*RCPCH EQIP

Epilepsy quality improvement programme

Summary report 2023-2024







Contents

- 3 Who we are
- 3 Aim of the collaborative programme
- 5 What did we achieve?
- 6 Summary of evaluation results 2023-2024
- 7 Lessons learned
- 10 Assessing Impact through case studies
- 15 Acknowledgements

Appreciation

The RCPCH Epilepsy Quality Improvement programme 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 considerable time and effort into service improvement during incredibly challenging circumstances. We also thank participant teams for the use of images and visual project outcomes captured during the programme.

Thank you to children, young people and families from the RCPCH Epilepsy12 Youth Advocates group, EQIP Steering group and Epilepsy Specialist Nurse Advisory group members and to all that have contributed to the training and delivery of this round of EQIP.

EQIP was funded by the NHS England Children and Young People (CYP) transformation team.

The RCPCH and EQIP Steering group would like to thank Melanie David-Feveck for managing EQIP and Dr Patricia O'Conner for providing QI leadership.

Programme collaborators:

EPILEPSY12











Who we are

The Epilepsy Quality Improvement Programme (EQIP) is the first quality improvement (QI) initiative supporting UK paediatric epilepsy care. It has been managed by the Royal College of Paediatrics and Child Health (RCPCH) and the 2023-24 training cycle was 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 quality improvement in epilepsy care. Epilepsy is currently one of the most common long-term conditions in children and young people 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 (LTP).

Aim of the collaborative programme

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 Epilepsyl2 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.

Aligned with the objectives outlined in the published NHS England National Epilepsy Bundle of Care, (2023) addressing challenges faced by both Integrated Care Boards (ICBs) and Trust paediatric epilepsy services. EQIP has focused on supporting NHS paediatric services with the guidance to help reduce national variation in clinical practice and lead to better outcomes for children and young people diagnosed with epilepsy.

EQIP 2023/4 areas of focus:

- Continue to assist healthcare professionals in addressing current challenges, by offering a programme to centrally support and embed quality improvement methodology within paediatric epilepsy teams throughout England.
- Continue to review Epilepsy12 baseline data with each participant team and discuss areas of improvement highlighted by audit results against key priority areas.
- Closely align project improvement goals with the four priority areas outlined by the National Epilepsy Oversight Group, established via the NHS England CYP Transformation Programme.
- Grow the skills and knowledge of teams and integrated care systems (ICS) to understand successful transformation and change at all levels in epilepsy services using a microsystems model embedded within local operational business.
- Use those new skills to build networks of improvers to deliver the priority areas of local services underpinning national NHS England epilepsy care goals.
- Develop customised programmes of capability building, linked to teams and responsibilities that are topic specific programmes of work.

Access the 2019/2023 full impact report for more information on the programme outcomes for participant teams on previous training waves.







Photos: Team participants attending EQIP training launch October 2023.





Weaning of antiseizure medications after acute symptomatic seizures: a quality improvement project

Jahziel Darisan, Husna Musa, Noelle Enright, Suresh Puiar, Maria Gogou

Alm: To make sure that by May 2024 for all children (0-18 years) admitted to GOSH and started on ansiseizure medications (ASM) after acute symptomatic seizures there will be a plan in their discharge summaries to start wearing ASM or consider wearing after a period of 2-3 months, if this is clinically appropriate.

What is the problem: Acute symptomatic seizures are seizures occurring in close temporal relationship with an acute CNS insult. Although treatment with ASM may be needed in the acute phase, they are usually not associated with future risk of epilepsy. However, there are no established guidelines about the duration of treatment with ASM and there is currently significant heterogeneity in daily practice, a fact which increases the risk of polypharmacy and associated adverse events.



Successful weaning requires collaboration of different teams & ngagement of carers and local medical teams

Patients with acute seizures: an heterogeneous group

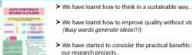
We have recruited and provided a writte children initially identified.





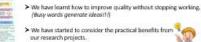


















> Projects ... build bonds! Next steps

Part of our project will be included in the induction package for junior doctors.

♦ We will write a literature review and try to establish

•We will re-audit the practice in our trust after completion of this project.

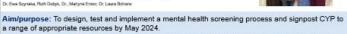




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Mental Health in Paediatric Epilepsy: Prioritising the needs of the Children and Young People

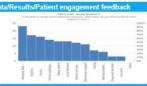
Isle of Wight NHS Trust "Epilepsy Fighters"



What is the problem: A number of gaps exist in the current IOW service. There is no dedicated epilepsy clinic and no Epilepsy Nurse Specialist, which causes a number of challenges. Our Epilepsy 12 audit highlighted that there was no Mental health screening process in place, and there was no access to tailored emotional well-being support or resources for our families.











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Photos: Team participants attending EQIP training launch October 2023.



A reminder phrase in discharge summaries A promotional video to increase awareness informative material for families and patients

Teaching sessions around the trust. Challenges:

Changes in our team's synthesis-how to keep team connected
Difficulties with engaging families & other teams:

(i) The fragmented nature of our job (iii) Workload, unpredicted discharges/transfers



What did we achieve?

Since its inception in 2019 EQIP has seen the participation of 49 NHS hospital Trusts and Health Boards in England and Wales, including three Integrated Care Boards (ICBs). The programme has trained 221 NHS staff within paediatric epilepsy services. This includes the nine service teams and 37 people trained in the 2023/2024 round, producing case studies and project posters to help share lessons learned with the wider epilepsy community and healthcare professionals.

Team working and communication

- Supported paediatric epilepsy services to identify and address gaps in care provision, including forging or strengthening links with other parts of healthcare service, community and support organisations.
- Increased growth in leadership skills within teams.
- Reduced silo working by encouraging teams to work together more cohesively and appreciating each team members contribution to changing service processes.

QI training and support

- Used methods and tools to coordinate and establish clear communication and implement processes that has led to change in processes and standardisation of systems locally within services.
- Provided coaching and support alongside live training webinars to help teams achieve the impactful outcomes described within team case studies.
- Embedded patient engagement tools and techniques and increased their understanding of children and young people support needs to help address health inequalities.
- Teams experienced increased collaboration with community/third sector organisations and mental health organisations. This helped to increase patient and family access to support needs in conjunction with the clinical care received.

Using data to drive change

- Team participants used national data from Epilepsy12 audit to gain a better understanding of service gaps and areas requiring improvement, with a focus of improving key clinical areas.
- Measurement data was captured and evidenced within cases studies to highlight service changes and presented as both quantitative and qualitative results.
- Project improvement goals were closely aligned with three of the four priority areas outlined by the National Epilepsy Oversight Group, established via the NHS England CYP Transformation Programme.



- Enabled a piece of work to look at the ICB approach that would benefit families across the system, not just at one place. This in turn would benefit clinicians and families.
- Gave us ideas on how to improve ourservice, we focused on transition but it gave us a general approach to any QI project we want to do. It was good to meet other epilepsy teams as well and learn.
- Knowing how to do a QI project.
 Having a common language will help communication within the team when designing further projects.
- We made a positive change that we would not have done without the push of the project to motivate us and make us find the time to do it!

Participant team evaluation feedback on the benefits of joining the EQIP, 2023/2024

Summary of evaluation results 2023/2024

Access full summary of evaluation results via the RCPCH website

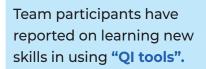
Common theme responses from team participants on the benefits experienced working within a team were "building positive relationships with colleagues", "enabled MDT approach", "sharing of ideas", "strengthening working relationships".





Paediatric epilepsy teams envisioned using their Epilepsyl2 audit data to inform future QI initiatives using "gap analysis", "addressing challenges and limitations", "focus on specific patient cohorts" and "future planning".

91% (21/23) reported they found monthly 1:1 team meetings "very useful".



55% (12/22) reported they found the EQIP website "very useful".

24% (17/70) reported they envision "time/capacity" as a barrier that would prevent the effectiveness in delivering their project intervention within their Trust.

96%_(22/23) reported engagement with patients and families increased since joining the EQIP.

100%_(23/23) found the training and course materials met the learning aims/objectives of EQIP.



48% (11/23) of team participants reported that they involved children and young people within their project by "obtaining feedback verbally in clinic to inform improvements".

74% (17/23) reported they captured feedback from patients and parents as part of their own service review and improvement activities.



Paediatric epilepsy service teams described sustaining their project by "continuous engagement", "protected time", "structure and support and "learning from other teams".

Lessons learned

The following lessons learned were based on participant project outcomes:

Whole team approach

An integrated approach involving the entire team in learning is crucial. Often, services tend to train/learn in isolation by discipline rather than collaboratively. Integrated training models where all members collaborate to address barriers or challenges are rare in the NHS but can significantly improve team effectiveness.

Importance of co-production

The project emphasised the value of involving children and young people in the development and delivery of services. Team participant case studies have highlighted the importance of gathering and responding to feedback, ensuring that service improvements are informed by the voices of those they aim to support.

Knowledge and skills

Service teams require the requisite skills and knowledge to effectively plan and execute improvement projects to address service gaps. It is imperative for teams to engage in collaborative learning with other services across regions to enhance their knowledge, share best practices, and contribute to reducing variation.

Support

Each training wave has consistently presented time and resource challenges for service teams, yet they have shown remarkable resilience and achieved commendable outcomes despite limited resources. However, these efforts often occur in their personal time without sufficient support to allocate focused time within their job plans. For sustainability, it is vital to provide teams with dedicated time and space for service improvement. Senior management involvement is crucial, as it enables them to understand the challenges, appreciate the work undertaken, and explore ways to disseminate best practices.

Engagement between ICB leads and local service providers

The programme highlighted the need for strategic engagement at both local and system-wide levels. The RCPCH should explore offering training modules or strategies focused on developing and implementing engagement strategies that connect different teams and services across an Integrated Care Board (ICB).

Introduction to addressing health inequalities

Training in EQIP 2023/2024 focused on addressing health inequalities, within project interventions. Training webinars featured guest facilitators from the Association for Young People's Health (AYPH) charity and RCPCH Officer for Health Improvement. Teams engaged underrepresented and marginalised groups through targeted outreach with community leaders, youth workers, and cultural organisations to build trust and ensure effective reach. Efforts included translated materials, training staff on cultural competency, and ensuring inclusive services. Accessibility was improved by offering flexible appointment times, virtual consultations, and mobile clinics. Teams also developed tailored health education materials and partnered with local charities, community groups, and healthcare providers for a coordinated approach to reducing health inequalities.

In person launch event and end of programme event

EQIP 2023/2024 participants experienced two in person events that fostered the networking and team building activities which formed a 'social contract' with EQIP facilitators and amongst participant teams. This significantly fed into the project achievements of service changes and the implementation of standardised processes.

Developing mental health support pathways

The team projects highlighted the many available validated screening tools accessible to service teams, however, through testing and engaging children, young people and their families, it became clear that not all tools met the needs of all young people. This lesson emphasised the importance of flexibility in using screening tools, allowing for adaptations or alternative methods to better support diverse patient needs.

Team improvement projects demonstrated the significance of adapting clinic times, locations, and resources to reduce DNA rates and improve access for underserved populations. Strategies for addressing health inequalities were developed to ensure that services are accessible to all patients, regardless of their circumstances. Interdisciplinary collaboration was undertaken to provide comprehensive care that meets the varied needs of patients.

Listed below are some commonly used mental health screening tools used by participant teams:

PedsQL, Paediatric Quality of Life Inventory <u>View</u>

Epilepsy-specific measure of quality of life, which is applicable to all age groups.

2. Strengths and Difficulties Questionnaire (SDQ) View

A behavioural screening tool for children and adolescents that covers emotional symptoms, conduct problems, hyperactivity, peer relationship problems, and prosocial behaviour.

3. Beck Depression Inventory (BDI) View

Assesses the intensity of depression in adolescents and adults. Widely used to screen for depression and to measure behavioural manifestations and severity of depression in people aged 13 to 80 years.

4. Generalised Anxiety Disorder Scale (GAD-7) View

A brief measure for assessing generalized anxiety disorder, covering core anxiety symptoms.

Revised Child Anxiety and Depression Scale (RCADS) <u>View</u>

Tool is a 47-item youth self-report questionnaire with subscales. This tool is also based on an American system which incorporates questions on school grades in the assessment.

6. HEADS-ED View

An easy-to-use screening tool that physicians, nurses, intake workers, and other mental health caregivers can use during a patient visit to identify mental health and addictions needs from early infancy to transitional aged youth.

7. PHQ-9 (Patient Health Questionnaire-9) <u>View</u>

Screens for depression by assessing the severity of depressive symptoms over the past two weeks.

8. WHO depression self-assessment tool View

The WHO depression self-assessment tool is used for the self-assessment of depressive symptoms.

Improving transition pathways

Team projects highlighted the importance of adapting engagement methods to better connect with children and young people. Using different methods for data collection, such as inperson feedback and interactive tools, provided richer insights. Project outcomes reinforced the importance of not making assumptions about patient needs. Establishing a clear transition pathway and engaging with community support such as youth workers were key lessons to incorporate within clearly defined processes to meet emerging needs in service delivery.

Improving variation in care

SUDEP discussions

This team project highlighted the necessity of adapting discussions to the specific needs of families, particularly those with children and young people who have learning disabilities or complex needs. Lessons learned included strategies for tailoring communication for different audiences and incorporate regular feedback mechanisms to refine and improve care practices continuously. Addressing language barriers, cultural differences and children and young people with complex needs is essential including strategies for tailoring communication for different audiences. This case study evidenced the benefits of involving the entire team, from doctors to administrative staff, in quality improvement efforts and demonstrated thinking beyond the initial scope to address broader healthcare needs.

Anti-seizure medication weaning plans

This team project highlighted the importance of fostering collaboration across different medical teams, including neurology, neurosurgery, and local medical teams. Effective communication and teamwork are crucial for identifying patients who might benefit from weaning plans. Emphasising the practical benefits of research and quality improvement projects can enhance clinical outcomes. Project outcomes demonstrate how theoretical knowledge can be applied in real-world settings and reinforcing the importance of ongoing education and awareness-raising efforts, such as the creation and dissemination of training videos, informative materials, and teaching sessions. This helps to ensure the sustainability of the QI intervention where all relevant staff are knowledgeable about the weaning plans and their implementation.



Photos: Images of patient engagement activities used to capture feedback, which fed into changes in service delivery.

Assessing impact through case studies

Multidisciplinary paediatric epilepsy teams produced project interventions that have been tested and adapted including actively involving patients and their families in the design and implementation of services, ensuring that their voices are heard and that services are better aligned with their needs, particularly for vulnerable children and young people.

Teams achieved incremental changes within the following areas:

- Mental health signposting pathways and screening tools
- SUDEP risk discussion
- Transition pathways and communication to adult services.
- Antiseizure medication
- Improving patient engagement

Access the 2023/2024 improvement case studies produced by the EQIP teams on the RCPCH website

For examples of the 2023/2024 team project journeys, project posters, video presentations and case studies from previous EQIP teams, visit the **EQIP microsite** or scan the QR codes below.



EQIP microsite: Case studies, posters and presentations

Improving patient engagement processes



Mental health and wellbeing



Transition pathways



Tertiary service pathways



Reducing variation



2023/2024 participant Health Board, Trust and ICB team project interventions

Team name	Project aim			
Improving and adapting transition process to adult services				
Hull University Teaching Hospitals NHS Foundation Trust	To develop and implement a personalised transition plan for children and young people with epilepsy for 40% of the caseload and map transition care pathways in line with the National Epilepsy Care Bundle, by May 2024.			
Northern Care Alliance NHS Trust (Oldham Care Organisation)	Design and implement a transition package for children and young people aged 16 years and over that enables them to understand and manage their epilepsy, by May 2024.			
West Hertfordshire University NHS Trust	To create a structured pathway for 50% of children and young people (aged 14-16 years) to transition into adult services by June 2024.			
Developing mental health and wellbeing pathways				
East Sussex Healthcare NHS Trust	By May 2024, every child and young person aged 13-18 years attending their epilepsy clinic will undergo mental health screening, with patient feedback being used to determine service needs.			
Northern Care Alliance NHS Trust (Salford Royal)	To utilise the Strengths and Difficulties (SDQ) screening tool in 50% of young people aged 14 years and above with a diagnosis of epilepsy on our caseload, by May 2024.			
Isle of wight NHS Trust	To design, test and implement a mental health screening process and signpost children and young people to a variety of mental health resources by May 2024.			
Improving variation in care				
Central North West London NHS Foundation Trust (Hillingdon Child Development Centre)	To discuss the risk of sudden death in epilepsy (SUDEP) with parents/carers and children/young people and provide them with written information in 75% of clinical encounters by May 2024.			
Great Ormond Street Hospital for Children	To make sure that by May 2024, for all children (0-18 years) admitted to Great Ormond Street Hospital (GOSH) and started on antiseizure medications (ASM) after acute symptomatic seizures, there will be a plan in their discharge summaries to start weaning ASM or consider weaning within a period of 2-3 months, if this is clinically appropriate.			
York and Scarborough and Hull Integrated Care Board (ICB)	To develop a strategic framework for children and young people engagement across the Integrated Care Board (ICB) by May 2024.			

RCPCH EQIP team project interventions 2023-2024 against Epilepsy 12 Audit baseline data, NICE guidance and National Epilepsy Bundle of Care for children and young people with epilepsy

Project area	Reducing variation - SUDEP risk - medication	RCPCH EQIP team project interventions 2023/2024
Epilepsy12 Audit Website	 Percentage of CYP with evidence of provision of information on SUDEP. Percentage of CYP with epilepsy after 12 months where there is evidence that a) care planning includes patient held individualised epilepsy document or copy clinic letter that includes care planning information, b) there is patient/carer/parent agreement, and c) care planning has been updated when necessary. Percentage of CYP diagnosed with epilepsy with documented evidence of communication regarding core elements of care planning: parental prolonged seizures care plan, water safety, first aid, general participation and risk, SUDEP, and service contact details. Percentage of children and young people with epilepsy aged 5 years and above with evidence of a school individual healthcare plan by 1 year after first paediatric assessment. 	To discuss the risk of sudden death in epilepsy (SUDEP) with parents/ carers and children/young people and provide them with written information in 75% of clinical encounters by May 2024. Central North West London NHS Foundation Trust To make sure that by May 2024, for all children (0-18 years) admitted to Great Ormond Street Hospital (GOSH) and started on antiseizure medications (ASM) after acute symptomatic seizures, there will be a plan in their discharge summaries to start weaning ASM or consider weaning within a period of 2-3 months, if this is clinically appropriate. Great Ormond Street Hospital for Children
National Epilepsy Bundle of Care recommendations (full list of recommendations)	 ICBs should identify and work with providers to increase provision of information on SUDEP where they fall below 75%, based on Epilepsy12 audit data. All CYP should have an agreed and comprehensive written care plan provided to them. This should be for home and education settings with evidence of involvement from the CYP and their parent/carer. The care plan should be a patient-held individualised document or copy of a clinic letter that includes care planning information. It should also include service contact details, have patient/carer/parent agreement and be updated when necessary. Providers should ensure care planning takes into account reasonable adjustments for CYP with a learning disability or autistic CYP. This should be reviewed at least annually and should help inform relevant school healthcare plans. 	
NICE Recommendations	 All CYP/parents/carers should receive personalised and developmentally appropriate information on the risks of Sudden Unexpected Death in Epilepsy (SUDEP). This should include discussions on minimising individual risks listed in NG217, 10.1. This should be documented and revisited annually as part of the care planning process. All CYP should have an agreed and comprehensive written care plan provided to them as per NICE guidelines (NG217, 2.1.7). This should be for home and education settings with evidence of involvement from the CYP and their parent/carer. 	

Project area	Improving transition pathways	RCPCH EQIP team project interventions 2023/2024
Epilepsy12 audit Website	 Percentage of Health Boards and Trusts that were using structured resources to support transition % of Trusts with outpatient service for epilepsy where there is a presence of both adult and paediatric professionals. % of Trusts where adult neurologists were routinely involved in transition to adult services. 	To develop and implement a personalised transition plan for children and young people with epilepsy for 40% of the caseload and map transition care pathways in line with the National Epilepsy Bundle of Care, by May 2024. Hull University Teaching Hospitals Design and implement a transition package for children and young people aged 16 years and over that enables them to understand and manage their epilepsy, by May 2024. Northern Care Alliance NHS Trust (Oldham)
National Epilepsy Bundle of Care recommendation (full list of recommendations)	 Transition provision and resources should include key essential components and take into account any co-existing conditions and the complexity of epilepsy. The information provided should be individually tailored to the CYP with epilepsy. 	
NICE Recommendations	2. All CYP with epilepsy should have a designated named worker responsible for initiating and planning for transition, taking into account any co-existent conditions, as per NICE guidelines (NG43, 1.2.5).	
		To create a structured pathway for 50% of children and young people (aged 14-16 years) to transition into adult services by June 2024. West Hertfordshire University NHS Trust

Project area	Supporting mental health pathways	RCPCH EQIP team project interventions 2023/2024
Epilepsy12 audit Website	 Percentage of CYP with epilepsy over five years where there is documented evidence that they have been asked about mental health either through clinical screening, or a questionnaire/measure. Percentage of CYP with epilepsy and a mental health problem who have evidence of mental health support. Percentage of Trusts with agreed referral pathways for CYP with mental health concerns. Percentage of Trusts where mental health provision is facilitated within epilepsy clinics. Local Audit: evidence of the availability of specialist psychological advice and local pathways 	By May 2024, every child and young person aged 13-18 years attending their epilepsy clinic will undergo mental health screening, with patient feedback being used to determine service needs. East Sussex Healthcare NHS Trust
National Epilepsy Bundle of Care recommendations (full list of recommendations)	 CYP over the age of five years old with epilepsy should have their mental health screened routinely within epilepsy clinics. Should mental health problems be identified, the use of a validated screening tool and clear pathways for onwards referral to appropriate providers should be considered. 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 health care. Self-help resources to support wellbeing should be made available to CYP with epilepsy. Providers should have access to clear referral pathways and an up-to-date directory of local services of providers/organisations offering the appropriate level of support. 	To utilise the Strengths and Difficulties (SDQ) screening tool in 50% of young people aged 14 years and above with a diagnosis of epilepsy on our caseload, by May 2024. Northern Care Alliance NHS Trust (Salford) To design, test and implement a
	 Providers should aim for mental health care to be integrated within the epilepsy service. This may comprise of epilepsy clinics where mental health professionals can provide direct input into clinical care, and meetings where epilepsy and mental health professionals can discuss individual patients. 	mental health screening process and signpost children and young people to a variety of mental health resources by May 2024. Isle of wight NHS Trust

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Michelle, Young Trainer, Association for Young People's Health

Dr Helen Stewart, Officer for Health Improvement, Royal College of Paediatrics and Child Health, Consultant in Paediatric Emergency Medicine, Emergency Department, Sheffield Children's Hospital

Jo Ball, Design and Brand Manager, RCPCH

Angela Mensah, Head of Grants and Partnerships, RCPCH

Faculty team

Jonathan Bamber, Head of Quality Improvement, Royal College of Paediatrics and Child Health **Dr Colin Dunkley**, Consultant Paediatrician and Epilepsyl2 Clinical Lead, Sherwood Forest Hospitals NHS Foundation Trust

Alison Fuller, Director Heath Improvement and Influencing, Epilepsy Action

Dr Patricia O'Connor, Honorary Professor, University of Stirling Faculty of Healthcare Sciences and Sport Executive Director QI Discovery

Niky Raja, Epilepsy12 Project Manager, RCPCH

Dr Rohini Rattihalli, Consultant Paediatric neurologist, Oxford university hospital

Dr Fraser Scott, Consultant Paediatrician, Mid Yorkshire Hospitals NHS Trust, OPEN UK lead

Emma Sparrow, Head of Children, Young People and Engagement, RCPCH

EQIP advisors

Christine Bennett, Senior Children's Epilepsy Nurse, Yorkshire Paediatric Epilepsy Network

Jill Conium, Children's Epilepsy Specialist Nurse, Eastern Paediatric Epilepsy Network

Emma Hassan, Children's Epilepsy Nurse, North Thames Paediatric Epilepsy Network

Carolyn McAskill, Paediatric Epilepsy Specialist Nurse, Eastern Paediatric Epilepsy Network

Alison Mollett, Paediatric Epilepsy Nurse Specialist, Oxford region epilepsy network group

Laura Neely, Team Leader; Epilepsy Nurse Specialists, Mersey and North Wales network 'Epilepsy in Childhood' interest group

Amanda Tomalin, Paediatric Epilepsy Clinical Nurse Specialist, South East Thames Paediatric Epilepsy group

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Summary report 2023-2024

