Australian Digital Health Technologies Needs Assessment and Gaps Analysis Report

September 2024

Created by

PEOPLE WITH DISABILITY AUSTRALIA

Acknowledgement of Country

People with Disability Australia (PWDA) acknowledge the Traditional Owners of Country throughout Australia, and their continuing connection to land, sea and community. We pay our respects to them, to their cultures, and to their Elders both past and present.

We thank all those Aboriginal and Torres Strait Islander people who have contributed to this project and who will continue to shape better outcomes for people with disability.

Acknowledgement of Research Participants and Co-Producers

PWDA acknowledges the lives and experiences of the people with disability represented in this report. We recognise the people with disability and their lived experiences that form the basis of this project.

PWDA thanks all the research participants and co-producers of this work who provided invaluable knowledge and insights into the ongoing barriers to access health care including digital health for people with disability in Australia.

States Parties, including Australia, recognise that persons with disability have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability – United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) Article 25. Australia is required to promote, protect, and ensure the human rights and fundamental freedoms for all Australians living with disability, by ensuring that the objects and principles of the UNCRPD underpin laws, standards and guidelines; essentially those that frame the Australian disability sector.

Contents

Contributors

Catherine Walsh

Project Manager, People with Disability Australia

Catherine, who is a queer person with lived experience of disability, resides on the lands of the Gadigal people. With a rich background in community development both internationally and locally, Catherine serves as the project manager for this initiative. Over the past five years, they have dedicated their career to the disability sector, driven by a passion for a rights-based approach to community development. Catherine holds a bachelor's degree in biotechnology from the University of Technology Sydney and is passionate about equitable health care. They also hold a master's degree in development studies from University of New South Wales and is a strong advocate for co-design and co-development as essential strategies for addressing and eliminating access challenges faced by people with disability.

Frances Quan Farrant

Consultant

Frances Quan Farrant has worked in the disability sector for two decades. She is a social scientist (B.A Macquarie University) and a graduate social worker (MSW QUT). Frances has an extensive background in advocacy, policy and disability rights including expertise on the UNCRPD and inclusive research methodologies.

Frances is a member of the Queensland University of Technology's Human Research Ethics Committee. They are currently completing a PhD at the University of Queensland researching the implementation of the CRPD in Australia and internationally. She is based on Kabi Kabi Country, north of Brisbane.

Heidi La Paglia Reid

Consultant

Heidi La Paglia Reid (she/her) is a proud autistic, queer, disabled consultant and advocate based on Muwinina Country, Lutriwita, Hobart, Tasmania. With over a decade of experience in disability and women's rights sectors, Heidi brings a wealth of professional and lived experience expertise to her work.

Heidi is an expert in human rights, gender equity, disability rights, and neuro-inclusion; and has actively contributed to multiple advisory groups focused on digital accessibility. Heidi also has a background in co-leading the development of digital resources tailored for women and girls with disability.

In her consultancy work, Heidi specialises in transforming organisations, political movements, and digital spaces to be inclusive and accessible to communities experiencing intersectional marginalisation. Her services encompass research, report writing, project management, facilitation, public speaking and neurodiversity training. Heidi works to ensure digital platforms and resources meet the highest standards of accessibility and align with human rights principles.

About PWDA

People with Disability Australia (PWDA) is the leading national cross-disability member driven organisation. We are a national peak disability rights and advocacy organisation, run by and for people with disability.

Founded in 1981, PWDA represents the interests of people with all kinds of disability. We're a not-for-profit, community-based organisation. Our membership is made up of people with disability and organisations constituted by people with disability.

Our vision is of a socially just, accessible and inclusive community, in which the human rights, belonging, contribution, potential and diversity of all people with disability are recognised, respected and celebrated with pride.

We work both nationally and internationally, and our work is grounded in a human rights framework that recognises the United Nations human rights conventions and related mechanisms as fundamental tools for advancing the rights of people with disability.

We deliver our programs, services and activities in partnership with our members and supporters as well as a variety of stakeholders across the government, disability, education and research sectors.

Disabled People's Organisations Australia

(DPO Australia)

PWDA is one of the four national peak bodies who form Disabled People's Organisations Australia (DPO Australia). Disabled People's Organisations (DPOs) are organisations that are led by and made up of people with disability.

The key purpose of DPO Australia is to promote, protect and advance the human rights and freedoms of people with disability in Australia by working collaboratively on areas of shared interests, purposes, strategic priorities and opportunities. The three other national peak bodies of DPO Australia are Women With Disabilities Australia (WWDA), First Peoples Disability Network Australia (FPDN) and National Ethnic Disability Alliance (NEDA).

Executive Summary

The basis of this report is underpinned by the fundamental rights that people with disability have under the UNCRPD. In particular Article 9 – Accessibility, UNCRPD which states that,

> “To enable persons with disability to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to **information and communications, including information and communications technologies and systems**, and to other facilities and services open or provided to the public, both in urban and in rural areas. These measures, which shall include the identification and elimination of obstacles and barriers to accessibility.”[1]

This report presents the findings of a comprehensive literature review and analysis of the challenges faced by people with disability in accessing digital health platforms. Conducted in May 2023, the literature review spans materials from 2018 to 2023, incorporating academic sources as well as grey literature such as media articles, government and industry publications. The analysis utilised the JBI framework.[2] The JBI framework is a systematic review approach used in qualitative evidence-based research. Four key themes emerged from the analysis which have been used to structure this report. These themes are:

- Accessibility
- Cybersecurity and Privacy
- Education and User Experience
- Geographic and Digital Equity.

Across these different themes, the report highlights the importance of aligning digital health initiatives with the principles of the UNCRPD.[1] To do this, the significant accessibility barriers faced by people with disability when using and accessing Digital Health Technologies need to be addressed.

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[1] United Nations (2024) ‘Convention on the Rights of Persons with Disabilities,’ United Nations website.

[2] Lockwood C, Porritt K, Munn Z, Rittenmeyer L, Salmond S, Bjerrum M, Loveday H, Carrier J, Stannard D. (2024) ‘Systematic reviews of qualitative evidence.’ In Aromataris E, Lockwood C, Porritt K, Pilla B, Jordan Z, editors. JBI Manual for Evidence Synthesis.

The key theme of cybersecurity and privacy concerns in relation to recent data breaches are linked to a fundamental lack of trust, not only with government, but the rise of digital reliance. Additionally, the report demonstrates there is a significant need to address digital literacy among people with disability, particularly for those living in rural and remote areas.

The report concludes with several recommendations aimed at enhancing digital health accessibility for people with disability, emphasising the need for ongoing consultation, co-design, improved cybersecurity measures, and targeted education and support for both users and health care providers.

Recommendation 1

The Australian Digital Health Agency (the Agency) commits to ongoing consultation and co-design of digital health platforms with people with disability under the National Digital Health Strategy 2023-28.

Recommendation 2

The Agency invests in increasing disability representation both internally and publicly to provide a visible liaison point for the disability community and ensure there is lived experience expertise within the Agency.

Recommendation 3

The Agency review the my health app, My Health Record and electronic prescriptions to include accessibility features for deaf, hard of hearing, vision impaired and blind consumers. This should include screen reader adaptability and text-to-speech.

Recommendation 4

The Agency upgrades my health app and My Health Record to have larger font, bolder icons and pictures to facilitate easier navigation.

Recommendation 5

The Agency commits to securing cybersecurity and confidentiality for all digital health platforms and communicates this clearly with people with disability.

Recommendation 6

The Agency should collaborate with medical and allied health professionals to enhance their understanding and usage of digital health platforms.

Recommendation 7

The Agency works with people with disability to co-design clear and accessible information and resources on how to use digital health platforms and services.

Recommendation 8

The Agency works with other federal agencies such as Services Australia, Medicare and the National Disability Insurance Agency (NDIA) to enhance access to digital health platforms and services for people living in regional, remote and rural areas.

Recommendation 9

The Agency works with the Digital Transformation Agency (DTA), software vendors and standards organisations to influence inclusion of accessibility into the design of digital health platforms and services.

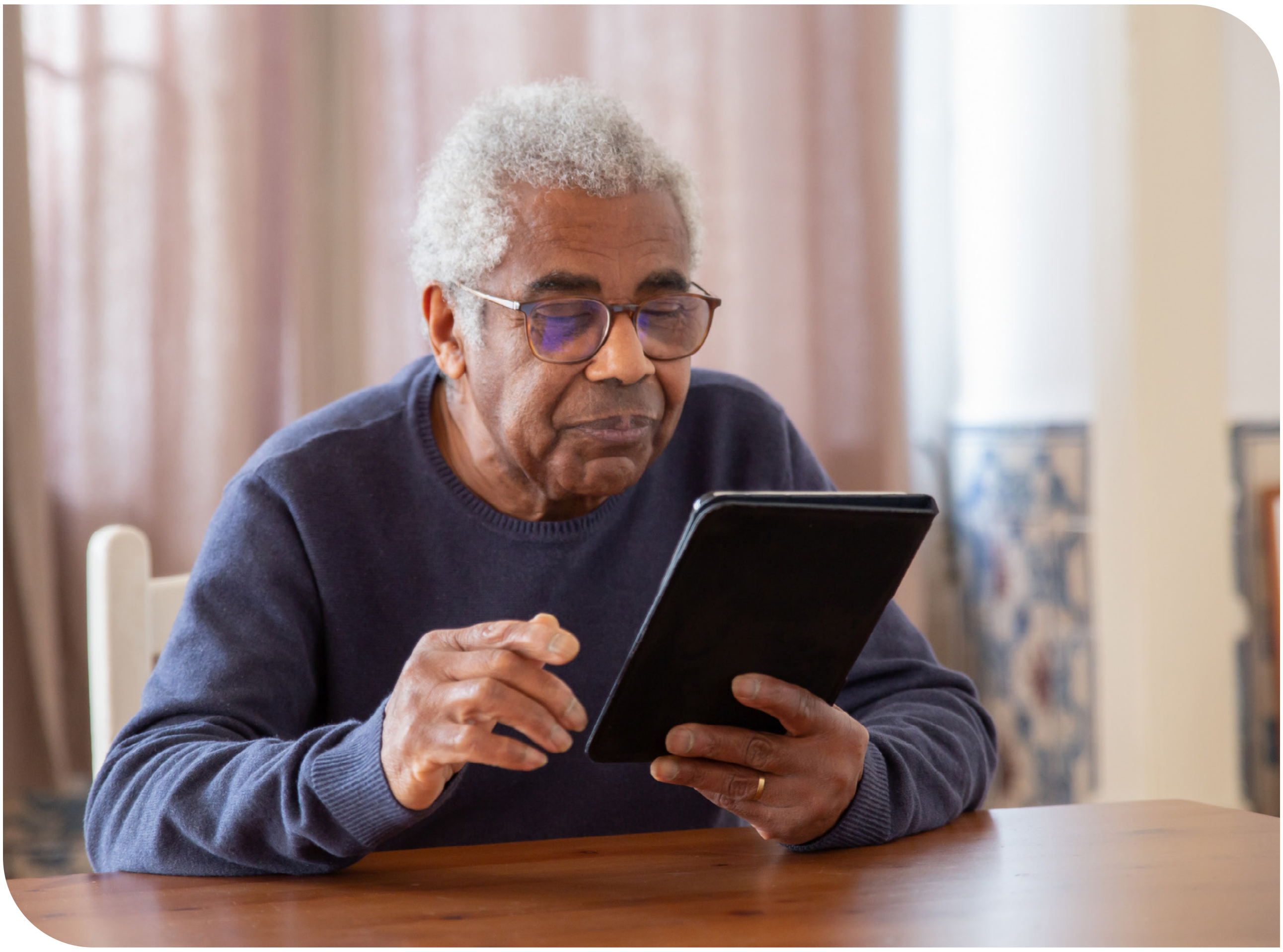
Recommendation 10

The Agency recognises not all people who wish to use digital health platforms have access to digital technologies or devices; and commits to working with local councils, libraries, community centres and neighbourhood houses to facilitate digital access for people on low or no incomes, including people with disability.

Project Overview

The “Enhancing Inclusion and Accessibility at the Australian Digital Health Agency (the Agency): An Initiative for Digital Health Engagement and Empowerment” project, running from May 2024 to February 2025, is a collaborative effort between the Agency and PWDA. This initiative aims to understand the barriers and enablers for people with disability in adopting the Agency’s digital health technologies and to engage the community through the development of accessible resources and events.

The project focuses on two main objectives. The first objective is to identify the challenges and enablers for people with disability using the Agency’s digital health tools. To achieve this, PWDA consulted with its members, who are people with a diverse range of disability and access needs. Consultation activities included a survey, focus groups and one-on-one interviews. The findings from these consultation activities have been compiled into this comprehensive Needs Assessment and Gaps Analysis report.



The second objective of the project is to engage PWDA members and the wider community by developing and promoting accessible resources. This includes creating additional Easy Read Documents to support people with intellectual disability in accessing digital health tools. Topics may cover areas such as advance care planning, telehealth, how technology can improve health, privacy and health information and the National Digital Health Strategy. Furthermore, accessible video content based on Easy Read resources will be developed to further aid those with intellectual disability.

This project is a first step towards making digital health services more inclusive and accessible, ensuring everyone can benefit from advancements in digital health technology. By understanding the barriers and enablers to adoption, and engaging the community through accessible resources, the initiative aims to enhance the overall digital health experience for people with disability.

Project Logic

Inputs

- Project team

Activities

- Project research
- Needs Assessment and Gap Analysis
- Resource development

Outputs

- Needs Assessment and Gap Analysis Report
- Easy Read resources
- Video resources
- Accessible webinars

Short and Midterm outcomes

- People with disability have access to accessible information on the Agency's digital health products and services.

Long term impact

- There is an increased use of the Agency's digital health products and services among people with disability.
- People with disability have increased knowledge and confidence in the Agency's digital health products and services.

Project Timeline

The project has been delivered across three sub-projects which have been broken down into phases. The project started in May 2024 and continued to February 2025.

Project 1

Comprehensive Needs Assessment and Gaps Analysis Report

Project 1 commenced in May 2024 and was completed in September 2024.

Project 1 was led by a project team with lived experience of disability and subject matter expertise and was informed by a desktop literature review as well as a survey, interviews and focus groups designed to capture the experiences and views of PWDA members.

→ Phase 1 - Planning and Research

→ Phase 2 - Active Outreach

→ Phase 3 - Comprehensive Needs Assessment and Gaps Analysis Report, Project Review and Closure.

Project 2

Accessible Resources

Project 2 commenced in July 2024 and continued to February 2025.

This project focused on developing accessible resources. Insights from the Needs Assessment and Gap Analysis will be used to develop a series of accessible resources to:

- Increase and inform understanding of the Agency's digital health technologies
- Increase the effective uptake in the use of the Agency's digital health technologies
- Develop accessible resources for people with disability. Formats included Easy Read, video format including webinar / information sessions, supported by Auslan and live transcription.

  → Phase 1 - Planning

  → Phase 2 - Development of Accessible Resources

  → Phase 3 - Project Review and Closure.

Project 3

Promotion and Education

The project commenced in August 2024 and continued to February 2025.

This project focused on increasing understanding and uptake of the Agency's digital health technologies among people with disability. To do this PWDA is:

- Promoting accessible resources and information developed by the Agency
- Promoting the Agency's digital health tools by delivering two accessible webinars that include Auslan and live transcription services.
  - → Phase 1 - Promotion
  - → Phase 2 - Education.

This report incorporates the Project 1 deliverables, including the **Comprehensive Needs Assessment and Gaps Analysis Report.**

Research

Research Constraints

The research is constrained by a number of assumptions. Those are:

- It was assumed the people consulted represent the target cohort – that is people with disability.
- It was assumed the experiences shared by interviewees, focus groups and survey respondents were truthful.

The research has also been limited by the number of respondents to the survey. The survey was shared with over 4000 people with disability, but completed by 117 people.

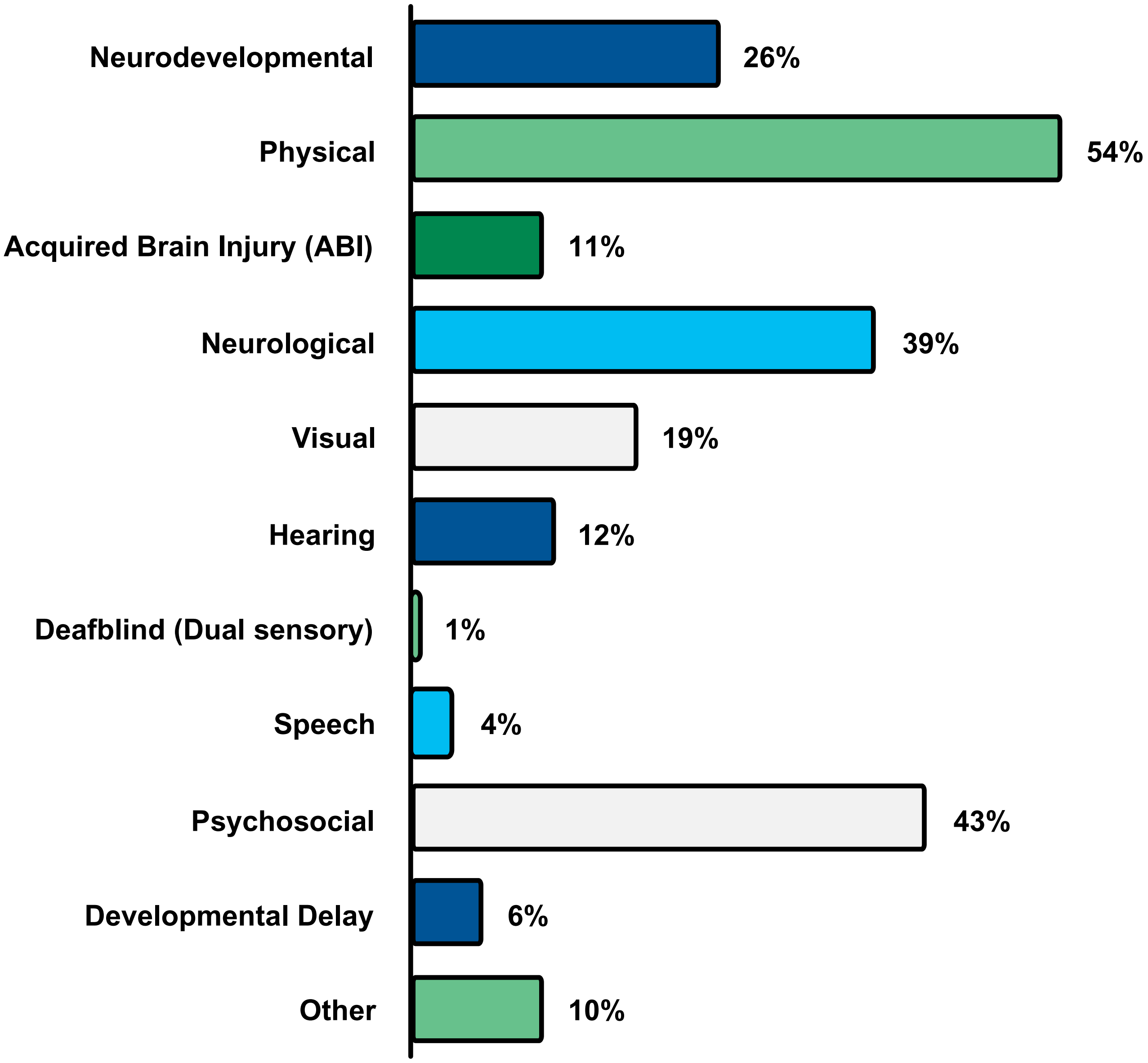
Another limitation is the diversity of disability experiences. While there is a wide range of different disability types represented, it is not possible to ensure the full diversity of people with disability have been captured.

Demographics

Survey demographics

Of the survey respondents, 99% identified as having a disability and a mix of disability types were represented. One person identified as not having a disability; they indicated they are a carer for their child who is a person with disability. Their data has been excluded from this report as it falls outside the scope of the research.

Figure 1: Graph showing respondents disability type by percentage.

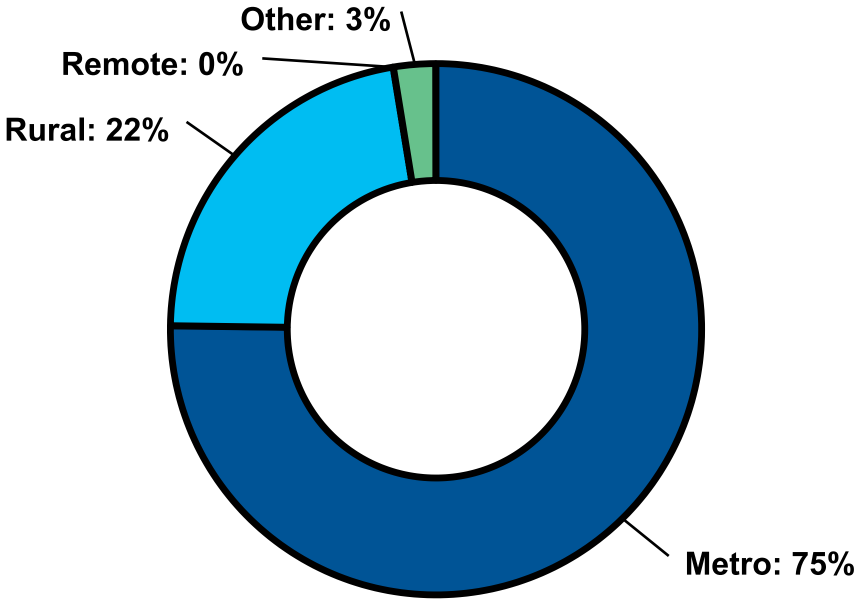


The largest age demographics from the survey were 35-44 years (22.8%) and 45-54 years (22%) followed by 55-64 years (21%). 6% of survey respondents identified as being Aboriginal and 0% identified as Torres Strait Islander. 63% of people identified as female and 24% as male. 8.4% identified as being non-binary along with 3.3% who said they 'use a different term' to identify their gender.

The majority (60%) of respondents did not have caring responsibility at the time of survey completion. Of those who did have caring responsibility, 18% were caring for their children, 19% caring for other family members, 3.5% caring for a friend, 4.3% and 3.5% reported 'prefer not to say' and 'other' respectively.

At the time of survey completion,19.6% of respondents reported they were retired, 18.8% of respondents were in full-time employment, followed by 18% of people reporting being unemployed. 11% of people were in part time employment, 12.8% were seeking employment and 12.8% were students. 9.4% reported being casually employed, 7.7% were unpaid carers, 5.1% were self-employed. 5% of people reported ‘prefer not to say’ and 1.7% reported ‘other’.

Figure 2: Circle chart showing distribution of respondents in metropolitan, rural and remote areas.



From the survey, 75% of responses came from people who live in a metropolitan area, 22% of responses came from people who live in rural areas and 3% of respondents indicated they were ‘homeless’; which has been listed as ‘Other’ in the pie chart. 0% of people came from a remote area.

The survey respondents also came from a cross section of states and territories with 39% of people indicating they reside in NSW, 18.2% in VIC, 18.8% in QLD, 9% in WA, 7% in SA, 6.3% in ACT and 0.7% in TAS.

Consultation area demographics

From the consultation sessions, 92% of responses came from people who live in a metropolitan area, 8% of responses came from people who live in rural areas and 0% of people came from a remote area.

Survey Results: People with Disability Accessing Digital Health Services

The survey was open from 15 July 2024 until 28 July 2024, during which a total of 117 responses were collected. The survey was open to people with disability and aimed to gather information about their experiences with the Agency's digital health services.

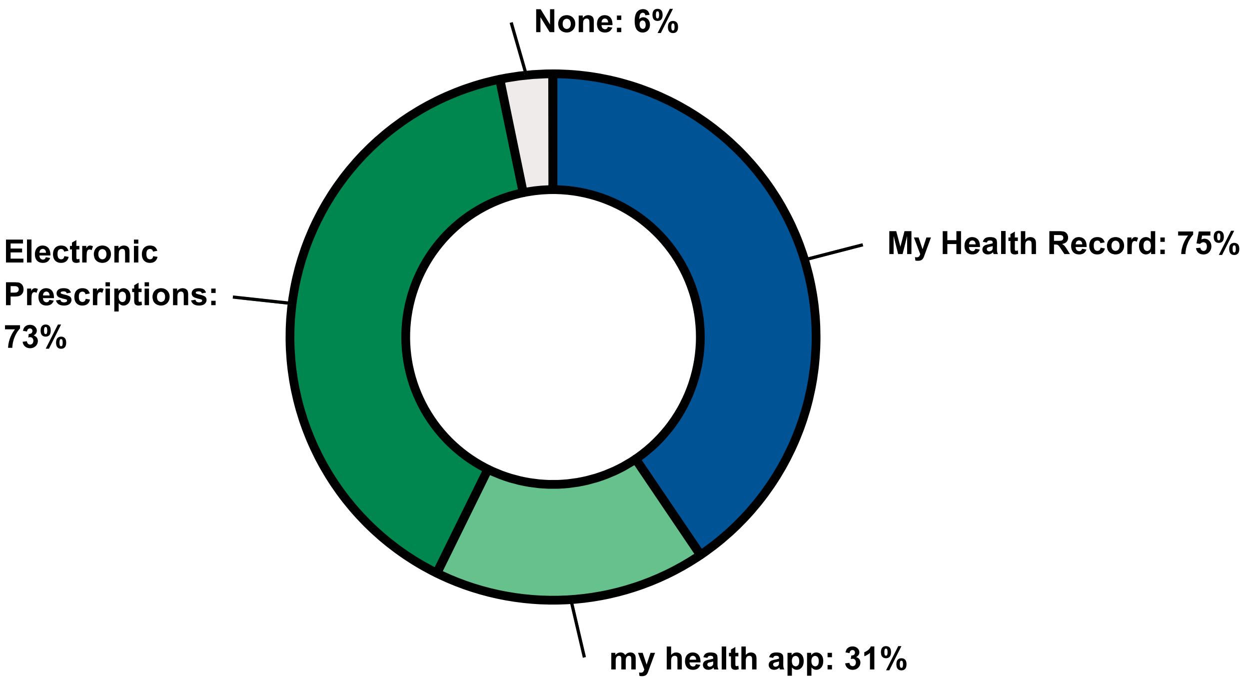
The survey was broken into two sections.

1. 'About You'
2. 'Australian Digital Health Agency Focused Questions'.

Section 1

The survey found there were reasonably high levels of awareness of the My Health Record (75%) and electronic prescriptions (73%) among respondents. However, there was significantly less awareness of the my health app (31%). 6% of respondents had no awareness of any of the Agency's digital services.

Figure 3: Graph showing survey respondents' awareness of the Agency's digital services.

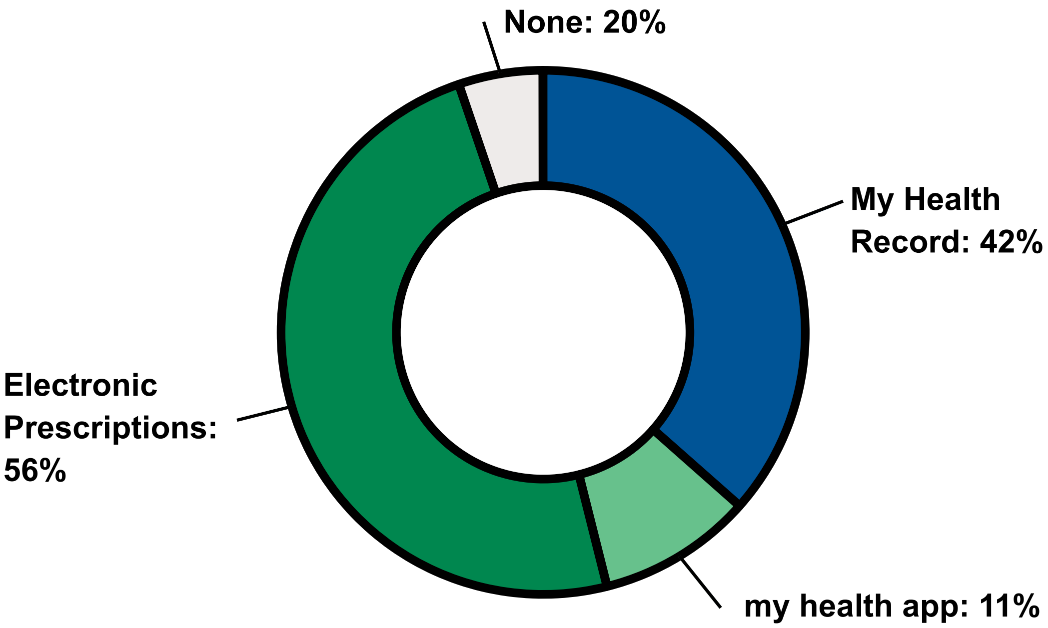


The data has also been arranged to view disability type and the levels of awareness of the three Agency digital health services.

Disability listed by respondent	My Health Record	my health app	Electronic prescriptions	None
Neurodevelopmental (30 people)	90%	33%	87%	7%
Physical Disability (63 people)	77%	29%	75%	5%
Acquired Brain Injury (ABI) (13 people)	54%	23%	69%	15%
Neurological Disability (45 people)	78%	22%	78%	2%
Vision Impairment (22 people)	55%	32%	59%	5%
Hearing Impairment (14 people)	86%	29%	71%	0%
Deafblind (Dual sensory) (1 person)	0%	0%	0%	0%
Speech Language Impairment (4 people)	50%	0%	50%	50%
Psychosocial Disability (50 people)	76%	24%	72%	4%
Development Delay (7 people)	86%	43%	57%	0%
Other (13 people)	85%	31%	70%	8%

The survey measured usage levels of the Agency's digital services. The highest usage was observed for electronic prescriptions at 56%. Additionally, 42% of respondents indicated they utilise My Health Record. 11% of respondents said they use my health app. 20% of respondents reported not using any digital health services.

Figure 4: Bar graph showing survey respondents' usage of the Agency digital health services.

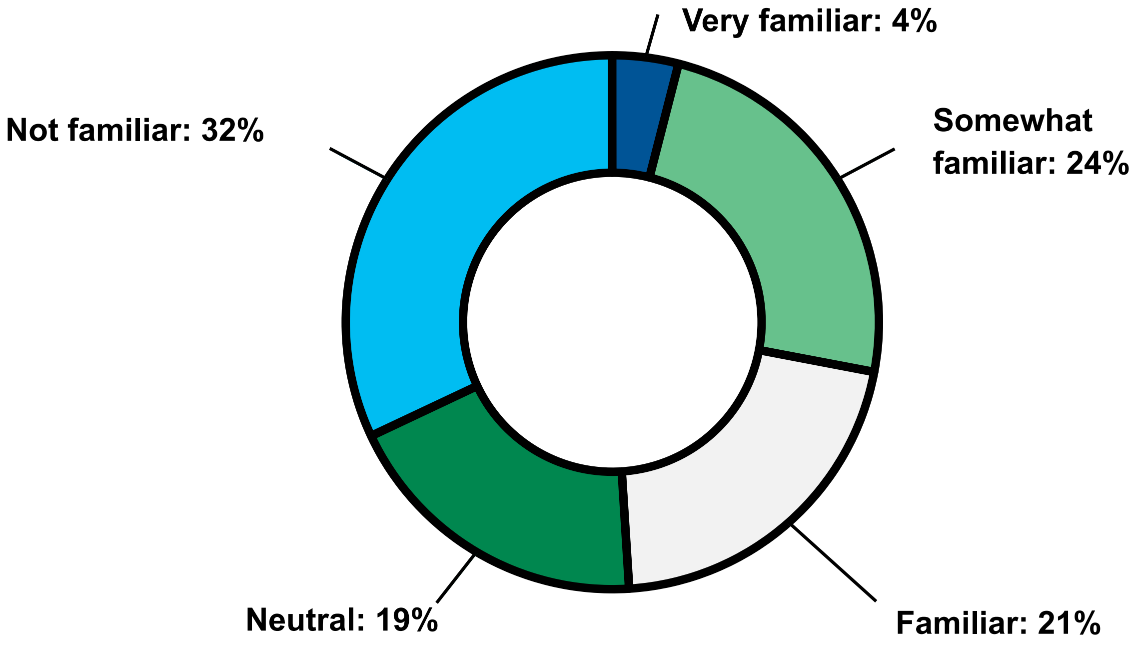


The data has also been arranged to view by disability type and the levels of usage of the three Agency digital health services.

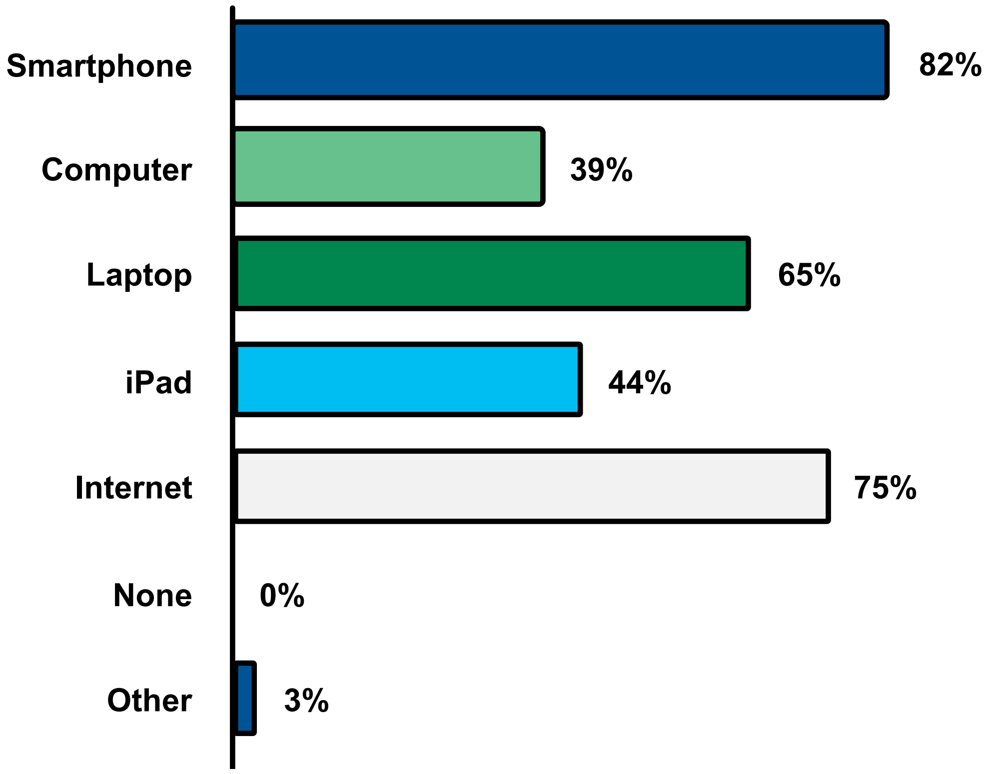
Disability listed by respondent	My Health Record	my health app	Electronic prescriptions	None
Neurodevelopmental (30 people)	40%	13%	77%	17%
Physical Disability (63 people)	37%	5%	58%	19%
Acquired Brain Injury (ABI) (13 people)	31%	15%	54%	23%
Neurological Disability (45 people)	33%	7%	51%	22%

Disability listed by respondent	My Health Record	my health app	Electronic prescriptions	None
Vision Impairment (22 people)	18%	9%	41%	36%
Hearing Impairment (14 people)	43%	0%	50%	21%
Deafblind (Dual sensory) (1 person)	0%	0%	0%	0%
Speech Language Impairment (4 people)	25%	0%	0%	75%
Psychosocial Disability (50 people)	32%	10%	60%	20%
Development Delay (7 people)	71%	29%	29%	0%
Other (13 people)	46%	8%	62%	23%

On familiarity with the Agency's services the responses were as follows.



On access to technology, respondents were asked; Do you have access to any of the following technology: smartphone, computer, or internet connection? Responses were as follows.



When asked what types of technology are used to access the various digital health services provided by the Agency, the most common response was smartphones at 62%, followed by laptops at 21% and internet connections at 18%. It is worth noting many respondents likely use an internet connection in conjunction with a device to access the services.

14% of respondents also reported using a computer, 10% reported using an iPad and 15% indicated they do not use any technology to access the products. Please note all survey respondents were asked this question regardless of how they answered the question of service usage.

In the survey, respondents were also asked about their frequency of use across the three Agency digital health services. Interestingly, most respondents said that while they were aware of the Agency's digital health services, they never use any of them. The next largest percentage indicated they used them a 'couple times a year.'

Table 1: Table showing how frequently survey respondents used the Agency's digital health services.

Frequency	My Health Record	my health app	Electronic prescriptions
Couple times a year	33%	19%	23%
Once a month	11%	6%	28%
Once a fortnight	3%	3%	12%
Once a week	4%	5%	5%
Never	49%	68%	32%

When asked about the ease of use across the three Agency digital health services, the most common answer was 'Neutral.'

Table 2: Table showing how easy survey respondents found the Agency's digital health services to use.

Sense of ease	My Health Record	my health app	Electronic prescriptions
Very easy	3%	5%	19%
Somewhat easy	12%	10%	8%
Easy	13%	9%	27%
Neutral	46%	52%	28%
Not easy at all	26%	25%	19%

Section 2

The second section of the survey focused on trying to understand the barriers people with disability face when accessing the Agency's digital health services.

> **59% of respondents reported they had experienced barriers that stopped them from using the Agency's digital health services. The most common barriers reported included:**

- Accessibility and design limitations
- Data safety concerns
- Privacy and confidentiality
- Lack of training
- Lack of knowledge
- Impact on quality of health care
- Attitudes and abilities of health care providers
- Access to technology
- Attitudes to digital health.

> **21% of respondents reported cost and affordability were barriers that stopped them from pursuing the Agency's digital health services. The main barriers associated with cost and affordability reported were:**

- Cost of devices
- Cost of internet
- Cost of transferring medical records
- Cost of health care services.

> **When asked how concerned people are about their privacy and security when using the Agency's digital health services:**
>
> **36% of respondents said they are 'very concerned'**
>
> **22% said 'concerned'**
>
> **11% said they are 'somewhat concerned'**
>
> **17% said 'neutral'**
>
> **13% said they are 'not concerned at all'.**

When asked what accessibility features would make the my health app more appealing to use, the main responses were:

- Simpler design
- Customisable font size and type
- Voice over and screen reader capabilities
- Text-to-speech function
- Ability to use Dragon voice software
- Compliance with WCAG 2.2 Level AA standards
- Easy Read information
- Ability to get definition of words that are unknown to a user in the my health app
- Larger photo sizes
- Integration with other health services including state government health services and General Practitioners (GPs)
- Two-factor authentication
- Greater privacy protection of personal data
- Access to electronic prescriptions in the my health app
- Showing health care appointments and details of your health care providers in one place
- More training on how to use the my health app and in person support
- Greater and clearer control of who has access to your My Health Record
- Improved usage of My Health Record by health care providers.

42% of respondents noted it is ‘very important’ they have customisation options in the my health app and online experiences.

27% said it was ‘important’

3% said ‘somewhat important’

20% said ‘neutral’

9% said it was ‘not important’.

When asked what customisation option people would like to use, the main responses were:

- Ability to adjust font size and type (26%)
- Different colour modes (9%)
- Greater screen reader capabilities including voice to text (9%)
- More options for different languages and Easy Read information (1%)
- More simple design (1%)
- Voice eye control (1%).

Semi-structured Interviews: Barriers to accessing Australian Digital Health Services

10 semi-structured interviews were conducted by two different project managers from PWDA who are both people with disability. The purpose of the interviews was to gain an in-depth understanding of people with disability's experiences with the Agency's digital health services and what barriers, if any, they have experienced in accessing them. The interviews provided valuable insight that has formed much of the analysis in this Needs Assessment and Gaps Analysis report. The interviews focused on how familiar people are with the Agency's digital health services and their current level of usage. The main themes the interviews discussed are outlined below.

Distribution of information

Interviewees shared they would prefer to receive health information by both email and text. They explained that email is good for receiving information and texts are good for reminders but are hard to keep track of. Many interviewees shared they would feel more comfortable receiving emails through the MyGov portal, as opposed to via their personal email, as this feels more secure.

Interviewees said they would also like to see greater information from the health care system itself. Many interviewees explained they would feel more comfortable using digital health services if they were encouraged and supported to use them by health care services they are already using.

Interviewees also said there isn't enough information and promotion of the digital health services in the community.

The COVID-19 pandemic

Interviewees shared their interactions with the Agency's digital health services were mostly during the COVID-19 pandemic, and some thought the services were solely for use during the height of the pandemic.

Systemic mistrust

A consistent factor across all the interviews was varying levels of systemic mistrust in the government and health care system. This mistrust was noted as a major barrier for people feeling confident to use the Agency's digital health services.

Format of information

Multiple interviewees who are hearing impaired shared that they would like integration of Auslan language into the my health app and other digital health services. Interviewees also shared the apps and services are complicated, not easy to navigate, and they would like greater customisation in formatting font, text and colour contrast.

Language

Many interviewees mentioned they found the language in the apps and services to be inaccessible. Multiple interviewees said they would like to see more illustrations and Easy Read information available. Interviewees said this should include Auslan as a language option.

Education equity

Some interviewees mentioned that not all people with disability have equitable access to education and said a diversity of methods need to be used for information dissemination. Some individuals said they rely on parents or friends to explain health information to them. However, it should be noted not all people with disability will have informal supports to assist them to keep up to date.

Security and digital safety

A major point of discussion in each interview was around security and digital safety. Interviewees indicated people with disability have great concerns about the risk of their private health records being leaked or shared with the wrong people. They also raised that unauthorised sharing of their information could have wider implications on other areas of their lives, which is a barrier people without disability may not face. Due to these concerns, interviewees said people with disability are very hesitant to use digital health services.

Disability representation

Many of the interviewees mentioned they would like to see a greater representation of people with disability in the development and promotion of digital health services. Interviewees said this representation would help to combat mistrust and make people aware, confident and comfortable in using digital health services.

Attitudes and practices of health care providers

Another main point of discussion in almost all the interviews was around attitudes and awareness among health care providers. Many people found health care professionals they interact with either don't know about My Health Record or don't want to use it. Interviewees said this makes the digital health service difficult to use in a meaningful way and places the burden of work on the person with disability. People also expressed they don't feel like it is their decision if they can use electronic prescriptions or not - as it is dependent on how clinicians dispense their prescriptions.

Integration with health services

Many interviewees shared that they have found it difficult to navigate the health care system, both public and private. They also said the Agency's digital health services don't translate well across the different sections of the health care system.

Focus Group Barriers to accessing Australian Digital Health Services

Two focus groups were conducted to gain additional information about people with disability's experiences with the Agency's digital health services. The focus groups included a total of 12 people with a diverse range of disability types and were facilitated by a PWDA project manager who is a person with disability. In the focus groups, participants were asked to discuss their experiences with the three different Agency digital health services and to identify any barriers they had faced in accessing and using them.

Focus group participants noted that most of them had used electronic prescriptions and overall found them to be useful. One participant who was homeless spoke about how electronic prescriptions have allowed them to still maintain access to good health care through their GP, without having a physical address.

> “(electronic prescriptons) have been a lifeline, even in rural areas, a doctor provided consistent digital health support across Australia, despite old technology.”
> - focus group participant.

Most individuals however, also noted they have encountered challenges, which included glitches that prevented them from accessing their prescriptions and in turn, their medications.

Like the interviewees, some people in the focus groups noted they felt their clinician decided whether to use electronic prescriptions rather than asking the consumer, and more broadly said many doctors don’t seem to use or want to use digital health services like electronic prescriptions or My Health Record.

For many individuals, these attitudes prevented their personal use of digital health services, noting they didn’t see the point of trying to use them if their doctor wouldn’t.

Another reason people said they don’t use the Agency’s digital health services is because the services don’t integrate well with other health services. People said this is a problem across both public and private services.

A main point of discussion in both focus groups was around people’s concerns about the security and safety of digital health. Almost everyone expressed concern about their data and the potential impacts on their privacy and health care. Focus group participants explained these concerns have caused people with disability a lot of distress and uncertainty. They all mentioned they would like more information on the security and data storage and would like to see privacy and security protections strengthened more.

Literature Review

A literature review (reference Appendix 1) was undertaken in May 2023, considering materials spanning from 2018 to 2023. 19 materials were examined in the literature review including academic journals and articles as well as materials such as media articles, government and industry publications.

Overview

The literature on digital health accessibility for people with disability has grown significantly over the past few years, reflecting broader trends in both health care and technology. Through a synthesis of literature published between 2018 and 2023, the review highlighted key issues for people with disability in accessing digital health services, such as a lack of accessibility features. Other key issues that emerged included concerns around cybersecurity, a lack of digital literacy and inequities across geographic locations.

Accessibility

One of the predominant themes in the literature is the inaccessibility of digital health platforms and services. Numerous studies highlight the struggles people with disability face in navigating e-health tools, particularly those related to visual and cognitive impairments. For instance, studies by Yoojung et al.[3] and Mason et al.[4] underscore that many digital health apps and websites are not fully compliant with Web Content Accessibility Guidelines (WCAG), making them difficult to use for individuals who use assistive technologies such as screen readers and/or who have disability. The literature suggests that while there has been some progress, significant work remains to make digital health truly accessible.

Cybersecurity and Privacy

Another critical area of concern identified in the literature was around cybersecurity and privacy, especially in the context of digital health platforms. Several sources, including the World Health Organisation[5] have outlined specific vulnerabilities people with disability face concerning data breaches and the mishandling of sensitive health information. The literature[6] indicate as digital health platforms expand, so too does the risk of cyber threats, making it essential to strengthen security measures, in particular for at risk populations, such as people with disability.

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[3] Yoojung Kim, Bongshin Lee, Eun Kyoung Choe, Investigating data accessibility of personal health apps, Journal of the American Medical Informatics Association, Volume 26, Issue 5, May 2019, Pages 412–419.

[4] Mason, A. M., Compton, J., & Bhati, S. (2021). Disabilities and the Digital Divide: Assessing Web Accessibility, Readability, and Mobility of Popular Health Websites. Journal of Health Communication, 26(10), 667–674.

[5] World Health Organization (2023), WHO Data Policy.

[6] Gerybaite, A. (2023). Exploring Regulatory Interplay in the Health Internet of Everything: Digital Health Technologies, Data Protection and Cybersecurity. European Journal of Health Law, 30(5), 533-549.

Education and User Experience

Education and user experience are also prominently discussed in the literature, with many authors emphasising the need for improved digital literacy among users with disability. According to a study by Tinmanz and Lee et al.7 digital literacy is a significant barrier that exacerbates existing inequalities in access to health care. The literature suggests without adequate training and support on digital literacy, many users are unable to effectively engage with digital health tools, thereby limiting the potential benefits of these technologies.

Geographic and Digital Equity

Geographic and digital equity is a recurring theme in the literature, particularly regarding access to digital health services in rural and remote areas. Research by Patel & Morris[8]. for example, has highlighted the disparities in digital health access between urban and rural populations. The literature reveals that people with disability in remote areas face compounded challenges, not only due to a lack of physical health care infrastructure but also because of limited internet connectivity and digital resources.

Alignment with UNCRPD Principles

The literature consistently points to the importance of aligning digital health initiatives with the principles of the UNCRPD. Studies by various authors emphasise that digital health platforms must be designed and implemented in ways that uphold the rights of people with disability, ensuring they have equal access to health services.

Gaps and Future Directions

While the literature offers valuable insights, it also reveals several gaps in information. For instance, there is limited research on the experiences of people with disability who face intersectional marginalisation based on factors such as race, gender and age. Additionally, the literature calls for more empirical studies that evaluate the effectiveness of specific interventions aimed at improving digital health accessibility.

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[7] Tinmaz, H., Lee, YT., Fanea-Ivanovici, M. et al. A systematic review on digital literacy. Smart Learn. Environ. 9, 21 (2022).

[8] Patel S, Akhtar A, Malins S, Wright N, Rowley E, Young E, Sampson S, Morriss R. The Acceptability and Usability of Digital Health Interventions for Adults With Depression, Anxiety, and Somatoform Disorders: Qualitative Systematic Review and Meta-Synthesis. J Med Internet Res. 2020 Jul 6;22(7):e16228. doi: 10.2196/16228. PMID: 32628116; PMCID: PMC7381032.

In comparing the literature review with the PWDA consultations, it is evident the themes align across the evidence, both highlighting issues related to accessibility, cybersecurity and digital literacy.

The literature review, in comparison to the consultations, however, severely lacks a lived experience perspective. Going forward, PWDA emphasises ongoing consultation and co-design with people with disability is essential for developing effective solutions to digital health access barriers. Additionally, the analysis underscores the urgency of addressing geographical disparities, an area while covered in the literature, could benefit from more targeted research and policy intervention.

Overall, the literature review and PWDA consultations are reflective of each other, with the former providing the academic and theoretical groundwork and the latter translating this and the overall research into actionable insights and recommendations for enhancing digital health accessibility for people with disability.

Analysis and themes

Introduction

The analysis for the interview, focus group and survey research data was undertaken using the JBI framework for systematic reviews of qualitative evidence[9]. The JBI framework supports an iterative approach to qualitative data, acknowledging that rich evidence can be extracted from narratives and stories including from semi-structured interviews and focus groups; as utilised within this research. JBI is especially utilised in research on health care and has a specific focus on feasibility, appropriateness, meaningfulness and effectiveness.

To this end, the analysis for this research extracted four key thematic areas:

- Accessibility
- Cybersecurity and Privacy
- Education and the User Experience
- Geographic and Digital Equity.

Additionally, as the research was about the experiences of people with disability and digital health, the principals of the UNCRPD were centred in this analysis.

> "Persons with disability include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (UNCRPD, Article 1)[9]

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[9] United Nations (2024) 'Convention on the Rights of Persons with Disabilities,' United Nations website.

Theme 1: Accessibility

Accessibility was the major theme across all the research with people with disability and their knowledge of and interface with digital health services.

Interview and focus group participants repeatedly recounted difficulties with access, especially with electronic prescriptions. This included technical issues such as having difficulty with text and font size, capture of QR codes and glitching across devices. These experiences were most common among users with older phones and devices. Participants noted if the platforms were more accessible then they would be more appealing to use.

> “I experience difficulty with the font size in the my health app and My Health Record, finding it too small for comfortable viewing”. – interview participant.

Participants also noted electronic prescriptions, and digital health apps more broadly, need to be made simpler to navigate and easier for people with disability to use. To do this, participants said the Agency’s staff needed to be educated on accessibility.

> “Deaf community advocates for greater effort from the Agency to engage and educate on accessibility” – interview participant.

Participants also noted the language used on digital health services and platforms need to be more inclusive, not just with options for Auslan but for other languages more generally and to be more culturally aware of First Nations users with disability.

> “Need to have different languages, acknowledge people with disability, First Nations” – interview participant.

Accessibility issues also included disparity in understanding or knowledge of digital health services by hospitals, health care practitioners and GPs. As a result of vital information not being uploaded and inconsistencies in practitioners using digital health services, a number of participants noted they had difficulty accessing treatment across health systems and hospitals.

> “It’s so hard to have consistent health care when every doctor or specialist uses a different system and don’t want to communicate” – focus group participant.

Others noted many professionals simply were not utilising digital health platforms at all (this is explored further in theme 3). It was noted there was an overall lack of integration of digital health across systems, states and territories.

Participants strongly noted to facilitate better accessibility for all digital health options including My Health Record, electronic prescriptions etc., the Agency needs to consciously work with "*Inclusive design, consultation and collaboration*"[10], especially with people with disability.

This confirms the previously identified issue of access and digital platforms in the literature review, that digital health care formats and touchscreen technology pose a significant access issue for blind and vision impaired people. Ensuring all available accessibility features are included and tested in digital technologies is paramount in access experiences of people with disability but especially blind and vision impaired people.[11]

Theme 2: Cybersecurity and Privacy

Privacy and cybersecurity were the second largest concern for participants after accessibility. Recent data breaches including breaches of private health insurers[12], electronic prescription platforms[13], and the NDIS,[14] led many participants to have serious concerns about using digital health platforms.

> "A Deaf person seeks control over health information, resisting Agency's potential "big brother" role" – Deaf interview participant (translated from Auslan).

Most participants were acutely aware of the need for data security regarding their health status. Participants expressed genuine concerns about their own experiences of having their data breached or leaked.

> "Radiology had a leak and Medicare leaked my information" – interview participant.
>
> "I don't trust the government with my data" – interview participant.

Others noted the very real risk of data breaches could have dire outcomes for people with disability as a systemically vulnerable population. People with disability often have

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[10] Interview participant

[11] Vision Australia (2019) 'The Trouble with Touchscreens,' Vision Australia.

[12] Robertson, J (2024) 'How Medibank allegedly ignored the warning signs in one of Australia's worst cybersecurity breaches,' ABC News Online.

[13] Department of Home Affairs (2023) 'Medisecure Cyber Security Incident,' Australian Government.

[14] National Disability Insurance Agency (2023) 'NDIA Detects Data Breach.'

very little agency over their lives, especially people living in congregate settings. As the Disability Royal Commission (DRC) identified, “many people with disability living in institutions were denied basic human rights and had little or no access to the wider community”[15]. A data breach and identity theft could have catastrophic consequences for people with disability in these situations.

> “I have a frustration with lack of privacy and confidentiality in digital health products and services”. – interview participant.
>
> “I think it would have to be in a secure system, and obviously people would have to learn how to do that”. – interview participant.

This is an ongoing concern for people with disability and a risk for the Agency. As noted in the literature review, the Agency had already flagged as far back as 2016 that cybersecurity was an issue regarding risks of hacking and data breaches.

Theme 3: Education and the User Experience

Several participants noted health care providers did not know how to use digital health platforms including My Health Record. Some noted they had to show their providers how to access their information. This lack of awareness among health professionals places an undue burden upon people with disability, who are already having to constantly repeat their medical history whilst managing their health.

> “I have frustration with medical providers’ slow adoption of My Health Record and wasted time during appointments”. – interview participant.

Other participants who had used electronic prescriptions noted they needed assistance and guidance. Participants, while finding electronic prescriptions useful, expressed a level of frustration about lack of support with using electronic prescriptions.

> “Electronic prescriptions…you just click on the link and that’s just take it to your pharmacist. But unless you actually haven’t had somebody explain that to you, you probably wouldn’t know what to do.” – interview participant.

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[15] Disability Royal Commission (2019) ‘Group Homes – Issues Paper,’ p. 3.

> "I thought it would be useful at the time, but just because I needed extra training and guidance on how to best use it, there wasn't any resources available"
> – interview participant.
>
> "[electronic prescriptions] Little awareness of it, in terms of usability".
> – interview participant.

Furthermore, several participants had heard of the my health app but had no further information about how to use it, and others had not heard of it at all; likely reflecting the fact that people rely on others for information and service developments. Many people with disability often rely on other people in their life to support them with daily activities which could include accessing and using inaccessible IT. Some focus group members noted they wished they could navigate and access My Health Record and the my health app without support, as they don't always feel comfortable sharing their personal information with support workers or family members.

> "No one has really told me about My Health Record." – interview participant.

In terms of the user experience, many participants felt that in addition to not being accessible, digital health services are not particularly user friendly overall. Participants felt better use of intuitive design would help with user experiences, such as including pictures and icons. Some participants also said the 'app' was limited because it only accepted a mobile number and not an email address. During the consultation, there was a mixed understanding regarding the role and functions of the my health app, with many individuals either unclear about its purpose or having misconceptions about its features. This highlights a significant need for more accessible information and education for individuals with disability regarding the services offered by the Agency and how to effectively utilise them.

> "Have different versions of the app so people with different disabilities can use the app" – focus group participant.

As identified in the literature review, only genuinely co-designed applications will provide meaningful access to health information for people with disability, thus confirming to improve both access and uptake of electronic prescriptions, My Health Record, and other digital health platforms, the Agency must engage directly with people with disability in a co-design manner.

Theme 4: Geographic and Digital Equity

22% of respondents to the initial survey came from rural, regional and remote communities, and 3% indicated they were homeless or had no fixed address. Interview participants from regional and rural areas highlighted the vital importance of telehealth as a key form of health care[16].

> "Telehealth has been a saving grace for booking appointments"
> – focus group participant.

While participants noted telehealth access increased during and since the COVID-19 pandemic, there is still a need to ensure providers of digital health care are competent to use digital health services.[17]

> "Remove the burden of responsibility on the consumer outside the metropolitan area" – interview participant.

Whilst there have been multiple studies on the benefits of telehealth and digital platforms for people – including people with disability – living in regional, remote and rural areas, the results of this research indicate that while consumers want the digital access, it is not necessarily available nor consistent in terms of service or user experience.

Additionally, participants noted digital access is not necessarily universal or equitable, especially for people with disability. People with disability experience far higher levels of socio-economic deprivation,[18, 19, 21] which has a direct impact on health and can preclude people with disability from accessing tools such as digital devices, which would otherwise facilitate pathways to digital health platforms.

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[16] Caffery LA, Muurlink OT, Taylor-Robinson AW (2022) 'Survival of rural telehealth services post-pandemic in Australia: A call to retain the gains in the 'new normal'.' Aust J Rural Health,.Vol. 30, no. 4, pp.:544 - 549. doi: 10.1111/ajr.12877.

[17] Ashley C, Williams A, Dennis S, McInnes S, Zwar NA, Morgan M, Halcomb E. (2023) 'Telehealth's future in Australian primary health care: a qualitative study exploring lessons learnt from the COVID-19 pandemic.' BJGP Open, Vol. 27, no. 2.

[18] People with Disability Australia (2023) 'Position Statement: Extent and nature of poverty in Australia.'

[19] Australian Insitute of Health and Welfare. (2024, July 2). Health of people with disability. Retrieved from Australian Insitute of Health and Welfare.

Conclusion

The research highlights critical gaps in the accessibility, security, and usability of digital health services for people with disability. Despite advancements in technology, the findings underscore the need for a more inclusive and user-centred approach in the design and implementation of digital health tools. Addressing these challenges requires a coordinated effort from the Agency, and across health care more broadly, to ensure digital health platforms are not only accessible and secure but also tailored to meet the diverse needs of people with disability. The recommendations provided in this report offer a roadmap for improving digital health equity, ultimately contributing to better health outcomes for people with disability.

Recommendations

Based on the findings of the research, and in looking ahead to the second and third sections of this project, the project team has made the following recommendations.

Recommendation 1

The Australian Digital Health Agency (the Agency) commits to ongoing consultation and co-design of digital health platforms with people with disability under the National Digital Health Strategy 2023-28.

This approach is crucial because it ensures these platforms are accessible and usable for everyone, empowering individuals with disability to manage their health more effectively. By engaging people with disability in the design process, the Agency can gain unique insights and perspectives that highlight potential barriers and usability issues which might not be apparent to others.

Ongoing consultation allows for continuous feedback and improvement of digital health platforms, ensuring they remain relevant and effective as technology and user needs evolve. This regular engagement also fosters trust and collaboration between the Agency and the disability community. A co-design approach involves working directly with people with disability throughout the entire development process, from initial concept to final implementation. This collaborative method ensures the end product truly meets the needs of its users, prioritising their needs and preferences to create digital health platforms that are not only accessible but also intuitive and easy to use.

Moreover, solutions designed with accessibility in mind often benefit a wider audience, including older adults, people with temporary impairments and those with varying levels of digital literacy. Platforms that are easy to navigate and understand improve the overall user experience for everyone, leading to higher adoption rates and better health outcomes. By committing to inclusive design practices, the Agency demonstrates its dedication to social responsibility and its commitment to serving all members of the community.

Recommendation 2

The Agency invests in increasing disability representation both internally and publicly to provide a visible liaison point for the disability community and ensure there is lived experience expertise within the Agency.

This investment is crucial for ensuring the voices and needs of people with disability are consistently heard and addressed in the development and implementation of digital health tools. It is also a key action that will build trust between the Agency and the disability community.

Having dedicated representatives who are people with disability within the Agency can facilitate more effective communication and collaboration with the disability community. These representatives can provide valuable insights and feedback on the accessibility and usability of digital health services, ensuring they meet the diverse needs of all users. They can also advocate for the inclusion of accessibility features and support the co-design process, working directly with people with disability to create more inclusive solutions.

Moreover, disability representatives can help bridge the gap between the Agency and the community by organising outreach programs, workshops and information sessions. These initiatives can raise awareness about digital health platforms and educate users on how to navigate and benefit from these services. By fostering a strong connection with the disability community, the Agency can build trust and ensure its digital health initiatives are truly inclusive and effective.

By investing in disability representation internally, the Agency can enhance its engagement with the disability community, improve the accessibility of its digital health platforms, and demonstrate its commitment to serving all Australians.

Recommendation 3

The Agency review the my health app, My Health Record and electronic prescriptions to include accessibility features for deaf, hard of hearing, vision impaired and blind consumers. This should include screen reader adaptability and text-to-speech.

Key accessibility features to be included are screen reader adaptability and text-to-speech functionality. Screen reader adaptability allows users with vision impairments to navigate and interact with the app using auditory feedback. Text-to-speech functionality converts written text into spoken words, making it easier for users with vision impairments to access information. Additionally, other features such as closed captions for videos and visual alerts for important notifications can greatly enhance the usability of these apps for people who are deaf or hard of hearing.

By incorporating these accessibility features, the Agency can ensure all users, regardless of their abilities, have equal access to digital health services. This commitment to inclusivity not only improves the user experience but also demonstrates the Agency's dedication to serving the diverse needs of the Australian community.

Recommendation 4

The Agency upgrades the my health app and My Health Record to have larger font, bolder icons and pictures to facilitate easier navigation.

These enhancements are essential for improving the usability of the my health app and My Health Record. They can be particularly important for users who may struggle with smaller text and less distinct icons, such as those with cognitive or visual impairments.

Larger fonts make text easier to read, reducing eye strain and ensuring important information is clearly visible. Bolder icons help users identify and select the functions they need, enhancing the overall user experience. Incorporating pictures provides visual cues to guide users through the app and online platform, making it more intuitive and user-friendly.

By implementing these upgrades, the Agency can ensure the my health app and My Health Record are accessible to a broader audience, including older adults and individuals with varying levels of digital literacy. This commitment to improving accessibility demonstrates the Agency's dedication to creating inclusive digital health solutions which cater to the diverse needs of all Australians.

Recommendation 5

The Agency commits to securing cybersecurity and confidentiality for all digital health platforms and communicates this clearly with people with disability.

Recommendation 5 emphasises the importance of the Agency committing to robust cybersecurity measures for all digital health platforms and clearly communicating these efforts to people with disability. Ensuring the security of digital health platforms is crucial to protect sensitive health information from unauthorised access, breaches and cyber threats.

By implementing strong cybersecurity protocols, the Agency can safeguard the privacy and integrity of users' health data. This includes using advanced encryption methods, regular security audits and timely updates to address potential vulnerabilities. Additionally, educating users about these security measures is essential to build trust and confidence in the digital health platforms.

Clear communication with people with disability about the cybersecurity measures in place is vital. This can be achieved through accessible formats such as plain language and Easy Read, visual aids, and assistive technologies like screen readers and text-to-speech. By ensuring all users understand how their data is protected, the Agency can foster a sense of security and encourage the adoption of digital health services. Additionally, the Agency can work with people with disability to build confidence in their commitment to upholding personal privacy and confidentiality best practice. This is specifically in regards to sharing information between health care providers and within users' support networks.

By committing to robust cybersecurity and transparent communication, the Agency can protect users' health information and build trust with the disability community, ensuring digital health platforms are both secure and inclusive.

Recommendation 6

The Agency should collaborate with medical and allied health professionals to enhance their understanding and usage of digital health platforms. This collaboration is essential to ensure health care providers are well-equipped to utilise these technologies effectively, ultimately improving patient care and outcomes.

By working closely with medical and allied health professionals, the Agency can provide targeted training and resources addressing the specific needs and challenges faced by these practitioners. This could include workshops, webinars and hands-on training sessions that cover the functionalities and benefits of digital health platforms. Additionally, creating user-friendly guides and support materials can help health care providers seamlessly integrate these tools into their daily practice.

Improving the understanding and usage of digital health platforms among health care professionals also ensures patients receive consistent and informed care. When providers are confident in using these technologies, they can better assist patients in navigating digital health tools, leading to more efficient and effective health care delivery.

By collaborating with medical and allied health professionals to enhance their understanding of digital health platforms, the Agency can foster a more integrated and proficient health care system that benefits both providers and patients.

Recommendation 7

The Agency works with people with disability to co-design clear and accessible information and resources on how to use digital health platforms and services.

This collaborative effort is essential to ensure all users can effectively navigate and benefit from digital health technologies.

By involving people with disability in the co-design process of educational resources the Agency can create materials that are truly user-friendly and tailored to the needs of this community. This includes developing guides, tutorials, and support resources that are available in various accessible formats, such as plain language, Easy Read, large print, braille and audio descriptions. Additionally, incorporating visual aids, step-by-step instructions, and interactive elements can further enhance the usability of these resources.

Clear and accessible information empowers individuals with disability to confidently use digital health platforms, leading to better health management and outcomes. It also ensures they are not excluded as health care increasingly moves towards digital solutions. By committing to this inclusive approach, the Agency demonstrates its dedication to providing equitable access to health care information and services for all Australians.

In addition to this, the Agency should work to better inform and educate all consumers and people with disability about entities responsibilities/legal obligations when using the systems. This should include functions such as how to set and manage privacy controls, such as Limited Document Access Code (LDAC) and Record Access Codes (RAC).

Recommendation 8

The Agency work with other federal agencies such as Services Australia, Medicare and the National Disability Insurance Agency (NDIA) to enhance access to digital health platforms and services for people living in regional, remote and rural areas.

This collaboration is crucial to ensure all Australians, regardless of their location, can benefit from digital health technologies.

Working together, these agencies can address the unique challenges faced by individuals in these areas, such as limited internet connectivity, lack of digital literacy and reduced access to health care services. By pooling resources and expertise, they can develop targeted strategies to overcome these barriers. This might include initiatives like improving internet infrastructure, providing digital literacy training and offering support services tailored to the needs of rural and remote communities.

Additionally, these agencies can work together to create outreach programs that raise awareness about the availability and benefits of digital health platforms. Ensuring information is accessible and understandable for all users, including those with disability, is essential. This could involve producing materials in various formats and languages and using community-based approaches to disseminate information.

By fostering collaboration between the Agency and other federal agencies, the goal is to create a more inclusive and equitable health care system that ensures everyone, no matter where they live, has access to the digital health services they need. This commitment to supporting regional, remote, and rural communities demonstrates a dedication to improving health outcomes for all Australians.

Recommendation 9

The Agency works with the Digital Transformation Agency (DTA), software vendors and standards organisations to influence inclusion of accessibility for all built into the design of digital health platforms and services.

This recommendation seeks to enhance technical integration and improve assistive technologies to better operate across the digital health sector or preferably as part of the eco-system. Collaborating with the DTA, software vendors and standards organisation to ensure accessibility features are built in at concept brief stage will ensure great accessibility of the Agency's digital health services. This recommendation not only benefits people with disability, it benefits older Australians and those with a temporary disability.

Recommendation 10

The Agency recognises not all people who wish to use digital health platforms have access to digital technologies or devices; and commits to working with local councils, libraries, community centres and neighbourhood houses to facilitate digital access for people on low or no incomes, including people with disability.

This collaboration can involve setting up public access points where individuals can use computers, tablets and internet services free of charge. These access points can be equipped with assistive technologies such as screen readers, magnifiers and other tools to support people with disability. Additionally, providing training sessions and workshops at these locations can help individuals develop the digital literacy skills needed to navigate digital health platforms effectively.

By working with local organisations, the Agency can ensure digital health services are accessible to everyone, regardless of their financial situation or ability to afford personal devices. This initiative not only promotes inclusivity but also helps bridge the digital divide, ensuring all Australians can benefit from digital health innovations.

Appendices

Appendix 1 | Literature Review – Digital Health and People with Disability

Access to digital health for people with disability

Introduction

This review aims to examine the key issues documented in selected literature on the topic of **access to digital health for people with disability**. This review will aim to identify the gaps in the current available literature on access to, suitability of, and overall usefulness of digital health options for people with disability in Australia. In turn and as a matter of disability rights advocacy, this review intends to clarify the impact of current digital health access for people with disability, with special consideration given to the COVID-19 pandemic; and to thus inform an ongoing digital health policy framework that should be based on the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and co-design principles.

Keywords: disability, people with disability, digital technology, digital health, pandemic, telehealth.

Methodology

This review has been undertaken within the framework of the Human Rights Model of Disability and uses the definition of disability as laid out in the UNCRPD.

> "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (UNCRPD, Article 1).

The references for this review were selected based on the client oriented, practice, evidence search protocol.[20] To be included for review, papers were selected based on fulfilling the following criteria:

a) Adequate description and identification of the topic

b) Currency of data and discussion

c) Effectiveness of material for recommendations and further investigation.

Material selected fell into two areas:

- Disability and access to digital health
- Digital health.

It must be noted this review is limited in scope due to the minimal number of academic articles on the topic. However, selected grey material including government reports are included to add currency and depth to the review. Currency of material selected spanned five years (2018 – 2023). Journals, articles and grey literature were selected using identified databases: JSTOR, Mediline and Google Scholar. Specific e-publications were also sourced using the Boolean search terms: **health AND disability**; **disability AND digital technology**; **COVID-19 AND disability**; and **telehealth AND disability**.

Human Rights Model of Disability

According to Degener and Quinn,[21] human dignity is central to human rights, thus each person is intrinsically valued and no person is insignificant. The Human Rights Model of Disability concentrates on the inherent dignity of the human being and then, but only if absolutely required, on the person's medical characteristics. It places the person at the centre of all decisions affecting them and, most significantly, identifies the main issues (barriers) outside the person and in mainstream society. This is clearly reflected in Article 9 – Accessibility of the UNCRPD.

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[20] Sackett, D. L., Richardson, W. S., Rosenberg, W., & Haynes, R. B. (1997). Evidence-based Medicine: How to practice and teach EBM. New York: Churchill Livingstone.

[21] Degener & Quinn (2002) 'A Survey of International, Comparative and Regional Disability Law Reform', in M. L. Breslin and S. Yee (eds), Disability Rights Law and Policy, Accessed online.

> “To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to **information and communications, including information and communications technologies and systems**, and to other facilities and services open or provided to the public, both in urban and in rural areas. These measures, which shall include the identification and elimination of obstacles and barriers to accessibility.”[22]

People with disability and access to health care

According to the Australian Institute of Health and Welfare report [23] on People with Disability,[24] people with disability aged between 15–64 are in fact more likely (92%) to see a particular GP or clinic when they are unwell or need health advice than those without disability (84%). However, whether these visits were of their own volition or not, was not identified in the data. As outlined by the Disability Royal Commission (DRC), many people with disability live in congregate settings and do not have a choice about who is their health care provider nor when they go to health-related services.[24]

A review on ‘Accessing Health care for people with disabilities,’ by Shakespeare et al., has emphasised the need for further research to better understand how people with disability are accessing health services [in the United Kingdom], not only in terms of service utilisation, but also access to preventive services, affordability of health services, and the quality of care received. The review noted that people with disability are not a homogenous group, but include people with different impairment types, people of different ages, genders, ethnicities and so on. All these factors can influence the relationship between disability and health care access. [25]

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[22] United Nations (2024) ‘Convention on the Rights of Persons with Disabilities,’ United Nations website.

[23] Australian Institute of Health and Welfare (2022) People with disability in Australia, AIHW, Australia.

[24] Disability Royal Commission (2020) ‘Report of Public hearing 4: Health Care and Services for People with Cognitive Disability,’ Novotel, Olympic Park, Sydney.

[25] Shakespeare T, Bright t, Kuper H (2018) ‘Access to health for persons with disabilities,’ Univervity of East Anglia Medical School, International Centre for Evidence in Disability, London School of Hygiene & Tropical Medicine, UK.

My Health Record and Disability

My Health Record (MHR) has been a contentious matter within the disability sector. At the time of launch, concerns were raised about the security of people's medical data and the risk of it being accessed by other government departments or external agencies.[26]

To this end, a Guardian article in 2019 [27] noted the Agency had identified in 2016 that there were potential risks of hacking MHR by "nation states and criminal actors". In 2019, the audit office subsequently reported not all Australian health care providers achieved minimum cybersecurity levels, and that the health care sector reported the most notifiable data breaches of any industry sector. **Confidence in the MHR by people with disability has not been well examined and remains an area for recommended further research.**

COVID-19, Disability and Digital Inequity

The COVID-19 pandemic had an enormous impact on people with disability in Australia, particularly on their health care. In March 2020, the DRC [28] sent a letter to the Federal Government outlining its concerns about how the government was responding to the risks the pandemic posed to people with disability. The letter highlighted the lack of clear communication for people with disability about the measures required to manage possible infection and the limitations of the health care available.

PWDA was funded by the Mental Health Commission to investigate the impacts of COVID-19 on women with disability. One of the key findings of the project[29] was the **benefits of telehealth**. **Increased scope of bulk-billed telehealth soon became an essential part of people with disability's access to health care across the country.**

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[26] People with Disability Australia (2019) 'My Health Record.'

[27] Davidson, H (2019) 'My Health Record failed to manage cybersecurity and privacy risks, audit finds,' The Guardian, Australia.

[28] Disability Royal Commission (2022) 'Statement of Concern: The response to the COVID-19 pandemic for people with disability.'

[29] People with Disability Australia (2023) 'Pandemic Research Project.'

The COVID-19 pandemic has also had a broader impact on the take up of digital health options, which has been examined in a limited number of studies worldwide. According to Gunasekeran,[30] countries with integrated digital health platforms such as South Korea were better able to manage the outbreak. In Hungary, access to digital health applications facilitated the uptake of electronic prescriptions.

The podcast 'The Painted Brain'[31] strongly noted that the uptake of digital health was perhaps transformative in terms of access to health care. However, it also pointed out the use of digital technologies could also exacerbate health care inequalities. This paradox also noted in the paper 'The Digital Health Paradox,[32] in which the authors called for a far more sophisticated understanding of digital literacy across the community to better understand it's uptake and ameliorate potential inequalities.

Significantly, a 2023 article titled, 'Use of Digital Health care among people living with disabilities'[33] surmised that uptake of digital health platforms for people with disability during COVID-19 was not adequately monitored and thus their effectiveness for people with disability is not clear. **This highlights the need for better data collection on the use of and effectiveness of digital health care for people with disability.**

Design barriers to accessing information on health care

Accessing health information digitally for people with disability can be a barrier as noted earlier, due to cost and to digital literacy. Barriers also exist in the design of digital technology.[34]

Vision Australia highlighted in 2019 that the increasing use of touchscreens across a range of services was becoming problematic for vision impaired and blind people. This is a genuine physical barrier to accessing e-health via smart phones and tablets.

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30 Gunasekeran, D.V., Tseng, R.M.W.W., Tham, YC. et al. (2021) 'Applications of digital health for public health responses to COVID-19: a systematic scoping review of artificial intelligence, telehealth and related technologies.' npj Digit. Med, Vol. 4, no. 40

31 Painted Brain, 'The Digital Divide and Mental Health.'

32 Van Kessel R, Hrzic R, O'Nuallain E, Weir E, Wong BLH, Anderson M, Baron-Cohen S, Mossialos E. (2022) 'Digital Health Paradox: International Policy Perspectives to Address Increased Health Inequalities for People Living With Disabilities.' J Med Internet Res, Vol. 24, no. 2, doi: 10.2196/33819. PMID: 35191848; PMCID: PMC8905475.

33 Boros, Julianna & Girasek, Edmond & Döbrössy, Bence & Gyorffy, Zsuzsa. (2023). 'Use of Digital Health care among People Living with Disabilities.' Fogyatékosság és Társadalom, Vol. 8, no. 10.

34 Vision Australia (2019) 'The trouble with touch screens.'

However, a 2021 article in The Conversation[35] by US based digital researchers/developers at the Rochester Institute of Technology stated that technology can be fully accessible if designed inclusively. They note that touchscreens are problematic unless a screen reader is installed on the device. **Having a well-designed platform that is *genuinely* accessible has the potential to increase access to vital information, such as health care.**

Gillian Mason[36] in the podcast ‘Talking Health,’ examined the role of digital health technology and inclusion for people with disability and concluded that **only genuinely co-designed applications would provide meaningful access to health information**. They note that designers must understand the problem that is to be solved, they must develop a genuine appreciation of the daily routines and battles a potential user may face and that the end user of the digital technology must be at the centre of its development.

Digital Access as a Human Right

The journal article ‘Disability Participation in the Digital Economy,’ identified barriers (whether environmental, technical, or attitudinal) to disability participation in society are significant; and consideration must be given to the **effects** and **outcomes** of disability engagement through digital technologies on inclusive citizenship. The article emphasised that people with disability are citizens and as such are rights holders with rights to access online content and have equal digital participation.

Former Australian Human Rights Commissioner Ed Santow[37] similarly examined the right to access digital technology for people with disability and concluded:

> “People with disability have a right to access technology. Access to new technology, especially Digital Communication Technology, is an enabling right for people with disability because it is critical to the enjoyment of a range of other civil, political, economic, social and cultural rights.”

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[35] Shinohara, K & Tigwell, G (2021) ‘Why getting more people with disabilities developing technology is good for everyone,’ The Conversation.

[36] Talking Health Tech (2022) ‘208 - Fully sick; disability inclusion in digital health. Gillian Mason.’

[37] Farthing, S, et. al., (2021) ‘Human Rights and Technology Final Report,’ Australian Human Rights Commission.

In their final report in 2021, the Human Rights Commission went so far as to outline legislative changes to facilitate access to digital technology for people with disability.

The report recommended the Attorney-General should:

- Develop a Digital Communication Technology Standard under section 31 of the *Disability Discrimination Act 1992* (Cth)
- Consider other law and policy reform to implement the full range of accessibility obligations regarding Digital Communication Technologies under the Convention on the Rights of Persons with Disabilities.

Access to digital content is a human right for people with disability and this is inherent to Article 9 of the UNCRPD.

Conclusion

There is little doubt that the use of digital technologies is profoundly transforming the nature and content of health care and health information. Potentially, digital health services could help to reduce health inequalities. It must, however, be noted that the COVID-19 pandemic highlighted the risk of digital exclusion is higher in certain cohorts, including people with disability. To achieve equitable access to digital health, people with disability, along with other marginalised groups, must be at the centre of digital health development.

Furthermore, access to well-designed digital platforms and content is a human right for people with disability. As the COVID-19 pandemic revealed, technology can be of enormous assistance, but it must be inclusive to serve the needs of *all* citizens.

This brief review has identified gaps in data about the use of digital health and people with disability, it has also noted the barriers that people with disability face when trying to access digital technologies, both physical and attitudinal.

It is recommended further investigation is undertaken to identify ***how*** and ***why*** people with disability use digital health platforms; that people with disability are included in a formal advisory capacity in the development of policies and frameworks on digital health – beyond mere inclusion in panels; and that all these undertakings are informed by and compliant with the UNCRPD.

Appendix 2 | Interview Protocol

Digital Health Interview Guide

Enhancing Inclusion and Accessibility: An Initiative for Digital Health Engagement and Empowerment.

Introduction

Thank you for your time and the generous sharing of your lived experience today.

This interview is taking place as part of PWDA's digital health engagement and empowerment project for the Agency. They help create and manage national digital health infrastructure.

I will not be video recording today's interview, however a transcript will be recorded and downloaded at the end of the interview. During the interview I will also be taking notes, these notes and the transcript will both be deidentified – meaning no identifiable information will be linked to what we gather.

Any ideas you share during this interview will be considered alongside the other research we have conducted and will guide the project's recommendations. This interview is to understand your personal experiences and there are no right or wrong answers.

People with disability are more likely to engage the services of a health professional than people without disability. While 65% of adults without disability rate their health as excellent or very good, just 24% of people with disability rate their health as excellent or very good. People with disability therefore represent a key community the Agency seeks to effectively service and support.

The Agency's digital products and services include:

- My Health Record – which provides you and your health care providers with secure access to your key health information. This includes pathology and diagnostic imaging reports, hospital discharge summaries, allergies, vaccination records and medication lists.
- my health app - a smartphone and tablet app that allows you to view your My Health Record.
- Electronic prescriptions - an alternative method to receiving and dispensing prescriptions. Electronic prescriptions are sent by your health care provider to you via a text with a link to a QR code for the chemist to scan.

In today's interview we seek your input on three areas:

- The barriers to accessing the Agency's digital health products and services for people with diverse disabilities, focusing on My Health Record, my health app and electronic prescriptions.
- The enablers that support people with diverse disabilities to access digital health products and services.
- Opportunities for future product and service development by the Agency.

Are you still comfortable taking part in today's interview?

During this interview, please let me know if you would like to take a break.

During the interview you may stop the interview and choose to no longer proceed.

Do you have any questions for me before we begin? Thank you.

Digital health use	Questions
1	How familiar are you with Australian Digital Health Agency (the Agency) products and services, specifically My Health Record, my health app and electronic prescriptions?
2	How did you learn about the Agency's digital health products and services?
3	How often do you currently use the Agency's products and services and what is your main reason for accessing them?
4	What is the best way to receive information and updates on available health services to you and why? i.e., email, text, GP, medical centre, post/mail.
5	How do you share your health information with a new health care provider?
6	Are there any opportunities you see where doing something digitally would save you time or effort?
7	Are there any inefficiencies or frustrations you currently experience when interacting with the health system that could be aided or improved by digital health products or services?

Break – 10 Minutes

Accessibility	Questions
8	Do you find the Agency's products and services easy and accessible to use? Please specify why or why not.
9	Have you encountered any specific challenges or barriers to using the Agency's products and services?
10	If you don't use the Agency's products and services, what are your reasons for not using them?
11	Are there other digital health apps, websites or similar that you find useful? What do you like about them? i.e. colour, font, ease of use, gamification.
12	What would make a digital health app more useful for managing your health?
13	Is there anything else anyone would like to share about digital health products and services?

Wrap Up

Feedback on interview: Questions earlier before the interview.

Debrief

Closing and Gift Vouchers

Appendix 3 | Focus Group Protocol

Digital Health Research Focus Groups

Enhancing Inclusion and Accessibility: An Initiative for Digital Health Engagement and Empowerment.

Introduction

Thank you for your time and the generous sharing of your lived experience today.

The focus of today's discussion, and the overall aim of the project, is to understand the accessibility and engagement of people with diverse disabilities when utilising the Australian Digital Health Agency's (the Agency) digital health tools. This discussion will guide findings for the Agency who help create and manage national digital health infrastructure.

The Agency's digital products and services include:

- My Health Record – which provides you and your health care providers with secure access to your key health information. This includes pathology and diagnostic imaging reports, hospital discharge summaries, allergies, vaccination records and medication lists.
- my health app - a smartphone and tablet app that allows you to view your My Health Record
- Electronic prescriptions - an alternative method to receiving and dispensing prescriptions. Electronic prescriptions are sent by your health care provider to you via a text with a link to a QR code for the chemist to scan.

People with disability are more likely to engage the services of health professionals than people without disability. While 65% of adults without disability rate their health as excellent or very good, just 24% of people with disability rate their health as excellent or very good. People with disability therefore represent a key community the Agency seeks to effectively service and support.

In today's focus group we seek your input on three areas:

- The barriers to accessing the Agency's digital health products and services for people with diverse disabilities, focusing on My Health Record, my health app and electronic prescriptions.
- The enablers that support people with diverse disabilities to access digital health products and services.

- Opportunities for future product and service development by the Agency.

Your input will only be used for research purposes and no identifiable quotes will be published.

Group Agreement

Before we begin, we ask everyone to agree with and adhere to the following expectations for our focus group:

- Be respectful of one another.
- Confidentiality to be maintained which means no recording or use of artificial intelligence (AI) during focus group interactions.
- One person to speak at a time.
- Be mindful of the impact of your trauma experience on other group members.

Are there any other group expectations you would like to include?

Digital health use	Questions
1	How frequently do you currently use digital health services and if so, what is your primary purpose for accessing them?
2	For those who don't currently use digital health services, have you encountered any specific challenges or barriers? Or why have you not used them?
3	How familiar are you with Australian Digital Health Agency's products and services, specifically My Health Record, my health app and electronic prescriptions? **[Show slides/screenshots of health services]**

Accessibility	Questions
4	We would like to hear from you about how we can provide more accessibility for Australian Digital Health Agency products and services. Do you find the Australian Digital Health Agency's products and services easy and accessible to use? And if not, why not?

Break – 10 Minutes

Accessibility (continued)	Questions
5	Are there other digital health apps, websites or similar that you find useful? What do you like about them? i.e. colour, font, ease of use, gamification.
6	What would make a digital health app more useful for managing your health?
7	Is there anything else anyone would like to share about digital health products and services?

Feedback on Focus Group

Debrief

Closing and Gift Vouchers

Appendix 4 | Member Survey

PWDA Digital Health Technology Survey

Thank you for providing feedback on the Australian Digital Health Agency (the Agency) services and digital health tools and apps.

Why is PWDA conducting this survey?

People with Disability Australia (PWDA) is working with the Agency to improve their tools and apps.

This survey will close on Sunday 28 July 2024.

Who can complete this survey?

People with disability currently living in Australia can complete this survey.

How long will the survey take?

Approximately 10 minutes. An asterisk (*) means an answer is required.

Who can I contact for support or to ask a question?

If you have a question, please contact training@pwd.org.au or call 1800 422 015.

If you complete the survey you can go into the draw to win 1 of 4 $100 prepaid visa gift card.

Section 1: About you

This set of questions will tell us a bit about you.

Q1. What is your gender?

- Male
- Female
- Non-Binary
- I use a different term
- Prefer not to say

Q2. How old are you?

- 18-24
- 25-34
- 35-44
- 45-54
- 55-64
- 65-74
- 75-84
- 85 and older
- Prefer not to say

Q3. Do you identify as being an Aboriginal and/or Torres Strait Islander?

- No
- Yes, Aboriginal
- Yes, Torres Strait Islander
- Yes, both aboriginal and Torres Strait Islander
- Prefer not to say

Q4. Do you identify as a person with a disability?

- Yes
- No
- Prefer not to say

Q5. If you responded yes, please indicate all relevant descriptions that apply to your disability. Please select all that apply.

- Neurodevelopmental Disorders
- Physical Disability
- Acquired Brain Injury (ABI)
- Neurological Disability
- Vision Impairment
- Hearing Impairment
- Deafblind (Dual sensory)
- Speech Language Impairment
- Psychosocial Disability
- Developmental Delay
- Other (please specify)

Q6. Do you have any care responsibilities? Please select all that apply.

- Yes, for my children (including adult children)
- Yes, for other family members
- Yes, for friends
- No
- Prefer not to say
- Other, please specify

Q7. What is your current employment status?

- Full-time employment
- Part-time employment
- Self-employed
- Casual employment
- On leave from work
- Seeking employment
- Student
- Home duties
- Unpaid carer
- Unemployed
- Retired
- Volunteer
- Prefer not to say
- Other, please specify

Q8. Where do you currently reside? (Please add your postcode into the box below)

Section 2: Australian Digital Health Agency Focused Questions

These questions are about your experience with Australia Digital Health Agency services and digital health apps

Q9. What is the best way to receive new information and updates on available health services to you? Choose the one that works best for you.

- Email
- Post or Mailbox
- Text Message
- Other, please specify

Q10. Awareness of Australian Digital Health Agency Services:

Are you aware of any of the following digital health services available to you? (Tick all that apply).

- My Health Record
- my health app
- Electronic Prescriptions – QR code scripts
- None

Q11. Do you use any of the following Australian Digital Health Agency Services? (Tick all that apply).

- My Health Record
- my health app
- Electronic Prescriptions – QR code scripts
- None

Q12. How familiar are you with the Australian Digital Health Agency's services?

- Very Familiar
- Familiar
- Neutral
- Somewhat Familiar
- Not Familiar

Q13. Access to Technology

Do you have access to any of the following technology: smartphone, computer, or internet connection? Tick the ones that apply to you.

- Smartphone (mobile application)
- Computer
- Laptop
- iPad
- Internet Connection
- None
- Other option (please specify)

Q14. Current Usage

If you currently use any Australian Digital Health Agency services, what technology do you use the most to access your My Health Record, my health app or Electronic Prescription's? (Please tick all that apply)

- Smartphone (mobile application)
- Computer
- Laptop
- iPad
- Internet Connection
- None

Q15 Frequency of Use: If you currently use My Health Record service, how often do you access it?

- Once a week
- Once a fortnight
- Once a month
- Couple times a year
- Never

Q16. If you currently use my health app service, how often do you access it?

- All the time
- Sometimes
- Neutral
- Not often
- Not at all

Q17. If you currently use electronic prescriptions – QR code script service, how often do you access it?

- All the time
- Sometimes
- Neutral
- Not often
- Not at all

Q18. Ease of Use: How easy do you find it to use the My Health Record Australian Digital Health Agency service?

- Very Easy
- Easy
- Neutral
- Somewhat easy
- Not easy at all

Q19. Ease of Use: How easy do you find it to use my health app Australian Digital Health Agency service?

- Very easy
- Easy
- Neutral
- Somewhat easy
- Not easy at all

Q20. Ease of Use: How easy do you find it to use electronic prescriptions – QR code prescriptions Australian Digital Health Agency services?

- Very easy
- Easy
- Neutral
- Somewhat easy
- Not easy at all

Q21. Barriers to Access

If you do not currently use Australian Digital Health services, have you encountered any specific challenges or barriers to using them?

- Yes, please specify
- No

Q22. Cost and Affordability

Have you faced any barriers related to cost or affordability when considering Australian Digital Health Agency services?

- Yes, please specify
- No

Q23. Privacy Concerns

How concerned are you about the privacy and security of your health data when using Australian Digital Health Agency services?

- Very concerned
- Concerned
- Neutral
- Somewhat concerned
- Not concerned at all

Q24. Features for Accessibility

What features would make a digital health app more appealing to you as a person with disability?

Q25. Customisation Importance

How important is customisation (e.g., font size, voice commands) in your app or online experience?

- Very important
- Important
- Neutral
- Somewhat important
- Not important

Q26. Are there any specific customisation options that would be important to you?

Q27. Is there anything else you would like to tell us?

Q28. Would you like to go into the running to win 1 of 4 $100 gift cards?

- No
- Yes – add your email to go into the running

Appendix 5 | Project Charter

Background & Objective

People with disability are more likely to engage the services of a health professional than people without disability. While 65% of adults without disability rate their health as excellent or very good, just 24% of people with disability rate their health as excellent or very good. People with disability therefore represent a key community that can benefit from the services of the Australian Digital Health Agency (the Agency). However, for the applications developed by the Agency to meet the needs of the community, community engagement and co-design, is required.

Between January and June 2023 People with Disability Australia (PWDA) worked with the Agency to deliver on a series of project outputs designed to achieve the following outcomes and objectives:

- Work with the Agency's Community Engagement and Program teams to increase the Agency's understanding of the needs, barriers, and enablers in the design and usage of the Agency's Digital Health technologies in the identified communities.
- Increase and inform understanding of the Agency's Digital Health technologies in the identified communities.
- Increase the effective use and uptake of the Agency's Digital Health technologies in the identified communities.

This project set up a working relationship between PWDA and the Agency with a view to working towards the delivery of a needs assessment in the 23/24 Financial Year – subject to the availability of ongoing funding. As part of the project, PWDA undertook a literature review, seeking to understand the key issues documented in academic literature on the topic of access to digital health for people with disability. The literature review recommended:

- Further research is undertaken to identify how and why people with disability use digital health platforms – and why they may not.
- People with disability are included in a formal advisory capacity in the development of policies, frameworks and products on digital health.
- All undertakings are informed by Australia's obligations under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), specifically Article 9.

Over the course of the project, PWDA made a number of observations that may support the Agency in improving the uptake of its digital health technologies for people with disability.

The project called on PWDA to increase the effective use and uptake of the Agency's Digital Health technologies and increase awareness of the technologies for people with disability in Australia. A key barrier to enabling PWDA to do this was the lack of accessible resources, materials and technologies developed by the Agency. PWDA found that during information sessions regarding the latest digital health technologies limited consideration was given to accessibility requirements such as Auslan and live transcription, therefore preventing communities from being able to access important information. As a Disabled Person's Organisation, this further prevented PWDA from sharing information with its members and engaged audiences.

A key recommendation, therefore, was that the Agency continue to prioritise disability awareness training for their workforce to ensure the needs of those who draw on health care services the most, can be central to the services and products the Agency creates.

This proposal seeks to support the Agency in better understanding the needs of people with disability, and in engaging people with disability to guide and advise on needs now and into the future.

Project objectives

1. Work with the Agency's Community Engagement and Program teams to increase the Agency's understanding of the needs, barriers, and enablers in the design and usage of the Agency's digital health technologies in the identified communities.
2. Increase and inform understanding of the Agency's digital health technologies in the identified communities.
3. Increase the effective uptake and use of the Agency's digital health technologies in the identified communities.

PWDA Overview

People with Disability Australia (PWDA) is a leading disability rights, advocacy, and representative organisation of and for all people with disability. PWDA is the only national, cross-disability organisation, representing the interests of people with all kinds of disability. PWDA is a non-profit, non-government organisation.

PWDA's primary membership is made up of people with disability and organisations primarily constituted of people with disability. PWDA also has a large associate membership of other individuals and organisations committed to the disability rights movement.

We have a vision of a socially just, accessible, and inclusive community, in which the human rights, belonging, contribution, potential and diversity of all people with disability are recognised, respected, and celebrated with pride. PWDA was founded in 1981, the International Year of Disabled Persons, to provide people with disability with a voice of our own.

Project Deliverables

The project will deliver several outputs:

1. Needs Assessment and Gap Analysis

- An accessible survey targeting PWDA members and the wider community canvassing opinions on the Agency's digital health tools including electronic prescriptions, My Health Record and the my health app.
- A series of two focus groups will be held to discuss interactions with the Agency's digital health tools. These will include people who identify as having a diverse range of disabilities, as well as diversity in location. Focus groups will centre on:
    - Electronic prescriptions
    - My Health Record
    - my health app.
- A series of up to 10 one on one interviews will be held to discuss interactions with the Agency's digital health tools. Each interview will cover e prescriptions, My Health Record and my health app and will also touch on general needs for digital health tools.
    - A report summarising the themes, findings and recommendations will be provided as an outcome of the activity.

2. Development and Promotion of Accessible Resources

- PWDA has provided costs to develop and deliver accessible resources as required by the Agency and as recommended following the completion of deliverable ‘Needs Assessment and Gap Analysis”.
- Development and promotion of additional Easy Read documents – noting that PWDA has worked with the Agency to develop Easy Read resources on My Health Record, electronic prescriptions and my health app, there may be additional documents that need to be developed to support people with intellectual disability to better access these digital health tools. Examples include:
  - Advance Care Planning
  - Telehealth
  - How can technology improve my health?
  - Privacy and your health information
  - The National Digital Health Strategy.
- Production and promotion of accessible video information – It is recommended that any Easy Read resources are adapted into accessible video format, to further support those with intellectual disability to access information relating to the Agency’s digital health tools. It is noted PWDA has an outstanding deliverable from FY23 project to adapt Easy Read content to video production.

Project phases

Project 1 -
Comprehensive Needs Assessment And Gaps Analysis Report

The project will commence in May 2024 and continue to August 2024 .

Project 1 will be led by a project team with lived experience of disability and subject matter expertise and will be informed by a desktop literature review as well as a survey, interviews and focus groups designed to capture the experiences and views of PWDA members.

- Phase 1 - Planning and Research
- Phase 2 - Active Outreach
- Phase 3 - Comprehensive Needs Assessment And Gaps Analysis Report, Project Review and Closure.

Project 2 - Accessible Resources

The project will commence in July 2024 and continue to February 2025. This project is focused on developing accessible resources. Insight from the outcome of the Needs Assessment and Gap Analysis will be used develop a series of Accessible Resources to;

- Increase and inform understanding of the Agency's digital health technologies
- Increase the effective uptake in the use of the Agency's digital health technologies
- Develop accessible resources for people with lived experience of disability.

Formats may include Easy Read, video format including Auslan webinar / information sessions, including by Auslan and live transcription.

- Phase 1 - Planning
- Phase 2 - Development of Accessible Resources
- Phase 3 - Project Review and Closure.

Project 3 - Promotion and Education

The project will commence in August 2024 and continue to February 2025. This project is focused on increasing understanding and uptake of the Agency's digital health technologies among people with disability. To do this PWDA will;

- Promote accessible resources and information developed by the Agency
- Promote the Agency's digital health tools by delivering two accessible webinars that include Auslan and live transcription services
- Phase 1 - Promotion
- Phase 2 - Education.

Activity workplan

Detailed activities aligned to each of the project phase are documented in activity workplans.

Project risks

Potential Risks	Risk management/mitigation
Failure to engage the target cohort	• The project will be delivered by a Disabled Persons Organisation, led by people with disability and representative of cross-disabilities. • The project will centre on co-design practices and principles, rather than consultation, and will therefore be led by people with lived and living experience of disability as well as subject matter expertise • As a DPO, PWDA has an extensive and engaged member base.
Project materials will not be accessible by the target cohort	Budget and project time has been allowed for the development of project outputs in accessible formats including Auslan, Easy Read and audio described video.
COVID-19 restrictions impact delivery of the Activity	PWDA has a COVID-19 Policy and Practices in place to ensure the safe delivery of services.
Budget under/ overspends	• Budget reflects scope of project. • Budget is fully considered and includes known likelihoods and relevant contingencies. • Specific activities and budget allocation will undergo ongoing review and any concerns will be discussed with the Agency.
Communication	A communications plan will be developed in Phase 1 (establishment) of the project with clear communication channels, tools and meetings established.
Failure to deliver useful outputs	To ensure all project outputs are of practical help to those they are designed for a co-design approach will be adopted. All outputs will be developed in collaboration with those with lived experience and the sector through consultation.

Potential Risks	Risk management/mitigation
Scope Creep	The scope of the project will be outlined in a detailed project initiation documentation with a change management plan adopted to track any change to the scope of the project.
Resource Availability	PWDA has a stable of talented project managers and educators with lived experience of disability to support in the delivery of the project and established partnerships with expertise.
Schedule Delays	Delays in the project timeline can occur due to various reasons such as resource unavailability, scope creep, or technical issues. A realistic timeframe for delivery has been developed accommodating scope of the project.

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