

Modernising My Health Record: *Sharing pathology and diagnostic imaging reports by default and removing consumer access delays' consultation*

**Response by the
Royal Australian College of General Practitioners**

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Introduction

The Royal Australian College of General Practitioners (RACGP) welcomes the opportunity to provide a response to the Department of Health and Aged Care's discussion papers on 'Modernising My Health Record – Sharing Pathology and diagnostic imaging reports by default and removing consumer access delays.'

The RACGP supports consumer ownership and control over their My Health Record. We support the "authority under the law" consent model where registered healthcare provider organisations are authorised to collect, use and disclose health information for the purpose of providing healthcare, subject to any access controls set by the recipient.¹ This model facilitates the sharing by default of pathology and diagnostic imaging. My Health Record is not a communication tool for direct communication between healthcare providers and does not replace the patient's health record or relationship with the usual general practice. It remains essential for healthcare providers to communicate directly with each other.

The RACGP has been a key stakeholder in the development of the My Health Record and encouraged its use across general practice. We have worked closely with relevant stakeholders to address usability issues and to ensure documents uploaded are safe, accurate and relevant to clinical practice. We have advocated for greater uptake of the My Health Record across the healthcare sector to improve patient outcomes.

About the RACGP

The RACGP is the voice of GPs in our growing cities and throughout rural and remote Australia. For more than 60 years, we have supported the backbone of Australia's health system by setting the standards for education and practice and advocating for better health and wellbeing for all Australians.

As a national peak body representing over 46,000 members working in or towards a career in general practice, our core commitment is to support GPs from across the entirety of general practice address the primary healthcare needs of the Australian population.

We cultivate a stronger profession by helping the GPs of today and tomorrow continue their professional development throughout their careers, from medical students and GPs in training to experienced GPs. We develop resources and guidelines to support GPs in providing their patients with world-class healthcare and help with the unique issues that affect their practices. We are a point of connection for GPs serving communities in every corner of the country.

Australia's GPs see more than two million patients each week, and support Australians through every stage of life. The scope of general practice is unmatched among medical professionals.

Patient-centred care is at the heart of every Australian general practice, and at the heart of everything we do.

Summary of RACGP Recommendations

In response to the Department of Health and Aged Care's (the Department's) consultation on Modernising My Health Record, the RACGP recommends:

- sharing of pathology and diagnostic imaging results by default should be required of all pathology and diagnostic imaging providers
- a thorough, and wide-reaching communication campaign needs to be delivered to ensure consumers are aware their pathology and diagnostic image reports are now shared by default to their My Health Record.
- **the 7-day delay to pathology and diagnostic imaging results being uploaded to My Health Record should remain in place**, except for tests already available in real time such as influenza and HbA1c

Maintaining the 7-day rule allows consumers to have access to their health information, albeit with a small delay that allows their GP or other clinician to discuss their results with them. We do not consider the benefit of real time access to results outweighs the potential harm of consumers misinterpreting results or receiving unfortunate results with no immediate clinical support.

If the 7-day rule is to be removed, the RACGP recommends evaluation is undertaken to provide data that this change to the My Health Record has achieved the goal of supporting better patient health outcomes.

RACGP Response

The September 2023 Modernising My Health Record Discussion Papers posed questions to explore how to implement changes to My Health Record which will allow sharing of pathology and diagnostic imaging results to My Health Record by default and removing the 7-day delay to consumers accessing these results.

The following section provides detailed responses to the questions most relevant to general practice and support the RACGP's recommendations.

Part A: Better Access – sharing pathology and diagnostic imaging reports to My Health Record by default

1. How can we most effectively provide or communicate change and adoption resources for:

- **Consumers:**

A wide-reaching awareness campaign should be rolled out to consumers, similar to previous My Health Record and other digital health campaigns run by the Australian Digital Health Agency (the Agency).

Messaging should include information reinforcing the My Health Record is a consumer-controlled record and consumers are able to manage the privacy controls of their record to restrict access to specific healthcare organisations.

GPs should not be expected to explain the changes to patients during consultations, so consumer resources available through practices (such as posters or flyers) that GPs can refer their patients to would be helpful.

- **Treating healthcare providers who may request tests and/or use test results:**

Communication with healthcare providers should begin well in advance of any changes coming into place. Peak primary healthcare organisations should be engaged to deliver information to their members to raise awareness of these changes, discuss potential impacts and provide direction on where to obtain assistance if required.

The RACGP has a long history of working with the Agency to shape and deliver messaging and education to GPs regarding changes to My Health Record and other digital health initiatives affecting general practice. We welcome the opportunity to work with the Agency and the Department again in this instance.

2. What barriers are there to better interoperability of My Health Record with existing software for diagnostic imaging and pathology customers?

Some RACGP members have described the My Health Record interface for viewing test results within their clinical information systems as “clunky, hard to navigate, and slow.”

It has also been noted it is particularly difficult to see each result where multiple test reports are available and that it is difficult to access images.

Once the mandatory uploading of pathology and diagnostic imaging is in place general practice systems will need to:

- efficiently search large volumes of data to ensure ease of access to relevant reports
- be responsive to ensure there are no system delays when displaying data
- display reports in a way that is easy to read and accessible
- provide consistency in terminology and reporting to support safe quality care.

Results will need to be sent to My Health Record as atomic data to support the seamless integration of reports into general practice clinical systems.

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

• Consumers and/or carers:

For consumers and/or carers who see multiple healthcare providers the impact could be significant. This could help support continuity of care and result in better patient outcomes.

It may save time and out-of-pocket expenses for consumers who may otherwise have to request copies of their test results or undergo testing again.

• Healthcare providers:

Healthcare providers may save time by being able to access test results ordered by other clinicians or by not having to re-order test already requested.

In some cases, having visibility of test results ordered by other clinicians may help with clinical decision making and will allow for longitudinal comparison of reports over time.

• The broader healthcare system:

The main benefit to the broader health system we foresee is a possible reduction in duplicate testing, thereby reducing cost to Medicare, and consumers via out-of-pocket expenses.

4. 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:

The government needs to ensure there are safeguards in place so pathology and diagnostic imaging results are uploaded to the correct My Health Record.

• Consumers' control of their health information:

With pathology and diagnostic imaging results being shared to My Health Record by default, many patient records will start to contain a lot more information where previously there may have been very little. Patients should be reminded of the controls in place to manage the information within their record, and the benefits of having such information available to their GP or other treating clinicians.

• Privacy:

Privacy issues may occur where a consumer is not aware their pathology and diagnostic imaging results are being uploaded to their My Health Record and are therefore not aware results are visible to people who may have access to their record.

This is particularly important to consider for vulnerable groups such as young people whose parents have access to their record or where there are risks to victims of domestic violence. Perpetrators of domestic violence may have access to their partner or child's My Health Record, and information within their record may put victims at further risk or reveal their locations. Adverse consequences may occur for these groups where a parent or partner has immediate access to the person's test results, more so where they are notified that data has been uploaded to My Health Record and may view it before the record owner has the chance to hide the documents if necessary.

A strong communication campaign aimed at consumers highlighting the need to set up privacy controls on their My Health Record will be critical to mitigate some of these risks.

- **Quality of information available in records:**

Data uploaded to My Health Record should be accurate, relevant, and consistent at the time of upload. All healthcare organisations that actively participate in My Health Record should ensure their local data is fit to be shared across the healthcare sector. Care should be taken to avoid duplication or omissions of test results being uploaded.

The RACGP supports the development of initiatives to drive data quality in the sector, which would in turn support the quality of information uploaded to My Health Record.

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

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

- **Consumers and/or carers:**

It may be helpful for some consumers to have immediate access to some results, however, it is important to consider the various ways results could be interpreted, including:

- an abnormal result that may not be clinically important or urgent
- a normal result that prompts subsequent tests to be performed
- an abnormal result that could suggest minor or serious diagnoses
- an abnormal result that indicates a life-changing diagnosis
- misinterpretation of terminology used in a medical report.

In any of these cases a consumer may experience anxiety or distress when no context is provided for the results. Consumers who choose to do their own research into the results may find information that is inaccurate and adds to their distress. It is also possible consumers may decide to self-manage their condition or avoid follow up with their GP if they don't perceive there is value in doing so, which could worsen their overall health outcomes.

There will be consumers who could view results that indicate an actual serious or life-changing diagnosis, without the support and guidance of their GP or other treating clinician. In normal circumstances, GPs have time to review the results, consult with other clinicians and formulate a considered plan going forward prior to discussing the results with their patients.

- **Healthcare providers:**

For the GP/practice who requested the tests, there is limited benefit as the results are viewable via their clinical information system. There may be benefit to other clinicians where the results are relevant to their interaction with that patient.

Additionally, GPs and their teams may have to deal with the fallout of patients misinterpreting their results and requiring reassurance including in situations where follow up is usually not required or could have waited until the next routine appointment. This can add unnecessary pressure to GP and practice staff workloads and reduce the availability of appointments.

The Department should also seek medicolegal advice to ensure GPs are not exposed to additional medicolegal risk. If a decision is made to progress real time access to pathology and diagnostic imaging results, consideration should be given to a no-liability clause for the requesting clinician in the event there are adverse outcomes following actions consumers may take after viewing their results in their My Health Record.

- **The broader healthcare system:**

It may reduce duplication in pathology and diagnostic imaging requests where a patient is hospitalised or seen by another clinician within 7 days of relevant tests being performed.

There appears to be a lack of robust data/evidence on the likely impact, both negative and positive, of such a change. Evaluation is warranted to provide insights into the impact of any change.

2. 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.

Before viewing results, patients should see a message reminding them that their results need to be interpreted by a clinician and to not take action until they have spoken with clinician who requested the tests. It should be emphasised that the clinician will be in contact with them, which is current standard practice for the follow up of test results.

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

GPs are already alerted through their clinical information systems when a patient's pathology or diagnostic imaging results become available. GPs are able to apply clinical judgment to determine whether the results require urgent follow up or not and have existing processes within their practice around how and when this happens. My Health Record is not part of this workflow.

Allowing consumers real time access to their results disrupts this existing process and may encourage patients to contact their GP to enquire about their results, and as discussed earlier, these patients may be distressed and wanting to see their GP urgently. This puts additional pressure on GPs and their practice teams to manage these enquiries and appointment requests.

Additionally, the patient's usual GP is unaware when new items are added to a My Health Record. Currently there are no options allowing GPs to be notified when information is added to My Health Record across most general practice systems. The RACGP recommends a notification process is established to advise requesting clinicians results and other new documents have been added to the My Health Record as a way to support patient safety This will require a detailed development and testing process which needs to be clinician led and not create additional medico legal risk for requesters.

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

The RACGP welcomes sharing of pathology and diagnostic imaging results to My Health Record by default. The shift to sharing by default is significant and is a welcome improvement to the functionality of My Health Record. However, the RACGP does not support near instant access to all results by consumers.

The RACGP appreciates the importance of consumers having real time access to test results such as influenza, COVID-19, HbA1c etc. (which should continue to be delivered instantly to My Health Record), and some consumer's preference for real time access to all results. Studies cited in the 'Part B' discussion paper highlight a preference by consumers to have immediate access to their results, however this does not necessarily mean there is a clinical benefit in doing so. As discussed throughout our response, there are many instances where instant access to results could lead to an adverse advent or unnecessary anxiety and worry for consumers.

[A survey](#) conducted by the American Medical Association found that while some consumers do want instant access to the test results, 65% of respondents wanted to speak with their clinician before receiving life changing results. While most patients will usually receive normal results, many will not, and receiving possibly life changing news via My Health Record with no support or context from the clinician who ordered the test is not appropriate.

If the 7-day rule is removed, the RACGP recommends evaluation is undertaken to provide data that this change to the My Health Record has achieved the goal of supporting better patient health outcomes. An evaluation process should also identify adverse outcomes due to patients having immediate access to their results and could support the further refinement of future policies related to My Health Record.

Conclusion

The RACGP supports consumers having access to their health information in a way that is safe, secure, and does not jeopardise the wellbeing of patients. Sharing of pathology and diagnostic imaging results by default is a welcome improvement, however, we do not support consumers having real time access to all results.

Maintaining the 7-day rule allows consumers to have access to their health information, albeit with a small delay that allows their GP or other clinician to discuss their results with them. We do not consider the benefit of real time access to results outweighs the potential harm of consumers misinterpreting results or receiving unfortunate results with no immediate clinical support.

The RACGP thanks the Department for the opportunity to provide this feedback. We are happy to discuss the issues raised in our submission and to work with the Department on supporting general practice through the proposed changes if enacted. To arrange a time to discuss further, please contact Joanne Hereward, Program Manager – Practice Management and Technology via joanne.hereward@racgp.org.au.

References

1. RACGP My Health Record position statement <https://www.racgp.org.au/running-a-practice/technology/clinical-technology/my-health-record-in-general-practice/racgp-my-health-record-position-statement>