This is the scientific abstract of the MyARM study, presented at the UK Stroke Forum Conference at the ACC Liverpool, from 28-30 November 2017.

Title: ‘If it works, fine. If it doesn’t, have hope’: A qualitative study to explore individuals’ experiences of managing their severely affected arm after stroke

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Introduction – Few evidence-based treatments address the severely affected arm after stroke. Current practice is largely based on predicting recovery and prescribing interventions. However, there is a gap in our understanding of what stroke survivors themselves find helpful. The aim of this study was to explore stroke survivors’ experience-based strategies for managing their severely affected arm.

Method – Stroke survivors (age ranges from 20 to 80+ years, time post-stroke 6 months to 46 years) were recruited purposively via community networks. Participants shared their experiences in semi-structured interviews (n=15), a focus group (n=6) and an online survey (n=18). Data were managed using NVivo® computer software, analysed through thematic framework analysis by one researcher, and peer reviewed by the study advisory group.

Results – Participants enacted a multitude of professionally driven management strategies for their severely affected arm, and then chose to continue with what worked for them. This was further expanded through self-discovery and interaction with peers, by modifying, finding and adding new strategies. There was sadness and frustration at the loss of their arm, but also satisfaction, pride and self-confidence when progress was made. Participants described an attitude of not giving up on their arm and remaining positive and hopeful. Several participants described the negative impact when professionals predicted the arm would never improve, and such predictions were often rejected.

Conclusion – These findings extend the current evidence base beyond existing prediction-based biomedical practice models, and provide valuable ideas and possible content for a co-produced self-management resource in the future.