RCPCH EQIP

Epilepsy quality improvement programme

Impact report 2019-2023

NHS England

RCPCH
Royal College of
Paediatrics and Child Health
Leading the way in Children's Health

Foreword

You might think improvement comes naturally and easily. Since calls for transformation in epilepsy care in 2003 and the first NICE guidelines for epilepsies in 2004, gaps and variation in care have been felt but often hard to see, with actual improvement for children and young people frustratingly difficult to achieve.

Improvement has turned out to be neither natural nor easy.

Since 2019, EQIP has provided training, integration, expertise, mentoring, time-out, local management buy-in, workshops, catch-ups, connections, and conferences. I have seen the EQIP faculty inject a ‘can-do’ attitude, help clinical teams become QI teams, make improvement a team sport, and assist teams in committing to realistic, measurable, and attainable goals. It has built up QI skills by rapidly applying them, provided mentorship, and ensured outputs and conferences to showcase the hard work and success.

...And there has been so much success!

There have been real moments of magic where something clicked, a project idea won consensus, a young person’s or parent’s participation changed a trajectory, an outcome showing the improvement was grasped, where another team in the room thought, “maybe we could do that.”

Within this report, there are visible threads of teams focusing together for the first time, leaders emerging from the shadows, ideas crystallising into co-created actions, and improved outcomes emerging as evidence in the data. The programme has been infectious, and we have felt motivation grow and seen many local ideas generate wider adoption.

I am very grateful to all who have contributed and participated within the three waves of this programme. There still needs to be multi-level and multi-system change. However, at the key level where the child, family, carer, and clinicians connect, EQIP has demonstrated several times over what happens when we together start creating waves.

Dr Colin Dunkley
Consultant Paediatrician
Epilepsy12 Clinical Lead

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Thank you!

The RCPCH EQIP project team would like to thank the multidisciplinary healthcare professionals, paediatric epilepsy service staff and administrators within participating Health Boards and Trusts. These teams have put time and effort into working on service improvement in incredibly challenging circumstances. We also thank participant teams for the use of images and visual project outcomes captured during the programme.

Programme collaborators:

EPILEPSY12

epilepsy action

RCPCH&Us
The voice of children, young people and families

OPEN UK
Organisation of Paediatric Epilepsy Networks in the United Kingdom

Young Epilepsy

Who we are

The Epilepsy Quality Improvement Programme (EQIP) is the first quality improvement (QI) initiative supporting paediatric epilepsy care. It is managed by the Royal College of Paediatrics and Child Health (RCPCH) and was funded by both NHS England and the Welsh government in 2019-2020. The programme was recommissioned in 2021 and is currently funded by the NHS England Children and Young People (CYP) transformation team. This unique undertaking revolves around a comprehensive QI training programme designed and specifically tailored to support paediatric epilepsy teams to deliver QI in epilepsy care. Epilepsy is currently one of the most common long-term conditions in CYP in the UK, and, as such, it has been identified as one of the priorities for improvement of effective and coordinated care in the published NHS Long Term Plan.

The national audit results reported in Epilepsy12 (The National Clinical Audit of Seizures and Epilepsies in Children and Young People), managed by the RCPCH and established in 2009, continues to report significant disparities among Trusts in England and Health Boards in Wales. These variations, particularly in terms of staffing adequacy and the timely execution of care processes, persist despite some progress over time.

QI training is a means to formally offer the knowledge and skills to plan, structure, and implement interventions that achieve change. It looks deeper into the quality of what is provided and uncover what is not working and why.

Since 2019, the vision for the RCPCH has been to lead the way in children's health. Working in collaboration with a network of experts in the field: a QI trainer, advisory groups, the Epilepsy12 project team, the Organisation of Paediatric Epilepsy Network UK (OPEN UK), the RCPCH &Us Children & Young People's Engagement Team, and links to epilepsy charity stakeholders. Our training package helps to build high performing service teams working together for continuous improvement in the care of children and young people with epilepsy.

Since its inception from 2019 to 2023, the RCPCH EQIP has seen the participation of 40 NHS hospital Trusts and Health Boards in England and Wales, including two Integrated Care Boards (ICBs). The programme has trained 184 NHS staff within paediatric epilepsy services. Our training aligns with national focus areas within the published NHS National Epilepsy Bundle of Care (2023), addressing challenges faced by both ICBs and Trust paediatric epilepsy services. The training supports the team to build capability for change and improvement at the frontline. Staff participation is highly rated, with the following testimonies captured in 2019-2023.

“

- **The programme was really useful and we have built on our generic EQIP skills.**
- **Taking on an EQIP is much less daunting now than I used to think it was, changing things as you go.**
- **It is particularly humbling to work with families and support them rather than lead them. Once you know your families and have built up good relationships with them, it is good to encourage families to lead discussions and consultations.**
- **The EQIP provides a more evidence-based and measurable approach to change at a local level.**
- **The EQIP community provides opportunities to recognise good practice and share with other teams doing the same kind of work.**
- **The networking structure of EQIP enabled two geographically distant teams to strengthen their engagement and communication to bring them together, aligning into a single service, reducing inequalities between services and providing a single learning platform.**

Participant team evaluation feedback

Aim of the collaborative programme

Epilepsy is one of the most prevalent long-term conditions affecting children and young people in the UK. Recognising its significance, the NHS Long Term Plan (2019) has prioritised the enhancement of effective and coordinated care for paediatric epilepsy.

The RCPCH EQIP objectives are:

- To assist healthcare professionals in addressing current challenges by providing centralised support and embedding QI methodology within paediatric epilepsy teams across England and the three UK nations.
- To enhance the skills and knowledge of service teams to comprehend successful transformation and change at all levels within epilepsy services, utilising a microsystems model integrated into local operational business.
- To utilise these newfound skills to build networks of improvers dedicated to delivering priority areas within local services, aligning with national NHS England epilepsy care objectives.
- To develop customised capability-building programmes linked to specific topics and responsibilities within multidisciplinary teams (MDT).

Our long-term vision encompasses:

- Recognition of paediatric epilepsy services as a high priority within the government health agenda at both national and local levels.
- Acknowledgement, support, and empowerment of child health practitioners specialising in epilepsy to work seamlessly across geographic and service boundaries, including the transition between paediatric and adult service provision.
- Ensuring children and young people with epilepsy have clear access to the necessary treatment and are actively involved in shaping how it is designed and delivered.

The programme is designed to empower paediatric epilepsy service teams by helping them to recognise everyone's role in driving transformative change. The programme is underpinned by the national objectives: to improve standards in providing patients access to tertiary care and mental health and wellbeing support, to reduce waiting times for key clinic appointments and investigations, and to reduce variation overall in the care provided across regional networks by paediatric epilepsy services.

Training in QI skills and knowledge ensures that paediatric epilepsy service teams acquire the necessary skills and knowledge to improve patient care. This can lead to improved health outcomes, reduced complications, and an overall better quality of life for all children and young people with epilepsy.

The RCPCH is committed to a rights-based approach, embedding the United Nation Convention on the Rights of the Child within the programme and QI practices. The right for children and young people's voices to inform decisions that affect them individually and collectively (article 12) and the right to the best healthcare possible (article 24) are key drivers to why this work is important for children and young people.

Photo: Paediatric epilepsy service teams sharing their improvement journey at the end of programme event, 2023.

Rationale: the critical role of the EQIP

Epilepsy can be diagnosed at any age. Some types of epilepsy are more complex and some are a life-long condition. Epilepsy is one of the most common long-term conditions for children and young people, affecting approximately 112,000 children and young people in the UK.[1] In 2017/2018, the rate of emergency admissions to hospital for epilepsy was 66.8 per 100,000 under 19-year-olds in England, compared to 73.8 per 100,000 in Scotland and 87.9 per 100,000 in Wales.[2]

When focusing on the effects of epilepsy for children and young people, the children's charity Young Epilepsy confirms the following information.[3]

- Epilepsy is more common in children and young people as they get older.
- Epilepsy affects approximately **1 in 200** school-age children (aged 5-19 years).
- Around **three-quarters of children** will either outgrow their epilepsy or it will be well controlled by anti-seizure medications.
- It is estimated that around **40%** of children with epilepsy have a learning disability.
- Each year in the UK, around **1,000** people die from causes related to epilepsy.

Aligned with the objectives outlined in the published NHS England National Epilepsy Bundle of Care, our focus is on supporting NHS paediatric services with the guidance to help reduce national variation in clinical practice and improve outcomes for children and young people diagnosed with epilepsy. Our engagement with service teams has raised a number of areas posing challenges for paediatric epilepsy services, such as:

- **Communication strategies:** The absence of well-defined communication plans to facilitate clear understanding of objectives towards common goals, promote collaboration, ensure timely dissemination of accurate information among service teams, departments and organisations. The identity of ICB leads are unknown to service-level staff.
- **Limited capacity and resources/staffing:** Paediatric epilepsy services often operate with limited resources, both in terms of staffing and financial support, resulting in a lack of team cohesiveness. Managing significant caseloads creates challenges in managing and providing adequate care to children and young people with epilepsy.
- **Engaging ineffectively with children and young people:** Services have identified difficulties in effectively engaging with children and young people. Lack of effective engagement hinders the involvement of patients in the co-design of services and improvements.
- **Cultural aspects in clinical services:** Paediatric epilepsy services encounter resistance to change in culture and often repeat practices that have provided no benefit to improving variation in care. They also encounter challenges related to cultural aspects within the patient population in terms of varying languages spoken or learning difficulties with reading and communication, which may impact patients' understanding of medical information, therefore requiring additional support and resources and impacting the overall effectiveness of service improvements.

These challenges highlight the importance of training programmes like the RCPCH EQIP in providing healthcare professionals with efficient methods and tools to help streamline processes. As a result, teams have reported improved communication and cross-collaboration and better resource utilisation, resulting in a contribution to the overall efficiency and improvement of healthcare in the country. As an organisation, we understand that adequately trained and supported healthcare professionals are more likely to stay in their roles. This reduces recruitment and training costs associated with high staff turnover. Teams are better equipped to provide high-quality care, which can lead to increased patient satisfaction. This, in turn, contributes to a positive reputation for the healthcare service and behavioural shifts across all organisational levels, from local teams to senior leadership in NHS Trusts/Health Boards.


#RCPCH EQIP

Implementation of the programme: the training of healthcare professionals

The RCPCH EQIP engages with multidisciplinary paediatric epilepsy service teams with a strategic approach to achieve tangible outcomes whenever feasible. The RCPCH offers a range of training and education opportunities that cover many of these elements, including previously delivering the paediatric diabetes collaborative, which we blend into QI elements of this programme. Our methodology underpins a variety of QI educational and training opportunities supported by our faculty EQIP team to ensure we have access to the most up-to-date evidence and practices in improvement science. An example of our model of improvement is closely aligned with the Quality Improvement Journey model by NHS Education Scotland[4] (see Figure 1), which provides a structured framework of training that brings knowledge to people, and the theory can be customised to apply to the local challenges and build solutions in situ. Our emphasis is on team development and building capability in the microsystem teams.

Figure 1: Example of Quality Improvement Journey model, NHS Education Scotland.

Feeding into the team development approach and offering bespoke training, paediatric epilepsy services were engaged across 76 Health Boards and Trusts to gain a better understanding of their knowledge of the behaviours and key processes undertaken by high-performing service teams. Over 100 responses were submitted and analysed to form a set of recommendations for comprehensive care delivery, as shown in Figure 2 below.

Collects regular feedback via more than one channel. Reviews after every clinic and in team meetings, reports to hospital management and implements measurable changes on its basis.

Involves children and young people and their families in service design and improvement.

Strong active links with local support groups, charities and schools, which supports their patients.

Provides a point of contact for schools and patients all year round.

Provides staff and peer training and materials for schools .

Has a coordinated team who meet regularly, develop objectives and agree actions together, monitors progress and evaluates the process.

Works closely with commissioners on its Best practice tariff and epilepsy specialist nurse funding.

Figure 2: Questionnaire feedback from epilepsy services across 76 Health Boards and Trusts elicited 116 responses on identifying high-performing services and key processes.

EQIP improvement engine and timeline

To achieve our aims, we focus on building the capability of teams, recognising that individuals develop skills and insights through various formal and informal experiences over their careers. However, it is important to acknowledge that the opportunity to apply these skills may fluctuate over time. Given the complexity of achieving sustained improvement across a system, our strategy prioritises collaboration and team development. Figure 3 below highlights the structure of the programme based on the Institute for Healthcare Improvement collaborative model.[5] The aim is to embed knowledge, support, and skills necessary for planning, measuring, monitoring and executing QI interventions within paediatric epilepsy services.

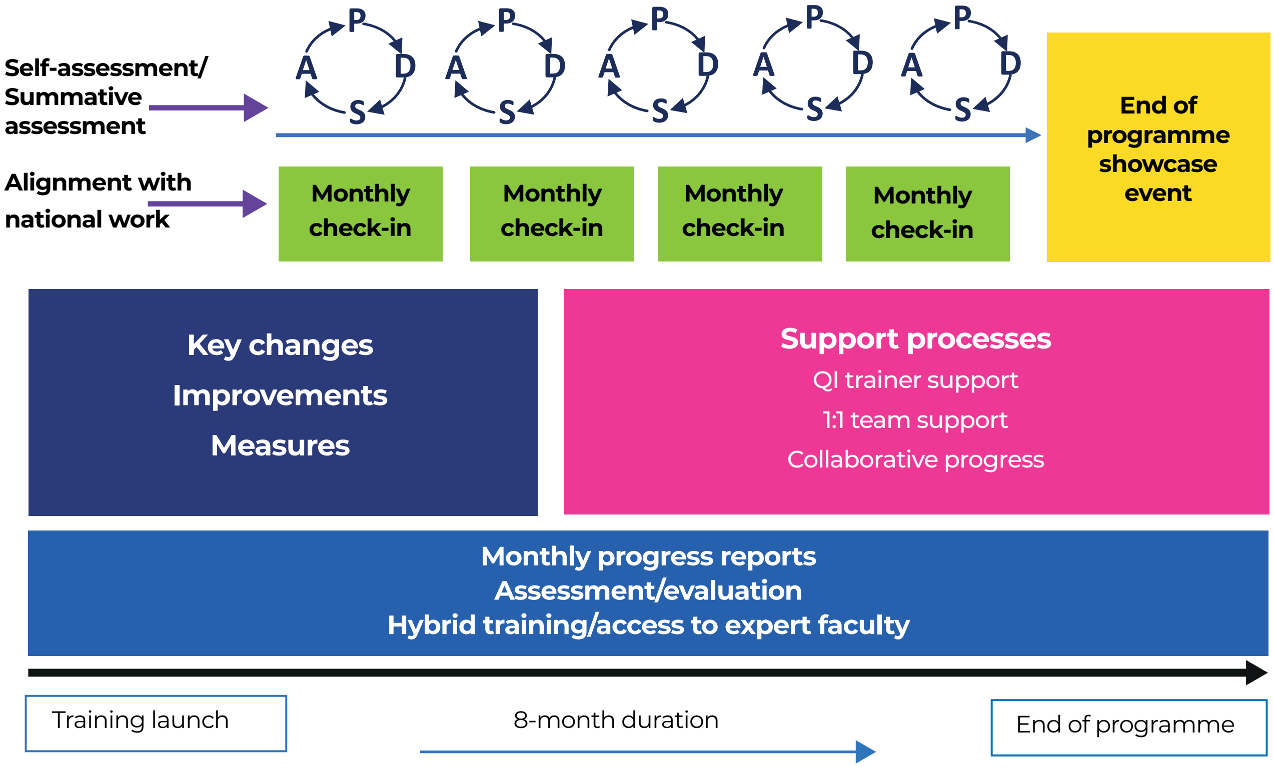


Figure 3: EQIP engine for improvement timeline.

Using methodology underpinned by evidence and research from existing collaborative models and feedback from paediatric epilepsy service level teams, our EQIP capability plan has been co-designed by staff who already have a level of expertise in how to make change happen. The programme works closely with key stakeholders, such as the OPEN UK and epilepsy charities, to ensure that all elements of training are delivered in a manner which best serves the whole paediatric epilepsy community. Our strategic approach plans to address the specific needs and challenges faced by paediatric epilepsy services working with MDTs, using a whole-team approach, providing knowledge and skills via hands-on training and opportunities for interactive learning.

Knowledge, skills and behaviours of teams

The range of knowledge and capability needed to achieve sustained improvement across a system is far greater than individual experts can be expected to possess on their own. Therefore, collaboration and team development are our focus. The order of importance in team training has evolved from knowledge, skills, and behaviours to skills, behaviours, and knowledge. Within teams, our aim is to create methodologies that bring knowledge directly to people. The EQIP teams enhance productivity by adopting a microsystems approach, where a collective range of expertise, skills, resources, and networks are harnessed from within the organisation and externally. Microsystems, fundamental building blocks within larger organisations and health and social care systems are the spaces where patients, families, and care teams intersect.

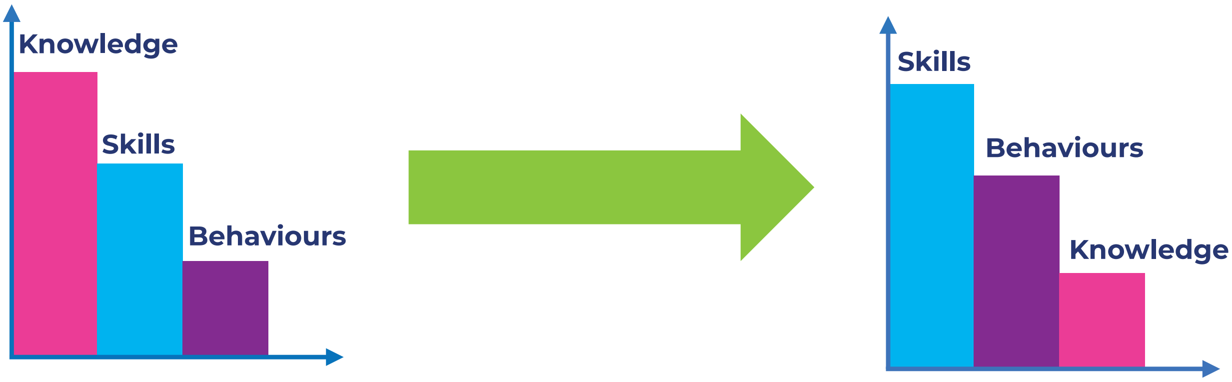


Figure 4: Knowledge, skills and behaviours of teams.

In theory, the more productive microsystems are those who between them have a range of expertise and the skills, resources, and networks to be able to tap into sources of insight and capability throughout the organisation and externally. This is a result of building capability in context with local resources. Microsystems are the essential building blocks of larger organisations and of our own health and social care systems. Many large-scale organisations in health have successfully used a microsystems model for change, including Salford NHS Trust, Kaiser Permanente, and Jonkoping County Council in Sweden. Clinical microsystems do the real, hands-on, value-added work within an organisation. They are living units that change over time and always have a patient (a person with a health need) at their centre. Clinical microsystems must find ways to improve and innovate on a day-to-day basis if they are to thrive in a changing environment.[6] The service infrastructure within NHS England lends itself to a microsystem's framework: in regions, Trusts, departments, divisions, and individual units and services.

A network of microsystems: delivering change at the edge.

Our training programme establishes and connects teams within each microsystem, promoting improvement science and cultivating expertise to apply whole systems thinking in practice. The intention is to develop proficiency where it is most needed, particularly at the edges of organisations. EQIP QI microsystems form a network of teams with advanced expertise, working collaboratively to:

- Create awareness of workflow throughout the organisation with interdependent groups capable of instigating change.
- Initiate and test changes to accelerate cycles of improvement.
- View them as a comprehensive system of care.

- Respond to strategic challenges and invitations.
- Explore new ways of working by reaching out to and into the organisation.
- Measure improvement and integrate multiple improvement cycles while prioritising patient care.

Our model builds QI skill programmes in collaboration with patients, families and clinical teams. Improvement projects are designed considering the diverse environments in which staff work, ensuring continuous progress to enhance patient experience and outcomes. Our change efforts embed formative and summative assessments to gauge the impact of our QI learning.

This comprehensive approach aims to facilitate measurable improvements in paediatric epilepsy services. However, it is important to acknowledge that not all changes may necessarily lead to improvement or the desired impact on services. Several challenges are evident: difficulties in communication, both internally and externally, among team members, other healthcare providers, and patients. External factors, such as the broader healthcare environment, policies, or external pressures, and services not being prepared for the culture shift that comes with change, may create additional struggle.

Photo: RCPCH EQIP project team with participant paediatric epilepsy service and MDTs at the 2019 residential training launch.

How do we know that change is an improvement?

To gauge team learning and progress, we employ formative assessments. Our measurement framework involves monthly reporting, team support sessions, and evaluations after each training session. End of programme reflection meetings further contribute to the evaluation process, aiding in the assessment of lessons learned and paving the way for sustained improvements beyond the training programme. This method provides comprehensive support throughout the teams' QI journey, offering detailed insights into the knowledge and skills required to plan, measure, and execute their project interventions effectively.

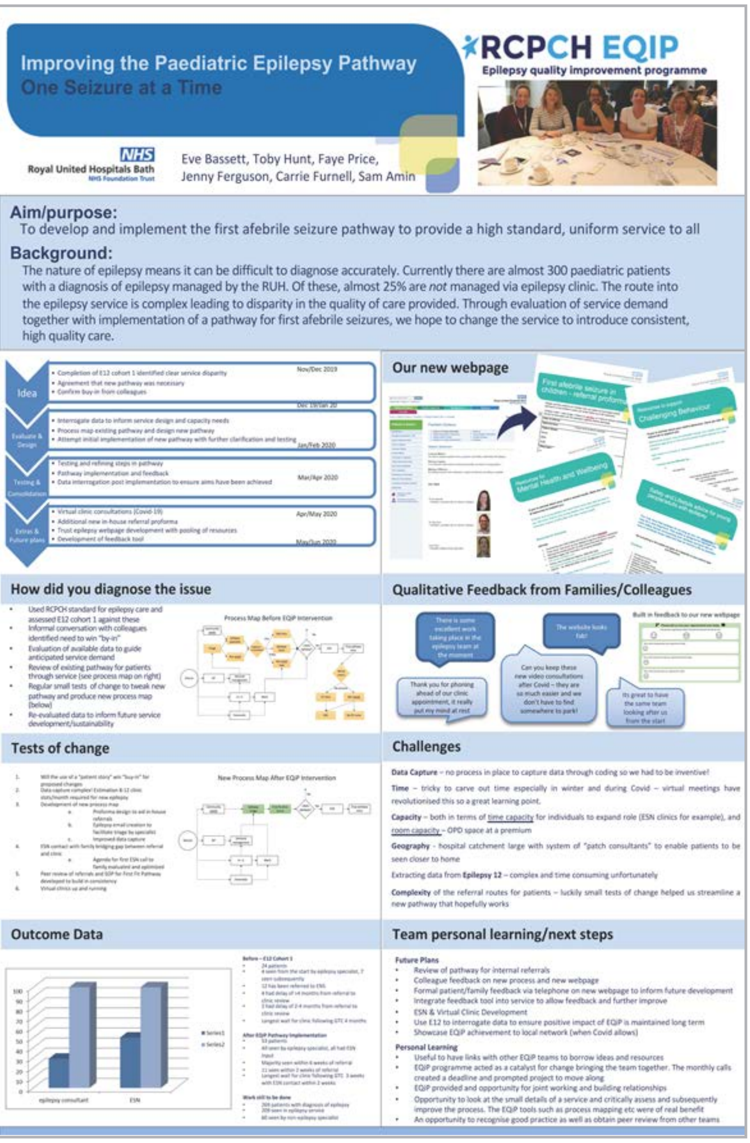
In tandem with formative assessments, summative assessment processes are employed to evaluate the programmes' success against project aims. When measuring improvement, only a small number of measures are required to monitor progress made towards the project goal. Using both quantitative and qualitative data can help decision-making and making judgements to support improvement in healthcare. When looking at a quality issue from an improvement perspective, teams review smaller amounts of data more frequently to see if project interventions are improving over time.

Progress is measured monthly, and each team collects qualitative and quantitative data (using run charts or Pareto charts) for their improvement efforts and based on tests of change performed in local services. The run chart is an analytical tool commonly used by professionals in QI but underutilised in healthcare.[7] In addition, team presentations and posters share the accomplishment of project goals, including the presentation of results from tests that demonstrate team learning. Participant teams showcase their outcomes at the end-of-programme shared learning event, attended by the wider epilepsy community. Direct ties to the Epilepsy12 audit enable teams to assess their service standards within the chosen improvement area, compared to regional and national averages, facilitating the review and monitoring of improvements through annually published results.

The evaluation process is rigorous, drawing insights from extensive sources collated throughout the programme, including:

- Thirty recorded end-of-project reflection sessions, ranging from 30 to 45 minutes each.
- Over 90 evaluation surveys were captured through platforms like Survey Monkey, Mentimeter, and idea boards.
- Over 70 submitted monthly progress reports detailing ongoing developments.
- Thirty recorded project presentation videos, edited to approximately seven to eight minutes in duration.
- Just under 40 project posters summarise key initiatives.

This extensive evaluation framework enables us to capture and communicate the impactful outcomes of the training programme, underscoring our commitment to continuous improvement in paediatric epilepsy services.



Improving the Paediatric Epilepsy Pathway One Seizure at a Time

RCPCH EQIP
Epilepsy quality improvement programme

NHS
Royal United Hospitals Bath
NHS Foundation Trust

Eve Bassett, Toby Hunt, Faye Price, Jenny Ferguson, Carrie Furnell, Sam Amin

Aim/purpose:

To develop and implement the first afebrile seizure pathway to provide a high standard, uniform service to all

Background:

The nature of epilepsy means it can be difficult to diagnose accurately. Currently there are almost 300 paediatric patients with a diagnosis of epilepsy managed by the RUH. Of these, almost 25% are *not* managed via epilepsy clinic. The route into the epilepsy service is complex leading to disparity in the quality of care provided. Through evaluation of service demand together with implementation of a pathway for first afebrile seizures, we hope to change the service to introduce consistent, high quality care.

Idea
- Completion of E12 cohort 1 identified clear service disparity
- Agreement that new pathway was necessary
- Confirm buy-in from colleagues

Nov/Dec 2019

Dec 19/Jan 20

Evaluate & Design
- Interrogate data to inform service design and capacity needs
- Process map existing pathway and design new pathway
- Attempt initial implementation of new pathway with further clarification and testing

Jan/Feb 2020

Testing & Consolidation
- Testing and refining steps in pathway
- Pathway implementation and feedback
- Data interrogation post implementation to ensure aims have been achieved

Mar/Apr 2020

Extras & Future plans
- Virtual clinic consultations (Covid-19)
- Additional new in-house referral proforma
- Trust epilepsy webpage development with pooling of resources
- Development of feedback tool

Apr/May 2020

May/Jun 2020

Our new webpage

How did you diagnose the issue

- Used RCPCH standard for epilepsy care and assessed E12 cohort 1 against these
- Informal conversation with colleagues identified need to win "by-in"
- Evaluation of available data to guide anticipated service demand
- Review of existing pathway for patients through service (see process map on right)
- Regular small tests of change to tweak new pathway and produce new process map (below)
- Re-evaluated data to inform future service development/sustainability

Process Map Before EQiP Intervention

Qualitative Feedback from Families/Colleagues

There is some excellent work taking place in the epilepsy team at the moment

The website looks fab!

Thank you for phoning ahead of our clinic appointment, it really put my mind at rest

Can you keep these new video consultations after Covid – they are so much easier and we don't have to find somewhere to park!

Its great to have the same team looking after us from the start

Built in feedback to our new webpage

Tests of change

1. Will the use of a "patient story" win "buy-in" for proposed changes
2. Data capture complex! Estimation & 12 clinic slots/month required for new epilepsy
3. Development of new process map
   a. Proforma design to aid in house referrals
   b. Epilepsy email creation to facilitate triage by specialist
   c. Improved data capture
4. ESN contact with family bridging gap between referral and clinic
   a. Agenda for first ESN call to family evaluated and optimised
5. Peer review of referrals and SOP for First Fit Pathway developed to build in consistency
6. Virtual clinics up and running

New Process Map After EQiP Intervention

Challenges

Data Capture – no process in place to capture data through coding so we had to be inventive!

Time – tricky to carve out time especially in winter and during Covid – virtual meetings have revolutionised this so a great learning point.

Capacity – both in terms of time capacity for individuals to expand role (ESN clinics for example), and room capacity – OPD space at a premium

Geography - hospital catchment large with system of "patch consultants" to enable patients to be seen closer to home

Extracting data from **Epilepsy 12** – complex and time consuming unfortunately

Complexity of the referral routes for patients – luckily small tests of change helped us streamline a new pathway that hopefully works

Outcome Data

Before – E12 Cohort 1
- 24 patients
- 4 seen from the start by epilepsy specialist, 7 seen subsequently
- 12 has been referred to ESN
- 4 had delay of >4 months from referral to clinic review
- 3 had delay of 2-4 months from referral to clinic review
- Longest wait for clinic following GTC 4 months

After EQiP Pathway Implementation
- 53 patients
- All seen by epilepsy specialist, all had ESN input
- Majority seen within 6 weeks of referral
- 21 seen within 2 weeks of referral
- Longest wait for clinic following GTC 3 weeks with ESN contact within 2 weeks

Work still to be done
- 269 patients with diagnosis of epilepsy
- 209 seen in epilepsy service
- 60 seen by non-epilepsy specialist

Team personal learning/next steps

Future Plans
- Review of pathway for internal referrals
- Colleague feedback on new process and new webpage
- Formal patient/family feedback via telephone on new webpage to inform future development
- Integrate feedback tool into service to allow feedback and further improve
- ESN & Virtual Clinic Development
- Use E12 to interrogate data to ensure positive impact of EQiP is maintained long term
- Showcase EQiP achievement to local network (when Covid allows)

Personal Learning
- Useful to have links with other EQiP teams to borrow ideas and resources
- EQiP programme acted as a catalyst for change bringing the team together. The monthly calls created a deadline and prompted project to move along
- EQiP provided and opportunity for joint working and building relationships
- Opportunity to look at the small details of a service and critically assess and subsequently improve the process. The EQiP tools such as process mapping etc were of real benefit
- An opportunity to recognise good practice as well as obtain peer review from other teams

Medway NHS Foundation Trust team sharing their service improvement outcomes at the end of programme event in 2023.

QI and Children and Young People engagement tools displayed during training launch.

Multidisciplinary service teams participating in QI training activities during residential training launch in 2019.

QI activities during training launch.

NHS
Medway
NHS Foundation Trust

RCPCH EQIP
Epilepsy quality improvement programme

Improving the wait time of first seizure presentations being seen in the epilepsy clinic

Ms. Teresa McIntyre, Dr Mercedes Munteanu, Dr Faisz Mohamed

Aim/purpose:

To achieve 60% of first seizure referrals being seen within 2 weeks by May 2023

What is the problem:

As a newly created local service, we identified capacity and processing issues emerging as the service evolved. We did not have first seizure clinics and wait times were increasing as our caseload grew. Referring and triaging processes were too complicated and there was great variation in practice for in-hospital referrals.

Change was necessary in order to improve patient journey and comply with National guidance.

Driver Diagram

Driver Diagram

60% First seizure referrals to be seen within two weeks by May 2023	Primary Drivers	Secondary Drivers	Change ideas
	Simplify referral process	Develop First seizure referral pathway SOP to clarify process Create electronic referral form	1.First seizure pathway and SOP with clear instructions on how to refer 2.Easy/quick referring: email EDN, EPR form 3.Visual prompts in clinical areas
	Streamline triage	Re-design triage process	1.Reduce time to triage – daily review/ common end-point for All referrals 2.Dedicated Epilepsy Pathway Coordinator 3.One Consultant to action All referrals in 24-48h
	Revise clinic capacity	New clinic template Monitor demand/ capacity Maximise capacity	1.'Reserve' 2 week wait appt., only fill 1-2 weeks before each clinic 2.Weekly reviews of available slots 3.Fill in all cancellations 4.Ad-hoc New two week appt./ move some follow-up patients in PENS led clinics
			Patients & Families feedback Involve Management Education and training for all staff (ED & Paed teams/ Admin staff)

Process map

Patient and Family journey before ...

Patient and Family journey after

PDSA cycles

Examples of our PDSA cycles

Cycle 5: First seizure referral pathway completed. Education sessions, visual prompts to reinforce learning. Goal to see First seizure referrals within two weeks achieved!

Cycle 4: Epilepsy Pathway coordinator. Regular contact, weekly meetings with Consultant. Issues: Ongoing issue: delay in hospital referrals.

Cycle 3: One Consultant to triage and keep records of 2 week wait referrals. 24-48h reviews and action of First seizure referrals. Issues: improved triaging & matching demand/capacity; variability in referring practice

Cycle 2: 'Reserve' First seizure (2 week wait) slots each clinic. Continue to record data on referrals (demand) and capacity. Start revise referral pathway. Issues: multiple people involved, recording of referrals inconsistent – duplication/ missed appointments.

Cycle 1: First seizure (2 week wait) slots introduced. Separate waiting lists for New appointments – First seizure (2 weeks) and Routine (4 months). Issues: multiple sources for referrals, multiple people involved in triage and keeping the lists - variation in practice, 2 week wait slots not 'reserved' so other patients also booked in these slots.

60% First seizure referrals to be seen within two weeks by May 2023.

What our tests revealed

Referral process tests

Triaging process tests

What worked well?

One end point for all referrals and record keeping

Clinic tests

Data/Results/Patient engagement feedback

% Referrals seen in 2 weeks Sept-22 to May-23

Questions for patients and families

Team personal learning/Team highlights

- We are a newly formed team and EQIP project brought us together quicker - we have learned each other's strengths and worked well to complete the project
- Wide consultation at the beginning and close collaboration with all the interested parties through the project was key
- Breaking down our task in to manageable pieces using a structured framework, setting specific timelines to review changes and being disciplined in doing it helped us achieve our goal
- Feedback from our patients and their families and seeing that we are making a difference motivated us to keep going

Successes/Challenges

Successes
- **We have achieved our goal!**
- Improved safety at discharge
- Listened to patients and families
- Enlisted our Service Manager's support early on
- Consulted and collaborated well with other teams
- Kept everybody updated and informed
- Consolidated our service and showcased our success

Challenges
- First seizure pathway/ electronic referral form and disseminating information took longer than estimated
- Project aim changed part way through programme meaning lost time in the initial stage
- Patient and family feedback should have been gained throughout process
- Ambitious to undertake project whilst setting up new service

Next steps

Assessing impact through case studies

Since the launch of the EQIP in 2019, most participant paediatric epilepsy service teams have experienced a transformation in terms of the skills learned from expert trainers and improved team leadership. Teams have benefited from the knowledge of methodologies provided through online webinars, available resources and templates to further understand how to plan, measure and test QI. Monthly coaching and support have facilitated continuous progress, fostering incremental changes in team interactions and overall service delivery. The training has served as a catalyst for teams embarking on their improvement journey, extending their change ideas beyond initial testing areas. The teams are now more confident in sharing best practices locally through network meetings, contributing to a culture of continuous improvement.

Case studies and examples of their team project journey are available on the EQIP website, which outline the challenges of overcoming barriers and ideas, both adopted and abandoned. Evidence collated by teams in the form of data, photos or images of engagement, and project outcomes are included within the case studies. Accompanying presentation video recordings that showcase their work are accessible to facilitate shared learning and help inspire other paediatric epilepsy service teams who may want to begin their own QI journey. Note that the case studies that include the outcomes of their national audit results cannot be solely attributed to the outcomes of the project interventions developed during the RCPCH EQIP.

National service improvements

The national service impact on NHS services can manifest in various ways, including by showcasing improvements and contributions at a broader level. EQIP teams located within various OPEN UK regional networks have facilitated the spread (the process by which we take change ideas beyond the initial area of testing to new areas or teams) of QI knowledge and skills by:

- Teams sharing their insights into their improvement journeys at internal MDT and network meetings.
- Collaborative efforts between NHS services have demonstrated shared learning on improvement that can be applied across multiple regions or specialties.
- Trust service teams are exploring with young people the adoption of mental health wellbeing packs developed by EQIP participant paediatric service teams.
- The training provided on the EQIP has contributed to the development of a skilled workforce, using a more measured approach towards the standardisation of practices in reducing wait times and developing first seizure pathways at a national level.
- Example project case studies have been shared on the Futures NHS website and with the National Epilepsy Oversight Group and the NHS England CYP Transformation team.
- Representatives from the EQIP project team, on behalf of the RCPCH, have active involvement in national health recommendations, discussions, and consultations in relation to the development of a National Epilepsy Bundle of Care, with the vision of helping to influence and shape healthcare approaches to service improvement.
- The participation of NHS services in the EQIP, a national programme, has led to the identification and dissemination of best practices by sharing successful interventions through conferences or online platforms, which contribute to the national knowledge pool.

Local service improvements

Each training wave since the pilot in 2019 has produced project interventions from multidisciplinary paediatric epilepsy teams that have been tested and adapted through making incremental changes within the following areas:

- Developing an integrated care pathway and increasing specialist input
- Digitalisation of the Epilepsy Passport
- Improving quality of electroencephalogram (EEG) recordings
- Improving emergency access to healthcare plans via the electronic patient record (EPR)
- Improving patient engagement leading to change in service
- Introducing telephone triage to support newly referred patients
- Mental health signposting pathways and screening tools
- Reducing waiting times for first seizure referrals
- Reducing wait times in clinics and for routine investigations
- Sudden unexpected death in epilepsy (SUDEP) risk discussion
- Transition pathways and communication to adult services

Service impact on reducing referral waiting times

NICE guidance recommends that epilepsy services should be able to offer newly diagnosed patients with epilepsy an appointment within 2 weeks from the time of diagnosis. The Epilepsy12 national audit[8] reported in 2021 that **19%** (392/2,106) of children and young people diagnosed with epilepsy were seen by a paediatrician with expertise in epilepsy within 2 weeks of first referral in England and Wales. **53%** (1,117/2,106) of children and young people diagnosed with epilepsy obtained an EEG within 4 weeks of request. Since then, the RCPCH highlighted this issue in 2023 and reported[9] that '*over 400,000 children were waiting for treatment amidst a child health crisis*' across paediatrics in the NHS.

The EQIP has worked with team participants on reducing variation in appointment waiting times for new seizure referrals from 8, 12 or even 16 week waiting times by mapping the patient journey, testing and gaining approval of new standardisation of appointment time allocations for new and review patients. Other examples of teams working towards reducing patient waiting times were for investigation appointments, such as EEGs. Using QI methodology tools, engagement skills and national Epilepsy12 audit data, teams were able to test, monitor and redesign pathway processes that were easier for patients and families to follow. Whilst on the EQIP, team participants reported achieving a reduction of waiting times from 16 weeks to 6 weeks and a reduction of appointment times from 12 weeks to 4 weeks.

Case study example: reducing EEG wait times

Nottingham University Hospitals NHS Trust, the neurophysiology team identified opportunities for improvement in EEG services which would involve collaborative work within the whole epilepsy team and would better meet the needs of children and young people with learning disabilities. The team used process mapping tools and patient engagement techniques to capture feedback and incorporate these into plans to improve processes and reduce waiting times.

Data captured from testing new processes showed in April 2020, the team were able to initially improve wait times and increase the percentage of patients who had full-quality EEGs recorded to over 95%, achieving their target. National Epilepsy12 audit data showed that in 2021, Nottingham University Hospitals NHS Trust has continued to maintain 100% of children and young people obtaining a first EEG, above regional and national averages. In 2021, there was a greater proportion of children and young people waiting less than 4 weeks for a first EEG.

Case study example: reducing clinic wait times

Royal United Hospitals Bath NHS Foundation Trust worked towards improving disparity and inconsistency in service provision by developing and implementing a pathway for first paroxysmal events, allowing review by paediatricians with special interest in epilepsy. The team used QI tools such as process mapping the patient journey to uncover barriers and gaps in service and improve the referral pathway, which achieved an increase in the number of patients processed through the new referral pathway. Local data captured from using Plan, Do, Study, Act (PDSA) cycles to test the new pathway provided evidence that the majority of patients were seen within 6 weeks of referral and 57% within 2 weeks. The team trialled the introduction of an epilepsy specialist nurse (ESN) phone call ahead of clinic review for the majority of patients, and national Epilepsy12 audit data reported the Trust's percentage of children and young people seen by a paediatrician with expertise in epilepsy within 2 weeks of first referral had continued to increase from 22% in 2020 to 47% in 2021, achieving above regional and national averages.

Reducing referral waiting times: top tips for service teams by service teams

Standardising processes:

- Begin mapping processes to identify bottlenecks, streamline the patient journey and evaluate existing processes to identify areas for improvement.
- Explore introducing a telephone contact service with an epilepsy nurse for children and young people presenting in emergency departments (ED), within 2 weeks of presentation following their first epileptic seizure.

Utilising technology:

- Explore the use of digital systems with admin assistants, secretaries and internal appointment booking departments to improve communication and coordination of appointment scheduling, which includes reminders and alerts.

Collaboration and communication:

- Establish clear communication channels to share information about patient status, appointments, processes among different healthcare teams involved in patient care such as ED, inpatient wards and GP professionals. Close collaboration with all the interested parties throughout is essential.
- Foster communication with booking departments and secretaries to help monitor opportunities for improving appointment systems to minimise delays.

Patient engagement:

- Involve children and young people in the improvement process by seeking feedback on their experiences and preferences. Contact patients and their families to gain a better understanding of immediate or urgent needs to help expedite their waiting time process.
- Contacting the parents and carers of children and young people with complex needs or learning disabilities prior to their investigation appointments can improve their clinic experience and provide an opportunity to answer any queries or anxieties from the patients and families.

Data monitoring and analysis:

- Implement regular monitoring of data related to wait times and patient flow.
- Utilise local and national data to identify trends, incorporating data-driven decision-making.

Staff training and resources:

- Provide training to staff on improved referral processes to ED teams, inpatient ward staff and when new staff members join the service.
- Senior members of staff should ensure that service teams have adequate resources to handle the patient caseloads, addressing any staffing or resource gaps.

Continuous improvement culture:

- Share ideas for reducing wait times within network and MDT meetings and implement small, incremental changes to enhance overall efficiency.

Service impact on developing mental health support and pathways

According to NICE guidance, there is a higher prevalence of mental health difficulties, learning disabilities, neurodevelopmental comorbidities and a higher risk of suicide in people with epilepsy compared with the general population. The National bundle of care for children and young people with epilepsy,[10] published in October 2023, recommends **CYP over the age of 5 years with epilepsy should have their mental health screened routinely within epilepsy clinics. CYP with epilepsy who have been identified as requiring additional support with their mental health and wellbeing should be referred to an appropriate service to manage their mental healthcare. Self-help resources to support wellbeing should be made available to CYP with epilepsy.**

Participant paediatric epilepsy teams identified the lack of support and access to mental health services for their patients and families and began to address these issues by testing mental health screening tools to assess the level of mental health support required for patients. Some developed mental health wellbeing packs or signposted information leaflets that provide details of organisations who can offer emotional support/mental health advice. Teams have ongoing communications with Child and Adolescent Mental Health Services (CAMHS) and Improving Access to Psychological Therapies (IAPT) to support patients who are identified by the team to have significant mental health symptoms. Teams have collaborated with Children and Young People Wellbeing Practitioners and piloted screening tools with patients which led to identifying children and young people with significant mental health problems who could be referred to local mental health services.

Case study example: mental health screening

The Epsom and St Helier University NHS Trust aimed to improve the way mental healthcare including learning and educational issues in young patients with epilepsy, were detected and how care is delivered. The team worked towards developing a standardised screening pathway to identify the mental health status of their patients. They found cause and effect QI tools helpful and researched existing screening tools already in place within the epilepsy community. They tested the suitability of two screening tools, the Strengths and Difficulties Questionnaire (SDQ) and HEADS-ED, with their patients. They found patient and family engagement played a crucial role in capturing preferences for the screening tool. HEADS-ED was identified as the more suitable tool for both patients and the service team, leading to outcomes that provided a better understanding of patients' support needs, establishing referral pathways. For the first time, eight patients were identified: two with having significant mental health conditions, two with minor conditions, and the rest with no identified mental health conditions.

National Epilepsy12 audit results showed that in 2022, Epsom and St Helier University NHS Trust was able to refer children and young people for clinical psychology assessment to either within or outside their Trust. In 2022, the Trust routinely formally screened for mental health conditions using screening questionnaires. The percentage of children and young people with evidence of neurological examination at first paediatric assessment increased from 89% in 2021 to 91% in 2022, meeting national average results.

Case study example: mental health signposting

Warrington and Halton Teaching Hospitals NHS Foundation Trust responded to patient feedback emphasising the need for increased mental health and wellbeing support. Using leadership and engagement skills, the team initiated discussions with senior Trust colleagues to reallocate funds towards appointing a Children and Young People Wellbeing Practitioner. Collaborating with CAMHS, they established a new pathway for patients with complex mental health conditions and for the first time, the service was able to signpost patients to schools within the area who have allocated Children and Young People Wellbeing Practitioners offering additional support. Achieving their goal in 2022, the service implemented a 'Happy Strong Healthy Mind' support package in collaboration with children, young people and mental health agencies. This package, consisting of 10 wallet-sized cards, offers tailored resources, advice, and signposting to children over 11 years old and has since been adapted and adopted locally by service teams within their region and team participants on the EQIP.

Mental health support pathways: top tips for service teams by service teams:

Early engagement and patient involvement:

- Engage patients, families, and carers early in the process to understand their needs and preferences regarding mental health support.
- Collaborate with patients and families in the design and development of mental health screening tools, resources and support packages to ensure they are useful and meet their support needs.
- Ask patients and families to advise on the organisations, charities, apps, groups and forums that they have found informative or supportive with their wellbeing.
- Parents/carers may need more time with your service team when addressing mental health support because they have reduced support elsewhere.

Collaboration and partnership:

- Where possible, establish strong links with local/community mental health services, such as CAMHS and IAPT, beginning with inviting them to team meetings.
- Foster relationships with local school head teachers, youth workers, play specialists, third sector/charities and mental health agencies within the area to enhance the support network for children and young people with epilepsy within community settings.
- Foster leadership skills within the team to drive initiatives to engage with stakeholders and navigate challenges in improving mental health pathways.

Screening and assessment:

- Screening tools tested by EQIP teams: The Lucy project, HEADS-ED, SDQ, Five-Well-Being tool by WHO, The Outcome Rating Scales (ORS) and Session Rating Scales (SRS), CHECC (CHild and young person Epilepsy Concerns Checklist) developed by Hampshire Hospitals NHS Foundation Trust (see case study on the website).
- Develop standardised screening pathways by working with patients to test validated tools that both the service staff and patients find easy to use and score, to identify the mental health needs in paediatric epilepsy patients.

Resource development:

- EQIP teams have identified that many patients have anxieties about their condition and worries about life in general and have created resources, that you can tailor, that provide practical support and signposting for children and young people to organisations offering emotional support and mental health advice.

Feedback mechanisms:

- Parents/carers and children and young people often have different worries. Consider addressing parental worries to ensure it limits the impact on their child/children. Capture feedback separately for both parents and their children.
- Regularly review and update digital resources and tools in response to feedback from patients, families, and carers from healthcare professionals and other stakeholders.

Measuring impact:

- Establish clear metrics to measure the impact of mental health improvements, such as referral rates, patient outcomes, and feedback from various stakeholders. Regularly review and analyse national audit data to assess the effectiveness of mental health interventions.

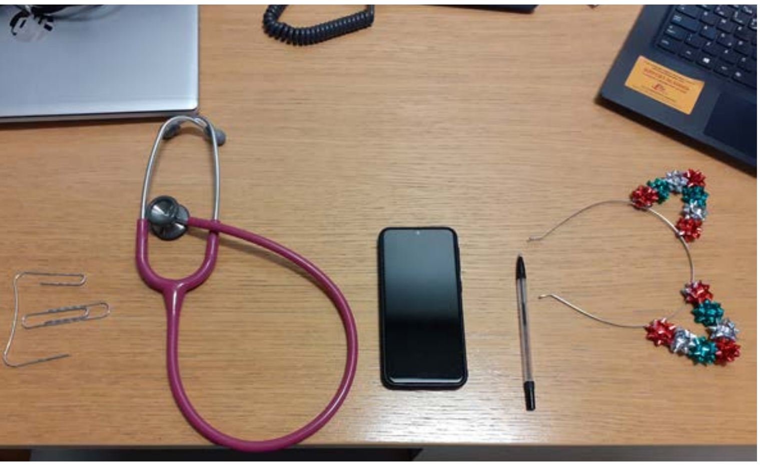
Sustainability and spread:

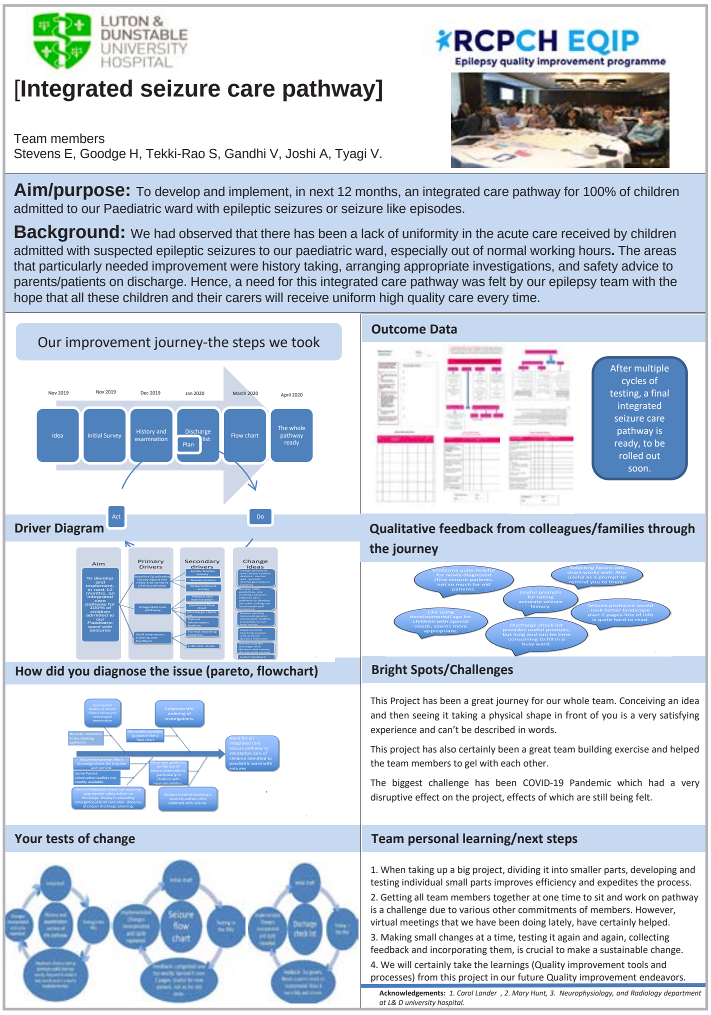
- Ensure that the improvements made in mental health pathways are sustainable and can be followed by service staff who join the service and share your learning with epilepsy services within and beyond the region.

Participant paediatric epilepsy service teams received engagement materials from the RCPCH &Us team.

QI patient engagement activities during training launch.

Royal Berkshire Hospital paediatric epilepsy team participation in QI training activities during training launch in 2019.





LUTON & DUNSTABLE UNIVERSITY HOSPITAL

RCPCH EQIP
Epilepsy quality improvement programme

[Integrated seizure care pathway]

Team members
Stevens E, Goodge H, Tekki-Rao S, Gandhi V, Joshi A, Tyagi V.

Aim/purpose: To develop and implement, in next 12 months, an integrated care pathway for 100% of children admitted to our Paediatric ward with epileptic seizures or seizure like episodes.

Background: We had observed that there has been a lack of uniformity in the acute care received by children admitted with suspected epileptic seizures to our paediatric ward, especially out of normal working hours. The areas that particularly needed improvement were history taking, arranging appropriate investigations, and safety advice to parents/patients on discharge. Hence, a need for this integrated care pathway was felt by our epilepsy team with the hope that all these children and their carers will receive uniform high quality care every time.

Our improvement journey-the steps we took

Outcome Data

After multiple cycles of testing, a final integrated seizure care pathway is ready, to be rolled out soon.

Driver Diagram

Qualitative feedback from colleagues/families through the journey

- Proforma quite helpful for newly diagnosed /first seizure patients, not so much for old patients.
- Selecting Neuro-obs chart works well. Also useful as a prompt to remind you to them.
- Useful prompts for taking accurate seizure history.
- Like using developmental age for children with special needs, seems more appropriate.
- Seizure proforma would look better landscape over 2 pages-lots of info is quite hard to read.
- Discharge check list provides useful prompts, but long and can be time consuming to fill in a busy ward.

How did you diagnose the issue (pareto, flowchart)

Bright Spots/Challenges

This Project has been a great journey for our whole team. Conceiving an idea and then seeing it taking a physical shape in front of you is a very satisfying experience and can't be described in words.

This project has also certainly been a great team building exercise and helped the team members to gel with each other.

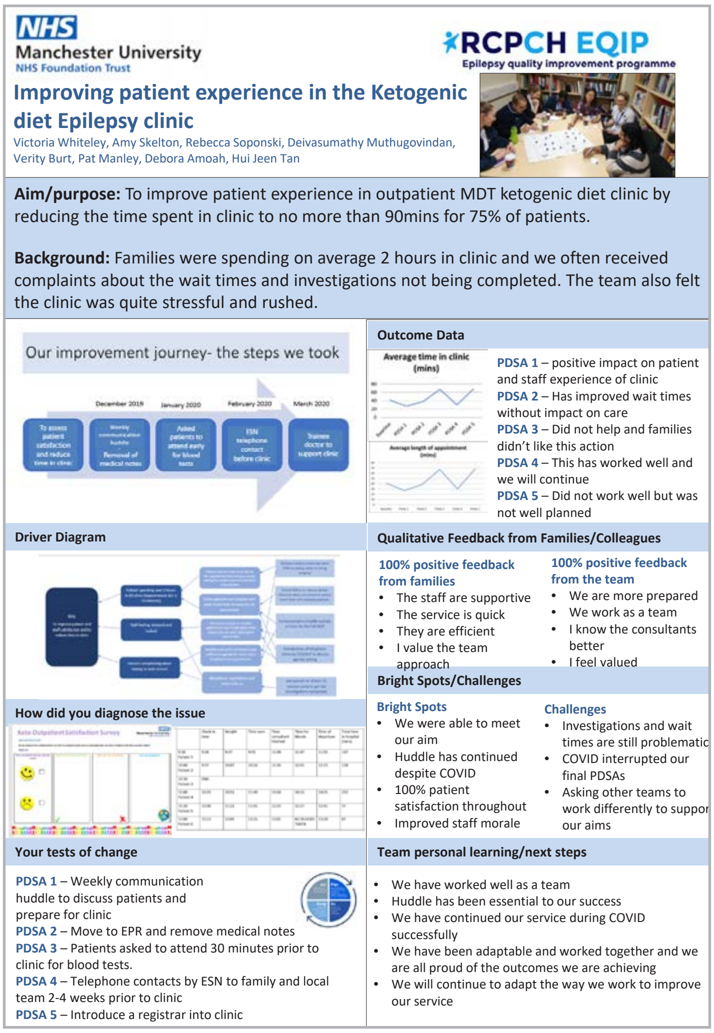
The biggest challenge has been COVID-19 Pandemic which had a very disruptive effect on the project, effects of which are still being felt.

Your tests of change

Team personal learning/next steps

1. When taking up a big project, dividing it into smaller parts, developing and testing individual small parts improves efficiency and expedites the process.
2. Getting all team members together at one time to sit and work on pathway is a challenge due to various other commitments of members. However, virtual meetings that we have been doing lately, have certainly helped.
3. Making small changes at a time, testing it again and again, collecting feedback and incorporating them, is crucial to make a sustainable change.
4. We will certainly take the learnings (Quality improvement tools and processes) from this project in our future Quality improvement endeavors.

Acknowledgements: *1. Carol Lander , 2. Mary Hunt, 3. Neurophysiology, and Radiology department at L& D university hospital.*



NHS
Manchester University
NHS Foundation Trust

RCPCH EQIP
Epilepsy quality improvement programme

Improving patient experience in the Ketogenic diet Epilepsy clinic

Victoria Whiteley, Amy Skelton, Rebecca Soponski, Deivasumathy Muthugovindan, Verity Burt, Pat Manley, Debora Amoah, Hui Jeen Tan

Aim/purpose: To improve patient experience in outpatient MDT ketogenic diet clinic by reducing the time spent in clinic to no more than 90mins for 75% of patients.

Background: Families were spending on average 2 hours in clinic and we often received complaints about the wait times and investigations not being completed. The team also felt the clinic was quite stressful and rushed.

Our improvement journey- the steps we took

Outcome Data

PDSA 1 – positive impact on patient and staff experience of clinic
PDSA 2 – Has improved wait times without impact on care
PDSA 3 – Did not help and families didn't like this action
PDSA 4 – This has worked well and we will continue
PDSA 5 – Did not work well but was not well planned

Driver Diagram

Qualitative Feedback from Families/Colleagues

100% positive feedback from families

- The staff are supportive
- The service is quick
- They are efficient
- I value the team approach

100% positive feedback from the team

- We are more prepared
- We work as a team
- I know the consultants better
- I feel valued

How did you diagnose the issue

Bright Spots/Challenges

Bright Spots

- We were able to meet our aim
- Huddle has continued despite COVID
- 100% patient satisfaction throughout
- Improved staff morale

Challenges

- Investigations and wait times are still problematic
- COVID interrupted our final PDSAs
- Asking other teams to work differently to suppor our aims

Your tests of change

PDSA 1 – Weekly communication huddle to discuss patients and prepare for clinic
PDSA 2 – Move to EPR and remove medical notes
PDSA 3 – Patients asked to attend 30 minutes prior to clinic for blood tests.
PDSA 4 – Telephone contacts by ESN to family and local team 2-4 weeks prior to clinic
PDSA 5 – Introduce a registrar into clinic

Team personal learning/next steps

- We have worked well as a team
- Huddle has been essential to our success
- We have continued our service during COVID successfully
- We have been adaptable and worked together and we are all proud of the outcomes we are achieving
- We will continue to adapt the way we work to improve our service

Service impact on developing transition pathways

According to NICE guidance, transition planning should be developmentally appropriate and take into account each young person's capabilities, needs and hopes for the future. Children and young people with epilepsy should have a designated named worker responsible for initiating and planning for transition, taking into account any co-existent conditions. Practitioners should start planning for adulthood from year 9 (age 13 or 14) at the latest. Epilepsy12 national audit data reported in 2021[11] that **60%** (71/119) of Health Boards and Trusts reported having an outpatient service for epilepsy where there is a presence of both adult and paediatric professionals and **66%** (79/119) of Health Boards and Trusts used structured resources to support transition to adult services.

It is key to recognise inefficiencies in existing transition procedures and the importance of early patient engagement and fostering relations between paediatric and adult services. As a first step, participant paediatric epilepsy teams focused on establishing a standardised administration process for information/resources related to transition, aiming to better prepare children and young people for their move to adult services. Training from the RCPCH &Us Children and Young People's Engagement Team has been essential for teams employing proactive patient engagement and gathering feedback from children and young people, families and carers to develop empowering tools and information. This initiative culminated in the creation of a dedicated transition nurse-led clinic, fostering understanding and readiness among patients and families transitioning from child to adult epilepsy services.

Case study example: developing a transition pathway

Croydon Health Service NHS Trust has an ethnically and culturally diverse population with clear areas of need and social deprivation. There were no clear transition pathways. Patients are informed from 14 years old that they will be transitioning to adult services, which can bring on additional anxieties to the children and young people, parents and carers. Using QI planning tools, the team used driver diagram visualisations to plan patient engagement activities for teenagers from 14 years of age to incorporate their ideas and co-produce changes in the way transition services are delivered.

The service team reviewed national Epilepsy12 audit data and performed process mapping of their patient referral pathway to better understand where the process breaks down. Other project improvements included hosting a dedicated workshop engagement session for the first time, led by drama therapy professionals to elicit patient and family feedback and ideas for change. The team developed and tested information and signposted resources, including versions for children and young people with learning difficulties. The introduction of nurse-led clinic sessions and the effects on transition processes were tested/trialled and colleagues were engaged with on a range of opportunities for dedicated multidisciplinary discussions, focused on transition care. Service improvements meant the team were able to establish continuous patient and family engagement systems to ensure services are adapting to patient and family needs, with the support of a drama therapist to continue open communication.

National Epilepsy12 audit results showed that in 2021 and 2022, Croydon Health Service NHS Trust's paediatric epilepsy outpatient service had a presence of both adult and paediatric professionals in single joint transition appointments. Additionally, 100% of children and young people transferred to adult services transitioned through this joint professional process, achieving above regional and national averages.

Transition pathways: top tips for service teams by service teams

Early engagement and communication:

- Engaging patients and families in transition discussions from an early age, starting around 14 years, could prove beneficial to begin the preparation process. Foster open and continuous communication to prepare children and young people for the transition process.

MDT collaboration:

- Early engagement and planning with the adult epilepsy services opens communication and support for patients and families. Where possible, look for opportunities that support both services to create buy-in.

Patient-centric approach:

- Utilise a patient-centric approach by involving patients and families in the co-design of transition services and work with them to tailor transition plans to their individual needs and preferences.
- Many different approaches to developing a transition pathway are necessary. A one-size-fits-all approach is not sufficient to meet the needs of children and young people, particularly in areas with large variations in socio-demographics, including parental education levels.

Dedicated transition nurse-led clinics:

- Where services do not have access to a transition nurse, consider developing a nurse-led clinic that supports transition pathways.
- Trust senior management should ensure both paediatric and adult healthcare teams are well equipped to address the specific challenges associated with transitioning from child to adult services.

Clear pathway documentation:

- Develop clear and comprehensive documentation outlining the transition pathway for both multidisciplinary healthcare professionals and patients.
- Mapping the patient transition journey/pathway highlights the process to uncover gaps where the system breaks down, creating opportunities to improve the patient/family experience.

Continuous feedback and improvement:

- Implement mechanisms for obtaining feedback to maintain standards from patients, families and healthcare professionals involved in the transition process.
- Use feedback to drive continuous improvement, making adjustments that address cultural aspects in clinical service to the transition pathway as needed.

Education and training:

- Provide education and training on transition plans to healthcare professionals involved in the transition process.
- Discuss within your team and service management ways to become prepared to support patients and families during the transition journey.
- Learn from services within your network or national benchmarking on best practice approaches to transition.
- Work with parents and carers on how they can help to empower their child/children with managing their condition and gaining independence as they progress through transition.

Service impact on reducing variation in a number of topic areas

NHS services strive to resolve the disparity in the quality of care provided to children and young people with epilepsy. The NHS England National Epilepsy Bundle of Care reports that variation in the delivery of key aspects of epilepsy care continues to persist, such as access to epilepsy specialist nurses and the provision of information on SUDEP.[11] Publication of the bundle will help to support their ambition to improve the quality of care for all children and young people with epilepsy. This includes working with systems to ensure they take a whole-system approach to the diagnosis, management and treatment of epilepsy. This will include mapping pathways of care, supporting the delivery of developmentally appropriate care and sharing examples of good practice.

Team participants have worked on developing and implementing the redesign of seizure pathways for new patients diagnosed with epilepsy, using engagement and leadership skills to develop an adapted digital Epilepsy Passport, to communicate information to children and young people with the aim of improving their care and reducing risk. Teams updated first afebrile seizure referral proformas, writing new process guidance to be approved by internal governance departments and drafted an entirely new integrated pathway document to be used with EDs to increase the accuracy of diagnosis. The document was tested and feedback was incorporated into the final version.

Case study example: developing an integrated care pathway

Recognising the inconsistencies in the acute care provided to children with suspected epileptic seizures, especially outside normal working hours, Luton and Dunstable University Hospital Trust decided to address this issue. The team focused on developing and implementing an integrated care pathway for children admitted to the hospital with seizures. Through meticulous planning, mapping and iterative PDSA cycles, the team engaged with patients, families and healthcare staff to create a comprehensive integrated pathway document. Incorporating feedback received on the new documentation, the team successfully embedded changes in processes within the acute paediatric assessment unit. National Epilepsy12 audit results for Luton and Dunstable University Hospital Trust paediatric epilepsy service showed increased percentages of children and young people receiving an appropriate paediatric assessment (63%), achieving above regional average and equalling national average results.

Case study example: SUDEP risk

Upon reviewing Epilepsy12 audit data, Oxford University Hospitals NHS Foundation Trust paediatric epilepsy service demonstrated proximity to the national average (44%), with 40% of families feeling conversations around SUDEP were occurring and information provided within the first year of care. However, in 2020, there was a decline to 29% of responses for the Trust, indicating a drop below the national average. Despite challenges during the pandemic, the team proactively created a checklist resource with a clear plan for implementation. They increased communication within the team and other healthcare colleagues and attended British Paediatric Neurology Association (BPNA) events to facilitate collection of feedback, ensuring the appropriateness of resource content to embed in practice. The team achieved buy-in from healthcare staff and qualitative data reflected a positive shift in attitudes toward discussing SUDEP within the Trust. Collaborating opportunities on the complete Children's Seizure Safety Checklist with SUDEP Action led to sustainable improvement with the checklist set for release in 2024.

National audit results showed that the percentage of children with evidence of care planning that encompassed provision of information on SUDEP increased from 35% in 2021 to 58% in 2022, surpassing the national average. The percentage of children with documented evidence of discussion for care planning have increased in all five core elements of care planning in 2022, compared with results in 2021, achieving above regional and national averages.

Case study example: digitalisation of Epilepsy Passport

The University hospitals of Morecambe Bay NHS foundation Trust team identified crucial improvements based on feedback from patients, families, colleagues, and local providers, revealing inconsistencies in accessing patient information, care plans, safety concerns, and fragmented communication about epilepsy conditions. Using process tools and stakeholder mapping, the team orchestrated the development of standardising information that is accessible digitally to professionals, service users, emergency services, and education. The team created a digital Trust version of the RCPCH Epilepsy Passport, and a collaborative effort with IT colleagues resulted in an integrated electronic editable version within the Trust EPR system. Post-EQIP, the team's sustainable project receives positive feedback and is recognised as a valuable resource in MDT meetings among other healthcare professionals.

Case study example: improving emergency access to healthcare plans

York Teaching Hospitals NHS Foundation Trust identified challenges in the management of patients with complex epilepsy in the ED due to misplaced paper copies of individualised emergency seizure plans. Additionally, 70% of families reported the service held sufficient information; however, only 20% felt the current system was helpful to their child and only 30% felt the schools found the current communication useful. Despite the challenges experienced during the pandemic, the team showcased leadership skills, fostering engagement with internal Trust departments, children, young people and healthcare staff. The team successfully implemented an alert system for individualised emergency seizure plans, achieving a 100% upload rate to the Trust system, and developed structured content for a locally tested Epilepsy Passport. National Epilepsy12 audit results reported that 100% of children and young people diagnosed with epilepsy in York Teaching Hospital NHS Foundation Trust had documented evidence of communication regarding relevant core elements of care planning, with most core elements achieving 100%, above regional and national average results. 80% of children and young people diagnosed with epilepsy and on rescue medication had a parental prolonged seizure care plan.

Reducing variation: top tips for service teams by service teams

Reducing variation in waiting times:

- Utilise QI methodologies to identify bottlenecks and streamline processes.
- Teamwork is key for any project.
- Continuously reviewing referral processes as a team can help to better understand each patient pathway to secure the correct allocation into the most appropriate service or clinician, reducing variation and wait times.
- Systematic analysis of current system failures is key, followed by a structured approach to your method of change. Using QI methods will ensure changes are embedded.
- Regularly monitoring national Epilepsy12 audit performance and measuring waiting times helps aim for consistency and efficiency.
- EQIP teams have found using a "Patient Story" to create buy-in from several consultant colleagues has been effective. Framing changes in this way brings a powerful dimension to discussions to motivate change.
- When planning several interventions, testing on a small scale allows faster learning and helps implementation and change for each patient. Get into the practice of duplicating good practice instead of reinventing the wheel.
- Share your work widely; celebrate your victories and your challenges with colleagues in Trust meetings and at local epilepsy networks and national events/platforms.

Reducing variation: top tips for service teams by service teams (continued)

SUDEP discussion:

- Develop and disseminate resources that facilitate conversations about SUDEP and processes to pre-warn parents and carers about the discussion before clinic appointments. Appointment letters can offer a means for communication with parents and carers to agree on when it is appropriate to explain SUDEP with or without the patient(s) at the appointment.
- Provide training for healthcare professionals to enhance their skills and confidence in discussing sensitive topics with patients.
- Access the Oxford University Trust case study to understand how they produced their checklist.
- Incorporate inclusive communication methods for the diverse cultural populations that you provide care for.
- Engage with local charity organisations such as SUDEP Action to help with communication plans and techniques that addresses inequalities in an appropriate way for SUDEP discussion with parents and carers, especially for those that may have learning disabilities or complex needs.

Care planning:

- Reduce variation by standardising and creating sustainable processes for care planning to ensure consistency and comprehensiveness, especially for new staff joining the team.
- Involve schools, youth workers, patients, families and caregivers in the care planning process.
- Implement training for healthcare professionals on effective care planning for children and young people with epilepsy.
- Establish regular review cycles and continue to make ongoing adjustments.

Emergency planning:

- Develop individualised and easily accessible emergency seizure plans for patients.
- Implement alerts or systems that help ED teams quickly access vital information about individualised emergency plans.
- Regularly review and update emergency planning tools based on patient and family feedback.

Patient and family engagement:

- Collating feedback using short and focused questions is preferred by children and young people.
- Instant feedback is powerful and can be achieved by verbally asking children, young people, parents and carers simple and easy questions before or at the end of clinic. This can also help improve their confidence about the service provision.
- Exploring different methods of interaction with children and young people and families is a great way to test and evaluate the service.
- Increased patient engagement helps to triangulate data locally to evidence the changes required, which can be underpinned by NICE guidance and audit results from Epilepsy12.
- Effective patient engagement practices can feed into business planning, for example, when highlighting how having an epilepsy specialist nurse is vital to the level of care provided by the service.
- Learn from the resources produced and the voices of the Epilepsy12 Youth Advocates, in collaboration with RCPCH &Us.
- EQIP teams discovered common topics that families want to know about through engagement practices. The common themes were:
  - What is epilepsy?
  - How can I keep my child safe?
  - How can we get counselling support?
  - How long will the treatment last?
  - Will my child be cured completely?
  - Will my other children get epilepsy?
- Clinical assumptions of what patients and families need and want may not align with the feedback from patients and families.
- It is important to consider the defined age range you plan to engage with, as one size does not fit all. How you may interact with a cohort of young children may differ from how you may interact with a cohort of teenagers.
- It can be effective to show parents and families that services have listened to and understood their views by developing and displaying visual aids or information that communicate “you said, we did”.
- Feedback from parents and children often highlights the difficulty they have with understanding the clinical terminology used.

Service impact on improving ketogentic clinics in tertiary services

The National Epilepsy Bundle of Care provides recommendations, in line with NICE guidance, on children and young people meeting criteria for tertiary neurology referral receiving timely access to the relevant tertiary specialist with expertise in managing complex epilepsy. Treatment via a high fat, controlled protein, low carbohydrate diet is called a ketogenic diet. This is a medical therapy used for drug-resistant epilepsy and can be effective at reducing seizure frequency and intensity in all types of epilepsy. The Epilepsy12 audit captures data on the professional input received by children and young people diagnosed with epilepsy, including whether they were seen by specialists such as paediatric neurologists, ketogenic dietitians and specialist nurses within tertiary care services.

Although the programme has not experienced many tertiary services joining the EQIP to improve waiting times or improve review and assessment of care provided for children with drug-resistant epilepsy. We hope to increase our engagement with these services to gain a better understanding of challenges with referral pathways preventing systematic improvements and reduced variation.

Case study example: reducing ketogenic clinic waiting times

Manchester University NHS Foundation Trust identified that families were spending an average of 2 hours in clinic and this often led to complaints received about the long wait times and families leaving before investigations were completed, impacting patient care. The clinic appointments often ran behind and staff felt under pressure to work faster, feeling unprepared prior to clinics due to the lack of accurate patient information within hospital notes. Despite the effects of the pandemic in 2020, the service team underwent a transformative process that involved team building to strengthen communication amongst the team and a service review that they were able to map against "what good would look like". They took small steps to improve the gaps and barriers in the service and involved patients and their families within the review and acted upon their feedback. The team worked together to collate data during the process on the effectiveness of the changes made and the adjustments that were required to the new processes they were developing, establishing a continuous feedback loop. By the end of the programme, the team achieved the following:

- Reduced clinic times by an average of 29 minutes.
- Time taken to weigh patients was reduced by 50% and patients were seen 10 minutes sooner in clinic.
- The team demonstrated improved communication within the team via the introduction of weekly huddles with the whole team to reduce staff stress by discussing the patients' needs and identifying any missing information, increasing clinic preparation.
- Trialling a telephone contact service with an ESN for patients and families and the local team 2-4 weeks prior to clinic to discuss any concerns/ queries has improved the family's relationship with the ESN.
- Implemented advanced clinical practitioner-led consultant replacement clinics.
- Developed a patient satisfaction survey with an option to provide information on what the clinic does well and identify areas for improvement. Achieved 100% satisfaction with clinic experience on baseline assessment.
- Developed a template for the team to record data on identified issues around clinic wait times, which included arrival time, appointment time, time to get anthropometry, time to see consultant, time appointment ended, when bloods were taken, time the patient left clinic.

Improving tertiary care referral pathways: top tips for service teams by service teams

Training and education:

- Actively participate in programmes like the RCPCH EQIP to gain insights, share experiences and collaborate on improving waiting times and assessment of referral processes.
- Leverage the expertise and resources offered by such programmes to address specific challenges unique to tertiary care services.
- Seek to gain better understanding of how to engage secondary services to communicate and educate them on how to appropriately refer patients with complex needs to tertiary services.
- Adopt a systematic approach to improvement by implementing small, manageable changes in processes.

Prioritise team building and leadership:

- Develop strong leadership skills that can guide the team through improvements, create a shared vision, and inspire commitment to achieving excellence in patient care.

Strengthen engagement with patients and healthcare teams:

- Establish communication channels that facilitate open dialogue, ensuring that the needs and concerns of both patients and healthcare providers are addressed.

Reduce variation in care:

- Identify areas of variation in care delivery using diagnostic QI tools and measurement data to help develop strategies to standardise processes, ensuring consistent and equitable services for all patients.
- Collaborate with other tertiary care services and share best practices to collectively reduce variation in care.

EQIP microsite:
Case studies, posters and presentations

Improving patient engagement processes

Mental health and wellbeing

Transition pathways

Tertiary service pathways

Reducing variation

Evaluation of service team outcomes

RCPCH EQIP wave 1 (pilot) teams, evaluation results, 2019/2020

In 2019/2020, we asked individual members of the 12 pilot teams to submit a pre/ post programme questionnaire to evaluate what they had learned, their project outcomes and the effectiveness of the pilot once teams had completed the EQIP training. A full report of responses received can be found on the EQIP website; only a summary of some responses is shown within this report.

- A total of 85 service staff from 12 Trusts applied to participate in the EQIP and after some changes to team member participation, a total of 83 service staff completed the EQIP.
- Eighty-five participant service staff completed most or part of the course pre-assessement surveys and a total of 50 participant service staff from the 12 Trust teams completed most or part of the post-evaluation survey.

The number of individual participants responding to pre/post-evaluation responses varied. Where necessary, e.g. for certain multiple-choice questions, only a summary of post-evaluation responses have been reported, as direct pre/post comparison at individual respondent level could not be performed.

The analysis of the qualitative data demonstrates that despite the effects of the COVID-19 pandemic, the EQIP pilot successfully enhanced teamwork and communication among participants. The following are examples of the questions and responses to the questions asked in 2019/2020.

1. Describe the key benefits of participating in the EQIP with your team.

Qualitative data was captured from team participants on team working and communication.

- *“Our team is split over two sites, and we work very differently in some areas and would rarely meet before this project. I feel this has made us all work more closely as a team.”*
- *“Teamwork across two hospital sites. Making time to do QI and networking nationally.”*
- *“Better communication and inter-team relationships.”*
- *“Excellent chance to get together outside of usual work demands to focus on a key area together.”*
- *“Allowed us as a team to become familiar with approaches to service improvement. It gave us an opportunity to brainstorm ideas and develop a greater team bond through the training weekend and through meeting regularly after to achieve the project. It has allowed us to identify other gaps within our service and improve communication drastically.”*
- *“Sense of team and shared purpose much stronger.”*
- *“Improved team working; improved knowledge and confidence to undertake future projects.”*
- *“Brought us together as a team. Allowed us to measure our service using our feedback from the service users.”*
- *“Team building across multiple professions.”*
- *“Improved team cohesion, motivated the team, improved cross-site working.”*
- *“Team building, identifying areas for improvement and implementing a specific project.”*
- *“Uniting the team through identifying and working towards patient-centred goals.”*
- *“Bringing the team together. Being in contact with the RCPCH to encourage change.”*

2. How confident is your team in using the following QI tools to analyse your systems and processes?

Figure 5 shows that in 2019/2020 pre-assessment and post-assessment responses from team participants on how confident their team were in using QI tools to analyse systems and processes, using a scale of 1 to 5, where 1 is “not confident” and 5 is “very confident”. In pre-assessment results, 26% (22/85) team participants responded, and 74% (63/85) team participants did not respond. In post-assessment results, 84% (42/50) team participants responded, and 16% (8/50) team participants did not respond.

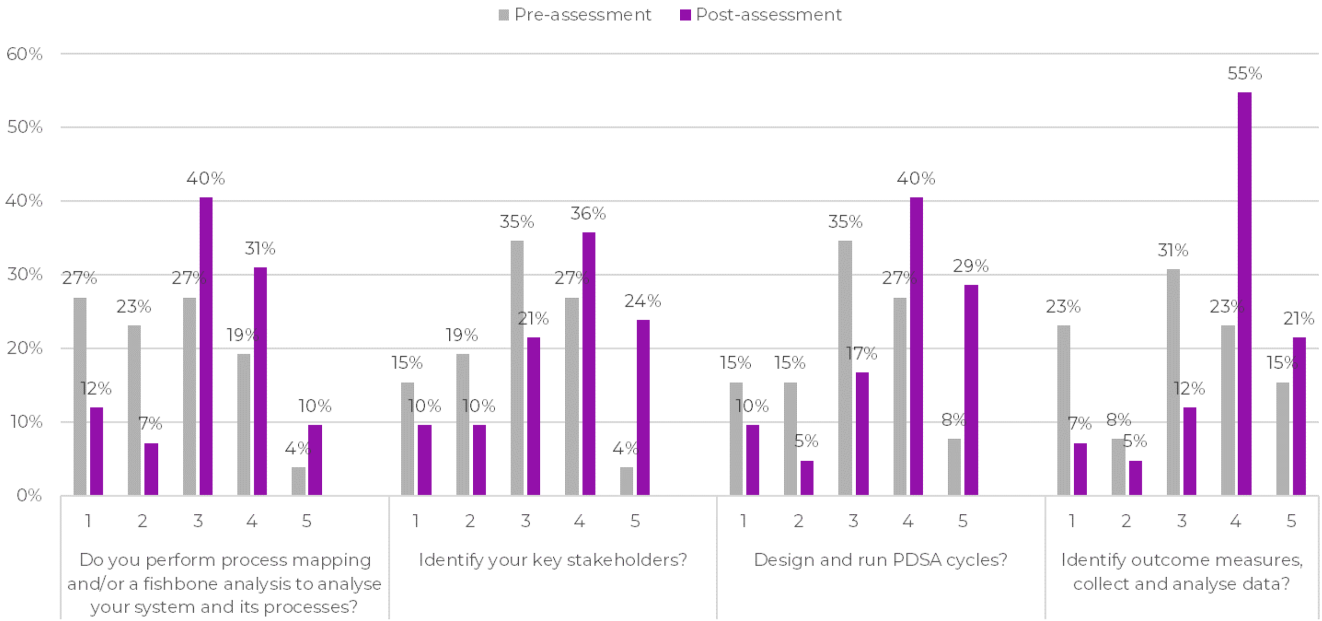


Figure 5: In the 2019/2020 pre/post-assessment, responses from team participants reported on how confident they were in using QI tools to analyse systems and processes, using a scale of 1 to 5, where 1 is “not confident” and 5 is “very confident”.

3. Does your team review their Epilepsy12 audit results?

Figure 6 shows pre-assessment and post-assessment responses from team participants that reported on whether they review their Epilepsy12 national audit results. In pre-assessment results, 80% (68/85) team participants responded, and 20% (17/85) team participants did not respond. In post-assessment results, 74% (37/50) team participants responded, and 26% (13/50) team participants did not respond.

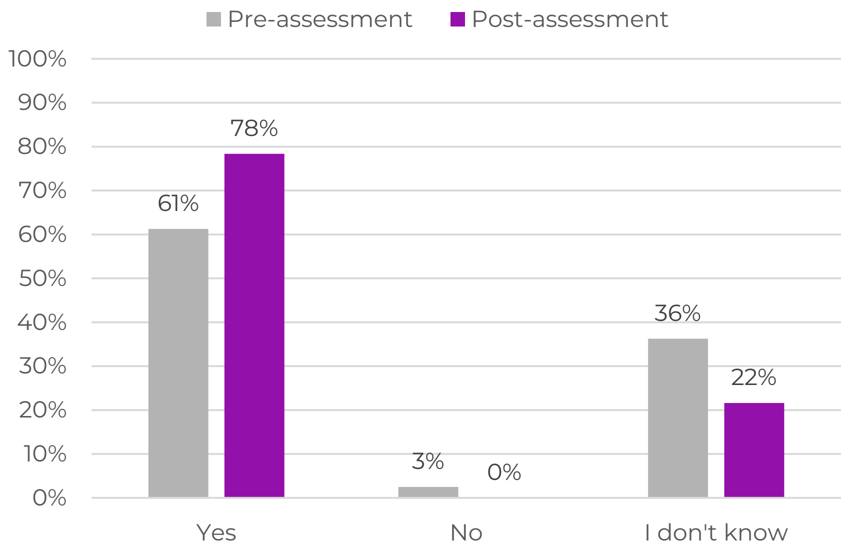


Figure 6: In the 2019/2020 pre/post assessment, responses from team participants reported on whether their team review their Epilepsy12 national audit data.

4. How does your team share their Epilepsy12 audit results?

Figure 7 shows in post-assessment results, 60% (30/50) of team participants responded to how their team share their Epilepsy12 audit results and 40% (20/50) of team participants did not respond. This was a multiple-choice question, therefore percentages displayed below are not expected to total 100%.

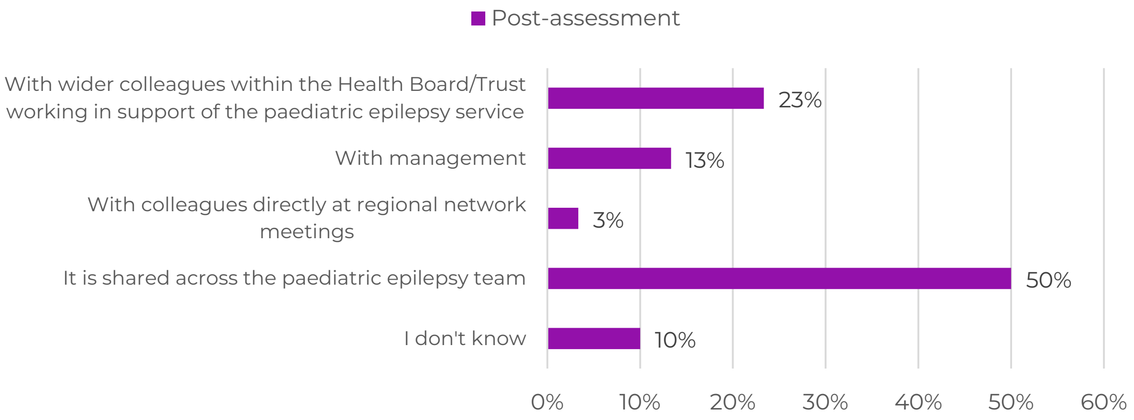


Figure 7: In the 2019/2020 post-assessment, responses from team participants reported on whether their team share their Epilepsy12 audit results

5. Does your team capture feedback from patients and parents as part of your own service review and improvement activities?

Figure 8 shows pre-assessment and post-assessment responses from team participants that reported on whether they captured feedback from patients and parents as part of their own service review and QI activities. In pre-assessment results, 100% (85/85) team participants responded, and 0% (0/85) team participants did not respond. In post-assessment results, 98% (49/50) team participants responded, and 2% (1/50) team participants did not respond.

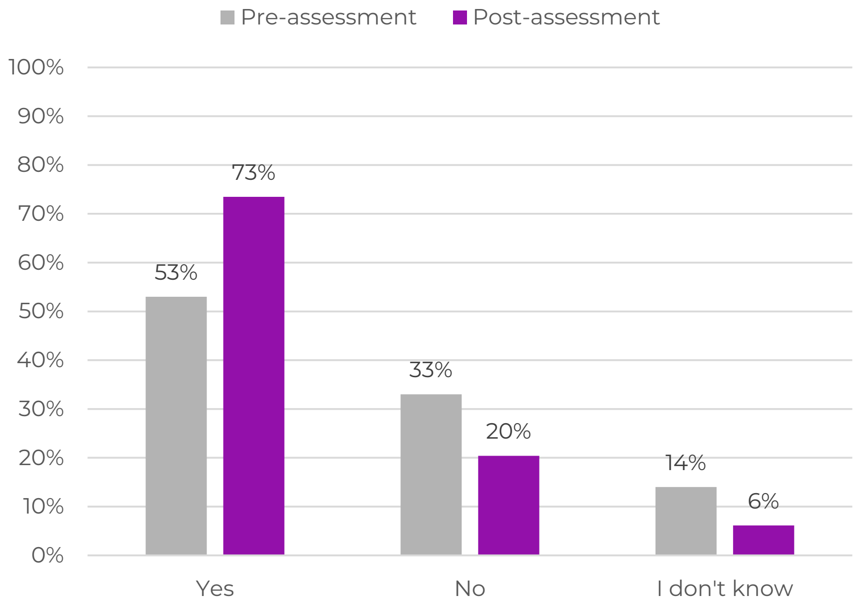


Figure 8: In the 2019/2020 pre/post assessment, responses from team participants reported on whether their team capture feedback from patients and parents/carers as part of their own service review and improvement activities.

6. How is this feedback reviewed by your team?

Figure 9 shows post-assessment responses from team participants that reported on how they reviewed feedback from patients and parents. In post-assessment results, 68% (34/50) team participants responded, and 32% (16/50) team participants did not respond. This was a multiple-choice question, therefore percentages displayed below are not expected to total 100%.

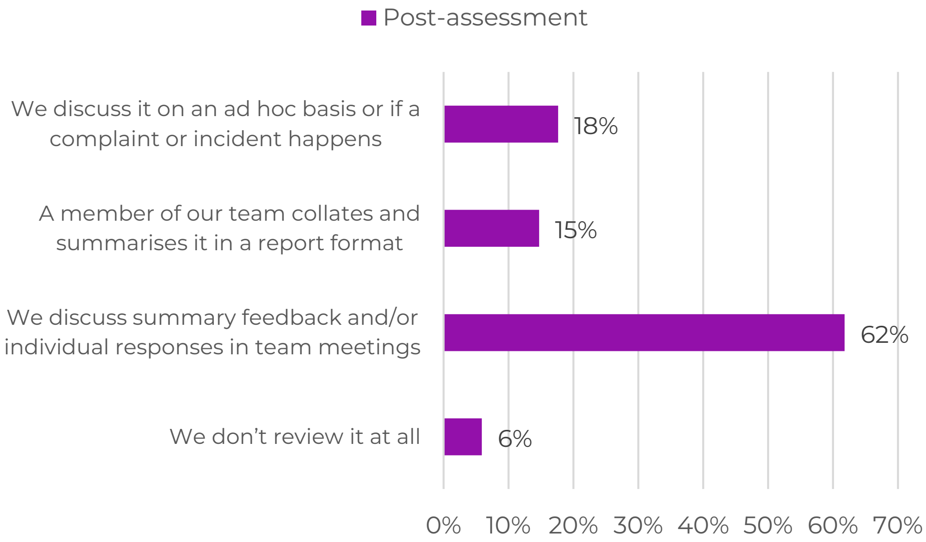


Figure 9: In the 2019/2020 post-assessment, responses from team participants reported on how they review feedback from patients and parents/carers.

7. How does your team use patient feedback to improve service delivery?

Figure 10 shows post-assessment responses from team participants reported that on how their team use patient feedback to improve service delivery. In post-assessment results, 68% (34/50) team participants responded, and 32% (16/50) team participants did not respond. This was a multiple-choice question, therefore percentages displayed below are not expected to total 100%.

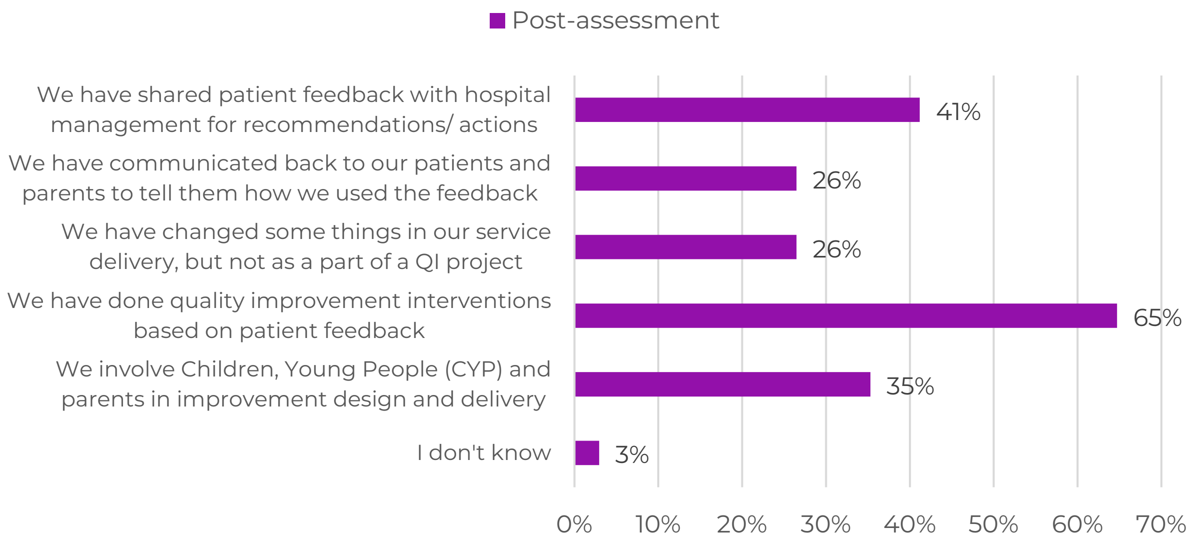


Figure 10: In the 2019/2020 post-assessment, responses from team participants reported on how they use patient feedback to improve service delivery.

8. How is QI embedded in your NHS Health Board/Trust?

Figure 11 shows post-assessment responses from team participants that reported on how QI is embedded within their NHS Health Board/Trust. In post-assessment results, 86% (43/50) team participants responded, and 14% (7/50) team participants did not respond. This was a multiple-choice question, therefore percentages displayed below are not expected to total 100%.

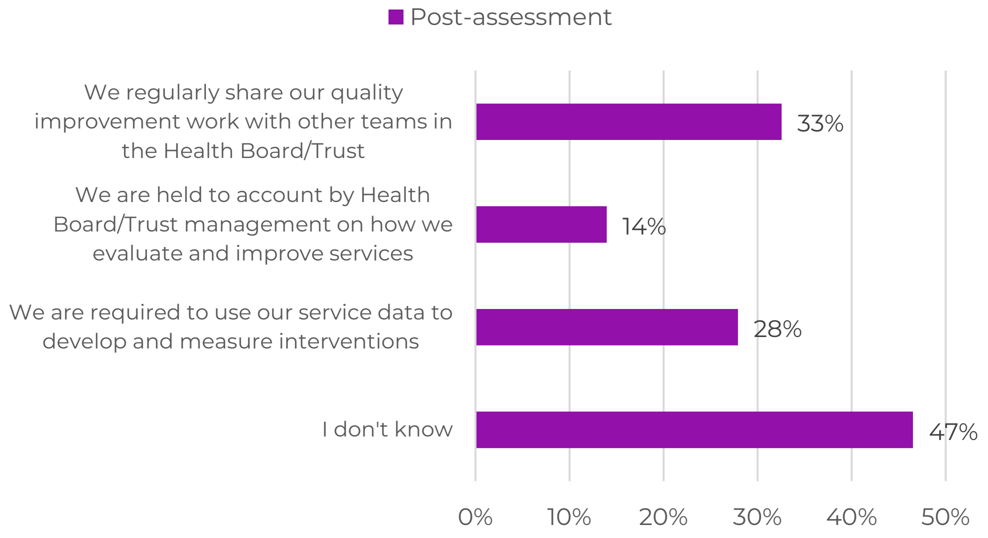


Figure 11: In the 2019/2020 post-assessment, responses from team participants reported on how QI is embedded within their NHS Health Board/Trust.

9. As a team are you planning on sharing your improvements with others?

Figure 12 shows post-assessment responses from team participants that reported on whether they had plans on sharing their improvements with others. In post-assessment results, 84% (42/50) team participants responded, and 16% (8/50) team participants did not respond.

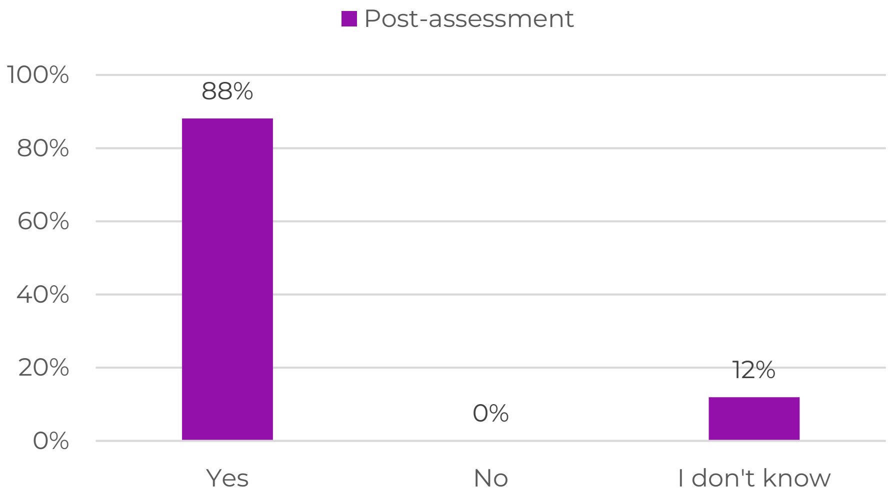


Figure 12: In the 2019/2020 post evaluation, responses from team participants reported if they were planning on sharing your improvements with others.

RCPCH EQIP (wave 2) evaluation results, 2021/2022

In 2021/2022, we asked individual members of the 17 Trust teams (including the ICB team) to provide pre-evaluation data. A total of 85 participants applied to join EQIP, 67 participants completed the training course. A total of 32 participants service staff from 17 Trust teams completed most or part of the pre-assessment survey.

We asked individual members of service teams to submit a post-programme questionnaire to evaluate what they had learned, their project outcomes and the effectiveness of the programme once teams had completed the EQIP training. A total of 28 participants service staff from 17 Trust teams completed most or part of the post evaluation of the programme. A full report of responses received can be found on the EQIP website; only a summary of some responses is shown within this report.

The number of responses per question varies, with percentages not equalling to 100% due to multiple choice options or questions being skipped by some participants. The following are examples of the questions and responses to the questions asked in 2021/2022.

What were the benefits experienced working within a team?

Qualitative evaluation responses captured by team participants described the benefits experienced working within a team. The common themes were as follows:

- **Collaboration**
- **Good communication**
- **Regular/structured meetings**
- **Shared experience/learning/skills**
- **Shared vision/ideas**

1. Do you have structured epilepsy team meetings?

Figure 13 shows that in pre-evaluation results, 68% (17/25) of team participants reported their teams had structured epilepsy team meetings and 32% (8/25) of team participants reported they did not have structured epilepsy team meetings.

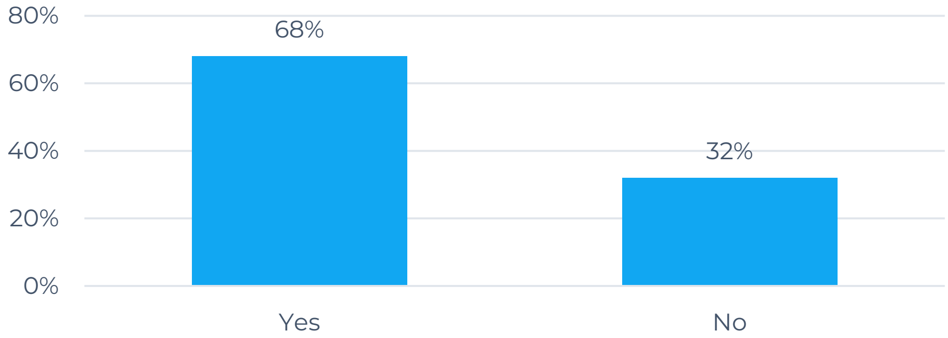


Figure 13: In the 2021/2022, pre-evaluation results from team participants reported on whether they have structured epilepsy team meetings.

2. How does your team organise the meetings to make them effective?

Figure 14 shows that in pre-evaluation results, 39% (12/31) of team participants reported they make their meetings effective by having a set time for them. 19% (6/31) of team participants reported they have a pre-agreed agenda and 19% (6/31) of team participants reported that their meetings were not organised effectively.

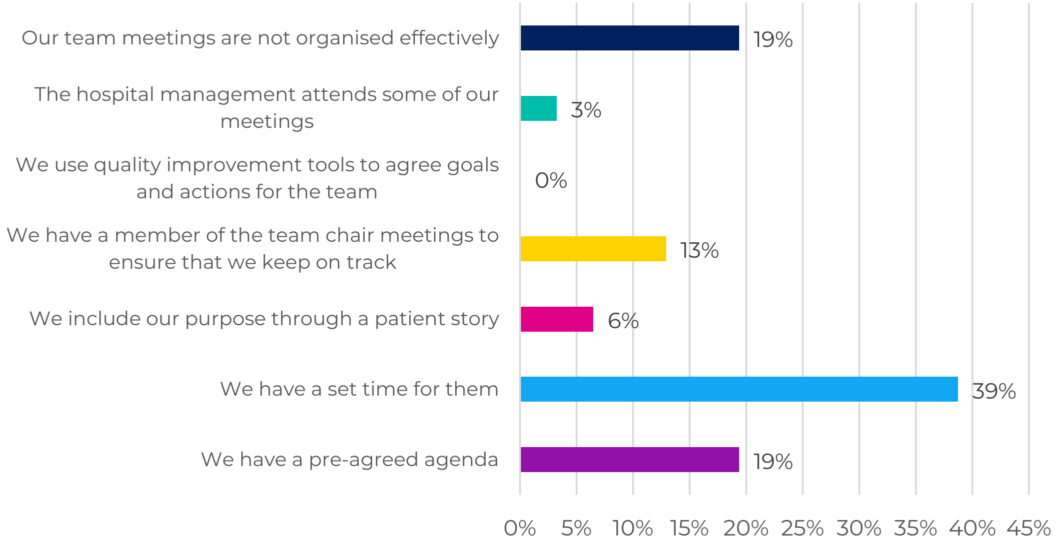


Figure 14: In the 2021/2022 pre-evaluation, responses from team participants reported via multiple choice options how their team organise the meetings to make them effective. The results for this question may not add up to 100%.

3. Has your team established new ways of working? For example, including regular, structured teams meetings and communication on a daily basis.

Figure 15 shows that in pre-evaluation results, 62% (16/26) of team participants reported they had established new ways of working. 38% (10/26) of team participants reported they had not established new ways of working.

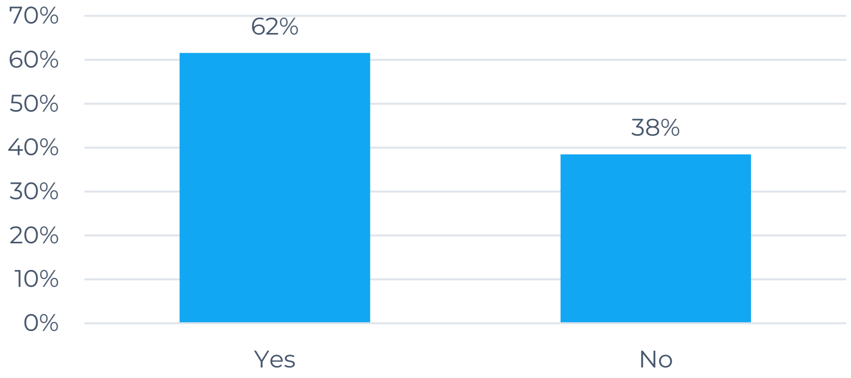


Figure 15: In the 2021/2022 pre-evaluation, responses from team participants reported they had established new ways of working.

4. What were the challenges experienced working within a team?

Figure 16 shows that 35% (16/46) of team participants in post-evaluation results, reported they were unable to attend team meetings, 30% (14/46) of team participants reported a lack of capacity, 17% (8/46) of team participants reported a lack of communication, and 15% (7/46) of team participants reported a reduction in patient engagement.

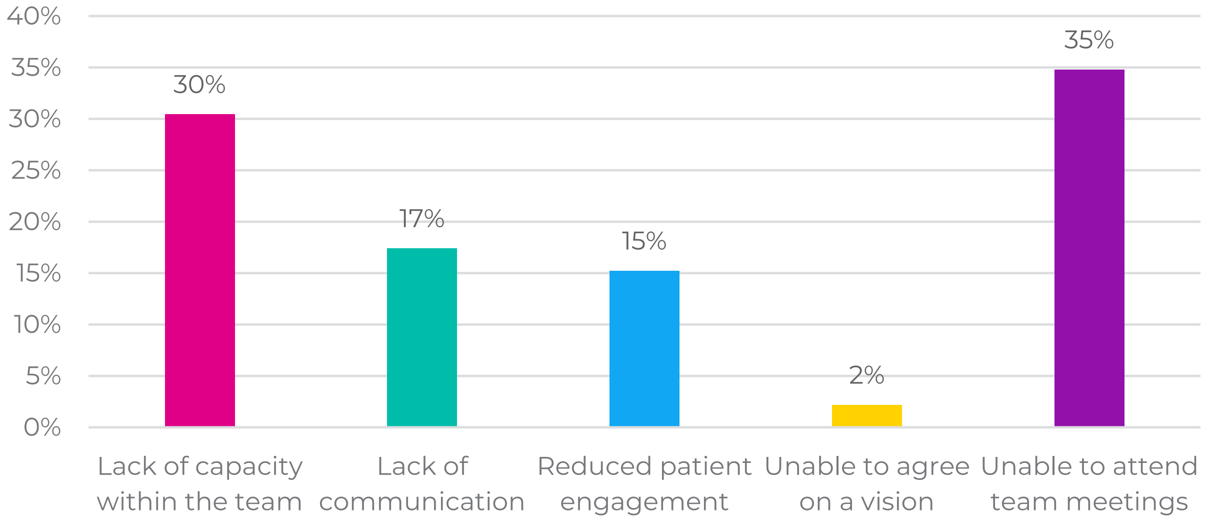


Figure 16: In the 2021/2022 post-evaluation, responses from team participants reported via multiple choice options, what were the challenges experienced working within their team. The results for this question may not add up to 100%.

5. How useful did you find the support webinars?

Figure 17 shows the post-evaluation results on how useful team participants found the webinar training (reported on a scale of 1-4, with 1 being "not useful" and 4 being "very useful"). 64% (18/28) found monthly progress updates and 75% (21/28) found monthly 1:1 team meetings "very useful".

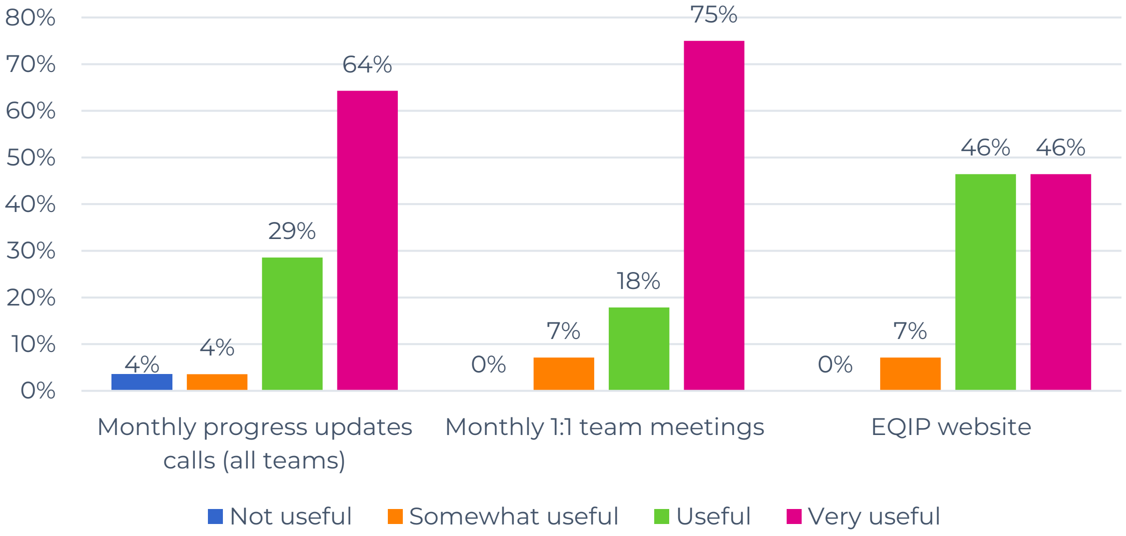


Figure 17: In the 2021/2022 post-evaluation, responses from team participants reported on how useful they found the training webinars. The results for this question may not add up to 100%.

6. How useful did you find the training webinars?

Figure 18 shows the post-evaluation results on how useful team participants found the EQIP training webinars (reported on a scale of 1-4, with 1 being "not useful" and 4 being "very useful"). 68% (19/28) found patient engagement training, understanding QI and using data to drive change 63% (17/27) 'very useful'.

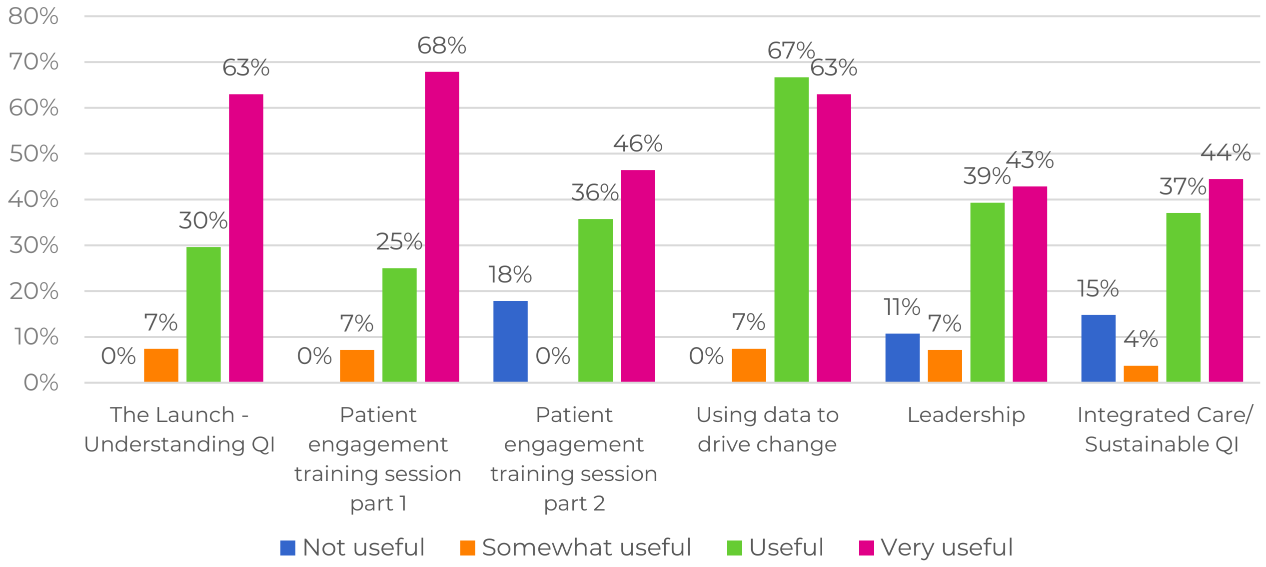


Figure 18: In the 2021/2022 post-evaluation, responses from team participants reported on how useful they found the support webinars. The results for this question may not add up to 100%.

7. Use a few words to describe what you have learnt from the training sessions provided on the programme.

Figure 19 shows a word cloud of participants, responses that was formed to describe what they had learnt over the course of the training programme. Key themes described were patient engagement, QI methodology/processes, using small incremental steps, coaching and support, and stakeholder engagement.

Figure 19: In the 2021/2022, post-evaluation, responses were captured in a word cloud by a proportion of team participants that best described how what they had learnt from the training sessions provided on the programme.

8. Does your team submit Epilepsy12 audit data?

Figure 20 shows that 83% (20/24) of team participants in pre-evaluation results reported that their teams submit Epilepsy12 audit data and 17% (4/24) of team participants reported they do not know if their team submitted Epilepsy12 data.

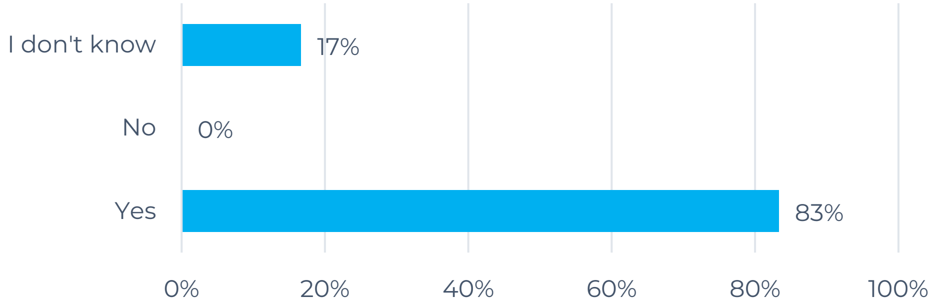


Figure 20: In the 2021/2022 pre-evaluation, responses from team participants reported on whether their team submit Epilepsy12 audit data.

9. How do you envision using your Epilepsy12 audit data to inform future QI initiatives?

In 2021-2022, qualitative post-evaluation results captured from a proportion of team participants described how they envision using their Epilepsy12 audit data to inform future QI initiatives. The common themes were as follows:

- **Helps to support improvement as identifies gaps to improve patient care**
- **Implement what we have learnt in future in projects**
- **Monitoring improvement**
- **Using QI to drive change**
- **Using the information to engage patients and families**

10. During the process of developing your project, did you engage with any of the following?

Figure 21 shows that in post-evaluation results, 54% (14/26) of team participants reported they engaged with other organisations outside of their Trust during the development of their project. 27% (7/26) of team participants reported they engaged with epilepsy charities.

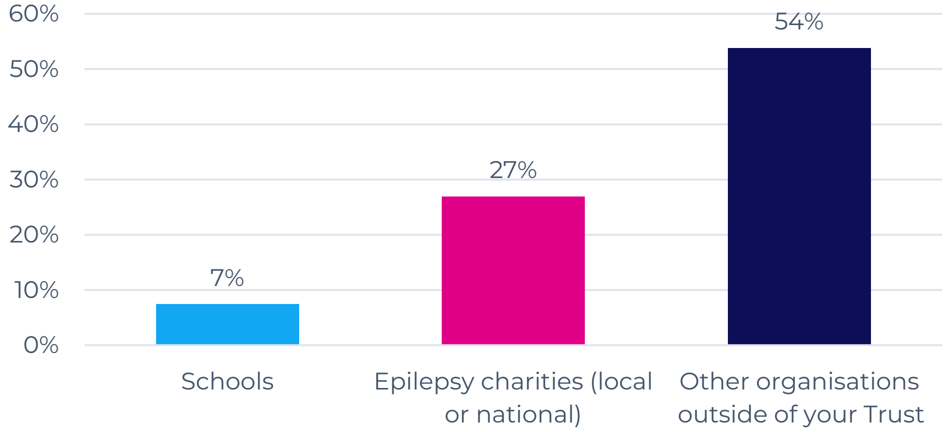


Figure 21: In the 2021/2022 post-evaluation, responses from team participants reported, via multiple choice options, on who their team engaged with during the process of developing their project. The results for this question may not add up to 100%.

11. How do you plan to embed what you have learnt into your day-to-day clinic processes/routines?

In 2021/2022, qualitative post-evaluation responses were captured in a word cloud by team participants that described how they plan to embed what they have learnt into their day-to-day clinic processes.

- **Collating feedback to identify improvements**
- **Continue to implement EQIP project**
- **Identify a new QI project**
- **Implement QI tools**
- **Increased signposting**
- **Patient engagement**
- **Presenting project results**
- **Team building**

Figure 22: In the 2021/2022 post-evaluation, responses were captured in a word cloud by a proportion of team participants that best described how they plan to embed what they have learnt into their day-to-day clinic processes/routines.

RCPCH EQIP (wave 3) evaluation results, 2022/2023

In 2022/2023, we asked individual members of the 13 Trust teams (including one ICB) to submit a post-programme questionnaire to evaluate what they had learned, their project outcomes and the effectiveness of the programme once teams had completed the EQIP training. A total of 47 participants applied to join the RCPCH EQIP and 32 participants completed the training course. 16 participant team members from 11 Trusts (including one ICB) provided a post-evaluation. Pre-evaluation data was not provided.

A full report of responses received can be found on the EQIP website; only a summary of some responses is shown within this report. The number of responses per question varies, with percentages not equalling to 100% due to multiple choice options or questions being skipped by some participants. The following are examples of the questions and responses to the questions asked in 2022/2023.

Use a few words to describe the benefits experienced working within a team.

Qualitative data of evaluation captured in 2022/2023, from a proportion of team participants that described the benefits experienced working within a team.

- *“Able to use the strengths of each team member.”*
- *“Collaboration and focused improvement.”*
- *“Could get feedback and advice about problems encountered.”*
- *“Got to know how we each work (under pressure), which was particularly useful as we had only been working together for 5 months before embarking on the project.”*
- *“Improved team working together, sharing the tasks so it didn’t fall to just one member of the team.”*
- *“It was good to see the journey we’d be on and the next steps we need to take.”*
- *“Knowing the service well.”*
- *“Learning about PDSA cycles and especially how to get feedback from clinic small numbers were ok and pasta voting, etc.”*
- *“Learning ideas from others. ESNs were full of ideas that were easy to work with different skills together.”*
- *“Felt valued and enabled to innovate within a safe framework.”*
- *“Shared learning and better bonding across the ICS.”*
- *“Sharing and learning.”*
- *“Time to make improvements.”*
- *“Very supportive and helpful.”*
- *“Ways to easily improve.”*
- *“We were able to understand/define our project aim better and we have learned how to achieve our aim.”*

1. What were the key challenges with participating in the EQIP for your team?

Figure 23 shows that 15% (5/34) of team participants reported a lack of capacity within the team and 65% (22/34) of team participants reported other key challenges with participating in the EQIP.

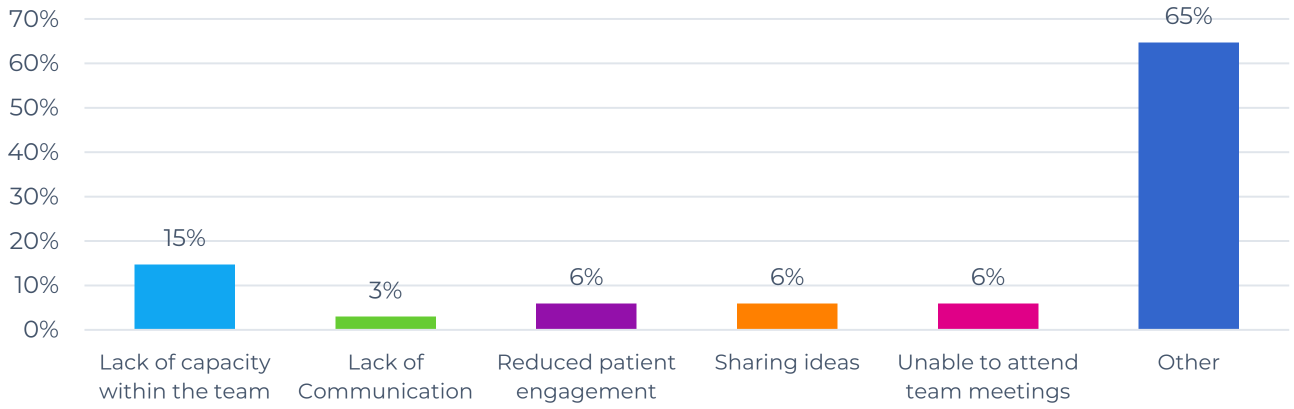


Figure 23: In the 2022/2023 post-evaluation, responses from team participants reported via multiple choice options, what were the key challenges with participating in the EQIP for their team. The results for this question may not add up to 100%.

Other additional statements:

- **Work caseload/capacity**
- **Time**
- **Team participation**
- **Lack of support**
- **Lack of resources**

2. Which of the following QI tools and techniques were most helpful to your project?

Figure 24 shows that 26% (15/57) of team participants reported they found the driver diagram QI tools useful. 23% (13/57) of team participants reported they found the PDSA methodology useful.

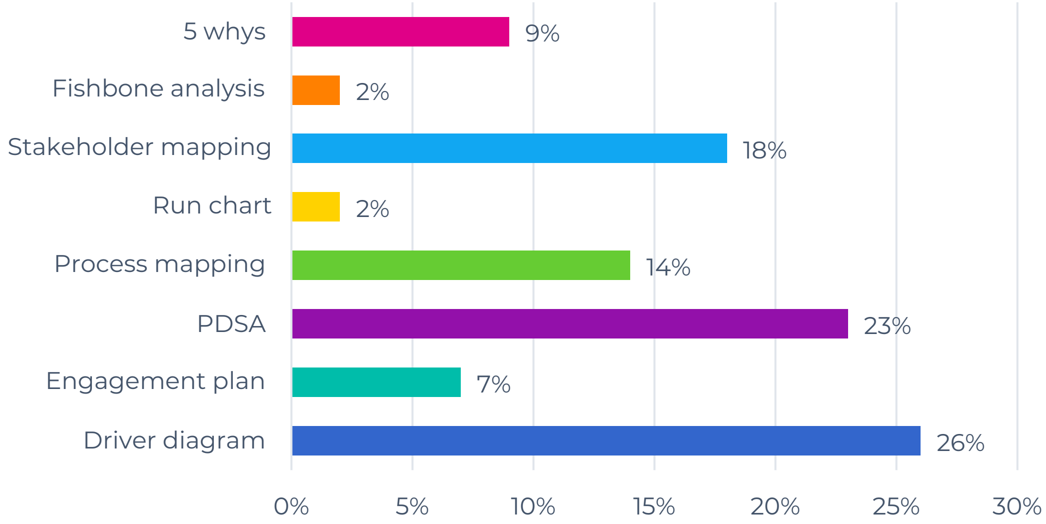


Figure 24: In the 2022/2023 post-evaluation, responses from team participants reported via multiple choice options, which of the following QI tools and techniques were most helpful to their project. The results for this question may not add up to 100%.

3. Did you find the following training sessions useful?

Figure 25 shows that team participants reported they found the webinar training sessions useful. 67% (8/12) of team participants reported they “strongly agreed they found the patient engagement sessions useful”. 50% (7/14) of team participants reported they “strongly agreed they found understanding QI sessions useful”.

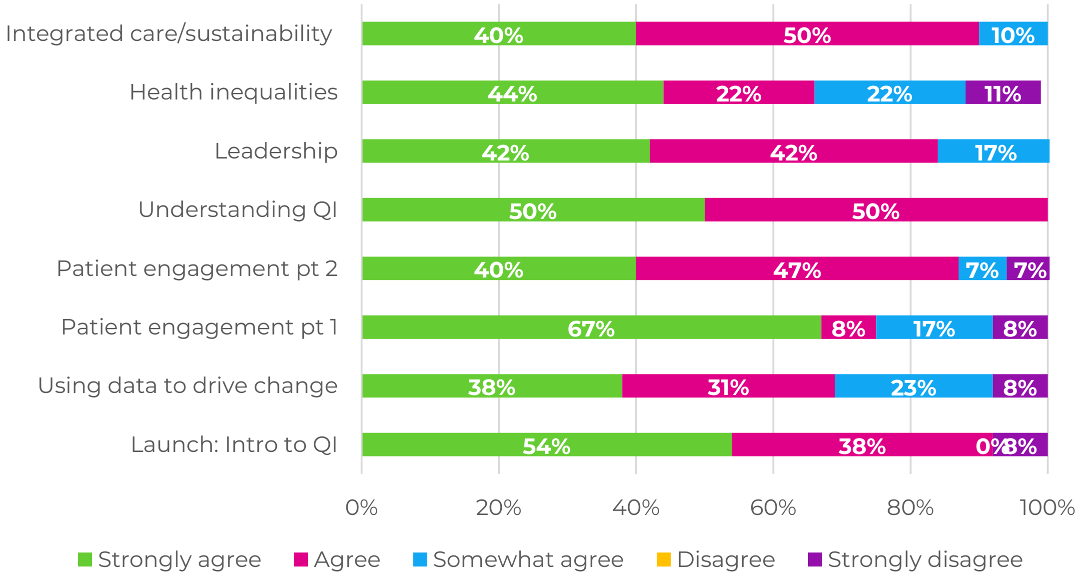


Figure 25: In 2022/2023, post-evaluation responses from team participants reported on a scale of 1-5, (1 being “strongly disagree” and 5 being “strongly agree”) whether they found the following training sessions useful. The results for this question may not add up to 100%.

4. Did you find the following support sessions useful?

Figure 26 shows that 69% (11/16) of team participants reported they strongly agreed they found monthly 1:1 team meetings useful; 63% (5/8) of team participants reported they strongly agreed they found the drop-in sessions useful.

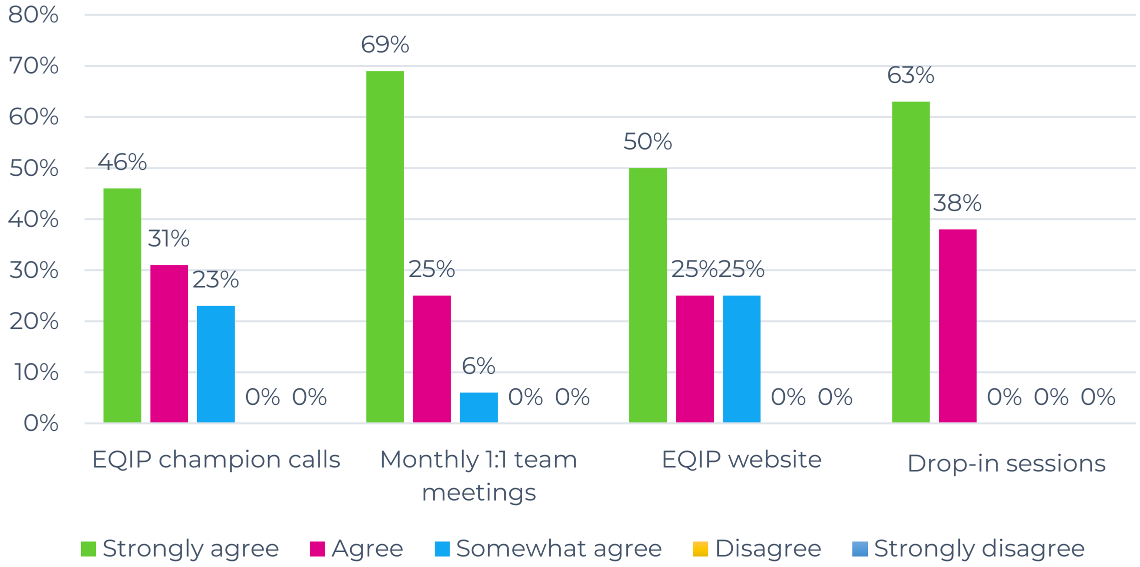


Figure 26: In the 2022/2023 post-evaluation, responses from team participants reported on a scale of 1-5, (1 being “strongly disagree” and 5 being “strongly agree”), whether they found the following the support sessions useful. The results for this question may not add up to 100%.

5. Use a few words to describe what you have learned from the training sessions provided on the programme.

In 2022/2023, qualitative data was captured from team participants to best describe what they had learned from the training sessions provided on the programme. Key themes from participants were as follows: how to run a QI project, leadership, QI tools such as PDSA cycles and stakeholder engagement, patient engagement, and data interpretation/qualitative data.

"I have learnt a wealth of knowledge on QI in epilepsy, including the process of a QI project, tools to utilise, team working. The importance of making small and steady progress. This can then be applied to future QI projects that I will be involved with."

"Learning about improvement methods and understanding how best to implement and monitor them, particularly small tests of change. Stimulated increased communication/sharing of ideas within the team."

EQIP team member participants.

6. How do you envision using your Epilepsy12 audit data to inform future QI initiatives?

In 2022/2023, qualitative evaluation results were captured from a proportion of team participants that described how they envision using the Epilepsy12 audit data to inform future QI initiatives. Common themes reported were:

- **Epilepsy12 provides many themes for QI that would help with sustainable service improvement**
- **Evidence improvements**
- **Helps to evidence the need for support with improvement**
- **Helps to provide evidence for improvements required in mental health support**
- **Identify gaps in the service**

7. Does your team capture feedback from patients and parents as part of your own service review and improvement activities?

Figure 27 shows that 73% (11/15) of team participants reported they capture feedback from patients and parents as part of their own service review and improvement activities, and 27% (4/15) of team participants reported they did not capture feedback for service review.

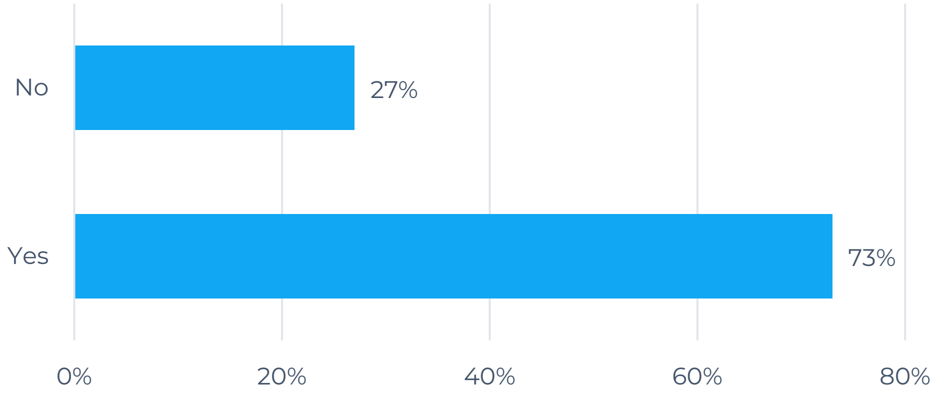


Figure 27: In the 2022/2023 post-evaluation, responses from team participants reported how they use patient and parent/carer feedback to improve service delivery.

8. Has your team's engagement with patients and families increased since joining the EQIP?

Figure 28 shows 100% (15/15) of team participants reported that team engagement with patient and families increased since joining the EQIP.

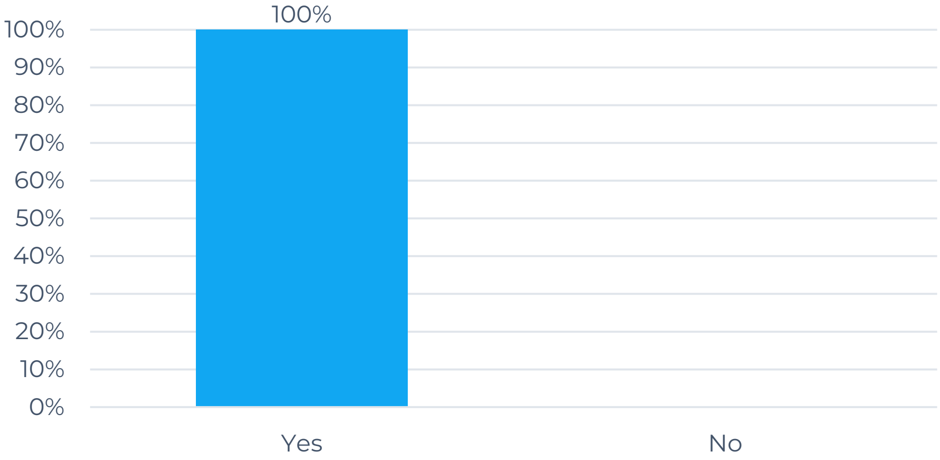


Figure 28: In the 2022/2023 post-evaluation, responses from team participants reported on whether their team engagement with patient and families increased since joining the EQIP.

9. During the process of developing your project, did you engage with any of the following organisations?

Figure 29 shows that 35% (9/26) of team participants reported engaging with mental health services during the process of developing their project and 27% (7/26) of team participants reported engaging with epilepsy charities, in post-evaluation results.

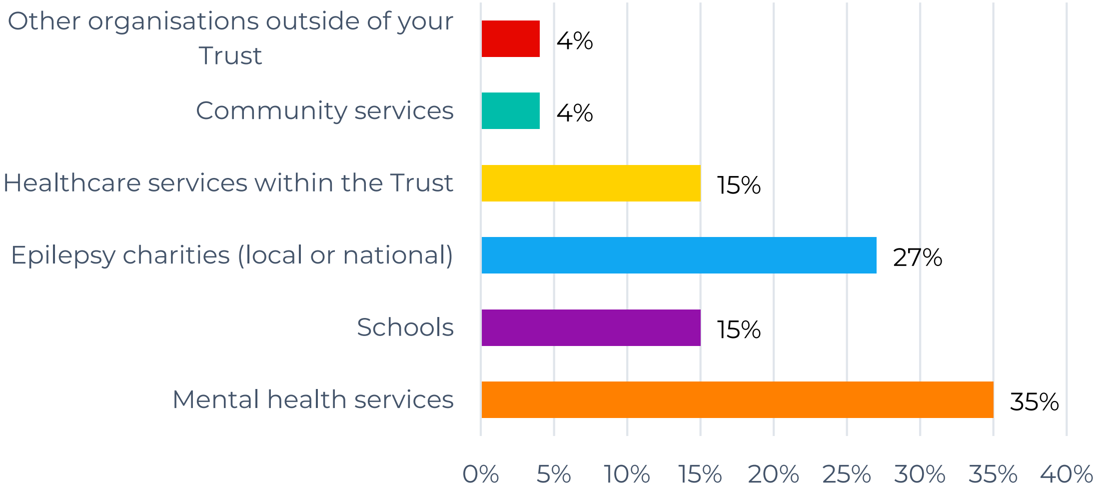


Figure 29: In the 2022/2023 post-evaluation, responses from team participants reported via multiple choice options, whether they engage with any of the following organisations during the process of developing their project. The results for this question may not add up to 100%.

10. What can be done to further enhance the sustainability of your project?

In 2022/2023, qualitative evaluation responses were reported by team participants that described how they plan to further enhance the sustainability of their project. Common themes reported were:

- **Change in culture**
- **Continue education and continue with small steps**
- **Continue to monitor patient waiting time data and sharing with senior management to ensure project goal is maintained**
- **Spreading awareness to the relevant teams**
- **Implement guidelines**

Summary of results

Incorporating rapid, integrated training for MDTs in QI methods to enhance patient care outcomes should be resourced and offered as an effective way of developing applied improvement skills for paediatric care teams.

2019/2020 – pilot wave

Paediatric epilepsy service teams reported an overall **"stronger sense of team and shared purpose"**. With many reporting an increase in team building and **"improved team cohesion"**.

Paediatric epilepsy service teams reported learning new skills and found using QI tools **"useful"** or **"very useful"**.

Participant teams explored ways to share their project interventions but more work is required from NHS Health Boards/Trusts to better inform service teams on how QI is embedded within clinical practice.

Paediatric epilepsy service teams reported capturing patients, and parents, feedback to improve service review and QI activities.

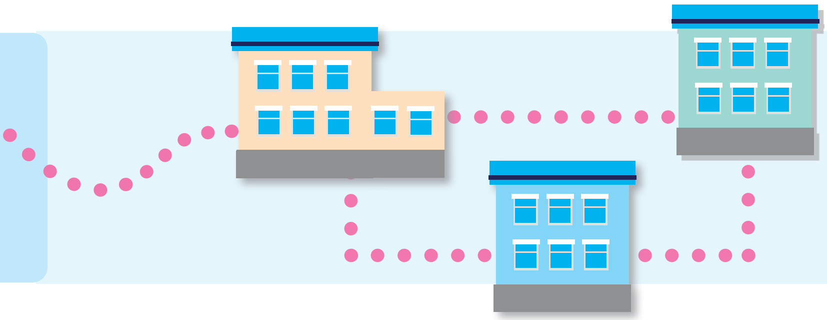
Paediatric epilepsy service teams increased their knowledge of the value of using measurement data and reviewing national Epilepsy12 audit data. Both quantitative and qualitative data are included within team project case studies.

2021/2022 – wave 2

Paediatric epilepsy service teams described the benefits experienced working within a team were **"collaboration"** and **"good communication"**.

62% reported establishing new ways of working, which included regular, structured team meetings and communication on a daily basis.

54% engaged with local support services during the training programme.



Paediatric epilepsy service teams are continuing to engage with national audit data and have a better understanding of how they envision using Epilepsy12 data to **"inform future QI initiatives"**.

Paediatric epilepsy service teams reported learning new skills in patient engagement, QI methodology/processes, using small incremental steps to implement change and stakeholder engagement from EQIP training sessions.

64% found monthly progress updates **"very useful"**

75% found monthly 1:1 team support meetings **"very useful"**.

Paediatric epilepsy service teams continue to experience challenges with the lack of capacity within the team and finding time to meet as a team. These ongoing challenges continue to create barriers for services to sustain the capability and build high-performing teams.

Paediatric epilepsy service teams plan to embed what they have learnt into their day-to-day clinic processes by continuing to engage with their patients and families and share best practice.

2022/2023 – wave 3

Common theme responses from team participants on the benefits experienced working within a team on the programme were **"collaboration and focused improvement"**, **"being able to use the strengths of each team member"** and **"shared learning; better bonding across the team"**.

Paediatric epilepsy service teams continued to engage with Epilepsy12 data to inform future QI initiatives. Teams have also demonstrated both quantitative and qualitative data within their project case studies.

69%
reported that they strongly agreed with finding monthly 1:1 team meetings useful.

63%
of team participants strongly agreed with finding the drop-in sessions useful.

73%
captured feedback from patients and parents as part of their own service review and improvement activities.

100%
reported engagement with patients and families increased since joining the EQIP.

Paediatric epilepsy service teams reported the challenges with lack of capacity within the team and the lack of support and resources.

Team participants have reported on learning new skills in using QI tools.

Team participants have reported on learning new skills in how to run a QI project from EQIP training sessions on **Leadership**, **QI tools and stakeholder engagement**, **patient engagement** and **data interpretation/qualitative data.**

Paediatric epilepsy service teams described sustaining their project by **"change in culture"**, **"continue education and continue with small steps"** and **"spreading awareness to the relevant teams"**.

2019-2023 participant Health Board, Trust, and ICB team project interventions

Team name	Project aim
Developing mental health and wellbeing pathways	
Epsom and St Helier University Hospitals NHS Trust	To develop a standardised screening tool to identify the mental health status of our patients.
Great Western Hospital NHS Foundation Trust	To optimise mental health support pathways for 10–16-year-olds with mental health difficulties and epilepsy by June 2023.
Hampshire Hospitals NHS Foundation Trust	To improve our knowledge about the wider needs of 10 patients with epilepsy under the care of the Basingstoke and North Hampshire Hospital paediatric epilepsy team by April 2023.
North West Anglia Foundation Trust	To create signposting processes to support patients' wellbeing and mental health via easily accessible applications and internet websites.
South Tees Hospitals NHS Foundation Trust	To obtain feedback on how the epilepsy service can support their wellbeing from 50% of children aged 12-16 years with a diagnosis of epilepsy attending their review clinic.
Tameside and Glossop Integrated Care NHS Foundation Trust	To develop and implement by Summer 2023 a mental health guide for all children and young people 11-17 years of age focused on understanding and managing emotions.
South Yorkshire Children & Young People's Alliance ICB	By 31 May, 2023, 60% of 9–18-year-old epilepsy patients in South Yorkshire ICS will have access to mental health screening supported with a referral pathway, as per local Trust pathway.
Warrington and Halton Teaching Hospitals NHS Foundation Trust	To engage with children and young people to improve the mental health referral pathways and create a mental healthcare package for children aged 11-17 years. All new patients in this age group will receive the package from March 2022.
Improving and adapting transition process to adult services	
Aneurin Bevan University Health Board	Achieving 90% of all 14–16-year-old children and young people with epilepsy being sent "Ready, Steady, Go" forms.
Croydon Health Services NHS Trust	To engage patients at 14 years and older with their families to determine their level of need for transition, and creating an efficient standard based on the needs expressed by children and young people in Croydon.
East Lancashire Hospitals NHS Trust	To offer transition as a staged approach equitably from 19% to 100% of our patients aged 16 years and over by March 2022.

Developing an integrated care pathway and increasing specialist input	
Luton and Dunstable University Hospital NHS Foundation Trust	To develop and implement an integrated care pathway for children admitted to hospital with seizures in 6 months.
Medway NHS Foundation Trust	60% of first seizure referrals are seen within 2 weeks by May 2023.
Royal Berkshire NHS Foundation Trust	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.
Reducing waiting times	
The Dudley Group NHS Foundation Trust	To reduce patient waiting times for first appointment in epilepsy clinic by 50% from 12 weeks to 6 weeks by May 2023.
North Tees & Hartlepool NHS Foundation Trust	To reduce waiting times for new seizure referrals by a paediatrician with expertise in epilepsy from 16 weeks to 4 weeks in 50% of referrals within 6 months of the project start by the end of March 2022.
Royal United Hospitals Bath NHS Foundation Trust	To develop and implement a pathway for first paroxysmal events allowing review by paediatricians with special interest in epilepsy. We aim that 90% of new epilepsy referrals will be seen within epilepsy clinic within 6 weeks (and 50% within 2 weeks) by May 2020.
Salisbury NHS Foundation Trust	Improve first seizure pathway with key aim to ensure 75% or more of first seizure patients are seen within 2-4 weeks.
Improving patient engagement processes	
Barts Health NHS Trust	To obtain meaningful feedback on our service from 50% of patients and families by March 2022, which will enable us to hear the voice of our patients and families and highlight areas of improvement within our service by March 2022.
Chelsea and Westminster Hospital NHS Foundation Trust	To access the patient voice in 80% of patients accessing epilepsy services at Chelsea & Westminster and West Middlesex Hospitals, between January and March 2020, to influence improvements in cross-site epilepsy care.
Doncaster and Bassetlaw Teaching Hospitals NHS Foundation Trust	To develop a signposted information pack about the children's epilepsy service, by involving the patients and parents in the whole process. 50% of patients will be signposted to the pack which would be available both electronically and in printed copies by May 2020.
Doncaster and Bassetlaw Teaching Hospitals NHS Foundation Trust	By March 2022, 70% of children aged 11-19 years with epilepsy will have digital feedback forms offered in clinics (consultant and nurse-led) and on acute wards.

Guy's and St Thomas' NHS Foundation Trust	To obtain feedback from 50% of patient/families seen in tertiary epilepsy clinic regarding their perceived appropriateness of the time interval between follow-up appointments by March 2020.
Southport and Ormskirk Hospital NHS Trust	To develop a feedback tool to obtain 50 pieces of feedback from children, young people and families by May 2020.
SUDEP risk	
Oxford University Hospitals NHS Foundation Trust	To standardise a toolkit for clinicians to use for providing information on SUDEP to families, to enable a personalised yearly discussion on SUDEP with at least 80% of children with epilepsy.
Digitalisation of Epilepsy Passport	
University Hospitals of Morecambe Bay NHS Foundation Trust	To improve patient outcomes in management and emergency care for 10% of CYP with complex epilepsy by testing and developing the rescue plan and Epilepsy Passport by March 2022.
York and Scarborough Teaching Hospitals NHS Foundation Trust	To develop an Epilepsy Passport to communicate information to children and young children with the aim of improving their care and reducing risk by June 2020.
Ketogenic diet clinics	
Manchester University NHS Trust	To improve patient experience and reduce clinic waiting times in outpatient MDT ketogenic diet clinic.
EEG reduced referral times	
Nottingham University Hospitals NHS Trust	To achieve quality routine EEG recordings in 95% of all paediatric patients referred within 4 weeks from referral.
Royal Free London NHS Foundation Trust	To develop and implement a pathway for melatonin EEGs in co-production with neurophysiology and pharmacy at the Royal Free site by May 2023.
ICS - improving the first year of care	
West Yorkshire & Harrogate Health and Care Partnership (six NHS Trusts)	Establish a standardised first year of care pathway for patients with epilepsy diagnosis (sub-projects include the areas of transition, mental health, reducing waiting times for first referral).

EQIP microsite:
case studies, posters and presentations

https://eqip.rcpch.ac.uk/case-studies/

Lessons learned

1. Team working and communication

Common themes captured from quantitative evaluation results highlight the programme's impact on the benefits service teams have reported in "working together more cohesively", and improved communication processes demonstrated within project case studies. However, some participant teams have also reported their lack of capacity within the team to attend internal team meetings or allocated time within job plans for QI and audit. This means that some teams experienced difficulties in completing the programme as a whole team, leaving only one or two team members driving the project. These challenges create ongoing barriers for service teams to effectively work together as high-performing teams. Other key lessons learned include:

- **Working with small project teams:** Some service teams that have participated within the programme have demonstrated impact on service delivery with small project teams that have included the consultant and nurse, or the consultant, nurse and secretary. Salisbury and North Tees hospital paediatric epilepsy service teams have demonstrated working cohesively to reduce waiting times for their patients whilst on the programme. These teams demonstrated increased organisation skills and commitment to the project, resulting in improved outcomes.

Photo: Dr Rohini Rattihalli, Consultant Paediatric Neurologist, Oxford University Hospital, shared learning on SUDEP discussion improvement project at the end-of-programme event, 2023.

- **Working with large project teams:** Working with larger service teams, cross-site teams and ICBs offers unique challenges, with effective communication and organisation processes needed. However, Luton and Dunstable paediatric epilepsy service team have demonstrated great team working with five or more individual staff members participating in the EQIP.

- **Leadership growth:** Many participant teams, such as Warrington and Halton Teaching Hospitals and Oxford Hospital Trusts, have demonstrated leadership skills in creating a vision and a shared purpose, implementing their project interventions and sharing their learning through networking, participating in local and national events and sharing best practices locally. However, there is still room for improvement in working with the teams experiencing significant capacity and resource issues.

2. Engagement and interaction with teams

The programme's structure enables the development of robust relationships with each team. Key observations include:

- **Programme participation and commitment:** We have assisted 184 healthcare professionals in addressing current challenges by providing centralised support and embedding QI methodology within paediatric epilepsy teams across England and one in Wales. Since the inception of the EQIP, we have observed service teams struggling with capacity issues, which have impacted on participation with training webinars, submission of evaluation responses and team performance. We often involve teams in the improvement of programme functions, which is incorporated into improving the next training wave, e.g, suitable times/days for training webinars and engagement days, but unfortunately, it is not always possible to meet the needs of all teams. Therefore, webinars are often recorded and accessible online for those who cannot attend. The first step in the change model shown in figure 1, page 8 of this report, is creating conditions for change and to build a willingness to improve. If the issue with capacity is not addressed and the right conditions for improvement are not put in place, then senior Trust staff, ICBs and commissioners will continue to witness services struggle to make significant improvements in service delivery.

- **Success of 1:1 support meetings**: The 1:1 support meetings offer a great opportunity to better understand team dynamics, strengths and areas for improvement, and teams have found these useful during their QI journey. Service teams exhibit a positive attitude, strong work ethic and determination to address ongoing barriers. However, achieving full team participation in these meetings can be challenging. To mitigate against this, the programme offers flexibility to help whole teams attend these crucial meetings.

- **Communication challenges:** Most service teams encountered challenges in effective communication, particularly when operating across different hospital sites. The tertiary centre based in Manchester University Hospital demonstrated service improvements, such as implementing team huddles to overcome communication barriers.

3. Transformation and skill development

Through evaluation and observation, the RCPCH EQIP has been the catalyst that has led to a transformation in most participant teams, acquiring new skills from our expert trainers. Utilising a microsystems model integrated into local operational business, the increase of monthly coaching has supported the incremental changes within team interactions and service delivery improvements described within project case studies.

- **Knowledge and skill enhancement:** We have enhanced the skills and knowledge of participant service teams to comprehend successful transformation and change within epilepsy services. In 2021/22, 100% (28/28) of team participants reported that the training and course materials met the learning aims/objectives of the programme and 100% (28/28) of team participants reported that the speakers/facilitators on the programme were knowledgeable. Many team participants lacked prior knowledge of QI methodology and tools and lacked a clear understanding of how QI concepts support clinical practice in reducing variation. Whilst on the programme, service teams learnt the importance of a shared vision and gained improved clarity of defining strategic improvement aims. For some teams, the EQIP has helped to foster a culture within service teams that embraces continuous improvement as an integral part of daily operations. This was achieved from a change in a mindset of adaptability and learning from every phase of the improvement process.

- **Embedding patient engagement:** Initially, most service teams faced difficulties with engaging with children and young people and lacked understanding in the importance of including patients and families in the co-design of service improvement. In collaboration with the RCPCH &Us Children, Young People & Engagement Team, training in patient engagement has proven essential for all teams. This has resulted in increased patient engagement practices within service

development and teams gaining new tools and techniques to produce engagement plans and inclusive approaches to patient demographics. In 2022/2023, 100% (15/15) of team participants reported that team engagement with patients and families increased since joining the EQIP. Quantitative feedback from participant teams suggests a positive shift, with teams incorporating patient engagement as a standard practice during each clinic consultation.

- **Resourceful EQIP microsite:** In 2022/23, 50% (8/16) of team participants found the EQIP website useful. The EQIP microsite has emerged as a valuable resource hub, created during the adaption to virtual online access during the pandemic. Participants can log in to access essential resources, recorded content, templates and examples, aiding in ongoing learning. We are constantly looking for ways to improve its usability and meet the needs of participants.

- **Measurement and use of local/national data:** Prior to the EQIP, some service teams lacked clear processes in using local data to measure improvement or to meet national standards, measured in Epilepsy12's audit key performance indicators. Some teams encountered challenges in understanding how to collate and present their local data for their project and how these later inform national audit results. In response, this has been addressed by recap sessions during the programme and resources on how to create run chart and Pareto chart and templates to guide teams on how to collate data to measure improvement.

- All participant teams have captured either quantitative or qualitative data, which is demonstrated within project case studies. Post-evaluation results show teams using national Epilepsy12 audit benchmarking indicators to identify and address variation in service and to evidence the need for support with improvement.

4. Overcoming barriers/challenges

Whilst the EQIP endeavours to provide comprehensive support for teams, the ultimate responsibility for driving and implementing solutions lies with the teams themselves. Challenges and barriers have been identified throughout the training programme, and addressing these challenges has been crucial for progress. Key challenges and the support provided include:

- **Time and capacity constraints:** Real issues relating to the time and capacity to participate emerged, particularly in NHS service teams like paediatric epilepsy. Staff turnover and ineffective delegation have been notable challenges, many of which are beyond the control of the service team. To address these issues where possible, we train teams in exploring communication techniques, building leadership skills, understanding the strengths and weaknesses of each team and involving key stakeholders, including other healthcare professionals, administrators, and service users, throughout the QI journey. By addressing these challenges and incorporating some of these ideas, NHS services can begin to enhance the sustainability of their QI project interventions and promote lasting positive changes in healthcare delivery. The commitment and enthusiasm of the teams play a pivotal role in finding effective solutions that lead to improved outcomes.

5. Network links and sharing of good practice

The EQIP facilitates opportunities for teams to connect, share experiences, and disseminate good practices within their professional community. Key observations include:

- **Showcasing project outcomes:**
  The programme provides a platform for teams to present and share their experiences and outcomes during an end-of-programme shared learning event. This event serves as a valuable opportunity for networking and idea exchange among participating units and regional networks. This is also an incentive, emphasising the importance of a significant goal in conclusion of completing the EQIP.

6. Improved links with support services

Participating paediatric epilepsy teams have established connections with local support services, such as with schools, charities and mental health services, to enhance ongoing care for patients and their families within the community, both locally and nationally. Some teams have outlined challenges in building engagement within their case studies, while others have successfully bridged this gap, demonstrating improved links with support services.

7. Sustainability

Sustainable impact for NHS services involves creating lasting improvements and maintaining positive changes over time. Ensuring sustainability in QI project interventions for NHS services poses several challenges. One key challenge is the need to navigate the complex healthcare environment and address issues that hinder long-term success. Many service teams struggle with sustaining improvements due to various factors such as staff turnover, changing priorities and resource constraints.

8. Navigating the impact of the COVID-19 pandemic

The transition from an in-person training course to a virtual format due to the COVID-19 pandemic had posed both challenges and opportunities for the paediatric epilepsy service teams. The shift to virtual training has had notable effects on team engagement, particularly at the outset of the programme for training waves 2 and 3 (2021–2023), team participants who did not experience an in-person event. Recognising the importance of fostering team commitment and understanding the unique dynamics of virtual interactions, we acknowledge that an effective training programme necessitates a balanced blend of face-to-face and online components. The pilot teams played a pivotal role in capturing their experiences and sharing numerous lessons, which are available on the EQIP website.

- **Adaptation to the pandemic:**
  The programme had to adapt to the ever-changing environment and challenges posed by the pandemic. Teams showed resilience and flexibility, changing the way they engaged with each other in a virtual environment.

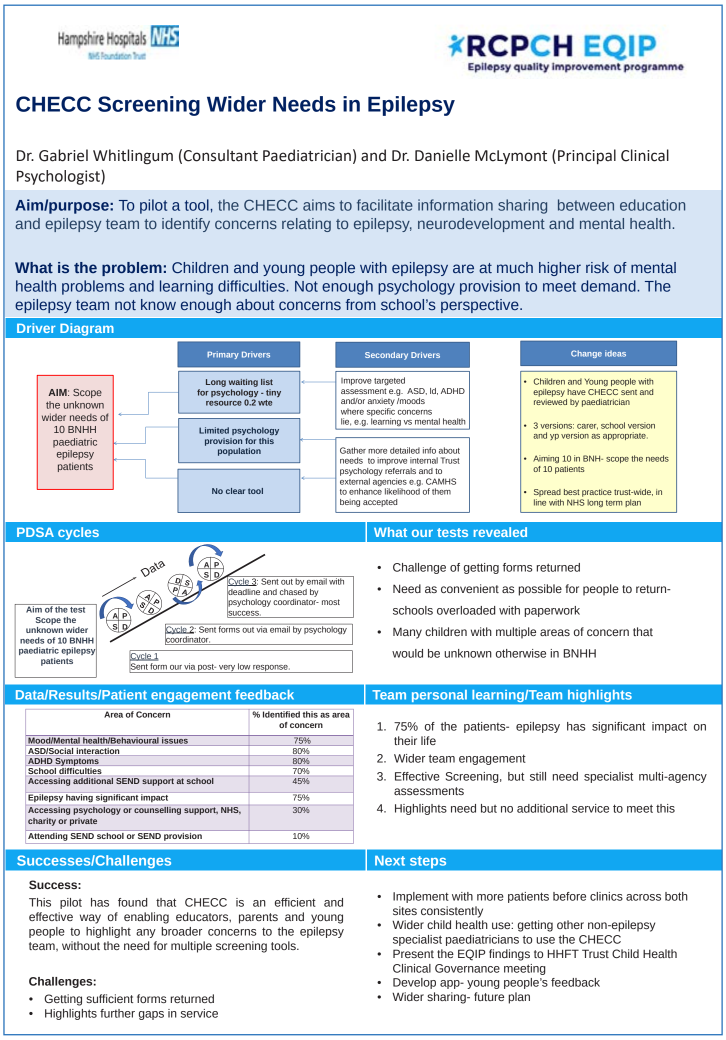
9. Working with the composition of ICB/ICS structures

There are huge complexities to consider within ICB structures, requiring leadership to implement strategic goals in providing cohesion and support across their regions that vary in size, numbers and geographic locations. Such complexities require significant training support to begin to embed clear communication and implement strategies that would lead to cultural changes and systemic processes to help reduce variation within their region. Not all NHS staff are aware of their ICB lead, highlighting the need for improved awareness and consideration of structures as support mechanisms. Quarterly meetings between ICB leads and individual Trusts' teams can enhance support, learning and collaboration to address regional variations.

- **Team structures and dynamics:**
  To strengthen team building and support, ICBs should establish an executive team when embarking on local service improvements. The executive team would include the ICB clinical lead, ICB CYP transformation manager for long-term conditions, and Trust-level service teams that include a clinical lead, ESN and administrator with input from multidiscipline healthcare professionals.

- **Measuring/monitoring variation:**
  All Trust service-level teams within an ICB should implement local processes for measuring and monitoring improvement areas and participate in the Epilepsy12 audit. Collaborative action planning and problem-solving through QI topics help to overcome challenges and reduce variation collectively. Multiple sources of data are required to understand how a complex system behaves and performs in healthcare. The NHS National Epilepsy Bundle of Care offers invaluable guidance for ICBs to support local services in improving care for children and young people with epilepsy.

- **Learning sharing and support:**
  ICB leads and project managers should establish a mechanism to spread learning and best practice with internal Trust management. Opportunities to seek support and participation in programmes such as the EQIP should be sought and leveraged to implement strategies that address barriers and reduce variation.



Hampshire Hospitals NHS Foundation Trust

RCPCH EQIP Epilepsy quality improvement programme

CHECC Screening Wider Needs in Epilepsy

Dr. Gabriel Whitlingum (Consultant Paediatrician) and Dr. Danielle McLymont (Principal Clinical Psychologist)

Aim/purpose: To pilot a tool, the CHECC aims to facilitate information sharing between education and epilepsy team to identify concerns relating to epilepsy, neurodevelopment and mental health.

What is the problem: Children and young people with epilepsy are at much higher risk of mental health problems and learning difficulties. Not enough psychology provision to meet demand. The epilepsy team not know enough about concerns from school's perspective.

Driver Diagram

AIM: Scope the unknown wider needs of 10 BNHH paediatric epilepsy patients

Primary Drivers
- **Long waiting list for psychology - tiny resource 0.2 wte**
- **Limited psychology provision for this population**
- **No clear tool**

Secondary Drivers
- Improve targeted assessment e.g. ASD, ld, ADHD and/or anxiety /moods where specific concerns lie, e.g. learning vs mental health
- Gather more detailed info about needs to improve internal Trust psychology referrals and to external agencies e.g. CAMHS to enhance likelihood of them being accepted

Change ideas
- Children and Young people with epilepsy have CHECC sent and reviewed by paediatrician
- 3 versions: carer, school version and yp version as appropriate.
- Aiming 10 in BNH- scope the needs of 10 patients
- Spread best practice trust-wide, in line with NHS long term plan

PDSA cycles

Aim of the test Scope the unknown wider needs of 10 BNHH paediatric epilepsy patients

Cycle 3: Sent out by email with deadline and chased by psychology coordinator- most success.

Cycle 2: Sent forms out via email by psychology coordinator.

Cycle 1
Sent form our via post- very low response.

What our tests revealed

- Challenge of getting forms returned
- Need as convenient as possible for people to return- schools overloaded with paperwork
- Many children with multiple areas of concern that would be unknown otherwise in BNHH

Data/Results/Patient engagement feedback

Area of Concern	% Identified this as area of concern
Mood/Mental health/Behavioural issues	75%
ASD/Social interaction	80%
ADHD Symptoms	80%
School difficulties	70%
Accessing additional SEND support at school	45%
Epilepsy having significant impact	75%
Accessing psychology or counselling support, NHS, charity or private	30%
Attending SEND school or SEND provision	10%

Team personal learning/Team highlights

1. 75% of the patients- epilepsy has significant impact on their life
2. Wider team engagement
3. Effective Screening, but still need specialist multi-agency assessments
4. Highlights need but no additional service to meet this

Successes/Challenges

Success:

This pilot has found that CHECC is an efficient and effective way of enabling educators, parents and young people to highlight any broader concerns to the epilepsy team, without the need for multiple screening tools.

Challenges:
- Getting sufficient forms returned
- Highlights further gaps in service

Next steps

- Implement with more patients before clinics across both sites consistently
- Wider child health use: getting other non-epilepsy specialist paediatricians to use the CHECC
- Present the EQIP findings to HHFT Trust Child Health Clinical Governance meeting
- Develop app- young people's feedback
- Wider sharing- future plan

Photo: Project outcomes and engagement activities undertaken by participant EQIP teams.

10. Commissioners/senior management/ICB leads

Time and capacity for NHS service teams to participate in programmes like the RCPCH EQIP are a real issue, especially in services such as paediatric epilepsy. Many service teams still lack a full-time ESN. Many are unable to bridge the gap between mental health services or have access to support from internal departments within the Trust. Teams shared within evaluation results that they often have no knowledge or connection to Trust QI services to support their team to make improvements or access to admin support to ease the burden of documentary evidence of change. This can lead to low morale, inequality in care and low standards in care which, if not monitored, can risk patient safety.

Service teams are ultimately responsible for the standard of care provided to their patients. They therefore must be supported with the time and space in job plans, and away from distractions, to plan as a team and implement QI interventions that enhance processes to improve clinical practice.

By investing in training to address challenges and improve service delivery, the NHS can prevent potential long-term costs associated with suboptimal care. Early intervention and improved processes can contribute to avoiding complications that might require costly treatments later.

These lessons learned provide a comprehensive understanding of the evolving landscape of QI training and support for paediatric epilepsy service teams, emphasising the importance of the ongoing adaptation and improvement in the learning process. These insights underscore the importance of continuous support and tailored solutions to strengthen team engagement, communication and overall effectiveness in delivering paediatric epilepsy services.

Conclusion

When trying to understand quality within a complex system, it is important to review a mix of outcomes (what matters to patients), processes (the way we do our work) and structures (resources, equipment, governance, etc).[12]

Reducing variation on a wide scale takes time, far beyond the scope of a 6 or 8 month programme. Possessing QI skills and knowledge alone is insufficient for achieving improvement. Trust-level teams and ICBs require access to expertise, energy, time and resources for learning and implementing what they have learned.

The ability to drive change is significantly influenced by the broader context, encompassing our behaviours and the continuous learning and improvement opportunities we foster. Merely training more individuals without addressing these critical factors may lead to lost investment and enthusiasm, remaining inactive until other opportunities arise. Any organisation aspiring to enhance quality, regardless of its starting point, must invest in the development of essential skills while addressing the broader contextual elements. The Health Foundation describes these as soft skills, technical skills and learning skills. Our EQIP programme has all these elements embedded.

As acknowledged earlier in this report, all changes may not necessarily lead to improvement or the desired impact on services. Therefore, more work needs to be done to support services and help them begin to lay the foundation for working towards best practices. Internal and external factors need to be addressed with the knowledge that there is support for areas of development that can be explored as a whole team in clinical practice. Examples of improved service delivery have been demonstrated by paediatric epilepsy service teams participating in the EQIP, who had access to resources and a willingness and commitment for change through team building and using new skills and knowledge to take small, progressive steps towards improving the impact of clinical care for their children and young people with epilepsy.

Recommendations

NHS England and NHS Wales

National health education bodies should consider the learning from initiatives like the RCPCH EQIP, which demonstrates the effectiveness of comprehensive team training in QI. This approach has shown increased team cohesion, leadership capabilities, and service improvement. Incorporating rapid, integrated training for MDTs in QI methods to enhance patient care outcomes should be resourced and offered as an effective way of developing applied improvement skills for paediatric care teams. Such models achieve meaningful outcomes contributing, to reducing variation in clinical practice whilst providing applied training for staff.

> Incorporating rapid, integrated training for MDTs in QI methods to enhance patient care outcomes should be resourced and offered as an effective way of developing applied improvement skills for paediatric care teams.

ICB and Trust/Health Board service management

ICB leads should support the RCPCH EQIP model as part of both their improvement strategy and staff training. ICBs should create comprehensive communication strategies that incorporate an overview of workforce/ resources and patient engagement models, allowing children and young people to actively participate in service design, evaluation, and improvement efforts. Trust service management should work collaboratively with ICB clinical leads to ensure dedicated time in service staff job plans and necessary support for implementing improvement initiatives. It is important that best practices and effective solutions are shared widely and among other long-term conditions, particularly in national priority areas such as transition, mental health support, patient engagement, and reducing wait times.

MDT and service-level teams

Implementing a comprehensive team-based training model is effective only when the service staff are ready for change and have buy-in from their MDTs. To achieve sustainable improvement, service teams will need to understand their internal systems and workforce dynamics, and identify key stakeholders. Understanding how to engage with children, young people and their families is central to improving outcomes and impact on service delivery. Multidisciplinary team training eliminates hierarchy, offering all stakeholders involved in providing care for children and young people the space to collaboratively address consistent barriers within their control, leading to sustainable solutions and continuous improvement integration.

Photo: Dr Patricia O’Connor, Quality Improvement Expert Trainer, delivering training on QI methodologies and techniques at training launch.

Acknowledgements

The RCPCH EQIP would like to thank all participant paediatric epilepsy teams administrators, doctors, nurses and others within participating Health Boards and Trusts who have given their time and effort to participate in the first ever epilepsy QI collaborative. We would particularly like to thank the pilot teams for their resilience, continued enthusiasm and brilliant work delivered in order to complete the programme in 2019/2020 during one of the most challenging times the NHS has had to endure during the COVID-19 pandemic.

Faculty team

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Special thanks

Children, young people and families, from the RCPCH Epilepsy12 Youth Advocates

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RCPCH EQIP
Epilepsy quality improvement programme
Impact report 2019-2023

Published RCPCH 2024
The Royal College of Paediatrics and Child Health (RCPCH) is a registered charity in England and Wales (1057744) and in Scotland (SC038299).

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