Research Protocol

Version 3.0 –18 December, 2018

Full title

Identifying appropriate symbol communication aids for children who are non-speaking: enhancing clinical decision making

Short Title

IASC: Identifying Appropriate Symbol Communication

Proposed start date: 1st January 2016

Proposed end date: 30th April 2019

Chief Investigator
Professor Janice Murray
Professor in Communication Disability & AAC, Department of Health Professions, Manchester Metropolitan University
Email: j.murray@mmu.ac.uk
Tel: 0161 247 2570

Co-investigator and Deputy Chief Investigator during Patient and Public Involvement Evaluation (WP8) to provide support to research fellow as required
Professor Sue Powell
Professor of Public Health, Faculty of Health, Psychology and Social Care
Manchester Metropolitan University
Email: s.powell@mmu.ac.uk
Tel: 0161 247 2283

Co-Investigators
Professor Juliet Goldbart
Professor of Developmental Disabilities, Faculty of Health, Psychology & Social Care, Manchester Metropolitan University
Email: j.goldbart@mmu.ac.uk
Tel: 0161 247 2578

Mr Simon Judge
Senior Clinical Scientist, Barnsley Assistive Technology Service, Barnsley Hospital NHS Foundation Trust
Email: barnsley.at@nhs.net
Tel: 01226 432 159

Mr David Meads
Associate Professor in Health Economics, Faculty of Medicine and Health, University of Leeds
Email: D.Meads@leeds.ac.uk
Tel: 0113 343 0860

Professor Stephane Hess
Professor of Choice Modelling, Director of Choice Modelling Centre, University of Leeds
Email: s.hess@its.leeds.ac.uk
Tel: 0113 34 36611

Professor Francis Fatoye (WP8 only)
Professor of Health Economics and Outcomes, Department of Health Professions, Manchester Metropolitan University
Email: f.fatoye@mmu.ac.uk
Tel: 0161 247 2963

Research Team

Dr Yvonne Lynch, Research Fellow, Manchester Metropolitan University

Stuart Meredith, Co-researcher (PI), Manchester Metropolitan University
Elizabeth Moulam, Co-researcher (PI), Manchester Metropolitan University

Dr Mark Jayes, Research Fellow, Manchester Metropolitan University (WP8 only)

Nicola Randall, Research Fellow, Barnsley Assistive Technology Service, Barnsley Hospital NHS Foundation Trust

Dr Edward Webb, Research Associate, University of Leeds

Background and rationale for the study

This project aims to improve the health and wellbeing outcomes of children and young people who have little or no intelligible speech and need to use symbol communication aids to communicate. The children who will benefit from such aids are a heterogeneous group, e.g. cerebral palsy, who frequently have several co-occurring impairments including motor deficits ranging from no control over any limb to minor impairment of one or more limbs, sensory and perceptual deficits (specifically hearing and vision), and in some instances cognitive deficits.

In an earlier study, findings suggest that 0.5% of the population are estimated to require Augmentative and Alternative Communication (AAC). This equates to 529 people per hundred thousand population (Enderby, Judge et al, 2013).

Communication aid services are commissioned by NHS England as specialised services, delivering high cost services to 1 in 2000 people including potentially 8, 627 children and young people under 25 years (ONS, 2014). These services are unique in achieving an additional £15m recurrent investment from 2014. Although fragmented services have existed, this is a newly established care pathway and at present there are no standardised decision making resources to support it, to assist in monitoring quality of provision or facilitate audit.

From June 2014, children and young people aged 0-25 years with special needs have a statutory right to an Education, Health and Care (EHC) Plan. The principles enshrined in the SEN & Disability Code of Practice (CoP) incorporate the need for Education, Health and Care to collaborate to jointly commission high quality services, resources and support. The key aims of the CoP are early identification and intervention, inclusion, removing learning barriers and successful preparation for adulthood. Specific reference is made within the code to NHS England’s responsibility to support the identification and provision of aided communication systems.

The need for this research is further reflected in the second priority selected by the James Lind Alliance Childhood Disability Research Priority Setting Partnership which asks “what is the best way to select the most appropriate communication strategies?” (JLA, 2014; Morris et al, 2015). The proposed work also reflects the need identified by the NIHR's call for research into the evaluation of health care interventions and health services to better manage long-term conditions in children & young people.

The consequences of inappropriate communication aid recommendation and provision can be significant, resulting in poorer communication outcomes impacting detrimentally on literacy, general education, wellbeing, health, employment, wealth and participation in society (Bryen, Chung & Lever, 2010; Lund & Light, 2007b). By concentrating on improving the process of making decisions about prescribing symbol communication aids the project will address these quality of life indicators (Boa, Murphy & Enderby, 2014; Milner & Kelly, 2009, Smith & Murray, 2011).

Symbol communication aids are comprised of three interconnected components: (i) the mode of communication (the aid), (ii) the means of access, and (iii) the language representation system (e.g. the symbol).

The mode is the method by which the message is sent to the communication partner, ranging from the direction of the child’s gaze to the use of a computer-based speech output device. This project is focused on computer based devices.
The means by which the child accesses the communication mode may involve direct access such as pointing, or pressing the keys on a keyboard. Children with very severe physical involvement, however, may not be able to access the communication mode directly. In this case, they will need to be taught to use an indirect approach: for example, using a scanning system involving one or two switches. Means of access will not be the focus of the proposed research.

The language representation system: In typical conversation we use spoken words to represent what we want to convey. In symbol communication aid use, many different types of symbol set may be used to substitute for spoken words, e.g. written words or letters, photographs, line drawings, or a formalized set of symbols such as Picture Communication Symbols. The use of symbols which appear less abstract in relation to the words or ideas they represent is often seen as facilitating the child's acquisition of language, especially when they are at a pre-literate stage of development (Murray & Goldbart, 2009). The clinical decision making around best type of language representation system to recommend is a particular focus in this research proposal.

Symbol communication aids for children are prescribed without reference to evidence or best practice (van der Meer et al, 2011, Lindsay, 2010). This is resulting in disturbing levels of aid abandonment, poorer educational, employment and quality of life outcomes and greater cost to the NHS (Murray & Goldbart, 2009; Schlosser, 2006). The process of decision making around the choice of communication aid is not well documented or evaluated and research evidence related to the provision and evaluation of these devices is limited (Baxter, Enderby, Evans, & Judge, 2012; Judge & Townend, 2010; McFadd & Wilkinson, 2010; WHO, 2001). Currently, there are inadequate decision making tools available to support robust and effective identification and provision of communication aids (Lund & Light, 2006, 2007a, 2007b, Murray & Goldbart, 2011; Parkes et al, 2010).

We know that, when successfully provided, communication aids can have significant positive impacts on the health and quality of life of children throughout their life (Granlund et al, 2008). Decisions about a communication aid, often made when a child is young, will affect their communication ability, social participation, education and future employment (Gibson et al, 2009, Milner & Kelly, 2009). When successfully prescribed, communication aids can have significant positive impacts on health and quality of life reducing risk of social isolation and mental health issues (Hamm & Mirenda, 2006; McDonald et al, 2008; Smith & Murray, 2011).

Financial costs to the NHS of inappropriate or non-provision of a communication aid have been estimated at £500K per individual (Gross, 2011). The social and economic consequences of an inappropriate aid is evidenced through research on communication aid abandonment figures of between 30 and 50% abandonment (Bailey et al, 2006; Johnson et al, 2006; Smith & Connolly, 2008; Smith & Murray, 2011).

Children who need to use symbolic communication aids are the most challenging population accessing specialised communication aid services. Currently there is a lack of understanding of the most valuable aspects of clinical expertise and a poor understanding of patient values within the clinical decision process (Scherer et al, 2007). Without research evidence to reinforce clinical expertise there is no means of determining the actual quality of provision (Batorowicz & Shepherd, 2011; Dietz et al, 2012). Clinicians make decisions between different communication aids based on clinical judgement, without guidelines based on research evidence or patient values (Bryen et al, 2010; Goldbart & Marshall, 2004; Murray et al, 2013; McFadd & Wilkinson, 2010; Schlosser, 2006).

This project will produce protocols and procedures that will be transferrable to a range of clinical dilemmas relevant to the wider NHS. Our involvement of service users with complex communication disability and family members in the construction, planning and delivery of the project is transferrable as a methodology and will ensure that the products/guidance will be transferable to different settings and resistant to technology change. The decision making findings and process of development are also anticipated to be particularly applicable to other specialised Complex Disability Equipment services.

These decision making protocols will inform product design through development of future communication aid technologies as aids will be able to be designed to target more closely user needs and characteristics identified in this project. The protocols will also support developers to increase the range of relevant characteristics their devices contain, offering greater flexibility of use and enhancing suppliers' market share. The characteristics identified in our clinical decision making findings will inform marketing of future communication aid products and also information resources that support device evaluation and comparison including 'Speech Bubble' (www.speechbubble.org.uk) and AACknowledge (www.aacknowledge.org.uk). Potential IP generation will be considered at each stage of the heuristic development. Our decision making findings will also inform communication aid recommendations and evaluations which in turn will influence the process of NHS tendering for contracts for communication aid suppliers.

The release of convergence funding of £15 million to address service inequities and inconsistencies based on prior evidence of highly variable and inconsistent provision (Enderby, Judge et al, 2013; Gross, 2011; NHS England, 2013) is a well-received service development. It brings an anxiety that there is a lack of effective, efficient and participatory decision making tools to support the increased level of activity. This research is timely and critical to the effective NHS investment in this specialised service provision.

The challenge of making appropriate and long lasting clinical decisions about complex communication aid technologies for children with neurodisability who have significant communication disability has long been debated within the field of practice and existing research highlights multiple critical issues:

i. Communication Aids are a key intervention for children who cannot speak. The positive effects of using these systems include well-being, sense of belonging, and educational attainment (Dada & Alant, 2009; Lund & Light, 2006, 2007a, 2007b; Schlosser & Lee, 2000).

ii. Expert clinicians make variable decisions about appropriate technologies based on their knowledge of available systems, the medical and physical characteristics of the child, and immediate, rather than long-term use of communication aids (Batorowicz, & Shepherd, 2011; Dietz et al, 2012; McFadd, & Wilkinson, 2010). This suggests that there is no available decision making tool to support consistency.

iii. Little research evidence is available to determine the characteristics and features of communication aids and how these relate to successful use by a child (Baxter et al., 2012; Binger & Light, 2007; Binger & Light, 2008; Blockberger & Sutton, 2003; McDonald et al, 2008).

iv. Patient and family involvement in the decision making process can be minimal although it is recognised as key to the effective adoption of communication aids

(Bailey et al, 2006 Bryen et al, 2010; Goldbart & Marshall, 2004; King et al, 2008; Milner & Kelly, 2009).
v. Little is known about the impact of acquiring language through communication aid technologies on the educational and social experiences of these children (Murray & Goldbart, 2011; Parkes et al, 2010).
vi. Although there is literature on typical speech, language, communication development, there is little research of symbolic aided language learning trajectories or how clinical decision making tools may support recommendations (Binger & Light, 2007, 2008; Choi & Pak, 2006; Fallon et al, 2003; Goetghebeur et al, 2010; Murray & Goldbart, 2011; Scherer et al, 2007).

Patient and public involvement (PI) is an integral component of the I-ASC project. The PI approach across this project ensures the co-production of research with the PI Co-Researchers having full parity within the project team. The two co-researchers bring unique insights from their lived experience; an adult who uses AAC, and a parent of a young woman who uses AAC. A review of the literature indicated that there are five key areas of challenge for public involvement research:

i. Policy Pressures created by a current lack of specific guidance and a disparity of interpretation locally, regionally and nationally (Staniszewska et al, 2018; Gibson et al, 2012).
ii. Tokenistic and box ticking through use of the same small pool of participants, where the emphasis is on consultation rather than participation, often using ‘consumer surveys’ to tick the box of inclusive research (Ocloo and Matthews, 2016).
iii. Power imbalances between the perceived expert professional view and that of the expert individual in-depth lived experience, leading to a lack of parity in the research process between co-researchers and researchers (Green, 2016; Snow 2016).
iv. Stigma around empowering vulnerable groups due to the mistaken beliefs that these groups can be ‘too hard’ to involve, have nothing to add, are frequently ‘too difficult to reach’ and a proxy is good enough. This results in a view that inclusion both as research participants and as co-researchers is both time consuming for researchers and too costly (Frankena et al, 2016; Ocloo & Matthews, 2016; Staniszewska et al, 2018).
v. Existing guidance and tool kits are aimed at mainstream adults, not children or vulnerable groups, and fails to support best practice in delivery, outcomes and expectations, as well as lacking guidance on making adjustments for vulnerable groups (Frankena et al, 2016; Ocloo & Matthews, 2016; Staniszewska et al, 2018).

I-ASC aims to evaluate its PI activity, in order to demonstrate how it is possible to address these challenges when conducting research that involves a cohort considered to be the most difficult to recruit and involve in research: people with significant physical disability, severe speech impairment and, in some cases, intellectual impairment. Using a framework provided by the National Standards for Public Involvement in Research (2018) benchmarks alongside theoretical frameworks that evaluate normalisation of working practices the I-ASC project aims to evaluate its co-production of research through the voices of the core research team, the wider research support team within Manchester Metropolitan University and the project Advisory Board and Critical Friends Group. The evaluation will also include an economic analysis of the co-production of research over the entire project and what variance might now exist against planned budget and resources.

The outputs of this evaluation will include detailed guidance and practical tools to inform other public involvement research, e.g., critical care research, public health research. Outcomes of the economic evaluation will include tools to translate PI co-production into everyday research practice (Sutton, Garfield-Birbeck, Martin, Meacock, Morris, Sculpher, Street, & Lilford, 2018).The implications of this may be far reaching. For example, AAC research needs to be extended into acquired conditions where speech and communication barriers often exist, such as following CVA/Stroke, or progressive conditions including dementia and Motor Neuron Disease. Evaluation of the I-ASC project PI activity will inform research protocols for this diverse range of clinical populations (Stevenson & Taylor, 2017).

Aims and Objectives

The overall aim is to improve the outcomes for children with little or no intelligible speech, who need symbol communication aids to communicate.

The specific aim is to influence current practice to improve the consistency and quality of clinical decision making in the provision of symbol communication aids.

A further aim is to develop an on-line toolkit, to include guidance about public involvement in co-production and participation in research for funders, policy makers, researchers, public involvement researchers and potential participants.

The objectives of the project, reflected in the research plan, are to:

(1) Understand what is perceived as important in terms of symbol communication aid provision; how decisions are currently made; and what barriers and facilitators impact on these decisions.
(2) Understand and agree the range of attributes that should be considered in these decisions, related to the child, the family and the communication aid.
(3) Establish how clinicians* actually currently make decisions (their stated preferences); how they consider these attributes.
(4) Explore how this process takes account of the perspectives of all involved; specifically how children, parents and clinicians perceive the effectiveness of existing and historic recommendations.
(5) To qualify and quantify processes that support public involvement across all aspects of co-production within the research process.
(6) To quantify protocols that facilitate marginalised and vulnerable public involvement groups to make meaningful contributions to the research process.
(7) To appraise costs and benefits of extensive public involvement in research.

*throughout the term 'Clinician' is taken to mean any health professional with specific remit to determine the best symbol communication system for a child with little or no intelligible speech. The majority of these clinicians are based within the NHS, but not exclusively.

And then, on the basis of the information gathered from (1) to (7) to:

(8) Develop decision guidance for clinicians and all involved to ensure that the best possible decisions are made in matching symbol communication aids to children.
(9) Develop guidance and practical tools to facilitate public involvement in research for diverse, hard to reach cohorts.
(10) To disseminate this guidance and the results of the project in order to: i) influence practice and improve the quality and consistency of decisions about symbol communication aid provision, thus reducing abandonment figures and improving the quality of life experiences of the children who benefit from such aids to communication; ii) improve the quantity and quality of public involvement in research

Research questions

The study will investigate four key research questions in order to meet the aims and objectives of the project:

1. What attributes related to the child, and generic communication aids, do clinicians consider important in making decisions about communication aid provision?
2. What other factors influence or inform the final decision?
3. What attributes are considered important by other participants (e.g. the child and family) and how do these impact in the short, medium and long term?
4. What decision support guidance and resources would enhance the quality, accountability and comparability of decision making?
5. How and what can we learn from an evaluation of public involvement in a nationally funded project focussing on vulnerable and hard to reach patients?
6. How can public involvement research, implementing current guidance with vulnerable and hard to reach groups, be structured to avoid pitfalls and improve impact?

Summary of Research

The main research aim is to determine how to optimise clinicians' decisions about the provision of symbol communication aids, which change with successive models/generations of devices. We use the term "clinician" to denote the health professionals in the assessment team; primarily speech and language therapists (SLTs), occupational therapists (OTs), psychologists and clinical scientists. These decisions are based on characteristics of the child, the family and their context, and characteristics of the symbol communication aid – but these characteristics, and how decisions are made based on these characteristics, are poorly understood.

The research adopts a mixed methods approach to address the research questions. The research will be managed in 8 work packages (WPs), 1 WP for project management and 7 research WPs exploring existing theory, current practice, how new theory will support evidence based clinical decision making and in developing resources to influence future practice, and an evaluation of PI co-production of research.

The PI co-researchers; an adult using a symbol communication aid and a parent of a young adult using a communication device, are integral to the development and delivery of each work package. The project will be overseen by a highly experienced project management group consisting of relevant academics, people who use communication aids, parents of aid users, expert clinicians and NHS England commissioning members. In conjunction with project outputs, IP exploitation opportunities will be considered at key points in each WP delivery. The project will also link closely to the NIHR D4D Healthcare Technology Collaborative.

Outputs will include new evidence syntheses from the literature reviews, qualitative evidence from key stakeholders, stated preference evidence, the decision making resources and the online PI guidance and resources toolkit.

Short-term outcomes of the project will include improved practice within the community of professionals and families involved in the project; better understanding of evidence within the community; improved efficiency related to assessment recommendations causing a step change in practice delivery. In addition providing new guidance and resources for the co-production of research with PI co-researchers.

Long-term outcomes of the project will be improved provision of symbol communication aids; more effective and efficient provision through specialised services and local services of symbol communication aids; improved Quality of Life outcomes for children, and their families, following provision of more appropriate symbol communication systems. Evidence that can be used by designers and manufacturers of symbol communication aids to develop appropriate systems for lifetime use. Characteristics from the heuristic may inform possible IP generation in the development of communication aid features. The PI evaluation outputs will provide guidance of how to involve the public meaningfully in the co-production of research.

Research Design and Methodology

Design: The proposed research design takes an ethnographic frame of reference with an exploratory approach to data modelling. This will be achieved through significant qualitative investigation of the nature of these decisions from all perspectives, including adults for whom the decisions were made (as children); establishing through focus groups and interviews the attributes deemed important for decision making. These results will inform a quantitative Discrete Choice Experiment design to establish what attributes clinicians consider, whilst simultaneously capturing what service users' value; and then adopting an EBP approach, synthesise this work to develop guidance and tools that will influence practice.

The evaluation of the PI component will also use an ethnographic approach to explore perceptions, preconceptions and phenomena that impact on how public involvement is conceptualised and delivered. Drawing upon implementation evaluation framing and theories, the economic evaluation will adopt a resource utilisation questionnaire which together will be used to quantify and qualify the impact of the implementation, together with the benefits of public co-production of research.

WP1: A Systematic Literature Review

Rationale: Three linked systematic reviews will address the current evidence relating to: (i) speech, language and communication development with specific reference to children using symbolic communication aids; (ii) the language and communication characteristics of both the child and the communication aids considered in decision making; and (iii) clinical decision making associated with aided communication in allied health professions and how this relates to the literature on developing decision making tools. The reviews contribute the "best available evidence" to inform WP2, WP3 and WP4 topic guides and the decision making tool.

Method: Although it is recognised that no one tool offers a gold standard approach for allied health researchers (Marshall et al, 2011) the research team will adopt the PRISMA approach (Moher et al, 2009). Relevance will be determined using robust inclusion and exclusion criteria. As research with a wide diversity of methodologies will be included, Reichow, Volkmar and Cichetti's (2008) rating will be used to determine the quality of individual studies and to identify sources of bias. This will include inter-rater reliability checks between members of the research team. Previous research in communication impairment (e.g. Marshall et al, 2011) has found a dearth of high quality studies, with no scope for meta-analysis. This is likely to be true of some or all of the proposed reviews, in which case, a narrative approach will be adopted, collating the results of studies, with due consideration to their relative quality. The weight of evidence supporting specific approaches or issues will then be graded using the Grades of Recommendation (http://www.cebm.net/oxford-centre-evidence-based-medicine-levels-evidence-march-2009/).

WP2: Qualitative Investigation of Specialised Professionals' decision making

Rationale: To understand the factors clinicians consider when making symbol communication aid recommendations. This will generate data for the DCE in WP4 and contributes one strand of the "expert clinical opinion" for the decision making tool.

Sampling: Purposive sampling of specialist practitioners, as defined through existing competency frameworks, based at specialised and local services. Recruited through existing networks, e.g. NHS specialised services network, Communication Matters.

Sample size is known to be feasible through previous research led by current team (Communication Matters, 2013).

Method: Focus groups (n=30) with clinicians involved in decision making related to symbol communication aids to establish the factors they consider when making provision choices. These will take the form of six live observations of an assessment and an interview debrief with the assessment team (N=5), delivered in the form of a focus group discussion.

Analysis: These focus groups will be transcribed and analysed using Framework Analysis (Gale et al., 2013; Ritchie & Spencer, 1994). The resulting themes will inform a *Best-Worst* scaling survey, to identify a detailed but constrained and feasible number of variables for the DCE (WP4).

WP3: A case series from a Service Users' perspective of decision making

Rationale: To provide a detailed understanding of the perspectives of all key stakeholders by exploring specific decisions for specific people. Child and family involvement is crucial to unpick the long-term impact of decisions on people who use symbol communication aids and their support networks. This will contribute service users' views and values to make up (with the results of WPs1, WP2 and WP4) the evidence based practice triad (Sackett et al, 1997).

Sampling: the participant groups will come from three specific communities of experience (i) Community 1: Adults reflecting on their past experience of symbol communication aid recommendation; (ii) Community 2: going through the process of symbol communication aid selection. Reflections for 10-12 year olds; (iii) Community 3: going through the process of symbol communication aid selection. Reflections (through proxies, i.e. parents) of 4-6 year olds, with18 months of symbol communication aid experience.
Stratified sampling by child characteristics to ensure a broad representation, e.g.
Group 1: A case series of interviews from adults/proxies who use or previously used symbol communication aids: (i) Cognitively able/literate, (ii) Moderate Learning Disability, (iii) Severe Learning Disability
Group 2: A case series of interviews from parents or significant persons of users in Group 1
Group 3: A case series of interviews from generalist practitioners of users in Group 1
Group 4: A case series of interviews from local specialist practitioners of users in Group 1
Group 5: A case series of interviews from specialised service practitioners of users in Group 1

Recruitment: Brokered through well-established networks including - Communication Matters Research Involvement Network, 1Voice, ISAAC- network, SCOPE/Capability Scotland, The Communication Trust, Cerebra, Social media, e.g. PMLD forum.

PI Co-Researchers are critical to the successful recruitment of children and young people within this work package, participant engagement is known to be feasible through previous research led by current team (Communication Matters, 2013).

Method: This case series will use in-depth interviews, vignettes and observational investigations to understand the perceptions of young people who have been part of a decision making process related to symbol communication aids. Participants will include the young person (n=15-20) , and key stakeholders in decision making process (n= 75-100), e.g. the family, local professionals (e.g. SLT, Teacher, Health Visitor, Teaching Assistants) specialist professionals in specialised and local services (e.g. Clinical Scientist, SLTs, OTs).

Analysis: These interviews will be transcribed and analysed using Framework Analysis (Gale et al., 2013; Ritchie & Spencer, 1994). The findings will complement the activities of WP2 & WP4 and be synthesised within WP5.

WP4: Discrete Choice Experiment with Professionals

Rationale: The DCE, specifically using Choice Modelling, will be used to identify which attributes of the symbol communication aid and the child clinicians take account of in recommending symbol communication aids and their relative importance in clinical decision making. These findings will inform WP5 in terms of determining hierarchies explicit to these attributes and how they may act as facilitators or barriers to the long term successful take up of symbol communication aid systems.

Sampling: Through a purposive recruitment process, health and educational professionals (a minimum of n=200) involved in current symbol communication aid decision making will be surveyed. Respondents will be sought from the well-established AAC (specialised) centres across the UK, ensuring appropriate and sufficient respondents.

Method: Informed by WP1, WP2 and WP3 the researchers will conduct two Discrete Choice Experiments (DCE). Experiment A) symbol communication system choice, where a child with communication difficulties is described along with 2 or more attributes from a symbol communication system and the respondent chooses which to provide; and Experiment B) Recipient/Child choice, where a symbol communication system is described along with 2 or more children with communication difficulties and the respondent has to choose which child is the best match for the symbol communication system.

Analysis: Analysis will use regression techniques (e.g. logit or probit regression) to identify the importance of each device and child attribute in the choices of respondents. The size and sign of the model coefficient relating to each device and child characteristic will inform us what drives the choices of clinicians. For any given characteristic of the child, we will be able to determine what aspects of the symbol communication system respondents considered most important in their decision. We will also explore the impact of heterogeneity in preferences across individual respondents (Flynn et al, 2010; Train 2009), for example exploring whether gender or professional experience plays a part in the matching of child and symbol communication system. Components of the model relating to attitudes will also help us to mitigate the effects of any strategic bias that may arise in the data.

WP5: Development of Decision Support Resources

Rationale: To influence practice within the NHS this phase will combine all Work Packages resulting in the development of a prototype decision support resource and decision making heuristic with guidance to ensure the best match between a symbol communication system and a child.

Sampling: Through a purposive recruitment process, health and educational professionals involved in current symbol communication aid decision making, along with PI representative groups (a maximum of n=200) will be invited to test the guidelines and heuristic. Respondents will be sought from the well-established AAC (specialised) centres across the UK, and well-established networks including - Communication Matters Research Involvement Network, 1Voice, ISAAC- network.

Method: A mang exercise will be conducted whereby the themes identified in the Framework Analyses WP2 and 3, along with the results from WP4 will be compared and mapped onto the themes from the systematic reviews (i), (ii) and (iii). This work package will take an explicitly EBP approach (Sackett et al, 1997), synthesising the triad of data; best available research (WP1), expert clinical opinion (WP2, WP3 and WP4), and service users' views and values (WP3).

Analysis: Testing the decision making support resource: In this phase we will test the guidelines and decision making heuristic derived from the synthesis process for feasibility through a further round of consultation, using an information pack and evaluation form for completion by respondents (Goehler et al, 2011; Goetghebeur et al, 2010; Shearer et al, 2011) . Testing will uncover information about acceptability and feasibility with supportive strategies which will be refined. Alternative pathways to implement these principles will be defined for different settings and caseloads. These data will be used to increase appropriate symbol communication aid recommendation.

The decision making heuristic will provide a matrix of priority characteristics for the different stakeholders rather than a match to specific, or existing currently available symbol communication aids, thus supporting the case for longevity in application and use of such a research product. This will inform four areas of practice: (i) specialised and local specialist service provision (Judge & Murray), (ii) family involvement in the decision making process (Moulam & Meredith), (iii) under graduate and post graduate education through the dissemination of findings and the well placed links the research team have to inform education (Murray, Goldbart & Judge), and, (iv) we will link the findings to national clinical audit (SSNAP) to determine what data should be routinely collected to inform findings (Murray & Judge).

WP6: Dissemination and outputs – translating findings for patient benefit

Dissemination: The final stage will be to translate the findings into practice through targeted dissemination of the guidance. Dissemination will be key throughout and the participants in the project will also be those to whom dissemination will be aimed; their involvement in the project will initiate the process of change.

The PI co-researchers will be central to the effective dissemination of the project outputs, and they will lead on this area. This will provide a greater level of engagement in the dissemination by all groups. In addition, the support of independent sector organisations, such as Communication Matters will provide dissemination routes.

Throughout the project a variety of media will be used to support dissemination including a project website, blog, social media presence, email forums, traditional publications and word of mouth through professional and service user networks. One of the most powerful methods of dissemination will be through the involvement of participants (from a relatively small, well-connected population) within the project. In addition to their contribution to design, data collection and data analysis, it is anticipated that this will initiate a process of reflection on practice.

Dissemination will be focused on the different participant groups: clinicians (including the wider community of professionals involved in these decisions, e.g. referring agents); service users and families; and commissioners.

- Clinicians will be targeted primarily through workshops, conferences, publications in academic and practice journals and web media. Previous studies by the applicants have involved 98 and 220 clinicians/services respectively. In addition, clinicians will be targeted through professional and independent organisations such as the Royal College of Speech and Language Therapists, ACE Centre, Foundation for Assistive Technology and Communication Matters. Three key events are planned for London, Manchester and Edinburgh.
- Service users and family members will be targeted through workshops, publications in relevant literature (e.g. Disability Now, Communication Matters Journal, 1Voice events) and web, social and mainstream media.
- Commissioners will be targeted through briefing documents and journal publications.
- The AAC research community will be targeted through high quality peer reviewed papers in high (for the sector) impact factor journals and ISAAC conference presentations .
- The findings will be submitted for presentation at the annual Communication Matters Conference (+/- 400 delegates from the Communication Aid community including communication aid designers and manufacturers, people who use communication aids, their families, clinicians, teachers, researchers) and at the International Conference on AAC (+/- 1000 delegates).

This work, led by our PI co-researchers, will be key to embedding change. Ultimately, this will result in better outcomes for the child.

WP7: Project Management

Project Management will ensure effective delivery of research project aims, objectives and deliverables; engagement of stakeholder groups, and efficient reporting and dissemination activities.
The research team will be supported by a highly expert Project Management Group and an Independent Steering Group. The Project Management Group will be composed of relevant academics, PI representatives, expert clinicians and NHS England commissioning members. The Independent Steering Group will offer an additional level of advice and audit.

WP8: Evaluation of project PI component

Rationale: This phase will evaluate the public involvement contribution within the I-ASC project, in order to identify processes that support public involvement in research and make it accessible to marginalised and vulnerable public involvement groups. The evaluation will appraise costs and benefits of extensive public involvement in research. This will result in guidance materials and resources on how to include vulnerable groups in research and the benefits of their inclusion.

Sampling: A purposive sampling strategy will be used to recruit four groups of participants: i) members of the inter-disciplinary project team involved in the construction, delivery and dissemination content of the I-ASC project (n=7); ii) members of the I-ASC team engaged on discreet sections of the project, e.g., WP4 delivery (n=3); iii) members of the wider I-ASC team who support the project from an organisational and operational perspective, e.g., HR (n=5); iv) the NIHR Advisory Board and I-ASC critical friends group who support the project and represent all stakeholder groups in the research (n=7). These participant groups (n=22) include public involvement representatives, academics, policy makers, administrators and practitioners.

Method: Participant data will be collected via semi-structured interviews, focus groups and a resource utilisation questionnaire. Groups (i), (ii) and (iii) will be interviewed on a 1-1 basis and asked to complete the resource utilisation questionnaire (n=15). Individual semi-structured interviews will be conducted face to face (or via skype) by Jayes. These will be short, focused relating to the public involvement component of the I-ASC project (e.g., 30 mins in total, this timeframe will be negotiated in regards to those with communication disability, where additional time will be offered to ensure they can convey what they would wish to). The key interview questions will be focused on each individual’s experience (including the co-researchers) of the project’s implementation.

Groups (i) and (iv) will each take part in one of two focus groups facilitated by Jayes (n=14). For group (i), the individual interviews should take place before the focus group to ensure group thinking does not influence individual viewpoints. The topics for discussion by group (i) are the collective implementation and process/procedures undertaken during the project. The topics for discussion by group (iv) will be similar to those discussed by group (i) but topic probes will be mindful of their advisory role on the project.

The economic analysis, led by Moulam, will adopt a cost consequence approach to demonstrate the costs and benefits of public involvement co-production of research (Drummond et al., 2015). The full I-ASC research team and the wider support team at MMU (groups i, ii, ii) will be asked to complete a resource utilisation questionnaire. This questionnaire will be used to examine resource use associated with the time commitment of human resources, facilities, equipment, consumables and additional staff who had not been initially anticipated to contribute. Costs of the resources will be estimated using the NHS reference unit cost, this will allow us to show any variance with planned costs and resources. Questions included in the interviews and focus groups are designed to also provide data for a narrative evaluation of the public involvement input to the I-ASC project, as part of the economic analysis.

Analysis: A mixed methods approach will be used. Deductive analysis will utilise Thematic Framework Analysis (e.g., Creswell, 2013) to interpret interview and focus group data. Aspects of the economic analysis will draw on qualitative findings from the interviews and focus groups for a narrative on the benefits of implementation. The economic analysis of co-production of research will be both an inclusion component of the qualitative data collection, as well adopting a resource allocation utilisation questionnaire to estimate variance between actual resource use and planned/budgeted costs.

The PI evaluation (work package 8) will result in guidance materials and resources on how to include vulnerable groups in the co-production of research and the benefits of their inclusion. Dissemination outputs will take a number of forms, including on-line materials, presentations, study days, videos, an online tool kit and publications. The I-ASC website, hosted by Manchester Metropolitan University will house both the I-ASC's explanatory model of AAC assessment, more detailed study findings and publications, as well as the tools and resources needed to answer the original research questions to develop best practice and improve the quality of life for children and young people who use AAC. The evaluation of the implementation of public involvement co-production of research will sit separately but alongside this as a resource for funders, researchers and members of the public who are interested in public involvement work.

The key UK dissemination events, led by the public involvement co-researchers, will be two study day events, (a) for people who might consider becoming public involvement researchers, and (b) researchers and funders who might consider becoming better informed on how to deliver quality public informed research projects. Whilst billed as separate events, both will include all stakeholder perspectives and be informed by the results of the I-ASC public involvement findings.

Other outputs will include submission of papers to peer reviewed publications, practice and service user informed publications including Health Expectations and the RCSLT Bulletin.

Outputs: The main output from this project will be an evidence based clinical resource with guidelines to inform clinical decision making in symbol communication aid selection, along with a parent friendly guide. This form of knowledge and decision support will strongly influence practice in this field.

Outputs from this research will support the decisions at the heart of the care pathway and drive a change in provision to being more evidence based, equitable and effective. Outcomes for the children who use, or may use, symbol communication aids will be improved and abandonment of communication aids will reduce. All involved in the decision will be better engaged in the whole care pathway and local services will be able to better identify children who may benefit.

Output from this project will also influence and inform research and development of future communication aid technologies. Characteristics identified in our clinical decision making findings will inform the marketing of symbol communication aid products, for example, on such sites as managed by the ACE Centre, ‘Speech Bubble’ (www.speechbubble.org.uk) and AACknowledge (www.aacknowledge.org.uk) and in quality assurance referral tools used by specialised services.

The findings will also inform symbol communication aid recommendations, which in turn will influence the process of symbol communication aid procurement.

The outputs from this project will also be developed into undergraduate and postgraduate training of speech and language therapists – through established academic networks (including Manchester Metropolitan, Leeds and Sheffield Universities).

Long term, the legacy of this project will impact positively on the health and wellbeing of children and young people who have little or no intelligible speech and need to use symbol communication aids to acquire language and hence to communicate, through the acquisition and use of more appropriate communication technologies to support them to develop to their full potential. The evidenced based resource developed from this project will focus on characteristics of children and language/communication strategies, rather than device specific, supporting sustained application and use.

The outputs of the PI evaluation will include guidance and practical tools to inform all other public involvement research. This has the potential to increase access to meaningful research participation and co-production for hard to reach cohorts and to increase the quantity and quality of research that benefits service users.

PI involvement

Our PI co-researchers are integral to the development and delivery of each work package, and will be supported effectively by staff across the MMU and Barnsley sites, as well as through the Project Management Group. Their input across all aspects of the project are detailed in each WP.

Data Management

All research data will be managed in accordance with the Data Protection Act (1998). Manchester Metropolitan University (MMU) will lead data collection/analysis. All original electronic data containing personal identifiable information will be stored in an encrypted folder at MMU following transcription and anonymising by a member of the research team. This encrypted folder will require a password for access. Personal identifiable information will be kept for 10 years in line with NIHR requirements and the files will be tagged with a destruction date. At times, data will need to be transferred between sites and files will be password protected and emailed. The transfer of password protected files containing identifiable information between MMU, Barnsley and Leeds will be kept to a minimum. All paper based study related documentation including consent forms will be stored in a locked filing cabinet in the Department of Health Professions Office (SLT), MMU. Access to the office is via swipe card.

Ethical Considerations

Aspects of the research focuses on interventions for a vulnerable group, that is, young children with disabilities and their families. Ethics approvals to undertake this study will be sought from MMU and University of Leeds, as well as through IRAS. All members of the team who will have contact with the children and family members will have Disclosure and Barring checks and approvals, as well as NHS research passports. The research project has collaborators and advisors who are experienced in working with children and adults with communication disability and any new team members will receive appropriate training and support from experienced members.

References

Bailey, R. et al. 2006. Family members' perceptions of augmentative and alternative communication device use. Language, Speech & Hearing Services in Schools. 37(1), pp.50-60.

Batorowicz, B. and Shepherd, T. 2011. Teamwork in AAC: Examining Clinical Perceptions. Augmentative and Alternative Communication. 27(1), pp.16–25.

Baxter ,S. et al. 2012. Barriers and facilitators to the use of high-technology augmentative and alternative communication devices: a systematic review and qualitative synthesis. International Journal of Language & Communication Disorders. 47(2), pp.115-129.

Binger, C. and Light, J. 2007. The effect of aided AAC modelling on the expression of multi-symbol messages by preschoolers who use AAC. Augmentative and Alternative Communication. 23(1), pp.30-43.

Binger, C. and Light, J. 2008. The morphology and syntax of individuals who use AAC: Research review and implications for effective practice. Augmentative and Alternative Communication. 24(2), pp.123-138.

Blockberger, S. and Sutton, A. 2003. Toward Linguistic Competence: Language experiences and knowledge of children with extremely limited speech. In: Light, J. Beukelman, D. and Reichle, J. ed. Communicative Competence for Individuals who use AAC: from research to effective practice. London: Brookes, pp.23-36.
Boa, S. et al. 2014. Testing the Validity and Inter-rater Reliability of the Therapy Outcome Measure for AAC. Communication Matters Journal. 28(3), pp.34-35.
Bryen, D. et al. 2010. What you might not find in a typical transition plan! Some important lessons from adults who rely on Augmentative and Alternative Communication. Perspectives on Augmentative and Alternative Communication, 19(June), pp.5-8.
Choi, B. C. K. and Pak, A.W. P. 2006. Multidisciplinarity, interdisciplinarity and transdisciplinarity in health research, services, education and policy: 1. Definitions, objectives, and evidence of effectiveness. Clinical and Investigative Medicine. 29, pp.351–364.
Communication Matters. 2013. Shining a Light on Augmentative and Alternative Communication: an AAC Evidence Base research project – final report (2013) (www.communicationmatters.org.uk)
Creswell, J. W. (2013). Qualitative inquiry and research design: choosing among five approaches. Vol. 3rd. Los Angeles: SAGE Publications.
Dada, S. and Alant, E. 2009. The effect of aided language stimulation on vocabulary acquisition in children with little or no functional speech. American Journal of Speech-Language Pathology. 18(1), pp.50-64.
Dietz, A. et al. 2012. AAC assessment and clinical decision making: the impact of experience. Augmentative and Alternative Communication. 28(3), pp.148-159.
Drummond, M.F., Sculpher, M.J., Claxton, K., Stoddart, G.L., & Torrance, G.W. (2015). Methods for the economic evaluation of health care programmes. Oxford: Oxford University Press
Enderby, P. et al. 2013. Examining the Need for and Provision of AAC Methods in the UK. Advances in Clinical Neuroscience & Rehabilitation. 13(4), pp.20-23.
Fallon, K. et al. 2003. The semantic organisation patterns of young children: Implications for augmentative and alternative communication. Augmentative and Alternative Communication. 19 (2), pp.74-85.
Flynn, T.N. et al. 2010. Using discrete choice experiments to understand preferences for quality of life. Variance-scale heterogeneity matters. Social Science & Medicine. 70, pp.1957-1965.
Frankena, T.K., Naaldenberg, J., Cardol, M., et al. (2016). Exploring academics' views on designs, methods, characteristics and outcomes of inclusive health research with people with intellectual disabilities: a modified Delphi study. BMJ Open, 6:e011861. doi: 10.1136/bmjopen-2016-011861
Gibson, A., Britten, N., & Lynch, J. (2012). Theoretical directions for an emancipatory concept of patient and public involvement, Health, Vol 16, Issue 5, pp. 531 – 547. https://doi.org/10.1177/1363459312438563
Gibson, B. et al. 2009. Revisiting therapy assumptions in children's rehabilitation: clinical and research implications. Disability and Rehabilitation. 31(17), pp.1446-1453.
Goehler, A. et al. 2011. Decision-Analytic Models to Simulate Health Outcomes and Costs in Heart Failure: A Systematic Review. PharmacoEconomics. 29(9), pp.753-769.
Goetghebeur, M.M. et al. 2010. Combining multicriteria decision analysis, ethics and health technology assessment: applying the EVIDEM decisionmaking framework to

growth hormone for Turner syndrome patients. Cost Effectiveness and Resource Allocation. 8(1), pp.4-14.

Goldbart, J. and Marshall, J. 2004. "Pushes and Pulls" on parents of children who use AAC. Augmentative and Alternative Communication. 20(4), pp.194-200.

Granlund, M. et al. 2008. AAC Interventions for Children in a Family Environment: Implementing Evidence in Practice. Augmentative and Alternative Communication. 24(3), pp.207–219.

Green, G. (2016). Power to the people: To what extent has public involvement in applied health research achieved this? *Research Involvement and Engagement*, 2:28 DOI 10.1186/s40900-016-0042-y

Gross, J. (2011) Two years on: final report of the Communication Champion for children, Office of the Communication Champion

Hamm, B. and Mirenda, P. 2006. Post-school quality of life for individuals with developmental disabilities who use AAC. Augmentative and Alternative Communication. 22, pp.134–146.

James Lind Alliance. 2014. Childhood Disability Research Priority Setting Partnership http://www.lindalliance.org/ChildhoodDisabilityPSP.asp

Johnson, J. et al. 2006. Perspectives of Speech Language Pathologists regarding success versus abandonment of AAC. Augmentative and Alternative Communication. 22(2), pp.85-99.

Judge, S. and Townend, J. 2010. Choosing voice output communication aids: A proposed decision-making tool. Paper presented at the biennial meeting of the International Society for Augmentative and Alternative Communication, Barcelona, Spain.

King, G. et al. 2008. Expertise in research-informed clinical decision making: Working effectively with families of children with little or no functional speech. Evidence-Based Communication Assessment and Intervention. 2(2), pp.106–116.

Lindsay, S. 2010. Perceptions of health care workers prescribing augmentative and alternative communication devices to children. Disability &Rehabilitation: Assistive Technology. 5, pp.209–222.

Lund, S. K. and Light, J. 2006. Long-term outcomes for individuals who use AAC: Part I - What is a "good" outcome? Augmentative and Alternative Communication. 22, pp.284-299.

Lund, S. K. and Light, J. 2007a. Long-term outcomes for individuals who use AAC: Part II - Expressive Communication. Augmentative and Alternative Communication. 23, pp.1-15.

Lund, S. K. and Light, J. 2007b. Long-term outcomes for individuals who use AAC: Part III - Factors contributing to outcomes. Augmentative and Alternative Communication. 23, pp.323-335.

Marshall, J. et al. 2011. The application of systematic reviews in speech and language therapy. International Journal of Language and Communication Disorders. 46(3), pp.261–272.

McDonald, R. et al. 2008. Elation or frustration? Outcomes following the provision of equipment during the communication aids project: Data from one CAP partner centre. Child: Care, Health & Development. 34, pp.223–229.

McFadd, E. and Wilkinson, K. 2010. Qualitative Analysis of Decision Making by Speech-Language Pathologists in Designing Aided Visual Displays. Augmentative and Alternative Communication. 26 (2), pp.136-147.

Milner, P. and Kelly, B. 2009. Community participation and inclusion: People with disabilities defining their place. Disability and Society. 24, pp.47-62.

Moher, D. et al for the PRSMA Group. 2009. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. BMJ 339:b2535. doi: 10.1136/bmj.b2535

Morris, C. et al. 2015. Setting research priorities to improve the health of children and young people with neurodisability: a British Academy of Childhood Disability-James Lind Alliance Research Priority Setting Partnership. BMJ Open 2015;5:e006233. doi:10.1136/bmjopen-2014-006233

Murray, J. and Goldbart, J. 2009. Augmentative and alternative communication: a review of current issues. Paediatrics and Child Health. 19(10), pp.464-468.

Murray, J. and Goldbart, J. 2011. Emergence of working memory in children using aided communication. Journal of Assistive Technologies. 5(4), pp.213-232.

Murray, J. et al. 2013. A case study template to support experimental design in Augmentative and Alternative Communication and Assistive technology. Disability & Rehabilitation: Assistive Technology. 9(1), pp.60-69.

National Standards for Public Involvement in Research V1 March (2018). https://sites.google.com/nihr.ac.uk/pi-standards/home

NHS England. 2013. NHS Standard Contract For Complex Disability Equipment: Alternative And Augmentative Communication/ Communication Aids, www.commissioningboard.nhs.uk/2012/12/12/ssc-consult

Ocloo, J., & Matthews, R. (2016). From tokenism to empowerment: progressing patient and public involvement in healthcare improvement. BMJ Qual Saf. doi: 10.1136/bmjqs-2015-004839

ONS(2014):http://www.ons.gov.uk/ons/taxonomy/index.html?nscl=Population+Estimates+by+Age+and+Sex#tab-data-tables

Parkes, J. et al. 2010. To what extent do children with cerebral palsy participate in everyday life situations? Health and social care in the community. 18 (3), pp.304-315.

Ritchie, J. and Spencer, L. 1994. ‘Qualitative data analysis for applied policy research’. In: Bryman and Burgess. eds. Analysing Qualitative Data. London: Routledge. pp.173-194.

Sackett, D. et al. 1997. *Evidence based medicine: How to practice and teach EBM*. New York: Churchill Livingstone.

Scherer, M. et al. 2007. A framework for modelling the selection of assistive technology devices (ATDs). Disability and Rehabilitation: Assistive Technology. 2(1), pp.1-8.

Schlosser, R. 2006. Evidence-Based Practice for AAC practitioners. Perspectives on Augmentative and Alternative Communication, 15(3), pp.8-9.

Schlosser, R. and Lee, D. 2000. Promoting generalization and maintenance in augmentative and alternative communication: A meta-analysis of 20 years of effectiveness research. Augmentative and Alternative Communication. 16(4), pp.208–227

Shearer, J. et al. 2011. The use of decision-analytic models in Parkinson’s disease: A systematic review and critical appraisal. Applied Health Economics and Health Policy. 9(4), pp.243-258.

Smith, M. M. and Connolly, I. 2008. Roles of aided communication: Perspectives of adults who use AAC. Disability and Rehabilitation: Assistive Technology. 3(5), pp.260–273.

Smith, M. M. and Murray, J. 2011. Parachute without a ripcord: The skydive of communication interaction. Augmentative and Alternative Communication. 27(4), pp.292–303.

Snow, R, (2016). What makes a real patient? BMJ Blogs: https://blogs.bmj.com/bmj/2016/07/19/rosamund-snow-what-makes-a-real-patient/

Staniszewska, S., Denegri, S., Matthews, R., Minogue. V. (2018). Reviewing progress in public involvement in NIHR research: developing and implementing a new vision for the future. BMJ Open 2018;8:e017124. doi: 10.1136/bmjopen-2017-017124

Stevenson, M., & Taylor, B. (2017). Involving individuals with dementia as co-researchers in analysis of findings from a qualitative study. Dementia. https://doi.org/10.1177/1471301217690904

Sutton, M., Garfield-Birkbeck, S., Martin, G., Meacock, R., Morris, S., Sculpher, M., & Lilford, R. (2018). Economic analysis of service and delivery interventions in health care. *Health Serv Deliv Res*. 6(5)

Train, K. E. 2009. Discrete choice methods with simulation. Cambridge, MA: Cambridge University Press.

van der Meer, L. et al. 2011. Assessing preferences for AAC options in communication interventions for individuals with developmental disabilities: A review of the literature. Research in Developmental Disabilities. 32, pp.1422–1431.

WHO, W. H. O. 2001. International classification of functioning, disability and health (ICF). Geneva: World Health Organization