

Youth Epilepsy Warriors: A Collective Voice for Change

In 2024, University Hospital Southampton (UHS) was invited to take part in the RCPCH *Impact and Influence in Epilepsy* pilot study, which explored how young people could be meaningfully involved in shaping a better experience for themselves as service users. The project included visits to RCPCH Headquarters in London and opportunities to collaborate with epilepsy teams from across the country. Southampton participated as a secondary care service and were the only organisation to include a dedicated youth worker as part of the project.



Grounded in the Lundy Model of Participation, the study focused on creating safe and supportive spaces where young people could express their views freely, be listened to, and influence decision-making. Importantly, no predetermined boundaries were placed on their ideas beyond what was realistically possible within the service, ensuring that their priorities—rather than those of professionals—guided the work.

From this approach, a small group of young patients came together and named themselves the **Youth Epilepsy Warriors (YEW)**. While they expressed that they were very happy with the care they received, one recurring theme emerged: the significant negative impact caused by the lack of knowledge and understanding about epilepsy among their peers and teachers.

In response, YEW developed the idea of producing a short film for social media to challenge myths and raise awareness. They wanted to show what living with epilepsy is really like, in the hope that better understanding would reduce stigma rooted in ignorance. The group met both online and in person to create the video, developing their own ideas, writing their own content, and completing the filming independently, seeking guidance only when needed. They have since produced a second film, celebrating their achievements and focusing on what they *can* do rather than the limitations they sometimes face.

Throughout the project, it became clear that the young people were not seeking major changes to the service itself; rather, they wanted to have a voice—and for that voice to be heard.

YEW have continued to meet and recently explored using art as an expressive outlet. Through organic and free creativity, four young people created a shared artwork representing their collective voice on canvas.

For more information, please contact and_us@rcpch.ac.uk.