

#VoiceMatters - Working with children and young people in the Epilepsy12 audit and quality improvement in paediatric epilepsy care

Involvement

The Epilepsy12 Youth Advocates are epilepsy experienced or interested children, young people, families, and an epilepsy specialist nurse. In 2021/22 this has included 156 hours volunteered by 10 young people.

They volunteer together to shape Epilepsy12 and to lead improvement activities with families and epilepsy services.



Communication & accessibility

Epilepsy12 has produced two guides aimed at patients and parents. In 2022, the audit team worked with the Youth Advocates to co-design a new leaflet ([print](#) | [online](#)). It uses language and content that the Advocates felt would be meaningful for children newly diagnosed with epilepsy to support their own care. Resources are on a [patient webpage](#).

In 2022, Epilepsy12 published one-page '[clinic posters](#)'; local summaries of audit results with brief descriptions and clear infographics. They are designed for services to share key results with patients and within their Trust/Health Board/ICS.

Epilepsy12's [2022 conference](#) focused on patient-led learning from the Youth Advocates, with research and improvement for difficult topics such as SUDEP and sodium valproate prescribing. Over 400 participants attended.

The Youth Advocates represented their volunteering, epilepsy journey and the work of the audit on the main stage at the 2022 RCPCH conference, where 3 advocates spoke at the opening plenary to 1700 paediatricians and allied health professionals in June 2022.

Impact

- Two new key Performance Indicators for the audit have been developed for 2022 which focus on **support for better mental health** in epilepsy care. These indicators were chosen by the audit's Methodology group in response to the emphasis placed on mental health by the Youth Advocates; both in their advice to the audit, and in their quality improvement projects.
- A topic kept popping up in group discussion, and from the audit data: **school care plans**. All the Advocates agreed that having good support at school, especially in your first year of having epilepsy, can make all the difference to your future. In 2022 they developed '[take home tips](#)' from the patient perspective, a [school care plan template](#), and [signposting](#) to other tools from Epilepsy Action, Young Epilepsy and RCPCH. Available for free the tips and template can be used by clinicians, as well as patients themselves.
- [RCPCH EQIP](#) launched new waves in 2022; delivering a virtual paediatric epilepsy **quality improvement collaborative** of NHS Trusts and an ICS region. Working collaboratively with stakeholder charities Epilepsy Action, Young Epilepsy, RCPCH &Us delivered their [patient engagement training](#) to the clinical teams taking part in EQIP. This aimed to provide the skills, [engagement tools](#), and case study examples to support the EQIP teams to involve patients in both their EQIP improvement project and in their services longer-term. A version of this training is free online, so it is also available to teams not taking part in the EQIP collaborative. EQIP teams from [Barts Health NHS Trust](#) and [Doncaster and Bassetlaw NHS Foundation Trust](#) made **improving patient and family engagement** the focus of their locally-developed improvement projects.
- The Advocates developed the 'Clinic Chat Check List'; a self-assessment for services to review and improve their support for children and young people with **worries and anxieties** linked to epilepsy. Eight clinics took part, working with the Advocates who fed back on the self-assessments. The Youth Advocates then shared the Check List process and learning at [the 2020 Epilepsy12 conference](#), in the [2021 Epilepsy12 annual report](#), and recently published a '[how to](#)' guide for other services to use.
- RCPCH &Us facilitation of the Advocates group helps ensure the volunteers are both enjoying and benefitting from the activity. Involvement in the Advocates is supporting children and young people to develop their **confidence, leadership, and skills**; using their voice to influence change and exercise their UNCRF rights within and beyond the Epilepsy12 audit (such as the Youth Advocates who also contributed to [children's mental health week](#) in 2022).

Sustainability

The Youth Advocates meet regularly as a group, both virtually and in person. Membership of the group is open and flexible - children and young people choose when, how, and how long they participate - which helps sustain volunteering and engagement in the long-term.

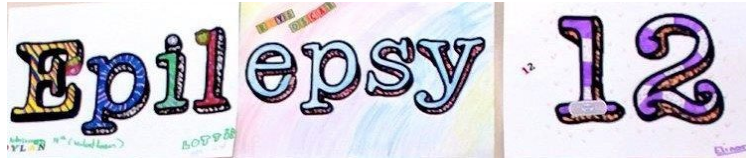
Typical activities for the group include discussion and planning of:

- their priority themes (which in 2021/22 have been epilepsy service support for worries and anxieties, and school care plans)
- developing and delivering improvement activities,
- reviewing Epilepsy12 results, planned activities, changes to the dataset or scope, plans for improvement resources/projects, and any publications; providing advice back to the Project Board and Methodology Group (e.g. on issues like the performance indicators and national recommendations).

The group have shared their work through Youth Advocate publications, in the Epilepsy12 annual reports, on social media (accounts in pink below), and through the RCPCH and Epilepsy12 conferences.

What next? The Advocates are continuing to have a central role in deciding how Epilepsy12 develops and reports. They are agreeing new priorities and improvement activities for 2022-24.

Epilepsy12 is working on patient access to their audit data, and new engagement on children's experiences of epilepsy care for groups affected by health inequality or who have additional learning or mental health needs.



Youth Advocates' reflections (2022)



“ As youth advocates we have made a difference by sharing our knowledge of epilepsy through our school experiences ”



Epilepsy12 Youth Advocates
Birthday Reflections



“ As a youth advocate I have shared the best and hardest parts of my epilepsy journey to help make it better for others ”



Epilepsy12 Youth Advocates
Birthday Reflections



“ As a youth advocate I have been able to normalise epilepsy slightly more at a time where stigmas in illnesses are so important to break down. ”



Epilepsy12 Youth Advocates
Birthday Reflections



"Working with the Epilepsy12 youth advocates group is very inspiring. You see first-hand that young people have wonderful ideas, but mostly importantly for me, they want to make change that helps everybody".

Jill Conium
Clinical Nurse Specialist Children's Epilepsy



#VoiceMatters



“ As a youth advocate I have helped start conversations about epilepsy and mental health ”



Epilepsy12 Youth Advocates
Birthday Reflections



“ The impact for me has been seeing how it started off so small with a few clinics to how well known it is nationwide, we're helping so many patients and families! ”



Epilepsy12 Youth Advocates
Birthday Reflections



“ We have made a difference by influencing the way paediatricians think of epilepsy ”



Epilepsy12 Youth Advocates
Birthday Reflections



“ As youth advocates we have made a difference by influencing other health professionals, spreading the word, raising awareness and working with specialist nurses and clinics. ”



Epilepsy12 Youth Advocates
Birthday Reflections



RCPCH_and_Us
@RCPCH_and_Us

Having peer support when you have a long term condition is important to share experiences. The @Epilepsy_12 youth advocates said it gives them confidence & empowers them living with #epilepsy when they can help others too.

#Volunteering #MentalHealth #VoiceMatters
@RCPCHtweets