



PART A

Better access – sharing pathology and diagnostic imaging reports to My Health Record by default

Consultation via Citizen Space
8 September 2023 to 31 October 2023

Introduction

My Health Record is Australia's electronic health record system. It's designed to give Australians easy access to their health information whenever it's needed, including in an emergency. Having key information readily available saves valuable time. It also reduces unnecessary tests and treatments and lowers the risk of medication-related errors. Ultimately it puts consumers at the centre of their health care.

Availability of records

Large numbers of consumers and healthcare providers use My Health Record to access and upload health information. But currently pathology and diagnostic imaging service providers are only sharing about:

- half of pathology reports
- one in five diagnostic imaging reports.

This means:

- consumers often won't have direct access to test results that are useful for monitoring and making informed health decisions
- healthcare providers may not have easy access to information that could help with making better informed clinical decisions.

Lack of access to test results can lead to duplicate tests, unnecessary treatments and poorer health outcomes. My Health Record is about improving health care and reducing unnecessary repeat tests, and increasing access to pathology and diagnostic imaging reports in My Health Record is a clear opportunity for the healthcare system.

Privacy and control

Personal control is central to My Health Record. Consumers can decide who can access their records and what information is shared and accessible. Consumers can choose to be notified when health providers access their records. They can also choose to cancel their My Health Record at any time.

This reform will not remove any of these controls.

Information on how to manage the privacy of a My Health Record is at:

<https://www.digitalhealth.gov.au/initiatives-and-programs/my-health-record/manage-your-record/privacy-and-access>.

Permission to share records

A common misunderstanding about My Health Record is that healthcare providers need to get consent from their patients each time they intend to share information. This isn't the case. The *My Health Records Act 2012* authorises registered healthcare providers to upload health information for patients who have a My Health Record. They don't need written or verbal consent to do this.

There are 2 exceptions to this:

1. **The consumer instructs the healthcare provider not to upload.** If a consumer requests that information not be uploaded to their record, the provider is legally obligated to comply.
2. **A state or territory law requires consent.** In most cases, healthcare providers don't need a consumer's consent before uploading health information to My Health Record. There are a few exceptions to this in the ACT, Queensland and New South Wales. In these places, the My Health Records Act requires healthcare providers to meet consent requirements in state and territory laws before uploading to My Health Record.¹ These 'prescribed state/territory laws' only apply to particular types of health information.

Otherwise, healthcare providers may share the information.

As My Health Record contains sensitive information, providers must use care when uploading records. They must take reasonable steps to ensure that any record they or their staff upload is accurate and up to date (at the time it's uploaded), not misleading and not defamatory.²

More guidance on sharing information to My Health Record is at <https://www.digitalhealth.gov.au/healthcare-providers/initiatives-and-programs/my-health-record>.

1 Regulation 3.1.1 of the My Health Records Regulation 2012

2 Subrule 29(1), My Health Records Rule 2016

The case for change

The Australian Digital Health Agency helps consumers and healthcare providers to use My Health Record through education and training activities and phone and online support services. It also supports clinical software vendors to upgrade their products to connect to My Health Record.

Despite those supports, inconsistent sharing of key health information is still a significant deterrent to using My Health Record. In 2020–21, 17.8 million (69%) of Australians accessed 204.1 million Medicare-subsidised pathology tests, imaging scans and other diagnostic services.³ Currently only around half of pathology reports and one in five diagnostic imaging reports are being shared to My Health Record. This is a clear gap which needs to change before we can get the full benefits of a digitally connected healthcare system.

The government's investment to modernise My Health Record aims to make health information much more accessible to consumers and their healthcare providers. Requiring private and public practitioners and services to share by default will achieve this. This change will make it easier for consumers and their healthcare providers to access health information. It will lead to better connections across care settings and better quality data in the system over time.

Healthcare providers will also benefit from a more integrated, seamless and efficient method of accessing their patients' health information. With easier access to the patient's details, they will spend less time finding key information. This will help them make more timely, better informed decisions about clinical treatments and care planning.

Better information sharing will also better support multidisciplinary care. Care teams will work together more effectively when everyone has easy access to the same up-to-date records. Patients will get more joined-up care and less exposure to unnecessary procedures. Having better access to their own health information will also enable them to be more involved in and better manage their care.

In summary, sharing by default will:

- support better informed healthcare decisions
- reduce the need for consumers to repeat their medical history to multiple providers
- enable timely access to key health information for patients and their healthcare providers
- empower consumers to actively participate in their own healthcare.

3 'Pathology, imaging and other diagnostic services'. Australian Institute of Health and Welfare. [Pathology, imaging and other diagnostic services - Australian Institute of Health and Welfare \(aihw.gov.au\)](https://www.aihw.gov.au/reports/100/pathology-imaging-and-other-diagnostic-services). Accessed 11 August 2023

Consumers want their healthcare providers to use My Health Record

Consumers and carers believe that we should be using digital technology to store and share their medical information among healthcare providers.

Prioritise making the My Health Record sharable and used by all health professionals and in all health settings. This fundamental step will have massive benefits to consumers, who will be able to trust that their information is being adequately communicated.

Consumers Health Forum of Australia submission on the National Digital Health Strategy

The Australian Digital Health Agency, as the operator of My Health Record, gets frequent feedback about the system. Around half relates to healthcare providers not making information available in My Health Record. Some consumers specifically say that it should be mandatory for healthcare providers to contribute to My Health Record.

Customer reviews of the Australian Digital Health Agency's new **my health** app highlight that consumers:

- value easy access to their My Health Record
- are frustrated that providers often don't share their health information to it.

This is so easy to use. Disappointing there's not more information about tests included but helpful that you tell users who is uploading to my health record via the link. I won't be getting tests with labs that don't upload anymore.

my health app customer review

Research and data show the value of digital access to health information

Timely access to care is critical to achieving the best possible health outcomes. We know that limited information transfer (such as paper-based referrals) and poor coordination between providers result in worse outcomes for consumers. These include more duplication of care, longer wait times, delayed diagnosis and fragmented and disrupted care.⁴

4 CY Lin, 'Improving care coordination in the specialty referral process between primary and specialty care', *North Carolina Medical Journal*, 2012, 73(1):61-62.

Not having digital access to health information also makes extra non-clinical work for healthcare providers. They and their administrative staff spend a lot of non-billable time contacting other care providers and arranging tests and referrals.⁵

Studies from around the world agree that digital access to consumers health information on national healthcare systems has a positive impact.⁶ For example, consumers being able to directly access their pathology and diagnostic imaging results has been linked to more effective health care and higher consumer engagement.⁷ Having time to review, research and process their own test results might allow consumers to prepare for discussions with their healthcare providers and may lead to better shared decision-making.^{8,9,10}

There is evidence that access to information in My Health Record supports crucial clinical decision-making. This is because it's quicker, easier and cheaper to get information from My Health Record. A recent research study examined My Health Record usage in 10 million GP-patient consultations in South Western Sydney between 2017 and 2021. GPs used My Health Record in 51% of these consultations in 2021, compared to 18% in 2017. The analysis revealed that access to health information in My Health Record improved clinical decision-making. GPs were more likely to make a new diagnosis and prescribe medication when they used My Health Record.¹¹

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- 5 J Henderson, L Valenti, HC Britt, C Bayram, C Wong, C Harrison ... and GC Miller, 'Estimating non-billable time in Australian general practice', *Medical Journal of Australia*, 2016, 205(2):79–83.
 - 6 McGovern M, Quinlan M, Doyle G, Moore G, Geiger S. Implementing a National Electronic Referral Program: Qualitative Study *JMIR Med Inform* 2018;6(3):e10488 URL: <https://medinform.jmir.org/2018/3/e10488> DOI: 10.2196/10488
 - 7 Zanaboni P, Kristiansen E, Lintvedt O, Wynn R, Johansen MA, Sørensen T and Fagerlund J (2022) '[Impact on patient-provider relationship and documentation practices when mental health patients access their electronic health records online: a qualitative study among health professionals in an outpatient setting](#)', *BMC Psychiatry*, 22(508), accessed 24 April 2023.
 - 8 Moore, K. and Belanger, P., 2016. Facilitating the sharing of patient information between health care providers. *Online Journal of Public Health Informatics*, 8(1)
 - 9 Singh, K., Meyer, S.R. and Westfall, J.M., 2019. Consumer-facing data, information, and tools: self-management of health in the digital age. *Health Affairs*, 38(3), pp.352-358
 - 10 *Appl Clin Inform*. 2021 Aug; 12(4): 954–959 Patient Perceptions of Receiving COVID-19 Test Results via an Online Patient Portal: An Open Results Survey
 - 11 Australian Digital Health Agency. My Health Record: data driven quality improvement and benefits realisation. Internally commissioned research with Outcome Health, 2022.

Adoption by some healthcare providers remains low despite the benefits

Around 90% of Australians have a My Health Record, and 98% of these records contain data.¹² But it's still far from being a comprehensive source of key information for consumers and their healthcare providers.

One reason for this is that some healthcare providers don't have clinical management software that seamlessly integrates My Health Record into their normal workflow.

Through a related project to modernise My Health Record, the Australian Government is reducing some of the technical barriers to using it. This includes a change from My Health Record mainly handling clinical documents (PDFs) to being able to capture information contained in documents in a way that makes it easier to share and use.

The government has also allocated funding over 2 years for developing national health information sharing priorities. This includes developing national core health information sharing standards and a legislative framework for exchanging health information. By developing health information sharing standards that are used nationally, we can create a seamless and connected healthcare system that meets the needs of consumers who want safe and secure access to their important health information.

There will be circumstances where reports should not be shared. We welcome advice on this through the consultation. But such circumstances should be the exception to the rule. Many of the reports not being shared to My Health Record could be used to provide more effective care and increase patient engagement.

12 'My Health Record – The Big Picture – June 2023. [Statistics | Australian Digital Health Agency](#). Accessed 11 August 2023

What we've done, what we've heard

In February 2023 the Australian Government released the Strengthening Medicare Taskforce Report.¹³ One of the report's recommendations was to:

Modernise My Health Record to significantly increase the health information available to consumers and their healthcare professionals, including by requiring sharing by default for private and public practitioners and services, and make it easier for people and their health care teams to use at the point of care.

The government has responded by:

- providing funds to modernise My Health Record
- starting the process to:
 - require healthcare providers to share key information to My Health Record by default – starting with pathology and diagnostic imaging reports
 - remove the delay between providers uploading tests results to My Health Record and consumers being able to access them.¹⁴

This consultation is about how best to implement these changes.

If a patient gets a diagnostic scan or pathology test, then those results should be uploaded. At the moment, this happens by exception. It is not the rule. I intend to make it the rule.

Minister for Health and Aged Care, the Hon Mark Butler MP (May 2023)

This approach is consistent with recommendations made by the Productivity Commission. A recent 5-Year Productivity Inquiry interim report¹⁵ highlighted the potential benefits of increased sharing of healthcare data. These include better service quality for patients and better informed health policy, funding allocation and service delivery.

This reform will require pathology and diagnostic imaging organisations to share pathology and diagnostic imaging reports to My Health Record by default from December 2024. These providers will need to have systems and procedures in place by then to share results to My Health Record as standard practice. Their systems and procedures should also support management of exceptions.

For example, it should record where a patient chooses not to share their information.

13 [Strengthening Medicare Taskforce Report, December 2022](#)

14 [Budget Paper No. 2: Budget Measures](#), Page 149

15 Productivity Commission 2023, 5-year Productivity Inquiry: Australia's data and digital dividend, Vol. 4, Inquiry Report no. 100, Canberra, <https://www.pc.gov.au/inquiries/completed/productivity/report/productivity-volume4-data-digital-dividend.pdf>

In April-May 2023 the Department of Health and Aged Care consulted with peak bodies in the pathology and diagnostic imaging sector about sharing to My Health Record by default.¹⁶ There was broad agreement that requiring sharing of diagnostic imaging and pathology reports to My Health Record will improve safety and quality in healthcare.

We heard these common themes in the consultation:

- **Acceptance of the need for upload by default.** Most stakeholders accepted the need for requirements to improve uploading of health information to My Health Record. They understood and commented on pathology and diagnostic reports being a good place to start. They mentioned the work this sector has already done to connect to My Health Record. They noted that the high rates of COVID-19 pathology reports being uploaded and viewed by consumers and healthcare providers set a good precedent.
- **Concerns and misconceptions about the need for patient consent.** There is a common misconception that providers need the patient's consent to upload their health information to My Health Record. This hasn't been the case since we changed to the opt-out system. Stakeholders correctly noted that some state and territory laws require consent for certain public health information to be uploaded to My Health Record.¹⁷ For example, healthcare providers in the ACT generally need written consent from consumers to upload information to My Health Record showing that the consumer has a notifiable condition. (A list of notifiable conditions in the ACT is available on the [ACT Government website](#) and includes conditions like measles or Hepatitis A.)
- **Concerns about clinical safety.** Stakeholders raised concerns about the clinical safety of uploading pathology and diagnostic imaging reports to My Health Record by default.

16 The government recognises this was limited, targeted consultation, and that the views of a broad range of stakeholders is important and will be used to inform this project.

17 These laws are specified by regulation 3.1.1 of the *My Health Records Regulation 2012*.

Proposed approach

The case for change is clear. We know that consumers and healthcare providers need better digital access to health information. We know that they want and would benefit from better access to pathology and digital imaging reports in particular. It's clear that this sector's use of My Health Record is lagging behind that demand.

The Australian Government is committed to an approach that:

- gives consumers and their healthcare providers better and faster access to key health information when they need it - making it easier for consumers to engage with their healthcare providers, make informed decisions about their health, and reduce avoidable adverse outcomes, duplicate tests and unnecessary treatments.
- maintains strong consumer control and privacy protections
- makes it simple for providers to understand their obligations
- maintains, and where possible increases, clinical safety
- maintains, and where possible increases, the quality of information on My Health Record
- reduces the barriers some healthcare providers face in participating in My Health Record
- is proportionate to the problem we are trying to solve
- does not impose excessive or unreasonable burdens on healthcare providers
- can extend to other types of health information in the future.

Exploring changes to legislation is one part of the proposed approach. Options are still being considered, which could include changes to the *Health Insurance Act 1973*, the *My Health Records Act 2012* and the *Healthcare Identifiers Act 2010*. Legislative changes could introduce an obligation on proprietors of pathology laboratories and proprietors of diagnostic imaging practices to upload the pathology results and reports of patients to the My Health Record system. These changes may include linking eligibility to receive Medicare rebates to sharing of diagnostic imaging or pathology reports.

The requirements will make provision for appropriate case-by-case exceptions, where the obligation to share by default will not apply. The case-by-case exceptions will include where the patient does not have a My Health Record or where the proprietor is unable to successfully upload to the My Health Record (for example, where data matching fails). Consideration will also be given to what healthcare providers can do if they have reasonable concerns for the health or safety of a patient if the upload were to take place.

Importantly, obligation to share by default will not prevent a patient from expressly advising they do not want the upload to occur.

Changing professional standards for diagnostic imaging and pathology providers is also being considered. The Australian Commission for Safety and Quality in Health Care (ACSQHC) sees opportunities to change the Diagnostic Imaging Accreditation Scheme Standards and the National Pathology Accreditation Standards to include sharing of imaging and pathology reports to My Health Record.

ACSQHC will undertake public consultation on diagnostic imaging and pathology accreditation standards from late 2023 or early 2024. The Department of Health and Aged Care will be seeking agreement to amend these standards to include actions similar to those in the National Safety and Quality Health Service Standards. These include:

- Action 1.17, which encourages health service organisations to securely share a patient's clinical information with authorised clinicians in other settings, including My Health Record
- Action 1.18, which aims to ensure that health service organisations providing clinical information into the My Health Record system have processes that ensure the information is accurate, complete and accessible by authorised clinicians.

The approach to increasing participation in My Health Record by diagnostic imaging and pathology providers will consider:

- varied levels of access to clinical software capable of connecting to My Health Record
- varied clinical settings and procedures across different providers and test types. For example, there will need to be clear guidance on what to do if:
 - one request involves multiple investigations which may produce multiple reports
 - imaging reports are amended after they have been uploaded to My Health Record.

The focus of this initiative is to increase consumer control over their healthcare information when and where they want it. Better informed consumers tend to make more cost-effective and less risky choices about their treatment options. The success of the initiative will also increase the use and value of My Health Record.

This initiative does not include:

- making changes to the usability of My Health Record
- providing funding for new software.

It does include supporting diagnostic imaging and pathology providers to make the necessary changes to:

- transition to sharing by default by 30 June 2024
- meet their obligations to share information from December 2024.

The Australian Digital Health Agency provides connection support, education and training for healthcare provider organisations to connect to and use the My Health Record system.

Visit their website to learn more:

www.digitalhealth.gov.au/initiatives-and-programs/my-health-record