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Making qualitative research accessible to people who have communication disability

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ABSTRACT

People with communication disability are often excluded from participating directly in research. This systematic exclusion from relevant research has a significant impact on the field's knowledge and limits the development of effective evidence-based practices. The purpose of this descriptive methods paper is to equip researchers with knowledge required to address the needs of people with communication disability, increasing the likelihood of their rights-based inclusion in research. In this paper, we combine what has been learned from the literature with content derived from a study that is currently underway. Using images and transcript excerpts as examples, we will describe practical methods to action recommendations. Three pillars of communication accessible research are proposed—participatory attitudes, flexibility and responsivity, and consumer involvement—which will empower researchers to make their own projects more inclusive to people with communication disability.

1. Introduction

People with communication disability, including those who do not use speech to communicate and who use augmentative and alternative communication (AAC), are likely to be excluded from qualitative research as primary informants, despite significant consequences of their underrepresentation (Dee-Price et al., 2021; Morris, 2003). Researchers therefore have a corresponding moral duty to facilitate their participation (Taylor & Balandin, 2020). This article primarily concerns itself with the inclusion of people with communication disability as primary informants in qualitative research. Their inclusion is important because the use of a proxy can be inaccurate or insufficient in many cases (e.g., Sentenac et al., 2021).

1.1. *Consequences of underrepresentation of people with communication disability in research*

Several papers describe the importance of including underrepresented groups in research. Northway (2014), for example, argues that measures put in place to safeguard people with intellectual disability from research-related coercion, exploitation, and harm, may

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be disproportionate in response, leading to “new harms”. It is worth noting that some of the evidence referenced in this section relates to people with intellectual disability, not specifically to people with communication disability; however, relevant insights can still be drawn upon.

The systematic exclusion of people with communication disabilities from relevant qualitative research has a significant impact on knowledge generation and limits the development of effective evidence-based practices. The exclusion of people with disability from health research can compromise its credibility (Banas et al., 2019). Williams and Moore (2011) describe the fallacy that people with disabilities are included in studies only because their disability is of interest, rather than as a “demographic characteristic of participants”. When people with communication disability are not included in research, they become unlikely to benefit from it (Vogt, 2024). Furthermore, since communication disability is not diagnosis-specific, their exclusion from mainstream health research (not just research about AAC) is relevant. Possible consequences include ineligibility for evidence-based interventions and inaccessible therapeutic programs, with resultant negative impacts on healthcare and perpetuation of existing health disparities between disabled and non-disabled people.

A recent systematic review by McDonald et al., (2025) argued that including people with developmental disability in research allows them “to contribute to scientific discovery”, and that their exclusion can diminish their experiences of social contribution and sense of purpose. As stipulated by the Australian National Health and Medical Research Council (NHMRC) National statement on ethical conduct in human research, (2023) (2023) “people with a cognitive impairment, an intellectual disability, or a mental illness are entitled to participate in research, and to do so for altruistic reasons.” Under-representation of AAC-users as primary participants in research reinforces the prevailing narrative of them as a vulnerable group, perpetuates their marginalisation, sustains ableist and paternalistic power imbalances between AAC-users and researchers, and contributes to a stereotyping of their capabilities (Northway, 2014; Shivas, 2004; Taylor & Balandin, 2020; Walsh et al., 2024a). Their exclusion from qualitative research is also at odds with the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006), which asserts the rights of community inclusion and freedom of expression.

1.2. *Direct and indirect exclusion of people with communication disability from research*

The consequences of the exclusion of people with communication disability from research are clear, therefore we need to address the barriers that perpetuate their underrepresentation. Their exclusion from research may be direct (e.g., restrictive selection criteria) or indirect (e.g., inaccessible recruitment, consent, and data collection materials).

Restrictive selection criteria present a significant barrier to AAC-users’ participation in research. Certainly, people with complex communication needs are sometimes explicitly excluded. For example, the following paraphrase, drawn from a range of studies, exemplifies a common sentiment in qualitative research selection criteria: “people who do not use speech were excluded as they would not be able to take part in an interview”. Other times, they are not technically excluded, but the phrasing of selection criteria might still result in their exclusion. For example, studies which permit the use of AAC in interviews might also have selection criteria stating participants require ‘verbal competency’ or ‘adequate conversational skills’, making these studies exclusionary to a significant portion of AAC-users.

Selection criteria phrasing is particularly important when reflecting on the characteristics and purpose of AAC. AAC is any means of communication other than speech and can be unaided or aided (Speech Pathology Australia, 2023). Unaided AAC does not require any equipment and includes modes such as Key Word Sign (Scope (n.d.)), natural gesture, and eye pointing. Aided AAC does require equipment and can be low-tech (e.g., paper-based communication books) or high-tech (e.g., speech generating devices). Aided AAC can employ a variety of vocabulary representations (e.g., words, symbols, or photos) depending on its user’s language skills and cognition. Aided AAC can be accessed in several ways (e.g., direct, scanning) depending on its user’s physical access needs. Importantly, AAC-users often use multi-modal communication—i.e., they use a combination of modes to share a message. They might use different modes in different interactions, or several modes in a single interaction.

Studies might have selection criteria which permit the use of a ‘communication device’—but if this means only people who use a high-tech AAC system are eligible for the study, a significant portion of AAC-users are again excluded. Individuals’ use of different AAC types can depend on their language availability, speed of message generation, portability, ease of use, fatigue levels, environmental factors, cost, and how other people might perceive them (Iacono et al., 2013). People might assume that people using high-tech AAC have more, or more important, experiences to share than people using low-tech AAC—which is a misinformed belief. However, this might not be common knowledge to researchers outside of the field of AAC, or indeed some AAC researchers, and so upskilling of researchers is needed.

1.3. *Purpose of this paper*

While it is possible to consider people with communication disorders a ‘hard-to-reach’ participant group, we argue that it is the research that is ‘hard-to-reach’. This rights-based perspective places the onus on researchers to support their access. Evidently, one barrier to inclusion is researchers’ lack of knowledge about effective strategies to support the participation of people with AAC in research. Of people with limited verbal and written communication skills, the National Statement (2023) states that “provision should be made for them to receive information, and to express their wishes, in other ways.” The ongoing underrepresentation of people with communication disability suggests there is a need for dedicated methods papers and published examples, in which the processes and strategies that support inclusion in research are described so as to promote communication access in qualitative research. Therefore, the purpose of this paper is to provide researchers with practical strategies for addressing the communication access needs of AAC-users and increase the likelihood of their inclusion in research.

2. Methods

This descriptive methods paper draws on what has been learned in the conduct of a consumer-involved qualitative study to produce a summary of inclusive strategies for conducting research with AAC-users as participants. The primary study aimed to explore and describe the mental health experiences of young AAC-users. The study outcomes will contribute to future codesign of mental health tools for AAC-users. By understanding how they experience and communicate about mental health, we can work towards measuring these constructs in ways that are relevant to them. To achieve this relevance, it was important to hear from AAC-users directly, and so communication accessible research practices were essential.

2.1. Consumer involvement

A crucial element of both the research and the development of this paper was the involvement of people with lived experience of communication support needs as co-researchers throughout every phase of the study. Authors {redacted} and {redacted} are people with communication support needs, and author {redacted} is the mother of an AAC-user. We adopted roles defined by Smits et al. (2020). In our primary study, consumer co-researchers held co-thinker (is asked to give an opinion), advisor (gives (un)solicited advice), and partner (works as an equal partner) roles across different research activities. Their contribution to the qualitative study aimed to ensure the research would be relevant to AAC-users, that it would be accessible for AAC-user participants, and that outcomes would reach AAC-users. For completeness, the other authors on this paper are a clinician-researcher {redacted} and senior researchers with clinical backgrounds {redacted}.

2.2. Data sources

The research team, as outlined above, developed the protocol for the primary qualitative study. During this time, a desktop review was completed to seek guidance about how to conduct communication-accessible research. The phrase “inclusive research practices for AAC users” was searched within Google Scholar, returning several relevant papers. The reference lists of these papers were then reviewed to locate additional relevant literature. Knowledge gained from this desktop review was the first data source for this paper. The second source of information for this paper were the materials and experiences gained through the conduct of the primary study. This included participant-facing material, interview transcripts, screenshots of interview activities, and interviewer reflections. Transcripts are written using notational conventions to describe conversations that happen using AAC (Von Tetzchner & Basil, 2011). This convention distinguishes modes of communication using font. Minor changes to the transcripts were made for clarity. All examples were included with the participants’ consent, and all names have been changed.

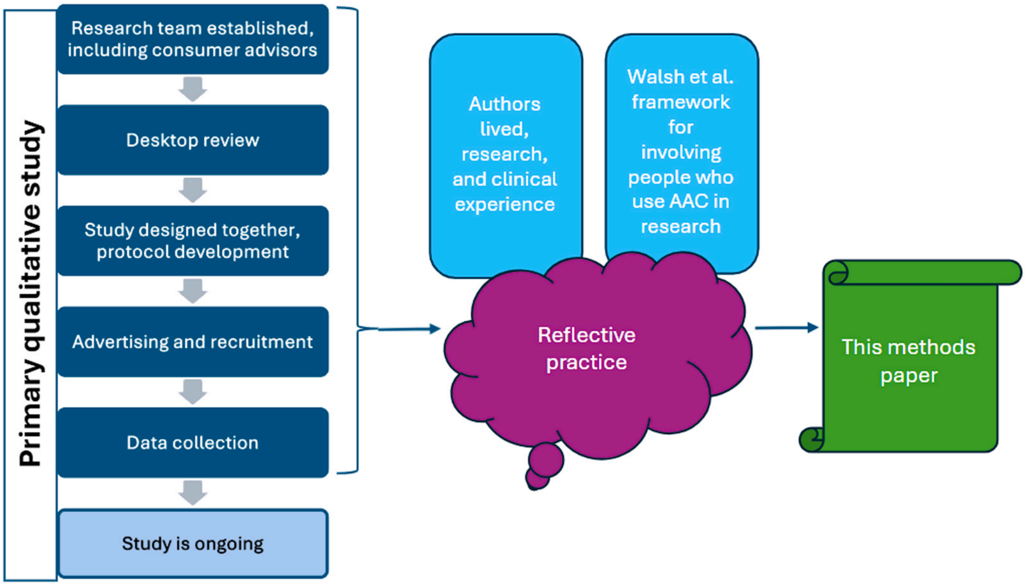


Fig. 1. Diagrammatical representation of methods. What was learned during the primary qualitative study was brought forward into reflective practice alongside authors’ experiences and a published framework. The integration of these data sources produced this current paper which describes and demonstrates communication accessible research practices.

2.3. Data integration

Walsh and colleagues (2024a) developed a framework for involving people with cerebral palsy who use AAC in research; their framework included five areas where accessibility is important to address: recruitment, consent, adapted research methods, communication supporters, and ethics. Using reflective practice, we addressed these five application areas by combining knowledge from authors' lived, research, and clinical experience with what was learned during the conduct of the qualitative study. We cross-referenced existing literature to draw readers' attention to other sources of information on the topic. This approach was selected as triangulation across multiple data sources enhances the robustness of this paper. Several images and transcript excerpts from the qualitative study were included as examples, with the intention of providing practical information that other researchers may apply.

An overview of how the primary mental health study is linked to the current methods paper is demonstrated in Fig. 1.

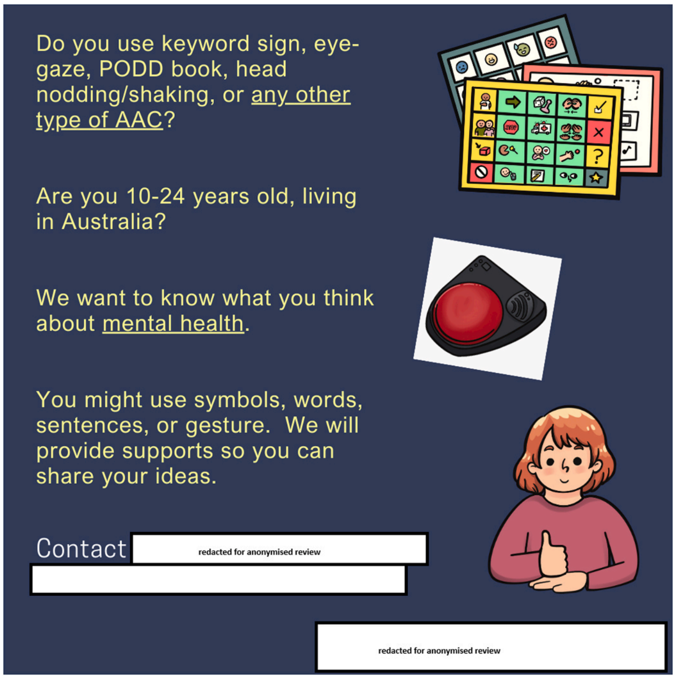
3. Outcomes: communication accessible research practices

3.1. Recruiting

Sampling and recruitment are crucial phases of research, the outcome of which determines the depth (qualitative) or representativeness (quantitative) of the study sample, and ultimately the applicability of study findings (Liamputtong, 2022). Therefore, communication accessible research practices must be applied to advertising and recruitment. If advertisements are not accessible to AAC-users, then they are inadvertently excluded almost immediately. In our study, we strived to develop communication-accessible advertisements and distribute them in ways that would reach AAC-users.

AAC-users are a heterogeneous group; they may or may not be literate, have comorbidities like intellectual disability and vision/hearing impairments, or have other physical access needs. We considered and integrated recommendations from the Web Content Accessibility Guidelines (WCAG; World Wide Web Consortium, 2008), the Centre for Inclusive Design (CID; Centre for Inclusive Design, 2025), and the Inclusive Research Toolkit (Walsh, Harman, et al., 2024b), alongside insights from consumer co-researchers, and clinician-researcher experience adapting materials for people with disability. We created flyers which used plain language written in high-contrast text, accompanied by graphic symbols (Fig. 2). Still images had alternative text so that they could be accessed by screen-readers. We also created videos which had both spoken word and closed captions.

Importantly, we wanted AAC-users to know that this research was *for them*. Consumer co-researchers and the Inclusive Research Toolkit (Walsh et al., 2024b) emphasised that AAC-users might need to be explicitly welcomed to participate. To address this, we a) listed specific AAC types in advertisements (e.g., *"Do you use Keyword Sign, eye-gaze, PODD book, heading nodding/shaking, or any other type of AAC?"*); and b) developed and shared a video in which {redacted author initials} used her AAC system to tell potential participants about the project. During study material development, we identified that AAC-users can feel discouraged by the word 'interview' so, in advertisements and emails, we were explicit about the range of alternative interview methods they could choose from



Do you use keyword sign, eye-gaze, PODD book, head nodding/shaking, or any other type of AAC?

Are you 10-24 years old, living in Australia?

We want to know what you think about mental health.

You might use symbols, words, sentences, or gesture. We will provide supports so you can share your ideas.

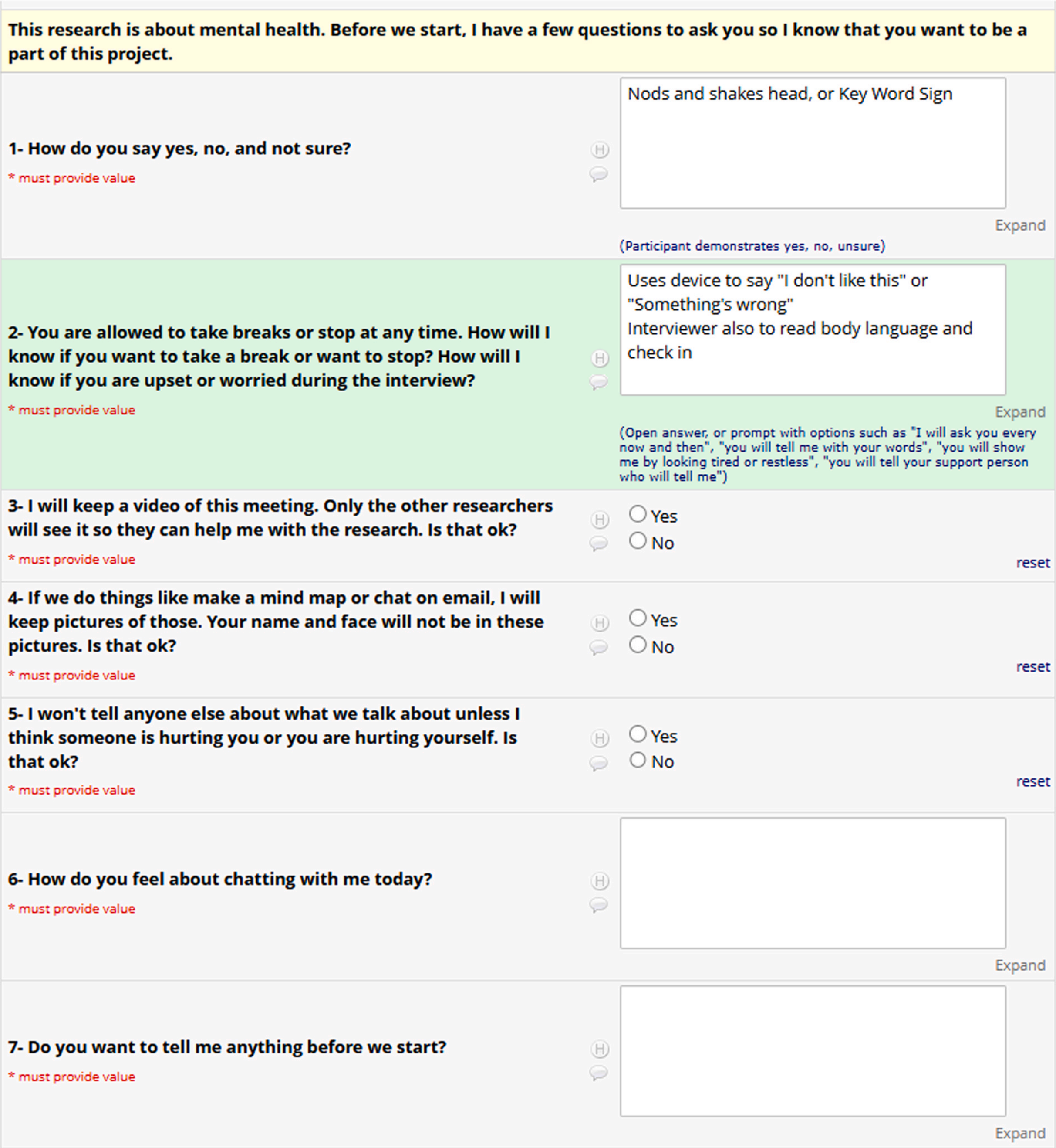
Contact redacted for anonymised review

redacted for anonymised review

Fig. 2. Research advertisement. Example of communication-accessible codesigned flyer.

(e.g., email, text; these will be described further in Section 3.3).

Once the recruitment material had been created, our consumer co-researchers led its distribution to relevant communities to increase the likelihood that advertisements would reach AAC-users directly. People with disability face additional barriers accessing digital media (Hynan et al., 2015; Raghavendra et al., 2012) and may have a reduced online presence, so relying on social media alone is not sufficient. Therefore, we also shared the recruitment materials directly with potential “gatekeepers”, such as parents and speech pathologists, explaining the research and its significance, and asking them to share the information with AAC-users known to them. We encouraged AAC-users to contact the research team in the way that suited them best, e.g., email, text message.



This research is about mental health. Before we start, I have a few questions to ask you so I know that you want to be a part of this project.

1- How do you say yes, no, and not sure?
* must provide value
Nods and shakes head, or Key Word Sign
(Participant demonstrates yes, no, unsure)

2- You are allowed to take breaks or stop at any time. How will I know if you want to take a break or want to stop? How will I know if you are upset or worried during the interview?
* must provide value
Uses device to say "I don't like this" or "Something's wrong"
Interviewer also to read body language and check in
(Open answer, or prompt with options such as "I will ask you every now and then", "you will tell me with your words", "you will show me by looking tired or restless", "you will tell your support person who will tell me")

3- I will keep a video of this meeting. Only the other researchers will see it so they can help me with the research. Is that ok?
* must provide value
○ Yes
○ No

4- If we do things like make a mind map or chat on email, I will keep pictures of those. Your name and face will not be in these pictures. Is that ok?
* must provide value
○ Yes
○ No

5- I won't tell anyone else about what we talk about unless I think someone is hurting you or you are hurting yourself. Is that ok?
* must provide value
○ Yes
○ No

6- How do you feel about chatting with me today?
* must provide value

7- Do you want to tell me anything before we start?
* must provide value

Fig. 3. Adapted verbal informed consent form: REDCap form used to record participants’ responses to the adapted verbal informed consent process.

3.2. Obtaining consent

Informed consent is the second crucial point of contact with AAC-users which can be a barrier to research participation. In research, informed consent is when a person understands what a study is about and then communicates their agreement to take part in it (Liamputtong, 2022). Traditional informed consent procedures usually involve written documents describing study aims, benefits/risks, participant rights, data management, etc.—often resulting in long, text-heavy documents that a person is expected to read, understand, and respond to. Informed consent might also involve a conversation between participant and researcher. However, researchers unfamiliar with AAC may hesitate to have these conversations or find it challenging to have them effectively. In most cases, if a person is unable to consent in the manner outlined in a research protocol, then they do not participate in the research. As such, we require inclusive consent practices.

Other researchers have used an informed consent process for AAC-users whereby they ask a potential participant several yes/no questions to assess their capacity to consent (Sellwood et al., 2022; Taylor et al., 2021). Examples of questions from these two studies include “can anyone other than me, my assistant and supervisors access your answers?”, “will your real name appear in the final thesis or any publication of this research?”, and “can you pull out of this study at any time without penalty?”. In our study, we considered a similar process; however, consumer co-researchers reflected that we do not typically quiz non-disabled people on study components before enrolling them and we should not hold AAC-users to a higher standard than others. This idea was also asserted in an evaluation of informed consent processes for adults with intellectual disability by Strickler and Havercamp (2023), along with a proposal that “the threshold for demonstrating capacity to consent should be proportional to the complexity and risk of each study”.

We therefore codesigned two methods of achieving informed consent: an adapted verbal informed consent procedure and a standard written informed consent procedure. Each method was described within the protocol, allowing researcher flexibility when engaging with eligible participants.

3.2.1. Adapted verbal informed consent

The adapted verbal informed consent process was codesigned to allow AAC-users to provide their informed consent in a way that met their cognitive and communication access needs. This consent process happened during a pre-interview meeting via Zoom. A crucial part of ensuring consent was *informed* was providing information about the research study in a format that was meaningful to the person (e.g., using our codesigned Young Person Information Sheet, using their AAC system, providing information with visual aids, and/or having a support person help explain concepts). The consent process then asked 1) how the participant indicates *yes*, *no*, *unsure*, *I want to stop/I need a break*, *I am upset*; 2) whether they agree to key components of the study such as video recording; 3) how they feel about participating overall (Fig. 3). Since the codesign process prioritised a flexible approach, participants could respond to these questions using multimodal communication, e.g., words, head nod/shake, device, Zoom chat function. The responses were recorded in REDCap, an electronic data capture tool hosted at The University of Melbourne. In addition to informed adapted verbal consent from the young person, in most cases, a parent or legal guardian also provided consent for their child or the young person in their care to participate in this study.

3.2.2. Standard written consent

We also recognised that some people with communication disability may be able to use standard written informed consent procedures (e.g., reading and signing a written document), so that option was available to participants for whom it was appropriate so as not to make providing consent a laboursome or disengaging process.

3.2.3. Continuous consent

The interviewer was vigilant in monitoring for continuous consent throughout the interview. Since initiation of new conversation topics can be challenging for AAC-users (Beukelman & Light, 2020), the interviewer gave participants frequent opportunities to exercise their rights, such as taking a break, skipping questions, or withdrawing from the study. The following transcript demonstrates an instance in which the interviewer immediately responded to a participant’s indication to stop the interview:

1. Interviewer: Yeah. Do you have {more MORE} to say about that topic? Is there something else you want to add?
2. Participant: WANT GO.
3. Interviewer: You want to go? Do you want a break?
4. Participant: NO
5. Interviewer: Do you want to stop completely?
6. [pause]
7. Interviewer: Do you want to stop this chat?
8. Participant: YES
9. Interviewer: Okay, of course.

3.3. Collecting data

Consumer co-researchers were involved in all study phases, however had a particularly instrumental role in brainstorming inclusive data collection strategies. Our discussions led to the conclusion that choice and responsivity were essential. In a pre-interview meeting, after obtaining consent, the interviewer and participant (with or without a support person) collaboratively determined the most suitable data collection method. While the interviewer could offer recommendations based on their clinical experience with AAC-users, we ensured that participants were fully informed about all the options available to them. A recent scoping review by Keane and Kocsis (2025) identified and described 32 studies that involved adult AAC-users in qualitative research—they asserted that giving participants choice about how they are interviewed is one way to uphold their agency.

In our study, the main choice that participants made was whether they wanted to complete the interview in-person, via Zoom, text, email, or a combination. This aimed to remove communication and physical barriers and capitalise on individual communication strengths. For AAC-users who can fluently type complex and detailed sentences with little effort, email or text message might work well; for AAC-users who are not literate and use a communication book and Key Word Sign, an in-person interview would be suitable. Other choices could be made to further tailor their interview process; participants could employ a mixture of any of these strategies and change their interview method depending on what was working or not. This responsiveness was embedded within the study design so that changes to interview methods, within reason, were not considered deviations from the protocol. An example of a change that is not reasonable is one where the AAC user's experience is no longer being directly represented, such as a parent fully responding on their behalf.

3.3.1. *Synchronicity, time, and preparation*

Participants using email/text message could choose to have conversations with the interviewer in real-time (like a live chat) or asynchronously with all prompts given at once and responses returned later. One benefit of live chat is a more natural flow and opportunities for follow-up questions; however asynchronous communication provides the participant with more thinking time and is useful for participants whose schedules do not allow real-time chats with the interviewer (Ison, 2009).

An important consideration for real-time interviews is to allow sufficient time. Communication rates for AAC-users are 15–25 times slower than for people using speech (Beukelman & Light, 2020). There are several strategies for addressing this, other than simply scheduling a longer interview. In our study, AAC-users could choose to be given the ideas or the exact prompts in advance of a Zoom or in-person interviews. This was appropriate for participants who preferred to reflect on the prompts and organise their thoughts, who wanted to check for relevant vocabulary in their AAC system, or who wanted to pre-program their responses on a high-tech device. Participants could also choose to split the interview into several sessions. This might address fatigue and scheduling challenges. The duration of involvement in this study would vary for each participant depending on their specific needs. For example, some participants may require only one or two meetings to share their ideas on the topic; other participants may need more meetings or want to follow up with email correspondence.

3.3.2. *Language and cognitive support*

Language may be supported by offering visual supports, simplified questions, and other strategies which reduce cognitive load. There is myriad of visual communication and cognitive supports, including Aided Language Displays, Picture Communication Symbols, Easy Read strategies, and Talking Mats™. We used these tools dynamically, responding to the needs of the participants as they arose. For example, different interview schedules were created—a standard schedule from which the interviewer read prompts, and a schedule where each prompt was presented with simplified text and a relevant image, shown one at a time to the participant using PowerPoint. While we endeavoured to find out what communication supports would be useful to a participant prior to beginning an

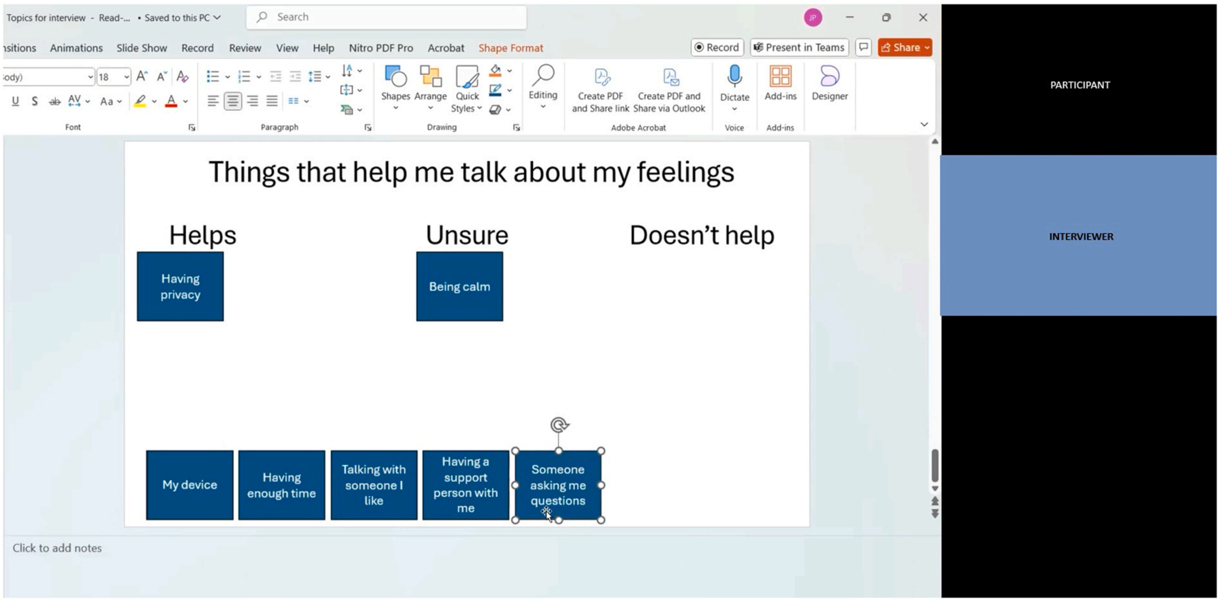


Fig. 4. Talking Mat completed online. Screenshot taken from a Zoom interview with a participant in which Talking Mats was used.

interview, we also planned to have a range of support tools ready to implement with little notice.

Talking Mats™ is a thinking tool which supports users to organise their ideas and provides a visual structure on which to base further discussion (Murphy & Cameron, 2008). Fig. 4 depicts Talking Mats™ completed digitally via Zoom. The options (blue boxes) began at the bottom of the PowerPoint page. The participant told the interviewer which column he felt they each belonged to, and the interviewer moved them into place. Fig. 5 depicts Talking Mats™ completed in-person. The interviewer planned to use traditional Talking Mats™ methods in which the participant would physically place the card in the relevant column themself. However, for this participant, the cognitive and physical demand of considering his response and placing the card was too high—so the interviewer physically placed the card into the column he indicated. In another example, a participant's mother vetted the wording of the options before her daughter completed a mat, e.g., suggesting "doing things for other people" be simplified to "helping others".

The following transcript demonstrates how the interviewer changed the questioning style to provide cognitive support. As asserted by Keane and Kocsis (2025), closed-questions, while usually considered restrictive, can support AAC-users' participation in interviews.

1. Interviewer: And why is that hard to do?
2. [pause]
3. Interviewer: I know that's a big question, right? So, do you want to use your device to come up with an idea…
4. [pause]
5. Interviewer: Or do you want me to come up with some reasons and you can tell me yes or no?
6. Participant: YES.

A research issue that some may pose in this context is about the richness or depth of qualitative data yielded, to which we (and others, e.g., Lloyd et al., 2006) argue is not justification for exclusion of people who require language or cognitive support. One solution is the tailoring of analysis methods; in our protocol, we explained that interpretive description or thematic summary would be considered, with the choice "depend[ing] on the depth of analysis that is possible from the data collected."

3.3.3. *Multimodal communication*

Consumer co-researchers emphasised that we should not make participation harder for an AAC-user than it needs to be, therefore multimodal communication was accepted and encouraged. For example, we did not try to elicit a response from a high-tech device if the participant communicated the message effectively in another way. Device-use can be fatiguing (Beukelman & Light, 2020) and can lack nuance due to limited vocabulary and a lack of prosodic features (Na et al., 2016; Pullin & Hennig, 2015), whereas natural gesture, facial expression, or Key Word Sign might better facilitate nuanced expressive communication. The following transcript demonstrates how a participant used multimodal communication in a single conversational exchange (natural gesture [line 2], spoken single word [line 5], picture communication symbol [line 5], and Key Word Sign [line 8]) to clearly express that *being around other people, such as his support worker, is very important to him.*

1. Interviewer: What about being around other {people PEOPLE}?
2. Participant reaches toward his support worker.
3. Mum: Yeah, like Dina.
4. Interviewer: Is that important?
5. Participant: Yeah. PEOPLE.
6. Mum: That must be very important because he touched [the People picture card].
7. Interviewer: Yep, he did. Alright, we'll put that on there.
8. Participant: LOVE. LOVE.

Fig. 5. Talking Mat completed in-person. Photo taken of a completed Talking Mat during an in-person interview. Image cropped to remove identifying features.

3.4. Using support people

Support people may be used in research by AAC-users for several reasons, including to disrupt power imbalances between interviewer and participant, to maximise AAC-user participation in a study (e.g., by supporting their communication competence), and to enhance authenticity of data collected (Lutz et al., 2016). Dee-Price (2023) described support people as a "communication bridge" between AAC-users and researchers, whereby they assist both the participant to communicate and the researcher to understand.

At any stage of our study, AAC-users were able to have a support person present to provide conversational support and/or help them feel at ease. The support person could be an informal carer (e.g., parent), a paid carer, or a consumer co-researcher. For participants who have access to a paid carer, we offered reimbursement of that cost, so as not to disservice participants by using their government-funded disability assistance for our research project. A consumer co-researcher was an appropriate option for participants who desired peer support and privacy from their own support people. Costs associated with paid carer reimbursement and consumer co-researcher interview support were built into the research budget.

The following transcript excerpt demonstrates how a support person facilitated data collection by adding contextual information essential for deriving meaning from what the participant had said:

1. Interviewer: How about… When you're feeling {good GOOD}, {where WHERE} are you?
2. Support person: Oh, where are you? If we go to {places PLACES}… Where are you when you feel good?
3. Participant uses her device to say the name of a place that the interviewer does not recognise. Actual name redacted for privacy.
4. Support person: That's her day program.
5. Interviewer: Yep, so you feel good when you're at day program!

The following transcript excerpt demonstrates how a support person provided conversational support by repairing a communication breakdown between the interviewer and participant:

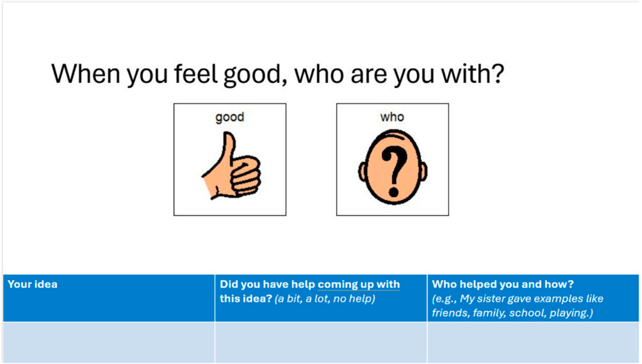
1. Participant: SICK. TOO-HARD. STOMACH. I-DON'T-WANT-TO-DO-IT.
2. Mum: Yeah, that's how he tells me…
3. Interviewer: Do you not want to do this [interview] anymore or-
4. Mum: No, I think he's telling you that's what he tells me to show his feelings.
5. Participant: YES.
6. Interviewer: Ah okay.

There are challenges when including support people in interviews (Dee-Price, 2023; Lutz et al., 2016). For one, it is important to be clear about whose ideas and experiences are being received to ensure data quality. In our research, participants who had a support person help them prepare responses without the interviewer present were asked to complete a table specifying to what extent the response was the AAC-user's own idea (Fig. 6). The interviewer also remained attuned to the limitations of a support person's assistance, as evident in the following excerpt from a post-interview reflection:

> "At times, the meaning of the participant's messages wasn't completely clear to me. The support person supported to construct meaning from the words he used; but sometimes, we both acknowledged that we didn't know what he meant."

3.5. Obtaining ethical approval

Two challenges related to gaining ethical approval for research involving vulnerable people are that Human Research Ethics



When you feel good, who are you with?

Your idea	**Did you have help coming up with this idea?** *(a bit, a lot, no help)*	**Who helped you and how?** *(e.g., My sister gave examples like friends, family, school, playing.)*

Fig. 6. Support received during an asynchronous interview. Screenshot showing the table filled out by participants to describe the support they received when responding to interview prompts.

Committees (HRECs) might not be familiar with proposed methods and that they may take a paternalistic and risk-averse approach (Schroeder et al., 2024).

In relation to the former challenge (unfamiliarity with methods), this is particularly relevant because, as seen in the above sections, research practices should be flexible and responsive to be inclusive of AAC-users. Walsh et al. (2024) stated that even though flexibility "reflects best practice in inclusive disability research", it produces uncertainty within HRECs. Therefore, ethical applications should be written in such a way that relays the imperative nature of responsive research practices. We suggest the inclusion of vignettes in study protocols/ethical applications to provide worked examples of planned methods. In our study, we used vignettes (**Supplementary 1**) to describe hypothetical participants and the processes by which they would provide consent, demonstrating the heterogeneity of our participant group and the responsivity with which we would meet their needs.

In relation to the latter challenge (paternalism, aversion to risk), we suggest the inclusion of a protocol section highlighting that vulnerability is context-dependent and should be "assessed on a protocol-by-protocol basis" (Shivas, 2004). We addressed potential concerns around vulnerability and risk, as demonstrated by the following excerpt from our protocol:

> "Many participants in this study will belong to one or more of the categories of vulnerable groups listed in Section 4 of the NHMRC National statement on ethical conduct in human research, (2023) (2023), in particular the following two groups:

- children and young people
- people with a cognitive impairment, an intellectual disability, or a mental illness

> Just because a person belongs to one of these groups, does not mean they shouldn't participate in research. As per Section 4.5.3, 'people with a cognitive impairment, an intellectual disability, or a mental illness are entitled to participate in research, and to do so for altruistic reasons.'
>
> As with any participant, the risks associated with research are 'ethically acceptable if they are justified by the potential benefits of the research' (NHMRC National Statement Section 2.1.2). The potential benefits of this research outweigh its potential risks. Risks and their management/mitigation strategies are identified in *Section 6* of this protocol. At a population/group level, the risks associated with not conducting research and progressing practice in this area (i.e., poor wellbeing, unmanaged mental health problems) are greater than the risks of conducting this study."

4. Discussion

The objective of this paper is to provide researchers with practical strategies for addressing the communication access needs of AAC-users and increase the likelihood of their inclusion in research. We integrated what was learned during our qualitative study with authors' lived and clinical experience and existing literature to identify three "pillars" of communication accessible research: participatory attitudes, flexibility and responsivity, and consumer engagement.

4.1. Three pillars of communication accessible research

Our results suggest that, to conduct communication accessible research, researchers must hold **participatory attitudes**, believing that AAC-users might want to participate in research (agency), can participate in research (competence), and it is fair for them to do so (equity). This finding aligns with the literature suggesting that beliefs about people, rather than the actual characteristics of those people, might determine their access to research participation opportunities (e.g., Gallegos et al., 2023). The strategies described in our results, along with several examples from the literature in which AAC-users were directly involved (Keane & Kocsis, 2025), demonstrate that, with scaffolding, AAC-users can participate in research even if that participation looks different to that with which a researcher is familiar.

A logical extension of participatory attitudes is the requirement for **flexibility and responsivity**. Researchers must recognise the necessity and benefit of flexible and responsive study design (Budworth, 2023) so they can advocate for and describe it in research protocols. In our experience, direct and prompt acknowledgment of ethical concerns associated with flexible and responsive design supported the ethical application process.

This excerpt from a post-interview reflection captures the first two pillars well:

> "This participant moved around a lot, between the table and the floor in different rooms. The only issue this posed was that I had to move my laptop to try find a good position each time whilst keeping the interview going at a suitable pace."

Given this participant's presentation, had the researcher's prevailing attitude been that he could not participate in an interview, he would have been excluded and his experiences not heard. The interviewer was responsive by taking a dynamic interview approach, rather than interpreting his presentation as an indication of not wanting or being able to participate. This situation was not a deviation from the study protocol, as we had embedded flexibility within it.

The third pillar is **consumer engagement**. Consumer co-researchers can be involved in projects to varying degrees. Ideally, consumers with lived experience of the study condition should be involved in all phases of the research cycle, right from setting the research agenda. However, there are reasons why consumer engagement will not always involve people with communication disability. One, resource availability can place constraints on consumer co-researcher involvement (Bailey et al., 2015); it might not be possible to facilitate involvement to a high degree for every research project due to time, funding, or availability constraints. Two, it is not only AAC-related research that is relevant to AAC-users; mainstream health research is also relevant (Rios et al., 2016), and not all mainstream health research should necessarily prioritise AAC-users as consumer advisors. To make efficient use of limited resources, and to support AAC-users' participation in mainstream health research, researchers should familiarise themselves with strategies already developed and published by people with communication disability such (e.g., Walsh et al., 2024b) and consider how what is proposed in the literature can be tailored to their specific project.

Since the aim of this paper is to describe communication accessible research practices, readers might perceive consumer involvement as purely a method to make study design more inclusive. This is a valid motivation, aligning with a substantive value system which focuses on the *consequences* of public engagement in research, e.g., effectiveness, quality/relevance (Gradinger et al., 2013). However, researchers, including ourselves, may value consumer involvement for reasons other than just its consequences. The normative value system focuses on *ethics* of consumer involvement (e.g., empowerment, rights) and the process value system focuses on the *conduct* of consumer involvement in research (e.g., openness, partnership). We invite readers to consider their own motivations for involving consumers in research, as this will influence their approach to consumer engagement (Popay & Collins, 2014).

4.2. A sixth application area

In this paper, we addressed Walsh and colleagues' five application areas for accessibility: recruitment, consent, adapted research methods, communication supporters, and ethics (2024a). We propose that another application area is the dissemination of findings. In our primary study, we have not yet reached this phase but have made provision for accessible dissemination methods. As suggested in existing literature (e.g., Parent-Johnson & Duncan, 2024), consumer co-investigators are crucial partners in dissemination as they are well-positioned to share findings with their respective communities. One example of consumer co-investigators as drivers of inclusive research dissemination is by Ćwirynkało et al. (2024); they reported that their co-researchers with intellectual disability were eager to produce an article for a magazine read by the disability community. In our own study, we will use strategies that reflect universal design because ensuring information is accessible to those with the greatest need means that it can be understood and used to the greatest extent possible (Centre for Universal Design Australia, 2021). Strategies include plain language summaries, Easy Read summaries, infographics that incorporate images from common AAC symbol sets, video summaries with closed captioning and Key Word Sign.

4.3. What this paper adds

This paper aimed to equip researchers with knowledge required to address the needs of people with communication disability, increasing the likelihood of their rights-based inclusion in research. We proposed several communication accessible research practices across different study phases. The inclusion of direct examples from a primary study will support readers to action the given recommendations. The integration of our learnings led us to propose three pillars of communication accessible research—participatory attitudes, flexibility and responsivity, and consumer involvement. It is our hope that this earnest and purpose-driven paper will empower researchers to make their own projects more inclusive to people with communication disability.

CRediT authorship contribution statement

Pennacchia Jacinta Molini: Writing – review & editing, Writing – original draft, Project administration, Methodology, Formal analysis, Conceptualization. **Pacheco Chris:** Writing – review & editing, Methodology, Conceptualization. **Coghill Dave:** Writing – review & editing, Supervision, Methodology, Conceptualization. **Bonyhady Greg:** Writing – review & editing, Methodology, Conceptualization. **Wong Shirley:** Writing – review & editing, Methodology, Conceptualization. **Granlund Mats:** Writing – review & editing, Supervision, Methodology, Conceptualization. **Imms Christine:** Writing – review & editing, Supervision, Methodology, Conceptualization.

Declaration of Competing Interest

The authors have no competing interests to declare.

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Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at doi:10.1016/j.ridd.2025.105108.

Data availability

Data will be made available on request.

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