

EPILEPSY12

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

Extended Analysis B

2024 Organisational audit national & regional results

Round 4, November 2023

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Introduction

This report focuses on **2023 organisational data from Epilepsy12 Round 4**. This describes paediatric epilepsy services as at **1 November 2023**. Data has been presented here at **national** (England and Wales combined), **country** and two **regional** levels; NHS England regions and Organisation of Paediatric Epilepsy Networks in the UK (OPEN UK). The 2024 annual report and accompanying outputs can be found [here](#)

Round 1 and 2 of the organisational audit took place in 2009 and 2014, respectively. The 2018, 2019, 2020, and 2021 organisational audits took place under Round 3 of the audit, and from 2022 under Round 4.

Epilepsy12 organisational audit metrics are used as evidence of achievement in the treatment function code (TFC) 223 Paediatric Epilepsy Best Practice Criteria (BPC). The relevant measures are indicated by '**(BPC)**'

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

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

The NHS England (NHSE) regions are named below.

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

Participation

117 out of the 138 (84.8%) registered Health Boards and Trusts submitted and locked organisational audit data by 8th February 2024, which is a decrease from **91%** in the 2022 organisational audit.

The total number of registered Health Boards and Trusts varies across the years due to Trust mergers.

Participation decreased in England, from **91% (128/140)** in 2022 to **84% (111/132)** in 2023. Participation was **100% (6/6)** in 2022 and 2023 in Wales. **Figure 1** shows participation rates since 2018. **Table 1** provides a breakdown of Epilepsy12 Round 4, 2023 Organisational audit participation by country, NHS England region, and Organisation of Paediatric Epilepsy Networks.

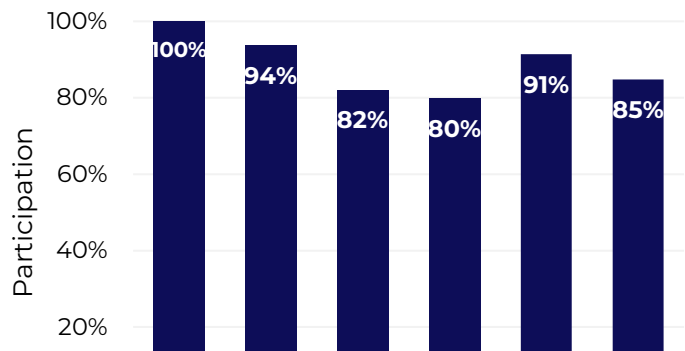


Figure 1: Percentage of Health Boards and Trusts that have completed the organisational audit between Round 1 and Round 4, 2023.

Table 1: Participation in the 2023 Organisational Audit by region.

Geographic Region	Number of HB/Ts registered	Percentage of HB/Ts that have a completed the Organisational Audit 2023
England and Wales	138	84.8% (117/138)
England	132	84.1% (111/132)
Wales	6	100% (6/6)
NHS England Region		
East of England	15	80% (12/15)
London	21	85.7% (18/21)
Midlands	26	76.0% (19/25)
North East and Yorkshire	22	95.5% (21/22)
North West	16	94.1% (16/17)
South East	20	75% (15/20)
South West	12	83.3% (10/12)
OPEN UK Region		
BRPNF	14	78.6% (11/14)
CEWT	6	66.7% (4/6)
EPEN	13	84.6% (11/13)
EPIC	8	100% (8/8)
NTPEN	15	80% (12/15)
NWEIG	12	83.3% (10/12)
ORENG	7	85.7% (6/7)

PENNEC	8	87.5% (7/8)
SETPEG	10	70% (7/10)
SWEP	5	100% (5/5)
SWIPE	8	87.5% (7/8)
SWTPEG	8	87.5% (7/8)
TEN	6	100% (6/6)
WPNN	9	77.8% (7/9)
YPEN	9	100% (9/9)

Workforce

The whole time equivalent (WTE) of consultant paediatricians with ‘expertise in epilepsy’ and Epilepsy Specialist Nurses (ESN) has increased steadily since Round 1, 2009 (**Figure 2**).

The mean WTE of paediatricians with ‘expertise in epilepsy’ and ESNs is greater in Wales than England, which is consistent with previous years. The mean WTE for paediatricians with expertise in epilepsy for a Health Board/Trust has increased since 2018 from **2.1** to **2.4** in England and **2.7** to **3.7** in Wales. Similarly, the mean WTE for ESNs epilepsy specialist nurses for a Health Board/Trust has increased since 2018 from **1.0** to **1.6** in England and **1.7** to **2.0** in Wales.

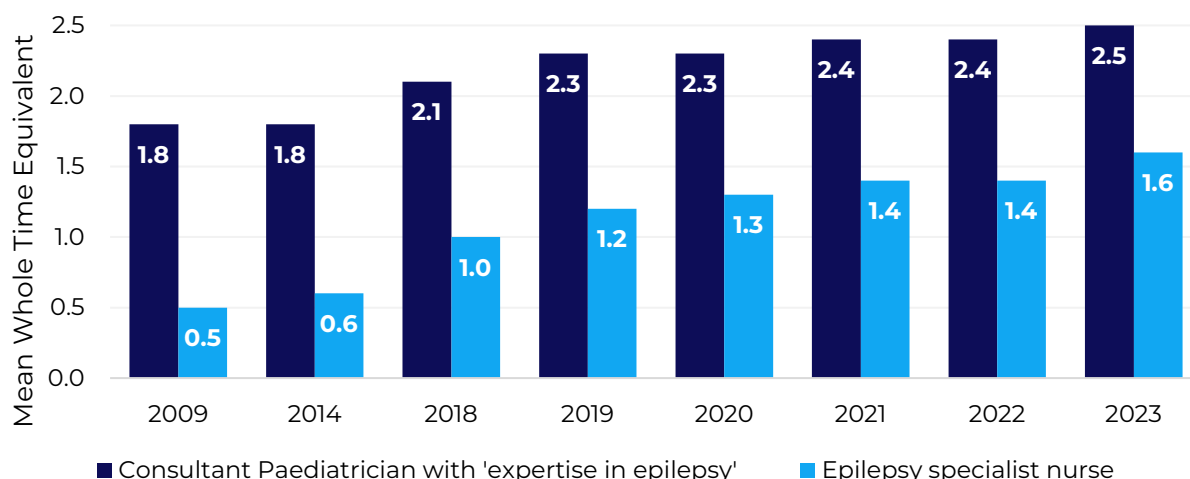


Figure 2: Mean Whole Time Equivalent (WTE) consultant paediatrician with ‘expertise in epilepsy’ and Epilepsy Specialist Nurse employed in Health Boards and Trusts across England and Wales in Rounds 1 – 4.

Consultant Paediatrician

All Health Boards and Trusts had at least some general paediatric consultant WTE, and **98% (115/117)** had a consultant paediatrician with ‘expertise in epilepsy’. This is consistent with the 2022 organisational audit. The mean WTE for general paediatric consultants is **17.2**, which is an increase from **16.8** in 2022.

Table 2: General paediatric consultant Whole Time Equivalent (WTE) by region.

Geographic Region	WTE General Paediatric Consultant			
	Percentage with some WTE	Total WTE	Mean WTE (Range)	Median WTE (Inter-quartile range)
England and Wales	100.0% (117/117)	2017.4	17.2 (5.0-42.0)	16.0 (12.0-20.7)
England	100.0% (111/111)	1879.2	16.9 (5.0-42.0)	16.0 (12.0-20.0)
Wales	100.0% (6/6)	138.2	23.0 (9.0-31.0)	24.1 (20.0-30.0)
NHS England Region				
East of England	100.0% (12/12)	163.7	13.6 (5.9-23.9)	13.0 (10.0-17.5)
London	100.0% (18/18)	338.0	18.8 (8.0-32.9)	18.6 (16.0-21.0)

Midlands	100.0% (19/19)	316.0	16.6 (5.0-36.5)	14.0 (12.0-21.5)
North East and Yorkshire	100.0% (21/21)	372.1	17.7 (7.9-35.0)	17.0 (13.0-21.0)
North West	100.0% (16/16)	272.5	17.0 (9.5-42.0)	14.6 (12.0-18.5)
South East	100.0% (15/15)	252.9	16.9 (7.0-29.3)	18.0 (11.1-20.0)
South West	100.0% (10/10)	164.1	16.4 (9.0-27.6)	13.5 (10.0-26.0)
OPEN UK Region				
BRPNF	100.0% (11/11)	152.4	13.9 (5.0-22.3)	13.4 (12.0-16.0)
CEWT	100.0% (4/4)	109.2	27.3 (20.7-36.5)	26.0 (21.4-33.2)
EPEN	100.0% (11/11)	150.7	13.7 (5.9-23.9)	13.0 (10.0-18.0)
EPIC	100.0% (8/8)	114.5	14.3 (9.5-30.0)	12.0 (11.0-14.5)
NTPEN	100.0% (12/12)	230.6	19.2 (8.0-32.9)	18.6 (12.6-25.5)
NWEIG	100.0% (10/10)	202.0	20.2 (13.6-42.0)	16.2 (14.2-23.6)
ORENG	100.0% (6/6)	102.6	17.1 (11.0-25.0)	17.3 (13.0-19.0)
PENNEC	100.0% (7/7)	143.9	20.6 (9.5-35.0)	20.0 (14.0-25.0)
SETPEG	100.0% (7/7)	117.8	16.8 (8.0-24.8)	17.0 (15.1-18.9)
SWEP	100.0% (5/5)	108.2	21.6 (9.0-31.0)	20.5 (20.0-27.7)
SWIPE	100.0% (7/7)	127.1	18.2 (9.0-27.6)	15.5 (9.5-27.5)
SWTPEG	100.0% (7/7)	134.5	19.2 (11.0-29.3)	19.6 (15.6-21.0)
TEN	100.0% (6/6)	83.8	14.0 (10.0-19.0)	12.8 (11.2-18.0)
WPNN	100.0% (7/7)	82.4	11.8 (7.0-20.0)	11.1 (7.3-15.0)
YPEN	100.0% (9/9)	157.8	17.5 (7.9-28.9)	16.8 (14.7-21.0)

Table 3: Consultant paediatrician with 'expertise in epilepsy' WTE by region.

Geographic Region	WTE Consultant Paediatrician with 'Expertise in Epilepsy'				
	Percentage with some WTE	Total WTE	Mean WTE (Range)	Excluding HBTs with zero WTE	
				Mean WTE (Range)	Median WTE (Inter-quartile range)
England and Wales	98.3% (115/117)	289.4	2.5 (0.0-9.0)	2.5 (0.2-9.0)	2.0 (1.5-3.0)
England	98.2% (109/111)	267.4	2.4 (0.0-9.0)	2.5 (0.2-9.0)	2.0 (1.5-3.0)
Wales	100.0% (6/6)	22.0	3.7 (0.8-7.6)	3.7 (0.8-7.6)	3.5 (2.6-4.0)
NHS England Region					
East of England	100.0% (12/12)	22.3	1.9 (0.6-4.0)	1.9 (0.6-4.0)	1.9 (1.0-2.2)
London	94.4% (17/18)	36.1	2.0 (0.0-7.0)	2.1 (0.7-7.0)	2.0 (1.0-2.5)
Midlands	94.7% (18/19)	49.3	2.6 (0.0-8.0)	2.7 (1.0-8.0)	2.0 (1.6-3.0)
North East and Yorkshire	100.0% (21/21)	60.3	2.9 (1.0-9.0)	2.9 (1.0-9.0)	2.0 (1.6-3.0)
North West	100.0% (16/16)	36.8	2.3 (0.2-4.5)	2.3 (0.2-4.5)	2.0 (1.6-3.0)
South East	100.0% (15/15)	39.7	2.6 (1.0-4.1)	2.6 (1.0-4.1)	2.9 (2.0-3.0)

South West	100.0% (10/10)	22.9	2.3 (1.0-4.8)	2.3 (1.0-4.8)	2.2 (1.2-3.0)
OPEN UK Region					
BRPNF	90.9% (10/11)	25.2	2.3 (0.0-8.0)	2.5 (1.0-8.0)	2.0 (1.3-3.0)
CEWT	100.0% (4/4)	12.5	3.1 (1.0-6.0)	3.1 (1.0-6.0)	2.8 (1.5-4.8)
EPEN	100.0% (11/11)	21.3	1.9 (0.6-4.0)	1.9 (0.6-4.0)	2.0 (1.0-2.5)
EPIC	100.0% (8/8)	26.0	3.3 (1.8-7.6)	3.3 (1.8-7.6)	2.8 (2.0-3.5)
NTPEN	91.7% (11/12)	26.7	2.2 (0.0-7.0)	2.4 (1.0-7.0)	2.0 (1.0-2.8)
NWEIG	100.0% (10/10)	21.3	2.1 (0.2-4.5)	2.1 (0.2-4.5)	2.0 (1.0-3.0)
ORENG	100.0% (6/6)	16.6	2.8 (1.0-5.0)	2.8 (1.0-5.0)	2.5 (1.6-4.0)
PENNEC	100.0% (7/7)	27.0	3.9 (1.2-9.0)	3.9 (1.2-9.0)	4.0 (2.0-4.3)
SETPEG	100.0% (7/7)	15.8	2.3 (1.0-3.0)	2.3 (1.0-3.0)	2.1 (1.7-3.0)
SWEP	100.0% (5/5)	14.4	2.9 (0.8-4.0)	2.9 (0.8-4.0)	3.0 (2.6-4.0)
SWIPE	100.0% (7/7)	17.7	2.5 (1.0-4.8)	2.5 (1.0-4.8)	2.6 (1.6-3.0)
SWTPEG	100.0% (7/7)	14.4	2.1 (0.7-4.1)	2.1 (0.7-4.1)	2.0 (1.0-3.0)
TEN	100.0% (6/6)	10.0	1.7 (1.0-3.0)	1.7 (1.0-3.0)	1.5 (1.0-2.0)
WPNN	100.0% (7/7)	15.1	2.2 (1.0-3.8)	2.2 (1.0-3.8)	2.2 (1.0-3.0)
YPEN	100.0% (9/9)	25.3	2.8 (1.0-9.0)	2.8 (1.0-9.0)	2.0 (1.8-2.5)

Table 4: The percentage of general paediatric workforce with 'expertise in epilepsy' and the percentage of Health Boards and Trusts with a paediatric epilepsy clinical lead by region. **(BPC)**

Geographic Region	Percentage of general paediatric workforce WTE with expertise in epilepsy	Percentage of HB/Ts with a defined paediatric epilepsy clinical lead
England and Wales	14.3% (289.4/2017.4)	89.7% (105/117)
England	14.2% (267.4/1879.2)	90.1% (100/111)
Wales	15.9% (22/138.2)	83.3% (5/6)
NHS England Region		
East of England	13.6% (22.3/163.7)	100.0% (12/12)
London	10.7% (36.1/338)	88.9% (16/18)
Midlands	15.6% (49.3/316)	89.5% (17/19)
North East and Yorkshire	16.2% (60.3/372.1)	85.7% (18/21)
North West	13.5% (36.8/272.5)	93.8% (15/16)
South East	15.7% (39.7/252.9)	86.7% (13/15)
South West	14.0% (22.9/164.1)	90.0% (9/10)
OPEN UK Region		
BRPNF	16.5% (25.2/152.4)	81.8% (9/11)
CEWT	11.4% (12.5/109.2)	100.0% (4/4)
EPEN	14.1% (21.3/150.7)	100.0% (11/11)
EPIC	22.7% (26/114.5)	87.5% (7/8)
NTPEN	11.6% (26.7/230.6)	83.3% (10/12)

NWEIG	10.5% (21.3/202)	100.0% (10/10)
ORENG	16.2% (16.6/102.6)	100.0% (6/6)
PENNEC	18.8% (27/143.9)	71.4% (5/7)
SETPEG	13.4% (15.8/117.8)	85.7% (6/7)
SWEP	13.3% (14.4/108.2)	80.0% (4/5)
SWIPE	13.9% (17.7/127.1)	85.7% (6/7)
SWTPEG	10.7% (14.4/134.5)	100.0% (7/7)
TEN	11.9% (10/83.8)	100.0% (6/6)
WPNN	18.3% (15.1/82.4)	85.7% (6/7)
YPEN	16.0% (25.3/157.8)	88.9% (8/9)

Epilepsy Specialist Nurse

In November 2023, the mean WTE for Epilepsy Specialist Nurses (ESNs) was **1.6**, which is an increase from **1.4** in 2023. **93% (109/117)** of Health Boards and Trusts in the audit had at least some ESN WTE, which is an increase from **91% (117/128)** in 2022, and a substantial increase from **49% (85/172)** in 2009 (**Figure 3**).

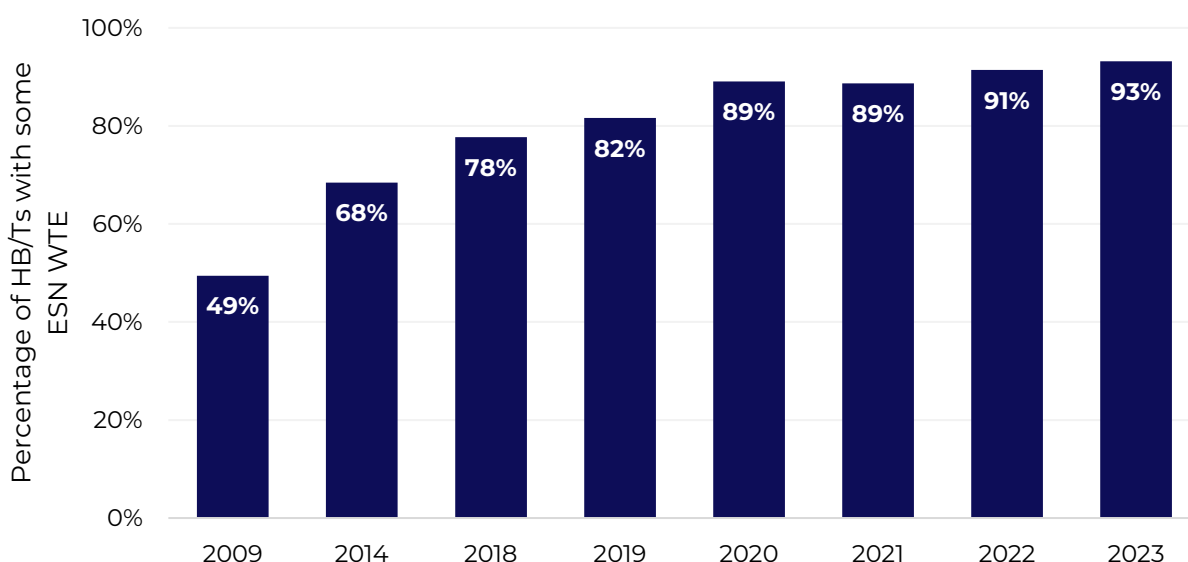


Figure 3: Percentage of Health Boards and Trusts in England and Wales with at least some Epilepsy Specialist Nurse (ESN) WTE, between Rounds 1 - 4.

Table 5: Epilepsy Specialist Nurse (ESN) WTE by region. (BPC)

Geographic Region	WTE Epilepsy Specialist Nurse				
	Percentage with some WTE	Total WTE	Mean WTE (Range)	Excluding HBTs with zero WTE	
				Mean WTE (Range)	Median WTE (Inter-quartile range)
England and Wales	93.2% (109/117)	188.6	1.6 (0.0-4.8)	1.7 (0.3-4.8)	1.6 (1.0-2.0)
England	93.7% (104/111)	176.6	1.6 (0.0-4.8)	1.7 (0.3-4.8)	1.6 (1.0-2.0)
Wales	83.3% (5/6)	12.0	2.0 (0.0-3.4)	2.4 (1.0-3.4)	2.8 (1.8-3.0)

NHS England Region					
East of England	91.7% (11/12)	15.0	1.2 (0.0-2.6)	1.4 (0.6-2.6)	1.0 (0.7-2.0)
London	100.0% (18/18)	29.3	1.6 (0.8-3.7)	1.6 (0.8-3.7)	1.1 (1.0-2.0)
Midlands	84.2% (16/19)	25.6	1.3 (0.0-3.8)	1.6 (0.8-3.8)	1.1 (1.0-2.0)
North East and Yorkshire	100.0% (21/21)	40.1	1.9 (0.6-4.8)	1.9 (0.6-4.8)	1.8 (1.2-2.3)
North West	100.0% (16/16)	31.6	2.0 (1.0-4.0)	2.0 (1.0-4.0)	2.0 (1.1-2.4)
South East	80.0% (12/15)	17.2	1.1 (0.0-2.5)	1.4 (0.6-2.5)	1.8 (1.0-2.0)
South West	100.0% (10/10)	17.7	1.8 (0.3-3.4)	1.8 (0.3-3.4)	1.5 (1.0-2.0)
OPEN UK Region					
BRPNF	72.7% (8/11)	9.9	0.9 (0.0-2.0)	1.2 (0.8-2.0)	1.0 (0.9-1.6)
CEWT	100.0% (4/4)	9.8	2.5 (1.0-3.8)	2.5 (1.0-3.8)	2.5 (1.5-3.4)
EPEN	100.0% (11/11)	15.0	1.4 (0.6-2.6)	1.4 (0.6-2.6)	1.0 (0.7-2.0)
EPIC	100.0% (8/8)	15.4	1.9 (1.0-3.8)	1.9 (1.0-3.8)	1.8 (1.0-2.5)
NTPEN	100.0% (12/12)	20.2	1.7 (1.0-3.7)	1.7 (1.0-3.7)	1.1 (1.0-2.2)
NWEIG	100.0% (10/10)	20.0	2.0 (1.0-4.0)	2.0 (1.0-4.0)	2.0 (1.2-2.6)
ORENG	66.7% (4/6)	4.6	0.8 (0.0-2.0)	1.2 (0.6-2.0)	1.0 (0.8-1.5)
PENNEC	100.0% (7/7)	12.0	1.7 (1.0-2.6)	1.7 (1.0-2.6)	1.8 (1.0-2.3)
SETPEG	85.7% (6/7)	11.2	1.6 (0.0-3.0)	1.9 (1.3-3.0)	1.7 (1.5-2.0)
SWEP	80.0% (4/5)	9.2	1.8 (0.0-3.4)	2.3 (1.0-3.4)	2.4 (1.4-3.2)
SWIPE	100.0% (7/7)	13.5	1.9 (0.3-3.4)	1.9 (0.3-3.4)	1.8 (1.0-3.3)
SWTPEG	100.0% (7/7)	8.4	1.2 (0.8-2.0)	1.2 (0.8-2.0)	1.0 (1.0-1.6)
TEN	100.0% (6/6)	12.7	2.1 (1.0-4.3)	2.1 (1.0-4.3)	2.0 (1.5-2.0)
WPNN	85.7% (6/7)	9.3	1.3 (0.0-2.5)	1.5 (0.6-2.5)	1.7 (0.8-2.0)
YPEN	100.0% (9/9)	17.3	1.9 (0.6-4.8)	1.9 (0.6-4.8)	1.8 (1.2-2.3)

Epilepsy Specialist Nurse Functions

Figure 4 shows the percentage of Health Boards and Trusts supporting key ESN functions. More than **90%** of Health Boards and Trusts offer ESN support for school meetings, School IHP (Individual Healthcare plan) facilitation, and rescue medication for parents. All functions had an increase in support from 2022, apart from home visits, which decreased to **72% (84/117)** from **74% (95/128)** in 2022.

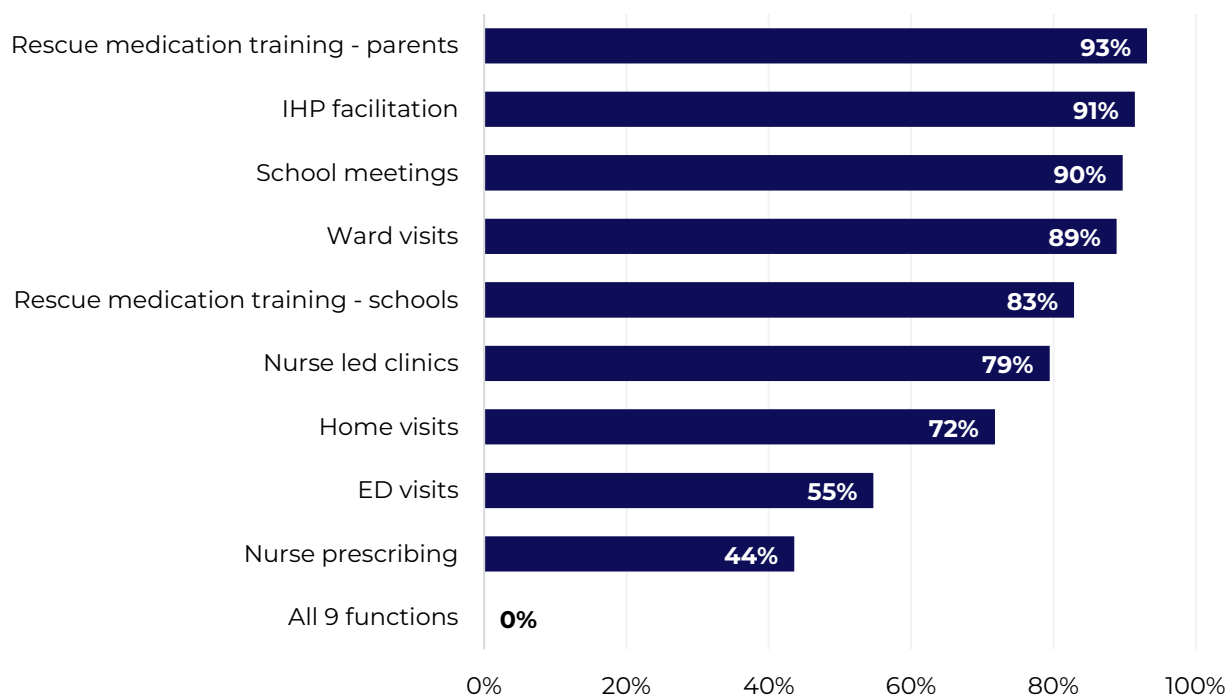


Figure 4: Epilepsy Specialist Nurse (ESN) functions supported.

Table 6: Percentage of Health Boards and Trusts supporting each Epilepsy Specialist Nurse (ESN) function in England and Wales.

Epilepsy Specialist Nurse Function	All Health Boards and Trusts			Health Boards and Trusts with some WTE ESN		
	England and Wales	England	Wales	England and Wales	England	Wales
All 9 functions	21.4% (25/117)	22.5% (25/111)	0.0% (0/6)	22.9% (25/109)	24.0% (25/104)	0.0% (0/5)
ED visits	54.7% (64/117)	57.7% (64/111)	0.0% (0/6)	58.7% (64/109)	61.5% (64/104)	0.0% (0/5)
Home visits	71.8% (84/117)	73.0% (81/111)	50.0% (3/6)	77.1% (84/109)	77.9% (81/104)	60.0% (3/5)
School individual healthcare plan facilitation	91.5% (107/117)	91.9% (102/111)	83.3% (5/6)	98.2% (107/109)	98.1% (102/104)	100.0% (5/5)
Nurse led clinics	79.5% (93/117)	79.3% (88/111)	83.3% (5/6)	85.3% (93/109)	84.6% (88/104)	100.0% (5/5)
Nurse prescribing	43.6% (51/117)	45.0% (50/111)	16.7% (1/6)	46.8% (51/109)	48.1% (50/104)	20.0% (1/5)
Rescue medication training for parents	93.2% (109/117)	93.7% (104/111)	83.3% (5/6)	100.0% (109/109)	100.0% (104/104)	100.0% (5/5)
Rescue medication training for schools	82.9% (97/117)	82.9% (92/111)	83.3% (5/6)	89.0% (97/109)	88.5% (92/104)	100.0% (5/5)
School meetings	89.7% (105/117)	90.1% (100/111)	83.3% (5/6)	96.3% (105/109)	96.2% (100/104)	100.0% (5/5)

Ward visits	88.9% (104/117)	89.2% (99/111)	83.3% (5/6)	95.4% (104/109)	95.2% (99/104)	100.0% (5/5)
None of the above	0.0% (0/117)	0.0% (0/111)	0.0% (0/6)	0.0% (0/109)	0.0% (0/104)	0.0% (0/5)

Clinic configuration

Defined epilepsy clinics

92% (108/117) of Health Boards and Trusts had a defined epilepsy clinic for patients at secondary level, which is consistent with the 2022 organisational audit. Of those, **83% (97/117)** held clinics that allowed at least 20 minutes with a consultant with expertise in epilepsy and an ESN, either simultaneously or in succession (**Table 7**).

Figure 5 shows that the mean number of consultant or associate specialist-led secondary level clinics has increased since Round 1 but remains constant between 2022 and 2023.

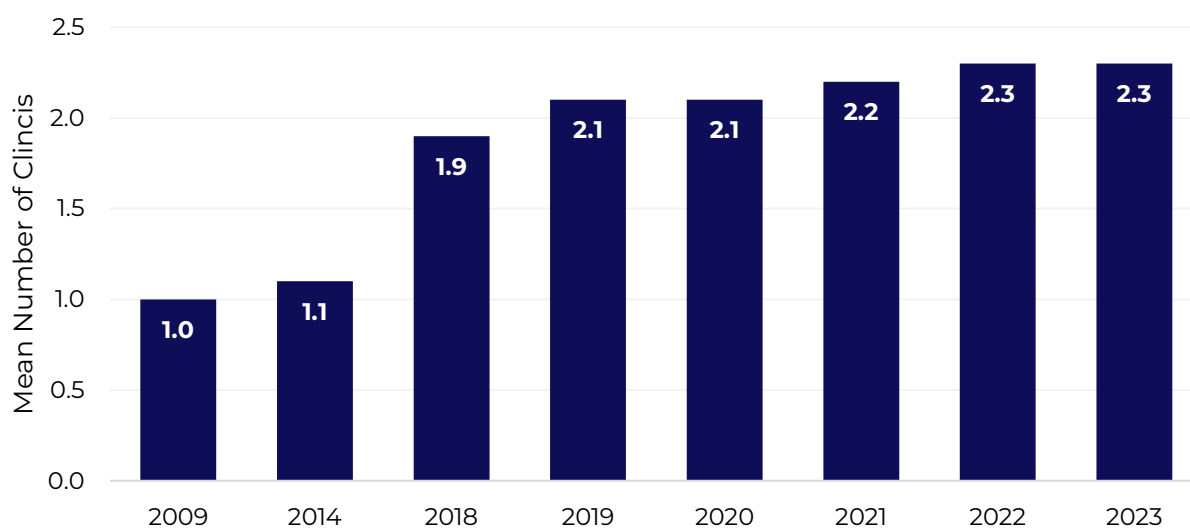


Figure 5: Mean number of secondary-level epilepsy clinics led by consultant or associate specialist in Round 1 to Round 4, November 2023.

Table 7: Percentage of Health Boards and Trusts with defined epilepsy clinics and the number of clinics per week, by region. (**BPC**)

Geographic Region	Defined epilepsy clinics per week				Percentage of clinics that allow ≥20 minutes with a paediatrician with expertise and an ESN
	Percentage with a defined epilepsy clinic	Total	Median (Inter-quartile range)	Mean (Range)	
England and Wales	92.3% (108/117)	265.2	2.0 (1.2-3.0)	2.3 (0.0-7.0)	89.8% (97/108)
England	92.8% (103/111)	249.9	2.0 (1.0-3.0)	2.3 (0.0-7.0)	90.3% (93/103)
Wales	83.3% (5/6)	15.3	3.0 (2.0-3.3)	2.5 (0.0-4.0)	80% (4/5)
NHS England Region					
East of England	91.7% (11/12)	22.3	1.8 (1.0-2.8)	1.9 (0.0-3.5)	100% (11/11)
London	94.4% (17/18)	48.5	2.4 (1.5-3.0)	2.7 (0.0-6.3)	88.2% (15/17)

Midlands	84.2% (16/19)	35.5	1.9 (1.5-2.5)	2.2 (1.0-6.5)	93.8% (15/16)
North East and Yorkshire	95.2% (20/21)	46.1	2.0 (1.0-2.8)	2.2 (0.0-4.0)	80% (16/20)
North West	100.0% (16/16)	37.8	2.0 (1.6-3.0)	2.4 (1.0-5.0)	93.8% (15/16)
South East	93.3% (14/15)	37.4	2.5 (1.5-4.0)	2.5 (0.0-4.5)	85.7% (12/14)
South West	90.0% (9/10)	22.4	1.8 (1.0-2.8)	2.2 (0.0-7.0)	100% (9/9)
OPEN UK Region					
BRPNF	72.7% (8/11)	15.7	1.5 (0.0-2.0)	1.4 (0.0-4.0)	100% (8/8)
CEWT	100.0% (4/4)	11.5	1.8 (1.5-4.2)	2.9 (1.5-6.5)	75% (3/4)
EPEN	90.9% (10/11)	21.3	2.0 (1.0-3.0)	1.9 (0.0-3.5)	100% (10/10)
EPIC	100.0% (8/8)	18.4	2.4 (1.6-3.0)	2.3 (1.0-3.3)	87.5% (7/8)
NTPEN	91.7% (11/12)	30.5	1.9 (1.1-3.4)	2.5 (0.0-6.3)	81.8% (9/11)
NWEIG	100.0% (10/10)	25.8	2.0 (1.8-3.0)	2.6 (1.0-5.0)	100% (10/10)
ORENG	100.0% (6/6)	7.6	1.2 (1.0-1.5)	1.3 (0.1-2.5)	66.7% (4/6)
PENNEC	100.0% (7/7)	17.5	2.8 (1.0-4.0)	2.5 (0.5-4.0)	71.4% (5/7)
SETPEG	100.0% (7/7)	23.8	3.0 (2.2-4.0)	3.4 (1.5-6.0)	100% (7/7)
SWEP	80.0% (4/5)	12.0	3.0 (2.0-3.0)	2.4 (0.0-4.0)	75% (3/4)
SWIPE	85.7% (6/7)	13.3	2.0 (1.0-2.8)	1.9 (0.0-3.9)	100% (6/6)
SWTPEG	100.0% (7/7)	20.5	2.8 (2.0-4.0)	2.9 (2.0-4.5)	100% (7/7)
TEN	100.0% (6/6)	9.3	1.9 (1.0-2.0)	1.5 (0.5-2.0)	83.3% (5/6)
WPNN	85.7% (6/7)	17.1	1.6 (0.5-4.0)	2.4 (0.0-7.0)	100% (6/6)
YPEN	88.9% (8/9)	21.1	2.5 (2.0-2.8)	2.3 (0.0-4.0)	87.5% (7/8)

Epilepsy Best Practice Criteria (BPC) – England Only

38% (42/111) of Trusts in England were running epilepsy clinics to the treatment function code (TFC) 223 Best Practice Criteria (BPC) standards. This figure has decreased over time (**Figure 6**).

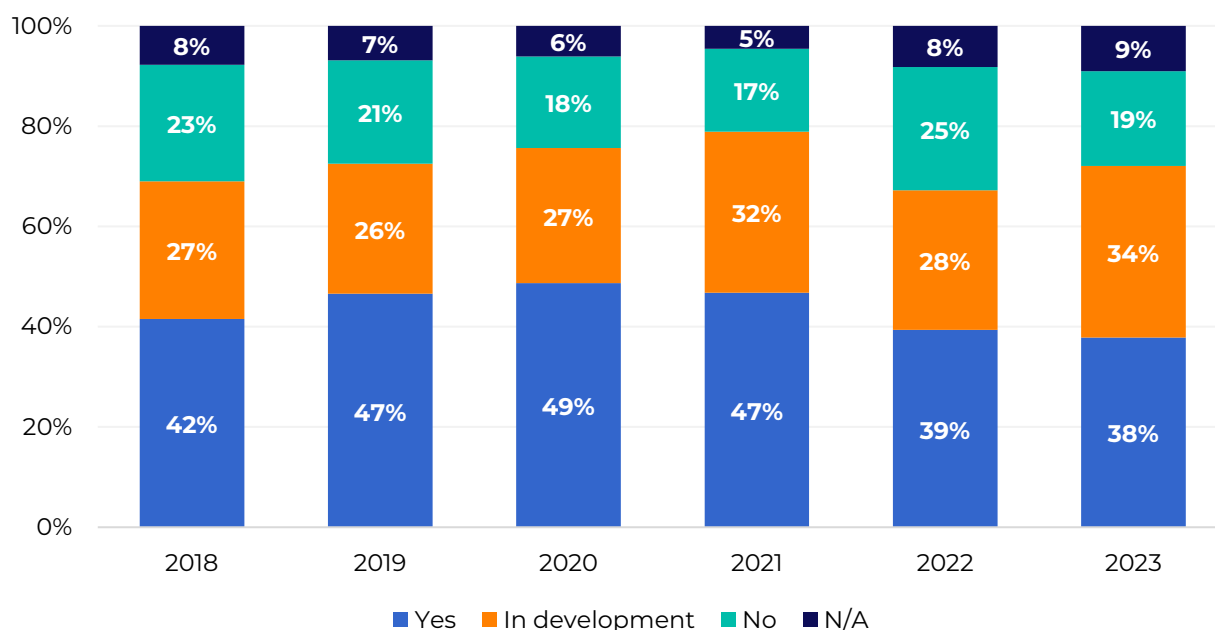


Figure 6: Percentage of Trusts in England receiving TFC 223 Epilepsy Best Practice Criteria between 2018 and 2023.

Table 8: Percentage of Trusts in England receiving TFC 223 Epilepsy Best Practice Criteria, by NHS England region.

Geographic Region	TFC 223 Epilepsy Best Practice Criteria			
	Yes	In development	No	N/A
England	37.8% (42/111)	34.2% (38/111)	18.9% (21/111)	9.0% (10/111)
NHS England Region				
East of England	33.3% (4/12)	8.3% (1/12)	33.3% (4/12)	25.0% (3/12)
London	27.8% (5/18)	38.9% (7/18)	11.1% (2/18)	22.2% (4/18)
Midlands	36.8% (7/19)	26.3% (5/19)	31.6% (6/19)	5.3% (1/19)
North East and Yorkshire	52.4% (11/21)	38.1% (8/21)	4.8% (1/21)	4.8% (1/21)
North West	18.8% (3/16)	56.2% (9/16)	25.0% (4/16)	0.0% (0/16)
South East	40.0% (6/15)	33.3% (5/15)	20.0% (3/15)	6.7% (1/15)
South West	60.0% (6/10)	30.0% (3/10)	10.0% (1/10)	0.0% (0/10)

Tertiary Provision

Paediatric Neurology Services

A total of **97.2** WTE consultant paediatric neurologists responsible for managing the care of children and young people with epilepsy, both acutely and non-acutely, were employed across England and Wales in 2023. **20% (23/117)** of Health Boards and Trusts had at least some paediatric neurologist WTE, which is an increase from **16% (21/128)** in 2022 (**Table 9**).

95% (111/117) of Health Boards and Trusts had agreed referral pathways

to tertiary paediatric neurology services (**Table 11**), which is consistent with previous years. Two thirds (65.0%) hosted satellite paediatric neurology clinics in 2023 (**Table 12**).

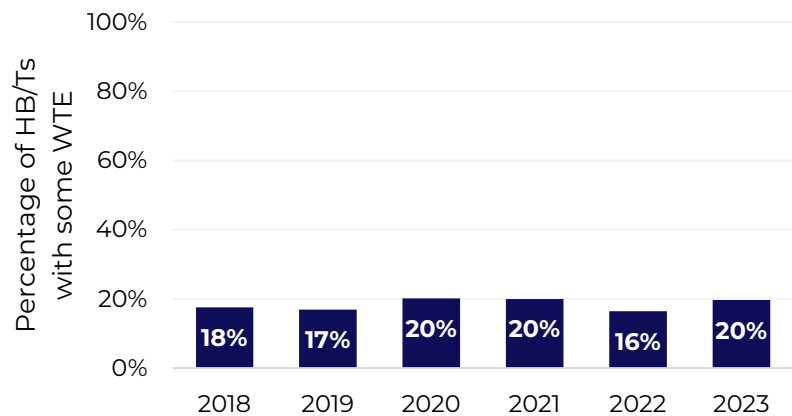


Figure 7: Percentage of Health Boards and Trusts with a Paediatric Neurologist employed across England and Wales since 2018.

Table 9: Paediatric neurologist whole time equivalent (WTE) by region.

Geographic Region	WTE Paediatric Neurologist				
	Percentage with some WTE	Total WTE	Mean WTE (Range)	Excluding HBTs with zero WTE	
				Mean WTE (Range)	Median WTE (Inter-quartile range)
England and Wales	19.7% (23/117)	97.2	0.8 (0.0-10.6)	4.2 (0.0-10.6)	4.0 (2.8-6.0)
England	19.8% (22/111)	94.4	0.9 (0.0-10.6)	4.3 (0.0-10.6)	4.2 (2.8-6.0)
Wales	16.7% (1/6)	2.8	0.5 (0.0-2.8)	2.8 (2.8-2.8)	2.8 (2.8-2.8)
NHS England Region					
East of England	8.3% (1/12)	4.4	0.4 (0.0-4.4)	4.4 (4.4-4.4)	4.4 (4.4-4.4)
London	38.9% (7/18)	31.1	1.7 (0.0-10.6)	4.4 (1.7-10.6)	4.0 (2.8-5.0)
Midlands	10.5% (2/19)	9.0	0.5 (0.0-6.0)	4.5 (3.0-6.0)	4.5 (3.0-6.0)
North East and Yorkshire	23.8% (5/21)	16.4	0.8 (0.0-5.0)	3.3 (0.0-5.0)	4.3 (2.6-4.5)
North West	25.0% (4/16)	13.0	0.8 (0.0-7.2)	3.2 (1.0-7.2)	2.4 (1.5-5.0)
South East	13.3% (2/15)	12.5	0.8 (0.0-6.5)	6.2 (6.0-6.5)	6.2 (6.0-6.5)
South West	10.0% (1/10)	8.0	0.8 (0.0-8.0)	8.0 (8.0-8.0)	8.0 (8.0-8.0)
OPEN UK Region					

BRPNF	9.1% (1/11)	6.0	0.5 (0.0-6.0)	6.0 (6.0-6.0)	6.0 (6.0-6.0)
CEWT	25.0% (1/4)	3.0	0.8 (0.0-3.0)	3.0 (3.0-3.0)	3.0 (3.0-3.0)
EPEN	9.1% (1/11)	4.4	0.4 (0.0-4.4)	4.4 (4.4-4.4)	4.4 (4.4-4.4)
EPIC	12.5% (1/8)	2.8	0.3 (0.0-2.8)	2.8 (2.8-2.8)	2.8 (2.8-2.8)
NTPEN	33.3% (4/12)	18.1	1.5 (0.0-10.6)	4.5 (1.7-10.6)	2.9 (2.2-6.8)
NWEIG	30.0% (3/10)	10.2	1.0 (0.0-7.2)	3.4 (1.0-7.2)	2.0 (1.0-7.2)
ORENG	16.7% (1/6)	6.0	1.0 (0.0-6.0)	6.0 (6.0-6.0)	6.0 (6.0-6.0)
PENNEC	14.3% (1/7)	4.3	0.6 (0.0-4.3)	4.3 (4.3-4.3)	4.3 (4.3-4.3)
SETPEG	28.6% (2/7)	9.0	1.3 (0.0-5.0)	4.5 (4.0-5.0)	4.5 (4.0-5.0)
SWEP	20.0% (1/5)	2.8	0.6 (0.0-2.8)	2.8 (2.8-2.8)	2.8 (2.8-2.8)
SWIPE	14.3% (1/7)	8.0	1.1 (0.0-8.0)	8.0 (8.0-8.0)	8.0 (8.0-8.0)
SWTPEG	14.3% (1/7)	4.0	0.6 (0.0-4.0)	4.0 (4.0-4.0)	4.0 (4.0-4.0)
TEN	33.3% (2/6)	9.5	1.6 (0.0-5.0)	4.8 (4.5-5.0)	4.8 (4.5-5.0)
WPNN	14.3% (1/7)	6.5	0.9 (0.0-6.5)	6.5 (6.5-6.5)	6.5 (6.5-6.5)
YPEN	22.2% (2/9)	2.6	0.3 (0.0-2.6)	1.9 (0.6-4.8)	1.3 (0.0-2.6)

Table 10: Percentage of Health Boards and Trusts where paediatric neurology can receive referrals from emergency departments (ED) or GP in England and Wales.

Can receive paediatric neurology referrals from ED or GP	England and Wales	England	Wales
Yes	15.4% (18/117)	16.2% (18/111)	0.0% (0/6)
No	63.2% (74/117)	61.3% (68/111)	100.0% (6/6)
N/A	21.4% (25/117)	22.5% (25/111)	0.0% (0/6)

Table 11: Percentage of Health Boards and Trusts with agreed referral pathways to paediatric neurology by region.

Geographic Region	Direct referral pathways to paediatric neurology	
	Yes	No
England and Wales	94.9% (111/117)	5.1% (6/117)
England	94.6% (105/111)	5.4% (6/111)
Wales	100.0% (6/6)	0.0% (0/6)
NHS England Region		
East of England	100.0% (12/12)	0.0% (0/12)
London	100.0% (18/18)	0.0% (0/18)
Midlands	89.5% (17/19)	10.5% (2/19)
North East and Yorkshire	95.2% (20/21)	4.8% (1/21)
North West	81.2% (13/16)	18.7% (3/16)
South East	100.0% (15/15)	0.0% (0/15)
South West	100.0% (10/10)	0.0% (0/10)
OPEN UK Region		
BRPNF	90.9% (10/11)	9.1% (1/11)

CEWT	75.0% (3/4)	25.0% (1/4)
EPEN	100.0% (11/11)	0.0% (0/11)
EPIC	75.0% (6/8)	25.0% (2/8)
NTPEN	100.0% (12/12)	0.0% (0/12)
NWEIG	90.0% (9/10)	10.0% (1/10)
ORENG	100.0% (6/6)	0.0% (0/6)
PENNEC	85.7% (6/7)	14.3% (1/7)
SETPEG	100.0% (7/7)	0.0% (0/7)
SWEP	100.0% (5/5)	0.0% (0/5)
SWIPE	100.0% (7/7)	0.0% (0/7)
SWTPEG	100.0% (7/7)	0.0% (0/7)
TEN	100.0% (6/6)	0.0% (0/6)
WPNN	100.0% (7/7)	0.0% (0/7)
YPEN	100.0% (9/9)	0.0% (0/9)

Table 12: Percentage of Health Boards and Trusts host satellite paediatric neurology clinics in England and Wales.

Hosts satellite paediatric neurology clinics	England and Wales	England	Wales
Yes	65.0% (76/117)	63.1% (70/111)	100.0% (6/6)
No	32.5% (38/117)	34.2% (38/111)	0.0% (0/6)
N/A	2.6% (3/117)	2.7% (3/111)	0.0% (0/6)

Other Services

The percentage of Health Boards and Trusts that facilitate ketogenic diet services and vagal nerve stimulator services has increased since 2022 (**Figure 8**).

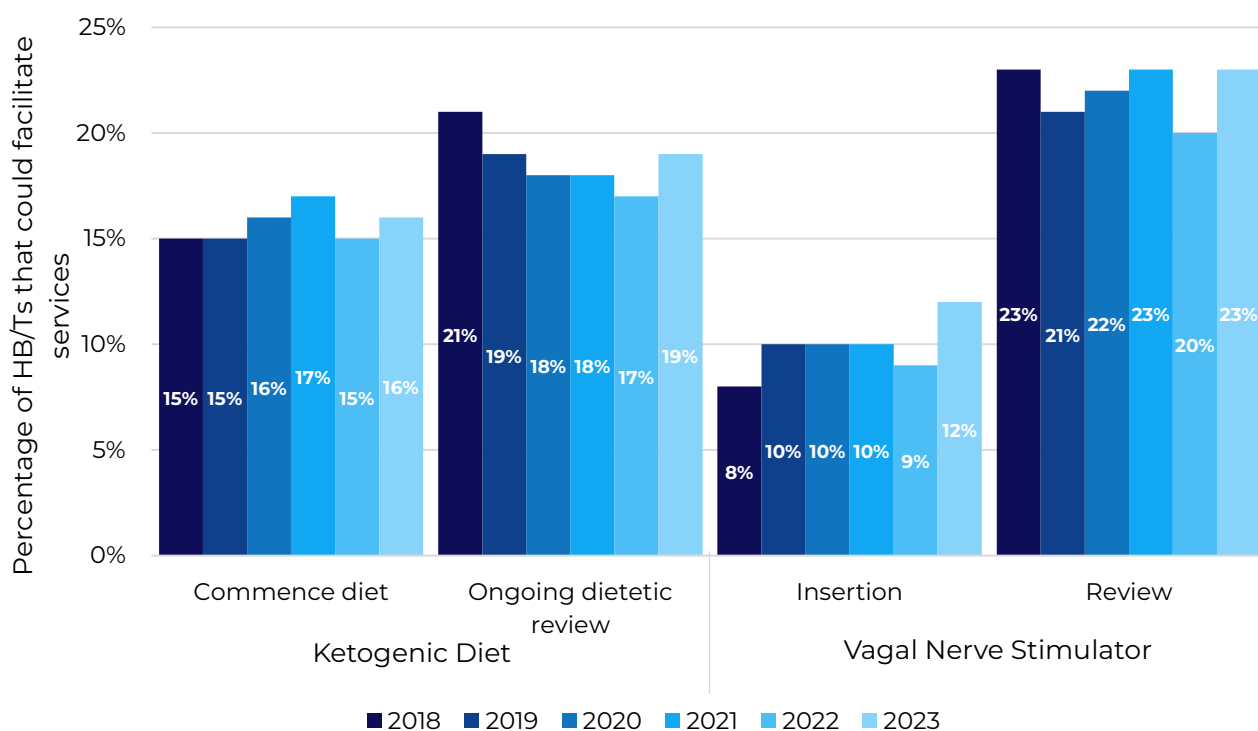


Figure 8: The percentage of Health Boards and Trusts that can facilitate ketogenic diet and vagal nerve stimulator services in England and Wales, between 2018 and 2023.

Table 13: Percentage of Health Boards and Trusts that could facilitate ketogenic diet and vagal nerve stimulator services in England and Wales.

Other services	England and Wales	England	Wales
Ketogenic diet Commence			
Yes	16.2% (19/117)	16.2% (18/111)	16.7% (1/6)
No	83.8% (98/117)	83.8% (93/111)	83.3% (5/6)
Ketogenic diet Review			
Yes	18.8% (22/117)	18.9% (21/111)	16.7% (1/6)
No	81.2% (95/117)	81.1% (90/111)	83.3% (5/6)
Vagal nerve stimulator Insertion			
Yes	12.0% (14/117)	12.6% (14/111)	0.0% (0/6)
No	88.0% (103/117)	87.4% (97/111)	100.0% (6/6)
Vagal nerve stimulator Review			
Yes	23.1% (27/117)	20.7% (23/111)	66.7% (4/6)
No	76.9% (90/117)	79.3% (88/111)	33.3% (2/6)

Investigations

Figure 9 shows that the percentage of Health Boards and Trusts that could provide epilepsy investigation services in England and Wales in 2023. Provision of all investigations either increased or remained the same compared to 2022. Whole genome sequencing was introduced into the organisational audit dataset for 2023.

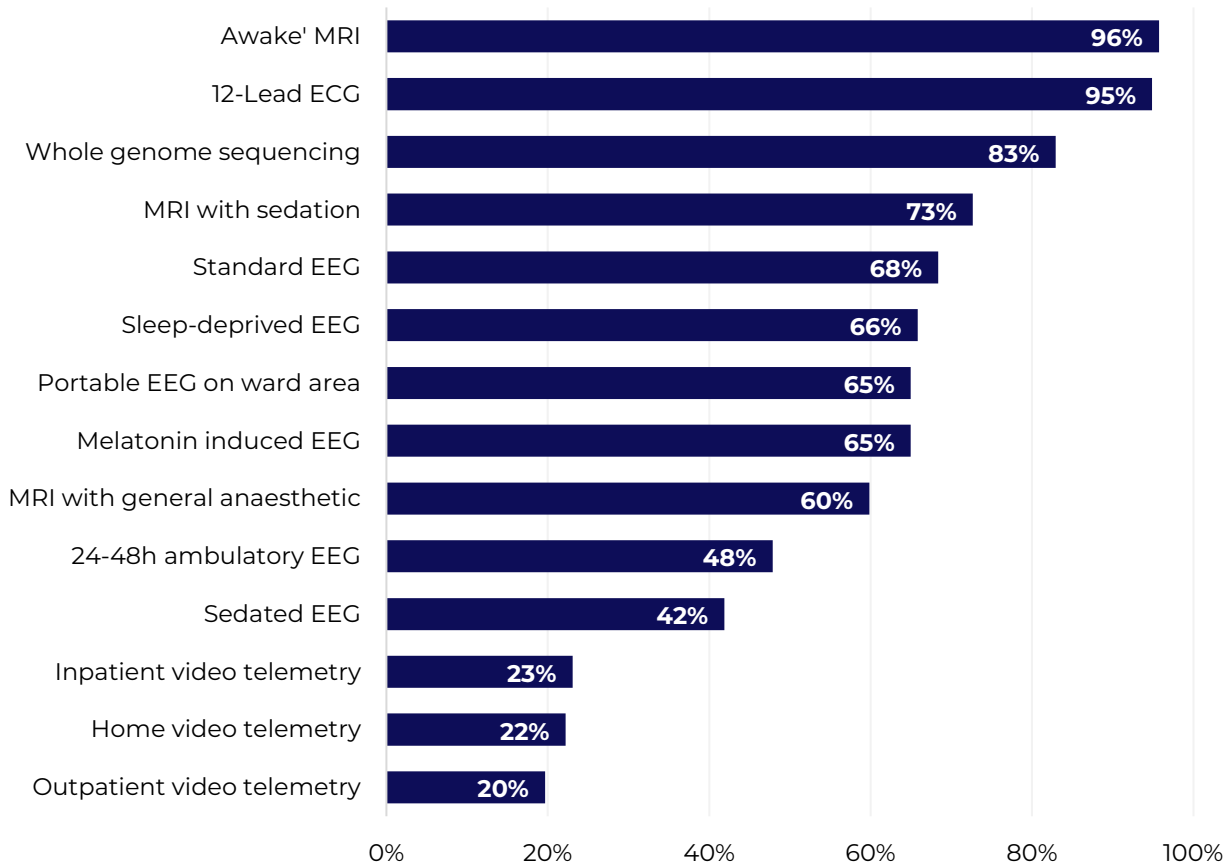


Figure 9: Percentage of Health Boards and Trusts that could provide investigation services in England and Wales.

Table 14: Percentage of Health Boards and trusts that could provide epilepsy investigations in England and Wales.

Investigation	England and Wales	England	Wales
12-Lead ECG			
Yes	94.9% (111/117)	94.6% (105/111)	100.0% (6/6)
No	5.1% (6/117)	5.4% (6/111)	0.0% (0/6)
Uncertain	0.0% (0/117)	0.0% (0/111)	0.0% (0/6)
'Awake' MRI			
Yes	95.7% (112/117)	95.5% (106/111)	100.0% (6/6)
No	4.3% (5/117)	4.5% (5/111)	0.0% (0/6)
Uncertain	0.0% (0/117)	0.0% (0/111)	0.0% (0/6)

MRI with sedation			
Yes	72.6% (85/117)	71.2% (79/111)	100.0% (6/6)
No	27.4% (32/117)	28.8% (32/111)	0.0% (0/6)
Uncertain	0.0% (0/117)	0.0% (0/111)	0.0% (0/6)
MRI with general anaesthetic			
Yes	59.8% (70/117)	57.7% (64/111)	100.0% (6/6)
No	40.2% (47/117)	42.3% (47/111)	0.0% (0/6)
Uncertain	0.0% (0/117)	0.0% (0/111)	0.0% (0/6)
Standard EEG			
Yes	68.4% (80/117)	66.7% (74/111)	100.0% (6/6)
No	31.6% (37/117)	33.3% (37/111)	0.0% (0/6)
Uncertain	0.0% (0/117)	0.0% (0/111)	0.0% (0/6)
Sleep-deprived EEG			
Yes	65.8% (77/117)	64.0% (71/111)	100.0% (6/6)
No	34.2% (40/117)	36.0% (40/111)	0.0% (0/6)
Uncertain	0.0% (0/117)	0.0% (0/111)	0.0% (0/6)
Melatonin induced EEG			
Yes	65.0% (76/117)	63.1% (70/111)	100.0% (6/6)
No	35.0% (41/117)	36.9% (41/111)	0.0% (0/6)
Uncertain	0.0% (0/117)	0.0% (0/111)	0.0% (0/6)
Sedated EEG			
Yes	41.9% (49/117)	40.5% (45/111)	66.7% (4/6)
No	55.6% (65/117)	57.7% (64/111)	16.7% (1/6)
Uncertain	2.6% (3/117)	1.8% (2/111)	16.7% (1/6)
24-48h ambulatory EEG			
Yes	47.9% (56/117)	45.9% (51/111)	83.3% (5/6)
No	51.3% (60/117)	54.1% (60/111)	0.0% (0/6)
Uncertain	0.9% (1/117)	0.0% (0/111)	16.7% (1/6)
Inpatient video telemetry			
Yes	23.1% (27/117)	23.4% (26/111)	16.7% (1/6)
No	76.1% (89/117)	75.7% (84/111)	83.3% (5/6)
Uncertain	0.9% (1/117)	0.9% (1/111)	0.0% (0/6)
Outpatient video telemetry			
Yes	19.7% (23/117)	19.8% (22/111)	16.7% (1/6)
No	79.5% (93/117)	79.3% (88/111)	83.3% (5/6)
Uncertain	0.9% (1/117)	0.9% (1/111)	0.0% (0/6)
Home video telemetry			
Yes	22.2% (26/117)	21.6% (24/111)	33.3% (2/6)
No	76.1% (89/117)	76.6% (85/111)	66.7% (4/6)
Uncertain	1.7% (2/117)	1.8% (2/111)	0.0% (0/6)
Portable EEG on ward area			
Yes	65.0% (76/117)	63.1% (70/111)	100.0% (6/6)

No	35.0% (41/117)	36.9% (41/111)	0.0% (0/6)
Uncertain	0.0% (0/117)	0.0% (0/111)	0.0% (0/6)
Requesting and consenting of Whole Genome Sequencing			
Yes	82.9% (97/117)	85.6% (95/111)	33.3% (2/6)
No	12.0% (14/117)	9.0% (10/111)	66.7% (4/6)
Uncertain	5.1% (6/117)	5.4% (6/111)	0.0% (0/6)

Service contact

In 2023, **97% (114/117)** of Health Boards and Trusts were able to provide specialist advice between scheduled reviews, which is consistent with the 2022 audit (**Table 15**). **60% (68/114)** of Health Boards and Trusts provided specialist advice on all weekdays for 52 weeks of the year, which is an increase from **57% (73/128)** in 2022.

Within the Health Boards and Trusts that could provide specialist advice, initial advice was typically provided by an epilepsy specialist nurse (**Table 17**). In the Health Boards and Trusts that selected other, responses indicated a joint response from either the paediatrician or the ESN:

Table 15: Specialist advice within Health Boards and Trusts in England and Wales.

Specialist Advice	England and Wales	England	Wales
Clear point of contact for non-paediatric professionals seeking advice	88.9% (104/117)	88.3% (98/111)	100.0% (6/6)
Provide specialist advice between scheduled reviews	97.4% (114/117)	97.3% (108/111)	100.0% (6/6)

Table 16: Of the 114 Health Boards and Trusts that provide specialist advice between scheduled reviews, the typical response time and availability of specialist advice in England and Wales.

Specialist Advice	England and Wales	England	Wales
Typical response time of specialist advice			
Same weekday	7.9% (9/114)	8.3% (9/108)	0.0% (0/6)
Next weekday	47.4% (54/114)	49.1% (53/108)	16.7% (1/6)
3 – 4 weekdays	36.8% (42/114)	35.2% (38/108)	66.7% (4/6)
Within the working week	7.9% (9/114)	7.4% (8/108)	16.7% (1/6)
Availability of specialist advice			
Available 52 weeks of the year	70.2% (80/114)	69.4% (75/108)	83.3% (5/6)
Some weekdays	3.8% (3/80)	2.7% (2/75)	20.0% (1/5)
Every weekday	85.0% (68/80)	85.3% (64/75)	80.0% (4/5)
Every weekday and out of hours	11.2% (9/80)	12.0% (9/75)	0.0% (0/5)
Not available 52 weeks of the year	29.8% (34/114)	30.6% (33/108)	16.7% (1/6)
Some weekdays	20.6% (7/34)	21.2% (7/33)	0.0% (0/1)
Every weekday	79.4% (27/34)	78.8% (26/33)	100.0% (1/1)
Every weekday and out of hours	0.0% (0/34)	0.0% (0/33)	0.0% (0/1)

Table 17: Of the Health Boards and Trusts that provide specialist advice between scheduled reviews, the professionals who 'typically' provide initial specialist advice in England and Wales by region.

Geographic Region	Professionals who 'typically' provide initial specialist advice				
	ESN	Consultant with 'expertise in epilepsy'	Paediatric neurologist	Trainee Paediatric neurologist	Other
England and Wales	57.9% (66/114)	31.6% (36/114)	0.9% (1/114)	0.0% (0/114)	9.6% (11/114)
England	57.4% (62/108)	31.5% (34/108)	0.9% (1/108)	0.0% (0/108)	10.2% (11/108)
Wales	66.7% (4/6)	33.3% (2/6)	0.0% (0/6)	0.0% (0/6)	0.0% (0/6)
NHS England Region					
East of England	41.7% (5/12)	58.3% (7/12)	0.0% (0/12)	0.0% (0/12)	0.0% (0/12)
London	77.8% (14/18)	11.1% (2/18)	5.6% (1/18)	0.0% (0/18)	5.6% (1/18)
Midlands	58.8% (10/17)	23.5% (4/17)	0.0% (0/17)	0.0% (0/17)	17.6% (3/17)
North East and Yorkshire	33.3% (7/21)	52.4% (11/21)	0.0% (0/21)	0.0% (0/21)	14.3% (3/21)
North West	81.2% (13/16)	12.5% (2/16)	0.0% (0/16)	0.0% (0/16)	6.2% (1/16)
South East	50.0% (7/14)	35.7% (5/14)	0.0% (0/14)	0.0% (0/14)	14.3% (2/14)
South West	60.0% (6/10)	30.0% (3/10)	0.0% (0/10)	0.0% (0/10)	10.0% (1/10)
OPEN UK Region					
BRPNF	44.4% (4/9)	33.3% (3/9)	0.0% (0/9)	0.0% (0/9)	22.2% (2/9)
CEWT	50.0% (2/4)	25.0% (1/4)	0.0% (0/4)	0.0% (0/4)	25.0% (1/4)
EPEN	45.5% (5/11)	54.5% (6/11)	0.0% (0/11)	0.0% (0/11)	0.0% (0/11)
EPIC	87.5% (7/8)	12.5% (1/8)	0.0% (0/8)	0.0% (0/8)	0.0% (0/8)
NTPEN	83.3% (10/12)	8.3% (1/12)	8.3% (1/12)	0.0% (0/12)	0.0% (0/12)
NWEIG	80.0% (8/10)	10.0% (1/10)	0.0% (0/10)	0.0% (0/10)	10.0% (1/10)
ORENG	33.3% (2/6)	50.0% (3/6)	0.0% (0/6)	0.0% (0/6)	16.7% (1/6)
PENNEC	42.9% (3/7)	57.1% (4/7)	0.0% (0/7)	0.0% (0/7)	0.0% (0/7)
SETPEG	71.4% (5/7)	14.3% (1/7)	0.0% (0/7)	0.0% (0/7)	14.3% (1/7)
SWEP	60.0% (3/5)	40.0% (2/5)	0.0% (0/5)	0.0% (0/5)	0.0% (0/5)
SWIPE	57.1% (4/7)	42.9% (3/7)	0.0% (0/7)	0.0% (0/7)	0.0% (0/7)
SWTPEG	71.4% (5/7)	28.6% (2/7)	0.0% (0/7)	0.0% (0/7)	0.0% (0/7)
TEN	33.3% (2/6)	50.0% (3/6)	0.0% (0/6)	0.0% (0/6)	16.7% (1/6)
WPNN	50.0% (3/6)	16.7% (1/6)	0.0% (0/6)	0.0% (0/6)	33.3% (2/6)
YPEN	33.3% (3/9)	44.4% (4/9)	0.0% (0/9)	0.0% (0/9)	22.2% (2/9)

Transition

Pathways

Table 18 shows that in 2023, **91% (106/117)** of Health Boards and Trusts had an agreed referral pathway to adult services and **72% (84/117)** used structured transition resources (e.g. Ready Steady Go), which is an increase from **88% (112/128)** and **66% (84/128)** respectively in 2022.

Table 18: Percentage of Health Boards and Trusts with an agreed referral pathway to adult services and using structured resources to support transition by region.

Geographic Region	Agreed referral pathway to adult services	Using structured resources to support transition
England and Wales	90.6% (106/117)	71.8% (84/117)
England	90.1% (100/111)	73.9% (82/111)
Wales	100.0% (6/6)	33.3% (2/6)
NHS England Region		
East of England	91.7% (11/12)	75.0% (9/12)
London	94.4% (17/18)	77.8% (14/18)
Midlands	89.5% (17/19)	63.2% (12/19)
North East and Yorkshire	85.7% (18/21)	85.7% (18/21)
North West	93.8% (15/16)	68.8% (11/16)
South East	86.7% (13/15)	73.3% (11/15)
South West	90.0% (9/10)	70.0% (7/10)
OPEN UK Region		
BRPNF	81.8% (9/11)	54.5% (6/11)
CEWT	100.0% (4/4)	50.0% (2/4)
EPEN	90.9% (10/11)	81.8% (9/11)
EPIC	87.5% (7/8)	37.5% (3/8)
NTPEN	91.7% (11/12)	83.3% (10/12)
NWEIG	100.0% (10/10)	90.0% (9/10)
ORENG	83.3% (5/6)	66.7% (4/6)
PENNEC	57.1% (4/7)	85.7% (6/7)
SETPEG	100.0% (7/7)	57.1% (4/7)
SWEP	100.0% (5/5)	40.0% (2/5)
SWIPE	85.7% (6/7)	85.7% (6/7)
SWTPEG	100.0% (7/7)	85.7% (6/7)
TEN	100.0% (6/6)	83.3% (5/6)
WPNN	85.7% (6/7)	57.1% (4/7)
YPEN	100.0% (9/9)	88.9% (8/9)

Transition Clinics

In 2023, **56% (65/117)** of Health Boards and Trusts in England and Wales had an outpatient transition clinic specifically for young people with epilepsy, which is an increase from **45% (58/128)** in 2022. The mean age that clinics accepted young people was 15 years, which is consistent with previous years (**Table 19**).

Table 19: Percentage of Health Boards and Trusts with an outpatient transition clinic specifically for young people with epilepsies, and the age these clinics typically accept patients, by region. **(BPC)**

Geographic Region	Outpatient clinic specifically for young people with epilepsies	Mean (Range) age clinics typically accept patients	Median (inter-quartile range) age clinics typically accept patients
England and Wales	55.6% (65/117)	15 (12-18)	15 (14-16)
England	55.0% (61/111)	15 (12-18)	15 (14-16)
Wales	66.7% (4/6)	16 (14-16)	16 (15-16)
NHS England Region			
East of England	58.3% (7/12)	14 (13-16)	14 (13-16)
London	55.6% (10/18)	15 (12-16)	16 (14-16)
Midlands	63.2% (12/19)	15 (12-16)	15 (14-16)
North East and Yorkshire	33.3% (7/21)	14 (13-16)	14 (13-15)
North West	68.8% (11/16)	15 (12-18)	14 (14-16)
South East	53.3% (8/15)	15 (12-18)	16 (14-16)
South West	60.0% (6/10)	16 (15-18)	16 (16-16)
OPEN UK Region			
BRPNF	54.5% (6/11)	15 (14-16)	15 (14-16)
CEWT	75.0% (3/4)	13 (12-15)	13 (12-15)
EPEN	54.5% (6/11)	14 (13-16)	14 (13-16)
EPIC	62.5% (5/8)	15 (14-18)	14 (14-15)
NTPEN	33.3% (4/12)	14 (12-16)	14 (12-15)
NWEIG	80.0% (8/10)	14 (12-16)	14 (14-16)
ORENG	50.0% (3/6)	14 (13-16)	14 (13-16)
PENNEC	42.9% (3/7)	15 (13-16)	15 (13-16)
SETPEG	71.4% (5/7)	15 (12-16)	16 (14-16)
SWEP	60.0% (3/5)	16 (16-16)	16 (16-16)
SWIPE	57.1% (4/7)	16 (15-18)	16 (16-17)
SWTPEG	85.7% (6/7)	16 (14-18)	16 (16-16)
TEN	33.3% (2/6)	15 (14-16)	15 (14-16)
WPNN	57.1% (4/7)	15 (13-16)	16 (14-16)
YPEN	33.3% (3/9)	13 (13-14)	13 (13-14)

Adult Professionals

Table 20 shows that in 2023, **68% (80/117)** of Health Boards and Trusts had outpatient transition services involving both adult and paediatric professionals, which is an increase from **64% (82/128)** in 2022. Of these, **61% (49/80)** provided several joint appointments (**Table 21**). In the Health Boards and Trusts that selected other, responses included:

- This clinic has started at an ESN level; the pathway is established but not yet formally agreed.
- Mostly single joint appointment, but for some patients 2 or 3 in the last year.
- a single joint appointment with paediatric and adult neurologist based at the adult centre
- Joint with adult but flexible
- Adult and Paediatric nurse specialist- now limited during COVID and staffing issue nurse led clinic.
- Teenage Clinic with adult ESN also present
- A flexible approach involving Adult and Paediatric ESN's happens only for children @ UHND.

Adult professionals involved in transition were typically adult neurologists and epilepsy specialist nurses (**Table 22**). In the Health Boards and Trusts that selected other, responses included:

- Consultant Psychiatrist
- Adult LD team
- GP and Adult Neurologist
- Adult LD team; adult rehab; GP
- GP
- Transition Nurse
- We give details of neurology specialist nurse contact and often offer ESN appointment at neuro hospt
- Neurologist if needed
- ESN
- Disability (Sometimes)
- Paediatric Epilepsy Nurse Specialist
- Transition nurses
- LD transition nurses
- Discussion with adult neurologist and neurophysiologist in Neurophysiology meeting
- Epilepsy specialist midwife
- Adolescent Nurse
- GP
- Adult learning disability nurse
- Adult psychiatrist with interest in learning difficulties
- Adult neuro/LD consultant involved though not in clinic
- Transition nurse
- Paediatric ESN
- Education/ social care/ LD consultant/ Transition nurse/ Therapy teams
- Specific adolescent transition clinic regionally, locally appointed transition nurse (new)
- Neurodisability transition nurse and transition to adult services nurse.

Table 20: Percentage of Health Boards and Trusts with outpatient services for young people with epilepsy where there is presence of both adult and paediatric professionals by region.

Geographic Region		Outpatient service involving adult and paediatric professionals
England and Wales		68.4% (80/117)
England		67.6% (75/111)
Wales		83.3% (5/6)
NHS England Region		
East of England		83.3% (10/12)
London		88.9% (16/18)
Midlands		57.9% (11/19)
North East and Yorkshire		52.4% (11/21)
North West		68.8% (11/16)
South East		60.0% (9/15)
South West		70.0% (7/10)
OPEN UK Region		
BRPNF		54.5% (6/11)
CEWT		50.0% (2/4)
EPEN		81.8% (9/11)
EPIC		75.0% (6/8)
NTPEN		83.3% (10/12)
NWEIG		70.0% (7/10)
ORENG		66.7% (4/6)
PENNEC		57.1% (4/7)
SETPEG		71.4% (5/7)
SWEP		80.0% (4/5)
SWIPE		85.7% (6/7)
SWTPEG		85.7% (6/7)
TEN		33.3% (2/6)
WPNN		42.9% (3/7)
YPEN		66.7% (6/9)

Table 21: Of the Health Boards and Trusts with an outpatient service where there is a presence of both adult and paediatric professionals, the structure of this service and the estimated percentage of young people transitioned to adult services through this joint professional process in England and Wales.

Service	England and Wales	England	Wales
Structure of outpatient service involving adult and paediatric professionals			
Single joint appointments	61.2% (49/80)	62.7% (47/75)	40.0% (2/5)

Mixed (joint and individual)	23.8% (19/80)	22.7% (17/75)	40.0% (2/5)
Several joint appointments	6.2% (5/80)	5.3% (4/75)	20.0% (1/5)
Other	8.8% (7/80)	9.3% (7/75)	0.0% (0/5)

Estimated percentage of young people transferred to adult services through a joint professional process

Mean (Range)	77.2 (1.0-100.0)	78.3 (1.0-100.0)	60.6 (30.0-100.0)
Median (Inter-quartile range)	90.0 (60.0-100.0)	90.0 (70.0-100.0)	50.0 (33.0-90.0)

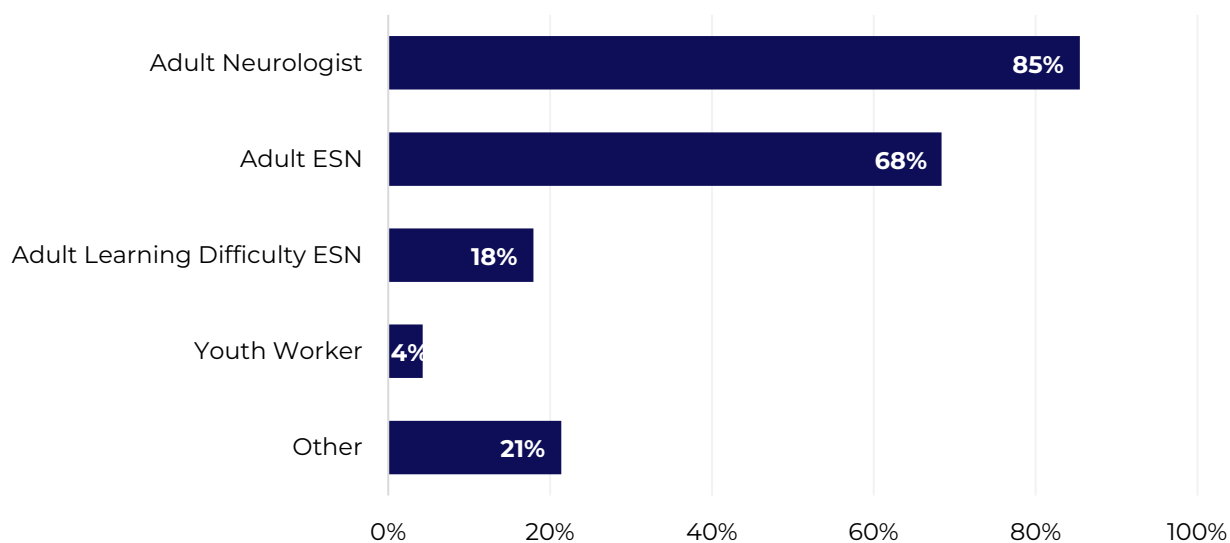


Figure 10: Adult professionals routinely involved in transition.

Table 22: Percentage of Health Boards and Trusts with adult professionals routinely involved in transition or transfer to adult services in England and Wales.

Adult professionals	England and Wales	England	Wales
Adult ESN	68.4% (80/117)	68.5% (76/111)	66.7% (4/6)
Adult learning difficulty ESN	17.9% (21/117)	18.0% (20/111)	16.7% (1/6)
Adult neurologist	85.5% (100/117)	84.7% (94/111)	100.0% (6/6)
Youth worker	4.3% (5/117)	4.5% (5/111)	0.0% (0/6)
Other	21.4% (25/117)	20.7% (23/111)	33.3% (2/6)

Mental Health and Neurodevelopment

Mental Health

In 2023, **30% (36/117)** of Health Boards and Trusts routinely, formally screened for mental health disorders, which is an increase from **20% (25/128)** in 2022 (**Table 23**). Of these, the majority used the Strengths and Difficulties Questionnaire or other questionnaires (**Table 24**). Other responses included:

- PI-ED
- York Questionnaire, Vandebilt and department behaviour assessment questionnaire
- Locally designed emotional wellbeing questionnaire
- Local wellbeing questionnaire
- Wellness questionnaire
- Wellbeing Qs
- PI-ED
- Mental health questionnaire
- PHQ 4
- Nice signs and symptoms, CHECC of ASD checklist, CHECC - Child and young person Epilepsy Concerns Checklist
- Mental health questionnaire
- Locally prepared questionnaire
- We are piloting an emotional well being questionnaire developed with jointly with psychology
- RCADS-Trial stage
- The wheel.

Table 25 shows that **27% (31/117)** of Health boards and Trusts did not have any agreed mental health referral pathways in 2023, while **69% (81/117)** had referral pathways for anxiety disorders and **69% (80/117)** had referral pathways for mood disorders. **8% (9/117)** had referral pathways for other mental health disorders, which included:

- ADHD
- Referral to psychology for difficulty in coping with diagnosis for patient and family.
Referral to CAMHS for other mental health concerns.
- Pathways in place with CAMHS services for mental health disorders; pathway in place for YP with anxiety relating to medical disorders including epilepsy
- Mental health support via in house Dramatherapy service
- We have a flexible approach with in-house mental health and adolescent medicine teams
- ADHD
- Children can be referred to CAHMS or clinical psychology depending on clinical needs
- Referrals to CAMHS and Psychology support
- Referral to Local Healthy Young Minds team.

Table 26 shows that in 2023, **18% (21/117)** of Health Boards and Trusts facilitated mental health provision within epilepsy clinics, which is a decrease from **19% (24/128)** in 2022. **68% (80/117)** did not facilitate mental health provision, nor had an action plan in place to introduce mental health provision.

Of the **21** Health Boards and Trusts that provided co-located mental healthcare, **57% (12/21)** provided co-located care through epilepsy clinics with mental health professionals present and **71.4% (15/21)** re in held MDT meetings with mental health professionals present(**Table 27**). In the Health Boards and Trusts that selected other, responses included:

- Discussion of individual cases at MDT and onward referral to psychology
- Clinical Psychologist
- Child psychiatry clinics where epilepsy specialists or ESN join to see pt on one site of our Trust
- Joint clinics with clinic psychologist with specific role for paediatric epilepsy
- We have access to psychology, psychiatry and psychotherapy on site. Some clinics together.
- Through referrals and liaison with CAMHS
- Limited psychology support for children with chronic health needs including epilepsy
- Psychologist post - unable to appoint !
- Patients concern raised - consultant referral of cases
- Clinical psychology service.

Table 23: Percentage of Health Boards and Trusts that routinely, formally screen for mental health disorders by region.

Geographic Region	Provides formal screening for mental health disorders
England and Wales	30.8% (36/117)
England	31.5% (35/111)
Wales	16.7% (1/6)
NHS England Region	
East of England	25.0% (3/12)
London	33.3% (6/18)
Midlands	42.1% (8/19)
North East and Yorkshire	42.9% (9/21)
North West	18.8% (3/16)
South East	26.7% (4/15)
South West	20.0% (2/10)
OPEN UK Region	
BRPNF	36.4% (4/11)
CEWT	25.0% (1/4)
EPEN	27.3% (3/11)
EPIC	12.5% (1/8)
NTPEN	33.3% (4/12)
NWEIG	30.0% (3/10)
ORENG	16.7% (1/6)
PENNEC	57.1% (4/7)

SETPEG	28.6% (2/7)
SWEP	20.0% (1/5)
SWIPE	28.6% (2/7)
SWTPEG	28.6% (2/7)
TEN	33.3% (2/6)
WPNN	28.6% (2/7)
YPEN	44.4% (4/9)

Table 24: Percentage of Health Boards and Trusts that use each mental health screening questionnaire in England and Wales.

Screening questionnaire	England and Wales	England	Wales
BDI – Beck Depression Inventory	0.9% (1/117)	0.9% (1/111)	0.0% (0/6)
Connor’s questionnaire	6.0% (7/117)	6.3% (7/111)	0.0% (0/6)
Emotional thermometers tool	0.0% (0/117)	0.0% (0/111)	0.0% (0/6)
GAD – Generalised anxiety disorder	0.9% (1/117)	0.0% (0/111)	16.7% (1/6)
GAD 2 – Generalised anxiety disorder 2	0.0% (0/117)	0.0% (0/111)	0.0% (0/6)
GAD 7 – Generalised anxiety disorder 7	0.0% (0/117)	0.0% (0/111)	0.0% (0/6)
HADS – Hospital Anxiety and Depression Scale	0.0% (0/117)	0.0% (0/111)	0.0% (0/6)
MFQ – Mood and Feelings Questionnaire (Child, Parent, Adult versions)	0.0% (0/117)	0.0% (0/111)	0.0% (0/6)
NDDI-E – Neurological Disorders	0.0% (0/117)	0.0% (0/111)	0.0% (0/6)
PHQ – Patient Health Questionnaire, PHQ2, PHQ9	1.7% (2/117)	0.9% (1/111)	16.7% (1/6)
SDQ – Strength and Difficulties Questionnaire)	11.1% (13/117)	11.7% (13/111)	0.0% (0/6)
Other	12.8% (15/117)	12.6% (14/111)	16.7% (1/6)
None of the above	2.6% (3/117)	2.7% (3/111)	0.0% (0/6)

Table 25: Percentage of Health Boards and Trusts with agreed referral pathways for mental health concerns and able to refer to mental health assessments in England and Wales. **(BPC)**

Referral pathways	England and Wales	England	Wales
Agreed Referral Pathways			
Anxiety	69.2% (81/117)	70.3% (78/111)	50.0% (3/6)
Mood disorders	68.4% (80/117)	69.4% (77/111)	50.0% (3/6)
Non-epileptic attack disorders	53.0% (62/117)	55.0% (61/111)	16.7% (1/6)
Other	7.7% (9/117)	7.2% (8/111)	16.7% (1/6)
None	26.5% (31/117)	25.2% (28/111)	50.0% (3/6)

Able to Refer for Assessment			
Clinical psychology assessment	82.1% (96/117)	81.1% (90/111)	100.0% (6/6)
Educational psychology assessment	44.4% (52/117)	42.3% (47/111)	83.3% (5/6)
Formal developmental assessment	88.0% (103/117)	87.4% (97/111)	100.0% (6/6)
Neuropsychology assessment	48.7% (57/117)	50.5% (56/111)	16.7% (1/6)
Psychiatric assessment	88.0% (103/117)	87.4% (97/111)	100.0% (6/6)
None of the above	4.3% (5/117)	4.5% (5/111)	0.0% (0/6)

Table 26: Percentage of Health Boards Trusts that facilitate mental health provision within epilepsy clinics or have an action plan describing steps towards co-located mental health provision within epilepsy clinics by region. **(BPC)**

Geographic Region	Facilitates Mental Health Provision within Epilepsy Clinics		
	Yes	No	
		Action plan	No action plan
England and Wales	17.9% (21/117)	13.7% (16/117)	68.4% (80/117)
England	18.9% (21/111)	13.5% (15/111)	67.6% (75/111)
Wales	0.0% (0/6)	16.7% (1/6)	83.3% (5/6)
NHS England Region			
East of England	33.3% (4/12)	8.3% (1/12)	58.3% (7/12)
London	27.8% (5/18)	11.1% (2/18)	61.1% (11/18)
Midlands	5.3% (1/19)	15.8% (3/19)	78.9% (15/19)
North East and Yorkshire	19.0% (4/21)	14.3% (3/21)	66.7% (14/21)
North West	25.0% (4/16)	12.5% (2/16)	62.5% (10/16)
South East	13.3% (2/15)	20.0% (3/15)	66.7% (10/15)
South West	10.0% (1/10)	10.0% (1/10)	80.0% (8/10)
OPEN UK Region			
BRPNF	9.1% (1/11)	9.1% (1/11)	81.8% (9/11)
CEWT	0.0% (0/4)	25.0% (1/4)	75.0% (3/4)
EPEN	36.4% (4/11)	9.1% (1/11)	54.5% (6/11)
EPIC	37.5% (3/8)	12.5% (1/8)	50.0% (4/8)
NTPEN	25.0% (3/12)	8.3% (1/12)	66.7% (8/12)
NWEIG	10.0% (1/10)	20.0% (2/10)	70.0% (7/10)
ORENG	0.0% (0/6)	0.0% (0/6)	100.0% (6/6)
PENNEC	14.3% (1/7)	14.3% (1/7)	71.4% (5/7)
SETPEG	28.6% (2/7)	42.9% (3/7)	28.6% (2/7)
SWEP	0.0% (0/5)	0.0% (0/5)	100.0% (5/5)
SWIPE	0.0% (0/7)	14.3% (1/7)	85.7% (6/7)
SWTPEG	14.3% (1/7)	14.3% (1/7)	71.4% (5/7)
TEN	0.0% (0/6)	16.7% (1/6)	83.3% (5/6)
WPNN	28.6% (2/7)	0.0% (0/7)	71.4% (5/7)
YPEN	33.3% (3/9)	22.2% (2/9)	44.4% (4/9)

Table 27: Of the Health Boards and Trusts that provide co-located mental health provision, the structure of this provision by region.

Geographic Region	Type of Co-located Mental Health Provision		
	Epilepsy clinics where mental health professionals can provide direct co-located clinical care	MDT meetings where epilepsy and mental health professionals can discuss individual patients	Other
England and Wales	57.1% (12/21)	71.4% (15/21)	47.6% (10/21)
England	57.1% (12/21)	71.4% (15/21)	47.6% (10/21)
Wales	00% (0/0)	00% (0/0)	00% (0/0)
NHS England Region			
East of England	50.0% (2/4)	100.0% (4/4)	25.0% (1/4)
London	80.0% (4/5)	80.0% (4/5)	60.0% (3/5)
Midlands	N/A	N/A	N/A
North East and Yorkshire	50.0% (2/4)	100.0% (4/4)	25.0% (1/4)
North West	20.0% (1/5)	20.0% (1/5)	60.0% (3/5)
South East	100.0% (2/2)	100.0% (2/2)	0.0% (0/2)
South West	100.0% (1/1)	0.0% (0/1)	100.0% (1/1)
OPEN UK Region			
BRPNF	0.0% (0/1)	0.0% (0/1)	100.0% (1/1)
CEWT	0% (0/0)	0% (0/0)	0% (0/0)
EPEN	50.0% (2/4)	100.0% (4/4)	25.0% (1/4)
EPIC	33.3% (1/3)	33.3% (1/3)	66.7% (2/3)
NTPEN	66.7% (2/3)	66.7% (2/3)	66.7% (2/3)
NWEIG	0.0% (0/1)	0.0% (0/1)	100.0% (1/1)
ORENG	0% (0/0)	0% (0/0)	0% (0/0)
PENNEC	100.0% (1/1)	100.0% (1/1)	0.0% (0/1)
SETPEG	100.0% (2/2)	100.0% (2/2)	50.0% (1/2)
SWEP	0% (0/0)	0% (0/0)	0% (0/0)
SWIPE	0% (0/0)	0% (0/0)	0% (0/0)
SWTPEG	100.0% (1/1)	100.0% (1/1)	0.0% (0/1)
TEN	0% (0/0)	0% (0/0)	0% (0/0)
WPNN	100.0% (2/2)	50.0% (1/2)	50.0% (1/2)
YPEN	33.3% (1/3)	100.0% (3/3)	33.3% (1/3)

Neurodevelopment

Table 28 shows that in 2023, **31% (36/117)** of Health Boards and Trusts routinely, formally screened for neurodevelopmental conditions, and the majority had agreed referral criteria for ADHD, ASD, Behavioural difficulties, Developmental Coordinator Disorder, and Intellectual Disability/Global Developmental Delay. Of the Health Boards and Trusts and had agreed referral criteria, the 'other neurodevelopmental conditions' responses included:

- Cerebral Palsy
- Genetics
- Space neurodevelopmental team referral pathways
- Challenging behaviour associated with severe learning difficulties
- CP, development delay, neuromuscular
- Referral is to community paediatric service who will direct referral to appropriate pathway
- Conditions details are not seen within our health board
- Developmental impairment
- Referral is to the local services by us - usually Camden and Islington and we have monthly MDT to discuss cases
- Tics/tourettes
- Can be referred for developmental problems but not as BPC criteria
- DCD
- Developmental Delay.

Table 28: Percentage of Health Boards and Trusts that routinely, formally screen for neurodevelopmental conditions and with agreed referral criteria for neurodevelopmental conditions in England and Wales. **(BPC)**

	England and Wales	England	Wales
Formal screening for neurodevelopmental conditions	30.8% (36/117)	31.5% (35/111)	16.7% (1/6)
Agreed Referral Criteria			
ADHD	65.0% (76/117)	64.9% (72/111)	66.7% (4/6)
ASD	86.3% (101/117)	85.6% (95/111)	100.0% (6/6)
Behaviour difficulties	69.2% (81/117)	69.4% (77/111)	66.7% (4/6)
Developmental coordination disorder	65.8% (77/117)	65.8% (73/111)	66.7% (4/6)
Intellectual disability/Global developmental delay	70.1% (82/117)	68.5% (76/111)	100.0% (6/6)
Learning disabilities	39.3% (46/117)	38.7% (43/111)	50.0% (3/6)
Other	11.1% (13/117)	9.0% (10/111)	50.0% (3/6)
None of the above	11.1% (13/117)	11.7% (13/111)	0.0% (0/6)

Care planning

Comprehensive care planning for children and young people with epilepsy was routinely undertaken in **91% (106/117)** of Health Boards and Trusts in England and Wales (**Table 29**). **Figure 11** shows how this figure has changed over time.

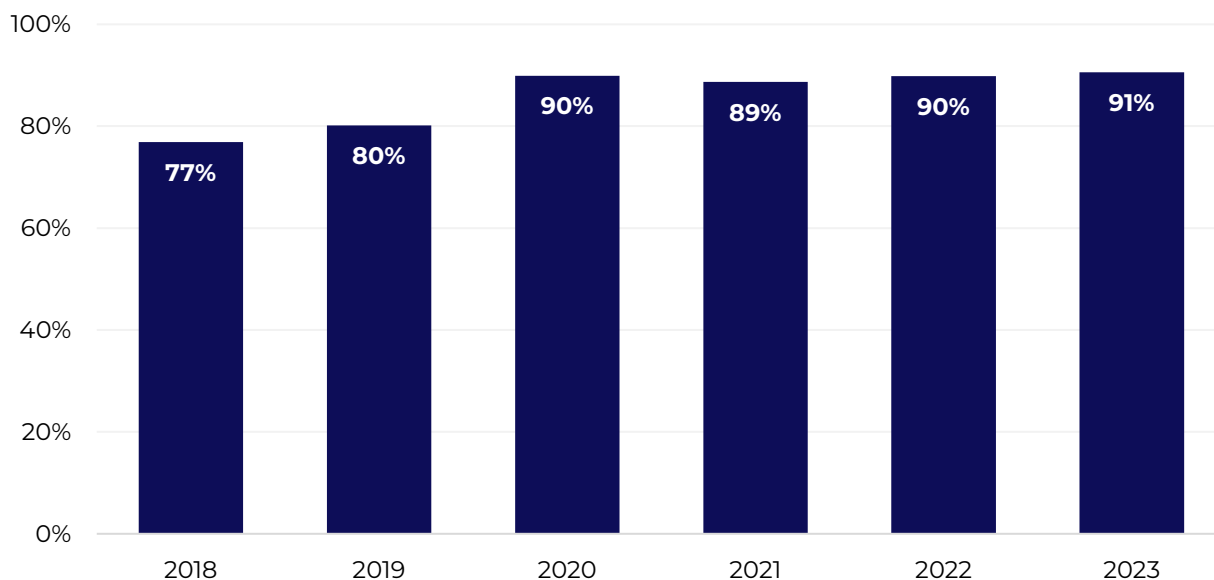


Figure 11: Health boards and Trusts that routinely undertake comprehensive care planning for children and young people with epilepsy between 2018 and 2023.

Table 29: Percentage of Health Boards and Trusts that routinely undertake comprehensive care planning for children and young people with epilepsy by region. (BPC)

Geographic Region	Routinely undertake comprehensive care planning
England and Wales	90.6% (106/117)
England	91.9% (102/111)
Wales	66.7% (4/6)
NHS England Region	
East of England	91.7% (11/12)
London	94.4% (17/18)
Midlands	89.5% (17/19)
North East and Yorkshire	90.5% (19/21)
North West	93.8% (15/16)
South East	86.7% (13/15)
South West	100.0% (10/10)
OPEN UK Region	
BRPNF	81.8% (9/11)
CEWT	100.0% (4/4)

EPEN	90.9% (10/11)
EPIC	87.5% (7/8)
NTPEN	91.7% (11/12)
NWEIG	100.0% (10/10)
ORENG	83.3% (5/6)
PENNEC	85.7% (6/7)
SETPEG	100.0% (7/7)
SWEP	60.0% (3/5)
SWIPE	100.0% (7/7)
SWTPEG	100.0% (7/7)
TEN	83.3% (5/6)
WPNN	85.7% (6/7)
YPEN	100.0% (9/9)

Patient database or register

In 2023, **44% (51/117)** of Health Boards and Trusts maintained a database of children with epilepsy, separate to Epilepsy12, in England and Wales (**Table 30**). This is an increase from **42% (54/128)** in 2022. **Figure 12** shows how the percentage of Health Boards and Trusts maintaining a patient database has changed over time.

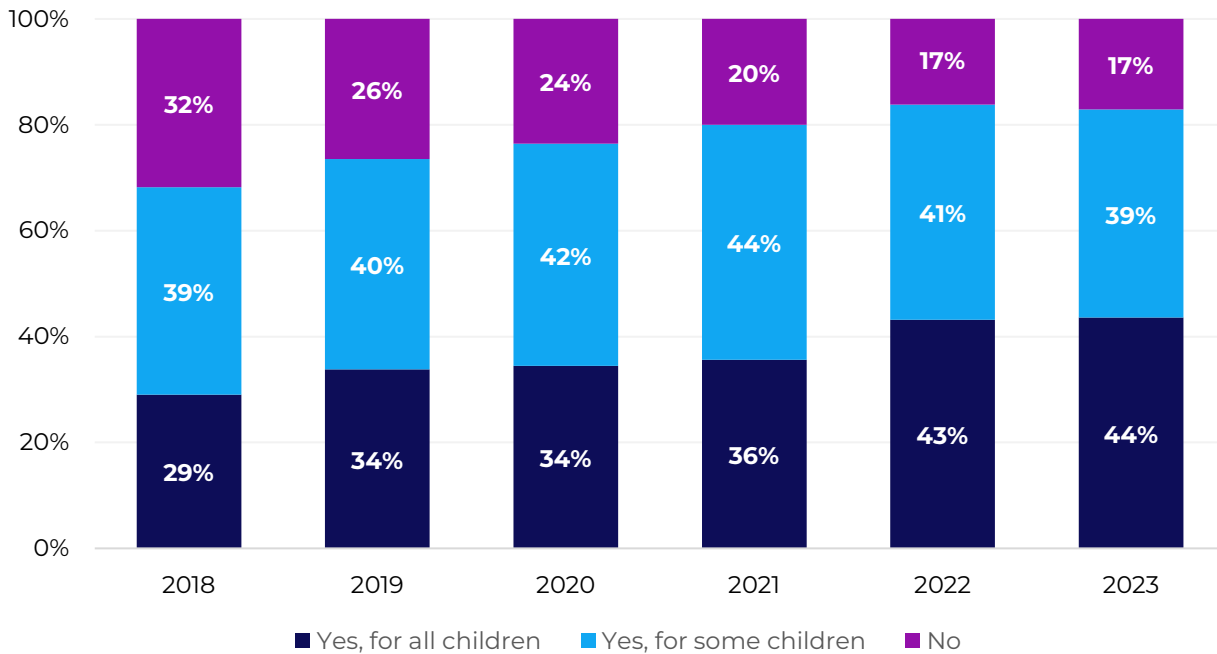


Figure 12: Health Boards and Trusts that maintain a database or register of children with epilepsies, apart from Epilepsy12 between 2018 and 2023.

Table 30: Percentage of Health Boards and Trusts that maintain a database or register of children with epilepsy separate to Epilepsy12 in England and Wales.

Patient database or register	England and Wales	England	Wales
Yes, for all children	43.6% (51/117)	45.9% (51/111)	0.0% (0/6)
Yes, for some children	39.3% (46/117)	38.7% (43/111)	50.0% (3/6)
No	17.1% (20/117)	15.3% (17/111)	50.0% (3/6)