

### Your Epilepsy12 audit news

The Epilepsy12 Project Team would like to thank the NHS Health Boards and Trusts in England and Wales for their continued support and participation in the Epilepsy12 audit, particularly during these challenging circumstances. We recognise the significant time and effort dedicated by NHS administrators, clinical audit department staff, data analysts, doctors, nurses, EEG teams and others to complete the audit. We thank you for your dedication to collect information and support the improvement of paediatric epilepsy services.

We are pleased that the RCPCH has been re-commissioned by HQIP to deliver the next round of Epilepsy12 from 1 April 2022 to 31 March 2025. It is positive that paediatric care is being recognised as a continuing priority. As the only national project investigating paediatric epilepsy, Epilepsy12 plays a fundamental role in improving the quality of epilepsy care provided to children and young people in England and Wales.

As we enter Round 4, the project team are working on improving the way we collect and report audit data. We have reviewed the feedback received from the Epilepsy12 and OPEN survey on user experience and incorporated your comments into our plans. In round 4 you can expect to see:

- Streamlined data collection; focused on the first year of care stage of children and young people (0-24 years) with a newly diagnosed epilepsy
- An increased focus on mental health support, transition service, care planning and input from tertiary services and epilepsy specialists
- Support for quality improvement at local, regional and national levels
- Regular reports, analyses and patient information
- Participation from children and young people to ensure they have a say in the audit and their care.

### Publication of the 2022 Combined Clinical and Organisational Audit Report

The Epilepsy12 project team are awaiting a confirmed publication date for this years' national report, however this is expected for Summer 2022. This report describes results from the 2021 organisational audit and cohort 3 of the clinical audit and includes the key findings and recommendations from our analyses.

We are preparing Trust/Health Board summary reports and clinic posters and a patient and parent guide to the audit to compliment the annual report. These resources will be available once the national results are published.

### Data submission for cohort 4 and 5

Thank you again for your data entry over the past 12 months that has made this national report possible. Please continue to **register and enter data for patients in Cohort 4** – patients with a first paediatric assessment between 01 December 2020 and 30 November 2021. You can **also register and verify patients in Cohort 5** - first paediatric assessment between 01 December 2021 and 30 November 2022.

For more information on how to use the platform, please refer to the user guides on our [website](#), or contact the Epilepsy12 team at [epilepsy12@rcpch.ac.uk](mailto:epilepsy12@rcpch.ac.uk) for assistance.

# SAVE THE DATE: 2022 Epilepsy12 & OPEN UK National conference

The fifth annual Epilepsy12 and OPEN UK annual conference will take place on **Wednesday 21<sup>st</sup> September 2022**. The event will take place in a completely virtual format and will begin at **12:30 pm**. We will be in contact soon with details on themes, speakers and how to register. You can expect to hear about:

- The **Epilepsy12 Youth advocates** and their project on care planning
- Work being overseen by the **NHS England Epilepsy Oversight Group**
- **SUDEP Action's** work on their Children's Checklist project
- A study exploring **sodium valproate use in Epilepsy**
- And exciting project updates from **Epilepsy12 and OPEN UK**.

## Call for poster abstracts – Deadline: Monday 11 July 2022

Have you been working on an improvement project, or have innovations and ideas to share with the epilepsy community? Please send us a short abstract (maximum 500 words) describing your work to [epilepsy12@rcpch.ac.uk](mailto:epilepsy12@rcpch.ac.uk) by **5pm on 11 July 2022**.

Abstracts should include: author(s), title, background, aims, methods, results, and conclusions. Not included in the word limit: please give brief details about the funding of the work, where applicable, and select which topic area is most relevant to your work.

NHS England and NHS Improvement



OPEN UK

Organisation of Paediatric Epilepsy Networks in the United Kingdom



# EPILEPSY WORKING



NHS England and NHS Improvement, in collaboration with Young Epilepsy and OPEN UK, are forming working groups for Children and Young People Epilepsy in the following areas:

- **Mental Health:** Access to mental health screening and psychosocial support
- **Tertiary Care & CESS:** Referrals into tertiary services and epilepsy surgery
- **Variation in Care:** Addressing variation in care delivery (e.g. access to epilepsy specialist nurses)
- **Transition Care:** Improving transition care from paediatric to adult epilepsy services (dates TBC)

The aim of the working groups is to improve epilepsy care for children and young people, and feed into the National CYP Epilepsy Oversight Group at NHS England and NHS Improvement. Each working group session is expected to run for 1.5 hours, every 3-4 weeks. If you are interested in joining these working groups, please complete this [short form](#) confirming your session availability. Please cascade these details to your networks, so that membership can be broad in terms of job roles and geography.

# Epilepsy12 Youth Advocates

Following the success of their [‘Clinic Chat Checklist’](#) project, our group of epilepsy experienced or interested children, young people and families have been hard at work on their new venture. The Epilepsy12 Youth Advocates agreed on the importance of having good support at school and were shocked to see that only 32% of children and young people had individual school healthcare plans in their first year of care ([Epilepsy12 national report on 2019-20 data](#)).

By reviewing and discussing the importance of school care plans, the Youth Advocates were able to design an example care plan. This is easy to use and will support patients, families, teachers and friends feel more confident about epilepsy experiences. The plans are designed to be holistic, relevant, and include information on school, seizures, aspirations, and mental health.



The Youth Advocates also have some take home tips for individual healthcare care plans:

- **Keep it personal**
- **Keep it relevant**
- **Keep it visual**
- **Keep it up to date**
- **Keep it short but useful!**

Find out more about the Epilepsy12 Youth Advocates’ on their [website](#) and download their [Example Epilepsy Care plan](#).

## RCPCH EQIP

Epilepsy quality improvement programme

### 2022 RCPCH EQIP – Innovations to improve care for paediatric epilepsy patients event

On the 17 March 2022, almost 20 paediatric epilepsy service teams took over 150 delegates on their quality improvement journeys. The EQIP teams showcased their activities, celebrated their achievements, explained what they learned and how they adapted through the COVID-19 pandemic.

The successful event fostered important shared learning, which was Chaired by Mr Mark Devlin, CEO of Young Epilepsy, who facilitated stimulating Q&A sessions around project outcomes, lessons learnt and ideas on how quality improvement can be sustained in future.

Presentations on the day covered a variety of QI topics such as the following: reducing waiting times for new referrals, SUDEP discussion, mental health support pathways and establishing a transition service, to name a few!

Teams shared their honest experiences during their journeys, which was well received by the audience and resulted in enthused interest. Delegates fed back that they left the event with ideas from the showcase to begin implementing improvements within their own local services.

Access team event posters and video presentation from the event today! Find out more information about the programme by visiting the [EQIP website](#).

