



Health Legislation Amendment  
(Modernising My Health Record—Sharing  
by Default) Bill 2024

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Consumers Health Forum of Australia (2024)  
*Health Legislation Amendment (Modernising My  
Health Record—Sharing by Default) Bill 2024.*  
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## Introduction

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Consumers Health Forum (CHF) is the national peak body representing the interests of Australian healthcare consumers and those interested in healthcare consumer affairs. CHF works to achieve safe, quality, and timely healthcare for all Australians, supported by accessible health information and systems. At the heart of CHF's policy agenda is consumer-centred care.

In the context of CHF's commitment to improving digital health services, CHF supports and recognises the importance of ensuring that healthcare providers fully engage in digital health and My Health Record.

In this submission, CHF is pleased to provide the Senate Community Affairs Legislation Committee with feedback and recommendations regarding the Health Legislation Amendment (Modernising My Health Record—Sharing by Default) Bill 2024.

In this submission, CHF will provide reasoning for supporting Sharing by Default Legislation. CHF will then discuss privacy and confidentiality, upload exceptions, and provide recommendations on what CHF identified as potential compliance loopholes.

The consumer views reported in this submission are the fruit of consultation with the Digital Health Consumer Panel, a panel of consumers with a strong interest in Digital Health, meeting six times a year and regularly providing advice to the Australian Digital Health Agency.

## Summary of Recommendations

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1. The addition of a feature to My Health Record that allows consumers also to add notes explaining - in their own words - why a specific medication was prescribed or why a particular test was performed.
2. More resources need to be put in place to ensure that consumers are aware of the changes and that they will have a much more active role in ensuring that the information they don't want on their records is not uploaded.
3. Mechanisms are put in place that detect operators with unusually high utilisation rates of upload exceptions, particularly based on an individual healthcare provider believing that the information should not be shared with the My Health Record system because of a serious concern for the individual's health, safety or wellbeing.
4. Compliance processes of the Health Legislation Amendment (Modernising My Health Record—Sharing by Default) Bill 2024 to not focus solely on quantitative markers for uploads but also qualitative.

5. A reporting mechanism is put in place, by which consumers can report to the System Operator instances of uploads that are of poor quality or that do not contain information sufficient for ensuring continuity of care.

## CHF supports Sharing by Default Legislation

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CHF strongly supports the Health Legislation Amendment (Modernising My Health Record—Sharing by Default) Bill 2024.

Consumers with complex health conditions have long highlighted the necessity for all health professionals to upload data on My Health Record promptly. This is important, especially for consumers with complex health conditions, for whom continuity of care is paramount. Consumers have expressed concerns about delays and difficulties in uploading their critical health information onto My Health Record. For many, these delays can lead to potentially life-threatening situations during episodes of urgent care.

*"It is so important for clinicians to use My Health Record, particularly if you do have complex health issues that can escalate very, very quickly. We're put in situations where we're seeing doctors that don't know our situation, and we may not be able to let them know because we are unwell..."*

*"It's a matter of saving people's lives"*

When consumers have enquired about delays or lack of uploading onto My Health Record, they have often been told that clinical and administrative staff are too busy to perform this task. CHF understands that the pressure on primary care staff is currently high. However, more widespread use of digital records is bound to reduce pressure on primary care by providing clinicians with the information they need, when they need it.

For all the above reasons, CHF welcomes the establishment of a compliance framework to set acceptable standards for data uploading onto My Health Record. While a compliance framework is fundamental, it is likely insufficient to produce change in behaviour. **CHF recommends allocating appropriate resources to raise awareness and upskill healthcare providers to use My Health Record.** Ultimately, it is the quality of the data uploaded onto My Health Record by default that will determine the success of this reform.

## Privacy, confidentiality and upload exceptions

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CHF is generally satisfied that the limitations to an individual's *right to privacy* posed by the Health Legislation Amendment (Modernising My Health Record—Sharing by Default) Bill 2024 are commensurate to ensure a better uptake and use of My Health Record.

The upload exceptions in the amendment (Subsection 10B) are reasonable, comprehensive and consistent with the ones requested by consumers. CHF welcomes the exception that allows healthcare providers to not share information with the My Health Record system if they believe the information would cause serious concerns for a consumer's health, safety and wellbeing.

### Subsection 10B

Relevantly, an upload exception applies if:

- the individual is not a registered healthcare recipient; or
- the individual, or their authorised or nominated representative have advised the entity, or the entity has otherwise been informed, that the individual, or their authorised or nominated representative has advised that the information must not be uploaded to the My Health Record system; or
- an individual healthcare provider reasonably believes that the information should not be shared with the My Health Record system because of a serious concern for the health, safety or wellbeing of the individual; or
- the information cannot be shared with the My Health Record system due to circumstances beyond the reasonable control of the entity. Circumstances beyond the reasonable control of the entity may include, for example, where that entity is unable to achieve an Individual Healthcare Identifier match for the purposes of the Healthcare Identifiers Act 2010.

The exceptions described in Subsection 10B are all significant and central to person-centred care. Consumers have often shared with CHF their worries about stigma in digital health. Consumers have spoken of how the ability of doctors to lodge statements on their My Health Record has the potential of disrupting treatment with other clinicians. This strongly affects – for example - consumers who are being prescribed a medication for a condition that carries social stigma, such as any medication that addresses mental health conditions.

To add nuance to the implementation of upload exceptions - and reduce instances in which consumers refuse to upload information to their My Health Record - **CHF recommends adding a feature to My Health Record that allows consumers also to lodge notes explaining - in their own words - why a specific medication was**

**prescribed, or why a particular test was performed.** This will empower consumers to be more in charge of their narrative.

Sharing by default will mean that instances in which consumers will want to withhold the upload of information on their My Health Record will increase exponentially. **CHF calls for more resources to be put in place to ensure that consumers are aware of the changes and the much more active role they will have to play in ensuring that the information they don't want on My Health Record is not uploaded.**

## Potential Compliance Loopholes

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CHF would like to bring to the attention of the Senate Community Affairs Legislation Committee two potential loopholes that might affect the Health Legislation Amendment (Modernising My Health Record—Sharing by Default) Bill 2024.

### Item 4 – After Section 10, Section 10 B – When an upload exception applies

The above-mentioned section discusses instances where an upload exception applies.

It is unclear to CHF how compliance for the third exception, "An individual healthcare provider reasonably believes that the information should not be shared with the My Health Record system because of a serious concern for the health, safety or wellbeing of the individual", will be managed.

Is there a mechanism preventing operators from excessively relying on this exception? CHF has not found in the Bill any suggestion that the System Operator in charge of compliance will be able to critically engage with the reasoning behind each exception being used by an operator.

CHF understands and supports this, as it is done to ensure that sensitive information remains private and confidential. While it could be for legitimate reasons (one would imagine a sexual health clinic – for example - will resort to this exception far more often than other healthcare providers), **CHF recommends that mechanisms are put in place that detect operators with unusually high utilisation rates for this exception.**

This mechanism will allow the System Operator to investigate unusually high rates of usage for this exception at the operator level without any need for disclosure of sensitive personal data.

### Item 13 – At the end of Subdivision B of Division 2 of Part 4

It is mentioned that new section 70A provides specific authorisations for collecting, using and disclosing information to support the monitoring, compliance and enforcement of the share by default provisions.

It also mentions that the types of information to be shared for compliance purposes are limited to:

- Record type/type of healthcare service or episode, for example, pathology test, diagnostic imaging scan, chronic disease management plan, and
- The date the healthcare service was performed.

It is not clear to CHF whether this means that operators only uploading a record type to My Health Record and the date a service was performed will then be marked as compliant.

From a healthcare consumer point of view, these two data points alone do not contain enough information to produce a clear overview of a person's clinical situation, nor are they enough to ensure continuity of care. As mentioned before, the success of sharing by default will largely depend on the quality of the information uploaded to My Health Record.

Therefore, CHF recommends that compliance processes of the Health Legislation Amendment (Modernising My Health Record—Sharing by Default) Bill 2024 do not solely focus on quantitative markers but also qualitative ones.

To that end, CHF recommends that a reporting mechanism be put in place by which consumers can report to the System Operator instances of uploads that are of poor quality or that do not contain information that is insufficient to ensure continuity of care.