

Response to ‘Modernising My Health Record - Sharing pathology and diagnostic imaging reports by default and removing consumer access delays’ online survey questions

What do you think the impact will be of diagnostic imaging and pathology providers having to share reports to My Health Record by default?

Stroke Foundation strongly supports the Department of Health and Aged Care mandating all public and private diagnostic imaging and pathology providers having to upload patient results to *My Health Record* by default (for those who have consented to participate in *My Health Record*), from December 2024. As mentioned in the Discussion Paper, currently, only about half of pathology reports and one in five diagnostic imaging reports are being shared to *My Health Record*. It is unacceptable that Australian patients, including survivors of stroke, are attending appointments to discuss their health, including specific medical issues and conditions, and the results of their diagnostic imaging and pathology tests are unavailable for their health professionals to use to inform decisions regarding diagnosis and treatment.

Survivors of stroke, their families and carers, and the health professionals who treat and care for them, are largely supportive of diagnostic imaging and pathology providers having to upload patient results to *My Health Record* by default, as it gives them all better access to important health information when they need it. This empowers survivors of stroke to manage their own health and make decisions about their health care. In Australia, chronic disease, which includes stroke, accounts for most of the total disease burden. The dynamic and evolving nature of chronic disease requires competent decision making and management by patients. As such, initiatives such as this, which facilitate patient self-management are key. Sharing by default also enables parents to feel more in control of their children’s health. As one parent of a childhood stroke survivor explained, ‘it can be anxiety-provoking to wait on reports, feeling clueless and helpless.’

Sharing by default will facilitate improved coordination of care, and support more effective decision making by health professionals, which will reduce avoidable adverse events and hospital admissions, and duplicate testing, and increase the use of appropriate, evidence-based treatments and interventions. This in turn will deliver savings to our health system. For community-based clinicians, including GPs and allied health professionals, who play a critical role in the treatment and care of survivors of stroke following their discharge from hospital, their preference would be to access diagnostic imaging and pathology results directly from a patient’s *My Health Record*, as hospital discharge summaries often do not arrive in a timely fashion, or at all, and are frequently unclear and/or incomplete.

While more than 90 percent (23.7 million) of Australians have a *My Health Record*, not all are familiar with how to use it. Navigating *My Health Record* via the MyGov website or the app can be challenging for those who are tech savvy, let alone those who are not used to apps or accessing information online. It has been suggested that one of the unintended consequences of providing patients with access to more information in their electronic medical records (EMRs) could be worsening inequality,

as resources are diverted to those who are able to read and understand the information in their EMR, or who have the confidence to ask questions. Therefore, developing and testing ways to mitigate this risk will be an important consideration when introducing the proposed changes to *My Health Record*.

For those patients who do not have a *My Health Record*, or who do not share their record with all of their treating health professionals, it is critical these health professionals continue to be able to access patients' diagnostic imaging and pathology test results and reports through the usual means, including via secure web-based password-protected Referrer Portals on imaging and pathology providers' websites.

What does the government need to consider when developing requirements to share diagnostic imaging and pathology results to *My Health Record*?

When the Australian Government is communicating these changes to *My Health Record* to the general public, it is critical it clearly states that this is not a diagnostic tool, and it is essential patients speak directly with their referring health professional about the results of their diagnostic imaging and pathology tests. Some patients may wrongly assume that once their results are shared to *My Health Record*, particularly results that are urgent or abnormal, this will automatically prompt a follow-up appointment with their referring health professional, and it is important this is clarified.

One of the concerns health professionals have expressed regarding providing patients with more information, is the transfer of responsibility to them to check for errors, deal with uncertainty, and worry about results, which is not something all patients will want. From a medico-legal perspective, if there is now an increasing responsibility on patients to ensure their referring health professionals have access to their *My Health Record*, this could mean imaging and pathology providers would need to include a disclaimer that they are not responsible if the health information they provide is not actioned in a timely fashion.

Privacy and access

Recent high profile data breaches, including the leak of sensitive Medibank customer health information, has undermined the public's trust in the ability of companies and governments to protect our private data. Many people, including many older Australians, remain worried about falling victim to scams, or having their confidential health record data hacked. As such, when the Australian Government is communicating these changes to *My Health Record* to the general public, it is important it clearly reiterates that the strict privacy and access standards that currently apply to *My Health Record* will continue to apply after sharing by default is implemented. Specifically, that *My Health Record* is a safe and secure system, and that the individual record holder is able to manage important information, control who has access to it, and see what has been accessed. This may also be an opportune time for the Government to promote the free, online courses it offers on cyber safety as part of [Be Connected](#).

Quality of information available in records

Sharing by default will put diagnostic imaging and pathology providers under increasing pressure, and it is critical they ensure the test results, images and reports they transmit to a patient's *My Health Record* are accurate, complete, and presented in a useable format. Importantly, diagnostic imaging and pathology providers do not have the same duty of personalised care to individual patients as

other health professionals do, and it is important there are clear guidelines about how the quality of information available in *My Health Record* will be monitored.

What do you think would be the impact of consumers having immediate access to diagnostic imaging and pathology reports in their *My Health Record*?

While there is agreement that providing patients with access to their own health information is an essential part of delivering high quality healthcare, there are concerns about the possible consequences of patients having *immediate* access to diagnostic imaging and pathology reports in their *My Health Record*. Importantly, complex pathology and radiology reports have usually been released to patients in a delayed fashion, rather than immediately, in order to allow health professionals to discuss and contextualise the results with the patient before providing them with the results.

In the US, the 21st Century Cures Act, which became law in 2016, includes a requirement that came into effect in 2021 requiring health care institutions to release all electronic health information, including diagnostic imaging and pathology reports, to patients immediately. A 2021 survey of US health professionals undertaken at the time this requirement was introduced, showed that 63 percent agreed the immediate release of electronic health information was more confusing than helpful to patients.¹

While immediate access to diagnostic imaging and pathology reports would be very useful for patients awaiting urgent results, health professionals have identified a number of key concerns with this proposed approach. For many of the patients who receive their diagnostic imaging and pathology results immediately on *My Health Record*, they will not have the expertise to understand, or determine the clinical importance of these results. As a result, they may contact their referring health professional to seek further explanation; however, many medical practices do not have workflows in place to be able to call patients back immediately. Depending on the nature of the test results, this delay could cause some patients considerable stress and anxiety.

These concerns have also been raised by Australian survivors of stroke, their families and carers, and the health professionals who treat and care for them:

“I’ve always been one to talk to my doctors and ask questions. I’m a visual person, so like to read reports and view scans. I believe it is important to understand and be informed about my health. I support access, but not before the information is explained to me.”

Survivor of stroke

“My concern is that patients may misinterpret results before they can be properly explained by a health professional. I would prefer for these results to be made available on *My Health Record* after a patient has had a chance to speak with their doctor about them.”

Family member and carer of a young survivor of stroke

“I do believe that patients having access to their medical reports and records is a fantastic idea; however, as a health professional I also have a few reservations about this. Diagnostic images and the results of pathology tests can provide us with important information about our health, but there is

also a risk they can be misinterpreted if the reader is not experienced, potentially causing undue stress or anxiety. I feel that any raw results or images should be accompanied by a report on the data presented. However, if the report provides information concerning a patient's ill health, which will require further consultation, treatment and care, it might be better to wait until a health professional has the opportunity to share the relevant information with the patient, and allow them the opportunity to ask questions. After appropriate consultation, the patient should then have full access to the images and test results."

Health professional and survivor of stroke

1. Leonard LD, Himelhoch B, Huynh V, Wolverton D, Jaiswal K, Ahrendt G, Sams S, Cumbler E, Schulick R, Tevis SE. Patient and clinician perceptions of the immediate release of electronic health information. *Am J Surg*. 2022. 224(1 Pt A):27-34.

In the proposed model of care, where consumers have immediate access to their pathology and diagnostic imaging results, what resources will they need to support them when viewing these results in *My Health Record*?

There are a number of approaches the Australian Government can use to support patients with this new level of information transparency.

Firstly, it is important that Government communicates to the general public about what the changes to *My Health Record* are, and what it means for them. Specifically, that they will now have immediate access to results such as blood tests, imaging and pathology through *My Health Record*, and because of this change, they may see their test results before their referring health professional has reviewed them.

Secondly, Government should work with patients, their families and carers, and health professionals, to co-design educational tools and resources focused on ensuring patients can better understand their health information and test results, and minimising the anxiety and stress that can accompany results. These educational tools should be integrated into *My Health Record*, or into the pathology and diagnostic imaging results reports themselves, to support patients while they review their results. One example could be the development of a glossary of commonly used terms, which will ensure patients are able to access accurate medical resources that have been appropriately reviewed, rather than consulting 'Dr Google', where they are likely to face misinformation.

An important part of this work should be a commitment from the Australian Government to the principles of digital inclusion with respect to *My Health Record*, with a particular focus on issues relating to the affordability and accessibility of data and digital services. Specifically, a focus is needed on groups within the population that may face greater barriers to accessing imaging and pathology results in *My Health Record*, due to the affordability of devices or the affordability and availability of broadband services. This includes, but is not limited to, people with a disability, regional, rural and remote Australians, First Nations Australians, people from culturally and linguistically diverse backgrounds and older Australians. In addition, it is important the Australian Government ensures any improvements or upgrades to *My Health Record* are designed with peak accessibility for people with disabilities (e.g. vision loss, cognitive issues, etc.), to avoid worsening health inequities.

What safety features could ensure follow-up clinical care happens promptly?

As mentioned previously, many of the patients who receive their diagnostic imaging and pathology results immediately in *My Health Record*, may contact their referring health professional to seek further explanation; however, many medical practices do not have workflows in place to be able to call patients back immediately. Specifically, many Australians are struggling to access GPs due to demand outstripping supply, particularly in outer metro and rural and regional locations and growth corridors, where 20 to 30 percent more GPs are needed to service the needs of these communities. Further, many GPs work part-time, or across several clinics, and may not be available to respond to patients immediately. Importantly however, there are several strategies that could be employed to better support health professionals and medical practices to create more efficient workflows, and ensure patients receive appropriate follow-up clinical care.

Firstly, it is important medical practices are able to clearly communicate to their patients the timeframe within which they can expect to hear from their referring health professional to discuss their test results, and how this timeframe will differ for normal and abnormal results. During the initial patient consultation, when a particular pathology or diagnostic imaging test is ordered, there is an opportunity for the referring health professional to counsel the patient proactively, and educate them about the possible and likely results of the test, as well as how different results may influence their treatment plan. This, coupled with the availability of patient-focused education tools and resources integrated into *My Health Record* mentioned previously, will better equip patients to interpret and contextualise their results while they are waiting for an appointment with their referring health professional, and help reduce any potential anxiety.

Secondly, there is an opportunity for the Australian Digital Health Agency to work with health professionals in order develop specific solutions using *My Health Record* to improve clinician workflows and the patient experience. For example, *My Health Record* could be adapted to enable it to flag high priority results, such as new cancer diagnoses or any result from a patient previously identified by the health professional as prone to high anxiety. Similarly, *My Health Record* could be used to automate test-result messages in cases where results are normal.

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