

Identifying appropriate communication aids for children and public involvement in research: a mixed methods study

Short title: I-ASC – Identifying Appropriate Symbol Communication

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Conflicts of interest

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None other declared.

Important

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Scientific Summary

This project explored UK decision-making practices within communication aid recommendations. Communication aids can have positive impacts on the health and quality of life outcomes for children and young people. Children who use communication aids are a heterogeneous group, i.e., presenting with differing medical diagnoses and co-occurring impairments (which may include language, motor, hearing, vision and/or cognitive impairments).

An estimated 0.5% of the population require Augmentative and Alternative Communication (AAC). This equates to 529 people per 100,000 population. Following a government funded initiative through the Office of the Communication Champion, financial costs to the NHS of inappropriate or non-provision of a communication aid was estimated at £500,000 per individual over their lifetime.

Why focus on decision-making?

The research evidence related to communication aid decision-making, communication aid provision and evaluation of use remains limited.

Consideration of the role of clinical expertise and patient values within the decision-making process has received insufficient attention. Without research evidence to reinforce clinical expertise there is no means of determining the actual quality of provision. Professionals make decisions between different communication aids based on clinical judgement, with guidelines based on some research evidence or patient values. Many professionals feel ill-equipped to make informed judgements. Such restricted decision-making contexts may be contributing to aid abandonment, poorer educational attainment, limited social participation, employment opportunities and longer-term quality of life outcomes for communication aid users.

Aim and objectives

The aim was to influence current practice and enhance the consistency and quality of clinical decision-making in communication aid provision for children and young people.

The research was delivered through specific work packages (WP). WP1 comprised three systematic literature reviews, WP2 & 3 were qualitative utilising focus groups and interviews with different stakeholder groups, WP4 was quantitative and delivered two surveys to AAC

professionals, WP5 involved resource development to inform decision making, WP6 focused on dissemination of findings. WP7 concerned project management. In 2018, a further work package was added (WP8) as a separate work stream that focused on retrospective evaluation of the study's public involvement (PI). This WP is addressed separately throughout this report.

The research objectives

- To understand what is perceived as important in communication aid provision; how decisions are currently made; and what barriers and facilitators impact decisions (WP1,2,3,4).
- To understand and agree the attributes considered in these decisions, related to the child/young person, the family and the communication aid (WP1,2,3,4).
- To establish how professionals currently make decisions (by exploring their stated preferences); how they consider these attributes (WP2,3,4).
- To explore how this process takes account of the perspectives of all involved; specifically, how children, young people and adults (who use AAC) reflect on their experiences and how parents and professionals perceive the effectiveness of existing or historic recommendations (WP2,3,4).

On the basis of the information gathered from (1) to (4) to:

- Develop guidance to support decision-making in communication aid recommendations (WP5).
- Disseminate this guidance and project findings to influence practice. (WP5&6).

Research Questions

Four key research questions underpinned the aim and objectives:

- What attributes related to the child/young person, and generic communication aids, do professionals consider important in communication aid decision-making? (WP1,2,3,4)
- What other factors influence or inform the final decision? (WP1,2,3,4)
- What attributes are considered important by other participants (e.g., the child/young person and family) and how do these impact in the short, medium and long term? (WP1,3)

- What decision support guidance would enhance the quality, accountability and comparability of decision-making? (WP1,2,3,4,5)

Public Involvement (PI) evaluation

WP8 was a post-hoc methodology to evaluate the PI contribution to the study. As it was not part of the original study, additional research questions were developed:

Research Questions

- How and what can we learn from a PI evaluation in a nationally funded project focusing on vulnerable and hard to reach patients?
- How can PI research, implementing current guidance with vulnerable and hard to reach groups, be structured to avoid pitfalls and improve impact?

WP8 is presented separately within this report as it offers insights that transcend the key objectives and research questions 1-4 related to children/young people who use communication aids.

Design

The over-arching research paradigm used was Pragmatism. Pragmatism accepts the existence of singular and multiple realities, and focuses on finding solutions to practical problems. Within this paradigm, a mixed methods approach is commonplace, and specifically supports an ethnographic frame of reference. This perspective was adopted specifically for WPs2-4, with an exploratory approach to data modelling that would typically include focus groups, interviews and surveys. An ethnographic lens also supports mixed methods that take qualitative perspectives (observed and lived experiences (WP2&3)) and apply them to quantitative interrogation, as happened in WP4. This approach also defines the work package dedicated to an evaluation of public involvement (WP8).

Method

In summary, for the main I-ASC research (WP1-4), our methodological investigation adopted a 3-tier approach. Firstly, through three linked systematic reviews (WP1), secondly, qualitative exploration of stakeholder perspectives through focus groups and interviews (WP2&3), and thirdly quantitative investigation of professional perspectives via two surveys (WP4). The PI evaluation in WP8 adopted a mixed-methods approach.

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Ethics

Approval was obtained from Manchester Metropolitan University (Reference 1316: approved 18/11/2015) and the North West-Lancashire NHS Research Ethics Committee (REC reference 16/NW/0165 approved 13/04/2016).

Participants

Participant demographics varied across the different components of the research:

- 31 specialized and local professionals (WP2)
- 15 children, young people and adults with lived experience (WP3) (*N.B. although the focus of the research was children and young people, adult AAC users were included as they were able to offer reflections on their AAC development*).
- 16 family members (WP3)
- 44 professionals and support team members (WP3)
- 248 specialized and local professionals (WP4)

A total of 354 participants contributed to the data collection components of the study.

22 participants contributed to the PI evaluation (WP8).

Data collection techniques

Primary data collection activities

Primary data collection activities included focus groups, semi-structured interviews and survey techniques.

Data management

Data were managed in accordance with the General Data Protection Regulation (GDPR) and Manchester Metropolitan University's (MMU) Data Protection Policy.

Systematic literature reviews (SR)

The review process followed the Preferred Reporting Items for Systematic reviews and Meta-Analyses guidelines (PRISMA). Due to the dispersed nature of AAC research, three linked SRs were completed exploring the language and communication characteristics of AAC users, the language and communication characteristics of communication aids and professionals' decision-making processes in communication aid recommendations.

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Analysis procedures: qualitative and quantitative processes

Two WPs were qualitative (WP2 & 3), one WP was quantitative (WP4) and one WP included mixed methods (WP8).

Qualitative data analysis

Coding scheme design

Two methods of data coding were adopted to support analysis of focus group (FG) and interview data, Thematic analysis and Framework approach. A process of inter-coder reliability testing was set up for qualitative activity in WP2 & 3.

Quantitative data analysis

Two stated preference surveys investigated the decision-making of AAC professionals. A best-worst scaling (BWS) determined the relative importance of factors in decision-making. A discrete choice experiment (DCE) built on the BWS findings. In this survey, professionals made choices between AAC systems for a hypothetical child. Analysis was grounded in random utility theory.

Public Involvement (PI)

Two PI co-researchers, an adult using AAC and a parent of a young adult using AAC were integral to the development and delivery of each work package. A Critical Friend Group comprised of different stakeholders.

Results (summary)

Communication aid decision-making practices

RQ1: What attributes related to the child/young person, and generic communication aids, do professionals consider important in communication aid decision making?

The findings from the context of making real clinical decisions (WP2) contrasted with those in a survey context (WP4). When delivered through an off-line interrogation (survey), children's physical characteristics are perceived to be relatively less important in AAC professionals' decision-making than their language, communication and cognitive abilities. However, when described during real-time decision-making contexts, the opposite appears to be true, with access needs and personality traits featuring above all other considerations.

Findings suggest that an AAC professional's decision-making can be strongly influenced by two child characteristics, namely, whether a child is perceived as motivated to communicate using AAC, and if they are predicted to progress in skills and abilities.

RQ2: What other factors influence or inform the final decision?

Decision-making is influenced by several factors which are not always under the control of the decision-makers, e.g., service structure and provision. These external factors mean families experiences of communication aid assessment vary greatly, and at times may result in their exclusion from the final decision-making process.

Team knowledge, skill and attitude also influence recommendations. Decisions are tailored based on external factors rather than being determined by what may best meet the child/young person's actual need. For example, decisions were made with incomplete information on the child/young person's existing language skills.

Real-time decisions (WP2 & 3) (influenced by several cultural and contextual factors) varied from simulated decisions (WP4) (vignettes and choices), suggesting caution is required in the interpretation of simulated decision-making scenarios.

RQ3: What attributes are considered important by other participants (e.g., the child/young person and family) and how do these impact in the short, medium and long term?

In contrast with professionals, users and family members value aesthetic and user-centred attributes when identifying their preferred communication aid (WP3 & 4). This reinforces the need for decision-making teams to be inclusive of all parties' perspectives and preferences.

Dosage of learning practice and translation into conversation success remains ill-defined. Communication and learning opportunities requires further investigation.

RQ4: What decision support guidance and resources would enhance the quality, accountability and comparability of decision-making?

The I-ASC research has informed the development of guidance resources to support critical thinking during communication aid decision-making processes. The on-line resource includes a research-informed theoretical model (<https://iasc.mmu.ac.uk/i-asc-explanatory-model-of-aac-decision-making/>) with materials designed for all (<https://iasc.mmu.ac.uk/>).

Public Involvement (PI) Research Questions

RQ5: How and what can we learn from an evaluation of public involvement in a nationally funded project focusing on vulnerable and hard to reach patients?

The data generated describe how PI, including those with significant disability can be enabled at all stages of a research project. It exemplifies how researchers and co-researchers can maximise the benefits of co-produced research. These qualitative data have informed the development of specific guidance to include within a PI toolkit (<https://iasc.mmu.ac.uk/publicinvolvement>).

RQ6: How can public involvement research, implementing current guidance with vulnerable and hard to reach groups, be structured to avoid pitfalls and improve impact?

Findings provide insights that could inform future quantitative investigations, the resources required and benefits associated with PI. Insights include resources related to staff time, training and personal support (<https://iasc.mmu.ac.uk/publicinvolvement>). These data highlight the need for mechanisms to enable PI co-researchers to be paid for their contributions to research bid preparation.

Methodological innovations – translational research

Our unique quantitative approach to AAC research offers a first step in quantifying professionals' priorities and identifying the most crucial characteristics of children/young people and attributes of communication aids.

The aim of synthesizing all findings has enabled the research to propose new theory and ways of conceptualizing the decision-making process. Making this theory accessible to all stakeholders via the on-line heuristic achieves one of the original aims of the study of promoting consistent aid recommendations (<https://iasc.mmu.ac.uk>).

One cornerstone of the research was the ethos of inclusion of PI researchers as core team members.

Further research

This research revealed several points for further research; some relate to the decision-making episode and others to the longer-term implications of those decisions. The following offers a prioritized list related to I-ASC findings. Key future work should include how to:

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- appraise the existing language abilities of children/young people prior to a decision-making episode. This requires skilled professionals and requires studies exploring existing standardized language assessment tools and how they might be modified for this group of children/young people.
- explore whether decision-making processes for second and subsequent communication aids have different qualities to an initial assessment. This requires further investigation of referral and re-referral pathways.
- identify how AAC systems and language learning opportunities can best support children to achieve their potential. Currently, we have limited knowledge of how to determine the amount of language learning (teaching) opportunities required to enable an AAC user to become proficient in their AAC system. To understand the process of aided-language learning would require longitudinal intervention studies.
- better describe and understand the impact of the attributes that make up graphic symbol communication aids. This requires quantitative and qualitative investigations of graphic symbol components and their usefulness to learning language through non-spoken media.
- explore external influencing factors during the recommendation process. This suggests research that looks at local service contexts is welcome. Local professionals deliver 90% of the service to those who might benefit from AAC. As yet, we have little understanding of local delivery. Future investigation could consider what local provision looks like and who is responsible for the elements that it should include.
- use quantitative methods to compare perspectives across stakeholders in the decision-making process. The I-ASC findings suggest that professionals and family/user perspectives have differing priorities. The research presented here suggests that there is value in revisiting stakeholder perspectives through survey design methodologies derived from the I-ASC research.

PI involvement in research, future work should include how to:

- support personal development for PI co-researcher, e.g., research methods training.
- support traditional research teams to better understand how to develop research submissions that embrace co-created PI involvement.

- develop mechanisms that enable reimbursement of PI co-researchers for their contributions to research funding bid preparation, which remain, at present, a “hidden” cost of PI research.

Conclusions

This study has gone some way to defining barriers and facilitators to research informed decision-making. The work has raised as many questions as offered answers suggesting that on-going research is needed to support this complex field of intervention.

PI involvement in research can be facilitated, even for those regarded as hard to include.

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