EPILEPSY12

RCPCHAudits

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

Epilepsy12 2025 combined organisational and clinical audits:

Report for England and Wales

Clinical Cohort 6 – The first year of care for children and young people following a first paediatric assessment undertaken between 1 December 2022 and 30 November 2023

HQIP
Healthcare Quality
Improvement Partnership

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

Epilepsy12 Summary Report for 2025 combined organisational and clinical audits

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 and crown dependencies. Find out more at www.hqip.org.uk/national-programmes.

Having also delivered Rounds 1 to 3 between 2009 and 2021, the RCPCH was awarded the contract to deliver Round 4 of Epilepsy12 from 1 April 2022 to 31 March 2025, with a further two-years to 31 March 2027.

Contents

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 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 – '**Live your Dream 1**' is an artwork created by Janet Lee, an international artist from Malaysia who lived with epilepsy (1989 - 2023). This was created using acrylic paints on a canvas surface, and with the following message: *someone once said, "You'll never know how far you can fly until you spread your wings. It is another glorious day. Follow your heart and set yourself free."*

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 epilepsy.

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

1

Auditing of the clinical care provided to children and young people newly diagnosed with epilepsy in 'cohort 6' (find out more here), and the **organisation and structure of epilepsy services** as at November 2024 (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 report and its accompanying 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 caring for children and young people with epilepsies to regional epilepsy networks. Guided by the OPEN UK Working Group, it represents 17 regional epilepsy networks in the UK and the British Paediatric Epilepsy Group.

OPEN UK:

- Encourages collaboration and sharing of ideas, pilots, and resources.
- Is a national resource and professional UK body for information, support, data, and clinical input.
- Maintains connections with 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. A National bundle of care for CYP with epilepsy was published, consisting of key standards and recommendations around the care and delivery of epilepsy services to support systems with epilepsy quality improvement within four areas:

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.

To support the identification and tracking of local improvement, key Epilepsy12 audit metrics are included as measures against the recommendations for ICBs within the bundle. Encouragingly, following the publication of the national bundle of care for CYP with epilepsy in October 2023, the Epilepsy12 cohort 6 data findings published in this report identify improvements across some of the key areas targeted for improvement in the bundle, including mental health provision, the proportion of children and young people (CYP) seen by an epilepsy specialist nurse and the proportion of CYP who met the CESS referral criteria and had evidence of a referral.

Epilepsy12 and Wales

Wales has ongoing representation within the UK Epilepsy Programme Board and OPEN UK. Epilepsy12 and NHS Wales are working together and plan to formalise Welsh representation within the Epilepsy12 Project Board.

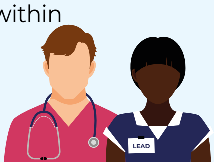
EPILEPSY12
Results at a glance: Update

Below are results from the Epilepsy12 'cohort 5' (2023) and 'cohort 6' (2024) clinical audit, focusing on the 10 key performance indicators (KPIs) relating to the first year of care provided to children and young people with a new diagnosis of epilepsy in England and Wales. For more information, please visit our website (or use the QR code to the right).

Involvement of appropriate professionals

KPI 1 Children and young people seen by a **consultant paediatrician with expertise in epilepsies** within two weeks from first paediatric assessment.

Cohort 5	50.8%
Cohort 6	32.4%



KPI 2 Children and young people seen by an **epilepsy specialist nurse (ESN)** within the first year of care.

Cohort 5	80.7%
Cohort 6	85.6%

KPI 3a Children and young people 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.

Cohort 5	49.25%
Cohort 6	49.2%

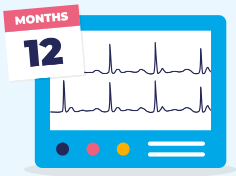
KPI 3b Children and young people who met CESS referral criteria had **evidence of a CESS referral.**

Cohort 5	37.3%
Cohort 6	42.0%

Appropriate assessment

KPI 4 Children and young people with convulsive seizures had an **ECG** within the first year of care.

Cohort 5	72.1%
Cohort 6	83.4%



KPI 5 Children and young people with defined indications for an MRI had an **MRI within 6 weeks of request**.

Cohort 5	53.1%
Cohort 6	49.2%

Mental health

KPI 6 Children and young people with documented evidence that they had been **asked about mental health**.

Cohort 5	22.4%
Cohort 6	38.2%

KPI 7 Children and young people with a mental health problem had evidence of receiving **mental health support** within the first year of care.

Cohort 5	61.5%
Cohort 6	76.6%

Care Planning

KPI 8 Female young people who are 12 years and over, currently on **valproate treatment had a risk acknowledgement form** completed.

Cohort 5	100%
Cohort 6	100%

KPI 9a Children and young people had evidence of **care planning agreement** within the first year of care.

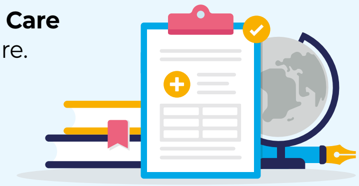
Cohort 5	80.8%
Cohort 6	85.8%

KPI 9b Children and young people had documented evidence of communication regarding **core components of care planning**.

Cohort 5	64.8%
Cohort 6	67.4%

KPI 10 Children and young people aged 5 years and above had evidence of a **School Individual Health Care Plan** within the first year of care.

Cohort 5	38.9%
Cohort 6	67.2%



National Recommendations

1

Support Health Boards and Trusts identified as non-participation outliers. Identify specific barriers and enablers to facilitate and resource epilepsy team involvement. Work with young people and families, including the Epilepsy12 Youth Advocates and RCPCH Engagement Team, to help promote and support local participation.

Action by: Integrated Care Boards across England and Local Health Boards across Wales.

Key Theme 1

2

Agree recommendations around appropriate allocation of time within multidisciplinary epilepsy teams and individual job plans for epilepsy specific audit participation, quality improvement and service leadership.

Action by: The UK Epilepsy Programme Board and the Organisation of Paediatric Epilepsy Networks in the UK (OPEN UK) working group.

Key Theme 1

3

To strengthen community and neighbourhood provision and address limitations in assessing quality of transition from paediatric to adult services, the long-term plans for NHS services in England and Wales should focus on the following to support children and young people with epilepsies:

- Developing digital tools and systems to support equitable communication, documentation and care planning, passports, mental health screening, transition, self-management and patient reported outcome and experience measures (PREM/PROM) within the home, community and education settings. This should include connecting families to their care quality information via NHS digital systems and the Epilepsy12 data platform.

Action by: NHS England and NHS Wales.

Key Theme 2

4

Improve timely and equitable access to tertiary and epilepsy surgery services by:

- Reviewing and updating referral criteria and pathways for epilepsy surgical evaluation, ensuring ongoing consistency between the evidence base, national recommendations and regional and local practices.
- Reviewing the specification of tertiary neuroscience services to ensure commissioning towards a sustainable workforce and capacity to meet the needs of local populations.

Action by: NHS England, the Children's Epilepsy Surgery Service (CESS) in England and Integrated Care Boards across England. The Welsh Government and Local Health Boards across Wales.

Key Theme 3

5

Support improvements in mental health provision, including screening, signposting, triaging, co-locating and clinical management, for children and young people with epilepsy in England and Wales. This could be achieved by:

- Completing the evaluation of mental health pilots in England including how they impact on Epilepsy12 performance metrics.
- Identifying opportunities for scaling and sustaining equitable mental health provision.

Action by: NHS England Epilepsy Oversight Group and Integrated Care Boards across England. The Welsh Government and Local Health Boards across Wales.

Key Theme 4

Key Themes

The following section describes key findings and messages from the 2025 analysis, alongside national recommendations based on the evidence.

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 the **2025 Epilepsy12 Longitudinal Trends Report**.

Epilepsy12 reports clinical and organisational data at local, regional and national levels. To align with the NHS England Core20PLUS5 approach to reducing health inequalities for children and young people, we are now also exploring variation by demographics. Last year, the Key Performance Indicators (KPIs) were broken down by ethnicity, deprivation, age, gender and geography. This year, the metrics are broken down further by the presence/absence of; 1) mental health conditions, and, 2) neurodevelopmental conditions or learning disabilities.

Cohort 6

Prior to the January 2025 deadline, **3,105 children and young people with an epilepsy diagnosis had a completed first year of care form in cohort 6**, and were therefore included in the analysis for this report. Epilepsy12 processes 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.

Description of cohort 6

The median **age** at first paediatric assessment was 7.9 years.

54.4% (1689/3,105) of children and young people had 'male' indicated as their **sex**.

Most children and young people were 'White' (64.8%). 8.2% were 'Asian', 5.1% were 'Black' and 16.1% did not have their **ethnicity** indicated.

28.5% (884/3,105) of children and young people lived in the most **deprived** quintile.

9% (278/3,105) of children and young people had a **mental health** condition identified.

27.5% (854/3,105) had a **neurodevelopmental condition** and/or **learning disability** identified.

**Deprivation quintile was derived by matching home postcodes to the English (IMD, 2019) and Welsh (WIMD, 2019) indices of multiple deprivation data.*

Key theme 1: Contributing and participating

There have been significant increases in total cohort size and data completeness this year. This improves the ability for Epilepsy12 to have confidence when drawing conclusions from the audit data, particularly when exploring longitudinally trends and variation between subgroups.

Achieving complete participation remains an issue; 30 Health Boards and Trusts did not enter clinical audit data this year.

Participation

150 NHS Health Boards and Trusts providing paediatric epilepsy care in England and Wales were registered into the Epilepsy12 audit, via a bespoke data platform launched in December 2023. This is an increase from the 138 Health Boards and Trusts registered to the old platform used in previous years.

- **80.0% (120/150**) of registered Health Boards and Trusts registered into Epilepsy12 participated in the cohort 6 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. Clinical audit participation has increased compared to 78% (108/138) for cohort 5 and 74% (103/140) in cohort 4.
- **75.5% (114/151)** submitted organisational data to describe their service as at 1 November 2023. This includes data from Jersey General Hospital which registered to participate after the clinical audit phase was underway. This is a decrease compared to the 85% (117/138) and 91% (120/140) of Health Boards and Trusts who participated in the 2023 and 2022 organisational audit respectively.

Cohort size

3,152 children and young people with epilepsy were registered onto the Epilepsy12 platform and allocated to cohort 6 before the January data submission deadline. **3,105** had fully completed first year of care forms and were included in analyses.

The cohort size has increased considerably in cohort 6, compared to the previous 5 cohorts which all had around 2,000 children and young people with epilepsy. Data completeness has also improved from 86% in cohort 5 to **98.5% (3,105/3,152)** in cohort 6. The increased cohort size and improved data completeness results may be a reflection of the streamlined data entry process established on the new Epilepsy12 data platform, launched for cohort 6. Find out more information below.

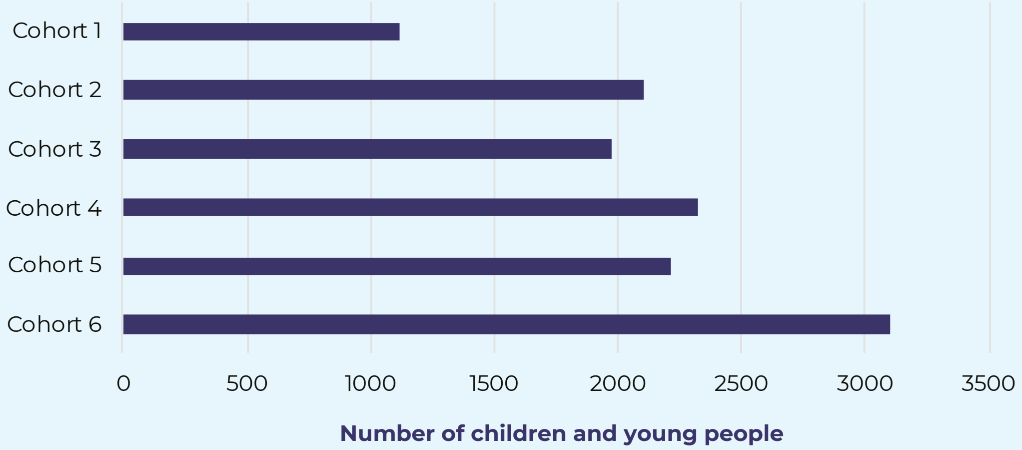


Figure 1 – the number of children and young people with epilepsy in each cohort.

Time allocated for audit, quality improvement and leadership

In 2024, **40.4% (46/114)** of Health Boards/Trusts did not have any time specified towards local epilepsy audit and quality improvement (QI) activity for teams, for example in nurse, doctor or allied professional's job plans. For teams with some time indicated, the median number of hours per week for audit/QI was 1 hour. **35.1% (40/114)** of Health Boards and Trust did not have any time specified for epilepsy leadership. For teams with some time indicated, the median numbers of hours per week for epilepsy leadership was 1 hour.

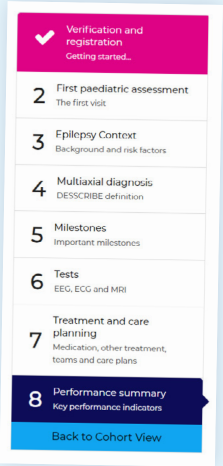
Epilepsy12 data collection and reporting

Epilepsy12, as the only national programme auditing and reporting on paediatric epilepsy care, plays an important role in measuring and improving quality of care and outcomes. We are also committed to reducing the data burden for clinical teams.

The launch of a bespoke Epilepsy12 data platform has considerably reduced the time required for data entry by hosting a minimised dataset and focused ascertainment methodology. The launch of the real-time and monthly KPI dashboards have improved the impact of audit data further, allowing services to benchmark and track their performance and improvement at frequent intervals. Access the monthly dashboard here.

The new platform has the capability to link directly to NHS digital systems via an Application Programme Interface (API) to allow data to flow automatically between patient electronic records and the audit platform. This will reduce data burden by eliminating manual data entry, reducing duplication of effort and streamlining processes. While further standardisation of epilepsy data recording within the NHS is needed for full implementation, Epilepsy12 has funded early work on an Epilepsy Information Standard in collaboration with the Professional Records Standards Body (PRSB) to support the interoperability needed. Find out more here.

Additionally, Epilepsy12 is exploring ways to introduce young person and family facing elements into the new platform.



Key theme 2: Building community and neighbourhood provision

Considerably more children and young people with epilepsy have a School Individual Health Care Plan in place within the first year of care, compared to previous years where it had been static. Progress has also been made in the agreement and contents within comprehensive care planning and key elements within transition services. There remain limitations in assessing and reporting the quality of transition from paediatric to adult services.

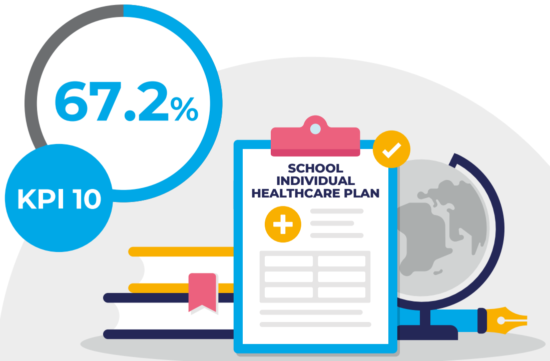
Care planning

85.8% (2,665/3,105) of children and young people with epilepsy had evidence of care planning agreement within the first year of care in cohort 6 (**KPI 9a**). **67.4% (2,093/3,105)** had evidence of achieving all core elements of care planning (**KPI 9b**). **Table 1** describes national results for the sub-metrics within KPI 9a and 9b.

	England and Wales
KPI 9a. All three elements of care planning agreement	**85.8% (2,665/3,105)**
Individualised epilepsy document or copy clinic letter that includes care planning information	90.8 % (2,819/3,105)
Evidence of agreement between the person, their family and/or carers as appropriate	87.6% (2,719/3,105)
The care plan has been updated where necessary	87.5% (2,716/3,105)
KPI 9b. All core elements of care planning	**67.4% (2,093/3,105)**
If prescribed rescue medication, prolonged seizures care plan	94.7% (748/790)
Water safety	86.7% (2,691/3,105)
First aid	89.3% (2,772/3,105)
General participation and risk	88.4% (2,744/3,105)
SUDEP	68.5% (2,127/3,105)
Service contact details	90.4% (2,806/3,105)

Table 1 – Cohort 6 results for Key Performance indicator (KPI) 9a and 9b in England and Wales.

KPI 10: 67.2% (1,427/2,125) of children and young people with epilepsy aged over 5 years had evidence of a School Individual Health Care Plan within the first year of care in cohort 6. This was a large increase compared to previous cohorts, for example 38.9% (573/1,472) in cohort 5, 36.9% (577/1,562) in cohort 4 and 36.1% (499/1,381) in cohort 3.



School Individual Health Care Plan

67.2% (1427/2125) of children and young people aged over 5 years had evidence of a School Individual Healthcare Plan within first year of care.

Transition from paediatric to adult services

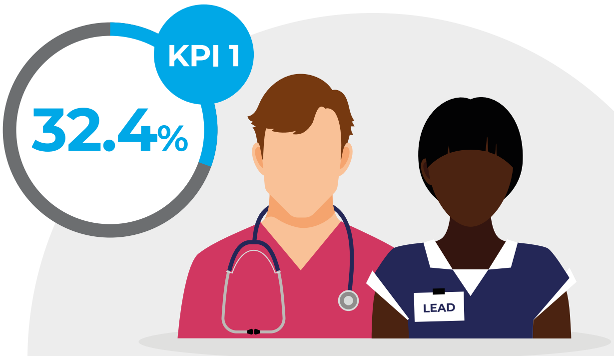
In 2024, **88.6% (101/114)** of participating Health Boards and Trusts had an agreed referral pathway to adult services, compared to 91% in 2023. **76.3% (87/114)** used structured transition resources, **61.4% (70/114)** had outpatient clinics specifically for young people with epilepsy and **66.7% (76/114)** involved both adult and paediatric professionals in transition services. In 2023, the results were 72% (84/117), 56% (65/117) and 68% (80/117), respectively.

Key theme 3: Strengthening epilepsy pathways

Epilepsy Specialist Nurse (ESN) provision is steadily improving over time since we began Epilepsy12 in 2009. More and more children and young people are having input from an ESN within the first year of care.

Since previous reports, a greater proportion of children and young people meeting the criteria for Children Epilepsy Surgical Services (CESS) are being referred to CESS within the first year of care.

There are emerging issues with timeliness within the initial referral and early management phases of paediatric seizure and epilepsy pathways.



Paediatrician with expertise in epilepsy within 2 weeks

32.4% (1007/3105) of children and young people were seen by a consultant paediatrician with expertise in epilepsies within two weeks from first paediatric assessment.

Paediatrician with expertise in epilepsy

- **KPI 1: 32.4% (1,007/3,105)** of children and young people with epilepsy were seen by a 'consultant paediatrician with expertise in epilepsy' within two weeks of referral. This was a decrease from 50.8% (1,123/2,212) in cohort 5.
- 90.2% (2,801/3,105) were seen within the first year of care, a decrease from 92% (2,077/2,212) in cohort 5.
- **96.5% (110/114)** of Health Boards/Trusts had some (ie. greater than 0) 'consultant paediatrician with expertise' provision. The remaining 4 Health Boards/ Trusts had 0.
- The mean Whole Time Equivalent (WTE) in Health Boards and Trusts for 'consultant paediatrician with expertise' was **2.2 WTE** in 2024, a decrease from 2.5 WTE in 2023.

Epilepsy Specialist Nurse (ESN)

- **KPI 2: 85.6% (2,659/3,105)** of children and young people with epilepsy were seen by an ESN within the first year of care. This was an increase compared to 80.7% (1,786/2,212) in cohort 5.
- **96.5% (110/114)** of Health Boards/Trusts had some (ie. greater than 0) ESN provision. The remaining 4 Health Boards/Trusts had 0 WTE.
- The mean WTE in Health Boards and Trusts for Epilepsy Specialist Nurses (ESN) was **1.8 WTE** in 2024, an increase from 1.6 in 2023.

Previously, Epilepsy12 has explored 'input' from key healthcare professionals. In the new platform and from cohort 6 onwards, we have refined the terminology of several KPIs to clarify the definition of 'input'. KPIs 1 – 3 now identify those children and young people being 'seen by' the relevant professional.

This includes emergency department reviews, face-to-face clinic appointments or virtual appointments, and captures the direct clinical interactions between the professional and the family in clinical or acute settings. Interactions between professionals, not involving the families, are not included.

Investigations

The majority of children and young people with epilepsy received an EEG (98.5% (3,057/3,105)). In England and Wales, the median wait time for an EEG was 3.3 weeks.

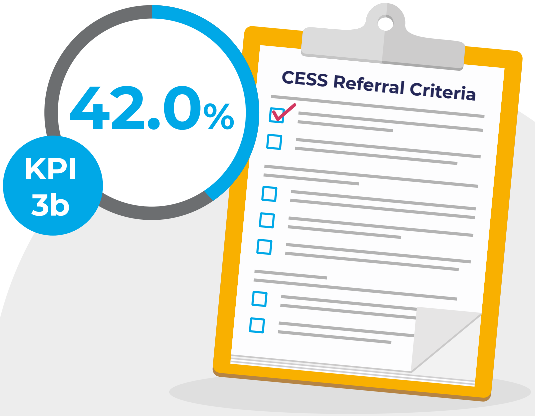
- **KPI 5: 49.2% (1,181/2,401)** of children and young people with epilepsy and defined indications for an MRI had an MRI brain scan within 6 weeks of request. This was a decrease from 53.1 % (385/725) in cohort 5.
- The MRI indications have evolved over time to align with NICE guidelines, creating challenges with longitudinal comparisons.

49.2% (388/788) of children and young people with epilepsy meeting defined criteria for tertiary input, received input of tertiary care and/or Children's Epilepsy Surgical Service (CESS) referral within the first year of care (**KPI 3a**). This measure has shown little improvement from previous cohorts.

- **KPI 3b: 42.0% (94/193)** of children and young people with epilepsy meeting CESS referral criteria had evidence of CESS referral within the first year of care. This was an increase compared to previous cohorts, for example 37.3% (41/110) in cohort 5.

19% (22/114) of Health Boards and Trusts had some (ie. greater than 0) paediatric neurologist provision. This ranged from 9.1% (East of England) to 47.1% (London) across NHS England regions and Wales.

- The mean WTE in Health Boards and Trusts for paediatric neurologists was **1.2**, which is an increase from 0.8 in 2023. Mean WTE ranged from 0.1 (South West) to 3.6 (North West) across NHS England regions and Wales.



Epilepsy surgery referral

42.0% (81/193) of children and young people who met Children's Epilepsy Surgical Service Referral (CESS) criteria had evidence of a CESS referral within the first year of care.

Figure 2 describes the mean Whole Time Equivalent (WTE) results for consultant paediatricians with 'expertise in epilepsy', epilepsy specialist nurses (ESN) and paediatric neurologists in England and Wales over time. Note, that these results include all Health Boards and Trusts participating in the relevant organisational audit, including those with 0 WTE of the professional.

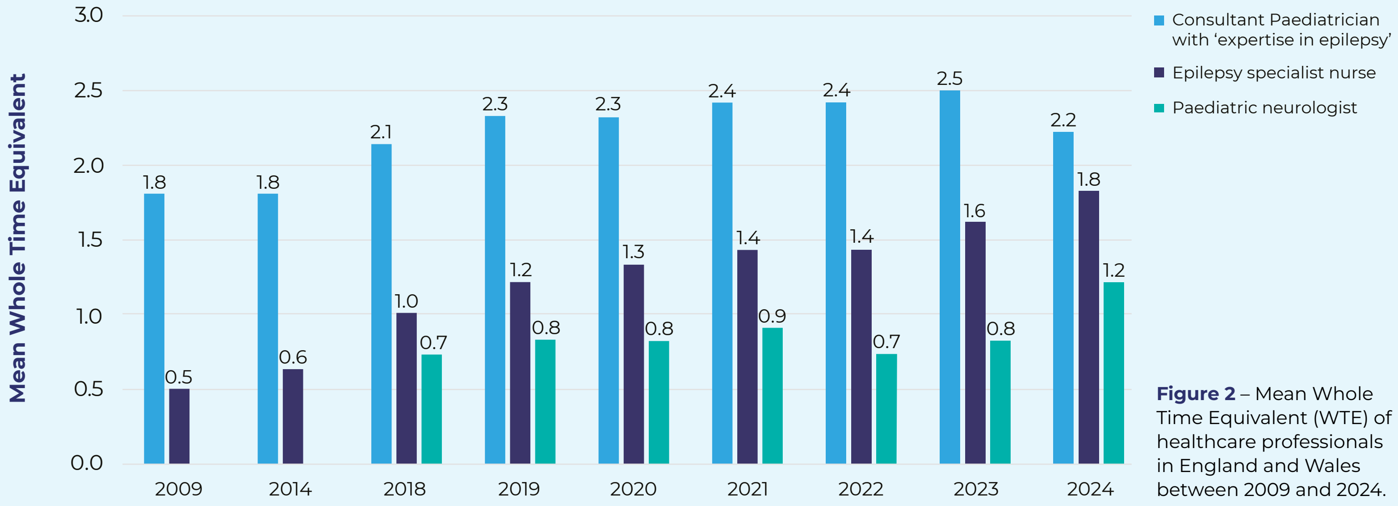


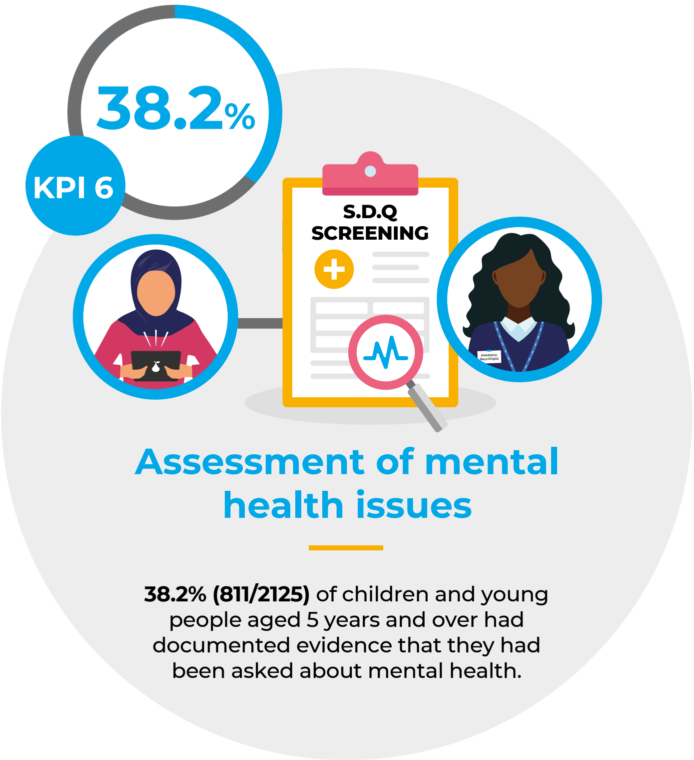
Figure 2 – Mean Whole Time Equivalent (WTE) of healthcare professionals in England and Wales between 2009 and 2024.

Key theme 4: Supporting mental health and wellbeing

Although there are some encouraging improvements in mental health enquiry and resulting provision, there remain many children and young people whose mental health is not being assessed, supported and resourced as needed.

Mental health provision

74.6% (85/114) of Health Boards and Trusts had agreed referral pathways for mental health conditions (2023 = 73.5%). Only **25.4% (29/114)** formally screened for mental health disorders (2023 = 30%) and **22.8% (26/114)** facilitated mental health provision within epilepsy clinics: 'co-located mental healthcare' (2023 = 18%).



Assessment of mental health issues

38.2% (811/2125) of children and young people aged 5 years and over had documented evidence that they had been asked about mental health.

Research suggests there is a high incidence of mental health conditions among children and young people with long term conditions[1]. Only **9% (278/3,105)** of children and young people in cohort 6 had a mental health condition identified, suggesting under-reporting of mental health.

- **38.2% (811/2,125)** of children and young people with epilepsy, aged 5 years and over, had documented evidence of assessment of mental health issues within the first year in cohort 6 (**KPI 6**). This increased from 22.4% (330/1472) in cohort 5.
- **76.6% (213/278)** of children and young people with epilepsy that had an identified mental health problem, also had evidence of receiving mental health support within the first year of care in cohort 6 (**KPI 7**). This increased from 61.5% (83/135) in cohort 5.

RCPCH Epilepsy Quality Improvement Programme (EQIP)

The **RCPCH Epilepsy Quality Improvement Programme (EQIP)** ran from 2019 to 2024, bringing together paediatric epilepsy teams across England and Wales to learn, implement, and share quality improvement (QI) projects. Their case studies offer valuable insights into local improvements, focusing on key themes such as mental health support, transition pathways, and health inequalities.

The EQIP Programme 2019–2023 Impact Report highlights how quality improvement training helps to transform NHS services. It showcases how incremental changes and whole-team training enhances patient care, reducing wait times, addressing mental health challenges, and improving outcomes for children and young people with epilepsy. You can access the full report here.

The 2023–2024 Summary Report for EQIP is now available. Building on the 2019–2023 Impact Report, it demonstrates ongoing improvements in patient care and service delivery for children with epilepsy. View the report here.

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[1] Buelow JM, et al. (2003) Behaviour and mental health problems in children with epilepsy and low IQ. Dev Med Child Neuro

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.

After reviewing the Epilepsy12 cohort 6 results, we were thrilled to see that the number of children and young people with epilepsy aged above 5 years who had a School Individual Health Care Plan within the first year of care had doubled. This is a significant improvement from cohort 5, though we acknowledge that further work is needed. We'd love to share our experiences and top tips to help support other children and young people in getting a School Individual Health Care Plan in place.

"I didn't have an individual care plan until sixth form, where I received support after sharing my disabilities. This included having someone write my notes out for me, my teachers and group one-to-ones would break down the assignments for me. This support at sixth form helped me achieve top grades. At University, I applied for disability student allowance and worked with Disability Support to create a care plan. My disability support officer assisted with my needs, and I had accommodations like recording lectures and advanced slides, making my studies and placements easier."

Top tips

- ✓ Children and young people with epilepsy need personalised plans tailored to their unique needs. This ensures they feel heard and supported, boosting their confidence for future steps, whether it's transitioning to a new school or embarking on a trip of a lifetime.
- ✓ Care plans should be clear, detailed, and comprehensive. They must offer extra help and advice, and be universally accessible to ensure the right information is easy to find.
- ✓ If health services could assist parents/carers by helping them apply for their children's care plans or directly contacting the child's school to ensure they receive a care plan. This support could be in the form of a letter for the school or providing guidance.

"I was diagnosed with epilepsy in 2018. My parents and I met with the School Nurse and Headmaster to create a plan. Teachers were informed and updates were made as needed. It was a learning curve for everyone. Before starting Senior School, the Senior School Nurse contacted us to ensure a plan was in place and teachers were aware. Over the past 7 years, she has kept teachers updated on any changes and ensured protocols were followed during school trips. Regular appointments with the Headmaster and School Nurse, who had experience with Health Care Plans, including epilepsy, made me feel calmer. The plan allowed me to attend day trips, complete two Duke of Edinburgh's expeditions, and go on a 7-night trip to America. Without this support, traveling would have been much more difficult."

Resource

With the right support at school, work, or home, children and young people can feel empowered. Keeping individualised care plans up-to-date is key.

Download our example School Individual Health Care Plan template here.

EPILEPSY12

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