

Patient and Public Involvement (PPI) in Research – Case Study

Provided by:

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How patients and the public were involved

Study feedback session – May 2014

Background: The study was a randomised controlled trial with stroke patients coming in every day for 2 weeks (Monday-Friday) for 2 hours of physio whilst also receiving a type of brain stimulation called **transcranial direct current stimulation (tDCS)**, which uses constant, low current delivered via electrodes on the scalp (either real or “sham” – equivalent to a placebo in a drug trial). Clinical measures (e.g. measures of motor function) were taken at the start and then 3 follow up sessions (1 week, 1 month and 3 months post intervention). The main findings were that the training led to a major improvement in how well people could move their hands. There was also a smaller effect of whether or not people had real brain stimulation (tDCS) compared with placebo, suggesting that those who had real tDCS tended to improve even more.

The feedback session included a presentation of the results and discussion of the trial (led by study Principle Investigator Heidi Johansen-Berg), talks about current and future trials, and participants also completed a questionnaire about their experience in the trial. The total number of patients & partners attending feedback was 7 patients & 3 partners (10 declined to come and we didn't hear back from around another 6 patients)

The impact of involving patients and public in the study

The feedback session provided useful feedback that could help us for future research, including:

- Patients felt they would've been able to take part in study earlier than 6 months post stroke which is useful for us to think about for future studies
- Patients would've preferred trial to take place at the Oxford Centre for Enablement (OCE) as it's easier to park
- Patients enjoyed coming in for sessions and having extra motivation / help during their recovery
- Patients found out about this study through OCE contacts and Different Strokes website – useful for us to know about how to recruit for future studies

It was also good to see patients post research participation and how their recovery has been, and useful to keep in touch with patients to include for future projects.

The importance of involving patients and the public in research

It is vital for us to get feedback from patients and the public in order to better design future studies, and also is useful to detail in applications for further funding.

The biggest challenges in PPI and what might help to overcome them

- Travel – we found a handful of patients who were located a fair distance away from the John Radcliffe were unable/less enthusiastic to make the journey for the feedback session.
- Up to date contact information – some patients had moved or changed phone numbers etc so we couldn't be sure that our invitations reached everyone