

# Children and Young People's Epilepsy Team, Hull University Teaching Hospital

## Improving clinical documentation for patients with young people



The Children and Young People's Epilepsy team at Hull University Hospital demonstrated the value of reaching out to a wider network to help support their engagement work get off the ground. Christine Bennet (Senior Epilepsy Nurse) and Dr Sandhya Jose (Consultant - specialist interest in Epilepsy) initiated the planning of their engagement project.

The team were keen to speak to young people about clinic documentation. Christine Bennet and colleagues made contact with their Integrated Care Board (ICB). Mike Foers, Community Integration and Transformation Manager (Children and Young People) was able to connect the team to the Local Authority youth service. These networks opened up doors to greater resources, expertise and support for their engagement activity.

### Space and Voice

The epilepsy nurses contacted young people who used the service to invite them along to a workshop to give their feedback and ideas on service improvement. Inspired by hearing from young people involved in the RCPCH &Us Impact and influence project, the team decided to broaden the invitation and invite young people to bring a friend or sibling along to the session. This helped to make young people feel more comfortable attending a new session.

The connection the team had made with their ICB and local youth services also had a direct impact on the space and voice aspect of their engagement work. The youth service was able to provide staff to facilitate the workshop as well as the use of a youth centre in the town centre close to transport hubs.

This was great as it was a more neutral and youth-friendly space to meet in the hospital. Christine and her team also felt that having youth workers lead the discussion was invaluable. They were much more informal and relaxed with a neutral person that the young people could speak frankly in front of.

The session had icebreakers, discussion activities and goody bags for the young people.

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### **Audience and Influence**

A key interest of the team was the clinical appointments and documentation that they provided to the young people after the appointment. Did they like coming in for appointments? Would they prefer remote? Was the documentation working for them?

Some of the feedback surprised the team. The young people did prefer to come in person to the appointment, but crucially, they had useful feedback about simplifying the documentation, so it was useful for them.

They also highlighted how important it was to have information and involvement of their friends and siblings as a key part of their support network. The young people were also keen on having a newsletter.

The team shared the feedback with their colleagues, and many of the ideas that the young people came up with have been possible to implement quite quickly. The clinical letters that are given out post-appointment are now simplified for the young people (although there is still some more detailed documentation provided by consultants). The team are looking into getting a newsletter up and running. Follow-up workshops are also being held with the young people to design information that they can give to their friends about their Epilepsy.

Christine shared how valuable the process had been. Her top tip for services looking to develop this work is to reach out to the wider network and keep an open mind.

**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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