



Improved sharing of pathology and diagnostic imaging reports to My Health Record

Summary of key themes and feedback from consultation process



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Introduction

The Department of Health and Aged Care (the department), in partnership with the Australian Digital Health Agency (the Agency), undertook a [public consultation process](#) from 8 September to 31 October 2023 to seek feedback to inform implementation of 2 changes to improve sharing of pathology and diagnostic imaging reports to My Health Record:

- **‘better access’**: introducing requirements for pathology and diagnostic imaging providers to share reports to My Health Record by default
- **‘faster access’**: removing the 7-day delay so consumers can see most pathology and diagnostic imaging results as soon as they have been uploaded to My Health Record.

These changes build on the extensive existing My Health Record program of work, which includes a strong legislative framework and system security settings, to give consumers and their healthcare providers better access to key health information when it is needed. As outlined in the [‘better access’](#) and [‘faster access’](#) consultation papers, these changes will not remove any of the consumer controls in My Health Record. Consumers will still be able to:

- set privacy controls in My Health Record, including who can access their record and what information is accessible, and see when healthcare providers have accessed their record
- request to not have their pathology and diagnostic imaging reports shared to My Health Record.

Submissions were sought via a survey (see **Appendix A**) on the department’s consultation hub. Stakeholders could also lodge a submission with the department. 416 submissions were received, noting this figure reflects adjustments to remove duplicates. Respondents included:

- consumers/individuals/patients/family members or carers of consumers
- pathology services delivery providers
- diagnostic imaging service delivery providers
- other healthcare providers/practitioners (excluding pathology and diagnostic imaging service providers)
- professional bodies/peak organisations
- state and territory government health departments/agencies
- others.

Submissions will be published on the department’s [consultation hub](#) where the respondent provided consent for this to occur.

The purpose of this report is to summarise the key themes and feedback provided across submissions in relation to barriers, enablers, concerns and opportunities. An overview is provided on the following pages. This report does not reflect a final policy position on the implementation approach for these changes.

Feedback is informing implementation, including opportunities to build on existing communication and education activities for consumers and healthcare providers. Further consultation will be undertaken as implementation progresses.

The department and Agency thank all respondents who provided feedback in response to the consultation process. The advice, expertise, insights and views shared in submissions will be invaluable in informing the implementation approach for these changes.

Overview of key themes and feedback

Table 1: Overview of key themes and feedback on ‘better access’

Barriers/concerns	Enablers/opportunities
<p><u>BARRIERS</u></p> <p>Legislation and policies may prevent or impact sharing by default</p> <ul style="list-style-type: none"> • Legislation in some states/territories prevents certain results from being uploaded without explicit patient consent. • Some organisation policies discourage or limit results from being uploaded without explicit patient consent. • Some results are not uploaded due to state and/or organisation policies. <p>Not all software is conformant or has the required functionality to enable sharing by default</p> <ul style="list-style-type: none"> • Some software does not meet conformance requirements to upload to My Health Record. • Some clinical information systems do not have the ‘do not send’ to My Health Record functionality. <p>Costs and availability of technical resources to implement changes</p> <ul style="list-style-type: none"> • Costs associated with implementation, particularly costs associated with initial software upgrades, may be a barrier for some providers. • Technical resources may not be readily available to implement required changes, particularly in smaller regional/rural services. <p>Sharing by default might not always be possible</p> <ul style="list-style-type: none"> • Some healthcare providers are not currently eligible for a Healthcare Provider Identifier (HPI-I) and are therefore unable to upload. • Upload is not possible where a consumer does not have an Individual Healthcare Identifier (IHI) or where IHI data matching fails. <p><u>CONCERNS</u></p> <p>Consumer misinterpretation of results, wellbeing and outcomes</p> <ul style="list-style-type: none"> • Consumer misinterpretation of results can lead to distress or loss of follow up care.* • Consumer distress if receiving sensitive or abnormal results in an unsupported environment.* 	<p><u>ENABLERS</u></p> <p>Establish a national approach for sharing by default</p> <ul style="list-style-type: none"> • Develop a nationally consistent approach for sharing by default to: <ul style="list-style-type: none"> ○ remove variation in circumstances where results are not uploaded ○ harmonise legislation/regulations/policies, particularly those that relate to privacy and consent. <p>Recognise that upload should be withheld in some circumstances and ensure safeguards for managing sensitive/abnormal/time-critical results</p> <ul style="list-style-type: none"> • Recognise that upload should be withheld in some circumstances. • Ensure safeguards for managing sensitive/abnormal/time-critical results.* <p>Review and standardise reporting and support consumers to understand results</p> <ul style="list-style-type: none"> • Review how reports are written and provide information to support consumers to understand results and next steps.* • Standardise reporting*, ensure accuracy and completeness of reports prior to upload, and determine how to handle preliminary reports*. <p>Implement supporting communication and education activities</p> <ul style="list-style-type: none"> • Support general awareness of the changes to share pathology and diagnostic imaging reports to My Health Record by default. • Support consumers to understand: <ul style="list-style-type: none"> ○ how information in My Health Record is kept safe and secure and how to apply access controls and hide/remove documents ○ they can choose to not have their pathology and diagnostic imaging reports shared to My Health Record. • Support healthcare providers to understand relevant considerations in relation to sharing by default, including those that relate to: <ul style="list-style-type: none"> ○ operationalising and managing consumer requests to not have their pathology and diagnostic imaging reports uploaded to My Health Record ○ follow up care. <p>Maintain cybersecurity and privacy safeguards</p> <ul style="list-style-type: none"> • Maintain safeguards to prevent unauthorised access and protect the privacy of consumer’s health information.

Barriers/concerns

Risks for vulnerable consumers

- Sharing by default may present risks for vulnerable consumers, such as people experiencing/victim survivors of family violence or people who are stigmatised.

Increased workload and demand on healthcare services

- Increased workload for healthcare providers due to a need to manage consumer misinterpretation of results/consumer distress.*
- Increased demand for appointments and enquiries by consumers seeking an explanation of their results.*
- Increased demand for emergency services where consumers are worried about their results.*

My Health Record can be difficult to use and navigate

- My Health Record can be difficult to use and navigate, and it can be difficult for healthcare providers to find pathology and diagnostic imaging results particularly where multiple test reports are available.

Medico-legal issues

- There may be medico-legal issues, particularly in terms of:
 - responsibilities in relation to notifying consumers of results and follow up*
 - an adverse outcome due to consumer misinterpretation of results*
 - managing consumer requests to not have their pathology and diagnostic imaging reports shared to My Health Record.
- Reports may become less definitive due to healthcare provider concerns about managing consumer distress and litigation/liability.*

Timeframes may be challenging

- It may not be possible to implement required changes across all services by December 2024.

Implementation will have a financial and administrative impact

- Implementation is associated with a range of costs*, such as those that relate to software upgrades and training of staff, and there may be flow-on costs to consumers.
- Software upgrades may disrupt existing service delivery.

Enablers/opportunities

Explore software functionalities and improvements to My Health Record

- Ensure functionalities to record reasons for not uploading a report and urgently retract reports in the event of errors.
- Explore notification functionalities to support follow up* and alert consumers if a report has been amended after initial upload.
- Make it easier for healthcare providers to find pathology and diagnostic imaging results in My Health Record.

Clarify policy settings

- Clarify the services that will be included in the requirement to share by default and who is responsible for upload.

Consider medico-legal issues and protections for providers

- Consider medico-legal issues and protections for providers.*

Provide flexibility in implementation timeframes

- Consider a phased approach to implementation or provisions to allow for necessary system/software changes.

Provide assistance, funding and/or incentives to support implementation

- Provide assistance to support implementation and funding to support system/software changes, staff training and other implementation costs.
- Provide incentives to upload.

Continue engagement with key stakeholders

- Continue engagement with key stakeholders to inform implementation.*

OPPORTUNITIES

Improved consumer engagement and ability to manage their health

- Enables consumers to have better access to their health information, which:
 - enables them to have more informed discussions with their healthcare providers
 - supports them to manage their health and seek follow up
 - improves their ability to self-monitor and self-manage chronic and long-term conditions.*

Improved care coordination and consumer outcomes

- Improves the availability of health information across settings, which:
 - improves coordination of care *
 - supports better informed clinical decision making*
 - reduces avoidable adverse events and hospital admissions.
- Reduces consumer burden associated with duplication of testing and the need for consumers to repeat their medical history.

Barriers/concerns	Enablers/opportunities
	<p>Cost and time efficiencies for healthcare providers and the healthcare system</p> <ul style="list-style-type: none"> • Reduces the need for healthcare providers to follow up results completed in another setting. • Reduces duplication of tests.* • Reduces unnecessary follow up for insignificant results.*

* Key theme was also raised in relation to Faster Access.

As annotated in Table 1, several key themes and feedback from ‘better access’ were also raised in relation to ‘faster access’. To avoid repetition, Table 2 focusses on additional or emphasised key themes and feedback that were raised in relation to ‘faster access’.

Consistent with the intent of the consultation process, Table 2 also focusses on key themes and feedback regarding the implementation approach for removing the 7-day delay. In addition to the below, a key theme was to retain the 7-day delay.

Table 2: Overview of key themes and feedback on ‘faster access’

Barriers/concerns	Enablers/opportunities
<p><u>BARRIERS</u></p> <p>Policies may stipulate upload delays</p> <ul style="list-style-type: none"> • Upload delays may be applied under state/territory and/or organisation polices. <p><u>CONCERNS</u></p> <p>Consumer misinterpretation of results, wellbeing and outcomes</p> <ul style="list-style-type: none"> • Consumer misinterpretation of results can lead to: <ul style="list-style-type: none"> ○ distress, particularly where consumers are unable to access timely follow up support ○ loss of follow up care. • Fragmentation of care where consumers seek an urgent explanation of their results from another healthcare provider. • Consumer distress if receiving sensitive or abnormal results in an unsupported environment. <p>Risks for vulnerable consumers</p> <ul style="list-style-type: none"> • Removal of consumer access delays may increase risks for victims of abuse and young people whose parents have access to their My Health Record. 	<p><u>ENABLERS</u></p> <p>Establish a national approach for sharing by default</p> <ul style="list-style-type: none"> • Develop a nationally consistent approach for sharing by default to remove variation in circumstances where consumer access to results is delayed. <p>Recognise that consumer access should be delayed in some circumstances</p> <ul style="list-style-type: none"> • Recognise that consumer access to results should be delayed in some circumstances, such as by: <ul style="list-style-type: none"> ○ allowing healthcare providers to manually release results ○ maintaining a delay for certain tests/results ○ providing healthcare providers with discretion to impose a delay in certain circumstances ○ recognising that decisions about the timing of consumer access to results should be made in consultation with the consumer. <p>Review reporting and support consumers to understand results and next steps</p> <ul style="list-style-type: none"> • Review how reports are written to support consumer understanding, including by providing clear advice on next steps and the urgency of any follow up. • Provide information to support consumers to understand results and next steps and connect with follow up care.

Barriers/concerns

Impacts on workflow and increased demand on healthcare services

- Limits the ability of healthcare providers to review and seek clarification of results, consult with other clinicians, and develop a treatment or care plan prior to discussions with consumers.
- Increased demand where consumers are seeking an urgent explanation of their results, including increased:
 - enquiries and demand for urgent appointments
 - demand for emergency services.

Enablers/opportunities

Ensure consumers have timely access to follow up support

- Ensure healthcare providers have:
 - processes in place to ensure timely follow up of sensitive/abnormal/time-critical results
 - systems in place to ensure timely follow up more broadly.
- Ensure consumers have timely access to follow up support to discuss their results and seek guidance on next steps.

Explore software functionalities to support follow up

- Explore notification and other functionalities to support follow up.

Consider medico-legal issues and protections for providers

- Consider medico-legal issues and protections for providers.

Phase or delay implementation

- Take a phased approach to implementation or delay implementation to allow for sharing by default to be progressed in the first instance.

Provide funding to support implementation

- Provide funding to support implementation, particularly funding to enable consumer access to timely follow up support to discuss results.

OPPORTUNITIES

Improved consumer engagement and ability to manage their health

- Enables consumers to have faster access to their health information, which:
 - enables them to have more informed discussions with their healthcare providers
 - supports them to manage their health, including by taking earlier action to manage their health and seek follow up
 - improves their ability to self-monitor and self-manage chronic and long-term conditions.

Improved care coordination and consumer outcomes

- Enables more timely availability of health information across settings, which:
 - improves coordination of care
 - supports better informed clinical decision making.
- Reduces consumer anxiety associated with waiting for results.

Cost efficiencies for the healthcare system

- Reduces duplication of tests.

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

Barriers

Legislation and policies may prevent or impact sharing by default

Feedback identified that:

- legislation in some states and territories prevents certain results from being uploaded to My Health Record without explicit patient consent
- some organisations have policies that discourage or limit results from being uploaded to My Health Record without explicit patient consent.

Feedback also identified that:

- some results (such as those that are deemed to be sensitive, those that relate to vulnerable consumers and those that relate to consumers under the age of 18 years) are not uploaded to My Health Record due to state and/or organisation policies
- some states and territories have their own Health Records Acts (or equivalents) which may have additional requirements regarding the sharing of health information.

It was noted that variation in legislative requirements can create complexities for providers who operate across multiple jurisdictions and the lack of a national approach on circumstances where results should not be uploaded to My Health Record may be a barrier.

Not all software is conformant or has the required functionality to enable sharing by default

Feedback identified that:

- the software used by some healthcare providers does not meet conformance requirements to enable uploading to My Health Record
- some clinical information systems do not have the 'do not send' to My Health Record functionality and this has resulted in some providers withholding all results from being uploaded to My Health Record.

Software conformance and functionality within healthcare provider legacy systems were noted as a particular issue. It was also noted that technical capability to withhold specific results from being uploaded to My Health Record may be a barrier.

Costs and availability of technical resources to implement changes

Feedback identified that costs associated with implementation, particularly costs associated with initial software upgrades, may be a barrier for some providers.

Feedback also identified that technical resources may not be readily available to implement the required changes, particularly in smaller regional/rural services.

Sharing by default might not always be possible

Feedback noted that some healthcare providers, such as sonographers, are not currently eligible for a Healthcare Provider Identifier (HPI-I) and are therefore unable to upload to My Health Record.

Feedback also noted that upload to My Health Record is not possible where a consumer does not have an Individual Healthcare Identifier (IHI) or where IHI data matching fails.

Enablers

The following section summarises feedback in relation to supports for consumers and healthcare providers with a view towards nationally consistent approaches, including those that relate to consumer safety and wellbeing.

A [Clinical Reference Group](#) (CRG) has been established to provide clinical advice and guidance, and ensure implementation is aligned with consumer needs and preferences and clinical workflows. Members include consumers with lived experience, relevant peaks and professional associations, and other stakeholders involved in pathology and diagnostic imaging services.

Advice from the CRG is supporting implementation.

Establish a national approach for sharing by default

Feedback called for a national approach for sharing by default to remove variation in the circumstances where results are not uploaded, avoid confusion and provide consistency.

It was noted that this should include developing national guidelines and/or a national list of exceptions outlining the circumstances where results should not be uploaded.

Feedback also identified that legislation/regulations/policies should be harmonised, particularly those that relate to privacy and consent. It was noted that:

- existing privacy and other relevant legislation may require amendments to cover the nuanced implications of sharing by default
- existing legislation and regulations should be harmonised and simplified to ensure a consistent approach, particularly in relation to consent
- standardisation of consent processes would reduce the administrative burden and legal complexities currently imposed on providers.

Recognise that upload should be withheld in some circumstances

Feedback identified a need to recognise that results should not be uploaded to My Health Record in some circumstances. It was noted that there should be:

- test based exceptions to cover specific results such as genetic test results, pregnancy results for minors, paediatric results, autopsy reports, forensic results, prisoner results and results from tests undertaken at sexual health services
- safety and wellness exceptions to be exercised where healthcare providers are concerned that upload of a result:
 - may present a risk to the consumer, such as where the consumer is at risk of/is experiencing/is a victim survivor of family violence
 - is not appropriate from a clinical safety perspective, such as where there are concerns that the result may cause serious harm to a consumer's life, health or wellbeing
- exceptions to cover results for consumers living with highly stigmatised conditions or who have undertaken/undertake highly stigmatised activities, such as:
 - consumers living with Human Immunodeficiency Virus (HIV), viral hepatitis and serious mental illness
 - consumers who use/have overdosed on licit or illicit substances
 - consumers who are/have been a sex worker
- exceptions where a consumer has opted to not have their results uploaded.

It was noted that consideration should also be given to:

- specific consumer groups such as children, mature minors, those that do not have capacity to consent and those experiencing vulnerability
- where parenting and/or court orders may be in place which prevent a parent from accessing health information about their child.

Ensure safeguards are in place for managing sensitive/abnormal/time-critical results

In addition to exceptions to sharing by default, feedback identified the importance of safeguards for managing sensitive/abnormal/time-critical results. It was noted that safeguards should include:

- delaying upload of sensitive/abnormal results to My Health Record through an in-built delay or until after the consumer has consulted with their referring healthcare provider
- notifying the referring healthcare provider if a consumer's result needs immediate attention/is abnormal and flagging abnormal results
- ensuring appropriate follow up of abnormal/time-critical results.

Review and standardise reporting and support consumers to understand results and next steps

Review how reports are written to support consumers to understand results and next steps

Feedback identified a need to review how reports are written to support consumers to understand results and next steps. This matter was more comprehensively addressed in feedback on 'faster access', but feedback on 'better access' noted that reports should:

- use clear and concise language that consumers can understand, provide 'plain English' explanations of results and avoid acronyms
- include advice if a consumer needs to see their referring healthcare provider for follow up care and/or further testing is required
- include advice to contact their referring healthcare provider if they have any questions or are concerned about their result.

Provide information to support consumers to understand results and next steps

In addition to reviewing how reports are written, feedback identified a need to provide information to support consumers to understand results and next steps. Again, this matter was more comprehensively addressed in feedback on 'faster access', but feedback on 'better access' noted a need to:

- provide information during the initial consultation to support consumers to understand results and next steps (pre-counselling)
- provide links to reliable information, such as Pathology Tests Explained, to support consumer understanding of results
- provide information on next steps, including what to do after viewing the result and pathways to follow up care
- have a disclaimer or provide clear advice that directs consumers to review results with their referring healthcare provider.

Standardise reporting, ensure accuracy and completeness of reports prior to upload, and determine how to handle preliminary reports

Feedback identified that reports should be standardised to support interpretation, not only by consumers but also across healthcare providers. It was noted that this should include use of:

- consistent reporting methodology (what is reported and when)
- consistent reporting format (how information is presented/structured)
- standardised terminology.

Feedback also identified a need to ensure the accuracy and completeness of information in reports prior to uploading to My Health Record and that consideration should be given to how to handle preliminary reports. It was noted that:

- mechanisms for ensuring the accuracy and completeness of information in reports should include automated and manual verification and validation processes
- preliminary reports should either not be uploaded or if they are uploaded:
 - there should be a disclaimer to clearly identify that the report is preliminary and information may be amended at a later date
 - any preliminary reports should be removed from My Health Record once the corresponding final report has been uploaded.

Implement supporting communication and education activities

In addition to supporting consumers to understand results, feedback emphasised the need to implement broader supporting communication and education activities.

The Agency currently provides a range of information and education supports for consumers and healthcare providers, including multilingual resources, webinars, online training courses and materials in written and video format. The following feedback reinforces the importance of these resources and will inform their further development.

Implement activities to support general awareness

Feedback identified that activities should be implemented to support general awareness of the changes to share pathology and diagnostic imaging reports to My Health Record by default. It was noted that these should be:

- implemented through a nationally led and consistent campaign that is wide-reaching, multi-channel and multi-lingual
- complemented by specific communication and education activities for consumers and healthcare providers.

Implement specific communication and education activities for consumers

In terms of specific communication and education activities for consumers, feedback identified that activities should be implemented to support consumers to understand:

- My Health Record and its functions, with a focus on:
 - the protections in place to keep information in My Health Record safe and secure
 - how they can apply access controls and hide/remove documents
- the changes to share pathology and diagnostic imaging reports to My Health Record by default, including:
 - what changes are being made, why they are being made, and their benefits and impacts
 - a reminder that they can choose to not have their pathology and diagnostic imaging reports shared to My Health Record.

It was noted that communication and education activities for consumers should be easy to understand and accessible for all members of the community, including those with complex communication needs and those from culturally and linguistically diverse backgrounds.

Implement specific communication and education activities for healthcare providers

In terms of specific communication and education activities for healthcare providers, feedback identified that activities should be implemented to support healthcare providers to understand:

- My Health Record, with a focus on supporting healthcare providers to understand:
 - that patient consent is not required to upload reports to My Health Record
 - obligations to ensure the integrity of information held in My Health Record
 - that consumers may hide/remove results or apply access controls and this will have implications on the completeness of information in their My Health Record
- the changes to share pathology and diagnostic imaging reports to My Health Record by default, including:
 - what changes are being made, why they are being made, and their benefits and impacts
 - requirements that pathology and diagnostic imaging providers must meet as a result of the changes
- relevant considerations in relation to sharing by default, such as:
 - operationalising and managing consumer requests to not have their pathology and diagnostic imaging reports uploaded to My Health Record
 - follow up care, including the importance of making and implementing a clear follow up plan with the consumer at the time the referral is made and advising the consumer of the pathway if they are concerned about their result.

Maintain cybersecurity and privacy safeguards

My Health Record is governed by strong cybersecurity monitoring by the Agency. A range of security processes limit access to My Health Record, with conformance requirements for healthcare provider software to support health information sharing to the system.

A range of technologies protect the sensitive information in My Health Record, including firewalls to block unauthorised access, auditing to track access to records, anti-virus scanning of documents uploaded to records and system monitoring to detect suspicious activity.

Feedback emphasised the need to maintain robust safeguards for both healthcare provider systems and My Health Record to prevent unauthorised access and protect the privacy of consumers' health information. Commentary identified that this was particularly important:

- since more health information would be available in My Health Record because of the requirement to share pathology and diagnostic imaging reports by default
- due to the increasing prevalence of cyber-attacks on healthcare systems by malicious third parties and heightened risk of data breaches.

It was noted that safeguards should include end-to-end encryption, two-factor/multi-factor authentication, access controls, audit trails, regular security audits and onshore storage of data. It was also noted that safeguards should be put in place to ensure pathology and diagnostic imaging results are uploaded to the correct My Health Record.

This feedback will inform implementation, including communication and education activities to support community understanding of the range of existing security and privacy safeguards.

Explore software functionalities and improvements to My Health Record

Feedback identified that there should be functionalities to record reasons for not uploading a report to My Health Record and urgently retract reports in the event of errors.

Feedback also identified that notification functionalities could be explored to:

- support follow up, noting this matter was more comprehensively addressed in feedback on 'faster access'
- alert consumers if a report had been amended after initial upload.

Feedback identified a need to make it easier for healthcare providers to find pathology and diagnostic imaging results in My Health Record, including ability to:

- efficiently search, sort and filter large volumes of data to ensure ease of access to relevant reports
- easily open and view reports, noting the need to reduce multiple clicks and facilitate meaningful comparison.

More broadly, feedback noted it would be useful for:

- pathology and diagnostic imaging reports to be sent to My Health Record with atomic data, as this would support clinical decision making and more efficient sharing of information
- images to be available in My Health Record, not just reports.

Clarify policy settings

Feedback identified a need to clarify the scope of services that will be included in the requirement to share by default.

Feedback also identified a need to clarify who is responsible for upload, noting the need to consider models where:

- diagnostic imaging services are performed by allied health professionals
- healthcare providers are located overseas and are involved in the reporting process via online digital hubs
- public pathology and/or diagnostic imaging services are outsourced to private providers.

Consider medico-legal issues and protections for providers

The existing My Health Record work program includes ongoing engagement with relevant stakeholders and resources to support healthcare providers, including on matters that relate to medico-legal issues.

Feedback identified a need to consider medico-legal issues. It was noted that this should include:

- the medico-legal liability of healthcare providers where reports, which are intended for requesting healthcare providers, are accessed by consumers through My Health Record
- issues relating to:
 - consent, including the adequacy of provisions under the *My Health Records Act 2012* for healthcare providers who upload reports to My Health Record
 - the management of consumer requests to opt-out of sharing their pathology and diagnostic imaging reports to My Health Record in a way that does not expose healthcare providers to legal issues.

Feedback also sought protections for healthcare providers, with calls to:

- indemnify healthcare providers against any unintended negative consequences and harm caused by sharing by default
- ensure healthcare providers are not held liable for failing to action a consumer's request to opt-out or any breaches of privacy arising from data uploaded to My Health Record.

This feedback will inform implementation activities, including engagement with relevant stakeholders and communication and education activities to support healthcare providers.

Provide flexibility in implementation timeframes

Feedback suggested a need to consider a phased approach to implementation or provisions to allow for necessary system/software changes. It was noted that this could include:

- incremental implementation or pilot tests to minimise disruption to ongoing operations, allow for initial evaluation and inform adjustments
- a progressive approach that prioritises systems of key clinical value and saturation
- case-by-case consideration of specific environments
- a grace period to undertake necessary development or temporary extension to allow for transition to new clinical information systems.

Provide assistance, funding and/or incentives to support implementation

Feedback called for assistance to support implementation. It was noted that this should include:

- technical and change and adoption support, such as resources to support training, support to address technical issues and assistance with questions
- free add-on software.

Feedback also called for funding to support necessary system/software changes, staff training and other costs associated with implementation. It was noted that this should include:

- a subsidy for small diagnostic imaging practices to offset clinical software upgrades and other administrative costs
- grants for providers to support system integration/necessary software upgrades and funding for smaller hospitals
- funding to support providers to implement change and adoption activities, including funding for training
- an adjustment in Medicare fees to partially subsidise costs incurred with the requirement to share by default.

In addition to assistance and funding, feedback suggested providing incentives to upload.

Continue engagement with key stakeholders

Feedback identified a need to continue engagement with key stakeholders to inform implementation. It was noted that this should include:

- undertaking further consultation with relevant stakeholders on operational factors
- working with relevant stakeholders to determine exceptions to sharing by default
- co-designing revised templates for pathology and diagnostic imaging reports with consumers
- co-designing communication and education activities and supporting resources with relevant stakeholders
- actively collaborating to share best practice and resolve shared challenges.

Concerns

Consumer misinterpretation of results, wellbeing and outcomes

Feedback identified a concern that consumers may misinterpret their results and subsequently experience undue distress.

Concerns were also expressed that consumer misinterpretation of results can lead to a loss of follow up care. It was noted that consumers may interpret their result as being normal and not return for or disengage with follow up care, but that:

- a result needs to be understood in the context of each consumer's individual circumstances and a normal result for one consumer may be abnormal for another
- a combination of normal results may be abnormal
- a normal result may still mean additional testing or follow up is required.

Feedback also identified a concern that consumers may be distressed if receiving sensitive or abnormal results in an unsupported environment (i.e., through My Health Record rather than by a healthcare provider) and that this may have a significant impact on their wellbeing.

Risks for vulnerable consumers

Feedback identified a concern that sharing by default may present risks for vulnerable consumers. It was noted that pathology and diagnostic imaging reports may contain a consumer's address and/or health information and that this may present risks for:

- people experiencing/victim survivors of family violence
- people who are stigmatised, such as people living with HIV or sex workers
- young people whose parents have access to their My Health Record.

It was also noted that some people experience barriers that may impact their ability to understand information and make decisions that are relevant to sharing by default.

Increased workload and demand on healthcare services

Feedback identified concerns that there would be an increased workload for healthcare providers and increased demand on healthcare services, which would add to existing pressures within the healthcare system. It was noted that:

- more time would need to be spent in appointments explaining minor or insignificant results, managing consumer misunderstanding of results and/or managing consumer distress
- there would be increased demand for appointments and enquiries by consumers seeking an explanation of their results, which may not be possible to meet due to current pressures within the healthcare system
- there would be increased demand for emergency services where consumers are worried about their results.

My Health Record can be difficult to use and navigate

Feedback identified that My Health Record can be clunky, difficult to navigate and time consuming to use.

Healthcare providers noted it can be difficult for them to find pathology and diagnostic imaging results in My Health Record, particularly where multiple test reports are available, and faster for them to order a repeat test than search My Health Record for relevant results.

Medico-legal issues

The requirement to share by default will not change existing healthcare provider responsibilities in relation to notifying consumers of results and follow up.

Feedback identified a concern that there may be medico-legal issues, particularly in terms of:

- responsibilities in relation to notifying consumers of results and follow up
- adverse outcomes where:
 - consumers have misinterpreted their results and experienced significant distress or not returned for follow up

- consumers have received sensitive/abnormal results in an unsupported environment and experienced significant distress
- a consumer's address has been released in information uploaded to My Health Record
- making accurate diagnoses where consumers have removed health information from their My Health Record and healthcare providers do not have visibility of this
- managing consumer requests to not have their pathology and diagnostic imaging reports shared to My Health Record, particularly where a consumer's request has not been correctly communicated by the referring healthcare provider or where upload has unintentionally occurred due to a human/system error.

Feedback also identified a concern that reports may become less definitive due to healthcare provider concerns about managing consumer distress and potential litigation/liability. It was noted that this may include:

- reluctance to provide an open opinion in reports due to the risk of consumer distress
- excessive caution, such as over-reporting insignificant findings
- in the context of child protection investigations, being less willing to stipulate suspicious findings on diagnostic imaging reports due to the risk of criticism or complaints.

Concerns about medico-legal issues will be worked through as part of ongoing engagement with relevant stakeholders.

Timeframes may be challenging

Feedback identified a concern that it may not be possible to implement required changes across all services by December 2024. It was noted that:

- software upgrades, particularly those involving legacy systems, may not be finalised across all services by December 2024
- there are interdependencies that will make implementation by December 2024 challenging
- a longer timeframe will be required for healthcare providers to update relevant systems, policies and processes.

Feedback also identified a concern that implementation may impact the progress of other digital health priorities.

Implementation will have a financial and administrative impact

Feedback identified a concern that implementation is associated with a range of costs. It was noted that these include:

- initial and ongoing costs relating to software upgrades, including accessing conformant software and upgrades to handle upload at scale
- potential overheads in managing legacy systems in parallel with new systems
- fees charged by some vendors per upload to My Health Record
- costs associated with training staff.

Feedback also identified a concern that there may be flow-on costs to consumers.

More broadly, feedback identified a concern that software upgrades may disrupt existing service delivery.

Opportunities

Improved consumer engagement and ability to manage their health

Feedback identified that sharing by default will enable consumers to have better access to their health information. It was noted that all their pathology and diagnostic imaging reports would be in one place, and they would be able to access their reports at any time and in any care setting. It was noted that this would be particularly beneficial where consumers travel to different locations for services or cross borders for services.

Feedback identified that, by having better access to their health information, sharing by default enables consumers to have more informed discussions with their healthcare providers. It was noted that consumers would be able to review results, prepare questions and contact their support network before seeing their healthcare provider. It was noted that this gives them time to gather their thoughts and allows them to feel better prepared for discussions with their healthcare providers.

Feedback also identified that, by having better access to their health information, sharing by default supports consumers to manage their health and seek follow up. It was noted that this:

- empowers them to make informed decisions about their own healthcare
- enables them to take a more active and meaningful role in their healthcare decisions
- improves their ability to proactively manage their own healthcare
- enables them to follow up their care.

It was noted that this would be particularly beneficial for consumers with chronic and long-term conditions, as it would improve their ability to self-monitor and self-manage their condition.

Improved care coordination and consumer outcomes

Feedback identified that sharing by default improves the availability of health information across settings, with quick and easy access to key health information at the point of care. It was noted that this:

- improves coordination of care, with particular benefits for consumers who access services across a number of healthcare providers and/or care settings
- supports better informed clinical decision making by simplifying access to key health information and enabling healthcare providers to gain a more comprehensive view of a consumer's medical history
- reduces the risk of avoidable adverse events and hospital admissions.

Feedback also identified that sharing by default reduces:

- consumer burden associated with duplication of testing, including out-of-pocket expenses and additional radiation/needle exposure
- the need for consumers to repeat their medical history.

Cost and time efficiencies for healthcare providers and the healthcare system

Feedback identified that sharing by default results in cost and time efficiencies for healthcare providers and the healthcare system. It was noted that it:

- enables healthcare providers to access key health information when it is needed, which reduces:
 - the need for healthcare providers to follow up results completed in another setting
 - duplication of tests
- reduces unnecessary follow up for insignificant results.

Faster access: removing the 7-day consumer access delay

Overview

Several key themes and feedback from 'better access' were also raised in relation to 'faster access' as follows:

Enablers

- ensure safeguards for managing sensitive/abnormal/time-critical results
- review how reports are written and provide information to support consumers to understand results and next steps
- standardise reporting and determine how to handle preliminary reports
- explore notification functionalities to support follow up
- consider medico-legal issues and protections for providers
- continue engagement with key stakeholders to inform implementation.

Concerns

- consumer misinterpretation of results can lead to distress or loss of follow up care
- consumer distress if receiving sensitive or abnormal results in an unsupported environment
- increased workload for healthcare providers due to a need to manage consumer misinterpretation of results/consumer distress
- increased demand for appointments and enquiries by consumers seeking an explanation of their results

- increased demand for emergency services where consumers are worried about their results
- there may be medico-legal issues, particularly in relation to:
 - responsibilities in relation to notifying consumers of results and follow up
 - an adverse outcome due to consumer misinterpretation of results
- reports may become less definitive due to healthcare provider concerns about managing consumer distress and litigation/liability
- implementation is associated with a range of costs.

Opportunities

- enables consumers to have better access to their health information, which:
 - enables them to have more informed discussions with their healthcare providers
 - supports them to manage their health and seek follow up
 - improves their ability to self-monitor and self-manage chronic and long-term conditions
- improves the availability of health information across settings, which:
 - improves coordination of care
 - supports better informed clinical decision making
- reduces duplication of tests
- reduces unnecessary follow up for insignificant results.

To avoid repetition, the below focusses on additional or emphasised key themes and feedback that were raised in relation to 'faster access'.

Consistent with the intent of the consultation process, the below also focusses on key themes and feedback regarding the implementation approach for removing the 7-day delay. In addition to the below, a key theme was to retain the 7-day delay.

Barriers

Policies may stipulate upload delays

Feedback identified that upload of some results to My Health Record is delayed due to state and territory and/or organisation policies, and that this has a flow-on impact for when consumers can access results. It was noted that these may include delays of:

- 14 days for upload of results performed in some hospitals
- 30 days for upload of genomic test results
- up to six weeks for upload of sensitive results.

It was also noted that a barrier may be the lack of a national approach on circumstances where consumer access to results is delayed.

Enablers

Establish a national approach for sharing by default

Feedback called for a national approach for sharing by default to remove variation in the circumstances where consumer access to results is delayed.

It was noted that this should include developing national guidelines and/or national agreement on an approach for defining and managing results that should not be immediately released.

Recognise that consumer access to results should be delayed in some circumstances

Feedback identified a need to recognise that consumer access to results should be delayed in some circumstances, such as by:

- allowing healthcare providers to manually release results once they have reviewed them and confirmed they should be released
- maintaining a delay for certain tests/results, such as:
 - anatomical and cytopathology results
 - sensitive results, such as those relating to histopathology, genetics and genomics
 - clinically significant/abnormal/serious results, including results that indicate a terminal or neurodegenerative condition and results that relate to cancer (suspected or new diagnosis, recurrence or progression)
 - results that may cause significant distress for consumers
 - preliminary or inconclusive results
- providing healthcare providers with discretion to impose a delay in certain circumstances, such as where a healthcare provider deems there is risk in releasing a result to a consumer without a supporting discussion
- recognising that decisions about the timing of consumer access to results should be made in consultation with the consumer.

It was noted that consideration should also be given to specific consumer groups such as children and those with limited decision-making capabilities.

Review reporting and support consumers to understand results and next steps

Review how reports are written to support consumers to understand results and next steps

Feedback identified a need to review how reports are written to support consumers to understand results and next steps. While this matter was raised in feedback on 'better access', it was more comprehensively addressed in feedback on 'faster access'.

In addition to feedback already outlined in 'better access', it was noted that reports should:

- use consumer-centred language, avoid technical jargon and explain abbreviations
- be presented in a logical way that makes it easy for consumers to locate key information
- be accessible for consumers who are blind or vision impaired
- include links to information to support consumers to understand results
- include a comparison to normal ranges, with colour coding to highlight if a result is within normal ranges or is abnormal
- provide clear advice on next steps and the urgency of any follow up, with colour coding based on a traffic light system to give a clear indication of next steps and the timing of any follow up.

Provide information to support consumers to understand results and next steps and connect with follow up care

Feedback identified a need to provide information to support consumers to understand results and next steps. While this matter was raised in feedback on 'better access', it was more comprehensively addressed in feedback on 'faster access' where it was noted that this is crucial in a model where consumers have near real time access to their results.

There was an emphasis in feedback on 'faster access' on the need to provide information during the initial consultation to support consumers to understand results and next steps (pre-counselling). It was noted that this should include:

- an explanation of the tests that are being conducted
- information on when the consumer should expect to hear from their referring healthcare provider and how this will differ for normal and abnormal results
- information on possible and likely results and how different results may influence a consumer's treatment plan
- information on what to do when the consumer receives their results and options if they need to escalate their results.

In addition to feedback already outlined in 'better access', it was noted that information to support consumers to understand results and next steps should include:

- a glossary of common terms and abbreviations
- guidelines/resources to explain results and what actions may be needed
- frequently asked questions to address common questions and concerns
- information on what consumers should do in the event of abnormal or urgent findings.

However, it was noted that it may be challenging to develop comprehensive resources to support consumers to understand results because reports are generally complex and nuanced and need to be interpreted in the context of each consumer's individual circumstances.

In line with this, there was an emphasis in feedback on 'faster access' on the need to have a disclaimer or provide clear advice that directs consumers to review results with their referring/a healthcare provider.

Feedback also identified that consumers should receive information to support them to connect with follow up care. It was noted that this should include:

- contact details for the referring healthcare provider, helplines and other supports
- a link to an online map that provides details of suitable and geographically relevant points of care
- standardised care pathways outlining recommended next steps for less critical but significant results
- decision support tools to help consumers make informed decisions based on their results.

In terms of information to support consumers, feedback identified a need to:

- make information available in multiple languages and formats, including non-written formats
- consider differences in health literacy and health beliefs across population groups
- consider the needs of people who have limited access to technology
- ensure information is accessible for people with a disability and consumers who have different accessibility needs.

Ensure consumers have timely access to follow up support

Feedback identified a need to ensure healthcare providers have:

- processes in place to ensure timely follow up of sensitive/abnormal/time-critical results
- systems in place to ensure timely follow up more broadly.

Feedback noted the existing processes and systems in place to support this, such as:

- the National Safety and Quality Health Service Communicating for Safety Standard
- the National Pathology Accreditation Advisory Council Requirements for the Communication of High Risk Pathology Results
- the Royal Australian and New Zealand College of Radiologists Standards of Practice for Clinical Radiology
- organisation policies for handling high risk results
- functionality in practice management systems to track and manage follow up.

Feedback also identified a need to ensure consumers have timely access to follow up support to discuss their results and seek guidance on next steps. It was noted that this could be facilitated through:

- telehealth
- secure messaging with their referring healthcare provider
- a dedicated enquiry line or use of existing enquiry lines such as NURSE-ON-CALL.

Explore software functionalities to support follow up

Feedback identified that notification and other functionalities could be explored to support follow up. It was noted that these could include:

- text messages/emails/notifications for consumers and healthcare providers, such as:
 - reminders for consumers to book a follow up appointment, if required
 - reminders for healthcare providers to review results and ensure any follow up has occurred
 - notifications for consumers if follow up is required
- notifications for referring healthcare providers to advise when results have been uploaded to My Health Record
- notifications for referring healthcare providers to advise when a consumer has accessed a result in My Health Record
- functionality that allows healthcare providers to see if a consumer has accessed a result in My Health Record
- alerts and/or flags for abnormal/time-critical results for referring healthcare providers and consumers
- an integrated feature that enables consumers to book follow up appointments.

Consider medico-legal issues and protections for providers

While the need to consider medico-legal issues and protections for healthcare providers was raised in feedback on 'better access', feedback on 'faster access' identified a need to consider whether immediate consumer access to pathology and diagnostic imaging reports:

- raises new legal and ethical issues
- exposes healthcare providers to additional medico-legal risk.

Phase or delay implementation

Feedback suggested taking a phased approach to implementation or delaying implementation to allow for sharing by default to be progressed in the first instance. In terms of phasing implementation, feedback suggested this could involve:

- lowering or removing consumer access delays on a test-by-test basis
- implementing pilot programs to provide insights into challenges and potential solutions.

Provide funding to support implementation

Feedback called for funding to support implementation, particularly funding to enable consumer access to timely follow up support to discuss results. It was noted that this should include consideration of funding telehealth more widely.

Concerns

Consumer misinterpretation of results, wellbeing and outcomes

Feedback identified concerns that consumer misinterpretation of results can lead to distress and loss of follow up care. While these concerns were raised in feedback on 'better access', they were emphasised in feedback on 'faster access' with commentary noting additional concerns where consumers have near real time access to their results.

Feedback identified concerns that:

- the potential for consumer distress may be greater where consumers have near real time access to their results and are unable to access timely follow up support
- care may become fragmented where consumers seek an urgent explanation of their results from another healthcare provider.

Feedback also emphasised a concern that consumers may be distressed if receiving sensitive or abnormal results in an unsupported environment (i.e., through My Health Record rather than by a healthcare provider) and that this may have a significant impact on their wellbeing.

Risks for vulnerable consumers

In addition to concerns raised in feedback on 'better access' about risks for vulnerable consumers, feedback on 'faster access' identified a concern that removal of consumer access delays may increase risks for victims of abuse and young people whose parents have access to their My Health Record. It was noted that near real time access to results could:

- have adverse consequences where a parent or partner can view results before the record owner has an opportunity to hide them
- alert a perpetrator about the outcome of results and potentially lead to them removing a child/other person at risk from a care setting or taking other measures before services such as child safety or the police have been alerted.

Impacts on workflow and increased demand on healthcare services

Feedback identified a concern that near real time consumer access to results will limit the ability of healthcare providers to review and seek clarification of results, consult with other clinicians, and develop a treatment or care plan prior to discussions with consumers.

Feedback also identified concerns that there would be an increased workload for healthcare providers and increased demand on healthcare services, which would add to existing pressures within the healthcare system. While these concerns were raised in feedback on 'better access', they were emphasised in feedback on 'faster access'.

In addition to the concerns raised in feedback on 'better access', feedback on 'faster access' identified a concern that there would be increased demand where consumers are seeking an urgent explanation of their results. It was noted that this included increased:

- enquiries and demand for urgent appointments
- demand for emergency services.

It was also noted that consumers may have increased expectations on healthcare providers to review results and make contact immediately.

Opportunities

Improved consumer engagement and ability to manage their health

Feedback identified that removal of the 7-day delay enables consumers to have faster access to their health information, which:

- enables them to have more informed discussions with their healthcare providers
- supports them to manage their health, including by taking earlier action to manage their health and seek follow up
- improves their ability to self-monitor and self-manage chronic and long-term conditions.

Improved care coordination and consumer outcomes

Feedback identified that removal of the 7-day delay enables more timely availability of health information across settings, which:

- improves coordination of care
- supports better informed clinical decision making.

Feedback also identified that removal of the 7-day delay reduces consumer anxiety associated with waiting for results.

Cost efficiencies for the healthcare system

Feedback identified that removal of the 7-day delay enables more timely availability of health information across settings, which reduces duplication of tests.

Appendix A: Consultation survey questions

Filtering of survey questions

Questions were filtered according to the stakeholder category selected by the respondent.

Questions 1-10 could be viewed by all respondent types **except**:

- consumer/individual/patient
- family member or carer of a consumer
- pharmacist
- First Nations/Aboriginal and Torres Strait Islander organisation
- not for profit/community organisation
- other industry/business
- other.

Questions 11-17 could be viewed by all respondent types.

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

1. What systems, processes or standards exist in the community (or need to be put in place) to ensure that providers can comply with this initiative from December 2024?
2. What change and adoption strategies are needed to enable sharing to My Health Record by default?
3. How can we most effectively provide or communicate change and adoption resources for:
 - consumers
 - organisations delivering diagnostic imaging and pathology services
 - staff in organisations delivering diagnostic imaging and pathology services
 - treating healthcare providers who may request tests and/or use test results?
4. What current laws or organisation policies prevent diagnostic imaging and pathology providers from sharing reports to My Health Record?
5. What barriers, if any, do you foresee to your organisation sharing by default from December 2024?
6. What would prevent or overcome the barriers identified in the previous question?
7. What improvements to existing software for diagnostic imaging and pathology services would help them upload diagnostic imaging and pathology reports by default? This includes the ability to keep a record of reasons why they have not uploaded a report.
8. What barriers are there to better interoperability of My Health Record with existing software for diagnostic imaging and pathology customers?

9. What opportunities are there for more automated management of reports? This includes sharing to My Health Record and documenting exceptions to reporting requirements.
10. What barriers are there to more automated management of reports? This includes sharing to My Health Record and documenting exceptions to reporting requirements.
11. 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
 - healthcare providers
 - the broader healthcare system.
12. 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.
13. Please share any advice or comments not covered by previous questions.

Faster access- removing delays to accessing pathology and diagnostic imaging reports to My Health Record

14. 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
 - healthcare providers
 - the broader healthcare system.
15. 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.
16. What safety features could ensure follow-up clinical care happens promptly?
17. Please share any advice or comments not covered by previous questions.

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All information in this publication is correct as at April 2024

