EPILEPSY12

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

Extended Analysis A

2024 Clinical audit national & regional results

Cohort 5

HQIP
Healthcare Quality Improvement Partnership

RCPCH
Royal College of
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Contents

Introduction

This report focuses on **clinical data from Epilepsy12 'cohort 5'**, which includes children and young people who had their first paediatric assessment for a paroxysmal episode(s) between 1 December 2021 and 30 November 2022. 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 18 January 2024, following the data submission deadline. The 2024 annual report and accompanying outputs can be found here.

Note: Asterisks (*) have been used to mask/supress 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 has been presented here at **national** (England and Wales combined), **country** and 2 types of **regional** levels; NHS England regions and Organisation of Paediatric Epilepsy Networks in the UK (OPEN UK).

The **OPEN UK** Regional Paediatric Epilepsy 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 and Wales.

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 138 Health Boards and Trusts registered in Epilepsy12 in cohort 5 (Round 4). This number has varied across the 5 cohorts due to Trust mergers. **84.8% (117/138)** Health Boards and Trusts had at least one child or young person allocated to cohort 5. **78.2% (108/138)** 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 5. Participation increased in cohort 5 compared to cohort 4.

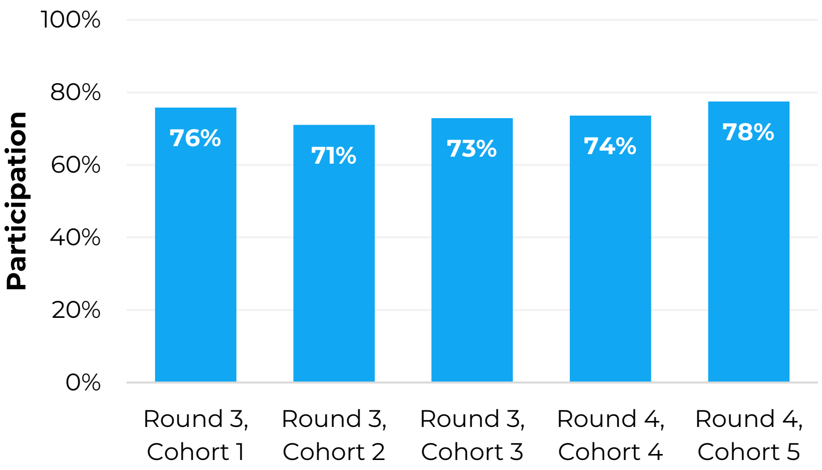


Figure 1: Percentage of Trusts and Health Boards that submitted clinical audit data in Rounds 3 and 4.

Case Ascertainment

Figure 2 shows the pathway by which children and young people 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.

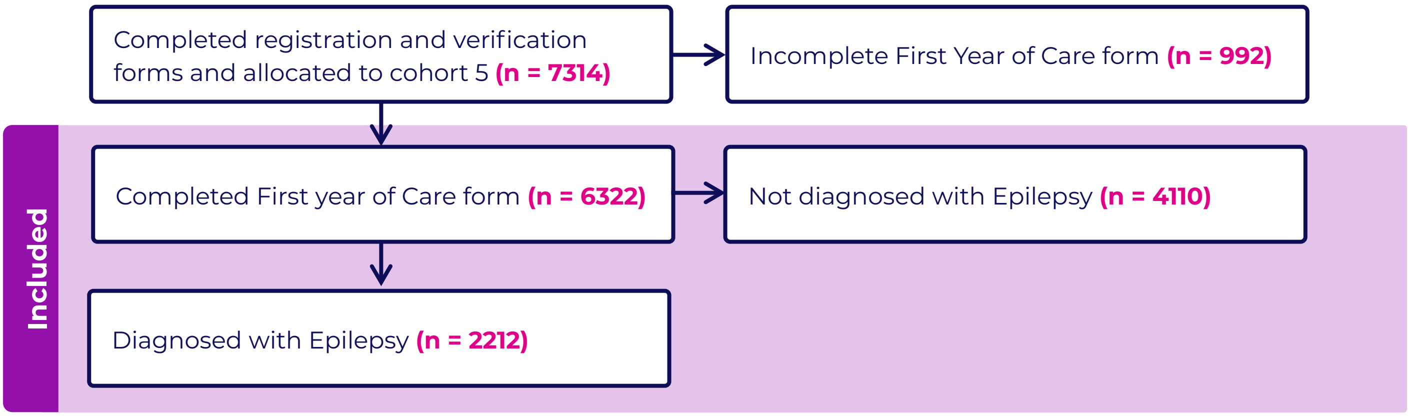


Figure 2: Consort diagram of audit registrations and inclusion in cohort 5, as at 18 January 2024

Data completeness

Table 1: Percentage of children and young people registered to cohort 5 with a first year of care form completed.

	England and Wales	England	Wales
Number of children and young people in cohort 5	7250	6969	281
Number of children and young people in cohort 5 with first year of care form completed	6322/7250 (87.2%)	6067/6969 (87.1%)	255/281 (90.7%)
Number with epilepsy	**2212/6322 (35.0%)**	**2074/6067 (34.2%)**	**138/255 (54.1%)**
Number without epilepsy	4110/6322 (65.0%)	3993/6067 (65.8%)	117/255 (45.9%)

A total of **7314** children and young were registered and verified in cohort 5 before the download date**. 60 (<1%)** of these children and young people were excluded from the audit as the NHS numbers recorded were invalid. **87% (6322/7250)** had first year of care forms completed, locked and submitted. **2212 (35%)** children and young people had a new diagnosis of epilepsy. **Figure 3** shows that data completeness has increased in cohort 5 from previous years, including pre-pandemic levels.

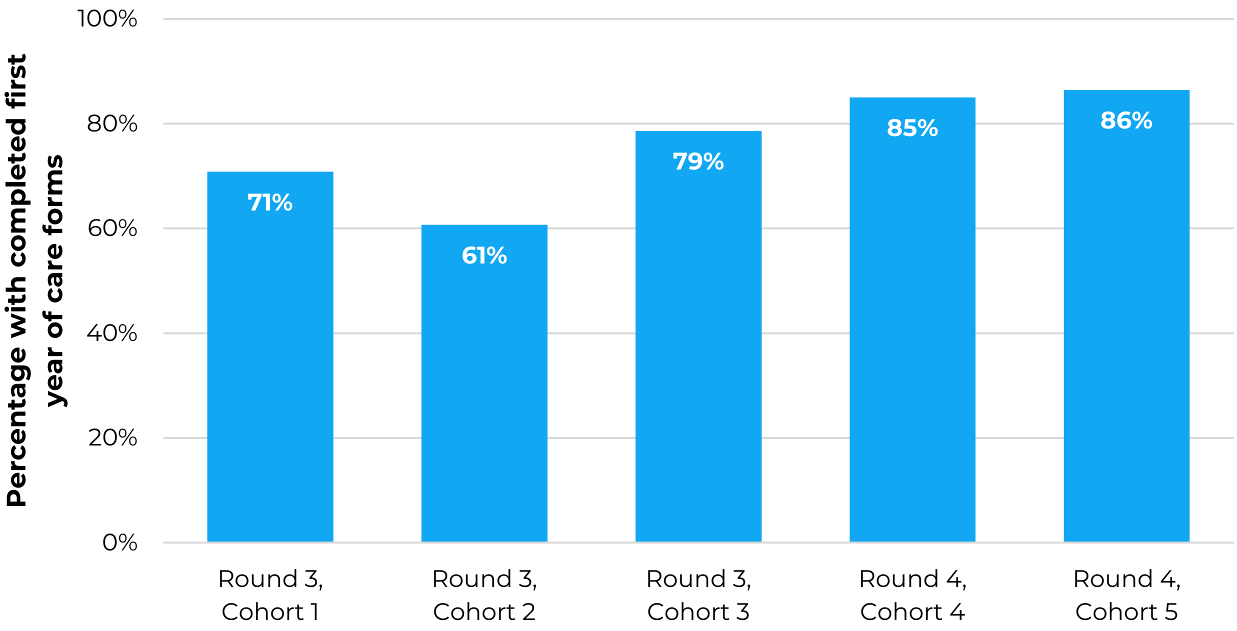


Figure 3: Data completeness in Round 3 and Round 4.

Figure 4 shows the percentage of children and young people in cohort 5 with a completed first year of care form by 18th January 2024. Each Health Board and Trust is represented by a vertical bar in order of the percentage score. This does not include Health Boards and Trusts that submitted had no patients registered and verified in cohort 5

Of the **117** Health Boards and Trusts that had at least one patient allocated to Cohort 5, **26.5% (31/117)** of Health Boards and Trusts had ascertainment below the England and Wales average, and **29.9% (35/117)** had **100%** data completeness.

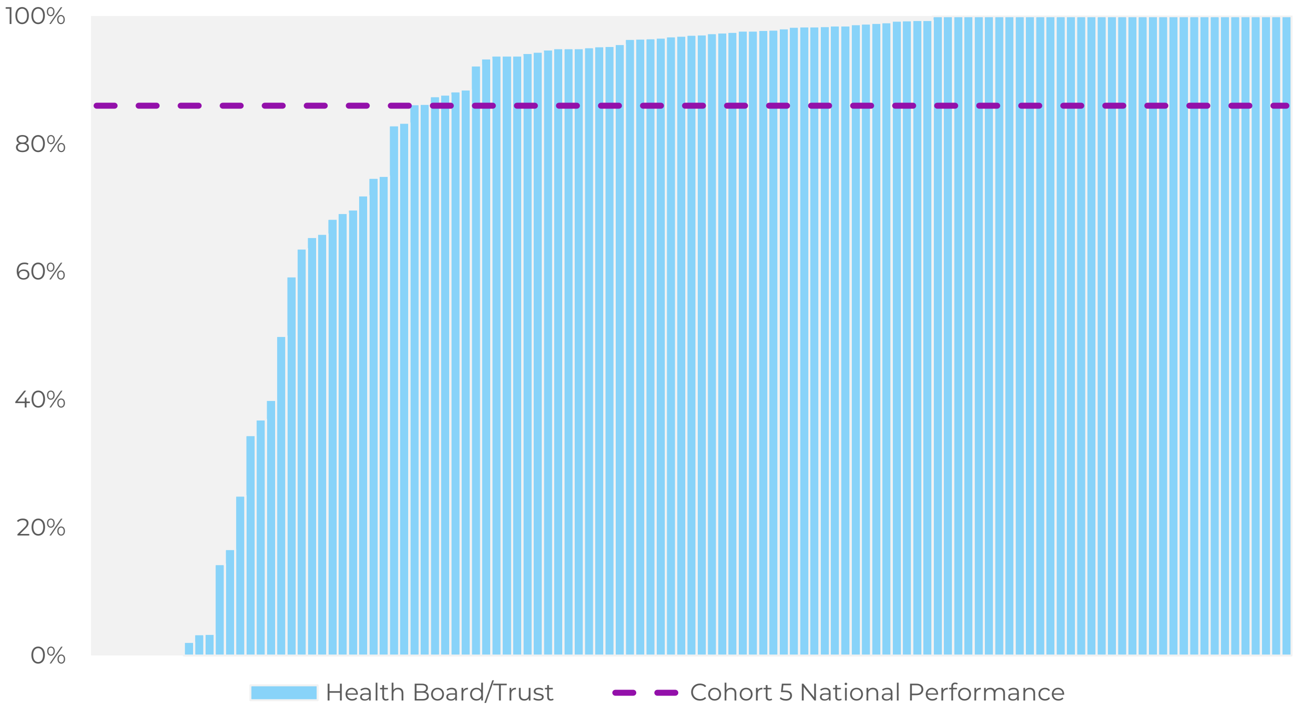


Figure 4: Percentage of children and young people with their first year of care form submitted and locked by Health Boards and Trusts in cohort 5.

Diagnostic Status

Table 2 shows the diagnostic status of children and young people in cohort 5 in the first year of care in England and Wales combined. **35% (2212/6322)** of children and young people were diagnosed with epilepsy in cohort 5. This is comparable with cohort 4, where the proportion was 35% (2324/.6564) with epilepsy. **34% (2147/6322)** had two or more epileptic episodes more than 24 hours apart and **1% (65/6322)** were diagnosed with epilepsy for other reasons.

Table 2: The diagnostic status of patients with and without epilepsy in cohort 5 in England and Wales.

Diagnostic Status	England and Wales	England	Wales
Epilepsy			
Epilepsy: 2 or more epileptic episodes more than 24 hours apart	34.0% (2147/6322)	33.1% (2009/6067)	54.1% (138/255)
Epilepsy: Other reason	1.0% (65/6322)	1.1% (65/6067)	0.0% (0/255)
Not epilepsy			
Not epilepsy: Single epileptic episode	2.5% (156/6322)	2.4% (148/6067)	3.1% (8/255)
Not epilepsy: Cluster of epileptic episodes within 24 hours	1.0% (63/6322)	1.0% (63/6067)	0.0% (0/255)
Non-epileptic episodes	40.9% (2584/6322)	41.3% (2506/6067)	30.6% (78/255)
Uncertain episodes	20.7% (1307/6322)	21.0% (1276/6067)	12.2% (31/255)

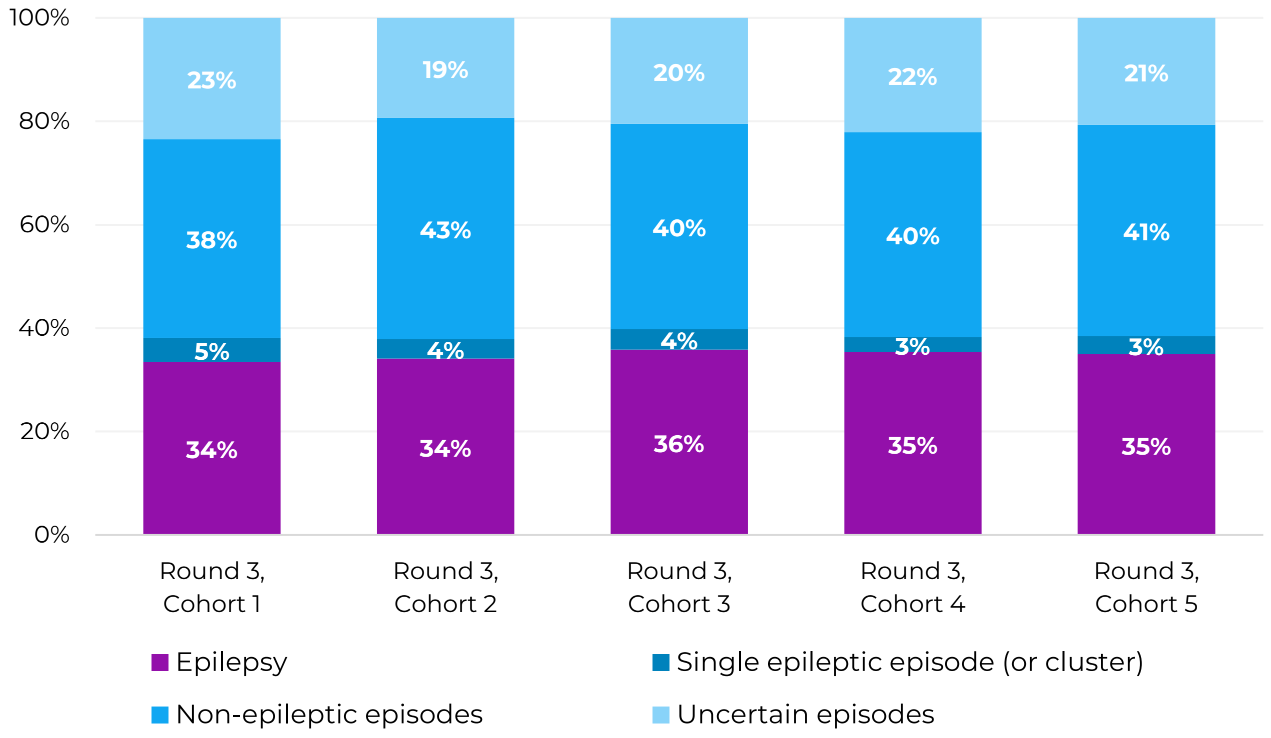


Figure 5: Diagnostic status by cohort in England and Wales across Round 3 and 4.

Table 3 describes the children and young people who had recorded seizure episodes, but were not diagnosed with epilepsy.

Only those children and young people with epilepsy, indicated by a recorded diagnostic status of 'Epilepsy: 2 or more epileptic episodes more than 24 hours apart' or 'Epilepsy: Other reason', were included in further analyses – this was **2212 children and young people in cohort 5.**

Table 3: Percentage of children and young people with non-epileptic seizure types of those with only non-epileptic episodes indicated in cohort 5 in England and Wales. *Note, that the totals do not add up, as more than one episode type could be recorded.*

Non-epileptic episode type	England and Wales	England	Wales
Syncope and Anoxic Seizures	12.3% (319/2584)	12.5% (312/2506)	9.0% (7/78)
Behavioural, Psychological and Psychiatric Disorders	37.7% (975/2584)	37.6% (943/2506)	41.0% (32/78)
Sleep related conditions	3.5% (91/2584)	3.4% (85/2506)	7.7% (6/78)
Paroxysmal movement disorders	7.9% (203/2584)	8.1% (203/2506)	0.0% (0/78)
Migraine associated disorder	1.8% (47/2584)	*	*
Miscellaneous events	5.6% (145/2584)	5.7% (142/2506)	3.8% (3/78)
Other	31.8% (823/2584)	31.7% (794/2506)	37.2% (29/78)

The remaining chapters of this report focus on the **2212 children and young people in cohort 5 with a confirmed new epilepsy diagnosis and first year of care form.** 'Epilepsy' is indicated by a recorded diagnostic status of 'Epilepsy: 2 or more epileptic episodes more than 24 hours apart' or 'Epilepsy: Other reason'.

Description of cohort

Demographics

Table 4 describes the georgical distribution of children and young people with epilepsy across England and Wales. **93.8% (2074/2212)** were under the care of Trusts in England, and **6.2% (138/2212)** in Welsh Health Boards. Geographical distributions ranged from 7.7% (East of England) to 20.2% (North East and Yorkshire) between NHS England Regions, and from 2.9% (WPNN) to 11.9% (NTPEN) between OPEN UK regions.

Table 4: Percentage of children and young people with epilepsy with a completed first year of care form by region in cohort 5.

Geographic Region	Percentage
Country	
England	93.8% (2074/2212)
Wales	6.2% (138/2212)
NHS England Region	
East of England	7.7% (159/2074)
London	18.5% (383/2074)
Midlands	18.0% (365/2074)
North East and Yorkshire	20.2% (419/2074)
North West	14.2% (294/2074)
South East	12.5% (260/2074)
South West	9.4% (194/2074)
OPEN UK Region	
BRPNF	4.6% (101/2212)
CEWT	5.7% (126/2212)
EPEN	7.1% (158/2212)
EPIC	7.5% (166/2212)
NTPEN	11.9% (263/2212)
NWEIG	9.7% (214/2212)
ORENG	8.0% (178/2212)
PENNEC	6.5% (144/2212)
SETPEG	5.4% (119/2212)
SWEP	5.0% (111/2212)
SWIPE	4.7% (103/2212)
SWTPEG	8.0% (178/2212)

TEN	5.2% (115/2212)
WPNN	2.9% (64/2212)
YPEN	7.8% (172/2212)

Tabel 5 shows the demographic characteristics of this cohort. **55.0% (1216/2212)** of children and young people with epilepsy in cohort 5 were male, which is consistent with previous cohorts, where the proportion was **57.1% (1326/2324)** in cohort 4.

Deprivation quintile was derived by matching home postcodes to the English (IMD, 2019) and Welsh (WIMD, 2019) indices of multiple deprivation data. **144 (7%)** 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.

The ethnicity variable was introduced to the dataset partway through the time period for data collection for cohort 5. Children and young people who had already been entered into the audit prior to this had their ethnicity automatically defaulted to 'Not Known', but this could be updated before the submission deadline. In cohort 5, 'Not Known' ethnicity is indicated in **64%** of children and young people. Data completeness for ethnicity is projected to improve in future cohorts.

Table 5: Summary of the demographic characteristics of children and young people with new diagnoses of epilepsy in cohort 5 in England and Wales.

Characteristic	England and Wales	England	Wales
Sex			
Females	44.9% (993/2212)	45.0% (934/2074)	42.8% (59/138)
Male	55.0% (1216/2212)	54.8% (1137/2074)	57.2% (79/138)
Not stated	0.1% (3/2212)	0.1% (3/2074)	0.0% (0/138)
Age			
Mean	7.2	7.2	7.1
Median (Interquartile range)	7 (3-11)	7 (3-11)	6.5 (3-12)
Range	0-17	0-17	0-17
Ethnicity			
White (British)	25.9% (574/2212)	24.4% (507/2074)	48.6% (67/138)
White (Irish)	*	*	*
White (Other)	1.5% (33/2212)	1.6% (33/2074)	0.0% (0/138)
Black (Caribbean)	0.1% (3/2212)	0.1% (3/2074)	0.0% (0/138)
Black (African)	0.9% (19/2212)	0.9% (19/2074)	0.0% (0/138)
Black (Other)	0.1% (3/2212)	0.1% (3/2074)	0.0% (0/138)
Asian (Indian)	0.3% (6/2212)	0.3% (6/2074)	0.0% (0/138)
Asian (Pakistani)	2.2% (49/2212)	2.4% (49/2074)	0.0% (0/138)
Asian (Bangladeshi)	0.4% (8/2212)	0.4% (8/2074)	0.0% (0/138)
Asian (Other)	0.5% (12/2212)	0.6% (12/2074)	0.0% (0/138)

Mixed (White and Black Caribbean)	0.5% (12/2212)	0.6% (12/2074)	0.0% (0/138)
Mixed (White and Black African)	0.4% (9/2212)	*	*
Mixed (White and Asian)	0.6% (14/2212)	0.7% (14/2074)	0.0% (0/138)
Mixed (Other)	0.4% (8/2212)	0.4% (8/2074)	0.0% (0/138)
Other (Chinese)	*	*	*
Other (Any other ethnic group)	1.1% (24/2212)	*	*
Prefer not to say	0.5% (11/2212)	0.5% (11/2074)	0.0% (0/138)
Not indicated	64.4% (1425/2212)	65.4% (1356/2074)	50.0% (69/138)
Deprivation			
Most deprived	24.2% (536/2212)	23.9% (496/2074)	29.0% (40/138)
Second most deprived	22.7% (502/2212)	22.8% (472/2074)	21.7% (30/138)
Third least deprived	16.6% (367/2212)	16.8% (348/2074)	13.8% (19/138)
Second least deprived	14.7% (325/2212)	14.8% (306/2074)	13.8% (19/138)
Least deprived	15.3% (338/2212)	15.3% (317/2074)	15.2% (21/138)
Not indicated	6.5% (144/2212)	6.5% (135/2074)	6.5% (9/138)

Figure 6 shows the age and sex of patients in cohort 5. The children and young people's ages are given in whole years, or in months for those under 2 years, giving their age at their first assessment. 3 children and young people in cohort 5 had unknown or unspecified gender.

Of those below 1 year of age at first paediatric assessment, **12.6% (26/206)** had their first paediatric assessment in their first month of life.

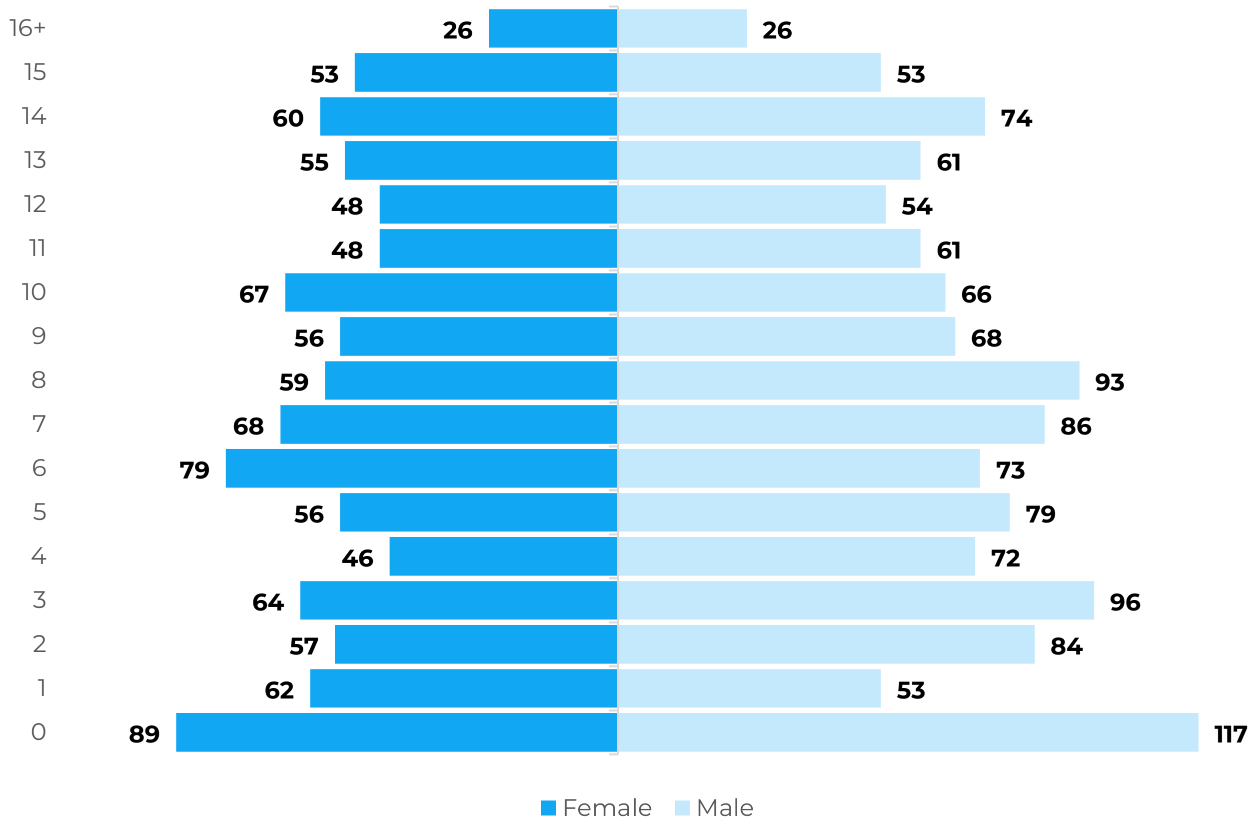


Figure 6 – Distribution of age and sex for children and young people at first paediatric assessment in cohort 5 in England and Wales.

Figure 7 shows that there are a higher proportion of children and young people in cohort 5 who indicated 'White' ethnicity, compared to other ethnicity categories. 'Not Known' ethnicity was indicated in **64%** of children and young people.

- This is the first year that ethnicity data was collected as part of the Epilepsy12 dataset, and the data field was introduced part way through the cohort 5 data collection time period.

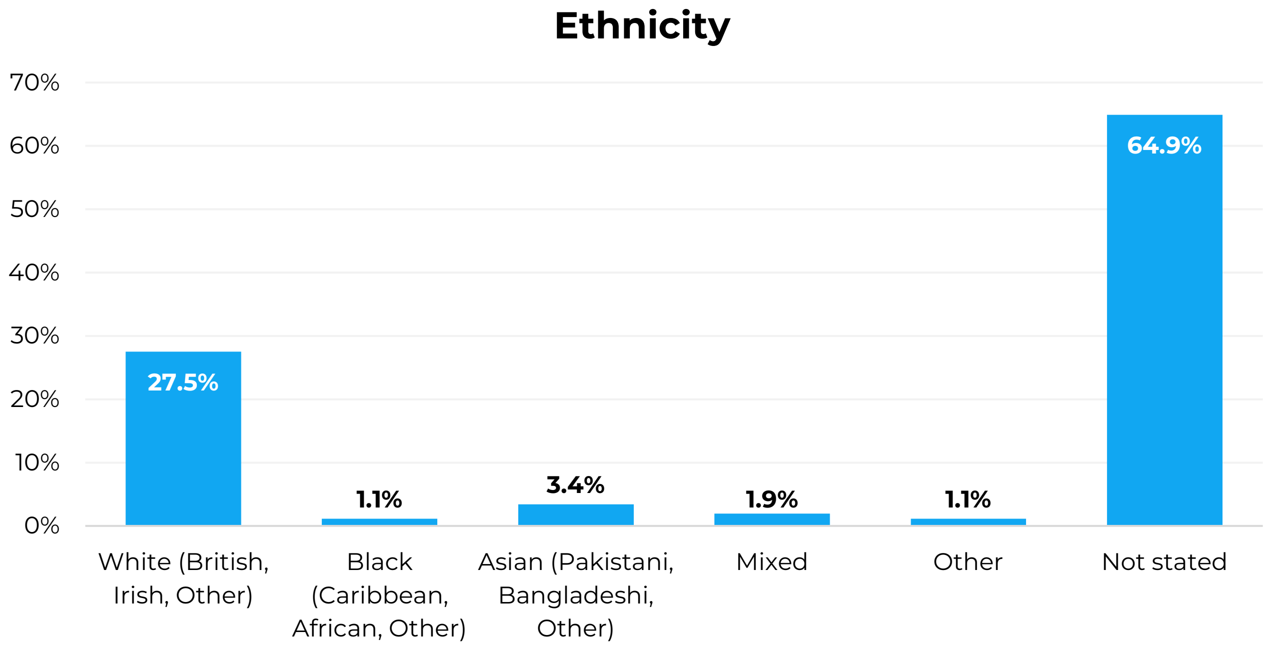


Figure 7 – Distribution of ethnicity for children and young people with epilepsy at first paediatric assessment in cohort 5. Please note that the ethnicity variable was added to the dataset part way through the audit year. Completed registration forms had the ethnicity automatically defaulted to ‘Not Known’.

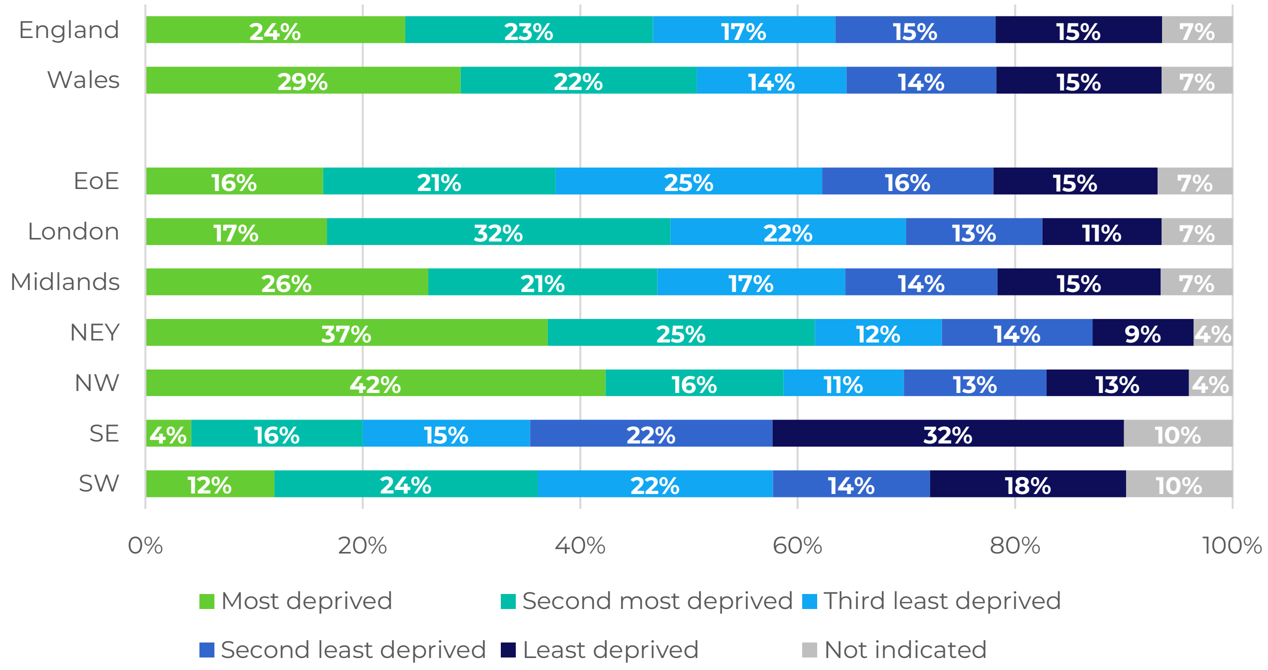


Figure 8 shows that a high proportion of children and young people in cohort 5 are living in areas in the most deprived quintile of England, with wide variation between NHS England regions. This is consistent with Round 4.

Multiaxial diagnosis

This section describes the seizure history (**Table 6**), seizure cause (**Table 7**), electroclinical syndrome (**Table 8**) and epileptic seizure types (**Table 9 and 10**) for children and young people with epilepsy in cohort 5.

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 5, which is consistent with cohorts 1-4.

Table 6: Percentage of children and young people with epilepsy with a family history of epilepsy or previous seizures in cohort 5 in England and Wales.

Prior History	England and Wales	England	Wales
Family history of epilepsy			
Yes	23.1% (510/2212)	23.0% (476/2074)	24.6% (34/138)
No	76.9% (1702/2212)	77.0% (1598/2074)	75.4% (104/138)
Uncertain	0.0% (0/2212)	0.0% (0/2074)	0.0% (0/138)
History of neonatal seizures			
Yes	3.1% (68/2212)	*	*
No	91.5% (2024/2212)	91.2% (1891/2074)	96.4% (133/138)
Uncertain	5.4% (120/2212)	*	*
History of febrile seizures			
Yes	12.1% (268/2212)	*	*
No	82.1% (1816/2212)	81.8% (1696/2074)	87.0% (120/138)
Uncertain	5.8% (128/2212)	*	*
History of acute asymptomatic seizures			
Yes	12.7% (282/2212)	*	*
No	82.7% (1830/2212)	81.9% (1699/2074)	94.9% (131/138)
Uncertain	4.5% (100/2212)	*	*

In cohort 5, **3.6% (79/2212)** of children and young people with epilepsy had a genetic cause of epilepsy indicated, **5.6% (123/2212)** had a structural epilepsy cause, **0.4% (9/2212)** had an infectious cause, **0.5% (11/2212)** had a metabolic cause, and **0.1%** had an immune cause. **12.0% (266/2212)** had their cause recorded as unknown. All epilepsy causes which were recorded for at least one child or young person in cohort 5 are listed in **Table 7**.

Causes that were not indicated for any children and young people with epilepsy in cohort 5 are omitted from this list. A complete list of epilepsy causes within the Epilepsy12 data collection platform can be found in the clinical audit dataset.

Table 7: Percentage of children and young people with epilepsy with each cause recorded in cohort 5 in England and Wales. Note, the total percentages may exceed 100% as more than one cause could be entered per child/young person.

Cause of epilepsy; % (n/N)	England and Wales	England	Wales
Structural	**5.6% (123/2212)**	**5.5% (115/2074)**	**5.8% (8/138)**
Tuberous Sclerosis	8.1% (10/123)	*	*
Sturge Weber	3.3% (4/123)	*	*
Focal cortical dysplasia	9.8% (12/123)	10.4% (12/115)	0.0% (0/8)
Hypothalamic Hamartoma	*	*	*
Low grade tumour	2.4% (3/123)	2.6% (3/115)	0.0% (0/8)
Tumour (other)	6.5% (8/123)	*	*
Malformations of Cortical Development	19.5% (24/123)	*	*
Vascular (eg. Arterial ischaemic stroke, venous ischaemia, cerebral haemorrhage)	27.6% (34/123)	*	*
Traumatic brain injury	9.8% (12/123)	10.4% (12/115)	0.0% (0/8)
Not stated	12.2% (15/123)	*	(
Genetic	**3.6% (79/2212)**	**3.5% (72/2074)**	**5.1% (7/138)**
Dravet Syndrome	*	*	*
Glucose Transporter Defect	0.0% (0/79)	0.0% (0/72)	0.0% (0/7)
Angelman Syndrome	*	*	*
Rett Syndrome	5.1% (4/79)	*	*
Chromosomal Abnormality	22.8% (18/79)	*	*
Gene Abnormality	68.4% (54/79)	68.1% (49/72)	71.4% (5/7)
Infectious	**0.4% (9/2212)**	**0.4% (9/2074)**	**0.0% (0/138)**
Metabolic	**0.5% (11/2212)**	*****	*****
Mitochondrial disorder	*	*	*
Neuronal Ceroid Lipofuscinosis (Batten Disease)	*	*	*
Disorder of pyridoxine/pyridoxal phosphate metabolism	*	*	*
Disorder of biotin metabolism	0.0% (0/11)	0.0% (0/10)	*
Disorder of creatine metabolism	0.0% (0/11)	0.0% (0/10)	*
Disorder of amino acid	0.0% (0/11)	0.0% (0/10)	*
Disorder of urea cycle	0.0% (0/11)	0.0% (0/10)	*
Disorder of pyrimidine and purine	0.0% (0/11)	0.0% (0/10)	*
Disorder of cholesterol	0.0% (0/11)	0.0% (0/10)	*
Other neurometabolic disorder	63.6% (7/11)	60.0% (6/10)	*
Immune	**0.1%**	*****	*****

Rasmussen Encephalitis	*	*	*
Antibody mediated	*	*	*
Not Known	**12.0% (266/2212)**	**12.2% (253/2074)**	**9.4% (13/138)**
Not Recorded	**78.0% (1726/2212)**	**78.0% (1617/2074)**	**79.0% (109/138)**

767 children and young people diagnosed with epilepsy in cohort 5 had an International League Against Epilepsy (ILAE, 2022) classified epilepsy syndrome. This figure excludes records where ‘unclassified syndrome’ or ‘no syndrome indicated’ were selected, as well as records where this question was not answered. ILAE epilepsy syndromes are shown in **Table 8**, where the syndrome was recorded for at least one child or young person in cohort 5.

Table 8: Summary of electroclinical syndromes in children and young people with epilepsy in cohort 5 in England and Wales. Electroclinical syndromes that were not indicated for any children and young people with epilepsy in cohort 5 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	**63.3% (1401/2212)**	**64.2% (1331/2074)**	**50.1% (70/138)**
'Unclassified syndrome'	**2.0% (44/2212)**	**2.0% (41/2074)**	**2.2% (3/138)**
‘ILAE Classified Syndrome	**34.5% (764/2212)**	**33.8% (702/2074)**	**47.1% (65/138)**
(Benign) Childhood epilepsy with centrotemporal spikes (BECTS) (benign Rolandic epilepsy)	5.8% (129/2212)	5.9% (123/2074)	4.3% (6/138)
(Benign) Myoclonic epilepsy in infancy	0.1% (3/2212)	*	*
Autosomal dominant nocturnal frontal lobe epilepsy	*	*	*
Benign familial neonatal seizures	0.1% (3/2212)	0.1% (3/2074)	0.0% (0/138)
Benign infantile seizures	0.1% (3/2212)	0.1% (3/2074)	0.0% (0/138)
Childhood absence epilepsy (CAE)	6.4% (142/2212)	6.0% (125/2074)	12.3% (17/138)
Childhood epilepsy with occipital paroxysms	0.2% (4/2212)	0.2% (4/2074)	0.0% (0/138)
Dravet syndrome (severe myoclonic epilepsy of/in infancy of SMEI)	*	*	*
Early myoclonic encephalopathy	0.2% (4/2212)	0.2% (4/2074)	0.0% (0/138)
Epilepsy with generalised tonic-clonic seizures only (Epilepsy with generalised tonic clonic seizures on awakening)	1.9% (41/2212)	*	*
Epilepsy with myoclonic absences	0.3% (6/2212)	0.3% (6/2074)	0.0% (0/138)
Epilepsy with myoclonic astatic seizures (Doose syndrome) (Myoclonic astatic epilepsy)	0.4% (8/2212)	0.4% (8/2074)	0.0% (0/138)
Eyelid myoclonia with absences	0.3% (6/2212)	0.2% (4/2074)	1.4% (2/138)

Familial focal epilepsy with variable foci	*	*	*
Frontal lobe epilepsy	0.7% (16/2212)	*	*
Generalised epilepsies with febrile seizures plus (FS+)	0.5% (11/2212)	0.5% (11/2074)	0.0% (0/138)
Idiopathic focal epilepsy of childhood	0.9% (21/2212)	1.0% (21/2074)	0.0% (0/138)
Juvenile absence epilepsy (JAE)	3.3% (73/2212)	3.3% (68/2074)	3.6% (5/138)
Juvenile myoclonic epilepsy (JME)	2.9% (64/2212)	2.8% (59/2074)	3.6% (5/138)
Landau-Kleffner syndrome	*	*	*
Lennox-Gastaut syndrome	*	*	*
Occipital lobe epilepsy	0.4% (9/2212)	*	*
Panayiotopoulos syndrome (Early onset (benign) childhood occipital epilepsy)	0.6% (13/2212)	0.6% (13/2074)	0.0% (0/138)
Parietal lobe epilepsy	0.2% (4/2212)	0.2% (4/2074)	0.0% (0/138)
Rasmussen's encephalitis (chronic progressive epilepsia partialis continua) (Kozhevnikov syndrome)	*	*	*
Reflex epilepsies	*	*	*
Temporal lobe epilepsy	1.4% (30/2212)	1.1% (23/2074)	5.1% (7/138)
West syndrome	1.7% (38/2212)	*	*
Other	6.1% (136/2212)	5.8% (121/2074)	10.9% (15/138)

94.8% (2097/2212) of children and young people with epilepsy had an ILAE seizure formulation within the first year of care in cohort 5, defined as having selected an ILAE epileptic seizure classification, including ‘unclassified’ and ‘unknown onset’. Records where only non-epileptic seizures or where it was uncertain in seizures were epileptic are not included in this figure.

95% (2105/2212) of children and young people with epilepsy had only one seizure type, and the most common seizure type recorded was generalised onset (**52.9%**), with the most common presentation being generalised tonic-clonic seizures. **0.6% (13/2212)** of children and young people with epilepsy had non-epileptic seizures, while **7.6% (168/2212)** had seizures of unknown onset.

Table 9: Percentage of children and young people with epilepsy with each seizure type in cohort 5 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; % (n/N)	England and Wales	England	Wales
Number of children and young people with ILAE seizure classification at first year	94.8% (2097/2212)	94.8% (1967/2074)	94.2% (130/138)
Number of seizure onset types (epileptic only)			
1 epileptic seizure types	92.6% (2049/2212)	92.7% (1922/2074)	92.0% (127/138)

2 epileptic seizure types	2.2% (48/2212)	2.2% (45/2074)	2.2% (3/138)
3 or more epileptic seizure types	0.0% (0/2212)	0.0% (0/2074)	0.0% (0/138)
Focal onset	**33.4% (738/2212)**	**33.1% (686/2074)**	**37.7% (52/138)**
Laterality	**27.0% (199/738)**	**27.4% (188/686)**	**21.2% (11/52)**
Left	13.7% (101/738)	13.8% (95/686)	11.5% (6/52)
Right	14.4% (106/738)	14.7% (101/686)	9.6% (5/52)
Motor manifestations	**53.4% (394/738)**	**52.3% (359/686)**	**67.3% (35/52)**
Atonic	2.8% (21/738)	*	*
Clonic	14.4% (106/738)	14.7% (101/686)	9.6% (5/52)
Spasms	*	*	*
Hyperkinetic	*	*	*
Myoclonic	2.4% (18/738)	2.6% (18/686)	0.0% (0/52)
Tonic	13.4% (99/738)	13.6% (93/686)	11.5% (6/52)
Focal to bilateral tonic-clonic	30.9% (228/738)	29.4% (202/686)	50.0% (26/52)
Non-motor manifestations	**45.8% (338/738)**	**45.9% (315/686)**	**44.2% (23/52)**
Automatisms	7.7% (57/738)	*	*
Impaired Awareness	39.4% (291/738)	39.4% (270/686)	40.4% (21/52)
Gelastic	*	*	*
Autonomic	4.2% (31/738)	4.2% (29/686)	3.8% (2/52)
Behavioural Arrest	10.2% (75/738)	10.3% (71/686)	7.7% (4/52)
Cognitive	1.4% (10/738)	1.5% (10/686)	0.0% (0/52)
Emotional	*	*	*
Sensory	3.9% (29/738)	3.8% (26/686)	5.8% (3/52)
EEG Findings	**27.2% (201/738)**	**27.3% (187/686)**	**26.9% (14/52)**
Centrotemporal	11.0% (81/738)	11.1% (76/686)	9.6% (5/52)
Temporal	8.3% (61/738)	8.0% (55/686)	11.5% (6/52)
Frontal	4.3% (32/738)	*	*
Parietal	1.6% (12/738)	*	*
Occipital	4.3% (32/738)	*	*
Other	**4.2% (31/738)**	*****	*****
Generalised Onset	**52.9% (1170/2212)**	**52.8% (1096/2074)**	**53.6% (74/138)**
Tonic-clonic	56.7% (663/1170)	57.2% (627/1096)	50.0% (37/74)
Clonic	*	*	*
Tonic	2.8% (33/1170)	2.7% (30/1096)	4.1% (3/74)
Myoclonic	7.2% (84/1170)	7.0% (77/1096)	9.5% (7/74)
Myoclonic-tonic-clonic	1.3% (15/1170)	1.4% (15/1096)	0.0% (0/74)
Myoclonic-atonic	0.9% (11/1170)	1.0% (11/1096)	0.0% (0/74)
Atonic	*	*	*
Epileptic Spasms	3.6% (42/1170)	3.6% (39/1096)	4.1% (3/74)
Typical absence	27.4% (321/1170)	27.2% (298/1096)	31.1% (23/74)
Atypical absence	5.6% (66/1170)	*	*
Myoclonic absence	0.9% (10/1170)	0.9% (10/1096)	0.0% (0/74)
Absence with eyelid myoclonia	1.5% (17/1170)	*	*
Other	1.6% (19/1170)	*	*
Unknown epileptic onset	**7.6% (168/2212)**	**7.8% (161/2074)**	**5.1% (7/138)**
Tonic-clonic	58.9% (99/168)	59.6% (96/161)	42.9% (3/7)

Epileptic spasms	9.5% (16/168)	*	*
Behaviour arrest	21.4% (36/168)	*	*
Other	13.7% (23/168)	14.3% (23/161)	0.0% (0/7)
Unclassified epileptic onset	**3.1% (69/2212)**	**3.3% (69/2074)**	**0.0% (0/138)**
Non-epileptic onset	**0.6% (13/2212)**	**0.6% (13/2074)**	**0.0% (0/0)**
Syncope and anoxic seizures	*	*	*
Behavioural, psychological and psychiatric disorders	30.1% (4/13)	30.1% (4/13)	0.0% (0/0)
Sleep related conditions	0.0% (0/13)	0.0% (0/13)	0.0% (0/0)
Paroxysmal movement disorders	*	*	*
Migraine associated disorders	0.0% (0/13)	0.0% (0/13)	0.0% (0/0)
Miscellaneous events	0.0% (0/13)	0.0% (0/13)	0.0% (0/0)
Other	53.8% (7/13)	53.8% (7/13)	0.0% (0/0)
Uncertain onset	**6.0% (132/2212)**	**5.9% (123/2074)**	**6.5% (9/138)**

Figure 9 shows that the percentage of children and young people in England and Wales with generalised seizures has increased between cohort 1 and cohort 5.

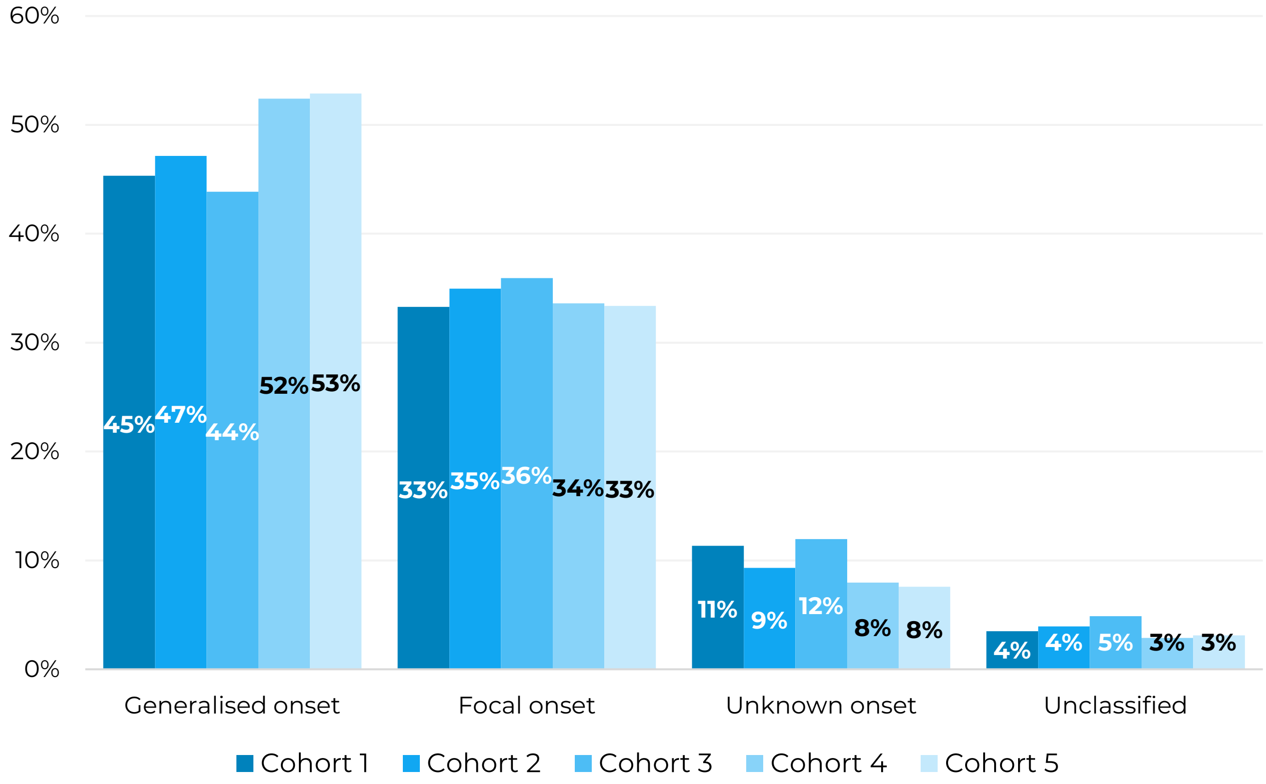


Figure 9: Percentage of children and young people with epilepsy with each seizure type, by cohort in Round 3 and 4.

In Round 4 cohort 5, **64.9% (1436/2212)** of children and young people with epilepsy had convulsive seizures, and **35.1% (776/2212)** did not have convulsive seizures. This is consistent with previous cohorts.

18.4% (408/2212) had prolonged generalised seizures and **10.1% (223/2212)** 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 an increase compared to **15.7% (364/2322)** and **9.6% (223/2322)** respectively in cohort 4.

Table 10: Percentage of children and young people with epilepsy with convulsive and prolonged seizures in cohort 5 in England and Wales.

	England and Wales	England	Wales
Convulsive seizures	**64.9% (1436/2212)**	**65.0% (1349/2074)**	**63.0% (87/138)**
Prolonged generalised convulsive seizures			
Yes	18.4% (408/2212)	*	*
No	77.7% (1718/2212)	77.5% (1608/2074)	79.7% (110/138)
Uncertain	3.9% (86/2212)	*	*
Prolonged focal convulsive seizures			
Yes	10.1% (223/2212)	*	*
No	85.2% (1884/2212)	85.2% (1767/2074)	84.8% (117/138)
Uncertain	4.7% (105/2212)	*	*

Mental health and neurodisability

Table 11 describes information collected around the neurodevelopmental conditions/learning disabilities and mental health conditions for children and young people with epilepsy in cohort 5.

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 11: Percentage of children and young people with epilepsy with neurodevelopmental conditions/learning disabilities and mental health conditions in cohort 5 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 conditions	**22.9% (506/2212)**	**23.1% (480/2074)**	**18.8% (26/138)**
Autistic Spectrum Disorder	9.4% (209/2212)	9.5% (197/2074)	8.7% (12/138)
Cerebral Palsy	2.2% (49/2212)	2.1% (44/2074)	3.6% (5/138)
Neurodegenerative disease or condition	0.4% (8/2212)	*	*
An identified chromosomal disorder with a neurological or developmental component	1.6% (35/2212)	*	*
Attention deficit hyperactivity disorder	2.3% (50/2212)	2.2% (46/2074)	2.9% (4/138)
Intellectual disability/global developmental delay/'learning disability'	**6.8% (151/2212)**	**6.9% (143/2074)**	**5.8% (8/138)**
Mild	23.8% (36/151)	*	*
Moderate	45.7% (69/151)	46.2% (66/143)	37.5% (3/8)
Profound	5.3% (8/151)	*	*
Severe	25.2% (38/151)	24.5% (35/143)	37.5% (3/8)
Dyspraxia	0.1% (3/2212)	0.1% (3/2074)	0.0% (0/138)
Dyslexia	0.4% (9/2212)	0.4% (9/2074)	0.0% (0/138)
Speech disorder	1.3% (28/2212)	*	*
Other learning difficulty	2.4% (54/2212)	*	*
Diagnosed mental health condition	**6.1% (135/2212)**	**6.2% (128/2074)**	**5.1% (7/138)**
Anxiety disorder	2.5% (56/2212)	*	*
Emotional/behavioural	0.7% (15/2212)	0.7% (15/2074)	0.0% (0/138)
Mood disorder	0.7% (15/2212)	*	*
Self-harm	0.2% (4/2212)	0.2% (4/2074)	0.0% (0/138)
Other	1.6% (36/2212)	1.6% (33/2074)	2.2% (3/138)
Not stated	0.7% (15/2212)	*	*

6.8% (151/2212) of children and young people with epilepsy in cohort 5 had an intellectual disability/global developmental delay/learning disability indicated, which is an increase from **6.4% (149/2324)** in cohort 4.

5.6% (123/2212) of children and young people with epilepsy had an identified mental health condition recorded in cohort 5, which is comparable to **5.1% (119/2324)** in cohort 4. **Figure 10** shows the increase in the percentage of children and young people with epilepsy with a diagnosed mental health condition between Round 3, cohort 1 and Round 4, cohort 5.

The responses that were entered when the 'other' diagnosed mental health condition option was selected are included below:

- Challenging Behaviour
- ?ASD/ADHD
- Patient has ASD with high anxiety
- temper tantrums, isolated sleep problems
- eating disorder
- anxiety
- suffered with sleep paralysis drug involvement multiple family issues
- Challenging behaviour
- Unhappiness with way school managing her seizures
- undergoing assessment, history of self harm, non-compliance, oppositional defiance
- Anorexia nervosa
- Eating disorder
- eating disorder
- asd
- ASD
- Possible eating disorder, awaiting CAMHS referral- referred by primary care
- Symptoms of traumatic anxiety Low mood
- Challenging behaviour
- Possible Autism
- Gender dysphoria
- ASD
- disordered eating
- Food refusal- eating disorder team involved
- Autism
- Autism ADHD Behavioural problems and school exclusion
- low mood
- Autism and challenging behaviour
- has LD , autism and adhd
- waiting for assessment of ADHD
- pathological demand avoidance
- anxiety, low mood, dysregulation, non-verbal, displays of physical behaviours
- Anxiety related to autism
- Autism spectrum disorder
- ADHD
- Anorexia Nervosa
- OCD
- ADD

- Emotional dysregulation
- suicidal ideation

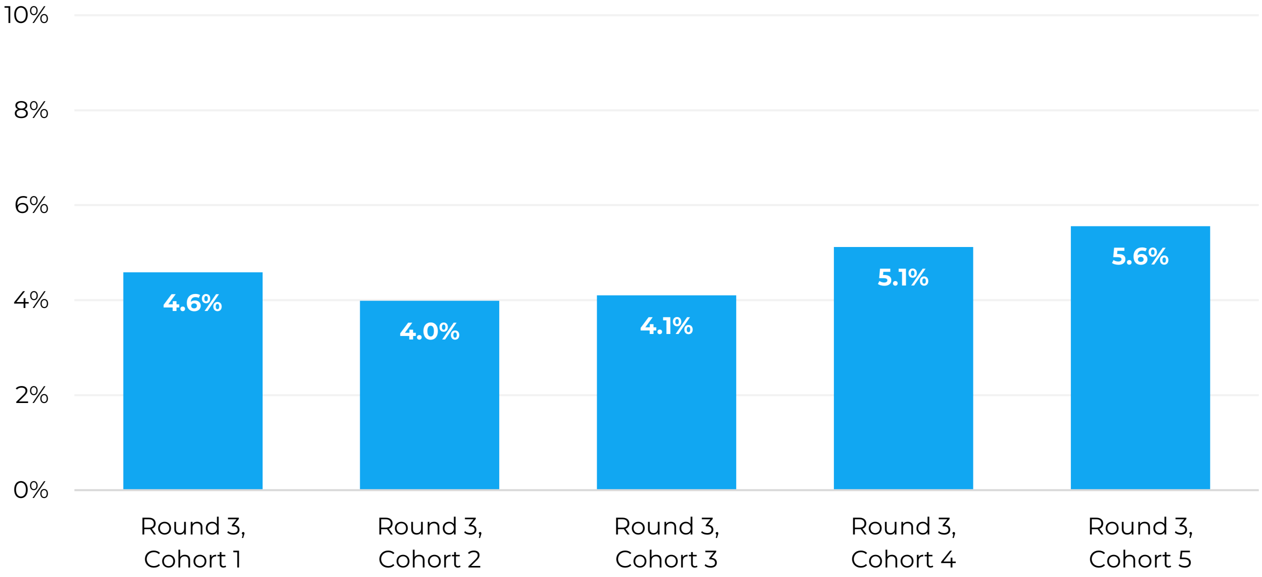


Figure 10: Percentage of children and young people with epilepsy with a mental health condition between cohort 1 and cohort 5.

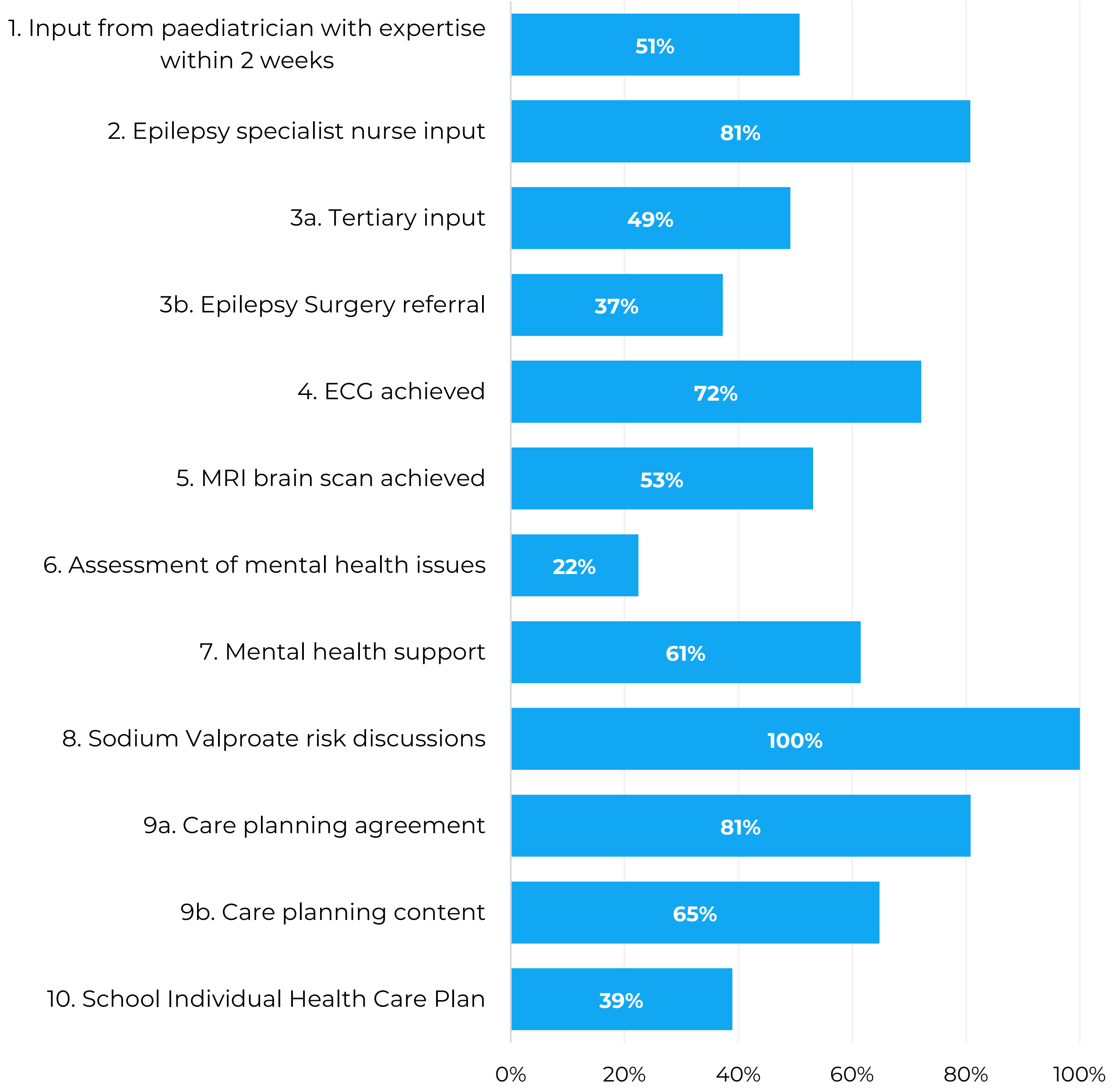
8.7% (128/1472) of children and young people with epilepsy and aged 5 years and older also had an identified mental health condition(s) by their first year of care in England and Wales in cohort 5.

Key Performance Indicators

In cohort 5, 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 5 national and regional performance data for each of the 10 KPIs in turn, including the variation in care between demographic population groups. As before, this section only includes the **2212 children and young people with a confirmed new epilepsy diagnosis** and a submitted first year of care form before the specified download date of 18 January 2024.

Figure 11 shows an overview of the 10 Epilepsy12 KPIs for England and Wales combined in Round 4, cohort 5.



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

Percentage of children and young people with epilepsy, with input from a 'paediatrician with expertise in epilepsies' within two weeks of referral. *The two-week timeframe was added to this KPI for cohort 5.

> *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.*

50.8% (1123/2212) of children and young people with epilepsy received input by a 'consultant paediatrician with expertise in epilepsies' within two weeks of referral. The 2-week timeframe was introduced to the KPI this year, and includes children and young people with input prior to their first paediatric assessment. This indicator ranged from **0.0%** to **100.0%,** with an interquartile range of **33.3%** to **69.7%**.

91.6% (2077/2212) of children and young people with epilepsy received input by a 'consultant paediatrician with expertise in epilepsies' within the first year of care. This was an increase, compared to **90.7% (2107/2324)** in cohort 4.

Table 12 shows how timely access to a paediatrician with expertise is distributed between demographic population groups and **Table 13** shows the variation in access to a paediatric)ian with expertise between England and Wales and across NHSE and OPEN UK regions. **Table 14** describes the time in weeks to achieving input from a paediatrician with expertise in epilepsy from first referral for all children and young people with epilepsy in cohort 5.

Table 12: Percentage of children and young people with epilepsy with input by a 'consultant paediatrician with expertise in epilepsies' within two weeks from referral by demographic.

Demographic Variables	England and Wales	England	Wales
Total	**50.8% (1123/2212)**	**50.4% (1045/2074)**	**56.2% (78/138)**
Age			
< 2 years	55.8% (179/321)	*	*
2 – 4 years	48.0% (201/419)	47.8% (184/385)	50.0% (17/34)
5 – 11 years	50.9% (488/959)	50.4% (457/907)	59.6% (31/52)
12 – 15 years	48.3% (222/460)	47.7% (203/426)	55.9% (19/34)
16+ years	62.3% (33/53)	*	*
Sex			
Female	52.1% (517/993)	52.1% (487/934)	50.8% (30/59)
Male	49.6% (603/1216)	48.8% (555/1137)	60.8% (48/79)
Not indicated	100.0% (3/3)	100.0% (3/3)	N/A
Ethnicity			
Asian	45.3% (34/75)	45.3% (34/75)	N/A
Black	52.0% (13/25)	52.0% (13/25)	N/A

Mixed	58.1% (25/43)	*	*
White	51.2% (311/608)	48.4% (262/541)	73.1% (49/67)
Other	40.0% (10/25)	*	*
Not indicated	50.8% (730/1436)	51.4% (703/1367)	39.1% (27/69)
Deprivation			
Most deprived	52.4% (281/536)	51.2% (254/496)	67.5% (27/40)
Second most deprived	48.4% (243/502)	48.1% (227/472)	53.3% (16/30)
Third least deprived	46.9% (172/367)	47.7% (166/348)	31.6% (6/19)
Second least deprived	47.4% (154/325)	46.7% (143/306)	57.9% (11/19)
Least deprived	56.5% (191/338)	56.8% (180/317)	52.4% (11/21)
Not indicated	56.9% (82/144)	55.6% (75/135)	77.8% (7/9)

Table 13: Percentage of children and young people with epilepsy with input 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 combined	**50.8% (1123/2212)**
Country	
England	50.4% (1045/2074)
Wales	56.5% (78/138)
NHS England Region	
East of England	60.4% (96/159)
London	51.4% (197/383)
Midlands	44.4% (162/365)
North East and Yorkshire	53.2% (223/419)
North West	55.4% (163/294)
South East	44.2% (115/260)
South West	45.9% (89/194)
OPEN UK Region	
BRPNF	62.4% (63/101)
CEWT	27.8% (35/126)
EPEN	60.1% (95/158)
EPIC	60.2% (100/166)
NTPEN	52.9% (139/263)
NWEIG	50.9% (109/214)
ORENG	47.2% (84/178)
PENNEC	56.9% (82/144)
SETPEG	35.3% (42/119)
SWEP	59.5% (66/111)
SWIPE	55.3% (57/103)

SWPEG	47.2% (84/178)
TEN	45.2% (52/115)
WPNN	34.4% (22/64)
YPEN	54.1% (93/172)

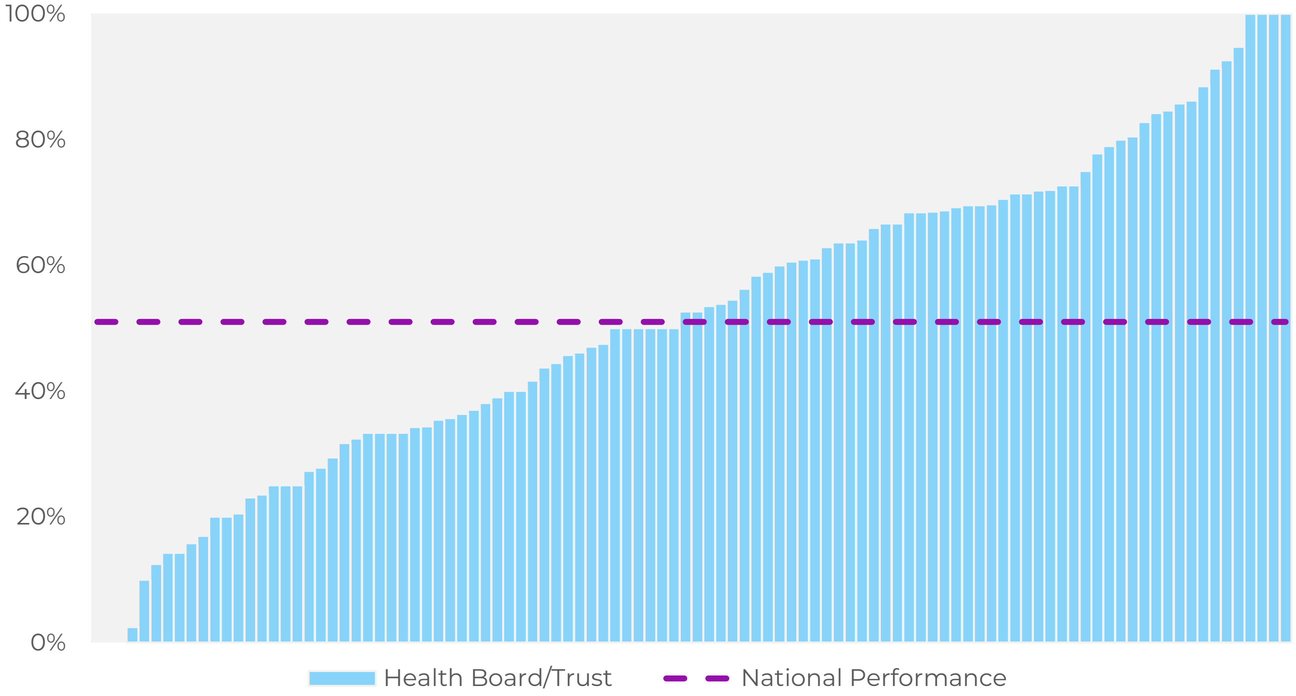


Figure 12: Paediatrician with expertise in epilepsies by Health Board and Trust, cohort 5. Each participating Health Board or Trust is represented by a vertical bar in the order of the percentage score, including those scoring 0% in this graph.

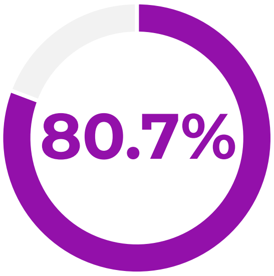
In cohort 5, **21.8%** of children and young people with epilepsy waited more than 16 weeks for input from a paediatrician with expertise.

Table 14: Time in weeks to achieving input from a paediatrician with expertise in epilepsy since first referral for children and young people with epilepsy in cohort 5.

Time in weeks	England and Wales	England	Wales
<2 weeks	50.8% (1123/2212)	50.4% (1045/2074)	56.5% (78/138)
2 – 4 weeks	5.5% (121/2212)	5.6% (116/2074)	3.6% (5/138)
4 – 8 weeks	10.3% (227/2212)	10.3% (213/2074)	10.1% (14/138)
8 – 12 weeks	7.0% (154/2212)	7.0% (145/2074)	6.5% (9/138)
12 – 16 weeks	4.8% (106/2212)	4.8% (100/2074)	4.3% (6/138)
16+ weeks	15.4% (340/2212)	15.5% (321/2074)	13.8% (19/138)
Input not achieved	6.4% (141/2212)	6.5% (134/2074)	5.1% (7/138)

2. Epilepsy Specialist Nurse

Percentage of children with epilepsy with input by an epilepsy specialist nurse by first year.



> *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.*

80.7% (1786/2212) of children and young people with epilepsy received input by an epilepsy specialist nurse within the first year of care. This was an increase compared to **77.2% (1793/2324)** in cohort 4. This indicator ranged from **0.0%** to **100.0%**, with an interquartile range of **75.0%** to **96.9%**.

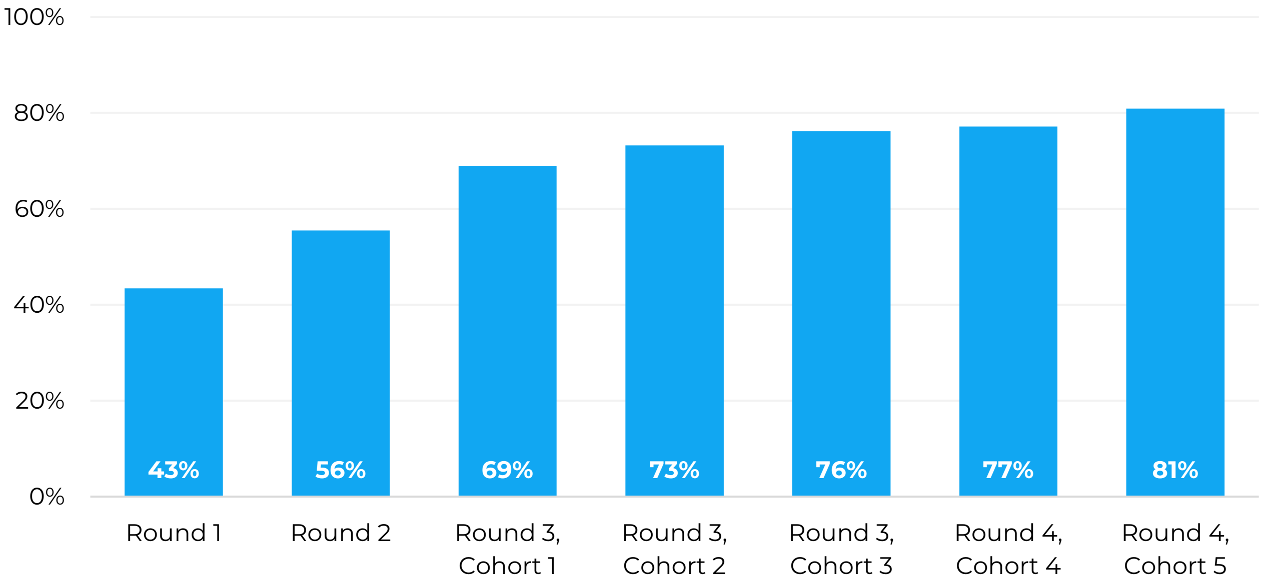


Figure 13: Epilepsy specialist nurse input for Rounds 3 and 4.

Table 15 describes epilepsy specialist nurse input over time in Rounds 3 and 4. **Table 16** shows how epilepsy specialist nurse input is distributed between demographic population groups and **Table 17** shows the variation in epilepsy specialist nurse input between England and Wales and across NHSE and OPEN UK regions.

Table 15: The percentage of children and young people with epilepsy who received input from 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)**

Table 16: Percentage of children and young people with epilepsy with input by an epilepsy specialist nurse within the first year of care by demographic.

Demographic Variables	England and Wales	England	Wales
Total	**80.7% (1786/2212)**	**80.3% (1665/2074)**	**87.7% (121/138)**
Age			
< 2 years	77.6% (249/321)	*	*
2 – 4 years	77.3% (324/419)	76.9% (296/385)	82.4% (28/34)
5 – 11 years	82.5% (791/959)	82.0% (744/907)	90.4% (47/52)
12 – 15 years	82.0% (377/460)	81.0% (345/426)	94.1% (32/34)
16+ years	84.9% (45/53)	*	*
Sex			
Female	79.2% (786/993)	78.7% (735/934)	86.4% (51/59)
Male	82.0% (997/1216)	81.5% (927/1137)	88.6% (70/79)
Not Indicated	100.0% (3/3)	100.0% (3/3)	N/A
Ethnicity			
Asian	74.7% (56/75)	74.7% (56/75)	N/A
Black	72.0% (18/25)	72.0% (18/25)	N/A
Mixed	88.4% (38/43)	*	*
White	82.9% (504/608)	82.4% (446/541)	86.6% (58/67)
Other	72.0% (18/25)	*	*
Not Indicated	80.2% (1152/1436)	79.8% (1091/1367)	88.4% (61/69)
Deprivation			
Most deprived	83.0% (445/536)	82.1% (407/496)	95.0% (38/40)
Second most deprived	78.5% (394/502)	78.4% (370/472)	80.0% (24/30)
Third least deprived	78.5% (288/367)	78.2% (272/348)	84.2% (16/19)
Second least deprived	81.8% (266/325)	82.0% (251/306)	78.9% (15/19)
Least deprived	83.4% (282/338)	82.6% (262/317)	95.2% (20/21)
Not indicated	77.1% (111/144)	76.3% (103/135)	88.9% (8/9)

Table 17: Percentage of children and young people with epilepsy with input by an epilepsy specialist nurse within the first year of care by region.

Geographic Region	KPI 2. Epilepsy Specialist Nurse input
England and Wales combined	**80.7% (1786/2212)**
Country	
England	80.3% (1665/2074)
Wales	87.7% (121/138)

NHS England Region	
East of England	91.2% (145/159)
London	76.0% (291/383)
Midlands	71.2% (260/365)
North East and Yorkshire	86.6% (363/419)
North West	84.4% (248/294)
South East	72.7% (189/260)
South West	87.1% (169/194)
OPEN UK Region	
BRPNF	76.2% (77/101)
CEWT	46.0% (58/126)
EPEN	91.1% (144/158)
EPIC	93.4% (155/166)
NTPEN	70.7% (186/263)
NWEIG	80.8% (173/214)
ORENG	72.5% (129/178)
PENNEC	76.4% (110/144)
SETPEG	86.6% (103/119)
SWEP	87.4% (97/111)
SWIPE	85.4% (88/103)
SWPEG	83.7% (149/178)
TEN	89.6% (103/115)
WPNN	82.8% (53/64)
YPEN	93.6% (161/172)

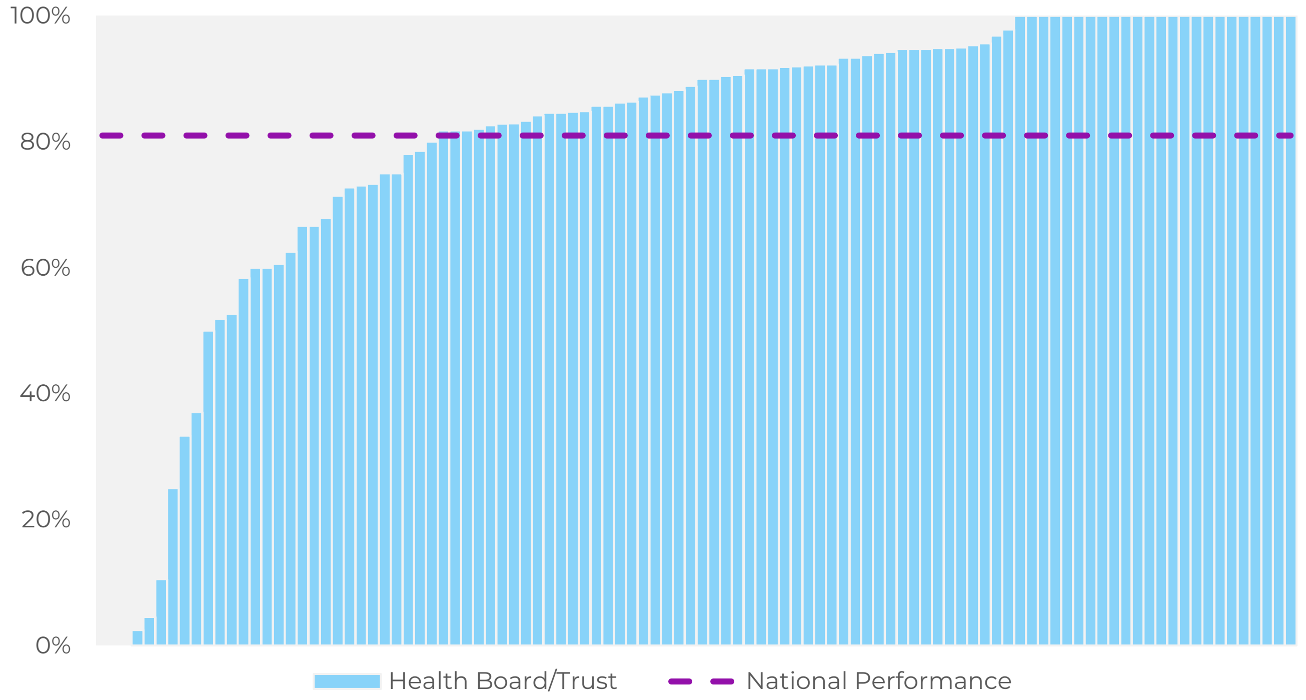
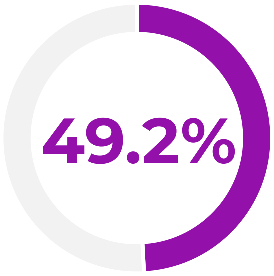


Figure 14: Epilepsy specialist nurse input by Health Board and Trust, cohort 5. Each participating Health Board or Trust is represented by a vertical bar in the order of the percentage score, including those scoring 0% in this graph.

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 by their first year.



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

49.2% (291/592) 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 indicator ranged from **0.0%** to **100.0%**, with an interquartile range of **28.6%** to **72.7%**. The criteria for tertiary input were updated in cohort 5 to include children with myoclonus and under 4 years of age at first paediatric assessment, aligning with the updated NICE guidelines.

Of the 291 children and young people who received tertiary input, **3.4% (10/291)** had a CESS referral by first year, **84.9% (247/291)** had paediatric neurology input by first year, and **11.7% (34/291)** had both.

Table 18 shows how tertiary input is distributed between demographic population groups and **Table 19** shows the variation in tertiary input between England and Wales and across NHSE and OPEN UK regions. **Table 20** shows the timeliness of paediatric neurologist input.

Table 18: Percentage of children and young people with epilepsy meeting defined criteria for paediatric neurology referral, with input of tertiary care and/or CESS referral by first year by demographic.

Demographic Variables	England and Wales	England	Wales
Total	**49.2% (291/592)**	**48.9% (272/556)**	**52.8% (19/36)**
Age			
< 2 years	58.6% (188/321)	57.6% (175/304)	76.5% (13/17)
2 – 4 years	34.1% (62/182)	33.9% (57/168)	35.7% (5/14)
5 – 11 years	44.4% (28/63)	*	*
12 – 15 years	56.5% (13/23)	*	*
16+ years	0.0% (0/3)	0.0% (0/3)	N/A
Sex			
Female	50.0% (135/270)	49.8% (126/253)	52.9% (9/17)
Male	48.4% (156/322)	48.2% (146/303)	52.6% (10/19)
Not Indicated	N/A	N/A	N/A
Ethnicity			
Asian	41.2% (7/17)	41.2% (7/17)	N/A
Black	60.0% (3/5)	60.0% (3/5)	N/A
Mixed	30.8% (4/13)	30.8% (4/13)	N/A
White	39.9% (73/183)	39.8% (66/166)	41.2% (7/17)

Other	57.1% (4/7)	57.1% (4/7)	N/A
Not Indicated	54.5% (200/367)	54.0% (188/348)	63.2% (12/19)
Deprivation			
Most deprived	42.1% (64/152)	40.4% (57/141)	63.6% (7/11)
Second most deprived	42.6% (60/141)	41.7% (55/132)	55.6% (5/9)
Third least deprived	55.6% (60/108)	56.0% (56/100)	50.0% (4/8)
Second least deprived	49.3% (36/73)	*	*
Least deprived	60.3% (44/73)	*	*
Not indicated	60.0% (27/45)	65.9% (27/41)	0.0% (0/4)

Table 19: Percentage of children and young people with epilepsy meeting defined criteria for paediatric neurology referral, with input of tertiary care and/or CESS referral by first year by region.

Geographic Region	KPI 3a. Tertiary Input
England and Wales	**49.2% (291/592)**
Country	
England	48.9% (272/556)
Wales	52.8% (19/36)
NHS England Region	
East of England	43.2% (19/44)
London	53.6% (45/84)
Midlands	44.3% (43/97)
North East and Yorkshire	53.4% (62/116)
North West	46.2% (37/80)
South East	55.0% (44/80)
South West	40.0% (22/55)
OPEN UK Region	
BRPNF	41.4% (12/29)
CEWT	48.3% (14/29)
EPEN	43.2% (19/44)
EPIC	46.8% (22/47)
NTPEN	45.3% (24/53)
NWEIG	43.1% (25/58)
ORENG	55.8% (29/52)
PENNEC	53.8% (28/52)
SETPEG	66.7% (20/30)
SWEP	55.6% (15/27)
SWIPE	37.5% (12/32)
SWPEG	48.1% (26/54)
TEN	55.6% (15/27)

WPNN	55.6% (10/18)
YPEN	50.0% (20/40)

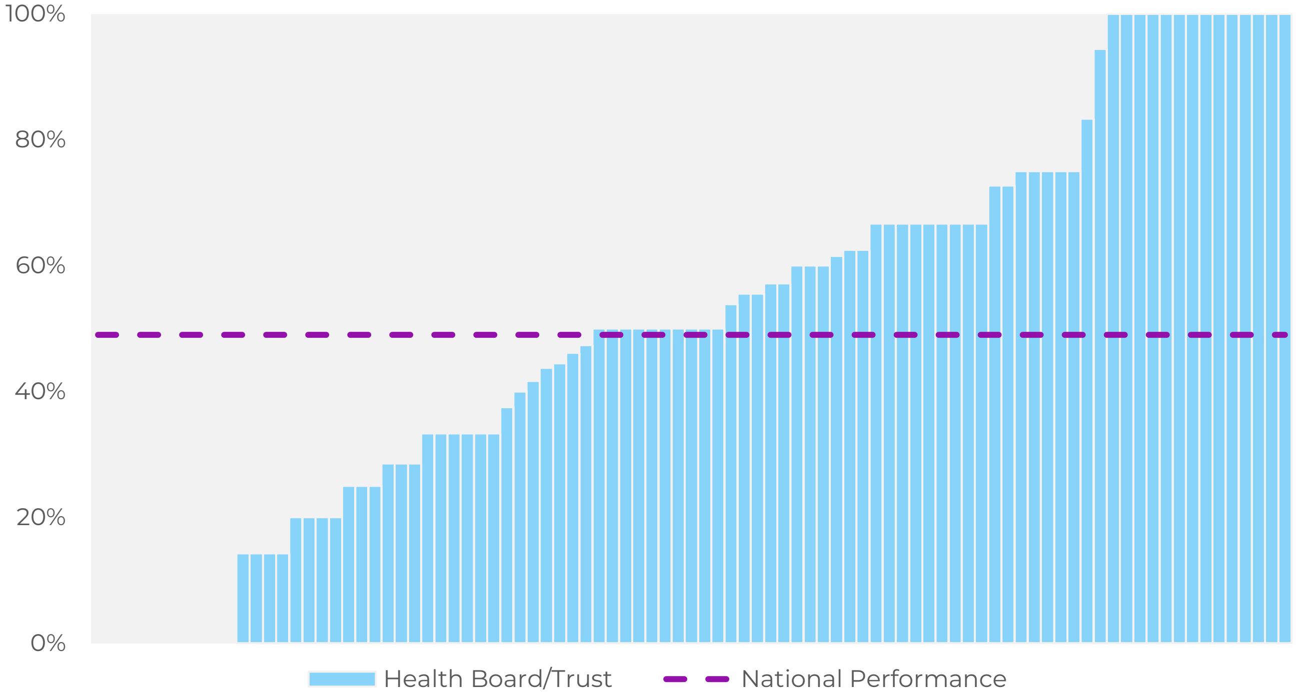
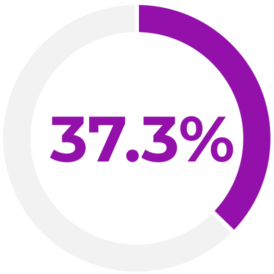


Figure 15: Tertiary input by Health Board and Trust, cohort 5. Each participating Health Board or Trust is represented by a vertical bar in the order of the percentage score, including those scoring 0% in this graph.

Table 20: Time in months to achieving input from a paediatric neurologist, since first referral, of the **281** 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	52.7% (148/281)	52.9% (139/263)	50.0% (9/18)
2 – 4 months	19.2% (54/281)	*	*
4 – 6 months	10.3% (29/281)	9.9% (26/263)	16.7% (3/18)
6 – 8 months	7.5% (21/281)	8.0% (21/263)	0.0% (0/18)
8 – 10 months	5.0% (14/281)	4.2% (11/263)	16.7% (3/18)
10 – 12 months	5.3% (15/281)	*	*

3b. Epilepsy Surgery Referral



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

37.3% (41/110) of children and young people with epilepsy meeting CESS referral criteria had evidence of CESS referral within the first year of care. This was an increase, compared to **33.1% (39/118)** in cohort 4. This indicator ranged from **0.0%** to **100.0%**, with an interquartile range of **0.0%** to **50.0%**.

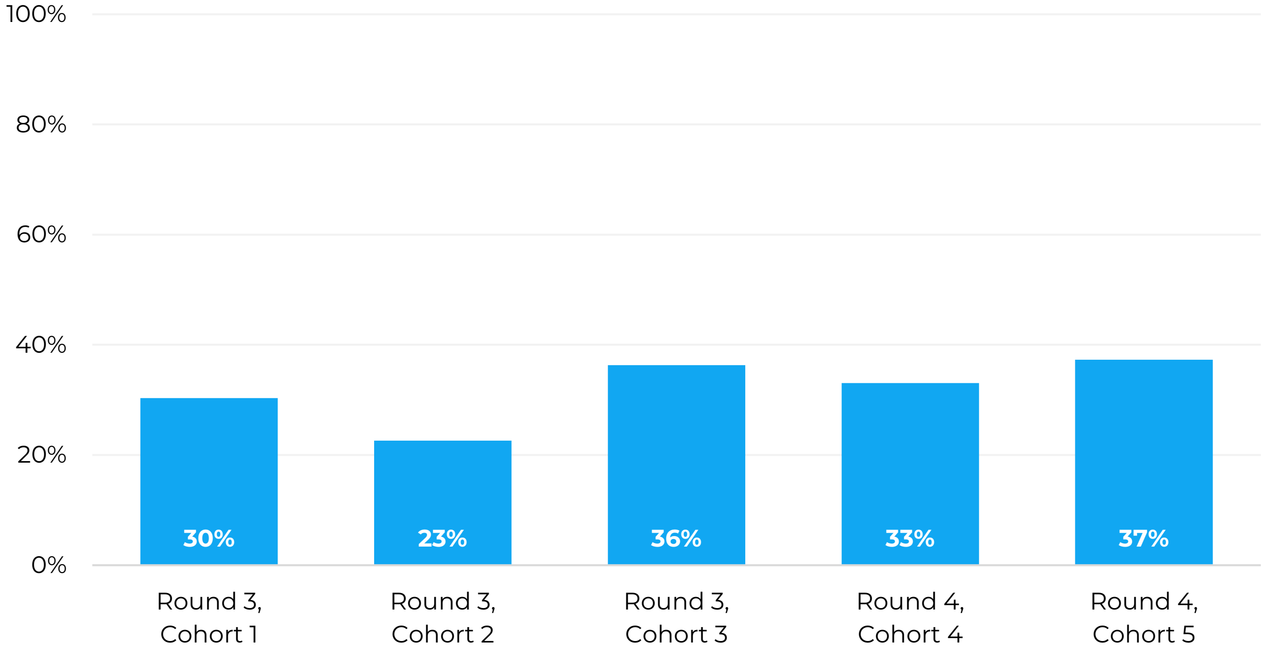


Figure 16: Epilepsy surgery referral in Rounds 3 and 4.

Table 21 shows epilepsy surgery referral over time in Rounds 3 and 4. **Table 22** shows how epilepsy surgery referrals are distributed between demographic population groups and **Table 23** shows the variation in epilepsy surgery referrals between England and Wales and across NHSE and OPEN UK regions.

Table 21: 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)	0% (0/2)
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)**	**28.6% (2/7)**

Table 22: 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
Total	**37.3% (41/110)**	**37.9% (39/103)**	**28.6% (2/7)**
Age			
< 2 years	31.8% (14/44)	*	*
2 – 4 years	*	*	*
5 – 11 years	48.1% (13/27)	48.1% (13/27)	N/A
12 – 15 years	60.0% (9/15)	*	*
16+ years	*	*	N/A
Sex			
Female	39.6% (19/48)	*	*
Male	35.5% (22/62)	*	*
Not Indicated	N/A	N/A	N/A
Ethnicity			
Asian	*	*	N/A
Black	*	*	N/A
Mixed	*	*	N/A
White	30.6% (11/36)	31.2% (10/32)	25.0% (1/4)
Other	*	*	N/A
Not Indicated	40.3% (25/62)	40.7% (24/59)	33.3% (1/3)
Deprivation			
Most deprived	13.0% (3/23)	15.8% (3/19)	0.0% (0/4)
Second most deprived	30.8% (8/26)	*	*
Third least deprived	59.1% (13/22)	*	*
Second least deprived	31.2% (5/16)	31.2% (5/16)	N/A
Least deprived	53.3% (8/15)	53.3% (8/15)	N/A
Not Indicated	50.0% (4/8)	50.0% (4/8)	N/A

Table 23: 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	**37.3% (41/110)**
Country	
England	37.9% (39/103)
Wales	*
NHS England Region	
East of England	66.7% (4/6)
London	46.7% (7/15)
Midlands	29.2% (7/24)

North East and Yorkshire	30.8% (4/13)
North West	40.0% (8/20)
South East	30.8% (4/13)
South West	41.7% (5/12)
OPEN UK Region	
BRPNF	37.5% (3/8)
CEWT	28.6% (2/7)
EPEN	66.7% (4/6)
EPIC	45.5% (5/11)
NTPEN	44.4% (4/9)
NWEIG	31.2% (5/16)
ORENG	57.1% (4/7)
PENNEC	50.0% (3/6)
SETPEG	44.4% (4/9)
SWEP	0.0% (0/4)
SWIPE	42.9% (3/7)
SWPEG	28.6% (2/7)
TEN	0.0% (0/3)
WPNN	20.0% (1/5)
YPEN	20.0% (1/5)

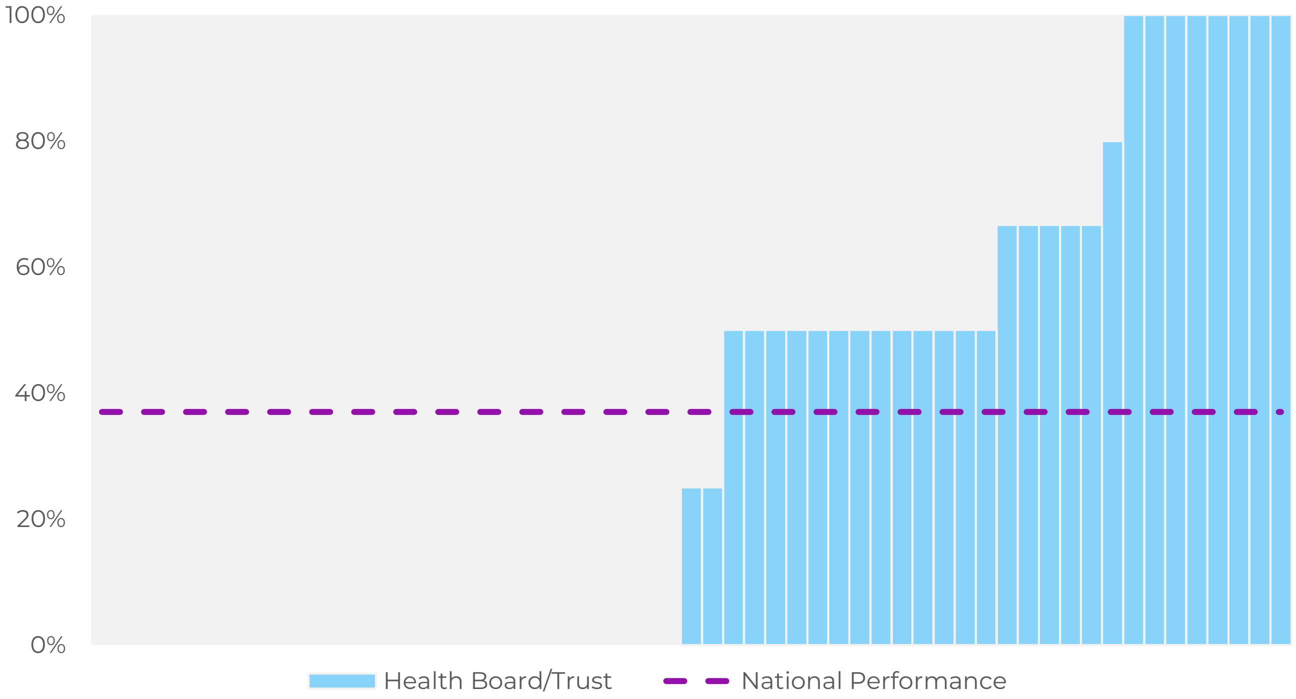
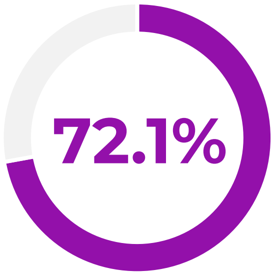


Figure 17: Epilepsy surgery referral by Health Board and Trust, cohort 5. Each participating Health Board or Trust is represented by a vertical bar in the order of the percentage score, including those scoring 0% in this graph.

4. ECG

Percentage of children and young people with convulsive seizures and epilepsy, with an ECG at first year.



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.

72.1% (1036/1436) of children and young people with epilepsy and convulsive seizures had an ECG within the first year of care in cohort 5. This was an increase compared to **69.6% (996/1431)** in cohort 4. This indicator ranged from **0.0%** to **100.0%**, with an interquartile range of **61.6%** to **90.0%**.

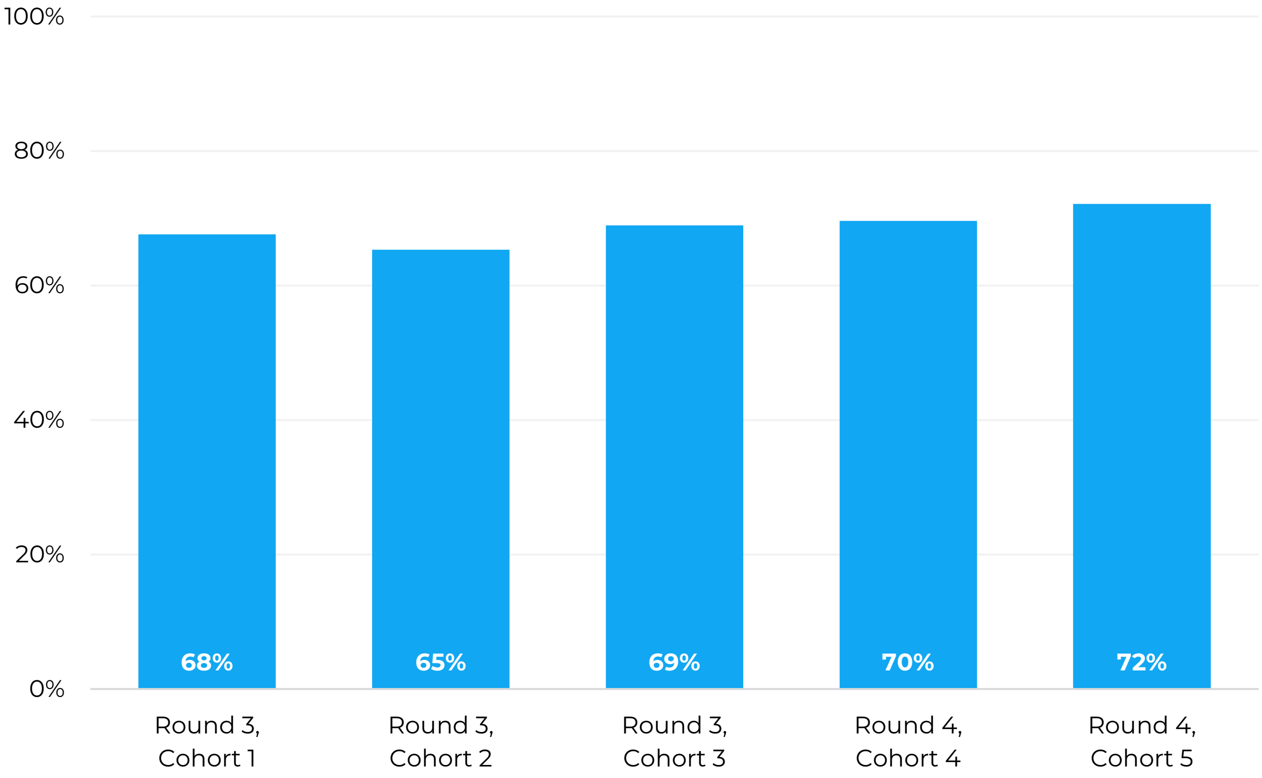


Figure 18: ECG access in Rounds 3 and 4.

Table 24 shows ECG access over time in Rounds 3 and 4. **Table 25** shows how access to ECG is distributed between demographic population groups and **Table 26** shows the variation in access to ECG between England and Wales and across NHSE and OPEN UK regions.

Table 24: 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)**

Table 25: 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
Total	**72.1% (1036/1436)**	**72.6% (979/1349)**	**65.5% (57/87)**
Age			
< 2 years	63.5% (134/211)	*	*
2 – 4 years	64.9% (183/282)	64.6% (170/263)	68.4% (13/19)
5 – 11 years	75.5% (419/555)	76.1% (398/523)	65.6% (21/32)
12 – 15 years	77.4% (271/350)	78.2% (254/325)	68.0% (17/25)
16+ years	76.3% (29/38)	*	*
Sex			
Female	72.9% (443/608)	73.9% (424/574)	55.9% (19/34)
Male	71.6% (591/825)	71.6% (553/772)	71.7% (38/53)
Not Indicated	*	*	N/A
Ethnicity			
Asian	74.5% (38/51)	74.5% (38/51)	N/A
Black	73.7% (14/19)	73.7% (14/19)	N/A
Mixed	69.0% (20/29)	*	*
White	65.6% (259/395)	*	*
Other	78.9% (15/19)	78.9% (15/19)	N/A
Not Indicated	74.8% (690/923)	74.4% (654/879)	81.8% (36/44)
Deprivation			
Most deprived	69.4% (243/350)	69.3% (226/326)	70.8% (17/24)
Second most deprived	70.8% (228/322)	71.4% (215/301)	61.9% (13/21)
Third least deprived	74.8% (178/238)	75.5% (173/229)	55.6% (5/9)
Second least deprived	71.5% (153/214)	71.2% (146/205)	77.8% (7/9)
Least deprived	75.2% (161/214)	76.3% (151/198)	62.5% (10/16)
Not Indicated	74.5% (73/98)	75.6% (68/90)	62.5% (5/8)

Table 26: 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	**72.1% (1036/1436)**
Country	
England	72.6% (979/1349)

Wales	65.5% (57/87)
NHS England Region	
East of England	78.8% (82/104)
London	80.3% (204/254)
Midlands	56.0% (140/250)
North East and Yorkshire	77.7% (220/283)
North West	67.3% (132/196)
South East	77.6% (118/152)
South West	75.5% (83/110)
OPEN UK Region	
BRPNF	76.5% (52/68)
CEWT	60.5% (49/81)
EPEN	79.6% (82/103)
EPIC	73.1% (76/104)
NTPEN	78.7% (140/178)
NWEIG	51.0% (79/155)
ORENG	57.4% (54/94)
PENNEC	78.3% (72/92)
SETPEG	80.8% (59/73)
SWEP	65.8% (50/76)
SWIPE	79.6% (43/54)
SWPEG	82.5% (99/120)
TEN	72.5% (58/80)
WPNN	74.4% (29/39)
YPEN	79.0% (94/119)

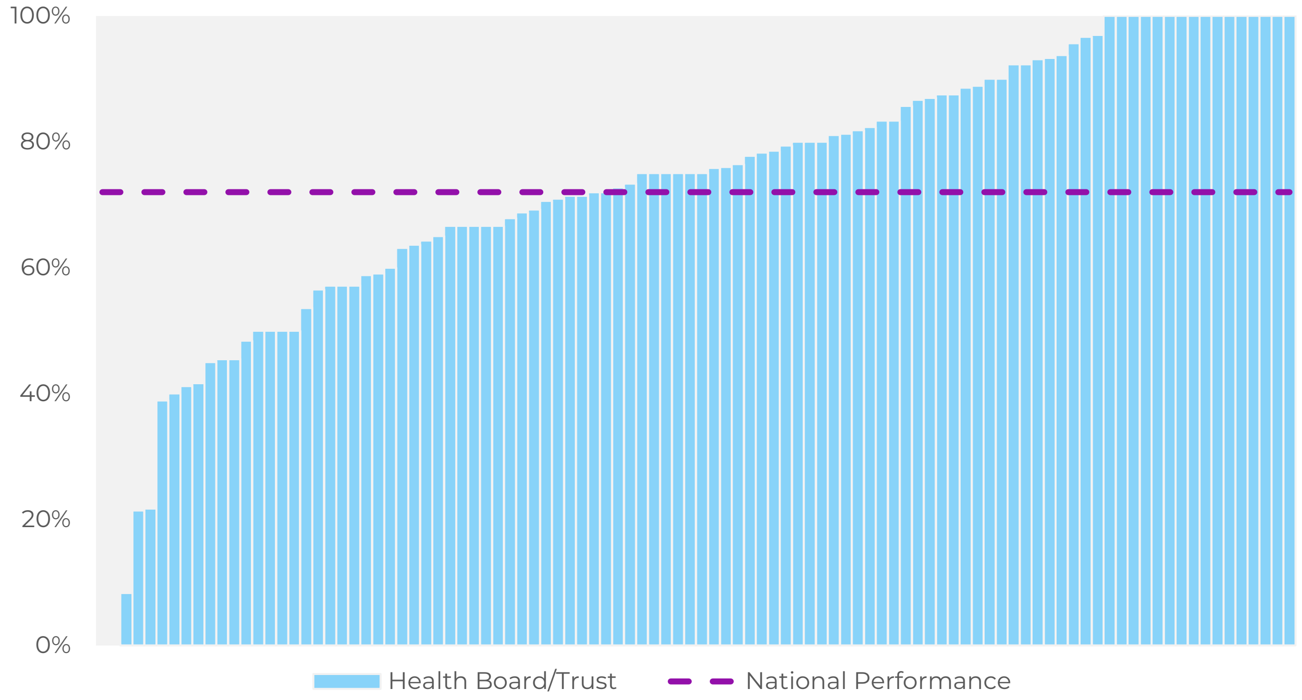
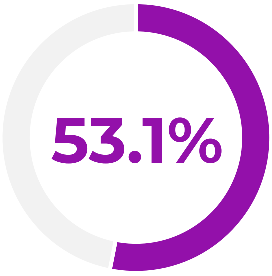


Figure 19: ECG by Health Board and Trust, cohort 5. Each participating Health Board or Trust is represented by a vertical bar in the order of the percentage score, including those scoring 0% in this graph.

5. MRI

Percentage of children and young people with epilepsy with defined indications for an MRI brain scan who had a timely MRI brain scan within 6 weeks of request.
*The 6-week timeframe was added to this KPI for cohort 5.



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.

53.1% (385/725) 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 **35.7%** to **75.0%**. The 6-week timeframe was introduced into the measure this year.

73.8% (535/725) of children and young people with defined indications for an MRI had an MRI brain scan in the first year of care. This was an increase from **70.6% (499/707)** in cohort 4.

Table 27 shows how access to MRIs is distributed between demographic population groups and **Table 28** shows the variation in access to MRIs between England and Wales and across NHSE and OPEN UK regions. **Table 29** shows the timeliness of MRI Brain from the date of request.

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 demographic.

Demographic Variables	England and Wales	England	Wales
Total	**53.1% (385/725)**	**53.6% (360/672)**	**47.2% (25/53)**
Age			
< 2 years	66.7% (214/321)	67.8% (206/304)	47.1% (8/17)
2 – 4 years	42.7% (44/103)	41.3% (38/92)	54.5% (6/11)
5 – 11 years	44.8% (86/192)	44.7% (80/179)	46.2% (6/13)
12 – 15 years	37.4% (37/99)	36.8% (32/87)	41.7% (5/12)
16+ years	40.0% (4/10)	40.0% (4/10)	N/A
Sex			
Female	53.8% (176/327)	53.5% (162/303)	58.3% (14/24)
Male	52.8% (209/396)	54.0% (198/367)	37.9% (11/29)
Not Indicated	*	*	N/A
Ethnicity			
Asian	44.4% (12/27)	44.4% (12/27)	N/A
Black	50.0% (5/10)	50.0% (5/10)	N/A
Mixed	37.5% (6/16)	37.5% (6/16)	N/A
White	52.5% (106/202)	53.6% (97/181)	42.9% (9/21)
Other	63.6% (7/11)	63.6% (7/11)	N/A

Not Indicated	54.2% (249/459)	54.6% (233/427)	50.0% (16/32)
Deprivation			
Most deprived	44.6% (86/193)	44.6% (79/177)	43.8% (7/16)
Second most deprived	55.6% (94/169)	56.1% (87/155)	50.0% (7/14)
Third least deprived	53.2% (66/124)	53.8% (63/117)	42.9% (3/7)
Second least deprived	58.4% (59/101)	*	*
Least deprived	57.6% (53/92)	58.5% (48/82)	50.0% (5/10)
Not Indicated	58.7% (27/46)	*	*

Table 28: 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	**53.1% (385/725)**
Country	
England	53.6% (360/672)
Wales	47.2% (25/53)
NHS England Region	
East of England	50.9% (28/55)
London	61.5% (83/135)
Midlands	48.9% (44/90)
North East and Yorkshire	45.6% (68/149)
North West	56.2% (45/80)
South East	54.1% (53/98)
South West	60.0% (39/65)
OPEN UK Region	
BRPNF	68.2% (15/22)
CEWT	29.2% (7/24)
EPEN	50.0% (27/54)
EPIC	41.3% (19/46)
NTPEN	58.8% (57/97)
NWEIG	59.1% (39/66)
ORENG	59.6% (31/52)
PENNEC	55.0% (22/40)
SETPEG	55.9% (19/34)
SWEP	47.7% (21/44)
SWIPE	56.2% (18/32)
SWPEG	56.9% (41/72)
TEN	33.9% (19/56)
WPNN	72.4% (21/29)
YPEN	50.9% (29/57)

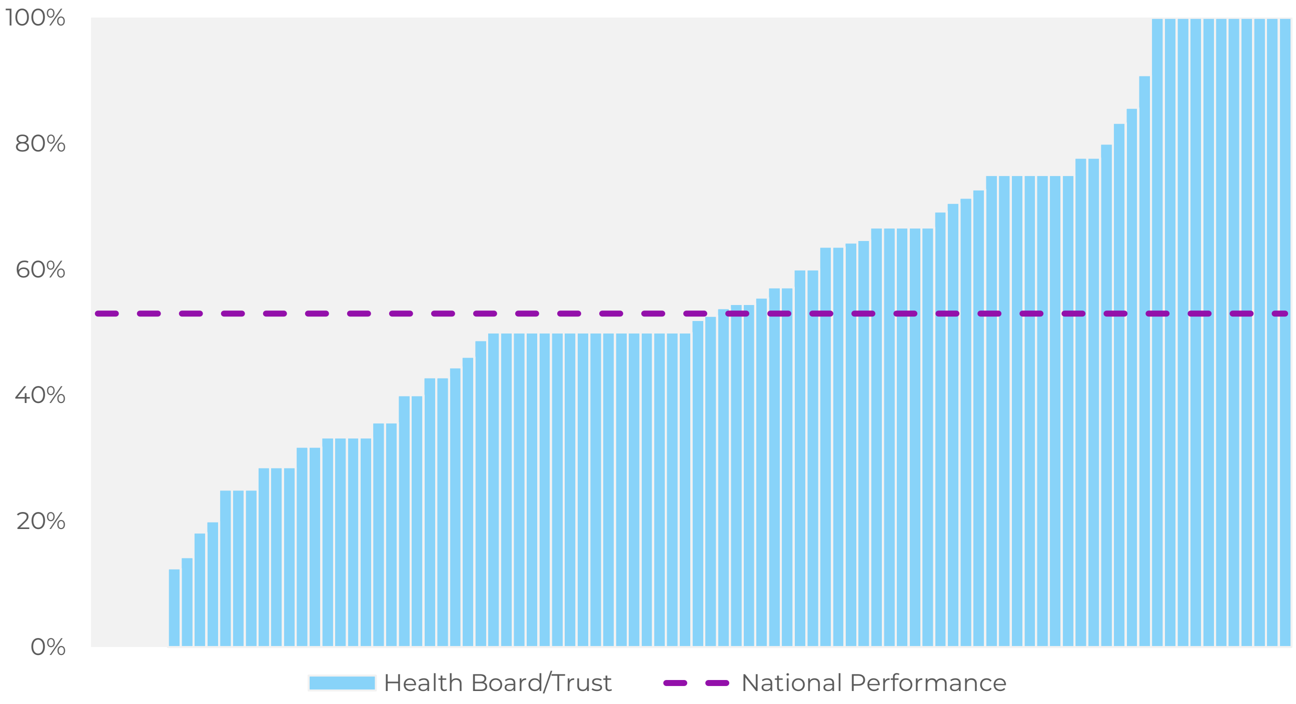


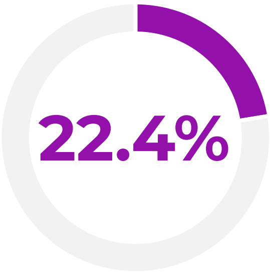
Figure 20: MRI brain scan achievement by Health Board and Trust, cohort 5. Each participating Health Board or Trust is represented by a vertical bar in the order of the percentage score, including those scoring 0% in this graph.

Table 29: Time in weeks to MRI from request, of the children meeting defined indications for an MRI in cohort 5.

Time in weeks	England and Wales	England	Wales
0 – 2 weeks	41.0% (297/725)	41.5% (279/672)	34.0% (18/53)
2 – 4 weeks	6.6% (48/725)	6.6% (44/672)	7.6% (4/53)
4 – 8 weeks	9.8% (71/725)	9.7% (65/672)	11.3% (6/53)
8 – 12 weeks	6.1% (44/725)	*	*
12 – 16 weeks	3.0% (22/725)	*	*
16+ weeks	11.9% (86/725)	11.5% (77/672)	17.0% (9/53)

6. Assessment of Mental Health issues

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



> *NICE guidelines [NG217], 2022 (Statement 2.1.11) 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.*

22.4% (330/1472) of children and young people with epilepsy, aged 5 years and over, had documented evidence of assessment of mental health issues within the first year in cohort 5. This indicator ranged from **0.0%** to **100.0%**, with an interquartile range of **0.0%** to **33.3%**. This performance indicator was introduced to the audit for cohort 5.

Table 30 shows how assessment of mental health issues is distributed between demographic population groups and **Table 31** shows the variation in the assessment of mental health issues between England and Wales and across NHSE and OPEN UK regions.

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

Demographic Variables	England and Wales	England	Wales
Total	**22.4% (330/1472)**	**21.7% (301/1385)**	**33.3% (29/87)**
Age			
5 – 11 years	21.3% (204/959)	21.1% (191/907)	25.0% (13/52)
12 – 15 years	25.4% (117/460)	23.7% (101/426)	47.1% (16/34)
16+ years	17.0% (9/53)	*	*
Sex			
Female	23.4% (158/675)	23.0% (146/636)	30.8% (12/39)
Male	21.5% (171/794)	20.6% (154/746)	35.4% (17/48)
Not Indicated	*	*	N/A
Ethnicity			
Asian	18.2% (10/55)	18.2% (10/55)	N/A
Black	23.1% (3/13)	23.1% (3/13)	N/A
Mixed	18.2% (4/22)	*	*
White	24.9% (95/382)	22.4% (75/335)	42.6% (20/47)
Other	27.8% (5/18)	*	*
Not Indicated	21.7% (213/982)	21.6% (204/944)	23.7% (9/38)
Deprivation			
Most deprived	19.1% (67/350)	18.2% (59/324)	30.8% (8/26)

Second most deprived	22.1% (73/331)	20.9% (65/311)	40.0% (8/20)
Third least deprived	23.0% (52/226)	*	*
Second least deprived	21.9% (49/224)	23.2% (49/211)	0.0% (0/13)
Least deprived	27.6% (69/250)	25.6% (60/234)	56.2% (9/16)
Not Indicated	22.0% (20/91)	*	*

Table 31: Percentage of children and young people with epilepsy with evidence of an assessment of mental health issues by region.

Geographic Region	KPI 6. Assessment of Mental Health Issues
England and Wales	**22.4% (330/1472)**
Country	
England	21.7% (301/1385)
Wales	33.3% (29/87)
NHS England Region	
East of England	23.5% (24/102)
London	27.4% (75/274)
Midlands	16.6% (40/241)
North East and Yorkshire	19.0% (52/274)
North West	26.8% (52/194)
South East	13.9% (23/166)
South West	26.1% (35/134)
OPEN UK Region	
BRPNF	12.5% (8/64)
CEWT	19.1% (18/94)
EPEN	23.8% (24/101)
EPIC	33.6% (36/107)
NTPEN	26.6% (51/192)
NWEIG	25.7% (36/140)
ORENG	7.3% (8/109)
PENNEC	27.9% (24/86)
SETPEG	18.8% (15/80)
SWEP	30.6% (22/72)
SWIPE	25.3% (19/75)
SWPEG	24.1% (27/112)
TEN	24.7% (19/77)
WPNN	31.1% (14/45)
YPEN	7.6% (9/118)

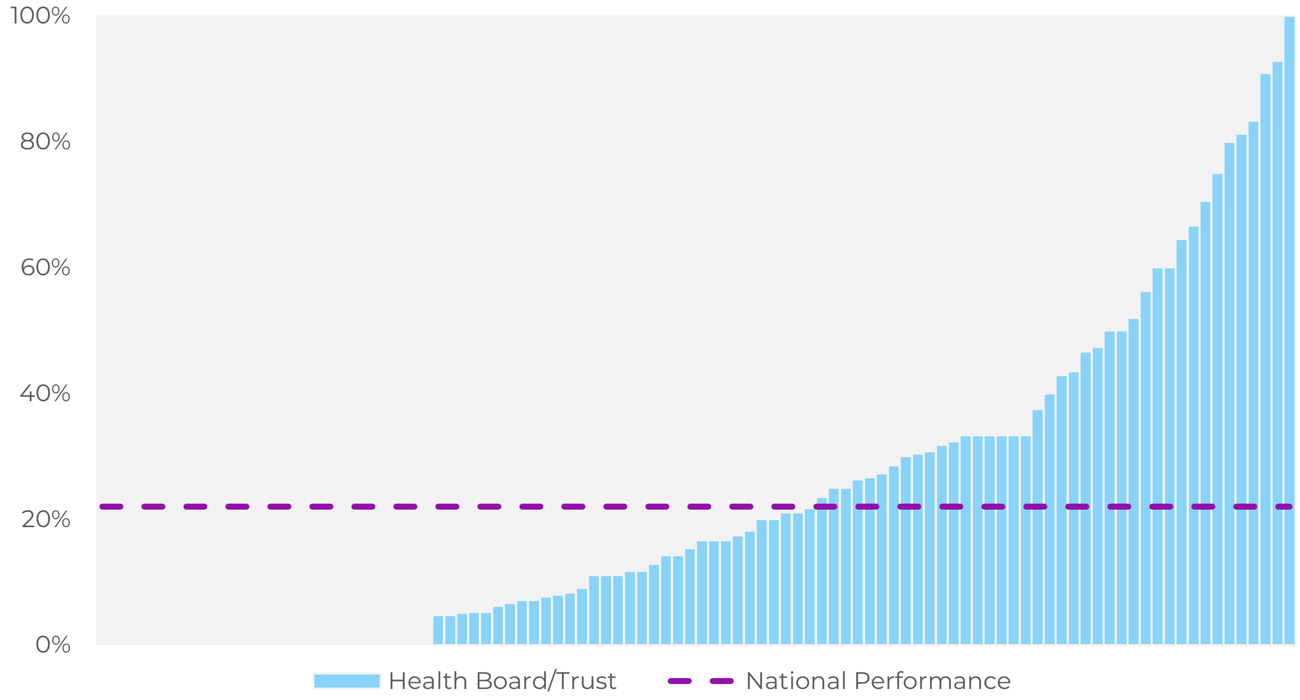
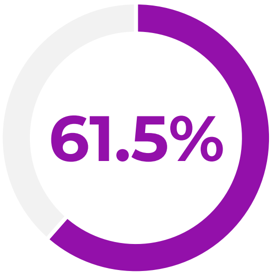


Figure 21: Assessment of mental health issues by Health Board and Trust, cohort 5. Each participating Health Board or Trust is represented by a vertical bar in the order of the percentage score, including those scoring 0% in this graph.

7. Mental Health Support



Percentage of children and young people with epilepsy and an identified mental health problem recorded who had evidence of receiving mental health support.
*New measure for cohort 5.

61.5% (83/135) of children and young people with epilepsy that had an identified mental health problem, also had evidence of receiving mental health support within the first year of care in cohort 5. This indicator ranged from **0.0%** to **100.0%**, with an interquartile range of **50.0%** to **100.0%**. This performance indicator was introduced to the audit for cohort 5.

Table 32 shows how mental health support is distributed between demographic population groups and **Table 33** shows the variation in access to mental health support between England and Wales and across NHSE and OPEN UK regions.

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

Demographic Variables	England and Wales	England	Wales
Total	**61.5% (83/135)**	**60.9% (78/128)**	**71.4% (5/7)**
Age			
< 2 years	*	*	N/A
2 – 4 years	50.0% (3/6)	*	*
5 – 11 years	51.6% (33/64)	*	*
12 – 15 years	72.4% (42/58)	70.9% (39/55)	100.0% (3/3)
16+ years	66.7% (4/6)	66.7% (4/6)	N/A
Sex			
Female	70.8% (46/65)	*	*
Male	52.9% (37/70)	51.6% (33/64)	66.7% (4/6)
Not Indicated	N/A	N/A	N/A
Ethnicity			
Asian	*	*	N/A
Black	*	*	N/A
Mixed	*	*	N/A
White	73.5% (25/34)	75.0% (21/28)	66.7% (4/6)
Other	*	*	N/A
Not Indicated	57.3% (55/96)	*	*
Deprivation			
Most deprived	60.7% (17/28)	*	*
Second most deprived	63.6% (21/33)	*	*
Third least deprived	54.2% (13/24)	*	*
Second least deprived	61.5% (8/13)	61.5% (8/13)	N/A
Least deprived	64.3% (18/28)	*	*

Not Indicated	66.7% (6/9)	*	*

Table 33: Percentage of children and young people with epilepsy and an identified mental health problem with evidence of receiving mental health support by region.

Geographic Region	KPI 7. MRI
England and Wales	**61.5% (83/135)**
Country	
England	60.9% (78/128)
Wales	71.4% (5/7)
NHS England Region	
East of England	53.8% (7/13)
London	56.7% (17/30)
Midlands	52.4% (11/21)
North East and Yorkshire	70.0% (14/20)
North West	75.0% (9/12)
South East	66.7% (8/12)
South West	60.0% (12/20)
OPEN UK Region	
BRPNF	57.1% (4/7)
CEWT	42.9% (3/7)
EPEN	53.8% (7/13)
EPIC	57.1% (4/7)
NTPEN	57.1% (12/21)
NWEIG	75.0% (9/12)
ORENG	75.0% (3/4)
PENNEC	64.3% (9/14)
SETPEG	100.0% (5/5)
SWEP	66.7% (4/6)
SWIPE	57.1% (4/7)
SWPEG	50.0% (7/14)
TEN	75.0% (3/4)
WPNN	58.3% (7/12)
YPEN	100.0% (2/2)

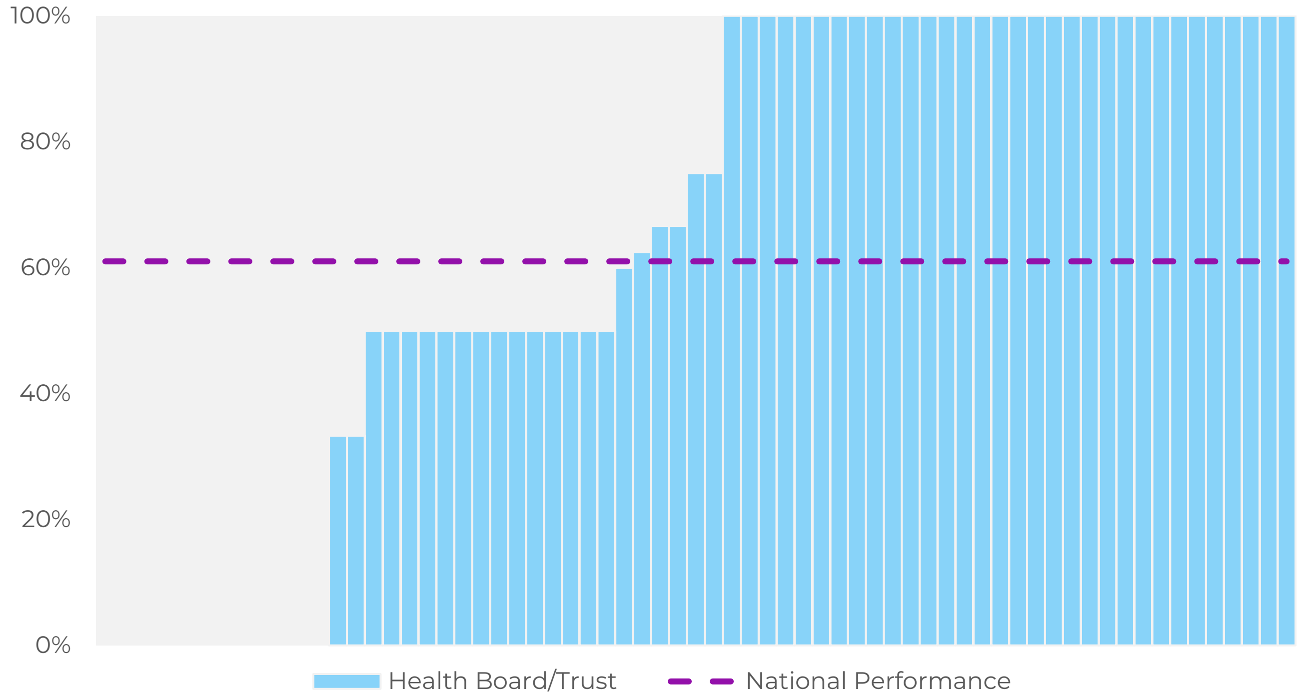


Figure 22: Mental health support by Health Board and Trust, cohort 5. Each participating Health Board or Trust is represented by a vertical bar in the order of the percentage score, including those scoring 0% in this graph.

8. Sodium Valproate

Percentage of all females with epilepsy aged 12 years and over currently on valproate treatment with an annual risk acknowledgement form completed and/or a Pregnancy Prevention Programme in place.
*Age criteria was refined in cohort 5.

> *NICE guidelines [NG217], 2022 (Statement 4.4.4) state that girls of childbearing potential who are receiving sodium valproate 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.*

100% (3/3) of females with epilepsy aged 12 years and over currently on valproate treatment had an annual risk acknowledgement form completed and/or a Pregnancy Prevention Programme in place by the first year in cohort 5. The age criterion was updated from 9-years to 12-years for cohort 5.

100% (3/3) of females with epilepsy aged 12 years and over currently on valproate treatment had an annual risk acknowledgement form completed and/or a Pregnancy Prevention Programme in place. These three young people were all aged 12 to 15 years and their ethnicity was not stated. All three were seen in England. The deprivation quintiles, NHS England Region, and OPEN UK regions are masked due to small numbers.

Table 34 shows how sodium valproate risk discussion is distributed between demographic population groups and **Table 35** shows the variation in sodium valproate risk acknowledgement between England and Wales and across NHSE and OPEN UK regions.

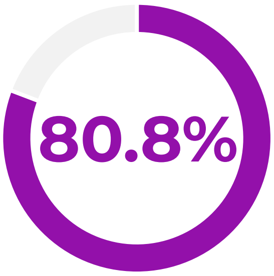
Table 34: Percentage of females with epilepsy aged 12 years and over currently on valproate treatment that have an annual risk acknowledgement form completed and/or a Pregnancy Prevention Programme in place by demographic. Note, that deprivation results have not been disclosed due to small numbers.

Demographic Variables	England and Wales	England	Wales
Age			
12 – 15 years	100.0% (3/3)	100.0% (3/3)	N/A
16+ years	N/A	N/A	N/A
Ethnicity			
Asian	N/A	N/A	N/A
Black	N/A	N/A	N/A
Mixed	N/A	N/A	N/A
White	N/A	N/A	N/A
Other	N/A	N/A	N/A
Not Indicated	100.0% (3/3)	100.0% (3/3)	N/A

Table 35: Percentage of females with epilepsy aged 12 years and over currently on valproate treatment that have an annual risk acknowledgement form completed and/or a Pregnancy Prevention Programme in place by region. Note, that regional results have not been disclosed due to small numbers.

Geographic Region	KPI 8. Sodium Valproate
Country	
England	100.0% (3/3)
Wales	N/A

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.*

80.8% (1787/2212) of children and young people with epilepsy had evidence of care planning agreement within the first year of care in cohort 5. This was an increase compared to **74.3% (1727/2324)** in cohort 4. This indicator ranged from **0.0%** to **100.0%**, with an interquartile range of **72.7%** to **100.0%**.

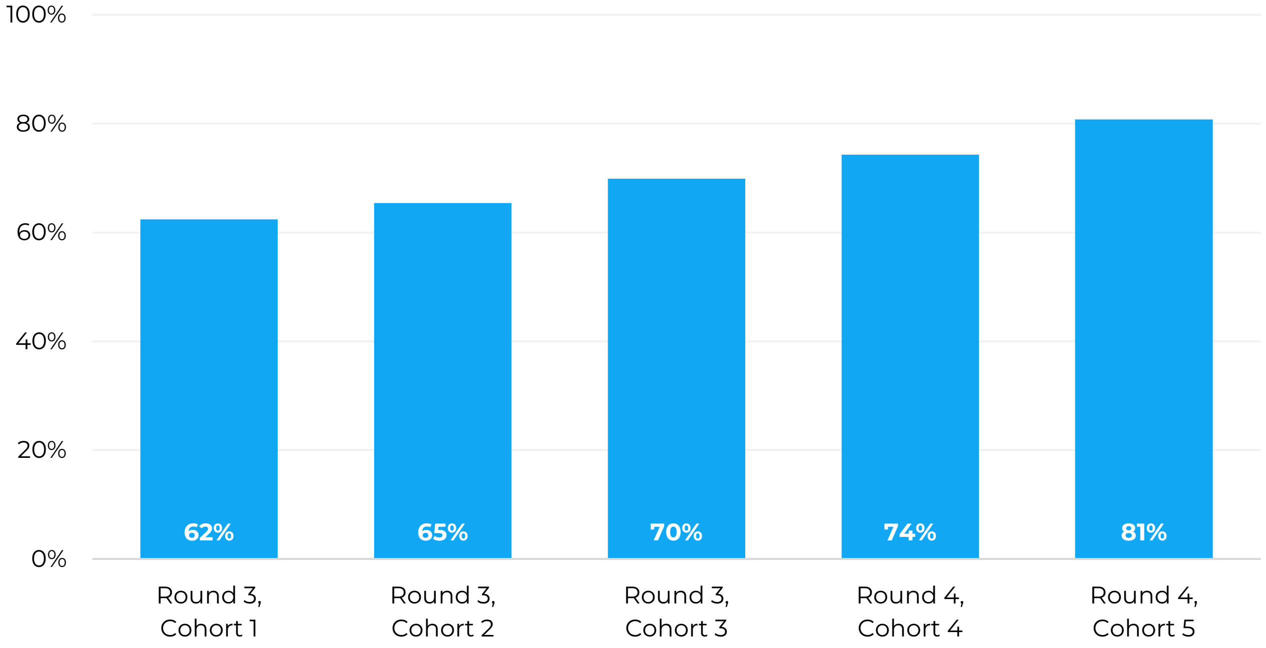


Figure 23: Care planning agreement in Rounds 3 and 4.

Table 36 shows care planning agreement over time in Rounds 3 and 4. **Table 37** shows how care planning agreement is distributed between demographic population groups and **Table 38** shows the variation in care planning agreement between England and Wales and across NHSE and OPEN UK regions. **Table 39** shows the breakdown of the sub-metrics that make up the care planning agreement measure.

Table 36: 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)**

Table 37: 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
Total	**80.8% (1787/2212)**	**80.5% (1670/2074)**	**84.8% (117/138)**
Age			
< 2 years	78.5% (252/321)	78.0% (237/304)	88.2% (15/17)
2 – 4 years	81.6% (342/419)	81.3% (313/385)	85.3% (29/34)
5 – 11 years	80.8% (775/959)	80.6% (731/907)	84.6% (44/52)
12 – 15 years	82.4% (379/460)	82.2% (350/426)	85.3% (29/34)
16+ years	73.6% (39/53)	*	*
Sex			
Female	81.8% (812/993)	81.4% (760/934)	88.1% (52/59)
Male	79.9% (972/1216)	79.8% (907/1137)	82.3% (65/79)
Not Indicated	100.0% (3/3)	100.0% (3/3)	N/A
Ethnicity			
Asian	81.3% (61/75)	81.3% (61/75)	N/A
Black	88.0% (22/25)	88.0% (22/25)	N/A
Mixed	93.0% (40/43)	*	*
White	81.6% (496/608)	80.2% (434/541)	92.5% (62/67)
Other	80.0% (20/25)	*	*
Not Indicated	79.9% (1148/1436)	80.0%(1094/1367)	78.3% (54/69)
Deprivation			
Most deprived	82.8% (444/536)	82.5% (409/496)	87.5% (35/40)
Second most deprived	77.3% (388/502)	76.3% (360/472)	93.3% (28/30)
Third least deprived	80.7% (296/367)	80.5% (280/348)	84.2% (16/19)
Second least deprived	84.6% (275/325)	85.0% (260/306)	78.9% (15/19)
Least deprived	80.2% (271/338)	80.4% (255/317)	76.2% (16/21)
Not Indicated	78.5% (113/144)	78.5% (106/135)	77.8% (7/9)

Table 38: 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	**80.8% (1787/2212)**
Country	
England	80.5% (1670/2074)
Wales	84.8% (117/138)
NHS England Region	
East of England	87.4% (139/159)
London	78.3% (300/383)
Midlands	67.1% (245/365)
North East and Yorkshire	90.9% (381/419)
North West	74.5% (219/294)
South East	78.8% (205/260)
South West	93.3% (181/194)
OPEN UK Region	
BRPNF	75.2% (76/101)
CEWT	86.5% (109/126)
EPEN	87.3% (138/158)
EPIC	85.5% (142/166)
NTPEN	74.9% (197/263)
NWEIG	57.5% (123/214)
ORENG	68.0% (121/178)
PENNEC	79.9% (115/144)
SETPEG	87.4% (104/119)
SWEP	83.8% (93/111)
SWIPE	93.2% (96/103)
SWPEG	78.7% (140/178)
TEN	98.3% (113/115)
WPNN	85.9% (55/64)
YPEN	95.9% (165/172)

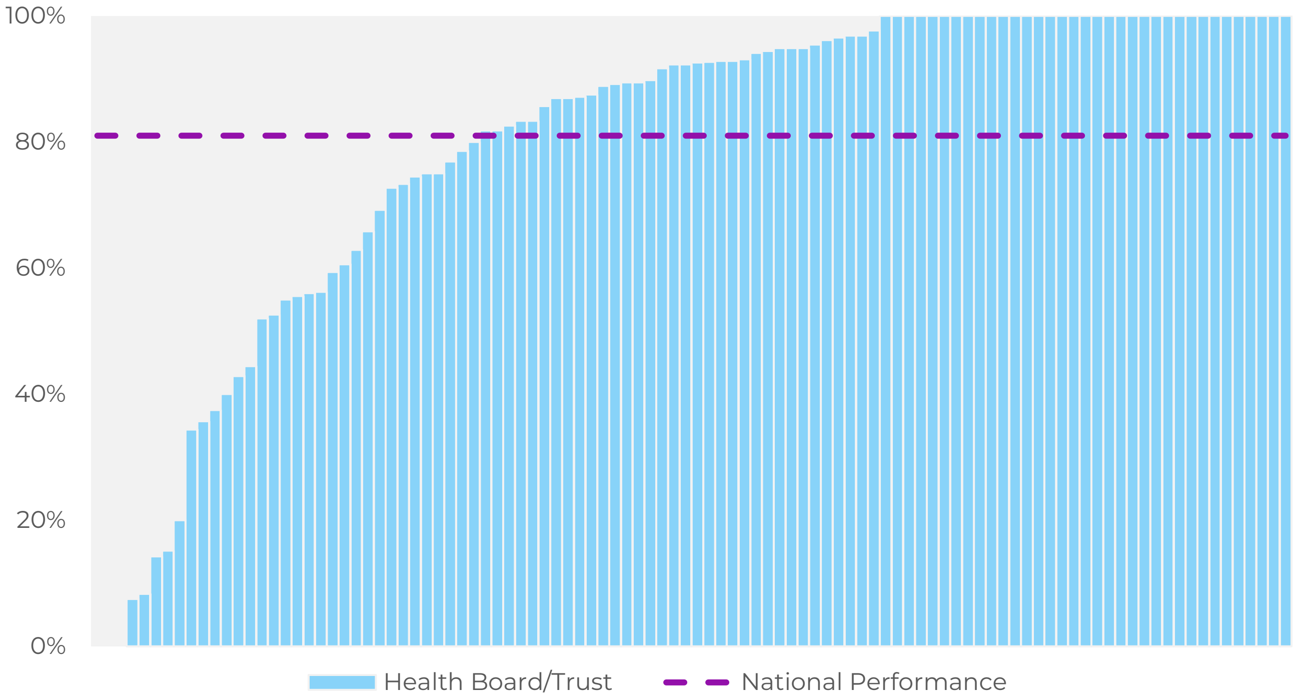


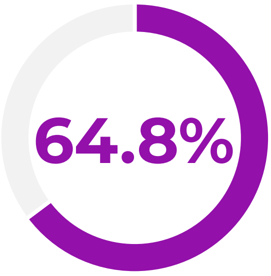
Figure 24: Care planning agreement by Health Board and Trust, cohort 5. Each participating Health Board or Trust is represented by a vertical bar in the order of the percentage score, including those scoring 0% in this graph.

Table 39: Comprehensive care planning agreement sub-metrics.

	England and Wales	England	Wales
All three elements of care planning agreement	**80.8% (1787/2212)**	**80.5% (1670/2074)**	**84.8% (117/138)**
Individualised epilepsy document or copy clinic letter that includes care planning information	95.5% (2112/2212)	95.7% (1984/2074)	92.8% (128/138)
Evidence of agreement between the person, their family and/or carers as appropriate	86.3% (1909/2212)	86.1% (1785/2074)	89.9% (124/138)
The care plan has been updated where necessary	84.4% (1867/2212)	84.3% (1748/2074)	86.2% (119/138)

9b. Care planning content

Percentage of children and young people with epilepsy with evidence of communication regarding core elements 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.
*This measure was updated in cohort 5.



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 2.1.11), first aid and safety information, service contact details (Statement 1.1.8), and information regarding the risk of SUDEP (Statement 10.1.4)

64.8% (1433/2212) of children and young people with epilepsy had evidence of achieving core elements of care planning. This indicator ranged from **0.0%** to **100.0%**, with an interquartile range of **36.6%** to **95.0%**. Evidence of discussion of SUDEP was added as an element of the care planning content indicator for cohort 5.

66.3% of children and young people with epilepsy had evidence of discussion regarding SUDEP in cohort 5. This was **56.5% (1313/2324)** in cohort 4.

Table 40 shows how care planning content is distributed between demographic population groups and **Table 41** shows the variation in care planning content between England and Wales and across NHSE and OPEN UK regions. **Table 42** shows the breakdown of the sub-metrics which make up the care planning content measure.

Table 40: Percentage of children and young people with epilepsy with evidence of achieving core elements of care planning by demographic.

Demographic Variables	England and Wales	England	Wales
Total	**64.8% (1433/2212)**	**66.2% (1374/2074)**	**42.8% (59/138)**
Age			
< 2 years	61.1% (196/321)	62.5% (190/304)	35.3% (6/17)
2 – 4 years	57.8% (242/419)	60.5% (233/385)	26.5% (9/34)
5 – 11 years	64.3% (617/959)	64.9% (589/907)	53.8% (28/52)
12 – 15 years	72.8% (335/460)	74.9% (319/426)	47.1% (16/34)
16+ years	81.1% (43/53)	*	*
Sex			
Female	66.0% (655/993)	68.0% (635/934)	33.9% (20/59)
Male	63.7% (775/1216)	64.7% (736/1137)	49.4% (39/79)
Not Indicated	100.0% (3/3)	100.0% (3/3)	N/A
Ethnicity			
Asian	73.3% (55/75)	73.3% (55/75)	N/A

Black	60.0% (15/25)	60.0% (15/25)	N/A
Mixed	51.2% (22/43)	*	*
White	63.5% (386/608)	64.3% (348/541)	56.7% (38/67)
Other	64.0% (16/25)	*	*
Not Indicated	65.4% (939/1436)	67.2% (919/1367)	29.0% (20/69)
Deprivation			
Most deprived	67.4% (361/536)	69.4% (344/496)	42.5% (17/40)
Second most deprived	61.2% (307/502)	61.9% (292/472)	50.0% (15/30)
Third least deprived	59.7% (219/367)	61.2% (213/348)	31.6% (6/19)
Second least deprived	69.5% (226/325)	71.9% (220/306)	31.6% (6/19)
Least deprived	66.9% (226/338)	68.5% (217/317)	42.9% (9/21)
Not Indicated	65.3% (94/144)	65.2% (88/135)	66.7% (6/9)

Table 41: Percentage of children and young people with epilepsy with evidence of communication regarding core elements of care planning by region.

Geographic Region	KPI 9b. Care Planning Content
England and Wales	**64.8% (1433/2212)**
Country	
England	66.2% (1374/2074)
Wales	42.8% (59/138)
NHS England Region	
East of England	48.4% (77/159)
London	58.2% (223/383)
Midlands	70.4% (257/365)
North East and Yorkshire	76.4% (320/419)
North West	61.6% (181/294)
South East	70.8% (184/260)
South West	68.0% (132/194)
OPEN UK Region	
BRPNF	87.1% (88/101)
CEWT	45.2% (57/126)
EPEN	48.1% (76/158)
EPIC	38.6% (64/166)
NTPEN	49.4% (130/263)
NWEIG	73.8% (158/214)
ORENG	72.5% (129/178)
PENNEC	53.5% (77/144)
SETPEG	79.8% (95/119)
SWEP	49.5% (55/111)
SWIPE	69.9% (72/103)

SWPEG	71.3% (127/178)
TEN	93.9% (108/115)
WPNN	78.1% (50/64)
YPEN	85.5% (147/172)

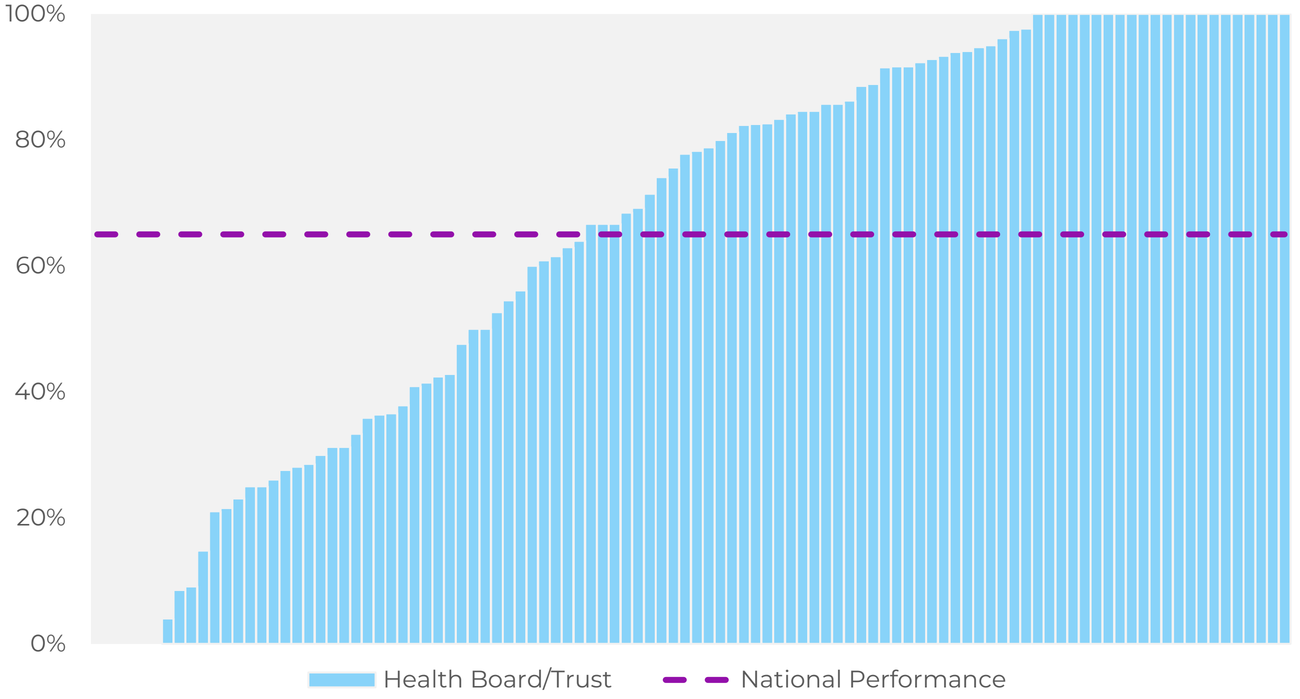


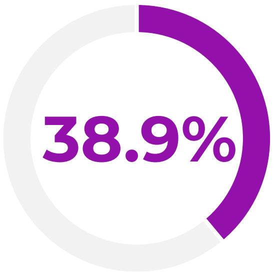
Figure 25: Care planning content by Health Board and Trust, cohort 5. Each participating Health Board or Trust is represented by a vertical bar in the order of the percentage score, including those scoring 0% in this graph.

Table 42: Comprehensive care planning content sub-metrics.

	England and Wales	England	Wales
All core elements of care planning	**64.8% (1433/2212)**	**66.3% (1374/2074)**	**42.8% (59/138)**
If prescribed rescue medication, prolonged seizures care plan	98.6% (577/585)	98.6% (542/550)	100.0% (35/35)
Water safety	90.6% (2003/2212)	90.7% (1881/2074)	88.4% (122/138)
First aid	95.5% (2112/2212)	95.5% (1981/2074)	94.9% (131/138)
General participation and risk	92.0% (2036/2212)	92.2% (1913/2074)	89.1% (123/138)
Service contact details	97.2% (2150/2212)	97.1% (2013/2074)	99.3% (137/138)
SUDEP	66.3% (1466/2212)	67.7% (1405/2074)	44.2% (61/138)

10. School Individual Health Care Plan

Percentage of children and young people with epilepsy aged 5 years and above with evidence of a school individual healthcare plan by first year.



38.9% (573/1472) of children and young people with epilepsy aged 5 years and above had evidence of a school individual health care plan within the first year of care in cohort 5. This was an increase compared to **36.9% (577/1562)** in cohort 4. This indicator ranged from **0.0%** to **100.0%**, with an interquartile range of **6.8%** to **68.3%**.

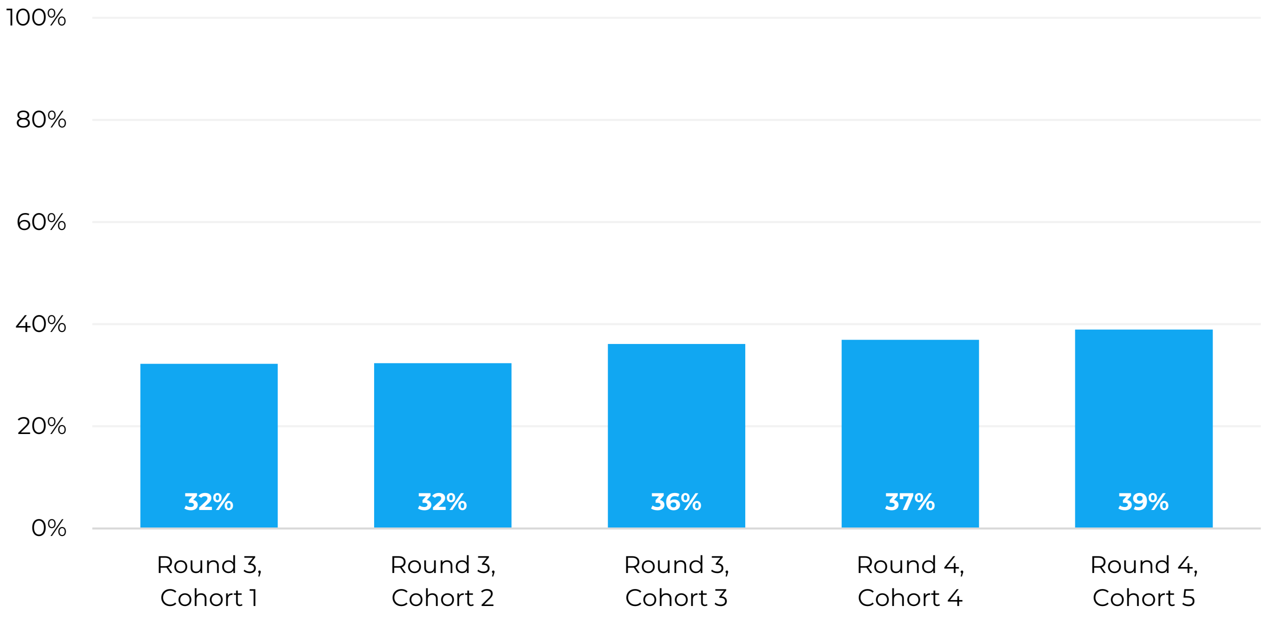


Figure 26: School individual health care plan in Rounds 3 and 4.

Table 43 shows evidence of school individual health care plans over time in Rounds 3 and 4. **Table 44** shows how the presence of school individual health care plans are distributed between demographic population groups and **Table 45** shows the variation in access to school individual health care plans between England and Wales and across NHSE and OPEN UK regions.

Table 43: The percentage of children and young people with epilepsy aged 5 years and above 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)**

Table 44: Percentage of children and young people with epilepsy aged 5 years and above with evidence of a school individual health care plan within the first year of cae by demographic.

Demographic Variables	England and Wales	England	Wales
Total	**38.9% (573/1472)**	**39.7% (550/1385)**	**26.4% (23/87)**
Age			
5 – 11 years	38.0% (364/959)	*	*
12 – 15 years	41.3% (190/460)	41.8% (178/426)	35.3% (12/34)
16+ years	35.8% (19/53)	*	*
Sex			
Female	40.4% (273/675)	40.9% (260/636)	33.3% (13/39)
Male	37.5% (298/794)	38.6% (288/746)	20.8% (10/48)
Not Indicated	*	*	N/A
Ethnicity			
Asian	12.7% (7/55)	12.7% (7/55)	N/A
Black	30.8% (4/13)	30.8% (4/13)	N/A
Mixed	36.4% (8/22)	*	*
White	38.5% (147/382)	41.2% (138/335)	19.1% (9/47)
Other	22.2% (4/18)	*	*
Not Indicated	41.0% (403/982)	41.2% (389/944)	36.8% (14/38)
Deprivation			
Most deprived	42.3% (148/350)	42.9% (139/324)	34.6% (9/26)
Second most deprived	35.0% (116/331)	36.0% (112/311)	20.0% (4/20)
Third least deprived	37.2% (84/226)	*	*
Second least deprived	40.6% (91/224)	41.7% (88/211)	23.1% (3/13)
Least deprived	42.0% (105/250)	*	*
Not Indicated	31.9% (29/91)	28.7% (25/87)	100.0% (4/4)

Table 45: Percentage of children and young people with epilepsy aged 5 years and above 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	**38.9% (573/1472)**
Country	
England	39.7% (550/1385)
Wales	26.4% (23/87)
NHS England Region	
East of England	41.2% (42/102)
London	29.9% (82/274)
Midlands	24.1% (58/241)
North East and Yorkshire	52.9% (145/274)
North West	57.2% (111/194)
South East	37.3% (62/166)

South West	37.3% (50/134)
OPEN UK Region	
BRPNF	25.0% (16/64)
CEWT	28.7% (27/94)
EPEN	41.6% (42/101)
EPIC	45.8% (49/107)
NTPEN	27.6% (53/192)
NWEIG	52.9% (74/140)
ORENG	24.8% (27/109)
PENNEC	38.4% (33/86)
SETPEG	43.8% (35/80)
SWEP	23.6% (17/72)
SWIPE	32.0% (24/75)
SWPEG	31.2% (35/112)
TEN	74.0% (57/77)
WPNN	48.9% (22/45)
YPEN	52.5% (62/118)

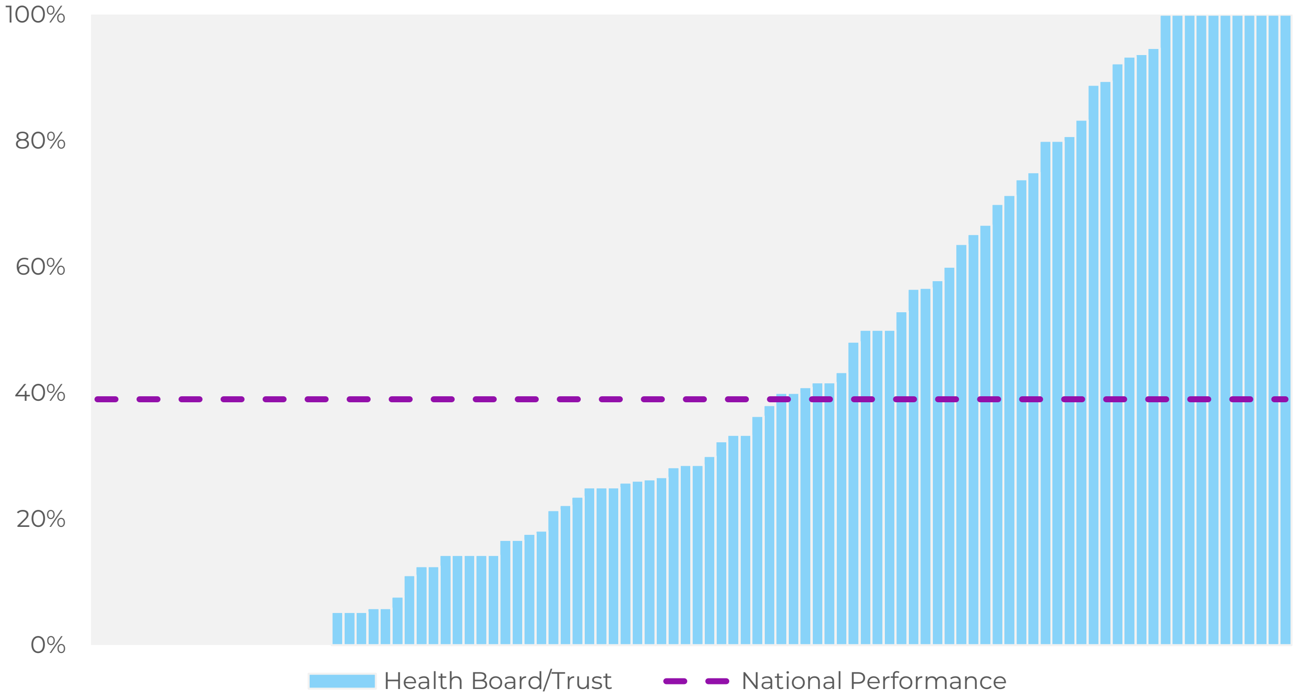


Figure 27: School individual health care plan by Health Board and Trust, cohort 5. Each participating Health Board or Trust is represented by a vertical bar in the order of the percentage score, including those scoring 0% in this graph.

Additional analyses

Accuracy of Diagnosis

0.01% (14/2212) of children and young people with epilepsy had their diagnosis withdrawn within the first year of care in England and Wales. This is consistent with cohort 4, where 0.01% (31/2325) of children and young people with epilepsy had their diagnosis withdrawn.

First Paediatric Assessment

In cohort 5, most children and young people with epilepsy had initial referrals from emergency departments, and the majority had their first paediatric assessment in an acute setting, which is consistent across all five cohorts.

Table 46: The referring service and setting of first paediatric assessment for children and young people with epilepsy in cohort 5 in England and Wales.

	England and Wales	England	Wales
Referring Service			
Emergency Department	45.8% (1014/2212)	46.8% (970/2074)	31.9% (44/138)
GP	30.7% (678/2212)	30.2% (627/2074)	37.0% (51/138)
Health Visitor	0.1% (3/2212)	0.1% (3/2074)	0.0% (0/138)
Outpatient Paediatrics	8.0% (177/2212)	8.0% (165/2074)	8.7% (12/138)
Inpatient Paediatrics	11.1% (245/2212)	10.5% (218/2074)	19.6% (27/138)
PICU	0.2% (4/2212)	0.2% (4/2074)	0.0% (0/138)
Neonatal Care	1.0% (23/2212)	*	*
Other	3.1% (68/2212)	*	*
Setting			
Acute	50.8% (1123/2212)	50.9% (1055/2074)	49.3% (68/138)
Non-acute	48.9% (1081/2212)	48.7% (1011/2074)	50.7% (70/138)
Unknown	0.4% (8/2212)	0.4% (8/2074)	0.0% (0/138)

'Appropriate first paediatric assessment' was previously included as a key performance indicator for cohorts 1-4, and is defined as a clinical assessment for paroxysmal episode(s) consisting of all the components deemed as necessary by Epilepsy12, with reference to NICE guidelines [NG217]. In cohort 5, **63.7% (1409/2212)** of children and young people with epilepsy had an appropriate first paediatric assessment. This was **63.4% (1475/2324)** in cohort 4. **Table 47** 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 5.

Table 47: Percentage of children and young people with epilepsy with evidence of receiving each element of an 'appropriate first paediatric assessment' in cohort 5 in England and Wales.

	England and Wales	England	Wales
Appropriate first paediatric assessment	**63.7% (1409/2212)**	**63.2% (1311/2074)**	**71.0% (98/138)**
Descriptions of episode	99.3% (2197/2212)	99.3%(2059/2074)	100.0% (138/138)
Descriptions of age of child/timing of the first episode	83.7% (1851/2212)	83.9% (1741/2074)	79.7% (110/138)
Descriptions of frequency	96.4% (2132/2212)	96.2% (1995/2074)	99.3% (137/138)
Descriptions of general examination	95.3% (2109/2212)	95.1% (1972/2074)	99.3% (137/138)
Descriptions of neurological examination	92.8% (2053/2212)	92.4% (1917/2074)	98.6% (136/138)
Descriptions of developmental, learning or schooling progress	88.2% (1952/2212)	87.8% (1821/2074)	94.9% (131/138)
If aged 3yrs and above, evidence of consideration of emotional or behavioural problems	78.3% (1731/2212)	77.7% (1611/2074)	87.0% (120/138)

Treatment

Table 48 and **table 49** 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 5 during their first year of care. **6.6%** of children and young people with epilepsy were prescribed three or more AEDs during their first year of care, which is consistent with cohort 4 **(6%)**.

Table 48: Number of anti-epileptic drugs (AEDs) prescribed to children and young people with epilepsy in cohort 5 within the first year of care.

Number of AEDs	England and Wales	England	Wales
1 or more AEDs	88.9% (1967/2212)	88.9%(1843/2074)	89.9% (124/138)
3 or more AEDs	6.6% (147/2212)	6.5% (135/2074)	8.7% (12/138)
No AED prescriptions recorded	11.1% (245/2212)	11.1% (231/2074)	10.1% (14/138)

In cohort 5, the most commonly prescribed anti-epileptic drugs were **Levetiracetam**, **sodium valproate**, **lamotrigine** and **carbamazepine**, which is consistent with cohorts 1 to 4.

Table 49: Percentage of children and young people with epilepsy prescribed each anti-epileptic drug (AED) in cohort 5 in England and Wales.

AED	England and Wales	England	Wales
ACTH	0.0% (0/2212)	0.0% (0/2074)	0.0% (0/138)
Acetazolamide	0.0% (0/2212)	0.0% (0/2074)	0.0% (0/138)
Carbamazepine	**11.7% (259/2212)**	**11.7% (242/2074)**	**12.3% (17/138)**
Clobazam	3.7% (81/2212)	3.7% (76/2074)	3.6% (5/138)
Clonazepam	0.2% (5/2212)	*	*
Eslicarbazepine acetate	0.0% (0/2212)	0.0% (0/2074)	0.0% (0/138)
Ethosuximide	7.9% (175/2212)	7.9% (164/2074)	8.0% (11/138)
Gabapentin	*	*	*
Lacosamide	0.5% (12/2212)	0.6% (12/2074)	0.0% (0/138)
Lamotrigine	**20.3% (450/2212)**	**20.0% (415/2074)**	**25.4% (35/138)**
Levetiracetam	**41.1% (909/2212)**	**41.6% (863/2074)**	**33.3% (46/138)**
Methylprednisolone	*	*	*
Nitrazepam	0.2% (4/2212)	0.2% (4/2074)	0.0% (0/138)
Oxcarbazepine	0.6% (14/2212)	*	*
Perampanel	*	*	*
Phenobarbital	0.9% (20/2212)	0.8% (17/2074)	2.2% (3/138)
Phenytoin	0.6% (14/2212)	0.7% (14/2074)	0.0% (0/138)
Piracetam	0.0% (0/2212)	0.0% (0/2074)	0.0% (0/138)
Prednisolone	2.5% (55/2212)	2.4% (49/2074)	4.3% (6/138)
Pregabalin	0.0% (0/2212)	0.0% (0/2074)	0.0% (0/138)
Primidone	0.0% (0/2212)	0.0% (0/2074)	0.0% (0/138)
Rufinamide	0.2% (4/2212)	0.2% (4/2074)	0.0% (0/138)

Sodium Valproate	**24.3% (538/2212)**	**24.3% (504/2074)**	**24.6% (34/138)**
Stiripentol	0.1% (3/2212)	0.1% (3/2074)	0.0% (0/138)
Sulthiame	*	*	*
Tiagabine	0.0% (0/2212)	0.0% (0/2074)	0.0% (0/138)
Topiramate	2.0% (44/2212)	*	*
Vigabatrin	2.9% (65/2212)	2.8% (58/2074)	5.1% (7/138)
Zonisamide	0.5% (10/2212)	*	*
Other	1.3% (29/2212)	1.1% (22/2074)	5.1% (7/138)

Figure 29 shows the number of males and females with epilepsy who were prescribed sodium valproate in the first year of care cohort 5. There were more males on sodium valproate than females across all ages, and very few females aged 9 and above on sodium valproate. This is consistent with cohort 4.

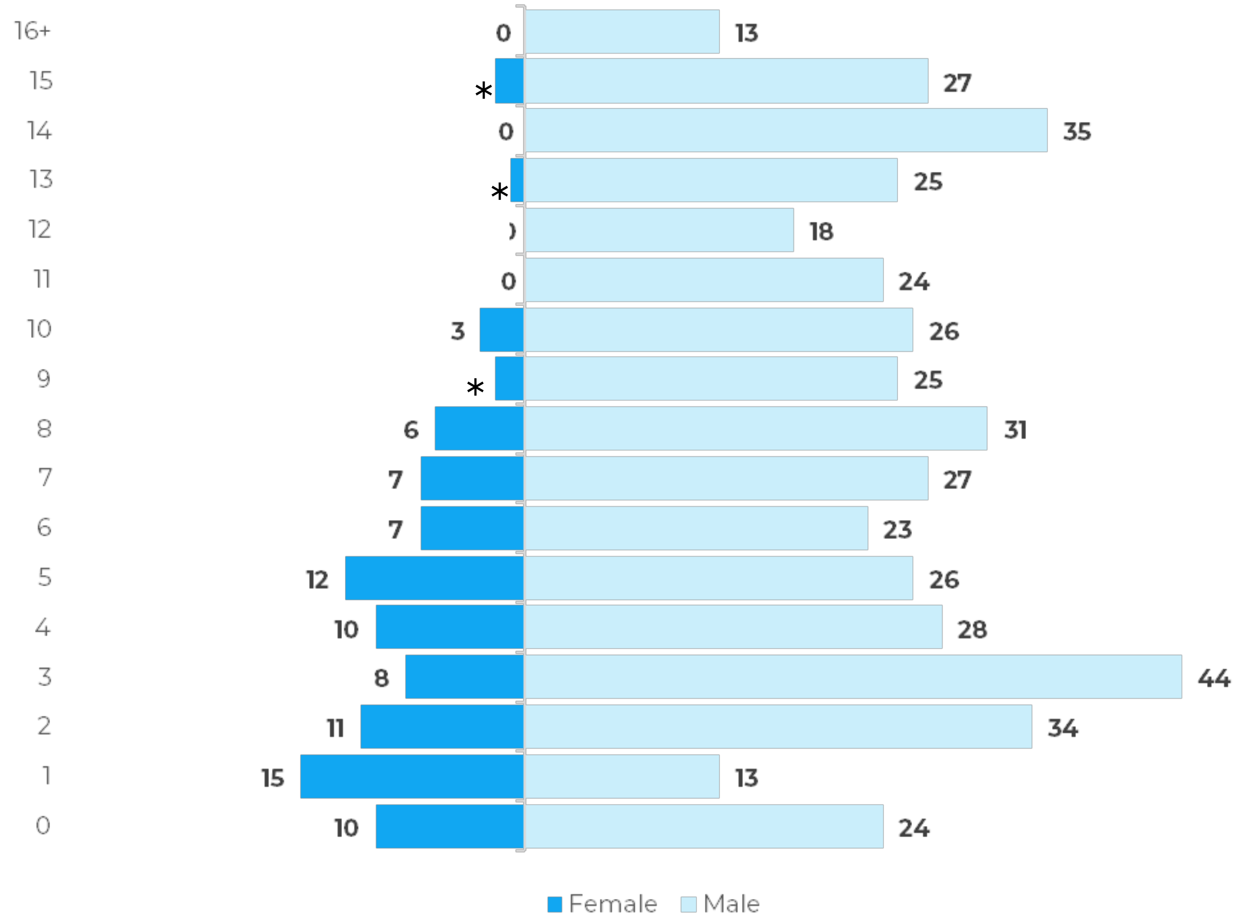


Figure 28: Number of children and young people with epilepsy on sodium valproate by sex in cohort 5 in England and Wales.

24.9% (552/2216) of children and young people diagnosed with epilepsy had rescue medication prescribed in the first year of care in cohort 5 in England and Wales. This figure was **24.8%** in England and **23.2%** in Wales. The proportion of children and young people prescribed rescue medication increased in cohort 5, compared to **23% (533/2324)** in cohort 4.

Table 50: Percentage of children and young people with epilepsy prescribed rescue medication in cohort 5 in England and Wales.

Rescue medication	England and Wales	England	Wales
Buccal midazolam	24.7% (547/2212)	24.8% (515/2074)	23.2% (32/138)
Rectal diazepam	*	*	*
Other	*	*	*
No record of rescue medication being prescribed	75.0% (1660/2212)	75.0% (1555/2074)	76.1% (105/138)

Investigations

Table 51 shows the percentage of children and young people with epilepsy in cohort 5 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 with epilepsy will require every investigation.

97% (2153/2212) of children and young people with epilepsy obtained a first EEG, **64%** obtained a 12-lead ECG, **64.6% (1429/2212)** obtained an MRI brain, and **14.5% (320/2212)** obtained a CT head scan within their first year of care. These figures have increased from cohort 4. **27.4% (605/2212)** had a formal developmental assessment, which was also an increase from cohort 4 (24%).

Table 51: Percentage of children and young people with epilepsy in cohort 5 who received each investigation within the first year of care in England and Wales.

Investigation	England and Wales	England	Wales
EEG obtained	97.3% (2153/2212)	97.5% (2023/2074)	94.2% (130/138)
EEG not requested	0.3% (7/2212)	*	*
EEG requested but not obtained	2.3% (51/2212)	2.1% (44/2074)	5.1% (7/138)
12 lead ECG	63.7% (1410/2212)	64.3% (1333/2074)	55.8% (77/138)
CT head scan	14.5% (320/2212)	13.9% (289/2074)	22.5% (31/138)
MRI Brain scan	64.6% (1429/2212)	64.8% (1344/2074)	61.6% (85/138)
Formal developmental assessment	27.4% (605/2212)	27.0% (561/2074)	31.9% (44/138)
Formal cognitive assessment	18.3% (404/2212)	18.5% (383/2074)	15.2% (21/138)

97.3% (2153/2324) of children and young people with epilepsy obtained an EEG within the first year of care and had a valid request date recorded. **53.6% (1154/2324)** had an EEG within four weeks of request, which is an increase from **52.0% (1209/2324)** in cohort 4. The proportion of children and young people waiting more than 16 weeks for an EEG from request increased to **7.7% (166/2212)** from **6.4% (148/2324)** in cohort 4.

Table 52 shows the time between EEG request and input in England and Wales in cohort 5. NICE guidelines state that children and young people having initial investigations for epilepsy undergo EEG investigations within 4 weeks of the initial request. Two children and young people did not have a valid EEG obtained date and are excluded from Table 52. **Table 53** and **Figure 29** shows the variation in time to EEG by deprivation quintile.

Table 52: Time in weeks between the date of initial EEG request and the date when the EEG was obtained, in cohort 5 in England and Wales.

Time in weeks	England and Wales	England	Wales
0 – 4 weeks	53.6% (1154/2153)	54.5% (1103/2023)	39.2% (51/130)
4 – 8 weeks	25.3% (544/2153)	25.7% (520/2023)	18.5% (24/130)
8 – 12 weeks	9.3% (201/2153)	8.6% (174/2023)	20.8% (27/130)
12 – 16 weeks	4.0% (86/2153)	3.7% (74/2023)	9.2% (12/130)
> 16 weeks	7.7% (166/2153)	7.4% (150/2023)	12.3% (16/130)

Table 53: Time in weeks between the date of initial EEG request and the date when the EEG was obtained, by deprivation quintile in cohort 5 in England and Wales.

	Most deprived	Second most deprived	Third least deprived	Second least deprived	Least deprived
0 – 4 weeks	54.1% (285/527)	49.0% (237/484)	55.3% (198/358)	55.4% (174/314)	55.0% (181/329)
4 – 8 weeks	24.1% (127/527)	26.4% (128/484)	22.3% (80/358)	25.2% (79/314)	28.6% (94/329)
8 – 12 weeks	10.2% (54/527)	11.2% (54/484)	7.3% (26/358)	8.9% (28/314)	8.8% (29/329)
12 – 16 weeks	2.8% (15/527)	4.8% (23/484)	5.6% (20/358)	4.1% (13/314)	2.7% (9/329)
> 16 weeks	8.7% (46/527)	8.3% (40/484)	9.5% (34/358)	6.4% (20/314)	4.9% (16/329)

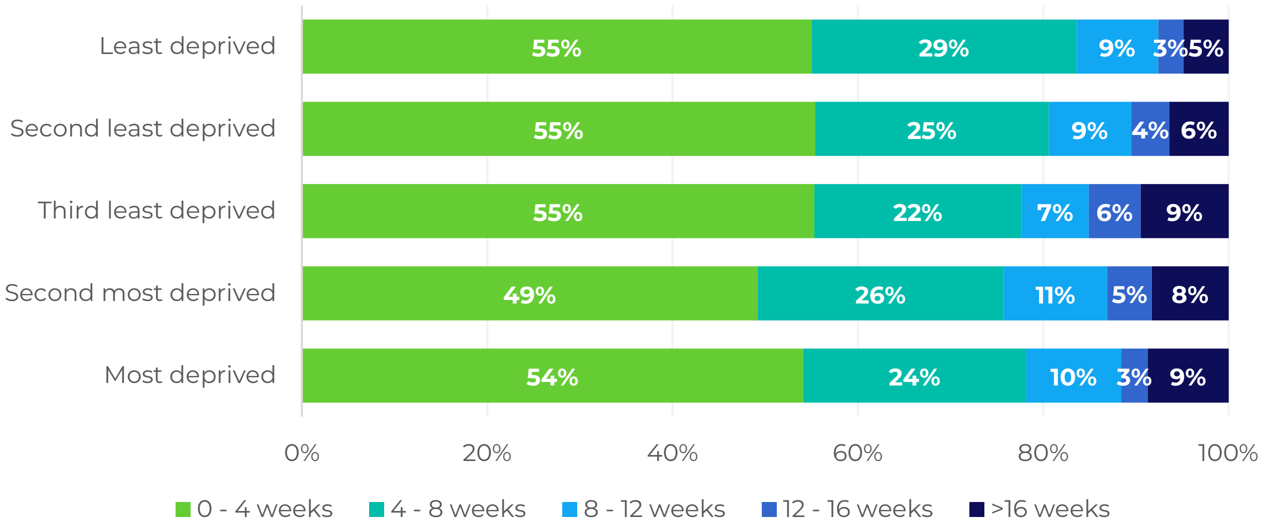


Figure 29: Time in weeks between the date of initial EEG request and the date when the EEG was obtained, by deprivation quintile in cohort 5 in England and Wales.

Professional input

In cohort 5, **89.7% (1984/2212)** of children and young people with epilepsy received input from a consultant paediatrician with expertise in epilepsy and **85.0% (1881/2212)** received input from an epilepsy specialist nurse within the first year of care. This is an increase from **88.9% (2065/2324)** and **79.7% (1852/2324)** respectively in cohort 4.

5.0% (110/2212) received input from a genetic service and **0.9% (19/2212)** from a ketogenic dietician, which is consistent with cohort 4.

Table 54: Percentage of children and young people with epilepsy receiving input by professionals and services in cohort 5 in England and Wales.

	England and Wales	England	Wales
Consultant paediatrician with expertise in epilepsies	89.7% (1984/2212)	89.4%(1854/2074)	94.2% (130/138)
Epilepsy specialist nurse	85.0% (1881/2212)	84.6% (1755/2074)	91.3% (126/138)
Paediatric neurologist	21.6% (477/2212)	21.2% (440/2074)	26.8% (37/138)
CESS	1.4% (32/2212)	*	*
Ketogenic dietician	0.9% (19/2212)	0.9% (19/2074)	0.0% (0/138)
VNS service	0.0% (0/2212)	0.0% (0/2074)	0.0% (0/138)
Genetic service	5.0% (110/2212)	5.1% (106/2074)	2.9% (4/138)
Clinical psychologist	2.2% (48/2212)	2.0% (41/2074)	5.1% (7/138)
Educational psychologist	0.5% (10/2212)	*	*
Psychiatrist	0.6% (13/2212)	0.6% (13/2074)	0.0% (0/138)
Neuropsychologist	*	*	*
Counselling service	0.7% (15/2212)	*	*
Other mental health professional	0.7% (16/2212)	*	*
Youth Worker	*	*	*
Other	0.0% (0/2212)	0.0% (0/2074)	0.0% (0/138)