**Experiences with AAC technologies and empathy – Method**

User testimonies were collected to learn from people’s experience with their AAC devices, their relationship with it, giving and receiving empathy, how certain design features play a role in this, and their recommendations for future improvements.

#### Method

It is of utmost importance to include first-person lived experiences of AAC technology use in research on the technology itself (Taylor and Balandin 2020), but this comes with unique methodological challenges (Blackstone, Williams et al. 2007). In live interviews using AAC technology, fatigue is a significant challenge, which is why an asynchronous interview method was chosen here instead (Beneteau 2020). This allowed respondents to formulate answers to the questions at their own pace[[1]](#footnote-1). The participants had the option to submit their answers to the question either via email or in a secured cloud[[2]](#footnote-2). Both options were provided because, while using a cloud is favored for security reasons, it does require more technical skills which compromises the accessibility of participation[[3]](#footnote-3). To accommodate expressive flexibility and diversity, the participants could not only answer the questions in written form (English, Dutch, or Flemish), but also send videos, pictures, artworks, etc. The interview consisted of 8 open questions (with sub-questions) that covered various topics that emerged from the theoretical exploration in the thesis this dataset supports. Abstract concepts and theories (such as “human-technology relationships”, and “empathy”) were translated into practical questions without jargon. The questions covered the topics:

1. interactions with, via, and through AAC technology in daily life with regards to empathy,
2. experience of human-technology relationship with the AAC device,
3. ideas for improvement of the technology, innovation process, and implementation.

#### Recruitment

Next to challenges in methodological design, recruitment is another significant barrier for the inclusion of AAC users in research (Taylor and Balandin 2020). The AAC technology company *AsssistiveWare* and the Dutch-Flemish division of ISAAC (International Society of Alternative and Augmentative Communication)[[4]](#footnote-4) shared the study with their network and on social media. This support was provided without compensation or interest, as to not compromise the integrity of the study. Those who were interested could contact me via email and received more information about the study both in a written document and animated video, along with a consent form. In total, this research collected the stories of 5 individuals, one of them formulated by the mother of the user (so not a first-person account). The testimonies vary in degree of detail and extensiveness. To recall, these stories were collected to provide examples of experiences that, together with other literature, supplement the used theoretical frameworks in the conceptual dissection of AAC technology mediated empathy. The collected data were not meant and do not function as a representative sample of the experiences of the widely diverse AAC technology user community.

#### Ethics

The research was reviewed and approved by the Human Research Ethics Committee of Delft University of Technology. Additionally, the data collection and management strategy was in line with the commitments of the program this research is part of, Ethics of Socially Disruptive Technologies (NWO: 024.004.031). Each participant provided written consent through a form that provided various options for participation. To accommodate diversity in knowledge acquisition and interpretation, the explanation of the research and the various options on the consent form were provided both in written text (in English and Dutch) and an animated video (in English).

**Interview Guide**

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| 1 | a. Which AAC technology(-ies) do you use?  b. For what and in what way do you use them?  c. Why do you use AAC technology? |
| 2 | a. Do you identify as neurodivergent? If yes, how? (think for example of autism ADHD, ADD, HSP, dyslexia etc.)  b. Do you think this impacts how you use AAC technology? If yes, how? |
| 3 | a. Do you have the feeling you can be yourself when you use the technology?  b. If not, what causes this?  c. What could make your experience better? |
| 4 | a. Do you feel that the use of AAC technology influences how you are respected by others?  b. What could make your experience better? |
| 5 | a. Does the technology help you explain to others what you think or feel?  b. Do others understand you better?  c. What could make your experience better? |
| 6 | a. Do you experience negativity or stigma around AAC technology in society?  b. If so, how does this impact how others treat you? |
| 7 | a. What kind of relationship do you have with your AAC technology? (Is it as a part of yourself, a partner, an enemy, a neutral tool, something else you can compare it to?)  b. What makes you experience it in this way? |
| 8 | a. Is the use of the technology empowering or limiting?  b. In which ways is it empowering?  c. In which ways is it limiting? |

Beneteau, E. (2020). Who Are You Asking?: Qualitative Methods for Involving AAC Users as Primary Research Participants. Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems.

Blackstone, S. W., M. B. Williams and D. P. Wilkins (2007). "Key principles underlying research and practice in AAC." Augmentative and alternative communication **23**(3): 191-203.

Taylor, S. and S. Balandin (2020). "The ethics of inclusion in AAC research of participants with complex communication needs." Scandinavian Journal of Disability Research **22**(1).

1. Yet, fatigue was still reported as a challenge in contributing to the study by one of the participants. [↑](#footnote-ref-1)
2. The participants could let their preference know on the consent form, which also explained the risks of using email. [↑](#footnote-ref-2)
3. Accessibility was a core value in the methodological approach. Yet, note that the method used here still required internet access and literacy (English or Dutch). [↑](#footnote-ref-3)
4. Other (similar) parties and media were contacted as well in (unsuccessful) attempts to increase visibility of the study. [↑](#footnote-ref-4)