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

UPCARE: 1.00 Programme name - please do not change this field.*	National Clinical Audit of Seizures and Epilepsies for Children and Young People
1.01 Abbreviation	Epilepsy12
1.1 Contract status	Ongoing
1.2 Audit or non-audit	Audit
1.3 HQIP commissioned*	Yes
1.40 Programme unique identifier*	HQIP106
1.41 HQIP AD	TS
1.42 HQIP PM	GC
1.5 Lead organisation*	Royal College of Paediatrics and Child Health
1.6 Programme homepage*	http://www.rcpch.ac.uk/epilepsy12
1.7 Programme summary	Epilepsy12 was established in 2009 and 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 audit 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).
	The audit collects and processes patient data to highlight the strengths of epilepsy services and identify areas for improvement. Epilepsy12 has two distinct workstreams; the clinical audit and the organisational audit. The annual report describes the care provided to children and young people with a new diagnosis of epilepsy (clinical audit) and the services and workforces of paediatric services at a Trust and Health Board level (organisational audit).
2.1 Organogram	https://www.rcpch.ac.uk/work-we-do/clinical-audits/epilepsy12/about
2.2 Organisations involved in delivering the programme	**The Association of Neurophysiological Scientists (www.ansuk.org)**
	The ANS (formerly EPTA) is the professional body for clinical physiologists working in the field of Clinical Neurophysiology. It's principle aims are to represent its members at a national level, set standards of practice, promote career development, set education and training standards and award qualifications.

British Academy of Childhood Disability (www.bacdis.org.uk)

Membership is open to all professionals working in the field of childhood disability, including paediatrics, psychiatry, specialist nursing, speech and language therapy, physiotherapy, occupational therapy, psychology and education.

British Paediatric Epilepsy Group (BPEG) (www.bpna.org.uk/?page=special-interest-groups)

BPEG is a membership organisation for clinicians specialising in paediatric epilepsies. It is one of the special interest groups of the British Neurology Association and provides professional support to the organisation's objectives and functions.

British Paediatric Neurology Association (www.bpna.org.uk)

The British Paediatric Neurology Association is the professional organisation for doctors who specialise in the care of children with neurological disorders. The BPNA delivers Paediatric Epilepsy Training (PET) courses which provide training for all health professionals diagnosing and managing children with an epilepsy or seizure disorder.

British Society for Clinical Neurophysiology (www.bscn.org.uk)

The BSCN is a medical charity whose aims, set out in its articles of association, are "to promote and encourage for the public benefit the science and practice of clinical neurophysiology and related sciences"

Epilepsy Action (www.epilepsy.org.uk)

Provides information about coping with epilepsy and seizures. It also provides free help and advice through the use of email and telephone helplines.

Epilepsy Scotland (www.epilepsyscotland.org.uk)

Epilepsy Scotland is Scotland's leading epilepsy charity campaigning for improved healthcare, better information provision and an end to stigma.

National Association of independent Schools & Non-Maintained Special Schools (NASS) (www.nasschools.org.uk/)

NASS is a membership organisation working with and for special schools in the independent, voluntary and private sectors in the UK> NASS aims to improve the opportunities and standards in special schools outside of Local Authority control.

Organisation of Paediatric Epilepsy Networks (OPEN UK) (www.rcpch.ac.uk/resources/open-uk-organisation-paediatric-epilepsy-networks-uk)

OPEN UK is a clinical network connecting NHS Health Boards and Trusts that provide care for children with epilepsies with regional epilepsy networks and a UK Working Group

RCPCH&US Team (www.rcpch.ac.uk/work-we-do/rcpch-and-us)

RCPCH&Us is the voice of children, young people, parents and carers, created to actively seek and share their views to influence and shape policy and practice. The team create resources, guides and activities to support patients and health professionals and improve epilepsy services.

Epilepsy Specialist Nurses Association (ESNA) (www.esna-online.org.uk)

ESNA is a professional organisation whose membership consists of nurses and other health professionals working to support people with epilepsy in the fields of adults, learning disabilities and paediatrics. ESNA works with its membership to raise the profile of epilepsy and to encourage a holistic and co-ordinated approach to care to enable our patients to reach the goal of self-management.

Royal College of Nursing (www.rcn.org.uk) - **Epilepsy Specialist Nurses Association (ESNA)** (www.esna-online.org.uk)

The RCN is a membership organisation of more than 465,000 registered nurses, midwives, nursing support workers and students working together to advance the profession. RCN is both a professional body carrying out nursing standards, education and practice, and a trade union

ESNA is the national professional organisation of all nurses and healthcare professionals working to support people with epilepsy in the fields of adult, learning disabilities and paediatrics. ESNA works with its membership to rise the profile of epilepsy and to encourage a holistic and coordinated approach to care to enable our patients to reach the goal of self-management.

Young Epilepsy (www.youngepilepsy.org.uk)

Young Epilepsy is the **national charity supporting children and young people aged 25 and under with epilepsy** and associated conditions, as well as their families. With over 100 years expertise we provide world class diagnosis, assessment and rehabilitation for children and young people with epilepsy. We also undertake research into the condition and how it can be treated.

2.3 Governance arrangements	The audit is governed by a Project Board, which meets four times a year. The Board is chaired by the RCPCH Vice President, Science and Research, and includes the organisations and individuals listed on the organogram (see section 3.1)
	The Board is responsible for overseeing the audit and providing oversight and advice to the programme. The Board is the guarantor of the data from the audit and is responsible for signing off the annual report. Overall clinical accountability is provided by the Vice President, Science and Research. Overall organisational and contractual accountability is provided by the Head of Audits, RCPCH. Additionally, representatives from HQIP and NHSE England are members of the Board, and a Welsh Government representative will be invited once identified.
	The Project Team reports to the Project Board and is responsible for delivering the audit.
2.4 Stakeholder engagement	Representatives of two epilepsy charities, Epilepsy Action and Young Epilepsy sit on the Epilepsy12 Project Board and Methodology and Dataset Group. They are involved in:

- Developing and approving audit measures
- Setting priorities and strategic objectives
- Developing communication strategy
- Selecting key findings and developing recommendations
- Communicating with audit participant units via meetings
- Governance, risk and issue management

- Designing the children, young people and families national report summary booklet
- Designing infographics

Children and young people are closely involved in Epilepsy12 as part of the Children and Young People Engagement Plan activities which are coordinated by the RCPCH Children and Young People's Engagement Team (RCPCH &Us) in conjunction with Epilepsy12 Youth Advocates.

Representatives from the paediatric epilepsy community and regional paediatric epilepsy networks are members of the Project Board and Methodology and Dataset Group. They are involved in:

- Developing and approving audit measures
- Developing audit methodology
- Setting priorities and strategic objectives
- Developing communication strategy
- Selecting key findings and developing recommendations
- Communicating with audit participant units via stakeholder events and meetings
- Governance, risk and issue management

Audit participants are involved by:

- Providing feedback via an annual user feedback survey which seeks feedback on various aspects of the audit.
- Attending, presenting and providing feedback at national and regional stakeholder events
- Using, and providing feedback on the data platform and live performance indicator reports designed to ensure data quality and completeness via a user Focus Group.

2.5 Conflict of interest policy

Members of the Project Board have completed a declaration of interests, as part of the RCPCH register of interests process. A standing item is included on the Project Board agenda notifying members of their responsibility to ensure that their declaration is up to date.

3.1 Quality improvement goals

The Epilepsy12 quality improvement objectives are to:

- Increase rates of compliance with guidelines and standards of care in relation to the Epilepsy12 audit measures to improve outcomes for children and young people with epilepsies.
- Identify Health Boards/Trusts who are positive and negative outliers on these metrics to support local, regional paediatric epilepsy network and national level improvement.
- Share best practice through dissemination and promotion of case studies, delivery of national and regional stakeholder meetings.

Round 4 Overarching quality improvement objectives are to:

- assess whether those admitted to epilepsy services receive high quality care when
  measured against adherence to agreed guidance and standards
- ensure clear % outcomes are agreed for all process measures
- identify areas for action through facilitation and stimulation of quality improvement in

- relation to delivery and outcomes of care
- reduce unit and network level variation through benchmarking of outcome measures
- measure health inequality in relation to impact on the specified measures
- report outlier identification and management using the appropriate guidance
- share best practice and QI examples, and signposting to resources available in the wider
children and young people (CYP) epilepsy care system
- adapt QI priorities in line with new evidence based practice and guidance.

The Epilepsy12 Quality Improvement Strategy, updated in January 2026 downloaded from our website: https://www.rcpch.ac.uk/work-we-do/clinical-audits/epilepsy12/about#downloadBox

Epilepsy12 engaged with stakeholders to identify priority areas of care and agree five Health Improvement Goals to align with these. These were last refreshed in the January 2026 update.

1. Increase the proportion of children and young people receiving input from an epilepsy specialist nurse by from 76% in Cohort 3 to 95% in Cohort 8.
2. For children and young people with complex epilepsy, increase the proportion receiving input from a tertiary specialist from 59% in Cohort 3 to 74% in Cohort 8.
3. Increase the proportion of children and young people receiving all core elements for care planning from 49% in Cohort 3 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 proportion of children and young people being screened for mental health conditions from 22% in Cohort 5 to 50% in Cohort 8.

3.2 Quality improvement driver diagram	https://www.rcpch.ac.uk/work-we-do/quality-improvement-patient-safety/epilepsy12-audit/about
3.3a Methods for stimulating quality improvement*	Improvement collaboratives; On-line Quality Improvement guides; Sharing good practice repository; NHS England improvement programme; Best practice tariff (BPT)
3.3b Quality improvement supplemental information	Epilepsy12 Youth Advocates: 'Clinic Chat Checklist' Project https://www.rcpch.ac.uk/sites/default/files/2021-09/Clinic%20Chat%20Check%20List%20Project%20FINAL.pdf Example School Individual Care Plan https://www.rcpch.ac.uk/resources/epilepsy12-youth-advocates#the-importance-of-school-care-plans Epilepsy Quality Improvement Programme (EQIP): https://www.rcpch.ac.uk/work-we-do/quality-improvement-patient-safety/eqip Quality improvement information and case studies are also included in annual reporting:

https://www.rcpch.ac.uk/resources/epilepsy12-national-organisational-audit-clinical-audit-2023

Epilepsy12 & OPEN UK National conference:

https://www.rcpch.ac.uk/resources/epilepsy12-open-uk-national-conference-2023-resources

4a. Please add the most recent date that you have reviewed and updated an online version of UPCARE Programme section on your project's website (click into the response to see pop-up guidance).	02/13/2026
4b. Please add a hyperlink to UPCARE Programme section on your website (click into the response to see pop-up guidance).*	https://www.rcpch.ac.uk/work-we-do/quality-improvement-patient-safety/epilepsy12-audit/methodology-data-submission#downloadBox