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

RCPCH Audits

EPILEPSY12

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

Appendix A: Epilepsy12 organisational audit results

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Healthcare Quality Improvement Partnership

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

Epilepsy12

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

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Published by RCPCH September 2020.

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Appendices

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

Appendix: Full Epilepsy12 clinical audit results for Round 3, Cohort 1 includes the publication of the clinical performance results and outcomes captured from Health Boards and Trusts with England and Wales. It is available to download from Epilepsy12.

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

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

Appendix A: Full Epilepsy12 Round 3 2019 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).

Paediatric epilepsy network names are abbreviated in the following tables of results and figures. The full names of the networks can be found on page 4 of this report.

Participation

Table 1 provides a breakdown of Epilepsy12 Round 3, 2019 Organisational audit participation by Paediatric Epilepsy Networks and by country.

- During the 2019 organisational audit, there were merges in eight Trusts in England, which resulted in four combined Trusts.
- There are 145 registered Health Boards and Trusts in Round 3 of Epilepsy12 (149 prior to the Trust merges).
- 136 out of 145 (93.8%) registered Health Boards and Trusts submitted and locked 2019 Organisational audit data.

Table 1: Epilepsy12 Round 3 2019 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 2019 organisational audit data
England &Wales	145	93.8% (136/145)
England	139	94.2% (131/139)
Wales	6	83.3% (5/6)
BRPNF	14	92.9% (13/14)
CEWT	6	83.3% (5/6)
EPEN	14	100% (14/14)
EPIC	9	100% (9/9)
NTPEN	17	94.1% (16/17)
NWEIG	12	100% (12/12)
ORENG	7	100% (7/7)
PENNEC	8	100% (8/8)
SETPEG	11	72.7% (8/11)
SWEP	5	80.0% (4/5)
SWIPE	11	81.8% (9/11)
SWTPEG	7	100% (7/7)
TEN	6	100% (6/6)
WPNN	9	100% (9/9)
YPEN	9	100% (9/9)

Workforce

Consultant paediatrician

The total whole time equivalent (WTE) for general paediatric consultants employed across England and Wales was **2146, (Table 2**). There was a total of **308.7** whole time equivalent (WTE) paediatric consultants with 'expertise in epilepsy' employed across England and Wales; this represented **14.4% (308.7/2146)** of the total WTE general paediatric (consultant or associate specialist) reported workforce, (**Table 3**). **93.4% (127/136)** of Health Boards and Trusts did employ a consultant paediatrician with 'expertise in epilepsy', this ranged from 0.6 WTE to 12 WTE, (**Table 4**). **11.8% (16/136)** of Health Boards and Trusts did not have a defined paediatric epilepsy clinical lead, (**Table 5**).

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

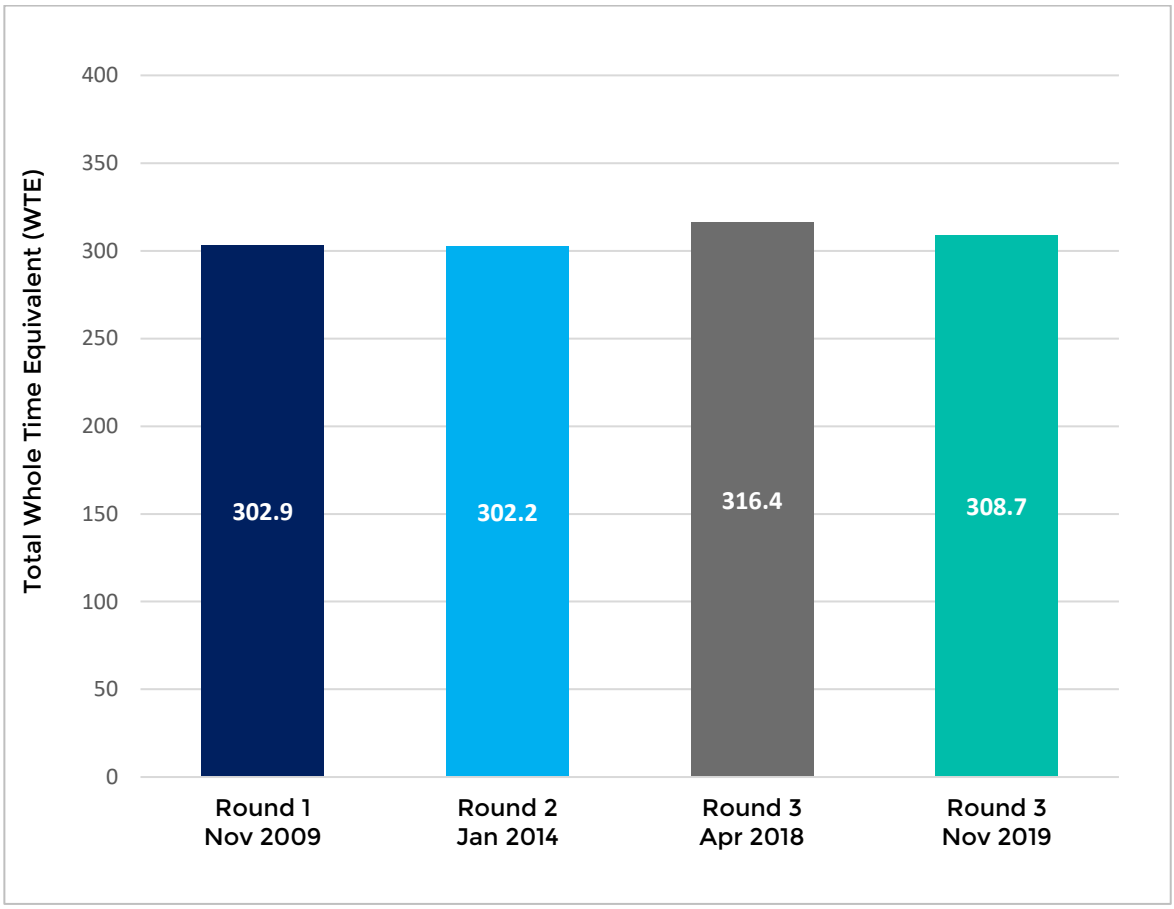


Figure 1: Total whole time equivalent consultant paediatrician with 'expertise in epilepsy' employed in England and Wales in Round 1, Round 2, Round 3 April 2018 and Round 3 November 2019.

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=136)	2146.0	15.8
England (N=131)	2016.1	15.4
Wales (N=5)	129.9	26.0
BRPNF (N=13)	186.1	14.3
CEWT (N=5)	114.7	22.9
EPEN (N=14)	182.9	13.1
EPIC (N=9)	116.1	12.9
NTPEN (N=16)	266.8	16.7
NWEIG (N=12)	227.0	18.9
ORENG (N=7)	113.3	16.2
PENNEC (N=8)	141.0	17.6
SETPEG (N=8)	130.8	16.3
SWEP (N=4)	98.9	24.7
SWIPE (N=9)	107.3	11.9
SWTPEG (N=7)	131.9	18.8
TEN (N=6)	75.4	12.6
WPNN (N=9)	113.9	12.7
YPEN (N=9)	140.0	15.6

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=136)	308.7	2.3	0.0	12.0	14.4% (308.7/2146.0)
England (N=131)	290.7	2.2	0.0	12.0	14.4% (290.7/2016.1)
Wales (N=5)	18.0	3.6	2.0	9.0	13.9% (18/129.9)
BRPNF (N=13)	23.6	1.8	0.0	4.5	12.7% (23.6/186.1)
CEWT (N=5)	13.5	2.7	0.0	7.0	11.8% (13.5/114.7)
EPEN (N=14)	23.8	1.7	0.0	4.0	13.0% (23.8/182.9)
EPIC (N=9)	24.5	2.7	0.0	9.0	21.1% (24.5/116.1)
NTPEN (N=16)	48.4	3.0	0.0	12.0	18.1% (48.4/266.8)
NWEIG (N=12)	23.5	2.0	1.0	5.0	10.3% (23.5/227.0)
ORENG (N=7)	13.5	1.9	1.0	5.0	11.9% (13.5/113.3)
PENNEC (N=8)	28.5	3.6	1.0	9.0	20.2% (28.5/141.0)
SETPEG (N=8)	17.4	2.2	1.0	3.9	13.3% (17.4/130.8)
SWEP (N=4)	9.0	2.3	2.0	3.0	9.1% (9.0/98.9)
SWIPE (N=9)	16.5	1.8	0.8	4.0	15.3% (16.5/107.3)
SWTPEG (N=7)	12.1	1.7	0.0	2.8	9.2% (12.1/131.9)
TEN (N=6)	12.8	2.1	1.8	3.0	17.0% (12.8/75.4)
WPNN (N=9)	17.0	1.9	0.0	3.8	14.9% (17.0/113.9)
YPEN (N=9)	24.8	2.8	1.0	11.2	17.7% (24.8/140.0)

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=136)	93.4% (127/136)	6.6% (9/136)	0.6 - 12.0
England (N=131)	93.1% (122/131)	6.9% (9/131)	0.6 - 12.0
Wales (N=5)	100% (5/5)	0.0% (0/5)	2.0 - 9.0
BRPNF (N=13)	92.3% (12/13)	7.7% (1/13)	1.0 - 4.5
CEWT (N=5)	60.0% (3/5)	40.0% (2/5)	2.0 - 7.0
EPEN (N=14)	92.9% (13/14)	7.1% (1/14)	0.6 - 4.0
EPIC (N=9)	88.9% (8/9)	11.1% (1/9)	1.0 - 9.0
NTPEN (N=16)	87.5% (14/16)	12.5% (2/16)	1.0 -12.0
NWEIG (N=12)	100% (12/12)	0.0% (0/12)	1.0 - 5.0
ORENG (N=7)	100% (7/7)	0.0% (0/7)	1.0 -5.0
PENNEC (N=8)	100% (8/8)	0.0% (0/8)	1.0 - 9.0
SETPEG (N=8)	100% (8/8)	0.0% (0/8)	1.0 -3.9
SWEP (N=4)	100% (4/4)	0.0% (0/4)	2.0 -3.0
SWIPE (N=9)	100% (9/9)	0.0% (0/9)	0.8 - 4.0
SWTPEG (N=7)	85.7% (6/7)	14.3% (1/7)	1.0 - 2.8
TEN (N=6)	100% (6/6)	0.0% (0/6)	1.8 - 3.0
WPNN (N=9)	88.9% (8/9)	11.1% (1/9)	1.0 - 3.8
YPEN (N=9)	100% (9/9)	0.0% (0/9)	1.0 - 11.2

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=136)	88.2% (120/136)	11.8% (16/136)
England (N=131)	88.5% (116/131)	11.5% (15/131)
Wales (N=5)	80.0% (4/5)	20.0% (1/5)
BRPNF (N=13)	84.6% (11/13)	15.4% (2/13)
CEWT (N=5)	80.0% (4/5)	20.0% (1/5)
EPEN (N=14)	92.9% (13/14)	7.1% (1/14)
EPIC (N=9)	100% (9/9)	0.0% (0/9)
NTPEN (N=16)	87.5% (14/16)	12.5% (2/16)
NWEIG (N=12)	100% (12/12)	0.0% (0/12)
ORENG (N=7)	100% (7/7)	0.0% (0/7)
PENNEC (N=8)	100% (8/8)	0.0% (0/8)
SETPEG (N=8)	50.0% (4/8)	50.0% (4/8)
SWEP (N=4)	75.0% (3/4)	25.0% (1/4)
SWIPE (N=9)	88.9% (8/9)	11.1% (1/9)
SWTPEG (N=7)	85.7% (6/7)	14.3% (1/7)
TEN (N=6)	100% (6/6)	0.0% (0/6)
WPNN (N=9)	77.8% (7/9)	22.2% (2/9)
YPEN (N=9)	88.9% (8/9)	11.1% (1/9)

Epilepsy specialist nurse

There was a total of **158.4 WTE** epilepsy specialist nurses (ESN) employed across England and Wales. The ESNs were employed across **81.6% (111/136)** of Health Boards and Trusts. Of those with an ESN, the number employed ranged from **0.2 WTE** to **5.0 WTE, (Table 7)**.

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

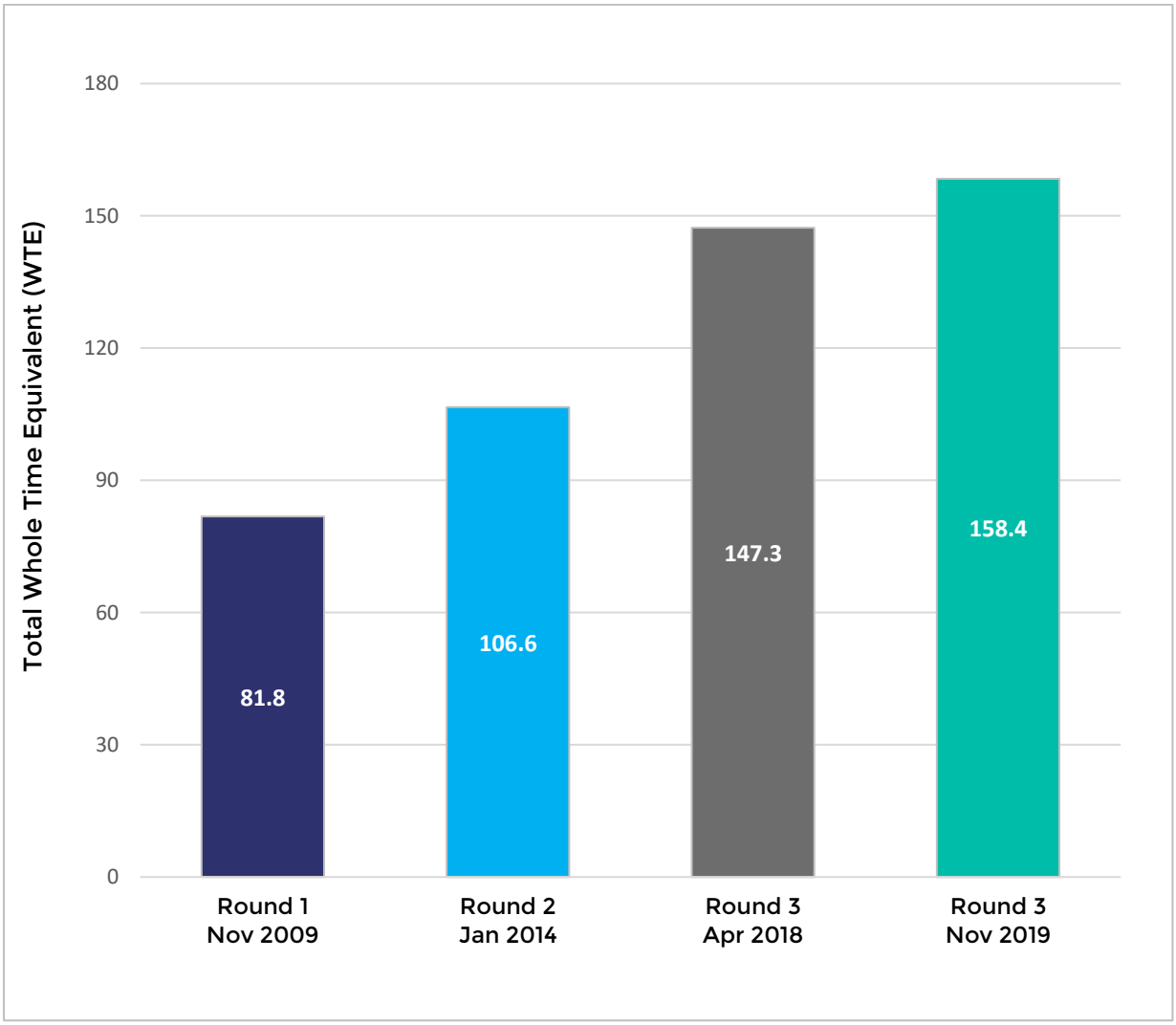


Figure 2: Total Whole Time Equivalent epilepsy specialist nurses employed in England and Wales in Round 1, Round 2, Round 3 April 2018 and November 2019.

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. **80.1% (109/136)** of Health Boards and Trusts indicated that they could offer ESN support for rescue medication training for parents, **77.9% (106/136)** could offer support in school meetings, **76.5% (104/136)** provided individual healthcare plan facilitation and **67.6% (92/136)** supported rescue medication training for schools. **55.9% (76/136)** supported nurse led clinics, **46.3% (63/136**) supported emergency department visits and **33.8% (46/136)** were able to support nurse prescribing. **68.4% (93/136)** were able to support home visits. **16.9% (23/136)** were able to support all nine functions.

Figure 4 shows a comparison of the percentage of Health Boards and Trusts that supported various epilepsy specialist nurse functions in Round 3 April 2018 and November 2019.

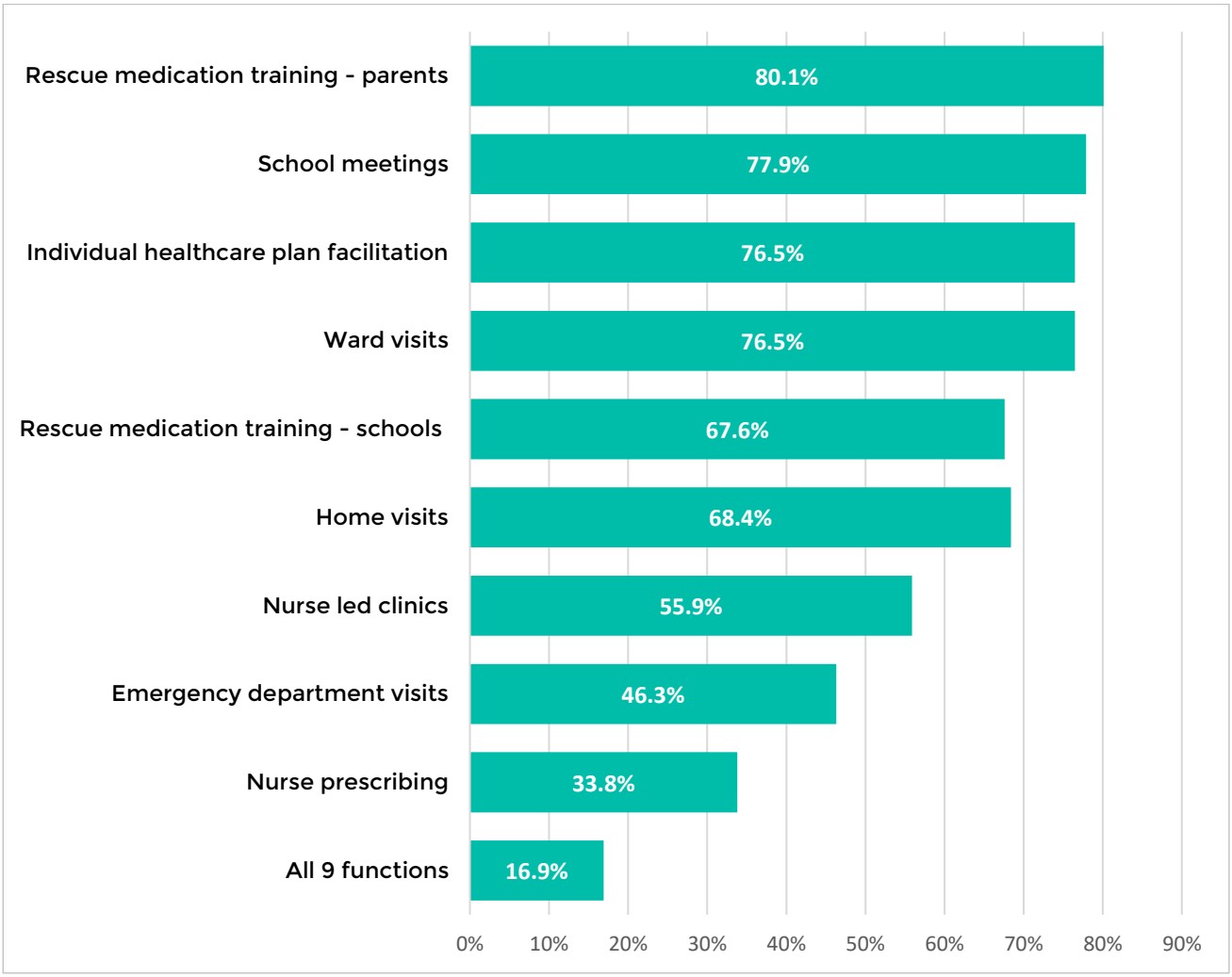


Figure 3: Percentage of Health Boards and Trusts that could support epilepsy specialist nurse functions (n=136).

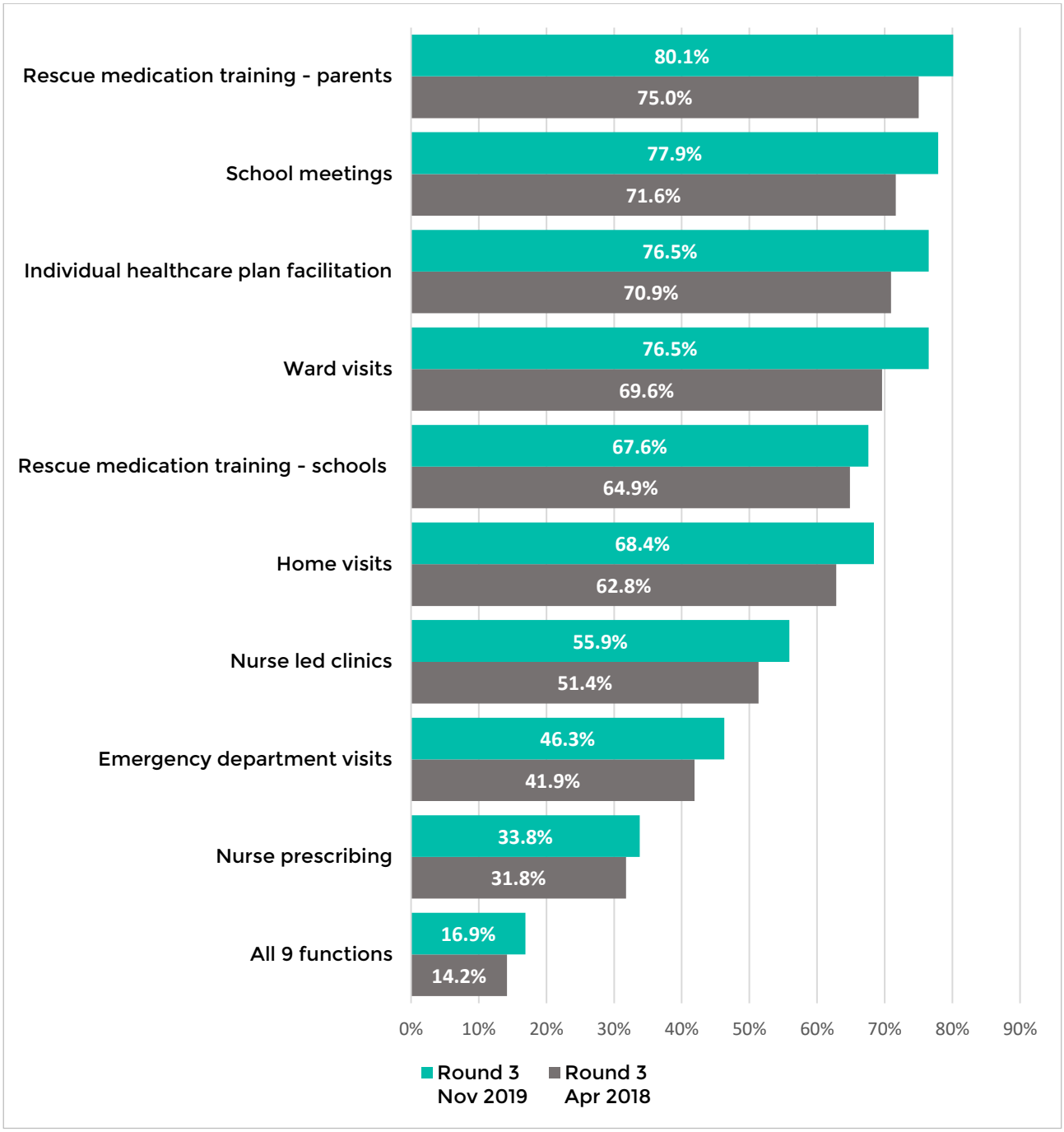


Figure 4: Percentage of Health Boards and Trusts that could support epilepsy specialist nurse functions in Round 3 April 2018 and November 2019.

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=136)	158.4	1.2	0.0	5.0
England (N=131)	148.0	1.1	0.0	5.0
Wales (N=5)	10.4	2.1	0.0	3.0
BRPNF (N=13)	7.1	0.5	0.0	1.0
CEWT (N=5)	6.8	1.4	0.0	2.0
EPEN (N=14)	15.2	1.1	0.0	2.9
EPIC (N=9)	13.1	1.5	0.3	3.6
NTPEN (N=16)	18.8	1.2	0.0	3.7
NWEIG (N=12)	18.1	1.5	0.0	5.0
ORENG (N=7)	4.2	0.6	0.0	1.0
PENNEC (N=8)	8.6	1.1	0.0	2.1
SETPEG (N=8)	8.8	1.1	0.0	2.5
SWEP (N=4)	8.0	2.0	0.0	3.0
SWIPE (N=9)	6.5	0.7	0.0	2.0
SWTPEG (N=7)	5.6	0.8	0.0	1.6
TEN (N=6)	12.0	2.0	1.0	4.0
WPNN (N=9)	10.4	1.2	0.0	2.1
YPEN (N=9)	15.1	1.7	0.5	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	% with no WTE	WTE range in T/HBs with some WTE
England and Wales (N=136)	81.6% (111/136)	18.4% (25/136)	0.2 - 5.0
England (N=131)	81.7% (107/131)	18.3% (24/131)	0.2 - 5.0
Wales (N=5)	80.0% (4/5)	20.0% (1/5)	2.0 - 3.0
BRPNF (N=13)	61.5% (8/13)	38.5% (5/13)	0.5 - 1.0
CEWT (N=5)	80.0% (4/5)	20.0% (1/5)	1.0 - 2.0
EPEN (N=14)	85.7% (12/14)	14.3% (2/14)	0.2 - 2.9
EPIC (N=9)	100% (9/9)	0.0% (0/9)	0.3 - 3.6
NTPEN (N=16)	81.3% (13/16)	18.8% (3/16)	0.4 - 3.7
NWEIG (N=12)	91.7% (11/12)	8.3% (1/12)	0.6 -5.0
ORENG (N=7)	71.4% (5/7)	28.6% (2/7)	0.6 - 1.0
PENNEC (N=8)	75.0% (6/8)	25.0% (2/8)	1.0 - 2.1
SETPEG (N=8)	75.0% (6/8)	25.0% (2/8)	0.3 - 2.5
SWEP (N=4)	75.0% (3/4)	25.0% (1/4)	2.0 - 3.0
SWIPE (N=9)	66.7% (6/9)	33.3% (3/9)	0.3 - 2.0
SWTPEG (N=7)	71.4% (5/7)	28.6% (2/7)	0.8 - 1.6
TEN (N=6)	100% (6/6)	0.0% (0/6)	1.0 - 4.0
WPNN (N=9)	88.9% (8/9)	11.1% (1/9)	0.2 - 2.1
YPEN (N=9)	100% (9/9)	0.0% (0/9)	0.5 - 4.8

Table 8: Health Boards and Trusts that could support epilepsy nurse functions (n=136).

Country/network	Home visits	Nurse led clinics	Emergency department visits	Ward visits	Nurse prescribing	School meetings
England and Wales (N=136)	68.4% (93/136)	55.9% (76/136)	46.3% (63/136)	76.5% (104/136)	33.8% (46/136)	77.9% (106/136)
England (N=131)	68.7% (90/131)	55.7% (73/131)	48.1% (63/131)	77.1% (101/131)	34.4% (45/131)	77.9% (102/131)
Wales (N=5)	60.0% (3/5)	60.0% (3/5)	0.0% (0/5)	60.0% (3/5)	20.0% (1/5)	80.0% (4/5)
BRPNF (N=13)	38.5% (5/13)	38.5% (5/13)	30.8% (4/13)	61.5% (8/13)	30.8% (4/13)	53.8% (7/13)
CEWT (N=5)	40.0% (2/5)	80.0% (4/5)	80.0% (4/5)	80.0% (4/5)	40.0% (2/5)	80.0% (4/5)
EPEN (N=14)	57.1% (8/14)	57.1% (8/14)	71.4% (10/14)	85.7% (12/14)	21.4% (3/14)	78.6% (11/14)
EPIC (N=9)	100% (9/9)	55.6% (5/9)	44.4% (4/9)	100% (9/9)	66.7% (6/9)	100% (9/9)
NTPEN (N=16)	68.8% (11/16)	56.3% (9/16)	56.3% (9/16)	81.3% (13/16)	18.8% (3/16)	68.8% (11/16)
NWEIG (N=12)	91.7% (11/12)	58.3% (7/12)	25.0% (3/12)	91.7% (11/12)	50.0% (6/12)	91.7% (11/12)
ORENG (N=7)	71.4% (5/7)	42.9% (3/7)	57.1% (4/7)	71.4% (5/7)	14.3% (1/7)	71.4% (5/7)
PENNEC (N=8)	62.5% (5/8)	62.5% (5/8)	50.0% (4/8)	62.5% (5/8)	50.0% (4/8)	75.0% (6/8)
SETPEG (N=8)	75% (6/8)	75.0% (6/8)	50.0% (4/8)	50.0% (4/8)	12.5% (1/8)	75.0% (6/8)
SWEP (N=4)	50.0% (2/4)	50.0% (2/4)	0.0% (0/4)	50.0% (2/4)	0.0% (0/4)	75.0% (3/4)
SWIPE (N=9)	44.4% (4/9)	33.3% (3/9)	55.6% (5/9)	66.7% (6/9)	44.4% (4/9)	55.6% (5/9)
SWTPEG (N=7)	71.4% (5/7)	57.1% (4/7)	28.6% (2/7)	71.4% (5/7)	28.6% (2/7)	71.4% (5/7)
TEN (N=6)	100% (6/6)	83.3% (5/6)	66.7% (4/6)	100% (6/6)	50.0% (3/6)	100% (6/6)
WPNN (N=9)	77.8% (7/9)	44.4% (4/9)	33.3% (3/9)	77.8% (7/9)	33.3% (3/9)	88.9% (8/9)
YPEN (N=9)	77.8% (7/9)	66.7% (6/9)	33.3% (3/9)	77.8% (7/9)	44.4% (4/9)	100% (9/9)

Table 8 (continued): Health Boards and Trusts that could support epilepsy nurse functions (n=136).

Country/network	Individual HCP facilitation	Rescue medication training parents	Rescue medication training schools	Supporting all 9 functions
England and Wales (N=136)	76.5% (104/136)	80.1% (109/136)	67.6% (92/136)	16.9% (23/136)
England (N=131)	76.3% (100/131)	80.2% (105/131)	67.2% (88/131)	17.6% (23/131)
Wales (N=5)	80.0% (4/5)	80.0% (4/5)	80.0% (4/5)	0.0% (0/5)
BRPNF (N=13)	53.8% (7/13)	61.5% (8/13)	46.2% (6/13)	15.4% (2/13)
CEWT (N=5)	80.0% (4/5)	80.0% (4/5)	60.0% (3/5)	20.0% (1/5)
EPEN (N=14)	85.7% (12/14)	85.7% (12/14)	50.0% (7/14)	14.3% (2/14)
EPIC (N=9)	100% (9/9)	100% (9/9)	100% (9/9)	33.3% (3/9)
NTPEN (N=16)	75.0% (12/16)	81.3% (13/16)	56.3% (9/16)	0.0% (0/16)
NWEIG (N=12)	91.7% (11/12)	83.3% (10/12)	83.3% (10/12)	8.3% (1/12)
ORENG (N=7)	71.4% (5/7)	71.4% (5/7)	57.1% (4/7)	0.0% (0/7)
PENNEC (N=8)	75.0% (6/8)	75.0% (6/8)	75.0% (6/8)	37.5% (3/8)
SETPEG (N=8)	75.0% (6/8)	75.0% (6/8)	75.0% (6/8)	12.5% (1/8)
SWEP (N=4)	75.0% (3/4)	75.0% (3/4)	75.0% (3/4)	0.0% (0/4)
SWIPE (N=9)	55.6% (5/9)	66.7% (6/9)	66.7% (6/9)	22.2% (2/9)
SWTPEG (N=7)	71.4% (5/7)	71.4% (5/7)	57.1% (4/7)	28.6% (2/7)
TEN (N=6)	83.3% (5/6)	100% (6/6)	100% (6/6)	33.3% (2/6)
WPNN (N=9)	77.8% (7/9)	77.8% (7/9)	44.4% (4/9)	11.1% (1/9)
YPEN (N=9)	77.8% (7/9)	100% (9/9)	100% (9/9)	33.3% (3/9)

Table 9: Health Boards and Trusts that could support epilepsy nurse functions (n=111). These are Health Boards and Trusts that had employed some level of ESN.

Country/network	Home visits	Nurse led clinics	Emergency department visits	Ward visits	Nurse prescribing	School meetings
England and Wales (N=111)	83.8% (93/111)	68.5% (76/111)	56.8% (63/111)	93.7% (104/111)	41.4% (46/111)	95.5% (106/111)
England (N=107)	84.1% (90/107)	68.2% (73/107)	58.9% (63/107)	94.4% (101/107)	42.1% (45/107)	95.3% (102/107)
Wales (N=4)	75.0% (3/4)	75.0% (3/4)	0.0% (0/4)	75.0% (3/4)	25.0% (1/4)	100% (4/4)
BRPNF (N=8)	62.5% (5/8)	62.5% (5/8)	50.0% (4/8)	100% (8/8)	50.0% (4/8)	87.5% (7/8)
CEWT (N=4)	50.0% (2/4)	100% (4/4)	100% (4/4)	100% (4/4)	50.0% (2/4)	100% (4/4)
EPEN (N=12)	66.7% (8/12)	66.7% (8/12)	83.3% (10/12)	100% (12/12)	25.0% (3/12)	91.7% (11/12)
EPIC (N=9)	100% (9/9)	55.6% (5/9)	44.4% (4/9)	100% (9/9)	66.7% (6/9)	100% (9/9)
NTPEN (N=13)	84.6% (11/13)	69.2% (9/13)	69.2% (9/13)	100% (13/13)	23.1% (3/13)	84.6% (11/13)
NWEIG (N=11)	100% (11/11)	63.6% (7/11)	27.3% (3/11)	100% (11/11)	54.5% (6/11)	100% (11/11)
ORENG (N=5)	100% (5/5)	60.0% (3/5)	80.0% (4/5)	100% (5/5)	20.0% (1/5)	100% (5/5)
PENNEC (N=6)	83.3% (5/6)	83.3% (5/6)	66.7% (4/6)	83.3% (5/6)	66.7% (4/6)	100% (6/6)
SETPEG (N=6)	100% (6/6)	100% (6/6)	66.7% (4/6)	66.7% (4/6)	16.7% (1/6)	100% (6/6)
SWEP (N=3)	66.7% (2/3)	66.7% (2/3)	0.0% (0/3)	66.7% (2/3)	0.0% (0/3)	100% (3/3)
SWIPE (N=6)	66.7% (4/6)	50.0% (3/6)	83.3% (5/6)	100% (6/6)	66.7% (4/6)	83.3% (5/6)
SWTPEG (N=5)	100% (5/5)	80.0% (4/5)	40.0% (2/5)	100% (5/5)	40.0% (2/5)	100% (5/5)
TEN (N=6)	100% (6/6)	83.3% (5/6)	66.7% (4/6)	100% (6/6)	50.0% (3/6)	100% (6/6)
WPNN (N=8)	87.5% (7/8)	50.0% (4/8)	37.5% (3/8)	87.5% (7/8)	37.5% (3/8)	100% (8/8)
YPEN (N=9)	77.8% (7/9)	66.7% (6/9)	33.3% (3/9)	77.8% (7/9)	44.4% (4/9)	100% (9/9)

Table 9 (continued): Health Boards and Trusts that could support epilepsy nurse functions (n=111). These are Health Boards and Trusts that had employed some level of ESN

Country/network	Individual HCP facilitation	Rescue medication training with parents	Rescue medication training in schools	Supporting all 9 functions
England and Wales (N=111)	93.7% (104/111)	98.2% (109/111)	82.9% (92/111)	20.7% (23/111)
England (N=107)	93.5% (100/107)	98.1% (105/107)	82.2% (88/107)	21.5% (23/107)
Wales (N=4)	100% (4/4)	100% (4/4)	100% (4/4)	0.0% (0/4)
BRPNF (N=8)	87.5% (7/8)	100% (8/8)	75.0% (6/8)	25.0% (2/8)
CEWT (N=4)	100% (4/4)	100% (4/4)	75.0% (3/4)	25.0% (1/4)
EPEN (N=12)	100% (12/12)	100% (12/12)	58.3% (7/12)	16.7% (2/12)
EPIC (N=9)	100% (9/9)	100% (9/9)	100% (9/9)	33.3% (3/9)
NTPEN (N=13)	92.3% (12/13)	100% (13/13)	69.2% (9/13)	0.0% (0/13)
NWEIG (N=11)	100% (11/11)	90.9% (10/11)	90.9% (10/11)	9.1% (1/11)
ORENG (N=5)	100% (5/5)	100% (5/5)	80.0% (4/5)	0.0% (0/5)
PENNEC (N=6)	100% (6/6)	100% (6/6)	100% (6/6)	50.0% (3/6)
SETPEG (N=6)	100% (6/6)	100% (6/6)	100% (6/6)	16.7% (1/6)
SWEP (N=3)	100% (3/3)	100% (3/3)	100% (3/3)	0.0% (0/3)
SWIPE (N=6)	83.3% (5/6)	100% (6/6)	100% (6/6)	33.3% (2/6)
SWTPEG (N=5)	100% (5/5)	100% (5/5)	80.0% (4/5)	40.0% (2/5)
TEN (N=6)	83.3% (5/6)	100% (6/6)	100% (6/6)	33.3% (2/6)
WPNN (N=8)	87.5% (7/8)	87.5% (7/8)	50.0% (4/8)	12.5% (1/8)
YPEN (N=9)	77.8% (7/9)	100% (9/9)	100% (9/9)	33.3% (3/9)

Clinic configuration

Defined epilepsy clinic

89.7% (122/136) of Health Boards and Trusts had a defined epilepsy clinic seeing patients at secondary level, (**Table 10**). **87.7% (107/122)** of Health Boards and Trusts holding defined epilepsy clinics allowed at least 20 minutes with a consultant with expertise in epilepsy and an ESN, either simultaneously or in succession, (**Table 12**). A total of **252.9** consultant or associate specialist led secondary level 'epilepsy clinics' took place each week across England and Wales. The mean number of consultant or associate specialist clinics taking place per week was **2.1 (range 0-6)**, (**Table 11**).

Figure 5 shows a comparison of the total number of consultant or associate specialist led secondary level epilepsy clinics in Round 1, Round 2, Round 3 April 2018 and November 2019.

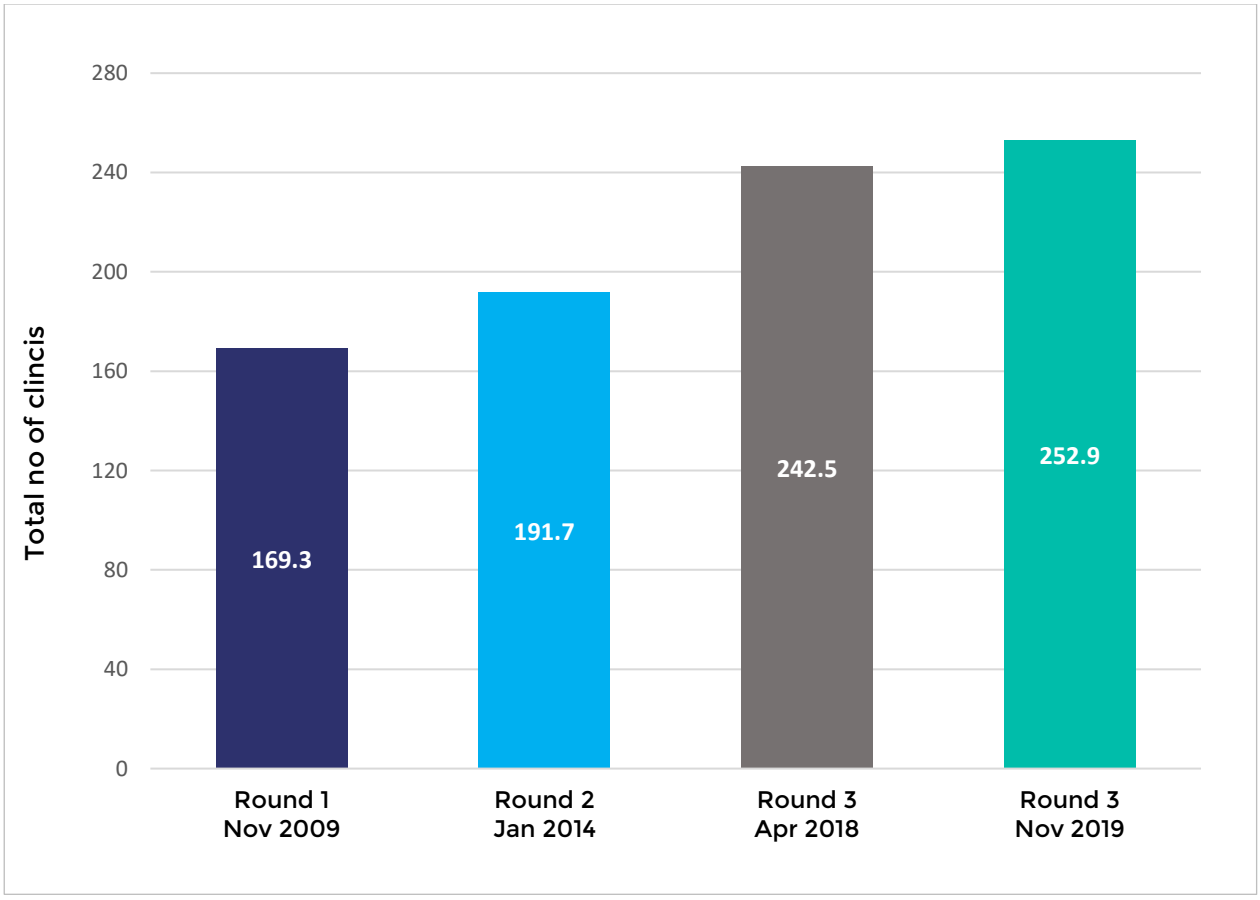


Figure 5: Total number of consultant or associate specialist led secondary level epilepsy clinics in Round 1, Round 2, Round 3 April 2018 and November 2019.

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

Country/network	% with a defined epilepsy clinic	% with no defined epilepsy clinic
England and Wales (N=136)	89.7% (122/136)	10.3% (14/136)
England (N=131)	89.3% (117/131)	10.7% (14/131)
Wales (N=5)	100% (5/5)	0.0% (0/5)
BRPNF (N=13)	69.2% (9/13)	30.8% (4/13)
CEWT (N=5)	100% (5/5)	0.0% (0/5)
EPEN (N=14)	85.7% (12/14)	14.3% (2/14)
EPIC (N=9)	100% (9/9)	0.0% (0/9)
NTPEN (N=16)	87.5% (14/16)	12.5% (2/16)
NWEIG (N=12)	100% (12/12)	0.0% (0/12)
ORENG (N=7)	85.7% (6/7)	14.3% (1/7)
PENNEC (N=8)	100% (8/8)	0.0% (0/8)
SETPEG (N=8)	87.5% (7/8)	12.5% (1/8)
SWEP (N=4)	100% (4/4)	0.0% (0/4)
SWIPE (N=9)	77.8% (7/9)	22.2% (2/9)
SWTPEG (N=7)	100% (7/7)	0.0% (0/7)
TEN (N=6)	100% (6/6)	0.0% (0/6)
WPNN (N=9)	88.9% (8/9)	11.1% (1/9)
YPEN (N=9)	88.9% (8/9)	11.1% (1/9)

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=122)	252.9	2.1	0.0	6.0
England (N=117)	237.7	2.0	0.0	6.0
Wales (N=5)	15.2	3.0	1.5	4.7
BRPNF (N=9)	13.9	1.5	1.0	3.0
CEWT (N=5)	12.0	2.4	1.0	4.5
EPEN (N=12)	23.9	2.0	0.6	4.5
EPIC (N=9)	19.1	2.1	0.5	4.7
NTPEN (N=14)	29.9	2.1	0.8	4.0
NWEIG (N=12)	26.3	2.2	1.0	4.5
ORENG (N=6)	9.2	1.5	0.8	3.0
PENNEC (N=8)	15.3	1.9	0.5	4.0
SETPEG (N=7)	20.0	2.9	1.3	6.0
SWEP (N=4)	10.5	2.6	1.5	4.0
SWIPE (N=7)	9.2	1.3	0.0	2.3
SWTPEG (N=7)	17.5	2.5	1.0	4.5
TEN (N=6)	9.5	1.6	0.5	2.0
WPNN (N=8)	19.3	2.4	0.5	4.8
YPEN (N=8)	17.6	2.2	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=122)	87.7% (107/122)	12.3% (15/122)
England (N=117)	87.2% (102/117)	12.8% (15/117)
Wales (N=5)	100% (5/5)	0.0% (0/5)
BRPNF (N=9)	88.9% (8/9)	11.1% (1/9)
CEWT (N=5)	100% (5/5)	0.0% (0/5)
EPEN (N=12)	91.7% (11/12)	8.3% (1/12)
EPIC (N=9)	100% (9/9)	0.0% (0/9)
NTPEN (N=14)	71.4% (10/14)	28.6% (4/14)
NWEIG (N=12)	100% (12/12)	0.0% (0/12)
ORENG (N=6)	83.3% (5/6)	16.7% (1/6)
PENNEC (N=8)	62.5% (5/8)	37.5% (3/8)
SETPEG (N=7)	100% (7/7)	0.0% (0/7)
SWEP (N=4)	100% (4/4)	0.0% (0/4)
SWIPE (N=7)	85.7% (6/7)	14.3% (1/7)
SWTPEG (N=7)	85.7% (6/7)	14.3% (1/7)
TEN (N=6)	100% (6/6)	0.0% (0/6)
WPNN (N=8)	87.5% (7/8)	12.5% (1/8)
YPEN (N=8)	75.0% (6/8)	25.0% (2/8)

Epilepsy Best Practice Tariff (BPC) – England only

Figure 6 shows **46.6% (61/131)** of Trusts in England were running an Epilepsy Best Practice Tariff (BPC) service. **26.0% (34/131)** Trusts were working toward BPT, **20.6% (27/131)** were not running a BPT service whilst **6.9% (9/131)** reported that this was not applicable, (**Table 13**).

Figure 7 shows a comparison of the percentage of Trusts running a BPT epilepsy service in Round 3 April 2018 and November 2019.

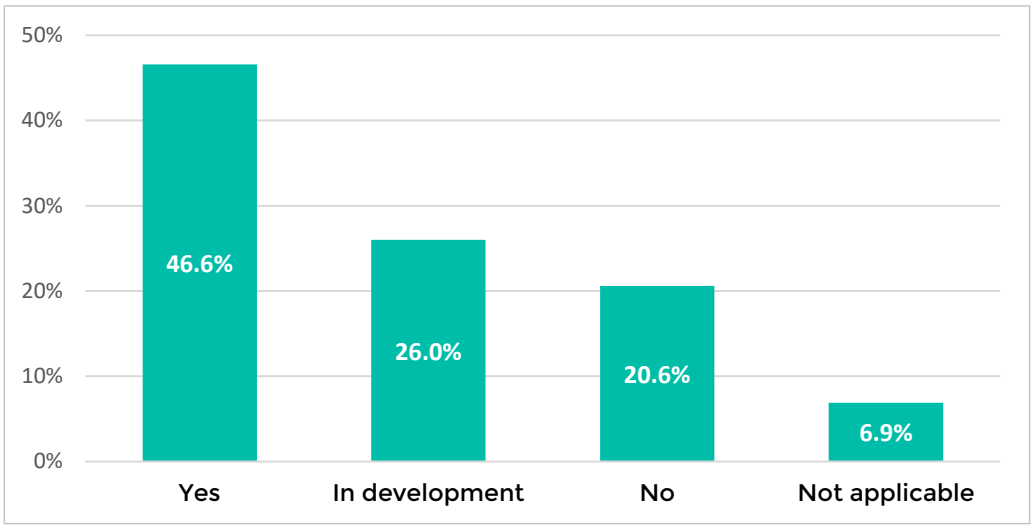


Figure 6: Percentage of Trusts receiving TFC 223 Epilepsy Best Practice Criteria (England only) (n=131)

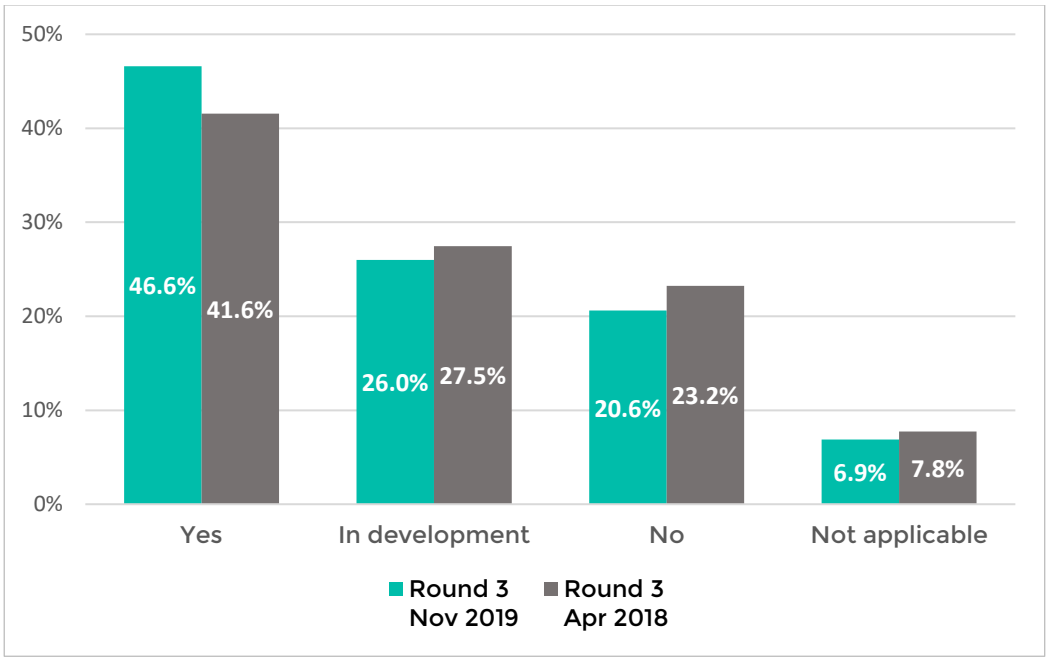


Figure 7: Percentage of Trusts receiving TFC 223 Epilepsy Best Practice Criteria (England only) in Round 3 April 2018 and November 2019.

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

Country/network	Yes	In development	No	N/A
England (N=131)	46.6% (61/131)	26.0% (34/131)	20.6% (27/131)	6.9% (9/131)
BRPNF (N=13)	30.8% (4/13)	30.8% (4/13)	38.5% (5/13)	0.0% (0/13)
CEWT (N=5)	60.0% (3/5)	0.0% (0/5)	20.0% (1/5)	20.0% (1/5)
EPEN (N=14)	50.0% (7/14)	21.4% (3/14)	14.3% (2/14)	14.3% (2/14)
EPIC (N=8)	37.5% (3/8)	50.0% (4/8)	12.5% (1/8)	0.0% (0/8)
NTPEN (N=16)	31.3% (5/16)	31.3% (5/16)	25.0% (4/16)	12.5% (2/16)
NWEIG (N=12)	41.7% (5/12)	33.3% (4/12)	25.0% (3/12)	0.0% (0/12)
ORENG (N=7)	57.1% (4/7)	0.0% (0/7)	42.9% (3/7)	0.0% (0/7)
PENNEC (N=8)	50.0% (4/8)	37.5% (3/8)	12.5% (1/8)	0.0% (0/8)
SETPEG (N=8)	37.5% (3/8)	12.5% (1/8)	37.5% (3/8)	12.5% (1/8)
SWIPE (N=9)	44.4% (4/9)	22.2% (2/9)	33.3% (3/9)	0.0% (0/9)
SWTPEG (N=7)	57.1% (4/7)	28.6% (2/7)	14.3% (1/7)	0.0% (0/7)
TEN (N=6)	66.7% (4/6)	33.3% (2/6)	0.0% (0/6)	0.0% (0/6)
WPNN (N=9)	66.7% (6/9)	11.1% (1/9)	0.0% (0/9)	22.2% (2/9)
YPEN (N=9)	55.6% (5/9)	33.3% (3/9)	0.0% (0/9)	11.1% (1/9)

Tertiary provision

Paediatric neurology services

A total of **109.4 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**). **16.9% (23/136)** of Health Boards and Trusts had some level of whole time equivalent (WTE) paediatric neurologists who manage children with epilepsy (acutely and/or non-acutely) employed (this ranged from 0.6 WTE to 10.6 WTE, (**Table 15**). **Table 16** shows, **92.6% (126/136)** of Health Boards and Trusts had agreed referral pathway to tertiary paediatric neurology services. **23.5% (32/136)** 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**). **73.5% (100/136)** of Health Boards and Trusts reported that they host satellite paediatric neurology clinics, (**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=136)	109.4	0.0	10.6
England (N=131)	108.8	0.0	10.6
Wales (N=5)	0.6	0.0	0.6
BRPNF (N=13)	7.0	0.0	7.0
CEWT (N=5)	5.5	0.0	3.0
EPEN (N=14)	4.4	0.0	4.4
EPIC (N=9)	5.2	0.0	5.2
NTPEN (N=16)	26.6	0.0	10.6
NWEIG (N=12)	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=8)	6.6	0.0	3.6
SWEP (N=4)	0.6	0.0	0.6
SWIPE (N=9)	7.0	0.0	7.0
SWTPEG (N=7)	3.0	0.0	3.0
TEN (N=6)	10.0	0.0	5.0
WPNN (N=9)	6.5	0.0	6.5
YPEN (N=9)	6.4	0.0	6.4

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=136)	16.9% (23/136)	83.1% (113/136)	0.6 - 10.6
England (N=131)	16.8% (22/131)	83.2% (109/131)	1.0 - 10.6
Wales (N=5)	20.0% (1/5)	80.0% (4/5)	0.6 - 0.6
BRPNF (N=13)	7.7% (1/13)	92.3% (12/13)	7.0 - 7.0
CEWT (N=5)	40.0% (2/5)	60.0% (3/5)	2.5 - 3.0
EPEN (N=14)	7.1% (1/14)	92.9% (13/14)	4.4 - 4.4
EPIC (N=9)	11.1% (1/9)	88.9% (8/9)	5.2 - 5.2
NTPEN (N=16)	25.0% (4/16)	75.0% (12/16)	3.0 - 10.6
NWEIG (N=12)	16.7% (2/12)	83.3% (10/12)	2.0 - 7.2
ORENG (N=7)	14.3% (1/7)	85.7% (6/7)	5.7 - 5.7
PENNEC (N=8)	25.0% (2/8)	75.0% (6/8)	1.0 - 4.7
SETPEG (N=8)	25.0% (2/8)	75.0% (6/8)	3.0 - 3.6
SWEP (N=4)	25.0% (1/4)	75.0% (3/4)	0.6 - 0.6
SWIPE (N=9)	11.1% (1/9)	88.9% (8/9)	7.0 -7.0
SWTPEG (N=7)	14.3% (1/7)	85.7% (6/7)	3.0 -3.0
TEN (N=6)	33.3% (2/6)	66.7% (4/6)	5.0 -5.0
WPNN (N=9)	11.1% (1/9)	88.9% (8/9)	6.5 - 6.5
YPEN (N=9)	11.1% (1/9)	88.9% (8/9)	6.4 - 6.4

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

Country/network	Yes	No
England and Wales (N=136)	92.6% (126/136)	7.4% (10/136)
England (N=131)	93.1% (122/131)	6.9% (9/131)
Wales (N=5)	80.0% (4/5)	20.0% (1/5)
BRPNF (N=13)	76.9% (10/13)	23.1% (3/13)
CEWT (N=5)	100% (5/5)	0.0% (0/5)
EPEN (N=14)	100% (14/14)	0.0% (0/14)
EPIC (N=9)	100% (9/9)	0.0% (0/9)
NTPEN (N=16)	100% (16/16)	0.0% (0/16)
NWEIG (N=12)	91.7% (11/12)	8.3% (1/12)
ORENG (N=7)	85.7% (6/7)	14.3% (1/7)
PENNEC (N=8)	87.5% (7/8)	12.5% (1/8)
SETPEG (N=8)	100% (8/8)	0.0% (0/8)
SWEP (N=4)	75.0% (3/4)	25.0% (1/4)
SWIPE (N=9)	88.9% (8/9)	11.1% (1/9)
SWTPEG (N=7)	100% (7/7)	0.0% (0/7)
TEN (N=6)	100% (6/6)	0.0% (0/6)
WPNN (N=9)	88.9% (8/9)	11.1% (1/9)
YPEN (N=9)	88.9% (8/9)	11.1% (1/9)

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=136)	23.5% (32/136)	50.0% (68/136)	26.5% (36/136)
England (N=131)	22.9% (30/131)	50.4% (66/131)	26.7% (35/131)
Wales (N=5)	40.0% (2/5)	40.0% (2/5)	20.0% (1/5)
BRPNF (N=13)	7.7% (1/13)	23.1% (3/13)	69.2% (9/13)
CEWT (N=5)	20.0% (1/5)	20.0% (1/5)	60.0% (3/5)
EPEN (N=14)	0.0% (0/14)	100% (14/14)	0.0% (0/14)
EPIC (N=9)	22.2% (2/9)	33.3% (3/9)	44.4% (4/9)
NTPEN (N=16)	18.8% (3/16)	56.3% (9/16)	25.0% (4/16)
NWEIG (N=12)	33.3% (4/12)	66.7% (8/12)	0.0% (0/12)
ORENG (N=7)	42.9% (3/7)	57.1% (4/7)	0.0% (0/7)
PENNEC (N=8)	25.0% (2/8)	62.5% (5/8)	12.5% (1/8)
SETPEG (N=8)	37.5% (3/8)	25.0% (2/8)	37.5% (3/8)
SWEP (N=4)	25.0% (1/4)	50.0% (2/4)	25.0% (1/4)
SWIPE (N=9)	22.2% (2/9)	44.4% (4/9)	33.3% (3/9)
SWTPEG (N=7)	14.3% (1/7)	71.4% (5/7)	14.3% (1/7)
TEN (N=6)	66.7% (4/6)	16.7% (1/6)	16.7% (1/6)
WPNN (N=9)	11.1% (1/9)	44.4% (4/9)	44.4% (4/9)
YPEN (N=9)	44.4% (4/9)	33.3% (3/9)	22.2% (2/9)

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=100)	32.0% (32/100)	68.0% (68/100)
England (N=96)	31.3% (30/96)	68.8% (66/96)
Wales (N=4)	50.0% (2/4)	50.0% (2/4)
BRPNF (N=4)	25.0% (1/4)	75.0% (3/4)
CEWT (N=2)	50.0% (1/2)	50.0% (1/2)
EPEN (N=14)	0.0% (0/14)	100% (14/14)
EPIC (N=5)	40.0% (2/5)	60.0% (3/5)
NTPEN (N=12)	25.0% (3/12)	75.0% (9/12)
NWEIG (N=12)	33.3% (4/12)	66.7% (8/12)
ORENG (N=7)	42.9% (3/7)	57.1% (4/7)
PENNEC (N=7)	28.6% (2/7)	71.4% (5/7)
SETPEG (N=5)	60.0% (3/5)	40.0% (2/5)
SWEP (N=3)	33.3% (1/3)	66.7% (2/3)
SWIPE (N=6)	33.3% (2/6)	66.7% (4/6)
SWTPEG (N=6)	16.7% (1/6)	83.3% (5/6)
TEN (N=5)	80.0% (4/5)	20.0% (1/5)
WPNN (N=5)	20.0% (1/5)	80.0% (4/5)
YPEN (N=7)	57.1% (4/7)	42.9% (3/7)

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

Country/network	Yes	No	N/A
England and Wales (N=136)	73.5% (100/136)	22.8% (31/136)	3.7% (5/136)
England (N=131)	72.5% (95/131)	23.7% (31/131)	3.8% (5/131)
Wales (N=5)	100% (5/5)	0.0% (0/5)	0.0% (0/5)
BRPNF (N=13)	23.1% (3/13)	53.8% (7/13)	23.1% (3/13)
CEWT (N=5)	80.0% (4/5)	0.0% (0/5)	20.0% (1/5)
EPEN (N=14)	78.6% (11/14)	21.4% (3/14)	0.0% (0/14)
EPIC (N=9)	100% (9/9)	0.0% (0/9)	0.0% (0/9)
NTPEN (N=16)	31.3% (5/16)	68.8% (11/16)	0.0% (0/16)
NWEIG (N=12)	83.3% (10/12)	8.3% (1/12)	8.3% (1/12)
ORENG (N=7)	100% (7/7)	0.0% (0/7)	0.0% (0/7)
PENNEC (N=8)	75.0% (6/8)	25.0% (2/8)	0.0% (0/8)
SETPEG (N=8)	75.0% (6/8)	25.0% (2/8)	0.0% (0/8)
SWEP (N=4)	100% (4/4)	0.0% (0/4)	0.0% (0/4)
SWIPE (N=9)	88.9% (8/9)	11.1% (1/9)	0.0% (0/9)
SWTPEG (N=7)	100% (7/7)	0.0% (0/7)	0.0% (0/7)
TEN (N=6)	100% (6/6)	0.0% (0/6)	0.0% (0/6)
WPNN (N=9)	77.8% (7/9)	22.2% (2/9)	0.0% (0/9)
YPEN (N=9)	77.8% (7/9)	22.2% (2/9)	0.0% (0/9)

Other services

14.7% (20/136) of Health Boards and Trusts provided commencement of a ketogenic diet service, whilst **19.1% (26/136)** provided the ongoing review of ketogenic diet services, (**Table 19** and **Table 20** respectively).

Figure 8 shows, **9.6% (13/136) of** Health Boards and Trusts provided insertion of a vagal nerve stimulator (VNS) within their locations, whilst **21.3% (29/136)** provided Vagal Nerve Stimulator (VNS) review services. A comparison of Health Boards and Trusts that provided ketogenetic diet and vagal nerve stimulator (VNS) services within their locations in Round 3 April 2018 and Round 3 November 2019 is shown in **Figure 9**.

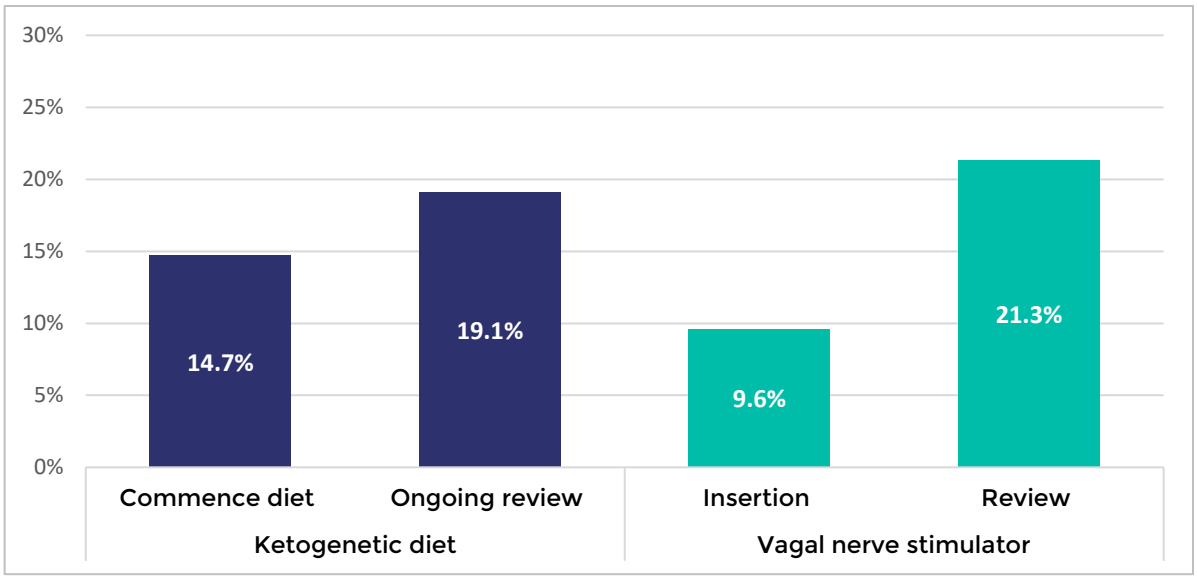


Figure 8: Percentage of Health Boards and Trusts that could provide ketogenetic diet and vagal nerve stimulator.

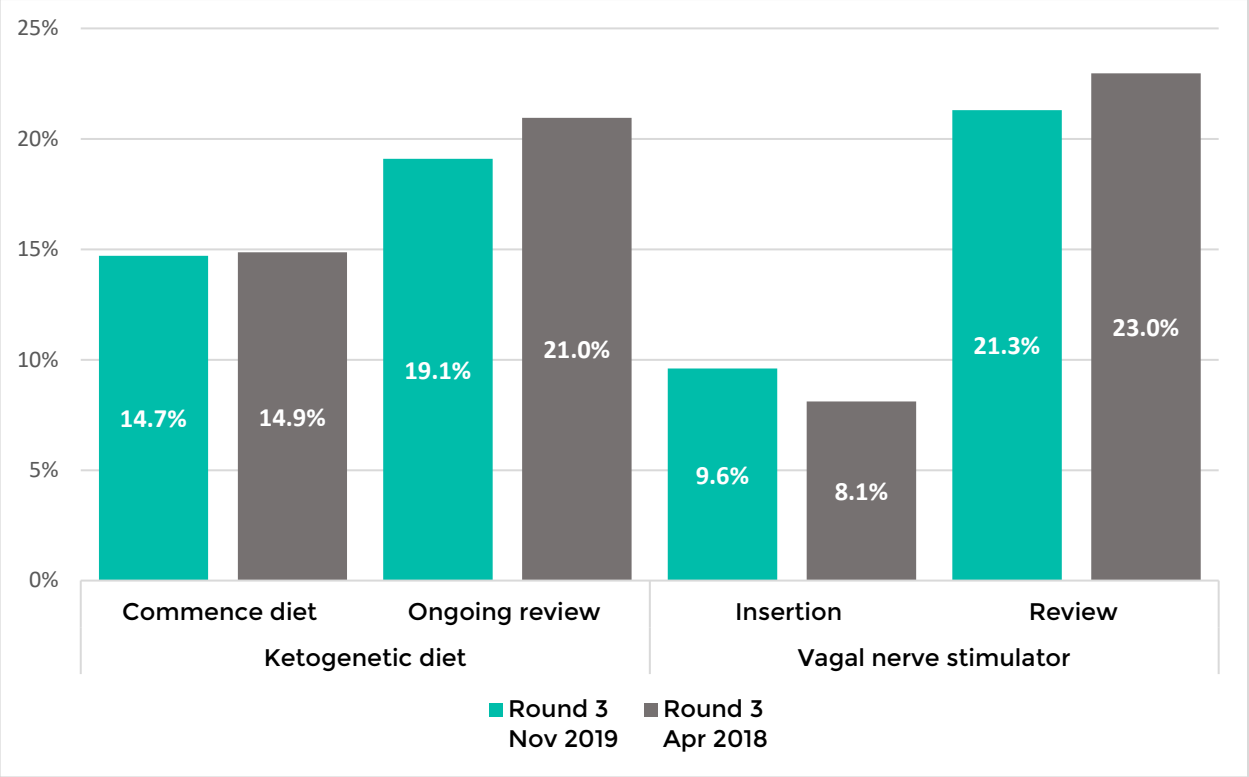


Figure 9: Percentage of Health Boards and Trusts that could provide ketogenetic diet and vagal nerve stimulator services in Round 3 April 2018 and November 2019.

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

Country/network	Yes	No	Uncertain
England and Wales (N=136)	14.7% (20/136)	85.3% (116/136)	0.0% (0/136)
England (N=131)	15.3% (20/131)	84.7% (111/131)	0.0% (0/131)
Wales (N=5)	0.0% (0/5)	100% (5/5)	0.0% (0/5)
BRPNF (N=13)	7.7% (1/13)	92.3% (12/13)	0.0% (0/13)
CEWT (N=5)	60.0% (3/5)	40.0% (2/5)	0.0% (0/5)
EPEN (N=14)	7.1% (1/14)	92.9% (13/14)	0.0% (0/14)
EPIC (N=9)	11.1% (1/9)	88.9% (8/9)	0.0% (0/9)
NTPEN (N=16)	6.3% (1/16)	93.8% (15/16)	0.0% (0/16)
NWEIG (N=12)	16.7% (2/12)	83.3% (10/12)	0.0% (0/12)
ORENG (N=7)	28.6% (2/7)	71.4% (5/7)	0.0% (0/7)
PENNEC (N=8)	12.5% (1/8)	87.5% (7/8)	0.0% (0/8)
SETPEG (N=8)	12.5% (1/8)	87.5% (7/8)	0.0% (0/8)
SWEP (N=4)	0.0% (0/4)	100% (4/4)	0.0% (0/4)
SWIPE (N=9)	22.2% (2/9)	77.8% (7/9)	0.0% (0/9)
SWTPEG (N=7)	14.3% (1/7)	85.7% (6/7)	0.0% (0/7)
TEN (N=6)	16.7% (1/6)	83.3% (5/6)	0.0% (0/6)
WPNN (N=9)	11.1% (1/9)	88.9% (8/9)	0.0% (0/9)
YPEN (N=9)	22.2% (2/9)	77.8% (7/9)	0.0% (0/9)

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

Country/network	Yes	No	Uncertain
England and Wales (N=136)	19.1% (26/136)	80.9% (110/136)	0.0% (0/136)
England (N=131)	19.8% (26/131)	80.2% (105/131)	0.0% (0/131)
Wales (N=5)	0.0% (0/5)	100% (5/5)	0.0% (0/5)
BRPNF (N=13)	7.7% (1/13)	92.3% (12/13)	0.0% (0/13)
CEWT (N=5)	60.0% (3/5)	40.0% (2/5)	0.0% (0/5)
EPEN (N=14)	7.1% (1/14)	92.9% (13/14)	0.0% (0/14)
EPIC (N=9)	11.1% (1/9)	88.9% (8/9)	0.0% (0/9)
NTPEN (N=16)	6.3% (1/16)	93.8% (15/16)	0.0% (0/16)
NWEIG (N=12)	16.7% (2/12)	83.3% (10/12)	0.0% (0/12)
ORENG (N=7)	28.6% (2/7)	71.4% (5/7)	0.0% (0/7)
PENNEC (N=8)	37.5% (3/8)	62.5% (5/8)	0.0% (0/8)
SETPEG (N=8)	12.5% (1/8)	87.5% (7/8)	0.0% (0/8)
SWEP (N=4)	0.0% (0/4)	100% (4/4)	0.0% (0/4)
SWIPE (N=9)	55.6% (5/9)	44.4% (4/9)	0.0% (0/9)
SWTPEG (N=7)	14.3% (1/7)	85.7% (6/7)	0.0% (0/7)
TEN (N=6)	16.7% (1/6)	83.3% (5/6)	0.0% (0/6)
WPNN (N=9)	22.2% (2/9)	77.8% (7/9)	0.0% (0/9)
YPEN (N=9)	22.2% (2/9)	77.8% (7/9)	0.0% (0/9)

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

Country/network	Yes	No	Uncertain
England and Wales (N=136)	9.6% (13/136)	90.4% (123/136)	0.0% (0/136)
England (N=131)	9.9% (13/131)	90.1% (118/131)	0.0% (0/131)
Wales (N=5)	0.0% (0/5)	100% (5/5)	0.0% (0/5)
BRPNF (N=13)	7.7% (1/13)	92.3% (12/13)	0.0% (0/13)
CEWT (N=5)	20.0% (1/5)	80.0% (4/5)	0.0% (0/5)
EPEN (N=14)	7.1% (1/14)	92.9% (13/14)	0.0% (0/14)
EPIC (N=9)	11.1% (1/9)	88.9% (8/9)	0.0% (0/9)
NTPEN (N=16)	6.3% (1/16)	93.8% (15/16)	0.0% (0/16)
NWEIG (N=12)	8.3% (1/12)	91.7% (11/12)	0.0% (0/12)
ORENG (N=7)	14.3% (1/7)	85.7% (6/7)	0.0% (0/7)
PENNEC (N=8)	12.5% (1/8)	87.5% (7/8)	0.0% (0/8)
SETPEG (N=8)	12.5% (1/8)	87.5% (7/8)	0.0% (0/8)
SWEP (N=4)	0.0% (0/4)	100% (4/4)	0.0% (0/4)
SWIPE (N=9)	11.1% (1/9)	88.9% (8/9)	0.0% (0/9)
SWTPEG (N=7)	0.0% (0/7)	100% (7/7)	0.0% (0/7)
TEN (N=6)	16.7% (1/6)	83.3% (5/6)	0.0% (0/6)
WPNN (N=9)	11.1% (1/9)	88.9% (8/9)	0.0% (0/9)
YPEN (N=9)	11.1% (1/9)	88.9% (8/9)	0.0% (0/9)

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

Country/network	Yes	No	Uncertain
England and Wales (N=136)	21.3% (29/136)	78.7% (107/136)	0.0% (0/136)
England (N=131)	19.8% (26/131)	80.2% (105/131)	0.0% (0/131)
Wales (N=5)	60.0% (3/5)	40.0% (2/5)	0.0% (0/5)
BRPNF (N=13)	7.7% (1/13)	92.3% (12/13)	0.0% (0/13)
CEWT (N=5)	40.0% (2/5)	60.0% (3/5)	0.0% (0/5)
EPEN (N=14)	14.3% (2/14)	85.7% (12/14)	0.0% (0/14)
EPIC (N=9)	11.1% (1/9)	88.9% (8/9)	0.0% (0/9)
NTPEN (N=16)	6.3% (1/16)	93.8% (15/16)	0.0% (0/16)
NWEIG (N=12)	25.0% (3/12)	75.0% (9/12)	0.0% (0/12)
ORENG (N=7)	14.3% (1/7)	85.7% (6/7)	0.0% (0/7)
PENNEC (N=8)	25.0% (2/8)	75.0% (6/8)	0.0% (0/8)
SETPEG (N=8)	50.0% (4/8)	50.0% (4/8)	0.0% (0/8)
SWEP (N=4)	75.0% (3/4)	25.0% (1/4)	0.0% (0/4)
SWIPE (N=9)	44.4% (4/9)	55.6% (5/9)	0.0% (0/9)
SWTPEG (N=7)	0.0% (0/7)	100% (7/7)	0.0% (0/7)
TEN (N=6)	33.3% (2/6)	66.7% (4/6)	0.0% (0/6)
WPNN (N=9)	11.1% (1/9)	88.9% (8/9)	0.0% (0/9)
YPEN (N=9)	22.2% (2/9)	77.8% (7/9)	0.0% (0/9)

Investigations

Figure 10 shows the percentage of Health Boards and Trusts offering epilepsy investigation services. **3.7% (5/136)** Health Boards and Trusts were not able to offer 12 lead ECG service. In **40.4% (55/136)** of Health Boards and Trusts, it was not possible to obtain a standard EEG at a location within their Trust, (**Table 23**).

Figure 11 shows a comparison of availability of epilepsy investigation services across England and Wales in Round 3 April 2018 and November 2019.

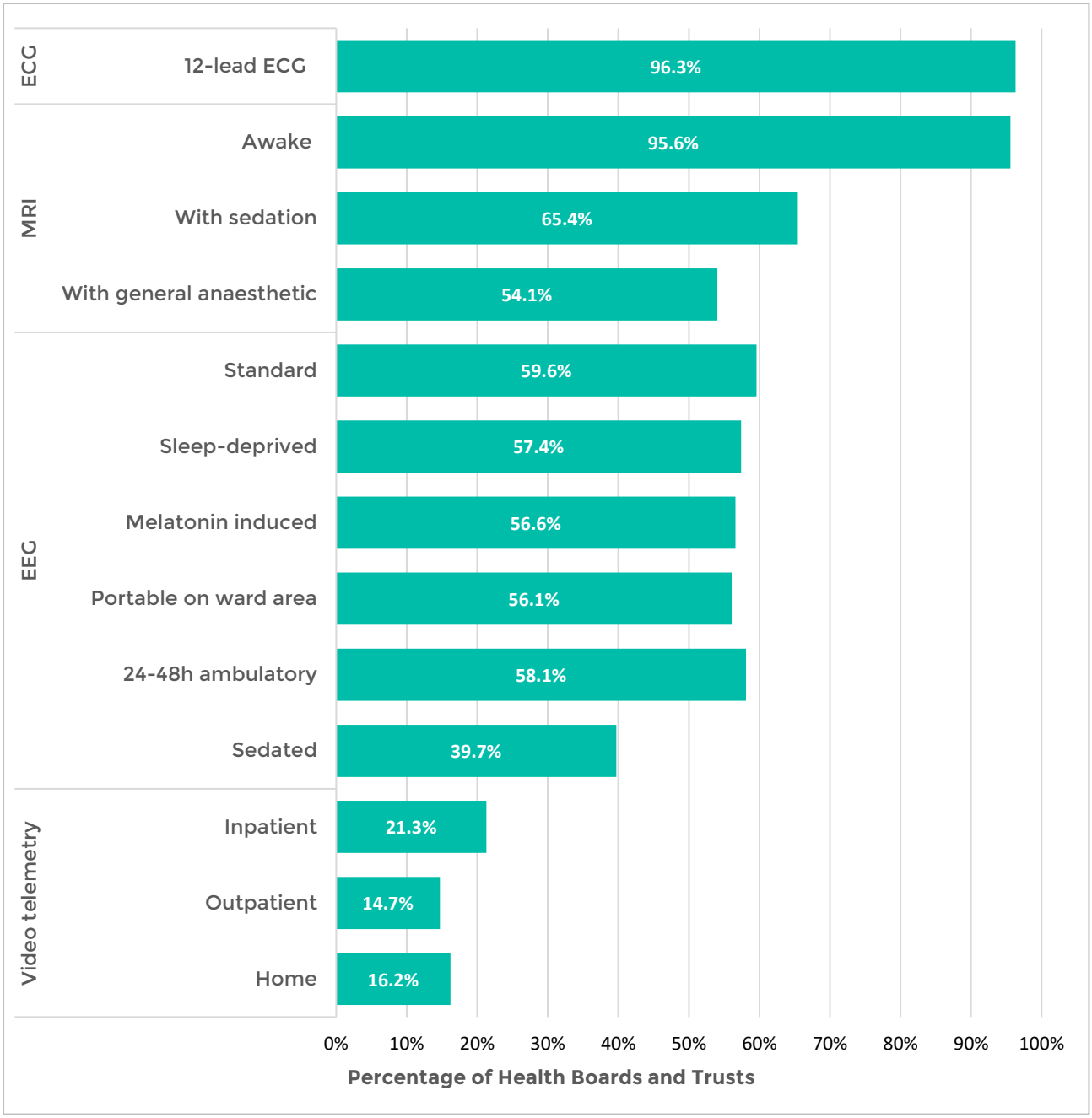


Figure 10: Percentage of Health Boards and Trusts that could provide investigation services (n=136).

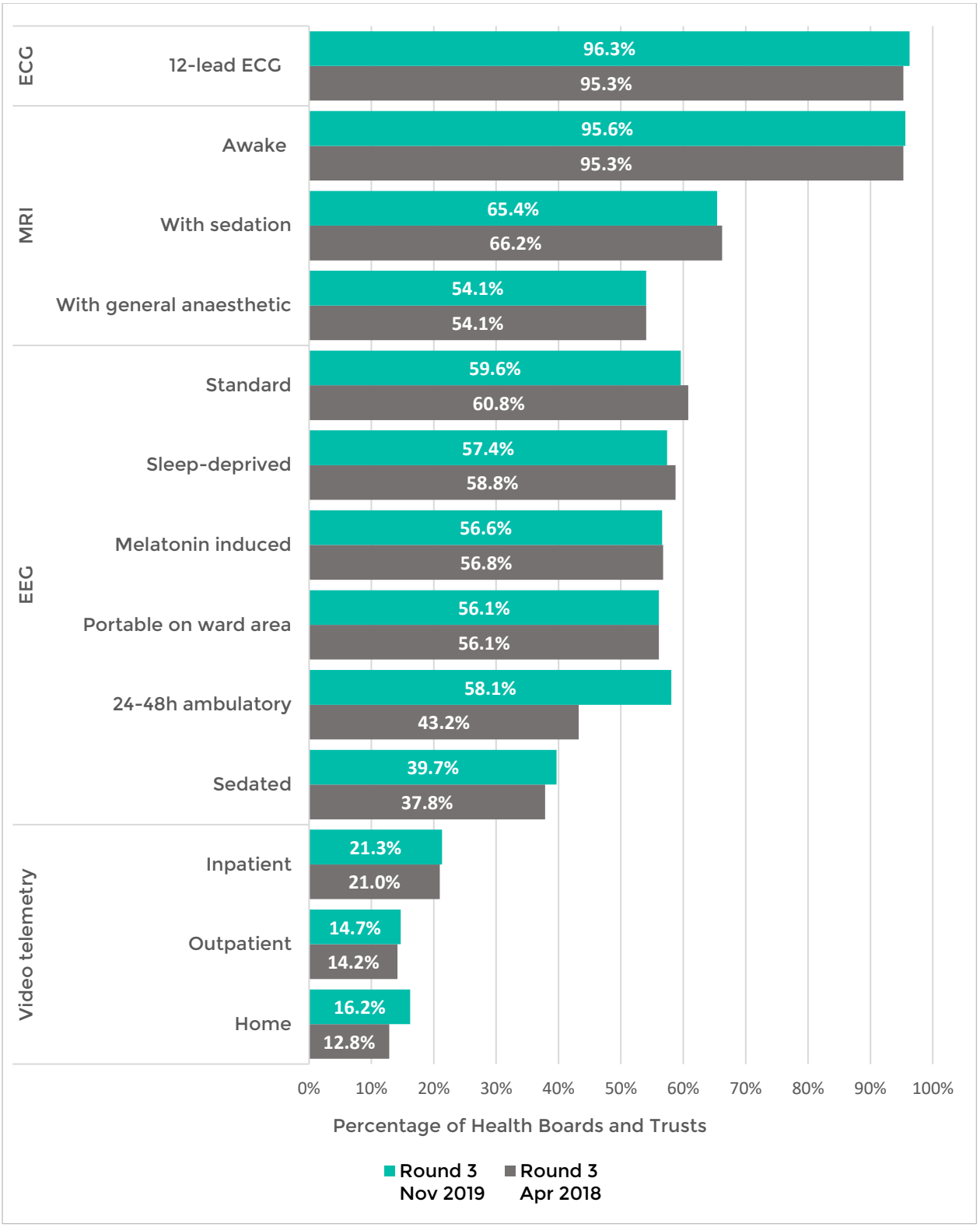


Figure 11: Percentage of Health Boards and Trusts that could provide investigation services in Round 3 April 2018 and November 2019.

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

Country/ network	12-lead ECG			'Awake' MRI			MRI with sedation		
	Yes	No	Uncertain	Yes	No	Uncertain	Yes	No	Uncertain
England and Wales (N=136)	96.3% (131/136)	3.7% (5/136)	0.0% (0/136)	95.6% (130/136)	4.4% (6/136)	0.0% (0/136)	65.4% (89/136)	34.6% (47/136)	0.0% (0/136)
England (N=131)	96.2% (126/131)	3.8% (5/131)	0.0% (0/131)	95.4% (125/131)	4.6% (6/131)	0.0% (0/131)	64.9% (85/131)	35.1% (46/131)	0.0% (0/131)
Wales (N=5)	100% (5/5)	0.0% (0/5)	0.0% (0/5)	100% (5/5)	0.0% (0/5)	0.0% (0/5)	80.0% (4/5)	20.0% (1/5)	0.0% (0/5)
BRPNF (N=13)	92.3% (12/13)	7.7% (1/13)	0.0% (0/13)	84.6% (11/13)	15.4% (2/13)	0.0% (0/13)	61.5% (8/13)	38.5% (5/13)	0.0% (0/13)
CEWT (N=5)	100% (5/5)	0.0% (0/5)	0.0% (0/5)	100% (5/5)	0.0% (0/5)	0.0% (0/5)	100% (5/5)	0.0% (0/5)	0.0% (0/5)
EPEN (N=14)	92.9% (13/14)	7.1% (1/14)	0.0% (0/14)	92.9% (13/14)	7.1% (1/14)	0.0% (0/14)	85.7% (12/14)	14.3% (2/14)	0.0% (0/14)
EPIC (N=9)	100% (9/9)	0.0% (0/9)	0.0% (0/9)	100% (9/9)	0.0% (0/9)	0.0% (0/9)	55.6% (5/9)	44.4% (4/9)	0.0% (0/9)
NTPEN (N=16)	100% (16/16)	0.0% (0/16)	0.0% (0/16)	100% (16/16)	0.0% (0/16)	0.0% (0/16)	93.8% (15/16)	6.3% (1/16)	0.0% (0/16)
NWEIG (N=12)	100% (12/12)	0.0% (0/12)	0.0% (0/12)	100% (12/12)	0.0% (0/12)	0.0% (0/12)	58.3% (7/12)	41.7% (5/12)	0.0% (0/12)
ORENG (N=7)	100% (7/7)	0.0% (0/7)	0.0% (0/7)	100% (7/7)	0.0% (0/7)	0.0% (0/7)	57.1% (4/7)	42.9% (3/7)	0.0% (0/7)
PENNEC (N=8)	100% (8/8)	0.0% (0/8)	0.0% (0/8)	100% (8/8)	0.0% (0/8)	0.0% (0/8)	50.0% (4/8)	50.0% (4/8)	0.0% (0/8)
SETPEG (N=8)	87.5% (7/8)	12.5% (1/8)	0.0% (0/8)	87.5% (7/8)	12.5% (1/8)	0.0% (0/8)	75.0% (6/8)	25.0% (2/8)	0.0% (0/8)
SWEP (N=4)	100% (4/4)	0.0% (0/4)	0.0% (0/4)	100% (4/4)	0.0% (0/4)	0.0% (0/4)	75.0% (3/4)	25.0% (1/4)	0.0% (0/4)
SWIPE (N=9)	100% (9/9)	0.0% (0/9)	0.0% (0/9)	100% (9/9)	0.0% (0/9)	0.0% (0/9)	55.6% (5/9)	44.4% (4/9)	0.0% (0/9)
SWTPEG (N=7)	100% (7/7)	0.0% (0/7)	0.0% (0/7)	100% (7/7)	0.0% (0/7)	0.0% (0/7)	28.6% (2/7)	71.4% (5/7)	0.0% (0/7)
TEN (N=6)	83.3% (5/6)	16.7% (1/6)	0.0% (0/6)	100% (6/6)	0.0% (0/6)	0.0% (0/6)	33.3% (2/6)	66.7% (4/6)	0.0% (0/6)
WPNN (N=9)	88.9% (8/9)	11.1% (1/9)	0.0% (0/9)	88.9% (8/9)	11.1% (1/9)	0.0% (0/9)	66.7% (6/9)	33.3% (3/9)	0.0% (0/9)
YPEN (N=9)	100% (9/9)	0.0% (0/9)	0.0% (0/9)	88.9% (8/9)	11.1% (1/9)	0.0% (0/9)	55.6% (5/9)	44.4% (4/9)	0.0% (0/9)

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

Country/ network	MRI with general anaesthetic			Standard EEG			Sleep deprived EEG		
	Yes	No	Uncertain	Yes	No	Uncertain	Yes	No	Uncertain
England and Wales (N=136)	55.9% (76/136)	44.1% (60/136)	0.0% (0/136)	59.6% (81/136)	40.4% (55/136)	0.0% (0/136)	57.4% (78/136)	42.6% (58/136)	0.0% (0/136)
England (N=131)	54.2% (71/131)	45.8% (60/131)	0.0% (0/131)	58% (76/131)	42.0% (55/131)	0.0% (0/131)	55.7% (73/131)	44.3% (58/131)	0.0% (0/131)
Wales (N=5)	100% (5/5)	0.0% (0/5)	0.0% (0/5)	100% (5/5)	0.0% (0/5)	0.0% (0/5)	100% (5/5)	0.0% (0/5)	0.0% (0/5)
BRPNF (N=13)	30.8% (4/13)	69.2% (9/13)	0.0% (0/13)	53.8% (7/13)	46.2% (6/13)	0.0% (0/13)	53.8% (7/13)	46.2% (6/13)	0.0% (0/13)
CEWT (N=5)	100% (5/5)	0.0% (0/5)	0.0% (0/5)	80.0% (4/5)	20.0% (1/5)	0.0% (0/5)	80.0% (4/5)	20.0% (1/5)	0.0% (0/5)
EPEN (N=14)	71.4% (10/14)	28.6% (4/14)	0.0% (0/14)	50.0% (7/14)	50.0% (7/14)	0.0% (0/14)	50.0% (7/14)	50.0% (7/14)	0.0% (0/14)
EPIC (N=9)	44.4% (4/9)	55.6% (5/9)	0.0% (0/9)	33.3% (3/9)	66.7% (6/9)	0.0% (0/9)	33.3% (3/9)	66.7% (6/9)	0.0% (0/9)
NTPEN (N=16)	43.8% (7/16)	56.3% (9/16)	0.0% (0/16)	62.5% (10/16)	37.5% (6/16)	0.0% (0/16)	62.5% (10/16)	37.5% (6/16)	0.0% (0/16)
NWEIG (N=12)	33.3% (4/12)	66.7% (8/12)	0.0% (0/12)	66.7% (8/12)	33.3% (4/12)	0.0% (0/12)	66.7% (8/12)	33.3% (4/12)	0.0% (0/12)
ORENG (N=7)	71.4% (5/7)	28.6% (2/7)	0.0% (0/7)	42.9% (3/7)	57.1% (4/7)	0.0% (0/7)	42.9% (3/7)	57.1% (4/7)	0.0% (0/7)
PENNEC (N=8)	50.0% (4/8)	50.0% (4/8)	0.0% (0/8)	50.0% (4/8)	50.0% (4/8)	0.0% (0/8)	50.0% (4/8)	50.0% (4/8)	0.0% (0/8)
SETPEG (N=8)	62.5% (5/8)	37.5% (3/8)	0.0% (0/8)	37.5% (3/8)	62.5% (5/8)	0.0% (0/8)	37.5% (3/8)	62.5% (5/8)	0.0% (0/8)
SWEP (N=4)	100% (4/4)	0.0% (0/4)	0.0% (0/4)	100% (4/4)	0.0% (0/4)	0.0% (0/4)	100% (4/4)	0.0% (0/4)	0.0% (0/4)
SWIPE (N=9)	66.7% (6/9)	33.3% (3/9)	0.0% (0/9)	77.8% (7/9)	22.2% (2/9)	0.0% (0/9)	55.6% (5/9)	44.4% (4/9)	0.0% (0/9)
SWTPEG (N=7)	57.1% (4/7)	42.9% (3/7)	0.0% (0/7)	85.7% (6/7)	14.3% (1/7)	0.0% (0/7)	71.4% (5/7)	28.6% (2/7)	0.0% (0/7)
TEN (N=6)	50.0% (3/6)	50.0% (3/6)	0.0% (0/6)	33.3% (2/6)	66.7% (4/6)	0.0% (0/6)	33.3% (2/6)	66.7% (4/6)	0.0% (0/6)
WPNN (N=9)	66.7% (6/9)	33.3% (3/9)	0.0% (0/9)	66.7% (6/9)	33.3% (3/9)	0.0% (0/9)	66.7% (6/9)	33.3% (3/9)	0.0% (0/9)
YPEN (N=9)	55.6% (5/9)	44.4% (4/9)	0.0% (0/9)	77.8% (7/9)	22.2% (2/9)	0.0% (0/9)	77.8% (7/9)	22.2% (2/9)	0.0% (0/9)

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

Country/ network	Melatonin EEG			Sedated EEG			24-48h ambulatory EEG		
	Yes	No	Uncertain	Yes	No	Uncertain	Yes	No	Uncertain
England and Wales (N=136)	56.6% (77/136)	43.4% (59/136)	0.0% (0/136)	39.7% (54/136)	58.8% (80/136)	1.5% (2/136)	40.4% (55/136)	58.8% (80/136)	0.7% (1/136)
England (N=131)	55.7% (73/131)	44.3% (58/131)	0.0% (0/131)	38.2% (50/131)	60.3% (79/131)	1.5% (2/131)	38.2% (50/131)	61.1% (80/131)	0.8% (1/131)
Wales (N=5)	80.0% (4/5)	20.0% (1/5)	0.0% (0/5)	80.0% (4/5)	20.0% (1/5)	0.0% (0/5)	100% (5/5)	0.0% (0/5)	0.0% (0/5)
BRPNF (N=13)	53.8% (7/13)	46.2% (6/13)	0.0% (0/13)	38.5% (5/13)	61.5% (8/13)	0.0% (0/13)	38.5% (5/13)	61.5% (8/13)	0.0% (0/13)
CEWT (N=5)	80.0% (4/5)	20.0% (1/5)	0.0% (0/5)	80.0% (4/5)	20.0% (1/5)	0.0% (0/5)	80.0% (4/5)	20.0% (1/5)	0.0% (0/5)
EPEN (N=14)	42.9% (6/14)	57.1% (8/14)	0.0% (0/14)	7.1% (1/14)	85.7% (12/14)	7.1% (1/14)	28.6% (4/14)	71.4% (10/14)	0.0% (0/14)
EPIC (N=9)	33.3% (3/9)	66.7% (6/9)	0.0% (0/9)	33.3% (3/9)	66.7% (6/9)	0.0% (0/9)	33.3% (3/9)	66.7% (6/9)	0.0% (0/9)
NTPEN (N=16)	56.3% (9/16)	43.8% (7/16)	0.0% (0/16)	43.8% (7/16)	56.3% (9/16)	0.0% (0/16)	12.5% (2/16)	87.5% (14/16)	0.0% (0/16)
NWEIG (N=12)	66.7% (8/12)	33.3% (4/12)	0.0% (0/12)	58.3% (7/12)	41.7% (5/12)	0.0% (0/12)	33.3% (4/12)	66.7% (8/12)	0.0% (0/12)
ORENG (N=7)	42.9% (3/7)	57.1% (4/7)	0.0% (0/7)	42.9% (3/7)	57.1% (4/7)	0.0% (0/7)	42.9% (3/7)	57.1% (4/7)	0.0% (0/7)
PENNEC (N=8)	50.0% (4/8)	50.0% (4/8)	0.0% (0/8)	37.5% (3/8)	62.5% (5/8)	0.0% (0/8)	37.5% (3/8)	50% (4/8)	12.5% (1/8)
SETPEG (N=8)	37.5% (3/8)	62.5% (5/8)	0.0% (0/8)	25.0% (2/8)	75.0% (6/8)	0.0% (0/8)	25.0% (2/8)	75.0% (6/8)	0.0% (0/8)
SWEP (N=4)	75.0% (3/4)	25.0% (1/4)	0.0% (0/4)	75.0% (3/4)	25.0% (1/4)	0.0% (0/4)	100% (4/4)	0.0% (0/4)	0.0% (0/4)
SWIPE (N=9)	66.7% (6/9)	33.3% (3/9)	0.0% (0/9)	55.6% (5/9)	44.4% (4/9)	0.0% (0/9)	44.4% (4/9)	55.6% (5/9)	0.0% (0/9)
SWTPEG (N=7)	85.7% (6/7)	14.3% (1/7)	0.0% (0/7)	14.3% (1/7)	71.4% (5/7)	14.3% (1/7)	28.6% (2/7)	71.4% (5/7)	0.0% (0/7)
TEN (N=6)	33.3% (2/6)	66.7% (4/6)	0.0% (0/6)	33.3% (2/6)	66.7% (4/6)	0.0% (0/6)	33.3% (2/6)	66.7% (4/6)	0.0% (0/6)
WPNN (N=9)	66.7% (6/9)	33.3% (3/9)	0.0% (0/9)	44.4% (4/9)	55.6% (5/9)	0.0% (0/9)	66.7% (6/9)	33.3% (3/9)	0.0% (0/9)
YPEN (N=9)	77.8% (7/9)	22.2% (2/9)	0.0% (0/9)	44.4% (4/9)	55.6% (5/9)	0.0% (0/9)	77.8% (7/9)	22.2% (2/9)	0.0% (0/9)

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

Country/ network	Inpatient Video Telemetry			Outpatient Video Telemetry			Home Video Telemetry		
	Yes	No	Uncertain	Yes	No	Uncertain	Yes	No	Uncertain
England and Wales (N=136)	21.3% (29/136)	78.7% (107/136)	0.0% (0/136)	14.7% (20/136)	83.8% (114/136)	1.5% (2/136)	16.2% (22/136)	82.4% (112/136)	1.5% (2/136)
England (N=131)	20.6% (27/131)	79.4% (104/131)	0.0% (0/131)	14.5% (19/131)	84.7% (111/131)	0.8% (1/131)	15.3% (20/131)	83.2% (109/131)	1.5% (2/131)
Wales (N=5)	40.0% (2/5)	60.0% (3/5)	0.0% (0/5)	20.0% (1/5)	60.0% (3/5)	20.0% (1/5)	40.0% (2/5)	60.0% (3/5)	0.0% (0/5)
BRPNF (N=13)	23.1% (3/13)	76.9% (10/13)	0.0% (0/13)	23.1% (3/13)	76.9% (10/13)	0.0% (0/13)	30.8% (4/13)	69.2% (9/13)	0.0% (0/13)
CEWT (N=5)	60.0% (3/5)	40.0% (2/5)	0.0% (0/5)	20.0% (1/5)	80.0% (4/5)	0.0% (0/5)	0.0% (0/5)	100% (5/5)	0.0% (0/5)
EPEN (N=14)	14.3% (2/14)	85.7% (12/14)	0.0% (0/14)	0.0% (0/14)	92.9% (13/14)	7.1% (1/14)	7.1% (1/14)	92.9% (13/14)	0.0% (0/14)
EPIC (N=9)	22.2% (2/9)	77.8% (7/9)	0.0% (0/9)	22.2% (2/9)	77.8% (7/9)	0.0% (0/9)	22.2% (2/9)	77.8% (7/9)	0.0% (0/9)
NTPEN (N=16)	12.5% (2/16)	87.5% (14/16)	0.0% (0/16)	6.3% (1/16)	93.8% (15/16)	0.0% (0/16)	12.5% (2/16)	87.5% (14/16)	0.0% (0/16)
NWEIG (N=12)	8.3% (1/12)	91.7% (11/12)	0.0% (0/12)	16.7% (2/12)	83.3% (10/12)	0.0% (0/12)	8.3% (1/12)	91.7% (11/12)	0.0% (0/12)
ORENG (N=7)	28.6% (2/7)	71.4% (5/7)	0.0% (0/7)	28.6% (2/7)	71.4% (5/7)	0.0% (0/7)	28.6% (2/7)	71.4% (5/7)	0.0% (0/7)
PENNEC (N=8)	25.0% (2/8)	75.0% (6/8)	0.0% (0/8)	12.5% (1/8)	87.5% (7/8)	0.0% (0/8)	12.5% (1/8)	87.5% (7/8)	0.0% (0/8)
SETPEG (N=8)	25.0% (2/8)	75.0% (6/8)	0.0% (0/8)	25.0% (2/8)	75.0% (6/8)	0.0% (0/8)	37.5% (3/8)	62.5% (5/8)	0.0% (0/8)
SWEP (N=4)	25.0% (1/4)	75.0% (3/4)	0.0% (0/4)	0.0% (0/4)	75.0% (3/4)	25.0% (1/4)	25.0% (1/4)	75.0% (3/4)	0.0% (0/4)
SWIPE (N=9)	33.3% (3/9)	66.7% (6/9)	0.0% (0/9)	11.1% (1/9)	88.9% (8/9)	0.0% (0/9)	11.1% (1/9)	77.8% (7/9)	11.1% (1/9)
SWTPEG (N=7)	14.3% (1/7)	85.7% (6/7)	0.0% (0/7)	14.3% (1/7)	85.7% (6/7)	0.0% (0/7)	14.3% (1/7)	71.4% (5/7)	14.3% (1/7)
TEN (N=6)	16.7% (1/6)	83.3% (5/6)	0.0% (0/6)	16.7% (1/6)	83.3% (5/6)	0.0% (0/6)	16.7% (1/6)	83.3% (5/6)	0.0% (0/6)
WPNN (N=9)	22.2% (2/9)	77.8% (7/9)	0.0% (0/9)	22.2% (2/9)	77.8% (7/9)	0.0% (0/9)	11.1% (1/9)	88.9% (8/9)	0.0% (0/9)
YPEN (N=9)	22.2% (2/9)	77.8% (7/9)	0.0% (0/9)	11.1% (1/9)	88.9% (8/9)	0.0% (0/9)	11.1% (1/9)	88.9% (8/9)	0.0% (0/9)

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

Country/network	Portable EEG on ward area		
	Yes	No	Uncertain
England and Wales (N=136)	58.1% (79/136)	40.4% (55/136)	1.5% (2/136)
England (N=131)	56.5% (74/131)	42.0% (55/131)	1.5% (2/131)
Wales (N=5)	100% (5/5)	0.0% (0/5)	0.0% (0/5)
BRPNF (N=13)	61.5% (8/13)	30.8% (4/13)	7.7% (1/13)
CEWT (N=5)	100% (5/5)	0.0% (0/5)	0.0% (0/5)
EPEN (N=14)	42.9% (6/14)	57.1% (8/14)	0.0% (0/14)
EPIC (N=9)	33.3% (3/9)	66.7% (6/9)	0.0% (0/9)
NTPEN (N=16)	50.0% (8/16)	50.0% (8/16)	0.0% (0/16)
NWEIG (N=12)	58.3% (7/12)	33.3% (4/12)	8.3% (1/12)
ORENG (N=7)	71.4% (5/7)	28.6% (2/7)	0.0% (0/7)
PENNEC (N=8)	50.0% (4/8)	50.0% (4/8)	0.0% (0/8)
SETPEG (N=8)	37.5% (3/8)	62.5% (5/8)	0.0% (0/8)
SWEP (N=4)	100% (4/4)	0.0% (0/4)	0.0% (0/4)
SWIPE (N=9)	66.7% (6/9)	33.3% (3/9)	0.0% (0/9)
SWTPEG (N=7)	85.7% (6/7)	14.3% (1/7)	0.0% (0/7)
TEN (N=6)	50.0% (3/6)	50.0% (3/6)	0.0% (0/6)
WPNN (N=9)	66.7% (6/9)	33.3% (3/9)	0.0% (0/9)
YPEN (N=9)	55.6% (5/9)	44.4% (4/9)	0.0% (0/9)

Service contact

95.6% (130/136) of Health Boards and Trusts were able to provide specialist advice between scheduled reviews across England and Wales, (**Table 24**). **Table 25/Figure 12** shows **48.5% (66/136)** of the Health Boards and Trusts that provided specialist advice during reviews reported that the service was available all weekdays for all 52 weeks of the year.

In **7.4% 10/136** of Health Boards and Trusts this service was available all weekdays and out of hours for 52 weeks of the year. **28.7% (39/136)** Health Boards and Trusts reported to provide this service on every weekday but for a part of the year.

Figure 13 shows a comparison of availability of specialist advice between scheduled reviews in Round 3 April 2018 and November 2019.

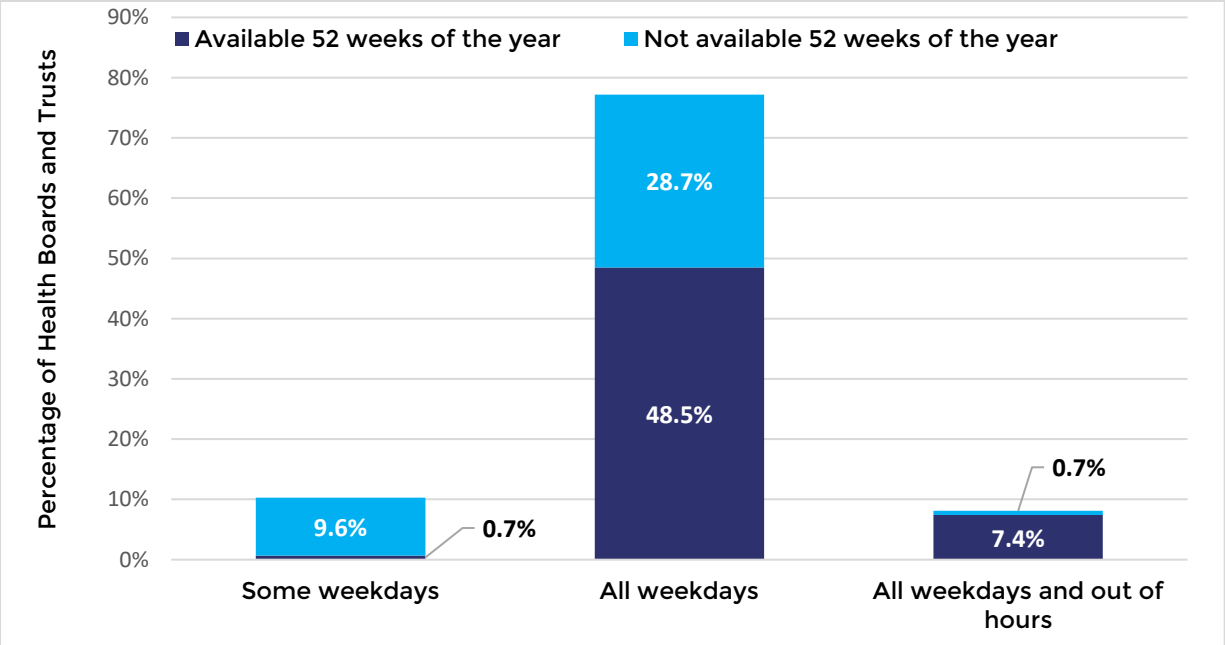


Figure 12: Availability of specialist advice between scheduled reviews (n=136).

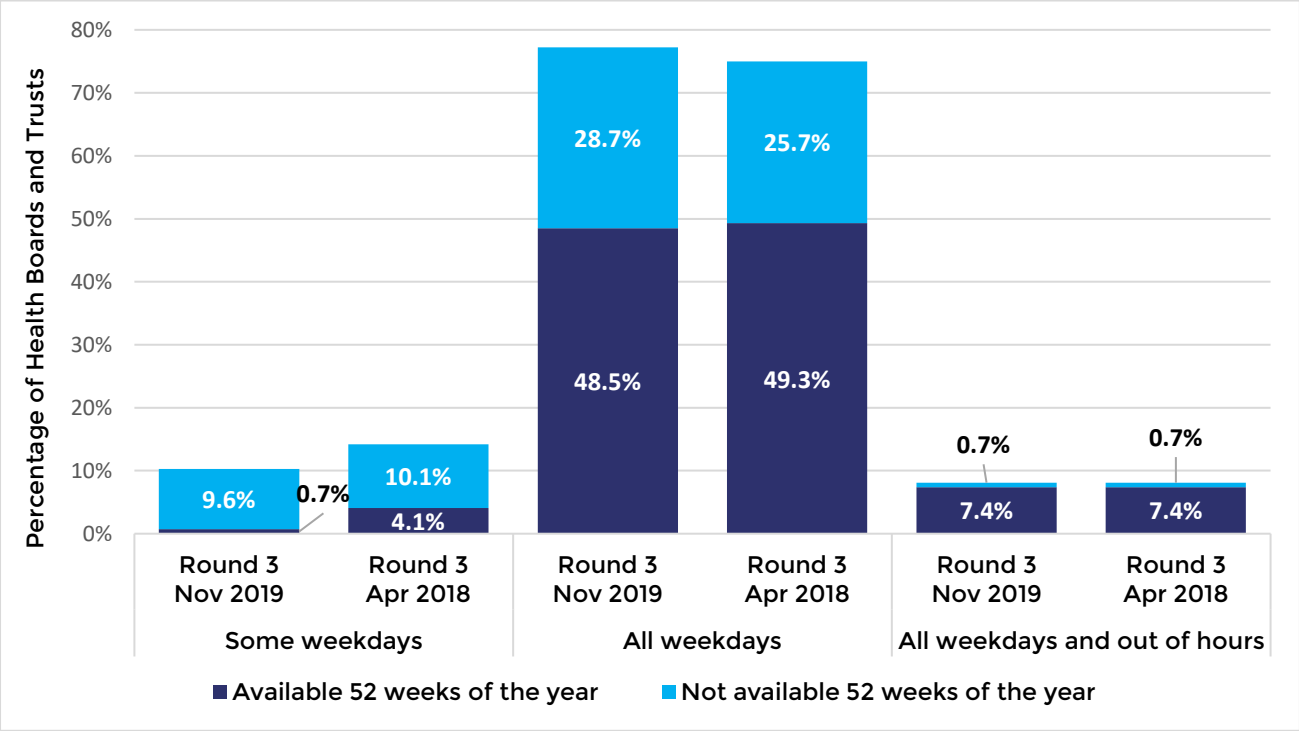


Figure 13: Percentage availability of specialist advice between scheduled reviews in Round 3 April 2018 and November 2019.

52.3% (68/130) of Health Boards and Trusts that reported to provide specialist advice between scheduled reviews described a typical response time of same or next weekday, (**Table 26/Figure 14**).

Figure 15 shows a comparison of the typical response time for specialist advice in Round 3 April 2018 and November 2019. **Table 27/ Figure 16** shows that **46.2% (60/130)** of initial specialist advice was 'typically' provided by an epilepsy specialist nurse and **40.8% (53/130)** were by a consultant paediatrician with expertise in epilepsy.

In the **11.5% (15/136)** 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 (8/130); a combination of all three (5/130); a community paediatrician (1/130); a named or on call paediatrician (1/130).

Figure 17 shows a comparison of professionals who 'typically' provided initial specialist advice in Round 3 April 2018 and November 2019.

76.5% (104/136) 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**).

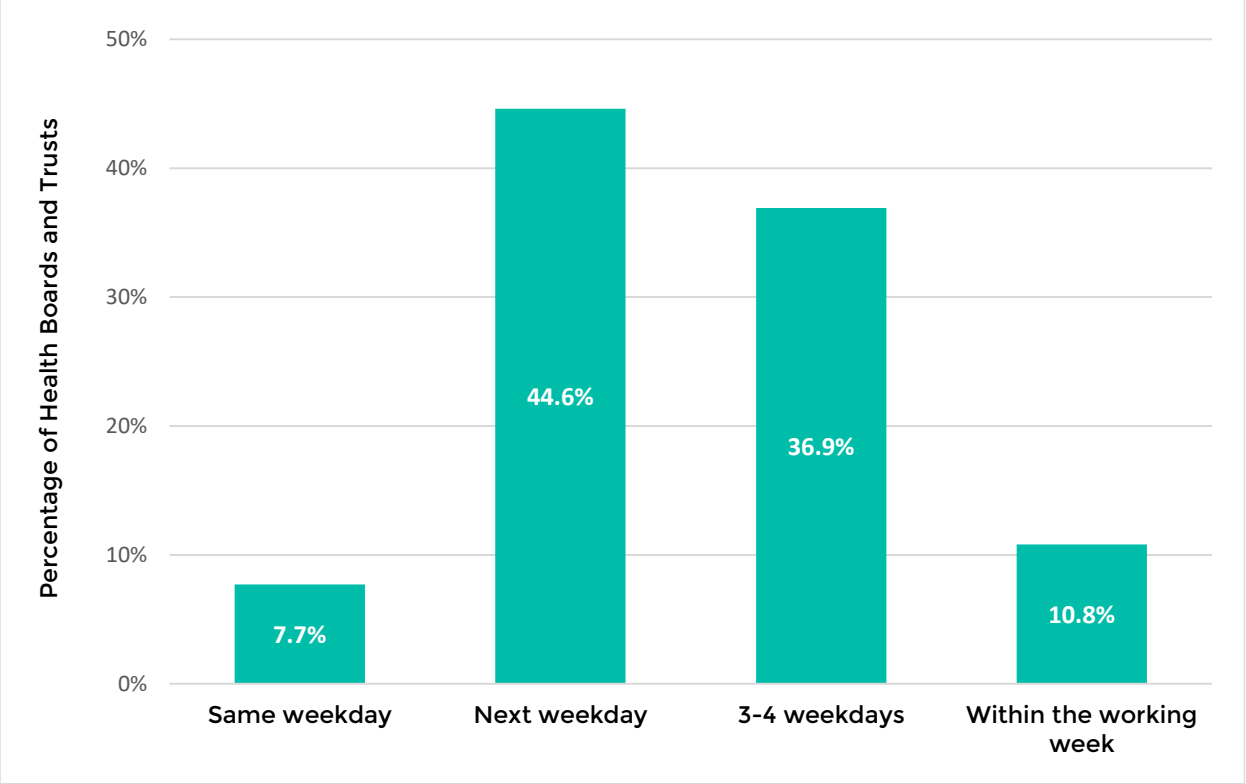


Figure 14: Typical response time for specialist advice (n=130)

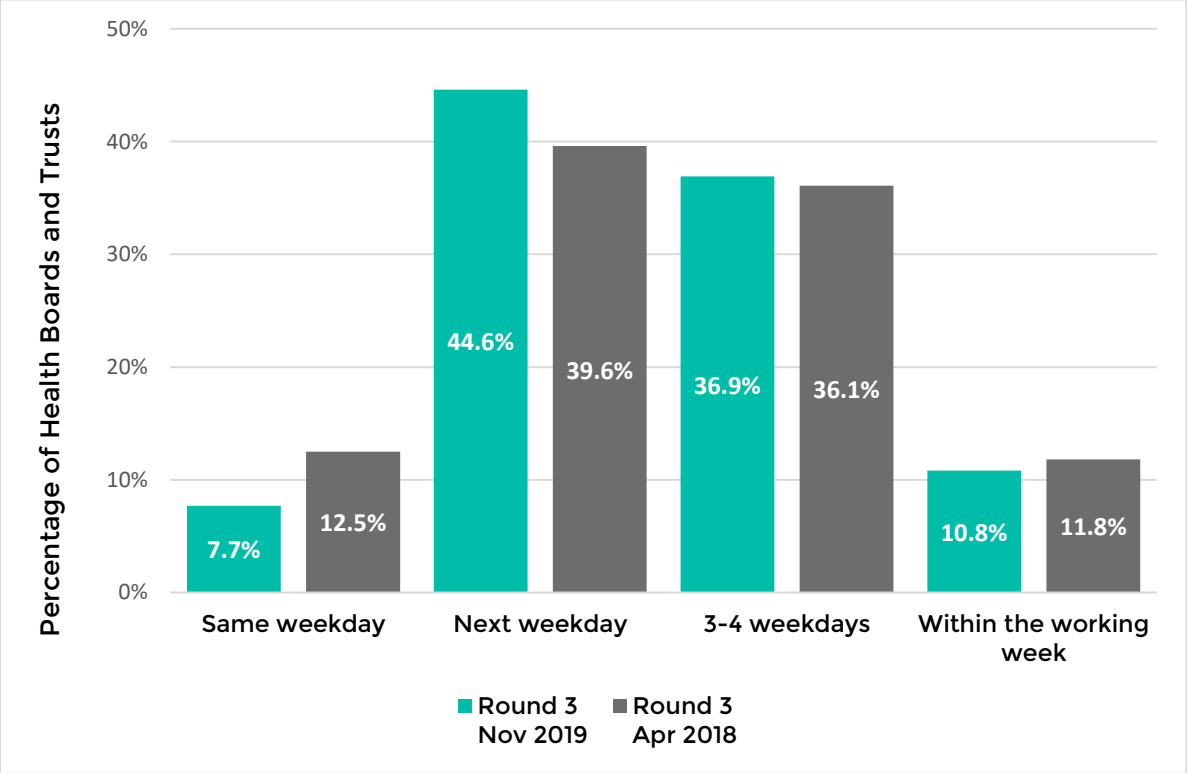


Figure 15:Typical response time for specialist advice in Round 3 April 2018 and November 2019

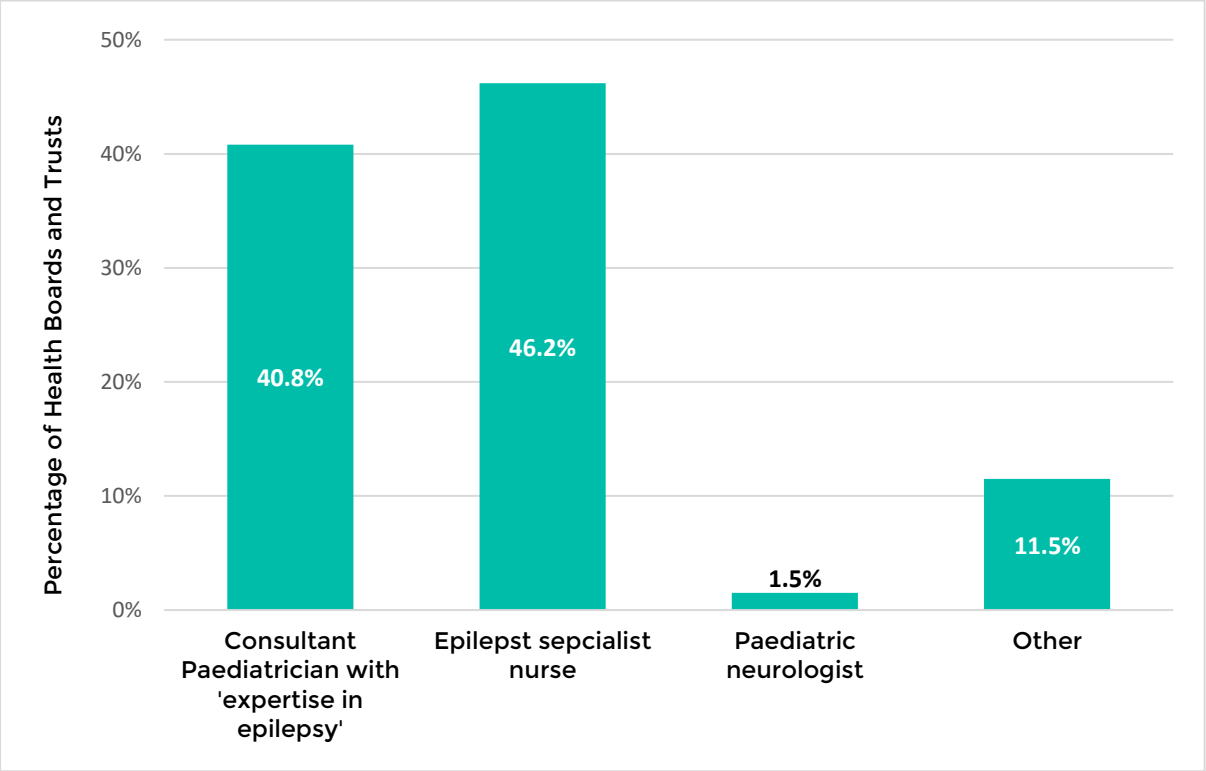


Figure 16: Professional who 'typically' provides initial specialist advice (n=130).

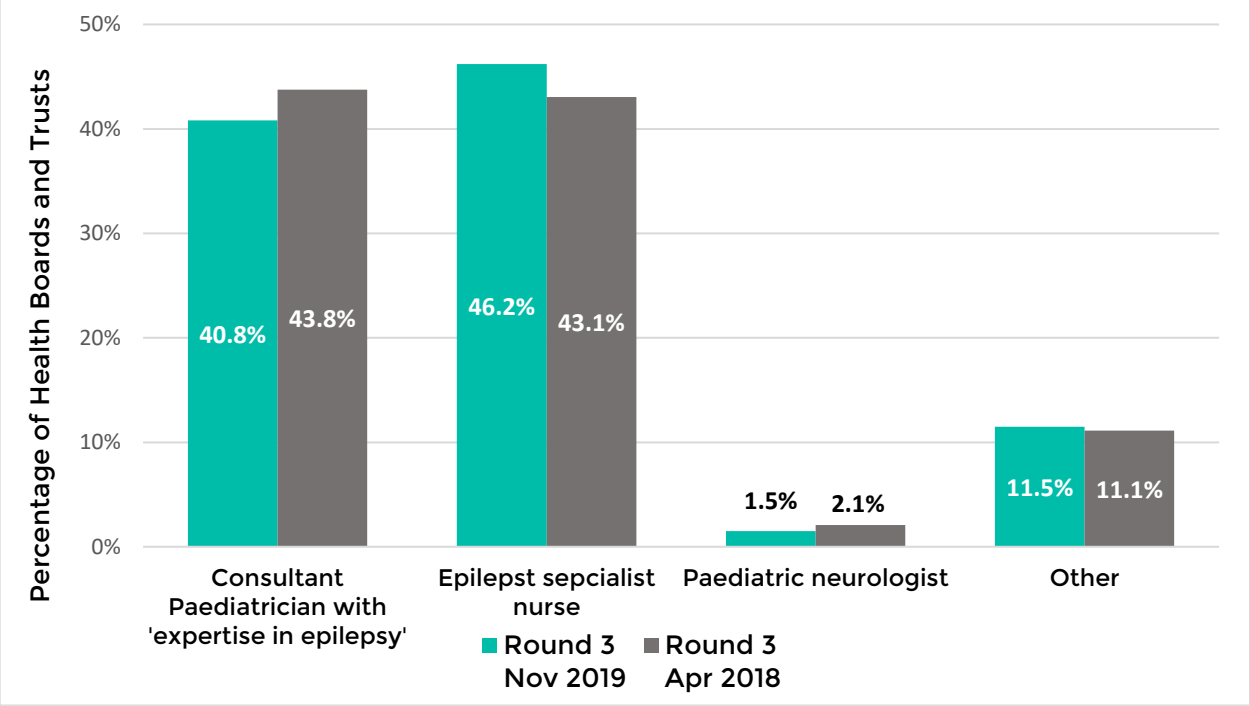


Figure 17: Professional who 'typically' provides initial specialist advice in Round 3 April 2018 and November 2019.

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

Country/network	Yes	No
England and Wales (N=136)	95.6% (130/136)	4.4% (6/136)
England (N=131)	95.4% (125/131)	4.6% (6/131)
Wales (N=5)	100% (5/5)	0.0% (0/5)
BRPNF (N=13)	84.6% (11/13)	15.4% (2/13)
CEWT (N=5)	80.0% (4/5)	20.0% (1/5)
EPEN (N=14)	100% (14/14)	0.0% (0/14)
EPIC (N=9)	100% (9/9)	0.0% (0/9)
NTPEN (N=16)	100% (16/16)	0.0% (0/16)
NWEIG (N=12)	100% (12/12)	0.0% (0/12)
ORENG (N=7)	100% (7/7)	0.0% (0/7)
PENNEC (N=8)	100% (8/8)	0.0% (0/8)
SETPEG (N=8)	87.5% (7/8)	12.5% (1/8)
SWEP (N=4)	100% (4/4)	0.0% (0/4)
SWIPE (N=9)	100% (9/9)	0.0% (0/9)
SWTPEG (N=7)	85.7% (6/7)	14.3% (1/7)
TEN (N=6)	100% (6/6)	0.0% (0/6)
WPNN (N=9)	88.9% (8/9)	11.1% (1/9)
YPEN (N=9)	100% (9/9)	0.0% (0/9)

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

Country/network	Available 52 weeks of the year			Not available 52 weeks of the year		
	Some weekdays	Every weekday	Every weekday and out of hours	Some weekdays	Every weekday	Every weekday and out of hours
England and Wales (N=136)	0.7% (1/136)	48.5% (66/136)	7.4% (10/136)	9.6% (13/136)	28.7% (39/136)	0.7% (1/136)
England (N=131)	0.8% (1/131)	47.3% (62/131)	7.6% (10/131)	9.2% (12/131)	29.8% (39/131)	0.8% (1/131)
Wales (N=5)	0.0% (0/5)	80.0% (4/5)	0.0% (0/5)	20.0% (1/5)	0.0% (0/5)	0.0% (0/5)
BRPNF (N=13)	0.0% (0/13)	38.5% (5/13)	0.0% (0/13)	0.0% (0/13)	46.2% (6/13)	0.0% (0/13)
CEWT (N=5)	0.0% (0/5)	80.0% (4/5)	0.0% (0/5)	0.0% (0/5)	0.0% (0/5)	0.0% (0/5)
EPEN (N=14)	0.0% (0/14)	42.9% (6/14)	0.0% (0/14)	0.0% (0/14)	57.1% (8/14)	0.0% (0/14)
EPIC (N=9)	0.0% (0/9)	77.8% (7/9)	0.0% (0/9)	11.1% (1/9)	11.1% (1/9)	0.0% (0/9)
NTPEN (N=16)	0.0% (0/16)	43.8% (7/16)	12.5% (2/16)	12.5% (2/16)	31.3% (5/16)	0.0% (0/16)
NWEIG (N=12)	0.0% (0/12)	75.0% (9/12)	8.3% (1/12)	8.3% (1/12)	8.3% (1/12)	0.0% (0/12)
ORENG (N=7)	0.0% (0/7)	57.1% (4/7)	14.3% (1/7)	0.0% (0/7)	28.6% (2/7)	0.0% (0/7)
PENNEC (N=8)	12.5% (1/8)	25.0% (2/8)	25.0% (2/8)	12.5% (1/8)	25.0% (2/8)	0.0% (0/8)
SETPEG (N=8)	0.0% (0/8)	25.0% (2/8)	0.0% (0/8)	0.0% (0/8)	62.5% (5/8)	0.0% (0/8)
SWEP (N=4)	0.0% (0/4)	75.0% (3/4)	0.0% (0/4)	25.0% (1/4)	0.0% (0/4)	0.0% (0/4)
SWIPE (N=9)	0.0% (0/9)	22.2% (2/9)	11.1% (1/9)	66.7% (6/9)	0.0% (0/9)	0.0% (0/9)
SWTPEG (N=7)	0.0% (0/7)	14.3% (1/7)	14.3% (1/7)	14.3% (1/7)	28.6% (2/7)	14.3% (1/7)
TEN (N=6)	0.0% (0/6)	33.3% (2/6)	33.3% (2/6)	0.0% (0/6)	33.3% (2/6)	0.0% (0/6)
WPNN (N=9)	0.0% (0/9)	55.6% (5/9)	0.0% (0/9)	0.0% (0/9)	33.3% (3/9)	0.0% (0/9)
YPEN (N=9)	0.0% (0/9)	77.8% (7/9)	0.0% (0/9)	0.0% (0/9)	22.2% (2/9)	0.0% (0/9)

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=130)	7.7% (10/130)	44.6% (58/130)	36.9% (48/130)	10.8% (14/130)
England (N=125)	8.0% (10/125)	45.6% (57/125)	36.0% (45/125)	10.4% (13/125)
Wales (N=5)	0.0% (0/5)	20.0% (1/5)	60.0% (3/5)	20.0% (1/5)
BRPNF (N=11)	0.0% (0/11)	36.4% (4/11)	45.5% (5/11)	18.2% (2/11)
CEWT (N=4)	25.0% (1/4)	50.0% (2/4)	25.0% (1/4)	0.0% (0/4)
EPEN (N=14)	0.0% (0/14)	42.9% (6/14)	50.0% (7/14)	7.1% (1/14)
EPIC (N=9)	0.0% (0/9)	66.7% (6/9)	22.2% (2/9)	11.1% (1/9)
NTPEN (N=16)	18.8% (3/16)	31.3% (5/16)	25.0% (4/16)	25.0% (4/16)
NWEIG (N=12)	8.3% (1/12)	66.7% (8/12)	25.0% (3/12)	0.0% (0/12)
ORENG (N=7)	28.6% (2/7)	42.9% (3/7)	14.3% (1/7)	14.3% (1/7)
PENNEC (N=8)	0.0% (0/8)	50.0% (4/8)	25.0% (2/8)	25.0% (2/8)
SETPEG (N=7)	0.0% (0/7)	42.9% (3/7)	42.9% (3/7)	14.3% (1/7)
SWEP (N=4)	0.0% (0/4)	0.0% (0/4)	75.0% (3/4)	25.0% (1/4)
SWIPE (N=9)	11.1% (1/9)	33.3% (3/9)	44.4% (4/9)	11.1% (1/9)
SWTPEG (N=6)	0.0% (0/6)	83.3% (5/6)	16.7% (1/6)	0.0% (0/6)
TEN (N=6)	0.0% (0/6)	33.3% (2/6)	66.7% (4/6)	0.0% (0/6)
WPNN (N=8)	12.5% (1/8)	25.0% (2/8)	62.5% (5/8)	0.0% (0/8)
YPEN (N=9)	11.1% (1/9)	55.6% (5/9)	33.3% (3/9)	0.0% (0/9)

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

Country/network	ESN	Consultant with 'expertise in epilepsy'	Paediatric neurologist	Other
England and Wales (N=130)	46.2% (60/130)	40.8% (53/130)	1.5% (2/130)	11.5% (15/130)
England (N=125)	46.4% (58/125)	40.0% (50/125)	1.6% (2/125)	12.0% (15/125)
Wales (N=5)	40.0% (2/5)	60.0% (3/5)	0.0% (0/5)	0.0% (0/5)
BRPNF (N=11)	27.3% (3/11)	45.5% (5/11)	0.0% (0/11)	27.3% (3/11)
CEWT (N=4)	50.0% (2/4)	0.0% (0/4)	25.0% (1/4)	25.0% (1/4)
EPEN (N=14)	50.0% (7/14)	50.0% (7/14)	0.0% (0/14)	0.0% (0/14)
EPIC (N=9)	66.7% (6/9)	33.3% (3/9)	0.0% (0/9)	0.0% (0/9)
NTPEN (N=16)	50.0% (8/16)	43.8% (7/16)	6.3% (1/16)	0.0% (0/16)
NWEIG (N=12)	41.7% (5/12)	50.0% (6/12)	0.0% (0/12)	8.3% (1/12)
ORENG (N=7)	57.1% (4/7)	28.6% (2/7)	0.0% (0/7)	14.3% (1/7)
PENNEC (N=8)	25.0% (2/8)	75.0% (6/8)	0.0% (0/8)	0.0% (0/8)
SETPEG (N=7)	57.1% (4/7)	14.3% (1/7)	0.0% (0/7)	28.6% (2/7)
SWEP (N=4)	50.0% (2/4)	50.0% (2/4)	0.0% (0/4)	0.0% (0/4)
SWIPE (N=9)	33.3% (3/9)	44.4% (4/9)	0.0% (0/9)	22.2% (2/9)
SWTPEG (N=6)	50.0% (3/6)	33.3% (2/6)	0.0% (0/6)	16.7% (1/6)
TEN (N=6)	33.3% (2/6)	50.0% (3/6)	0.0% (0/6)	16.7% (1/6)
WPNN (N=8)	62.5% (5/8)	25.0% (2/8)	0.0% (0/8)	12.5% (1/8)
YPEN (N=9)	44.4% (4/9)	33.3% (3/9)	0.0% (0/9)	22.2% (2/9)

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=136)	76.5% (104/136)	23.5% (32/136)
England (N=131)	75.6% (99/131)	24.4% (32/131)
Wales (N=5)	100% (5/5)	0.0% (0/5)
BRPNF (N=13)	61.5% (8/13)	38.5% (5/13)
CEWT (N=5)	60.0% (3/5)	40.0% (2/5)
EPEN (N=14)	85.7% (12/14)	14.3% (2/14)
EPIC (N=9)	88.9% (8/9)	11.1% (1/9)
NTPEN (N=16)	81.3% (13/16)	18.8% (3/16)
NWEIG (N=12)	91.7% (11/12)	8.3% (1/12)
ORENG (N=7)	71.4% (5/7)	28.6% (2/7)
PENNEC (N=8)	50.0% (4/8)	50.0% (4/8)
SETPEG (N=8)	75.0% (6/8)	25.0% (2/8)
SWEP (N=4)	100% (4/4)	0.0% (0/4)
SWIPE (N=9)	77.8% (7/9)	22.2% (2/9)
SWTPEG (N=7)	71.4% (5/7)	28.6% (2/7)
TEN (N=6)	83.3% (5/6)	16.7% (1/6)
WPNN (N=9)	66.7% (6/9)	33.3% (3/9)
YPEN (N=9)	77.8% (7/9)	22.2% (2/9)

Transition

Table 29 shows **20.6% (28/136)** of Health Boards and Trusts did not have agreed referral pathway for young people to adult services. **36.8% (50/136) of** Health Boards and Trusts had an outpatient clinic specifically for young people with epilepsies, (**Table 30**). The median age of acceptance of young people into adult clinics was 15 years with a minimum acceptance age of 11 years and a maximum acceptance age of 18 as shown on **Table 31**.

Figure 18 shows the proportion of Health Boards and Trusts with specific outpatient clinic for 'young people' with epilepsies in Rounds 1, Round 2, Round 3 April 2018 and November 2019.

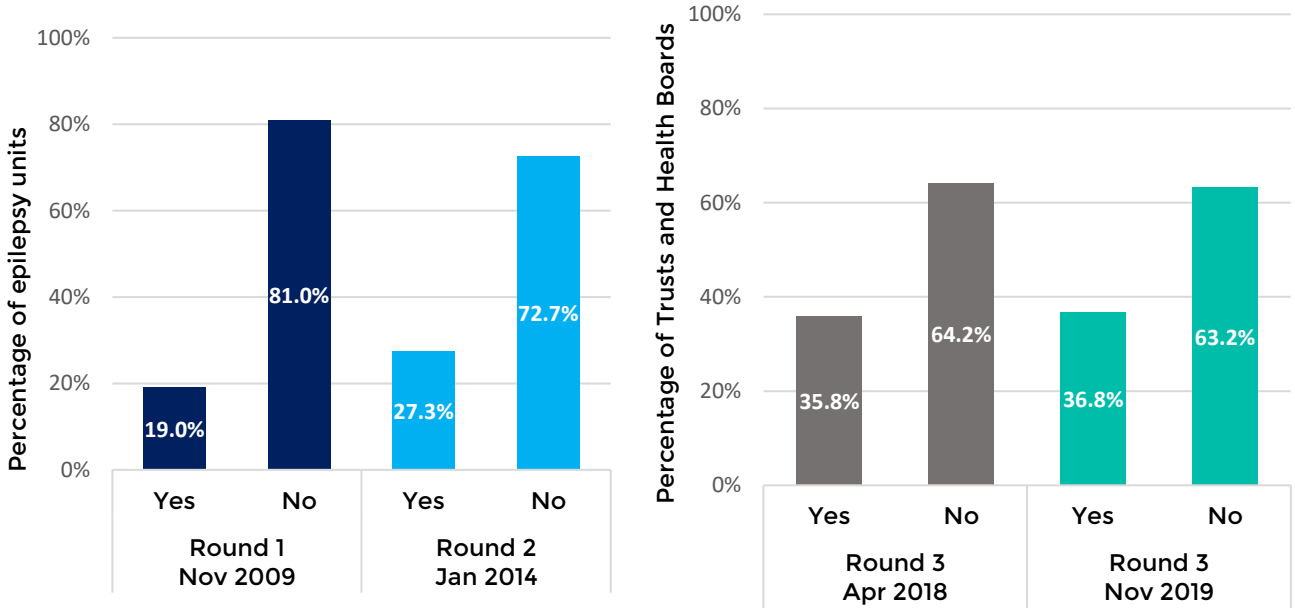


Figure 18: Clinics for young people across Rounds 1, Round 2, Round 3 April 2018 and Round 3 November 2019.

55.9% (76/136) Health Boards and Trusts reported to have outpatient service for epilepsy where there is a presence of both adult and paediatric professionals. **Figure 19/Table 33** shows **53.9% (41/76)** had single joint appointments, **9.2% (7/76)** have a series of several joint appointments, **27.6% (21/76)** have a flexible approach that included a mixture of joint or individual reviews. 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 /Sees Neurologist/back to paediatrics for final appointment.

Figure 20 shows a comparison of composition of joint transition in Round 3 April 2018 and November 2019. The mean of the percentage of young people transferred to adult services who transitioned through the joint professional process was **72.1%**. This ranged from **1% to 100%** as shown in **Table 34**.

Table 35/ Figure 23 shows **58.1% (79/136)** of Health Boards and Trusts, used structured resources (for example Ready, Steady, Go) to support transition to adult services.

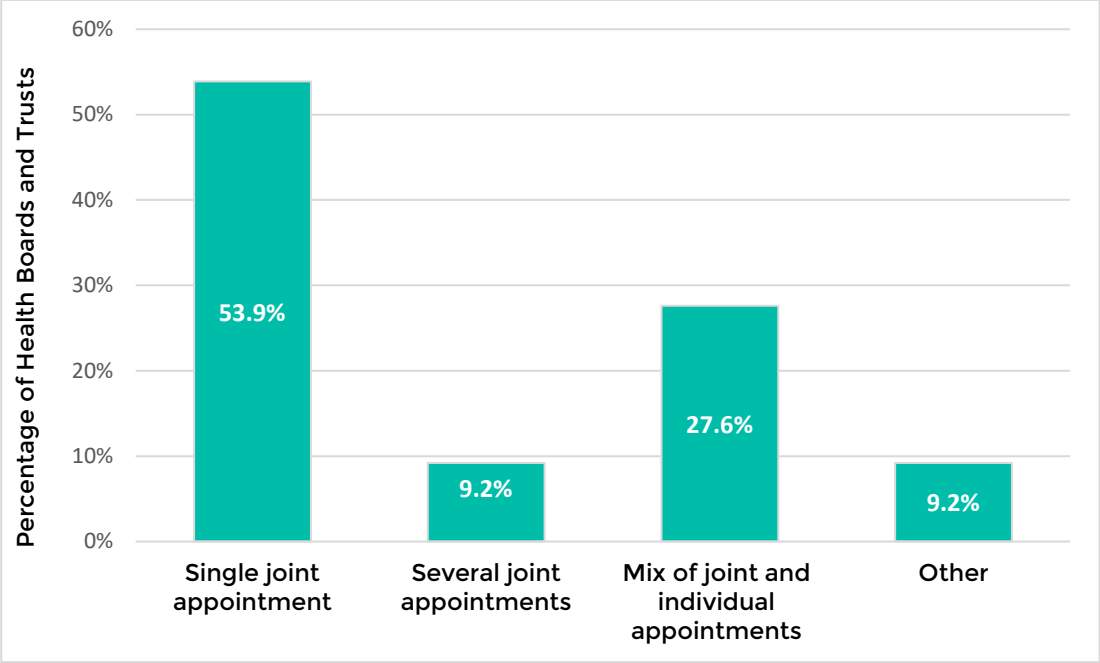


Figure 19: Composition of the joint transition process (n=76).

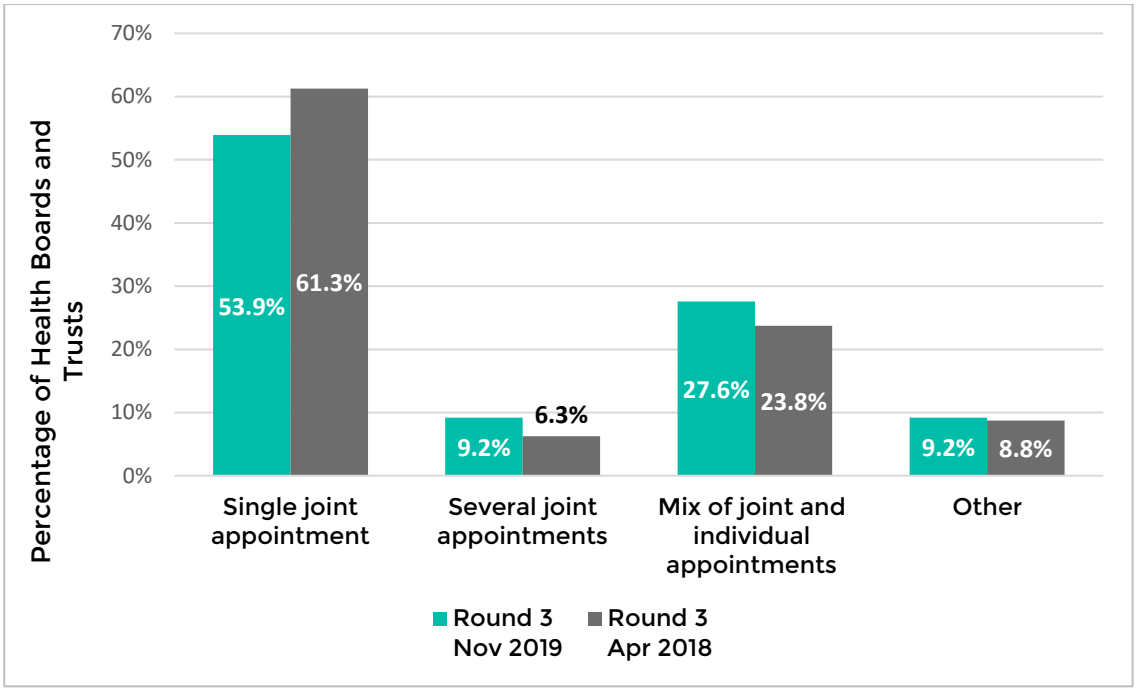


Figure 20: Composition of the joint transition process in Round 3 April 2018 and November 2019.

Figure 21 shows the various professionals who were routinely involved in transition or transfer to adult services. A majority of the Health Boards and Trusts **83.8% (114/136)** had an adult neurologist supporting transition to adult services, whilst **54.4% (74/136)** had an adult ESN supporting the transition as shown on **Table 36**. Other responses included:

- Adult Learning Disability Consultant,
- Adult Learning Disability Psychiatrist,
- Consultant Psychiatrist,
- GP,
- GP and Adult Neurologist,
- GP with Epilepsy interest,
- Education or social care,
- Adult Learning Disability team,
- Adult Learning Disability team/ adult rehab/ GP,
- discussion with adult neurologist and neurophysiologist in Neurophysiology meeting,
- Learning Disability transition nurses,
- specific young people transition clinic with adult neurology, paediatric neurology and adult ESN - run by a different Trust,
- Youth worker from an epilepsy charity may attend,
- Learning Disability Partnership
- Transition nurses,

- Details of neurology specialist nurse contact and often offer ESN appointment at neuro hospital.

Figure 22 shows a comparison of professionals who were routinely involved in transition or transfer to adult services in Round 3 April 2018 and November 2019.

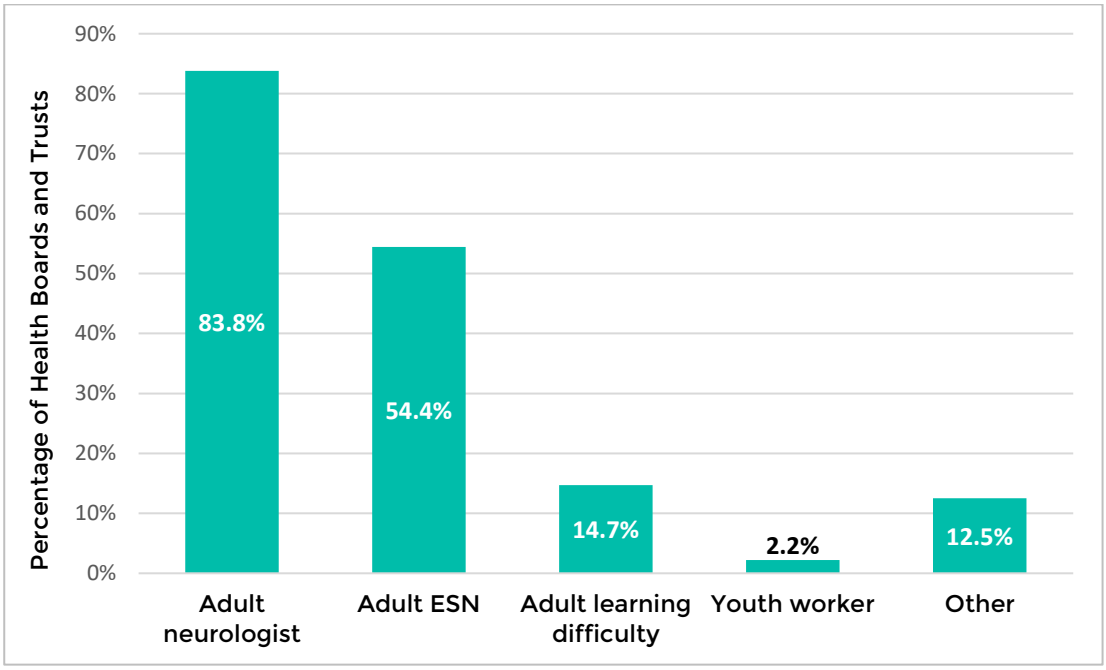


Figure 21: Professionals routinely involved in transition or transfer to adult services (n=136).

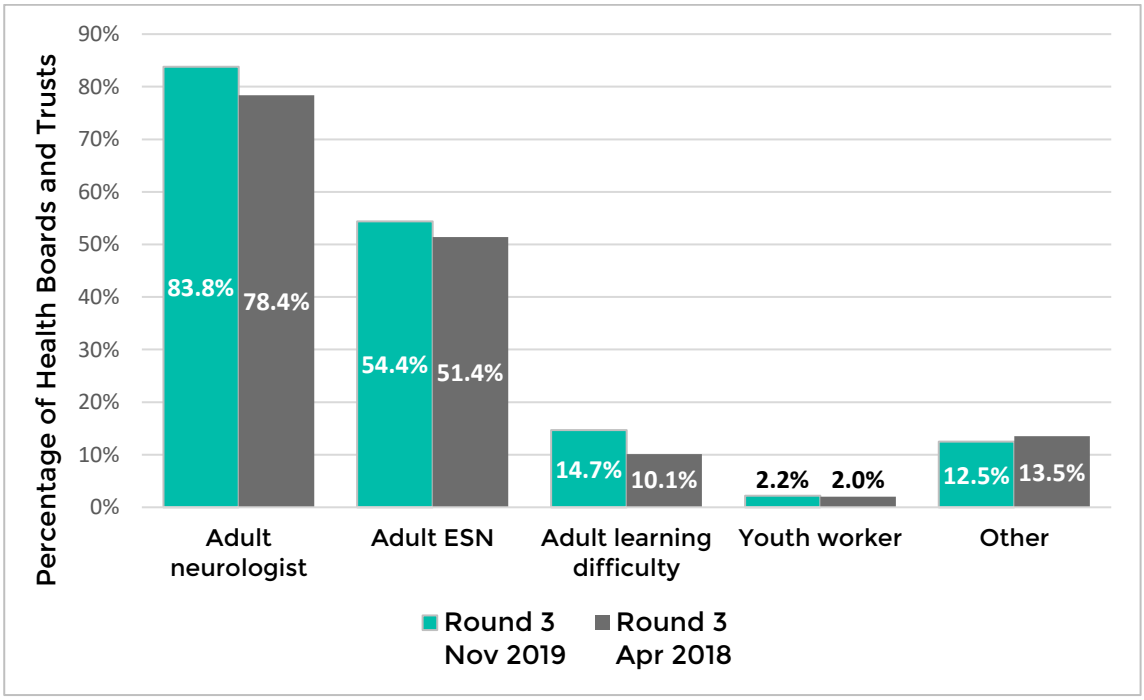


Figure 22: Professionals routinely involved in transition or transfer to adult services in Round 3 April 2018 and November 2019.

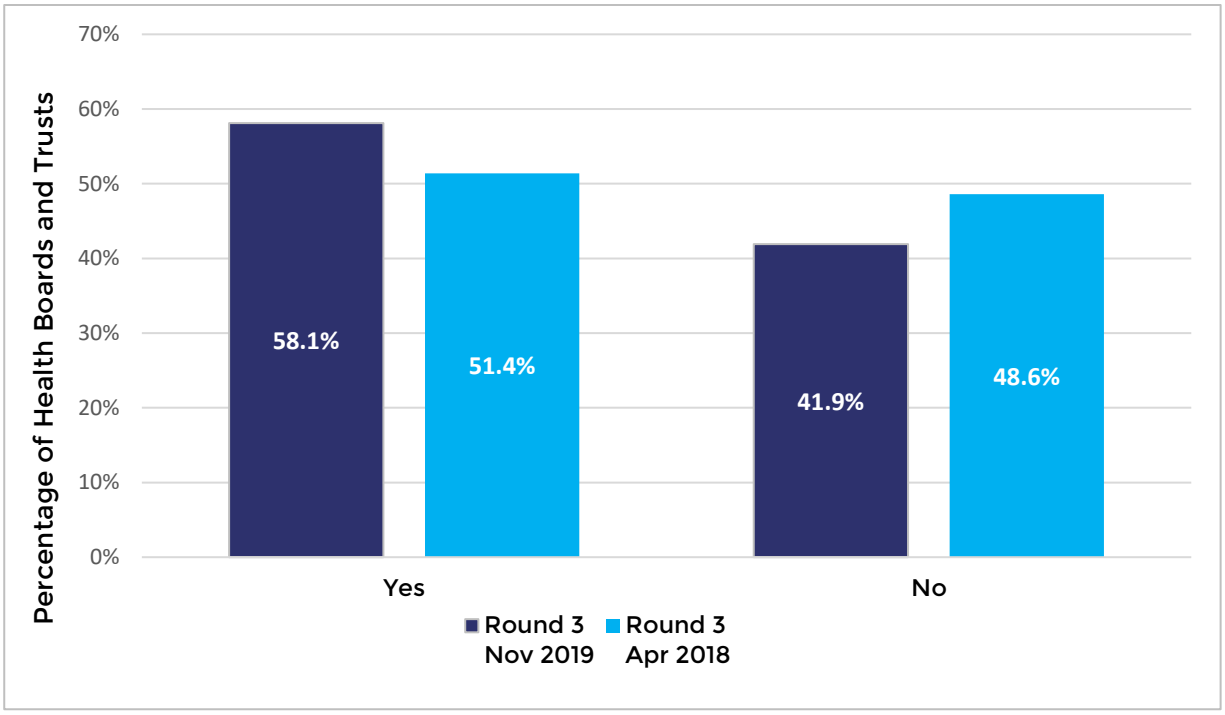


Figure 23: Percentage of Health Boards and Trusts that were using structured resources to support transition in Round 3 April 2018 and November 2019.

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

Country/network	Yes	No
England and Wales (N=136)	79.4% (108/136)	20.6% (28/136)
England (N=131)	79.4% (104/131)	20.6% (27/131)
Wales (N=5)	80.0% (4/5)	20.0% (1/5)
BRPNF (N=13)	61.5% (8/13)	38.5% (5/13)
CEWT (N=5)	80.0% (4/5)	20.0% (1/5)
EPEN (N=14)	92.9% (13/14)	7.1% (1/14)
EPIC (N=9)	88.9% (8/9)	11.1% (1/9)
NTPEN (N=16)	75.0% (12/16)	25.0% (4/16)
NWEIG (N=12)	75.0% (9/12)	25.0% (3/12)
ORENG (N=7)	85.7% (6/7)	14.3% (1/7)
PENNEC (N=8)	62.5% (5/8)	37.5% (3/8)
SETPEG (N=8)	75.0% (6/8)	25.0% (2/8)
SWEP (N=4)	75.0% (3/4)	25.0% (1/4)
SWIPE (N=9)	66.7% (6/9)	33.3% (3/9)
SWTPEG (N=7)	100% (7/7)	0.0% (0/7)
TEN (N=6)	83.3% (5/6)	16.7% (1/6)
WPNN (N=9)	77.8% (7/9)	22.2% (2/9)
YPEN (N=9)	100% (9/9)	0.0% (0/9)

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

Country/network	Yes	No
England and Wales (N=136)	36.8% (50/136)	63.2% (86/136)
England (N=131)	37.4% (49/131)	62.6% (82/131)
Wales (N=5)	20.0% (1/5)	80.0% (4/5)
BRPNF (N=13)	38.5% (5/13)	61.5% (8/13)
CEWT (N=5)	60.0% (3/5)	40.0% (2/5)
EPEN (N=14)	57.1% (8/14)	42.9% (6/14)
EPIC (N=9)	22.2% (2/9)	77.8% (7/9)
NTPEN (N=16)	31.3% (5/16)	68.8% (11/16)
NWEIG (N=12)	50.0% (6/12)	50.0% (6/12)
ORENG (N=7)	28.6% (2/7)	71.4% (5/7)
PENNEC (N=8)	12.5% (1/8)	87.5% (7/8)
SETPEG (N=8)	50.0% (4/8)	50.0% (4/8)
SWEP (N=4)	25.0% (1/4)	75.0% (3/4)
SWIPE (N=9)	33.3% (3/9)	66.7% (6/9)
SWTPEG (N=7)	42.9% (3/7)	57.1% (4/7)
TEN (N=6)	16.7% (1/6)	83.3% (5/6)
WPNN (N=9)	55.6% (5/9)	44.4% (4/9)
YPEN (N=9)	11.1% (1/9)	88.9% (8/9)

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=50)	14.7	15.0	11	18
England (N=49)	14.6	15.0	11	18
Wales (N=1)	16.0	16.0	16	16
BRPNF (N=5)	14.8	14.0	14	16
CEWT (N=3)	13.0	13.0	12	14
EPEN (N=8)	14.8	15.0	13	16
EPIC (N=2)	14.0	14.0	14	14
NTPEN (N=5)	14.6	15.0	12	17
NWEIG (N=6)	13.7	14.0	12	16
ORENG (N=2)	16.0	16.0	16	16
PENNEC (N=1)	14.0	14.0	14	14
SETPEG (N=4)	16.0	16.0	15	17
SWEP (N=1)	16.0	16.0	16	16
SWIPE (N=3)	16.7	16.0	16	18
SWTPEG (N=3)	14.7	16.0	12	16
TEN (N=1)	11.0	11.0	11	11
WPNN (N=5)	14.6	14.0	13	16
YPEN (N=1)	15.0	15.0	15	15

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

Country/network	Yes	No
England and Wales (N=136)	55.9% (76/136)	44.1% (60/136)
England (N=131)	55.0% (72/131)	45.0% (59/131)
Wales (N=5)	80.0% (4/5)	20.0% (1/5)
BRPNF (N=13)	61.5% (8/13)	38.5% (5/13)
CEWT (N=5)	60.0% (3/5)	40.0% (2/5)
EPEN (N=14)	50.0% (7/14)	50.0% (7/14)
EPIC (N=9)	44.4% (4/9)	55.6% (5/9)
NTPEN (N=16)	68.8% (11/16)	31.3% (5/16)
NWEIG (N=12)	66.7% (8/12)	33.3% (4/12)
ORENG (N=7)	71.4% (5/7)	28.6% (2/7)
PENNEC (N=8)	12.5% (1/8)	87.5% (7/8)
SETPEG (N=8)	50.0% (4/8)	50.0% (4/8)
SWEP (N=4)	75.0% (3/4)	25.0% (1/4)
SWIPE (N=9)	66.7% (6/9)	33.3% (3/9)
SWTPEG (N=7)	71.4% (5/7)	28.6% (2/7)
TEN (N=6)	16.7% (1/6)	83.3% (5/6)
WPNN (N=9)	55.6% (5/9)	44.4% (4/9)
YPEN (N=9)	55.6% (5/9)	44.4% (4/9)

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=76)	9.2% (7/76)	53.9% (41/76)	27.6% (21/76)	9.2% (7/76)
England (N=72)	9.7% (7/72)	55.6% (40/72)	25.0% (18/72)	9.7% (7/72)
Wales (N=4)	0.0% (0/4)	25.0% (1/4)	75.0% (3/4)	0.0% (0/4)
BRPNF (N=8)	12.5% (1/8)	62.5% (5/8)	25.0% (2/8)	0.0% (0/8)
CEWT (N=3)	66.7% (2/3)	0.0% (0/3)	0.0% (0/3)	33.3% (1/3)
EPEN (N=7)	0.0% (0/7)	42.9% (3/7)	42.9% (3/7)	14.3% (1/7)
EPIC (N=4)	0.0% (0/4)	50.0% (2/4)	25.0% (1/4)	25.0% (1/4)
NTPEN (N=11)	9.1% (1/11)	63.6% (7/11)	18.2% (2/11)	9.1% (1/11)
NWEIG (N=8)	0.0% (0/8)	87.5% (7/8)	12.5% (1/8)	0.0% (0/8)
ORENG (N=5)	0.0% (0/5)	60.0% (3/5)	40.0% (2/5)	0.0% (0/5)
PENNEC (N=1)	0.0% (0/1)	100% (1/1)	0.0% (0/1)	0.0% (0/1)
SETPEG (N=4)	0.0% (0/4)	50.0% (2/4)	50.0% (2/4)	0.0% (0/4)
SWEP (N=3)	0.0% (0/3)	33.3% (1/3)	66.7% (2/3)	0.0% (0/3)
SWIPE (N=6)	0.0% (0/6)	33.3% (2/6)	66.7% (4/6)	0.0% (0/6)
SWTPEG (N=5)	20.0% (1/5)	20.0% (1/5)	20.0% (1/5)	40.0% (2/5)
TEN (N=1)	0.0% (0/1)	0.0% (0/1)	0.0% (0/1)	100% (1/1)
WPNN (N=5)	40.0% (2/5)	40.0% (2/5)	20.0% (1/5)	0.0% (0/5)
YPEN (N=5)	0.0% (0/5)	100% (5/5)	0.0% (0/5)	0.0% (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=76)	72.1%	1.0%	100.0%
England (N=72)	73.0%	1.0%	100.0%
Wales (N=4)	56.3%	30.0%	80.0%
BRPNF (N=8)	79.4%	10.0%	100.0%
CEWT (N=3)	43.3%	30.0%	70.0%
EPEN (N=7)	79.8%	1.0%	100.0%
EPIC (N=4)	75.0%	20.0%	100.0%
NTPEN (N=11)	65.1%	1.0%	100.0%
NWEIG (N=8)	75.8%	50.0%	100.0%
ORENG (N=5)	81.0%	40.0%	95.0%
PENNEC (N=1)	100.0%	100.0%	100.0%
SETPEG (N=4)	72.5%	50.0%	100.0%
SWEP (N=3)	48.3%	30.0%	65.0%
SWIPE (N=6)	58.3%	10.0%	90.0%
SWTPEG (N=5)	86.0%	50.0%	100.0%
TEN (N=1)	100.0%	100.0%	100.0%
WPNN (N=5)	60.0%	25.0%	100.0%
YPEN (N=5)	83.0%	55.0%	100.0%

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

Country/network	Yes	No
England and Wales (N=136)	58.1% (79/136)	41.9% (57/136)
England (N=131)	59.5% (78/131)	40.5% (53/131)
Wales (N=5)	20.0% (1/5)	80.0% (4/5)
BRPNF (N=13)	46.2% (6/13)	53.8% (7/13)
CEWT (N=5)	60.0% (3/5)	40.0% (2/5)
EPEN (N=14)	64.3% (9/14)	35.7% (5/14)
EPIC (N=9)	22.2% (2/9)	77.8% (7/9)
NTPEN (N=16)	43.8% (7/16)	56.3% (9/16)
NWEIG (N=12)	75.0% (9/12)	25.0% (3/12)
ORENG (N=7)	57.1% (4/7)	42.9% (3/7)
PENNEC (N=8)	62.5% (5/8)	37.5% (3/8)
SETPEG (N=8)	37.5% (3/8)	62.5% (5/8)
SWEP (N=4)	25.0% (1/4)	75.0% (3/4)
SWIPE (N=9)	88.9% (8/9)	11.1% (1/9)
SWTPEG (N=7)	71.4% (5/7)	28.6% (2/7)
TEN (N=6)	66.7% (4/6)	33.3% (2/6)
WPNN (N=9)	66.7% (6/9)	33.3% (3/9)
YPEN (N=9)	77.8% (7/9)	22.2% (2/9)

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=136)	54.4% (74/136)	14.7% (20/136)	83.8% (114/136)	2.2% (3/136)	12.5% (17/136)
England (N=131)	53.4% (70/131)	13% (17/131)	83.2% (109/131)	2.3% (3/131)	11.5% (15/131)
Wales (N=5)	80.0% (4/5)	60.0% (3/5)	100% (5/5)	0.0% (0/5)	40.0% (2/5)
BRPNF (N=13)	38.5% (5/13)	7.7% (1/13)	76.9% (10/13)	0.0% (0/13)	7.7% (1/13)
CEWT (N=5)	80.0% (4/5)	20.0% (1/5)	60.0% (3/5)	0.0% (0/5)	0.0% (0/5)
EPEN (N=14)	50.0% (7/14)	21.4% (3/14)	92.9% (13/14)	14.3% (2/14)	28.6% (4/14)
EPIC (N=9)	33.3% (3/9)	0.0% (0/9)	88.9% (8/9)	0.0% (0/9)	33.3% (3/9)
NTPEN (N=16)	37.5% (6/16)	0.0% (0/16)	93.8% (15/16)	0.0% (0/16)	6.3% (1/16)
NWEIG (N=12)	58.3% (7/12)	0.0% (0/12)	66.7% (8/12)	0.0% (0/12)	0.0% (0/12)
ORENG (N=7)	85.7% (6/7)	57.1% (4/7)	100% (7/7)	0.0% (0/7)	14.3% (1/7)
PENNEC (N=8)	37.5% (3/8)	25.0% (2/8)	75.0% (6/8)	0.0% (0/8)	25.0% (2/8)
SETPEG (N=8)	50.0% (4/8)	12.5% (1/8)	100% (8/8)	0.0% (0/8)	0.0% (0/8)
SWEP (N=4)	75.0% (3/4)	75.0% (3/4)	100% (4/4)	0.0% (0/4)	50.0% (2/4)
SWIPE (N=9)	66.7% (6/9)	22.2% (2/9)	55.6% (5/9)	0.0% (0/9)	0.0% (0/9)
SWTPEG (N=7)	57.1% (4/7)	14.3% (1/7)	100% (7/7)	0.0% (0/7)	0.0% (0/7)
TEN (N=6)	83.3% (5/6)	0.0% (0/6)	83.3% (5/6)	0.0% (0/6)	0.0% (0/6)
WPNN (N=9)	66.7% (6/9)	11.1% (1/9)	88.9% (8/9)	11.1% (1/9)	22.2% (2/9)
YPEN (N=9)	55.6% (5/9)	11.1% (1/9)	77.8% (7/9)	0.0% (0/9)	11.1% (1/9)

Mental health

Figure 24 shows the proportion of Health Boards and Trusts that routinely provide formal screening services. **77.2% (105/136)** of Health Boards and Trusts undertook no formal screening for Attention Deficit Hyperactivity Disorder (ADHD), Autistic Spectrum Disorder (ASD) or mental health disorders. Only **14.7% (20/136)** Health Boards and Trusts routinely provide formal screening services for mental health disorders (**Table 37**).

Figure 25 shows the comparison of formal screening services in Round 3 April 2018 and November 2019.

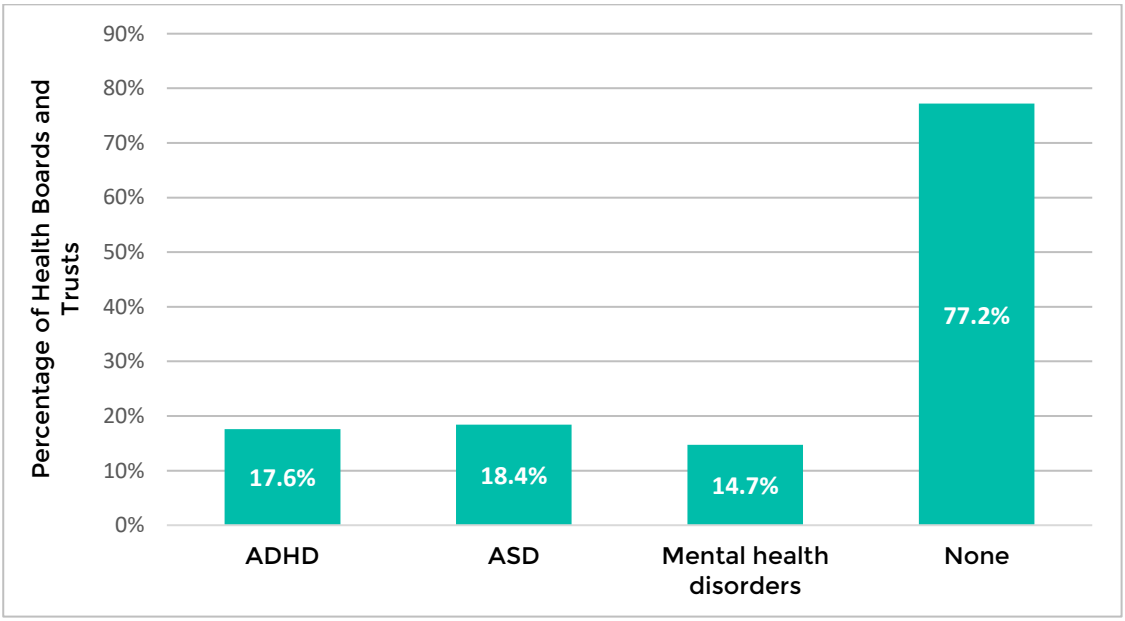


Figure 24: Percentage of Health Boards and Trusts routinely providing formal screening services (n=136).

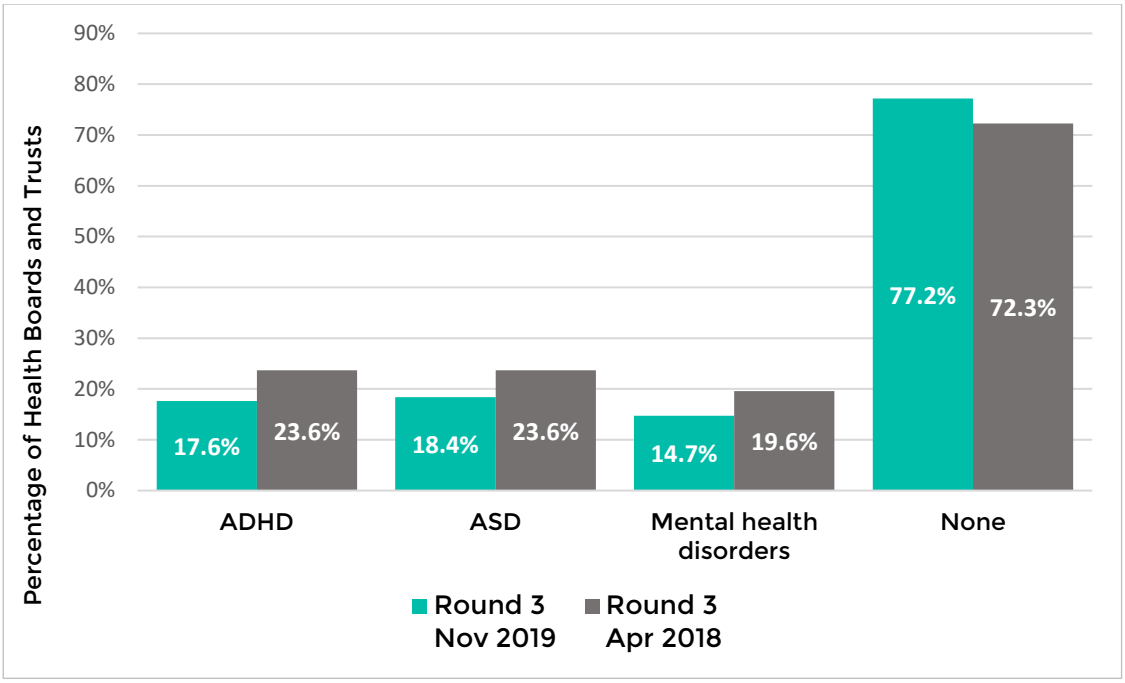


Figure 25: Percentage of Health Boards and Trusts routinely providing formal screening services in Round 3 April 2018 and November 2019

41.9% (57/136) of Health Boards 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 (8.1%)** Connor's Questionnaire,
- **10 (7.4%)** SDQ (Strength and Difficulties Questionnaire),
- **7 (5.1%)** Other,

Other responses included:

- Five point locally made questionnaire,
- NICE signs and symptoms of ASD checklist,
- PI-ED,
- SNAP4,
- Social skills teacher questionnaire,
- York Questionnaire, Vanderbilt and department behaviour assessment questionnaire,
- Wellness questionnaire,

Figure 26 shows the proportion of Health Boards and Trusts that had agreed referral pathways for children and young people with mental health concerns. **42.6% (58/136)** of Health Boards and Trusts did not have agreed referral pathways for children with mental health concerns. **54.4% (74/136)** of Health Boards and Trusts had agreed referral pathways for children with anxiety; **55.1% (75/136)** for depression; **54.4% (74/136)** for mood disorder; **37.5% (51/136)** for non-epileptic attack disorder, **6.6% (9/136)** for other mental health concerns (**Table 39**).

Other responses included:

- Attention Deficit Hyperactivity Disorder (ADHD),
- Behavioural and emotional,
- No agreed pathway, but we refer to Healthy Young Minds when we have these concerns,
- Not specific to epilepsy,
- Referral to Local Healthy Young Minds team,
- A flexible approach with in-house mental health and adolescent medicine teams,
- Referral to psychology for difficulty in coping with diagnosis for patient and family
- Referral to CAMHS for other mental health concerns,
- Tics or Tourette's.

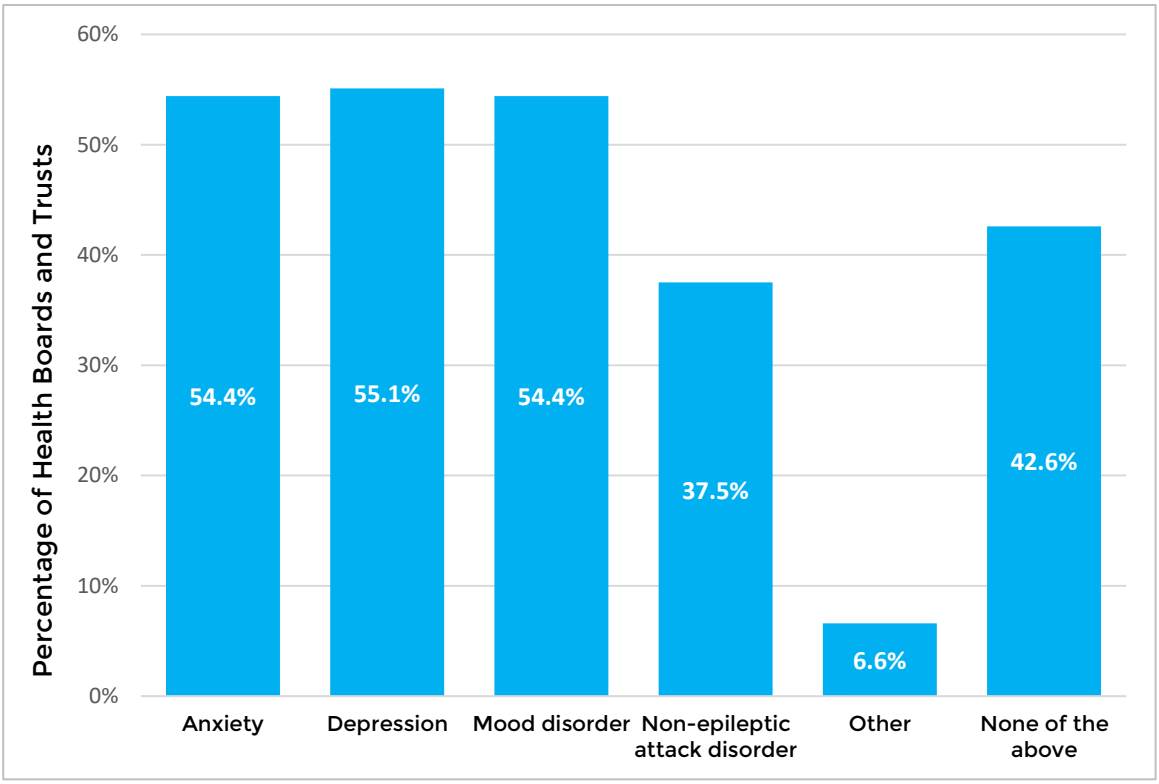


Figure 26: Percentage of Health Boards and Trusts with agreed referral pathways for children with mental health concerns (n=136)

14.0% 19/136 Health Boards and Trusts were able to facilitate mental health provision within epilepsy clinics, (**Table 40**). 10 of these had epilepsy clinics where mental health professionals can provide direct co-located clinical care and 12 had MDT meetings where epilepsy and mental health professionals discuss individual patients, (**Table 41**).

7.7% (9/117) of the Health Boards and Trusts that were not able to facilitate mental health provision within epilepsy clinics had an action plan describing steps towards co-located mental health provision, (**Table 42**).

Figure 27 (below) shows the percentage of Health Boards and Trusts that could refer children and young people to mental health services, either within or outside of your Health Board and Trust where required. **79.4% (108/136)** of Health Boards and Trusts were able to refer to clinical psychology services; **92.6% (126/136)** to psychiatric services; **46.3% (63/136)** to education psychology; **52.2% (71/136)** to neuropsychology services and **86.8% (118/136)** to formal developmental assessment.

4.4% (6/136) were not able to offer referrals to mental health services, (**Table 43**).

Figure 28 shows the comparison of ability to refer to mental health services in Round 3 April 2018 and November 2019.

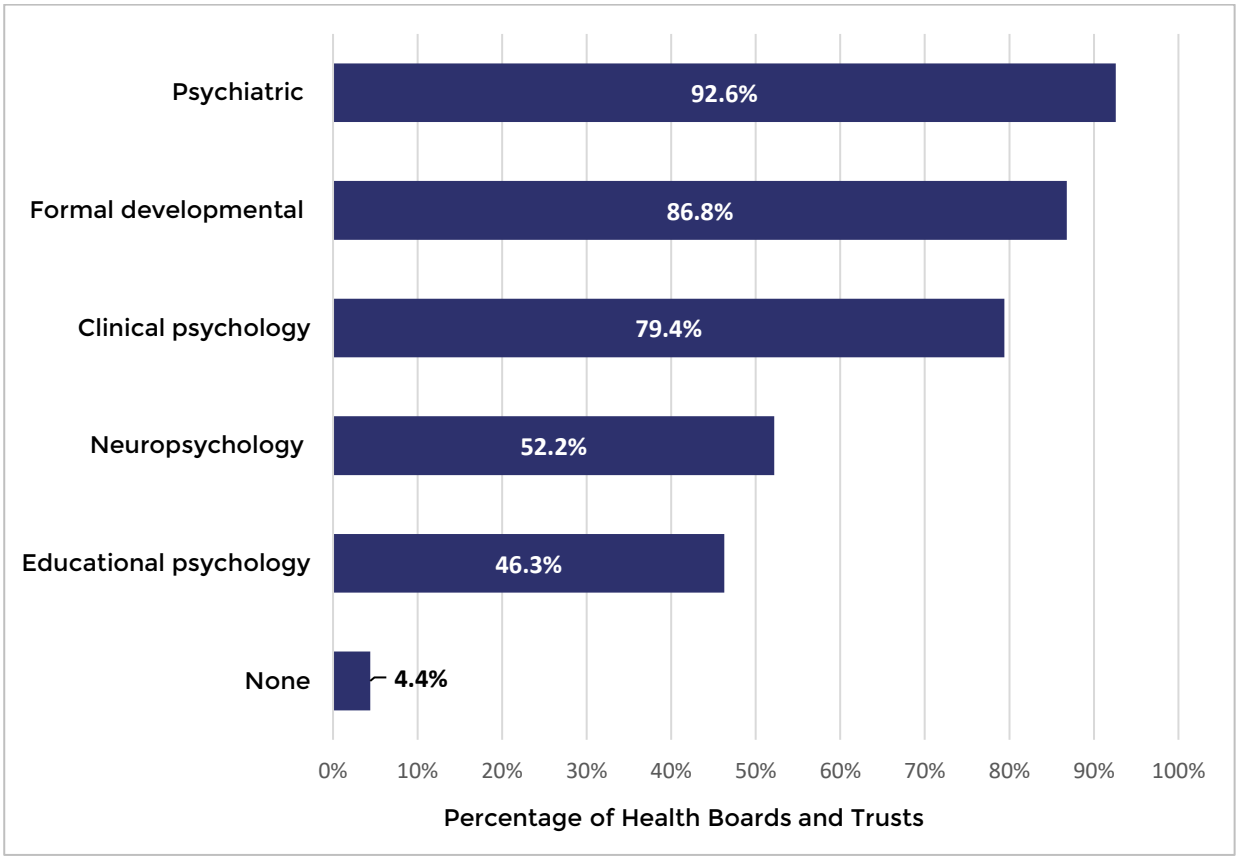


Figure 27: Percentage of Health Boards and Trusts that could refer to mental health services (n=136).

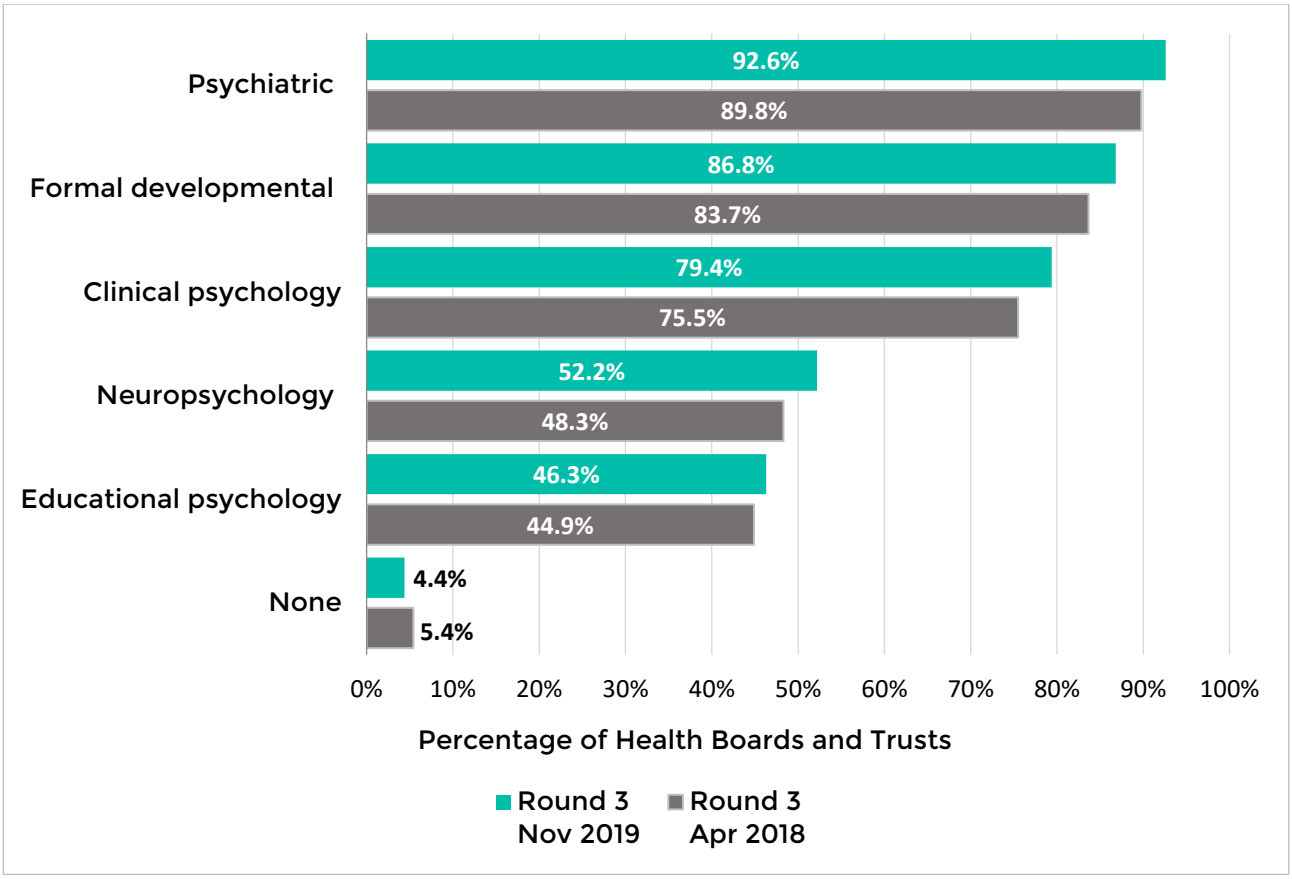


Figure 28: Percentage of Health Boards and Trusts that could refer to mental health services in Round 3 April 2018 and November 2019.

Table 37: Health Boards and Trusts that formally screen for diagnoses related to epilepsy.

Country/network	ADHD	ASD	Mental health disorders	None
England and Wales (N=136)	17.6% (24/136)	18.4% (25/136)	14.7% (20/136)	77.2% (105/136)
England (N=131)	18.3% (24/131)	19.1% (25/131)	15.3% (20/131)	76.3% (100/131)
Wales (N=5)	0.0% (0/5)	0.0% (0/5)	0.0% (0/5)	100% (5/5)
BRPNF (N=13)	30.8% (4/13)	30.8% (4/13)	15.4% (2/13)	69.2% (9/13)
CEWT (N=5)	40.0% (2/5)	40.0% (2/5)	20.0% (1/5)	60.0% (3/5)
EPEN (N=14)	7.1% (1/14)	7.1% (1/14)	7.1% (1/14)	85.7% (12/14)
EPIC (N=9)	11.1% (1/9)	11.1% (1/9)	0.0% (0/9)	88.9% (8/9)
NTPEN (N=16)	18.8% (3/16)	12.5% (2/16)	18.8% (3/16)	75.0% (12/16)
NWEIG (N=12)	25.0% (3/12)	16.7% (2/12)	25.0% (3/12)	66.7% (8/12)
ORENG (N=7)	42.9% (3/7)	42.9% (3/7)	28.6% (2/7)	57.1% (4/7)
PENNEC (N=8)	25.0% (2/8)	25.0% (2/8)	25.0% (2/8)	75.0% (6/8)
SETPEG (N=8)	12.5% (1/8)	12.5% (1/8)	12.5% (1/8)	87.5% (7/8)
SWEP (N=4)	0.0% (0/4)	0.0% (0/4)	0.0% (0/4)	100% (4/4)
SWIPE (N=9)	0.0% (0/9)	0.0% (0/9)	0.0% (0/9)	100% (9/9)
SWTPEG (N=7)	14.3% (1/7)	28.6% (2/7)	28.6% (2/7)	57.1% (4/7)
TEN (N=6)	16.7% (1/6)	33.3% (2/6)	0.0% (0/6)	66.7% (4/6)
WPNN (N=9)	11.1% (1/9)	11.1% (1/9)	11.1% (1/9)	88.9% (8/9)
YPEN (N=9)	11.1% (1/9)	22.2% (2/9)	22.2% (2/9)	77.8% (7/9)

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 Neurological Disorders Depression Inventory for Epilepsy
England and Wales (N=136)	0.0% (0/136)	8.1% (11/136)	0.0% (0/136)	0.0% (0/136)	0.0% (0/136)	0.0% (0/136)	0.0% (0/136)	0.0% (0/136)	0.0% (0/136)
England (N=131)	0.0% (0/131)	8.4% (11/131)	0.0% (0/131)	0.0% (0/131)	0.0% (0/131)	0.0% (0/131)	0.0% (0/131)	0.0% (0/131)	0.0% (0/131)
Wales (N=5)	0.0% (0/5)	0.0% (0/5)	0.0% (0/5)	0.0% (0/5)	0.0% (0/5)	0.0% (0/5)	0.0% (0/5)	0.0% (0/5)	0.0% (0/5)
BRPNF (N=13)	0.0% (0/13)	7.7% (1/13)	0.0% (0/13)	0.0% (0/13)	0.0% (0/13)	0.0% (0/13)	0.0% (0/13)	0.0% (0/13)	0.0% (0/13)
CEWT (N=5)	0.0% (0/5)	20.0% (1/5)	0.0% (0/5)	0.0% (0/5)	0.0% (0/5)	0.0% (0/5)	0.0% (0/5)	0.0% (0/5)	0.0% (0/5)
EPEN (N=14)	0.0% (0/14)	0.0% (0/14)	0.0% (0/14)	0.0% (0/14)	0.0% (0/14)	0.0% (0/14)	0.0% (0/14)	0.0% (0/14)	0.0% (0/14)
EPIC (N=9)	0.0% (0/9)	11.1% (1/9)	0.0% (0/9)	0.0% (0/9)	0.0% (0/9)	0.0% (0/9)	0.0% (0/9)	0.0% (0/9)	0.0% (0/9)
NTPEN (N=16)	0.0% (0/16)	18.8% (3/16)	0.0% (0/16)	0.0% (0/16)	0.0% (0/16)	0.0% (0/16)	0.0% (0/16)	0.0% (0/16)	0.0% (0/16)
NWEIG (N=12)	0.0% (0/12)	8.3% (1/12)	0.0% (0/12)	0.0% (0/12)	0.0% (0/12)	0.0% (0/12)	0.0% (0/12)	0.0% (0/12)	0.0% (0/12)
ORENG (N=7)	0.0% (0/7)	28.6% (2/7)	0.0% (0/7)	0.0% (0/7)	0.0% (0/7)	0.0% (0/7)	0.0% (0/7)	0.0% (0/7)	0.0% (0/7)
PENNEC (N=8)	0.0% (0/8)	0.0% (0/8)	0.0% (0/8)	0.0% (0/8)	0.0% (0/8)	0.0% (0/8)	0.0% (0/8)	0.0% (0/8)	0.0% (0/8)
SETPEG (N=8)	0.0% (0/8)	0.0% (0/8)	0.0% (0/8)	0.0% (0/8)	0.0% (0/8)	0.0% (0/8)	0.0% (0/8)	0.0% (0/8)	0.0% (0/8)
SWEP (N=4)	0.0% (0/4)	0.0% (0/4)	0.0% (0/4)	0.0% (0/4)	0.0% (0/4)	0.0% (0/4)	0.0% (0/4)	0.0% (0/4)	0.0% (0/4)
SWIPE (N=9)	0.0% (0/9)	0.0% (0/9)	0.0% (0/9)	0.0% (0/9)	0.0% (0/9)	0.0% (0/9)	0.0% (0/9)	0.0% (0/9)	0.0% (0/9)
SWTPEG (N=7)	0.0% (0/7)	0.0% (0/7)	0.0% (0/7)	0.0% (0/7)	0.0% (0/7)	0.0% (0/7)	0.0% (0/7)	0.0% (0/7)	0.0% (0/7)
TEN (N=6)	0.0% (0/6)	16.7% (1/6)	0.0% (0/6)	0.0% (0/6)	0.0% (0/6)	0.0% (0/6)	0.0% (0/6)	0.0% (0/6)	0.0% (0/6)
WPNN (N=9)	0.0% (0/9)	11.1% (1/9)	0.0% (0/9)	0.0% (0/9)	0.0% (0/9)	0.0% (0/9)	0.0% (0/9)	0.0% (0/9)	0.0% (0/9)
YPEN (N=9)	0.0% (0/9)	0.0% (0/9)	0.0% (0/9)	0.0% (0/9)	0.0% (0/9)	0.0% (0/9)	0.0% (0/9)	0.0% (0/9)	0.0% (0/9)

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=136)	0.0% (0/136)	7.4% (10/136)	5.1% (7/136)	41.9% (57/136)
England (N=131)	0.0% (0/131)	7.6% (10/131)	5.3% (7/131)	42.0% (55/131)
Wales (N=5)	0.0% (0/5)	0.0% (0/5)	0.0% (0/5)	40.0% (2/5)
BRPNF (N=13)	0.0% (0/13)	15.4% (2/13)	7.7% (1/13)	30.8% (4/13)
CEWT (N=5)	0.0% (0/5)	20.0% (1/5)	0.0% (0/5)	40.0% (2/5)
EPEN (N=14)	0.0% (0/14)	0.0% (0/14)	7.1% (1/14)	50.0% (7/14)
EPIC (N=9)	0.0% (0/9)	0.0% (0/9)	0.0% (0/9)	33.3% (3/9)
NTPEN (N=16)	0.0% (0/16)	18.8% (3/16)	6.3% (1/16)	25.0% (4/16)
NWEIG (N=12)	0.0% (0/12)	8.3% (1/12)	8.3% (1/12)	50.0% (6/12)
ORENG (N=7)	0.0% (0/7)	0.0% (0/7)	0.0% (0/7)	42.9% (3/7)
PENNEC (N=8)	0.0% (0/8)	0.0% (0/8)	12.5% (1/8)	50.0% (4/8)
SETPEG (N=8)	0.0% (0/8)	0.0% (0/8)	0.0% (0/8)	50.0% (4/8)
SWEP (N=4)	0.0% (0/4)	0.0% (0/4)	0.0% (0/4)	50.0% (2/4)
SWIPE (N=9)	0.0% (0/9)	0.0% (0/9)	0.0% (0/9)	55.6% (5/9)
SWTPEG (N=7)	0.0% (0/7)	14.3% (1/7)	14.3% (1/7)	28.6% (2/7)
TEN (N=6)	0.0% (0/6)	16.7% (1/6)	0.0% (0/6)	33.3% (2/6)
WPNN (N=9)	0.0% (0/9)	0.0% (0/9)	11.1% (1/9)	44.4% (4/9)
YPEN (N=9)	0.0% (0/9)	11.1% (1/9)	0.0% (0/9)	55.6% (5/9)

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

Country/network	Anxiety	Depression	Mood Disorder	Non-epileptic attack disorders	Other	None of the above
England and Wales (N=136)	54.4% (74/136)	55.1% (75/136)	54.4% (74/136)	37.5% (51/136)	6.6% (9/136)	42.6% (58/136)
England (N=131)	55.7% (73/131)	56.5% (74/131)	55.7% (73/131)	38.9% (51/131)	6.1% (8/131)	41.2% (54/131)
Wales (N=5)	20.0% (1/5)	20.0% (1/5)	20.0% (1/5)	0.0% (0/5)	20.0% (1/5)	80.0% (4/5)
BRPNF (N=13)	61.5% (8/13)	61.5% (8/13)	61.5% (8/13)	46.2% (6/13)	0.0% (0/13)	38.5% (5/13)
CEWT (N=5)	80.0% (4/5)	80.0% (4/5)	80.0% (4/5)	40.0% (2/5)	20.0% (1/5)	20.0% (1/5)
EPEN (N=14)	42.9% (6/14)	42.9% (6/14)	42.9% (6/14)	35.7% (5/14)	0.0% (0/14)	50.0% (7/14)
EPIC (N=9)	55.6% (5/9)	66.7% (6/9)	66.7% (6/9)	44.4% (4/9)	22.2% (2/9)	33.3% (3/9)
NTPEN (N=16)	43.8% (7/16)	43.8% (7/16)	43.8% (7/16)	37.5% (6/16)	12.5% (2/16)	50.0% (8/16)
NWEIG (N=12)	58.3% (7/12)	58.3% (7/12)	58.3% (7/12)	25.0% (3/12)	16.7% (2/12)	33.3% (4/12)
ORENG (N=7)	28.6% (2/7)	28.6% (2/7)	28.6% (2/7)	14.3% (1/7)	0.0% (0/7)	71.4% (5/7)
PENNEC (N=8)	87.5% (7/8)	87.5% (7/8)	87.5% (7/8)	62.5% (5/8)	12.5% (1/8)	25.0% (2/8)
SETPEG (N=8)	62.5% (5/8)	62.5% (5/8)	62.5% (5/8)	50.0% (4/8)	0.0% (0/8)	37.5% (3/8)
SWEP (N=4)	0.0% (0/4)	0.0% (0/4)	0.0% (0/4)	0.0% (0/4)	0.0% (0/4)	100% (4/4)
SWIPE (N=9)	44.4% (4/9)	44.4% (4/9)	44.4% (4/9)	22.2% (2/9)	0.0% (0/9)	55.6% (5/9)
SWTPEG (N=7)	71.4% (5/7)	71.4% (5/7)	71.4% (5/7)	42.9% (3/7)	0.0% (0/7)	28.6% (2/7)
TEN (N=6)	66.7% (4/6)	66.7% (4/6)	50.0% (3/6)	33.3% (2/6)	16.7% (1/6)	33.3% (2/6)
WPNN (N=9)	66.7% (6/9)	66.7% (6/9)	66.7% (6/9)	44.4% (4/9)	0.0% (0/9)	33.3% (3/9)
YPEN (N=9)	44.4% (4/9)	44.4% (4/9)	44.4% (4/9)	44.4% (4/9)	0.0% (0/9)	44.4% (4/9)

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

Country/network	Yes	No
England and Wales (N=136)	14.0% (19/136)	86.0% (117/136)
England (N=131)	14.5% (19/131)	85.5% (112/131)
Wales (N=5)	0.0% (0/5)	100% (5/5)
BRPNF (N=13)	0.0% (0/13)	100% (13/13)
CEWT (N=5)	0.0% (0/5)	100% (5/5)
EPEN (N=14)	14.3% (2/14)	85.7% (12/14)
EPIC (N=9)	22.2% (2/9)	77.8% (7/9)
NTPEN (N=16)	25.0% (4/16)	75.0% (12/16)
NWEIG (N=12)	16.7% (2/12)	83.3% (10/12)
ORENG (N=7)	0.0% (0/7)	100% (7/7)
PENNEC (N=8)	0.0% (0/8)	100% (8/8)
SETPEG (N=8)	37.5% (3/8)	62.5% (5/8)
SWEP (N=4)	0.0% (0/4)	100% (4/4)
SWIPE (N=9)	0.0% (0/9)	100% (9/9)
SWTPEG (N=7)	28.6% (2/7)	71.4% (5/7)
TEN (N=6)	16.7% (1/6)	83.3% (5/6)
WPNN (N=9)	22.2% (2/9)	77.8% (7/9)
YPEN (N=9)	11.1% (1/9)	88.9% (8/9)

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=136)	7.4% (10/136)	8.8% (12/136)	8.1% (11/136)
England (N=131)	7.6% (10/131)	9.2% (12/131)	8.4% (11/131)
Wales (N=5)	0.0% (0/5)	0.0% (0/5)	0.0% (0/5)
BRPNF (N=13)	0.0% (0/13)	0.0% (0/13)	0.0% (0/13)
CEWT (N=5)	0.0% (0/5)	0.0% (0/5)	0.0% (0/5)
EPEN (N=14)	14.3% (2/14)	14.3% (2/14)	7.1% (1/14)
EPIC (N=9)	11.1% (1/9)	11.1% (1/9)	22.2% (2/9)
NTPEN (N=16)	6.3% (1/16)	12.5% (2/16)	18.8% (3/16)
NWEIG (N=12)	8.3% (1/12)	16.7% (2/12)	0.0% (0/12)
ORENG (N=7)	0.0% (0/7)	0.0% (0/7)	0.0% (0/7)
PENNEC (N=8)	0.0% (0/8)	0.0% (0/8)	0.0% (0/8)
SETPEG (N=8)	37.5% (3/8)	25.0% (2/8)	12.5% (1/8)
SWEP (N=4)	0.0% (0/4)	0.0% (0/4)	0.0% (0/4)
SWIPE (N=9)	0.0% (0/9)	0.0% (0/9)	0.0% (0/9)
SWTPEG (N=7)	14.3% (1/7)	14.3% (1/7)	14.3% (1/7)
TEN (N=6)	0.0% (0/6)	0.0% (0/6)	16.7% (1/6)
WPNN (N=9)	11.1% (1/9)	11.1% (1/9)	11.1% (1/9)
YPEN (N=9)	0.0% (0/9)	11.1% (1/9)	11.1% (1/9)

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=117)	7.7% (9/117)	92.3% (108/117)
England (N=112)	8.0% (9/112)	92.0% (103/112)
Wales (N=5)	0.0% (0/5)	100% (5/5)
BRPNF (N=13)	7.7% (1/13)	92.3% (12/13)
CEWT (N=5)	40.0% (2/5)	60.0% (3/5)
EPEN (N=12)	0.0% (0/12)	100% (12/12)
EPIC (N=7)	14.3% (1/7)	85.7% (6/7)
NTPEN (N=12)	8.3% (1/12)	91.7% (11/12)
NWEIG (N=10)	0.0% (0/10)	100% (10/10)
ORENG (N=7)	0.0% (0/7)	100% (7/7)
PENNEC (N=8)	12.5% (1/8)	87.5% (7/8)
SETPEG (N=5)	0.0% (0/5)	100% (5/5)
SWEP (N=4)	0.0% (0/4)	100% (4/4)
SWIPE (N=9)	0.0% (0/9)	100% (9/9)
SWTPEG (N=5)	0.0% (0/5)	100% (5/5)
TEN (N=5)	20.0% (1/5)	80.0% (4/5)
WPNN (N=7)	0.0% (0/7)	100% (7/7)
YPEN (N=8)	25.0% (2/8)	75.0% (6/8)

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=136)	79.4% (108/136)	92.6% (126/136)	46.3% (63/136)	52.2% (71/136)	86.8% (118/136)	4.4% (6/136)
England (N=131)	80.2% (105/131)	92.4% (121/131)	45.8% (60/131)	54.2% (71/131)	86.3% (113/131)	4.6% (6/131)
Wales (N=5)	60.0% (3/5)	100% (5/5)	60.0% (3/5)	0.0% (0/5)	100% (5/5)	0.0% (0/5)
BRPNF (N=13)	92.3% (12/13)	100% (13/13)	69.2% (9/13)	46.2% (6/13)	92.3% (12/13)	0.0% (0/13)
CEWT (N=5)	100% (5/5)	100% (5/5)	20.0% (1/5)	80.0% (4/5)	100% (5/5)	0.0% (0/5)
EPEN (N=14)	64.3% (9/14)	85.7% (12/14)	57.1% (8/14)	28.6% (4/14)	85.7% (12/14)	14.3% (2/14)
EPIC (N=9)	66.7% (6/9)	88.9% (8/9)	22.2% (2/9)	55.6% (5/9)	77.8% (7/9)	0.0% (0/9)
NTPEN (N=16)	87.5% (14/16)	93.8% (15/16)	31.3% (5/16)	68.8% (11/16)	100% (16/16)	0.0% (0/16)
NWEIG (N=12)	91.7% (11/12)	91.7% (11/12)	58.3% (7/12)	58.3% (7/12)	83.3% (10/12)	0.0% (0/12)
ORENG (N=7)	85.7% (6/7)	100% (7/7)	57.1% (4/7)	71.4% (5/7)	85.7% (6/7)	0.0% (0/7)
PENNEC (N=8)	87.5% (7/8)	100% (8/8)	87.5% (7/8)	75.0% (6/8)	100% (8/8)	0.0% (0/8)
SETPEG (N=8)	100% (8/8)	100% (8/8)	62.5% (5/8)	75.0% (6/8)	100% (8/8)	0.0% (0/8)
SWEP (N=4)	50.0% (2/4)	100% (4/4)	50.0% (2/4)	0.0% (0/4)	100% (4/4)	0.0% (0/4)
SWIPE (N=9)	88.9% (8/9)	100% (9/9)	55.6% (5/9)	77.8% (7/9)	77.8% (7/9)	0.0% (0/9)
SWTPEG (N=7)	42.9% (3/7)	71.4% (5/7)	14.3% (1/7)	28.6% (2/7)	71.4% (5/7)	28.6% (2/7)
TEN (N=6)	50.0% (3/6)	66.7% (4/6)	0.0% (0/6)	33.3% (2/6)	66.7% (4/6)	16.7% (1/6)
WPNN (N=9)	66.7% (6/9)	88.9% (8/9)	33.3% (3/9)	22.2% (2/9)	77.8% (7/9)	11.1% (1/9)
YPEN (N=9)	88.9% (8/9)	100% (9/9)	44.4% (4/9)	44.4% (4/9)	77.8% (7/9)	0.0% (0/9)

Neurodevelopmental support

16.2% (22/136) of Health Boards and Trusts did not have agreed referral criteria for children and young people with neurodevelopmental problems. **77.2% (105/136)** had an agreed referral for children with ADHD; **80.9% (110/136)** for ASD; **55.1% (75/136)** for behaviour difficulties; **55.9% (76/136)** for developmental coordination disorder; **49.3% (67/136)** for intellectual disability (**Table 44/ Figure 29**). In the **5.9% (8/136)** that selected other, the responses included:

- Developmental delay,
- CP, development delay, neuromuscular,
- Global developmental delay,
- Challenging behaviour associated with severe learning difficulties,
- Early Health Assessment pathway,
- Referral is to community paediatric service who will direct referral to appropriate pathway,

Conditions details are not seen within our Trust or Health Board.

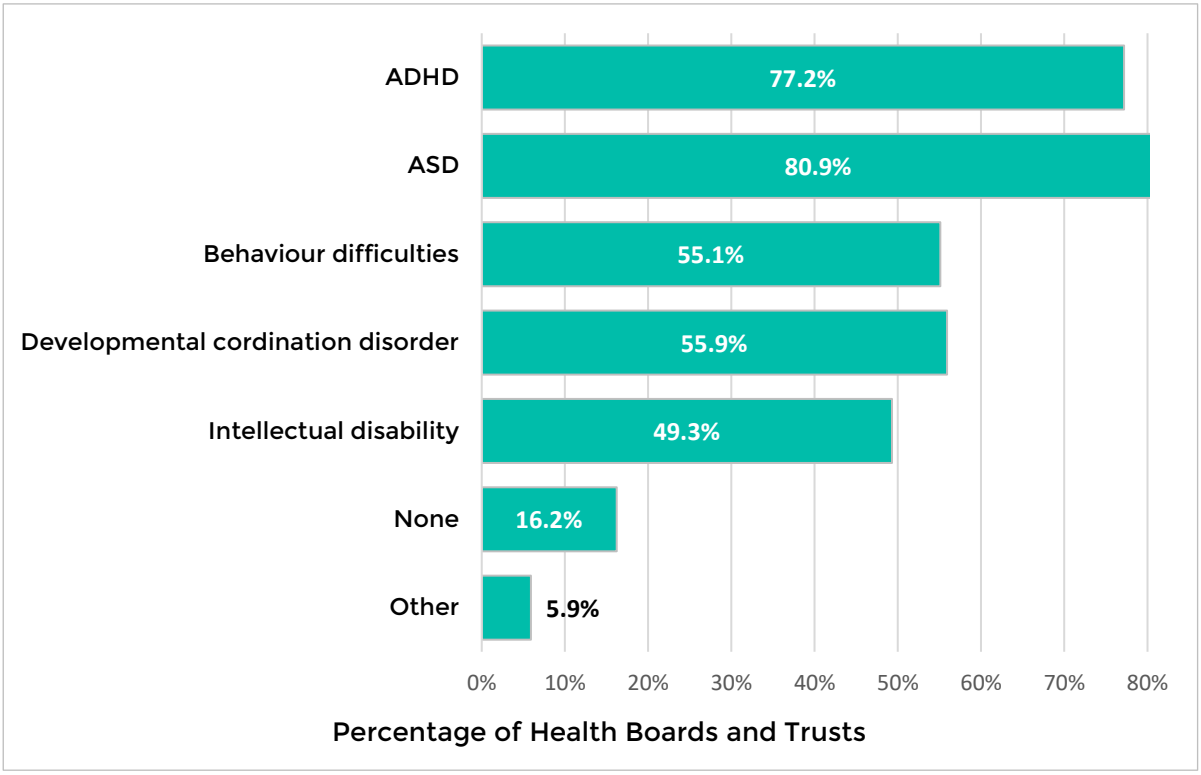


Figure 29: Percentage of Health Boards and Trusts that had agreed referral criteria for children and young people with neuro-developmental problems (n=136).

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

Country/network	ADHD	ASD	Behaviour difficulties	Developmental Coordination Disorder	Intellectual disability	Other	None
England and Wales (N=136)	77.2% (105/136)	80.9% (110/136)	55.1% (75/136)	55.9% (76/136)	49.3% (67/136)	5.9% (8/136)	16.2% (22/136)
England (N=131)	76.3% (100/131)	80.2% (105/131)	55.0% (72/131)	55.0% (72/131)	49.6% (65/131)	6.1% (8/131)	16.8% (22/131)
Wales (N=5)	100% (5/5)	100% (5/5)	60.0% (3/5)	80.0% (4/5)	40.0% (2/5)	0.0% (0/5)	0.0% (0/5)
BRPNF (N=13)	92.3% (12/13)	100% (13/13)	84.6% (11/13)	76.9% (10/13)	84.6% (11/13)	0.0% (0/13)	0.0% (0/13)
CEWT (N=5)	100% (5/5)	100% (5/5)	80.0% (4/5)	80.0% (4/5)	80.0% (4/5)	20.0% (1/5)	0.0% (0/5)
EPEN (N=14)	57.1% (8/14)	57.1% (8/14)	50.0% (7/14)	50.0% (7/14)	21.4% (3/14)	7.1% (1/14)	28.6% (4/14)
EPIC (N=9)	88.9% (8/9)	88.9% (8/9)	55.6% (5/9)	44.4% (4/9)	44.4% (4/9)	11.1% (1/9)	11.1% (1/9)
NTPEN (N=16)	62.5% (10/16)	75.0% (12/16)	56.3% (9/16)	37.5% (6/16)	50.0% (8/16)	6.3% (1/16)	25.0% (4/16)
NWEIG (N=12)	91.7% (11/12)	91.7% (11/12)	58.3% (7/12)	75.0% (9/12)	66.7% (8/12)	0.0%(0/12)	8.3% (1/12)
ORENG (N=7)	71.4% (5/7)	71.4% (5/7)	28.6% (2/7)	42.9% (3/7)	28.6% (2/7)	0.0% (0/7)	28.6% (2/7)
PENNEC (N=8)	87.5% (7/8)	87.5% (7/8)	62.5% (5/8)	62.5% (5/8)	50.0% (4/8)	0.0% (0/8)	12.5% (1/8)
SETPEG (N=8)	75.0% (6/8)	87.5% (7/8)	62.5% (5/8)	62.5% (5/8)	62.5% (5/8)	0.0% (0/8)	12.5% (1/8)
SWEP (N=4)	100% (4/4)	100% (4/4)	75.0% (3/4)	75.0% (3/4)	50.0% (2/4)	0.0% (0/4)	0.0% (0/4)
SWIPE (N=9)	77.8% (7/9)	77.8% (7/9)	33.3% (3/9)	44.4% (4/9)	33.3% (3/9)	22.2% (2/9)	11.1% (1/9)
SWTPEG (N=7)	71.4% (5/7)	85.7% (6/7)	57.1% (4/7)	42.9% (3/7)	57.1% (4/7)	0.0% (0/7)	14.3% (1/7)
TEN (N=6)	66.7% (4/6)	83.3% (5/6)	66.7% (4/6)	83.3% (5/6)	50.0% (3/6)	0.0% (0/6)	16.7% (1/6)
WPNN (N=9)	55.6% (5/9)	44.4% (4/9)	33.3% (3/9)	33.3% (3/9)	33.3% (3/9)	11.1% (1/9)	44.4% (4/9)
YPEN (N=9)	88.9% (8/9)	88.9% (8/9)	33.3% (3/9)	55.6% (5/9)	33.3% (3/9)	11.1% (1/9)	11.1% (1/9)

Care planning

80.1% (109/136) of Health Boards and Trusts reported that they routinely undertook comprehensive care planning for children and young people with epilepsy.

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=136)	80.1% (109/136)	19.9% (27/136)
England (N=131)	80.2% (105/131)	19.8% (26/131)
Wales (N=5)	80.0% (4/5)	20.0% (1/5)
BRPNF (N=13)	76.9% (10/13)	23.1% (3/13)
CEWT (N=5)	80.0% (4/5)	20.0% (1/5)
EPEN (N=14)	85.7% (12/14)	14.3% (2/14)
EPIC (N=9)	88.9% (8/9)	11.1% (1/9)
NTPEN (N=16)	87.5% (14/16)	12.5% (2/16)
NWEIG (N=12)	83.3% (10/12)	16.7% (2/12)
ORENG (N=7)	71.4% (5/7)	28.6% (2/7)
PENNEC (N=8)	62.5% (5/8)	37.5% (3/8)
SETPEG (N=8)	87.5% (7/8)	12.5% (1/8)
SWEP (N=4)	75.0% (3/4)	25.0% (1/4)
SWIPE (N=9)	55.6% (5/9)	44.4% (4/9)
SWTPEG (N=7)	85.7% (6/7)	14.3% (1/7)
TEN (N=6)	83.3% (5/6)	16.7% (1/6)
WPNN (N=9)	77.8% (7/9)	22.2% (2/9)
YPEN (N=9)	88.9% (8/9)	11.1% (1/9)

Patient database or registry

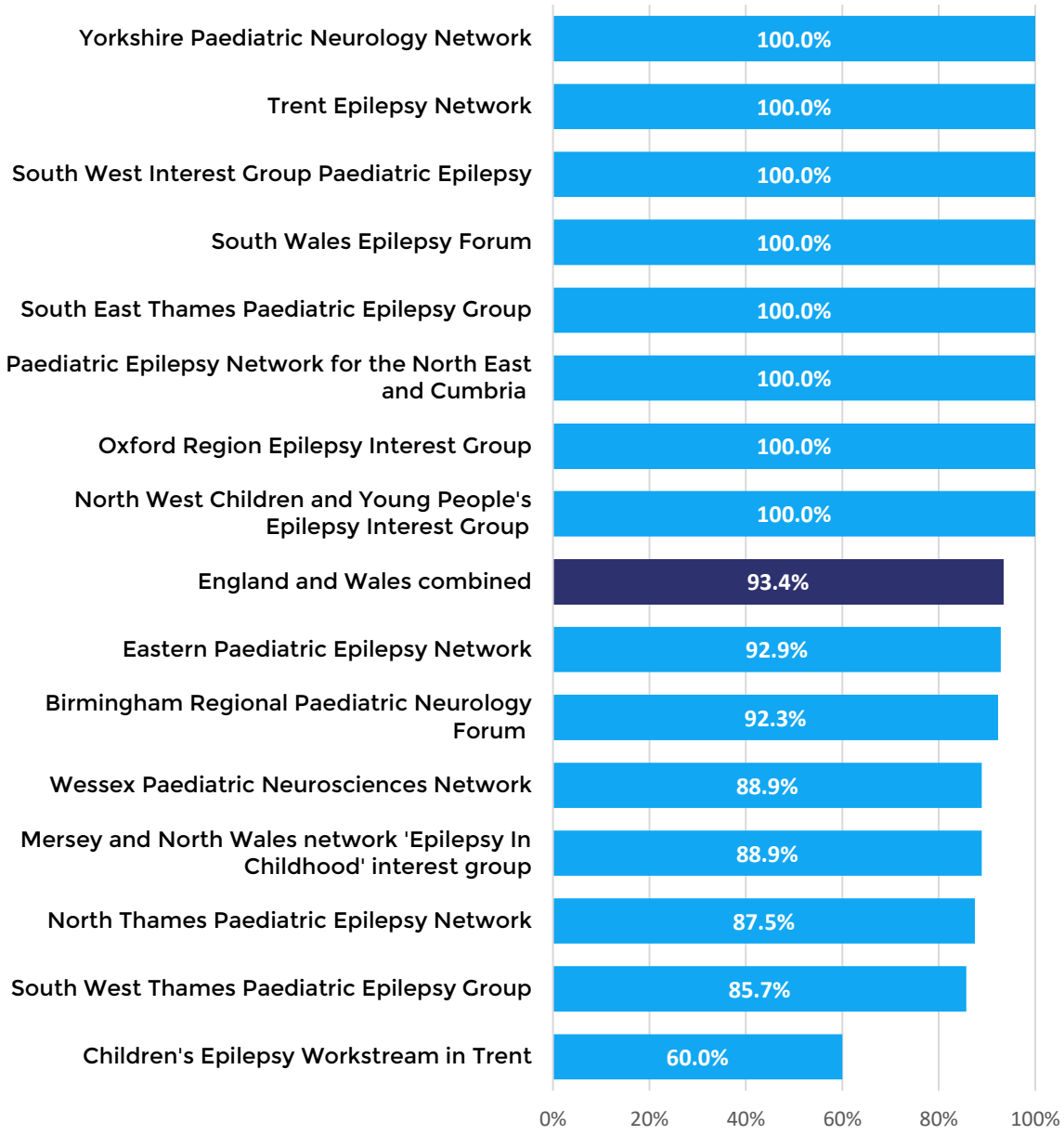
33.8% (46/136) of Health Boards and Trusts reported that they maintain a database or register for all children and young people with epilepsies; **39.7% (54/136)** reported that they maintain a database or register for some children and young people with epilepsies; and **26.5% (36/136)** Health Boards and Trusts, reported that they do not maintain a database or register, (**Table 46**).

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

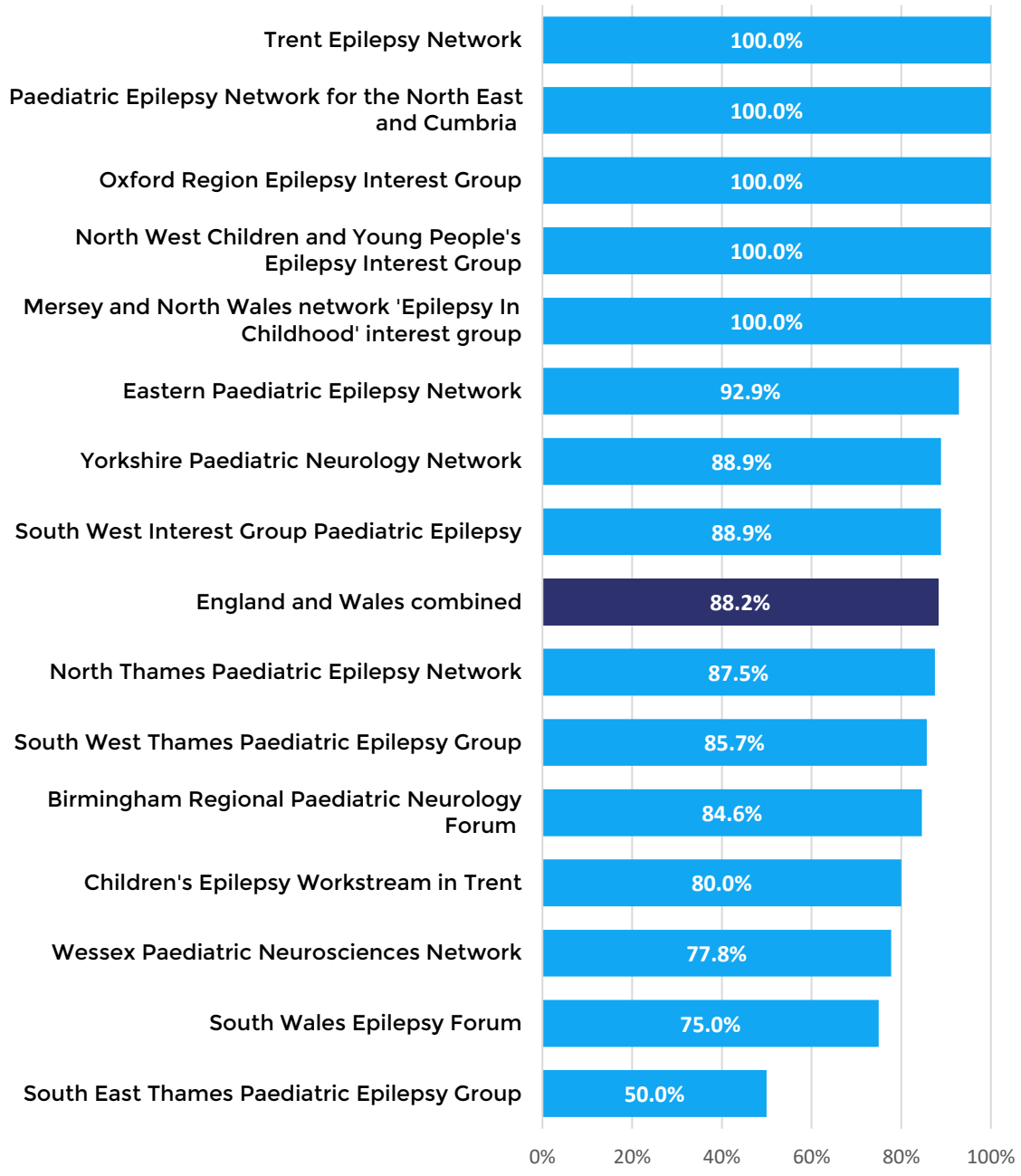
Country/network	Yes, all	Yes, some	No
England and Wales (N=136)	33.8% (46/136)	39.7% (54/136)	26.5% (36/136)
England (N=131)	35.1% (46/131)	38.9% (51/131)	26.0% (34/131)
Wales (N=5)	0.0% (0/5)	60.0% (3/5)	40.0% (2/5)
BRPNF (N=13)	7.7% (1/13)	53.8% (7/13)	38.5% (5/13)
CEWT (N=5)	0.0% (0/5)	40.0% (2/5)	60.0% (3/5)
EPEN (N=14)	42.9% (6/14)	28.6% (4/14)	28.6% (4/14)
EPIC (N=9)	44.4% (4/9)	22.2% (2/9)	33.3% (3/9)
NTPEN (N=16)	31.3% (5/16)	50.0% (8/16)	18.8% (3/16)
NWEIG (N=12)	41.7% (5/12)	41.7% (5/12)	16.7% (2/12)
ORENG (N=7)	28.6% (2/7)	42.9% (3/7)	28.6% (2/7)
PENNEC (N=8)	37.5% (3/8)	37.5% (3/8)	25.0% (2/8)
SETPEG (N=8)	50.0% (4/8)	12.5% (1/8)	37.5% (3/8)
SWEP (N=4)	0.0% (0/4)	50.0% (2/4)	50.0% (2/4)
SWIPE (N=9)	33.3% (3/9)	44.4% (4/9)	22.2% (2/9)
SWTPEG (N=7)	42.9% (3/7)	42.9% (3/7)	14.3% (1/7)
TEN (N=6)	33.3% (2/6)	33.3% (2/6)	33.3% (2/6)
WPNN (N=9)	44.4% (4/9)	44.4% (4/9)	11.1% (1/9)
YPEN (N=9)	44.4% (4/9)	44.4% (4/9)	11.1% (1/9)

Appendix B: Organisational findings by OPEN UK regional networks

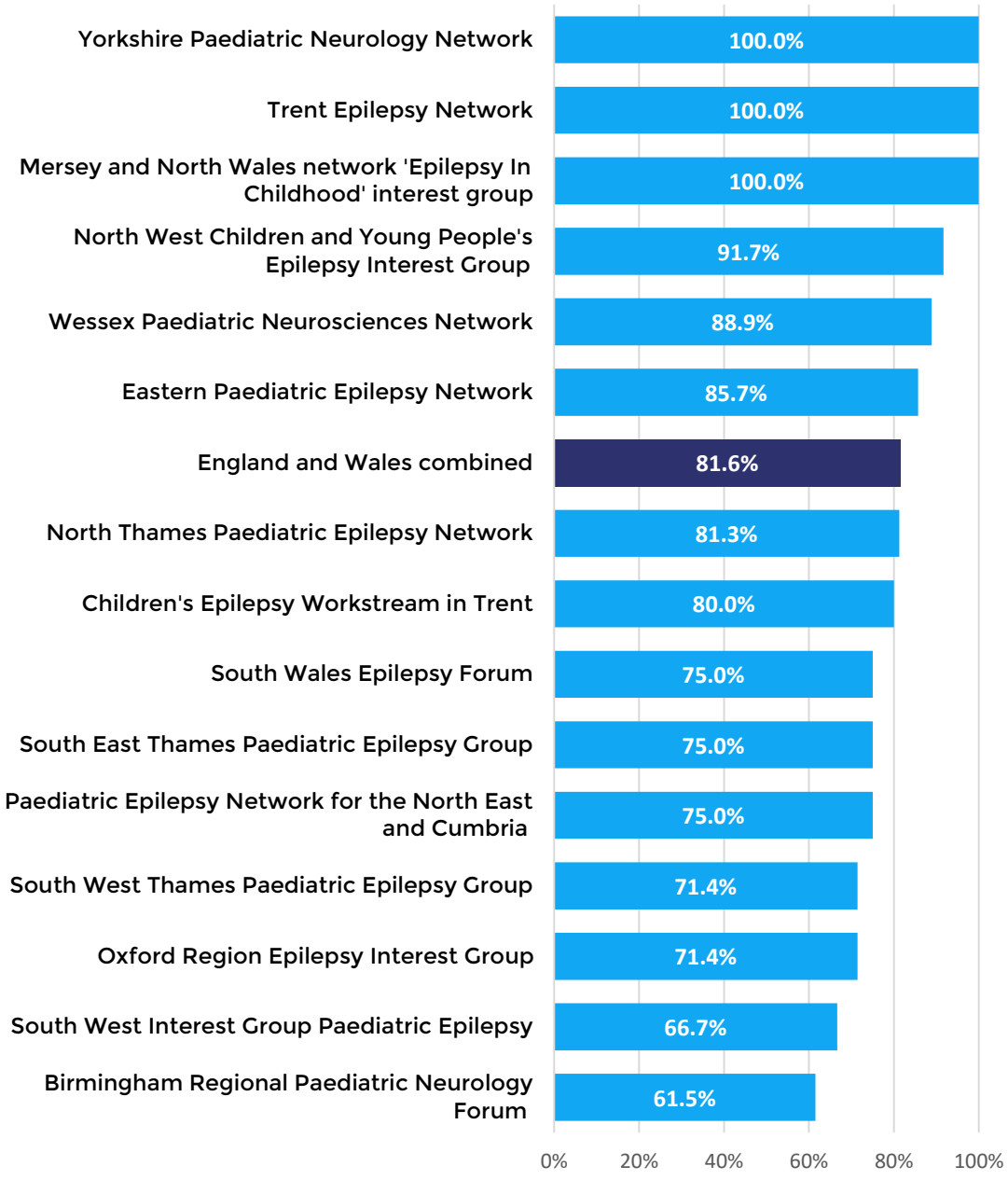
% of Health Boards and Trusts employing a consultant paediatrician with expertise in epilepsy



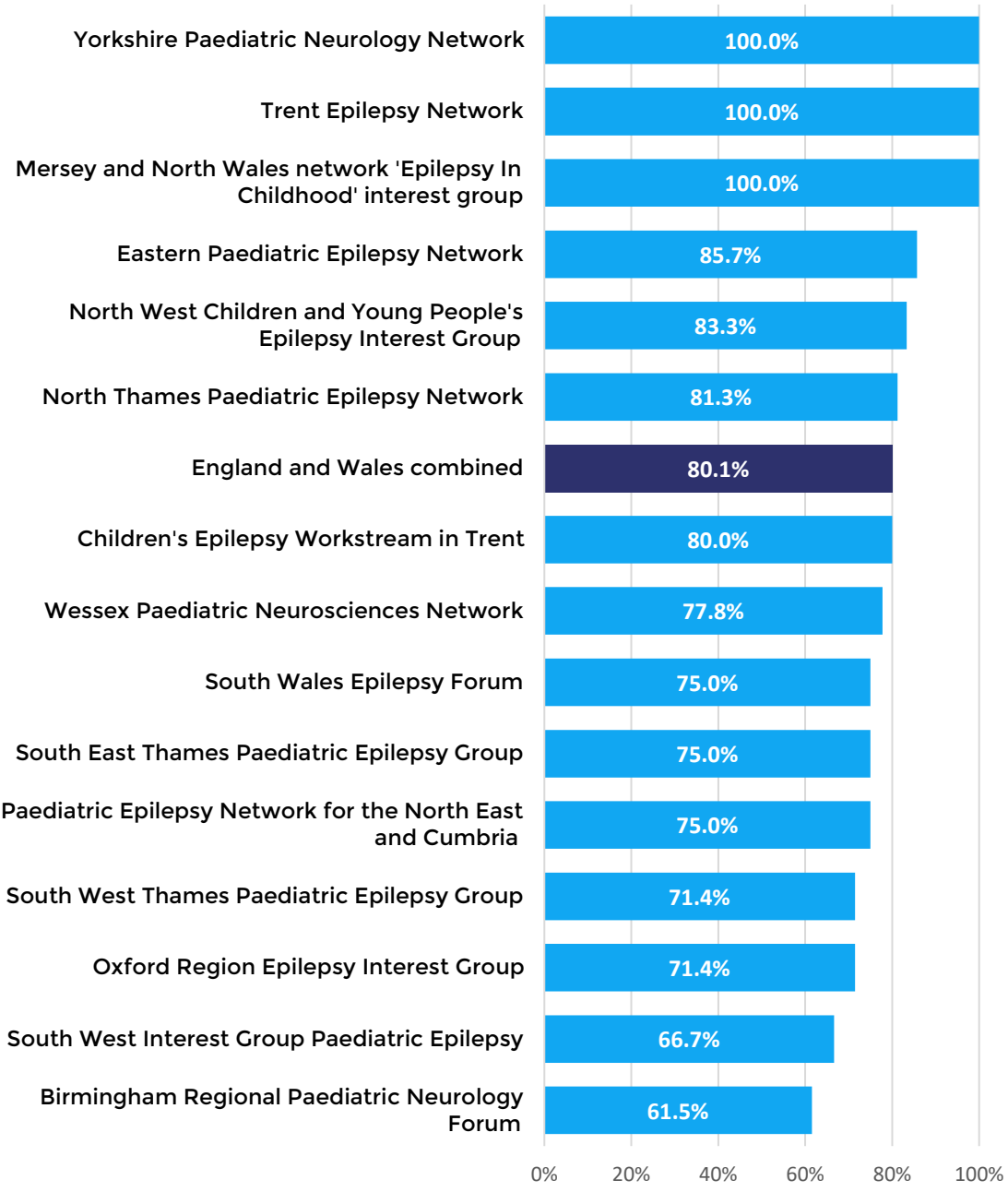
% of Health Boards and Trusts that had a defined paediatric epilepsy clinical lead



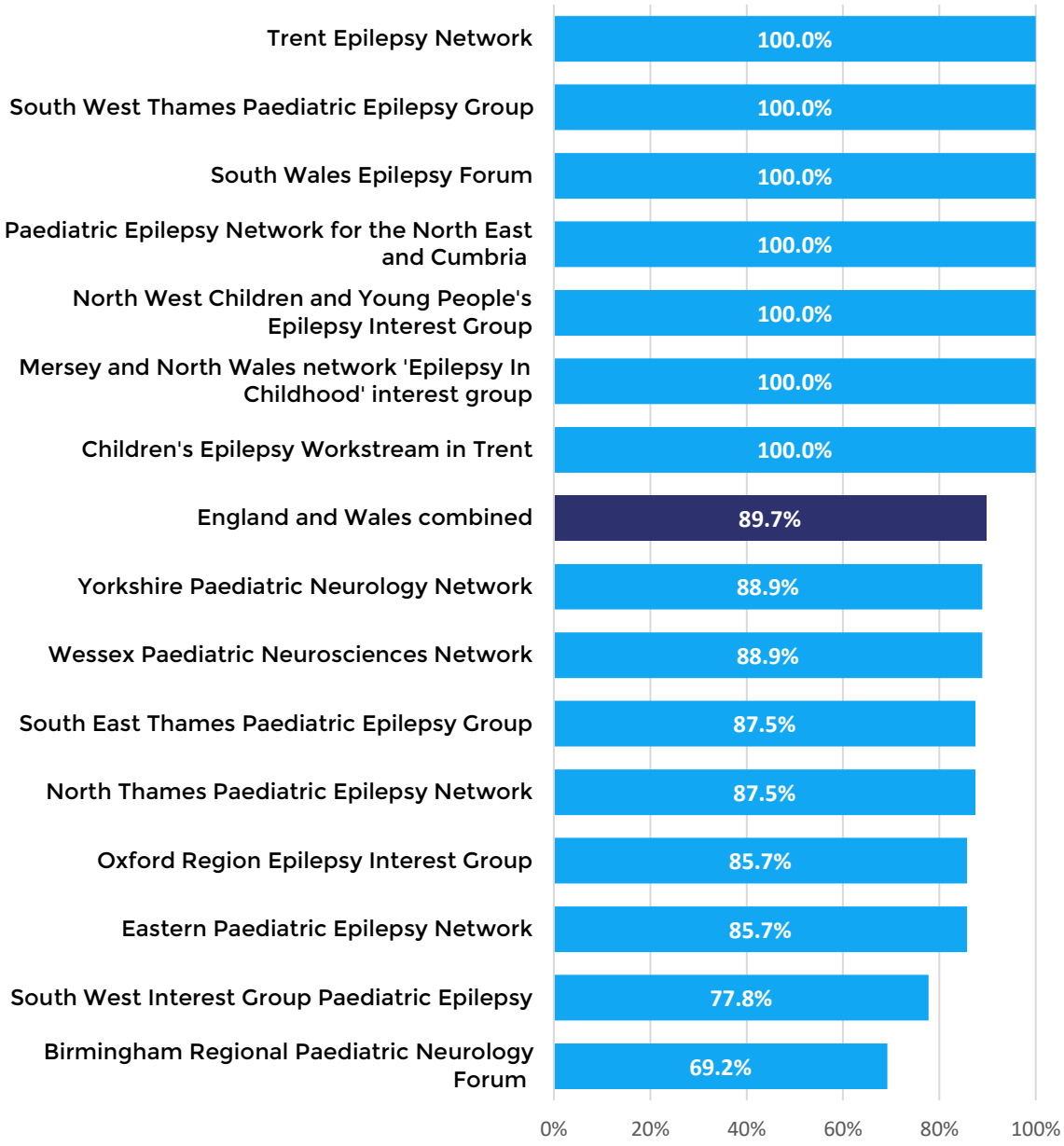
% of Health Boards and Trusts who had some epilepsy specialist nurse (ESN) provision within their paediatric service



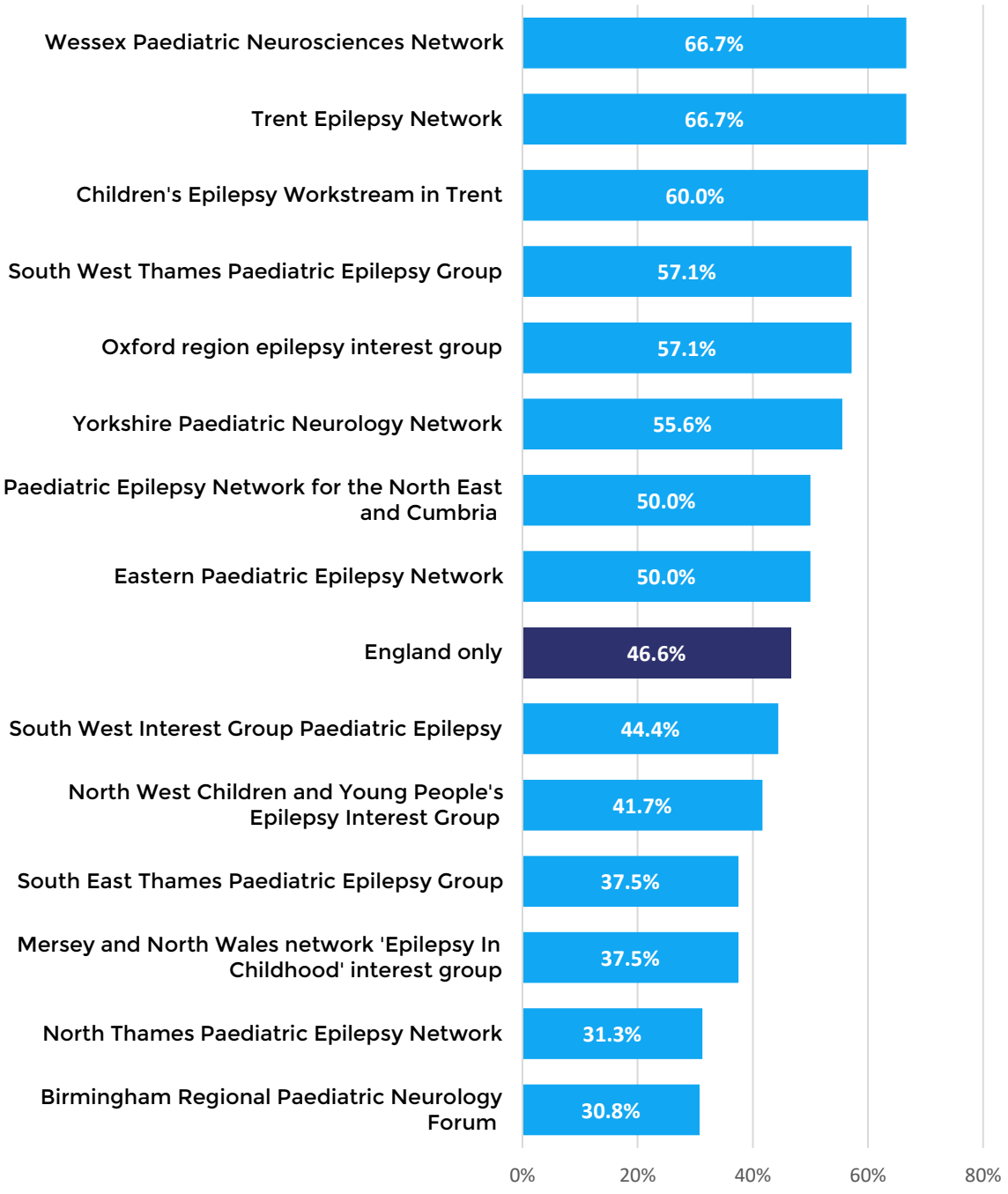
% of Health Boards Trusts that indicated that they could offer ESN support for rescue medication training for parents



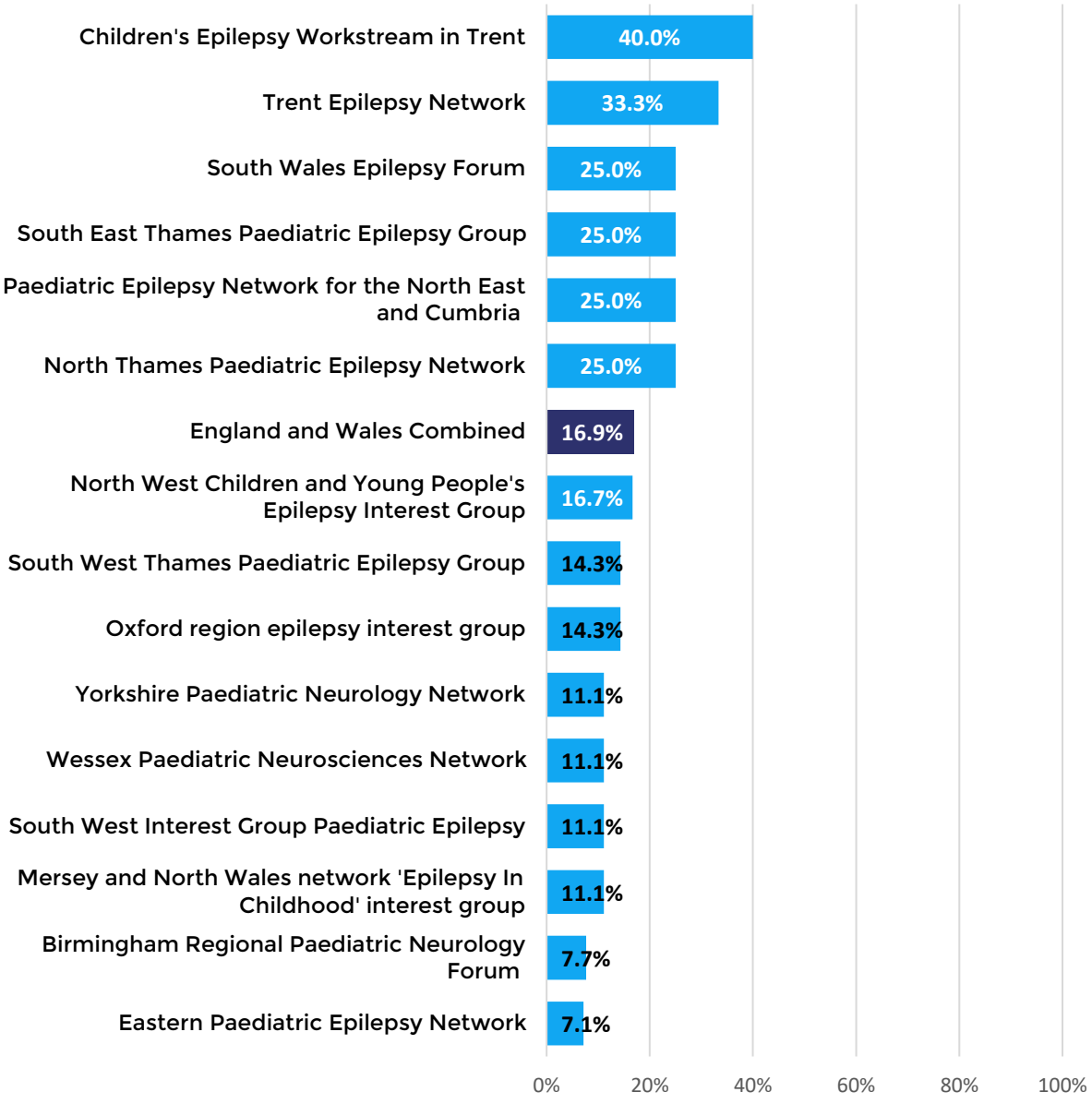
% of Health Boards and Trusts that had a defined epilepsy clinic seeing patients at secondary level



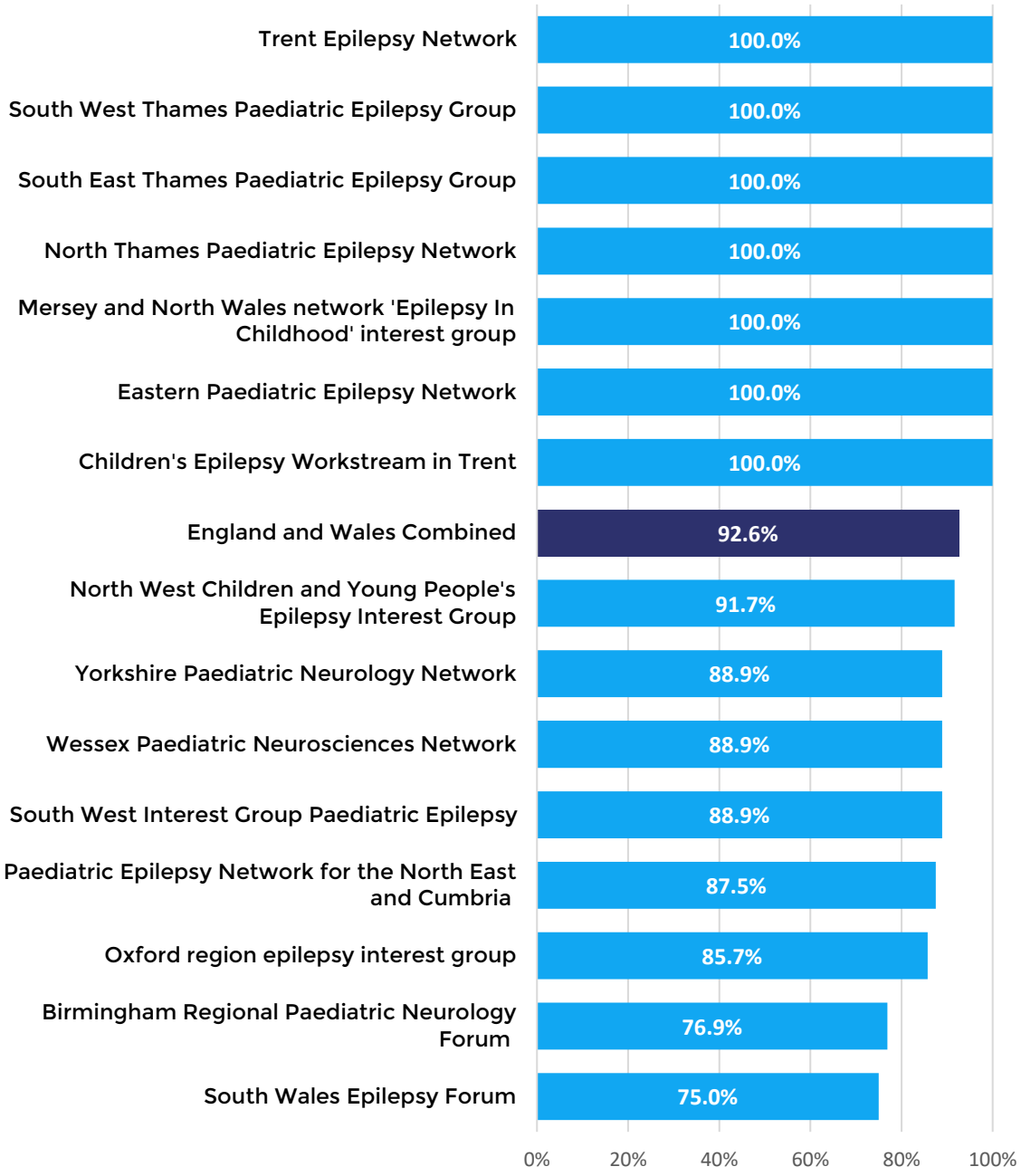
% of Trusts in England that currently run Epilepsy Best Practice Criteria (BPC) clinics



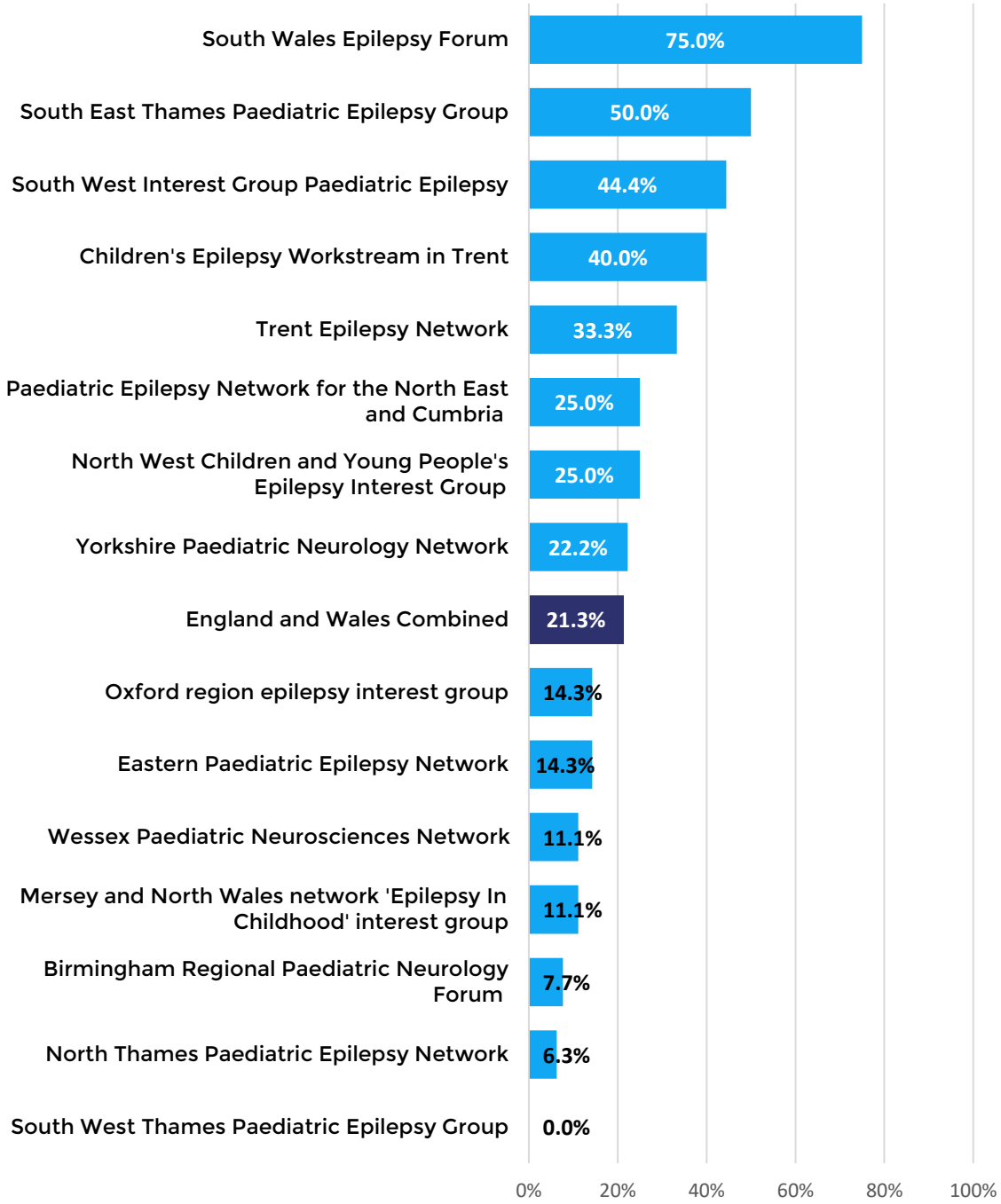
% of Health Boards and Trusts that have some tertiary provision within their paediatric service (paediatric neurologists who manage children with epilepsy (acutely and/or non-acutely))



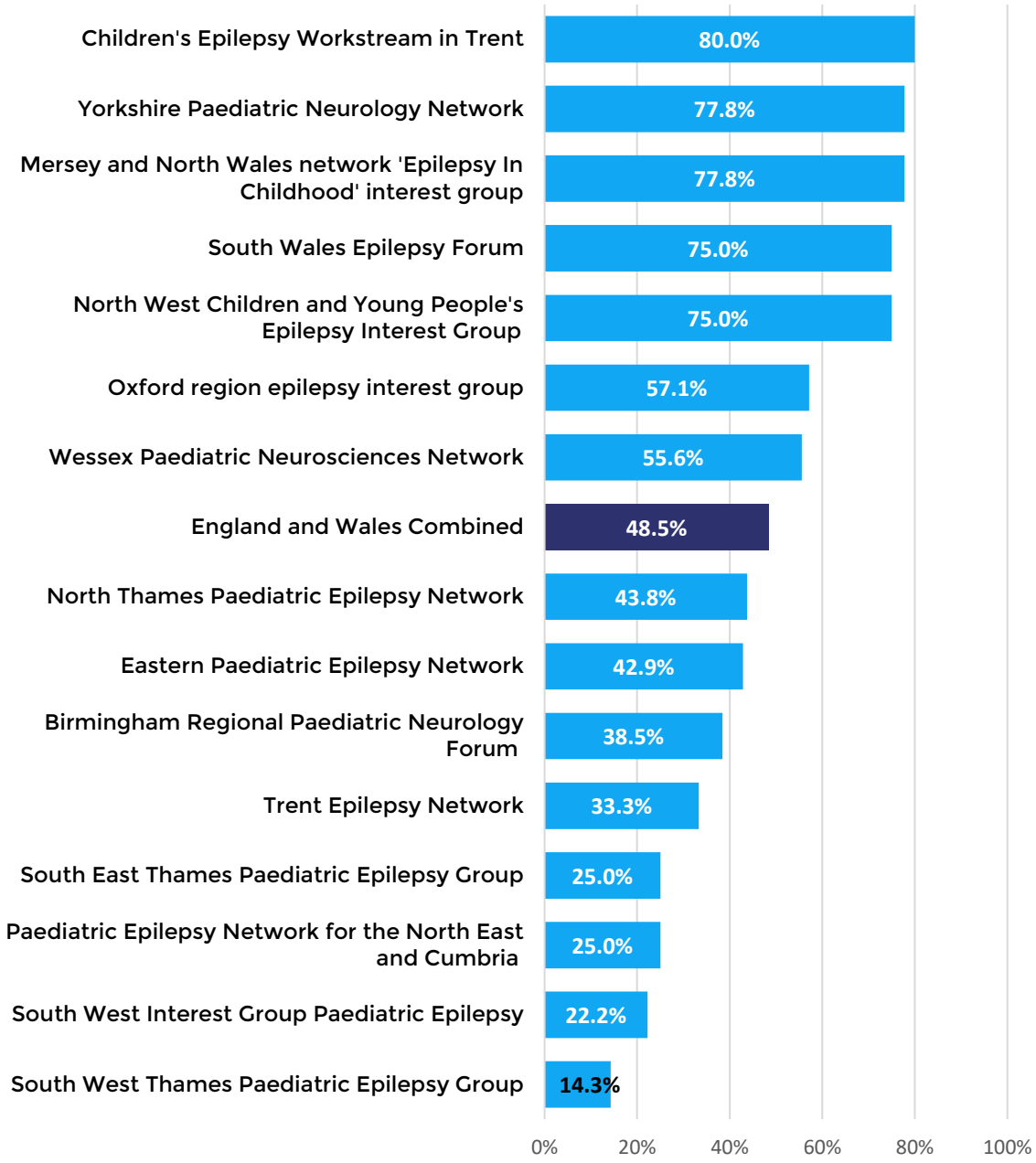
% of Health Boards and Trusts that had agreed referral pathways to tertiary paediatric neurology services



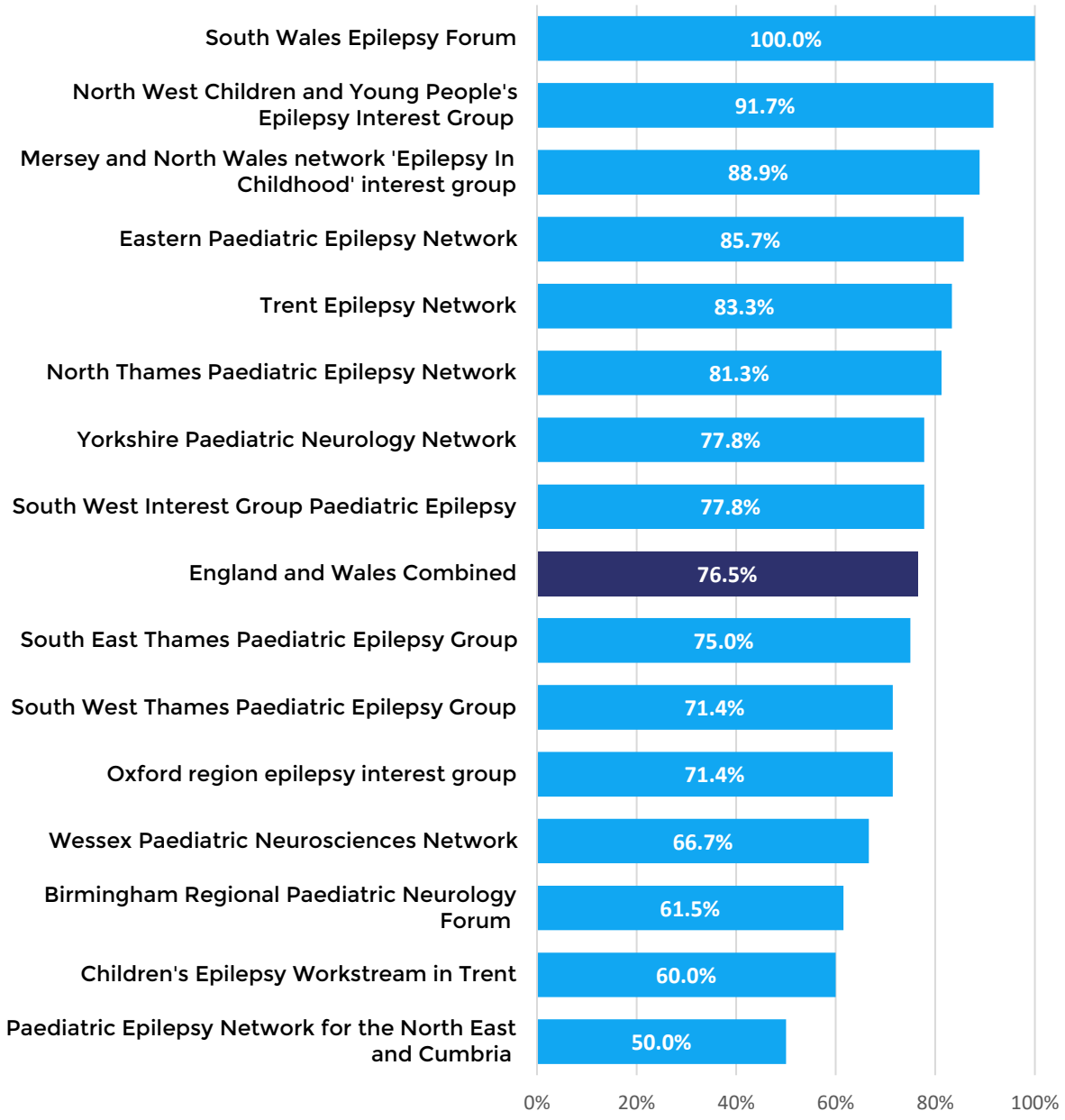
% of Health Boards and Trusts that were able to facilitate Vagal Nerve Stimulation (VNS) review at a location within the Health Board or Trust



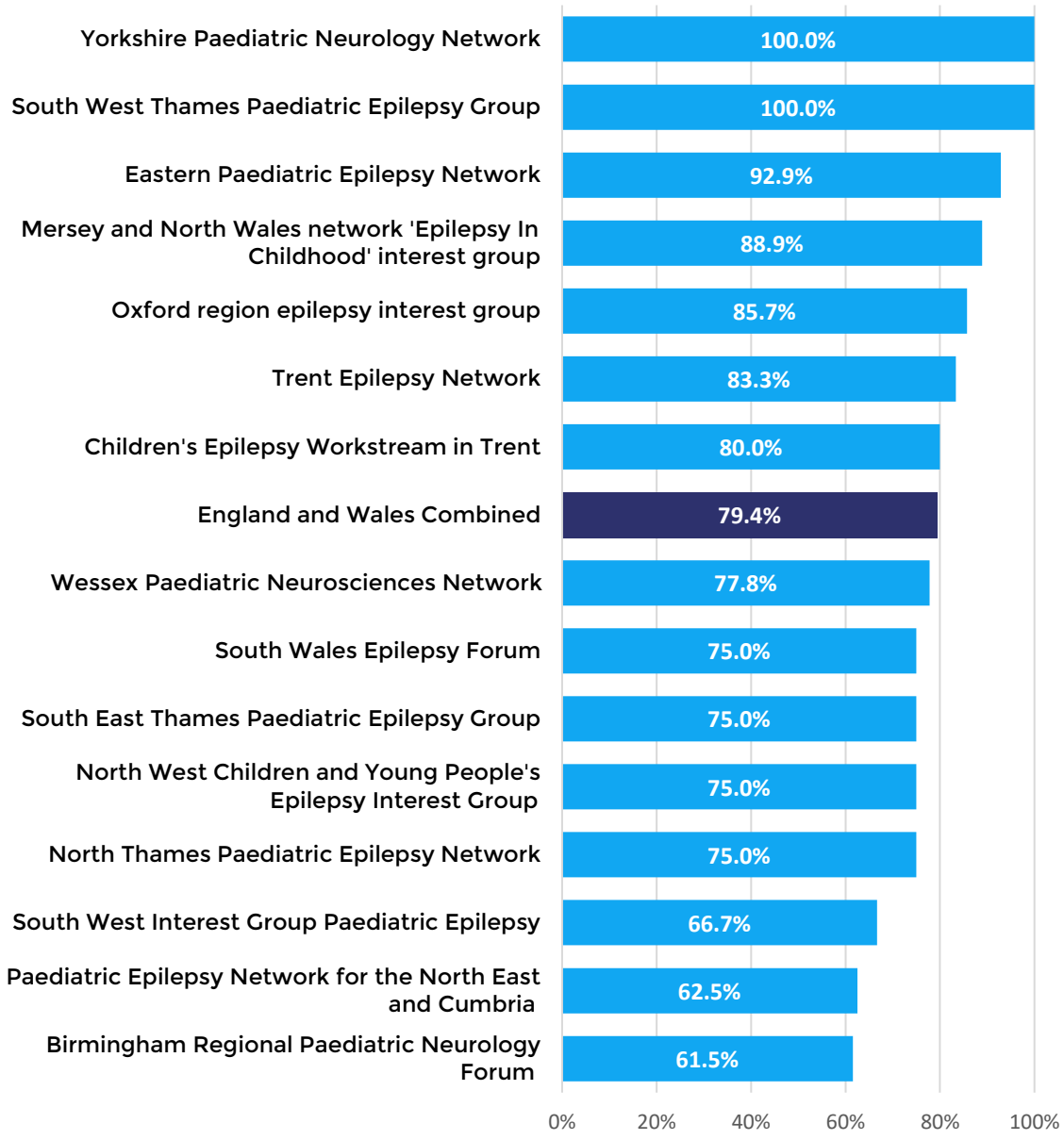
% of Health Boards and Trusts that could provide specialist advice between scheduled reviews every weekday for 52 weeks per year



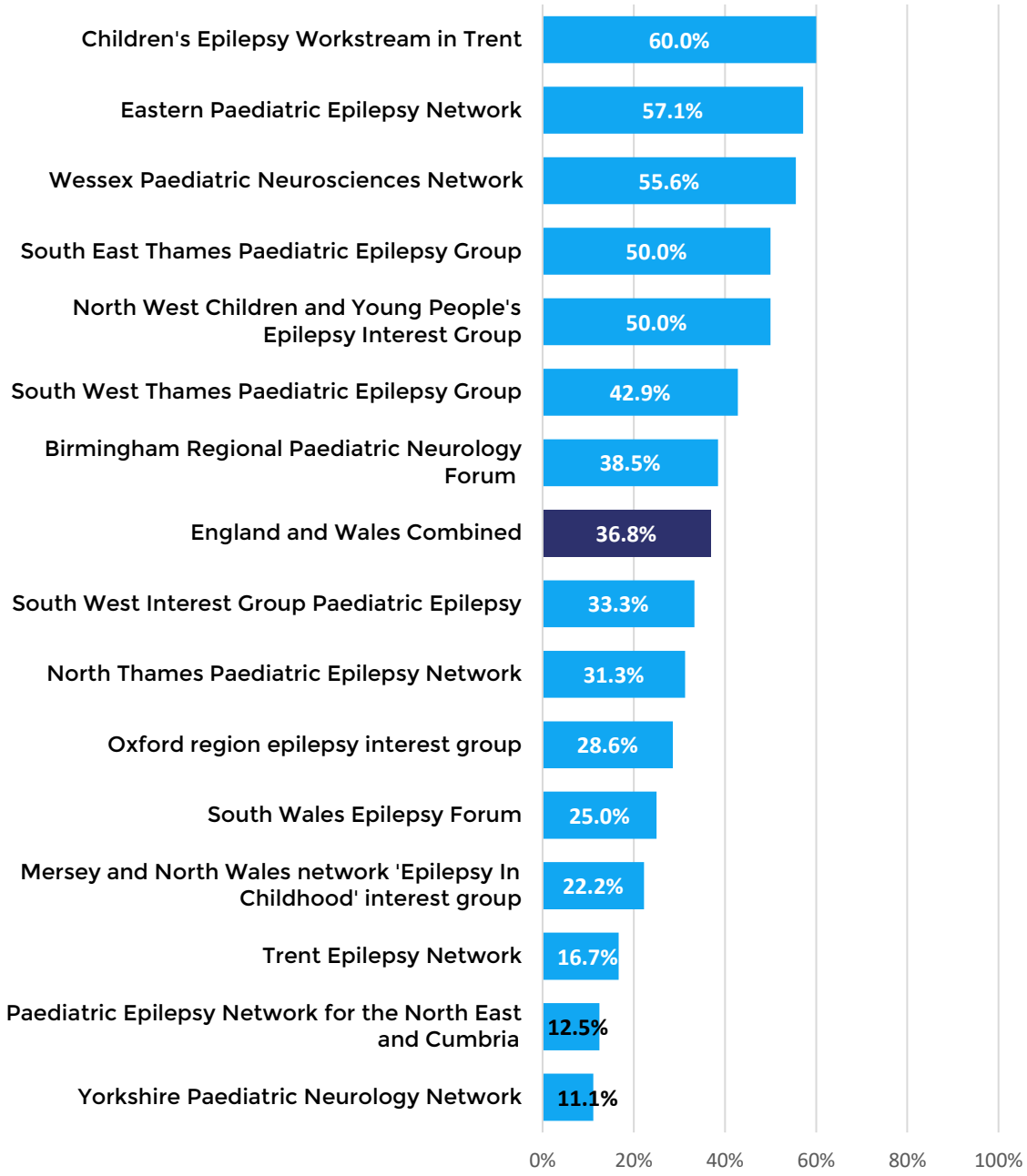
% of Health Boards and Trusts that have evidence of a clear point of contact for non-paediatric professionals seeking paediatric epilepsy support.



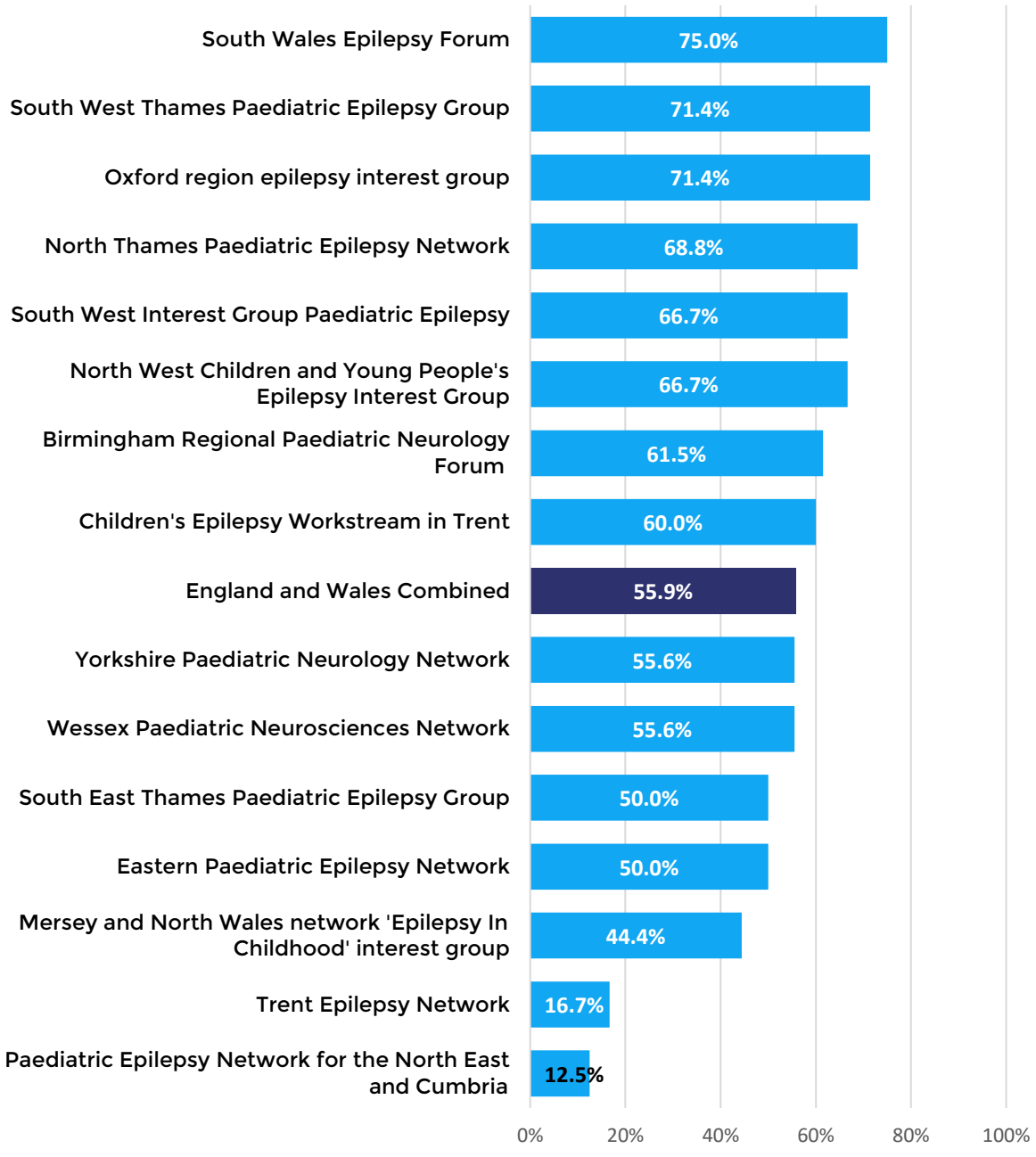
% of Health Boards and Trusts that have agreed referral pathway to adult services.



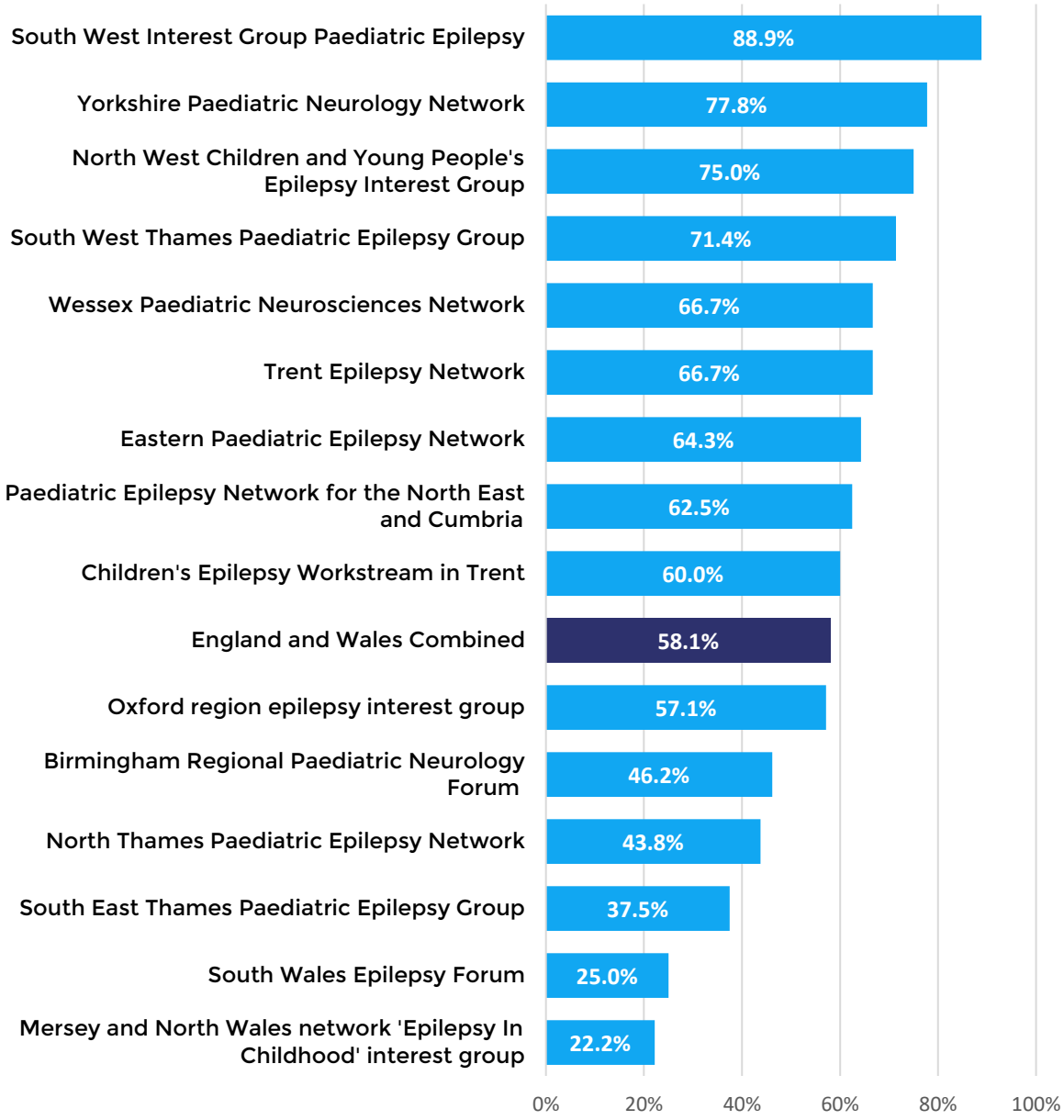
% of Health Boards and Trusts that have an outpatient clinic specifically for young people with epilepsies



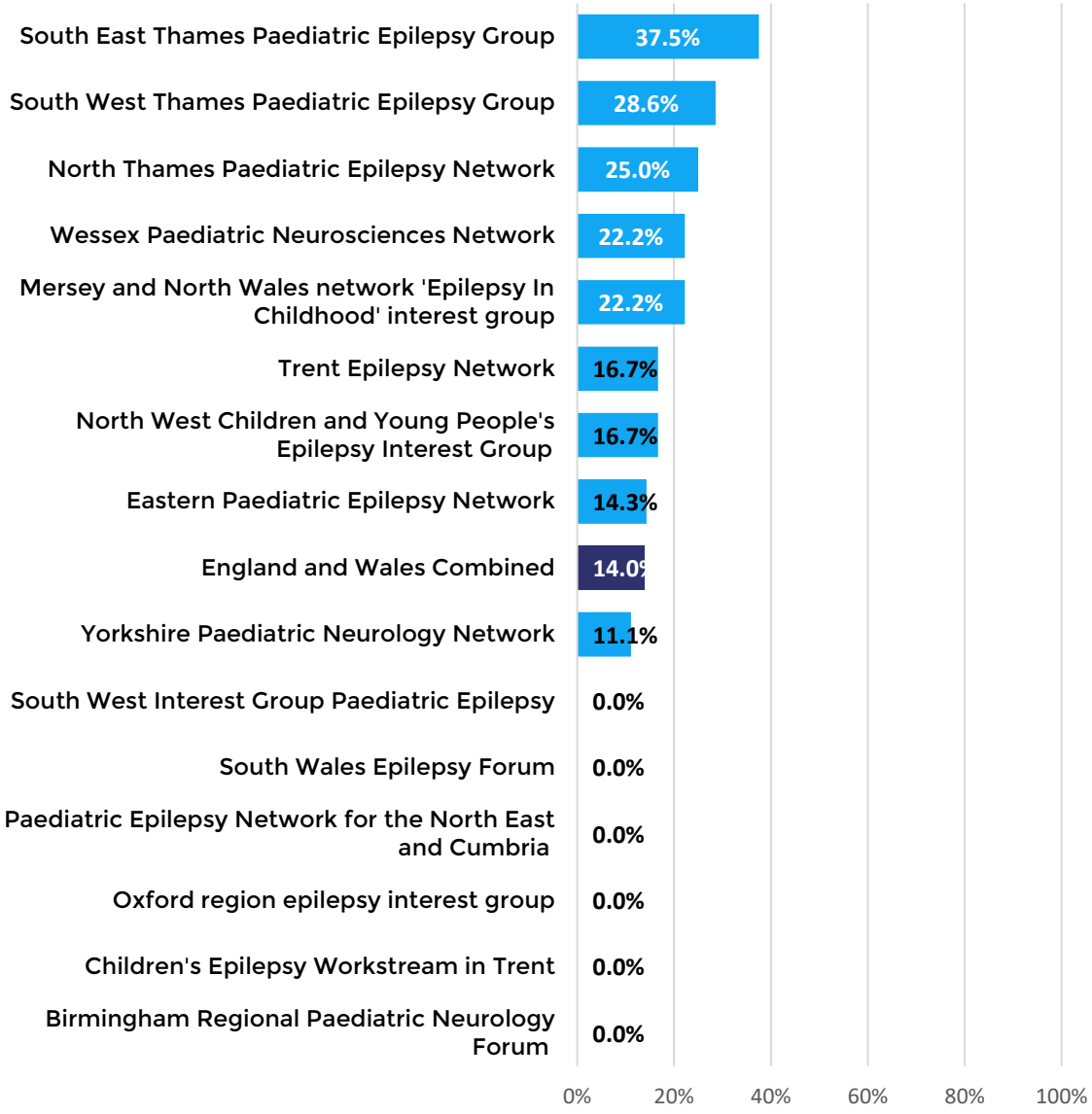
% of Health Boards and Trusts that have an outpatient epilepsy service involving adult and paediatric professionals



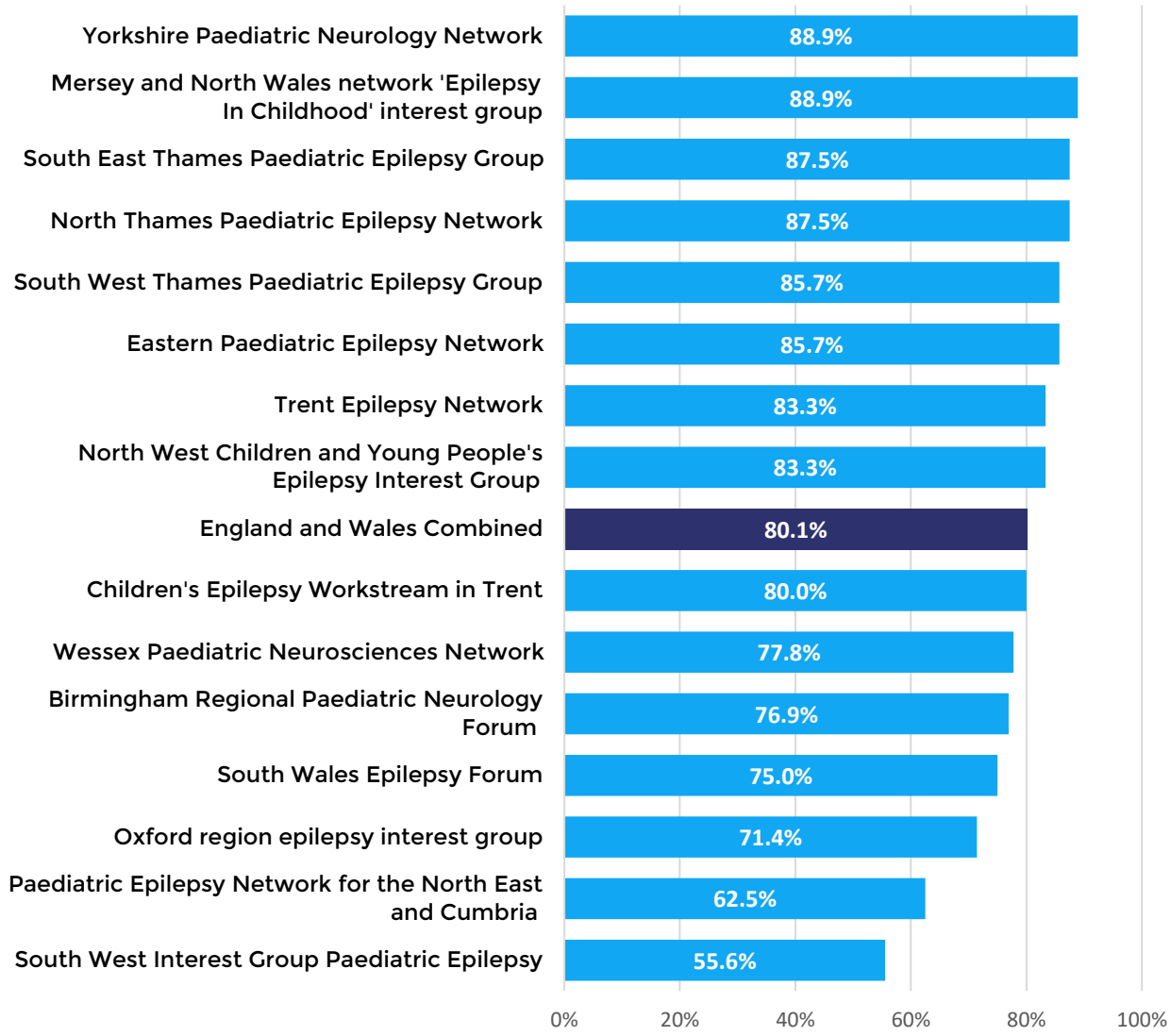
% of Health Boards and Trusts that have structured resources to support Young People transition



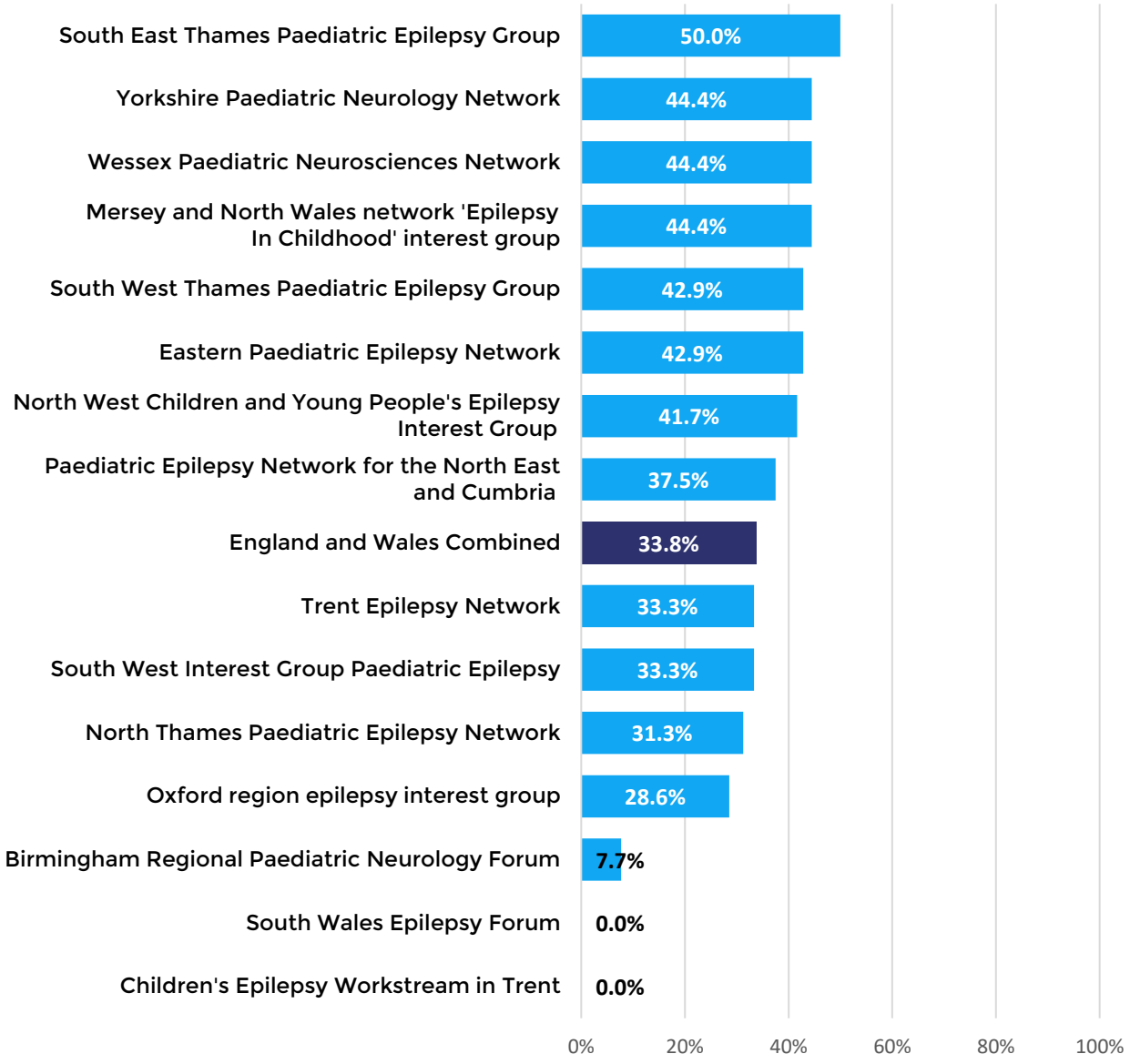
% of Health Boards and Trusts that facilitate mental health provision within epilepsy clinics



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

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

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

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

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

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

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

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

Appendix E: 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 British Association for Community Child Health (BACCH) and Royal College of Paediatrics and Child Health (RCPCH) publication "Covering all bases - Community Child Health: A paediatric workforce guide".

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

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

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

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

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

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

Appendix F: Useful resources

The Royal College of Paediatrics and Child Health

The Royal College of Paediatrics and Child Health (RCPCH) was founded in 1996. We play a major role in postgraduate medical education, professional standards, research and policy. The RCPCH has a number of useful resources, including:

- **British Paediatric Surveillance Unit** www.rcpch.ac.uk/work-we-do/bpsu
  The BPSU is a world leading centre for rare paediatric disease surveillance. It enables doctors and researchers to investigate how many children in the UK and Republic of Ireland are affected by particular rare diseases, conditions or treatments each year.

- **Courses and online learning** www.rcpch.ac.uk/education/courses

- **Continuing professional development** www.rcpch.ac.uk/education/continuing-professional-development

- **Invited reviews** www.rcpch.ac.uk/invitedreviews
  We support healthcare organisations, commissioners and clinical teams to resolve concerns about paediatric service provision, safety, training, compliance with standards, and proposals for paediatric reconfiguration or service design. Our service is confidential, established and influential, and tailored to each organisation's needs.

- **Medicines for Children** www.medicinesforchildren.org.uk
  The Medicines for Children website provides parents and carers with information they can trust on over 200 medicines commonly prescribed to children. It offers free access to patient information leaflets and videos specifically developed to advice parents and carers how to give medicine to their child.

- **MedsIQ** www.qicentral.org.uk/meds-iq
  Medication errors are a significant but preventable cause of harm to children and young people.

  Research activities www.rcpch.ac.uk/work-we-do/research-activities
- We aim to improve children's health outcomes through supporting high quality and trusted research. Let's share our expertise, collaborate with others and promote the evidence to drive forward improvements in child health.

- **RCPCH QI Central:** www.qicentral.org.uk
  QI Central is a free online resource open to all child health professionals to help embed QI projects in clinical practice and continually improve services and outcomes for infants, children and young people. As an online repository of peer-reviewed tools and projects, healthcare professionals are also able to submit their own projects and resources to share their experiences with others and propagate knowledge in quality improvement.

- **Workforce and service design** www.rcpch.ac.uk/workforce
  We play a key role in workforce planning to ensure there is an appropriately trained paediatric medical workforce to deliver safe and sustainable services for children in the UK - in the present and in the future.

Epilepsy12 Audit Key Stakeholder Organisations

British Paediatric Neurology Association bpna.org.uk

The British Paediatric Neurology Association is the professional organisation for doctors who specialise in the care of children with neurological disorders.

Epilepsy Action www.epilepsy.org.uk

Epilepsy Action is a community of people committed to a better life for everyone affected by epilepsy. We want high quality, accessible epilepsy healthcare services, so that people with epilepsy have the support they need to manage their condition. We want wider awareness and understanding of epilepsy, so that people living with the condition are treated with fairness and respect.

Epilepsy Scotland www.epilepsyscotland.org.uk

In Scotland 54,000 people live with epilepsy. Children and older people are most at risk of developing this common serious neurological condition but anyone can develop epilepsy at any time, and 8 people a day in Scotland do. We want to make sure the needs of people with epilepsy are met. This is why we campaign for improved healthcare, better information provision and an end to stigma.

Royal College of Nursing www.rcn.org.uk

The RCN is a membership organisation of more than 435,000 registered nurses, midwives, health care assistants and nursing students. We are both a professional body, carrying out work on nursing standards, education and practice, and a trade union.

Epilepsy Specialist Nurses Association (ESNA) www.esna-online.org.uk

ESNA is a professional organisation whose membership consists of nurses and other health professionals working to support people with epilepsy in the fields of adults, learning disabilities and paediatrics. ESNA works with its membership to raise the profile of epilepsy and to encourage a holistic and co-ordinated approach to care to enable our patients to reach the goal of self-management.

Young Epilepsy www.youngepilepsy.org.uk

Young Epilepsy is the national charity supporting children and young people aged 25 and under with epilepsy and associated conditions, as well as their families. With over 100 years expertise we provide world class diagnosis, assessment and rehabilitation for children and young people with epilepsy. We also undertake research into the condition and how it can be treated.

British Academy of Childhood Disability www.bacdis.org.uk

Membership is open to all professionals working in the field of childhood disability, including paediatrics, psychiatry, specialist nursing, speech and language therapy, physiotherapy, occupational therapy, psychology and education.

British Society for Clinical Neurophysiology www.bscn.org.uk

The BSCN is a medical charity whose aims, set out in our articles of association, are "to promote and encourage for the public benefit the science and practice of clinical neurophysiology and related sciences".