

# HQIP Case Study:

## PPI in national clinical audit – Submission to the Richard Driscoll Memorial Award 2018

This submission demonstrates:

Patient – led activity

Impact from PPI

Embedded involvement to sustain QI

**Date:** Autumn 2018

**NCAPOP:** Epilepsy12

**Organisation:** Royal College of Paediatrics and Child Health

**Website address:** <https://www.rcpch.ac.uk/epilepsy12>

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### Brief background of the project

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.

Epilepsy12 is delivered by the Royal College of Paediatrics and Child Health (RCPCH) and sits within the National Clinical Audit and Patient Outcomes Programme.

Children and young people, parents and epilepsy charity representatives were included in the development of the methodology for all rounds of the audit and are represented on the project methodology and dataset group and project board. The RCPCH published national reports of rounds 1 and 2 of Epilepsy12 in 2012 and 2014 respectively and round 3 began in April 2017.

The national report of round 2 identified some significant improvements in care, but also highlighted that concerns remained about the gaps and variations in care across geographical regions.

For Round 2, children and young people with epilepsy, and their parents and carers, were invited to complete a Patient Reported Experience Measure (PREM) questionnaire on their experiences of the care that they have received from their local epilepsy service over the preceding 12-month period.

PREM questions were derived from surveying the views of young people with epilepsy through workshops coordinated by national voluntary sector groups. The questionnaire was designed to ensure consent, confidentiality and to directly capture the perspectives of young people. The RCPCH Youth Advisory Panel critiqued the PREM tool ensuring clarity and appeal.

2,335 completed PREM questionnaires (from 145 Epilepsy12 units) were returned and some key findings of the subsequent analysis of the views of children and young people and their parents/carers were:

- 88% said they were satisfied with the overall care they receive from their epilepsy service
- 20% of parents/carers said staff are not good at working together with others e.g. GP, school or nursery
- 62% of children and young people asked felt there weren't appropriate activities for their age in the waiting area
- 37% said the information they were given was hard to understand

## Aim

At the start of round 3 of the audit in April 2017 the project methodology group and project board members reflected on the work that had been carried out on the PREM for the previous round. The project team then worked with the RCPCH Children and Young People's (CYP) Engagement Team on the design and scope for a CYP Engagement Plan for round 3.

As a result, and in order to keep children and young people at the centre of everything that Epilepsy12 does, the project team and RCPCH CYP team agreed to run a series of engagement sessions with children and young people to enable effective involvement in;

Audit design – commenting on what the audit performance indicators mean to them, particularly indicators relating to specialist nursing, care planning and school healthcare plans which will support future PREM development. This would also provide context to project board members on the individual impact the audit could have on children and young people living with epilepsy if quality improvement initiatives are actioned at local, regional and national levels by the wider epilepsy community.

Audit delivery – supporting the development of publicity and promotional items to help share information about the epilepsy 12 programme with patients, parents and clinicians. Encourage people to take part, share their ideas and options and help shape social media campaign messaging for national awareness days.

Dissemination of audit findings – supporting development of CYP-focused materials relating to the audit findings and provide feedback on how their results have contributed to the national programme.

## Planning and delivery

Between April and June 2018, over 130 children, young people and families took part in clinic chats run by the RCPCH CYP Engagement Team to collect views on 'service contactability' (identified as a result of the review of the last 2 audit cycles) and family mental health (an emerging area for consultation).

10 hospitals were visited and two charity family days were held in partnership with Epilepsy Action, with children as young as 3 contributing and up to 25 with parent/carer views also being captured. Each clinic chat setting had a near verbatim internal report of views shared and these were reviewed by a small group of Epilepsy12 youth advocates aged 15 - 20, who conducted a thematic analysis to identify key themes.



*Owen and Rachael, RCPCH &Us members and Epilepsy12 youth advocates, delivering a 75-minute session on the themes identified from the Epilepsy12 clinic chat activities at the inaugural Epilepsy12/OPEN UK National Conference in London on 22 June 2018*

## Impact

Epilepsy12 youth advocates' top priorities were identified based on a thematic analysis of clinic chat reports as follows:

- Schools (support, good care plans, awareness, training, visits from nurses)
- Support for worries and anxieties (Why me? transition, mental health, school support, 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 to have time for questions)

Other regularly occurring themes;

- Positive adult relationships (school, with 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 use to explain it to children or others)
- Emerging topics (employment, sleep, independence)

Other important points of interest were responses from sibling carers aged 3 - 11, who created Epilepsy Superheroes who could be on hand with super powers if someone had a seizure.



*Epilepsy12 Clinic Chat "Superheroes"*

Two of the Epilepsy12 youth advocates then created a 75-minute session on the themes identified from the clinic chats activities and delivered it at the inaugural Epilepsy12/OPEN UK Conference on 22 June 2018 to over 160 paediatric epilepsy specialists, patient charity members and healthcare commissioners. This CYP-led session received overwhelmingly positive support from attendees as evidenced by post event feedback survey responses.

The next phase of the engagement work (September 2018 to August 2019) will focus on developing the Epilepsy12 Youth Advocates to work within a small number participating Epilepsy12 units. They will review audit data from a CYP perspective, receive training in children and young people's involvement in service design and identify their own quality improvement projects. An update on these activities will be shared at the 2019 Epilepsy12/OPEN UK National Conference.

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**Project:** Epilepsy12

**Team involved:**

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Owen, RCPCH &Us member and Epilepsy12 youth advocate

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