EPILEPSY12 IMPACT REPORT

Established in 2009, Epilepsy12 has the continued aim of ***helping epilepsy services and those who commission health services, to measure and improve the quality of care for children and young people with seizures and epilepsies***. The national clinical audit is commissioned by the Healthcare Quality Improvement Partnership (HQIP) and is delivered by the Royal College of Paediatrics and Child Health (RCPCH).

The Epilepsy12 audit is comprised of two main audit domains:

- **Clinical audit** - the epilepsy care provided to children and young people with a new diagnosis of epilepsy during the first 12 months following a first paediatric assessment. Key Performance Indicators (KPI) were selected on priority areas of paediatric epilepsy care.
- **Organisational audit** (service descriptor) - organisation of paediatric epilepsy services

Epilepsy12 engaged with relevant stakeholders to identify priority areas of care and agree five Quality Improvement Goals to align with these. These are described in the **Epilepsy Quality Improvement Strategy**, alongside improvement methods and progress against the goals to date.

NATIONAL

How the project provides evidence of quality and outcomes of care nationally

National reporting and publications:

80.0% (120/150) of Health Boards and Trusts participated in the cohort 6 clinical audit, an increase from 78% in cohort 5 and 74% in cohort 4.
The cohort size has increased considerably, from around 2000 in cohorts 1-5 to 3105 in cohort 6.

In 2024, **88.6%** (101/114) of participating Health Boards and Trusts indicated having an agreed referral pathway to adult services, and 76.3% (87/114) used structured transition resources.

In cohort 6, **85.6%** of children and young people with epilepsy received input by an epilepsy specialist nurse within the first year of care. This has increased steadily from 69% in cohort 1.

Annual audits reports with QI case studies

Epilepsy12 Quality Improvement plan

More children and young people had evidence of care planning agreement (85.8%), achieving all core elements of care planning (67.4%) and School Individual Health Care Plans (67.2%) in cohort 6 than in previous years.

Epilepsy12 has aligned its reporting to the NHS England **Core20PLUS5** framework for children by exploring variation by deprivation, ethnicity and the presence/absence of neurodevelopmental conditions or learning disabilities and mental health conditions. This is alongside variation by geography, age and gender.

SYSTEM

How the project supports policy development & system management

Epilepsy12 are represented on the **NHS England Epilepsy Oversight Group**, and have supported the development of the National Bundle of care for children and young people with epilepsy.
Cohort 2-5 data packs were shared with the group reporting audit data at NHS region, ICS & Trust level to support policy and improvements in 4 priority areas of epilepsy care, described in the Bundle.

Epilepsy12 publishes **data, reports and findings** online. Monthly data on KPIs are available online. Live KPI dashboards are available to registered users of the Epilepsy12 platform.

The 2024 annual outputs present national, regional and local findings, alongside a a summary report with national recommendations for policy-makers and commissioners.

The **new Epilepsy12 data platform** was launched in 2024, designed to streamline data entry, reduce the burden on clinical teams and enhance reporting capabilities. The new system has improved the quality and quantity of data submitted in 2025.

Epilepsy12 are also working with the Professional Records Standards Body (PRSB) to develop an **Epilepsy Information Standard**. The standard will support the integrated and continuous care of epilepsy across settings and help facilitate automatic data flows between NHS systems and audit platforms.

Epilepsy12 host the OPEN UK national group and the UK Epilepsy Programme Board. Both bring **stakeholders** together, co-ordinating on policy and ways to improve the overall system management.

LOCAL

How the project stimulates quality improvement

The 2023/2024 Summary Report for the RCPCH **Epilepsy Quality Improvement Programme (EQIP)** was published in 2024. It follows on from the 2019/2023 Impact Report, highlighting the impact of the EQIP and the continued improvements in patient care and service delivery for children and young people with epilepsy.

EQIP has helped teams develop transition pathways, improve mental health care, and engage effectively with patients and families.

With data published in July 2024, each **Trust/Health Board** received detailed datasets and pdf reports of local results with regional and national benchmarks. KPI data are also available within monthly and live dashboards.

The 7th **Epilepsy12/OPEN UK annual conference** took place in September 2024 with 440 virtual attendees and 65 in-person. The conference focused on: Individualised emergency seizure plans, Mapping transition, NHS England Mental Health Screening Pilot and the Epilepsy Impact and Influence Project. 7 poster submissions describing local quality improvement projects were also featured.

The **Epilepsy12 Youth Advocates** published an Example Individual School Care Plan to enhance the use of school individual care plans and help children and young people to feel empowered and positive. A Clinic Chat Checklist guide / tool was established to support services in asking children, young people and families about their worries and anxieties.

PUBLIC

How the project is used by the public and the demand for it

Children and young people are actively involved in Epilepsy12. Their views influence the areas of care in the audit, and improvement activities are led by the '**Epilepsy12 Youth Advocates**' (epilepsy experienced children, young people, families and an epilepsy specialist nurses).

An infographic has been created to showcase all of their incredible contributions.

Epilepsy12 have worked with the **Association for Young People's Health (AYPH)** to understand more about the experiences of managing epilepsy care from children, young people and families from groups which may be more likely to face marginalisation, and work to embed key learnings to support services. The work and findings are described online.

Various **patient and parent resources** are created to support Epilepsy12 annual reports, including guides and leaflets.

Social media: @epilepsy_12, and @RCPCH_&_US

Impact examples from June 2022 to March 2025. Impact report updated in March 2025.