

## My Health Record

### ***What is My Health Record (MHR)?***

MHR is an online file of your medical history and Medicare information that is accessible by you and your health providers. Only healthcare provider organisations involved in your care, who are registered with the My Health Record System Operator, are allowed by law to access your MHR. This may include [GPs, pharmacies, pathology labs, hospitals, specialists and allied health professionals](#).<sup>(1)</sup> The aim of the MHR is to provide these practitioners with your medical information at any location, and thus improve the quality of your care and lower medical errors, especially in the case of emergencies.

### ***How does it work?***

The new records will be activated when logging in for the first time or when healthcare providers access a patient's records. Two years of Medicare and pharmaceutical benefits scheme (PBS) data will be uploaded, unless an individual chooses to exclude this information. Individuals will be able to upload personal notes, advanced care documentation, and medication and allergy information. Authorised healthcare providers using approved clinical information software will upload health information on allergies, medical conditions and treatments, medicine details, and test results.

Australian Digital Health Agency (ADHA) CEO Tim Kelsey stated that "Strict privacy control, set by an individual, is a central feature of My Health Record. Each person can control the information in his or her My Health Record, and the healthcare provider organisations that can have access".<sup>(2)</sup>

Individuals can ask their healthcare provider not to add specific test reports and other medical information. Individuals can restrict access to specific information in their record by applying a Limited Access Code, or by applying a Personal Access Code to the entire record.

MHR cannot store genomic or genetic data, but it can support the uploading of genetic test reports so that you and your authorised healthcare providers can view them.

### ***The Mito Foundation's position***

There are considerable arguments both for and against MHR. While there is a risk of a privacy breach, people with mito and other chronic diseases are the most likely to benefit because of their high number of medical appointments and hospital stays, and so MHR could provide better treatment outcomes.

**Every Australian will have a MHR unless they opt out by 31 January 2019.**

## Arguments for having a MHR:

1. **Better management of health.** The scheme gives health care professionals access to information on your medications and allergies, immunisation records, summaries of hospital and GP care, investigation reports, and advance care plans. This information could save lives in emergencies by providing health workers with information about drug allergies, medications, and medical history.

Better continuity in the management of this information could help reduce the 27 per cent of clinical incidents in Australian hospitals currently caused by medication (mis)management. <sup>(3)</sup> Drug incompatibility and negative reactions result in 230,000 hospital admissions costing more than \$1.2 billion annually in Australia due to [medicine misadventure](#). However, if an individual's MHR is not updated with new information or contains incorrect information, this may result in mistakes that are outside the practitioner's control. <sup>(4)</sup>

2. **Improves health literacy.** MHR offers new possibilities for linking up the fragmented health system, making it easier to navigate. Just as importantly, it can help you to become more informed and engaged with your own health care. And better health literacy is a necessary step in shifting the balance of the system towards patients. MHR is a small step towards empowering patients with greater knowledge about their health. Pressures to present records in terms that are comprehensible to consumers may even take us towards interactive "learning communities" – the basis of a more [people-centred health system](#). Better-informed patients can enable more effective communication and mutual learning from health professionals. <sup>(3)</sup>

3. **Access to information in emergency situations.** If you suffer from chronic illnesses, have allergic reactions or anaphylactic shocks, and otherwise need information to be conveyed to a medical professional when you are unable to, then the benefits will outweigh the risks in a situation of life or death, assuming your MHR is up to date.

## 4. **Benefits for those with chronic conditions:**

- **Better treatment outcomes** – Your health information is available in one place and can be accessed by treating doctors, specialists and hospital staff. This gives your healthcare providers a clearer picture of your health needs to inform their clinical decisions and diagnoses.
- **You're in control** – You decide what information healthcare providers have access to and maintain control over your documents.
- **Portable healthcare** – A digital record makes it easier to move between healthcare providers, without having to repeat your entire medical history on every visit
- **Safer care** – In a medical emergency, doctors can view your information, including allergies and current medications, to provide you with the best possible treatment. It also means if you're unable to communicate your health details, hospital staff will have access to your health information.
- **Keeping track** – You can access details of test results, diagnostic reports and prescribed medicines or upload additional health information. This reduces the need for repeated tests, and means you don't need to remember all of the details. <sup>(5)</sup>

5. **Better palliative care.** Carers Australia CEO Ara Cresswell said MHR can assist with carers or loved ones who want to assist the patient going through palliative care. “MHR can lessen the stress of having to remember details of the diagnoses and treatments of others, and help prevent adverse medication events. The ability to upload the patient’s end-of-life preferences can also lessen the distress of those forced into making very difficult decisions on behalf of a family member not able to communicate their own wishes.”

Australian Digital Health Agency Chief Clinical Information Officer and Executive General Manager Dr Monica Trujillo stated “My Health Record can enable important health information including allergies, medical conditions, medicines, pathology and imaging reports to be accessed through one system. The benefits could include reduced hospital admissions, reduced duplication of tests, better coordination of care for people with chronic and complex conditions, and better informed treatment decisions,” <sup>(6)</sup>

6. **Faster discharge from hospital.** Researchers in the USA found the average patient was discharged roughly four hours earlier in hospitals whose electronic health records met meaningful use criteria, (a set of five criteria introduced to improve patient care by the US government) representing a three percent decrease from the typical five-day hospital stay. Patients with complex or multiple chronic conditions, meanwhile, saw a 3.5 percent drop in average length of stay. “Electronic health records, when meaningfully implemented, help patients go home sooner, reducing their exposure to germs in the hospital and likelihood of having to come back,” Manoj Malhotra, Ph.D., study co-author and dean of Case Western’s Weatherhead School of Management, said. “Longer hospital stays cost more money for all involved.” <sup>(7)</sup> Whether this will be similar in Australian hospitals is unclear.

### Arguments for opting out of MHR:

1. **It can’t be relied upon as a clinical record.** MHR is *not* a clinically-reliable medical record, and was not designed to be. It is not up-to-date and comprehensive.

*‘The My Health Record system contains an online summary of a patient’s key health information; not a complete record of their clinical history.’* - Office of the Australian Information Commissioner (OAIC)

If, for example, a doctor was treating a child in an emergency, the doctor could *not* rely on an MHR to know what medications the child has been prescribed up to that date. In an emergency, an unreliable record is a distraction, not a help.

Many doctors have in fact objected to the incompleteness and lack of utility of the MHR. A recent poll on the AMA’s doctors portal suggests 76% of respondents think the MHR will not improve patient outcomes while 12% think it will. Notwithstanding this fundamental deficiency, the government is pushing ahead with an inherently risky scheme.

2. **It creates a security risk.** Storing records digitally with online access greatly increases their accessibility for criminals and hackers. Health records are valuable as a means of identity theft due to the wealth of personal information they contain.

myGov (the system securing MHR) has experienced a lack of security protection in the past. Improvements have been made, but some remain concerned. <sup>(8)</sup>

Up to 900,000 health professionals will be able to gain access to an individual's records but there is no guarantee that the security of their computers will be kept up-to-date.

Centralising health data increases the risk an unauthorised party can gain access to it. Currently, a hacker would have to know who your GP is to access your data.

PINs on individual records can be broken in "emergency" situations using an override function or potentially by unauthorised criminals <sup>(9)</sup>, however this is an issue with most online systems.

**3. An 'opt-out' scheme goes against best practice.** The opt-out consent mechanism for MHR is in direct contradiction to global best practice for informed consent – and our own federal privacy regulator's guidelines on the sort of consent necessary for use of health information.

Consent for use of personal information should be express, fully informed, easy to understand, and should require action on the part of the individual.

MHR does not seek your *express* consent. Instead, if you do not take the necessary steps before 31 January, your health records will automatically be copied, stored and shared. You will also not be *fully informed*.

MHR is likely to create very limited benefits for many, if not most, Australians. It creates unacceptable security risks for our most sensitive personal information. And the government's method of obtaining "consent" goes against international best practice. <sup>(8)</sup>

There are likely to be instances where a record is uploaded without your genuine, informed consent. Tick boxes are in use that state: "Do not send to My Health Record" rather than "Do you want this sent to My Health Record?"

**4. Privacy.** The records can be disclosed to government agencies in the enforcement of "the protection of the public revenue" or preventing and detecting crime and improper conduct, among other reasons (at present, doctors can reject requests and ask for a warrant).

**5. Questionable support by doctors.** A survey of 471 doctors found that 8 out of 10 plan to opt out of MHR citing mistrust for the system being useful or up to date. <sup>(10)</sup> If the health professionals, whose responsibility it will be to enter data, don't have confidence in the system, how can it succeed? <sup>(11)</sup>

## References

1. Australian Digital Health Agency, 2018 – *My Health Record, Frequently Asked Questions*. <https://www.myhealthrecord.gov.au/for-you-your-family/howtos/frequently-asked-questions>
2. Australian Digital Health Agency, 2018 – *My Health Record Opt Out Date Announced*. <https://www.myhealthrecord.gov.au/news-and-media/media-releases/my-health-record-opt-out-date-announced>
3. J. Gillespie. July 2018. *My Health Record: The Case for Opting In*. The Conversation. <https://theconversation.com/my-health-record-the-case-for-opting-in-99850>
4. T. Bartone, July 2018 – *My Health Record Could Save Your Life One Day*. Sydney Morning Herald. <https://www.smh.com.au/national/my-health-record-could-save-your-life-one-day-20180723-p4zt4z.html>
5. Australian Digital Health Agency. *My Health Record Benefits While Managing a Chronic Condition*. <https://www.myhealthrecord.gov.au/for-managing-chronic-condition>
6. Australian Digital Health Agency. *My Health Record Improving Outcomes for People in Palliative Care*. <https://www.myhealthrecord.gov.au/news-and-media/media-releases/improving-outcomes-palliative-care>
7. J. Murtha. November 2018. *HER's Cut Costs, Hospitalisation Times*. Healthcare Analytics News. <https://www.hcanews.com/news/ehrs-cut-costs-hospitalization-time>
8. K. Kemp, B.B Arnold, D. Vaile, July 2018 - *My Health Record: The Case for Opting Out*. The Conversation. <https://theconversation.com/my-health-record-the-case-for-opting-out-99302>
9. B Grubb and J. Duke, July 2018. *Breach Inevitable in Digital Health Records*. The Sydney Morning Herald. <https://www.smh.com.au/technology/breach-inevitable-in-digital-health-records-20180715-p4zrmb.html>
10. P. Smith, July 2018. *Poll Shows Majority of Doctors Say They Won't Use My Health Record for Their Own Care: Survey*. Australian Doctor. <https://www.australiandoctor.com.au/news/majority-doctors-say-they-wont-use-my-health-record-their-own-care-survey>
11. B. Grubb, July 2018. *Why I'm Opting Out of the Government's Digital Health Record and You Should Too*. The Sydney Morning Herald. <https://www.smh.com.au/technology/why-i-m-opting-out-of-the-government-s-digital-health-record-and-you-should-too-20180715-p4zrna.html>
12. Australian Digital Health Agency, July 2018, *Media Release*. [https://www.myhealthrecord.gov.au/sites/g/files/net4206/f/media\\_release\\_-\\_my\\_health\\_record\\_expansion\\_16\\_july\\_2018.pdf](https://www.myhealthrecord.gov.au/sites/g/files/net4206/f/media_release_-_my_health_record_expansion_16_july_2018.pdf)