

Communication Change in ALS: Engaging People Living with ALS and their Partners in Future Research

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For which topic were research priorities identified?

amyotrophic lateral sclerosis (ALS)

In which location was the research priority setting conducted?

Europe - United Kingdom

Why was it conducted at all?

Significantly, the communication needs of plwALS change over time. This might typically be described as a spectrum covering people with mild dysarthria, who use their speech and are understandable to most people, to those with little or no intelligible speech who may be totally reliant on AAC to communicate. This transition has to date received little attention. Inevitably communication changes as end of life approaches, with a decrease in all modes of communication including natural speech, gesture and AAC. There is no doubt that AAC is viewed as important by plwALS and their significant others. What we have yet to establish are expectations of communication and change over time by plwALS, what is most important to people about their communication changes, how best to support these changes and what interventions to support communication we should be researching. At present much of the evidence is survey or questionnaire based with a focus on the use of AAC rather than communication between plwALS and others.

What was the objective?

to involve people living with amyotrophic lateral sclerosis in the scoping and identification of research priorities related to the changes in ALS communication including the use of augmentative and alternative communication

What was the outcome?

a list of 4 research areas

How long did the research prioritization take?

October 2015 - November 2015

Which methods were used to identify research priorities?

focus group

How were the priorities for research identified exactly?

Step 1: topic guides developed for focus groups based on literature review. Step 2: focus groups: brainstorming of potential research ideas, 3 patients with ALS attended the first focus group of which 2 attended with their partners, 3 patients with ALS and partner dyads attended the second focus group (for those living with ALS and affected speech) with 2 additional partners of individuals who had lived with ALS and had since died. Step 3: data processing: thematic analysis.

Which stakeholders took part?

Patients with ALS at early and late stages of change to speech intelligibility and their families. 3 patients with ALS attended the first focus group of which 2 attended with their partners, 3 patients with ALS and partner dyads attended the second focus group (for those living with ALS and affected speech) with 2 additional partners of individuals who had lived with ALS and had since died.

How were stakeholders recruited?

Recruitment of participants was carried out via a single UK ALS centre. PlwALS known to the centre and who had previously indicated that they could be contacted about PPI opportunities were screened by a member of the ALS centre care team based on their last recorded The Amyotrophic Lateral Sclerosis Functional Rating Scale (ALSFRS) recorded speech score. Those with a score of 3 (detectable speech disturbance") or 4 (normal speech process") were assigned to Group 1 whereas those with a score of between 0, 1 or 2 on the scale (loss of useful speech" to intelligible with repeating") were assigned to Group 2. Potential participants in each of these groups were contacted.

Were stakeholders actively involved or did they just participate?

Stakeholders were mere participants of the research prioritization process; they were not actively involved in the process.