

**Combined organisational
and clinical audits:
Report for England and Wales
Round 3 Cohort 2 (2019-20)**

✧RCPCH Audits

EPILEPSY12

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

Appendix B: Epilepsy12 Clinical audit – Round 3, Cohort 2



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 3 (2019-20).

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Appendices

The Epilepsy12 combined report for 2021 includes a description of key findings, recommendations, quality improvement activities, and patient involvement in Epilepsy12. It is available to download from [Epilepsy12](#).

Appendix A: Full Epilepsy12 2020 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 B: Epilepsy12 Clinical audit - Round 3, Cohort 2

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Appendix B: Full Epilepsy12 Round 3 cohort 2 clinical audit results

In this section, we present the full tables of results and figures for each of the Epilepsy12 Round 3 cohort 2 audit measures. Results are presented by England, Wales and each OPEN UK regional epilepsy network.

For individual Health Board or Trust level results, please go to the Epilepsy12 website (www.rcpch.ac.uk/epilepsy12).

Paediatric epilepsy network names are abbreviated in the following tables of results and figures. The OPEN UK Regional Paediatric Epilepsy Networks are named in the following table.

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
	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

Participation and case ascertainment

Participation

Table 1 provides a breakdown on Epilepsy12 Round 3 cohort 2 participation by Paediatric Epilepsy Networks and by country.

There are 145 registered Health Boards and Trusts in Round 3 cohort 2 of Epilepsy12 (149 prior to the Trust merges-cohort 1). **103/145 (71%)** 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 2. There was a 5% reduction in the percentage of Health Boards and Trusts that submitted a record of the first year of care clinical data for one or more children and young people in cohort 2 (71%) compared to cohort 1 (76%).

Table 1: Participation in Round 3 of Epilepsy12.

Country/network	Number of registered Health Boards and Trusts	Number of Health Boards and Trusts that have submitted cohort 1 clinical audit data	Number of Health Boards and Trusts that have submitted cohort 2 clinical audit data
England and Wales	145	76% (113/149)	71% (103/145)
England	139	76% (109/143)	73% (101/139)
Wales	6	67% (4/6)	33% (2/6)
BRPNF	14	73% (11/15)	57% (8/14)
CEWT	6	100% (6/6)	67% (4/6)
EPEN	14	67% (10/15)	57% (8/14)
EPIC	9	100% (9/9)	89% (8/9)
NTPEN	17	71% (12/17)	76% (13/17)
NWEIG	12	85% (11/13)	75% (9/12)
ORENG	7	100% (7/7)	86% (6/7)
PENNEC	8	78% (7/9)	100% (8/8)
SETPEG	10	50% (5/10)	70% (7/10)
SWEP	5	60% (3/5)	20% (1/5)
SWIPE	11	55% (6/11)	64% (7/11)
SWTPEG	8	63% (5/8)	75% (6/8)
TEN	6	100% (6/6)	100% (6/6)
WPNN	9	78% (7/9)	56% (5/9)
YPEN	9	89% (8/9)	78% (7/9)

Case ascertainment

Table 2 shows a total of **22,569** children and young people were registered in the Round 3, audit between 5th July 2018 and 11th January 2021. 68% (**15,442**) were registered via an EEG service and a further 32% (**7127**) registered by the Health Boards and Trusts. **18,440** children and young people were verified for inclusion in Round 3 and beyond cohorts by 11th January 2021. There were **34** opt outs post the verification stage.

Table 2: 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 and beyond 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 and Wales	15442	7127	18440	4095	34	1669
England	14941	6928	17844	3999	26	1547
Wales	501	199	596	96	8	122
BRPNF	1043	451	1278	216	0	156
CEWT	1381	131	1170	338	4	77
EPEN	1206	615	1329	492	0	176
EPIC	94	958	1016	26	10	55
NTPEN	1715	373	1702	386	0	240
NWEIG	961	437	1215	183	0	160
ORENG	1932	253	1696	489	0	148
PENNEC	838	787	1542	83	0	52
SETPEG	319	654	936	37	0	117
SWEP	408	184	522	70	0	90
SWIPE	1622	530	1340	803	9	116
SWTPEG	661	781	1385	48	9	57
TEN	1102	267	1024	345	0	46
WPNN	1492	116	1073	534	1	141
YPEN	668	590	1212	45	1	38

Figure 1 shows that there was reduced percentage of children and young people registered in the Round 3 and beyond cohorts via an EEG service in the download taken on 11th January 2021 (**68%**) compared to the download taken on 8th January 2020 (**73%**). Health Boards and Trusts registrations increased by the same percentage.

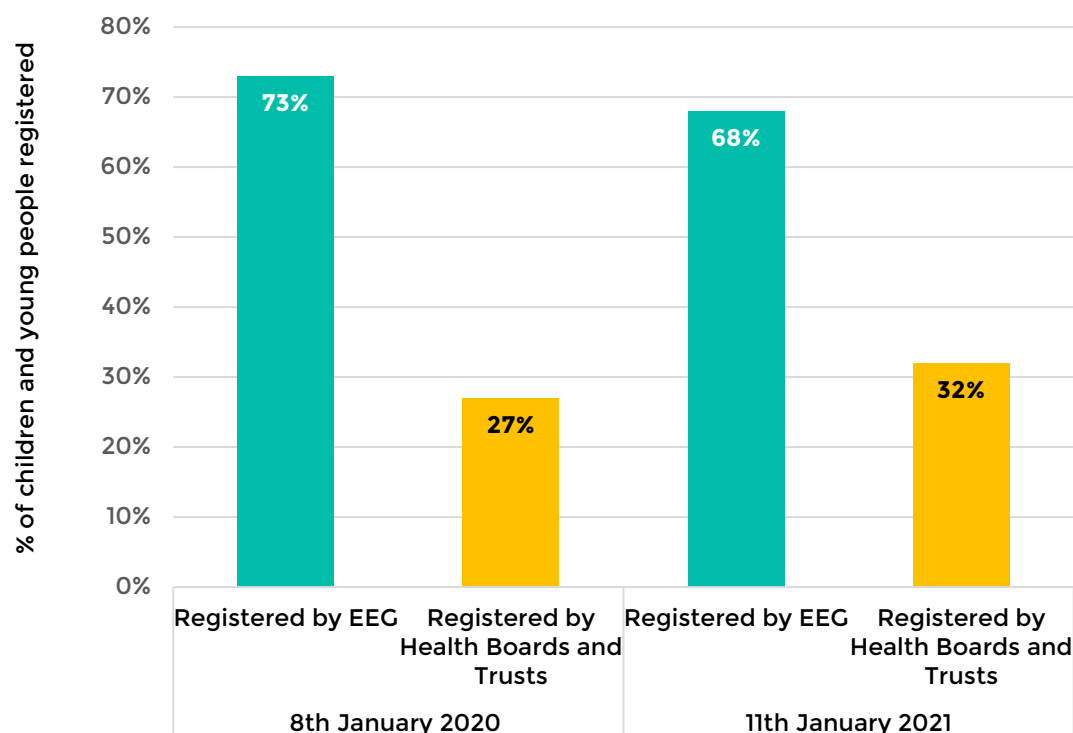


Figure 1: Percentage of children and young people registered in Round 3 by EEG and Health Boards and Trusts by download date

Table 3 below shows the number of children and young people that were assessed as eligible for Round 2 and Round 3 audits. More children and young people were verified and allocated to Round 3 cohort 2 (**10,181**) compared to Cohort 1 (**4684**).

61% (6177/10181) of the children and young people allocated to Round 3 cohort 2 data was successfully entered on the audit data capture system. Nationally, there was a decrease in data completeness in Round 3 cohort 2 (**61%**) compared to cohort 1 (**71%**) (Figure 2).

Table 3: Number of children and young people registered as eligible for the audit

	Round 2			Round 3-January 2020 download			Round 3-January 2021 download		
Description of eligible criteria	England and Wales	England	Wales	England and Wales	England	Wales	England and Wales	England	Wales
Children registered (by EEG services and the HBTs)	12973	12391	582	14591	14051	540	22569	21869	700
Children excluded (did not meet audit inclusion criteria)	8832	8479	353	1280	1177	103	1669	1547	122
Children allocated to respective cohorts	3350	3174	176	4684	4490	194	10181	9804	377
Children allocated to respective cohorts who had their first year of care data successfully entered on data capture system	3072	2907	165	3318	3195	123	6177	6102	75
Children allocated to respective cohorts but their first year of care data was not successfully entered on data capture system	272	261	11	1366	1295	71	4004	3702	302
Data completeness	92% (3072/3350)	92% (2907/3174)	94% (165/176)	71% (3318/4684)	71% (3195/4490)	63% (123/194)	61% (6177/10181)	62% (6102/9804)	20% (75/377)

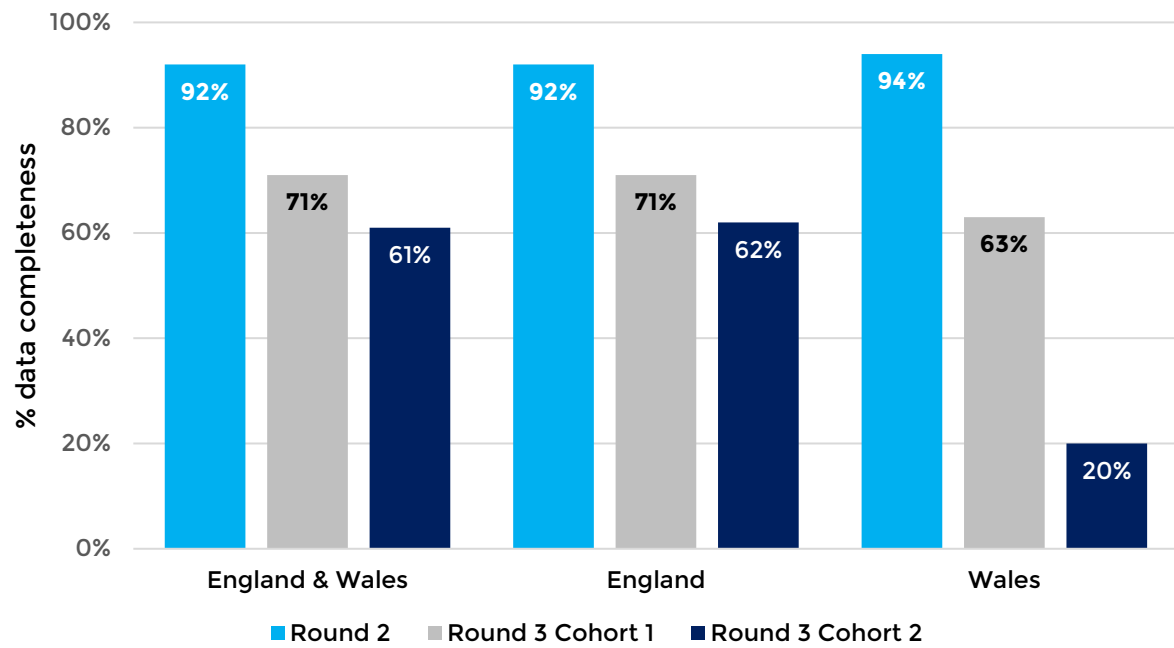


Figure 2: Percentage of data completeness by country in Round 2, Round 3 cohort 1 and Round 3 cohort 3.

Health Board and Trust ascertainment

Figure 3 shows the percentage of children and young people who were successfully registered and verified on the audit data capture system by the respective Health Boards and Trusts by the data download date (11th January 2021). Nationally, **82%** (18,440/22569) of the children and young people registered were verified. Over one third of the Health Boards and Trusts registered and verified all the children and young people on the audit data capture system. Some Health Boards and Trusts did not register or verify any children and young people on the system.

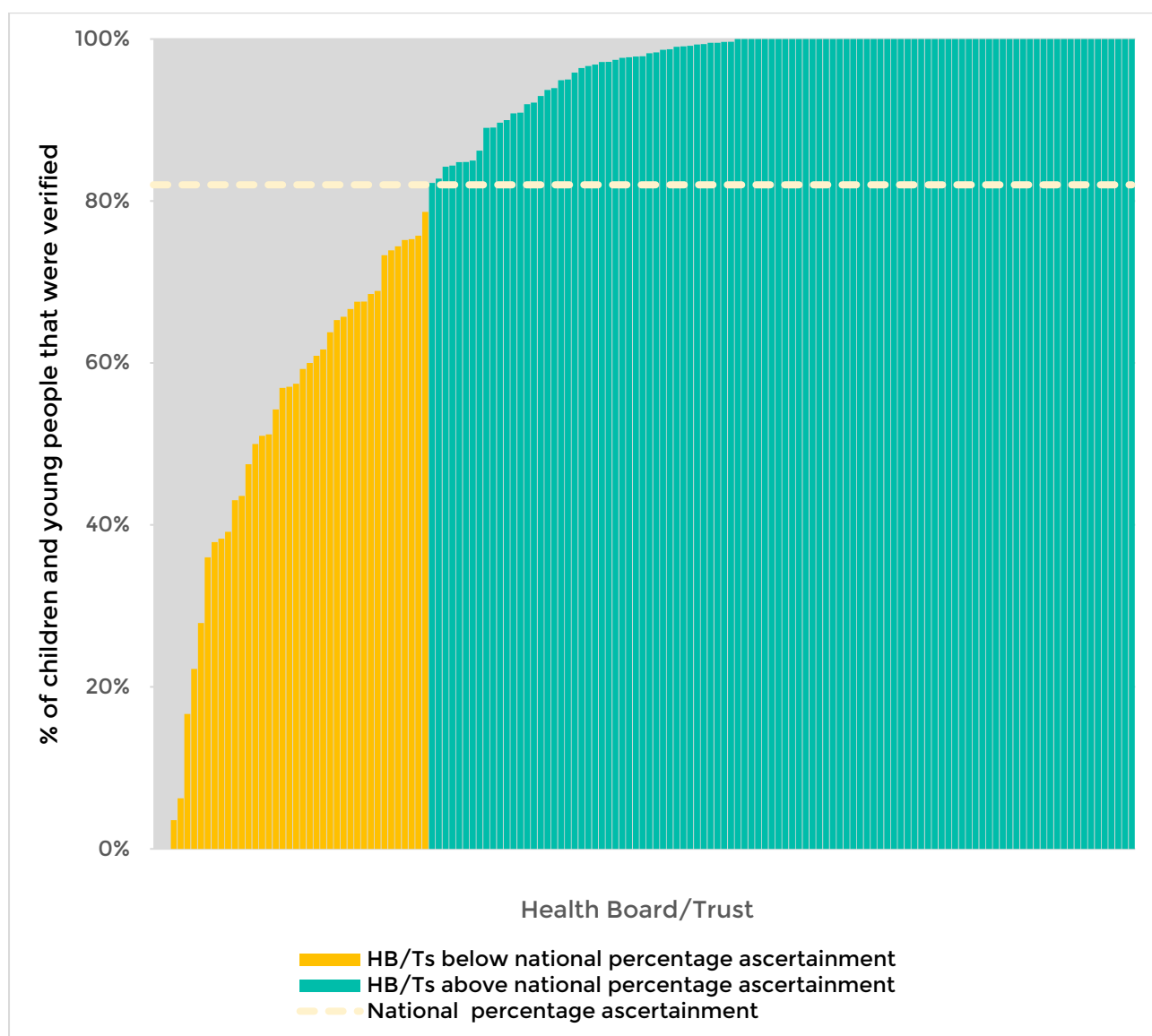


Figure 3: Percentage of children and young people verified by Health Boards and Trusts in Round 3.

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 4 below shows the percentage of children and young people verified and allocated to Round 3, cohort 2, that had their first year of care form submitted and locked on the data capture system, by the download date (11th January 2021). Nationally, **61%** (6177/10181) of the children allocated to cohort 2 had a submitted and locked first year of care form. One fifth of the Health Boards and trusts did not successfully submit and lock a single first year of care form for the children and young people allocated to cohort 2. Nearly one third of the Health Board and Trust submitted and locked the first year of care form for all the children allocated to cohort 2.

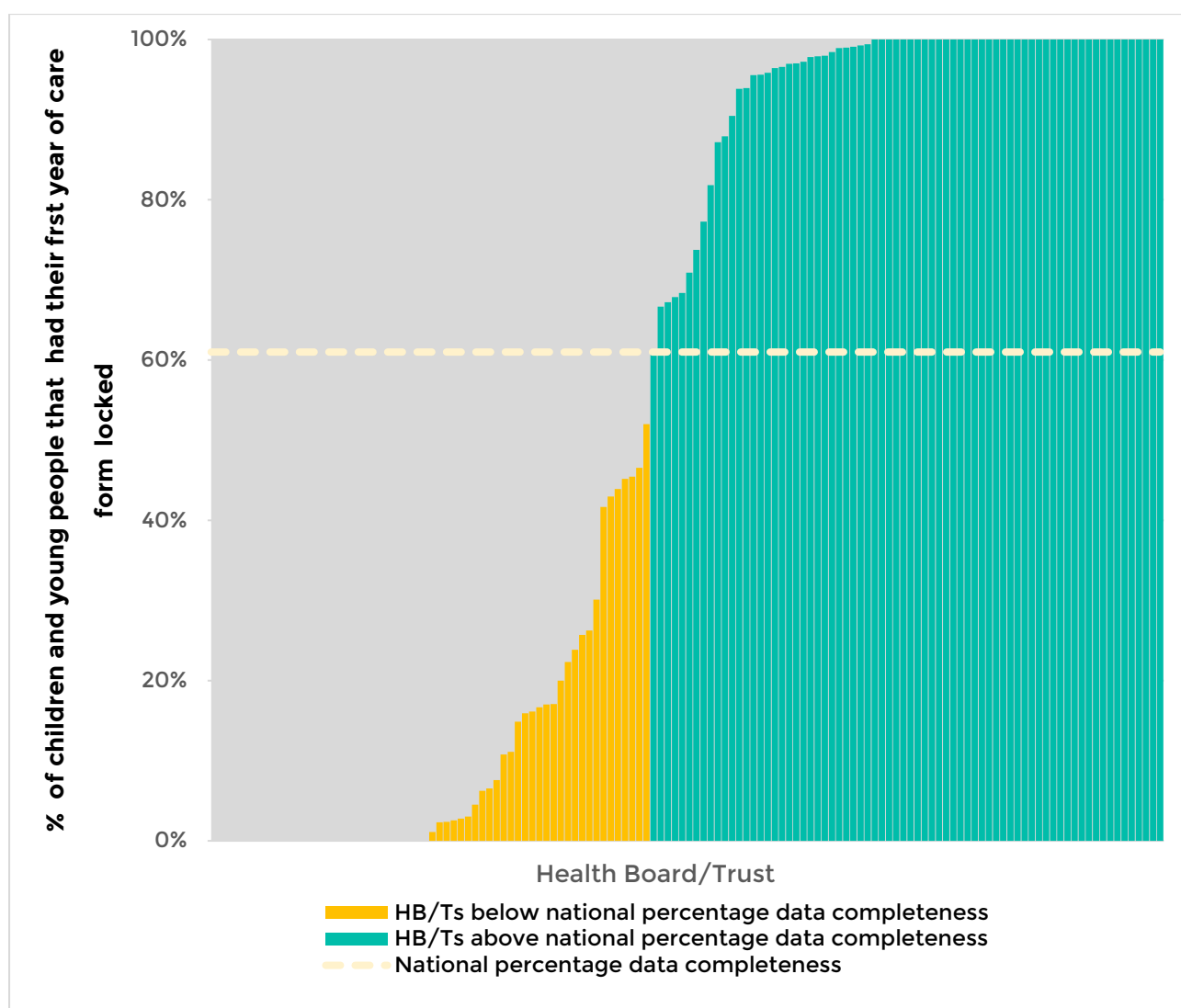


Figure 4: The percentage of children and young people within cohort 2 with their first year of care form submitted and locked.

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 2

Age and sex

Figure 5 shows the number of children and young people in cohort 2 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. Two children and young people were excluded for having invalid dates of birth (birthday after first paediatric assessment). Almost all (99.8%) of the children in cohort 2 had a known or specified sex. 15 children and young people had their gender recorded as unknown. The largest age groups in cohort 2 were younger children; infants below one year of age, and children aged one or two years old which is consistent with cohort 1. The number of children and young people was higher in the younger age groups up to the age of 15, when many young people start to transition to adult services. Boys account for 54% of the cohort 2 which is consistent with cohort 1.

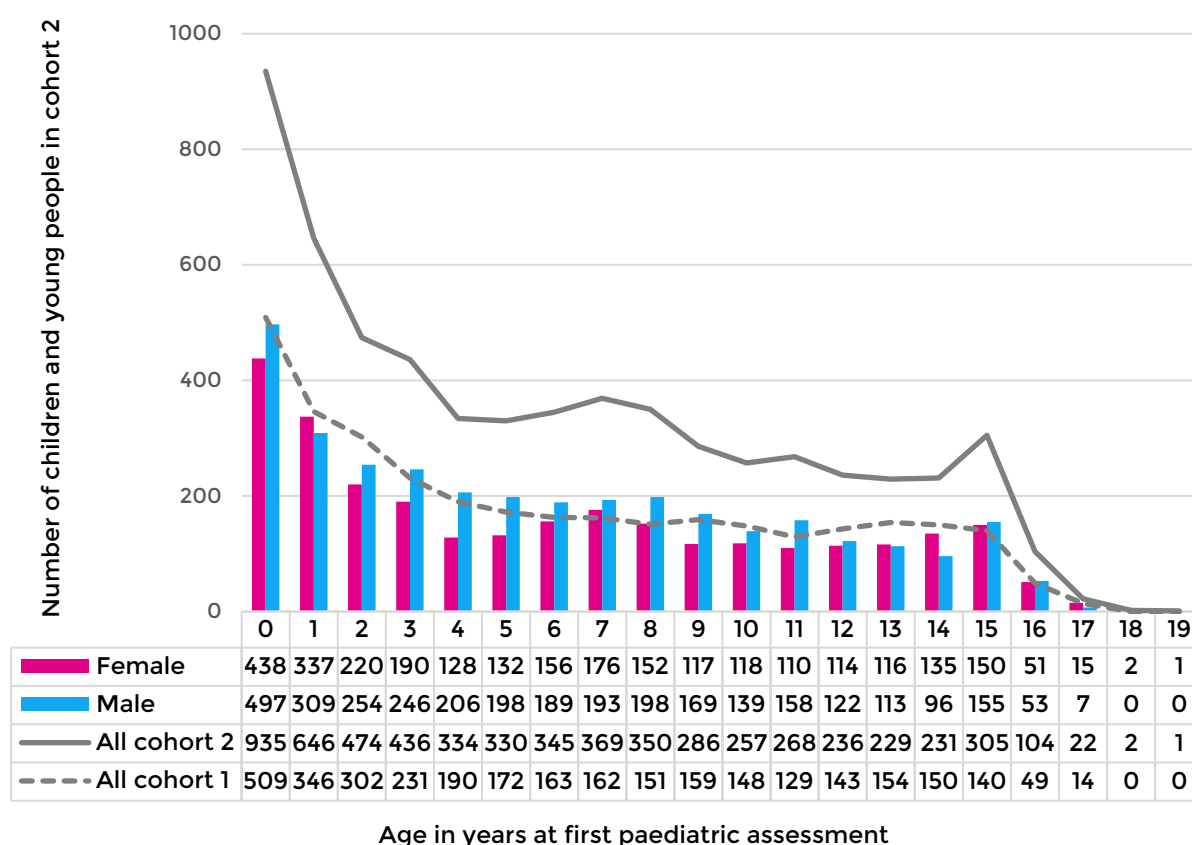


Figure 5: Numbers of children and young people included in cohort 2 by age in years at first paediatric assessment and gender. (This figure excludes 15 children with unknown gender and two with invalid dates of birth).

Figure 6 shows the number of children and young people in cohort 2 who were under two years of age at first paediatric assessment broken down by age in months and gender. Most children were below the age of two years and had their first paediatric assessment either on their first month of life (150) or at seven-months old (89) which is consistent with cohort 1.

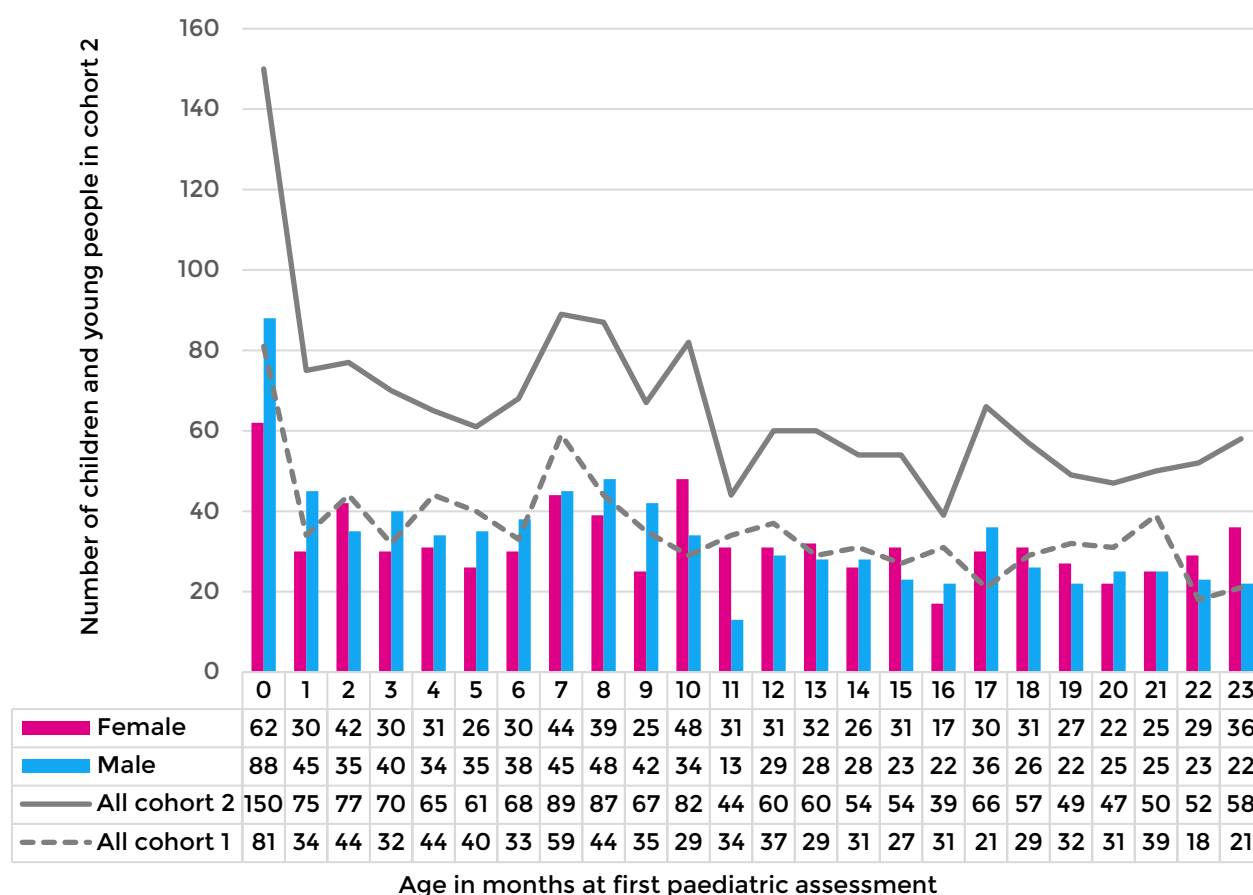


Figure 6: Numbers of children and young people included in cohort 2 by age in months at first paediatric assessment and gender. (This figure excludes five children with unknown gender and two children with invalid dates of birth).

Table 4 shows the proportion of children and young people in different age groups, by country or by paediatric epilepsy network area. Two children were excluded due to invalid dates of birth. In cohort 2:

- **26%** of the children and young people were aged between one month and two years (26% in cohort 1),
- **20%** were aged between two and four years (22% in cohort 1),
- **36%** were aged between five and eleven years (33% in cohort 1),
- **18%** were aged over twelve years of age (20% in cohort 1).

Table 4: Number of children and young people in cohort 2 by country, network and age-group. This table excludes two children with invalid dates of birth.

Country/network	% <2 years	% 2 - 4 years	% 5 - 11 years	% >=12 years
England and Wales (N=6175)	26% (1586/6175)	20% (1249/6175)	36% (2209/6175)	18% (1131/6175)
England (N=6100)	26% (1564/6100)	20% (1237/6100)	36% (2187/6100)	18% (1112/6100)
Wales (N=75)	29% (22/75)	16% (12/75)	29% (22/75)	25% (19/75)
BRPNF (N=240)	30% (71/240)	15% (37/240)	37% (88/240)	18% (44/240)
CEWT (N=525)	27% (144/525)	21% (112/525)	34% (176/525)	18% (93/525)
EPEN (N=294)	24% (72/294)	23% (67/294)	40% (119/294)	12% (36/294)
EPIC (N=470)	22% (102/470)	21% (100/470)	40% (186/470)	17% (82/470)
NTPEN (N=389)	19% (74/389)	19% (72/389)	41% (160/389)	21% (83/389)
NWEIG (N=388)	21% (81/388)	21% (80/388)	38% (149/388)	20% (78/388)
ORENG (N=429)	24% (104/429)	20% (86/429)	36% (156/429)	19% (83/429)
PENNEC (N=671)	30% (203/671)	18% (124/671)	33% (223/671)	18% (121/671)
SETPEG (N=310)	33% (102/310)	19% (59/310)	33% (102/310)	15% (47/310)
SWEP (N=67)	31% (21/67)	12% (8/67)	30% (20/67)	27% (18/67)
SWIPE (N=524)	25% (131/524)	22% (116/524)	33% (173/524)	20% (104/524)
SWTPEG (N=747)	25% (187/747)	20% (151/747)	35% (258/747)	20% (151/747)
TEN (N=457)	27% (123/457)	23% (104/457)	35% (159/457)	16% (71/457)
WPNN (N=168)	31% (52/168)	19% (32/168)	34% (57/168)	16% (27/168)
YPEN (N=496)	24% (119/496)	20% (101/496)	37% (183/496)	19% (93/496)

Table 5 (below) shows the median age of children allocated to Round 3 cohort 2 was similar to cohort 1 (5 years old). **46%** of the children were female which is consistent in the four rounds. Round 3 cohort 2 had the largest sample (**6177**). The sample window for Round 1, Round 2, Round 3 cohort 1, Round 3 cohort 2 were: 6 months, 4 months and 4.5 months and 12 months respectively, hence the difference in cohort sizes.

Table 5: Demographic characteristics of children included in Round 1, 2 and 3 of Epilepsy12.

	Round 1			Round 2			Round 3 cohort 1			Round 3 cohort 2		
	UK	England	Wales	UK	England	Wales	UK	England	Wales	UK	England	Wales
N	4310	4085	225	3072	2907	165	3318	3195	123	6177	6102	75
% Female	46%	46%	49%	45%	45%	45%	45%	45%	48%	46%	46%	55%
Median age (years)	-	6.4	7.5	-	5.3	5.9	5.4	5.4	5.3	5.0	5.0	5.0
25th centile (years)	-	2.2	3.1	-	2	2.5	1.8	1.8	2.3	1.0	1.0	1.0
75th centile (years)	-	10.7	12.1	-	10.2	10.3	10.6	10.6	10.7	10.0	10.0	12.0
Infants (1 month to < 2 years)	23%	23%	18%	25%	25%	21%	26%	26%	21%	26%	26%	29%
Pre-school (2-4 years)	20%	20%	17%	24%	24%	21%	22%	22%	27%	20%	20%	16%
School (5-11 years)	37%	37%	39%	34%	34%	39%	33%	33%	33%	36%	36%	29%
Young people (12-15 years)	19%	19%	25%	17%	17%	19%	18%	18%	17%	16%	16%	21%

- Comparable data is not available for Rounds 1 and 2

Figure 7 shows the overall proportions of the children and young people by age groups are similar in Round 1, Round 2, Round 3 cohort 1 and cohort 2. The largest age-group in the four rounds are school age children between 5 to 11 years.

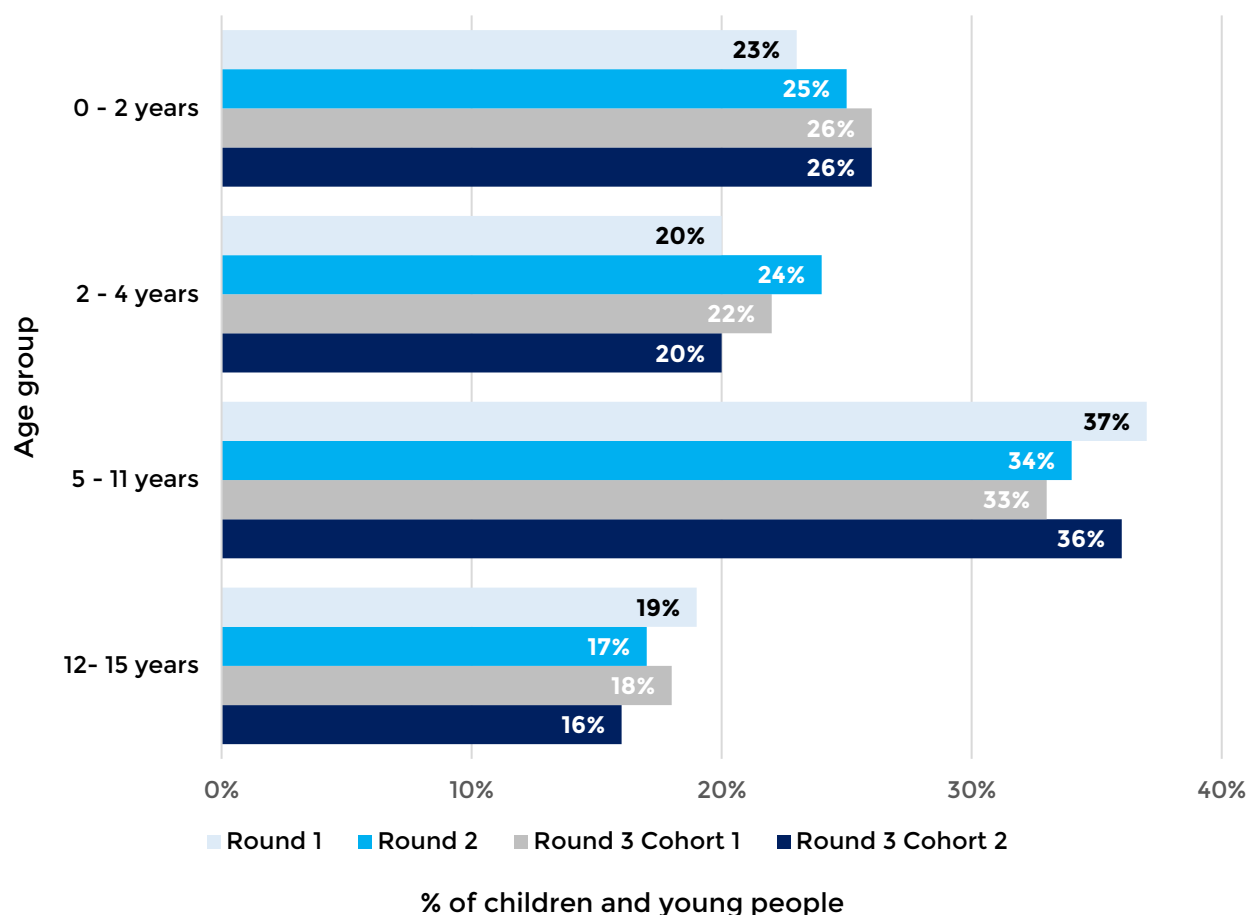


Figure 7: Comparison of the proportion of children and young people by age group in Round 1, Round 2, Round 3 cohort 1 and cohort 2.

Deprivation

Table 6 shows the breakdown of children and young people in Epilepsy12 cohort 2 by deprivation quintile derived by matching home postcodes to the English (IMD, 2019) and Welsh (WIMD, 2019) indices of multiple deprivation data. A small proportion **59 (1%)** of children and young people could not be allocated to a deprivation quintile, because their postcodes were invalid or did not match lower super output area (LSOA).

Table 6: Percentage and number of children and young people in cohort 2 by deprivation by country and network.

Country/network	Most deprived	Second most deprived	Third least deprived	Second least deprived	Least deprived
England and Wales (N=6118)	28% (1737/6118)	20% (1224/6118)	19% (1135/6118)	17% (1022/6118)	16% (1000/6118)
England (N=6043)	28% (1715/6043)	20% (1197/6043)	19% (1122/6043)	17% (1016/6043)	16% (993/6043)
Wales (N=75)	29% (22/75)	36% (27/75)	17% (13/75)	8% (6/75)	9% (7/75)
BRPNF (N=237)	26% (61/237)	17% (41/237)	17% (41/237)	22% (53/237)	17% (41/237)
CEWT (N=521)	34% (176/521)	18% (93/521)	17% (86/521)	16% (85/521)	16% (81/521)
EPEN (N=288)	17% (49/288)	23% (67/288)	24% (70/288)	14% (40/288)	22% (62/288)
EPIC (N=468)	52% (242/468)	15% (68/468)	11% (53/468)	13% (62/468)	9% (43/468)
NTPEN (N=385)	25% (98/385)	30% (117/385)	23% (90/385)	14% (53/385)	7% (27/385)
NWEIG (N=385)	48% (185/385)	19% (73/385)	14% (55/385)	10% (40/385)	8% (32/385)
ORENG (N=425)	13% (55/425)	17% (72/425)	18% (78/425)	24% (101/425)	28% (119/425)
PENNEC (N=660)	46% (301/660)	24% (156/660)	12% (79/660)	12% (77/660)	7% (47/660)
SETPEG (N=308)	23% (72/308)	18% (56/308)	23% (72/308)	21% (65/308)	14% (43/308)
SWEP (N=67)	33% (22/67)	36% (24/67)	15% (10/67)	7% (5/67)	9% (6/67)
SWIPE (N=522)	13% (66/522)	25% (132/522)	30% (157/522)	18% (96/522)	14% (71/522)
SWTPEG (N=739)	4% (26/739)	15% (112/739)	19% (142/739)	24% (175/739)	38% (284/739)
TEN (N=452)	43% (196/452)	21% (96/452)	15% (66/452)	13% (60/452)	8% (34/452)
WPNN (N=167)	10% (17/167)	17% (28/167)	30% (50/167)	22% (37/167)	21% (35/167)
YPEN (N=494)	35% (171/494)	18% (89/494)	17% (86/494)	15% (73/494)	15% (75/494)

Figure 8 shows that the proportion of children and young people in cohort 2 living in the most deprived quintiles was higher and this is consistent with cohort 1.

Figure 9 shows the deprivation indices for children and young people's home addresses by regional paediatric epilepsy networks. This shows that there is considerable variation between networks which is consistent with cohort 1.

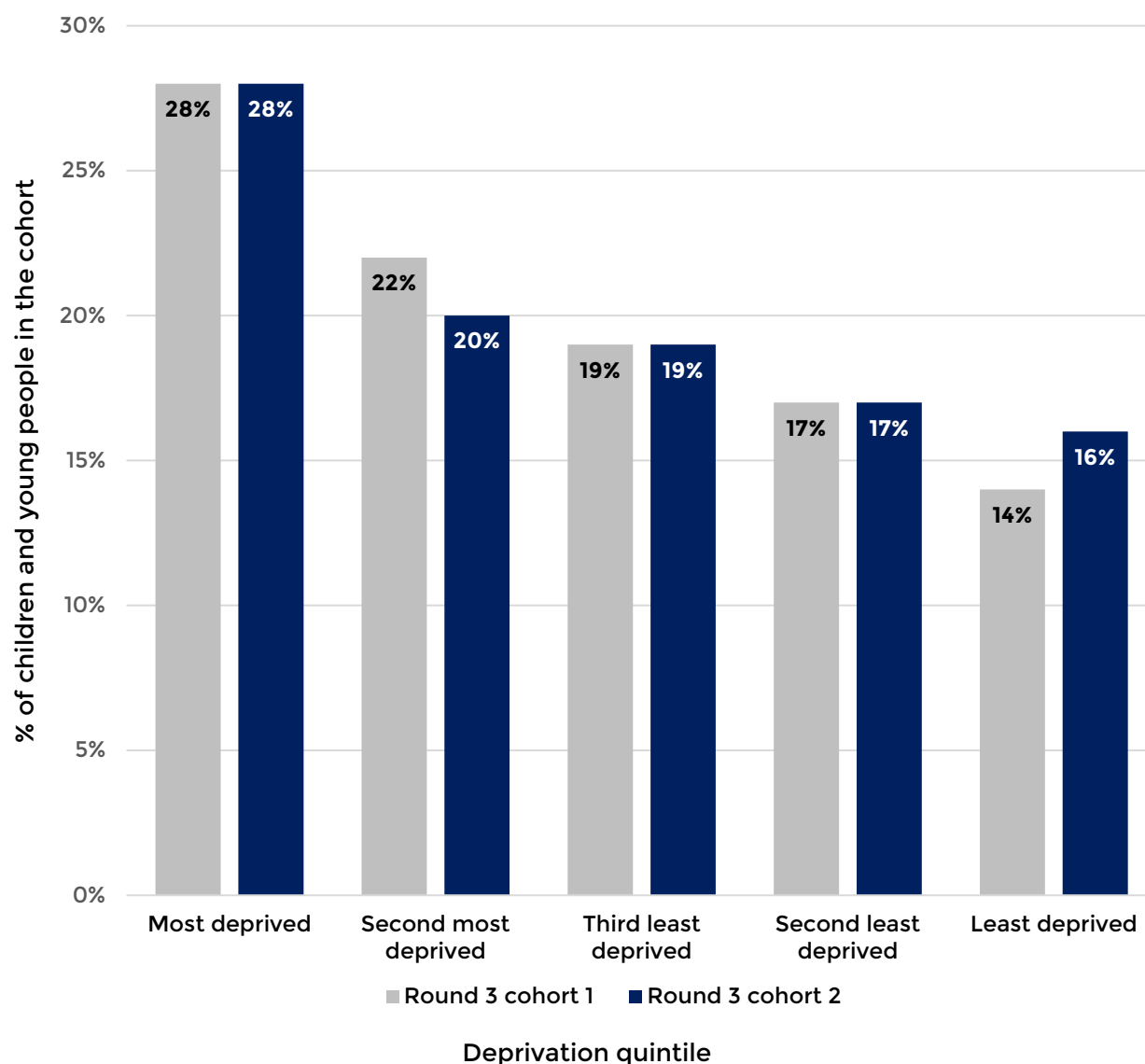


Figure 8: Percentage of children and young people in the cohorts by deprivation quintile in England and Wales combined.

Figure 9 shows a comparison of the proportion of children and young people by deprivation quintile and by country/network.

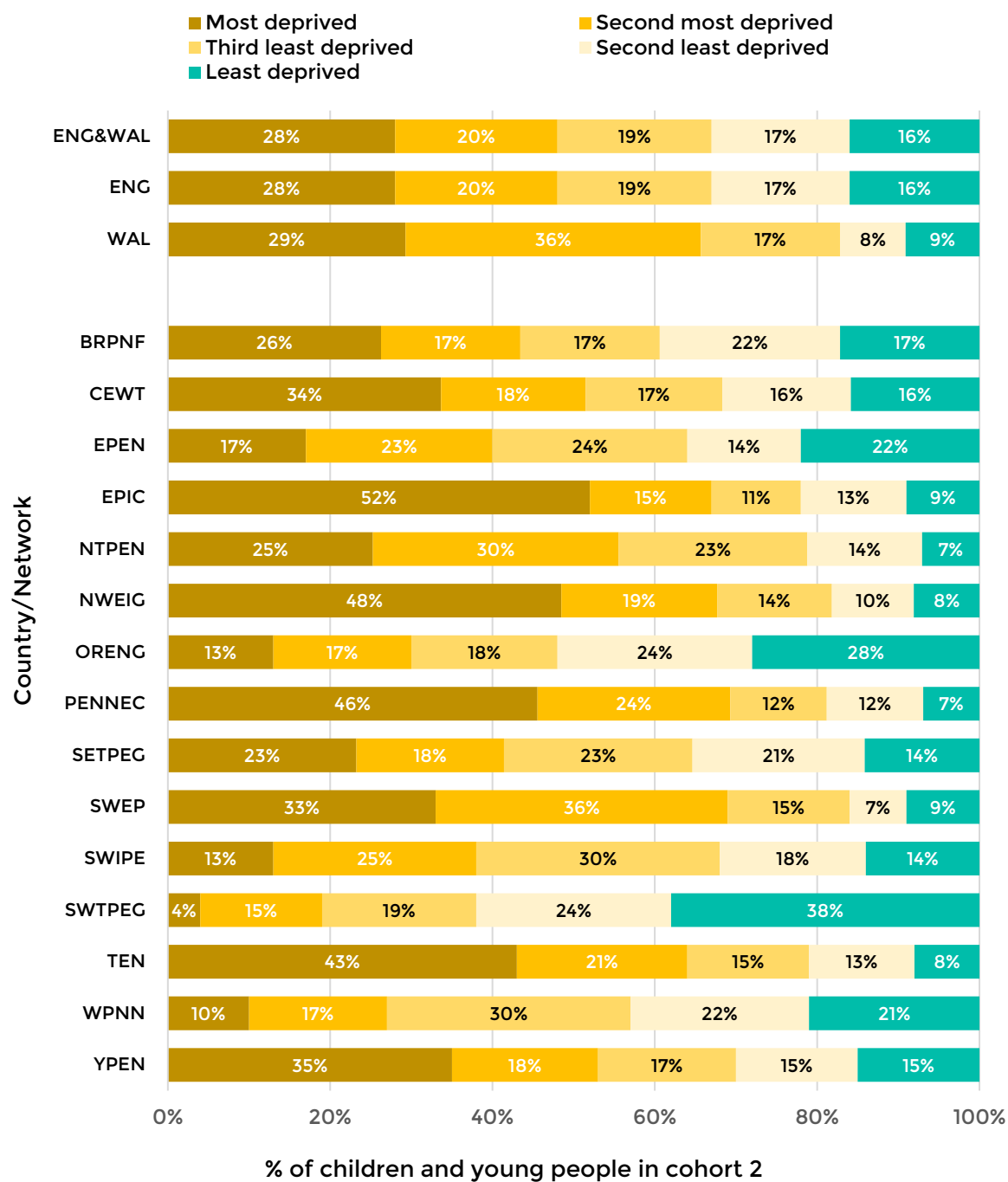


Figure 9: Percentage of children and young people in cohort 2 by deprivation by country/network.

Diagnostic status

Prior experience of seizures

Table 7 shows that over 500 children and young people in Round 3 cohort 2 were uncertain whether they had prior experience of neonatal, febrile or acute symptomatic seizures.

- **3% (162/6177)** had prior experience of neonatal seizures.
- **9% (562/6177)** had prior experience of febrile seizures.
- **8% (476/6177)** 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 in cohort 2 which is consistent with cohort 1 (**Figure 10**).

Table 7: Prior experience of seizures in children and young people in cohort 2 in England and Wales.

Description of neonatal seizures	% with prior seizures	% without prior seizures	% Uncertain about prior seizures
Neonatal seizure(s)	3% (162/6177)	88% (5455/6177)	9% (560/6177)
Febrile seizure(s)	9% (562/6177)	81% (5021/6177)	10% (594/6177)
Acute symptomatic seizure (s)	8% (476/6177)	84% (5176/6177)	8% (525/6177)

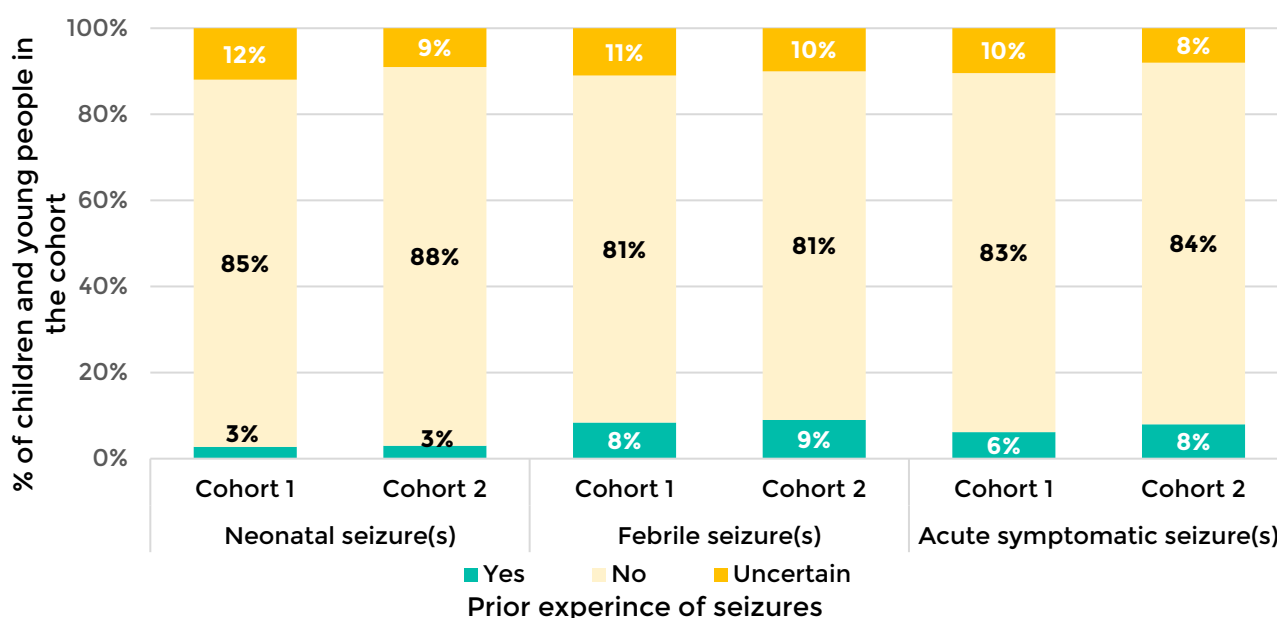


Figure 10: Percentage of children and young people with/without prior experience of seizures.

Table 8 shows the diagnostic status of children and young people in cohort 2 in the first year of care in England and Wales combined. **34% (2106/6177)** children and young people were diagnosed with epilepsy in cohort 2. Of these, **33% (2028/6177)** had two or more epileptic episodes more than 24 hours apart and **1% (78/6177)** were diagnosed with epilepsy for other reasons.

Figure 11 shows the percentages of children and young people in cohort 2 by diagnostic status in England and Wales.

Table 8: 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 and Wales (N=6177)	33% (2028/6177)	1% (78/6177)	3% (172/6177)	1% (63/6177)	43% (2644/6177)	19% (1192/6177)
England (N=6102)	33% (2008/6102)	1% (78/6102)	*	1% (63/6102)	43% (2595/6102)	*
Wales (N=75)	27% (20/75)	0% (0/75)	*	0% (0/75)	65% (49/75)	*
BRPNF (N=240)	34% (82/240)	2% (5/240)	5% (12/240)	0% (0/240)	35% (84/240)	24% (57/240)
CEWT (N=525)	29% (151/525)	0% (2/525)	4% (19/525)	2% (9/525)	41% (217/525)	24% (127/525)
EPEN (N=294)	30% (87/294)	*	4% (13/294)	*	43% (125/294)	19% (56/294)
EPIC (N=470)	47% (221/470)	*	*	1% (4/470)	34% (162/470)	16% (76/470)
NTPEN (N=390)	49% (191/390)	0% (0/390)	4% (16/390)	2% (9/390)	28% (111/390)	16% (63/390)
NWEIG (N=389)	32% (123/389)	*	*	*	38% (148/389)	29% (114/389)
ORENG (N=429)	28% (119/429)	*	3% (14/429)	*	39% (166/429)	29% (123/429)
PENNEC (N=671)	34% (228/671)	3% (17/671)	4% (30/671)	2% (15/671)	39% (262/671)	18% (119/671)
SETPEG (N=310)	25% (76/310)	5% (14/310)	2% (6/310)	*	49% (152/310)	19% (58/310)
SWEP (N=67)	22% (15/67)	0% (0/67)	*	*	69% (46/67)	*
SWIPE (N=524)	36% (188/524)	*	1% (6/524)	*	48% (252/524)	14% (73/524)
SWTPEG (N=747)	27% (204/747)	3% (19/747)	4% (28/747)	*	52% (388/747)	14% (105/747)
TEN (N=457)	26% (117/457)	*	*	1% (5/457)	49% (223/457)	24% (108/457)
WPNN (N=168)	34% (57/168)	*	3% (5/168)	0% (0/168)	52% (88/168)	*
YPEN (N=496)	34% (169/496)	*	2% (10/496)	*	44% (220/496)	19% (93/496)

* In accordance with information governance rules, potentially sensitive data based small numbers have been masked

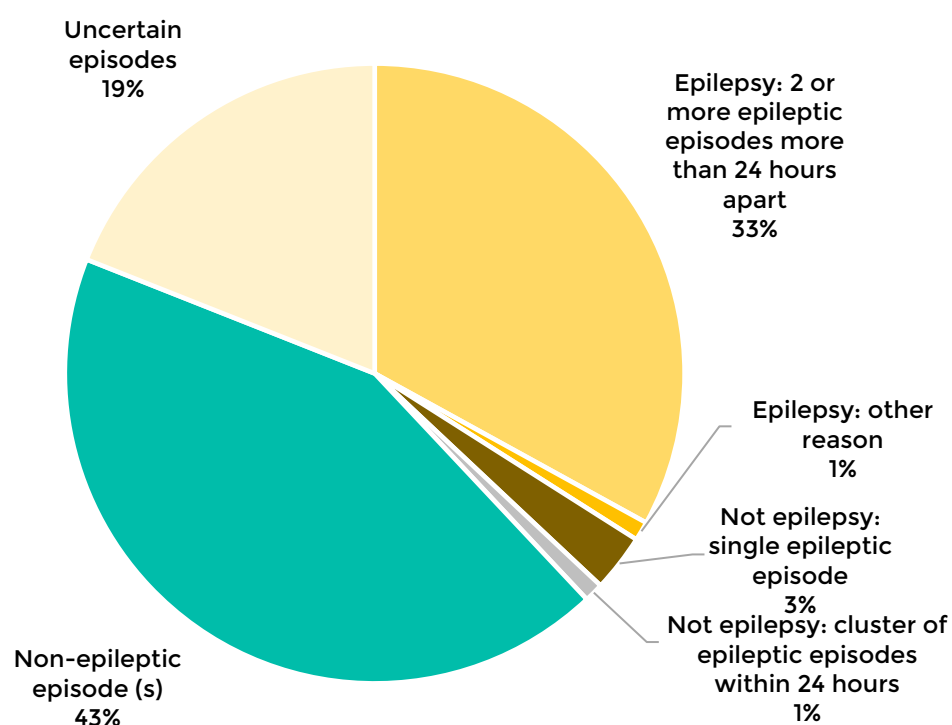


Figure 11: Percentage of children and young people in Cohort 2 by diagnostic status at first year of care, in England and Wales.

Table 9 shows the diagnostic status of children and young people in cohort 2 in the first paediatric assessment. **30% (1872/6177)** children and young people were diagnosed with epilepsy in cohort 2 in the first paediatric assessment. Of these, **29% (1790/6177)** had two or more epileptic episodes more than 24 hours apart and **1% (82/6177)** were diagnosed with epilepsy for other reasons. The number of children where there remains uncertainty as to whether the episodes were epileptic or not, reduced from **34% (2117/6177)** in the first paediatric assessment, to **19% (1192/6177)** in the first year of care (**Figure 12**).

Table 9: 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 and Wales (N=6177)	29% (1790/6177)	1% (82/6177)	4% (232/6177)	2% (95/6177)	30% (1861/6177)	34% (2117/6177)
England (N=6102)	29% (1765/6102)	*	*	*	30% (1826/6102)	34% (2105/6102)
Wales (N=75)	33% (25/75)	*	*	*	47% (35/75)	16% (12/75)
BRPNF (N=240)	32% (77/240)	*	6% (14/240)	*	18% (44/240)	40% (95/240)
CEWT (N=525)	25% (129/525)	0% (0/525)	6% (29/525)	3% (15/525)	33% (171/525)	34% (181/525)
EPEN (N=294)	32% (93/294)	2% (6/294)	6% (17/294)	0% (0/294)	29% (86/294)	31% (92/294)
EPIC (N=470)	49% (228/470)	1% (7/470)	1% (7/470)	1% (5/470)	21% (100/470)	26% (123/470)
NTPEN (N=390)	47% (185/390)	1% (5/390)	4% (16/390)	2% (8/390)	23% (89/390)	22% (87/390)
NWEIG (N=389)	20% (77/389)	*	*	*	22% (85/389)	57% (221/389)
ORENG (N=429)	19% (80/429)	*	7% (29/429)	*	16% (70/429)	54% (231/429)
PENNEC (N=671)	30% (198/671)	2% (14/671)	4% (30/671)	2% (16/671)	31% (205/671)	31% (208/671)
SETPEG (N=310)	24% (75/310)	3% (10/310)	2% (6/310)	2% (5/310)	44% (136/310)	25% (78/310)
SWEP (N=67)	30% (20/67)	*	*	*	49% (33/67)	16% (11/67)
SWIPE (N=524)	33% (173/524)	1% (5/524)	4% (19/524)	1% (6/524)	32% (169/524)	29% (152/524)
SWTPEG (N=747)	23% (172/747)	*	5% (34/747)	*	42% (316/747)	27% (202/747)
TEN (N=457)	26% (119/457)	0% (0/457)	1% (5/457)	2% (7/457)	42% (191/457)	30% (135/457)
WPNN (N=168)	25% (42/168)	*	4% (7/168)	*	21% (35/168)	48% (80/168)
YPEN (N=496)	25% (122/496)	0% (2/496)	3% (13/496)	1% (7/496)	26% (131/496)	45% (221/496)

* In accordance with information governance rules, potentially sensitive data based small numbers have been masked

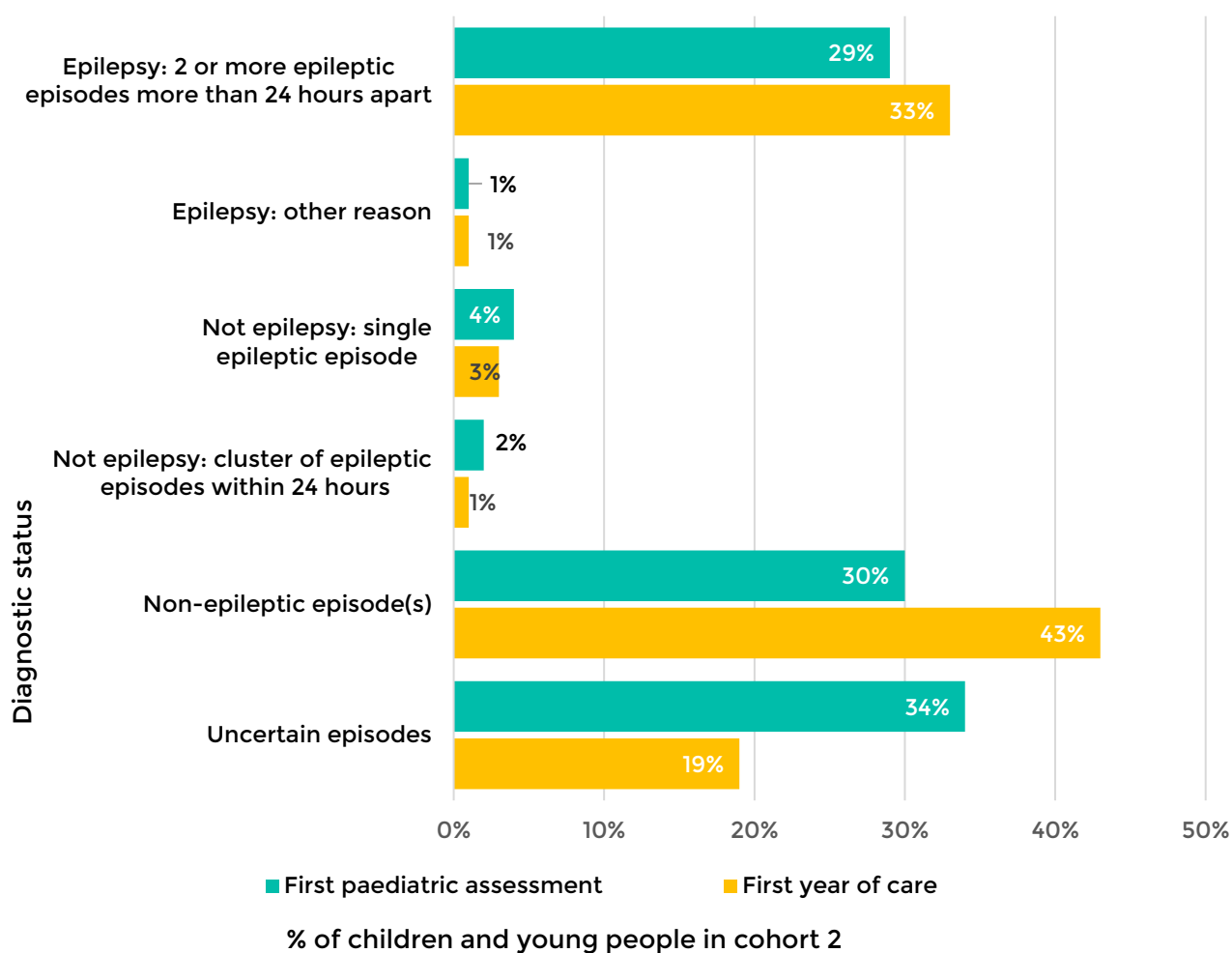


Figure 12: Percentage of children and young people by diagnostic status in first paediatric assessment and first year of care in England and Wales, in Round 3 cohort 2.

Figure 13 shows a comparison of diagnostic status by Round 1, Round 2, Round 3 cohort 1 and cohort 2 in the first paediatric assessment and 12 months after first paediatric assessment.

More children and young people were diagnosed with epilepsy 12 months after first paediatric assessment compared to the first paediatric assessment. This is a trend in Round 1, Round 2, Round 3 cohort 1 and cohort 2.

Approximately one third of children and young people in the cohorts were diagnosed with epilepsy 12 months after first paediatric assessment across Round 1, Round 2 and Round 3 cohort 1 and Round 3 cohort 2.

The proportion of children and young people where there was uncertainty whether the episodes were epileptic or not is higher in the first paediatric assessment compared to 12 months after first paediatric assessment across all the Rounds.

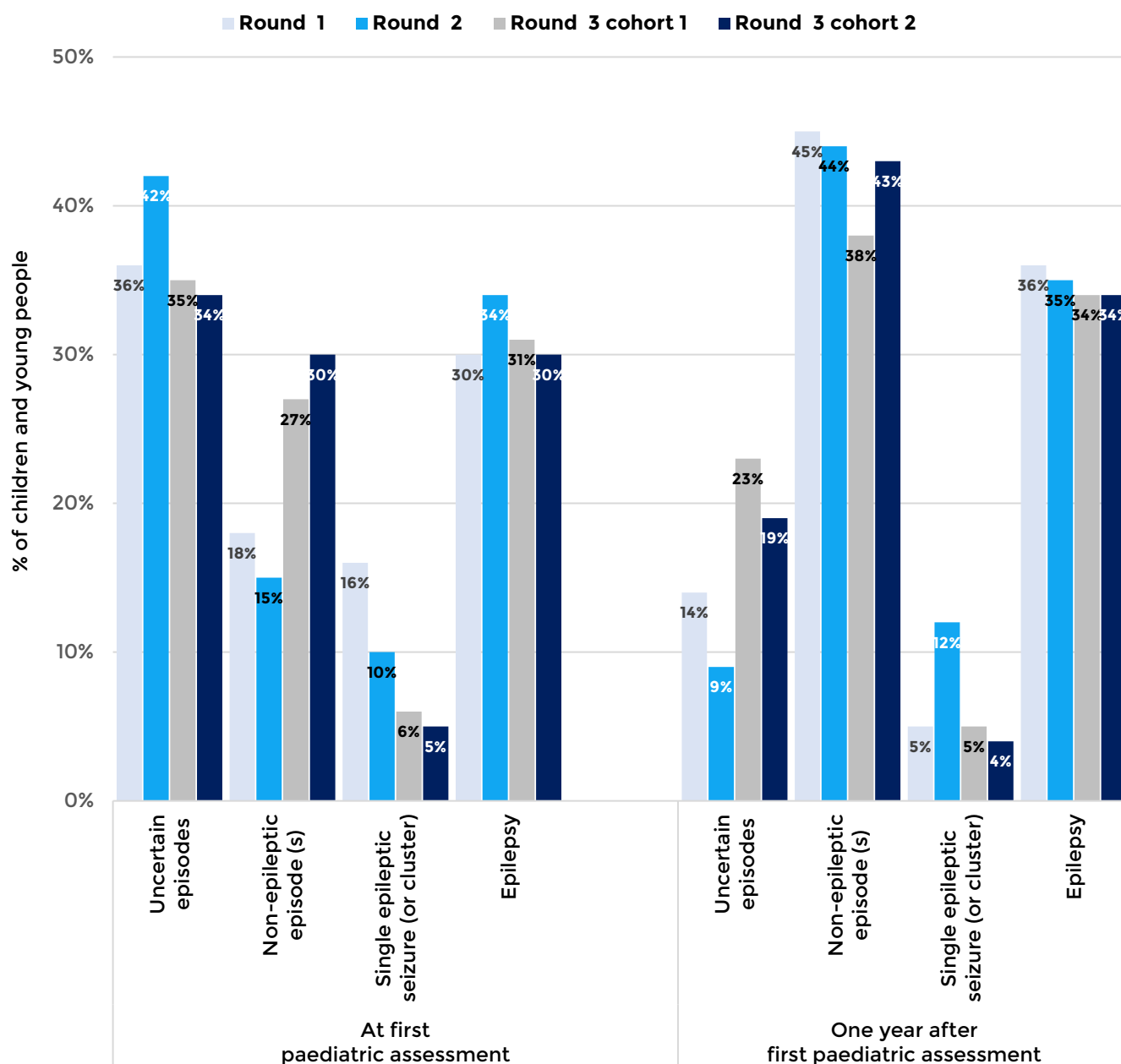


Figure 13: Diagnosis at first assessment and one year after first assessment in Round 1, Round 2, Round 3 cohort 1 and cohort 2.

Non-epileptic episodes

Table 10 shows a description of the non-epileptic episodes recorded for children in cohort 2. The proportion of children and young people with non-epileptic episodes was comparable in Round 3 cohort 2 and cohort 1. The percentage of children with behavioural, psychological and psychiatric disorders in cohort 2 (19%) was slightly higher than cohort 1 (16%) as shown in Figure 14.

Table 10: Description of non-epileptic episodes in children in cohort 2 at one year after first assessment in England and Wales.

Description of non-epileptic episodes	Percentage of children and young people in cohort 1	Percentage of children and young people in cohort 2
Syncope and Anoxic Seizures	6% (215/3318)	6% (398/6177)
Behavioural, Psychological and Psychiatric Disorders	16% (541/3318)	19% (1197/6177)
Sleep Related Conditions	2% (77/3318)	2% (139/6177)
Paroxysmal Movement Disorders	3% (103/3318)	4% (225/6177)
Migraine Associated Disorders	1% (22/3318)	1% (57/6177)
Miscellaneous Events	2% (71/3318)	2% (121/6177)
Other	16% (535/3318)	16% (963/6177)

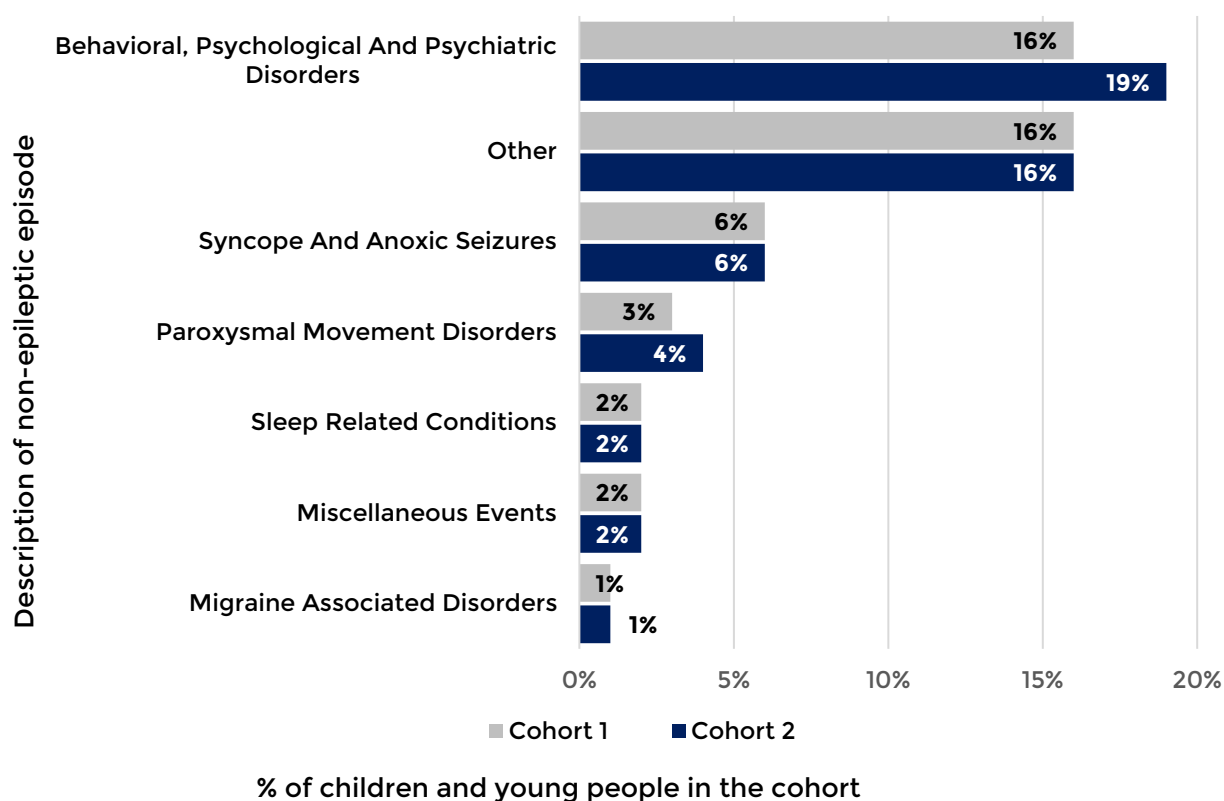


Figure 14: Percentage of children and young people by description of non-epileptic episode.

Initial referral and examination

Referring service to first paediatric assessment

Table 11 shows the service from which a referral was made for a first paediatric assessment for children and young people who were diagnosed with epilepsy in cohort 2. Majority of children and young people diagnosed with epilepsy in England and Wales were referred by the emergency department (ED) **40% (834/2106)** or had a referral from the general practitioner (GP) **36% (768/2106)**.

Figure 15 shows the percentage of referrals received from different services in England and Wales in cohort 2 and cohort 1.

Table 11: 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=2106)	40% (834/2106)	36% (768/2106)	<1% (1/2106)	9% (188/2106)	10% (210/2106)	1% (15/2106)	1% (18/2106)	3% (72/2106)
England (N=2086)	40% (829/2086)	36% (757/2086)	<1% (1/2086)	9% (187/2086)	10% (208/2086)	1% (15/2086)	1% (18/2086)	3% (71/2086)
Wales (N=20)	25% (5/20)	55% (11/20)	0% (0/20)	5% (1/20)	10% (2/20)	0% (0/20)	0% (0/20)	5% (1/20)

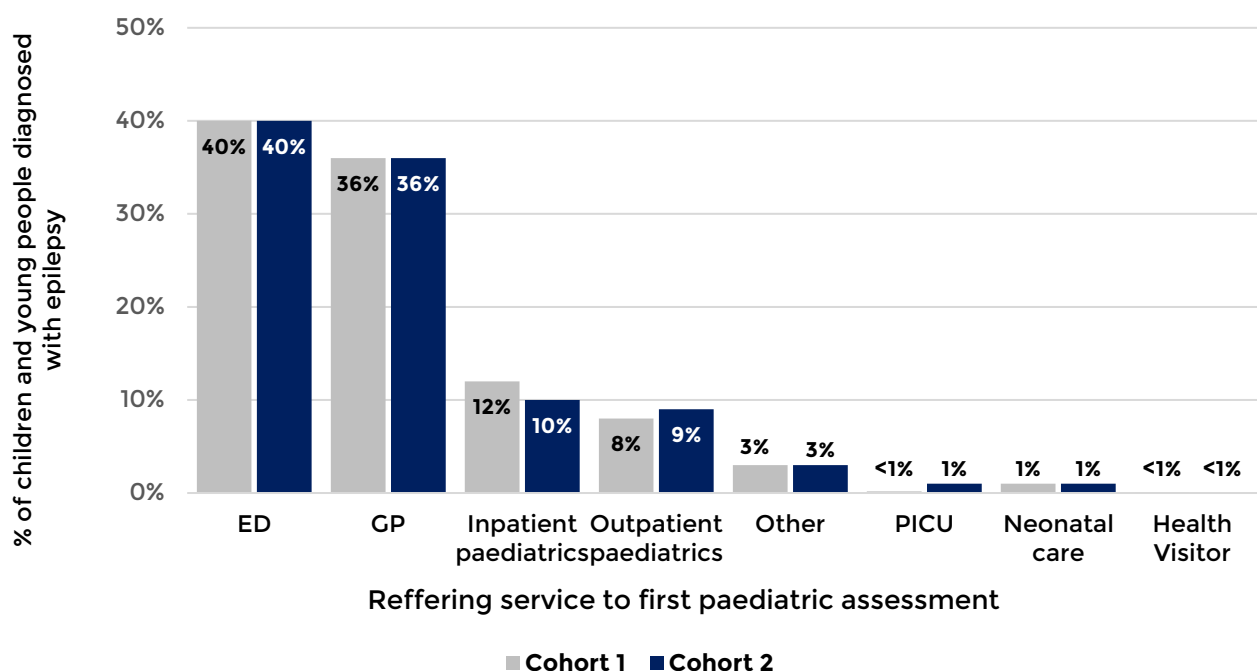


Figure 15: Referring service to first paediatric assessment in England and Wales.

Time since first referral to first paediatric assessment

17% (348/2106) of the children and young people diagnosed with epilepsy had not received input from a paediatrician with expertise in epilepsies.

11% (224/2106) of the children diagnosed with epilepsy had a date of referral to first paediatric assessment recorded as unknown.

<1% (9/2106) 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).

75% (1583/2106) of children and young people diagnosed with epilepsy had a valid date entered describing referral to first paediatric assessment.

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 2, **19% (392/2106)** 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 12a**).

The proportion of children and young people diagnosed with epilepsy that were seen by a paediatrician with expertise in epilepsy within 2 weeks of first referral in England and Wales increased from **16%** in cohort 1 to **19%** in cohort 2 (**Figure 16a**). There was a slight reduction in the proportion of children and young people seen by a paediatrician with expertise in epilepsies after 12 weeks in cohort 2 compared to cohort 1.

Table 12a: 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=2106)	19% (392/2106)	10% (211/2106)	16% (335/2106)	10% (217/2106)	6% (122/2106)	15% (306/2106)
England (N=2086)	19% (388/2086)	10% (210/2086)	16% (331/2086)	10% (215/2086)	6% (120/2086)	14% (301/2086)
Wales (N=20)	20% (4/20)	5% (1/20)	20% (4/20)	10% (2/20)	10% (2/20)	25% (5/20)

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

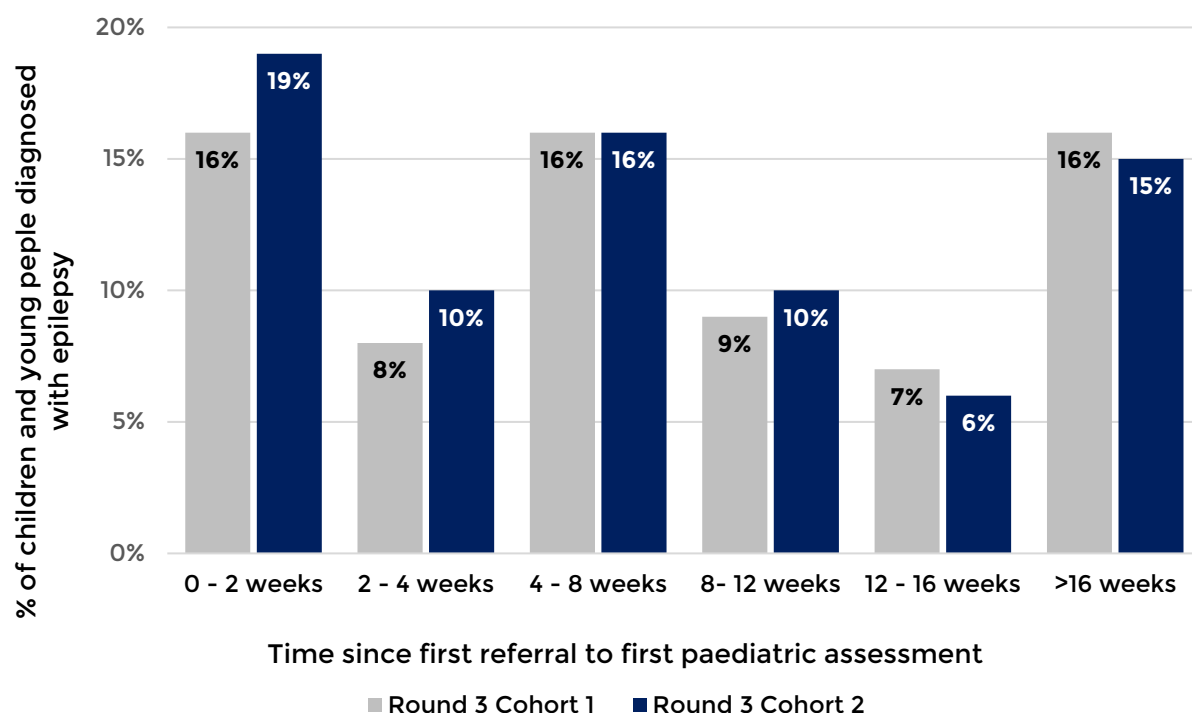


Figure 16a: Time since first referral to first paediatric assessment in England and Wales.

75% (1583/2106) of children and young people diagnosed with epilepsy had a valid date entered describing referral to first paediatric assessment. **Nineteen** of these could not be allocated to a deprivation quintile, because their postcodes were invalid or did not match lower super output area (LSOA). **74% (1564/2106)** were included for the analysis in **Table 12b**.

More than one quarter (**28%**) of children that were seen by paediatrician with expertise in epilepsy after sixteen weeks were in the most deprived quintile, **Figure 16b**.

Table 12b: Time in weeks to achieving input from paediatrician with expertise in epilepsy since the first referral to paediatrics by deprivation quintiles in England and Wales.

	Most deprived	Second most deprived	Third least deprived	Second least deprived	Least deprived
0 - 2 weeks (N=388)	26% (101/388)	21% (82/388)	22% (85/388)	15% (60/388)	15% (60/388)
2 - 4 weeks (N=207)	26% (54/207)	18% (37/207)	18% (38/207)	17% (36/207)	20% (42/207)
4 - 8 weeks (N=329)	25% (83/329)	19% (61/329)	23% (75/329)	17% (57/329)	16% (53/329)
8- 12 weeks (N=215)	36% (77/215)	19% (40/215)	18% (38/215)	14% (30/215)	14% (30/215)
12 - 16 weeks (N=120)	24% (29/120)	30% (36/120)	16% (19/120)	15% (18/120)	15% (18/120)
>16 weeks (N=305)	28% (85/305)	21% (63/305)	18% (54/305)	16% (48/305)	18% (55/305)

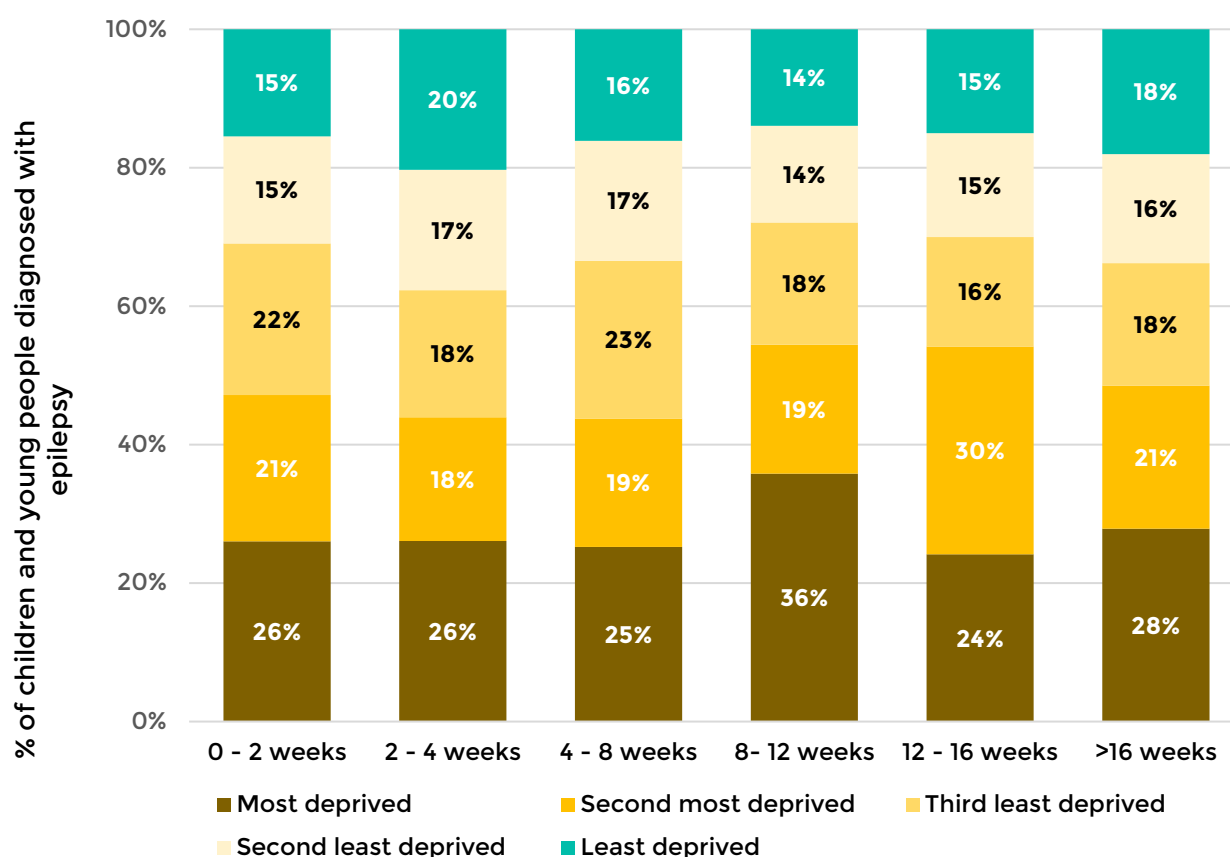


Figure 16b: Time since first referral to first paediatric assessment by deprivation quintile in England and Wales.

Age at first paediatric assessment

Figure 17 shows the number of children and young people diagnosed with epilepsy in cohort 2 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. There were more males than females diagnosed with epilepsy in cohort 2, **1160** males and **946** females.

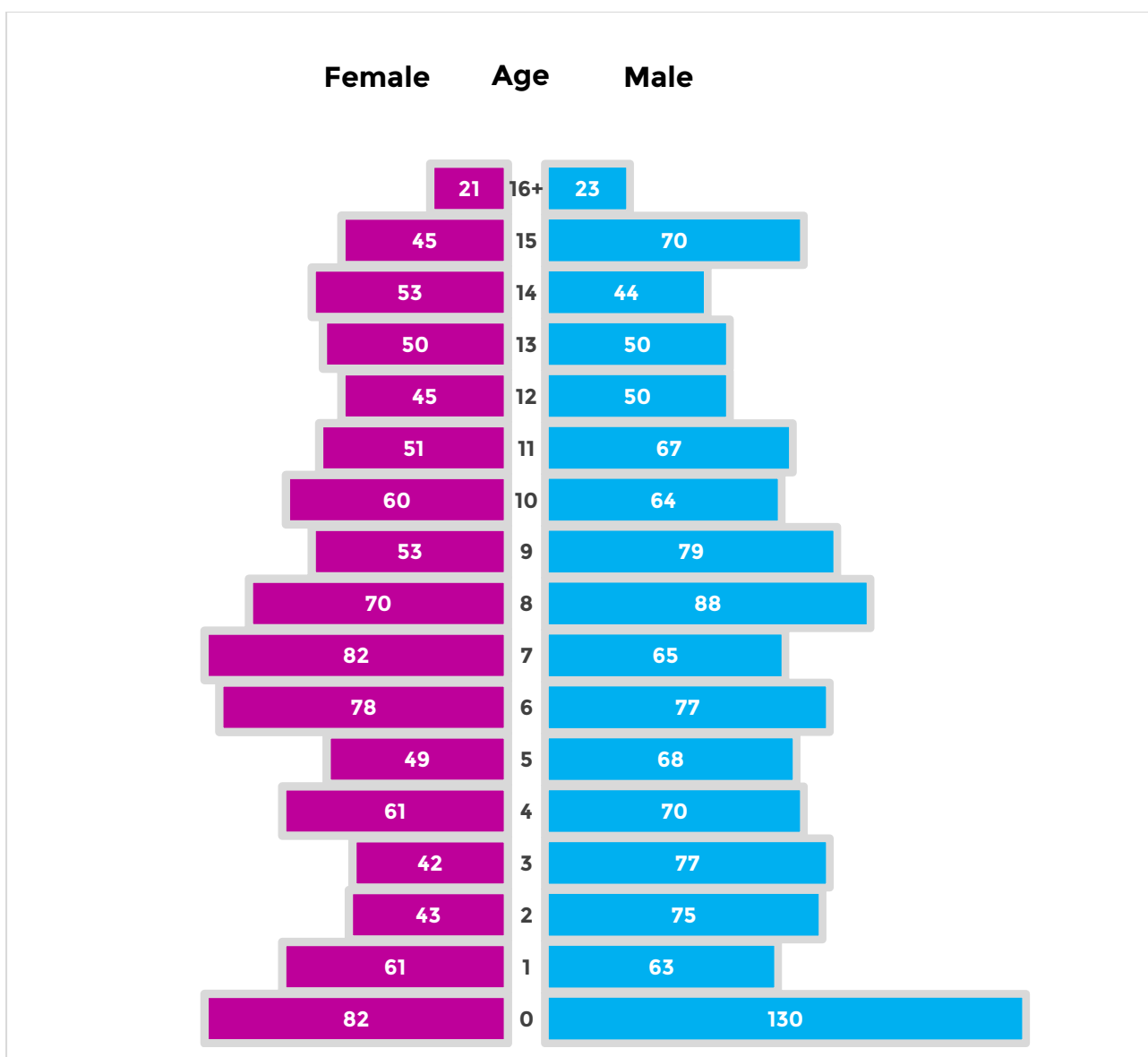


Figure 17: Numbers of children and young people diagnosed with epilepsy by age in years at first paediatric assessment and gender in England and Wales.

Setting of the first paediatric assessment

In England and Wales, **50% (1044/2106)** of children and young people diagnosed with epilepsy had their first paediatric assessment in an acute setting. An equal proportion of children and young people had their first assessment in non-acute setting **50% (1054/2106)** as shown on **Table 13**.

Figure 18 shows a comparison of the setting of first paediatric assessment in Round 1, Round 2 and Round 3, cohort 1 and cohort 2, in England and Wales. The proportion of children and young people diagnosed with epilepsy who had their first paediatric assessment in acute setting has been increasing across the cohorts.

Table 13: Setting of the first paediatric assessment by country.

Country	% Acute	% Non-acute	% Don't know
England and Wales (N=2106)	50% (1044/2106)	50% (1054/2106)	<1% (8/2106)
England (N=2086)	50% (1034/2086)	50% (1044/2086)	<1% (8/2086)
Wales (N=20)	50% (10/20)	50% (10/20)	0% (0/20)

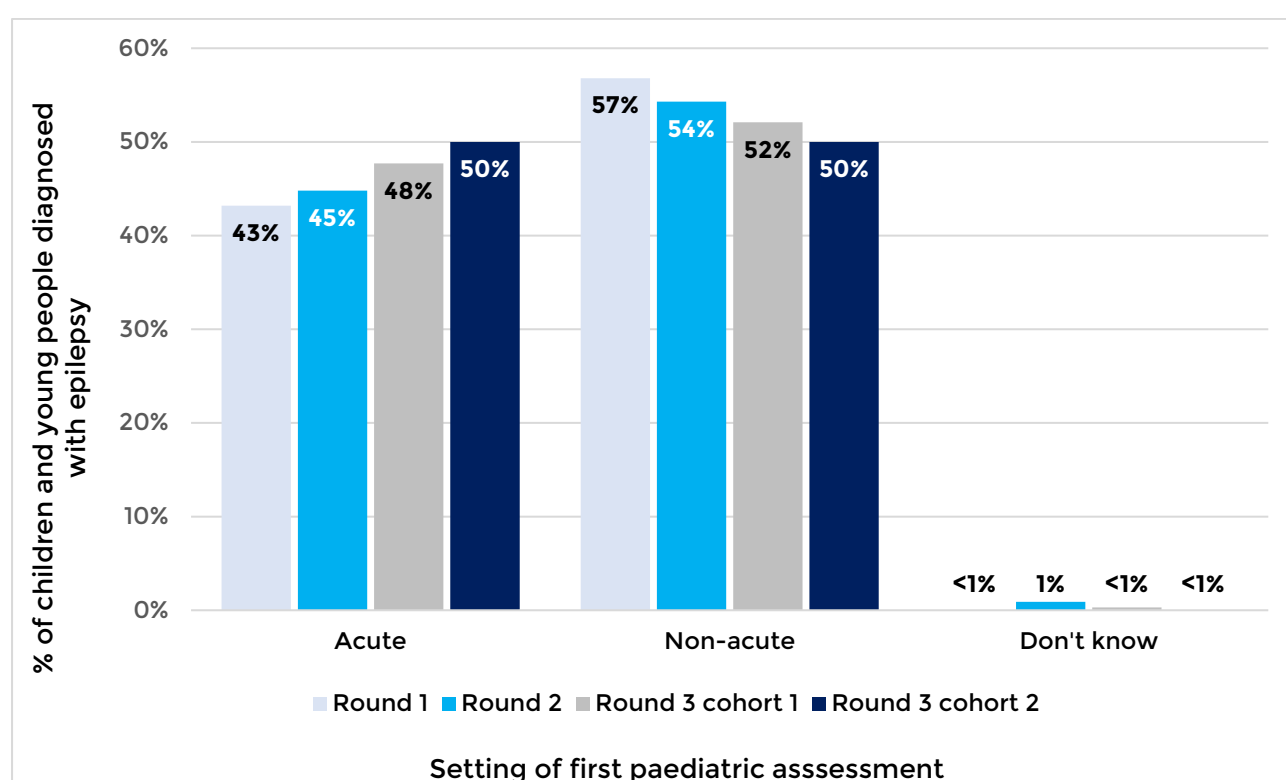


Figure 18: Setting of first paediatric assessment in Round 1, Round 2 and Round 3 cohort 1 and cohort 2 in England and Wales.

Appropriate first assessment

Performance indicator 4: Appropriate first paediatric assessment

In Round 3, cohort 2, **61% (1281/2106)** of children and young people diagnosed with epilepsy had appropriate first paediatric assessment, (**Table 14**). There was a slight reduction in the proportion of children and young people that had appropriate first paediatric assessment in cohort 2 (**61%**) compared to cohort 1 (**62%**). This indicator ranged from 0% to 100% and had an interquartile range of 44% to 76%.

Table 14: 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 Cohort 1	62% (685/1112)	60% (632/1051)	87% (53/61)
		Round 3 Cohort 2	61% (1281/2106)	61% (1264/2086)	85% (17/20)
4a	% children and young people with evidence of descriptions of episode	Round 3 Cohort 1	98% (1094/1112)	98% (1033/1051)	100% (61/61)
		Round 3 Cohort 2	99% (2077/2106)	99% (2057/2086)	100% (20/20)
4b	% children and young people with evidence of descriptions of age of child/timing of the first episode	Round 3 Cohort 1	81% (901/1112)	81% (846/1051)	90% (55/61)
		Round 3 Cohort 2	79% (1670/2106)	79% (1652/2086)	90% (18/20)
4c	% children and young people with evidence of descriptions of frequency	Round 3 Cohort 1	94% (1040/1112)	93% (979/1051)	100% (61/61)
		Round 3 Cohort 2	95% (1991/2106)	95% (1973/2086)	90% (18/20)
4d	% children and young people with evidence of descriptions of general examination	Round 3 Cohort 1	94% (1048/1112)	94% (987/1051)	100% (61/61)
		Round 3 Cohort 2	94% (1982/2106)	94% (1963/2086)	95% (19/20)

4e	% children and young people with evidence of descriptions of neurological examination	Round 3 Cohort 1	92% (1018/1112)	91% (959/1051)	97% (59/61)
		Round 3 Cohort 2	91% (1911/2106)	91% (1892/2086)	95% (19/20)
4f	% children and young people with evidence of description of developmental, learning or schooling progress	Round 3 Cohort 1	83% (918/1112)	82% (857/1051)	100% (61/61)
		Round 3 Cohort 2	83% (1743/2106)	83% (1723/2086)	100% (20/20)
4g	% children aged 3 years and over with evidence of consideration of emotional or behavioural problems	Round 3 Cohort 1	66% (734/1112)	65% (680/1051)	89% (54/61)
		Round 3 Cohort 2	68% (1435/2106)	68% (1420/2086)	75% (15/20)

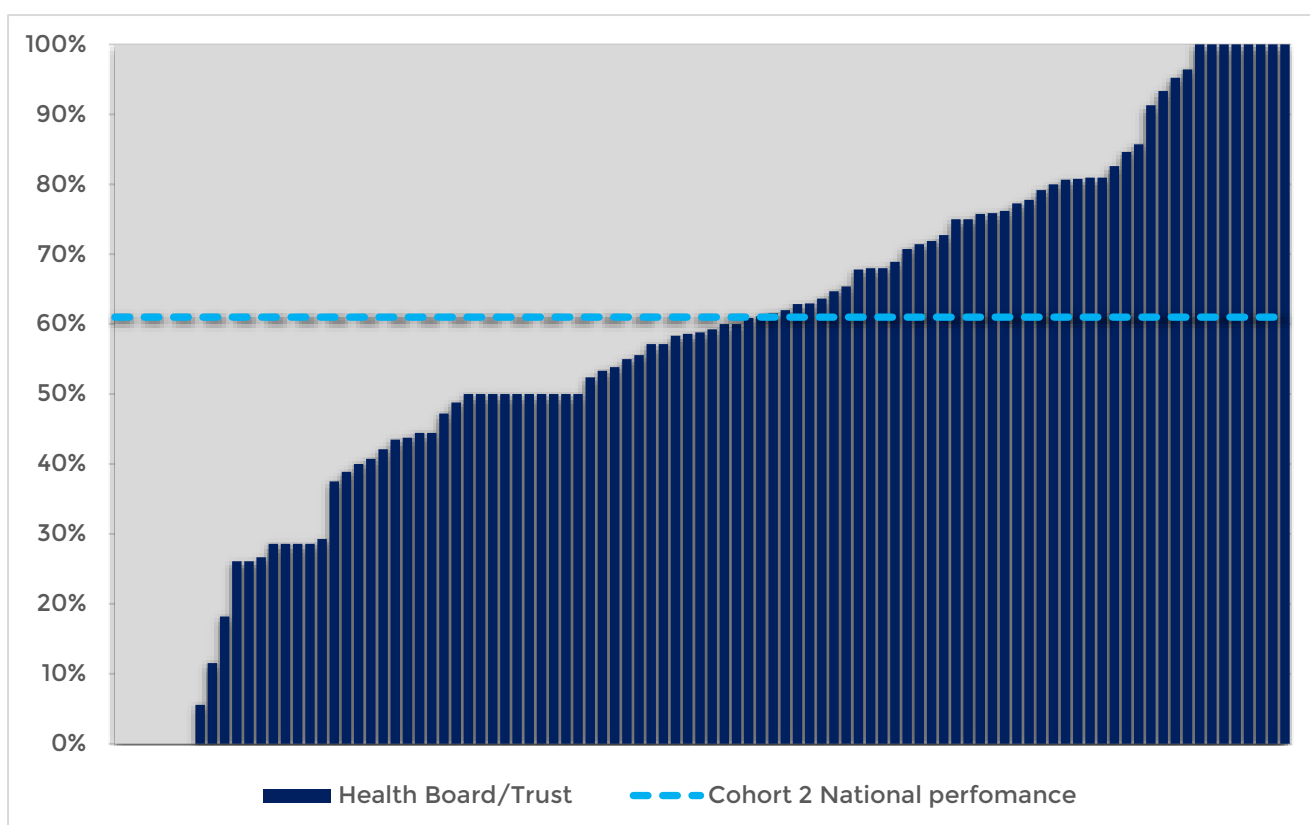


Figure 19: Appropriate first paediatric assessment by unit, Round 3, cohort 2

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 15 shows, **40** children and young people diagnosed with epilepsy had more than three seizures by year one in England and Wales.

Table 16 shows **92% (1948/2106)** of the children and young people diagnosed with epilepsy in England and Wales at one year, had an epileptic seizure defined. Some children had more than one seizure type identified.

In **13% (269/2106)** children and young people diagnosed with epilepsy, there were also episodes where there was uncertainty whether the seizures were epileptic or not. **1% (16/2106)** of children with epilepsy had non-epileptic seizures identified.

Table 15: Number of seizures in children diagnosed with epilepsy, Round 3, cohort 1 and cohort 2.

Country	Audit Round	1 seizure	2 seizures	3 seizures	More than 3 seizures
England and Wales	Cohort 1	82% (908/1112)	12% (137/1112)	4% (39/1112)	3% (28/1112)
	Cohort 2	83% (1739/2106)	13% (273/2106)	3% (54/2106)	2% (40/2106)

Table 16: Seizure type, Round 3, cohort 1 and cohort 2.

Country	Audit Round	% with epileptic seizures	% with non-epileptic seizures	% with uncertain seizures
England and Wales	Cohort 1	91% (1012/1112)	1% (10/1112)	15% (164/1112)
	Cohort 2	92% (1948/2106)	1% (16/2106)	13% (269/2106)

Epileptic seizure type

1% (16/2106) children and young people diagnosed with epilepsy had more than three epileptic seizures by year one in England and Wales (**Table 17**).

Table 17: Epileptic seizure type, Round 3, cohort 1 and cohort 2.

Country	Audit Round	1 epileptic seizure	2 epileptic seizures	3 epileptic seizures	More than 3 epileptic seizures
England and Wales	Cohort 1	78% (866/1112)	9% (99/1112)	2% (27/1112)	2% (20/1112)
	Cohort 2	80% (1688/2106)	10% (201/2106)	3% (59/2106)	1% (16/2106)

Figure 20 shows that in England and Wales, children and young people diagnosed with epilepsy:

- **47% (993/2106)** had generalised onset epileptic seizures,
- **35% (736/2106)** had focal onset epileptic seizures,
- **9% (196/2106)** had unknown onset epileptic seizures,
- **4% (83/2106)** had unclassified epileptic seizures.

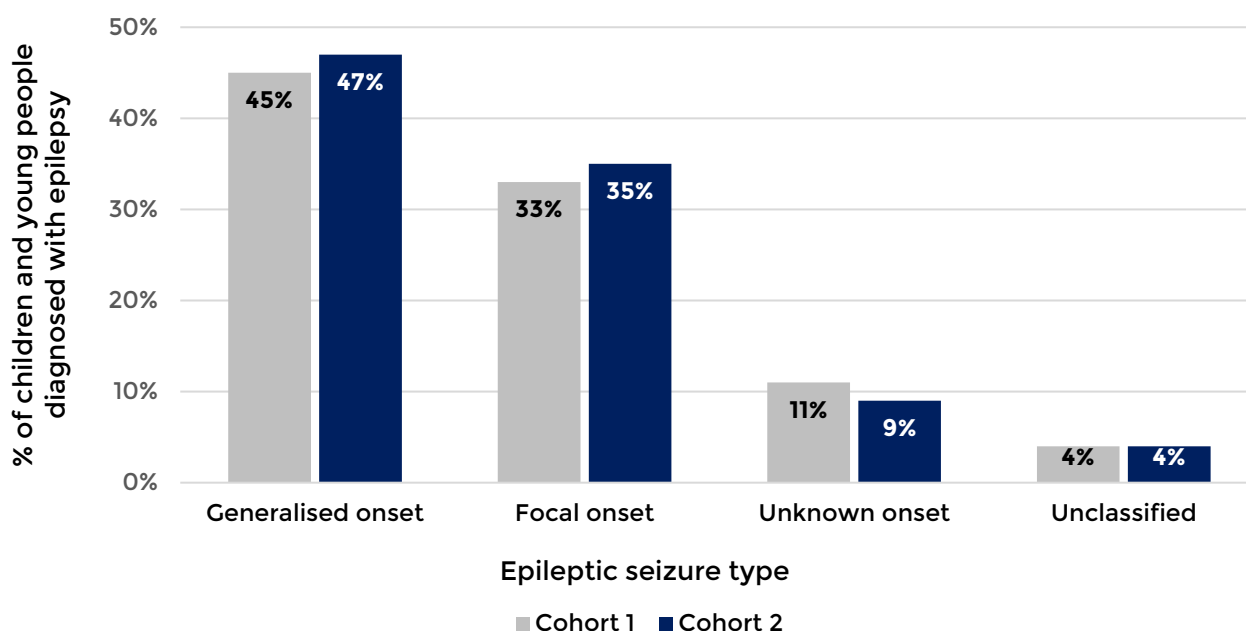


Figure 20: Percentage of children diagnosed with epilepsy by epileptic seizure type in England and Wales.

Focal onset

Table 18 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 **322 (15%)** children and young people who had impaired awareness focal onset seizures. This was the most common characteristic where a focal onset seizure was recorded in both cohorts.

Table 18: 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)	Round 3 cohort 2 (N=2106)
Impaired awareness	174 (16%)	322 (15%)
Focal to bilateral tonic-clonic	91 (8%)	170 (8%)
Clonic	66 (6%)	141 (7%)
Left	78 (7%)	136 (6%)
Tonic	56 (5%)	120 (6%)
Right	64 (6%)	106 (5%)
Behaviour arrest	35 (3%)	96 (5%)
Centro-temporal	51 (5%)	84 (4%)
Automatisms	33 (3%)	59 (3%)
Temporal	40 (4%)	54 (3%)
Sensory	18 (2%)	37 (2%)
Frontal	22 (2%)	37 (2%)
Other	12 (1%)	33 (2%)
Autonomic	11 (1%)	30 (1%)
Occipital	10 (1%)	25 (1%)
Parietal	*	20 (1%)
Epileptic spasms	5 (<1%)	15 (1%)
Myoclonic	*	15 (1%)
Emotional	5 (<1%)	13 (1%)
Cognitive	*	9 (<1%)
Atonic	7 (1%)	6 (<1%)
Gelastic	*	*
Hyperkinetic	*	*

* In accordance with information governance rules, potentially sensitive data based small numbers have been masked

Out of the **736** children and young people diagnosed with epilepsy with focal onset seizures in cohort 2, **44%** had impaired awareness seizures in England and Wales, (**Figure 21**). In cohort 1, out of the **370** of children and young people diagnosed with epilepsy with focal onset seizures, **47%** had impaired awareness seizures.

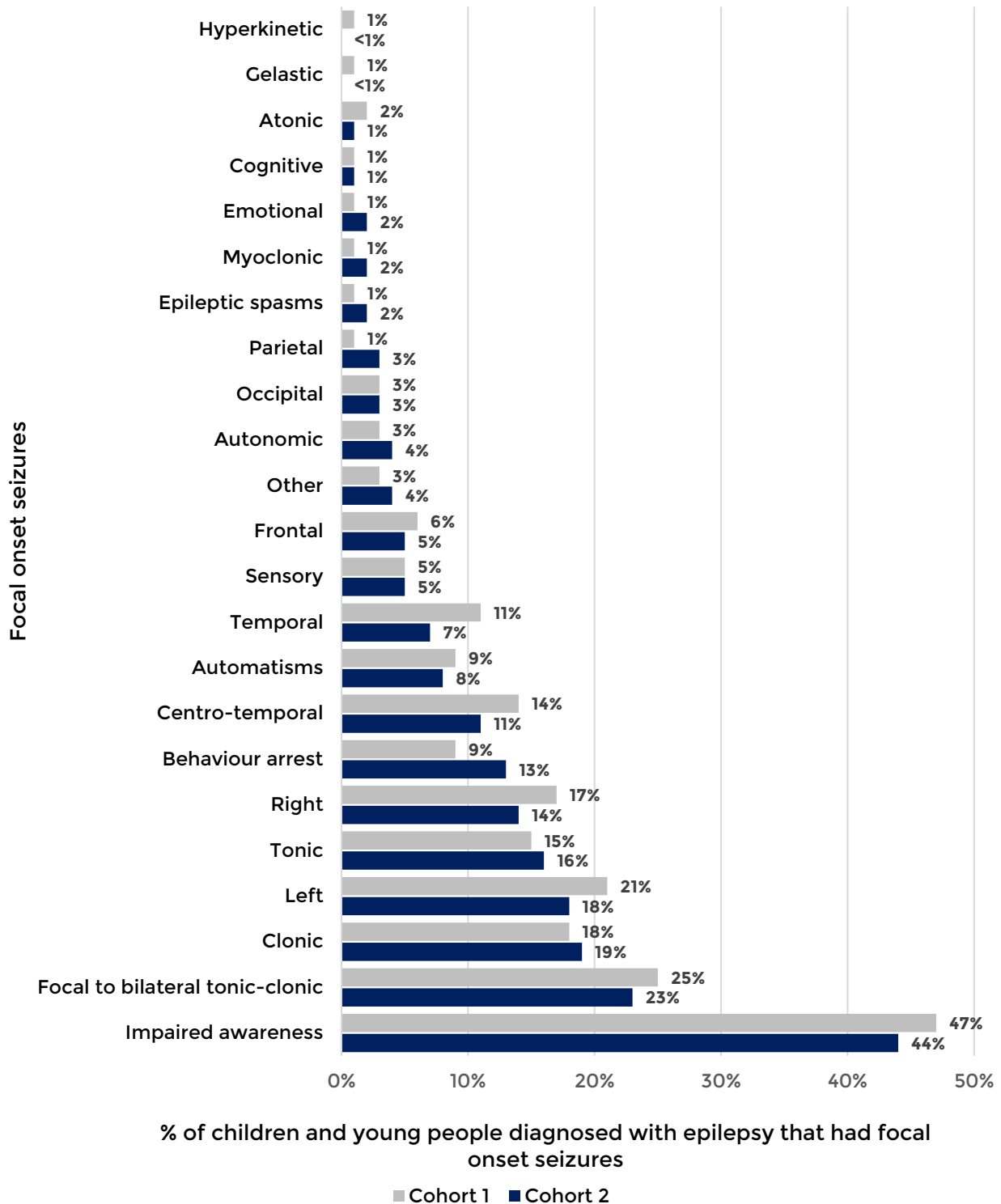


Figure 21: Percentage of children and young people diagnosed with epilepsy who had focal onset seizures in England and Wales, Round 3, cohort 1 and cohort 2.

Generalised onset

Table 19 shows the proportion of children and young people diagnosed with epilepsy who had generalised onset seizures during their first year of care in England and Wales. **475 (23%)** of children and young people diagnosed with epilepsy had generalised onset tonic-clonic seizures. This was the most common characteristic where a generalised onset seizure was recorded in both cohorts.

Table 19: 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)	Round 3 cohort 2 (N=2106)
Tonic-clonic	258 (23%)	475 (23%)
Typical absence	138 (12%)	312 (15%)
Myoclonic	42 (4%)	72 (3%)
Atypical absence	46 (4%)	65 (3%)
Epileptic spasms	14 (1%)	40 (2%)
Other	8 (1%)	24 (1%)
Tonic	24 (2%)	22 (1%)
Atonic	12 (1%)	17 (1%)
Myoclonic-tonic-clonic	11 (1%)	16 (1%)
Absence with eyelid myoclonia	10 (1%)	15 (1%)
Myoclonic absence	9 (1%)	15 (1%)
Clonic	*	*
Myoclonic-atonic	*	*

* In accordance with information governance rules, potentially sensitive data based small numbers have been masked

In cohort 2, out of the **993** children and young people diagnosed with epilepsy with generalised onset seizures, **48%**, had tonic-clonic seizures in England and Wales, **51%** in cohort 1. **Figure 22.**

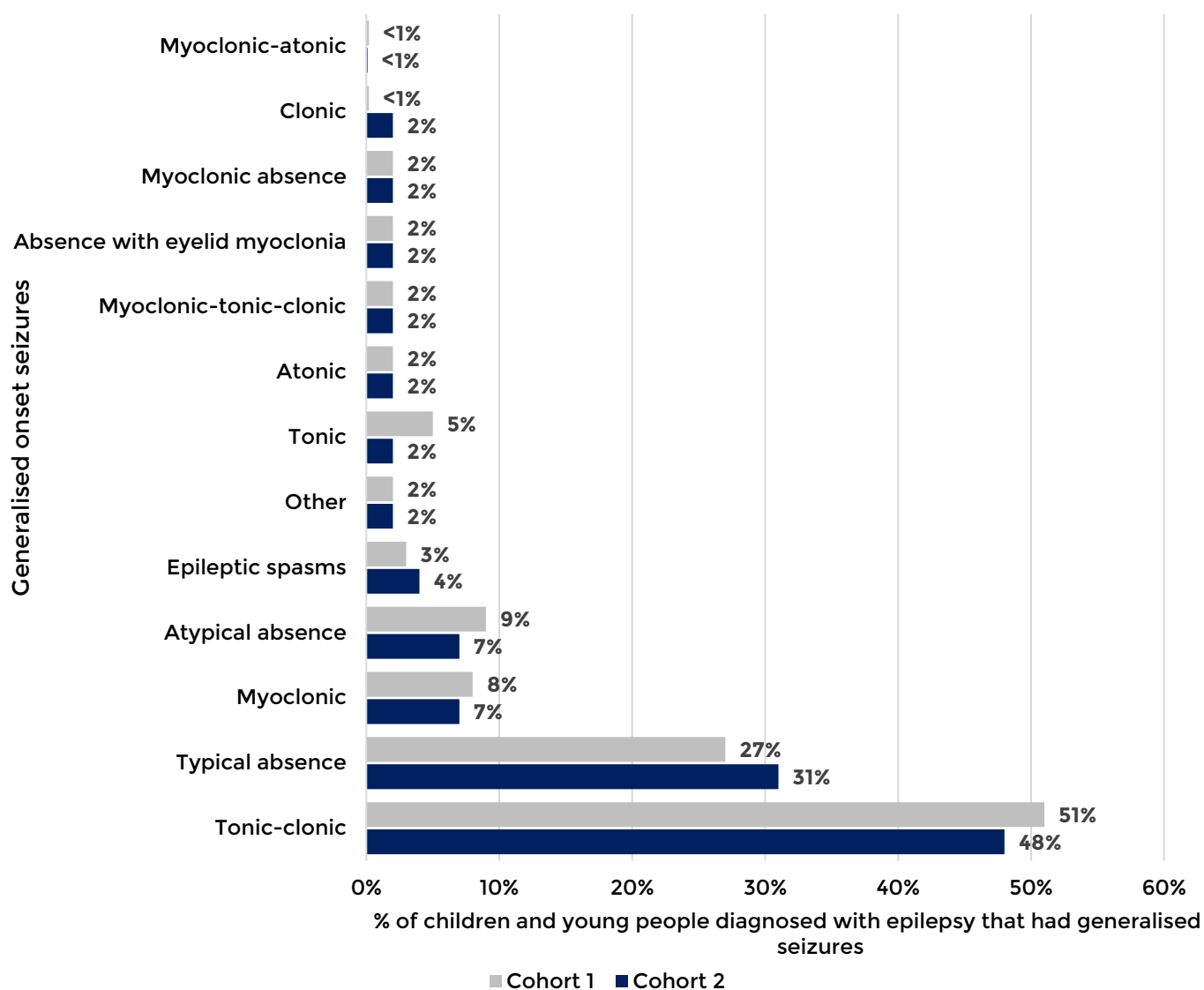


Figure 22: Percentage of children and young people diagnosed with epilepsy who had generalised onset seizures in England and Wales, Round 3, cohort 1 and cohort 2.

Unknown onset

Table 20 shows, 143 (7%) of children and young people diagnosed with epilepsy had unknown onset seizures in England and Wales in cohort 2. A similar proportion was reported in cohort 1.

Table 20: 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)	Round 3 cohort 2 (N=2106)
Tonic-clonic	85 (8%)	143 (7%)
Other	16 (1%)	30 (1%)
Behaviour arrest	25 (2%)	21 (1%)
Epileptic spasms	11 (1%)	13 (1%)

Out of the **196** children and young people diagnosed with epilepsy with unknown onset seizures, **73%** had tonic-clonic seizures in England and Wales in cohort 2, compared to **68%** in cohort 1. (Figure 23).

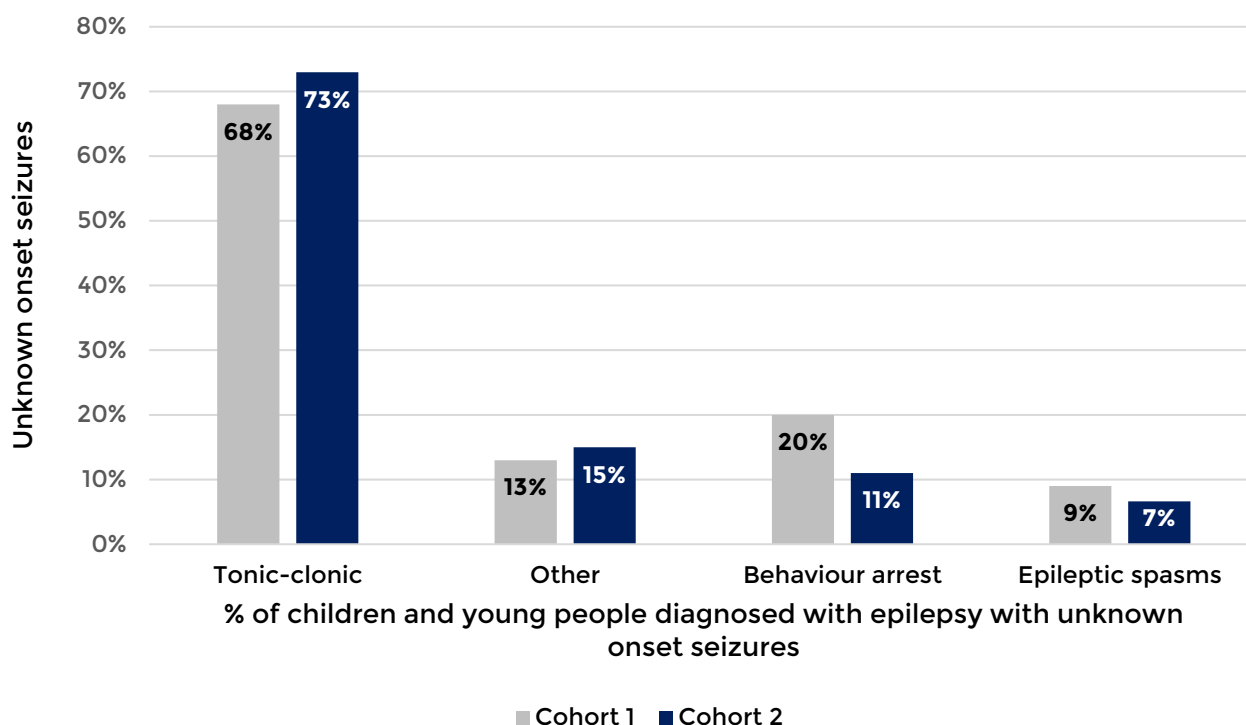


Figure 23: Percentage of children and young people diagnosed with epilepsy that had unknown onset seizures in England and Wales.

Non-epileptic seizure type

There were **16** children and young people diagnosed with epilepsy who had non-epileptic seizures. **3 (19%)** of the children and young people diagnosed with epilepsy had non-epileptic seizures and behavioural, psychological or psychiatric disorders. **3 (19%)** had non-epileptic seizures and syncope and anoxic Seizures.

Electroclinical syndrome

914 children and young people diagnosed with epilepsy had International League Against Epilepsy (ILAE) classification. **Three** children had more than one International League Against Epilepsy (ILAE) classification. ILAE classifications are shown in **Figure 24**, where the electroclinical syndrome was recorded for at least one child or young person.

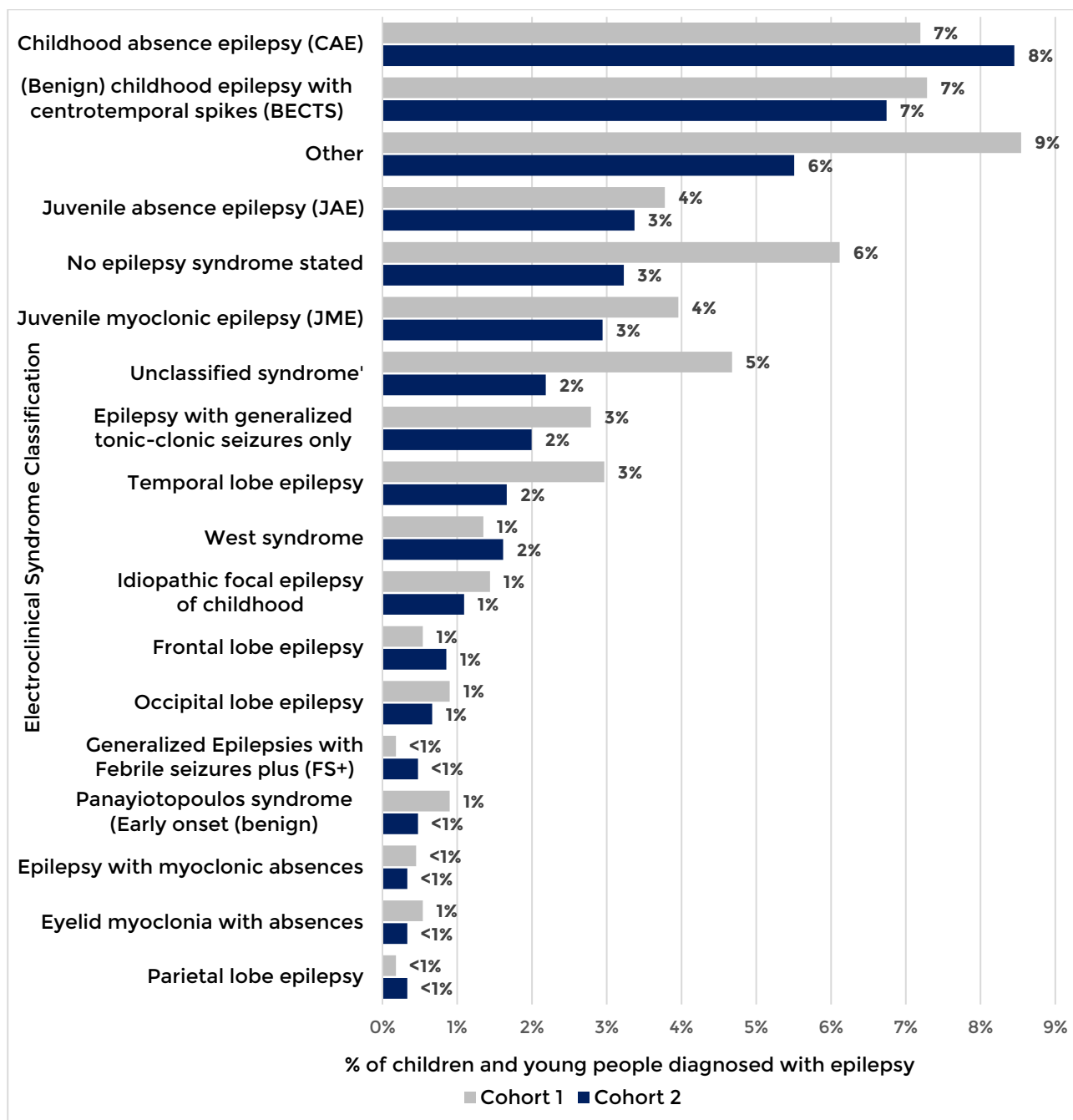


Figure 24: Percentage of children and young people diagnosed with epilepsy by electroclinical syndrome in England and Wales, Round 3, cohort 1 and cohort 2.

Certain categories are not shown in **Figure 24** as there were very few children and young people in those categories. These are: Early myoclonic encephalopathy, Lennox-Gastaut syndrome, Dravet syndrome, Gelastic seizures due to hypothalamic hamartoma, Familial focal epilepsy with variable foci, Migrating partial (focal) seizures of infancy, Late onset childhood occipital epilepsy (Gastaut type), Landau-Kleffner syndrome, Progressive myoclonus (myoclonic), Autosomal dominant nocturnal frontal lobe epilepsy (ADNFLE), Doose syndrome, Benign familial neonatal seizures, Visual sensitive epilepsies, Childhood epilepsy with occipital paroxysms, Reflex epilepsies, Ohtahara syndrome, (Benign) Myoclonic epilepsy in infancy, Benign infantile seizures.

Performance indicator 5: Seizure formulation

In Round 3, cohort 2, **91% (1911/2106)** of children and young people diagnosed with epilepsy had an appropriate seizure classification in the first year of care. Appropriate seizure formulation was defined as having selected an International League Against Epilepsy (ILAE) seizure classification (all ILAE seizure types or 'unclassified'). There was an increase in the proportion of children and young people diagnosed with epilepsy that had appropriate seizure classification in cohort 2 (**91%**) compared to cohort 1 (**88%**), **Table 21**. At a Health Board and Trust level, this indicator ranged from 33% to 100% and had an interquartile range of 87% to 100%.

Table 21: Seizure formulation across Rounds 1, 2, 3, cohort 1 and cohort 2.

Performance indicator: 5		Audit Round	England and Wales	England	Wales
Seizure formulation	% of children and young people with epilepsy with appropriate seizure classification at first year.	Round 1	87% (1318/1516)	87% (1235/1423)	89% (83/93)
		Round 2	95% (1040/1096)	95% (973/1019)	94% (67/77)
		Round 3, Cohort 1	88% (979/1112)	87% (919/1051)	98% (60/61)
		Round 3, Cohort 2	91% (1911/2106)	91% (1893/2086)	90% (18/20)

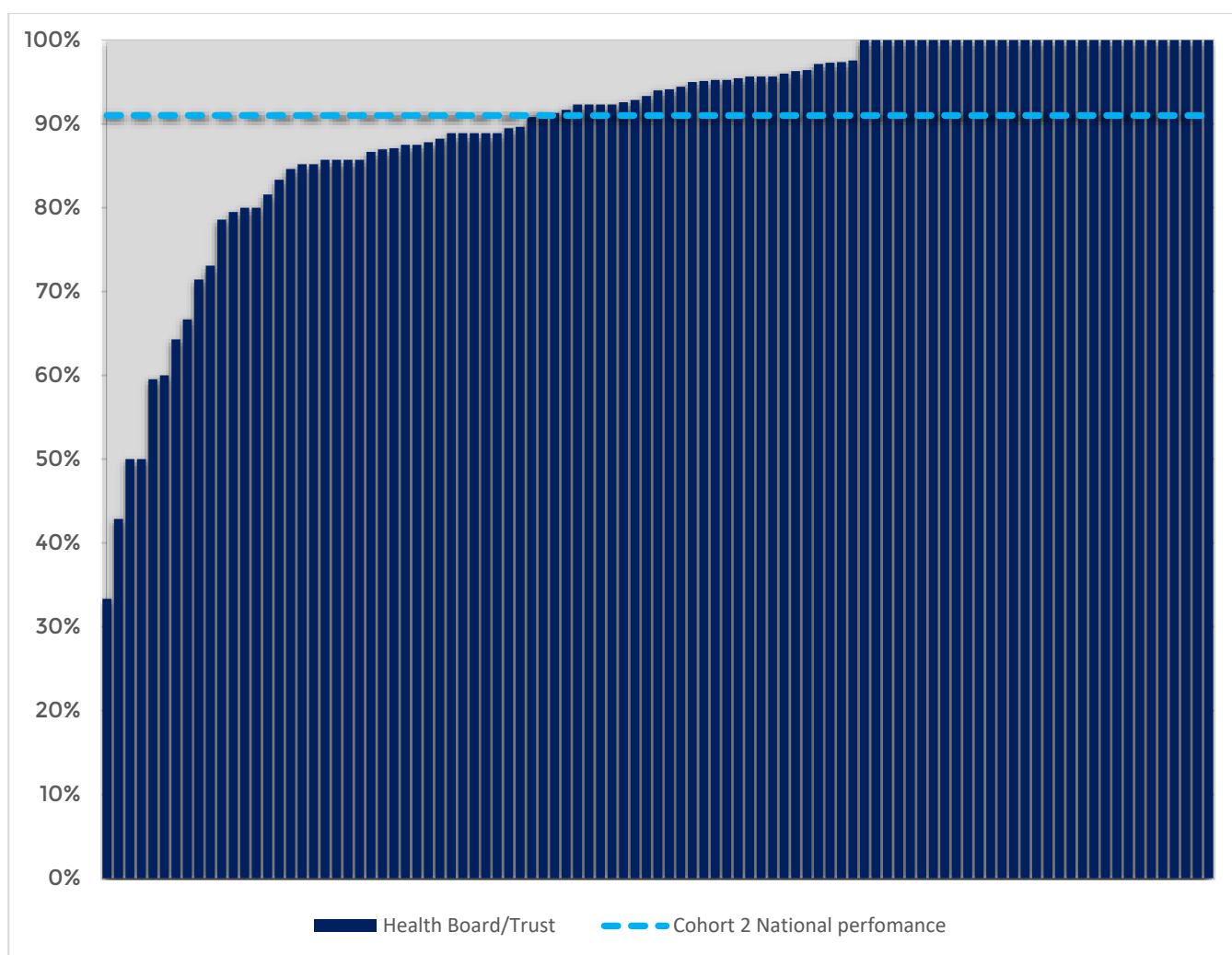


Figure 25: Seizure formulation, by Health Board and Trust, Round 3, cohort 2.

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

In cohort 2, **4% (74/2106)** of children and young people in England and Wales diagnosed with epilepsy had a genetic seizure cause. **6% (134/2106)** had a structural seizure cause. **11% (238/2106)** had seizure cause recorded as unknown (**Table 22**).

Table 22: Percentage of children and young people diagnosed with epilepsy by seizure cause in England and Wales.

Seizure Cause	Round 3 cohort 1 (N=1112)	Round 3 cohort 2 (2106)
Genetic	31 (3%)	74 (4%)
Immune	*	*
Infectious	10 (1%)	*
Metabolic	*	10(<1%)
Not known	221 (20%)	238(11%)
Structural	84 (8%)	134(6%)

* In accordance with information governance rules, potentially sensitive data based small numbers have been masked

Of the **74** children with genetic seizure cause, **25 (34%)** had chromosomal abnormality, **46 (62%)** had genetic abnormality and fewer than five had Angelman Syndrome or Rett Syndrome.

Out of the **134** children and young people diagnosed with a structural seizure cause of their epilepsy, **29%** had a vascular cause (e.g. arterial ischaemic stroke), (**Figure 26**). The percentage of children with traumatic brain injury structural seizure cause is higher in cohort 2 (13%) compared to cohort 1 (2%).

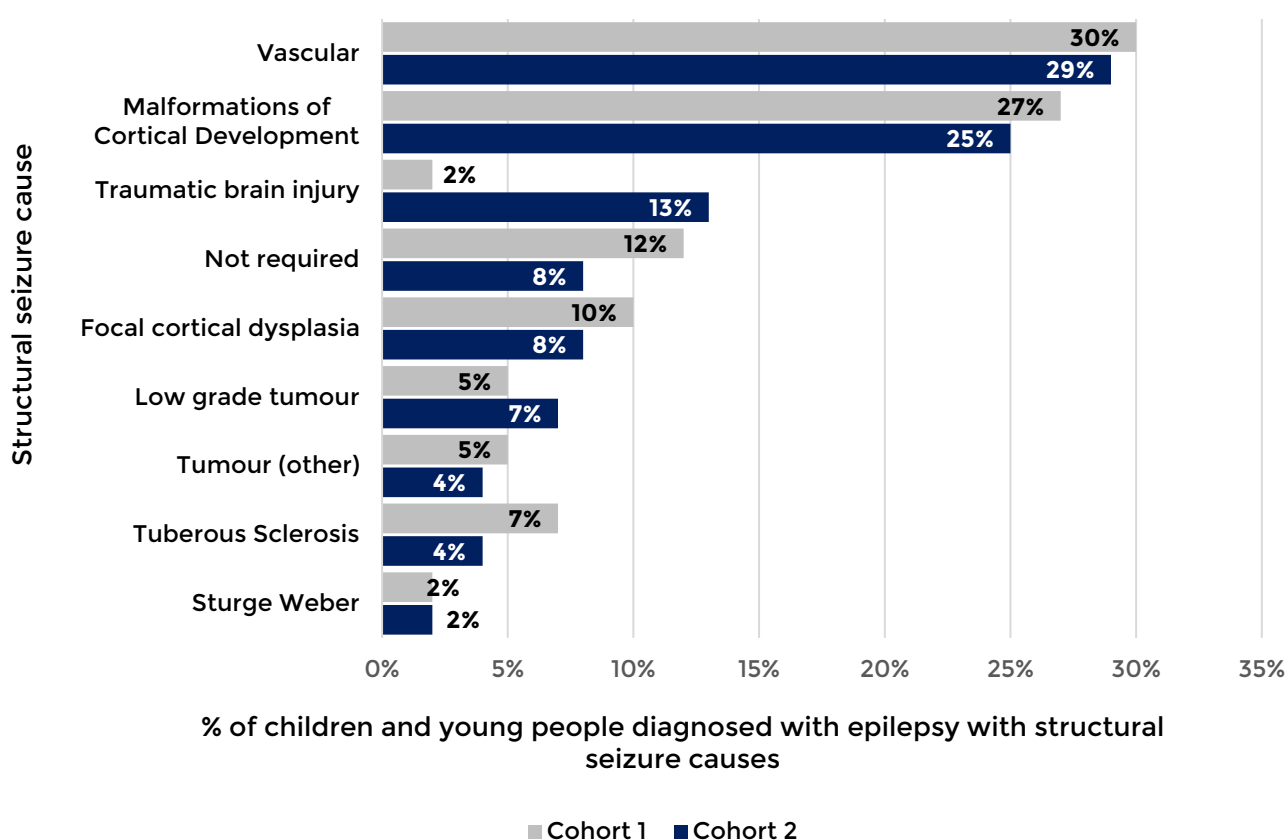


Figure 26: Percentage of children and young people diagnosed with epilepsy who had structural seizure cause.

Convulsive seizures

Convulsive epileptic seizures

In cohort 2, **62% (1309/2106)** of children and young people diagnosed with epilepsy had convulsive seizures, **38% (797/2106)** did not have convulsive seizures in England and Wales, **Table 23**.

Figure 27 shows the percentage of children and young people diagnosed with epilepsy by convulsive seizures in England and Wales by cohort. The proportion of children and young people diagnosed with epilepsy with convulsive seizures was slightly lower in cohort 2 (**62%**) compared to cohort 1 (**63%**).

Table 23: Convulsive epileptic seizures in children and young people diagnosed with epilepsy by country.

Country	% with convulsive seizures	% with no convulsive seizures
England and Wales(N=2106)	62% (1309/2106)	38% (797/2106)
England (N=2086)	62% (1300/2086)	38% (786/2086)
Wales (N=20)	45% (9/20)	55% (11/20)

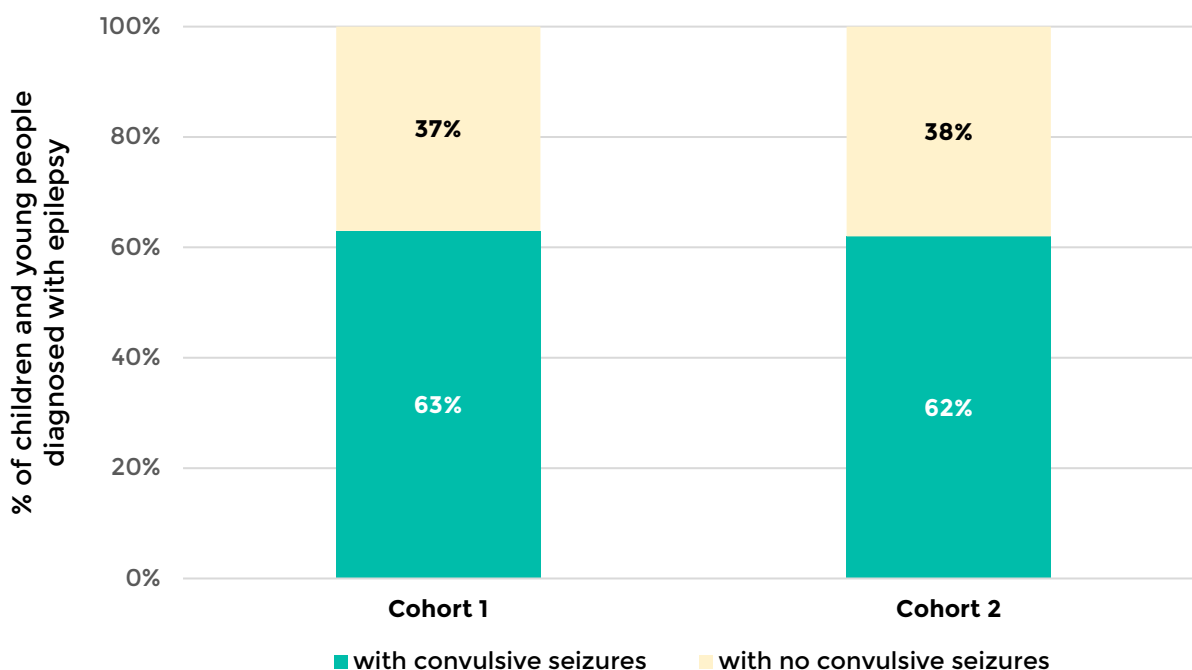


Figure 27: Percentage of children and young people diagnosed with epilepsy /with no convulsive epileptic seizures in England and Wales by Round 3 cohort 1 and cohort 2.

Prolonged generalised convulsive seizures

In cohort 2, **16% (341/2106)** of the children and young people diagnosed with epilepsy, experienced prolonged generalised 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 generalised convulsive seizures or not in **4% (82/2106)** of children and young people (**Table 24**).

Figure 28 shows the percentage of children and young people diagnosed with epilepsy by prolonged generalised convulsive epileptic seizures in England and Wales in Round 3. The proportion of children with generalised convulsive seizures was similar in cohorts 1 and 2.

Table 24: Prolonged generalised convulsive epileptic seizures in children and young people diagnosed with epilepsy in cohort 2.

Country	% yes	% no	% uncertain
England and Wales (N=2106)	16% (341/2106)	80% (1683/2106)	4% (82/2106)

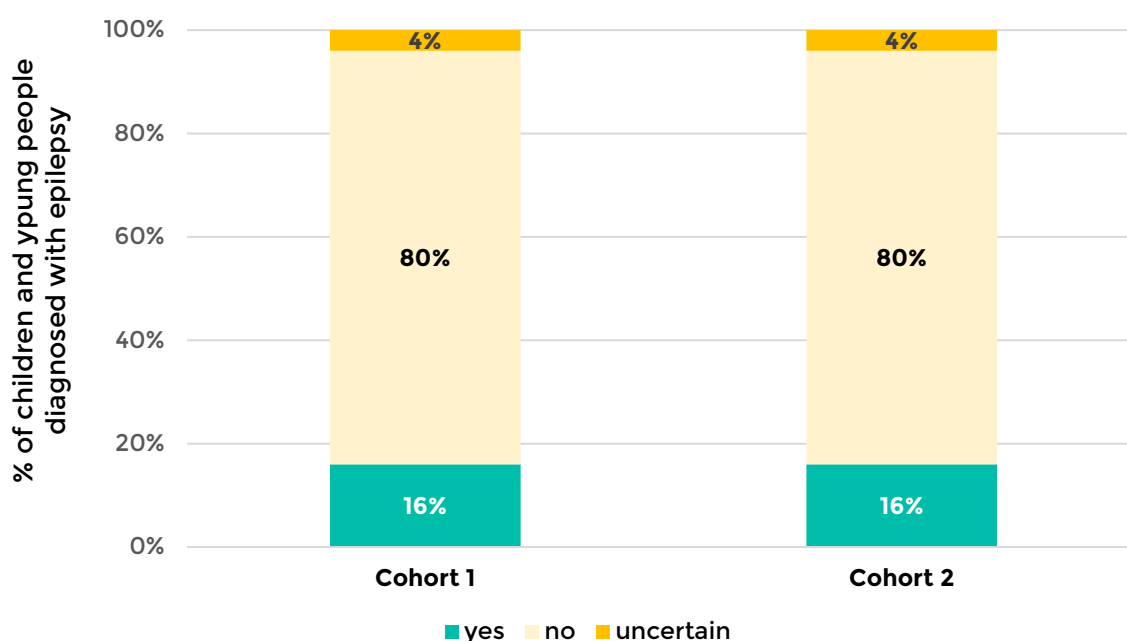


Figure 28: Percentage of children and young people diagnosed with epilepsy by prolonged generalised convulsive epileptic seizures in England and Wales by Round 3 cohort 1 and cohort 2.

Prolonged focal convulsive seizures

In cohort 2, **10% (204/2106)** 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 **6% (127/2106)** of children and young people (**Table 25**).

Figure 29 shows the percentage of children and young people diagnosed with epilepsy by prolonged generalised convulsive epileptic seizures in England and Wales in Round 3. The proportion of children with focal convulsive seizures was similar in cohorts 1 and 2.

Table 25: Prolonged focal convulsive epileptic seizures in children and young people diagnosed with epilepsy by country in cohort 2.

Country	% yes	% no	% uncertain
England and Wales (N=2106)	10% (204/2106)	84% (1775/2106)	6% (127/2106)

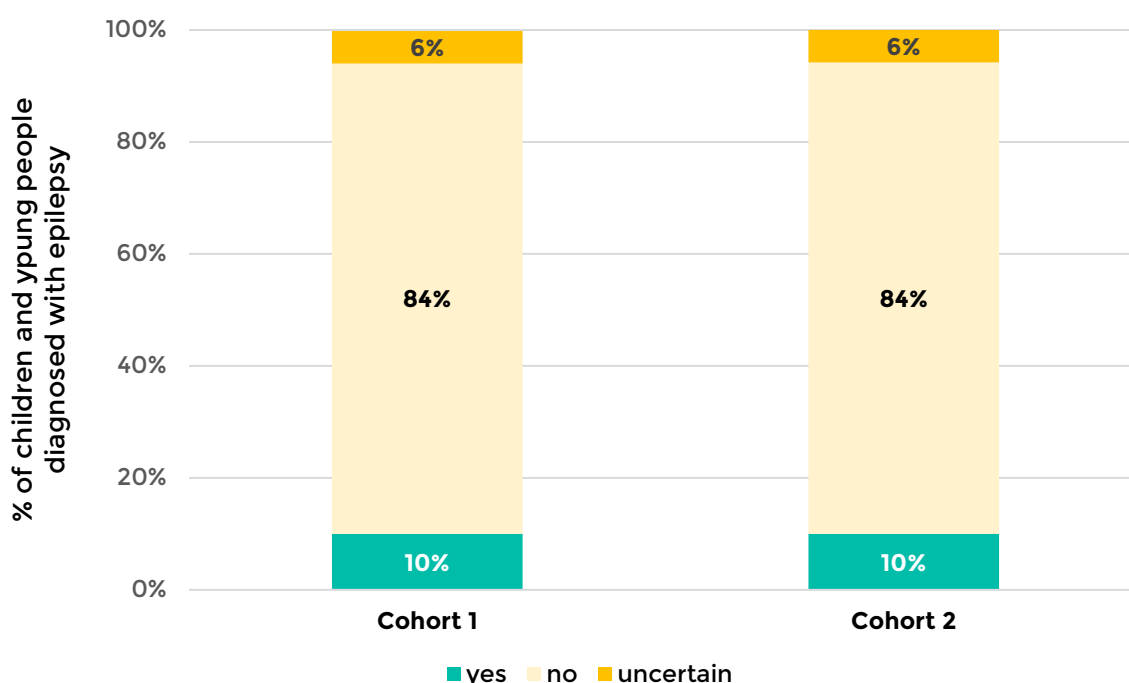


Figure 29: Percentage of children and young people diagnosed with epilepsy by prolonged focal convulsive epileptic seizures in England and Wales by Round 3 cohort 1 and cohort 2.

Family history of epilepsy

In cohort 2, **25% (534/2106)** of children and young people in England and Wales diagnosed with epilepsy had a family history of epilepsy. **75% (1572/2106)** did not have any family history of epilepsy (Table 26).

Figure 30 shows the percentage of children and young people diagnosed with epilepsy by family history of epilepsy in England and Wales in Round 3. The proportion of children and young people diagnosed with epilepsy and with a family history of epilepsy was slightly lower in cohort 2 (**25%, 534/2106**) compared to cohort 1 (**27%, 298/1112**).

Table 26: 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=2106)	25% (534/2106)	75% (1572/2106)
England (N=2086)	25% (526/2086)	75% (1560/2086)
Wales (N=20)	40% (8/20)	60% (12/20)

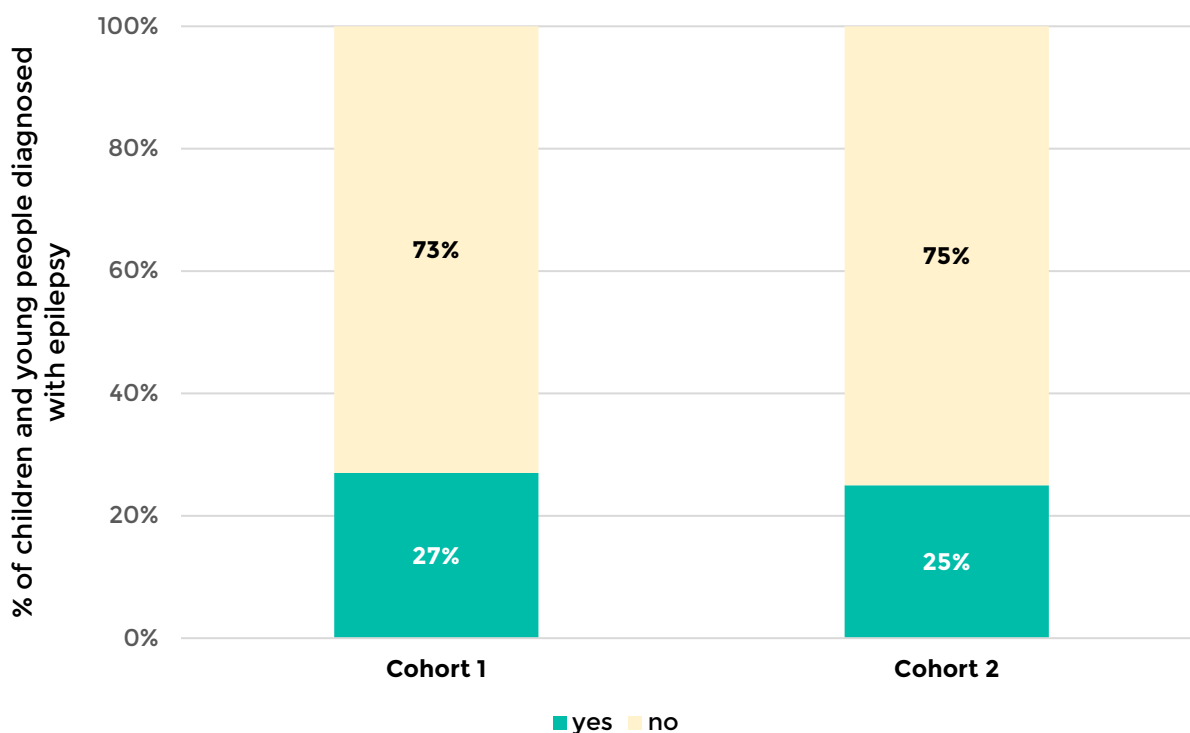


Figure 30: Percentage of children and young people diagnosed with epilepsy with/with no family history of epilepsy in England and Wales by Round 3 cohort 1 and cohort 2.

Neurodisability or neurodevelopmental problems

In Round 3 cohort 2, **22% (469/2106)** of children and young people diagnosed with epilepsy had one or more neurodisability or neurodevelopmental problem identified during their first year of care. There were **3% (66/2106)** who had more than one type of neurodisability/neurodevelopmental problem. The most common neurodisability/neurodevelopmental problems in children in cohort 2 were autistic spectrum disorder **7% (142/2106)** and intellectual disability/global development delay/learning disability, **6% (131/2106)** as shown in **Table 27**. **Figure 31** shows a breakdown of the neurodisability or neurodevelopmental problems among children diagnosed with epilepsy in Round 3.

Table 27: Neurodisability/neurodevelopmental problems among children diagnosed with epilepsy in Round 3 cohort 2.

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 and Wales (N=2106)	7% (142/2106)	3% (59/2106)	<1% (10/2106)	2% (46/2106)	2% (36/2106)	6% (131/2106)	<1% (5/2106)	<1% (6/2106)	2% (42/2106)	3% (61/2106)
England (N=2086)	7% (142/2086)	3% (59/2086)	<1% (10/2086)	2% (46/2086)	2% (36/2086)	6% (131/2086)	<1% (5/2086)	<1% (6/2086)	2% (42/2086)	3% (61/2086)
Wales (N=20)	0% (0/20)	0% (0/20)	0% (0/20)	0% (0/20)	0% (0/20)	0% (0/20)	0% (0/20)	0% (0/20)	0% (0/20)	0% (0/20)
BRPNF (N=87)	*	*	0% (0/87)	*	0% (0/87)	*	0% (0/87)	0% (0/87)	*	*
CEWT (N=153)	8% (12/153)	*	0% (0/153)	*	*	7% (11/153)	*	0% (0/153)	*	4% (6/153)
EPEN (N=98)	*	0% (0/98)	0% (0/98)	0% (0/98)	*	9% (9/98)	0% (0/98)	0% (0/98)	*	*
EPIC (N=224)	5% (12/224)	8% (17/224)	*	3% (6/224)	4% (8/224)	6% (13/224)	*	*	3% (6/224)	4% (10/224)
NTPEN (N=191)	15% (29/191)	*	*	*	*	6% (11/191)	0% (0/191)	0% (0/191)	4% (8/191)	5% (9/191)
NWEIG (N=124)	6% (7/124)	6% (7/124)	0% (0/124)	*	*	7% (9/124)	*	*	*	*
ORENG (N=123)	4% (5/123)	*	0% (0/123)	*	0% (0/123)	4% (5/123)	0% (0/123)	0% (0/123)	*	*
PENNEC (N=245)	6% (15/245)	2% (6/245)	*	4% (9/245)	1% (2/245)	7% (16/245)	*	0% (0/245)	*	*
SETPEG (N=90)	8% (7/90)	*	*		0% (0/90)	7% (6/90)	0% (0/90)	0% (0/90)	*	*
SWEP (N=15)	0% (0/15)	0% (0/15)	0% (0/15)	0% (0/15)	0% (0/15)	0% (0/15)	0% (0/15)	0% (0/15)	0% (0/15)	0% (0/15)
SWIPE (N=189)	5% (9/189)	3% (6/189)	*	*	3% (5/189)	11% (20/189)	*	*	3% (6/189)	3% (6/189)
SWTPEG (N=223)	5% (12/223)	2% (5/223)	0% (0/223)	*	4% (9/223)	4% (9/223)	0% (0/223)	0% (0/223)	3% (6/223)	4% (8/223)
TEN (N=117)	10% (12/117)	*	0% (0/117)	0% (0/117)	*	*	0% (0/117)	0% (0/117)	*	*
WPNN (N=58)	9% (5/58)	*	0% (0/58)	*	*	*	0% (0/58)	0% (0/58)	0% (0/58)	*
YPEN (N=169)	5% (9/169)	*	*	5% (9/169)	*	7% (11/169)	0% (0/169)	*	*	4% (6/169)

** In accordance with information governance rules, potentially sensitive data based small numbers have been masked*

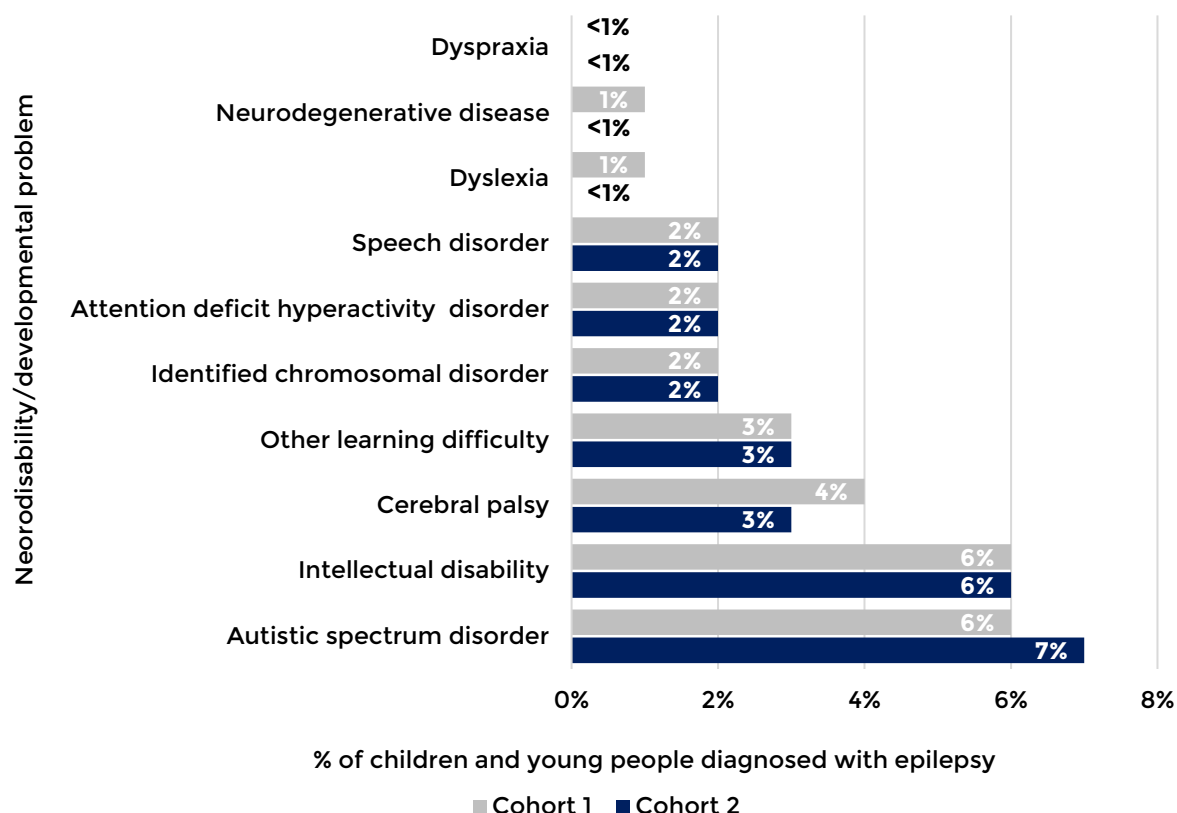


Figure 31: Neurodisability/neurodevelopmental problems among children diagnosed with epilepsy.

6% (131/2106) children and young people diagnosed with epilepsy in cohort 2 had intellectual disability/global development delay/learning disability. Of these, **31% (41/131)** were severe or profound compared to **23% (16/70)** in cohort 1 (**Table 28**).

Table 28: 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 in cohort 1	% of children and young people with intellectual disability in cohort 2
Mild	23% (16/70)	22% (29/131)
Moderate	54% (38/70)	47% (61/131)
Severe or Profound	23% (16/70)	31% (41/131)

Mental health conditions

4% (84/2106) of children and young people had an identified mental health condition in cohort 2. **<1% (5/2106)** of children and young people had more than one mental health condition identified. **1% (13/2106)** had a mood disorder, **1% (25/2106)** had an anxiety disorder and a further **2% (33/2106)** had other mental health concerns (**Table 29**).

Other responses included:

- Sleep issues, survives on very little sleep
- Alcohol
- Sensory processing disorder
- Complex social background giving rise to emotional difficulties
- Aggressive behaviour
- Severe learning difficulties
- Suffers with anxiety, fickle behaviours, and mood swings
- Referred to CAMHS for behavioural concerns. No formal diagnosis
- Auditory hallucinations
- Disturbed, confused
- Eating disorder
- Anxiety or stress triggering episodes - referred to psychology for input (rejected)
- Anxiety - referred to psychology and YPAS details given for family to self-refer
- Possible autism, self-harm
- PTSD or anxiety - referred to YPAS / CAMHS / psychology having FU
- Having assessment for behavioural problems by CAMHS

5% (68/1358) of children and young people between the age of 5-15 years and diagnosed with epilepsy in cohort 2, had an identified mental health condition(s) by their first year of care in England and Wales.

27% (18/68) of these had formal development assessment compared to **23% (10/43)** in cohort 1. **21% (14/68)** had formal cognitive assessment by their first year of care, which was similar in cohort 1 (**21%, 9/43**) (**Table 30**).

50% (5/10) of children and young people diagnosed with emotional/behavioural problems had Oppositional Defiant Disorder. **50% (5/10)** had a Conduct Disorder.

Table 29: 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 in cohort 2	% of children and young people ages 5-15 with mental health conditions in cohort 2	% of children and young people ages 5-15 with mental health conditions in cohort 1
Mood disorder	1% (13/2106)	1% (11/1358)	*
Anxiety disorder	1% (25/2106)	2% (24/1358)	1% (8/701)
Emotional/behavioural	<1% (10/2106)	1% (8/1358)	1% (10/701)
Self-harm	<1% (7/2106)	<1% (5/1358)	*
Other	2% (33/2106)	2% (22/1358)	3% (19/701)

** In accordance with information governance rules, potentially sensitive data based small numbers have been masked*

Table 30: Percentage of children and young people diagnosed with a mental health condition that had ongoing investigations in England and Wales.

Mental health condition that requires ongoing investigations	% of all children and young people with mental health conditions in cohort 1	% of children and young people with mental health conditions in cohort 2
Formal developmental assessment	23% (10/43)	27% (18/68)
Formal cognitive assessment	21% (9/43)	21% (14/68)

Investigations

Time since first request for EEG

- **<1% (4/2106)** of the children and young people diagnosed with epilepsy did not have an EEG.
- **1% (11/2106)** had an invalid EEG request date/EEG obtained date (date of EEG request is after the date EEG was obtained).
- **2% (34/2106)** of children and young people diagnosed with epilepsy did not obtain an EEG.
- **98% (2057/2106)** of 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 2, **53% (1117/2106)** of children and young people diagnosed with epilepsy, obtained their EEG within four weeks of request in England and Wales, (**Table 31**).

Figure 32 below shows a higher proportion of children and young people had to wait more than 4 weeks for their first EEG from the time of request in cohort 2 (**47%**) compared to cohort 1 (**44%**).

Table 31: 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 and Wales (N=2106)	53% (1117/2106)	30% (624/2106)	7% (152/2106)	3% (69/2106)	5% (95/2106)
England (N=2086)	53% (1108/2086)	30% (619/2086)	7% (148/2086)	3% (69/2086)	5% (94/2086)
Wales (N=20)	45% (9/20)	25% (5/20)	20% (4/20)	0% (0/20)	5% (1/20)

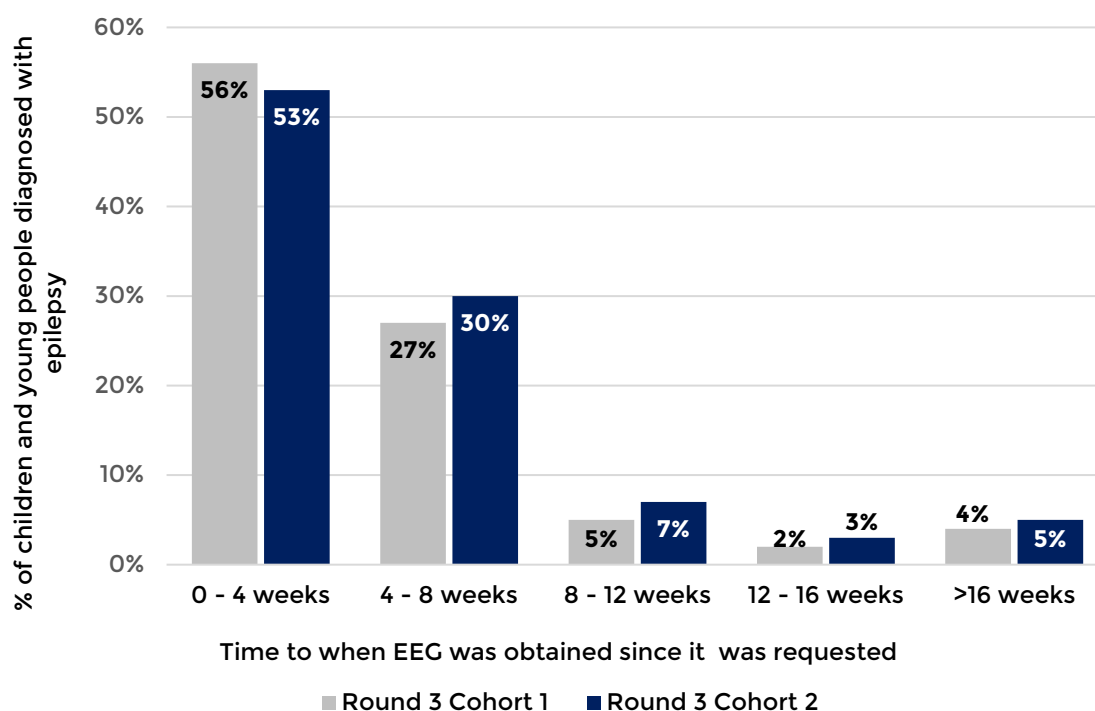


Figure 32: Time in weeks to when EEG was obtained since EEG request date in England and Wales, Round 3, cohort 1 and cohort 2.

Table 32 shows **98% (2070/2106)** of children and young people diagnosed with epilepsy obtained the first EEG in year one. **57% (1202/2106)** obtained an MRI brain, **56% (1182/2106)** obtained 12 lead ECG and **12% (248/2106)** obtained a CT head scan in their first year of care one, in England and Wales.

Figure 33 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 32: 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 and Wales (N=2106)	98% (2070/2106)	56% (1182/2106)	12% (248/2106)	57% (1202/2106)
England(N=2086)	98% (2051/2086)	56% (1172/2086)	12% (246/2086)	57% (1193/2086)
Wales (N=20)	95% (19/20)	50% (10/20)	10% (2/20)	45% (9/20)
BRPNF (N=87)	99% (86/87)	53% (46/87)	6% (5/87)	39% (34/87)
CEWT (N=153)	100% (153/153)	65% (100/153)	15% (23/153)	65% (99/153)
EPEN (N=98)	99% (97/98)	63% (62/98)	5% (5/98)	60% (59/98)
EPIC (N=224)	99% (221/224)	51% (114/224)	11% (25/224)	63% (140/224)
NTPEN (N=191)	94% (180/191)	51% (98/191)	12% (22/191)	55% (105/191)
NWEIG (N=124)	98% (122/124)	59% (73/124)	7% (9/124)	56% (70/124)
ORENG (N=123)	98% (121/123)	51% (63/123)	20% (24/123)	54% (66/123)
PENNEC (N=245)	97% (238/245)	49% (120/245)	11% (28/245)	60% (148/245)
SETPEG (N=90)	97% (87/90)	39% (35/90)	12% (11/90)	66% (59/90)
SWEP (N=15)	93% (14/15)	53% (8/15)	7% (1/15)	40% (6/15)
SWIPE (N=189)	99% (188/189)	50% (94/189)	10% (19/189)	59% (111/189)
SWTPEG (N=223)	99% (221/223)	69% (153/223)	12% (26/223)	49% (109/223)
TEN (N=117)	99% (116/117)	61% (71/117)	10% (12/117)	51% (60/117)
WPNN (N=58)	100% (58/58)	72% (42/58)	12% (7/58)	69% (40/58)
YPEN (N=169)	99% (168/169)	61% (103/169)	18% (31/169)	57% (96/169)

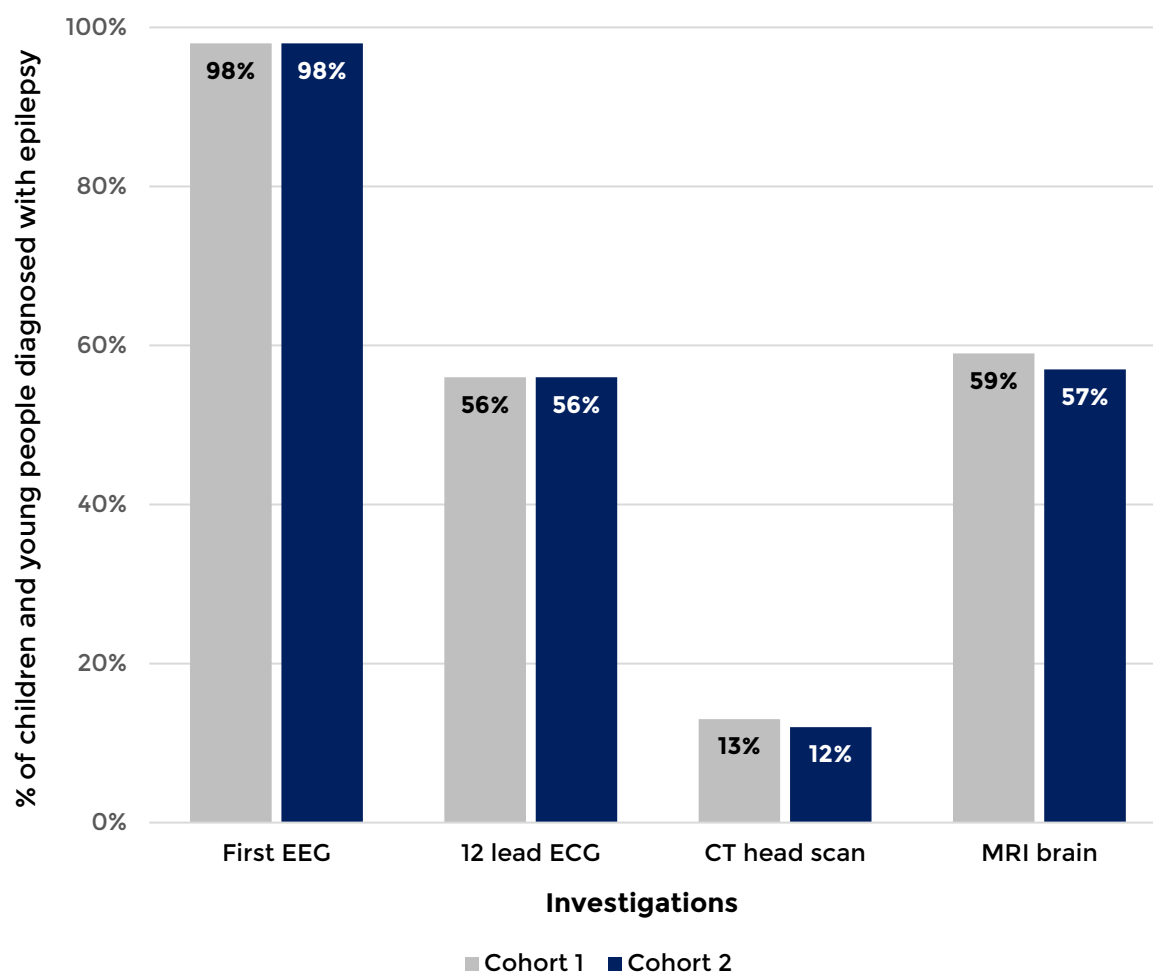


Figure 33: Percentage of children and young people diagnosed with epilepsy that obtained First EEG, 12 lead ECG, CT head scan and MRI brain investigations in England and Wales, Round 3, cohort 1 and cohort 2.

Performance Indicator 6: ECG

In Round 3 cohort 2, **65% (855/1309)** of children and young people diagnosed with epilepsy and who had convulsive seizures, obtained a 12 lead ECG by the first year in England and Wales, (**Table 33**). The proportion of children and young people with epilepsy and convulsive seizures that obtained a 12 lead ECG decreased from **68%** in cohort 1 to **65%** in cohort 2. This indicator ranged from 0% to 100% and the inter-quartile range was 50% to 81% at a Health Board and Trust level.

Table 33: Percentage of children and young people with convulsive seizures and epilepsy, with an ECG by the first year of care.

Performance Indicator: 6		Audit Round	England and Wales	England	Wales
ECG	% of children and young people with convulsive seizures and epilepsy, with an ECG by the first year of year	Round 3, Cohort 1	68% (474/701)	69% (460/662)	39% (14/39)
		Round 3, Cohort 2	65% (855/1309)	65% (850/1300)	56% (5/9)

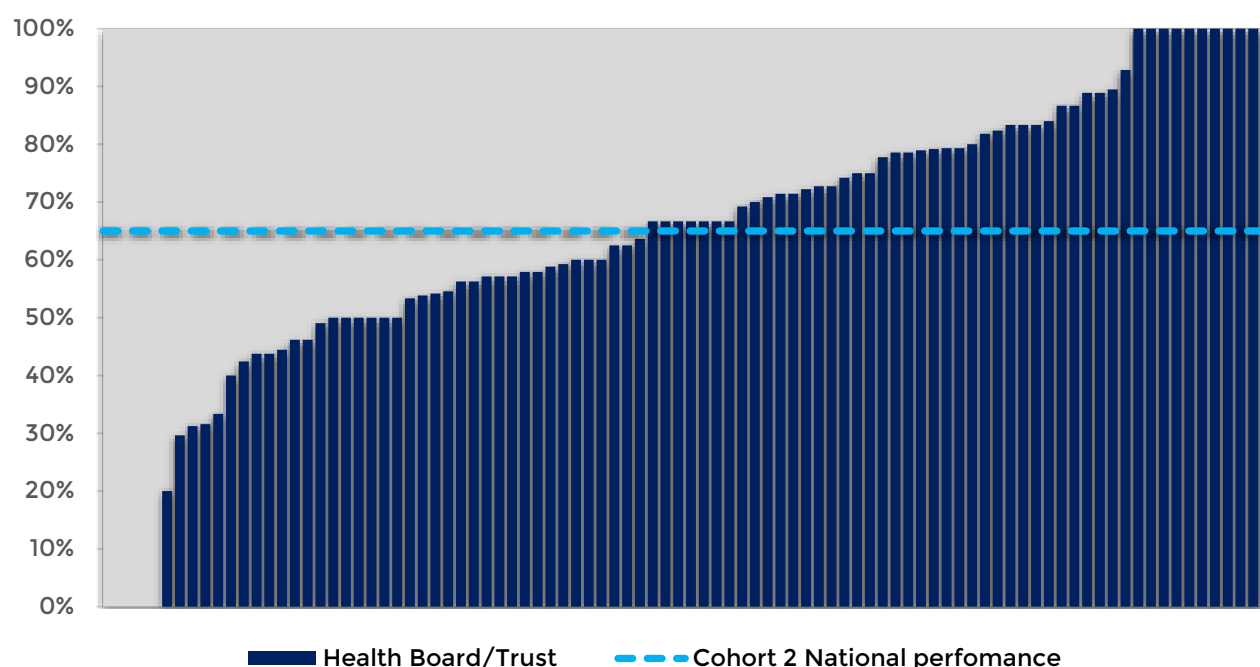


Figure 34: Percentage of children and young people with convulsive seizures and epilepsy, with an ECG at first year of care by Health Board and Trust, Round 3, cohort 2.

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 2, **71% (491/687)** of children and young people diagnosed with epilepsy and with defined indications for an MRI, had an MRI by their first year of care in England and Wales. The proportion of these children and young people who had an MRI, increased from **69% (317/462)** in cohort 1 to **71% (491/687)** in cohort 2 (**Table 34**). This indicator ranged from 0% to 100%, the inter-quartile range was 56% to 92% at Health Board and Trust level.

Table 34: Percentage of children and young people with defined indications for an MRI, who had an 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 at first year	Round 1	64% (602/948)	64% (578/899)	49% (24/49)
		Round 2	72% (481/666)	73% (458/630)	64% (23/36)
		Round 3 Cohort 1	69% (317/462)	70% (307/436)	38% (10/26)
		Round 3 Cohort 2	71% (491/687)	72% (486/679)	63% (5/8)

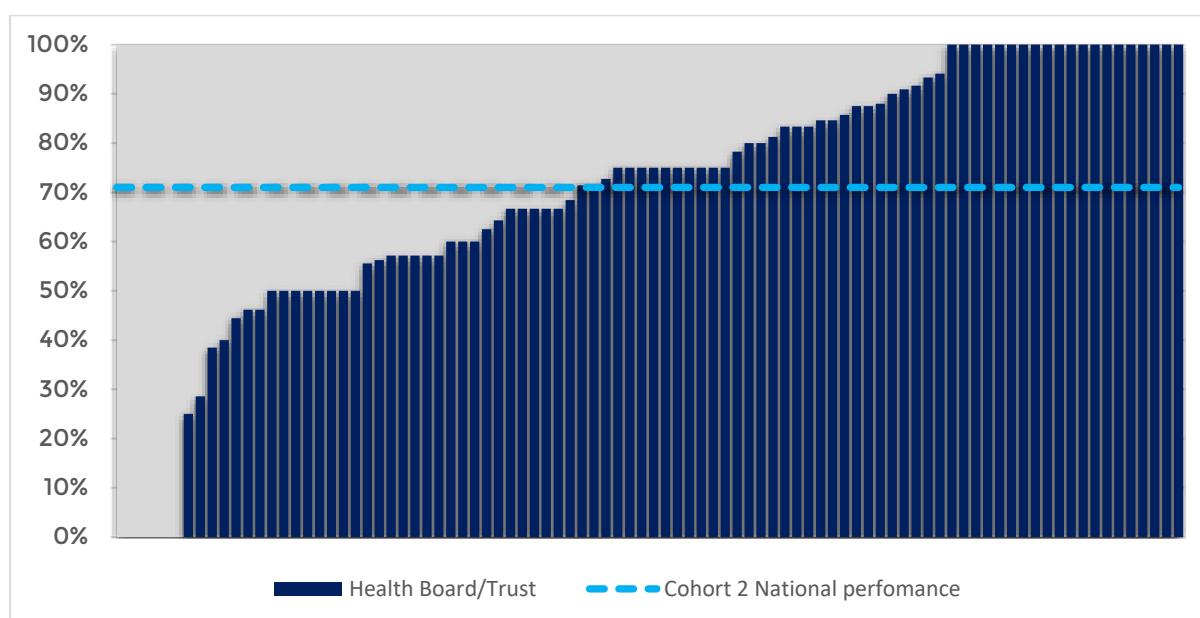


Figure 35: Percentage of children and young people with defined indications for an MRI, who had MRI by first year of care by Health Board and Trust, Round 3, cohort 2.

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.

Treatment

Anti-epileptic drugs (AEDs)

Table 35 below shows the diagnosis of children and young people together with the number of different AEDs prescribed over their first year of care. In Round 3, cohort 2, **1703** children and young people were prescribed one or more anti-epileptic drugs (AEDs) during their first 12 months of care. **164** children and young people were prescribed three or more AEDs during their first 12 months of care. **Most (98%, 1661/1703)** of the children and young people that had anti-epileptic drugs prescribed had an epilepsy diagnosis.

Table 35: Diagnosis and AEDs.

	Round 1		Round 2		Round 3, cohort 1		Round 3, cohort 2	
	1 or more AEDs N=1538	3 or more AEDs N=135	1 or more AEDs N=1059	3 or more AEDs N=84	1 or more AEDs N=190	3 or more AEDs N=9	1 or more AEDs N=1703	3 or more AEDs N=164
Epilepsy	1406 (91%)	129 (96%)	976 (92%)	82 (98%)	856 (97%)	71 (99%)	1661 (98%)	163 (99%)
Single epileptic seizure (or cluster)	68 (4%)	6 (4%)	9 (1%)	0 (0%)	10 (1%)	0 (0%)	16(1%)	0 (0%)
Non-epileptic episode (s)	44 (3%)	0 (0%)	20 (2%)	1 (1%)	7 (1%)	1 (1%)	13(1%)	0 (0%)
Uncertain episodes	20 (1%)	0 (0%)	55 (5%)	1 (1%)	6 (1%)	0 (0%)	13(1%)	1(1%)

Figure 36 shows the frequency of AEDs use among children diagnosed with epilepsy. Levetiracetam, sodium valproate, carbamazepine and lamotrigine were the most prescribed AEDs for children diagnosed with epilepsy in Round 3, cohort 2. Certain categories are not shown in **Figure 36** as there were very few children and young people in those categories. These are: Nitrazepam, Stiripentol, Eslicarbazepine, Gabapentin, Rufinamide and ACTH.

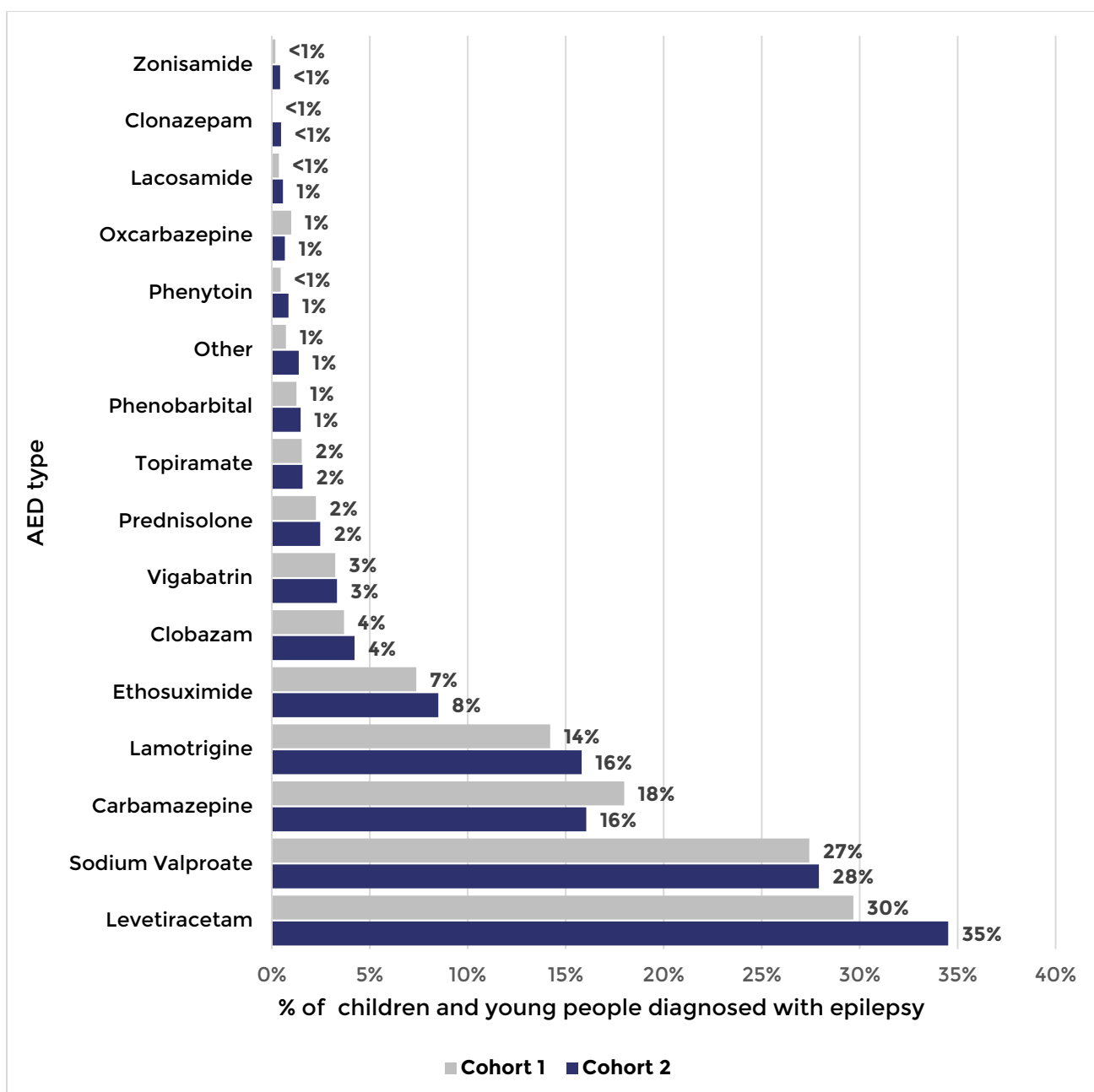
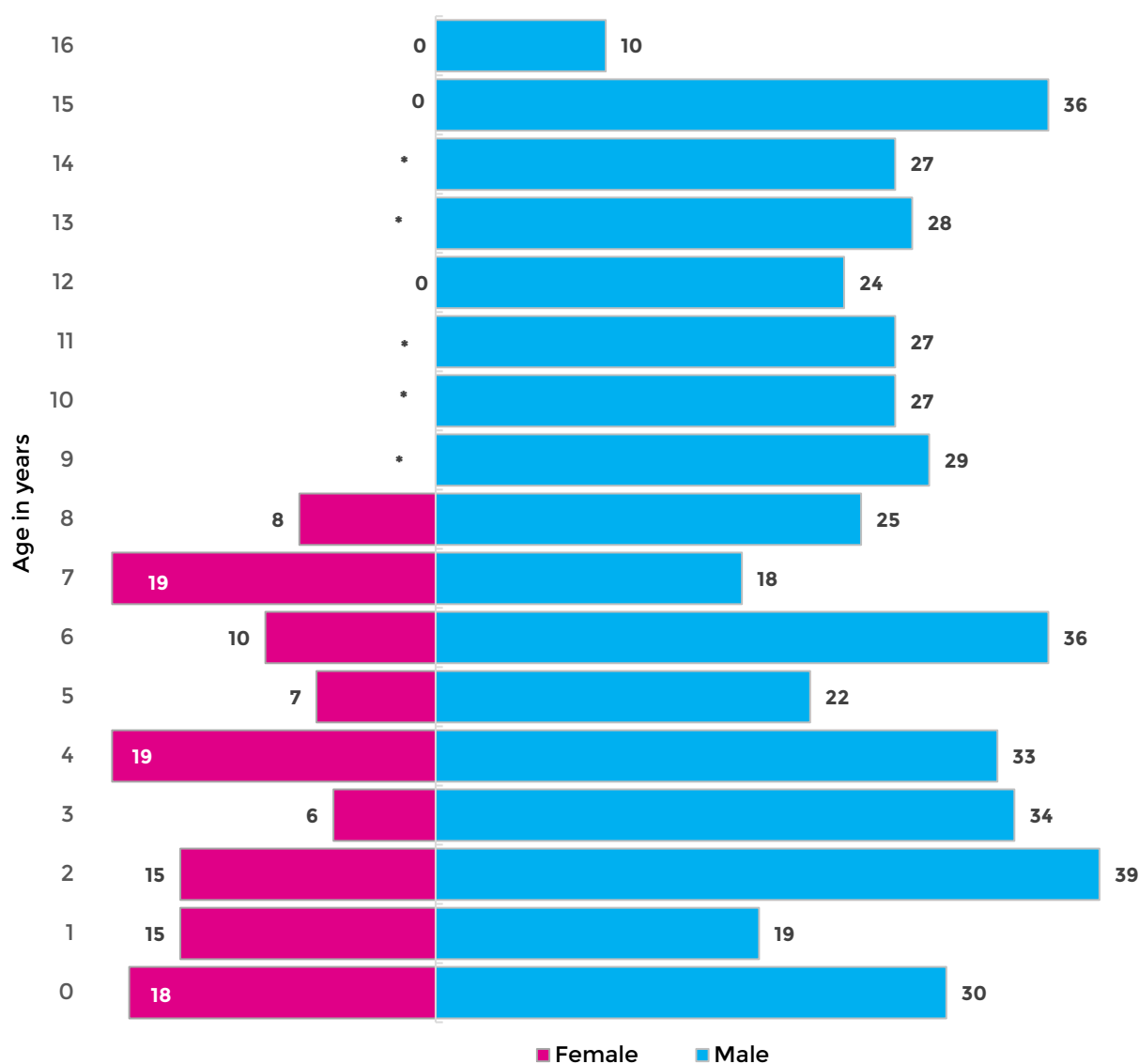


Figure 36: Percentage of children and young people diagnosed with epilepsy by AED type in England and Wales, Round 3, cohort 2.

Sodium valproate use

Figure 37 shows the number of children and young people diagnosed with epilepsy on sodium valproate by gender, in England and Wales, in Round 3 cohort 2. There were more boys on sodium valproate than girls across all ages.



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

Figure 37: Number of children and young people diagnosed with epilepsy on sodium valproate by gender in England and Wales, Round 3, cohort 2.

Performance indicator 9 and 9b: Sodium Valproate

In Round 3, cohort 2, **124** females diagnosed with epilepsy were on sodium valproate treatment, **48% (60/124)** had evidence of previous discussion of risk regarding birth defects and/or neurodevelopmental outcomes compared to **40% (25/63)** in cohort 1 (**Table 36**). This indicator ranged from 0% to 100% and had an interquartile range of 0% to 80% at a Health Board and Trust level.

There were seven females aged nine years and above, who were diagnosed with epilepsy and receiving treatment with sodium valproate. **71% (5/7)** of them had evidence of a previous discussion of risk regarding birth defects and/or neurodevelopmental outcomes compared to **100% (>5)** in Round 3 cohort 1 (**Table 36**).

Table 36: 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, cohort 1	100% (>5)
		Round 3, cohort 2	71% (5/7)
9b	% of all females currently on valproate treatment with evidence of discussion of foetal risk.	Round 3, cohort 1	40% (25/63)
		Round 3, cohort 2	48% (60/124)

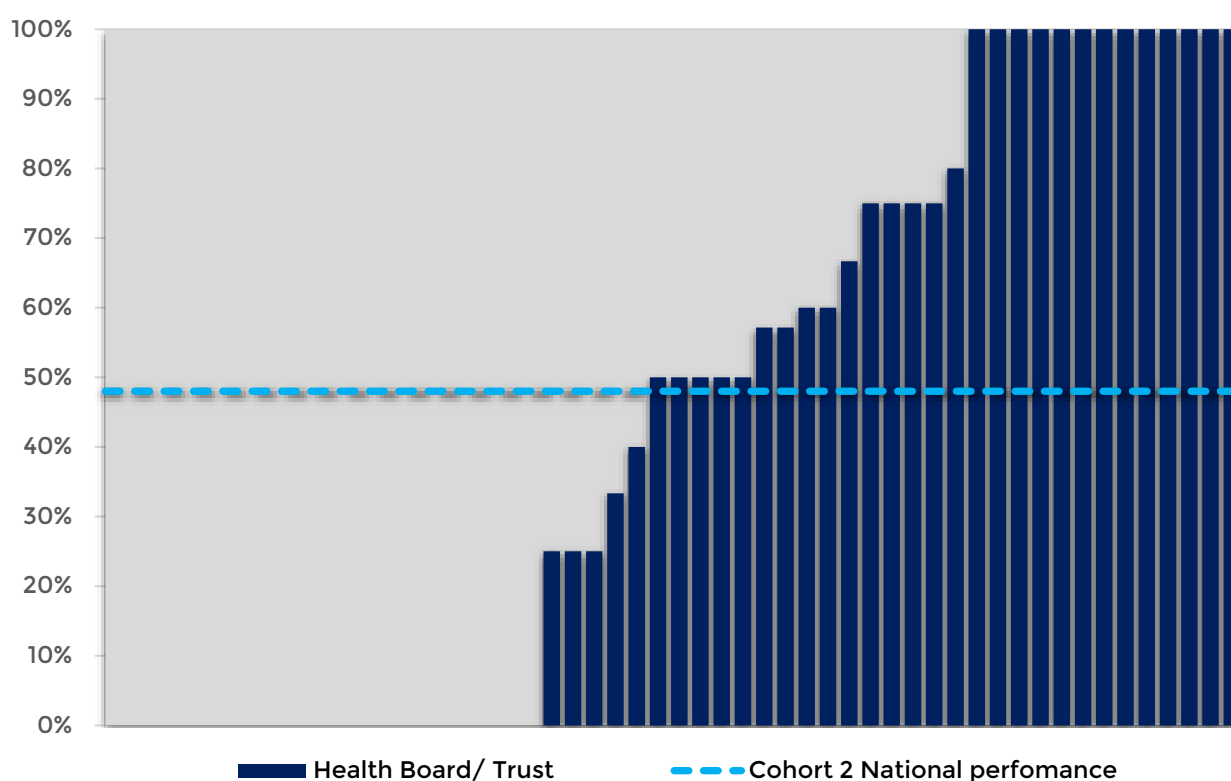


Figure 38: Percentage of females currently on sodium valproate treatment with evidence of discussion of foetal risk by Health Board and Trust, Round 3, cohort 2.

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

22% (458/2106) of the children and young people diagnosed with epilepsy, had rescue medication prescribed in England and Wales in cohort 2. **78% (1648/2106)** of children and young people did not have rescue medication prescribed, (**Figure 39**).

Figure 40 shows the percentage of children and young people diagnosed with epilepsy that had rescue medication prescribed by country and network. There were a higher proportion of children and young people diagnosed with epilepsy that had rescue medication prescribed in cohort 2 (**22%**) compared to cohort 1 (**20%**).

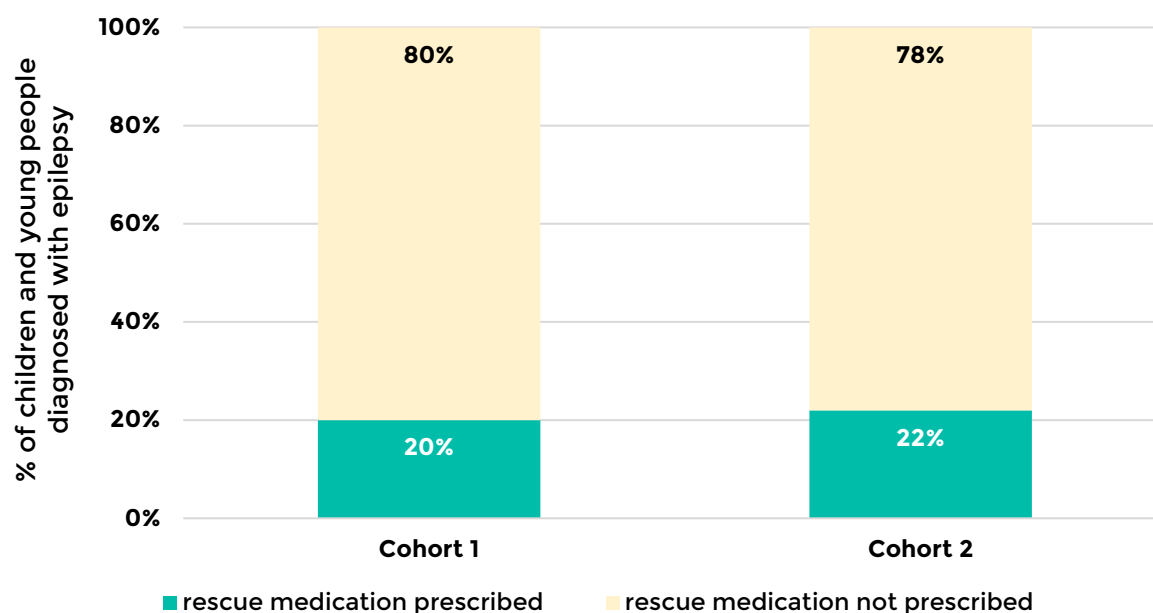


Figure 39: Percentage of children and young people diagnosed with epilepsy that had/did not have rescue medication prescribed in England and Wales.

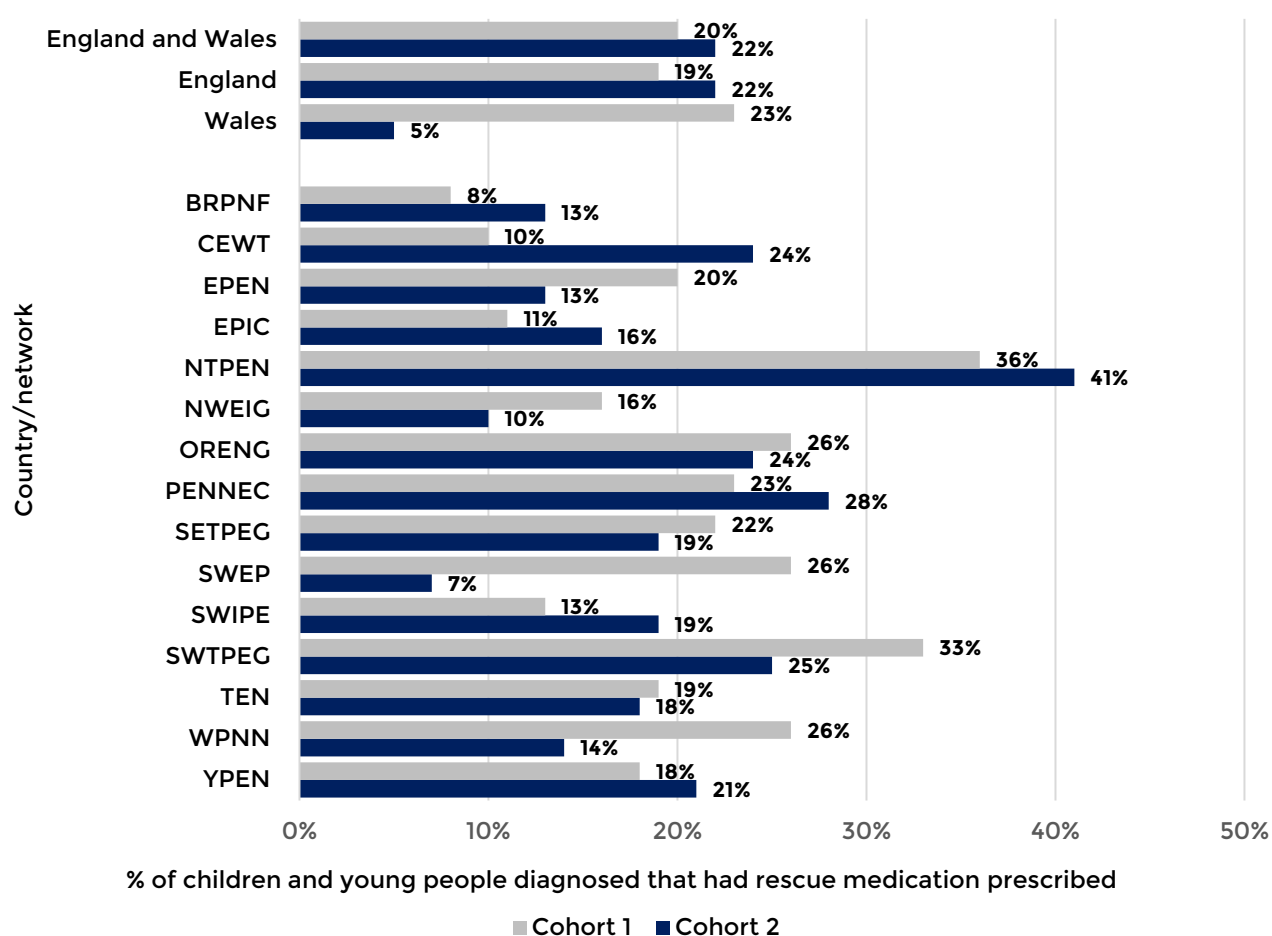


Figure 40: Percentage of children and young people diagnosed with epilepsy that had rescue medication prescribed by country and network.

Children's Epilepsy Surgery Service (CESS) referral criteria

Figure 41 shows, **5% (107/2106)** of the children and young people diagnosed with epilepsy, met one or more of the CESS referral criteria in England and Wales in cohort 2. **95% (1999/2106)** of children and young people did not meet any CESS referral criteria. A smaller proportion of children and young people diagnosed with epilepsy met one or more CESS referral criteria in cohort 2 (**5%**) compared to cohort 1 (**8%**).

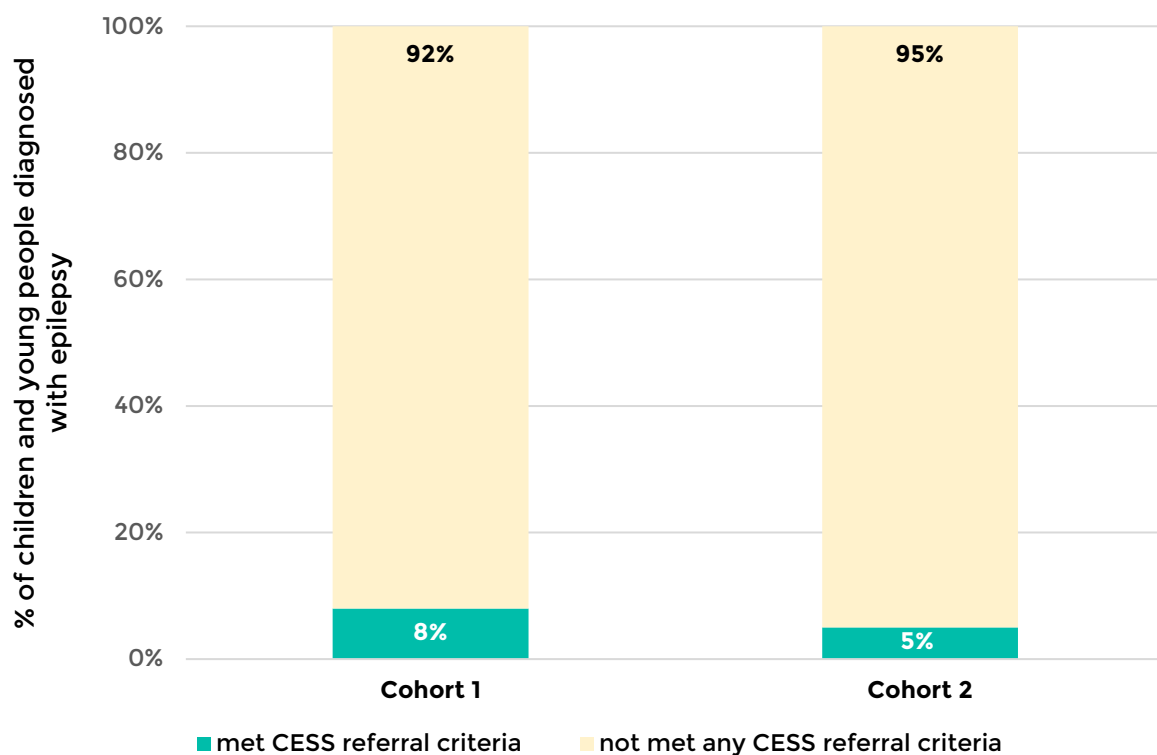


Figure 41: Percentage of children and young people diagnosed with epilepsy that met/did not meet any CESS referral criteria in England and Wales, Round 3, cohort 1 and cohort 2.

Figure 42 shows the percentage of children and young people diagnosed with epilepsy that met any CESS referral criteria by country and network.

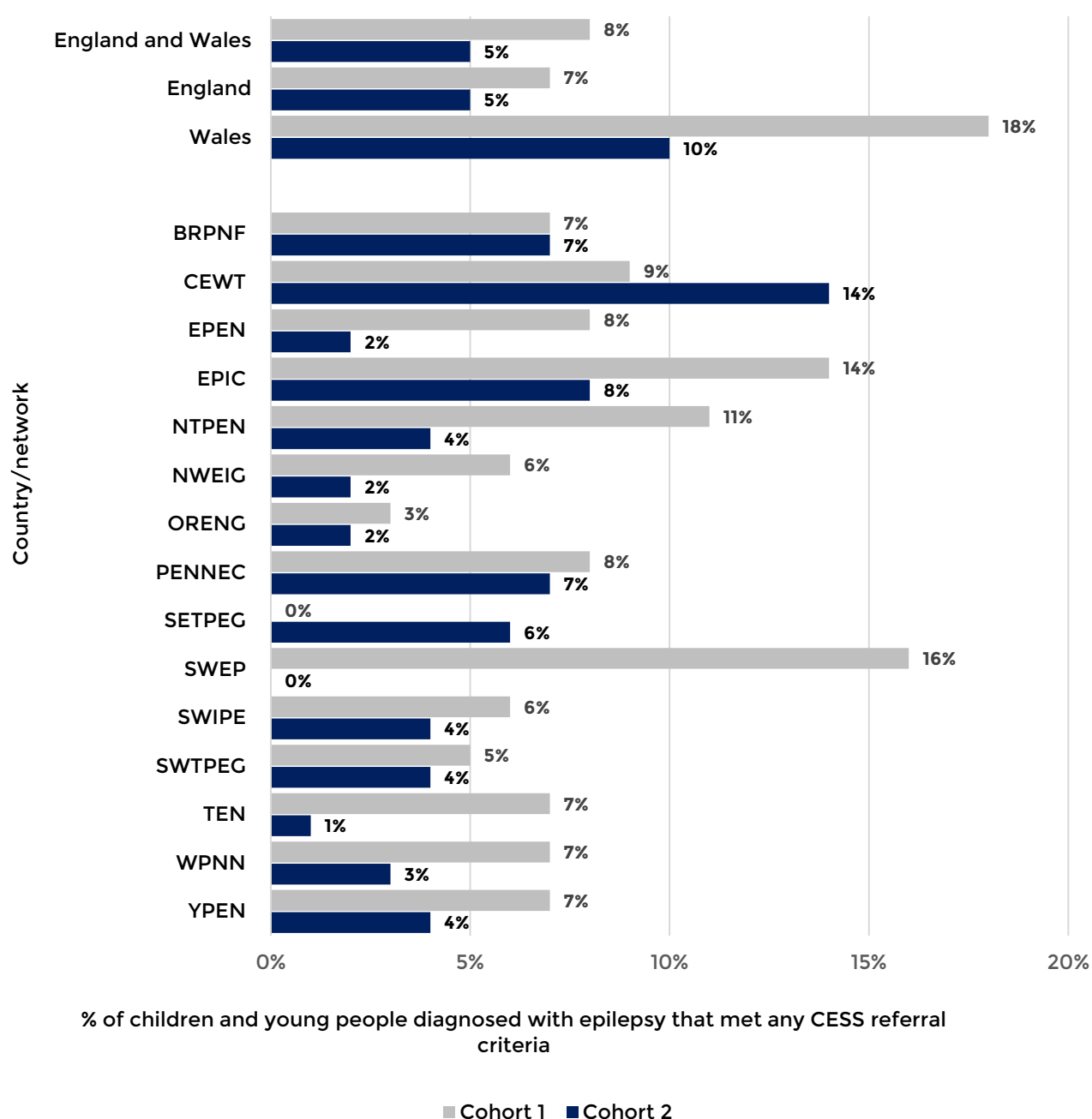


Figure 42: Percentage of children and young people diagnosed with epilepsy that met any CESS referral criteria by country and network.

Performance indicator 3b: Epilepsy surgery referral

In Round 3, cohort 2, a smaller proportion of children and young people diagnosed with epilepsy that met CESS referral criteria, had an epilepsy surgery referral in cohort 2, **23% (25/107)**, compared to cohort 1 **30% (27/89)**, (Table 37). Table 38 shows the breakdown of this performance indicator by network.

Table 37: Epilepsy surgery referral, Round 3, cohort 1 and cohort 2

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, cohort 1	30% (27/89)	33% (26/78)	9% (1/11)
		Round 3, cohort 2	23% (25/107)	24% (25/105)	0% (0/2)

Table 38: 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 in cohort 1	Epilepsy surgery referral in cohort 2
England and Wales	30% (27/89)	23% (25/107)
England	33% (26/78)	24% (25/105)
Wales	9% (1/11)	0% (0/2)
BRPNF	83% (5/6)	0% (0/6)
CEWT	13% (1/8)	5% (1/21)
EPEN	33% (2/6)	50% (1/2)
EPIC	25.0% (4/16)	33% (6/18)
NTPEN	36% (4/11)	57% (4/7)
NWEIG	25% (1/4)	50% (1/2)
ORENG	0% (0/3)	0% (0/2)
PENNEC	0% (0/5)	11% (2/18)
SETPEG	0% (0/0)	40% (2/5)
SWEP	13% (1/8)	0% (0/0)
SWIPE	50% (2/4)	63% (5/8)
SWTPEG	33% (1/3)	25% (2/8)
TEN	75% (3/4)	0% (0/1)
WPNN	33% (1/3)	0% (0/2)
YPEN	25% (2/8)	17% (1/6)

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.

4% (9/243) of children and young people that met the defined criteria for a paediatric neurology referral, did not have a paediatric neurologist input date.

62% (151/243) 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 39**). A higher proportion of children and young people who met the criteria for referral to a neurologist, were seen within four weeks of referral in cohort 2 (**62%**) compared to cohort 1 (**53%**) as shown in **Figure 43**.

Table 39: 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	62% (151/243)	11% (26/243)	10% (23/243)	4% (10/243)	10% (24/243)
England	63% (151/242)	11% (26/242)	10% (23/242)	4% (10/242)	10% (24/242)
Wales	100% (1/1)	0% (0/1)	0% (0/1)	0% (0/1)	0% (0/1)

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

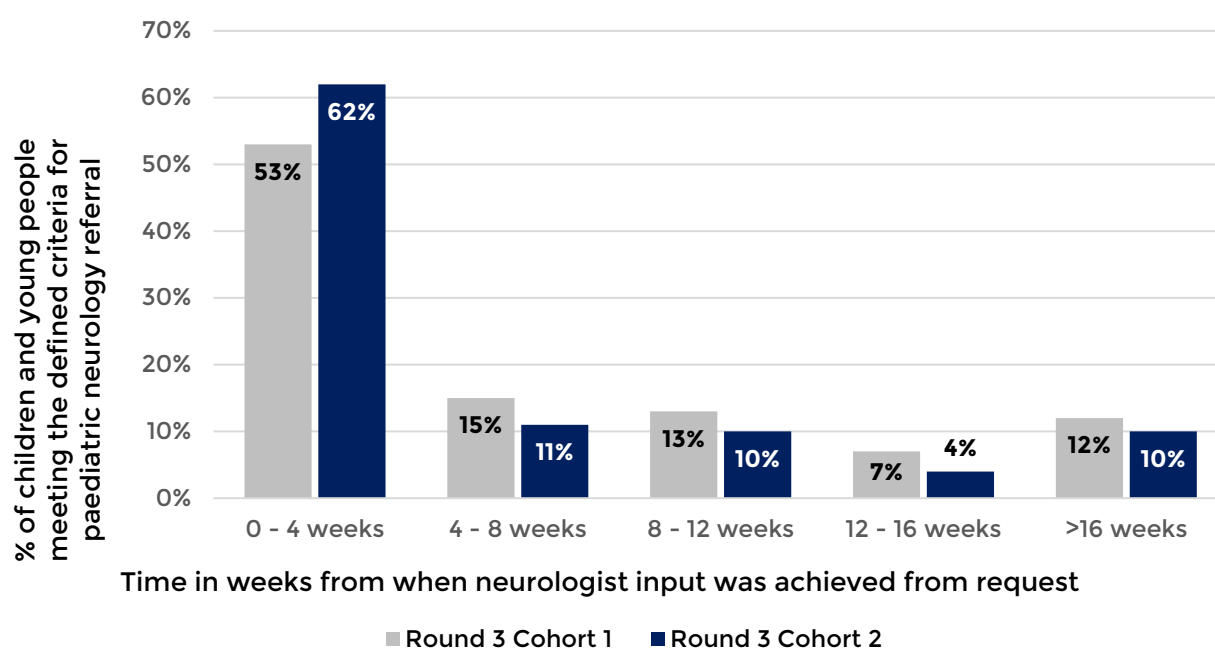


Figure 43: Time in weeks from referral to neurologist input in England and Wales.

Care planning

Appropriate care planning

Performance indicator 10: Comprehensive Care Planning agreement

In Round 3, cohort 2, **65% (1379/2106)** of children and young people diagnosed with epilepsy had evidence of a comprehensive care plan that had been updated and was agreed between the patient, their family and their healthcare providers (**Table 40**). There was an increase in the proportion of children and young people diagnosed with epilepsy and with a comprehensive care plan in cohort 2 (**66%, 1379/2106**) compared to cohort 1 (**62%, 694/1112**). This indicator ranged from 0% to 100% and had an interquartile range of 46% to 90% at a Health Board or Trust level.

Table 40: Comprehensive Care Planning agreement, Round 3, cohort 1 and cohort 2.

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, cohort 1	62% (694/1112)	64% (667/1051)	44% (27/61)
		Round 3, cohort 2	65% (1379/2106)	65% (1364/2086)	75% (15/20)
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, cohort 1	88% (982/1112)	89% (933/1051)	80% (49/61)
		Round 3, Cohort 2	91% (1907/2106)	91% (1889/2086)	90% (18/20)
10b	% of children and young people with epilepsy after 12 months where there was evidence of an agreement between the person, their family and/or carers as appropriate.	Round 3, cohort 1	74% (825/1112)	75% (786/1051)	64% (39/61)
		Round 3, cohort 2	76% (1606/2106)	76% (1589/2086)	85% (17/20)
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, cohort 1	70% (774/1112)	71% (746/1051)	46% (28/61)
		Round 3, cohort 2	72% (1505/2106)	71% (1489/2086)	80% (16/20)

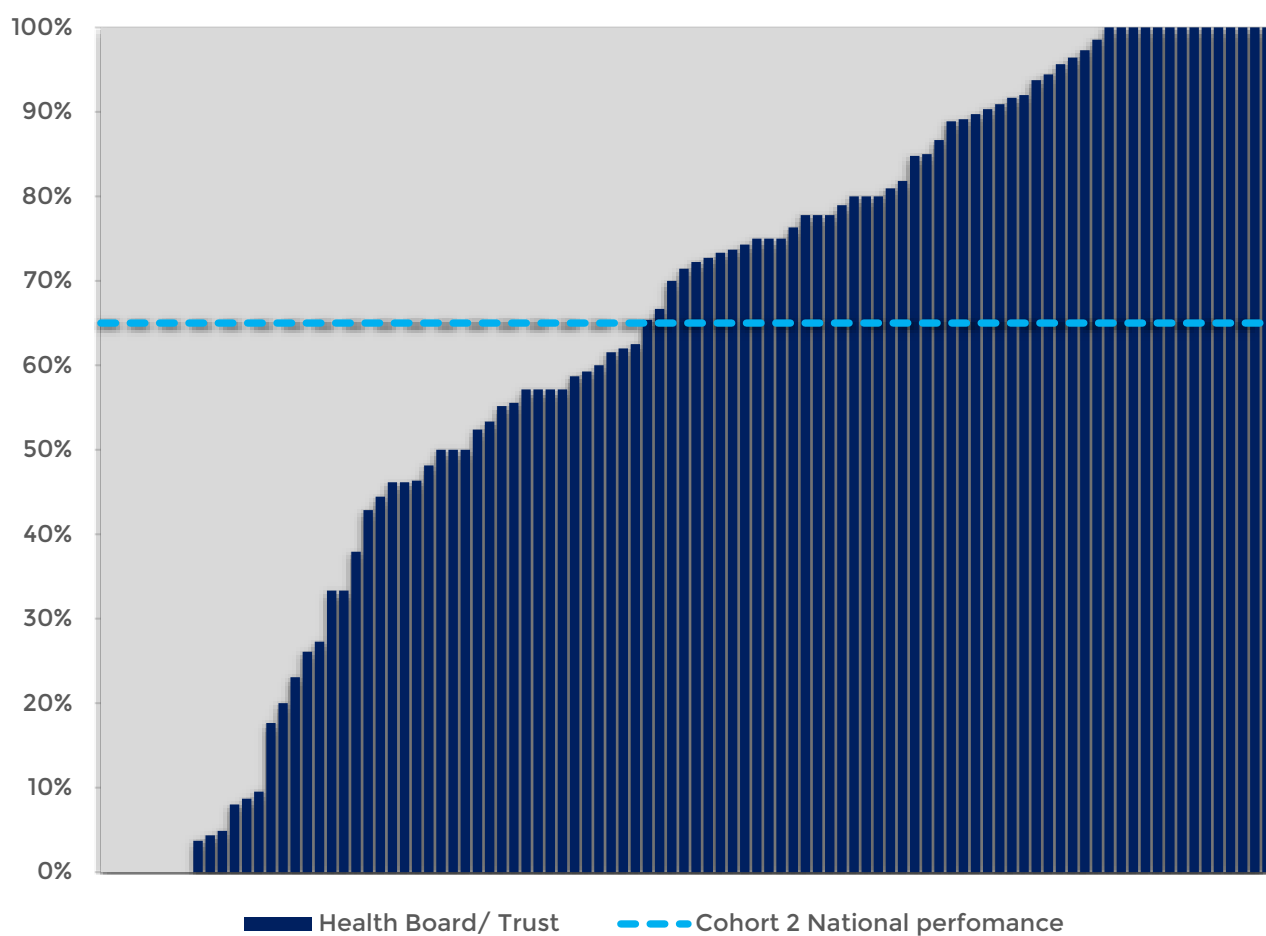


Figure 44: Comprehensive Care Planning agreement, Round 3 cohort 2.

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 2, **70% (1465/2106)** of children and young people diagnosed with epilepsy had documented evidence of communication regarding relevant core elements of care planning, (Table 41). This proportion was static compared to Round 3 Cohort 1. This indicator ranged from 0% to 100% and had an interquartile range of 48% to 94% 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.

90% (412/458) of children and young people diagnosed with epilepsy and on rescue medication, had a parental prolonged seizure care plan in England and Wales in cohort 2 compared to **89% (193/218)** in cohort 1, (Table 41).

Table 41: Comprehensive Care Planning content, Round 3, cohort 1 and cohort 2.

Performance indicator: Comprehensive Care Planning agreement		Audit Round	England and Wales	England	Wales
11	% of children diagnosed with epilepsy with documented evidence of communication regarding core elements of care planning.	Round 3, cohort 1	70% (779/1112)	72% (754/1051)	41% (25/61)
		Round 3, cohort 2	70% (1465/2106)	70% (1450/2086)	75% (15/20)
11a	% of children diagnosed with epilepsy with parental prolonged seizures care plan.	Round 3, cohort 1	89% (193/218)	89% (182/204)	79% (11/14)
		Round 3, cohort 2	90% (412/458)	90% (412/457)	0% (0/1)
11b	% of children diagnosed with epilepsy with evidence of discussion regarding water safety.	Round 3, cohort 1	80% (886/1112)	81% (856/1051)	49% (30/61)
		Round 3, cohort 2	80% (1681/2106)	80% (1665/2086)	80% (16/20)
11c	% of children diagnosed with epilepsy with evidence of discussion regarding first aid.	Round 3, cohort 1	85% (943/1112)	86% (906/1051)	61% (37/61)
		Round 3, cohort 2	85% (1796/2106)	85% (1778/2086)	90% (18/20)
11d	% of children diagnosed with epilepsy with evidence of discussion regarding general participation and risk.	Round 3, cohort 1	80% (890/1112)	81% (852/1051)	62% (38/61)
		Round 3, cohort 2	81% (1697/2106)	81% (1680/2086)	85% (17/20)
11e	% of children diagnosed with epilepsy evidence of discussion of been given service contact details.	Round 3, cohort 1	91% (1009/1112)	91% (960/1051)	80% (49/61)
		Round 3, cohort 2	92% (1927/2106)	92% (1908/2086)	95% (19/20)

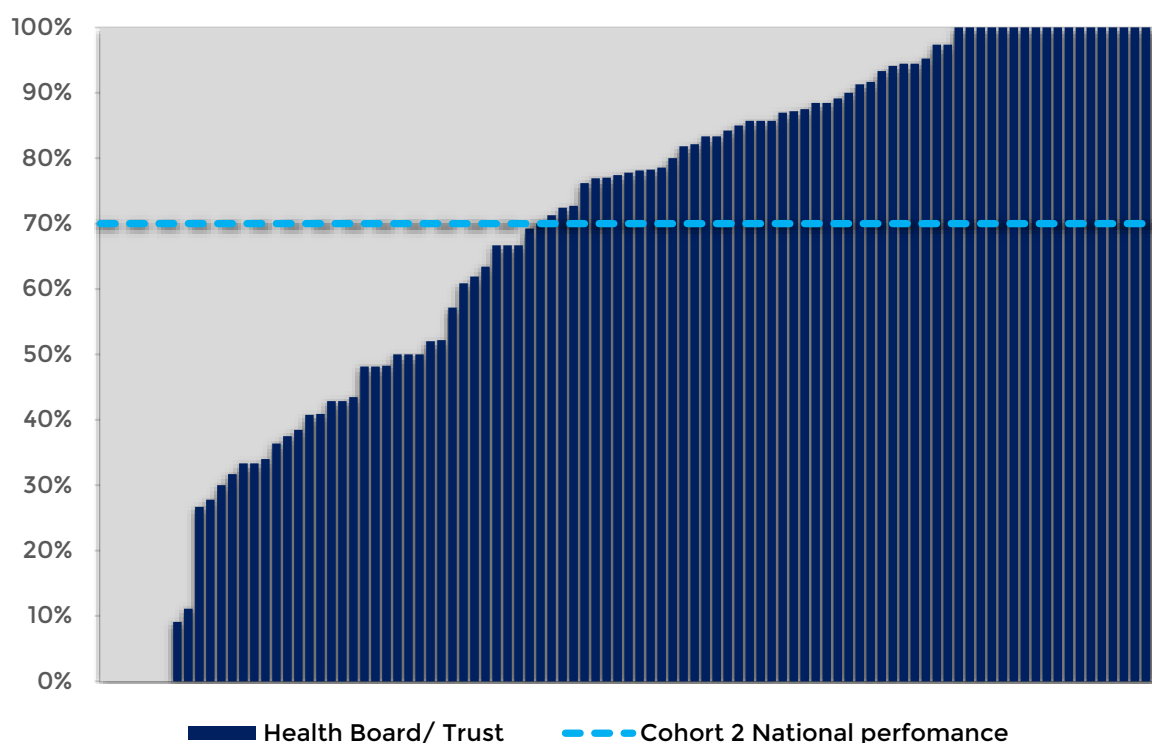


Figure 45: Comprehensive Care Planning content by Health Board and Trust, Round 3 cohort 2.

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 2, **32% (455/1402)** of children and young people diagnosed with epilepsy and aged five years and above, had evidence of a school individual healthcare plan by their first year of care, (**Table 42**). This proportion was static compared to Round 3, cohort 1. This indicator ranged from 0% to 100% and had an interquartile range of 5% to 58% at Health Board and Trust level.

Table 42: School Individual Healthcare Plan, Round 3, cohort 1 and cohort 2.

Performance indicator 12:		Audit Round	England and Wales	England	Wales
School Individual Healthcare Plan	% of children and young people with epilepsy aged 5 years and above with evidence of a school individual healthcare plan by 1 year after first paediatric assessment.	Round 3, cohort 1	32% (231/717)	32% (219/676)	29% (12/41)
		Round 3, cohort 2	32% (455/1402)	32% (447/1391)	73% (8/11)

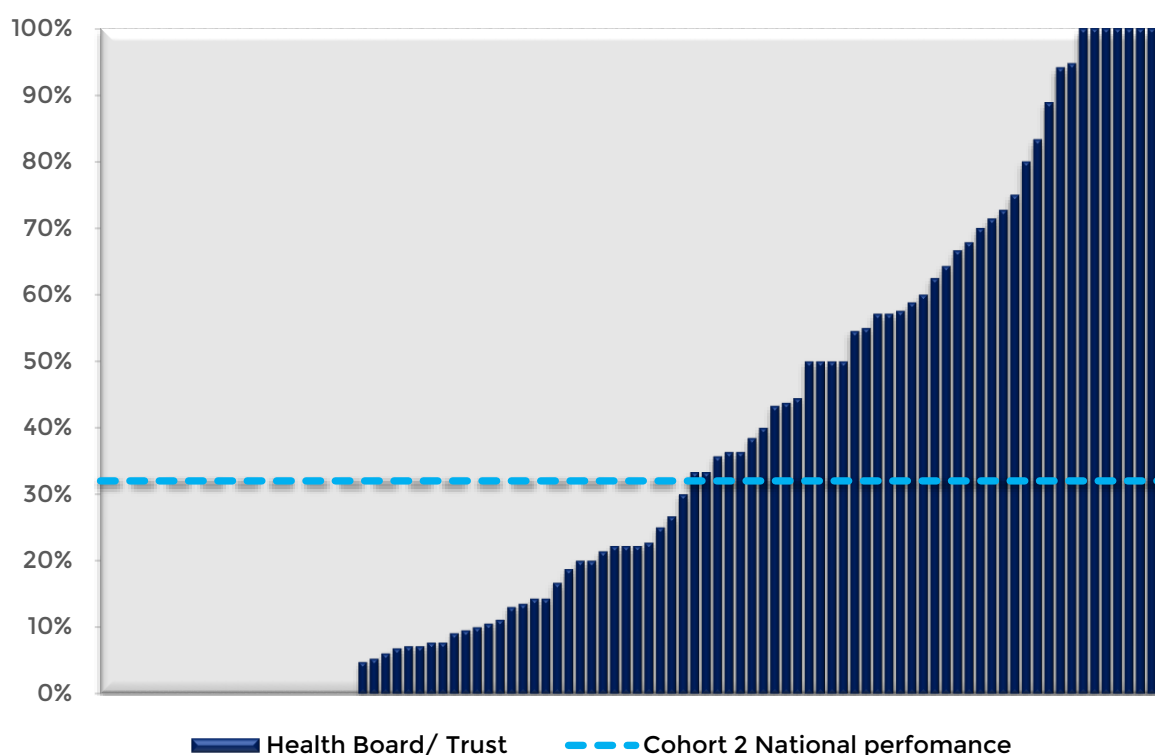


Figure 46: School Individual Healthcare Plan, by Health Board or Trust, Round 3, cohort 2.

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)

43% (915/2106) of children and young people diagnosed with epilepsy, had evidence of information on SUDEP in England and Wales in cohort 2. **57% (1191/2106)** of children and young people did not have SUDEP information provided. **Figure 47** shows the proportion of children with SUDEP information was equal in the two cohorts. **Figure 48** shows the percentage of children and young people with evidence of SUDEP information by country and network in Round 3.

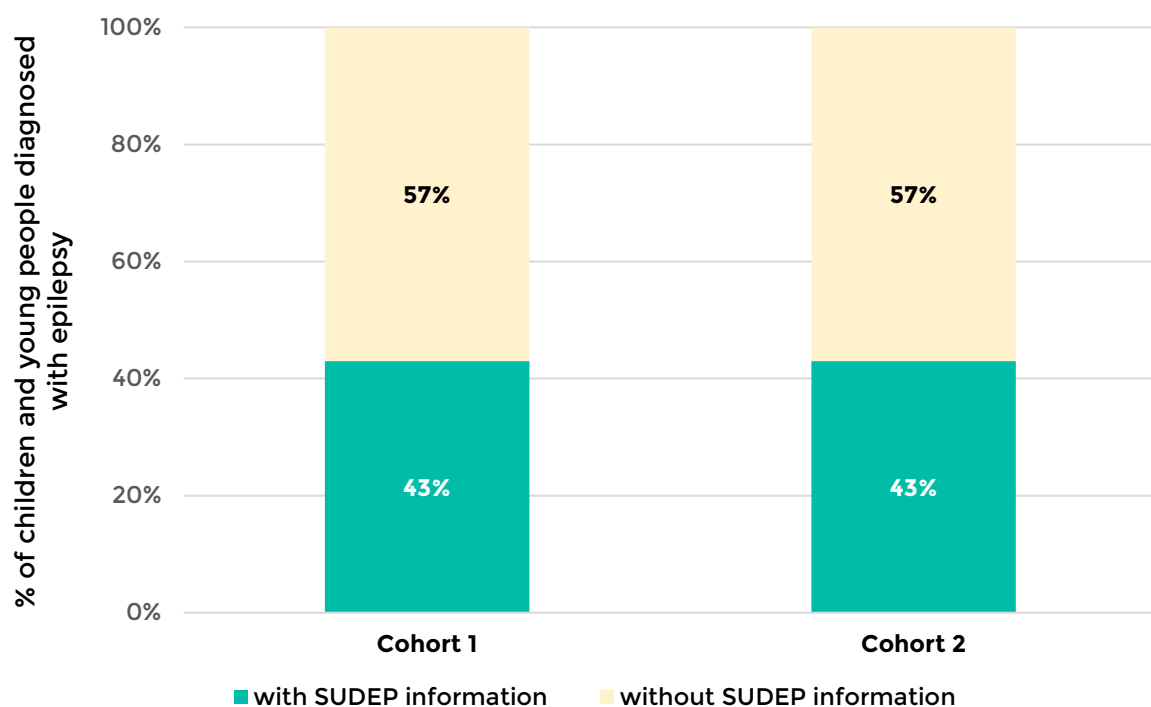


Figure 47: Percentage of children and young people diagnosed with Epilepsy with/without evidence of SUDEP information in England and Wales.

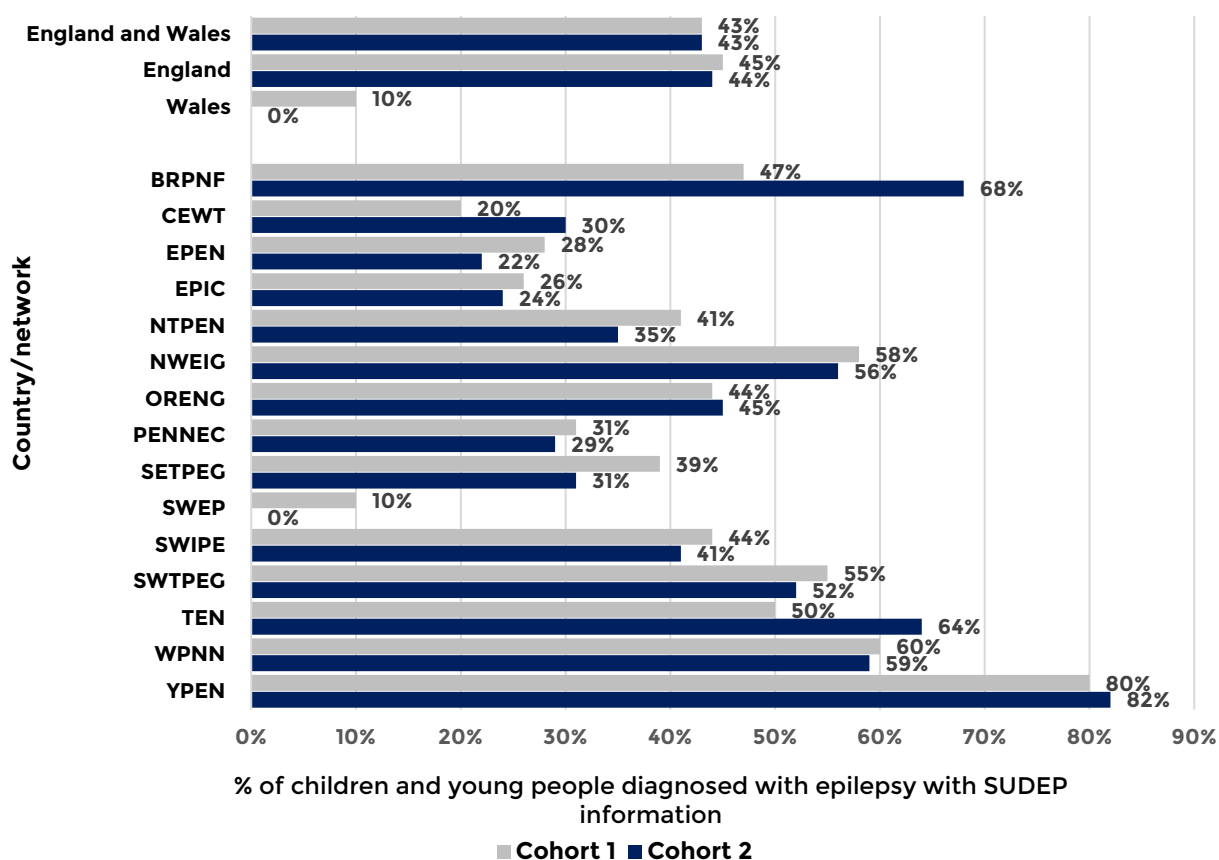


Figure 48: Percentage of children and young people diagnosed with evidence of SUDEP information by country and network.

Professionals and services involved in care

Professionals

Table 43 shows that **83% (1757/2106)** of the children and young people diagnosed with epilepsy had input from a paediatrician with expertise in epilepsies in England and Wales. **21% (447/2106)** of children and young people diagnosed with epilepsy had input from a paediatric neurologist. **78% (1644/2106)** of children and young people diagnosed with epilepsy had an input from an epilepsy specialist nurse (ESN).

Figure 49 shows the percentage of children and young people diagnosed with epilepsy with an input from various professionals in England and Wales. There was an increase in the proportion of children and young people diagnosed with epilepsy and had input from an epilepsy specialist nurse (ESN) in cohort 2 (**78%**) compared to cohort 1 (**72%**).

Table 43: 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	83% (1757/2106)	83% (1739/2086)	90% (18/20)
ESN	78% (1644/2106)	78% (1625/2086)	95% (19/20)
Paediatric neurologist	21% (447/2106)	21% (445/2086)	10% (2/20)
CESS	1% (17/2106)	1% (17/2086)	0% (0/20)
Ketogenic dietician	1% (19/2106)	1% (19/2086)	0% (0/20)
VNS service	0% (0/2106)	0% (0/2086)	0% (0/20)
Genetic service	5% (114/2106)	5% (114/2086)	0% (0/20)
Clinical psychologist	2% (41/2106)	2% (41/2086)	0% (0/20)
Educational psychologist	1% (15/2106)	1% (14/2086)	5% (1/20)
Psychiatrist	<1% (7/2106)	<1% (7/2086)	0% (0/20)
Neuropsychologist	1% (12/2106)	1% (12/2086)	0% (0/20)
Counselling service	<1% (6/2106)	<1% (6/2086)	0% (0/20)
Other mental health professional	1% (22/2106)	1% (22/2086)	0% (0/20)
Youth worker	<1% (4/2106)	<1% (4/2086)	0% (0/20)
Other	2% (35/2106)	2% (35/2086)	0% (0/20)

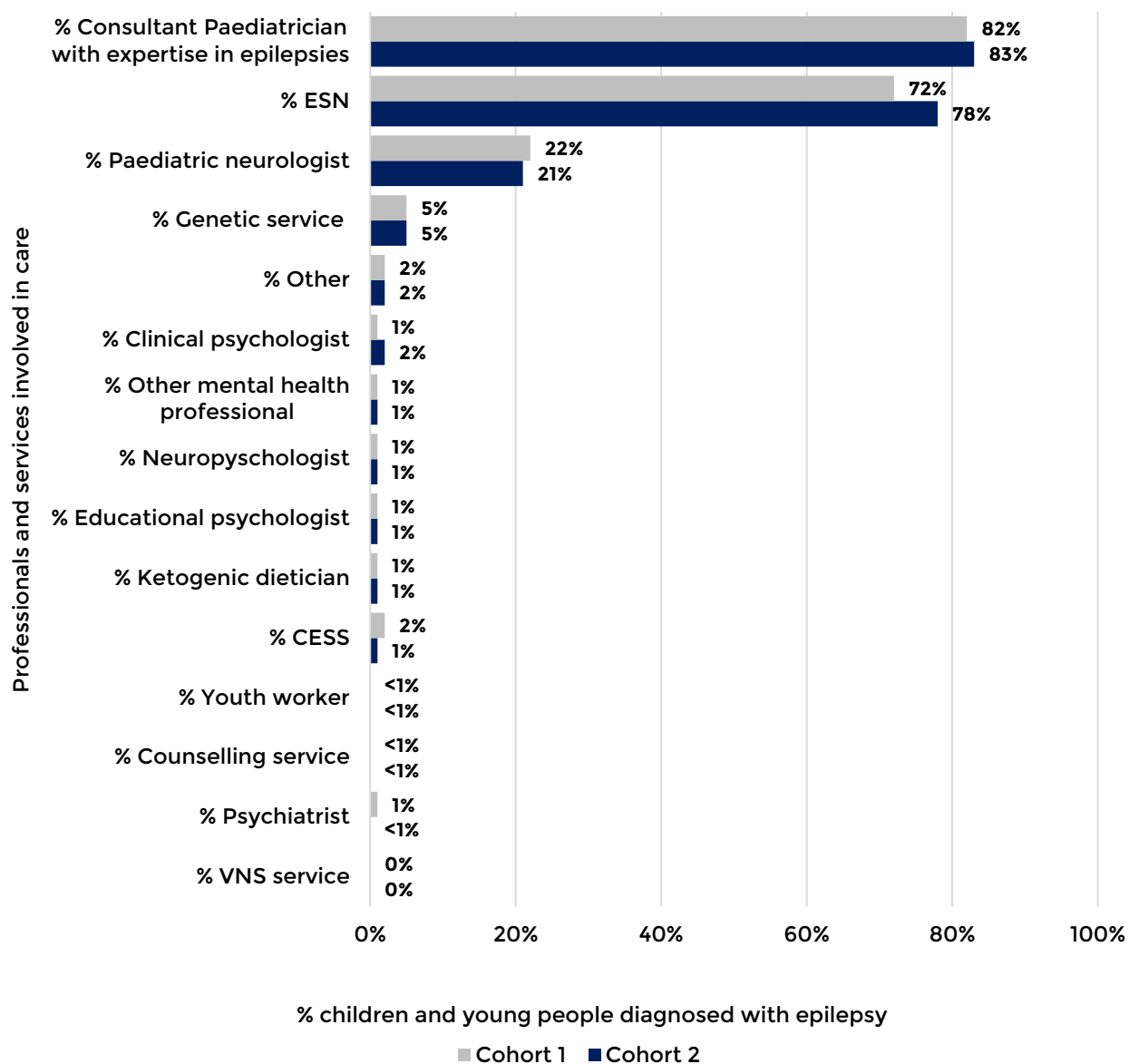


Figure 49: Percentage of children and young people diagnosed with epilepsy with input from various professionals in England and Wales.

Performance indicator 1: Paediatrician with expertise in epilepsies

In Round 3 cohort 2, **87% (1830/2106)** of children and young people diagnosed with epilepsy, had input from a paediatrician with expertise in epilepsies in their first year of care, (**Table 44**). This proportion is slightly lower in cohort 2 compared to cohort 1, **88% (977/1112)**. This indicator ranged from 0% to 100% and had an interquartile range of 88% to 100% at a Health Board and Trust level.

Table 44: Paediatrician with expertise in epilepsies across Rounds 1, 2, 3, cohort 1 and cohort 2.

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% (1183/1516)	78% (1106/1423)	83% (77/93)
		Round 2	86% (938/1090)	86% (877/1019)	64% (61/71)
		Round 3 cohort 1	88% (977/1112)	88% (924/1051)	87% (53/61)
		Round 3 cohort 2	87% (1830/2106)	87% (1813/2086)	85% (17/20)

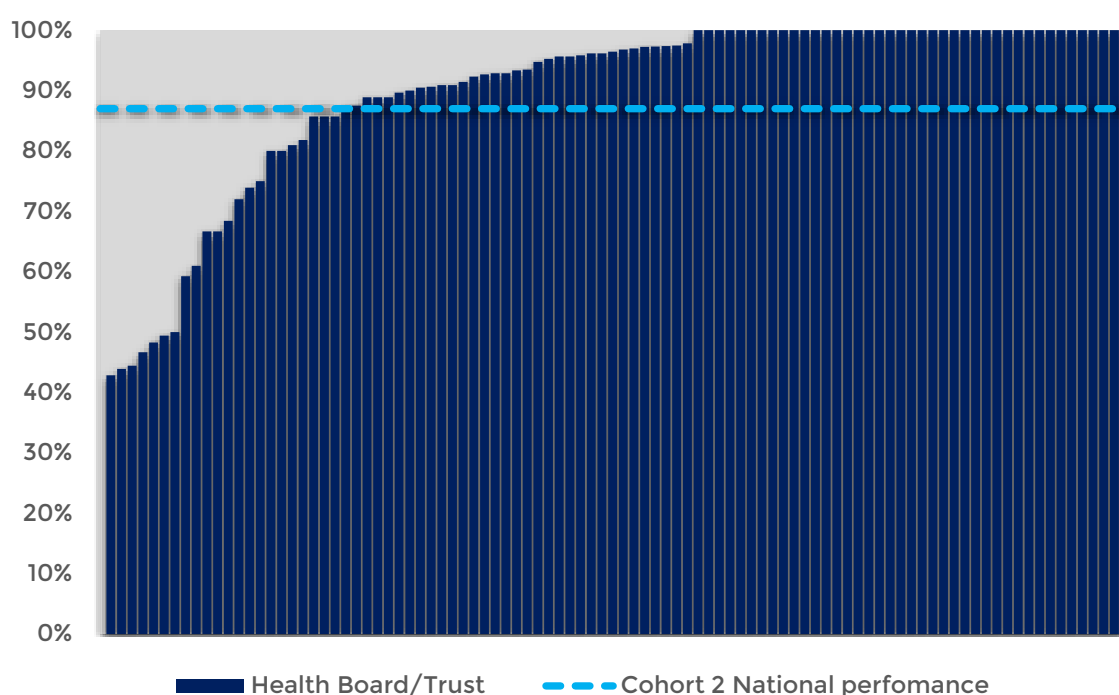


Figure 50: Paediatrician with expertise in epilepsies by Health Board and Trust, Round 3, cohort 2.

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 2, **73% (1543/2106)** of children and young people diagnosed with epilepsy, had input from an epilepsy specialist nurse (ESN) by their first year of care, (**Table 45**). This proportion is higher than Round 3 cohort 1, **69% (767/1112)**. This indicator ranged from 0% to 100% and had an interquartile range of 58 % to 94%.

Table 45: Epilepsy specialist nurse across Rounds 1, 2, 3, cohort 1 and cohort 2.

Performance indicator: 2		Audit Round	England and Wales	England	Wales
Epilepsy specialist nurse	% of children and young people with epilepsy, with input by epilepsy specialist nurse within the first year of care.	Round 1	43% (658/1516)	42% (592/1423)	71% (66/93)
		Round 2	56% (605/1090)	54% (555/1019)	70% (50/71)
		Round 3 Cohort 1	69% (767/1112)	70% (738/1051)	48% (29/61)
		Round 3 Cohort 2	73% (1543/2106)	73% (1525/2086)	90% (18/20)

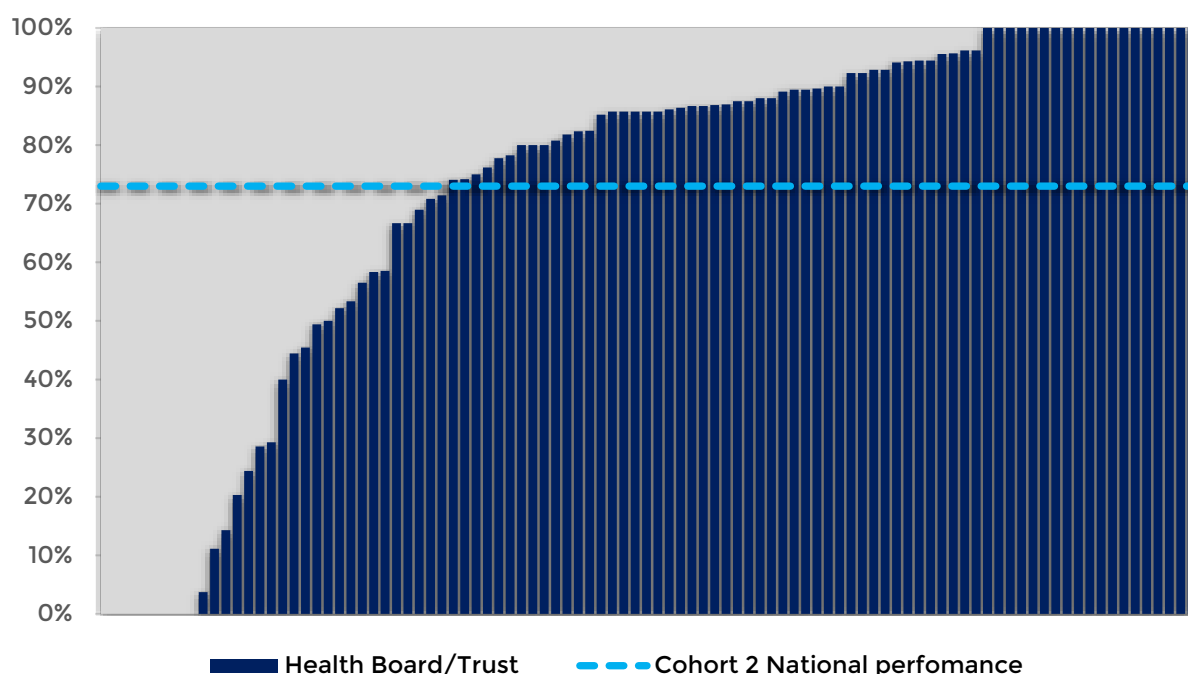


Figure 51: Input from an ESN by Health Board and Trust, Round 3, cohort 2.

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 2, **52% (243/464)** of children and young people who met paediatric neurology referral criteria had paediatric neurologist input or Children's Epilepsy Surgical service (CESS) referral by their first year of care, (**Table 46**). There was a decline in the proportion of children and young people that met paediatric neurology referral criteria and had paediatric neurologist input or Children's Epilepsy Surgical service (CESS) referral in cohort 2 compared to cohort 1, **59% (150/253)**. This indicator ranged from 0% to 100% and had an interquartile range of 29% to 73% at Health Board or Trust level.

Table 46: Tertiary input across Rounds 1, 2, 3, cohort 1 and cohort 2.

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% (205/347)	59% (200/338)	56% (5/9)
		Round 2	54% (119/220)	54% (115/214)	67% (4/6)
		Round 3 cohort 1	59% (150/253)	59% (142/240)	62% (8/13)
		Round 3 cohort 2	52% (243/464)	53% (242/458)	17% (1/6)

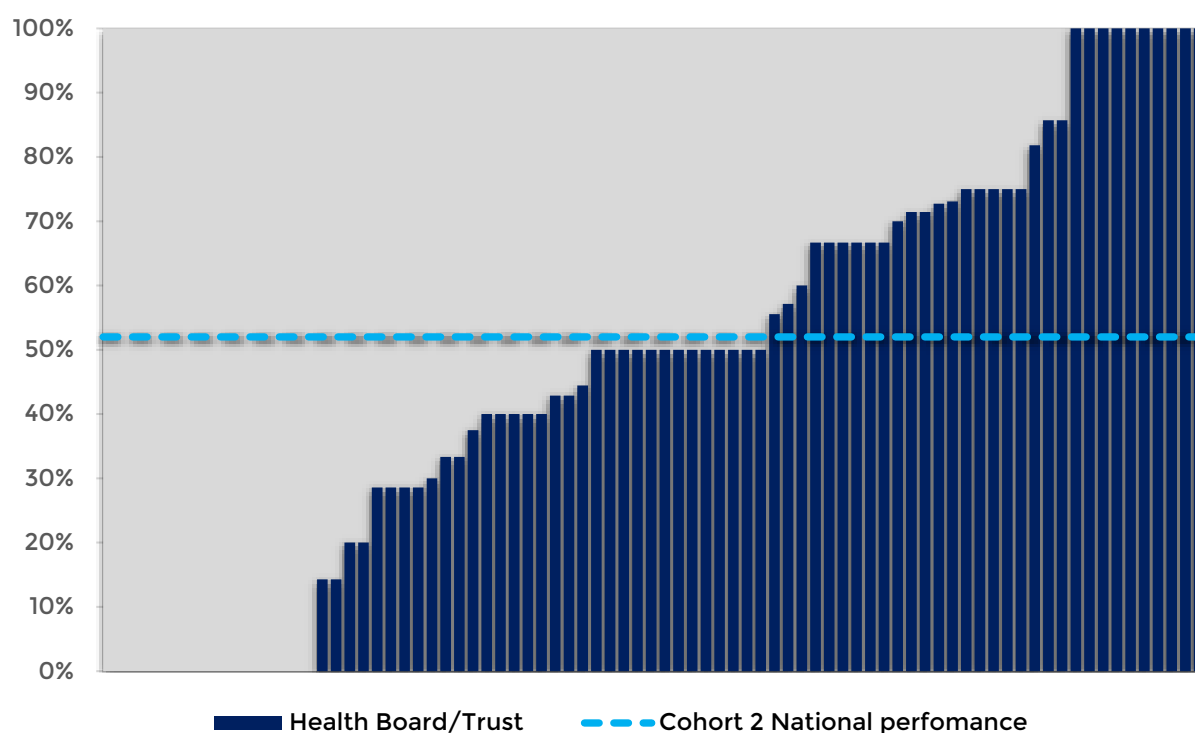


Figure 52: Tertiary input by Health Board and Trust, Round 3, cohort 2.

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 47 shows the children and young people who were diagnosed with epilepsy in England and Wales that had relevant ongoing investigations in the first year of care.

23% (477/2106) had a formal development assessment compared to **20%** in cohort 1. **10% (213/2106)** had formal cognitive assessment compared to **7%** in cohort 1 (**Figure 53**).

Figure 53 shows the percentage of children and young people that had relevant ongoing assessment in England and Wales.

Table 47: 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 and Wales (N=2106)	23% (477/2106)	10% (213/2106)
England (N=2086)	23% (476/2086)	10% (213/2086)
Wales (N=20)	5% (1/20)	0% (0/20)

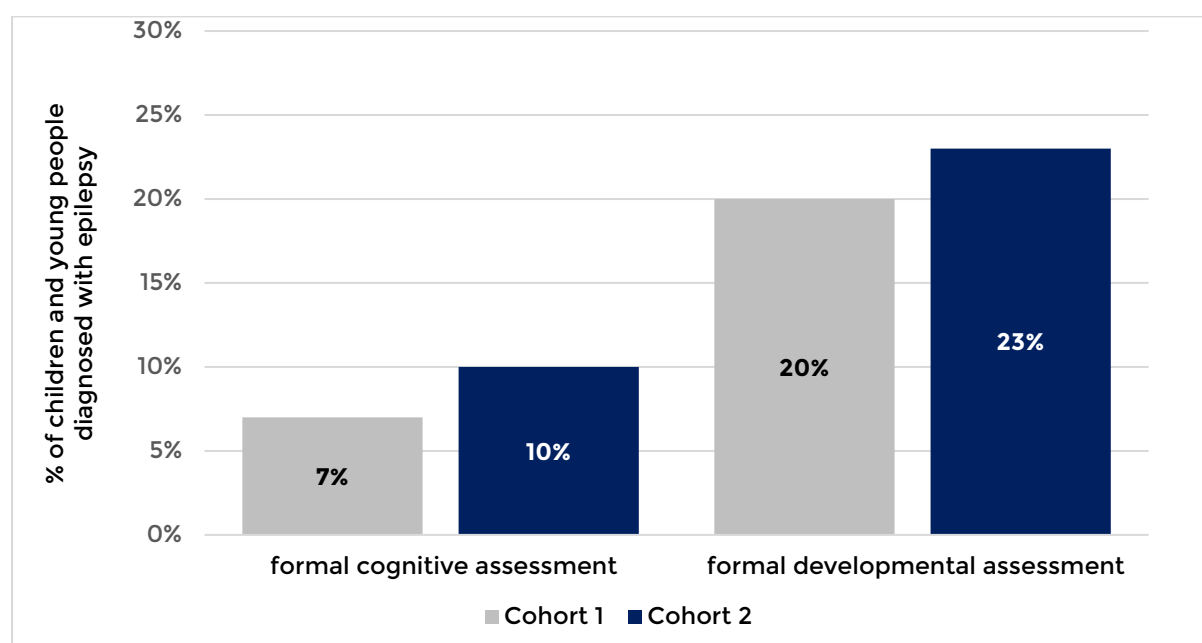


Figure 53: Percentage of children and young people diagnosed with epilepsy with relevant ongoing investigation in England and Wales.

Performance indicator 8: Accuracy of diagnosis

In Round 3, cohort 2, **98% (2081/2126)** of children and young people had the same diagnosis by their first year of care, (**Table 48**). This proportion has been increasing in every audit round. This indicator ranged from 50% to 100% and had an interquartile range of 98% to 100% at a Health Board and Trust level.

Table 48: Accuracy of diagnosis across Rounds 1, 2, 3, cohort 1 and cohort 2.

Performance indicator: 8		Audit Round	England and Wales	England	Wales
Accuracy of diagnosis	% of children diagnosed with epilepsy, who still had that diagnosis at 1 year.	Round 1	88% (1516/1721)	88% (1423/1624)	96% (93/97)
		Round 2	93% (1077/1156)	93% (1007/1080)	92% (70/76)
		Round 3 cohort 1	97% (1093/1124)	97% (1032/1063)	100% (61/61)
		Round 3 cohort 2	98% (2081/2126)	98% (2061/2104)	91% (20/22)

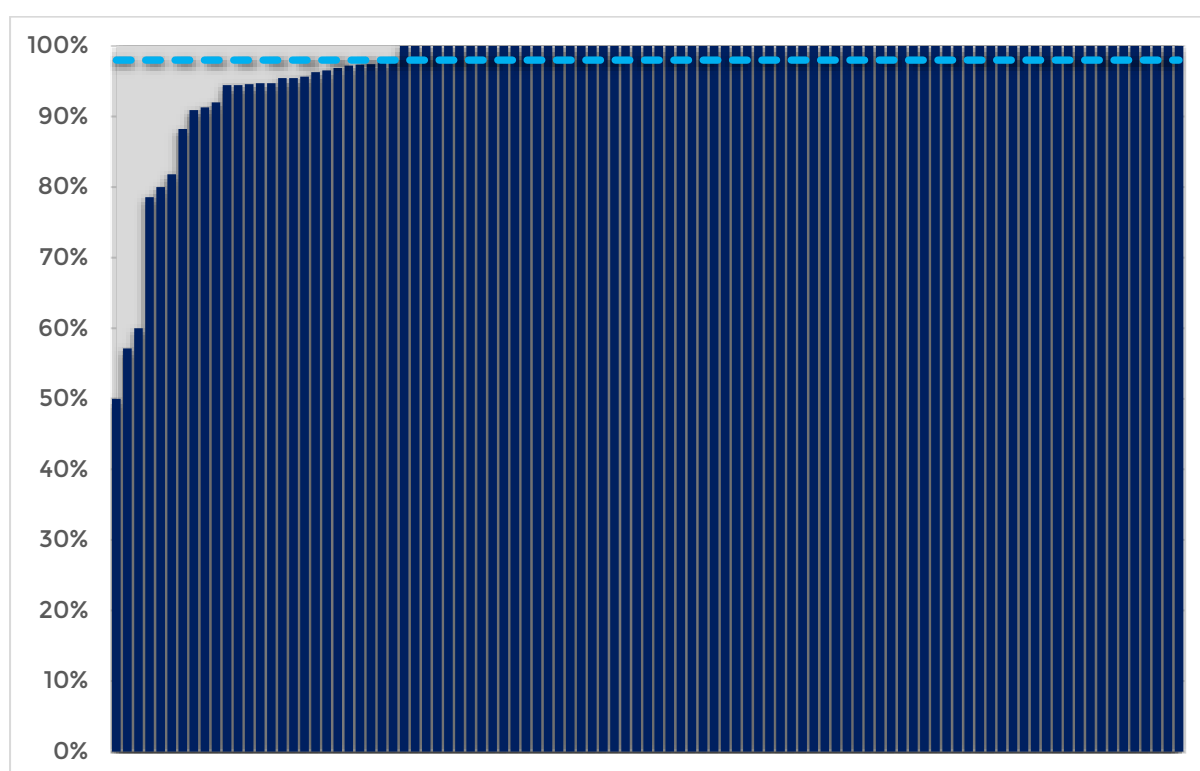


Figure 54: Accuracy of diagnosis by Health Board and Trust, Round 3, cohort 2.

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

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

Performance Indicators		Audit Round	England and Wales	England	Wales
1	Paediatrician with expertise in epilepsies	Round 1	78% (1183/1516)	78% (1106/1423)	83% (77/93)
		Round 2	86% (938/1090)	86% (877/1019)	64% (61/71)
		Round 3, cohort 1	88% (977/1112)	88% (924/1051)	87% (53/61)
		Round 3, cohort 2	87% (1830/2106)	87% (1813/2086)	85% (17/20)
2	Epilepsy Specialist Nurse	Round 1	43% (658/1516)	42% (592/1423)	71% (66/93)
		Round 2	56% (605/1090)	54% (555/1019)	70% (50/71)
		Round 3, cohort 1	69% (767/1112)	70% (738/1051)	48% (29/61)
		Round 3, cohort 2	73% (1543/2106)	73% (1525/2086)	90% (18/20)
3	Tertiary input	Round 1	59% (205/347)	59% (200/338)	56% (5/9)
		Round 2	54% (119/220)	54% (115/214)	67% (4/6)
		Round 3, cohort 1	59% (150/253)	59% (142/240)	62% (8/13)
		Round 3, cohort 2	52% (243/464)	53% (242/458)	17% (1/6)
5	Seizure formulation	Round 1	87% (1318/1516)	87% (1235/1423)	89% (83/93)
		Round 2	95% (1040/1096)	95% (973/1019)	94% (67/77)
		Round 3, cohort 1	88% (979/1112)	87% (919/1051)	98% (60/61)
		Round 3, cohort 2	91% (1911/2106)	91% (1893/2086)	90% (18/20)
7	MRI	Round 1	64% (602/948)	64% (578/899)	49% (24/49)
		Round 2	72% (481/666)	73% (458/630)	64% (23/36)
		Round 3, cohort 1	69% (317/462)	70% (307/436)	38% (10/26)
		Round 3, cohort 2	71% (491/687)	72% (486/679)	63% (5/8)
8	Accuracy of diagnosis	Round 1	88% (1516/1721)	88% (1423/1624)	96% (93/97)
		Round 2	93% (1077/1156)	93% (1007/1080)	92% (70/76)
		Round 3, cohort 1	97% (1093/1124)	97% (1032/1063)	100% (61/61)
		Round 3, cohort 2	98% (2081/2126)	98% (2061/2104)	91% (20/22)

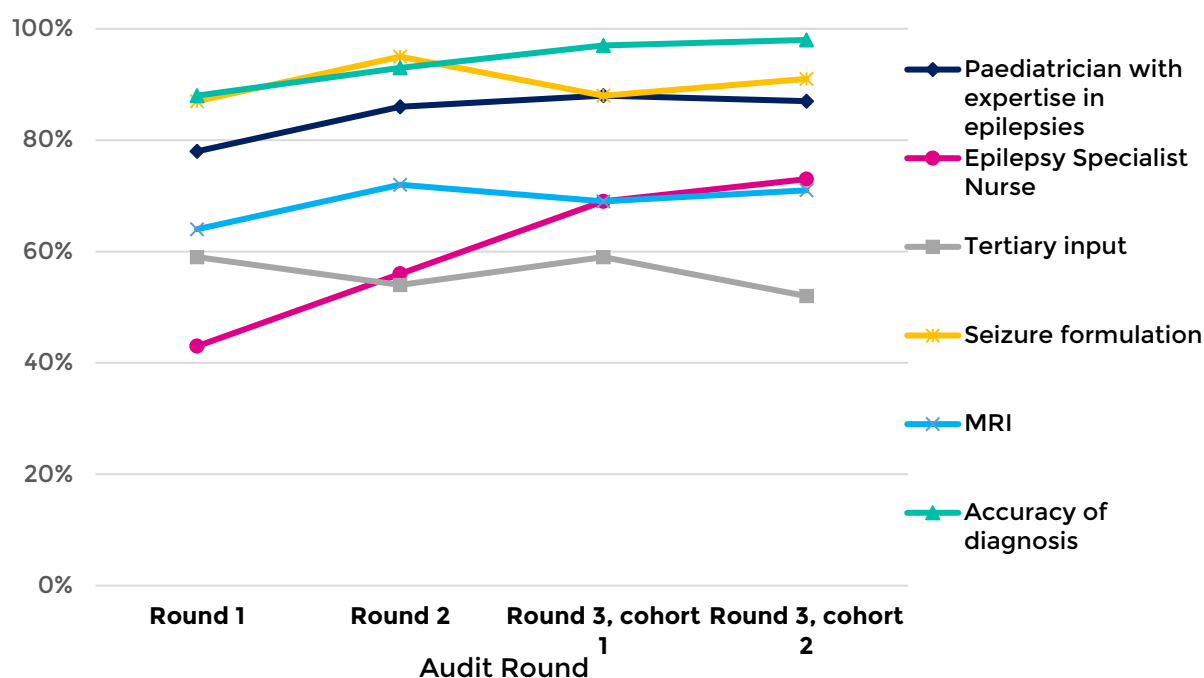


Figure 1: Performance indicators in England and Wales across Rounds 1, 2, 3, cohort 1 and cohort 2.

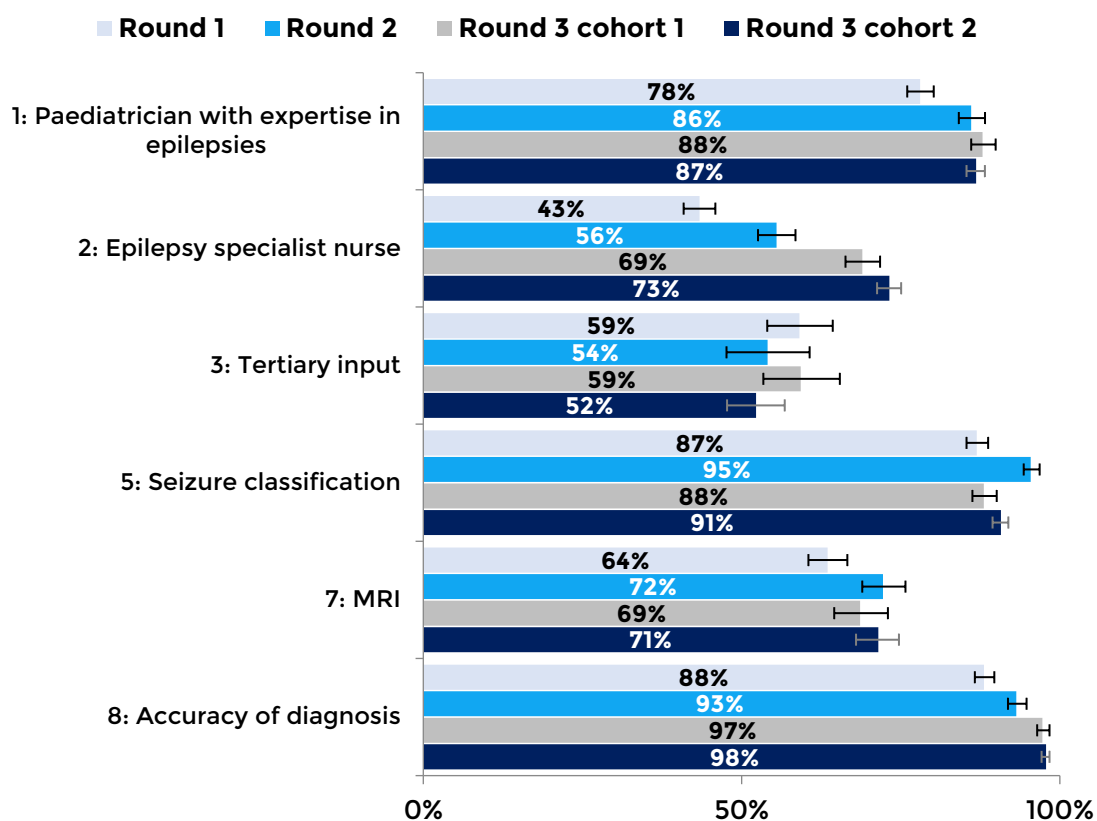


Figure 2: Epilepsy12 Performance indicators for England and Wales, across Rounds 1, 2, 3, cohort 1 and cohort 2.

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.

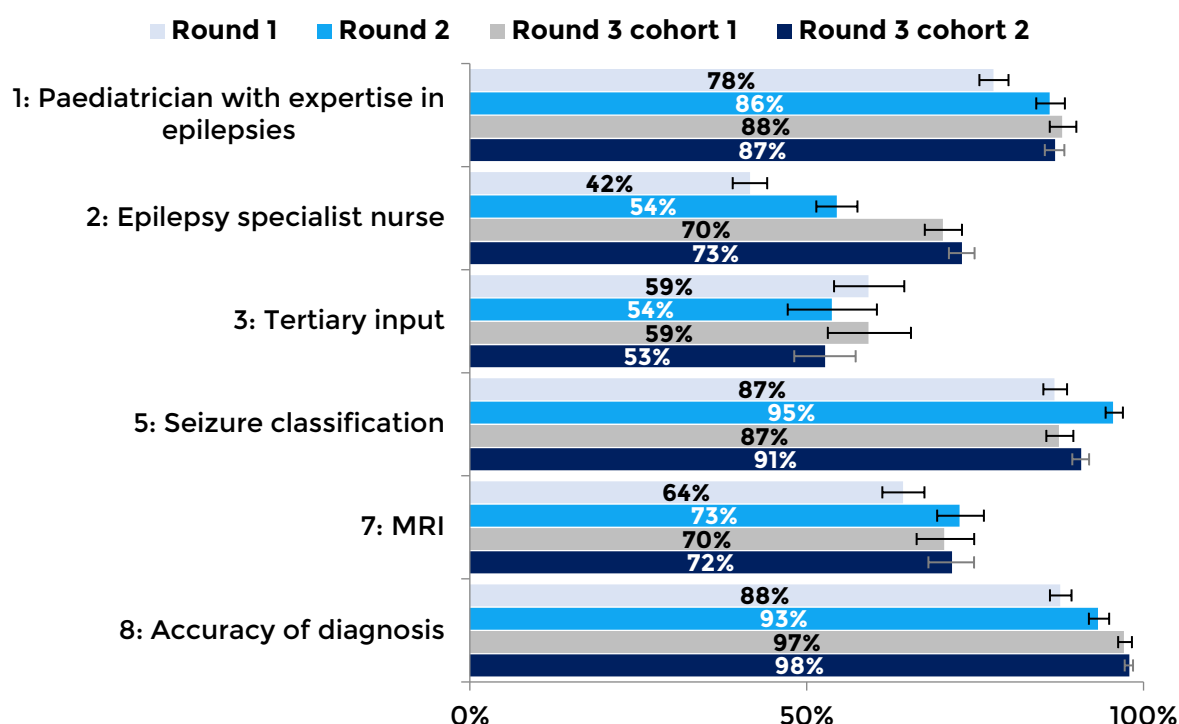


Figure 3: Epilepsy12 Performance indicators for England, across Rounds 1, 2, 3, cohort 1 and cohort 2.

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.

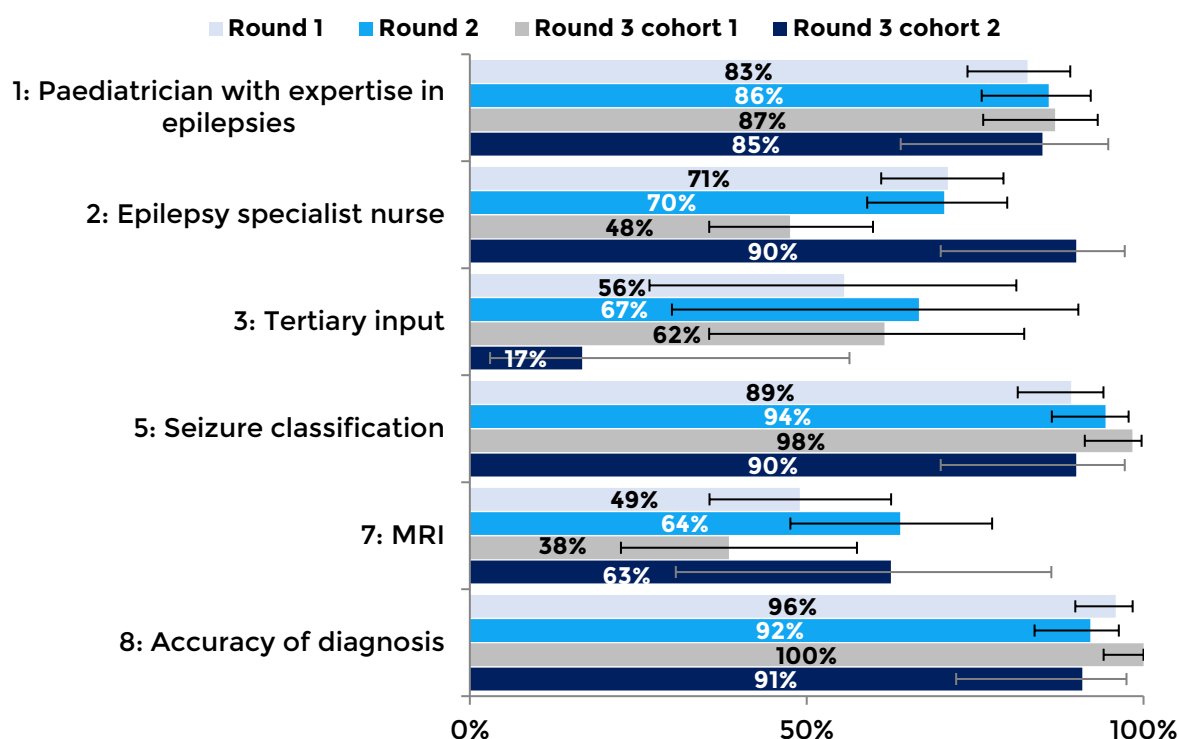


Figure 4: Epilepsy12 Performance indicators for Wales, across Rounds 1, 2, 3, cohort 1 and cohort 2.

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.

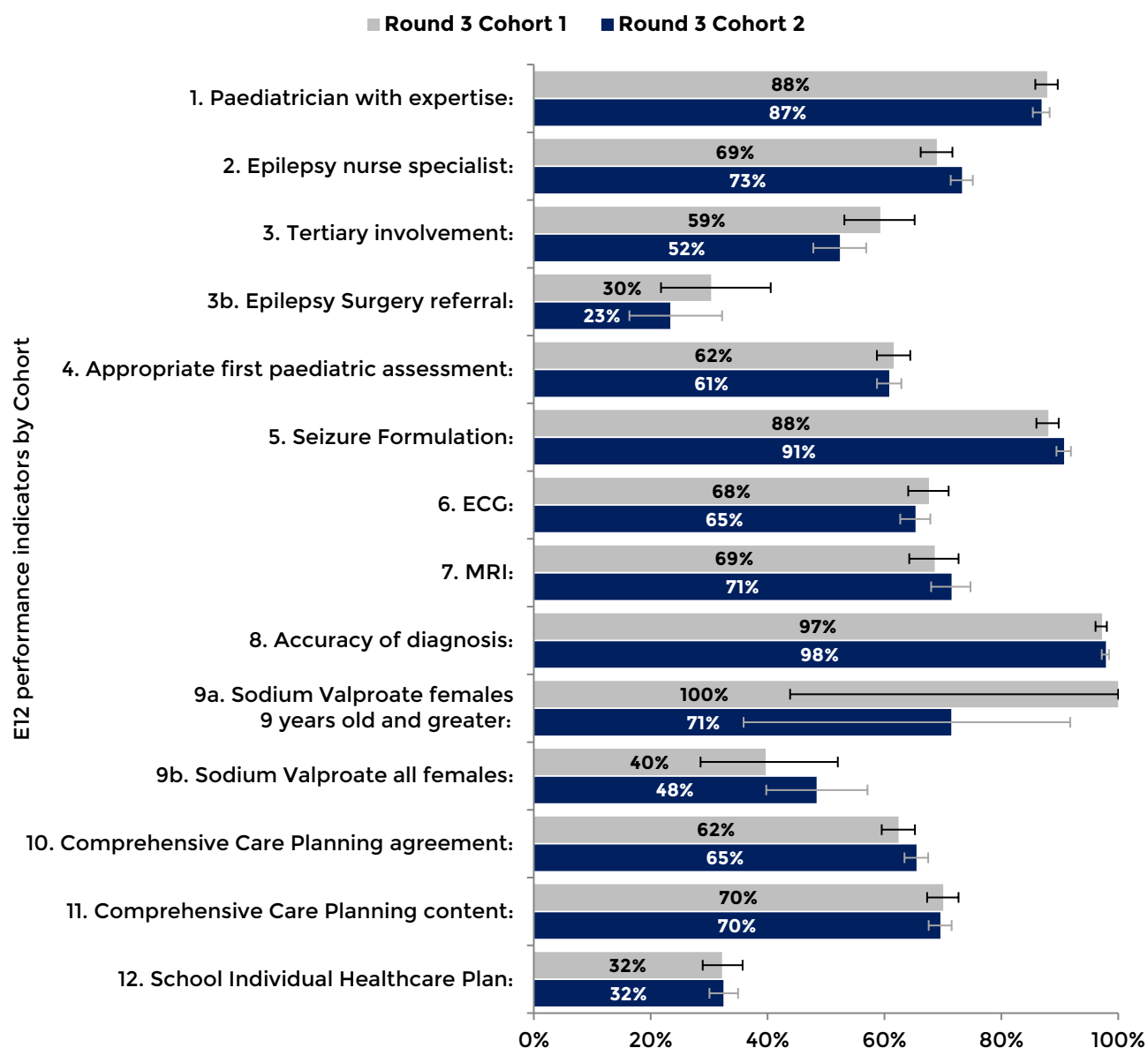


Figure 5: Epilepsy12 Performance indicators in England and Wales in Round 3 cohort 2 and Cohort 1.

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.

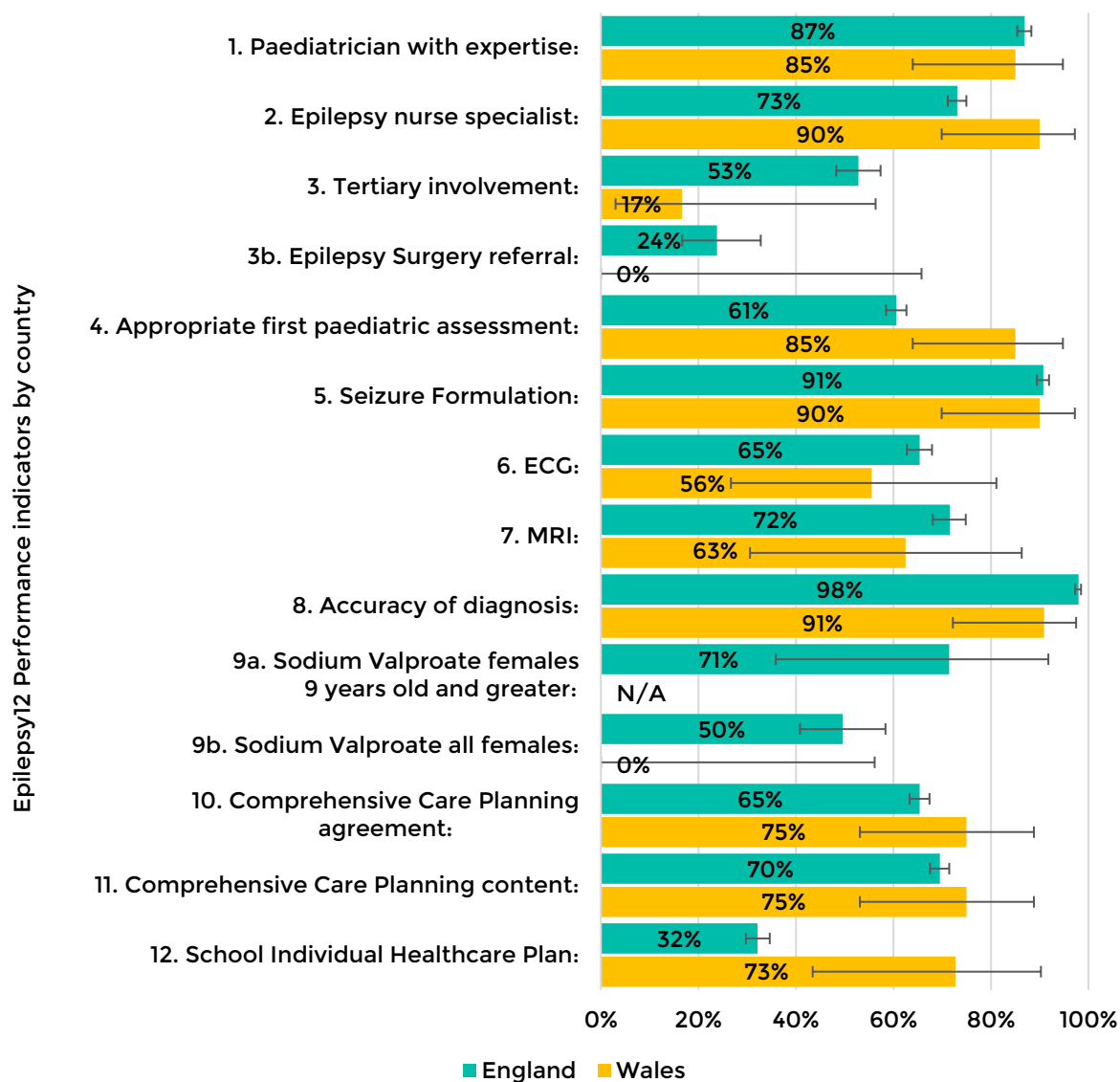


Figure 6: Epilepsy12 Performance indicators by country, Round 3 cohort 2.

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.

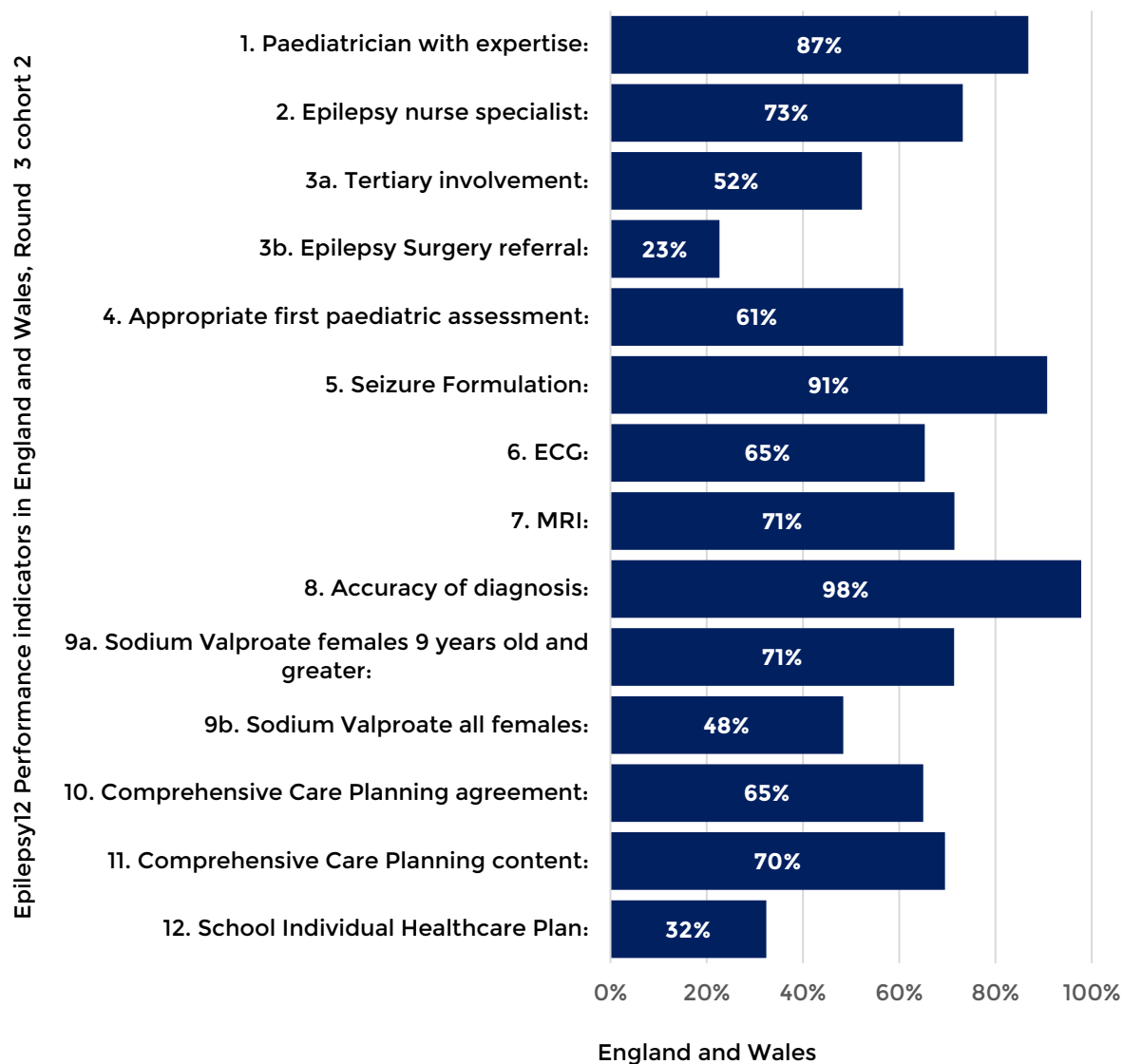


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Data completeness

The data submitted to Epilepsy12 shows that during the COVID-19 pandemic services have done very well to maintain care for children and young people with epilepsy. However, there were also services and aspects of 'timeliness' that indicate some of the risks and pressures in the system.

We recommend that epilepsy services be supported by their **Trust or Health Board's management** and the **commissioning organisations** to:

- develop a defined epilepsy team approach to service provision and service improvement,
- allocate time within job plans to support team functions including dedicated time for audit participation and related quality improvement actions.

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.

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 cohort 2 clinical and organisational audit in 2019-20.

Birmingham Regional Paediatric Neurology Forum (BRPNF)
Birmingham Women's and Children's NHS Foundation Trust*
South Warwickshire NHS Foundation Trust
The Dudley Group 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)
Nottingham University Hospitals NHS Trust
Sherwood Forest Hospitals NHS Foundation Trust
United Lincolnshire Hospitals NHS Trust
University Hospitals of Derby and Burton NHS Foundation Trust
Eastern Paediatric Epilepsy Network (EPEN)
Bedford Hospital NHS Trust
Cambridge University Hospitals NHS Foundation Trust
East and North Hertfordshire NHS Trust
East Suffolk and North Essex NHS Foundation Trust
Luton and Dunstable University Hospital NHS Foundation Trust
Norfolk Community Health and Care NHS Trust
North West Anglia NHS Foundation Trust
The Queen Elizabeth Hospital, King's Lynn, 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
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)
Barts Health NHS Trust
Central and North West London NHS Foundation Trust
Chelsea and Westminster Hospital NHS Foundation Trust
Homerton University Hospital NHS Foundation Trust
Imperial College Healthcare NHS Trust
London North West Healthcare NHS 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)
Bolton NHS Foundation Trust
East Cheshire NHS Trust*
East Lancashire Hospitals NHS Trust*
Manchester University NHS Foundation Trust
Northern Care Alliance NHS Group
Stockport NHS Foundation Trust*
Tameside and Glossop Integrated Care NHS Foundation Trust
University Hospitals of Morecambe Bay NHS Foundation Trust*
Wrightington, Wigan and Leigh NHS Foundation Trust
Oxford region epilepsy interest group (ORENG)
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)
County Durham and Darlington NHS Foundation Trust
Gateshead Health NHS Foundation Trust
North Cumbria Integrated Care NHS Foundation Trust

North Tees and Hartlepool NHS Foundation Trust
Northumbria Healthcare NHS Foundation Trust
South Tees Hospitals NHS Foundation Trust
South Tyneside and Sunderland NHS Foundation Trust
The Newcastle Upon Tyne Hospitals NHS Foundation Trust
South East Thames Paediatric Epilepsy Group (SETPEG)
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
South Wales Epilepsy Forum (SWEP)
Cwm Taf LHB
South West Interest Group Paediatric Epilepsy (SWIPE)
Gloucestershire Hospitals NHS Foundation Trust
Royal Cornwall Hospitals NHS Trust
Royal Devon and Exeter NHS Foundation Trust
Royal United Hospitals Bath NHS Foundation Trust
Somerset NHS Foundation Trust*
Torbay and South Devon NHS Foundation Trust
University Hospitals Bristol NHS Foundation Trust
South West Thames Paediatric Epilepsy Group (SWTPEG)
Ashford and St Peter's Hospitals NHS Foundation 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
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
Isle of Wight NHS Trust*
Poole Hospital NHS Foundation Trust
Salisbury NHS Foundation Trust
Western Sussex Hospitals NHS Foundation Trust*
Yorkshire Paediatric Neurology Network (YPEN)
Airedale NHS Foundation Trust
Bradford Teaching Hospitals NHS Foundation Trust
Harrogate and District NHS Foundation Trust
Hull and East Yorkshire Hospitals NHS Trust*
Leeds Teaching Hospitals NHS Trust
Mid Yorkshire Hospitals NHS Trust
York Teaching Hospital NHS Foundation Trust

*Trusts that were not included within the 2020 organisational results due to data that was not submitted on time to the audit.

The following Trusts merged prior to the November 2020 organisational audit.

Merged Trust title	Regional Network	Before Trusts merged
East Suffolk and North Essex NHS Foundation Trust	EPEN	Colchester Hospital University NHS Foundation Trust
		Ipswich Hospital NHS Trust
Northern care Alliance NHS Group	NWEIG	Salford Royal NHS Foundation Trust
		Northern Care Alliance NHS Group
South Tyneside and Sunderland NHS Foundation Trust	PENNEC	City Hospitals Sunderland NHS Foundation Trust
		South Tyneside NHS Foundation Trust
University Hospitals of Derby and Burton NHS Foundation Trust	CEWT	Derby Teaching Hospitals NHS Foundation Trust
		Burton Hospitals NHS Foundation Trust
Somerset NHS Foundation Trust	SWIPE	Taunton and Somerset NHS Foundation Trust
		Somerset Partnership NHS Foundation Trust
Swansea Bay UHB	SWEP	Abertawe Bro Morgannwg University Health Board

The following Trusts and Health Boards were not included within the cohort 2 clinical audit results:

Health Board or Trust	Regional Network
Swansea Bay UHB	SWEP
Aneurin Bevan LHB ⁺	SWEP
Barking, Havering and Redbridge University Hospitals NHS Trust	NTPEN
Basildon and Thurrock University Hospitals NHS Foundation Trust ⁺	NTPEN
Birmingham Community Healthcare NHS Foundation Trust	BRPNF
Blackpool Teaching Hospitals NHS Foundation Trust ⁺	NWEIG
Brighton and Sussex University Hospitals NHS Trust	SETPEG
Brighton and Sussex University Hospitals NHS Trust ⁺	SETPEG
Buckinghamshire Healthcare NHS Trust	ORENG
Calderdale and Huddersfield NHS Foundation Trust	YPEN
Cambridgeshire Community Services NHS Trust	EPEN
Cardiff & Vale University LHB ⁺	SWEP
Coventry and Warwickshire Partnership NHS Trust ⁺	BRPNF
Croydon Health Services NHS Trust ⁺	SWTPEG
George Eliot Hospital NHS Trust ⁺	BRPNF
Great Ormond Street Hospital for Children NHS Foundation Trust ~	NTPEN
Hampshire Hospitals NHS Foundation Trust	WPNN
Hywel Dda LHB	SWEP
James Paget University Hospitals NHS Foundation Trust ⁺	EPEN
Lancashire Teaching Hospitals NHS Foundation Trust	NWEIG
Leeds Community Healthcare NHS Trust ⁺	YPEN
Leicestershire Partnership NHS Trust	CEWT
Medway NHS Foundation Trust ⁺	SETPEG
Mid Cheshire Hospitals NHS Foundation Trust	EPIC
Mid Essex Hospital Services NHS Trust	EPEN
Norfolk and Norwich University Hospitals NHS Foundation Trust	EPEN
North East London NHS Foundation Trust ⁺	NTPEN
Northern Devon Healthcare NHS Trust ⁺	SWIPE
Plymouth Hospitals NHS Trust ⁺	SWIPE
Portsmouth Hospitals NHS Trust ⁺	WPNN
Sandwell and West Birmingham Hospitals NHS Trust ⁺	BRPNF
Solent NHS Trust	WPNN
Surrey and Sussex Healthcare NHS Trust ⁺	SWTPEG

Sussex Community NHS Foundation Trust ⁺	SETPEG
The Princess Alexandra Hospital NHS Trust ⁺	EPEN
The Royal Wolverhampton NHS Trust	BRPNF
University Hospitals Birmingham NHS Foundation Trust	BRPNF
University Hospitals of Leicester NHS Trust	CEWT
University Hospitals of North Midlands NHS Trust	NWEIG
West Suffolk NHS Foundation Trust	EPEN
Weston Area Health NHS Trust ⁺	SWIPE
Yeovil District Hospital NHS Foundation Trust ⁺	SWIPE

~Tertiary Trust that does not conduct first assessments for children with epilepsy or seizures.

+ Health Boards or Trusts that were not included within the 2018-2019 cohort 1 clinical audit results.

Epilepsy12

Combined organisational and clinical audits:
Report for England and Wales Round 3 Cohort 2 (2019-20)

Published by the RCPCH July 2021



**Healthcare Quality
Improvement Partnership (HQIP)**
Dawson House, 5 Jewry Street,
London EC3N 2EX



**Royal College of Paediatrics
and Child Health**
5-11 Theobalds Road,
London, WC1X 8SH

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