MULTIPLE SCLEROSIS AUSTRALIA

Submission to the Senate Standing Committee on Community Affairs inquiry into the My Health Record system.

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About Multiple Sclerosis Australia

MS Australia (MSA) is the national peak body for people living with multiple sclerosis (MS) in Australia. Our role is to work on behalf of all state and territory based member organisations to provide a voice for people living with multiple sclerosis across the country to support the development of:

- Research
- Advocacy and awareness
- Communication and information
- Services provided by our member organisations
- International collaboration

MSA advocates across all stakeholders, governments and communities, on behalf of our members, to represent people who are diagnosed with MS, their carers and the broader MS community.

Our Vision

Is consistent with the vision of the Multiple Sclerosis International Federation – **'A world without MS'**

Our Mission

MSA will support our members and work towards meeting the needs of people with MS, their families and carers. We will facilitate a national comprehensive representation of the Member organisations through advocacy and communication.

Our Purpose

On behalf of our members and people with MS, our purpose is to develop:

- **Research:**
  Supporting ongoing research to pursue further knowledge in targeting prevention, improving treatment, enhancing quality of life and ultimately, to find a cure.
- **Advocacy and Awareness:**
  Although MS impacts people differently, there are common, fundamental issues for people affected by the disease. We are steadfastly committed to giving these people a voice and remain willing and able to work with government and the Australian society to champion issues in a dynamic policy environment to bring about change to the lives of people living with MS.
- **Communication and Information:**
  Utilising traditional, contemporary and innovative channels to source information and share it with people with MS, our member organisations and our key stakeholders.
- **Support for our member organisations:**
  As MS specialists providing and facilitating high quality services that span the life-time needs of people affected by MS and other degenerative neurological conditions, their families and carers – from the point of early symptoms and pre-diagnosis, that addresses their changing needs.
- **International Collaboration:**
  Representing the MS cause and promoting collaboration with our domestic and international partners.

Introduction

MS Australia (MSA) is pleased to provide a submission to the Senate Standing Committee on Community Affairs inquiry into the My Health Record system.

The focus of the comments provided in this submission are on key areas that will impact on people affected by MS.

Our submission is framed around the following inquiry terms of reference:

a. the expected benefits of the My Health Record system;
b. the decision to shift from opt-in to opt-out;
c. privacy and security, including concerns regarding:
    i. the vulnerability of the system to unauthorised access,
    ii. the arrangements for third party access by law enforcement, government agencies, researchers and commercial interests, and
    iii. arrangements to exclude third party access arrangements to include any other party, including health or life insurers;
d. the Government's administration of the My Health Record system roll-out, including:
    i. the public information campaign, and
    ii. the prevalence of 'informed consent' amongst users; and
e. measures that are necessary to address community privacy concerns in the My Health Record system.

The expected benefits of the My Health Record system

MS is a debilitating disease of the central nervous system (specifically the brain, spinal cord and optic nerves). It is the most common chronic neurological condition affecting young adults in Australia. The average age of diagnosis is between 20 and 40 years of age, and 75% of people diagnosed are women.

The progress, severity and specific symptoms of MS cannot be predicted. MS is a lifelong disease for which a cause and cure are yet to be found. People often experience a complex set of symptoms and MS can sometimes be difficult to diagnose, requiring a series of tests and examinations.

People with MS typically have large set of medical records to manage consisting of test results, medications and treatments, sometimes over the course of many years as the disease progresses.

As stated in the MSA news item dated 16 July 2018, we feel that the My Health Record system has many potential benefits for the MS community including:

- a centralised health record so that people with MS don't have to continually explain the complexities of their symptoms, medications, MRI and other test results over and over to health professionals at accident and emergency or when visiting a new doctor.
- A useful tool to empower consumers to make decisions about their healthcare and manage their MS with their health team.

- A potential time and energy-saver so consumers can focus on their day to day life, health and wellbeing – it's sometimes hard for people to remember the smallest things, let alone their health/medication details!
- A way to share information with the people closest to the person with MS e.g. family, carers and healthcare professionals.

In short, we believe that this new system has many advantages for people with MS as it will consolidate all of their medical records in the one place, enable consumers to access them, and save people having to remember details or keep their own records – great for those travelling/working interstate or changing doctors or medications.

The decision to shift from opt-in to opt-out

MSA supported this decision, and endorsed several points raised in two Consumers Health Forum of Australia media releases (16/7/18) and (19/7/18), which we consider relevant to the MS community, including:

- *The advantages of a single electronic health record are significant particularly for those with complex and chronic conditions…*
- *…our health information concerning medical treatment, medicines, tests, scans and hospital care still often remains widely scattered and not immediately available in the way we take for granted in other spheres, such as banking and travel.*
- *Prompt access to a complete and current health record is particularly important for those with complex and chronic conditions requiring a range of different treatments and medicines, often urgently.*

We believe that the shift to opt-out will ensure that MHRs are created for more people, which will ultimately lead to a more robust and reliable system that all Australians are familiar with. This has the further potential for more people to become involved with, and take control of, their own health outcomes. Once the MHR system is better understood, it will become more universal, and through regular use, a routine part of health care.

Privacy and security, including concerns regarding:

i. **the vulnerability of the system to unauthorised access,**
ii. **the arrangements for third party access by law enforcement, government agencies, researchers and commercial interests, and**
iii. **arrangements to exclude third party access arrangements to include any other party, including health or life insurers**

As stated in the most recent news item in the attachment to this submission, the concerns expressed by consumers in particular about the security of their information and who has control over it need to be further addressed by the Australian Government and its Agency. It is important to note that the Australian Government has reported the MHR has not been breached within its current six years of operation and undergoes constant surveillance and threat testing. In general, the security is much higher than that of the local GP or specialist, where consumer information will continue to be held.

The Government's administration of the My Health Record system roll-out, including:

i. **the public information campaign, and**
ii. **the prevalence of 'informed consent' amongst users;**

The MHR public information campaign has been followed closely by MS Australia and we produced three news items on the roll-out, which are set out in the attachment along with associated messages on our social media channels. Whilst we did not receive overwhelming response to these informative news items, we did receive both positive and negative feedback, indicating that there was, and probably still is, some work to be done via the MHR public information campaign, for the broader community to more clearly understand the benefits of the MHR system and the ways individuals can control the information in their own records.

It would be disappointing if large sections of the community make the decision to opt out, without having made an informed decision using all of the information available, regarding the benefits and risks as they apply to their own individual circumstances.

Measures that are necessary to address community privacy concerns in the My Health Record system

Our analysis of the check and balances in place under the MHR system indicates that there are adequate measures in place to address individual privacy concerns, though these are perhaps still not widely understood in the broader community.

We hoped to address some of the privacy concerns in the MS community in the news item attached where we have suggested that "it is entirely appropriate to have a discussion with your GP about what information should be uploaded that would be relevant to your future healthcare. It is important to ensure that the health summary held by your GP is accurate and does not contain any information that you do not want included."

We would hope that as more people access their own MHR and become familiar with the ways they can manage their own records, many of the current concerns will be addressed.

KEY FACTS ABOUT MS:

- Multiple sclerosis (MS) is a neurological condition affecting the central nervous system (brain and spinal cord) that affects more than 25,600 people throughout Australia
- It is the most common chronic neurological condition diagnosed in young adults.
- MS is most commonly diagnosed between the ages of 20 and 40
- 75% of people diagnosed are women.
- MS varies significantly from person to person. For some people, it is a disease that comes and goes in severity with periods of unpredictable relapse and remission. For others it means a progressive decline over time. For all, it is life changing.
- Symptoms vary between people and can come and go; they can include severe pain, walking difficulties, debilitating fatigue, partial blindness and thinking and memory problems.
- There is no known cause or cure.

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Attachment

MS AUSTRALIA NEWS ITEM – THURSDAY 13 AUGUST 2018

My Health Record for people with multiple sclerosis: information to make an informed decision.

The Australian Government has announced that in 2018, every Australian will get a My Health Record (MHR) unless they opt out. If you don't want a MHR you have until 15 November to visit the MHR web-site to follow the 'opt out' process.

Before making the decision whether to opt out or not, it is worth finding out more about MHR so that you can make an informed decision.

There is a long history that has brought us to this point in the life of MHR. Since at least the 1990's an enormous amount of effort has gone into developing a secure electronic health record system for Australians. In fact, an opt-in personally controlled electronic health record has been available since 2012. Almost 6 million people have signed up for the record since then, mostly by invitation from their general practitioner. What has become clear is that to realise the benefits of the electronic health record it needs to be better understood, become more universal, and through regular use, a routine part of health care.

The strength of MHR lies in its opportunity to have a person's key health information in one place allowing individuals, their doctors and other health professionals to have ready access to information about their healthcare. This is important for people with MS who often see multiple health care providers, and particularly when moving to another region or specialist. The information contained within the MHR will have enormous value in assisting individuals and their healthcare professionals to be well informed of an existing healthcare plan including your MS diagnosis, any previous treatments and what medications have been prescribed.

The MHR has potential to for clinicians in particular treating doctors find information quickly and make safer health care decisions. We know that 230,000 hospital admissions per year are due to medical misadventure and that much of this is preventable with access to the right information. 17% of pathology and radiology tests are currently duplicated, often because the previous results are not readily available, an extraordinary waste of community resources. MHR can help prevent people with MS having unnecessary tests when previous results are unavailable.

It is not generally understood that after the opt-out period concludes in November a record for each person will be created. Each person then has to activate their record, by doing it themselves online, giving permission for the GP to download a health summary, or allowing a discharge summary to be uploaded if there is a visit to hospital. Until this occurs the MHR will not contain any information.

It is entirely appropriate to have a discussion with your GP about what information should be uploaded that would be relevant to your future healthcare. It is important to ensure that the health summary held by your GP is accurate and does not contain any information that you do not want included. At the time of activation, two years of data on the Medicare Benefits Schedule, item numbers, providers and dispensing of Pharmaceutical Benefits Medicines will download. Your previous medical records from any source are NOT downloaded or accessible excepting the GP Health Summary. Going forward, updated health summaries, event summaries, specialist letters, hospital discharge summaries, pathology and radiology results and prescribed medication information will be added. A consumer can create their own health summary in addition to the GP summary. Other useful information will be your immunisation history from the Australian Immunisation Register. An Advance Care Planning document can be created by the consumer and uploaded and information from the Organ Donor Register will also be available.

Importantly, a person's MHR is controlled by them. Consumers have control over record access. They also control which healthcare professionals including their doctors, allied healthcare professionals, and healthcare organisations are able to see their record and or which organisations can see specific information within their MHR. There is a "break glass" (emergency access) facility available in life threatening situations to allow doctors to see vital information, however, all instances of this are audited and logged and people can choose to receive a text or email to let them know in the event that this occurs. With emergency access, any access controls that the individual has set will be overridden. This means doctors will have full access to their record. However, information that has been entered in the consumer-only notes section of the record, and any documents that the person has previously removed will not be visible. Consumers can also see a complete audit history of access to their record in real time and set up notifications for when their record is accessed.

The importance of timely and comprehensive medical information cannot be understated. Access to this information will greatly enhance the likelihood of improved healthcare through better coordination of service providers, greater depth of information and in the event of emergencies improved access to life saving treatment.

One major concern however that consumers and the broader community are seeking reassurance from the Australian Government on relates to the security of their information, essentially asking are their documents and information contained within their MHR confidential? This discussion relates largely to Section 70 in the legislation which enables the Australian Digital Health Agency to release information to agencies such as the police or Home Affairs in certain serious situations without a warrant. This has never occurred to date but was of such concern to organisations such as the Australian Medical Association and the Royal Australian College of General Practitioners that they have appropriately lobbied for this to be changed (though at the time or writing, these changes to the legislation are yet to be made).

Trust is a vital component of the relationship between you and your doctor and confidentiality is an important part of that trust. Information from the My Health Record can be subpoenaed just as your doctor records currently can be. Access by insurance companies to your medical records can only happen with your signed consent and this is unchanged. In general, there will be much less information on your My Health Record than is held by your GP.

The concerns expressed by consumers in particular about the security of their information and who has control over it need to be further addressed by the Australian Government and its Agency. It is important to note that the Australian Government has reported the MHR has not been breached within its current six years of operation and undergoes constant surveillance and threat testing. In general, the security is much higher than that of your local GP or specialist, where your information will continue to be held.

As information accumulates over time, people with MS will be more informed about their test results and better able to monitor their response to various treatments. Their MHR has the potential to be an invaluable tool to consumers and their healthcare professionals. The potential advantages of My Health Record for people with MS, their families and carers, are significant. It is also understood and appreciated that some individuals want to wait until further information becomes available about the Australian Governments proposed changes to the relevant legislation, hopefully this will be forthcoming in the immediate future.

For further information on the importance of your MHR and to gain further updates on the progress of its security under legislation please speak to your healthcare professional including your GP or access these websites. These discussions and further information will assist you in deciding whether you opt out before the deadline of 15 November.

If you are seeking more information about the My Health Record system, including information regarding the opt out process, and how your privacy and security is managed, please visit: https://www.myhealthrecord.gov.au/for-you-your-family/opt-out-my-health-record.

13 September, 2018

My Health Record in the news - Monday 16 July 2018

MS Australia continues to monitor with interest the progress of the Federal Government's **My Health Record**.

Today's announcement of the (three month) opt out period for **My Health Record** (more than 5.9 million Australians already have one) has, not surprisingly, generated more spirited discussion (in particular about the pros and cons) - in the media, the health sector and amongst the public.

This national online system for every Australian citizen, promises to combat double-handling and significantly, raise awareness of a person's medical condition, wherever they happen to be around the country.

What does it mean for the MS community?

It's always good to see opportunities for the MS community to become informed about proposed systemic changes, policies and/or options related to their healthcare.

With **My Health Record**, for the first time, your important health information such as diagnosis, treatments, medicine details, test and scan results will be available to you and your health care providers (doctors, specialists, hospital staff), digitally, and in one place.

We feel that **My Health Record** has many potential benefits for the MS community including:

- a centralised health record so that people with MS don't have to continually explain the complexities of their symptoms, medications, MRI and other test results over and over to health professionals at accident and emergency or when visiting a new doctor.
- A possible useful tool to empower you to make decisions about your healthcare and manage your MS with your health team.
- A potential time and energy-saver so you can focus on your day to day life, health and wellbeing – it's hard to remember the smallest things, let alone your health/medication details!
- A way to share information with the people closest to you e.g. family, carers and healthcare professionals.

In short, we believe that this new system has many advantages for people with MS as it will consolidate all of your medical records in the one place, enable you to access them, and save you having to remember details or keep your own records – great if you're travelling/working interstate or changing doctors or medications.

We encourage you to read the media release, check out the **My Health Record** website, encourage your health team to get involved and, once fully informed and if you're satisfied, consider uploading your record into the system - or update your existing one.

We will continue to update you, as developments come to hand.

My Health Record further details:

- **Australian Government 16/7/18 Media Release (including opt out details)**: https://www.myhealthrecord.gov.au/news/media-release-australians-decide-my-health-record
- **Website (including How to Guides)**: https://www.myhealthrecord.gov.au/

My Health Record in the news - Follow up - *-30 July 2018

Following the recent Federal Government opt out announcement, My Health Record is currently one of the most talked-about topics in Australia. Debate continues around important privacy and other concerns, versus the systems potential benefits.

We endorse various points raised in two recent Consumers Health Forum of Australia media releases (16/7/18) and (19/7/18), in many ways relevant to the MS community, including:

- *The advantages of a single electronic health record are significant particularly for those with complex and chronic conditions…*
- *…our health information concerning medical treatment, medicines, tests, scans and hospital care still often remains widely scattered and not immediately available in the way we take for granted in other spheres, such as banking and travel.*
- *Prompt access to a complete and current health record is particularly important for those with complex and chronic conditions requiring a range of different treatments and medicines, often urgently.*

Further to the points above and those raised in our recent news item, we think My Health Record's potential value for people living with MS - an acknowledged complex and chronic condition - may also include, a systematic way to address and treat any co-morbidities (other conditions which may occur alongside your MS), the potential to speed up diagnosis (critical for a tailored MS action plan) and treatment, and making sure various symptoms are addressed.

To make an informed decision, we encourage you to stay across the national debate, read information, ask questions and consider your individual situation.

For further information visit: www.myhealthrecord.gov.au