Consumers Health Forum OF Australia

SUBMISSION

Review of My Health Record legislative instruments

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Consumers Health Forum of Australia (2025)
Submission to the Review of
My Health Record Legislative Instruments

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Introduction

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

CHF welcomes the opportunity to provide a submission to the Department of Health, Disability and Aged Care's (DHDA) Review of My Health Record Legislative Instruments.

In the context of CHF's commitment to improving digital health services, CHF supports and recognises the importance of ensuring that My Health Record legislative instruments are appropriate, current, robust and fit for purpose.

The key purpose of My Health Record (MHR) is to provide consumers with a secure, online, personal health summary. This is a system designed for consumers, and as such any significant changes to the system must be informed by meaningful consultation with consumers.

Unfortunately, the very short timeframe of the consultation period for the legislative review and the lack of specific resourcing for consumer consultation means we are unable to consult with the wider community to provide DHDA with in-depth and broad consumer input on this important legislation. We strongly recommend that future consultations allow appropriate time and resources to enable meaningful consumer input into the development and implementation of digital services designed to service them. To build trust in the system and ensure that reforms to My Health Record are fit for purpose it is essential that government prioritises consumer engagement.

Given the significant time and resource limitations, CHF engaged an existing consumer panel to provide input into this consultation. As part of our contract with the Australian Digital Health Agency (the Agency), CHF facilitates a Digital Health Project Consumer Panel (the Panel). The Panel consists of thirteen (13) healthcare consumers, with a diversity of backgrounds and experiences. The Panel has already made recommendations to the Agency in relation to My Health Record including potential improvements to user interface and accessibility, and suggestions for promotional and educational materials and resources. They have also provided feedback on the recent Share by Default legislation amendment (CHF's submission on this topic can be found online here).

To inform this submission CHF consulted directly with Digital Health Project Panel members. We have also incorporated consumer feedback gathered in other forums, including a recent pilot research project undertaken for the Australian Digital Health agency investigating young people's engagement with My Health Record[1], and data from CHF's recent National Consumer Sentiment Surveys.

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[1] Consumers Health Forum of Australia (2025) *Young People and My Health Record*. Not yet published.

Responses to Consultation Questions

Consumer feedback on the key consultation questions is provided below. The consultation questions have been modified in places to make them clearer, more relevant and easier to understand. Consumers also fed back to CHF that the background information to the consultation was lacking useful details, such as data on current consumer uptake of certain processes or features (such as assisted registration).

Consumers are not a homogenous group and even within this small sample feedback was varied. While there was clear consensus on responses to some of the key questions, others received mixed feedback. We have summarised the feedback below for DHDA's consideration and included direct quotes from consumers (Digital Health Panel Members) within the text.

Overall, consumers are generally happy with the current MHR legislative instruments – although they do have a number of suggestions for changes and improvements. This warrants broader and more in-depth consumer consultation to ensure any legislative changes accurately reflect consumer needs.

Restrictions on uploads

Question 1: Should the current restrictions on uploading certain health information be reviewed? If so, what changed would you propose and why?

Consumers understand and appreciate why the current restrictions are in place and recognise the importance of ensuring that any uploads to MHR are authored by registered healthcare professionals. However, they also recognise that there may be important and relevant health information that they receive from other healthcare professionals that are not registered with Ahpra. For example, as identified within the consultation paper, certain Aboriginal and Torres Strait Islander health professionals are not registered with Ahpra.

Consumers agreed that excluding such contributions may lead to an incomplete health record, which contradicts the purpose of a comprehensive health summary.

> *"MHR is advertised as something that is comprehensive about all of your health and to exclude providers who are contributing to your health is counter intuitive."*

Consumers emphasised that this was their health information and that they deserve a complete record of all the care they receive. Consumers also noted that they should be able to remove records if they wish. Given this, they were supportive of reducing the restrictions so that all healthcare providers were able to upload information, as long as the details on who has uploaded the information was clear.

> *"If consumers don't want certain things, then there are personalised settings available to everyone."*

Nominated Healthcare Providers and Shared Health Summaries

Question 2: Do you think the definition of a 'nominated healthcare provider' should be changed to include other health professionals such as pharmacists, enrolled nurses, or midwives who are not registered nurses? Why or why not?

Consumers questioned why they were limited to nominating only one 'nominated healthcare provider'. They felt that this was based on an outdated model of consumers seeing one regular GP. Currently many consumers see various GPs due to a variety of reasons including cost, travel, location, specialisation or staff turnover at clinics. For the significant number of consumers who may be seeing multiple healthcare providers, selecting only one as their 'nominated healthcare provider' is not realistic.

Consumers agreed that there needs to be a shift towards a more contemporary "care team" approach. This would allow consumers to nominate a pool of trusted healthcare providers who are actively involved in their care.

Consumers agreed that all healthcare professionals registered with the Australian Health Practitioner Regulation Agency (Ahpra) (including allied health professionals) – not just GPs, registered nurses and ATSI Health practitioners - should be able to be nominated to contribute to Shared Health Summaries.

Question 3: Have you ever used a shared health summary? Do you think this is a useful document? Why/Why not?

Consumers recognised the potential benefits of a Shared Health Summary and its purpose to provide an overview of an individual's health. However, only 30% of the consumers consulted had ever used a Shared Health Summary, suggesting there may be both a lack of awareness of this document's purpose and existence, as well as limitations to its usefulness. Further, there was some confusion amongst consumers between a "Shared Health Summary" and a "Patient Health Summary".

Consumers recognised that a Shared Health Summary could be valuable for parents monitoring their children's health and consumers who see multiple different doctors. For these individuals, access to a current summary could mean they don't have to repeat their entire medical history at every appointment. Consumers also saw the benefits of Shared Health Summaries for Australians with chronic or complex care needs, given they are more likely to be receiving care from a large number of providers and be taking multiple medications etc.

However, consumers emphasised that the value of a Shared Health Summary relied on it being current and up to date. Consumers noted flaws with the existing template, particularly it's apparent inability to be automatically updated when, for example, a new medication is dispensed. Consumers agreed that Shared Health Summaries should ideally be a living document that is automatically updated as information in a consumer's MHR changes, and then reviewed as needed to ensure the summary is up to date and relevant.

> *"There are certain fields within the shared health summary that doesn't really need to be typed in by people anymore. And so…if it's a living document, then some of it will automatically update when someone cares for that section of you."*

Other consumers felt that accessing and understanding a Shared Health Summary required a consumer to be highly health literate, making the document inaccessible to many people.

Overall, consumer feedback warrants further consideration of the usefulness of a Shared Health Summary in its current form. It may be more helpful for this document to be re-designed with consumers and healthcare providers to increase its relevance, accessibility and usefulness.

Question 4: Do you think any other health professionals should also be able to write and upload a shared health summary? If so, what types of health professionals and why?

Consumers believe that other health professionals should be able to contribute to a Shared Health Summary. As mentioned above they feel that any healthcare professional who has provided them with care should be able to contribute to a summary (recognising that they also feel contributions should happen automatically).

> *"I think it makes sense for other healthcare providers involved in a person's care to be able to contribute to the summary. I think there shouldn't be a restriction on the number of people who can create the summary – why can't the summary bring together information from all of the people involved in someone's health care, each writing about the aspect of care they are involved in? This would make more sense that relying on a single person."*

Healthcare organisation obligations

Question 5: Do you think there is anything missing from the current list of essential requirements for a healthcare provider organisation to register with the MHR system? Anything that needs to be changed?

Consumers generally agreed that the current list of essential requirements for a healthcare provider organisation to register with the MHR system seemed comprehensive and appropriate.

Regarding the requirement for organisations to have a security and access policy, consumers suggested that there should be a standardised template for such a policy provided to registering organisations. A template would ensure consistency and a high-quality minimum standard, while also allowing organisations to adapt it to their specific needs.

Consumers also noted that it would be useful to require healthcare providers to promote their commitment to the essential requirements to the public through resources/information made available in their waiting room or on their website.

Question 6: In terms of cybersecurity – what would you specifically want to know is required of organisations?

Consumers recognised that the current legislation was originally developed in 2016 and there have been significant advances in cybersecurity since then. They want legislation to ensure that any healthcare organisation registered with MHR has robust policies and processes in place with regard to cybersecurity – and that these are reviewed and updated regularly to ensure currency. They also wanted to know that organisations were adequately resourced and supported to enable this.

> *"[I want to know] they have the necessary tools to enable sufficient cybersecurity – for example, IT systems, personnel training, and access to federally funded resources (organisations should be able to contact a department easily and get prompt, tailored support if they ever have any queries / issues / concerns about the record)."*

Consumers also want to be provided with clear information from healthcare providers about who is accessing their data. Consumers wanted to be assured that any data breaches would be treated seriously and that consumers would be notified of security breaches immediately. They want to see a preventative approach in place where incidents trigger investigations aimed at system improvements and organisational accountability.

Emergency Access

Question 7: Do you think the current emergency access process and rules need to be changed in any way?

Consumers felt that the current emergency access process and rules were ambiguous in relation to exactly who could use emergency access, and how its use was justified. They believe some of the current wording around this is too interpretive and needed to be more prescriptive.

Consumers also wanted to be notified when their record was accessed via the emergency access function. They recognised that this is recorded in their MHR, but felt that an instant notification was also important. The notification should inform consumers that this event has occurred, by whom and how long their access will last.

Consumers wanted the legislation to provide clarity around the following:

- Whether access is permitted for 5 calendar days or 5 business days
- What exactly constitutes a consumer or their authorised representative not being able to provide consent.
- Whether carers, family members or nominated representatives are consulted in any way prior to use of emergency access
- Whether a carer can request access to someone’s record via emergency access if the criteria are met (and they don’t already have access).

My Health Record access after a recordholder’s death

Question 8: Do you think nominated and/or authorised reps should continue to have access to a person’s My Health Record after they have died? Why or why not?

Consumers agreed that both nominated and authorised representatives should continue to have access to a person’s My Health Record after they have died.

> *“I understand the first principle of the system is to provide healthcare to the recordholder, however, there are valid reasons why a person might want to refer to the record after someone’s death”*

If this was not possible, at the very least consumer suggested a process should be put in place whereby an authorised or nominated representative could request access to the information within the retired record.

a. If access was to be continued, should this apply equally to both authorised and nominated representatives? Why/why not?

Consumers agreed that access should apply equally to both authorised and nominated representatives as both are trusted by the record holder to manage or view their health information.

b. What should that access involve? (e.g. view all or limited information?)

Consumers were divided regarding full or limited access, although most felt full access was appropriate. Most consumers also supported the implementation of a consent feature within MHR which allows the recordholder to specify their preference in the event of their death.

c. For what purpose/s should access be granted?

Consumers noted multiple potential reasons to grant access including:

- Administrative and legal purposes
    - To assist in finalising the deceased estate and seek knowledge regarding the circumstances of their death.
- Family health
    - To investigate genetic or hereditary conditions to benefit the health of living family members.
- Personal
    - To provide a sense of closure for the family.

- If applicable, for how long should such access be in place?

There was no clear consensus on the period access should be in place, with suggestions ranging from a minimum of 90 days to 50 years. Due to the varying responses, consumers suggested that the representative should have the ability to archive or download an offline copy of the record.

> *"Personal representatives should be allowed a minimum of 90 days access after the consumers death. The personal representative may wish to seek legal advice regarding the death, or download records for posterity, historical records or genetics."*

Question 9: Do you think nominated healthcare providers and/or other healthcare providers should continue to have access to a person's MHR after they have died? Why or why not.

Consumers agreed that healthcare providers should not have ongoing access to an individual's MHR after their death. If access is required for a specific and valid reason, there should be a robust process in place that the provider must undertake before being granted access.

> *"No, I don't think they should be able to access it. This is identifiable information about an individual. If they wish to access it, there needs to be a stringent process in place and a valid reason for accessing it. As the person has died, they can't provide consent – so this would be an issue."*

a. What should that access involve? (e.g. view all or limited information?)

Consumers agreed that access should be limited and only for the specific purpose for which it is granted (either via the aforementioned formal process, or due to consent granted by the recordholder prior to their death).

b. For what purposes should access be granted?

Consumers recognised the following potential reasons to grant health provider's access:

- Legal and Coronial Duties
- Clinical Quality Improvement
    - As a learning opportunity for the deceased's care team to review the case for quality assurance and educational purposes
- Research
    - Only if explicit consent was provided before the recordholder's death. Any system of implied consent was rejected by consumers

c. If applicable, for how long should such access be in place?

Consumers agreed that access must be time limited, however they did not specify the timeframe.

Furthermore, consumers agreed there is a need for clear and transparent policies regarding how a deceased person's data is eventually destroyed and a system in place to inform their representative/s if and when their MHR data is shared or deleted.

Assisted Registration

Question 10: Do you think there is an ongoing need for assisted registration?

There was unanimous agreement from the consumers consulted that there was an ongoing need for assisted registration. Consumers agreed that it was important to have such a process available to those who need it, recognising that not everyone is digitally literate and there are multiple reasons a person may need assistance registering for MHR.

> *"If people want to register and need help to do so, they should get all the help that they need, for as long as they need it."*

Consumers listed a number of potential hurdles to consumers self-registering for MHR including:

- Technological barriers
- Systemic hurdles
    - Not everyone has a myGov account, and multiple consumers spoke about myGov itself being a complex system to navigate
- Language and cultural barriers
    - New immigrants in particular may face language barriers and may struggle to understand the process given they are not familiar with the Australian healthcare system.

Question 11: If assisted registration continues to be an option, should any changes be made to the process?

Consumers felt there was a lack of general awareness that assisted registration was an option and felt strongly that it needed to be promoted more effectively. They also felt that the current voluntary model where healthcare organisations decide if they will offer the service or not is not appropriate.

To improve the assisted registration process, consumers proposed the following:

- Universal offering
    - All healthcare providers should be required to offer assisted registration to consumers who need it. This requires that all organisations registered for MHR are trained in the process.
- Beyond healthcare providers
    - Some consumers felt that the assisted registration process should not be confined to healthcare providers but also be offered at appropriate existing community hubs to reach key demographics. Specifically, consumers wanted assisted registration to be offered at new migrant and multicultural centres.
- Offered as a bulk-billed appointment
    - Consumers would like this service to be offered as an appointment that is bulk billed. During the appointment a staff member at the healthcare organisation (e.g. a nurse, the GP, admin staff) could help a consumer to register and then go through their record with them.

Additional feedback

Question 12: Are there any other changes you think need to be made to how My Health Record works and the related rules and restrictions?

Consumers provided the following suggestions on other changes to how MHR works and related rules and restrictions:

- Valuing consumer additions to MHR
    - Consumers feel that the current 'personal notes' feature is flawed in that it is not visible to healthcare providers. Consumers felt that this suggests health information added to a record by a consumer is not considered as important or legitimate as other information. For MHR to be a genuinely shared record, an individual's personal notes should be visible and valued by their care team (unless a consumer decides they would like them to remain private).

  "What's the point of having like a shared record if your information that you're uploading about your own health is not going to even be valued?"

- Regular uploads, more consistent and more detailed information
    - Consumers agree that one of the key improvements they would like to see to MHR is more consistent and regular uploading and updating of information by healthcare professionals. All consumers agreed that this would result in a more useful and reliable record. The upcoming 'Share by Default' changes will hopefully assist with this.
    - To ensure consistency in what is uploaded, consumers feel there should be more standardised policies and templates in place. Currently consumers experience significant variability in the detail and quality of what is uploaded.
    - Consumers would also like the broader range of healthcare providers to be encouraged and supported to upload information, including allied health practitioners. This would result in a more complete record and support communication and coordination across different providers.

- Transparency
    - Consumers consistently emphasise the importance that healthcare professionals are open and transparent with them in relation to what is/isn't going to be uploaded to MHR – and ensure that this is well understood before proceeding.
    - Consumers would also like assurance that an individual practitioner's details as well as the organisation where they work are both included in anything uploaded to MHR.

Question 13: Is there anything else you would like the government to know about your experience with My Health Record, or any ideas you have for how it could be improved?

Consumers have provided suggestions for improving MHR in various consultations facilitated by CHF. We recognise that some of these changes are outside of the scope of this specific review, but have still included them as important considerations for both the Department and the Agency moving forward.

- Co-design with consumers
    - Consumer engagement should be embedded in the design, operation, governance and ongoing improvement of MHR. Genuine co-design creates a system that is more trusted, usable, accessible and effective for the entire population.
- Promote MHR more effectively and build awareness of its functionality
    - There is a widespread lack of awareness amongst consumers about MHR and its features. CHF's National Consumer Sentiment Survey (NCSS) is an annual national survey of 5,000 consumers, representative of the Australian population based on age, gender and state of residence. Results from the 2024 survey showed that almost 25% of the consumers had not heard of My Health Record.[2] Consumers consistently tell us that MHR, its features, and existing resources need to be more widely promoted to build awareness.
    - A multi-faceted approach to increasing awareness of MHR is required, this should involve targeted campaigns that are co-designed with consumers and should incorporate:
        - Development of MHR resources (including clear, short step-by-step guides and 'welcome packs') that are targeted at specific cohorts and available in a variety of accessible formats. These resources should respond to the needs of specific cohorts including (but not limited to) new migrants, culturally and linguistically diverse communities, First Nations people, people who may be experiencing violence or abuse, and people with disability. This could also incorporate a review of existing resources, and greater promotion of relevant and appropriate resources that already exist.
        - Introducing MHR education in schools, as part of broader digital and health literacy programs. This should include building awareness of the transfer of control of MHR at age 14.

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[2] Consumers Health Forum of Australia (2025) *National Consumer Sentiment Survey 2024*. Not yet published.

        - Social media campaigns
        - Brochures and posters about MHR available in various appropriate locations including GP clinics, community hubs, schools, etc. This collateral could include a QR code that links to the resources mentioned above.
        - Supporting healthcare professionals to more actively and consistently promote and explain MHR during appointments.
- Enhance accessibility
    - Consumers feel that the MHR website and apps could be made more accessible.
    - Translator and interpreter service should be clearly and consistently available.
    - MHR should use plain language as much as possible and reduce medical jargon to ensure information is easily understood by consumers.
- Consistency between platforms
    - A source of frustration for many consumers was the inconsistency between the web and mobile versions of MHR. The mobile app seems to have only “read-only” capabilities, whereas the web version allows for editing and uploading. Consumers indicated that the two platforms need to be made as consistent as possible.
- Supporting the transfer of control at age 14
    - There is a need for provision of clear and structured guidance and education for young people and their parents/guardians in the lead up to the transfer of control of MHR at age 14. Currently there is a significant lack of awareness of this change amongst young people and their families.
- Connect MHR with broader health information
    - Many consumers would like to see more general health information available on MHR (or at least links to where they could find it). Greater integration between MHR and trusted health information sources like *Healthdirect* could help to connect MHR users to reliable health information and resources.

Conclusion

While consumers are generally satisfied with the current My Health Record legislative framework, they have identified important areas for improvement. This underscores the need for broader and more in-depth consumer engagement to ensure that any legislative reforms genuinely reflect consumer needs and expectations. To build trust and deliver a My Health Record system that is truly fit for purpose, government must move beyond limited consultation and place consumers at the centre of the reform process.