

# **“Take the time to get to know us”: a framework and toolkit for inclusive research with people with cerebral palsy who use alternative and augmentative communication (AAC)**

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## **Short Abstract**

### **Plain Language Abstract**

People who use augmentative and alternative communication (AAC) are often excluded from research, leaving their views and needs unheard. Sometimes AAC users are excluded because researchers do not have the knowledge or confidence to include them.

We've created a toolkit to help researchers include AAC users as both participants and research partners. This toolkit is also useful for those working with AAC users on projects or advisory boards.

This workshop will be run by a researcher and a research partner who uses AAC. We will discuss why including AAC users in research is important and what gets in the way of doing it. We'll introduce our toolkit, demonstrate how it helps researchers and project leaders, and share our process of developing it with AAC users. You will practice using the toolkit. We will allow time for everyone to participate.

Here is what you will learn and do in the workshop:

1. **Understand the Challenges:** Learn how power imbalances and other factors affect the involvement of AAC users in research and collaborative projects.
2. **Use the Framework:** Discover how to use our framework to include AAC users in research studies and collaborative projects.
3. **Find Accessibility Tips:** Get practical tips for making research and collaborative projects more accessible to AAC users.
4. **Practice:** Practice using the framework and toolkit in important parts of research or collaborative projects.
5. **Access More Resources:** Know where to find additional resources to support including AAC users in research or collaborative projects.

## **Long Abstract**

## **Academic Abstract:**

One third of people with cerebral palsy have complex communication support needs, many using augmentative and alternative communication (AAC) to communicate (Himmelman et al., 2013; McIntyre et al., 2018; Nordberg et al., 2013). Yet AAC users are severely under-represented in research, including in cerebral palsy research and disability research more broadly (Dee-Price et al., 2021; Taylor & Balandin, 2020; Walsh et al., 2024). The significant challenges of including people with cerebral palsy who use AAC in research means that it is rarely done. Challenges include a lack of researcher confidence and skill, time and costs of involvement, and attitudes towards those with significant disability (Taylor & Balandin, 2020; Walsh et al., 2024).

The United Nations Convention on the Rights of Persons with Disabilities specifically identifies full and effective participation and inclusion in society as a fundamental right, along with the supports necessary to achieve this (United Nations, 2006). Adolescents and young adults with cerebral palsy who use AAC have a right to participate in research about them and to benefit from that experience. Exclusion from research denies them a voice and the opportunity to influence research which directly involves them. Conversely, involving people with lived experience in decisions about every aspect of research benefits the research, researchers, and people with lived experience (Brett et al., 2014).

CP-Achieve is a five-year, NHMRC-funded, Centre for Research Excellence committed to empowering adolescents and young adults with cerebral palsy to participate fully in life. CP-Achieve strongly believes that people with cerebral palsy (consumers) have a right to be involved in research that impacts them. Consumer involvement is a key theme underpinning CP-Achieve's activities and is embedded at every level.

In 2022, CP-Achieve undertook a project to address the exclusion of AAC users from research. Our team included a group of consumer research partners with cerebral palsy who use AAC, a researcher with cerebral palsy who uses AAC, and a team of researchers from clinical backgrounds including speech pathology and occupational therapy. Together, we developed a framework for inclusive research with AAC users who have cerebral palsy.

Following the development of the framework, we co-designed the Inclusive Research Toolkit. The toolkit provides practical information and resources for including AAC users with cerebral palsy in research both as research partners (involved in every step of the research process including development) and as research participants. The toolkit is also useful for anyone working collaboratively with AAC users, such as with advisory boards, or on project or policy development.

Presented by a clinician-researcher and a consumer research partner with cerebral palsy who uses AAC, we will briefly describe the rigorous and collaborative way we developed the inclusive research framework. We will introduce workshop participants to the framework and toolkit, providing practical examples and highlighting opportunities for application along the way. Workshop participants will then apply the toolkit in considering how working with communication supporters might impact the AAC users' participation in critical phases of research and collaborative projects.

**Target audience:** People who collaborate with, or want to collaborate with, AAC users in research or other projects. AAC users are invited to attend. Please let us know if

you have access needs we can accommodate, such as providing prompts for the practical activity ahead of time so that you can formulate your responses in advance.

### **In this workshop, participants will:**

1. Explore the impact of power imbalances and other factors that influence the participation of AAC users in research and collaborative initiatives.
2. Understand the framework designed to facilitate the meaningful inclusion of AAC users in research studies and collaborative projects.
3. Learn practical strategies for improving accessibility in research and collaborative efforts, specifically tailored to the needs of AAC users.
4. Participate in hands-on exercises to apply the framework and toolkit to critical phases of research and collaborative work.
5. Learn where to find additional resources and tools that provide ongoing support for the inclusion of AAC users in research and collaborative endeavours.

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