

Paediatric Secondary Care Epilepsy Service, University Hospital Southampton



Supporting young people to lead the change – Youth Epilepsy Warriors

University Hospital Southampton provides us with an example of what is possible with the extra resource of an in-house youth worker. Marisa Findlay is an Epilepsy Youth Development Worker working with the Paediatric Epilepsy Team led by Consultant Paediatrician Dr Kate Pryde.

Marisa planned to get a group of young people together and imagined that they would problem-solve issues around the waiting room and waiting time, which young people had previously identified as 'dead time'. However, the plan changed significantly once the young people took charge of the project!

Space and Voice

Marisa worked hard to recruit young people for the project. This didn't always prove easy!

"At one point it didn't look like the project was going to get off the ground. Young people were showing initial interest but not completing the sign up forms"

Marisa went back to the drawing board and started a different approach. The team tried emails, posters and fliers handed out at the clinic and through perseverance, they eventually had a group of five young people keen to do something.

The geographical spread and the challenges around finding times and dates that the group could easily come together (and when parents could help with transport to get there) meant that the initial meeting had to be online. Follow-up meetings were in person.

One thing that helped create a safe space and support young people's voices was that the group of five were encouraged to take ownership of the project. What did they want to do, and, what was the issue they wanted to focus on?

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The young people renamed their group the Young Epilepsy Warriors and helped to set ground rules around their group. It was stressed that the group was theirs to take ownership of, and the team would just help facilitate the outcomes. These included making sure everyone who wanted a say, had one and was listened to. The space was non-judgemental – no idea is a silly idea.

Soon, the young people ditched the initial idea of looking at waiting rooms. Overall, they said they were very happy with the clinical service that was provided. Their issues were more out in the community, specifically at school. A common theme that emerged through discussion was that friends, teachers and other pupils had a very stereotypical view of epilepsy. The group thought that others had little understanding beyond a tonic-clonic seizure. The group believed this may have been fuelled by ignorance, and ignorance often equals fear, which can lead to ridicule. The young people wanted to focus their energy on doing something about this. They wanted an approach that was accessible, conveying in their own words what living with epilepsy was like, and would be attention-grabbing.

They decided to make a short film that could be shared on TikTok or social media.



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Audience and Voice

A key audience that needed to hear and be open to the young people's ideas was the youth work team itself. Marisa's role became that of an advocate, supporting the young people to make their idea happen. This involved working with the Hospital Trust social media manager and liaising with medical teams to ensure that all information in the video was checked by the medical team to ensure it was factually correct.

The ideas and feedback from the young people were also emailed out to the wider Epilepsy team.

The key impact of this project is that young people were empowered to lead the changes they wanted to see, rather than having the team decide on their behalf. Moving forward, the team recognizes the importance of ensuring that change is driven by the needs and desires of users, rather than assumptions about what needs improvement.

Rather than dismissing the idea of a TikTok video as not being part of the clinical service, the resources and support of a youth work team were available to help the young people make this happen. As a result, the team has added this resource to their welcome pack, which is written by young people. The young Epilepsy Warriors have moved onto their next project. They are creating another video that highlights what young people with epilepsy *can and* do achieve, rather than focusing on limitations. Watch this space!

You can watch and share the Young Epilepsy Warriors video [here](#)

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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