Case studies
Condition based individual engagement

What was issue?
Organisations needed to understand more about the needs, wishes and views of young people with epilepsy in order to inform future thinking around services, the national audit programme and joint working. They had identified through the first 6 years of audit data that there challenges around contacting services, so this was the first line of enquiry.

We ran a number of in clinic discussions with patients and families 1:1 and also visited charity family days to do group work activities. Across all of them we were exploring how they contacted services and what their wishes or hopes were for epilepsy care.

Opportunities or limitations of activity? (Time, resources, impact etc)
Opportunities: access to clinics through RCPCH Members and the Epilepsy12 Audit, good working relationship with charities, support from the programme board and team to think through what we were asking and how it was going to be used to make a difference, recruiting patients into the project group through the clinic chats

Limitations: getting coverage across the full audit area to be truly representative, hospitals being able to support our access to clinics and patients (some needed honorary contracts, others needed new DBS checks, others were open access), creating a method that didn't' add burden or worry to patients and families taking part and that kept their views anonymous.

Which children or young people?
Children and young people with epilepsy, their siblings and parents/carers.

Recruitment plan?
Clinics in 10 different parts of the country chosen for their different demographic e.g. ethnicity, geography, clinic type. Working closely with a charity, we were also given access to family activity sessions in different parts of the country.

What did you (professionals) hope to achieve?
Identity themes/trends/priorities for improving services, understanding the challenges around contacting services to then create quality improvement approaches with the audit team, to have voices influencing thinking in the audit programme.

What did children /young people hope to achieve?
A chance to chat, to make a difference and to have fun!

How did you do it? (method)
Letters issued explaining clinic chat approach, 1:1 (1:family) conversations using trigger materials like a gingerbread person, bear cards, objects, drawing, stickers and discussion. Group work sessions were discussion based (semi structured interviews) with parents/carers and art based with children and young people.

Condition based individual engagement

How did it impact change?

We were able to understand the contact needs for families and share with the audit team. We picked up great needs around other areas of support and access which were then prioritised by the Epilepsy12 Youth Advocates who identified a quality improvement social action project that became their focus for 18 months on support for worries and anxieties.

What worked, what didn't, limitations?

Being in clinics and working with charities was a brilliant way to go to where children, young people and families were, rather than expecting them to fill out a survey or come to a focus group that we were putting on. It meant that our engagement rates were higher, we were able to unpack comments that came up in a way that you can't with a questionnaire and we were able to do something fun and engaging, even in 5 minutes. It also helped to give people something to do while they were waiting and made them feel valued and important in being able to influence thinking.

It was more challenging than expected to recruit people from the clinic chats to the project, partly due to not taking details in the sessions on purpose (GDPR, not wanting people to feel like it wasn't anonymous) so we gave them postcards with our details to then get in touch with but only a handful did. At times there was real issues being raised by patients and families that we wanted to then support and deal with, so we created a signposting resource to give out and personalised links in the discussion so that if they raised they were struggling with benefits, or EHCPs at school we could give them links to get more help with.

How did you celebrate / reward young people input?

In chat we thanked them, explained where it will be used, gave a signpost card and goodies (pen, fluffy bug). There was no sign up to the project (by design) but CYP involved as a cohort were thanked in the report, on social media and at the Epilepsy12 OPEN UK conference.

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