The Toolkit

Inclusive Research Toolkit

Including people who use augmentative and alternative communication (AAC) in research

The Team

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The Toolkit

Version: 1.0

Current version dated: May 2024

Acknowledging use of the Toolkit. The Toolkit has been developed as a resource for researchers and the authors encourage use and amendment of the Toolkit material to suit researchers' needs and context. The authors request that the source of any information from, or adapted from, this Toolkit be accurately cited.

Suggested citation: Walsh, M., Harman, I., Manning, P., Ponza, B., Wong, S., Shaw, B., Sellwood, D., Anderson, K., Reddihough, D., & Wallen, M. (2024). Inclusive research toolkit - including people who use augmentative and alternative communication (AAC) in research. https://acu.qualtrics.com/jfe/form/SV_3aU481INyYDhaZg

Available at: Click this link or scan the QR code to download a copy of the Toolkit.

Acknowledgements

State Trustees. This work was supported by State Trustees Australia Foundation (Grant ID: STAF-CI-FY22-25).

CP-ACHIEVE. All authors of this Toolkit are affiliated with, and Megan Walsh is supported through, the Centre of Research Excellence: CP-ACHIEVE funded by the NHMRC (Grant ID: APP1171758).

The team would like to thank the communication supporters of One Group Our Voice Advisors and Millie Cook for their invaluable contribution to the Toolkit.

We are also very grateful for the support of all the CP-ACHIEVE "family", the researchers and staff who provided practical support and input to this Toolkit.

The authors acknowledge and pay our respects to the Traditional Owners and Custodians of the lands on which each of us live and work. We recognise and honour the importance of Aboriginal and Torres Strait Islander peoples' spiritual and cultural connection to Country. Sovereignty of the lands and waterways which Aboriginal and Torres Strait Islander peoples have cared for and nurtured for millennia has never been ceded. They always were and always will be Aboriginal and Torres Strait Islander peoples' lands and waterways.

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We appreciate your interest in this Toolkit and would value your feedback.

Tell us what we need to work on, other resources to include, and what is working well.

Scan the QR code or click here to answer six quick questions.

Your feedback will be completely anonymous.

INTRODUCTION

About this Toolkit

We identified that people with cerebral palsy who use augmentative and alternative communication (AAC) are infrequently included in research. AAC users have a right to be involved in research, both as participants and as consumer research partners.

Researchers and AAC users collaborated to address this inequity. We developed a *framework for involving people who use AAC as research participants and consumer research partners*. The Framework and accompanying knowledge and practical resources are contained in this Toolkit.

Background to the Toolkit

Details about the background information on involving AAC users in research and the methods we used to develop the Toolkit are contained in this companion publication (available at the link below or using the QR code):

Walsh, M., Harman, I., Manning, P., Ponza, B., Wong, S., Shaw, B., Sellwood, D., Anderson, K., Reddihough, D., & Wallen, M. (2024). Including people who use augmentative and alternative communication in qualitative research: Can you hear us? *International Journal of Qualitative Methods, 23*, 1-13.

Click this link to access a copy of this article.

Who we are

We are a team of people with cerebral palsy who use AAC, researchers and consumer involvement advocates. We are part of CP-ACHIEVE. CP-ACHIEVE is an NHMRC-funded Centre for Research Excellence with a focus on research to improve the health, well-being and participation of adolescents and young adults with cerebral palsy. CP-ACHIEVE is committed to involving people with lived experience of cerebral palsy as consumer research partners in our activities. The AAC users on the team form an advisory group – One Group Our Voice.

Click here for more information about CP-ACHIEVE

Meet our team

Megan Walsh	Speech pathologist PhD Candidate with CP-ACHIEVE
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Dr Darryl Sellwood	Person with lived experience of cerebral palsy AAC user
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Dr Kate Anderson	Research Associate – CP-ACHIEVE
Prof Dinah Reddihough	Chief Investigator – CP-ACHIEVE
Associate Professor Margaret Wallen	Occupational therapist and researcher at Australian Catholic University CP-ACHIEVE Consumer Involvement Theme Team Leader

Defining AAC users for this Toolkit

Many terms are used to describe people who use AAC. Some of these are: non-speaking or semi-speaking, non-verbal, people with complex communication needs, people with complex communication access needs, people who use AAC, and AAC users.

Which terminology to use?

In 2022, AAC vocabulary company AssistiveWare completed a survey of AAC users and people associated with AAC users (including family members and speech therapists) about the terminology they preferred. A recommendations from the survey was, where possible, to ask the person what terminology they preferred. Click here for a summary of AssistiveWare's survey findings

One Group Our Voice decided to use the terminology: "AAC user" or "person who uses AAC"

Intentional communication

For this project, we distinguish between people with profound intellectual and multiple disabilities, who may not be able to intentionally send a message to communicate, and AAC users who communicate intentionally.

We have focused on strategies to include *intentional symbolic* communicators in research. That is, people who use AAC to intentionally communicate a message, and use AAC which includes symbols such as pictures, signs, or written and device-generated spoken words.

People with profound intellectual and multiple disabilities, who may unintentionally communicate, will need different skills, knowledge and strategies to support their communication than AAC users. See Appendix 1 for resources which illustrate authentic involvement of people with profound intellectual and multiple disabilities in research, and may prove helpful for those seeking to include this particular sub-group of people with complex communication needs.

Defining consumer research partners versus research participants.

This Toolkit aims to support involvement of AAC users as consumer research partners and research participants.

Research participants are AAC users who are the "subject" of the research. We collect data from them and these data are analysed and interpreted to answer research questions. Research is done "to", "about" or "on" research participants.

Consumer research partners, however, are AAC users who consult with, or advise researchers, or collaborate with researchers to influence any or all stages of research. Research is done "with" consumer research partners. The aim of involving consumer research partners is to design and implement research informed by their lived experience which will be accessible for AAC users as participants.

Accessible research will enable AAC users to be fully included, ensure the research is applicable and acceptable to AAC users, and the findings are meaningful and translatable (p.3, Walsh et al., 2024)

Who could use the Toolkit?

We developed the Toolkit to support researchers to involve AAC users in research as research participants or research partners.

This toolkit may be helpful for:

- Researchers who work in the field of cerebral palsy preparing to involve AAC users in research, who wish to develop their confidence, or who want to increase the scope of their involvement.
- Researchers who work with other kinds of AAC users, especially AAC users with childhood-onset disability (for example, people with Angelman Syndrome)

This Toolkit is intended for researchers and we have not yet created a version which is accessible for people with disability.

What to expect in this Toolkit

This toolkit will:

- Introduce you to members of the team who use AAC and provide authentic examples to illustrate aspects of the Toolkit. We have drawn on practical examples from One Group Our Voice to illustrate some of the main ideas presented in the Toolkit. Several sections feature video of One Group Our Voice members explaining concepts and practical applications in their own words to illustrate the information being provided.
- Provide a framework for making research accessible to AAC users at each stage of the research process.
- Present practical strategies, examples and resources to support you in involving AAC users as research participants and consumer research partners.
- Provide links to additional information or support about specific aspects of including AAC users in research.

How to use this toolkit

Read the background section. This section delivers information about a range of issues that are useful background to using the Toolkit.

Familiarise yourself with the Framework. We provide an overview of the framework for involving people who use AAC as research participants and consumer research partners and identify which components are the priorities to inform your work.

Work through details of each component of the Framework – either systematically or focussing on those you need to impact your work. We encourage you to engage with the Balancing Power section – understanding power and power imbalance is crucial to approaching the remainder of the Framework.

Explore the resources and templates. Links to resources and templates that you can use and adapt when working with AAC users are embedded in each relevant section.

BACKGROUND

More on AAC

AAC (augmentative and alternative communication) is any kind of communication that is not speech. It can help people make their speech understood. It can be used instead of speaking to communicate. It can also help with comprehension, that is to support the AAC user to understand what is being said to them (often by supplementing spoken language with visuals such as Key Word Sign™).

Some AAC user will use an electronic communication device like a speech generating device which is accessed with a keyboard or using eye-gaze control technology. Other ways of communicating are not electronic and include signing, printed out boards of letter and/or symbols, gestures, and communication books.

Each AAC user employs a combination of AAC strategies to communicate, and each person's combination of strategies is unique to them. The combination of strategies may change based on a range of factors such as the environment the AAC user is in and who they are talking to.

Example - One Group Our Voice advisor, Shirley

Shirley uses many strategies including speech; nodding her head to indicate yes or no; typing into the chat box of Zoom/Teams from an adapted keyboard; using a text-to-speech app on an iPad and making choices from a list.

With familiar communication partners, Shirls primarily speaks and uses a printed out, laminated letter board to spell.

Resources - AAC

Speech Pathology Australia's plain language explanation of AAC

https://www.communicationhub.com.au/CommunicationHub/Communication_Hub/Resources/Fact_Sheets/Augmentative-and-Alternative-Communication.aspx

AGOSCI: An Australian and New Zealand organisation which "aims to serve people who may not rely on speech alone to understand or be understood by others."

https://www.agosci.org.au/

International Society for Augmentative or Alternative Communication (ISAAC) is "a membership organization working to improve the lives of children and adults with complex communication needs"

https://isaac-online.org/english/home/

Developed by Speech Pathology Australia and AGOSCI, the Communication Hub is a website with excellent resources and videos for people with communication difficulties, their communication partners, and the wider community.

https://communicationhub.com.au/

The official journal of ISAAC, *Augmentative and Alternative Communication, "*publishes peer-reviewed papers focused on all aspects of augmentative and alternative communication (AAC)."

https://www.tandfonline.com/journals/iaac20

How people with cerebral palsy use, or access, AAC

Approximately 1 in 3 people with cerebral palsy have complex communications needs, that is do not use speech alone for everyday functional communication (Australian Cerebral Palsy Register, 2018; Nordberg et al., 2013; Novak, 2014). Many of these people will use AAC to support their communication.

Motor difficulties associated with cerebral palsy affect the way people access their AAC devices. Examples of ways of accessing AAC devices including pointing at symbols or words, typing on an adapted keyboard, scrolling through options using a switch which is activated with head, elbow or foot movement, and using eye-gaze control technology.

Some people with cerebral palsy and motor difficulties access their communication using partner-assisted scanning. The AAC user will move their eyes, blink, or otherwise indicate yes/no to make selections while their communication partner scans through options of words or symbols in a communication book or on a communication board.

Examples of accessing AAC devices from One Group Our Voice

- Brenton and Shirley push buttons on their devices with their fingers, but they need their bodies and the devices to be positioned properly in order to accurately make the selection.
- Penny uses two switches to move a cursor around her device screen to select the picture symbol she wants to say, and that is then spoken by a speech generating device.
- Brodie uses a combination of eye-gaze to move a cursor around her screen, and a device on her wrist that she moves to select the picture symbol on her screen. Her computer will then speak information she selects.

Watch these videos to observe how different AAC users communicate using an electronic device and about involvement in One Group Our Voice.

Click this link to watch Brenton talk about including AAC users as consumer research partners.

Click this link to hear Brodie's views on being involved in One Group Our Voice.

Common myths and misconceptions about AAC and AAC users.

We've addressed these common myths and misconceptions in the table below:

Myth or misconception	True or False	Fact
AAC users have an intellectual disability.	False	Many AAC users do not have intellectual disabilities. Some AAC users do have intellectual disabilities. An AAC user with intellectual disability can participate in research as a research participant or consumer research partner. Accessible methods will be needed.
People with a certain level of intellectual disability can't participate in research.	False	Research methods can be adapted for everyone to be involved, regardless of their intellectual disability. People who communicate using symbols like Key Word Sign, picture symbols, or written words can participate as co-researchers and research participants. This is true even if they only use one word at a time. This Toolkit applies to this group. People who cannot communicate intentionally rely on other people to support their communication and interactions. They can still participate in research. See the resources in Appendix 1 for more information.
I can make a good guess about an AAC user's intellectual ability based on their expressive communication.	False	Expressive communication using AAC is not indicative of an intellectual disability. Assessments to determine intellectual ability are usually inaccessible to AAC users and often inaccurate (O'Regan et al., 2023). Results of those assessments should be viewed critically.
Inability to read or spell means a person has an intellectual disability.	False	Many AAC users do not have access to the full education curriculum and don't receive accessible literacy instruction (ref). This is because they do not have adequate AAC which can support this learning or people assume they couldn't learn to read or spell.
All AAC users use a communication device.	False	Each AAC user will have their own combination of communication methods that they use with different people, in different contexts, and at different times.

Myth or misconception	True or False	Fact
		Some people, particularly people with cerebral palsy, find electronic communication devices difficult to use due to physical disability. Those people may use other systems like a non-electronic communication book (for example, a PODD communication book*), where a communication supporter can help them access the book. Some people choose to use systems which are non-electronic and don't require having anything with you, such as Key Word Sign **. These options can be faster, lower cost, and transportable. Some AAC users communicate through a communication supporter who "revoices" their speech or other symbolic communication. For example, an AAC user may speak to the communication supporter, who is a familiar listener and can understand their speech. The communication supporter relays what the AAC user has said.

* PODD stands for pragmatic organisation dynamic display. A PODD communication book is a kind of AAC which contains symbols and/or words to aid communication between an AAC user and their communication supporters.

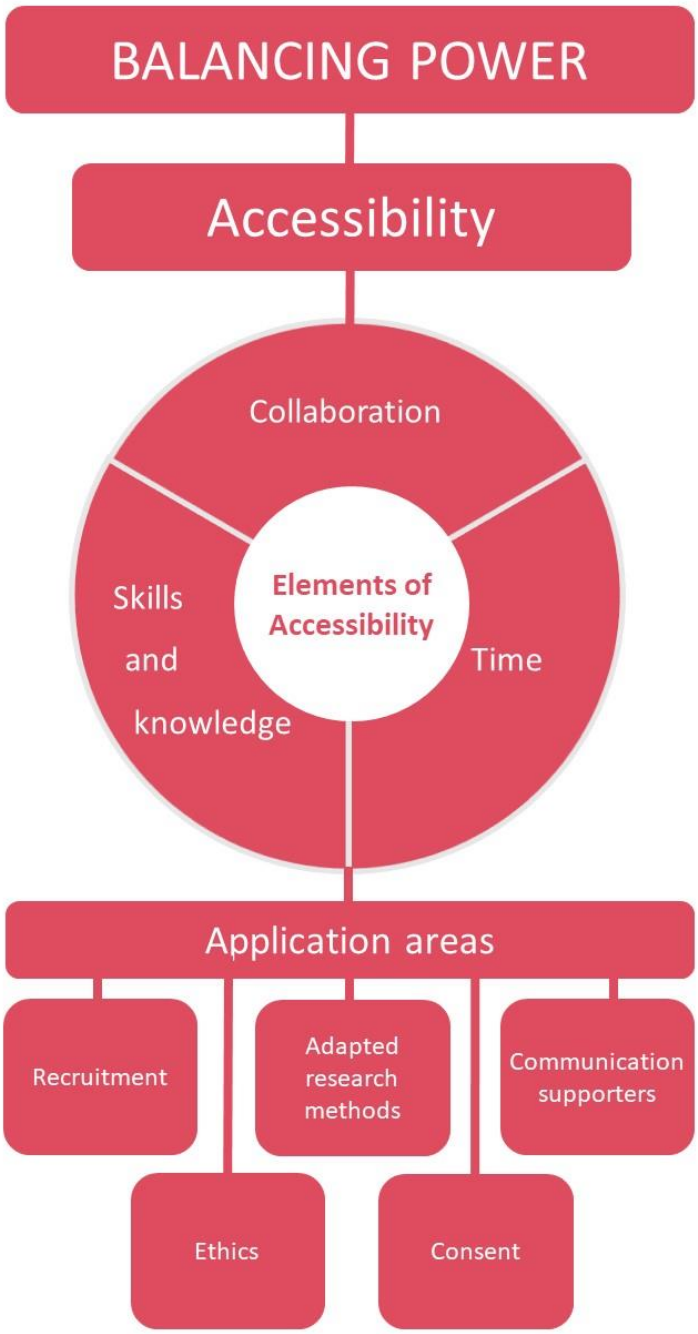
Click this link for more information about PODD communication books.

** Key Word Sign Australia.

Click her for more information on Key Word Sign

THE FRAMEWORK for involving people who use AAC as research participants and consumer research partners (The Framework)

Overview of the Framework



Power is a critical perspective in this framework.

Accessibility. Researchers can optimize AAC user involvement in research by addressing power imbalances and designing **accessible** research and research materials.

Three elements of accessibility:

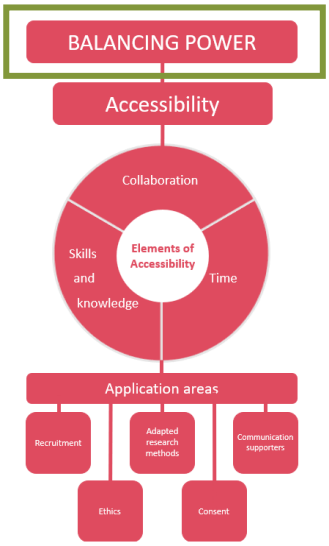
- **Collaboration** with AAC users
- Acquiring **skills and knowledge** to adapt research and materials
- Dedicating sufficient **time** to enable meaningful contributions from AAC users.

We identified five **application areas** where applying these three elements of accessibility can yield the most substantial impact:

- **Recruitment**
- **Working with communication supporters**
- **Adapted research methods**
- **Ethics**
- **Consent**

BALANCING POWER

The Framework – Balancing power



Power is an important consideration in all human research. Researchers working with people who use AAC need to be highly attuned to power imbalance. A power imbalance exists when one person is perceived to have more control or power in a situation than the other person, or exerts more control or power in a given situation. Power imbalance can be influenced by perceived power, which is the subjective belief or impression individuals hold about their own or someone else's influence. Perceived power is influenced by factors like communication skills, social status, age, presence of disability, and interpersonal dynamics.

People who exert power over AAC users can be parents, researchers, therapists, or communication support people. Sometimes people with perceived power are trying to be helpful, or protect AAC users, but their actions are still taking the power or control away from the AAC user.

Power imbalances often take the forms of **ableism** and **paternalism**.

Ableism

Ableism is the conscious or unconscious assumption that being non-disabled is superior to being disabled (Bogart & Dunn, 2019; Dirth & Branscombe, 2019). According to One Group Our Voice, ableism comes across to AAC users as:

- Being underestimated
- Facing (often false) assumptions about their intellectual ability
- Imposing expectations of communication and conversations that are true for “typical” people. For example, a speaking person not pausing and waiting for an AAC user to communicate, because in “typical conversations” lengthy pauses are unnatural and uncomfortable.

When asked what researchers should know about working with AAC users, One Group Our Voice advisors offered: “I am smart and I am funny”; “I understand but need time to process things” and “I’m not deaf, so don’t yell at me.” These responses reflect the legacy of common stereotypes ascribed to AAC users by professionals and community members, contributed to by underlying ableism (Bogart & Dunn, 2019).

Example from One Group Our Voice - Brodie

Click here to hear Brodie tell us her experience of power imbalance

Paternalism

Paternalism reflects a societal attitude whereby non-disabled people assume responsibility for looking after the best interests of people with disabilities, thereby taking away the people with disability's choice and control (Carney et al., 2021; Van Goidsenhoven & De Schauwer, 2022).

Paternalism can manifest in research involving AAC users, especially around opportunity to be involved in research and consent. Taylor and Balandin (2020), for example, describe a situation in which a disability organisation did not pass on invitations to be involved in research to AAC users, assuming they would not be interested or not be able to participate.

AAC users report that people often ignore or override their choices. For example, an AAC user may not be asked for their consent to be transferred out of a wheelchair, or they might state their choice and a person in power does something else that the person in power views as preferable for the AAC user.

Examples from One Group Our Voice - Brenton

Click here to hear about Brenton's experience of paternalism.

Mental health, power imbalance, and AAC users

Many AAC users report experiencing medical trauma, often related to failure to seek their consent, or their consent being ignored or overridden. AAC users also face social isolation and reduced social participation, in part because of the limited numbers of people who can communicate with them, and the inaccessibility of physical and social environments. Finally, like anyone else, AAC users' lives are intersectional. AAC users may have mental health concerns which are not directly related to their disability.

Mental health and its relationship to balancing power must be considered when working with AAC users both as participants and as co-researchers. Watson and colleagues (2023) offer guidance for improving communication access in psychoeducational interventions for people with complex communication needs.

Examples from One Group Our Voice - reflections on power

- Some AAC users in One Group Our Voice communicate much more quickly than others. We needed to make sure we were not preferencing the input from the faster communicators. We negotiated guidelines about respectfully waiting in silence while AAC users constructed and conveyed their views.
- In groups with both speaking people and AAC users, the speaking people can at times take over. One Group Our Voice's general guideline for our group is to have fewer speaking people than AAC users in the group, and for the AAC users to have the opportunity to answer first.

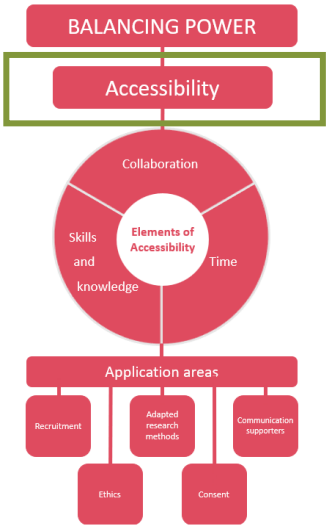
Some Advisors were initially hesitant to give their opinion. Some weren't sure what the "right" answer was, and others were wary of disagreeing with the coordinator (person in perceived authority). We addressed this in a couple of ways:

- Creating a role for an AAC user to become the group facilitator. Shirley, the AAC facilitator, says: "Each person in the group has their different way of communicating. As the group facilitator, my role is to make sure everyone has a chance to speak."
- Addressing the issue directly - helping advisors understand that the group exists because we want to hear their opinion, even if they think their opinion isn't what we want to hear.
- Adding a reminder on every meeting agenda, which says "Reminder: your feedback is valued. We want to hear your opinions, even if they are different than what you think we want to hear."

Click here to see an example of an agenda from a One Group Our Voice Advisory Group meeting

ACCESSIBILITY

The Framework – Accessibility



Researchers can address power imbalance by making research accessible.

We have identified three elements of accessibility:

1. Collaboration with AAC users
2. Acquiring skills and knowledge for working with AAC users
3. Allowing ample time to develop skills and knowledge, collaborate with AAC users and to ensure research materials are accessible.

1. Collaboration with AAC users

Collaboration with AAC users

Early and ongoing collaboration with AAC users is key to addressing accessibility of research.

Collaboration applies to two broad aspects of interaction between researchers and AAC users:

1.1. Collaboration with individual AAC users to understand their unique communication access needs.

Researchers will need to collaborate with AAC users to identify each individual's unique means of communication to ensure that their involvement in research is optimised. Communication may vary across different environments and platforms, and with different communication supporters. This collaboration is needed whether the AAC user involvement is as a consumer research partner or participant.

This Toolkit provides an Access Profile to guide and record this collaboration with consumers. The Access Profile guides conversations between AAC users and researchers and record the ways that the AAC user communicate, their guidance about facilitators to their involvement, and how they work with their support people.

Example - Access profile template and examples

Click here to access a template for the Access Profile

Click here to read Shirls' Access Profile

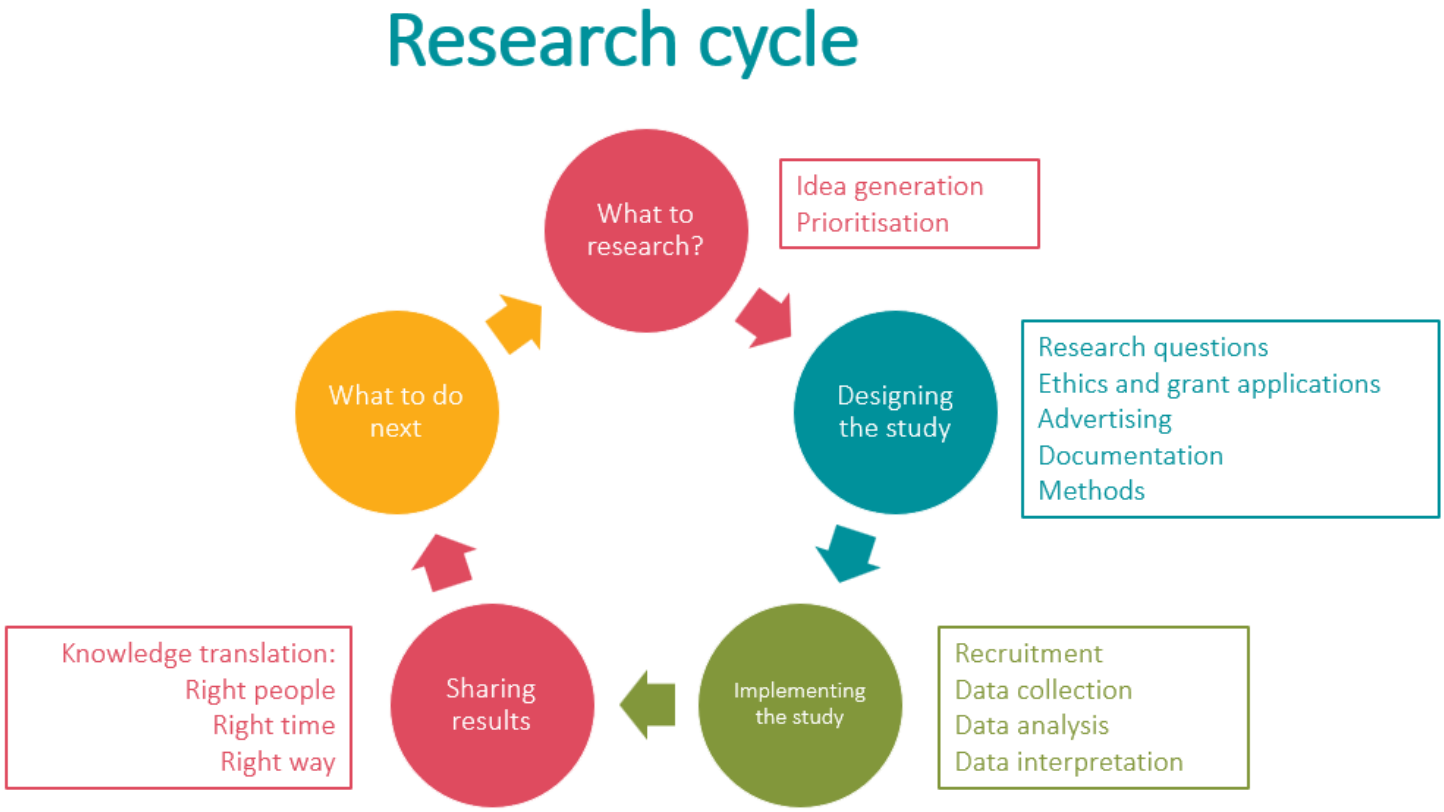
Click here to read Penny's Access Profile

Identifying accessibility of the physical environment. The physical environment will need to be accessible for any research activities which are in-person, for instance, in the community or a university. Collaboration with AAC users will involve identifying their mode of transport, need for a support person to accompany them, mobility and any use of assistive technology such as wheelchairs. Access to parking, buildings, rooms within buildings, bathrooms, and refreshments are all considerations, as are the time and funding to ensure access.

1.2. Collaboration with AAC users as consumer research partners throughout the research cycle

The second aspect of collaboration is partnering with AAC users to inform research. Collaboration can take various forms, such as consulting with an advisory group, closely collaborating with a group like One Group Our Voice, or involving AAC users as part of the research team. These forms of collaboration will have different amounts of influence on the research. Close collaboration with AAC users who are part of the research team at every stage of the research cycle is ideal. This degree of involvement may not be possible or affordable, so some collaboration, rather than none, in some research activities rather than none, is preferable. Refer to Figure 1 below for some of the activities that AAC users who are consumer research partners may be involved in.

Figure 1. Some examples of research activities that consumer research partners are involved in during the stages of the research cycle.



Collaboration will ensure that research is designed which meets the needs of AAC users, is respectful, authentic, inclusive and accessible. Collaboration will also enhance recruitment, retention, and participant motivation and well-being, contributing to meaningful implementation of findings in practice. The companion publication to this Toolkit states:

> By involving AAC users in the development of research methods, researchers can create feasible and accessible participant information materials and interview schedules that respectfully address important topics. Data collection facilitated by consumer research partners is likely to enhance participant engagement and authenticity. Collaborating with AAC users during data analysis and interpretation brings the perspective of lived experience, and a deeper understanding of the data and research findings, contributing to impactful, translatable outputs. Finally, collaboration will identify and implement the most impactful knowledge translation strategies. (Walsh et al., 2024, p. 7)

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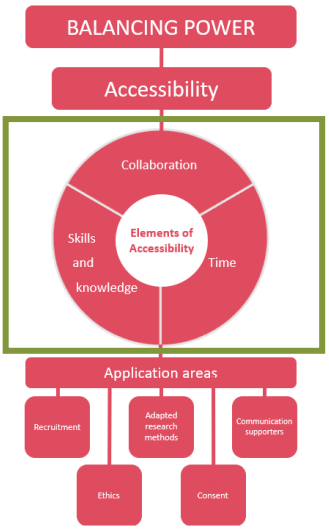
2. Acquiring skills and knowledge for working with AAC users

Acquiring skills and knowledge for working with AAC users



The second element of accessibility involves researchers acquiring skills and knowledge to involve AAC user in research. We present three main skills and knowledge sets: i) general knowledge about AAC users which will assist in delivering accessible materials, ii) knowing the etiquette to use when communicating with AAC users, and iii) the skills needed to adapt materials to optimise access for AAC users

2.1 General knowledge about AAC users which will assist in delivering accessible materials.

- Many AAC users, especially those with cerebral palsy, experience a range of health and co-existing conditions in addition to physical disability which impact on their ability to be involved in research. Some health conditions, such as epilepsy. fatigue and pain contribute to fragile health and difficulties meeting commitments. Others such as hearing and vision impairment contribute to the complexity of adapting and accessing communication.
- As a group, AAC users have lower literacy rates than their non-disabled peers (Machalicek et al., 2010; Taylor & Balandin, 2020). This may or may not be associated with intellectual disability and is frequently a reflection of an inadequately accessible education curriculum contributing to reduced opportunity to develop literacy.
- AAC users have a smaller online presence (Raghavendra et al, 2013; Taylor & Balandin, 2020), which could be due to inaccessibility of technology, reliance on others to access technology, fewer social networks, and lower literacy.

2.2. Etiquette when communicating with AAC users.

Several resources guiding etiquette when communicating with AAC users exist. Every AAC user's preferences are different and individual, however, following are the key points we focus on when involving AAC users in research.

- Address an AAC user directly, maintain eye contact and engagement. Don't look at their device unless needed.
- Ensure that AAC users have adequate and equitable opportunity to speak.
- AAC users are likely to take extra time to generate a message or response and may take more time to understand or process a question or comment.
    - Find out how to know that an AAC user is generating a response, especially if communicating over videoconference.
    - Watch for whether an AAC user is generating a response
    - Maintain silence while a message or response is being generated. Be comfortable with silence, don't try to fill the silence. Don't interrupt.
    - Leave plenty of time in meetings for the time taken for AAC users to generate their messages or responses.
    - Make sure that individuals who communicate more quickly do not dominate a conversation or meeting.
- Provide meeting or research materials in advance to assist AAC users to prepare their thoughts and/or queries or responses on devices.
- Know how AAC user wish to work with the support workers. AAC users will have preferences about how and when they need support, and whether and under what circumstances they are willing for a support worker to speak, translate or re-voice for them.
- Transparently negotiate the etiquette as part of establishing research partnerships with individuals or advisory groups.

Resources – AAC etiquette

ACC etiquette. International Society for Augmentative and Alternative Communication (ISAAC)

https://isaac-online.org/wp-content/uploads/AAC-Etiquette-FINAL-FOR-WEBSITE.pdf

AAC etiquette essentials: Chatting with someone using tech to talk. MonTECH

https://montech.ruralinstitute.umt.edu/aac-etiquette-essentials-chatting-with-someone-using-tech-to-talk/

Etiquette for Communicating with a Person who uses AAC. Augmentative Communication Community Partnerships

https://www.cdacanada.com/wp-content/uploads/2014/02/5_Etiquette_tips.pdf

How to be a respectful communication partner. AssistiveWare

https://www.assistiveware.com/learn-aac/follow-their-lead-how-to-be-a-respectful-communication-partner

Proper AAC etiquette: How to communicate respectfully with AAC users. Spoken AAC

https://spokenaac.com/blog/proper-aac-etiquette/#:~:text=Address%20the%20AAC%20User%20Directly,you%20would%20with%20anyone%20else.

2.3. Skills to adapt materials to optimise access for AAC users.

Communicate in plain language. Collaborate with AAC users to identify if their written messaging should be in Plain English or Easy English.

> The Centre for Inclusive Design defines Plain and Easy English as:
>
> Plain English: "a direct style of writing for people who can read at a reasonable level. It helps people who want to read and understand information quickly" (p.4). It uses simple words in short sentences and paragraphs and avoids jargon. The reading level is directed to 12- to 14-year-olds.
>
> Easy English: "helps people who find it hard to read and understand English" (p.4). It is simpler and has a lower reading level than Plain English. Easy English uses short sentences of simple everyday words, with an image or picture. It uses dot points and large font sizes.

Speaking people working with One Group Our Voice are asked to speak in Plain English. Our agendas are written in Plain English with some visual supports to help identify the different parts of the meeting.

Avoid acronyms and jargon. People with cerebral palsy tell us that communicating in any kind of jargon or using acronyms is a significant barrier to accessibility of communication.

Use videos. Consider videos as an alternative or adjunct to written communication.

Example from One Group Our Voice – adapting materials

Click here for an example of an agenda for a One Group Our Voice meeting

Videos are the preferred format for One Group Our Voice to receive information in preparation for meetings as well as their recommended strategy for recruiting AAC users to be research partners or participants.

We use videos as part of One Group Our Voice advisory group planning and agenda. The coordinator makes a video summarizing the topic we'll be talking about, including using slides with visual supports. We also co-developed videos to invite more people to join One Group Our Voice.

These are the preferences for enhancing access that have been identified with One Group Our Voice. The AAC users you work with might have different access needs and preferences, so it is important you work with individual AAC users and advisory groups to determine their specific requirements.

Click here to see an example of a video to assist with recruiting AAC users to One Group Our Voice.

Resources – Plain and Easy English

Easy English versus Plain English. A guide to creating accessible content. Centre for Inclusive Design

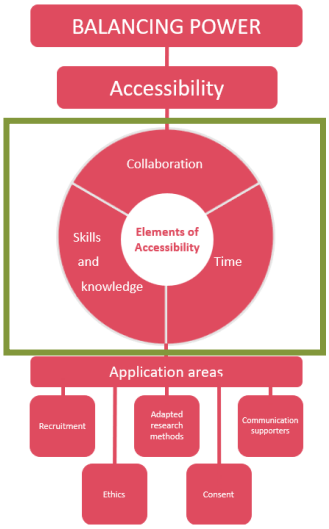
https://centreforinclusivedesign.org.au/wp-content/uploads/2020/04/Easy-English-vs-Plain-English_accessible.pdf

Working with people who use Plain and Easy English. Voices Together

https://www.voicestogether.com.au/wp-content/uploads/2019/05/A4-Working-with-Plain_easy-English.pdf

3. Time

Time



The third element of accessibility is time, specifically time to involve AAC users and time to prepare accessible research and research resources.

Time needs funding.

See Appendix 2 for budget considerations.

Using AAC requires significantly more time than speaking. Researchers need to allow sufficient time for AAC users to express themselves and to process or understand what has been said. Fatigue can impact conversation length for AAC users.

Following are issues to consider.

Preparation Time: Preparing for research takes longer for both AAC users and researchers.

AAC users may need to pre-program their answers into their communication devices before a meeting or require assistance in understanding the questions being asked.

Researchers must invest time in making research materials accessible. This may involve creating materials in easy-to-understand language or producing videos to enhance comprehension.

Managing Time Expectations: **Researchers** will need to consider and plan for how much time they allocate for working with AAC users, considering the length of time required for preparation, establishing rapport and interviews or meetings. Questions or discussion points may need to be prioritised and alternative response forms considered. For example, sorting tasks and scales can be used to answer question efficiently, while in-depth answers provide deeper insight but take longer to acquire.

Accepting silence. Researchers may experience discomfort while waiting in silence for AAC users to prepare and communicate a response. Researchers and AAC users can discuss this and identify a plan for these silences, for instance, that the researcher may work on other activities while waiting as long as the AAC is not distracted. Hearing from individuals who have learned to work through this discomfort, can provide valuable insights and strategies for managing this aspect effectively.

Plan for ample time to ensure AAC users can actively participate and effectively convey their thoughts.

Examples of time considerations

Frequency of meetings. In 2023, One Group Our Voice met once every 3 weeks for 75 minutes. This was long enough to discuss a topic, but short enough to avoid fatigue. This frequency of meeting was needed because we had so much we wanted to talk about, and knew that we would be limited in how much we could achieve each meeting.

Time needed for meetings. One Group Our Voice meetings required about 6 hours of coordinator time per meeting, not including meeting attendance. During those 6 hours, the coordinator worked with researchers to prepare to consult with the group, prepared a Plain English agenda with visuals, recorded, or supported the researchers to record a video, sent out the agenda and preparation material in the formats that each person required, wrote and distributed minutes, and submitted documentation to initiate payment of One Group Our Voice Advisors and the coordinator.

Time to acquire AAC users' response. Our experience is that AAC users may take up to 20 minutes to generate a response to a question for which they have not been prepared.

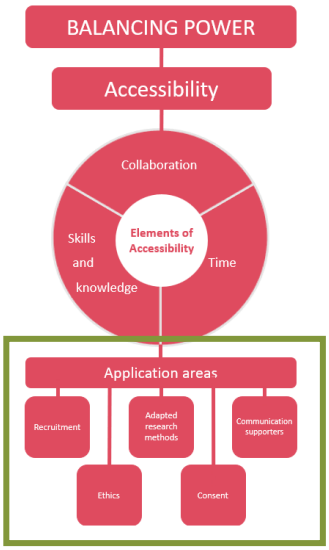
Click here to watch an example of waiting while One Group Our Voice Advisors prepared their responses in a meeting.

APPLICATION AREAS

The Framework – Application areas

We identified five areas where applying these three elements of accessibility may yield the most substantial impact for involving AAC user as consumer research partners or research participants.

- Recruitment
- Working with communication supporters
- Adapted research methods
- Ethics - navigation ethics applications and approvals
- Consent



Recruitment

Recruitment

Historically, AAC users have been excluded from research. One Group Our Voice advisors say that they assume that research does not include them or won't accommodate their communication needs, unless it is explicitly stated otherwise. We have found recruitment of AAC users as both research partners and participants to be challenging and have strived to learn how to do this more effectively. The suggestions below aim to ensure that AAC users feel invited, welcome, and empowered to contribute their valuable insights to research endeavours.

- **Clear invitations.** Researchers should explicitly state that AAC users are invited to participate in their research. This may counteract any beliefs that AAC users may have about being excluded from research opportunities. By making it clear that their voice and perspectives are valued, researchers can foster inclusivity from the onset.
- **Visibility.** Consider using images of AAC users and AAC tools, such as communication devices, picture symbols, signs, or letterboards, in recruitment materials. These visual cues convey that AAC users are explicitly included, welcome, and that access needs will be accommodated in the research. Video invitations featuring AAC users delivering the content are also suggested.
- **Assuring accessibility**. Researchers can emphasise that the research will be accessible for AAC users and provide examples of how accessibility will be achieved and tailored for individuals. This assurance addresses the concern that AAC users might have regarding assumptions about their ability to be included in research. By conveying an understanding of the unique needs of AAC users, researchers can instill confidence and trust in their willingness and ability to include AAC users in research.
- **Importance of research.** Specify the expected benefits of the research to individuals and the AAC community more broadly.

- **Distributing recruitment materials and invitations**. Identify the means through which AAC users are likely to receive information by asking AAC users. These means may include:
    - Networks of AAC users
    - Parents, families and support networks via social media and support groups
    - Clinics and service delivery organisations
    - Trusted disability and advocacy organisations
    - A cerebral palsy register
- **Mitigate gatekeeping.** People other than AAC users themselves who receive invitations may decide not to pass on the invitation – that is, act as a gatekeeper. The suggestion above about visibility of AAC users and assuring accessibility will help mitigate this. In addition,
    - Identify from potential gatekeepers what the concerns or barriers to progressing invitations may be and address these.
    - Indicate that the researchers value AAC users' contributions
    - Clarify the experience the research team has in involving AAC user.
    - Outline any benefits for AAC users of being involved
- **Personal contact**. Our most effective strategy has been to personally invite AAC users already known to us.

One Group Our Voice suggests making the research look inviting and a pleasure to be involved with.

Important note when recruiting AAC users as research participants. The suggestions in this section will need to be considered alongside guidelines for ethical conduct of research such as those presented in the National Statement on Ethical Conduct in Human Research (NHMRC, 2023).

Examples of recruitment material

We have included a link to a video and a flyer we used to recruit AAC users to join the Advisory Group. Similar principles apply when recruiting participants to studies. We aim to incorporate the following strategies to make material more inclusive:

- Showcasing AAC users as prominent in the videos
- Using Plain English or Easy English
- Creating recruitment materials in various modalities to accommodate differing communication and literacy abilities.

Click this link to see Shirley speaking about why CP-ACHIEVE has an Advisory Group of AAC users.

Click this link to see a flyer

Resources – Recruitment

Contact details for the Australian and State and Territory Cerebral Palsy Registries

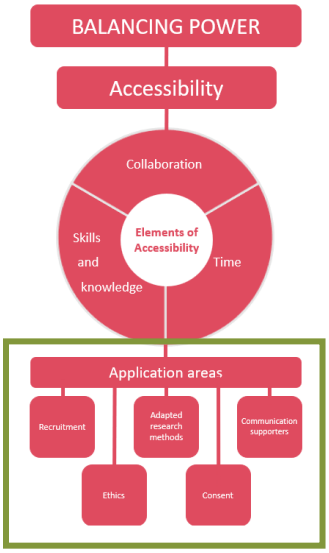
https://cpregister.com/contact-us/

National Health and Medical Research Council (NHMRC) National Statement on Ethical Conduct in Human Research (2023)

https://www.nhmrc.gov.au/about-us/publications/national-statement-ethical-conduct-human-research-2023#block-views-block-file-attachments-content-block-1

Working with communication supporters

Working with communication supporters



In this section, we explore ways of working with communication supporters to optimise the involvement of AAC users in research.

What is a communication supporter?

A communication supporter is an individual who provides support to optimise an AAC user's access to communication. They may facilitate access to and use of AAC, like setting up a speech generating device, reading out responses created with a PODD book, troubleshooting technology difficulties, or re-voicing speech. This support can be crucial to ensure AAC users express themselves and participate in social, educational, work, leisure and research situations.

Communication supporters can be formal supporters (e.g., paid support workers, health professionals) or informal supporters (e.g., family members, friends). Some will be very familiar with communicating with the AAC user, others will not. Communication supporters will bring with them a range of perspectives associated with their level of education, cultural background, gender, age, comfort with technology, and knowledge of disability.

Various other terms are used to describe communication supporters such as communication assistant, personal support worker and communication partner.

Considerations when involving AAC users with communication supporters

Communication supporters are essential for some AAC users to be involved in research and make important contributions to how the research can be made accessible.

The presence of a communication supporter may influence what is communicated by the AAC user.

- Communication supporters are frequently accustomed to speaking or advocating *for* the AAC user. This can be a barrier to authentic AAC user involvement, for example, when a communication supporter talks over an AAC user in an interaction with a researcher or speaks for the AAC user.
- AAC users may be managing two relationships in one interaction – one with the researcher and one with the communication supporter. The relationship with the communication supporter is ongoing, and needs to be maintained. AAC users may filter or censor their responses to researchers in the presence of communication supporters to protect that relationship, to maintain their own sense of privacy, or if there is a perceived or actual conflict or discrepancy of opinion.

Communication supporters may view the researcher in a position of authority, making it difficult for the communication supporter to speak up when they want to advocate for the AAC user or provide suggestions for promoting accessibility of the research.

AAC users may not have the same communication supporter with them at each research encounter, creating challenges to continuity of AAC user involvement in the research as participant or research partner.

Researchers may need to consider if communication supporters should be regarded as participants in their particular project, depending on their role. This has implications for applications for ethics approval and how to approach seeking consent from the AAC user and communication supporter.

Suggestions for engaging with communication supporters

Begin discussions with AAC users early about the involvement of their communication supporters.

Identify how individual AAC users prefer to navigate the relationship with their communication supporter for the purposes of the specific project. Some AAC users manage their support teams themselves, while others will want the researcher to be involved in conversations to establish roles, responsibilities and ways of working. AAC users may wish to identify a specific communication supporter for research activity to build constructive ways of working and respective specific and consistent approaches to working in a research context.

Identify, with each AAC user, how to navigate discussions with communication supporters about how they will support the AAC user in the particular project. Identify whether the AAC user or the researcher will lead this conversation.

Communication supporters may have no experience of research and may benefit from jargon-free information about the research provided in plain English.

Consider negotiating a role description with each AAC user and communication supporter to outline respective roles and responsibilities. This process can ensure that the AAC user's preferences and needs are forefont, the experience of communication supporters is harnessed and respected, and the researcher can educate about research and the importance of ensuring the AAC user contributes their own perspectives to the research.

Considerations when negotiating roles and responsibilities of AAC users, communication supporters and researchers.

- Discuss the types of responses the AAC user may be asked to generate and may wish to contribute, how they might make these responses, how long it may take, and what supports they would prefer.
- Discuss the communication interactions, for instance should the researcher talk directly to the AAC user, or does the AAC user prefer for the researcher to speak to both the AAC user and the communication supporter.
- Identify what the AAC user, communication supporter or researcher should do if they think something is not right/not working for the AAC user or that there might be a better way.

- Consider logistics like the best means of communication, for instance, if it is by email - who to email and who to copy in. Identify who is responsible for coordinating scheduling, and the hours that the AAC user and preferred communication supporter are available.
- Ask communication supporters if they need "check-in points." These are opportunities to tell the AAC user and the researcher how the collaboration is going from their perspective, and if they have observations and suggestions, or need anything from the researcher.
- Consider whether the AAC user researcher or communication supporter will coordinate communication between communication supporters. Other suggestions are:
    - Identify ways to ensure that an AAC user is supported consistently across time and research meetings and activities.
    - Ensure documentation around respective roles and responsibilities is shared with all communication supporters so they are aware of the research, the tasks involved, and the approaches for supporting the AAC user in their role.
    - For AAC users who are consumer research partners: circulate an agenda and any preparation materials (reading/videos) at least two weeks in advance, allowing time for the AAC user to engage with the material and prepare their thoughts and responses.
        - Share research materials, such as interview guides, with AAC users in advance of research activities when feasible.
        - Clear notes of each meeting, including alerts for completion of any activities or commitments to be completed between encounters, are important to ensure information is handed over between communication supporters.
        - At the start of meetings or research encounters, provide a summary of the last meeting.

Examples of communication supporter roles

See what Brenton and Brodie have written in their Access Profiles about working with their communication supporters

Click here to read how Brenton collaborates with a communication supporter

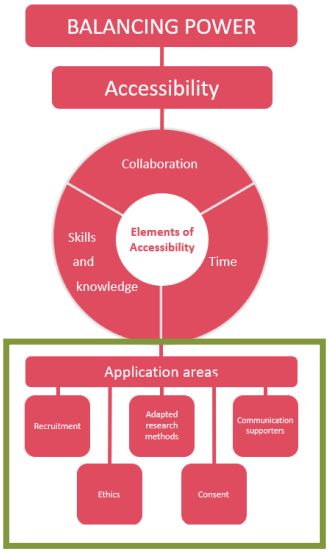
Click here to read how Brodie collaborates with a communication supporter

Adapting research methods for accessibility

Adapting research methods for accessibility

Adapting research methods is another key means for ensuring research is accessible for people who use AAC. We have identified a selection of strategies to adapt frequently used data collection methods.

These methods are suggested for research participants and may apply when collaborating with AAC users as research partners in meetings and as diverse means for seeking their lived experience.



Adapting research methods for focus groups and interviews

- Meet with each AAC user before interviews and focus groups to ascertain access needs and build rapport.
- Consider risk of fatigue in negotiating the length of focus groups or interviews.
- Consider whether AAC users involved in focus groups and interviews will need or choose to have communication support assistance to engage with materials, and availability of communication supporters. Working with a communication supporter and the choice of communication supporter raises additional issues. See section on communication supporters above. Early discussions about ways to ensure that AAC users' own perspectives are provided are important. Depending on the research topic and questions asked of AAC users, additional discussion with communication supporters may be needed around issues of privacy and disclosure.
- Where appropriate, provide topics or interview questions ahead of focus groups and interviews, allowing AAC users time to prepare their contributions. Research methods, topic and the access needs and preferences of AAC users will inform the decision to provide interview questions in advance.
- Sequential focus group or interview sessions may be an option, so that AAC users can formulate responses or elaborate on previous responses in between occasions and so that there is enough time to fully seek the perspectives and responses of AAC users.
- Consider asynchronous means of seeking responses using platforms like email, message boards or messaging groups (WhatsApp, Facebook Messenger), where participants can contribute at a pace that suits them. The choice of platform will depend on the access needs and preferences of AAC users.
- Incorporate a range of response options as described in the sections below, to optimise participants' time and energy for providing in-depth responses to other questions.

Focus groups

- Consider the advantages and disadvantages of convening focus groups which include both AAC users and speaking participants. In some research it might be appropriate to have both in which case some of the strategies will apply, in other research it might be appropriate to convene separate groups for AAC users and speaking group members and then other strategies might apply. Group sizes will need to be small.

- Implement strategies to facilitate AAC users to actively contribute, and have equal opportunity to contribute as do speaking members of the group, or AAC users who are quicker at contributing. For example, watch for signs that an AAC user is preparing a response, and check in with all members frequently during the group. AAC users frequently report that they have less opportunity to share their views than speaking members in a group.
- Request adherence to AAC etiquette guidelines (outlined above), for example, asking everyone to wait quietly while an AAC user formulates their response.

Adapting research methods for surveys

Researchers may use surveys as a data collection method which allows participants to respond in their own time, however many AAC users may find surveys challenging to access and complete. Researchers should consider whether surveys are appropriate for all their target participant group and how surveys can be adapted to ensure accessibility.

Considerations in selecting surveys for data collection

- Many AAC users do not have a regular or accessible online presence.
- Physical disability will impact ability to access and complete a survey – including ticking responses, scrolling screens, and typing text-based responses.
- Literacy level
- Intellectual disability.
- Need for assistance from a communication supporter to access and complete a survey
- Presence and impact of communication supporters, and the influence on the content of AAC user's responses

Suggestions for optimising accessibility of surveys

- Present surveys in Easy and Plain English to enhance readability and comprehension.
- Use visuals and adapted response options such as the emoji scale (developed for this Toolkit) and the Emotional Faces Scale (Lutz et al., 2016; Nilsson et al., 2017) displayed in Figures 2 and 3. Other adapted response options are:
    - Talking Mats. A Talking Mat is a visual communication form of AAC which can be set up on a physical mat (a large table mat) or digitally, for example, on a computer screen. Pictures, images, and words are portrayed on the mat to optimise an AAC user's ability to express their views or feelings. See the resources section below for more information.
    - Yes/no options. There are multiple ways of eliciting yes/no responses – find this out from the AAC user and communication supporters.
    - Provide lists of choices. An AAC user can respond yes/no to indicate which of the items on the list relate to them. They may also use a scale such as the emoji scale or the Emotional Faces Scale to indicate degree of agreement for example.
- Use large font size in colours which contrast with the screen background. Sans serif font styles are generally considered more accessible, these include Calibri, Verdana, Tahoma, Helvetica and Arial.
- Text-based survey questions can be accompanied by mini video- or audio-clips which speak the question and response options.
- Devise surveys which are accessible for screen readers.
- Consider the accessibility options of various platforms to allow options for completion, such as online (e.g., REDCap, Qualtrics, SurveyMonkey), fillable pdf, and MS Word. Each platform will have a form of accessibility checker to assist in optimising accessibility.
- AAC users need adequate time to complete surveys, which has implications for the length of surveys, and number and nature of items.
    - Limit surveys to essential questions
    - Position more critical questions at the beginning of the survey
    - Enable participants to save responses and return later.
    - Minimise the number and complexity of open-ended questions as it may take an AAC user considerable time to type responses.

Figure 2: Example of an adapted response option. The emoji scale. The large faces can be clicked to select the response as well as the small button response option.

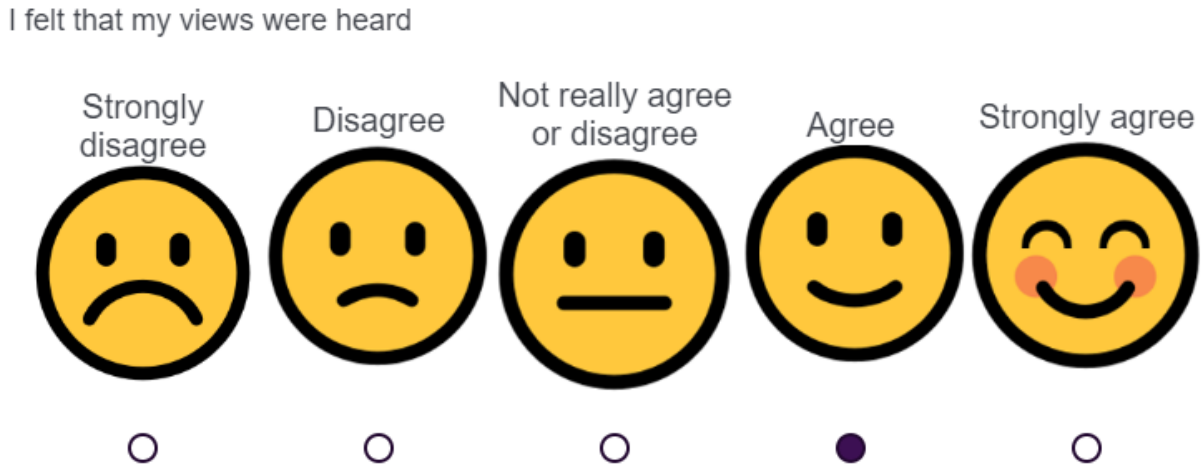
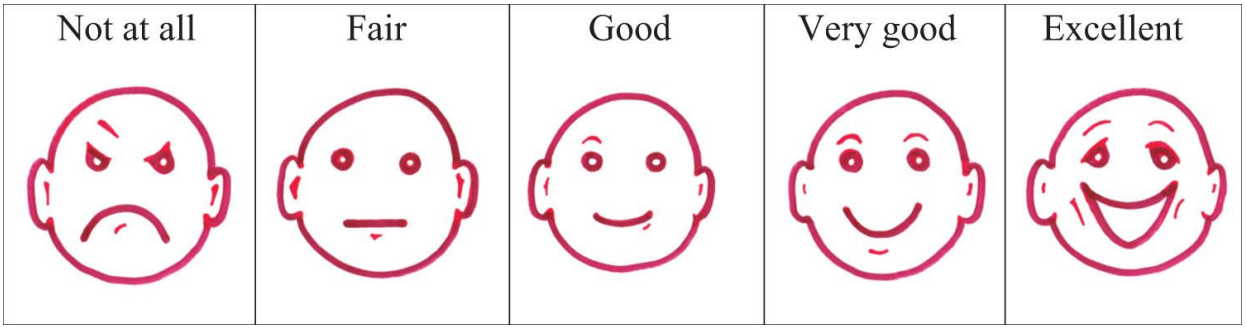


Figure 3: Example of the Emotional Faces Scale (ref) as an adapted response option.



Examples of using Emotional Faces Scale

Click this link to view how the Emotional Faces Scale can be used to seek One Group Our Voice Advisors' views on using Talking Mats as an adapted research method.

Observational Methods

Observational methods could involve:

Observing participants in their natural or clinical environment to gain insights into abilities, behaviours, interactions, and communication.

Taking measurements from AAC users. Examples are taking blood samples and blood pressure readings, measuring muscle tone and range of motion, asking participants to complete motor tasks and standardized and non-standardised assessments.

Considerations for observational methods

- Pitch assessments at an appropriate level. Standardised assessments are rarely accessible or designed to elicit appropriate responses from AAC users. AAC users may experience a sense of failure and frustration to be offered tasks that are clearly inappropriate or inaccessible for their level of motor, communication, literacy or intellectual ability.
- Fatigue needs to be monitored as responses which are representative of a person's usual ability will not be possible if an AAC user becomes fatigued. Becoming fatigued will also impact the remainder of an AAC user's day.
- Explain what is being asked of the AAC user, give clear instructions and information, and check that they have understood.
- Check consent for each measurement and each occasion of measurement using pre-determined response options.
- Explain the need for any assessments which are "hands-on", where the AAC user will be touched, and check consent.
- Constant monitoring and checking-in will be needed to capture signs of fatigue, pain, and distress, and a desire to communicate, pause, stop or withdraw.

Resources and research – Talking Mats

Talking Mats website:

https://www.talkingmats.com/about/what-is-a-talking-mat/

Broomfield, K., Craig, C., Smith, S. et al. (2021). Creativity in public involvement: Supporting authentic collaboration and inclusive research with seldom heard voices. *Research Involvement and Engagement, 7*, 17.

https://doi.org/10.1186/s40900-021-00260-7

Gore, N.J., McGill, P. & Hastings, R.P. (2021). Personalized goals for positive behavioral support: Engaging directly with children who have intellectual and developmental disabilities. *Journal of Child and Family Studies, 30*, 375–387.

https://doi.org/10.1007/s10826-020-01867-2

Hagelskjær, V., Krohn, K., Christensen, P. S., Jeanette Reffstrup Christensen, J. R. (2019). Canadian Occupational Performance Measure supported by Talking Mats: An evaluation of the clinical utility. *Occupational Therapy International*, 1-11.

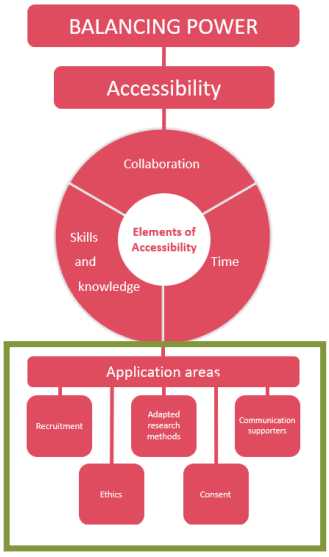
https://doi.org/10.1155/2019/9367315

Murphy, J., & Mackay, M. (2015). Will anyone listen to us? What matters to young people with complex and exceptional health needs and their families during health transitions. https://www.talkingmats.com/wp-content/uploads/2015/11/20151027-CEN-report.pdf

Talking Mats Research Network:

https://www.talkingmats.com/category/research/

Ethics – navigating ethics applications and approvals



Ethics - Navigating ethics applications and approvals

All research that involves humans in Australia must be approved by a Human Research Ethics Committee, or similar in other countries (e.g., Institutional Review Board). The ethical approval process is intended to ensure that the research is safe and fair, and protects the rights and dignity of research participants. Ethical scrutiny aims to minimise power imbalance and to ensure that research participants know their rights about participating in, and withdrawing from, research.

An important way of ensuring ethical research which is accessible to AAC users is to collaborate with consumer research partners from the early stages of research. Consumer research partners will contribute expertise about all aspects of the research to ensure is it feasible and accessible. Accessible research will optimise recruitment and retention, and the translation of the findings to maximise impact. Evidence of involvement of consumer research partners and their influence will reassure ethics committees that the research will minimise power imbalance.

Knowledge and skills related to ethics committees and processes

Members of ethics committees come from different backgrounds and disciplines, and may be unfamiliar with disability. Potentially this may lead to ableist and paternalistic assumptions about the vulnerability of AAC users, resulting in underestimation of their abilities, and an over-reliance on insisting on proxy-consent. Overprotecting AAC users will perpetuate their exclusion from research. Some suggestions for forestalling barriers to ethics approval based on these assumptions are:

- Know the guidelines that inform ethics committees about vulnerability and refer to these in developing an ethics application. See for instance Australia's National Statement (National Health and Medical Research Council, 2023)
- Ensure that the significance of including AAC users in the research is clearly articulated.
- Caution against reliance on seeking proxy-consent which may potentially result in inclusion of AAC users in, or exclusion from, research against the wishes of the AAC user.
- Describe the accessible and inclusive ways that AAC users will be adequately informed about the research, given options for providing consent, and optimising the ways they can make their own decisions.
- Clearly state the accessible and inclusive ways that AAC users will be invited to provide their views, perspectives and data.
- Reinforce that it is a human right for AAC users to be involved in research and that researchers are obliged to ensure accessible and inclusive ways to involve AAC users. Cite the Convention on the Rights of Persons with Disabilities (United Nations, 2006) and the Universal Declaration of Human Rights (United Nations, 1948).

Resources – National Health and Medical Research Council

Australia's National Health and Medical Research Council, publishes the following two documents to guide ethical conduct in human research and consumer and community involvement in research.

National Health and Medical Research Council. (2023). National Statement on Ethical Conduct in Human Research. National Health and Medical Research Council.

https://www.nhmrc.gov.au/about-us/publications/national-statement-ethical-conduct-human-research-2023#block-views-block-file-attachments-content-block-1

NHMRC. (2016). Statement on consumer and community involvement in health and medical research. National Health and Medical Research Council.

https://nhmrc.gov.au/about-us/publications/statement-consumer-and-community-involvement-health-and-medical-research

Navigating the ethics process with participants who use AAC

Walsh, M., Stead, V., Sawyer, S., O'Shea, A., Watson, J., & Anderson, K. (2024). In pursuit of ethical and inclusive research: What ethics committees and disability researchers can learn from each other. *International Journal of Qualitative Methods, 23.*

https://doi.org/10.1177/16094069241237549

Sources on human rights.

United Nations. (1948). Universal declaration of human rights.

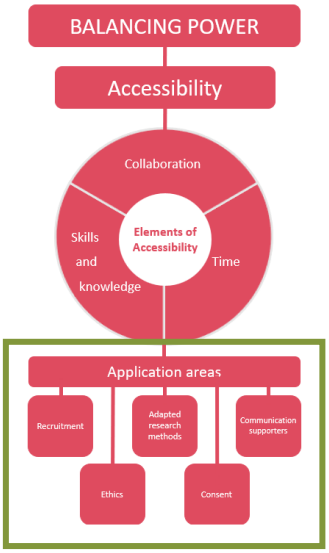
https://www.un.org/en/about-us/universal-declaration-ofhuman-rights

United Nations. (2006). Convention on the rights of persons with disabilities.

https://www.ohchr.org/en/instrumentsmechanisms/instruments/convention-rights-persons-disabilities

Consent

Consent



Potential participants in research must be fully informed about the research before providing consent to be involved. Information will be in the form of a Participant Information Letter and, as a minimum, will identify the researchers, their professional background and affiliations, all the activities and time commitments involved in participating, the risks and benefits, how the information they provide is kept securely and confidentially, and how their anonymity will be assured. Potential participants will also have been given the opportunity to ask question before providing consents and be assured that their decision to decline to be involved will not impact their relationships with any stakeholders.

Consent and power imbalances

Ethics committees look for the potential for power imbalances when researchers seek consent from participants. Recruitment and consent should be free from coercion. Potential participants need to feel they are making a decision to take part without any pressure or any risk of adverse consequences should they decide not to take part, or decide to take part and then withdraw from a study.

Power imbalance may be exaggerated when working with AAC users and potentially communication supporters. AAC users may find it difficult to initiate a conversation with a person in a (perceived) position of authority about declining to participate or to withdraw having previously consented. Researchers can transparently identify with an AAC user how they will indicate that they wish to stop or withdraw, and to check with the AAC user frequently about their willingness to continue.

Accessible informed consent

Conventionally, participants give consent by signing a paper or online consent form. Many AAC users will have difficulty accessing, reading, understanding and/or signing forms presented in these ways. Researchers can use skills and knowledge about accessible research materials and collaborate with consumer research partners to develop and incorporate alternative ways to obtain fully informed consent . These means may include:

- Providing consent wording in video form or Easy English
- Recording yes/no with icons presented on a touch screen or accessible using eye-gaze control technology
- Enacting verbal consent
- Supported decision making

Example of verbal consent process

Sellwood and colleagues used a verbal consent process that AAC users could engage with using their AAC systems. The process is described in these resources:

Sellwood, D., Raghavendra, P., & Walker, R. (2022). Facilitators and barriers to developing romantic and sexual relationships: Lived experiences of people with complex communication needs. Augmentative and Alternative Communication, 38(1), 1-14. https://doi.org/10.1080/07434618.2022.2046852

Sellwood, D. (2019). Lived experiences of people with complex communication needs: Romantic and sexual relationships Flinders University]. College of Nursing and Health Sciences. https://theses.flinders.edu.au/view/30531f24-94f2-4bfe-94e8-395affe0ae9a/1

Supported decision-making and consent:

AAC users who are under 18 years, have an intellectual disability or who have complex support needs may have difficulty understanding the activities, time commitment, risks and benefits of the research that they are being invited to participate in. Conversely, researchers may find it hard to convince themselves that such participants are providing fully informed consent. In these instances, AAC users can be supported in the consent process by a parent or guardian who knows them well and following supported decision-making principles. These principles involve AAC users making decisions supported by people who know them well, are familiar with interpreting the AAC user's body language and communicating with their AAC, and have an understanding of their preferences, conflicting commitments, fatigue, and so on. Supported decision might involve:

- Assisting the AAC user to weigh up pros and cons of participation
- Assisting the person to understand the consequences of their decision
- Using an AAC user's unique communication strategies to assist in understanding consent, for instance, through speaking in Plain English, using AAC, and other means of adapting provision of information

The consent of participants who are supported in these ways to make a decision to participate in research will be documented in addition to their parent's or guardian's (proxy) consent.

Resources – supported decision-making

Van Goidsenhoven, L., & De Schauwer, E. (2022). Relational ethics, informed consent, and informed assent in participatory research with children with complex communication needs. *Developmental Medicine & Child Neurology, 64*(11), 1323-1329.

https://doi.org/10.1111/dmcn.15297

Watson, J. (2023). Stretching beyond our perceived boundaries: The role of speech-language pathology in realising autonomy through supported decision-making. *International Journal of Speech-Language Pathology, 25*(3), 355–362.

https://doi.org/10.1080/17549507.2023.2187331

Watson, J. (2019). The role of speech-language pathology in supporting legal capacity. *Journal of Clinical Practice in Speech-Language Pathology, 21*(1), 25–28.

https://doi.org/10.1080/22087168.2019.12370242

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Scan the QR code or click here to answer six quick questions.

Your feedback will be completely anonymous.

APPENDICES

Appendix 1 - Resources about involving people with profound intellectual and multiple disabilities (unintentional communicators) in research

Dee-Price, B.-J. M., Hallahan, L., Nelson Bryen, D., & Watson, J. M. (2021). Every voice counts: Exploring communication accessible research methods. *Disability & Society, 36*(2), 240-264.

https://doi.org/10.1080/09687599.2020.1715924

Pickering, D. M., Gill, P., & Reagon, C. (2024). A kaleidoscope of well-being to authentically represent the voices of children and young people with complex cerebral palsy: A case study series. *Disability and Rehabilitation, 46*(7), 1339-1353.

https://doi.org/10.1080/09638288.2023.2194680

Watson, J. (2019). The role of speech-language pathology in supporting legal capacity. *Journal of Clinical Practice in Speech-Language Pathology, 21*(1), 25–28.

https://doi.org/10.1080/22087168.2019.12370242

Watson, J., Wilson, E., & Hagiliassis, N. (2017). Supporting end of life decision making: Case studies of relational closeness in supported decision making for people with severe or profound intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 30(*6), 1022-1034.

https://doi.org/https://doi.org/10.1111/jar.12393

Van Goidsenhoven, L., & De Schauwer, E. (2022). Relational ethics, informed consent, and informed assent in participatory research with children with complex communication needs. *Developmental Medicine & Child Neurology, 64*(11), 1323-1329.

https://doi.org/https://doi.org/10.1111/dmcn.15297

This book provides guidance on structured observational methods, including with people with profound intellectual and multiple disabilities.

Mansell, J. (2011). Structured observational research in services for people with learning disabilities. *SSCR methods review (10)*. NIHR School for Social Care Research, London, UK. ISBN 9780853284468

https://eprints.lse.ac.uk/43159/

Appendix 2: Budget considerations when working with consumer research partners

Build in adequate funding for involvement of AAC in any grant applications.

Essential budget items

Payment for AAC users.

AAC users should be paid for the expertise contributed to research as consumer research partners. Payment should cover:

- Orientation and induction to projects and their roles as consumer research partners
- Preparation time for meetings
- Attending meetings
- All other work completed as part of the role (e.g., reviewing documents, developing materials, data collecting, etc)
- Attending any courses required for the role
- Presenting at meetings, webinars, conferences

Researcher/coordinator time.

Time for researchers to coordinate AAC user involvement, prepare accessible materials, collaborate with AAC users and support AAC users in their role.

Other budget considerations

Other expenditure is likely to be needed:

- Communication supporters
- Travel and parking
- Childcare
- Accommodation
- Internet
- Refreshments
- Conference costs for presenting or co-presenting – including registration, travel, accommodation, per diem, communication supporters.

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