***RCPCH Audits**

Combined organisational and clinical audits:

Report for England and Wales Round 3 Cohort 2 (2019-20)

EPILEPSY12

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

Appendix A: Epilepsy12 Round 3 2020 organisational audit







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).

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

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Appendices

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

This appendix presents organisational data describing the services as they were in November 2020. At this time the NHS were dealing with a significant surge in COVID-19 cases and hospitalisations in both England and Wales.

Appendix B: Full Epilepsy12 clinical audit results for Round 3, Cohort 2 includes the publication of the clinical performance results and outcomes captured from Health Boards and Trusts in England and Wales. It is available to download from Epilepsy12.

Appendix A: Epilepsy12 Round 3 2020 Organisational audit

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Appendix A: Epilepsy12 Round 3 2020 Organisational audit results

In this section, we present the full tables of results and figures, attributed by England and Wales combined, England, Wales and by each OPEN UK regional network, for each of the Epilepsy12 Round 3 Organisational audit measures.

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

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

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

Participation

Table 1 provides a breakdown of Epilepsy12 Round 3, 2020 Organisational audit participation by Paediatric Epilepsy Networks and by country.

- 119 out of 145 (82%) registered Health Boards and Trusts (T/HBs) submitted and locked November 2020 Organisational audit data.
- 94% (136/145) and 100% (148/148) of registered Health Boards and Trusts submitted and locked 2019 and 2018 Organisational audit data respectively.

Table 1: Epilepsy12 Round 3 2020 Organisational Audit participation by paediatric epilepsy networks and by country.

Country/network	Number of registered T/HBs	Number of T/HBs that have submitted and locked their 2020 organisational audit data
England and Wales	145	82% (119/145)
England	139	83% (115/139)
Wales	6	67% (4/6)
BRPNF	14	71% (10/14)
CEWT	6	83% (5/6)
EPEN	14	93% (13/14)
EPIC	9	89% (8/9)
NTPEN	17	88% (15/17)
NWEIG	12	58% (7/12)
ORENG	7	100% (7/7)
PENNEC	8	100% (8/8)
SETPEG	10	70% (7/10)
SWEP	5	60% (3/5)
SWIPE	11	82% (9/11)
SWTPEG	8	75% (6/8)
TEN	6	100% (6/6)
WPNN	9	78% (7/9)
YPEN	9	89% (8/9)

Workforce

Consultant paediatrician

Table 2 shows that the total whole time equivalent (WTE) for general paediatric consultants employed across England and Wales was 1902.3. There were a total of 268.7 whole time equivalent (WTE) paediatric consultants with 'expertise in epilepsy' employed across England and Wales and is equivalent to 14% (268.7/1902.3) of the total reported WTE general paediatric (consultant or associate specialist) workforce, (Table 3). 97% (116/119) of Health Boards and Trusts did employ a consultant paediatrician with 'expertise in epilepsy', this ranged from 0.5 WTE to 10.5 WTE, (Table 4). In 7% (8/119) of Health Boards and Trusts, there was no defined paediatric epilepsy clinical lead, (Table 5).

Figure 1 shows a comparison of the mean whole-time equivalent consultant paediatrician with expertise in epilepsy employed across England and Wales in Round 1, Round 2, Round 3 April 2018, Round 3 November 2019 and Round 3 November 2020.

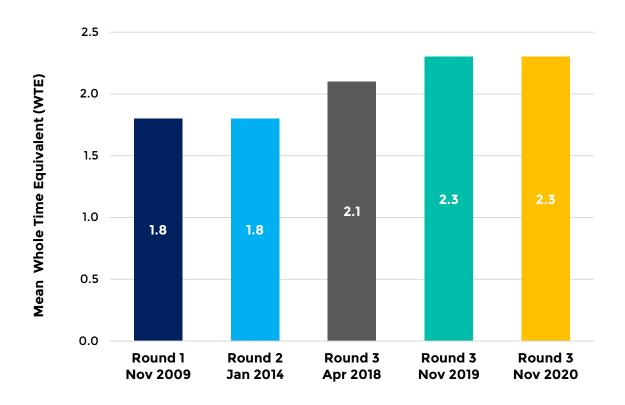


Figure 1: Mean whole time equivalent consultant paediatrician with 'expertise in epilepsy' employed in England and Wales in Round 1, Round 2, Round 3 April 2018, Round 3 November 2019 and Round 3 November 2020.

Table 2: Whole time equivalent (WTE) general paediatric consultants, community or hospital based, employed within Health Boards and Trusts.

Country/network	Total WTE	Mean WTE
England and Wales (N=119)	1902.3	16.0
England (N=115)	1800.1	15.7
Wales (N=4)	102.2	25.6
BRPNF (N=10)	127.1	12.7
CEWT (N=5)	108.7	21.7
EPEN (N=13)	188.9	14.5
EPIC (N=8)	108.6	13.6
NTPEN (N=15)	264.8	17.7
NWEIG (N=7)	116.0	16.6
ORENG (N=7)	114.1	16.3
PENNEC (N=8)	147.0	18.4
SETPEG (N=7)	112.9	16.1
SWEP (N=3)	71.2	23.7
SWIPE (N=9)	133.3	14.8
SWTPEG (N=6)	118.9	19.8
TEN (N=6)	79.2	13.2
WPNN (N=7)	82.7	11.8
YPEN (N=8)	129.0	16.1

Table 3: Whole time equivalent (WTE) general paediatric consultants with 'expertise in epilepsy', excluding paediatric neurologists, employed within Health Boards and Trusts.

Country/network	Total WTE	Mean WTE	Min WTE	Max WTE	% of general paediatric workforce with 'expertise in epilepsy'
England and Wales (N=119)	268.7	2.3	0.0	10.5	14% (268.7/1902.3)
England (N=115)	252.7	2.2	0.0	10.5	14% (252.7/1800.1)
Wales (N=4)	16.0	4.0	2.0	9.0	16% (16.0/102.2)
				ı	
BRPNF (N=10)	19.1	1.9	0.5	7.4	15% (19.1/127.1)
CEWT (N=5)	12.9	2.6	0.0	7.0	12% (12.9/108.7)
EPEN (N=13)	23.8	1.8	0.6	4.0	13% (23.8/188.9)
EPIC (N=8)	24.5	3.1	1.0	9.0	23% (24.5/108.6)
NTPEN (N=15)	31.9	2.1	0.0	6.2	12% (31.9/264.8)
NWEIG (N=7)	11.2	1.6	0.9	3.0	10% (11.2/116.0)
ORENG (N=7)	15.5	2.2	1.0	5.0	14% (15.5/114.1)
PENNEC (N=8)	28.6	3.6	1.0	9.0	19% (28.6/147.0)
SETPEG (N=7)	14.4	2.1	1.0	3.9	13% (14.4/112.9)
SWEP (N=3)	7.0	2.3	2.0	3.0	10% (7.0/71.2)
SWIPE (N=9)	17.2	1.9	0.8	4.0	13% (17.2/133.3)
SWTPEG (N=6)	12.1	2.0	1.0	2.8	10% (12.1/118.9)
TEN (N=6)	12.8	2.1	1.0	3.0	16% (12.8/79.2)
WPNN (N=7)	15.0	2.1	1.1	3.8	18% (15.0/82.7)
YPEN (N=8)	22.8	2.8	1.0	10.5	18% (22.8/129.0)

Table 4: Health Boards and Trusts that employed at least some level of whole time equivalent (WTE) consultant paediatrician with 'expertise in epilepsy'.

Country/network	% with some WTE	% with no WTE	WTE range in T/HBs with some WTE
England and Wales (N=119)	97% (116/119)	3% (3/119)	0.5 - 10.5
England (N=115)	97% (112/115)	3% (3/115)	0.5 - 10.5
Wales (N=4)	100% (4/4)	0% (0/4)	2.0 - 9.0
BRPNF (N=10)	100% (10/10)	0% (0/10)	0.5 - 7.4
CEWT (N=5)	80% (4/5)	20% (1/5)	1.0 - 7.0
EPEN (N=13)	100% (13/13)	0% (0/13)	0.6 - 4.0
EPIC (N=8)	100% (8/8)	0% (0/8)	1.0 - 9.0
NTPEN (N=15)	87% (13/15)	13% (2/15)	1.0 - 6.2
NWEIG (N=7)	100% (7/7)	0% (0/7)	0.9 - 3.0
ORENG (N=7)	100% (7/7)	0% (0/7)	1.0 - 5.0
PENNEC (N=8)	100% (8/8)	0% (0/8)	1.0 - 9.0
SETPEG (N=7)	100% (7/7)	0% (0/7)	1.0 - 3.9
SWEP (N=3)	100% (3/3)	0% (0/3)	2.0 - 3.0
SWIPE (N=9)	100% (9/9)	0% (0/9)	0.8 - 4.0
SWTPEG (N=6)	100% (6/6)	0% (0/6)	1.0 - 2.8
TEN (N=6)	100% (6/6)	0% (0/6)	1.0 - 3.0
WPNN (N=7)	100% (7/7)	0% (0/7)	1.1 - 3.8
YPEN (N=8)	100% (8/8)	0% (0/8)	1.0 - 10.5

Table 5: Health Boards and Trusts that had a defined paediatric epilepsy clinical lead.

Country/network	% with a defined lead	% with no defined lead
England and Wales (N=119)	93% (111/119)	7% (8/119)
England (N=115)	93% (107/115)	7% (8/115)
Wales (N=4)	100% (4/4)	0% (0/4)
BRPNF (N=10)	90% (9/10)	10% (1/10)
CEWT (N=5)	100% (5/5)	0% (0/5)
EPEN (N=13)	100% (13/13)	0% (0/13)
EPIC (N=8)	100% (8/8)	0% (0/8)
NTPEN (N=15)	87% (13/15)	13% (2/15)
NWEIG (N=7)	100% (7/7)	0% (0/7)
ORENG (N=7)	100% (7/7)	0% (0/7)
PENNEC (N=8)	88% (7/8)	13% (1/8)
SETPEG (N=7)	71% (5/7)	29% (2/7)
SWEP (N=3)	100% (3/3)	0% (0/3)
SWIPE (N=9)	100% (9/9)	0% (0/9)
SWTPEG (N=6)	100% (6/6)	0% (0/6)
TEN (N=6)	100% (6/6)	0% (0/6)
WPNN (N=7)	100% (7/7)	0% (0/7)
YPEN (N=8)	75% (6/8)	25% (2/8)

Epilepsy specialist nurse

There was a total of **151.6 WTE** epilepsy specialist nurses (ESN) reported to be employed across England and Wales (Table 6). **89%** (**106/119**) of Health Boards and Trusts had some epilepsy specialist nurses (ESN) provision (i.e. greater than 0 WTE). Of those with an ESN, the number employed ranged from **0.2 WTE** to **4.8 WTE**, (**Table 7**).

Figure 2 shows a comparison of the mean WTE for epilepsy specialist nurses (ESN) employed in England and Wales in Round 1, April 2018, Round 2, November 2019 and Round 3, November 2020.

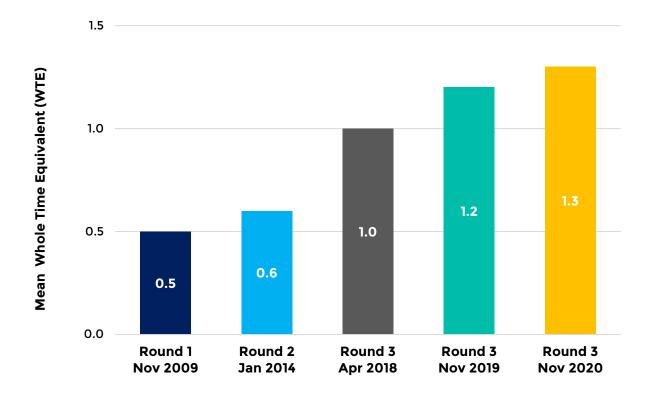


Figure 2: Mean Whole Time Equivalent epilepsy specialist nurses employed in England and Wales in Round 1, Round 2, Round 3 April 2018, November 2019 and November 2020.

Functions supported by epilepsy specialist nurses (all Health Boards or Trusts)

Figure 3 shows the percentage of Health Boards and Trusts supporting key ESN functions. More than 80% of Health boards and Trusts indicated that they could offer ESN support for: rescue medication training for parents (104/119), school meetings (102/119), individual healthcare plan facilitation (99/119) or ward visits (101/119). 18% (21/119) of Health Boards and Trusts reported they could support all nine functions, Table 8.

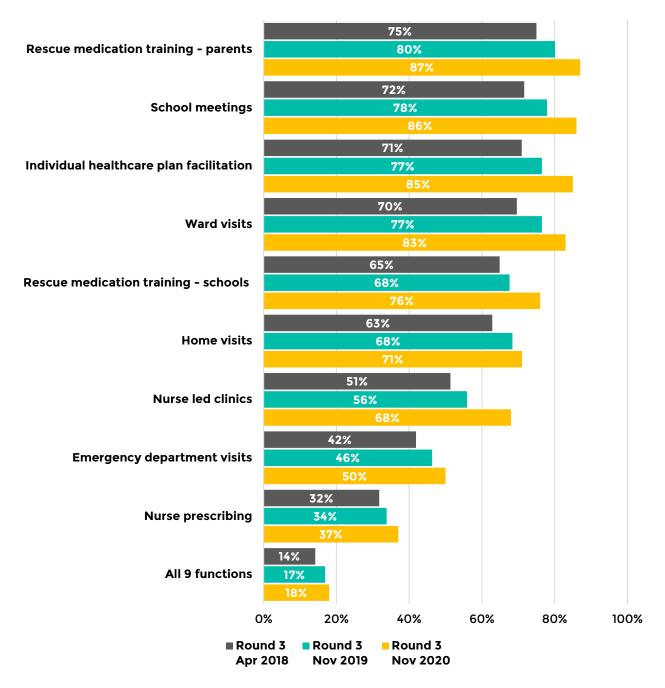


Figure 3: Percentage of Health Boards and Trusts that could support epilepsy specialist nurse functions in Round 3 April 2018, November 2019 and November 2020.

Table 6: Whole time equivalent (WTE) epilepsy specialist nurses employed within Health Boards and Trusts.

Country/network	Total WTE	Mean WTE	Min WTE	Max WTE
England and Wales (N=119)	151.6	1.3	0.0	4.8
England (N=115)	144.2	1.3	0.0	4.8
Wales (N=4)	7.4	1.9	0.0	3.0
BRPNF (N=10)	5.7	0.6	0.0	1.2
CEWT (N=5)	6.8	1.4	0.0	2.0
EPEN (N=13)	15.8	1.2	0.0	2.4
EPIC (N=8)	13.2	1.7	0.6	3.8
NTPEN (N=15)	18.7	1.2	0.0	3.7
NWEIG (N=7)	10.3	1.5	1.0	2.6
ORENG (N=7)	4.6	0.7	0.0	1.0
PENNEC (N=8)	10.1	1.3	0.0	2.3
SETPEG (N=7)	10.1	1.4	0.3	2.5
SWEP (N=3)	5.0	1.7	0.0	3.0
SWIPE (N=9)	10.9	1.2	0.0	2.0
SWTPEG (N=6)	6.6	1.1	0.8	1.6
TEN (N=6)	12.0	2.0	1.0	4.0
WPNN (N=7)	8.4	1.2	0.2	2.1
YPEN (N=8)	13.4	1.7	0.6	4.8

Table 7: Health Boards and Trusts that employed at least some level of whole time equivalent (WTE) epilepsy specialist nurse.

Country/network	% with some WTE		
England and Wales (N=119)	89% (106/119)	11% (13/119)	0.2 - 4.8
England (N=115)	90% (103/115)	10% (12/115)	0.2 - 4.8
Wales (N=4)	75% (3/4)	25% (1/4)	0.2 - 3.0
BRPNF (N=10)	70% (7/10)	30% (3/10)	0.5 - 1.2
CEWT (N=5)	80% (4/5)	20% (1/5)	1.0 - 2.0
EPEN (N=13)	92% (12/13)	8% (1/13)	0.5 - 2.4
EPIC (N=8)	100% (8/8)	0% (0/8)	0.6 - 3.8
NTPEN (N=15)	87% (13/15)	13% (2/15)	0.4 - 3.7
NWEIG (N=7)	100% (7/7)	0% (0/7)	1.0 - 2.6
ORENG (N=7)	71% (5/7)	29% (2/7)	0.6 - 1.0
PENNEC (N=8)	75% (6/8)	25% (2/8)	1.0 - 2.3
SETPEG (N=7)	100% (7/7)	0% (0/7)	0.3 - 2.5
SWEP (N=3)	67% (2/3)	33% (1/3)	2.0 - 3.0
SWIPE (N=9)	89% (8/9)	11% (1/9)	0.3 - 2.0
SWTPEG (N=6)	100% (6/6)	0% (0/6)	0.8 - 1.6
TEN (N=6)	100% (6/6)	0% (0/6)	1.0 - 4.0
WPNN (N=7)	100% (7/7)	0% (0/7)	0.2 - 2.1
YPEN (N=8)	100% (8/8)	0% (0/8)	0.6 - 4.8

Table 8: Health Boards and Trusts that could support epilepsy nurse functions (n=119).

Country/network	Home visits	Nurse led clinics	Emergency department visits	Ward visits	Nurse prescribing	School meetings
England and Wales	71% (84/119)	68% (81/119)	50% (60/119)	85% (101/119)	37% (44/119)	86% (102/119)
(N=119)						
England (N=115)	70% (81/115)	68% (78/115)	52% (60/115)	85% (98/115)	37% (43/115)	86% (99/115)
Wales (N=4)	75% (3/4)	75% (3/4)	0% (0/4)	75% (3/4)	25% (1/4)	75% (3/4)
BRPNF (N=10)	40% (4/10)	40% (4/10)	30% (3/10)	70% (7/10)	30% (3/10)	70% (7/10)
CEWT (N=5)	40% (2/5)	80% (4/5)	60% (3/5)	80% (4/5)	40% (2/5)	60% (3/5)
EPEN (N=13)	54% (7/13)	69% (9/13)	77% (10/13)	85% (11/13)	15% (2/13)	85% (11/13)
EPIC (N=8)	100% (8/8)	63% (5/8)	63% (5/8)	100% (8/8)	75% (6/8)	100% (8/8)
NTPEN (N=15)	67% (10/15)	60% (9/15)	53% (8/15)	87% (13/15)	20% (3/15)	80% (12/15)
NWEIG (N=7)	100% (7/7)	71% (5/7)	14% (1/7)	100% (7/7)	86% (6/7)	100% (7/7)
ORENG (N=7)	71% (5/7)	57% (4/7)	57% (4/7)	71% (5/7)	14% (1/7)	71% (5/7)
PENNEC (N=8)	75% (6/8)	63% (5/8)	50% (4/8)	63% (5/8)	63% (5/8)	75% (6/8)
SETPEG (N=7)	71% (5/7)	100% (7/7)	71% (5/7)	71% (5/7)	0% (0/7)	100% (7/7)
SWEP (N=3)	67% (2/3)	67% (2/3)	0% (0/3)	67% (2/3)	0% (0/3)	67% (2/3)
SWIPE (N=9)	67% (6/9)	67% (6/9)	67% (6/9)	89% (8/9)	56% (5/9)	89% (8/9)
SWTPEG (N=6)	67% (4/6)	83% (5/6)	50% (3/6)	100% (6/6)	33% (2/6)	83% (5/6)
TEN (N=6)	100% (6/6)	83% (5/6)	67% (4/6)	100% (6/6)	50% (3/6)	100% (6/6)
WPNN (N=7)	86% (6/7)	71% (5/7)	29% (2/7)	100% (7/7)	43% (3/7)	100% (7/7)
YPEN (N=8)	75% (6/8)	75% (6/8)	25% (2/8)	88% (7/8)	38% (3/8)	100% (8/8)

Table 8 (continued): Health Boards and Trusts that could support epilepsy nurse functions (n=119).

Country/network	Individual HCP facilitation	Rescue medication training parents	Rescue medication training schools	Supporting all 9 functions
England and Wales (N=119)	83% (99/119)	87% (104/119)	76% (90/119)	18% (21/119)
England (N=115)	83% (96/115)	88% (101/115)	76% (87/115)	18% (21/115)
Wales (N=4)	75% (3/4)	75% (3/4)	75% (3/4)	0% (0/4)
BRPNF (N=10)	70% (7/10)	70% (7/10)	50% (5/10)	10% (1/10)
CEWT (N=5)	80% (4/5)	80% (4/5)	60% (3/5)	20% (1/5)
EPEN (N=13)	92% (12/13)	92% (12/13)	54% (7/13)	8% (1/13)
EPIC (N=8)	100% (8/8)	100% (8/8)	100% (8/8)	38% (3/8)
NTPEN (N=15)	73% (11/15)	80% (12/15)	67% (10/15)	0% (0/15)
NWEIG (N=7)	100% (7/7)	100% (7/7)	100% (7/7)	14% (1/7)
ORENG (N=7)	71% (5/7)	71% (5/7)	57% (4/7)	0% (0/7)
PENNEC (N=8)	75% (6/8)	75% (6/8)	75% (6/8)	50% (4/8)
SETPEG (N=7)	100% (7/7)	100% (7/7)	100% (7/7)	0% (0/7)
SWEP (N=3)	67% (2/3)	67% (2/3)	67% (2/3)	0% (0/3)
SWIPE (N=9)	78% (7/9)	89% (8/9)	89% (8/9)	33% (3/9)
SWTPEG (N=6)	100% (6/6)	100% (6/6)	100% (6/6)	33% (2/6)
TEN (N=6)	83% (5/6)	100% (6/6)	100% (6/6)	33% (2/6)
WPNN (N=7)	86% (6/7)	86% (6/7)	43% (3/7)	14% (1/7)
YPEN (N=8)	75% (6/8)	100% (8/8)	100% (8/8)	25% (2/8)

Table 9: Health Boards and Trusts that employed at least some level of whole time equivalent (WTE) epilepsy specialist nurse that could support epilepsy nurse functions (n=106).

Country/network	Home visits	Nurse led clinics	Emergency department visits	Ward visits	Nurse prescribing	School meetings
England and Wales (N=106)	79% (84/106)	76% (81/106)	57% (60/106)	95% (101/106)	42% (44/106)	96% (102/106)
England (N=103)	79% (81/103)	76% (78/103)	58% (60/103)	95% (98/103)	42% (43/103)	96% (99/103)
Wales (N=3)	100% (3/3)	100% (3/3)	0% (0/3)	100% (3/3)	33% (1/3)	100% (3/3)
BRPNF (N=7)	57% (4/7)	57% (4/7)	43% (3/7)	100% (7/7)	43% (3/7)	100% (7/7)
CEWT (N=4)	50% (2/4)	100% (4/4)	75% (3/4)	100% (4/4)	50% (2/4)	75% (3/4)
EPEN (N=12)	58% (7/12)	75% (9/12)	83% (10/12)	92% (11/12)	17% (2/12)	92% (11/12)
EPIC (N=8)	100% (8/8)	63% (5/8)	63% (5/8)	100% (8/8)	75% (6/8)	100% (8/8)
NTPEN (N=13)	77% (10/13)	69% (9/13)	62% (8/13)	100% (13/13)	23% (3/13)	92% (12/13)
NWEIG (N=7)	100% (7/7)	71% (5/7)	14% (1/7)	100% (7/7)	86% (6/7)	100% (7/7)
ORENG (N=5)	100% (5/5)	80% (4/5)	80% (4/5)	100% (5/5)	20% (1/5)	100% (5/5)
PENNEC (N=6)	100% (6/6)	83% (5/6)	67% (4/6)	83% (5/6)	83% (5/6)	100% (6/6)
SETPEG (N=7)	71% (5/7)	100% (7/7)	71% (5/7)	71% (5/7)	0% (0/7)	100% (7/7)
SWEP (N=2)	100% (2/2)	100% (2/2)	0% (0/2)	100% (2/2)	0% (0/2)	100% (2/2)
SWIPE (N=8)	75% (6/8)	75% (6/8)	75% (6/8)	100% (8/8)	63% (5/8)	100% (8/8)
SWTPEG (N=6)	67% (4/6)	83% (5/6)	50% (3/6)	100% (6/6)	33% (2/6)	83% (5/6)
TEN (N=6)	100% (6/6)	83% (5/6)	67% (4/6)	100% (6/6)	50% (3/6)	100% (6/6)
WPNN (N=7)	86% (6/7)	71% (5/7)	29% (2/7)	100% (7/7)	43% (3/7)	100% (7/7)
YPEN (N=8)	75% (6/8)	75% (6/8)	25% (2/8)	88% (7/8)	38% (3/8)	100% (8/8)

Table 9 (continued): Health Boards and Trusts that employed at least some level of whole time equivalent (WTE) epilepsy specialist nurse that could support epilepsy nurse functions (n=106).

Country/network	Individual HCP	Rescue medication	Rescue medication	Supporting all 9
	facilitation	training with parents	training in schools	functions
England and Wales (N=106)	93% (99/106)	98% (104/106)	85% (90/106)	20% (21/106)
England (N=103)	93% (96/103)	98% (101/103)	84% (87/103)	20% (21/103)
Wales (N=3)	100% (3/3)	100% (3/3)	100% (3/3)	0% (0/3)
BRPNF (N=7)	100% (7/7)	100% (7/7)	71% (5/7)	14% (1/7)
CEWT (N=4)	100% (4/4)	100% (4/4)	75% (3/4)	25% (1/4)
EPEN (N=12)	100% (12/12)	100% (12/12)	58% (7/12)	8% (1/12)
EPIC (N=8)	100% (8/8)	100% (8/8)	100% (8/8)	38% (3/8)
NTPEN (N=13)	85% (11/13)	92% (12/13)	77% (10/13)	0% (0/13)
NWEIG (N=7)	100% (7/7)	100% (7/7)	100% (7/7)	14% (1/7)
ORENG (N=5)	100% (5/5)	100% (5/5)	80% (4/5)	0% (0/5)
PENNEC (N=6)	100% (6/6)	100% (6/6)	100% (6/6)	67% (4/6)
SETPEG (N=7)	100% (7/7)	100% (7/7)	100% (7/7)	0% (0/7)
SWEP (N=2)	100% (2/2)	100% (2/2)	100% (2/2)	0% (0/2)
SWIPE (N=8)	88% (7/8)	100% (8/8)	100% (8/8)	38% (3/8)
SWTPEG (N=6)	100% (6/6)	100% (6/6)	100% (6/6)	33% (2/6)
TEN (N=6)	83% (5/6)	100% (6/6)	100% (6/6)	33% (2/6)
WPNN (N=7)	86% (6/7)	86% (6/7)	43% (3/7)	14% (1/7)
YPEN (N=8)	75% (6/8)	100% (8/8)	100% (8/8)	25% (2/8)

Clinic configuration

Defined epilepsy clinic

There was a defined epilepsy clinic, seeing patients at secondary level, in 93% (111/119) of Health Boards and Trusts, (Table 10). Of those, 89% (99/111) were holding defined epilepsy clinics that allowed at least 20 minutes with a consultant with expertise in epilepsy and an ESN, either simultaneously or in succession, (Table 12). There was a total of 232.4 consultant or associate specialist led secondary level 'epilepsy clinics' taking place each week across England and Wales. The mean number of consultant or associate specialist clinics taking place per week was 2.1 (range 0.1 - 6.0), (Table 11).

Figure 4 shows a comparison of the mean of consultant or associate specialist led secondary level epilepsy clinics in in Round 1, April 2018, Round 2, November 2019 and Round 3, November 2020.

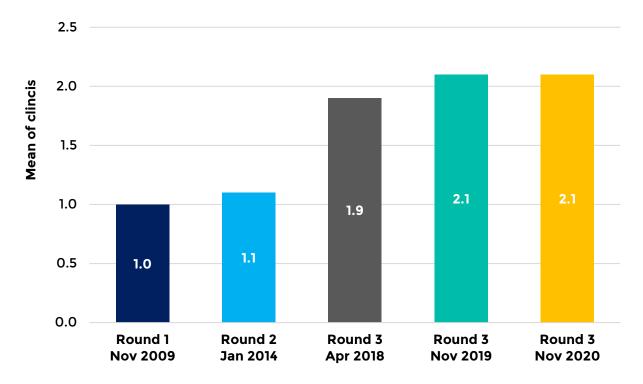


Figure 4: Mean of consultant or associate specialist led secondary level epilepsy clinics in Round 1, April 2018, Round 2, November 2019 and Round 3 November 2020.

Table 10: Health Boards and Trusts that had a defined epilepsy clinic.

Country/network	% with a defined epilepsy	% with no defined epilepsy
Gountry, necwork	clinic	clinic
England and Wales (N=119)	93% (111/119)	7% (8/119)
England (N=115)	93% (107/115)	7% (8/115)
Wales (N=4)	100% (4/4)	0% (0/4)
BRPNF (N=10)	80% (8/10)	20% (2/10)
CEWT (N=5)	100% (5/5)	0% (0/5)
EPEN (N=13)	92% (12/13)	8% (1/13)
EPIC (N=8)	100% (8/8)	0% (0/8)
NTPEN (N=15)	87% (13/15)	13% (2/15)
NWEIG (N=7)	100% (7/7)	0% (0/7)
ORENG (N=7)	100% (7/7)	0% (0/7)
PENNEC (N=8)	100% (8/8)	0% (0/8)
SETPEG (N=7)	100% (7/7)	0% (0/7)
SWEP (N=3)	100% (3/3)	0% (0/3)
SWIPE (N=9)	78% (7/9)	22% (2/9)
SWTPEG (N=6)	100% (6/6)	0% (0/6)
TEN (N=6)	100% (6/6)	0% (0/6)
WPNN (N=7)	100% (7/7)	0% (0/7)
YPEN (N=8)	88% (7/8)	13% (1/8)

Table 11: Number of consultant or associate specialist led secondary level 'epilepsy clinics' taking place within Health Boards and Trusts per week.

Country/network	Total no. clinics per week	Mean no. clinics per week	Min no. clinics per week	Max no. clinics per week
England and Wales (N=111)	232.4	2.1	0.1	6.0
England (N=107)	220.2	2.1	0.1	6.0
Wales (N=4)	12.2	3.0	1.5	4.7
BRPNF (N=8)	12.7	1.6	1.0	3.0
CEWT (N=5)	12.5	2.5	1.0	5.0
EPEN (N=12)	24.6	2.0	0.8	4.0
EPIC (N=8)	20.0	2.5	1.0	4.7
NTPEN (N=13)	26.6	2.0	0.8	5.3
NWEIG (N=7)	14.3	2.0	1.0	4.0
ORENG (N=7)	11.4	1.6	0.1	5.0
PENNEC (N=8)	17.3	2.2	0.5	4.0
SETPEG (N=7)	20.0	2.9	1.3	6.0
SWEP (N=3)	7.5	2.5	1.5	4.0
SWIPE (N=7)	12.1	1.7	0.3	3.0
SWTPEG (N=6)	16.5	2.8	2.0	4.5
TEN (N=6)	8.5	1.4	0.5	2.0
WPNN (N=7)	14.5	2.1	0.5	5.0
YPEN (N=7)	14.1	2.0	0.5	3.0

Table 12: Defined epilepsy clinics that allowed at least 20 minutes with a consultant with 'expertise in epilepsy' and/or an epilepsy specialist nurse.

Country/network	% with a defined epilepsy clinic	% with no defined epilepsy clinic
England and Wales (N=111)	89% (99/111)	11% (12/111)
England (N=107)	89% (95/107)	11% (12/107)
Wales (N=4)	100% (4/4)	0% (0/4)
BRPNF (N=8)	100% (8/8)	0% (0/8)
CEWT (N=5)	100% (5/5)	0% (0/5)
EPEN (N=12)	92% (11/12)	8% (1/12)
EPIC (N=8)	88% (7/8)	13% (1/8)
NTPEN (N=13)	77% (10/13)	23% (3/13)
NWEIG (N=7)	100% (7/7)	0% (0/7)
ORENG (N=7)	71% (5/7)	29% (2/7)
PENNEC (N=8)	63% (5/8)	38% (3/8)
SETPEG (N=7)	100% (7/7)	0% (0/7)
SWEP (N=3)	100% (3/3)	0% (0/3)
SWIPE (N=7)	100% (7/7)	0% (0/7)
SWTPEG (N=6)	100% (6/6)	0% (0/6)
TEN (N=6)	83% (5/6)	17% (1/6)
WPNN (N=7)	86% (6/7)	14% (1/7)
YPEN (N=7)	100% (7/7)	0% (0/7)

Epilepsy Best Practice Tariff (BPC) - England only

Table 13 shows **49%** (56/115) of Trusts in England were running Epilepsy Best Practice Criteria clinics. A further **27%** (31/115) were working towards BPT, **18%** (21/115) were not running a BPT service whilst **6%** (7/115) reported that this was not applicable,

Figure 5 shows a comparison of the percentage of Trusts running a BPT epilepsy service in Round 3 April 2018, November 2019 and November 2020.

Figure 5: Percentage of Trusts receiving TFC 223 Epilepsy Best Practice Criteria (England only) (n=115).

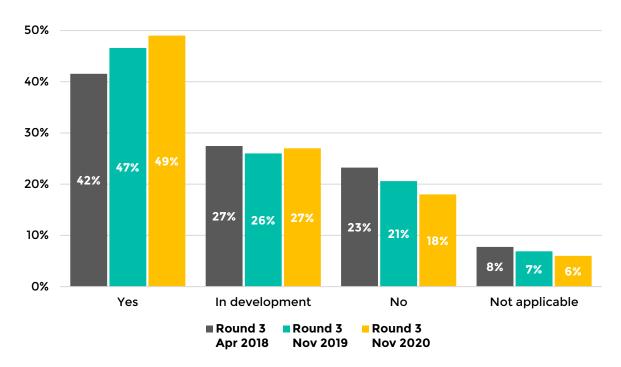


Figure 5: Percentage of Trusts receiving TFC 223 Epilepsy Best Practice Criteria (England only) in Round 3 April 2018, November 2019 and November 2020.

Table 13: Trusts that were running TFC 223 Epilepsy Best Practice Criteria (BPC) clinics.

Country/network	Yes	In development	No	N/A
England (N=115)	49% (56/115)	27% (31/115)	18% (21/115)	6% (7/115)
DDDNE (N-10)	70% (7 /10)	(0% (/ /10)	700/ (7 /10)	00/ (0 /10)
BRPNF (N=10)	30% (3/10)	40% (4/10)	30% (3/10)	0% (0/10)
CEWT (N=5)	60% (3/5)	0% (0/5)	20% (1/5)	20% (1/5)
EPEN (N=13)	54% (7/13)	15% (2/13)	15% (2/13)	15% (2/13)
EPIC (N=7)	43% (3/7)	57% (4/7)	0% (0/7)	0% (0/7)
NTPEN (N=15)	27% (4/15)	40% (6/15)	20% (3/15)	13% (2/15)
NWEIG (N=7)	29% (2/7)	29% (2/7)	43% (3/7)	0% (0/7)
ORENG (N=7)	43% (3/7)	14% (1/7)	43% (3/7)	0% (0/7)
PENNEC (N=8)	50% (4/8)	25% (2/8)	25% (2/8)	0% (0/8)
SETPEG (N=7)	43% (3/7)	29% (2/7)	29% (2/7)	0% (0/7)
SWIPE (N=9)	56% (5/9)	22% (2/9)	22% (2/9)	0% (0/9)
SWTPEG (N=6)	83% (5/6)	17% (1/6)	0% (0/6)	0% (0/6)
TEN (N=6)	67% (4/6)	33% (2/6)	0% (0/6)	0% (0/6)
WPNN (N=7)	71% (5/7)	14% (1/7)	0% (0/7)	14% (1/7)
YPEN (N=8)	63% (5/8)	25% (2/8)	0% (0/8)	13% (1/8)

Tertiary provision

Paediatric neurology services

A total of **91.1 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, (**Table 14**). Consultant paediatric neurologists were employed across **24** of the **119** of Health Boards and Trusts, (this ranged from 0.0 WTE to 10.6 WTE, (**Table 15**).

95% (113/119) of Health Boards and Trusts had agreed referral pathways to tertiary paediatric neurology services, **Table 16**. 20% (24/119) of Health Boards and Trusts reported that paediatric neurologists could receive direct referrals from general practice or emergency services to assess children with possible epilepsy, (**Table 17a**). Satellite paediatric neurology clinics were hosted in **75%** (89/119) of Health Boards and Trusts, (**Table 18**).

Table 14: Whole time equivalent (WTE) paediatric neurologists, acutely and/or non-acutely, employed within Health Boards or Trusts.

Country/network	Total WTE	Min WTE	Max WTE
England and Wales (N=119)	91.1	0.0	10.6
England (N=115)	90.5	0.0	10.6
Wales (N=4)	0.6	0.0	0.6
BRPNF (N=10)	0.0	0.0	0.0
CEWT (N=5)	5.5	0.0	3.0
EPEN (N=13)	4.4	0.0	4.4
EPIC (N=8)	3.8	0.0	3.8
NTPEN (N=15)	17.6	0.0	10.6
NWEIG (N=7)	9.2	0.0	7.2
ORENG (N=7)	5.7	0.0	5.7
PENNEC (N=8)	5.7	0.0	4.7
SETPEG (N=7)	8.0	0.0	5.0
SWEP (N=3)	0.6	0.0	0.6
SWIPE (N=9)	7.0	0.0	7.0
SWTPEG (N=6)	3.0	0.0	3.0
TEN (N=6)	10.0	0.0	5.0
WPNN (N=7)	7.5	0.0	7.5
YPEN (N=8)	3.1	0.0	3.1

Table 15: Health Boards and Trusts that employed at least some level of whole time equivalent (WTE) paediatric neurologists, acutely and/or non-acutely.

Country/network	% with some WTE	% with no WTE	WTE range in T/HBs with some WTE
England and Wales (N=119)	20% (24/119)	80% (95/119)	0.0 - 10.6
England (N=115)	20% (23/115)	80% (92/115)	0.0 - 10.6
Wales (N=4)	25% (1/4)	75% (3/4)	0.6 - 0.6
BRPNF (N=10)	10% (1/10)	90% (9/10)	0.02 - 0.02
CEWT (N=5)	40% (2/5)	60% (3/5)	2.5 - 3.0
EPEN (N=13)	8% (1/13)	92% (12/13)	4.4 - 4.4
EPIC (N=8)	13% (1/8)	88% (7/8)	3.8 - 3.8
NTPEN (N=15)	27% (4/15)	73% (11/15)	1.0 - 10.6
NWEIG (N=7)	29% (2/7)	71% (5/7)	2.0 - 7.2
ORENG (N=7)	14% (1/7)	86% (6/7)	5.7 - 5.7
PENNEC (N=8)	25% (2/8)	75% (6/8)	1.0 - 4.7
SETPEG (N=7)	29% (2/7)	71% (5/7)	3.0 - 5.0
SWEP (N=3)	33% (1/3)	67% (2/3)	0.6 - 0.6
SWIPE (N=9)	11% (1/9)	89% (8/9)	7.0 -7.0
SWTPEG (N=6)	17% (1/6)	83% (5/6)	3.0 -3.0
TEN (N=6)	33% (2/6)	67% (4/6)	5.0 - 5.0
WPNN (N=7)	14% (1/7)	86% (6/7)	7.5 - 7.5
YPEN (N=8)	25% (2/8)	75% (6/8)	0.0 - 3.1

Table 16: Health Boards and Trusts with agreed referral pathways to tertiary paediatric neurology services.

Country/network	Yes	No
England and Wales (N=119)	95% (113/119)	5% (6/119)
England (N=115)	96% (110/115)	4% (5/115)
Wales (N=4)	75% (3/4)	25% (1/4)
BRPNF (N=10)	80% (8/10)	20% (2/10)
CEWT (N=5)	100% (5/5)	0% (0/5)
EPEN (N=13)	100% (13/13)	0% (0/13)
EPIC (N=8)	100% (8/8)	0% (0/8)
NTPEN (N=15)	100% (15/15)	0% (0/15)
NWEIG (N=7)	86% (6/7)	14% (1/7)
ORENG (N=7)	100% (7/7)	0% (0/7)
PENNEC (N=8)	88% (7/8)	13% (1/8)
SETPEG (N=7)	100% (7/7)	0% (0/7)
SWEP (N=3)	67% (2/3)	33% (1/3)
SWIPE (N=9)	100% (9/9)	0% (0/9)
SWTPEG (N=6)	100% (6/6)	0% (0/6)
TEN (N=6)	100% (6/6)	0% (0/6)
WPNN (N=7)	100% (7/7)	0% (0/7)
YPEN (N=8)	88% (7/8)	13% (1/8)

Table 17a: Health Boards and Trusts that could receive paediatric neurological direct referrals from general practice and emergency departments.

Country/network	Yes	No	N/A
England and Wales (N=119)	20% (24/119)	54% (64/119)	26% (31/119)
England (N=115)	19% (22/115)	54% (62/115)	27% (31/115)
Wales (N=4)	50% (2/4)	50% (2/4)	0% (0/4)
BRPNF (N=10)	10% (1/10)	20% (2/10)	70% (7/10)
CEWT (N=5)	20% (1/5)	20% (1/5)	60% (3/5)
EPEN (N=13)	0% (0/13)	100% (13/13)	0% (0/13)
EPIC (N=8)	13% (1/8)	50% (4/8)	38% (3/8)
NTPEN (N=15)	20% (3/15)	53% (8/15)	27% (4/15)
NWEIG (N=7)	29% (2/7)	71% (5/7)	0% (0/7)
ORENG (N=7)	29% (2/7)	57% (4/7)	14% (1/7)
PENNEC (N=8)	25% (2/8)	63% (5/8)	13% (1/8)
SETPEG (N=7)	43% (3/7)	57% (4/7)	0% (0/7)
SWEP (N=3)	33% (1/3)	67% (2/3)	0% (0/3)
SWIPE (N=9)	11% (1/9)	44% (4/9)	44% (4/9)
SWTPEG (N=6)	17% (1/6)	67% (4/6)	17% (1/6)
TEN (N=6)	67% (4/6)	17% (1/6)	17% (1/6)
WPNN (N=7)	0% (0/7)	29% (2/7)	71% (5/7)
YPEN (N=8)	25% (2/8)	63% (5/8)	13% (1/8)

Table 17b: Health Boards and Trusts that could receive paediatric neurological direct referrals from general practice and emergency departments (excl. N/A).

Country/network	Yes	No
England and Wales (N=88)	27% (24/88)	73% (64/88)
England (N=84)	26% (22/84)	74% (62/84)
Wales (N=4)	50% (2/4)	50% (2/4)
BRPNF (N=3)	33% (1/3)	67% (2/3)
CEWT (N=2)	50% (1/2)	50% (1/2)
EPEN (N=13)	0% (0/13)	100% (13/13)
EPIC (N=5)	20% (1/5)	80% (4/5)
NTPEN (N=11)	27% (3/11)	73% (8/11)
NWEIG (N=7)	29% (2/7)	71% (5/7)
ORENG (N=6)	33% (2/6)	67% (4/6)
PENNEC (N=7)	29% (2/7)	71% (5/7)
SETPEG (N=7)	43% (3/7)	57% (4/7)
SWEP (N=3)	33% (1/3)	67% (2/3)
SWIPE (N=5)	20% (1/5)	80% (4/5)
SWTPEG (N=5)	20% (1/5)	80% (4/5)
TEN (N=5)	80% (4/5)	20% (1/5)
WPNN (N=2)	0% (0/2)	100% (2/2)
YPEN (N=7)	29% (2/7)	71% (5/7)

Table 18: Health Boards and Trusts that were hosting satellite paediatric neurology clinics.

Country/network	Yes	No	N/A
England and Wales (N=119)	75% (89/119)	22% (26/119)	3% (4/119)
England (N=115)	74% (85/115)	23% (26/115)	3% (4/115)
Wales (N=4)	100% (4/4)	0% (0/4)	0% (0/4)
BRPNF (N=10)	20% (2/10)	60% (6/10)	20% (2/10)
CEWT (N=5)	80% (4/5)	0% (0/5)	20% (1/5)
EPEN (N=13)	85% (11/13)	15% (2/13)	0% (0/13)
EPIC (N=8)	75% (6/8)	25% (2/8)	0% (0/8)
NTPEN (N=15)	33% (5/15)	67% (10/15)	0% (0/15)
NWEIG (N=7)	86% (6/7)	0% (0/7)	14% (1/7)
ORENG (N=7)	86% (6/7)	14% (1/7)	0% (0/7)
PENNEC (N=8)	88% (7/8)	13% (1/8)	0% (0/8)
SETPEG (N=7)	86% (6/7)	14% (1/7)	0% (0/7)
SWEP (N=3)	100% (3/3)	0% (0/3)	0% (0/3)
SWIPE (N=9)	100% (9/9)	0% (0/9)	0% (0/9)
SWTPEG (N=6)	100% (6/6)	0% (0/6)	0% (0/6)
TEN (N=6)	100% (6/6)	0% (0/6)	0% (0/6)
WPNN (N=7)	100% (7/7)	0% (0/7)	0% (0/7)
YPEN (N=8)	63% (5/8)	38% (3/8)	0% (0/8)

Other services

16% (19/119) of Health Boards and Trusts reported they could facilitate commencement of the ketogenic diet and 18% (22/119) reported they could facilitate ongoing review of the diet, (Table 19 and Table 20 respectively). 10% (12/119) reported they could provide Vagal Nerve Stimulator (VNS) insertion services and 22% (26/119) reported that they could facilitate VNS review services, (Table 21 and Table 22 respectively).

Figure 6 shows, a comparison of Health Boards and Trusts that provided ketogenic diet and vagal nerve stimulator (VNS) services within their locations in Round 3 April 2018, Round 3 November 2019 and November 2020.

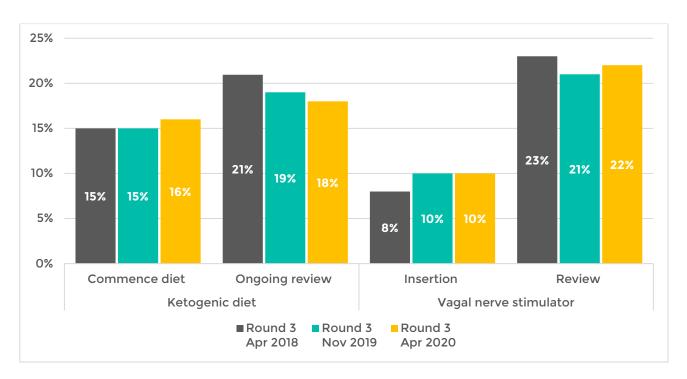


Figure 6: Percentage of Health Boards and Trusts that could provide ketogenic diet and vagal nerve stimulator services in Round 3 April 2018, November 2019 and November 2020.

Table 19: Health Boards and Trusts that could facilitate the commencement of a ketogenic diet.

Country/network Yes No Uncertain **England and Wales** 16% (19/119) 82% (98/119) 2% (2/119) (N=119) England (N=115) 17% (19/115) 82% (94/115) 2% (2/115) Wales (N=4) 0% (0/4) 100% (4/4) 0% (0/4) BRPNF (N=10) 0% (0/10) 100% (10/10) 0% (0/10) CEWT (N=5) 60% (3/5) 40% (2/5) 0% (0/5) **EPEN (N=13)** 8% (1/13) 92% (12/13) 0% (0/13) EPIC (N=8) 13% (1/8) 88% (7/8) 0% (0/8) NTPEN (N=15) 7% (1/15) 93% (14/15) 0% (0/15) NWEIG (N=7) 29% (2/7) 71% (5/7) 0% (0/7) ORENG (N=7) 29% (2/7) 71% (5/7) 0% (0/7) PENNEC (N=8) 13% (1/8) 88% (7/8) 0% (0/8) SETPEG (N=7) 14% (1/7) 86% (6/7) 0% (0/7) SWEP (N=3) 0% (0/3) 100% (3/3) 0% (0/3) SWIPE (N=9) 22% (2/9) 56% (5/9) 22% (2/9) SWTPEG (N=6) 17% (1/6) 83% (5/6) 0% (0/6) TEN (N=6) 17% (1/6) 83% (5/6) 0% (0/6) **WPNN (N=7)** 14% (1/7) 86% (6/7) 0% (0/7) YPEN (N=8) 25% (2/8) 75% (6/8) 0% (0/8)

Table 20: Health Boards and Trusts that could undertake ongoing review of a ketogenic diet.

Country/network	Yes	No	Uncertain
England and Wales (N=119)	18% (22/119)	82% (97/119)	0% (0/119)
England (N=115)	19% (22/115)	81% (93/115)	0% (0/115)
Wales (N=4)	0% (0/4)	100% (4/4)	0% (0/4)
BRPNF (N=10)	0% (0/10)	100% (10/10)	0% (0/10)
CEWT (N=5)	60% (3/5)	40% (2/5)	0% (0/5)
EPEN (N=13)	8% (1/13)	92% (12/13)	0% (0/13)
EPIC (N=8)	13% (1/8)	88% (7/8)	0% (0/8)
NTPEN (N=15)	7% (1/15)	93% (14/15)	0% (0/15)
NWEIG (N=7)	29% (2/7)	71% (5/7)	0% (0/7)
ORENG (N=7)	29% (2/7)	71% (5/7)	0% (0/7)
PENNEC (N=8)	25% (2/8)	75% (6/8)	0% (0/8)
SETPEG (N=7)	14% (1/7)	86% (6/7)	0% (0/7)
SWEP (N=3)	0% (0/3)	100% (3/3)	0% (0/3)
SWIPE (N=9)	44% (4/9)	56% (5/9)	0% (0/9)
SWTPEG (N=6)	17% (1/6)	83% (5/6)	0% (0/6)
TEN (N=6)	17% (1/6)	83% (5/6)	0% (0/6)
WPNN (N=7)	14% (1/7)	86% (6/7)	0% (0/7)
YPEN (N=8)	25% (2/8)	75% (6/8)	0% (0/8)

Table 21: Health Boards and Trusts that were able to insert vagal nerve stimulators.

Country/network	Yes	No	Uncertain
England and Wales (N=119)	10% (12/119)	90% (107/119)	0% (0/119)
England (N=115)	10% (12/115)	90% (103/115)	0% (0/115)
Wales (N=4)	0% (0/4)	100% (4/4)	0% (0/4)
BRPNF (N=10)	0% (0/10)	100% (10/10)	0% (0/10)
CEWT (N=5)	20% (1/5)	80% (4/5)	0% (0/5)
EPEN (N=13)	8% (1/13)	92% (12/13)	0% (0/13)
EPIC (N=8)	13% (1/8)	88% (7/8)	0% (0/8)
NTPEN (N=15)	7% (1/15)	93% (14/15)	0% (0/15)
NWEIG (N=7)	14% (1/7)	86% (6/7)	0% (0/7)
ORENG (N=7)	14% (1/7)	86% (6/7)	0% (0/7)
PENNEC (N=8)	13% (1/8)	88% (7/8)	0% (0/8)
SETPEG (N=7)	14% (1/7)	86% (6/7)	0% (0/7)
SWEP (N=3)	0% (0/3)	100% (3/3)	0% (0/3)
SWIPE (N=9)	11% (1/9)	89% (8/9)	0% (0/9)
SWTPEG (N=6)	0% (0/6)	100% (6/6)	0% (0/6)
TEN (N=6)	17% (1/6)	83% (5/6)	0% (0/6)
WPNN (N=7)	14% (1/7)	86% (6/7)	0% (0/7)
YPEN (N=8)	13% (1/8)	88% (7/8)	0% (0/8)

Table 22: Health Boards and Trusts that were able to review vagal nerve stimulators.

Country/network	Yes	No	Uncertain	
England and Wales (N=119)	22% (26/119)	78% (93/119)	0% (0/119)	
England (N=115)	21% (24/115)	79% (91/115)	0% (0/115)	
Wales (N=4)	50% (2/4)	50% (2/4)	0% (0/4)	
BRPNF (N=10)	10% (1/10)	90% (9/10)	0% (0/10)	
CEWT (N=5)	40% (2/5)	60% (3/5)	0% (0/5)	
EPEN (N=13)	15% (2/13)	85% (11/13)	0% (0/13)	
EPIC (N=8)	13% (1/8)	88% (7/8)	0% (0/8)	
NTPEN (N=15)	7% (1/15)	93% (14/15)	0% (0/15)	
NWEIG (N=7)	43% (3/7)	57% (4/7)	0% (0/7)	
ORENG (N=7)	14% (1/7)	86% (6/7)	0% (0/7)	
PENNEC (N=8)	25% (2/8)	75% (6/8)	0% (0/8)	
SETPEG (N=7)	57% (4/7)	43% (3/7)	0% (0/7)	
SWEP (N=3)	67% (2/3)	33% (1/3)	0% (0/3)	
SWIPE (N=9)	44% (4/9)	56% (5/9)	0% (0/9)	
SWTPEG (N=6)	0% (0/6)	100% (6/6)	0% (0/6)	
TEN (N=6)	17% (1/6)	83% (5/6)	0% (0/6)	
WPNN (N=7)	14% (1/7)	86% (6/7)	0% (0/7)	
YPEN (N=8)	13% (1/8)	88% (7/8)	0% (0/8)	

Investigations

4% (5/119) Health Boards and Trusts were not able to offer 12 lead ECG service. In **39% (46/119)** of Health Boards and Trusts, it was not possible to obtain a standard EEG at a location within their Trust, (**Table 23**).

Figure 7 shows a comparison of availability of epilepsy investigation services across England and Wales in Round 3 April 2018, November 2019 and November 2020.

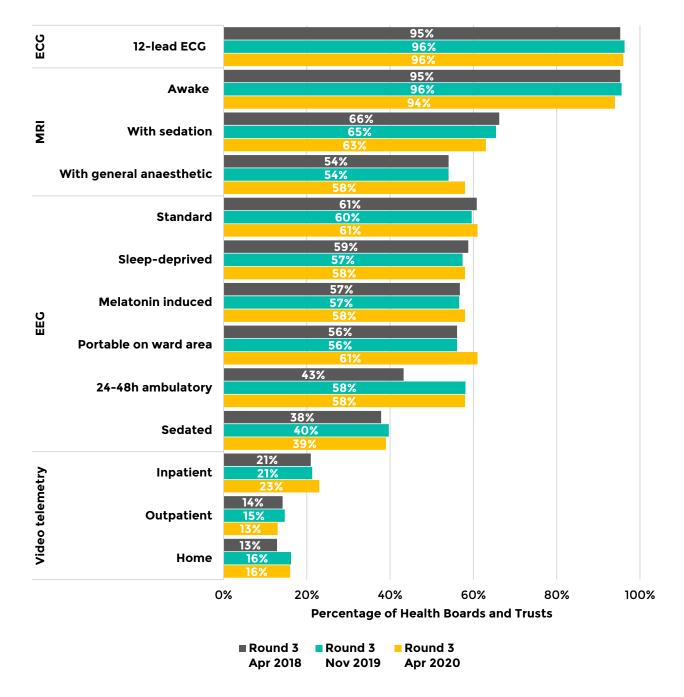


Figure 7: Percentage of Health Boards and Trusts that could provide investigation services in Round 3, April 2018, November 2019 and November 2020.

Table 23: Health Boards and Trusts that could provide epilepsy investigation services.

Country/	1:	12-lead ECG			'Awake' MRI		М	RI with sedation	1
network	Yes	No	Uncertain	Yes	No	Uncertain	Yes	No	Uncertain
England and Wales (N=119)	96% (114/119)	4% (5/119)	0% (0/119)	94% (112/119)	6% (7/119)	0% (0/119)	63% (75/119)	37% (44/119)	0% (0/119)
England (N=115)	96% (110/115)	4% (5/115)	0% (0/115)	94% (108/115)	6% (7/115)	0% (0/115)	62% (71/115)	38% (44/115)	0% (0/115)
Wales (N=4)	100% (4/4)	0% (0/4)	0% (0/4)	100% (4/4)	0% (0/4)	0% (0/4)	100% (4/4)	0% (0/4)	0% (0/4)
BRPNF (N=10)	90% (9/10)	10% (1/10)	0% (0/10)	80% (8/10)	20% (2/10)	0% (0/10)	60% (6/10)	40% (4/10)	0% (0/10)
CEWT (N=5)	100% (5/5)	0% (0/5)	0% (0/5)	100% (5/5)	0% (0/5)	0% (0/5)	100% (5/5)	0% (0/5)	0% (0/5)
EPEN (N=13)	92% (12/13)	8% (1/13)	0% (0/13)	92% (12/13)	8% (1/13)	0% (0/13)	85% (11/13)	15% (2/13)	0% (0/13)
EPIC (N=8)	100% (8/8)	0% (0/8)	0% (0/8)	100% (8/8)	0% (0/8)	0% (0/8)	63% (5/8)	38% (3/8)	0% (0/8)
NTPEN (N=15)	100% (15/15)	0% (0/15)	0% (0/15)	100% (15/15)	0% (0/15)	0% (0/15)	87% (13/15)	13% (2/15)	0% (0/15)
NWEIG (N=7)	100% (7/7)	0% (0/7)	0% (0/7)	86% (6/7)	14% (1/7)	0% (0/7)	43% (3/7)	57% (4/7)	0% (0/7)
ORENG (N=7)	100% (7/7)	0% (0/7)	0% (0/7)	100% (7/7)	0% (0/7)	0% (0/7)	57% (4/7)	43% (3/7)	0% (0/7)
PENNEC (N=8)	100% (8/8)	0% (0/8)	0% (0/8)	100% (8/8)	0% (0/8)	0% (0/8)	50% (4/8)	50% (4/8)	0% (0/8)
SETPEG (N=7)	86% (6/7)	14% (1/7)	0% (0/7)	86% (6/7)	14% (1/7)	0% (0/7)	71% (5/7)	29% (2/7)	0% (0/7)
SWEP (N=3)	100% (3/3)	0% (0/3)	0% (0/3)	100% (3/3)	0% (0/3)	0% (0/3)	100% (3/3)	0% (0/3)	0% (0/3)
SWIPE (N=9)	100% (9/9)	0% (0/9)	0% (0/9)	100% (9/9)	0% (0/9)	0% (0/9)	56% (5/9)	44% (4/9)	0% (0/9)
SWTPEG (N=6)	100% (6/6)	0% (0/6)	0% (0/6)	100% (6/6)	0% (0/6)	0% (0/6)	17% (1/6)	83% (5/6)	0% (0/6)
TEN (N=6)	83% (5/6)	17% (1/6)	0% (0/6)	100% (6/6)	0% (0/6)	0% (0/6)	33% (2/6)	67% (4/6)	0% (0/6)
WPNN (N=7)	86% (6/7)	14% (1/7)	0% (0/7)	86% (6/7)	14% (1/7)	0% (0/7)	57% (4/7)	43% (3/7)	0% (0/7)
YPEN (N=8)	100% (8/8)	0% (0/8)	0% (0/8)	88% (7/8)	13% (1/8)	0% (0/8)	50% (4/8)	50% (4/8)	0% (0/8)

Table 23 (continued): Health Boards and Trusts that could provide epilepsy investigation services.

Country/	MRI with general anaesthetic			Standard EEG			Sleep deprived EEG		
network	Yes	No	Uncertain	Yes	No	Uncertain	Yes	No	Uncertain
England and Wales (N=119)	58% (69/119)	42% (50/119)	0% (0/119)	61% (73/119)	39% (46/119)	0% (0/119)	58% (69/119)	42% (50/119)	0% (0/119)
England (N=115)	57% (65/115)	43% (50/115)	0% (0/115)	60% (69/115)	40% (46/115)	0% (0/115)	57% (65/115)	43% (50/115)	0% (0/115)
Wales (N=4)	100% (4/4)	0% (0/4)	0% (0/4)	100% (4/4)	0% (0/4)	0% (0/4)	100% (4/4)	0% (0/4)	0% (0/4)
BRPNF (N=10)	30% (3/10)	70% (7/10)	0% (0/10)	60% (6/10)	40% (4/10)	0% (0/10)	60% (6/10)	40% (4/10)	0% (0/10)
CEWT (N=5)	100% (5/5)	0% (0/5)	0% (0/5)	80% (4/5)	20% (1/5)	0% (0/5)	80% (4/5)	20% (1/5)	0% (0/5)
EPEN (N=13)	69% (9/13)	31% (4/13)	0% (0/13)	62% (8/13)	38% (5/13)	0% (0/13)	54% (7/13)	46% (6/13)	0% (0/13)
EPIC (N=8)	50% (4/8)	50% (4/8)	0% (0/8)	38% (3/8)	63% (5/8)	0% (0/8)	38% (3/8)	63% (5/8)	0% (0/8)
NTPEN (N=15)	47% (7/15)	53% (8/15)	0% (0/15)	67% (10/15)	33% (5/15)	0% (0/15)	67% (10/15)	33% (5/15)	0% (0/15)
NWEIG (N=7)	43% (3/7)	57% (4/7)	0% (0/7)	57% (4/7)	43% (3/7)	0% (0/7)	57% (4/7)	43% (3/7)	0% (0/7)
ORENG (N=7)	71% (5/7)	29% (2/7)	0% (0/7)	43% (3/7)	57% (4/7)	0% (0/7)	43% (3/7)	57% (4/7)	0% (0/7)
PENNEC (N=8)	50% (4/8)	50% (4/8)	0% (0/8)	50% (4/8)	50% (4/8)	0% (0/8)	50% (4/8)	50% (4/8)	0% (0/8)
SETPEG (N=7)	43% (3/7)	57% (4/7)	0% (0/7)	29% (2/7)	71% (5/7)	0% (0/7)	29% (2/7)	71% (5/7)	0% (0/7)
SWEP (N=3)	100% (3/3)	0% (0/3)	0% (0/3)	100% (3/3)	0% (0/3)	0% (0/3)	100% (3/3)	0% (0/3)	0% (0/3)
SWIPE (N=9)	78% (7/9)	22% (2/9)	0% (0/9)	89% (8/9)	11% (1/9)	0% (0/9)	67% (6/9)	33% (3/9)	0% (0/9)
SWTPEG (N=6)	67% (4/6)	33% (2/6)	0% (0/6)	83% (5/6)	17% (1/6)	0% (0/6)	67% (4/6)	33% (2/6)	0% (0/6)
TEN (N=6)	50% (3/6)	50% (3/6)	0% (0/6)	33% (2/6)	67% (4/6)	0% (0/6)	33% (2/6)	67% (4/6)	0% (0/6)
WPNN (N=7)	71% (5/7)	29% (2/7)	0% (0/7)	71% (5/7)	29% (2/7)	0% (0/7)	71% (5/7)	29% (2/7)	0% (0/7)
YPEN (N=8)	50% (4/8)	50% (4/8)	0% (0/8)	75% (6/8)	25% (2/8)	0% (0/8)	75% (6/8)	25% (2/8)	0% (0/8)

Table 23 (continued): Health Boards and Trusts that could provide epilepsy investigation services.

Country/	ry/ Melatonin EEG				Sedated EEG			24-48h ambulatory EEG		
network	Yes	No	Uncertain	Yes	No	Uncertain	Yes	No	Uncertain	
England and Wales (N=119)	58% (69/119)	42% (50/119)	0% (0/119)	39% (47/119)	60% (71/119)	1% (1/119)	58% (69/119)	42% (50/119)	0% (0/119)	
England (N=115)	57% (65/115)	43% (50/115)	0% (0/115)	37% (43/115)	62% (71/115)	1% (1/115)	57% (65/115)	43% (50/115)	0% (0/115)	
Wales (N=4)	100% (4/4)	0% (0/4)	0% (0/4)	100% (4/4)	0% (0/4)	0% (0/4)	100% (4/4)	0% (0/4)	0% (0/4)	
	1									
BRPNF (N=10)	60% (6/10)	40% (4/10)	0% (0/10)	30% (3/10)	70% (7/10)	0% (0/10)	60% (6/10)	40% (4/10)	0% (0/10)	
CEWT (N=5)	80% (4/5)	20% (1/5)	0% (0/5)	80% (4/5)	20% (1/5)	0% (0/5)	20% (1/5)	80% (4/5)	0% (0/5)	
EPEN (N=13)	46% (6/13)	54% (7/13)	0% (0/13)	15% (2/13)	85% (11/13)	0% (0/13)	69% (9/13)	31% (4/13)	0% (0/13)	
EPIC (N=8)	38% (3/8)	63% (5/8)	0% (0/8)	38% (3/8)	63% (5/8)	0% (0/8)	63% (5/8)	38% (3/8)	0% (0/8)	
NTPEN (N=15)	60% (9/15)	40% (6/15)	0% (0/15)	40% (6/15)	60% (9/15)	0% (0/15)	87% (13/15)	13% (2/15)	0% (0/15)	
NWEIG (N=7)	57% (4/7)	43% (3/7)	0% (0/7)	43% (3/7)	57% (4/7)	0% (0/7)	71% (5/7)	29% (2/7)	0% (0/7)	
ORENG (N=7)	43% (3/7)	57% (4/7)	0% (0/7)	43% (3/7)	57% (4/7)	0% (0/7)	57% (4/7)	43% (3/7)	0% (0/7)	
PENNEC (N=8)	50% (4/8)	50% (4/8)	0% (0/8)	38% (3/8)	63% (5/8)	0% (0/8)	63% (5/8)	38% (3/8)	0% (0/8)	
SETPEG (N=7)	29% (2/7)	71% (5/7)	0% (0/7)	29% (2/7)	71% (5/7)	0% (0/7)	71% (5/7)	29% (2/7)	0% (0/7)	
SWEP (N=3)	100% (3/3)	0% (0/3)	0% (0/3)	100% (3/3)	0% (0/3)	0% (0/3)	0% (0/3)	100% (3/3)	0% (0/3)	
SWIPE (N=9)	78% (7/9)	22% (2/9)	0% (0/9)	67% (6/9)	33% (3/9)	0% (0/9)	44% (4/9)	56% (5/9)	0% (0/9)	
SWTPEG (N=6)	83% (5/6)	17% (1/6)	0% (0/6)	17% (1/6)	67% (4/6)	17% (1/6)	67% (4/6)	33% (2/6)	0% (0/6)	
TEN (N=6)	33% (2/6)	67% (4/6)	0% (0/6)	33% (2/6)	67% (4/6)	0% (0/6)	67% (4/6)	33% (2/6)	0% (0/6)	
WPNN (N=7)	71% (5/7)	29% (2/7)	0% (0/7)	43% (3/7)	57% (4/7)	0% (0/7)	29% (2/7)	71% (5/7)	0% (0/7)	
YPEN (N=8)	75% (6/8)	25% (2/8)	0% (0/8)	38% (3/8)	63% (5/8)	0% (0/8)	25% (2/8)	75% (6/8)	0% (0/8)	

Table 23 (continued): Health Boards and Trusts that could provide epilepsy investigation services.

Country/										
network Inpatient Video Te		ent Video Telem	etry	Outpa	Outpatient Video Telemetry			Home Video Telemetry		
	Yes	No	Uncertain	Yes	No	Uncertain	Yes	No	Uncertain	
England and Wales (N=119)	23% (27/119)	77% (92/119)	0% (0/119)	13% (16/119)	86% (102/119)	1% (1/119)	16% (19/119)	84% (100/119)	0% (0/119)	
England (N=115)	22% (25/115)	78% (90/115)	0% (0/115)	12% (14/115)	87% (100/115)	1% (1/115)	15% (17/115)	85% (98/115)	0% (0/115)	
Wales (N=4)	50% (2/4)	50% (2/4)	0% (0/4)	50% (2/4)	50% (2/4)	0% (0/4)	50% (2/4)	50% (2/4)	0% (0/4)	
BRPNF (N=10)	20% (2/10)	80% (8/10)	0% (0/10)	0% (0/10)	100% (10/10)	0% (0/10)	10% (1/10)	90% (9/10)	0% (0/10)	
CEWT (N=5)	60% (3/5)	40% (2/5)	0% (0/5)	20% (1/5)	80% (4/5)	0% (0/5)	20% (1/5)	80% (4/5)	0% (0/5)	
EPEN (N=13)	15% (2/13)	85% (11/13)	0% (0/13)	0% (0/13)	92% (12/13)	8% (1/13)	8% (1/13)	92% (12/13)	0% (0/13)	
EPIC (N=8)	38% (3/8)	63% (5/8)	0% (0/8)	38% (3/8)	63% (5/8)	0% (0/8)	25% (2/8)	75% (6/8)	0% (0/8)	
NTPEN (N=15)	13% (2/15)	87% (13/15)	0% (0/15)	7% (1/15)	93% (14/15)	0% (0/15)	13% (2/15)	87% (13/15)	0% (0/15)	
NWEIG (N=7)	14% (1/7)	86% (6/7)	0% (0/7)	14% (1/7)	86% (6/7)	0% (0/7)	14% (1/7)	86% (6/7)	0% (0/7)	
ORENG (N=7)	29% (2/7)	71% (5/7)	0% (0/7)	14% (1/7)	86% (6/7)	0% (0/7)	14% (1/7)	86% (6/7)	0% (0/7)	
PENNEC (N=8)	13% (1/8)	88% (7/8)	0% (0/8)	13% (1/8)	88% (7/8)	0% (0/8)	13% (1/8)	88% (7/8)	0% (0/8)	
SETPEG (N=7)	29% (2/7)	71% (5/7)	0% (0/7)	29% (2/7)	71% (5/7)	0% (0/7)	29% (2/7)	71% (5/7)	0% (0/7)	
SWEP (N=3)	33% (1/3)	67% (2/3)	0% (0/3)	33% (1/3)	67% (2/3)	0% (0/3)	33% (1/3)	67% (2/3)	0% (0/3)	
SWIPE (N=9)	33% (3/9)	67% (6/9)	0% (0/9)	11% (1/9)	89% (8/9)	0% (0/9)	22% (2/9)	78% (7/9)	0% (0/9)	
SWTPEG (N=6)	17% (1/6)	83% (5/6)	0% (0/6)	17% (1/6)	83% (5/6)	0% (0/6)	17% (1/6)	83% (5/6)	0% (0/6)	
TEN (N=6)	17% (1/6)	83% (5/6)	0% (0/6)	17% (1/6)	83% (5/6)	0% (0/6)	17% (1/6)	83% (5/6)	0% (0/6)	
WPNN (N=7)	29% (2/7)	71% (5/7)	0% (0/7)	29% (2/7)	71% (5/7)	0% (0/7)	29% (2/7)	71% (5/7)	0% (0/7)	
YPEN (N=8)	13% (1/8)	88% (7/8)	0% (0/8)	0% (0/8)	100% (8/8)	0% (0/8)	0% (0/8)	100% (8/8)	0% (0/8)	

Table 23 (continued): Health Boards and Trusts that could provide epilepsy investigation services.

Country/network	Portable EEG on ward area							
Country/ network	Yes	No	Uncertain					
England and Wales (N=119)	61% (72/119)	39% (47/119)	0% (0/119)					
England (N=115)	59% (68/115)	41% (47/115)	0% (0/115)					
Wales (N=4)	100% (4/4)	0% (0/4)	0% (0/4)					
BRPNF (N=10)	70% (7/10)	30% (3/10)	0% (0/10)					
CEWT (N=5)	100% (5/5)	0% (0/5)	0% (0/5)					
EPEN (N=13)	46% (6/13)	54% (7/13)	0% (0/13)					
EPIC (N=8)	38% (3/8)	63% (5/8)	0% (0/8)					
NTPEN (N=15)	53% (8/15)	47% (7/15)	0% (0/15)					
NWEIG (N=7)	57% (4/7)	43% (3/7)	0% (0/7)					
ORENG (N=7)	86% (6/7)	14% (1/7)	0% (0/7)					
PENNEC (N=8)	50% (4/8)	50% (4/8)	0% (0/8)					
SETPEG (N=7)	29% (2/7)	71% (5/7)	0% (0/7)					
SWEP (N=3)	100% (3/3)	0% (0/3)	0% (0/3)					
SWIPE (N=9)	78% (7/9)	22% (2/9)	0% (0/9)					
SWTPEG (N=6)	83% (5/6)	17% (1/6)	0% (0/6)					
TEN (N=6)	50% (3/6)	50% (3/6)	0% (0/6)					
WPNN (N=7)	71% (5/7)	29% (2/7)	0% (0/7)					
YPEN (N=8)	50% (4/8)	50% (4/8)	0% (0/8)					

Service contact

All of Health Boards and Trusts, 100% (119/119) reported availability of specialist epilepsy advice between scheduled reviews across England and Wales, (Table 24). It was reported that the service was available; some weekdays for 52 weeks of the year in 1% (1/119) Health Boards and Trusts; every weekday for 52 weeks of the year in 55% (66/119) of Health Boards and Trusts; all weekday and out of hours for 52 weeks of the year in 8% (9/119) of Health Boards and Trusts; some weekdays for part of the year in 10% (12/119) of Health Boards and Trusts; all weekdays for part of the year in 25% (30/119) Health Boards and Trusts; or all weekdays and out of hours for part of the year in 1% (1/119) Health Boards and Trusts, (Table 25).

Figure 8 shows a comparison of availability of specialist advice between scheduled reviews in Round 3, April 2018, November 2019 and November 2020.

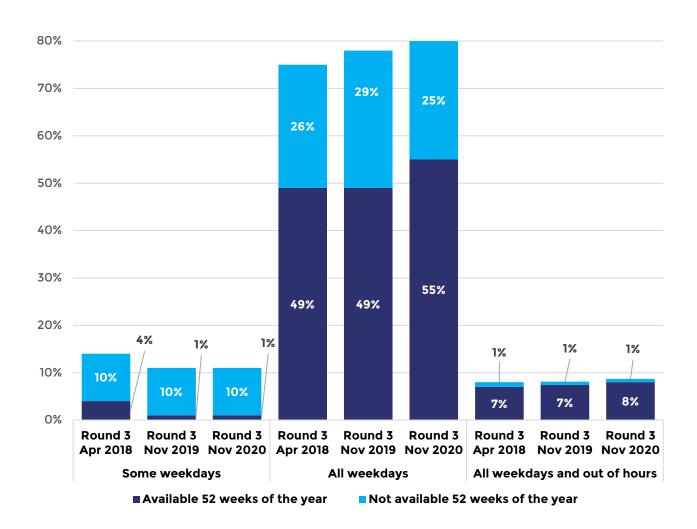


Figure 8: Percentage availability of specialist advice between scheduled reviews in Round 3, April 2018, November 2019 and November 2020.

Half, 50% (59/119) of Health Boards and Trusts described a typical response time of the next weekday, (Table 26). Initial specialist advice was 'typically' provided by an epilepsy specialist nurse 50% (59/119), (Table 27).

In the 12% (14/119) of Health Boards and Trusts that selected 'other', advice is typically provided by: both a consultant paediatrician with expertise in epilepsy and an epilepsy specialist nurse (10/119); a combination of all three (3/119); a community paediatrician (1/119).

Figure 9 shows a comparison of the typical response time for specialist advice in Round 3, April 2018, November 2019 and November 2020.

Figure 10 shows a comparison of professionals who 'typically' provided initial specialist advice in Round 3, April 2018, November 2019 and November 2020.

83% (99/119) of Trusts and Health Boards reported to have a clear point of contact for non-paediatric professionals seeking paediatric epilepsy support across England and Wales (Table 28).

Figure 11 shows a comparison of Health Boards and Trusts with evidence/no evidence of a clear point of contact for non-paediatric professionals seeking paediatric epilepsy support in November 2019 and November 2020.

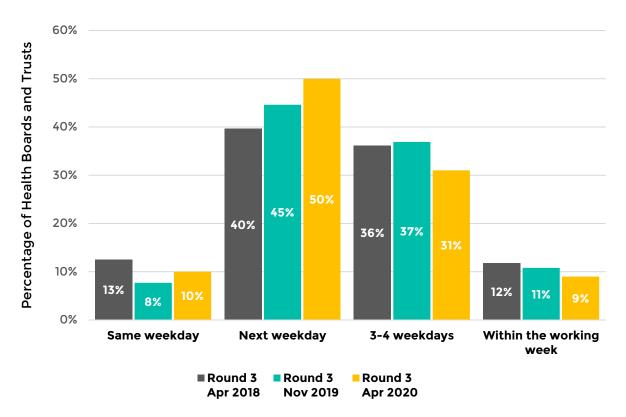


Figure 9: Typical response time for specialist advice in Round 3 April 2018, November 2019 and November 2020.

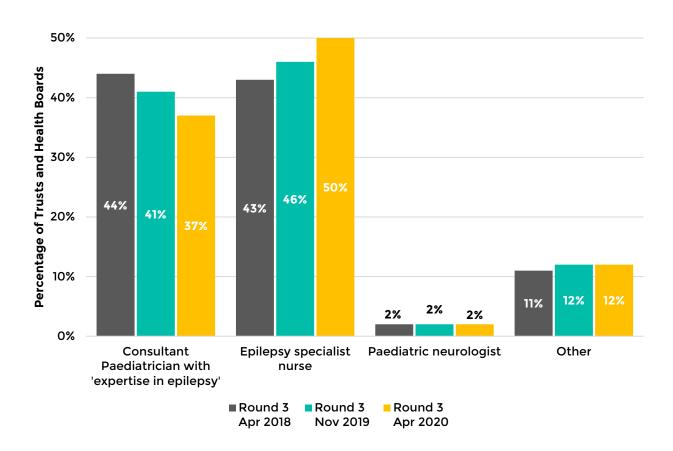


Figure 10: Professional who 'typically' provides initial specialist advice in Round 3, April 2018, November 2019 and November 2020.

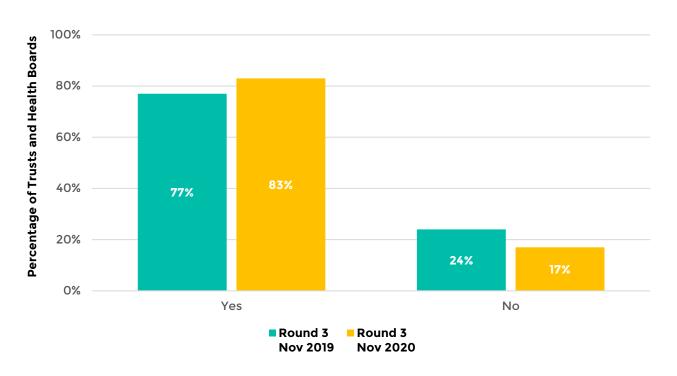


Figure 11: Health Boards and Trusts with evidence of a clear point of contact for non-paediatric professionals seeking paediatric epilepsy support in November 2019 and November 2020.

Table 24: Health Boards and Trusts providing specialist advice between scheduled reviews.

Country/network	Yes	No
England and Wales (N=119)	100% (119/119)	0% (0/119)
England (N=115)	100% (115/115)	0% (0/115)
Wales (N=4)	100% (4/4)	0% (0/4)
BRPNF (N=10)	100% (10/10)	0% (0/10)
CEWT (N=5)	100% (5/5)	0% (0/5)
EPEN (N=13)	100% (13/13)	0% (0/13)
EPIC (N=8)	100% (8/8)	0% (0/8)
NTPEN (N=15)	100% (15/15)	0% (0/15)
NWEIG (N=7)	100% (7/7)	0% (0/7)
ORENG (N=7)	100% (7/7)	0% (0/7)
PENNEC (N=8)	100% (8/8)	0% (0/8)
SETPEG (N=7)	100% (7/7)	0% (0/7)
SWEP (N=3)	100% (3/3)	0% (0/3)
SWIPE (N=9)	100% (9/9)	0% (0/9)
SWTPEG (N=6)	100% (6/6)	0% (0/6)
TEN (N=6)	100% (6/6)	0% (0/6)
WPNN (N=7)	100% (7/7)	0% (0/7)
YPEN (N=8)	100% (8/8)	0% (0/8)

Table 25: Availability of Health Boards and Trusts between scheduled reviews.

	Availa	able 52 weeks of th	ne year	Not available 52 weeks of the year		the year
Country/network	Some weekdays	Every weekday	Every weekday and out of hours	Some weekdays	Every weekday	Every weekday and out of hours
England and Wales (N=119)	1% (1/119)	55% (66/119)	8% (9/119)	10% (12/119)	25% (30/119)	1% (1/119)
England (N=115)	1% (1/115)	55% (63/115)	8% (9/115)	10% (11/115)	26% (30/115)	1% (1/115)
Wales (N=4)	0% (0/4)	75% (3/4)	0% (0/4)	25% (1/4)	0% (0/4)	0% (0/4)
BRPNF (N=10)	0% (0/10)	40% (4/10)	0% (0/10)	10% (1/10)	50% (5/10)	0% (0/10)
CEWT (N=5)	0% (0/5)	100% (5/5)	0% (0/5)	0% (0/5)	0% (0/5)	0% (0/5)
EPEN (N=13)	0% (0/13)	54% (7/13)	0% (0/13)	8% (1/13)	38% (5/13)	0% (0/13)
EPIC (N=8)	0% (0/8)	88% (7/8)	0% (0/8)	0% (0/8)	13% (1/8)	0% (0/8)
NTPEN (N=15)	0% (0/15)	53% (8/15)	13% (2/15)	13% (2/15)	20% (3/15)	0% (0/15)
NWEIG (N=7)	0% (0/7)	86% (6/7)	0% (0/7)	0% (0/7)	14% (1/7)	0% (0/7)
ORENG (N=7)	0% (0/7)	71% (5/7)	14% (1/7)	0% (0/7)	14% (1/7)	0% (0/7)
PENNEC (N=8)	13% (1/8)	38% (3/8)	25% (2/8)	13% (1/8)	13% (1/8)	0% (0/8)
SETPEG (N=7)	0% (0/7)	43% (3/7)	0% (0/7)	0% (0/7)	57% (4/7)	0% (0/7)
SWEP (N=3)	0% (0/3)	67% (2/3)	0% (0/3)	33% (1/3)	0% (0/3)	0% (0/3)
SWIPE (N=9)	0% (0/9)	33% (3/9)	11% (1/9)	56% (5/9)	0% (0/9)	0% (0/9)
SWTPEG (N=6)	0% (0/6)	17% (1/6)	17% (1/6)	17% (1/6)	33% (2/6)	17% (1/6)
TEN (N=6)	0% (0/6)	33% (2/6)	33% (2/6)	0% (0/6)	33% (2/6)	0% (0/6)
WPNN (N=7)	0% (0/7)	57% (4/7)	0% (0/7)	0% (0/7)	43% (3/7)	0% (0/7)
YPEN (N=8)	0% (0/8)	75% (6/8)	0% (0/8)	0% (0/8)	25% (2/8)	0% (0/8)

Table 26: Typical response time to specialist advice.

Country/network	Same weekday	Next weekday	3-4 weekdays	Within the working week
England and Wales (N=119)	10% (12/119)	50% (59/119)	31% (37/119)	9% (11/119)
England (N=115)	10% (12/115)	50% (58/115)	30% (35/115)	9% (10/115)
Wales (N=4)	0% (0/4)	25% (1/4)	50% (2/4)	25% (1/4)
			1	
BRPNF (N=10)	0% (0/10)	30% (3/10)	50% (5/10)	20% (2/10)
CEWT (N=5)	20% (1/5)	40% (2/5)	40% (2/5)	0% (0/5)
EPEN (N=13)	0% (0/13)	46% (6/13)	46% (6/13)	8% (1/13)
EPIC (N=8)	0% (0/8)	75% (6/8)	25% (2/8)	0% (0/8)
NTPEN (N=15)	20% (3/15)	47% (7/15)	13% (2/15)	20% (3/15)
NWEIG (N=7)	14% (1/7)	71% (5/7)	14% (1/7)	0% (0/7)
ORENG (N=7)	29% (2/7)	43% (3/7)	14% (1/7)	14% (1/7)
PENNEC (N=8)	0% (0/8)	63% (5/8)	13% (1/8)	25% (2/8)
SETPEG (N=7)	0% (0/7)	57% (4/7)	29% (2/7)	14% (1/7)
SWEP (N=3)	0% (0/3)	0% (0/3)	67% (2/3)	33% (1/3)
SWIPE (N=9)	33% (3/9)	33% (3/9)	33% (3/9)	0% (0/9)
SWTPEG (N=6)	0% (0/6)	83% (5/6)	17% (1/6)	0% (0/6)
TEN (N=6)	33% (2/6)	33% (2/6)	33% (2/6)	0% (0/6)
WPNN (N=7)	0% (0/7)	43% (3/7)	57% (4/7)	0% (0/7)
YPEN (N=8)	0% (0/8)	63% (5/8)	38% (3/8)	0% (0/8)

Table 27: Professional who 'typically' provides initial specialist advice.

Country/networ k	ESN	Consultant with 'expertise in epilepsy'	Paediatric neurologist	Other
England and Wales (N=119)	50% (59/119)	37% (44/119)	2% (2/119)	12% (14/119)
England (N=115)	50% (57/115)	37% (42/115)	2% (2/115)	12% (14/115)
Wales (N=4)	50% (2/4)	50% (2/4)	0% (0/4)	0% (0/4)
BRPNF (N=10)	20% (2/10)	50% (5/10)	0% (0/10)	30% (3/10)
CEWT (N=5)	40% (2/5)	20% (1/5)	20% (1/5)	20% (1/5)
EPEN (N=13)	54% (7/13)	46% (6/13)	0% (0/13)	0% (0/13)
EPIC (N=8)	63% (5/8)	38% (3/8)	0% (0/8)	0% (0/8)
NTPEN (N=15)	60% (9/15)	33% (5/15)	7% (1/15)	0% (0/15)
NWEIG (N=7)	57% (4/7)	14% (1/7)	0% (0/7)	29% (2/7)
ORENG (N=7)	57% (4/7)	43% (3/7)	0% (0/7)	0% (0/7)
PENNEC (N=8)	25% (2/8)	63% (5/8)	0% (0/8)	13% (1/8)
SETPEG (N=7)	71% (5/7)	14% (1/7)	0% (0/7)	14% (1/7)
SWEP (N=3)	67% (2/3)	33% (1/3)	0% (0/3)	0% (0/3)
SWIPE (N=9)	44% (4/9)	33% (3/9)	0% (0/9)	22% (2/9)
SWTPEG (N=6)	67% (4/6)	17% (1/6)	0% (0/6)	17% (1/6)
TEN (N=6)	33% (2/6)	50% (3/6)	0% (0/6)	17% (1/6)
WPNN (N=7)	57% (4/7)	29% (2/7)	0% (0/7)	14% (1/7)
YPEN (N=8)	38% (3/8)	50% (4/8)	0% (0/8)	13% (1/8)

Table 28: Health Boards and Trusts with evidence of a clear point of contact for non-paediatric professionals seeking paediatric epilepsy support.

Country/network	Yes	No	
England and Wales (N=119)	83% (99/119)	17% (20/119)	
England (N=115)	83% (95/115)	17% (20/115)	
Wales (N=4)	100% (4/4)	0% (0/4)	
BRPNF (N=10)	60% (6/10)	40% (4/10)	
CEWT (N=5)	60% (3/5)	40% (2/5)	
EPEN (N=13)	92% (12/13)	8% (1/13)	
EPIC (N=8)	88% (7/8)	13% (1/8)	
NTPEN (N=15)	93% (14/15)	7% (1/15)	
NWEIG (N=7)	100% (7/7)	0% (0/7)	
ORENG (N=7)	71% (5/7)	29% (2/7)	
PENNEC (N=8)	63% (5/8)	38% (3/8)	
SETPEG (N=7)	100% (7/7)	0% (0/7)	
SWEP (N=3)	100% (3/3)	0% (0/3)	
SWIPE (N=9)	78% (7/9)	22% (2/9)	
SWTPEG (N=6)	100% (6/6)	0% (0/6)	
TEN (N=6)	83% (5/6)	17% (1/6)	
WPNN (N=7)	71% (5/7)	29% (2/7)	
YPEN (N=8)	88% (7/8)	13% (1/8)	

Transition

Table 29 shows 14% (17/119) of Health Boards and Trusts did not have agreed referral pathways for young people to adult services. An outpatient clinic specifically for young people with epilepsies was reported to be in place in 39% (47/119) of Health Boards and Trusts (Table 30). The median age of acceptance into these clinics was 15 years with a minimum acceptance age of 11 years and a maximum acceptance age of 17 (Table 31).

Figure 12 shows the proportion of Health Boards and Trusts with specific outpatient clinic for 'young people' with epilepsies in Round 1, Round 2, and Round 3.

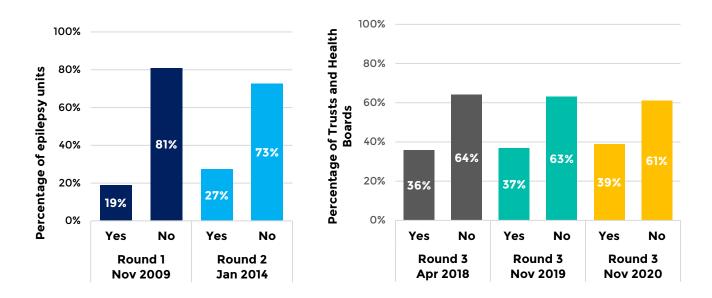


Figure 12: Clinics for young people across Rounds 1, Round 2, and Round 3.

60% (71/119) of Health Boards and Trusts reported to have outpatient service for epilepsy where there is a presence of both adult and paediatric professionals (Table 32). Of those 71 Health Boards and Trusts, a mean of 71% of young people were indicated as being transitioned through a joint professional process. The process comprised of either: a single joint appointment 49% (35/71), several joint appoints 7% (5/71), a mix of joint and individual appointments 34% (24/71) or 'other' (10% (7/71), (Tables 33 and 34). In the seven Health Boards and Trusts that responded 'other', the responses included:

- Adult and paediatric nurse led clinic,
- Adult epilepsy nurse attends teenage clinics,
- Single joint appointment with paediatric and adult neurologist based at the adult centre,
- Some single joint appointments and some a series,
- Single joint appointment and Transition Clinic for one consultant only,

- Joint transition appointment / see neurologist/ back to paediatrics for final appointment,
- Joint appointment in one site only.

Figure 13 shows a comparison of composition of joint transition in Round 3, April 2018, November 2019 and November 2020.

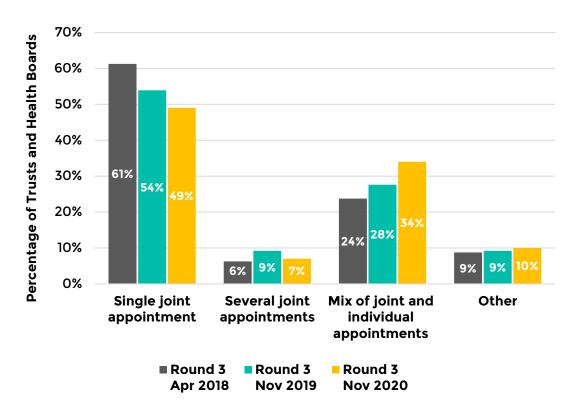


Figure 13: Composition of the joint transition process in Round 3, April 2018, November 2019 and November 2020.

Table 35 shows that 66% (79/119) of Health Boards and Trusts, used structured resources (for example Ready, Steady, Go) to support transition to adult services. Various professionals were indicated as routinely involved in the transition or transfer of paediatric patients to adult services. 85% (101/119) of the Health Boards and Trusts had an adult neurologist supporting transition to adult services, whilst 63% (75/119) had an adult ESN supporting the transition (Table 36). Other responses included:

- Adult Learning Disability Consultant,
- Adult Learning Disability Psychiatrist,
- Consultant Psychiatrist,
- GP,
- GP and Adult Neurologist,
- GP with Epilepsy interest,

- Details of neurology specialist nurse contact and often offer ESN appointment at neuro hospital,
- Adult Learning Disability team,
- Adult Learning Disability team/ adult rehab/ GP,
- Discussion with adult neurologist and neurophysiologist in Neurophysiology meeting,
- Learning Disability transition nurses,
- Youth worker from an epilepsy charity may attend,
- Specific adolescent transition clinic regionally, locally appointed transition nurse,
- Transition nurses,
- Adult neurologist/Learning Disability consultant involved though not in clinic.
- Paediatric Epilepsy Nurse Specialist.

Figure 14 shows a comparison of professionals who were routinely involved in transition or transfer to adult services in Round 3 April 2018, November 2019 and November 2020.

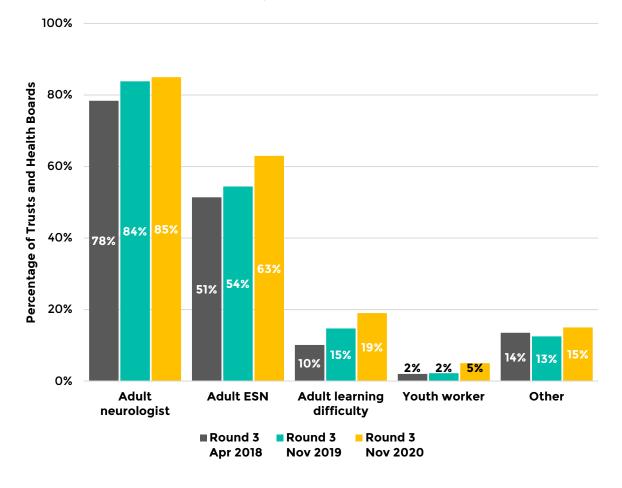


Figure 14: Professionals routinely involved in transition or transfer to adult services in Round 3, April 2018, November 2019 and November 2020.

Figure 15 shows a comparison of Health Boards and Trusts that were using structured resources to support transition in Round 3, April 2018, November 2019 and November 2020.

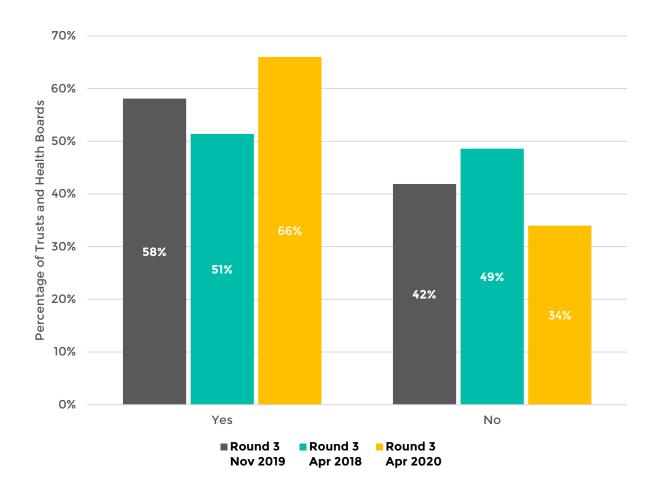


Figure 15: Percentage of Health Boards and Trusts that were using structured resources to support transition in Round 3, April 2018, November 2019 and November 2020.

Table 29: Health Boards and Trusts that had an agreed referral pathway to adult services.

Country/network	Yes	No
England and Wales (N=119)	86% (102/119)	14% (17/119)
England (N=115)	85% (98/115)	15% (17/115)
Wales (N=4)	100% (4/4)	0% (0/4)
BRPNF (N=10)	60% (6/10)	40% (4/10)
CEWT (N=5)	100% (5/5)	0% (0/5)
EPEN (N=13)	92% (12/13)	8% (1/13)
EPIC (N=8)	88% (7/8)	13% (1/8)
NTPEN (N=15)	80% (12/15)	20% (3/15)
NWEIG (N=7)	100% (7/7)	0% (0/7)
ORENG (N=7)	86% (6/7)	14% (1/7)
PENNEC (N=8)	63% (5/8)	38% (3/8)
SETPEG (N=7)	86% (6/7)	14% (1/7)
SWEP (N=3)	100% (3/3)	0% (0/3)
SWIPE (N=9)	78% (7/9)	22% (2/9)
SWTPEG (N=6)	100% (6/6)	0% (0/6)
TEN (N=6)	83% (5/6)	17% (1/6)
WPNN (N=7)	100% (7/7)	0% (0/7)
YPEN (N=8)	100% (8/8)	0% (0/8)

Table 30: Health Boards and Trusts that had an outpatient clinic specifically for young people with epilepsies.

Country/network Yes No **England and Wales** 39% (47/119) 61% (72/119) (N=119) England (N=115) 40% (46/115) 60% (69/115) Wales (N=4) 25% (1/4) 75% (3/4) BRPNF (N=10) 40% (4/10) 60% (6/10) CEWT (N=5) 60% (3/5) 40% (2/5) **EPEN (N=13)** 69% (9/13) 31% (4/13) EPIC (N=8) 25% (2/8) 75% (6/8) NTPEN (N=15) 27% (4/15) 73% (11/15) NWEIG (N=7) 71% (5/7) 29% (2/7) ORENG (N=7) 29% (2/7) 71% (5/7) PENNEC (N=8) 13% (1/8) 88% (7/8) SETPEG (N=7) 71% (5/7) 29% (2/7) 33% (1/3) SWEP (N=3) 67% (2/3) 33% (3/9) SWIPE (N=9) 67% (6/9) SWTPEG (N=6) 33% (2/6) 67% (4/6) **TEN (N=6)** 33% (2/6) 67% (4/6) **WPNN (N=7)** 57% (4/7) 43% (3/7) 0% (0/8) YPEN (N=8) 100% (8/8)

Table 31: Age at which the outpatient clinic typically accepted young people with epilepsies

Country/network	Mean age	Median age	Minimum age	Maximum age
England and Wales (N=47)	14.6	15	11	17
England (N=46)	14.6	14.5	11	18
Wales (N=1)	16.0	16	16	16
BRPNF (N=4)	15.5	16	14	16
CEWT (N=3)	13.3	13	12	15
EPEN (N=9)	14.7	15	13	16
EPIC (N=2)	14.0	14	14	14
NTPEN (N=4)	14.0	14	12	16
NWEIG (N=5)	13.2	14	12	14
ORENG (N=2)	16.0	16	16	16
PENNEC (N=1)	14.0	14	14	14
SETPEG (N=5)	15.6	16	14	16
SWEP (N=1)	16.0	16	16	16
SWIPE (N=3)	16.7	16	16	18
SWTPEG (N=2)	14.0	14	12	16
TEN (N=2)	12.5	12.5	11	14
WPNN (N=4)	14.8	15	13	16
YPEN (N=0)	NA	NA	NA	NA

Table 32: Health Boards and Trusts that had an outpatient service involving adult and paediatric professionals.

Country/network	Yes	No
England and Wales (N=119)	60% (71/119)	40% (48/119)
England (N=115)	59% (68/115)	41% (47/115)
Wales (N=4)	75% (3/4)	25% (1/4)
BRPNF (N=10)	60% (6/10)	40% (4/10)
CEWT (N=5)	60% (3/5)	40% (2/5)
EPEN (N=13)	62% (8/13)	38% (5/13)
EPIC (N=8)	63% (5/8)	38% (3/8)
NTPEN (N=15)	60% (9/15)	40% (6/15)
NWEIG (N=7)	71% (5/7)	29% (2/7)
ORENG (N=7)	71% (5/7)	29% (2/7)
PENNEC (N=8)	13% (1/8)	88% (7/8)
SETPEG (N=7)	57% (4/7)	43% (3/7)
SWEP (N=3)	67% (2/3)	33% (1/3)
SWIPE (N=9)	78% (7/9)	22% (2/9)
SWTPEG (N=6)	83% (5/6)	17% (1/6)
TEN (N=6)	17% (1/6)	83% (5/6)
WPNN (N=7)	71% (5/7)	29% (2/7)
YPEN (N=8)	63% (5/8)	38% (3/8)

Table 33: Structure of outpatient service involving both adult and paediatric professionals.

Country/network	Several joint appointments	Single joint appointments	Mixed (joint and individual)	Other
England and Wales (N=71)	7% (5/71)	49% (35/71)	34% (24/71)	10% (7/71)
England (N=68)	7% (5/68)	51% (35/68)	31% (21/68)	10% (7/68)
Wales (N=3)	0% (0/3)	0% (0/3)	100% (3/3)	0% (0/3)
BRPNF (N=6)	0% (0/6)	67% (4/6)	33% (2/6)	0% (0/6)
CEWT (N=3)	67% (2/3)	0% (0/3)	0% (0/3)	33% (1/3)
EPEN (N=8)	0% (0/8)	38% (3/8)	50% (4/8)	13% (1/8)
EPIC (N=5)	20% (1/5)	40% (2/5)	20% (1/5)	20% (1/5)
NTPEN (N=9)	11% (1/9)	56% (5/9)	22% (2/9)	11% (1/9)
NWEIG (N=5)	0% (0/5)	80% (4/5)	20% (1/5)	0% (0/5)
ORENG (N=5)	0% (0/5)	60% (3/5)	40% (2/5)	0% (0/5)
PENNEC (N=1)	0% (0/1)	100% (1/1)	0% (0/1)	0% (0/1)
SETPEG (N=4)	0% (0/4)	50% (2/4)	50% (2/4)	0% (0/4)
SWEP (N=2)	0% (0/2)	0% (0/2)	100% (2/2)	0% (0/2)
SWIPE (N=7)	0% (0/7)	29% (2/7)	71% (5/7)	0% (0/7)
SWTPEG (N=5)	0% (0/5)	40% (2/5)	20% (1/5)	40% (2/5)
TEN (N=1)	0% (0/1)	0% (0/1)	0% (0/1)	100% (1/1)
WPNN (N=5)	20% (1/5)	40% (2/5)	40% (2/5)	0% (0/5)
YPEN (N=5)	0% (0/5)	100% (5/5)	0% (0/5)	0% (0/5)

Table 34: Estimated percentage of young people transferred to adult services through a joint professional process.

Country/network	Mean	Minimum	Maximum
England and Wales (N=71)	71%	0%	100%
England (N=68)	72%	0%	100%
Wales (N=3)	53%	30%	80%
BRPNF (N=6)	92%	75%	100%
CEWT (N=3)	50%	30%	70%
EPEN (N=8)	80%	1%	100%
EPIC (N=5)	73%	5%	100%
NTPEN (N=9)	63%	1%	100%
NWEIG (N=5)	75%	50%	100%
ORENG (N=5)	78%	40%	100%
PENNEC (N=1)	100%	100%	100%
SETPEG (N=4)	60%	0%	100%
SWEP (N=2)	40%	30%	50%
SWIPE (N=7)	63%	0%	90%
SWTPEG (N=5)	86%	50%	100%
TEN (N=1)	100%	100%	100%
WPNN (N=5)	58%	25%	95%
YPEN (N=5)	67%	30%	100%

Table 35: Health Boards and Trusts that were using structured resources to support transition.

Country/network	Yes	No
England and Wales (N=119)	66% (79/119)	34% (40/119)
England (N=115)	69% (79/115)	31% (36/115)
Wales (N=4)	0% (0/4)	100% (4/4)
BRPNF (N=10)	40% (4/10)	60% (6/10)
CEWT (N=5)	60% (3/5)	40% (2/5)
EPEN (N=13)	85% (11/13)	15% (2/13)
EPIC (N=8)	38% (3/8)	63% (5/8)
NTPEN (N=15)	53% (8/15)	47% (7/15)
NWEIG (N=7)	100% (7/7)	0% (0/7)
ORENG (N=7)	57% (4/7)	43% (3/7)
PENNEC (N=8)	75% (6/8)	25% (2/8)
SETPEG (N=7)	57% (4/7)	43% (3/7)
SWEP (N=3)	0% (0/3)	100% (3/3)
SWIPE (N=9)	100% (9/9)	0% (0/9)
SWTPEG (N=6)	83% (5/6)	17% (1/6)
TEN (N=6)	67% (4/6)	33% (2/6)
WPNN (N=7)	71% (5/7)	29% (2/7)
YPEN (N=8)	75% (6/8)	25% (2/8)

Table 36: Adult professionals routinely involved in transition or transfer to adult services.

Country/network	Adult epilepsy specialist nurse	Adult learning difficulty ESN	Adult neurologist	Youth worker	Other
England and Wales (N=119)	63% (75/119)	19% (23/119)	85% (101/119)	5% (6/119)	15% (18/119)
England (N=115)	63% (72/115)	18% (21/115)	84% (97/115)	5% (6/115)	14% (16/115)
Wales (N=4)	75% (3/4)	50% (2/4)	100% (4/4)	0% (0/4)	50% (2/4)
BRPNF (N=10)	40% (4/10)	10% (1/10)	80% (8/10)	0% (0/10)	20% (2/10)
CEWT (N=5)	80% (4/5)	20% (1/5)	60% (3/5)	0% (0/5)	0% (0/5)
EPEN (N=13)	77% (10/13)	31% (4/13)	92% (12/13)	23% (3/13)	23% (3/13)
EPIC (N=8)	38% (3/8)	0% (0/8)	88% (7/8)	0% (0/8)	38% (3/8)
NTPEN (N=15)	33% (5/15)	7% (1/15)	93% (14/15)	7% (1/15)	13% (2/15)
NWEIG (N=7)	71% (5/7)	0% (0/7)	71% (5/7)	0% (0/7)	0% (0/7)
ORENG (N=7)	86% (6/7)	57% (4/7)	100% (7/7)	14% (1/7)	29% (2/7)
PENNEC (N=8)	50% (4/8)	25% (2/8)	75% (6/8)	0% (0/8)	25% (2/8)
SETPEG (N=7)	71% (5/7)	29% (2/7)	100% (7/7)	0% (0/7)	0% (0/7)
SWEP (N=3)	67% (2/3)	67% (2/3)	100% (3/3)	0% (0/3)	67% (2/3)
SWIPE (N=9)	89% (8/9)	33% (3/9)	67% (6/9)	0% (0/9)	11% (1/9)
SWTPEG (N=6)	67% (4/6)	17% (1/6)	100% (6/6)	0% (0/6)	0% (0/6)
TEN (N=6)	83% (5/6)	0% (0/6)	83% (5/6)	0% (0/6)	0% (0/6)
WPNN (N=7)	86% (6/7)	29% (2/7)	86% (6/7)	14% (1/7)	14% (1/7)
YPEN (N=8)	50% (4/8)	0% (0/8)	75% (6/8)	0% (0/8)	0% (0/8)

Mental health

Three quarters, **75%** (**89/119**) of Health Boards and Trusts indicated they had no formal screening services for Attention Deficit Hyperactivity Disorder (ADHD), Autistic Spectrum Disorder (ASD) and mental health disorders (**Table 37**).

Figure 16 shows the comparison of formal screening services in Round 3, April 2018, November 2019 and November 2020.

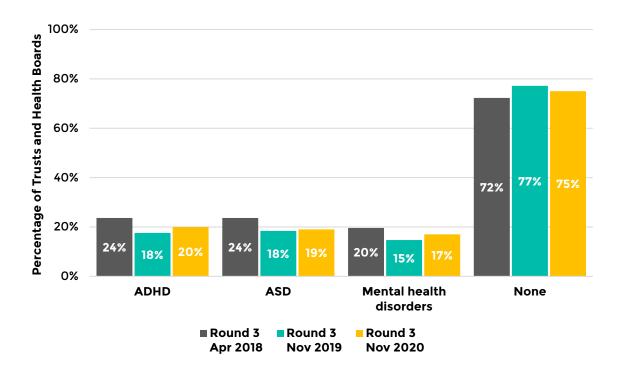


Figure 16: Percentage of Health Boards and Trusts routinely providing formal screening services in Round 3, April 2018, November 2019 and November 2020.

Half of Health Boards and Trusts, **50%** (**60/119**) were not using any of the questionnaires that were listed for mental health screening, (**Table 38**). The questionnaires reported to be used by Health Boards and Trusts in mental health screening were:

- 11% (13/119) Connor's Questionnaire,
- 11% (13/119) SDQ (Strength and Difficulties Questionnaire),
- 7% (8/119) 'Other'.

'Other' responses included:

- York Questionnaire, Vanderbilt and department behaviour assessment questionnaire,
- Social skills teacher questionnaire
- Wellness questionnaire,
- PI-ED,

- NICE signs and symptoms of ASD checklist,
- ADOS.
- Locally prepared questionnaire,
- Vanderbilt ADHD.

36% (43/119) of Health Boards and Trusts did not have agreed referral pathways for children with mental health conditions. 61% (72/119) of Health Boards and Trusts had agreed referral pathways for children with anxiety; 61% (72/119) for depression; 59% (70/119) for mood disorder; 42% (50/119) for non-epileptic attack disorder, 6% (7/119) for other mental health conditions (Table 39).

'Other' responses included:

- Attention Deficit Hyperactivity Disorder
- Behavioural and emotional.
- Tic disorders, OCD, eating disorders,
- A flexible approach with in-house mental health and adolescent medicine teams,
- Referral to CAHMS or clinical psychology depending on clinical needs,
- Referral to psychology for difficulty in coping with diagnosis for patient and family,
- Referral to CAMHS for other mental health concerns.

Figure 17 shows the proportion of Health Boards and Trusts that had agreed referral pathways for children and young people with mental health conditions, in November 2019 and November 2020.

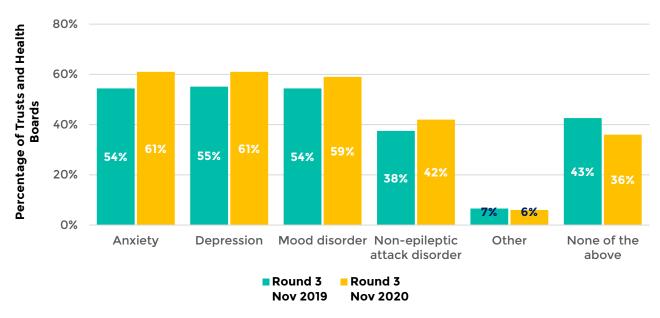


Figure 17: Percentage of Health Boards and Trusts that had agreed referral pathways for children and young people with mental health conditions, in November 2019 and November 2020.

Table 40 shows that in **15%** (**18/119**) of Health Boards and Trusts mental health provision is facilitated within epilepsy clinics. In **eleven** of those eighteen Health Boards and Trusts this mental health provision involved co-located clinical care. In **twelve** of the eighteen it comprised multi-disciplinary team meetings where epilepsy and mental health professionals discussed individual patients, (**Table 41**).

Of the 101 Health Boards and Trusts that were unable to facilitate mental health provision within epilepsy clinics only, 11% (11/101) indicated they had an action plan describing steps towards colocated mental health provision, (Table 42).

7% (8/119) of Health Boards and Trusts could not refer to mental health assessment services, either within or outside of their Health Board or Trust, (Table 43). 79% (94/119) of Health Boards and Trusts were able to refer to clinical psychology services; 91% (108/119) to psychiatric services; 49% (58/119) to education psychology; 56% (67/119) to neuropsychology services and 87% (103/119) to formal developmental assessment.

Figure 18 shows the comparison of ability to refer to mental health services in Round 3, April 2018, November 2019 and November 2020

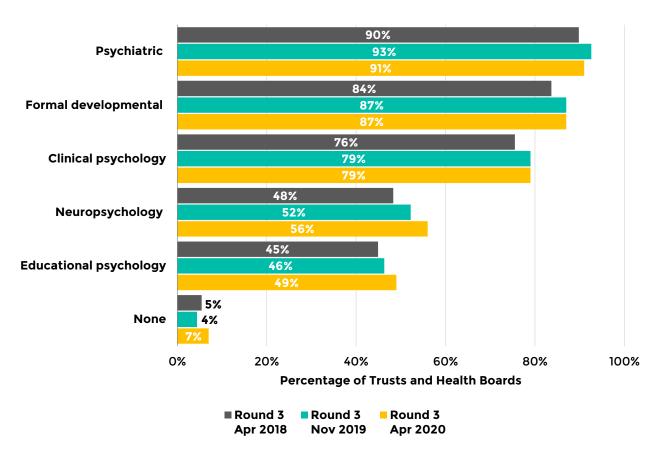


Figure 18: Percentage of Health Boards and Trusts that could refer to mental health services in Round 3, April 2018, November 2019 and November 2020.

Table 37: Health Boards and Trusts that formally screen for any of the listed conditions related to epilepsy.

Country/network	ADHD	ASD	Mental health disorders	None
England and Wales (N=119)	20% (24/119)	19% (23/119)	17% (20/119)	75% (89/119)
England (N=115)	21% (24/115)	20% (23/115)	17% (20/115)	74% (85/115)
Wales (N=4)	0% (0/4)	0% (0/4)	0% (0/4)	100% (4/4)
	'	'		
BRPNF (N=10)	50% (5/10)	50% (5/10)	30% (3/10)	50% (5/10)
CEWT (N=5)	40% (2/5)	40% (2/5)	20% (1/5)	60% (3/5)
EPEN (N=13)	8% (1/13)	8% (1/13)	8% (1/13)	85% (11/13)
EPIC (N=8)	13% (1/8)	13% (1/8)	0% (0/8)	88% (7/8)
NTPEN (N=15)	20% (3/15)	13% (2/15)	20% (3/15)	73% (11/15)
NWEIG (N=7)	29% (2/7)	29% (2/7)	43% (3/7)	57% (4/7)
ORENG (N=7)	57% (4/7)	57% (4/7)	29% (2/7)	43% (3/7)
PENNEC (N=8)	0% (0/8)	0% (0/8)	13% (1/8)	88% (7/8)
SETPEG (N=7)	14% (1/7)	14% (1/7)	14% (1/7)	86% (6/7)
SWEP (N=3)	0% (0/3)	0% (0/3)	0% (0/3)	100% (3/3)
SWIPE (N=9)	0% (0/9)	0% (0/9)	0% (0/9)	100% (9/9)
SWTPEG (N=6)	17% (1/6)	17% (1/6)	33% (2/6)	67% (4/6)
TEN (N=6)	33% (2/6)	33% (2/6)	0% (0/6)	67% (4/6)
WPNN (N=7)	14% (1/7)	14% (1/7)	14% (1/7)	86% (6/7)
YPEN (N=8)	13% (1/8)	13% (1/8)	25% (2/8)	75% (6/8)

Table 38: Health Boards and Trusts using particular mental health screening questionnaires.

Country/ network	BDI - Beck Depression Inventory	Connor's Questionnaire	Emotional Thermometers Tool	GAD – Generalised Anxiety Disorder	GAD 2 - Generalised Anxiety Disorder 2	GAD 7 - Generalised Anxiety Disorder GAD 7	HADS - Hospital Anxiety and Depression Scale	MFQ - Mood and Feelings Questionnaire (Child, Parent, adult versions)	NDDI -E Neurologic al Disorders Depression Inventory for Epilepsy
England and Wales (N=119)	0% (0/119)	11% (13/119)	0% (0/119)	0% (0/119)	0% (0/119)	0% (0/119)	0% (0/119)	0% (0/119)	0% (0/119)
England (N=115)	0% (0/115)	11% (13/115)	0% (0/115)	0% (0/115)	0% (0/115)	0% (0/115)	0% (0/115)	0% (0/115)	0% (0/115)
Wales (N=4)	0% (0/4)	0% (0/4)	0% (0/4)	0% (0/4)	0% (0/4)	0% (0/4)	0% (0/4)	0% (0/4)	0% (0/4)
BRPNF (N=10)	0% (0/10)	20% (2/10)	0% (0/10)	0% (0/10)	0% (0/10)	0% (0/10)	0% (0/10)	0% (0/10)	0% (0/10)
CEWT (N=5)	0% (0/5)	20% (1/5)	0% (0/5)	0% (0/5)	0% (0/5)	0% (0/5)	0% (0/5)	0% (0/5)	0% (0/5)
EPEN (N=13)	0% (0/13)	0% (0/13)	0% (0/13)	0% (0/13)	0% (0/13)	0% (0/13)	0% (0/13)	0% (0/13)	0% (0/13)
EPIC (N=8)	0% (0/8)	13% (1/8)	0% (0/8)	0% (0/8)	0% (0/8)	0% (0/8)	0% (0/8)	0% (0/8)	0% (0/8)
NTPEN (N=15)	0% (0/15)	20% (3/15)	0% (0/15)	0% (0/15)	0% (0/15)	0% (0/15)	0% (0/15)	0% (0/15)	0% (0/15)
NWEIG (N=7)	0% (0/7)	14% (1/7)	0% (0/7)	0% (0/7)	0% (0/7)	0% (0/7)	0% (0/7)	0% (0/7)	0% (0/7)
ORENG (N=7)	0% (0/7)	43% (3/7)	0% (0/7)	0% (0/7)	0% (0/7)	0% (0/7)	0% (0/7)	0% (0/7)	0% (0/7)
PENNEC (N=8)	0% (0/8)	0% (0/8)	0% (0/8)	0% (0/8)	0% (0/8)	0% (0/8)	0% (0/8)	0% (0/8)	0% (0/8)
SETPEG (N=7)	0% (0/7)	0% (0/7)	0% (0/7)	0% (0/7)	0% (0/7)	0% (0/7)	0% (0/7)	0% (0/7)	0% (0/7)
SWEP (N=3)	0% (0/3)	0% (0/3)	0% (0/3)	0% (0/3)	0% (0/3)	0% (0/3)	0% (0/3)	0% (0/3)	0% (0/3)
SWIPE (N=9)	0% (0/9)	0% (0/9)	0% (0/9)	0% (0/9)	0% (0/9)	0% (0/9)	0% (0/9)	0% (0/9)	0% (0/9)
SWTPEG (N=6)	0% (0/6)	0% (0/6)	0% (0/6)	0% (0/6)	0% (0/6)	0% (0/6)	0% (0/6)	0% (0/6)	0% (0/6)
TEN (N=6)	0% (0/6)	17% (1/6)	0% (0/6)	0% (0/6)	0% (0/6)	0% (0/6)	0% (0/6)	0% (0/6)	0% (0/6)
WPNN (N=7)	0% (0/7)	14% (1/7)	0% (0/7)	0% (0/7)	0% (0/7)	0% (0/7)	0% (0/7)	0% (0/7)	0% (0/7)
YPEN (N=8)	0% (0/8)	0% (0/8)	0% (0/8)	0% (0/8)	0% (0/8)	0% (0/8)	0% (0/8)	0% (0/8)	0% (0/8)

Table 38 (continued): Health Boards and Trusts using particular mental health screening questionnaires.

Country/network	PHQ – Patient Health Questionnaire, PHQ 2, PHQ 9	SDQ (Strength and Difficulties Questionnaire)	Other	None of the above
England and Wales (N=119)	0% (0/119)	11% (13/119)	7% (8/119)	50% (60/119)
England (N=115)	0% (0/115)	11% (13/115)	7% (8/115)	50% (57/115)
Wales (N=4)	0% (0/4)	0% (0/4)	0% (0/4)	75% (3/4)
BRPNF (N=10)	0% (0/10)	30% (3/10)	20% (2/10)	30% (3/10)
CEWT (N=5)	0% (0/5)	20% (1/5)	0% (0/5)	60% (3/5)
EPEN (N=13)	0% (0/13)	0% (0/13)	8% (1/13)	62% (8/13)
EPIC (N=8)	0% (0/8)	0% (0/8)	0% (0/8)	25% (2/8)
NTPEN (N=15)	0% (0/15)	20% (3/15)	7% (1/15)	33% (5/15)
NWEIG (N=7)	0% (0/7)	14% (1/7)	0% (0/7)	71% (5/7)
ORENG (N=7)	0% (0/7)	0% (0/7)	14% (1/7)	43% (3/7)
PENNEC (N=8)	0% (0/8)	0% (0/8)	13% (1/8)	50% (4/8)
SETPEG (N=7)	0% (0/7)	0% (0/7)	0% (0/7)	71% (5/7)
SWEP (N=3)	0% (0/3)	0% (0/3)	0% (0/3)	100% (3/3)
SWIPE (N=9)	0% (0/9)	0% (0/9)	0% (0/9)	67% (6/9)
SWTPEG (N=6)	0% (0/6)	17% (1/6)	17% (1/6)	33% (2/6)
TEN (N=6)	0% (0/6)	17% (1/6)	0% (0/6)	50% (3/6)
WPNN (N=7)	0% (0/7)	14% (1/7)	14% (1/7)	57% (4/7)
YPEN (N=8)	0% (0/8)	25% (2/8)	0% (0/8)	50% (4/8)

Table 39: Health Boards and Trusts with agreed referral pathways for children and young people with mental health conditions.

Country/network	Anxiety	Depression	Mood Disorder	Non-epileptic attack disorders	Other	None of the above
England and Wales (N=119)	61% (72/119)	61% (72/119)	59% (70/119)	42% (50/119)	6% (7/119)	36% (43/119)
England (N=115)	62% (71/115)	62% (71/115)	60% (69/115)	43% (50/115)	5% (6/115)	35% (40/115)
Wales (N=4)	25% (1/4)	25% (1/4)	25% (1/4)	0% (0/4)	25% (1/4)	75% (3/4)
BRPNF (N=10)	70% (7/10)	70% (7/10)	70% (7/10)	40% (4/10)	0% (0/10)	30% (3/10)
CEWT (N=5)	80% (4/5)	80% (4/5)	80% (4/5)	40% (2/5)	20% (1/5)	20% (1/5)
EPEN (N=13)	54% (7/13)	54% (7/13)	54% (7/13)	38% (5/13)	0% (0/13)	38% (5/13)
EPIC (N=8)	75% (6/8)	75% (6/8)	75% (6/8)	63% (5/8)	25% (2/8)	25% (2/8)
NTPEN (N=15)	53% (8/15)	53% (8/15)	53% (8/15)	47% (7/15)	13% (2/15)	40% (6/15)
NWEIG (N=7)	100% (7/7)	100% (7/7)	100% (7/7)	57% (4/7)	0% (0/7)	0% (0/7)
ORENG (N=7)	29% (2/7)	29% (2/7)	29% (2/7)	14% (1/7)	0% (0/7)	71% (5/7)
PENNEC (N=8)	75% (6/8)	75% (6/8)	75% (6/8)	38% (3/8)	25% (2/8)	13% (1/8)
SETPEG (N=7)	71% (5/7)	71% (5/7)	57% (4/7)	57% (4/7)	0% (0/7)	29% (2/7)
SWEP (N=3)	0% (0/3)	0% (0/3)	0% (0/3)	0% (0/3)	0% (0/3)	100% (3/3)
SWIPE (N=9)	33% (3/9)	33% (3/9)	33% (3/9)	22% (2/9)	0% (0/9)	67% (6/9)
SWTPEG (N=6)	83% (5/6)	83% (5/6)	83% (5/6)	50% (3/6)	0% (0/6)	17% (1/6)
ΓΕΝ (N=6)	67% (4/6)	67% (4/6)	50% (3/6)	50% (3/6)	0% (0/6)	33% (2/6)
WPNN (N=7)	57% (4/7)	57% (4/7)	57% (4/7)	43% (3/7)	0% (0/7)	43% (3/7)
YPEN (N=8)	50% (4/8)	50% (4/8)	50% (4/8)	50% (4/8)	0% (0/8)	38% (3/8)

Table 40: Health Boards and Trusts that were facilitating mental health provision within epilepsy clinics.

Country/network	Yes	No
,		
England and Wales (N=119)	15% (18/119)	85% (101/119)
England (N=115)	16% (18/115)	84% (97/115)
Wales (N=4)	0% (0/4)	100% (4/4)
BRPNF (N=10)	0% (0/10)	100% (10/10)
CEWT (N=5)	0% (0/5)	100% (5/5)
EPEN (N=13)	15% (2/13)	85% (11/13)
EPIC (N=8)	25% (2/8)	75% (6/8)
NTPEN (N=15)	27% (4/15)	73% (11/15)
NWEIG (N=7)	14% (1/7)	86% (6/7)
ORENG (N=7)	0% (0/7)	100% (7/7)
PENNEC (N=8)	13% (1/8)	88% (7/8)
SETPEG (N=7)	29% (2/7)	71% (5/7)
SWEP (N=3)	0% (0/3)	100% (3/3)
SWIPE (N=9)	11% (1/9)	89% (8/9)
SWTPEG (N=6)	33% (2/6)	67% (4/6)
TEN (N=6)	17% (1/6)	83% (5/6)
WPNN (N=7)	14% (1/7)	86% (6/7)
YPEN (N=8)	13% (1/8)	88% (7/8)

Table 41: Composition of mental health provision within epilepsy clinics.

Country/network	Epilepsy Clinics where mental health professionals can provide direct co- located clinical care	MDT meetings where epilepsy and mental health professionals discuss individual patients	Other
England and Wales (N=119)	9% (11/119)	10% (12/119)	7% (8/119)
England (N=115)	10% (11/115)	10% (12/115)	7% (8/115)
Wales (N=4)	0% (0/4)	0% (0/4)	0% (0/4)
BRPNF (N=10)	0% (0/10)	0% (0/10)	0% (0/10)
CEWT (N=5)	0% (0/5)	0% (0/5)	0% (0/5)
EPEN (N=13)	15% (2/13)	15% (2/13)	8% (1/13)
EPIC (N=8)	13% (1/8)	13% (1/8)	13% (1/8)
NTPEN (N=15)	7% (1/15)	13% (2/15)	13% (2/15)
NWEIG (N=7)	14% (1/7)	14% (1/7)	14% (1/7)
ORENG (N=7)	0% (0/7)	0% (0/7)	0% (0/7)
PENNEC (N=8)	13% (1/8)	13% (1/8)	0% (0/8)
SETPEG (N=7)	29% (2/7)	14% (1/7)	14% (1/7)
SWEP (N=3)	0% (0/3)	0% (0/3)	0% (0/3)
SWIPE (N=9)	0% (0/9)	11% (1/9)	0% (0/9)
SWTPEG (N=6)	33% (2/6)	17% (1/6)	17% (1/6)
TEN (N=6)	0% (0/6)	0% (0/6)	17% (1/6)
WPNN (N=7)	14% (1/7)	14% (1/7)	0% (0/7)
YPEN (N=8)	0% (0/8)	13% (1/8)	0% (0/8)

Table 42: Health Boards and Trusts that had an action plan describing steps towards co-located mental health provision.

Country/network	Yes	No
England and Wales (N=101)	11% (11/101)	89% (90/101)
England (N=97)	11% (11/97)	89% (86/97)
Wales (N=4)	0% (0/4)	100% (4/4)
BRPNF (N=10)	20% (2/10)	80% (8/10)
CEWT (N=5)	40% (2/5)	60% (3/5)
EPEN (N=11)	0% (0/11)	100% (11/11)
EPIC (N=6)	17% (1/6)	83% (5/6)
NTPEN (N=11)	0% (0/11)	100% (11/11)
NWEIG (N=6)	0% (0/6)	100% (6/6)
ORENG (N=7)	0% (0/7)	100% (7/7)
PENNEC (N=7)	14% (1/7)	86% (6/7)
SETPEG (N=5)	20% (1/5)	80% (4/5)
SWEP (N=3)	0% (0/3)	100% (3/3)
SWIPE (N=8)	13% (1/8)	88% (7/8)
SWTPEG (N=4)	0% (0/4)	100% (4/4)
TEN (N=5)	20% (1/5)	80% (4/5)
WPNN (N=6)	17% (1/6)	83% (5/6)
YPEN (N=7)	14% (1/7)	86% (6/7)

Table 43: Health Boards and Trusts that could refer to mental health services.

Country/network	Clinical psychology	Psychiatric	Educational psychology	Neuropsychology	Formal developmental	None
England and Wales (N=119)	79% (94/119)	91% (108/119)	49% (58/119)	56% (67/119)	87% (103/119)	7% (8/119)
England (N=115)	79% (91/115)	90% (104/115)	48% (55/115)	58% (67/115)	86% (99/115)	7% (8/115)
Wales (N=4)	75% (3/4)	100% (4/4)	75% (3/4)	0% (0/4)	100% (4/4)	0% (0/4)
BRPNF (N=10)	90% (9/10)	100% (10/10)	60% (6/10)	40% (4/10)	90% (9/10)	0% (0/10)
CEWT (N=5)	80% (4/5)	80% (4/5)	20% (1/5)	80% (4/5)	80% (4/5)	20% (1/5)
EPEN (N=13)	69% (9/13)	85% (11/13)	62% (8/13)	31% (4/13)	85% (11/13)	15% (2/13)
EPIC (N=8)	63% (5/8)	100% (8/8)	25% (2/8)	50% (4/8)	100% (8/8)	0% (0/8)
NTPEN (N=15)	93% (14/15)	100% (15/15)	40% (6/15)	73% (11/15)	100% (15/15)	0% (0/15)
NWEIG (N=7)	100% (7/7)	100% (7/7)	57% (4/7)	86% (6/7)	71% (5/7)	0% (0/7)
ORENG (N=7)	86% (6/7)	100% (7/7)	57% (4/7)	71% (5/7)	86% (6/7)	0% (0/7)
PENNEC (N=8)	88% (7/8)	88% (7/8)	88% (7/8)	75% (6/8)	88% (7/8)	0% (0/8)
SETPEG (N=7)	100% (7/7)	86% (6/7)	71% (5/7)	71% (5/7)	100% (7/7)	0% (0/7)
SWEP (N=3)	67% (2/3)	100% (3/3)	67% (2/3)	0% (0/3)	100% (3/3)	0% (0/3)
SWIPE (N=9)	89% (8/9)	89% (8/9)	56% (5/9)	89% (8/9)	78% (7/9)	11% (1/9)
SWTPEG (N=6)	33% (2/6)	67% (4/6)	17% (1/6)	33% (2/6)	67% (4/6)	33% (2/6)
TEN (N=6)	50% (3/6)	50% (3/6)	17% (1/6)	50% (3/6)	67% (4/6)	33% (2/6)
WPNN (N=7)	71% (5/7)	100% (7/7)	43% (3/7)	29% (2/7)	100% (7/7)	0% (0/7)
YPEN (N=8)	75% (6/8)	100% (8/8)	38% (3/8)	38% (3/8)	75% (6/8)	0% (0/8)

Neurodevelopmental support

In 13% (15/119) of Health Boards and Trusts, there were no agreed referral criteria for children and young people with neurodevelopmental conditions. 80% (95/119) had agreed referral criteria for children with ADHD; 85% (101/119) for ASD; 60% (71/119) for behaviour difficulties; 62% (74/119) for developmental coordination disorder; 56% (67/119) for intellectual disability and 8% (10/119) for other neurodevelopmental problems. (Table 44/ Figure 19).

'Other' responses included:

- Challenging behaviour associated with severe learning difficulties,
- · Global developmental delay,
- 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
- Early Health Assessment pathway,
- ADHD, ASD and developmental concern pathways are with Separate Health Board,
- No agreed criteria however we have referral pathway to CAHMS and psychology,
- Developmental delay.

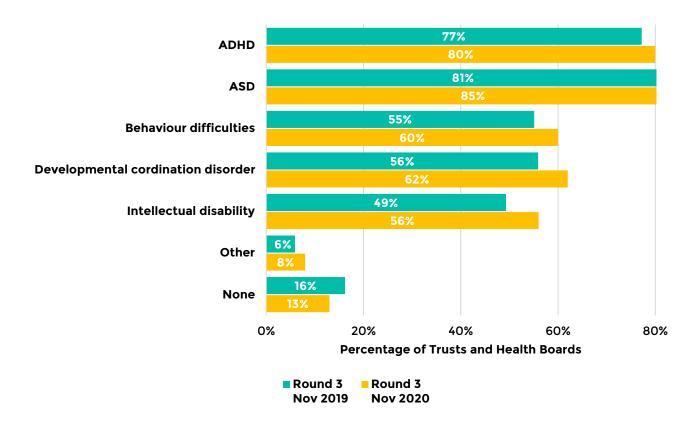


Figure 19: Percentage of Health Boards and Trusts that had agreed referral criteria for children and young people with neurodevelopmental conditions services in November 2019 and November 2020.

Table 44: Health Boards and Trusts that had agreed referral criteria for children and young people with neuro-developmental conditions.

Country/network	ADHD	ASD	Behaviour difficulties	Developmental Coordination Disorder	Intellectual disability	Other	None
England and Wales (N=119)	80% (95/119)	85% (101/119)	60% (71/119)	62% (74/119)	56% (67/119)	8% (10/119)	13% (15/119)
England (N=115)	79% (91/115)	84% (97/115)	60% (69/115)	62% (71/115)	56% (64/115)	9% (10/115)	13% (15/115)
Wales (N=4)	100% (4/4)	100% (4/4)	50% (2/4)	75% (3/4)	75% (3/4)	0% (0/4)	0% (0/4)
BRPNF (N=10)	90% (9/10)	100% (10/10)	90% (9/10)	100% (10/10)	90% (9/10)	0% (0/10)	0% (0/10)
CEWT (N=5)	100% (5/5)	100% (5/5)	80% (4/5)	80% (4/5)	80% (4/5)	20% (1/5)	0% (0/5)
EPEN (N=13)	69% (9/13)	77% (10/13)	54% (7/13)	54% (7/13)	31% (4/13)	8% (1/13)	15% (2/13)
EPIC (N=8)	88% (7/8)	88% (7/8)	75% (6/8)	50% (4/8)	63% (5/8)	13% (1/8)	13% (1/8)
NTPEN (N=15)	60% (9/15)	73% (11/15)	60% (9/15)	47% (7/15)	53% (8/15)	7% (1/15)	27% (4/15)
NWEIG (N=7)	100% (7/7)	100% (7/7)	71% (5/7)	100% (7/7)	100% (7/7)	0% (0/7)	0% (0/7)
ORENG (N=7)	71% (5/7)	86% (6/7)	29% (2/7)	43% (3/7)	29% (2/7)	0% (0/7)	14% (1/7)
PENNEC (N=8)	75% (6/8)	75% (6/8)	63% (5/8)	50% (4/8)	63% (5/8)	13% (1/8)	13% (1/8)
SETPEG (N=7)	71% (5/7)	86% (6/7)	71% (5/7)	71% (5/7)	57% (4/7)	0% (0/7)	14% (1/7)
SWEP (N=3)	100% (3/3)	100% (3/3)	67% (2/3)	67% (2/3)	100% (3/3)	0% (0/3)	0% (0/3)
SWIPE (N=9)	78% (7/9)	78% (7/9)	33% (3/9)	44% (4/9)	22% (2/9)	22% (2/9)	11% (1/9)
SWTPEG (N=6)	83% (5/6)	83% (5/6)	50% (3/6)	50% (3/6)	67% (4/6)	0% (0/6)	17% (1/6)
TEN (N=6)	100% (6/6)	100% (6/6)	83% (5/6)	100% (6/6)	67% (4/6)	0% (0/6)	0% (0/6)
WPNN (N=7)	71% (5/7)	71% (5/7)	57% (4/7)	43% (3/7)	43% (3/7)	29% (2/7)	29% (2/7)
YPEN (N=8)	88% (7/8)	88% (7/8)	25% (2/8)	63% (5/8)	38% (3/8)	13% (1/8)	13% (1/8)

Care planning

Comprehensive care planning for children and young people with epilepsy was reported to routinely take place in 90% (107/119) of Health Boards and Trusts, (Table 45).

Figure 20 shows the proportion of Health Boards and Trusts that routinely undertake comprehensive care planning for children and young people with epilepsy in Round 3, April 2018, November 2019 and November 2020.

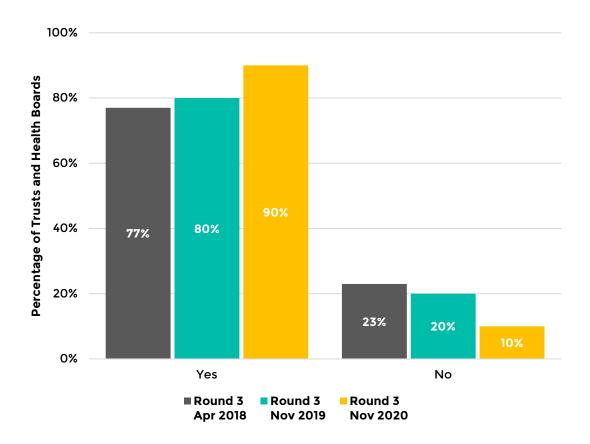


Figure 20: Health Boards and Trusts that routinely undertake comprehensive care planning for children and young people with epilepsy in Round 3 April 2018, November 2019 and November 2020.

Table 45: Health Boards and Trusts that routinely undertake comprehensive care planning for children and young people with epilepsy.

Country/network	Yes	No
England and Wales (N=119)	90% (107/119)	10% (12/119)
England (N=115)	90% (103/115)	10% (12/115)
Wales (N=4)	100% (4/4)	0% (0/4)
BRPNF (N=10)	90% (9/10)	10% (1/10)
CEWT (N=5)	100% (5/5)	0% (0/5)
EPEN (N=13)	92% (12/13)	8% (1/13)
EPIC (N=8)	100% (8/8)	0% (0/8)
NTPEN (N=15)	87% (13/15)	13% (2/15)
NWEIG (N=7)	100% (7/7)	0% (0/7)
ORENG (N=7)	71% (5/7)	29% (2/7)
PENNEC (N=8)	63% (5/8)	38% (3/8)
SETPEG (N=7)	100% (7/7)	0% (0/7)
SWEP (N=3)	100% (3/3)	0% (0/3)
SWIPE (N=9)	67% (6/9)	33% (3/9)
SWTPEG (N=6)	100% (6/6)	0% (0/6)
TEN (N=6)	100% (6/6)	0% (0/6)
WPNN (N=7)	100% (7/7)	0% (0/7)
YPEN (N=8)	100% (8/8)	0% (0/8)

Patient database or registry

Over three-quarters of Health Boards and Trusts 77% (91/119), reported that they maintain a database or register for children and young people with epilepsies under their care. Of these, 34% (41/119) maintain a registry for all children and young people with epilepsies and 42% (50/119) maintain a database or registry for some children and young people with epilepsies. 24% (28/119) of Health Boards and Trusts, reported that they do not maintain a database or registry, (Table 46).

Figure 21 shows the proportion of Health Boards and Trusts maintaining a database or register of children and young people with epilepsies, other than Epilepsyl2, in Round 3, April 2018, November 2019 and November 2020.

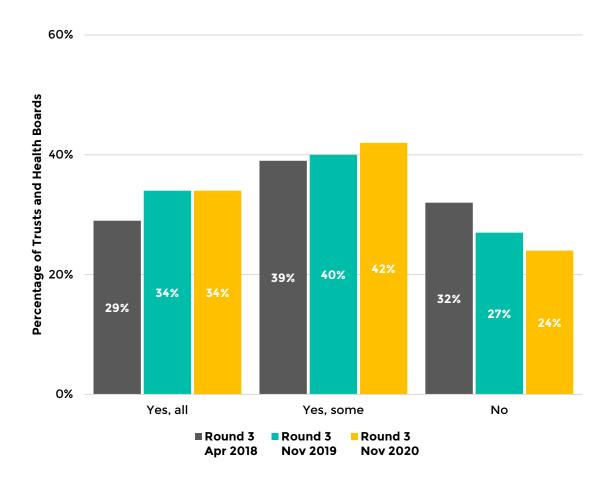


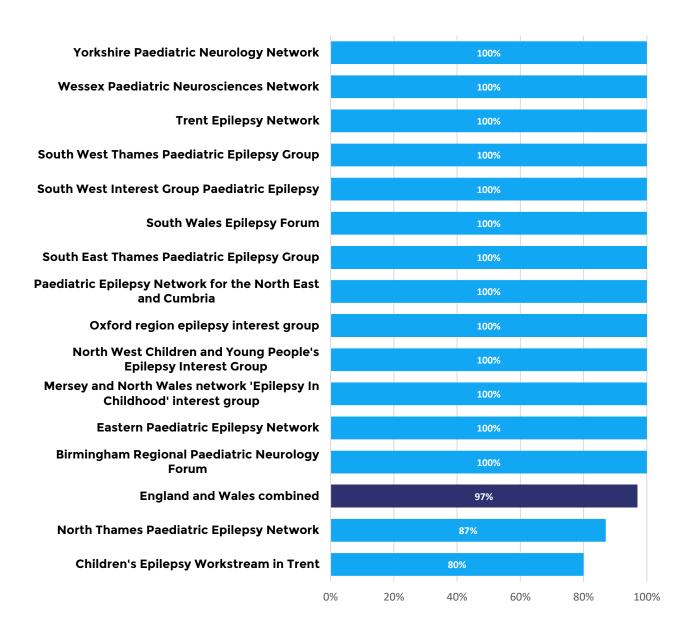
Figure 21: Percentage of Health Boards and Trusts maintaining/not maintaining a database or registry of children and young people with epilepsies, other than Epilepsy12, in Round 3 April 2018, November 2019 and November 2020.

Table 46: Health Boards and Trusts maintaining a database or registry of children and young people with epilepsies, other than Epilepsy12.

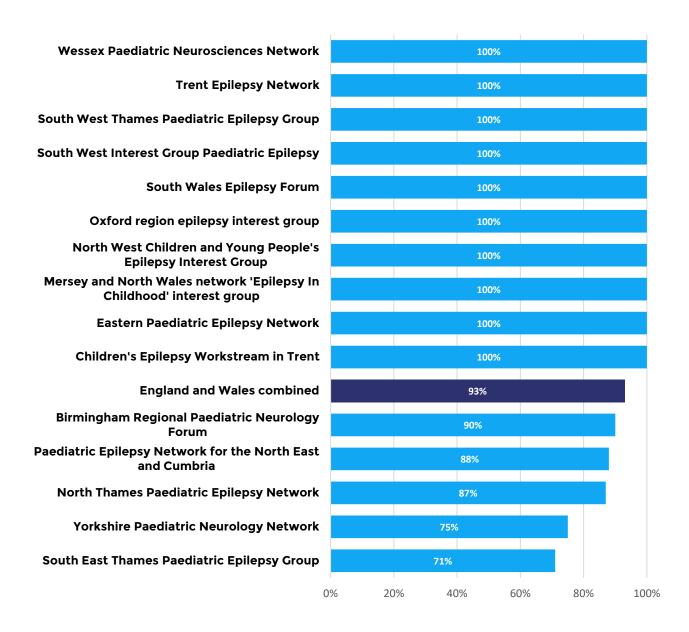
Country/network	Yes, all	Yes, some	No
England and Wales (N=119)	34% (41/119)	42% (50/119)	24% (28/119)
England (N=115)	36% (41/115)	41% (47/115)	23% (27/115)
Wales (N=4)	0% (0/4)	75% (3/4)	25% (1/4)
BRPNF (N=10)	20% (2/10)	30% (3/10)	50% (5/10)
CEWT (N=5)	0% (0/5)	20% (1/5)	80% (4/5)
EPEN (N=13)	38% (5/13)	46% (6/13)	15% (2/13)
EPIC (N=8)	13% (1/8)	50% (4/8)	38% (3/8)
NTPEN (N=15)	27% (4/15)	53% (8/15)	20% (3/15)
NWEIG (N=7)	43% (3/7)	57% (4/7)	0% (0/7)
ORENG (N=7)	29% (2/7)	43% (3/7)	29% (2/7)
PENNEC (N=8)	50% (4/8)	25% (2/8)	25% (2/8)
SETPEG (N=7)	71% (5/7)	29% (2/7)	0% (0/7)
SWEP (N=3)	0% (0/3)	67% (2/3)	33% (1/3)
SWIPE (N=9)	33% (3/9)	44% (4/9)	22% (2/9)
SWTPEG (N=6)	50% (3/6)	33% (2/6)	17% (1/6)
TEN (N=6)	33% (2/6)	33% (2/6)	33% (2/6)
WPNN (N=7)	57% (4/7)	43% (3/7)	0% (0/7)
YPEN (N=8)	38% (3/8)	50% (4/8)	13% (1/8)

Findings by OPEN UK regional networks

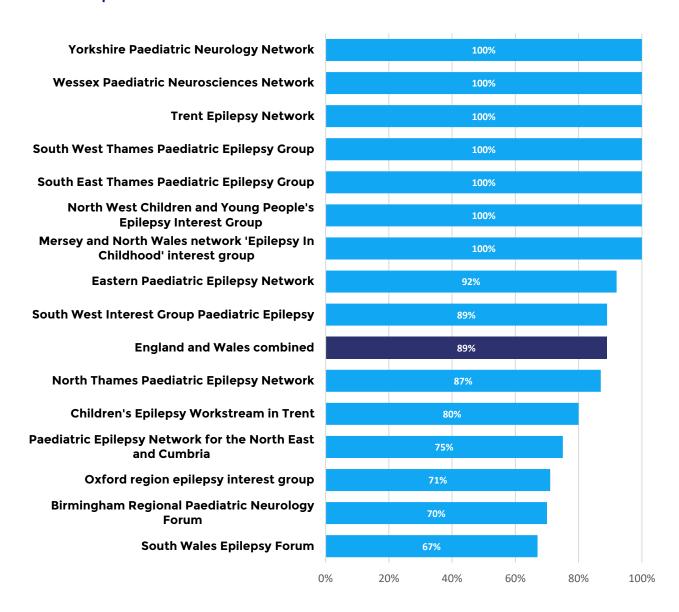
% of Health Boards and Trusts employing a consultant paediatrician with expertise in epilepsy.



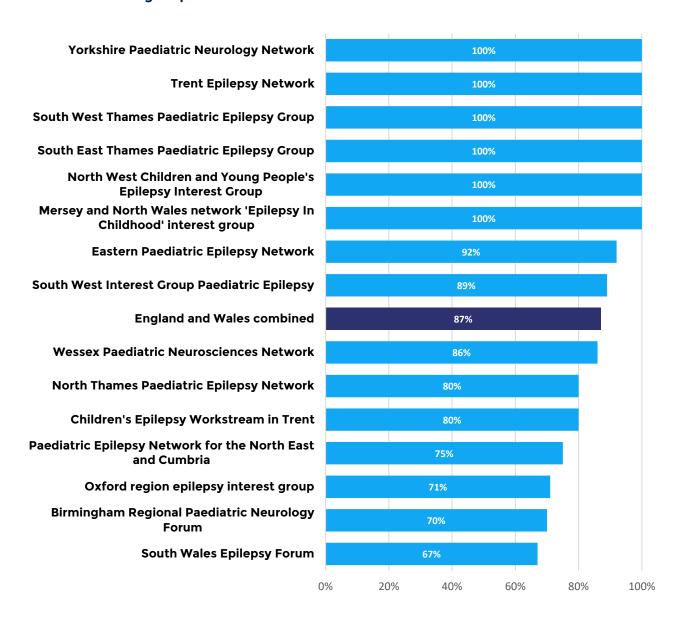
% of Health Boards and Trusts that had a defined paediatric epilepsy clinical lead.



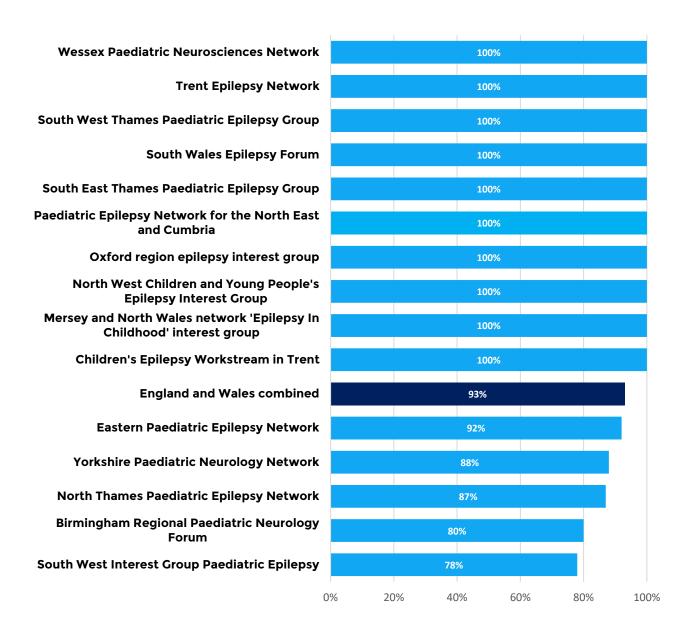
% of Health Boards and Trusts who had some epilepsy specialist nurse (ESN) provision within their paediatric service.



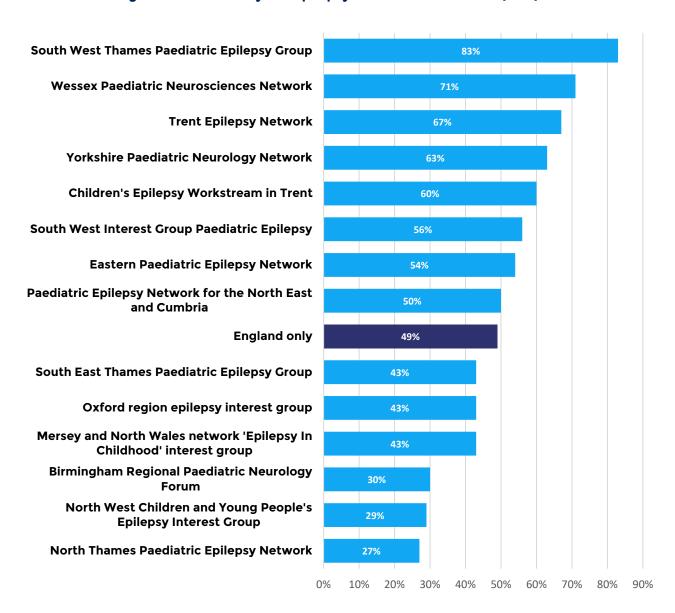
% of Health Boards Trusts that indicated that they could offer ESN support for rescue medication training for parents.



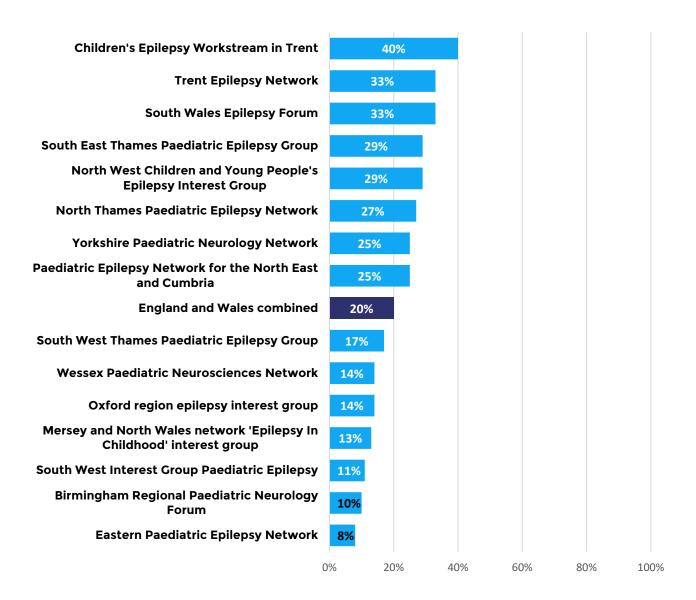
% of Health Boards and Trusts that had a defined epilepsy clinic seeing patients at secondary level.



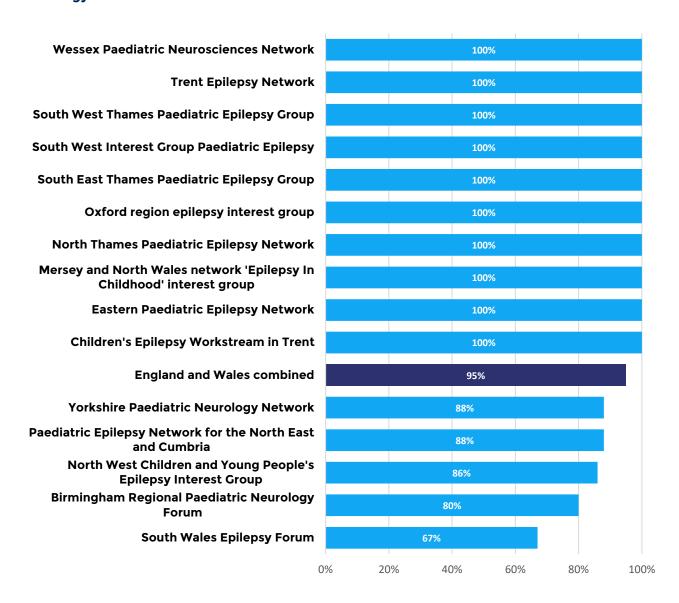
% of Trusts in England that currently run Epilepsy Best Practice Criteria (BPC) clinics.



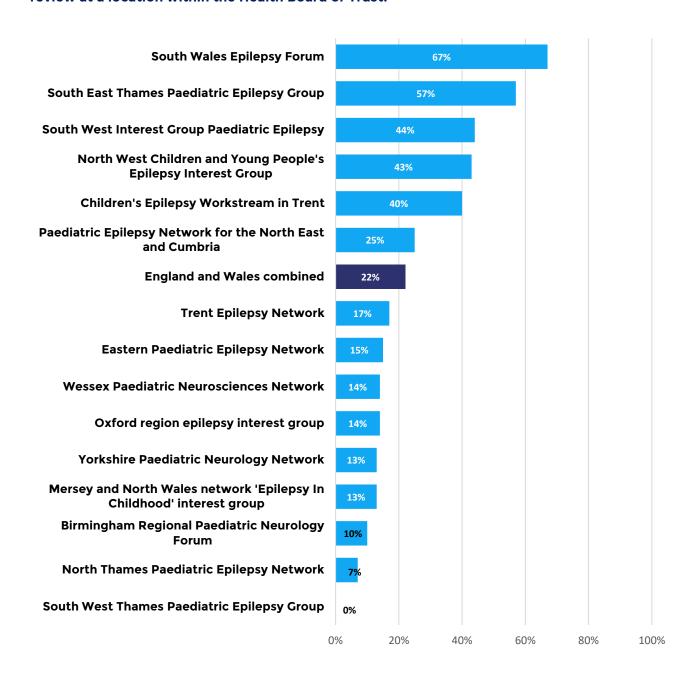
% of Health Boards and Trusts that have some tertiary provision within their paediatric service (paediatric neurologists who manage children with epilepsy (acutely and/or non-acutely)).



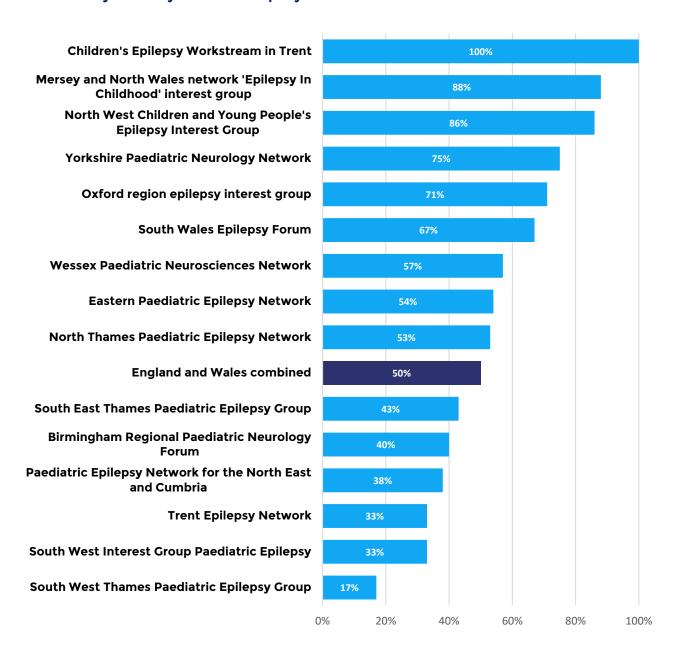
% of Health Boards and Trusts that had agreed referral pathways to tertiary paediatric neurology services.



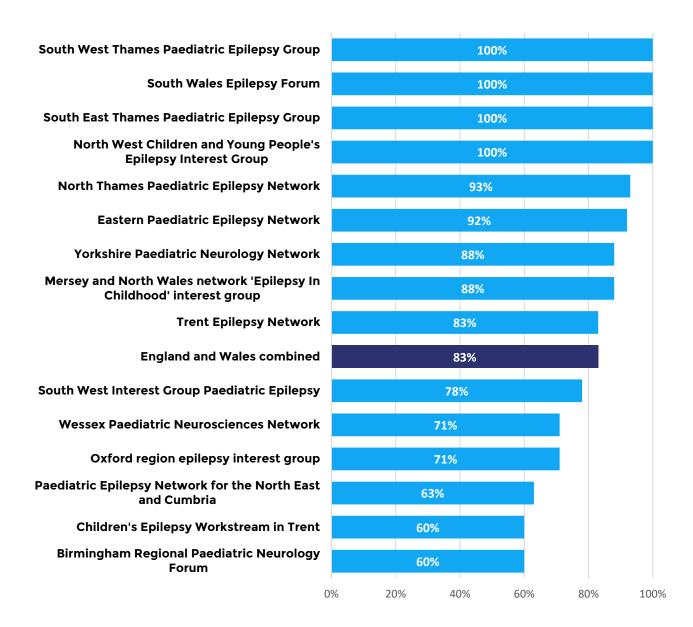
% of Health Boards and Trusts that were able to facilitate Vagal Nerve Stimulation (VNS) review at a location within the Health Board or Trust.



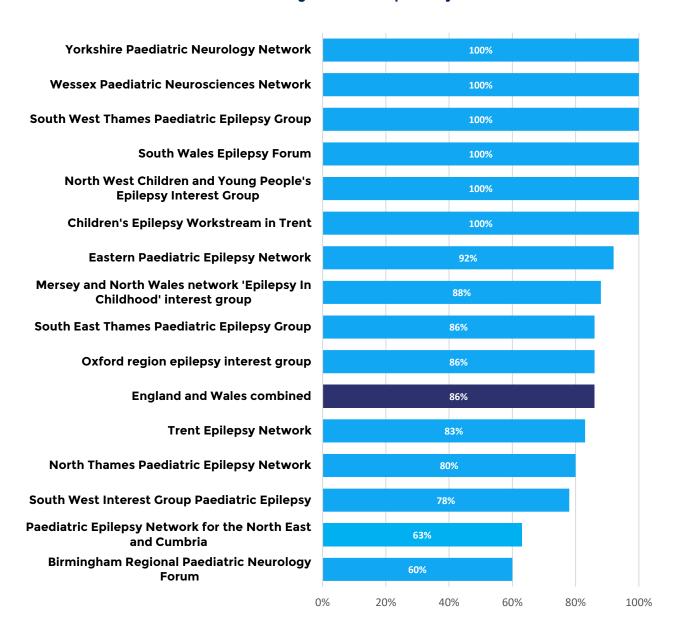
% of Health Boards and Trusts that could provide specialist advice between scheduled reviews every weekday for 52 weeks per year.



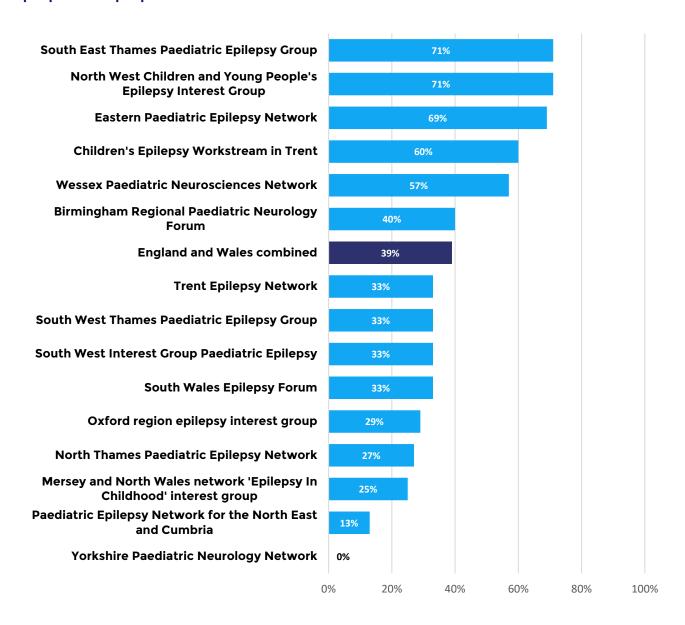
% of Health Boards and Trusts that have evidence of a clear point of contact for non-paediatric professionals seeking paediatric epilepsy support.



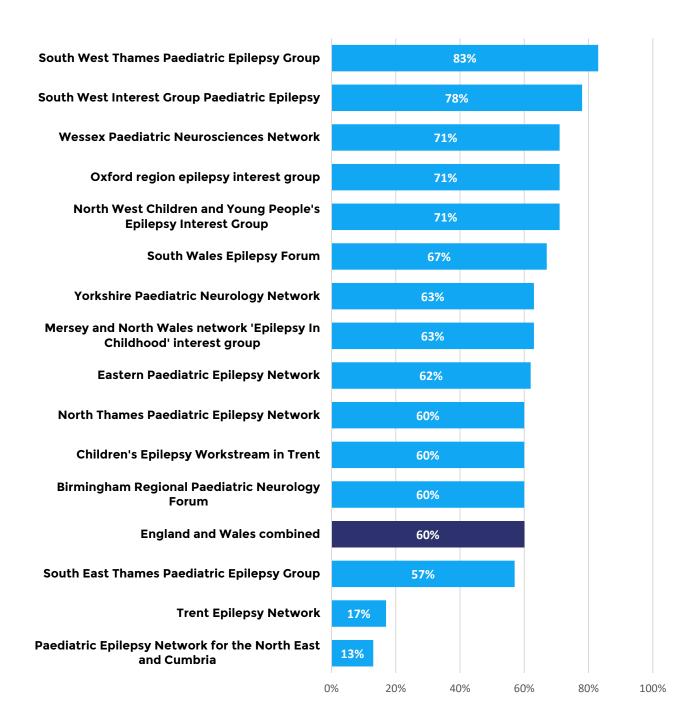
% of Health Boards and Trusts that have agreed referral pathway to adult services.



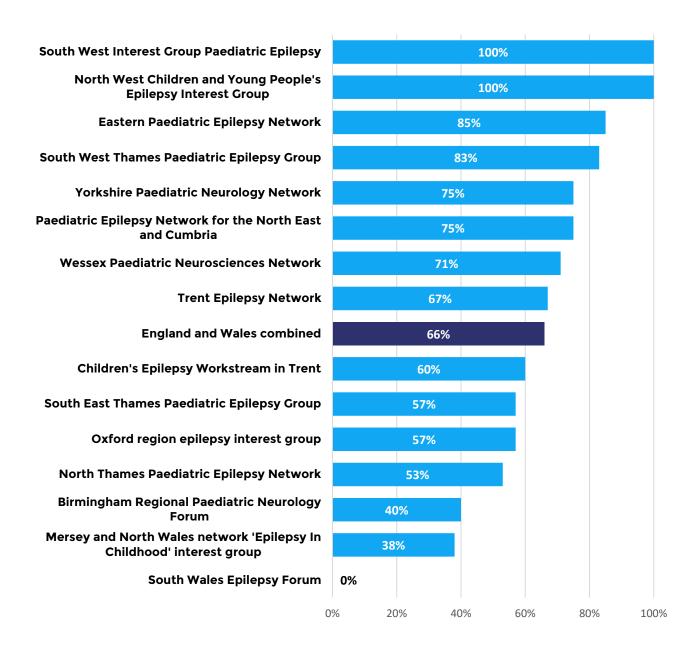
% of Health Boards and Trusts that have an outpatient clinic specifically for young people with epilepsies.



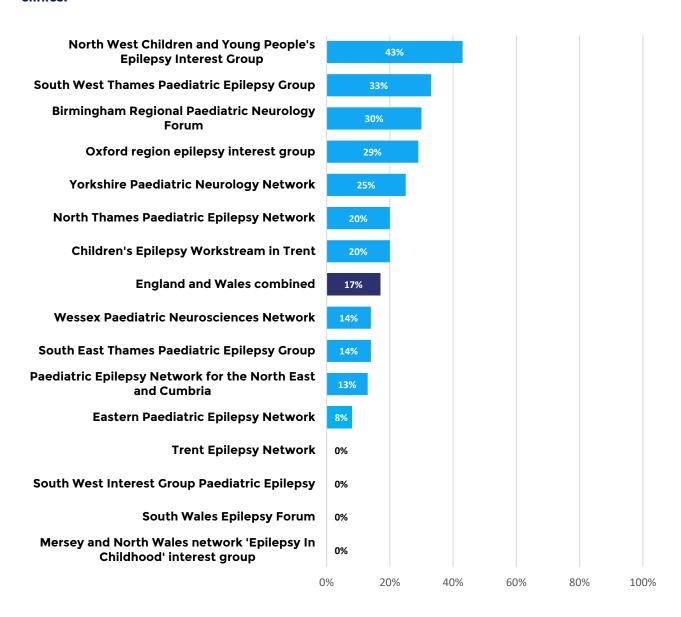
% of Health Boards and Trusts that have an outpatient epilepsy service involving adult and paediatric professionals.



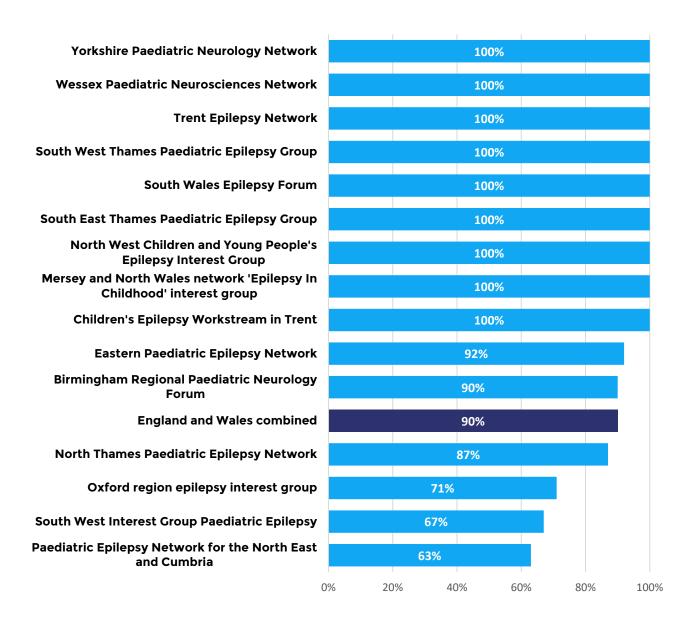
% of Health Boards and Trusts that have structured resources to support Young People transition.



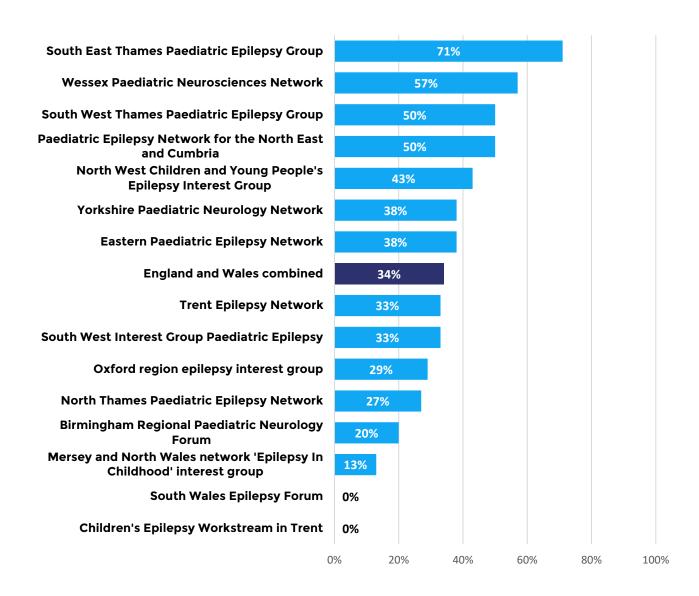
% of Health Boards and Trusts that facilitate mental health provision within epilepsy clinics.



% of Health Boards and Trusts that routinely undertook comprehensive care planning for children with epilepsy.



% of Health Boards and Trusts that maintain a database or register for all the children with epilepsies



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Data completeness

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

Of the 163, one Health Board in Wales did not register and five acute Trusts in England were no longer eligible due to mergers. Nine of the remaining 157 were community Trusts which were excluded because they either had no paediatric services, or they defined their paediatric service as not assessing or managing children with seizures or epilepsies.

As of November 2020 there were 145 registered Health Boards and Trusts in Epilepsy12. This was originally 148, however the number has reduced following mergers. Of these, 119 Health Boards and Trusts were able to submit and lock their November 2020 organisational audit data. The data were provided to Epilepsy12 between November 2020 and February 2021. This report presents organisational data describing the services as they were in November 2020. At this time the NHS were dealing with a significant surge in COVID-19 cases and hospitalisations in both England and Wales.

The following list shows the NHS Health Boards and Trusts across England and Wales that submitted data to the Epilepsy12 Round 3 2020 organisational audit.

Birmingham Regional Paediatric Neurology Forum (BRPNF)

Birmingham Community Healthcare NHS Foundation Trust

Coventry and Warwickshire Partnership NHS Trust

Sandwell and West Birmingham Hospitals NHS Trust

South Warwickshire NHS Foundation Trust

The Dudley Group NHS Foundation Trust

The Royal Wolverhampton NHS Trust

University Hospitals Coventry and Warwickshire 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

University Hospitals of Leicester NHS 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

James Paget University Hospitals NHS Foundation Trust

Luton and Dunstable University Hospital NHS Foundation Trust

Mid Essex Hospital Services NHS Trust

Norfolk and Norwich University Hospitals NHS Foundation Trust

Norfolk Community Health and Care NHS Trust

North West Anglia NHS Foundation Trust

The Princess Alexandra Hospital NHS Trust

The Queen Elizabeth Hospital, King's Lynn, NHS Foundation Trust

West Suffolk NHS Foundation Trust

Mersey and North Wales network 'Epilepsy In Childhood' interest group (EPIC)

Alder Hey Children's NHS Foundation Trust

Betsi Cadwaladr University LHB

Countess of Chester Hospital NHS Foundation Trust Shrewsbury and Telford Hospital NHS Trust Southport and Ormskirk Hospital NHS Trust St Helens and Knowsley Hospitals NHS Trust Warrington and Halton Hospitals NHS Foundation Trust Wirral University Teaching Hospital NHS Foundation Trust **North Thames Paediatric Epilepsy Network (NTPEN)** Barking, Havering and Redbridge University Hospitals NHS Trust **Barts Health NHS Trust** Central and North West London NHS Foundation Trust **Chelsea and Westminster Hospital NHS Foundation Trust Great Ormond Street Hospital For Children NHS Foundation Trust** Homerton University Hospital NHS Foundation Trust Imperial College Healthcare NHS Trust London North West Healthcare NHS Trust North Middlesex University Hospital NHS Trust **Royal Free London NHS Foundation Trust** Southend University Hospital NHS Foundation Trust The Hillingdon Hospitals NHS Foundation Trust The Whittington Hospital NHS Trust University College London Hospitals NHS Foundation Trust **West Hertfordshire Hospitals NHS Trust** North West Children and Young People's Epilepsy Interest Group (NWEIG) **Blackpool Teaching Hospitals NHS Foundation Trust Bolton NHS Foundation Trust Lancashire Teaching Hospitals NHS Foundation Trust Manchester University NHS Foundation Trust** Northern Care Alliance NHS Group **Tameside and Glossop Integrated Care NHS Foundation Trust** Wrightington, Wigan and Leigh NHS Foundation Trust Oxford region epilepsy interest group (ORENG) **Buckinghamshire Healthcare NHS Trust Great Western Hospitals NHS Foundation Trust Kettering General Hospital NHS Foundation Trust** Milton Keynes University Hospital NHS Foundation Trust **Northampton General Hospital NHS Trust** Oxford University Hospitals NHS Foundation Trust

Royal Berkshire NHS Foundation Trust Paediatric Epilepsy Network for the North East and Cumbria (PENNEC) **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 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 **Sussex Community NHS Foundation Trust South Wales Epilepsy Forum (SWEP)** Cwm Taf LHB Hywel Dda LHB Swansea Bay UHB South West Interest Group Paediatric Epilepsy (SWIPE) Gloucestershire Hospitals NHS Foundation Trust Northern Devon Healthcare NHS 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 Yeovil District Hospital 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

Hampshire Hospitals NHS Foundation Trust

Poole Hospital NHS Foundation Trust

Portsmouth Hospitals NHS Trust

Salisbury NHS Foundation Trust

Solent NHS Trust

University Hospital Southampton NHS Foundation Trust

Yorkshire Paediatric Neurology Network (YPEN)

Airedale NHS Foundation Trust

Bradford Teaching Hospitals NHS Foundation Trust

Calderdale and Huddersfield NHS Foundation Trust

Harrogate and District NHS Foundation Trust

Leeds Community Healthcare NHS Trust

Leeds Teaching Hospitals NHS Trust

Mid Yorkshire Hospitals NHS Trust

York Teaching Hospital NHS Foundation Trust

The following Trusts merged prior to the November 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	PENNEC	City Hospitals Sunderland NHS Foundation Trust
Trust		South Tyneside NHS Foundation Trust
University Hospitals of Derby and Burton NHS	CEWT	Derby Teaching Hospitals NHS Foundation Trust
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 Health Boards and Trusts were not included within the 2020 organisational audit results due to data that was either not submitted in time, or not 'locked' (a form of verification).

Health Board or Trust	Regional Network
Aneurin Bevan LHB ⁺	SWEP
Basildon and Thurrock University Hospitals NHS Foundation	NTPEN
Trust*	
Birmingham Women's and Children's NHS Foundation Trust*	BRPNF
Brighton and Sussex University Hospitals NHS Trust⁺	SETPEG
Cambridgeshire Community Services NHS Trust ⁺	EPEN
Cardiff & Vale University LHB*	SWEP
Croydon Health Services NHS Trust⁺	SWTPEG
East Cheshire NHS Trust	NWEIG
East Kent: QEQM, Margate and WHM, Ashford, Kent	SETPEG
East Lancashire Hospitals NHS Trust	NWEIG
George Eliot Hospital NHS Trust ⁺	BRPNF
Hull and East Yorkshire Hospitals NHS Trust	YPEN
Isle of Wight NHS Trust	WPNN
Leicestershire Partnership NHS Trust*	CEWT
Medway NHS Foundation Trust⁺	SETPEG
Mid Cheshire Hospitals NHS Foundation Trust⁺	EPIC
North East London NHS Foundation Trust**	NTPEN
Plymouth Hospitals NHS Trust**	SWIPE
Stockport NHS Foundation Trust	NWEIG
Surrey and Sussex Healthcare NHS Trust**	SWTPEG
University Hospitals Birmingham NHS Foundation Trust ⁺	BRPNF
University Hospitals of Morecambe Bay NHS Foundation Trust	NWEIG
University Hospitals of North Midlands NHS Trust ⁺	NWEIG
Walsall Healthcare NHS Trust	BRPNF
Western Sussex Hospitals NHS Foundation Trust	WPNN
Weston Area Health NHS Trust⁺	SWIPE

⁺Trusts or Health Boards that were not included within the 2019/20 cohort 2, clinical audit results due to data that was either not submitted in time, or not 'locked' (a form of verification).

^{*}Trusts or Health Boards were not included within the 2019 organisational audit results due to data that was either not submitted in time, or not 'locked' (a form of verification).

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