

INFORMATION SHEET

Giving Voice to Experience: A Users' History of Augmentative and Alternative Communication

You are invited to take part in **Giving Voice to Experience: A Users' History of Augmentative and Alternative Communication** (AAC), a PhD research project which aims to collect AAC user testimonies.

Thank you for your interest in my study. Before you decide whether to participate, I will outline why the research is being conducted and what it will involve. Please take the time to read this information and discuss with others if you wish. Feel free to ask me any further questions you may have, if anything is unclear, or if you would like further information. Take your time deciding whether or not you wish to take part. Thank you in advance for taking the time to read this.

Who will conduct the research?

The research is being conducted by Ally Keane, Newcastle University, under the supervision of Professor Graham Smith and Doctor Vicky Long. Ally will conduct all interviews. Ally has partaken in the necessary training provided by the Oral History Society and both supervisors have experience in undertaking oral history interviews.

What is the purpose of the research?

This study aims to fill a gap in current knowledge about Augmentative and Alternative Communication (AAC), specifically from a user perspective. There has been little history on this topic, and the research which does exist tends to focus on legislation, assessment, and technological advances, rather than the experiences of those who use the devices. This research will try to fill this gap by collating oral history interviews with 20 AAC users and 10 familiar communication partners (relatives, partners, carers) to access user experiences of using the devices, adaptations that have been made, and the services involved with provision and training. To ensure these interviews can be collected, a new oral history methodology will be created specifically for AAC voices and will highlight that people who use AAC are able to participate in research like this. By conducting this research, it will ensure that experiences of using AAC are available for future generations to learn about. The interviews will be used as part of the PhD thesis, with analysis being undertaken on the interviews looking for emerging themes and to explore the experiences of AAC users for the first time using oral history.

I hope that the interview will provide you with an opportunity to relive some of your experiences. We also hope that you will find it rewarding to have your stories recognised publicly and an opportunity to add your account to the history of these devices. These interviews could be useful to a range of AAC technology companies, engineers, AAC services and health professionals associated with these (such as speech and language therapists).

Why have I been invited?

I aim to interview 20 AAC users and 10 familiar communication partners from across the UK. I invite participants of different ages and length of AAC use to get involved. Your stories, memories, and experiences of AAC use will be an important contribution to the project.

What would I be asked to do if I took part?

If you agree to take part, we will arrange a time to record a video or audio oral history interview with you. An oral history interview is a sound and/or video recording of an individual's unique memories and stories from life. I will ask you open questions, allowing you to answer the question in your own way and share memories, experiences, and stories which are important to you. Each interview session with an AAC user would last approximately one hour, with the hope to do multiple interviews over several months so we can continue to explore your experiences (availability dependent). We may only do one interview with a familiar communication partner to supplement what has already been said by the AAC user, approximately one to two hours of interviewing, with scope for more if necessary. The interview is an opportunity for you to share your stories and experiences of AAC. The interview itself is very flexible and you are free to answer the open-ended questions with what you would like to say. If you get tired during the process, you can ask to stop and take a break, continue on another date or terminate the interview completely. We will discuss childhood, AAC use and services, identity, and any recommendations you have.

We would prefer to interview you in your own home but if you would rather the interview be arranged for elsewhere, that too can be arranged, as long as there is access to a quiet, private space. A quiet, comfortable space with minimum interruption is ideal. Interviews will be conducted at a time or place convenient to you.

With your permission, your recorded interview will become part of my PhD thesis and future publications. You will have the right to decide how you would like your interview to be used.

At the end of the interviewing process, feedback will be asked from you to give your honest opinions about how you think the interviewing process went and how you felt after being part of this research.

What happens to the data collected?

A key part of this project is that the interviews will be deposited in the British Library which will preserve and make publicly accessible the stories contributed by interviewees. With your permission, your recorded interview would be made accessible and preserved so it can be used in future research and publications. I will never use your information without your agreement, and you can tell me how you would like it to be used (and any conditions of use) on the Recording Agreement which you will complete after your interview has been completed. It is good, however, to think about how you would like your interview to be used before the interview so you can decide about what you may or may not wish to discuss.

I will not be using pseudonyms or offering anonymity as standard so your stories and memories can be claimed as your own – an important part of this history where AAC users have historically been silenced. The 1988 Copyright Act gave oral history interviewees the

right to be named as the 'authors' of their recorded words if they are published or broadcast, with these rights being followed by the Oral History Society and the British Library. However, you can choose how you would like to be referred to in my research: I can use either your full name or first name.

Once the interview is completed, I will upload the recording using an encrypted personal laptop computer to the secure Newcastle University server where it will only be accessible to myself, alongside two encrypted hard drives.

I will summarise and transcribe the interview and review it to ensure compliance with GDPR requirements before sending a copy of your interview for you to look over.

The project will end in September 2026, with the audio and video interview recordings and transcripts will be deposited at the British Library for use by researchers in the future. All future use will adhere to the same access and privacy conditions that you select now.

What will I need to sign?

Before the interview takes place, I will ask you to sign a Participation Agreement. This agreement captures your agreement for me to use the interview material for my PhD thesis and further research. It confirms that you have read this information sheet and understand what the project is about, the ways in which the interviews will be used, the interview questions and who to contact with any queries. It also shows that you have agreed to the collection, storage and processing of your personal data so that both myself and the British Library comply with the General Data Protection Regulation (UK GDPR)

After the interview I will ask you to sign a Recording Agreement in order to specify the terms under which the recording will be archived and be accessed at the British Library. All material will be treated as confidential until a Recording Agreement has been completed. It would be possible, for example, to request that part, or all, of the recording is closed to public access for a specific period of time. Any closed material is bound by a duty of confidentiality for both myself and any British Library staff who have access to the recording for preservation and cataloguing purposes. Copyright for the recordings will be assigned to me until 1st September 2026 after which copyright will be solely assigned to the British Library.

Will the outcomes of the research be published?

The outcomes of the research will be used in my PhD thesis and further research publications. Your information will never be used without your agreement, and you can tell us how it should be used on the Recording Agreement.

Once in the British Archive and accessible to the public, future researchers may re-use your information, dependent on the restrictions which you put on the use of your data.

What happens if I do not want to take part or if I change my mind?

It is not compulsory to take part – however, by sending you this information, I think that you may have something important to contribute to the study and to further researchers not just

in user experiences of AAC, but the wider history of the devices, and disability, medical, and oral history more generally. I hope you would like to contribute.

If you agree to take part, you will be asked to sign a participation agreement form before the interview and a Recording Agreement form after the interview. This can be done either manually (by a physical signature), an e-signature on a PDF, or if you are unable to do this, a verbal agreement at the beginning of the oral history recording.

Please note that even after signing the recording agreement you will be free to withdraw from the study at any time, with no reason needed and without detriment to yourself. You will be free to withdraw from the research, even after the interview has finished until the data collection finishes in November 2024. If you do this, all information about yourself and data gathered will be deleted.

Once your interview is deposited at the British Library it cannot be deleted but you can contact the Oral History Curators to discuss changes to the access restrictions.

Is there any support if my story is difficult?

Whilst we hope oral history interviews are a positive experience for everyone, but as with all memory work, we are aware that sometimes memories can be difficult to discuss. During the interview, you have the right to not answer a question when asked, no reason necessary, and to also ask for a break or to stop the recording at any time.

You may also want to discuss with someone close to you how the interview went and anything you want to reflect on. I will provide helplines and other contact information to various charities which may be able to help you should you feel any distress after an interview.

Who has reviewed the research project?

The research has been reviewed by the Newcastle University Research Ethics Committee (reference number: 32403) and by the Oral History department at the British Library.

Your Personal Data:

I am collecting and storing this personal information in accordance with the General Data Protection Regulation (GDPR) and Data Protection Act 2018 which legislate to protect your personal information. The legal basis for using your personal information is 'public interest task' and 'for research purposes' if sensitive information is collected. We will use your name and contact details (telephone number, address, email address) to contact you about the research study. We will use your date of birth in order to help identify you. Individuals at Newcastle University may look at your research data to check the accuracy of the research study. The only individuals at Newcastle University who will have access to information that identifies you will be individuals who need to contact you to discuss anything regarding the oral history testimonies or audit the data collection process.

<https://www.ncl.ac.uk/research/researchgovernance/ethics/gdpr/>

Newcastle University, as Data Controller for this research, takes responsibility for the protection of the personal information that this study is collecting about you. In order to comply with the legal obligations to protect your personal data the University has safeguards in place such as policies and procedures.

Further Information and Contact Details:

Thank you again for agreeing to take part in the project. Without participants such as yourself offering your time, thoughts and memories, this research could never happen. For further information, please contact:

Ally Keane: a.j.keane@newcastle.ac.uk

If you have any questions about the long term storage of, and access to, your interview after deposit at the British Library, including any requests to change your access restrictions, please contact the British Library Oral History Curators at oralhistory@bl.uk or 020 7412 7404.

Thank you for taking the time to read this information – we hope you take part in this research.