

## Epilepsy12 Quality Improvement Strategy

### Introduction

Epilepsy12, the **National Clinical Audit of Seizures and Epilepsies for Children and Young People**, measures the quality and safety of care for children and young people with epilepsy in England and Wales. The audit is commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the wider National Clinical Audit and Patient Outcomes Programme (NCAPOP) and includes NHS services in England and Wales. Epilepsy12 has been delivered by the Royal College of Paediatrics and Child Health (RCPCH) since 2009, with the most recent Round 4 contract awarded to run from April 2022 to March 2025. Epilepsy12 collaborates with clinicians, children and young people, families, charity organisations and wider stakeholders with an interest in paediatric epilepsy to ensure that their needs are reflected in our work.

The audit aims to facilitate continuous improvement in epilepsy care through providing a trusted source of accurate benchmarking data in support of quality improvement (QI) activities. In round 4, members of the audit methodology and dataset group (M&DG) and project board have identified 10 key performance indicators, aligning with the NICE Guidelines and Quality Standards for epilepsy in children and young people. Since the audit started in 2009, Epilepsy12 has also expanded its scope to reflect the priorities raised by key stakeholders, including children and young people who have themselves chosen, developed and helped to deliver innovative activities for the audit.

There has been considerable variation in the ability of NHS Health Boards and Trusts to submit data and participate in the audit. Ongoing efforts by the Epilepsy12 team, informed by feedback from participating clinical teams, have aimed to enhance the value of the audit, reduce the workload associated with submitting data to the audit and produce more frequent and useful reporting outputs to encourage prospective data submission. Greater data completeness will improve data accuracy, better our understanding, and drive improvement at local, regional and national levels.

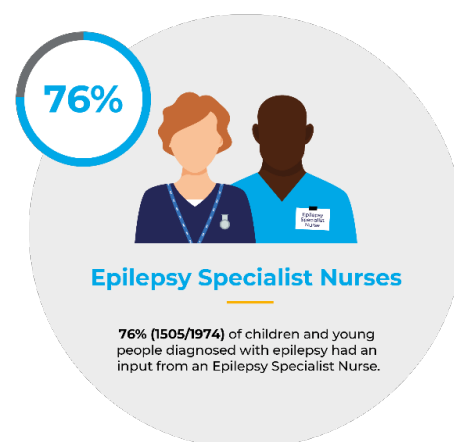
### Key Findings and Recommendations

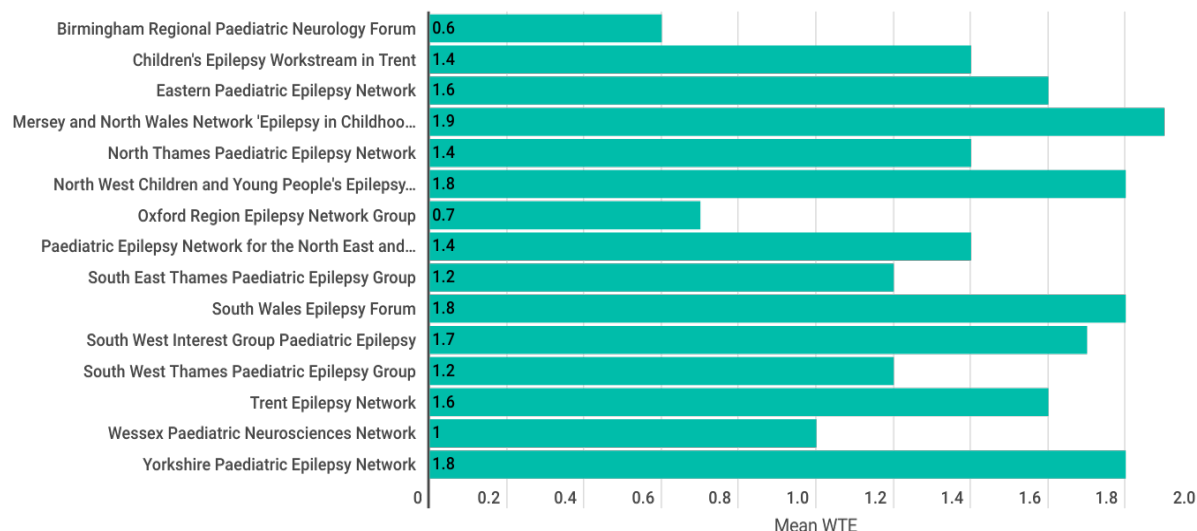
**Epilepsy12 Annual Report, published in September 2022 (updated Nov 2022)**

#### Access to Health Professionals

Epilepsy12 recommends that all children and young people with epilepsy receive input from a paediatrician with expertise and an Epilepsy Specialist Nurse (ESN) within the first year of care following first paediatric assessment. Access to these key health professionals ensure patients reliably receive responsive, individualised, specialist input into their epilepsy care.

The mean whole time equivalent (WTE) for general paediatric consultants, paediatric consultants with expertise in epilepsy and ESNs have increased over time. However, not all children and young people are receiving input from these professionals, and there is considerable variation between services, as highlighted in figure 1.





**Figure 1 - Mean whole time equivalent (WTE) for ESNs per Trust/Health Board by OPEN UK region (Cohort 3).**

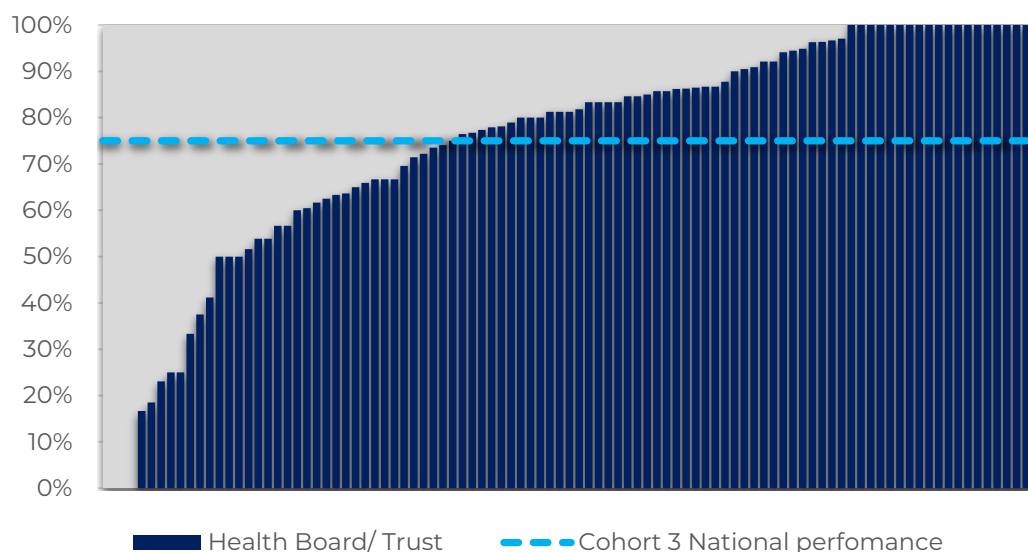
There is evidence that some children and young people with epilepsy may not be being referred as appropriate to tertiary care and also missing out on, or having delayed referral for, epilepsy surgery assessment and intervention.



36% of children and young people diagnosed with epilepsy who met surgical referral criteria had a referral to CESS for surgical evaluation during their first year of care in cohort 3. This has increased from figures in cohort 1 and 2 (30% and 23%, respectively).

## Care Planning

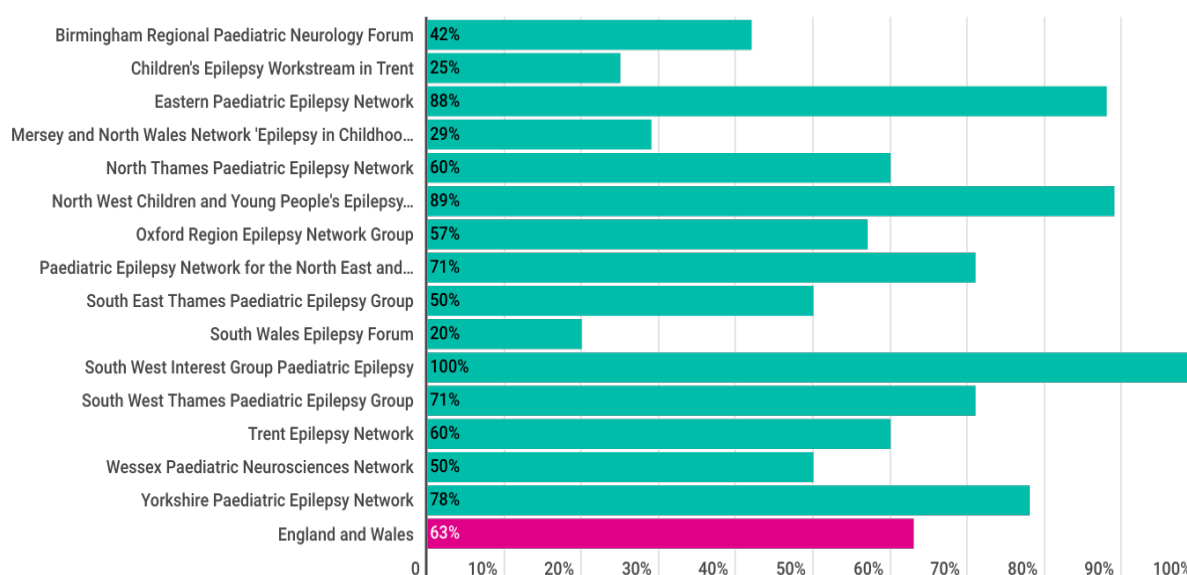
All children and young people with epilepsy should have agreed and up to date care planning, agreeing key information on their seizures, treatment, and other safety and participation information. There is widespread care planning, however planning was missing vital information (figure 2). Epilepsy12 also recommends all school age children have a School Individual Health Care Plan, so that educational facilities have agreed key information on their epilepsy and potential impact and provision needed in their education environment. However, only 32% of children and young people with epilepsy had evidence of a School Individual Health Care plan in cohort 3, with considerable variation between services.



**Figure 2 – Comprehensive care planning content by Health Board and Trust (cohort 3).**  
Each Health Board/Trust is represented by a vertical bar, including those scoring 0%.

## Transition

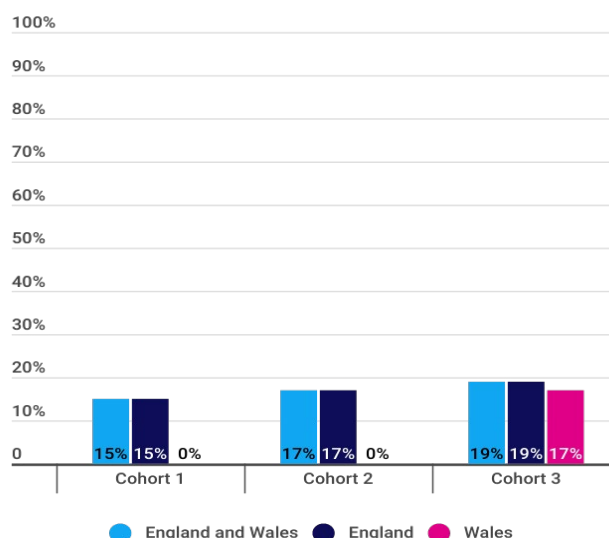
There can be challenges when young people with epilepsy transition their care from paediatric to adult services. Epilepsy12 recommends joint-working across the two services to support young people through this transition. In 2021, 65% of Trust/Health Boards had adult ESNs routinely involved in the transition of young people to adult serves. The provision of transition services has increased over time, however, the available support and pathways for patients varies between services, as highlighted in figure 3.



**Figure 3 - Percentage of Health Boards/Trusts using structured transition resources in 2021.**

## Mental Health

Research shows there is a high incidence of mental health problems among children and young people with long term conditions, particularly epilepsy, yet less than expected of those with epilepsy had a mental health condition identified<sup>1</sup>. Few epilepsy services use formal screening tools to identify mental health conditions, have agreed referral pathways for children and young people or co-located mental health services within their Trust/Health Board.



**Figure 4 - Percentage of Health Boards/Trusts screening for mental health conditions.**

## Healthcare Improvement Strategy

Epilepsy12 aims to improve clinical outcomes and reduce variation for children and young people with epilepsy in England and Wales. This Health Improvement Strategy outlines how the audit will deliver against those aims across 2022 to 2025.

To focus this strategy, Epilepsy12 engaged with relevant stakeholders to identify the priority areas of care and agree five aligning **Health Improvement Goals**.

- 1 Increase the proportion of children receiving input from an epilepsy specialist nurse by 5% per year; from 76% in Cohort 3 to 91% in Cohort 6
- 2 For children with complex epilepsy, increase the proportion receiving input from tertiary specialist by 5% per year; from 59% in Cohort 3 to 74% in Cohort 6
- 3 Increase the proportion of children receiving all core elements of care planning by 5% per year; from 75% in Cohort 3 to 90% in Cohort 6
- 4 Increase the proportion of Health Boards and Trusts using structured transition resources by 5% per year; from 62% in Cohort 3 to 77% in Cohort 6
- 5 Increase the number of Health Boards and Trusts screening children with epilepsy for mental health disorders by 5%; from 19% in Cohort 3 to 34% in Cohort 6

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

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## Improvement Methods

Expert advice and support will continue to be provided by the RCPCH Head of Quality Improvement, RCPCH Officers for Clinical Standards and Quality Improvement and the Epilepsy12 Clinical Lead, as well as by members of the Epilepsy12 Project Board and Methodology & Dataset Group (MD&G), the Epilepsy12 Youth Advocates and the Epilepsy Quality Improvement Programme (EQIP) Advisory Panel.

Epilepsy12 collaborated with these QI experts when designing the improvement goals and strategies. We will continue to receive their input as we review the delivery of this strategy and we will seek guidance on how we can best incorporate monitoring and evaluation into the process so as to learn, amend and improve the strategy over time and explore avenues of collaboration colleagues within the NHS, professional bodies such as the BPNA, HQIP and other improvement programmes.

The improvement strategy will be delivered at **local, regional and national** levels, and will encompass the following Epilepsy12 activities and outputs.

- **NHS Health Boards and Trusts**

The **Epilepsy12 State of the Nation annual report** will describe national results (England and Wales combined) for the audit's 10 key performance indicators and will describe the key findings and national recommendations based on these data. Health boards/Trusts will also be provided with detailed reports specific to their service(s), describing their clinical and organisational data compared to regional and national data. These outputs, alongside the new audit dashboards which are described later, will include reporting of data for audit measures directly relating to the improvement goals, and the information will drive local benchmarking and help services identify key areas of quality improvement.

The **Epilepsy12 and Organisation of Paediatric Epilepsy Networks (OPEN UK) National Conference** takes place annually and brings together experienced healthcare professionals, children and young people, charity organisations, commissioners and other Epilepsy12 stakeholders to discuss how to support paediatric epilepsy services and improve paediatric epilepsy care.

QI will continue to be a key element which is embedded into the event, with a clear focus in the programme on the priority areas associated with the Epilepsy12 improvement goals. We will also collaborate with experts to deliver improvement goal-focused workshops to attendees.

Epilepsy12 will publish QI case studies, presentations and resources generated at the conference and across other audit activities, such as focused webinars via RCPCH QI Central and other relevant platforms. This repository will showcase QI successes, inspire and guide other teams to implement similar improvement strategies and encourage shared learning.

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- **Patients and the public**

Public-facing Epilepsy12 data reporting will be accompanied by narratives to describe the results in language accessible to patients, families, and the public. Patient resources, such as leaflets and/or clinic posters, will continue to be co-designed with patients, parents and relevant third-sector groups. These outputs will help raise awareness and understanding of audit key performance measures and improvement goals.

Epilepsy12 has commissioned the **Association for Young People's Health (AYPH)** to carry out an engagement and scoping project to 'Understanding the experiences of young people with epilepsy from communities that experience marginalisation'. This project, which started in January 2023, will reflect patient experiences from marginalised groups and facilitate the ability of the group of patients and their family members to influence the audit design, respond to the improvement goals, and help direct appropriate audit reporting and communications.

The Epilepsy12 '**Impact and Influence of CYP Voice**' project is a tiered programme which will aim to create one product, one video and one training resource, focusing on Epilepsy12 and Youth Advocate priority areas, for five distinct audiences: (1) Child/young person, (2) family, (3) doctor/ESN, (4) Epilepsy service manager, (5) Health Board/Trust/ICS. The RCPCH Children and Young Person Engagement Team are delivering this project as part of the RCPCH &Us programme and the products will be designed to drive QI across the five different groups.

We will continue to work with RCPCH& Us to deliver the **Youth Advocates** participation programme. The Epilepsy12 Youth Advocates are a group of epilepsy experienced or interested children, young people and families who volunteer to help improve care for patients and their families. This programme supports young people with epilepsies to design improvement activities and provide input into the design, delivery and governance of Epilepsy12. The Youth Advocates have helped shape our new performance metrics and quality improvement goals to ensure alignment with patient needs.

Over the years, the Youth Advocates have implemented successful improvement projects and developed several patient resources, including a [Clinic Chat Checklist](#) for worries and anxieties, [patient leaflets](#) and [School Individual Health Care Plan](#) examples. These resources provide patients with the tools to ensure that they are receiving the best standard of care, particularly around ESN input and care planning. The Youth Advocates have recently won the **HQIP Richard Driscoll Memorial Award** for the second time for outstanding patient engagement. Epilepsy12 will continue to work with, support and be guided by the Youth Advocates in future quality improvement work.

- **Integrated Care Systems (ICS) and Regional Networks**

Epilepsy12 will continue to host national meetings to bring together the 17 regional leads of the [OPEN UK](#) regional networks. These meetings take place virtually every two months to maximise attendance, and the space is used to highlight regional successes, identify common challenges experienced across the UK and facilitate national collaboration and learning.

Through the Epilepsy12 frequent reporting dashboards, ICS, NHS Region, and OPEN UK leads will have access to Epilepsy12 participation and performance data for the Health Boards/Trusts that they

oversee. These data will allow regional benchmarking, highlight variation within and between regions and inform QI and planning.

The Epilepsy12 team will continue to engage ICSs and other commissioning bodies to ensure audit reporting provides an evidence base for describing, prioritising and monitoring the impact of improvement interventions.

## • National organisations and initiatives

Epilepsy12 will support coordinated efforts to improve paediatric epilepsy care by collaborating with NHS England, NHS Wales, OPEN UK, the British Paediatric Neurology Association (BPNA) and members of the RCPCH-hosted UK Epilepsy Programme Board. The audit will also continue to align itself with national QI initiatives, such as GIRFT. Our datasets remain mapped via clear 'line of sight' with the NICE guidelines on 'Epilepsies in children, young people and adults' [updated April 2022], and we are involved in the update of the NICE Quality Standards [QS27] Epilepsy in children and young people.

Epilepsy12 has agreed to fund the Professional Record Standards Body (PRSB) to conduct the Discovery phase for the project that it will create standards for health and social care records for epilepsies. We will support this process through the subsequent stages and plan to align the audit's dataset and collection platforms to these standards once ratified and published.

The Epilepsy Oversight group, established via the **NHS England Children and Young People Transformation Programme**, has used Epilepsy12 data as part of its process to define four priority areas, which are also aligned with our improvement goals.

Access to <b>mental health</b> screening & psychosocial support	<b>Transition</b> from paediatric to adult epilepsy services
Access to <b>tertiary services</b> , including epilepsy surgery	<b>Variation</b> in care provided.

Epilepsy12 will continue to support the Epilepsy Oversight group by providing quarterly data on key audit metrics and monthly if requested from 2024, to help inform improvement and planning, and help shape the recommendations made by these working groups.

Additionally, we will continue to deliver an **outlier identification and management process** and share the results of this process with the CQC and Welsh Government. Our [outlier management documentation](#) outlines the analyses determining which Health Boards and Trusts are positive or negative outliers on the following three measures:

1. **Epilepsy Specialist Nurse (ESN) input** - The proportion of children and young people diagnosed with epilepsy receiving input from an ESN during their first year of care.
2. **Tertiary input** - The proportion of children and young people diagnosed with epilepsy receiving input from tertiary services during their first year of care.
3. **Case Ascertainment** – the proportion of children and young people registered into Epilepsy12 who were verified on the audit data system by their NHS Health Board/Trust

Alerting clinical leads, chief executives and medical directors of a negative outlier status will promote organisational awareness of local challenges and invoke QI activities, as teams will be required to submit action plans tackling the areas of concern identified by Epilepsy12 to the CQC and/or the Welsh Government.



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## Epilepsy Quality Improvement Programme (EQIP)

The [EQIP](#) supports paediatric epilepsy service teams to make improvements at a local Health Board/Trust and ICS level. The programme's design was supported by the EQIP Advisory Panel, a group of epilepsy specialist nurses with extensive knowledge of our patient group and paediatric epilepsy services. The EQIP Faculty sets the strategy and direction of the programme and brings together different improvement expertise and perspectives, including patient organisations, clinicians, and audit stakeholders. Both groups would input into future activities to ensure these meet the needs of healthcare providers and the patients and families that they care for.

By participating in the EQIP, teams learn core quality improvement methods and are supported in designing and implementing an improvement project in their own service. At the end of the programme, they showcase their findings to encourage shared learning between services and with subsequent EQIP teams.

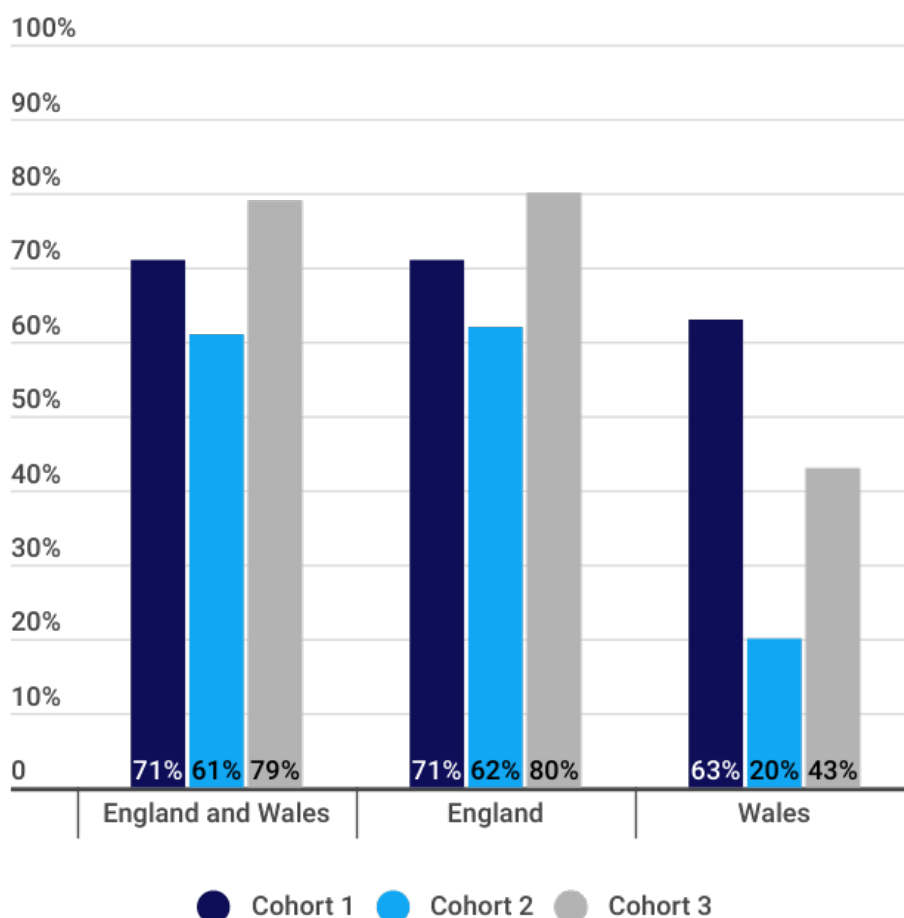
## Improving Epilepsy12 data collection and reporting

### Case ascertainment and data completeness

The aim is for all relevant NHS Health Boards and Trusts to register and fully participate in Epilepsy12. Case ascertainment and participation rates have increased over the past years, however, they are not currently at 100%, as shown in figure 5 below. Some paediatric epilepsy teams have expressed that they are struggling to enter audit data on top of their clinical duties, particularly during the COVID-19 pandemic but also during annual winter pressures.

Epilepsy 12 will continue to work to increase these rates by monitoring the capacity of paediatric epilepsy teams to supply data and by facilitating additional and/or alternative data flows if required. The audit has worked to establish strong relationships and user engagement and will continue to build on this. For Round 4, we are implementing several changes to the way Epilepsy 12 collects and reports data. These improvements are intended to reduce the data burden experienced by teams and increase user accessibility to encourage full participation.





**Figure 5** - Clinical audit data completeness; percentage of children and young people with first year of care forms locked and submitted.

## Data Collection and Reporting in Round 4

Epilepsy12 will follow the 10-page 'State of the Nation' template set out by HQIP when producing future annual reports. This summary report will highlight key findings and national recommendations, in a format easily accessible by the public, as well as by senior management teams within services to facilitate organisational awareness of Epilepsy12 results. Detailed analyses will be provided in a layered fashion to allow services to explore their local data, benchmark against other services across the country and their respective region and ICS and carry out 'deep-dives'.

After discussions with the Epilepsy12 Youth Advocates, relevant stakeholders and the audit's Project Board and M&DG, Epilepsy12 has refined the number of audit performance indicators from 12 to 10 metrics, which also closely align to the improvement goals. Several measures were maintained to continue capturing the involvement of appropriate health professionals, assessments and the presence of care planning elements within the first 12 months following first paediatric assessment. Two mental health measures, and the aspect of timely access to health professionals and vital investigations were introduced to initiate improvement within these areas.

To safeguard patient confidentiality and avoid publishing patient identifiable information in the public domain, the audit masks small numbers within its reports. Previously, numbers less than 5, but different to 0, were replaced by asterisks. In 2023, following discussion with the audit's Project Board and MD&G, we have revised the guidance, such that numbers less than 3, but different to 0, are masked. This change aligns Epilepsy12 with the other NCAPOP audits delivered by the RCPCH, and ensures we are able to share data in audit reports where small patient numbers are expected, such as in the frequent reporting dashboard.

Health Boards/Trusts will be able to access the public-facing Epilepsy12 dashboard to find more frequent information on how their service, ICS, network or region performed on key Epilepsy12 and NHSE metrics, compared to the national average. These data will be updated every quarter from Spring 2023 and monthly from Spring 2024, contingent on protecting patient confidentiality, and will help monitor improvement activities. In addition to describing the geographical variation in Epilepsy12 data, the audit will also begin investigating the variation in care between sociodemographic population groups, by reporting data by deprivation quintile and ethnicity.

Providing clinical teams with accurate and complete data regularly will highlight the importance of data in measuring performance and identifying areas of improvement. This will help encourage further participation in Epilepsy12 and timely data submission when both users and the wider organisations experience the benefits.

## New Epilepsy12 Data Platform

The RCPCH started developing an **Epilepsy Application Programming Interface (API)** to power responsive data and intelligence. Epilepsy12 data is currently inputted into our online data platform by members of the clinical team or admin support in the Health Board/Trust, either prospectively or retrospectively. Data entry is time consuming and increasingly duplicates information teams are entering into Electronic Patient Records (EPR), increasing the overall burden on teams. An API would solve this by allowing data to flow directly from EPRs into the Epilepsy12 platform.

There are considerable challenges around securing data flows from EPRs into the audit, due to the complexity and variability in EPR formats across different services. We have responded to this and continued to develop a platform which would:

- **Reduce the data burden** for clinicians and increase data completeness, by:
  - Hosting a **minimised dataset**.
  - **Only collecting information on patients with confirmed epilepsy diagnoses**, compared to the current inclusion criteria of all children and young people with paroxysmal episode(s). In cohort 3, we had 5,946 first year of care forms submitted, of which 1,957 were epilepsy patients. Only entering data for children and young people with a confirmed epilepsy diagnosis will reduce data entry time significantly.
  - Having a platform that is **easier to use & navigate** for users.
- Host our frequent **public-facing reporting dashboards**.
- Allow for real-time feedback via live **clinician facing dashboards**, where performance refreshes every time a new patient record has been completed.
- **Identify potential gaps in patient care**

- A 'performance summary' tab will be available in each patient record to display whether the 10 performance metrics have been met yet. This will identify the gaps in key elements of care and allow for correction before the first year has been completed.
- Introducing a **child/young person/parent/carer facing element** to the Epilepsy12 API
  - When further developed, and subject to all necessary information governance approvals, this will also allow patients and their parents/carers to access their own audit record. There is potential to have patients provide their consent to the audit here, update any information themselves or participate in a PREM/PROMs.

## Epilepsy12 API data platform example – patient performance summary

- ✓ **Verification and registration**  
Getting started...
- ✓ **First paediatric assessment**  
The first visit
- ✓ **Epilepsy Context**  
Background and risk factors
- 4 Multiaxial diagnosis**  
DESCRIBE definition
- ✓ **Milestones**  
Important milestones
- ✓ **Tests**  
EEG, ECG and MRI
- ✓ **Treatment and care planning**  
Medication, other treatment, teams and care plans
- 8 Performance summary**  
Key performance indicators

**Performance summary for Josh Albie**

Clinical Team

Indicator	Performance
Paediatrician with expertise in epilepsies	⚠
Epilepsy Specialist Nurse	✓
Tertiary input	✓
Epilepsy surgery referral	⚠

Investigations

Indicator	Performance
ECG	⚠
MRI	⚠

\*Note this image shows a dummy patient record and does not contain real patient information.

Demographic data, such as patients' names and dates of births, could flow directly from EPRs to the API test platform. Clinicians can then complete the remaining fields on the platform. Additionally, there is potential to link complete data from EPRs in future if a data standard for epilepsy is developed, for instance via the PRSB work referenced above, and adopted by all services.

The platform has been developed and tested internally. The next step will be to carry out further testing with stakeholders; (1) have OPEN UK volunteers enter dummy data and (2) select a small number of Health Boards/Trusts to begin entering patient data. Following successful testing, we propose to move all registered services to the new platform by December 2023, to align with the cohort 6 start date.

Changing the way Epilepsy12 collects and reports data will reduce the audit's data burden, increase the frequency and utility of audit outputs and improve user experience to encourage participation. Additionally, this new technology will promote digital improvement in the wider healthcare community. A complete dataset submission by all participating Health Boards/Trusts will help Epilepsy12 report on and work towards achieving our improvement goals, and the new data platform will be a key quality improvement tool to help local teams monitor their performance.

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## Communications Strategy

The development and delivery of the Epilepsy12 communications strategy will continue to involve national stakeholder organisations, regional networks, and parent representatives. Users registered onto the data platform receive regular emails on upcoming activities, updates or deadlines. We also produce quarterly newsletters to summarise our activities, and these are emailed to users, regional leads, members of our Project Board and MD&G and other stakeholders. Epilepsy12 can highlight QI activities and tools in these communications, as well as at quarterly Epilepsy12 Project Board and M&DG meetings, bi-annual contract review meetings with HQIP colleagues and at the joint Epilepsy12 and OPEN UK annual conferences. This will ensure QI plans are guided and monitored by key stakeholders.

We engage with the Epilepsy12 Youth Advocates and our charity organisations to develop and disseminate appropriately worded information more widely into the public domain. Our patient resources, such as the [patient and parent guides](#) and a [young person leaflet](#), include lay summaries of key audit messages and describe the elements of high-quality epilepsy care and how services can and should be meeting them. Clinic posters display recent Epilepsy12 results for the Health Board/Trust, and these are displayed in clinic rooms to raise awareness amongst the families of children and young people with epilepsy and help them understand how their service is performing.

The [Epilepsy12 website](#) contains up to date information on the audit's data collection, methodology, recent QI activities and other resources to help clinicians with data entry. These will be updated as and when any methodological changes occur and when the new data platform is launched and will help users learn how to get the best use out of the platform and the improvement tools within it. QI case studies from local services have been published in annual reports and at Epilepsy12 and OPEN UK conferences to highlight successes and encourage shared learning, and these will continue to be published in an online repository. Teams can access the [EQIP website](#) to learn about legacy projects developed and delivered as part of that programme.

## Evaluation

The total longitudinal impact of Epilepsy12 and other national and local QI initiatives will be demonstrated within the audit outputs; the annual State of the Nation report, and quarterly and monthly dashboard outputs showing Epilepsy12 results at all levels of granularity. An iterative process of clinical audit and improvement interventions can allow NCAPOP audits, such as Epilepsy12, to extend our focus to areas of service delivery which the audit alone may not capture. This process allows us to track sustained improvement over time and helps create a continuous commitment to improvement<sup>2</sup>.

Future Epilepsy12 audit rounds could also allow for the collection of patient reported experience and/or outcome measures (PREM/PROMs) through the API platform, if directed by our commissioners to do so, which might also be beneficial in collecting patient narratives to evaluate the efficacy of Epilepsy12 QI interventions. We will assess for and mitigate against any unintended consequences of interventions, for example, increasing the number of ESN clinics, may result in

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<sup>2</sup> Backhouse, A. & Ogunlayi, F. (2020) Quality improvement into practice. BMJ

fatigue and affect the quality of care provided. This will also be monitored through ongoing audit cycles and a systems approach to analysis.

Our evaluation will allow for the recognition and sharing of successful interventions within the paediatric epilepsy community. We will share impact evaluation at Project Board, M&DG, HQIP contract review meetings, and in Epilepsy12 communications. We will also monitor outputs including engagement with social media, workshops attendance, accessing online reporting, and feedback surveys. The elements above allow multiple ways to co-produce the audit design and share learning for continuous improvement.

## Key References

- Buelow JM, et al. (2003) Behavior and mental health problems in children with epilepsy and low IQ. *Dev Med Child Neurol*
- Backhouse, A. & Ogunlayi, F. (2020) Quality improvement into practice. *BMJ*
- Epilepsies in children, young people and adults [NG217] April 2022
- Epilepsy12 2022 Combined organisational and clinical audits: Report for England and Wales Round 3, Cohort 3 (2019-21) – Version 2.0: Updated November 2022
- Epilepsy12 Overview of the methodology for Round 4 – September 2022
- RCPCH Detection and Management of Outlier Status for Clinical Indicators in Epilepsy12 – Version 5.0: Updated November 2021

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## 2023 – 2024 Update

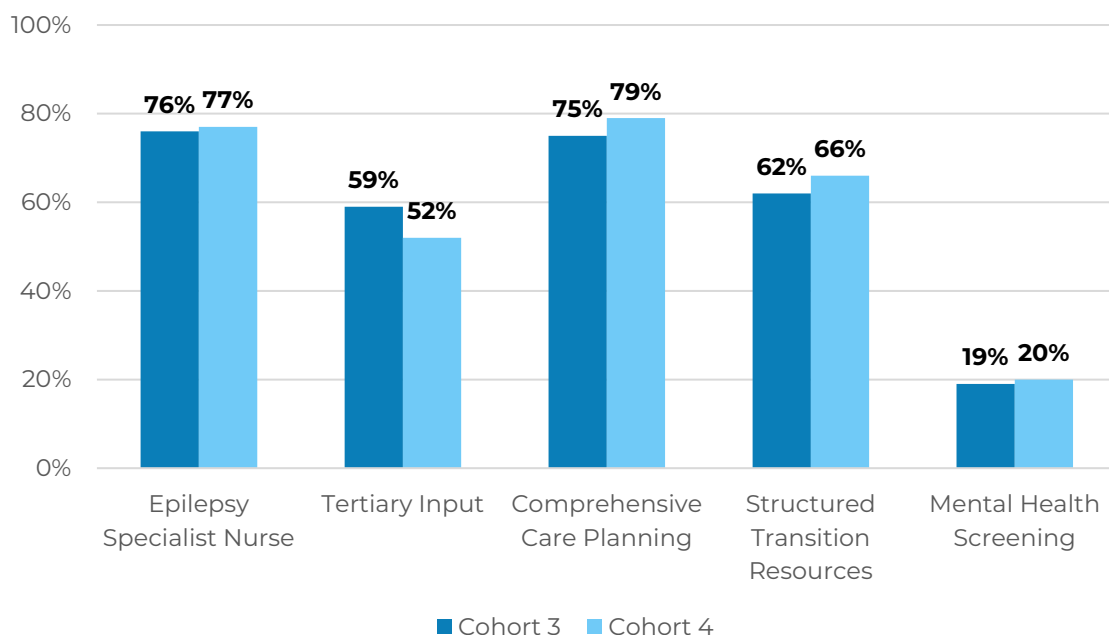
As part of an annual process, the Epilepsy12 Quality Improvement Strategy was reviewed to provide an update on audit activity, evaluate progress against the health improvement goals and ensure the strategy continues to be aligned with the needs of children and young people with epilepsy and support clinical and stakeholder priorities.

### Health Improvement Goals

The [2023 annual report](#), published in July 2023, reported on clinical data from Epilepsy12 Round 4, cohort 4, which encompassed children and young people who had their first paediatric assessment for a paroxysmal episode(s) between 1 December 2020 and 30 November 2021. Additionally, it reports on the organisation and structure of epilepsy services as at 1 November 2022, as part of the organisational audit.

- 1 The proportion of children receiving input from an epilepsy specialist nurse **increased by 1%**
- 2 For children with complex epilepsy, the proportion receiving input from tertiary specialist by **decreased by 7%**
- 3 The proportion of children receiving all core elements of care planning **increased by 4%**
- 4 The proportion of Health Boards and Trusts using structured transition resources **increased by 4%**
- 5 The number of Health Boards and Trusts screening children with epilepsy for mental health disorders **increased by 1%**

Within the 2023 results, positive increases were observed in four of the five health improvement goals compared to the previous year (2022 report, cohort 3). The aim of 5% improvement was not surpassed in any of the goals, and there was a decrease in performance in the tertiary input goal.



**Figure 6** – Change in performance in the 5 health improvement goal metrics between Cohort 3 and Cohort 4

## Round 4 Methodology

There have been changes to the way we calculate our performance indicators, which will be implemented for cohort 5 onwards. This impacts health improvement goal 2 (tertiary input) and goal 3 (comprehensive care planning).

The tertiary input measure was updated in line with the [NICE guidelines](#) to broaden the criteria for requiring tertiary input. Tertiary input is recommended for children less than 3 years old at first paediatric assessment or less than 4 years old with myoclonus. The comprehensive care planning measure was updated to require evidence of discussion of SUDEP.

To manage these changes, we will provide the data from cohort 1 to 4 with the new analyses retrospectively applied in the 2024-2025 review of the quality improvement strategy and other longitudinal analyses.

To note, the newly defined 10 key performance indicators (KPIs) will be reported in 2024 for children and young people in cohort 5. Full details on the methodology and KPIs can be found on [our website](#).

## Improvement Methods

### NHS Health Boards and Trusts

Epilepsy12 produced Health Board/Trust-level reports and clinic posters to accompany the 2023 annual report. [Quality improvement case studies](#) submitted by local services to highlight successes and encourage shared learning were also published alongside annual results



The Epilepsy12 and OPEN UK national conference took place in September 2023 in a hybrid format, and was a resounding success with over 500 attendees joining live. This was the first hybrid event, and the first time an in-person element was offered since the pandemic. The event featured talks from the Epilepsy12 Youth Advocates, NHS England, the Mental Health Intervention for Children with Epilepsy (MICE) research team, and hosted a panel around genomics. Attendees were also invited to submit posters outlining their quality improvement work. The event also provided booths for our stakeholders, including Young Epilepsy, the AYPH, RCPCH&Us, and EQIP. The resources are [available online](#).

## Patients and the public

The [AYPH report](#) commissioned by Epilepsy12 was published in November 2023, and lays out recommendations to improve the care that young people with epilepsy from marginalised communities receive.

Epilepsy12 have continued to work with the Epilepsy12 Youth Advocates, who were joint recipients of the 2023 HQIP Clinical Audit Heroes Award for Patient and Public Involvement and were highly commended in the RCPCH&Us Volunteer Awards. They have worked on a number of projects this year, including health facilitation and leadership and development training, sitting on the RCPCH Epilepsy Programme Board, supporting the Public Reporting Standards Body (PRSB) on the development of an epilepsy information standard and supporting the RCPCH&Us innovation labs, which provide paediatric epilepsy services with training to improve their patient engagement.

## National organisations and initiatives

Epilepsy12 successfully implemented the 2023 outlier identification and management process and the results were published [online](#) and shared with the CQC and Welsh Government where required.

The third wave of EQIP came to completion with a [shared learning event](#), where the participating services presented on their projects, the highlights, and the lessons learned from the process. Following the successful third wave, the fourth wave has begun and 10 teams have been enrolled with funding from NHS England.

The audit has acted as an important vehicle for change in national paediatric epilepsy care standards. The NHS England Bundle of Care for CYP with Epilepsy was informed by Epilepsy12 audit data. Epilepsy12 audit metrics are included within the National CYP Transformation Programme Dashboard and are key measurables for the standards included within the bundle. Epilepsy12 also contributed to the NICE Quality Standard for epilepsy and Epilepsy12 audit metrics are included within the document as key measurables. The Epilepsy12 project team sit on a number of working groups and boards, including the NHS England Epilepsy Oversight Group, the Organisation of Paediatric Epilepsy Networks in the UK (OPEN UK) and the UK Paediatric Epilepsy Programme Board. Epilepsy12 is involved in key discussions on challenges, issues and ideas relating to epilepsy care and service provision.

## Improving Epilepsy12 data collection and reporting

The 2023 Epilepsy12 annual report was published in the 10-page 'State of the Nation' format for the first time and described national recommendations based on the key messages and findings of the report. To further improve the accessibility and readability of the annual outputs, we plan to re-

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design the annual report extended analyses in time for the 2024 publication. The updated analyses will also draw a greater focus on the [NHS England Bundle of Care for CYP with epilepsy](#).

The [frequent reporting dashboard](#) was launched in July 2023, and has updated quarterly since to make local, regional and national key performance indicator data available in the public domain at more frequent intervals. Epilepsy12 are progressing towards monthly reporting in 2024.

The new Epilepsy12 data platform also launched for data collection and reporting in December 2023 for cohort 6 onwards. The platform features simplified data entry forms, improved usability, and greater control for users. The clinician facing dashboard is also live, allowing organisations to see their key performance indicator data in real time. Patient KPI summaries also allow clinicians to identify potential gaps in care and/or data entry errors as the patient record is updated and allow rectification before the data submission deadline. The new platform will continue to be further developed to maximise impact. Additional features may include the API function, a child/young person/parent/carer facing element and embedding the public facing frequent reporting dashboard within the platform, as described above.

## 2024 – 2025 Update

Round 4 of Epilepsy12 is currently underway, and is being delivered by RCPCH from 1 April 2022 to 31 March 2025. We are pleased to share that a two-year extension has been awarded for RCPCH to continue delivering Epilepsy12 until 31 March 2027.

The Epilepsy12 Quality Improvement Strategy was reviewed in January 2025 to provide an update on audit activity and evaluate progress against the health improvement goals. As with the 2023 – 2024 update, the Epilepsy12 Project Board confirmed in 2025 that the Health Improvement goals and strategy outlined in this document remain aligned with the needs of children and young people with epilepsy and support clinical and stakeholder priorities.

The next review will take place in January 2026.

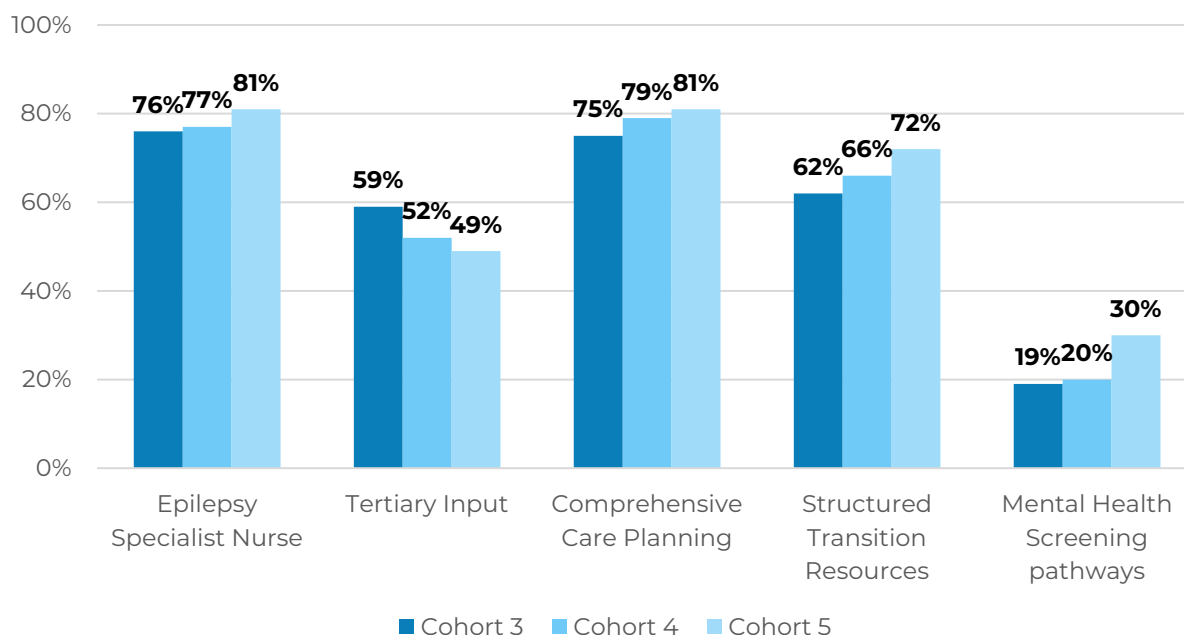
## Health Improvement Goals

The [2024 annual report](#), published in July 2024, reported on clinical data from Epilepsy12 Round 4, cohort 5, which encompassed children and young people who had their first paediatric assessment for a paroxysmal episode(s) between 1 December 2021 and 30 November 2022. Additionally, it reports on the organisation and structure of epilepsy services as at 1 November 2023, as part of the organisational audit.

Between cohort 3 and cohort 5:

- 1 The proportion of children receiving input from an epilepsy specialist nurse **increased by 5%**
- 2 For children with complex epilepsy, the proportion receiving input from tertiary specialist by **decreased by 10%**
- 3 The proportion of children receiving all core elements of care planning **increased by 6%**
- 4 The proportion of Health Boards and Trusts using structured transition resources **increased by 10%**
- 5 The number of Health Boards and Trusts screening children with epilepsy for mental health disorders **increased by 11%**

Within the 2024 results, positive increases were observed in four of the five health improvement goals compared to the previous years (2022 report, cohort 3 and 2023 report, cohort 4). The aims of the health improvement goals are on track to be achieved for cohort 6 for the four, however a decrease in performance remains for the tertiary input goal.



**Figure 6** – Change in performance in the 5 health improvement goal metrics between cohort 3 and cohort 5

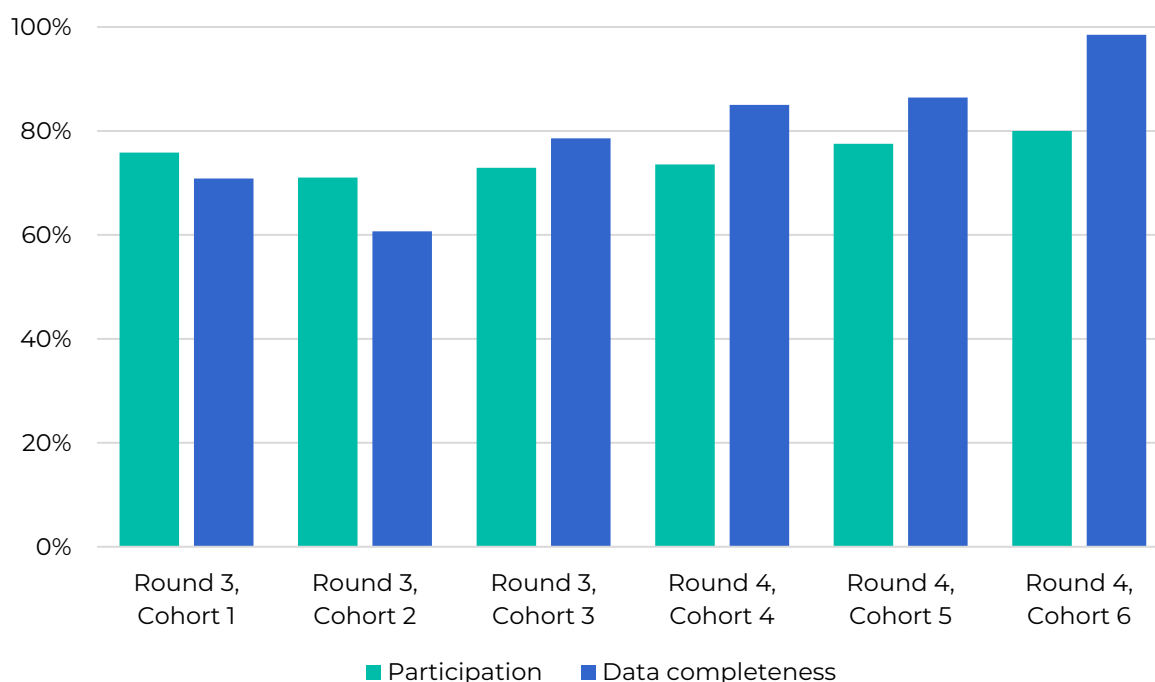
## Improving Epilepsy12 data collection & reporting

The changes to the 10 key performance indicators (KPIs) are described in the 2023/24 update. Reporting began on these from cohort 5. Full details on the methodology and KPIs can be found on [our website](#).

As the definitions of some of our KPIs have changed over time, we retrospectively calculated some measures for the previous cohorts with the new methodology, where possible. A longitudinal trends report was created as an additional extended analyses to the 2024 report to display these data. This can be found [online](#), and will be updated with data from the 2025 report (cohort 6).

A new data platform was launched in December 2023 to begin collecting data from cohort 6, which includes children and young people with first assessments between 1 December 2022 and 30 November 2023. The bespoke platform enhances usability and hosts a minimised dataset to cut down data entry times and reduce burden for clinical teams. We have also targeted our case ascertainment methodology on CYP with confirmed epilepsy diagnosis, reducing audit caseloads by 65%. New platform features encourage participation by improving frequency and utility of data through patient performance summaries and live KPI dashboards providing real-time information on performance.

These changes have brought increased participation and data completeness within the cohort 6 data; 80% of Health Boards and Trusts submitted some clinical data and data completeness rose to 99%. The total cohort numbers increased by 50%; ~2000 in earlier cohorts compared to >3000 in cohort 6.



**Figure 7:** Clinical audit participation and data completes in Rounds 3 and 4.

Epilepsy12 continue to follow the 10-page 'State of the Nation' format for the annual reports, describing national recommendations based on the key messages and findings of the data. To further improve the accessibility and readability of the annual outputs, the 2024 clinical extended analyses were re-designed to focus on the key performance indicators and the [NHS England Bundle of Care for CYP with epilepsy](#), and an additional report was created to explore longitudinal trends.

Bespoke data packs are shared with NHSE annually to support benchmarking and monitoring of progress against recommendations within the four priority areas within the Bundle; mental health, tertiary input, transition and variation in care. Two KPI measures were introduced around mental health, and from 2025, KPI results will be cut by demographic variables, including ethnicity, deprivation, the presence/absence of mental health conditions and neurodevelopmental conditions/learning disabilities, alongside age, sex and geographical analyses. This aligns to the NHS Core20PLUS 5 framework for CYP and explores variation in paediatric epilepsy care to support reduction of health inequalities.

Epilepsy12 are working with NHSE to explore further alignment of work, such as the possibility of outcome reporting within the audit, how to facilitate improvements in tertiary input and additional ways to report on transition.

The [frequent reporting dashboard](#), launched in July 2023, is now updated on a monthly basis to make local, regional and national key performance indicator data available in the public domain at more frequent intervals. User guides and a 10-minute demo video is available online to help users navigate the dashboard and understand the data within. Epilepsy12 are progressing towards reporting of longitudinal trends within the dashboard in 2025.

Following the successful launch on the new Epilepsy12 data platform, a webinar was held in May 2024 to showcase the system. A short [demo video](#) was created to support users with data entry. The project team will work closely with platform developers throughout 2025 to continue refining and enhancing the platform based on user feedback.

Epilepsy12 will also continue to support the work of the Professional Records Standards Body (PRSB) to develop a UK epilepsy information standard for children, young people and adults. The standard aims to support clinical care and automatic data flows to audit, whilst minimising duplication and data burden. Once fully developed and implemented across NHS service electronic records, the approach will facilitate automated data flows between patient records and the Epilepsy12 platform.

## Improvement Methods

### NHS Health Boards and Trusts

Epilepsy12 produced Health Board/Trust-level reports and clinic posters to accompany the 2024 annual report. [Quality improvement case studies](#) submitted by local services to highlight successes and encourage shared learning were also published alongside annual results.

The Epilepsy12 and OPEN UK national conference took place in September 2024 in a hybrid format, with 500 attendees joining live. The event featured talks from the Epilepsy12 Youth Advocates, national engagement projects, the EQIP, an epilepsy health economics research project, NHS England Mental Health screening pilots and Epilepsy12 and OPEN UK. Attendees were invited to submit posters outlining their quality improvement work, and the event provided booths for stakeholders, including Young Epilepsy and BPNA (British Paediatric Neurology Association). The resources are [available online](#).

### Patients and the public

The [AYPH report](#) commissioned by Epilepsy12 was published in November 2023, and lays out recommendations to improve the care that young people with epilepsy from marginalised communities receive. A follow-up project was commissioned, where AYPH held workshops with ICB areas to help them better engage with families from marginalised communities and embed the learnings from the initial reports. An online webinar was held to share the learning more widely. Once finalised, project outputs and a recording of the webinar will be published online.

The Epilepsy12 '**Impact and Influence of CYP Voice**' project has now concluded. The successful project included youth-led engagement days with services, coaching calls with clinical teams and youth worker visits to services to help paediatric epilepsy teams better engage with CYP and families. Additional sessions were held with participating teams to develop a 'toolkit' which could be widely used by services to improve engagement. The final project report and engagement toolkits are being finalised ahead of publication.

Epilepsy12 have continued to work with the **Epilepsy12 Youth Advocates**, and the group were able to share their work at the 2024 Epilepsy12 & OPEN UK conference and the 2024 RCPCH conference where they raised awareness for epilepsy on 'purple day'. The group won the 2024 RCPCH & Us volunteer award within the 'change category' – video available [online](#). A couple of the Youth Advocates have recently stepped away from the project due to their age. They have created a 'Legacy Award' as a way to recognise outstanding engagement work with children and young people with epilepsy and their families. The 2024 Legacy Award was awarded to Dr Colin Dunkley at the

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Epilepsy12/OPEN UK conference for his unstoppable ability to hear and act on Youth Advocate voices within the audit. The 2025 award will be launched on 'purple day' at the RCPCH conference, and the winner announced at the 2025 Epilepsy/OPEN UK conference.

## National organisations and initiatives

Epilepsy12 successfully implemented the 2024 outlier identification and management process and the results were published [online](#) and shared with the CQC and Welsh Government where required.

The identification of 'non-participation' outliers were introduced in 2024, to align with updated guidance from HQIP and NHS England. Participation is defined as submitting at least one first year of care record in the relevant cohort before the data submission deadline. Any Health Boards or Trusts not meeting this were a non-participation outlier.

The forth wave of EQIP, funded by NHS England, came to completion with a [shared learning event in June 2024](#). Participating services presented on their projects, the highlights, and the lessons learned from the process. The RCPCH EQIP published their [impact reports](#) that evaluate the progress and outcomes of initiatives aimed at paediatric epilepsy service teams and wider MDT.

Epilepsy12 continues to act as an important vehicle for change in national paediatric epilepsy care standards, by remaining a key references for adherence to national standards and recommendations within the NICE guidelines and quality standards, the NHS England Bundle of Care for CYP and the NHS England Best Practice Tariff. The Epilepsy12 project team also sit on a number of working groups and boards, including the NHS England Epilepsy Oversight Group, OPEN UK and the UK Paediatric Epilepsy Programme Board. Epilepsy12 is involved in key discussions on challenges, issues and ideas relating to epilepsy care and service provision.