Communicating My Preferences: My Health Record and Advance Care Planning

Final Survey Report
for Mental Health Australia

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Introduction

Lived Experience Australia Ltd (LEA) is a national representative organisation for Australian mental health consumers and carers, families, and kin, formed in 2002 with a focus on the private sector. All members of our Board and staff have mental health lived experience as either a consumer, family carer or both.

Our core business is to advocate for systemic change to improve mental health care (including psychosocial disability) across the whole Australian health system. This includes advocating for empowerment of people with mental health lived experience (people with mental ill-health and their family, carers and kin) in the broad range of issues that impact their mental and physical health, and their lives more broadly. It includes empowering them in their own care and contact with health and social services, promoting their engagement and inclusion within system design, planning and evaluation, and most importantly, advocating for systems that promote choice, inclusion, justice and fairness, and address stigma, discrimination, and prejudice.

This report involves the analysis of a survey conducted by Lived Experience Australia with mental health consumers and carers across Australia. It forms part of a larger project undertaken by Mental Health Australia for the Australian Digital Health Agency.

The aim of the survey was to seek the views of mental health service users on digital health records and advanced directives and to understand current use of and access to digital health records. We thank Mental Health Australia for the opportunity to partner on this survey activity.

Executive Summary

In total, 884 survey responses were received - 647 responses for the consumer survey and 237 responses for the carer survey.

Consumer and carer participants from diverse locations, age, gender and population groups were represented in the survey. Bias within the overall sample means that the results may not be generalisable to the broader population of people with lived experience of mental ill-health across Australia.

My Health Record

Approximately 84% of consumer participants said they have a My Health Record, though almost half of this number (47.27%) said that they don’t really use it. Approximately 70% of carer participants said the person they support has a My Health Record, though almost 40% of this number said that they don’t really use it.

Approximately one quarter of consumer participants did not know that they could nominate a trusted person to have access to view or help them manage their My Health Record. This level of awareness was similar for carers.

One third of consumer participants (32.93%) did not know that they could control which health professionals can access information in their My Health Record. This was similar for carers, with approximately one third (35.19%) not aware that the person they support could control which health professionals access information in their My Health Record.

Consumers and carers rated convenience in storage of and access to health information and paperwork as the main benefit of My Health Record.

Experiences with My Health Record varied, with many consumer responses suggesting people are willing to use My Health Record but that healthcare providers and the system of care also need to engage more fully and consistently in using it. Concerns prevailed about security of information and trust in how confidential information is accessed and shared. Similar experiences and concerns were noted by carers.

Misinformation, incompleteness of the records, and consequent experiences of stigma and discrimination were prominent concerns for consumers and carers. These issues were described as inter-related and had the potential to disempower the person further and to adversely impact their quality of care.

Mental Health Advance Directives

Less than 3% of consumer participants said they had a Mental Health Advance Directive. However, almost half said they were likely or very likely to create one. Less than 5% of carer participants said the person they support had a Mental Health Advance Directive.

Almost two thirds of consumer and carer participants said that they were aware of the option to create a Mental Health Advance Directive, whereas one third were unsure or not aware.

Almost 60% of consumer participants did not know that they could upload Advance Care Plans to their My Health Record, whereas almost 50% said they would be likely or very likely to do so, if they made one. Similar levels of awareness were apparent for carers.

Approximately one third of consumer participants (36.56%) were unaware that they could update or remove an Advance Care Plan from their My Health Record at any time. Almost half of carer participants (43.48%) were unaware that people could do so.

Overall, only 2% of participants said they had already uploaded a Mental Health Advance Directive to My Health Record, though this represents a high proportion (80%) of the small number who said they had a Mental Health Advance Directive. Similarly, 3.65% of carer participants said the person they support already had a Mental Health Advance Directive uploaded to My Health Record, representing a high proportion (80%) of carers who said the person they support has a Mental Health Advance Directive.

Consumers' highest rated concern about uploading a Mental Health Advance Directive to My Health Record was the security of their personal information. Similar to consumers, the highest rated concern for carers was also the security of the person's personal information.

Around half of consumer participants and nearly two thirds of carer participants said support to understand how My Health Record works, and how to upload a Mental Health Advance Care Directive to My Health Record would be useful for them.

Approximately half of consumer participants (53.32%) said they needed support to upload their Mental Health Advance Directive to My Health Record. Less than 15% of consumer participants said they did not need or want any support with these processes. These rates of support need were similar for carers.

What Needs to Improve – Summary Recommendations

1. Access to more user-friendly information about the security and safety of My Health Record.
2. More education and easy-read information for consumers, carers, and health professionals on how to use My Health Record. Consumers' and carers' education needs varied somewhat.
3. More support and easy-read information for consumers and carers about how to develop Mental Health Advance Directives.
4. More consistent use of My Health Records by health professionals and services across the health system.

Methods & Features Noted

Mental Health Australia invited Lived Experience Australia to partner on this survey activity. The purpose of the survey was to gather up-to-date information about the perspectives and experiences of people with lived experience of mental health challenges (consumers) and carers about My Health Record, and advance care planning. This information will inform Mental Health Australia and the Australian Digital Health Agency's work in this area, and support promotion of resources for consumers and carers on My Health Record. Secondly, the survey provided an opportunity to increase awareness and understanding about My Health Record amongst participants – particularly regarding the new option to upload an advance care planning document (including Mental Health Advance Directives).

For this project, Lived Experience Australia was asked to:

- provide advice to support survey development;
- undertake administration of inputting questions in Survey Monkey;
- provide a survey link to Mental Health Australia for distribution through its electronic networks in addition to distribution to Lived Experience Australia's national network of consumers and carers;
- undertake data analysis including both quantitative (descriptive) and qualitative (thematic); and
- provide a report on findings.

While Mental Health Australia did not seek ethics approval for the project, it was conducted in accordance with the National Health and Medical Research Council guidelines for the ethical conduct of research.

The survey questions were drafted collaboratively by Mental Health Australia and Lived Experience Australia and were informed by a Lived Experience advisory group gathered by Mental Health Australia for the broader project. The survey was divided into two streams (for consumers and carers), with 18 questions in each, to enable separate analyses from a consumer and carer perspective (**see Appendix 1**). The advisory group and the Australian Digital Health Agency reviewed and approved the survey questions in late February 2023.

The anonymous online survey was open from 27 February to 20 March 2023 and was designed to take up to 15 minutes to complete. Participants could choose to opt out of answering questions which meant that overall response rates varied across questions.

The survey was advertised through Mental Health Australia and Lived Experience Australia networks. Mental Health Australia also invited state and territory lived experience representative organisations, peer support networks and other lived experience networks to promote the survey. An honorarium was not offered for individual participation. Instead, participants could choose to enter a draw to win one of 10 gift cards worth $50 each. The contact details for participants who chose to do this were kept separate and confidential to ensure that survey responses could not be linked to identifiable details.

During analysis it was noted that a number of participants had provided multiple responses. This has not previously occurred with other surveys conducted by Lived Experience Australia. We proposed that this may be due to the higher number of gift card incentives used for this survey or involvement of malicious activity by survey bots. To preserve the integrity of the survey data, we removed all data for responses (n=485) where it was apparent that there was participation in the survey by the same individual multiple times. This left a total of 884 responses - 647 responses for the consumer survey and 237 responses for the carer survey.

We also noted that the pattern of participant demographics did not reflect our prior experience with similar surveys to the lived experience community, for example with higher-than-expected proportions of Aboriginal and Torres Strait Islander and Culturally and Linguistically Diverse participants. This may reflect targeted distribution of the survey to stakeholder organisations representing these populations. Overall, survey results should therefore be interpreted with caution. Regardless, qualitative feedback in open-ended questions provided invaluable insight for Mental Health Australia and the Australian Digital Health Agency.

Consumer Perspectives

Demographic Details

Consumer participants were drawn from all Australian states and territories, with some bias which likely reflected the more prominent reach of Mental Health Australia towards some Eastern Australia jurisdictions. This was evidenced by the higher proportion of ACT responses and lower proportion of QLD responses in comparison with the spread of the Australian population (see Figure 1).

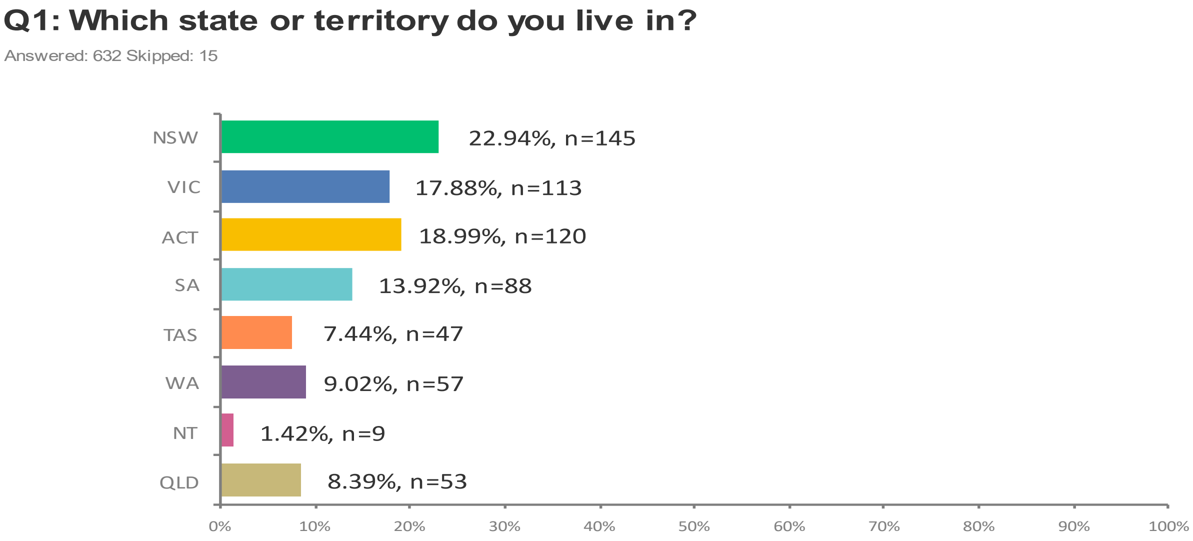

Figure 1: Location of Consumer Participants

Most consumer participants were aged between 18 and 59 years, likely reflecting those who are more engaged with digital technology and more likely to complete online surveys. Of note, few people under 18 years participated. It may be that younger participants are less likely to be reached by the mental health consumer and carer networks utilised for this survey methodology. Also of note, few people in the 60-79 years age group participated and none over 80 years participated. This may reflect lower levels of computer literacy in these age groups or trends in earlier morbidity and mortality for people with mental health conditions, generally (see Figure 2).

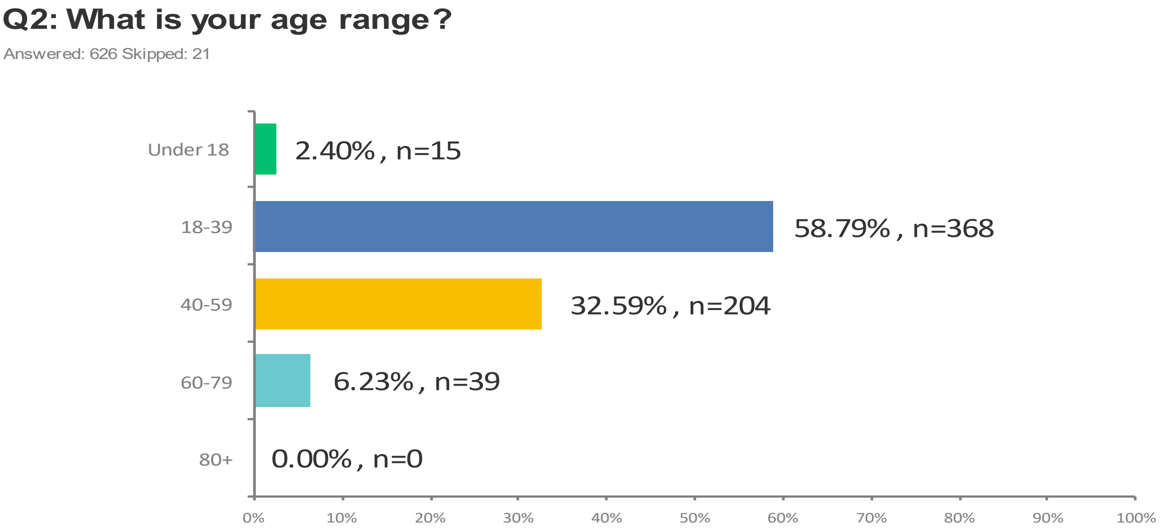

Figure 2: Age Range of Consumer Participants

Women were the most prevalent gender group that participated in the survey, with other genders also well represented; of note in particular was the participation by individuals who identify as non-binary (see Figure 3).

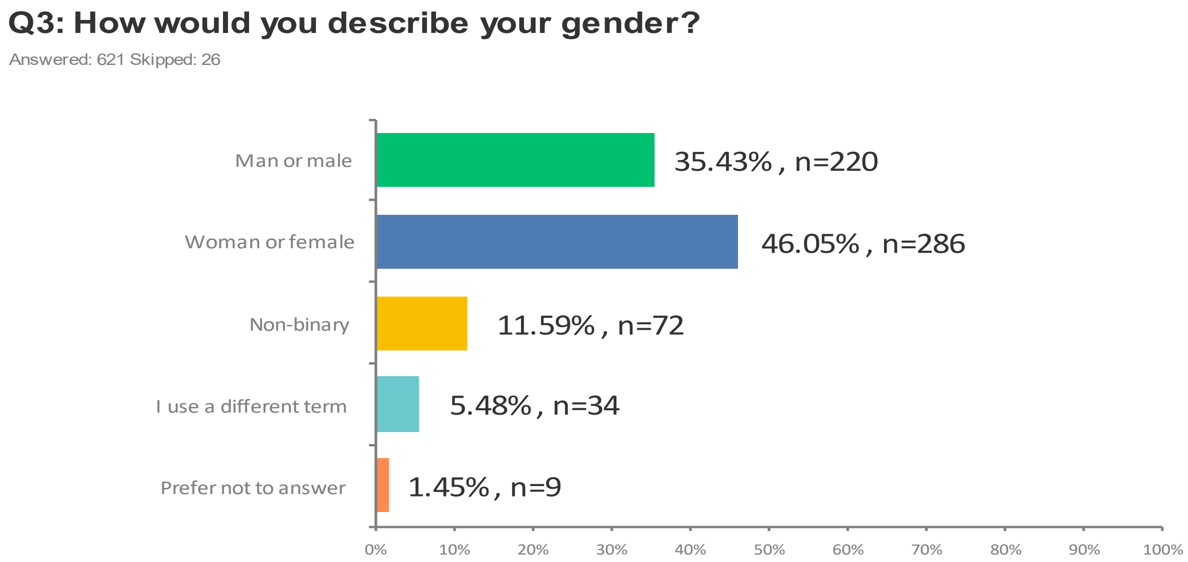

Figure 3: Gender of Consumer Participants

Consumer participants identified with a range of population groups. As noted in the methods, higher than expected proportions of First Nations and Culturally and Linguistically Diverse individuals participated in the survey. Participants could select multiple groups that they identify with. Of the 626 consumer participants who responded to this question, 482 identified with being First Nations, CALD, LGBTQIA+ or living with disability. The 715 responses across these 4 groups suggests that at least a third of participants chose to select more than one group. Of note, about a third (n=204, 32.59%) of total responses involved the participant identifying as a person with disability. As a proportion of the sample that identified as belonging within the 4 population groups, this reflected 42.32% of consumer participants (see Figure 4).

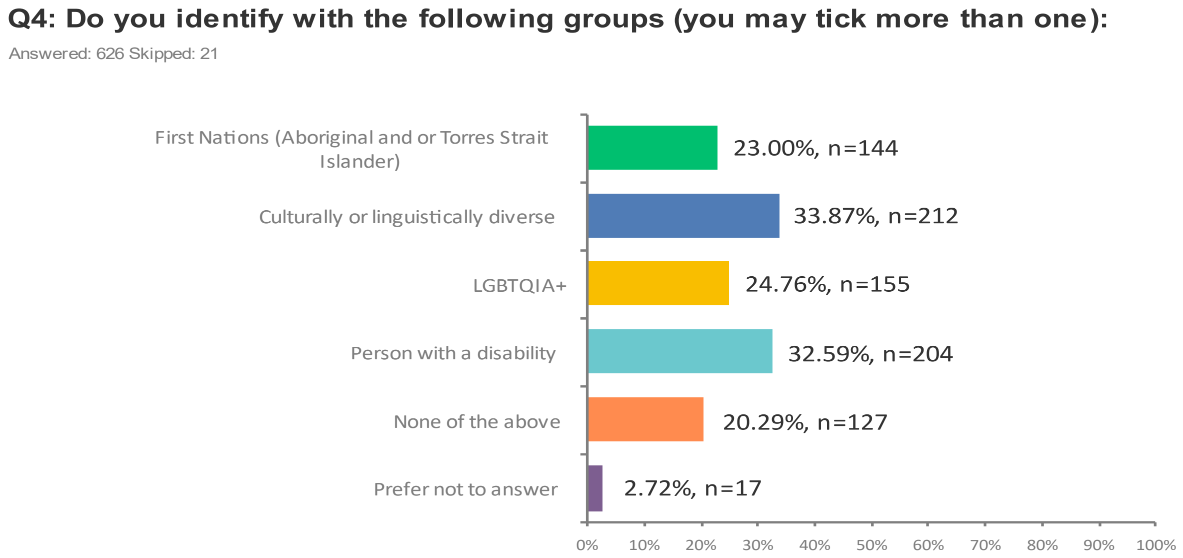

Figure 4: Consumer Participants by Population Group

Consumers’ Awareness and Use of My Health Record

Approximately 84% (n=495) of consumer participants said they have a My Health Record, though almost half of this number (47.27%) said that they don’t really use it (see Figure 5).

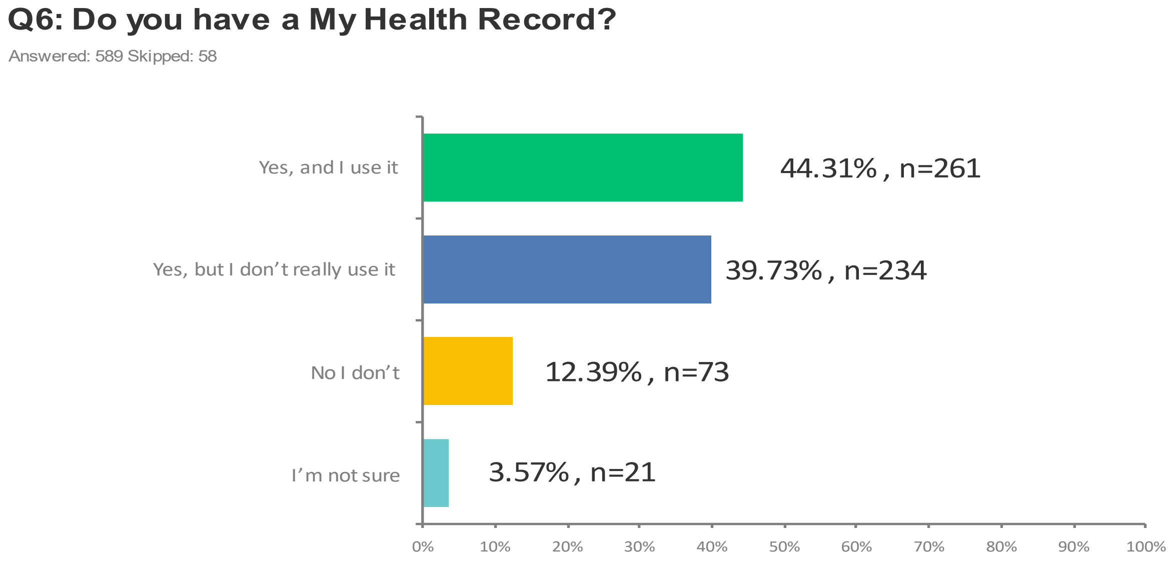

Figure 5: Consumers - Do you have a My Health Record?

Almost three quarters (n=423, 73.82%) of consumer participants who answered this question were aware that they could nominate someone they trust to have access to view or help manage their My Health Record. Though this also indicated that one quarter were not aware of this option (see Figure 6).

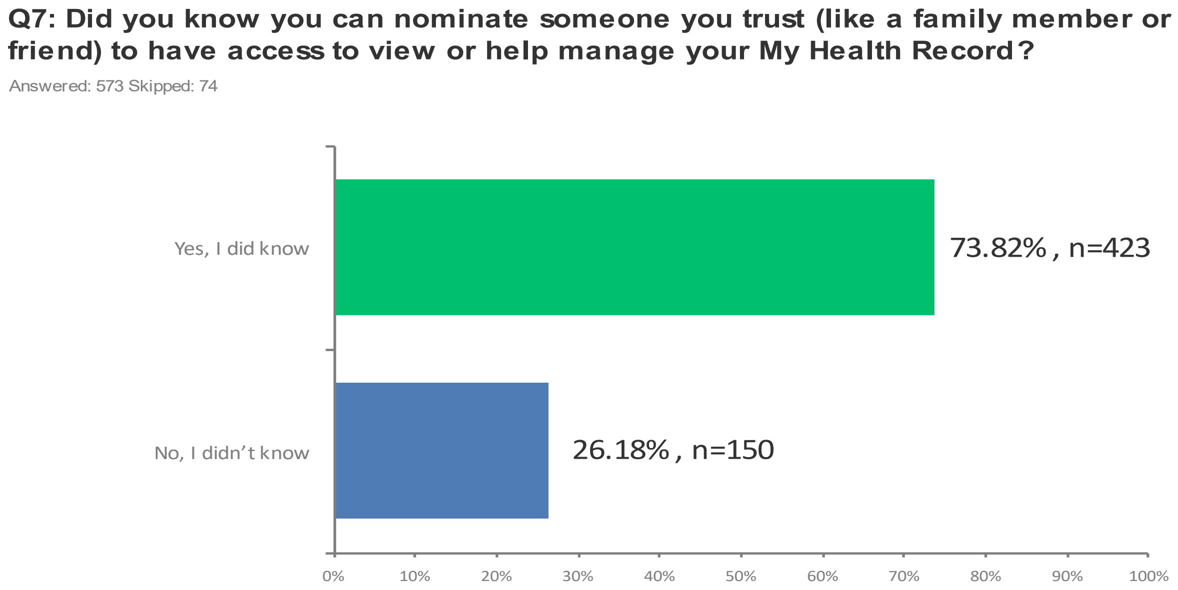

Figure 6: Consumers - Trusted Nominees and Managing My Health Record

While the majority (n=387, 67.07%) of consumer participants were aware they could control which health professionals access information in their My Health Record, a third (n=190, 32.93%) were still unaware (see Figure 7).

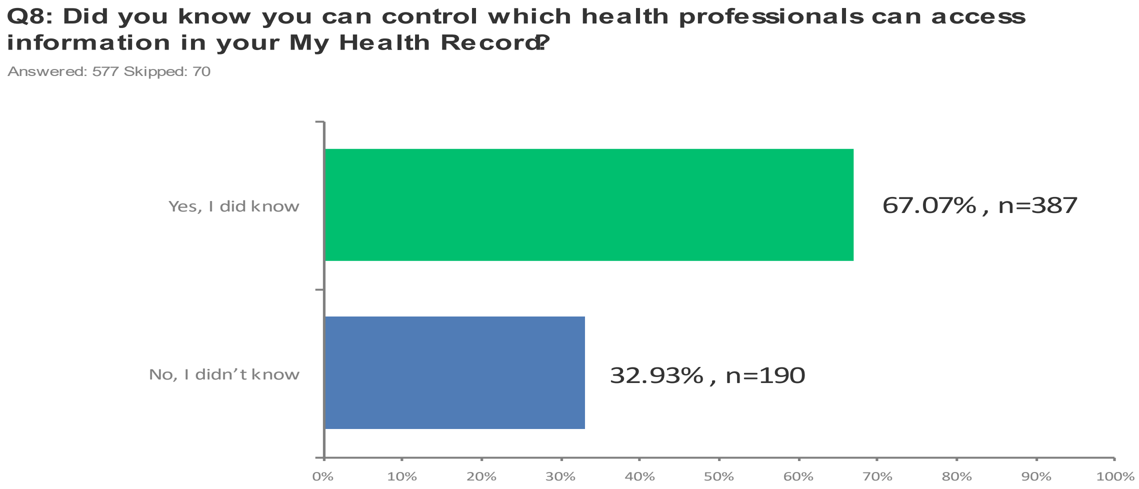

Figure 7: Consumers - Control of Health Professional Access to My Health Record

Consumers were asked which benefits of using My Health Record they personally agreed with. They could choose multiple options from a list of nine. No option was selected by more than 41% of consumer respondents.

Overall, the five most commonly selected benefits by consumers were: convenience while travelling;

- alleviating the need to remember/use paper copies;
- being able to choose who can see the information on My Health Record;
- ability to keep health documents in one place; and
- fewer delays in accessing treatment because health professionals have ready access to information.

Of note, 'Having greater access to my own health record' was rated of lowest benefit (see Figure 8).

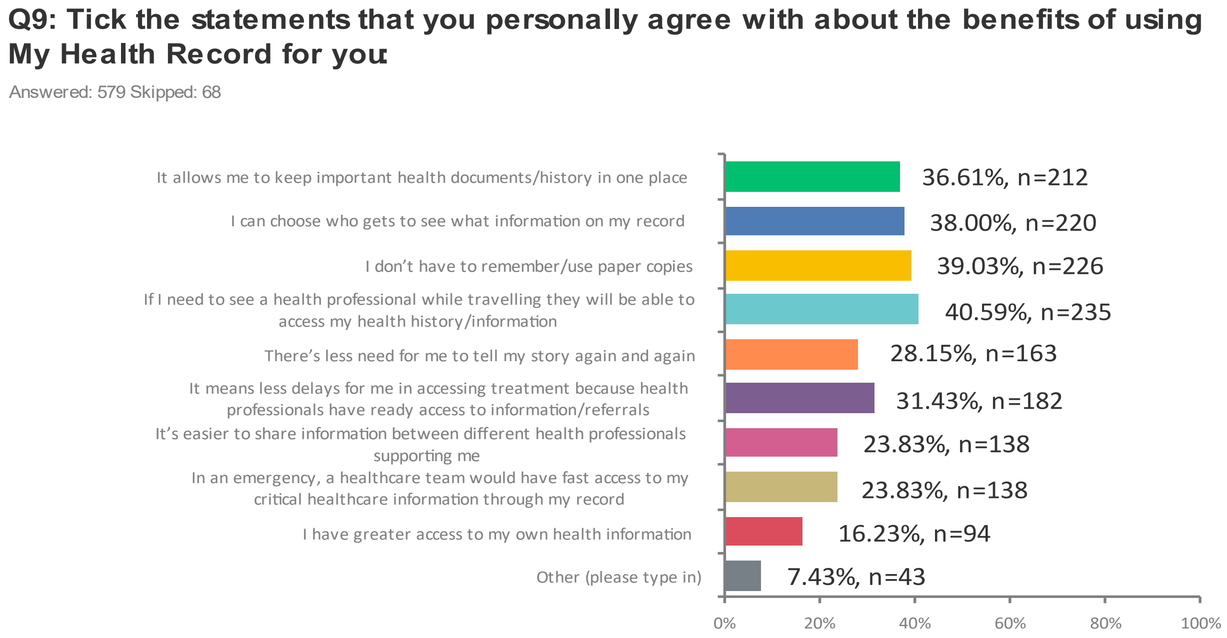

Figure 8: Consumers - Benefits of Using My Health Record

Forty-three participants provided further comments, though only 5 responses related to benefits. Two of these participants noted benefits related to convenience:

- *Easy way to keep track of when my health check-ups are due.*

- *It's mostly useful for pathology tests.*

Two described benefits to their own self-care activation and their interactions with health professionals:

- *I can understand and learn my own health information. Access to it allows me to ask questions so I feel like I am fully involved in my own care.*

- *I would love my care team to all use my digital health record. I get tired of repeating my story over and over, and as time goes by, it becomes more difficult to recall details.*

One described the benefit of helping the system and health professionals be more accountable:

- *Removes the silos, takes away the excuse that organisations and professionals use "well I didn't know" if they have access. More accountability by health professionals.*

Several participants took the opportunity to reiterate that they did not use My Health Record or did not trust it. Some participants' comments provided useful ideas for how My Health Record could be of more benefit by being a more complete record and editable:

- *It has no benefits while it continues to be a haphazard and incomplete record - which is wildly misleading and totally foolish to think it is a reliable resource for comprehensive medical information for anything besides data (test results).*

- *I don't personally feel comfortable having a My Health Record as I do not have the ability to edit what comments are made.*

Some made comments about their concerns for the security of their information:

- *I don't trust the security level of My Heath Record therefore I don't use it.*

- *I don't have a health record because I don't believe that anything on the internet is safe no matter what they say about their security.*

- *I don't trust having an online record given the current state of data breaches despite all the benefits.*

Related to this concern, some participants highlighted concerns about stigma and discrimination from health professionals which they felt prevented the full benefits of My Health Record from being realised:

- *I worry about having my mental health issues being accessed by other health staff. So much stigma and I've been treated poorly by health practitioners in the past due to my schizoaffective diagnosis.*

- *I didn't opt in for it as I was concerned about discrimination of doctors seeing my BPD diagnosis.*

- *I do not share my mental health history with My Health Record due to prior judgements by other health professionals who tend to dismiss women in particular if they have a history of mental illness as a symptom of mental illness.*

- *I chose to opt out of My Health Record because I have been discriminated against so many times due to a record of ongoing MH issues. In one instance where a friend who was a nurse took me to emergency because of extreme abdominal pain, we heard the nursing staff saying "she's mental health, it's probably nothing" and I sat in agony for 6 hours before my friend took me home - without seeing anyone. I went to the GP who referred me to a gynaecologist and found out I had ovarian cysts and required surgery….I'm not prepared to not get treated in an emergency, or have symptoms downplayed.*

Consumers' Experiences of My Health Record

Consumer participants' experiences of My Health Record were mixed, with more than one third having ambivalent experiences (neither positive or negative) and approximately 45% having positive or very positive experiences and less than 20% have negative or very negative experiences (see Figure 9).

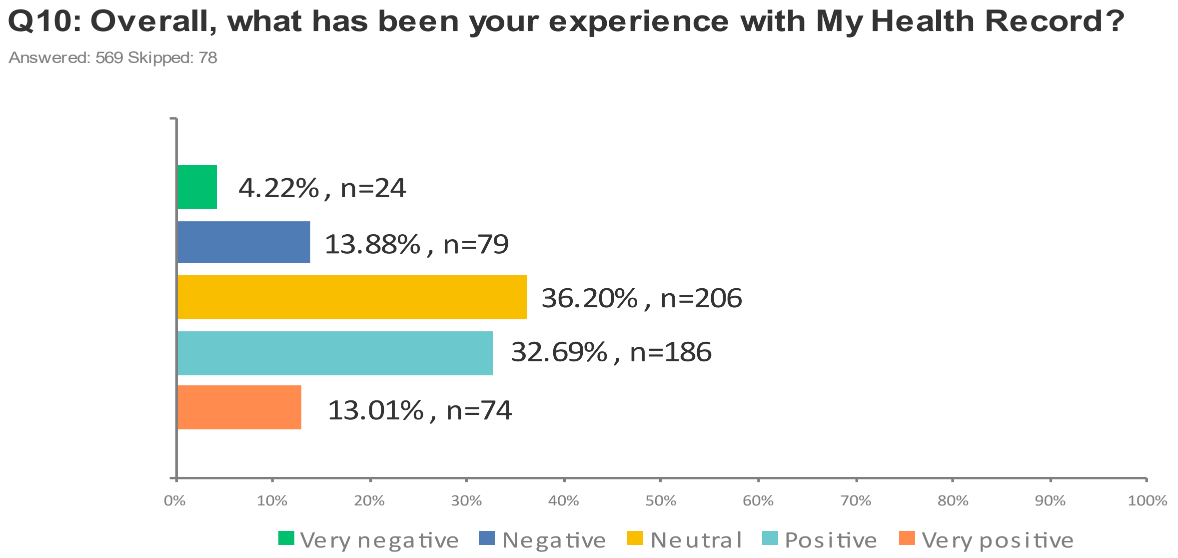

Figure 9: Consumers' Experience of My Health Record

Of the 569 participants who responded to this question, 129 provided further comments. Some comments related to benefits, while most comments centred around concerns related to stigma and trust, with others commenting on health professionals' inconsistent use of My Health Record, and inconsistency in the records themselves. Some participants, like the following which reflect the range of experiences, recounted both positive and negative experiences. These responses suggest people are willing to use My Health Record but that healthcare providers and the system of care also needs to engage more fully and more consistently with using it:

- *Having access to my own health information in one place has been very empowering and important to me and my family who have chronic health issues. My negative experiences with it have been from health care providers and hospital services who still need reminding to upload and access my information. It is also frustrating that some organisations are not consistently uploading e.g. diagnostics and pathology so this means there are some gaps in my record.... I also love the new My Health app it is really easy to use.*

- *In principle the idea of not having to tell my story over and over is appealing however having my story accessible to any person, with medical or stated ethical access, is too broad for my liking.*

- *It’s great for keeping pathology results in one place. They’re the only thing I’ve had reliably stored there and the only record they manage to lose internally. While I like that I can disable access for certain practitioners, it seems like internal hospital record keeping is pretty open to anyone within that local health district that requests it, without my consenting. It’s pretty hard to actually ‘destroy’ medical records / regain control of access to information.*

- *It’s good for me as I can record updated information about my medications, other supplements I take, health conditions and allergies. On the downside, none of my care team use it, and despite me asking for results to be added to the record, the only things that I see are pathology and radiology requests and doctor visits.*

- *I have very little engagement with the platform and even when I consent to my information being shared on there, it seems health care professionals don't refer to it.*

- *Not all health professionals upload information into the portal. For example, mine is very empty as my doctor has not put anything in there. The only information in there, is information I have put in.*

A small number of participants described further positive experiences of My Health Records:

- *Negates the need to keep paper copies.*

- *I was recently surprised I could access my pathology reports.*

- *Use of my health record while I was in hospital made it easy not to have to tell the doctors treating me the extensive list of medications I am on.*

- *I feel it helps me get health problems tended to sooner!!*

Many participants recounted negative experiences of how My Health Record has been used, or concerns about how it might be used in the future. The incompleteness of the record had adverse and inter-related consequences for several participants such as being misleading or inaccurate about the person’s history and circumstances, disempowerment when they then attempted to be heard about these inaccuracies, which in turn reinforced their sense of stigma and discrimination within the process of receiving treatment and care.

- *It has been used to access information about me, which is inherently incomplete due to the system not facilitating all records from all providers being able to be uploaded, to be viewed and used by other medical staff to form an opinion of me that clearly due to the inadequacy of comprehensive information does not outline anything close to what my medical situation is in reality. Therefore I deleted the entire record as it is a useless, biased, and totally uninformative source of misinformation that needs me to restate and contextualise for every staff member who reads it anyway, but in a much more complicated way as they were trying to join dots that were not joinable, requiring me to back track and fill in information - much easier if I just tell the story straight anyway!!*

- *Its intrusive and a psychiatrist can write a report you cannot challenge or have changed. Another medical person will treat you based on this information.*

- *I have had medical staff access my record under the guise of helping but it was then used against me by the medic forming opinions about me without comprehensive information that I myself or other professionals can provide in context of the consultation.*

- *No one has talked to me or asked me if I want to be part of it. Computers are difficult. Could it be judgemental. What if it gets into the wrong hands. I want to know that I have the last say; the last person to sign off. I feel very left out already; this is just another way to be on the outside. I haven't seen any information that relates to me about this. I don't read or look at anything with a lot of words and computer stuff click here, there, etc. It's very scary for me.*

Further to these negative experiences, some participants' comments suggest there may be unintended negative impacts that need to be understood:

- *I'm not in the best of health. I don't like looking at it. It reminds me of bad things.*

- *Since finding out that health professionals can access these documents, I believe it limits the care and support I receive.*

Consumers' Perspectives of Mental Health Advance Directives

Almost two thirds of consumer participants said that they were aware of the option to create a Mental Health Advance Directive, whereas one third were unsure or not aware (see Figure 10).

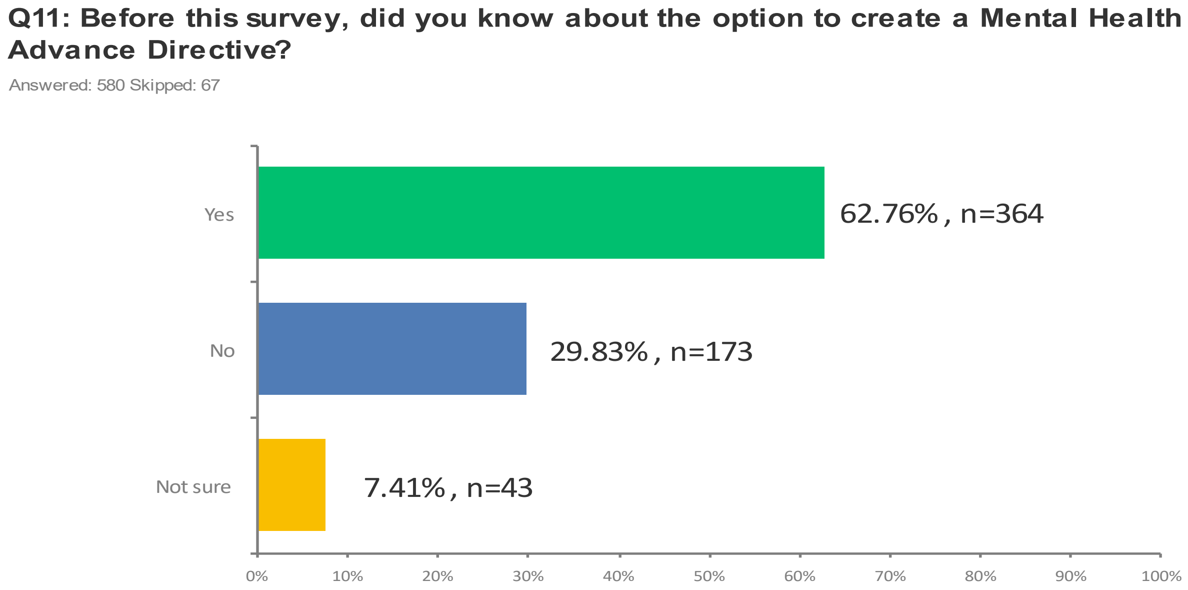

Figure 10: Consumers' Awareness of Mental Health Advance Directives

By contrast, less than 3% of consumer participants said they had a Mental Health Advance Directive. This is in line with other reporting of low rates of mental health advance directives amongst people accessing public mental health services.[1] However, almost half (n= 263, 45.64%) of participants said they were likely or very likely to create one, with around half (n=303, 51.79%) undecided or unlikely to do so (see Figure 11).

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[1] Productivity Commission, *Mental Health* (Canberra: 2020), 1070, https://www.pc.gov.au/inquiries/completed/mental-health/report/mental-health-volume3.pdf

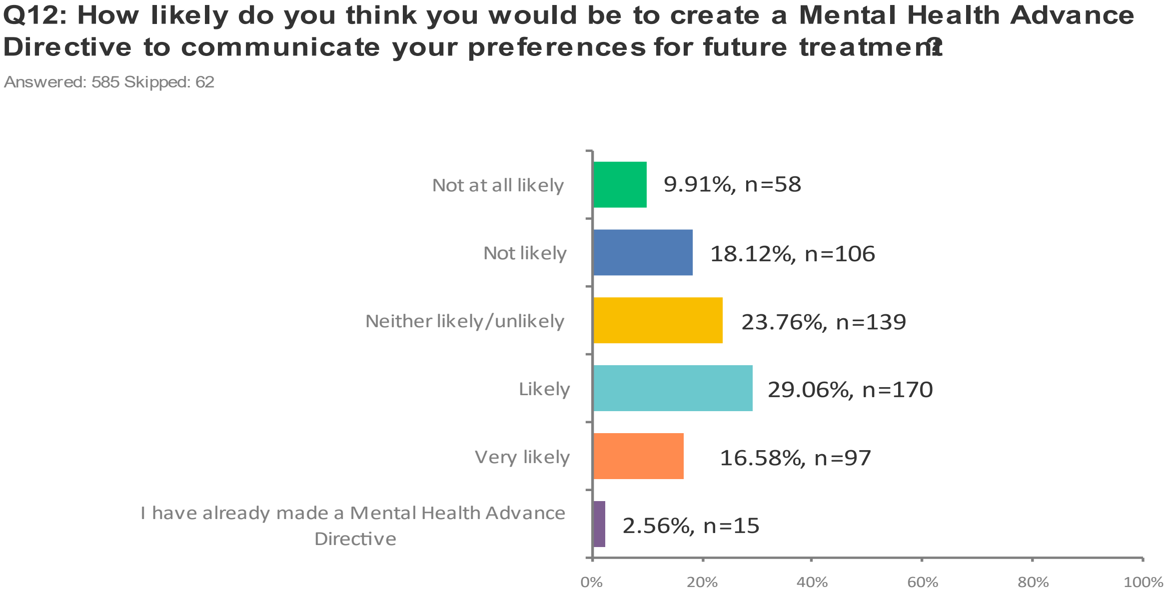


Figure 11: Consumers' Likelihood of Creating a Mental Health Advance Directive

Almost 60% of consumer participants did not know that they could upload Advance Care Plans to their My Health Record (see Figure 12). This makes sense as it is a recent feature of My Health Record. However, almost 50% said they would be likely or very likely to upload a Mental Health Advance Directive to My Health Record if they made one. A very small number (12 consumer participants,2.06%) said they already had a Mental Health Advance Directive uploaded to My Health Record (see Figure 13). Approximately one third of consumer participants (n=200, 36.56%) were unaware that they could update or remove an Advance Care Plan from their My Health Record at any time (see Figure 14).

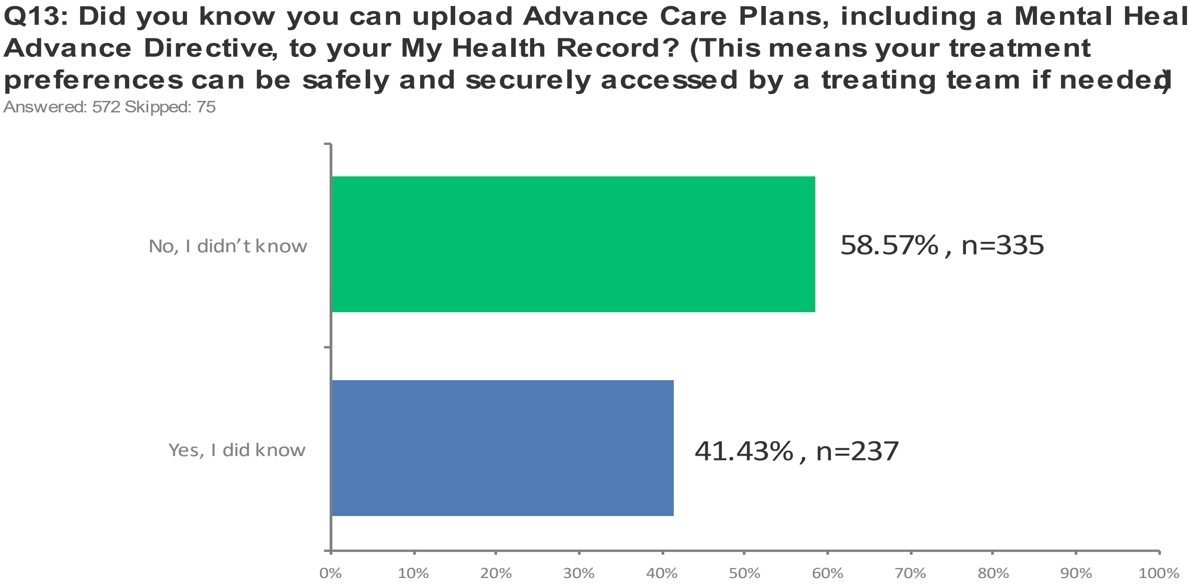


Figure 12: Consumers' Awareness of Ability to Upload Advance Care Plans to My Health Record

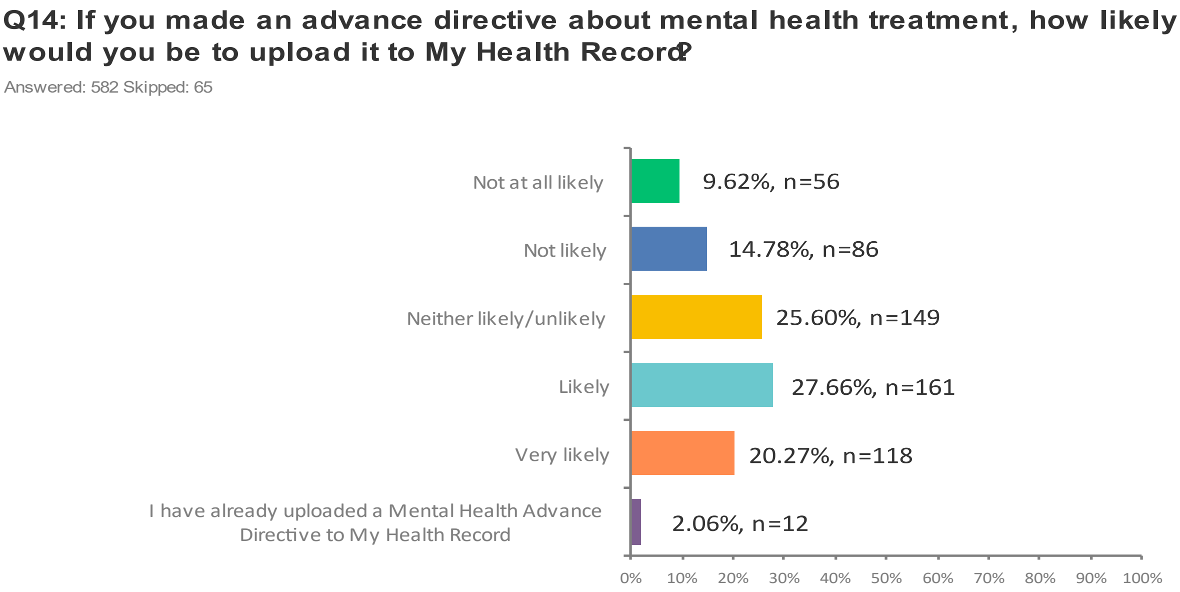


Figure 13: Consumers' Likelihood of Uploading a Mental Health Advance Directive to My Health Record

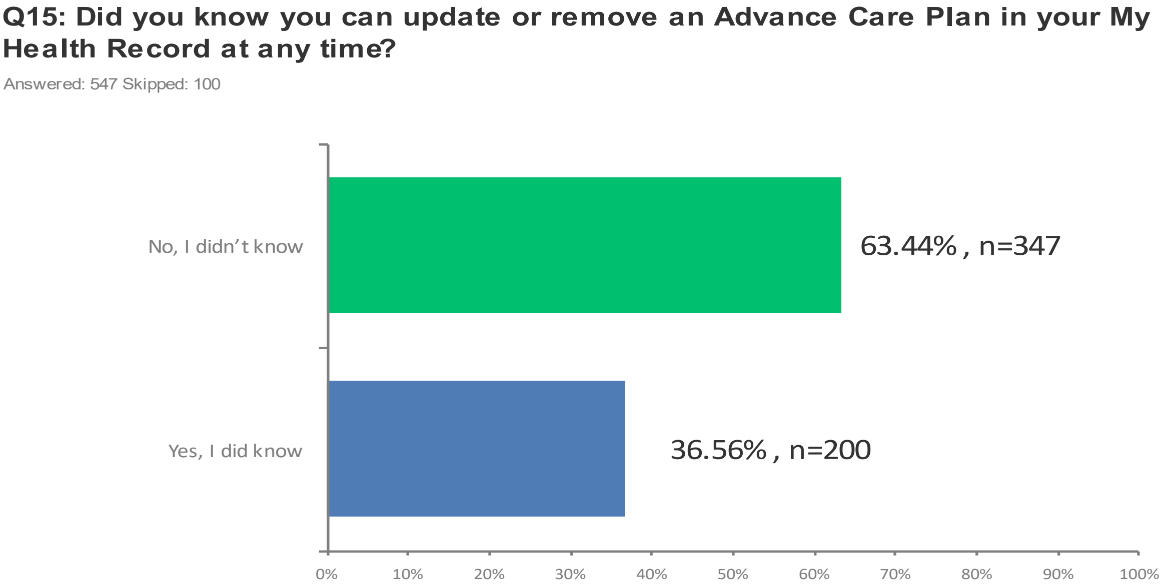


Figure 14: Consumers' Awareness of Ability to Update or Remove Advance Care Plans from My Health Record

Consumer participants expressed several concerns about uploading a Mental Health Advance Directive to My Health Record which may help to explain why many were unaware, uncertain, or reluctant to upload these care plans to their digital health record. From the 578 consumers who answered this question, 491 said they had concerns, with many selecting concerns across more than one option (n=1044 responses). The most commonly selected concerns were around security of personal information online and concern around unwanted people having access to personal information in their record (see Figure 15).

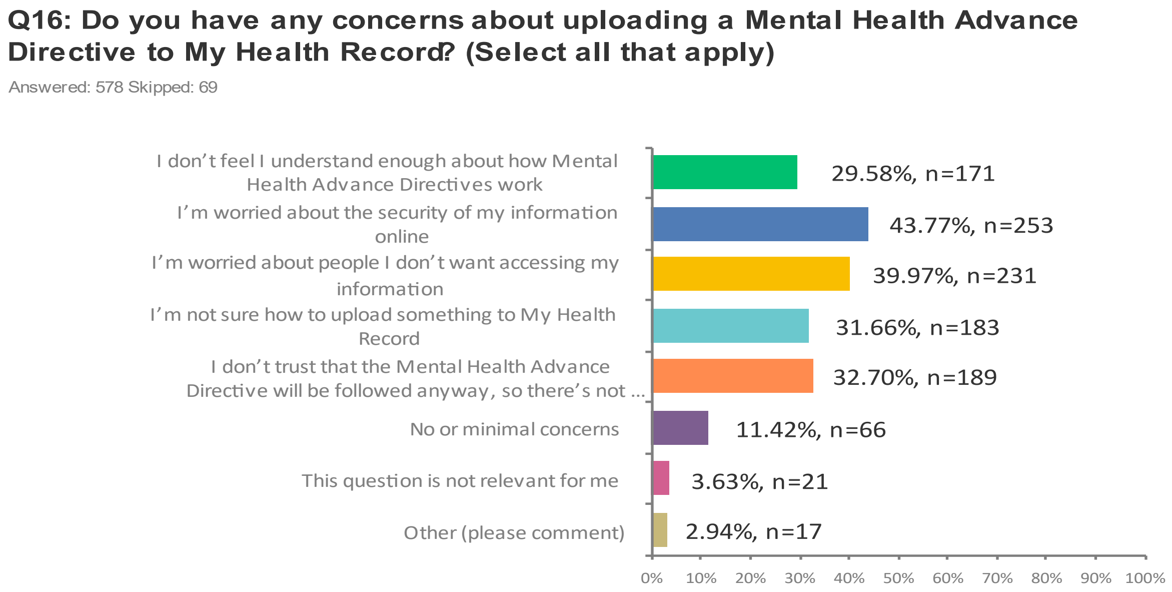


Figure 15: Consumers' Concerns about Uploading a Mental Health Advance Directive to My Health Record

Seventeen consumer participants provided comments about other concerns. Again, these centred on concerns about security of their information, trust in how their information would be used, and need for more knowledge about how to develop a Mental Health Advance Directive or use My Health Record:

- *Until systemic stigmatisation is addressed, I want to be in control of my sensitive personal information.*
- *I don't think My Health Record is good for people that don't engage well with the system.*
- *I assume that the current NSW Mental Health Act would grant any "authorised person" the ability to override my advanced planning if they deem it "reasonably necessary".*
- *If I make an advanced MH directive available on my record, I don't trust that health care professionals will consult me personally before or while also looking at the directive. No matter my state of wellness/illness, I and other MH patients should ALWAYS be included in decision-making and explained the rationale and any implications of these. Plus, the patient may not agree that they are not fit for decision-making in the first place, so there is even more reason for transparency from professionals/the system. If MH patients cannot trust their treating team, the trajectory for successful recovery is significantly negatively impacted.*
- *I'm not sure how to upload something to My Health Record.*
- *I was told if I opt out of My Health Record I can never have one again. Not sure if that was just to try to stop me opting out or not but seems really offensive that you can never change your mind about something so important. For example, nobody told me I could control who had access to it, there was no information provided at all.*

More than half (n=305, 53.32%) of consumer participants said they would like more information on how My Health Record works. Almost half (n=247, 43.18%) wanted support to develop a Mental Health Advance Directive and half (n=286, 50%) said they wanted support to upload it to My Health Record. Less than 15% of consumer participants said they did not need or want any support with these processes (see Figure 16).

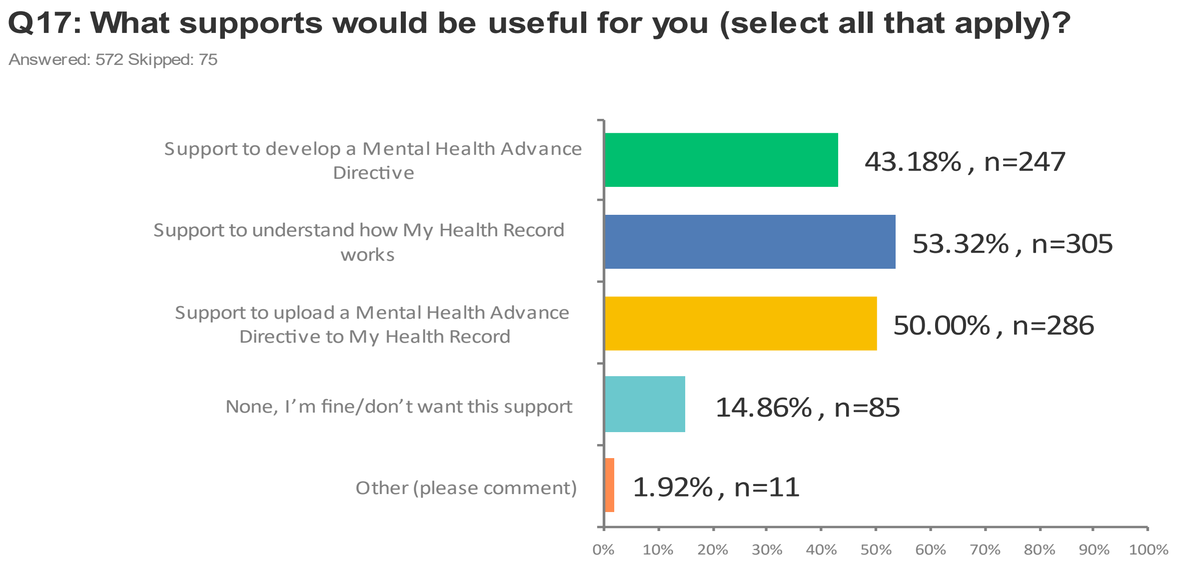


Figure 16: Consumers' Needs for Support

Eleven consumer participants provided further comments about their support needs. These related mainly to others who could provide support, the need to improve systems of communication, and greater understanding of how these processes sit within mental health legislation and service delivery systems:

- *It would be great if my GP could upload it from their clinical software system.*
- *Give a person the opportunity to develop it in conjunction with NSW Trustee and Guardian, in the context of their Will, Guardianship and Executor instructions, and other ACD's.*
- *Need help understanding forms so carer would have to be involved, so I can make a decision.*
- *Assurance of clear Standards of practice, and comprehensive guidelines to govern and scope practice that surrounds a Mental Health Advance Directive.*
- *Understanding of how that would play out in different scenarios and in the context of legislation.*
- *A FAQ sheet/link about privacy and confidentiality and rights and responsibilities. Full 3 level encryption. A policy and procedure doc about WorkSafe and how it may cross-over.*
- *Human connectors to the system that I trust and self-determined continuity of care.*

Further Comments from Consumers

Of the 152 further comments made by consumer participants, 107 stated that they had no further comments, leaving 46 consumers who provided further perspectives. Again, many comments centred on concerns about security and trust in the use of these digital health systems:

- *I've not engaged with My Health Record because I had no faith in the process when it was initiated by the previous government. If security was fully addressed, and people trusted the process, I think it would be a very valuable tool for all Australians.*

- *I believe My HR is totally unusable until they ensure it has much better safeguards against inappropriate access and use, as well as comprehensive records that actually reflect the person's complete medical information - without these, I think it's dangerous and totally useless.*

- *I wouldn't upload a Mental Health Care Directive because health professionals have been unable to follow verbal directives from my next of kin, while I'm coherent in the room, so I have major concerns they'd be ethical or respect my wishes if I needed someone to advocate for me or they were required to follow a written document.*

- *It would be better if you were able to completely dispel my fears.*

- *Until there is guaranteed security of online information I am not interested in this option. I also have some doubts as I have a family member who has had 6 admissions to the same hospital in the last 6 months and every time they go through the same things and ask us all the same questions without referring to any prior documentation that must surely exist. If they don't use what is there now what confidence is there 'they will use My Health Records?*

- *The reason I personally did not make a My Health Record is that I find I am repeatedly misunderstood by clinicians. I feel if I needed to get a second opinion on management/diagnosis or anything, the new clinician would read the previous clinician's perspective, and their assessment would be tainted by that. Any negative, stigmatic, or inaccurate conclusions would follow me right over to the next person I saw. I didn't know you could elect who could see what.*

- *My GP a few years back actually directed me and my family not to use my health. Said it had been breached overseas so entire family opted out and I trust her word.*

- *Very important not to set up false expectations e.g. that this advanced mental health care plan would give someone immunity to being sectioned because they don't wish to be sectioned. I highly doubt that's the case, and a false sense of security would only compound feelings of system betrayal. I also don't think there is adequate resourcing to cater to individual need. Again, setting up false expectations of what a crisis response will look like is, in my opinion, worse. Many people don't know they'll be sent police instead of ambulance for example. Knowing what your care will look like is important, having choice is important. Having a plan and then having it tossed out is significant to outcome and has long lasting negative impacts to wellbeing and service trust.*

Some consumer participants offered practical ideas for how consumers might be supported better to develop Mental Health Advance Directives and how their use could be promoted:

- *For people like myself who are dyslexic, neurodiverse, who learn & connect differently, I personally would prefer a video option / audio visual options of uploading an advanced care plan & mental health advance care directive audio visually instead of having to complete it in writing. The video version could be transcribed to written content also.*

- *I have previously downloaded documents to complete an Advanced Care Directive but have hesitated about how to fill it in...what wording etc. I know there are suggested statement ideas, but it is a bit confronting actually putting it in to words. Actual real time assistance from a person would be extremely helpful for me.*

- *Advanced care directives are so variable with haphazard templates that it would be good to have an easy access template with room for additional information for those who have specific knowledge (e.g. health clinicians who have seen situations patients may not have) and have these on hand at general practices and hospitals so the public can see the option exists and request help from a trusted clinician to complete and explain options as/if needed. Also, have the option for paper and digital as not everyone is tech literate and those who are don't always trust data security.*

Some consumer participants made comments about the need for health professionals to use and promote the use of My Health Record more:

- *More importance needs to be put on health professionals to ensure they are uploading all information including blood results.*
- *It's a poorly promoted system.*
- *I don't think doctors are promoting it at all.*

Carer Perspectives

Demographic Details

Overall, there were fewer respondents who identified as carers than mental health consumers. This could reflect the nature of lived experience networks, carers' perceived or actual levels of involvement in supporting the people they provide care to with online health information, carers' own digital literacy, challenges in people identifying as a mental health carer more broadly, time constraints on carers to participate in surveys and reach of the survey itself.

Carer participants were drawn from all Australian states and territories, with some bias which likely reflected the more prominent reach of Mental Health Australia towards some Eastern Australia jurisdictions similar to patterns found with the consumer data (see Figure 17).

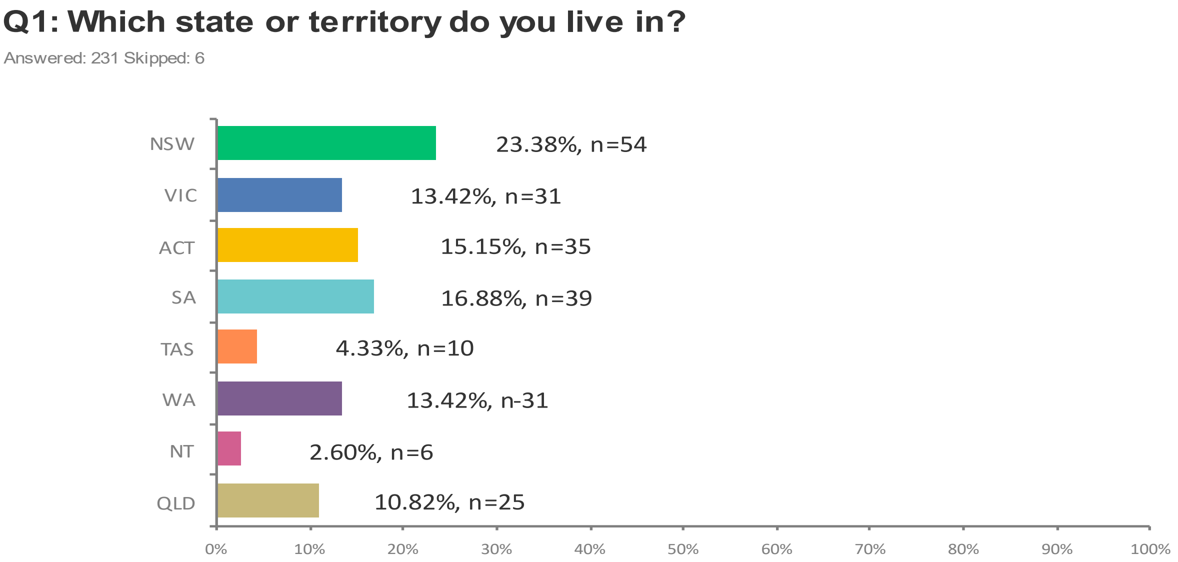


Figure 17: Location of Carer Participants

Most carer participants were aged between 18 and 59 years, likely reflecting those who are more engaged with digital technology and more likely to complete online surveys. Fewer carers in the 60-79 years age group participated (see Figure 18). Carers were not asked whether they were providing support to a parent, child, adult child, sibling or other family or kin.

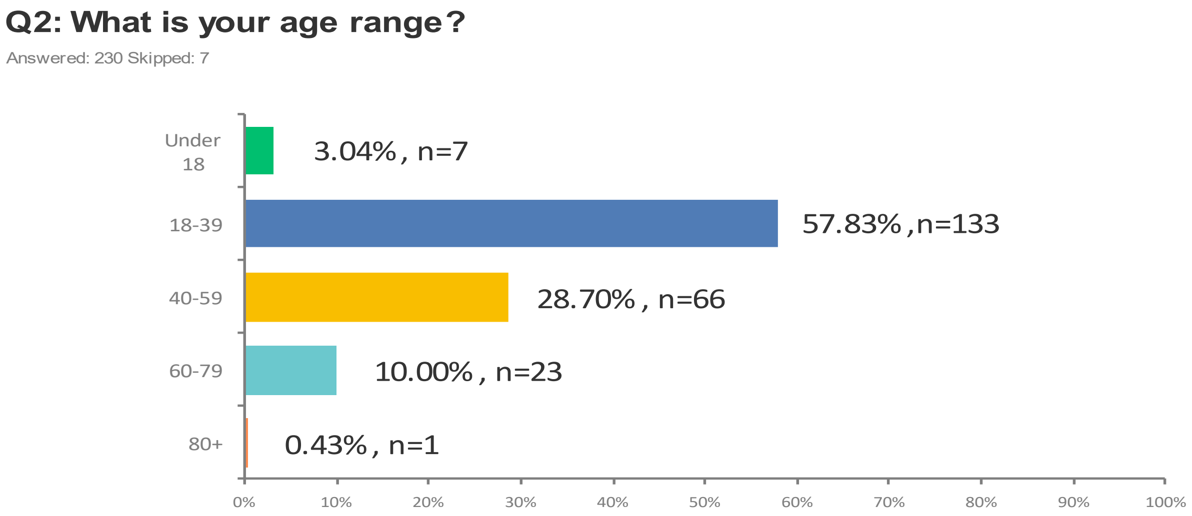


Figure 18: Age Range of Carer Participants

Similar to results from the consumer survey, almost half of carers identified as women or female. Of note, almost 40% of carers identified as men or male, and a small percentage of carer identified as non-binary or used a different term (see Figure 19).

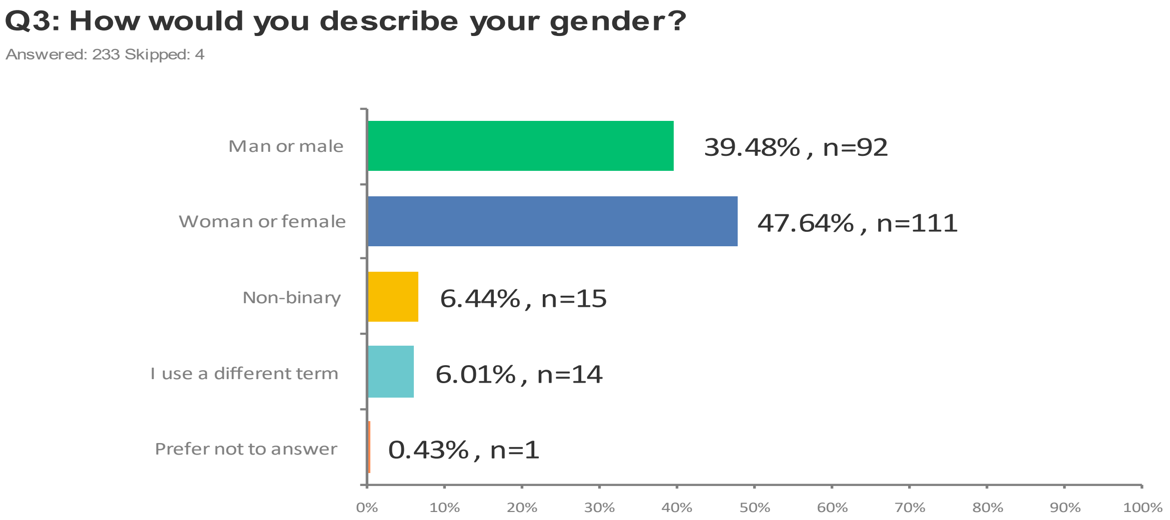


Figure 19: Gender of Carer Participants

Like consumers, carer participants identified with a range of population groups. Of the 229 participants who responded to this question, 129 identified with being First Nations, CALD, LGBTQIA+ or living with disability. The 205 responses across these 4 groups suggests that almost half of carer participants chose to select more than one group. Of note, almost a third (n=111, 30.13%) of total responses involved the carer participant identifying as culturally and linguistically diverse, and more than 20% (21.83%, n=50) identified as a person with disability. As a proportion of the sample that identified as belonging within the 4 population groups, this reflected 38.76% of carer participants (see Figure 20).

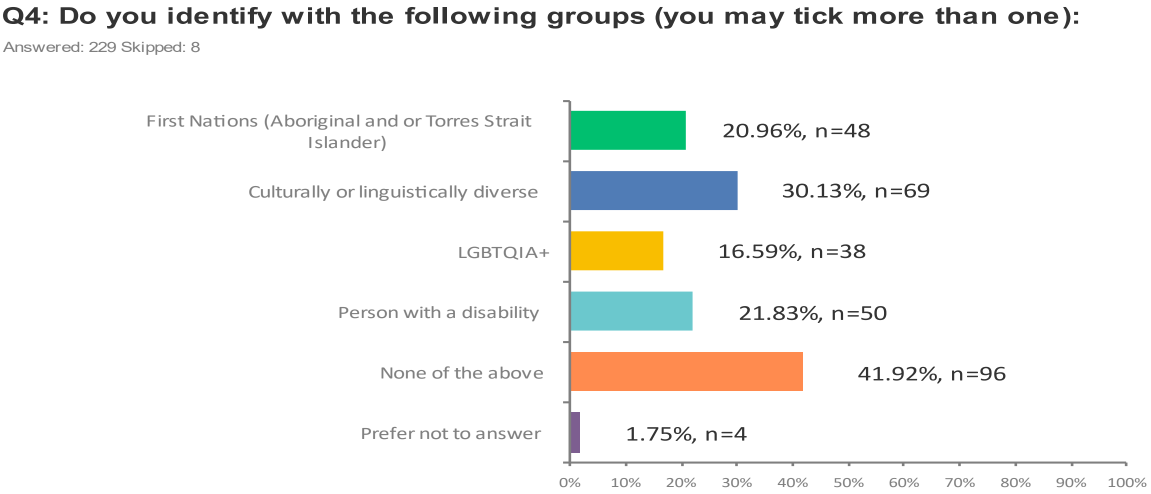


Figure 20: Carer Participants by Population Group

Carers’ Awareness and Use of My Health Record

Approximately 70% (n=153) of carer participants said the person they support does have a My Health Record, though almost 40% of this number said that they don’t really use it (see Figure 21).

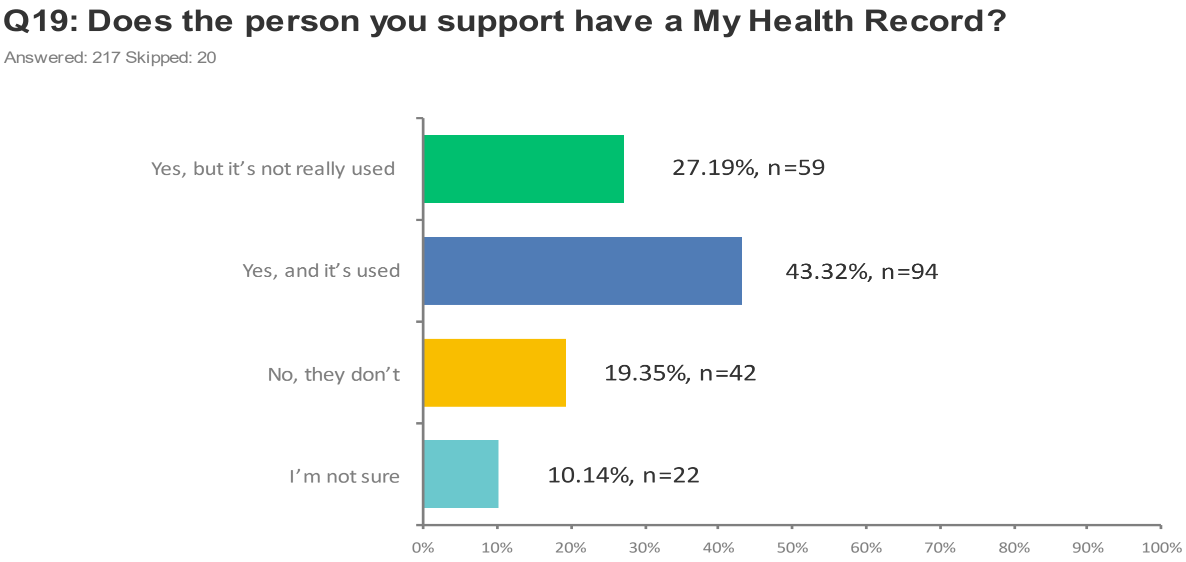
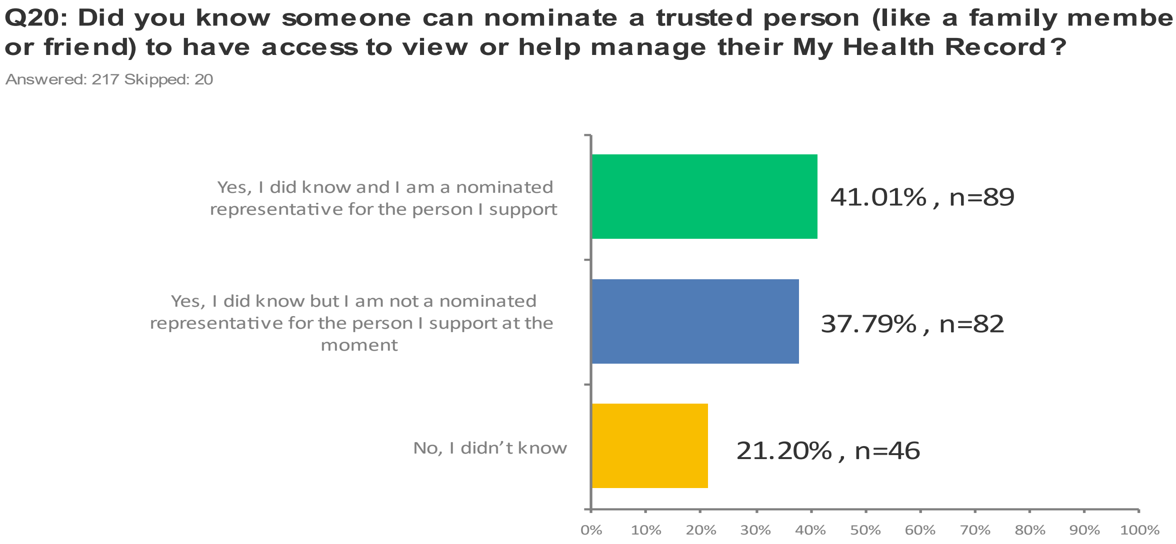


Figure 21: Carers – Does the Person Supported have a My Health Record?

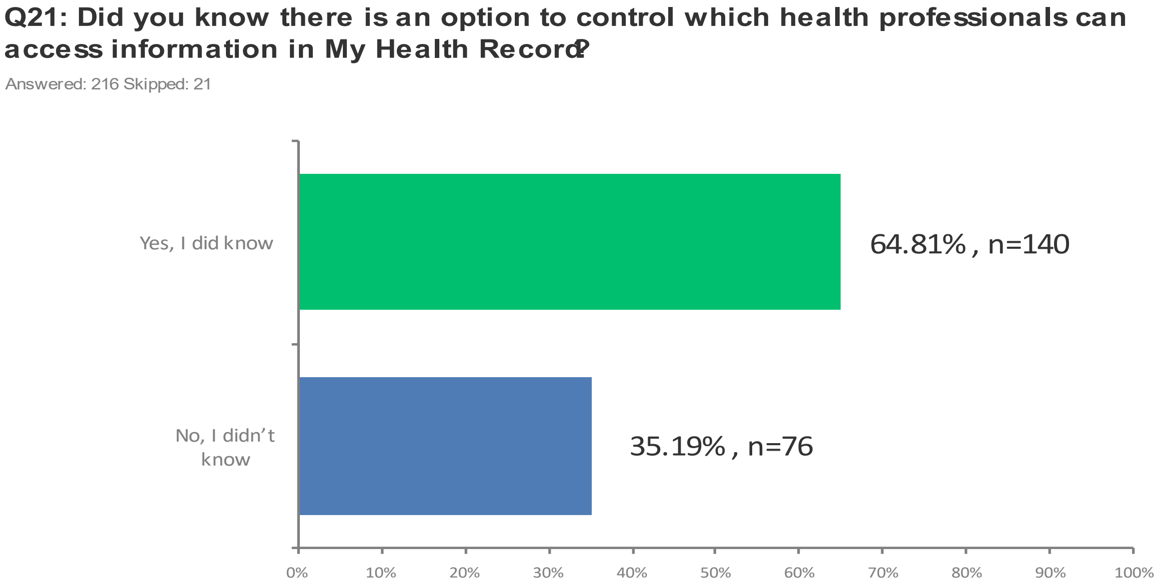
Almost three quarters (n=171, 78.80%) of carer participants who answered this question were aware that the person they support could nominate someone they trust to have access to view or help them manage their My Health Record, with just over half of these respondents already being a nominated representative for the person they support. However, approximately 20% of carers were not aware of this option (see Figure 22).


Q20: Did you know someone can nominate a trusted person (like a family member or friend) to have access to view or help manage their My Health Record?

Answered: 217 Skipped: 20

Figure 22: Carers - Trusted Nominees and Managing My Health Record

More than one third of carer participants (n=76, 35.19%) did not know that the person they support could control which health professionals access information in their My Health Record (see Figure 23).


Q21: Did you know there is an option to control which health professionals can access information in My Health Record?

Answered: 216 Skipped: 21

Figure 23: Carers - Control of Health Professional Access to My Health Record

Carers were asked which benefits of using My Health Record for the person they support they personally agreed with. They could choose multiple options from a list of nine. The most common option was selected by 53% of carer respondents.

Overall, the five most commonly selected benefits by carers were:

- convenience while travelling;
- being able to choose who can see the information on My Health Record;
- ability to keep health documents in one place;
- alleviating the need to remember/use paper copies; and
- fewer delays in accessing treatment because health professionals have ready access to information.

These were the same most common benefits chosen by consumer participants, but with minor variation to the order. Similar to consumers, 'Having greater access to their own health record' was rated of lowest benefit by carers (see Figure 24).

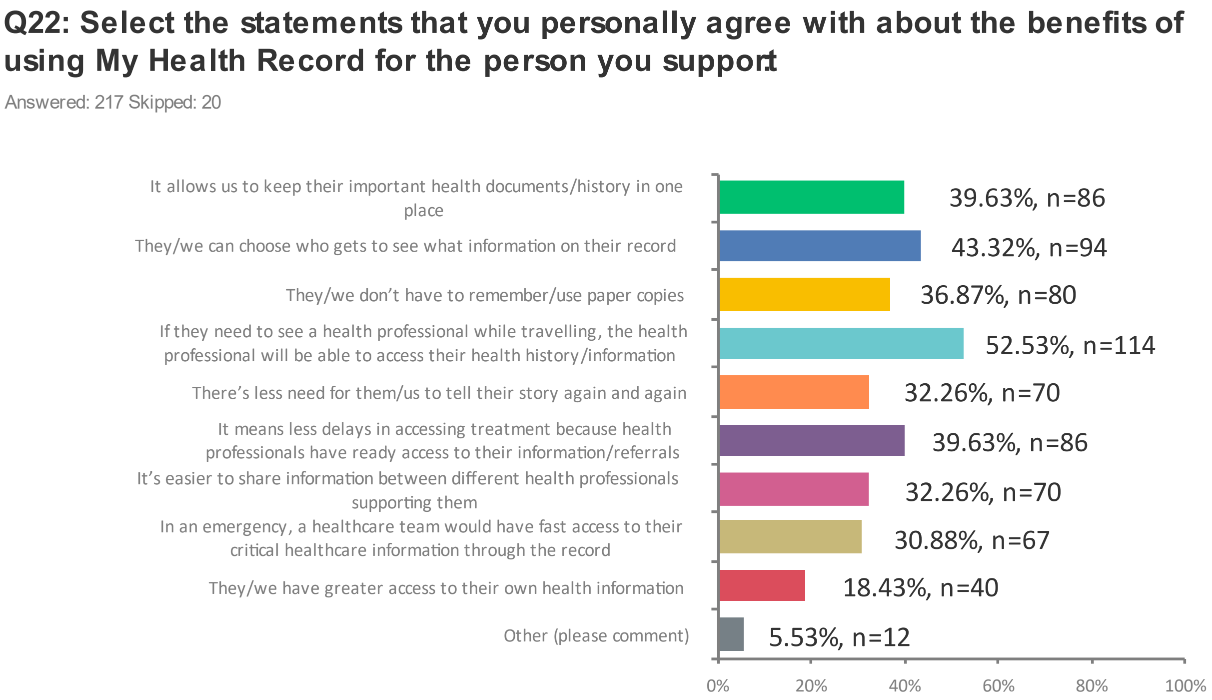


Figure 24: Carers – Benefits of Using My Health Record for the Person They Support

Twelve carer participants provided further comments about the benefits of My Health Record. Some took the opportunity to express their lack of trust in this system of information sharing:

- *I am a health information manager and so have dealt with medical records all my life and believe in their importance. However, after experiencing the treatment of both me and my daughter in the Mental Health system and the misinformation, judgement and lies that have been documented, I refuse to have this disseminated to all who have contact with us.*

Other comments were more positive about the ability to share health information:

- *The Advance Care Directive is an excellent idea as far as I am concerned particularly as I am aging. It makes it easier for relatives or carers to follow up with suitable care in the future.*

- *It allows clinical staff to know the preference of the person they provide mental health care to.*

Some carer participants expressed concerns about the impacts on the person or family having access to so much mental health information and the potential for it to be traumatic for them:

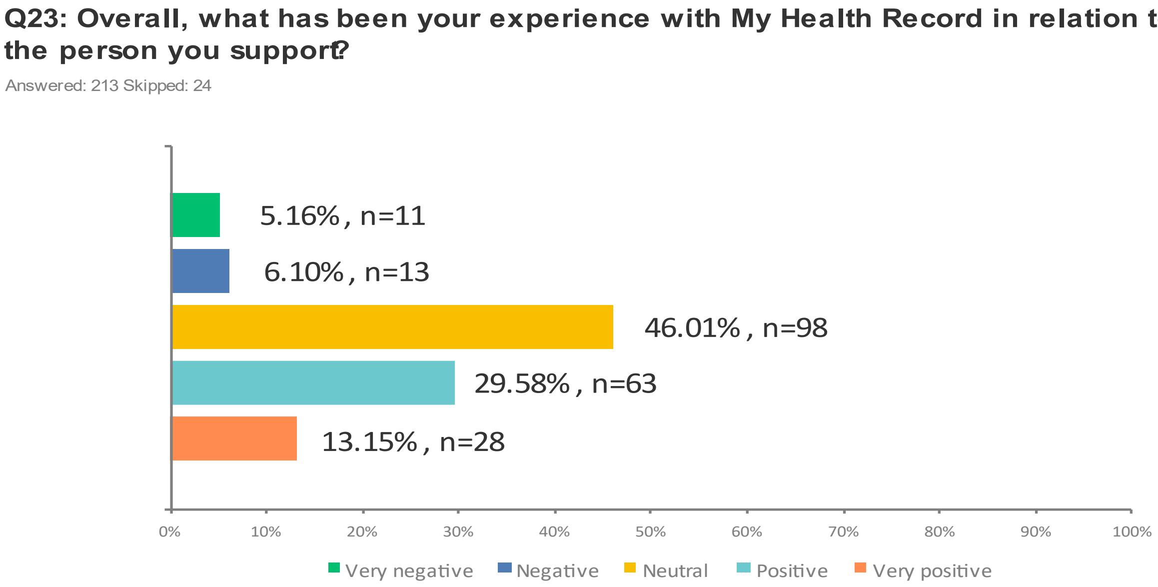
- *It totally depends on what is written as to whether the information is helpful or relevant or it is problematic. Every case should be treated as individual and there should not be a generalised systematic approach with regards to what information in stored and how it is shared. I would be fearful of my son seeing his mental health records and this relapsing his suicidality. I would also struggle to view this information due to serious PTSD from my experiences as his mum and carer. I completely disapprove of the current system particularly for those who have been discriminated against for having a mental health condition and/or suicidal attempts needing treatment.*

Some comments highlighted practical problems with the online system:

- *We live on a border and My Health Record does not work with cross border services; your information is not loaded in a timely manner and medical professional do not share information*.

Carers’ Experiences of My Health Record

Carer participants’ experiences of My Health Record in relation to the person they support were mixed, though generally more positive than consumer experiences, with almost half having ambivalent experiences (neither positive or negative), approximately 43% having positive or very positive experiences, and less than 12% have negative or very negative experiences (see Figure 25).


Q23: Overall, what has been your experience with My Health Record in relation to the person you support?

Answered: 213 Skipped: 24

Figure 25: Carers’ Experiences of My Health Record

Sixty-nine carer participants made further comments about their experience of My Health Record in relation to the person they support. Some reiterated the positive aspects such as convenience in storing records so that families and health professionals could have ready access to them when needed:

- *It's great to allow health care professionals to treat people faster and better in an emergency.*

- *Good for keeping records for the elderly.*

However, there were also several comments indicating that carer participants also had negative experiences in their role as carers. These included being concerned about the person’s perceived trust in the security and privacy of their mental health information, and well as their own concerns about the security of the system:

- *It does depend on if they are well at the time. If unwell there are issues as they do not trust the system.*

- *Even though these above statements are ' true' about the purported benefits of My Health Record, the perception of lack of privacy and safety is a huge concern and one that my brother living with psychosis identifies. He does not trust it and therefore will not use it. He is intelligent, watches the news and knows that data breeches occur. Also, he is in his mid-60's does not have a smart phone - does not want one - and is not computer literate.*

- *I know it exists however I can't recall if myself or my loved one are signed up. We have also been part of the recent Medibank & Optus privacy breaches as well as I have had a significant personal privacy breach which is currently with the OAIC. All have left me very cautious & wary to the protection of our personal & sensitive in formation. Particularly for my son given the nature of his medical history.*

Other carer participants reiterated concerns about the consistency and integrity of the online system to work as it is intended:

- *My daughter had test results that was detrimental to her health and her information was not shared until 3 weeks later and she became sicker during that time. My Health Record doesn't share information as it is meant to and the doctors don't have time to read it.*

- *Nothing is ever upgraded, or incorrect information is included!*

- *The information isn't there e.g. recent test results done in the public health system weren't available for the GP to see, interpret and explain to us. Had to fill out forms requesting the different hospitals to release information and remembering dates, times and who we saw for what is extremely difficult. This also incurred an extra cost ($170.00) now that GP's no longer Bulk Bill long term clients who don't have a concession card. Can no longer afford to go back to GP.*

Carers' Perspectives of Mental Health Advance Directives

Almost two thirds of carer participants said that they were aware of the option to create a Mental Health Advance Directive, whereas one third were unsure or not aware (see Figure 26).

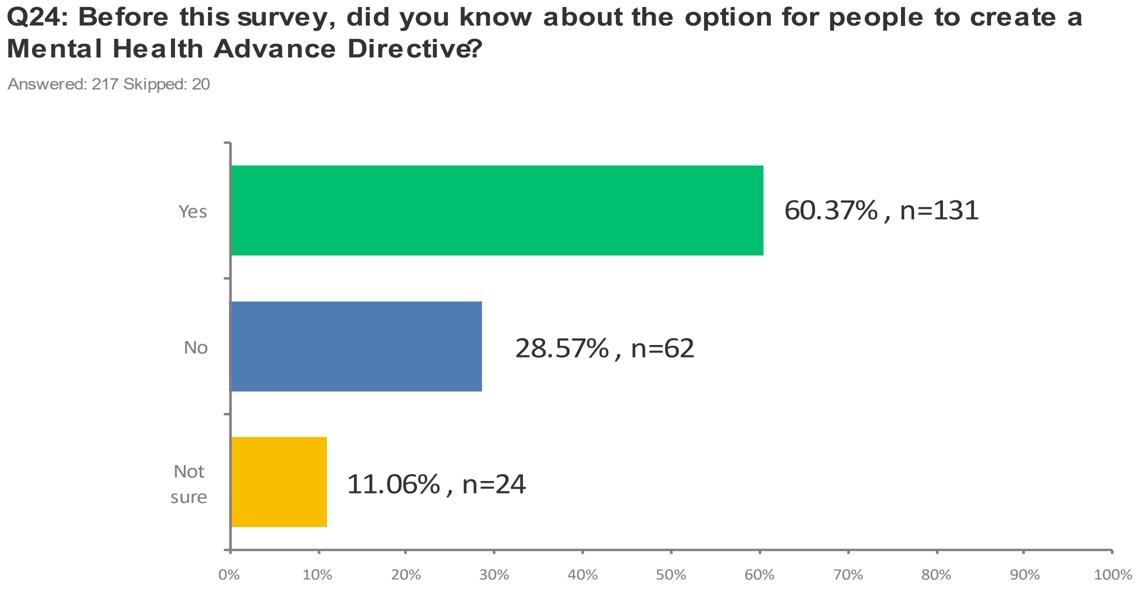
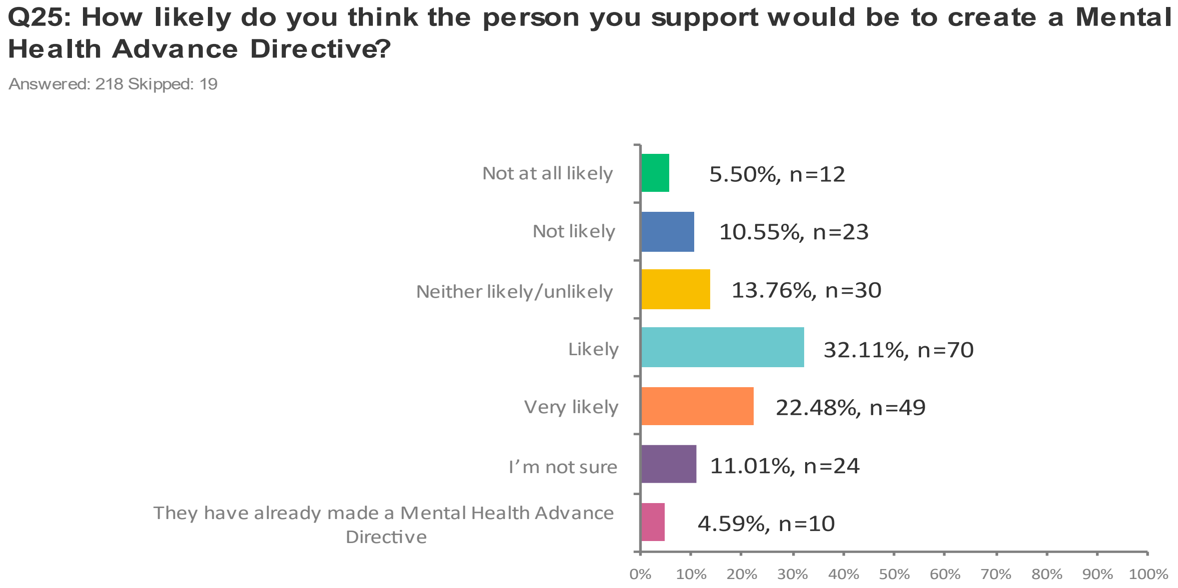


Figure 26: Carers' Awareness of Mental Health Advance Directives

Less than 5% of carer participants said the person they support had a Mental Health Advance Directive. However, more than half (n=119, 54.59%) said the person would be likely or very likely to create one, with less than one third (n=65, 29.81%) undecided or unlikely to do so (see Figure 27).

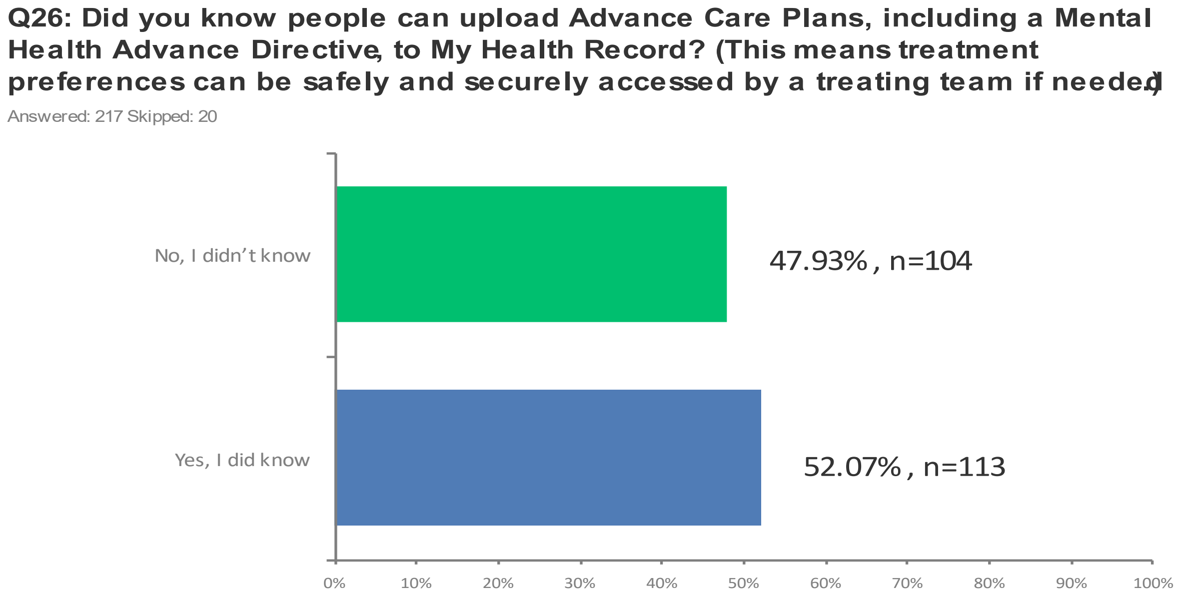


Q25: How likely do you think the person you support would be to create a Mental Health Advance Directive?

Answered: 218 Skipped: 19

Figure 27: Carers – The Person's Likelihood of Creating a Mental Health Advance Directive

Almost half of carer participants (n=104, 47.93%) did not know that people could upload Advance Care Plans to their My Health Record (see Figure 28), whereas more than half (n=123, 56.17%) said the person they support would be likely or very likely to do so, if they made one. Only 8 carer participants (3.65%) said the person they support already had a Mental Health Advance Directive uploaded to My Health Record (see Figure 29). Almost half of carer participants (n=90, 43.48%) were unaware that people could update or remove an Advance Care Plan from their My Health Record at any time (see Figure 30).



Q26: Did you know people can upload Advance Care Plans, including a Mental Health Advance Directive, to My Health Record? (This means treatment preferences can be safely and securely accessed by a treating team if needed)

Answered: 217 Skipped: 20

Figure 28: Carers' Awareness of Ability to Upload Advance Care Plans to My Health Record

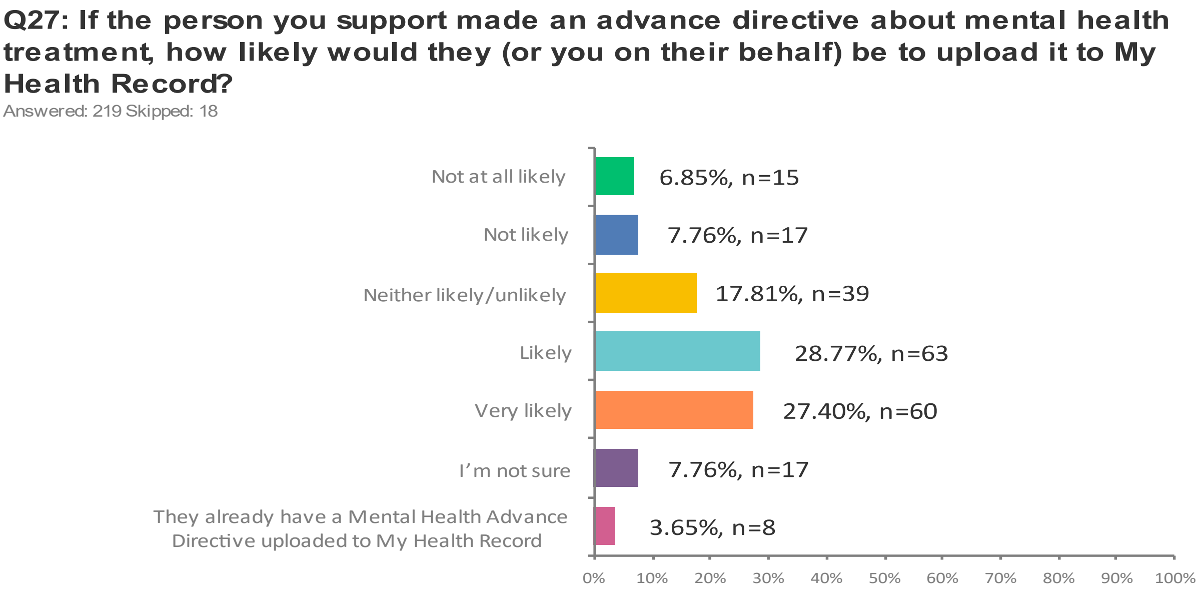


Figure 29: Carers – The Person's Likelihood of Uploading a Mental Health Advance Directive to My Health Record

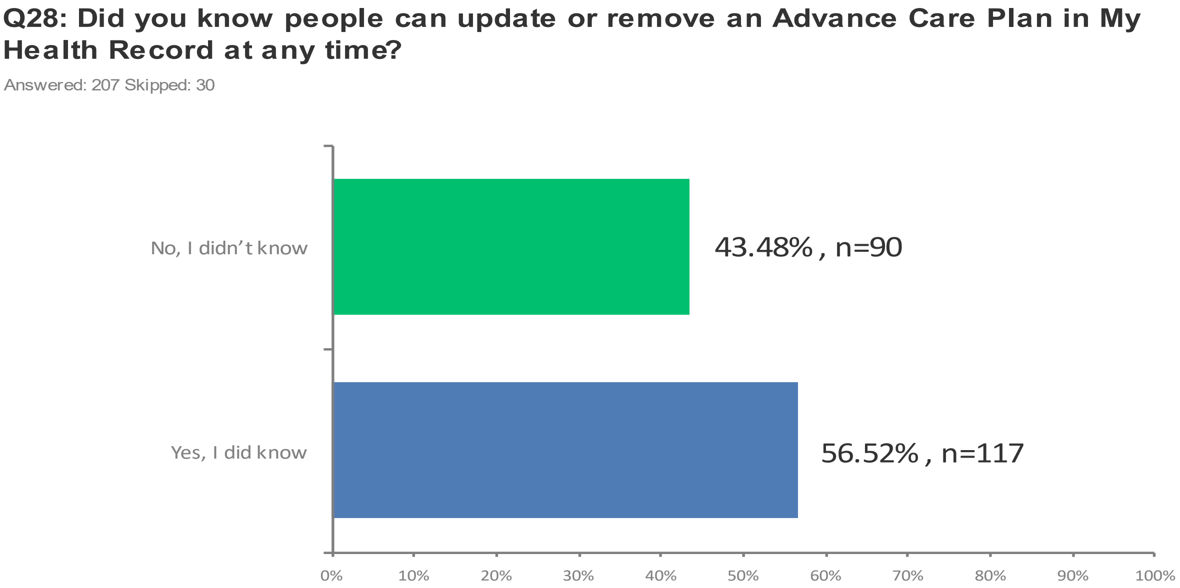
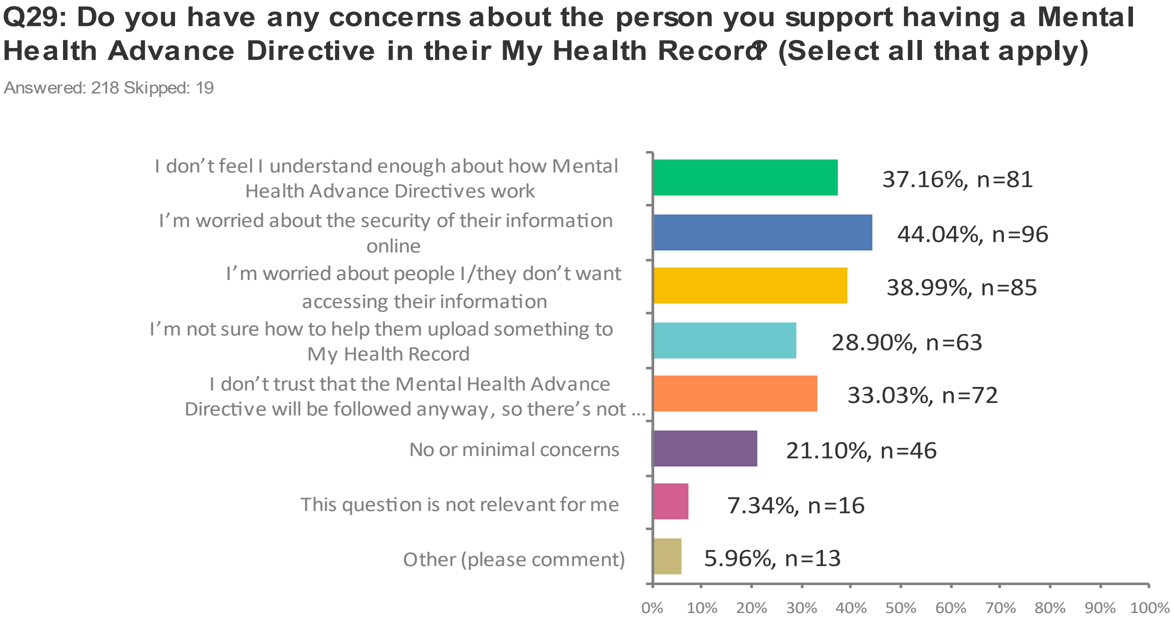


Figure 30: Carers' Awareness of Ability to Update or Remove Advance Care Plans from My Health Record

Carer participants expressed several concerns about the person they support having a Mental Health Advance Directive in their My Health Record. From the 218 carers who answered this question, 156 ticked at least one concern, with many selecting multiple concerns (n=338 responses). Similar to consumers, the highest rated concern for carers was the security of the person's personal information online; their ratings for other concerns were also similar to consumers (see Figure 31).


Q29: Do you have any concerns about the person you support having a Mental Health Advance Directive in their My Health Record? (Select all that apply)

Answered: 218 Skipped: 19

Figure 31: Carers' Concerns about the Person having a Mental Health Advance Directive in My Health Record

Thirteen carer participants provided further comments about their concerns, with several comments being about inconsistency in how Mental Health Advance Directives would be adhered to by health professionals.

- *I'm not confident mental health services would use it.*
- *Given our past experiences within the public & private health care sectors particularly in crisis, I have little to no confidence that this would be followed when we couldn't get basic care or treatment in crisis.*
- *Only concern is the medical practitioners do not use them.*
- *I would agree with anything the person I care for chooses in their Mental Health Advance Directive, but I think distant family members would try to overrule their wishes.*

Some comments were focused on concerns about the person and how the Mental Health Advance Directive would impact them:

- *I trust the Mental Health Advance Directive, but I am unsure my son would do so.*
- *My experience with the Mental Health system has been so negative. They do not understand Autism and how this affects a patient. It is not catered for. My daughter is highly suicidal and traumatised by the Mental Health System. I think an Advance Directive by her may include letting her die and that concerns me. She has been in ICU 6 times and jumped off a bridge & broken her back.*
- *With this directive being treated differently in each state there will be a lack of consistency and this could pose issues for people who may live in two states or travel regularly to see family but could need help in two different jurisdictions. The rules may vary, causing someone great distress!*

Almost two thirds (n=134, 62.33%) of carer participants said they wanted support to upload the person's Mental Health Advance Directive to My Health Record, with slightly less (n=126, 60%) saying they wanted help to understand how My Health Record works. Of note, approximately half of consumer participants said they wanted these supports, suggesting that carers were particularly keen open to receiving support and information about Mental health Advance Directives and My Health Record processes.

Half of carer participants (n=108, 50.23%) wanting help to develop a Mental Health Advance Directive with the person they support. Less than 13% of carer participants said they did not need or want any support with these processes (see Figure 32). These results were similar to consumer survey participants.

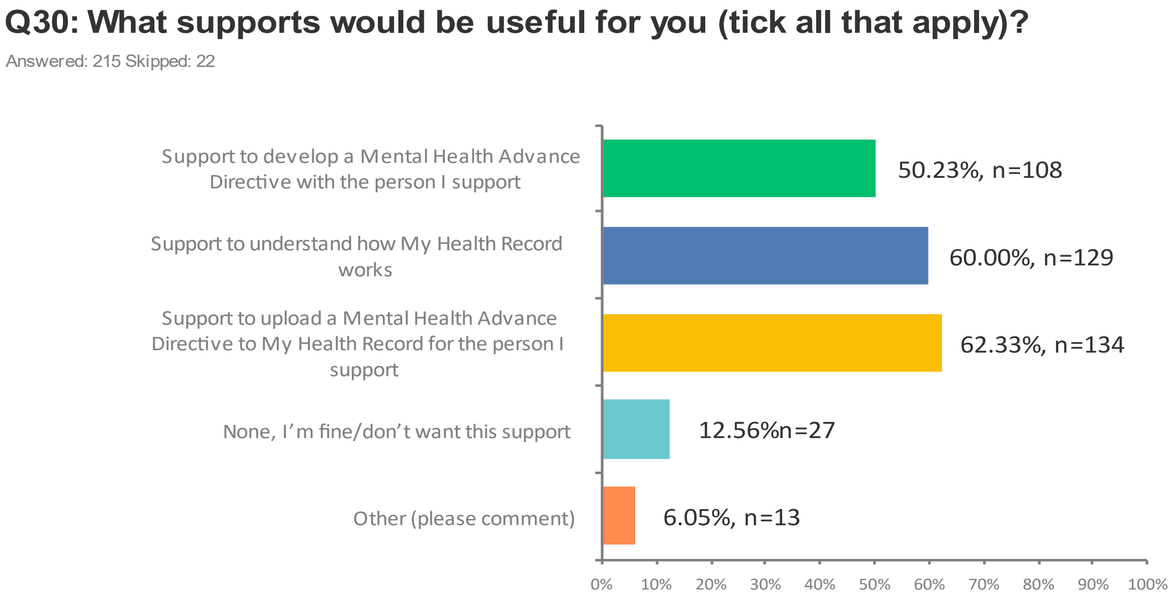


Figure 32: Carers' Needs for Support

Thirteen carer participants provided further comments about support that they would find useful. Several carers said more practical education and information was needed:

- *Maybe being guided once on how to do it would help.*
- *More education about MHADs & My Health Record for both consumers & medical professionals.*
- *Clear and easy reading guides about the rights of the person I care for and our family.*
- *More online/pamphlet information regarding My Health Record.*

Several carers also expressed concerns about the system of mental health care and the need for improved care and communication with the person and their family carers:

- *Why when we ring emergency services do we have to tell them what is happening to 000, then ambulance, then a second ambulance call taker, then police, then ambulance when they arrive, then emergency when she gets to hospital. Too much duplication, too many times going over a story when it is traumatising enough, and you are in the middle of a crisis.*
- *An improvement in the health sector to guarantee people get appropriate crisis & ongoing health care treatment for Mental Health, Addiction and Suicide Prevention.*

- *Support to decide what goes on the record and what is shared period. If there is difficulty in taking information away that could potentially be harmful then it greatly negates the benefits of My Health Record.*

Further Comments from Carers

Of the 83 further comments made by carer participants, 61 stated that they had no further comments, leaving 22 carers who provided further perspectives. Again, several comments centred on concerns about security and trust in the use of digital health systems:

- *Don't trust my health records - prefer to complete and keep secure with doctor.*
- *It's just that when we share our stories from the bottom of our hearts, they won't be taken advantage of, and they won't be discriminated against, and they won't be manipulated.*
- *Improve online health information to protect personal privacy.*
- *I think it is a very hard sell to convince people of data security and privacy, particularly for people with psychosocial disability resulting from long term mental illness and poverty.*

Several comments were also made about the need for health professionals to receive more education about how to develop and implement Mental Health Advance Directives, particularly in the context of consumer rights and legislation underpinning these processes:

- *ACD are essential to protect the right to self-determination of people receiving mental health care. Lived Experience workers are the best placed to support people to have their ACD in place, but they need training as legislation can be complex. Independent non-legal advocacy (as is happening in Victoria) is essential to protect the legal capacity of people receiving treatment. ACD needs to be accessible to any clinician making decisions about the person receiving MH care, however it should be supported with clear procedures and technology that protect the privacy of people.*
- *Sometimes it is the health professionals who do not understand the process or information.*
- *I feel this is a great initiative however until Consumers & Carers are provided with appropriate treatment care & support, they will be reluctant to sign up for this. Also there needs to be further education and investment NOW to reduce stigma, shame and discrimination across Mental Health, Addiction and Suicide Prevention.*
- *Each person should have the right to access their information say through the hospital system or any other health system before it becomes a part of the My Health Record system. This right is currently being denied therefore the My Health Record system only perpetuates the current issues around access and rights on what is stored and removed.*

Conclusion

This survey found that amongst a large sample of people with lived experience of mental health challenges (n=647) and mental health carers (n=237), just under half reported using My Health Record (44% of consumers and 43% of carers said the person they support uses it). There was general awareness that people could nominate a family member/carer to help manage their My Health Record (74% of consumers), control which health professionals can access information in the record (67% of consumers) and create a Mental Health Advance Directive (63% of consumers). Fewer people were aware of the option to upload a Mental Health Advance Directive to My Health Record (only 42% of consumers and 52% of carers). Further work to increase awareness about all of these options is still needed, particularly given feedback indicating the value to mental health consumers and carers of being able to control their record and who has access.

Overall, participants were more likely to report positive experiences of My Health Record (45% of consumers, 43% carers) than negative (20% consumers, 12% carers). The most common benefits consumers and carers identified with about using My Health Record were convenience while travelling, alleviating need to remember/use paper copies, being able to choose who can see their information in the Record, ability to keep all health documents in one place and fewer delays in treatment. However, many participants across both groups raised significant concerns about privacy and security of information in My Health Record, experience of stigma from health professionals related to mental health information in their record. Participants also raised concerns about incompleteness of information in their Record and inconsistent use of My Health Record by health providers – both of which significantly limits the usefulness of My Health Record and in some cases has created further challenges for consumers.

A significant proportion of participants indicated they would be likely to create a Mental Health Advance Directive in the future (46% of consumers), and that if they made a Mental Health Advance Directive they would be likely to upload it to their My Health Record (48%). The most common concerns expressed around uploading a Mental Health Advance Directive to My Health Record were in relation to security of personal information online and concern around unwanted people having access to information in their record.

Many consumers and carers said that further support to understand how My Health Record works and how to upload a Mental Health Advance Directive to My Health Record would be useful for them.

While the findings of this survey should be interpreted with caution, feedback from participants points to clear areas for further work:

1. Access to more user-friendly information about the security and safety of My Health Record.
2. More education and easy-read information for consumers, carers, and health professionals on how to use My Health Record.
3. More support and easy-read information for consumers and carers about how to develop Mental Health Advance Directives and upload them to My Health Record.
4. More consistent use of My Health Record by health professionals and services across the health system.

Appendix 1: Survey Questions

Communicating my preferences: Survey for people with lived experience of mental health challenges and carers on My Health Record and Advance Care Planning

This survey has been developed by Mental Health Australia, informed by a lived experience advisory group, and in partnership with Lived Experience Australia. It is part of activity funded by the Australian Digital Health Agency, to promote use of My Health Record.

This survey is for people with lived experience of mental health challenges and family members/carers. If you identify as both a person with personal lived experience and a carer, you are welcome to fill out the survey twice, from each perspective.

We want to understand your views and experiences of My Health Record. There is now an option to upload Advance Care Planning documents to My Health Record, including advance mental health directives. We're interested in what you think about this and if you might use this option to communicate your preferences about future mental health care.

This survey should take about 15 minutes to complete. **The survey is completely anonymous and voluntary.** You may choose not to answer some questions or stop at any time.

At the end of the survey, you will be invited to enter your details to enter a draw to win one of 10 gift cards worth $50 each, as a thank you for your participation. This is voluntary and these details will be stored separately to your survey response.

Thank you for your participation.

Demographics (Completed by all participants)

1. Which state or territory do you live in?
    - ○ (single choice from list of states/territories)

2. What is your age?
    - ○ under 18
    - ○ 18 - 39
    - ○ 40 - 59
    - ○ 60 - 79
    - ○ 80+

3. How do you describe your gender?
    - ○ Man or male
    - ○ Woman or female
    - ○ Non-binary
    - ○ I use a different term
    - ○ Prefer not to answer

4. Do you identify with the following groups (you may tick more than one):
    - ○ First Nations (Aboriginal and or Torres Strait Islander)
    - ○ Culturally or linguistically diverse
    - ○ LGBTQIA+
    - ○ Person with a disability
    - ○ None of the above
    - ○ Prefer not to answer

5. For the purpose of completing this survey, do you identify as
    - Someone with lived/living experience of mental health challenges or mental ill-health
    - A carer or family member of someone living with mental health challenges/ill-health

My Health Record

My Health Record is a secure digital record of your healthcare information. This information might include details of your medical conditions and treatments, medicines you take, your allergies, and test or scan results. Both you and your healthcare providers can add information to your record. You and your healthcare providers, such as doctors, specialists and hospital staff, can check your My Health Record whenever needed.

6. Do you have a My Health Record?

    - Yes, and I use it
    - Yes, but I don't really use it
    - No I don't
    - I'm not sure

7. Did you know you can nominate someone you trust (like a family member or friend) to have access to view or help manage your My Health Record?

    - Yes, I did know
    - No, I didn't know

8. Did you know you can control which health professionals can access information in your My Health Record?

    - Yes, I did know
    - No, I didn't know

9. Tick the statements that you personally agree with about the benefits of using My Health Record for you:

    - It allows me to keep important health documents/history in one place
    - I can choose who gets to see what information on my record
    - I don't have to remember/use paper copies
    - If I need to see a health professional while travelling they will be able to access my health history/information
    - There's less need for me to tell my story again and again
    - It means less delays for me in accessing treatment because health professionals have ready access to information/referrals
    - It's easier to share information between different health professionals supporting me
    - In an emergency, a healthcare team would have fast access to my critical healthcare information through my record
    - I have greater access to my own health information
    - Other (please type in…)

10. Overall, what has been your experience with My Health Record?

    [Likert Scale] Very negative, negative, neutral, positive, very positive

    Please comment:

Advance care planning and mental health directives

Advance care planning is a voluntary process about communicating your preferences for future health care. This includes **Mental Health Advance Directives** where you can document your preferences about future mental health treatment if you become unwell and are unable to communicate or deemed to have reduced decision-making capacity. For example, you can document your values and preferences around treatment and recovery, including medication and nominating carers and what information is shared with them.

There are different rules in different states and territories about how to make an advance directive about general healthcare or mental health treatment, and the extent to which treating teams must follow this guidance.

11. Before this survey, did you know about the option to create a Mental Health Advance Directive?

    ○ Yes
    ○ No
    ○ Not sure

12. How likely do you think you would be to create a Mental Health Advance Directive to communicate your preferences for future treatment?

    ○ Not at all likely
    ○ Not likely
    ○ Neither likely/unlikely
    ○ Likely
    ○ Very likely
    ○ I have already made a Mental Health Advance Directive

Uploading advance care planning documents to My Health Record

13. Did you know you can upload Advance Care Plans, including a Mental Health Advance Directive, to your My Health Record? (This means your treatment preferences can be safely and securely accessed by a treating team if needed.)

    ○ No, I didn’t know
    ○ Yes, I did know

14. If you made an advance directive about mental health treatment, how likely would you be to upload it to My Health Record?

    ○ Not at all likely
    ○ Not likely
    ○ Neither likely/unlikely
    ○ Likely
    ○ Very likely

- ○ I have already uploaded a Mental Health Advance Directive to My Health Record

15. Did you know you can update or remove an Advance Care Plan in your My Health Record at any time?

    - ○ No, I didn't know
    - ○ Yes, I did know

16. Do you have any concerns about uploading a Mental Health Advance Directive to My Health Record? (Tick all that apply)

    - ○ I don't feel I understand enough about how Mental Health Advance Directives work
    - ○ I'm worried about the security of my information online
    - ○ I'm worried about people I don't want accessing my information
    - ○ I'm not sure how to upload something to My Health Record
    - ○ I don't trust that the Mental Health Advance Directive will be followed anyway, so there's not much value to me
    - ○ Other (please comment)
    - ○ No or minimal concerns
    - ○ This question is not relevant for me

17. What supports would be useful for you (tick all that apply)?
    - ○ Support to develop a Mental Health Advance Directive
    - ○ Support to understand how My Health Record works
    - ○ Support to upload a Mental Health Advance Directive to My Health Record
    - ○ None, I'm fine/don't want this support
    - ○ Other (please comment)

18. Would you like to make any further comments? [long answer response option]

Thank you for your participation! Your responses will help to better support people to communicate their preferences for mental health care in My Health Record.

For more information…

on My Health Record, call the My Health Record help line 1800 723 471 or visit https://www.digitalhealth.gov.au/initiatives-and-programs/my-health-record

on advance care planning in relation to mental health, see information related to your state/territory ACT NSW NT Qld SA Tas Vic WA

on how to upload an advance care plan to My Health Record, visit https://www.digitalhealth.gov.au/initiatives-and-programs/my-health-record/whats-inside/advance-care-planning

Questions for Carers

[following question 5 in demographics question on whether identify as person with lived/living experience or carer]

The following questions ask about your experience supporting someone close to you who has lived/living experience of mental health challenges. If you are supporting more than one person, please choose one person to have in mind when giving your responses. You are welcome to provide further information about your experiences supporting multiple people in the comments section.

My Health Record

My Health Record is a secure digital record of a person's healthcare information. This information might include details of a person's medical conditions and treatments, medicines they take, allergies, and test or scan results. The person, nominated representatives, and their healthcare providers can add information to the record and check the My Health Record whenever needed.

6. Does the person you support have a My Health Record?

   ○ Yes, but it's not really used
   ○ Yes, and it's used
   ○ No, they don't
   ○ I'm not sure

7. Did you know someone can nominate a trusted person (like a family member or friend) to have access to view or help manage their My Health Record?

   ○ Yes, I did know
   ○ Yes, I did know but I am *not* a nominated representative for the person I support at the moment
   ○ No, I didn't know

8. Did you know there is an option to control which health professionals can access information in My Health Record?

   ○ Yes, I did know
   ○ No, I didn't know

9. Tick the statements that you personally agree with about the benefits of using My Health Record for the person you support:

   ○ It allows us to keep their important health documents/history in one place
   ○ They/we can choose who gets to see what information on their record
   ○ They/we don't have to remember/use paper copies
   ○ If they need to see a health professional while travelling, the health professional will be able to access their health history/information
   ○ There's less need for them/us to tell their story again and again
   ○ It means less delays in accessing treatment because health professionals have ready access to their information/referrals
   ○ It's easier to share information between different health professionals supporting them
   ○ In an emergency, a healthcare team would have fast access to their critical healthcare information through the record

- ○ They/we have greater access to their own health information
- ○ Other (please comment)

10. Overall, what has been your experience with My Health Record in relation to the person you support?

    [Likert Scale] Very negative, negative, neutral, positive, very positive

    Please comment:

Advance care planning and mental health directives

Advance care planning is a voluntary process for people to communicate their preferences about their future health care. This includes **Mental Health Advance Directives** where people can document their preferences about future mental health treatment should they become unwell and unable to communicate or deemed to have reduced decision-making capacity. For example, people can document their values and preferences around treatment and recovery, including medication and nominating carers and what information is shared with them.

There are different rules in different states and territories about how to make an advance directive about general healthcare or mental health treatment, and the extent to which treating teams must follow this guidance.

11. Before this survey, did you know about the option for people to create a Mental Health Advance Directive?

    - ○ Yes
    - ○ No
    - ○ Not sure

12. How likely do you think the person you support would be to create a Mental Health Advance Directive?

    - ○ Not at all likely
    - ○ Not likely
    - ○ Neither likely/unlikely
    - ○ Likely
    - ○ Very likely
    - ○ I'm not sure
    - ○ They have already made a Mental Health Advance Directive

Uploading advance care planning documents to My Health Record

13. Did you know people can upload Advance Care Plans, including a Mental Health Advance Directive, to My Health Record? (This means treatment preferences can be safely and securely accessed by a treating team if needed.)

    - ○ No, I didn't know
    - ○ Yes, I did know

14. If the person you support made an advance directive about mental health treatment, how likely would they (or you on their behalf) be to upload it to My Health Record?

- ○ Not at all likely
- ○ Not likely
- ○ Neither likely/unlikely
- ○ Likely
- ○ Very likely
- ○ I'm not sure
- ○ They already have a Mental Health Advance Directive uploaded to My Health Record

15. Did you know people can update or remove an Advance Care Plan in My Health Record at any time?

- ○ No, I didn't know
- ○ Yes, I did know

16. Do you have any concerns about the person you support having a Mental Health Advance Directive in their My Health Record? (Tick all that apply)

- ○ I don't feel I understand enough about how Mental Health Advance Directives work
- ○ I'm worried about the security of their information online
- ○ I'm worried about people I/they don't want accessing their information
- ○ I'm not sure how to help them upload something to My Health Record
- ○ I don't trust that the Mental Health Advance Directive will be followed anyway, so there's not much value to having it
- ○ No or minimal concerns
- ○ This question is not relevant for me
- ○ Other (please comment)

17. What supports would be useful for you (tick all that apply)?

- ○ Support to develop a Mental Health Advance Directive with the person I support
- ○ Support to understand how My Health Record works
- ○ Support to upload a Mental Health Advance Directive to My Health Record for the person I support
- ○ None, I'm fine/don't want this support
- ○ Other (please comment)

18. Any further comments [long answer response option]

Thank you for your participation! Your responses will help to better support people to communicate their preferences for mental health care in My Health Record.

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