Lay summary

Speech difficulties are an early symptom of MSA and can have significant impact on people's quality of life. Although a few studies have recently shown that speech can improve after therapy, they used intensive therapy models that are not always possible to deliver under the NHS. Our study compared two alternative types of therapy. The first modelled the therapy often provided by the NHS, i.e. one individual session a week over 6 weeks. The second type, ClearSpeechTogether, consisted of a novel approach which combines individual with group therapy. Patients received 4 individual sessions over 2 weeks followed by 4 weeks of daily, patient led group practice resulting in 24 sessions in total, thus simulating intense therapy delivery without added workload on the speech and language therapist (SLT). Our study aimed to establish whether either of the two therapy types could have communication benefits for people with MSA-C (signal of efficacy), how acceptable the therapies would be to individuals (acceptability) and how feasible it would be to compare the two therapy types with each other in a larger trial to test their effectiveness (feasibility).

Each participant's speech and communication participation and confidence was assessed before and after therapy, and they were interviewed about their views about the therapy outcomes. Furthermore, the SLT delivering the therapy was interviewed about her views on the CST versus standard NHS programme and how well CST could be integrated into usual NHS practice.

The results were as follows:

- (1) Feasibility: We succeeded in recruiting the required number of participants (12 for each group). Dropouts stayed within acceptable limits. In the end we had 9 people completing all stages of the NHS arm, and 11 the CST arm. A number of participants required additional support with using the technology for the online meetings but everybody managed to join the sessions successfully.
- (2) <u>Acceptability</u>: We had 100% attendance at the NHS sessions, and 80% for the CST programme, which fell within expectations. Nobody reported any negative impact on their energy levels from the therapy. Participants reported that the therapy fully addressed their needs The SLT reported no issues in providing the therapy.
- (3) Signal for efficacy: Both types of therapy resulted in improvements for at least some of our participants in terms of the quality of their voice, how much breath they had available for speaking, and how well they were understood by others. The biggest improvements were observed for people's confidence and also how much their MSA affected them in various speaking situations. We saw improvements in these aspects even if their speech did not change noticeably. There was a small indication, that CST might be more successful in achieving positive communication outcomes than the standard provision, but participant numbers were too small to show this reliably. About 30% of participants showed no change post-therapy, but at the same time reported that their overall condition had declined between assessments. Many in this group felt that if they had not received therapy, their communication would have declined in line with the rest of their status. This suggests that maintenance of abilities might also be an important outcome to consider in studies with people with MSA and that overall health status is an important aspect to monitor in any future trials.

Overall, this pilot RCT achieved its aims. We succeeded in delivering an RCT involving a group of patients that are significantly impacted by their condition with severe disability and rapid progression of their ataxia. Given the excellent feasibility achieved we believe that a larger trial involving a wider group of people with ataxia, the majority of which will be less severely affected that the group studied would be very feasible, Results on the acceptability of both therapy types are

also promising, both from a patient and health care provider point of view. Finally, both therapies resulted in positive communication change in some of the participants, indicating that either of them has the potential to be an effective therapy approach for people with MSA. The outcomes of this study provide a clear rationale and justification for a larger trial involving patients with ataxia of diverse aetiology to investigate the effectiveness of ClearSpeechTogether and potential superiority over other approaches.