

## Epilepsy12 Quality Improvement Strategy

This document describes the Epilepsy12 Quality Improvement Strategy, and how the audit supports continuous improvement in paediatric epilepsy care by collecting, analysing, and sharing high-quality data. The strategy describes recent developments in audit methodology, progress achieved to date, and the future priorities that will guide improvement across England, Wales, and Jersey from April 2025 to March 2027.

### Introduction

Epilepsy12, the **National Clinical Audit of Seizures and Epilepsies for Children and Young People**, evaluates the quality and safety of epilepsy care provided to children and young people with epilepsy across England, Wales, and Jersey. Commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP), the audit encompasses NHS services in England, Wales and Jersey.

Delivered by the Royal College of Paediatrics and Child Health (RCPCH) since 2009, Epilepsy12 is now in its fourth round, covering April 2022 to March 2025, with a 2-year extension confirmed until March 2027. Jersey joined the programme in 2024, participating in the organisational audit initially, with clinical audit involvement commencing in April 2025 (cohort 7).

Epilepsy12 works collaboratively with clinicians, children and young people (CYP), families, charity organisations, and wider stakeholders with an interest in paediatric epilepsy to ensure their perspectives are represented in its work. The audit's aim is to drive continuous improvement in epilepsy care by providing a trusted source of benchmarking data to support Quality Improvement (QI) activities across England, Wales, and Jersey.

### Key updates to audit methodology, data entry and reporting

Epilepsy12 continues to evolve its scope and methodology to reflect the changing priorities of clinicians, commissioners, and children and young people (CYP), and maintain alignment with national policies and guidelines. In Round 4, 10 Key Performance Indicators (KPIs) were identified by the Epilepsy12 Methodology and Dataset Group (M&DG) and the Project Board, in collaboration with key stakeholders. These align closely with NICE Guidelines and Quality Standards for epilepsy.

From Cohort 5 onwards, several updates were implemented to improve the accuracy and clarity of KPI calculations. Terminology was standardised across all KPIs to consistently use the term "children and young people," and references to "input" from key professionals were replaced with "seen by" to clarify that indicators measure direct clinician to family contact.

Following recommendations from the E12 Youth advocates, two new mental health indicators were introduced to emphasise the importance of emotional wellbeing in holistic

epilepsy care: **Assessment of mental health issues** (KPI 6) and **Mental health support** (KPI 7).

Additional changes to the KPIs include;

- Introducing timeliness into 2 measures; paediatrician with expertise in epilepsies within 2 weeks (KPI 1) and MRI within 6 weeks (KPI 5),
- Revising the criteria for tertiary input (KPI 3b) to reflect updated NICE guidance,
- Adding evidence of SUDEP risk discussions to the care planning components measure (KPI 9b), and,
- From cohort 7, adjusting the sodium valproate measure (KPI 8) to include Topiramate for females over 12 years and a wider age group of females on valproate, in line with updated MHRA guidance.

These refinements affected Quality Improvement Goal 2 because the criteria for KPI 3a (tertiary Input) were updated to align with new NICE guidance and terminology. They also impacted Quality Improvement Goal 3 as KPI 9b (care planning components) was expanded to include SUDEP discussions. To maintain consistency and comparability over time, data from Cohorts 1–4 were re-analysed using the updated methodology.

Recognising variation in participation and data submission across NHS Health Boards and Trusts, Epilepsy12 implemented measures to improve data quality and reduce burden through a new data platform, launched in December 2023. Case ascertainment now focuses solely on children and young people with confirmed epilepsy, supported by a minimised dataset and streamlined data entry process. Reporting has been strengthened through the introduction of public-facing monthly dashboards and real-time KPI reporting at local, regional, and national levels within the restricted data platform.

The new data collection processes support more accurate benchmarking, reduce administrative burden, and enhance data quality and transparency, driving continuous quality improvement in epilepsy care for children and young people. There is the potential to facilitate automatic data flows between NHS systems and the audit platform, and Epilepsy12 are supporting this through the development of an epilepsy information standard with the Professional Reporting Standards Body (PRSB). These developments reflect Epilepsy12's ongoing commitment to efficiency and supporting high-quality clinical care. More information is available on the [Epilepsy12 website](#).

## **Quality Improvement Goals**

The Quality Improvement Goals established in 2022 were informed by the KPIs and improvement priorities identified at the time. The Epilepsy12 M&DG and Project Board undertook a full review of the goals and strategy, and agreed on updated goals for the 2-year extension period between April 2025 and March 2027. This process aimed to ensure continued alignment between audit KPIs and national clinical guidelines and standards, strategic priorities within paediatric epilepsy care, and the evolving needs of CYP and their families. Key changes are described below:

- Using the care planning components measure (KPI 9b) to switch the focus from achieving 'agreement' on care planning to ensuring care plans are comprehensive and include key 'components'.

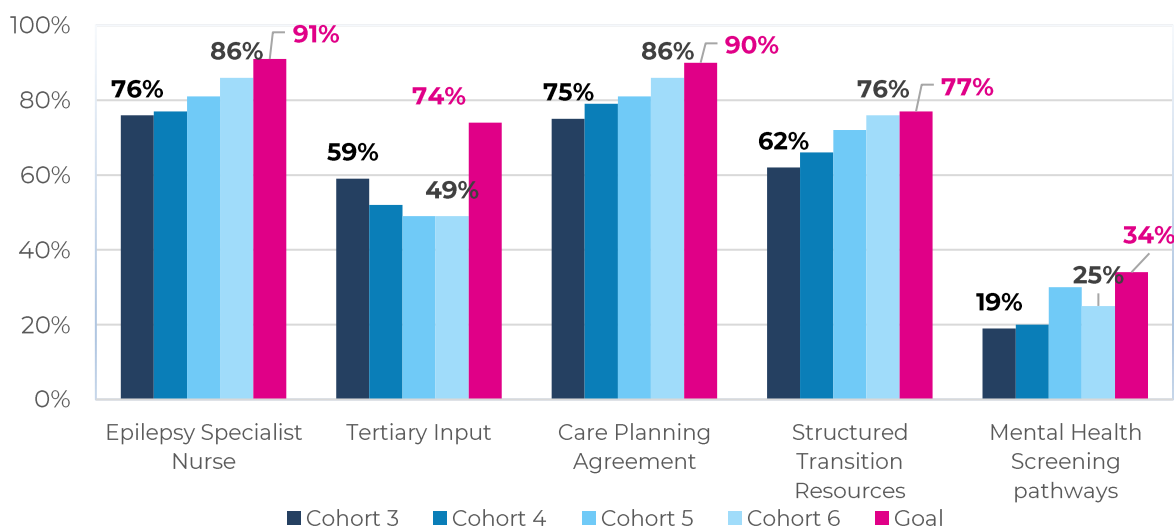
- Introducing the new clinical mental health measure (KPI 6) in place of the organisational measure, to ensure all CYP with epilepsy are being asked about their mental health and wellbeing.

The updated Quality Improvement Goals for 2025–2027 are outlined in the following section, alongside progress made so far against the goals. These revised goals will continue to guide the audit's focus on delivering equitable, high-quality epilepsy care and measurable improvement across participating services.

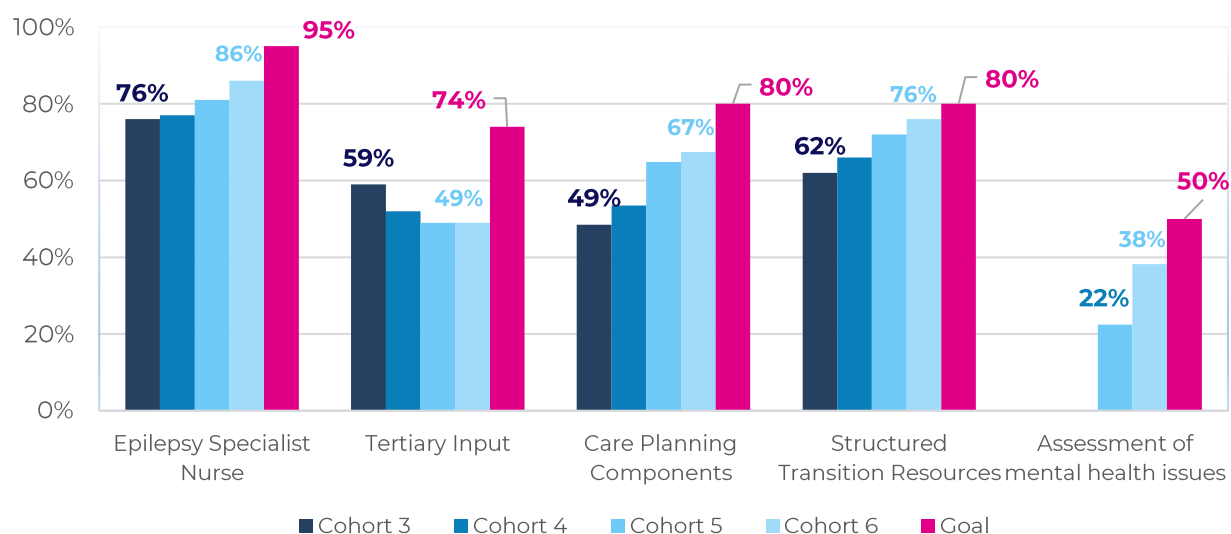
- 1 Increase the proportion of children receiving input from an epilepsy specialist nurse from **76%** in Cohort 3 to **95%** in Cohort 8
- 2 For children with complex epilepsy, increase the proportion receiving input from tertiary specialist from **59%** in Cohort 3 to **74%** in Cohort 8
- 3 Increase the proportion of children receiving all core elements of care planning content to **80%** in Cohort 8
- 4 Increase the proportion of Health Boards and Trusts using structured transition resources from **62%** in Cohort 3 to **80%** in Cohort 8
- 5 Increase the number of Health Boards and Trusts screening children with epilepsy for mental health disorders from **19%** in Cohort 3 to **50%** in Cohort 8

## Progress and revised goals

Audit data shows steady improvement across cohorts, with clear progress in access to epilepsy specialist nurses, care planning, and transition support. Mental health screening has also shown gradual improvement from cohort 3 onwards, with only a slight dip in cohort 6. However, tertiary input has shown no improvement across cohorts. Although none of the targets were fully achieved in cohort 6, substantial progress was made across all areas, bringing results much closer to the established goals.



**Figure 1** - KPI results for the five Quality Improvement Goals (2022) (Cohorts 3–6, England and Wales only, Jersey excluded).



**Figure 2** - KPI results for the revised five Quality Improvement Goals (2025) (Cohorts 3–6, England and Wales only, Jersey excluded).

Care planning components have shown consistent improvement across the cohorts, indicating steady progress in this area over time. The newly added goal, Assessment of mental health issues has also increased from Cohort 5 to Cohort 6 significantly.

## Improvement Methods

Expert advice and support are provided by senior RCPCH colleagues, including the Vice President for Science and Research, Executive Director of Research and QI, Head of Audits, Head of QI, as well as RCPCH Officers for Clinical Standards and Quality Improvement, the Epilepsy12 Clinical Lead, members of the Epilepsy12 Project Board, Methodology & Dataset Group (M&DG) and the Epilepsy12 Youth Advocates.

Epilepsy12 works closely with these quality improvement experts when developing its improvement goals and strategies. Their input continues throughout delivery and review to ensure the strategy remains appropriate, effective and evidence-based, and that sufficient monitoring and evaluation methods are considered within all improvement activities.

Opportunities for collaboration with colleagues across the NHS, professional bodies, charities and other improvement programmes will also continue to be explored. The improvement strategy will be implemented at local, regional, and national levels, including the following Epilepsy12 activities and outputs.

## NHS Health Boards and Trusts

The Epilepsy12 [State of the Nation Annual Report](#) presents combined national results for England and Wales across the audit's ten KPIs, alongside key findings and national recommendations. Extended analysis reports for both organisational and clinical audits, as well as a longitudinal trends report, allows deep dives into audit data at national and regional levels. Each NHS Health Board and Trust receives a detailed local report with comparative analysis of clinical and organisational data against regional and national

benchmarks. Together with the [monthly reporting dashboard](#) and the live dashboard on the [data entry platform](#), these outputs support local benchmarking, help identify priority areas for quality improvement, and enable ongoing monitoring against Epilepsy12 Improvement Goals.

The Epilepsy12 and Organisation of Paediatric Epilepsy Networks (OPEN UK) National Conference is an annual stakeholder event hosting roughly 500 participants from across the United Kingdom, including healthcare professionals, young people, commissioners, charitable organisations, and partner bodies such as NHS England, Young Epilepsy, RCPCH &Us, EQIP, and the British Paediatric Neurology Association (BPNA). The conference provides a key platform for collaboration, shared learning, and dissemination of effective practice, with a strong focus on QI aligned to Epilepsy12 priorities. Conference materials, case studies, and related resources are published [online](#) to promote continued engagement and learning.

## **Integrated Care Systems and Regional Networks**

Epilepsy12 hosts national meetings that bring together the 17 regional leads of [OPEN UK](#). These quarterly virtual meetings provide a platform to share regional successes, identify common challenges, and promote national collaboration and shared learning.

Through the public facing [Epilepsy12 monthly reporting dashboard](#), Integrated Care Boards (ICBs), NHS England regional teams, and OPEN UK leads can access participation and performance data for Health Boards and Trusts within their areas. These data support regional benchmarking, highlight variation, and inform quality improvement and service planning. The Epilepsy12 team works closely with ICBs, commissioners, and other system partners to ensure that audit outputs provide a robust evidence base for prioritising, implementing, and monitoring improvement initiatives.

## **National organisations and initiatives**

As part of its commitment to improving paediatric epilepsy care, Epilepsy12 delivers a structured [outlier identification and management process](#). This highlights NHS Health Boards and Trusts whose results fall significantly above or below expected performance levels. Findings are published annually on the [Epilepsy12 website](#) and, where required, shared with the Care Quality Commission (CQC) and Welsh Government in line with HQIP's outlier guidance.

Epilepsy12 also lead the Epilepsy Quality Improvement Programme (EQIP), a national initiative supporting epilepsy teams to design, test, and share improvement projects. The third wave concluded with a shared learning event showcasing project outcomes and lessons learned. The fourth wave, involving ten multidisciplinary teams funded by NHS England, has also been completed, with programme details available [online](#).

Epilepsy12 continues to play a central role in shaping national paediatric epilepsy care standards. Audit data have informed the NHS England Bundle of Care for Children and Young People with Epilepsy, and Epilepsy12 metrics feature within the National CYP Transformation Programme Dashboard and the NICE Quality Standard for Epilepsy as key indicators of care quality.

The Epilepsy12 team also contributes to national strategy and policy development through membership of the NHS England Epilepsy Oversight Group, OPEN UK, and the UK Paediatric Epilepsy Programme Board, ensuring that audit insights inform service improvement across the UK.

## Patients and the public

Patient and family involvement are central to Epilepsy12 and the Quality Improvement Strategy, ensuring that the experiences of children and young people inform all aspects of audit design and delivery.

Epilepsy12 works collaboratively with young people, families, and epilepsy charities to make audit findings accessible and meaningful. Public-facing data are presented with clear narratives and co-designed resources, such as young people & parent leaflets and clinic posters, to improve understanding of key measures and QI goals.

The audit commissioned the Association for Young People's Health (AYPH) to explore the experiences of young people with epilepsy from marginalised communities. The findings, [published in November 2023](#), provide recommendations to promote equity of care and ensure these voices shape ongoing improvement work.

The [Epilepsy12 Youth Advocates](#) Programme, delivered with RCPCH &Us, brings together young people and families to influence service improvement and audit priorities. Their contributions have directly shaped performance metrics and produced practical tools such as clinic checklists and care planning resources. Their achievements have been recognised through national awards, including the HQIP Richard Driscoll Memorial Award.

Epilepsy12 will continue to ensure that patient experience and engagement remain integral to driving improvements in paediatric epilepsy care.

## Communication Strategy

Epilepsy12 delivers a comprehensive communication approach to share progress, learning, and outcomes from its Quality Improvement (QI) activities in a clear, accessible and engaging format.

Registered audit users receive regular updates and newsletters highlighting audit outputs and activities, key deadlines, and examples of good practice. [The Epilepsy12 website](#) serves as the central platform for information on audit data, methodology, and QI resources, including case studies and training materials.

Collaboration with the Epilepsy12 Youth Advocates and charity partners helps ensure that communication is accessible to families and young people. Public resources such as parent guides, young person leaflets, and clinic posters summarise key findings and outline what high quality epilepsy care should look like.

## Evaluation

The longitudinal impact of Epilepsy12 and its Quality Improvement initiatives is assessed through regular outputs, including the annual State of the Nation report, annual longitudinal trends report and both monthly and real-time dashboard updates, which

present KPI results at national, regional, and local levels. This continuous cycle of data collection, reporting, and informed improvement enables Epilepsy12 to evaluate service delivery, monitor variation and highlight progress over time.

Future audit rounds may include patient-reported experience and outcome measures (PREMs and PROMs), collected through the Epilepsy12 data platform, to provide deeper insight into the effectiveness of QI initiatives and their impact on children, young people, and families.

Our evaluation will allow for the recognition and sharing of successful interventions within the paediatric epilepsy community. 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 within the audit.

## **Conclusion**

This strategy sets clear priorities for strengthening paediatric epilepsy care, including improving access to specialist expertise, enhancing care planning, supporting mental health, and reducing unwarranted variation. The next phase will focus on embedding the updated KPIs, maximising the use of real-time data, and supporting targeted quality improvement activity across all levels to drive sustained progress through to 2027.

## **Useful Resources**

- [Epilepsy12 Website](#)
- [Methodology Overview](#)
- [Reports and resources](#)
  - [E12 State of the Nation Report 2025](#)
- [Data Entry Platform](#)
- [Frequent Reporting Dashboard](#)
- [Epilepsy12 Youth Advocates](#)