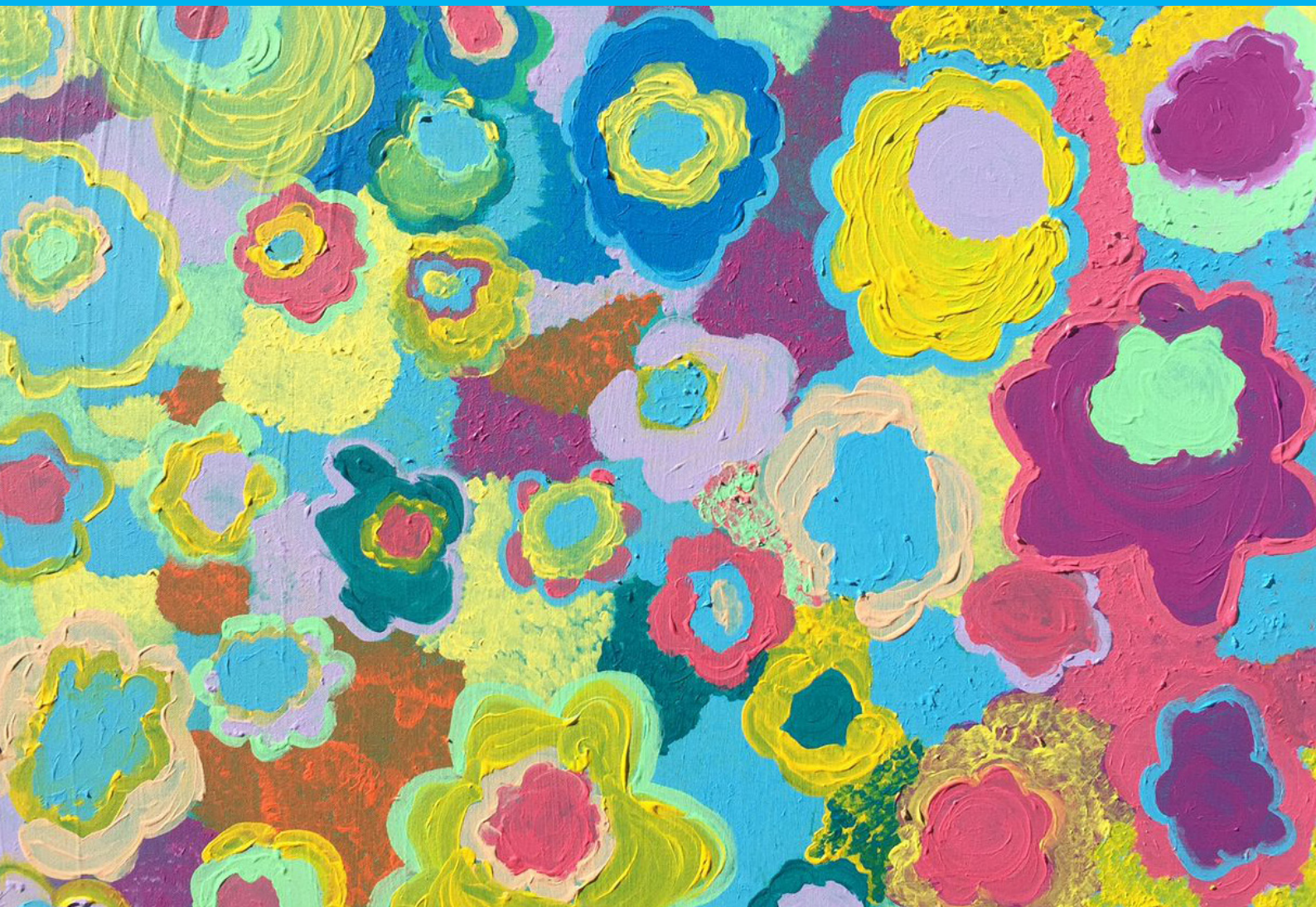


EPILEPSY12

✧RCPCHAudits

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

Epilepsy12 2023 combined organisational and clinical audits: Report for England and Wales Round 4, Cohort 4 (2020-22)



Epilepsy12 Summary Report for 2023 combined organisational and clinical audits Round 4, Cohort 4 (2020-22)

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, 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 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. [Click here to find out more.](#)

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.

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Thank you

The Epilepsy12 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 incredibly 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 - Flower Garden is a painting by Janet Lee (from Malaysia), an international artist and colourist who is living with epilepsy. The artwork is an explosion of vibrant colours that declares being “perfectly imperfect” is far from boring. Janet’s artwork embodies the spirit of resilience, where she empowers and enlightens others, reminding us that beauty and joy can be found in the most unexpected places. [Read Janet’s story here.](#)

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 and structure of services. This information is used by the audit to highlight areas where services are doing well, and also to identify areas in which they need to improve.

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 4' ([find out more here](#)), and the **organisation and structure of epilepsy services** as at November 2022 ([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 the British Paediatric Epilepsy Group and 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. The Group uses Epilepsy12 data to identify variation and areas for improvement, and to benchmark and monitor progress at Trust, Integrated Care Board (ICB), NHS region and national levels. Four key areas of focus have been determined based on analyses of successive Epilepsy12 data:

1. Addressing **variation in care** between epilepsy services
2. Supporting the **mental health** 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.

Summary results

Epilepsy12 performance indicators for clinical data from cohorts 1-4 for England and Wales combined

This report focuses on Epilepsy12 Round 4, 'cohort 4' which encompasses children and young people who had their first paediatric assessment for a suspected seizure between 1 December 2020 and 30 November 2021. Prior to the January 2023 deadline, **2324 children and young people with an epilepsy diagnosis** had complete first year of care forms submitted, and were therefore included in the analyses for this report.

The Epilepsy12 Project Team processed data relating to both the first paediatric assessment and the 12 months of subsequent care (the first year of care) delivered to all children and young people within the cohort. There

are 12 **'Performance Indicator' (PI)** measures for the audit which are derived from national guidelines and recommendations. Results for these Performance Indicator measures across cohorts 1-4 are shown in **figure 1**.

This report provides evidence of improvements in care for children and young people with epilepsy in England and Wales for 8 of these 12 performance indicators across the past 4 cohorts of the audit, which spanned July 2018 to December 2022, including timely access to key professionals, investigations, treatments and the agreement and content of care plans.

Note: The whiskers on the chart represent 95% confidence intervals.

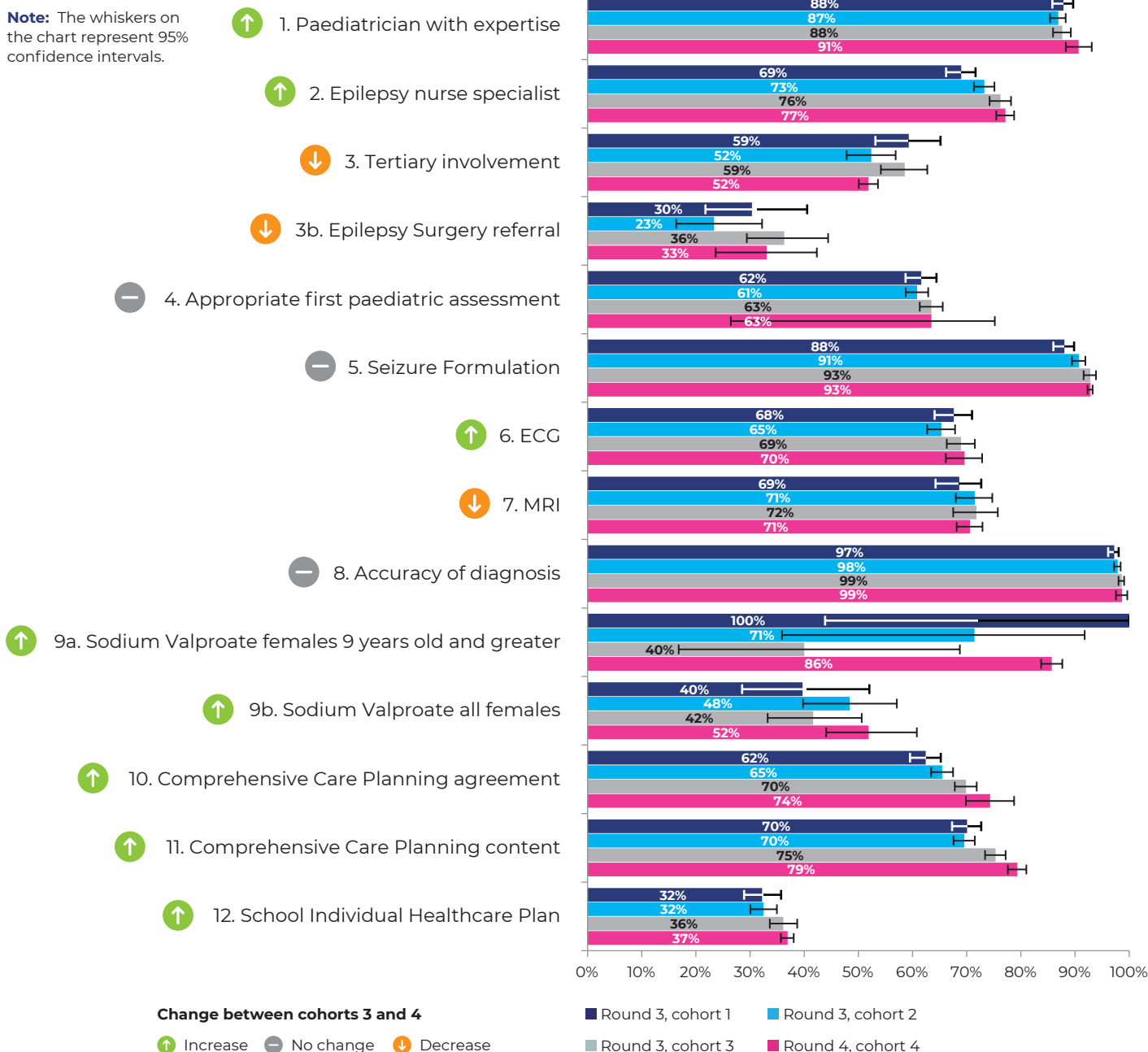


Figure 1 – Epilepsy12 Performance indicators for England and Wales combined in Round 3, cohorts 1-3 and Round 4, cohort 4.

Key findings & recommendations

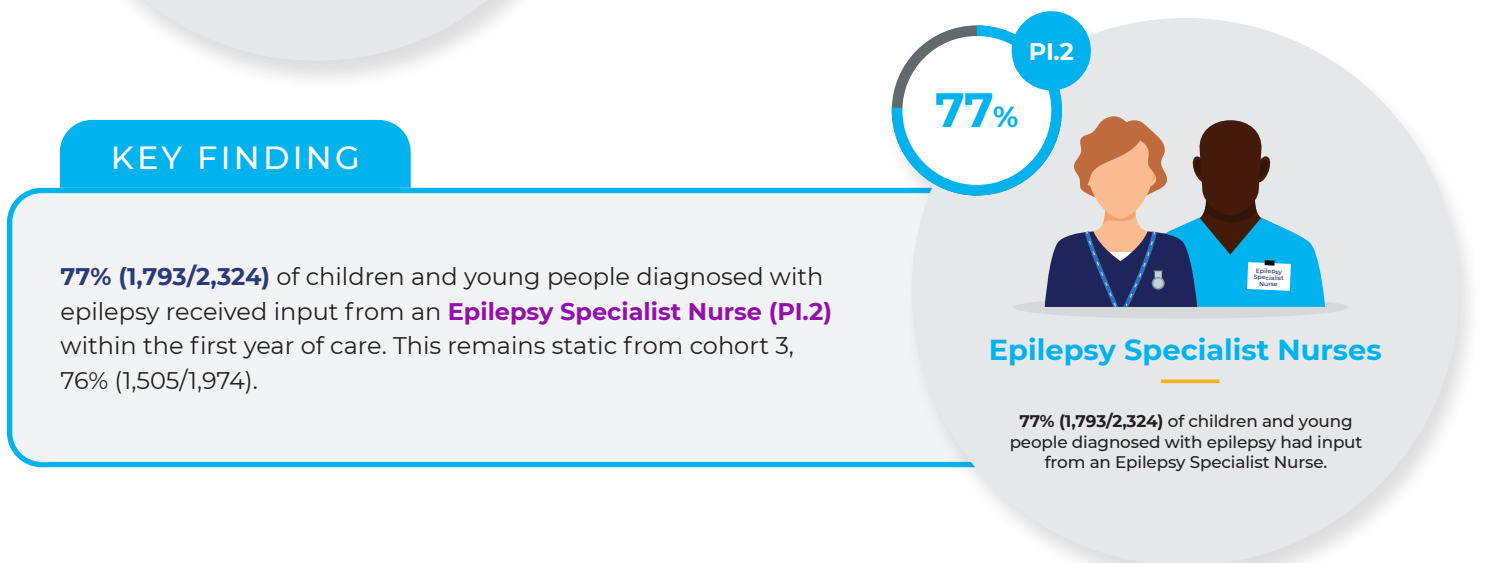
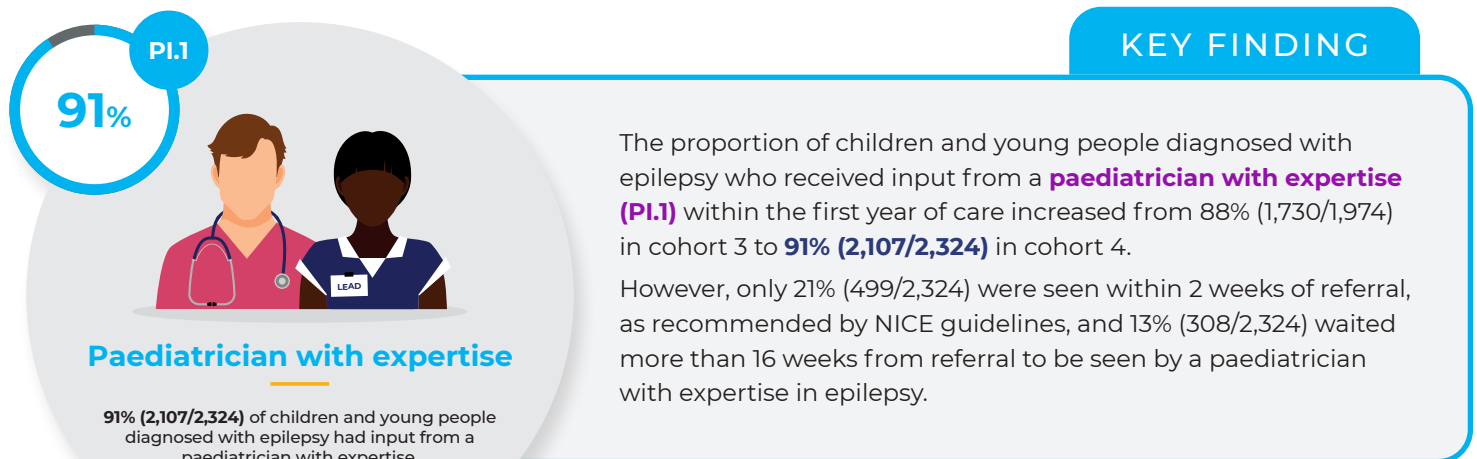
Key message 1: Holistic care

More and more children and young people with epilepsy are receiving input from epilepsy specialist nurses and paediatricians with expertise. However, there remain some children without such access, and rates of wider involvement from other key health professionals remain low.



Multidisciplinary Team

More children and young people with epilepsy are receiving input from key health professionals in their first year of care following first paediatric assessment, compared to previous years.



- **66% (85/128)** of Health Boards and Trusts had both an adult and paediatric ESN routinely involved in the transition of young people with epilepsy to Adult Services, and **66% (85/128)** used structured resources during the transition process.
- Only **7% (9/128)** of Health Boards and Trusts were able to provide specialist advice to children and young people with epilepsy on all weekdays and out of hours for 52 weeks of the year.

Mental Health

Research suggests there is a high incidence of mental health conditions among children and young people with long term conditions¹.

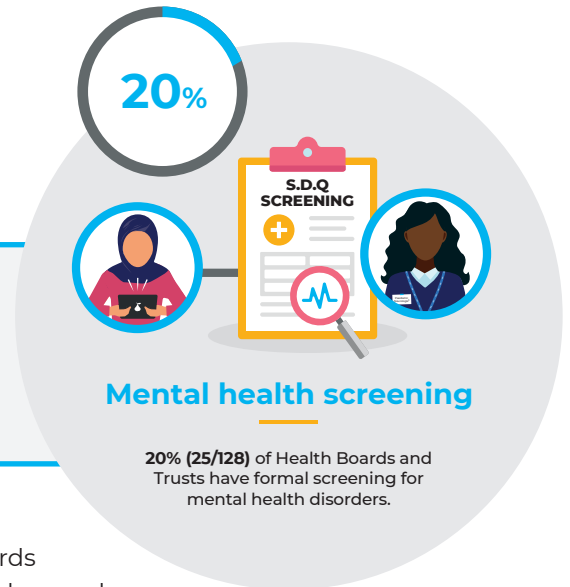
KEY FINDING

5% (119/2,324) of children and young people in cohort 4 had an identified mental health condition, similar to 4% in cohort 3. Mood disorder was indicated for 2% and anxiety disorder directly for <1%, although 'anxiety' was frequently listed under the 'other category'.

These results for cohort 4 suggest that some children and young people with epilepsy may be missing out on, or having a delayed identification of, mental health conditions and that 'anxiety' in particular may be being under reported as a distinct mental health condition.

In 2022, only **20% (25/128)** of Health Boards and Trusts had formal screening for mental health disorders and **26% (33/128)** had formal screening for Attention Deficit Hyperactivity Disorder (ADHD), Autistic Spectrum Disorder (ASD) and mental health conditions.

64% (82/128) of Health Boards and Trusts had agreed referral pathways for children and young people with anxiety; **65% (83/128)** for depression; and **63% (81/128)** for mood disorder. Only **9% (12/128)** of epilepsy services provided co-located mental health provision, as recommended within the NHS England Paediatric Epilepsy best practice tariff (BPT), and **40% (51/128)** were using established questionnaires for mental health screening.



★ Recommendation 1

All children and young people with epilepsy should be supported holistically from a network of professionals and services. A multi-agency directory outlining epilepsy provision and pathways should be maintained to signpost the public and professionals to locally available services.

This should include health, social care, the voluntary sector and education professionals and services.

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

Quality improvement at University College London Hospitals NHS Foundation Trust

NHS
University College London Hospitals
NHS Foundation Trust

The clinical team at the Trust has aimed to increase the psychological support available in their service to young people with epilepsy through innovative engagement and delivery of care. They recruited a 0.2 Whole-Time Equivalent (WTE) Clinical Psychologist who became an expert in the needs and common psychological difficulties experienced by young people with epilepsy. This psychological provision included inclusion of a psychologist at MDT meetings, monthly slots for psychological assessments dedicated to young people with epilepsy, and two new psychology-based groups:

Tree of Life – a narrative therapy-based project helping young people build confidence and strengthen alternative stories of their life that do not foreground around epilepsy.

The forum encourages discussion on the challenges of being a young person with epilepsy and a collective exploration of responses to those challenges.

Study skills for epilepsy – a workshop addressing, normalising, and providing support for common cognitive difficulties experienced by young people with epilepsy. A pamphlet was created with the workshop information to be made available for all young people with epilepsy at UCLH.

The outcomes so far have been:

- quicker access to a psychologist following referral,
- access to a psychologist with epilepsy specific expertise,
- positive feedback from the team and patients.

Key message 2: Equitable care

There is wide variation in care between OPEN UK regions and Health Boards/Trusts. There are significant differences in deprivation rates between regions. There is limited data on other population attributes and their associations with service configuration and quality of care.



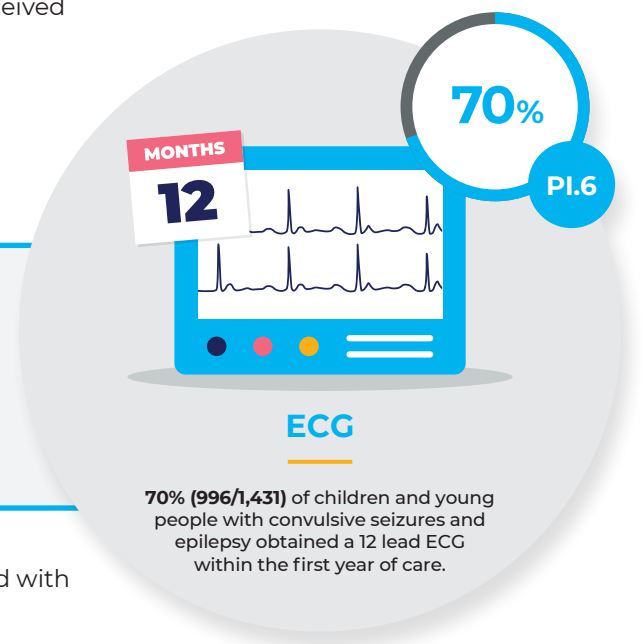
Investigations

More children and young people with epilepsy within cohort 4 received timely access to key investigations to diagnose and monitor their epilepsy compared to earlier Epilepsy12 cohorts, however this access varied between Health Boards and Trusts.

KEY FINDING

70% (996/1,431) of children and young people with epilepsy and convulsive seizures obtained a **12 lead ECG (PI.6)** within their first year of care. This indicator ranged from 13% to 100% at a Health Board and Trust level.

- Only 52% (1,209/2,324) of children and young people diagnosed with epilepsy obtained their EEG within four weeks of request.



Treatment

All females of child-bearing potential and prescribed Sodium Valproate should receive information on the possible foetal risks and should have ongoing documentation regarding their status within the Valproate Pregnancy Prevention Programme.

- **86%** of all females aged over 9 years currently on **sodium valproate treatment had evidence of discussions of foetal risk (PI.9a)**, and this has increased from 41% in cohort 3. For females of all ages currently on valproate treatment, **52% (55/106)** had evidence of discussions of foetal risk **(PI.9b)**.
- Additionally, there were low levels of rescue medication use, where 23% (533/2,324) of children and young people diagnosed with epilepsy had rescue medication prescribed.

Care planning

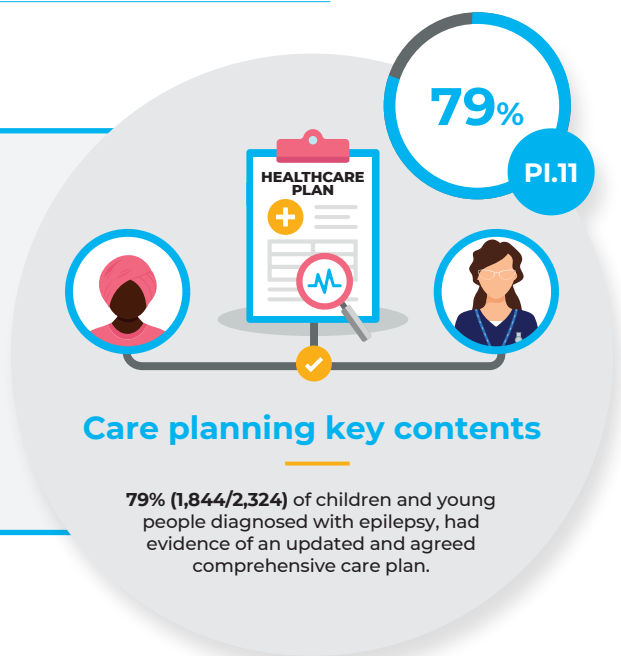
There is widespread use of care planning, where most children and young people with epilepsy had evidence of an agreed and updated comprehensive care plan, and there has also been improvement over time.

- **74% (1,727/2,324)** of children and young people diagnosed with epilepsy had evidence of a **comprehensive care plan (PI.10)** that had been agreed between the child or young person, their family and/or carers and primary and secondary care health providers, and had been updated where necessary during the first year of care.

KEY FINDING

79% (1,844/2,324) of children and young people diagnosed with epilepsy had documented evidence of communication regarding the **core elements of comprehensive care planning (PI.11)** within the first year of care.

Although only 56% (1,313/2,324) had evidence of receiving information on Sudden Unexpected Death in Epilepsy (SUDEP), and access to SUDEP information varied between regions, ranging from 32% to 90% at OPEN UK region levels.



KEY FINDING

Deprivation

In cohort 4, there were a higher proportion of children and young people diagnosed with epilepsy living in the most deprived quintile, compared to other quintiles. In England and Wales, **28% (654/2,306)** of children and young people with epilepsy were living in the most deprived quintile. **Figure 2** displays that, at an OPEN UK level, this proportion ranged from 4% to 58% across paediatric epilepsy networks.

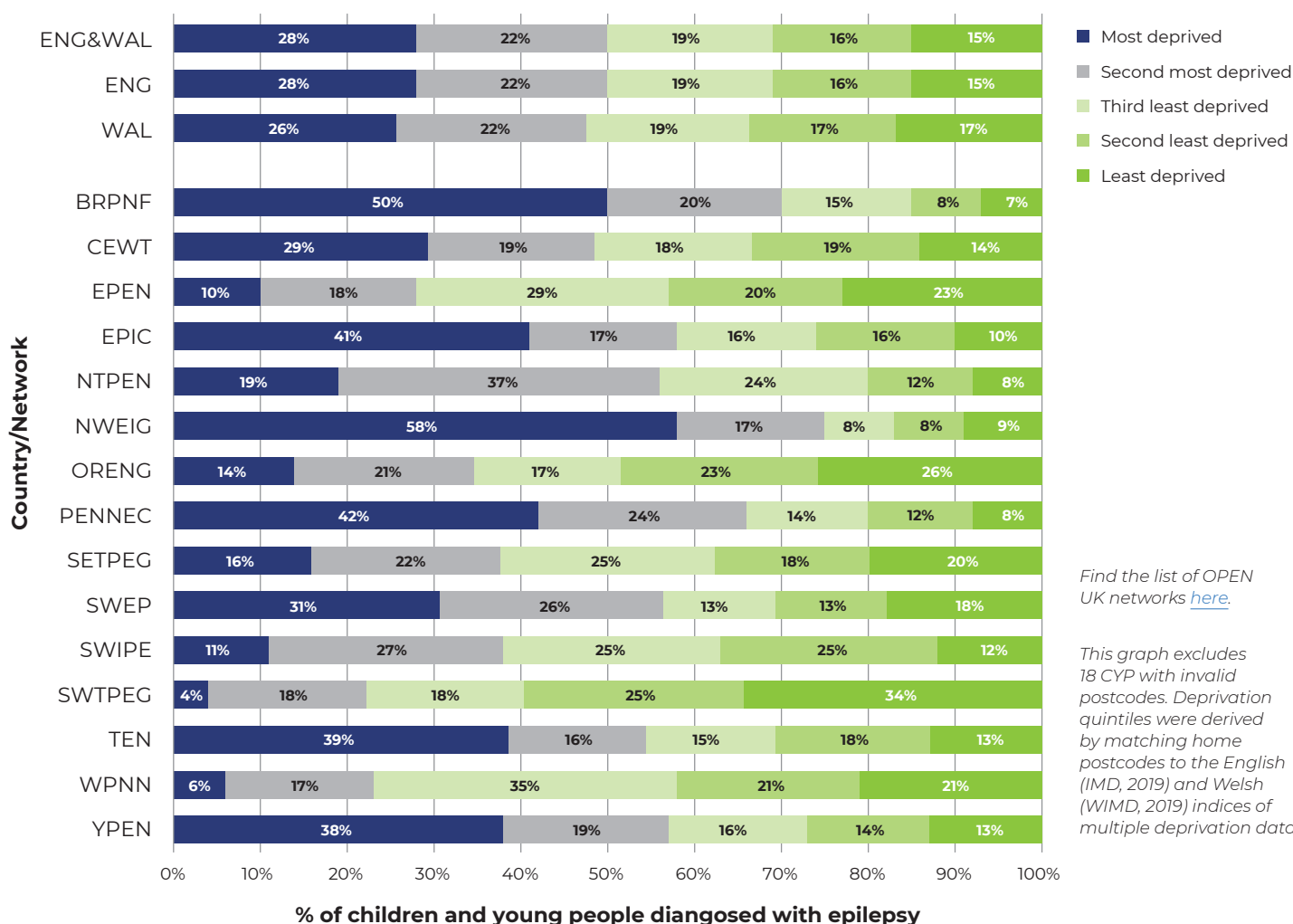


Figure 2 – Percentage of children and young people diagnosed with epilepsy in cohort 4 by deprivation quintile and country/network.

Neurodisability and neurodevelopmental problems

Research suggests that school-aged children and young people with epilepsy commonly experience difficulties in academic achievement, which could be attributed to lowered global cognition².

- In cohort 4, **6% (149/2,324)** of children and young people diagnosed with epilepsy had an identified intellectual disability/global development delay/learning disability. The severity of the disability/delay was severe/profound in 29% (43/149) of these children and young people. Autistic spectrum disorder, speech disorder and 'other learning difficulties' were indicated for 8%, 1% and 3% respectively.

The cohort 4 results suggest that some children and young people with epilepsy may be missing out on, or having a delayed identification of, neurodisability and neurodevelopmental problems.

★ Recommendation 2

All children and young people with epilepsy should have appropriate access to care, including professionals, services, investigations and treatments. This should be irrespective of age, sex, ethnicity, social deprivation status, learning disability, autism or geography. Integrated Care Boards, regional teams and associated health systems should use Epilepsy12 data, alongside other trusted data sources, to ensure equitable delivery of care and outcomes.

Action by: Integrated Care Boards across England in line with the aims for epilepsy care set out within Core20PLUS5 – the NHS England approach to reducing health inequalities for children and young people. Regional Partnership Boards across NHS Wales and Public Health Wales.

Key message 3: Care within education

There continues to be few children and young people with epilepsy who have evidence of a School Individual Health Care Plan.

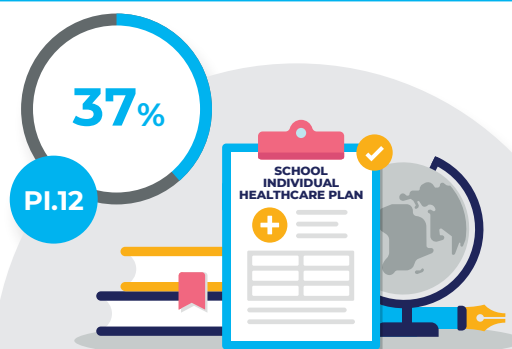


School Individual Healthcare Plan

It is important that children and young people receive care and support for their epilepsy within education settings. This can be facilitated by appropriate, up-to-date health care planning within education and two-way information sharing between those working in healthcare and education.

KEY FINDING

Few children and young people had evidence of a **School Individual Healthcare Plan (IHP) (PI.12)** in England and Wales, **37% (577/1,562)**. The documented use of school IHPs has increased little since cohort 1 (5% increase) and there is large variation between Health Boards and Trusts, with 28/128 services having 0% performance on this indicator.



School Individual Health Care Plan

37% (577/1,562) 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 3

Health services should explore with education services ways to improve the number of children having effective ongoing School Individual Health Care Plans (IHP) and Education Health Care Plans (EHCP). The use of established templates and contents, for example those

created by [Young Epilepsy](#), [Epilepsy Action](#) and the [Epilepsy12 Youth Advocates](#) is recommended.

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

Key message 4: Limited improvements in care

Whilst there is evidence of significant improvements in some aspects of epilepsy care, there are some areas of care that are showing no improvement over time.



Certain areas of epilepsy care, such as access to paediatricians with expertise in epilepsy and epilepsy specialist nurses, have improved from cohort 1. However, there is evidence that some areas of epilepsy care are showing no improvement over time. **Figure 3** displays the results for 5 performance indicators which have remained static in England and Wales across Round 3, cohorts 1 – 3 and Round 4, cohort 4.

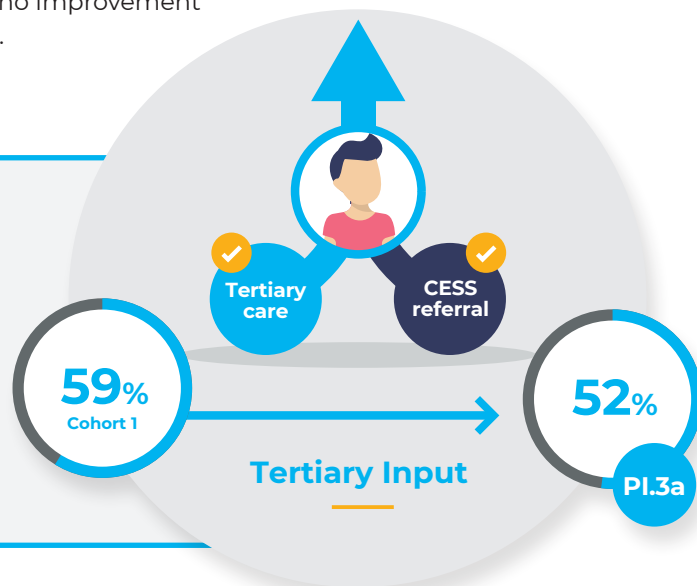
Performance Indicator 3 - Tertiary input

When indicated, input from specialised tertiary services can be crucial to epilepsy care and treatment. There is evidence that some children and young people with epilepsy may be missing out on, or having delayed referral to, these specialised services. Tertiary input has shown no improvement over time and access varies between Health Boards and Trusts.

KEY FINDING

In England and Wales, **52% (249/480)** of children meeting the defined criteria for paediatric neurology referral received **input from tertiary care (PI.3a)** and/or Children's Epilepsy Surgery Service (CESS) referral within the first year of care. This proportion was 59%, 52% and 59% in cohorts 1, 2 and 3 respectively.

Only **33% (39/118)** of children and young people diagnosed with epilepsy and meeting CESS referral criteria had an **epilepsy surgery referral (PI.3b)**.



Performance Indicator 4 - Appropriate first paediatric assessment

'Appropriate first paediatric assessment' was defined as a clinical assessment for paroxysmal episode(s) consisting of all the components deemed as necessary by Epilepsy12, with reference to NICE/SIGN guidelines. The proportion of children and young people receiving appropriate first paediatric assessments has remained static over time.

KEY FINDING

63% (1,475/2,324) of all children and young people in cohort 4 had **appropriate first paediatric clinical assessments (PI.4)**. Most children and young people had evidence of assessment for key components, including description of episodes (99%), timing (95%), general examination (93%) and neurological examination (91%).

However, some sub-categories within this indicator were performing lower than others. For example, only 81% of children and young people had documentation of the descriptions of age of child / timing of the first episode, and 86% had documentation of the description of developmental, learning or schooling progress.

62%
Cohort 1

Appropriate first
paediatric assessment

63%
Cohort 4

PI.4

Performance Indicator 7 - MRI brain scan

KEY FINDING

In cohort 4, **71% (499/707)** of children and young people diagnosed with epilepsy, and with defined indications for an **MRI Brain Scan (PI.7)**, had an MRI brain scan by their first year of care in England and Wales. The proportion of children and young people receiving an MRI was 69%, 71% and 72% in cohorts 1, 2 and 3 respectively.

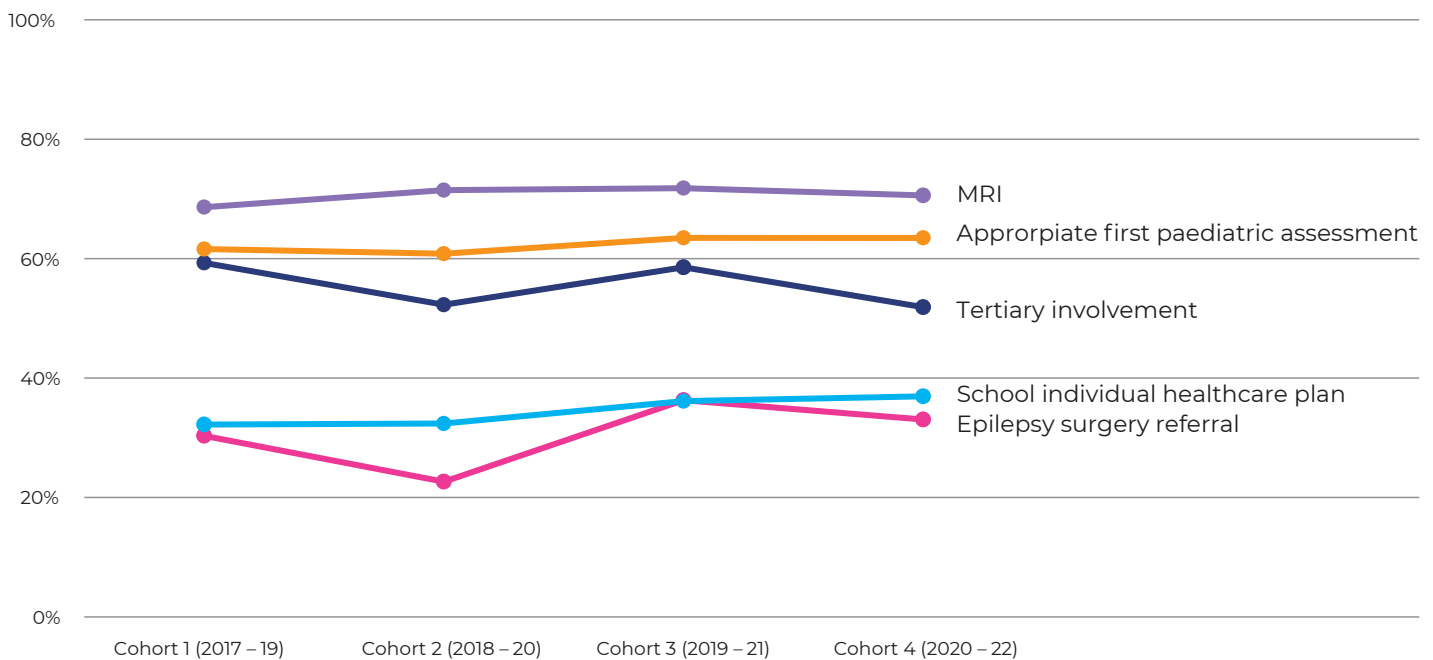


Figure 3 – Performance indicators in England and Wales across Round 3, cohorts 1-3, and Round 4 cohort 4 (2017 to 2022).



Recommendation 4

Coordinated reviews should be carried out to identify barriers, establish enablers and implement improvement plans for those areas of paediatric epilepsy care where Epilepsy12 highlights little or no improvement over time.

Action by: Regions and Integrated Care Boards (ICBs) in England and Regional Partnership Boards in Wales.



Epilepsy Quality Improvement Programme (EQIP)

RCPCH EQIP is a tailored programme supporting teams to work together to define shared aims and develop practical interventions which incorporate QI methods and match their capacity and resource. A third wave of training is underway for 12 paediatric epilepsy service teams (7 Health Boards/Trusts and 1 Integrated Care Board (ICB) made up of 5 Trusts) focusing on planning and implementing their project interventions within key national priority areas in mental health screening and wellbeing, transition and reducing waiting times. Find out more information on the EQIP [here](#).



Quality Improvement (QI) case studies

NHS Health Boards and Trusts in England and Wales have been undertaking additional QI projects, where clinical teams have used innovative approaches to design, implement and evaluate interventions, processes and pathways to optimise the care provided to children and young people with epilepsy. Projects focused on psychological provision, checklists for educational support, transition, SUDEP information and much more!

You can find the detailed case studies on our [website](#).

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](#).

patient voice



2022/23 Activities

The Epilepsy12 Youth Advocates champion ways to improve care for children and young people with epilepsy. This year we have:

- ✓ Created a **new young person and parent/carer leaflet**, with a checklist so you know what to ask or talk about and to show the good things that are happening.
- ✓ Presented at the **RCPCH Annual Conference** and the **Epilepsy12 & OPEN UK Conference** in 2022.
- ✓ We wanted to make a difference following on from the audit figures about **School Individual Healthcare Plans**. We looked at 7 different templates, talked about what was important to us and created a leaflet to help everyone involved and made sure it is relevant, personal and useful.
- ✓ We won our 3rd **national HQIP award** in November 2022 for patient and public involvement! We're so proud of that!
- ✓ Published a **podcast all about being diagnosed with epilepsy** with Medicines for Children.
- ✓ **Agreed new priorities for 2023** onwards, where we'll be looking at **mental health support** for parents and families, **independence and life skills** for children and young people, **raising awareness** of the Epilepsy12 Youth Advocates and doing **clinic chats** to hear more from people living with epilepsy.



Did you know?

- We meet in person and online and most of that we are laughing and having fun.
- We always have a mental health check in at the start of our meetings and a check out at the end.
- Sometimes we play music really loud in the Collage (and forget it's a weekday meeting so everyone hears in the building?!).

Future areas of focus

- Increasing the numbers of **school care plans** and whole school awareness/teacher training.
- Increasing access to **youth workers and youth mental health workers** in the first year of care.
- Improving **out of hours contact** about worries/anxieties about your epilepsy.
- Increase the number of **young people's/young adult clinics**.
- Improve **mental health screening** to support with worries and anxieties.

The E12 Youth Advocates, basically ROCK!!

We worked so well together with a common goal, which is to get how important epilepsy care is for all young people and we will keep fighting on!! To find out more get in touch with us [here](#).

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**Healthcare Quality
Improvement Partnership (HQIP)**
Dawson House, 5 Jewry Street,
London EC3N 2EX



**Royal College of Paediatrics
and Child Health**
5-11 Theobalds Road,
London, WC1X 8SH