Council of Social Services (ACOSS), Mental Health Australia, LGBTI Health Alliance, National Rural Health Alliance, National Aboriginal Community Controlled Health Organisation, Positive Life NSW, Australian Association for Adolescent Health and others across the Expansion Program (July 2018 – end of January 2019).

Communication, and information developed for these groups, was provided through these organisations to reach their member bases.

The Agency engaged all 31 Primary Health Networks (PHNs) throughout Australia to provide locally based engagement within the community, which includes hard to reach and vulnerable groups. Over 850 local events were delivered across the country during the opt-out period specifically targeting vulnerable groups. Remote access community engagement plans were implemented in 5 highly remote regions of Australia.

A suite of communication materials was made available via multiple channels in text, audio and video. Key materials were translated into 17 different languages and an additional 15 indigenous languages. Low literacy and ASLAN materials were also created. Messaging included the benefits of MHR, how to opt-out, where to go for help and how to control privacy settings.

Materials developed during the expansion period will continue to be accessible via the MHR website, microsite and via print-on-demand.

It is an ongoing priority of the Australian Digital Health Agency to focus on communication, authentic engagement and support to ensure the user experience for a consumer or healthcare provider accessing the MHR system is positive and promotes effective use.

#### **Recommendation 12**

5.37 The committee recommends that the Australian Government commit additional funding for a broad-based education campaign regarding My Health Record, with particular regard to communicating with vulnerable and hard to reach communities.

The Government supports this recommendation.

Since the conclusion of the Inquiry the Agency has undertaken a range of communication activities to educate and inform consumers that they now have a record and can start using and adding information to theirs. The focus of the activity is to encourage healthcare providers to start viewing and uploading information to the system given that most of their patients now have a MHR, and inform consumers they have a MHR they can now access and to start a conversation with their doctors to view and upload their important medical information to their record.

Key audiences who are high health system users were targeted. These include: consumers (parents with young children, people with chronic illness, carers, older Australians and primary health provider audiences), GPs, pharmacists and to increase connectivity, specialists. Channels to reach these audiences included GP waiting room media, digital and social channels and health advocacy member communication.

Additionally, over 70 co-design workshops were run between January and June 2019 to inform the development of communication and education materials that are used to support vulnerable and hard to reach communities on how to utilise MHR and engage effectively with their healthcare provider.

Consumer and peak representatives at the co-design workshops identified the need for more MHR education for people with low digital health literacy or vulnerabilities including children and youth.

In response to this feedback, the Agency entered into a number of arrangements including:

- a partnership with the Good Things Foundation to deliver a MHR education program;
- a bi-lingual education pilot in 13 different languages in Victorian communities with Diverseworks; and
- a partnership with the Australian Library and Information Association to train library staff across Australia to equip them with the confidence and knowledge to provide information on MHR specific to the needs of the different consumer cohorts.

The National Children's Commissioner is also engaged through the Australian Human Rights Commission to develop and deliver engagement and education materials for children and youth about MHR and their privacy and rights.

The MHR Story Books designed by the Aboriginal Health and Medical Research Council of New South Wales with the Agency are an example of materials recently released to address the needs of Aboriginal and Torres Strait Islanders. The works of three Aboriginal artists help to present information on MHR in a highly visual way specific for the audience.

Other examples of material soon to be released include Auslan-translated guidance for deaf Australians and information tailored for families and people at risk such as those experiencing domestic violence.

### **Recommendation 13**

5.38 The committee recommends that the Australian Government extend the opt-out period for the My Health Record system for a further twelve months.

The Government notes this recommendation because it has been superseded by the creation of the records.

The Australian Government extended the opt-out period twice from its original conclusion date of 15 October 2018 through to 31 January 2019, to ensure consumers had adequate time to time to consider whether they wish to opt-out of having a MHR.

The 2018 Strengthening Privacy amendments to the MHR Act (which took effect on 11 December 2018) enable individuals to permanently delete their records, and any backups, at any time. This effectively means than an individual's right to opt-out remains

constant, even after the after the conclusion of the formal opt-out period, negating the need to extend the opt-out period.

The legislation that enabled the MHR system to move to an opt-out system passed Parliament in 2015. It received bipartisan support during this period.

The opt-out approach has the support of major health peak bodies including the Consumer Health Forum, the Australian Medical Association, and the Royal Australian College of General Practitioners.

Continued support from these peak bodies for an opt-out approach was reaffirmed during their appearance before the hearings for this inquiry on 11 September and 17 September 2018. In addition, all state and territory health ministers unanimously reaffirmed their support for an opt-out approach during the COAG Health Council Meeting in August 2018.

#### **Recommendation 14**

5.45 The committee recommends that the My Health Record system's operator, or operators, report regularly and comprehensively to Parliament on the management of the My Health Record system.

The Government supports this recommendation.

In accordance with the *Public Governance, Performance and Accountability Act 2013* and the MHR Act, the Agency as the System Operator is required to provide an annual report that is tabled in Parliament.

Additionally, in accordance with section 106 of the MHR Act, and section 30 of the *Healthcare Identifiers Act 2010* the Australian Information Commissioner is required to produce an annual report on the work of the Agency as the MHR System Operator, regarding their digital health compliance and enforcement activity.