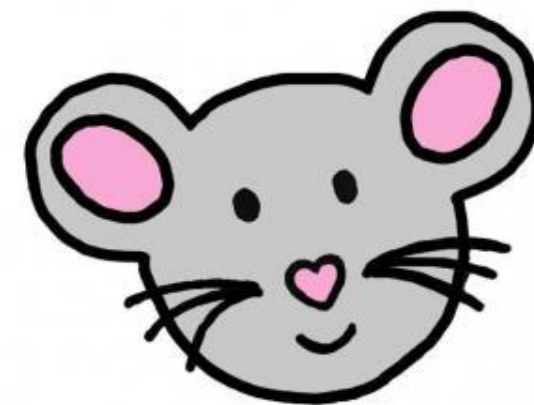


How patients and the public can shape research: the Mental Health Intervention for Children with Epilepsy (MICE) randomised controlled trial

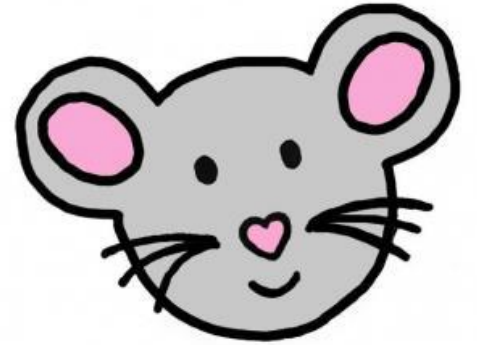


Great Ormond Street
Hospital for Children
NHS Foundation Trust



Introduction to MICE

- There are 4 work packages, WP1 and WP2 are complete and we are now in WP3 and WP4 stages.
- Randomised controlled trial.
- Effectiveness of remotely delivered CBT for children with epilepsy and mental health condition(s).
- Delivered from within epilepsy services (e.g. Assistant Psychologists, Nurses).
- Primary outcome: results on strengths and difficulties questionnaire (SDQ) at 6 months post-randomisation.
- Scores compared with children in the Treatment As Usual (TAU) arm of the study.





Introduction to the PPI group at MICE

What it's like to be a member of a PPI group



You Said

We did

How the PPI group shapes the trial

- **Dissemination:**
Producing a blog which is now published in Epilepsy Research UK



Parents of children with epilepsy share experiences of research involvement

The MICE Study PPI Group
Great Ormond Street Hospital for Children

This week, we have handed over our research blog to parents participating in the MICE Study Patient and Public Involvement (PPI) Group. The MICE Study is the Mental Health Intervention for Children with Epilepsy (MICE) at Great Ormond Street Hospital, led by Professor Roz Shafran and Professor Helen Cross. Earlier this year Epilepsy Research UK awarded an Endeavour Project Grant to Dr Sophie Bennett at UCL Great Ormond Street Institute of Child Health to build on the work of the MICE Study. We asked the PPI group to provide some insights into participating in research to help anyone considering getting involved in ERUK's **SHAPE EPILEPSY RESEARCH NETWORK**.

Here, in their own words, they describe why being involved in research is important and some share their own perspectives and experiences of mental health and epilepsy.

We would like to thank Emma, Andrea, Jemma, Bron and Ben from The MICE PPI Group for contributing to this article, and to Amy and Tyler for supporting this blog.

The MICE Study – Background

There is a significant body of evidence demonstrating that common mental health conditions are more prevalent in children with epilepsy compared with their peers. The MICE Study was set up at Great Ormond Street Hospital to trial the effectiveness of telephone-delivered cognitive behavioural therapy for young people. Epilepsy Research UK has recently funded further research involving the MICE Study, led by Sophie Bennett, to investigate whether treating mental health problems in children with epilepsy affects certain outcomes, such as education, health and parents' mental health.

- <https://epilepsyresearch.org.uk/our-research/research-blog/research-involvement/>

How the PPI group shapes the trial

Dissemination: participating in the production of a peer reviewed paper on how to deliver PPI remotely (currently in progress).

- 9 of our members answered questions about their involvement in the PPI group remotely.
- There is current research on remote delivered mental health interventions, but nothing on remote delivered PPI.
- In light of COVID-19 and lack of research, we felt it was important to look at the advantages and disadvantages.
- Aim to publish in 'Research for All' journal.

Lessons Learned

- When PPI is done well it can have a clear impact on research design, implementation and outcomes.
- Nobody cares more about improving treatment outcomes than the people who need those treatments.
- Being a part of the PPI group has taught me so much about my condition, provided support and helped me to feel listened to.
- How our members are truly altruistic, prepared to give up their time and energy to contribute to research that will benefit others in the future.



Any questions?

