

EPILEPSY12

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

Extended Analysis A
2026 Clinical audit national & regional results
Cohort 7

Contents

Introduction	3
Participation, case ascertainment and data completeness	4
Participation	4
Case Ascertainment	4
Data completeness	5
Description of cohort	7
Demographics	7
Multiaxial diagnosis	11
Mental health and neurodevelopmental conditions	17
Key Performance Indicators	19
1. Paediatrician with expertise in epilepsies; input within 2 weeks	20
2. Epilepsy Specialist Nurse (ESN)	24
3a. Tertiary Input	28
3b. Epilepsy Surgery Referral	32
4. ECG	36
5. MRI	40
6. Assessment of Mental Health issues	43
7. Mental Health Support	46
8. Medication and reproduction risks	49
9a. Care Planning agreement	52
9b. Care planning components	56
10. School Individual Health Care Plan	59
Additional analyses	63
First Paediatric Assessment	63
Treatment	64
Investigations	66
Professional input	67

Introduction

This report focuses on **clinical data from Epilepsy12 'cohort 7' (2026)**, which includes children and young people with epilepsy who had their first paediatric assessment for a paroxysmal episode(s) between 1 December 2023 and 30 November 2024. Epilepsy12 processes data relating to the care provided to children and young people during the first 12 months following the first assessment. Clinical data was downloaded from the online data platform on 14th January 2026, following the data submission deadline. The 2026 annual report and accompanying outputs can be found [here](#).

Note: Asterisks (*) have been used to mask/suppress data where either the numerator and/or denominator are less than 3, but not 0. This is in line with the RCPCH data disclosure risk management policy.

Data are presented at national (England and Wales combined), country and two regional levels: NHS England regions and the Organisation of Paediatric Epilepsy Networks in the UK (OPEN UK). Jersey participated in the clinical audit, however their data have been excluded from the main clinical analyses in order to manage disclosure risks due to small patient numbers.

The **OPEN UK** networks are named below. The abbreviated regional network names appear in the regional network results in this report. The Scottish and Irish OPEN UK regions have not been listed below, as the audit currently only covers England, Wales and Jersey.

BRPNF	Birmingham Regional Paediatric Neurology Forum
CEWT	Children's Epilepsy Workstream in Trent
EPEN	Eastern Paediatric Epilepsy Network
EPIC	Mersey and North Wales network 'Epilepsy in Childhood' interest group
NTPEN	North Thames Paediatric Epilepsy Network
NWEIG	North West Children and Young People's Epilepsy Interest Group
ORENG	Oxford Region Epilepsy Interest Group
PENNEC	Paediatric Epilepsy network for the North East and Cumbria
SETPEG	South East Thames Paediatric Epilepsy Group
SWEP	South Wales Epilepsy Forum
SWIPE	South West Interest Group Paediatric Epilepsy
SWTPEG	South West Thames Paediatric Epilepsy Group
TEN	Trent Epilepsy Network
WPNN	Wessex Paediatric Neurosciences Network
YPEN	Yorkshire Paediatric Neurology Network

The NHS England (NHSE) regions are named below.

EoE	East of England
London	London
Midlands	Midlands
NEY	North East and Yorkshire
NW	North West
SE	South East
SW	South West

Participation, case ascertainment and data completeness

Participation

There are **133** Health Boards and Trusts registered in Epilepsy12 in cohort 7 (2026) across England, Wales and Jersey. This number has varied across the 7 cohorts due to Trust mergers and eligibility. **130 (97.7%)** Health Boards and Trusts had at least one child or young person allocated to cohort 7. **97.7% (130/133)** of Health Boards and Trusts submitted clinical data by completing a first year of care record for one or more children and young people in cohort 7. Participation increased in cohort 7 compared to cohort 6 (**80%**).

In cohort 7, **15** Health Boards/Trusts were deemed as 'not eligible' for the audit, as there were no eligible children or young people with epilepsy under the care of their services during the cohort 7 time period.

The following information relates only to data from Trusts and Health Boards in England and Wales. Patient data from Jersey have been excluded from the main clinical analyses in order to manage disclosure risks due to small patient numbers.

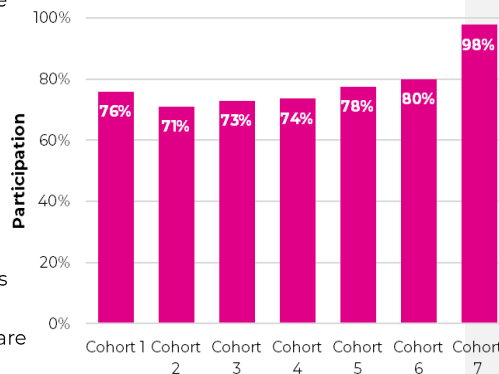


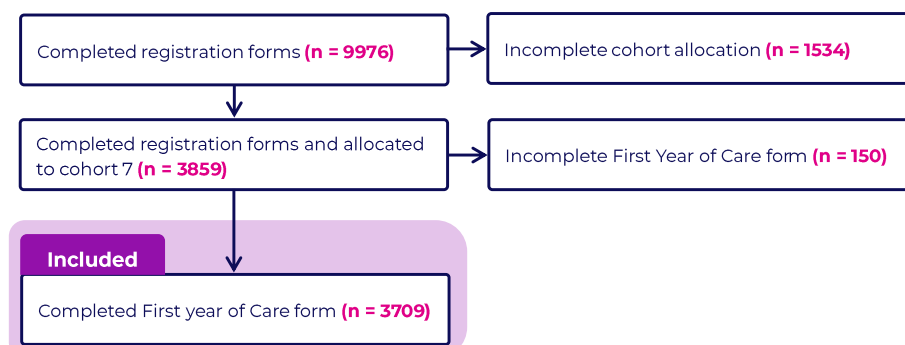
Figure 1: Percentage of Trusts and Health Boards that submitted clinical audit data in cohorts 1-7.

Case Ascertainment

The Epilepsy12 eligibility criteria was revised from cohort 6, to only include children and young people with a confirmed new epilepsy diagnosis, compared to the previous approach of initially including all those assessed for paroxysmal episodes.

Figure 2 shows the pathway by which children and young people with epilepsy are registered into the audit, allocated to a discrete cohort, and included in the final dataset used in annual analyses. These figures reflect the data at the point of download from the online platform.

Figure 2: Consort diagram of total audit registrations to platform and inclusion in cohort 7, on 14 January 2026



Epilepsy12: Clinical audit national and regional results; 2026, cohort 7

Data completeness

Table 1: Percentage of children and young people with epilepsy registered to cohort 7 with a first year of care form completed.

	England and Wales	England	Wales
Number of children and young people allocated to cohort 7	3859	3691	168
Number of children and young people in cohort 7 with first year of care form completed	3709/3859 (96.1%)	(3545/3691) (96%)	(164/168) (97.6%)

A total of **3859** children and young people with epilepsy were registered onto the platform and allocated to cohort 7 before the download date. All children and young people had valid NHS numbers recorded. There were an additional **8** children and young people with epilepsy registered to the clinical audit from Jersey, of which **8/8 (100%)** were complete. These children and young people have not been included in the following analysis.

3709/3859 (96.1%) had first year of care forms completed in England and Wales and were therefore included in the main annual analyses. **Figure 3** shows data completeness rates between cohort 1 and 7. Note, that eligibility criteria evolved in cohort 6 to only include children and young people with a confirmed new epilepsy diagnosis.

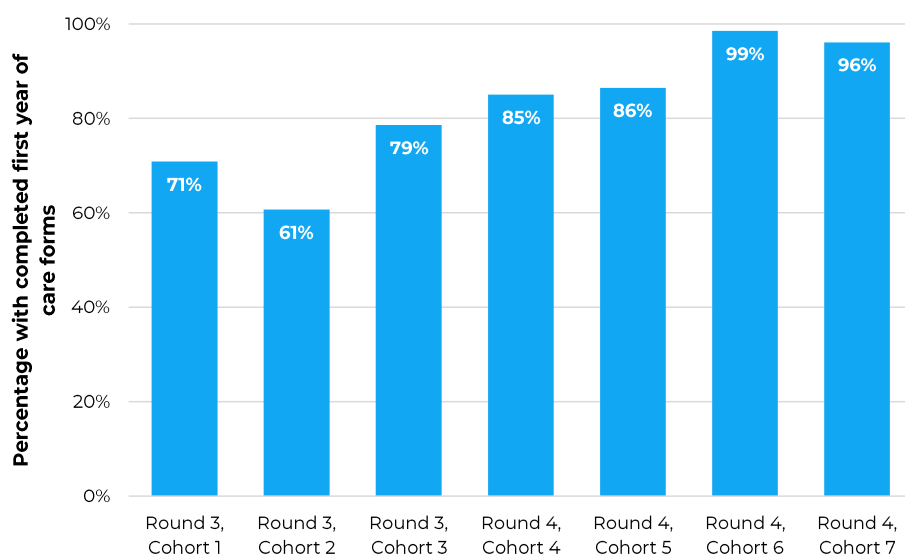


Figure 3: Data completeness in Round 3 and Round 4.

Figure 4 shows the percentage of children and young people with epilepsy in cohort 7 with a completed first year of care form by 14th January 2026. Each Health Board and Trust is represented by a vertical bar in order of the percentage score. This does not include the 3 Health Boards and Trusts that had no patients registered to cohort 7.

Of the **129** Health Boards and Trusts from England and Wales, that had at least one patient allocated to cohort 7, **103** had **100%** data completeness.

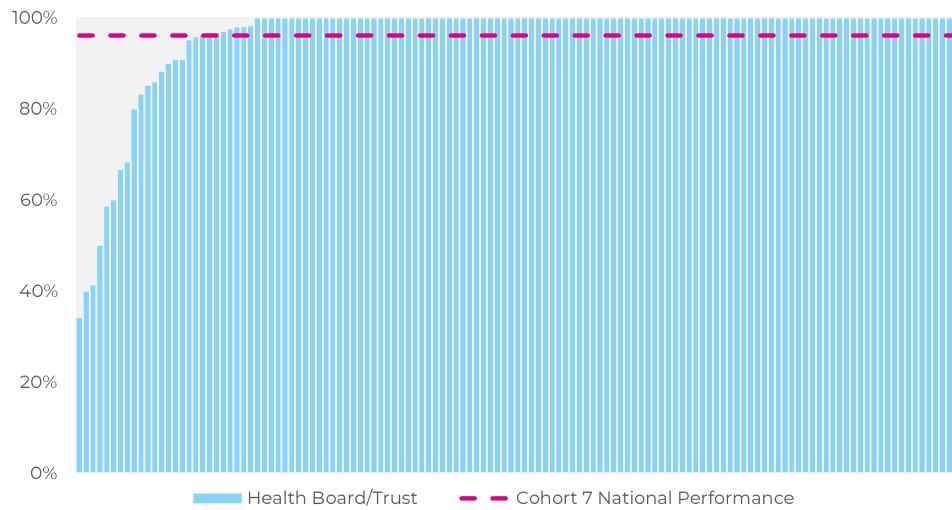


Figure 4: Percentage of children and young people with their first year of care form submitted and locked by Health Boards and Trusts in cohort 7.

The remaining chapters of this report focus on the **3709** children and young people with epilepsy in cohort 7 with a completed first year of care form in England and Wales.

Description of cohort

Demographics

Table 2 describes the geographical distribution of children and young people with epilepsy across England and Wales. **3545** were under the care of Trusts in England, and **164** in Welsh Health Boards. Geographical distributions ranged from **245** (South West) to **640** (North West) between NHS England Regions, and from **104** (CEWT) to **440** (NWEIG) between OPEN UK regions.

Table 2: Proportion of children and young people with epilepsy by region in cohort 7.

Geographic Region	Percentage
Country	
England	95.6% (3545/3709)
Wales	4.4% (164/3709)
NHS England Region	
East of England	8.6% (305/3545)
London	14.4% (510/3545)
Midlands	16.9% (599/3545)
North East and Yorkshire	18% (637/3545)
North West	18.1% (640/3545)
South East	17.2% (609/3545)
South West	6.9% (245/3545)
OPEN UK Region	
BRPNF	7.8% (291/3709)
CEWT	2.8% (104/3709)
EPEN	6% (224/3709)
EPIC	8.6% (320/3709)
NTPEN	11.5% (428/3709)
NWEIG	11.9% (440/3709)
ORENG	5.8% (216/3709)
PENNEC	5.3% (198/3709)
SETPEG	6.8% (253/3709)
SWEP	3.7% (138/3709)
SWIPE	3.7% (139/3709)
SWTPEG	6.8% (252/3709)
TEN	4.5% (167/3709)
WPNN	6.4% (237/3709)
YPEN	8.1% (302/3709)

Table 3 shows the demographic characteristics of cohort 7.

56.1% (2082/3709) of children and young people with epilepsy in cohort 7 were male, which is consistent with previous cohorts; **54.4% (1689/3105)** in cohort 6. **1.3% (49/3709)** had their sex indicated as 'not known' or 'not specified'.

The mean age at first assessment in cohort 7 was **8 years**, and the range was **0 – 17.7 years**. The majority **66.6% (2469/3709)** of children and young people in cohort 7 had 'White' ethnicity indicated, compared to **74.1%** of the 2025 general population estimates of children and young people aged 0-24 years. For **13.3% (495/3709)** of children and young people ethnicity was not stated.

A high proportion **27.6% (1025/3709)** of children and young people in cohort 7 were living in areas in the most deprived quintile. This is higher than the 2025 population estimate for children and young people aged 0-24 years, where only **23.4%** live in the most deprived areas.

Deprivation quintile was derived by matching home postcodes to the English (IMD, 2019) and Welsh (WIMD, 2019) indices of multiple deprivation data. **0.6% (23/3709)** of children and young people could not be allocated to a deprivation quintile, because their recorded postcodes were invalid or did not match a Lower layer Super Output Area ([LSOA](#)), and were therefore excluded from all deprivation analyses.

Table 3: Summary of the demographic characteristics of children and young people with epilepsy in cohort 7 in England and Wales.

Characteristic	England and Wales	England	Wales
Sex			
Females	42.5% (1578/3709)	42.7% (1512/3545)	40.2% (66/164)
Male	56.1% (2082/3709)	56.1% (1987/3545)	57.9% (95/164)
Not stated	1.3% (49/3709)	1.3% (46/3545)	1.8% (3/164)
Age			
Mean	8.0	7.9	8.3
Median (Interquartile range)	7.9 (4.1-11.8)	7.9 (4-11.9)	8 (5-11.6)
Range	0-17.7	0-17.7	0-15.8
Ethnicity			
Asian	8.4% (310/3709)	8.5% (303/3545)	4.3% (7/164)
Black	5.1% (189/3709)	*	*
Mixed	3.6% (132/3709)	*	*
White	66.6% (2469/3709)	65.8% (2332/3545)	83.5% (137/164)
Other	3.1% (114/3709)	*	*
Not Stated	13.3% (495/3709)	13.5% (480/3545)	9.1% (15/164)
Deprivation			
Least deprived	15.4% (571/3709)	15.3% (544/3545)	16.5% (27/164)
Second least deprived	16.5% (611/3709)	16.5% (585/3545)	15.9% (26/164)
Third least deprived	17.7% (658/3709)	17.8% (632/3545)	15.9% (26/164)
Second most deprived	22.1% (821/3709)	21.9% (777/3545)	26.8% (44/164)

Most deprived	27.6% (1025/3709)	27.8% (984/3545)	25% (41/164)
Not Indicated	0.6% (23/3709)	0.6% (23/3545)	N/A

Figure 5 shows the age and sex of patients in cohort 7. The children and young people's ages are given in whole years, giving their age at their first assessment. **49** children and young people in cohort 7 had unknown or unspecified sex, and were therefore excluded from Figure 5.

Of those below 1 year of age at first paediatric assessment **10.9% (35/321)** had their first paediatric assessment in their first month of life.

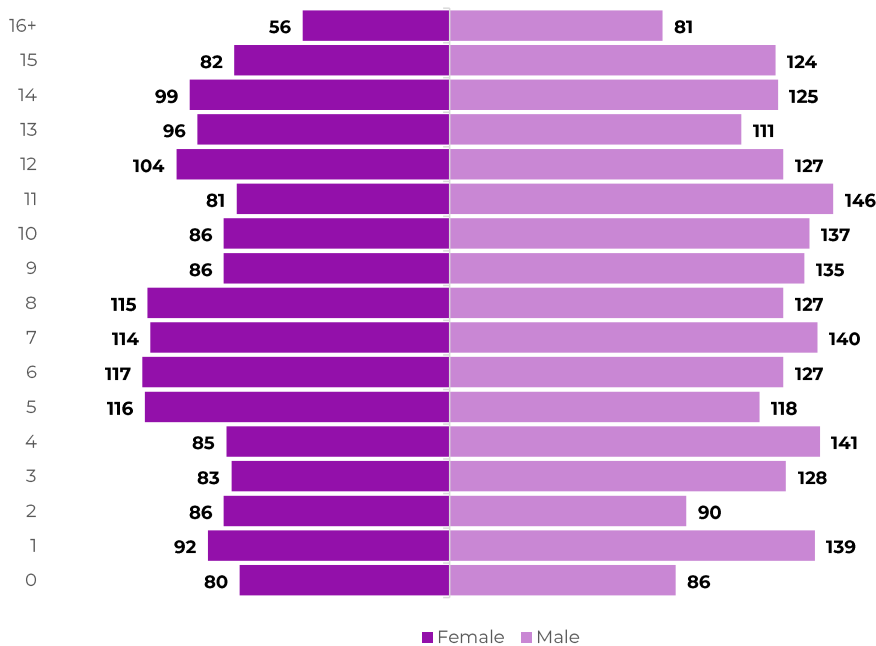


Figure 5: Distribution of age and sex for children and young people at first paediatric assessment in cohort 7 in England and Wales.

Figure 6 shows that there are a higher proportion of children and young people in cohort 7 who indicated 'White' ethnicity (**66.6%**), compared to other ethnicity categories.

Figure 7 shows that a high proportion (**27.6%**) of children and young people in cohort 7 are living in areas in the most deprived quintile of England, with wide variation between NHS England regions. This is consistent with cohort 6.

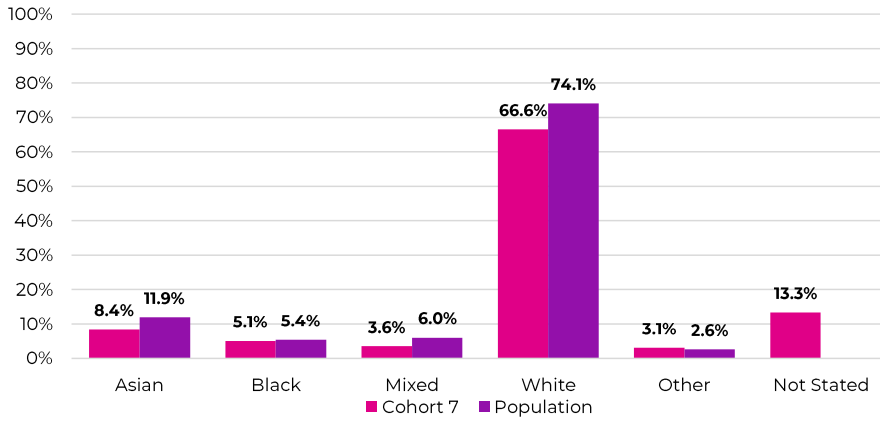


Figure 6: Distribution of ethnicity for children and young people in cohort 7 in England and Wales, compared to the 2025 population estimates for children and young people aged 0-24 years.

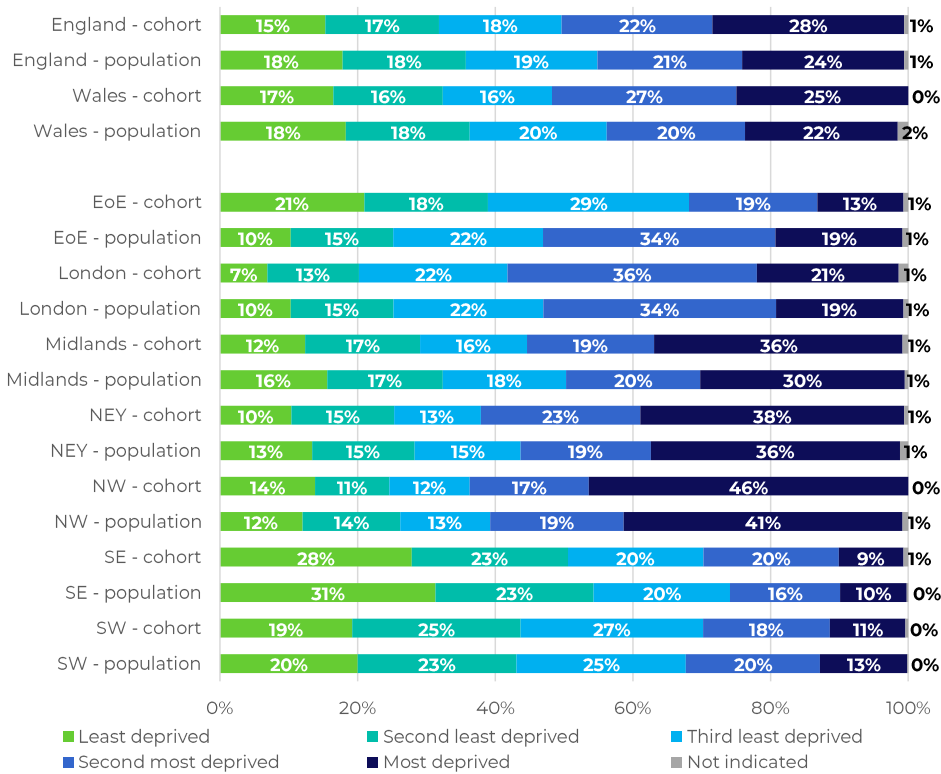


Figure 7: Children and young people with epilepsy in cohort 7 by deprivation quintile in England and Wales, compared to the 2025 general population estimates for children and young people aged 0-24 years.

Multiaxial diagnosis

This section describes the seizure history (**Table 4**), seizure cause (**Table 5**), electroclinical syndrome (**Table 6**) and epileptic seizure types (**Table 7 and 8**) for children and young people with epilepsy in cohort 7.

Most children and young people had no family history of epilepsy, and did not have any prior history of neonatal, febrile, or acute seizures in cohort 7, which is consistent with cohorts 1-6.

Table 4: Percentage of children and young people with epilepsy with a family history of epilepsy or previous seizures in cohort 7 in England and Wales.

Prior History	England and Wales	England	Wales
Family history of epilepsy			
Yes	24.1% (893/3709)	24% (850/3545)	26.2% (43/164)
No	68.9% (2554/3709)	68.8% (2440/3545)	69.5% (114/164)
Uncertain	7.1% (262/3709)	7.2% (255/3545)	4.3% (7/164)
History of neonatal seizures			
Yes	3% (110/3709)	*	*
No	92.9% (3445/3709)	*	*
Uncertain	4.2% (154/3709)	*	*
History of febrile seizures			
Yes	13.6% (504/3709)	13.6% (481/3545)	14% (23/164)
No	79.4% (2946/3709)	79.3% (2812/3545)	81.7% (134/164)
Uncertain	7% (259/3709)	7.1% (252/3545)	4.3% (7/164)
History of acute asymptomatic seizures			
Yes	21% (778/3709)	*	*
No	75.8% (2812/3709)	*	*
Uncertain	3.2% (119/3709)	*	*

Table 5 describes the main causes of epilepsy recorded in cohort 7. In England and Wales, **13.6% (505/3709)** of children and young people with epilepsy had a genetic cause of epilepsy indicated, **6.7% (247/3709)** had a structural epilepsy cause, **0.2% (9/3709)** had an infectious cause, **0.4% (15/3709)** had a metabolic cause, and **0.2% (6/3709)** had an immune cause **86.4% (3204/3709)** of the cohort had an unknown cause.

Table 5: Percentage of children and young people with epilepsy with each cause recorded in cohort 7 in England and Wales.

Cause of epilepsy	England and Wales	England	Wales
Structural	6.7% (247/3709)	6.8% (241/3545)	3.7% (6/164)
Genetic	7% (259/3709)	7% (249/3545)	6.1% (10/164)
Infectious	0.2% (9/3709)	0.3% (9/3545)	0% (0/164)
Metabolic	0.4% (15/3709)	0.4% (15/3545)	0% (0/164)
Immune	0.2% (6/3709)	0.2% (6/3545)	0% (0/164)

Table 6: Summary of electroclinical syndromes in children and young people with epilepsy in cohort 7 in England and Wales. Electroclinical syndromes that were not indicated for any children and young people with epilepsy in cohort 7 are omitted from this list. Note, the total percentages may exceed 100% as more than one syndrome could be entered per child/young person.

Electroclinical Syndrome	England and Wales	England	Wales
No epilepsy syndrome stated	70.7% (2624/3709)	70.8% (2511/3545)	68.9% (113/164)
CDKL5-DEE	0.1% (4/3709)	0.1% (4/3545)	N/A
Childhood absence epilepsy	6.8% (252/3709)	6.9% (243/3545)	5.5% (9/164)
Childhood occipital visual epilepsy	0.4% (13/3709)	0.4% (13/3545)	N/A
DEE or EE with spike-and-wave activation in sleep	0.1% (3/3709)	0.1% (3/3545)	N/A
Dravet syndrome	0.2% (9/3709)	0.3% (9/3545)	N/A
Early infantile DEE	0.2% (8/3709)	0.2% (8/3545)	N/A
Epilepsy of infancy with migrating focal seizures	*	*	*
Epilepsy with eyelid myoclonia	0.4% (16/3709)	*	*
Epilepsy with generalized tonic-clonic seizures alone	3.2% (119/3709)	3.2% (115/3545)	2.4% (4/164)
Epilepsy with myoclonic absences	0.6% (21/3709)	0.5% (17/3545)	2.4% (4/164)
Epilepsy with myoclonic- atonic seizures (Doose syndrome)	0.2% (9/3709)	*	*
Aetiology-specific DEEs	0.2% (7/3709)	0.2% (7/3545)	N/A
Familial focal epilepsy with variable foci	0.2% (7/3709)	0.2% (7/3545)	N/A
Familial mesial temporal lobe epilepsy	0.1% (4/3709)	0.1% (4/3545)	N/A
GLUT1-DEE	*	*	*
Gelastic seizures with HH	*	*	*
Genetic epilepsy with febrile seizures plus	0.3% (10/3709)	*	*
Hemiconvulsion-hemiplegia-epilepsy	*	*	*
Infantile epileptic spasms syndrome	1.9% (71/3709)	1.9% (68/3545)	1.8% (3/164)
Juvenile absence epilepsy	2.9% (106/3709)	2.9% (103/3545)	1.8% (3/164)
Juvenile myoclonic epilepsy	3.2% (120/3709)	3.2% (112/3545)	4.9% (8/164)
KCNQ2-DEE	*	*	*
Lennox-Gastaut syndrome	0.1% (4/3709)	0.1% (4/3545)	N/A

Mesial temporal lobe epilepsy with hippocampal sclerosis	0.1% (4/3709)	0.1% (4/3545)	N/A
Myoclonic epilepsy in infancy	0.2% (7/3709)	0.2% (7/3545)	N/A
PCDH19 clustering epilepsy	*	*	*
Photosensitive occipital lobe epilepsy	*	*	*
Progressive myoclonus epilepsies	*	*	*
Pyridoxine-dependent and pyridox(am)ine 5' phosphate deficiency DEE	*	*	*
Self-limited (familial) infantile epilepsy	0.2% (8/3709)	0.2% (8/3545)	N/A
Self-limited (familial) neonatal epilepsy	0.1% (4/3709)	*	*
Self-limited epilepsy with autonomic seizures	1% (38/3709)	*	*
Self-limited epilepsy with centrotemporal spikes	6.3% (233/3709)	6.2% (220/3545)	7.9% (13/164)
Sturge-Weber syndrome	0.1% (4/3709)	0.1% (4/3545)	N/A

In cohort 7, **95.1% (3528/3709)** of children and young people with epilepsy in England and Wales had only one epileptic seizure type, and the most common seizure type recorded was generalised onset **54.1% (2007/3709)** with the most common presentation being generalised tonic-clonic seizures **55.9% (1122/2007)**. **0.7% (25/3709)** of children and young people with epilepsy had non-epileptic seizures, while **4.9% (183/3709)** had seizures of unknown onset (**Table 7**).

Table 7: Percentage of children and young people with epilepsy with each seizure type in cohort 7 in England and Wales. Note, the total percentages may exceed 100% as more than one seizure episode type could be entered per child/young person.

Episode type	England and Wales	England	Wales
Number of seizure onset types (epileptic only)			
1 epileptic seizure type	95.1% (3528/3709)	95% (3367/3545)	98.2% (161/164)
2 epileptic seizure types	4.7% (176/3709)	4.9% (173/3545)	1.8% (3/164)
3 or more epileptic seizure types	0.1% (5/3709)	0.1% (5/3545)	N/A
Focal Onset	35.5% (1315/3709)	35.5% (1260/3545)	33.5% (55/164)
Focal onset laterality known	49.4% (650/1315)	49.7% (626/1260)	43.6% (24/55)
Left	30.6% (402/1315)	30.7% (387/1260)	27.3% (15/55)
Right	30.6% (403/1315)	31.1% (392/1260)	20% (11/55)
Motor manifestations	66% (868/1315)	65.6% (827/1260)	74.5% (41/55)
Atonic	3.8% (50/1315)	*	*
Clonic	21.7% (286/1315)	21.9% (276/1260)	18.2% (10/55)
Spasms	3.2% (42/1315)	*	*

Hyperkinetic	1.2% (16/1315)	1.3% (16/1260)	N/A
Myoclonic	3% (39/1315)	3.1% (39/1260)	N/A
Tonic	18.6% (244/1315)	18.7% (236/1260)	14.5% (8/55)
Focal to bilateral tonic-clonic	27.1% (357/1315)	26.4% (333/1260)	43.6% (24/55)
Non-motor manifestations	72.2% (950/1315)	72% (907/1260)	78.2% (43/55)
Automatisms	8.9% (117/1315)	8.9% (112/1260)	9.1% (5/55)
Impaired Awareness	59.8% (786/1315)	59.8% (754/1260)	58.2% (32/55)
Gelastic	0.4% (5/1315)	0.4% (5/1260)	N/A
Autonomic	9.4% (123/1315)	9.5% (120/1260)	5.5% (3/55)
Behavioural Arrest	17.3% (228/1315)	17.2% (217/1260)	20% (11/55)
Cognitive	2.5% (33/1315)	*	*
Emotional	2.5% (33/1315)	*	*
Sensory	6.2% (82/1315)	6.3% (79/1260)	5.5% (3/55)
EEG Findings	43.6% (573/1315)	43.2% (544/1260)	52.7% (29/55)
Centrotemporal	14.2% (187/1315)	13.8% (174/1260)	23.6% (13/55)
Temporal	16.3% (215/1315)	16.3% (206/1260)	16.4% (9/55)
Frontal	10.7% (141/1315)	10.7% (135/1260)	10.9% (6/55)
Parietal	5.7% (75/1315)	*	*
Occipital	5.9% (78/1315)	5.9% (74/1260)	7.3% (4/55)
Generalised Onset	54.1% (2007/3709)	54% (1914/3545)	56.7% (93/164)
Tonic-clonic	55.9% (1122/2007)	55.9% (1070/1914)	55.9% (52/93)
Clonic	2% (40/2007)	*	*
Tonic	3% (60/2007)	2.8% (54/1914)	6.5% (6/93)
Myoclonic	5.5% (110/2007)	*	*
Myoclonic-tonic-clonic	1.4% (28/2007)	*	*
Myoclonic-atonic	0.3% (7/2007)	0.4% (7/1914)	N/A
Atonic	1.5% (31/2007)	1.5% (28/1914)	3.2% (3/93)
Epileptic Spasms	3.9% (78/2007)	3.9% (75/1914)	3.2% (3/93)
Typical absence	22.7% (455/2007)	22.9% (438/1914)	18.3% (17/93)
Atypical absence	7.1% (142/2007)	6.9% (133/1914)	9.7% (9/93)
Myoclonic absence	2.3% (46/2007)	2.1% (41/1914)	5.4% (5/93)
Absence with eyelid myoclonia	2.6% (53/2007)	2.6% (49/1914)	4.3% (4/93)
Other	2.6% (53/2007)	2.5% (47/1914)	6.5% (6/93)
Unknown epileptic onset	12% (445/3709)	12.1% (430/3545)	9.1% (15/164)
Unclassified epileptic onset	3.5% (128/3709)	3.5% (124/3545)	2.4% (4/164)
Non-epileptic onset	0.7% (25/3709)	0.7% (25/3545)	N/A
Syncope and anoxic seizures	*	*	N/A
Behavioural, psychological and psychiatric disorders	20% (5/25)	20% (5/25)	N/A
Sleep related conditions	*	*	N/A
Other	64% (16/25)	64% (16/25)	N/A

Figure 8 shows that the percentage of children and young people in England and Wales with generalised seizures, focal seizures, unknown and unclassified seizures has remained fairly similar to cohort 6.

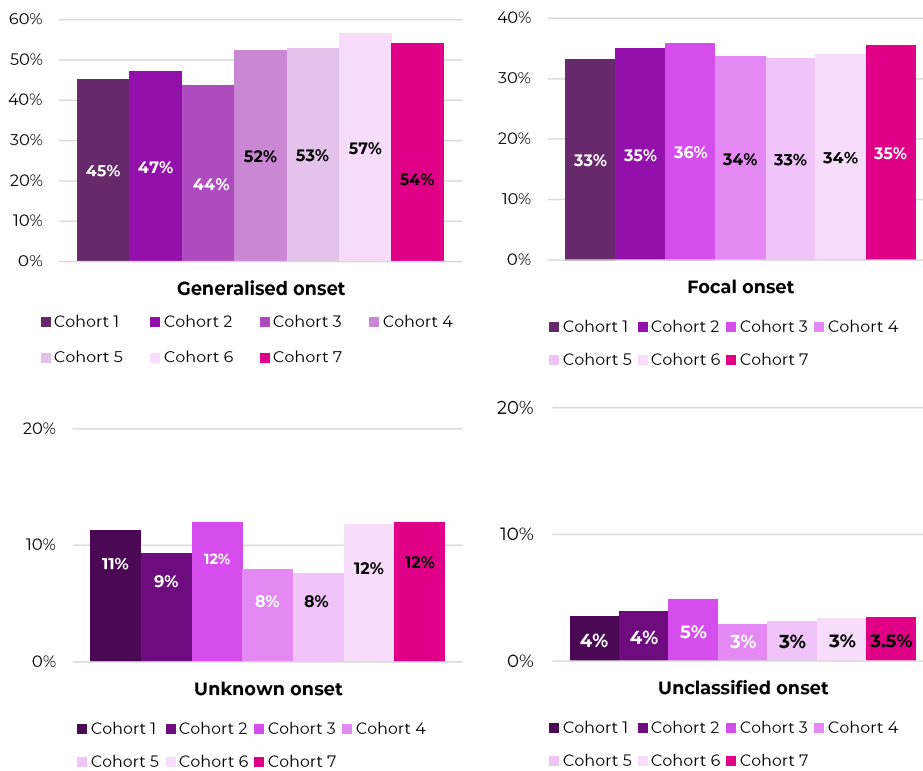


Figure 8: Percentage of children and young people in England and Wales with generalised seizures, focal seizures, unknown and unclassified seizures between cohort 1 and cohort 7.

In cohort 7, **64.5% (2391/3709)** of children and young people with epilepsy in England and Wales had convulsive seizures (**Table 8**). This is consistent with previous cohorts.

18.1% (673/3709) had prolonged generalised seizures and **10.5% (389/3709)** had prolonged focal seizures. These are seizures with a duration of more than five minutes or successive seizures continuing for more than five minutes. This is a slight decrease compared to **19% (590/3105)** and an increase from **9.9% (307/3105)** respectively in cohort 6.

Table 8: Percentage of children and young people with epilepsy with convulsive and prolonged seizures in cohort 7 in England and Wales.

	England and Wales	England	Wales
Convulsive seizures			
Yes	18.1% (673/3709)	*	*
No	78.4% (2908/3709)	78.2% (2771/3545)	83.5% (137/164)
Uncertain	3.5% (128/3709)	*	*
Prolonged Focal Seizures			
Yes	10.5% (389/3709)	10.7% (381/3545)	4.9% (8/164)
No	84.6% (3137/3709)	84.3% (2989/3545)	90.2% (148/164)
Uncertain	4.9% (183/3709)	4.9% (175/3545)	4.9% (8/164)

Mental health and neurodevelopmental conditions

Table 9 describes information collected around the neurodevelopmental conditions and/or learning disabilities and mental health conditions for children and young people with epilepsy in cohort 7.

The terms global developmental delay, intellectual disability, and learning disability have been grouped into a single category here for ease of reporting. We acknowledge that there is variation in these definitions, and use of these terms across the world, and that they may be applied to different age groups. We recognise that 'learning difficulties' are different to 'learning disabilities' and refer to a group of conditions.

Table 9: Percentage of children and young people with epilepsy with neurodevelopmental conditions/learning disabilities and mental health conditions in cohort 7 in England and Wales. Note, the total percentages may exceed 100% as more than one condition could be entered per child/young person.

	England and Wales	England	Wales
Neurodevelopmental condition	31% (1149/3709)	31.3% (1108/3545)	25% (41/164)
Autistic Spectrum Disorder	18% (667/3709)	18.1% (642/3545)	15.2% (25/164)
Intellectual disability/global developmental delay/'learning disability'	23.4% (869/3709)	23.5% (834/3545)	21.3% (35/164)
Behavioural educational	16.9% (626/3709)	17.1% (605/3545)	12.8% (21/164)
Mental health condition	9.4% (349/3709)	9.3% (330/3545)	11.6% (19/164)
Anxiety disorder	3.7% (138/3709)	3.7% (132/3545)	3.7% (6/164)
Emotional/behavioural	4.8% (177/3709)	4.7% (166/3545)	6.7% (11/164)
Mood disorder	1% (36/3709)	*	*
Self-harm	0.6% (22/3709)	*	*
Other	0.7% (26/3709)	0.6% (23/3545)	1.8% (3/164)

In England and Wales, **31% (1149/3709)** of children and young people with epilepsy in cohort 7 had a neurodevelopmental condition, autism spectrum disorder, and/or learning disability indicated, which is an increase from **27.5% (854/3105)** in cohort 6.

9.4% (349/3709) of children and young people with epilepsy had an identified mental health condition recorded in cohort 7, which is comparable to **9% (278/3105)** in cohort 6.

Figure 9 shows the increase in the percentage of children and young people with epilepsy with a diagnosed mental health condition in England and Wales between cohort 1 and cohort 7.

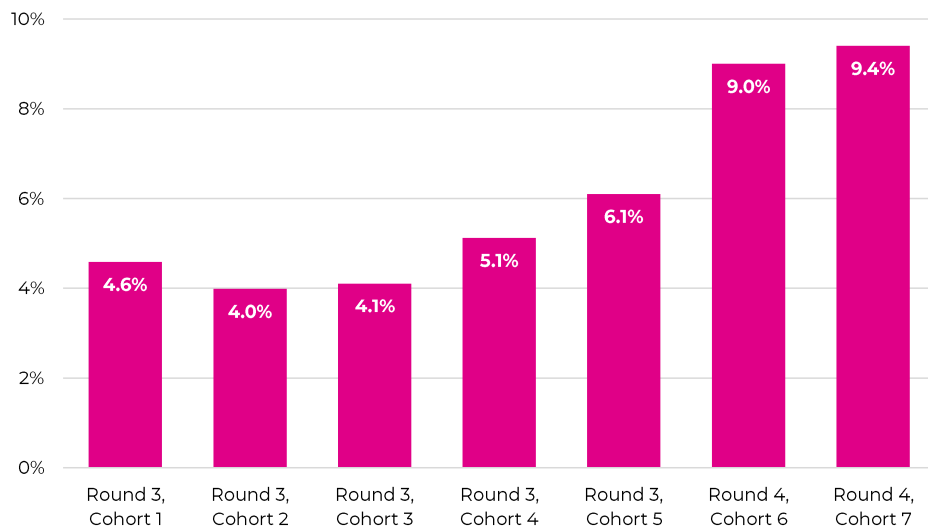


Figure 9: Percentage of children and young people with epilepsy with a mental health condition between cohort 1 and cohort 7.

13.5% (349/2580) of children and young people with epilepsy and aged 5 years and older had an identified mental health condition(s) by their first year of care in England and Wales in cohort 7.

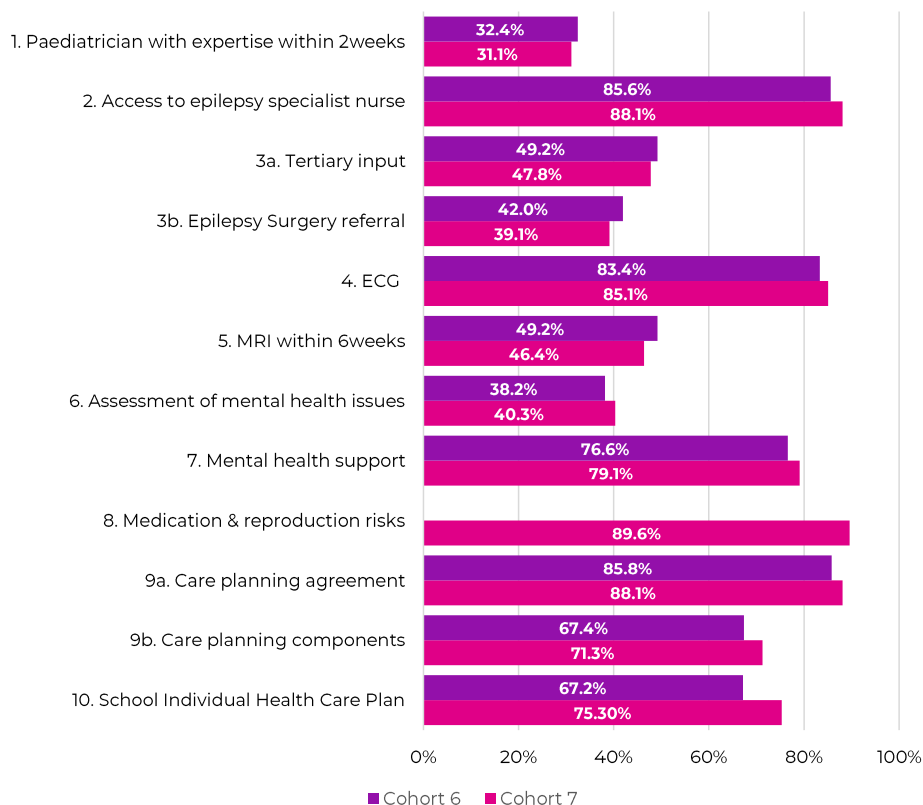
Key Performance Indicators

In cohort 7, Epilepsy12 has identified 10 Key Performance Indicator (KPI) measures which are derived from national guidelines and recommendations. These are detailed in the [Round 4 methodology overview](#).

This chapter will explore the cohort 7 England and Wales and regional performance data for each of the 10 KPIs in turn, including the variation in care between demographic population groups; age, sex, ethnicity, deprivation, as well as the presence/absence of mental health conditions and of neurodevelopmental conditions, including global developmental disorder or autism spectrum disorder, or learning disabilities.

As before, this section only includes the **3709 children and young people with a confirmed new epilepsy diagnosis** and a submitted first year of care form before the specified download date of 14 January 2026. Jersey has been excluded from the analysis due to small patient numbers, which presents possible data disclosure and patient confidentiality risks.

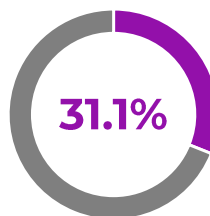
Figure 10: shows an overview of the 10 Epilepsy12 KPIs for England and Wales combined in cohort 6 and 7.



Note: KPI 8 has been revised in cohort 7, and so a cohort 6 comparison has not been provided.

1. Paediatrician with expertise in epilepsies; input within 2 weeks

Percentage of children and young people with epilepsy seen by a 'paediatrician with expertise in epilepsies' within two weeks of referral.



NICE Guidelines [NG217], 2022 (Statement 1.1.1) state that the diagnosis of epilepsy in children should be established by a specialist paediatrician with training and expertise in epilepsy and this should be within two weeks of initial referral.

31.1% (1152/3709) of children and young people with epilepsy were seen by a 'consultant paediatrician with expertise in epilepsies' within two weeks of referral. This was a decrease from **32.4% (1007/3105)** in cohort 6. This indicator ranged from **0%** to **94.1%**, with an interquartile range of **17.7%** to **37.8%**.

The 2-week timeframe was introduced to the KPI in 2024 and includes children and young people with input prior to their first paediatric assessment. The measure was focused to 'seen by' compared to 'received input from' between cohort 5 and 6.

92.6% (3434/3709) of children and young people with epilepsy were seen by a 'consultant paediatrician with expertise in epilepsies' within the first year of care. This was an increase compared to **90.3% (2803/3105)** in cohort 6.

Table 10 shows how timely access to a paediatrician with expertise is distributed between demographic population groups and **Table 11** shows the variation in access to a paediatrician with expertise between England and Wales and across NHSE and OPEN UK regions. **Table 12** describes the time in weeks to being seen by a paediatrician with expertise in epilepsy from first referral for all children and young people with epilepsy in cohort 7.

Table 10: Percentage of children and young people with epilepsy seen by a 'consultant paediatrician with expertise in epilepsies' within two weeks from referral by demographic.

Demographic Variables	England and Wales	England	Wales
Age			
< 2 years	58.8% (283/481)	58.3% (274/470)	81.8% (9/11)
2 – 4 years	32.6% (211/648)	33.2% (205/618)	20% (6/30)
5 – 11 years	25.6% (433/1689)	26.5% (425/1603)	9.3% (8/86)
12 – 15 years	25.2% (213/844)	25.8% (208/807)	13.5% (5/37)
16+ years	25.5% (12/47)	25.5% (12/47)	N/A
Sex			
Female	30.7% (484/1578)	31.4% (475/1512)	13.6% (9/66)
Male	31.2% (650/2082)	31.8% (631/1987)	20% (19/95)
Not indicated	36.7% (18/49)	39.1% (18/46)	N/A
Ethnicity			
Asian	27.1% (84/310)	*	*
Black	30.2% (57/189)	30.5% (57/187)	N/A
Mixed	32.6% (43/132)	33.1% (43/130)	N/A

Other	26.3% (30/114)	26.5% (30/113)	N/A
White	32.5% (803/2469)	33.4% (778/2332)	18.2% (25/137)
Not indicated	27.3% (135/495)	*	*
Deprivation			
Most deprived	30.3% (311/1025)	31% (305/984)	14.6% (6/41)
Second most deprived	30.5% (250/821)	30.9% (240/777)	22.7% (10/44)
Third least deprived	31.2% (205/658)	32% (202/632)	11.5% (3/26)
Second least deprived	31.9% (195/611)	32.8% (192/585)	11.5% (3/26)
Least deprived	32% (183/571)	32.5% (177/544)	22.2% (6/27)
Not indicated	34.8% (8/23)	34.8% (8/23)	N/A
Mental health			
Mental health condition identified	28.7% (100/349)	*	*
No mental health condition identified	31.3% (1052/3360)	*	*
Neurodevelopmental condition/learning disability			
Neurodevelopmental condition/learning disability identified	34.1% (392/1149)	34.4% (381/1108)	26.8% (11/41)
No neurodevelopmental condition/learning disability identified	29.7% (760/2560)	30.5% (743/2437)	13.8% (17/123)

Table 11: Percentage of children and young people with epilepsy seen by a 'consultant paediatrician with expertise in epilepsies' within two weeks from referral by region.

Geographic Region	KPI 1. Paediatrician with expertise; input within 2 weeks
England and Wales	31.1% (1152/3709)
Country	
England	31.7% (1124/3545)
Wales	17.1% (28/164)
NHS England Region	
East of England	36.7% (112/305)
London	26.5% (135/510)
Midlands	36.4% (218/599)
North East and Yorkshire	29.7% (189/637)
North West	31.9% (204/640)
South East	31.7% (193/609)
South West	29.8% (73/245)
OPEN UK Region	
BRPNF	33.3% (97/291)
CEWT	51% (53/104)

EPEN	40.6% (91/224)
EPIC	39.1% (125/320)
NTPEN	25% (107/428)
NWEIG	28% (123/440)
ORENG	33.8% (73/216)
PENNEC	26.3% (52/198)
SETPEG	32.4% (82/253)
SWEP	17.4% (24/138)
SWIPE	26.6% (37/139)
SWTPEG	33.3% (84/252)
TEN	18.6% (31/167)
WPNN	30.4% (72/237)
YPEN	33.4% (101/302)

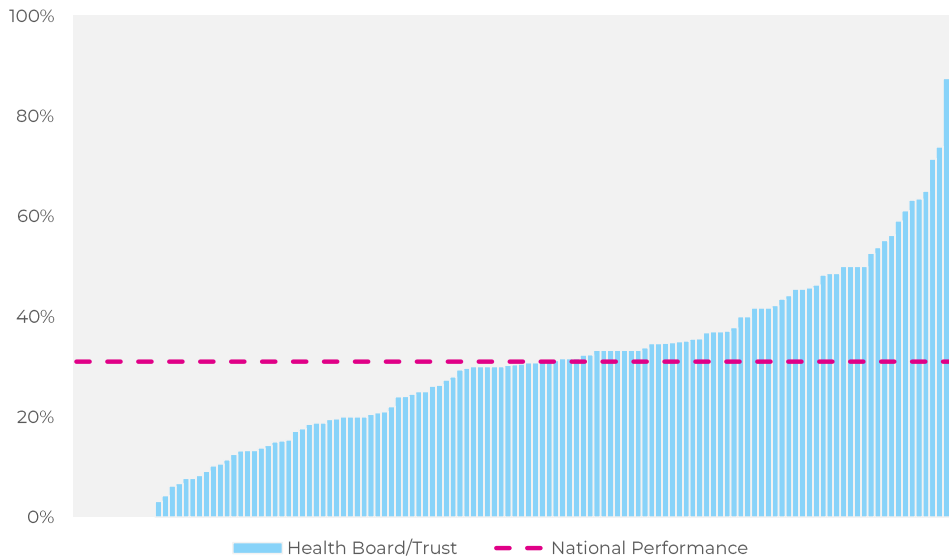


Figure 11: KPI 1 - Paediatrician with expertise in epilepsies by Health Board and Trust, cohort 7. Each participating Health Board or Trust is represented by a vertical bar in the order of the percentage score, including those scoring 0% in this graph.

In cohort 7, **9% (332/3709)** of children and young people with epilepsy waited more than 16 weeks to be seen by a paediatrician with expertise (**Table 12**).

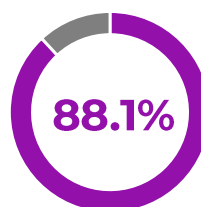
Table 12: Time in weeks to be seen by a paediatrician with expertise in epilepsy since first referral for children and young people with epilepsy in cohort 7.

Time in weeks	England and Wales	England	Wales
Within 2 weeks	31.1% (1152/3709)	31.7% (1124/3545)	17.1% (28/164)
2 - 4 weeks	15.3% (568/3709)	15.7% (557/3545)	6.7% (11/164)
4 - 8 weeks	22.3% (828/3709)	22.3% (789/3545)	23.8% (39/164)
8 - 12 weeks	11.5% (427/3709)	11.2% (397/3545)	18.3% (30/164)
12 - 16 weeks	6.1% (227/3709)	6% (212/3545)	9.1% (15/164)
16+ weeks	9% (332/3709)	8.7% (310/3545)	13.4% (22/164)
Input not achieved	4.7% (175/3709)	4.4% (156/3545)	11.6% (19/164)

2. Epilepsy Specialist Nurse (ESN)

Percentage of children and young people with epilepsy seen by an epilepsy specialist nurse within the first year of care.

NICE guidelines [NG217], 2022 (Statement 11.1.1) state that all children and young people with epilepsy should have access to an epilepsy specialist nurse.



88.1% (3268/3709) of children and young people with epilepsy were seen by an epilepsy specialist nurse (ESN) within the first year of care. This was an increase compared to **85.6% (2659/3105)** in cohort 6. This indicator ranged from **0%** to **100%**, with an interquartile range of **83.3%** to **100%**.

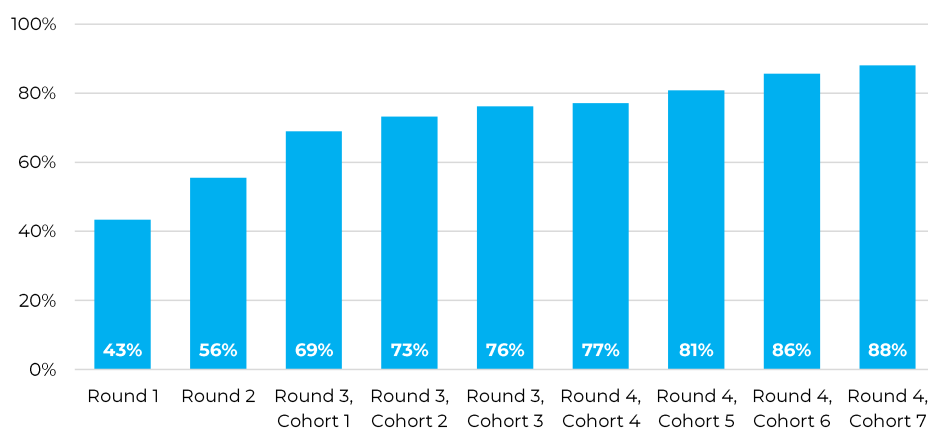


Figure 12: Access to Epilepsy Specialist Nurse (ESN) between Rounds 1 and 4.

Figure 12 and **Table 13** describe access to epilepsy specialist nurse over time between Rounds 1 and 4. **Table 14** shows how access to epilepsy specialist nurse is distributed between demographic population groups and **Table 15** shows the variation in access to epilepsy specialist nurse between England and Wales and across NHSE and OPEN UK regions.

Table 13: The percentage of children and young people with epilepsy who were seen by an epilepsy specialist nurse within the first year of care in each cohort.

	England and Wales	England	Wales
Round 1	43.4% (658/1516)	41.6% (592/1423)	70.1% (66/93)
Round 2	55.5% (605/1090)	54.5% (555/1019)	70.4% (50/71)
Round 3, Cohort 1	69.0% (767/1112)	70.2% (738/1051)	47.5% (29/61)
Round 3, Cohort 2	73.2% (1542/2106)	73.1% (1524/2086)	90.0% (18/20)
Round 3, Cohort 3	76.2% (1505/1974)	76.7% (1471/1918)	60.7% (34/56)
Round 4, Cohort 4	77.2% (1793/2324)	76.8% (1701/2215)	84.4% (92/109)
Round 4, Cohort 5	80.7% (1786/2212)	80.3% (1665/2074)	87.7% (121/138)
Round 4, Cohort 6	85.6% (2659/3105)	85.9% (2530/2947)	81.6% (129/158)
Round 4, Cohort 7	88.1% (3268/3709)	88.3% (3132/3545)	82.9% (136/164)

Table 14: Percentage of children and young people with epilepsy seen by an epilepsy specialist nurse within the first year of care by demographic.

Demographic Variables	England and Wales	England	Wales
Age			
< 2 years	89.4% (430/481)	89.4% (420/470)	90.9% (10/11)
2 – 4 years	88.3% (572/648)	88.7% (548/618)	80% (24/30)
5 – 11 years	87.7% (1481/1689)	87.9% (1409/1603)	83.7% (72/86)
12 – 15 years	87.6% (739/844)	87.9% (709/807)	81.1% (30/37)
16+ years	97.9% (46/47)	97.9% (46/47)	N/A
Sex			
Female	87.8% (1385/1578)	88% (1330/1512)	83.3% (55/66)
Male	88.2% (1837/2082)	88.5% (1759/1987)	82.1% (78/95)
Not Indicated	93.9% (46/49)	93.5% (43/46)	100% (3/3)
Ethnicity			
Asian	81% (251/310)	81.2% (246/303)	71.4% (5/7)
Black	81.5% (154/189)	*	*
Mixed	89.4% (118/132)	*	*
Other	81.6% (93/114)	*	*
White	90.5% (2235/2469)	91% (2122/2332)	82.5% (113/137)
Not Indicated	84.2% (417/495)	83.8% (402/480)	100% (15/15)
Deprivation			
Most deprived	87.5% (897/1025)	87.8% (864/984)	80.5% (33/41)
Second most deprived	87.8% (721/821)	87.6% (681/777)	90.9% (40/44)
Third least deprived	87.5% (576/658)	88% (556/632)	76.9% (20/26)
Second least deprived	88.9% (543/611)	89.2% (522/585)	80.8% (21/26)
Least deprived	90% (514/571)	90.4% (492/544)	81.5% (22/27)
Not indicated	73.9% (17/23)	73.9% (17/23)	N/A
Mental health			
Mental health condition identified	91.1% (318/349)	92.4% (305/330)	68.4% (13/19)
No mental health condition identified	87.8% (2950/3360)	87.9% (2827/3215)	84.8% (123/145)
Neurodevelopmental condition/learning disability			
Neurodevelopmental condition /learning disability identified	88.9% (1022/1149)	89.3% (989/1108)	80.5% (33/41)
No neurodevelopmental condition/learning disability identified	87.7% (2246/2560)	87.9% (2143/2437)	83.7% (103/123)

Table 15: Percentage of children and young people with epilepsy seen by an epilepsy specialist nurse within the first year of care by region.

Geographic Region	KPI 2. Epilepsy Specialist Nurse input
England and Wales	88.1% (3268/3709)
Country	
England	88.3% (3132/3545)
Wales	82.9% (136/164)
NHS England Region	
East of England	91.1% (278/305)
London	84.5% (431/510)
Midlands	84.3% (505/599)
North East and Yorkshire	92% (586/637)
North West	90.9% (582/640)
South East	85.1% (518/609)
South West	94.7% (232/245)
OPEN UK Region	
BRPNF	77.3% (225/291)
CEWT	81.7% (85/104)
EPEN	97.3% (218/224)
EPIC	94.4% (302/320)
NTPEN	82.9% (355/428)
NWEIG	85.7% (377/440)
ORENG	70.8% (153/216)
PENNEC	90.9% (180/198)
SETPEG	94.9% (240/253)
SWEP	85.5% (118/138)
SWIPE	95% (132/139)
SWTPEG	88.5% (223/252)
TEN	92.8% (155/167)
WPNN	90.3% (214/237)
YPEN	96.4% (291/302)

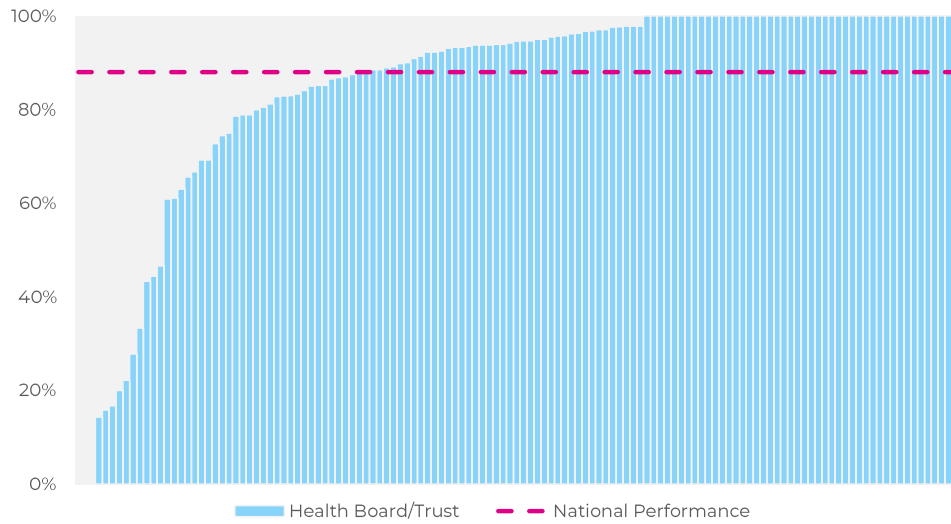
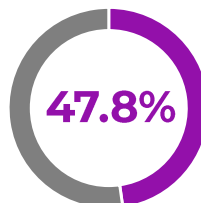


Figure 13: Access to Epilepsy Specialist Nurse by Health Board and Trust, cohort 7. Each participating Health Board or Trust is represented by a vertical bar in the order of the percentage score, including those scoring 0% in this graph.

3a. Tertiary Input

Percentage of children and young people meeting defined criteria for paediatric neurology referral, with input of tertiary care and/or CESS referral within the first year of care.



NICE guidelines [NG217], 2022 (Statement 3.1.4) state that referral to tertiary paediatric epilepsy services should be considered when defined criteria are met.

47.8% (437/915) of children and young people with epilepsy meeting defined criteria for tertiary input, received input of tertiary care and/or CESS referral within the first year of care. This is a slight decrease from cohort 6 **49.2% (388/788)**. This indicator ranged from **0%** to **100%**, with an interquartile range of **33.3%** to **66.7%**.

The criteria for tertiary input were updated in cohort 6 to include children with myoclonus and under 4 years of age at first paediatric assessment, aligning with the updated NICE guidelines.

Of the **437** children and young people who received tertiary input, **18.8% (82/437)** had a CESS referral by first year, **92.7% (405/437)** had paediatric neurology input by first year, and **11.7% (51/437)** had both.

Table 16 shows how tertiary input is distributed between demographic population groups and **Table 17** shows the variation in tertiary input between England and Wales and across NHSE and OPEN UK regions. **Table 18** shows the timeliness of paediatric neurologist input.

Table 16: Percentage of children and young people with epilepsy meeting defined criteria for paediatric neurology referral, with input of tertiary care and/or CESS referral within the first year of care by demographic.

Demographic Variables	England and Wales	England	Wales
Age			
< 2 years	57% (274/481)	56.8% (267/470)	63.6% (7/11)
2 – 4 years	27.5% (70/255)	27.3% (67/245)	30% (3/10)
5 – 11 years	52% (65/125)	52.1% (61/117)	50% (4/8)
12 – 15 years	50.9% (27/53)	53.1% (26/49)	*
16+ years	*	*	*
Sex			
Female	47.3% (186/393)	48% (183/381)	25% (3/12)
Male	47.9% (246/514)	47.5% (234/493)	57.1% (12/21)
Not Indicated	62.5% (5/8)	62.5% (5/8)	N/A
Ethnicity			
Asian	51.5% (34/66)	*	*
Black	37.3% (22/59)	38.6% (22/57)	N/A
Mixed	42.1% (16/38)	42.1% (16/38)	N/A
Other	59.1% (13/22)	59.1% (13/22)	N/A
White	47.8% (298/623)	48.1% (286/595)	42.9% (12/28)

Not Indicated	50.5% (54/107)	*	*
Deprivation			
Most deprived	41.8% (102/244)	41.9% (99/236)	37.5% (3/8)
Second most deprived	47.1% (90/191)	46.4% (85/183)	62.5% (5/8)
Third least deprived	47.3% (80/169)	*	*
Second least deprived	50.9% (81/159)	50.3% (78/155)	75% (3/4)
Least deprived	56.2% (81/144)	56.9% (78/137)	42.9% (3/7)
Not indicated	37.5% (3/8)	*	*
Mental health			
Mental health condition identified	42.9% (18/42)	*	*
No mental health condition identified	48% (419/873)	*	*
Neurodevelopmental condition/learning disability			
Neurodevelopmental condition /learning disability identified	51.7% (151/292)	51.8% (144/278)	50% (7/14)
No neurodevelopmental condition/learning disability identified	45.9% (286/623)	46% (278/604)	42.1% (8/19)

Table 17: Percentage of children and young people with epilepsy meeting defined criteria for paediatric neurology referral, with input of tertiary care and/or CESS referral within the first year of care by region.

Geographic Region	KPI 3a. Tertiary Input
England and Wales	47.8% (437/915)
Country	
England	47.8% (422/882)
Wales	45.5% (15/33)
NHS England Region	
East of England	52.6% (40/76)
London	51.3% (61/119)
Midlands	46.8% (72/154)
North East and Yorkshire	47.1% (74/157)
North West	39.9% (67/168)
South East	54.4% (80/147)
South West	45.9% (28/61)
OPEN UK Region	
BRPNF	41.7% (30/72)
CEWT	63% (17/27)
EPEN	51.7% (30/58)
EPIC	36.4% (32/88)

NTPEN	48.1% (50/104)
NWEIG	40.7% (46/113)
ORENG	43.9% (25/57)
PENNEC	39.1% (18/46)
SETPEG	60% (33/55)
SWEP	48.1% (13/27)
SWIPE	44.1% (15/34)
SWTPEG	62.9% (39/62)
TEN	70.7% (29/41)
WPNN	47.4% (27/57)
YPEN	44.6% (33/74)

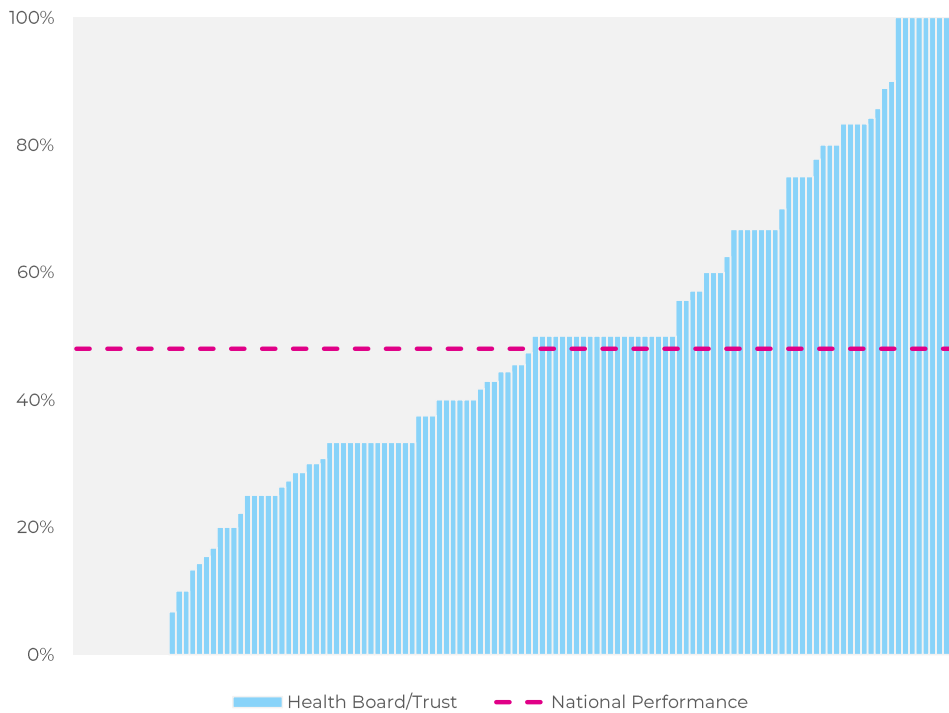


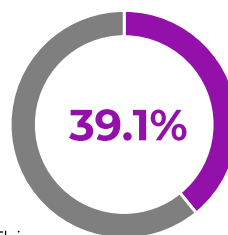
Figure 14: Tertiary input by Health Board and Trust, cohort 7. Each participating Health Board or Trust is represented by a vertical bar in the order of the percentage score, including those scoring 0% in this graph.

Table 18: Time in months to achieving input from a paediatric neurologist since first referral of the 405 patients meeting defined criteria for tertiary input with paediatric neurology input within first year.

Time in months	England and Wales	England	Wales
0 - 2 months	65.9% (267/405)	66.7% (260/390)	46.7% (7/15)
2 - 4 months	21.2% (86/405)	20.8% (81/390)	33.3% (5/15)
2 - 6 months	7.7% (31/405)	*	*
6 - 8 months	4% (16/405)	*	*
8 - 10 months	1% (4/405)	1% (4/390)	N/A
10 - 12 months	*	*	*

3b. Epilepsy Surgery Referral

Percentage of children and young people meeting defined Children's Epilepsy Surgery Service (CESS) referral criteria with evidence of CESS referral within the first year of care.



39.1% (79/202) of children and young people with epilepsy meeting CESS referral criteria had evidence of CESS referral within the first year of care. This was a decrease compared to **42% (81/193)** in cohort 6. This indicator ranged from **0%** to **100%**, with an interquartile range of **0%** to **100%**.

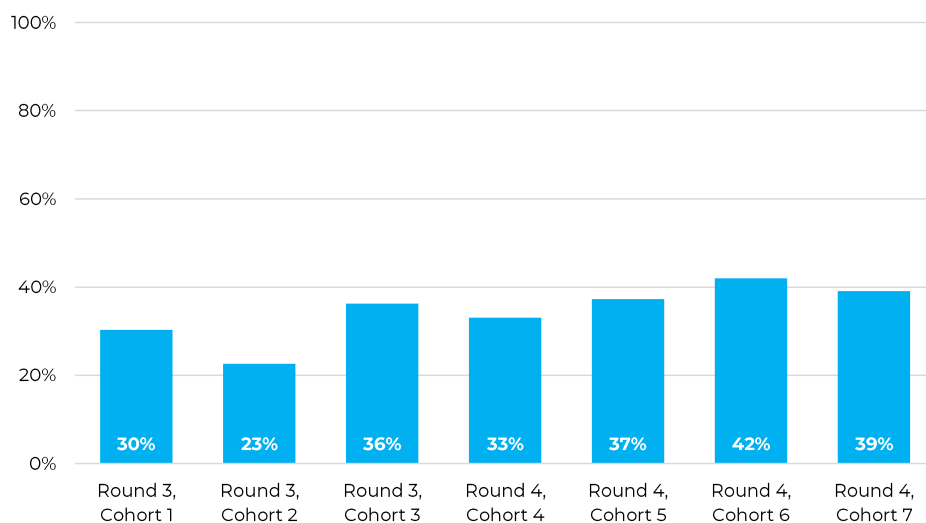


Figure 15: Epilepsy surgery referral in Rounds 3 and 4.

Figure 15 and **Table 19** shows epilepsy surgery referral over time in Rounds 3 and 4. **Table 20** shows how epilepsy surgery referrals are distributed between demographic population groups and **Table 21** shows the variation in epilepsy surgery referrals between England and Wales and across NHSE and OPEN UK regions. **Table 22** shows CESS and paediatric neurology input for children and young people meeting CESS referral criteria.

Table 19: The percentage of children and young people meeting defined criteria for epilepsy surgery referral with evidence of epilepsy surgery referral by cohort.

Cohort	England and Wales	England	Wales
Round 3, Cohort 1	30.3% (27/89)	*	*
Round 3, Cohort 2	22.6% (24/106)	23.1% (24/104)	*
Round 3, Cohort 3	36.3% (49/135)	*	*
Round 4, Cohort 4	33.1% (39/118)	*	*
Round 4, Cohort 5	37.3% (41/110)	37.9% (39/103)	*
Round 4, Cohort 6	42% (81/193)	42.2% (79/187)	*
Round 4, Cohort 7	39.1% (79/202)	*	*

Table 20: Percentage of children and young people meeting defined criteria for epilepsy surgery referral with evidence of epilepsy surgery referral by demographic.

Demographic Variables	England and Wales	England	Wales
Age			
< 2 years	27.9% (19/68)	*	*
2 – 4 years	48.6% (17/35)	48.6% (17/35)	N/A
5 – 11 years	41.9% (31/74)	41.9% (31/74)	N/A
12 – 15 years	45.8% (11/24)	*	*
16+ years	*	*	*
Sex			
Female	41.2% (33/80)	*	*
Male	37.8% (45/119)	37.8% (45/119)	N/A
Not Indicated	*	*	*
Ethnicity			
Asian	28.6% (4/14)	28.6% (4/14)	N/A
Black	27.3% (3/11)	27.3% (3/11)	N/A
Mixed	50% (3/6)	50% (3/6)	N/A
Other	66.7% (6/9)	66.7% (6/9)	N/A
White	36.9% (52/141)	*	*
Not Indicated	52.4% (11/21)	*	*
Deprivation			
Most deprived	23.9% (11/46)	23.9% (11/46)	N/A
Second most deprived	38.3% (18/47)	*	*
Third least deprived	34.4% (11/32)	34.4% (11/32)	N/A
Second least deprived	46.9% (15/32)	46.9% (15/32)	N/A
Least deprived	54.5% (24/44)	54.5% (24/44)	N/A
Not indicated	*	*	*
Mental health			
Mental health condition identified	33.3% (6/18)	*	*
No mental health condition identified	39.7% (73/184)	*	*
Neurodevelopmental condition/learning disability			
Neurodevelopmental condition /learning disability identified	30.5% (18/59)	*	*
No neurodevelopmental condition/learning disability identified	42.7% (61/143)	*	*

Table 21: Percentage of children and young people meeting defined criteria for epilepsy surgery referral with evidence of epilepsy surgery referral by region.

Geographic Region	KPI 3b. Epilepsy Surgery Referral
England and Wales	39.1% (79/202)
Country	
England	*
Wales	*
NHS England Region	
East of England	50% (12/24)
London	37.5% (9/24)
Midlands	48.4% (15/31)
North East and Yorkshire	16.7% (5/30)
North West	28.9% (13/45)
South East	55.9% (19/34)
South West	*
OPEN UK Region	
BRPNF	42.9% (6/14)
CEWT	75% (3/4)
EPEN	55.6% (10/18)
EPIC	36.8% (7/19)
NTPEN	33.3% (9/27)
NWEIG	35.3% (12/34)
ORENG	21.4% (3/14)
PENNEC	37.5% (3/8)
SETPEG	70% (7/10)
SWEP	*
SWIPE	50% (4/8)
SWTPEG	66.7% (8/12)
TEN	*
WPNN	36.4% (4/11)
YPEN	*

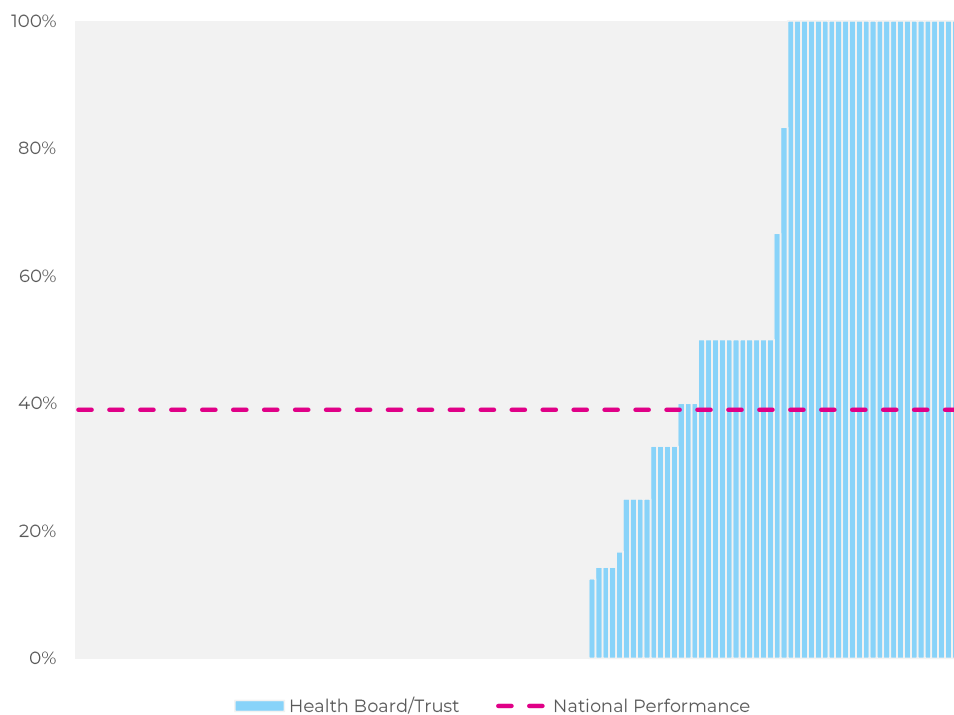


Figure 16: Epilepsy surgery referral by Health Board and Trust, cohort 7. Each participating Health Board or Trust is represented by a vertical bar in the order of the percentage score, including those scoring 0% in this graph.

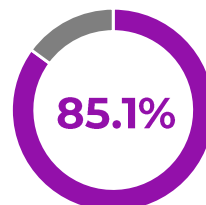
Table 22: CESS and paediatric neurology input for children and young people within their first year of care, that met CESS referral criteria.

	England and Wales	England	Wales
CESS input achieved	39.1% (79/202)	*	*
CESS input only (no neuro input)	13.9% (28/202)	*	*
Neuro input achieved	48.5% (98/202)	*	*
Neuro input only (no CESS input)	23.3% (47/202)	*	*
Both CESS and neuro input achieved	25.2% (51/202)	*	*
Neither CESS nor neuro input achieved	37.6% (76/202)	*	*

4. ECG

Percentage of children and young people with epilepsy and convulsive seizures with an ECG within the first year of care.

NICE guidelines [NG217], 2022 (Statement 1.2.2) state that all children and young people with a suspected seizure should have a 12-lead ECG to identify cardiac-related conditions that could mimic an epileptic seizure.



85.1% (2034/2391) of children and young people with epilepsy and convulsive seizures had an ECG within the first year of care in cohort 7. This was an increase compared to **83.4% (1658/1989)** in cohort 6. This indicator ranged from **25.0%** to **100.0%**, with an interquartile range of **75.0%** to **100%**.



Figure 17: ECG access in Rounds 3 and 4.

Figure 17 and **Table 23** shows ECG access over time in Rounds 3 and 4. **Table 24** shows how access to ECG is distributed between demographic population groups and **Table 25** shows the variation in access to ECG between England and Wales and across NHSE and OPEN UK regions.

Table 23: The percentage of children and young people with epilepsy and convulsive seizures that had an ECG within the first year of care by cohort.

	England and Wales	England	Wales
Round 3, Cohort 1	67.6% (474/701)	69.5% (460/662)	35.9% (14/39)
Round 3, Cohort 2	65.3% (855/1309)	65.4% (850/1300)	55.6% (5/9)
Round 3, Cohort 3	69.0% (840/1218)	68.8% (814/1184)	76.5% (26/34)
Round 4, Cohort 4	69.6% (996/1431)	69.5% (942/1356)	72.0% (54/75)
Round 4, Cohort 5	72.1% (1036/1436)	72.6% (979/1349)	65.5% (57/87)
Round 4, Cohort 6	83.4% (1658/1989)	83.1% (1570/1890)	88.9% (88/99)
Round 4, Cohort 7	85.1% (2034/2391)	85% (1935/2276)	86.1% (99/115)

Table 24: Percentage of children and young people with epilepsy and convulsive seizures that had an ECG within the first year of care by demographic.

Demographic Variables	England and Wales	England	Wales
Age			
< 2 years	79.9% (243/304)	79.5% (236/297)	100% (7/7)
2 – 4 years	83.7% (344/411)	84.5% (327/387)	70.8% (17/24)
5 – 11 years	83.6% (792/947)	83.6% (750/897)	84% (42/50)
12 – 15 years	89.7% (620/691)	89.3% (587/657)	97.1% (33/34)
16+ years	92.1% (35/38)	92.1% (35/38)	N/A
Sex			
Female	84.9% (818/964)	84.4% (774/917)	93.6% (44/47)
Male	85.2% (1189/1395)	85.3% (1135/1330)	83.1% (54/65)
Not Indicated	*	*	*
Ethnicity			
Asian	84.4% (190/225)	84% (184/219)	100% (6/6)
Black	82.9% (107/129)	*	*
Mixed	89% (81/91)	*	*
Other	88.2% (67/76)	*	*
White	85.5% (1357/1587)	85.5% (1275/1491)	85.4% (82/96)
Not Indicated	82% (232/283)	81.4% (223/274)	100% (9/9)
Deprivation			
Most deprived	85.9% (591/688)	86.1% (571/663)	80% (20/25)
Second most deprived	86.2% (470/545)	86.4% (444/514)	83.9% (26/31)
Third least deprived	83.7% (350/418)	83.8% (336/401)	82.4% (14/17)
Second least deprived	82.7% (310/375)	82% (291/355)	95% (19/20)
Least deprived	86.3% (303/351)	86% (283/329)	90.9% (20/22)
Not indicated	71.4% (10/14)	71.4% (10/14)	N/A
Mental health			
Mental health condition identified	92.1% (220/239)	92% (207/225)	92.9% (13/14)
No mental health condition identified	84.3% (1814/2152)	84.3% (1728/2051)	85.1% (86/101)
Neurodevelopmental condition/learning disability			
Neurodevelopmental condition/learning disability identified	82.6% (655/793)	82.9% (633/764)	75.9% (22/29)
No neurodevelopmental condition/learning disability identified	86.3% (1379/1598)	86.1% (1302/1512)	89.5% (77/86)

Table 25: Percentage of children and young people with epilepsy and convulsive seizures that had an ECG within the first year of care by region.

Geographic Region	KPI 4. ECG
England and Wales	85.1% (2034/2391)
Country	
England	85% (1935/2276)
Wales	86.1% (99/115)
NHS England Region	
East of England	85.6% (178/208)
London	91.4% (297/325)
Midlands	77.8% (316/406)
North East and Yorkshire	89.2% (357/400)
North West	85.4% (344/403)
South East	85.7% (336/392)
South West	75.4% (107/142)
OPEN UK Region	
BRPNF	81.4% (171/210)
CEWT	70.3% (45/64)
EPEN	88% (132/150)
EPIC	87.4% (167/191)
NTPEN	89.4% (252/282)
NWEIG	79.8% (225/282)
ORENG	81.2% (117/144)
PENNEC	88.2% (112/127)
SETPEG	88% (147/167)
SWEP	83.8% (83/99)
SWIPE	71.1% (54/76)
SWTPEG	90.6% (145/160)
TEN	92.4% (85/92)
WPNN	79.7% (118/148)
YPEN	91% (181/199)

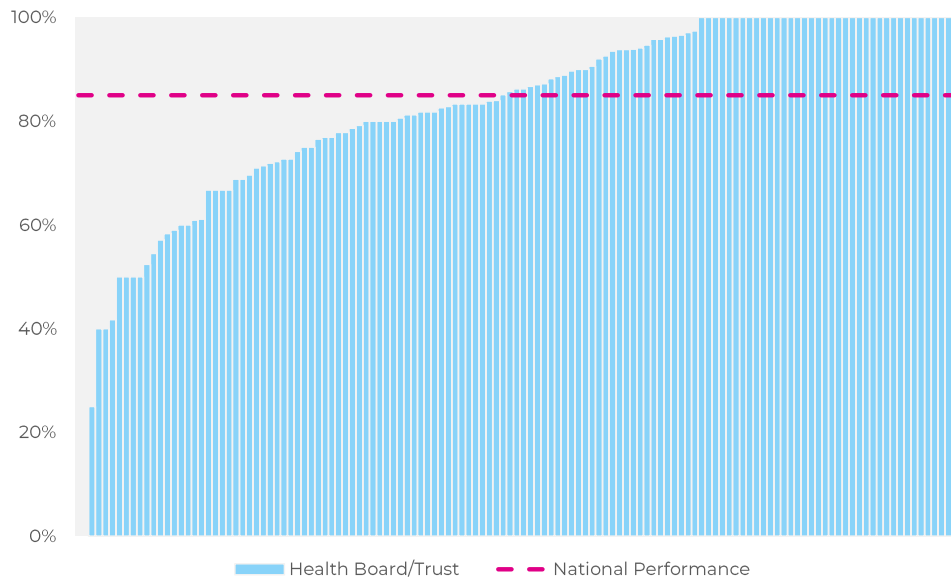
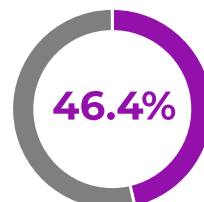


Figure 19: ECG by Health Board and Trust, cohort 7. Each participating Health Board or Trust is represented by a vertical bar in the order of the percentage score, including those scoring 0% in this graph.

5. MRI

Percentage of children and young people with epilepsy with defined indications for an MRI brain scan who had an MRI brain scan within 6 weeks of request.



NICE guidelines [NG217], 2022 (Statement 1.3.1) state that MRI should be the imaging investigation of choice in individuals with epilepsy, and this should be within 6 weeks of referral.

46.4% (1337/2884) of children and young people with epilepsy and defined indications for an MRI had an MRI brain scan within 6 weeks of request. This indicator ranged from **0.0%** to **100.0%**, with an interquartile range of **36.6%** to **62.5%**.

69.6% (2007/2884) of children and young people with defined indications for an MRI had an MRI brain scan in the first year of care. This was a decrease from **84.5% (2028/2401)** in cohort 6.

Table 26 shows how access to MRIs is distributed between demographic population groups and **Table 27** shows the variation in access to MRIs between England and Wales and across NHSE and OPEN UK regions. **Table 28** shows the timeliness of MRIs from the date of request.

Table 26: Percentage of children and young people with epilepsy with defined indications for an MRI who had an MRI brain scan within 6 weeks of request by demographic.

Demographic Variables	England and Wales	England	Wales
Age			
< 2 years	69.3% (327/472)	69% (318/461)	81.8% (9/11)
2 – 4 years	37.8% (215/569)	38.5% (208/540)	24.1% (7/29)
5 – 11 years	42.9% (507/1183)	43.5% (488/1123)	31.7% (19/60)
12 – 15 years	44.4% (278/626)	44.7% (268/599)	37% (10/27)
16+ years	29.4% (10/34)	29.4% (10/34)	N/A
Sex			
Female	48.6% (570/1172)	48.9% (546/1117)	43.6% (24/55)
Male	44.9% (751/1671)	45.6% (730/1601)	30% (21/70)
Not Indicated	*	*	*
Ethnicity			
Asian	48.6% (119/245)	*	*
Black	48% (73/152)	*	*
Mixed	46.8% (51/109)	*	*
Other	52.9% (46/87)	*	*
White	45.7% (865/1894)	46.3% (827/1788)	35.8% (38/106)
Not Indicated	46.1% (183/397)	46.2% (178/385)	41.7% (5/12)
Deprivation			
Most deprived	38.7% (307/793)	39.9% (303/760)	12.1% (4/33)
Second most deprived	42.4% (278/655)	43.1% (268/622)	30.3% (10/33)
Third least deprived	51.6% (260/504)	51.4% (250/486)	55.6% (10/18)

Second least deprived	52.8% (242/458)	53.2% (232/436)	45.5% (10/22)
Least deprived	52.7% (238/452)	52.7% (227/431)	52.4% (11/21)
Not indicated	54.5% (12/22)	54.5% (12/22)	N/A
Mental health			
Mental health condition identified	46.9% (122/260)	47.1% (115/244)	43.8% (7/16)
No mental health condition identified	46.3% (1215/2624)	46.8% (1177/2513)	34.2% (38/111)
Neurodevelopmental condition/learning disability			
Neurodevelopmental condition /learning disability identified	39.5% (409/1035)	39.5% (393/995)	40% (16/40)
No neurodevelopmental condition/learning disability identified	50.2% (928/1849)	51% (899/1762)	33.3% (29/87)

Table 27: Percentage of children and young people with epilepsy with defined indications for an MRI who had an MRI brain scan within 6 weeks of request by region.

Geographic Region	KPI 5. MRI
England and Wales	46.4% (1337/2884)
Country	
England	46.9% (1292/2757)
Wales	35.4% (45/127)
NHS England Region	
East of England	50.6% (123/243)
London	51.6% (210/407)
Midlands	42.6% (199/467)
North East and Yorkshire	44.1% (207/469)
North West	41.1% (206/501)
South East	52.6% (257/489)
South West	49.7% (90/181)
OPEN UK Region	
BRPNF	42.4% (98/231)
CEWT	56.6% (47/83)
EPEN	47.2% (83/176)
EPIC	39.2% (98/250)
NTPEN	52.2% (177/339)
NWEIG	44.8% (155/346)
ORENG	53.3% (96/180)
PENNEC	33.1% (54/163)
SETPEG	47% (101/215)

SWEP	29.1% (30/103)
SWIPE	43.5% (47/108)
SWTPEG	61.8% (123/199)
TEN	32.7% (37/113)
WPNN	50% (85/170)
YPEN	51% (106/208)

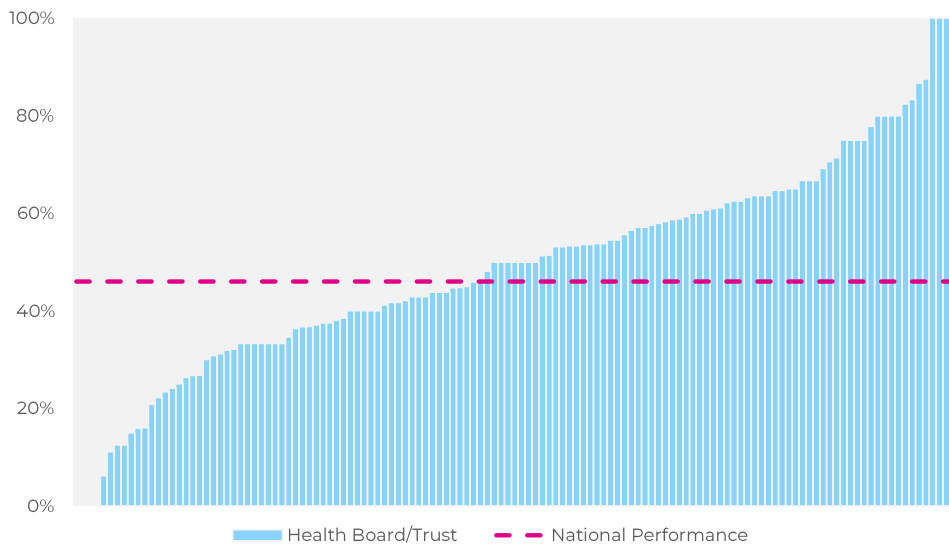


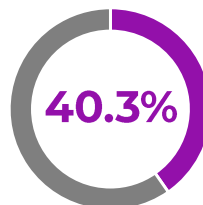
Figure 20: MRI brain scan achievement by Health Board and Trust, cohort 7. Each participating Health Board or Trust is represented by a vertical bar in the order of the percentage score, including those scoring 0% in this graph.

Table 28: Time in weeks to MRI from request, of the children and young people meeting defined indications for an MRI in cohort 7.

Time in weeks	England and Wales	England	Wales
Within 2 weeks	26.8% (774/2884)	27.4% (755/2757)	15% (19/127)
2 - 4 weeks	10% (287/2884)	9.8% (270/2757)	13.4% (17/127)
4 - 8 weeks	16.3% (471/2884)	16.3% (450/2757)	16.5% (21/127)
8 - 12 weeks	6.9% (198/2884)	6.6% (183/2757)	11.8% (15/127)
12 - 16 weeks	4.6% (132/2884)	4.6% (128/2757)	3.1% (4/127)
16+ weeks	9.2% (265/2884)	9.1% (252/2757)	10.2% (13/127)
Input not achieved	26.2% (757/2884)	26.1% (719/2757)	29.9% (38/127)

6. Assessment of Mental Health issues

Percentage of children and young people with epilepsy aged over 5 years where there is documented evidence that they have been asked about mental health either through clinical screening or a questionnaire/measure.



NICE guidelines [NG217], 2022 (Statement 2.1.1) state that children and young people with epilepsy and their family and/or carers should be offered opportunities to discuss emotional health and psychological wellbeing.

40.3% (1040/2580) of children and young people with epilepsy, aged over 5 years, had documented evidence of assessment of mental health within the first year of care in cohort 7. This increased from **38.2% (811/2125)** in cohort 6. This indicator ranged from **0.0% to 100.0%**, with an interquartile range of **10.5% to 60.0%**.

Table 29 shows how assessment of mental health is distributed between demographic population groups and **Table 30** shows the variation in the assessment of mental health between England and Wales and across NHSE and OPEN UK regions.

Table 29: Percentage of children and young people with epilepsy with evidence of an assessment of mental health by demographic.

Demographic Variables	England and Wales	England	Wales
Age			
5 – 11 years	35.9% (606/1689)	35.3% (566/1603)	46.5% (40/86)
12 – 15 years	48.5% (409/844)	47.2% (381/807)	75.7% (28/37)
16+ years	53.2% (25/47)	53.2% (25/47)	N/A
Sex			
Female	41.9% (459/1095)	41.5% (433/1044)	51% (26/51)
Male	38.9% (563/1447)	38% (523/1377)	57.1% (40/70)
Not Indicated	*	*	*
Ethnicity			
Asian	38.4% (83/216)	37.1% (78/210)	83.3% (5/6)
Black	41.8% (46/110)	41.8% (46/110)	N/A
Mixed	33.7% (28/83)	*	*
Other	31.9% (29/91)	*	*
White	43.6% (754/1730)	42.6% (693/1626)	58.7% (61/104)
Not Indicated	28.6% (100/350)	*	*
Deprivation			
Most deprived	40.1% (278/694)	39.8% (265/665)	44.8% (13/29)
Second most deprived	41.2% (235/571)	40.6% (218/537)	50% (17/34)
Third least deprived	43.9% (201/458)	43% (190/442)	68.8% (11/16)
Second least deprived	37.5% (163/435)	36.5% (151/414)	57.1% (12/21)

Least deprived	39.6% (162/409)	38.1% (147/386)	65.2% (15/23)
Not indicated	*	*	*
Mental health			
Mental health condition identified	93.1% (310/333)	93% (293/315)	94.4% (17/18)
No mental health condition identified	32.5% (730/2247)	31.7% (679/2142)	48.6% (51/105)
Neurodevelopmental condition/learning disability			
Neurodevelopmental condition /learning disability identified	41.9% (329/785)	41.4% (315/761)	58.3% (14/24)
No neurodevelopmental condition/learning disability identified	39.6% (711/1795)	38.7% (657/1696)	54.5% (54/99)

Table 30: Percentage of children and young people with epilepsy with evidence of an assessment of mental health by region.

Geographic Region	KPI 6. Assessment of Mental Health Issues
England and Wales	40.3% (1040/2580)
Country	
England	39.6% (972/2457)
Wales	55.3% (68/123)
NHS England Region	
East of England	24.4% (54/221)
London	48.2% (173/359)
Midlands	29.7% (120/404)
North East and Yorkshire	51.5% (227/441)
North West	36.1% (156/432)
South East	38.1% (164/431)
South West	46.2% (78/169)
OPEN UK Region	
BRPNF	26.4% (52/197)
CEWT	26.1% (18/69)
EPEN	27% (44/163)
EPIC	54.1% (118/218)
NTPEN	41.5% (124/299)
NWEIG	23.2% (69/297)
ORENG	27.7% (43/155)
PENNEC	59.7% (83/139)
SETPEG	47.7% (83/174)
SWEP	58.1% (61/105)
SWIPE	52% (51/98)

SWTPEG	50.3% (90/179)
TEN	35% (41/117)
WPNN	34% (55/162)
YPEN	51.9% (108/208)

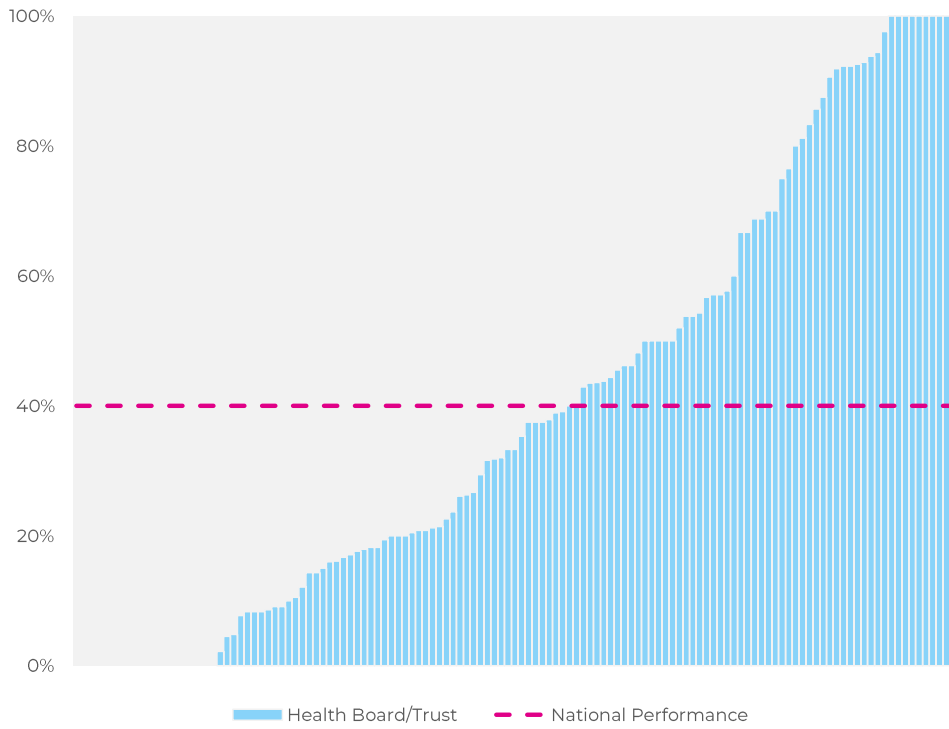


Figure 21: Assessment of mental health by Health Board and Trust, cohort 7. Each participating Health Board or Trust is represented by a vertical bar in the order of the percentage score, including those scoring 0% in this graph.

7. Mental Health Support

Percentage of children and young people with epilepsy and an identified mental health condition recorded who had evidence of receiving mental health support.

79.1% (276/349) of children and young people with epilepsy that had an identified mental health condition, also had evidence of receiving mental health support within the first year of care in cohort 7. This increased from **76.6% (213/278)** in cohort 6. This indicator ranged from **0.0%** to **100.0%**, with an interquartile range of **66.7%** to **100%**.

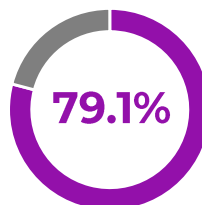


Table 31 shows how mental health support is distributed between demographic population groups and **Table 32** shows the variation in access to mental health support between England and Wales and across NHSE and OPEN UK regions.

Table 31: Percentage of children and young people with epilepsy and an identified mental health condition with evidence of receiving mental health support by demographic.

Demographic Variables	England and Wales	England	Wales
Age			
< 2 years	*	*	*
2 – 4 years	76.9% (10/13)	*	*
5 – 11 years	79% (124/157)	80.3% (118/147)	60% (6/10)
12 – 15 years	79% (132/167)	81.1% (129/159)	37.5% (3/8)
16+ years	*	*	*
Sex			
Female	79.4% (139/175)	*	*
Male	78.3% (130/166)	80% (124/155)	54.5% (6/11)
Not Indicated	87.5% (7/8)	*	*
Ethnicity			
Asian	61.9% (13/21)	*	*
Black	63.6% (7/11)	*	*
Mixed	66.7% (10/15)	66.7% (10/15)	N/A
Other	80% (8/10)	*	*
White	81.5% (211/259)	82.9% (203/245)	57.1% (8/14)
Not Indicated	81.8% (27/33)	*	*
Deprivation			
Most deprived	74.7% (65/87)	*	*
Second most deprived	77.8% (63/81)	79.7% (59/74)	57.1% (4/7)
Third least deprived	83.9% (52/62)	*	*
Second least deprived	88.9% (48/54)	*	*
Least deprived	73.8% (48/65)	75% (45/60)	60% (3/5)
Not indicated	N/A	N/A	N/A

Neurodevelopmental condition/learning disability			
Neurodevelopmental condition/learning disability identified	76.6% (111/145)	77.5% (107/138)	57.1% (4/7)
No Neurodevelopmental condition/learning disability identified	80.9% (165/204)	83.3% (160/192)	41.7% (5/12)

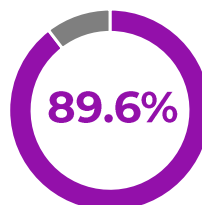
Table 32: Percentage of children and young people with epilepsy and an identified mental health condition with evidence of receiving mental health support by region.

Geographic Region	KPI 7. Mental Health Support
England and Wales	79.1% (276/349)
Country	
England	80.9% (267/330)
Wales	47.4% (9/19)
NHS England Region	
East of England	65.5% (19/29)
London	87.8% (43/49)
Midlands	87.2% (41/47)
North East and Yorkshire	80% (60/75)
North West	80% (28/35)
South East	76.6% (49/64)
South West	87.1% (27/31)
OPEN UK Region	
BRPNF	79.2% (19/24)
CEWT	90% (9/10)
EPEN	70% (14/20)
EPIC	84.2% (16/19)
NTPEN	76.7% (23/30)
NWEIG	76% (19/25)
ORENG	86.4% (19/22)
PENNEC	86.2% (25/29)
SETPEG	90% (27/30)
SWEP	50% (8/16)
SWIPE	88.9% (16/18)
SWTPEG	80.6% (29/36)
TEN	75% (6/8)
WPNN	70.8% (17/24)
YPEN	76.3% (29/38)

8. Medication and reproduction risks

Percentage of females on valproate treatment and females aged 12 years and above on topiramate with a risk acknowledgement form completed or Pregnancy Prevention Programme in place.

Note, this indicator previously focused only on females aged 12 years and over currently on valproate treatment and has been expanded for cohort 7 to reflect recent MRHA guidance.



NICE guidelines [NG217], 2022 (Statement 4.3.9/4.4.4) state that girls of childbearing potential who are receiving sodium valproate or topiramate treatment should be informed of the risk of harm in pregnancy and an assessment should be made as to the risks and benefits of sodium valproate.

89.6% (43/48) of females on valproate treatment and females aged 12 years and above on topiramate had an annual risk acknowledgement form completed and/or a Pregnancy Prevention Programme in place within the first year of care in cohort 7.

Table 33: The percentage of females currently on valproate treatment and females aged 12 years and above on topiramate that had an annual risk acknowledgement form completed and/or a Pregnancy Prevention Programme by demographic.

Demographic Variables	England and Wales	England	Wales
Age			
< 2 years	81.8% (9/11)	*	*
2 – 4 years	92.3% (12/13)	*	*
5 – 11 years	89.5% (17/19)	87.5% (14/16)	100% (3/3)
12 – 15 years	100% (5/5)	100% (5/5)	N/A
16+ years	N/A	N/A	N/A
Sex			
Female	89.6% (43/48)	93% (40/43)	60% (3/5)
Ethnicity			
Asian	*	*	*
Black	*	*	*
Mixed	*	*	*
Other	*	*	*
White	91.9% (34/37)	*	*
Not Indicated	83.3% (5/6)	80% (4/5)	N/A
Deprivation			
Most deprived	100% (10/10)	100% (10/10)	N/A
Second most deprived	76.9% (10/13)	90.9% (10/11)	N/A
Third least deprived	100% (5/5)	100% (5/5)	N/A
Second least deprived	81.8% (9/11)	*	*
Least deprived	100% (9/9)	*	*
Not indicated	N/A	N/A	N/A

Mental Health			
Mental health condition identified	100% (5/5)	100% (5/5)	N/A
No mental health condition identified	88.4% (38/43)	92.1% (35/38)	60% (3/5)
Neurodevelopmental condition/learning disability			
Neurodevelopmental condition /learning disability identified	95.5% (21/22)	100% (21/21)	N/A
No neurodevelopmental condition/learning disability identified	84.6% (22/26)	86.4% (19/22)	75% (3/4)

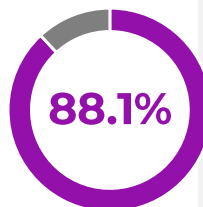
Table 34: The percentage of females currently on valproate treatment and females aged 12 years and above on topiramate that had an annual risk acknowledgement form completed and/or a Pregnancy Prevention Programme by region.

Geographic Region	KPI 8. Medication & reproduction risks
England and Wales	89.6% (43/48)
Country	
England	93% (40/43)
Wales	60% (3/5)
NHS England Region	
East of England	83.3% (5/6)
London	100% (5/5)
Midlands	*
North East and Yorkshire	100% (9/9)
North West	100% (6/6)
South East	90.9% (10/11)
South West	*
OPEN UK Region	
BRPNF	*
CEWT	*
EPEN	75% (3/4)
EPIC	100% (6/6)
NTPEN	100% (6/6)
NWEIG	*
ORENG	*
PENNEC	*
SETPEG	100% (5/5)
SWEP	*
SWIPE	*

SWTPEG	83.3% (5/6)
TEN	*
WPNN	N/A
YPEN	100% (7/7)

9a. Care Planning agreement

Percentage of children and young people with epilepsy with evidence of care planning agreement by first year. This requires evidence of a patient-held individualised epilepsy document that includes all care planning information at 12 months, that this care plan has been updated where necessary, and that there is evidence of agreement to the care plan.



NICE guidelines [NG217], 2022 (Statement 2.1.7) state that children and young people with epilepsy should have a comprehensive care plan that is agreed between the person, their family and/or carers, and primary and secondary care providers.

88.1% (3,267/3,709) of children and young people with epilepsy had evidence of care planning agreement within the first year of care in cohort 6. This was an increase compared to **85.8% (2,665/3,105)** in cohort 6. This indicator ranged from **8.90%** to **100.0%**, with an interquartile range of **84.6%** to **100%**.

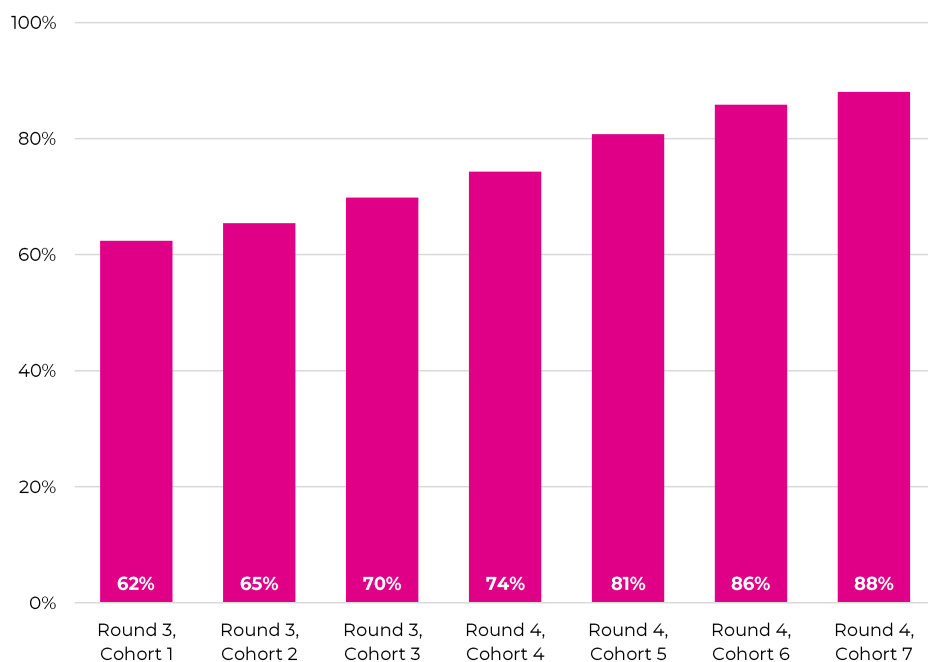


Figure 23: Care planning agreement in Rounds 3 and 4.

Table 35 and **Figure 23** shows care planning agreement over time in Rounds 3 and 4. **Table 36** shows how care planning agreement is distributed between demographic population groups and **Table 37** shows the variation in care planning agreement between England and Wales and across NHSE and OPEN UK regions. **Table 38** shows the breakdown of the sub-metrics that make up the care planning agreement KPI.

Table 35: The percentage of children and young people with epilepsy with evidence of care planning agreement within the first year of care by cohort.

	England and Wales	England	Wales
Round 3, Cohort 1	62.4% (694/1112)	63.5% (667/1051)	44.3% (27/61)
Round 3, Cohort 2	65.4% (1378/2106)	65.3% (1363/2086)	75.0% (15/20)
Round 3, Cohort 3	70.0% (1379/1974)	70.0% (1343/1918)	64.3% (36/56)
Round 4, Cohort 4	74.3% (1727/2324)	74.6% (1652/2215)	68.8% (75/109)
Round 4, Cohort 5	80.8% (1787/2212)	80.5% (1670/2074)	84.8% (117/138)
Round 4, Cohort 6	85.8% (2665/3105)	85.6% (2522/2947)	90.5% (143/158)
Round 4, Cohort 7	88.1% (3267/3709)	87.9% (3116/3545)	92.1% (151/164)

Table 36: Percentage of children and young people with epilepsy with evidence of care planning agreement within the first year of care by demographic.

Demographic Variables	England and Wales	England	Wales
Age			
< 2 years	85.7% (412/481)	85.5% (402/470)	90.9% (10/11)
2 – 4 years	88.4% (573/648)	88.2% (545/618)	93.3% (28/30)
5 – 11 years	88% (1487/1689)	87.8% (1407/1603)	93% (80/86)
12 – 15 years	89% (751/844)	89% (718/807)	89.2% (33/37)
16+ years	93.6% (44/47)	93.6% (44/47)	N/A
Sex			
Female	88.5% (1397/1578)	88.4% (1336/1512)	92.4% (61/66)
Male	87.6% (1824/2082)	87.4% (1737/1987)	91.6% (87/95)
Not Indicated	93.9% (46/49)	93.5% (43/46)	100% (3/3)
Ethnicity			
Asian	82.6% (256/310)	82.2% (249/303)	100% (7/7)
Black	84.7% (160/189)	*	*
Mixed	83.3% (110/132)	*	*
Other	80.7% (92/114)	*	*
White	89.8% (2218/2469)	89.8% (2094/2332)	90.5% (124/137)
Not Indicated	87.1% (431/495)	86.7% (416/480)	100% (15/15)
Deprivation			
Most deprived	89.3% (915/1025)	89.1% (877/984)	92.7% (38/41)
Second most deprived	89.8% (737/821)	89.3% (694/777)	97.7% (43/44)
Third least deprived	86.6% (570/658)	86.6% (547/632)	88.5% (23/26)
Second least deprived	88.9% (543/611)	88.9% (520/585)	88.5% (23/26)
Least deprived	85.1% (486/571)	84.9% (462/544)	88.9% (24/27)
Not indicated	69.6% (16/23)	69.6% (16/23)	N/A
Mental health			

Mental health condition identified	91.4% (319/349)	91.5% (302/330)	89.5% (17/19)
No mental health condition identified	87.7% (2948/3360)	87.5% (2814/3215)	92.4% (134/145)
Neurodevelopmental condition/learning disability			
Neurodevelopmental condition /learning disability identified	87.2% (1002/1149)	87.2% (966/1108)	87.8% (36/41)
No neurodevelopmental condition/learning disability identified	88.5% (2265/2560)	88.2% (2150/2437)	93.5% (115/123)

Table 37: Percentage of children and young people with epilepsy with evidence of care planning agreement by region.

Geographic Region	KPI 9a. Care Planning Agreement
England and Wales	88.1% (3267/3709)
Country	
England	87.9% (3116/3545)
Wales	92.1% (151/164)
NHS England Region	
East of England	84.9% (259/305)
London	83.3% (425/510)
Midlands	77.3% (463/599)
North East and Yorkshire	93.9% (598/637)
North West	91.9% (588/640)
South East	91.1% (555/609)
South West	93.1% (228/245)
OPEN UK Region	
BRPNF	76.3% (222/291)
CEWT	92.3% (96/104)
EPEN	90.2% (202/224)
EPIC	98.4% (315/320)
NTPEN	79.4% (340/428)
NWEIG	84.1% (370/440)
ORENG	63% (136/216)
PENNEC	91.9% (182/198)
SETPEG	94.1% (238/253)
SWEP	92.8% (128/138)
SWIPE	89.2% (124/139)
SWTPEG	93.3% (235/252)
TEN	96.4% (161/167)

WPNN 97% (230/237)
 YPEN 95.4% (288/302)

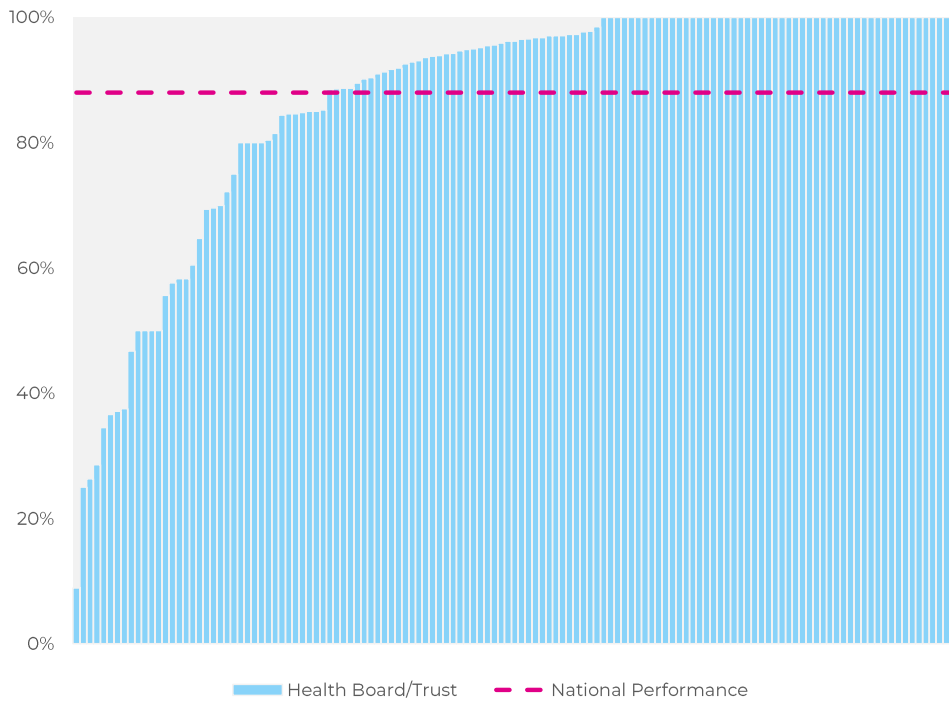


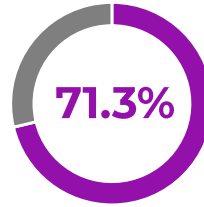
Figure 24: Care planning agreement by Health Board and Trust, cohort 7. Each participating Health Board or Trust is represented by a vertical bar in the order of the percentage score, including those scoring 0% in this graph.

Table 38: Comprehensive care planning agreement sub-metrics.

	England and Wales	England	Wales
All three elements of care planning agreement	88.1% (3267/3709)	87.9% (3116/3545)	92.1% (151/164)
Individualised epilepsy document or copy clinic letter that includes care planning information	92% (3411/3709)	91.9% (3257/3545)	93.9% (154/164)
Evidence of agreement between the person, their family and/or carers as appropriate	89.5% (3321/3709)	89.3% (3167/3545)	93.9% (154/164)
The care plan has been updated in the last year	88.8% (3294/3709)	88.7% (3143/3545)	92.1% (151/164)

9b. Care planning components

Percentage of children and young people with epilepsy with evidence of communication regarding core components of care planning by first year. This requires evidence of discussion of water safety, first aid, general risk and participation, service contact details and sudden unexpected death in epilepsy (SUDEP), and a parental prolonged seizures care plan if also prescribed rescue medication.



NICE guidelines [NG217], 2022 state that children and young people with epilepsy should have a protocol for administering rescue medication (Statement 7.3), a water safety risk assessment (Statement 2.1.1), first aid and safety information, service contact details (Statement 1.1.8), and information regarding the risk of SUDEP (Statement 10.1.4)

71.3% (2,643/3,709) of children and young people with epilepsy had evidence of achieving all core components of care planning. This was an increase compared to **67.4% (2,093/3,105)** in cohort 6. This indicator ranged from **0.0%** to **100.0%**, with an interquartile range of **51.4%** to **95.6%**.

73.6% (2,728/3,709) of children and young people with epilepsy had evidence of discussion regarding SUDEP in cohort 7. This was **68.5% (2,127/3,105)** in cohort 6. Evidence of discussion of SUDEP was added as an element of the care planning components indicator from cohort 5.

Table 39 shows how care planning components is distributed between demographic population groups and **Table 40** shows the variation in care planning components between England and Wales and across NHSE and OPEN UK regions. **Table 41** shows the breakdown of the sub-metrics which make up the care planning components measure.

Table 39: Percentage of children and young people with epilepsy with evidence of achieving core components of care planning by demographic.

Demographic Variables	England and Wales	England	Wales
Age			
< 2 years	64.2% (309/481)	63.6% (299/470)	90.9% (10/11)
2 – 4 years	70.8% (459/648)	70.7% (437/618)	73.3% (22/30)
5 – 11 years	71.3% (1204/1689)	71.4% (1145/1603)	68.6% (59/86)
12 – 15 years	75.2% (635/844)	74.8% (604/807)	83.8% (31/37)
16+ years	76.6% (36/47)	76.6% (36/47)	N/A
Sex			
Female	69% (1089/1578)	68.8% (1040/1512)	74.2% (49/66)
Male	72.6% (1512/2082)	72.6% (1442/1987)	73.7% (70/95)
Not Indicated	85.7% (42/49)	84.8% (39/46)	100% (3/3)
Ethnicity			
Asian	69% (214/310)	68.6% (208/303)	85.7% (6/7)
Black	66.7% (126/189)	*	*
Mixed	62.1% (82/132)	*	*
Other	63.2% (72/114)	*	*
White	74.9% (1849/2469)	74.9% (1747/2332)	74.5% (102/137)

Not Indicated	60.6% (300/495)	60.2% (289/480)	73.3% (11/15)
Deprivation			
Most deprived	75.9% (778/1025)	75.8% (746/984)	78% (32/41)
Second most deprived	71.6% (588/821)	70.8% (550/777)	86.4% (38/44)
Third least deprived	67.5% (444/658)	67.6% (427/632)	65.4% (17/26)
Second least deprived	68.7% (420/611)	69.2% (405/585)	57.7% (15/26)
Least deprived	70.2% (401/571)	70% (381/544)	74.1% (20/27)
Not indicated	52.2% (12/23)	52.2% (12/23)	N/A
Mental health			
Mental health condition identified	77.9% (272/349)	78.2% (258/330)	73.7% (14/19)
No mental health condition identified	70.6% (2371/3360)	70.4% (2263/3215)	74.5% (108/145)
Neurodevelopmental condition/learning disability			
Neurodevelopmental condition /learning disability identified	70.8% (814/1149)	70.7% (783/1108)	75.6% (31/41)
No neurodevelopmental condition/learning disability identified	71.4% (1829/2560)	71.3% (1738/2437)	74% (91/123)

Table 40: Percentage of children and young people with epilepsy with evidence of communication regarding core components of care planning by region.

Geographic Region	KPI 9b. Care Planning Components
England and Wales	71.3% (2643/3709)
Country	
England	71.1% (2521/3545)
Wales	74.4% (122/164)
NHS England Region	
East of England	65.9% (201/305)
London	56.3% (287/510)
Midlands	71.5% (428/599)
North East and Yorkshire	85.6% (545/637)
North West	78.9% (505/640)
South East	63.1% (384/609)
South West	69.8% (171/245)
OPEN UK Region	
BRPNF	65.3% (190/291)
CEWT	77.9% (81/104)
EPEN	80.8% (181/224)
EPIC	75% (240/320)
NTPEN	44.2% (189/428)

NWEIG	70.5% (310/440)
ORENG	73.6% (159/216)
PENNEC	80.3% (159/198)
SETPEG	71.1% (180/253)
SWEP	83.3% (115/138)
SWIPE	71.2% (99/139)
SWTPEG	68.7% (173/252)
TEN	91.6% (153/167)
WPNN	58.6% (139/237)
YPEN	91.1% (275/302)

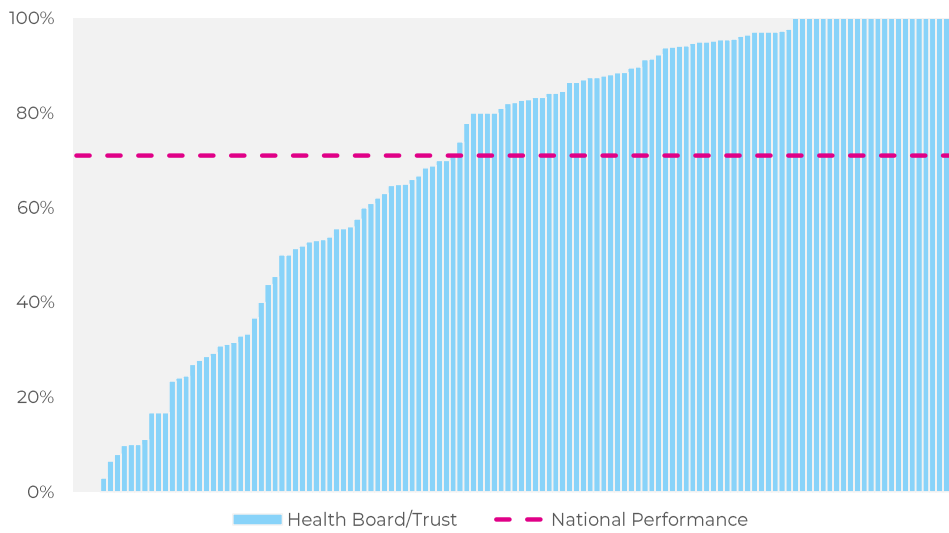


Figure 25: Care planning components by Health Board and Trust, cohort 7. Each participating Health Board or Trust is represented by a vertical bar in the order of the percentage score, including those scoring 0% in this graph.

Table 41: Comprehensive care planning components sub-metrics.

	England and Wales	England	Wales
All core elements of care planning			
If prescribed rescue medication, prolonged seizures care plan	95.6% (867/907)	95.4% (824/864)	100% (43/43)
Water safety	88.6% (3285/3709)	88.3% (3132/3545)	93.3% (153/164)
First aid	90.6% (3362/3709)	90.5% (3208/3545)	93.9% (154/164)
General participation and risk	88.8% (3295/3709)	88.7% (3145/3545)	91.5% (150/164)
Service contact details	91.5% (3395/3709)	91.4% (3241/3545)	93.9% (154/164)
SUDEP	73.6% (2728/3709)	73.5% (2604/3545)	75.6% (124/164)

10. School Individual Health Care Plan

Percentage of children and young people with epilepsy aged over 5 years with evidence of a School Individual Health Care Plan within the first year of care.

75.3% (1,942/2,580) of children and young people with epilepsy aged over 5 years had evidence of a School Individual Health Care Plan within the first year of care in cohort 7. This was an increase compared to **67.2% (1,427/2,125)** in cohort 6. This indicator ranged from **0.0%** to **100.0%**, with an interquartile range of **60%** to **96.9%**.

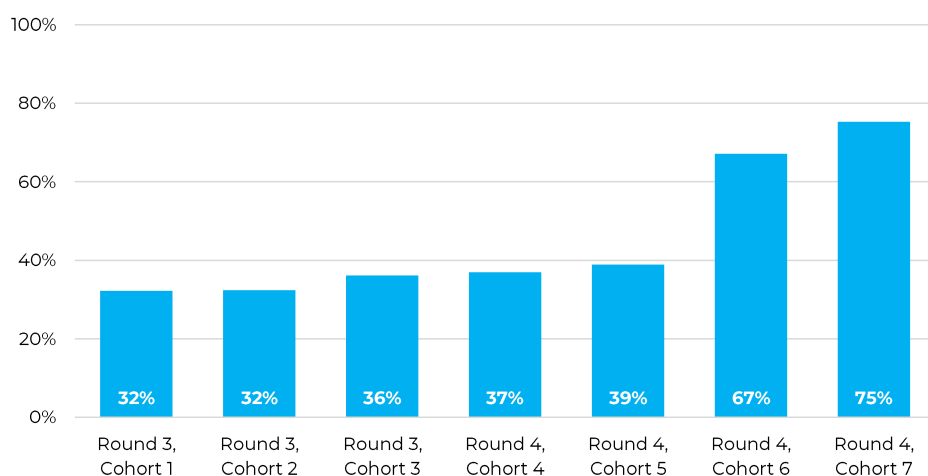
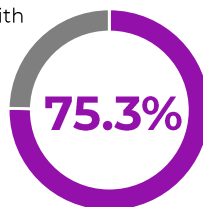


Figure 26: School Individual Health Care Plans in Rounds 3 and 4.

Table 42 shows evidence of School Individual Health Care Plan over time in Rounds 3 and 4.

Table 43 shows how the presence of School Individual Health Care Plans are distributed between demographic population groups and **Table 44** shows the variation in access to School Individual Health Care Plan between England and Wales and across NHSE and OPEN UK regions.

Table 42: The percentage of children and young people with epilepsy aged over 5 years with evidence of a School Individual Health Care Plan within the first year of care by cohort.

	England and Wales	England	Wales
Round 3, Cohort 1	32.2% (231/717)	32.4% (219/676)	29.3% (12/41)
Round 3, Cohort 2	32.4% (454/1402)	23.1% (446/1931)	72.7% (8/11)
Round 3, Cohort 3	36.1% (499/1381)	36.3% (487/1343)	31.6% (12/38)
Round 4, Cohort 4	36.9% (577/1562)	36.9% (555/1503)	40.7% (24/59)
Round 4, Cohort 5	38.9% (573/1472)	39.7% (550/1385)	26.4% (23/87)
Round 4, Cohort 6	67.2% (1427/2125)	67.3% (1354/2012)	64.6% (73/113)
Round 4, Cohort 7	75.3% (1942/2580)	75.2% (1847/2457)	77.2% (95/123)

Table 43: Percentage of children and young people with epilepsy aged over 5 years with evidence of a School Individual Health Care Plan within the first year of care by demographic.

Demographic Variables	England and Wales	England	Wales
Age			
5 – 11 years	74.4% (1257/1689)	74.2% (1190/1603)	77.9% (67/86)
12 – 15 years	76.5% (646/844)	76.6% (618/807)	75.7% (28/37)
16+ years	83% (39/47)	83% (39/47)	N/A
Sex			
Female	75.1% (822/1095)	75% (783/1044)	76.5% (39/51)
Male	75.1% (1087/1447)	75% (1033/1377)	77.1% (54/70)
Not Indicated	*	*	*
Ethnicity			
Asian	69.4% (150/216)	68.6% (144/210)	100% (6/6)
Black	74.5% (82/110)	74.5% (82/110)	N/A
Mixed	69.9% (58/83)	*	*
Other	58.2% (53/91)	*	*
White	77.5% (1340/1730)	77.4% (1258/1626)	78.8% (82/104)
Not Indicated	74% (259/350)	74.9% (254/339)	45.5% (5/11)
Deprivation			
Most deprived	76.2% (529/694)	76.4% (508/665)	72.4% (21/29)
Second most deprived	75% (428/571)	74.9% (402/537)	76.5% (26/34)
Third least deprived	76% (348/458)	75.8% (335/442)	81.2% (13/16)
Second least deprived	77.5% (337/435)	77.1% (319/414)	85.7% (18/21)
Least deprived	71.4% (292/409)	71.2% (275/386)	73.9% (17/23)
Not indicated	61.5% (8/13)	61.5% (8/13)	N/A
Mental health			
Mental health condition identified	81.7% (272/333)	81.3% (256/315)	88.9% (16/18)
No mental health condition identified	74.3% (1670/2247)	74.3% (1591/2142)	75.2% (79/105)
Neurodevelopmental condition/learning disability			
Neurodevelopmental condition/learning disability identified	76.8% (603/785)	76.7% (584/761)	79.2% (19/24)
No neurodevelopmental condition/learning disability identified	74.6% (1339/1795)	74.5% (1263/1696)	76.8% (76/99)

Table 44: Percentage of children and young people with epilepsy aged over 5 years with evidence of a School Individual Health Care Plan within the first year of care by region.

Geographic Region	KPI 10. School Individual Health Care Plan
England and Wales	75.3% (1942/2580)
Country	
England	75.2% (1847/2457)
Wales	77.2% (95/123)
NHS England Region	
East of England	81% (179/221)
London	70.5% (253/359)
Midlands	65.1% (263/404)
North East and Yorkshire	77.3% (341/441)
North West	83.8% (362/432)
South East	75.4% (325/431)
South West	73.4% (124/169)
OPEN UK Region	
BRPNF	66.5% (131/197)
CEWT	69.6% (48/69)
EPEN	83.4% (136/163)
EPIC	88.5% (193/218)
NTPEN	65.2% (195/299)
NWEIG	77.1% (229/297)
ORENG	45.8% (71/155)
PENNEC	87.8% (122/139)
SETPEG	87.9% (153/174)
SWEP	75.2% (79/105)
SWIPE	62.2% (61/98)
SWTPEG	76% (136/179)
TEN	85.5% (100/117)
WPNN	86.4% (140/162)
YPEN	71.2% (148/208)

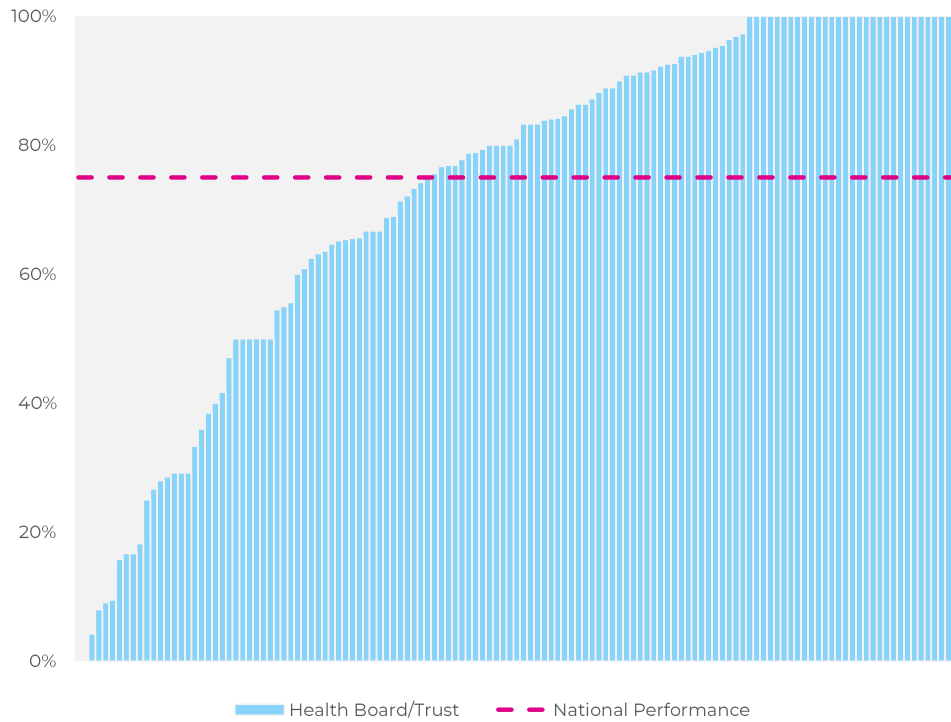


Figure 27: School Individual Health Care Plans by Health Board and Trust, cohort 7. Each participating Health Board or Trust is represented by a vertical bar in the order of the percentage score, including those scoring 0% in this graph.

Additional analyses

First Paediatric Assessment

In cohort 7, **55.3% (2051/3709)** of children and young people with epilepsy had their first paediatric assessment in an acute setting (**Table 45**), which is consistent across all five previous cohorts.

Table 45: The setting of first paediatric assessments for children and young people with epilepsy in cohort 7 in England and Wales.

	England and Wales	England	Wales
Setting			
Acute	55.3% (2051/3709)	55.7% (1973/3545)	47.6% (78/164)
Non-acute	44.4% (1646/3709)	44% (1560/3545)	52.4% (86/16)
Unknown	0.3% (12/3709)	0.3% (12/3545)	N/A

Table 46 shows the percentage of children and young people with epilepsy who had evidence of receiving each element of an 'appropriate first paediatric assessment' in cohort 7.

Table 46: Percentage of children and young people with epilepsy with evidence of receiving each element of an 'appropriate first paediatric assessment' in cohort 7 in England and Wales.

	England and Wales	England	Wales
The number of episodes since the first documented.	97.1% (3603/3709)	97% (3440/3545)	99.4% (163/164)
Descriptions of general examination	96.4% (3575/3709)	96.3% (3414/3545)	98.2% (161/164)
Descriptions of neurological examination	92.6% (3436/3709)	92.4% (3275/3545)	98.2% (161/164)
Descriptions of developmental, learning or schooling progress	83.2% (3085/3709)	82.6% (2928/3545)	95.7% (157/164)
If aged 3 yrs and above, evidence of consideration of emotional or behavioural problems	71.6% (2656/3709)	70.9% (2512/3545)	87.8% (144/164)

Treatment

Table 47 and **Table 48** shows the number and types of anti-epileptic drugs (AEDs) (also referred to as anti-seizure medication) prescribed to children and young people with epilepsy in cohort 7 during their first year of care. **9.2% (341/3709)** children and young people with epilepsy were prescribed three or more AEDs during their first year of care, which is consistent with cohort 6 (**9.6%**).

Table 47: Number of anti-epileptic drugs (AEDs) prescribed to children and young people with epilepsy in cohort 7 within the first year of care.

Number of AEDs	England and Wales	England	Wales
1 or more AEDs	89.2% (3309/3709)	89.3% (3167/3545)	86.6% (142/164)
3 or more AEDs	9.2% (341/3709)	8.9% (317/3545)	14.6% (24/164)
No AED prescriptions recorded	10.8% (400/3709)	10.7% (378/3545)	13.4% (22/164)

In cohort 7, the most commonly prescribed anti-epileptic drugs were **Levetiracetam**, which is consistent with cohorts 1 to 6.

Table 48: Percentage of children and young people with epilepsy prescribed each anti-epileptic drug (AED) in cohort 7 in England and Wales.

AED	England and Wales	England	Wales
ACTH	*	*	*
Brivaracetam	3.3% (124/3709)	3.1% (111/3545)	7.9% (13/164)
Buccal midazolam	22.3% (827/3709)	22.1% (785/3545)	25.6% (42/164)
Carbamazepine	9.1% (336/3709)	9.2% (325/3545)	6.7% (11/164)
Clobazam	4.7% (173/3709)	4.7% (165/3545)	4.9% (8/164)
Clonazepam	0.2% (6/3709)	0.2% (6/3545)	N/A
Ethosuximide	9.2% (342/3709)	9.3% (331/3545)	6.7% (11/164)
Lacosamide	0.3% (12/3709)	*	*
Lamotrigine	23.5% (870/3709)	22.9% (813/3545)	34.8% (57/164)
Levetiracetam	54.1% (2006/3709)	54.4% (1930/3545)	46.3% (76/164)
Lorazepam	*	*	*
Methylprednisolone	*	*	*
Nitrazepam	0.2% (7/3709)	0.2% (7/3545)	N/A
Other	0.5% (18/3709)	0.5% (18/3545)	N/A
Oxcarbazepine	0.5% (20/3709)	*	*
Perampanel	*	*	*
Phenobarbital	0.8% (31/3709)	*	*
Phenytoin	0.3% (10/3709)	0.3% (10/3545)	N/A
Prednisolone	1.9% (69/3709)	1.9% (66/3545)	1.8% (3/164)
Rectal diazepam	*	*	*

Rufinamide	*	*	*
Sodium valproate	3.6% (133/3709)	3.4% (120/3545)	7.9% (13/164)
Stiripentol	0.1% (4/3709)	0.1% (4/3545)	N/A
Topiramate	1.1% (39/3709)	*	*
Vigabatrin	2.7% (99/3709)	2.7% (96/3545)	1.8% (3/164)
Zonisamide	0.5% (19/3709)	0.5% (16/3545)	1.8% (3/164)

Figure 28 shows the number of males and females who were prescribed sodium valproate in the first year of care in cohort 7. There were more males on sodium valproate than females across all ages, and very few females aged 9 and above on sodium valproate, consistent with cohort 6.

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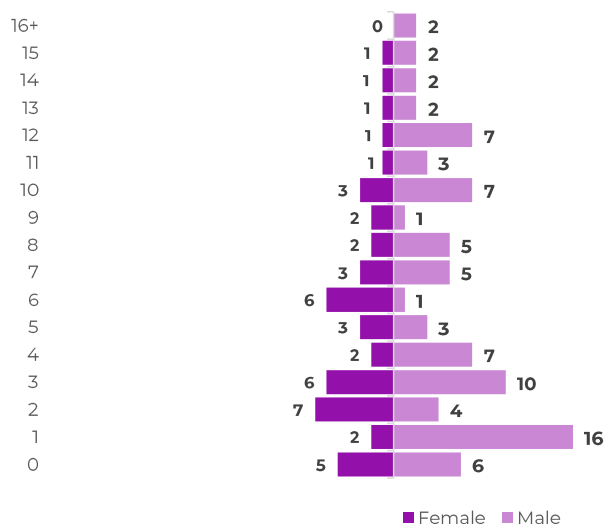


Figure 28: Number of males and females on sodium valproate by age.

In England and Wales, **835 (22.5%)** children and young people diagnosed with epilepsy had rescue medication prescribed in the first year of care in cohort 6 in England and Wales. This figure was **793 (22.0%)** in England and **42 (25.6%)** in Wales (**Table 49**). The proportion of children and young people prescribed rescue medication increased in cohort 7, compared to **723 (23.3%)** in cohort 6.

Table 49: Percentage of children and young people with epilepsy prescribed rescue medication in cohort 7 in England and Wales.

Rescue medication	England and Wales	England	Wales
Buccal midazolam	22.3% (827/3709)	22.1% (785/3545)	25.6% (42/164)
Rectal diazepam	*	*	*
Other	0.2% (7/3709)	*	*
No record of rescue medication being prescribed	77.5% (2875/3709)	77.7% (2753/3545)	74.4%(122/164)

Investigations

Table 50 shows the percentage of children and young people with epilepsy in cohort 7 who obtained each investigation in the first year of care in England and Wales. These are descriptive results and are not performance-related percentages, as not all children and young people will require every investigation.

In England and Wales, **97.5% (3615/3709)** of children and young people with epilepsy obtained a first EEG, **75.9% (2815/3709)** obtained a 12-lead ECG, **19.2% (711/3709)** obtained a CT head scan and **65.9% (2445/3709)** obtained an MRI brain scan within their first year of care. These figures are consistent with cohort 6 results (**98%**, **74.5%**, **18.5%** and **65.3%**), respectively.

Table 50: Percentage of children and young people with epilepsy in cohort 6 who received each investigation within the first year of care in England and Wales.

Investigation	England and Wales	England	Wales
EEG obtained	97.5% (3615/3709)	97.4% (3453/3545)	98.8%(162/164)
EEG not requested	0.8% (31/3709)	*	*
EEG requested but not obtained	1.3% (50/3709)	*	*
12 lead ECG	75.9% (2815/3709)	75.9% (2691/3545)	75.6%(124/164)
CT head scan	19.2% (711/3709)	18.9% (671/3545)	24.4% (40/164)
MRI Brain scan	65.9% (2445/3709)	66% (2340/3545)	64% (105/164)

97.5% (3615/3709) of children and young people with epilepsy in England and Wales obtained an EEG within the first year of care and had a valid request date recorded. **53.6% (1989/3709)** had an EEG within four weeks of request, which decreased slightly from **56.5% (1755/3105)** in cohort 6. The proportion of children and young people waiting more than 16 weeks for an EEG from request increased **4.9% (153/3105)** in cohort 6 to **5.4% (200/3709)** in cohort 7.

The mean time between requesting an EEG in weeks was **5.4** (range **0 – 164** weeks) and the median was **3.6** (interquartile range **1.1 – 6.7**) weeks.

Table 51 shows the time between EEG request and input in England and Wales in cohort 7. NICE guidelines state that children and young people having initial investigations for epilepsy should undergo EEG investigations within 4 weeks of the initial request. **Table 52** and **Figure 29** show the variation in time to EEG by deprivation quintile.

Table 51: Time in weeks between the date of initial EEG request and the date when the EEG was obtained, in cohort 7 in England and Wales.

Time in weeks	England and Wales	England	Wales
0 - 4 weeks	53.6% (1989/3709)	54.1% (1919/3545)	42.7% (70/164)
4 - 8 weeks	25.9% (962/3709)	26.3% (933/3545)	17.7% (29/164)
8 - 12 weeks	9.6% (357/3709)	9.5% (336/3545)	12.8% (21/164)
12 - 16 weeks	3.2% (120/3709)	3% (107/3545)	7.9% (13/164)
16+ weeks	5.4% (200/3709)	4.8% (171/3545)	17.7% (29/164)
Input not achieved	2.2% (81/3709)	2.2% (79/3545)	1.2% (2/164)

Table 52: Time in weeks between the date of initial EEG request and the date when the EEG was obtained, by deprivation quintile in cohort 7 in England and Wales.

	Most deprived	Second most deprived	Third least deprived	Second least deprived	Least deprived
0 - 4 weeks	55.1% (565/1025)	50.8% (417/821)	51.5% (339/658)	54.5% (333/611)	56.7% (324/571)
4 - 8 weeks	24.2% (248/1025)	27.9% (229/821)	28.6% (188/658)	24.5% (150/611)	24.5% (140/571)
8 - 12 weeks	9.7% (99/1025)	9.1% (75/821)	9.1% (60/658)	10.6% (65/611)	9.8% (56/571)
12 - 16 weeks	2.6% (27/1025)	4.3% (35/821)	3.3% (22/658)	3.4% (21/611)	2.5% (14/571)
> 16 weeks	6.2% (64/1025)	5.8% (48/821)	5.8% (38/658)	4.3% (26/611)	3.9% (22/571)
Input not achieved	2.1% (22/1025)	2.1% (17/821)	1.7% (11/658)	2.6% (16/611)	N/A

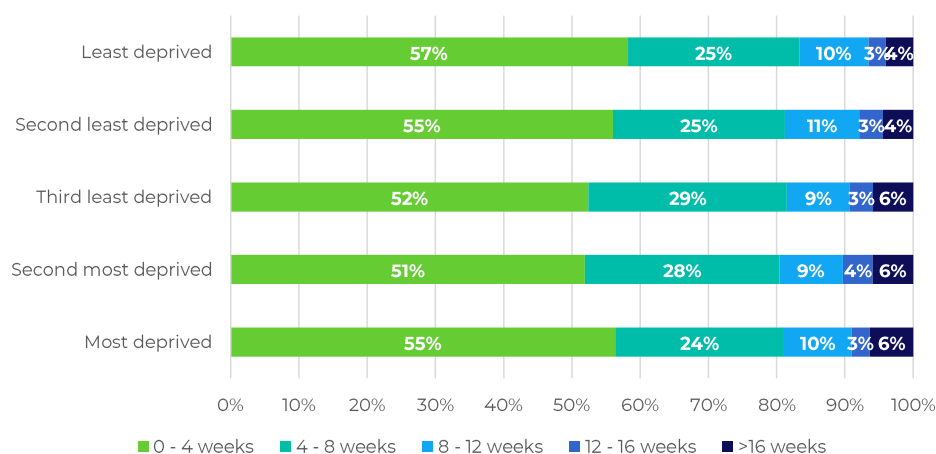


Figure 29: Time in weeks between the date of initial EEG request and the date when the EEG was obtained, by deprivation quintile in cohort 7 in England and Wales.

Professional input

In cohort 7, **92.6% (3434/3709)** of children and young people with epilepsy in England and Wales were seen by a consultant paediatrician with expertise in epilepsy and **88% (3265/3709)** were seen by an epilepsy specialist nurse within the first year of care (**Table 53**). This is an increase from **90.3% (2803/3105)** and **85.6% (2659/3105)** respectively in cohort 6.

Table 53: Percentage of children and young people with epilepsy seen by key professionals in cohort 7 in England and Wales.

	England and Wales	England	Wales
Consultant paediatrician with expertise in epilepsies	92.6% (3434/3709)	92.9% (3293/3545)	86% (141/164)
Epilepsy specialist nurse	88% (3265/3709)	88.3% (3129/3545)	82.9% (136/164)
Paediatric neurologist	15.4% (570/3709)	15.5% (550/3545)	12.2% (20/164)
CESS	0.5% (18/3709)	0.5% (18/3545)	N/A