

Combined organisational
and clinical audits:
Report for England and Wales
Round 3 Cohort 2 (2019-20)

 **RCPCH Audits**

EPILEPSY12

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



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 2 (2019-20).

The Healthcare Quality Improvement Partnership (HQIP) is led by a consortium of the Academy of Medical Royal Colleges, the Royal College of Nursing and National Voices. Its aim is to promote quality improvement in patient outcomes, and in particular, to increase the impact that clinical audit, outcome review programmes and registries have on healthcare quality in England and Wales. HQIP holds the contract to commission, manage and develop the National Clinical Audit and Patient Outcomes Programme (NCAPOP), comprising around 40 projects covering care provided to people with a wide range of medical, surgical and mental health conditions. The programme is funded by NHS England, the Welsh Government and, with some individual projects, other devolved administrations and crown dependencies.

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EQIP Faculty & Advisory groups

OPEN UK Network Leads Working Group

Contents

Foreword	8
Executive summary	9
1.Introduction	13
Quality improvement	13
2.Clinical and organisational audits	15
Clinical audit of ‘cohort 2’	15
Organisational audit of November 2020	16
3.Key findings and recommendations	17
Mental health support	19
Care planning	21
Sustainable paediatric epilepsy care.....	23
Specialist input into care	25
Neurology services and epilepsy surgery.....	27
Diagnoses and use of medications.....	28
4.Organisation of Paediatric Epilepsy Networks in the UK (OPEN UK)	29
5.Epilepsy12 Youth Advocate Clinic Chat Checklist	32
6.Epilepsy Quality Improvement Programme (EQIP)	39
7.Worcester Acute Hospitals Trust: using Epilepsy12 to drive service improvements	43
8.Summary of recommendations	48
Useful resources	53
Glossary of terms and abbreviations	55

The full audit results and additional information are listed below. These are available to download from [Epilepsy12](#).

[Appendix A: Epilepsy12 Round 3, 2020 Organisational audit](#)

Full results:

- Participation
- Workforce
- Clinic configuration
- Tertiary provision
- Investigations
- Service contact
- Transition
- Mental health
- Neurodevelopmental support
- Care planning
- Patient database or registry
- Findings by OPEN UK regional networks

List of organisational data figures & tables

Data completeness

[Appendix B: Epilepsy12 Round 3, Cohort 2 Clinical audit](#)

Full results:

- Participation and case ascertainment
- Description of cohort
- Diagnostic status
- Initial referral and examination
- Description of episodes
- Convulsive seizures
- Neurodisability or neurodevelopmental problems
- Mental health conditions
- Investigations
- Treatment
- Overview of performance indicators
- Care planning
- Professionals and services involved in care

List of clinical data figures & tables

Data completeness

Foreword

Epilepsy can start at any age and there are many different types. Epilepsy changes through your life, sometimes with more seizures, sometimes with different seizures, or it is stable and in the background. It can affect anyone, at any age, from any walk of life.

Supporting children and young people during this journey and providing good quality care is essential. We have been talking about all the different elements that make up good care. It isn't one person or one action that supports children, young people and their families but lots of people and actions that made the difference.

Good transitions, mental health support and accessible information need to be part of standard care. Having access to an epilepsy specialist nurse (ESN), consultant paediatrician with epilepsy specialist knowledge and the ability to contact your epilepsy service when you need support, help or guidance is really important as well.

Looking at the Epilepsy12 National Organisational and Clinical Audits it is exciting to see improvements that have been made in care, but we need to keep this going. We want people to recognise that having a full picture of care for children and young people with epilepsy is important. So, continuing to ask what children, young people and families think, what they want and involving them is really important. We want to make sure that the needs of children and young people with long term conditions, including epilepsy, are recognised. We want everyone to continue to raise awareness of epilepsy to other health staff, in education and the wider community.

RCPCH &Us Epilepsy12 Youth Advocates



Executive summary

This report presents data and evidence from the three main domains of Epilepsy12: a clinical audit describing patient care, an organisational audit describing service structures, and related quality improvement activities.

The clinical audit data describes patient care of 'cohort 2'. This is children and young people who had a first paediatric assessment for a 'paroxysmal episode' (or episodes) between 1 December 2018 and 30 November 2019. Paroxysmal episodes are any epileptic seizures, non-epileptic seizures, or seizures of uncertain origin. Epilepsy12 follows patients for twelve months of care following their first assessment. For many children and young people in cohort 2, this includes care provided during the COVID-19 pandemic in 2020.

The organisational audit data describes the services and workforces of paediatric services, at Trust and Health Board level, in England and Wales as they were in November 2020. At this time the NHS was dealing with a significant surge in COVID-19 cases and hospitalisations in both England and Wales.



Care provided to 6177 children and young people; 34% (2106) were diagnosed with epilepsy.



Children and young people were referred in 2018/19 with 12 months of subsequent care, some during the COVID-19 pandemic.

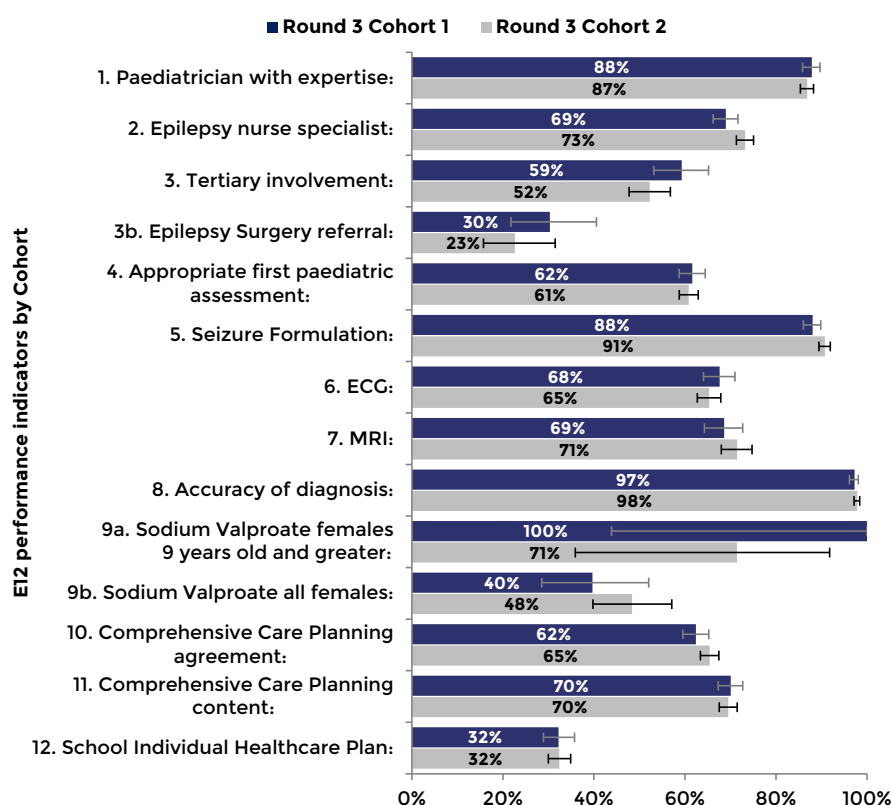


The patient care described is from 103 (of 145) English NHS Trusts and Welsh NHS Health Boards.



Organisational structure data is from 119 (of 145) English NHS Trusts and Welsh NHS Health Boards.

In previous stages of Epilepsy12, there has been considerable variation in the ability of different Health Boards and Trusts in England and Wales to provide adequate workforce time and resources to participate in the national audit. In 2020 this has been more challenging than ever. We want to recognise the sheer dedication to children and young people with epilepsy that has driven participation in the audit and quality improvement activities this past year. However, gaps in both clinical and organisational audit data indicate that some services had to suspend their activities to focus on maintaining core clinical duties.



There are 12 'Performance Indicator' measures which were derived from national guidelines and recommendations. The summary chart above shows the proportion of care which met the criteria of each indicator, for children and young people with epilepsy in cohorts 1 and 2. Patients in cohort 2 completed their first year of care between 1 December 2019 to 30 November 2020. Patients in cohort 1 did so a year earlier, between 1 December 2018 to 30 November 2019.

Overall the results for the two cohorts are similar, which highlights both consistent areas of strength as well as continued scope for improvement in aspects such as input from ESNs, comprehensive care planning, access to epilepsy surgery services, and links to school epilepsy care plans.

Key themes and recommendations for improvement

There were very few children and young people with an identified mental health condition in cohort 2. Without wide-spread use of screening, opportunities for referral into the appropriate pathway for assessment could be missed.

1. All Health Boards and Trusts should ensure that:

- All children and young people with epilepsy are provided with psychosocial support and signposting to help them manage their condition and their related worries or anxieties,
- All children and young people with epilepsy have ongoing screening for mental health problems using a validated tool as part of their routine epilepsy care. Where there are concerns about mental health, children and young people are referred to an appropriate mental health service via an agreed pathway. There should be timely access to diagnosis and treatment.

2. Hospital and community commissioners should commission increased integrated psychosocial and mental health support for children and young people receiving care for long-term conditions. This should be co-located within the epilepsy clinic, and inclusive of co-morbidities.

There was also evidence of wide-spread care planning for children with epilepsy. However, at patient-level there was inconsistency in the care plans achieving all the core elements.

3. All Health Board and Trust managers and epilepsy clinical teams should implement standardised approaches to epilepsy care planning content provision to ensure that essential elements of care are always provided for all children and young people with epilepsy and these are reviewed on an ongoing basis.

4. Health Board and Trust managers, epilepsy clinical teams, school head teachers, and school nurses should agree processes to facilitate appropriate, up-to-date health care planning within education and two-way information sharing.

Epilepsy12 is developing a new tool for 2021 to help teams evidence in real-time the core elements of care planning for the children and young people with epilepsy in their care.

The data submitted to Epilepsy12 shows that during the COVID-19 pandemic, services have done very well to maintain care for children and young people with epilepsy. However, there were also services and aspects of 'timeliness' that indicate some of the risks and pressures in the system.

5. Epilepsy services should be supported by their Trust or Health Board's management and the commissioning organisations to:

- Develop a defined epilepsy team approach to service provision and service improvement,
- Allocate time within job plans to support team functions including dedicated time for audit participation and related quality improvement actions.

6. Hospital commissioners, NHS Regional Offices, Regional Partnership Boards, NHS England and NHS Wales should ensure that there is capacity to provide timely access to necessary epilepsy investigations (such as EEG, ECG, MRI and CT), so that children and young people are not disadvantaged by the variation in availability of diagnostic services between Health Boards and Trusts.

Epilepsy Specialist Nurses (ESNs) and Paediatric Consultants with expertise in epilepsies play crucial roles in epilepsy diagnosis and ongoing care. Most children and young people received specialist input during their first year of care, but this was not available in every Trust and Health Board.

7. All Health Board and Trust managers should employ sufficient Epilepsy Specialist Nurses and consultant paediatricians "with expertise" in epilepsy to ensure all children and young people with epilepsy can reliably receive responsive, individualised, specialist input into their care for epilepsy and related concerns, for example, psychological and developmental issues.

8. All Health Board and Trust managers and hospital and community commissioners should ensure that adult and paediatric epilepsy teams are resourced to allow, and have time allocated in job plans, for joint transition-related clinical appointments and quality improvement work.

A smaller proportion of children and young people who met surgical referral criteria had been referred to neurology or the Children's Epilepsy Surgery Service (CESS). Children and young people may be missing out on, or having delayed access to, epilepsy surgeries and specialist neurological care.

9. OPEN UK regional networks, NHS England, NHS Wales, BPNA, RCPCH, Health Education England and Health Education and Improvement Wales should work together to review the Epilepsy12 findings in their area and ensure there are:

- Sufficient paediatric neurologists to provide timely assessment and ongoing management,
- Robust referral pathways to paediatric neurology such that children and young people are not disadvantaged by the variation in access to specialists between Health Boards and Trusts.

10. The specialist CESS centres should collectively:

- Review the referral criteria to ensure these are clear, consistent, and embedded in shared care pathways from secondary care and paediatric neurology, and
- Agree a communications strategy to raise awareness of referral criteria and encourage early referral of appropriate children and young people.

Quality Improvement

The third domain of Epilepsy12 is our quality improvement activities, including our work with the regional epilepsy networks and annual stakeholder conference. There were two Epilepsy12 quality improvement pilots taking place in 2019/20.

The RCPCH Epilepsy Quality Improvement Programme (EQIP) was piloted in 2019/20. EQIP formed a collaborative with 12 epilepsy teams, each receiving training and support to implement a range of quality improvement projects in their services.

A group of epilepsy-experienced young people, the 'Epilepsy12 Youth Advocates' have been working with services to improve support for children and young people with epilepsy. Their impact on quality improvement was nationally recognised, as they were awarded joint 'National Volunteers of the Year' in the HQIP Audit Heroes 2020.

Based on this work, the Epilepsy12 Youth Advocates chose four top things which make a 'gold standard' approach to supporting patient's anxieties and worries with their epilepsy:

1. access to information at the right time,
2. having an Epilepsy Specialist Nurse who is easy to contact,
3. having a calm, kind and understanding team,
4. access to mental health services.

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).

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. Epilepsy12 seeks to help improve the standard of care for children and young people with epilepsies. To do this, the audit collects and processes patient data. This information is used by the audit to highlight areas where services are doing well, and also identify areas in which they need to improve.

The RCPCH delivered Rounds 1 and 2 of Epilepsy12 between 2009 and 2014, 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. In 2020 the contract with RCPCH to deliver the audit was extended up to 31 March 2022.

Rounds 1 and 2 of the audit included Health Boards and Trusts across England, Northern Ireland, Scotland and Wales. Round 3 has included Health Boards and Trusts in England and Wales. It is comprised of three main audit domains: the organisational audit (service descriptor), the clinical audit (clinical care domain) and associated quality improvement activities.

In Round 3, Epilepsy12's aims are to:

- Continue to measure and improve care and outcomes for 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 alongside metrics about mental health, education and transition to adult services,
- Provide services with local real-time patient- and service-level reporting.

All current and previous publications from Epilepsy12 are available at www.rcpch.ac.uk/epilepsy12.

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 in the UK (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 third Epilepsy12 & OPEN UK National Conference was hosted online on 10 September 2020. More than 170 health professionals, working in support of paediatric epilepsy services and patient organisations, came together with the aim of learning from each other and improving care for children and young people with epilepsies. The conference was chaired by Professor Finbar O'Callaghan, Professor of Paediatric Neuroscience at UCL, (Hon) Consultant Paediatric Neurologist, and President of the British Paediatric Neurology Association (BPNA). The event included a young people-led symposium, discussion of the Epilepsy12 2020 national report which was published on the day, and an Epilepsy Quality Improvement Programme showcase. Presentations delivered on the day can be viewed via the project website: www.rcpch.ac.uk/epilepsy12.

Epilepsy Quality Improvement Programme (EQIP)

The RCPCH Epilepsy Quality Improvement Programme (EQIP) is a model for a comprehensive Quality Improvement (QI) programme, tailored to support paediatric epilepsy teams to work together to define their shared aims and identify current gaps in service provision. This pilot took place from June 2019 until July 2020. A supplement detailing the pilot aims, activities and outcomes is planned for later in 2021. Further information can be found online at www.rcpch.ac.uk/eqip.

Involving children and young people

The Epilepsy12 Youth Advocates have been working with services to improve support for worries and anxieties of children and young people with epilepsy. Based on their earlier research with children and young people, the Youth Advocates designed a self-assessment process for paediatric epilepsy services, the 'Clinic Chat Check List'. Their work piloting this with eight services was recognised through being named joint winners of the 'National Volunteer of the Year' in the HQIP Audit Heroes 2020 Awards which highlight work taking place all over the country to improve health care for patients. See chapter 5 for more information on the Youth Advocates.

2. Clinical and organisational audits

There are two separate datasets for Round 3 of the Epilepsy12 audit. The organisational audit covers the configuration of Trust- or Health Board-level services and workforce in paediatric epilepsy. The clinical audit is patient-level descriptions of clinical care.

The measures and analysis used in Epilepsy12 are directed by our Epilepsy12 Methodology and Dataset Group, which brings together a range of clinical, patient and parent, and statistical experts. The measures used in Epilepsy12 were developed to align to national standards and guidelines, including:

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

The Epilepsy12 measures and results have been reviewed to manage the risk of disclosure of protected personal information in the audit data. This was risk assessed on each measure, and at points in this report results with small numbers have been masked. Masked results have been marked with an asterisk (*) and footnoted.

There were 145 registered Health Boards and Trusts for cohort 2 of Epilepsy12. This had previously been 149 Trusts and Health Boards, however the number has reduced following mergers.

Full details of the Epilepsy12 Round 3 datasets can be viewed on the [Epilepsy12 website](#).



Care provided to 6177 children and young people; 34% (2106) were diagnosed with epilepsy.



Children and young people were referred in 2018/19 with 12 months of subsequent care, some during the COVID-19 pandemic.



The patient care described is from 103 (of 145) English NHS Trusts and Welsh NHS Health Boards.



Organisational structure data is from 119 (of 145) English NHS Trusts and Welsh NHS Health Boards.

Figure 1: Epilepsy12 audits at a glance

Clinical audit of ‘cohort 2’

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 cohorts based on when they are first assessed by the paediatric service. This report focuses on ‘cohort 2’ which is the second group of patients in Round 3 of Epilepsy12. Cohort 2 includes children and young people who had a first paediatric assessment for a ‘paroxysmal episode’ (or episodes) between 1 December 2018 and 30 November 2019. Paroxysmal episodes are any epileptic seizures, non-epileptic seizures, or seizures of uncertain origin.

Epilepsy12 follows patients for twelve months of care following their first assessment; we refer to this as the ‘first year of care’. Depending on when they had entered the audit, children and young people in cohort 2 completed their first year of care between 1 December 2019 to 30 November 2020.

Children and young people in cohort 2 had their first paediatric assessment in 2018/19, prior to the COVID-19 pandemic. Some of the children and young people in cohort 2 had completed their first year of care prior to March 2020. However, especially for the patients with a first assessment between March and November 2019, the ‘first year of care’ data in this report includes care provided during the COVID-19 pandemic in 2020.

Electroencephalogram (EEG) services and paediatric epilepsy services provide audit data to Epilepsy12. These data for cohort 2 were supplied between December 2018 and January 2021. During 2020-21 the guidance for the NHS was to protect clinical activity, so services could pause other activities (including the mandatory submission of audit data) when necessary. The pandemic has, by necessity, limited the audit data available. As data can be entered retrospectively this also affected data about care in for children and young people in cohort 2 provided prior to the pandemic.

103 Health Boards and Trusts were able to submit a full first year of care clinical record for one or more children and young people in cohort 2. First year of care records were submitted for 6,177 children and young people in cohort 2.

Organisational audit - November 2020

The Epilepsy12 audit of the organisation of paediatric epilepsy services in England and Wales focuses on services and workforce at Trust and Health Board level, describing a designated point in time. This report presents organisational data describing the services as they were in November 2020. At this time the NHS was dealing with a significant surge in COVID-19 cases and hospitalisations in both England and Wales. 119 Health Boards and Trusts were able to submit and lock their November 2020 organisational audit data. The data were provided to Epilepsy12 between November 2020 and February 2021.

3. 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 2021 (clinical data) and February 2021 (organisational data).

In previous rounds of Epilepsy12 there has been considerable variation in the ability of different Health Boards and Trusts in England and Wales to provide adequate workforce time and resources to participate in this national audit. In 2020 this has been more challenging than ever for the paediatric epilepsy teams. We want to recognise the dedication to children with epilepsy that has driven data submissions to the audit this past year, enabling insights into care during the pandemic. However, gaps in data entry indicate that some teams had to suspend participation completely.

Health Boards and Trusts can use audit data for benchmarking practices to identify areas to focus on in service improvements, share best practice and improve care outcomes. It is essential that Health Board and Trusts managers support and resource their paediatric epilepsy services to improve data completeness, ensuring an accurate reflection of their standard of care. Epilepsy12 aims to share performance analysis with the regulator, Care Quality Commission, and are reviewing the methodology and selection of measures to do so.

Detailed results from the clinical and organisational data are available in appendices A and B. This includes the results of analysis for each Epilepsy12 audit measure, and analysis by country and regional epilepsy network areas.

There are 12 'Performance Indicator' measures which were derived from national guidelines and recommendations. The performance indicators measures are:

1. Input into care from a paediatrician with expertise in epilepsies,
2. Input into care from an epilepsy specialist nurse (ESNs),
3. (a) Appropriate tertiary input into care, and (b) appropriate epilepsy surgery referral
4. Appropriate first paediatric assessment,
5. Recorded seizure formulation,
6. Access to electrocardiogram (ECG),
7. Access to magnetic resonance imaging (MRI),
8. Accuracy of diagnosis,
9. (a) Discussion of the risks where sodium valproate is used in treatment for girls aged 9 and over, and (b) girls and young women prescribed sodium valproate
10. Comprehensive care plan that is updated and agreed with the patient,
11. Documented evidence of all key elements of care planning content,
12. Record of a school individual healthcare plan.

Figure 2 shows the proportion of care which met the criteria of each indicator, for children and young people with epilepsy in cohorts 1 and 2. Patients in cohort 2 completed their first year of care between 1 December 2019 to 30 November 2020. Patients in cohort 1 did so a year earlier, between 1 December 2018 to 30 November 2019.

Overall the results for the two cohorts are similar, which highlights both consistent areas of strength as well as continued scope for improvement in aspects such as input from ESNs, comprehensive care planning, access to epilepsy surgery services, and school epilepsy care plans.

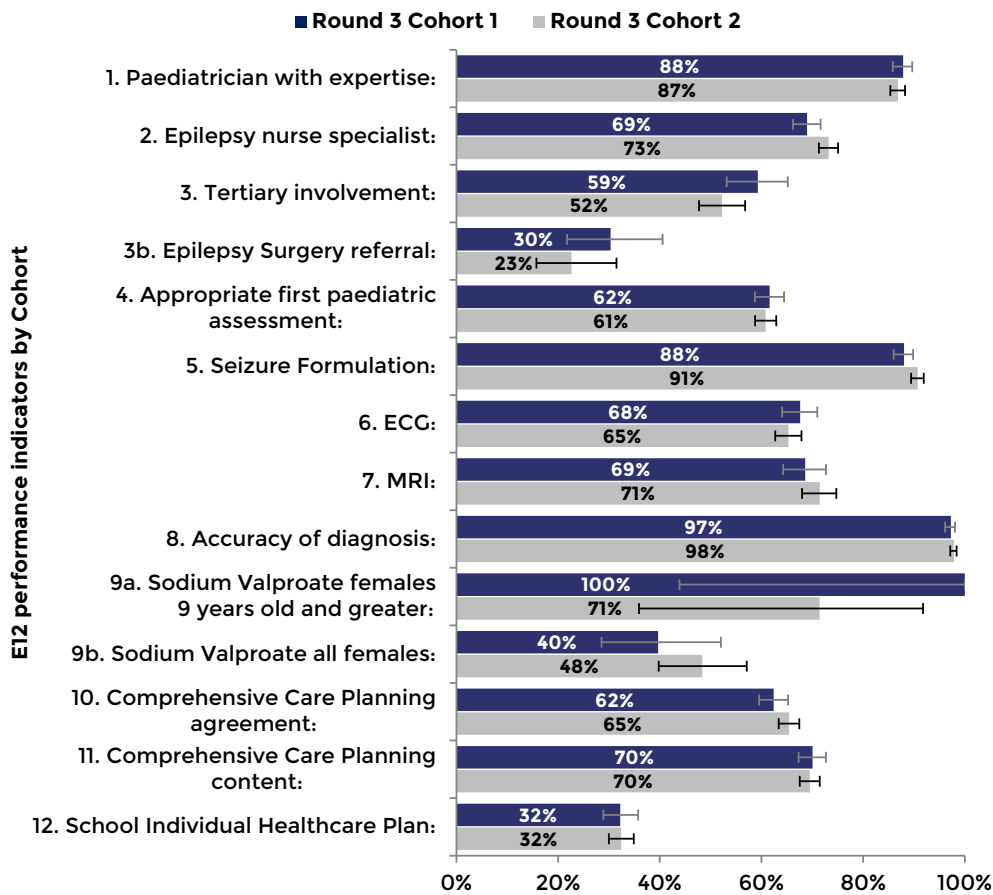
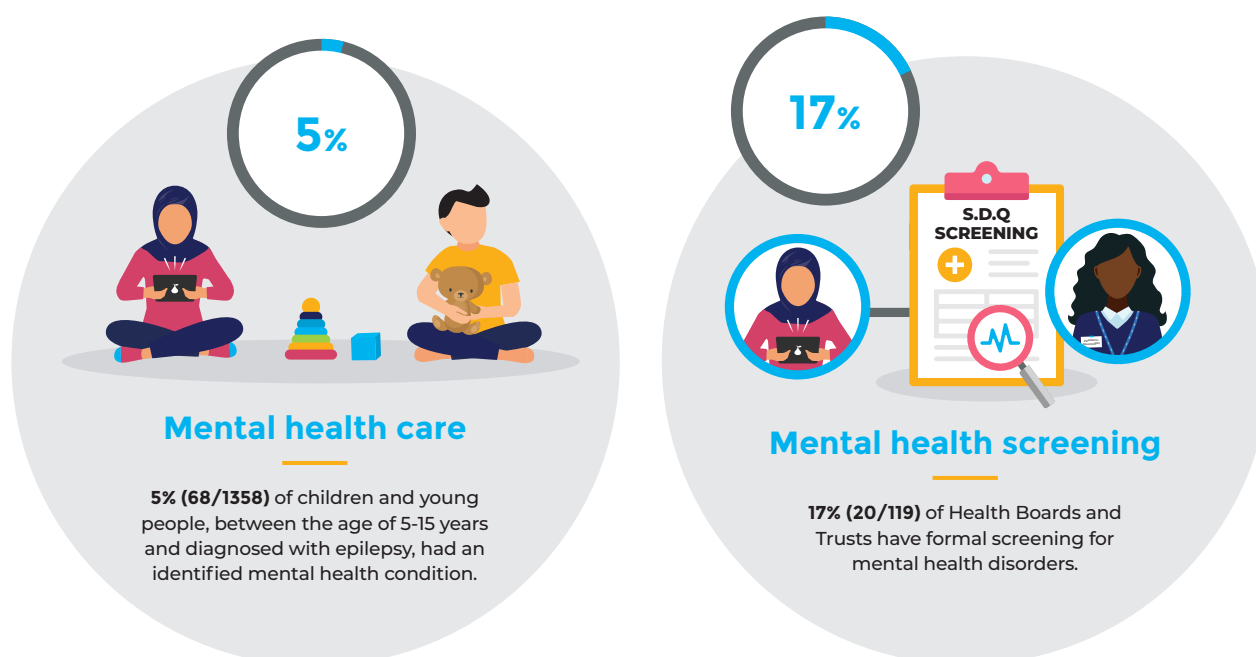


Figure 2: Epilepsy12 performance indicators in England and Wales (Round 3 Cohorts 1 and 2)

These performance indicators 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 results of both the clinical and organisational audits. They were developed with a multi-disciplinary group of members of the Epilepsy12 Project Board, the Methodology and Dataset Group, and other audit stakeholders who met online to review the data analysis.

Mental health support



There were very few children and young people with an identified mental health condition in cohort 2, despite research¹ suggesting a higher incidence of mental health problems among children and young people with long term conditions. An earlier study reported 37% of 5 to 15 year olds with epilepsy had a co-existing mental health condition. While co-located mental health care is recommended as best practice, few paediatric epilepsy services had been able to achieve this.

Few of the Health Boards and Trusts had a formal screening process for children and young people receiving care from the epilepsy team. Without wide-spread use of screening, opportunities for referral into the appropriate pathway for assessment could be missed.

An integrated approach to psychosocial support is important to help children and young people manage a long-term condition like epilepsy. In Chapter 5, the Epilepsy12 Youth Advocates have highlighted ways that services can support and signpost children and young people to help with their worries and anxieties.

The findings for cohort 1 and cohort 2 were very consistent, however there is a significant concern about increased longer-term psychological impacts of the COVID-19 pandemic for children and young people.

- **36% (43/119) of Health Boards and Trusts did not have agreed referral pathways for children with mental health conditions.**
- **7% (8/119) of Health Boards and Trusts could not refer to mental health assessment services, either within or outside of their Health Board or Trust.**
- **15% (18/119) of Health Boards and Trusts facilitate mental health provision within epilepsy clinics. Only 11% (11/101) of Health Boards and Trusts without co-located provision indicated they had an action plan describing steps towards co-located mental health provision.**
- **17% (20/119) of Health Boards and Trusts have formal screening for mental health disorders.**

¹ Buelow JM, et al. (2003) Behavior and mental health problems in children with epilepsy and low IQ. Dev Med Child Neurol

- **68% (1435/2106) of children aged 3 years and over with epilepsy had evidence that emotional or behavioural problems were considered during their first assessment.**
- **5% (68/1358) of children and young people between the age of 5-15 years and diagnosed with epilepsy had an identified mental health condition.**
- **Few children with epilepsy had input into their care from mental health specialists such as a clinical psychologist (2%, 41/2106), psychiatrist (<1%, 7/2106), educational psychologist (1%, 15/2106) or other mental health professional (1%, 22/2106).**

There are signs that support and identification of neurodevelopmental issues are more embedded into paediatric epilepsy care, particularly as an area reviewed in the initial paediatric assessment. However, there is also limited access to formal screening.

- **83% (1743/2106) children and young people had evidence that description of developmental, learning or schooling progress was included in their first paediatric assessment for epilepsy.**
- **22% (469/2106) of children and young people diagnosed with epilepsy had an identified neurodisability or neurodevelopmental condition.**
- **Screening for Attention Deficit Hyperactivity Disorder (ADHD) and Autism Spectrum Disorders (ASD) were available in a minority of Trusts (20%, 24/119, and 19%, 23/119, respectively).**
- **80% (95/119) of Health Boards and Trusts had agreed referral criteria for ADHD, 85% (101/119) for ASD, 60% (71/119) had criteria for behaviour difficulties, 62% (74/119) for developmental coordination disorder, 56% (67/119) for intellectual disability and 8% (10/119) for other neurodevelopmental problems.**

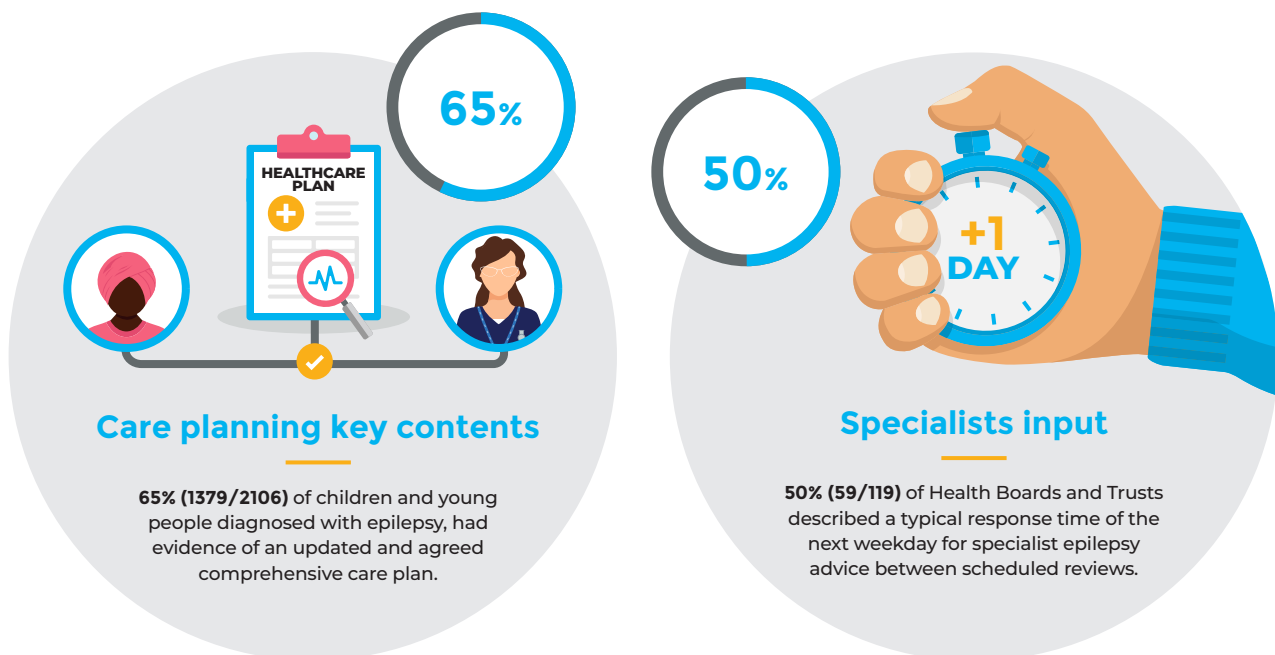
Recommendation 1 and 2

Health Board and Trust managers should ensure that:

- All children and young people with epilepsy are provided with psychosocial support and signposting to help them manage their condition and their related worries or anxieties, and
- All children and young people with epilepsy have ongoing screening for mental health problems using a validated tool as part of their routine epilepsy care. Where there are concerns about mental health, children and young people are referred to an appropriate mental health service via an agreed pathway. There should be timely access to diagnosis and treatment.

Hospital and community commissioners should commission increased integrated psychosocial and mental health support for children and young people receiving care for long-term conditions. This should be co-located within the epilepsy clinic, and inclusive of co-morbidities.

Care planning



Health Boards and Trusts describe providing children, young people and/or their families with contact details for the epilepsy service, and that typically they are able to provide specialist advice promptly between scheduled reviews. Patient organisations for epilepsy, as well as research undertaken with children, young people and their families by the Youth Advocates, emphasise the importance of services being responsive and having clear points of contact.

There was also evidence of wide-spread use of care planning for children with epilepsy, which often had been agreed with children, young people and their families. At patient-level we found that core elements of content were present in the majority of care plans.

However, there was less consistency in care plans including all core elements of content, which meant our overall finding of comprehensive care planning was lower than for individual elements. There were apparent gaps in safety information provided in care planning: a fifth of care plans lacked evidence that water safety had been discussed, and a similar proportion lacked evidence around general participation and risk information.

- **All of Health Boards and Trusts, 100% (119/119) reported availability of specialist epilepsy advice between scheduled reviews across England and Wales.**
- **50% (59/119) of Health Boards and Trusts described a typical response time of the next weekday for requests for advice between scheduled reviews. Initial specialist advice was 'typically' provided by an epilepsy specialist nurse in 50% (59/119) of Health Boards and Trusts.**
- **Comprehensive care planning for children and young people with epilepsy was reported to routinely take place in 90% (107/119) of Health Boards and Trusts.**
- **65% (1379/2106) of children and young people diagnosed with epilepsy, had evidence of an updated and agreed comprehensive care plan.**
- **There was evidence of the plan being agreed with the child, young person, their family/carer and their healthcare provider in 76% (1606/2106) of care plans.**
- **92% (1927/2106) of care plans included evidence that children and young people are given contact details for their epilepsy service.**

- **90% (412/458) of children and young people diagnosed with epilepsy and on rescue medication, had a parental prolonged seizure care plan.**
- **80% (1681/2106) of care plans included discussion of water safety and 81% (1697/2106) had evidence of discussion regarding general participation and risks.**
- **32% (455/1402) of school-aged children and young people with epilepsy were identified as having a school Individual Healthcare Plan.**
- **Less than half of children and young people diagnosed with epilepsy (or their parent/carer) had evidence that information on Sudden Unexpected Death in Epilepsy (SUDEP) had been provided (43% 915/2106).**

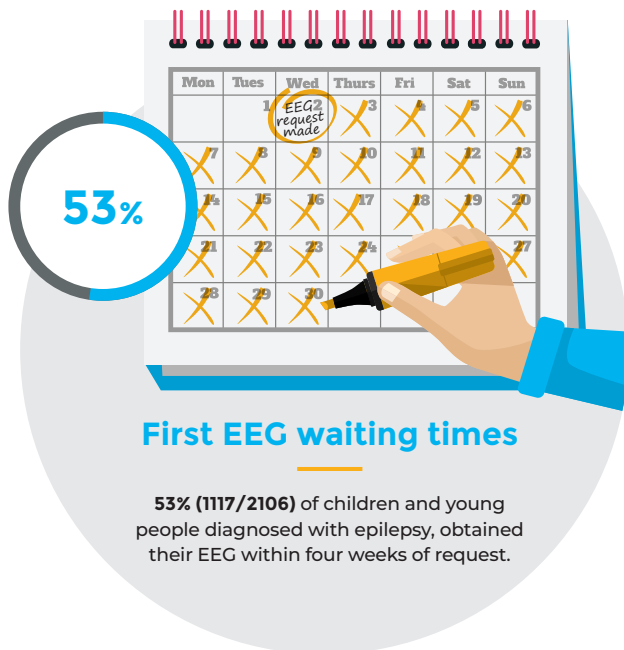
Recommendations 3 and 4 (repeated from 2020):

All **Health Board and Trust managers and epilepsy clinical teams** should implement standardised approaches to epilepsy care planning content provision to ensure that essential elements of care are always provided for all children and young people with epilepsy and these are reviewed on an ongoing basis.

Health Board and Trust managers, epilepsy clinical teams, school head teachers, and school nurses should agree processes to facilitate appropriate, up-to-date health care planning within education and two-way information sharing.

Epilepsy12 is developing a new tool for 2021 to help teams evidence in real-time the core elements of care planning for the children and young people with epilepsy in their care.

Sustainable paediatric epilepsy care



The children and young people in cohort 2 were referred and assessed prior to COVID-19 having an impact on NHS services. However, a proportion of their ongoing care took place during the two main waves of the pandemic in 2020. The data submitted to Epilepsy12 shows both signs that services have done very well to maintain standards given the challenges they have faced, as well as issues with 'timeliness' of care that indicate some of the pressures in the system.

Most children and young people are registered into the audit by an EEG service. This continues to be the case, but the overall proportion of Epilepsy12's patient registrations coming from an EEG service reduced over the course of 2020. This gives a small indication of how significantly these vital partner services were impacted when face-to-face patient

care was limited by both public-health necessity and overall healthcare capacity. Cohort 2 registration was relatively advanced in early 2020 because the patients included had been referred for their EEG in 2018/19: we can expect to see additional impacts on later cohorts, many of whom were first referred and needed an initial EEG during 2020/21.

When considering the care and services described in this report, it is important to be aware that there is some data missing and that this should not be assumed as a random sample. There were services without any capacity to submit Epilepsy12 data this year; whether due to reduced workforce, redeployment of personnel and services to respond to COVID-19, or other factors. Their absence in the clinical and organisational data has likely influenced the results in important ways.

After coping with exceptionally difficult circumstances urgent action is needed to ensure paediatric epilepsy teams, and the services they rely on, have sufficient capacity and resources to build sustainable services, include appropriate specialities within the paediatric epilepsy team, and are able to maintain quality standards for children and young people in their care.

- **71% (103/145) Health Boards and Trusts submitted a record of the first year of care for one or more children and young people in cohort 2; compared to 76% (113/149) in cohort 1.**
- **There was a decrease in clinical 'data completeness' for cohort 2 (61%, 6177/10181) compared to cohort 1 (71%, 3318/4684). This is the proportion of patients registered into a cohort whose first year of care record was completed and submitted.**
- **82% (119 out of 145) registered Health Boards and Trusts completed and submitted the November 2020 organisational audit data, compared to 94% (136/145) in 2019.**
- **There was a reduction in the proportion of new patient registrations submitted by EEG services in 2020. In the Epilepsy12 Round 3 data downloaded in January 2021 68% (15442/22569) of patient registrations were received from an EEG service, compared to 73% (10649/14591) of registrations when data was downloaded in January 2020.**
- **53% (1117/2106) of children and young people diagnosed with epilepsy, obtained an EEG within four weeks of request.**

- **There were signs that children and young people were able to access appropriate investigations during the first year of care: 98% (2070/2106) of children with epilepsy received an EEG, 56% (1182/2106) had a 12-lead ECG, 12% (248/2106) had a CT head scan, 57% (1202/2106) MRI brain scan.**
- **Variation in available services: 61% (73/119) of Trusts and Health Boards could provide a standard EEG within their location; 96% (114/119) could provide a 12-lead ECG; 94% (112/119) an 'awake' MRI or 63% (75/119) 'with sedation'; and 23% (27/119) inpatient video telemetry or 16% (19/119) for home video telemetry.**
- **In November 2020, there was a defined paediatric epilepsy clinic or clinics, seeing patients at secondary level, in 93% (111/119) of Health Boards and Trusts.**

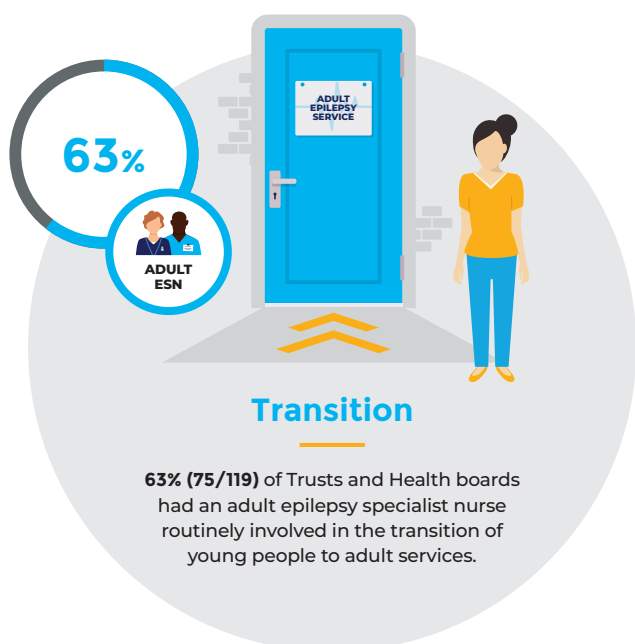
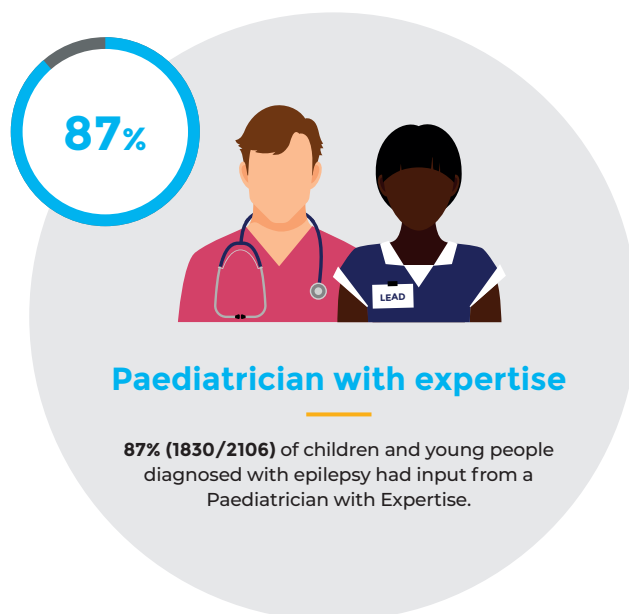
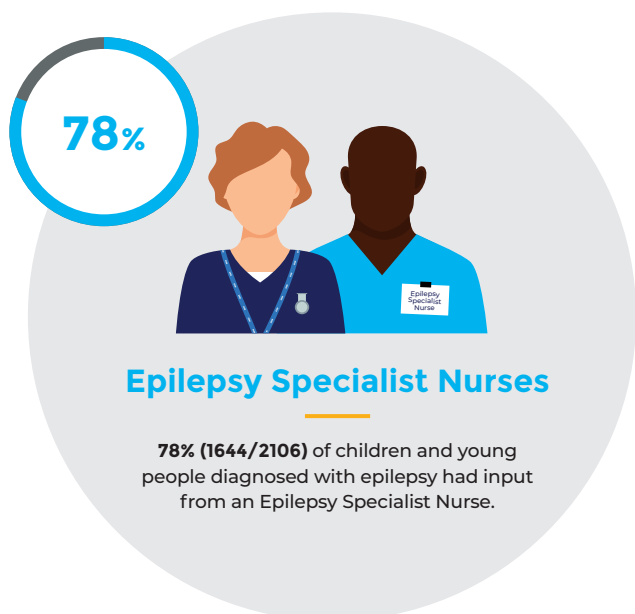
Recommendations 5 and 6:

Epilepsy services should be supported by their **Trust or Health Board's management** and the **commissioning organisations** to:

- Develop a defined epilepsy team approach to service provision and service improvement,
- Allocate time within job plans to support team functions including dedicated time for audit participation and related quality improvement actions.

Hospital commissioners, NHS Regional Offices, Regional Partnership Boards, NHS England and NHS Wales should ensure that there is capacity to provide timely access to necessary epilepsy investigations (such as EEG, ECG, MRI and CT), so that children and young people are not disadvantaged by the variation in availability of diagnostic services between Health Boards and Trusts.

Specialist input into care



During the three rounds of Epilepsy12 (2009-20) there has been an increase in epilepsy specialists employed by Health Board and Trusts, and this has been reflected in the records of specialist input into the care of children and young people with epilepsy. Presence of paediatric consultants ‘with expertise’ in epilepsy and ESNs was relatively stable between cohort 1 and cohort 2 (2019 and 2020 for the organisational data). ESNs and paediatric consultants with expertise play crucial roles in epilepsy diagnosis and ongoing care. It encouraging to see that most children and young people receive specialist input during their first year of care, but this should be available to all.

It is also positive to see evidence of increased joint-working to support young people to transition to adult services. In particular, Health Boards and Trusts reported more involvement of adult specialists in transition processes.

- **78% (1644/2106) of children and young people diagnosed with epilepsy had an input from an ESN. This had been 72% (798/1112) in cohort 1.**
- **89% (106/119) of Health Boards and Trusts had some provision of ESNs, an average of 1.3 whole time equivalents (WTEs) per Health Board and Trust. This was an increase from 2019 (1.2 WTEs), 2018 (1.0 WTEs), 2014 (0.6 WTEs), and 2009 (0.5 WTEs).**
- **Between 2018-2020 there has been an increase in the functions supported by ESNs in Health Boards and Trusts. This includes providing rescue medication training for parents (in 87%, 104/119, of Health Boards and Trusts in 2020 from 75%, 111/148, in 2018), and facilitating meetings with schools (86%, 102/119, of Health Boards and Trusts in 2020 from 72%, 106/148, in 2018).**

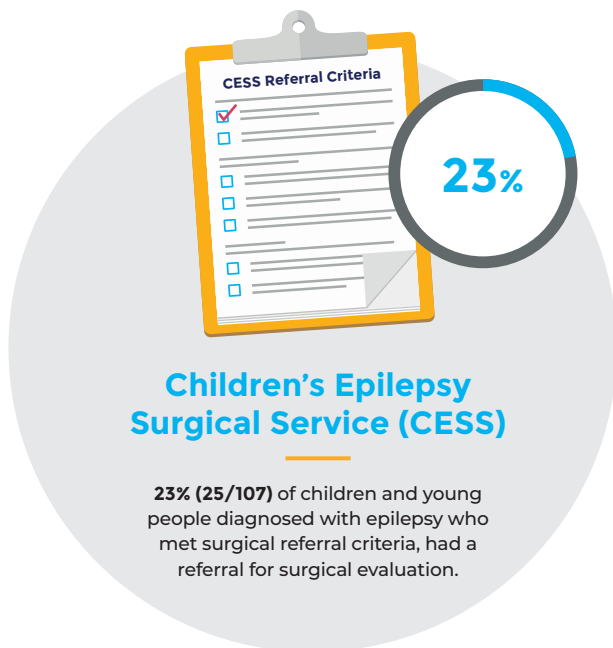
- **19% (392/2106) of children and young people diagnosed with epilepsy were seen by a paediatrician with expertise in epilepsy within 2 weeks of first referral in England and Wales. 87% (1830/2106) were seen during their first year of care.**
- **97% (116/119) of Health Boards and Trusts employed at least some time of a consultant paediatrician ‘with expertise’ in epilepsy. Health Boards and Trusts employed an average of 2.3 WTE consultants with expertise. This was the same as November 2019; after increasing from 2.1 WTEs in 2018 and 1.8 WTEs in both 2009 and 2014.**
- **60% (71/119) of Health Boards and Trusts reported having an outpatient service for epilepsy where there is a presence of both adult and paediatric professionals.**
- **There was an increase in adult specialists participating in transition services for young people. In 85% (101/119) of Health Boards and Trusts adult neurologists were routinely involved in transition to adult services, compared to 78% (116/148) in 2018 and 84% (114/136) in 2019.**
- **Adult ESNs were routinely involved in the transition services at 63% (75/119) of Health Boards and Trusts, which had been 51% (76/148) in 2018 and 54% (74/136) in 2019.**
- **66% (79/119) of Health Boards and Trusts, used structured resources to support transition to adult services.**
- **86% (102/119) of Health Boards and Trusts had an agreed referral pathway to adult services.**

Recommendations 7 and 8:

All **Health Board and Trust managers** should employ sufficient Epilepsy Specialist Nurses and consultant paediatricians “with expertise” in epilepsy to ensure all children and young people with epilepsy can reliably receive responsive, individualised, specialist input into care for epilepsy and related concerns, for example, psychological and developmental issues.

All Health Board and Trust managers and hospital and community commissioners should ensure that adult and paediatric epilepsy teams are resourced to allow, and have time allocated in job plans, for joint transition-related clinical appointments and quality improvement work.

Neurology services and epilepsy surgery



There was evidence that some children and young people who had on-going seizures, or whose condition did not respond to AEDs, may not be receiving appropriate referrals to tertiary care.

Compared to cohort 1, a smaller proportion of children and young people who met surgical referral criteria or paediatric neurology criteria had evidence that such referrals were made or had been followed up with specialist input where appropriate. Children and young people are missing out on, or having delayed access to, epilepsy surgery and specialist neurological care.

- **5% (107/2106) of the children and young people diagnosed with epilepsy, met one or more of the Children's Epilepsy Surgery Service (CESS) referral criteria in England and Wales in cohort 2.**
- **23% (25/107) of children and young people diagnosed with epilepsy who met surgical referral criteria had**

a referral to CESS for surgical evaluation during their first year of care. This is compared to 30% (27/89) of appropriate children and young people in cohort 1.

- **Around half of children and young people who met paediatric neurology referral criteria had either paediatric neurologist input or a referral to CESS during their first year of care, 52% (243/464).**
- **21% (447/2106) of children and young people diagnosed with epilepsy had input from a paediatric neurologist.**
- **95% (113/119) of Health Boards and Trusts had agreed referral pathways to tertiary paediatric neurology services.**
- **There were a total of 91.1 WTE consultant paediatric neurologists providing care across England and Wales.**

Recommendations 9 and 10:

OPEN UK regional networks, NHS England, NHS Wales, BPNA, RCPCH, Health Education England and Health Education and Improvement Wales should work together to review the Epilepsy12 findings in their area and ensure there are:

- Sufficient paediatric neurologists to provide timely assessment and ongoing management,
- Robust referral pathways to paediatric neurology such that children and young people are not disadvantaged by the variation in access to specialists between Health Boards and Trusts.

The **specialist CESS** centres should collectively:

- Review the referral criteria to ensure these are clear, consistent, and embedded in shared care pathways from secondary care and paediatric neurology, and
- Agree a communications strategy to raise awareness of referral criteria and encourage early referral of appropriate children and young people.

Diagnoses and use of medications

The audit also highlighted a number of significant strengths in the care provided to children and young people in cohort 2. Evidence suggests a high degree of appropriate diagnosis – with most children and young people having a consistent epilepsy diagnosis.

Few girls and young women in the audit cohort were prescribed sodium valproate medication. However in two cases, for patients aged over 9, there was not a record that the risks of sodium valproate medication during pregnancy had been discussed as part of a required pregnancy prevention programme. In 2020 the Cumberlege Review² reported clinical harm which resulted from a lack of medical advice given to women about sodium valproate. The report recommended that healthcare professionals ensure there is a clear process to provide appropriate information to women and girls on sodium valproate about their epilepsy treatment and contraceptive choices.

There was significant variation in many audit measures at regional level including use of rescue medication, routine specialist involvement in care, and access to key investigation or screening services. While we do not make a national recommendation, full regional results are presented in the appendices.

- **34% (2106/6177) children and young people were diagnosed with epilepsy in cohort 2.**
- **98% (2081/2126) of children and young people diagnosed with epilepsy, still had that diagnosis after one year of care. This proportion has been increasing in every audit round.**
- **91% (1911/2106) of children and young people diagnosed with epilepsy had an appropriate seizure classification in the first year of care.**
- **1703 children and young people were prescribed one or more AEDs during their first year of care. 1661 of the children and young people prescribed AEDs had epileptic episodes.**
- **71% (5/7) of females aged nine or above diagnosed with epilepsy and prescribed sodium valproate treatment, had evidence of previous discussion of risk regarding birth defects and neurodevelopmental risks.**
- **22% (458/2106) of the children and young people diagnosed with epilepsy, had rescue medication prescribed in England and Wales in cohort 2. This varied between 5% and 41% across different regional networks.**
- **In many cases paediatric epilepsy care requires access to services outside the Trust or Health Board: 96% (114/119) of Health Boards and Trusts were able to provide a 12-lead ECG, 61% (73/119) could provide a standard EEG, 16% (19/119) could facilitate commencement of a ketogenic diet, and 10% (12/119) provide a Vagal Nerve Stimulator procedure.**

² First Do No Harm (2020) Independent Medicines and Medical Devices Safety Review

4. 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 is well illustrated by the joint Epilepsy12/OPEN UK annual national conferences held since 2018, at which many fabulous projects and ideas are shared from across the UK. In 2020 this was held virtually for the first time. This brought the sector together to reflect on what Epilepsy12 findings mean for epilepsy care; learn from their peers' experience of delivering quality improvement projects as part of the RCPCH Epilepsy Quality Improvement Programme (EQIP); hear from the Youth Advocates' who have been working with services to improve patient support for worries and anxieties; and for the BPNA and OPEN UK to reflect on their work in 2020 and future plans.

OPEN UK are working with the RCPCH to set out a strategic vision of how paediatric epilepsy regional networks could be commissioned, resourced and structured by NHS England to support improvements in the quality of care for children with epilepsies in line with the commitments to long term conditions set of by NHS England in the Long Term Plan (published in January 2019). The vision that we have set out is one which we feel could be applied to paediatric epilepsy services across the whole of the UK. OPEN UK will also engage with departments of health in Northern Ireland, Scotland and Wales in conjunction with the BPNA and RCPCH to promote it.

Understandably, with NHS England stretched to capacity responding to the COVID-19 pandemic, implementation of the commitments set out in the Long-Term Plan have very much slowed. Members of the OPEN UK Working Group remain available to work alongside colleagues in the NHS England Children and Young People's Transformation Team to deliver on their vision of resourcing paediatric epilepsy networks drive improvements in the quality of patient care.

The OPEN UK Working Group meetings have provided a forum for epilepsy services to share how they have been responding to the pandemic, and how their services were re-structured to maintain patient care with fewer face-to-face interactions and - at times - limited access to vital diagnostic investigations. Across the country new technologies were rapidly implanted, with significant confidentiality and safeguarding risks needing careful management. The Working Group saw that despite the limitations of remote clinics, some of the changes proved to be both effective and appreciated by families. A renewal of the focus on ensuring a national strategy, including adequate resourcing and support for robust clinical networks, for paediatric epilepsy, will doubtless be shaped in many ways by the experience of providing care throughout the pandemic with the priority being, as was the case before the pandemic, providing the best possible care for children and young people with epilepsies and their families.

In 2021 the networks and OPEN UK Working Group will focus on:

- Improving access to technologies and tools that provide more integrated, responsive care for children and families,
- Helping departments of health to progress a national paediatric epilepsy strategy, working towards robust clinical networks and stronger care pathways for mental health, tertiary care and epilepsy surgeries,
- Providing a forum for quality improvement, rapid sharing of effective practices, and collaboration across the country.

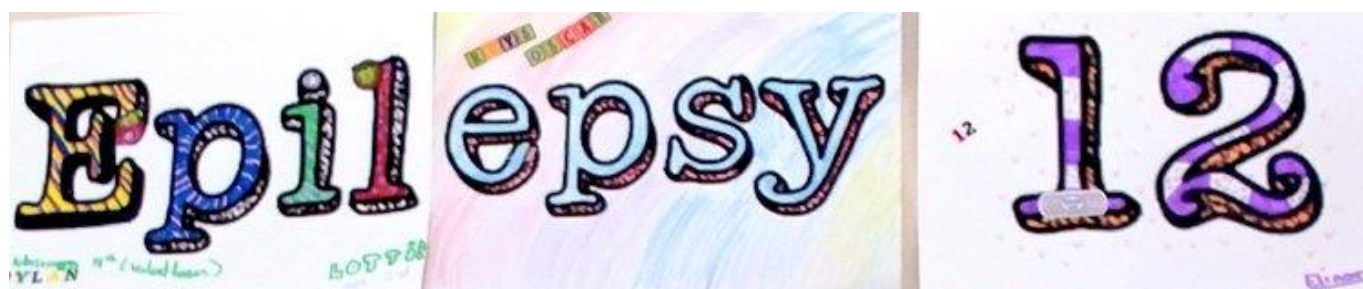
OPEN UK previously highlighted the need for co-located mental health support within epilepsy teams, which was included in the April 2019 iteration of the NHS England Best Practice Tariff for Paediatric Epilepsy. We join the Epilepsy12 Project Board and the Youth Advocates in calling for more psychological support and mental health services for children and young people with long term conditions. The benefits of co-located mental health provision are well recognised however greater resourcing is required to translate this best practice standard into properly commissioned mental health screening and psychology support 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
	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

5. Epilepsy12 Youth Advocate Clinic Chat Checklist: 2020-2021 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 or interested children, young people and families with two epilepsy specialist nurses with support from RCPCH. They volunteer together to improve care for epilepsy patients and their families.

Based on research conducted in 2018, children and young people wanted more support in helping anxieties and worries. In 2019 the Epilepsy12 Youth Advocates designed a self-assessment tool, a Clinic Chat Check List for paediatric epilepsy services, to help them think about what makes “gold standard” support for patients’ worries and anxieties. For more about the Clinic Chat Check List findings please also see the [Epilepsy12 2020 combined report](#).

Virtual Visits

In 2020 we started with the next stage of the Clinic Chat Check List which involved visiting each of the eight clinics that were part of our project. Due to COVID-19 the visits were moved from physical visits to being virtual. The visits concentrated on:

- What was going well,
- Ideas for change,
- How COVID-19 impacted services.

Between December 2020 and January 2021, the Epilepsy12 Youth Advocates ‘virtually’ visited six out of the eight clinics who completed the Clinic Chat Check List. Before the visit, they asked each clinic to send a short film to introduce their team and to show them around the clinic. The films provided an insight into the clinics and teams. The Epilepsy12 Youth Advocates liked:

- How clinics showed them around the physical space with some focusing on what children and young people would see when they come in for their appointment,
- Clinics’ focus on explaining what would happen i.e. having their height and weight measured, EEG’s and meeting their consultant,
- Clinics showing the waiting spaces for children and older young people and consultation rooms,
- That all the clinics introduced many members of the team and explained their roles.

Who was involved?

During their visits the Epilepsy12 Youth Advocates met:

2 Clinical Directors

7 Paediatrician Consultant

6 Epilepsy Specialist Nurse

1 Learning Disabilities Epilepsy Specialist

1 Neurologist

1 Transition Epilepsy Specialist Nurse

1 Consultant Nurse (Children's Rights)

#Voicematters

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

As the visits were virtual, this enabled more members of the epilepsy team to be involved in the visits. It was great to meet with different members of the team including Clinical Directors. The conversations offered an opportunity for teams to think about what they were proud of and consider plans for the future.

The Epilepsy12 Youth Advocates were pleased that clinics improved their scores between their visit and completing the Clinic Chat Check List in 2019 due to the work that they had achieved over the last year.

What award you would give your epilepsy service for "Helping patients and their families who need support with worries and anxieties linked to their epilepsy?"

Before the visit	After the visits
1 clinic didn't grade themselves	3 clinics considered themselves to be bronze - we are doing some things really well
4 clinics considered themselves to be bronze - we are doing some things really well	2 clinics considered themselves to be silver - we are doing most things really well
3 clinics considered themselves to be silver - we are doing most things really well	3 clinic considered themselves to be gold - we are doing lots of things really well or some things AMAZINGLY!

#Voicematters

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

What did we learn?

Epilepsy services gave great examples of a range of activities they were doing to support patients with anxieties and worries. The Epilepsy12 Youth Advocates heard more detail about what clinics were currently doing and what their plans were for the future.

Some examples that stood out included:

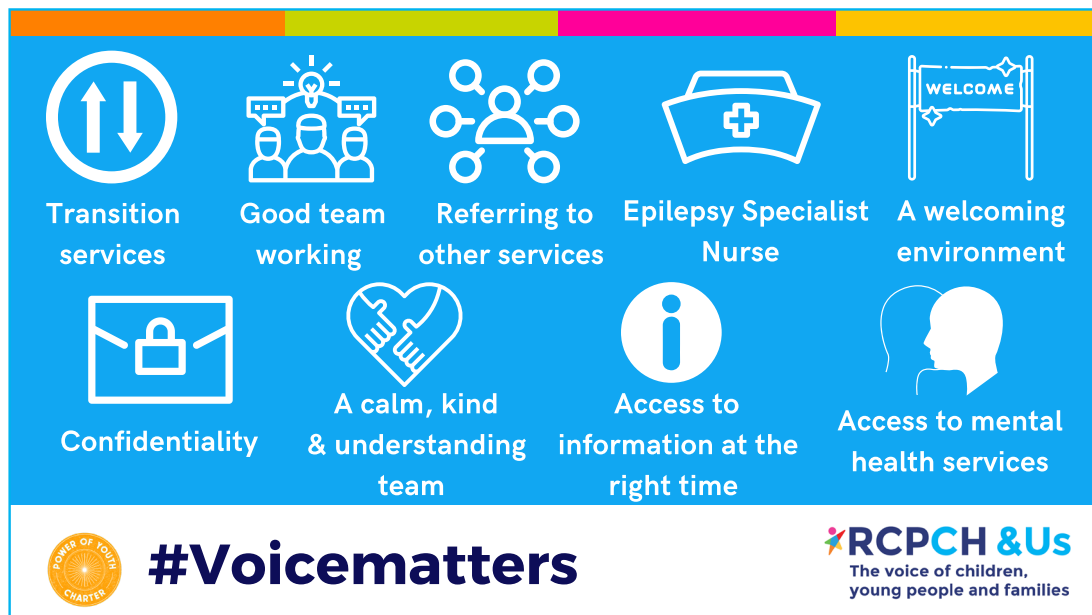
- An A&E referral form which includes a tick box to say they have given the patient information leaflets,
- Using the 'Ready, Steady, Go' transition programme and embedding the 'Go' section into adult services,
- Neurologists signposting patients to support for anxieties and worries. A future idea could be that they become an ambassador for mental health and be supported to provide mental health signposting information to patients,
- ESN-led clinics to support different conversations with patients around anxieties and worries,
- Websites which contain local information and resources,
- Creating information leaflets based on patients' and families' feedback on what they would like to know,
- The ability to be able to access and contact paediatric services for the first 6 months after transition to adult services.

After the visits the Epilepsy12 Youth Advocates said that the things that were important to support with anxieties and worries were:

understanding calm
transition service
additional services
psychology nurse
confidentiality
kind

What makes a 'gold standard' service for anxieties and worries?

After reviewing all the visits, the Epilepsy12 Youth Advocates concluded that a 'gold standard' service for anxieties and worries linked to the patient's epilepsy should contain:



The Epilepsy12 Youth Advocates chose four top things needed to make a ‘gold standard’ clinic which supports patient’s anxieties and worries with their epilepsy:

1. Access to information at the right time,
2. Having an ESN who is easy to contact,
3. Having a calm, kind and understanding team,
4. Access to mental health services.

They created some tips about important points within each theme:

1. Access to information at the right time
 - Having mental health resources patients can access,
 - A clinic website and/or helpline,
 - Formal information/welcome packs.
2. Having an ESN who is easy to contact
 - Being able to contact the ESN at any time through a variety of ways,
 - Home visits, school visits, school training,
 - ESN to meet patients early after diagnosis.
3. Being calm, kind and understanding
 - Listening to children and young people,
 - Asking about mood at every appointment,
 - Time to voice concerns.
4. Access to mental health services
 - Access to mental health services who have knowledge of long-term conditions and how they affect children and young people,

- Information about self-referrals to mental health services,
- Good access to mental health services to support children and young people with other aspects of their lives.

What was important to clinics?

When talking to the clinics, topics that were important to them included:

- Clear information which is accessible and is in helpful formats for patients and families (printed, website and apps),
- Having access to a range of services for mental health and wellbeing,
- Access to epilepsy support groups and national charity information,
- Ensuring clear pathways from A&E and primary care so patients are seen quickly and feel supported,
- Patient involvement in individual care plans and school education plans.

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

- Asking about mood at every appointment and allowing time for patients and families to voice concerns,
- Clear information about self-referral pathways to mental health services and to actively promote them,
- Starting to talk about transition early (12 + years).

Might need a bit more time and planning

- Developing good relationships with A&E to offer support and quick referrals to clinics,
- Having the ability to access children's services for the first 6 months after transition to adult services,
- Ensuring the opportunity for being referred to a variety of mental health services,
- Having a structured transition programme,
- Meeting the adult team & ESN before transition.

After the completion of the Clinic Chat Check List project the Epilepsy12 Youth Advocates said:

“All the clinics’ approaches were different, but they all had good attitudes and care about patients.”

“It felt nice to give good feedback to clinics. Communication worked both ways.”

“The clinics work so hard. I think they were quite modest. I liked their ‘can do’ attitude.”

“Before the visits I was worried they might talk in ways I wouldn’t understand, so it was great that we talked the same language.”

They summed up the visits with the following words:



What happens next?

The Epilepsy12 Youth Advocates will provide each clinic with a summary of their visit on what we learnt and ideas for the future before creating a report and film which can be shared with all Epilepsy12 clinics about our findings. We aim for the Clinic Chat Check List to be made available so that many more clinics can benefit from using it. We plan to use the information gathered to create new projects to improve care for epilepsy patients and their families.

Newsflash... COVID-19

The COVID-19 pandemic has had a huge impact on everyone. During the support with worries and anxieties project virtual visits, the Epilepsy12 Youth Advocates wanted to see how clinics were coping with changes due to COVID-19. All clinics expressed that it has been a challenging time but were able to recognise many similar positives.

Clinics highlighted the following positives:

- Clinics had to adapt and adapt quickly. This supported service redesign in action,
- Clinics were proud that they have met the challenge and worked as a team. They have done amazingly well!
- It has enabled clinics to use new technology such as 'Attend Anywhere' and telephone appointments,
- Technology has supported families to send video of seizures to support diagnostics. Parents have become more confident in capturing seizures on film and sending them in,
- Clinics have had 100% attendance using phone appointments. Parents have said they like that their child wasn't missing as much school or missing work themselves,
- Phoning helped with "did not attends" and created opportunities to talk about medication and compliance,
- It has provided quicker and more effective relationships with schools in delivering training without

travel time or costs,

- Some EEGs were easier, when the adult services stopped in the first wave, as the waiting list was much shorter,
- Clinic ESN had spoken to every new patient,
- Clinics have still had face to face appointments where needed. They used risk assessments and COVID-19 procedures. It was important that families felt safe but still had the option to have face-to-face appointments.

The clinics also identified some difficulties that COVID-19 presented:

- Face-to-face, there was no substitute to seeing a patient,
- Clinics commented that 'you don't get the same input with young people and can't read the room as well',
- Clinics missed talking to young people,
- Breaking bad news is difficult through a phone or video appointment,
- Clinics missed having toys in the waiting room.

What was important to clinics in the future?

- Focusing on creating a recovery plan which allows clinics to keep the positives,
- Time to embed changes and to see what works long term,
- Returning to face-to-face, though clinics said they might continue with blended appointments,
- Clinics wanted to think about and explore other ways to see patients with disabilities online,
- Catching up on missed tests,
- Sometimes clinics noticed that young people weren't part of the consultation (made worse with telephone appointments). Clinics want to ensure they are encouraging young people to speak to them.

RCPCH &Us have done lots of work with children and young people about their COVID-19 experiences including:

- Over 100,000 views shared from under 25s about life in lockdown. You can read these at <https://www.rcpch.ac.uk/resources/covid-19-research-studies-children-young-peoples-views>,
- A COVID Book Club Project which included a rep from the Epilepsy12 Youth Advocates, who created priorities for COVID-19 recovery plans. You can see their priorities at www.rcpch.ac.uk/covid-book-club,
- A project looking at supporting mental health in a national crisis which included a rep from the Epilepsy12 Youth Advocates, who created priorities for services going forward. You can see their report at <https://www.rcpch.ac.uk/resources/covid-19-us-views-rcpch-us#supporting-mental-health-in-a-national-crisis>.

Special thanks

We want to thank all the clinics involved in the Clinic Chat Check List!

Contact details to find out more

For more information about the Epilepsy12 Youth Advocates please visit [Epilepsy12 &Us](#) or contact and_us@rcpch.ac.uk.

6. Epilepsy Quality Improvement Programme (EQIP)

RCPCH EQIP

Epilepsy12 quality improvement programme

The EQIP pilot was a quality improvement collaborative which was developed with epilepsy practitioners, ensuring that it best suits the needs of teams providing epilepsy care while also borrowing from a similar model delivered with success in paediatric diabetes in the UK. The programme's aim was to help to build high performing 'service' teams that worked together for continuous improvement in the care of children and young people with epilepsy. The 12 participant teams were given the training and tools to successfully develop their service to deliver highly person-centred care and sustained improvement in clinical outcomes for children, young people and their families.

Training facilitators of the programme supported the teams in designing, implementing and monitoring their projects via two-day residential training, access to online resources and monthly support calls. Ultimately, the programme sought to support all members of the teams to feel empowered to make changes, to gain leadership skills, and to spread improvement ideas in their networks.

During the programme the teams faced many challenges during the COVID-19 pandemic. However, the 'EQIP champions', nominated by each team, were very impressive and determined to continue their participation; working with their team locally, attending the monthly programme calls, and sharing their teams' progress. It was inspiring to witness the time and energy that the participant teams put into their projects - despite the limited time, resources, and capacity challenges that teams faced. Month by month the teams shared their journeys within the collaborative, learning and achieving together.

A learning and celebratory event for the end of the pilot programme was rescheduled and hosted online on Thursday 16 July 2020. Each of the 12 teams were able to come together with their peers and with colleagues from their Trusts and Health Boards. Teams showcased their completed improvement projects and reflected on their journey, sharing their lessons learnt and successes. We are very proud of all the teams sustaining their QI projects through such difficult times and feel truly inspired by their commitment.

EQIP teams and their project aims

Project Summary	EQIP team
Achieving 90% of all 14-16 year old children and young people with epilepsy being sent 'Ready, Steady, Go' forms.	Aneurin Bevan University Health Board
Accessing the patient voice to influence improvements in cross-site epilepsy care for patients and families that attend the epilepsy services.	Chelsea and Westminster Hospitals NHS Foundation Trust
Achieving 50% of patients and their families being signposted with Information Packs about their epilepsy service.	Doncaster and Bassetlaw Teaching Hospitals NHS Foundation Trust
Obtaining feedback from patient/families seen in tertiary epilepsy clinics, regarding the appropriateness of the time interval between follow up and appointments.	Guy's and St Thomas' NHS Foundation Trust
Developing an integrated care pathway for children and young people admitted with seizures.	Luton and Dunstable University Hospital NHS Foundation Trust
Improving patient experience in outpatient MDT ketogenic diet clinics.	Manchester University Hospitals NHS Trust
To achieve quality routine EEG recordings in 95% of all paediatric patients referred within four weeks from referral.	Nottingham University Hospitals NHS Trust
Children and young people presenting in A+E with a first seizure provided with telephone contact from an Epilepsy Nurse within two weeks of presentation.	Royal Berkshire NHS Foundation Trust
Developing and implementing a pathway for patients with first seizure events; and ensuring patients are reviewed by paediatricians with special interest in epilepsy.	Royal United Hospitals Bath NHS Foundation Trust
Implementing an ongoing feedback loop with patients and their families with the aim of establishing a feedback forum.	Southport and Ormskirk Hospital NHS Trust
To obtain feedback on how the epilepsy service can support their wellbeing from 50% of children aged 12-16 years with a diagnosis of epilepsy attending their review clinic.	South Tees Hospitals NHS Foundation Trust
Improving epilepsy information on electronic records including emergency health care plans becoming more easily accessible via an electronic record.	York Teaching Hospitals NHS Foundation Trust

A supplement detailing the pilot aims, activities and outcomes is planned for later in 2021. Further information can be found online at www.rcpch.ac.uk/eqip

Quality improvement in response to COVID-19

During the monthly support calls, the teams discussed the impact of COVID-19 on their paediatric epilepsy services. They described their responses and new processes for challenges with changes to contact with patients, team members' re-deployment, and changes to work shift patterns. Within the initial phases of the pandemic, there was a significant drop of referrals from emergency care and general practice to paediatric epilepsy services. The use of technology made a big impact with how teams now communicate with other members of staff, as well as with patients and their families.

The social distance restrictions have led to teams experiencing changes that may become permanent and have, in some cases, introduced new ways of engaging previously 'hard to reach' children, young people and families.

The main areas discussed that teams found challenging were the following:

- Staffing and team availability,
- Use of virtual/video clinics and telephone clinics,
- Staff meetings taking place using technology and connecting with those working from home,
- Alternative communication methods,
- Processing and prioritising EEG referrals.

Royal Berkshire Hospital NHS Trust Foundation shared their experience responding to such challenges:

"The current pandemic has affected our work as an epilepsy service in a number of ways, although within that has also demonstrated opportunities and ideas of how we can grow as a service. The direct effect of the current descaling of services from late March 2020 onwards has led to the following:

- Cancellation of face to face outpatient clinic appointments,
- Inability for members of the team to have regular communications (particularly face to face),
- Restriction in supplementary investigations apart from in exceptional circumstances, e.g. EEG, blood tests and MRI brain, reduction in genetic lab testing,
- Restrictions to participation in audits and QI projects already in place (including EQIP).

It has forced us to make conscious changes to how we operate - the use of technology not previously relied on has become more prominent - the use of video consultation platforms has been a primary change. This has been used for various purposes - patient contact, team meetings, neurology outreach clinics.

Whilst not without technical difficulties, at times we have found that it has been a positive experience in being able to reach out to patients and families. In being able to see patients and speak to them, we were able to have better interactions than having none or even having telephone consultations. Even from an examination perspective, there was some value in using the video interface. From a service provision perspective, it opens up opportunities for

expanding our service. We are now considering possibilities of ad-hoc consultations and evening clinics (e.g. for teenagers with epilepsy).

We have had to take a pragmatic approach given COVID-19 restrictions when having to assess new patients, without access to investigations and/or direct patient contact, and in some cases had to make diagnostic and treatment decisions. We have endeavoured to highlight these in our consultations with patients and their families while discussing management plans and this generally has gone well.

This could also have a lasting effect in terms of how we manage patients with epilepsy, immediate feedback is that the patient experience is maintained or enhanced with video consultations although we will look to better capture this with more qualitative feedback to see how well we are doing and where things could be improved.”

Dr Ahmed Aldouri, Consultant Paediatrician, Royal Berkshire Hospital NHS Trust Foundation
For more information on services’ responses during the COVID-19 pandemic, please visit www.rcpch.ac.uk/eqip

We would like to take this opportunity to congratulate the first EQIP pioneers who successfully completed this pilot programme and wish them well with future quality improvement.



Congratulations on completing the EQIP

7. Worcester Acute Hospitals Trust: using Epilepsy12 to drive service improvements

Presented by:

Dr Andrew Gallagher, Consultant Paediatrician

Ms Cheryl Byrd, ESN

Ms Erica Brotherton, Secretary

Ms Lydia Collins, clinical scientist neurophysiology

Ms Kelly Bill, clinical scientist neurophysiology

Background



Worcestershire has a population of approximately 600,000 people with 130,000 aged 18 years or under. We have a single Inpatient Unit and neurophysiology in Worcester, with epilepsy clinics on three hospital sites around the county. The paediatric epilepsy team consists of one and a half consultants, a part time epilepsy nurse, plus much valued secretarial support. We are well supported by neurophysiology, adult neurology and our local tertiary and the Epilepsy Surgery Centre at Birmingham Children's Hospital.

Children with epilepsy in the pre-school years and those children in mainstream school are managed by the acute Trust, while children with a special school placement are managed by the community paediatric team with many appointments taking place within school. There are around 300 patients attending the epilepsy clinics in the acute trust with approximately three new referrals each week.

The Epilepsy12 2018 organisational audit report, published in January 2019, highlighted several weaknesses in our service and focused on identifying improvements based on the reports' following recommendations:

- **Recommendation 3:** 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 10:** Commissioners, Health Boards and Trusts should ensure that ongoing epilepsy care includes mental health assessment, diagnosis and treatment alongside management of seizures. If paediatric services do not have co-located mental health provision, Commissioners, Health Boards and Trusts should ensure they have action plans towards achieving co-located professionals with mental health competences within epilepsy clinics.
- **Recommendation 12:** Health Boards and Trusts should also 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 referral and handover to appropriate adult services.



County paediatric epilepsy clinics.

What we did and what we achieved

This led to the construction of an action plan with clear goals, time frames and responsibilities. The action plan was monitored through the paediatric directorate and Trust clinical governance structures. We engaged with service managers and other directorates where necessary to unblock the barriers to aid implementation. Agreed targets which were not attained in a timely fashion are placed on the Directorate Risk Register to highlight these both within and without the directorate and to keep them at the forefront of long-term directorate planning.

Targets in our first action plan included improving service 'contact-ability' with a dedicated email address and a promise to return calls within three working days. We have subsequently audited service 'contact-ability' and we have achieved very high levels of patient satisfaction. Auditing processes involved achieving high levels of patient satisfaction by incorporating the help of our secretary to send out 50 questionnaires, plus stamped return envelopes, randomly to patients and we collated the results via our epilepsy database.

Not the most scientific study ever but it was able to confirm what we thought we already knew. As a consequence of patients knowing we will respond quickly by phone/email, we found we can reduce the number of patients seen in clinic, leaving space to offer speedier appointments to see new patients or urgent face-to-face reviews of existing patients. We have identified the need for a second consultant with an epilepsy interest and a second epilepsy specialist nurse. This remains on our action plan as it has not been achieved and has been escalated accordingly.

We continue to work towards achieving this goal and it has been agreed that we will be appointing two new consultant posts this year, so we move from 12 to 14 acute consultants. Additionally, it has also been agreed that one of these will be an epilepsy post and we have an ST8 with relevant SPIN training very interested in joining our service, so fingers crossed. In terms of the epilepsy specialist nurse, the 2019 Epilepsy12 organisational audit, reported '*All Health Boards and Trusts should employ sufficient ESNs to ensure at least 1 WTE ESN for every 250 children with epilepsy*'. This was helpful, because our database show we are about 0.8 WTE per 275 patients at present, but this has not progressed further yet.

It will be difficult to achieve as we would need to demonstrate a substantial need to get funding agreed;

if it were a Best Practice Tariff criterion maybe we could make a stronger case. We do plan an epilepsy liaison post on the children's ward for one of the band 6 nurses. This should help with aspects like referrals, medication training, and documentation.

The subsequent Epilepsy12 organisational audit and the results of patient data from the cohort 1 clinical audit, published in September 2020, added new goals to our action plan. The patients' first paediatric assessment for cohort 1 were entered between July and November 2018. Their first year of care patient data was entered until November 2019. The clinical audit met with mixed reactions! We were proud of some of our achievements but disappointed with some of the clinical data. It was clear that there were some gaps in our service that we had not recognised, for example low ECG rates in children with convulsive seizures and long EEG waiting times.

We are now focusing on trying to see new patients within two weeks, this is usually by phone or video consultation and we ask parents to send videos to our dedicated email address. Often, we will request an EEG at this stage. The patient's first EEG is highlighted with a bright sticker to ensure that they are completed within a month of request. Our neurophysiology department has agreed to champion this goal. In addition, if the child has had a convulsive seizure neurophysiology will ensure a 12-lead ECG is completed at the same visit.

As part of discussions to ensure timely EEGs we have started including print outs of abnormalities seen on EEG along with the formal reports. We find that it is very powerful for children and their families to see their own spike wave discharge or centrotemporal spikes which helps with gaining a better understanding of the child's epilepsy. As part of these discussions and being presented with raw EEG data, we have established regular EEG meetings where cases are discussed. These meetings include epilepsy clinicians from our community Trust, which further aids joint working and management of complex patients.

Cohort 1 data led us to consider whether there is a treatment gap where children who could benefit from tertiary centre input are not being referred appropriately. We appear to be referring patients who meet surgery criteria but perhaps not all those where paediatric neurology input is recommended. We found that in practice many of the cases had been discussed with neurology informally or via email, which was not captured in the audit data unless it had led to a formal referral. We reflected that these informal contacts were often sufficient, particularly where the purpose of further input was not clear. For instance, it is questionable whether an infant with well-controlled epilepsy with a known genetic basis needs paediatric neurology input, for example patients with benign focal epilepsy of infancy and PRRT2 mutations.

Like many units we are struggling to achieve formal mental health screening and input. We are looking at increasing the use of mental health and neurodevelopmental screening questionnaires; and we have implemented education information forms to aid communication with schools. The Trust is also scoping psychology services and we are hoping for some dedicated psychology time to follow.

Based on the organisational report, recommendation 12, we interpreted this to mean we should explore establishing a teenager clinic. We currently have specific epilepsy clinics for children and young people of all ages and a transition clinic that includes adult neurology service team. We plan to start the Teenager Epilepsy Clinic when COVID-19 restrictions allow. This will be held in the late afternoon to avoid loss of school-time. Teenagers and their families would be invited to attend in a dedicated clinic area to meet for tea and cakes, so that young people and their families can meet others in the same situation. We will then see the teenagers individually as per a normal clinic.

Lessons learnt and top tips

We have found that by focusing on small improvements and ensuring that these happen and remain embedded within the service, patient satisfaction and job satisfaction for professionals has increased. In addition, we felt the following may also be helpful tips based on our QI experience:

1. Phone parents as soon as you get a referral, take a history, obtain videos, decide if there is enough to warrant EEG or ECG – if so, arrange it there and then, provide contact details.
2. Show children, young people and their families their own EEG print out and scans (if abnormal); a picture is worth a thousand words.
3. Develop and maintain an epilepsy database, this can be a simple spreadsheet.
4. Make Epilepsy12 work for you and your patients. Trusts should be asking for and expecting action plans from directorates and helping us to agree and achieve our targets (make them “SMART”). If we cannot achieve actions due to lack of staff or resources, it needs to be escalated to clinical directors, managers, Trust/Health Board clinical governance divisions, children and young people boards, commissioners etc.
5. Ask for videos to be shared and make this part of the clinical record, stress the usefulness of this to parents when there is diagnostic uncertainty.
6. Meet with EEG colleagues and discuss patient cases; they value hearing about scan findings, genetics, and responses to treatment. You get a more responsive service.

Special thanks

None of this could have been achieved without the continued support and enthusiasm we have experienced from Birmingham Children’s Hospital, Neurophysiology and the Adult Neurology Service locally.

<p><u>Epilepsy Service Survey Results;</u></p> <p><u>We had 28 patients respond to the survey – below are the responses</u></p> <p>How satisfied are you with how quickly we respond to you when you contact our service?</p> <p>10 being great. 1 being poor</p> <table border="1"> <tr> <td>1 <small>(poor)</small></td> <td>2</td> <td>3</td> <td>4</td> <td>5</td> <td>6</td> <td>7</td> <td>8</td> <td>9</td> <td>10 <small>(great)</small></td> </tr> <tr> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td>3</td> <td>1</td> <td>1</td> <td>23</td> </tr> </table> <p>23 out of 28 patients agree that our service response is great!</p> <p>1 out of 28 are a 9 for response.</p> <p>1 out of 28 are a 8 for response.</p> <p>3 out of 28 are 7 for response.</p> <p>How quickly do you feel we respond to you when you contact our service?</p> <table border="1"> <tr> <td>1-2 days</td> <td>2-3 days</td> <td>3-4 days</td> <td>5 days +</td> </tr> <tr> <td>20</td> <td>6</td> <td>2</td> <td></td> </tr> </table> <p>20 out of 28 patients feel we responds in 1-2 days – many commenting it is usually on the same day.</p> <p>6 out 28 within 2-3 days.</p> <p>2 out of 28 within 3-4 days.</p> <p>Do you feel you our service would benefit from offering more psychological support for children and families?</p> <table border="1"> <tr> <td>YES</td> <td>19</td> <td>NO</td> <td>1</td> <td>Not sure</td> <td>8</td> </tr> </table>		1 <small>(poor)</small>	2	3	4	5	6	7	8	9	10 <small>(great)</small>							3	1	1	23	1-2 days	2-3 days	3-4 days	5 days +	20	6	2		YES	19	NO	1	Not sure	8	<p>1 out of 28 did not feel they needed support</p> <p>8 out of 28 were not sure as they did not know what it was all about.</p> <p><u>What do we do well?</u></p> <p><u>What can we improve?</u></p>
1 <small>(poor)</small>	2	3	4	5	6	7	8	9	10 <small>(great)</small>																											
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20	6	2																																		
YES	19	NO	1	Not sure	8																															

Responses received from the 50 stamped addressed envelope questionnaires sent to patients and their families to feedback on service ‘contactability’.

<p style="text-align: center;">DEPARTMENT OF PAEDIATRICS EPILEPSY SERVICE</p> <p style="text-align: center;">SCHOOL COMMUNICATION FORM</p> <p>Dear Education</p> <p>Please could you complete this form and either return the form to the child's family to bring to their next clinic appointment or email your responses to If you email this address we can send an electronic copy out for you to complete. The epilepsy team would like to understand the child's educational progress and any concerns the school may have.</p> <p>Child's Name Date of Birth</p> <p>Nursery/School attended</p> <p>School Year.....</p> <p>Please comment on</p> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td style="height: 20px;">General health</td></tr> <tr><td style="height: 20px;">Physical abilities</td></tr> <tr><td style="height: 20px;">Learning</td></tr> <tr><td style="height: 20px;">Behaviour</td></tr> <tr><td style="height: 20px;">Mood/coping</td></tr> <tr><td style="height: 20px;">Other</td></tr> <tr><td style="height: 20px;">Attendance</td></tr> </table>	General health	Physical abilities	Learning	Behaviour	Mood/coping	Other	Attendance	<p>What support, if required, is in place for the child? </p> <p>Does the child have an EHCP? </p> <p>Does the Child have an ICP? </p> <p>Name of any other professionals involved with educational support (eg educational psychologist or physical disability outreach team)</p> <p>Name</p> <p>Name</p> <p>Name of person completing form</p> <p style="text-align: center;"><i>Thank you for completing this questionnaire and returning. This information will be kept confidentially in your child's hospital notes.</i></p>
General health								
Physical abilities								
Learning								
Behaviour								
Mood/coping								
Other								
Attendance								

Example of the template of the school communication form.

8. Summary of recommendations

Mental health	
Recommendations	<ol style="list-style-type: none"> Health Board and Trust managers should ensure that: <ul style="list-style-type: none"> All children and young people with epilepsy are provided with psychosocial support and signposting to help them manage their condition and their related worries or anxieties, and All children and young people with epilepsy have ongoing screening for mental health problems using a validated tool as part of their routine epilepsy care. Where there are concerns about mental health, children and young people are referred to an appropriate mental health service via an agreed pathway. There should be timely access to diagnosis and treatment. Hospital and community commissioners should commission increased integrated psychosocial and mental health support for children and young people receiving care for long-term conditions. This should be co-located within the epilepsy clinic, and inclusive of co-morbidities.
Source	<p>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 priority areas.</p> <p>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.</p> <p>NICE Clinical Guideline 137 states that children and young people 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.</p>
Epilepsy12 Key finding(s)	<p>17% (20/119) of Health Boards and Trusts have formal screening for mental health disorders.</p> <p>68% (1435/2106) of children aged three years and over with epilepsy had evidence that emotional or behavioural problems were considered during their first assessment.</p> <p>5% (68/1358) of children and young people between the age of 5-15 years and diagnosed with epilepsy had an identified mental health condition. Few children with epilepsy had mental health input into their care: clinical psychologist (2%, 41/2106), psychiatrist (<1%, 7/2106), educational psychologist (1%, 15/2106) or other mental health professional (1%, 22/2106).</p> <p>36% (43/119) of Health Boards and Trusts did not have agreed referral pathways for children with mental health conditions.</p> <p>7% (8/119) of Health Boards and Trusts could not refer to mental health assessment services, either in or outside of their Health Board or Trust.</p> <p>15% (18/119) of Health Boards' and Trusts' mental health provision is within epilepsy clinics. Only 11% (11/101) of others indicated they had an action plan towards co-located mental health provision.</p>
Target audience(s)	<p>Health Board and Trust managers, epilepsy clinical leads, and hospital and community commissioners.</p>

Care Planning	
Recommendations	<p>3. All Health Board and Trust managers and epilepsy clinical teams should implement standardised approaches to epilepsy care planning content provision to ensure that essential elements of care are always provided for all children and young people with epilepsy and these are reviewed on an ongoing basis.</p> <p>4. Health Board and Trust managers, epilepsy clinical teams, school head teachers, and school nurses should agree processes to facilitate appropriate, up-to-date health care planning within education and two-way information sharing.</p>
Source	<p>NICE Quality Standard 27 (statement 4) states that children and young people with epilepsy have an agreed and comprehensive care plan.</p> <p>NICE Quality Standard 27 (statement 6) states that children and young people with a history of prolonged or repeated seizures have an agreed, written emergency care plan.</p> <p>NICE Clinical Guideline 137 states that children, young people 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.</p> <p>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.</p>
Epilepsy12 Key findings	<p>65% (1379/2106) of children and young people diagnosed with epilepsy had evidence of an updated and agreed comprehensive care plan.</p> <p>There was evidence of involvement of the child, young person, or their family/carer in 76% (1606/2106) of care plans.</p> <p>80% (1681/2106) of care plans included discussion of water safety and 81% (1697/2106) had evidence of discussion regarding general participation and risks.</p> <p>32% (455/1402) of school-aged children and young people with epilepsy were identified as having a school Individual Healthcare Plan.</p> <p>43% (915/2106) of children and young people diagnosed with epilepsy (or their parent/carer) had evidence that information on Sudden Unexpected Death in Epilepsy (SUDEP) had been provided.</p>
Target audience(s)	Health Board and Trust managers, epilepsy clinical teams, school head teachers, and school nurses.

Sustainable paediatric epilepsy care	
Recommendations	<p>5. Epilepsy services should be supported by their Trust or Health Board's management and the commissioning organisations to:</p> <ul style="list-style-type: none"> • Develop a defined epilepsy team approach to service provision and service improvement. • Allocate time within job plans to support team functions including dedicated time for audit participation and related quality improvement actions. <p>6. Hospital commissioners, NHS Regional Offices, Regional Partnership Boards, NHS England and NHS Wales should ensure that there is capacity to provide timely access to necessary epilepsy investigations (such as EEG, ECG, MRI and CT), so that children and young people are not disadvantaged by the variation in availability of diagnostic services between Health Boards and Trusts.</p>
Source	<p>NICE Quality Standard 27 (statement 2) states that children and young people having initial investigations for epilepsy undergo the tests within 4 weeks of being requested.</p> <p>NICE Quality Standard 27 (Statement 3) states that children and young people who meet the criteria for neuroimaging for epilepsy should have magnetic resonance imaging (MRI).</p> <p>Current British Paediatric Neurology Association (BPNA) PET teaching curriculum, states that all children with a convulsive seizure should have a 12-lead ECG.</p>
Epilepsy12 Key finding(s)	<p>71% (103/145) 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 2; compared to 76% (113/149) in cohort 1.</p> <p>There was a decrease in clinical 'data completeness' for cohort 2 (61%, 6177/10181) compared to cohort 1 (71%, 3318/4684). This is the proportion of patients registered into a cohort whose first year of care record was completed and submitted.</p> <p>82% (119 out of 145) registered Health Boards and Trusts completed and submitted the November 2020 organisational audit data, compared to 94% (136/145) in 2019.</p> <p>53% (1117/2106) of children and young people diagnosed with epilepsy, obtained an EEG within four weeks of request.</p> <p>Variation in available services: 61% (73/119) of Trusts and Health Boards could provide a standard EEG within their location; 96% (114/119) could provide a 12-lead ECG; 94% (112/119) an 'awake' MRI or 63% (75/119) 'with sedation'; and 23% (27/119) inpatient video telemetry or 16% (19/119) for home video telemetry.</p>
Target audience(s)	<p>Health Board and Trust managers and hospital commissioners, NHS Regional Offices, Regional Partnership Boards, NHS England and NHS Wales.</p>

Specialist input into care	
Recommendations	<p>7. All Health Board and Trust managers should employ sufficient Epilepsy Specialist Nurses and consultant paediatricians “with expertise” in epilepsy to ensure all children and young people with epilepsy can reliably receive responsive, individualised, specialist input into their care for epilepsy and related concerns, for example, psychological and developmental issues.</p> <p>8. All Health Board and Trust managers and hospital and community commissioners should ensure that adult and paediatric epilepsy teams are resourced to allow, and have time allocated in job plans, for joint transition-related clinical appointments and quality improvement work.</p>
Source	<p>NICE Quality Standard 27 (statement 1) states that children and young people presenting with a suspected seizure are seen by a specialist in the diagnosis and management of the epilepsies within two weeks of presentation.</p> <p>NICE Quality Standard 27 (statement 5) states that children and young people with epilepsy are seen by an epilepsy specialist nurse who they can contact between scheduled reviews.</p> <p>NICE Quality Standard 27 (statement 7) states that children and young people who meet the criteria for referral to a neurologist are seen within four weeks of referral.</p> <p>NICE Clinical Guideline 137 states that children, young people 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.</p>
Epilepsy12 Key finding(s) and comparison to previous findings	<p>78% (1644/2106) of children and young people diagnosed with epilepsy had an input from an ESN. This had been 72% (798/1112) in cohort 1.</p> <p>89% (106/119) of Health Boards and Trusts had some provision of ESNs, an average of 1.3 whole time equivalents (WTEs) per Health Board and Trust. This was an increase from 2019 (1.2 WTEs), 2018 (1.0 WTEs), 2014 (0.6 WTEs), and 2009 (0.5 WTEs).</p> <p>19% (392/2106) of children and young people diagnosed with epilepsy were seen by a paediatrician with expertise in epilepsy within two weeks of first referral in England and Wales. 87% (1830/2106) were seen during their first year of care.</p> <p>97% (116/119) of Health Boards and Trusts employed at least some time of a consultant paediatrician ‘with expertise’ in epilepsy. Health Boards and Trusts employed an average of 2.3 WTE consultants with expertise; increasing from 2.1 WTEs in 2018 and 1.8 WTEs in both 2009 and 2014.</p>
Target audience(s)	Health Board and Trust managers, hospital and community commissioners.

Epilepsy surgery and neurology	
Recommendation	<p>9. OPEN UK regional networks, NHS England, NHS Wales, BPNA, RCPCH, Health Education England and Health Education and Improvement Wales should work together to review the Epilepsy12 findings in their area and ensure there are:</p> <ul style="list-style-type: none"> • Sufficient paediatric neurologists to provide timely assessment and ongoing management. • Robust referral pathways to paediatric neurology such that children and young people are not disadvantaged by the variation in access to specialists between Health Boards and Trusts.
	<p>10. The specialist CESS centres should collectively:</p> <ul style="list-style-type: none"> • Review the referral criteria to ensure these are clear, consistent, and embedded in shared care pathways from secondary care and paediatric neurology, and • Agree a communications strategy to raise awareness of referral criteria and encourage early referral of appropriate children and young people.
Source	NICE Clinical Guideline 137 states that children, young people 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)	<p>21% (447/2106) of children and young people diagnosed with epilepsy had input from a paediatric neurologist.</p> <p>Around half of children and young people who met neurology referral criteria had either paediatric neurologist input or a referral to CESS during their first year of care, 52% (243/463). There were a total of 91.1 WTE consultant paediatric neurologists.</p> <p>5% (107/2106) of the children and young people diagnosed with epilepsy, met one or more of the CESS referral criteria in England and Wales in cohort 2.</p> <p>23% (25/107) of children and young people diagnosed with epilepsy who surgical referral criteria had a referral to CESS for surgical evaluation during their first year of care. This is compared to 30% (27/89) of eligible children and young people in cohort 1.</p>
Target audience(s)	OPEN UK networks, NHS England, NHS Wales, BPNA, RCPCH, Health Education England, specialist CESS centres and Health Education and Improvement Wales.

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.
- **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** qicentral.rcpch.ac.uk/medsiq/
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**
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).
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 are payment incentives designed to encourage best practice care and reduce variation in the quality of care.
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'.
ECC	An electrocardiogram (ECC) 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: <ul style="list-style-type: none"> • 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: <ul style="list-style-type: none"> • training and continuing education in epilepsies • AND peer review of practice • AND regular audit of diagnosis (e.g. participation in Epilepsy12) <p>(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'.</p>
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 found.
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

Combined organisational and clinical audits:
Report for England and Wales Round 3 Cohort 2 (2019-20)

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