



2023 Carer Wellbeing Survey Snapshot

Carer experiences of digital health tools

December 2023

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Executive Summary

Being able to access and / or manage the My Health Record of care recipients can enable carers to access important health information associated with their caring role in one place. However, little is known about how carers access My Health Record and in what capacity, and what some of the barriers to doing so might be.

This year, the Carer Wellbeing Survey asked thousands of carers about their use of My Health Record for themselves and the person they care for.

The results show that while My Health Record has the potential to make caring easier, not all carers currently find it highly useful. Use of My Health Record amongst carers is at least as high as use amongst the general population. However, more than two thirds of carers still do not access the My Health Record of the person/people they care for, often due to lack of awareness and knowledge about it, or in some cases due to reluctance of care recipients to permit this access.

Only 18% of carers reported their doctor had discussed My Health Record with them, suggesting potential opportunities to support and encourage carers to use this resource are often being missed.

Overall, the findings suggest My Health Record is a useful resource, however its utility to carers could be significantly increased through supporting carers and care recipients to understand its availability and useability.

This report has been prepared for the Australian Digital Health Agency by Carers Australia and Mel Mylek and Jacki Schirmer, University of Canberra.

Overview of the Carer Wellbeing Survey

Carers provide unpaid assistance to people living with disability, illness, chronic conditions or old-age related frailty. As of 2018, there were at least 2.65 million unpaid carers in Australia, representing 11% of the Australian population. About one third of these carers were primary carers, meaning they provided the majority of care to a person in one or more core activities (for example assisting with self-care, getting around and communication) (ABS 2019).

It is estimated the equivalent paid services would cost \$77.9 billion annually if not provided by unpaid carers (Deloitte 2022). It is essential to support carer's financial, emotional and social wellbeing so they can continue to provide high quality care to those they care for over the long term.

Carers are known to experience poorer wellbeing compared to other Australians, with the risk of poor wellbeing being higher amongst carers who have more complex, time consuming or otherwise challenging caring commitments. Carers are also more likely than non- carers to have significant health problems, and to experience loneliness and financial hardship (Cummins et al. 2007; Schirmer and Riyanti 2021, Schirmer et al. 2022).

Determining how best to support carers in their role, and improve their wellbeing, requires understanding their baseline wellbeing as well as their experiences as a carer and the supports and services they access.

In 2021, the national Carer Wellbeing Survey (CWS) was launched as a partnership between Carers Australia, the Australian Government Department of Social Services (DSS), and the University of Canberra (UC). The survey aims to develop a comprehensive picture of the wellbeing of carers, how that wellbeing is changing over time, and how wellbeing of carers can be supported. The 2021 CWS provided an initial baseline set of insights from which change over time could begin to be examined.

Marking the third year of the survey, the 2023 CWS was conducted by the University of Canberra's WellRes unit and was funded by Carers Australia with support from DSS.

The aims of the CWS are to:

- Understand different dimensions of wellbeing and quality of life of Australian carers
- Understand how wellbeing and quality of life is changing for carers
- Understand how the wellbeing differs depending on the type of carer role a person has, and wellbeing risks associated with different carer roles
- Identify which types of support are effective in supporting the wellbeing of carers and their ability to be an effective and successful carer

The Full Report for the 2023 Carer Wellbeing Final can be [accessed here](#).

Methodology

The Carer Wellbeing Survey is a survey of Australian carers aged 14 and older, with carers defined as any person who provides unpaid assistance to a person with a disability, mental illness, drug or alcohol dependency, chronic condition, dementia, terminal/serious illness, or old-age related frailty. The 2023 CWS was conducted during February and March 2023. Participants could complete the survey online or on a paper form, and was translated into simplified Chinese, Arabic, Italian and Vietnamese, selected as the highest prevalence languages other than English spoken by carers based on data from the 2021 ABS *Census of Population and Housing*.

Survey participants were recruited through multiple methods:

- Previous participants: Carers who participated in the 2021 and/or 2022 CWS and who had given permission to be contacted about future surveys were invited to take part in the 2023 CWS.
- Care provider organisations: Organisations who provide professional services to carers across Australia were asked to email their clients to request their participation in the survey.
- Carer representative organisations: A number of carer organisations around Australia sent emails to their membership inviting participation, advertised the survey on their websites, and promoted the survey on their social media channels.
- Social media advertising: Advertising on Facebook and Instagram was used to recruit carers, including some advertising in the different languages the survey had been translated into.
- Gift incentive: A prize draw was offered to encourage participants to take part in the survey. Prizes offered were gift cards, with winners able to choose their preferred gift card from a list of options.

In 2023, there were a total of 5,881 valid responses to the survey, with 5,328 being defined as those who were current carers at the time of the survey (current carers), and 553 who were defined as being carers in the past, but who were not currently active carers at the time of the survey (past carers).

Throughout this Snapshot, unless otherwise stated, findings for current carers have been weighted to adjust for differences between demographics observed in the sample and known benchmarks taken from the 2021 (where available), the 2016 Census of Population and Housing and the Survey of Disability, Ageing and Carers, 2018-19. Data were weighted by the following characteristics: (i) gender, (ii) age, (iii) State/Territory, (iv) labour force status and (v) weekly caring hours. Past carers were not weighted.

Confidence intervals were used to identify where there was a high level of confidence that differences between different groups were likely to be the result of actual differences, rather than sampling variance. A confidence interval, put simply, is a measure of the level of confidence that the results are accurate, through identifying the boundaries between which there is high confidence the true finding lies. More accurately, it tells you the boundaries between which, statistically, the mean value of a given variable would be 95% likely to fall if the survey was repeated multiple times with a similar sample. In all cases, 95% confidence intervals were used.

The methods used to collect and analyse data in the 2023 CWS are described in more detail in the CWS User Guide (Mylek and Schirmer 2023), including more information about data weighting and sampling. As data are updated periodically, there may be small differences between what was published in previous reports (Schirmer et al. 2022, Schirmer and Riyanti 2021), and data published in this report for those years.

Use of Digital Health Tools by Carers

Australians are increasingly using digital health tools to assist with storing and tracking health records. One tool that can be particularly useful to carers is My Health Record, managed by the Australian Digital Health Agency. My Health Record provides secure access to key healthcare information available to individuals and healthcare providers.

In some cases, carers may access the My Health Record of their care recipient or act as their nominated representative. Depending on the level of access granted, a carer can view healthcare documents, upload and add information and be responsible for managing the recipients' My Health Record (Australian Digital Health Agency 2023a). Some of the types of information that can be stored in My Health Records include:

- Advance Care Plans – a plan that enables people to make decisions about their future health care in the event they are no longer able to communicate their preferences or make treatment decisions.
- Clinical documents like diagnostic imaging reports, event summaries, immunisations, specialist letters etc uploaded by healthcare providers such as doctors and pharmacists
- Medicare information held by Services Australia including Medicare Benefits Schedule, Pharmaceutical Benefits Scheme, Australian Immunisation Register, Australian organ Donor Register etc.
- Health information that might be useful in an emergency, such as emergency contact details, current medications, allergies, preferred language etc. can be added by individuals.
- COVID-19 vaccination details.

Being able to access and/or manage the My Health Record of care recipients can enable carers to access all important health information associated with their caring role in one place. However, little is known about how carers access My Health Record and in what capacity, and what some of the barriers to doing so might be.

The 2023 Carer Wellbeing Survey (CWS) asked carers about their use of My Health Record for themselves and the person they care for. The CWS is run in partnership between Carers Australia, the Australian Government Department of Social Services (DSS) and the University of Canberra (UC) to develop a comprehensive picture of the wellbeing of carers, how that wellbeing is changing over time, and how wellbeing of carers can be supported (Mylek and Schirmer 2023).

Use of My Health Record by Carers

Carers are just as likely (and possibly more likely) to use My Health Record as other Australians. According to the Australian Digital Health Agency, as of August 2023 90% of Australians had a My Health Record, with over 98% of these records having data in them. A total of 24% of Australians had looked at the information in their My Health Record during the month of August (Australian Digital Health Agency 2023b, Pricor 2023).

The 2023 CWS findings suggest that use of My Health Record amongst carers may be higher¹, with 39.4% reporting that they access My Health Record for themselves, 28% access My Health Record for the person/people they care for, and 36.1% are a Nominated Representative for the person they care for to access their My Health Record (Figure 1). A total of 27.8% of carers reported that the person they care for has an Advance Care Plan, however only 7.3% said that this plan was on My Health Record.

While almost all GPs, pharmacists and hospitals Australia wide are connected to My Health Record (Pricor 2023), only 18.0% of carers reported that their doctor had discussed My Health Record with them, whether for themselves or the person they care for. Medical practitioners are an important point of contact for many carers, therefore ongoing investment is potentially needed to ensure medical practitioners are supporting carers to become aware of digital technologies such as My Health Record to assist in their caring role.

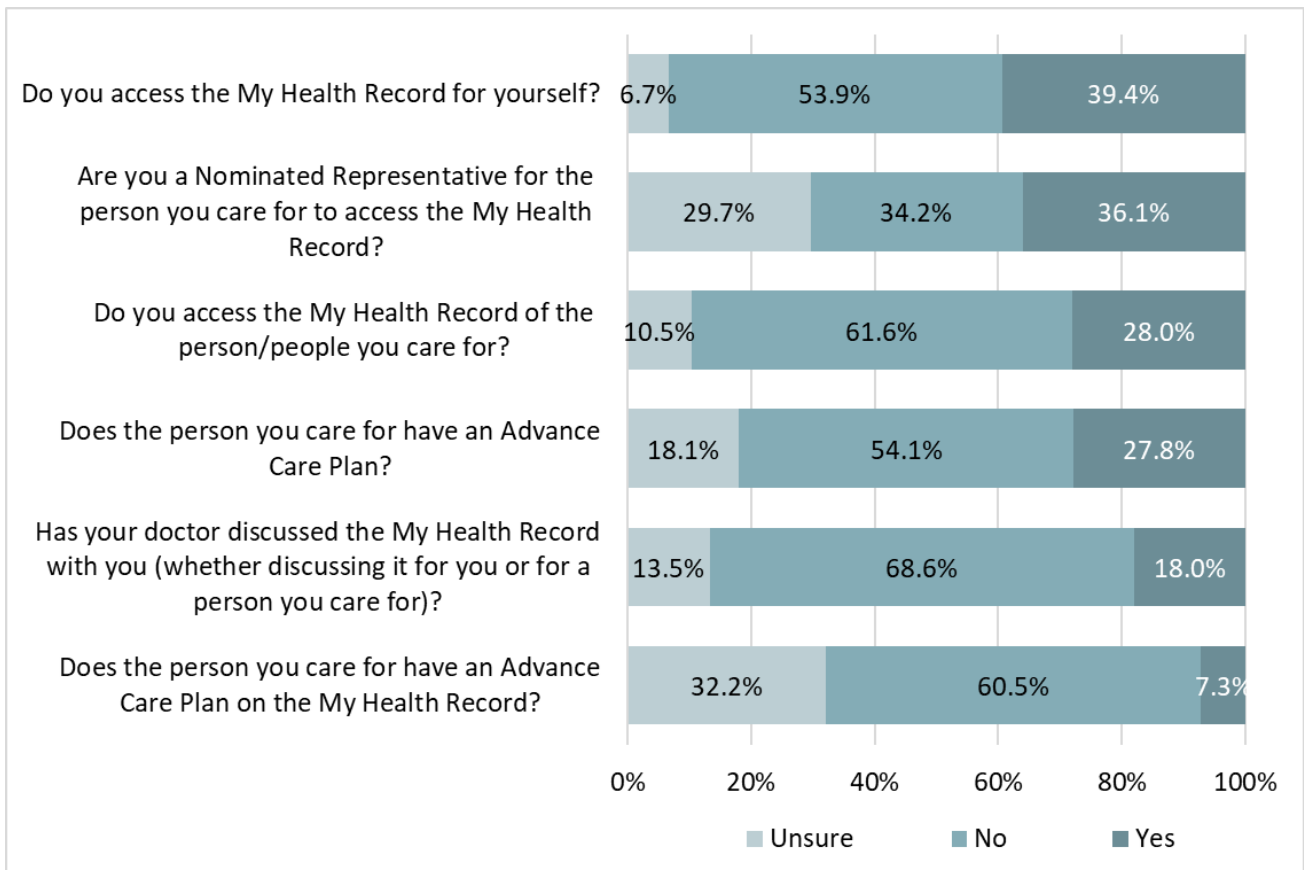


Figure 1 Use of My Health Record by carers

The types of carers most likely to report accessing My Health Record for themselves or the people they are caring for are younger carers, those who identify as Aboriginal or Torres Strait Islander, those caring for a person with a terminal illness, and those living in QLD, WA and NT (Table 1). Carers with high caring commitments were less likely to access My Health Record for themselves.

Being a nominated representative enables carers to access and manage the My Health Record of those they care for. Carers were more likely to be a nominated representatives if the person they cared for had very high assistance needs and/or dementia. Being a nominated representative was also more common amongst carers aged 25 to 34 and those aged 75 and older, and carers who identify as Aboriginal or Torres Strait Islander. Those with lower caring commitments were less likely to be a nominated representative, as were very young carers aged 15-24 and carers aged 45-54.

When asked if their doctor had discussed My Health Record with them, there were distinct differences between different groups of carers. Carers were much more likely to report their GP discussing My Health Record with them if they were male, younger, had been a carer for less than five years, were Aboriginal or Torres Strait Islander or lived in regional Australia rather than in a city. Additionally, those caring for people with dementia, old-age frailty or short term non-terminal illness were more likely to report their GP had raised My Health Record with them, suggesting it is discussed more often in relation to elderly care recipients with specific types of caring needs.

Those least likely to report My Health Record being raised by their GP have some common characteristics: overall, female carers of children are significantly less likely to have My Health Record raised by their GP compared to others. Specifically, discussion of My Health Record by a GP was reported least by female carers, carers aged 45-54, those who have been caring for more than five years, carers of children or grandchildren, carers of people with Autism Spectrum Disorder or other development disorders, and carers who are unemployed. This may in part reflect that parents/guardians of children are typically able to access My Health Record without applying to be a Nominated Representative, however is still concerning because not all may be aware that they can access the My Health Record of the children they care for.

Table 1 Type of carers more and less likely to report accessing My Health record, be a Nominated Representative, or have had their doctor discuss it with them

Use of My Health Record by Carers	Types of carers MORE likely to use My Health Record	Types of carers LESS likely to use My Health Record
Access MHR for themselves	<ul style="list-style-type: none"> • Carers aged 25-34 • Aboriginal or Torres Strait Islander carers • Carers living in QLD, WA and NT • Those who have been caring for less than 1 year • Carers of people with a terminal illness or a drug / alcohol dependency • Carers of friends or other types of relatives 	<ul style="list-style-type: none"> • Carers aged 75+ • Carers with more than 40 hours per week caring commitments • Carers living in Victoria • Carers of people with very high assistance needs
Access MHR for the person/people they care for	<ul style="list-style-type: none"> • Carers aged 35 or younger • Aboriginal or Torres Strait Islander carers • Carers living in QLD, WA and NT • Carers of people with a terminal illness, or with a 	<ul style="list-style-type: none"> • Carers aged 55-64, or 75+ • Carers with less than 20 hours per week caring commitments • Carers of parents / grandparents

	short term non-terminal illness	
Nominated Representative for the person they care fore to access the MHR	<ul style="list-style-type: none"> • Carers aged 25-34 • Carers aged 75+ • Aboriginal or Torres Strait Islander carers • Carers living in QLD • Carers of people with dementia • Carers of people with very high assistance needs 	<ul style="list-style-type: none"> • Carers aged 15-24, and 45-54 • Carers with less than 20 hours per week caring commitments • Carers of people with mental illness / psychosocial disability • Carers of people with low-moderate assistance needs
Doctor has discussed MHR with them	<ul style="list-style-type: none"> • Male carers • Carers aged under 34 • Aboriginal and Torres Strait Islander carers • Carers living in outer regional and remote Australia • Those who have been caring for less than 5 years • Carers of people with dementia, old-age frailty or short term non-terminal illness • Carers for friends or other types of relatives 	<ul style="list-style-type: none"> • Female carers • Carers aged 45-54 • Those who have been caring for more than 5 years • Carers of people with Autism Spectrum Disorder or other development disorders • Carers of children / grandchildren • Carers who are unemployed

Barriers to using My Health Record

Carers who had not accessed the My Health Record of the person/people they cared for were asked to select the reasons for not accessing it (Figure 2).

Not all care recipients require assistance with their health records or have opted out of using My Health Record, therefore not all carers need to/are able to access the My Health Record of the person they care for. A total of 22% of carers indicated the person/people they care for don't need them to access their My Health Record, and 23.6% reported their care recipient/s had opted out of using My Health Record. Only 5.1% indicated the person they care for would not give them permission to access their My Health Record.

A lack of awareness about and capacity to use My Health Record were common barriers for many carers to use My Health Record. Many carers reported they did not know they could apply to access the My Health Record of the person/people they care for (30.3%), they did not know how to use My Health Record (29.3%), they didn't know how to get permission to access the My Health Record of the person/people they care for (17.1%), and/or felt that accessing online health records is too difficult (10.4%). Only 6.9% indicated they couldn't find the information they needed when they accessed the record in the past.

Despite these barriers, 67.3% of carers who access My Health Record for themselves and/or for the person they care for still reported they would be moderately to highly likely to recommend using My Health Record to other carers, and 66.9% moderately/highly likely to recommend using My Health Record to others wanting to access their health records. Carers aged 75 and over were most likely to recommend using My Health Record to other carers.

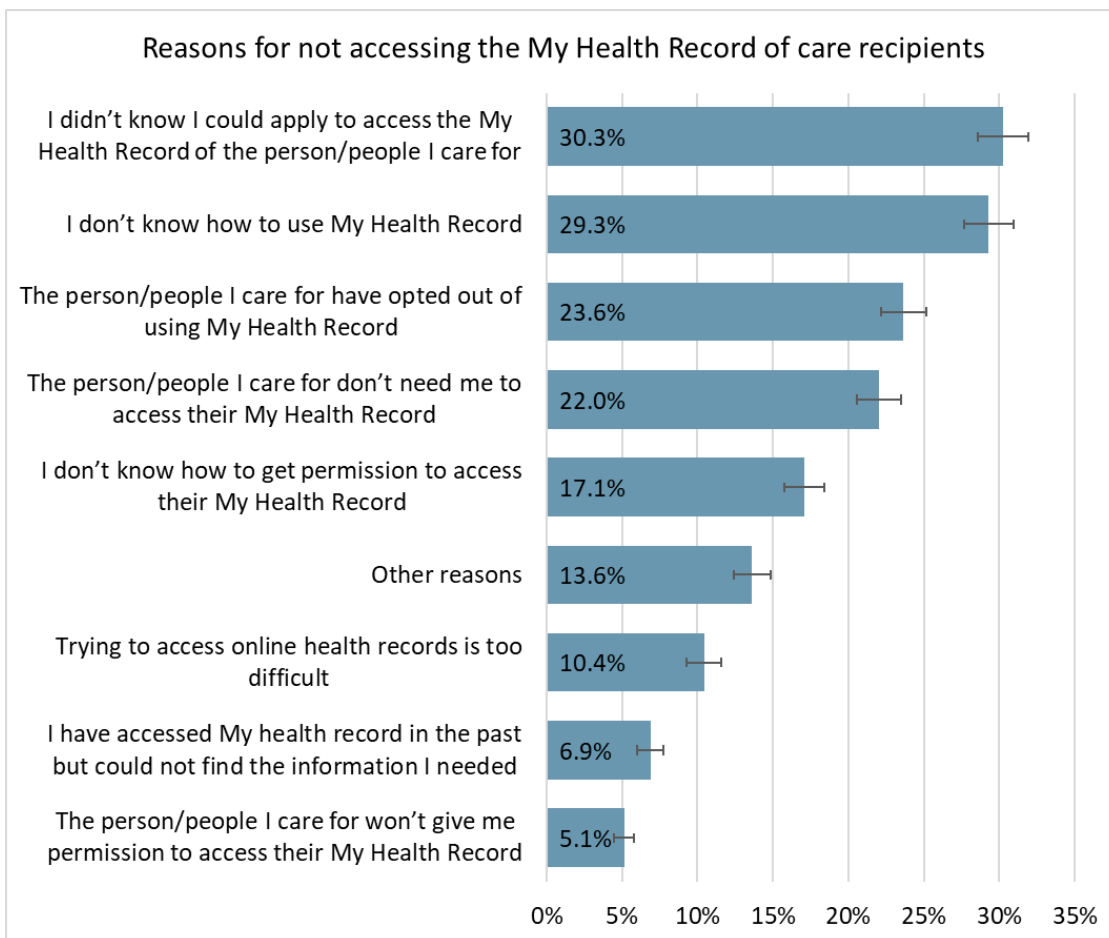


Figure 2 Reasons for not accessing My Health Record

A total of 13.6% of carers indicated there were other reasons for not accessing the My Health Record of the person/people they cared for. Many carers preferred not to use My Health Record, felt the information on My Health Record was not useful, or had concerns about disclosing personal information and/or security breaches. Of the carers that selected 'other reasons' for not using My Health Record:

- Many reported a preference not to use My Health Record or that they were not interested in using My Health Record (14.9%)
- A lack of useful information being uploaded by health professionals, or that health professionals are not using it was the reason for 12.4% of carers not using My Health Record
- Some carers reported they prefer to keep health records in their own way/system (10.7%)
- A lack of trust in My Health Record by doctors/medical professionals was reported by 10.2%
- A total of 9.2% reported concerns about privacy or disclosing personal information online
- Some carers reported that too much effort is involved in working out how to access the My Health Record of the person/people they care for, or that they don't have enough energy/capacity to try (6.9%)
- Concerns about the security of the website/data breaches was reported by 6.9%
- A total of 9.6% reported they felt My Health Records is not useful
- Some reported a lack of trust in My Health Record or Government in general (6.2%)
- A lack of available technology or quality internet to be able to access many of the services online was reported by 5.7%
- Some reported that it is difficult to access the website or perceived it as unreliable (5.7%)
- A lack of time to investigate how to best use My Health Record was reported by 4.4%

Carer experiences of My Health Record – in carer’s words

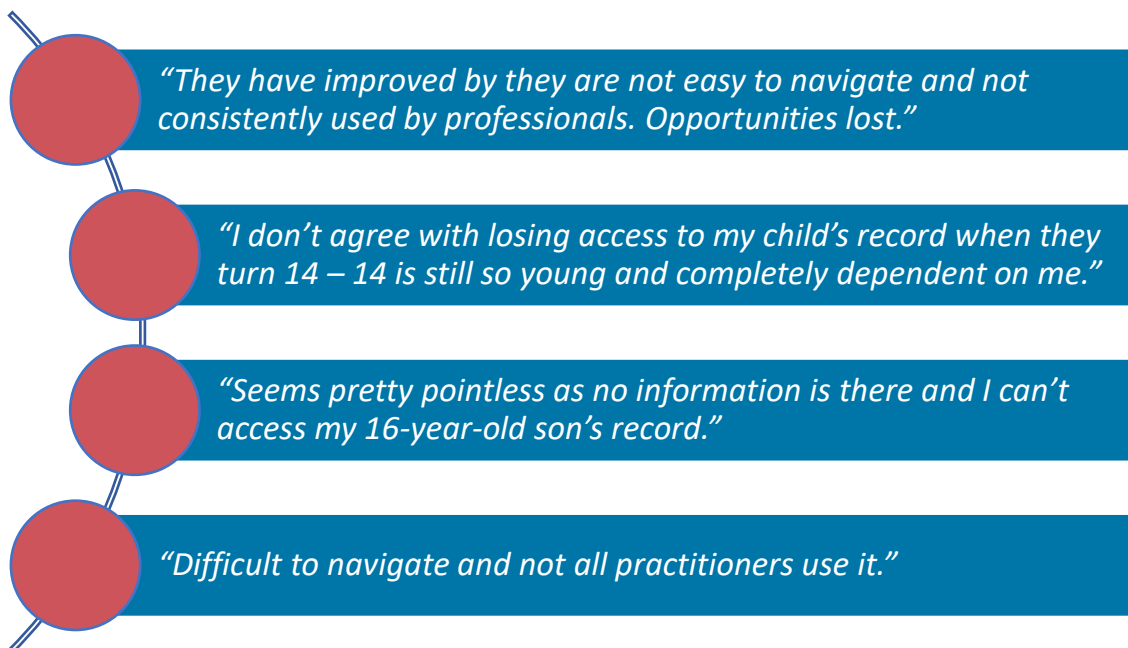
Carers were asked in the 2023 CWS to write any comments they might have about My Health Record or digital health, with a total of 1309 carers providing further comment. Responses varied from concerns about keeping details secure, to the difficulty of managing digital health records or getting permission to access records, to concerns about misuse of the information stored on My Health Record.

While many responses (45.0%) were general or vague including both positive and negative comments (for example 'good', 'interested', 'sounds good', 'bad', 'I hate it'), many carers provided detailed feedback on their concerns about using My Health Record, the types of information kept on it, its accessibility and concerns about the security of the information uploaded.

General concerns

Of the feedback provided, 54.4% reflected a range of concerns about difficulties using My Health Record. These difficulties related to multiple aspects, including processes for accessing records, usefulness of what is stored, and concerns about access over time particularly for children when they turn 14.

The following quotes are from 2023 CWS participants.



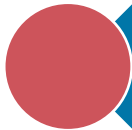
Information kept on My Health Record

Over half of the carers who provided a written response (53.6%) commented on issues related to the types of information being accessed or stored on My Health Record. These comments included:


1. Not being able to access the information when needed,
2. Information not being uploaded by medical professionals,
3. A lack of useful information being uploaded or accessible,
4. concerns about data being out of date and/or having medical decisions based on out of date or incorrect information,
5. concerns about information being misinterpreted,

6. A preference to use their own systems to keep medical records.


The following quotes are from 2023 CWS participants.



"If all medics would use My Health, and upload all relevant material reports etc, it has the capacity to be an excellent tool!"



"The My Health Record would be fantastic and I would love to recommend it to other carers and/or others wanting to access their health records, but it isn't utilised by Health Professionals in [my state]. None of the doctors' notes, test results, x-rays or any other health information is available on the My Health Record Website; we have to request any information directly from the Health Professional involved."



"The information does not get updated. It should be easier for treating health professionals to enter information to the Health Record. It is pointless having the Record if the information is not there."

Safety, security, and privacy

Just over two thirds of those who provided feedback (35.6%) had concerns about the safety, security, and privacy of uploading highly personal information online. Concerns included:

1. Issues surrounding confidentiality,
2. Potential misuse of information,
3. Information resulting in intentional or unintentional discrimination when being treated,
4. Potential for security breaches where data is stolen,
5. Identity theft and,
6. General mistrust over the security of the website.

The following quotes are from 2023 CWS participants.

"It was a nice idea until the access potential for government agencies was extended beyond those required for healthcare. I don't fancy Centrelink having access to our records because they could take it upon themselves to review eligibility for DSP without our input."

"Given recent cyber security breaches I am not convinced that My Health Record is secure from data breaches."

"I have very little trust in the digital security of Australian government records."

Accessibility

A total of 28.8% of carers who provided feedback left comments about the accessibility of My Health Record. These comments included:

1. The website/application not being user friendly or not intuitive,
2. A lack of access due to difficulty with technology or internet,
3. It being difficult to understand,
4. Not having the capacity or energy to access it, or
5. Not having permission to use it.

The following quotes are from 2023 CWS participants.



Do carers who access care recipient My Health Record have more positive caring experiences?

Many factors influence a person’s experience of caring, one of which may be the ease with which they can access health records of the person they care for. Similarly, having a more positive experience of being a carer may increase the likelihood of a carer feeling confident to become a Nominated Representative and of them accessing the My Health Record of the person they care for. Figure 3 shows that carers who accessed the My Health Record of the person they care for were significantly more likely to:

- Feel that caring was satisfying overall
- Feel that being a carer was a positive experience
- Encourage others to become carers
- Be confident that they can find out about and organise access to services for the person/people they care for

And be less likely to feel that:

- They have lost control over their life
- Too much responsibility falls of them as a caregiver

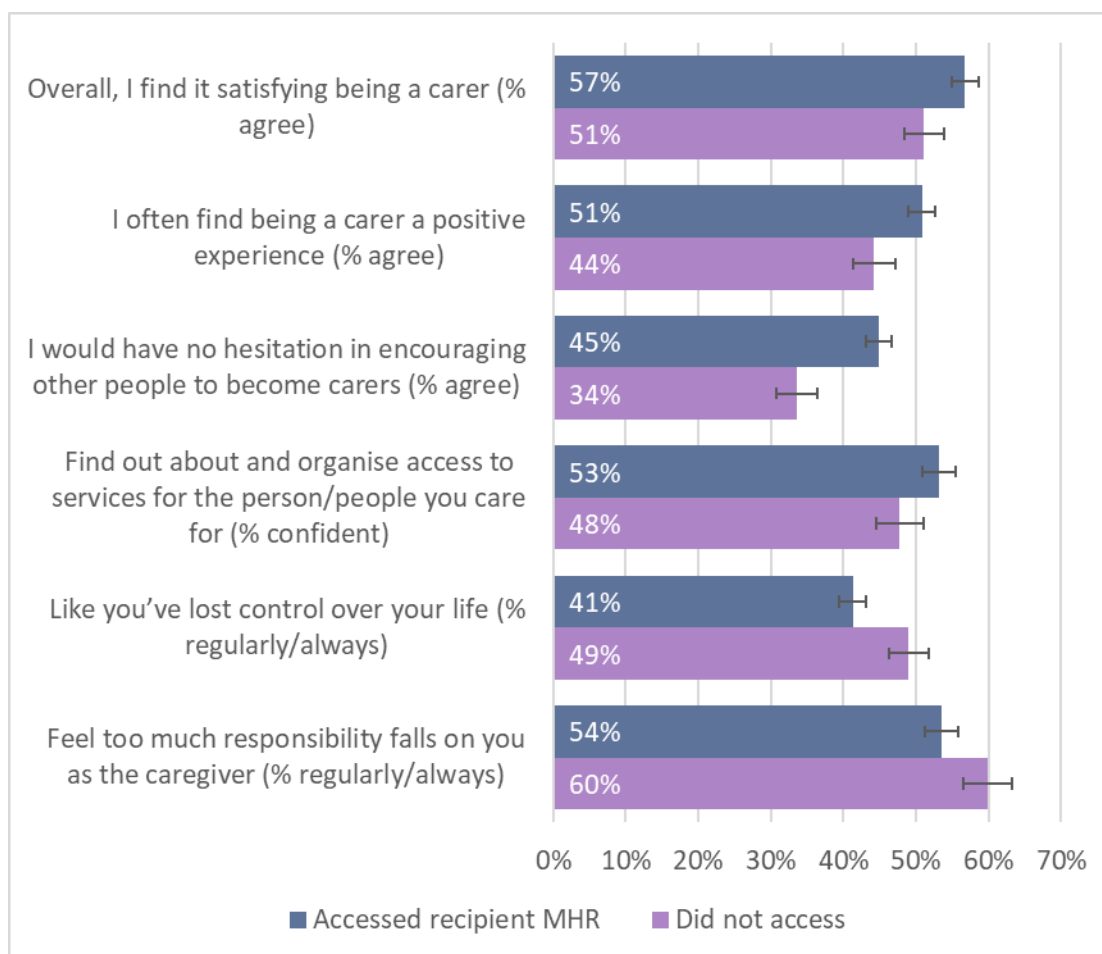


Figure 3 Experiences of carers who accessed care recipient My Health Record

These findings suggest that accessing My Health Record is more common amongst those with more positive caring experiences – and may help support that more positive caring experience. Over time, it will be possible to better identify whether the latter occurs, through monitoring whether those who begin accessing My Health Record have a more positive carer experience in the subsequent years after they begin to do this.

The findings do suggest that carers who are feeling overwhelmed by their carer role or otherwise finding being a carer a difficult experience may find it more difficult to engage with the process of accessing and using My Health Record for the people they care for. This suggests a need to provide support for this group of carers to enable them to easily access and use My Health Record.

Conclusions

While My Health Record has the potential to make caring easier, through facilitating easier access to health carers across health settings for the people they care for, not all carers currently find it highly useful. Use of My Health Record amongst carers is at least as high as use amongst the general population. However more than two thirds of carers still do not access the My Health Record of the person/people they care for, often due to lack of awareness and knowledge about it, or in some cases due to reluctance of care recipients to permit this access.

Only 18% of carers reported their doctor had discussed My Health Record with them, suggesting that potential opportunities to support and encourage carers to use this resource are often being missed.

Encouraging medical practitioners to discuss My Health Record might increase use.

Of those who are accessing My Health Record, many report that its usefulness is limited by a lack of information being uploaded. Despite this, two thirds of carers who access My Health Record for themselves and/or for the person they care for would be moderately to highly likely to recommend using My Health Record to other carers.

Overall, the findings suggest that My Health Record is a useful resource, however its utility to carers could be significantly increased through supporting carers and care recipients to understand its availability and useability, to advocate for their medical practitioners to upload records, and to address some of the concerns raised about privacy and security of the information stored on My Health Record.

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