

The decision-making process in recommending electronic communication aids for children and young people who are non-speaking: the I-ASC mixed-methods study

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Scientific summary

I-ASC – Identifying Appropriate Symbol Communication

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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; that is, they present 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. 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 provision or non-provision of a communication aid was estimated to be £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 communication aid use remains limited.

Consideration of the role of clinical expertise and patient values in 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 contribute to aid abandonment, poorer educational attainment, limited social participation, limited employment opportunities and poorer 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. Work package 1 comprised three systematic literature reviews; work packages 2 and 3 were qualitative, utilising focus groups and interviews with different stakeholder groups; work package 4 was quantitative and delivered two surveys to augmentative and alternative communication professionals; work package 5 involved resource development to inform decision-making; work package 6 focused on the dissemination of findings; and work package 7 concerned project management. In 2018, a further work package was added (work package 8) as a separate work stream that focused on retrospectively evaluating the study's public involvement. This work package is addressed separately throughout this report.

Research objectives

- To understand what is perceived as important in communication aid provision; how decisions are currently made; and what barriers and facilitators have an impact on decisions (work packages 1–4).
- To understand and agree the attributes considered in these decisions, related to the child/young person, the family and the communication aid (work packages 1–4).
- To establish how professionals currently make decisions (by exploring their stated preferences); and how they consider these attributes (work packages 2–4).

- To explore how this process takes account of the perspectives of all involved, specifically how children, young people and adults (who use augmentative and alternative communication) reflect on their experiences and how parents and professionals perceive the effectiveness of existing or historic recommendations (work packages 2–4).

On the basis of the information gathered from work packages 1–4 to:

- develop guidance to support decision-making in communication aid recommendations (work package 5)
- disseminate this guidance and project findings to influence practice (work packages 5 and 6).

Research questions

Four key research questions underpinned the aim and objectives:

1. What attributes related to the child/young person, and generic communication aids, do professionals consider important in communication aid decision-making (work packages 1–4)?
2. What other factors influence or inform the final decision (work packages 1–4)?
3. 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 (work packages 1 and 3)?
4. What decision support guidance would enhance the quality, accountability and comparability of decision-making (work packages 1–5)?

Public involvement evaluation

Work package 8 used a post hoc methodology to evaluate the public involvement contribution to the study. As this was not part of the original study, additional research questions were developed.

Research questions

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

Work package 8 is presented separately in this report as it offers insights that transcend the key objectives and research questions 1–4 related to children and young people who use communication aids.

Design

The overarching 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 work packages 2–4, 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 (work packages 2 and 3)] and apply them to quantitative interrogation, as happened in work package 4. This approach also defines the work package dedicated to an evaluation of public involvement (work package 8).

Method

In summary, for the main I-ASC research (work packages 1–4), our methodological investigation adopted a three-tier approach: first, through three linked systematic reviews (work package 1); second, qualitative exploration of stakeholder perspectives through focus groups and interviews (work packages 2 and 3); and, third, quantitative investigation of professional perspectives via two surveys (work package 4). The public involvement evaluation in work package 8 adopted a mixed-methods approach.

Ethics

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

Participants

Participant demographics varied across the components of the research:

- 31 specialised and local professionals (work package 2)
- 15 children, young people and adults with lived experience (work package 3) (note that, although the focus of the research was children and young people, adult augmentative and alternative communication users were included as they were able to offer reflections on their augmentative and alternative communication development)
- 16 family members (work package 3)
- 44 professionals and support team members (work package 3)
- 248 specialised and local professionals (work package 4).

A total of 354 participants contributed to the data collection components of the study and 22 participants contributed to the public involvement evaluation (work package 8).

Data collection techniques

Primary data collection activities

The primary data collection activities were focus groups, semistructured interviews and survey techniques.

Data management

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

Systematic literature reviews

The review process followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines. Owing to the dispersed nature of augmentative and alternative communication research, three linked systematic reviews were completed exploring the language and communication characteristics of augmentative and alternative communication users, the language and communication characteristics of communication aids and professionals' decision-making processes in communication aid recommendations.

Analysis procedures: qualitative and quantitative processes

Two work packages were qualitative (work packages 2 and 3), one work package was quantitative (work package 4) and one work package included mixed methods (work package 8).

Qualitative data analysis

Coding scheme design

Two methods of data coding were adopted to support the analysis of focus group and interview data: thematic analysis and framework approach. A process of intercoder reliability testing was set up for qualitative activity in work packages 2 and 3.

Quantitative data analysis

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

Public involvement

Two public involvement co-researchers, an adult using augmentative and alternative communication and a parent of a young adult using augmentative and alternative communication were integral to the development and delivery of each work package. A critical friend group comprised different stakeholders.

Results (summary)

Communication aid decision-making practices

Research question 1: what attributes related to the child/young person, and to generic communication aids, do professionals consider important in communication aid decision-making?

The findings from the context of making real clinical decisions (work package 2) contrasted with those in a survey context (work package 4). When an offline interrogation (survey) is used, children's physical characteristics are perceived to be relatively less important in augmentative and alternative communication 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 augmentative and alternative communication professional's decision-making can be strongly influenced by two characteristics of a child, namely whether the child is perceived as motivated to communicate using augmentative and alternative communication, and whether they are predicted to progress in skills and abilities.

Research question 2: what other factors influence or inform the final decision?

Decision-making is influenced by several factors that are not always under the control of the decision-makers, such as service structure and provision. These external factors mean that 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 influenced recommendations. Decisions were tailored based on external factors rather than being determined by what may best meet the child/young person's actual needs. For example, decisions were made with incomplete information on the child/young person's existing language skills.

Real-time decisions (work packages 2 and 3) (influenced by several cultural and contextual factors) were quite different from simulated decisions (work package 4) (vignettes and choices), suggesting that caution is required when interpreting simulated decision-making scenarios.

Research question 3: 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 (work packages 3 and 4). This reinforces the need for decision-making teams to be inclusive of all parties' perspectives and preferences.

The relationship between the dosage of learning practice and its translation into conversation success remains ill defined. This suggests that communication and learning opportunities require further investigation.

Research question 4: 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 online resource includes a research-informed theoretical model (URL: <https://iasc.mmu.ac.uk/i-asc-explanatory-model-of-aac-decision-making/>) with materials designed for all (URL: <https://iasc.mmu.ac.uk/>).

Public involvement research questions

Research question 5: 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 public involvement, including those people 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 informed the development of specific guidance to include in a public involvement toolkit (URL: <https://iasc.mmu.ac.uk/publicinvolvement>).

Research question 6: 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 public involvement. Insights include resources related to staff time, training and personal support (URL: <https://iasc.mmu.ac.uk/publicinvolvement>). These data highlight the need for mechanisms to enable public involvement co-researchers to be paid for their contributions to research bid preparation.

Methodological innovations: translational research

Our unique quantitative approach to augmentative and alternative communication 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 synthesising all findings has enabled the research to propose new theory and ways of conceptualising the decision-making process. Making this theory accessible to all stakeholders via the online heuristic achieves one of the original aims of the study, namely promoting consistent aid recommendations (URL: <https://iasc.mmu.ac.uk>).

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

Further research

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

- Appraise the existing language abilities of children/young people prior to a decision-making episode. This requires skilled professionals and requires studies exploring existing standardised language assessment tools and how they might be modified for this group of children/young people.
- Explore whether or not decision-making processes for second and subsequent communication aids have different qualities from an initial assessment. This requires further investigation of referral and re-referral pathways.
- Identify how augmentative and alternative communication 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 augmentative and alternative communication user to become proficient in their augmentative and alternative communication 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 that research that looks at local service contexts is welcome. Local professionals deliver 90% of the service to those who might benefit from augmentative and alternative communication. 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 this provision should include.
- Use quantitative methods to compare perspectives across stakeholders in the decision-making process. The I-ASC findings suggest that professionals and family members/users 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.

Future work on public involvement in research should include how to:

- support personal development of public involvement co-researchers, for example research methods training
- support traditional research teams to better understand how to develop research submissions that embrace co-created public involvement
- develop mechanisms that enable public involvement co-researchers to be reimbursed for their contributions to research funding bid preparation, which remain, at present, a 'hidden' cost of public involvement research.

Conclusions

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

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

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