

Modernising My Health Record – Sharing Pathology and Diagnostic Imaging Reports by Default and Removing Consumer Access Delays Submission

31 October 2023



OUR VISION

A healthy Australia, supported by the best possible healthcare system.

OUR MISSION

To conduct research, educate and influence the healthcare system to achieve better health outcomes, improved patient and provider experience, greater equity and sustainability.

OUR GUIDING PRINCIPLES

Healthcare in Australia should be:

Effective

Accessible

Equitable

Sustainable

Outcomes-focused.

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INTRODUCTION

The Australian Healthcare and Hospitals Association (AHHA) welcomes the opportunity to provide feedback on the *Modernising My Health Record – Sharing pathology and diagnostic imaging reports by default and removing consumer access delays* Consultation. AHHA commends the commitment of the government in responding to the Strengthening Medicare Taskforce Report.

ABOUT AHHA

AHHA has been the national voice for public health care for more than 70 years, maintaining its vision for an effective, innovative, and sustainable health system where all Australians have equitable access to health care of the highest standard, when and where they need it.

AHHA is Australia's national peak body for public hospitals and healthcare providers. Our membership includes state and territory health departments, Local Hospital Networks (LHNs) and public hospitals, community health services, Primary Health Networks (PHNs) and primary healthcare providers, aged care providers, universities, individual health professionals and academics. As such, we are uniquely placed to be an independent, national voice for universal high-quality healthcare to benefit the whole community.

To achieve a healthy Australia supported by the best possible healthcare system, AHHA recommends Australia reform the healthcare system over the next 10 years by enabling person-centred, outcomes-focused, and value-based healthcare. This requires:

- 1. A nationally unified and regionally controlled health system that puts people at the centre
- 2. Performance information and reporting that is fit for purpose
- 3. A health workforce that exists to serve and meet population health needs
- 4. Funding that is sustainable and appropriate to support a high-quality health system.

AHHA's *Healthy people, healthy systems*¹ is a blueprint for reform (the Blueprint) with a series of short, medium, and long-term actions to achieve these goals.



PART A: BETTER ACCESS

Q1. What do you think will be the impact of diagnostic imaging and pathology providers having to share results to My Health Record by default? This includes the impact on:

a). Consumers and/or carers:

The AHHA commends the action to mandate uploading of pathology and diagnostic imaging results to My Health Record, assuming current jurisdictional exceptions should continue to apply (e.g., genetics, pregnancy results for minors, paediatric results, autopsy reports, and test results relating to prisoners).

As a collective, consumers, healthcare providers, and the healthcare system benefit from initiatives that seek to enable person-centred, team-based models of care that are respectful of, and responsive to, the preferences, needs and values of individuals, their carers and families².

Achieving this requires people to be seen as more than just their care needs. Rather, they should be viewed first as experts in their own health and also as being in charge of their own lives. Yet, consumers have reported entering healthcare settings fearful for their wellbeing, and anxious due to their lack of control over healthcare processes and outcomes³. Transparency of and access to testing results, will enable consumers to regain control and reassures them about actively participating in their healthcare as an equal participant within the care team.

Ensuring consumer engagement in the proposed change to improved sharing of information to My Health Record is imperative. The AHHA recommends the government develop a timely communication campaign aimed at consumers that builds awareness of the proposed changes to improve sharing of information to My Health Record prior to its enaction. This includes communication of consumers' right to prevent results from being uploaded.

b). Healthcare providers:

Achieving person-centred, team-based models of care requires efficient and effective collaboration of clinicians together with the resources available to them. My Health Record has provided an opportunity to centralise sharing of information between clinicians but has so far been ineffective in building collaborative capacity due to low submission rates. The mandatory uploading of pathology and diagnostic imaging results to My Health Record will support collaboration, and assist in reducing the opportunistic provision of low value care (as described in the *Part A: Better Access* Consultation Paper).

Following consultation with AHHA members, we have identified the following areas within the proposed changes for improved sharing of information to My Health Record that require further consideration of their impact on the workforce:



1. Accountability:

- There must be an agreed process and responsibility for who sorts out error queues.
- There should be advice given to the pathology sector with respect to the medico-legal liability of pathologists in relation to MHR reports accessed directly by consumers which are intended for requesting clinicians who are providing clinical care to patients.
- It is important that the reports uploaded to the MHR are the final and complete reports. A statement on the report or MHR that the report may be subject to changes, alterations, errors and omissions is inadequate as patients may not see the qualifying statement.

2. Interoperability:

- Some Laboratory Information Systems (LIS') do not allow reasons for <u>not</u> uploading reports to My Health Record. This should be amended to ensure transparency.
- Using a Hospital Registration Number (HRN) to upload data to the Individual Healthcare Identifier (IHI) isn't possible when using forms in private pathology practices.
- Continuation of interoperability funding for My Health Record will be necessary.

3. Translation from clinical to consumer-friendly results:

As it stands, reports submitted to My Health Record can be commented on by pathologists
and diagnostic imagists. However, there is concern that adding comments may generate an
additional report and cause confusion for the consumer, who may be unaware that further
review and confirmation, or a change to the report is required. Deliberation of the
appropriate solution is required through consultation with clinicians.

c). The Health System:

The current Australian healthcare system is unsustainable. Both healthcare systems and consumers are struggling with rising costs and increasing demands on services, perpetuating inequitable access to and reduced quality of services⁴. A value-based health care approach offers a consumer-centric way to design and manage health systems, capturing the health outcomes that matter to people and communities, relative to the costs required to achieve them⁵. The AHHA commends that the Modernising My Health Record initiatives reflect a value-based healthcare approach.

Successful transformation of the health system towards a person-centred, outcomes-focused, value-based healthcare fundamentally requires effective partnership and collaboration with consumers. The impact of mandatory uploading of pathology and diagnostic imaging results to My Health Record will foster this, most notably through the empowerment of consumers and the reduction in provision of low value care.

It is hard to define and appropriately measure low value and harmful care. As such, and despite ongoing efforts to identify and reduce it, low value care continues to permeate the provision of healthcare services in Australia. What is clear is that many laboratory tests are overused, with an estimated 10-40% of haematology, biochemistry and immunology tests in 2020 being unnecessary⁶. Investment in the improved sharing of information to My Health Record to reduce unnecessary or repetitive medical testing will improve the both the financial and climate sustainability of the sector through the reduction in medical indemnity claims and the number of unnecessary referrals⁷.



Q2. What does the government need to consider when developing requirements to share diagnostic imaging and pathology results to My Health Record? Particularly consider:

- Clinical safety
- Consumers' control of their health information
- Privacy
- Quality of information available in records

The AHHA requests that the government consider the risks associated for consumers accessing their reports without supplementary education and support resources. Currently, reports submitted to My Health Record are primarily intended for clinicians, containing clinical dialog, and requiring a high level of health literacy to comprehend. Consumer experiences of waiting for reports, and then attempting to comprehend test results contained within the reports, is often associated with heightened anxiety⁸. While the latter of the two proposed changes to improved sharing of information to My Health Record (*Part B: Faster Access*) addresses the anxiety associated with waiting for diagnostic results, the AHHA suggests the publication of current pathology and diagnostic imaging results, alongside;

- I. workforce support to allow the translation of test results from clinician-oriented language to consumer-friendly language,
- II. the inclusion of support services and contacts, such as an after-hours GP phone line, and,
- III. a series of validated, consumer-friendly health resources for further education and reading to support health literacy development (such as Pathology Tests Explained [formerly Lab Tests Online] as is currently present on My Health Record:

 https://pathologytestsexplained.org.au/).

The AHHA recommends the government consult directly with consumers and clinicians to inform best practice and capture what matters to consumers in an attainable way.

A complimentary or alternative awareness campaign for consumers may be necessary to prevent consumers from attempting to interpret results in isolation from their clinical care provider, or misinterpretation of clinical comments intended for the referring clinician.

The AHHA further recommends the government pursue direct consultation with pathology and diagnostic imaging providers to address jurisdictional differences in uploading results to My Health Record. Through consultation with our members, we have heard that:

- There needs to be consideration of excluding test results that could have significant
 implications to patients and require healthcare providers to provide additional appropriate
 advice and support. To do so would require a national list of exceptions agreed to by
 pathologists and medical imagists from across jurisdictions to unify consumers' experiences
 of care.
- Currently, some jurisdictions have legislative or policy positions on prohibiting the sharing of
 certain reports to My Health Record, such as pregnancy tests for minors or paediatric results
 (as discussed in Q1.). Similarly, there needs to be a national list of agreed upon exceptions
 for mandatory uploading.



Q3. Please share any advice or comments not covered by previous questions:

n/a

PART B: FASTER ACCESS

Q1. What do you think the impact of consumers having immediate access to diagnostic imaging and pathology reports in their My Health Record? This includes the impact on:

a). Consumers and/or carers:

As described in *Part A: Better Access* Q2, consumers are prone to heightened levels of anxiety following the release of their test results onto My Health Record. Without the appropriate contextual information, health education resources, and appropriate support contacts, consumers may fail to fully comprehend test results, leading to feelings of disempowerment and becoming overwhelmed navigating and participating in the health system⁹.

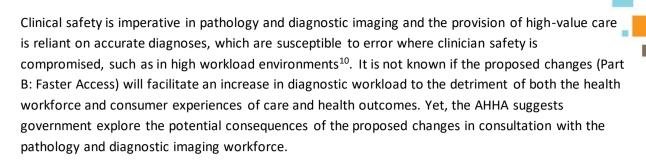
Immediate access to results (as described in *Part B: Faster Access*) may exacerbate these experiences of anxiety, particularly given the absence of a mechanism to address publication of preliminary results. Without a formal process to identify incomplete or amended results for consumers, there is concern that consumers will act on inaccurate or complex results to an unknown effect on their wellbeing. The AHHA recommends a 24 hour hold on inconclusive or preliminary results to enable clinicians to address clinical errors. Further, both a 'flag' mechanism on the results, and a process to contact the consumer to inform them of amendments to previously published results should be developed for transparency in care.

Beyond these concerns, expedited access to test results will enable consumers to access care in a timely manner, circumventing unnecessary delays. The AHHA highly commends this given the use of pathology testing and diagnostic imaging to identify serious health conditions, enabling prompt clinical management.

b). Healthcare providers:

The healthcare workforce underpins the success of delivering the proposed changes to improve sharing of information to My Health Record, described in this consultation. It is the workforce that will shoulder the burden of the proposed changes, providing both clinical, technical, and emotional support to consumers to coordinate their care. Yet, the impact of faster access to results on workforce sustainability has not been considered.

The healthcare workforce is in crisis, struggling to meet the increase in demands for health services post COVID-19. The pathology sector is still recovering from strained workforce capacity brought about by the increase in workload volume as a cause of the COVID-19 pandemic. Both pathologists and medical imagists frequently deal with time sensitive diagnoses, where delayed results can have adverse health outcomes for the intended consumer^{10,11}.



c). The Health System:

Covered in earlier responses.

Q2. What resources should consumers have access to when they view a result in My Health Record? This question is about how to support consumers in a model of care where they have near real time access to their pathology and diagnostic imaging results.

Broadly, the AHHA suggests that the government consider the health literacy of the Australian population in developing or embedding resources alongside results in My Health Record. Beyond this, resources identified for consideration, either in the development of further resources or for direct use, can be characterised as follows:

1. Contextual medical information:

Such as a scale of normal to abnormal results¹², or the inclusion of diagnostic images to accompany written results¹³, to gauge the severity of test results on their wellbeing.

Self-management guidance and resources have also been suggested¹².

2. Further educational resources:

As already suggested, the website Pathology Tests Explained¹⁴ is a consumer-friendly resource for the translation and comprehension of pathology results. HealthDirect is a government website that provides a plethora of validated, consumer-friendly medical information, including *Understanding Pathology Tests*¹⁵ and *Diagnostic Tests*¹⁶ more broadly.

3. Support services and contacts:

This includes providing clinician or practice contact details for ease of access alongside results for consumers to use, should they require clarification or additional support.

There may also be local health networks to support consumers navigating complex health diagnoses, that can be identified and listed through HealthPathways, translated to a consumer-friendly format.



Q3. What safety features could ensure follow-up clinical care happens promptly?

The AHHA suggests consulting with both consumers and clinicians to inform best practice to automise appropriate follow-up care. However, it must be made clear that the responsibility for follow-up clinical care resides with the clinician who has referred the consumer for pathology testing or diagnostic imaging. This is necessary to ensure continuity of care for consumers who may not be aware of the need for a follow-up, or who may not check their results in My Health Record.

For prompt follow-up for high-risk pathology results, the AHHA recommends consideration of the National Pathology Accreditation Advisory Council's (NPAAC), Requirements for the communication of high-risk pathology results¹⁷. While each Approved Pathology Authority has their own high-risk result communication policy, the NPAAC's may present a basis to develop a wider communication plan from.

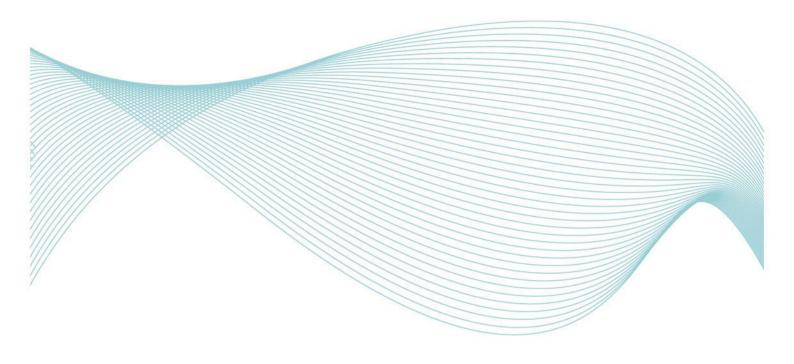
Q4. Please share any advice or comments not covered by previous questions.

n/a



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