



## **PART B**

**Faster access** – removing delays to accessing pathology and diagnostic imaging reports in My Health Record

Consultation via Citizen Space  
**8 September 2023 to 31 October 2023**

## Introduction

My Health Record is Australia's national electronic health record system. It's designed to give consumers and their healthcare providers easy access to health information whenever it is needed, including in an emergency. Having key information readily available saves valuable time when someone needs treatment. 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.

### Delay in access

In 2014 the government agreed that healthcare providers responsible for follow-up care should have 7 days to review diagnostic imaging and pathology results and discuss them with their patient before the patient can access the result on their My Health Record.

The 7-day delay has been removed for a small number of tests, to ensure consumers have fast access to their results. These include:

- COVID-19 pathology results
- pathology results for 13 other respiratory pathogens (including flu)
- International Normalised Ratio (INR) results – how long it takes for blood to clot, used to monitor the effects of blood-thinning medicines
- Glycated Haemoglobin (HbA1C) results – a 3-month average of blood sugar, used to monitor diabetes.

More recently, increasing numbers of consumers and others have raised the need to remove the 7-day delay, to make My Health Record more consumer-centred.

Timely access to diagnostic imaging and pathology reports empowers consumers to better manage their own health and protect others in the community. It also helps them have informed discussions and make decisions with healthcare providers.

Because the benefits to consumers of timely access are so clear, the government is proposing to remove the 7-day delay for all diagnostic imaging and pathology tests. This consultation welcomes views on other strategies to ensure that consumers who have access to results before they've consulted with their healthcare provider maintain strong links with their provider. Views are also welcome on how to better support consumers to use their results to make informed decisions about their health and have informed discussions with their healthcare providers.

It is expected that this initiative will be implemented in 2024. More specific implementation timeframes will be determined following consideration of advice to be provided by a clinical and consumer advisory group and feedback from this consultation process.

## **Privacy and control**

At all times consumers can request the test provider not to upload diagnostic imaging or pathology reports to My Health Record. The provider then has a legal obligation not to upload it. Consumers can also restrict who has access to their pathology or diagnostic imaging reports, or remove these reports from their record immediately.

This reform will not remove any of these controls.

Information on how to manage the privacy of a My Health Record is at [www.digitalhealth.gov.au/initiatives-and-programs/my-health-record/manage-your-record/privacy-and-access](https://www.digitalhealth.gov.au/initiatives-and-programs/my-health-record/manage-your-record/privacy-and-access).

## The case for change

Consumers and some healthcare providers have expressed a strong preference for removing the 7-day delay so they can see their results as soon as they're ready. Some consumers have told us that delayed access to their test results prevents them from self-managing their health. The delay is sometimes worse if providers are slow to upload test results to My Health Record.

Several medical peak bodies and state and territory governments have proposed removing the 7-day delay for certain diagnostic imaging and pathology reports, but feel a delay should be retained in some circumstances, based on individual needs.

The delay may still be needed for some reports. Decisions on whether certain reports shared to My Health Record should remain 'locked' for a particular time will be based on available evidence. We welcome your advice on this through the consultation.

### Timely access to health information benefits patients

International experience shows that most consumers want access to their health information, even if it indicates a health problem. In a recent study, a Dutch hospital conducted an online survey asking 'When do patients want their test results to be disclosed on the patient portal and what are the reasons for these choices?' More than 4,500 consumers responded. The study found that most consumers want to know their test results as soon as possible.<sup>1</sup> Similarly, a survey of more than 8,000 consumers in the United States showed a strong preference for the immediate release of tests results via a patient portal.<sup>2</sup>

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1 Hulter P, Langendoen W, Pluut B, Schoonman GG, Luijten R, van Wetten F, et al. (2023) Patients' choices regarding online access to laboratory, radiology and pathology test results on a hospital patient portal. PLoS ONE 18(2): e0280768. <https://doi.org/10.1371/journal.pone.0280768>

2 Steitz BD, Turer RW, Lin CT, MacDonald S, Salmi L, Wright A, Lehmann CU, Langford K, McDonald SA, Reese TJ, Sternberg P, Chen Q, Rosenbloom ST, DesRoches CM. (2023) Perspectives of Patients About Immediate Access to Test Results Through an Online Patient Portal. JAMA Netw Open. 2023 Mar 1;6(3):e233572. doi: 10.1001/jamanetworkopen.2023.3572. PMID: 36939703; PMCID: PMC10028486.

Some healthcare providers have raised concerns about how immediate access to pathology notes might affect patient wellbeing.<sup>3</sup> However, there is some evidence that consumers prefer immediate access even when they receive non-normal results. Other studies have reported that transparent medical records do not seem to greatly increase consumers' health-related worry.<sup>4,5,6</sup>

Some healthcare providers are also concerned about consumers not seeking follow-up care if they have direct access to their diagnostic imaging and pathology reports. However, research shows that ready access to health information can increase engagement between healthcare providers and consumers. In at least one study, faster access was associated with an **increase** in the number of messages from consumers to healthcare providers within 6 hours of reviewing a test.<sup>7</sup> This suggests that we should see immediate release of test results as an opportunity, and consider how we can best support consumers to seek healthcare provider expertise and interpretation of results.

More broadly, there is evidence that transparent health information has a positive impact on consumer trust in their healthcare provider.<sup>8</sup> Greater access to health information may also reduce health inequities. Studies from the US suggest that traditionally under-served or minority populations who gain access to their medical notes, including pathology, report greater benefit than those who don't. The benefits particularly relate to trust and teamwork.

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- 3 Steitz BD, Sulieman L, Wright A, Rosenbloom ST. Association of Immediate Release of Test Results to Patients With Implications for Clinical Workflow (2021). *JAMA Network Open*. 2021 Oct;4(10):e2129553. DOI: 10.1001/jamanetworkopen.2021.29553. PMID: 34661667; PMCID: PMC8524306.
  - 4 Blease, C., McMillan, B., Salmi, L., Davidge, G., Delbanco, T., (2022) Adapting to transparent medical records: international experience with "open notes" *BMJ* 2022; 379: e069861 doi: <https://doi.org/10.1136/bmj-2021-069861>
  - 5 Rexhepi H, et al. (2018) Cancer patients' attitudes and experiences of online access to their electronic medical records: A qualitative study *Health Informatics Journal*, 2018;24(2):115-124 <https://doi.org/10.1177/1460458216658778>
  - 6 Walker J, Leveille S, Bell S, Chimowitz H, Dong Z, Elmore JG, Fernandez L, Fossa A, Gerard M, Fitzgerald P, Harcourt K, Jackson S, Payne TH, Perez J, Shucard H, Stametz R, DesRoches C, Delbanco T (2019) [OpenNotes After 7 Years: Patient Experiences With Ongoing Access to Their Clinicians' Outpatient Visit Notes](https://doi.org/10.1177/1460458216658778). *J Med Internet Res*. 2019 May 6;21(5):e13876. doi: 10.2196/13876. Erratum in: *J Med Internet Res*. 2020 Apr 30;22(4):e18639. PMID: 31066717; PMCID: PMC6526690.
  - 7 Steitz BD, Turer RW, Lin CT, MacDonald S, Salmi L, Wright A, Lehmann CU, Langford K, McDonald SA, Reese TJ, Sternberg P, Chen Q, Rosenbloom ST, DesRoches CM. (2023) Perspectives of Patients About Immediate Access to Test Results Through an Online Patient Portal. *JAMA Netw Open*. 2023 Mar 1;6(3):e233572. doi: 10.1001/jamanetworkopen.2023.3572. PMID: 36939703; PMCID: PMC10028486.
  - 8 Blease, C., McMillan, B., Salmi, L., Davidge, G., Delbanco, T., (2022) Adapting to transparent medical records: international experience with "open notes" *BMJ* 2022; 379: e069861 doi: <https://doi.org/10.1136/bmj-2021-069861>

Instant access to test results is likely to improve health outcomes in regional and remote areas. We expect that immediate access to diagnostic imaging and pathology results will:

- strengthen continuity of care for people in regional and remote areas
- reduce unnecessary diagnostic procedures.

At present, consumers typically need to book an appointment with their healthcare providers to find out their test results within the 7-day delay period. Seeing test results immediately can save a trip to the healthcare provider. It will also prompt consumers to book a follow-up appointment quickly if it is needed. This is especially helpful if consumers live in a place with long wait times and travel times to see a healthcare provider.

## Case study #1

Richard, a 77-year-old father of 3, sadly passed away in April this year. Richard had been diagnosed with leukaemia a short 5 weeks before he died. Naturally, this was a very difficult time for his family. And while managing their own shock and grief, Richard's family were also assisting in his treatment.

In Richard's case, blood transfusions were a vital part of his care. A timely transfusion provided some quality of life for him and a little more time with his family. The threshold for Richard to be transfused was a haemoglobin level falling below a certain limit, following a blood test in the morning.

Normally, his family would have had an anxious wait for Richard's clinical team to call them with his test results and to give instructions. However, in this case Richard's haematologist suggested he have his blood tests done by ACT Pathology, so that he would get his test results immediately via MyDHR.

This proved invaluable. Richard's family were notified as soon as the results were reported from the lab. And they could spring into action to get Richard to hospital as soon as possible.

As his daughter Louise says, 'We would instantly know whether we needed to attend hospital that day for a transfusion. This allowed us time to get Dad ready as well as manage his busy schedule (such as altering other appointments that had been booked for that day). MyDHR gave my family peace of mind that we had some control and understanding of the situation that was occurring. We never felt lost or left in the dark as to Dad's condition.'

*ACT Health*

## Case study #2

Lisa, a 52-year-old with type 2 diabetes, previously felt overwhelmed with fluctuating sugar levels due to the delay in accessing her HbA1c results, a key indicator of blood sugar control. With the introduction of pathology and diagnostic imaging uploads to her My Health Record, it allows Lisa real-time access to her results online, seeing a significant change in her health management journey.

Now, immediately upon viewing her HbA1c results, Lisa can promptly consult both her GP and endocrinologist and make necessary adjustments to her medications. This not only helps her to stabilise her sugar levels but also empowers Lisa in managing her own care. With My Health Record, she no longer feels like a passive player but an informed and active participant, collaborating closely with her care team to achieve optimal health outcomes.

## What we've done, what we've heard

In February 2023 the Australian Government released the Strengthening Medicare Taskforce Report.<sup>9</sup> One of the report's recommendations was to:

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***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 healthcare teams to use at the point of care.***

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The government has responded by:

- providing funds to upgrade and modernise My Health Record
- starting the process to change the *My Health Records Act 2012* 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.<sup>10</sup>

This consultation is about how to implement those changes.

## Proposed approach

We will remove the 7-day delay policy for diagnostic imaging and pathology reports shared to My Health Record. Consumers will be able to see these reports as soon as they're uploaded to My Health Record.

The delay may remain if there's evidence of privacy, clinical safety or other risks.

We're consulting with a diverse range of stakeholders to work out the best policies and approaches to:

- use My Health Record to give consumers faster access to their health information
- support consumers to
  - plan and coordinate their care, particularly if they have chronic conditions
  - have more informed discussions with their healthcare providers
- support healthcare providers to work with patients in managing their health and wellbeing.

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<sup>9</sup> [Strengthening Medicare Taskforce Report, December 2022](#)

<sup>10</sup> [Budget Paper No. 2: Budget Measures, Page 149](#)