

EPILEPSY12

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

Extended Analysis C
Longitudinal Trends Report
2024

Introduction

Epilepsy12 captures information on the care provided to children and young people (aged 0 – 24 years) with a new diagnosis of epilepsy in England and Wales. The audit focus on the first year of care following a first assessment for paroxysmal episode(s). Rounds 3 and 4 of the audit have so far collected data between 2018 and 2023, where children and young people are categorised into ‘cohorts’ depending on the date of their first assessment.

Table 1 outlines the timeframes of each of the cohorts. Note, that cohort 1 had a shorter timeframe compared to subsequent cohorts.

Table 1: Description of cohorts in Rounds 3 and 4 of Epilepsy12.

Round	Cohort	England
3	1	Between 1 July 2018 and 30 November 2018
3	2	Between 1 December 2018 and 30 November 2019
3	3	Between 1 December 2019 and 30 November 2020
4	4	Between 1 December 2020 and 30 November 2021
4	5	Between 1 December 2021 and 30 November 2022

Longitudinal Analyses

This report describes longitudinal data for the **10 Key performance Indicator (KPI) measures** for England and Wales combined across the 5 cohorts. Data is displayed to explore trends in performance over time in Rounds 3 and 4.

As the definitions of some of our KPIs have changed for Round 4 cohort 5, **we have retrospectively calculated** KPI 1 (Paediatrician with expertise), KPI 3a (Tertiary input), and KPI 9b (Comprehensive care planning content) for the previous cohorts **with the new methodology**. This means that performance on the below KPIs will differ from previous reporting.

We were unable to retrospectively calculate KPI 5 (MRI), KPI 6 (Assessment of mental health issues), KPI 7 (Mental health support), and KPI 8 (Sodium valproate). That is because these measures are calculated using data that was not collected prior to cohort 5.

Table 2 describes the 8 KPI measures included in this report. Further details on our methodology, including how the KPIs are calculated (numerators and denominators), can be found in the [Round 4 Methodology Overview document](#).

Table 3: Description of Epilepsy12 KPI measures.

KPI	Full Title
1. Paediatrician with expertise	Percentage of children with epilepsy, with input by a 'consultant paediatrician with expertise in epilepsies' within two weeks from first paediatric assessment
2. Epilepsy Specialist Nurse (ESN)	Percentage of children with epilepsy input by an epilepsy specialist nurse by first year
3a. Tertiary Input	Percentage of children meeting defined criteria for paediatric neurology referral, with input of tertiary care and/or CESS referral by first year
3b. Epilepsy surgery referral	Percentage of ongoing children meeting defined Children's Epilepsy Surgery Service (CESS) referral criteria with evidence of CESS referral
4. ECG	Percentage of children with convulsive seizures and epilepsy, with an ECG at first year
9a. Care planning agreement	The percentage of children with epilepsy after 12 months where there is evidence of an individualised and updated care plan that is agreed by the patient/parent/carer.
9b. Care planning content	Percentage of children diagnosed with epilepsy with documented evidence of communication regarding core elements of care planning, including, parental prolonged seizures care plan*, water safety, first aid, general participation/risk, SUDEP and service contact details.
10. School Individual Care Plan	Percentage of children and young people with epilepsy aged 5 years and above with evidence of a school individual healthcare plan by 1 year after first paediatric assessment.

Table 3 shows the national (England and Wales combined) averages for the 10 KPI measures between cohort 1 and 5. **Figure 1** displays the longitudinal trends in the KPI measures over time for England and Wales combined.

Table 3: Longitudinal data for KPI measures for England and Wales combined across the 5 cohorts.

KPI	Cohort 1	Cohort 2	Cohort 3	Cohort 4	Cohort 5
1. Paediatrician with expertise	43.9% (448/1112)	50.0% (1054/2106)	51.7% (1021/1974)	52.6% (1222/2324)	50.8% (1123/2212)
2. Epilepsy Specialist Nurse Input (ESN)	69.3% (771/1112)	73.2% (1542/2106)	76.2% (1505/1974)	77.5% (1800/2324)	80.7% (1786/2212)
3a. Tertiary Input	50.8% (162/319)	45.1% (257/570)	52.2% (251/480)	45.1% (268/594)	49.2% (291/592)
3b. Epilepsy surgery referral	30.3% (27/89)	22.6% (24/106)	36.3% (49/135)	33.1% (39/118)	37.3% (41/110)
4. ECG	68.2% (478/701)	65.4% (856/1309)	67.8% (827/1218)	70.1% (1003/1431)	72.1% (1036/1436)
5. MRI	-	-	-	-	
6. Mental Health screening	-	-	-	-	
7. Mental Health support	-	-	-	-	
8. Sodium Valproate	-	-	-	-	
9a. Care planning agreement	62.4% (694/1112)	65.4% (1378/2106)	69.9% (1379/1974)	74.3% (1727/2324)	80.8% (1787/2212)
9b. Care panning content	38.5% (428/1112)	40.0% (842/2106)	48.5% (957/1974)	53.5% (1244/2324)	64.8% (1433/2212)
10. School Individual Care Plan	32.2% (231/717)	32.4% (454/1402)	35.0% (484/1381)	36.9% (577/1562)	38.9% (573/1472)

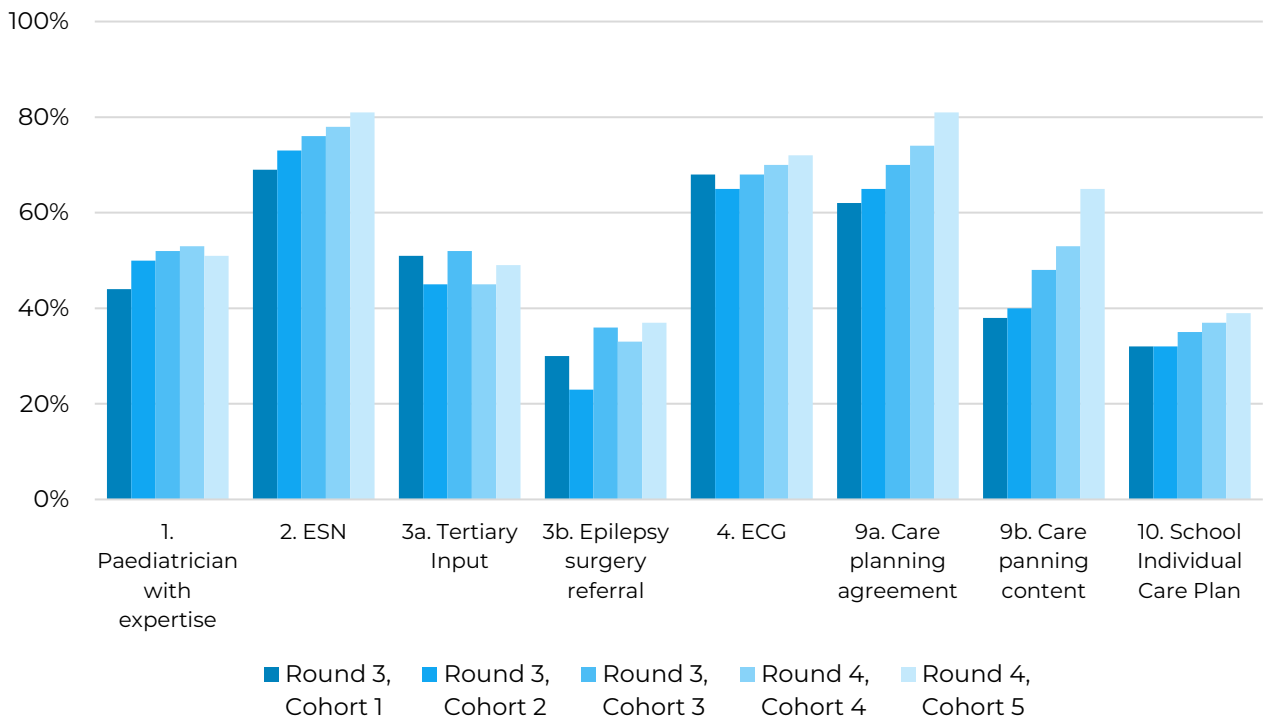


Figure 30: Longitudinal data for KPI measures for England and Wales combined across the 5 cohorts.