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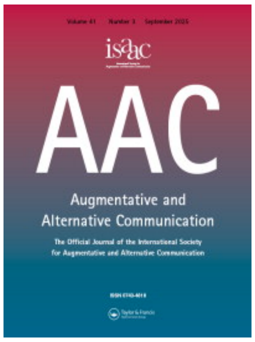

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RESEARCH ARTICLE

Defining outcomes: exploring the perspectives of people who use aided augmentative and alternative communication to develop the content for a patient-reported outcome measure

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ABSTRACT

Evaluating clinical interventions is an important component of quality assurance and informs decision making about the funding and commissioning of health and care services. Patient-reported outcome measures (PROMs) are tools that evaluate health interventions from the perspective of people receiving care. There is no validated PROM tool that evaluates the impact of augmentative and alternative communication (AAC) interventions. The current study was designed to understand what outcomes are important to people who use aided AAC. The study aimed to generate measurement items and to confirm the conceptual framework for a PROM for AAC. Seventeen participants aged 14 to 72 who use AAC were recruited. Each participant contributed to a one-to-one interview, informed by a topic guide developed in collaboration with a group of people with experience of using AAC. The research team used framework analysis to map data into an analytic framework informed by previous research. Analysis resulted in the development 33 items within seven domains that constitute the content for a PROM for AAC. The domains were mapped onto two conceptual models: Participation, including the Family of Participation-Related Constructs (fPRC), and the Communication Capability Approach. This research contributes rigorously developed PROM content grounded in the voices of people who use AAC and offers two conceptual frameworks to guide future tool development. It also raises critical questions about the theoretical underpinnings of AAC interventions and the need for outcome measures that reflect the evolving aspirations of users. The findings have implications for clinical practice, service delivery, and the ethical development of person-centred outcome measures in AAC.

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Evaluating the effectiveness of interventions informs service quality improvement initiatives (Moyse et al., 2020) and enables funders to make decisions about whether services are meeting their stated objectives (Enderby, 2014). Augmentative and alternative communication (AAC) refers to a range of strategies, both aided and unaided, that support the communication needs of people who have complex communication disability (Beukelman & Light, 2020). This paper focuses on AAC interventions consisting of aided AAC, specifically people who use AAC devices to support their communication, while recognizing that unaided AAC may also be part of an individual's communication system. AAC interventions are poorly defined (Baxter et al., 2012) and frequently focus on an intervention being the provision and/or training of an aided AAC strategy or device (Brittlebank et al., 2024; Drager et al., 2010). There are tools that clinicians can use to evaluate AAC interventions, such as Therapy Outcome Measures for AAC (Enderby & John, 2015), however there is limited evidence to suggest that measurement tools are being used consistently in clinical practice with people who use AAC (Enderby, 2014), nor in AAC research (Prinsloo et al., 2024). There are also tools that report on the impact of AAC from a family members perspective (Delarosa et al., 2012) but very few evaluation tools that report outcomes from the perspective of people who use AAC (Broomfield et al., 2019).

There is a move toward greater person-centred care in health systems and understanding the values and perceptions of people receiving care and support has become an increasingly important part of healthcare conversations and evaluation (Baylor & Darling-White, 2020). Patient-reported outcome measures (PROMs) are measurement tools that evaluate the impact of an intervention or condition from the perspective of the person, via self-report (Vet et al., 2018). Recent evidence syntheses have identified that there are currently no validated PROMs for AAC interventions (Broomfield et al., 2019; Gardner et al., 2024). Of the tools that do exist, there are significant limitations in the reporting on (a) whether they are accessible for people with communication disability, (b)

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whether the outcomes being measured are those that are important to people who use AAC, and (c) inconsistency in reporting the theoretical bases of the AAC intervention being evaluated (Broomfield et al., 2019).

The development of a PROM is based on a theoretical model of the outcomes that are important to the target population (Mokkink et al., 2019; U.S. Department of Health and Human Services et al., 2009; Vet et al., 2018). The PROM development process then involves generating a framework mapping how the constructs (the subject of measurement) that constitute outcomes are connected (the conceptual framework), and identification of a set of measurement items. The theoretical model of outcomes is derived from existing literature in conjunction with feedback from people with lived experience of the condition of interest. The content of the conceptual framework for a PROM—the constructs or domains of interest and measurement items—is established using qualitative methods to gather insights from people with whom the tool is to be implemented (Mokkink et al., 2019). Initially interviews or focus groups gather data to understand the important outcomes and generate a set of items with which to measure them (Patrick et al., 2011; Vet et al., 2018).

A hypothesized conceptual framework for a PROM for AAC was proposed following a qualitative evidence synthesis of the research literature about the experiences of adults and children using AAC to support their communication (Broomfield, Harrop, et al., 2024). The review identified important outcomes from AAC in terms of three main constructs: (a) the direct impact of AAC on communication, (b) changes to the contextual factors that influence AAC use, and (c) the value that individuals ascribed to using AAC. The first two constructs can be described in relation to the activities that people use AAC for, and the environment that facilitates or inhibits these. The idea of value from AAC requires further exploration as it a less tangible construct, pertaining to an individual's relationship with AAC and/or the meaning or importance that they attribute to communication AAC enables. Further research is required to understand more about the value people ascribe to AAC to refine the constructs (domains) for a PROM and to establish a conceptual framework that represents the important outcome/s from AAC interventions.

The World Health Organization International Classification of Functioning, Disability and Health (WHO ICF, 2001) presents components of health and functioning within a biopsychosocial framework. ICF is used to frame the impact of communication disability, and related interventions, by considering the interplay between an individual's underlying impairments, activity limitations, participation restrictions, and the environmental and personal factors that influence their communication outcomes. The ICF has been applied widely as a theoretical framing for understanding outcomes from children who use AAC (King et al., 2014; Pless & Granlund, 2012; Rowland et al., 2012), largely with a focus on the concept of participation and how AAC enables greater participation in activities of daily life. Rigorous work has been undertaken to refine the conceptual clarity of the participation component of the ICF framework with children who use AAC resulting in the development of the family of participation related constructs (fPRC) (Imms et al., 2016, 2017). The fPRC differentiates between participation in terms of attendance and involvement in life situations and participation-related constructs such as activity competence, sense of self, and preference, with both as distinct from the environment and context in which participation takes place (Imms et al., 2017). However, studies investigating AAC interventions for children and young people still focus on activity competence as the outcome over other participation and fPRC concepts such as attendance, involvement, and sense of self (Prinsloo et al., 2024). Furthermore, studies with adolescents suggest that experiencing belonging and positive interaction become increasingly important with maturity and that these are not sufficiently conceptualized with the fPRC to capture the nuance of these social participation outcomes (Bärwalde et al., 2023).

Quality of life is a multidimensional concept that encompasses an individual's perception of their position in life in relation to their goals, expectations, standards, and concerns within the context of their culture and value systems (World Health Organization, 1997). The concept of quality of life (QoL) has evolved to encompass various dimensions of individual well-being (Hausman, 2015). Health-related quality of life (HRQoL) focuses specifically on the impact of health conditions on overall life quality, whereas there are also context or condition specific measures of quality of life that are more focused on well-being (Alexandrova, 2017). For example, ASHA developed the Quality of Communication Life Scale which includes items that measure constructs such as positive relationships, meaningful life-engagement, and self-determination (Paul et al., 2004). QoL has been used as a theoretical frame to understand the impact of AAC interventions on adults who acquire communication disability (Corallo et al., 2017; Hill, 2010; Maresca et al., 2019), where the aim of AAC is to strengthening the communication capabilities of the individual so that they have greater choice and control over how they communicate, when, and with whom. Smidt and Pebdani (2023) propose a communication capability approach to AAC outcomes to extend clinical thinking about the implications of device use with a focus on individual strengths as well as agency, and how these influence AAC device use and/elected nonuse.

Whilst the theoretical framing of QoL and the ICF level of participation are closely related, they have been applied differently in consideration of outcomes from AAC. QoL has been used with adults who use AAC to frame the impact of AAC on agency, wellbeing, and self-determination. Participation and the fPRC has been widely used in childhood disabilities studies and elevates engagement in life situations as the focus for outcomes from AAC interventions. People who use AAC frequently have life-long communication disability, and research has illuminated how people's perspectives of the value of AAC shift and change over time due to the influence of experience, social, and contextual factors (Batorowicz et al., 2016; Broomfield, Judge, et al., 2024; Lund & Light, 2006). For AAC interventions it is therefore important to understand not only the immediate and short-term activity changes that interventions yield but how lives, perspectives, and horizons shift with experience. The long-term nature of AAC device use demands careful consideration of the theoretical bases for AAC interventions and therefore the focus for outcome measurement.

The qualitative research study reported in this paper was designed in line with the COSMIN framework (Mokkink et al., 2019), an international set of guidelines for PROM development, to establish a set of items and to refine the conceptual framework for a PROM for AAC. It builds on preliminary work developing a hypothesized conceptual framework derived from the qualitative evidence synthesis (Broomfield, Harrop, et al., 2024). The study addresses the question: what outcomes from AAC interventions are important to people who have communication disability? The research was guided by the following aims: (a) to generate items for a PROM for AAC, and (b) to establish a conceptual framework for a PROM for AAC by attributing items and constructs/domains to a theoretical proposition for important outcomes from aided AAC interventions.

Method

This study was part of a wider doctoral research project that investigated the role of AAC in supporting people toward greater involvement in activities of daily life. The wider project focused on adolescents (over 12 years) and adults, in recognition that younger children who use AAC will have different and distinct priorities from communication, such as language learning, literacy development, and access to education. Adolescents were included in the project in recognition that adolescence is a stage where people develop greater agency, their sense of identity and belonging, and seek self-determination. The current study formed a discreet aspect of that project with its own methodology and protocol, described below.

Public involvement group

A public involvement group consisting of six people who use AAC and their family or carers supported the development and implementation of this study. Public involvement (PI) in research is a mechanism to ensure that research is done with or by the public, not to, about, or for them (INVOLVE, 2012). In the United Kingdom (UK), PI is an integral component of health research and a requirement for all research funded by the National Institute for Health and Care Research (NIHR). The PI group supported the development of accessible materials for recruitment and offered invaluable insights to the academic team as data were being collected and interpreted. The activity and impact of this PI group in the project have been reported in detail elsewhere (Broomfield et al., 2021).

Participants

Participants were recruited from a regional specialist AAC assessment service in the north and a special school in the southwest of England, UK. Maximum variation sampling was used to recruit a cohort of participants that reflect the diversity within the population who use AAC devices. Following discussion between clinical colleagues on the research team and the PI group, three broad categories of AAC users were identified: young people (12–18 years), adults (18+ years) with communication difficulties from childhood, and adults (18+ years) with acquired communication difficulties. The aim was to recruit an equal number of people from each of these categories and to invite participation from people who used a variety of AAC devices, symbol and text-based language, and access methods.

A member of the clinical teams at both recruitment sites, both speech and language therapists, reviewed their service caseloads and screened for the inclusion/exclusion criteria with the above variety of participants in mind.

Eligibility criteria

The following inclusion criteria were used to recruit participants to the study: 12+ years old; have a communication disability; have the potential to benefit from AAC; have capacity to consent to being involved in the study; sufficient language comprehension to understand short sentences or questions in English; able to respond or construct responses using symbols, pictures, letters, or words; have 2 years' experience of using AAC (or 6 months if have a diagnosis of Motor Neuron Disease (MND)). People were excluded if they: did not have the capacity to consent; experienced a significant cognitive impairment that affects their ability to remain alert, maintain attention, or recall information in the short term sufficiently well to engage in an interview; had a communication impairment which affects their understanding of phrases that contain a minimum of 3 information carrying words in English; were only able to communicate using a language other than English.

Procedure

A study pack comprising a participant information sheet and a study consent form was sent to participants who met the eligibility criteria by email or post. Email contacts included a link to the film of the participant information sheets available on YouTube™. Participants who consented, or whose parents consented in the case of people under 18 years old, were contacted by telephone or email by the first author (either directly or via their delegated proxy) to arrange data collection. Nineteen participants consented to involvement in the project but two were unable to engage in data collection due to a lack of logistical support. In total, 17 participants were recruited and provided data to the study. Participant's medical conditions, age, sex and AAC system (device, vocabulary, and language representation) were recorded (Table 1). All participants had access to speech generating devices, but this was not a criterion for inclusion in the study.

Setting

Data was collected via qualitative interviews carried out by the first author using MS Teams™ due to movement restrictions in place under COVID19 legislation in the UK during the data collection period. One participant elected to wait until restrictions were lifted and participate in an in-person data-collection appointment. Another participant sent written responses and was not available for a follow-up appointment online. Where communication partners were present during data collection their consent for inclusion of their contributions in the data was gathered by the first author at the start

Table 1. Participant information: demographics, AAC details, and interview information.

Recruitment Center	Participant code	Sex	Age	Primary Diagnosis	AAC device	Vocabulary used	Symbol set used	Interview format	Communica-tion partner
Specialist assessment service (SAS)	C1	Male	65	Motor Neurone Disease (MND)	Grid Pad	Grid 3 Fast Talker	Text	MS Teams	Nil
SAS	C2	Male	23	Cerebral Palsy	Accent	Picture Word Power	PCS	MS Teams	2× personal assistants
SAS	C3	Male	59	Stroke	iPad	Proloquo2Go & ClaroComm	Text and Symbol Stix	MS Teams	Wife
SAS	C4	Male	36	Cerebral Palsy	Accent	LLL and Text	LLL and Text	MS Teams	Nil
SAS	C5	Female	51	MND	Grid pad	Fast Talker	Text	MS Teams	Sister
SAS	C6	Male	12	Cerebral Palsy	iPad	Predictable	Text	MS Teams	Mother
SAS	C7	Female	72	MND	Surface Pro	Grid3 Fast Talker	Text	MS Teams	Carer
SAS	C8	Male	12	Cerebral Palsy	Surface Pro	GRid3 Fast Talker	Text	Written response	Nil
SAS	C9	Female	28	Cerebral Palsy	Tobii i12+	Grid 3 Fast Talker	Text	MS Teams	Personal assistant
SAS	C10	Female	20	Cerebral Palsy	Grid Pad	Grid 3 Vocab for life	Widget and text	MS Teams	Mother
SAS	C11	Female	20	Cerebral Palsy	Gridpad	Vocabulary for life	Widget	MS Teams	Head of care team
SAS	C12	Male	45	MND	Grid pad	Fast talker	Text	MS Teams	Wife
SAS	C13	Female	20	Neurofibromatosis	Accent	LLL	PRC	MS Teams	Mother
SAS	C14	Female	47	MND	Grid Pad	Grid 3 Alphacore	Text	MS Teams	Husband
SAS	C15	Male	52	Cerebral palsy	Gridpad	Grid 3 Fast talker	Text	In person	Nil
Special school	C16	Female	17	Aicardi Goutières Syndrome	Accent 800	Supercore 50	Widget	MS Teams	Speech & Language Therapist
Special school	C17	Male	14	Cerebral Palsy	Grid Pad 12	Word Power 100	Widget	MS Teams	Speech & Language Therapist

of the appointment and recorded. The communication mode and methods used by participants in the interviews were observed and recorded by the researcher (Table 1).

Materials

Participants were sent a copy of the topic guide in advance of their data collection appointment so they could prepare pre-programmed responses into their AAC if they wished (see Appendix 1). The topic guide was generated in collaboration with the public involvement group to explore the experience of and important outcomes from using AAC. Questions were designed to link to themes derived from the narrative review that informed the development of the hypothesized conceptual framework (Broomfield, Harrop, et al., 2024), offering opportunities for participants to share feedback about their devices, the support they like, what AAC helps them to do, what else they would like to do etc.

Resources inspired by Talking Mats™ were also prepared by the first author to support the interviews. Talking Mats™ is a collaboratively produced picture or text-based tool that clinicians and researchers have used to gather opinions and feedback from people who have communication difficulties, in both research and service settings (Murphy, 2010). Symbol resources that equated to questions in the topic guide were made available as paper copies and sent by post for use by conversation partners who were familiar with a Talking Mats™ approach, or were used during data collection appointments by researcher (also experienced in the Talking Mats™ approach) using the screen-share function of MS Teams™.

Research design

Methodology

A qualitative research methodology was adopted to address the study aims. A critical pragmatic epistemological perspective enabled the team to include a range of data sources in the analysis (Midtgarden, 2012), such as spoken responses, text responses, and images or Talking Mats™ generated responses. Critical pragmatism is a position that acknowledges the role that social relationships and cultural practices have on the generation of meaning, within a shared reality. This philosophical perspective provided the research team with the conceptual bandwidth to employ the critical interpretivism necessary to analyze multi-modal data generated with people who use AAC (Broomfield et al., 2023), while recognizing that the overall aim for this project is to develop a tool that reflects some form of shared, measurable reality.

Ethics

This study was approved by the Health Research Authority in the UK (IRAS ID: 227722/REC reference 18/YH/0001) and Manchester Metropolitan University (Ethos Reference Number 25217).

Positionality

The first author, responsible for data collection, is a speech and language therapist and researcher. The first author actively engaged their clinical skills to facilitate the involvement of participants during data collection by amending the wording of questions, checking back on responses, identifying when communication supports were required, and interpreting participants' use of pre-programmed language sets where words or phrases selected were not direct linguistic responses to the questions. The wider research team provided support and guidance to the first author. The team had extensive and challenging discussions about voice, positionality, and professional identity in the context of conducting qualitative research with people who use AAC (Broomfield et al., 2023). These conversations led to a deeper, analytic, and conceptual engagement with the data and enhanced the rigor in which the method was applied to this study.

Procedures

Data collection

One semi-structured interview, informed by the topic guide, was conducted with each participant by the first author between November 2020 and September 2021. Interviews were audio and video-recorded and field notes were made by the first author, noting salient information about the context of the interviews, any remarkable aspects of the interview interaction, and making personal reflections about the experience of carrying out the interview. Additional interview data was also collated including email correspondence containing information pertinent to the interview, text files of pre-prepared responses, two participants used the Talking Mats™ inspired symbol-based resources to support their interview, and one participant sent an audio file of their spoken responses produced by their AAC device (see Table 1 for participant and interview details). Interview audio and video recordings were transcribed by the first author and these transcripts alongside field notes, emails, text documents, audio files, photographs or screen shots of Talking Mats™ inspired resources, and other visual materials used in interactions with participants all constitute data sources in this study. Participants were offered the opportunity to receive transcripts of the interviews; none opted to be sent the transcripts.

Data analysis

Framework analysis was used to analyze the data; it is a flexible method that can be employed to identify commonalities and differences in qualitative data by visually presenting examples from the data in a matrix that allows for comparison and contrast within and between data sources (Gale et al., 2013). In this study, the Framework method was used deductively to organize data into an existing analytic framework, provided by the hypothesized conceptual framework for a PROM for AAC (Broomfield, Judge, et al., 2024; Broomfield, Harrop, et al., 2024). The analytic procedure broadly followed the method described by Gale et al. (2013) and is described below, with an additional step to develop the PROM items.

Transcription. Audio data was transcribed verbatim by the first author. The video recordings were used to add information to the transcripts such as gestures, movements, and any additional communicative features of the interview. Transcriptions were uploaded into NVivo (for Mac, v11) along with the field notes and any additional data sources. Participants were anonymized by using alphanumeric codes instead of names.

Familiarization. The process of familiarization began during transcription. The first author made analytic notes using the comments feature in Microsoft Word™ documents and in the NVivo software concerning their thoughts or impressions on the data.

Coding and indexing. Initially, the first author looked at three transcripts (C1, C2, C3) and identified preliminary codes. Preliminary codes were allocated to units of meaning within the data which represent a particular concept or idea. The preliminary codes were then mapped to the three constructs within the hypothesized conceptual framework that was guiding the analysis (communication, context, and values). The transcripts, preliminary codes, and initial analysis in NVivo were shared with the wider multi-disciplinary research team who read them independently, discussed as well as agreed on a coding and indexing method through consensus.

Developing the analytic framework. The first author commenced line by line coding of each transcript, field notes, and relevant additional data such as emails, text documents, and pictures of Talking Mats™.

Applying the analytic framework. As coding progressed through participant level data, the first author began to index codes into themes (top-level codes in NVivo), clustered within the constructs informed by the hypothesized conceptual framework and by the similarities and synergies across the codes.

Charting data to the framework matrix. The "matrix coding query" function in NVivo was used to identify relationships across themes—where data from one theme was also present in another.

Interpreting data. Once all the data had been coded, themed, and charted into the framework the first author iteratively developed subthemes within themes—looking for trends and coherence across the data that pointed toward similar impacts or outcomes from AAC. Indicative quotes were identified for each subtheme.

PROM item development. The quotes identified during analysis were used to generate the PROM item or items by extracting specific phrases or creating phrases from the words used by participants (see supplementary material). These PROM items thus reflected a distinct outcome from AAC in the words of people who use AAC (Table 2). The list of the PROM items was shared by email with members of the PI group and they were asked for feedback specifically concerning accessibility, relevance, and acceptability. Two members of the group responded by email, and one engaged in a MS Teams™ call.

Rigor

Methodological rigor was pursued by using verification strategies suggested by Morse (Morse, 2015): member checking, peer-review, and audit trails. The public involvement group, as members of the AAC community, provided check and challenge as it was logistically unachievable to gather meaningful feedback from participants. Interpretations of data were checked with the group to validate themes and subthemes

Table 2. The themes, sub-themes, and items for a PROM for AAC developed from the framework analysis of qualitative data.

Theme	Sub-theme	PROM item
Basic communication	Speech	I am able to talk in my own voice
	Language	I am able to talk with the words I want to use
	Message	I am able to talk to tell others what I want
AAC device use	Support	I have been shown how to use my AAC
	Access	I can access my AAC with a method that I like
	Integration	I can use my AAC to access other technologies
	Mobility	I can move my AAC to where I want it to be
	Skills and abilities	I have the skills I need to use my AAC
	Usability	I can use my AAC wherever I need to
Conducive environment	Availability	I can use my AAC all the time
	People and places	I have the chance to use my AAC in different places
	Actions and reactions	Other people respond well to my AAC
	Team	My family and/or care team are supportive of my AAC
	Who, how, and when	I know who to ask for help with my AAC
Readiness	Deterioration	I have accepted that AAC will help me to communicate
	Not knowing a difference	I have always used AAC – it is part of how I communicate
	Proactive	I want to do whatever it takes to use AAC
	Perspective	I feel positive about using AAC
	Technical skills	I have used technology before to help me to communicate
	Physical access to AAC	I have a system that I can use to access AAC
	Familiarity	I am comfortable using technology
	Challenge	I have had some difficulty with technology in the past
Opportunity	New Designs	I can think of changes that would improve my AAC
	Access to activity	My AAC helps me to be able to learn/work/do the activities that I enjoy
	Relationships	My AAC helps me to meet new people and build relationships
Agency	What AAC does for me	My AAC is easy for me to use
		My AAC gives me confidence
		My AAC helps me talk to others
		My AAC lets me have my say
		I can play on my AAC
		I feel more independent with my AAC
Sentiment	How I feel about AAC	I feel like my AAC is a piece of me
		I can't imagine not having AAC

during analysis. The feedback from this group supported the research team to refine the wording of the PROM items. The wider research team provided peer review during the analytic process by supporting the development of a coding and indexing strategy, scrutinizing the themes and subthemes, and by reviewing the reporting of the study in this article.

Results

Seven themes and 27 subthemes were generated from the framework analysis. Data to support the themes are described below (further data pertaining to subthemes are available in the Supplementary Material). Thirty-three items for a PROM, representing the important outcomes from AAC in words that came directly from the participants or evolved with input from the PI group, were generated and are presented in Table 2. The items have been arranged into conceptual models for participation (Imms et al., 2017) and communication capabilities (based on principles of quality of life) (Smidt & Pebdani, 2023) to evaluate a best-fit conceptual framework for a PROM for AAC.

Quotes presented in italics and quotation marks represent synthetic speech output from AAC devices (Von Tetzchner & Basil, 2011), the interviewer is denoted as I, and communication partners involved in the interviews are denoted as CoPr.

Themes

Basic communication

Basic communication has been used to represent the core components of AAC use that enabled functional interactions. Participants recognized that AAC provided them with augmented speech, language, and the means to get their message across. For those with an acquired communication disability, AAC was not always an adequate communication substitute for a natural speaking voice. C5, who had MND and had acquired a communication disability, was entirely dependent on AAC to communicate but was also critical about what AAC did not enable her to do:

> Yes. I get misunderstood but not constantly. It has no sense of humour. It gets lost in translation. So, I don't bother anymore. And I remembered my dad I didn't think I liked the doctor because the machine isn't right. I quite often say the new carers don't be offended by my machine. (Interview transcript, typed response C5)

Other participants were very positive about the access to communication that AAC provided for them. C9, who had a communication disability from birth and who also used an idiosyncratic form of British Sign Language (BSL), was effusive about her AAC *"my communication aid allows me to have a voice and for everyone to understand what I am communicating"* (interview transcript, C9) and C4, who also had communication disability from birth, reported *"I am mute without it"* (interview transcript, C4).

The capacity of AAC to meet people's basic communication needs depended on their expectations at the outset, and this was related to whether AAC was a replacement for natural speech or a habituated part of a communication system. This suggests that the extent to which AAC can improve communication function is contingent on the individual's expectation from a device; this may be shaped by their previous experience of communication and whether that was natural speech or other forms of augmented communication.

AAC device use

Being able to access a suitable AAC device and integrate it into an existing communication system was influenced by factors related to the device design, access methods, and the physical abilities of the individual. AAC device use was also heavily influenced by the availability of professionals who had the requisite AAC knowledge and skills concerning AAC to provide suitable devices and targeted support. Participants had significantly different experiences of the professional support they received. C1 reported that he had struggled to access the appropriate professional support for his AAC:

> C1: *I won't name them, but the MND speech therapist […] she was and remains bloody hopeless.*
>
> I: *Oh no really*
>
> C1: *She's not in any way up to speed with technology.*
>
> (Interview transcript, C1)

In contrast, the interviewer observed that the support that the speech and language therapist (SLP) provided C16 during the interviews was exemplary:

> It was interesting to observe an interview being supported by a speech and language therapist rather than a family member or carer as she was able to use some notably different strategies – asking C16 whether she wanted help finding the pages, encouraging her to use specific pages to access relevant topic vocab, etc. (Field notes, interview C16)

The role of the professional, and the nature of the relationship between professional and person using AAC, is important not just in identifying a suitable device but in facilitating the process of integrating AAC into the communication system and broader environmental context.

Conducive environment

Participants described how the support and advice available from outside of their immediate milieu, frequently provided by services, promoted a conducive environment for AAC use. Participants described their individual requirements of external support services including how they are contacted (email, phone, online chat), how frequently, and by which service (statutory or private). C4 liked to receive support from the AAC device supplier as he could connect with them easily online:

> I: *Yes. When they give you a new device or new AAC what support do they [specialist assessment service] give you?*
>
> C4: 'give me equipment' (looks directly at screen)
>
> I: *What else do they do, do they just give you the equipment?*
>
> C4: 'yes' (TAPS RIGHT ARM ON RIGHT SHOULDER).
>
> I: *Yes, okay. Would you like them to do anything else?*
>
> C4: 'no' (MOVES ARM IN FRONT OF CHEST VERTICALLY)
>
> I: *Not really, okay. So you prefer to get your equipment and ask for help from [supplier] when you need it?*
>
> C4; 'yes' (TAPS RIGHT ARM ON RIGHT SHOULDER).

C14 was happy with the regular contact and check-ins that she received from the statutory specialist AAC service:

> I: *Yes and in terms of getting access from the team, do you see—do they contact you regularly or would you just contact them when you need their support?*
>
> C14: *They contact me*
>
> CP: *They contact you don't they*
>
> K: *Okay*
>
> C14: *But I can* (gestures towards CP and nods)
>
> CP: 'Email'. *Yes they do regularly contact but there have been occasions when C14's given them a nudge sort of in-between those times.*

C14 demonstrates the high level of expertise that he and his communication partners have developed within their interactions. His need for support from the supplier is akin to the maintenance that he would require for other daily living technologies. It is the nature of the conducive environment in which he exists that creates the conditions for positive AAC use—as part of a wider, nuanced, and well-established communicative system. The type of support that is required to enhance the environmental context, and the preferred provider of that support, can be significantly influenced by the personal skill, attitude, and experience of the individual using AAC and/or their communication network—family, carers, communication partners.

Readiness

Participant's readiness for AAC was contingent on a range of personal factors from their levels of motivation to their medical conditions. Participants had communication disability because of a range of medical conditions. Whether the participant's medical condition was stable or deteriorating influenced how they used AAC and how they felt about using it. Some participants experienced medical conditions that progressively altered their communication:

> C14 and her husband explained early in the interview that her mum had MND and so she knows what was coming and wanted to be as prepared as possible…They both reported that they have been proactive in accessing all assistive technologies and want to pre-empt the deterioration of function and be prepared for it in advance. (written field notes, C14)

Other participants had communication disability from birth or early childhood and so didn't remember a time without having one, *She did have a communication aid, she's had one since she was 5 haven't you. So C10 doesn't know a life without one* (interview transcript, CoPr/C10).

The nature of these individual differences in the context of broader components of their lifeworld influenced people's experience of using AAC and what was important to them about communication. The actual and/or potential impact of AAC was shaped by how they wished to access components of self-determination that were most important to them and their close network.

Opportunities

Participants were able to imagine different future possibilities that AAC might afford them once they had achieved a level of functional competence with their existing device. They identified a range of new or different activities or occupations that motivated them to continue to seek change and improvements either in their device, skills, or in opportunities for personal growth. For some this represented an extension of what they were already doing: *"I am currently working on a website for training purposes. … and also I am looking into the possibility doing some online teaching from home"* (interview transcript, C15), whereas others were looking to find a new vocation, *"I want teach anyone to chat"* (interview transcript, C4).

The experience of using AAC successfully in some aspects of their lives enabled them to see different possibilities and opportunities elsewhere. Their outlook and the horizons available to them shaped how they defined the impact of AAC.

Agency

Using AAC changed individuals' sense of agency, which was connected to their sense of identity—how identity is formed and how it is expressed. Some participants described the social connectivity that AAC enabled: "I can talk to friends" (typed response, C8); *"I love facetime"* (interview transcript, C17). Others liked being able to express aspects of their personality which were important to how they saw themselves: "C9 reported that she found humour was a useful tool to communication and that this helped her to feel more at ease with people" (written field notes, C9). AAC provided a means by which people could actively engage in their communities, and have their opinion heard: *I'm a member of a disability forum. I use it there regularly. NHS wheelchair service users' forum, national disability advisory group, and then I've use it on 3 occasions to communicate in court* (interview transcript, C1). AAC was also associated with feelings of greater independence: *"I feel very independent to be able communicate with people"* (interview transcript, C15) and to engage in play or playfulness for example using pre-programmed content in unusual ways, or to interact with pets: "*Find your stick*" (C10).

Participants who reported outcomes from AAC positively had integrated it into their communication system, were using it in a variety of ways with different people, and it was part of how they represented aspects of their sense of self and felt a greater sense of agency.

Sentiment

Perhaps one of the most significant barometers of a favorable outcome from using AAC as expressed by participants was in the positivity people felt toward their AAC. Despite reporting honestly on the challenges and barriers that having a communication disability requiring AAC presented to them, participants were overwhelmingly positive in how they felt about their AAC devices. Participants reported a sense of both connection and dependence on their AAC which represented how central it was to their sense of being: *"It has changed my life and without it I would feel lost and trapped"* (interview transcript, C9). These expressions of ownership were important indicators of participants' acceptance and integration of AAC into their lives; they are also necessary for people to believe that they can make the necessary tweaks and changes that will ultimately support long term and successful use of AAC. C3's partner summed up the conundrum of ownership when they said: *I would think that some people wouldn't dare, you know because it was kind of having to go into the settings and change things*; success is contingent on people believing that they can do just this.

PROM items

Following the analysis and elicitation of themes and subthemes from the data by the framework analysis, thirty-three PROM items were identified. Key quotes from participants were selected, and reworded where necessary to improve the clarity, to create an item that encapsulated the concept of each sub-theme. When consulted, the PI group concurred that all the PROM items generated during analysis were relevant. One group member selected items from the list that resonated with him and provided personal examples to evidence why he highlighted these outcomes. A second group member saw the relevance of all the items and was able to provide examples from his own experience or that of others that he knew which supported each item. He found it helpful to have some context about each item to understand the intended meaning. He also suggested that "*I feel happy with my AAC*" would be a good additional item.

Conceptual framework

The themes generated during the framework analysis can be used to represent constructs, or domains, for AAC outcomes. These domains were arranged by the first author onto models for participation and quality of life provided by previous research (Imms et al., 2017; Smidt & Pebdani, 2023) to test whether either model could provide the conceptual framework for a PROM for AAC. These were reviewed and critically appraised by the final paper-author.

In the participation model (Figure 1), involvement in life situations is the overall outcome of interest. Outcome domains are: AAC device use (participation), basic communication, preferences, and sense of self (family of participation related constructs); all of which are influenced the environment or context. Interconnections and interdependencies between the domains are represented on the diagram by unidirectional and bidirectional arrows.

The domains generated from the themes also fit within the model representing the communication capability approach to AAC proposed by Smith and Pebdani (2023), based on the concept of quality of life (see Figure 2). This model highlights how outcomes pertaining to the environment, readiness for AAC, device use, and basic communication are interconnected but ultimately lead to greater freedom through access to opportunity, agency, and feelings of positivity. These final three domains, relating to 'freedom' in the communication capability model, ultimately lead to improved quality of life or wellbeing.

Either model may be relevant as the conceptual framework for the further development of a PROM for AAC. The

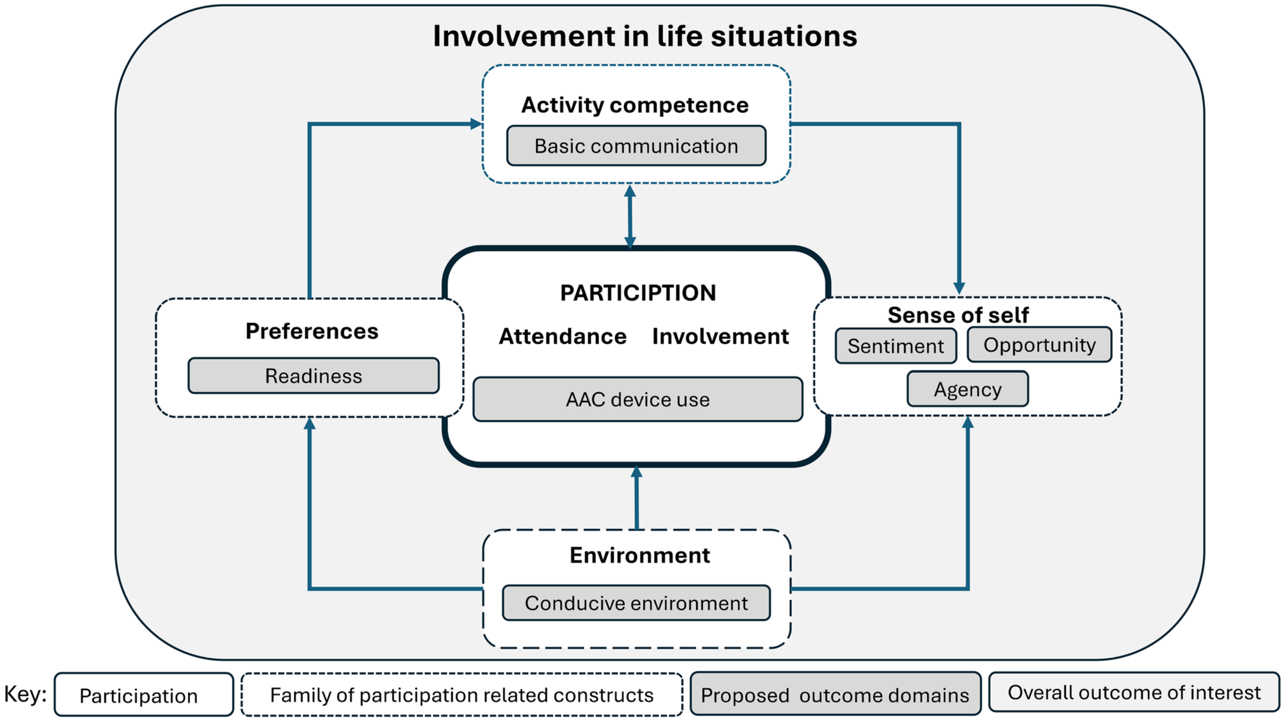

Figure 1. Diagram of the relationship between participation, the family of participation related constructs, and the themes generated from the framework analysis in the current study as proposed outcome domains for a PROM for AAC.

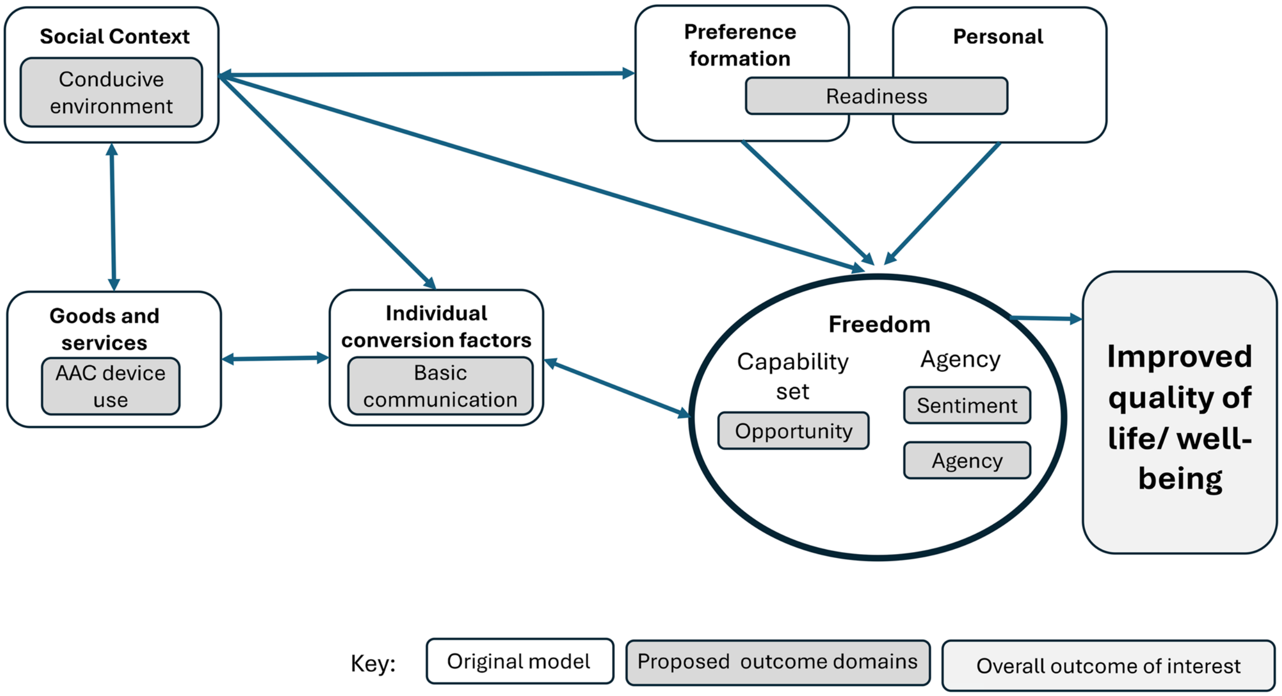

Figure 2. Diagram, based on the communication capabilities for AAC proposed by Smidt and Pebdani (2023), showing the original model with superimposed themes generated from the framework analysis in the current study as proposed outcome domains for a PROM.

choice of model may depend on variables pertaining to the population of people who use AAC with whon the PROM is being used for example age, medical condition, or the individual's goals and aims from AAC. The overall outcome of interest may be dictated by service delivery models that are time-limited or that provide interventions at a particular stage of the individual's life journey such as immediately following a diagnosis, or in a particular context such as school or college.

Discussion

This qualitative research study investigated important outcomes from using AAC with experienced AAC users. Data analysis informed the generation of 33 items that can be used to develop a PROM for AAC. We also demonstrated how these data align with conceptual frameworks for AAC interventions that focus on both participation and quality of life as the overall outcome of interest. These results provide a basis upon which to further develop and implement an outcome tool for AAC. They have also surfaced tensions that reflect some of core challenges to outcome measurement in healthcare currently, and how these manifest in the field of AAC.

Whose outcomes?

There is a growing understanding of what is important to people who use AAC about their AAC and their communication (Broomfield, Harrop, et al., 2024; Ripat et al., 2019; Smith & Murray, 2011). The results from this study explicate how much of what people consider to be positive outcomes from AAC interventions are not just observable improvements in their basic communicative function through access to an AAC device, which is frequently the focus of AAC interventions (Brittlebank et al., 2024; Drager et al., 2010; Prinsloo et al., 2024). They also sought changes related to their environment and/or the expanded horizons and future opportunities available to them because of augmented communication capabilities. This finding has implications for our understanding of what is important to measure but also how to measure it.

Measuring outcomes in healthcare is either based on clinician observation and rating of an impairment of functioning (through specific technical tools or checklists), or a patient report of their symptoms and/or concerns (Vet et al., 2018). Measuring outcomes of interventions with people who have communication disability is challenging because of the limitations of the conceptual basis for understanding communication and is compounded by the challenges that people may experience in reporting their symptoms (Barnes & Bloch, 2018). Measurement tools have therefore tended to target observable and classifiable changes to the communication impairment rather than to the impact on participation or quality of life (Baylor & Darling-White, 2020; Prinsloo et al., 2024). This tendency places primacy on the clinician judgment of a communication disability rather than the person who uses AAC's perspective about their concerns. PROMs are a clinical tool that prioritize the perspective of the person receiving the intervention. There has been increasing emphasis recently on the importance of the service-user perspective on the development of PROMs (Carlton et al., 2020) and on the primacy of content validity over other measurement properties (Patrick et al., 2007); that is, that the content of measurement tools reflects what is important to the end user. This has led to a call for ethical development of person-centred outcome measures that are generated in dialogue with the people with whom they will be used (McClimans, 2024).

The outcomes of importance to people who use AAC, identified in the current study, can be best evaluated through individual/patient-reported measures, and the results provide suitable content for a PROM tool. However, attributing a suitable measurement scale to the constructs within a PROM is typically contingent on there being a single underlying concept of interest (Mokkink et al., 2019). The conceptual basis for the range of important outcomes from AAC that were confirmed in the current study could be participation or quality of life. This reflects a current tension within our field between the overall outcome of interest which for children is considered participation (Batorowicz et al., 2014; Imms et al., 2016; Prinsloo et al., 2024), ; but for adults who acquire communication disability may be context specific quality of life (Corallo et al., 2017; Hill, 2010; Maresca et al., 2019).

Participation or quality of life?

A contemporary conceptualization of participation in relation to the ICF for children and youth (ICF-CY) extends the concept beyond being individual-focused and toward a dynamic interplay between an individual and their activities and preferences, and the extrinsic and intrinsic influences of both contextual and personal factors that influence participatory outcomes (Imms et al., 2017). This conceptual approach to participation aligns closely to the social model of disability and connects to the idea of QoL in terms of the wider impact of disability, and related health interventions, on self-determination and agency. However, critique of the use of the ICF in clinical assessment and practice with adults who have communication disability is that over-reliance on this framework continues to lead to interventions that are targeted toward the abilities of an individual, thereby overlooking gains in wellness and improved quality of life over short term functional gains in specific abilities (Baylor & Darling-White, 2020; Cruice, 2008). Recent debate has suggested QoL as a more suitable barometer of the impact of health-related interventions than participation as it acknowledges the changing nature of many health conditions during the life course (Mitra & Shakespeare, 2019). More explicitly, the concept of QoL acknowledges the nature of individual choice and agency in defining their own parameters about what good looks like (Cruice, 2008; Mitra & Shakespeare, 2019). In defining quality of life for people who have aphasia, Cruice (2008) argues that "quality of life reminds us who the individual is, what he or she wants in life, and who he or she wants to be" (Cruice, 2008, p. 47).

Much of the clinical and research work in the field of AAC is anchored in the ICF with little critical engagement as to whether this is a suitable conceptual model for AAC interventions (Teachman & Gibson, 2014). Imms et al. (2016, 2017) have to some extent countered this critique by extending the definition of participation to include a wider a family of constructs that are both intrinsic and extrinsic to the person, situated within an ever-changing environment, and related to both the process of change and the outcome achieved. The ICF-CY has been used widely to structure clinical interventions and inform goal setting with children who use AAC (Klang et al., 2016; Pless & Granlund, 2012; Zerbeto et al., 2020). However, while environmental and personal factors are included in Imms' model of participation, the overall outcome of interest is concerned with the extent to which children and young people are involved in life situations, rather than how they want to be perceived within those situations. The concept of social participation is still not clearly defined which then risks outcomes related to sense of self, identity, belonging, and self-determination being overlooked or deprioritised as the foci for intervention (Bärwalde et al., 2023). Moreover, research has indicated that the operationalization of the ICF in practice can lead to a lack of specificity in intervention planning, potentially limiting the ability to address societal attitudes or individual preferences that profoundly influence communication outcomes (Cronin et al., 2020; Cruice, 2008; Smidt & Pebdani, 2023).

While the contemporary framing of participation as a family of constructs pertains well to children and youth, there is a question over whether this conceptualization extends as well into adolescence and adulthood: children arguably have less agency over their choices about life situations and less experience with which to gauge physical, emotional, and social well-being. Furthermore, there is also evidence to suggest that the ICF is not always used consistently by clinical professionals, it is not familiar to educational professionals, and that both groups experience some difficulty in differentiating between the levels of the traditional model (Westby & Washington, 2017), let alone the extended family of participation-related constructs. The domains represented by themes ‘opportunity’, ‘agency’, and ‘sentiment’ identified in the current study all represent important outcomes from using AAC that extend beyond the device, or communicative function it enabled. The ideas expressed by participants that constitute these themes represent dynamic and fluid concepts that emerge through experience with the device, and the personal growth that is realized consequently. These data extend the notion of values, presented in the hypothesized conceptual framework by Broomfield, Harrop, et al. (2024), by elucidating what people want to be able to achieve in life from enhancing their communicative capability through AAC. These concepts may be better accentuated in a conceptual framework where the overall outcome of interest is quality of life or wellbeing rather than participation.

Person-centred outcomes

The results of the present study, and the items that were identified to measure outcomes from AAC interventions, have been rigorously developed with people with lived experience of AAC. We have demonstrated how these outcomes align to both participation and quality of life based conceptual frameworks. How this work is taken forward into developing clinical tools that can influence practice will depend on the epistemological drivers of the clinicians or academics who engage with this task.

PROM development guidelines suggest that the next steps for tool development would involve designing the tool and training programme for implementation, followed by data collection to inform the psychometric evaluation of the construct validity of the measurement properties (Mokkink et al., 2019). Recent developments considering person-centred outcome measurement more generally, suggest that truly meaningful measures are developed iteratively, through trial and dialogue with the people using them, along with consideration of how the constructs may mean different things to different people (McClimans, 2024; Schwartz et al., 2022). This study has proposed one set of measurement items but two conceptual frameworks that could be used to further develop a PROM for AAC. There is currently no consensus about the overall aim from AAC device interventions that encompasses the heterogeneity of the population who may benefit from AAC across the lifespan. Participation and quality of life are both valid and valuable but currently draw attention for AAC interventions in slightly different directions, either toward activity and involvement, or to wellbeing. Future development of a tool to measure person-centred outcomes from AAC may well be contingent on the local, regional, and national drivers that shape which of these directions is the priority for practice. Ultimately, the priority is that any person-centred outcome measurement is continually and iteratively developed with people with use AAC to ensure that the concepts and constructs reflect the outcomes that are important to them.

Implications for practice

PROMs are evaluation tools but they can also be used to facilitate clinician-patient communication and to build shared understanding about interventions (Greenhalgh et al., 2018). The content validity of the tool is important but how the tool is used by clinicians to support dialogue with people experiencing communication disability, and their communication partners, will be the key to building shared understanding and to channeling suitable interventions toward their priorities in the moment. The next step in developing a PROM for AAC will be to co-design a tool and evaluate its face validity with professionals and service-users so that it is accessible, acceptable, and implementable in practice.

Aspects of an individual’s communication, their AAC system, their wider environment, and their future aspirations are all valid foci for attention during AAC interventions. This finding has implications for models of service delivery and how services are designed to best meet need for individuals at different time points, and when different outcomes are of greatest import to them and their families and carers. For example, interventions focusing on the provision of equipment, programming of software, training, conversation partner support, embedding AAC in existing communication systems, increasing communicative opportunity, therapeutically working with people to accept the need for AAC, and developing individual autonomy or agency all target different yet important outcomes. Each of these interventions require different models of service delivery and clinical perspectives on practice. AAC interventions have tended to focus on activity, and hence the skills and abilities of the individual with communication disability. Interventions that strive to change quality of life require a perspective, and service delivery models, that value (and evaluate) communication opportunity, autonomy, and complex or nuanced communication beyond message transmission. The professional vision of what constitutes an AAC intervention may benefit from further critical engagement to this end.

Limitations & future directions

The present study has established a set of items for a PROM for AAC that have been thoroughly and rigorously developed with people who use AAC. The content validity of these items should be confirmed using cognitive interviewing (Patrick et al., 2011), which is not an inclusive method appropriate for many people who use AAC. Checking and evaluating the content with a wider group of people who use AAC as well as professionals through an accessible and inclusive face validity or acceptability study will be necessary if the PROM is to be implemented in clinical practice.

Several of the PROM items look very similar to one another for example "I am able to talk in my own voice" and "my AAC helps me to talk to others." This demonstrates the challenge of using a limited vocabulary to present a range of complex ideas and concepts. Although this is reflective of the experience of using AAC to communicate, it could be problematic during implementation of a PROM in clinical practice and when measuring the construct validity of the measurement tool. The challenge posed by overlapping terminology and constructs could also be reflective of the relationships between aspects of the experience of using AAC. Interventions targeted at one domain of interest may have an impact on individuals' responses to items in another domain. The tension presented by such a challenge will have implications for how the tool is further developed, tested, and implemented in clinical practice in future.

The choice of conceptual framework proposed by this research presents a future challenge for the attribution of a measurement scales to the constructs, domains, and items of each distinct concept to further evaluate the validity of the content of the PROM. However, greater engagement with the conceptual bases for outcome measurement may help practitioners to employ PROM tools collaboratively to facilitate greater person-centredness in practice and to reflect on the ultimate aims of the interventions of offer. The influence of the clinical tools that are available on clinical practice warrants further exploration and discussion.

Finally, this study focused on people who use aided AAC and all participants in the study used powered, speech-generating devices, although not all of them used these devices to communicate during the interviews. Interventions that focus on unaided AAC are even less well defined and therefore more challenging to evaluate. Further research into the experiences and outcomes of people who use unaided AAC is necessary to fill this knowledge gap.

Conclusion

This study has resulted in the rigorous development of a set of 33 measurement items within seven domains, or constructs of interest, that can form the content of a PROM for AAC. The constructs of interest for measuring outcomes from AAC can be arranged into a conceptual framework for a PROM using theoretical models provided by the ICF level of participation (the overall outcome being involvement in life situations) or the notion of quality of life (improved wellbeing). This research suggests that reasons to forefront one overall outcome from the other might include age, life experience, service delivery models, and/or the priorities of the individual using AAC at the time the intervention is offered. The PROM content proposed from this study is reflective of the range of outcomes desired by people who use AAC but creates a challenge to future tool development in terms of the application of measurement scales and evaluation of measurement properties. This work also poses questions to services and professionals who support people who use AAC about the theoretical focus for their practice, and to what constitutes an AAC intervention. The study results provide insight into the positive, longer-term outcomes from AAC, which are achieved when people can look beyond specific functions of the device for communicating basic messages and toward what it can enable in terms of achieving greater personal satisfaction, agency, and fulfillment.

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Figure 2 has been adapted from Figure 2 in "Rethinking device abandonment: a capability approach focused model" Andy Smidt & Roxanna N. Pebdani, Journal of Augmentative and Alternative Communication copyright © 2023 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group. This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives License (http://creativecommons.org/licenses/by-nc-nd/4.0/), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited, and is not altered, transformed, or built upon in any way. The terms on which this article has been published allow the posting of the Accepted Manuscript in a repository by the author(s) or with their consent.

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Data availability statement

Data used in this study is stored securely with Manchester Metropolitan University and can be made available, subject to appropriate ethical provisions, by contacting Katherine Broomfield0

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