

Chelsea and Westminster – Neurophysiology team

Improving the experience of having and EEG



Dr Sutapa Biswas, Consultant Neurophysiologist at Chelsea and Westminster, was keen to hear what her team could do to improve the experience of coming in to have an EEG. Many of the children and young people who attend the clinic had complex support needs, including non-verbal communication, and the team were curious about their experience coming into an adult-orientated service.

The team do not hold the ongoing relationship with the families so opportunities to get feedback about the experience of coming in for an EEG have been limited. This project offered a window to do some specific engagement work on this topic.

Space and Voice

The team worked with Epilepsy Nurses to share the information with families. Contact from staff that they had a current and ongoing contact with really helped to recruit families to get involved. Initially, the team intended to hold an after-school workshop for families to attend. The plan was to have some discussion and creative activities and then some snacks.

Feedback from the families was that as many of them lived quite a distance from the hospital so this would be tricky. However, they were very keen to share their feedback, especially if it would help other families.

The team changed the plan and agreed to call the parents/carers and get their feedback over the phone.

Dr Biswas called the families in advance, checked that they were still ok to speak and gave an overview of what we wanted to hear about. The calls were then made by a member of an engagement team with Dr Biswas. The conversations had a couple of prompt questions but were generally led by the parents sharing what they felt was important. Often, to put the experience of attending EEG appointments in context, they wanted to discuss their journey from first seizure to diagnosis. This was, at times, an emotional story to tell, and it was important to allow space and sensitivity for this.

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Providing feedback over the phone seemed to work very well for these parents. They were keen to talk, and this enabled them to participate whilst still managing their family commitments.

This approach didn't work so well for the children and young people. A number were not keen to speak to adults they didn't know on the phone during their free time. Obviously, it wasn't an accessible approach for children and young people who didn't communicate verbally. One child was happy to talk on the phone and gave some valuable feedback. However, it would probably have been a more fulfilling experience if they had been in person with a choice of ways to communicate their thoughts.

Audience and Impact

At the beginning of calls, it was explained that all feedback would be anonymised, and a short report would be written up with key themes that emerged from discussions. This report would be shared back with families, with Dr Biswas's team and with senior management.

Many of the recommendations were not expensive service adaptations but requests for sharing of tips from other parents, accessible visual materials that could help prepare children for appointments and some adaptations to the clinical environment to make it a more relaxing space, especially for children with additional sensory needs.

The feedback has been shared with the team, and there are plans to share it at a strategic level with commissioning teams and senior managers.

**Thank you to the team for being involved in
our pilot and sharing your experience.**

**To find out more, please contact
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