

EXPLANATORY STATEMENT

Issued by Authority of the Minister for Health

My Health Records Act 2012

My Health Records (National Application) Amendment (Extension of Opt-out Period No. 2) Rules 2018

The *My Health Records Act 2012* (the Act) enabled the establishment of the My Health Record system (formerly referred to as the personally controlled electronic health record or PCEHR system). The My Health Record system allows people and their healthcare providers to access their key health information online where and when they need it. A My Health Record is an electronic summary of a person's health records.

The My Health Record system operated on an opt-in basis from July 2012 which meant that a person needed to register in order to get a My Health Record. The *My Health Records (National Application) Rules 2017* (the National Opt-out Rules) implemented an opt-out model so that people no longer need to register; instead a My Health Record is created for every eligible person unless they choose not to have one (i.e. opt-out).

The National Opt-out Rules, as made, provided that the period in which people can choose to opt-out was three months from a date prescribed by the Minister for Health. On 25 March 2018 the Hon. Greg Hunt MP, Minister for Health, prescribed that opt-out period would commence on 16 July 2018. On 9 August 2018 the Minister for Health extended the opt-out period to four months to provide additional time for consumers to be informed about the My Health Record system and their right to opt-out.

The purpose of the *My Health Records (National Application) Amendment (Extension of Opt-out Period No. 2) Rules 2018* (the Amendment Rule) is to amend the National Opt-out Rules to further extend the opt-out period so that it ends on 31 January 2019. This means that people will have until 31 January 2019 to opt-out of having a My Health Record.

The Amendment Rule is made under section 109 of the *My Health Records Act 2012*.

The extension of the opt-out period will provide additional time for consumers to be informed about the My Health Record system and their right to opt-out.

Detail of the Amendment Rule is set out in the [Attachment](#).

Subsection 109(2) of the *My Health Records Act 2012* provides that before making My Health Records Rules, the Minister must consult with the Australian Health Ministers' Advisory Council (AHMAC) and the System Operator (i.e. the Australian Digital Health Agency). The System Operator and AHMAC were consulted on 14 November 2018 and were supportive of the proposed change.

The Amendment Rule commences on the day after it is registered on the Federal Register of Legislation.

The Amendment Rule is a legislative instrument and is subject to the *Legislation Act 2003*.

Details of the *My Health Records (National Application) Amendment (Extension of Opt-out Period No. 2) Rules 2018*

1 Name of Rules

Rule 1 provides that the title of the Amendment Rule is the *My Health Records (National Application) Amendment (Extension of Opt-out Period No. 2) Rules 2018*.

2 Commencement

Rule 2 provides that the Amendment Rule will commence on the day after it is registered on the Federal Register of Legislation.

3 Authority

Rule 3 identifies that the legal authority for making the Amendment Rule is provided under section 109 of the *My Health Records Act 2012*.

4 Schedules

Each instrument that is specified in a Schedule to this Amendment Rule is amended or repealed as set out in the applicable items in the Schedule concerned, and any other item has effect according to its terms.

SCHEDULE 1 – AMENDMENTS

My Health Records (National Application) Rules 2017

Item 1 Paragraph 6(3)(b)

Paragraph 6(3)(b) of the National Opt-out Rules currently specifies that the opt-out period during which a consumer must give notice if they do not want a My Health Record created for them is four months. The opt-out period began on 16 July 2018 as specified by the *My Health Records (National Application) Commencement Instrument 2018*. This means the opt-out period currently ends on 15 November 2018.

Item 1 amends paragraph 6(3)(b) to extend the opt-out period so that it will end on 31 January 2019.

Statement of Compatibility with Human Rights

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

My Health Records (National Application) Amendment (Extension of Opt-out Period No. 2) Rules 2018

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 is made under section 109 of the *My Health Records Act 2012*.

The purpose of the *My Health Records (National Application) Amendment (Extension of Opt-out Period No. 2) Rules 2018* is to extend the opt-out period so that it will end on 31 January 2019 instead of 15 November 2018.

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 promotes 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. Consumers are provided ready access to their own information, empowering them to make informed decisions about their healthcare.

Having a My Health Record is likely to improve health outcomes, making getting the right treatment faster, safer, easier and more cost-effective:

- faster – because doctors and nurses and other healthcare providers will not have to spend time searching for past treatment information;
- safer – because authorised healthcare providers can view a consumer’s important health care information, including any allergies and vaccinations and the treatment the consumer has received;
- easier – because consumers will not have to remember the results of tests they have had, or all the medication they have been prescribed; and
- more cost-effective – because healthcare providers won’t have to order duplicate tests – for example, when a consumer visits a different general practitioner whilst on holidays. The time necessary to provide treatment may also be reduced as a consumer’s health information will be available in one place. As a result, the cost of treatment may be reduced, freeing up funds for improving health outcomes in other areas.

The current system provides a four month opt-out period, enabling consumers to make an informed choice as to whether they want a My Health Record or not.

The Legislative Instrument extends the opt-out period to 31 January 2019, allowing more time for consumers to be informed about the My Health Record system and their right to opt-out, and to decide whether to opt-out. It is anticipated that allowing more time for consumers to develop a well-informed decision will increase uptake and meaningful use of the My Health Record system with the aim of achieving a greater standard of physical and mental health for all Australians.

Protection of privacy and reputation

Article 17 of the *International Covenant on Civil and Political Rights* prohibits unlawful or arbitrary interference with a person's privacy and unlawful attacks on a person's reputation. This right is also reflected in Article 22 of the *Convention on the Rights of Persons with Disabilities* and Article 16 of the *Convention on the Rights of the Child*.

The right to privacy encompasses respect for informational privacy, including the right to respect the storing, use and sharing of private information and the right to control the dissemination of private information. The Legislative Instrument engages the right to privacy by prescribing an opt-out period of six and a half months for all eligible people to choose not to have a My Health Record created for them.

The Legislative Instrument, the *My Health Records (National Application) Rules 2017* and the Act together counterbalance any limitation of the right to privacy by providing an opportunity for every consumer (or their representative) across Australia to opt-out so that a My Health Record is not created for them. The Legislative instrument extends the period in which consumers can choose to opt-out, ensuring sufficient time is provided to establish a well-informed decision. Consumers who opt-out may later apply for registration, should they change their mind. Alternatively, consumers who do not opt-out and are registered are able to take advantage of a wide range of privacy protections, or may cancel their My Health Record.

Communication activities over the opt-out period includes thousands of face-to-face briefings at community events around the country, distribution of collateral through consumer peak organisations, and the provision of information at the point of care and other community places such as doctors' surgeries, hospitals, libraries and post offices.

A consumer can opt-out by going online to the opt-out portal, or by calling the helpline on 1800 723 471 (free call). These channels became available on 16 July 2018 when the opt-out period commenced. A consumer simply needs to identify themselves and, if applicable, their children or dependents in order to opt-out.

If a consumer chooses not to opt-out, a My Health Record will be created for them and they will be able to exercise their rights to control how their information is collected, used and disclosed.

They will be able to:

- set access controls restricting access to their My Health Record entirely or restricting access to certain information in their My Health Record – for example, they can set an access code so that a healthcare provider organisation can only access the My Health Record if they have been given this code;

- request that their healthcare provider not upload certain information or documents to their My Health Record, in which case the healthcare provider will be required not to upload that information or those documents;
- request that their Medicare data not be included in their My Health Record, in which case the Chief Executive Medicare will be required to not make the data available to the System Operator;
- monitor activity in relation to their My Health Record using the audit log or via electronic messages alerting them that someone has accessed their My Health Record;
- effectively remove documents from their My Health Record;
- make a complaint if they consider there has been a breach of privacy; and
- cancel their My Health Record.

Consumers can set these access controls online or over the telephone.

If a consumer decides that they no longer want a My Health Record, they can choose to cancel their record at any time. This can be done online via the consumer portal, by calling the helpline on 1800 723 471 (free call), or by visiting a Department of Human Services Medicare service centre.

In an opt-out setting, health information is not automatically uploaded to a My Health Record. When a My Health Record is created, the only information that may be included is information held by Medicare, specifically two years' of Medicare and Pharmaceutical Benefits claiming information, Australian Organ Donation Register information and Australian Immunisation Register information. A consumer can choose not to include this information.

Conclusion

The Legislative Instrument is compatible with human rights because it advances the right to health. Any limitation of the right to privacy is proportionate, necessary and reasonable to achieving improved healthcare for Australians.