RCPCH Audits

Combined organisational and clinical audits:
Report for England and Wales
Round 3 Cohort 1 (2018-19)

EPILEPSY12

National Clinical Audit of Seizures and Epilepsies for Children and Young People

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Healthcare Quality Improvement Partnership

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Royal College of Paediatrics and Child Health
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Epilepsy12
National Clinical Audit of Seizures and Epilepsies for Children and Young People
Combined organisational and clinical audits: Report for England and Wales, Round 3 Cohort 1 (2018-19)

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Epilepsy12 Youth Advocates

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Foreword

Epilepsy is the commonest significant neurological disorder affecting children. The needs of children with long term conditions, including epilepsy, are recognised as requiring particular attention in the NHS Long Term Plan. It is critical that children and young people have sufficient access to the full paediatric epilepsy team, and are supported to navigate the transition from child to adult health services.

The National Epilepsy12 audit was first undertaken in 2009, and in this, its third incarnation, we can see that significant improvements in epilepsy services for children have come through. There is no room for complacency, however. In these challenging times, with so many resources being directed towards saving the lives of those affected by the current Coronavirus pandemic, we need to also maintain focus on supporting children with epilepsy and their families. The Royal College of Paediatrics and Child Health with Epilepsy12 will continue to support the NHS services who have done so much to improve epilepsy care for children and young people.

My heartfelt thanks go to all of those involved in this important work at this difficult time.

Professor Nicholas Bishop
Vice President for Science and Research, Royal College of Paediatrics and Child Health, and Chair of the Epilepsy12 Project Board

Executive summary

Epilepsy is the most common significant long-term neurological condition of childhood and affects an estimated 112,000 children and young people in the UK.[1] The State of Child Health[2] has highlighted some key trends in paediatric epilepsy, showing that prevalence of epilepsy has reduced in recent years which may partly reflect more specific diagnosis and that there has been progress towards closing the inequality gap in emergency admissions for children with epilepsy. Epilepsy12 (the National Clinical Audit of Seizures and Epilepsies for Children and Young People) uses data collected from hospitals and clinics to support further quality improvement in paediatric epilepsy services.

This is a combined report of the organisational and clinical audits. The results are of the organisation of paediatric epilepsy services for children and young people in England and Wales as described at November 2019, and the standard of clinical care provided by services that focuses on patients with a new diagnosis of epilepsy between 12 July 2019 – 30 November 2019 for cohort 1.

Key findings

The key findings bring together important results the organisational and clinical audits, alongside new recommendations for quality improvement. (The full audit key findings and recommendations are listed further within the report from pg 17 - pg 32)

Key finding (A) - First EEG waiting times: Almost half of children with an epilepsy had to wait more than four weeks for their first EEG from the time of request. This is outside the four weeks stated in NICE's Quality Statement 2 for children and young people having initial investigations for epilepsy.

Recommendation (1) All Health Boards and Trusts* should:

- review and improve their referral pathways to ensure all first EEGs are achieved within a maximum of four weeks of request date. Health Boards and Trusts with EEG services should co-ordinate with their commissioners and regional OPEN UK network to ensure timely access to EEG services for all relevant Trusts and Health Boards.

*This may include: Trust medical director and paediatric epilepsy clinical lead

Key finding (B) - ECG and MRI investigations: A little over two thirds of children and young people who met the defined indications for an MRI, had received an MRI during their first year of care. A similar proportion of children and young people with epilepsy and had convulsive seizures obtained a 12-lead ECG during their first year of care. SIGN guidance, and current British Paediatric Neurology Association (BPNA) PET teaching curriculum, state that all children with a convulsive seizure should have a 12-lead ECG.

Recommendation (2) Health Boards and Trusts* should:

- ensure that they can provide MRI to children of all ages via a sedation and/or anaesthetic pathway,
- document within medical records and Epilepsy12 audit the confirmed epilepsy syndrome diagnosis (including BECTS, CAE, JAE, JME and 'epilepsy with generalised tonic clonic seizures only') as MRI is not routinely indicated for these children,
- review local pathways to include routine 12-lead ECG for children with convulsive seizures,
- ensure 12-lead ECG results are accessible within the ongoing clinic health records.

* This may include: Department leads at MRI, EEG services within Trusts or Health Boards, paediatric epilepsy services

1 Joint Epilepsy Council of the UK and Ireland. (2011). **Epilepsy prevalence, incidence, and other statistics**
2 Royal College of Paediatrics and Child Health (2020) State of Child Health in the UK

Key finding (C) - Mental health provision: Few Trusts and Health Boards are able to provide co-located mental health services for children and young people with epilepsy. Routine screening for mental health was not widely available.

There was a very small number of children and young people with epilepsy who had an identified mental health condition. This was lower than would be expected based on other available evidence about the incidence of mental health conditions for children with epilepsy.

Recommendation (3) Commissioners, Health Boards and Trusts* should ensure that:

- all children with an epilepsy should have ongoing screening for a range of mental health problems using a validated tool (e.g. Strengths and Difficulties Questionnaire),
- where there are concerns about mental health problems the child and young person should be referred to an appropriate mental health service via an agreed pathway for ongoing diagnosis and treatment,
- services for children and young people with epilepsy should include sufficient integrated mental health provision, some of which should be co-located within the epilepsy clinic.

*This may include: Mental health department leads, BPT commissioners, Paediatric epilepsy clinical lead

Key finding (D) - Epilepsy Specialist Nurses: There was evidence of an increasing epilepsy specialist nurse (ESN) workforce and more widespread involvement within the first year. This positive development is alongside encouraging increases in contact with specialists and fewer withdrawals of epilepsy diagnoses. NICE CG 137 and SIGN guidance both highlight the importance of ESNs as part of paediatric epilepsy care networks and teams. There remain some Health Boards and Trusts where ESN involvement is absent or insufficient.

Recommendation (4) Epilepsy Specialist Nurses provide a wide-ranging contribution to the care of the child and roles should take account of local populations and service configurations. **All Health Boards and Trusts** should employ sufficient ESNs to ensure at least 1 WTE ESN for every 250 children with epilepsy. This is so that families, alongside other ESN roles, can reliably receive direct individualised specialist advice by the same or next working day between scheduled reviews.

*This may include: Paediatric commissioners, Trust medical director and paediatric epilepsy clinical lead

Key finding (E) - Specialist paediatricians and clinical leads: There is evidence of increasing "paediatrician with expertise" involvement within the first year of care, although access to paediatric neurology where indicated remains static. While children with epilepsy received specialist input during the first year of care, there was evidence that in many cases there were waits for input beyond 2 weeks. NICE CG137 and NICE QS1 state that children and young people presenting with a suspected seizure are seen by a specialist in the diagnosis and management of the epilepsies within 2 weeks of presentation.

Recommendation (5) All OPEN UK regional networks and commissioners* should:

- review the Epilepsy12 findings in their area and ensure there is sufficient capacity for paediatric neurologists to provide timely assessment and ongoing management.
- support Trusts and Health Boards to define a paediatric clinical lead for their epilepsy services.

* This may include: OPEN UK, Regional Network Epilepsy leads, paediatric commissioners, and regulators (including CQC)

Key finding (F) - Best Practice Criteria for clinics: There are few Trusts and Health Boards able to provide, or working towards, clinics for paediatric epilepsy which meet the Best Practice Criteria (BPC). There has been a slight increase between April 2018 and November 2019.

Key finding (G) - Children's Epilepsy Surgical Service (CESS): There is evidence that many children who meet the Children's Epilepsy Surgical Service (CESS) referral criteria are not being referred according to

those criteria, including variation in referral rates between regions. This finding - together with the MRI findings - suggests there may be children with surgically treatable epilepsies who are missing out on, or having delayed access to, surgical evaluation and treatment.

Recommendation (6) OPEN UK regional epilepsy networks and CESS should:

- coordinate clear, embedded referral criteria and shared care pathways from secondary care and paediatric neurology to CESS,
- ensure early identification of referral criteria and ensure referral to CESS where appropriate.

Key finding (H) - Sodium valproate: Sodium valproate must no longer be used in any woman or girl of childbearing age unless they are enrolled in the pregnancy prevention programme. The results showed a clear reduction in use of sodium valproate in girls compared to boys after age 9. There was good evidence of discussion of the associated risks.

Key finding (I) - Comprehensive care plans: The majority of Health Boards and Trusts report routinely undertaking comprehensive care plans for all children with epilepsy. Yet at individual level there were gaps in provision of essential elements including the ease of contacting services and guidance for water safety.

Recommendation (7) All Health Boards and Trusts should implement standardised approaches to care planning content, or other robust mechanisms, to ensure that essential elements of care are provided routinely to children with epilepsy at diagnosis and reviewed on an ongoing basis.

Education and health providers* at national, regional and local level should agree procedures to facilitate appropriate, up-to-date health care planning within education and two-way information sharing.

*This may include: OFSTED, head teachers, school nurses, paediatric epilepsy service staff, patients and their families, youth workers, healthcare assistants, sports coaches or out of school organisations that provide activities

Key finding (J) - Transition to adult services: Over half of Health Boards and Trusts hold outpatient services that combine adult and paediatric professionals. For most paediatric epilepsy services there are no agreed pathways for children and young people to transition to adult services.

Key finding (K) - Diagnosis and Anti-Epileptic Drugs: There has been an apparent reduction in the rates of children misdiagnosed with epilepsy. There was very little evidence of children receiving anti-epilepsy medication unnecessarily. NICE's CG 137 states that AED therapy should only be started once the diagnosis of epilepsy is confirmed, except in exceptional circumstances that require discussion and agreement between the prescriber, the specialist and the individual and their family and/or carers as appropriate.

Key finding (L) - Local and regional variation: There was marked regional variation in the socioeconomic distributions within the epilepsy populations. There was also regional variation in the proportion of children diagnosed with epilepsy as a proportion of EEGs requested.

Recommendation (8) Epilepsy12 should develop an ascertainment measure based on estimated population sizes and estimates of epilepsy incidence according to Health Boards and Trust. This would allow case ascertainment of the audit to be compared with a measure of the expected epilepsy incidence and variation in EEG rates.

All Trusts and Health Boards* should ensure that epilepsy services have sufficient clinician time job-planned to ensure capacity to submit accurate audit data and implement quality improvement, in addition to clinical activities.

*This may include: Trust medical director, lead for EEG, and paediatric epilepsy clinical lead

1. Introduction

Epilepsy12 was established in 2009 and has the continued aim of helping epilepsy services, and those who commission health services, to measure and improve the quality of care for children and young people with seizures and epilepsies. The audit is commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP) and is delivered by the Royal College of Paediatrics and Child Health (RCPCH).

The RCPCH delivered Rounds 1 and 2 of Epilepsy12 between 2009 and 2015, publishing related national reports for each Round in 2012 and 2014 respectively. Paediatric epilepsy was once again prioritised as a topic for the NCAPOP and the RCPCH was re-commissioned by HQIP to deliver Round 3 of Epilepsy12 from 1 April 2017 to 31 March 2021.

Rounds 1 and 2 of the audit included Health Boards and Trusts across England, Northern Ireland, Scotland and Wales. This report covers the analysis of data collected by the audit on the organisation of paediatric epilepsy services within Health Boards and Trusts in England and Wales. It is hoped that in future, Health and Social Care Trusts in Northern Ireland and Health Boards in Scotland will also join Round 3 of the audit, subject to contractual and governance arrangements being put in place.

As per Rounds 1 and 2, the work of Round 3 of the audit is overseen by a Project Board which includes representatives of patient and professional organisations and a dedicated project team within the RCPCH.

Audit aims and scope

Epilepsy is the most common significant long-term neurological condition of childhood and affects an estimated 112,000 children and young people in the UK.[3] The aim of Epilepsy12 is to help to improve the standard of care for children and young people with epilepsies. To be able to do this, the audit will collect and process patient identifiable data. By collecting and processing such information the audit is able to highlight areas where hospitals and clinics are doing well, and also identify areas in which they need to improve.

In Round 3, Epilepsy12 has expanded the scope and aims of the audit to:

- continue to measure and improve care and outcomes for UK children and young people with epilepsies,
- include all children and young people with a new onset of epilepsy,
- enable continuous patient ascertainment,
- use a pragmatic and concise dataset,
- incorporate NICE Quality Standards, Mental Health, Educational and Transition metrics,
- obtain approval to include patient identifiers to allow local real-time individual and service dashboard elements within the audit reporting platform.

Data completeness

There were 149 registered Health Boards and Trusts in Round 3 of Epilepsy12. Eight of the registered Trusts merged to form four Trusts in 2019, leaving a total of 145 registered Health Boards and Trusts participating within the audit. The clinical audit phase began in July 2018 and focuses on performance indicators relating to the first paediatric assessments undertaken for children and young people who

3 Joint Epilepsy Council of the UK and Ireland. (2011). Epilepsy prevalence, incidence, and other statistics.

experience a paroxysmal episode or episodes (includes all epileptic or non-epileptic seizures and also seizures of uncertain in origin) between July 2018 – December 2018 and the first year of care that follows those initial assessments up until 30 November 2019. Nine of the registered Health Boards and Trusts did not submit a 2019 organisation report to the 2018/2019 Epilepsy12 audit and 36 Health Boards and Trusts were excluded within the clinical audit due to data incompleteness.

There remains considerable variation in respect to Health Boards and Trusts in England and Wales regarding their ability to staff, resource time within job plans, and adequate IT systems to collect and submit accurate and complete data to the national audit. We would like to stress the importance of all paediatric epilepsy services within Health Boards and Trusts being supported with their data submission to national clinical audits. Health Boards and Trusts can use audit data for benchmarking practices to identify gaps that require service improvements, share best practice and improve the completeness. We urge senior Health Board and Trusts management to support their paediatric epilepsy services to improve upon data completeness to ensure it reflects a more accurate picture of their standard of practice.

Audit outputs and publications

Round 3 of Epilepsy12 is comprised of three main audit domains: the organisational audit (service descriptor), the clinical audit (clinical care domain) and associated Health Boards and Trusts profile and Quality improvement (Patient reported experience measures, EQIP, children and young people's engagement). The Epilepsy12 produces the following current and future reports, all of which can be viewed and downloaded from **www.rcpch.ac.uk/epilepsy12**

- Epilepsy12 National Organisational Audit Report 2018
- Epilepsy12 National Organisational Audit Report 2018: Health Board and Trusts level results
- 2018 Epilepsy12 &Us - voices from the RCPCH &Us network booklet
- A guide to the 2018 Epilepsy12 National Organisational Audit report for parents and young people
- Epilepsy12 Combined National report 2018/19 key messages
- Epilepsy12 National Organisational Audit Report 2019: Regional/National Results
- Epilepsy12 National Organisational Audit Report 2019: Health Board and Trusts level Results
- Epilepsy12 National Clinical Audit Report 2018/19: Regional/National Results
- Epilepsy12 National Clinical Audit Report 2018/19: Health Board and Trusts level Results
- RCPCH Epilepsy Quality Improvement Programme (EQIP): Supplement (released later this year)
- A guide to the 2018/19 combined Epilepsy12 National Audit report for parents and young people booklet (released later this year)
- 2018/19 combined Epilepsy12 National Audit report clinic posters (released later this year)
- 2019 Epilepsy12 &Us - voices from the RCPCH &Us network booklet (released later this year)

Quality improvement

Facilitating quality improvement activities is a core element of Epilepsy12. The audit supports these activities in the following ways.

Supporting regional and national quality improvement activities

Epilepsy12 has continued to support the Organisation of Paediatric Epilepsy Networks (OPEN UK), hosting quarterly national meetings to help regional leads share learning and co-ordinate strategy.

Epilepsy12 and OPEN UK are working together to highlight the importance of appropriate resources for paediatric epilepsy networks, identify opportunities for regional QI activities, and share learning across the whole OPEN UK network.

The second Epilepsy12 & OPEN UK National Conference took place on 17 June 2019. More than 160 health professionals working in support of paediatric epilepsy services and patient organisation representatives came together with the aim of learning from each other and improving care for all children and young people with epilepsies. The conference was chaired by Dr Sophia Varadkar, Consultant Paediatric Neurologist & Chief of Service for Brain Directorate, GOSH and included a young people-led symposium, keynote speaker and related Q&A session, Epilepsy12 updates and a quality improvement (QI) showcase session with associated QI poster displays. The conference also marked the launch of the RCPCH Epilepsy Quality Improvement Programme (EQIP). Copies of the presentations delivered on the day can be viewed via the project website: **www.rcpch.ac.uk/epilepsy12**

Epilepsy12 audit data was linked with Office of National Statistics and NHS datasets in recently published research.[4] The study examined whether there were associations between quality of paediatric care, hospital admissions, and all-cause deaths among epilepsy patients. The authors report that for adolescents with epilepsy, greater involvement of tertiary specialists in paediatric care was associated with decreased mortality after transition to adult services. Reduced access to an epilepsy specialist nurse was associated with an increase in paediatric epilepsy hospital admissions.

Epilepsy Quality Improvement Programme (EQIP)

The RCPCH EQIP launched on 17 June 2019 and has been designed as a model for a comprehensive quality improvement programme, tailored to support paediatric epilepsy teams to work together to define their shared aims and identify current gaps in service provision. This pilot programme will run for six months. The programme launched with a weekend training residential event taking place on 16/17 November 2019 and a follow up event of shared learning in July 2020. See chapter 5 for more information on the programme and visit the project website for updated information on the teams' journeys via **www.rcpch.ac.uk/eqip** .

Children and young people engagement

The Epilepsy12 Youth Advocates have been developing a new quality improvement project relating to "Clinic Checks". A pilot has been taking place in paediatric epilepsy services across England and Wales to assess the support that they provide to young people for their anxieties and worries. See chapter 4 for more information on the Youth Advocates.

Audit methodology and dataset development

The Epilepsy12 Methodology and Dataset Group was established in April 2017 and tasked with the development of the methodology and related datasets for both the clinical and organisational audit phases of Round 3 of Epilepsy12. The development of the methodology and datasets was broken down into separate work streams which covered different aspects of paediatric epilepsy care.

4 Hargreaves, D S. et al. (2019) Association of quality of paediatric epilepsy care with mortality and unplanned hospital admissions among children and young people with epilepsy in England: a national longitudinal data linkage study. Lancet Child Adolesc Health. 3(9):627-635

Audit measures were subsequently developed which aligned to:

- *Epilepsies: diagnosis and management (2012) NICE guideline CG137,*
- *Epilepsy in children and young people (2013): NICE Quality Standard 27*.

Members of the Epilepsy12 project Board reviewed and signed off the Epilepsy12 Round 3 methodology and dataset in September 2017.

Data entry

The Epilepsy12 Round 3 data platform was configured to allow the registered Health Boards and Trusts and EEG services to register and complete the clinical and organisational audits. The clinical audit focuses on care provided to patients with a new diagnosis of epilepsy. Clinical audit data entry is prospective, with eligible patients grouped into three cohorts. The first cohort is defined by patients with a first paediatric assessment for a paroxysmal episode (or episodes) between the "Go live" date (12 July 2018) and 30 November 2018. The first year of care data entry timeframe is 12 July 2018 to 30 November 2019. The organisational audit focuses on services and workforce at Trust and Health Board level at a designated point in time, this report presents organisational data from November 2019.

Using the Epilepsy12 platform EEG services can register patients that have been referred for their first EEG for a paroxysmal episode. Designated leads and Health Board/Trust staff members were able to edit and update their data entry up until 31 December 2019, by which time they had to formally submit and lock their assessment and first year of care data in order for it to be included in the final data download for analysis by the Epilepsy12 project team.

Analysis and identification of key findings and recommendations

The Epilepsy12 project team downloaded all submitted and locked clinical and organisational audit data from participating Health Boards and Trusts in January 2020. Members of the Epilepsy12 project board and methodology and dataset group then met to review the analysis of submitted data and agree key findings and recommendations for the report.

Managing small numbers

The Epilepsy12 measures and results have been reviewed to manage the risk of disclosure of protected information about individuals included in the audit data (or those connected to them). This was assessed on a case-by-case basis, and at points in this report results with small numbers have been masked. Masked results have been marked with an asterisk (*) and footnoted.

2. Themes and recommendations

Clinical audit 2018-2019 results

The clinical audit phase of Epilepsy12 began in July 2018. It focuses on performance indicators relating to the first paediatric assessments undertaken for children and young people who experience a paroxysmal episode (or episodes) between July 2018 – December 2018 and the first year of care that follows those initial assessments up until 30 November 2019. This national report includes the analysis of data from the first cohort of patients from Round 3 clinical audit phase. The performance indicators align with NICE Guidelines and Quality Standards[5] and cover the following areas:

- input from a paediatrician with expertise in epilepsies
- input from an epilepsy specialist nurse
- tertiary input
- epilepsy surgery referral
- appropriate first paediatric assessment
- seizure formulation
- access to electrocardiogram (ECG)
- access to magnetic resonance imaging (MRI)
- accuracy of diagnosis
- discussion of the risks of treatment with sodium valproate
- comprehensive care planning agreement and content
- school individual healthcare plans.

The Epilepsy12 data platform allows participating Health Boards and Trusts to enter data on the care that they provide to children and young people for the clinical audit phase and view real time outputs including individual patient timeline and care planning reports and a performance indicator dashboard.

Full details of the Epilepsy12 Round 3 performance indicators can be viewed on the **Epilepsy12 website**.

Organisational audit 2019 results

Epilepsy12 brings together a multidisciplinary group of representatives to highlight key findings and results and translate these into a set of recommendations that can be acted upon to improve paediatric epilepsy care. The Epilepsy12 audit of the organisation of paediatric services in England and Wales covered the following areas:

- workforce
- epilepsy clinic configuration
- tertiary provision
- investigations
- service contact
- young people and transition
- mental health provision
- neurodevelopmental support
- care planning
- patient databases or registers.

5 NICE (2012) Clinical Guideline 137 - Epilepsies: diagnosis and management
NICE (2013) Quality Standard 27 - Epilepsy in children and Young People

General and specific recommendations are made to support the existing goals and priorities of paediatric epilepsy services and regional networks, and are targeted to those with the ability to action the recommendation.

Full details of the Epilepsy12 Organisational audit indicators can be viewed on the **Epilepsy12 website**.

Combined key findings and recommendations

The clinical audit covers from the first paediatric assessments undertaken for children and young people who experience a paroxysmal episode (or episodes), to a record of care for the next 12 months. The organisational audit supplements this data with insight into the provision of staff and service availability in each Health Board and Trust.

Within the clinical audit, there are 12 measures which were derived from national guidelines and recommendations. These are referred to as the 'Performance Indicators' in the full results presented in Appendices A and G. The chart below summarises the results for these 12 measures, showing where care met the required standards for children and young people in Round 3, cohort 1. There are some very positive results. Children and young people with epilepsy are receiving care from specialist paediatricians and nurses, and they are being correctly diagnosed. There is, however, scope for improvement in aspects including comprehensive care planning and referral to epilepsy surgery services where children and young people meet relevant criteria.

The performance indicators shown in Figure 1 provide an overview of important aspects of care. The key findings and recommendations presented in the next section go beyond this, drawing on the full sets of results from the clinical and organisational audits. Due to this, the key finding sections, and numbering of recommendations, do not directly match those of the 12 performance indicators.

Detailed results from the clinical and organisational data are available in Appendices A and G. This includes the results for each measure and analysis by country and regional epilepsy network areas. Comparisons with previous rounds of the audits are made where available.

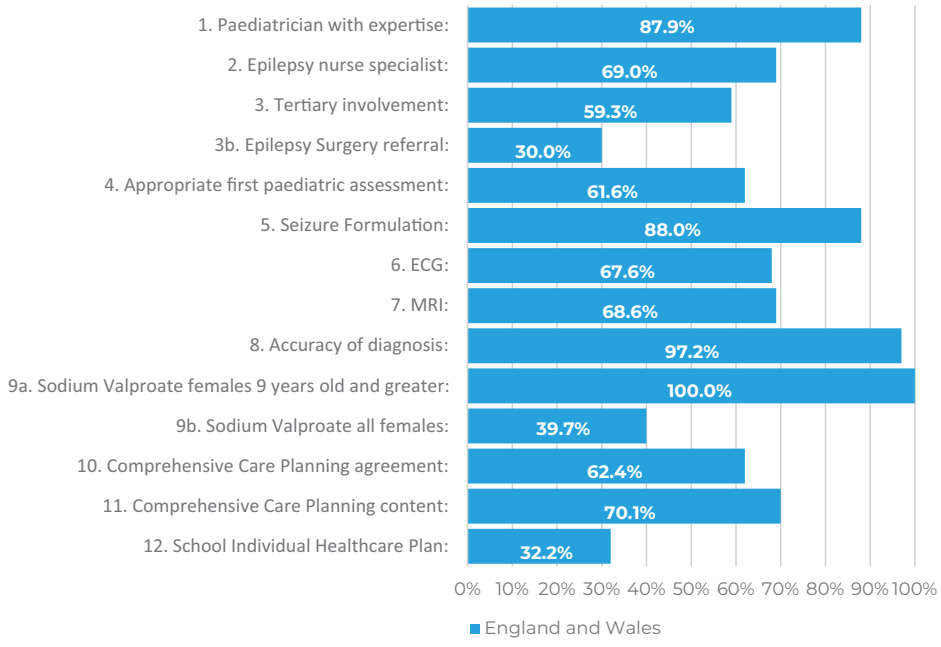
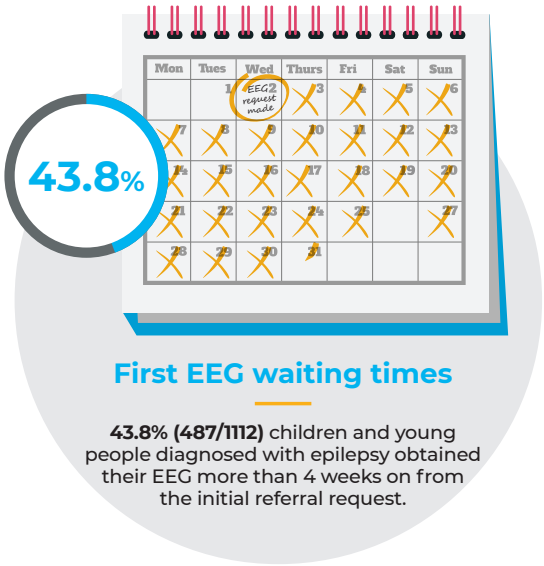


Figure 1: Epilepsy12 Performance indicators in England and Wales, Round 3 Cohort 1

Key finding A: First EEG waiting times



An electroencephalogram (EEG) is a recording of brain activity. During the test, small sensors are attached to the scalp to pick up the electrical signals produced when brain cells send messages to each other.

Almost half of children with an epilepsy had to wait more than 4 weeks for their first EEG from the time of request. NICE guidelines (Quality Statement 2) state that children and young people having initial investigations for epilepsy undergo the tests within 4 weeks of being requested.

- **43.8% (487/1112) children and young people diagnosed with epilepsy obtained their EEG more than 4 weeks on from the initial referral request.**

Recommendation 1

All Health Boards and Trusts* should:

- review and improve their referral pathways to ensure all first EEGs are achieved within a maximum of 4 weeks of request date.

Health Boards and Trusts with EEG services should:

- co-ordinate with their commissioners and regional OPEN UK network to ensure timely access to EEG services for all relevant Trusts and Health Boards.

*This may include: Trust Medical director and Paediatric epilepsy clinical lead

Key finding B: ECG and MRI investigations

Magnetic resonance imaging (MRI) is a type of scan that uses strong magnetic fields and radio waves to produce detailed images of the inside of the body. An electrocardiogram (or 12-lead ECG) gathers information from 12 different areas of the heart.

The Epilepsy12 performance indicator is based on SIGN guidance and current British Paediatric Neurology Association (BPNA), Paediatric Epilepsy Training (PET) curriculum. This states that all children with a convulsive seizure should have a 12-lead ECG.

- **68.6% (317/462) children and young people diagnosed with epilepsy and who met the defined indications for an MRI, had received an MRI during their first year of care.**
- **67.6% (474/701) children and young people diagnosed with epilepsy and who had convulsive seizures obtained a 12 lead ECG during their first year of care.**
- **Previously, 63.5% (Round 1, 2012) and 72.2% (Round 2, 2014) of children and young people who met the defined indications had received an MRI. In earlier rounds investigations by 12-lead ECG were reported for all children with epilepsy.**

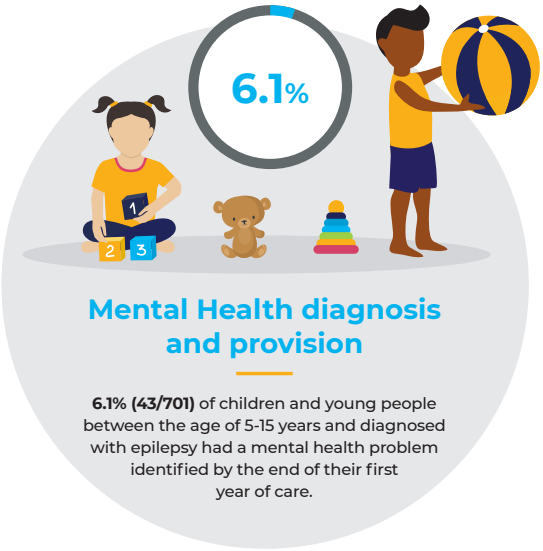
Recommendation 2

All Health Boards and Trusts* should:

- ensure that they can provide MRI to children of all ages via a sedation and/or anaesthetic pathway,
- document within medical records and Epilepsy12 audit the confirmed epilepsy syndrome diagnosis (including BECTS, CAE, JAE, JME and 'epilepsy with generalised tonic clonic seizures only') as MRI is not routinely indicated for these children,
- review local pathways to include routine 12-lead ECG for children with convulsive seizures,
- ensure 12- lead ECG results are accessible within the ongoing clinic health records.

*This may include: Department leads at MRI, EEG services within Trusts or Health Boards, paediatric epilepsy services/ teams

Key finding C: Mental health provision



Mental health diagnoses and evidence of involvement of mental health professionals was very low, considering the rates of mental health diagnoses in children with epilepsy evidenced in research.

NHS Best Practice Criteria (2019) states that there should be some co-located mental health provision within epilepsy clinics. Few services have co-located services, and in addition only a small number of Health Boards and Trusts report routinely screening young people for mental health conditions.

- **6.1% (43/701) of children and young people between the age of 5-15 years and diagnosed with epilepsy in cohort 1 had an identified mental health condition by year one in England and Wales.**
- **4.1% (45/1112) of children and young people with epilepsy had some evidence of involvement of a mental health professional or service by the end of their first year of care.**
- **However, a study of mental health in children with epilepsy (Dev Med Child Neurol. 2003) reported a much higher incidence where 37% of 5-15 year olds with epilepsy had a co-existing mental health disorder.**
- **14.0% (19/136) Health Boards and Trusts were able to facilitate mental health provision within epilepsy clinics.**
- **14.7% (20/136) of Health Boards and Trusts routinely provided formal screening services for mental health disorders, a decrease from 19.6% (29/148) in 2018.**

Recommendation 3

Commissioners, Health Boards and Trusts* should ensure that:

- all children with an epilepsy should have ongoing screening for a range of mental health problems using a validated tool (e.g. Strengths and Difficulties Questionnaire),
- where there are concerns about mental health problems the child or young person should be referred to an appropriate mental health service via an agreed pathway for ongoing diagnosis and treatment,
- services for children and young people with epilepsy should include sufficient integrated mental health provision, some of which should be co-located within the epilepsy clinic.

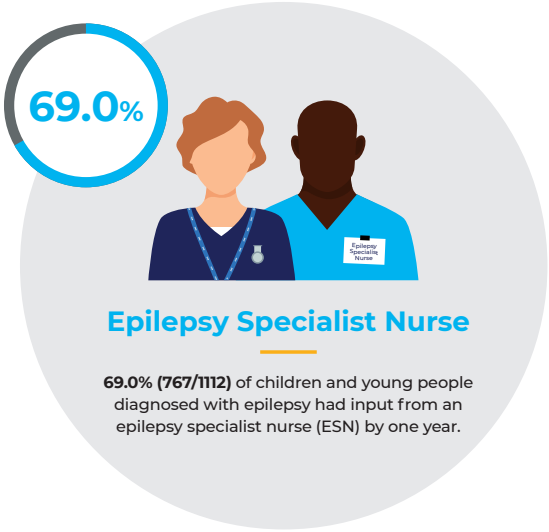
*This may include: Mental health department leads, BPT commissioners, Paediatric epilepsy clinical lead

Support for worries and anxieties

Epilepsy12 Youth Advocates selected 'support for worries and anxieties', 'face to face support', and 'school' as their three priority areas.

The areas were chosen after consultation with other children and young people, published in Epilepsy12 &Us - Voices from the RCPCH &Us network (January 2019). Children and young people wanted more support in helping to explain questions such as "why me? when will it stop?". They asked for help to establish coping strategies for themselves and their families.

Key finding D: Epilepsy Specialist Nurses



There is evidence of an increasing epilepsy specialist nurse (ESN) workforce and more widespread involvement within the first year. There remains some Health Boards and Trusts where ESN involvement is absent or insufficient. This positive development is alongside encouraging increases in contact with specialists and fewer withdrawals of epilepsy diagnoses. NICE Clinical Guideline 137 highlights the need for ESN to be part of the network of care in epilepsy, and in SIGN Guidance each epilepsy team should include paediatric epilepsy nurse specialists.

- **69.0% (767/1112) of children and young people diagnosed with epilepsy had input from an epilepsy specialist nurse during their first year of care.**
- **95.6% (130/136) of Health Boards and Trusts described advice available between scheduled reviews. However, 47.7% (62/130) of Health Boards and Trusts reported typical response times of three or more days.**
- **In 2019 there was a total of 158.4 WTE epilepsy specialist nurses (ESN) employed in participating Health Boards and Trusts across England and Wales.**
- **81.6% (111/136) of Health Boards and Trusts employed some ESN time.**

Drawing together the findings from both the clinical and organisational audit data, there was a correlation between having ESNs as part of the local workforce and some positive clinical indicators. In Health Boards and Trusts that employed some ESN time, children and young people with epilepsy were more likely to:

- be seen by an epilepsy specialist nurse,
- have school Individual Healthcare Plan,
- have an MRI.

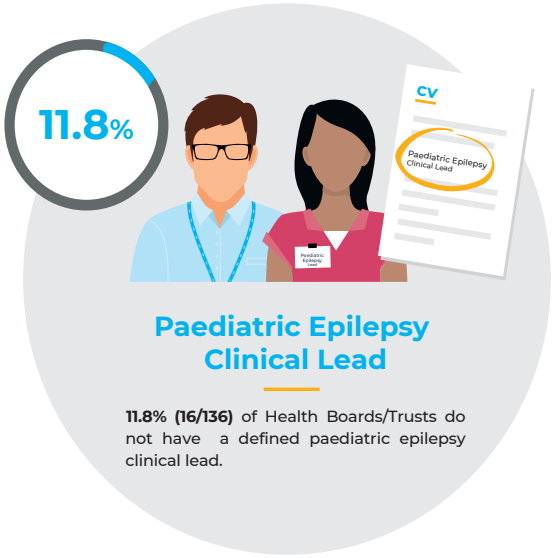
Recommendation 4

Epilepsy Specialist Nurses provide a wide-ranging contribution to the care of the child and roles should take account of local populations and service configurations.

All Health Boards and Trusts* should employ sufficient ESNs to ensure at least 1 WTE ESN for every 250 children with epilepsy. This is so that families, alongside other ESN roles, can reliably receive direct individualised specialist advice by the same or next working day between scheduled reviews.

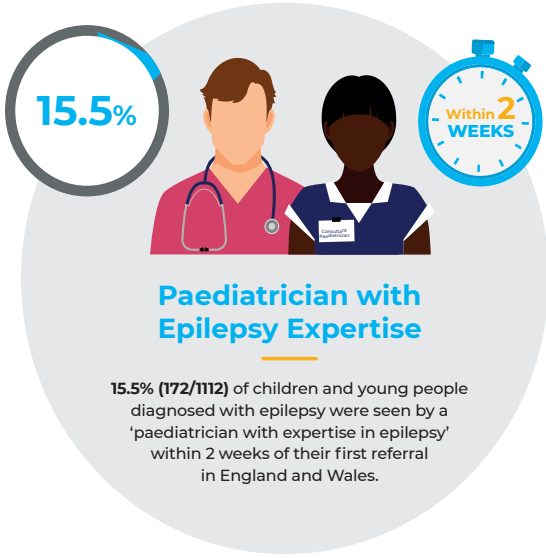
*This may include: Paediatric commissioners, Trust Medical director and Paediatric epilepsy clinical lead

Key finding E: Specialist paediatricians and clinical leads



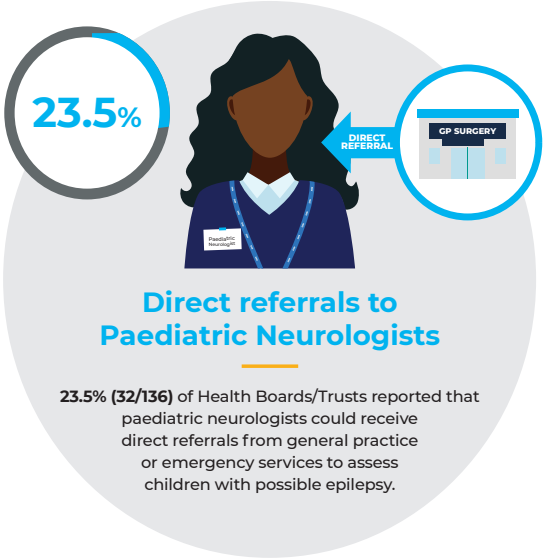
Paediatric Epilepsy Clinical Lead

11.8% (16/136) of Health Boards/Trusts do not have a defined paediatric epilepsy clinical lead.



Paediatrician with Epilepsy Expertise

15.5% (172/1112) of children and young people diagnosed with epilepsy were seen by a 'paediatrician with expertise in epilepsy' within 2 weeks of their first referral in England and Wales.



Direct referrals to Paediatric Neurologists

23.5% (32/136) of Health Boards/Trusts reported that paediatric neurologists could receive direct referrals from general practice or emergency services to assess children with possible epilepsy.

There is evidence of increasing paediatrician with expertise involvement within the first year, although access to paediatric neurology where indicated remains static. While children with epilepsy received specialist input during the first year of care, there was evidence that in many cases there were waits for input beyond the 2 weeks from presentation that is recommended in NICE guidelines (NG137 and NICE QS1).

The neurology services provide specialist input into paediatric epilepsy care across England and Wales. Where neurology services are setup to accept direct referrals from general practice and emergency departments this will contribute significant additional new patient and follow up activity, some of which could otherwise be managed by general paediatric services. This pathway configuration should have ongoing review by the Trust/ Health board and commissioners to ensure adequate workforce, value and service capacity for both the patients with seizures and also other children needing paediatric neurology input.

- **11.8% (16/136) of Health Boards and Trusts do not have a defined paediatric epilepsy clinical lead.**
- **In Round 3, cohort 1, 15.5% (172/1112) 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.**
- **23.5% (32/136) of Health Boards and Trusts reported that paediatric neurologists could receive direct referrals from general practice or emergency services to assess children with possible epilepsy.**
- **82.3% (915/1112) of the children and young people diagnosed with epilepsy had input from a paediatrician with expertise in epilepsies in England and Wales in year one. This was similar to Round 2, 86.1% (938/1090).**

- **In Round 3 cohort 1, 59.3% (150/253) of children and young people who met paediatric neurology referral criteria had paediatric neurologist input or Children's Epilepsy Surgical Service (CESS) referral by one year of care.**
- **92.6% (126/136) of Health Boards and Trusts had agreed referral pathway to tertiary paediatric neurology services.**

We repeat our previous recommendation that:

"All Health Boards and Trusts should ensure they have sufficient defined general paediatricians with expertise in epilepsies to correctly diagnose epilepsy and provide appropriate ongoing management for all children with epilepsy.

Children with 'complex epilepsy' should also have evidence of input from a paediatric neurologist."

Recommendation 5

All OPEN UK regional networks and commissioners* should:

- review the Epilepsy12 findings in their area and ensure there is sufficient capacity for paediatric neurologists to provide timely assessment and ongoing management,
- support Trusts and Health Boards to define a paediatric clinical lead for their epilepsy services.

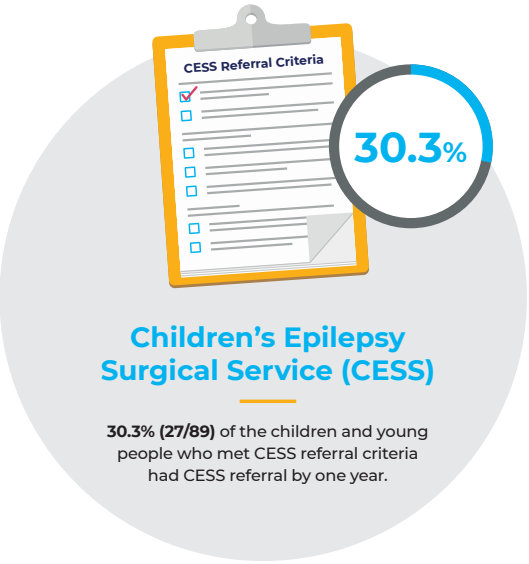
* This may include: OPEN UK, Regional Network Epilepsy leads, paediatric commissioners, and regulators (including CQC)

Key finding F: Best Practice Criteria for clinics

There are few Trusts and Health Boards able to provide, or working towards, clinics for paediatric epilepsy which meet the Best Practice Criteria (BPC). There has been a slight increase between April 2018 and November 2019.

- **46.6% (61/131) of Health Boards and Trusts hold clinics that meet the BPC, and a further 26.0% (34/131) are developing towards this standard.**

Key finding G: Children's Epilepsy Surgical Service (CESS)



There is evidence that many children who meet CESS referral criteria are not being referred according to those criteria, including variation in referral rates between regions. This finding together with the MRI performance indicators suggests there may be children with surgically treatable epilepsies who are missing out on or having delayed surgical evaluation and treatment.

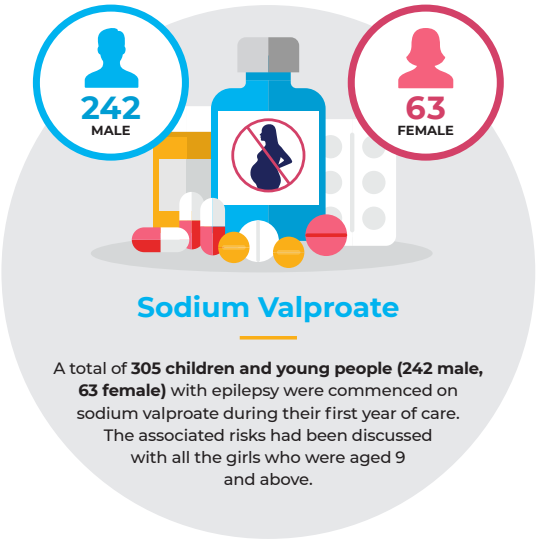
- **30.3% (27/89) of the children and young people who met CESS referral criteria had CESS referral by one year.**
- **In Round 3, 8.0% (89/1112) of the children and young people diagnosed with epilepsy met one or more of the CESS referral criteria in England and Wales.**

Recommendation 6

OPEN UK regional epilepsy networks and CESS should:

- coordinate clear, embedded referral criteria and shared care pathways from secondary care and paediatric neurology to CESS,
- ensure early identification of referral criteria and ensure referral to CESS where appropriate.

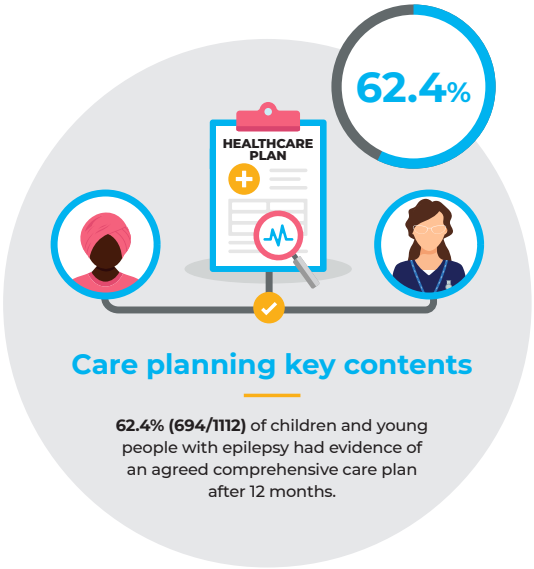
Key finding H: Sodium valproate



Sodium valproate must no longer be used in any woman or girl of childbearing age unless they are enrolled in the pregnancy prevention programme. This is designed to ensure patients are fully aware of the risks and the need to avoid becoming pregnant (MHRA 2018). From 9 years old there was a clear trend in reduced prescribing of sodium valproate for girls in cohort 1. There was good evidence of discussion of the associated risks.

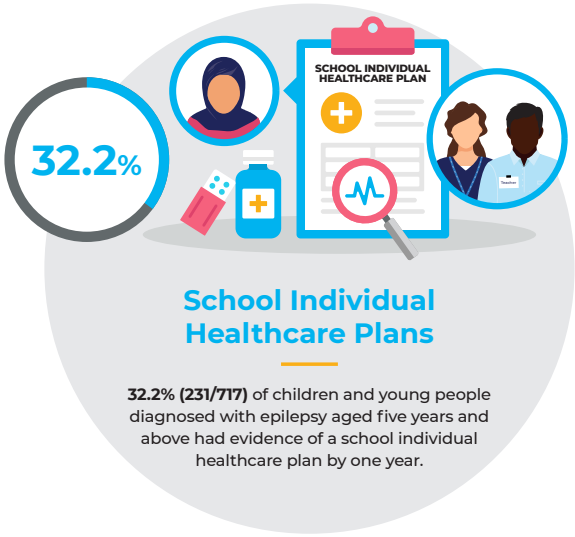
- **A total of 305 children and young people (63 female, 242 male) with epilepsy were commenced on sodium valproate during their first year of care.**
- **There were fewer than 5 females with epilepsy who were 9 years or over and prescribed sodium valproate. All had evidence of discussion of the risks of pregnancy regarding birth defects and/or neurodevelopmental outcomes.**

Key finding I: Comprehensive care plans



Children and young people with epilepsy should have an agreed and comprehensive clinical care plan (NICE QS4). The evidence suggests that there are inconsistencies in the delivery of core care planning components. The majority of Health Boards and Trusts report routinely undertaking comprehensive care plans for all children with epilepsy, yet at individual level there were gaps in provision of essential elements including relating to 'contact-ability' of services and guidance for water safety.

- **62.4% (694/1112) of children and young people with epilepsy had evidence after 12 months of an agreed comprehensive care plan.**
- **80.1% (109/136) of Health Boards and Trusts report 'routinely undertaking comprehensive care plans for children with epilepsy'.**
- **70.1% (779/1112) of children and young people diagnosed with epilepsy had documented evidence of appropriate core content.**
- **79.7% (886/1112) of children and young people diagnosed with epilepsy had evidence of discussion regarding water safety.**
- **79.7% (886/1112) of children and young people diagnosed with epilepsy were provided service contact by Health Boards and Trusts.**
- **88.5% (193/218) of children and young people diagnosed with epilepsy and on rescue medication had a parental prolonged seizure care plan.**
- **42.6% (474/1112) of children and young people diagnosed with epilepsy had evidence of information on Sudden Unexpected Death in Epilepsy (SUDEP), with noticeable regional variation.**



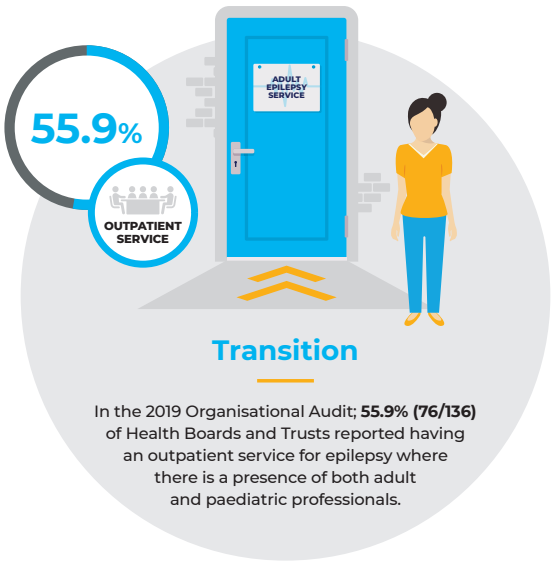
There also appears to be a disconnect between care planning by epilepsy services and education. For cohort 1, clinicians had evidence that 32.2% (231/717) of school-age children and young people with epilepsy had an Individual Healthcare Plan (IHP) at school. In contrast Epilepsy Support in Schools (Young Epilepsy, 2019), a survey of 356 children with epilepsy, reports that 37% did not have an IHP at school.

Recommendation 7

- **All Health Boards and Trusts*** should implement standardised approaches to care planning content, or other robust mechanisms, to ensure that essential elements of care are provided routinely to children with epilepsy at diagnosis and reviewed on an ongoing basis.
- **Education and health providers*** at national, regional and local level should agree procedures to facilitate appropriate, up-to-date health care planning within education and two-way information sharing.

*This may include: OFSTED, School head teachers, School nurse, paediatric epilepsy service staff, patients and their families, Youth workers, Healthcare assistants, Sports coaches or out of school organisations that provide activities

Key finding J: Transition to adult services



Over half of Health Boards and Trusts hold outpatient services that combine adult and paediatric professionals.

In almost four fifths of paediatric epilepsy services there are no agreed pathways for children and young people to transition to adult services, and where these pathways are in place this often constitutes a single joint meeting between the child or young person and both adult and paediatric services. In general, the child or young person receives input during their transition from an adult neurologist with input from an adult ESN being less common.

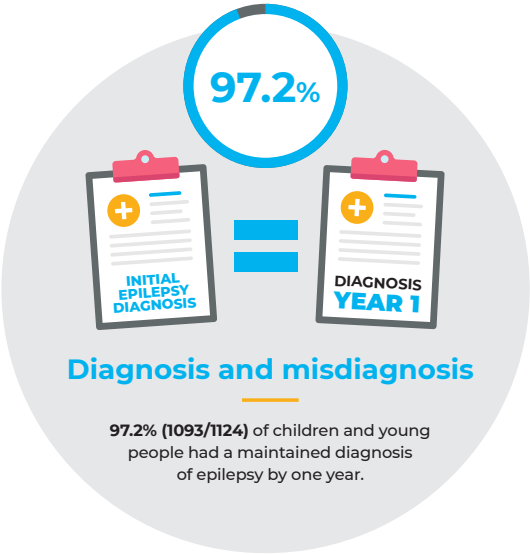
- **In the 2019 Organisational Audit; 55.9% (76/136) of Health Boards and Trusts reported having an outpatient service for epilepsy where there is a presence of both adult and paediatric professionals.**
- **When transferring young people to adult services, 53.9% (41/76) of Health Boards and Trusts report holding a single joint appointment with the adult service.**
- **20.6% (28/136) of Health Boards and Trusts had agreed referral pathways for young people to adult services.**
- **83.8% (114/136) of Health Boards and Trusts had an adult neurologist supporting transition to adult services.**
- **54.4% (74/136) of Health Boards and Trusts had an adult Epilepsy Specialist Nurse (ESN) supporting transition to adult services.**

We repeat our previous recommendations:

"Health Boards and Trusts should formally agree transition pathways from paediatric to adult services. Local arrangements should define how this is achieved for different young people with epilepsies with different associated problems, for example children and young people with an intellectual disability or neuro-disability.

Health Boards and Trusts should establish secondary tier clinics specifically for young people with epilepsies. This should support the evolving needs of the young person and their family throughout adolescence as well as during handover to adult services."

Key finding K: Diagnosis and Anti-Epileptic Drugs



There has been an apparent reduction in the rates of children misdiagnosed with epilepsy. There was very little evidence of children receiving anti-epilepsy medication unnecessarily. In NICE's CG 137, AED therapy should only be started once the diagnosis of epilepsy is confirmed, except in exceptional circumstances that require discussion and agreement between the prescriber, the specialist and the individual and their family and/or carers as appropriate.

- **97.2% (1093/1124) of children and young people had a maintained diagnosis of epilepsy by one year.**
- **36.8% (50/136) of Health Boards and Trusts have a specific outpatient clinic for young people with epilepsy.**
- **1.5% (13/856) of children and young people receiving epilepsy medication did not have a diagnosis of epilepsy at 1 year.**

Key finding L: Local and regional variation in Epilepsy12

There is variability in both the levels of engagement and performance at local Health Board and Trust and regional (OPEN UK) paediatric epilepsy network levels. In 2020, there are emerging structures of resourcing, support and leadership for regional and local commissioning which will need to link in effectively with OPEN UK paediatric epilepsy networks in future.

There was marked regional variation in the socioeconomic distributions within the epilepsy populations. There was also regional variation in the proportion of children diagnosed with epilepsy as a proportion of EEGs requested.

- **127 out of 136 Health Boards and Trusts submitted and locked the data describing their organisation and services in November 2019.**
- **113 out of 149 Health Boards and Trusts submitted a record of the first year of care clinical data for one or more children and young people in cohort 1.**

We repeat a recommendation from the 2018 organisational audit results, which should now be updated to include the emerging commissioning structures:

"Regional (OPEN UK) paediatric epilepsy networks and commissioners should:

- ***review Epilepsy12 results for their respective region(s) and associated Health Boards and Trusts,***
- ***support the development of local or regional quality improvement initiatives and knowledge sharing,***
- ***build links between those with commissioning, clinical and provider roles (including the Integrated Care Systems, STPs and NHS regional leadership)."***

Recommendation 8

Epilepsy12 should develop an ascertainment measure based on estimated population sizes and estimates of epilepsy incidence according to Trust/Health Boards. This would allow case ascertainment of the audit to be compared with a measure of the expected epilepsy incidence and variation in EEG rates.

All Health Boards and Trusts* should ensure that epilepsy services have sufficient clinician time job-planned to ensure capacity to submit accurate audit data and implement quality improvement, in addition to clinical activities.

*This may include: Trust Medical director, lead for EEG, and Paediatric epilepsy clinical lead

Epilepsy12 Youth Advocates

The Epilepsy12 Youth Advocates used their learning and work around the Clinic Chat Checklist to review the findings from the clinical and organisational audits. They have shared their ideas which link the key findings with their priority area of "support with worries and anxieties".

Report topic	What would good "support with worries and anxieties" look like for this topic?
Mental health diagnosis and provision	Work with patients and families to: • understand their worries and anxieties around living with epilepsy, • be flexible in your support and approach so it changes with the age and needs of the patient, • check back in with patients to give feedback on services or support they might need.
Care planning key contents	Identify the key services within your Trust and Health Board, and work with them to input into your clinics and care plans: • access to play specialists, youth workers, and advocates, • wellbeing passports or 'quick access' cards, • involve your NHS **Accessible Information Standards** lead and aim to meet the best practice guidance, • input from the LLDD team and look at the NHS England **Ask, Listen, Do** for best practices.
Epilepsy specialist nurses	Develop information that can be shared with patients and families that helps them to know: • what they need to know or think about in their first month, sixth month, and first year after being diagnosed with epilepsy, • who is in the Epilepsy Service and how to get in touch with them, • what other support or services are available, and how to contact them (remember to include: mental health support, exam support, play specialists), • what to do if you are worried out of hours, • what support is offered by an Epilepsy Specialist Nurse (or plans to develop this role if not in place).

Summary of Recommendations

The Epilepsy12 2020 National Audit Report makes a number of key recommendations of how to address the issues identified within the 2018-19 clinical and 2019 organisational audit key findings and results of the audit. The tables on the following pages group the key recommendations by:

- the related guidelines or standards
- the relevant audit findings
- comparison to previous audit round findings (where valid)
- the recommendation target audience
- the intended outcome of the recommendation.

1. First EEG waiting times	
Recommendation	All Health Boards and Trusts should review and improve their referral pathways to ensure all first EEGs are achieved within a maximum of 4 weeks of request date. Health Boards and Trusts with EEG services should co-ordinate with their commissioners and regional OPEN UK network to ensure timely access to EEG services for all relevant Trusts and Health Boards.
Source	NICE guidelines (Quality Statement 2): Children and young people having initial investigations for epilepsy undergo the tests within 4 weeks of being requested.
Epilepsy12 Key finding(s) and comparison to previous findings	43.8% (487/1112) children and young people diagnosed with epilepsy obtained their EEG more than 4 weeks from referral request.
Target audience(s)	Health Boards and Trusts - Trust medical director and paediatric epilepsy clinical lead EEG services

2. ECG and MRI investigations	
Recommendation	Health Boards and Trusts should: • ensure that they can provide MRI to children of all ages via a sedation and/ or anaesthetic pathway, • document within medical records and Epilepsy12 audit the confirmed epilepsy syndrome diagnosis (including BECTS, CAE, JAE, JME and 'epilepsy with generalised tonic clonic seizures only') as MRI is not routinely indicated for these children, • review local pathways to include routine 12-lead ECG for children with convulsive seizures, • ensure 12- lead ECG results are accessible within the ongoing clinic health records.
Source	SIGN guidance, and current British Paediatric Neurology Association (BPNA) PET teaching curriculum, states that all children with a convulsive seizure should have a 12-lead ECG.
Epilepsy12 Key finding(s) and comparison to previous findings	68.6% (317/462) children and young people diagnosed with epilepsy and who met the defined indications for an MRI, had received an MRI during their first year of care. 67.6% (474/701) children and young people diagnosed with epilepsy and who had convulsive seizures obtained a 12 lead ECG during their first year of care. Previously, 63.5% (Round 1, 2012) and 72.2% (Round 2, 2014) of children and young people who met the defined indications had received an MRI. In earlier rounds investigations by 12-lead ECG were reported for all children with epilepsy.
Target audience(s)	Health Boards and Trusts - Department leads at MRI, EEG services within Trusts or Health Boards, paediatric epilepsy services/ teams

3. Mental health	
Recommendation	Commissioners, Health Boards and Trusts should ensure that: • all children with an epilepsy should have ongoing screening for a range of mental health problems using a validated tool (e.g. Strengths and Difficulties Questionnaire), • where there are concerns about mental health problems the child and young person should be referred to an appropriate mental health service via an agreed pathway for ongoing diagnosis and treatment, • services for children and young people with epilepsy should include sufficient integrated mental health provision, some of which should be co-located within the epilepsy clinic.
Source	NHS Best Practice Criteria (2019) states that there should be some co-located mental health provision within epilepsy clinics. Epilepsy12 Youth Advocates selected 'support for worries and anxieties', 'face to face support', and 'school' as their three priority areas. A study of mental health problems in children with epilepsy (Dev Med Child Neurol. 2003) reported a much higher incidence where 37% of 5-15 year olds with epilepsy had a co-existing mental health disorder.
Epilepsy12 Key finding(s) and comparison to previous findings	4.1% (45/1112) of children and young people with epilepsy had some evidence of involvement of a mental health professional or service by the end of their first year of care. 6.1% (43/701) of children and young people between the age of 5-15 years and diagnosed with epilepsy in cohort 1 had an identified mental health problem by 1 year in England and Wales. 14.0% (19/136) Health Boards and Trusts were able to facilitate mental health provision within epilepsy clinics. 14.7% (20/136) of Health Boards and Trusts routinely provided formal screening services for mental health disorders, a decrease from 19.6% in 2018.
Target audience(s)	Commissioners, Health Boards and Trusts - Mental health department leads, BPT commissioners, paediatric epilepsy clinical lead

4. Epilepsy Specialist Nurses	
Recommendation	• Epilepsy Specialist Nurses provide a wide-ranging contribution to the care of the child and roles should take account of local populations and service configurations. • All Health Boards and Trusts should employ sufficient ESNs to ensure at least 1 WTE ESN for every 250 children with epilepsy. This is so that families, alongside other ESN roles, can reliably receive direct individualised specialist advice by the same or next working day between scheduled reviews.
Source	NICE Clinical guidelines 137: Epilepsy specialist nurses (ESNs) should be an integral part of the network of care of individuals with epilepsy. SIGN guidance 'Epilepsies: Diagnosis and Management': Each epilepsy team should include paediatric epilepsy nurse specialists.
Epilepsy12 Key finding(s) and comparison to previous findings	In 2019 there was a total of 158.4 WTE epilepsy specialist nurses (ESN) employed in participating Trusts and Health Boards across England and Wales. 95.6% (130/136) of Trusts and Health Boards described advice available between scheduled reviews. 47.7% (62/130) of Trusts and Health Boards reported typical response times of 3 or more days. 81.6% (111/136) of Trusts and Health Boards employed some ESN time. In Round 3 cohort 1, 69.0% (767/1112) of children and young people diagnosed with epilepsy had input from an epilepsy specialist nurse during their first year of care.
Target audience(s)	Health Boards and Trusts - Paediatric commissioners, Trust medical director and paediatric epilepsy clinical lead

5. Specialist paediatricians and clinical leads	
Recommendation	All OPEN UK regional networks and commissioners should: • review the Epilepsy12 findings in their area and ensure there is sufficient capacity for paediatric neurologists to provide timely assessment and ongoing management. • support Trusts and Health Boards to define a paediatric clinical lead for their epilepsy services.
Source	NICE CG137 and NICE QS1 state that children and young people presenting with a suspected seizure are seen by a specialist in the diagnosis and manage-ment of the epilepsies within two weeks of presentation.
Epilepsy12 Key finding(s) and comparison to previous findings	82.3% (915/1112) of the children and young people diagnosed with epilepsy had an input from a paediatrician with expertise in epilepsies in England and Wales in year one. This was similar to Round 2 (85%, 938/1090). In Round 3, cohort 1, 15.5% (172/1112) 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 In Round 3 cohort 1, 59.3% (150/253) of children and young people who met paediatric neurology referral criteria had paediatric neurologist input or Children's Epilepsy Surgical service (CESS) referral by one year of care. 11.8% (16/136) of Health Boards and Trusts do not have a defined paediatric epilepsy clinical lead. 92.6% (126/136) of Health Boards and Trusts had agreed referral pathway to tertiary paediatric neurology services. 23.5% (32/136) of Health Boards and Trusts reported that paediatric neurologists could receive direct referrals from general practice or emergency services to assess children with possible epilepsy.
Target audience(s)	OPEN UK , Regional Network epilepsy leads, paediatric commissioners, and regulators (including CQC)

6. Children's Epilepsy Surgical Service (CESS)	
Recommendation	OPEN UK regional epilepsy networks and CESS should: • coordinate clear, embedded referral criteria and shared care pathways from secondary care and paediatric neurology to CESS, • ensure early identification of referral criteria and ensure referral to CESS where appropriate.
Source	NICE CG 137: At the review, children, young people and adults should have access to: written and visual information; counselling services; information about voluntary organisations; epilepsy specialist nurses; timely and appropriate investigations; referral to tertiary services, including surgery if appropriate.
Epilepsy12 Key finding(s) and comparison to previous findings	In Round 3, 8.0% (89/1112) of the children and young people diagnosed with epilepsy met one or more of the CESS referral criteria in England and Wales. 30.3% (27/89) of the children and young people who met CESS referral criteria had CESS referral by one year.
Target audience(s)	OPEN UK regional epilepsy networks and CESS Paediatric epilepsy clinicians

7. Comprehensive care plans	
Recommendation	• All Health Boards and Trusts should implement standardised approaches to care planning content, or other robust mechanisms, to ensure that essential elements of care are provided routinely to children with epilepsy at diagnosis and reviewed on an ongoing basis. • Education and health providers at national, regional and local level should agree procedures to facilitate appropriate, up-to-date health care planning within education and two way information sharing.
Source	Children and young people with epilepsy should have an agreed and comprehensive clinical care plan (NICE QS4). Epilepsy Support in Schools (Young Epilepsy, 2019), a survey of 356 children with epilepsy, reports that 37% did not have an Individual Healthcare Plan at school.
Epilepsy12 Key finding(s) and comparison to previous findings	80.1% (109/136) of Trusts/Health Boards report 'routinely undertaking comprehensive care plans for children with epilepsy'. 62.4% (694/1112) of children and young people with epilepsy had evidence after 12 months of an agreed comprehensive care plan. 70.1% (779/1112) had documented evidence of appropriate core content. 79.7% (886/1112) had evidence of discussion regarding water safety. 79.7% (886/1112) had service contact details. 88.5% (193/218) of children and young people diagnosed with epilepsy and on rescue medication had a parental prolonged seizure care plan. 42.6% (474/1112) of children and young people diagnosed with epilepsy had evidence of information on SUDEP with noticeable regional variation. 32.2% (231/717) of school-age children and young people with epilepsy had an IHP at school.
Target audience(s)	Health Boards and Trusts, with Education and health providers – OFSTED, school head teachers, school nurse, paediatric epilepsy service staff, patients and their families, youth workers, healthcare assistants, sports coaches or out of school organisations that provide activities

8. Local and regional variation	
Recommendation	• Epilepsy12 should develop an ascertainment measure based on estimated population sizes and estimates of epilepsy incidence according to Trust and Health Boards. This would allow case ascertainment of the audit to be compared with a measure of the expected epilepsy incidence and variation in EEG rates. • All Trusts and Health Boards should ensure that epilepsy services have sufficient clinician time job-planned to ensure capacity to submit accurate audit data and implement quality improvement, in addition to clinical activities
Source	This recommendation has been developed based on the Epilepsy12 Methodology and Dataset Group's on-going review of the audit methodology and of the results reported here.
Epilepsy12 Key finding(s) and comparison to previous findings	127 out of 136 Health Boards and Trusts submitted and locked the data describing their organisation and services in November 2019. 113 out of 149 Health Boards and Trusts submitted a record of the first year of care clinical data for one or more children and young people in cohort 1.
Target audience(s)	Epilepsy12 provider Health Boards and Trusts - Trust medical director, lead for EEG, and paediatric epilepsy clinical lead

3. Organisation of Paediatric Epilepsy Networks in the UK (OPEN UK)

The Organisation of Paediatric Epilepsy Networks in the UK (OPEN UK) began in late 2015, as a confederation of the sixteen individual regional clinical paediatric epilepsy networks, working closely with the British Paediatric Neurology Association (BPNA) and British Academy of Childhood Disability (BACD). The OPEN UK Working Group is hosted by the RCPCH, and connects local Health Board, Trust and regional leads to each other and to the Epilepsy12 national audit. OPEN UK also represents clinicians on the UK Paediatric Epilepsy Programme Board alongside the BPNA.

The OPEN UK aims are to encourage the sharing of local, regional and national ideas, pilots and resources. This was well illustrated by the joint Epilepsy12/OPEN UK annual national conferences in 2018 and 2019, at which many fabulous projects and ideas were shared from across the UK. We hope to return in 2020 with a programme planned to share quality improvements, technologies and innovations in paediatric epilepsy care.

OPEN UK works to provide and strengthen the links between local, regional and national bodies. We are currently working with the RCPCH and NHS England to input into national strategy and shape ambitions for the future delivery and commissioning structures in paediatric epilepsy care. Examples of our success in this area include the recognition of the need for co-located mental health support within epilepsy teams, which was included in the April 2019 iteration of the NHS England Best Practice Tariff for Paediatric Epilepsy. A giant pillar of our agenda for the next few years is translating this into properly commissioned mental health screening and psychology support, across the UK. We are currently working with NHS England to ensure that the proposed rollout of 'clinical networks' in the Long Term Plan is translated into a high-functioning scaffolding for quality improvement at local, regional and national level.

To inform and guide future strategy, the regional network leads for OPEN UK shared information about their local activity to provide a better picture of how networks are operating across the UK. The networks shared how, with no or little dedicated time and resource, they have managed to meet up to eight times in the previous two years. This has brought together impressive multi-disciplinary epilepsy representatives including:

- adult health professionals
- commissioners
- community nurses
- analysts
- education professionals
- EEG services
- epilepsy specialist nurses
- epilepsy charities and third sector organisations
- IT professionals
- mental health professionals
- paediatricians and epilepsy specialists
- social care professionals.

Networks have been focusing on paediatric epilepsy care as well as more specific areas such as

neurodisability, neurology, and neurosurgery for children with epilepsy. At network meetings, or through communication channels between meetings, the regular activities include case discussions, learning and development presentations, regional data and evidence about quality of care, Health Board and Trusts level data, young people's participation, risk assessments, action and strategy planning. In the past two years networks have shaped and agreed new patient pathways and guidelines.

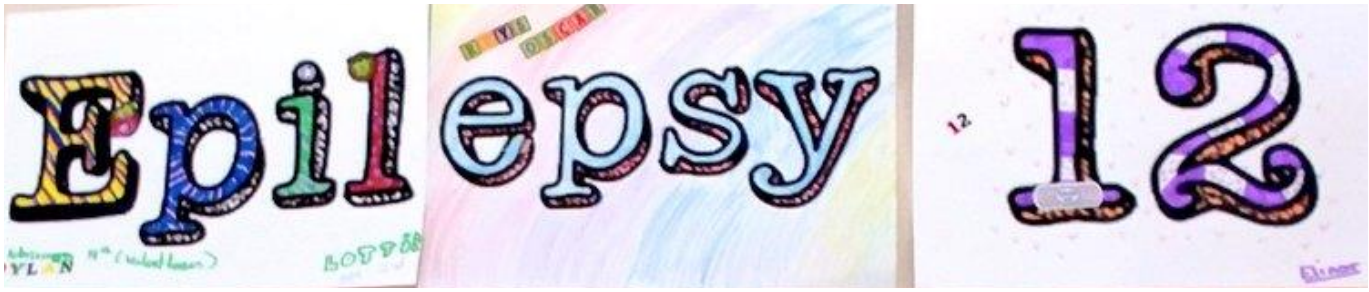
OPEN UK regional network will continue to work in conjunction with the regional clinical leads and receive support from Epilepsy12. We will support each other to building on the results and recommendations made in this report, and bringing our teams together to continue to make positive improvements for all children and young people with seizures and epilepsies across the UK.

Dr Richard Brown, Consultant Paediatrician, Cambridge University Hospitals NHS Foundation Trust & Chair of the OPEN UK Working Group

The 16 OPEN UK Regional Paediatric Epilepsy Networks are named in the following table. The abbreviated regional network names appear in the regional network results of both the clinical and organisational audits in this report.

OPEN UK Regional Paediatric Epilepsy Network	Regional Network full name
BRPNF	Birmingham Regional Paediatric Neurology Forum
CEWT	Children's Epilepsy Workstream in Trent
EPEN	Eastern Paediatric Epilepsy Network
EPIC	Mersey and North Wales network 'Epilepsy in Childhood' interest group
NTPEN	North Thames Paediatric Epilepsy Network
NWEIG	North West Children and Young People's Epilepsy Interest Group
NI	Northern Ireland epilepsy services
ORENG	Oxford Region Epilepsy Interest Group
PENNEC	Paediatric Epilepsy Network for the North East and Cumbria
SETPEG	South East Thames Paediatric Epilepsy Group
SPEN	Scottish Paediatric Epilepsy Network
SWEP	South Wales Epilepsy Forum
SWIPE	South West Interest Group Paediatric Epilepsy
SWTPEG	South West Thames Paediatric Epilepsy Group
TEN	Trent Epilepsy Network
WPNN	Wessex Paediatric Neurosciences Network
YPEN	Yorkshire Paediatric Neurology Network

4. Epilepsy12 Youth Advocate Clinic Chat Checklist: 2019-2020 progress report



"Helping patients and their families who need support with worries and anxieties linked to their epilepsy."

The Epilepsy12 Youth Advocates are a group of epilepsy experienced children, young people and families with two epilepsy specialist nurses from OPEN UK. We meet and work together as volunteers to look at projects which improve care for epilepsy patients and their families linked to the Epilepsy12 national audit programme.

Support with worries and anxieties

In 2018, we asked more than 130 children, young people and families what "creates the best epilepsy service". They shared with us things that were working well and ideas for areas for improvement. You can read the report of what we found out at https://www.rcpch.ac.uk/resources/epilepsy12-us-voices-rcpch-us-network

From looking at all the information patients and their families said, we realised they wanted more support with worries and anxieties linked to epilepsy. This was chosen as our top priority to do something to help it to improve.

Clinic Chat Checklist

We wanted to find out what makes "gold standard services" and what is or could be offered to patients in relation to worries and anxieties. We didn't want a long and boring process that people can ignore or leave the results on a shelf. We wanted to make something that is easy to do and that helps everyone – patients, families, doctors, nurses, the NHS – everyone. It isn't about finding out what people aren't doing. It's about helping everyone to know about the good practice that is already out there and sharing it for others to learn from.

Creating the Clinic Chat Checklist

We wanted to know, directly from clinics, about the care they already provide and what ideas they have for the future in relation to anxieties and worries.

We drafted questions and refined them before testing them out with two clinics. This really helped us to create the right set of questions and to check that they would be easily understood.

We also attended the Epilepsy12 & OPEN UK National Conference in 2019 to present our ideas about the checklist. We asked the 100+ epilepsy specialists present, what their wishes were for the Clinic Chat Checklist and how it might help them and their service, and for ideas on what would be the barriers to clinics taking part.

The clinic teams present told us that the Clinic Chat Checklist would improve care for patients by sharing ideas and resources, increasing joint working in the 'team', and would help to create child and young people friendly services.

They also said the process needed to be straightforward and not take lots of time, that it shouldn't identify individual patients and that the results should be shared with everyone.

This help was essential to supporting us to come up with our final set of questions. They included:

- What information and advice do you provide to Epilepsy patients to help them manage their condition?
- What support and information do you give to A&E staff to pass on to those who have had first-time seizures?
- How do you introduce patients and their families to their wider Epilepsy Care Team?

We felt it was important that the whole 'team', that help patients and their family, answered the questions, and really encouraged this as part of the process.

Figure 2: Epilepsy12 & OPEN UK 2019 annual conference: Youth Advocates CYP session and Clinic Chat pledges

Our Clinic Chat Checklist Plan

Our plan was simple:

- work with 8 clinics spread geographically across England and Wales,
- send them an email to explain who we are and why we wanted to do this along with helpful information: **https://youtu.be/3aw1aN4xSDA**,
- send them the "Clinic Chat Checklist" to complete and return to us,
- look at all the responses and provide individualised feedback.

The clinics

During the Epilepsy12 & OPEN UK National Conference we asked for clinics to be part of the project. Lots of clinics contacted us on the day and others afterwards.

We felt it was important that we had a large geographical spread of clinics and that at least two clinics should be in Wales. We also wanted some big clinics and some others small. We had clinics from the following regions:

- North East
- North West
- South East
- South West
- London
- South Wales.

✓ 10 clinics registered interested

✓ 8 clinics completed their Clinic Chat Check List (2 Wales, 6 England)

✓ 100% completed by deadline

What we have found so far

We were very impressed with how clinics involved many members of their team to complete the checklist and the ideas they have for change. There were lots of great examples of clinics doing a range of activities to support worries and anxieties with lots of resources. We were impressed with the hard work and dedication shown by each clinic.

We looked each Clinic Chat Checklist and discussed:

- things they were doing well,
- ideas for change,
- our top tips.

We provided individual clinics with feedback and ideas as well as top tips, links to resources and good ideas from others.

We asked all clinics what level of award they would give to their epilepsy service for "*helping patients and their families who need support with worries and anxieties linked to their epilepsy*".

- **3 clinics considered themselves to be silver: "*We are doing most things really well.*"**
- **4 clinics considered themselves to be bronze: "*We are doing some things really well.*"**
- **1 clinic didn't grade themselves**

Our top tips

It was really clear that a lot of simple changes could make a huge difference to patients and their families. A lot of ideas were cheap, quick and easy however others required some further thought and planning.

Cheap, quick and easy:

- A clear out of hours voice message for patients with advice and signposting where appropriate.
- Linking to local support for worries and anxieties e.g. Kooth (online service), MeeTwo (online service) local counselling services, charities, school services, youth services etc.
- Provide 'protected time' to discuss anxieties and worries with patients and families, including where age appropriate the patient being offered to be seen alone.
-

With more time and planning:

- Develop new patient packs which are age related – which includes signposting to local and hospital services, national charities, helplines and includes specific information e.g. driving, exams and travel.
- Ensure good timely processes between A&E and being seen in clinic.
- First aid training for patients and families.
- The ability to offer school or home visits especially for newly diagnosed patients.

What next?

Part two of the plan will be to visit the clinics and talk about ideas and thoughts together and come up with a plan. Some things will cost nothing (we are very creative!), some of the ideas that clinics, patients and the E12 Youth Advocates might have will need some money. We even have ideas about where they can get it!

We will be thinking about how to share the Clinic Chat Checklist process and learning with more clinics so that they can do it as a self-assessment. We are also keen that we are able to define what a 'gold standard' clinic looks like in relation to worries and anxieties. Keep checking the RCPCH &Us and Epilepsy12 webpages for more information over the coming year!

We want to thank all the clinics involved in the Clinic Chat Check list and are looking forward to working with more of you over the next year!

5. Epilepsy Quality Improvement Programme (EQIP)

Background

Despite progress shown in the Epilepsy12 audit data, the provision and quality of specialist epilepsy care continues to vary between Health Boards or Trusts in England and Wales, particularly around adequate staffing and timely delivery of care processes. Given the complexity of the epilepsy spectrum of conditions, quality care requires holistic support, including mental health, educational and community awareness support. Consequently, improvement in care cannot be confined to just clinical processes, but also include other parts of the health service, schools, charity and community organisations. It requires a patient-centred approach, involving co-design and shared ownership of the care experience and outcome between service providers and patients and their families.

One of the activities of the audit was to set up a support system for QI activities to be undertaken by epilepsy services in the 16 regions of the Organisation of Paediatric Epilepsy Networks (OPEN UK). Given this aim, and in the wider context of the priorities set out in the NHS Long Term Plan, Epilepsy12 project and OPEN UK networks worked in collaboration to set up a Quality Improvement project supporting epilepsy services and utilising the epilepsy regional network structure.

The programme advisory group agreed on the following vision for the QI programme:

Epilepsy services are equitable and underpinned by the principles of continuous improvement for all children and young people regardless of background, material status and location. Epilepsy services are recognised as a high priority in public policy and the health service, at national and local levels. Child health practitioners, who specialise in epilepsy, are recognised, supported and empowered to work across geographic and service boundaries, including transition between paediatric and adult service provision. Children and young people with epilepsy enjoy clear access to the treatment they need and have a say in how it is designed and delivered.

Project scope

In September 2018, the Epilepsy12 project team, in collaboration with OPEN UK, recruited a group of specialist epilepsy nurses representing the OPEN UK regions, to act as advisors in the development of a QI project supporting the results of the Epilepsy12 audit. As a first step in the scoping phase, the group has informed the development of a survey to be conducted with epilepsy services, with a view to identifying high performing services and key processes involved in service delivery. The subsequent survey elicited 116 responses from 76 Health Boards and Trusts and its analysis produced a list of recommendations for a comprehensive care delivery including:

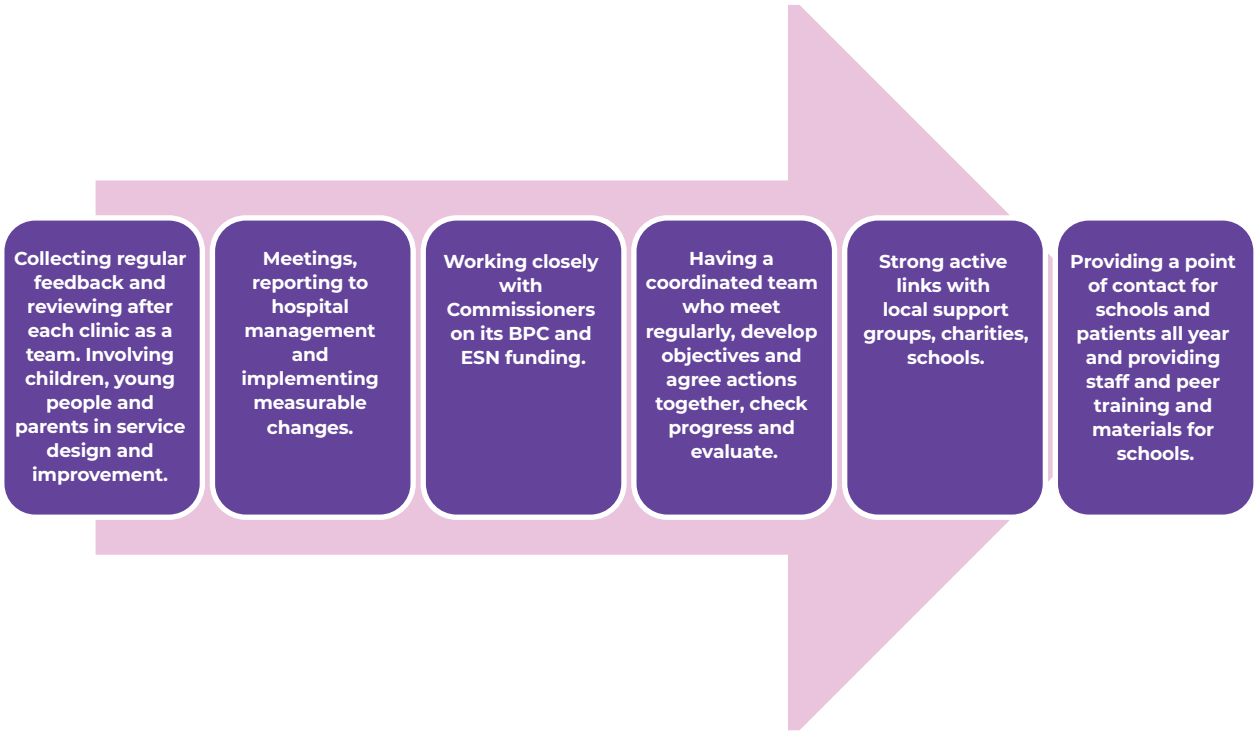


Figure 3: Example of comprehensive care delivery process map

Based on the results of the survey and further desktop research, the advisory group worked with the Epilepsy12 project team to establish the aims and vision for the programme. In order to achieve this vision the advisory group then worked with the team to establish the following aims of the programme:

- support paediatric epilepsy services to identify and address gaps in care provision, including forging or strengthening links with other parts of healthcare service, schools and support organisations,
- enable information sharing and operational integration between services and across regional networks.

In particular, the project objectives are to:

- assess the training and support needs of paediatric epilepsy services in order to optimise care,
- provide needs-based training to epilepsy teams to equip them with skills and capabilities to improve care,
- provide ongoing advice and support to teams implementing service improvements,
- ensure collection of intervention measures to assess impact,
- enable information and good practice sharing via the OPEN UK network,
- evaluate the project as proof of concept and adapt for scale-up.

Project outcomes

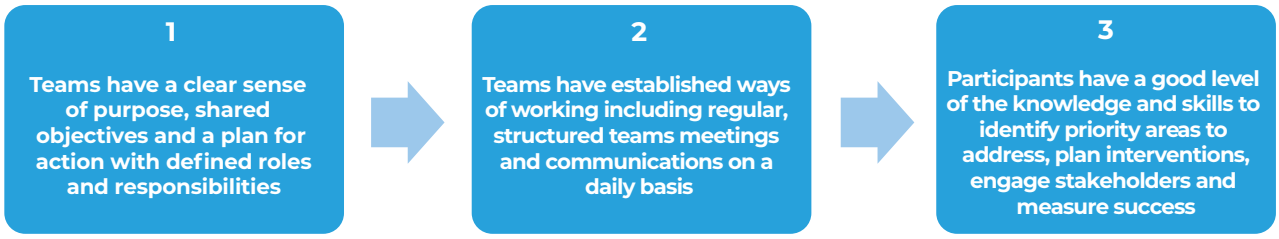


Figure 4: EQIP project outcomes

Service outcomes

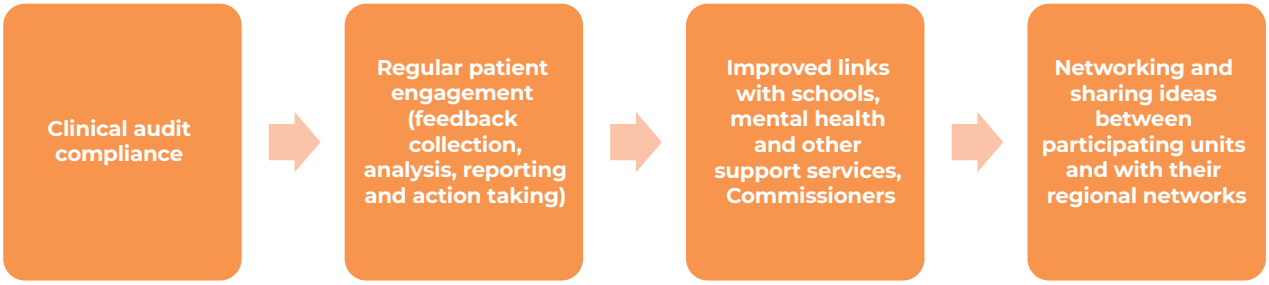


Figure 5: Service outcomes for EQIP teams

Project delivery

The RCPCH Epilepsy Quality Improvement Programme was developed in consultation with epilepsy practitioners, ensuring that it best suits their needs, while also borrowing from a similar model delivered with success in paediatric diabetes services in the UK. This model was originally started in Sweden, where it engaged with 85% of paediatric diabetes services over the period of 3 years and, in that time, it managed to significantly improve treatment outcomes and reduce variation between units.

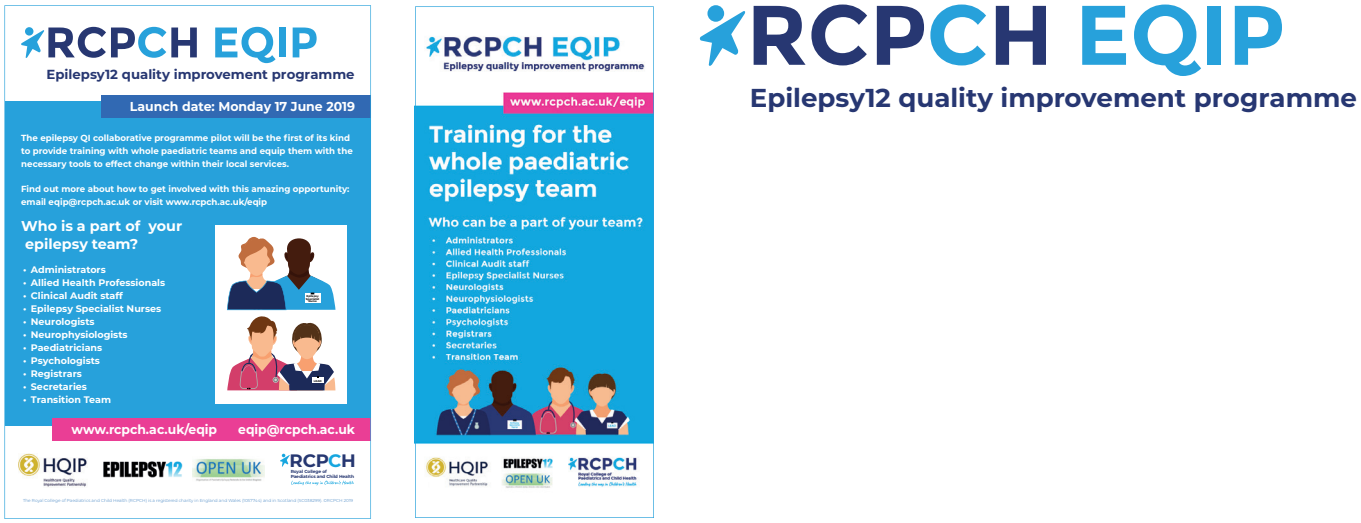


Figure 6: RCPCH EQIP brand and promotional material

How the programme works

RCPCH EQIP has been tailored to support paediatric epilepsy teams to work together to define their shared aims and develop practical interventions matching their capacity and resources. The six-month programme will require participating teams to come together for two bespoke training/sharing events, supporting them to:

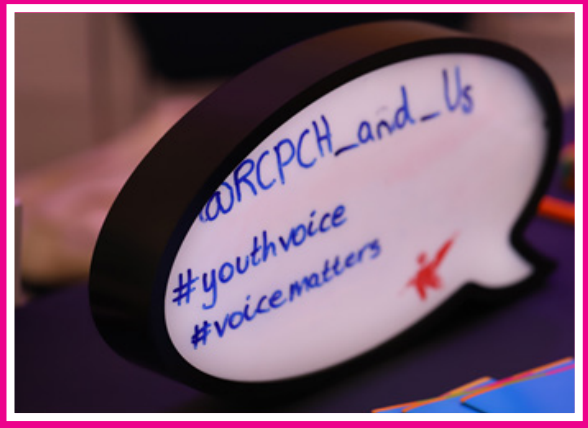
- develop more cohesive teams with clearly defined roles and a shared sense of mission and responsibility,
- identify areas for improvement in care delivery,
- design sustainable interventions to address these areas, that are manageable within their existing set-up.

The training will be practical and hands-on, combining select quality improvement tools, high-performing team development, patient and family engagement, leadership and influencing skills. We deliberately picked and chose elements of quality improvement methodology and combined it with other types of skills training, to provide a package which will correspond to the working reality of epilepsy teams – often struggling with people capacity, fragmented teamwork and limited resourcing. The project is designed to enable teams to learn and make action plans together in training. The teams will be given hands-on support during and between training sessions to design their interventions and will have the opportunity to learn from the experience of other participants as they go along.

Teams are invited to apply as a whole, via application with everyone attending together. Each team would nominate an EQIP Champion to galvanise and motivate the team in between learning sessions and report on progress to the trainers at the RCPCH. See our promotional video via the website www.rcpch.ac.uk/eqip.

The learning events will be held in the Midlands, in a location with good transport links to ensure maximum possible convenience for services travelling in.

It is expected that, following the completion of the pilot, its evaluation will serve as a foundation for reflection and consolidation of learning with a view to adapt and scale-up the programme with more epilepsy services across the country. This further iteration of the collaborative will depend on the pilot's success and ongoing funding via the Epilepsy12 clinical audit contract.



Residential weekend training

Our two-day residential weekend with the 12 teams participating in our pilot took place on 16 and 17 November 2019. It kicked off with interactive QI training by expert QI trainer Dr Pat O'Connor - paediatric epilepsy NHS staff worked together to identify gaps and find sustainable improvements that would be tried and tested over the six-month programme.

The teams worked hard, learning and using many of the QI tools to help support them refine their local improvement projects. But the programme also included fun action learning sets and networking - breaking those silo barriers. By the end of the second day, each of the teams left the weekend energised and with a plan of action to move forward with their projects.

Further feedback from EQIP team members from the weekend include:

"Witnessing the motivation and commitment from everyone, and within the teams."

"Interactive games/activities, e.g. skittles and pasta tasks, which highlighted QI in an abstract way."

"All activities associated with practical application of QI models to our projects."

"Having the opportunity for the team to write a plan and evaluate out aims, and how to change and improve."

Participant teams

The 12 participant teams that will become EQIP pioneers are as follows:

- Aneurin Bevan University Health Board
- Chelsea and Westminster Hospital NHS Foundation Trust
- Doncaster and Bassetlaw Teaching Hospitals NHS Foundation Trust
- Guy's and St Thomas' NHS Foundation Trust
- Luton and Dunstable University Hospital NHS Foundation Trust
- Manchester University NHS Foundation Trust
- Nottingham University Hospitals NHS Trust
- Royal Berkshire NHS Foundation Trust
- Royal United Hospitals Bath NHS Foundation Trust
- South Tees Hospitals NHS Foundation Trust
- Southport and Ormskirk Hospital NHS Trust
- York Teaching Hospital NHS Foundation Trust.

Acknowledgements

We would like to say a special thanks for their valuable input on the scope and delivery of this programme to the EQIP ESN advisors: Alison Mollett, Amanda Hirst, Carolyn McAskil, Christine Bennett, Debbie Dean, Emma Hassan, Jill Conium, Laura Neely, Rachel Wheway, QI Trainer: Dr Pat O'Connor, QI Discovery and the faculty team: Ms Angie Pullen, Dr Colin Dunkley, Mr Mirek Skrypak, Ms Peri O'Connor, Dr Richard Brown

Visit the RCPCH EQIP website or Twitter to access updates on the teams progress as they continue through their journey on this programme. www.rcpch.ac.uk/eqip #RCPCHEQIP

The spring 2020 edition of Milestones, our member magazine has a piece from an EQIP Pioneer. Visit the milestone website for more updates on the EQIP.

Useful resources

The Royal College of Paediatrics and Child Health

The Royal College of Paediatrics and Child Health (RCPCH) was founded in 1996. We play a major role in postgraduate medical education, professional standards, research and policy. The RCPCH has a number of useful resources, including:

- **British Paediatric Surveillance Unit** www.rcpch.ac.uk/work-we-do/bpsu
  The BPSU is a world leading centre for rare paediatric disease surveillance. It enables doctors and researchers to investigate how many children in the UK and Republic of Ireland are affected by particular rare diseases, conditions or treatments each year.

- **Courses and online learning** www.rcpch.ac.uk/education/courses

- **Continuing professional development** www.rcpch.ac.uk/education/continuing-professional-development

- **Invited reviews** www.rcpch.ac.uk/invitedreviews
  We support healthcare organisations, commissioners and clinical teams to resolve concerns about paediatric service provision, safety, training, compliance with standards, and proposals for paediatric reconfiguration or service design. Our service is confidential, established and influential, and tailored to each organisation's needs.

- **Medicines for Children** www.medicinesforchildren.org.uk
  The Medicines for Children website provides parents and carers with information they can trust on over 200 medicines commonly prescribed to children. It offers free access to patient information leaflets and videos specifically developed to advice parents and carers how to give medicine to their child.

- **MedsIQ** www.qicentral.org.uk/meds-iq
  Medication errors are a significant but preventable cause of harm to children and young people.

- **Research activities** www.rcpch.ac.uk/work-we-do/research-activities
  We aim to improve children's health outcomes through supporting high quality and trusted research. Let's share our expertise, collaborate with others and promote the evidence to drive forward improvements in child health.

- **RCPCH Child Protection portal** https://childprotection.rcpch.ac.uk/
  RCPCH Child Protection portal is an online resource to help inform clinical practice, child protection procedures, and professional and expert opinion in the legal system.

- **RCPCH QI Central:** www.qicentral.org.uk
  QI Central is a free online resource open to all child health professionals to help embed QI projects in clinical practice and continually improve services and outcomes for infants, children and young

people. As an online repository of peer-reviewed tools and projects, healthcare professionals are also able to submit their own projects and resources to share their experiences with others and propagate knowledge in quality improvement.

- **Workforce and service design** www.rcpch.ac.uk/workforce
  We play a key role in workforce planning to ensure there is an appropriately trained paediatric medical workforce to deliver safe and sustainable services for children in the UK - in the present and in the future.

Epilepsy12 Audit Key Stakeholder Organisations

- **British Paediatric Neurology Association** bpna.org.uk
  The British Paediatric Neurology Association is the professional organisation for doctors who specialise in the care of children with neurological disorders.

- **Epilepsy Action** www.epilepsy.org.uk
  Epilepsy Action is a community of people committed to a better life for everyone affected by epilepsy. We want high quality, accessible epilepsy healthcare services, so that people with epilepsy have the support they need to manage their condition. We want wider awareness and understanding of epilepsy, so that people living with the condition are treated with fairness and respect.

- **Epilepsy Scotland** www.epilepsyscotland.org.uk
  In Scotland 54,000 people live with epilepsy. Children and older people are most at risk of developing this common serious neurological condition but anyone can develop epilepsy at any time, and 8 people a day in Scotland do. We want to make sure the needs of people with epilepsy are met. This is why we campaign for improved healthcare, better information provision and an end to stigma. In April 2008 Enlighten, Tackling Epilepsy merged with Epilepsy Scotland.

- **Royal College of Nursing** www.rcn.org.uk
  The RCN is a membership organisation of more than 435,000 registered nurses, midwives, health care assistants and nursing students. We are both a professional body, carrying out work on nursing standards, education and practice, and a trade union.

- **Epilepsy Specialist Nurses Association (ESNA)** www.esna-online.org.uk
  ESNA is a professional organisation whose membership consists of nurses and other health professionals working to support people with epilepsy in the fields of adults, learning disabilities and paediatrics. ESNA works with its membership to raise the profile of epilepsy and to encourage a holistic and co-ordinated approach to care to enable our patients to reach the goal of self-management.

- **Young Epilepsy** www.youngepilepsy.org.uk
  Young Epilepsy is the national charity supporting children and young people aged 25 and under with epilepsy and associated conditions, as well as their families. With over 100 years expertise we provide world class diagnosis, assessment and rehabilitation for children and young people with epilepsy. We also undertake research into the condition and how it can be treated.

- **British Academy of Childhood Disability** www.bacdis.org.uk
  Membership is open to all professionals working in the field of childhood disability, including paediatrics, psychiatry, specialist nursing, speech and language therapy, physiotherapy, occupational therapy, psychology and education.

- **British Society for Clinical Neurophysiology** www.bscn.org.uk
  The BSCN is a medical charity whose aims, set out in our articles of association, are “to promote and encourage for the public benefit the science and practice of clinical neurophysiology and related sciences”.

Glossary of terms and abbreviations

Absence seizure	A type of generalised seizure where the person briefly loses awareness and becomes blank or unresponsive. Absences often last a few seconds and the person is unconscious. If they are walking they might carry on walking.
Acute	Inpatient review, or paediatric review in emergency department, or other clinical assessment in an acute paediatric setting
Adherence	When someone takes their medication as they have agreed with their doctor. This is a more modern term than 'compliance' (doing what your doctor tells you to), and implies that there has been some discussion between the individual and their doctor to agree upon a plan of treatment. Whether someone is adherent or not is a measure of how closely they adhere (or 'stick to') taking their medication or treatment as agreed.
Adverse events	Another term for 'side effects'. These are effects of medication that happen alongside the effects you are expecting (the reason you are taking it). Side effects are usually, but not always, unwanted.
AED (Anti-epileptic drug)	Anti-epileptic drugs (AEDs) are the main type of treatment for most people with epilepsy. AEDs are a type of medication that aims to stop seizures. There are many different AEDs and they work in different ways and stop different types of seizures. Up to 70% of people with epilepsy could have their seizures stopped with the right AEDs.
Atonic or atonic seizure	A type of generalised seizure where the person's muscles suddenly lose tone, go floppy, and they fall down (usually forwards) if they are standing up. Although the seizures themselves don't hurt, the person might hurt themselves, especially their head and face, when they fall. These seizures are usually very brief and the person becomes conscious again very quickly. This is sometimes called a 'drop attack'.
BPT/BPC	Best Practice Tariff/Best Practice Criteria
Children's Epilepsy Specialist Nurse	A children's nurse with a defined role and specific qualification and/or training in children's epilepsies
Childhood epilepsy syndrome	A type of epilepsy that happens in children and young people, and follows a particular, typical pattern: the age that the seizures start, the type of seizures, the EEG recording and the progression or outcome. Some syndromes are benign and either go away or have little impact on the child. Others are severe and can affect the child's behaviour, learning and life expectancy. This is sometimes just referred to as a 'syndrome'.
Clonic seizures	These are seizures where the person convulses (jerks or shakes). Unlike tonic clonic seizures, the person does not go stiff at the start of the seizure.
Clusters	When a series or group of seizures happen close together in time, with gaps between each cluster. For example, in catamenial epilepsy, a woman might have a cluster of seizures around ovulation and no seizures at other times.

Complex focal seizures (CFS), Complex partial seizures (CPS)	Seizures that involve just part (not the whole) of the brain. These seizures used to be called 'complex partial seizures' or 'CPS'. The person will not be fully conscious and they are often very confused and may not remember what happens during the seizure. During CFS the person may behave strangely or make repetitive movements called automatisms.
Consultant General Paediatrician	A paediatric consultant (or associate specialist) with a role that includes seeing children or young people in a general outpatient or community clinic setting. They may or may not have other specialty or acute roles. They are likely to receive referrals directly from primary care. Neonatologists would not be included in this definition unless they also fulfil general paediatric roles.
Convulsive seizure	A seizure where the person's body jerks or shakes. It is another name for tonic clonic or clonic seizures.
Diazepam	A type of sedative medication that is given to someone in status epilepticus to stop the seizures. Diazepam is given rectally (up the bottom). This is sometimes referred to as a type of 'emergency medication'.
ECG	An electrocardiogram (ECG) is a simple test that can be used to check your heart's rhythm and electrical activity. Sensors attached to the skin are used to detect the electrical signals produced by your heart each time it beats.
ED	Emergency Department
Electroencephalogram (EEG)	An electroencephalogram (EEG) is a recording of brain activity. During the test, small sensors are attached to the scalp to pick up the electrical signals produced when brain cells send messages to each other. These signals are recorded by a machine and are looked at by a doctor later to see if they're unusual.
Emergency medication	Medication that is given to stop prolonged or repeated seizures (to stop status epilepticus from happening).
Epilepsy	A chronic neurological condition characterised by two or more epileptic seizures (International League Against Epilepsy, ILAE). A pragmatic definition for epilepsy in this audit is 2 or more epileptic seizures more than 24 hours apart that are not acute symptomatic seizures or febrile seizures.
Epilepsy surgery	Different types of surgery on the brain to try to reduce or stop seizures. Some people with epilepsy, whose seizures are not controlled or significantly reduced with medication, are able to have epilepsy surgery. Also called neurosurgery.
Epilepsy syndrome	A complex of clinical features, signs and symptoms that together define a distinctive, recognizable clinical disorder (ILAE)
'Epilepsy syndrome category'	A group of epilepsies described using the terms idiopathic primary, symptomatic, probably symptomatic and cryptogenic and focal, partial, multifocal or generalized
Epileptic seizure	Seizures that start due to interrupted electrical activity in the brain but can affect the body in many different ways. Clinical manifestation(s) of epileptic (excessive and/or hypersynchronous), usually self-limited activity of neurons in the brain. (ILAE)

Febrile convulsions	Convulsive seizures that can happen in young children (from about six months to six years of age) when they have a high temperature or fever. Febrile convulsions happen because very young children cannot control their body temperature very well. Although they can look like epileptic seizures they are not: they are caused by high temperatures not interrupted brain activity.
First paediatric assessment	A 'face to face' assessment by a secondary level/tier doctor in a paediatric service occurring in any non-acute or acute setting. Assessment within emergency department counts if performed by paediatric team rather than an emergency department team. Some paediatric neurologists see referrals direct from GP or ED and these would count as both a first paediatric assessment and tertiary input
Focal seizures	These are seizures that happen in, and affect, only part or one side of the brain (not both sides of the brain) and start from a 'focal point' in the brain. What happens in focal seizures varies depending on which part of the brain is affected and what that part of the brain normally does. Also known as 'partial seizures'.
Frontal lobe seizures	Focal seizures that start in the frontal lobe. Simple focal seizures from the frontal lobe include making strange movements or stiffness or jerking in part of the body such as the arm. Complex focal seizures from this area include making strange postures with the arms or legs or making juddering movements.
General examination	Any evidence of a multisystem examination of the child other than neurological examination
General practitioners (GP)	A doctor based in the community who treats patients with all common medical conditions with minor or chronic illnesses and refers those with serious conditions to a hospital. for urgent and specialist treatment. They focus on the health of the whole person combining physical, psychological and social aspects of care.
Generalised seizures	Seizures that happen in, and affect, the both sides of the brain from the start. There are many different types of generalised seizures, but they all involve the person becoming unconscious, even just for a few seconds, and they won't remember the seizure itself. The most well-known generalised seizure is the tonic clonic (convulsive) seizure.
Genetic	The information in the DNA in our cells that controls our characteristics, for example hair colour, sex and height.
Handover clinic	A clinic where a young people 'leaves the paediatric service and joins an adult service' and comprises both adult and paediatric health professionals
Infantile spasms (also called West Syndrome)	A rare childhood epilepsy syndrome that starts in the first year of life. The child has brief jerks or spasms of the arms, legs or whole body, often in clusters. Some children have problems with learning or behaviour.
Input	Any form of documented clinical contact including face to face clinical, written, electronic or telephone contact
Juvenile myoclonic epilepsy (JME)	A type of childhood epilepsy syndrome that starts between the ages of 11 and 18 years. The person usually has myoclonic seizures when they are waking up and might also have absences and tonic clonic seizures. This syndrome usually responds well to medication.

Ketogenic diet	A high fat, controlled protein, low carbohydrate diet that helps control seizures in some children with epilepsy. The diet works by encouraging the body to get energy from fat (rather than from carbohydrates). When this happens, the body produces chemicals called ketones which, for some children, help prevent seizures from happening.
Ketones	Chemicals produced in the body when the body uses fat for energy. This happens in high-fat diets such as the ketogenic diet. Ketones can help prevent seizures from happening for some people.
Ketosis	The process of producing ketones in the body, when the body uses fat for energy.
Magnetic resonance imaging (MRI)	A type of scan that uses strong magnetic fields and radio waves to produce detailed images of the inside of the body. An MRI scanner is a large tube that contains powerful magnets
Midazolam	A type of medication that is given to someone who is having prolonged or repeated seizures, to stop status epilepticus from happening. Buccal means it is given into the mouth between the teeth and the cheek. Midazolam is a type of emergency medication.
Myoclonic seizure	A type of generalised seizure where just part of the body (for example, a leg or arm) suddenly jerks. Myoclonic jerks often happen in clusters (several happening in a row) and often early in the morning.
Neurodisability	Documented diagnosis including any of the following phrases indicating the diagnosis made by the assessing team: • Autistic spectrum disorder • Moderate, severe (or profound) learning difficulty or global development delay • Cerebral palsy • Neurodegenerative disease or condition • An identified chromosomal disorder with a neurological or developmental component • Attention deficit hyperactivity disorder (ADHD) • Exclusions e.g. hypermobility, dyspraxia, specific learning difficulties e.g. (dyslexia, dyscalculia)
Neurological examination	Any evidence of a neurological examination of the child
Paediatrician with expertise	A paediatric consultant (or associate specialist) defined by themselves, their employer and tertiary service/network as having: • training and continuing education in epilepsies • AND peer review of practice • AND regular audit of diagnosis (e.g. participation in Epilepsy12) (Consensus Conference on Better care for children and adults with epilepsy- Final Statement, Royal College of Physicians of Edinburgh, 2002). A paediatric neurologist is also defined as a 'paediatrician with expertise'.
Parietal lobe seizures	Focal seizures that start in the parietal lobe. Simple focal seizures from the parietal lobe include feeling numb or tingling in part of the body, a burning sensation or feeling of heat, or feeling that parts of the body are bigger or smaller than they really are. Complex focal seizures from this area are rare.

Partial seizures	Another name for 'focal seizures'. There are seizures that happen in, and affect, only part of the brain (not both sides of the brain) and start from a 'focal point' in the brain. What happens in these seizures varies depending on which part of the brain is affected and what that part of the brain normally does.
Paroxysmal episodes	This is the term chosen in this audit to represent the events causing concern. It includes all epileptic and non-epileptic seizures and also seizures of uncertain in origin.
Psychiatrist	A medically trained doctor who specialises in mental health problems. Psychiatrists are medically qualified and can prescribe medications.
Psychologist	Someone who studies the way the mind works and how people behave. Clinical psychologists are trained to help people manage mental health and social problems and they cannot prescribe medications.
Refractory epilepsy	Epilepsy that does not respond to AEDs (AEDs do not stop the seizures). This is also called intractable, drug-resistant or difficult to control epilepsy.
Rescue medication	Medication that is given to a person when they are having prolonged or repeated seizures to stop status epilepticus from happening. It is usually either rectal diazepam or buccal midazolam. These are only given in an emergency: they are not the same as AEDs, which are taken every day to prevent seizures.
Risk assessment	An assessment of someone's safety and possible risks. This might be at work, at home or any other area. Assessments look at risks to health and safety as well as ways to reduce risk, such as making reasonable adjustments or taking safety measures.
Secondarily generalised seizures	Seizures that start as a focal seizure (in part of the brain) but the seizure activity spreads and affects the whole of the brain. In simple terms these are ‘small seizures’ that become ‘big seizures’. The focal seizure start is sometimes called an ‘aura’ or ‘seizure warning’, and the seizure usually spreads to become a tonic clonic seizure.
Seizure	A sudden, short-lived event that causes a change in the person’s behaviour, awareness or consciousness. There are lots of different causes and types of seizures including epileptic seizures, hypoglycaemic (diabetic) seizures, non-epileptic seizures, syncope (fainting), and seizures caused by a heart problem.
Seizure control	When seizures are completely stopped, and the person experiences no seizures anymore. This is usually achieved by taking AEDs.
Seizure-free	When a person’s seizures are fully controlled and stop happening (they don't have seizures anymore).
Severe Myoclonic Epilepsy in Infancy (SMEI) (also called Dravet Syndrome)	A rare childhood epilepsy syndrome that starts in a child’s first few years of life. The child has jerking seizures, usually on one side of the body. They may also be photosensitive. Learning, speech and general development may be affected.
SUDEP (Sudden Unexpected Death in Epilepsy)	When a person with epilepsy suddenly dies and no reason for their death can be seen.
Symptomatic epilepsy	Epilepsy where there is a known physical cause of the person’s seizures. This could be due to a scar on the brain, an accident or head injury, or a stroke or brain tumour. Structural causes can often be seen on an MRI.

Syncope	When someone loses consciousness and collapses because the oxygen getting to their brain temporarily stops. This can be because of a drop-in blood pressure, a change in the heartbeat (and not enough blood is pumped through the heart), or because of a reduced amount of oxygen in the blood. Syncope is also another word for 'faint'.
'School age'	Child 5 years and older (past their 5th birthday)
Temporal lobe seizures	Focal seizures that start in the temporal lobe. Simple focal seizures from the temporal lobe include an epigastric rising sensation, a sudden feeling of fear or joy or a funny taste or smell.
Tonic clonic seizure	A type of generalised seizure where the person stiffens (the 'tonic' part), falls down if they are standing, and then shakes, jerks or convulses (the 'clonic' part).
Transition	When the management of someone's epilepsy moves ('transfers') from a paediatrician to an adult neurologist. Transition usually happens at around 16 - 18 years of age.
Treatment plan	A record of the number and types of AED taken, when to take them and what to do if they do not work or need adjusting or changing. This is also called a drug plan.
Vagus nerve	The Vagus nerves connect to many different parts of the body and passes messages between the brain and various organs, including the throat, the heart, organs in the chest and abdomen.
Vagus Nerve Stimulation (VNS)	A type of treatment for epilepsy. It involves having a generator implanted in the chest wall attached to electrical wires around the Vagus nerve in the neck. The generator sends regular electrical signals through the Vagus nerve into the brain. For some people, this prevents or reduces the brain activity that causes seizures, and can reduce the number, length or severity of seizures they have.
Video telemetry	A test which involves having an EEG and being videotaped at the same time. This means that the EEG recording of a seizure can be compared to what is seen happening to the person. This can help to diagnose epilepsy and non-epileptic seizures.

Epilepsy12
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