

EXPLANATORY STATEMENT

Issued by Authority of the Minister for Health

My Health Records Act 2012

My Health Records Amendment (Advance Care Planning Information and Professional Representatives) Rule 2016

The *My Health Records Act 2012* (the Act) enables the establishment of the My Health Record system to provide individuals and their healthcare providers with access to key health information online where and when they need it. Section 109 of the Act provides that the Minister may make rules, known as My Health Records Rules, about matters that are required or permitted by the Act to be dealt with in the My Health Record Rules.

The *My Health Records Rule 2016* (the Rules) prescribes rules relating to the operation of the My Health Record system, such as the nature of records that can be uploaded to the system and the operation of access arrangements to the system. The Rules are part of a suite of My Health Records Rules, including the *My Health Records (Assisted Registration) Rule 2015* and *My Health Records (Opt-out Trials) Rule 2016*, made by the Minister to support the operation of the system.

The Rules do not relate to the professional activities of healthcare providers. Professional obligations and professional bodies exist for this purpose. The Rules only regulate matters necessary to ensure the efficient and secure operations of the My Health Record system, and the other purposes permitted by section 109 of the Act.

The purpose of the *My Health Records Amendment (Advance Care Planning Information and Professional Representatives) Rule 2016* (the Amendment Rule) is to amend the Rules to:

- permit advance care planning information that is not prepared by a healthcare provider to be uploaded to the My Health Record system – all other documents uploaded to the system must be prepared by a healthcare provider; and
- permit care agencies employees to act as authorised representatives and nominated representatives (with full access) for individuals without the need to provide an Individual Healthcare Identifier (IHI) – generally, a person must provide their IHI in order to become an authorised or nominated (full access) representative and act on behalf of another person.

Advance care planning information

Healthcare provider organisations are not permitted to upload to the My Health Record system any documents unless they have been prepared by a healthcare provider. The Amendment Rule will permit healthcare provider organisations to upload advance care planning information that is prepared by an individual or someone acting on their behalf (such as by a lawyer), at the individual's request.

A healthcare provider organisation that uploads advance care planning information must comply with the My Health Records Rules. Paragraph 43(b) of the Act provides that healthcare provider organisations are not eligible to be registered to participate in the My Health Record system unless, among other things, they comply with the My Health Records Rules.

Subsection 51(3) of the Act provides that failure to comply with the My Health Records Rules (including this Amendment Rule) may result in a decision of the System Operator to cancel or suspend the registration of a healthcare provider organisation. Further, section 78 of the Act provides that a healthcare provider organisation, regardless of whether they are still registered, may be subject to a civil penalty of up to 100 penalty units (\$18,000 for individuals or \$90,000 for bodies corporate) if they contravene the My Health Records Rules.

Care agency employees

Sections 6 and 7 of the Act provide that other people can act on behalf of children, people who are unable to manage their own My Health Record, and people who need or want assistance in managing their My Health Record, to manage (or help manage) their My Health Record – these people are known as *authorised representatives* and *nominated representatives*. A person cannot be an authorised or a nominated representative (with full access to the My Health Record) unless they have a healthcare identifier.

The Amendment Rule provides that people who act on behalf of other people as a result of their employment (*professional representatives*), such as for children in out of home care, do not need a healthcare identifier to become authorised or nominated representatives (with full access).

A professional representative who is an authorised or nominated representative is required to act in accordance with the will and preferences of the person they represent in accordance with section 7A of the Act.

The System Operator may suspend or cancel the status of a person as an authorised or nominated representative, and therefore their ability to manage the My Health Record of the person they represent, if the System Operator finds that the representative is not acting in accordance with the will and preferences of the person they represent or they pose a serious risk to the person they represent.

Detail of the Amendment Rule is set out in the Attachment.

Section 109 of the Act requires that, before making My Health Record Rules, the Minister must consult the Jurisdictional Advisory Committee and Independent Advisory Council, although failure to consult these committees does not affect the validity of the My Health Record Rules.

In November 2015 and January 2016 the Independent Advisory Council and the Jurisdictional Advisory Committee were consulted on the proposed Amendment Rule and supported the Amendment Rule. The Australian Health Ministers' Advisory Council was also consulted and it agreed to the Amendment Rule.

The Amendment Rule commences on the day after registration on the Federal Register of Legislative Instruments.

The Rule is a legislative instrument for the purposes of the *Legislative Instruments Act 2003*.

ATTACHMENT**Details of the *My Health Records (Advance Care Planning Information and Professional Representatives) Rule 2016*****PART 1—PRELIMINARY****1. Name of Rule**

Rule 1 provides that the title of the rule is the *My Health Records Amendment (Advance Care Planning Information and Professional Representatives) Rule 2016*. In this explanatory statement it is referred to as the Amendment Rule.

2. Commencement

Rule 2 provides that the Amendment Rule will take effect and amend the *My Health Records Rule 2016* on the day after it is registered on the Federal Register of Legislative Instruments.

3. Amendment of *My Health Records Rule 2016*

Rule 3 provides that Schedule 1 amends the *My Health Records Rule 2016* (the Rules).

SCHEDULE 1—AMENDMENTS**[1] Rule 4**

Rule 4 defines particular terms used in the Rules. Item 1 inserts the following new definitions into Rule 4:

- *advance care planning information* – this means a document prepared by, or on behalf of, an individual that states the individual’s preferences about their health and personal care and preferred health outcomes. This definition is consistent with the *Advance Care Directives Framework September 2011*, as indicated by the Note to this definition, in reflecting the nature of advance care planning information around Australia; and
- *professional representative* – this definition establishes a type of person who is eligible to become an authorised representative and nominated representative for the purposes of new rules 24A and 24B (item 5 refers). It specifically refers to people who act on behalf of other people as a result of their employment.

[2] Paragraph 6(2)(a)

Rules 5 and 6 set out the default and advanced access control settings that the System Operator must make available for individuals to manage access to their My Health Record.

Subrule 6(2) provides the ability for individuals to restrict access to their My Health Record as a whole, or to individual documents in their My Health Record. However, paragraph 6(2)(a) provides that there are some types of records to which individuals cannot restrict access – specifically shared health summaries (prepared by their nominated healthcare provider) or the health summaries they have created themselves. Individuals can still restrict

access to other types of documents such as specialist letters, discharge summaries or pathology test results.

This is intended to ensure that there is a minimum of key health information available in a My Health Record.

To reflect the new capability to upload advance care planning information (item 3 refers), item 2 inserts into paragraph 6(2)(a) of the Rules another type of document to which an individual cannot restrict access – advance care planning information. This type of information is critical in ensuring the preferences of the individual about their health and personal care (such as advance care directives) are available to any treating healthcare provider.

[3] Rule 19

Paragraph 45(b)(ii) of the Act places a condition on the registration of healthcare provider organisations that they must not upload documents to the My Health Record if they are of a kind specified by the Rules, unless it has been prepared by an individual healthcare provider who has been assigned a healthcare identifier under paragraph 9(1)(a) of the *Healthcare Identifiers Act 2010*. This type of identifier is known as a Healthcare Provider Identifier – Individual (HPI-I).

Rule 19 provides that all documents are specified for the purpose of paragraph 45(b)(ii) of the Act, other than shared health summaries (which are subject to separate restrictions as specified in section 10 of the Act, including that they must be prepared by an individual healthcare provider with an HPI-I). This means that healthcare provider organisations cannot upload any document to the My Health Record system unless it has been prepared by an individual healthcare provider with an HPI-I.

Item 3 repeals this Rule and replaces it with a new Rule 19 that provides that advance care planning information (i.e. information prepared by an individual or someone acting on their behalf relating to their future healthcare or health decisions) is not specified for the purpose of paragraph 45(b)(ii) of the Act. This means that healthcare provider organisations may upload to the My Health Record system these types of documents, even though they haven't been prepared by a healthcare provider with an HPI-I.

Healthcare provider organisations can only upload these documents at the request of the individual (or their authorised or nominated representative) (item 6 refers).

Note 1 to new Rule 19 makes clear to readers that the Act imposes restrictions on the uploading of documents to the My Health Record system.

Note 2 helps readers to understand that healthcare provider organisations are already authorised to upload clinical documents that may be advance care planning information, if they are prepared by a healthcare provider with an HPI-I, such as clinical care plans.

[4] Subrule 13(4)

Rule 13 requires the System Operator to cancel the access of an authorised representative to an individual's My Health Record if they die, are no longer eligible to be an authorised representative (such as where they no longer have the necessary legal authority to do so or are

not acting in accordance with the will and preferences of the person they represent), or have notified the System Operator that they no longer wish to be an authorised representative.

As part of managing an individual's My Health Record, an authorised representative may appoint other people to be nominated representatives and have access (full or read-only) to the individual's My Health Record.

Subrule 13(4) requires the System Operator to cancel a nominated representative's access to an individual's My Health Record if they were appointed by an authorised representative whose access to that My Health Record is being suspended or cancelled.

Item 4 repeals this subrule and replaces it with new subrules 13(4) and (5). Subrule 13(4) still requires the System Operator to cancel access by nominated representatives who are appointed by an authorised representative whose own access is being suspended or cancelled. However subrule 13(5) provides an exception to this requirement in the case of nominated representatives who have been appointed by an authorised representative who is a professional representative (i.e. people who act on behalf of other people as a result of their employment).

As a result of the addition of new Part 4A (item 5 refers), a person who acts on behalf of another person as a result of their employment can become an authorised representative without a healthcare identifier – these people are known as *professional representatives*. New subrule 13(5) therefore means that if:

- a nominated representative has been appointed by an authorised representative who is a professional representative;
- that authorised representative's access to a My Health Record is being suspended or cancelled; and
- there is another authorised representative who is a professional representative from the same employer with access to the My Health Record,

the System Operator is not required to cancel that nominated representative's access to the My Health Record.

This is intended to recognise that the responsibilities of care agency employees may regularly change – such as being assigned to represent different children – and it would pose a significant burden on these agencies to have to reinstate access for nominated representatives as a result of employee changes when the agency continues to have overall responsibility for a person.

[5] After Part 4

Subsection 6(6) of the Act provides that a person cannot be an authorised representative unless they have a healthcare identifier (an Individual Healthcare Identifier or an IHI) (paragraph 6(6)(a)), or the My Health Records Rules make an exception (paragraph 6(6)(b)). Similarly, subsection 7(3) of the Act provides that a person cannot be a nominated representative with full access unless they have an IHI (paragraph 7(3)(a)), or the My Health Records Rules make an exception (paragraph 7(3)(b)).

The IHI is required in these settings to enable the System Operator to verify the identity of an authorised or nominated representative, both at the time they become an authorised or nominated representative or any subsequent occasion they access the My Health Record of the person they represent.

Item 5 inserts new Part 4A for the purpose of making an exception as provided by paragraphs 6(6)(b) and 7(3)(b) of the Act.

New Part 4A provides a class of persons who may be authorised representatives and nominated representatives without an IHI. This type of person is known as a *professional representative* (defined by item 1).

There are various types of agencies that are responsible for providing services specifically to care for minors (such as children under the guardianship of a state) or mature individuals who do not have capacity. Employees in these agencies, referred to as care agencies, have specific responsibilities to act on behalf of these people in health and other matters.

A key purpose of healthcare identifiers is to identify the person for the purposes of providing healthcare. While it is acceptable to use an IHI to verify a representative's identity in a personal setting since they are likely a family member or close friend of the person they are voluntarily representing, it is considered inappropriate for employees of care agencies (whose duties require them to act for another person) to use their personal IHI for identity verification purposes in a professional capacity.

As a result, these care agency employees are currently unable to participate in the My Health Record system to either register, or manage the My Health Record of, the person they represent.

To allow these care agency employees to participate in the system for the people they represent, new Part 4A establishes an exception so they do not need an IHI to become either an authorised representative (new rule 24A) or a nominated representative with full access (new rule 24B).

This exception will operate as part of broader contractual arrangements with the My Health Record system. Care agencies who wish their employees to be able to become the authorised and/or nominated representatives of people they represent will need to enter into a contract with the System Operator. This contract will impose obligations on the agencies which relate to, among other things, security and identity verification (thereby taking the place of the IHI).

[6] After Rule 32

Item 6 inserts new Rule 32A into the Rules.

New Rule 19 (item 3 refers) provides that healthcare provider organisations may upload advance care planning information to the My Health Record, if it is prepared by the individual or someone acting on their behalf.

Further to new Rule 19, new Rule 32A provides the conditions that healthcare provider organisations can only upload advance care planning information to the My Health Record system if the individual (or their authorised or nominated representative) instructs them to do so.

Individuals will be able to upload non-clinical advance care planning information, such as advance care directives and substitute decision-maker documents, to their My Health Record. However some individuals may not have the ability or access to do this. These individuals will be able to seek their healthcare provider's assistance in uploading this information, and new Rule 32A in conjunction with new Rule 19 (item 3 refers) allows the healthcare provider to do this.

It is important to note that there is no obligation on healthcare providers to upload advance care planning information, that is prepared by an individual or someone acting on their behalf, to the My Health Record system – this decision is at the healthcare provider's discretion.

Some types of advance care planning information are clinical in nature and are prepared by a healthcare provider rather than an individual. Healthcare providers are already permitted to upload this information to the My Health Record system without the need for the individual to instruct them to do so. This is unchanged by the Amendment Rule.

Statement of Compatibility with Human Rights

Prepared in accordance with Part 3 of the Human Rights (Parliamentary Scrutiny) Act 2011

My Health Records Amendment (Advance Care Planning Information and Professional Representatives) Rule 2016

This Legislative Instrument is compatible with the human rights and freedoms recognised or declared in the international instruments listed in section 3 of the *Human Rights (Parliamentary Scrutiny) Act 2011*.

Overview of the Legislative Instrument

The Legislative Instrument amends the *My Health Records Rule 2016*, which is part of a collection of rules that provide the detail necessary to support the operation of My Health Record system, as established by the *My Health Records Act 2012*.

The Legislative Instrument, in summary, makes amendments that:

- permit advance care planning information that is not prepared by a healthcare provider to be uploaded to the My Health Record system – all other documents uploaded to the system must be prepared by a healthcare provider; and
- permit care agencies employees to act as authorised representatives and nominated representatives (with full access) for individuals without the need to provide an Individual Healthcare Identifier (IHI) – generally, a person must provide their IHI in order to become an authorised or nominated (full access) representative and act on behalf of another person.

Human rights implications

The Legislative Instrument engages the following human rights and freedoms:

Right to health

Article 12(1) of the *International Covenant on Economic, Social and Cultural Rights* provides for the right to the enjoyment of the highest attainable standard of physical and mental health.

The My Health Record system and this Legislative Instrument promote the right to health by facilitating and improving the sharing of health information between treating healthcare providers, leading to quicker and safer treatment decisions and reducing repetition of information for patients and duplication of tests. These benefits can be realised sooner with greater participation of individuals and healthcare providers to interact with the My Health Record system, and the Legislative Instrument encourages participation of a greater number of individuals through the changes to professional representatives and additional functionality of the My Health Record system. Individuals are provided ready access to their own information, empowering them to make informed decisions about their healthcare.

The Legislative Instrument promotes the right to health by enabling a healthcare recipient, or a representative or lawyer acting on behalf of the healthcare recipient, to prepare a document that states the preferences about her or his health and personal care and preferred health

outcomes. Without limiting the preparation of an advance care document to an identified healthcare provider, the healthcare recipient has greater control of her or his healthcare.

The Legislative Instrument also helps vulnerable people, such as children in care, to interact with the My Health Record system by allowing certain types of people (known as *professional representatives*), who act on behalf of another person as a result of their employment, to become authorised and nominated representatives without having to satisfy the requirement to have an IHI. Without this Legislative Instrument, it is assumed the provision of care to vulnerable people would be more limited than if access for professional representatives without an IHI was allowed. This change to representatives will increase the number of vulnerable people who can have a My Health Record and will allow them to access the benefits available through the My Health Record system.

Conclusion

This Legislative Instrument is compatible with the human rights and freedoms recognised or declared in the international instruments listed in section 3 of the *Human Rights (Parliamentary Scrutiny) Act 2011*.

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Minister for Health