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10 January 2015

Senate Standing Committees on Community Affairs
PO Box 6100
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Canberra ACT 2600

via email community.affairs.sen@aph.gov.au

Submission to the Inquiry into the *Health Legislation Amendment (Modernising My Health Record—Sharing by Default) Bill 2024 [Provisions]*.

Dear Committee Secretary

COTA Australia welcomes the opportunity to contribute to the Senate Standing Committees on Community Affairs' inquiry into the *Health Legislation Amendment (Modernising My Health Record—Sharing by Default) Bill 2024 [Provisions]*.

As Australia's peak body representing older people, with almost nine million Australians over 50, we are uniquely positioned to identify how the welcomed changes will enable individuals to partner more informatively in decisions affecting their health and wellbeing. Over the last three years we have conducted a series of surveys, focus groups and other engagement activities on digital technologies, particularly My Health Record (MHR). We have listened to what older Australians have told us about MHR, and the improvements they have identified and want, some of which will be met in part by the introduction of the new rules.

Older Australians' current experience and use of My Health Record

While many older Australians appreciate the multiple personal, professional and systemic benefits of MHR, factors such as trust, digital literacy and privacy concerns still influence how positively they engage. From our engagement with older Australians, we know that many:

- value the convenience of having their healthcare records available to them online (although, at present these records are far from comprehensive)
- appreciate having control over who can access their online healthcare records and to what extent
- acknowledge that having a centralised, easily accessible online healthcare record facilitates better coordination and delivery of healthcare care especially if experiencing chronic health or complex health needs
- understand that digital services are now part and parcel of service delivery and, appreciate the potential of My Health Record as a critical part of the wider move

towards increased, appropriate use of digitalisation in healthcare aimed at improving service efficiency and personal responsiveness

These engagements also advise that while many older people see value in digital technologies and know that a lack of access can exacerbate health inequalities, they face personal and systemic barriers optimising their use. Research COTA Australia conducted for the Australian Digital Health Agency in 2023 suggests that while most older Australians who are online are aware of MHR, many are tentative in progressing their use. Key personal concerns voiced include:

- privacy and security – not having sufficient control over their healthcare information
- scepticism regarding the usefulness of MHR when medical practitioners do not upload information and/or communicate negativity about its worth to individuals
- Amongst older people, an often-cited reason for not using MHR was because “my GP does not use it.” Another is that home care and aged care providers do not/cannot access MHR.
- lack of understanding of the purpose, workings or benefits of MHR
- limited digital skills and/or believing managing MHR is a daunting process

Older people also feel that the advocacy burden for the use of the MHR (particularly with GPs) falls onto them. Whilst they understand they have and want a major role to play in advocating for their own medical and health professionals to use MHR, they are calling for greater systemic change to compel health providers to populate information within MHR to enable its wider usage.

COTA Australia supports **removing healthcare access delays (pathology and diagnostic imaging reports)**, the key intent of the *Health Legislation Amendment (Modernising My Health Record—Sharing by Default) Bill 2024*. We welcome the mandated requirement that healthcare providers upload a healthcare consumer’s health information to their My Health Record. Albeit, the current Bill’s provisions, are limited to reports on pathology and diagnostic imaging tests, they open the way for a more comprehensive implementation of the Bill’s provisions within the healthcare system in the future.

The Bill reinforces the centrality of the healthcare consumer in deciding if their test results should be uploaded to their MHR and, if so, by whom their information can be accessed and we fully support this. This clearly highlights that each healthcare consumer is the owner of their healthcare information and maintains control over access.

We note advice that the current 7-day consumer access delay policy is not affected by this legislation, however, this policy is currently being reviewed by the Australian Digital Health Agency’s Clinical Reference Group.¹ As a principle we believe timely and immediate access by an individual to the results of their health information should be the default. We hope that

¹ See <https://www.health.gov.au/sites/default/files/2024-11/health-legislation-amendment-modernising-my-health-record-sharing-by-default-bill-2024-frequently-asked-questions.pdf>

the default 7 day consumer access delay is removed, but that an optional health provider initiated delay is maintained. We acknowledge that some information (e.g. a specific test result), or for all results relating to a particular person, a healthcare professional should be able to delay its uploading to enable a patient/ health professional discussion, where required, in the first instance.

We do not however support a healthcare provider being able to permanently prevent information being included in My Health Record and propose that the very broad exemption that exists in clause 10B (c) and clause 19AD (3) (c) of the Bill be removed. These clauses states that an exemption to upload occurs where *“an individual healthcare provider (within the meaning of the My Health Records Act 2012) 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”*.

This exemption removes consumer choice and control and allows the continuation of paternalistic approaches to health care information by health professionals. Removal of these clauses is critical to stop this behaviour. I

If however the clauses are retained healthcare care providers must be required to obtain explicit informed consent from the patient that such information should never be uploaded.

We understand that enhancing our digital health system, requires time and resources. We appreciate that healthcare providers will be provided information, education a grace period to undertake the necessary changes. We also appreciate the Australian Digital Health Agency will continue to collaborate with and provide technical support to in-scope healthcare providers and their software suppliers.

We also welcomed the Australian Government’s decision that after the initial grace period to enable healthcare providers to implement the necessary changes. We support requiring healthcare providers who can’t or chose not to upload healthcare information to MHR to make this matter public at their premises and online or face the prospect of financial penalty.

While these changes will be welcomed by many older Australians who are online and use MHR with ease, they must be accompanied by targeted and appropriate information for all healthcare consumers. Our experience suggests that strong stakeholder engagement and education commitments will add to the effectiveness of the new rules.

Though the Inquiry is limited in scope to pathology and diagnostic imaging service providers, COTA Australia looks to the progressive rollout of the intent of the *Health Legislation Amendment (Modernising My Health Record—Sharing by Default) Bill 2024* to all healthcare providers. We believe this will foster the growth of a contemporary consumer focused healthcare system that embraces a multistakeholder approach to more appropriate, safer medical and health provider care provision.

On a personal and system level the benefits will include more empowered and active healthcare consumers, fewer avoidable adverse outcomes, inappropriate hospital admissions and unnecessary duplicate testing and further enhance Australia's position as a leader in healthcare provision.

Building trust and enabling access to more comprehensive healthcare information will support the full implementation of MHR. For older Australians, distrust is a significant impediment to their uptake of MHR and other digital technologies. We have heard from many older Australians that they do not trust the government's ability to maintain secure, safe databases that protect people's health data and protect people from scammers, and many are disappointed by the usefulness and/or timeliness of the information uploaded onto MHR. A frequent complaint is. 'My vaccination history is uploaded, but little else.' These concerns need to be addressed by the Australian Digital Health Agency and by health providers.

For older Australians to achieve digital health equity, all healthcare reform must be combined with community engagement, education and targeted information measures. We would welcome further discussion about our research and solutions proposed by the older people we work with.

Yours sincerely,

Patricia Sparrow

Chief Executive Officer

COTA Australia