RCPCH Epilepsy Quality Improvement Programme November 2019 – July 2020

Improving the quality of EEG clinic

Nottingham University Hospitals NHS 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 Epilepsyl2.



Project aim

Achieve a full, quality and interpretable routine EEG recording in 95% of all paediatric patients referred within 4 weeks from referral by May 2020.

Background

The neurophysiology team identified opportunities for improvement in EEG services which would involve collaborative work within the whole epilepsy team. This would provide opportunities to better meet the needs of our children and young people with a learning disability, autism spectrum disorder or anxiety undergoing an EEG by seeking innovation and input from patients, families and carers and the wider team. Whilst the aim of the project applies to all paediatric patients, many patients present with learning disability and/or anxiety. The recording of full, quality EEGs in this cohort can be challenging for all involved.

Area of focus

By improving the preparation and experience for patients and families through effective patient engagement, resulting in improving the quality of the recorded EEG to aid in epilepsy diagnosis. Simultaneously, the team plan to reduce the waiting list time from 6 to 4 weeks in line with NICE guidelines.

Changes

- The team trialled calling parents and carers of patients with autism or a learning disability the day before they attended their EEG appointment to provide advance patient information and the ability to answer any queries or address their concerns.
- Patients and their families were signposted to a <u>video produced by Evelina hospital</u>, in London, which explains what to expect at their EEG appointment.
- The team designed a questionnaire that was given to parents and carers after their child's EEG appointment to gain feedback on their experience. This allowed families to reflect on their experience and feedback was used to shape the service to better meet the needs of patients. The questionnaires were also available in recording rooms for staff to distribute.
- Used patient engagement techniques to capture patient views through the pasta voting method.
- Introduced a follow-up call service to the parent/carer if a child found the appointment upsetting to gain feedback on what could have been done better. Staff were encouraged to capture patient experiences.
- Created an additional leaflet to accompany the existing patient leaflet that includes links to online resources and directs patients to the online video made by Evelina London Hospital (YouTube).

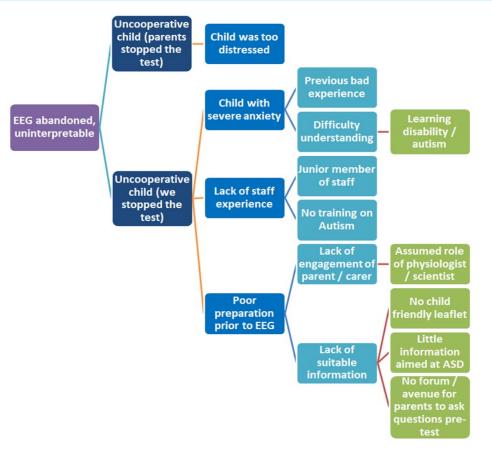


Results

- Reduced breach date from 6 weeks to 4 weeks.
- There has been very positive feedback from parents and carers so far. Appreciated the call before their appointment to discuss their needs or concerns.
- December 2019: Received questionnaires back with feedback requests for a pre-EEG phone call, visits to the department beforehand, and an EEG video of what the test involves.
- January 2020: Continued to receive positive feedback during the call. The team observed that follow-up calls were relieving the anxiety of parents and carers as well as the patient!
- January 2020: Results from the questionnaire confirmed the need for pre-EEG phone calls and possible play-date visits to the department for especially anxious patients.
- Jan 2020: 4-week breach date is still manageable, with 95% of patients seen within 4 weeks.
- Feb 2020: Eight questionnaires have been returned so far. When asked where they would like the EEG test to be performed, half confirmed they wanted to come to the hospital.









Parent/carers were given questionnaires after their EEG appointment to gain feedback on their experience.

Here in Clinical Neurophysiology we recognise that coming to hospital for tests can be quite a stressful experience. We have asked if you'll complete this short questionnaire to help us improve	3. How would you like to access the information about the EEG test? Please tick all that apply	7. I (the patient) have a		
our services, particularly to those with learning difficulties, autistic spectrum disorder and / or anxiety.	By post	Learning disability		
Thank you	By phone	Autism		
 If you had the choice, where would you have preferred the EEG test be performed? Please 	Hospital internet site	Anxiety		
note that we can only test to see if you are affected by flashing lights in the hospital	Podcast video's	Prefer not to say		
department and so this is a more thorough test. Please tick all that apply	Social media page	C Other		
	Facebook	Please state		
Hospital department School	Instagram			
□ School		It would be really useful to gather a small working group together of parents or carers to discuss		
Home Other	L Other	how we can improve in more detail. If you would be happy to get involved, please supply us with contact details		
	Please state			
Please state		Telephone Email Email		
2. What information would you have liked before coming for the EEG test? Please tick all that	4. Would it be helpful to ask questions about the test before coming?			
 what information would you have liked before coming for the EEG test? Please tick all that apply 		Thank you		
Leaflet explaining the test	Yes			
Cue cards (simple leaflet flash-card style)	By phone			
Visit to the department beforehand (look round, familiarise and play!)	Bytext			
Online video – e.g. YouTube	By email			
Virtual visit (photo's /360-degree video of the EEG rooms)	Facetime / video call			
Phone call to discuss needs and anxieties	Are there any other changes that you would like to see?			
Other	change of room layout			
Please state	more sensory toys			
	staff not in uniform			
	Other			
	Please state			
	6. What other information would you like us to know about before you come for the test?			



Results

- Many patients and their families wanted a phone call to discuss their needs and anxieties, coupled with a leaflet or online video. This was also reflected in how patients wanted to access information by post, phone call, and internet as top scorers.
- February 2020: Similar results for the 4 week breach date as seen in January. Additionally, the service is experiencing an increase in staff on annual leave before the end of the financial year.
- February 2020: Pasta voting is underway and actively seeking feedback from the patients rather than their parents/carers. Received 27 happy faces and 4 not sure. No sad faces.
- Mar 2020: Had a successful patient aged 11 years old with severe autism who came for a repeat EEG after struggling on the first occasion. Parents feedback: "This is 100% better than last time; thank you so much".

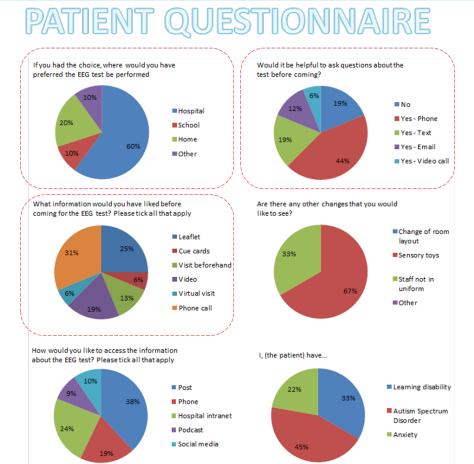


- Created a "pasta poll" to gain feedback direct from patients rather than parents/carers.
- Asked the question: "How did we make you feel today?"
- Used two different coloured ping-pong balls to differentiate between routine neurotypical patients and those with a learning difficulty, ASD, etc.
- Voting options were **happy**, **not sure** or **sad**.
- Patients seemed happy to get involved.
- There were concerns that children can be eager to please and will always select the "happy" tube.
- Would be good to follow-up on patients who weren't happy with a keep-in-touch/follow-up phone call, to see how their experience could be improved.



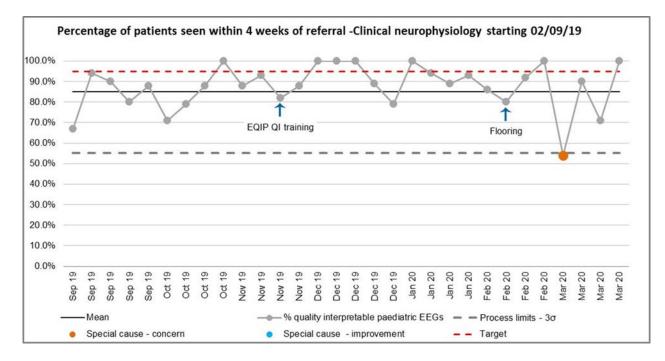








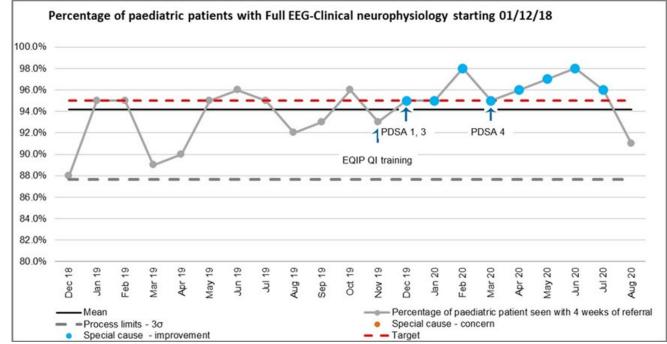
Graph 1, April 2020, shows how the team were initially able to improve wait times. Unfortunately, due to the knock-on effect of Christmas annual leave, COVID and staff using their annual leave before the end of the financial year, waiting times increased.





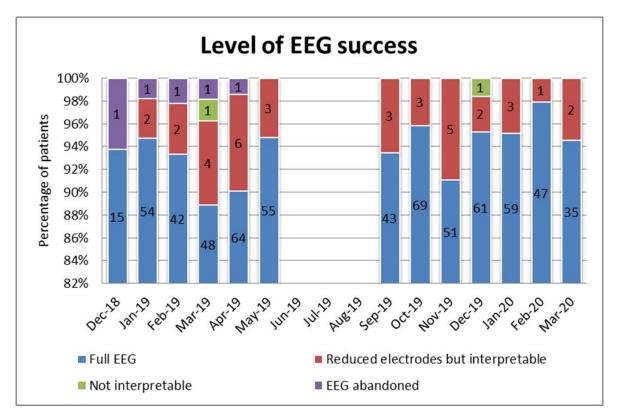
Graph 2 shows an increase in the percentage of patients who have been able to record a full, quality EEG.

The team have hit target of over 95% since the EQIP training.



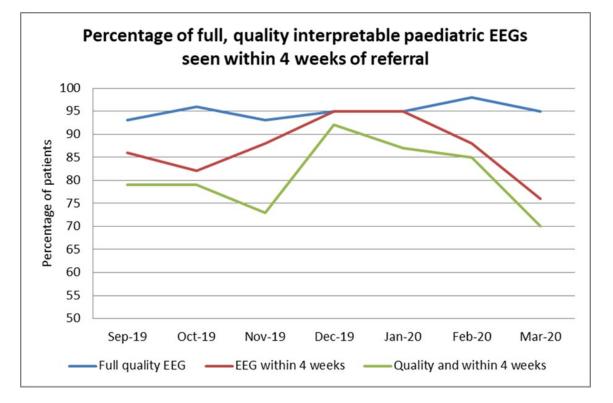


Additionally, the team have not had to abandon any recordings since starting the project (Graph 3).





Plotting both these together in **graph 4** shows us that it is the wait times that have affected the overall ability to meet the project aim, but there has been a considerable improvement in communication within the team and families to improve quality and hopefully experience for our patients.





Audit results for cohort 3 – First EEG – Nottingham **University Hospitals NHS Trust**

	2019	2020	2021	2021 – CEWT	2021 – England & Wales	In 2021, Nottingh University Hospi NHS Trust has continued to ma
Percentage of CYP who obtained a first EEG	100%	100%	100%	97%	98%	100% of CYP obt first EEG, above
						regional and nat average. COVID emergen
Time since first request for EEG	2019	2020	2021	2021 –	2021 –	nlanning for the

Time since first request for EEG	2019	2020	2021	CEWT	2021 – England & Wales
0-4 weeks	79%	54%	45%	54%	54%
4-8 weeks	13%	35%	29%	18%	23%
8-12 weeks	0%	9%	13%	5%	7 %
12-16 weeks	8%	1%	10%	7 %	4%
>16 weeks	0%	1%	3%	13%	10%

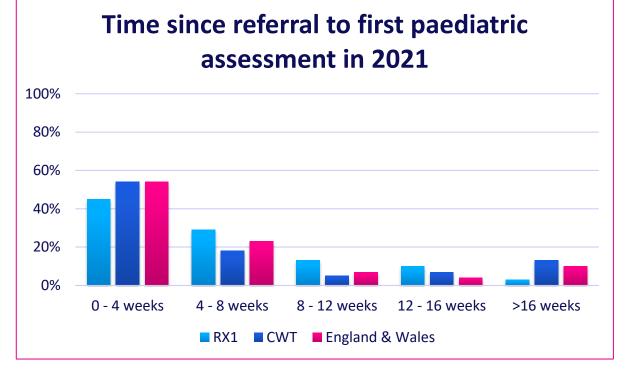
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ncy planning for their Children's Hospital involved suspension of usual outpatient clinics, with very limited provision of emergency face-to-face clinic slots for both general and community paediatric clinics, and neurology/ neurodisability clinics.



Audit results for cohort 3 – EEG wait times – Nottingham University Hospitals NHS Trust

- In 2021, there was a greater proportion of children and young people waiting less than 4 weeks for a first EEG.
- During the early stages of • lockdown, referrals for new possible diagnoses of epilepsy were reduced, in line with general reduction in GP and ED attendance; the referral rate was starting to increase back to usual levels but the impact of these lower numbers previously was not clear at this stage.





Challenges

- Emailing staff to ask for patient experience proved difficult due to staff forgetting or being unwilling to capture feedback on difficult appointments for fear of unfavourable feedback.
- COVID emergency planning for their Children's Hospital involved the suspension of usual outpatient clinics, with very limited provision of emergency face-to-face clinic slots for both general and community paediatric clinics and neurology/neurodisability clinics.
- The leaflet that was created to be sent out with all paediatric appointments was put on hold due to the COVID-19 pandemic.
- Continuous issues around time resourcing to make phone calls to patients and their families.
- The quote sourced to create a departmental video was approximately £1,200; due to the cost, it may become a long-term goal or project.
- The issue of physiologists and scientists not passing on information continues.
- No formal feedback had been collected from patients and families regarding their experience of the service during the pandemic. Informal verbal feedback from families highlighted the advantages of epilepsy clinic remote consultation (more convenient, avoids the hassle of travelling and parking).



Outcomes

- April 2020: The team temporarily achieved their target of over 95% pre-pandemic while participating in the EQIP.
- Increased patient and engagement, and the theme of feedback coming through from parents and carers was the request to talk the visit through with staff before they attended their appointment.
- Improved preparation prior to the EEG.
- Contacted parents and carers and signposting them to relevant videos and information.
- Increased team communication between the epilepsy and neurophysiology teams.

National audit data showed that in 2021:

- Nottingham University Hospitals NHS Trust has continued to maintain 100% of CYP obtaining a first EEG above regional and national average.
 - In 2021, there was a greater proportion of children and young people waiting less than 4 weeks for a first EEG.
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Lessons learnt

- It helped form a more cohesive team of professionals interested in epilepsy QI; the most valuable thing was that it strengthened communication with EEG colleagues and with each other to share challenges and ideas.
- Keeping a weekly meeting going for both clinical care teams to discuss service needs was significantly positive too.
- Other quality improvement projects that have been undertaken simultaneously from the EEG project have led to working on implementing a teenage clinic (led by ESN), including the youth team at the clinic each month, with the aim of working on further information and resources for young people.

Visual presentation of team project intervention

Video presentation

Team poster



Team update in 2024

The team successfully created their own EEG appointment video using mobile phone and computer software, saving the Trust the cost of £1,200. The video is accessible via the QR code below which is now sent to all children and young people and their families.







https://eqip.rcpch.ac.uk

eqip@rcpch.ac.uk





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