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## RESEARCH REPORT

# Using longitudinal qualitative research to explore the experience of receiving and using augmentative and alternative communication

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## Abstract

**Background:** People who have communication difficulties may benefit from using augmentative and alternative communication (AAC). Understanding and measuring outcomes from the use of AAC is an important part of evaluating the impact of devices and services. Outcome measurement needs to reflect the changing nature of the impact of using AAC on an individual's ability to participate in activities of daily life. There is a limited understanding of the concepts that should inform the evaluation of outcomes from AAC device provision, nor how people's expectations from AAC may change over time.

**Aims:** To inform the development of a patient-reported outcome measure for AAC by understanding more about people's expectations from AAC and how these change over time.

**Methods & Procedures:** A longitudinal qualitative research study was designed and carried out with seven participants over a period of 2 years. Participants were recruited from a regional specialist assessment service for AAC in the south-west of the UK. Four semi-structured interviews were carried out: (1) before assessment for AAC, (2) after assessment, (3) directly after provision of an AAC device and (4) between 6 and 12 months after provision. An original analytic method was used in this study that built on the principles of longitudinal interpretative phenomenology analysis, applied with a dialogic theoretical lens. This approach enabled the inclusion of a range of multimodal and embodied data collected to this study and allowed the research team to draw out salient themes across the cohort group while attending to the influence of time and context on experience.

**Outcomes & Results:** The results confirm and extend the three core concepts that were used to guide analysis: changes; contexts; future possibilities. The contextual and temporal influences on outcomes attainable from AAC for this cohort were also identified and illustrated through

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cross-case comparison. Deeper, analytic, and conceptual engagement with theory, which was then applied to analysis of the data, provided methodological rigour in the study. The results enhance our understanding of people's hopes and expectations from AAC and how these change over time.

**Conclusions & Implications:** This qualitative longitudinal research study provides new insights into the journeys of people who experience communication disability, and the shifting nature of their sense of identity as they engage with, and learn from using, AAC. The study is significant as it attends to the dynamic nature of experience and how contextual and experiential factors influence people's hopes and expectations from AAC. The paper presents an original application of longitudinal qualitative research methodology with people who use AAC which can be further applied and tested in the field of communication disability research.

#### KEYWORDS

augmentative and alternative communication, longitudinal qualitative research, dialogic analysis, patient-reported outcome measures, perspective, experience

#### WHAT THIS PAPER ADDS

*What is already known on this subject*

- We did not know the impact that time has on the concepts that have been identified to represent important outcomes from AAC. The existing concepts used to define outcomes from AAC were not adequately conceptualized to develop a patient-reported outcome measure. This study sought to extend our knowledge about outcomes from AAC.

*What this paper adds to the existing knowledge*

- This study adds to the methodological toolkit available for qualitative inquiry in the field of communication disability research by presenting a longitudinal qualitative research methodology. It adds depth to our understanding of the concepts that underpin outcomes from AAC and highlights the dynamic nature of contexts and how this influences desired outcomes.

*What are the potential or actual clinical implications of this work?*

- This longitudinal qualitative research study provides a broader perspective on the experience of getting AAC. It will enable clinicians to better navigate the contextual and transitional factors that influence people's experience of acquiring AAC devices. The enhanced concepts described will also support clinical conversations that consider the wider facets of communication and what AAC can add to existing communicative tool kits beyond getting a message across.

## BACKGROUND

### Augmentative and alternative communication (AAC)

AAC refers to a set of strategies that include gestures, paper-based resources such as alphabet charts or picture books, and electronic or computer-based devices that have synthesized voice outputs produced from messages that are either entered into or are pre-stored within them (Beukelman & Light, 2020). AAC strategies are used by people who experience difficulties communicating with speech and language because of a range of conditions both congenital, such as cerebral palsy, and acquired, for example, motor neurone disease (MND). People who use AAC may also experience complex physical and/or cognitive disability. Most people who use AAC have long-term conditions that cause communication disability and so their AAC strategies and devices periodically require updating or renewal either because their needs change or the device becomes outdated or malfunctions (Hall et al., 2023).

AAC devices and support are provided in England, UK via two pathways. Regional specialist assessment centres serve people who require specialist assessment and/or complex AAC systems and are funded by the National Health Service (NHS). Specialist services, consisting of speech and language therapists, occupational therapists, rehabilitation engineers and clinical scientists assess and provide AAC devices, and then transfer people for ongoing, longer term support and follow up from local services. Local services support the use of AAC in individual's homes, schools or communities and provide strategies and/or devices to those who do not require the services of regional centres (NHS England, 2016); funding arrangements for local services vary. Understanding and measuring outcomes is an important part of a quality cycle in all clinical services, allowing clinicians and services to monitor the impact of their interventions and evaluate the effectiveness of practice (Enderby & John, 2015). Yet the outcomes that are important to people from AAC interventions, either the provision of a device or of targeted support, to facilitate their communication have not been clearly described (Baxter et al., 2012). Measuring outcomes from people who use AAC is also challenging not least because receiving an AAC device or system is rarely the main goal for an intervention; AAC frequently represents part of a process of expanding communication options to achieve other goals, for example, self-determination and social inclusion (Lund & Light, 2006). The outcomes that are important to people may vary between regional and local services as these services engage with people who use AAC at different stages of their life-course. Smith and

Murray (2011: 302) highlight that 'inclusion evolves over time, through extended participation, as part of a valued social identity' (Smith & Murray, 2011) suggesting that outcome measurement needs to reflect the changing nature of the impact of AAC on individuals' abilities to participate in social and daily life.

Patient-reported outcome measures (PROMs) are an outcome measurement tool that evaluate the impact of an intervention from the perspective of the person receiving care (Devlin et al., 2010). Recent research found that there are currently no PROMs that adequately capture the perspectives of people who use AAC about devices and/or the services that support their use (Broomfield et al., 2019). Developing PROMs to evaluate healthcare interventions requires establishing the core concepts and constructs of interest and then identifying which specific outcomes are most important to the population with whom the PROM is to be used (Meadows, 2022). A hypothesized conceptual framework for a PROM for AAC has been developed from a qualitative evidence synthesis, consisting of three core concepts: outcomes, values, and contexts (Broomfield et al., 2022). These concepts are broad, and the review authors recommend that further refinement of the constructs is necessary to develop terms and descriptions that hold a shared meaning people who use AAC and clinicians who may use a PROM (Broomfield et al., 2022). This review supports the findings of previous research that recognized individual's contexts as being complex, dynamic, and multifactorial (Murray et al., 2020), yet qualitative research in the field of AAC currently represents snapshots of experience across the population. Attending to how outcomes manifest for people at different stages of their AAC journey can inform the development of clinical measurement tools, such as PROMs, that reflect the nature of change over time.

AAC interventions are aimed at enhancing and improving communication (Beukelman & Light, 2020). The meaning of the term 'communication' is rarely fully conceptualized in communication disability research which poses an additional challenge to developing outcome measures; the complexity of interactive communication has been described as 'resistant to singular cognitive explanations or behavioural description' (Barnes & Bloch, 2018: 5). Peters (2000) describes communication as a social construct, one that is concerned with meaning-making and the negotiation of one's individual and collective identity, and which realizes a sense of humanness. People's sense of identity can be disrupted if they acquire communication disabilities because of the changes in their level of and abilities in social engagement (Shadden, 2005; Taubner, Hallén & Wengelin, 2020). People who have congenital communication difficulties and have used AAC from early childhood describe the impact of using AAC as

a means of accessing social membership (Allan, 2006), a voice that expresses aspects of personality such as accent or wit (Martin & Newell, 2013), and as providing a sense of collective identity amongst a community of people who use AAC (Moulam, 2021). Contextual factors, such as the communication partners, the AAC device, and the circumstances in which AAC is used also have a significant impact on the experience of using AAC (Broomfield et al., 2022; Iacono et al., 2013; Lund & Light, 2007). Sociological conceptualizations of communication can aid our understanding of the context-dependent, social, and dynamic nature of interactions mediated by AAC (Broomfield et al., 2023; Teachman, et al., 2018). The interconnections between social communication, identity, and humanness, how they emerge and how they influence or are influenced by the contexts in which AAC is used, warrant further enquiry. A deeper understanding of the connectivity between these facets of communication will support clinicians and clinical services to understand what people value about AAC, how these change over time, and how to support them to achieve personally relevant outcomes.

## Longitudinal qualitative research (LQR)

Qualitative research can provide insights into lived experience that can help shape health interventions. There are some inherent challenges when conducting qualitative research with people who use AAC. Speech cannot be used in the way that many qualitative methods assume and during communication using AAC messages are necessarily brief to accommodate the slow pace of interaction (Philpin et al., 2005). Innovative research approaches have been used to more authentically represent the experiences of people who use AAC based on dialogic theory that expands the conceptualization of communication beyond the spoken or written word and attend to the dynamic and responsive nature of interaction (Broomfield et al., 2023; Teachman et al., 2018). Such approaches involve researchers working alongside participants to navigate topics and co-construct a shared understanding of their experiences.

Longitudinal qualitative research (LQR) is a methodology that foregrounds an understanding of change across time during analysis (Sheard & Marsh, 2019). LQR is an emerging methodology in healthcare research (Tuthill et al., 2020). It has been used with people who have communication disabilities resulting from aphasia to explore communication changes during the first-year post-stroke (Grohn et al., 2014) but has yet to be applied to people who use AAC. LQR allows researchers to walk alongside people (Neale, 2021) and can be used to understand how the fluidity of time reveals ways in which change man-

ifests for individuals who use AAC through attending to the complex processes that influence these developments in context. LQR methodologies are congruent with a dialogic theoretical lens as they enable the research team to attend more to *how* people navigate the experiences that their context affords them. Longitudinal interpretative phenomenological analysis (LIPA) is a method of conducting longitudinal in-depth, experiential research over multiple time points with a small number of participants. LIPA adds a temporal dimension to interpretative phenomenological analysis (IPA), to draw idiographic insights from individual experience across multiple data points (Farr & Nizza, 2019). LIPA is a useful methodology for exploring life transitions and has been used to add depth to understanding health interventions (Spiers et al., 2016).

Public involvement (PI) is another mechanism by which insights into lived experience of people can be explored by developing collaborative relationships and bringing multiple perspectives to research (Romslund et al., 2019). PI is gaining traction in healthcare generally (Brett et al., 2014) and is recognized as having particular importance in the development of PROMs research because of the patient-centred nature of these tools (Carlton et al., 2020; Grundy et al., 2019). Although carrying out PI with people who use AAC also presents some significant challenges to researchers, flexible approaches (Jayes et al., 2021) and creative, visually mediated techniques (Broomfield et al., 2021) have fostered productive collaborative relationships between researchers and people with lived experience of using AAC.

## Aims and research questions

This paper reports on a LQR study that sought to attend to the more expansive, interactive facets of communication involving AAC and how they shape and are shaped by experience over time. The study uses longitudinal qualitative methods, routed in dialogic theory and applied alongside collaborative engagement with a PI group, to explore the expectations and experiences of people with communication disabilities who are referred to a specialist AAC service over a year. This LQR study is part of a wider project focused on developing a PROM for AAC. This study explored the following questions:

- What outcomes are important to people following the provision of AAC devices?
- How are people's expectations from AAC shaped over time by the circumstances in which AAC is being introduced?
- What features of people's context and environment support and/or inhibit their engagement with AAC?

## Methodological approach and theoretical framing

This study used a LQR methodology informed by a dialogic theoretical lens. Qualitative longitudinal analysis has been described as a journey from summative to descriptive and then to interpretative accounts of data (Neale, 2021). The interpretation of data involves iterative and reflexive movement between cases, themes, and processes to draw together synergistic threads and create a 'diachronic (through-time)' (Neale, 2021: 266) representation. Analysis is underpinned by abductive logic and reasoning, accepting the non-neutral nature of data, and hence that theory and background knowledge inform the analytic process (Neale, 2021).

Inspired by the work of Shotter (2011), and building on the work of Teachman et al. (2018), we engaged a dialogic theory, which conceptualizes communication as an interactive process involving the dynamic, active, relationally responsive reactions between people. In applying dialogic theory to LQR, we posit that meaning is co-constructed between participants, communication partners, and interviewer during the data collection interviews (Broomfield et al., 2023). Shotter's dialogic theory of communication enabled us to move between linguistic, non-linguistic, and embodied responses noticed within agents' interactions represented both during data collection and in attending to our responses to data during analysis. This theoretical approach is situated within a social constructivist epistemology—one that seeks tendency and coherence across a range of data sources over and above semantic connections between words.

## METHOD

### Ethics review and approval

This study was approved by the Health Research Authority in the UK (IRAS ID: 227722/REC reference 18/YH/0001).

### Design and participants

The study followed a cohort of participants from pre-assessment with a regional specialist AAC service until up to 12 months after receipt of a new AAC device. The aim was to recruit 6 participants in total; two from each of the following categories: (1) young people between 12 and 18 years old, (2) adults (18 years old or older) who had communication disabilities from birth or early childhood and (3) adults (18 years old or older) who acquired communication

disabilities. Members of the research team with clinical experience of working with people who use AAC identified that these groupings broadly represented people who used AAC for a variety of communication purposes, in several contexts, and therefore have a range of experiences to report. A series of four semi-structured interviews were conducted with each participant: (1) before their assessment, (2) after their assessment, (3) after they received AAC equipment and (4) six months after receipt of equipment.

### Recruitment

Participants were recruited from a regional specialist AAC service in the south-west of the UK. People were identified from the service referrals list by the service clinical lead and approached to be involved in the project if they met the following inclusion criteria; aged 12 years old or over; had a communication difficulty; had the potential to benefit from AAC; be able to consent to participate; and were able to participate in an interview. Purposeful sampling was used to recruit individuals from each of the three categories stated above. The list of referrals was scrutinized by the clinical lead who then sent participant information packs to those who met the eligibility criteria and who were judged from the referral information available to have capacity to consent to being involved in the study. Once sufficient participants had been recruited to a category, the clinical lead stopped searching the referrals for people from that category.

People who consented to having their information shared with the research team were contacted by a researcher (K.B.) to arrange the initial interview and to confirm participants had capacity to consent to involvement in the project by checking their understanding of the participant information. The participant's communication partners were invited to be involved in the interview when this was the preference of the participant or where they facilitated the participant's communication. Where communication partners were present during the interviews (including carers, family members, and professionals), they were provided with participant information and consent for their contributions to be recorded in the data was obtained before commencing the interview recording. Participants have been anonymised in this report using pseudonyms created by K.B., communication partners are referred to as CP, and the interviewer as I. A total of seven participants were recruited to the study, four of whom had communication partners present during each interview. Two participants withdrew after interview 2 (Nick and Ivy). For a summary of participant demographics and interview information, see Table 1.

TABLE 1 Participant demographics, communication style, communication partners, AAC devices issued and interview mode.

Participant	Age (years)	Diagnosis	Communication mode (before assessment)	Communication partner	Interview 1	Interview 2	Communication aid issued	Software package	Interview 3	Interview 4
Nick	68	Stroke	Speech (short phrases); alphabet spell chart	Not present	In-person	In-person	0	0	0	0
Ivy	67	Stroke	Speech (single syllable); gesture; intonation	Daughter	In-person	In-person	0	0	0	0
Monica	64	Multi-Systems Atrophy (MSA)	Speech (whisper, interviews 1–3); AAC only (interview 4)	Not present	In-person	In-person	Tellus vibe	Me 4	In-person	In-person
Jeff	26	Cerebral Palsy	AAC; facial expression for yes/no	Mother (CP1); key worker (CP2)	In-person	In-person	Tobii Dynavox i16	Communicator 5	In-person	MS Teams
Bill	17	Learning difficulties	AAC; Makaton	Mother (CP1); Teacher (CP2)	In-person	0	iPad mini in Chat wrap	SuperCore 50 on Grid for iPad	MS Teams	MS Teams
Dave	50	Down Syndrome	Speech (short phrases); Makaton	SLT (CP1); Father (CP2)	In-person	In-person	iPad	Grid 3, Symbol Talker	MS Teams	MS Teams
Peter	44	Cerebral Palsy	Written sentences (computer); facial expression for yes/no	Not present	In-person	In-person	Gridpad	Grid 3	Email	In-person



## Study materials and patient and public involvement (PI)

A PI group for this project, consisting of people who use AAC and their family and carers, were involved in developing all the materials used for recruitment and interviews to ensure that they were accessible to people who have communication disabilities (see Broomfield et al., 2021, for further detailed information). For example, written information in recruitment materials was kept to a minimum and pictures were included to support potential participant's understanding of the material. A recruitment video was also produced and made available via YouTube<sup>TM</sup> with a link.

A topic guide for each interview stage was generated with the PI group so that questions would provoke responses that added to existing knowledge about the experiences of communicating using AAC reported in a qualitative evidence synthesis (Broomfield et al., 2022). They were also involved in data analysis, checking and challenging interpretations and results (see data analysis section for details).

## Data collection interviews

Interviews were conducted by one researcher (K.B.) and took place at a venue of the participants choosing (Table 1). Data were collected between July 2019 and September 2021. During the study period restrictions were put in place by the UK government in response to the COVID19 pandemic and during this time interviews were conducted virtually using the online videoconferencing platform MS Teams®. Interviews were video- and audio-recorded and followed the semi-structured interview topic guide prepared with the PI group. A copy of the topic guide was sent to the participant in advance so they could prepare responses, including pre-storing responses on their AAC system, if they chose. The researcher who conducted the interviews is also an experienced speech and language therapist and, when necessary, supported the participant to engage with interviews in several ways: adapting the questions to aid understanding, checking responses with closed questions, and using gestures and images to support understanding and facilitate expression.

Interview audio-recordings were transcribed verbatim, video recordings were reviewed by one author (K.B.) and gestures or non-verbal communication were noted in the transcripts.

## Analytic method

The analytic method built on principles of LIPA to explore the experiences of a small number of participants in depth,

over multiple time points. Inherent to traditional IPA is creation of a double-hermeneutic wherein the researcher tries to make sense of participant making sense of a phenomenon or phenomena (Smith et al., 2009). We extended the core facets of IPA, through applying a dialogic theoretical lens that elucidated the cocreation of interpretations in vivo (during interviews) and during a reflexive, abductive and interactive analytic process carried out between researcher, wider research team, and PI group.

We initially conducted a case analysis, exploring participant level data at each time point and then looked across time points to understand similarities and differences across participant's experiences. During initial case analyses, we followed the phases of data preparation, familiarization, and initial noting described for IPA (Smith et al., 2009). Data for each participant, at each time point was uploaded to NVivo for Mac (version 11; QSR International, 2020). Tables were then devised in MS Word® by K.B. to organize data and to document how an abductive interpretative strategy, moving between data sources and across columns in the table, resulted in the development of conceptual interpretations from the data (final column). An example of the data table used for analysis can be seen in Table 2.

The thematic aspect of the analysis was informed by the hypothesized conceptual framework for a PROM for AAC presented in a previous narrative review (Broomfield et al., 2022), and the core concepts: outcomes, values and contexts. The PI group provided feedback on the concept labels used in the hypothesized framework and felt that 'changes' was more suitable than 'outcomes' as the latter suggests an end point. The PI group also favoured the phrase 'future possibilities' rather than 'values' because the group felt it better reflected the temporal influence of people's hopes and expectations from AAC and represented how people feel about what having AAC enabled them to do. Data from the analysis were organized into the guiding concepts of changes, future possibilities and contexts.

We then considered individual cases across time points to draw out aspects of the context and circumstances of individuals that appeared to influence their experiences of using AAC. The dialogic theoretical lens focused our attention during analysis towards key moments in the data (Sullivan, 2012); moments that provoked our noticing because they pointed to an important experience. These moments were noticed because they represented novelty, similarity, or dissonance across individual's experiences (Neale, 2021) and enabled us to shape our understanding of how concepts evolved or morphed over time. We then sought to connect these moments in streams of linked events where experience coalesced between participants (Neale, 2021). Interpretations were drawn out by a reflexive research team working collaboratively with the PI group



TABLE 2 Example of a data table.

Topic guide questions ( <i>prompts in italics</i> )	Data: video transcript	Descriptive comments	Linguistic/non-linguistic comments	Data: field notes	Reflection	Conceptual comments <i>Conceptual interpretation</i>
'Tell me about your current communication.'	<b>Nick:</b> No (whispers) <b>INTERVIEWER:</b> No. Do you use anything to support you to communicate?	I look for cues within the room for an existing means to support communication during the interview and find only an uncharged iPad.	P1 currently uses single words and short phrases to communicate.	The interviewee is bed-bound, side-lying and largely non-verbal. Some very dysarthric single word and short phrase utterances. His iPad lay uncharged and unused on the bedside table and his communication book was only located at the end of the interview, the care centre manager insisting that he refused to use any communication aids.	P1 is minimally communicative, relying on single words and short phrases. He requires a lot of prompting from the interviewer to be able to participate in the interview.	Current communication is ineffective/insufficient
<i>What do you use to support you to communicate?</i>	<b>Nick:</b> (pointing with left finger towards K. Whispers something unintelligible)					The role of the communication partner is critical to generating meaning
<i>In what ways does it not help?</i>	<b>INTERVIEWER:</b> Are you saying a letterboard?					
<i>In which situations? With whom?</i>	<b>Nick:</b> Laptop (whispers)					
<i>Why?</i>	<b>INTERVIEWER:</b> A laptop, ok. Not this one the one we were looking at earlier? (shows P1 the iPad) Do you ever use this?					<b>Communication dependent on connection</b>
	<b>Nick:</b> (Mouth movement. <i>Unintelligible speech</i> )					
	<b>INTERVIEWER:</b> Yes. An iPad. And you mentioned a laptop do you have a laptop as well?					
	<b>Nick:</b> (Pointing to iPad)					



and engaging responsively with a range of data sources during analysis. The causal processes that appeared to be shaping the experience of using AAC were then illuminated to build an understanding of *how* different outcomes are realized for individuals.

## Reflexivity

As a clinician (speech and language therapist) and a researcher, K.B. actively engaged with her clinical skills to facilitate the interviews. She noticed embodied actions and reactions within interviews and during analysis and recognized where her experience was being confirmed and challenged by the data. This recognition of her activity during data collection provoked conversations with the wider research team (K.B., D.J., G.J., S.J.), and during meetings with the PI group, that led the team to search for a methodological approach that acknowledged this embodied engagement. We had extensive and challenging discussions about voice, positionality, and professional identity. In parallel with reading the work of John Shotter and establishing a theoretical position for the analysis (Broomfield et al., 2023; James et al., 2021) we began to attend to how AAC is used in context, rather than simply to why it is used. These conversations lead to a deeper, analytic, and conceptual engagement with the data and enhanced the rigour in which the method was applied to this study. The field notes written immediately after data collection interviews and the reflective comments made during analysis and in discussion with the wider team and PI group were used to document these responses and were include in the data set.

## Rigour

We adopted a whole process approach to our pursuit of rigour (Neale, 2021). We invested significant time and thought in establishing and explicating a theoretical position that supported the development of the methodology described in this paper. We applied dialogic theory to all aspects of the study—during data collection, analysis, in PI collaboration, in research team discussions, and with the concepts that were identified. We aimed for the quality of the study to be inherent in the integrity of our application and reporting of the method, and in the coherence of the theoretical and methodological approach. These efforts also addressed an identified need for greater depth in qualitative research with people who use AAC (Broomfield et al., 2022; Broomfield et al., 2023). The authors considered that the approach to whole process appraisal of rigour over critique of individual internal processes suited the ontological positioning of the research.

## RESULTS

The results confirm and extend the core concepts that were used to guide the analysis: changes, future possibilities, and contexts. The longitudinal dialogic analysis also allowed us to explore how these core concepts shifted and expanded during the study by attending to the temporal flows and circumstantial forces that influenced participant's experience. The following narrative presents the core concepts as themes, and details how they were adapted and expanded through the LQR data. We present some data in the text to exemplify the themes with further data to evidence the themes presented in Table 3. We then present cases that exemplify how outcomes, represented by the core concepts, manifest for participants differently, and what the longitudinal element of this study adds to our understanding of experience. Direct quotes, with synthetic speech produced from AAC is denoted in **bold font**, and images from the data are used to illustrate the themes in the narrative. Reflections from field notes and comments made by K.B. during analysis are presented in *italic font*. These reflective data evidence the dialogic nature of analysis and how meaning and interpretations are created within and between the interactions during data collection interviews and the analytic process.

## Themes

### Changes

This theme reflects the expectations and experience of change that the introduction of a new AAC device had on the individual. Participants described communication as being an important outcome from receiving an AAC device. However, how they perceived the concept of communication and the change they wanted AAC-enhanced communicative abilities to support evolved over time as they integrated the new device into their communicative milieu.

During the first set of interviews, before assessment by the specialist service, participants had a range of AAC systems that they used to support their communication, including Makaton™ signs, alphabet charts, and some computer-based devices. K.B. commented in the field notes that AAC was '*part of a "communication system"; the role it plays is dictated by what is already in the system*' (field notes). Following assessment with the specialist AAC service, during interview 2, participants and their communication partners recognized '*a new [AAC] device opens possibilities for conversation*' (field notes). The concept of communication expanded beyond functional message production towards being able to identify



TABLE 3 Data to represent the themes derived from the analysis.

Interview stage	Concept	Interview data representing key moments	Researcher reflections
1	Changes	<p>MONICA: I'd like to be able to speak to people I: Just like to speak to people MONICA: Yes. I: Ok MONICA: In any situation I: In any situation MONICA: Yea. To not lose any more communication than I've already lost</p> <p>MONICA: Some kind of magical machine I: A magical machine MONICA: that could make me speak clearly I: Yea. That would help you speak clearly or would speak for you? MONICA: Whichever [...] yea. I've no idea what it is though. Just something magical really</p>	<p><i>As an SLT I break down communication into a range of different acts used for a range of purposes. P3 seems to not really comprehend this question in the same way that I do i.e. she just wants to 'speak' to people. She doesn't view conversation as different from functional communication or narrative.</i></p> <p><i>AAC possibilities are little known—therefore have a mystical quality</i></p>
	Future possibilities	<p>I: What would you like to use a new type of thing for (points to tablet)? IVY: Me me, me me, aw CP: I guess it would be nice if you could get some more independence back wouldn't it. If you could go somewhere on your own. Go to the shop and if you had something to IVY: Me me, me me ah, me me, me ah me me, me me awe me me awe (makes a fist, clenches jaw as if holding back/wanting to go)</p> <p>There's something there about the voice... That's missing from the written word (PETER)</p>	<p><i>She [P2] is entirely dependent on family and/or visitors. She doesn't have any friends locally. As it must've been her daughter who signed her up to the study, and her daughter who mentioned the word 'independence' here, I wonder whether it is actually the daughter who would like her mother to have independence and connections outside the family home.</i></p> <p><i>Synthetic voices do not sound like him and because of celebrity users, they sound like the familiar person using them, i.e. not like he thinks he should sound.</i></p>
	Context	<p>CP2: In the future, yea? What do you want to use it in the future for? DAVE: <i>unintelligible</i> [2 syllables, 2 syllables] I: Going out? DAVE: No, move out (uses a hand gesture) CP1: Oh, when you're moving out? CP2: To move out. SLT: This is an excellent point P6.</p> <p>I: What's going to help you learn to use it? DAVE: A lot CP2: A lot, what does that mean? CP1: A lot of help DAVE: Yea, a lot I: A lot of help. From who? DAVE: (looks towards SLT, smiles, then laughs)</p>	<p><i>Dave wants to more out of home. This is a future goal that he self-initiated... Perhaps the SLT identified AAC as a way in which she could help him to achieve this end?</i></p> <p><i>The SLT (CP1) has already put a lot of time and thought into preparing the support that Dave will access to help him learn to use a new AAC device and to integrate it into his current day to day. Dave is aware that he will need support from the SLT and that he will require ongoing support for some time in order to use AAC.</i></p>

(Continues)



TABLE 3 (Continued)

Interview stage	Concept	Interview data representing key moments	Researcher reflections
2	Changes	<p>IVY: Me me, me me, me me, me me (points to items on screen, then to K, then makes forward moving gesture), ah, me me, me me, me me, me (rising intonation, palm upturned, as in 'don't know'), ah me me, me me, me me, ah me me, ah (looks to K and then points to different items in the surrounding area, on sofa).</p> <p>I: So that's there</p> <p>IVY Ah</p> <p>I: So the pictures you've got on here (points to tablet) are things within your environment</p> <p>I: Ah me me, ah me me, ah (scrolling through items on the tablet)</p> <p>CP: The programme that the team were on about doing was more of a—like on the left hand side it's not like a start of the conversation and more of a sentence other than just words.</p> <p>I: Ah me me (nods)</p> <p>CP: that's what they've been trying with.</p> <p>It's like being given the use of a voice, a pen and partial use of my hands (PETER)</p>	<p><i>Communication is negotiated between the three of us. The interpretation of Ivy tends to rely on the interpreter and their understanding of the context i.e. is it related to the question (K) or is it related to communication (CP)?</i></p> <p><i>Ivy uses existing AAC to communicate about things in her current environment. A new device opens up possibilities of conversation</i></p> <p><i>I really liked the way PETER: framed AAC in terms of: 'a voice, a pen and use of his hands'. I highlighted it when I was transcribing the video and also noted it in my reflective fieldnotes following the interview. Although I try to tease out specific functions [during the interview], I am also drawn to the openness and potential that access to over-arching functions has. Is it reductive to try to identify specific goals or roles of having a voice, or a pen?</i></p>
	Future possibilities	<p>JEFF: Yea [looks at communication aid] <b>I want to be more impatient</b></p> <p>I: You want to be more impatient?</p> <p>JEFF: [looks at communication aid]</p> <p>CP: (looks at communication aid screen) are you trying to say independent?</p> <p>JEFF: Yea</p> <p>I: Independent?</p> <p>CP: Yes</p> <p>MONICA: One think I talked to them about was, sort of an amplifier that amplified my voice</p> <p>I: yea</p>	<p><i>Jeff wants greater independent control of his environment</i></p> <p><i>She still wants to be able to use her voice in this situation. Does voice and the meaning of voice change depending on the situation and what influences this?</i></p>

(Continues)



TABLE 3 (Continued)

Interview stage	Concept	Interview data representing key moments	Researcher reflections
	Context	<p>JEFF: [looks at communication aid] <b>a little bit worried about how Microsoft office—a little bit worried about how we put Microsoft office on my new device.</b></p> <p>I: Ok</p> <p>JEFF: Yes</p> <p>I: And did you talk about that with the communication aid service?</p> <p>JEFF: Yes</p> <p>I: Yes. And um were they able to reassure you about that or are you still not sure?</p> <p>JEFF: vocalization – 2 syllables</p> <p>I: You're still not sure</p> <p>JEFF: Yes</p> <p>I: Ok</p> <p>CP: Did they say it was doable?</p> <p>JEFF: Yes, yes</p> <p>CP: But you need help with it?</p> <p>JEFF: Yes. [looks at communication aid] licensing</p>	<p><i>In the past he has reported that he doesn't like change and I wonder whether there is a role for supporting him with what functions he may have lost or look significantly different on a new device? Are these the sorts of issues that we should be addressing as therapy services—adjustment, change and setting new expectations?</i></p>
		<p>MONICA: I'm not very sure. Aside from them saying that they were going to take it away and program it for me, working through the speech therapist. She and I met on Monday morning just to start to put some questions together</p> <p>I: Great.</p> <p>MONICA: And Jane joined us too. She' my carer</p> <p>I: OK, great.</p> <p>MONICA: It was brilliant to have there too</p> <p>I: Yea</p> <p>MONICA: We came up with reams and reams of stuff. And we're going to meet again, either next week or the week after to get cracking on with it. And then the speech therapist will feed them through to the team.</p> <p>I: Yea.</p> <p>MONICA: So I found that support very useful. And that they are actually going to program it for me.</p>	<p><i>She appears to want support with setting it up, programming the content but not learning how to do either of these things herself. I wonder how much, therefore the AAC becomes an output mechanism only? Is there a sense of ownership which needs to accompany it in order that it becomes more incorporated into a communication system?</i></p>
3	Changes	<p>JEFF: <b>very important to talk my mum and dad.</b></p> <p>I: Yes, that's a real priority</p> <p>JEFF: Yes</p> <p>I: So you don't want to switch over devices until you've sorted out the phone</p> <p>JEFF: Yes (nods head)</p> <p>I: That's your priority okay.</p> <p>I am disappointed that it is only a talker, and does not do some of the extras like we discussed, e.g. environmental control, word processor, playing music etc</p>	<p><i>Initially, the priority for a new AAC device was speed and reliability as his existing device wasn't working consistently. However, once he had the new device, other functions (or lack of them) became a priority. P4 would not use the new device until it was set up with his phone and TV control. Connection and not losing existing agency were more important outcomes from a new AAC device that speed and reliability.</i></p> <p><i>Suggests a disconnect between what he was hoping for and what he received.</i></p>

(Continues)



TABLE 3 (Continued)

Interview stage	Concept	Interview data representing key moments	Researcher reflections
	Future possibilities	<p>CP: So go to your favourite page then. What is your favourite page, what is your favourite one? So what have you pressed, so press that word and it might say</p> <p>BILL: <b>food</b></p> <p>I: Food</p> <p>M: Did you hear that</p> <p>I: Food</p> <p>CP: Yes</p> <p>I: Great so what is your favourite food on that page?</p> <p>CP: We can do that easy, so what's your favourite, what's your favourite foods, what's your favourite for lunch? so put your—what is it.</p> <p>BILL: <b>Sausage</b> (P5 looks at I once he has selected the word)</p> <p>I: Sausages, yum yum. Yes I can see you're smiling at that one, yes.</p> <p>CP: 'I hope Bill has had his little voice come—I didn't want to do all the talking also I wanted him to answer the questions to the best of his ability and stuff, so you know his voice has come through and it's not just all my voice, even though as I say a lot of it is but P5 voice is there as well as my voice.'</p>	<p><i>AAC is being used to communicate basic wants and needs but who benefits from this? Could P5 communicate this information in any other way? How much of the use of AAC is initiated by Mum because she needs to hear his voice?</i></p> <p><i>Bill demonstrates his ability to follow and respond appropriately to direct and specific questions when there is content available on his AAC. He is not able to respond to many of the interview questions in this way as he doesn't have access on his AAC to the correct vocab. The Talking Mats were also helpful in this respect... enabling P5 to actively participate in the interview</i></p>
	Context	<p>It is also useful with my PA, although she is very laid back, and already she is in tune with most of my looks. The big test will come when I have a changeover in PA's. I still use eye spelling because it is so quick, much to her annoyance!! And, of course, due to Covid, I have not been anywhere to talk to anyone. (Written response send by email by PETER:</p> <p>CP2: His -he's supposed to be moving out. Leaving home, um ... and I don't know we've just had a message today to say that they can conduct an interview on the internet only, but it looks like they've found a place, they've found a place for him.</p> <p>I: Okay</p> <p>CP2: So he wants to move out. I don't know whether I do, but that's another matter.</p> <p>I: Yes</p> <p>CP2: But, yes it's going to cause a bit of a problem, that was one of the reasons why I had to learn how to edit it over the internet, so that I could change stuff for him after he's moved out.</p> <p>I: Right okay.</p> <p>CP2: So um—but yes that's going to be a bit of a problem then.</p>	<p><i>The timing of receipt of his AAC is interesting. I wonder whether it is a coincidence that his wife and son move out as his new device is set up or whether this is something that they were waiting for in order to make that break?</i></p> <p><i>Dave initiates the conversation about moving out, about which Dad is quite negative again—in terms of how he will edit AAC content, about how we will conduct these interviews, about how and whether P6 will be able to practice [using his AAC]</i></p>

(Continues)



TABLE 3 (Continued)

Interview stage	Concept	Interview data representing key moments	Researcher reflections
4	Changes	<p>CP2: What he's very good at is finding stuff to tell me things.</p> <p>I: Really (Dave smiles)</p> <p>CP2: So I mean he can, as long as he's got his own time, but if you start asking questions then it's all—then he starts dithering all over the place trying to find what the answer is.</p> <p>I: Okay, that's interesting.</p> <p>CP2: But when he uses it—because he can use it, he can be quite inventive and he can use things for which they're not intended in other ways sort of thing, which I hadn't thought of but are actually quite useful, so. But we probably aren't using it the right way, but we're using it so (all talking)</p>	<p><i>CP2 expresses pleasure and surprise at the creativity involved in using the AAC to point backwards and forwards to different events to help sense-making in the present moment.</i></p>
		<p><b>JEFF: I would love it if I make big stream in every home and show off fireworks display.</b></p>	<p><i>Perhaps lockdown has also shifted the horizons of what is possible and what is required from AAC for a new or different future? Suddenly things that weren't important on a new device previously are becoming important</i></p>
		<p>I: Ok. And 9, what additional support would you like to receive. You said: 'It's difficult to answer because I don't know what I'm missing until I'm shown.'</p>	<p><i>PETER highlights that individualizing care is important. He also flags that he doesn't know what is available, and what new devices are capable of until he is shown. This points to the specific role of healthcare staff informing people what is available to them and enabling them to imagine what might be of interest and of value to them</i></p>
	Future possibilities	<p>I: Do you think there is anything they could have done differently that might have helped you—that might have helped you more?</p> <p>JEFF: Yes</p> <p>I: Yes, you're not sure?</p> <p><b>JEFF: give me windows control and communication 5 on the device.</b></p> <p><b>MONICA: Alexa connection is fab</b></p> <p>I: Great. So one of the things you mentioned last time you were quite pleased about was the fact your device would be able to talk to your Alexa,</p> <p>MONICA: (right hand shake with thumbs up)</p> <p>I: And it works really well?</p> <p>MONICA: (right hand shake with thumbs up)</p> <p>I: ... You've also said the accent (reading again from the iPad)—that's something we talked about before—you'd prefer to have a Northern Irish accent.</p> <p><b>MONICA: i poss</b></p>	<p><i>The barriers with accessing Windows control are presenting as barriers to P4 accessing anything else This is his priority for moving forward with a new AAC</i></p> <p><i>Being able to control her environment is an unexpected benefit of AAC for Monica</i></p> <p><i>... what about voice and identity—is connecting with the device going to support a person to use it more</i></p>

(Continues)



TABLE 3 (Continued)

Interview stage	Concept	Interview data representing key moments	Researcher reflections
		I: If poss. If possible, yes of course. (Looks towards iPad again and reads from it) and it says 'Graham's responses' MONICA: <b>I emailed h-m her said you would like to (unintell) laid. Accent but never been asked.</b>	
	Context	I: Can you tell me a little bit about how you're using your communication aid at the moment to support your communication? MONICA: <b>a lot</b> I: Yes, so your voice is very quiet today I think compared with when we last met. MONICA: <b>it's gone</b> I: Gone altogether, is that every day or just—do you still have good days when it's better? MONICA: <b>some mornings yes it's okay.</b> I: Yes, brilliant and you found you've had the help you needed when you needed it.  CP2: Yes, oh yes. I: Brilliant CP2: Yes I mean in the first place they helped me because they showed me how to use it and how to programme and what to do and everything and then we had a few blips and they sorted those out for us and then since then it's been okay. I: Yes CP2: Yes, but yes.	<i>Voice deteriorating as a marker of physical deterioration: although Monica otherwise looked well, and had kept safe during the lockdown, she no longer had any voice left and is entirely dependent on her communication aid.</i>  <i>It really seems as though dad has invested in the device, despite his initial reservations, and that perhaps lockdown has encouraged him to do this as he and Dave used to get stuck when communication broke down and now they have a way to work around it.</i>

what communication may enable participants to do such as making social connections or accessing wider opportunities. More interactive conceptualizations of communication, and how AAC can enable these interactions, emerged in the interview dialogue.

After receiving new AAC devices from the specialist service, during interview 3, participants recognized the social and emotional value of communicating for building and maintaining relationships: 'I went to the pub with my friend one evening and we had great fun with it' (Monica). This was an *'example of making connections with friends through the AAC i.e. something that couldn't happen without it'* (field notes), where AAC provided a shared modality for connecting rather than just a means of producing words; '[They were] *able to make jokes and to use the device as a tool in their interaction*' (field notes). AAC began to be perceived as part of a communication system rather than a tool to express specific linguistic messages.

By interview 4, the new device was being used to support relationships at home (Dave), enable participants to join online social events (Monica), and provided the means to foster deeper emotional connections within families: 'I have been able to express my feelings and emotions,

especially to my son, and to potential strangers' (email response, Peter). The nature of the changes to communication that the new AAC device enabled extended beyond the participants' initial hopes for greater access to message generation, towards changes in their social and relational interactions.

## Support

The theme 'support' is represented by the actions of others and the contextual opportunities available; support varied considerably amongst the participants. During interview 1 participants described, or were observed to have, different degrees of access to opportunities and advocates to help them to engage with AAC. Some had communication partners present throughout the interviews, whereas others had scarce support: '*Nick has limited access to communication partners or communication opportunities*' (field notes). It appeared that some participants' contexts were more communicatively nurturing than others. The participants all found it difficult to imagine or describe what support they might want with a new AAC device.





By interview 2, participants recognized the need for support from services to embed the new AAC device: **'I would like to get someone out of [home name] to do some training'** (Jeff). Others were still unable to identify what that support should look like: 'That's a hard question to answer. Because I don't know what support I will need until I start using it' (typed response, Peter). Knowing what support was needed was identified as a challenge and knowing how to access that support was another.

For many of the participants, interview 3 coincided with the COVID19 pandemic and subsequent periods of lockdown. The lack of availability of external support influenced some participants' ability to engage with the new AAC device: **'them saying that it your not our jobs to set up it'** (Jeff). Having opportunities to use AAC was important. For some participants COVID19 inhibited their use of AAC, whereas for others it enhanced the opportunity for one-to-one interactions with friends and family (see case studies below for further examples).

By interview 4 participants who had continued to use their new devices and the people in their support networks were increasingly confident with AAC. Some participants were interested in what more AAC could do for them. They may have benefitted from additional guidance from AAC services about what other possibilities were available from their AAC to help them to further embed the new devices in their communication systems:

I: Ok. And [question] 9, what additional support would you like to receive? You said: 'It's difficult to answer because I don't know what I'm missing until I'm shown.' (Peter, interview 4)

## Future possibilities

Initially communication was the key motivating factor for getting AAC. However, over time participants started to recognize, both explicitly and implicitly, that communication gave them access to something more than being able to express basic messages; it was a mechanism for achieving greater independent control.

During interview 1 participants and their communication partners, without experience of using AAC, tacitly connected communication with individual agency and the potential to support greater independence:

CP2: In the future, yea? What do you want to use it in the future for?

Dave: (unintell) (2 syllables)

I: Going out?

Dave: No, move out (uses a hand gesture)

Whereas those with experience of using AAC already recognized how AAC had a fundamental impact on them: **'it changes my life'** (Jeff).

Being able to exert some control over their choices and environments became increasingly important to all participants as they were introduced to wider functions of AAC, beyond communication. By interview 2, participants identified other assistive technologies that they could access via AAC such as environmental controls: **'It was nice to see software that I'm going to use, also they are looking into putting an environmental control into it which would be brilliant'** (Peter).

During interview 3, *'Bill is using his AAC to make choices at home, particularly in relation to food and drink'* (field notes):

CP1: So go to your favourite page then. What is your favourite page, what is your favourite one? So what have you pressed? So press that word and it might say ...

Bill: **Food**

And Jeff described why it was important for him to use Microsoft Office features on his AAC to: **'I use words [MS Word] to work as events manager'**. Being able to make choices and engage in occupation were important outcomes from having access to a physical voice.

By interview 4, all participants saw AAC as a more flexible technology than just a communication aid: **'Alexa connection is fab'** (Monica); **'give me windows control and communication 5 on the device'** (Jeff); 'Word process. Although I would be worried about the battery life' (response typed into computer, Peter), and Jeff wanted to use his AAC to watch TV (Figure 1).

Equally, not being able to access these additional features was a source of significant disappointment when it did not materialize: 'Environmental controls have proved to be too complicated ... and too complex' (response typed into computer, Peter). The significance of control and agency were realized by both the raised awareness of what AAC can do and the participant's experience of using it in different ways.

## Cases

### Changes: circumstances and tipping points

The outcomes that people were able to achieve from access to new AAC devices were enabled and inhibited by the

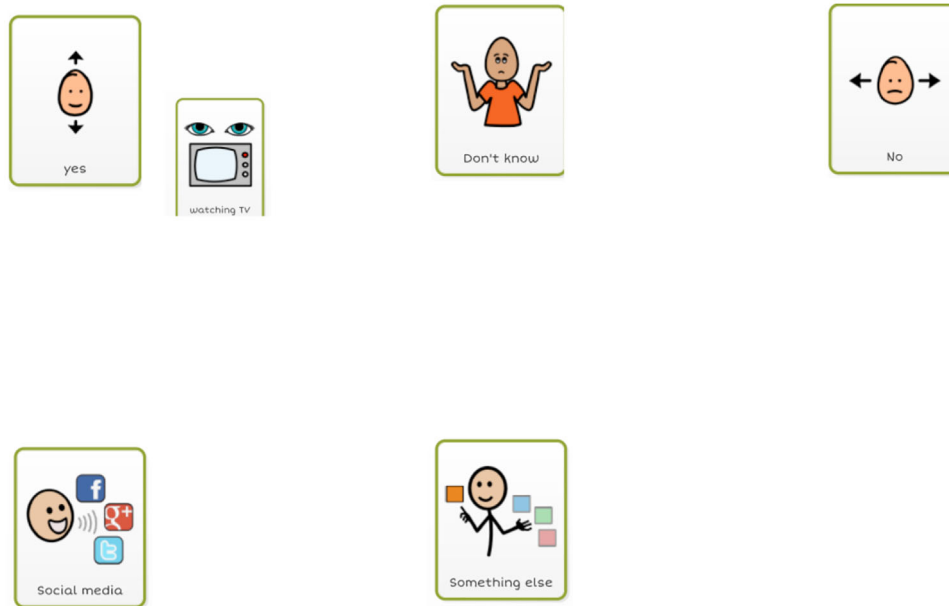


FIGURE 1 Talking Mat™ response, Bill. [Colour figure can be viewed at [wileyonlinelibrary.com](http://wileyonlinelibrary.com)]

circumstances and life events that coincided with AAC assessment and device provision. Bill and Dave both had learning disabilities and lived at home with their parents. Bill attended a special school and Dave had a variety of vocational activities that he was engaged with for 4 days each week. Opportunities to use AAC had been identified in their education and work contexts before referral for AAC and they both had access to keyworkers in these environments to support with programming and implementation of AAC. They experienced a significant and unexpected change in their communicative contexts during the COVID19 pandemic when their educational and work establishments closed.

The government-imposed periods of lockdown during the pandemic resulted in Dave spending more time at home with his father. This shifted the potential for AAC from being a device to support Dave at work and in a new supported living environment, towards AAC becoming a conduit for communication between him and his father. Dave's father had been sceptical about Dave's motivation to use AAC in early interviews: 'The trouble is, he doesn't think he's got a problem with communication. He thinks other people have got a problem with understanding' (Dave's father, interview 1). During the lockdowns, he took a very active role supporting Dave to use his AAC device. Spending more time together at home allowed both Dave and his father time to discuss and update the AAC device with relevant vocabulary to support their relationship. Dave and his father had conversations about football using the device and Dave was able to participate in decision-making about shopping and meals:

I: Yes, okay brilliant. And what other things do you use it for with Dad at home then, if you're using it everyday? What other things do you tell dad about when you're using it?

Dave: **Lamb**

CPI: Food

The change of circumstance that the pandemic provoked led to the AAC device playing a greater role at home than had been initially envisaged. The device supported Dave and his father to build their relationship and enabled Dave's role at home to develop, leading to a sense of personal growth. The interviewer reflected that:

*Priorities from AAC may be different for people who have never had a voice ... perhaps gaining one is less of a priority than gaining independence (field notes)*

Whereas for Bill, periods of lockdown reduced his ability to practise using his new AAC device: 'But I think [not] being at school has made a massive impact on the VOCA, because obviously he has VOCA groups in school' (Bill's mother). During the interviews, the interviewer observed that Bill tended to interact with the device on demand only, and often to repeat what he had already expressed in Makaton™ sign or using the paper-based resources provided for the interview. Bill's mother was not confident at updating the device with new vocabulary and its use at home was limited to routine choice making: 'But as you can see, I've



used the homepage like he is but just trying to do that it takes a bit longer because obviously it's not something that we can use at the moment in that sense, with a lot of people. We're just using the basics' (Bill's mother). Although Bill's mother was a driving force in having his AAC needs reviewed and updated, the interviewer reflected in an analytic comment that '*she is not confident to programme it, or for Bill to use it for anything other than talking*', which impeded Bill's ability to practise using it during lockdown and therefore to impact on his outcomes from using his new AAC device.

## Support: Transitions and changing contexts

All participants experienced a period of transition either before or during the series of data collection interviews, or they were anticipating a transition on the horizon. For some, a transition was the catalyst for referral to the specialist AAC service as family members or professionals sought to maintain or improve communication and/or opportunities in a new home. Exploring the reasons for the referrals and understanding more about the historical and possible future landscapes of the participants added greater perspective to interpretations of their experiences and suggested explanations for participant's non-use and disengagement from AAC and the project.

Nick and Ivy had both experienced stroke and had aphasia. For Nick, a referral for AAC assessment was made by a local speech and language therapist because he had recently been discharged from hospital and moved into a nursing home. At interview 1, the interviewer noted that Nick had an iPad in his room, but it was not charged:

I: It's obviously not charged at the moment, who do you use it with?

Nick: My daughter

I: Your daughter, anyone else?

Nick: No

I: No. Do you use it with the staff here at the care home?

Nick: very rarely (whispers)

This suggested that there was lack of support within the nursing home to set up AAC. Nick spent all his time in bed, had very few visitors, and staff reported that he didn't engage with activities that were on offer in the nursing home. During data analysis, K.B. noted in the

analytic comments that the communicative environment was '*malnourished*'.

Ivy was 8 years post-stroke but had moved home to be closer to her daughter, who precipitated the referral for an AAC review. Ivy also had existing technology that supported her to communicate: 'Um me me, me me, me me, ah me me (points to tablet and phone on the table next to I. I passes tablet and phone to Ivy)' (Ivy, interview 1), which her daughter explained how she used: 'If she's talking about somebody then she can get the photo up, to explain obviously who she's talking about' (CPI, Ivy, Interview 1). Ivy had previously lived in the centre of a bustling town, but her general health and mobility had deteriorated to the point that her daughter felt unable to provide her the support that she required from afar. Ivy had moved next to her daughter's house which was in a very rural location. Ivy was a wheelchair user and required transport to get to shops or social opportunities.

Both Ivy and Nick had existing AAC systems available to them, but their recent change of circumstance had initiated a search, by other people, for something new or different to enhance their communication. The AAC prescribed by the specialist services were not successful for either participant and both were withdrawn from the project after interview 2; Nick's medical condition had deteriorated, and Ivy's daughter was no longer able to support the interviews. Both participants had family members who were initially motivated to pursue new AAC options and both were in environments where support was nominally available to set up and supervise AAC use. However, neither participant had access to opportunities or communication partners outside of immediate family with whom they could interact socially and/or use AAC. The 'snapshot' data from the interview visits provided clues as to the nature of support and opportunity that was available to these participants, or lack thereof. Looking backwards and forwards, beyond the data collection interviews, to the historical and possible future circumstances of individual's lives provided greater insight into the contexts for AAC use and of the transitions they were both experiencing in communicative opportunity. Understanding the motivations for referrals to AAC services, and the conditions into which AAC will be used may help clinicians and services to anticipate potential challenges to engagement with AAC.

## Future possibilities: Identity and reality

Participants' hopes and expectations from AAC shifted over the course of the study. They recognized that they wanted to improve or change their communication but could not identify specifically what they wanted new AAC to enable them to do. Their experience of using

AAC, alongside the support they received, helped them to form clearer ideas about what was important to them about communication and voice. The outcomes from AAC that were most important to them formed iteratively over time.

Monica and Jeff had different historical experiences of communication. Monica had acquired a communication difficulty because of a progressive neurological condition. Whereas Jeff had cerebral palsy and had never had a natural speaking voice. During interview 1, both these participants had a desire for AAC that was connected to how they wanted to be represented. Monica linked her inability to speak as the root of her misrepresentation to others: 'Sometimes people think I have a learning disability ... Drives me nuts. The other thing that drives me nuts, think I'm deaf'. For Monica, representation was related to having a physical and intelligible voice, whereas for Jeff a new AAC device promised greater efficiency of communication and more independence: '*Priorities from AAC may be different for people who have never had a voice ... perhaps gaining one is less of a priority than gaining independence*' (field notes):

CP1: Would you like to talk for yourself, use your own voice?

Jeff: No (shakes head)

CP1: You wouldn't like to use your own voice now?

Jeff: no (shakes head)

CP2: Would you change anything about Tobii?

Jeff: Yes

CP2: Yes, what would you change?

Jeff: **quicker**

But Monica and Jeff also had almost fantastical expectations from AAC at the outset of their journey to getting new devices. During interview 1, Monica described wanting 'a magical machine' and Jeff hoped that '**in the future someone who is going to invent a special equipment for me**'. They both recognized that they wanted AAC to fulfil an unmet need but could not specify what that was.

For Jeff, lofty expectations about the potential for AAC persisted following his specialist assessment:

I: Have you thought any more about if there's anywhere else you'd like to use the device?

Jeff: Um, yea [looks at communication aid] **at the big talks**

I: At big talks

Jeff: Yes

I: Can you give me examples? what big talks is that?

Jeff: [looks at communication aid] **like open Glastonbury** [music festival]

Whereas for Monica, the assessment helped to clarify what an AAC device could offer, and she began to contextualize the device within her existing circumstances:

Monica: I think accessing Alexa would be very helpful

I: Accessing the accent

Monica: so provided this machine can talk to Alexa

I: Yea

Monica: ... it just opens up the whole Alexa thing for me

By the time interview 3 is carried out, Monica had integrated her new AAC with her existing communication systems: 'I suppose it's about having a mix, using it and not using it' (Monica). She was using AAC to join online dancing classes and social events as well as accessing Alexa (a commercially available voice-controlled technology) but was still using natural speech with her partner at home. Jeff had struggled to integrate the new system with his old device: '**at first I got to it everything was going well, later on in the session on them saying that. Oh this device is not available with my phone and controls**'. He returned the new AAC device to the specialist service. Jeff recognized how some of his personal characteristics influenced his acceptance of new AAC: '**if you mess anything up with my device or put anything different on then I try to get used to it but I don't like change**'.

By interview 4, Monica had a device that met her functional requirements, helped her maintain her social relationships with friends, and she had secured an accented voice on the device that she felt reflected an important aspect of her identity. During interview 1 Jeff had wanted to change the world, but by interview 4 he had arrived at a place where he had accepted that change was difficult

for him, and that it was more important to him to be connected to family and friends rather than to be independent and occupied. He was using his existing AAC to access social media apps, which he had previously avoided, to stay connected with people outside of his residential home during the pandemic. The interviewer reflected that their *'communication goals vs life goals are indistinguishable'*.

## DISCUSSION

This study has provided data that enhances our understanding of people's expectations and experiences of acquiring and using AAC over time. The results support the conceptual framework for a PROM (Broomfield et al., 2022) and informed the relabelling and extension of the core concepts: changes, future possibilities and contexts. Extending these concepts enabled us to look across the continuum of experience rather than attending only to moments in time. Close collaboration with a PI group with lived experience provided new insights into the interpretations of the core concepts and how the process of negotiated meaning-making helps to clarify terminology and foster a shared understanding. The longitudinal qualitative method, informed by Shotter's dialogic lens, enabled us to expand our conceptual interpretations and to consider how these manifest for participants differently over time. These data enhance our understanding of how identity and voice emerge as people become familiar with AAC and its potential to influence different facets of their lives. They also enable us to consider outcomes in the context of time, and how individual circumstances influence the outcomes that they can identify or are able to achieve from the use of AAC.

## Methodology and concepts

The analytic method employed with data in this study was informed by dialogism (Broomfield et al., 2023; Shotter, 2011; Sullivan, 2012) enabling the research team to incorporate multimodal data into the analysis. This novel application of Shotter's theory, and the expanded conceptualization of communication that it informed, allowed us to better attend to the nature of using AAC: to *how* they are used as well as what they are used for. The analytic method described in this paper allowed for the inclusion of a range of data sources, representative of the nature of communication by people who use AAC. Field notes and reflective comments were used to represent aspects of the embodied knowledge of all the agents in the data collection interview and the clinical academic research team involved in the analysis. It is suggested that such a method has a strong

justification in the field of communication disability research because of the nature of the non-linguistic signals that are inherent in interactions with people who cannot use words and language (Broomfield et al., 2023). These theoretical principles can have application to clinical as well as research practice, allowing professionals the conceptual tools to work collaboratively with people who have communication disability to negotiate, through dialogue, a shared understanding of key concepts and terminology as a basis for clinician interventions.

Communication was identified as an important outcome from access to new or different AAC devices by all participants in this study. However, after their initial assessment with the AAC service, they all begin to imagine more than just transmitting messages but what communication enables them to do. Communication may be concerned with getting a message across, building or maintaining connections and relationships, and accessing further occupational and leisure activities (Smith & Murray, 2011). Data from this study suggest that AAC also provides a focus for joint attention, a mechanism for accessing online communication, and a means to realize closer emotional connections between relatives.

The PI group changed one of the core concept labels from 'outcomes' to 'changes' in recognition of the dynamic and evolving nature of people's expectations from AAC and their expanded understanding of the concept of communication. Working with people who use AAC in the PI group to understand what functions of communication are most important to them and to reflect with them on the experiences of the participants added depth and authenticity to the results of this study. The strength of this process, and the resulting collaboratively generated shared meaning, offers a model for clinical services. Greater collaborative working and joint decision-making with people who use AAC can enable services to become more dynamic and responsive to their changing needs and expectations, and to be receptive to the evolving nature of outcomes.

## Identity and voice

Previous research described AAC as providing a sense of 'humanness' because of how it allows people to interact as social beings (Dickerson et al., 2002), and as a term to capture the power of AAC in relation to an individual's ability to realize their role, identity, and independence (Broomfield et al., 2021). Beth Moulam and Meredith Allan are both AAC users who explore identity and AAC (Allan, 2006; Moulam, 2021) and describe how access to language and to social connections support them to explore their identities as people who use AAC. Wickenden (2011) explored identity and voice with young people who



use AAC and concludes that voice is both physical and cultural: having a synthetic voice was an element of self-expression, but *how* people used AAC within their social milieu was more indicative of their sense of identity. The longitudinal data in the present study allowed us to recognize that the concept of identity is one that evolves; it is shaped by people's perception of what using AAC enables them to do beyond communicating. People may focus on having a synthetic voice at the beginning of their journey, particularly if they have lost a natural speaking voice. Their understanding of what voice enables and represents, such as self-expression and independent control, grows over time.

Humanness cannot be realized just through the provision of AAC to enable people to interact socially (Dickerson et al., 2002), but through the process of embedding AAC with a communicative system which enables access important elements of identity and supports self-determination (Allan, 2006; Martin & Newell, 2013; Moulam, 2021). Participant's expectations ebbed and flowed over time as they reorganized their understanding of what was achievable through their experience of weaving the new AAC device into their lives, or not as the case was for some participants. It is therefore incumbent on those supporting people on their journey with AAC to remain open to changing and evolving hopes and expectations from devices, but also the changing conceptualizations of communication and voice of people engaging with the device. This has implications for the organization of services; clinical services need to be able to help navigate a path from the point at which they meet a potential AAC user and their communication partners, through the shifting landscape of their life-worlds, towards greater agency and control.

## Time and outcomes

All the participants in this study were accessing AAC assessment at a period of transition in their lives, a change of personal circumstances or of a health condition. For some, these transitions were a driving force in seeking out AAC assessment, whereas others less explicitly connected the transition they were experiencing to their quest for AAC. The findings from this LQR highlight the dynamic nature of the lifeworld and serve to remind us that what is important to people on one day may be less so on another. PROM tools are designed to measure the impact of an intervention from the perspective of the person receiving it (Devlin et al., 2010). However, it can be difficult to extrapolate whether it is the active components of the intervention over other variables in a person's circumstances that are effecting change (Schwartz et al., 2022). Gaining insights

into lived experience provide more nuanced and situated knowledge that can help avoid narrow or prescriptive instruments that measure 'what works' and can provide valuable insights into causes and consequences of change (Neale, 2021). Using longitudinal qualitative research to inform the development of a PROM for AAC has provoked an ontological shift in the research team from focusing on what changes to an appreciation that everything changes, and consequently to consider how and why the change occurs.

Participants in this study recognized the need for support for themselves and for their communication partners, but few could specify what type of support they would want to receive at the outset of their assessment journey. This implies that there is a prerequisite need for services to establish some shared expectations to enable productive interventions to manifest. Looking beyond the data collection interviews, both to the past and to the possible future circumstances of participants also suggested that the concept of 'support' may not always be practical but may take the shape of increasing communicative opportunity, nurturing a nourishing environment, or even prompting individual motivation. Access to suitable support for participants varied depending on individual circumstances, reinforcing what we know about environmental barriers and enablers to using AAC (Iacono et al., 2013; Lund & Light, 2007). If AAC interventions are to target the support structures (both intrinsic and extrinsic) as well as the AAC equipment provided, it will be important to have a means to evaluate the outcomes of such interventions. PROMs to evaluate AAC must therefore account for the wider contextual factors that will impact the success, or not, of AAC device use.

## Limitations

A significant amount of data was generated from a small number of participants ( $n = 7$ ) during this LQR. Although the number of participants could be considered a limitation, the recruitment strategy was consistent with the aims of the study: to enhance our focus on understanding the depth of experience over the breadth. We were unable to recruit the target of 2 participants to the category '12–18 year olds'. An alternative recruitment strategy may have yielded more participants from this category. It may have been helpful to get a young person's perspective in the PI group to support recruitment of participants from this demographic or to seek alternative recruitment sites.

The research funder required that all non-COVID related research pause between April 2020 and June 2020 resulting in a missed data collection interview (interview 2)

with Bill. Bill had received his new AAC device before the research team being permitted to reopen data collection by the funder. The research team was able to maintain relationships with all the participants to the study during the data collection period, despite the movement restrictions imposed because of the pandemic. This ensured no further disruption to data collection and resulted in the collation of a significant and rare data set from people who use AAC, despite the single missing data point.

## CONCLUSIONS

This longitudinal qualitative research study provides original insight into the experiences of people journeying through a specialist AAC assessment service and illuminates their shifting sense of identity during the process of embedding new AAC in their communicative milieu. The expanded concepts of 'changes', 'contexts' and 'future possibilities' offer a foundation upon which to base the development a PROM for AAC hand for other studies investigating the experiences of people using AAC. The significance of studying participants over time highlights the value of using dynamic approaches to explore the nature of experience, and identifies the impact of contextual and transitional factors on what people want to (and are able to) achieve from using AAC. These data call for the development of outcome measures that can reflect some of the more complex and dynamic elements of AAC interventions and outcomes; such a tool will help clinicians and services who provide AAC interventions to channel support to changing areas of priority for people who use AAC.

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## CONFLICT OF INTEREST STATEMENT

The authors have no conflicts of interest to declare.

## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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