EPILEPSY12

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

RCPCHAudits

Epilepsy12 2024 combined organisational and clinical audits:

Report for England and Wales

Cohort 5 – The first year of care for children and young people after a first paediatric assessment between 1 December 2021 and 30 November 2022

HQIP
Healthcare Quality
Improvement Partnership

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

Epilepsy12 Summary Report for 2024 combined organisational and clinical audits

Cohort 5 – The first year of care for children and young people after a first paediatric assessment between 1 December 2021 and 30 November 2022

Epilepsy12, the National Clinical Audit of Seizures and Epilepsies for Children and Young People, 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).

HQIP is led by a consortium of the Academy of Medical Royal Colleges, and the Royal College of Nursing. 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 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. Find out more at www.hqip.org.uk/national-programmes

The RCPCH was awarded the contract to deliver Round 4 of Epilepsy12 from 1 April 2022 to 31 March 2025, having also delivered Rounds 1 to 3 between 2009 and 2021.

Contents

Thank you

The Epilepsyl2 Project Board would like to thank the administrators, clinical audit department staff, data analysts, doctors, nurses and others within participating Health Boards and Trusts. These teams have put time and effort into collecting information and entering data for the audit and are working to improve paediatric epilepsy services during challenging circumstances.

Epilepsy12 structure

The Epilepsy12 Audit works collaboratively with stakeholder organisations and within the RCPCH to deliver the audit programme accurately and efficiently.

Information on the governance structure of Epilepsy12 and the membership of the Project Team, Project Board and Methodology and Dataset Group are available online here.

Front Cover – '**White Butterflies**' is a neurographic artwork by Jeremy Ryan Smith, a mixed-media artist from Illinois, USA, living with epilepsy. Neurographic art allows artists to process complex emotions in a meditative and mindful way. 'White Butterflies' was created as part of his Art Therapy collection.

Introduction

Epilepsy12 was established in 2009 and has the continuing 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.

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 data relating to the delivery of patient care and the organisation of services. This information is used by the audit to highlight areas where services are doing well, and to identify areas for improvement.

There are three main elements within Epilepsy12 which are referred to in this report:

1. **Auditing of the clinical care** provided to children and young people newly diagnosed with epilepsy in 'cohort 5' (find out more here), and the **organisation and structure of epilepsy services** as of November 2023 (find out more here).

2. **Quality improvement** activities and projects related to the audit, including the Epilepsy Quality Improvement Programme (EQIP), a RCPCH Quality Improvement (QI) collaborative for paediatric epilepsy teams. Find out more here.

3. The **Epilepsy12 Youth Advocate** programme, RCPCH &Us - a group of epilepsy experienced or interested children, young people and families volunteering to improve epilepsy care. Find out more here.

This year's annual report, including the appendices, glossary and useful resources can be found here. All current and previous publications from Epilepsy12 are available here. For more information on Epilepsy12 methodology and data collection, please click here.

Organisation of Paediatric Epilepsy Networks in the United Kingdom (OPEN UK)

OPEN UK is a clinical network connecting NHS Health Boards and Trusts that provide care for children with epilepsies with regional epilepsy networks and under the guidance of the OPEN UK Working Group. The group has representation from 17 regional epilepsy networks across the UK and British Paediatric Epilepsy Group. It aims to unite children's regional and national epilepsy networks to improve integrated care for children and young people with epilepsies.

OPEN UK:

- encourages collaboration and sharing of regional and national ideas, pilots, and resources,
- is a national resource and professional UK body to which other organisations may come to for information, support, data and strategic or clinical input,
- facilitates links to local, regional and national funding bodies.

Click here to find out more

NHS England Children and Young People (CYP) Transformation Programme Team

NHS England established an **Epilepsy Oversight Group** in 2021 to help improve epilepsy care for children and young people, as part of the implementation of the NHS Long Term Plan. In October 2023, a National bundle of care for CYP with epilepsy was published, consisting of key standards and recommendations to support systems with epilepsy quality improvement. The Epilepsy Oversight Group uses Epilepsy12 data to identify variation and areas for improvement, and to benchmark and monitor progress at Trust, Integrated Care Board (ICB), NHSE region and national levels.

The bundle of care describes four key areas of focus, informed by analyses of successive Epilepsy12 data:

1. Addressing **variation in care** between epilepsy services
2. Supporting the **mental health and wellbeing** of children and young people with epilepsy
3. Improving referrals into **tertiary services** and the **Children's Epilepsy Surgery Service (CESS)**
4. Improving the **transition** from paediatric to adult epilepsy services.

EPILEPSY12

Results at a glance

Results are from Epilepsy12 Round 4, ‘cohort 5’ which encompasses children and young people who had their first paediatric assessment for a suspected seizure between 1 December 2021 and 30 November 2022.

Prior to the January 2024 deadline, 2212 children and young people with an epilepsy diagnosis had completed first year of care forms submitted and were therefore included in the analysis for this report.

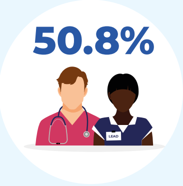
We process data relating to the first 12 months of care for all children and young people within the cohort. There are 10 ‘Key Performance Indicator’ (KPI) measures for the audit which are derived from national guidelines and quality standards.

We have begun to collate results since 2018 to capture longitudinal trends. This is showing improvement in some aspects of care and other areas where progress appears limited. For further information see our new Epilepsy12 Longitudinal Trends Report.

Involvement of appropriate professionals

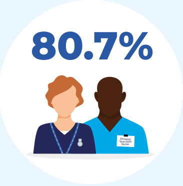
KPI 1 Paediatrician with expertise in epilepsies

50.8% (1123/2212) of children and young people with epilepsy received input by a ‘consultant Paediatrician with expertise in epilepsies’ within two weeks of initial referral.



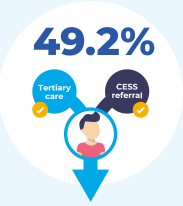
KPI 2 Epilepsy Specialist Nurse

80.7% (1786/2212) of children and young people with epilepsy received input by an Epilepsy Specialist Nurse within the first year of care.



KPI 3a Tertiary input

49.2% (291/592) of children and young people with epilepsy meeting defined criteria for tertiary input received input from a paediatric neurologist or a referral to Children’s Epilepsy Surgery Service (CESS) within the first year of care.



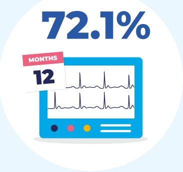
KPI 3b Epilepsy surgery referral

37.3% (41/110) of children and young people with epilepsy who met CESS referral criteria had evidence of a CESS referral.

Appropriate assessment

KPI 4 ECG

72.1% (1036/1436) of children and young people with epilepsy and convulsive seizures had an ECG within the first year of care.



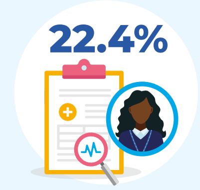
KPI 5 MRI

53.1% (385/725) of children and young people with epilepsy and defined indications for an MRI brain had an MRI brain scan within 6 weeks of request.

Mental health

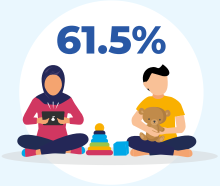
KPI 6 Assessment of mental health issues

22.4% (330/1472) of children and young people with epilepsy had documented evidence that they had been asked about mental health.



KPI 7 Mental health support

61.5% (83/135) of children and young people with epilepsy and a mental health problem had evidence of receiving mental health support.



Care Planning

KPI 8 Sodium Valproate

100% (3/3) of female young people with epilepsy who are 12 years and over and currently on valproate treatment had a risk acknowledgement form completed.

KPI 9a Care planning agreement

80.8% (1787/2212) of children and young people with epilepsy had evidence of care planning agreement.

KPI 9b Care planning content

64.8% (1433/2212) of children and young people with epilepsy had documented evidence of communication regarding core elements of care planning.

KPI 10 School Individual Health Care Plan

38.9% (573/1472) of children and young people with epilepsy aged 5 years and above had evidence of a School Individual Health Care Plan within the first year of care.

Key findings & recommendations

Key message 1: Contributing and participating

Epilepsy12, as the only national programme investigating paediatric epilepsy care, plays an important role in measuring and improving quality of care and outcomes.

We are aiming for all Health Boards and Trusts providing care to children and young people with epilepsy in England and Wales to participate within Epilepsy12, however participation has not improved considerably since cohort 1.

A total of **7314** children and young were registered and verified in cohort 5 (first assessment between 1 December 2021 and 30 November 2022) before the download date.

87.2% (6322/7250) had first year of care forms completed, locked and submitted, and were therefore included in the analysis for this report.

And **2212 out of those 6322 (34.9%**) children and young people had a new diagnosis of epilepsy. Data completeness increased from 71% in cohort 1 to 87% in cohort 5.

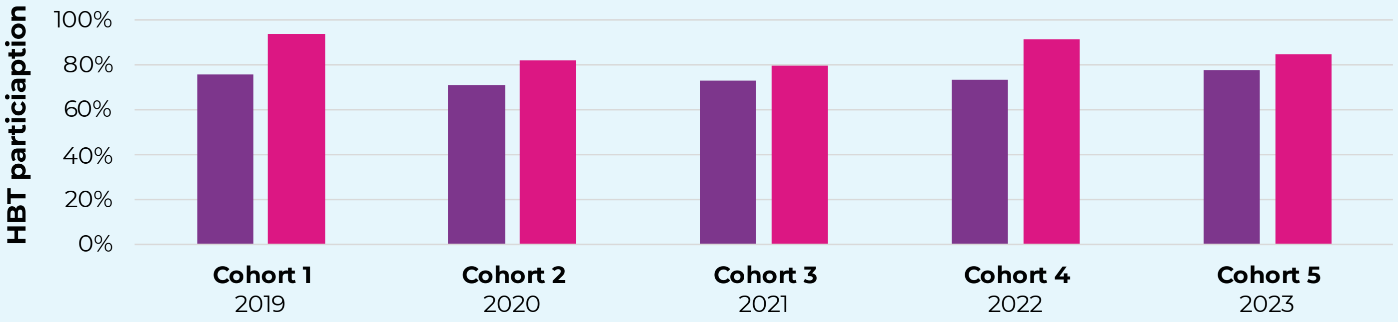


Figure 1 – In England and Wales, percentage of NHS Health Boards and Trusts (HBT) participating in the Epilepsy12 clinical audit between cohort 1 and 5; children and young people having a first assessment between 5 July 2018 and 30 November 2022, and the organisational audit between 2019 and 2023.

138 NHS Health Boards and Trusts providing paediatric epilepsy care in England and Wales are registered onto the Epilepsy12 audit. **Figure 1** displays clinical and organisational audit participation between cohort 1 and 5 (2019 – 2023).

- **78.2% (108/138)** participated in the cohort 5 clinical audit by completing data entry and submitting a first year of care record for at least one child or young person who was eligible for inclusion within the audit. Clinical audit participation has increased compared to 74% for cohort 4.
- **85% (117/138)** submitted organisational data to describe the service as at 1 November 2023. This is a decrease compared to the 91% of Health Boards and Trusts who participated in the 2022 organisational audit.
- In 2024, clinical audit participation ranged from 56% to 100% of Health Boards and Trusts within individual OPEN UK regions, and organisational audit participation ranged from 67% to 100%.
- Overall, Epilepsy12 data submission numbers have remained constant over time, and there have not been sustained improvements in clinical and organisational audit participation rates.

Recommendation 1

Support Epilepsy teams not yet participating in the audit to value, contribute and improve together through Epilepsy12 participation. This might be through promotion of the audit, training, workforce and team development, job planning or identifying and solving specific local barriers. ICBs should identify supporting routes and engage with quality improvement programmes, such as the Epilepsy Quality Improvement Programme (EQIP), managed by the RCPCH, to assess quality of care and provision within those services not yet participating.

Action by: Integrated Care Boards (ICBs) in England and local Health Boards in Wales, in collaboration with OPEN UK regional networks.

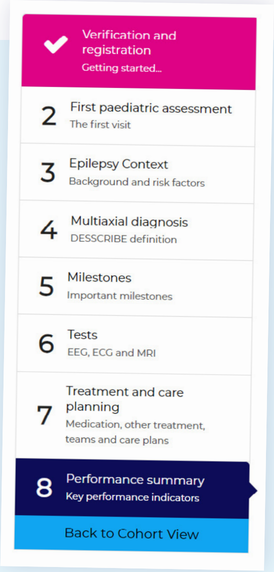
Epilepsy12 data collection and reporting

New data capture platform

Epilepsy12 launched a new platform in December 2023 to collect and report audit data. The novel system streamlines data entry and has features which support benchmarking, catalyse service improvement and minimise both data entry errors and potential gaps in patient care.

More frequent, public facing reporting

An interactive accessible dashboard was published in July 2023 to maximise the impact of audit data. The dashboard displays KPI data at Health Board/Trust, ICB, NHSE region, OPEN UK region, country and national levels. Data was initially updated on a quarterly basis, ahead of beginning monthly refreshes in 2024. Access the dashboard here.



Key message 2: Widening and strengthening epilepsy team provision

Epilepsy Specialist Nurses (ESNs) are essential members of epilepsy teams for children and young people, and have extending key responsibilities including care planning, and within this, discussions around Sudden Unexpected Death in Epilepsy (SUDEP), 'service contactability', planning with schools, transition and mental health support.

KPI 2

80.7%

Epilepsy Specialist Nurses

80.7% (1786/2212) of children and young people diagnosed with epilepsy had input from an Epilepsy Specialist Nurse within the first year of care.

Epilepsy Specialist Nurse (ESN) input and provision

80.7% (1786/2212) of children and young people diagnosed with epilepsy had input from an Epilepsy Specialist Nurse (ESN) within the first year of care (**KPI 2**). ESN input has increased gradually over time from 69% in cohort 1, (73%, 76% and 77% in cohorts 2, 3 and 4 respectively).

- Within the 138 Health Boards and Trusts participating in the 2023 organisational audit, the mean whole-time equivalent (WTE) of ESNs within a service was **1.6 WTE**, an increase from 0.5 in 2009.
- **93.2% (109/117)** of Health Boards and Trusts had ESN provision, indicated by having at least some contracted hours of ESN support.

Care planning

Comprehensive care planning for children and young people with epilepsy was routinely undertaken in **91% (106/117)** of participating Health Boards and Trusts.

- **80.8% (1787/2212)** of children and young people with epilepsy had evidence of care planning agreement within the first year of care (**KPI 9a**).
- However, only **64.8% (1433/2212)** of children and young people with epilepsy had documented evidence of communication regarding core elements of care planning within the first year of care (**KPI 9b**). Within this indicator, the proportion with evidence of SUDEP discussions was 66.3%, whereas performance was >90% for all other care planning sub-metrics.

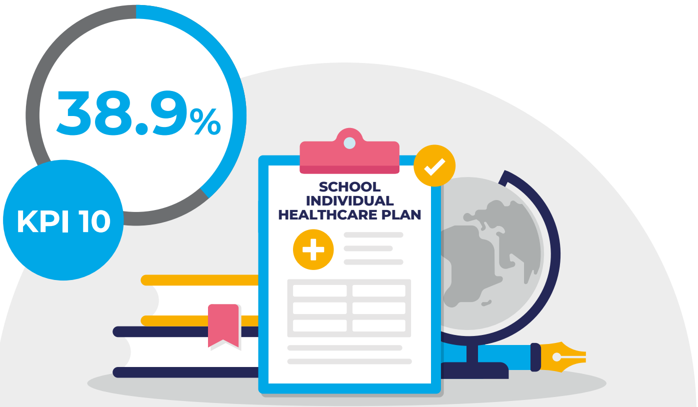
Support in schools

Over **90% (105/117)** of participating Health Boards and Trusts offered ESN support for school meetings and School Individual Health Care Plan (IHP) facilitation.

- However, only **38.9% (573/1472)** of children and young people with epilepsy aged 5 years and above had evidence of a School IHP within the first year of care (**KPI 10**). This indicator was 37% in cohort 4, 36% in cohort 3 and 32% in both cohorts 1 and 2.

Transition from paediatric to adult services

91% (106/117) of participating Health Boards and Trusts indicated having an agreed referral pathway to adult services. **72% (84/117)** used structured transition resources, **56% (65/117)** had outpatient clinics specifically for young people with epilepsy and **68% (80/117)** involved both adult and paediatric professionals in transition services.



School Individual Health Care Plan

38.9% (573/1472) of children and young people diagnosed with epilepsy and aged 5 years and above had evidence of a School Individual Healthcare Plan by their first year of care.

Recommendation 2

Increase the scope and breadth of the epilepsy team and ensure sufficient provision of Epilepsy Specialist Nurses (ESN) and other professionals to support their population needs. Core and specialised competences required within a team to match population needs might include mental health, transition from paediatric to adult services, learning difficulties, neurodisability, medical complexity, etc.

Action by: Integrated Care Boards (ICBs) in England and local Health Boards in Wales.

Key message 3:
Ensuring timeliness of input

Most children and young people are being seen by a Paediatrician with expertise in epilepsy, however the majority are waiting more than the recommended 2 weeks, and some are waiting more than 1 year.

Considerable numbers of children and young people indicated as requiring input from a paediatric neurologist or Children's Epilepsy Surgical Service (CESS) were not seen by those key professionals within 1 year of diagnosis. Where as, 74% of children and young people with epilepsy achieved an MRI brain scan by 1 year, only 53% achieved this within the recommend 6 weeks.

Professional Input

Most children and young people diagnosed with epilepsy had input from a Paediatrician with expertise within the first year of care; 92% (2077/2212).

- However, only **50.8% (1123/2212)** received input within 2 weeks of referral (**KPI 1**). Note, that the timeliness criteria for this indicator was introduced in cohort 5 to align with the updated NICE guidelines published in 2022 [NG217].
- 15.4% were waiting more than 16 weeks to be seen by a Paediatrician with expertise, and for 6.4% of children and young people, no date of input from a Paediatrician with expertise in epilepsy was recorded within a year of diagnosis.

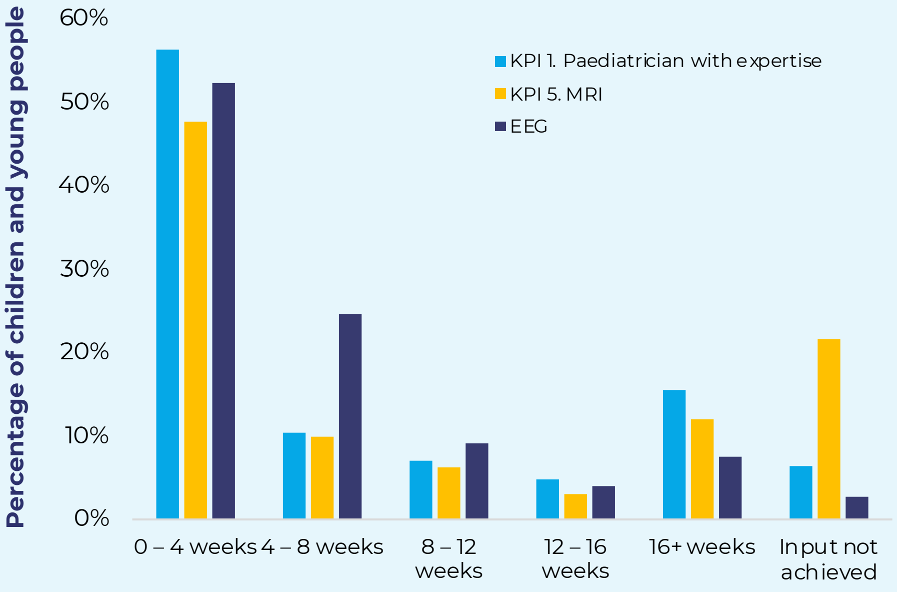


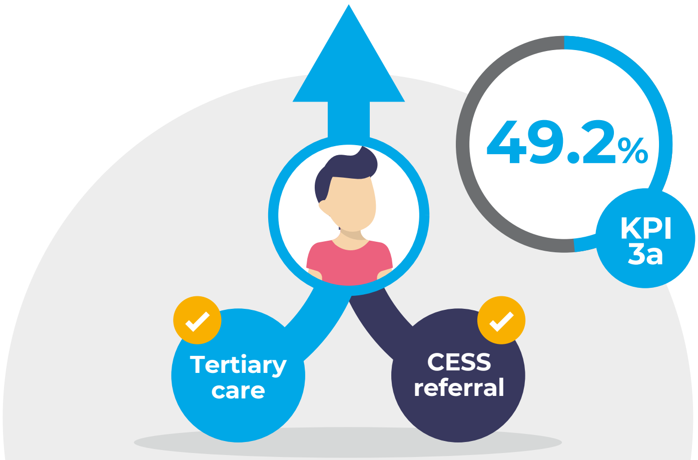
Figure 2 –Time in weeks to achieving professional input and investigations since first referral for children and young people with epilepsy in cohort 5; children and young people in England and Wales with a first assessment between 1 December 2021 and 30 November 2022.

Figure 2 shows the percentage of children and young people receiving timely access to professional input and investigations.

Tertiary Input

49.2% (291/592) of children and young people meeting defined criteria for paediatric neurology referral received input of tertiary care and/or Children's Epilepsy Surgery Service (CESS) referral in the first year (**KPI 3a**). Note, that the criteria for this indicator was revised in cohort 5 to align with the updated NICE guidelines published in 2022 [NG217].

- **KPI 3b: 37.3% (41/110)** of children and young people diagnosed with epilepsy that met CESS referral criteria had an epilepsy surgery referral within the first year of care. This has remained constant from 37% in cohort 4.



Tertiary Input

49.2% (291/592) of children and young people with epilepsy meeting defined criteria for tertiary input received input from a paediatric neurologist or a referral to CESS within the first year of care.

MRI Brain scan

53.1% (385/725) of children and young people with defined indications for an MRI had an MRI brain scan within 6 weeks of request.

MRI Brain Scan

73.8% (535/725) of children and young people diagnosed with epilepsy and with defined indications for an MRI, had an MRI brain scan within their first year of care.

- However, only **53.1% (385/725)** had an MRI brain scan within the NICE recommended 6 weeks from request (**KPI 5**). Note, that the timeliness criteria for this indicator was introduced in cohort 5 to align with the updated NICE guidelines published in 2022 [NG217].

53.6% (1154/2324) of children and young people with epilepsy received an EEG within 4 weeks of referral in cohort 5, an increase from 52% in cohort 4.

Recommendation 3

Establish or improve the processes and pathways in place to ensure children and young people receive timely access to care. This could include identifying and understanding where the gaps in provision are, or establishing structured referral pathways with designated coordinators.

Action by: Integrated Care Boards (ICBs) in England and local Health Boards in Wales.

Quality Improvement at York and Scarborough Teaching Hospitals NHS Foundation Trust

NHS
York and Scarborough
Teaching Hospitals
NHS Foundation Trust

Misplaced paper copies of individualised emergency seizure plans were resulting in treatment delays for children and young people with epilepsy presenting to the emergency department (ED). While 70% of families reported the service held sufficient information, only 20% felt the system was helpful to their child, and 30% felt their child's school found the communication useful.

To address these challenges, the paediatric epilepsy service joined the RCPCH Epilepsy Quality Improvement Programme (EQIP) and implemented the following initiatives:

1. **Electronic medical records** – Finding emergency seizure plans was time-consuming and delayed critical treatment. The service worked with the Trust's IT development team and patient safety lead to implement an alert in hospital records for children and young people emergency seizure plans, ensuring faster access during emergencies.
2. **Patient-held epilepsy passport** – Building upon the RCPCH epilepsy passport, the team co-created a local version which incorporated feedback from patients, families, and NHS colleagues and offered more space for detailed seizure descriptions and emergency rescue plans.

The outcomes so far within the Trust:

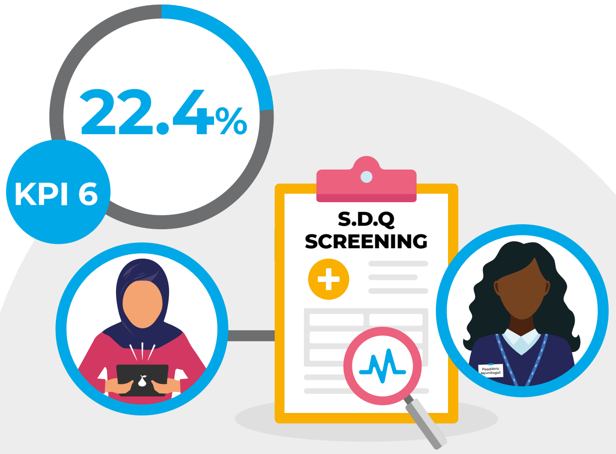
- In Epilepsy12 cohort 4, 100% of children and young people with epilepsy had documented evidence of communication regarding core elements of care planning, and 93% had a patient-held care plan that was up-to-date and agreed-upon.
- 100% of children and young people with epilepsy had an emergency care plan uploaded to ED systems.
- The project fostered engagement and leadership skills within the team, along with stronger collaboration with children, young people, families, clinicians, and internal Trust departments.

Key message 4: Tackling variations in care

Epilepsy12 is increasingly examining quality of care data against different characteristics and there is emerging evidence of variation. Documentation of mental health assessment is lower in those children in more deprived groups where mental health issues are more prevalent[1]. There are also differences in achieving ECG and MRI investigations for children from more deprived groups.

Deprivation quintiles were derived by matching home postcodes to the English (IMD, 2019) and Welsh (WIMD, 2019) indices of multiple deprivation data. Achievement of KPIs varied between Health Boards and Trusts, regions and deprivation groups. Higher performance results were seen in the least deprived groups for several KPI measures compared to the most deprived group. The variation in the assessment of mental health issues (KPI 6) between Health Boards and Trusts and deprivation groups is demonstrated in **figure 3 and 4** respectively.

- **72.1% (1036/1436)** of children and young people with epilepsy and convulsive seizures had an ECG within the first year (**KPI 4**). This indicator ranged from 69.4% in the most deprived group to 75.2% in the least deprived group.
- **53.1% (385/725)** of children and young people with epilepsy and defined indications for an MRI had an MRI brain scan within 6 weeks of request (**KPI 5**). This indicator ranged from 44.6% in the most deprived group to 57.6% in the least deprived group.
- **22.4% (330/1472)** of children and young people with epilepsy had documented evidence of assessment of mental health issues within the first year of care (**KPI 6**). This indicator ranged from 19.1% in the most deprived group to 27.6% in the least deprived group.



Assessment of mental health issues

22.4% (330/1472) of children and young people with epilepsy aged 5 years and over had evidence of assessment of mental health issues.

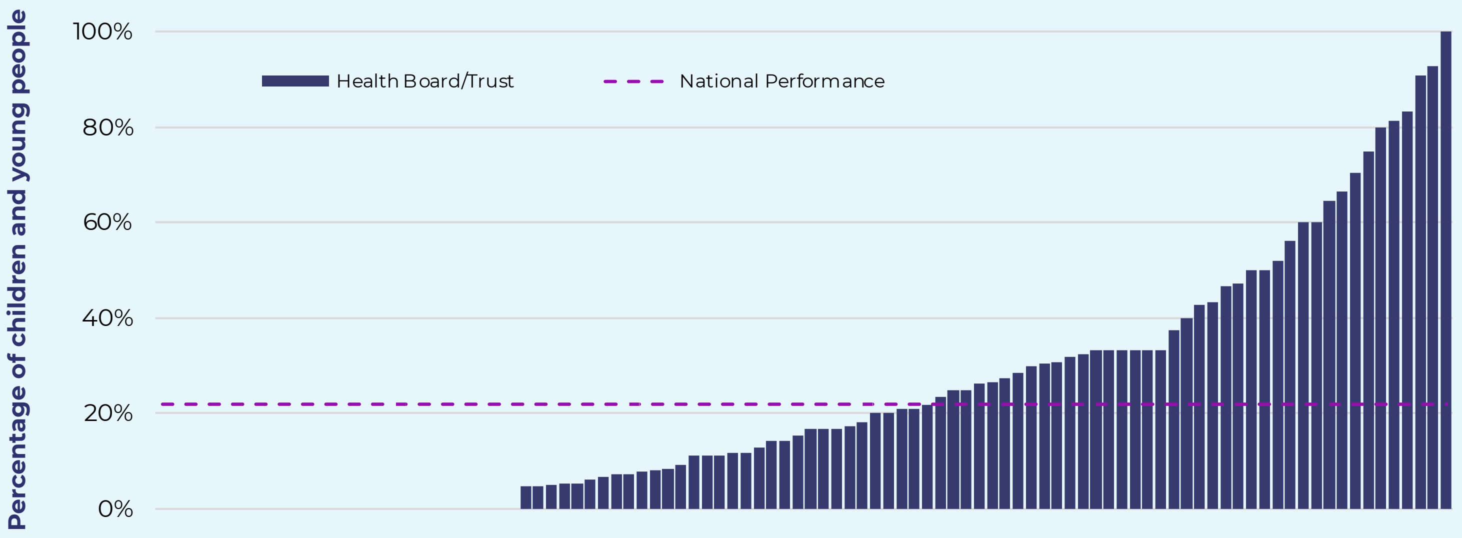


Figure 3 – Assessment of mental health issues (KPI 6) by Health Board and Trust in England and Wales, cohort 5 (children and young people with a first assessment between 1 December 2021 and 30 November 2022). Each participating Health Board or Trust (HBT) is represented by a vertical bar in the order of the percentage score, including the 28 HBTs scoring 0% in this graph.

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[1] F Reiss, 2013; Socioeconomic inequalities and mental health problems in children and adolescents: A systematic review.

- In 2023, **30% (36/117)** of Health Boards and Trusts routinely, formally screened for mental health disorders, which is an increase from 20% (25/128) in 2022, and **31% (36/117)** routinely, formally screened for neurodevelopmental conditions, an increase from 26% (33/128) in 2022.
- 74% (84/117) of Health Boards and Trusts had agreed mental health referral pathways in 2023, however only **18% (21/117)** of epilepsy services provided co-located mental health provision, as recommended within the NHS England Paediatric Epilepsy best practice criteria (BPC).

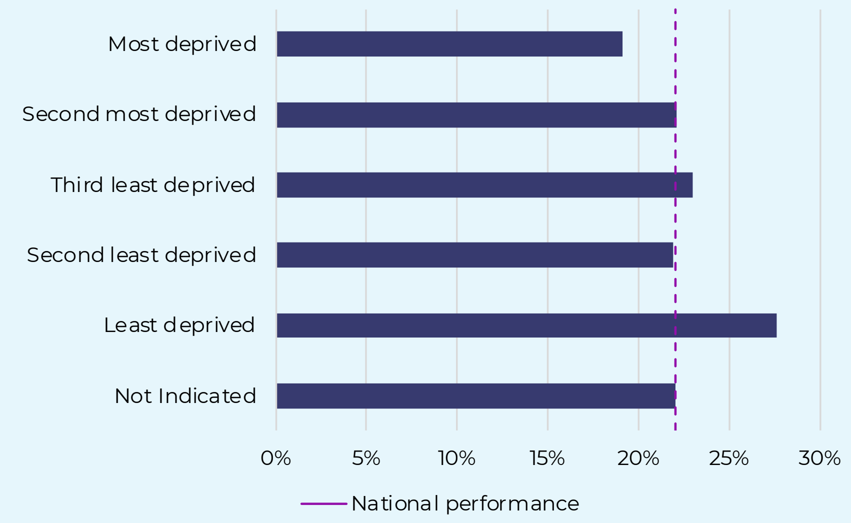

Figure 4 – Assessment of mental health issues (KPI 6) by deprivation quintile in cohort 5 (children and young people with a first assessment between 1 December 2021 and 30 November 2022). Deprivation quintiles were derived by matching home postcodes to the English (IMD, 2019) and Welsh (WIMD, 2019) indices of multiple deprivation data.

Recommendation 4

Integrated Care Boards (ICBs) and local Health Boards should develop models of engagement that enable groups where there may be inequalities, eg. within the Core20PLUS5 framework, to contribute to service improvement. This can be by identifying challenges and co-creating alternative service models to ensure equitable access and care for epilepsy aligned with work supporting other long-term health conditions.

Action by: Integrated Care Boards (ICBs) in England and local Health Boards in Wales, in collaboration with OPEN UK networks.

RCPCH Epilepsy Quality Improvement Programme (EQIP)

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

Case studies, video presentations and examples of quality project journeys are available on the EQIP website. Participating teams have chosen a variety of areas of epilepsy care to focus their improvement projects on, including reducing waiting times, mental health, SUDEP, care planning and transition.

The fourth wave of EQIP began in October 2023 with an in-person training launch, and a celebratory event was held in June 2024 to showcase the improvement projects.

Recommendation 5

Support participation and benchmarking against relevant ongoing quality improvement projects, in order to promote system-wide shared learning, collaboration and knowledge exchange.

Action by: Integrated Care Boards (ICBs) in England and local Health Boards in Wales, in collaboration with OPEN UK regional networks.

Epilepsy12 Youth Advocates

We are Epilepsy12 Youth Advocates and we volunteer across the year to help improve epilepsy care across England and Wales. Read more about us here.

This year we've been thinking about "Epilepsy is more than the condition, it is epilepsy with…"

- ✓ Me thinking about how I find a work experience placement that will take me on,
- ✓ Me being told not to think about going to university because of my epilepsy being a barrier,
- ✓ Me being a sibling to an older brother with epilepsy,
- ✓ Me loving animals,
- ✓ Me being worried about having a seizure and people not knowing how to put me into the recovery position,
- ✓ Me thinking about how different it will be in adult services, and not sure how I'll manage,
- ✓ Me wishing that I got a school care plan 10 years sooner than I did, then I wouldn't have missed out on so much,
- ✓ Me feeling lucky to have an ESN and a consultant paediatrician who talks to me, not just my parents.'

We want all children and young people to have the best health possible, at home, at school or in the care we have from health services, and for this to be the same across the UK. It needs to be fair for everyone as this is part of the United Nation Convention on the Rights of the Child.

These are not gifts; these are our rights.

We need you to make sure this happens, regardless of where you live, what age you are, what your gender is, what language you speak, if you have a disability or what your ethnicity is.

Our highlights this year:

- Presented to the **Epilepsy12 OPEN UK Conference** about "epilepsy with… and what it means to us."
- Trained as **youth facilitators, co-facilitated the Epilepsy Innovators project**, training 10 hospitals in engagement.
- Won the **HQIP Clinical Audit Heroes award** for Patient and Public Involvement in summer 2023 and had an article published on our work.
- Felt really proud that our **ESN for our project, Jill, won the UK wide RCPCH &Us Voice Champion Award** 2023.
- Started our 2-year project on **family mental health and independent life skills**.

Did you know?

We know that there is great work happening, so we asked 600 clinicians at the national conference what they are proud of and made an A-Z of the answers.

Download the poster here

A-Z of things of which we are proud in our Epilepsy Services

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

This A-Z was created by the Epilepsy12 Youth Advocates at the Epilepsy12 OPEN UK Conference with epilepsy teams. Check it out for new ideas from epilepsy services, or spot ones you might already be doing!

When we think of our epilepsy care, we are proud of:

Auditing epilepsy care
Being able to offer support at home and out of hours as well as in the hospital
Collaborating with children and young people = patient-centred care
Diversity and inclusion in epilepsy care
Excellent specialist nurses (ESNs!)
Families' mental health focus
Genetic testing
Helping families learn more about epilepsy and medication
Inclusivity, accessibility and multicultural services
Joined up working with schools, youth workers, family support workers & MDTs
Ketogenic diet services
Listening to children, young people and families
Me and Epilepsy Tool
Newly diagnosed being given safety netting advice
Online referrals improving patient experience
Proud of offering nurse-led clinics and teenage clinics
Quality of epilepsy care for children, young people and their families
Reducing seizure burden
SUDEP conversations
Teaching about reducing risk and creating safety care plans
Unafraid children and young people learning about epilepsy
Voices of children and young people promoted and acted on
Waiting times reduced
Xenodochial epilepsy services - hospitable or kind to strangers
Young adults' transitions clinics
Zone of care around children, young people and their families

EPILEPSY12 RCPCH Royal College of Paediatrics and Child Health Leading the way in Children's Health

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EPILEPSY12

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