

Epilepsy12 &Us

Giving a real voice to children, young people and families as part of a national audit

It all starts with rights:

The 54 articles of the United Nations Convention on the Rights of the Child (UNCRC) concern the survival and well-being of children, their development, protection, and participation in social life. The articles provide a framework for all engagement work undertaken by the Royal College of Paediatrics and Child Health (RCPCH), for example, Article 12 indicates that children have the right to be involved in decisions that affect them and Article 24 which states that children have the right to the best health care.

United Nations – Rights of the Child

ARTICLE 12, THE VIEWS OF THE CHILD

“Every child has the right to say what they think in all decisions affecting them, and to have their views taken seriously.”

ARTICLE 24, HEALTH AND HEALTH SERVICES

“Children have the right to good quality health care – the best health care possible – to safe drinking water, nutritious food, a clean and safe environment, and information to keep them healthy.”

The RCPCH believes that children and young people with epilepsy and their families are the ones who should be shaping the future of paediatric epilepsy services. The Children and Young People’s Engagement Team at the Royal College of Paediatrics and Child Health (RCPCH) works to ensure that the voices of children, young people and families are making a difference in child health and healthcare for young patients. Through the RCPCH &Us network for children, young people, families, we actively seek and share their views to influence and shape policy and practice.

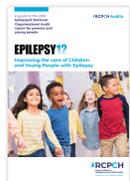
Epilepsy12 was established in 2009 and has the continued aim of helping epilepsy services, and those who commission health services, to measure and improve the quality of care for children and young people with seizures and epilepsies. Round 3 of the audit began in April 2017 and runs until March 2021.

Epilepsy12 has four main elements:



Organisational Audit

A yearly snapshot of the organisation and structure of individual Health Board/Trust paediatric epilepsy services. Also reported at Organisation of Paediatric Epilepsy Networks in the UK (OPEN UK) regional paediatric epilepsy network and national (England and Wales combined) levels.



Clinical Audit

Focus on initial assessment and first year of care for children with a new diagnosis.

Children & Young People Engagement Plan – Epilepsy12 &Us

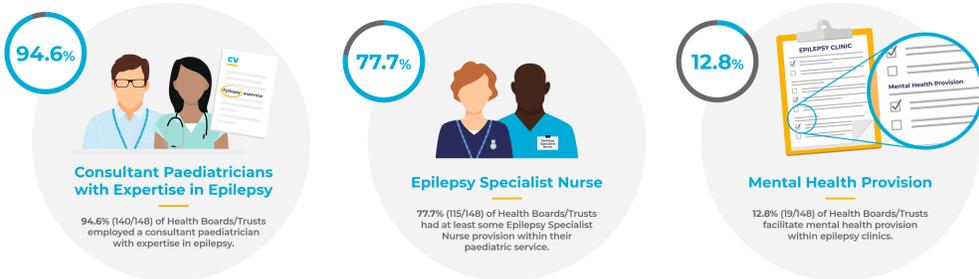
Children & Young People-led activities which align with project aims and activities.

Quality Improvement Activities

A range of Quality Improvement (QI) activities and a focused QI programme set by the Epilepsy12/OPEN UK QI Advisory Group.

What Epilepsy12 identified:

The 2018 Epilepsy12 Organisational Audit National Report, published in January 2019, identified a number of key findings and recommendations:



For Round 2 of the audit, children and young people with epilepsy, and their parents/carers, were invited to complete a Patient Reported Experience Measure (PREM) questionnaire on their experiences of care from their local epilepsy service over the previous year.

Some key findings were:

Patient Reported Experience Measure (PREM) questionnaire results



What we did:

Between April and June 2018, the RCPCH CYP engagement team visited ten epilepsy clinics across the country and engaged families in ‘clinic chats’. These were about “creating the best epilepsy service”. In total, more than 130 children, young people and families took part and gave their views on ‘service contactability’ and family mental health. Visits to charity ‘Family Days’ also took place in two locations.

The Children and Young People’s Engagement Team worked with children and young people through art-based activities, whilst parents shared their views and wishes in a forum meeting. Children as young as three years old contributed. They said:

“My epilepsy specialist nurse was fabulous throughout my care, putting on social events for patients and families. Sadly, it’s not the same for everyone and now being in adult care, it’s a completely scary journey.”
Epilepsy12 Clinic Chat

“Sometimes living with an invisible illness, it can seem that seizures are unstoppable. But looking at the results of the clinic chats, the children and young people are the ones who are unstoppable.”
Epilepsy12 Youth Advocates

Sibling carers aged 3 – 11 also contributed views and created Epilepsy Superheroes who could be on hand with super powers if someone had a seizure.



Epilepsy Ed

His superpower is to have magic medicine fingers to get medicine to the person quickly, along with rocket shoes to ensure he gets there super-fast. He also helps people come out of their seizure.

Sibling Carer, 10 years old



Super Epilepsy

Her superpower is to get to the person with epilepsy within 5 seconds to give the tablets straight away, helping to make them feel better.

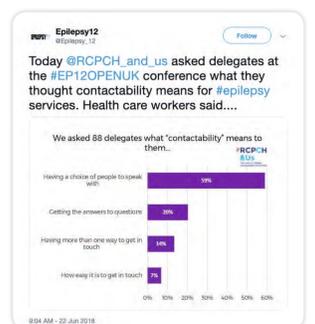
Sibling Carer, 7 years old



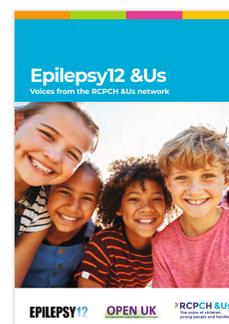
Reports from clinic chats were reviewed by Epilepsy12 youth advocates who identified top priorities via thematic analysis as follows:

- Schools (support, good care plans, awareness, training, visits from nurses)
- Support for worries and anxieties (Why me? transition, mental health, messages of hope and coping strategies)
- Face to face support (value of group work / support groups, engagement sessions, parent/carer groups, young people groups, more time with health workers)
- Positive adult relationships (school, clinicians, specialist nurses, family, support workers)
- More services (mental health and wellbeing, weekends/evening non-emergency support, home visits, support groups)
- Practical help (lifestyle tips, family-based training, coping mechanisms, products to explain epilepsy to children)
- Emerging topics (employment, independence)

Two of the Epilepsy12 Youth Advocates delivered a 75-minute session on the clinic chat themes at the Epilepsy12 National Conference in June 2018 to over 160 paediatric epilepsy specialists. This CYP-led session received overwhelmingly positive support from attendees. During their session the Youth Advocates posed a number of questions to attendees.



What's next:



Launch of the Epilepsy12 &Us Youth Advocates' Report

Read the resulting Epilepsy12 Youth Advocates' Report & find out how they want to get in touch with services, the kind of support they want to receive, their best experiences and their ideas for the future.

Quality Improvement Project

The Epilepsy12 Youth Advocates have been developing their own quality improvement project relating to “Clinic Checks” that they will undertake in paediatric epilepsy services across England and Wales to assess the support that they provide for anxieties and worries. They will report on their progress at the 2019 Epilepsy12/OPEN UK National Conference in London on 17 June 2019. Look out for a film of their session on the Epilepsy12 project website soon: www.rcpch.ac.uk/epilepsy12

Contact us or find out more:

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