Health Legislation Amendment (Modernising My Health Record—Sharing by Default) Bill 2024 [Provisions] Submission 12



Australian Government Department of Health and Aged Care

Australian Government

Australian Digital Health Agency

Department of Health and Aged Care and Australian Digital Health Agency joint submission to the Senate Community Affairs Legislation Committee regarding the Health Legislation Amendment (Modernising My Health Record – Sharing by Default) Bill 2024

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# 1. Introduction

The Department of Health and Aged Care (the Department) and the Australian Digital Health Agency (the Agency) welcome the opportunity to provide a joint submission to the Senate Community Affairs Legislation Committee's inquiry into the Health Legislation Amendment (Modernising My Health Record – Sharing by Default) Bill 2024 (the Bill).

Access to key health information can lead to better healthcare decision making between clinicians and their patients, reduce the need for unnecessary investigations and hospital admission, improve the accuracy and continuity of treatment, and reduce the incidence of adverse events <sup>1,2,3</sup>.

The Australian health system has more than 1.1 million individual healthcare providers in public and private services, delivering health services to almost 27 million Australians<sup>4,5.</sup> Too often, health information is locked in siloed clinical information systems across public and private health services, jurisdictional borders, and care settings. Many systems do not enable - and in some cases intentionally adopt business models that prevent - sharing of health information with healthcare recipients or other clinical information systems.

My Health Record is Australia's only national electronic health record and is uniquely positioned to:

- empower healthcare recipients to safely and securely access their key health information to support them to actively engage as partners in their own healthcare
- make it easier for healthcare providers to access key health information about their patients, enhancing clinical decision making
- improve care coordination across care settings in both public and private health services, and across jurisdictional borders.

The Bill seeks to change the current model of sharing of key health information to My Health Record from voluntary to mandatory. This will drive the behaviour change necessary to ensure secure access to key health information is available when needed; better connecting healthcare recipients, general practices, hospitals, specialists, pharmacies and allied health professionals.

This submission outlines the rationale behind the Bill's intentional design to provide a strong yet flexible framework for establishing requirements to share key health information about specific (prescribed) healthcare services.

<sup>&</sup>lt;sup>1</sup> Productivity Commission (2023) <u>5-year Productivity Inquiry: Advancing Prosperity</u>, accessed 24 June 2024.

<sup>&</sup>lt;sup>2</sup> Productivity Commission (2024) <u>Leveraging digital technology in healthcare</u>, accessed 24 June 2024.

<sup>&</sup>lt;sup>3</sup> ACSQHC (Australian Commission on Safety and Quality in Healthcare) (2021) <u>My Health Record in emergency</u> <u>departments: final report and adoption model</u>, accessed 16 July 2024.

<sup>&</sup>lt;sup>4</sup> Australian Bureau of Statistics (2024) National, State and Territory Population, accessed 05 November 2024

<sup>&</sup>lt;sup>5</sup> Services Australia (2024) <u>Healthcare Identifiers Annual Report 2023-24</u>, <u>www.servicesaustralia.gov.au</u>, accessed 5 November 2024.

This submission will consider the operation of the Bill and application of legislative instruments (Rules) to prescribe which health services and what health information is required to be shared. Initially it is proposed to require the sharing of information associated with pathology and diagnostic imaging services. Over time, requirements will be able to be applied to other health services and types of health information.

A decision to start with pathology and diagnostic imaging services was informed by consideration of both clinical value and sector readiness to comply with the requirements. Based on the Agency's engagement with the sector, we understand most large pathology and diagnostic imaging providers are using clinical information systems with capability to upload to the My Health Record system. Despite this, upload volumes still represent only around half of pathology reports and one in three diagnostic imaging reports. This is not enough to provide healthcare recipients and their healthcare providers with confidence that when they need to access a test result it will be available.

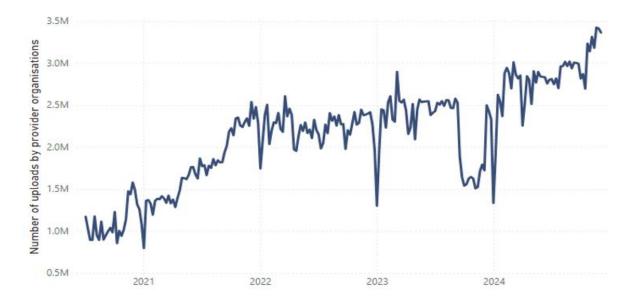
Pathology and diagnostic imaging results are an important piece of health information. In 2022–23, 17.4 million (67%) Australians accessed 196.9 million Medicare-subsidised pathology services, imaging scans and a range of diagnostic services<sup>6</sup>. Consistent access to results from these services will support both healthcare providers and their patients<sup>7,8,9</sup>.

While the level of uploads to My Health Record are not at the desired level, there has been a sustained positive trend in uploading to My Health Record by the pathology and diagnostic imaging sectors since 2021 (see Figure 1).

 <sup>7</sup> Petrovskaya O, Karpman A, Schilling J, Singh S, Wegren L, Caine V, Kusi-Appiah E, Geen W. (2023) <u>Patient and Health Care</u> <u>Provider Perspectives on Patient Access to Test Results via Web Portals: Scoping Review</u>, accessed 12 December 2024.
<sup>8</sup> Phelan A, Broughan J, McCombe G, Collins C, Fawsitt R, O'Callaghan M, Quinlan D, Stanley F, Cullen W. (2023) <u>Impact of enhancing GP access to diagnostic imaging: A scoping review</u>, accessed 12 December 2024.

<sup>&</sup>lt;sup>6</sup> Australian Institute of Health and Welfare (2024), <u>Pathology, imaging and other diagnostic services - Australian Institute</u> of <u>Health and Welfare</u>, accessed 12 December 2024.

<sup>&</sup>lt;sup>9</sup> AMA (Australian Medical Association (2018) <u>AMA Position Statement on Diagnostic Imaging 2018</u>, ama.com.au, accessed 13 December 2024.



**Figure 1**: Combined pathology and diagnostic imaging reports uploaded to My Health Record per week

The COVID-19 pandemic prompted an increase in uploading of health information to My Health Record, particularly COVID-19 related pathology results. Uploading of pathology and diagnostic imaging results have increased steadily since that time.

In the first five months of the current financial year (July to November 2024), uploading of reports by public and private pathology and diagnostic imaging providers reached:

- 59.9 million pathology reports, a 32% increase compared to the same period the previous year
- 6.4 million diagnostic imaging reports, a 66% increase compared to the same period the previous year.

While the trend in uploading is positive, more is needed to ensure healthcare recipients and their healthcare teams can reliably access all results when needed.

### **1.1 Consultation**

In making this submission we acknowledge the feedback that has informed the development of the Bill. This feedback has been received from a broad range of stakeholders including healthcare recipients, the pathology and diagnostic imaging sectors, healthcare peaks, the medical technology sector, states and territories, and a <u>Clinical Reference Group</u> established by the Agency.

Public consultation conducted by the Department in late 2023 received 416 submissions, of which approximately half were from healthcare recipients and their carers<sup>10</sup>. These

<sup>&</sup>lt;sup>10</sup> Department of Health and Aged Care (2024) <u>Summary of key themes and feedback from consultation process</u>, accessed 20 December 2024.

submissions indicated broad support for sharing by default, with healthcare recipients wanting better access to their health information.

Ongoing consultation has explored the readiness, barriers and challenges of the public and private sectors' ability to comply with the proposed requirements for the initial intended application to pathology and diagnostic imaging services.

The Department and the Agency have worked closely with states and territories over the last 18 months. States and territories will continue to play a key role in informing the proposed requirements and expansion to future prescribed healthcare services. This will ensure that My Health Record can begin to provide a comprehensive view of a patient's key health information regardless of where health services are received.

#### **1.2 Overview of the Bill and the Rules**

The framework outlined by the Bill will require the sharing of key information about prescribed health services by constitutional corporations and as a condition of claiming Medicare benefits. Limited exceptions will apply including for practical necessity, the healthcare recipient's preference and clinical discretion in cases of serious concern for a healthcare recipient's health, safety or wellbeing.

It is intended the Bill will be supported by the development of Rules that will be made under the *My Health Records Act 2012 (My Health Records Act)* and the *Health Insurance Act 1973* ("Share by Default Rules") to specify which health services and what health information will need to be shared. These rules will be disallowable<sup>11</sup>.

Development of Share by Default Rules will require further consultation with stakeholders including healthcare providers, peak bodies, healthcare recipients as well as software vendors. The *My Health Records Act* also requires the Minister to consult with states and territories and with the My Health Record System Operator (the Agency), before making rules.

Further detail on the operation of the Bill is provided below.

## 2. Why government action is needed

Much of the data sharing needed to drive benefits and healthcare outcomes is hampered by complex, disjointed and imperfect market arrangements, which mean healthcare recipients must retell their story repeatedly.

Whilst there is a positive trend towards more information being uploaded to My Health Record, it is not happening fast enough. Healthcare providers' engagement with My Health Record is not keeping pace with healthcare recipients' expectations for greater flexibility in where they access healthcare and for easier access to their health information when they

<sup>&</sup>lt;sup>11</sup> The Share by Default rules will be subject to the disallowance process under the *Legislation Act 2003*. Under those provisions, a motion to disallow the instrument may be brought before the House of Representatives or the Senate, and if agreed, the instrument is effectively repealed.

need it. Nor do the current levels of healthcare provider engagement with My Health Record meet the growing needs of the health system to improve care coordination to tackle the challenges of an ageing population, rising rates of chronic health conditions and workforce shortages.

Current incentives, settings and approaches have taken the My Health Record system as far as they can. After twelve years of operation, the voluntary nature of health information sharing requirements for healthcare providers has meant only limited health information has flowed into My Health Record.

#### 2.1 Efforts to increase health information in My Health Record

A range of policy interventions have been attempted to improve key health information being shared to My Health Record.

The most significant of these involved the transition of the My Health Record system from an opt-in consumer participation model to an opt-out model. In 2013, the Royle Review<sup>12</sup> of the (then named) Personally Controlled Electronic Health Record system highlighted that without a critical mass of healthcare recipients registered, healthcare providers had no incentive to use the system.

Legislative amendments were made to support trials of an opt-out model and to change the name of the system to My Health Record. Following an opt-out period, the opt-out model took effect in early 2019. As of November 2024, more than 24.1 million Australians have a My Health Record. Despite the high healthcare recipient participation rates, healthcare providers have not made the transition to routinely using My Health Record in their clinical workflows.

Other interventions have included:

- financial incentives through the Practice Incentive Program eHealth Incentive (ePIP)
- industry offers made by the Agency, through Austender, to provide funding to subsidise the development and implementation of My Health Record functionality in clinical information systems, including approximately \$1.7 million to the pathology and diagnostic imaging sectors
- extensive engagement, support and education with the sector by the Department and the Agency
- collaborative work with states and territories towards national harmonisation of local policies and legislation.

<sup>&</sup>lt;sup>12</sup> Royle R, Hambleton S, and Walduck A (2013) Review of the Personally Controlled Electronic Health Record, Department of Health.

While these measures have improved healthcare provider engagement with the My Health Record system, more is needed to give healthcare recipients and their healthcare providers confidence that when they need to access key health information it will be available.

# **2.2** Healthcare recipients are experiencing barriers accessing their health information

Healthcare recipients expect and deserve much more from their health system including an integrated and coordinated approach to their care, no matter what parts of the health system they are accessing. The need for better approaches to coordination of care is evident in a 2023-24 survey conducted by the Australian Bureau of Statistics (ABS), in which respondents with a long-term health condition were more likely than those without a long-term health condition to see three or more health professionals (28.5% compared to 6.7%) and report issues caused by a lack of communication between health professionals (17.1% compared to 12.4%). They were also more likely to use telehealth than those without a long-term health condition (32.7% compared to 13.8%)<sup>13</sup>, which indicates the value of greater flexibility and convenience in access to care and health information through increasing use of digital health technologies.

Healthcare recipients' expectations around access and coordination of care extends to their healthcare providers, who are expected to have much richer and connected access to their medical history, medicines and allergies, diagnostic investigations, and treatment plans so they don't have to share their medical history with each new service they access. They want their healthcare providers to upload their health information and use it when they access healthcare<sup>14</sup>.

Evidence that healthcare recipients want better access to their information, is seen in growing trends in healthcare recipients' viewing of their health information in My Health Record (**see Figure 2**).

<sup>&</sup>lt;sup>13</sup> Australian Bureau of Statistics, (2024) <u>Patient Experiences, 2023-24 financial year | Australian Bureau of Statistics</u>, accessed 6 January 2025.

<sup>&</sup>lt;sup>14</sup> Department of Health and Aged Care(2023) <u>Consultation paper – Better access – sharing pathology and diagnostic</u> <u>imaging reports to My Health Record by default</u>, p. 5, accessed 26 June 2024.

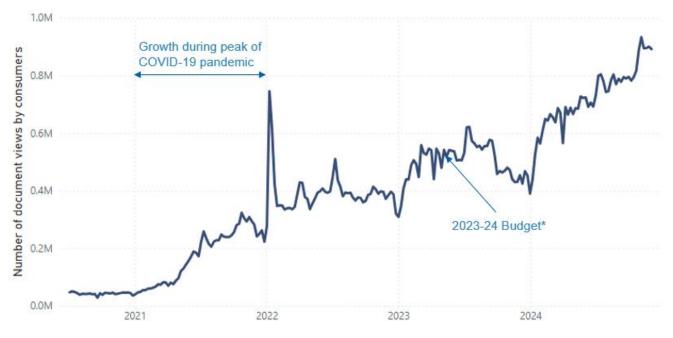


Figure 2: Combined healthcare recipient views of diagnostic and pathology reports per week

\* In the 2023-24 Budget, the Australian Government provided \$13.1 million over 2 years to transition the My Health Record system to require healthcare providers to share health information 'by default', beginning with pathology and diagnostic imaging providers.

In the first five months of the current financial year (July to November 2024) healthcare recipients had viewed:

- pathology reports 16.6 million times, which is a 59% increase over the same period last year
- diagnostic imaging reports 2.2 million times, which is a 56% increase over the same period last year.

In November 2024, the number of weekly views of pathology and diagnostic imaging reports by healthcare recipients reached almost one million. This is above the previous peak viewing rate seen in the COVID-19 pandemic in January 2022.

The limited sharing of pathology and diagnostic imaging reports creates a burden on healthcare recipients. When healthcare professionals are unable to access a full view of their patient's current health information, it puts the onus on the patient (and their carers), to not only keep a record of their health history, but to also keep their healthcare providers updated on any recent health events, such as hospital admissions. This means that healthcare recipients, especially those with complex healthcare needs, need to retell their personal stories to different healthcare professionals.

Placing the burden on healthcare recipients or their carers to keep healthcare providers connected to health events increases the potential for medical errors as important health

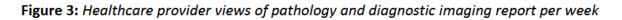
information, such as diagnoses, or dispensed medicines could be missed or misinterpreted through inaccurate, incomplete, or inconsistent verbal sharing.

Sharing of key health information not only alleviates the burden for healthcare recipients needing to repeatedly retell their medical history. It can also alleviate time and financial burdens, including reducing avoidable repeat tests and consultations, which are scheduled when relevant health information is not easily available.

# **2.3 Healthcare providers have inconsistent access to patient health information**

Healthcare providers too are frustrated with inconsistent access to health information to support their clinical decision making and care coordination for their patients. Increased availability of information in My Health Record supports healthcare providers inform their clinical decision making, while also reducing duplicate and unnecessary testing<sup>15</sup> <sup>16</sup>.

The efforts made in the past 18 months to prepare the pathology and diagnostic imaging sector for sharing by default, has demonstrated that as uploading increases, there is a corresponding increase in healthcare providers viewing results (see Figure 3).





<sup>&</sup>lt;sup>15</sup> ACSQHC (Australian Commission on Safety and Quality in Healthcare) (2021) <u>My Health Record in emergency</u> <u>departments: final report and adoption model</u>, accessed 16 July 2024.

<sup>&</sup>lt;sup>16</sup> Mesquita R and Edwards I (2020) <u>Systematic Literature Review of My Health Record System</u>, Asia-Pacific Journal of Health Management, 15 (1): 14-25, doi:10.24083/apjhm.v15i1.311, accessed 16 July 2024.

Between July and November 2024 healthcare providers viewed:

- 2.7 million pathology reports, which is a 43% increase over the same period last year
- 555,000 diagnostic imaging reports, which is a 94% increase over the same period last year.

The growing trend in health practitioner use of information in My Health Record, as more health information becomes available, is an important indicator of the potential impact that can be achieved by requiring healthcare providers to share key health information by default.

### 2.4 Recommendations to share by default to My Health Record

Several recommendations have been made to introduce a mandatory requirement to upload information to My Health Record, including by the <u>Strengthening Medicare Taskforce</u> in 2023<sup>17</sup>. The Taskforce recommended 'sharing by default' as one element necessary to modernise primary care and empower people to participate in their own healthcare.

The taskforce also saw the opportunity for sharing key health information to provide rich data insights for planning, resourcing and to underpin a learning health system. A learning health system is broader than an individual patient episode of care. It is a continuous feedback loop that pursues meaningful patient-centred improvement and informs preventative health measures, through the sharing of strong, actionable evidence to health administrators and healthcare professionals to guide and improve patient care outcomes.

The Taskforce recommendations were informed by other reviews including the Review of the My Health Records Legislation in 2020<sup>18</sup>. This review recommended that the Australian Government examine options for tying eligibility criteria for specific government health payments to support increased core clinical content in My Health Record and extensive adoption by healthcare providers.

The Productivity Commission's 2023 <u>5-year Productivity Inquiry: Advancing Prosperity</u> report further identified My Health Record as a foundation for comprehensive data sharing of health information in Australia, supporting a requirement for healthcare providers to share relevant health records to My Health Record unless a healthcare recipient opts out<sup>19</sup>.

# **3.** How sharing by default will benefit healthcare recipients

When healthcare recipients can access and are supported to use and understand their health information, they are better able to actively participate in their care and make informed decisions<sup>20</sup>. Sharing by default is crucial to increase this participation and empower healthcare recipients to engage with their healthcare providers in shared decision making.

<sup>&</sup>lt;sup>17</sup> Department of Health and Aged Care (2022) <u>Strengthening Medicare Taskforce Report</u>, accessed 20 December 2024

<sup>&</sup>lt;sup>18</sup> McMillian J (2020) <u>Review of the My Health Records Legislation - Final Report</u>, DHAC, accessed 24 June 2024.

<sup>&</sup>lt;sup>19</sup> Productivity Commission (2023) <u>5-year Productivity Inquiry: Advancing Prosperity</u>, accessed 24 June 2024.

<sup>&</sup>lt;sup>20</sup> Department of Health and Aged Care (2022) <u>Strengthening Medicare Taskforce Report</u>, accessed 24 June 2024.

Sharing by default will support healthcare recipients to make informed decisions - both independently and with their healthcare providers - that meet their clinical needs, expectations of care, and goals in their healthcare journey.

Improved access to health information provides the additional benefit of minimising unnecessary and duplicate testing and imaging, leading to shorter wait times and faster diagnoses, especially in emergencies. This access enables faster, more informed care decisions without the need for unnecessary repeated tests where this is not clinically necessary, promoting consistent treatment strategies and reducing time and costs for healthcare recipients.

#### Case Study – living with a chronic illness

I'm living with type one diabetes. I was diagnosed at 14 years of age... In the beginning it was quite hard being so young, really hard at school. Managing diabetes can be difficult. I found it quite overwhelming... So I downloaded the my health app and I was really surprised that actually how far back there was records on there.

So it's really important to have the pathology history all in one place because there's so many things that they look at when they do my bloods. Yeah, I really want to be able to access my HbA1C tests. My last one was the best one I've ever had, just to see that improvement is a really positive thing and empowering.

Now that I know that that test result can be uploaded to My Health Record, I will be requesting that it does every time.



ADHA (Australian Digital Health Agency) 'Digital Bytes: Accessing pathology results in My Health Record', 19 November 2024 <u>https://www.youtube.com/watch?v=7VGth3E8XAQ</u>

# How sharing by default will benefit and impact healthcare providers

This Bill will give healthcare providers across the health system, from primary to acute settings, near real time access to key health information. Access to current and historical information supports their decision making so they can provide safe and high-quality care.

This will support services to be more person-centred and integrated, allowing healthcare providers to focus on delivering care and spend less time on avoidable administrative activities, including gathering information from their patients and retrieving copies of health information. It will also minimise the need for duplicate or unnecessary tests and treatments, improving efficiency and resource allocation across the health system.

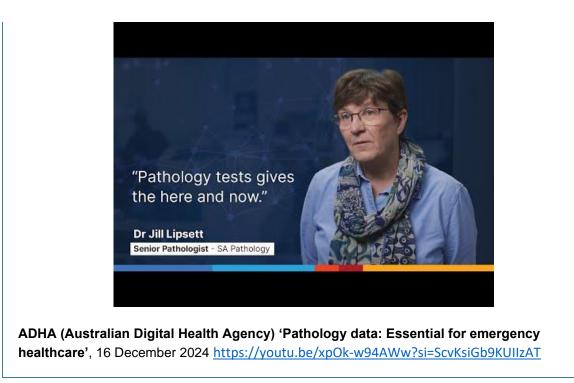
#### Case study – My Health Record in emergency departments

Consider a scenario where a patient arrives at the emergency department with symptoms of severe chest pain. As Dr. Lipsett states, "The results from the initial pathology tests provide the health carers in that setting with the roadmap as to what they actually are going to do next." This information directs the medical team's actions, whether it involves administering medication or preparing for surgical intervention.

In addition to immediate test results, an understanding of a patient's medical history is necessary for effective treatment. "We need to know what diagnoses that patient has had in the past. We need to know what medications they're on," Dr. Lipsett emphasizes. Traditionally, this information might be scattered across various paper records or within different healthcare facilities' databases, which can be time-consuming and prone to errors.

"Actually, having access to a person's My Health Record, including their pathology tests, is actually very critical," Dr. Lipsett notes. This system allows healthcare providers to quickly access a patient's key health information, including past diagnoses, medications, and previous pathology test results.

Digital technologies not only streamline the process of accessing patient records but also ensure that all healthcare providers involved in a patient's care are well-informed. As Dr. Lipsett points out, "Digital technologies actually allow us to rapidly put people on the same page." This unity of information can significantly improve patient outcomes by facilitating coordinated care and reducing the risk of errors. Health Legislation Amendment (Modernising My Health Record—Sharing by Default) Bill 2024 [Provisions] Submission 12



As the number of older Australians, rates of chronic health conditions, and workforce shortages continue to rise, healthcare providers must be supported to collaborate effectively and to work to their full scope of practice. Sharing by default will support healthcare providers to communicate health information, coordinate care planning in a collaborative way, and access information shared by other healthcare providers to make timely and informed decisions.

This is particularly important for effective care planning and service coordination for Australia's ageing population, people living with complex chronic health conditions, people with disability, people living in regional and remote areas, and for the escalation of support and clinical interventions during an urgent care episode or emergency.

For example, the Agency has been working closely with the Residential Aged Care sector to embed the use of My Health Record and better support nurses and other staff who care for residents. My Health Record can provide a resident's complete medical history in one place, including health information related to services provided through GPs, specialists, allied health providers and hospital admissions. This enables healthcare workers in aged care residential settings to develop a complete picture of a resident's clinical health needs and make more informed decisions to improve the health and wellbeing outcomes of residents.

#### 4.1 Costs for pathology and diagnostic imaging providers

Sharing by default is expected to have negligible cost implications for the seven largest pathology and 130 biggest diagnostic imaging providers, which together account for 98% of MBS pathology and diagnostic imaging claims respectively. All seven large pathology providers are known to be connected to My Health Record, and 90% of large diagnostic

imaging providers use My Health Record-conformant software and can upload reports. Some costs may be incurred in the first year to develop and operationalise minor changes to administrative processes and uplift in staff training to comply with requirements.

Remaining pathology and diagnostic imaging providers have identified barriers such as a lack of financial or technical capability to purchase and implement My Health Record-compliant software and train staff. Although costs are expected to be incurred by some pathology and diagnostic imaging providers to implement conformant software, a formal extension process established under the Bill will provide for additional time, where needed, to obtain appropriate technical capabilities to adhere to requirements.

Further information on the estimated benefits and impacts associated with sharing by default is available in the published <u>Policy Impact Analysis</u>.

## 5. My Health Record privacy and security safeguards

#### **5.1 Privacy and security management**

The My Health Record system has comprehensive controls in place that comply with all relevant government privacy, security and cyber security standards. Any misuse of information held by the My Health Record system is prohibited and is subject to heavy penalties under the My Health Records Act and the *Privacy Act 1988* (Cth).

The personal choice of healthcare recipients in relation to their My Health Record is maintained under the proposed framework. Individuals will continue to exercise consent over whether to have a My Health Record and what information should be shared to their record.

The Bill confirms that healthcare recipients may request that information not be uploaded to their My Health Record. The obligation for providers to upload will not override the decisions of healthcare recipients. Further, there is no change to the existing privacy and security in place for healthcare recipients, who will continue to have choice and control regarding the access and management of their information in My Health Record, including the ability to:

- elect to receive notifications when registered healthcare providers access their record or when certain health information is added to their record
- use privacy and access controls, including record and document codes, which limit who can access their My Health Record or specific documents in their record
- permanently delete, or hide and restore a document within their record
- appoint an authorised representative (such as a family member) to view and manage their record.

The personal safety and wellbeing of healthcare recipients is paramount and the Bill includes an exception to the requirement to upload where a healthcare provider has serious concerns for an individual's health, safety or wellbeing. This provision reflects feedback received during consultation, with some healthcare providers highlighting the importance of ongoing discretion to act in the interests of their individual patients if there are concerns related to the uploading of information. The exception built into the framework responds to this feedback and will ensure healthcare providers can exercise discretion not to upload on a caseby-case basis, where that would be in the best interest of the healthcare recipient.

#### Case Study – Consumer control of their health information in My Health Record

Michael Brown has been living with HIV, a condition often surrounded by stigma. As someone deeply involved in health education, he understands the importance of privacy and confidentiality in managing his health information. Dr. Nicolette Roux, a GP at Wuchopperen Health Service in Queensland, has been instrumental in guiding Michael through the process of using My Health Record effectively.

"The stigma of having HIV is enough on its own to deal with as an individual," says Dr Roux. This stigma can make it difficult for individuals to feel safe sharing their health information. Ensuring privacy and control over their health data is crucial for patients like Michael, who wish to manage their condition discreetly.

Dr. Roux explains, "Michael and I have had a conversation about privacy and digital health. And so what I was saying to Michael is that he can be in control of his My Health Record. He can actually go and have a look himself at what information is shared on his record." This empowerment through control is a significant benefit for patients using My Health Record.



ADHA (Australian Digital Health Agency) 'My Health Record privacy controls', 19 November 2024, <u>https://youtu.be/v7dICU5s0M4?si=afNfsaboTzQX-Whm</u>

# 6. The Rules and requirements to share by default

Subject to passage of the Bill, rules will be made under the My Health Records Act and the Health Insurance Act, which will prescribe matters to give effect to the requirement to share.

### 6.1 Who will need to share by default to My Health Record

Based on consultation to date, the readiness of the pathology and diagnostic imaging sectors, and the clinical impact of associated health services, it is proposed to initially consult on a proposal that would include the following:

- Amendment to the My Health Records Rules that would require constitutional corporations that are proprietors of pathology labs and diagnostic imaging premises to upload reports about prescribed pathology and diagnostic imaging services.
- Upload Rules to be made under the Health Insurance Act that would require the uploading of reports related to specific pathology and diagnostic imaging services carried out by specialist pathologists and radiologists, in order to claim Medicare benefits for those services. Pathology and diagnostic imaging services carried out by other types of medical practitioners (e.g. dentists or cardiologists) are not intended to be included in the initial scope of the mandate.

# 6.2 Future health information to be shared by default to My Health Record

The Bill establishes the framework for making requirements on healthcare providers to share key health information, but intentionally does not dictate what health service, or health practitioner and what health information, is in scope of the requirement. This detail is intentionally prescribed in Rules to support flexibility to adapt as health services and community health needs change over time. Different health services might result in different types of relevant information, which might be usefully shared to the healthcare recipient's My Health Record.

During previous consultations on the proposal to share by default, suggestions were raised regarding what other types of health services or information may be beneficial to include in the future. For example, the benefits of sharing information about medication management have been highlighted consistently. While no decision will be made without consultation, such suggestions highlight the importance of the flexibility that has been built into the Bill, as the Rules will be able to specify what information is required to be shared in relation to a particular health service.

Initially, it is proposed that the Share by Default Rules will require reports or results to be uploaded regarding the following types of pathology and diagnostic imaging services, subject to exceptions:

- Services listed in the tables under Part 2 Services and fees of the Health Insurance (Pathology Services Table) Regulation 2020
- R-type services listed in the tables under Part 2 Services and fees of the Health Insurance (Diagnostic Imaging Services Table) Regulations (No. 2) 2020.

The Share by Default Rules may also make provision for types of health information or health services not to be subject to uploading requirements, for example, because they were not conducted primarily for healthcare purposes. Relevant exceptions that may apply to pathology and diagnostic imaging services are still under consideration and are subject to further consultation. Examples of reports that could be excluded from uploading requirements include the results of workplace drug and alcohol testing, and reports produced for migration or visa purposes, or as part of forensic or court-ordered processes.

All information required to be shared to My Health Record will also be subject to the exceptions outlined in the Bill, including if the:

- healthcare recipient has advised that they don't want the information uploaded
- healthcare recipient is not registered for My Health Record
- healthcare provider reasonably believes that the information should not be uploaded due to a serious concern for the health, safety or wellbeing of the healthcare recipient
- information cannot be shared due to other reasons beyond the control of the healthcare provider.

### 6.3 Timeframes for uploading to My Health Record

The Share by Default Rules will prescribe the period within which information needs to be uploaded to My Health Record. As with the other rule-making powers, the required timeframe for upload has been intentionally deferred to rules under the Bill. This is because the timing for sharing relevant information may differ for different types of health information, as the scope of this requirement is expanded in future.

It is intended that healthcare recipients should have access to their health information at the same time as their healthcare provider, unless exceptions, including those related to clinical safety apply.

For pathology and diagnostic imaging, it is proposed to require sharing at the same time as results are sent to the referring healthcare provider. This timeframe may also provide scope to allow for technical processes, such as uploading reports in bulk outside of business hours.

## 7. How healthcare providers will be supported

To support transition to the new arrangements, the requirement to share, including the enforcement of any penalties, and conditional Medicare payments, will only start when the Share by Default Rules commence. Dependant on the outcomes of consultation, it is anticipated that once the Share by Default Rules are finalised, they will have a delayed commencement to provide time for industry and providers to transition.

Support from the Agency will also be available for healthcare providers who are unable to immediately fulfil uploading requirements. The Bill provides the Agency, as the My Health Record System Operator, the ability to grant providers additional time to connect and meet the share by default requirements, having regard to their size, technical capabilities, impacts on the provision of healthcare and other relevant considerations. A decision made by the System Operator to deny an extension would be an administrative decision subject to review by the Administrative Review Tribunal.

This process will ensure that the delivery of health services by smaller or remote providers, who may not have in place the technology to support sharing, is not interrupted as they will have a formal exception to the upload requirement during the additional time granted to establish systems to support their connection to My Health Record.

Software vendors also play a role in supporting healthcare providers with solutions to meet their evolving needs. While some small providers are not currently connected to My Health Record, the Agency has been working with software developers to explore new ways to deliver the technical ability to share reports with My Health Record, including via enhancements to existing workflows and capabilities.

The Agency also continues to work with software vendors to encourage uplift of clinical information systems in response to feedback that access to information in a healthcare recipient's My Health Record should seamlessly integrate with the systems used by healthcare providers. Work to increase the availability of information in My Health Record and to ensure it is easily accessible by healthcare providers, will help to deliver the benefits sought through this reform.

The Agency is keen to support developers that may wish to bring solutions to market to support sharing with My Health Record. This assistance, combined with the formal process to seek additional time to share, will support providers to methodically transition to the new requirements.

# 8. Compliance

There will be two distinct methods for enforcing the requirement to upload:

- **1.** Recouping Medicare benefits payable for health services under the Health Insurance Act.
- 2. Pursuing civil penalties against corporations under the My Health Records Act.

The new civil penalties will apply where there is a failure to:

- upload to My Health Record where an obligation to share applies
- keep records where an exception to upload has been applied
- publish notices to advise healthcare recipients where the provider is not uploading.

Healthcare recipients will not be adversely impacted by the compliance framework and will continue to receive their Medicare benefit as they do today.

In relation to the provisions under the Health Insurance Act, the proposed compliance framework seeks to align with existing post payment compliance provisions in place for Medicare.

The Bill also provides for Medicare benefits to be paid in advance of uploading the required health information by the healthcare provider. That is, if a healthcare recipient pays for a service upfront, they would receive the Medicare benefit as per current processes and not be delayed until upload has occurred. Should the healthcare provider then fail to upload the relevant health information, the Medicare benefit would be retained by the healthcare recipient but be repayable by the healthcare provider.

Healthcare recipients will also be supported to choose providers that are sharing to My Health Record. The Bill incorporates a requirement for healthcare providers to publish notices online and on-premises, to advise where the organisation is not uploading.

The Bill provides for limited information to be shared from My Health Record to enable data matching for the purpose of enforcing compliance with the share by default requirements. The Bill provides that such information may be shared to the Chief Executive of Medicare, the Secretary of the Department of Health and Aged Care, or another Commonwealth entity prescribed in rules. The provision to prescribe additional Commonwealth entities recognises the need for flexibility in the event of future government restructures impacting the compliance functions under the Bill.

Data to be shared will be prescribed in the Rules to ensure that it is limited to data attributes necessary to specifically support compliance. Prescribing in Rules what data and information can be shared also provides flexibility to update relevant data points as systems evolve over time. Any exchange of data will occur in accordance with the security classification of the data in a secure and safe manner.

Guidance is to be developed regarding the limited My Health Record data required for compliance-related purposes, specifically for pathology and diagnostic imaging reports in the first instance. It is likely that metadata will be needed indicating whether the test was a pathology or diagnostic imaging test (but not the name or sub-type of test), the date of the request for the relevant test, the date the images were taken or specimen was collected, and the healthcare identifiers of the healthcare recipient, provider and organisation. These requirements will be subject to further consultation.

The Bill also provides for information relating to compliance with share by default requirements to be shared to and from the Australian Commission on Safety and Quality in Health Care, to support the Commission's role in the oversight of accreditation standards for healthcare providers. These complementary provisions offer a further mechanism to support the objectives of the share by default provisions, to achieve better access to key health information to support healthcare recipients and their healthcare teams.

While the Bill establishes a strong compliance framework to support the shift to mandatory sharing to My Health Record, it is intended that the focus of compliance efforts will be educative, supporting providers to upload and respond in the event of technical issues.

# 9. Concluding remarks

The Department and Agency thank you for the opportunity to provide a submission to the inquiry regarding the Bill.

We look forward to continuing to work with stakeholders in response to this important reform.

We would welcome the opportunity to provide further information if requested to support the Committee in its consideration of the Bill.