Australian Government
Department of Health, Disability and Ageing

My Health Record

Review of the My Health Records Legislative Instruments

Public Consultation Paper

August 2025

Purpose of the consultation

Legislative instruments are laws that are made under the authority of an Act and contain legal rules that affect lives and businesses. The My Health Record (MHR) system is established by the *My Health Records Act 2012* (MHR Act). There are four legislative instruments under the MHR Act that are due to sunset (cease) on 1 April 2026:

1. *My Health Records Regulation 2012*
2. *My Health Records Rule 2016*
3. *My Health Records (Assisted Registration) Rule 2015*
4. *My Health Records (Opt-Out Trials) Rule 2016*

A fifth instrument, the *My Health Records (National Application) Rules 2017* is also within scope for review, however, are not due to sunset until 1 April 2028. Under the *Legislation Act 2003*, most legislative instruments automatically repeal after 10 years of operation. In order to continue, they must be reviewed and remade, to ensure they remain necessary and are aligned with current government policy.

The purpose of this consultation is to determine whether the listed legislative instruments continue to remain necessary and are fit for purpose.

Please note this review will not seek to make amendments to the primary legislation (*My Health Records Act 2012*).

This review is also not considering the Rules to be made to give effect to the Share by Default requirements arising from the *Health Legislation Amendment (Modernising My Health Record – Sharing by Default) Act 2025*, which amended the My Health Records Act and other legislation. Rules to prescribe the scope of entities and health services subject to the Share by Default requirements will be considered separately from this review.

We invite you to have your say on the consultation paper by:

- Responding to the survey on the Department of Health, Disability and Ageing Consultation Hub at consultations.health.gov.au
- Emailing your thoughts to DigitalHealthFoundations@health.gov.au

We are seeking your feedback by **3 September 2025**.

Thank you for taking the time to contribute to this process.

About this review

Since its inception in 2012, the My Health Record (MHR) system, and its governing legislation, has undergone several changes and enhancements to better service its purpose, making it a unique national digital health record for all Australians. As of April 2025[1]:

- There are over 24 million healthcare recipients with a My Health Record, with over 99% of those records containing health data, equating to over 1.7 billion documents that have been uploaded by consumers or healthcare providers.
- A large majority of healthcare providers are now registered to participate in the MHR system - 99% of general practices, 99% of pharmacies and 97% of public hospitals. Other healthcare providers are also registered to participate in the MHR system, including 63% of specialists and 43% of aged care providers.

There are six legislative instruments authorised under the *My Health Records Act 2012* (MHR Act). Five of the six instruments authorised by the MHR Act will sunset or cease on 1 April 2026 (see Table 1).

Table 1: My Health Records legislative instruments - Rule Maker and Sunset Date

Legislative Instrument	Rule Maker	Sunset Date
My Health Records Regulation 2012	Governor General	1-Apr-26
My Health Records Rule 2016	Minister for Health and Ageing	1-Apr-26
My Health Records (Assisted Registration) Rule 2015	Minister for Health and Ageing	1-Apr-26
My Health Records (Opt-Out Trials) Rule 2016	Minister for Health and Ageing	1-Apr-26
My Health Records (Information Commissioner Enforcement Powers) Guidelines 2016	Australian Information Commissioner	1-Apr-26
My Health Records (National Application) Rules 2017	Minister for Health and Ageing	1-Apr-28

The five sunsetting instruments to be reviewed before April 2026 contain a mix of provisions - some that may be allowed to be repealed, some that will be required to be retained to ensure the continued good operation of the My Health Record system and some that may benefit from revision. The Opt-out Trials Rule contains provisions that are no longer relevant and can be repealed.

The Office of the Australian Information Commissioner (OAIC) is responsible for the *My Health Records (Information Commissioner Enforcement Powers) Guidelines 2016*. The Department of Health, Disability and Ageing (the department) will not be reviewing this

[1] My Health Record statistics and insights April 2025, Australian Digital Health Agency, Statistics

instrument as part of this review. The department is working closely with the OAIC to align the delivery of the review of the various instruments. For those with interest in the Information Commissioner Enforcement Powers Guidelines, you are encouraged to contact the OAIC directly.

Under the *Legislation Act 2003*, most legislative instruments automatically repeal after 10 years of operation. In order to continue, they must be reviewed and remade, to ensure they remain necessary and are aligned with current government policy. In particular, the My Health Record system depends on the continued operation of *the My Health Records Regulation 2012* and the *My Health Records Rule 2016*, however these instruments may benefit from some revision.

On 8 February 2022, the then Attorney General tabled *the Legislation (My Health Records Instruments) Sunset-altering Declaration 2022* in Parliament, to facilitate a single review of all legislative instruments authorised by the MHR Act.

The review will take into consideration the following factors:

a. the views of key partners and stakeholders in the delivery of the digital health reform agenda,
b. relevant recommendations of the *Review of the Operation of the My Health Records Act 2012*[2] *(McMillan Review)* by Professor John McMillan AO,
c. that any new or remade instruments are consistent with objectives of the digital health reform agenda set by the *National Healthcare Interoperability Plan 2023-28*[3], *National Digital Health Strategy 2023-28*[4], and *Digital Health Blueprint 2023-33*[5]; and
d. that any amendments to the My Health Record instruments are complementary and effectively support the delivery of the My Health Record system.

Having regard to the broader digital health reform agenda, the department understands feedback may be provided that is beyond the scope of the technical issues needed for a review of the legislative instruments. Such considerations may inform the development of policy approaches to the modernisation of My Health Record and as such, feedback on the broader operation of the My Health Record system is welcome. However please be aware that any proposed reform which is beyond the scope of the legislative instruments under review will be considered in due course, as appropriate, to inform other digital health reforms. There will be further opportunity for consultation and input as other reforms are progressed.

[2] Review of the My Health Records legislation – Final report
[3] National Healthcare Interoperability Plan
[4] National Digital Health Strategy
[5] The Digital Health Blueprint and Action Plan 2023–2033 | Australian Government Department of Health, Disability and Ageing

My Health Record overview

My Health Record is Australia's secure national electronic health record system that contains an individual's online summary of health information such as:

- Clinical and other documents uploaded by healthcare providers (e.g. allergies, medicines, immunisations, pathology and diagnostic imaging reports)
- Medicare documents (e.g. Medicare and Pharmaceutical Benefits scheme claims, and Australian organ donor register information)
- Consumer uploaded information (e.g. advanced care plans and notes).

It was originally established in 2012 under a different name, the Personally Controlled Electronic Health Record (PCEHR). The implementation and adoption of the system sought to address the siloing of health information contained within the nation's fragmented health ecosystem[6]. The intent was and continues to be to ensure that all Australians are able to easily and conveniently access their key health information when they want it and to be able to securely share this information with their healthcare team for informed treatment and care.

The initial iteration of the system adopted an opt-in model, whereby individuals had to authorise the creation of their MHR. Unfortunately, this model did not yield the expected uptake in registrations, so in 2016, a small trial piloting an opt-out model was conducted to determine whether MHR would benefit from transitioning to an opt-out approach, in a bid to increase registrations. The *My Health Records (Opt-Out Trials) Rule 2016* supported these early trials. The results from the trials and proceeding consultations were a success and MHR subsequently transitioned to the opt-out model in 2019. The national implementation of the opt-out model was facilitated by the *My Health Records (National Application) Rule 2017*.

Although MHR operates under an opt-out model, this does not mean that consumers do not retain choice and control over who can access their record or what information is held within their record. The *My Health Records Rule 2016* details the access control mechanisms for consumers that the System Operator must establish and maintain as part of the operation of the MHR system.

The System Operator as prescribed in the *My Health Records Regulation 2012* is the Australian Digital Health Agency (the Agency). The Agency is responsible for the operation and delivery of high quality, trusted, reliable, and secure national digital health

[6] Concept of operations: relating to the introduction of a Personally Controlled Electronic Health Record (PCEHR) system, Australian Department of Health and Aging and National E-Health Transition Authority Ltd, 9 September 2011

infrastructure and health support systems, such as the MHR system[7]. The *My Health Records Act 2012* establishes the role and functions of the System Operator.

Other participants[8] of the MHR system include:

- Registered healthcare provider organisations: an organisation that provides healthcare to healthcare recipients that is registered to connect with the MHR system
- National Repositories Service operator: an entity who ensures that there is capacity to store a minimum critical set of health information about registered individuals
- Registered repository operator: an entity that holds, or can keep records of, information included in the MHR system
- Contracted service provider: an organisation that provides technology services or health information management services related to the MHR system, to a healthcare provider organisation
- Registered portal operators: an entity who is the operator of an electronic interface that facilitates or can facilitate access to the MHR system.

These participants are required to adhere to a set of participation requirements prescribed in the *My Health Records Rule 2016*.

Issues for consideration

The department is interested in feedback on any issues related to the legislative instruments made under the *My Health Records Act 2012*, and potential opportunities for reform to ensure they are fit for purpose to continue to support the operation of the system.

Some issues are discussed below to provide additional context for the operation of the My Health Record system and to prompt consideration of possible areas where revision of the current provisions might be appropriate. The scope of the review is not limited to the issue areas raised in this paper. Respondents are encouraged to consider and respond to the issues raised, as well as to provide feedback on any other provisions to inform this review.

[7] Australian Digital Health Agency, About us, About us

[8] Section 5 Definitions of the *My Health Records Act 2012*, Federal Register of Legislation - My Health Records Act 2012

Relationship between the Healthcare Identifier Service and the My Health Record system

Introduction

Establishing confidence in a person's identity is a critical starting point for delivering a range of government services and benefits. Identity proofing[9] is critical to promote trust and confidence. Identity is a combination of characteristics or attributes that allows a person to be uniquely distinguished from other people within a specific context. To prove our identity, we use attributes or characteristics such as our date and place of birth, our address, and increasingly biometrics, such as an image of our face[10].

The My Health Record (MHR) system relies on the Healthcare Identifier Service (HI Service) to match the relevant attributes of an individual to provide certainty that the right health information is attributed to the right individual. Using healthcare identifiers promotes privacy and security by reducing the need for transmission of individual identifying attributes each time the MHR system is interrogated. An individual healthcare identifier (IHI) is used to match the right information to the right person, to ensure that the right clinical documents are attached to the right record of a MHR recordholder. A healthcare provider organisation that has been assigned a healthcare provider organisation identifier (HPI-O), can register to access MHR for the purposes of providing healthcare, provided they meet the requirements specified in the My Health Records Rules.

The *Healthcare Identifiers Act 2010* (Cth) (HI Act) establishes the HI Service, limits the purposes for which healthcare identifiers may be used and imposes penalties for breaches. The Office of the Australian Information Commissioner (OAIC) has responsibility for oversight of healthcare providers' compliance with the HI Act and Regulations in relation to their handling of healthcare identifiers. The HI Act states that any breach of the HI Act or Regulations in connection with an IHI/HPI-I or identifying information will also be a breach of the *Privacy Act 1988* (Cth). The OAIC handles complaints about the handling of healthcare identifiers and identifying information by healthcare providers and conducts assessments of privacy aspects of the HI Service.

Healthcare identifiers are assigned and administered through the HI Service, currently operated by the Chief Executive Medicare. The My Health Record system uses healthcare identifiers (as opposed to an individual's Medicare number) to provide greater certainty that the right information is attributed to the right individual[11].

[9] The Attorney-General's Department is the lead Commonwealth agency on identity policy. It published the National Identity Proofing Guidelines 2016, which strengthen identity-proofing processes and increase trust through a standardised and transparent national approach.

[10] National Strategy for Identity Resilience, agreed by the Data and Digital Ministers Meeting in June 2023, published August 2023.

[11] Healthcare Identifiers, OAIC, Healthcare identifiers | OAIC

Professional Accreditation

As noted above, healthcare provider organisations are authorised to register to access the My Health Record system if their organisation has been assigned a HPI-O under the HI Act and complies with other My Health Records requirements, including the requirements set out in the My Health Records Rules.

A HPI-I may be assigned to a healthcare provider by a national registration authority where the healthcare provider is a member of a particular health profession and the national registration authority is responsible for registering members of that profession. HPI-Is may also be assigned by the HI Service Operator where the individual healthcare provider meets certain criteria.

At present, the Australian Health Practitioner Regulation Agency (Ahpra) is the national registration authority and assigns HPI-Is to healthcare providers registered with Ahpra under one of the 15 national health profession boards[12], which includes the Aboriginal and Torres Strait Islander Health Practice Board of Australia.

Aboriginal and Torres Strait Islander Health Practitioners and Workers

The programs of study (Cert IV) that are approved[13] by Ahpra for the Aboriginal and Torres Strait Islander Health Practitioner Profession determine HPI-I eligibility. Aboriginal and Torres Strait Islander Health Practitioners who have a qualification from an unapproved education provider are not eligible to register with Ahpra.

The current provisions of the HI Act related to assignment of a HPI-I by the HI Service Operator to health professionals who are not registered with Ahpra, also do not apply to Aboriginal and Torres Strait Islander health practitioners and workers[14].

Further, the effect of section 45 of the MHR Act and rule 19 of the MHR Rule is such that other than shared health summaries and advanced care plans, all records uploaded to an individual's My Health Record must be prepared by an individual healthcare provider who has been assigned a HPI-I. This was intended to ensure that records uploaded are appropriately authored and there is transparency and accountability in relation to records shared to My Health Record.[15] However, the combined operation of the provisions means that health information authored by some Aboriginal and Torres Strait Islander health professionals is not able to be shared to My Health Record.

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[12] List of National Boards, Ahpra, https://www.ahpra.gov.au/National-Boards.aspx

[13] Approved programs of study for Aboriginal and Torres Strait Islander Health Practitioner, Ahpra, Australian Health Practitioner Regulation Agency - Approved Programs of Study

[14] Note the department is currently considering whether to recommend amendments to the HI Act to provide for eligibility to be assigned a HPI-I where a provider meets the definition of an allied health professional for the provision of an allied health service, in Schedule 1 Health Insurance (Section 3C General Medical Services – Allied Health Services) Determination 2024.

[15] Explanatory Memorandum, *Personally Controlled Electronic Health Records Bill 2011*, pp. 25-26; Explanatory Statement, *Personally Controlled Electronic Health Records Act 2012 PCEHR Rules 2012*, p. 17.

Nominated Healthcare Providers

The My Health Records Act currently prescribes a nominated healthcare provider as being an individual who has been assigned an HPI-I and is registered by a registration authority as one of the following health professionals:

- Medical practitioner
- Registered nurse
- An Aboriginal health practitioner, a Torres Strait Islander health practitioner, or an Aboriginal and Torres Strait Islander health practitioner, within the meaning of the National Law, who is included in a class prescribed under the regulations - currently the My Health Records Regulations prescribe individuals who have been awarded a Certificate IV in Aboriginal and/or Torres Strait Islander Primary Health Care (Practice), and
- An individual, or an individual included in a class, prescribed by the regulations – currently no additional professions have been prescribed in the My Health Records Regulations.

At any point in time, only one person can act in the capacity of a nominated healthcare provider for an individual for the purposes of the My Health Records Act. For this relationship to be in force, there must be a mutual agreement between the consumer and the healthcare provider.

The relevance of the nominated healthcare provider is that under the My Health Records Act, a shared health summary can only be prepared by the consumer's nominated healthcare provider. A shared health summary is a clinical record of a consumer at a point in time and can include the following information:

- known allergies and adverse reactions
- current medications
- medical history
- immunisations.

Questions

1. Should rule 19 of the *My Health Records Rule 2016*, which relates to restrictions on uploading certain health information, be reviewed? If so, what amendments would you propose and why? What considerations should guide the review of this rule?

2. Should the definition of a 'nominated healthcare provider' be expanded to include other health professionals involved in patient care (e.g. pharmacists, or enrolled nurses, or midwives who are not registered nurses)? Explain why or why not.

3. Should other health professionals also be able to author a shared health summary? If so, what types of health professionals and why?

4. Do you think that shared health summaries are still relevant as we modernise the MHR system? Explain why or why not and if possible, detail your experience with shared health summaries.

System Operator functions and My Health Record user requirements for Maintaining Interoperability

Introduction

Interoperability is the seamless transfer of information within and between systems and products without requiring special effort from the user. It relies on clear, precise and consistent implementation of standards or specifications[16].

Agreed digital health standards underpin the seamless transfer of information and understanding across the ecosystem. There are various national and international digital health standards, however, Australia lacks a centralised approach to using such standards. Adopting digital health standards is generally voluntary, which has hindered information sharing and integration, resulting in fragmented interoperability.

The My Health Record system is an important tool to overcome the fragmentation of Australia's health system. It enables the sharing of key health information between an individual's healthcare providers, while providing the ability for individuals to control who has access to their record.

The My Health Records legislation establishes a number of requirements to ensure the security and interoperability of the system is maintained and a framework for the Agency to specify conformance requirements to facilitate the sharing of information.

Information and cyber security

Australia is an attractive target for cyber criminals and recent events have brought cyber security to the forefront of the minds of all Australians, especially those who have fallen victim to these crimes. Effective use of data helps Australian citizens get access to goods and services that are tailored to their needs. In the wrong hands, data can allow malicious actors to do harm. It can be held for ransom and used as a tool for coercion and fraud. Mishandling of sensitive and critical datasets can cause grave damage to Australia's national interests.[17]

Healthcare provider organisations who are participants in the My Health Record system must meet and maintain certain obligations in order to operate and remain compliant with the system. Part 5 of the MHR Rule provides for the participation requirements for healthcare provider organisations and contracted service providers and Part 6 sets out the requirements for other operators.

[16] Global Digital Health Partnership (GDHP). https://gdhp.health/work-streams/interoperability/

[17] 2023-2030 Australian Cyber Security Strategy, Department of Home Affairs 2023-2030 Australian Cyber Security Strategy (homeaffairs.gov.au)

Examples of the types of participation requirements include the requirement to have a written security and access policy, in accordance with rule 42 of the MHR Rule. There is a requirement to confirm that such a policy is in place when registering for MHR. The bespoke policy must set out security measures and access requirements to help the healthcare provider organisation to safeguard sensitive patient information by ensuring appropriate access and use of the MHR system[18]. Subrule (4) of rule 42 outlines what must be reasonably addressed in the policy:

- manner of authorising and process for suspending and deactivating user accounts
- training for authorised users, before they access the system
- process for identifying the individual who accesses a person's record (on each occasion)
- physical and information security measures, including user account management processes
- strategies for identifying, responding to, and reporting system-related security risks
- assisted registration (if registered)
- policy implementation and maintenance.

All of the above outlined requirements need to be addressed, unless a healthcare provider organisation chooses to apply subrule (5), which states, if in the reasonable opinion of a healthcare provider organisation, a requirement in subrule (4) is not applicable to the organisation due to the limited size of the organisation, the organisation's policy need not address that requirement. Similar provisions exist for contracted service providers and operators, per rules 47 and 59 respectively.

Healthcare provider organisations failing to maintain a security and access policy would be in breach of rule 42 of the MHR Rule and this may result in the revocation of their registration. Rule 43 of the MHR Rule provides the System Operator with the authority to request the healthcare provider to provide their written policy within 7 days of the request. The MHR Rule also extends the same security requirements to contracted service providers and operators in rules 47 and 59 respectively.

There is also a requirement to maintain interoperability with the MHR system, in accordance with the System Operator's interoperability requirements, per rule 31 of the MHR Rule. Other participation requirements include obligations to notify certain information to the MHR System Operator and to provide assistance to the MHR System Operator on request.

[18] My Health Record participation obligations for healthcare providers, ADHA, My Health Record participation obligations (digitalhealth.gov.au)

Access control mechanisms

The MHR Rule also provides for a series of access controls, some operating by default and other advanced controls that may be set up by individuals. These access controls support individuals to manage the information in, and access to, their My Health Record.

Emergency access function

The emergency access function (the function) exists as an override mechanism when advanced control settings are in place and can be enacted when a registered healthcare provider organisation asserts to the System Operator that the circumstances have been met under paragraph 64(1)(a) of the MHR Act. The emergency access is granted for 5 days. As per rule 7 and 8 of the MHR Rule, the System Operator must permit access to the healthcare recipient's MHR regardless of whether the individual has set up record access or document access codes, if a healthcare provider reasonably believes that:

- it is necessary to lessen or prevent a serious threat to an individual's life, health, or safety, and it is unreasonable or impracticable to obtain the healthcare recipient's consent, or
- it is necessary to lessen or prevent a serious threat to public health or safety.

In each event that this function is used, an organisation must maintain accurate records of the circumstances that triggered the use of the emergency access function, including the circumstances of access and the reasons why it was not reasonable or practicable to obtain the patient's consent[19].

This emergency access (break glass) function acts as a failsafe to ensure healthcare providers can gain timely access to valuable information contained within a MHR in an emergency situation to ensure appropriate care and treatment is provided. It has been identified that some healthcare providers are using this function to gain access to the MHR of their patients in situations that are not emergency related, where their patient has forgotten their access code.

If it has been identified that there has been unauthorised use of the emergency function, healthcare provider organisations are subject to reporting obligations under section 75 of the MHR Act. Consequently, unauthorised use of the emergency access function may be reportable to the Office of the Australian Information Commissioner (OAIC) and the System Operator.

[19] My Health Record emergency access function, OAIC, My Health Record emergency access function | OAIC

Nominated and authorised representatives

Nominated representatives

The MHR system allows recordholders to elect for a family member, friend, carer, or someone else they trust to act as a representative so they can view or help manage their MHR. These representatives are called nominated representatives. Nominated representatives can be invited to act as such by either the recordholder or someone who is an authorised representative for that recordholder and must act in accordance with the recordholder's will and preferences. Invitations are issued with one of three preferred levels of access; however, access levels can be changed at any time[20]:

- General access gives representatives view only access, whereby they can view all documents (excluding those marked 'restricted') and cannot add or alter any information
- Restricted access gives representatives view only access, whereby they can view all documents (including those marked 'restricted') and cannot add or alter any information
- Full access gives representatives access to view all documents (including those marked 'restricted') and information. Certain functions are restricted and nominated representatives with this level of access cannot give another person access to the record, make changes to other representatives on the record, make changes to the recordholder's Medicare information or cancel the record.

Although nominated representatives need to have a myGov[21] account in order to accept an invitation to act as a nominated representative, they do not need to have a MHR of their own. Persons acting in the nominated representative capacity do not need to prove relationship to the recordholder, justify reasons for acting in this capacity or satisfy identity requirements.

Authorised representatives

The function of an authorised representative exists for those who are responsible for managing the affairs of someone who is their dependent. An authorised representative may be someone with parental responsibility, a carer, family member, legal guardian, or someone with enduring power of attorney and must act in accordance with the recordholder's will and preferences. A person with parental responsibility cannot be an authorised representative if, under a court order of Commonwealth, state, or territory law, they must be supervised while spending time with the dependant or if the life, health or safety of the

[20] Nominated representatives, ADHA, Nominated representatives (digitalhealth.gov.au)
[21] myGov is a simple and secure way to access government services online in one place.

dependant or another person would be at risk. Authorised representatives do not need to have a MHR of their own.

An authorised representative is for persons who are:

- under the age of 14, or
- 18 years or older and not capable of making decisions for themselves.

Individuals 14 years or older[22] are responsible for their own MHR. Although Australian law recognises the age of 18 as being the age at which an individual transitions into adulthood, in the health care sphere the generally accepted age of competency and capacity is 14 years. When a child turns 14 years of age, authorised representatives are automatically removed from their record, however, they can choose to provide access as a nominated representative. Difficulties present for the 14- to 17-year-old category in instances where there is a lack of capacity. If a child who has turned 14 lacks capacity to make decisions for themselves, their representative may need to apply to be their authorised representative again. In order to be authorised to act as an authorised representative for persons over the age of 14 who lack capacity to make their owns decisions, the representative must[23]:

- complete the required application form
- provide evidence of relationship
- provide evidence that the person lacks capacity to make their own decisions
- provide evidence to support the authority to act.

While an authorised representative is attached to a record, the recordholder of that record will not be able to access their MHR unless their authorised representative grants them access as a nominated representative.

My Health Record access after recordholder death

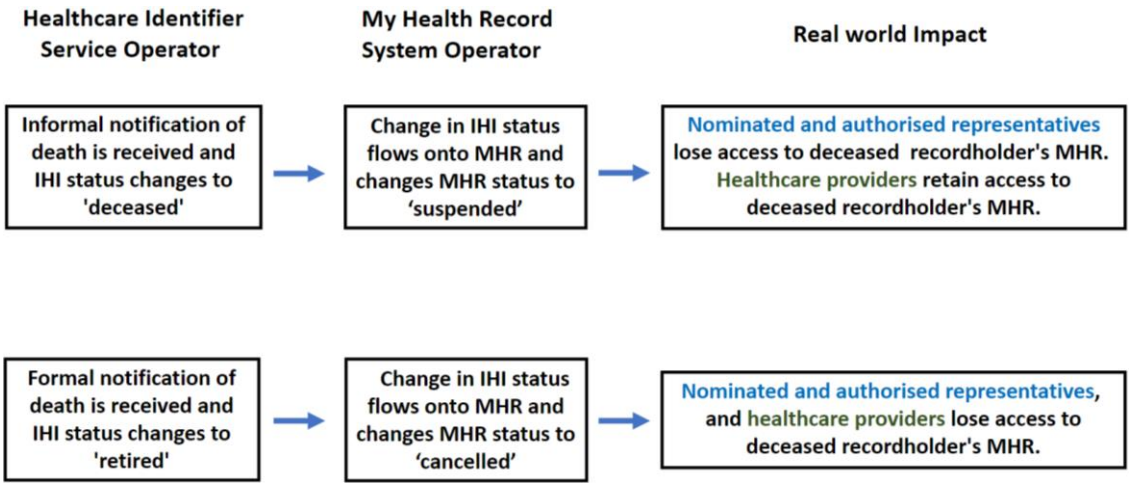
The MHR system is founded on two fundamental principles: that the only legitimate purpose for a healthcare recipient's MHR is to provide healthcare to that recordholder and that a healthcare recipient's MHR is personally controllable by them or their authorised representative. The current MHR legislative and policy framework, including the *Privacy Act 1988* (Cth) (Privacy Act), is explicitly designed to limit access to and disclosure of information from a recordholder's MHR following their death.

[22] *My Health Records Act 2012*, Section 6(3) *Healthcare recipients aged between 14 and 17,* For the purposes of this Act, a person is the ***authorised representative*** of a healthcare recipient aged between 14 and 17 years if the healthcare recipient, by written notice given to the System Operator in the approved form, nominates the person to be his or her authorised representative. Federal Register of Legislation - My Health Records Act 2012

[23] Authorised representatives (digitalhealth.gov.au)

Changes to a healthcare recipient's individual healthcare identifier (IHI) status has consequential impacts to their MHR status. The status of an IHI changes upon notification of an IHI-holder's death, leading to the suspension and subsequent cancellation of their MHR. These changes limit future access to their MHR and the information contained within it (see Figure 1).

Figure 1: Notification of death: IHI status and impact on MHR



When the Service Operator receives informal notification (notification without supporting evidence) of death, this causes the IHI status to change to 'deceased'. This information then flows onto the System Operator, which causes the MHR status to change to 'suspended' as per rule 12 of the MHR Rule. The suspension of the MHR means that all authorised and nominated representatives attached to that MHR will lose all access, however, healthcare providers will continue to retain access at this stage.

When the Service Operator receives formal notification (notification with supporting evidence) of death, this causes the IHI status to change to 'retired'. This information then flows onto the System Operator, which causes the MHR status to change to 'cancelled' as per subsection 51(6) of the MHR Act. The cancellation of the MHR means that all authorised and nominated representatives attached to that MHR, and all healthcare providers will also lose all access.

Cancellation of the registration where a healthcare recipient is deceased does not result in the destruction of the record, or any health information included within it. The operation of subsections 17(2), 17(3) and 51(6) of the MHR Act requires that the System Operator retain the information in the deceased recordholder's MHR for 30 years from the recordholder's death (or 130 years if the date of death is unknown).

Currently, there are limited purposes for access and disclosure of information in a deceased recordholder's MHR, including:

- Coroner's Court submissions to the System Operator to request disclosure of health information contained within a deceased recordholder's MHR[24], and
- Requests from the Auditor-General for Australia, Commonwealth Ombudsman or Australian Information Commissioner for the disclosure of a recordholder's MHR health information for the purpose of executing their functions[25].

Section 55 of the MHR Act provides that the MHR Rule may specify the requirements to which the System Operator or another entity is subject after the registration of a healthcare recipient is cancelled or suspended.

The McMillan Review recommended that consideration be given to whether there should be amendments to the provisions that deal with managing and accessing the MHR of a deceased person. For example, consideration could be given to additional purposes for which an individual or healthcare provider organisation may require to have access to a deceased recordholder's MHR. This could potentially include circumstances where a person is bereaving the loss of their loved one or investigating medical and genetic family history for healthcare purposes.

Questions

5. Are the participation requirements as set out in the *My Health Record Rule 2016* fit for purpose?

6. Do the provisions in the *My Health Records Rule 2016* need to be more specific in their application to cyber security?

7. Are Rules 7 and 8 under the *My Health Records Rule 2016*, which pertain to emergency access, still fit for purpose in their current form?

8. Should authorised and nominated representatives continue to have access to a deceased recordholder's MHR? Explain why or why not.
    a. If access was to be continued, should this apply equally to authorised and nominated representatives? If not, why?
    b. What should that access involve? (e.g. view all or limited information?)
    c. For what purposes should access be granted?
    d. If applicable, for how long should such access be retained?

9. Should nominated healthcare providers and/or other healthcare providers continue to have access to a deceased recordholder's MHR? Explain why or why not.
    a. What should that access involve? (e.g. view all or limited information?)
    b. For what purposes should access be granted?
    c. If applicable, for how long should such access be retained?

[24] *My Health Records Act 2012*, Subsection 69(2) Federal Register of Legislation - My Health Records Act 2012

[25] *My Health Records Act 2012*, Section 65 Federal Register of Legislation - My Health Records Act 2012

Assisted Registration

Registration to the MHR system is now largely automatic, with individuals opting out if they prefer not to participate. Assisted registration is a process for individuals who:

- Previously opted out and now wish to re-register.
- Require assistance with registration due to age or other circumstances.

This process allows a registered healthcare provider organisation to assist a consumer to apply to register for a My Health Record and allows that healthcare provider organisation to submit identifying information to the System Operator on behalf of a consumer who is applying to be:

- registered for a MHR
- an authorised representative of a person aged under 18 years for whom the consumer asserts parental responsibility.

The *Assisted Registration: A guide for Healthcare Provider Organisations*[26] (Assisted registration guide), details that authorised employees of an organisation may choose one of the following processes to identify an individual for the purposes of Assisted Registration:

- individual presents for a consultation and has presented on at least three occasions (inclusive of the presentation at which Assisted Registration is being provided) and the Medicare or DVA card is sighted;
- by meeting another of the 'Known Customer Models'; or
- by providing 100 points of Documentary Evidence of Identity.

If the application is successful, the System Operator will send the individual's Identity Verification Code (IVC) in the manner elected by the individual (text message, email or through the healthcare provider). An IVC will allow the individual to set up online access to their record.

Organisations that choose to provide Assisted Registration must develop, maintain, and enforce an Assisted Registration policy that addresses the four matters specified in subrule 42(4) of the MHR Rule. The policy must be in writing, up-to-date and reviewed at least once a year.

As the digital health ecosystem continues to evolve and become ever more connected, it also brings with it the challenges of ensuring that information contained within a MHR is

[26] The Australian Digital Health Agency published a guide for Healthcare Provider Organisations to navigate through Assisted Registrations. The content from the document is current as of April 2016. MHR Assisted Registration: A guide for Healthcare Provider Organisations

only accessible by those who own the record, unless otherwise authorised by the recordholder. Poor identity security practices in one jurisdiction can be exploited in all others. Australian governments are committed to achieving consistent national standards across jurisdictions, to build trust and confidence in the identity system[27]. The *National Strategy for Identity Resilience*[28] may provide some guidance in relation to any proposal to revise the MHR assisted registration processes.

Parental responsibility

Under the MHR Act, a person is considered to have parental responsibility[29] for a healthcare recipient (the child) if:

(a) the person:
  (i) is the child's parent (including a person who is presumed to be the child's parent because of a presumption (other than in section 69Q) in Subdivision D of Division 12 of Part VII of the *Family Law Act 1975* (Cth) (Family Law Act)); and
  (ii) has not ceased to have parental responsibility for the child because of an order made under the Family Law Act or a law of a State or Territory; or
(b) under a parenting order (within the meaning of the Family Law Act):
  (i) the child is to live with the person; or
  (ii) the child is to spend time with the person; or
  (iii) the person is responsible for the child's long-term or day-to-day care, welfare and development; or
(c) the person is entitled to guardianship or custody of, or access to, the child under a law of the Commonwealth, a State or a Territory.

Note: The presumptions in the Family Law Act include a presumption arising from a court finding that a person is the child's parent, and a presumption arising from a man executing an instrument under law acknowledging that he is the father of the child.

As per rule 8 of the MHR Assisted Registration Rule, before making a declaration to support a healthcare recipient's assertion of parental responsibility for a person, the healthcare provider organisation must exercise reasonable care.

The *Assisted Registration: A guide for Healthcare Provider Organisations*[30] details relationship identification for the assertion of parental responsibility as the following:

- the individual making the application must assert that they have parental responsibility for the child; and
- the child must be listed on the Medicare card of the individual applying; or

[27] National Strategy for Identity Resilience (ag.gov.au)
[28] National Strategy for Identity Resilience (ag.gov.au)
[29] Section 5 Definitions of the *My Health Records Act 2012*, Federal Register of Legislation - My Health Records Act 2012
[30] MHR Assisted Registration: A guide for Healthcare Provider Organisations

- the healthcare organisation must support the person's assertion of parental responsibility.

At any given time, a child can be listed on two Medicare cards. Unless Services Australia is notified of any changes in relationship status, the child will remain on these Medicare cards, allowing assertions of parental responsibility for the purposes of creating a MHR for the child and/or becoming an authorised representative for the child. Further rigour in the process of asserting parental responsibility may be required to avoid instances of inadvertent access to information.

The McMillan Review had recommended that the Assisted Registration Rule could be repealed, on the basis that it is redundant following the implementation of the opt-out model.

Questions

10. Is there an ongoing need for assisted registration?

11. If assisted registration should be retained, should any revisions to the process be considered?

Feedback and Questions

As noted earlier, the department is interested in feedback on any issues related to the legislative instruments made under the My Health Records Act, and potential opportunities for reform to ensure they are fit for purpose to continue to support the operation of the system.

This consultation paper has highlighted a number of issues for consideration. The scope of the review is not limited to the issue areas raised in this paper. Respondents are encouraged to consider and respond to the issues raised, as well as to provide feedback on any other provisions to inform this review.

Throughout this paper, a series of questions were posed. For ease of reference, these questions have been reproduced below.

A number of general questions have also been posed to seek feedback on other issues relevant to the scope of this review.

Specific questions

1. Should rule 19 of the *My Health Records Rule 2016*, which relates to restrictions on uploading certain health information, be reviewed? If so, what amendments would you propose and why? What considerations should guide the review of this rule?

2. Should the definition of a 'nominated healthcare provider' be expanded to include other health professionals involved in patient care (e.g. pharmacists, or enrolled nurses, or midwives who are not registered nurses)? Explain why or why not.

3. Should other health professionals also be able to author a shared health summary? If so, what types of health professionals and why?

4. Do you think that shared health summaries are still relevant as we modernise the MHR system? Explain why or why not and if possible, detail your experience with shared health summaries.

5. Are the participation requirements as set out in the *My Health Records Rule 2016* fit for purpose?

6. Do the provisions in the *My Health Records Rule 2016* need to be more specific in their application to cyber security?

7. Are rules 7 and 8 under the *My Health Records 2016*, which pertains to emergency access, still fit for purpose in their current form?

8. Should authorised and nominated representatives continue to have access to a deceased recordholder's MHR? Explain why or why not.

a. If access was to be continued, should this apply equally to authorised and nominated representatives? If not, why?
b. What should that access involve? (e.g. view all or limited information?)
c. For what purposes should access be granted?
d. If applicable, for how long should such access be retained?

9. Should nominated healthcare providers and/or other healthcare providers continue to have access to a deceased recordholder's MHR? Explain why or why not.
    a. What should that access involve? (e.g. view all or limited information?)
    b. For what purposes should access be granted?
    c. If applicable, for how long should such access be retained?

10. Is there an ongoing need for assisted registration?

11. If assisted registration is to be retained, should any revisions to the process be considered?

General questions

12. Are there any instruments that you believe are no longer fit for purpose, necessary or require revision? If yes, please explain reasoning.

13. Are there any specific provisions in the instruments that you believe are no longer fit for purpose, necessary or require revision to better support the operation of the MHR system? If yes, please explain reasoning.

14. Are there any issues that you would like to address that have not been covered by any other questions? If yes, please explain reasoning.

15. Do you have any concerns or comments about the *My Health Records (National Application) Rules 2017* being repealed and remade into a new instrument with alignment of the other instruments?

16. Do you have any other comments related to the scope of the review?

17. Do you have any overall feedback or comments about the operation of the MHR system?

Note that while this review is focused on the operation of the legislative instruments made under the My Health Records Act, there is opportunity to provide feedback on broader issues related to the operation of the MHR system. There will be further opportunities for consultation on the broader digital health landscape, including the My Health Records Act, however you are welcome to provide preliminary thoughts as part of this review process and such considerations will inform a subsequent phase of review of the My Health Records Act.