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Exploring the perspectives of people who use alternative and augmentative communication aids (AAC)

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Abstract. This paper outlines the clinical doctoral research plan (funded by HEE/NIHR Integrated Clinical Academic Programme) to engage the wide range of people who use alternative and augmentative communication (AAC) to understand the perspectives of users in order to develop a Patient Reported Outcome Measure (PROM) to evaluate equipment and services.

Keywords. alternative and augmentative communication, user perspectives, patient reported outcome measure

1. Introduction

Speech, language and communication (SLC) difficulties directly affect up to 20% of the population at some point during a lifetime [1]. People with SLC needs are at greater risk of social isolation and low mood than the rest of the population [2] which can impact on their ability to engage in relationships, occupation, employment and/or education [3].

Augmentative and alternative communication, or AAC, is one method used to support those people. AAC includes strategies that involve simple technology such as pointing to objects, letters or pictures as well as electronic or computer-based systems that turn messages into synthesised speech. Approximately 1 in 150 people in England (0.5% of the population) have significant communication difficulties and could benefit from using AAC [4].

Obsolescence and non-use of assistive technologies has been identified as a concern for a long time [5] and AAC is not immune to this phenomenon [6]. Obstacles to effective AAC use include the availability of devices, knowledge of family or carers and the level of support provided by AAC services [7]. What is not clear is why people engage with AAC or not, what outcomes are considered successful to people who use AAC and how services can support people to use AAC [8]. There are currently no

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consistently used outcome measures to evaluate the impact of AAC interventions [9] and few examples of user-reported outcomes described or recorded in the literature.

Current health policy promotes the inclusion of service users in the evaluation of services [10]. Engaging people who use AAC in using these traditional feedback methods can be challenging by virtue of their difficulties with communication and potentially, difficulties with physical access [11]. Specific strategies need to be employed to overcome potential barriers to inclusion for people who use AAC to engage them in both research and the evaluation of equipment and services [12].

The aims of this study are:

1) To develop a better understanding of the characteristics of people who engage with AAC and those who do not.

2) To identify what constitutes a successful outcome following AAC provision from the perspective of the person using the AAC equipment.

3) To establish whether there is a consensus amongst the population of people who use AAC to support the development of a patient reported outcome measure.

2. Method

This study will use a range of research methods and skills in order to gather information and opinion from available research literature and people who use AAC. Ongoing analysis of the data collected will inform subsequent stages resulting in an iterative and comprehensive appraisal of opinions.

2.1. Stage 1

2.1.1 Systematic review

A systematic review of literature will build on the recent review into barriers and facilitators to AAC use [9] and will identify how user engagement affects the outcomes of AAC use.

2.1.2. Qualitative data collection

Qualitative interviews will be carried out to gather data from people who use AAC at different stages of their journey through AAC services. The aims of this phase of the study are to develop a clearer understanding of the barriers and facilitators to engagement with AAC services and the use of AAC equipment as well as establish what the important outcomes from AAC intervention are.

2.1.2.1. Perspectives study

This phase will form the basis of a qualitative longitudinal cohort study. Participants recruited at the point of referral to NHS services will be asked to engage in a series of face to face interviews aimed at gathering data at different stages of their involvement with the AAC care pathway. Data gathered will provide information about the overall experience of people accessing AAC services as well provide some indication as to if and how perspectives change during the course of AAC intervention. It may also provide some insights into why people engage or disengage with services and/or AAC equipment and whether what supports people to use AAC and their projected outcomes, changes over time.

2.1.2.2. Retrospective study

Individual, face to face interviews will be carried out with people experienced in using AAC to support their communication in order to establish their views and opinions about the outcomes they regard as important from using AAC, how they define successful AAC use and what supported them to achieve these.

2.1.3. Analysis

A framework analysis approach will be used with both sets of data. It allows the use of *a priori* themes from the research question and objectives and from the relevant literature, while ensuring these themes are congruent with emergent themes. Analysis of the cohort study data will focus on themes around engagement and support, whereas analysis of data from experienced AAC users will focus more on descriptors of support and success.

2.2. Stage 2: Developing consensus

The development of a patient reported outcome measure involves the development of a list of items that represent the opinions of the group being evaluated, plus evidence that steps have been taken to ensure completeness of the concepts contained within the items [14]. Stage 1 of the project will generate a list of important outcomes for people who use AAC. Further ratification of items on this list may be required, depending on the depth of qualitative information attained during the first stage of the project.

2.2.1. Analysis

Analysis will indicate the extent to which consensus can be achieved across the population of people who use AAC as to what constitutes a successful outcome. These results will be used to develop a patient reported outcome measure which has undergone the initial stage of face-validity checking and can then be further evaluated for validity and reliability.

3. Results

A list of definitions of the types of support that facilitate people to use AAC will provide the basis upon which to develop further trials evaluating which supports are most effective and for whom. The consensus study will establish whether there are items that can be distilled from these checklists to produce a patient reported outcome measure (PROM) that reflects the diverse population who use AAC. The longitudinal cohort study will provide useful ongoing information about the experiences of people who use AAC as well as insights into the outcomes for people who do not engage in AAC.

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