Combined organisational and clinical audits:
Report for England and Wales
Round 3 Cohort 1 (2018-19)

RCPCH Audits

EPILEPSY12

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

Appendix G: Epilepsy12 clinical audit results

HQIP
Healthcare Quality Improvement Partnership

RCPCH
Royal College of Paediatrics and Child Health
Leading the way in Children's Health

Epilepsy12

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

Combined organisational and clinical audits: Report for England and Wales, Round 3 Cohort 1 (2018-19)

The Healthcare Quality Improvement Partnership (HQIP) is led by a consortium of the Academy of Medical Royal Colleges, the Royal College of Nursing and National Voices. Its aim is to promote quality improvement in patient outcomes, and in particular, to increase the impact that clinical audit, outcome review programmes and registries have on healthcare quality in England and Wales. HQIP holds the contract to commission, manage and develop the National Clinical Audit and Patient Outcomes Programme (NCAPOP), comprising around 40 projects covering care provided to people with a wide range of medical, surgical and mental health conditions. The programme is funded by NHS England, the Welsh Government and, with some individual projects, other devolved administrations and crown dependencies.
www.hqip.org.uk/national-programmes

© 2020 Healthcare Quality Improvement Partnership (HQIP)

Published by RCPCH September 2020.

The Royal College of Paediatrics and Child Health is a registered charity in England and Wales (1057744) and in Scotland (SCO38299).

Appendices

The Epilepsy12 combined report for 2020 includes a description of key findings, recommendations, quality improvement activities, and patient involvement in Epilepsy12. It is available to download from Epilepsy12.

Appendix: Full Epilepsy12 organisational audit results for Round 3, includes the publication of the structure of services and available workforce for paediatric epilepsy service staff within Health Boards and Trusts with England and Wales. It is available to download from Epilepsy12.

Appendix G: Full Epilepsy12 clinical audit results for Round 3, Cohort 1 **5**

Appendix H: List of clinical data figures & tables **87**

Appendix I: Data completeness **92**

Appendix J: Participating Health Boards and Trusts by OPEN UK region **95**

Appendix K: Glossary of terms and abbreviations **100**

The 16 OPEN UK Regional Paediatric Epilepsy Networks are named in the following table. The abbreviated regional network names appear in the regional network results of both the clinical and organisational audits in this report.

OPEN UK Regional Paediatric Epilepsy Network	Regional Network full name
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
NI	Northern Ireland epilepsy services
ORENG	Oxford Region Epilepsy Interest Group
PENNEC	Paediatric Epilepsy Network for the North East and Cumbria
SETPEG	South East Thames Paediatric Epilepsy Group
SPEN	Scottish Paediatric Epilepsy Network
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

Appendix D: Full Epilepsy12 clinical audit results for Round 3, Cohort 1

Participation and case ascertainment

Participation

Table 47 provides a breakdown on Epilepsy12 Round 3 participation by Paediatric Epilepsy Networks and by country.

- There are 149 registered Health Boards and Trusts in Round 3 of Epilepsy12,
- 113 out of 149 (75.8%) Health Boards and Trusts submitted a record of the first year of care clinical data for one or more children and young people in cohort 1.

Table 47: Participation in Round 3 of Epilepsy12.

Country/network	Number of registered Health Boards and Trusts	Number of Health Boards and Trusts that have submitted clinical audit data
England & Wales	149	75.8% (113/149)
England	143	76.2% (109/143)
Wales	6	66.7% (4/6)
BRPNF	15	73.3% (11/15)
CEWT	6	100% (6/6)
EPEN	15	66.7% (10/15)
EPIC	9	100% (9/9)
NTPEN	17	70.6% (12/17)
NWEIG	13	84.6% (11/13)
ORENG	7	100% (7/7)
PENNEC	9	77.8% (7/9)
SETPEG	11	45.5% (5/11)
SWEP	5	60.0% (3/5)
SWIPE	11	54.5% (6/11)
SWTPEG	7	71.4% (5/7)
TEN	6	100% (6/6)
WPNN	9	77.8% (7/9)
YPEN	9	88.9% (8/9)

Case ascertainment

Table 48 shows between 5th July 2018 and 8th January 2020, a total of **10,649** children and young people were registered via an EEG service and a further **3,954** registered by the Health Boards and Trusts.

- By download date (8th January 2020) 10,954 children and young people were verified for inclusion in Round 3 and beyond cohorts.
- In addition to the registered children and young people, 1,280 children and young people were excluded at verification stage because they did not meet the audit inclusion criteria,
- 22 families had requested their children to be opted out of the audit post verification stage.

Table 48: Shows the flow of children and young people through the data capture system i.e. entry via EEG or Health Boards and Trusts through to inclusion in Round 3 cohorts.

Country/network	No. registered by EEG	No. registered by Health Boards and Trusts	No. verified by Health Boards and Trusts	No. not yet verified by Health Boards and Trusts	No. opt out	No. excluded
England &Wales	10649	3942	10954	3615	22	1280
England	10228	3823	10542	3488	21	1177
Wales	421	119	412	127	1	103
BRPNF	919	299	967	251	0	154
CEWT	828	125	743	206	4	60
EPEN	774	273	648	399	0	144
EPIC	98	455	508	44	1	68
NTPEN	1602	219	1189	631	1	188
NWEIG	728	296	773	251	0	124
ORENG	1278	225	993	510	0	114
PENNEC	536	434	841	129	0	35
SETPEG	316	275	521	70	0	59
SWEP	324	100	337	87	0	75
SWIPE	887	288	936	231	8	105
SWTPEG	457	350	658	142	7	35
TEN	624	125	592	157	0	32
WPNN	795	106	483	417	1	65
YPEN	483	372	765	90	0	22

Table 49 (below) shows a comparison of the details of the number of children and young people that were assessed as eligible for Round 2 and Round 3 audits. The total number of children and young people allocated to the cohort was higher in Round 3 (**4684**) than Round 2 (**3350**) in England and Wales combined.

Of the **4684** children and young people who met the audit criteria in Round 3 and were verified and allocated to cohort 1, **70.8%** were successfully entered on the data capture system. The data completeness in Round 3 was lower (**70.8%**) compared to Round 2 (**91.7%**).

Table 49: Number of children and young people registered as eligible for the audit

	Round 2			Round 3		
Description of eligible criteria	**England and Wales**	**England**	**Wales**	**England and Wales**	**England**	**Wales**
Children registered (by EEG services and the HBTs)	12973	12391	582	14591	14051	540
Children excluded (did not meet audit inclusion criteria)	8832	8479	353	1280	1177	103
Children allocated to cohort **(for Round 3 the data refers to only cohort 1)**	3350	3174	176	4684	4490	194
Children allocated to cohort who had their first year of care data successfully entered on data capture system	3072	2907	165	3318	3195	123
Children allocated to cohort but their first year of care data was not successfully entered on data capture system	272	261	11	1366	1295	71
Data completeness	91.7% (3072/3350)	91.6% (2907/3174)	93.8% (165/176)	70.8% (3318/4684)	71.1% (3195/4490)	63.4 % (123/194)

Health Board and Trust ascertainment

Figure 30 shows the proportion of children and young people who were registered and verified on the data capture system by each of the Health Boards and Trusts by the download date (8th January 2020). One quarter of the Health Boards and Trusts verified all the children and young people that were registered as eligible for the audit. Unverified children and young people includes children who may be allocated to cohort 1, 2 or 3 at verification stage, or who may be excluded.

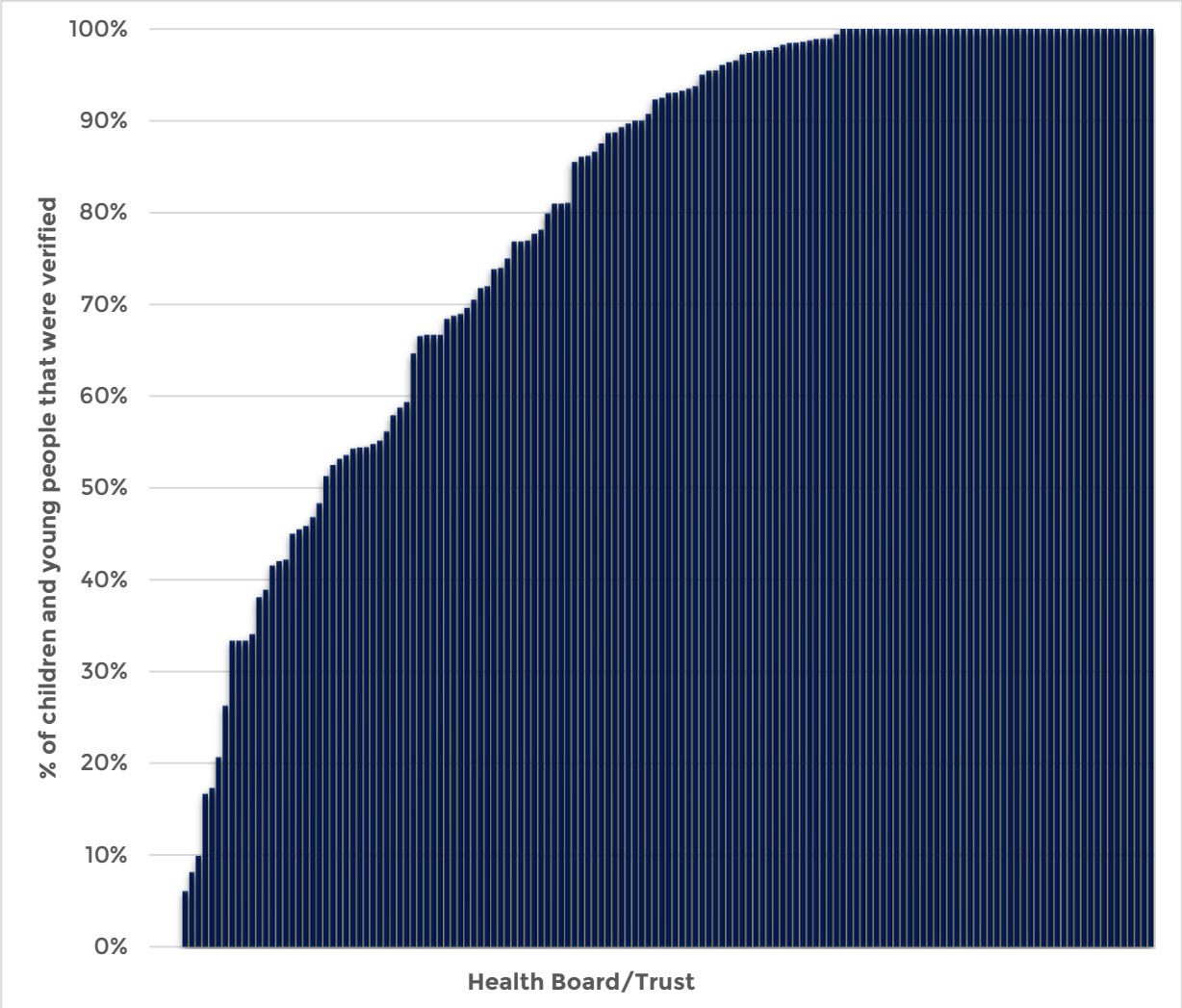


Figure 30: Percentage of children and young people verified by Health Boards and Trusts in Round 3.

Each Health Board and Trust is represented by a vertical bar in the order of the percentage score, including those scoring 0%.

Health Board and Trust data completeness

Figure 31 shows the proportion of children and young people allocated to Round 3, cohort 1, that had their first year of care form submitted and locked on the data capture system, by each of the Health Boards and Trusts by the download date (8th January 2020). Nationally nearly half of the registered Health Board or Trust submitted and locked the first year of care form for all the children allocated to cohort 1 in Round 3.

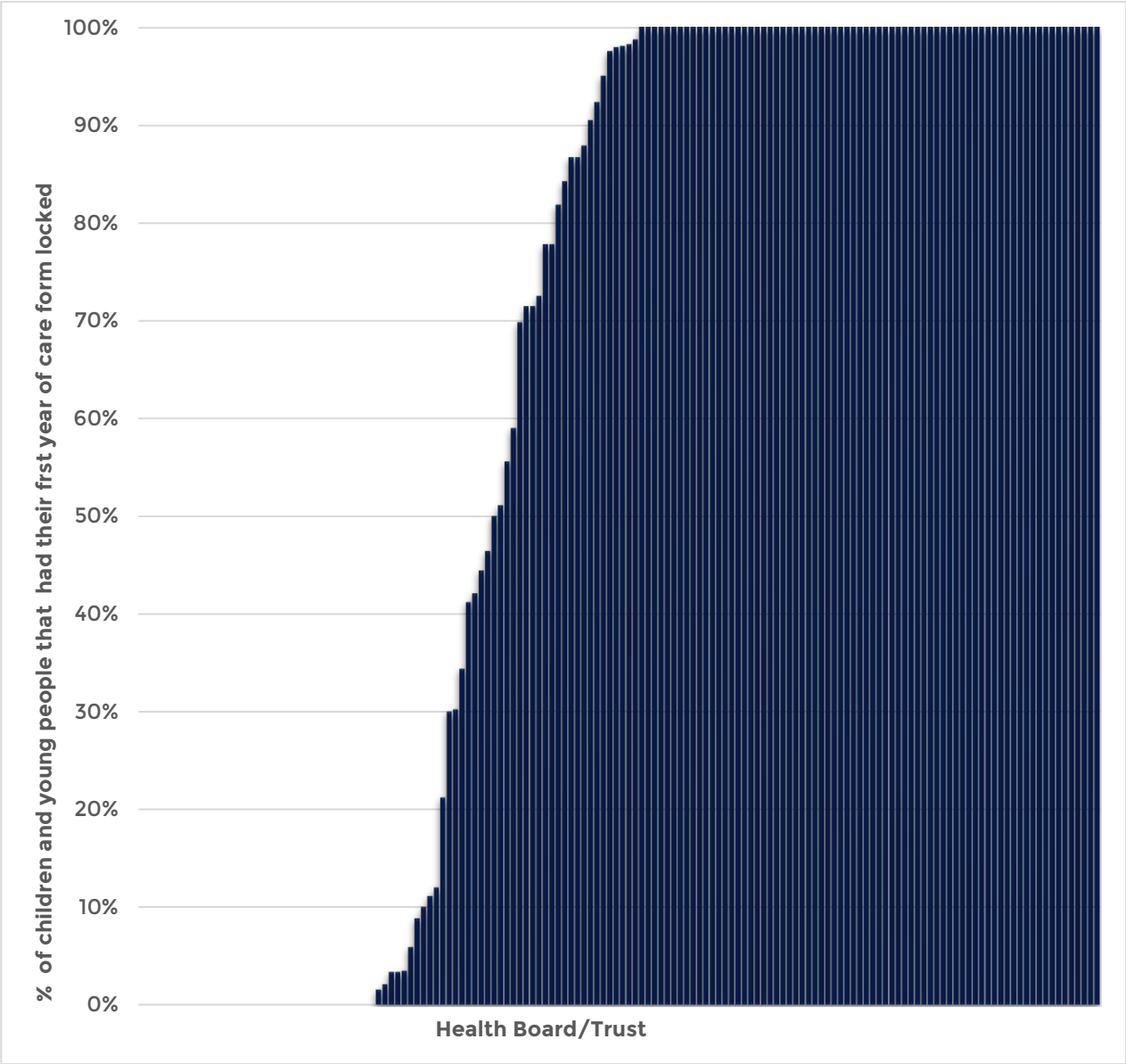


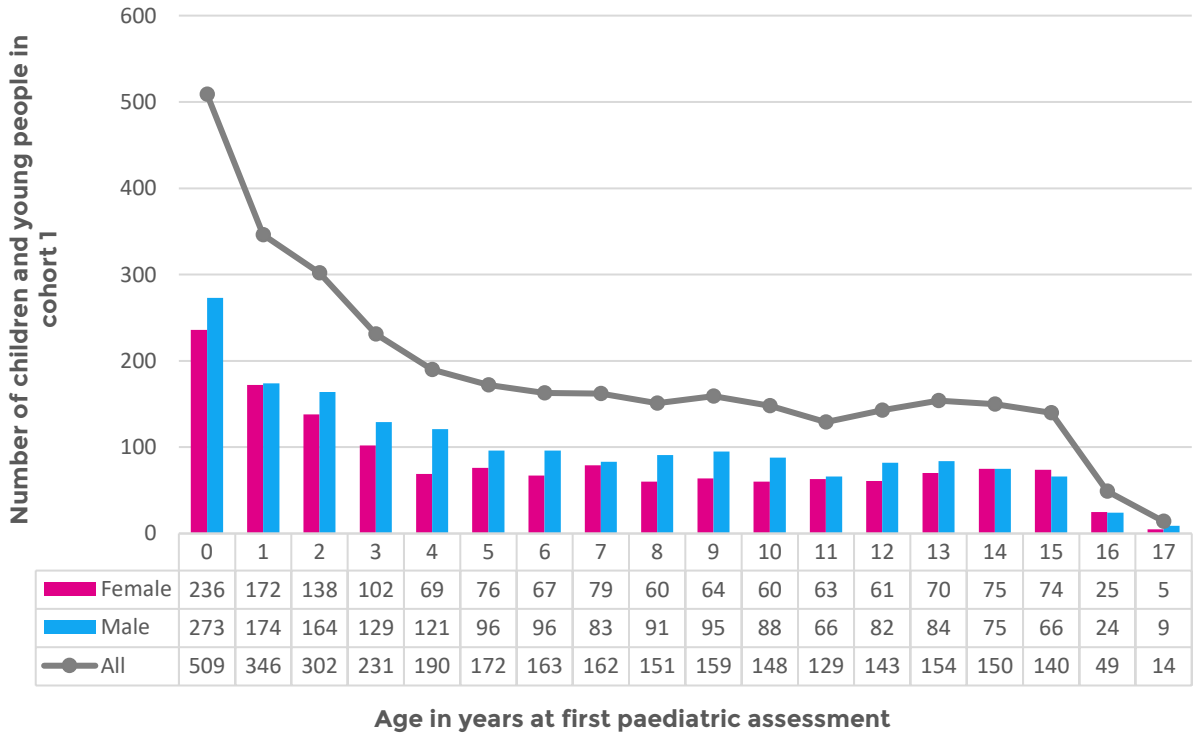
Figure 31: The percentage of children and young people within cohort 1 with their first year of care form submitted and locked.

Each Health Board and Trust is represented by a vertical bar in the order of the percentage score, including those scoring 0%.

Description of cohort 1

Age and sex

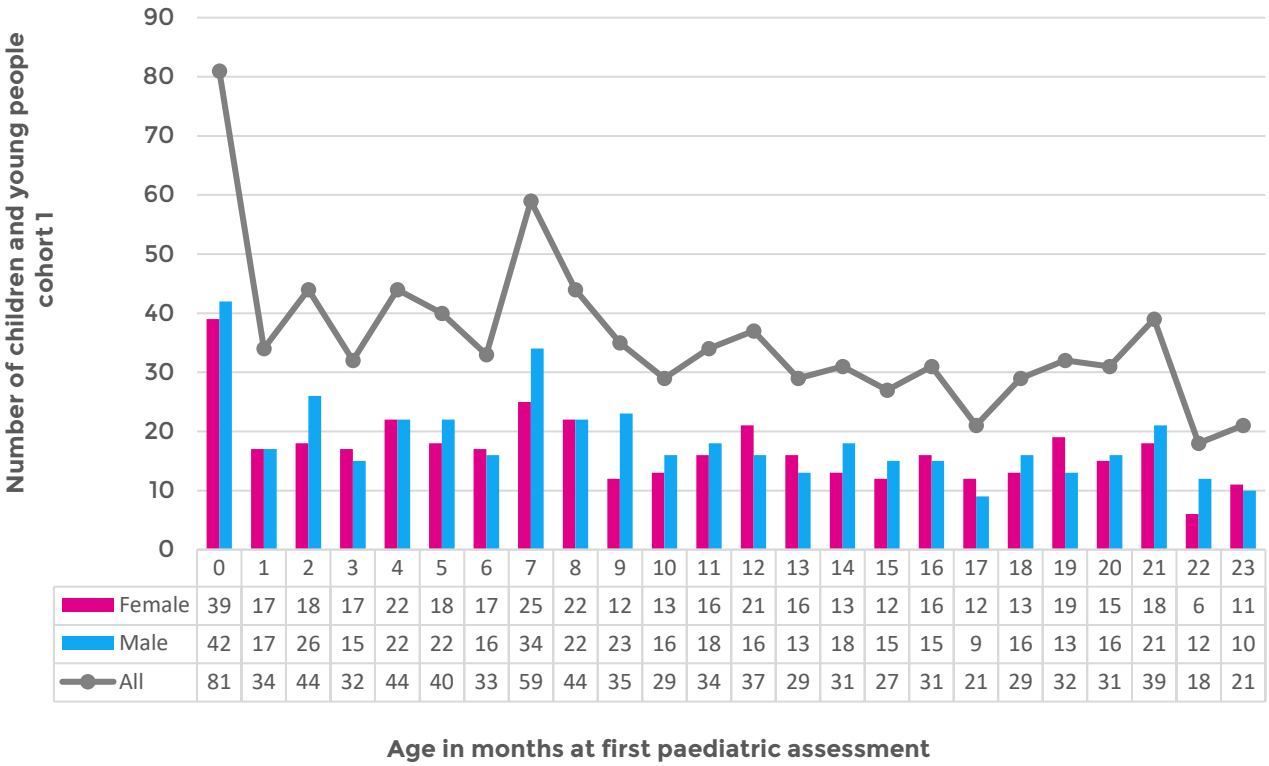
Figure 32 shows the number of children and young people in cohort 1 by their age at the time of their first paediatric assessment. The children and young people's ages are given in whole years, giving their age at their last birthday. The largest age groups in cohort 1 were younger children; infants below one year of age, and children aged one or two years old. The number of children and young people in cohort 1 is highest in infancy and decreases among older year groups, in particular for young people aged 16 or 17. This is likely to reflect some of the older young people in our cohort age range being assessed within adult services. There were more boys than girls in each year group until age 14.



	0	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
Female	236	172	138	102	69	76	67	79	60	64	60	63	61	70	75	74	25	5
Male	273	174	164	129	121	96	96	83	91	95	88	66	82	84	75	66	24	9
All	509	346	302	231	190	172	163	162	151	159	148	129	143	154	150	140	49	14

Figure 32: Numbers of children and young people included in cohort 1 by age in years at first paediatric assessment and gender. (This figure excludes 6 children with unknown gender).

Figure 33 shows the number of children and young people in cohort 1 who were less than two years of age at first paediatric assessment. This is broken down by age in months and gender. The most common time for children below two years of age to have a first paediatric assessment was in either their first month of life (81) or at seven-months old (59).



	0	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23
Female	39	17	18	17	22	18	17	25	22	12	13	16	21	16	13	12	16	12	13	19	15	18	6	11
Male	42	17	26	15	22	22	16	34	22	23	16	18	16	13	18	15	15	9	16	13	16	21	12	10
All	81	34	44	32	44	40	33	59	44	35	29	34	37	29	31	27	31	21	29	32	31	39	18	21

Figure 33: Numbers of children and young people included in cohort 1 by age in months at first paediatric assessment and gender. (This figure excludes 3 children with unknown gender).

Table 50 shows the proportion of children and young people in different age groups, by country or by paediatric epilepsy network area. In cohort 1:

- 25.9% of the children and young people were aged between one month and two years,
- 21.8 % were aged between two and four years,
- 32.7% were aged between five and eleven years,
- 19.6% were aged over twelve years of age.

Table 50: Number of children and young people in cohort 1 by country, network and age-group.

Country/network	% <2 years	% 2 - 4 years	% 5 - 11 years	% >=12 years
England & Wales (N=3318)	25.9% (858/3318)	21.8% (723/3318)	32.7% (1086/3318)	19.6% (651/3318)
England (N=3195)	26% (832/3195)	21.6% (690/3195)	32.7% (1046/3195)	19.6% (627/3195)
Wales (N=123)	21.1% (26/123)	26.8% (33/123)	32.5% (40/123)	19.5% (24/123)
BRPNF (N=248)	23.8% (59/248)	17.7% (44/248)	33.5% (83/248)	25.0% (62/248)
CEWT (N=281)	27.4% (77/281)	16.7% (47/281)	35.2% (99/281)	20.6% (58/281)
EPEN (N=210)	23.8% (50/210)	23.3% (49/210)	38.1% (80/210)	14.8% (31/210)
EPIC (N=207)	24.2% (50/207)	28.5% (59/207)	32.4% (67/207)	15.0% (31/207)
NTPEN (N=298)	27.9% (83/298)	18.1% (54/298)	35.6% (106/298)	18.5% (55/298)
NWEIG (N=222)	25.2% (56/222)	21.6% (48/222)	36.0% (80/222)	17.1% (38/222)
ORENG (N=299)	22.4% (67/299)	20.7% (62/299)	35.1% (105/299)	21.7% (65/299)
PENNEC (N=237)	27.4% (65/237)	25.3% (60/237)	29.1% (69/237)	18.1% (43/237)
SETPEG (N=52)	30.8% (16/52)	17.3% (9/52)	23.1% (12/52)	28.8% (15/52)
SWEP (N=112)	21.4% (24/112)	26.8% (30/112)	30.4% (34/112)	21.4% (24/112)
SWIPE (N=272)	26.1% (71/272)	27.2% (74/272)	26.8% (73/272)	19.9% (54/272)
SWTPEG (N=186)	29.0% (54/186)	19.9% (37/186)	31.7% (59/186)	19.4% (36/186)
TEN (N=222)	28.8% (64/222)	23.0% (51/222)	29.7% (66/222)	18.5% (41/222)
WPNN (N=152)	28.9% (44/152)	24.3% (37/152)	30.3% (46/152)	16.4% (25/152)
YPEN (N=320)	24.4% (78/320)	19.4% (62/320)	33.4% (107/320)	22.8% (73/320)

Table 51 (below) shows the median age of children included in Round 3, cohort 1, was 5 years old. **45.1%** of the children were female. There are no clear differences in demographics between England and Wales. The sample window for Round 1, Round 2 and Round 3, cohort 1, was; 6 months, 4 months and 4.5 months respectively, hence the difference in cohort sizes.

Table 51: Demographic characteristics of children included in Round 1, 2 and 3 of Epilepsy12.

Median age	Round 1			Round 2			Round 3		
	UK	England	Wales	UK	England	Wales	UK	England	Wales
N	4310	4085	225	3072	2907	165	3318	3195	123
% Female	46.0%	46.0%	49.0%	45.0%	45.0%	45.0%	45.1%	45.0%	48.0%
Median age (years)	+	6.4	7.5	+	5.3	5.9	5.4	5.4	5.3
25th centile (years)	+	2.2	3.1	+	2	2.5	1.8	1.8	2.3
75thcentile (years)	+	10.7	12.1	+	10.2	10.3	10.6	10.6	10.7
Infants (1 month to < 2 years)	22.7%	23.0%	18.0%	24.7%	25.0%	21.0%	25.9%	26.0%	21.1%
Pre-school (2-4 years)	19.8%	20.0%	17.0%	23.8%	24.0%	21.0%	21.8%	21.6%	26.8%
School (5-11 years)	37.1%	37.0%	39.0%	34.3%	34.0%	39.0%	32.7%	32.7%	32.5%
Young people (12-15 years)	19.3%	19.0%	25.0%	17.1%	17.0%	19.0%	17.7%	17.7%	17.1%

+ UK median and centile values were not available for comparison for this metric

Figure 34 shows the overall proportions of the children by age groups are similar in Round 1, Round 2 and Round 3.

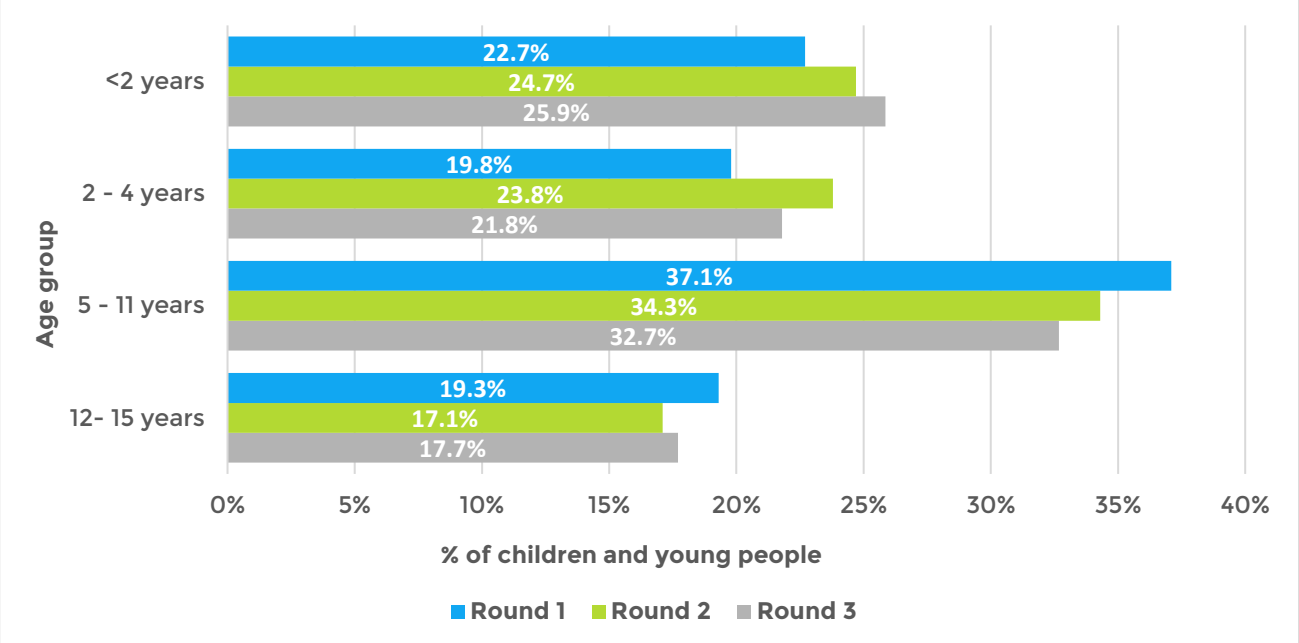


Figure 34: Comparison of the proportion of children and young people by age group in Round 1, Round 2 and Round 3.

Deprivation

Table 52 shows the breakdown of children and young people in Epilepsy12 cohort 1 by deprivation quintile. This was derived by matching home postcodes to the English (IMD, 2019) and Welsh (WIMD, 2019) indices of multiple deprivation data. A small proportion **32 (1.0%)** of children and young people could not be allocated to a deprivation quintile, because their postcodes had no matching lower super output area (LSOA) in the deprivation datasets. Over half of the children and young people in cohort 1 lived in neighbourhoods that are among the most deprived areas of England and Wales, (**50.2%** in the top two most deprived quintiles).

Table 52: Percentage and number of children and young people in cohort 1 by deprivation by country and network.

Country/network	Most deprived	Second most deprived	Third least deprived	Second least deprived	Least deprived
England &Wales (N=3286)	28.2% (926/3286)	22% (724/3286)	18.8% (619/3286)	17.3% (567/3286)	13.7% (450/3286)
England (N=3166)	28.2% (892/3166)	22.0% (698/3166)	18.7% (591/3166)	17.2% (545/3166)	13.9% (440/3166)
Wales (N=120)	28.3% (34/120)	21.7% (26/120)	23.3% (28/120)	18.3% (22/120)	8.3% (10/120)
BRPNF (N=247)	37.7% (93/247)	18.6% (46/247)	17.4% (43/247)	15.4% (38/247)	10.9% (27/247)
CEWT (N=281)	27.8% (78/281)	22.1% (62/281)	18.9% (53/281)	17.1% (48/281)	14.2% (40/281)
EPEN (N=209)	15.3% (32/209)	15.8% (33/209)	25.4% (53/209)	24.9% (52/209)	18.7% (39/209)
EPIC (N=203)	43.3% (88/203)	17.2% (35/203)	16.7% (34/203)	16.3% (33/203)	6.4% (13/203)
NTPEN (N=295)	25.4% (75/295)	31.9% (94/295)	19.7% (58/295)	13.2% (39/295)	9.8% (29/295)
NWEIG (N=221)	48.4% (107/221)	20.8% (46/221)	10.9% (24/221)	12.7% (28/221)	7.2% (16/221)
ORENG (N=292)	15.1% (44/292)	16.8% (49/292)	16.1% (47/292)	27.1% (79/292)	25% (73/292)
PENNEC (N=234)	44.4% (104/234)	24.4% (57/234)	11.5% (27/234)	13.2% (31/234)	6.4% (15/234)
SETPEG (N=52)	19.2% (10/52)	34.6% (18/52)	21.2% (11/52)	17.3% (9/52)	7.7% (4/52)
SWEP (N=109)	30.3% (33/109)	22.0% (24/109)	23.9% (26/109)	16.5% (18/109)	7.3% (8/109)
SWIPE (N=271)	12.9% (35/271)	26.6% (72/271)	30.3% (82/271)	17.3% (47/271)	12.9% (35/271)
SWTPEG (N=184)	1.1% (2/184)	19.6% (36/184)	15.8% (29/184)	25% (46/184)	38.6% (71/184)
TEN (N=221)	42.1% (93/221)	25.3% (56/221)	15.8% (35/221)	8.6% (19/221)	8.1% (18/221)
WPNN (N=151)	10.6% (16/151)	21.9% (33/151)	33.1% (50/151)	17.9% (27/151)	16.6% (25/151)
YPEN (N=316)	36.7% (116/316)	19.9% (63/316)	14.9% (47/316)	16.8% (53/316)	11.7% (37/316)

Figure 35 shows that the proportion of children and young people in cohort 1 living in the most deprived quintiles was significantly higher than the proportion living in the least deprived quintiles of England and Wales.

Figure 36 shows the deprivation indices for children and young people's home addresses for each of the regional paediatric epilepsy networks. This shows that there are considerable differences between networks, and also variation from the overall picture for England and Wales.

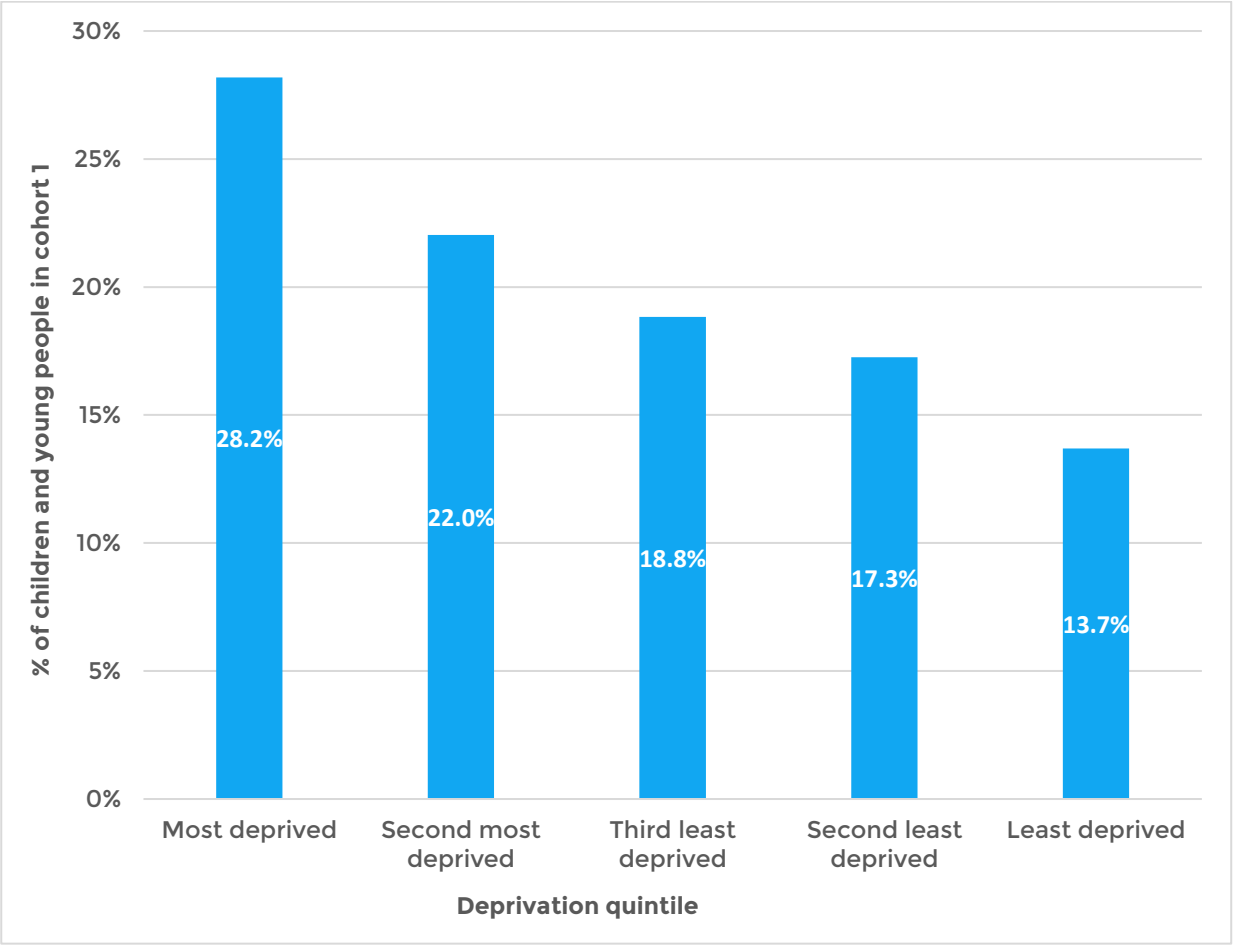


Figure 35: Percentage of children and young people in cohort 1 by deprivation quintile in England and Wales combined.

Figure 36 shows a comparison of the proportion of children and young people by deprivation quintile and by country/network.

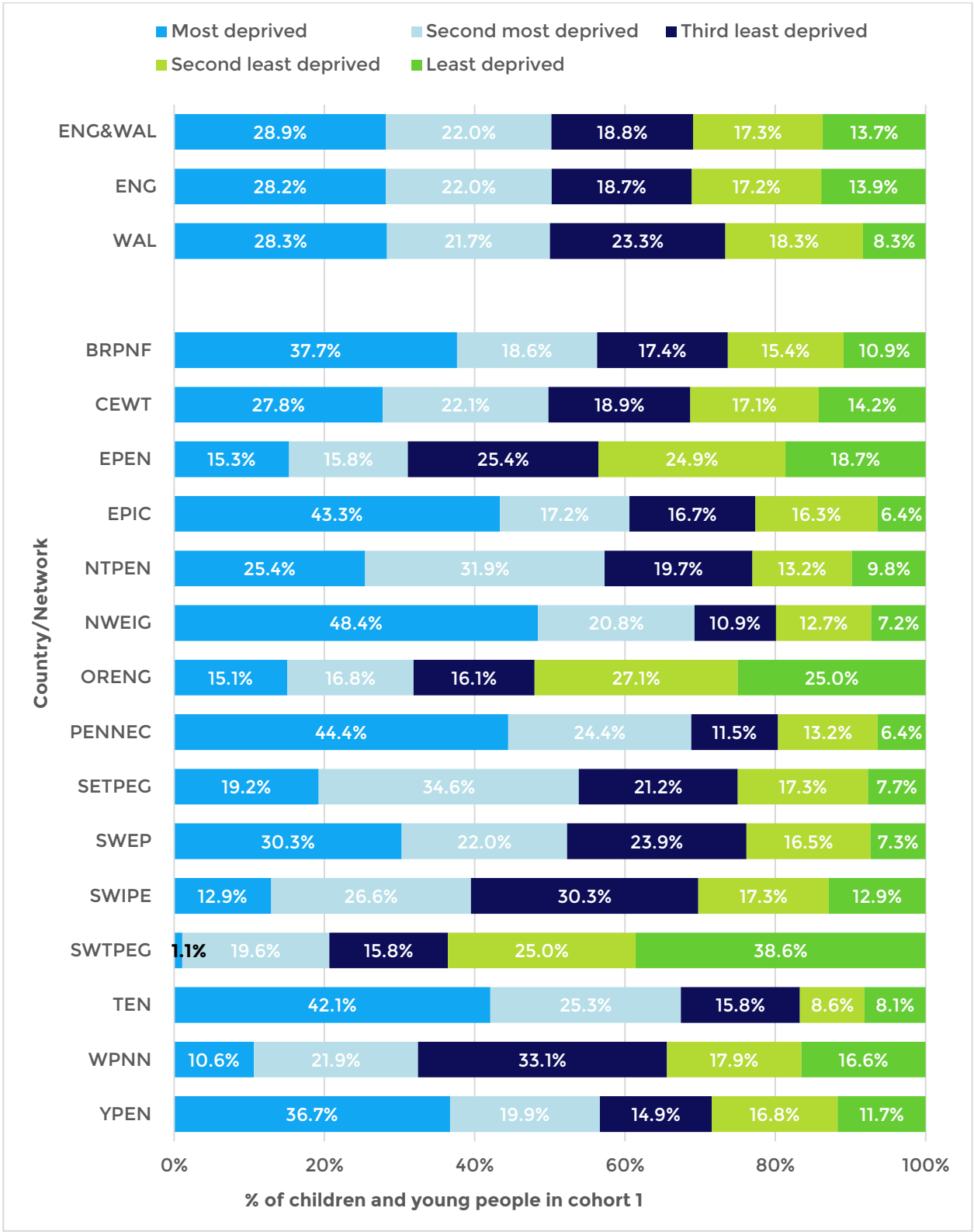


Figure 36: Percentage of children and young people in cohort 1 by deprivation by country/network.

Diagnostic status

Prior experience of seizures

Table 53 shows **2.7% (91/3318)** of children and young people in Round 3, cohort 1, had prior experience of neonatal seizures.

8.4% (279/3318) had prior experience of febrile seizures. **6.2% (205/3318)** had prior experience of acute symptomatic seizures. Most children and young people did not have any prior experience of neonatal, febrile or acute symptomatic seizures, (**Figure 38**).

Table 53: Prior experience of seizures in children and young people in cohort 1 in England and Wales.

Description of neonatal seizures	% with prior seizures	% without prior seizures	% Uncertain about prior seizures
Neonatal seizure(s)	2.7% (91/3318)	85.3% (2831/3318)	11.9% (396/3318)
Febrile seizure(s)	8.4% (279/3318)	80.6% (2674/3318)	11.0% (365/3318)
Acute symptomatic seizure (s)	6.2% (205/3318)	83.4% (2767/3318)	10.4% (346/3318)

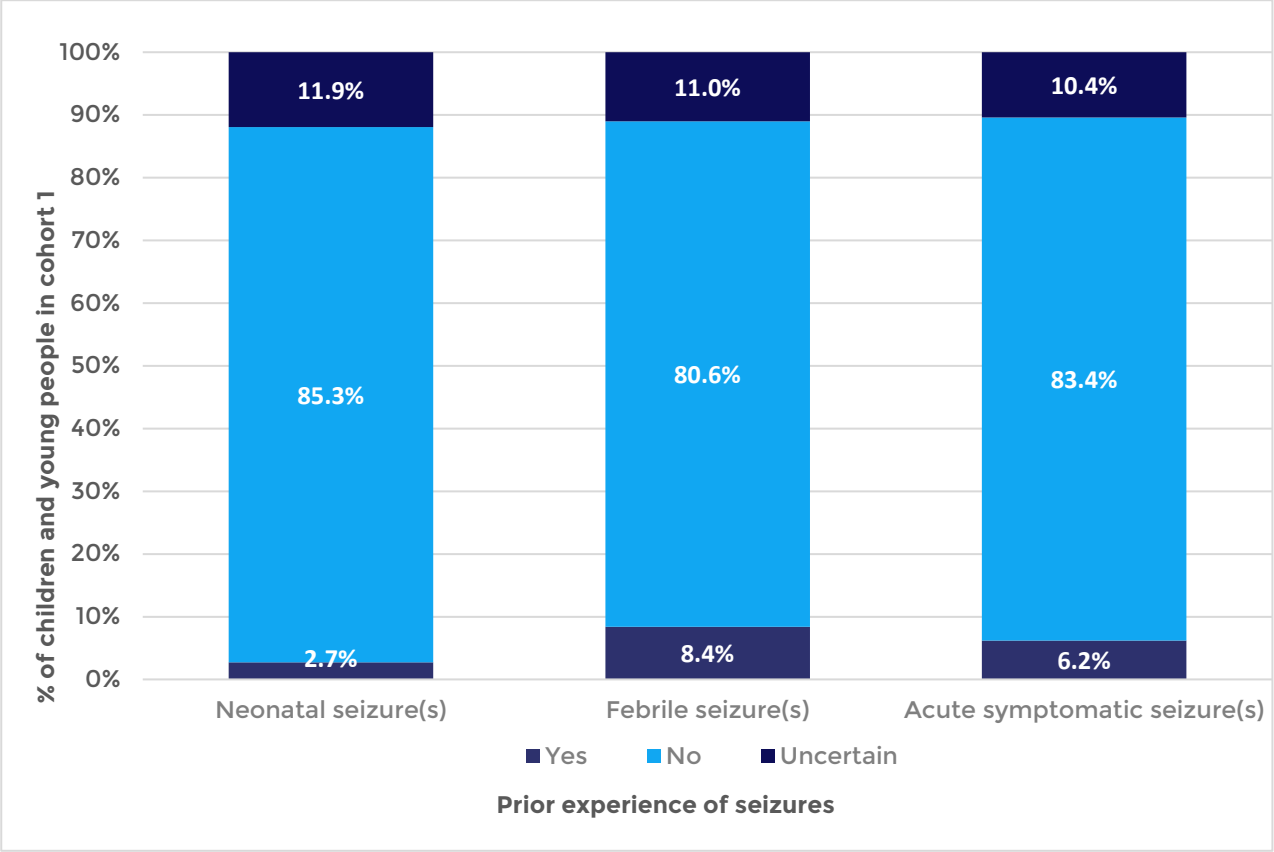


Figure 37: Percentage of children and young with/without prior experience of seizures.

Table 54 shows the diagnostic status of children and young people in cohort 1 in the first year of care. In England and Wales combined, **32.3% (1073/3318)**, children and young people were diagnosed with epilepsy because they had two or more epileptic episodes more than 24 hours apart. **1.2% (39/3318)** of children and young people were diagnosed with epilepsy for other reasons. This means, in total, **33.5% (1112)** of children were diagnosed with epilepsy in cohort 1.

For children and young people who had recorded seizure episodes, but were not diagnosed with epilepsy, there were:

- **38.4% (1275/3318)** who had non-epileptic episodes only,
- **3.2% (107/3318)** who had a single epileptic episode,
- **1.4% (46/3318)** who had a cluster of epileptic episodes within 24 hours,
- For **23.4% (778/3318)** children and young people, there was uncertainty whether the episodes were epileptic or not.

Figure 38 shows the percentages of children and young people in cohort 1 by diagnostic status in England and Wales.

Table 54: Diagnostic status at first year of care by country and network.

Country/ network	Epilepsy: 2 or more epileptic episodes more than 24 hours apart	Epilepsy: other reason	Not epilepsy: single epileptic episode	Not epilepsy: cluster of epileptic episodes within 24 hours	Non-epileptic episode (s)	Uncertain episodes
England & Wales (N=3318)	32.3% (1073/3318)	1.2% (39/3318)	3.2% (107/3318)	1.4% (46/3318)	38.4% (1275/3318)	23.4% (778/3318)
England (N=3195)	31.7% (1013/3195)	1.2% (38/3195)	3.3% (105/3195)	1.4% (46/3195)	39.1% (1248/3195)	23.3% (745/3195)
Wales (N=123)	48.8% (60/123)	*	*	0.0% (0/123)	22.0% (27/123)	26.8% (33/123)
BRPNF (N=248)	36.3% (90/248)	*	2.4% (6/248)	*	36.3% (90/248)	22.6% (56/248)
CEWT (N=281)	32.4% (91/281)	*	4.3% (12/281)	*	42.7% (120/281)	16.4% (46/281)
EPEN (N=210)	30.5% (64/210)	5.2% (11/210)	*	*	24.3% (51/210)	35.7% (75/210)
EPIC (N=207)	53.1% (110/207)	*	2.4.0% (5/207)	*	28.5% (59/207)	14.5% (30/207)
NTPEN (N=298)	32.2% (96/298)	*	4.4% (13/298)	*	31.2% (93/298)	30.2% (90/298)
NWEIG (N=222)	30.2% (67/222)	*	4.1% (9/222)	*	41.9% (93/222)	23.4% (52/222)
ORENG (N=299)	29.1% (87/299)	*	4.0% (12/299)	*	37.8% (113/299)	25.8% (77/299)
PENNEC (N=237)	26.6% (63/237)	*	2.5% (6/237)	*	43% (102/237)	25.7% (61/237)
SETPEG (N=52)	36.5% (19/52)	*	0.0% (0/52)	*	19.2% (10/52)	34.6% (18/52)
SWEP (N=112)	44.6% (50/112)	*	*	0.0% (0/112)	24.1% (27/112)	28.6% (32/112)
SWIPE (N=272)	26.1% (71/272)	*	1.8% (5/272)	*	50.4% (137/272)	20.6% (56/272)
SWTPEG (N=186)	34.4% (64/186)	*	5.9% (11/186)	*	45.2% (84/186)	12.4% (23/186)
TEN (N=222)	23.4% (52/222)	*	2.7% (6/222)	*	47.3% (105/222)	24.8% (55/222)
WPNN (N=152)	26.3% (40/152)	*	*	*	44.1% (67/152)	25.0% (38/152)
YPEN (N=320)	34.1% (109/320)	*	3.1% (10/320)	*	38.8% (124/320)	21.6% (69/320)

** In accordance with information governance rules, data based on a number less than five has been masked*

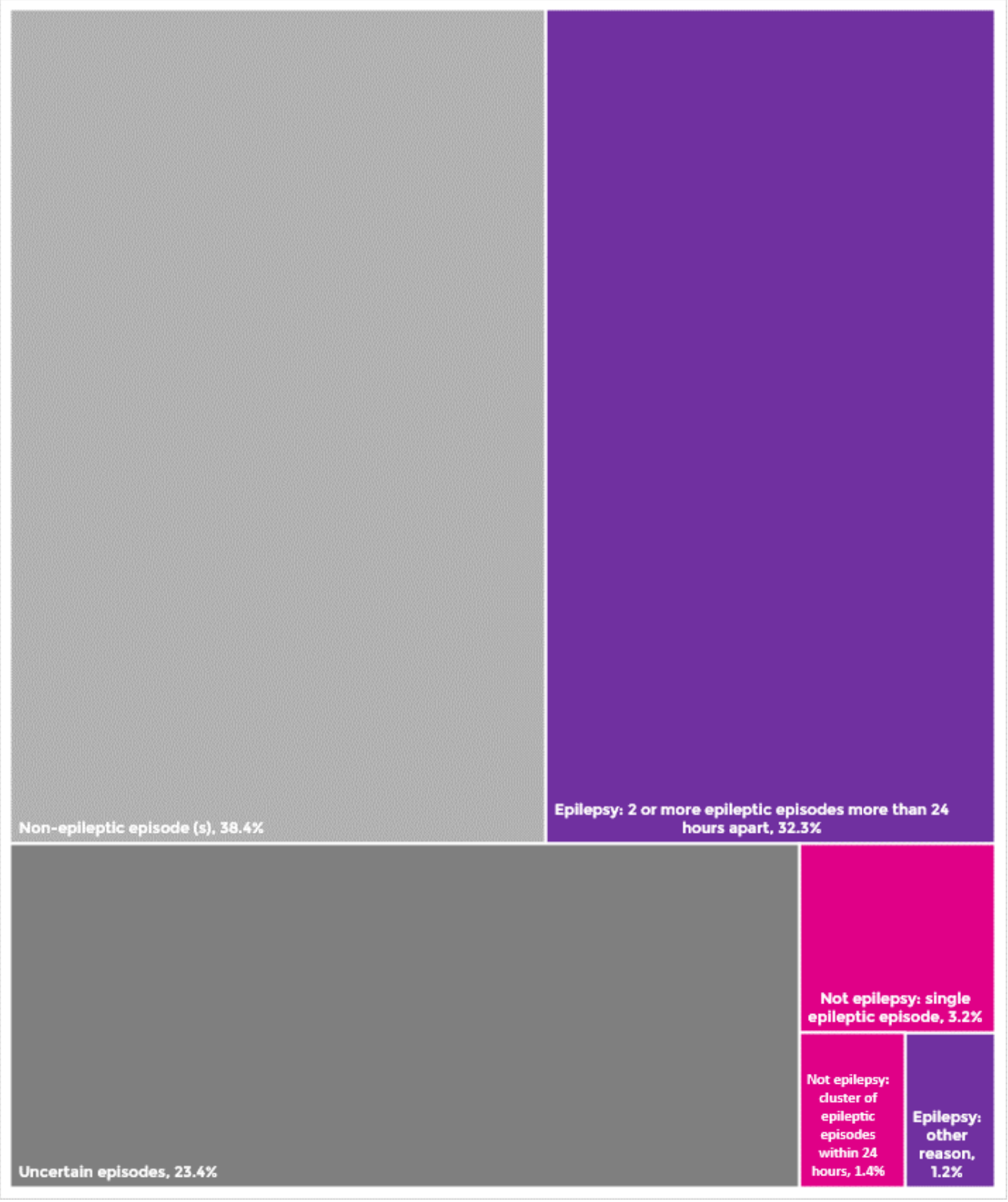


Figure 38: Percentage of children and young people in Cohort 1 by diagnostic status at first year of care, in England and Wales.

Table 55 shows the diagnostic status of children and young people in cohort 1 in the first paediatric assessment. The number of children where there remains uncertainty as to whether the episodes were epileptic or not, reduced from **35.8% (1172)** in the first paediatric assessment, to **23.4% (778)** in the first year of care, (**Figure 39**).

Table 55: Diagnostic status at first paediatric assessment by country and network.

Country/ network	Epilepsy: 2 or more epileptic episodes more than 24 hours apart	Epilepsy: other reason	Not epilepsy: single epileptic episode	Not epilepsy: cluster of epileptic episodes within 24 hours	Non-epileptic episode (s)	Uncertain episodes
England &Wales (N=3318)	29.9% (992/3318)	1.5% (49/3318)	4.2% (141/3318)	1.8% (61/3318)	27.2% (903/3318)	35.3% (1172/3318)
England (N=3195)	29.2% (932/3195)	1.5% (48/3195)	4.3% (137/3195)	1.9% (61/3195)	27.4% (877/3195)	35.7% (1140/3195)
Wales (N=123)	48.8% (60/123)	*	*	0.0% (0/123)	21.1% (26/123)	26.0% (32/123)
BRPNF (N=248)	31.9% (79/248)	*	4.8% (12/248)	*	28.6% (71/248)	29.8% (74/248)
CEWT (N=281)	25.6% (72/281)	*	*	3.6% (10/281)	29.9% (84/281)	37.7% (106/281)
EPEN (N=210)	32.4% (68/210)	5.2% (11/210)	*	*	24.8% (52/210)	33.3% (70/210)
EPIC (N=207)	49.8% (103/207)	*	2.9% (6/207)	*	16.4% (34/207)	27.5% (57/207)
NTPEN (N=298)	29.5% (88/298)	*	7.4% (22/298)	*	22.8% (68/298)	38.3% (114/298)
NWEIG (N=222)	23.9% (53/222)	*	*	*	23% (51/222)	49.1% (109/222)
ORENG (N=299)	26.4% (79/299)	2.0% (6/299)	7.4% (22/299)	2.0% (6/299)	32.4% (97/299)	29.8% (89/299)
PENNEC (N=237)	26.2% (62/237)	*	3.8% (9/237)	*	27.8% (66/237)	40.1% (95/237)
SETPEG (N=52)	36.5% (19/52)	*	*	*	11.5% (6/52)	40.4% (21/52)
SWEP (N=112)	45.5% (51/112)	*	*	0.0% (0/112)	23.2% (26/112)	27.7% (31/112)
SWIPE (N=272)	25.7% (70/272)	*	1.8% (5/272)	*	34.2% (93/272)	36.8% (100/272)
SWTPEG (N=186)	32.3% (60/186)	*	10.2% (19/186)	*	30.6% (57/186)	25.3% (47/186)
TEN (N=222)	25.2% (56/222)	*	5.0% (11/222)	*	36.5% (81/222)	28.8% (64/222)
WPNN (N=152)	27.6% (42/152)	*	4.6% (7/152)	*	36.2% (55/152)	29.6% (45/152)
YPEN (N=320)	28.1% (90/320)	*	*	2.8% (9/320)	19.4% (62/320)	46.9% (150/320)

** In accordance with information governance rules, data based on a number less than five has been masked*

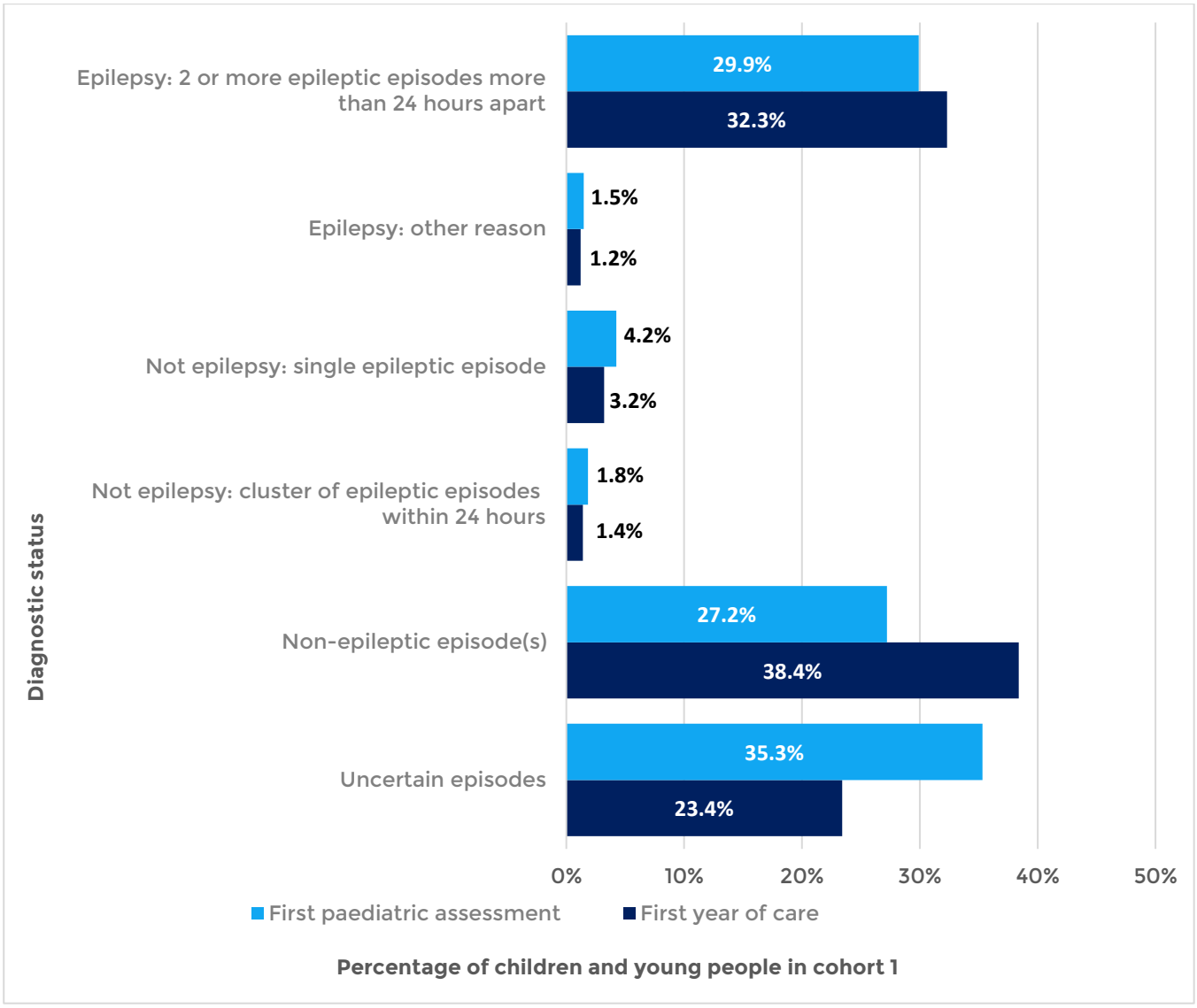


Figure 39: Percentage of children and young people by diagnostic status in first paediatric assessment and first year of care in England and Wales, in Round 3.

Figure 40 shows the proportion of children that had uncertain episodes at 12 months and after the first paediatric assessment. There was a higher proportion of children and young people with non-epileptic episode(s) at first paediatric assessment (**27.2%**), compared to Round 1 and Round 2 (**18.0%** and **15.0%** respectively).

There were a higher proportion of children and young people who had episodes that were considered uncertain after the first year of care in Round 3 (**23.4%**), compared to Round 1 and Round 2 (**14.0%** and **9.0%** respectively).

The proportion of children and young people diagnosed with epilepsy in the 12 months after their first paediatric assessment is comparable in across Round 1, Round 2 and Round 3 (**36.0%, 35.0%** and **33.5%** respectively).

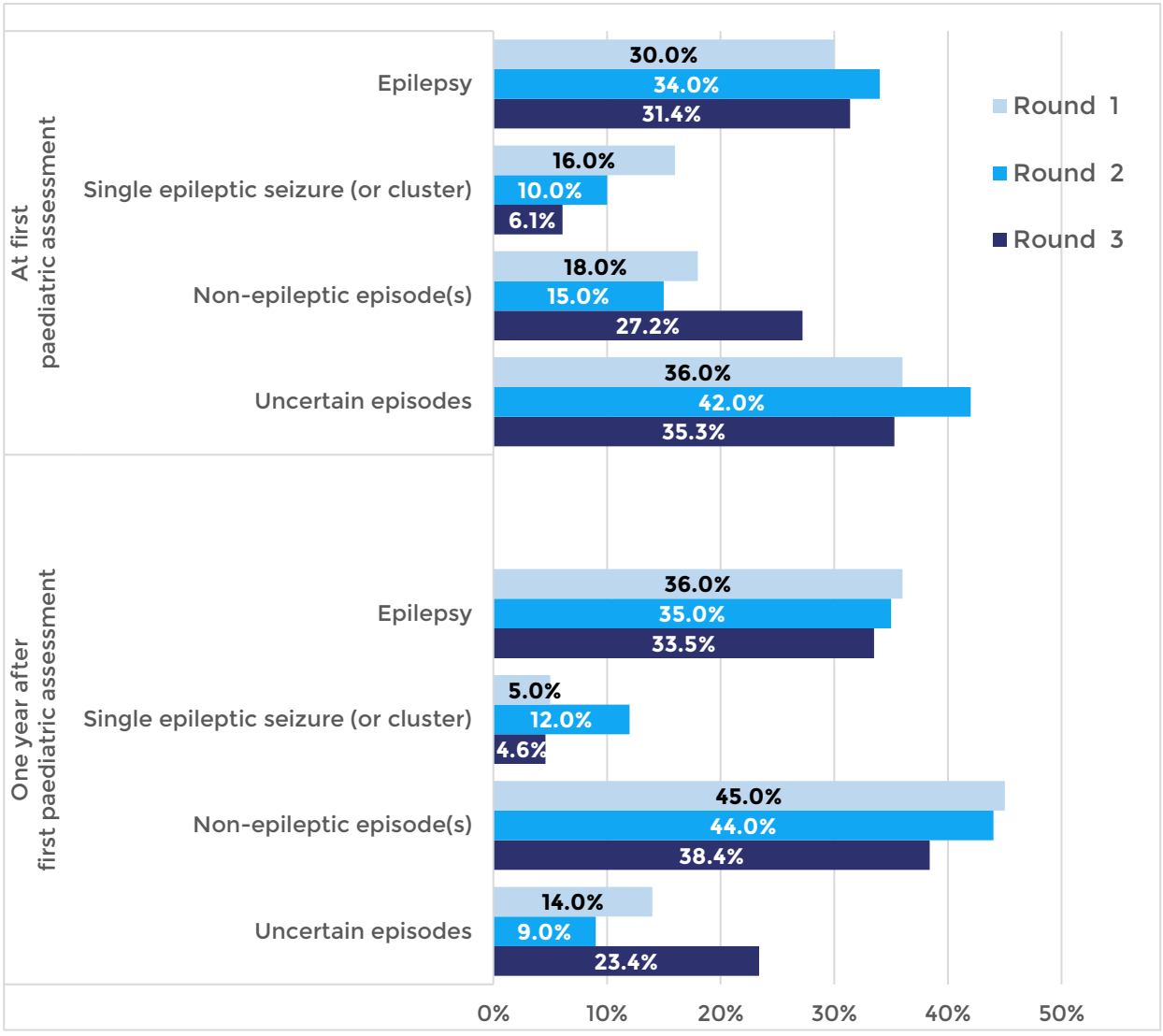


Figure 40: Diagnosis at first assessment and one year after first assessment in Round 1, Round 2, Round 3.

Non-epileptic episodes

Table 56 shows a description of the non-epileptic episodes recorded for children in cohort 1.

Table 56: Description of non-epileptic episodes in children in cohort 1 at one year after first assessment in England and Wales.

Description of non-epileptic episodes	No. of children and young people in cohort 1	% of total sample
Syncope and Anoxic Seizures	215	6.5%
Behavioural, Psychological and Psychiatric Disorders	541	16.3%
Sleep Related Conditions	77	2.3%
Paroxysmal Movement Disorders	103	3.1%
Migraine Associated Disorders	22	0.7%
Miscellaneous Events	71	2.1%
Other	535	16.1%

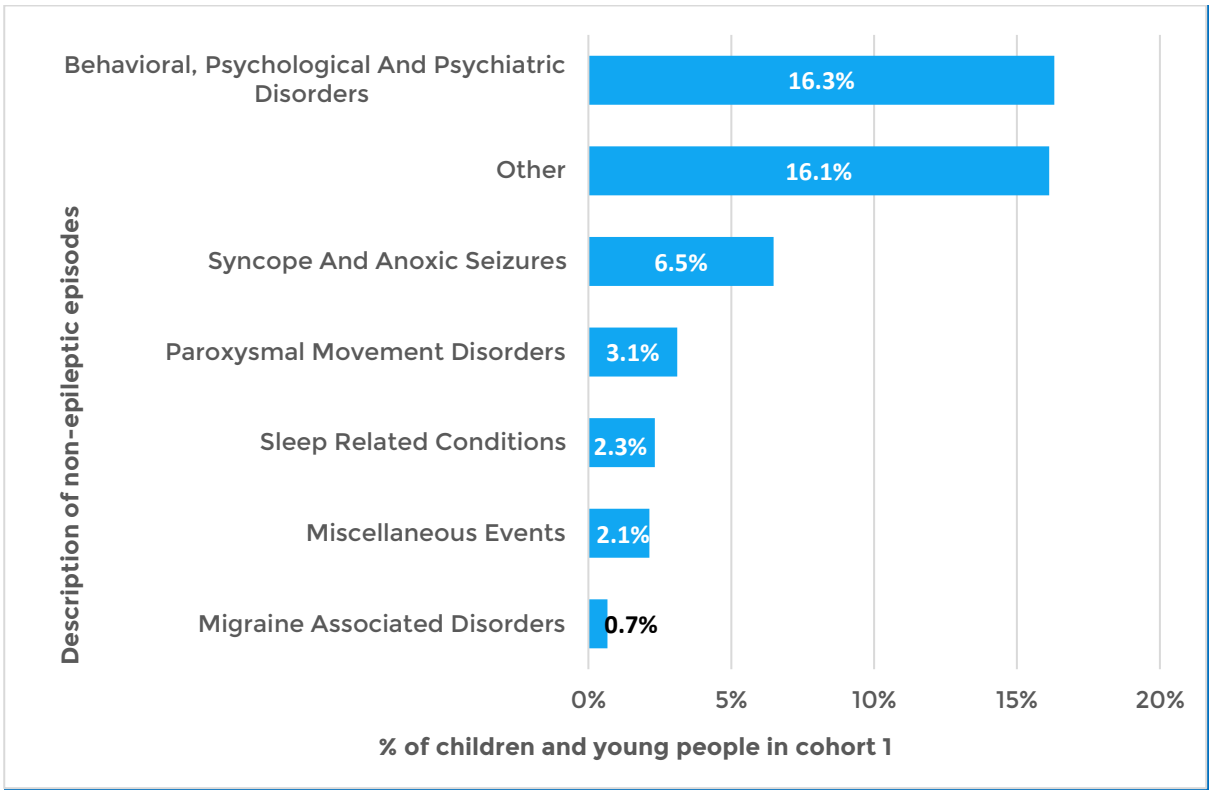


Figure 41: Percentage of children and young people by description of non-epileptic episode

Initial referral and examination

Referring service to first paediatric assessment

Table 57 shows the service from which a referral was made for a first paediatric assessment for children and young people who were diagnosed with epilepsy by the end of the first year of care. In England and Wales, **39.6% (440/ 1112)** children and young people were referred by the emergency department (ED). **36.0% (400/1112)** had a referral from the general practitioner (GP).

Figure 42 shows the percentage of referrals received from different services in England and Wales.

Table 57: Referring service to first paediatric assessment by country.

Country	% ED	% GP	% Health Visitor	% Outpatient paediatrics	% Inpatient paediatrics	% PICU	% Neonatal care	% Other
England and wales (N=1112)	39.6% (440/1112)	36.0% (400/1112)	0.1% (1/1112)	7.8% (87/1112)	12.2% (136/1112)	0.2% (2/1112)	1.4% (16/1112)	2.7% (30/1112)
England (N=1051)	39.5% (415/1051)	35.5% (373/1051)	0.1% (1/1051)	8.2% (86/1051)	12.3% (129/1051)	0.2% (2/1051)	1.4% (15/1051)	2.9% (30/1051)
Wales (N=61)	41.0% (25/61)	44.3% (27/61)	0.0% (0/61)	1.6% (1/61)	11.5% (7/61)	0.0% (0/61)	1.6% (1/61)	0.0% (0/61)

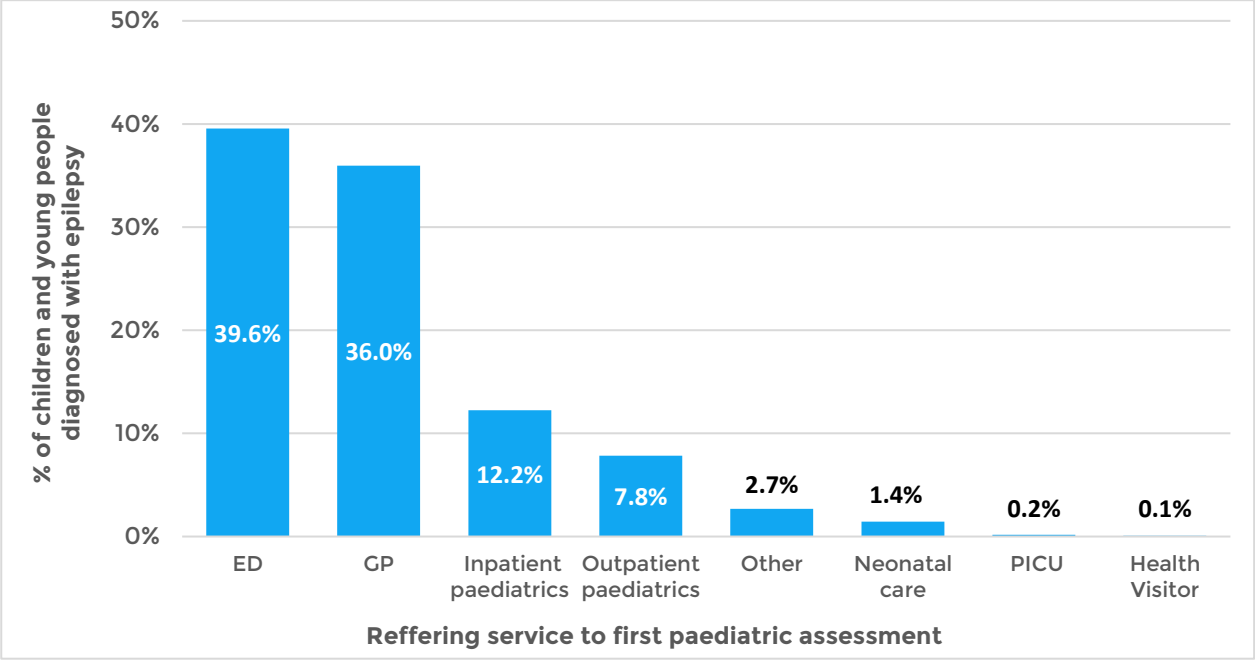


Figure 42: Referring service to first paediatric assessment in England and Wales.

Time since first referral to first paediatric assessment

71.2% (792/1112) of children and young people diagnosed with epilepsy had a valid date entered describing referral to first paediatric assessment.

14.4% (160/1112) of the children and young people diagnosed with epilepsy had not received input from a paediatrician with expertise in epilepsies.

11.0% (122/1112) of the children diagnosed with epilepsy had a date of referral to first paediatric assessment recorded as unknown.

3.4% (38/1112) had an invalid date of referral to first paediatric assessment (date of referral to first paediatric assessment was recorded as occurring after the date input from a paediatrician with expertise in epilepsy was achieved and therefore interpreted as invalid).

NICE guidelines (Quality statement 1) state that children and young people presenting with a suspected seizure are seen by a specialist in the diagnosis and management of the epilepsies within 2 weeks of presentation.

In Round 3, cohort 1, **15.5% (172/1112)** children and young people diagnosed with epilepsy were seen by a paediatrician with expertise in epilepsy within 2 weeks of first referral in England and Wales (**Table 58**).

Table 58: Time in weeks to achieving input from paediatrician with expertise in epilepsy since the first referral to paediatrics by country.

Country	0 - 2 weeks	2 - 4 weeks	4 - 8 weeks	8- 12 weeks	12 - 16 weeks	>16 weeks
England and Wales (N=1112)	15.5% (172/1112)	7.8% (87/1112)	16.3% (181/1112)	9.4% (105/1112)	6.7% (75/1112)	15.5% (172/1112)
England (N=1051)	16.0% (168/1051)	7.9% (83/1051)	16.4% (172/1051)	9.0% (95/1051)	6.6% (69/1051)	15.2% (160/1051)
Wales (N=61)	6.6% (4/61)	6.6% (4/61)	14.8% (9/61)	4.9% (3/61)	9.8% (6/61)	19.7% (12/61)

Only the children with valid date of referral were included in this table. Therefore, the percentages do not add up to 100%.

Age at first paediatric assessment

Figure 43 shows the number of children and young people diagnosed with epilepsy by their age and gender at the time of their first paediatric assessment.

The largest age group was younger children; infants below one years of age.

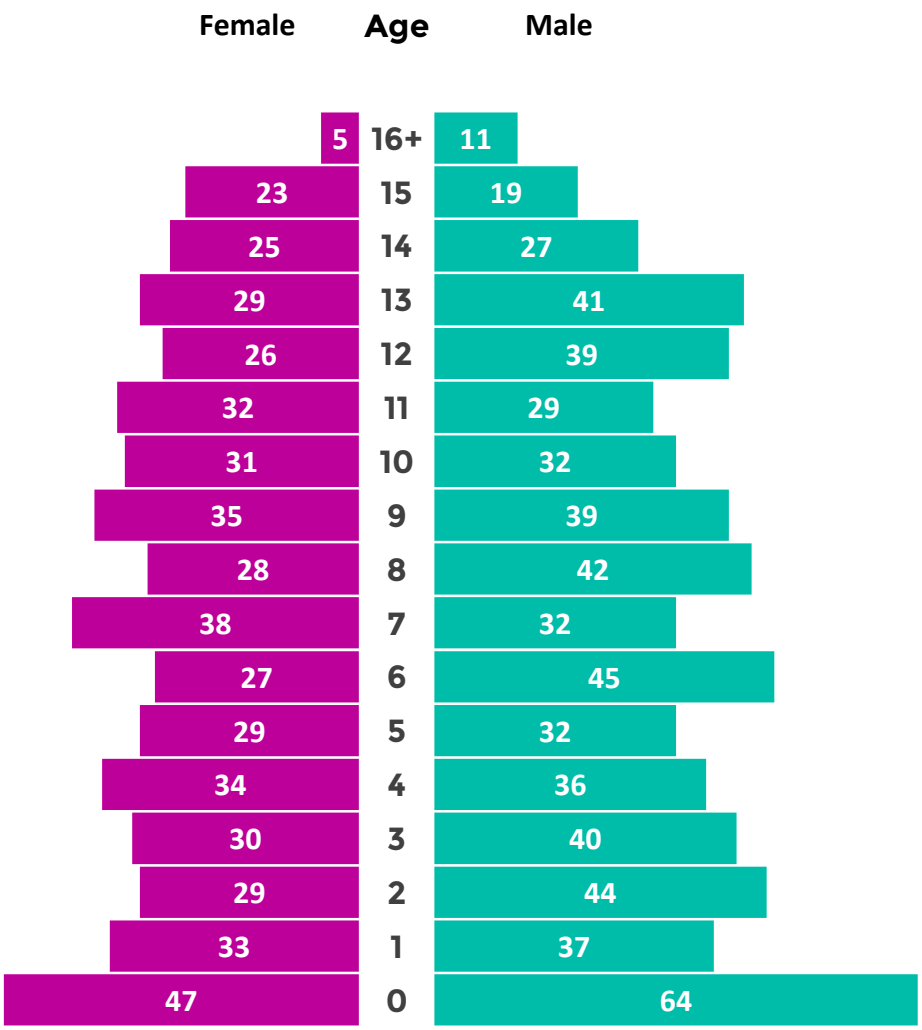


Figure 43: Numbers of children and young people diagnosed with epilepsy by age in years at first paediatric assessment and gender in England and Wales. (This figure excludes 2 children with unknown gender).

Setting of the first paediatric assessment

In England and Wales, **47.7% (530/1112)** of children and young people diagnosed with epilepsy had their first paediatric assessment in an acute setting.

52.1% (579/1112) had their first paediatric assessments in a non-acute setting, (**Table 59**).

Figure 44 shows a comparison of the setting of first paediatric assessment in Round 1, Round 2 and Round 3, cohort 1, in England and Wales.

Table 59: Setting of the first paediatric assessment by country.

Country	% Acute	% Non-acute	% Don't know
England and Wales (N=1112)	47.7% (530/1112)	52.1% (579/1112)	0.3% (3/1112)
England (N=1051)	48.0% (504/1051)	51.8% (544/1051)	0.3% (3/1051)
Wales (N=61)	42.6% (26/61)	57.4% (35/61)	0.0% (0/61)

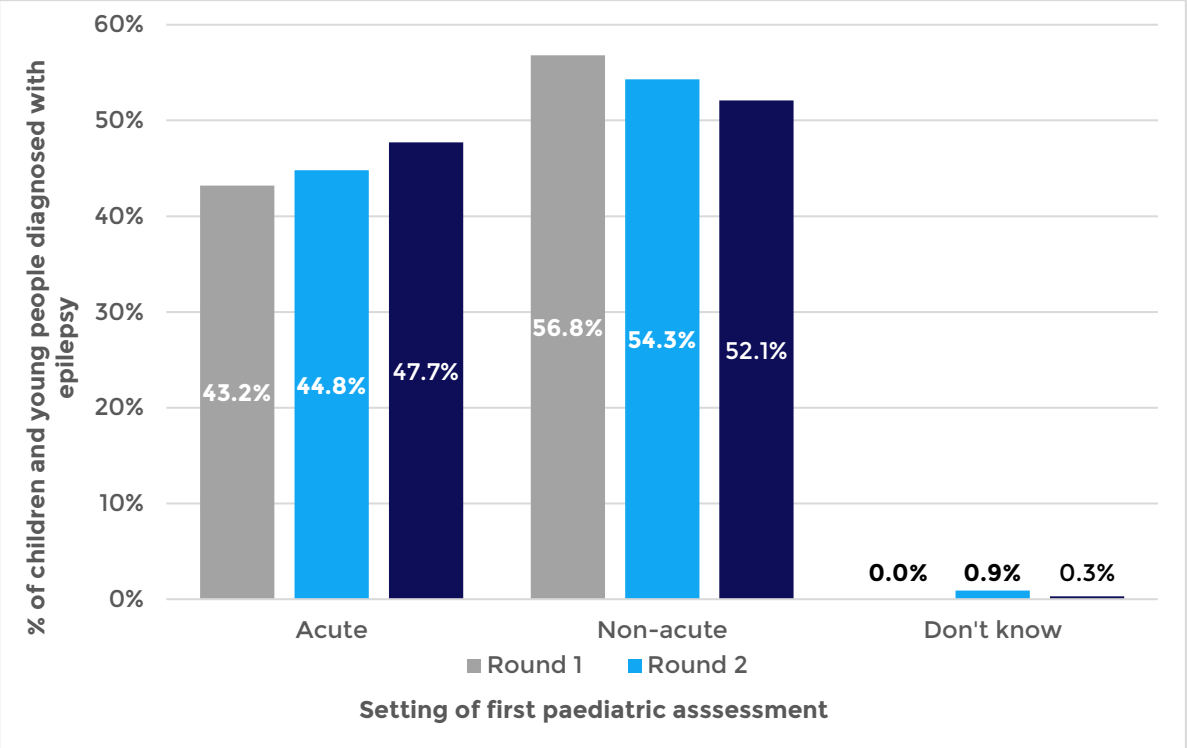


Figure 44: Setting of first paediatric assessment in Round 1, Round 2 and Round 3 in England and Wales.

Appropriate first assessment

Performance indicator 4: Appropriate first paediatric assessment

In Round 3, cohort 1, **61.6% (685/1112)** of children and young people diagnosed with epilepsy had appropriate first paediatric assessment, (**Table 60**). This indicator ranged from 0% to 100% and had an interquartile range of 43.0% to 81.0%. In previous rounds, this performance indicator was applied to the whole cohort, rather than just the epilepsy subgroup, therefore longitudinal comparison is not meaningful.

Table 60: Appropriate first paediatric assessment.

	Evidence of an appropriate assessment	Audit Rounds	England and Wales	England	Wales
4	% of all children and young people with evidence of appropriate first paediatric clinical assessment	Round 3	61.6% (685/1112)	60.1% (632/1051)	86.9% (53/61)
4a	% of children and young people with evidence of descriptions of episode	Round 3	98.4% (1094/1112)	98.3% (1033/1051)	100% (61/61)
4b	% of children and young people with evidence of descriptions of age of child/timing of the first episode	Round 3	81.0% (901/1112)	80.5% (846/1051)	90.2% (55/61)
4c	% of children and young people with evidence of descriptions of frequency	Round 3	93.5% (1040/1112)	93.1% (979/1051)	100% (61/61)
4d	% of children and young people with evidence of descriptions of general examination	Round 3	94.2% (1048/1112)	93.9% (987/1051)	100% (61/61)
4e	% of children and young people with evidence of descriptions of neurological examination	Round 3	91.5% (1018/1112)	91.2% (959/1051)	96.7% (59/61)
4f	% of children and young people with evidence of description of developmental, learning or schooling progress	Round 3	82.6% (918/1112)	81.5% (857/1051)	100% (61/61)
4g	% of children aged 3 years and over with evidence of consideration of emotional or behavioural problems	Round 3	66.0% (734/1112)	64.7% (680/1051)	88.5% (54/61)

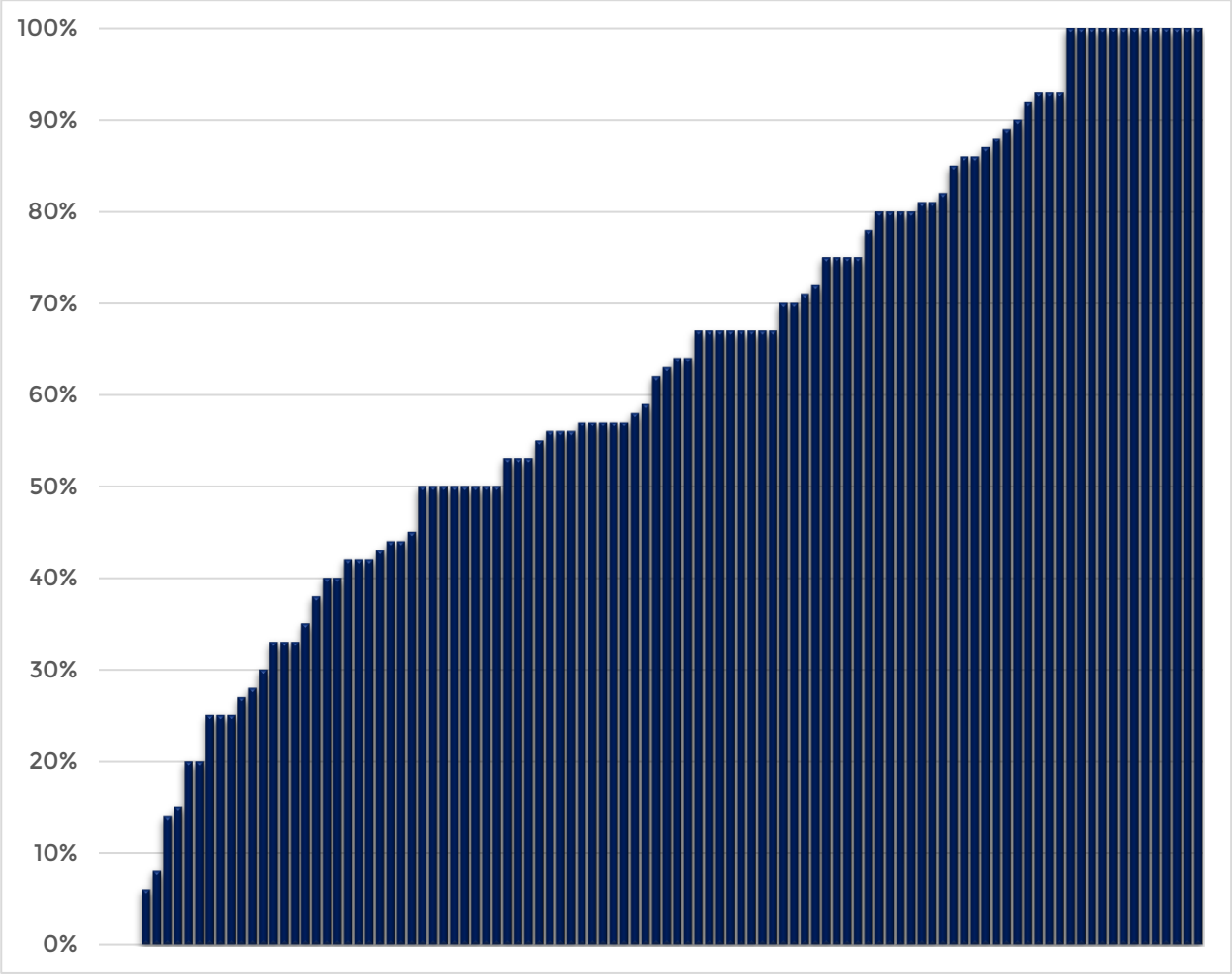


Figure 45: Appropriate first paediatric assessment by unit, Round 3, cohort 1

Each Health Board or Trust is represented by a vertical bar in the order of the percentage score, including those scoring 0% in this graph.

Description of episodes

Seizure type

Table 62 shows **91.0% (1012/1112)** of the children and young people diagnosed with epilepsy in England and Wales at 1 year, had an epileptic seizure defined. Some children had more than one seizure type identified.

In the children with epilepsy, there were also episodes where there was uncertainty whether the seizures were epileptic or not for **14.7% (164/1112),** and **0.9% (10/1112)** where there were non-epileptic seizures identified, (**Table 62**). **28** children and young people diagnosed with epilepsy had more than three seizures by year one in England and Wales, (**Table 61**).

Table 61: Number of seizures in children diagnosed with epilepsy

Country	1 seizure	2 seizures	3 seizures	More than 3 seizures
England and Wales	908	137	39	28

Table 62: Seizure type

Country	% with epileptic seizures	% with non-epileptic seizures	% with uncertain seizures
England and Wales (N=1112)	91.0% (1012/1112)	0.9% (10/1112)	14.7% (164/1112)

Epileptic seizure type

20 children and young people diagnosed with epilepsy had more than three epileptic seizures by year one in England and Wales (**Table 63**).

Table 63: Epileptic seizure type

Country	1 epileptic seizure	2 epileptic seizures	3 epileptic seizures	More than 3 epileptic seizures
England and Wales	866	99	27	20

Figure 46 shows that in England and Wales, in their first year of care, children and young people diagnosed with epilepsy:

- **504 (45.3%)** had generalised onset epileptic seizures,
- **370 (33.3%)** had focal onset epileptic seizures,
- **126 (11.3%)** had unknown onset epileptic seizures,
- **39 (3.5%)** had unclassified epileptic seizures.

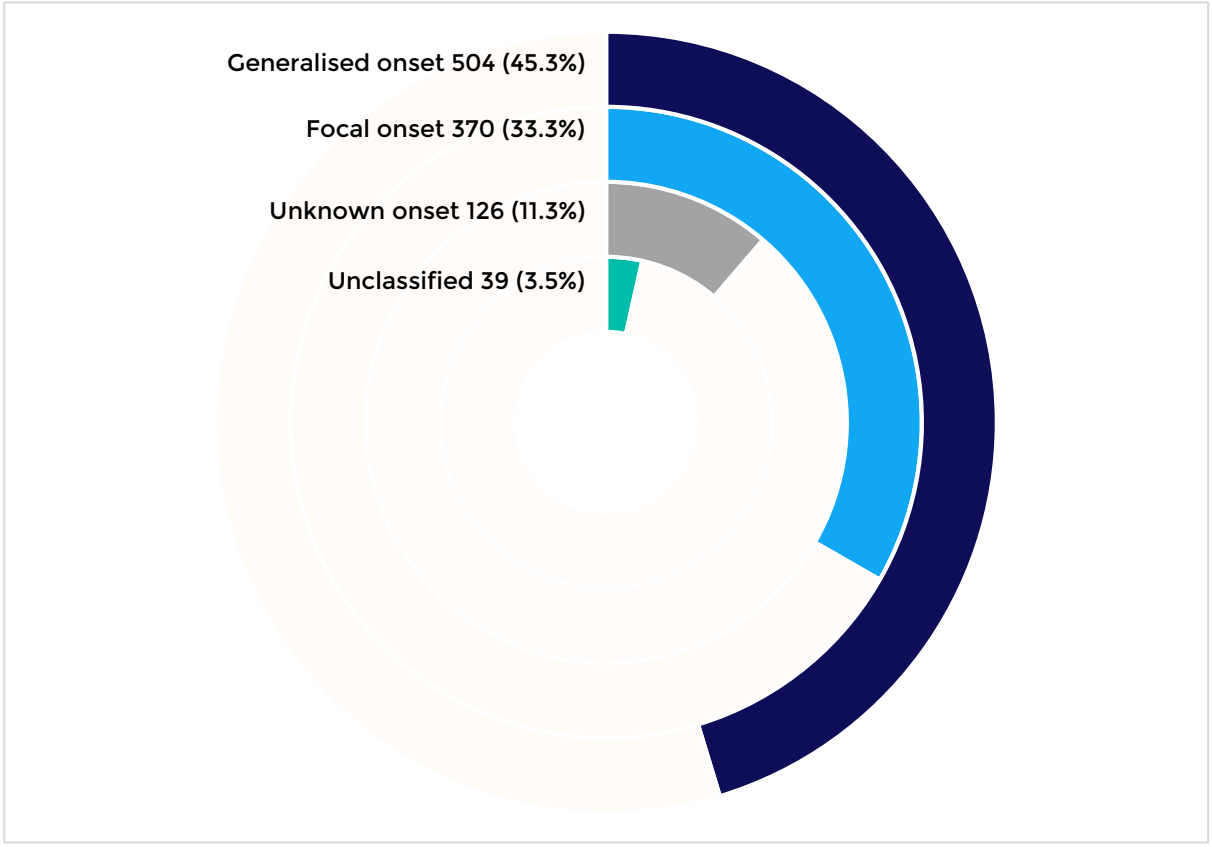


Figure 46: Percentage of children diagnosed with epilepsy by epileptic seizure type in England and Wales.

Focal onset

Table 64 shows the proportion of children and young people diagnosed with epilepsy who had focal onset seizures during their first year of care in England and Wales. There were **174 (15.6%)** children and young people who had impaired awareness focal onset seizures, (**Table 64**), which was the most common characteristic where a focal onset seizure was recorded.

Table 64: Percentage of children and young people diagnosed with epilepsy who had focal onset seizures in England and Wales.

Focal Onset seizures	Round 3 cohort 1 (N=1112)
Impaired awareness	174 (15.6%)
Focal to bilateral tonic-clonic	91 (8.2%)
Left	78 (7.0%)
Clonic	66 (5.9%)
Right	64 (5.8%)
Tonic	56 (5.0%)
Centro-temporal	51 (4.6%)
Temporal	40 (3.6%)
Behaviour arrest	35 (3.1%)
Automatisms	33 (3.0%)
Frontal	22 (2.0%)
Sensory	18 (1.6%)
Other	12 (1.1%)
Autonomic	11 (1.0%)
Occipital	10 (0.9%)
Atonic	7 (0.6%)
Epileptic spasms	5 (0.4%)
Emotional	5 (0.4%)
Parietal	*
Gelastic	*
Myoclonic	*
Cognitive	*
Hyperkinetic	*

** In accordance with information governance rules, data based on a number less than five has been masked*

Out of the **370** children and young people diagnosed with epilepsy with focal onset seizures, **47%** had impaired awareness seizures in England and Wales, (**Figure 47**).

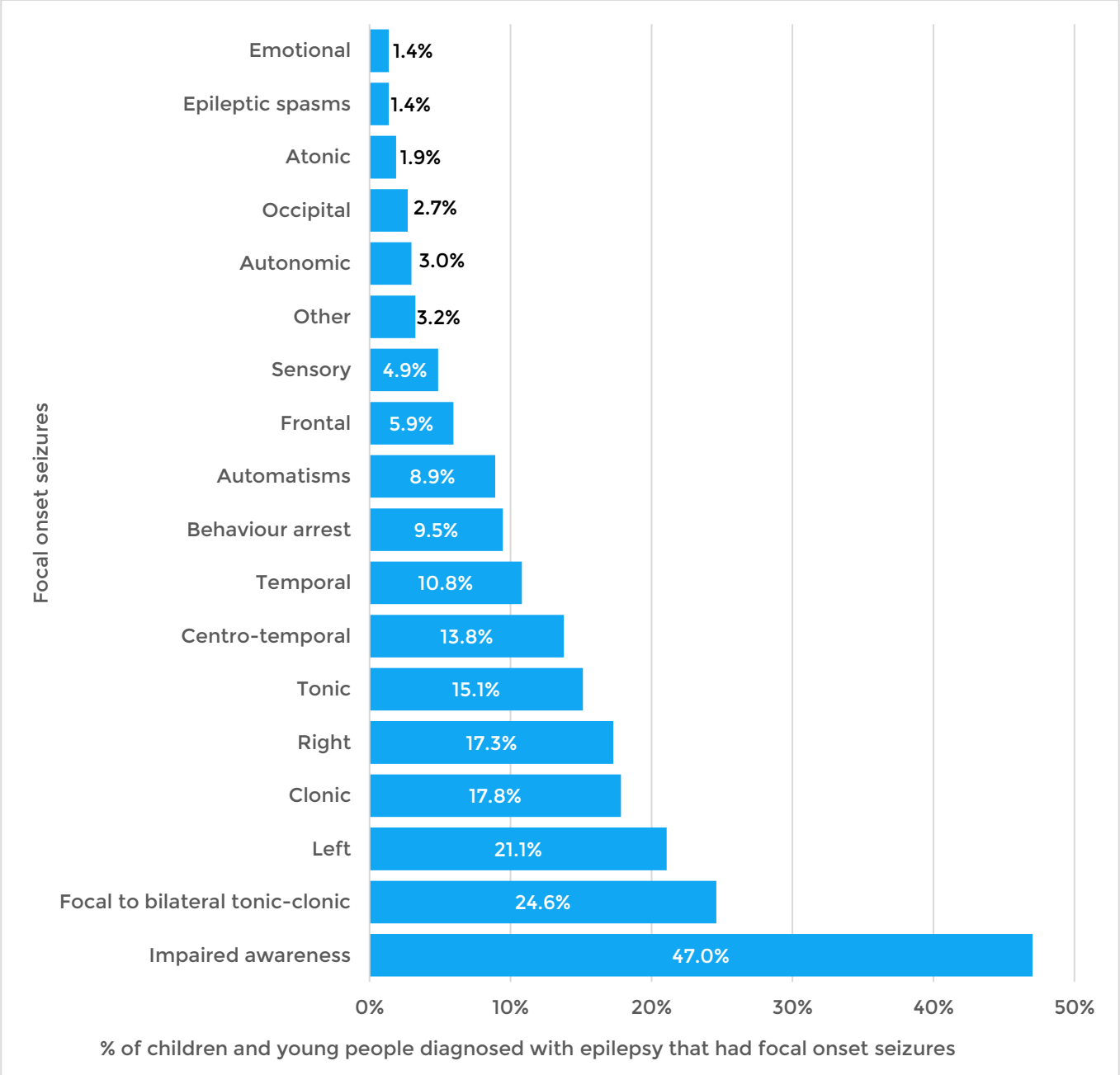


Figure 47: Percentage of children and young people diagnosed with epilepsy who had focal onset seizures in England and Wales.

Parietal, Gelastic, Myoclonic, Cognitive, Hyperkinetic are not shown as there were fewer than five children and young people were recorded for each of these focal onset seizures.

Generalised onset

258 (23.2%) of children and young people diagnosed with epilepsy had generalised onset tonic-clonic seizures in England and Wales, (**Table 65**).

Table 65: Percentage of children and young people diagnosed with epilepsy who had generalised onset seizures in England and Wales.

General Onset Seizures	Round 3 cohort 1 (N=1112)
Tonic-clonic	258 (23.2%)
Typical absence	138 (12.4%)
Atypical absence	46 (4.1%)
Tonic	24 (2.2%)
Epileptic spasms	14 (1.3%)
Atonic	12 (1.1%)
Myoclonic	11 (1.0%)
Absence with eyelid myoclonia	10 (0.9%)
Myoclonic-atonic	9 (0.8%)
Other	8 (0.7%)
Clonic	*
Myoclonic-tonic-clonic	*

** In accordance with information governance rules, data based on a number less than five has been masked*

Out of the **504** children and young people diagnosed with epilepsy with generalised onset seizures, **51.2%,** had tonic-clonic seizures in England and Wales, (**Figure 48**).

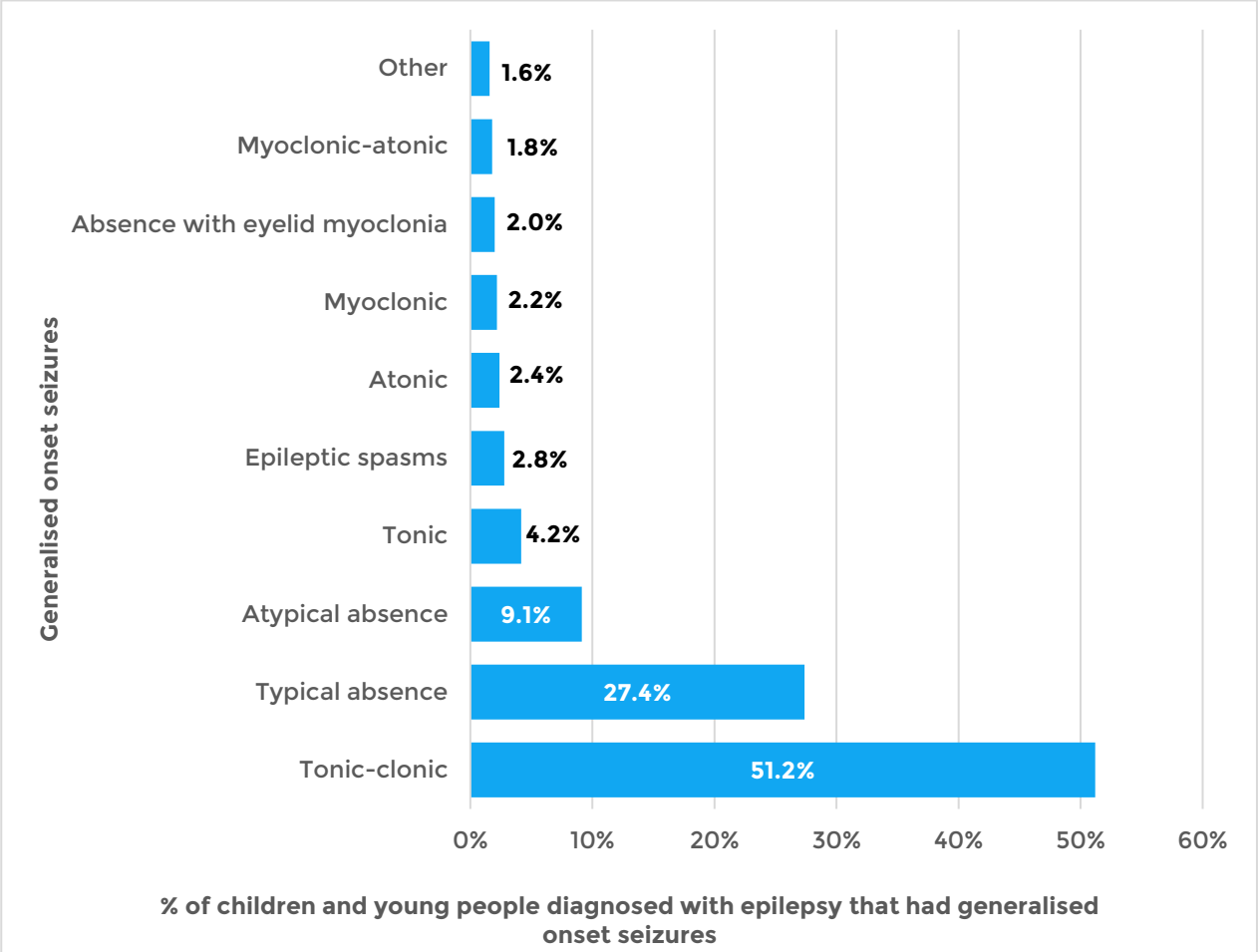


Figure 48: Percentage of children and young people diagnosed with epilepsy who had generalised onset seizures in England and Wales. (Clonic and Myoclonic-tonic-clonic are not shown as there were fewer than five children and young people in each).

Unknown onset

85 (7.6%) of children and young people diagnosed with epilepsy had unknown onset seizures in England and Wales, (**Table 66**).

Table 66: Percentage of children and young people diagnosed with epilepsy who had unknown onset seizures in England and Wales.

Unknown Onset Seizures	Round 3, cohort 1 (N=1112)
Tonic-clonic	85 (7.6%)
Behaviour arrest	25 (2.2%)
Other	16 (1.4%)
Epileptic spasms	11 (1.0%)

Out of the **126** children and young people diagnosed with epilepsy with unknown onset seizures, **67.5%** had tonic-clonic seizures in England and Wales, (**Figure 49**).

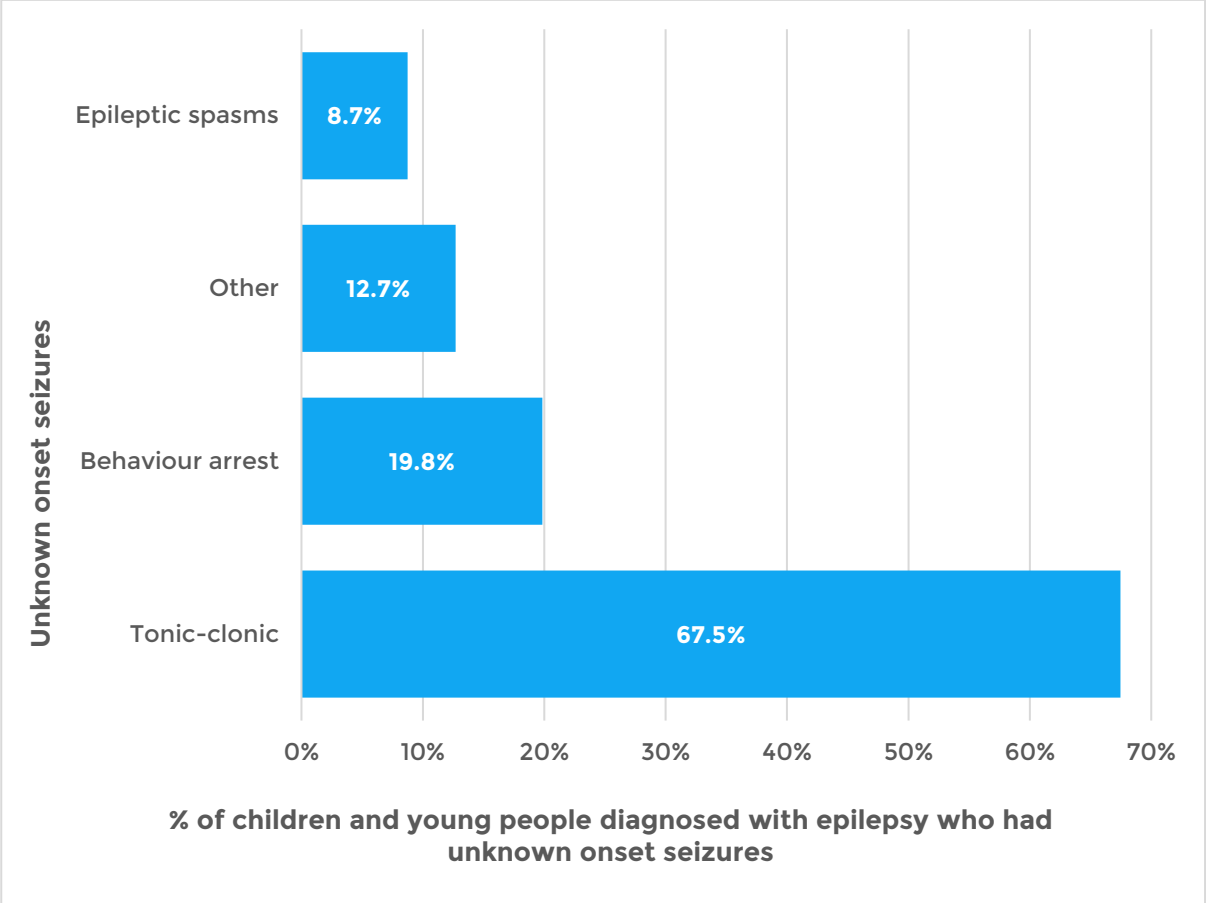


Figure 49: Percentage of children and young people diagnosed with epilepsy that had unknown onset seizures in England and Wales.

Non-epileptic seizure type

There were **10** children and young people diagnosed with epilepsy who had non-epileptic seizures. **6 (0.5%)** of the children and young people diagnosed with epilepsy had non-epileptic seizures and behavioural, psychological or psychiatric disorders.

Electroclinical syndrome

Figure 50 shows the electroclinical syndrome classification. Eight children had more than one International League Against Epilepsy (ILAE) classification. ILAE classifications are shown in **Figure 50,** where the electroclinical syndrome was recorded for at least one child or young person.

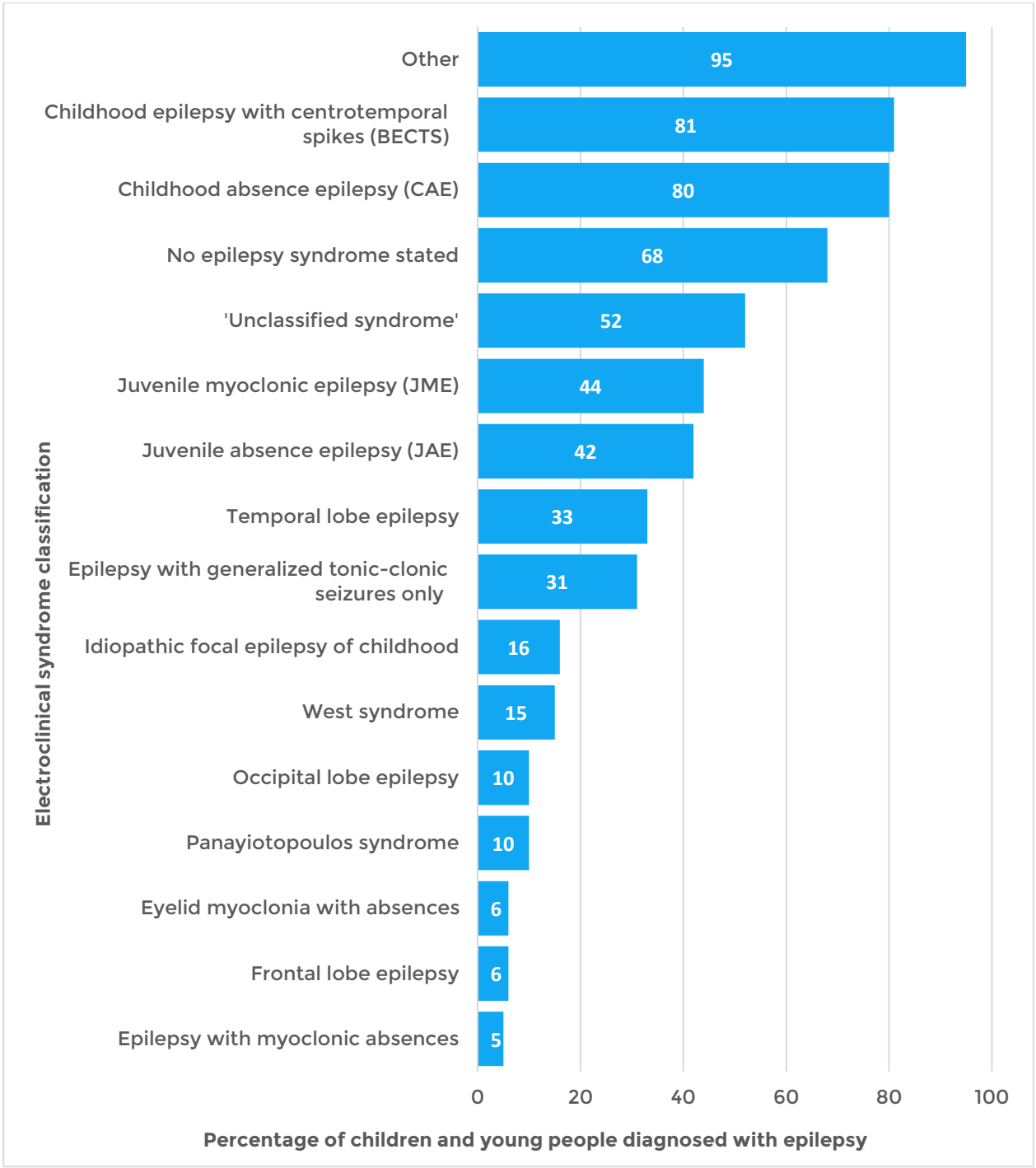


Figure 50: Number of children and young people diagnosed with epilepsy by electroclinical syndrome in England and Wales.

Certain categories are not shown in **Figure 50** as there were fewer than five children and young people. These are: Epilepsy with myoclonic astatic seizures, Benign familial neonatal seizures, Early myoclonic encephalopathy, Ohtahara syndrome, Benign infantile seizure, Late onset childhood occipital epilepsy, Lennox-Gastaut syndrome, Parietal lobe epilepsy, Dravet syndrome, Visual sensitive epilepsies, Childhood epilepsy with occipital paroxysms, Generalized Epilepsies with Febrile seizures and (Benign) Myoclonic epilepsy in infancy.

Performance indicator 5: Seizure formulation

In Round 3, cohort 1, **88.0% (979/1112)** of children and young people diagnosed with epilepsy had an appropriate seizure classification in the first year of care, (**Table 67**). Appropriate seizure formulation was defined as having selected an International League Against Epilepsy (ILAE) seizure classification (all ILAE seizure types or 'unclassified'). At a Health Board and Trust level, this indicator ranged from 25% to 100% and had an interquartile range of 83% to 100%.

Table 67: Seizure formulation.

Seizure Formulation	Audit Round	England and Wales	England	Wales
% of children and young people with epilepsy with appropriate seizure classification at first year of care	Round 1	86.9% (1318/1516)	86.8% (1235/1423)	89.2% (83/93)
	Round 2	94.9% (1040/1096)	95.5% (973/1019)	94.4% (67/71)
	Round 3	88.0% (979/1112)	87.4% (919/1051)	98.4% (60/61)

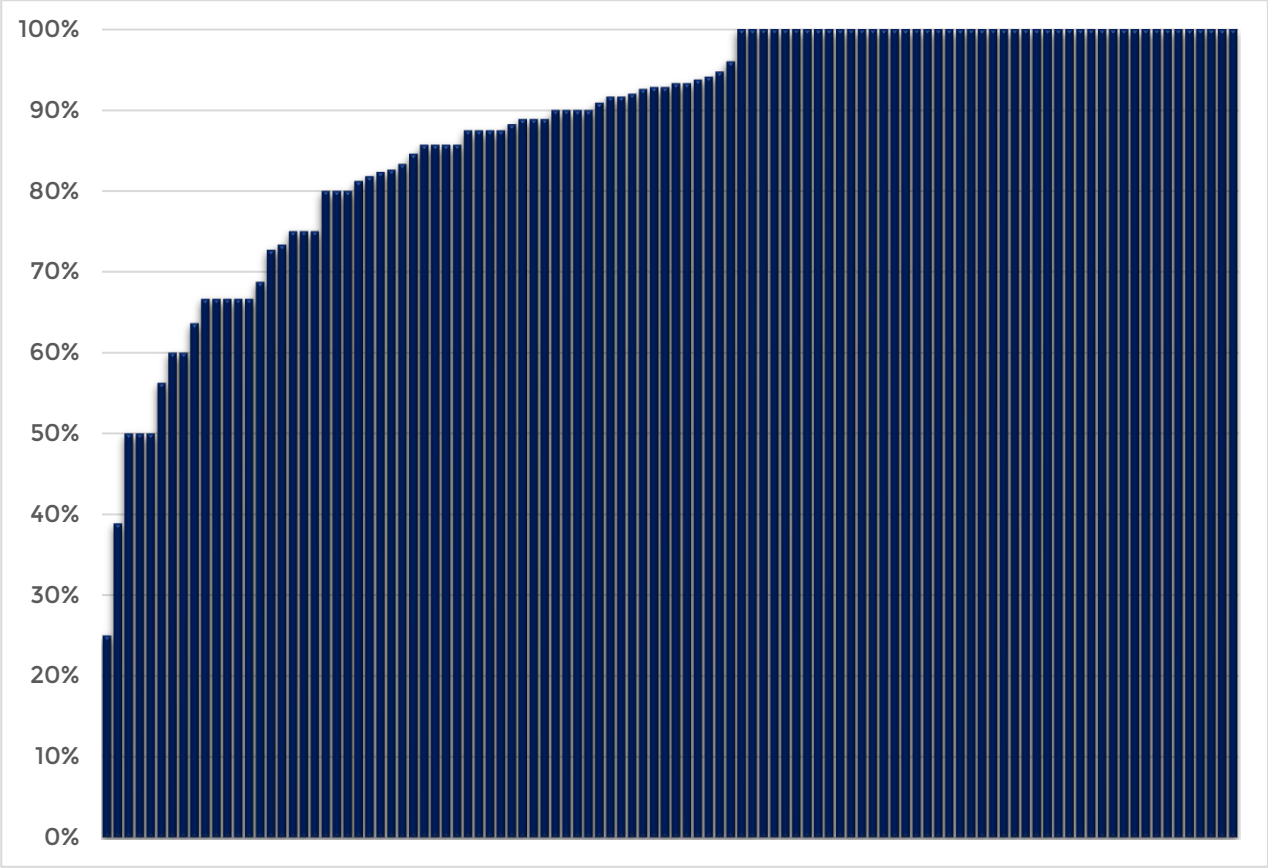


Figure 51: Seizure formulation, by Health Board and Trust, Round 3, cohort 1.

Each Health Board or Trust is represented by a vertical bar in the order of the percentage score, including any recording 0% of children and young people with epilepsy who had an appropriate seizure classification.

Seizure cause

31 (2.8%) children and young people in England and Wales diagnosed with epilepsy had a genetic seizure cause, whilst **84 (7.6%)** had a structural seizure cause, (**Table 68**). The cause of seizure in **221 (19.9%)** children and young people diagnosed with epilepsy was unknown.

Table 68: Percentage of children and young people diagnosed with epilepsy by seizure cause in England and Wales.

Seizure Cause	Round 3 cohort 1 (N=1112)
Genetic	31 (2.8%)
Immune	*
Infectious	10 (0.9%)
Metabolic	*
Not known	221 (19.9%)
Structural	84 (7.6%)

** In accordance with information governance rules, data based on a number less than five has been masked*

Of the **31** children with genetic cause of their epilepsy, **12 (30.7%)** had chromosomal abnormality, **18 (58.1%)** had genetic abnormality and fewer than five had Rett Syndrome. Out of the **84** children and young people diagnosed with a structural seizure cause of their epilepsy, **29.8%** had a vascular cause (e.g. arterial ischaemic stroke), (**Figure 52**).

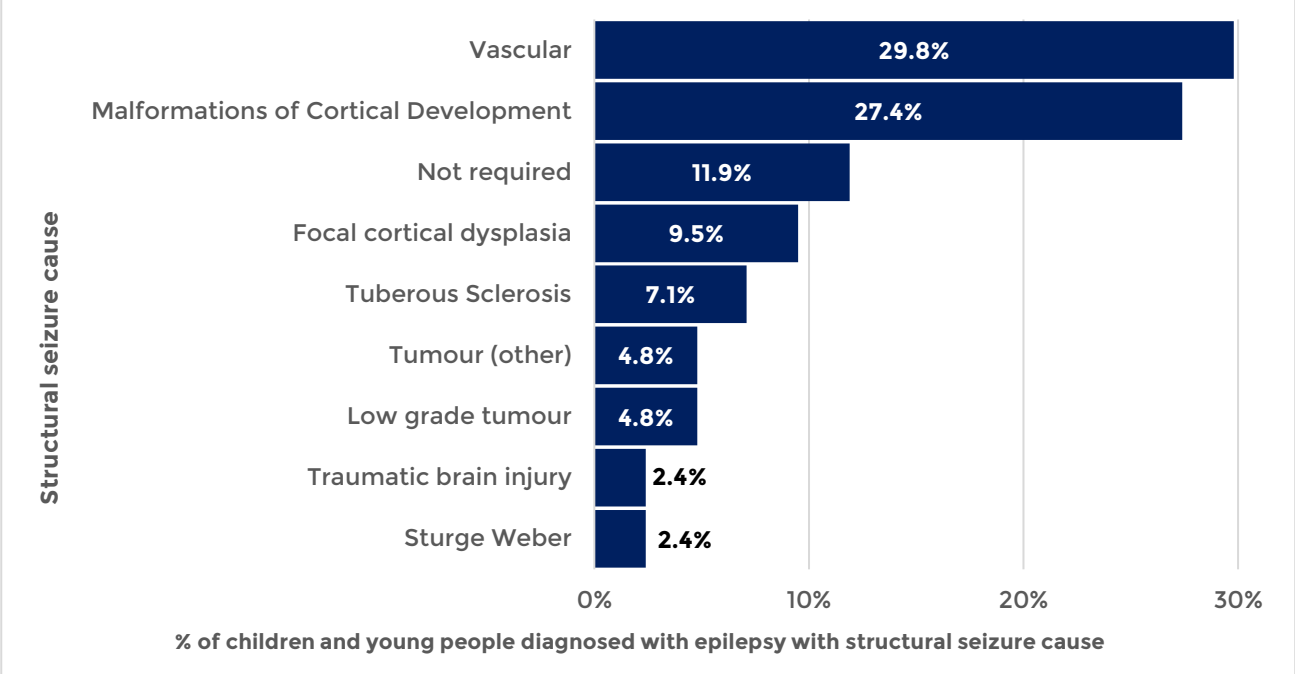


Figure 52: Percentage of children and young people diagnosed with epilepsy who had structural seizure cause.

Convulsive seizures

Convulsive epileptic seizures

63% (701/1112) of children and young people diagnosed with epilepsy had convulsive seizures, whilst **37% (411/1112)** did not have convulsive seizures in England and Wales, (**Table 69/Figure 53**). The proportion of children and young people with convulsive seizures in England was similar to Wales.

Table 69: Convulsive epileptic seizures in children and young people diagnosed with epilepsy by country.

Country	% with convulsive seizures	% with no convulsive seizures
England & Wales (N=1112)	63.0% (701/1112)	37.0% (411/1112)
England (N=1051)	63.0% (662/1051)	37.0% (389/1051)
Wales (N=61)	63.9% (39/61)	36.1% (22/61)

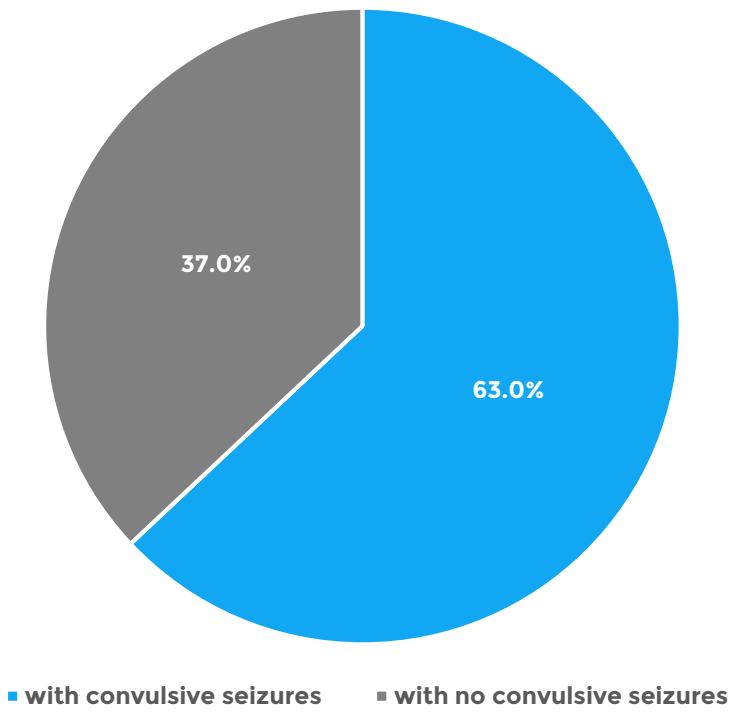


Figure 53: Percentage of children and young people diagnosed with epilepsy with/with no convulsive epileptic seizures in England and Wales.

Prolonged generalised convulsive seizures

Table 70 shows that **16.3% (181/1112)** of the children and young people diagnosed with epilepsy, experienced prolonged generalised convulsive seizures in year one. Prolonged seizures are those with a duration of more than five minutes or successive seizures continuing for more than five minutes.

79.8% (887/1112) of children and young people with epilepsy did not experience prolonged generalised convulsive seizures. There was uncertainty whether the seizures were prolonged generalised convulsive seizures or not for **4.0% (44/1112)** of children and young people.

Figure 54 shows the percentage of children and young people diagnosed with epilepsy by prolonged generalised convulsive epileptic seizures in England and Wales.

Table 70: Prolonged generalised convulsive epileptic seizures in children and young people diagnosed with epilepsy.

Country	% yes	% no	% uncertain
England and Wales (N=1112)	16.3% (181/1112)	79.8% (887/1112)	4.0% (44/1112)

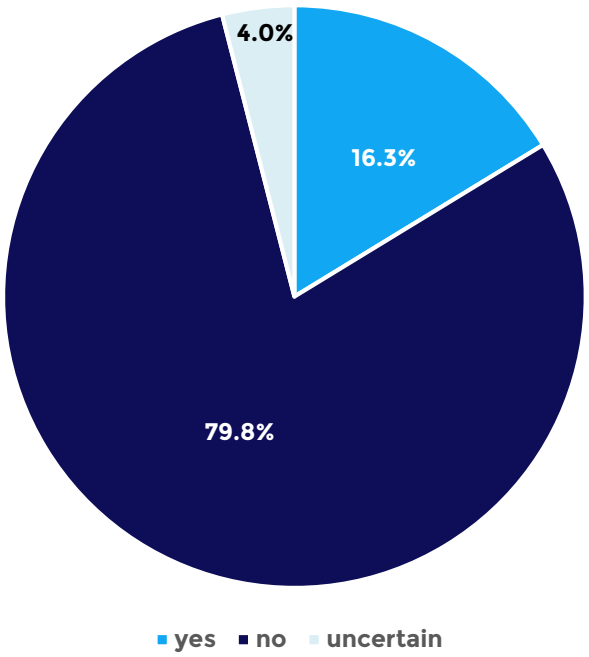


Figure 54: Percentage of children and young people diagnosed with epilepsy by prolonged generalised convulsive epileptic seizures in England and Wales.

Prolonged focal convulsive seizures

Table 71 shows **10.0% (111/1112)** of the children and young people diagnosed with epilepsy, experienced prolonged focal convulsive seizures in their first year of care. Prolonged seizures are those with a duration of more than five minutes or successive seizures continuing for more than five minutes.

There was uncertainty whether the seizures were prolonged focal convulsive seizures or not in **5.8% (65/1112)** of children and young people. **Figure 55** shows the percentage of children and young people diagnosed with epilepsy by prolonged generalised convulsive epileptic seizures in England and Wales.

Table 71: Prolonged focal convulsive epileptic seizures in children and young people diagnosed with epilepsy by country.

Country	% yes	% no	% uncertain
England and Wales (N=1112)	10.0% (111/1112)	84.2% (936/1112)	5.8% (65/1112)

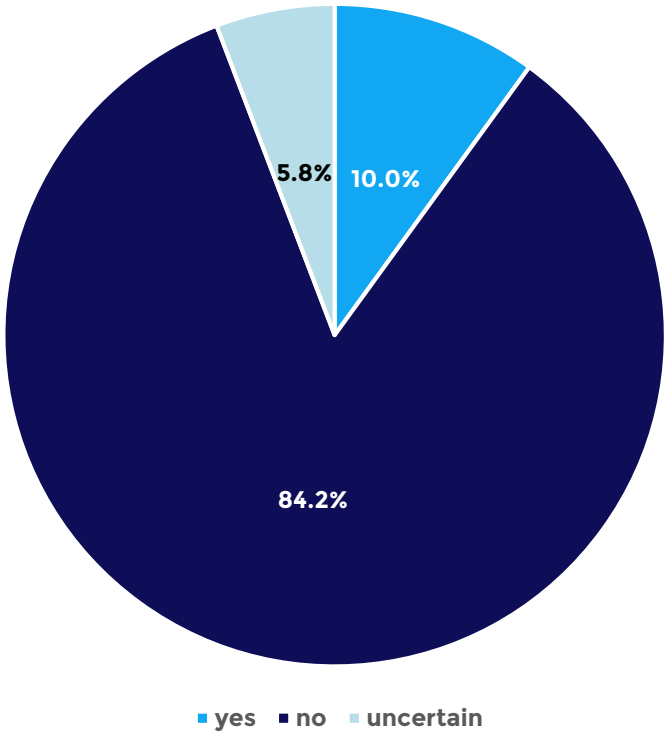


Figure 55: Percentage of children and young people diagnosed with epilepsy by prolonged focal convulsive epileptic seizures in England and Wales.

Family history of epilepsy

26.8% (298/1112) of children and young people in England and Wales diagnosed with epilepsy had a family history of epilepsy. **73.2% (814/1112)** did not have any family history of epilepsy, (**Table 72**).

Figure 56 shows the percentage of children and young people diagnosed with epilepsy by family history of epilepsy in England and Wales.

Table 72: Family history of epilepsy in children and young people diagnosed with epilepsy by country.

Country/ network	% with family history of epilepsy	% with no family history of epilepsy
England and Wales (N=1112)	26.8% (298/1112)	73.2% (814/1112)
England (N=1051)	26.4% (277/1051)	73.6% (774/1051)
Wales (N=61)	34.4% (21/61)	65.6% (40/61)

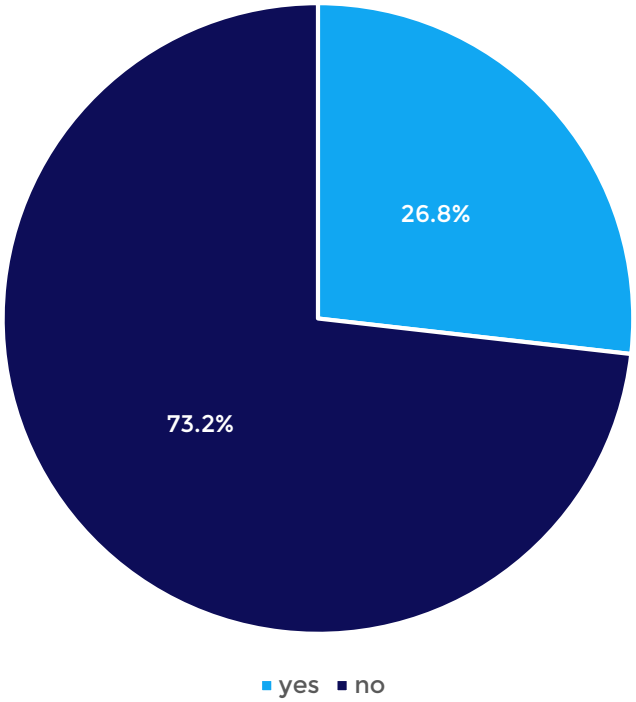


Figure 56: Percentage of children and young people diagnosed with epilepsy with/with no family history of epilepsy in England and Wales.

Neurodisability or neurodevelopmental problems

24.4% (271/1112) of children and young people diagnosed with epilepsy had a neurodisability/neurodevelopmental problem described by one year in England and Wales in Round 3, cohort 1. **6.4% (71/1112)** had autistic spectrum disorder and **6.3% (70/1112)** had an intellectual disability/global development delay/learning disability as shown in **Table 73**. **Figure 57** shows a breakdown of the neurodisability or neurodevelopmental problems among children diagnosed with epilepsy in Round 3, cohort 1.

Table 73: Neurodisability/neurodevelopmental problems among children diagnosed with epilepsy in Round 3.

Country/ network	% Autistic spectrum disorder	% Cerebral palsy	% Neuro-degenerative disease	% Identified chromosomal disorder	% Attention deficit hyperactivity	% Intellectual disability	% Dyspraxia	% Dyslexia	% Speech disorder	% Other learning difficulty
England &Wales (N=1112)	6.4% (71/1112)	3.6% (40/1112)	*	1.9% (21/1112)	1.7% (19/1112)	6.3% (70/1112)	*	0.7% (8/1112)	1.6% (18/1112)	3.4% (38/1112)
England (N=1051)	6.7% (70/1051)	3.6% (38/1051)	*	2.0% (21/1051)	1.8% (19/1051)	6.2% (65/1051)	*	0.7% (7/1051)	1.5% (16/1051)	3.5% (37/1051)
Wales (N=61)	*	*	0.0% (0/61)	0.0% (0/61)	0.0% (0/61)	8.2% (5/61)	*	*	*	*
BRPNF (N=92)	5.4% (5/92)	*	0.0% (0/92)	0.0% (0/92)	*	7.6% (7/92)	0.0% (0/92)	*	*	*
CEWT (N=94)	5.3% (5/94)	*	*	*	*	6.4% (6/94)	0.0% (0/94)	*	*	*
EPEN (N=75)	6.7% (5/75)	0.0% (0/75)	0.0% (0/75)	*	0.0% (0/75)	*	0.0% (0/75)	0.0% (0/75)	*	*
EPIC (N=112)	4.5% (5/112)	*	*	*	*	*	*	*	4.5% (5/112)	8.9% (10/112)
NTPEN (N=99)	15.2% (15/99)	5.1% (5/99)	0.0% (0/99)	*	*	8.1% (8/99)	0.0% (0/99)	0.0% (0/99)	*	*
NWEIG (N=67)	*	*	0.0% (0/67)	0.0% (0/67)	*	14.9% (10/67)	0.0% (0/67)	0.0% (0/67)	*	0.0% (0/67)
ORENG (N=91)	*	*	*	0.0% (0/91)	*	5.5% (5/91)	0.0% (0/91)	0.0% (0/91)	*	*
PENNEC (N=65)	10.8% (7/65)	7.7% (5/65)	0.0% (0/65)	*	0.0% (0/65)	*	0.0% (0/65)	0.0% (0/65)	*	*
SETPEG (N=23)	*	0.0% (0/23)	0.0% (0/23)	0.0% (0/23)	0.0% (0/23)	*	0.0% (0/23)	0.0% (0/23)	0.0% (0/23)	0.0% (0/23)
SWEP (N=51)	*	*	0.0% (0/51)	0.0% (0/51)	0.0% (0/51)	9.8% (5/51)	*	*	0.0% (0/51)	*
SWIPE (N=72)	6.9% (5/72)	6.9% (5/72)	0.0% (0/72)	6.9% (5/72)	*	*	*	0.0% (0/72)	*	*
SWTPEG (N=64)	10.9% (7/64)	9.4% (6/64)	*	*	*	10.9% (7/64)	0.0% (0/64)	*	*	*
TEN (N=54)	*	*	0.0% (0/54)	0.0% (0/54)	*	0.0% (0/54)	0.0% (0/54)	0.0% (0/54)	0.0% (0/54)	*
WPNN (N=42)	*	0.0% (0/42)	0.0% (0/42)	0.0% (0/42)	0.0% (0/42)	*	0.0% (0/42)	*	*	*
YPEN (N=111)	4.5% (5/111)	*	*	*	0.0% (0/111)	*	0.0% (0/111)	0.0% (0/111)	*	*

** In accordance with information governance rules, data based on a number less than five has been masked*

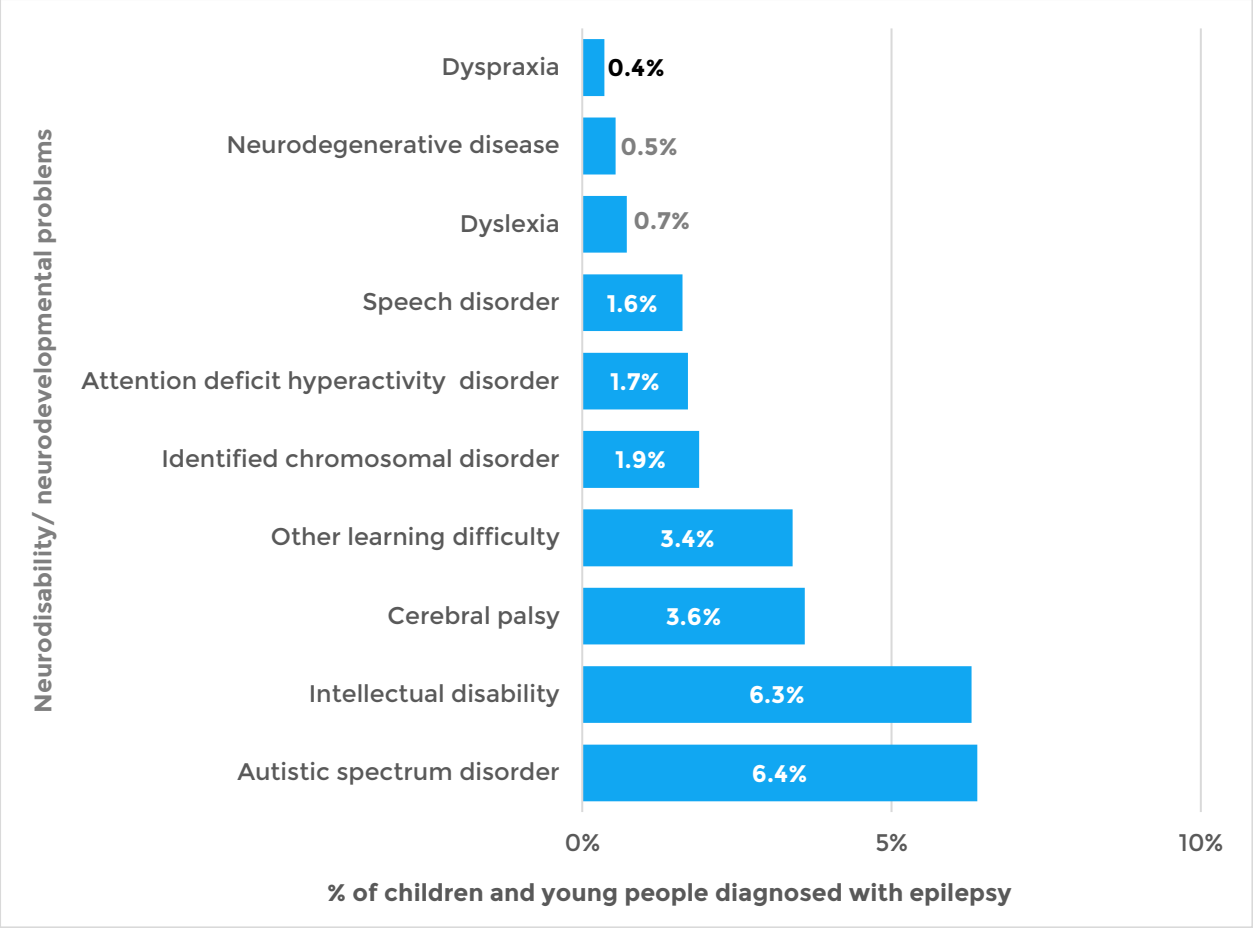


Figure 57: Neurodisability/neurodevelopmental problems among children diagnosed with epilepsy in cohort 1.

Table 74 shows, out of **70** children and young people diagnosed with epilepsy with intellectual disability/global development delay/learning disability, **54.3% (38/70)** had moderate severity in England and wales.

Table 74: Percentage of severity of neurodevelopmental problems among the children and young people with intellectual disability, global development delay, or learning disability in England and Wales.

Severity of neurodevelopmental problems	% of children and young people with intellectual disability
Mild	22.9% (16/70)
Moderate	54.3% (38/70)
Severe or Profound	22.8% (16/70)

Mental health conditions

4.6% (51/1112) of children and young people diagnosed with epilepsy in cohort 1 had an identified mental health condition(s) by one year in England and Wales. **0.5% (6/112)** had a mood disorder, **0.7% (8/112)** had an anxiety disorder and **2.3% (26/1112**) had other mental health concerns.

6.1% (43/701) of children and young people between the age of 5-15 years and diagnosed with epilepsy in cohort 1, had an identified mental health condition(s) by one year in England and Wales. **23.3% (10/43)** of these had formal development assessment, **20.9% (9/43)** had formal cognitive assessment by one year, (**Table 76**).

There were **11** children and young people with emotional/behavioural problems, which included conduct disorders and Oppositional Defiant Disorder (ODD).

Table 75: Percentage of children and young people diagnosed with mental health conditions in England and Wales.

Mental health condition	% of children and young people with mental health conditions	% of children and young people ages 5-15 with mental health conditions
Mood disorder	0.5% (6/1112)	0.7% (5/701)
Anxiety disorder	0.7% (8/1112)	1.1% (8/701)
Emotional/behavioural	1.0% (11/1112)	1.4% (10/701)
Other*	2.3% (26/1112)	2.8% (20/701)

**Includes self-harm as there were fewer than 5 children and young people*

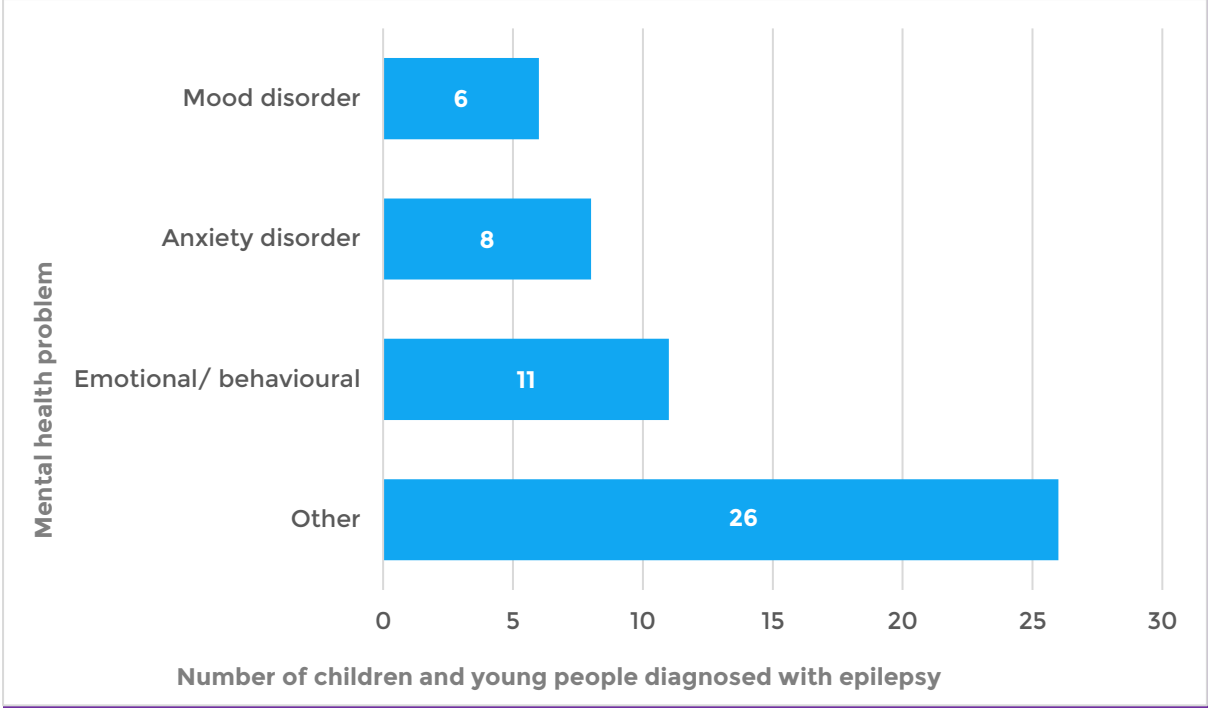


Figure 58: Number of children diagnosed with epilepsy by mental health condition in England and Wales.

Table 76: Percentage of children and young people between the age of 5-15 years and diagnosed with a mental health condition that had ongoing investigations in England and Wales.

Mental health condition that requires ongoing investigations	% of children and young people with mental health conditions
Formal developmental assessment	23.3% (10/43)
Formal cognitive assessment	20.9% (9/43)

Investigations

Time since first request for EEG

- **0.4% (4/1112)** of the children and young people diagnosed with epilepsy did not have an EEG.
- **3.1% (35/1112)** had an invalid EEG request date/EEG obtained date (date of EEG request is after the date EEG was obtained).
- **96.5% (1073/1112)** children and young people diagnosed with epilepsy had a valid EEG request date.
- **94.2% (1047/1112)** children and young people diagnosed with epilepsy obtained an EEG and had a valid EEG request date.

NICE guidelines (Quality Statement 2) state that children and young people having initial investigations for epilepsy undergo the tests within 4 weeks of being requested.

In Round 3, cohort 1, **56.2% (625/1112)** of children and young people diagnosed with epilepsy, obtained their EEG within four weeks of request in England and Wales, (**Table 77**).

Table 77: Time in weeks to when EEG was obtained since EEG request date by country

Country	0 - 4 weeks	4 - 8 weeks	8 - 12 weeks	12 - 16 weeks	>16 weeks
England &Wales (N=1112)	56.2% (625/1112)	26.6% (296/1112)	5.2% (58/1112)	2.3% (26/1112)	3.8% (42/1112)
England (N=1051)	57% (599/1051)	26.1% (274/1051)	4.7% (49/1051)	2.3% (24/1051)	4.0% (42/1051)
Wales (N=61)	42.6% (26/61)	36.1% (22/61)	14.8% (9/61)	3.3% (2/61)	0.0% (0/61)

The four children and young people who did not have an EEG and those with invalid dates are not included in the analysis on this table, hence the percentages do not add up to 100%.

Table 78 shows **97.5% (1084/1112)** of children and young people diagnosed with epilepsy obtained the first EEG in year one. **59.1% (657/1112)** obtained MRI brain, **56.4% (627/1112)** obtained 12 lead ECG and **13.1% (146/1112)** obtained a CT head scan in year one, in England and Wales.

Figure 59 shows the percentages of children and young people who obtained each investigation in England and Wales. These are displayed as descriptions, rather than performance-related percentages because not all children with epilepsy require each investigation.

Table 78: Number and percentage of children and young people diagnosed with epilepsy that obtained First EEG, 12 lead ECG, CT head scan and MRI brain investigations by country and OPEN UK network.

Country/ Network	% First EEG	% 12 lead ECG	% CT head scan	% MRI brain
England &Wales (N=1112)	97.5% (1084/1112)	56.4% (627/1112)	13.1% (146/1112)	59.1% (657/1112)
England (N=1051)	97.3% (1023/1051)	57.8% (607/1051)	13.6% (143/1051)	59.7% (627/1051)
Wales (N=61)	100% (61/61)	32.8% (20/61)	4.9% (3/61)	49.2% (30/61)
BRPNF (N=92)	97.8% (90/92)	62% (57/92)	9.8% (9/92)	56.5% (52/92)
CEWT (N=94)	100% (94/94)	68.1% (64/94)	8.5% (8/94)	61.7% (58/94)
EPEN (N=75)	94.7% (71/75)	45.3% (34/75)	10.7% (8/75)	53.3% (40/75)
EPIC (N=112)	100% (112/112)	46.4% (52/112)	11.6% (13/112)	59.8% (67/112)
NTPEN (N=99)	97.0% (96/99)	58.6% (58/99)	9.1% (9/99)	64.6% (64/99)
NWEIG (N=67)	100% (67/67)	55.2% (37/67)	19.4% (13/67)	55.2% (37/67)
ORENG (N=91)	93.4% (85/91)	51.6% (47/91)	20.9% (19/91)	53.8% (49/91)
PENNEC (N=65)	95.4% (62/65)	52.3% (34/65)	15.4% (10/65)	55.4% (36/65)
SETPEG (N=23)	100% (23/23)	82.6% (19/23)	17.4% (4/23)	73.9% (17/23)
SWEP (N=51)	100% (51/51)	33.3% (17/51)	5.9% (3/51)	49.0% (25/51)
SWIPE (N=72)	98.6% (71/72)	48.6% (35/72)	8.3% (6/72)	61.1% (44/72)
SWTPEG (N=64)	96.9% (62/64)	81.3% (52/64)	17.2% (11/64)	67.2% (43/64)
TEN (N=54)	98.1% (53/54)	59.3% (32/54)	11.1% (6/54)	38.9% (21/54)
WPNN (N=42)	97.6% (41/42)	42.9% (18/42)	14.3% (6/42)	69.0% (29/42)
YPEN (N=111)	95.5% (106/111)	64% (71/111)	18.9% (21/111)	67.6% (75/111)

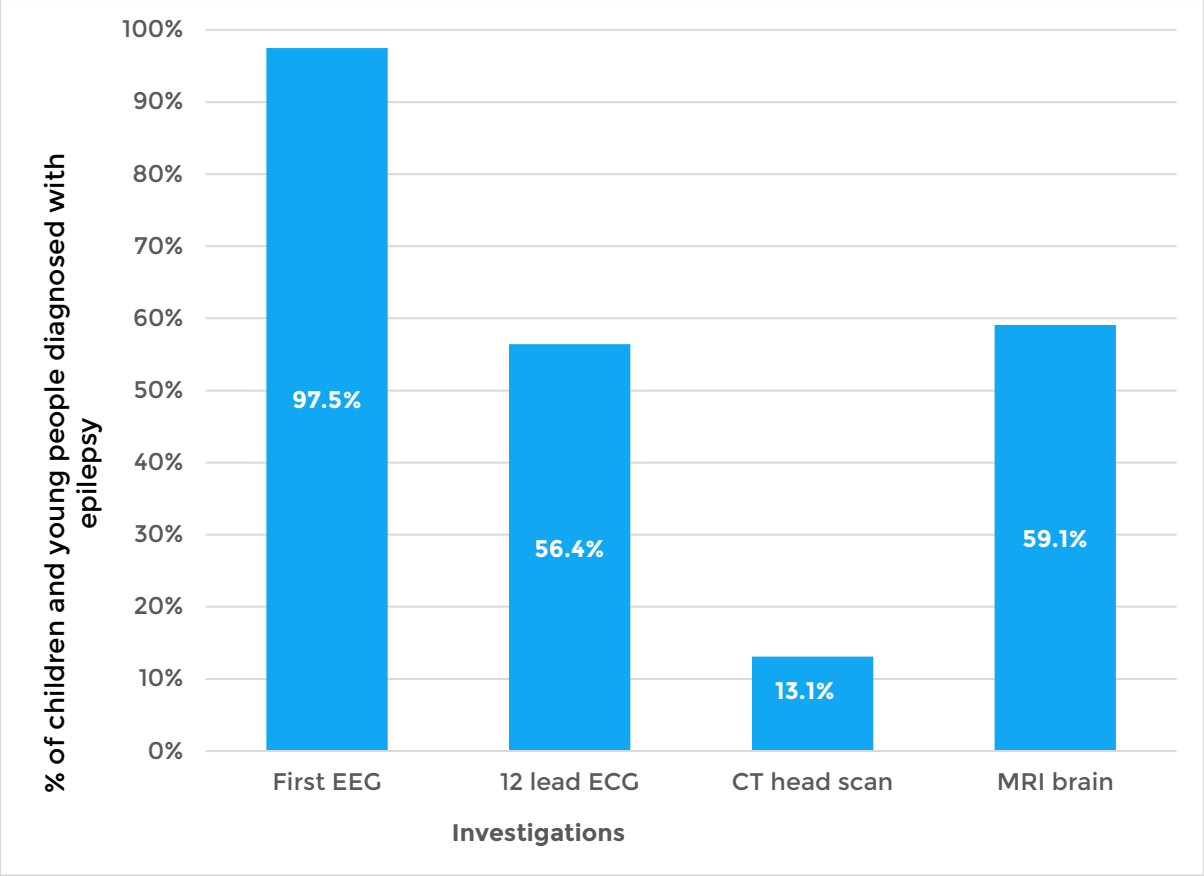


Figure 59: Percentage of children and young people diagnosed with epilepsy that obtained First EEG, 12 lead ECG, CT head scan and MRI brain investigations in England and Wales.

Performance Indicator 6: ECG

In Round 3 cohort 1, **67.6% (474/701)** of children and young people diagnosed with epilepsy and had convulsive seizures, obtained a 12 lead ECG by the first year in England and Wales, (**Table 79**). This indicator ranged from 0% to 100% and the inter-quartile range was 46.0% to 100% at a Health Board or Trust level. In Round 3, this performance indicator was just applied to children with epilepsy and convulsive seizures, rather than all children with convulsive seizures. This means that longitudinal comparison is not meaningful and therefore has not been reported.

Table 79: Percentage of children and young people with convulsive seizures and epilepsy, with an ECG by the first year, Round 3, cohort 1.

Performance Indicator: 6		England and Wales	England	Wales
ECG	% of children and young people with convulsive seizures and epilepsy, with an ECG by the first year	67.6% (474/701)	69.5% (460/662)	35.9% (14/39)

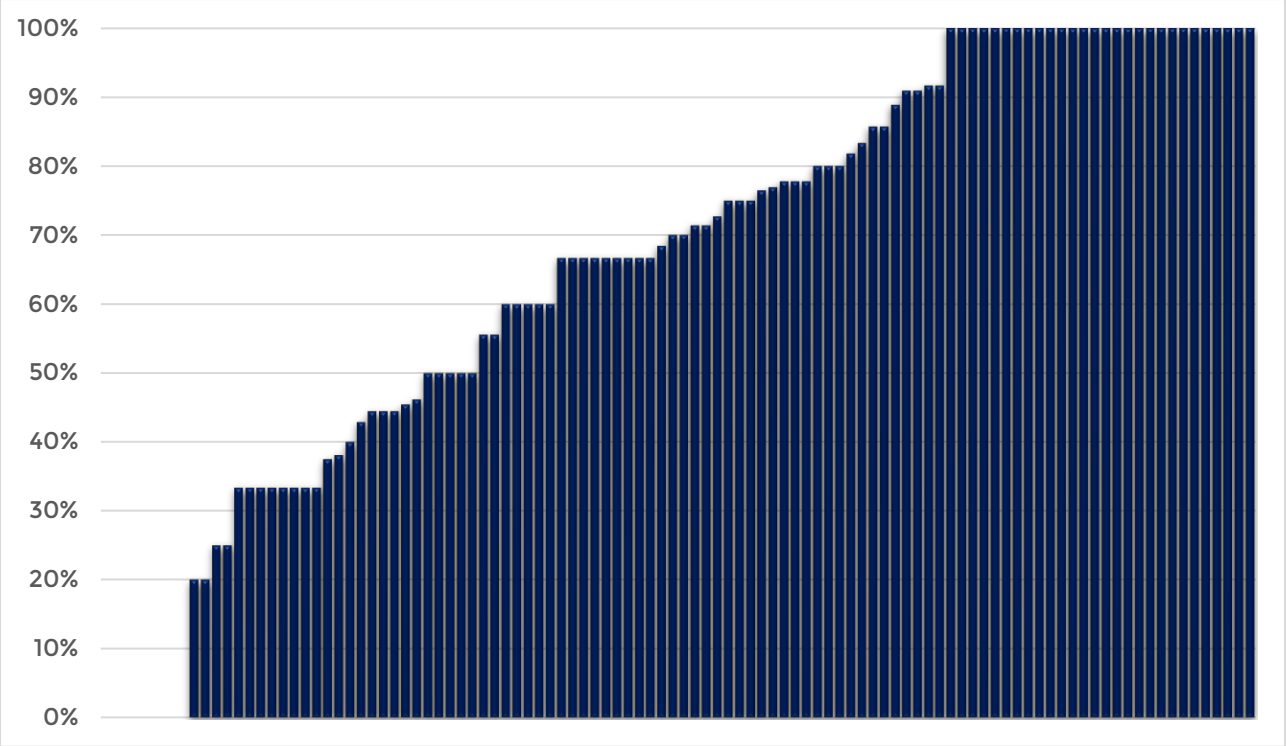


Figure 60: Percentage of children and young people with convulsive seizures and epilepsy, with an ECG at first year by Health Board and Trust, Round 3, cohort 1.

Each Health Board or Trust is represented by a vertical bar in the order of the percentage score, including those scoring 0% in this graph.

Performance Indicator 7: MRI

NICE guidelines (Quality Statement 3) states that children and young people who meet the criteria for neuroimaging for epilepsy to have magnetic resonance imaging (MRI).

In Round 3, cohort 1, **68.6% (317/462)** children and young people diagnosed with epilepsy and with defined indications for an MRI, who had MRI by their first year of care in England and Wales, (**Table 80**). At a Health Board or Trust level in Round 3, this indicator ranged from 0% to 100%, the inter-quartile range was 50% to 100%.

Table 80: Percentage of children and young people with defined indications for an MRI, who had MRI by their first year of care.

Performance Indicator: 7		Audit Round	England and Wales	England	Wales
MRI	% of children and young people with defined indications for an MRI, who had MRI by first year	Round 1	63.5% (602/948)	64.3% (578/899)	49.0% (24/49)
		Round 2	72.2% (481/666)	72.7% (458/630)	63.9% (23/36)
		Round 3	68.6% (317/462)	70.4% (307/436)	38.5% (10/26)

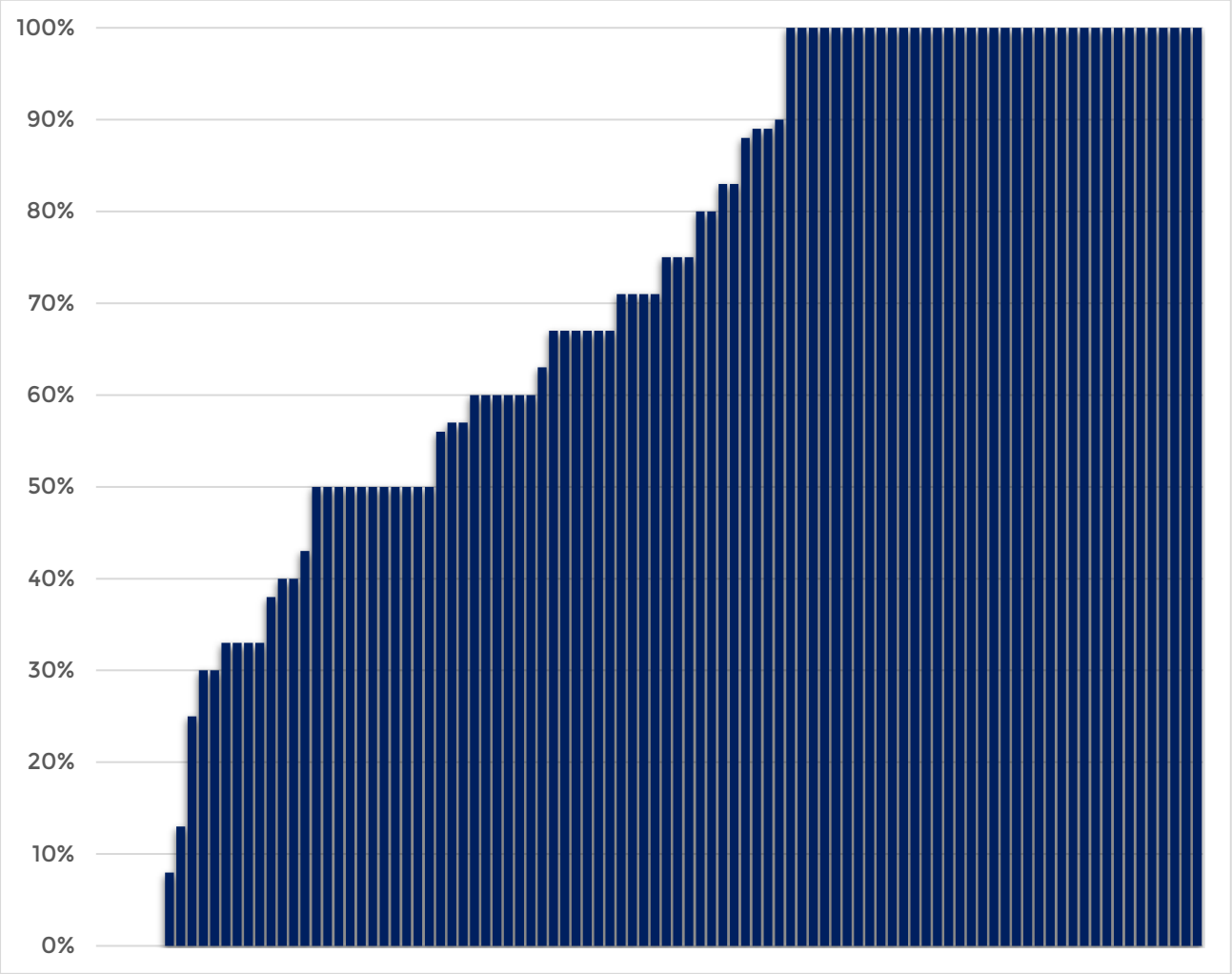


Figure 61: Percentage of children and young people with defined indications for an MRI, who had MRI by first year by Health Board and Trust, Round 3, cohort 1.

Each Health Board or Trust is represented by a vertical bar in the order of the percentage score, including those scoring 0% in this graph.

Treatment

Anti-epileptic drug (AED)

In Round 3, cohort 1, **879** children and young people were prescribed one or more anti-epileptic drugs (AEDs) during their first 12 months of care. **72** children and young people had begun three or more AEDs during their first 12 months of care.

Table 81 below shows the diagnosis of children and young people together with the number of different AEDs prescribed over their first year of care.

Table 81: Diagnosis and AEDs.

	Round 1		Round 2		Round 3	
Diagnoses	**1 or more AED N=1538**	**3 or more AEDs N=135**	**1 or more AED N=1059**	**3 or more AEDs N=84**	**1 or more AED N=879**	**3 or more AEDs N=72**
Epilepsy	1406 (91.0%)	129 (96.0%)	976 (92.0%)	82 (98.0%)	856 (97.4%)	71 (98.6%)
Single epileptic seizure (or cluster)	68 (4.0%)	6 (4.0%)	9 (1.0%)	0 (0.0%)	10 (1.1%)	0 (0.0%)
Non-epileptic episode (s)	44 (3.0%)	0 (0.0%)	20 (2.0%)	1 (1.0%)	7 (0.8%)	1 (1.4%)
Uncertain episodes	20 (1.0%)	0 (0.0%)	55 (5.0%)	1 (1.0%)	6 (0.7%)	0 (0.0%)

Figure 62 shows the frequency of AEDs use among children diagnosed with epilepsy. Carbamazepine, sodium valproate and levetiracetam were the most commonly used AEDs for children diagnosed with epilepsy in Round 3, cohort 1.

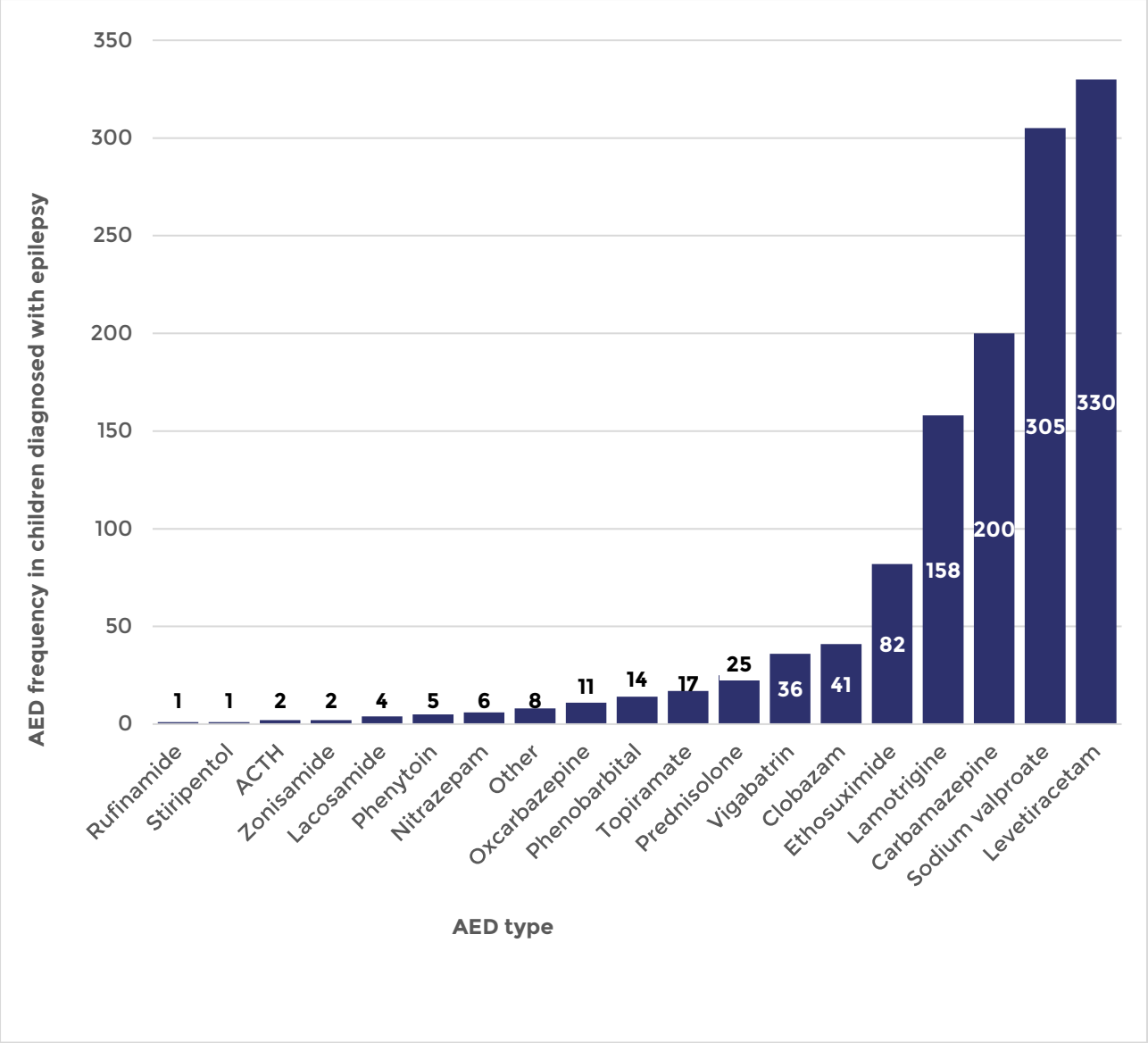


Figure 62: Frequency by AED type in England and Wales, Round 3, cohort 1.

Sodium valproate use

Figure 63 below shows the number of children and young people diagnosed with epilepsy on sodium valproate by gender in England and Wales, Round 3 cohort 1. There were more boys on sodium valproate than girls across all ages.

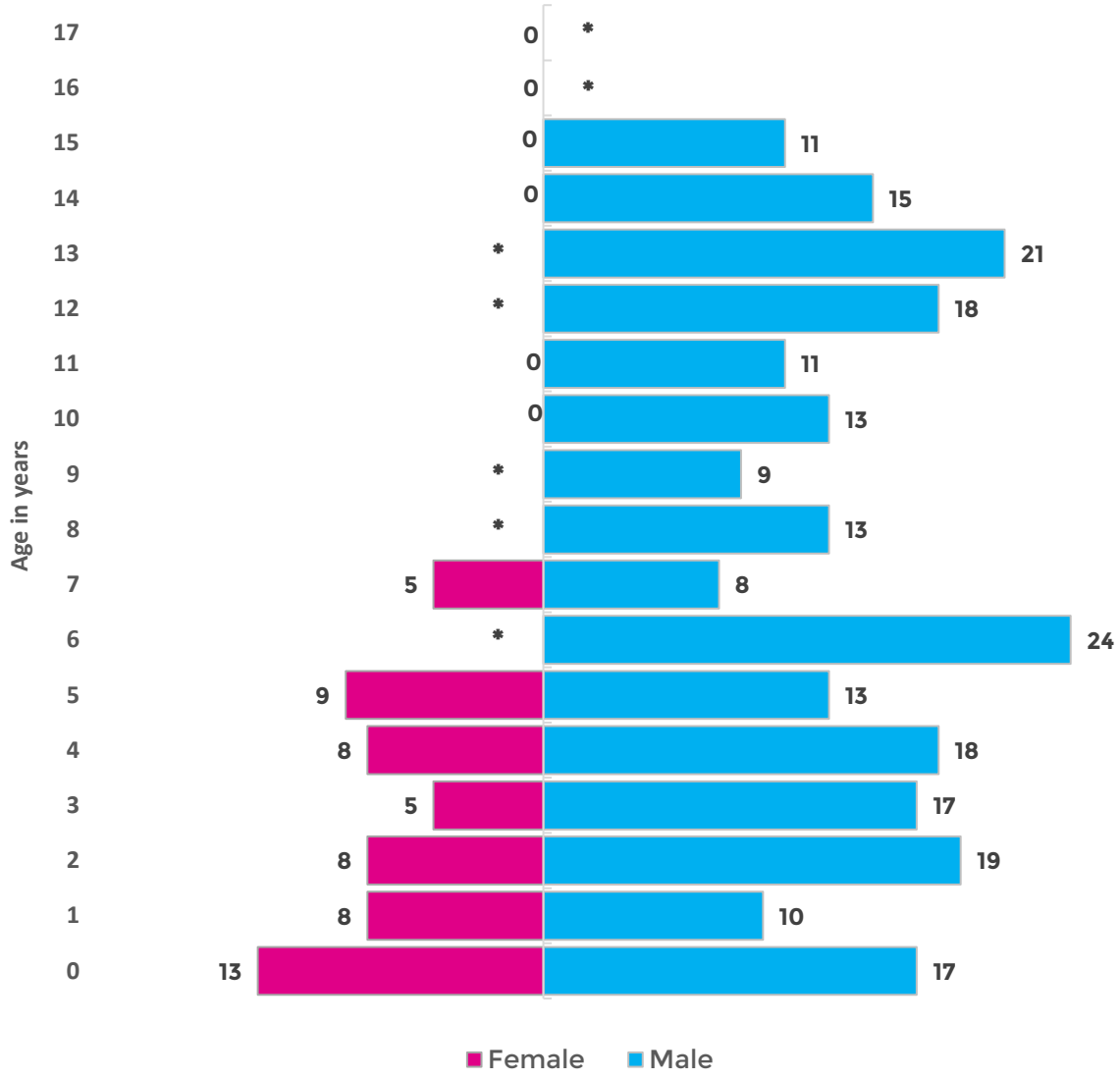


Figure 63: Number of children and young people diagnosed with epilepsy on sodium valproate by gender in England and Wales, Round 3 cohort 1.

*Age groups with fewer than five children and young people are not shown.

Performance indicator 9 and 9b: Sodium Valproate

In Round 3, cohort 1, **39.7% (25/63)** of all females diagnosed with epilepsy and on sodium valproate treatment, had evidence of previous discussion of risk regarding birth defects and/or neurodevelopmental outcomes, (**Table 82**). This indicator ranged from 0% to 100% and had an interquartile range of 0% to 100% at a Health Board and Trust level.

There were fewer than five females aged nine years and above, who were diagnosed with epilepsy and receiving treatment with sodium valproate. All (100%) of them had evidence of previous discussion of risk regarding birth defects and/or neurodevelopmental outcomes.

Table 82: Sodium Valproate in females

Performance indicator: Sodium valproate		Audit Round	England and Wales
9	% of all females >9 years currently on valproate treatment with evidence of discussion of foetal risk	Round 3	100% (>5)
9b	% of all females currently on valproate treatment with evidence of discussion of foetal risk	Round 3	39.7% (25/63)

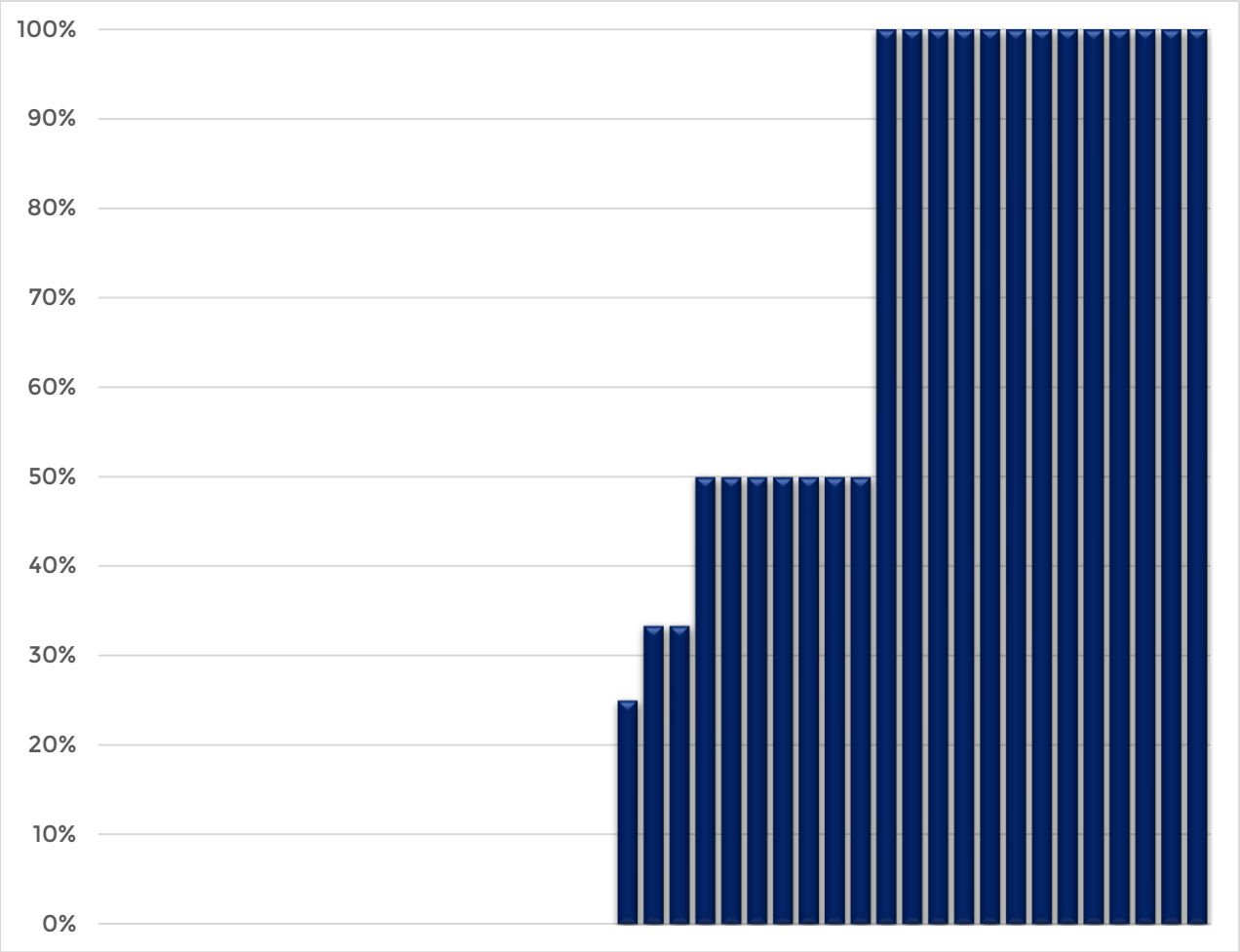


Figure 64: Percentage of females currently on sodium valproate treatment with evidence of discussion of foetal risk by Health Board and Trust, Round 3, cohort 1.

Each Health Board and Trust is represented by a vertical bar in the order of the percentage score, including those scoring 0% in this graph.

Rescue medication prescribed

19.6% (218/1112) of the children and young people diagnosed with epilepsy had rescue medication prescription in England and Wales, (**Figure 65**). **80.4% (894/1112)** of children and young people did not have rescue medication prescribed.

Figure 66 shows the percentage of children and young people diagnosed with epilepsy that had rescue medication prescribed by country and network.

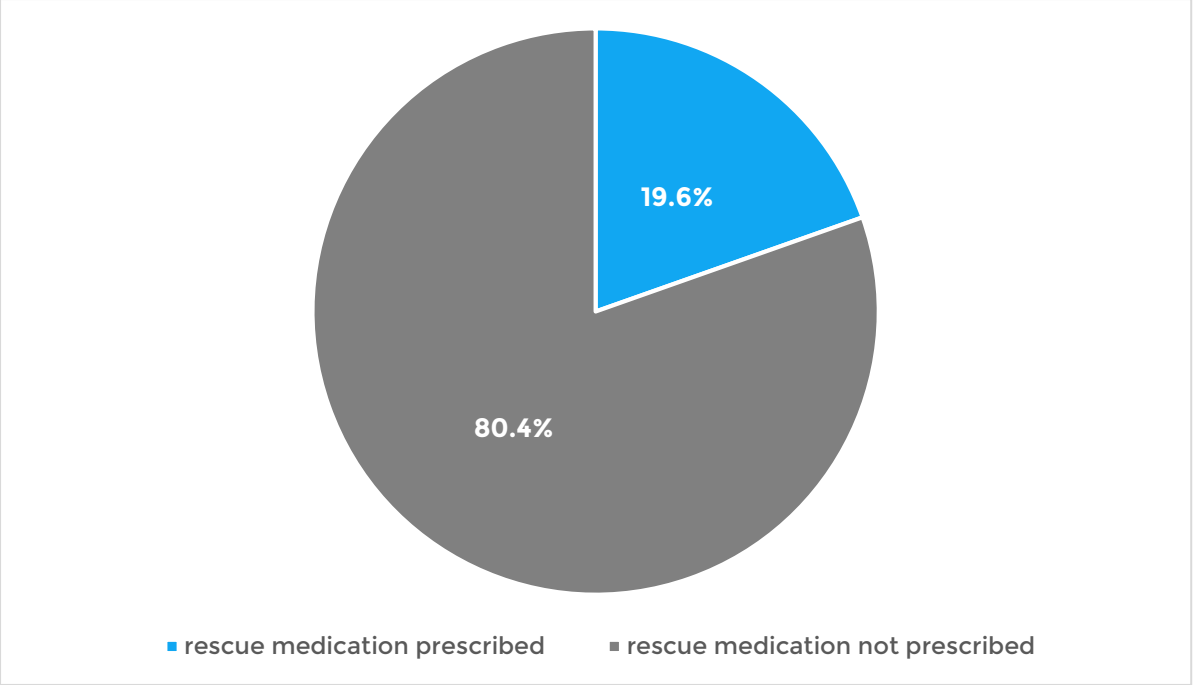


Figure 65: Percentage of children and young people diagnosed with epilepsy that had/did not have rescue medication prescribed in England and Wales.

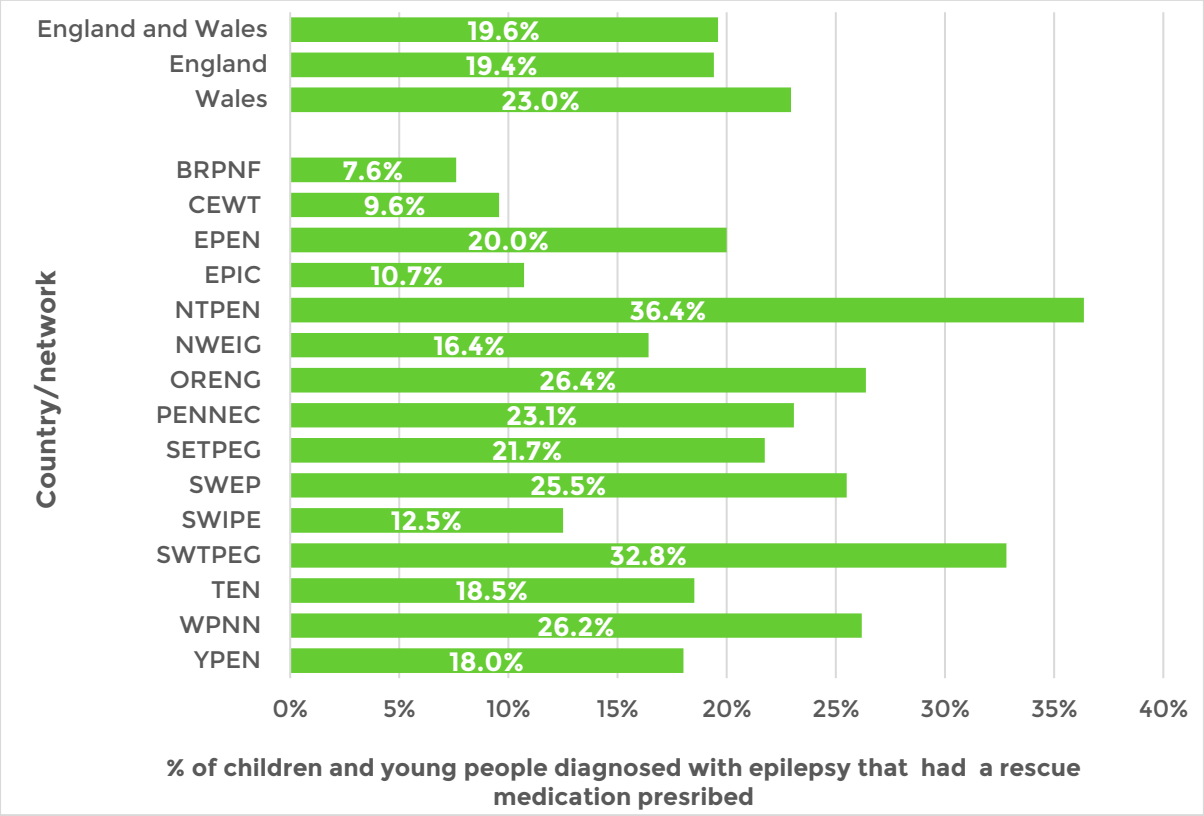


Figure 66: Percentage of children and young people diagnosed with epilepsy that had rescue medication prescribed by country and network.

Children's Epilepsy Surgery Service (CESS) referral criteria

8.0% (89/1112) of the children and young people diagnosed with epilepsy, met one or more of the CESS referral criteria in England and Wales, (**Figure 66**). **92.0% (1023/1112**) of children and young people did not meet any CESS referral criteria.

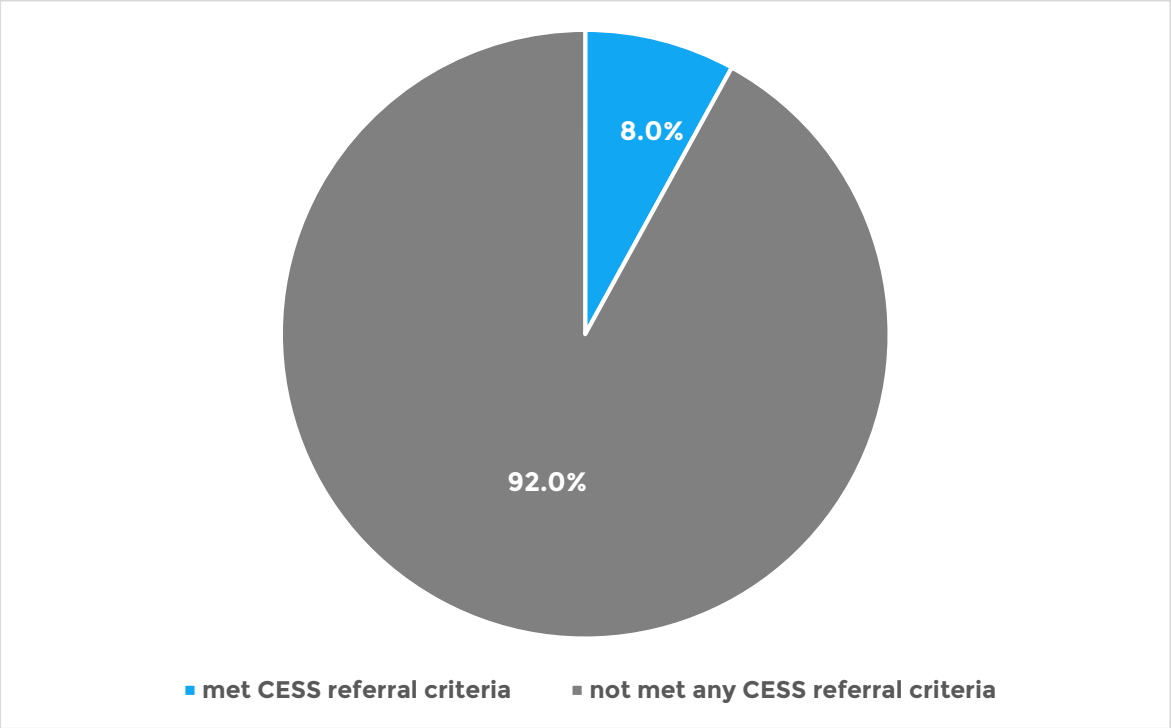


Figure 67: Percentage of children and young people diagnosed with epilepsy that met/did not meet any CESS referral criteria in England and Wales.

Figure 68 shows the percentage of children and young people diagnosed with epilepsy that met any CESS referral criteria by country and network. In the paediatric network areas, this varied between 0% and 16.0% of children and young people meeting any CESS referral criteria.

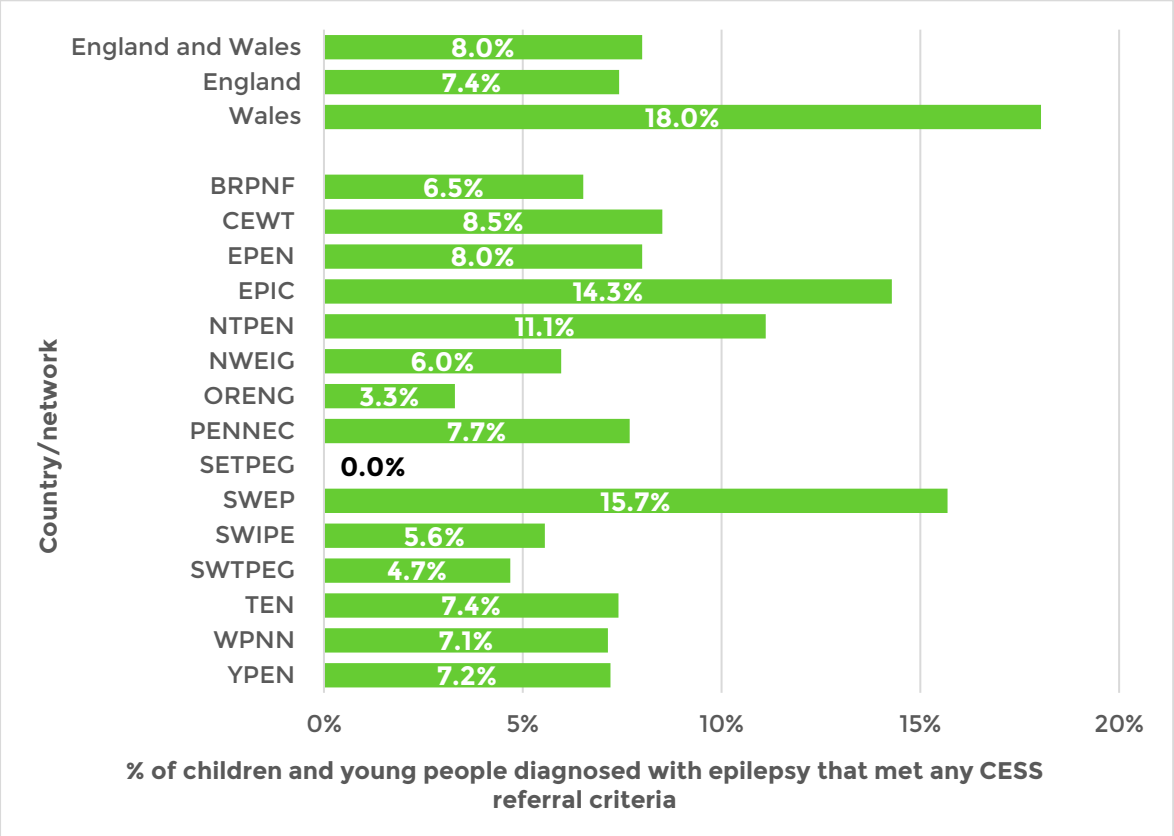


Figure 68: Percentage of children and young people diagnosed with epilepsy that met any CESS referral criteria by country and network.

Performance indicator 3b: Epilepsy surgery referral

In Round 3, cohort 1, **30.0% (27/89)** of the children and young people who met CESS referral criteria had epilepsy surgery referral by one year, (**Table 83**). **Table 84** shows the breakdown of this performance indicator by network. This is a new indicator for Round 3 and therefore longitudinal comparison will not be possible.

Table 83: Epilepsy surgery referral.

Performance Indicator: 3b		Audit Round	England and Wales	England	Wales
Epilepsy Surgery Referral.	% of ongoing children and young people meeting defined epilepsy surgery referral criteria with evidence of epilepsy surgery referral	Round 3	30.0% (27/89)	33.0% (26/78)	9.1% (1/11)

Table 84: Percentage of ongoing children and young people meeting defined epilepsy surgery referral criteria with evidence of epilepsy surgery referral by country and network.

Country/network	Epilepsy surgery referral
England and Wales	30% (27/89)
England	33% (26/78)
Wales	9.1% (1/11)
BRPNF	83.3% (5/6)
CEWT	12.5% (1/8)
EPEN	33.3% (2/6)
EPIC	25.0% (4/16)
NTPEN	36.4% (4/11)
NWEIG	25.0% (1/4)
ORENG	0.0% (0/3)
PENNEC	0.0% (0/5)
SETPEG	(0/0)
SWEP	12.5% (1/8)
SWIPE	50.0% (2/4)
SWTPEG	33.3% (1/3)
TEN	75.0% (3/4)
WPNN	33.3% (1/3)
YPEN	25.0% (2/8)

4.0% (6/150) of children and young people meeting the defined criteria for paediatric neurology referral, did not have a paediatric neurologist input date.

NICE guidelines (Quality statement 7) state that children and young people who meet the criteria for referral to a neurologist are seen within 4 weeks of referral.

52.8% (76/144) of children and young people who met the criteria for referral to a neurologist, were seen within four weeks of referral in England and Wales, **(Table 85).**

Table 85: Time in weeks since referral to neurologist by country.

Country	0 - 4 weeks	4 - 8 weeks	8 - 12 weeks	12 - 16 weeks	>16 weeks
England and Wales	52.8% (76/144)	14.6% (21/144)	12.5% (18/144)	6.9% (10/144)	11.8% (17/144)
England	52.9% (72/136)	14.7% (20/136)	12.5% (17/136)	6.6% (9/136)	11.8% (16/136)
Wales	50.0% (4/8)	12.5% (1/8)	12.5% (1/8)	12.5% (1/8)	12.5% (1/8)

Only the children with a paediatric neurologist input date were included in this analysis, hence the percentages on the table may not add up to 100%.

Care planning

Appropriate care planning

Performance indicator 10: Comprehensive Care Planning agreement

In Round 3, cohort 1, **62.4% (694/1112)** of children and young people diagnosed with epilepsy had evidence of a comprehensive care plan that had been updated where necessary and was agreed between the patient, their family and/or carers and primary and secondary care providers, for the first year of care (**Table 86**). This indicator ranged from 0% to 100% and had an interquartile range of 43% to 81% at a Health Board or Trust level.

Table 86: Comprehensive Care Planning agreement

	Performance indicator: Comprehensive Care Planning agreement	Audit Round	England and Wales	England	Wales
10	% of children and young people with epilepsy after 12 months where there is evidence of a comprehensive care plan that is agreed between the person, their family and/or carers and primary and secondary care providers, and the care plan has been updated where necessary	Round 3	62.4% (694/1112)	63.5% (667/1051)	44.3% (27/61)
10a	% of children and young people with epilepsy after 12 months that had an individualised epilepsy document with individualised epilepsy document or a copy clinic letter that includes care planning information	Round 3	88.3% (982/1112)	88.8% (933/1051)	80.3% (49/61)
10b	% of children and young people with epilepsy after 12 months where there was evidence of agreement between the person, their family and/or carers as appropriate	Round 3	74.2% (825/1112)	74.8% (786/1051)	63.9% (39/61)
10c	% of children and young people with epilepsy after 12 months where there is evidence that the care plan has been updated where necessary	Round 3	69.6% (774/1112)	71.0% (746/1051)	45.9% (28/61)

.

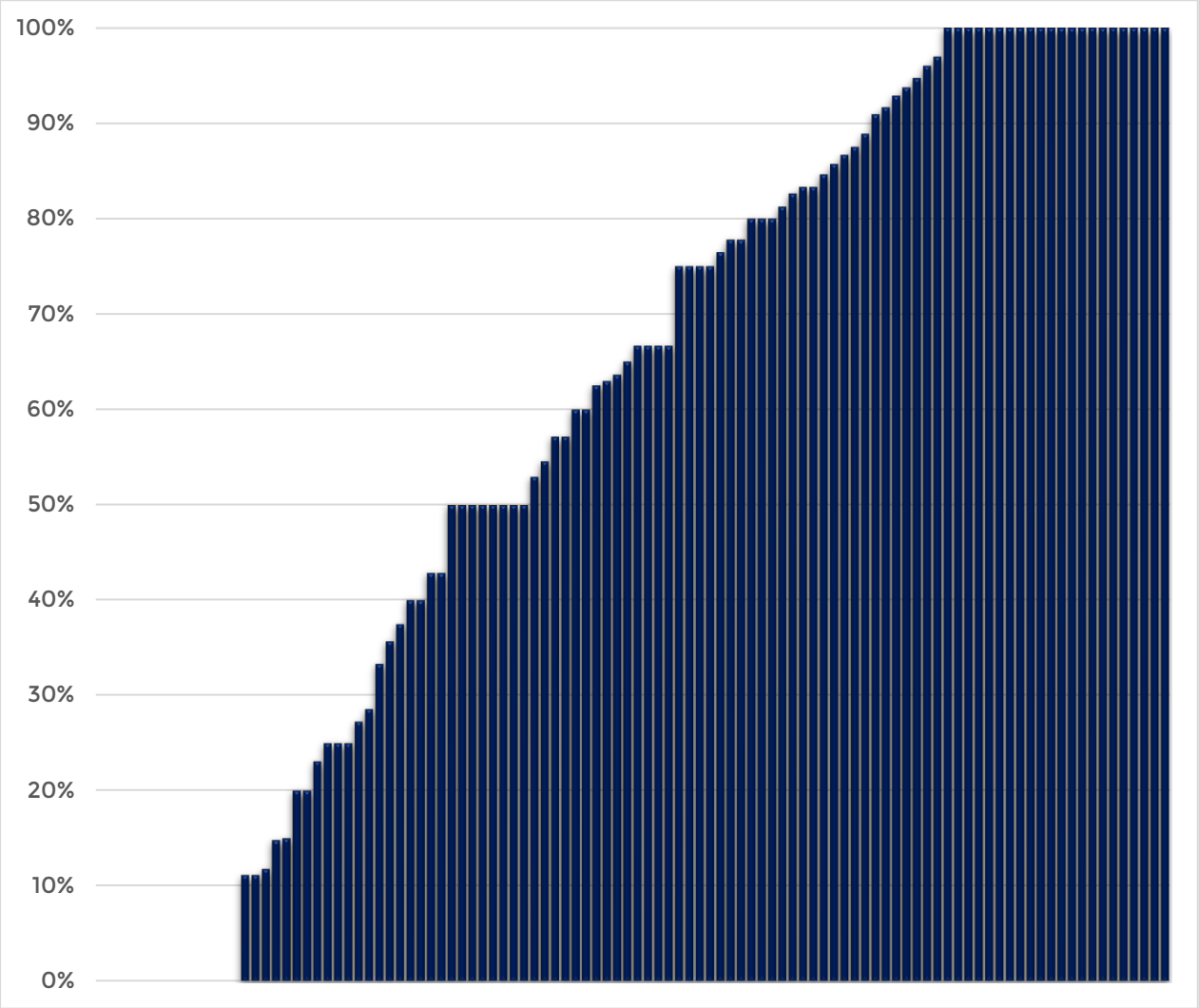


Figure 69: Comprehensive Care Planning agreement, Round 3

Each Health Board and Trust is represented by a vertical bar in the order of the percentage score, including those scoring 0% in this graph.

Performance indicator 11: Comprehensive Care Planning content

NICE guidelines (Quality statement 4) state that children and young people with epilepsy have an agreed and comprehensive care plan.

In Round 3, cohort 1, **70.1% (779/1112)** of children and young people diagnosed with epilepsy had documented evidence of communication regarding relevant core elements of care planning, (**Table 87**). This indicator ranged from 0% to 100% and had an interquartile range of 50% to 100% at a Health Board and Trust level.

NICE guidelines (Quality statement 6) state that children and young people with a history of prolonged or repeated seizures have an agreed written emergency care plan.

88.5% (193/218) of children and young people diagnosed with epilepsy and on rescue medication, had a parental prolonged seizure care plan in England and Wales, (**Table 87**).

Table 87: Comprehensive Care Planning content.

Performance indicator: Comprehensive Care Planning content		Audit Round	England and Wales	England	Wales
11	% of children diagnosed with epilepsy with documented evidence of communication regarding relevant core elements of care planning	Round 3	70.1% (779/1112)	71.7% (754/1051)	41.0% (25/61)
11a	% of children diagnosed with epilepsy with parental prolonged seizures care plan	Round 3	88.5% (193/218)	89.2% (182/204)	78.6% (11/14)
11b	% of children diagnosed with epilepsy with evidence of discussion regarding water safety	Round 3	79.7% (886/1112)	81.4% (856/1051)	49.2% (30/61)
11c	% of children diagnosed with epilepsy with evidence of discussion regarding first aid	Round 3	84.8% (943/1112)	86.2% (906/1051)	60.7% (37/61)
11d	% of children diagnosed with epilepsy with evidence of discussion regarding general participation and risk	Round 3	80% (890/1112)	81.1% (852/1051)	62.3% (38/61)
11e	% of children diagnosed with epilepsy evidence of discussion of been given service contact details	Round 3	90.7% (1009/1112)	91.3% (960/1051)	80.3% (49/61)

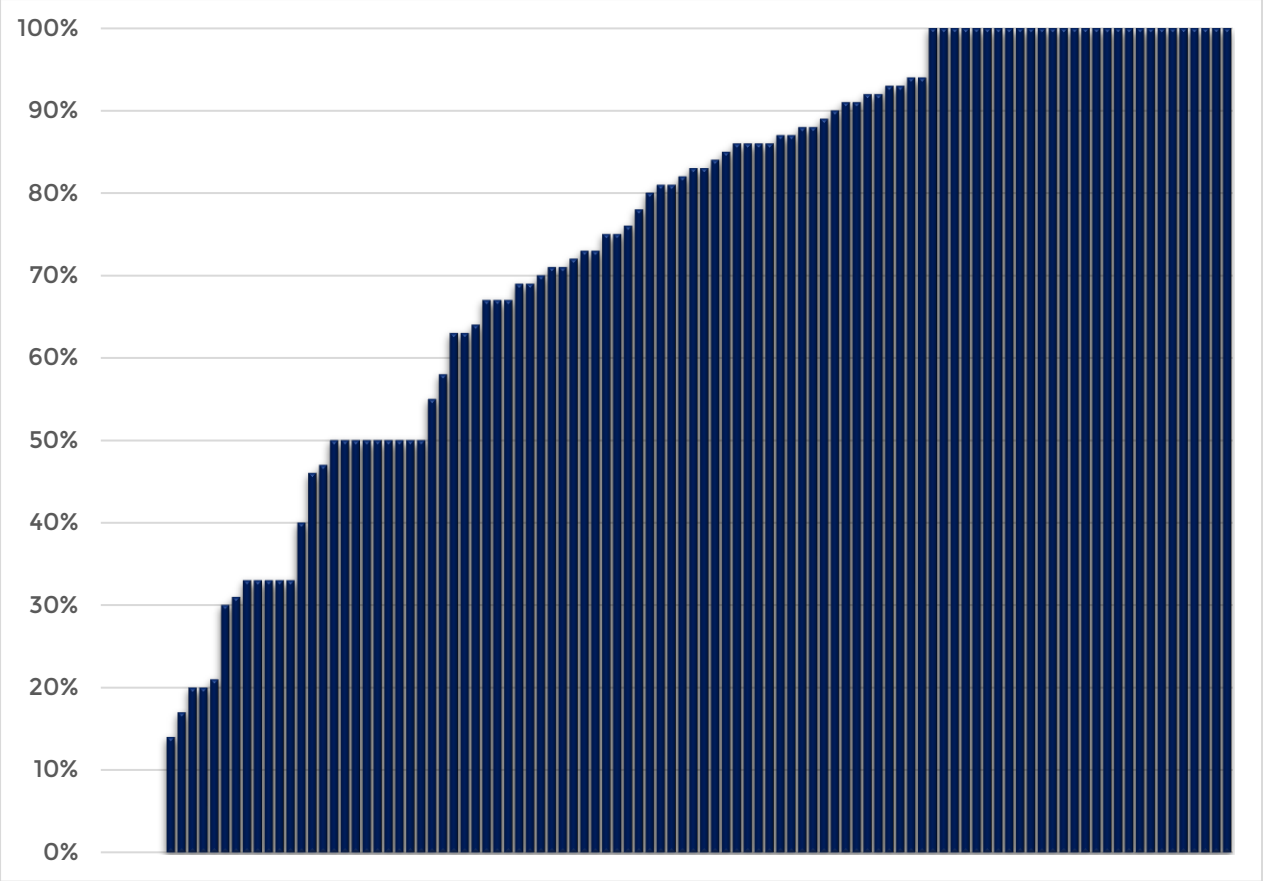


Figure 70: Comprehensive Care Planning content by Health Board and Trust, Round 3.

Each Health Board and Trust is represented by a vertical bar in the order of the percentage score, including those scoring 0% in this graph.

Performance indicator 12: School Individual Healthcare Plan

In Round 3 cohort 1, **32.2% (231/717)** of children and young people diagnosed with epilepsy and aged five years and above had evidence of a school individual healthcare plan by one year (**Table 88**). This indicator ranged from 0% to 100% and had an interquartile range of 0% to 63% at Health Board or Trust level.

Table 88: School Individual Healthcare Plan

Performance indicator 12:		Audit Round	England and Wales	England	Wales
School Individual Healthcare Plan	% of children and young people with epilepsy aged 5years and above with evidence of a school individual healthcare plan by 1 year after first paediatric assessment.	Round 3	32.2% (231/717)	32.4% (219/676)	29.3% (12/41)

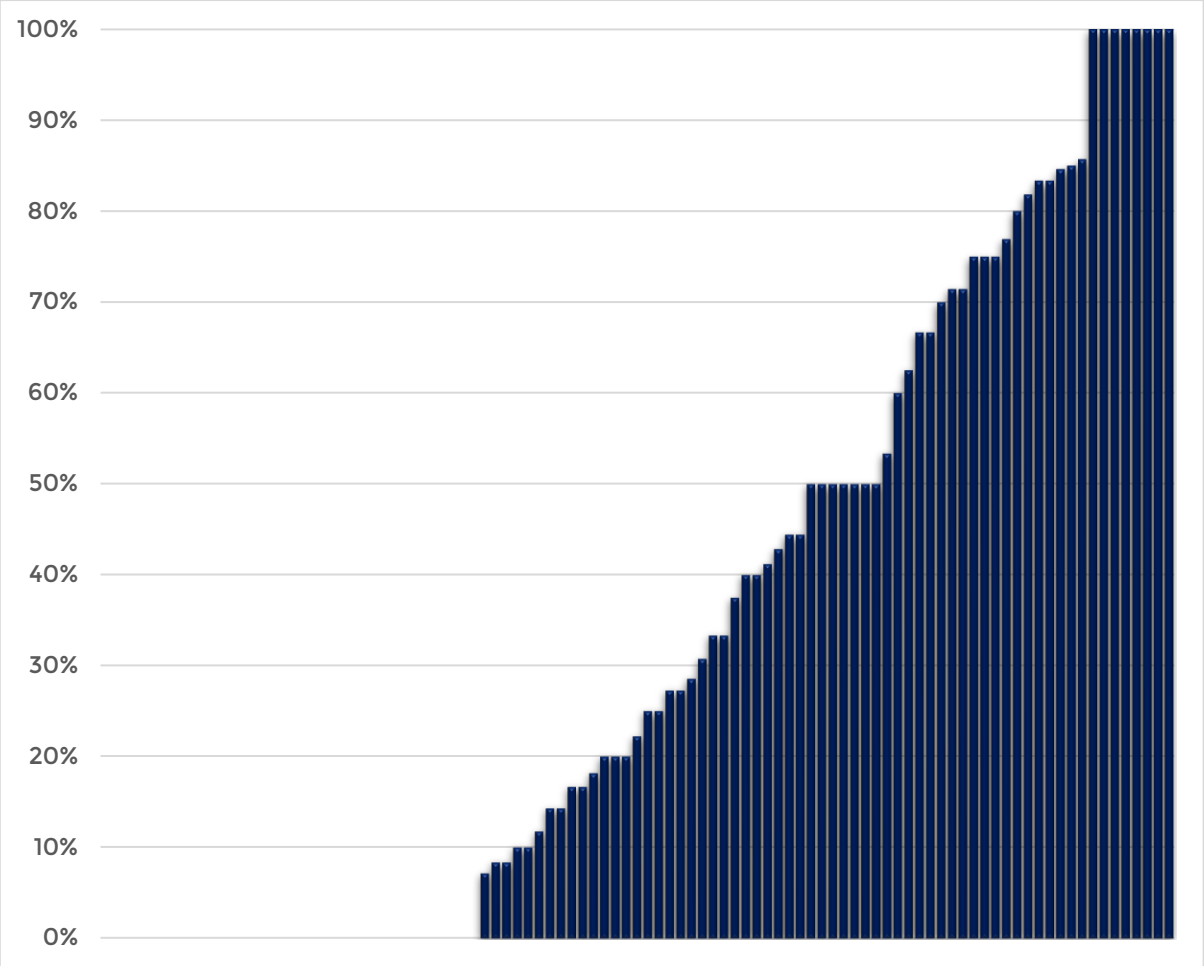


Figure 71: School Individual Healthcare Plan, by Health Board or Trust, Round 3, cohort 1

Each Health Board and Trust is represented by a vertical bar in the order of the percentage score, including those scoring 0% in this graph.

Sudden Unexpected Death in Epilepsy (SUDEP)

42.6% (474/1112) of children and young people diagnosed with epilepsy had evidence of information on SUDEP in England and Wales (**Figure 72**). **57.4% (638/1112)** of children and young people did not have SUDEP information provided. Figure 73 shows the percentage of children and young people with evidence of SUDEP information by country and network.

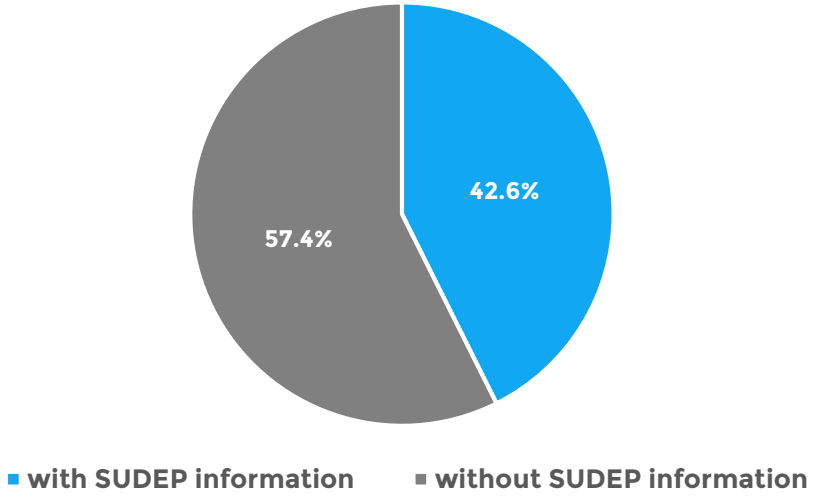


Figure 72: Percentage of children and young people diagnosed with Epilepsy with/without evidence of SUDEP information in England and Wales.

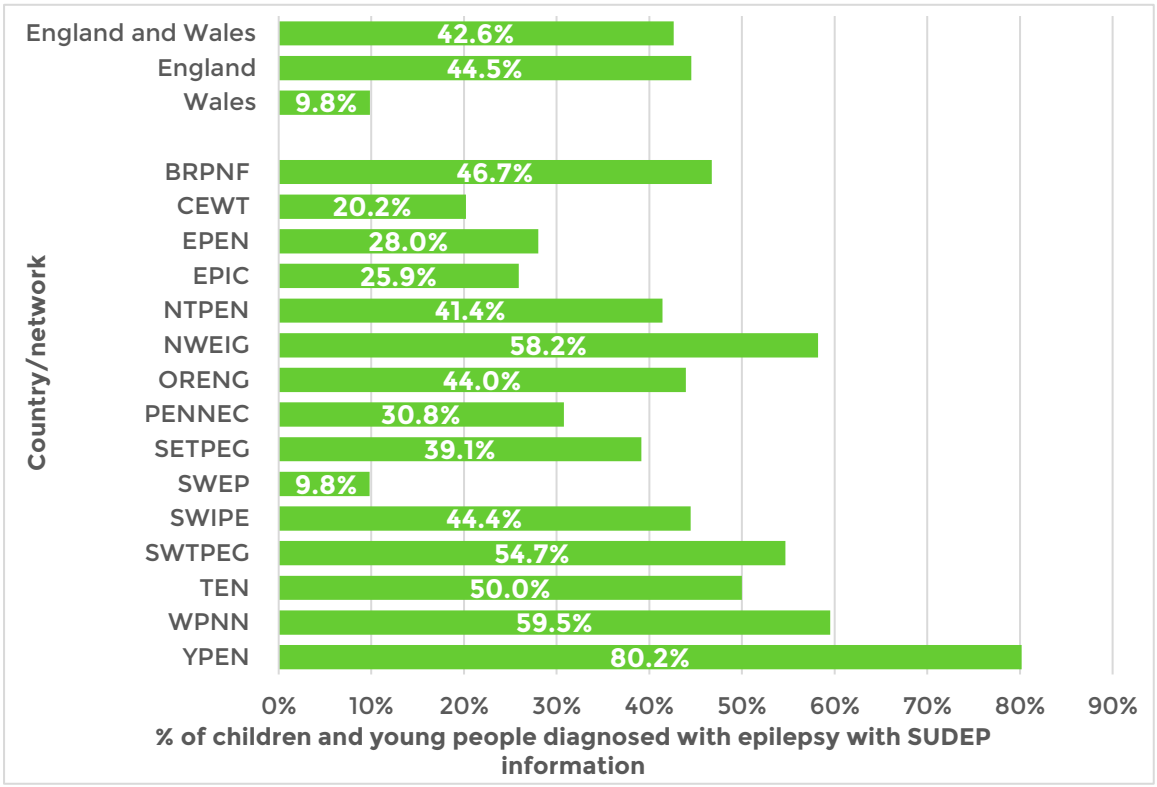


Figure 73: Percentage of children and young people diagnosed with evidence of SUDEP information by country and network.

Professionals and services involved in care

Professionals

Table 89 shows that **82.3% (915/1112)** of the children and young people diagnosed with epilepsy had input from a paediatrician with expertise in epilepsies in England and Wales in their first year of care. **71.8% (798/1112)** of children and young people diagnosed with epilepsy had an input from an epilepsy specialist nurse (ESN).

Figure 74 shows the percentage of children and young people diagnosed with epilepsy with an input from various professionals in England and Wales.

Table 89: Percentage of children and young people diagnosed with epilepsy with an input from various professionals by Country.

Professionals and services involved in care	England and Wales	England	Wales
% Consultant Paediatrician with expertise in epilepsies	82.3% (915/1112)	81.9% (861/1051)	88.5% (54/61)
% ESN	71.8% (798/1112)	73.2% (769/1051)	47.5% (29/61)
% Paediatric neurologist	22.4% (249/1112)	22.1% (232/1051)	27.9% (17/61)
% CESS	1.6% (18/1112)	1.7% (18/1051)	0.0% (0/61)
% Ketogenic dietician	0.6% (7/1112)	0.7% (7/1051)	0.0% (0/61)
% VNS service	0.0% (0/1112)	0.0% (0/1051)	0.0% (0/61)
% Genetic service	4.8% (53/1112)	4.9% (52/1051)	1.6% (1/61)
% Clinical psychologist	1.2% (13/1112)	1.2% (13/1051)	0.0% (0/61)
% Educational psychologist	0.6% (7/1112)	0.7% (7/1051)	0.0% (0/61)
% Psychiatrist	0.6% (7/1112)	0.7% (7/1051)	0.0% (0/61)
% Neuropsychologist	0.5% (6/1112)	0.6% (6/1051)	0.0% (0/61)
% Counselling service	0.4% (4/1112)	0.4% (4/1051)	0.0% (0/61)
% Other mental health professional	0.7% (8/1112)	0.8% (8/1051)	0.0% (0/61)
% Youth worker	0.0% (0/1112)	0.0% (0/1051)	0.0% (0/61)
% Other	1.5% (17/1112)	1.5% (16/1051)	1.6% (1/61)

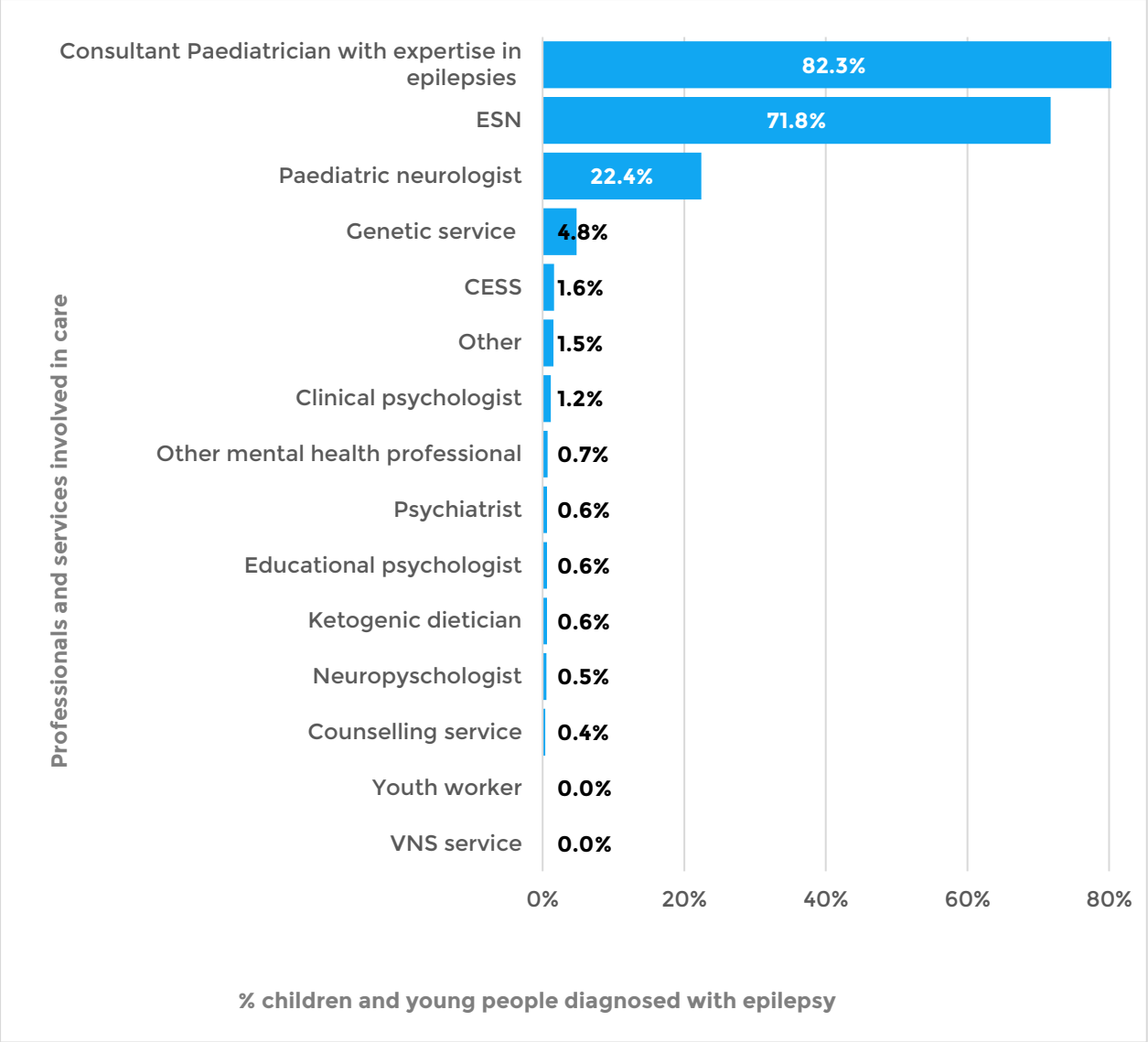


Figure 74: Percentage of children and young people diagnosed with epilepsy with input from various professionals in England and Wales.

Performance indicator 1: Paediatrician with expertise in epilepsies

In Round 3 cohort 1, **87.9% (977/1112)** of children and young people diagnosed with epilepsy, had input from a paediatrician with expertise in epilepsies in their first year of care, (**Table 90**). This is slightly higher than in Round 2, **86.1% (938/1090).**

This indicator ranged from 20% to 100% and had an interquartile range of 84% to 100% at a Health Board and Trust level.

Table 90: Paediatrician with expertise in epilepsies.

Performance indicator: 1		Audit Round	England and Wales	England	Wales
Paediatrician with expertise in epilepsies	% of children and young people with epilepsy, with input by a 'consultant paediatrician with expertise in epilepsies' within the first year of care	Round 1	78.0% (1183/1516)	77.7% (1106/1423)	82.8% (77/93)
		Round 2	86.1% (938/1090)	86.1% (877/1019)	85.9% (61/71)
		Round 3	87.9% (977/1112)	87.9% (924/1051)	86.9% (53/61)

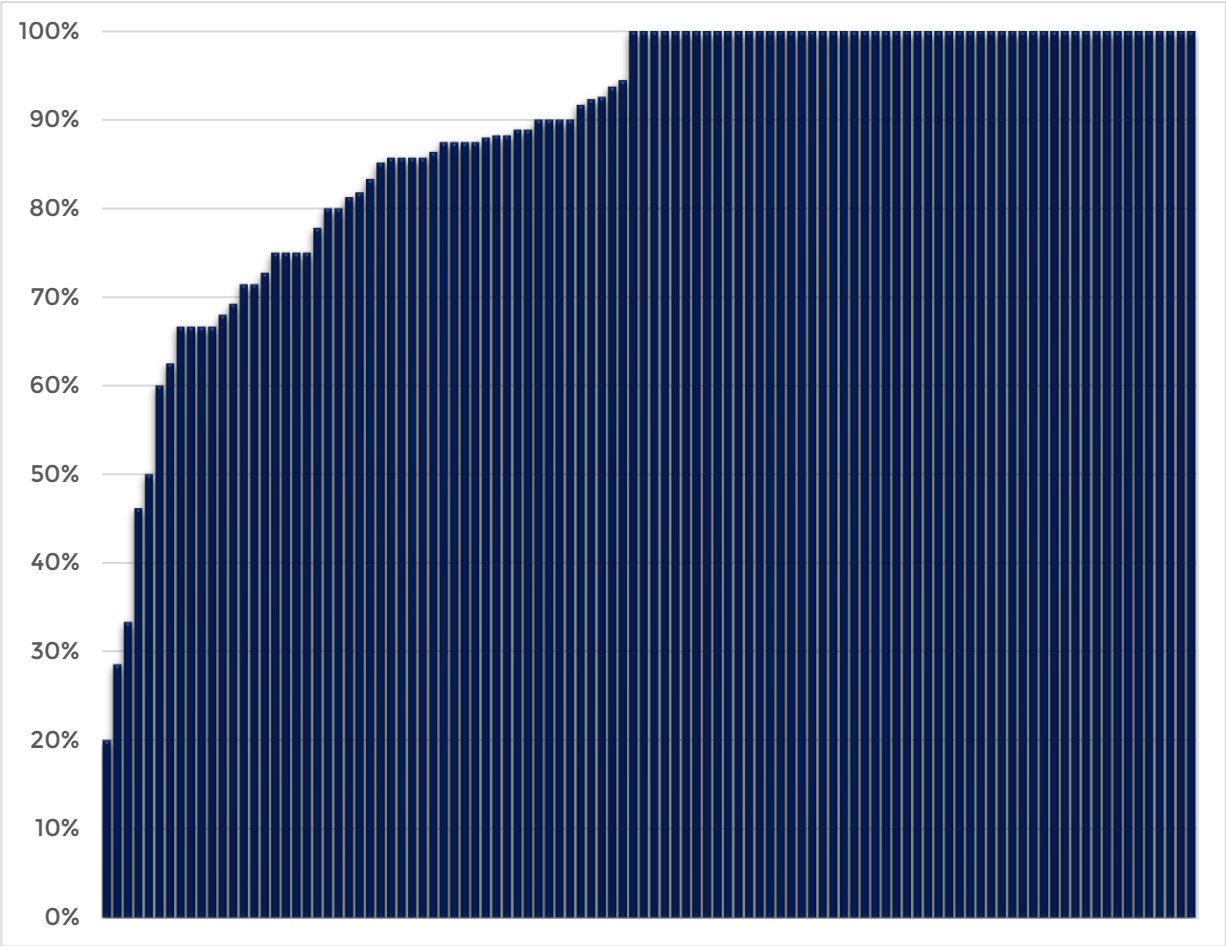


Figure 75: Paediatrician with expertise in epilepsies by Health Board and Trust, Round 3, cohort 1.

Each Health Board and Trust is represented by a vertical bar in the order of the percentage score, including those scoring 0% in this graph.

Performance indicator 2: Epilepsy specialist nurse

NICE guidelines (Quality statement 5) state that children and young people with epilepsy are seen by an epilepsy specialist nurse who they can contact between scheduled reviews.

In Round 3, cohort 1, **69.0% (767/1112)** of children and young people diagnosed with epilepsy, had input from an epilepsy specialist nurse (ESN) by one year, (**Table 91**). This is proportion is higher than Round 2. This indicator ranged from 0% to 100% and had an interquartile range of 58.0% to 100% at a Health Board or Trust level.

Table 91: Epilepsy specialist nurse

Performance indicator: 2		Audit Round	England and Wales	England	Wales
Epilepsy specialist nurse	% of children and young people with epilepsy, with input by an epilepsy specialist nurse within the first year of care	Round 1	43.4% (658/1516)	41.6% (592/1423)	71.0% (66/93)
		Round 2	55.5% (605/1090)	54.5% (555/1019)	70.4% (50/71)
		Round 3	69.0% (767/1112)	70.2% (738/1051)	47.5% (29/61)

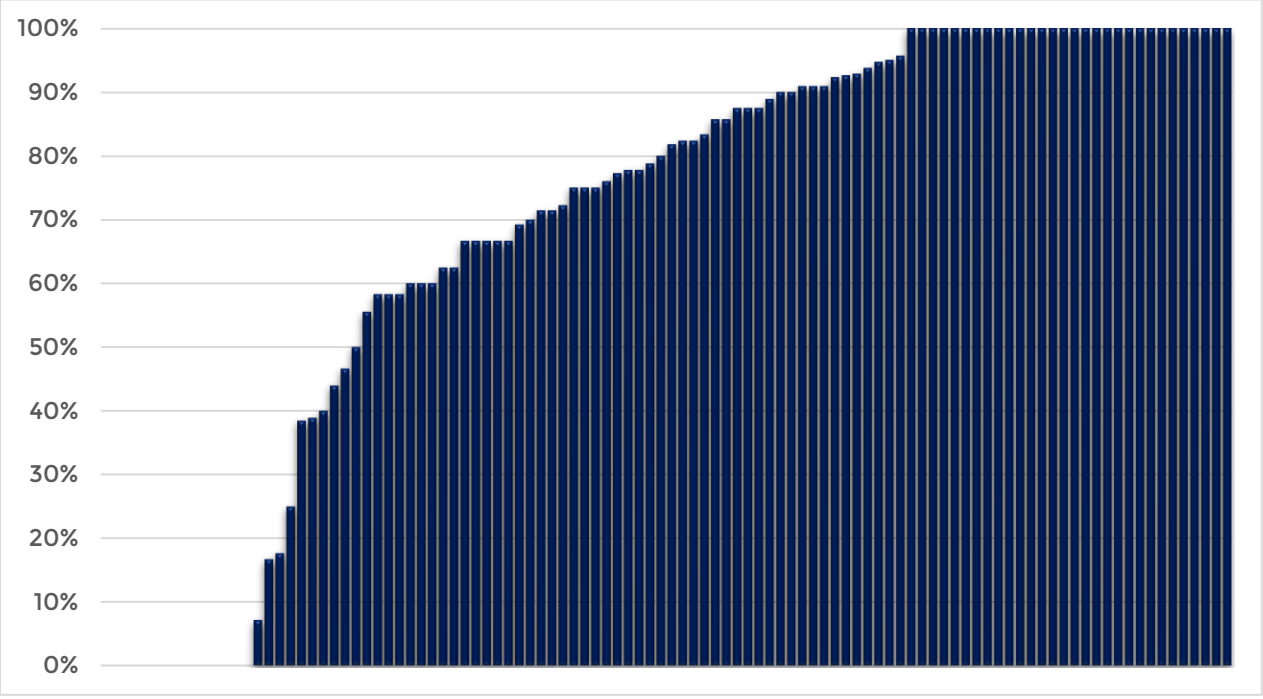


Figure 76: Input from an ESN by Health Board and Trust, Round 3, cohort 1.

Each Health Board or Trust is represented by a vertical bar in the order of the percentage score, including those scoring 0% in this graph.

Performance indicator 3: Tertiary input

In Round 3 cohort 1, **59.3% (150/253)** of children and young people who met paediatric neurology referral criteria had paediatric neurologist input or Children's Epilepsy Surgical service (CESS) referral by one year (**Table 92**). This is slightly higher than Round 2. This indicator ranged from 0% to 100% and had an interquartile range of 33% to 100% at Health Board or Trust level.

Table 92: Tertiary input.

Performance indicator: 3		Audit Round	England and Wales	England	Wales
Tertiary input	% of children and young people meeting defined criteria for paediatric neurology referral, with input of tertiary care and/or CESS referral within the first year of care	Round 1	59.1% (205/347)	59.2% (200/338)	55.6% (5/9)
		Round 2	54.1% (119/220)	53.7% (115/214)	66.7% (4/6)
		Round 3	59.3% (150/253)	59.2% (142/240)	61.5% (8/13)

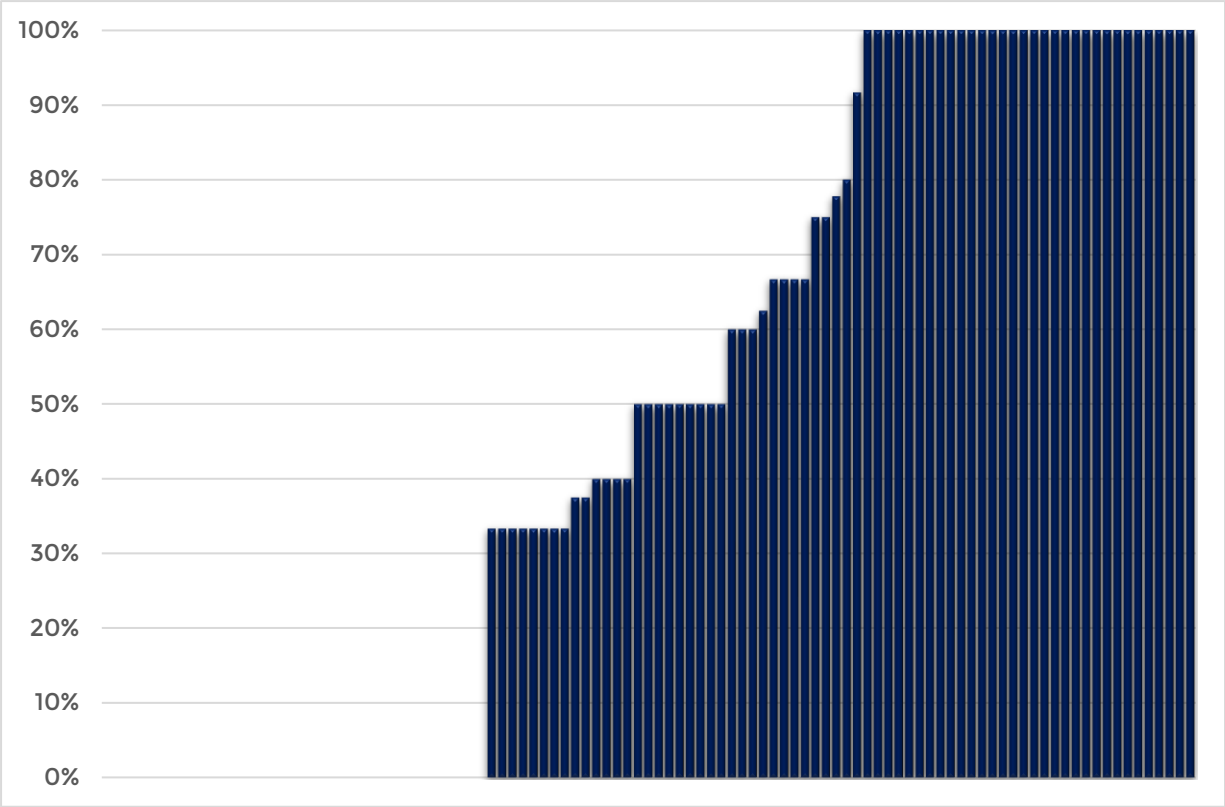


Figure 77: Tertiary input by Health Board and Trust, Round 3, cohort 1.

Each Health Board and Trust is represented by a vertical bar in the order of the percentage score, including those scoring 0% in this graph.

Ongoing investigations

Table 93 shows that in the first year of care for children and young people who were diagnosed with epilepsy in England and Wales:

- **20.2% (225/1112)** had a formal development assessment,
- **7.0% (78/1112)** had formal cognitive assessment.

Figure 78 shows the percentage of children and young people that had relevant ongoing assessment in England and Wales.

Table 93: Number of children and young people diagnosed with epilepsy with relevant ongoing investigation by country.

Country	% with formal developmental assessment	% with formal cognitive assessment
England &Wales (N=1112)	20.2% (225/1112)	7.0% (78/1112)
England (N=1051)	21.1% (222/1051)	7.4% (78/1051)
Wales (N=61)	4.9% (3/61)	0.0% (0/61)

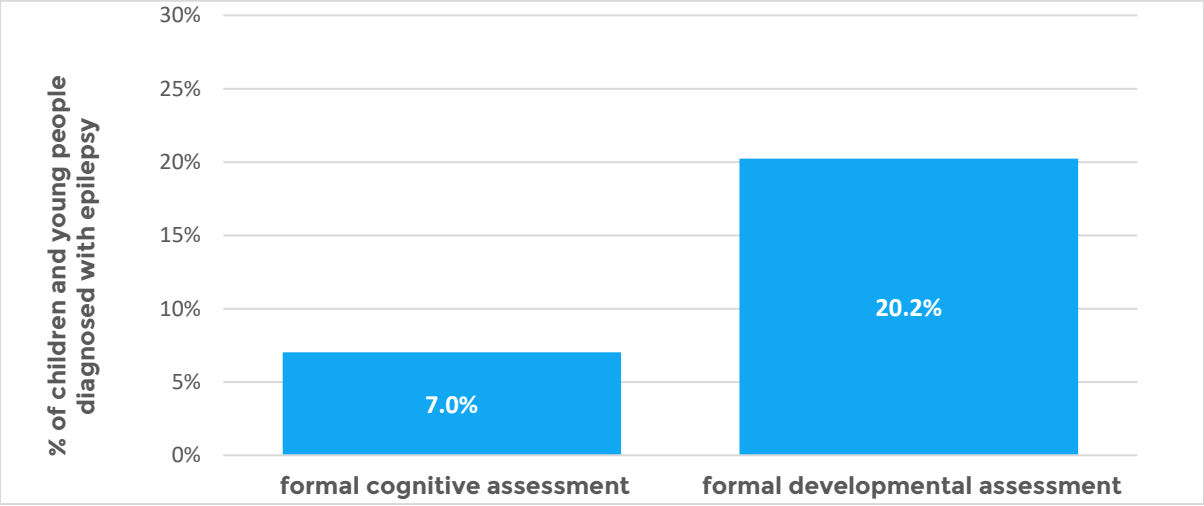


Figure 78: Percentage of children and young people diagnosed with epilepsy with relevant ongoing investigation in England and Wales.

Performance indicator 8: Accuracy of diagnosis

In Round 3, cohort 1, **97.2% (1093/1124)** of children and young people had the same diagnosis by their first year of care, (**Table 94**). This proportion is higher than Round 2. This indicator ranged from 71.0% to 100% and had an interquartile range of 100% to 100% at a Health Board or Trust level.

Table 94: Accuracy of diagnosis

Performance indicator 8		Audit Round	England and Wales	England	Wales
Accuracy of diagnosis	% of children diagnosed with epilepsy, who still had that diagnosis at one year	Round 1	88.1% (1516/1721)	87.6% (1423/1624)	95.9% (93/97)
		Round 2	93.2% (1077/1156)	93.2% (1007/1080)	92.1% (70/76)
		Round 3	97.2% (1093/1124)	97.1% (1032/1063)	100% (61/61)

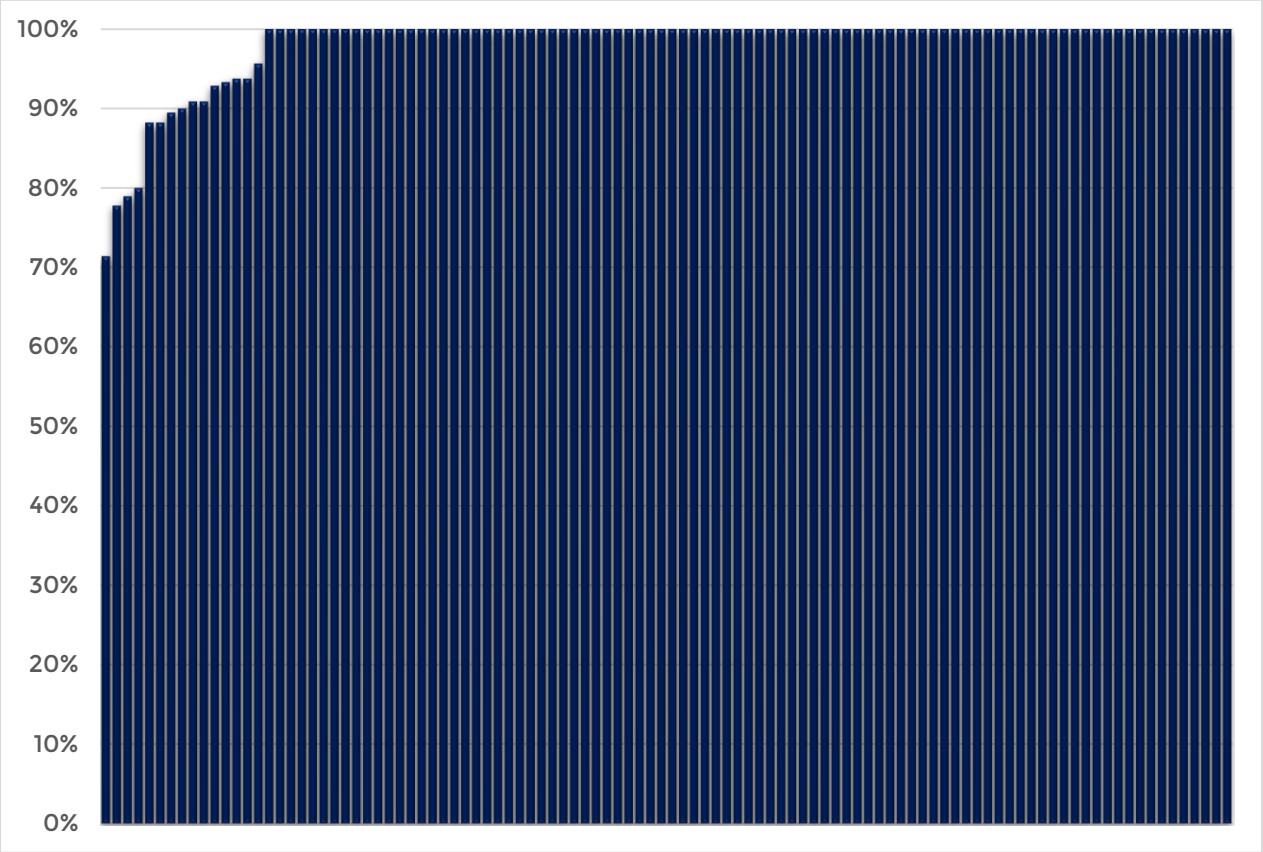


Figure 79: Accuracy of diagnosis by Health Board and Trust, Round 3, cohort 1.

Each Health Board and Trust is represented by a vertical bar in the order of the percentage score, including those scoring 0% in this graph.

Overview of performance indicators

Rounds 1, 2 and 3, cohort 1

Table 95: Performance indicators by country across Rounds 1, 2 and 3, cohort 1

Performance Indicators		Audit Round	England and Wales	England	Wales
1	Paediatrician with expertise in epilepsies	Round 1	78.0% (1183/1516)	77.7% (1106/1423)	82.8% (77/93)
		Round 2	86.1% (938/1090)	86.1% (877/1019)	85.9% (61/71)
		Round 3	87.9% (977/1112)	87.9% (924/1051)	86.9% (53/61)
2	Epilepsy Specialist Nurse	Round 1	43.4% (658/1516)	41.6% (592/1423)	71.0% (66/93)
		Round 2	55.5% (605/1090)	54.5% (555/1019)	70.4% (50/71)
		Round 3	69.0% (767/1112)	70.2% (738/1051)	47.5% (29/61)
3	Tertiary input	Round 1	59.1% (205/347)	59.2% (200/338)	55.6% (5/9)
		Round 2	54.1% (119/220)	53.7% (115/214)	66.7% (4/6)
		Round 3	59.3% (150/253)	59.2% (142/240)	61.5% (8/13)
5	Seizure formulation	Round 1	86.9% (1318/1516)	86.8% (1235/1423)	89.2% (83/93)
		Round 2	94.9% (1040/1096)	95.5% (973/1019)	94.4% (67/71)
		Round 3	88.0% (979/1112)	87.4% (919/1051)	98.4% (60/61)
7	MRI	Round 1	63.5% (602/948)	64.3% (578/899)	49.0% (24/49)
		Round 2	72.2% (481/666)	72.7% (458/630)	63.9% (23/36)
		Round 3	68.6% (317/462)	70.4% (307/436)	38.5% (10/26)
8	Accuracy of diagnosis	Round 1	88.1% (1516/1721)	87.6% (1423/1624)	95.9% (93/97)
		Round 2	93.2% (1077/1156	93.2% (1007/1080)	92.1% (70/76)
		Round 3	97.2% (1093/1124)	97.1% (1032/1063)	100% (61/61)

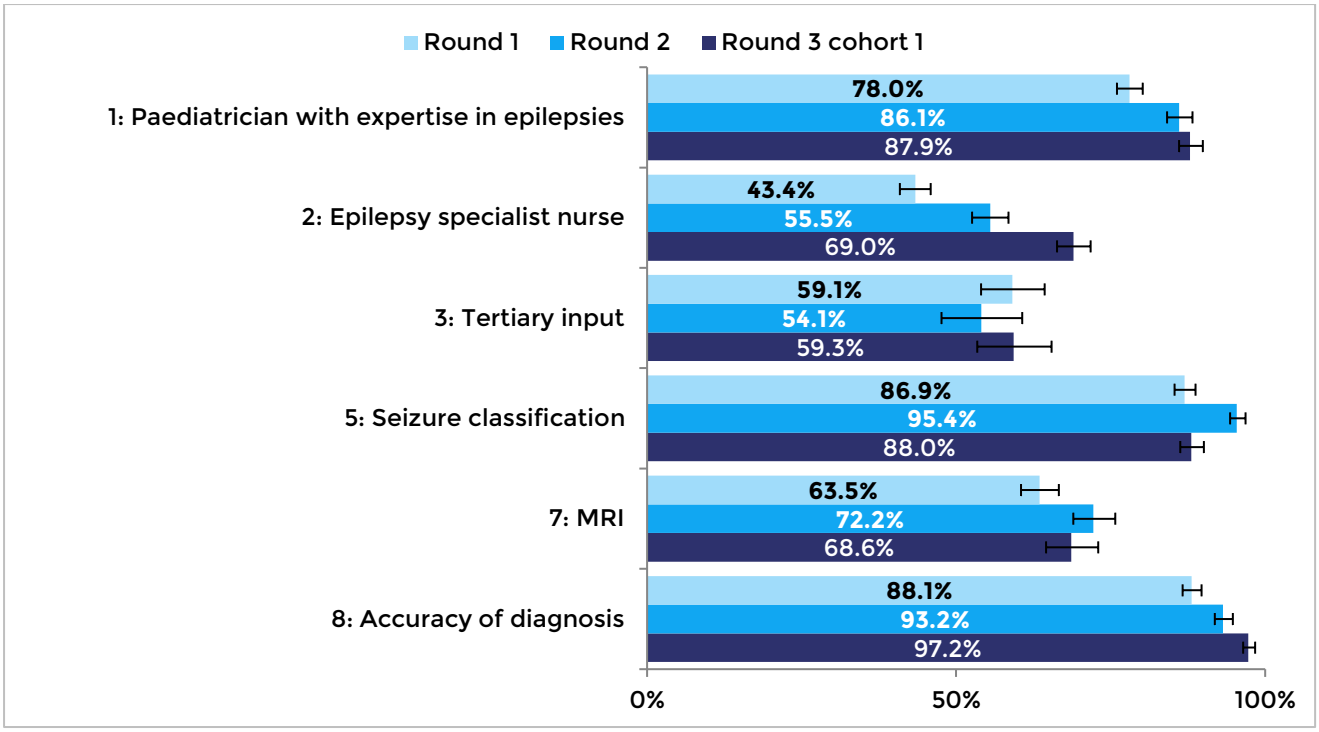


Figure 80: Epilepsy12 Performance indicators for England and Wales

The 'whiskers' on the chart above represent 95% confidence intervals. If these whiskers overlap, the difference in the achievement of the indicator is not statistically significant.

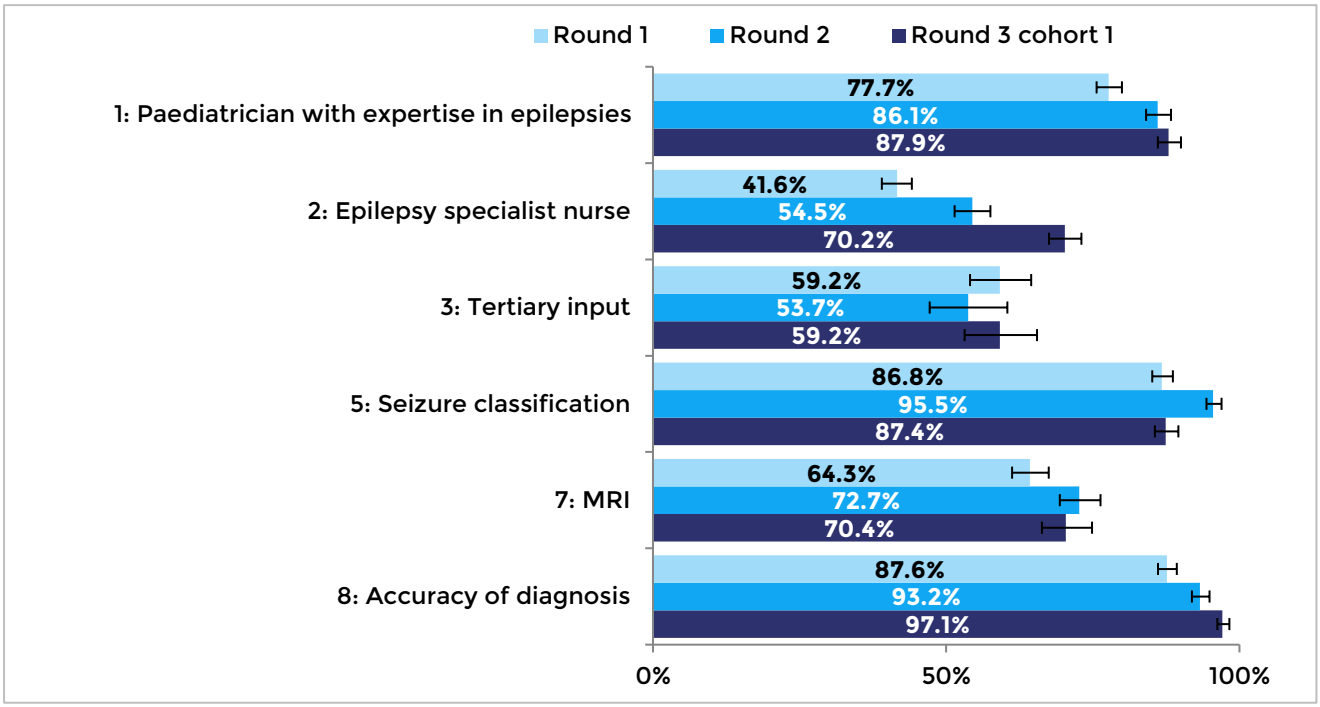


Figure 81: Epilepsy12 Performance indicators for England.

The 'whiskers' on the chart above represent 95% confidence intervals. If these whiskers overlap the difference in the achievement of the indicator is not statistically significant.

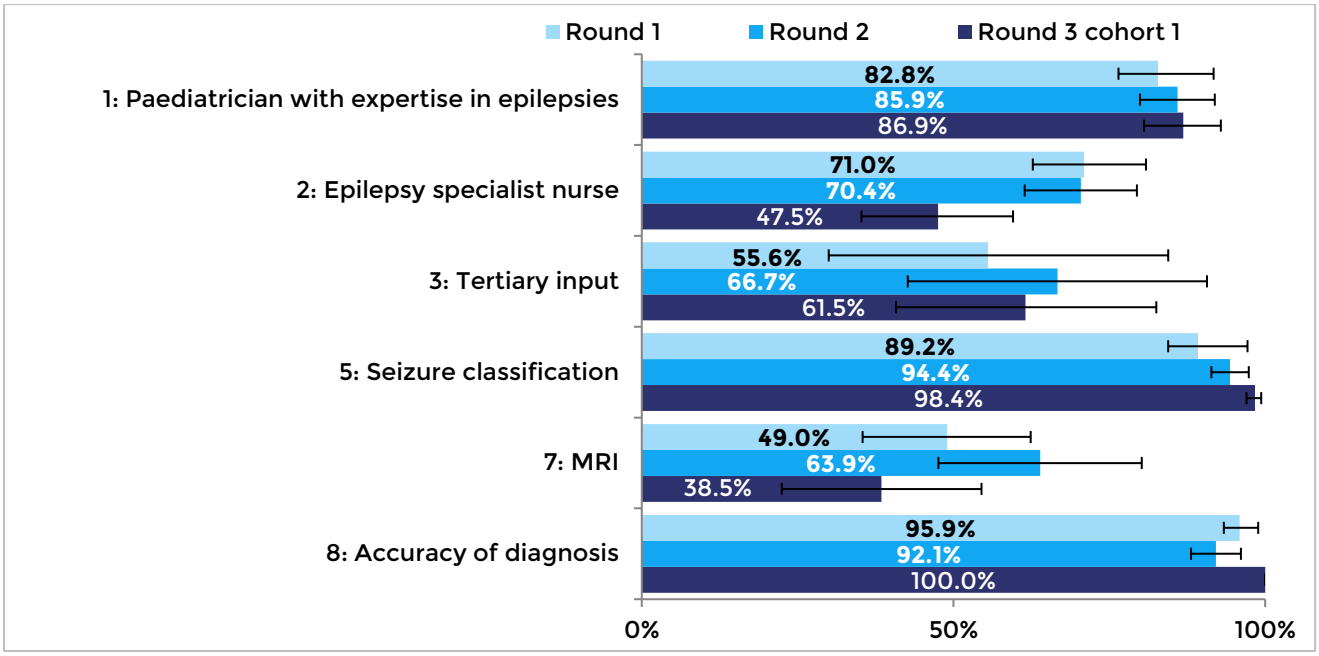


Figure 82: Epilepsy12 Performance indicators for Wales

The 'whiskers' on the chart above represent 95% confidence intervals. If these whiskers overlap, the difference in the achievement of the indicator is not statistically significant.

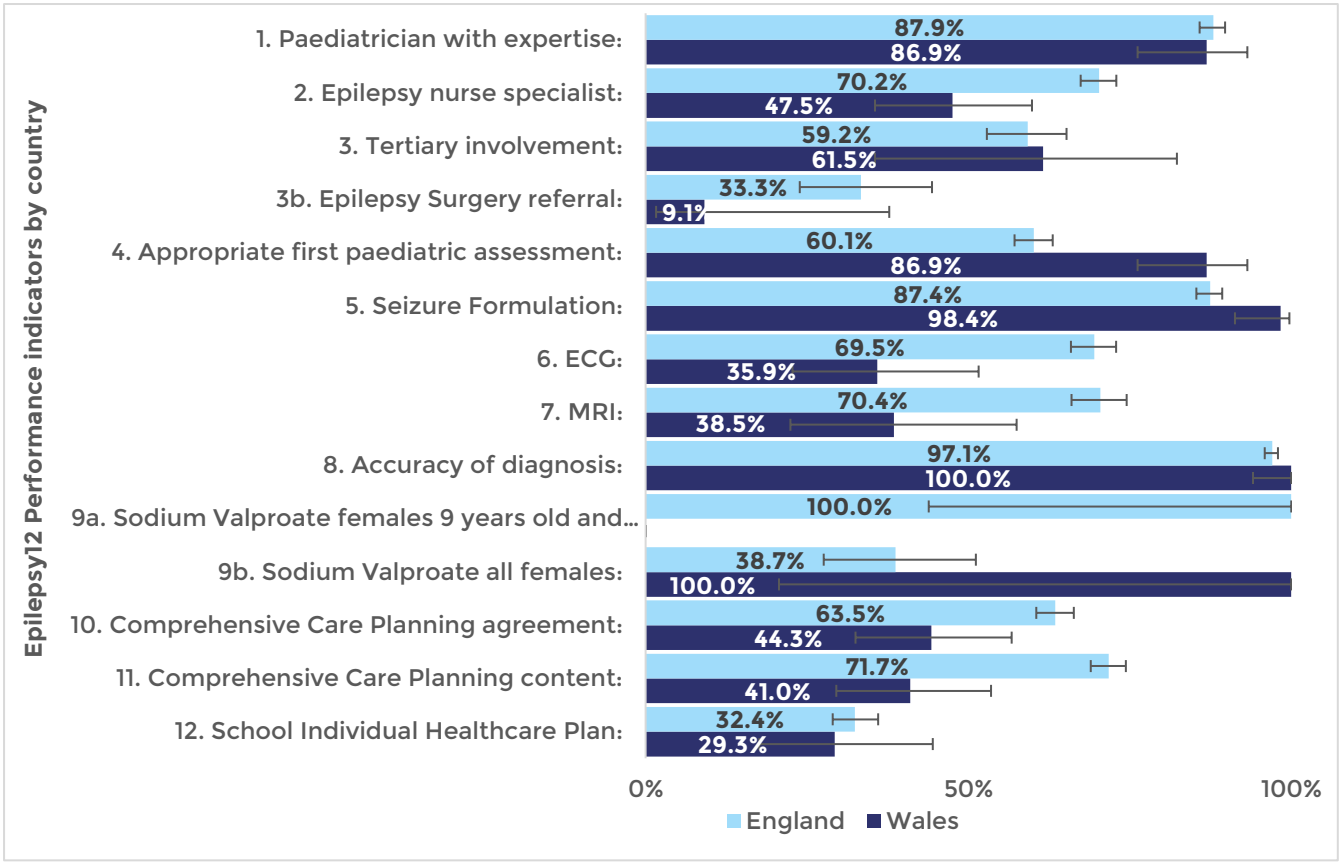


Figure 83: Epilepsy12 Performance indicators by country, Round 3 cohort 1

The 'whiskers' on the chart above represent 95% confidence intervals. If these whiskers overlap the difference in the achievement of the indicator is not statistically significant

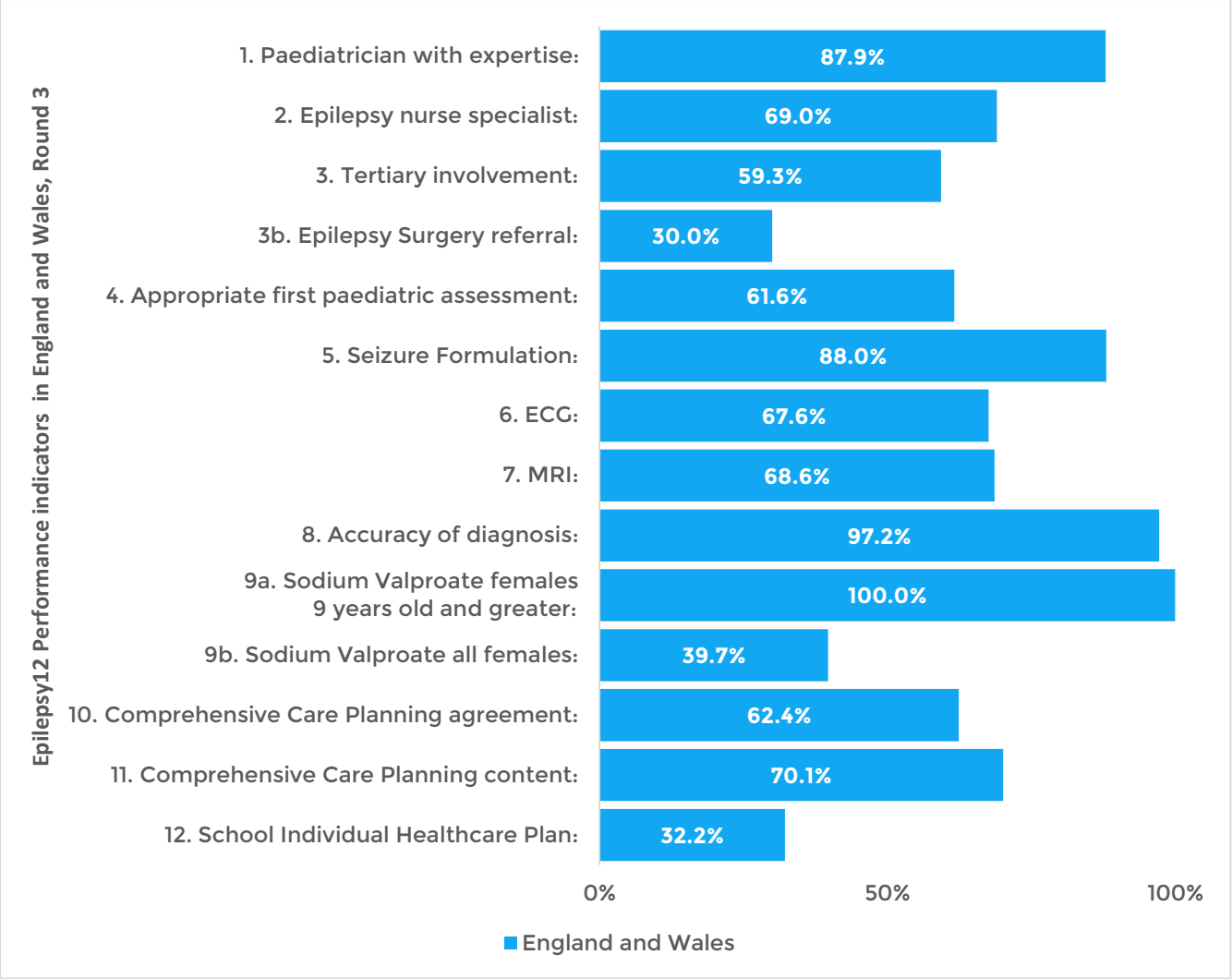


Figure 84: Epilepsy12 Performance indicators in England and Wales, Round 3, cohort 1 only

Figure 85 below compares the organisational audit results of the epilepsy specialist nurses in the workforce with the clinical performance indicators. It sets out the performance indicators for Health Boards and Trusts which employed at least some level of whole time equivalent (WTE) epilepsy specialist nurse, versus Health Boards and Trusts with no whole time equivalent (WTE) epilepsy specialist nurse employed.

In Health Boards and Trusts with ESN provision, children and young people diagnosed with epilepsy were more likely to:

- be seen by an epilepsy specialist nurse,
- have individual healthcare plan,
- have an MRI.

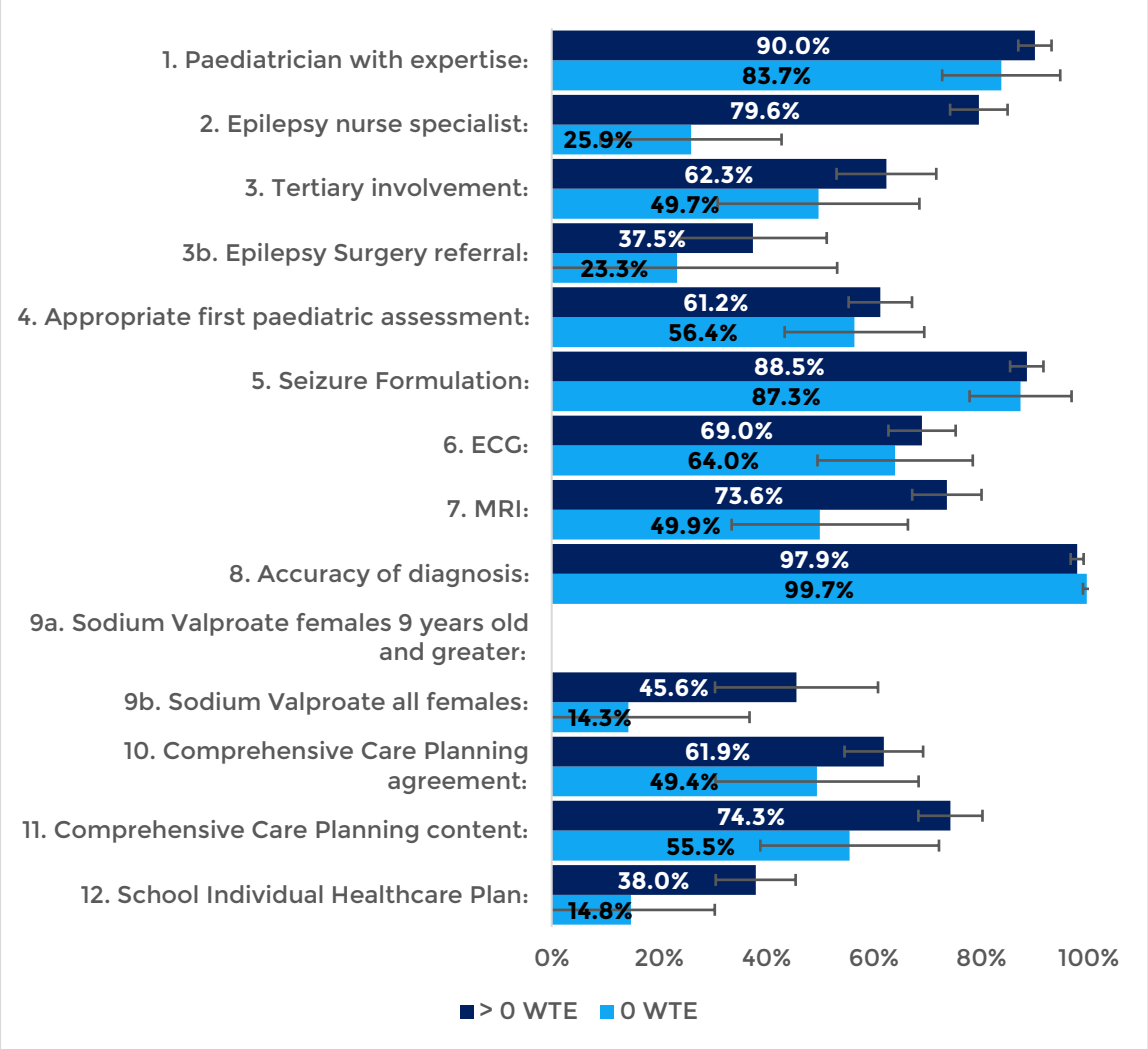


Figure 85: Performance indicators for England and Wales by ESN provision

The 'whiskers' on the chart above represents 95% confidence intervals. If these whiskers do not overlap, the difference is statistically significant. Only three Health Boards and Trusts had females 9 years old and greater on sodium valproate hence performance indicator 9a was not included in this analysis.

Appendix H: List of clinical data figures & tables

List of figures (clinical audit)

Figure 30: Percentage of children and young people verified by Health Boards and Trusts in Round 3 – page 8

Figure 31: The percentage of children and young people within cohort 1 with their first year of care form submitted and locked – page 9

Figure 32: Numbers of children and young people included in cohort 1 by age in years at first paediatric assessment and gender. – page 10

Figure 33: Numbers of children and young people included in cohort 1 by age in months at first paediatric assessment and gender. – page 11

Figure 34: Comparison of the proportion of children and young people by age group in Round 1, Round 2 and Round 3 – page 13

Figure 35: Percentage of children and young people in cohort 1 by deprivation in England and Wales combined – page 15

Figure 36: Percentage of children and young people in cohort 1 by deprivation by country/network – page 16

Figure 37: Percentage of children and young with/without prior experience of seizures – page 18

Figure 38: Percentage of children and young people in Cohort 1 by diagnostic status at first year of care, in England and Wales – page 20

Figure 39: Percentage of children and young people by diagnostic status in first paediatric assessment and first year of care in England and Wales in Round 3 – page 22

Figure 40: Diagnosis at first assessment and one year after first assessment in Round 1, Round 2, Round 3 – page 23

Figure 41: Percentage of children and young people by description of non-epileptic episode – page 24

Figure 42: Referring service to first paediatric assessment in England and Wales -page 25

Figure 43: Numbers of children and young people diagnosed with epilepsy by age in years at first paediatric assessment and gender in England and Wales – page 27

Figure 44: Setting of first paediatric assessment in Round 1, Round 2 and Round 3 in England and Wales – page 28

Figure 45: Appropriate first paediatric assessment by unit, Round 3 cohort 1 – page 30

Figure 46: Percentage of children and young people diagnosed with epilepsy who had focal onset seizures in England and Wales – page 32

Figure 47: Percentage of children and young people diagnosed with epilepsy who had generalised onset seizures in England and Wales – page 34

Figure 48: Percentage of children and young people diagnosed with epilepsy who had generalised onset seizures in England and Wales – page 36

Figure 49: Percentage of children and young people diagnosed with epilepsy that had unknown onset seizures in England and Wales. – page 37

Figure 50: Number of children and young people diagnosed with epilepsy by electroclinical syndrome in England and Wales. – page 38

Figure 51: Seizure formulation, by Health Board or Trust, Round 3. – page 40

Figure 52: Percentage of children and young people diagnosed with epilepsy who had structural seizure cause. – page 41

Figure 53: Percentage of children and young people diagnosed with epilepsy with/with no convulsive epileptic seizures in England and Wales. – page 42

Figure 54: Percentage of children and young people diagnosed with epilepsy by prolonged generalised convulsive epileptic seizures in England and Wales. – page 43

Figure 55: Percentage of children and young people diagnosed with epilepsy by prolonged focal convulsive epileptic seizures in England and Wales – page 44

Figure 56: Percentage of children and young people diagnosed with epilepsy with/with no family history of epilepsy in England and Wales. – page 45

Figure 57: Neurodisability/neurodevelopmental problems among children diagnosed with epilepsy in cohort 1. – page 48

Figure 58: Number of children diagnosed with epilepsy by mental health problem in England and Wales. – page 50

Figure 59: Percentage of children and young people diagnosed with epilepsy that obtained First EEG, 12 lead ECG, CT head scan and MRI brain investigations in England and Wales – page 53

Figure 60: Percentage of children and young people with convulsive seizures and epilepsy, with an ECG at first year by Health Board or Trust, Round 3. – page 55

Figure 61: Percentage of children and young people with defined indications for an MRI, who had MRI by first year by Health Board or Trust, Round 3 – page 57

Figure 62: Frequency by AED type in England and Wales (Round 3). – page 59

Figure 63: Number of children and young people diagnosed with epilepsy on sodium valproate by gender in England and Wales, Round 3 cohort 1. – page 60

Figure 64: Percentage females currently on sodium valproate treatment with evidence of discussion of foetal risk by Health Board or Trust, Round 3. – page 62

Figure 65: Percentage of children and young people diagnosed with epilepsy that had/did not have rescue medication prescribed in England and Wales. – page 63

Figure 66: Percentage of children and young people diagnosed with epilepsy that had rescue medication prescribed by country and network – page 63

Figure 67: Percentage of children and young people diagnosed with epilepsy that met/did not meet any CESS referral criteria in England and Wales. – page 64

Figure 68: Percentage of children and young people diagnosed with epilepsy that met any CESS referral criteria by country and network. – page 65

Figure 69: Comprehensive Care Planning agreement, Round 3. – page 69

Figure 70: Comprehensive Care Planning content by Health Board or Trust, Round 3. – page 71

Figure 71: School Individual Healthcare Plan, by Health Board or Trust, Round 3 – page 72

Figure 72: Percentage of children and young people diagnosed with Epilepsy with/without evidence of SUDEP information in England and Wales. – page 73

Figure 73: Percentage of children and young people diagnosed with evidence of SUDEP information by country and network. – page 73

Figure 74: Percentage of children and young people diagnosed with epilepsy with input from various professionals in England and Wales. – page 75

Figure 75: Paediatrician with expertise in epilepsies by Health Board or Trust, Round 3. – page 77

Figure 76: Epilepsy Specialist Nurse by Health Board or Trust, Round 3. – page 78

Figure 77: Tertiary input by Health Board or Trust, Round 3. – page 79

Figure 78: Percentage of children and young people diagnosed with epilepsy with relevant ongoing investigation in England and Wales. – page 80

Figure 79: Accuracy of diagnosis by Health Board or Trust, Round 3. – page 81

Figure 80: Epilepsy12 Performance indicators for England and Wales – page 83

Figure 81: Epilepsy12 Performance indicators for England – page 83

Figure 82: Epilepsy12 Performance indicators for Wales. – page 84

Figure 83: Epilepsy12 Performance indicators by country, Round 3 cohort 1 – page 84

Figure 84: Epilepsy12 Performance indicators in England and Wales, Round 3 cohort 1 only – page 85

Figure 85: Performance indicators for England and Wales by ESN provision – page 86

List of tables (clinical audit)

Table 47: Participation in Round 3 of Epilepsy12 – page 5

Table 48: Shows the flow of children and young people through the data capture system – page 6

Table 49: Number of children and young people registered as eligible for the audit. – page 7

Table 50: Number of children and young people in cohort 1 by country, network and age-group. – page 12

Table 51: Demographic characteristics of children included in Round 1, 2 and 3 of Epilepsy12. – page 13

Table 52: Percentage and number of children and young people in cohort 1 by deprivation by country and Open UK network. – page 14

Table 53: Prior experience of seizures in children and young people in cohort 1 in England and Wales. – page 17

Table 54: Diagnostic status at first year of care by country and Open UK network. – page 19

Table 55: Diagnostic status at first paediatric assessment by country and Open UK network. – page 21

Table 56: Description of non-epileptic episodes in children in cohort 1 at one year after first assessment in England and Wales – page 24

Table 57: Referring service to first paediatric assessment by country. – page 25

Table 58: Time in weeks to achieving input from paediatrician with expertise in epilepsy since the first referral to paediatrics by country. – page 26

Table 59: Setting of the first paediatric assessment by country. – page 28

Table 60: Appropriate first paediatric assessment. – page 29

Table 61: Number of seizures in children diagnosed with epilepsy by country. – page 31

Table 62: Seizure type. – page 31

Table 63: Epileptic seizure type. – page 32

Table 64: Percentage of children and young people diagnosed with epilepsy who had focal onset seizures in England and Wales. – page 33

Table 65: Percentage of children and young people diagnosed with epilepsy who had generalised onset seizures in England and Wales. – page 35

Table 66: Percentage of children and young people diagnosed with epilepsy who had unknown onset seizures in England and Wales. – page 36

Table 67: Seizure formulation. – page 39

Table 68: Percentage of children and young people diagnosed with epilepsy by seizure cause in England and Wales. – page 41

Table 69: Convulsive epileptic seizures in children and young people diagnosed with epilepsy by country – page 42

Table 70: Prolonged generalised convulsive epileptic seizures in children and young people diagnosed with epilepsy. – page 43

Table 71: Prolonged focal convulsive epileptic seizures in children and young people diagnosed with epilepsy by country. – page 44

Table 72: Family history of epilepsy in children and young people diagnosed with epilepsy by country. – page 45

Table 73: Neurodisability / neurodevelopmental problems among children diagnosed with epilepsy in Round 3. – page 47

Table 74: Percentage of severity of neurodevelopmental problems among the children and young people with intellectual disability, global development delay, or learning disability in England and Wales. – page 48

Table 75: Percentage of children and young people diagnosed with mental health problems in England and Wales. – page 49

Table 76: Percentage of children and young people between age 5-15 years and diagnosed with mental health condition that had ongoing investigations in England and Wales. – page 50

Table 77: Time in weeks to when EEG was obtained since EEG request date by country – page 51

Table 78: Number and percentage of children and young people diagnosed with epilepsy that obtained First EEG, 12 lead ECG, CT head scan and MRI brain investigations by country and OPEN UK network. – page 52

Table 79: Percentage of children and young people with convulsive seizures and epilepsy, with an ECG at first year. - 54

Table 80: Percentage of children and young people with defined indications for an MRI, who had MRI by first year – page 56

Table 81: Diagnosis and AEDs. – page 58

Table 82: Sodium Valproate in females. – page 61

Table 83: Epilepsy surgery referral. – page 66

Table 84: Time in weeks since referral to neurologist by country. – page 66

Table 85: Time in weeks since referral to neurologist by country. – page 67

Table 86: Comprehensive Care Planning agreement. – page 68

Table 87: Comprehensive Care Planning content. – page 70

Table 88: School Individual Healthcare Plan. – page 72

Table 89: Percentage of children and young people diagnosed with epilepsy with input from various professionals by Country. – page 74

Table 90: Paediatrician with expertise in epilepsies. – page 76

Table 91: Epilepsy Specialist Nurse. – page 78

Table 92: Tertiary input. – page 79

Table 93: Number of children and young people diagnosed with epilepsy with relevant ongoing investigation by country – page 80

Table 94: Accuracy of diagnosis – page 81

Table 95: Performance indicators by country across Rounds 1, 2 and 3 cohort 1 – page 82

Appendix I: Data completeness

Outlier identification and management

Epilepsy12 manages outlier status in line with the RCPCH policy Detection and Management of Outlier Status for Clinical Indicators in National Clinical Audits. The approach and timelines associated with Epilepsy12 are set out in a document entitled *RCPCH management of outlier management policy for national clinical audits*.

Preliminary outlier analysis against cohort 1 data was undertaken for three audit measures: children verified on the data platform, children with a locked first year of care record, children with epilepsy who saw a paediatrician with expertise in the first year of care. The data for children verified on the system and those seen by a specialist measures did not form a 'normal' distribution. This meant the planned analytical approach was unsuitable and we were unable to reliably identify outliers based on these measures. On the third measure, children with a complete year of care record, the relatively small dataset was a risk to identifying outliers with statistical validity.

Cohort 1 was based on a patient group who underwent a first paediatric assessment within a five-month period between July and November 2018. After piloting this outlier analysis with cohort 1, the outlier analysis for cohorts 2 and 3 will both be based on 12-month periods. Therefore we expect future datasets to be sufficiently robust to allow us to complete the full outlier analysis for these data.

Health Boards and Trusts in the results

Organisational audit

The Epilepsy12 project team originally identified 163 Health Boards and Trusts (acute, community and tertiary) with paediatric services across England and Wales in August 2017 as potentially eligible to participate in Round 3 of Epilepsy12. This was based on information from the 2017 British Association for Community Child Health (BACCH) and Royal College of Paediatrics and Child Health (RCPCH) publication "Covering all bases - Community Child Health: A paediatric workforce guide".

Of the 163, one Health Board in Wales did not register and five acute Trusts in England were no longer eligible due to mergers. Nine of the remaining 157 were community Trusts which were excluded because they either had no paediatric services, or they

defined their paediatric service as not assessing or managing children with seizures or epilepsies.

This left 148 registered Health Boards and Trusts, all of whom provided a submitted a full 2018 organisational audit submission for Round 3 of Epilepsy12 (including 100% of acute Trusts in England).

The 2019 Organisational audit saw the inclusion of Birmingham Community Healthcare NHS Foundation Trust which made 149 registered Health Boards and Trusts. There were eight separate Trusts mergers which meant a total of 141 of Health Boards and Trusts.

The following Health Boards and Trusts were not included within the 2019 organisational audit results:

	Health Board or Trust	Regional Network
1	Brighton and Sussex University Hospitals NHS Trust[+]	SETPEG
2	Cardiff & Vale University LHB[+]	SWEP
3	Coventry and Warwickshire Partnership NHS Trust[+]	BRPNF
4	Gloucestershire Hospitals NHS Foundation Trust	SWIPE
5	Leicestershire Partnership NHS Trust	CEWT
6	Maidstone and Tunbridge Wells NHS Trust[+]	SETPEG
7	North East London NHS Foundation Trust[+]	NTPEN
8	Plymouth Hospitals NHS Trust[+]	SWIPE
9	Surrey and Sussex Healthcare NHS Trust[+]	SWTPEG

[+]Trusts that were not included within the 2019 organisational results due to data that was either not submitted in time, or not 'locked' (a form of verification).

Clinical audit

The following Trusts and Health Boards were not included within the 2018-2019 national clinical audit results:

	Health Board or Trust	Regional Network
1	Aneurin Bevan LHB	SWEP
2	Barking, Havering and Redbridge University Hospitals NHS Trust	NTPEN
3	Barts Health NHS Trust	NTPEN
4	Basildon and Thurrock University Hospitals NHS Foundation Trust	NTPEN
5	Blackpool Teaching Hospitals NHS Foundation Trust	NWEIG
6	Brighton and Sussex University Hospitals NHS Trust[+]	SETPEG
7	Burton Hospitals NHS Foundation Trust	BRPNF
8	Cambridge University Hospitals NHS Foundation Trust	EPEN
9	Cardiff & Vale University LHB[+]	SWEP
10	Coventry and Warwickshire Partnership NHS Trust[+]	BRPNF
11	Croydon Health Services NHS Trust	SWTPEG
12	East Cheshire NHS Trust	NWEIG
13	Epsom and St Helier University Hospitals NHS Trust	SWTPEG
14	George Eliot Hospital NHS Trust	BRPNF
15	*Great Ormond Street Hospital for Children NHS Foundation Trust	NTPEN
16	Guy's and St Thomas' NHS Foundation Trust	SETPEG
17	James Paget University Hospitals NHS Foundation Trust	EPEN
18	Leeds Community Healthcare NHS Trust	YPEN
19	Luton and Dunstable University Hospital NHS Foundation Trust	EPEN
20	Maidstone and Tunbridge Wells NHS Trust[+]	SETPEG
21	Medway NHS Foundation Trust	SETPEG
22	North East London NHS Foundation Trust[+]	NTPEN
23	North Tees and Hartlepool NHS Foundation Trust	PENNEC
24	Northern Devon Healthcare NHS Trust	SWIPE
25	Plymouth Hospitals NHS Trust[+]	SWIPE
26	Portsmouth Hospitals NHS Trust	WPNN
27	Sandwell and West Birmingham Hospitals NHS Trust	BRPNF
28	South Tyneside NHS Foundation Trust	PENNEC
29	Surrey and Sussex Healthcare NHS Trust[+]	SWTPEG
30	Sussex Community NHS Foundation Trust	SETPEG
31	The Princess Alexandra Hospital NHS Trust	EPEN
32	The Queen Elizabeth Hospital, King's Lynn, NHS Foundation Trust	EPEN
33	University Hospital Southampton NHS Foundation Trust	WPNN
34	University Hospitals Bristol NHS Foundation Trust	SWIPE
35	Weston Area Health NHS Trust	SWIPE
36	Yeovil District Hospital NHS Foundation Trust	SWIPE

**Tertiary Trust that does not conduct first assessments for children with epilepsy or seizures*
[+]Trusts that were not included within the 2019 organisational results due to data that was not submitted to the audit.

Appendix J: Participating Health Boards and Trusts by OPEN UK region

The following list shows the NHS Health Boards and Trusts across England and Wales that submitted data to the Epilepsy12 Round 3 clinical and organisational audit in 2018-19.

Birmingham Regional Paediatric Neurology Forum (BRPNF)
Birmingham Community Healthcare NHS Foundation Trust
Birmingham Women's and Children's NHS Foundation Trust
Burton Hospitals NHS Foundation Trust[+]
Coventry and Warwickshire Partnership NHS Trust
George Eliot Hospital NHS Trust
Sandwell and West Birmingham Hospitals NHS Trust
South Warwickshire NHS Foundation Trust
The Dudley Group NHS Foundation Trust
The Royal Wolverhampton NHS Trust
University Hospitals Birmingham NHS Foundation Trust
University Hospitals Coventry and Warwickshire NHS Trust
Walsall Healthcare NHS Trust
Worcestershire Acute Hospitals NHS Trust
Worcestershire Health and Care NHS Trust
Wye Valley NHS Trust
Children's Epilepsy Workstream in Trent (CEWT)
Derby Teaching Hospitals NHS Foundation Trust[+]
Leicestershire Partnership NHS Trust
Nottingham University Hospitals NHS Trust
Sherwood Forest Hospitals NHS Foundation Trust
United Lincolnshire Hospitals NHS Trust
University Hospitals of Leicester NHS Trust
Eastern Paediatric Epilepsy Network (EPEN)
Bedford Hospital NHS Trust
Cambridge University Hospitals NHS Foundation Trust
Cambridgeshire Community Services NHS Trust
Colchester Hospital University NHS Foundation Trust[+]
East and North Hertfordshire NHS Trust

Ipswich Hospital NHS Trust+
James Paget University Hospitals NHS Foundation Trust
Luton and Dunstable University Hospital NHS Foundation Trust
Mid Essex Hospital Services NHS Trust
Norfolk and Norwich University Hospitals NHS Foundation Trust
Norfolk Community Health and Care NHS Trust
North West Anglia NHS Foundation Trust
The Princess Alexandra Hospital NHS Trust
The Queen Elizabeth Hospital, King's Lynn, NHS Foundation Trust
West Suffolk NHS Foundation Trust
Mersey and North Wales network 'Epilepsy In Childhood' interest group (EPIC)
Alder Hey Children's NHS Foundation Trust
Betsi Cadwaladr University LHB
Countess of Chester Hospital NHS Foundation Trust
Mid Cheshire Hospitals NHS Foundation Trust
Shrewsbury and Telford Hospital NHS Trust
Southport and Ormskirk Hospital NHS Trust
St Helens and Knowsley Hospitals NHS Trust
Warrington and Halton Hospitals NHS Foundation Trust
Wirral University Teaching Hospital NHS Foundation Trust
North Thames Paediatric Epilepsy Network (NTPEN)
Barking, Havering and Redbridge University Hospitals NHS Trust
Barts Health NHS Trust
Basildon and Thurrock University Hospitals NHS Foundation Trust
Central and North West London NHS Foundation Trust
Chelsea and Westminster Hospital NHS Foundation Trust
Great Ormond Street Hospital For Children NHS Foundation Trust
Homerton University Hospital NHS Foundation Trust
Imperial College Healthcare NHS Trust
London North West Healthcare NHS Trust
North East London NHS Foundation Trust
North Middlesex University Hospital NHS Trust
Royal Free London NHS Foundation Trust
Southend University Hospital NHS Foundation Trust
The Hillingdon Hospitals NHS Foundation Trust
The Whittington Hospital NHS Trust
University College London Hospitals NHS Foundation Trust

West Hertfordshire Hospitals NHS Trust
North West Children and Young People's Epilepsy Interest Group (NWEIG)
Blackpool Teaching Hospitals NHS Foundation Trust
Bolton NHS Foundation Trust
East Cheshire NHS Trust
East Lancashire Hospitals NHS Trust
Lancashire Teaching Hospitals NHS Foundation Trust
Manchester University NHS Foundation Trust
Northern Care Alliance NHS Group
Salford Royal NHS Foundation Trust[+]
Stockport NHS Foundation Trust
Tameside and Glossop Integrated Care NHS Foundation Trust
University Hospitals of Morecambe Bay NHS Foundation Trust
University Hospitals of North Midlands NHS Trust
Wrightington, Wigan and Leigh NHS Foundation Trust
Oxford region epilepsy interest group (ORENG)
Buckinghamshire Healthcare NHS Trust
Great Western Hospitals NHS Foundation Trust
Kettering General Hospital NHS Foundation Trust
Milton Keynes University Hospital NHS Foundation Trust
Northampton General Hospital NHS Trust
Oxford University Hospitals NHS Foundation Trust
Royal Berkshire NHS Foundation Trust
Paediatric Epilepsy Network for the North East and Cumbria (PENNEC)
City Hospitals Sunderland NHS Foundation Trust[+]
County Durham and Darlington NHS Foundation Trust
Gateshead Health NHS Foundation Trust
North Cumbria University Hospitals NHS Trust
North Tees and Hartlepool NHS Foundation Trust
Northumbria Healthcare NHS Foundation Trust
South Tees Hospitals NHS Foundation Trust
South Tyneside NHS Foundation Trust[+]
The Newcastle Upon Tyne Hospitals NHS Foundation Trust
South East Thames Paediatric Epilepsy Group (SETPEG)
Brighton and Sussex University Hospitals NHS Trust
Dartford and Gravesham NHS Trust
East Kent : QEQM, Margate and WHM, Ashford, Kent

East Sussex Healthcare NHS Trust
Guy's and St Thomas' NHS Foundation Trust
King's College Hospital NHS Foundation Trust
Lewisham and Greenwich NHS Trust
Maidstone and Tunbridge Wells NHS Trust
Medway NHS Foundation Trust
Sussex Community NHS Foundation Trust
South Wales Epilepsy Forum (SWEP)
Abertawe Bro Morgannwg University LHB
Aneurin Bevan LHB
*Cardiff & Vale University LHB
Cwm Taf LHB
Hywel Dda LHB
South West Interest Group Paediatric Epilepsy (SWIPE)
Gloucestershire Hospitals NHS Foundation Trust
Northern Devon Healthcare NHS Trust
Plymouth Hospitals NHS Trust
Royal Cornwall Hospitals NHS Trust
Royal Devon and Exeter NHS Foundation Trust
Royal United Hospitals Bath NHS Foundation Trust
Taunton and Somerset NHS Foundation Trust
Torbay and South Devon NHS Foundation Trust
University Hospitals Bristol NHS Foundation Trust
Weston Area Health NHS Trust
Yeovil District Hospital NHS Foundation Trust
South West Thames Paediatric Epilepsy Group (SWTPEG)
Ashford and St Peter's Hospitals NHS Foundation Trust
Croydon Health Services NHS Trust
Epsom and St Helier University Hospitals NHS Trust
Frimley Health NHS Foundation Trust
Kingston Hospital NHS Foundation Trust
Royal Surrey County Hospital NHS Foundation Trust
St George's University Hospitals NHS Foundation Trust
Surrey and Sussex Healthcare NHS Trust
Trent Epilepsy Network (TEN)
Barnsley Hospital NHS Foundation Trust
Chesterfield Royal Hospital NHS Foundation Trust

Doncaster and Bassetlaw Teaching Hospitals Foundation Trust
Northern Lincolnshire and Goole NHS Foundation Trust
Sheffield Children's NHS Foundation Trust
The Rotherham NHS Foundation Trust
Wessex Paediatric Neurosciences Network (WPNN)
Dorset County Hospital NHS Foundation Trust
Hampshire Hospitals NHS Foundation Trust
Isle of Wight NHS Trust
Poole Hospital NHS Foundation Trust
Portsmouth Hospitals NHS Trust
Salisbury NHS Foundation Trust
Solent NHS Trust
University Hospital Southampton NHS Foundation Trust
Western Sussex Hospitals NHS Foundation Trust
Yorkshire Paediatric Neurology Network (YPEN)
Airedale NHS Foundation Trust
Bradford Teaching Hospitals NHS Foundation Trust
Calderdale and Huddersfield NHS Foundation Trust
Harrogate and District NHS Foundation Trust
Hull and East Yorkshire Hospitals NHS Trust
Leeds Community Healthcare NHS Trust
Leeds Teaching Hospitals NHS Trust
Mid Yorkshire Hospitals NHS Trust
York Teaching Hospital NHS Foundation Trust

The following Trusts merged prior to the November 2019 organisational audit.

Trust mergers
East Suffolk and North Essex NHS Foundation Trust (formerly Colchester Hospital University NHS Foundation Trust & Ipswich Hospital NHS Trust, merged July 2018)
Northern care Alliance (Merged with Salford Royal NHS Foundation Trust, April 2017)
University Hospitals of Derby and Burton NHS Foundation Trust (formerly Burton Hospitals NHS Foundation Trust & Derby Hospitals NHS Foundation Trust, merged July 2018)
South Tyneside and Sunderland NHS Foundation Trust (formerly South Tyneside NHS Foundation Trust & City Hospitals Sunderland NHS Foundation Trust, merged April 2019)

Appendix K: Glossary of terms and abbreviations

Absence seizure	A type of generalised seizure where the person briefly loses awareness and becomes blank or unresponsive. Absences often last a few seconds and the person is unconscious. If they are walking they might carry on walking.
Acute	Inpatient review, or paediatric review in emergency department, or other clinical assessment in an acute paediatric setting
Adherence	When someone takes their medication as they have agreed with their doctor. This is a more modern term than 'compliance' (doing what your doctor tells you to), and implies that there has been some discussion between the individual and their doctor to agree upon a plan of treatment. Whether someone is adherent or not is a measure of how closely they adhere (or 'stick to') taking their medication or treatment as agreed.
Adverse events	Another term for 'side effects'. These are effects of medication that happen alongside the effects you are expecting (the reason you are taking it). Side effects are usually, but not always, unwanted.
AED (Anti-epileptic drug)	Anti-epileptic drugs (AEDs) are the main type of treatment for most people with epilepsy. AEDs are a type of medication that aims to stop seizures. There are many different AEDs and they work in different ways and stop different types of seizures. Up to 70% of people with epilepsy could have their seizures stopped with the right AEDs.
Atonic or atonic seizure	A type of generalised seizure where the person's muscles suddenly lose tone, go floppy, and they fall down (usually forwards) if they are standing up. Although the seizures themselves don't hurt, the person might hurt themselves, especially their head and face, when they fall. These seizures are usually very brief and the person becomes conscious again very quickly. This is sometimes called a 'drop attack'.
BPT/BPC	Best Practice Tariff/Best Practice Criteria
Children's Epilepsy Specialist Nurse	A children's nurse with a defined role and specific qualification and/or training in children's epilepsies

Childhood epilepsy syndrome	A type of epilepsy that happens in children and young people, and follows a particular, typical pattern: the age that the seizures start, the type of seizures, the EEG recording and the progression or outcome. Some syndromes are benign and either go away or have little impact on the child. Others are severe and can affect the child's behaviour, learning and life expectancy. This is sometimes just referred to as a 'syndrome'.
Clonic seizures	These are seizures where the person convulses (jerks or shakes). Unlike tonic clonic seizures, the person does not go stiff at the start of the seizure.
Clusters	When a series or group of seizures happen close together in time, with gaps between each cluster. For example, in catamenial epilepsy, a woman might have a cluster of seizures around ovulation and no seizures at other times.
Complex focal seizures (CFS), Complex partial seizures (CPS)	Seizures that involve just part (not the whole) of the brain. These seizures used to be called 'complex partial seizures' or 'CPS'. The person will not be fully conscious and they are often very confused and may not remember what happens during the seizure. During CFS the person may behave strangely or make repetitive movements called automatisms.
Consultant General Paediatrician	A paediatric consultant (or associate specialist) with a role that includes seeing children or young people in a general outpatient or community clinic setting. They may or may not have other specialty or acute roles. They are likely to receive referrals directly from primary care. Neonatologists would not be included in this definition unless they also fulfil general paediatric roles.
Convulsive seizure	A seizure where the person's body jerks or shakes. It is another name for tonic clonic or clonic seizures.
Diazepam	A type of sedative medication that is given to someone in status epilepticus to stop the seizures. Diazepam is given rectally (up the bottom). This is sometimes referred to as a type of 'emergency medication'.
ECG	An electrocardiogram (ECG) is a simple test that can be used to check your heart's rhythm and electrical activity. Sensors attached to the skin are used to detect the electrical signals produced by your heart each time it beats.
ED	Emergency Department
Electroencephalogram (EEG)	An electroencephalogram (EEG) is a recording of brain activity. During the test, small sensors are attached to the scalp to pick up the electrical signals produced when brain cells send messages to each other. These signals are recorded by a machine and are looked at by a doctor later to see if they're unusual.
Emergency medication	Medication that is given to stop prolonged or repeated seizures (to stop status epilepticus from happening).

Epilepsy	A chronic neurological condition characterised by two or more epileptic seizures (International League Against Epilepsy, ILAE). A pragmatic definition for epilepsy in this audit is 2 or more epileptic seizures more than 24 hours apart that are not acute symptomatic seizures or febrile seizures.
Epilepsy surgery	Different types of surgery on the brain to try to reduce or stop seizures. Some people with epilepsy, whose seizures are not controlled or significantly reduced with medication, are able to have epilepsy surgery. Also called neurosurgery.
Epilepsy syndrome	A complex of clinical features, signs and symptoms that together define a distinctive, recognizable clinical disorder (ILAE)
'Epilepsy syndrome category'	A group of epilepsies described using the terms idiopathic primary, symptomatic, probably symptomatic and cryptogenic and focal, partial, multifocal or generalized
Epileptic seizure	Seizures that start due to interrupted electrical activity in the brain but can affect the body in many different ways. Clinical manifestation(s) of epileptic (excessive and/or hypersynchronous), usually self-limited activity of neurons in the brain. (ILAE)
Febrile convulsions	Convulsive seizures that can happen in young children (from about six months to six years of age) when they have a high temperature or fever. Febrile convulsions happen because very young children cannot control their body temperature very well. Although they can look like epileptic seizures they are not: they are caused by high temperatures not interrupted brain activity.
First paediatric assessment	A 'face to face' assessment by a secondary level/tier doctor in a paediatric service occurring in any non-acute or acute setting. Assessment within emergency department counts if performed by paediatric team rather than an emergency department team. Some paediatric neurologists see referrals direct from GP or ED and these would count as both a first paediatric assessment and tertiary input
Focal seizures	These are seizures that happen in, and affect, only part or one side of the brain (not both sides of the brain) and start from a 'focal point' in the brain. What happens in focal seizures varies depending on which part of the brain is affected and what that part of the brain normally does. Also known as 'partial seizures'.
Frontal lobe seizures	Focal seizures that start in the frontal lobe. Simple focal seizures from the frontal lobe include making strange movements or stiffness or jerking in part of the body such as the arm. Complex focal seizures from this area include making strange postures with the arms or legs or making juddering movements.

General examination	Any evidence of a multisystem examination of the child other than neurological examination
General practitioners (GP)	A doctor based in the community who treats patients with all common medical conditions with minor or chronic illnesses and refers those with serious conditions to a hospital. for urgent and specialist treatment. They focus on the health of the whole person combining physical, psychological and social aspects of care.
Generalised seizures	Seizures that happen in, and affect, the both sides of the brain from the start. There are many different types of generalised seizures, but they all involve the person becoming unconscious, even just for a few seconds, and they won't remember the seizure itself. The most well-known generalised seizure is the tonic clonic (convulsive) seizure.
Genetic	The information in the DNA in our cells that controls our characteristics, for example hair colour, sex and height.
Handover clinic	A clinic where a young people 'leaves the paediatric service and joins an adult service' and comprises both adult and paediatric health professionals
Infantile spasms (also called West Syndrome)	A rare childhood epilepsy syndrome that starts in the first year of life. The child has brief jerks or spasms of the arms, legs or whole body, often in clusters. Some children have problems with learning or behaviour.
Input	Any form of documented clinical contact including face to face clinical, written, electronic or telephone contact
Juvenile myoclonic epilepsy (JME)	A type of childhood epilepsy syndrome that starts between the ages of 11 and 18 years. The person usually has myoclonic seizures when they are waking up and might also have absences and tonic clonic seizures. This syndrome usually responds well to medication.
Ketogenic diet	A high fat, controlled protein, low carbohydrate diet that helps control seizures in some children with epilepsy. The diet works by encouraging the body to get energy from fat (rather than from carbohydrates). When this happens, the body produces chemicals called ketones which, for some children, help prevent seizures from happening.
Ketones	Chemicals produced in the body when the body uses fat for energy. This happens in high-fat diets such as the ketogenic diet. Ketones can help prevent seizures from happening for some people.
Ketosis	The process of producing ketones in the body, when the body uses fat for energy.
Magnetic resonance imaging (MRI)	A type of scan that uses strong magnetic fields and radio waves to produce detailed images of the inside of the body. An MRI scanner is a large tube that contains powerful magnets
Midazolam	A type of medication that is given to someone who is having prolonged or repeated seizures, to stop status

	epilepticus from happening. Buccal means it is given into the mouth between the teeth and the cheek. Midazolam is a type of emergency medication.
Myoclonic seizure	A type of generalised seizure where just part of the body (for example, a leg or arm) suddenly jerks. Myoclonic jerks often happen in clusters (several happening in a row) and often early in the morning.
Neurodisability	Documented diagnosis including any of the following phrases indicating the diagnosis made by the assessing team: • Autistic spectrum disorder • Moderate, severe (or profound) learning difficulty or global development delay • Cerebral palsy • Neurodegenerative disease or condition • An identified chromosomal disorder with a neurological or developmental component • Attention deficit hyperactivity disorder (ADHD) • Exclusions e.g. hypermobility, dyspraxia, specific learning difficulties e.g. (dyslexia, dyscalculia)
Neurological examination	Any evidence of a neurological examination of the child
Paediatrician with expertise	A paediatric consultant (or associate specialist) defined by themselves, their employer and tertiary service/network as having: • training and continuing education in epilepsies • AND peer review of practice • AND regular audit of diagnosis (e.g. participation in Epilepsy12) (Consensus Conference on Better care for children and adults with epilepsy- Final Statement, Royal College of Physicians of Edinburgh,2002) A paediatric neurologist is also defined as a 'paediatrician with expertise'.
Parietal lobe seizures	Focal seizures that start in the parietal lobe. Simple focal seizures from the parietal lobe include feeling numb or tingling in part of the body, a burning sensation or feeling of heat, or feeling that parts of the body are bigger or smaller than they really are. Complex focal seizures from this area are rare.
Partial seizures	Another name for 'focal seizures'. There are seizures that happen in, and affect, only part of the brain (not both sides of the brain) and start from a 'focal point' in the brain. What happens in these seizures varies depending on which part of the brain is affected and what that part of the brain normally does.

Paroxysmal episodes	This is the term chosen in this audit to represent the events causing concern. It includes all epileptic and non-epileptic seizures and also seizures of uncertain in origin.
Psychiatrist	A medically trained doctor who specialises in mental health problems. Psychiatrists are medically qualified and can prescribe medications.
Psychologist	Someone who studies the way the mind works and how people behave. Clinical psychologists are trained to help people manage mental health and social problems and they cannot prescribe medications.
Refractory epilepsy	Epilepsy that does not respond to AEDs (AEDs do not stop the seizures). This is also called intractable, drug-resistant or difficult to control epilepsy.
Rescue medication	Medication that is given to a person when they are having prolonged or repeated seizures to stop status epilepticus from happening. It is usually either rectal diazepam or buccal midazolam. These are only given in an emergency: they are not the same as AEDs, which are taken every day to prevent seizures.
Risk assessment	An assessment of someone's safety and possible risks. This might be at work, at home or any other area. Assessments look at risks to health and safety as well as ways to reduce risk, such as making reasonable adjustments or taking safety measures.
Secondarily generalised seizures	Seizures that start as a focal seizure (in part of the brain) but the seizure activity spreads and affects the whole of the brain. In simple terms these are 'small seizures' that become 'big seizures'. The focal seizure start is sometimes called an 'aura' or 'seizure warning', and the seizure usually spreads to become a tonic clonic seizure.
Seizure	A sudden, short-lived event that causes a change in the person's behaviour, awareness or consciousness. There are lots of different causes and types of seizures including epileptic seizures, hypoglycaemic (diabetic) seizures, non-epileptic seizures, syncope (fainting), and seizures caused by a heart problem.
Seizure control	When seizures are completely stopped, and the person experiences no seizures anymore. This is usually achieved by taking AEDs.
Seizure-free	When a person's seizures are fully controlled and stop happening (they don't have seizures anymore).
Severe Myoclonic Epilepsy in Infancy (SMEI) (also called Dravet Syndrome)	A rare childhood epilepsy syndrome that starts in a child's first few years of life. The child has jerking seizures, usually on one side of the body. They may also be photosensitive. Learning, speech and general development may be affected.
SUDEP (Sudden Unexpected Death in Epilepsy)	When a person with epilepsy suddenly dies and no reason for their death can be seen.

Symptomatic epilepsy	Epilepsy where there is a known physical cause of the person's seizures. This could be due to a scar on the brain, an accident or head injury, or a stroke or brain tumour. Structural causes can often be seen on an MRI.
Syncope	When someone loses consciousness and collapses because the oxygen getting to their brain temporarily stops. This can be because of a drop-in blood pressure, a change in the heartbeat (and not enough blood is pumped through the heart), or because of a reduced amount of oxygen in the blood. Syncope is also another word for 'faint'.
'School age'	Child 5 years and older (past their 5th birthday)
Temporal lobe seizures	Focal seizures that start in the temporal lobe. Simple focal seizures from the temporal lobe include an epigastric rising sensation, a sudden feeling of fear or joy or a funny taste or smell.
Tonic clonic seizure	A type of generalised seizure where the person stiffens (the 'tonic' part), falls down if they are standing, and then shakes, jerks or convulses (the 'clonic' part).
Transition	When the management of someone's epilepsy moves ('transfers') from a paediatrician to an adult neurologist. Transition usually happens at around 16 - 18 years of age.
Treatment plan	A record of the number and types of AED taken, when to take them and what to do if they do not work or need adjusting or changing. This is also called a drug plan.
Vagus nerve	The Vagus nerves connect to many different parts of the body and passes messages between the brain and various organs, including the throat, the heart, organs in the chest and abdomen.
Vagus Nerve Stimulation (VNS)	A type of treatment for epilepsy. It involves having a generator implanted in the chest wall attached to electrical wires around the Vagus nerve in the neck. The generator sends regular electrical signals through the Vagus nerve into the brain. For some people, this prevents or reduces the brain activity that causes seizures, and can reduce the number, length or severity of seizures they have.
Video telemetry	A test which involves having an EEG and being videotaped at the same time. This means that the EEG recording of a seizure can be compared to what is seen happening to the person. This can help to diagnose epilepsy and non-epileptic seizures.