

Developing a first seizure telephone clinic

Royal Berkshire NHS Foundation Trust

RCPCH Epilepsy Quality Improvement Programme project team:

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National audit results included within this case study acts as a guide only to performance standards. The service improvements made during the EQIP cannot be entirely attributed to the reported results in the Epilepsy12.

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Project aim:

95% of children and young people presenting in A+E with a first fit will have telephone contact from an epilepsy nurse within 2 weeks of presentation by May 2020.

Background:

Children and young people presenting with a first seizure at Accident & Emergency, in most cases, are not seen for follow-up by paediatric epilepsy clinics and instead are given a first-fit information sheet by the reviewing trainee. A first seizure clinic is not currently in place at Royal Berkshire Hospital, and currently the service team is unaware of the number of children and young people presenting with a first seizure via GP referral.

Area of focus:

This project will be a stepping stone to developing a first-fit clinic in line with NICE guidance by standardising processes that will:

- Identify the number of referrals and, therefore, the capacity required.
- Confirm good safety advice is being delivered in A+E.
- Provide a point of contact between patients/families and the epilepsy CNS.
- Provide an additional safety net by checking for other types of seizures being reported by parents/carers.
- Feed into the business plan to request the addition of a full-time clinical epilepsy nurse specialist.

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Changes

- Trialled the development of a telephone service with the aim of providing follow-up calls to families after the referral is received. Feedback from initial calls was very positive; parents appreciated having a direct contact number for the epilepsy nurse in case they required any further queries. The data collected also highlighted that parents did not always remember receiving verbal safety net advice but were able to remember it when given a leaflet, which they retained for future use.
- The epilepsy nurse organised the set-up of regular clinic dates and times, which ran between January and June 2020.
- The team implemented structural processes that enabled the admin team to effectively manage the booking of patient slots for families, ensuring they received the required safety support advice and guidance.
- Clinics were booked in 30-minute slots, with up to four slots per clinic, to meet demand. This proved sufficient given the subsequent rate of first seizure attendances. Calls lasted between 10 minutes (shortest) and 1 hour (longest).
- Improvements to written information were undertaken and provided to patients and their families when admitted with their first seizures.
- The introduction of a new electronic referral system provided a simpler and speedier referral process.

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Changes

- The team used local and national audit data to present at internal departmental meetings, resulting in the opportunity for the team to present their findings and remind colleagues of the purpose of the project.
- The team achieved the completion of referral forms made in a timely manner by allocating a single point of contact to a member of the team. However, this was not sustainable due to pandemic related pressures.

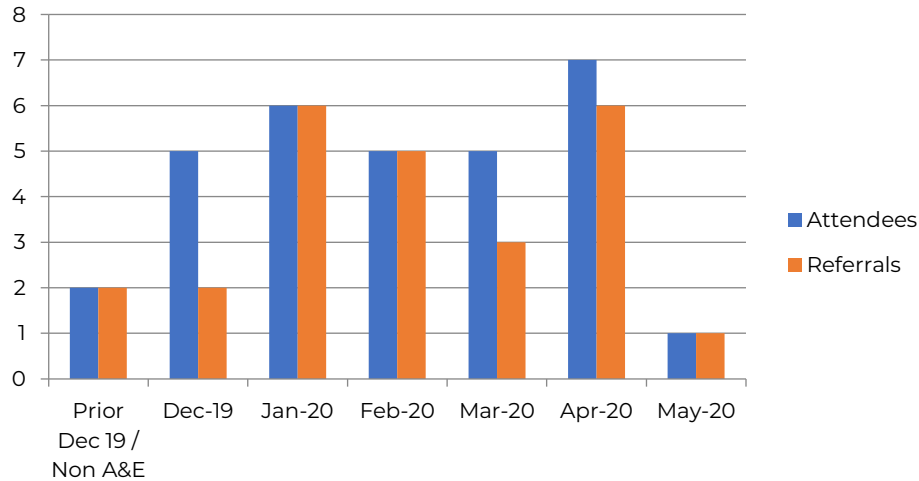
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Results from the trial first fit telephone service:

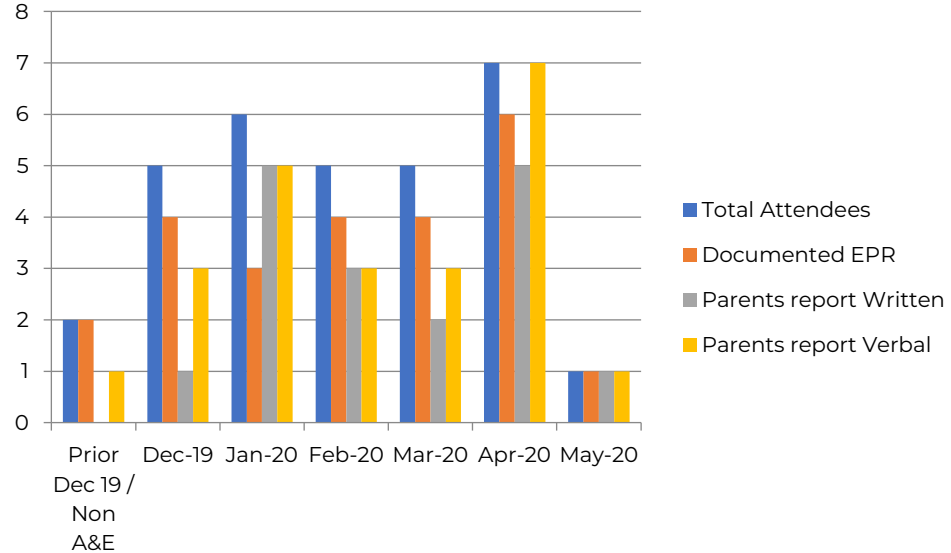
- **24** patients participated in calls from the beginning of process in December.
- **8** children who were sent back into the service provided comments to the acute team on how visible the posters were and how keen they were for the new service to begin.
- **8** out of the **31** telephone clinic contacts held, resulted in patients being offered an appointment to be seen in the epilepsy clinic. Several of the patients had other seizure types not identified in A+E and were under investigation for a possible epilepsy diagnosis.
- By May, **31** calls made in total resulted in the following outcomes:
- **8** referrals were made to the epilepsy service.
- Time from A+E attendance to first fit telephone call went down from 40+ days to 21 days,
- **77%** of safety advice was documented on EPR system.
- **55%** of written advice was reported as being received from parents.
- **74%** of verbal advice was reported as being received (but not always remembered).
- **10%** were signposted to the Epilepsy Action website for information.

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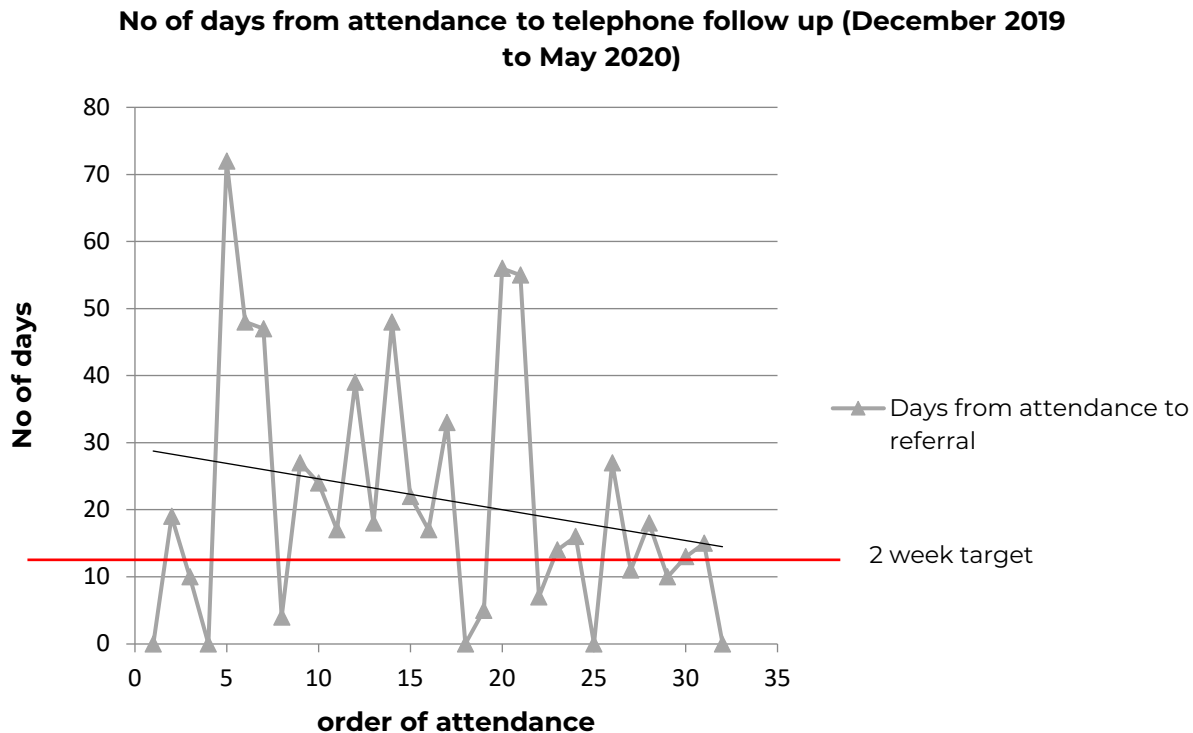
Number of children referred into the First Fit Telephone Clinic



Safety Information Documented and Reported Received



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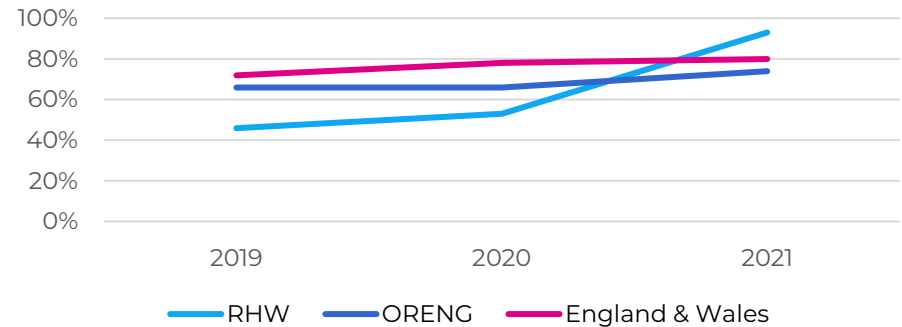


Audit results for cohort 3 - Performance indicators – Royal Berkshire NHS Foundation Trust

NICE recommends that children and young people with epilepsy are seen by an epilepsy specialist nurse (ESN) who they can contact between scheduled reviews (Quality statement 5).

88% of children and young people diagnosed with epilepsy had input from an epilepsy specialist nurse (ESN) by one year in Royal Berkshire NHS Foundation Trust as shown in Performance indicator 2. Additionally achieving above regional and national average.

Percentage of CYP with input from an epilepsy specialist nurse



The percentage of CYP seen by an ESN in their first year of care has increased from 53% in 2020 to 88% in 2021 and has risen above national and regional levels.

Performance Indicators	2019	2020	2021	2021 - ORENG	2021- England & Wales
1. Paediatrician with expertise in epilepsy	69%	47%	67%	69%	88%
2. Epilepsy nurse specialist	39%	53%	88%	68%	76%

Epilepsy12 Performance indicators by HB/Ts, Network and England and Wales combined

Audit results for cohort 3 - Performance indicators - Royal Berkshire NHS Foundation Trust

NICE recommends that children and young people with epilepsy have an agreed and comprehensive care plan (Quality statement 4).

The percentage of CYP with Comprehensive Care Planning agreement in the first year of care has increased from 20% in 2020 to 67% in 2021 and has risen above regional averages. Additionally, the percentage of CYP with Comprehensive Care Planning content in their first year of care has increased from 27% in 2020 to 60% in 2021.

Performance Indicators	2019	2020	2021	2021 - ORENG	2021- England & Wales
10. Comprehensive Care Planning agreement	23%	20%	67%	62%	70%
11. . Comprehensive Care Planning content	31%	27%	60%	74%	75%

Audit results for cohort 3 - Performance indicators - Royal Berkshire NHS Foundation Trust

NICE recommends that children and young people with epilepsy have an agreed and comprehensive care plan (Quality statement 4).

The percentage of CYP with a Comprehensive Care Planning agreement in the first year of care has increased in 2021 and has risen above regional and national averages.

Performance indicator 10: Comprehensive Care Planning agreement	2019	2020	2021	2021 - ORENG	2021 – England & Wales
% of children and young people with epilepsy after 12 months where there is evidence of a comprehensive care plan that is agreed between the person, their family and/or carers and primary and secondary care providers, and the care plan has been updated where necessary	23%	20%	67%	62%	70%
% of children and young people with epilepsy after 12 months that had an individualised epilepsy document with individualised epilepsy document or a copy clinic letter that includes care planning information	77%	53%	100%	93%	91%
% of children and young people with epilepsy after 12 months where there was evidence of agreement between the person, their family and/or carers as appropriate	54%	53%	100%	74%	79%
% of children and young people with epilepsy after 12 months where there is evidence that the care plan has been updated where necessary	46%	33%	67%	72%	75%

Audit results for cohort 3 – Professional Input – Royal Berkshire NHS Foundation Trust

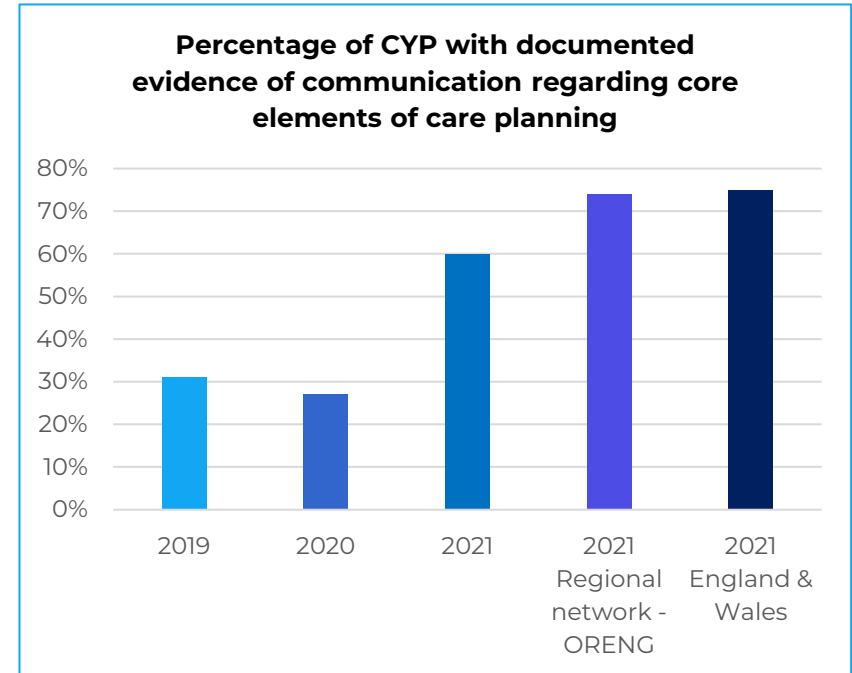
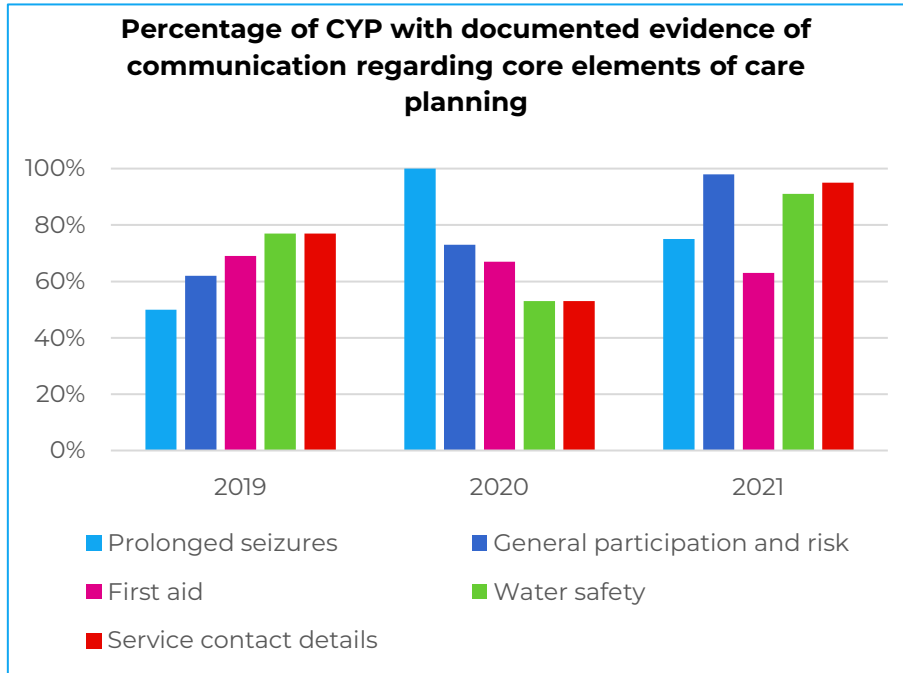
NICE recommends that children and young people presenting with suspected seizure are seen by a specialist in the diagnosis and management of epilepsies within 2 weeks of presentation (Quality statement 1).

The percentage of CYP with input from a paediatrician with expertise in the first year of care has increased from 40% in 2020 to 72% in 2021. Additionally, the percentage of CYP with input from an epilepsy specialist nurse in their first year of care has increased from 53% in 2020 to 93% in 2021 and has risen above national and regional averages.

Percentage of CYP with input from:	2019	2020	2021	2021 – ORENG	2021 – England & Wales
Paediatrician with expertise OR paediatric neurologist (PI.1)	69%	47%	67%	69%	88%
Paediatrician with expertise	69%	40%	72%	56%	85%
Paediatric neurologist	15%	27%	9%	28%	25%
Epilepsy specialist nurse	46%	53%	93%	74%	80%

Audit results for cohort 3 - Comprehensive care planning content - Royal Berkshire NHS Foundation Trust

The percentage of CYP with documented evidence of communication regarding core elements of care planning has increased in 2021.



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Challenges

- Although there were improved referral rates overall, there was a noted drop in the number of direct referrals made in March (60%).
- The effects of the pandemic had reduced paediatric A+E numbers considerably, and while it was expected to have a drop in numbers due to the national guidance in place (lack of vehicles on the roads, no sports being played, and reduced child-to-child contact spreading illness), the team found the reduction in attendance of first seizures a cause for concern.
- Nursing staff had to highlight the new process in place to medical staff, which included additional time to send direct emails to highlight incoming referrals to ensure patients were captured.
- Clinic request forms were not being completed, and a CCM (Chronic Care Management) was raised despite leaving voicemails for families.
- Explaining to patients and families that the new telephone clinic in place was not an in-person appointment.

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Outcomes

- Developed and embedded a standardised process for first-fit nurse calls as a routine part of service.
- Embedded service development meetings are routine, and service development ½ day annually.
- Streamlined processes were used to ensure patients with an epilepsy diagnosis were seen within the paediatric epilepsy service.
- Reduced waiting times through the implementation of nurse telephone clinic calls.
- Increased teamwork through identifying stakeholders and working together to improve service delivery.
- Raised awareness about the epilepsy service in general within the Trust.
- Increased parental knowledge and confidence levels.

National audit results revealed:

- An increase in the percentage of children and young people with input from a paediatrician with expertise (72%), and an epilepsy specialist nurse (93%), in the first year of care.
- The percentage of CYP seen by an ESN in their first year of care has increased to 88% in 2021 and has risen above national and regional levels.
- Increased the percentage of children and young people with Comprehensive Care Planning agreement in the first year of care.
- Increased the percentage of children and young people with Comprehensive Care Planning content in their first year of care.

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Lessons learnt

Regarding the training:

- “The programme was really useful, and we have built on our generic EQIP skills”
- “Taking on a EQIP is much less daunting now than we used to think it was, changing things as you go”
- “The process of PDSA has taught me the usefulness of trying something on a small scale and then embedding that process as it expands out”.

Regarding the team and services:

- “We feel like a team”
- “This has helped move our team forward and is helping improve the services for our children”.
- “Communication is better in the team”.
- “I enjoyed the increased meetings and teamwork that the project generated”
- “This brought me into contact with stakeholders I have never worked with previously, which means I have a useful network of colleagues throughout the Trust”.

Spreading the word:

- “I used these methods in another QIP I am involved with, looking at developing a hospital passport with our tertiary centre”.

Visual presentation of team project intervention [Video presentation](#) [Team poster](#)

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