

# EPILEPSY12

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

Extended Analysis 2

Organisational audit national and  
regional results

Round 4, November 2022

# Participation

The OPEN UK Regional Paediatric Epilepsy Networks are named below. The abbreviated regional network names appear in the regional network results of the organisational audit in this report.

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

**Table 1** provides a breakdown of Epilepsy12 Round 4, 2022 Organisational audit participation by Paediatric Epilepsy Networks and by country.

- **128 out of 140 (91%)** registered Health Boards and Trusts submitted and locked November 2022 Organisational audit data.
- **80% (115/144), 82% (119/145), 94% (136/145) and 100% (148/148)** of registered Health Boards and Trusts submitted and locked 2021, 2020, 2019 and 2018 Organisational audit data respectively.

Health Boards and Trusts submitted data to describe their paediatric epilepsy service as of 1 November 2022, and this information was used to describe the organisation of epilepsy services for children and young people in England and Wales.

**Table 1: Epilepsy12 Round 4 2022 Organisational Audit participation by Paediatric Epilepsy Networks and by country.**

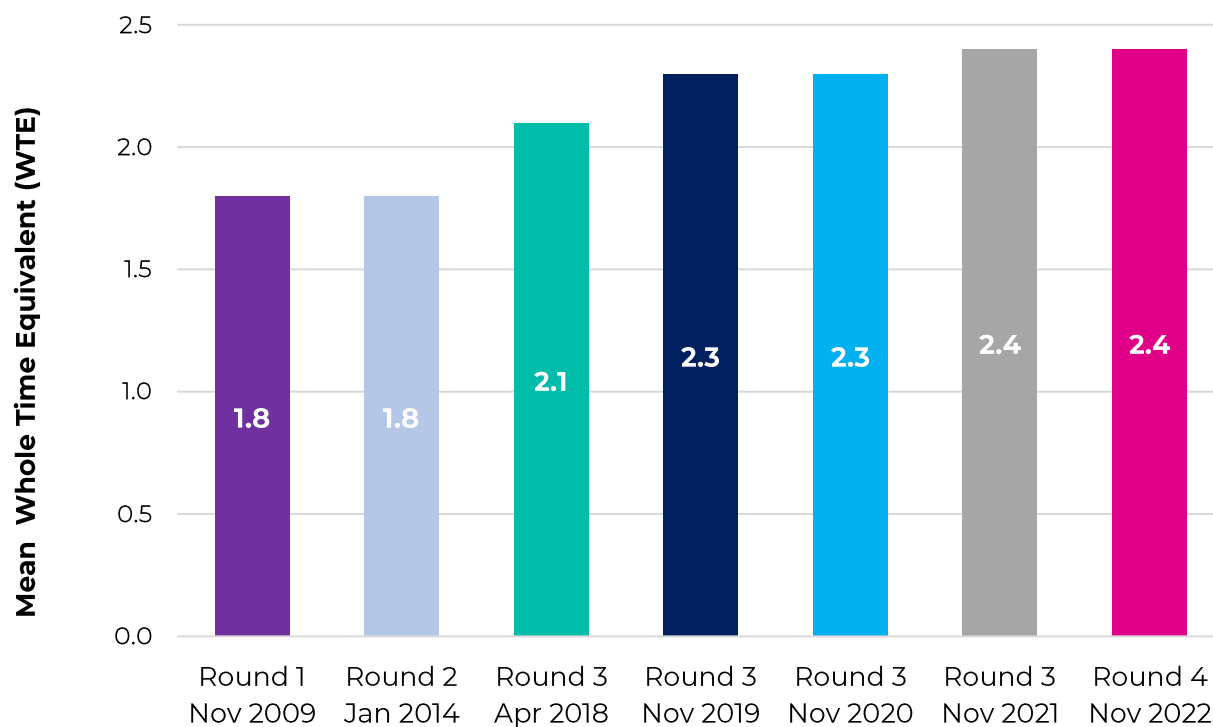
| Country/network   | Number of registered T/HBs | Number of Ts/HBs that have submitted and locked 2022 organisational audit data |
|-------------------|----------------------------|--|
| England and Wales | 140                        | 91% (128/140)  |
| England           | 134                        | 91% (122/134)  |
| Wales             | 6                          | 100% (6/6)   |
|                   |                            |  |
| BRPNF             | 14                         | 86% (12/14)  |
| CEWT              | 6                          | 67% (4/6)  |
| EPEN              | 13                         | 100% (13/13)   |
| EPIC              | 9                          | 89% (8/9)  |
| NTPEN             | 15                         | 87% (13/15)  |
| NWEIG             | 12                         | 92% (11/12)  |
| ORENG             | 7                          | 100% (7/7)   |
| PENNEC            | 8                          | 88% (7/8)  |
| SETPEG            | 10                         | 90% (9/10)   |
| SWEP              | 5                          | 100% (5/5)   |
| SWIPE             | 9                          | 100% (9/9)   |
| SWTPEG            | 8                          | 100% (8/8)   |
| TEN               | 6                          | 100% (6/6)   |
| WPNN              | 9                          | 89% (8/9)  |
| YPEN              | 9                          | 89% (8/9)  |

## Workforce

### Consultant paediatrician

**Table 2** shows that in November 2022, the total whole time equivalent (WTE) for general paediatric consultants employed across England and Wales was **2156.7**. A total of **310.0** WTE paediatric consultants with 'expertise in epilepsy' were employed across England and Wales. This is equivalent to **14% (310/2156.7)** of the total reported WTE general paediatric (consultant or associate specialist) workforce, (**Table 3**). **98% (126/128)** of Health Boards and Trusts employed a consultant paediatrician with 'expertise in epilepsy', this ranged from 0.2 WTE to 15.8 WTE, (**Table 4**). In **12% (15/128)** of Health Boards and Trusts, there was no defined paediatric epilepsy clinical lead, (**Table 5**).

**Figure 1** shows a comparison of the mean WTE consultant paediatrician with expertise in epilepsy employed in Health Boards and Trusts across England and Wales in Round 1 (November 2009), Round 2 (January 2014), Round 3; April 2018, November 2019, November 2020, November 2021 and Round 4 November 2022.



**Figure 1: Mean Whole Time Equivalent (WTE) consultant paediatrician with 'expertise in epilepsy' employed in Health Boards and Trusts across England and Wales in Round 1, Round 2, Round 3 April 2018, November 2019, November 2020, November 2021 and Round 4 November 2022.**

**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 |
|------------------------------------|-----------|----------|
| <b>England &amp; Wales (N=128)</b> | 2156.7    | 16.8     |
| <b>England (N=122)</b>             | 2017.5    | 16.5     |
| <b>Wales (N=6)</b>                 | 139.2     | 23.2     |
|                                    |           |          |
| <b>BRPNF (N=12)</b>                | 157.6     | 13.1     |
| <b>CEWT (N=4)</b>                  | 99.2      | 24.8     |
| <b>EPEN (N=13)</b>                 | 192.5     | 14.8     |
| <b>EPIC (N=8)</b>                  | 110.0     | 13.8     |
| <b>NTPEN (N=13)</b>                | 216.4     | 16.6     |
| <b>NWEIG (N=11)</b>                | 194.0     | 17.6     |
| <b>ORENG (N=7)</b>                 | 112.1     | 16.0     |
| <b>PENNEC (N=7)</b>                | 138.0     | 19.7     |
| <b>SETPEG (N=9)</b>                | 184.5     | 20.5     |
| <b>SWEP (N=5)</b>                  | 109.2     | 21.8     |
| <b>SWIPE (N=9)</b>                 | 154.6     | 17.2     |
| <b>SWTPEG (N=8)</b>                | 163.2     | 20.4     |
| <b>TEN (N=6)</b>                   | 84.1      | 14.0     |
| <b>WPNN (N=8)</b>                  | 107.3     | 13.4     |
| <b>YPEN (N=8)</b>                  | 134.2     | 16.8     |

**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' |
|------------------------------------|-----------|----------|---------|---------|--|
| <b>England &amp; Wales (N=128)</b> | 310.0     | 2.4      | 0.0     | 15.8    | 14% (310/2156.7)   |
| <b>England (N=122)</b>             | 290.4     | 2.4      | 0.0     | 15.8    | 14% (290.4/2017.5)   |
| <b>Wales (N=6)</b>                 | 19.6      | 3.3      | 1.0     | 7.6     | 14% (19.6/139.2)   |
|                                    |           |          |         |         |  |
| <b>BRPNF (N=12)</b>                | 25.5      | 2.1      | 0.0     | 8.0     | 16% (25.5/157.6)   |
| <b>CEWT (N=4)</b>                  | 11.7      | 2.9      | 1.0     | 6.0     | 12% (11.7/99.2)  |
| <b>EPEN (N=13)</b>                 | 25.3      | 1.9      | 0.6     | 4.0     | 13% (25.3/192.5)   |
| <b>EPIC (N=8)</b>                  | 23.1      | 2.9      | 1.0     | 7.6     | 21% (23.05/110)  |
| <b>NTPEN (N=13)</b>                | 28.2      | 2.2      | 0.0     | 7.0     | 13% (28.2/216.4)   |
| <b>NWEIG (N=11)</b>                | 34.0      | 3.1      | 0.2     | 15.8    | 18% (34/194)   |
| <b>ORENG (N=7)</b>                 | 16.0      | 2.3      | 1.0     | 5.0     | 14% (16/112.1)   |
| <b>PENNEC (N=7)</b>                | 26.2      | 3.7      | 1.2     | 9.0     | 19% (26.2/138)   |
| <b>SETPEG (N=9)</b>                | 18.8      | 2.1      | 1.0     | 3.0     | 10% (18.8/184.5)   |
| <b>SWEP (N=5)</b>                  | 12.0      | 2.4      | 1.0     | 3.0     | 11% (12/109.2)   |
| <b>SWIPE (N=9)</b>                 | 20.5      | 2.3      | 1.0     | 4.8     | 13% (20.5/154.6)   |
| <b>SWTPEG (N=8)</b>                | 16.6      | 2.1      | 1.0     | 4.2     | 10% (16.6/163.2)   |
| <b>TEN (N=6)</b>                   | 10.0      | 1.7      | 1.0     | 3.0     | 12% (10/84.101)  |
| <b>WPNN (N=8)</b>                  | 19.4      | 2.4      | 1.0     | 4.0     | 18% (19.4/107.3)   |
| <b>YPEN (N=8)</b>                  | 22.8      | 2.9      | 1.0     | 9.0     | 17% (22.8/134.2)   |

**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 |
|------------------------------------|-----------------|---------------|----------------------------------|
| <b>England &amp; Wales (N=128)</b> | 98% (126/128)   | 2% (2/128)    | 0.2 - 15.8                       |
| <b>England (N=122)</b>             | 98% (120/122)   | 2% (2/122)    | 0.2 - 15.8                       |
| <b>Wales (N=6)</b>                 | 100% (6/6)      | 0% (0/6)      | 1.0 - 7.6                        |
|                                    |                 |               |                                  |
| <b>BRPNF (N=12)</b>                | 92% (11/12)     | 8% (1/12)     | 0.7 - 8.0                        |
| <b>CEWT (N=4)</b>                  | 100% (4/4)      | 0% (0/4)      | 1.0 - 6.0                        |
| <b>EPEN (N=13)</b>                 | 100% (13/13)    | 0% (0/13)     | 0.6 - 4.0                        |
| <b>EPIC (N=8)</b>                  | 100% (8/8)      | 0% (0/8)      | 1.0 - 7.6                        |
| <b>NTPEN (N=13)</b>                | 92% (12/13)     | 8% (1/13)     | 1.0 - 7.0                        |
| <b>NWEIG (N=11)</b>                | 100% (11/11)    | 0% (0/11)     | 0.2 - 15.8                       |
| <b>ORENG (N=7)</b>                 | 100% (7/7)      | 0% (0/7)      | 1.0 - 5.0                        |
| <b>PENNEC (N=7)</b>                | 100% (7/7)      | 0% (0/7)      | 1.2 - 9.0                        |
| <b>SETPEG (N=9)</b>                | 100% (9/9)      | 0% (0/9)      | 1.0 - 3.0                        |
| <b>SWEP (N=5)</b>                  | 100% (5/5)      | 0% (0/5)      | 1.0 - 3.0                        |
| <b>SWIPE (N=9)</b>                 | 100% (9/9)      | 0% (0/9)      | 1.0 - 4.8                        |
| <b>SWTPEG (N=8)</b>                | 100% (8/8)      | 0% (0/8)      | 1.0 - 4.2                        |
| <b>TEN (N=6)</b>                   | 100% (6/6)      | 0% (0/6)      | 1.0 - 3.0                        |
| <b>WPNN (N=8)</b>                  | 100% (8/8)      | 0% (0/8)      | 1.0 - 4.0                        |
| <b>YPEN (N=8)</b>                  | 100% (8/8)      | 0% (0/8)      | 1.0 - 9.0                        |

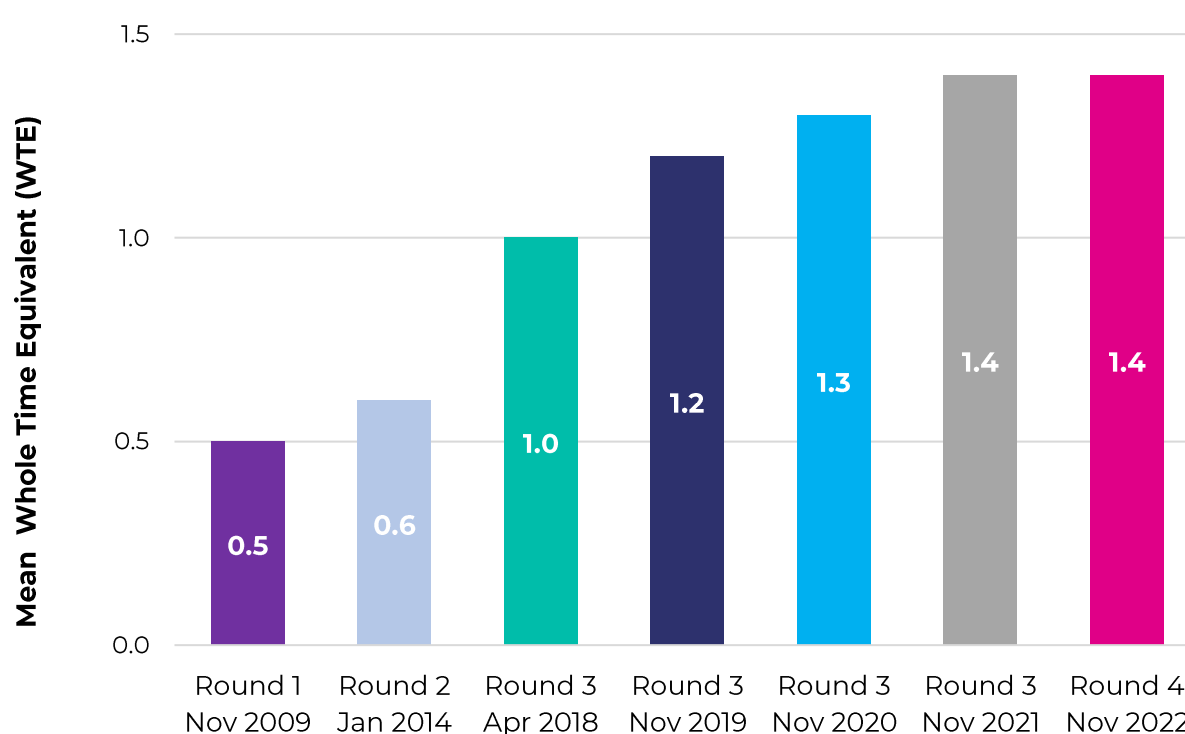
**Table 5: Health Boards and Trusts that had a defined paediatric epilepsy clinical lead.**

| Country/network                    | % with a defined lead | % with no defined lead |
|------------------------------------|-----------------------|------------------------|
| <b>England &amp; Wales (N=128)</b> | 88% (113/128)         | 12% (15/128)           |
| <b>England (N=122)</b>             | 89% (108/122)         | 11% (14/122)           |
| <b>Wales (N=6)</b>                 | 83% (5/6)             | 17% (1/6)              |
|                                    |                       |                        |
| <b>BRPNF (N=12)</b>                | 67% (8/12)            | 33% (4/12)             |
| <b>CEWT (N=4)</b>                  | 100% (4/4)            | 0% (0/4)               |
| <b>EPEN (N=13)</b>                 | 100% (13/13)          | 0% (0/13)              |
| <b>EPIC (N=8)</b>                  | 100% (8/8)            | 0% (0/8)               |
| <b>NTPEN (N=13)</b>                | 85% (11/13)           | 15% (2/13)             |
| <b>NWEIG (N=11)</b>                | 100% (11/11)          | 0% (0/11)              |
| <b>ORENG (N=7)</b>                 | 100% (7/7)            | 0% (0/7)               |
| <b>PENNEC (N=7)</b>                | 71% (5/7)             | 29% (2/7)              |
| <b>SETPEG (N=9)</b>                | 67% (6/9)             | 33% (3/9)              |
| <b>SWEP (N=5)</b>                  | 80% (4/5)             | 20% (1/5)              |
| <b>SWIPE (N=9)</b>                 | 89% (8/9)             | 11% (1/9)              |
| <b>SWTPEG (N=8)</b>                | 100% (8/8)            | 0% (0/8)               |
| <b>TEN (N=6)</b>                   | 100% (6/6)            | 0% (0/6)               |
| <b>WPNN (N=8)</b>                  | 88% (7/8)             | 13% (1/8)              |
| <b>YPEN (N=8)</b>                  | 88% (7/8)             | 13% (1/8)              |

## Epilepsy specialist nurse

In November 2022, there was a total of **178.4** WTE epilepsy specialist nurses (ESN) reported to be employed across England and Wales. **91% (117/128)** of Health Boards and Trusts had some epilepsy specialist nurses (ESN) provision (i.e. greater than 0 WTE). Of those with an ESN, the number employed ranged from **0.02 WTE** to **4.4 WTE**, (Table 7).

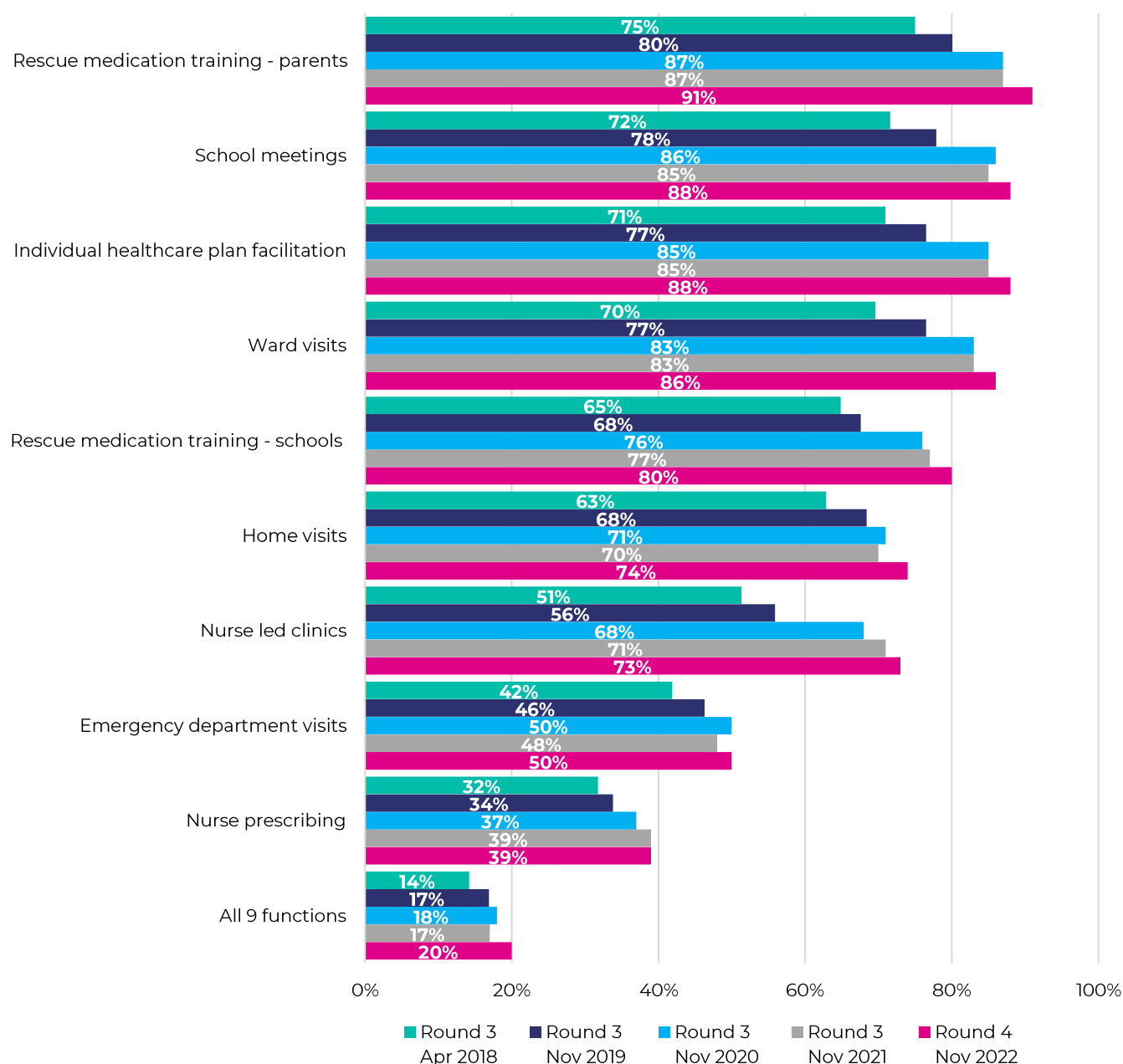
**Figure 2** shows a comparison of the mean WTE for epilepsy specialist nurses (ESN) employed in England and Wales in Round 1 (November 2009), Round 2 (January 2014), Round 3; April 2018, November 2019, November 2020, November 2021 and Round 4 November 2022.



**Figure 2: Mean Whole Time Equivalent (WTE) epilepsy specialist nurses employed in England and Wales in Round 1, Round 2, Round 3 April 2018, November 2019, November 2020, November 2021 and Round 4 November 2022.**

### Functions supported by Epilepsy Specialist Nurses (all Health Boards or Trusts)

Figure 3 shows the percentage of Health Boards and Trusts supporting key ESN functions. More than **80%** of Health Boards/Trusts indicated that they could offer ESN support for; rescue medication training for parents, school meetings, individual healthcare plan facilitation, ward visits and rescue medication training for parents. **20% (25/128)** of Health Boards and Trusts reported they could support all nine functions, **Table 8**.



**Figure 3: Percentage of Health Boards and Trusts that could support epilepsy specialist nurse functions in Round 3 April 2018, November 2019, November 2020, November 2021 and Round 4 November 2022.**



**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 |
|------------------------------------|-----------|----------|---------|---------|
| <b>England &amp; Wales (N=128)</b> | 178.4     | 1.4      | 0.0     | 4.4     |
| <b>England (N=122)</b>             | 167.3     | 1.4      | 0.0     | 4.4     |
| <b>Wales (N=6)</b>                 | 11.1      | 1.9      | 0.0     | 3.0     |
|                                    |           |          |         |         |
| <b>BRPNF (N=12)</b>                | 8.5       | 0.7      | 0.0     | 2.0     |
| <b>CEWT (N=4)</b>                  | 8.6       | 2.2      | 1.0     | 4.0     |
| <b>EPEN (N=13)</b>                 | 17.5      | 1.3      | 0.6     | 3.0     |
| <b>EPIC (N=8)</b>                  | 13.9      | 1.7      | 0.7     | 3.8     |
| <b>NTPEN (N=13)</b>                | 19.4      | 1.5      | 0.0     | 3.7     |
| <b>NWEIG (N=11)</b>                | 16.2      | 1.5      | 0.0     | 2.6     |
| <b>ORENG (N=7)</b>                 | 5.1       | 0.7      | 0.0     | 1.5     |
| <b>PENNEC (N=7)</b>                | 11.6      | 1.7      | 1.0     | 2.5     |
| <b>SETPEG (N=9)</b>                | 10.9      | 1.2      | 0.0     | 3.0     |
| <b>SWEP (N=5)</b>                  | 8.3       | 1.7      | 0.0     | 3.0     |
| <b>SWIPE (N=9)</b>                 | 14.3      | 1.6      | 0.3     | 2.8     |
| <b>SWTPEG (N=8)</b>                | 8.6       | 1.1      | 0.8     | 1.6     |
| <b>TEN (N=6)</b>                   | 12.4      | 2.1      | 1.0     | 4.4     |
| <b>WPNN (N=8)</b>                  | 10.3      | 1.3      | 0.0     | 2.5     |
| <b>YPEN (N=8)</b>                  | 12.7      | 1.6      | 0.6     | 2.5     |

**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 |
|------------------------------------|-----------------|---------------|----------------------------------|
| <b>England &amp; Wales (N=128)</b> | 91% (117/128)   | 9% (11/128)   | 0.02 - 4.4                       |
| <b>England (N=122)</b>             | 92% (112/122)   | 8% (10/122)   | 0.02 - 4.4                       |
| <b>Wales (N=6)</b>                 | 83% (5/6)       | 17% (1/6)     | 1.0 - 3.0                        |
|                                    |                 |               |                                  |
| <b>BRPNF (N=12)</b>                | 67% (8/12)      | 33% (4/12)    | 0.8 - 2.0                        |
| <b>CEWT (N=4)</b>                  | 100% (4/4)      | 0% (0/4)      | 1.0 - 4.0                        |
| <b>EPEN (N=13)</b>                 | 100% (13/13)    | 0% (0/13)     | 0.6 - 3.0                        |
| <b>EPIC (N=8)</b>                  | 100% (8/8)      | 0% (0/8)      | 0.7 - 3.8                        |
| <b>NTPEN (N=13)</b>                | 100% (13/13)    | 0% (0/13)     | 0.02 - 3.7                       |
| <b>NWEIG (N=11)</b>                | 91% (10/11)     | 9% (1/11)     | 1.0 - 2.6                        |
| <b>ORENG (N=7)</b>                 | 71% (5/7)       | 29% (2/7)     | 0.6 - 1.5                        |
| <b>PENNEC (N=7)</b>                | 100% (7/7)      | 0% (0/7)      | 1.0 - 2.5                        |
| <b>SETPEG (N=9)</b>                | 78% (7/9)       | 22% (2/9)     | 0.8 - 3.0                        |
| <b>SWEP (N=5)</b>                  | 80% (4/5)       | 20% (1/5)     | 1.0 - 3.0                        |
| <b>SWIPE (N=9)</b>                 | 100% (9/9)      | 0% (0/9)      | 0.3 - 2.8                        |
| <b>SWTPEG (N=8)</b>                | 100% (8/8)      | 0% (0/8)      | 0.8 - 1.6                        |
| <b>TEN (N=6)</b>                   | 100% (6/6)      | 0% (0/6)      | 1.0 - 4.4                        |
| <b>WPNN (N=8)</b>                  | 88% (7/8)       | 13% (1/8)     | 0.2 - 2.5                        |
| <b>YPEN (N=8)</b>                  | 100% (8/8)      | 0% (0/8)      | 0.6 - 2.5                        |

**Table 8: Health Boards and Trusts that could support epilepsy nurse functions.**

| Country/network                    | Home visits  | Nurse led clinics | Emergency department visits | Ward visits   | Nurse prescribing | School meetings |
|------------------------------------|--------------|-------------------|-----------------------------|---------------|-------------------|-----------------|
| <b>England &amp; Wales (N=128)</b> | 74% (95/128) | 73% (94/128)      | 50% (64/128)                | 86% (110/128) | 39% (50/128)      | 88% (112/128)   |
| <b>England (N=122)</b>             | 75% (91/122) | 74% (90/122)      | 52% (64/122)                | 86% (105/122) | 40% (49/122)      | 88% (107/122)   |
| <b>Wales (N=6)</b>                 | 67% (4/6)    | 67% (4/6)         | 0% (0/6)                    | 83% (5/6)     | 17% (1/6)         | 83% (5/6)       |
|                                    |              |                   |                             |               |                   |                 |
| <b>BRPNF (N=12)</b>                | 42% (5/12)   | 50% (6/12)        | 25% (3/12)                  | 58% (7/12)    | 25% (3/12)        | 58% (7/12)      |
| <b>CEWT (N=4)</b>                  | 50% (2/4)    | 75% (3/4)         | 50% (2/4)                   | 75% (3/4)     | 25% (1/4)         | 50% (2/4)       |
| <b>EPEN (N=13)</b>                 | 69% (9/13)   | 85% (11/13)       | 77% (10/13)                 | 100% (13/13)  | 38% (5/13)        | 92% (12/13)     |
| <b>EPIC (N=8)</b>                  | 100% (8/8)   | 63% (5/8)         | 50% (4/8)                   | 100% (8/8)    | 75% (6/8)         | 100% (8/8)      |
| <b>NTPEN (N=13)</b>                | 85% (11/13)  | 85% (11/13)       | 69% (9/13)                  | 100% (13/13)  | 31% (4/13)        | 92% (12/13)     |
| <b>NWEIG (N=11)</b>                | 91% (10/11)  | 73% (8/11)        | 36% (4/11)                  | 91% (10/11)   | 55% (6/11)        | 91% (10/11)     |
| <b>ORENG (N=7)</b>                 | 71% (5/7)    | 71% (5/7)         | 57% (4/7)                   | 71% (5/7)     | 29% (2/7)         | 71% (5/7)       |
| <b>PENNEC (N=7)</b>                | 100% (7/7)   | 86% (6/7)         | 57% (4/7)                   | 71% (5/7)     | 71% (5/7)         | 100% (7/7)      |
| <b>SETPEG (N=9)</b>                | 33% (3/9)    | 56% (5/9)         | 56% (5/9)                   | 78% (7/9)     | 11% (1/9)         | 78% (7/9)       |
| <b>SWEP (N=5)</b>                  | 60% (3/5)    | 60% (3/5)         | 0% (0/5)                    | 80% (4/5)     | 0% (0/5)          | 80% (4/5)       |
| <b>SWIPE (N=9)</b>                 | 78% (7/9)    | 78% (7/9)         | 78% (7/9)                   | 100% (9/9)    | 67% (6/9)         | 100% (9/9)      |
| <b>SWTPEG (N=8)</b>                | 88% (7/8)    | 75% (6/8)         | 63% (5/8)                   | 100% (8/8)    | 25% (2/8)         | 100% (8/8)      |
| <b>TEN (N=6)</b>                   | 100% (6/6)   | 83% (5/6)         | 33% (2/6)                   | 83% (5/6)     | 50% (3/6)         | 100% (6/6)      |
| <b>WPNN (N=8)</b>                  | 75% (6/8)    | 75% (6/8)         | 38% (3/8)                   | 88% (7/8)     | 38% (3/8)         | 88% (7/8)       |
| <b>YPEN (N=8)</b>                  | 75% (6/8)    | 88% (7/8)         | 25% (2/8)                   | 75% (6/8)     | 38% (3/8)         | 100% (8/8)      |

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

| Country/network                    | Individual HCP facilitation | Rescue medication training parents | Rescue medication training schools | Supporting all 9 functions |
|------------------------------------|-----------------------------|------------------------------------|------------------------------------|----------------------------|
| <b>England &amp; Wales (N=128)</b> | 88% (113/128)               | 91% (116/128)                      | 80% (102/128)                      | 20% (25/128)               |
| <b>England (N=122)</b>             | 89% (108/122)               | 91% (111/122)                      | 80% (97/122)                       | 20% (25/122)               |
| <b>Wales (N=6)</b>                 | 83% (5/6)                   | 83% (5/6)                          | 83% (5/6)                          | 0% (0/6)                   |
|                                    |                             |                                    |                                    |                            |
| <b>BRPNF (N=12)</b>                | 67% (8/12)                  | 67% (8/12)                         | 33% (4/12)                         | 8% (1/12)                  |
| <b>CEWT (N=4)</b>                  | 100% (4/4)                  | 100% (4/4)                         | 75% (3/4)                          | 25% (1/4)                  |
| <b>EPEN (N=13)</b>                 | 92% (12/13)                 | 92% (12/13)                        | 92% (12/13)                        | 31% (4/13)                 |
| <b>EPIC (N=8)</b>                  | 100% (8/8)                  | 100% (8/8)                         | 100% (8/8)                         | 25% (2/8)                  |
| <b>NTPEN (N=13)</b>                | 92% (12/13)                 | 100% (13/13)                       | 77% (10/13)                        | 15% (2/13)                 |
| <b>NWEIG (N=11)</b>                | 91% (10/11)                 | 91% (10/11)                        | 91% (10/11)                        | 18% (2/11)                 |
| <b>ORENG (N=7)</b>                 | 71% (5/7)                   | 71% (5/7)                          | 43% (3/7)                          | 14% (1/7)                  |
| <b>PENNEC (N=7)</b>                | 100% (7/7)                  | 100% (7/7)                         | 100% (7/7)                         | 57% (4/7)                  |
| <b>SETPEG (N=9)</b>                | 78% (7/9)                   | 78% (7/9)                          | 78% (7/9)                          | 0% (0/9)                   |
| <b>SWEP (N=5)</b>                  | 80% (4/5)                   | 80% (4/5)                          | 80% (4/5)                          | 0% (0/5)                   |
| <b>SWIPE (N=9)</b>                 | 100% (9/9)                  | 100% (9/9)                         | 100% (9/9)                         | 33% (3/9)                  |
| <b>SWTPEG (N=8)</b>                | 100% (8/8)                  | 100% (8/8)                         | 100% (8/8)                         | 25% (2/8)                  |
| <b>TEN (N=6)</b>                   | 83% (5/6)                   | 100% (6/6)                         | 100% (6/6)                         | 0% (0/6)                   |
| <b>WPNN (N=8)</b>                  | 88% (7/8)                   | 88% (7/8)                          | 38% (3/8)                          | 13% (1/8)                  |
| <b>YPEN (N=8)</b>                  | 88% (7/8)                   | 100% (8/8)                         | 100% (8/8)                         | 25% (2/8)                  |

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

| Country/network                    | Home visits  | Nurse led clinics | Emergency department visits | Ward visits   | Nurse prescribing | School meetings |
|------------------------------------|--------------|-------------------|-----------------------------|---------------|-------------------|-----------------|
| <b>England &amp; Wales (N=117)</b> | 81% (95/117) | 80% (94/117)      | 55% (64/117)                | 94% (110/117) | 43% (50/117)      | 96% (112/117)   |
| <b>England (N=112)</b>             | 81% (91/112) | 80% (90/112)      | 57% (64/112)                | 94% (105/112) | 44% (49/112)      | 96% (107/112)   |
| <b>Wales (N=5)</b>                 | 80% (4/5)    | 80% (4/5)         | 0% (0/5)                    | 100% (5/5)    | 20% (1/5)         | 100% (5/5)      |
|                                    |              |                   |                             |               |                   |                 |
| <b>BRPNF (N=8)</b>                 | 63% (5/8)    | 75% (6/8)         | 38% (3/8)                   | 88% (7/8)     | 38% (3/8)         | 88% (7/8)       |
| <b>CEWT (N=4)</b>                  | 50% (2/4)    | 75% (3/4)         | 50% (2/4)                   | 75% (3/4)     | 25% (1/4)         | 50% (2/4)       |
| <b>EPEN (N=13)</b>                 | 69% (9/13)   | 85% (11/13)       | 77% (10/13)                 | 100% (13/13)  | 38% (5/13)        | 92% (12/13)     |
| <b>EPIC (N=8)</b>                  | 100% (8/8)   | 63% (5/8)         | 50% (4/8)                   | 100% (8/8)    | 75% (6/8)         | 100% (8/8)      |
| <b>NTPEN (N=13)</b>                | 85% (11/13)  | 85% (11/13)       | 69% (9/13)                  | 100% (13/13)  | 31% (4/13)        | 92% (12/13)     |
| <b>NWEIG (N=10)</b>                | 100% (10/10) | 80% (8/10)        | 40% (4/10)                  | 100% (10/10)  | 60% (6/10)        | 100% (10/10)    |
| <b>ORENG (N=5)</b>                 | 100% (5/5)   | 100% (5/5)        | 80% (4/5)                   | 100% (5/5)    | 40% (2/5)         | 100% (5/5)      |
| <b>PENNEC (N=7)</b>                | 100% (7/7)   | 86% (6/7)         | 57% (4/7)                   | 71% (5/7)     | 71% (5/7)         | 100% (7/7)      |
| <b>SETPEG (N=7)</b>                | 43% (3/7)    | 71% (5/7)         | 71% (5/7)                   | 100% (7/7)    | 14% (1/7)         | 100% (7/7)      |
| <b>SWEP (N=4)</b>                  | 75% (3/4)    | 75% (3/4)         | 0% (0/4)                    | 100% (4/4)    | 0% (0/4)          | 100% (4/4)      |
| <b>SWIPE (N=9)</b>                 | 78% (7/9)    | 78% (7/9)         | 78% (7/9)                   | 100% (9/9)    | 67% (6/9)         | 100% (9/9)      |
| <b>SWTPEG (N=8)</b>                | 88% (7/8)    | 75% (6/8)         | 63% (5/8)                   | 100% (8/8)    | 25% (2/8)         | 100% (8/8)      |
| <b>TEN (N=6)</b>                   | 100% (6/6)   | 83% (5/6)         | 33% (2/6)                   | 83% (5/6)     | 50% (3/6)         | 100% (6/6)      |
| <b>WPNN (N=7)</b>                  | 86% (6/7)    | 86% (6/7)         | 43% (3/7)                   | 100% (7/7)    | 43% (3/7)         | 100% (7/7)      |
| <b>YPEN (N=8)</b>                  | 75% (6/8)    | 88% (7/8)         | 25% (2/8)                   | 75% (6/8)     | 38% (3/8)         | 100% (8/8)      |

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

| Country/network                    | Individual HCP facilitation | Rescue medication training with parents | Rescue medication training in schools | Supporting all 9 functions |
|------------------------------------|-----------------------------|---|---------------------------------------|----------------------------|
| <b>England &amp; Wales (N=117)</b> | 97% (113/117)               | 99% (116/117)                           | 87% (102/117)                         | 21% (25/117)               |
| <b>England (N=112)</b>             | 96% (108/112)               | 99% (111/112)                           | 87% (97/112)                          | 22% (25/112)               |
| <b>Wales (N=5)</b>                 | 100% (5/5)                  | 100% (5/5)                              | 100% (5/5)                            | 0% (0/5)                   |
|                                    |                             |   |                                       |                            |
| <b>BRPNF (N=8)</b>                 | 100% (8/8)                  | 100% (8/8)                              | 50% (4/8)                             | 13% (1/8)                  |
| <b>CEWT (N=4)</b>                  | 100% (4/4)                  | 100% (4/4)                              | 75% (3/4)                             | 25% (1/4)                  |
| <b>EPEN (N=13)</b>                 | 92% (12/13)                 | 92% (12/13)                             | 92% (12/13)                           | 31% (4/13)                 |
| <b>EPIC (N=8)</b>                  | 100% (8/8)                  | 100% (8/8)                              | 100% (8/8)                            | 25% (2/8)                  |
| <b>NTPEN (N=13)</b>                | 92% (12/13)                 | 100% (13/13)                            | 77% (10/13)                           | 15% (2/13)                 |
| <b>NWEIG (N=10)</b>                | 100% (10/10)                | 100% (10/10)                            | 100% (10/10)                          | 20% (2/10)                 |
| <b>ORENG (N=5)</b>                 | 100% (5/5)                  | 100% (5/5)                              | 60% (3/5)                             | 20% (1/5)                  |
| <b>PENNEC (N=7)</b>                | 100% (7/7)                  | 100% (7/7)                              | 100% (7/7)                            | 57% (4/7)                  |
| <b>SETPEG (N=7)</b>                | 100% (7/7)                  | 100% (7/7)                              | 100% (7/7)                            | 0% (0/7)                   |
| <b>SWEP (N=4)</b>                  | 100% (4/4)                  | 100% (4/4)                              | 100% (4/4)                            | 0% (0/4)                   |
| <b>SWIPE (N=9)</b>                 | 100% (9/9)                  | 100% (9/9)                              | 100% (9/9)                            | 33% (3/9)                  |
| <b>SWTPEG (N=8)</b>                | 100% (8/8)                  | 100% (8/8)                              | 100% (8/8)                            | 25% (2/8)                  |
| <b>TEN (N=6)</b>                   | 83% (5/6)                   | 100% (6/6)                              | 100% (6/6)                            | 0% (0/6)                   |
| <b>WPNN (N=7)</b>                  | 100% (7/7)                  | 100% (7/7)                              | 43% (3/7)                             | 14% (1/7)                  |
| <b>YPEN (N=8)</b>                  | 88% (7/8)                   | 100% (8/8)                              | 100% (8/8)                            | 25% (2/8)                  |

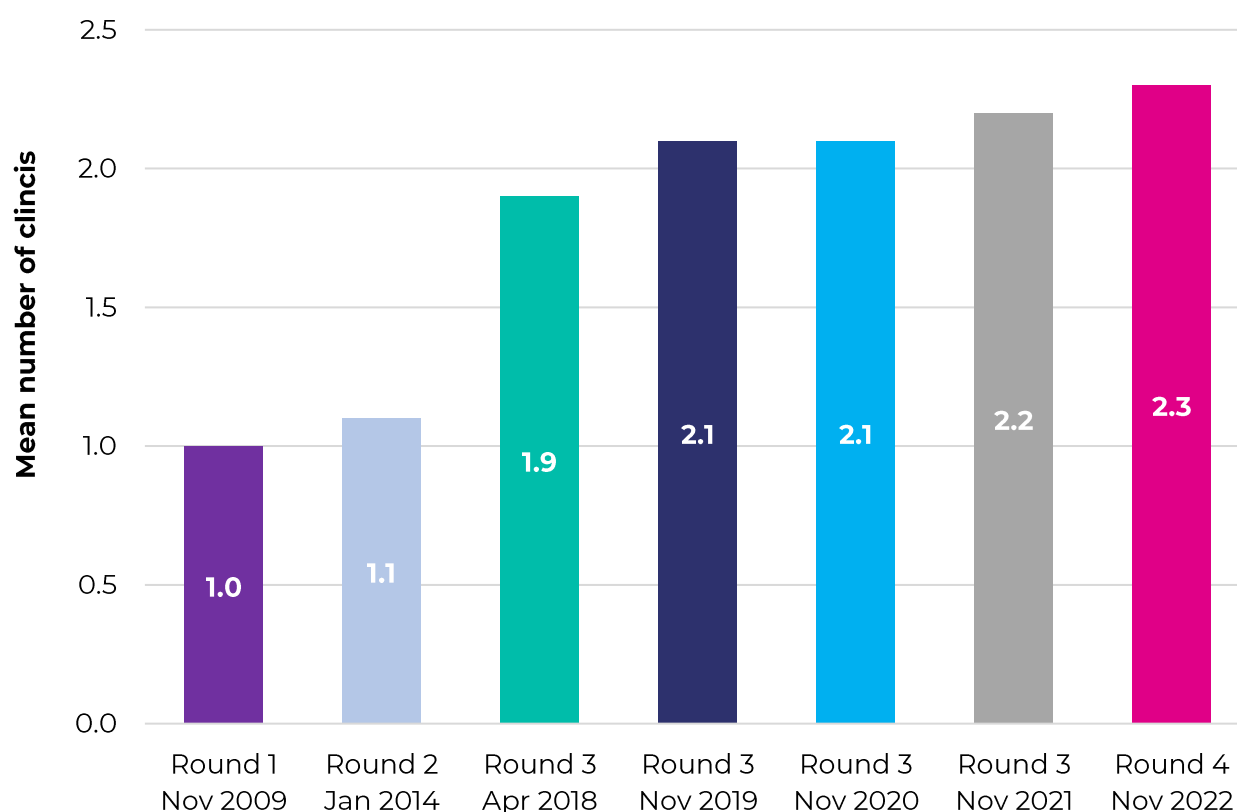
# Clinic configuration

## Defined epilepsy clinic

**92% (118/128)** of Health Boards and Trusts had defined epilepsy clinic, seeing patients at secondary level, (**Table 10**). Of those, **87% (103/118)** were holding defined epilepsy clinics that allowed at least 20 minutes with a consultant with expertise in epilepsy and an ESN, either simultaneously or in succession, (**Table 12**).

**Figure 4** shows a comparison of the mean of consultant or associate specialist led secondary level epilepsy clinics in

Round 1 (November 2009), Round 2 (January 2014), Round 3; April 2018, November 2019, November 2020, November 2021 and Round 4 November 2022.



**Figure 4: Mean number of consultant or associate specialist led secondary level epilepsy clinics in Round 1, Round 2, Round 3 April 2018, November 2019, November 2020, November 2021 and Round 4 November 2022.**

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

| Country/network                    | % with a defined epilepsy clinic | % with no defined epilepsy clinic |
|------------------------------------|----------------------------------|-----------------------------------|
| <b>England &amp; Wales (N=128)</b> | 92% (118/128)                    | 8% (10/128)                       |
| <b>England (N=122)</b>             | 93% (113/122)                    | 7% (9/122)                        |
| <b>Wales (N=6)</b>                 | 83% (5/6)                        | 17% (1/6)                         |
|                                    |                                  |                                   |
| <b>BRPNF (N=12)</b>                | 67% (8/12)                       | 33% (4/12)                        |
| <b>CEWT (N=4)</b>                  | 100% (4/4)                       | 0% (0/4)                          |
| <b>EPEN (N=13)</b>                 | 92% (12/13)                      | 8% (1/13)                         |
| <b>EPIC (N=8)</b>                  | 100% (8/8)                       | 0% (0/8)                          |
| <b>NTPEN (N=13)</b>                | 92% (12/13)                      | 8% (1/13)                         |
| <b>NWEIG (N=11)</b>                | 100% (11/11)                     | 0% (0/11)                         |
| <b>ORENG (N=7)</b>                 | 100% (7/7)                       | 0% (0/7)                          |
| <b>PENNEC (N=7)</b>                | 100% (7/7)                       | 0% (0/7)                          |
| <b>SETPEG (N=9)</b>                | 100% (9/9)                       | 0% (0/9)                          |
| <b>SWEP (N=5)</b>                  | 80% (4/5)                        | 20% (1/5)                         |
| <b>SWIPE (N=9)</b>                 | 89% (8/9)                        | 11% (1/9)                         |
| <b>SWTPEG (N=8)</b>                | 100% (8/8)                       | 0% (0/8)                          |
| <b>TEN (N=6)</b>                   | 100% (6/6)                       | 0% (0/6)                          |
| <b>WPNN (N=8)</b>                  | 88% (7/8)                        | 13% (1/8)                         |
| <b>YPEN (N=8)</b>                  | 88% (7/8)                        | 13% (1/8)                         |

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

| Country/network                    | Total no. clinics per week | Mean no. clinics per week | Min no. clinics per week | Max no. clinics per week |
|------------------------------------|----------------------------|---------------------------|--------------------------|--------------------------|
| <b>England &amp; Wales (N=118)</b> | 268.1                      | 2.3                       | 0.1                      | 7.0                      |
| <b>England (N=113)</b>             | 252.8                      | 2.2                       | 0.1                      | 7.0                      |
| <b>Wales (N=5)</b>                 | 15.3                       | 3.1                       | 2.0                      | 4.0                      |
|                                    |                            |                           |                          |                          |
| <b>BRPNF (N=8)</b>                 | 15.7                       | 2.0                       | 1.0                      | 4.0                      |
| <b>CEWT (N=4)</b>                  | 9.0                        | 2.3                       | 1.5                      | 4.0                      |
| <b>EPEN (N=12)</b>                 | 25.9                       | 2.2                       | 0.8                      | 4.5                      |
| <b>EPIC (N=8)</b>                  | 16.4                       | 2.1                       | 0.8                      | 3.3                      |
| <b>NTPEN (N=12)</b>                | 22.3                       | 1.9                       | 1.0                      | 3.8                      |
| <b>NWEIG (N=11)</b>                | 24.0                       | 2.2                       | 1.0                      | 5.0                      |
| <b>ORENG (N=7)</b>                 | 11.1                       | 1.6                       | 0.1                      | 4.5                      |
| <b>PENNEC (N=7)</b>                | 16.3                       | 2.3                       | 0.5                      | 4.0                      |
| <b>SETPEG (N=9)</b>                | 27.5                       | 3.1                       | 2.0                      | 6.0                      |
| <b>SWEP (N=4)</b>                  | 12.0                       | 3.0                       | 2.0                      | 4.0                      |
| <b>SWIPE (N=8)</b>                 | 16.0                       | 2.0                       | 1.0                      | 3.3                      |
| <b>SWTPEG (N=8)</b>                | 24.9                       | 3.1                       | 2.0                      | 4.7                      |
| <b>TEN (N=6)</b>                   | 9.3                        | 1.5                       | 0.5                      | 2.0                      |
| <b>WPNN (N=7)</b>                  | 21.8                       | 3.1                       | 0.5                      | 7.0                      |
| <b>YPEN (N=7)</b>                  | 16.1                       | 2.3                       | 1.0                      | 4.0                      |

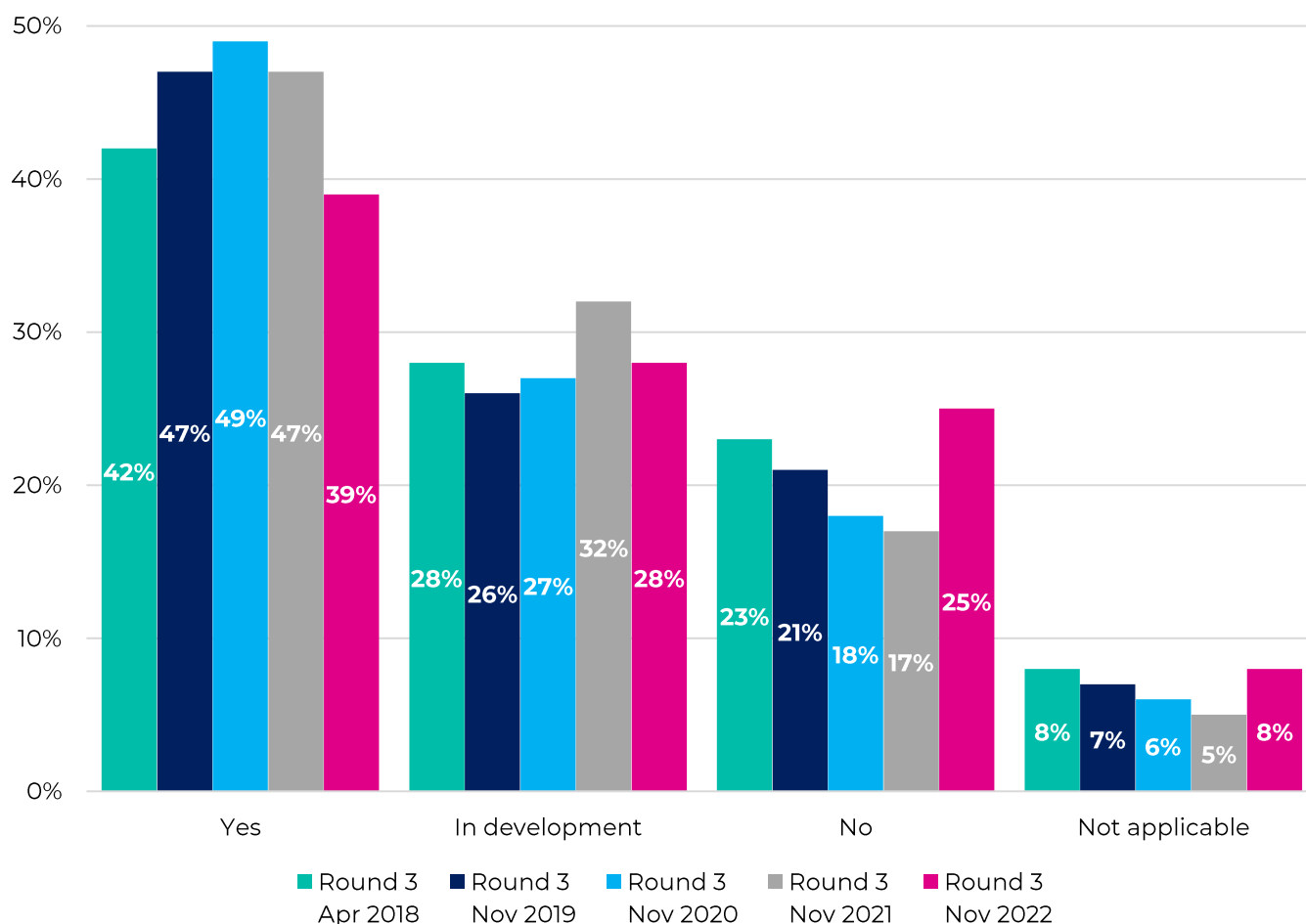


**Table 12: Defined epilepsy clinics that allowed at least 20 minutes with a consultant with ‘expertise in epilepsy’ and/or an epilepsy specialist nurse.**

| Country/network                    | % with a defined epilepsy clinic | % with no defined epilepsy clinic |
|------------------------------------|----------------------------------|-----------------------------------|
| <b>England &amp; Wales (N=118)</b> | 87% (103/118)                    | 13% (15/118)                      |
| <b>England (N=113)</b>             | 87% (98/113)                     | 13% (15/113)                      |
| <b>Wales (N=5)</b>                 | 100% (5/5)                       | 0% (0/5)                          |
|                                    |                                  |                                   |
| <b>BRPNF (N=8)</b>                 | 100% (8/8)                       | 0% (0/8)                          |
| <b>CEWT (N=4)</b>                  | 50% (2/4)                        | 50% (2/4)                         |
| <b>EPEN (N=12)</b>                 | 75% (9/12)                       | 25% (3/12)                        |
| <b>EPIC (N=8)</b>                  | 88% (7/8)                        | 13% (1/8)                         |
| <b>NTPEN (N=12)</b>                | 83% (10/12)                      | 17% (2/12)                        |
| <b>NWEIG (N=11)</b>                | 100% (11/11)                     | 0% (0/11)                         |
| <b>ORENG (N=7)</b>                 | 71% (5/7)                        | 29% (2/7)                         |
| <b>PENNEC (N=7)</b>                | 71% (5/7)                        | 29% (2/7)                         |
| <b>SETPEG (N=9)</b>                | 100% (9/9)                       | 0% (0/9)                          |
| <b>SWEP (N=4)</b>                  | 100% (4/4)                       | 0% (0/4)                          |
| <b>SWIPE (N=8)</b>                 | 88% (7/8)                        | 13% (1/8)                         |
| <b>SWTPEG (N=8)</b>                | 100% (8/8)                       | 0% (0/8)                          |
| <b>TEN (N=6)</b>                   | 83% (5/6)                        | 17% (1/6)                         |
| <b>WPNN (N=7)</b>                  | 100% (7/7)                       | 0% (0/7)                          |
| <b>YPEN (N=7)</b>                  | 86% (6/7)                        | 14% (1/7)                         |

## Epilepsy Best Practice Criteria (BPC) – England only

**Table 13** shows **39% (48/122)** of Trusts in England were running epilepsy clinics to 2019 Best Practice Criteria standards. This was a decrease compared to previous Round 3 cohorts.



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

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

| Country/network        | Yes          | In development | No           | N/A         |
|------------------------|--------------|----------------|--------------|-------------|
| <b>England (N=122)</b> | 39% (48/122) | 28% (34/122)   | 25% (30/122) | 8% (10/122) |
| <b>BRPNF (N=12)</b>    | 25% (3/12)   | 25% (3/12)     | 50% (6/12)   | 0% (0/12)   |
| <b>CEWT (N=4)</b>      | 25% (1/4)    | 25% (1/4)      | 25% (1/4)    | 25% (1/4)   |
| <b>EPEN (N=13)</b>     | 46% (6/13)   | 15% (2/13)     | 23% (3/13)   | 15% (2/13)  |
| <b>EPIC (N=8)</b>      | 13% (1/8)    | 63% (5/8)      | 13% (1/8)    | 0% (0/8)    |
| <b>NTPEN (N=13)</b>    | 15% (2/13)   | 46% (6/13)     | 15% (2/13)   | 23% (3/13)  |
| <b>NWEIG (N=11)</b>    | 18% (2/11)   | 45% (5/11)     | 36% (4/11)   | 0% (0/11)   |
| <b>ORENG (N=7)</b>     | 29% (2/7)    | 29% (2/7)      | 43% (3/7)    | 0% (0/7)    |
| <b>PENNEC (N=7)</b>    | 57% (4/7)    | 0% (0/7)       | 43% (3/7)    | 0% (0/7)    |
| <b>SETPEG (N=9)</b>    | 56% (5/9)    | 11% (1/9)      | 33% (3/9)    | 0% (0/9)    |
| <b>SWIPE (N=9)</b>     | 56% (5/9)    | 22% (2/9)      | 22% (2/9)    | 0% (0/9)    |
| <b>SWTPEG (N=8)</b>    | 75% (6/8)    | 0% (0/8)       | 13% (1/8)    | 13% (1/8)   |
| <b>TEN (N=6)</b>       | 67% (4/6)    | 33% (2/6)      | 0% (0/6)     | 0% (0/6)    |
| <b>WPNN (N=8)</b>      | 38% (3/8)    | 38% (3/8)      | 0% (0/8)     | 25% (2/8)   |
| <b>YPEN (N=8)</b>      | 50% (4/8)    | 25% (2/8)      | 13% (1/8)    | 13% (1/8)   |

## Tertiary provision

### Paediatric neurology services

A total of **89.4** 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% (21/128)** of Health Boards and Trusts employed a paediatric neurologist, this ranged from **0.001 WTE** to **10.6 WTE**, (**Table 15**).

**95% (121/128)** of Health Boards and Trusts had agreed referral pathways to tertiary paediatric neurology services, **Table 16**.

**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 |
|------------------------------------|-----------|---------|---------|
| <b>England &amp; Wales (N=128)</b> | 89.4      | 0.0     | 10.6    |
| <b>England (N=122)</b>             | 86.6      | 0.0     | 10.6    |
| <b>Wales (N=6)</b>                 | 2.8       | 0.0     | 2.8     |
|                                    |           |         |         |
| <b>BRPNF (N=12)</b>                | 6.0       | 0.0     | 6.0     |
| <b>CEWT (N=4)</b>                  | 3.0       | 0.0     | 3.0     |
| <b>EPEN (N=13)</b>                 | 4.4       | 0.0     | 4.4     |
| <b>EPIC (N=8)</b>                  | 2.8       | 0.0     | 2.8     |
| <b>NTPEN (N=13)</b>                | 16.6      | 0.0     | 10.6    |
| <b>NWEIG (N=11)</b>                | 9.2       | 0.0     | 7.2     |
| <b>ORENG (N=7)</b>                 | 6.0       | 0.0     | 6.0     |
| <b>PENNEC (N=7)</b>                | 4.3       | 0.0     | 4.3     |
| <b>SETPEG (N=9)</b>                | 5.0       | 0.0     | 4.0     |
| <b>SWEP (N=5)</b>                  | 2.8       | 0.0     | 2.8     |
| <b>SWIPE (N=9)</b>                 | 8.0       | 0.0     | 8.0     |
| <b>SWTPEG (N=8)</b>                | 4.0       | 0.0     | 4.0     |
| <b>TEN (N=6)</b>                   | 10.8      | 0.0     | 5.8     |
| <b>WPNN (N=8)</b>                  | 6.5       | 0.0     | 6.5     |
| <b>YPEN (N=8)</b>                  | 0.0       | 0.0     | 0.0     |

**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 |
|------------------------------------|-----------------|---------------|----------------------------------|
| <b>England &amp; Wales (N=128)</b> | 16% (21/128)    | 84% (107/128) | 0.001- 10.6                      |
| <b>England (N=122)</b>             | 16% (20/122)    | 84% (102/122) | 0.001 - 10.6                     |
| <b>Wales (N=6)</b>                 | 17% (1/6)       | 83% (5/6)     | 2.8 - 2.8                        |
|                                    |                 |               |                                  |
| <b>BRPNF (N=12)</b>                | 17% (2/12)      | 83% (10/12)   | 0.02 - 6.0                       |
| <b>CEWT (N=4)</b>                  | 25% (1/4)       | 75% (3/4)     | 3.0 - 3.0                        |
| <b>EPEN (N=13)</b>                 | 8% (1/13)       | 92% (12/13)   | 4.4 - 4.4                        |
| <b>EPIC (N=8)</b>                  | 13% (1/8)       | 88% (7/8)     | 2.8 - 2.8                        |
| <b>NTPEN (N=13)</b>                | 23% (3/13)      | 77% (10/13)   | 3.0 - 10.6                       |
| <b>NWEIG (N=11)</b>                | 18% (2/11)      | 82% (9/11)    | 2.0 - 7.2                        |
| <b>ORENG (N=7)</b>                 | 14% (1/7)       | 86% (6/7)     | 6.0 - 6.0                        |
| <b>PENNEC (N=7)</b>                | 14% (1/7)       | 86% (6/7)     | 4.3 - 4.3                        |
| <b>SETPEG (N=9)</b>                | 22% (2/9)       | 78% (7/9)     | 1.0 - 4.0                        |
| <b>SWEP (N=5)</b>                  | 20% (1/5)       | 80% (4/5)     | 2.8 - 2.8                        |
| <b>SWIPE (N=9)</b>                 | 11% (1/9)       | 89% (8/9)     | 8.0 - 8.0                        |
| <b>SWTPEG (N=8)</b>                | 13% (1/8)       | 88% (7/8)     | 4.0 - 4.0                        |
| <b>TEN (N=6)</b>                   | 33% (2/6)       | 67% (4/6)     | 5.0 - 5.8                        |
| <b>WPNN (N=8)</b>                  | 13% (1/8)       | 88% (7/8)     | 6.5 - 6.5                        |
| <b>YPEN (N=8)</b>                  | 13% (1/8)       | 88% (7/8)     | 0.001 - 0.001                    |

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

| Country/network                    | Yes           | No         |
|------------------------------------|---------------|------------|
| <b>England &amp; Wales (N=128)</b> | 95% (121/128) | 5% (7/128) |
| <b>England (N=122)</b>             | 94% (115/122) | 6% (7/122) |
| <b>Wales (N=6)</b>                 | 100% (6/6)    | 0% (0/6)   |
| <b>BRPNF (N=12)</b>                | 83% (10/12)   | 17% (2/12) |
| <b>CEWT (N=4)</b>                  | 75% (3/4)     | 25% (1/4)  |
| <b>EPEN (N=13)</b>                 | 100% (13/13)  | 0% (0/13)  |
| <b>EPIC (N=8)</b>                  | 88% (7/8)     | 13% (1/8)  |
| <b>NTPEN (N=13)</b>                | 100% (13/13)  | 0% (0/13)  |
| <b>NWEIG (N=11)</b>                | 82% (9/11)    | 18% (2/11) |
| <b>ORENG (N=7)</b>                 | 100% (7/7)    | 0% (0/7)   |
| <b>PENNEC (N=7)</b>                | 86% (6/7)     | 14% (1/7)  |
| <b>SETPEG (N=9)</b>                | 100% (9/9)    | 0% (0/9)   |
| <b>SWEP (N=5)</b>                  | 100% (5/5)    | 0% (0/5)   |
| <b>SWIPE (N=9)</b>                 | 100% (9/9)    | 0% (0/9)   |
| <b>SWTPEG (N=8)</b>                | 100% (8/8)    | 0% (0/8)   |
| <b>TEN (N=6)</b>                   | 100% (6/6)    | 0% (0/6)   |
| <b>WPNN (N=8)</b>                  | 100% (8/8)    | 0% (0/8)   |
| <b>YPEN (N=8)</b>                  | 100% (8/8)    | 0% (0/8)   |

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

| Country/network                    | Yes          | No           | N/A          |
|------------------------------------|--------------|--------------|--------------|
| <b>England &amp; Wales (N=128)</b> | 16% (21/128) | 56% (72/128) | 27% (35/128) |
| <b>England (N=122)</b>             | 17% (21/122) | 55% (67/122) | 28% (34/122) |
| <b>Wales (N=6)</b>                 | 0% (0/6)     | 83% (5/6)    | 17% (1/6)    |
| <b>BRPNF (N=12)</b>                | 8% (1/12)    | 33% (4/12)   | 58% (7/12)   |
| <b>CEWT (N=4)</b>                  | 0% (0/4)     | 25% (1/4)    | 75% (3/4)    |
| <b>EPEN (N=13)</b>                 | 0% (0/13)    | 92% (12/13)  | 8% (1/13)    |
| <b>EPIC (N=8)</b>                  | 0% (0/8)     | 63% (5/8)    | 38% (3/8)    |
| <b>NTPEN (N=13)</b>                | 23% (3/13)   | 54% (7/13)   | 23% (3/13)   |
| <b>NWEIG (N=11)</b>                | 36% (4/11)   | 64% (7/11)   | 0% (0/11)    |
| <b>ORENG (N=7)</b>                 | 43% (3/7)    | 43% (3/7)    | 14% (1/7)    |
| <b>PENNEC (N=7)</b>                | 14% (1/7)    | 71% (5/7)    | 14% (1/7)    |
| <b>SETPEG (N=9)</b>                | 33% (3/9)    | 56% (5/9)    | 11% (1/9)    |
| <b>SWEP (N=5)</b>                  | 0% (0/5)     | 80% (4/5)    | 20% (1/5)    |
| <b>SWIPE (N=9)</b>                 | 11% (1/9)    | 22% (2/9)    | 67% (6/9)    |
| <b>SWTPEG (N=8)</b>                | 13% (1/8)    | 75% (6/8)    | 13% (1/8)    |
| <b>TEN (N=6)</b>                   | 50% (3/6)    | 33% (2/6)    | 17% (1/6)    |
| <b>WPNN (N=8)</b>                  | 13% (1/8)    | 38% (3/8)    | 50% (4/8)    |
| <b>YPEN (N=8)</b>                  | 0% (0/8)     | 75% (6/8)    | 25% (2/8)    |

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

| Country/network                   | Yes         | No           |
|-----------------------------------|-------------|--------------|
| <b>England &amp; Wales (N=93)</b> | 23% (21/93) | 77% (72/93)  |
| <b>England (N=88)</b>             | 24% (21/88) | 76% (67/88)  |
| <b>Wales (N=5)</b>                | 0% (0/5)    | 100% (5/5)   |
| <b>BRPNF (N=5)</b>                | 20% (1/5)   | 80% (4/5)    |
| <b>CEWT (N=1)</b>                 | 0% (0/1)    | 100% (1/1)   |
| <b>EPEN (N=12)</b>                | 0% (0/12)   | 100% (12/12) |
| <b>EPIC (N=5)</b>                 | 0% (0/5)    | 100% (5/5)   |
| <b>NTPEN (N=10)</b>               | 30% (3/10)  | 70% (7/10)   |
| <b>NWEIG (N=11)</b>               | 36% (4/11)  | 64% (7/11)   |
| <b>ORENG (N=6)</b>                | 50% (3/6)   | 50% (3/6)    |
| <b>PENNEC (N=6)</b>               | 17% (1/6)   | 83% (5/6)    |
| <b>SETPEG (N=8)</b>               | 38% (3/8)   | 63% (5/8)    |
| <b>SWEP (N=4)</b>                 | 0% (0/4)    | 100% (4/4)   |
| <b>SWIPE (N=3)</b>                | 33% (1/3)   | 67% (2/3)    |
| <b>SWTPEG (N=7)</b>               | 14% (1/7)   | 86% (6/7)    |
| <b>TEN (N=5)</b>                  | 60% (3/5)   | 40% (2/5)    |
| <b>WPNN (N=4)</b>                 | 25% (1/4)   | 75% (3/4)    |
| <b>YPEN (N=6)</b>                 | 0% (0/6)    | 100% (6/6)   |

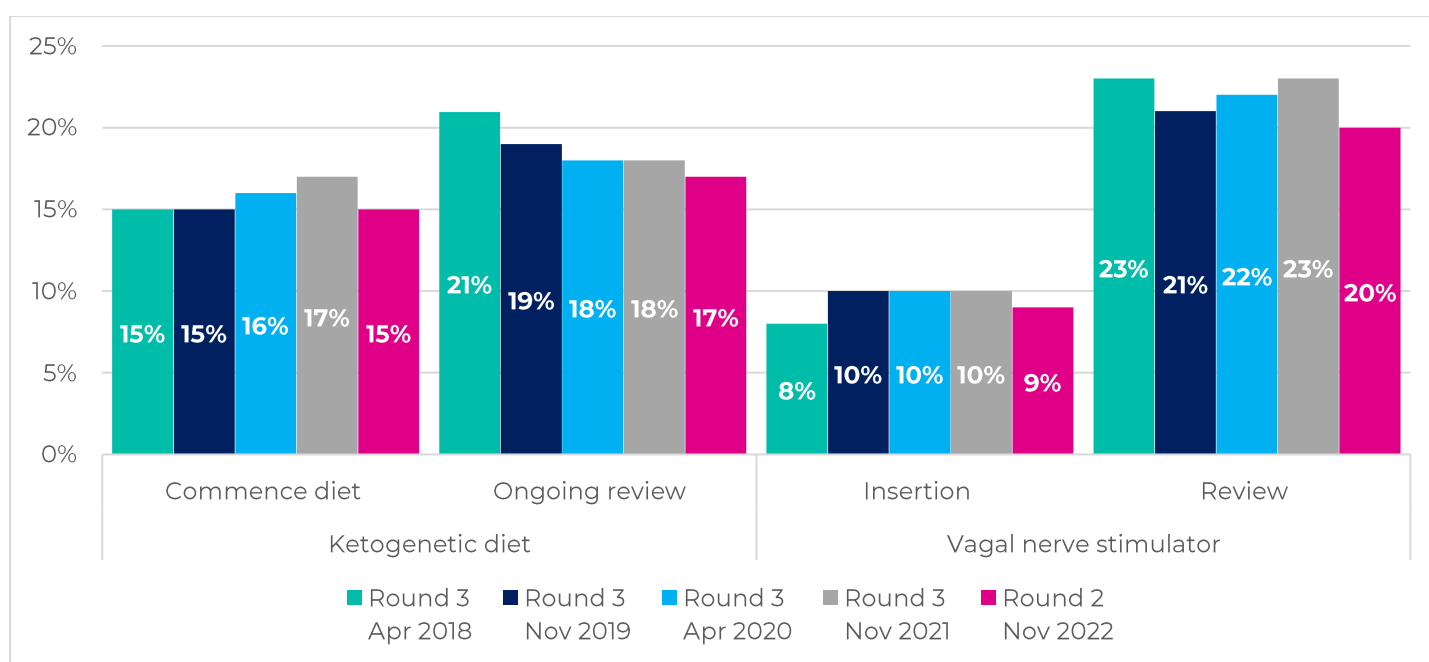
**Table 18: Health Boards and Trusts that were hosting satellite paediatric neurology clinics.**

| Country/network                    | Yes          | No           | N/A        |
|------------------------------------|--------------|--------------|------------|
| <b>England &amp; Wales (N=128)</b> | 69% (88/128) | 28% (36/128) | 3% (4/128) |
| <b>England (N=122)</b>             | 69% (84/122) | 29% (35/122) | 2% (3/122) |
| <b>Wales (N=6)</b>                 | 67% (4/6)    | 17% (1/6)    | 17% (1/6)  |
| <b>BRPNF (N=12)</b>                | 17% (2/12)   | 75% (9/12)   | 8% (1/12)  |
| <b>CEWT (N=4)</b>                  | 50% (2/4)    | 25% (1/4)    | 25% (1/4)  |
| <b>EPEN (N=13)</b>                 | 85% (11/13)  | 15% (2/13)   | 0% (0/13)  |
| <b>EPIC (N=8)</b>                  | 88% (7/8)    | 13% (1/8)    | 0% (0/8)   |
| <b>NTPEN (N=13)</b>                | 23% (3/13)   | 77% (10/13)  | 0% (0/13)  |
| <b>NWEIG (N=11)</b>                | 82% (9/11)   | 9% (1/11)    | 9% (1/11)  |
| <b>ORENG (N=7)</b>                 | 86% (6/7)    | 14% (1/7)    | 0% (0/7)   |
| <b>PENNEC (N=7)</b>                | 100% (7/7)   | 0% (0/7)     | 0% (0/7)   |
| <b>SETPEG (N=9)</b>                | 100% (9/9)   | 0% (0/9)     | 0% (0/9)   |
| <b>SWEP (N=5)</b>                  | 60% (3/5)    | 20% (1/5)    | 20% (1/5)  |
| <b>SWIPE (N=9)</b>                 | 100% (9/9)   | 0% (0/9)     | 0% (0/9)   |
| <b>SWTPEG (N=8)</b>                | 100% (8/8)   | 0% (0/8)     | 0% (0/8)   |
| <b>TEN (N=6)</b>                   | 83% (5/6)    | 17% (1/6)    | 0% (0/6)   |
| <b>WPNN (N=8)</b>                  | 88% (7/8)    | 13% (1/8)    | 0% (0/8)   |
| <b>YPEN (N=8)</b>                  | 0% (0/8)     | 100% (8/8)   | 0% (0/8)   |

## Other services

**15% (19/128)** of Health Boards and Trusts reported they could facilitate commencement of the ketogenic diet and **17% (22/128)** reported they could facilitate ongoing review of the diet, (Table 19 and Table 20 respectively). **9% (12/128)** reported they could provide Vagal Nerve Stimulator (VNS) insertion services and **20% (26/128)** reported that they could facilitate VNS review services, (Table 21 and Table 22 respectively).

**Figure 6** shows, a comparison of Health Boards and Trusts that provided ketogenic diet and vagal nerve stimulator (VNS) services within their locations in Round 3 April 2018, Round 3 November 2019, November 2020, November 2021 and Round 4 November 2022.



**Figure 6: Percentage of Health Boards and Trusts that could provide ketogenic diet and vagal nerve stimulator services.**

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

| Country/network                    | Yes          | No            |
|------------------------------------|--------------|---------------|
| <b>England &amp; Wales (N=128)</b> | 15% (19/128) | 85% (109/128) |
| <b>England (N=122)</b>             | 15% (18/122) | 85% (104/122) |
| <b>Wales (N=6)</b>                 | 17% (1/6)    | 83% (5/6)     |
|                                    |              |               |
| <b>BRPNF (N=12)</b>                | 8% (1/12)    | 92% (11/12)   |
| <b>CEWT (N=4)</b>                  | 50% (2/4)    | 50% (2/4)     |
| <b>EPEN (N=13)</b>                 | 8% (1/13)    | 92% (12/13)   |
| <b>EPIC (N=8)</b>                  | 13% (1/8)    | 88% (7/8)     |
| <b>NTPEN (N=13)</b>                | 8% (1/13)    | 92% (12/13)   |
| <b>NWEIG (N=11)</b>                | 9% (1/11)    | 91% (10/11)   |
| <b>ORENG (N=7)</b>                 | 29% (2/7)    | 71% (5/7)     |
| <b>PENNEC (N=7)</b>                | 14% (1/7)    | 86% (6/7)     |
| <b>SETPEG (N=9)</b>                | 0% (0/9)     | 100% (9/9)    |
| <b>SWEP (N=5)</b>                  | 20% (1/5)    | 80% (4/5)     |
| <b>SWIPE (N=9)</b>                 | 56% (5/9)    | 44% (4/9)     |
| <b>SWTPEG (N=8)</b>                | 13% (1/8)    | 88% (7/8)     |
| <b>TEN (N=6)</b>                   | 17% (1/6)    | 83% (5/6)     |
| <b>WPNN (N=8)</b>                  | 13% (1/8)    | 88% (7/8)     |
| <b>YPEN (N=8)</b>                  | 0% (0/8)     | 100% (8/8)    |

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

| Country/network                    | Yes          | No            |
|------------------------------------|--------------|---------------|
| <b>England &amp; Wales (N=128)</b> | 17% (22/128) | 83% (106/128) |
| <b>England (N=122)</b>             | 17% (21/122) | 83% (101/122) |
| <b>Wales (N=6)</b>                 | 17% (1/6)    | 83% (5/6)     |
|                                    |              |               |
| <b>BRPNF (N=12)</b>                | 8% (1/12)    | 92% (11/12)   |
| <b>CEWT (N=4)</b>                  | 50% (2/4)    | 50% (2/4)     |
| <b>EPEN (N=13)</b>                 | 8% (1/13)    | 92% (12/13)   |
| <b>EPIC (N=8)</b>                  | 13% (1/8)    | 88% (7/8)     |
| <b>NTPEN (N=13)</b>                | 8% (1/13)    | 92% (12/13)   |
| <b>NWEIG (N=11)</b>                | 9% (1/11)    | 91% (10/11)   |
| <b>ORENG (N=7)</b>                 | 29% (2/7)    | 71% (5/7)     |
| <b>PENNEC (N=7)</b>                | 29% (2/7)    | 71% (5/7)     |
| <b>SETPEG (N=9)</b>                | 0% (0/9)     | 100% (9/9)    |
| <b>SWEP (N=5)</b>                  | 20% (1/5)    | 80% (4/5)     |
| <b>SWIPE (N=9)</b>                 | 67% (6/9)    | 33% (3/9)     |
| <b>SWTPEG (N=8)</b>                | 13% (1/8)    | 88% (7/8)     |
| <b>TEN (N=6)</b>                   | 17% (1/6)    | 83% (5/6)     |
| <b>WPNN (N=8)</b>                  | 13% (1/8)    | 88% (7/8)     |
| <b>YPEN (N=8)</b>                  | 13% (1/8)    | 88% (7/8)     |



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

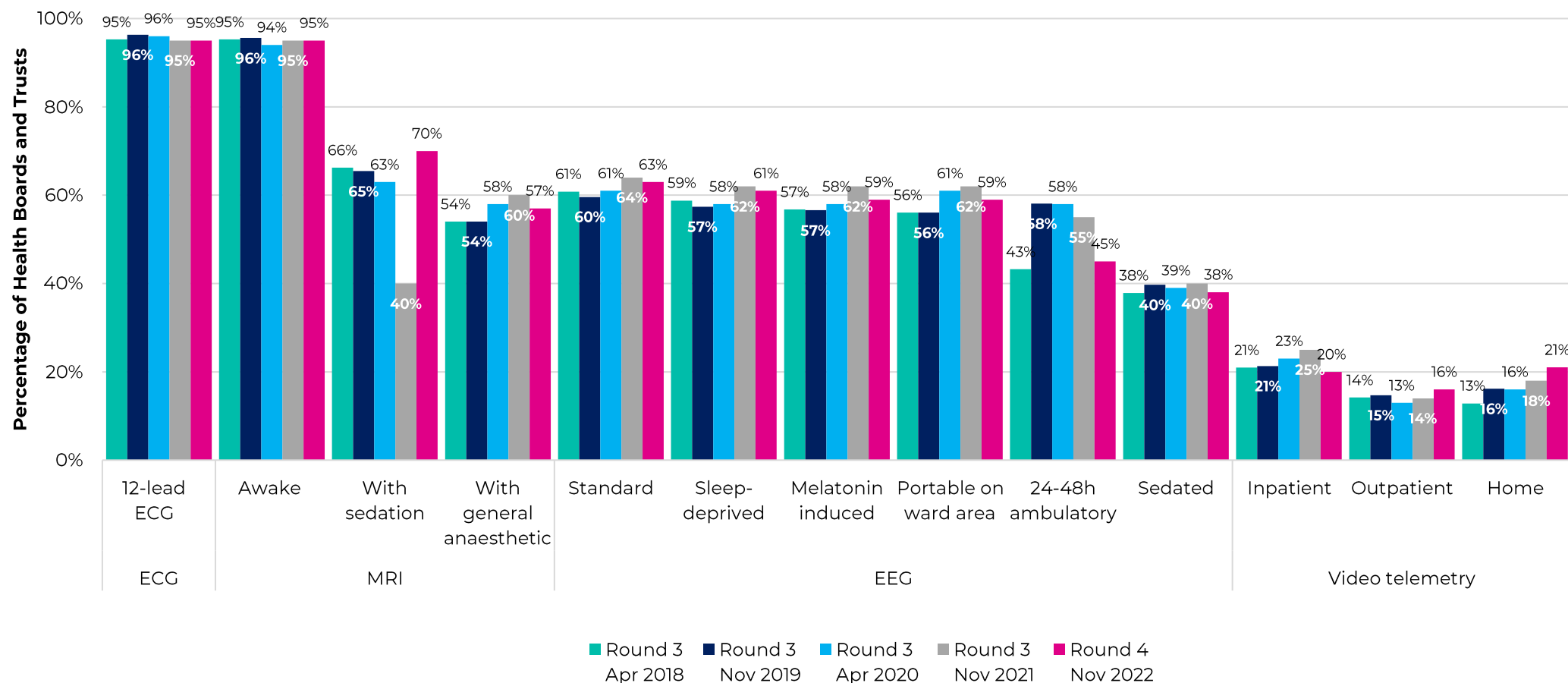
| Country/network                    | Yes          | No            |
|------------------------------------|--------------|---------------|
| <b>England &amp; Wales (N=128)</b> | 9% (12/128)  | 91% (116/128) |
| <b>England (N=122)</b>             | 10% (12/122) | 90% (110/122) |
| <b>Wales (N=6)</b>                 | 0% (0/6)     | 100% (6/6)    |
|                                    |              |               |
| <b>BRPNF (N=12)</b>                | 8% (1/12)    | 92% (11/12)   |
| <b>CEWT (N=4)</b>                  | 25% (1/4)    | 75% (3/4)     |
| <b>EPEN (N=13)</b>                 | 8% (1/13)    | 92% (12/13)   |
| <b>EPIC (N=8)</b>                  | 13% (1/8)    | 88% (7/8)     |
| <b>NTPEN (N=13)</b>                | 8% (1/13)    | 92% (12/13)   |
| <b>NWEIG (N=11)</b>                | 9% (1/11)    | 91% (10/11)   |
| <b>ORENG (N=7)</b>                 | 14% (1/7)    | 86% (6/7)     |
| <b>PENNEC (N=7)</b>                | 14% (1/7)    | 86% (6/7)     |
| <b>SETPEG (N=9)</b>                | 11% (1/9)    | 89% (8/9)     |
| <b>SWEP (N=5)</b>                  | 0% (0/5)     | 100% (5/5)    |
| <b>SWIPE (N=9)</b>                 | 11% (1/9)    | 89% (8/9)     |
| <b>SWTPEG (N=8)</b>                | 0% (0/8)     | 100% (8/8)    |
| <b>TEN (N=6)</b>                   | 17% (1/6)    | 83% (5/6)     |
| <b>WPNN (N=8)</b>                  | 13% (1/8)    | 88% (7/8)     |
| <b>YPEN (N=8)</b>                  | 0% (0/8)     | 100% (8/8)    |

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

| Country/network                    | Yes          | No            |
|------------------------------------|--------------|---------------|
| <b>England &amp; Wales (N=128)</b> | 20% (26/128) | 80% (102/128) |
| <b>England (N=122)</b>             | 19% (23/122) | 81% (99/122)  |
| <b>Wales (N=6)</b>                 | 50% (3/6)    | 50% (3/6)     |
|                                    |              |               |
| <b>BRPNF (N=12)</b>                | 8% (1/12)    | 92% (11/12)   |
| <b>CEWT (N=4)</b>                  | 25% (1/4)    | 75% (3/4)     |
| <b>EPEN (N=13)</b>                 | 23% (3/13)   | 77% (10/13)   |
| <b>EPIC (N=8)</b>                  | 13% (1/8)    | 88% (7/8)     |
| <b>NTPEN (N=13)</b>                | 8% (1/13)    | 92% (12/13)   |
| <b>NWEIG (N=11)</b>                | 18% (2/11)   | 82% (9/11)    |
| <b>ORENG (N=7)</b>                 | 14% (1/7)    | 86% (6/7)     |
| <b>PENNEC (N=7)</b>                | 29% (2/7)    | 71% (5/7)     |
| <b>SETPEG (N=9)</b>                | 33% (3/9)    | 67% (6/9)     |
| <b>SWEP (N=5)</b>                  | 60% (3/5)    | 40% (2/5)     |
| <b>SWIPE (N=9)</b>                 | 56% (5/9)    | 44% (4/9)     |
| <b>SWTPEG (N=8)</b>                | 0% (0/8)     | 100% (8/8)    |
| <b>TEN (N=6)</b>                   | 17% (1/6)    | 83% (5/6)     |
| <b>WPNN (N=8)</b>                  | 13% (1/8)    | 88% (7/8)     |
| <b>YPEN (N=8)</b>                  | 13% (1/8)    | 88% (7/8)     |

# Investigations

**Figure 7** shows a comparison of the availability of epilepsy investigation services across England and Wales in Round 3 April 2018, November 2019, November 2020, November 2021 and Round 4 November 2022.



**Figure 7: Percentage of Health Boards and Trusts that could provide investigation services in Round 3 April 2018, November 2019, November 2020, November 2021 and Round 4 November 2022.**

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

| Country/<br>network                | 12-lead ECG   |            |            | 'Awake' MRI   |            |            | MRI with sedation |              |            |
|------------------------------------|---------------|------------|------------|---------------|------------|------------|-------------------|--------------|------------|
|                                    | Yes           | No         | Uncertain  | Yes           | No         | Uncertain  | Yes               | No           | Uncertain  |
| <b>England &amp; Wales (N=128)</b> | 95% (121/128) | 5% (7/128) | 0% (0/128) | 95% (121/128) | 5% (7/128) | 0% (0/128) | 70% (89/128)      | 30% (39/128) | 0% (0/128) |
| <b>England (N=122)</b>             | 94% (115/122) | 6% (7/122) | 0% (0/122) | 94% (115/122) | 6% (7/122) | 0% (0/122) | 69% (84/122)      | 31% (38/122) | 0% (0/122) |
| <b>Wales (N=6)</b>                 | 100% (6/6)    | 0% (0/6)   | 0% (0/6)   | 100% (6/6)    | 0% (0/6)   | 0% (0/6)   | 83% (5/6)         | 17% (1/6)    | 0% (0/6)   |
|                                    |               |            |            |               |            |            |                   |              |            |
| <b>BRPNF (N=12)</b>                | 92% (11/12)   | 8% (1/12)  | 0% (0/12)  | 83% (10/12)   | 17% (2/12) | 0% (0/12)  | 75% (9/12)        | 25% (3/12)   | 0% (0/12)  |
| <b>CEWT (N=4)</b>                  | 100% (4/4)    | 0% (0/4)   | 0% (0/4)   | 100% (4/4)    | 0% (0/4)   | 0% (0/4)   | 100% (4/4)        | 0% (0/4)     | 0% (0/4)   |
| <b>EPEN (N=13)</b>                 | 92% (12/13)   | 8% (1/13)  | 0% (0/13)  | 92% (12/13)   | 8% (1/13)  | 0% (0/13)  | 92% (12/13)       | 8% (1/13)    | 0% (0/13)  |
| <b>EPIC (N=8)</b>                  | 100% (8/8)    | 0% (0/8)   | 0% (0/8)   | 100% (8/8)    | 0% (0/8)   | 0% (0/8)   | 63% (5/8)         | 38% (3/8)    | 0% (0/8)   |
| <b>NTPEN (N=13)</b>                | 92% (12/13)   | 8% (1/13)  | 0% (0/13)  | 92% (12/13)   | 8% (1/13)  | 0% (0/13)  | 85% (11/13)       | 15% (2/13)   | 0% (0/13)  |
| <b>NWEIG (N=11)</b>                | 100% (11/11)  | 0% (0/11)  | 0% (0/11)  | 100% (11/11)  | 0% (0/11)  | 0% (0/11)  | 64% (7/11)        | 36% (4/11)   | 0% (0/11)  |
| <b>ORENG (N=7)</b>                 | 100% (7/7)    | 0% (0/7)   | 0% (0/7)   | 100% (7/7)    | 0% (0/7)   | 0% (0/7)   | 71% (5/7)         | 29% (2/7)    | 0% (0/7)   |
| <b>PENNEC (N=7)</b>                | 100% (7/7)    | 0% (0/7)   | 0% (0/7)   | 100% (7/7)    | 0% (0/7)   | 0% (0/7)   | 71% (5/7)         | 29% (2/7)    | 0% (0/7)   |
| <b>SETPEG (N=9)</b>                | 89% (8/9)     | 11% (1/9)  | 0% (0/9)   | 89% (8/9)     | 11% (1/9)  | 0% (0/9)   | 78% (7/9)         | 22% (2/9)    | 0% (0/9)   |
| <b>SWEP (N=5)</b>                  | 100% (5/5)    | 0% (0/5)   | 0% (0/5)   | 100% (5/5)    | 0% (0/5)   | 0% (0/5)   | 80% (4/5)         | 20% (1/5)    | 0% (0/5)   |
| <b>SWIPE (N=9)</b>                 | 100% (9/9)    | 0% (0/9)   | 0% (0/9)   | 100% (9/9)    | 0% (0/9)   | 0% (0/9)   | 67% (6/9)         | 33% (3/9)    | 0% (0/9)   |
| <b>SWTPEG (N=8)</b>                | 100% (8/8)    | 0% (0/8)   | 0% (0/8)   | 100% (8/8)    | 0% (0/8)   | 0% (0/8)   | 50% (4/8)         | 50% (4/8)    | 0% (0/8)   |
| <b>TEN (N=6)</b>                   | 83% (5/6)     | 17% (1/6)  | 0% (0/6)   | 100% (6/6)    | 0% (0/6)   | 0% (0/6)   | 33% (2/6)         | 67% (4/6)    | 0% (0/6)   |
| <b>WPNN (N=8)</b>                  | 88% (7/8)     | 13% (1/8)  | 0% (0/8)   | 88% (7/8)     | 13% (1/8)  | 0% (0/8)   | 63% (5/8)         | 38% (3/8)    | 0% (0/8)   |
| <b>YPEN (N=8)</b>                  | 88% (7/8)     | 13% (1/8)  | 0% (0/8)   | 88% (7/8)     | 13% (1/8)  | 0% (0/8)   | 38% (3/8)         | 63% (5/8)    | 0% (0/8)   |

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

| Country/<br>network                | MRI with general anaesthetic |              |            | Standard EEG |              |            | Sleep deprived EEG |              |            |
|------------------------------------|------------------------------|--------------|------------|--------------|--------------|------------|--------------------|--------------|------------|
|                                    | Yes                          | No           | Uncertain  | Yes          | No           | Uncertain  | Yes                | No           | Uncertain  |
| <b>England &amp; Wales (N=128)</b> | 57% (73/128)                 | 42% (54/128) | 1% (1/128) | 63% (80/128) | 38% (48/128) | 0% (0/128) | 61% (78/128)       | 39% (50/128) | 0% (0/128) |
| <b>England (N=122)</b>             | 55% (67/122)                 | 44% (54/122) | 1% (1/122) | 61% (74/122) | 39% (48/122) | 0% (0/122) | 59% (72/122)       | 41% (50/122) | 0% (0/122) |
| <b>Wales (N=6)</b>                 | 100% (6/6)                   | 0% (0/6)     | 0% (0/6)   | 100% (6/6)   | 0% (0/6)     | 0% (0/6)   | 100% (6/6)         | 0% (0/6)     | 0% (0/6)   |
|                                    |                              |              |            |              |              |            |                    |              |            |
| <b>BRPNF (N=12)</b>                | 50% (6/12)                   | 50% (6/12)   | 0% (0/12)  | 58% (7/12)   | 42% (5/12)   | 0% (0/12)  | 58% (7/12)         | 42% (5/12)   | 0% (0/12)  |
| <b>CEWT (N=4)</b>                  | 100% (4/4)                   | 0% (0/4)     | 0% (0/4)   | 75% (3/4)    | 25% (1/4)    | 0% (0/4)   | 75% (3/4)          | 25% (1/4)    | 0% (0/4)   |
| <b>EPEN (N=13)</b>                 | 62% (8/13)                   | 31% (4/13)   | 8% (1/13)  | 62% (8/13)   | 38% (5/13)   | 0% (0/13)  | 62% (8/13)         | 38% (5/13)   | 0% (0/13)  |
| <b>EPIC (N=8)</b>                  | 50% (4/8)                    | 50% (4/8)    | 0% (0/8)   | 38% (3/8)    | 63% (5/8)    | 0% (0/8)   | 38% (3/8)          | 63% (5/8)    | 0% (0/8)   |
| <b>NTPEN (N=13)</b>                | 38% (5/13)                   | 62% (8/13)   | 0% (0/13)  | 62% (8/13)   | 38% (5/13)   | 0% (0/13)  | 62% (8/13)         | 38% (5/13)   | 0% (0/13)  |
| <b>NWEIG (N=11)</b>                | 27% (3/11)                   | 73% (8/11)   | 0% (0/11)  | 55% (6/11)   | 45% (5/11)   | 0% (0/11)  | 55% (6/11)         | 45% (5/11)   | 0% (0/11)  |
| <b>ORENG (N=7)</b>                 | 71% (5/7)                    | 29% (2/7)    | 0% (0/7)   | 57% (4/7)    | 43% (3/7)    | 0% (0/7)   | 57% (4/7)          | 43% (3/7)    | 0% (0/7)   |
| <b>PENNEC (N=7)</b>                | 57% (4/7)                    | 43% (3/7)    | 0% (0/7)   | 71% (5/7)    | 29% (2/7)    | 0% (0/7)   | 71% (5/7)          | 29% (2/7)    | 0% (0/7)   |
| <b>SETPEG (N=9)</b>                | 56% (5/9)                    | 44% (4/9)    | 0% (0/9)   | 33% (3/9)    | 67% (6/9)    | 0% (0/9)   | 33% (3/9)          | 67% (6/9)    | 0% (0/9)   |
| <b>SWEP (N=5)</b>                  | 100% (5/5)                   | 0% (0/5)     | 0% (0/5)   | 100% (5/5)   | 0% (0/5)     | 0% (0/5)   | 100% (5/5)         | 0% (0/5)     | 0% (0/5)   |
| <b>SWIPE (N=9)</b>                 | 89% (8/9)                    | 11% (1/9)    | 0% (0/9)   | 89% (8/9)    | 11% (1/9)    | 0% (0/9)   | 78% (7/9)          | 22% (2/9)    | 0% (0/9)   |
| <b>SWTPEG (N=8)</b>                | 50% (4/8)                    | 50% (4/8)    | 0% (0/8)   | 88% (7/8)    | 13% (1/8)    | 0% (0/8)   | 75% (6/8)          | 25% (2/8)    | 0% (0/8)   |
| <b>TEN (N=6)</b>                   | 50% (3/6)                    | 50% (3/6)    | 0% (0/6)   | 33% (2/6)    | 67% (4/6)    | 0% (0/6)   | 33% (2/6)          | 67% (4/6)    | 0% (0/6)   |
| <b>WPNN (N=8)</b>                  | 63% (5/8)                    | 38% (3/8)    | 0% (0/8)   | 63% (5/8)    | 38% (3/8)    | 0% (0/8)   | 63% (5/8)          | 38% (3/8)    | 0% (0/8)   |
| <b>YPEN (N=8)</b>                  | 50% (4/8)                    | 50% (4/8)    | 0% (0/8)   | 75% (6/8)    | 25% (2/8)    | 0% (0/8)   | 75% (6/8)          | 25% (2/8)    | 0% (0/8)   |

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

| Country/<br>network                | Melatonin EEG |              |            | Sedated EEG  |              |            | 24-48h ambulatory EEG |              |            |
|------------------------------------|---------------|--------------|------------|--------------|--------------|------------|-----------------------|--------------|------------|
|                                    | Yes           | No           | Uncertain  | Yes          | No           | Uncertain  | Yes                   | No           | Uncertain  |
| <b>England &amp; Wales (N=128)</b> | 59% (76/128)  | 40% (51/128) | 1% (1/128) | 38% (48/128) | 61% (78/128) | 2% (2/128) | 45% (58/128)          | 55% (70/128) | 0% (0/128) |
| <b>England (N=122)</b>             | 58% (71/122)  | 42% (51/122) | 0% (0/122) | 36% (44/122) | 63% (77/122) | 1% (1/122) | 43% (53/122)          | 57% (69/122) | 0% (0/122) |
| <b>Wales (N=6)</b>                 | 83% (5/6)     | 0% (0/6)     | 17% (1/6)  | 67% (4/6)    | 17% (1/6)    | 17% (1/6)  | 83% (5/6)             | 17% (1/6)    | 0% (0/6)   |
|                                    |               |              |            |              |              |            |                       |              |            |
| <b>BRPNF (N=12)</b>                | 58% (7/12)    | 42% (5/12)   | 0% (0/12)  | 33% (4/12)   | 67% (8/12)   | 0% (0/12)  | 42% (5/12)            | 58% (7/12)   | 0% (0/12)  |
| <b>CEWT (N=4)</b>                  | 75% (3/4)     | 25% (1/4)    | 0% (0/4)   | 25% (1/4)    | 75% (3/4)    | 0% (0/4)   | 75% (3/4)             | 25% (1/4)    | 0% (0/4)   |
| <b>EPEN (N=13)</b>                 | 62% (8/13)    | 38% (5/13)   | 0% (0/13)  | 15% (2/13)   | 85% (11/13)  | 0% (0/13)  | 31% (4/13)            | 69% (9/13)   | 0% (0/13)  |
| <b>EPIC (N=8)</b>                  | 38% (3/8)     | 63% (5/8)    | 0% (0/8)   | 25% (2/8)    | 75% (6/8)    | 0% (0/8)   | 38% (3/8)             | 63% (5/8)    | 0% (0/8)   |
| <b>NTPEN (N=13)</b>                | 54% (7/13)    | 46% (6/13)   | 0% (0/13)  | 38% (5/13)   | 62% (8/13)   | 0% (0/13)  | 31% (4/13)            | 69% (9/13)   | 0% (0/13)  |
| <b>NWEIG (N=11)</b>                | 55% (6/11)    | 45% (5/11)   | 0% (0/11)  | 45% (5/11)   | 55% (6/11)   | 0% (0/11)  | 27% (3/11)            | 73% (8/11)   | 0% (0/11)  |
| <b>ORENG (N=7)</b>                 | 57% (4/7)     | 43% (3/7)    | 0% (0/7)   | 57% (4/7)    | 43% (3/7)    | 0% (0/7)   | 57% (4/7)             | 43% (3/7)    | 0% (0/7)   |
| <b>PENNEC (N=7)</b>                | 57% (4/7)     | 43% (3/7)    | 0% (0/7)   | 57% (4/7)    | 43% (3/7)    | 0% (0/7)   | 43% (3/7)             | 57% (4/7)    | 0% (0/7)   |
| <b>SETPEG (N=9)</b>                | 33% (3/9)     | 67% (6/9)    | 0% (0/9)   | 22% (2/9)    | 78% (7/9)    | 0% (0/9)   | 22% (2/9)             | 78% (7/9)    | 0% (0/9)   |
| <b>SWEP (N=5)</b>                  | 80% (4/5)     | 0% (0/5)     | 20% (1/5)  | 80% (4/5)    | 0% (0/5)     | 20% (1/5)  | 80% (4/5)             | 20% (1/5)    | 0% (0/5)   |
| <b>SWIPE (N=9)</b>                 | 78% (7/9)     | 22% (2/9)    | 0% (0/9)   | 78% (7/9)    | 22% (2/9)    | 0% (0/9)   | 67% (6/9)             | 33% (3/9)    | 0% (0/9)   |
| <b>SWTPEG (N=8)</b>                | 88% (7/8)     | 13% (1/8)    | 0% (0/8)   | 13% (1/8)    | 88% (7/8)    | 0% (0/8)   | 50% (4/8)             | 50% (4/8)    | 0% (0/8)   |
| <b>TEN (N=6)</b>                   | 33% (2/6)     | 67% (4/6)    | 0% (0/6)   | 33% (2/6)    | 67% (4/6)    | 0% (0/6)   | 33% (2/6)             | 67% (4/6)    | 0% (0/6)   |
| <b>WPNN (N=8)</b>                  | 63% (5/8)     | 38% (3/8)    | 0% (0/8)   | 25% (2/8)    | 63% (5/8)    | 13% (1/8)  | 63% (5/8)             | 38% (3/8)    | 0% (0/8)   |
| <b>YPEN (N=8)</b>                  | 75% (6/8)     | 25% (2/8)    | 0% (0/8)   | 38% (3/8)    | 63% (5/8)    | 0% (0/8)   | 75% (6/8)             | 25% (2/8)    | 0% (0/8)   |

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

| Country/<br>network                | Inpatient Video Telemetry |               |            | Outpatient Video Telemetry |               |            | Home Video Telemetry |               |            |
|------------------------------------|---------------------------|---------------|------------|----------------------------|---------------|------------|----------------------|---------------|------------|
|                                    | Yes                       | No            | Uncertain  | Yes                        | No            | Uncertain  | Yes                  | No            | Uncertain  |
| <b>England &amp; Wales (N=128)</b> | 20% (26/128)              | 80% (102/128) | 0% (0/128) | 16% (21/128)               | 83% (106/128) | 1% (1/128) | 21% (27/128)         | 78% (100/128) | 1% (1/128) |
| <b>England (N=122)</b>             | 20% (25/122)              | 80% (97/122)  | 0% (0/122) | 16% (20/122)               | 83% (101/122) | 1% (1/122) | 20% (25/122)         | 79% (96/122)  | 1% (1/122) |
| <b>Wales (N=6)</b>                 | 17% (1/6)                 | 83% (5/6)     | 0% (0/6)   | 17% (1/6)                  | 83% (5/6)     | 0% (0/6)   | 33% (2/6)            | 67% (4/6)     | 0% (0/6)   |
|                                    |                           |               |            |                            |               |            |                      |               |            |
| <b>BRPNF (N=12)</b>                | 25% (3/12)                | 75% (9/12)    | 0% (0/12)  | 17% (2/12)                 | 83% (10/12)   | 0% (0/12)  | 17% (2/12)           | 83% (10/12)   | 0% (0/12)  |
| <b>CEWT (N=4)</b>                  | 50% (2/4)                 | 50% (2/4)     | 0% (0/4)   | 25% (1/4)                  | 75% (3/4)     | 0% (0/4)   | 25% (1/4)            | 75% (3/4)     | 0% (0/4)   |
| <b>EPEN (N=13)</b>                 | 8% (1/13)                 | 92% (12/13)   | 0% (0/13)  | 0% (0/13)                  | 92% (12/13)   | 8% (1/13)  | 15% (2/13)           | 77% (10/13)   | 8% (1/13)  |
| <b>EPIC (N=8)</b>                  | 25% (2/8)                 | 75% (6/8)     | 0% (0/8)   | 25% (2/8)                  | 75% (6/8)     | 0% (0/8)   | 25% (2/8)            | 75% (6/8)     | 0% (0/8)   |
| <b>NTPEN (N=13)</b>                | 15% (2/13)                | 85% (11/13)   | 0% (0/13)  | 8% (1/13)                  | 92% (12/13)   | 0% (0/13)  | 8% (1/13)            | 92% (12/13)   | 0% (0/13)  |
| <b>NWEIG (N=11)</b>                | 9% (1/11)                 | 91% (10/11)   | 0% (0/11)  | 9% (1/11)                  | 91% (10/11)   | 0% (0/11)  | 9% (1/11)            | 91% (10/11)   | 0% (0/11)  |
| <b>ORENG (N=7)</b>                 | 29% (2/7)                 | 71% (5/7)     | 0% (0/7)   | 14% (1/7)                  | 86% (6/7)     | 0% (0/7)   | 43% (3/7)            | 57% (4/7)     | 0% (0/7)   |
| <b>PENNEC (N=7)</b>                | 14% (1/7)                 | 86% (6/7)     | 0% (0/7)   | 29% (2/7)                  | 71% (5/7)     | 0% (0/7)   | 14% (1/7)            | 86% (6/7)     | 0% (0/7)   |
| <b>SETPEG (N=9)</b>                | 11% (1/9)                 | 89% (8/9)     | 0% (0/9)   | 11% (1/9)                  | 89% (8/9)     | 0% (0/9)   | 22% (2/9)            | 78% (7/9)     | 0% (0/9)   |
| <b>SWEP (N=5)</b>                  | 20% (1/5)                 | 80% (4/5)     | 0% (0/5)   | 20% (1/5)                  | 80% (4/5)     | 0% (0/5)   | 20% (1/5)            | 80% (4/5)     | 0% (0/5)   |
| <b>SWIPE (N=9)</b>                 | 44% (4/9)                 | 56% (5/9)     | 0% (0/9)   | 44% (4/9)                  | 56% (5/9)     | 0% (0/9)   | 44% (4/9)            | 56% (5/9)     | 0% (0/9)   |
| <b>SWTPEG (N=8)</b>                | 25% (2/8)                 | 75% (6/8)     | 0% (0/8)   | 0% (0/8)                   | 100% (8/8)    | 0% (0/8)   | 13% (1/8)            | 88% (7/8)     | 0% (0/8)   |
| <b>TEN (N=6)</b>                   | 17% (1/6)                 | 83% (5/6)     | 0% (0/6)   | 33% (2/6)                  | 67% (4/6)     | 0% (0/6)   | 33% (2/6)            | 67% (4/6)     | 0% (0/6)   |
| <b>WPNN (N=8)</b>                  | 25% (2/8)                 | 75% (6/8)     | 0% (0/8)   | 25% (2/8)                  | 75% (6/8)     | 0% (0/8)   | 38% (3/8)            | 63% (5/8)     | 0% (0/8)   |
| <b>YPEN (N=8)</b>                  | 13% (1/8)                 | 88% (7/8)     | 0% (0/8)   | 13% (1/8)                  | 88% (7/8)     | 0% (0/8)   | 13% (1/8)            | 88% (7/8)     | 0% (0/8)   |

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

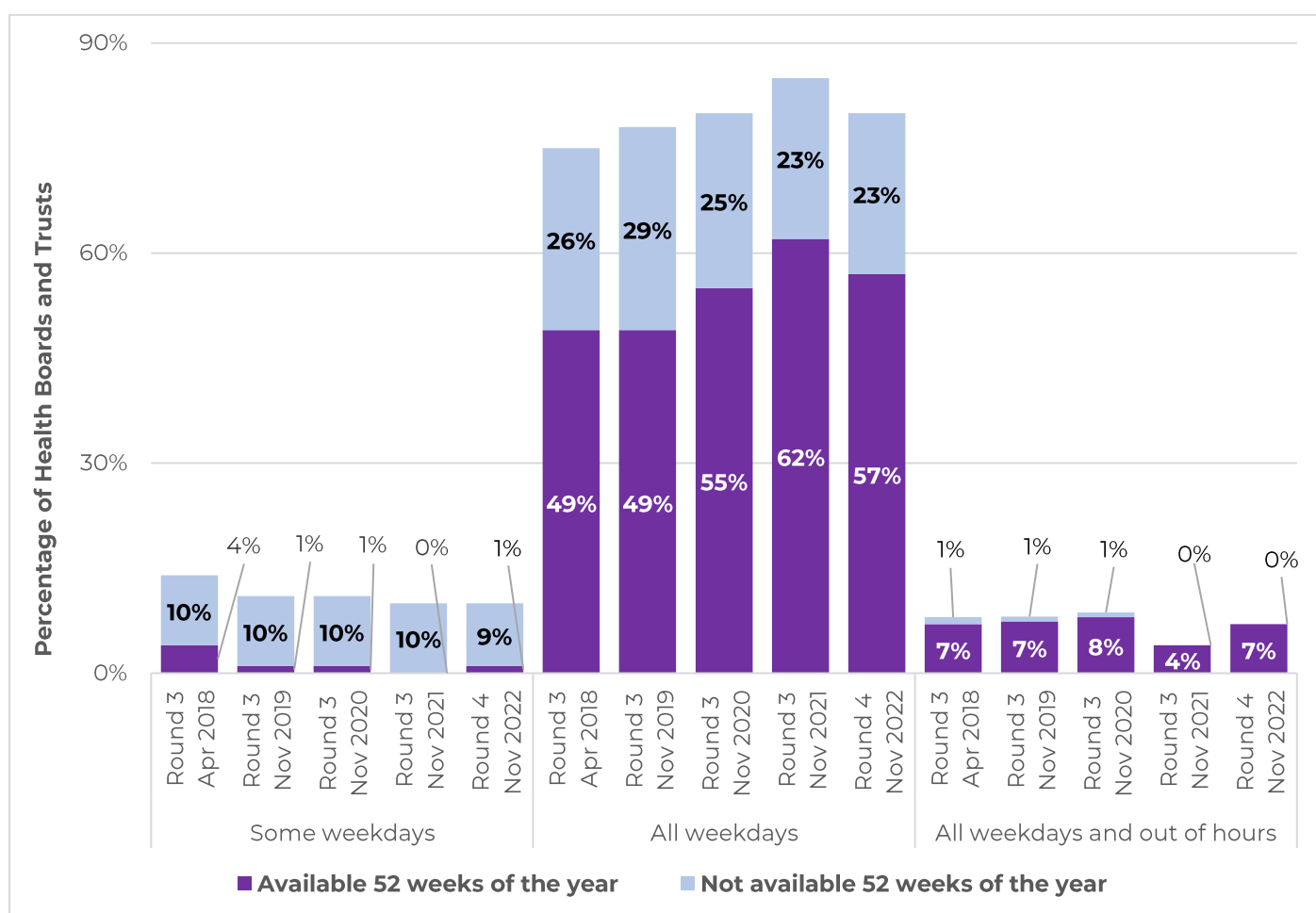
| Country/network                    | Portable EEG on ward area |              |            |
|------------------------------------|---------------------------|--------------|------------|
|                                    | Yes                       | No           | Uncertain  |
| <b>England &amp; Wales (N=128)</b> | 59% (75/128)              | 41% (53/128) | 0% (0/128) |
| <b>England (N=122)</b>             | 57% (70/122)              | 43% (52/122) | 0% (0/122) |
| <b>Wales (N=6)</b>                 | 83% (5/6)                 | 17% (1/6)    | 0% (0/6)   |
|                                    |                           |              |            |
| <b>BRPNF (N=12)</b>                | 58% (7/12)                | 42% (5/12)   | 0% (0/12)  |
| <b>CEWT (N=4)</b>                  | 100% (4/4)                | 0% (0/4)     | 0% (0/4)   |
| <b>EPEN (N=13)</b>                 | 54% (7/13)                | 46% (6/13)   | 0% (0/13)  |
| <b>EPIC (N=8)</b>                  | 38% (3/8)                 | 63% (5/8)    | 0% (0/8)   |
| <b>NTPEN (N=13)</b>                | 54% (7/13)                | 46% (6/13)   | 0% (0/13)  |
| <b>NWEIG (N=11)</b>                | 45% (5/11)                | 55% (6/11)   | 0% (0/11)  |
| <b>ORENG (N=7)</b>                 | 86% (6/7)                 | 14% (1/7)    | 0% (0/7)   |
| <b>PENNEC (N=7)</b>                | 43% (3/7)                 | 57% (4/7)    | 0% (0/7)   |
| <b>SETPEG (N=9)</b>                | 33% (3/9)                 | 67% (6/9)    | 0% (0/9)   |
| <b>SWEP (N=5)</b>                  | 80% (4/5)                 | 20% (1/5)    | 0% (0/5)   |
| <b>SWIPE (N=9)</b>                 | 78% (7/9)                 | 22% (2/9)    | 0% (0/9)   |
| <b>SWTPEG (N=8)</b>                | 75% (6/8)                 | 25% (2/8)    | 0% (0/8)   |
| <b>TEN (N=6)</b>                   | 50% (3/6)                 | 50% (3/6)    | 0% (0/6)   |
| <b>WPNN (N=8)</b>                  | 63% (5/8)                 | 38% (3/8)    | 0% (0/8)   |
| <b>YPEN (N=8)</b>                  | 63% (5/8)                 | 38% (3/8)    | 0% (0/8)   |

# Service contact

**98% (125/128)** of Heath Boards and Trusts reported availability of specialist epilepsy advice between scheduled reviews across England and Wales, (**Table 24**).

**Table 25** shows that **57% (73/128)** of the Health Boards and Trusts provided specialist advice between scheduled reviews on all weekdays for all 52 weeks of the year. This was a decrease from the previous year (**62% in November 2021**). In **7% (9/128)** of Health Boards and Trusts, this service was available on all weekdays and out of hours for 52 weeks of the year.

**Figure 8** shows a comparison of the availability of specialist advice between scheduled reviews in Round 3 April 2018, November 2019, November 2020, November 2021 and Round 4 November 2022.



**Figure 8: Percentage availability of specialist advice between scheduled reviews in Round 3 April 2018, November 2019, November 2020, November 2021 and Round 4 November 2022.**

**50% (62/125)** of Health Boards and Trusts providing specialist advice between scheduled reviews had a typical response time of the next weekday, **Table 26**. Initial specialist advice was ‘typically’ provided by; an epilepsy specialist nurse in **56% (70/125)**, a consultant paediatrician with expertise in epilepsy in **33% (41/125)** and other professionals in **10% (13/125)**, **Table 27**.



In the Health Boards and Trusts that selected other, advice was typically provided by;

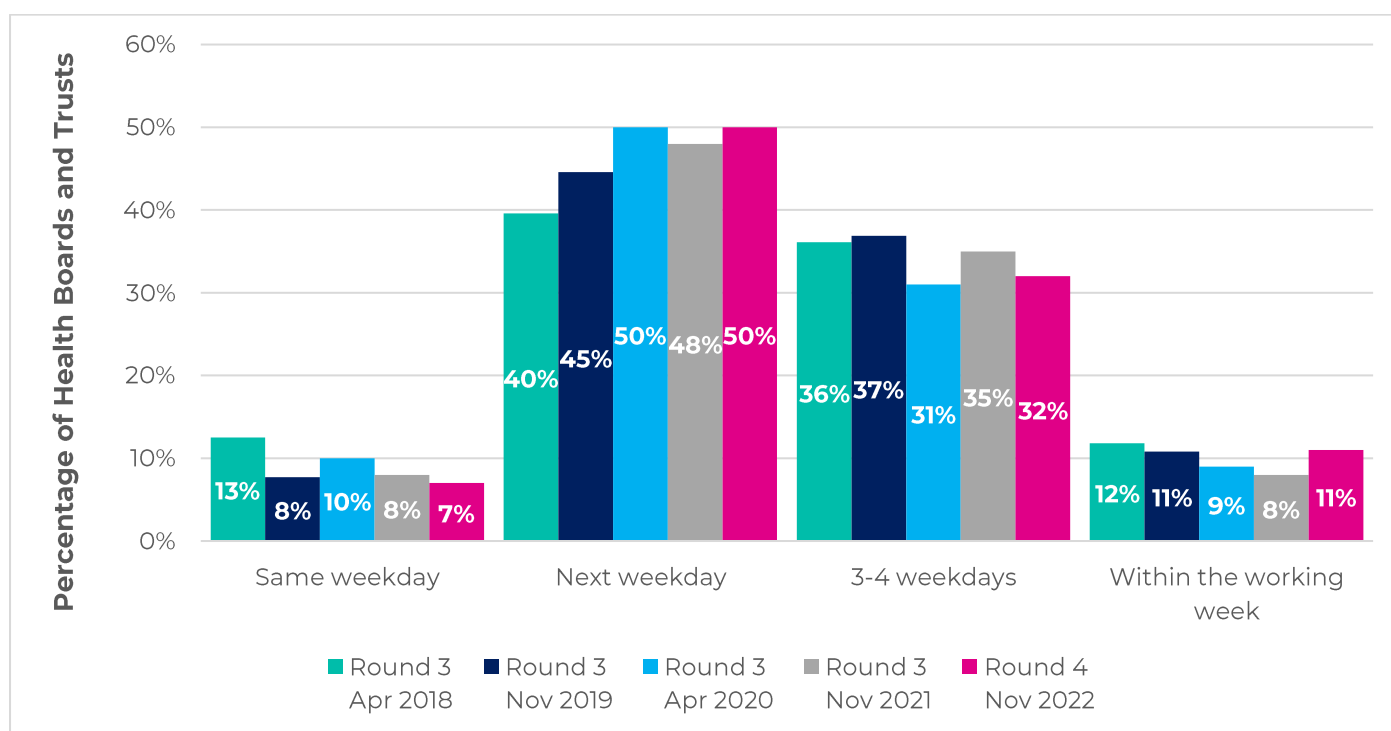
- A community paediatrician including consultant and non-consultant doctors
- Both a consultant paediatrician with expertise in epilepsy and an epilepsy specialist nurse
- A combination of all three.

**Figure 9** shows a comparison of the typical response time for specialist advice in Round 3 April 2018, November 2019, November 2020, November 2021 and Round 4 November 2022.

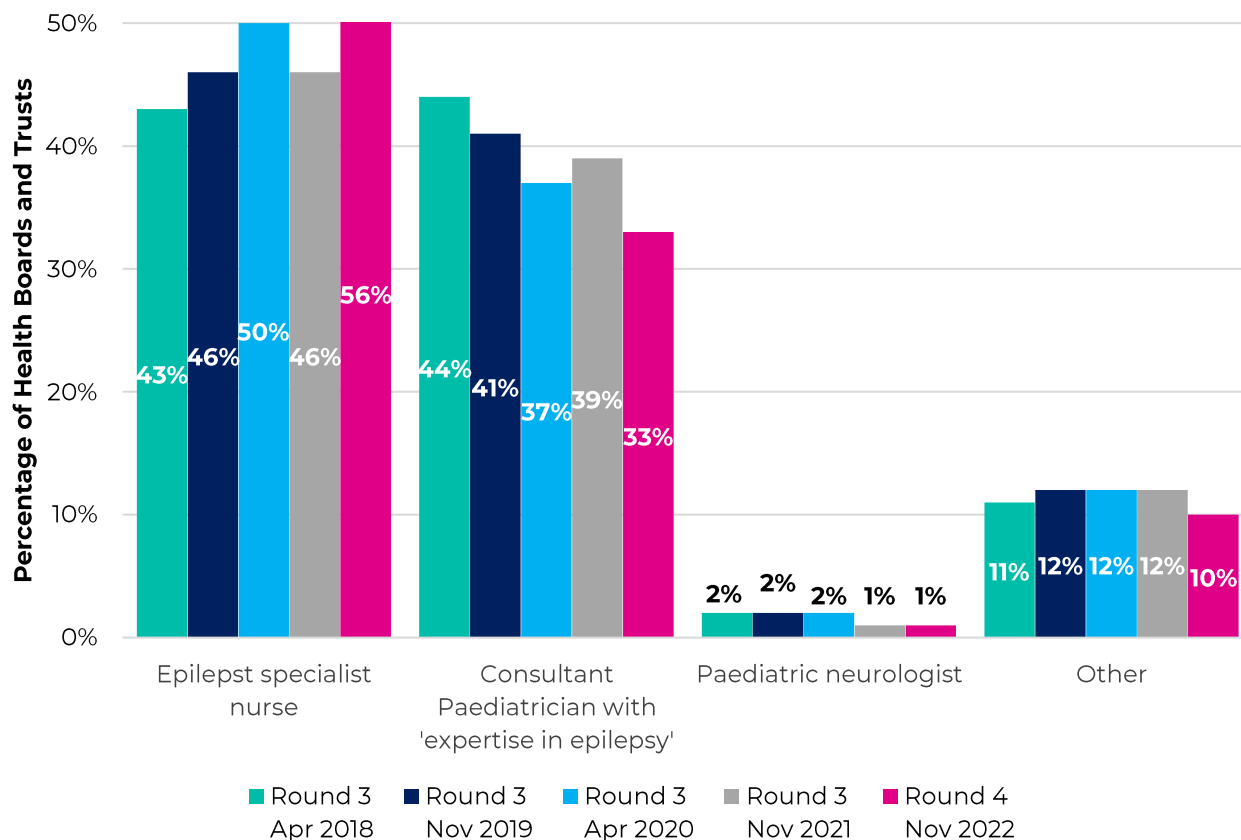
**Figure 10** shows a comparison of professionals who 'typically' provided initial specialist advice in Round 3 April 2018, November 2019, November 2020, November 2021 and Round 4 November 2022.

**88% (113/128)** of Trusts and Health Boards reported having a clear point of contact for non-paediatric professionals seeking paediatric epilepsy support across England and Wales (**Table 28**).

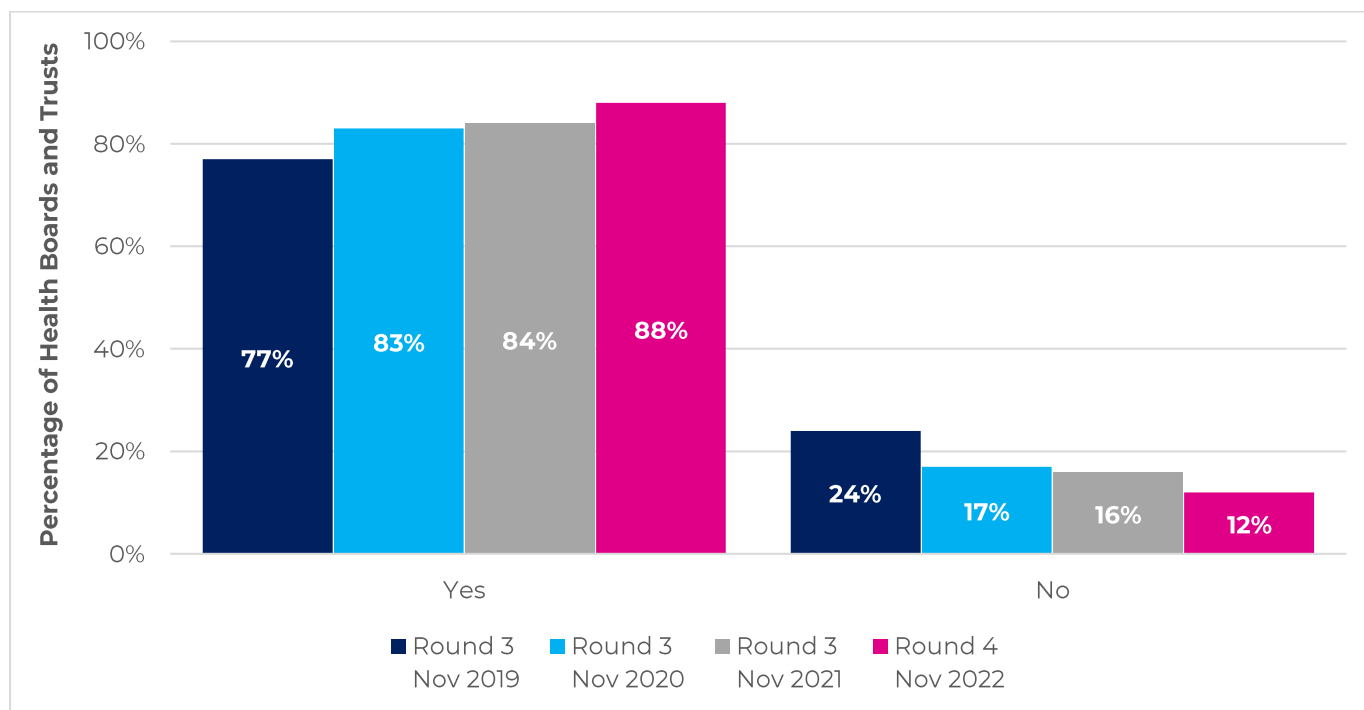
**Figure 11** shows a comparison of Health Boards and Trusts with evidence/no evidence of a clear point of contact for non-paediatric professionals seeking paediatric epilepsy support in Round 3 November 2019, November 2020, November 2021 and Round 4 November 2022.



**Figure 9: Typical response time for specialist advice in Round 3 April 2018, November 2019, November 2020, November 2021 and Round 4 November 2022.**



**Figure 10: Professionals who ‘typically’ provide initial specialist advice in Round 3 November 2019, November 2020, November 2021 and Round 4 November 2022.**



**Figure 11: Health Boards and Trusts with evidence of a clear point of contact for non-paediatric professionals seeking paediatric epilepsy support in Round 3 November 2019, November 2020, November 2021 and Round 4 November 2022.**

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

| Country/network                    | Yes           | No         |
|------------------------------------|---------------|------------|
| <b>England &amp; Wales (N=128)</b> | 98% (125/128) | 2% (3/128) |
| <b>England (N=122)</b>             | 98% (119/122) | 2% (3/122) |
| <b>Wales (N=6)</b>                 | 100% (6/6)    | 0% (0/6)   |
|                                    |               |            |
| <b>BRPNF (N=12)</b>                | 83% (10/12)   | 17% (2/12) |
| <b>CEWT (N=4)</b>                  | 100% (4/4)    | 0% (0/4)   |
| <b>EPEN (N=13)</b>                 | 100% (13/13)  | 0% (0/13)  |
| <b>EPIC (N=8)</b>                  | 100% (8/8)    | 0% (0/8)   |
| <b>NTPEN (N=13)</b>                | 100% (13/13)  | 0% (0/13)  |
| <b>NWEIG (N=11)</b>                | 100% (11/11)  | 0% (0/11)  |
| <b>ORENG (N=7)</b>                 | 100% (7/7)    | 0% (0/7)   |
| <b>PENNEC (N=7)</b>                | 100% (7/7)    | 0% (0/7)   |
| <b>SETPEG (N=9)</b>                | 100% (9/9)    | 0% (0/9)   |
| <b>SWEP (N=5)</b>                  | 100% (5/5)    | 0% (0/5)   |
| <b>SWIPE (N=9)</b>                 | 100% (9/9)    | 0% (0/9)   |
| <b>SWTPEG (N=8)</b>                | 100% (8/8)    | 0% (0/8)   |
| <b>TEN (N=6)</b>                   | 100% (6/6)    | 0% (0/6)   |
| <b>WPNN (N=8)</b>                  | 88% (7/8)     | 13% (1/8)  |
| <b>YPEN (N=8)</b>                  | 100% (8/8)    | 0% (0/8)   |

**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 |
| <b>England &amp; Wales (N=128)</b> | 1% (1/128)                     | 57% (73/128)  | 7% (9/128)                     | 9% (12/128)                        | 23% (30/128)  | 0% (0/128)                     |
| <b>England (N=122)</b>             | 1% (1/122)                     | 57% (69/122)  | 7% (9/122)                     | 9% (11/122)                        | 24% (29/122)  | 0% (0/122)                     |
| <b>Wales (N=6)</b>                 | 0% (0/6)                       | 67% (4/6)     | 0% (0/6)                       | 17% (1/6)                          | 17% (1/6)     | 0% (0/6)                       |
|                                    |                                |               |                                |                                    |               |                                |
| <b>BRPNF (N=12)</b>                | 0% (0/12)                      | 42% (5/12)    | 0% (0/12)                      | 8% (1/12)                          | 33% (4/12)    | 0% (0/12)                      |
| <b>CEWT (N=4)</b>                  | 0% (0/4)                       | 50% (2/4)     | 25% (1/4)                      | 0% (0/4)                           | 25% (1/4)     | 0% (0/4)                       |
| <b>EPEN (N=13)</b>                 | 0% (0/13)                      | 54% (7/13)    | 0% (0/13)                      | 8% (1/13)                          | 38% (5/13)    | 0% (0/13)                      |
| <b>EPIC (N=8)</b>                  | 0% (0/8)                       | 88% (7/8)     | 0% (0/8)                       | 13% (1/8)                          | 0% (0/8)      | 0% (0/8)                       |
| <b>NTPEN (N=13)</b>                | 0% (0/13)                      | 62% (8/13)    | 8% (1/13)                      | 15% (2/13)                         | 15% (2/13)    | 0% (0/13)                      |
| <b>NWEIG (N=11)</b>                | 0% (0/11)                      | 73% (8/11)    | 0% (0/11)                      | 9% (1/11)                          | 18% (2/11)    | 0% (0/11)                      |
| <b>ORENG (N=7)</b>                 | 0% (0/7)                       | 86% (6/7)     | 14% (1/7)                      | 0% (0/7)                           | 0% (0/7)      | 0% (0/7)                       |
| <b>PENNEC (N=7)</b>                | 0% (0/7)                       | 71% (5/7)     | 14% (1/7)                      | 0% (0/7)                           | 14% (1/7)     | 0% (0/7)                       |
| <b>SETPEG (N=9)</b>                | 11% (1/9)                      | 44% (4/9)     | 0% (0/9)                       | 0% (0/9)                           | 44% (4/9)     | 0% (0/9)                       |
| <b>SWEP (N=5)</b>                  | 0% (0/5)                       | 60% (3/5)     | 0% (0/5)                       | 20% (1/5)                          | 20% (1/5)     | 0% (0/5)                       |
| <b>SWIPE (N=9)</b>                 | 0% (0/9)                       | 33% (3/9)     | 11% (1/9)                      | 22% (2/9)                          | 33% (3/9)     | 0% (0/9)                       |
| <b>SWTPEG (N=8)</b>                | 0% (0/8)                       | 50% (4/8)     | 13% (1/8)                      | 13% (1/8)                          | 25% (2/8)     | 0% (0/8)                       |
| <b>TEN (N=6)</b>                   | 0% (0/6)                       | 50% (3/6)     | 33% (2/6)                      | 0% (0/6)                           | 17% (1/6)     | 0% (0/6)                       |
| <b>WPNN (N=8)</b>                  | 0% (0/8)                       | 25% (2/8)     | 13% (1/8)                      | 25% (2/8)                          | 25% (2/8)     | 0% (0/8)                       |
| <b>YPEN (N=8)</b>                  | 0% (0/8)                       | 75% (6/8)     | 0% (0/8)                       | 0% (0/8)                           | 25% (2/8)     | 0% (0/8)                       |

**Table 26: Typical response time to specialist advice.**

| Country/network                    | Same weekday | Next weekday | 3-4 weekdays | Within the working week |
|------------------------------------|--------------|--------------|--------------|-------------------------|
| <b>England &amp; Wales (N=125)</b> | 7% (9/125)   | 50% (62/125) | 32% (40/125) | 11% (14/125)            |
| <b>England (N=119)</b>             | 8% (9/119)   | 51% (61/119) | 32% (38/119) | 9% (11/119)             |
| <b>Wales (N=6)</b>                 | 0% (0/6)     | 17% (1/6)    | 33% (2/6)    | 50% (3/6)               |
|                                    |              |              |              |                         |
| <b>BRPNF (N=10)</b>                | 0% (0/10)    | 50% (5/10)   | 30% (3/10)   | 20% (2/10)              |
| <b>CEWT (N=4)</b>                  | 0% (0/4)     | 50% (2/4)    | 50% (2/4)    | 0% (0/4)                |
| <b>EPEN (N=13)</b>                 | 0% (0/13)    | 54% (7/13)   | 38% (5/13)   | 8% (1/13)               |
| <b>EPIC (N=8)</b>                  | 0% (0/8)     | 63% (5/8)    | 25% (2/8)    | 13% (1/8)               |
| <b>NTPEN (N=13)</b>                | 31% (4/13)   | 46% (6/13)   | 15% (2/13)   | 8% (1/13)               |
| <b>NWEIG (N=11)</b>                | 9% (1/11)    | 64% (7/11)   | 18% (2/11)   | 9% (1/11)               |
| <b>ORENG (N=7)</b>                 | 0% (0/7)     | 43% (3/7)    | 43% (3/7)    | 14% (1/7)               |
| <b>PENNEC (N=7)</b>                | 0% (0/7)     | 71% (5/7)    | 29% (2/7)    | 0% (0/7)                |
| <b>SETPEG (N=9)</b>                | 0% (0/9)     | 33% (3/9)    | 33% (3/9)    | 33% (3/9)               |
| <b>SWEP (N=5)</b>                  | 0% (0/5)     | 0% (0/5)     | 40% (2/5)    | 60% (3/5)               |
| <b>SWIPE (N=9)</b>                 | 22% (2/9)    | 33% (3/9)    | 44% (4/9)    | 0% (0/9)                |
| <b>SWTPEG (N=8)</b>                | 0% (0/8)     | 75% (6/8)    | 25% (2/8)    | 0% (0/8)                |
| <b>TEN (N=6)</b>                   | 17% (1/6)    | 33% (2/6)    | 50% (3/6)    | 0% (0/6)                |
| <b>WPNN (N=7)</b>                  | 0% (0/7)     | 43% (3/7)    | 57% (4/7)    | 0% (0/7)                |
| <b>YPEN (N=8)</b>                  | 13% (1/8)    | 63% (5/8)    | 13% (1/8)    | 13% (1/8)               |

**Table 27: Professionals who ‘typically’ provide initial specialist advice.**

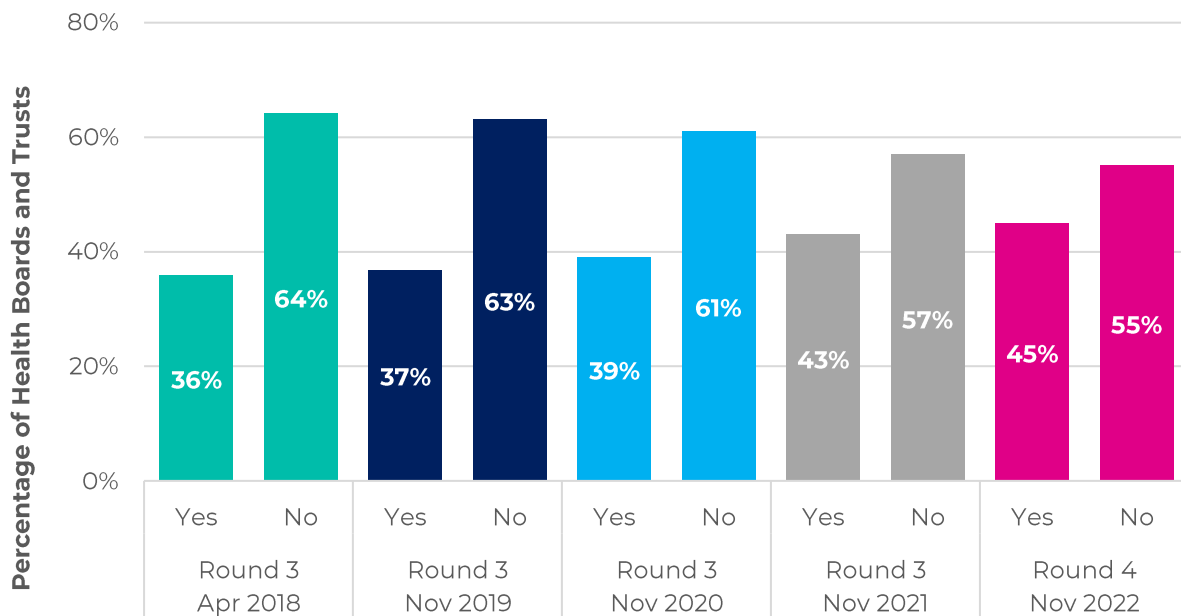
| Country/network                        | ESN          | Consultant with<br>‘expertise in<br>epilepsy’ | Paediatric<br>neurologist | Other        |
|--|--------------|---|---------------------------|--------------|
| <b>England &amp; Wales<br/>(N=125)</b> | 56% (70/125) | 33% (41/125)                                  | 1% (1/125)                | 10% (13/125) |
| <b>England (N=119)</b>                 | 56% (67/119) | 32% (38/119)                                  | 1% (1/119)                | 11% (13/119) |
| <b>Wales (N=6)</b>                     | 50% (3/6)    | 50% (3/6)                                     | 0% (0/6)                  | 0% (0/6)     |
|  |              |   |                           |              |
| <b>BRPNF (N=10)</b>                    | 50% (5/10)   | 40% (4/10)                                    | 0% (0/10)                 | 10% (1/10)   |
| <b>CEWT (N=4)</b>                      | 50% (2/4)    | 25% (1/4)                                     | 0% (0/4)                  | 25% (1/4)    |
| <b>EPEN (N=13)</b>                     | 62% (8/13)   | 38% (5/13)                                    | 0% (0/13)                 | 0% (0/13)    |
| <b>EPIC (N=8)</b>                      | 88% (7/8)    | 13% (1/8)                                     | 0% (0/8)                  | 0% (0/8)     |
| <b>NTPEN (N=13)</b>                    | 69% (9/13)   | 23% (3/13)                                    | 8% (1/13)                 | 0% (0/13)    |
| <b>NWEIG (N=11)</b>                    | 64% (7/11)   | 27% (3/11)                                    | 0% (0/11)                 | 9% (1/11)    |
| <b>ORENG (N=7)</b>                     | 43% (3/7)    | 43% (3/7)                                     | 0% (0/7)                  | 14% (1/7)    |
| <b>PENNEC (N=7)</b>                    | 43% (3/7)    | 43% (3/7)                                     | 0% (0/7)                  | 14% (1/7)    |
| <b>SETPEG (N=9)</b>                    | 56% (5/9)    | 33% (3/9)                                     | 0% (0/9)                  | 11% (1/9)    |
| <b>SWEP (N=5)</b>                      | 40% (2/5)    | 60% (3/5)                                     | 0% (0/5)                  | 0% (0/5)     |
| <b>SWIPE (N=9)</b>                     | 56% (5/9)    | 33% (3/9)                                     | 0% (0/9)                  | 11% (1/9)    |
| <b>SWTPEG (N=8)</b>                    | 75% (6/8)    | 13% (1/8)                                     | 0% (0/8)                  | 13% (1/8)    |
| <b>TEN (N=6)</b>                       | 33% (2/6)    | 50% (3/6)                                     | 0% (0/6)                  | 17% (1/6)    |
| <b>WPNN (N=7)</b>                      | 57% (4/7)    | 14% (1/7)                                     | 0% (0/7)                  | 29% (2/7)    |
| <b>YPEN (N=8)</b>                      | 25% (2/8)    | 50% (4/8)                                     | 0% (0/8)                  | 25% (2/8)    |

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

| Country/network                    | Yes           | No           |
|------------------------------------|---------------|--------------|
| <b>England &amp; Wales (N=128)</b> | 88% (113/128) | 12% (15/128) |
| <b>England (N=122)</b>             | 89% (108/122) | 11% (14/122) |
| <b>Wales (N=6)</b>                 | 83% (5/6)     | 17% (1/6)    |
|                                    |               |              |
| <b>BRPNF (N=12)</b>                | 67% (8/12)    | 33% (4/12)   |
| <b>CEWT (N=4)</b>                  | 75% (3/4)     | 25% (1/4)    |
| <b>EPEN (N=13)</b>                 | 92% (12/13)   | 8% (1/13)    |
| <b>EPIC (N=8)</b>                  | 100% (8/8)    | 0% (0/8)     |
| <b>NTPEN (N=13)</b>                | 92% (12/13)   | 8% (1/13)    |
| <b>NWEIG (N=11)</b>                | 91% (10/11)   | 9% (1/11)    |
| <b>ORENG (N=7)</b>                 | 86% (6/7)     | 14% (1/7)    |
| <b>PENNEC (N=7)</b>                | 71% (5/7)     | 29% (2/7)    |
| <b>SETPEG (N=9)</b>                | 100% (9/9)    | 0% (0/9)     |
| <b>SWEP (N=5)</b>                  | 80% (4/5)     | 20% (1/5)    |
| <b>SWIPE (N=9)</b>                 | 100% (9/9)    | 0% (0/9)     |
| <b>SWTPEG (N=8)</b>                | 100% (8/8)    | 0% (0/8)     |
| <b>TEN (N=6)</b>                   | 83% (5/6)     | 17% (1/6)    |
| <b>WPNN (N=8)</b>                  | 75% (6/8)     | 25% (2/8)    |
| <b>YPEN (N=8)</b>                  | 100% (8/8)    | 0% (0/8)     |

# Transition

**Table 29** shows **13% (16/128)** of Health Boards and Trusts did not have agreed referral pathways for young people to adult services. **45% (58/128)** of Health Boards and Trusts had an outpatient clinic specifically for young people with epilepsies, **Table 30**. The median age of acceptance into these clinics was **15 years**, with a minimum acceptance age of **11 years** and a maximum acceptance age of **18 years**, as shown on **Table 31**.



**Figure 12: Outpatient clinics for young people across Round 3 April 2018, November 2019, November 2020, November 2021 and Round 4 November 2022.**

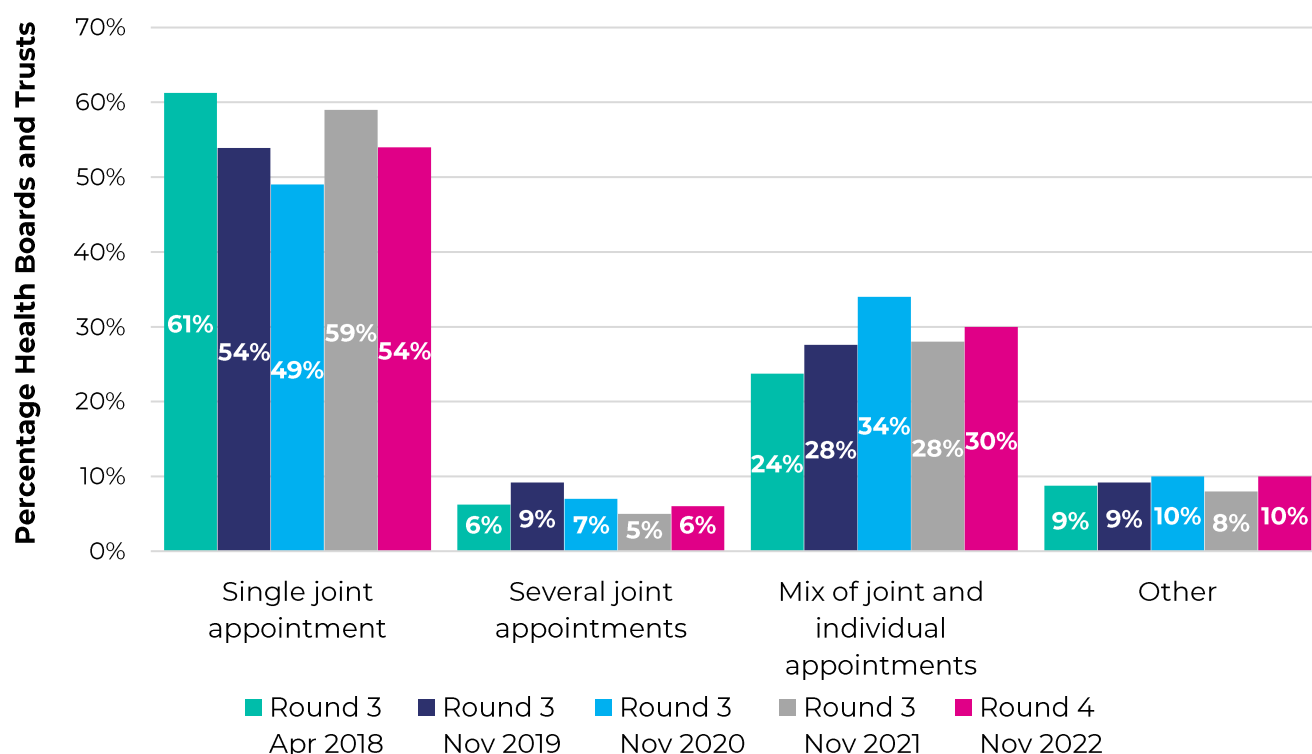
**64% (82/128)** of Health Boards and Trusts reported having outpatient services for epilepsy where there was a presence of both adult and paediatric professionals, **Table 32**.

**Table 33** shows that **54% (44/82)** had single joint appointments, **6% (5/82)** had a series of several joint appointments and **30% (25/82)** had a flexible approach that included a mixture of joint or individual reviews. In the eight Health Boards and Trusts that responded other, the responses included:

- This clinic has started at an ESN level; the pathway is established but not yet formally agreed,
- Mostly single joint appointment, but for some patients two or three in the last year,
- A single joint appointment with paediatric and adult neurologist based at the adult centre,
- Joint with adult but flexible,
- Teenage clinic with adult ESN also present,
- Adult and Paediatric nurse specialist- now limited during COVID and staffing issue nurse led clinic,
- Joint epilepsy nurse clinic,
- Have a specific adolescent clinic at another adult hospital but also a new local clinic.



**Figure 13** shows a comparison of the composition of joint transition processes in Round 3 April 2018, November 2019, November 2020, November 2021 and Round 4 November 2022.



**Figure 13: Composition of the joint transition process in Round 3 April 2018, November 2019, November 2020, November 2021 and Round 4 November 2022.**

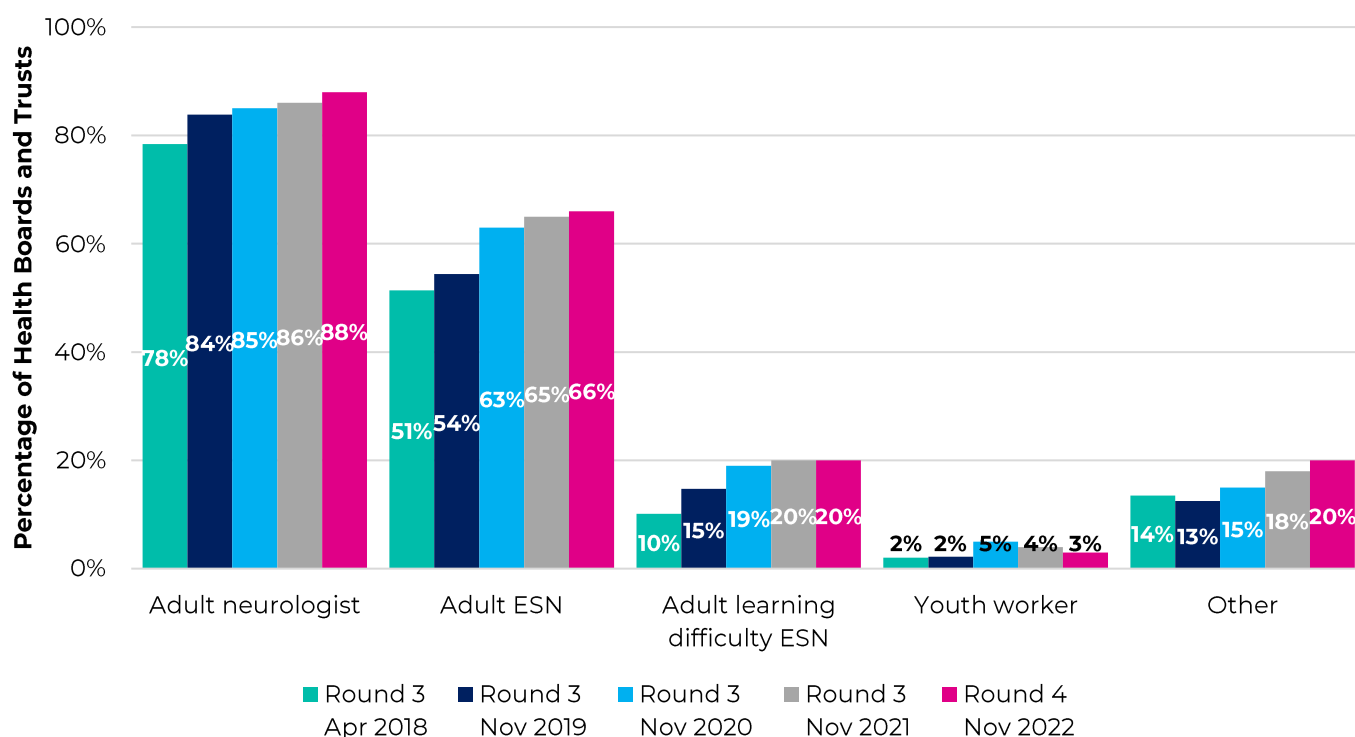
**Table 35** shows that **66% (84/128)** of Health Boards and Trusts used structured resources (for example Ready, Steady, Go) to support young people transition from paediatric to adult services.

Various professionals were indicated as routinely involved in the transition or transfer of paediatric patients to adult services (**Table 36**). Most of the Health Boards and Trusts, **88% (112/128)**, had an adult neurologist supporting transition to adult services, whilst **66% (84/128)** had an adult ESN supporting the transition process. In the Health Boards and Trusts that responded other, the responses included:

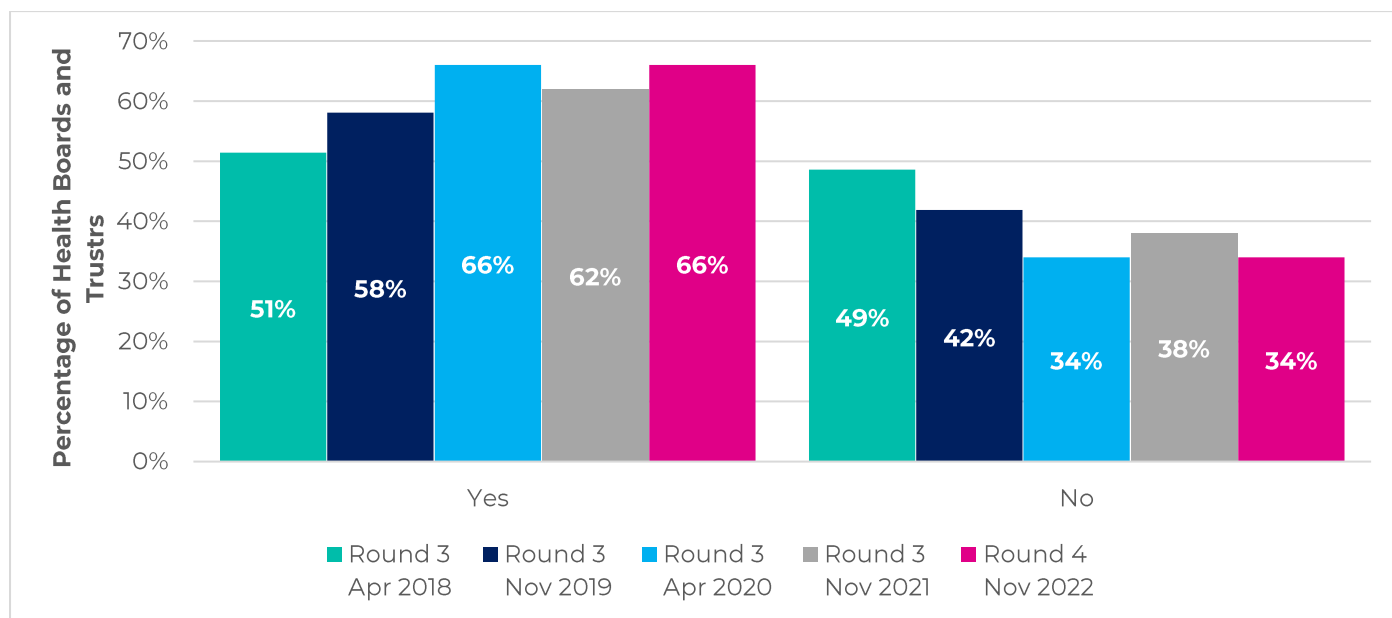
- Consultant Psychiatrist,
- Adult Learning Disability team,
- GP and Adult Neurologist,
- Adult Learning Disability team, adult rehab and GP,
- GPs,
- Neurology specialist nurse contact and often offer ESN appointment at neurology hospital,
- Neurologist,
- Paediatric Epilepsy Nurse Specialist,

- Transition nurses,
- Consultant Paediatrician with Interest in Epilepsy,
- Learning Disability transition nurses,
- Discussion with adult neurologist and neurophysiologist in Neurophysiology meeting,
- Epilepsy specialist midwife,
- Adult psychiatrist with interest in learning difficulties,
- Adult neurologist/ Learning Disability consultant involved though not in clinic,
- Education/ social care,
- Adult Learning Disability Psychiatrist,
- Specific adolescent transition clinic regionally, locally appointed transition nurse,
- Neurodisability transition nurse and transition to adult services nurse,
- Adult Learning Disability Consultant.

**Figure 14** shows a comparison of professionals who were routinely involved in the transition or transfer of young people with epilepsies to adult services in Round 3 April 2018, November 2019, November 2020, November 2021 and Round 4 November 2022.



**Figure 14: Professionals routinely involved in the transition or transfer to adult services in Round 3 April 2018, November 2019, November 2020, November 2021 and Round 4 November 2022.**



**Figure 15: Percentage of Health Boards and Trusts that were using structured resources to support transition in Round 3 April 2018, November 2019, November 2020, November 2021 and Round 4 November 2022.**

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

| Country/network                    | Yes           | No           |
|------------------------------------|---------------|--------------|
| <b>England &amp; Wales (N=128)</b> | 88% (112/128) | 13% (16/128) |
| <b>England (N=122)</b>             | 87% (106/122) | 13% (16/122) |
| <b>Wales (N=6)</b>                 | 100% (6/6)    | 0% (0/6)     |
|                                    |               |              |
| <b>BRPNF (N=12)</b>                | 67% (8/12)    | 33% (4/12)   |
| <b>CEWT (N=4)</b>                  | 100% (4/4)    | 0% (0/4)     |
| <b>EPEN (N=13)</b>                 | 92% (12/13)   | 8% (1/13)    |
| <b>EPIC (N=8)</b>                  | 88% (7/8)     | 13% (1/8)    |
| <b>NTPEN (N=13)</b>                | 85% (11/13)   | 15% (2/13)   |
| <b>NWEIG (N=11)</b>                | 91% (10/11)   | 9% (1/11)    |
| <b>ORENG (N=7)</b>                 | 86% (6/7)     | 14% (1/7)    |
| <b>PENNEC (N=7)</b>                | 57% (4/7)     | 43% (3/7)    |
| <b>SETPEG (N=9)</b>                | 89% (8/9)     | 11% (1/9)    |
| <b>SWEP (N=5)</b>                  | 100% (5/5)    | 0% (0/5)     |
| <b>SWIPE (N=9)</b>                 | 89% (8/9)     | 11% (1/9)    |
| <b>SWTPEG (N=8)</b>                | 100% (8/8)    | 0% (0/8)     |
| <b>TEN (N=6)</b>                   | 100% (6/6)    | 0% (0/6)     |
| <b>WPNN (N=8)</b>                  | 88% (7/8)     | 13% (1/8)    |
| <b>YPEN (N=8)</b>                  | 100% (8/8)    | 0% (0/8)     |

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

| Country/network                    | Yes          | No           |
|------------------------------------|--------------|--------------|
| <b>England &amp; Wales (N=128)</b> | 45% (58/128) | 55% (70/128) |
| <b>England (N=122)</b>             | 45% (55/122) | 55% (67/122) |
| <b>Wales (N=6)</b>                 | 50% (3/6)    | 50% (3/6)    |
|                                    |              |              |
| <b>BRPNF (N=12)</b>                | 25% (3/12)   | 75% (9/12)   |
| <b>CEWT (N=4)</b>                  | 75% (3/4)    | 25% (1/4)    |
| <b>EPEN (N=13)</b>                 | 54% (7/13)   | 46% (6/13)   |
| <b>EPIC (N=8)</b>                  | 50% (4/8)    | 50% (4/8)    |
| <b>NTPEN (N=13)</b>                | 38% (5/13)   | 62% (8/13)   |
| <b>NWEIG (N=11)</b>                | 55% (6/11)   | 45% (5/11)   |
| <b>ORENG (N=7)</b>                 | 57% (4/7)    | 43% (3/7)    |
| <b>PENNEC (N=7)</b>                | 29% (2/7)    | 71% (5/7)    |
| <b>SETPEG (N=9)</b>                | 33% (3/9)    | 67% (6/9)    |
| <b>SWEP (N=5)</b>                  | 40% (2/5)    | 60% (3/5)    |
| <b>SWIPE (N=9)</b>                 | 56% (5/9)    | 44% (4/9)    |
| <b>SWTPEG (N=8)</b>                | 63% (5/8)    | 38% (3/8)    |
| <b>TEN (N=6)</b>                   | 33% (2/6)    | 67% (4/6)    |
| <b>WPNN (N=8)</b>                  | 38% (3/8)    | 63% (5/8)    |
| <b>YPEN (N=8)</b>                  | 50% (4/8)    | 50% (4/8)    |

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

| Country/network                   | Mean age | Median age | Minimum age | Maximum age |
|-----------------------------------|----------|------------|-------------|-------------|
| <b>England &amp; Wales (N=58)</b> | 14.7     | 15         | 11          | 18          |
| <b>England (N=55)</b>             | 14.6     | 15         | 11          | 18          |
| <b>Wales (N=3)</b>                | 15.3     | 16         | 14          | 16          |
|                                   |          |            |             |             |
| <b>BRPNF (N=3)</b>                | 15.3     | 16         | 14          | 16          |
| <b>CEWT (N=3)</b>                 | 13.3     | 13         | 12          | 15          |
| <b>EPEN (N=7)</b>                 | 14.4     | 14         | 13          | 16          |
| <b>EPIC (N=4)</b>                 | 14.5     | 14         | 12          | 18          |
| <b>NTPEN (N=5)</b>                | 14.0     | 14         | 12          | 16          |
| <b>NWEIG (N=6)</b>                | 14.2     | 14         | 12          | 16          |
| <b>ORENG (N=4)</b>                | 14.8     | 15         | 13          | 16          |
| <b>PENNEC (N=2)</b>               | 14.5     | 15         | 13          | 16          |
| <b>SETPEG (N=3)</b>               | 15.3     | 16         | 14          | 16          |
| <b>SWEP (N=2)</b>                 | 16.0     | 16         | 16          | 16          |
| <b>SWIPE (N=5)</b>                | 16.2     | 16         | 15          | 18          |
| <b>SWTPEG (N=5)</b>               | 15.2     | 16         | 12          | 18          |
| <b>TEN (N=2)</b>                  | 12.5     | 12.5       | 11          | 14          |
| <b>WPNN (N=3)</b>                 | 15.0     | 16         | 13          | 16          |
| <b>YPEN (N=4)</b>                 | 14.5     | 14.5       | 13          | 16          |

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

| Country/network                    | Yes          | No           |
|------------------------------------|--------------|--------------|
| <b>England &amp; Wales (N=128)</b> | 64% (82/128) | 36% (46/128) |
| <b>England (N=122)</b>             | 63% (77/122) | 37% (45/122) |
| <b>Wales (N=6)</b>                 | 83% (5/6)    | 17% (1/6)    |
|                                    |              |              |
| <b>BRPNF (N=12)</b>                | 50% (6/12)   | 50% (6/12)   |
| <b>CEWT (N=4)</b>                  | 50% (2/4)    | 50% (2/4)    |
| <b>EPEN (N=13)</b>                 | 85% (11/13)  | 15% (2/13)   |
| <b>EPIC (N=8)</b>                  | 63% (5/8)    | 38% (3/8)    |
| <b>NTPEN (N=13)</b>                | 77% (10/13)  | 23% (3/13)   |
| <b>NWEIG (N=11)</b>                | 64% (7/11)   | 36% (4/11)   |
| <b>ORENG (N=7)</b>                 | 71% (5/7)    | 29% (2/7)    |
| <b>PENNEC (N=7)</b>                | 43% (3/7)    | 57% (4/7)    |
| <b>SETPEG (N=9)</b>                | 44% (4/9)    | 56% (5/9)    |
| <b>SWEP (N=5)</b>                  | 80% (4/5)    | 20% (1/5)    |
| <b>SWIPE (N=9)</b>                 | 89% (8/9)    | 11% (1/9)    |
| <b>SWTPEG (N=8)</b>                | 88% (7/8)    | 13% (1/8)    |
| <b>TEN (N=6)</b>                   | 17% (1/6)    | 83% (5/6)    |
| <b>WPNN (N=8)</b>                  | 38% (3/8)    | 63% (5/8)    |
| <b>YPEN (N=8)</b>                  | 75% (6/8)    | 25% (2/8)    |

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

| Country/network                   | Several joint appointments | Single joint appointments | Mixed (joint and individual) | Other      |
|-----------------------------------|----------------------------|---------------------------|------------------------------|------------|
| <b>England &amp; Wales (N=82)</b> | 6% (5/82)                  | 54% (44/82)               | 30% (25/82)                  | 10% (8/82) |
| <b>England (N=77)</b>             | 4% (3/77)                  | 56% (43/77)               | 30% (23/77)                  | 10% (8/77) |
| <b>Wales (N=5)</b>                | 40% (2/5)                  | 20% (1/5)                 | 40% (2/5)                    | 0% (0/5)   |
|                                   |                            |                           |                              |            |
| <b>BRPNF (N=6)</b>                | 17% (1/6)                  | 50% (3/6)                 | 33% (2/6)                    | 0% (0/6)   |
| <b>CEWT (N=2)</b>                 | 0% (0/2)                   | 50% (1/2)                 | 0% (0/2)                     | 50% (1/2)  |
| <b>EPEN (N=11)</b>                | 0% (0/11)                  | 64% (7/11)                | 27% (3/11)                   | 9% (1/11)  |
| <b>EPIC (N=5)</b>                 | 20% (1/5)                  | 40% (2/5)                 | 0% (0/5)                     | 40% (2/5)  |
| <b>NTPEN (N=10)</b>               | 10% (1/10)                 | 50% (5/10)                | 30% (3/10)                   | 10% (1/10) |
| <b>NWEIG (N=7)</b>                | 0% (0/7)                   | 86% (6/7)                 | 14% (1/7)                    | 0% (0/7)   |
| <b>ORENG (N=5)</b>                | 0% (0/5)                   | 60% (3/5)                 | 40% (2/5)                    | 0% (0/5)   |
| <b>PENNEC (N=3)</b>               | 0% (0/3)                   | 67% (2/3)                 | 0% (0/3)                     | 33% (1/3)  |
| <b>SETPEG (N=4)</b>               | 25% (1/4)                  | 25% (1/4)                 | 50% (2/4)                    | 0% (0/4)   |
| <b>SWEP (N=4)</b>                 | 25% (1/4)                  | 25% (1/4)                 | 50% (2/4)                    | 0% (0/4)   |
| <b>SWIPE (N=8)</b>                | 0% (0/8)                   | 38% (3/8)                 | 50% (4/8)                    | 13% (1/8)  |
| <b>SWTPEG (N=7)</b>               | 0% (0/7)                   | 57% (4/7)                 | 29% (2/7)                    | 14% (1/7)  |
| <b>TEN (N=1)</b>                  | 0% (0/1)                   | 100% (1/1)                | 0% (0/1)                     | 0% (0/1)   |
| <b>WPNN (N=3)</b>                 | 0% (0/3)                   | 33% (1/3)                 | 67% (2/3)                    | 0% (0/3)   |
| <b>YPEN (N=6)</b>                 | 0% (0/6)                   | 67% (4/6)                 | 33% (2/6)                    | 0% (0/6)   |

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

| Country/network                   | Mean | Minimum | Maximum |
|-----------------------------------|------|---------|---------|
| <b>England &amp; Wales (N=82)</b> | 75%  | 1%      | 100%    |
| <b>England (N=77)</b>             | 78%  | 1%      | 100%    |
| <b>Wales (N=5)</b>                | 44%  | 30%     | 75%     |
|                                   |      |         |         |
| <b>BRPNF (N=6)</b>                | 88%  | 50%     | 100%    |
| <b>CEWT (N=2)</b>                 | 48%  | 25%     | 70%     |
| <b>EPEN (N=11)</b>                | 77%  | 1%      | 100%    |
| <b>EPIC (N=5)</b>                 | 62%  | 30%     | 90%     |
| <b>NTPEN (N=10)</b>               | 79%  | 25%     | 100%    |
| <b>NWEIG (N=7)</b>                | 81%  | 50%     | 100%    |
| <b>ORENG (N=5)</b>                | 79%  | 40%     | 100%    |
| <b>PENNEC (N=3)</b>               | 72%  | 25%     | 100%    |
| <b>SETPEG (N=4)</b>               | 83%  | 50%     | 100%    |
| <b>SWEP (N=4)</b>                 | 46%  | 30%     | 75%     |
| <b>SWIPE (N=8)</b>                | 74%  | 5%      | 90%     |
| <b>SWTPEG (N=7)</b>               | 90%  | 45%     | 100%    |
| <b>TEN (N=1)</b>                  | 50%  | 50%     | 50%     |
| <b>WPNN (N=3)</b>                 | 73%  | 60%     | 100%    |
| <b>YPEN (N=6)</b>                 | 73%  | 10%     | 100%    |

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

| Country/network                    | Yes          | No           |
|------------------------------------|--------------|--------------|
| <b>England &amp; Wales (N=128)</b> | 66% (84/128) | 34% (44/128) |
| <b>England (N=122)</b>             | 68% (83/122) | 32% (39/122) |
| <b>Wales (N=6)</b>                 | 17% (1/6)    | 83% (5/6)    |
|                                    |              |              |
| <b>BRPNF (N=12)</b>                | 42% (5/12)   | 58% (7/12)   |
| <b>CEWT (N=4)</b>                  | 50% (2/4)    | 50% (2/4)    |
| <b>EPEN (N=13)</b>                 | 62% (8/13)   | 38% (5/13)   |
| <b>EPIC (N=8)</b>                  | 25% (2/8)    | 75% (6/8)    |
| <b>NTPEN (N=13)</b>                | 69% (9/13)   | 31% (4/13)   |
| <b>NWEIG (N=11)</b>                | 91% (10/11)  | 9% (1/11)    |
| <b>ORENG (N=7)</b>                 | 71% (5/7)    | 29% (2/7)    |
| <b>PENNEC (N=7)</b>                | 86% (6/7)    | 14% (1/7)    |
| <b>SETPEG (N=9)</b>                | 44% (4/9)    | 56% (5/9)    |
| <b>SWEP (N=5)</b>                  | 20% (1/5)    | 80% (4/5)    |
| <b>SWIPE (N=9)</b>                 | 89% (8/9)    | 11% (1/9)    |
| <b>SWTPEG (N=8)</b>                | 88% (7/8)    | 13% (1/8)    |
| <b>TEN (N=6)</b>                   | 83% (5/6)    | 17% (1/6)    |
| <b>WPNN (N=8)</b>                  | 63% (5/8)    | 38% (3/8)    |
| <b>YPEN (N=8)</b>                  | 88% (7/8)    | 13% (1/8)    |

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

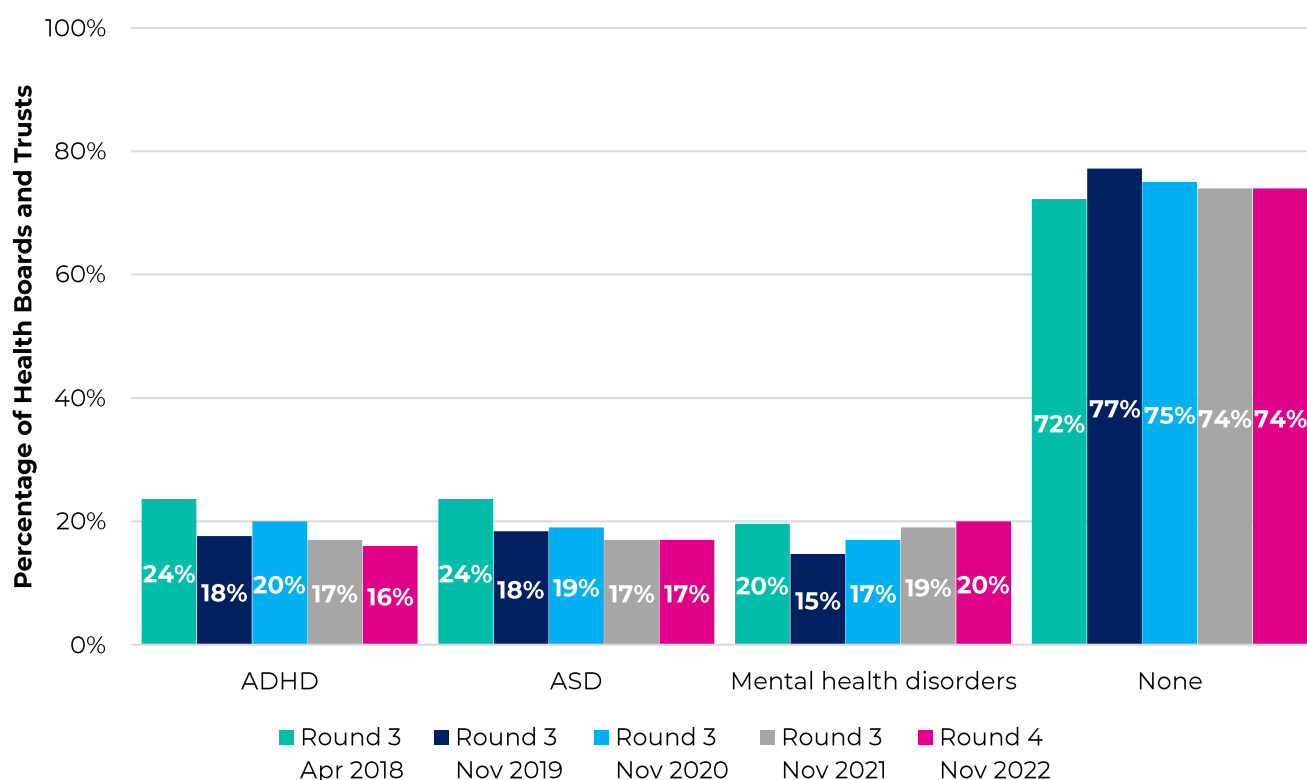
| Country/network                    | Adult epilepsy specialist nurse | Adult learning difficulty ESN | Adult neurologist | Youth worker | Other        |
|------------------------------------|---------------------------------|-------------------------------|-------------------|--------------|--------------|
| <b>England &amp; Wales (N=128)</b> | 66% (84/128)                    | 20% (25/128)                  | 88% (112/128)     | 3% (4/128)   | 20% (26/128) |
| <b>England (N=122)</b>             | 66% (80/122)                    | 19% (23/122)                  | 87% (106/122)     | 3% (4/122)   | 20% (24/122) |
| <b>Wales (N=6)</b>                 | 67% (4/6)                       | 33% (2/6)                     | 100% (6/6)        | 0% (0/6)     | 33% (2/6)    |
|                                    |                                 |                               |                   |              |              |
| <b>BRPNF (N=12)</b>                | 33% (4/12)                      | 8% (1/12)                     | 83% (10/12)       | 0% (0/12)    | 17% (2/12)   |
| <b>CEWT (N=4)</b>                  | 75% (3/4)                       | 25% (1/4)                     | 75% (3/4)         | 0% (0/4)     | 0% (0/4)     |
| <b>EPEN (N=13)</b>                 | 85% (11/13)                     | 31% (4/13)                    | 85% (11/13)       | 15% (2/13)   | 38% (5/13)   |
| <b>EPIC (N=8)</b>                  | 25% (2/8)                       | 0% (0/8)                      | 100% (8/8)        | 0% (0/8)     | 38% (3/8)    |
| <b>NTPEN (N=13)</b>                | 54% (7/13)                      | 8% (1/13)                     | 100% (13/13)      | 0% (0/13)    | 15% (2/13)   |
| <b>NWEIG (N=11)</b>                | 64% (7/11)                      | 0% (0/11)                     | 82% (9/11)        | 0% (0/11)    | 0% (0/11)    |
| <b>ORENG (N=7)</b>                 | 86% (6/7)                       | 57% (4/7)                     | 100% (7/7)        | 14% (1/7)    | 29% (2/7)    |
| <b>PENNEC (N=7)</b>                | 57% (4/7)                       | 29% (2/7)                     | 71% (5/7)         | 0% (0/7)     | 29% (2/7)    |
| <b>SETPEG (N=9)</b>                | 78% (7/9)                       | 44% (4/9)                     | 100% (9/9)        | 0% (0/9)     | 11% (1/9)    |
| <b>SWEP (N=5)</b>                  | 60% (3/5)                       | 40% (2/5)                     | 100% (5/5)        | 0% (0/5)     | 40% (2/5)    |
| <b>SWIPE (N=9)</b>                 | 100% (9/9)                      | 33% (3/9)                     | 67% (6/9)         | 0% (0/9)     | 22% (2/9)    |
| <b>SWTPEG (N=8)</b>                | 63% (5/8)                       | 0% (0/8)                      | 88% (7/8)         | 0% (0/8)     | 0% (0/8)     |
| <b>TEN (N=6)</b>                   | 100% (6/6)                      | 0% (0/6)                      | 83% (5/6)         | 0% (0/6)     | 0% (0/6)     |
| <b>WPNN (N=8)</b>                  | 63% (5/8)                       | 25% (2/8)                     | 100% (8/8)        | 13% (1/8)    | 50% (4/8)    |
| <b>YPEN (N=8)</b>                  | 63% (5/8)                       | 13% (1/8)                     | 75% (6/8)         | 0% (0/8)     | 13% (1/8)    |



# Mental health and Neurodevelopment

**74% (95/128)** of Health Boards and Trusts indicated that they had no formal screening services for Attention Deficit Hyperactivity Disorder (ADHD), Autistic Spectrum Disorder (ASD) and mental health disorders, **Table 37**.

**Figure 16** shows the comparison of routinely provided formal screening services in Round 3 April 2018, November 2019, November 2020, November 2021 and Round 4 November 2022.



**Figure 16: Percentage of Health Boards and Trusts routinely providing formal screening services in Round 3 April 2018, November 2019, November 2020, November 2021 and Round 4 November 2022.**

Over half of Health Boards and Trusts, **60% (77/128)** 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:

- **12% (15/128)** SDQ (Strength and Difficulties Questionnaire),
- **7% (9/128)** Connor's Questionnaire,
- **9% (11/128)** Other.

Other responses included:

- York Questionnaire, Vanderbilt and department behaviour assessment questionnaire,
- Locally designed emotional wellbeing questionnaire,

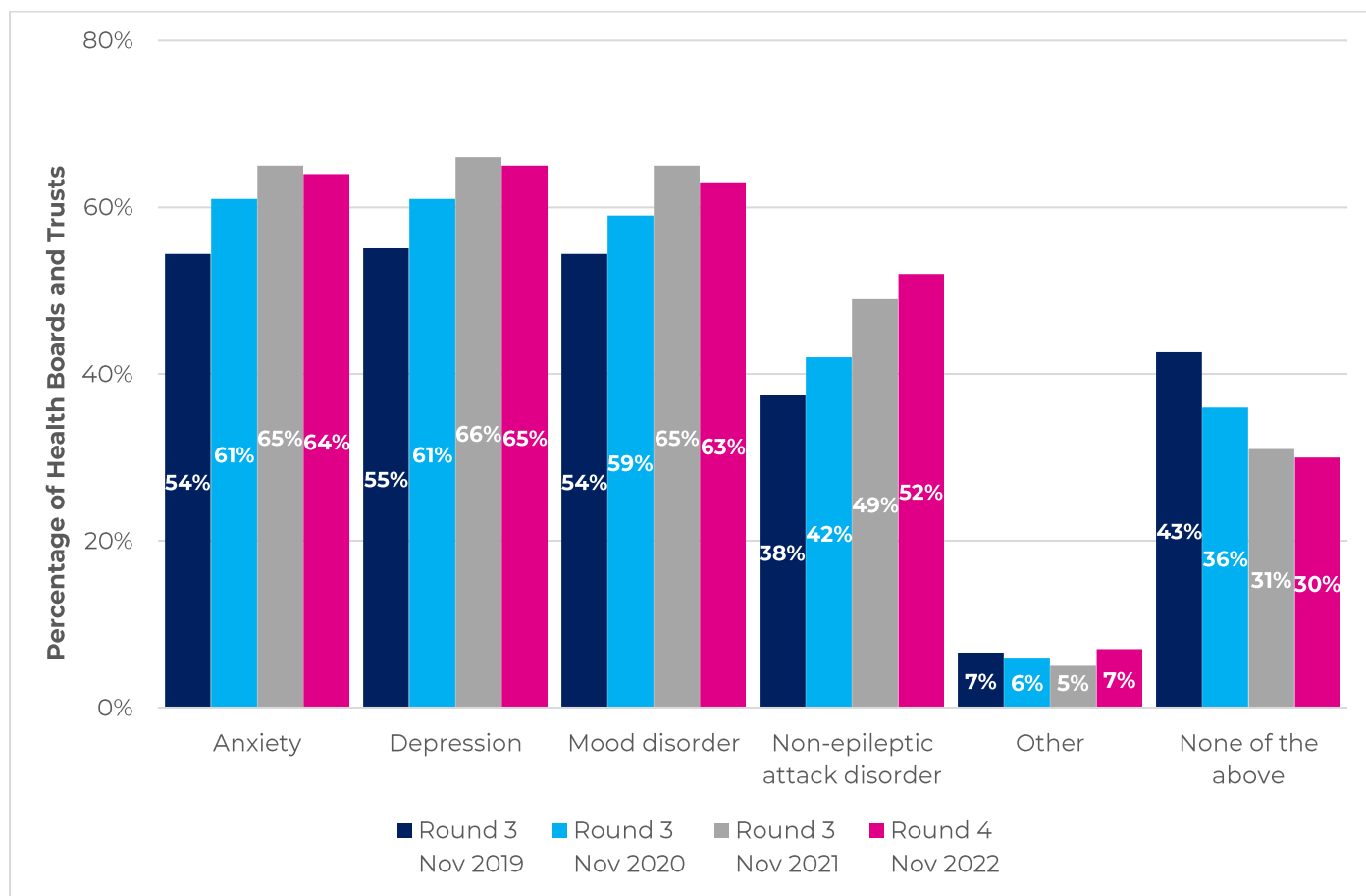
- Local wellbeing questionnaire,
- Wellness questionnaire,
- PI-ED,
- PHQ 4,
- Nice signs and symptoms of ASD checklist, CHECC - Child and Young person Epilepsy Concerns Checklist,
- Locally prepared questionnaire,
- HEADSED,
- We are piloting an emotional well-being questionnaire developed with jointly with psychology,
- PEDsQL

**30% (39/128)** of Health Boards and Trusts did not have agreed referral pathways for children and young people with mental health conditions. **64% (82/128)** of Health Boards and Trusts had agreed referral pathways for children and young people with anxiety; **65% (83/128)** for depression; **63% (81/128)** for mood disorder; **52% (66/128)** for non-epileptic attack disorder, **7% (9/128)** for other mental health conditions (**Table 39**).

Other responses included:

- Attention Deficit Hyperactivity Disorder,
- Referral to psychology for difficulty in coping with diagnosis for patient and family and referral to CAMHS for other mental health concerns,
- Pathways in place with CAMHS services for mental health disorders; pathway in place for young people with anxiety relating to medical disorders including epilepsy,
- Mental health support via in house Dramatherapy service,
- We have a flexible approach with in-house mental health and adolescent medicine teams,
- Children can be referred to CAHMS or clinical psychology depending on clinical needs,
- Referrals to CAMHS and Psychology support.

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



**Figure 17: Percentage of Health Boards and Trusts that had agreed referral pathways for children and young people with mental health conditions in Round 3 November 2019, November 2020, November 2021 and Round 4 November 2022.**

**Table 41** shows that mental health provision was facilitated within epilepsy clinics, in **9% (12/128)** of Health Boards and Trusts. In **13% (16/128)** of Health Boards and Trusts, MDT meetings where epilepsy and mental health professionals discuss individual patients were facilitated. Other mental health provision was facilitated in **9% (11/128)** Health Boards and Trusts.

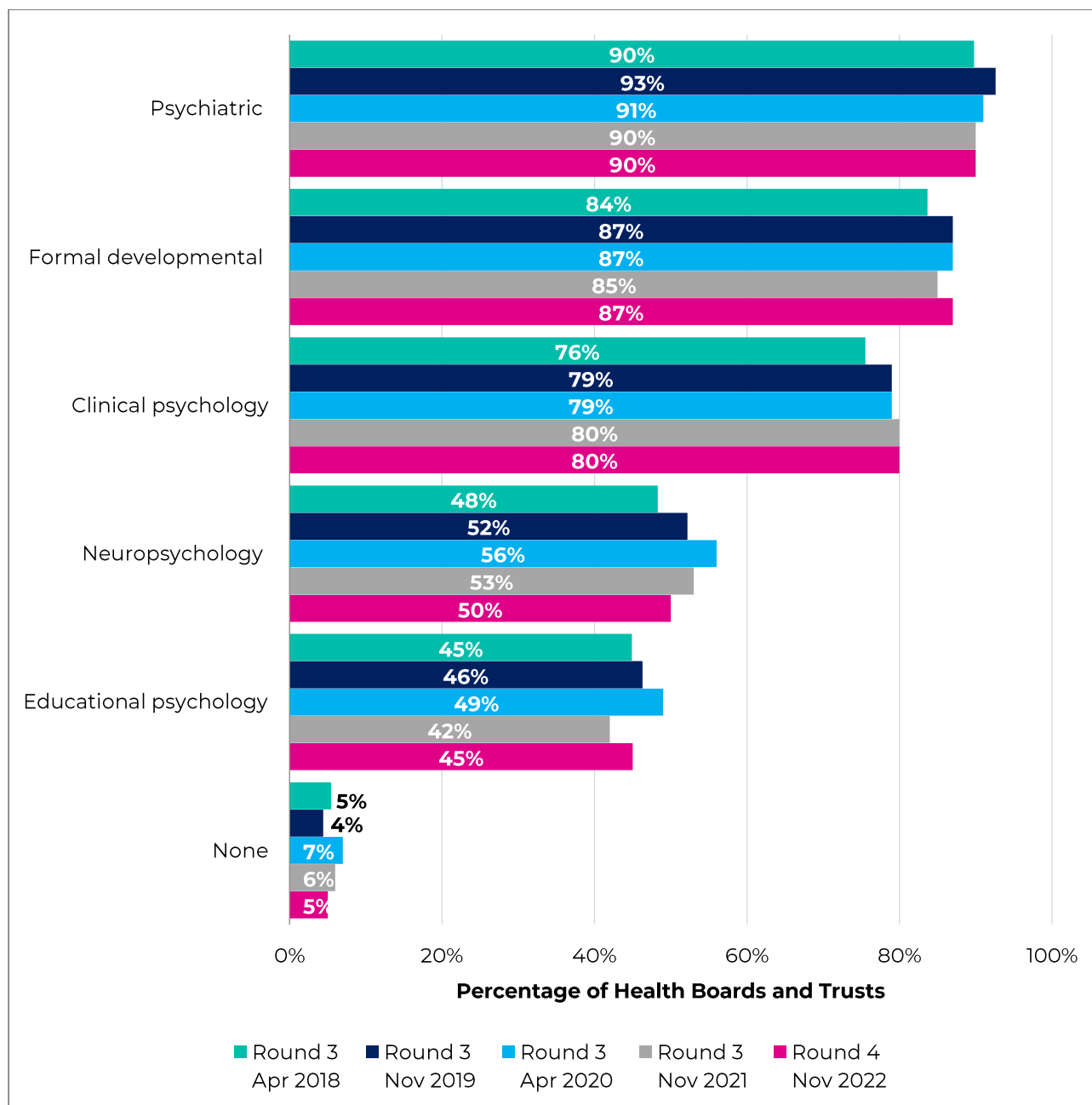
Other responses included:

- Psychologist available for referrals,
- Discussion of individual cases at MDT and onward referral to psychology,
- Clinical Psychologist,
- Referral after discussion,
- Child psychiatry clinics where epilepsy specialists or ESN join to see patients on one site of our Trust,
- We have access to psychology, psychiatry and psychotherapy on site. Some clinics together,
- Through referrals and liaison with CAMHS,
- Limited psychology support for children with chronic health needs including epilepsy,

- New appointment - consultant referral of cases,
- Clinical psychology service,
- Limited access to psychologist employed by trust.

**5% (6/128)** of Health Boards and Trusts could not refer to mental health assessment services, either within or outside of their Health Board or Trust, (**Table 43**).

**80% (103/128)** of Health Boards and Trusts were able to refer to clinical psychology services; **90% (115/128)** to psychiatric services; **45% (57/128)** to education psychology; **50% (64/128)** to neuropsychology services and **87% (111/128)** to formal developmental assessment.



**Figure 18: Percentage of Health Boards and Trusts that could refer to mental health services in Round 3 April 2018, November 2019, November 2020, November 2021 and Round 4 November 2022.**

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

| Country/network                    | ADHD         | ASD          | Mental health disorders | None         |
|------------------------------------|--------------|--------------|-------------------------|--------------|
| <b>England &amp; Wales (N=128)</b> | 16% (21/128) | 17% (22/128) | 20% (25/128)            | 74% (95/128) |
| <b>England (N=122)</b>             | 17% (21/122) | 18% (22/122) | 20% (24/122)            | 74% (90/122) |
| <b>Wales (N=6)</b>                 | 0% (0/6)     | 0% (0/6)     | 17% (1/6)               | 83% (5/6)    |
|                                    |              |              |                         |              |
| <b>BRPNF (N=12)</b>                | 33% (4/12)   | 33% (4/12)   | 25% (3/12)              | 67% (8/12)   |
| <b>CEWT (N=4)</b>                  | 25% (1/4)    | 25% (1/4)    | 0% (0/4)                | 75% (3/4)    |
| <b>EPEN (N=13)</b>                 | 8% (1/13)    | 8% (1/13)    | 8% (1/13)               | 85% (11/13)  |
| <b>EPIC (N=8)</b>                  | 13% (1/8)    | 13% (1/8)    | 13% (1/8)               | 75% (6/8)    |
| <b>NTPEN (N=13)</b>                | 0% (0/13)    | 8% (1/13)    | 8% (1/13)               | 85% (11/13)  |
| <b>NWEIG (N=11)</b>                | 9% (1/11)    | 9% (1/11)    | 9% (1/11)               | 91% (10/11)  |
| <b>ORENG (N=7)</b>                 | 29% (2/7)    | 29% (2/7)    | 29% (2/7)               | 71% (5/7)    |
| <b>PENNEC (N=7)</b>                | 14% (1/7)    | 14% (1/7)    | 29% (2/7)               | 71% (5/7)    |
| <b>SETPEG (N=9)</b>                | 11% (1/9)    | 11% (1/9)    | 11% (1/9)               | 89% (8/9)    |
| <b>SWEP (N=5)</b>                  | 0% (0/5)     | 0% (0/5)     | 20% (1/5)               | 80% (4/5)    |
| <b>SWIPE (N=9)</b>                 | 0% (0/9)     | 0% (0/9)     | 0% (0/9)                | 100% (9/9)   |
| <b>SWTPEG (N=8)</b>                | 38% (3/8)    | 38% (3/8)    | 50% (4/8)               | 38% (3/8)    |
| <b>TEN (N=6)</b>                   | 67% (4/6)    | 67% (4/6)    | 33% (2/6)               | 33% (2/6)    |
| <b>WPNN (N=8)</b>                  | 13% (1/8)    | 13% (1/8)    | 25% (2/8)               | 75% (6/8)    |
| <b>YPEN (N=8)</b>                  | 13% (1/8)    | 13% (1/8)    | 50% (4/8)               | 50% (4/8)    |

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

| Country/<br>network        | BDI – Beck<br>Depression<br>Inventory | Connor’s<br>Questionnaire | Emotional<br>Thermometers<br>Tool | GAD –<br>Generalised<br>Anxiety<br>Disorder | GAD 2 –<br>Generalised<br>Anxiety<br>Disorder 2 | GAD 7 –<br>Generalised<br>Anxiety<br>Disorder GAD 7 | HADS –<br>Hospital<br>Anxiety and<br>Depression<br>Scale | MFQ – Mood<br>and Feelings<br>Questionnaire<br>(Child, Parent,<br>adult versions) | NDDI -E<br>Neurological<br>Disorders<br>Depression<br>Inventory for<br>Epilepsy |
|----------------------------|---------------------------------------|---------------------------|-----------------------------------|---|---|---|--|---|---|
| England &<br>Wales (N=128) | 1% (1/128)                            | 7% (9/128)                | 0% (0/128)                        | 1% (1/128)                                  | 0% (0/128)                                      | 0% (0/128)  | 0% (0/128)   | 0% (0/128)  | 0% (0/128)  |
| England<br>(N=122)         | 1% (1/122)                            | 7% (9/122)                | 0% (0/122)                        | 0% (0/122)                                  | 0% (0/122)                                      | 0% (0/122)  | 0% (0/122)   | 0% (0/122)  | 0% (0/122)  |
| Wales (N=6)                | 0% (0/6)                              | 0% (0/6)                  | 0% (0/6)                          | 17% (1/6)                                   | 0% (0/6)  | 0% (0/6)  | 0% (0/6)   | 0% (0/6)  | 0% (0/6)  |
|                            |                                       |                           |                                   |   |   |   |  |   |   |
| BRPNF (N=12)               | 0% (0/12)                             | 17% (2/12)                | 0% (0/12)                         | 0% (0/12)                                   | 0% (0/12)                                       | 0% (0/12)   | 0% (0/12)  | 0% (0/12)   | 0% (0/12)   |
| CEWT (N=4)                 | 0% (0/4)                              | 0% (0/4)                  | 0% (0/4)                          | 0% (0/4)                                    | 0% (0/4)  | 0% (0/4)  | 0% (0/4)   | 0% (0/4)  | 0% (0/4)  |
| EPEN (N=13)                | 0% (0/13)                             | 0% (0/13)                 | 0% (0/13)                         | 0% (0/13)                                   | 0% (0/13)                                       | 0% (0/13)   | 0% (0/13)  | 0% (0/13)   | 0% (0/13)   |
| EPIC (N=8)                 | 0% (0/8)                              | 13% (1/8)                 | 0% (0/8)                          | 0% (0/8)                                    | 0% (0/8)  | 0% (0/8)  | 0% (0/8)   | 0% (0/8)  | 0% (0/8)  |
| NTPEN (N=13)               | 0% (0/13)                             | 8% (1/13)                 | 0% (0/13)                         | 0% (0/13)                                   | 0% (0/13)                                       | 0% (0/13)   | 0% (0/13)  | 0% (0/13)   | 0% (0/13)   |
| NWEIG (N=11)               | 0% (0/11)                             | 9% (1/11)                 | 0% (0/11)                         | 0% (0/11)                                   | 0% (0/11)                                       | 0% (0/11)   | 0% (0/11)  | 0% (0/11)   | 0% (0/11)   |
| ORENG (N=7)                | 0% (0/7)                              | 14% (1/7)                 | 0% (0/7)                          | 0% (0/7)                                    | 0% (0/7)  | 0% (0/7)  | 0% (0/7)   | 0% (0/7)  | 0% (0/7)  |
| PENNEC (N=7)               | 0% (0/7)                              | 14% (1/7)                 | 0% (0/7)                          | 0% (0/7)                                    | 0% (0/7)  | 0% (0/7)  | 0% (0/7)   | 0% (0/7)  | 0% (0/7)  |
| SETPEG (N=9)               | 11% (1/9)                             | 0% (0/9)                  | 0% (0/9)                          | 0% (0/9)                                    | 0% (0/9)  | 0% (0/9)  | 0% (0/9)   | 0% (0/9)  | 0% (0/9)  |
| SWEP (N=5)                 | 0% (0/5)                              | 0% (0/5)                  | 0% (0/5)                          | 20% (1/5)                                   | 0% (0/5)  | 0% (0/5)  | 0% (0/5)   | 0% (0/5)  | 0% (0/5)  |
| SWIPE (N=9)                | 0% (0/9)                              | 0% (0/9)                  | 0% (0/9)                          | 0% (0/9)                                    | 0% (0/9)  | 0% (0/9)  | 0% (0/9)   | 0% (0/9)  | 0% (0/9)  |
| SWTPEG (N=8)               | 0% (0/8)                              | 0% (0/8)                  | 0% (0/8)                          | 0% (0/8)                                    | 0% (0/8)  | 0% (0/8)  | 0% (0/8)   | 0% (0/8)  | 0% (0/8)  |
| TEN (N=6)                  | 0% (0/6)                              | 17% (1/6)                 | 0% (0/6)                          | 0% (0/6)                                    | 0% (0/6)  | 0% (0/6)  | 0% (0/6)   | 0% (0/6)  | 0% (0/6)  |
| WPNN (N=8)                 | 0% (0/8)                              | 13% (1/8)                 | 0% (0/8)                          | 0% (0/8)                                    | 0% (0/8)  | 0% (0/8)  | 0% (0/8)   | 0% (0/8)  | 0% (0/8)  |
| YPEN (N=8)                 | 0% (0/8)                              | 0% (0/8)                  | 0% (0/8)                          | 0% (0/8)                                    | 0% (0/8)  | 0% (0/8)  | 0% (0/8)   | 0% (0/8)  | 0% (0/8)  |

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

| Country/network                    | PHQ – Patient Health Questionnaire, PHQ 2, PHQ 9 | SDQ (Strength and Difficulties Questionnaire) | Other       | None of the above |
|------------------------------------|--|---|-------------|-------------------|
| <b>England &amp; Wales (N=128)</b> | 2% (2/128)                                       | 12% (15/128)                                  | 9% (11/128) | 60% (77/128)      |
| <b>England (N=122)</b>             | 1% (1/122)                                       | 12% (15/122)                                  | 9% (11/122) | 59% (72/122)      |
| <b>Wales (N=6)</b>                 | 17% (1/6)  | 0% (0/6)                                      | 0% (0/6)    | 83% (5/6)         |
|                                    |  |   |             |                   |
| <b>BRPNF (N=12)</b>                | 0% (0/12)  | 25% (3/12)                                    | 8% (1/12)   | 33% (4/12)        |
| <b>CEWT (N=4)</b>                  | 0% (0/4)   | 0% (0/4)                                      | 0% (0/4)    | 75% (3/4)         |
| <b>EPEN (N=13)</b>                 | 0% (0/13)  | 0% (0/13)                                     | 8% (1/13)   | 77% (10/13)       |
| <b>EPIC (N=8)</b>                  | 0% (0/8)   | 0% (0/8)                                      | 13% (1/8)   | 63% (5/8)         |
| <b>NTPEN (N=13)</b>                | 0% (0/13)  | 15% (2/13)                                    | 0% (0/13)   | 62% (8/13)        |
| <b>NWEIG (N=11)</b>                | 0% (0/11)  | 9% (1/11)                                     | 0% (0/11)   | 82% (9/11)        |
| <b>ORENG (N=7)</b>                 | 0% (0/7)   | 0% (0/7)                                      | 0% (0/7)    | 57% (4/7)         |
| <b>PENNEC (N=7)</b>                | 0% (0/7)   | 14% (1/7)                                     | 14% (1/7)   | 43% (3/7)         |
| <b>SETPEG (N=9)</b>                | 0% (0/9)   | 11% (1/9)                                     | 0% (0/9)    | 56% (5/9)         |
| <b>SWEP (N=5)</b>                  | 20% (1/5)  | 0% (0/5)                                      | 0% (0/5)    | 80% (4/5)         |
| <b>SWIPE (N=9)</b>                 | 0% (0/9)   | 0% (0/9)                                      | 0% (0/9)    | 89% (8/9)         |
| <b>SWTPEG (N=8)</b>                | 13% (1/8)  | 25% (2/8)                                     | 38% (3/8)   | 25% (2/8)         |
| <b>TEN (N=6)</b>                   | 0% (0/6)   | 33% (2/6)                                     | 0% (0/6)    | 67% (4/6)         |
| <b>WPNN (N=8)</b>                  | 0% (0/8)   | 13% (1/8)                                     | 25% (2/8)   | 63% (5/8)         |
| <b>YPEN (N=8)</b>                  | 0% (0/8)   | 25% (2/8)                                     | 25% (2/8)   | 38% (3/8)         |



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

| Country/network                    | Anxiety      | Depression   | Mood Disorder | Non-epileptic attack disorders | Other      | None of the above |
|------------------------------------|--------------|--------------|---------------|--------------------------------|------------|-------------------|
| <b>England &amp; Wales (N=128)</b> | 64% (82/128) | 65% (83/128) | 63% (81/128)  | 52% (66/128)                   | 7% (9/128) | 30% (39/128)      |
| <b>England (N=122)</b>             | 66% (80/122) | 66% (81/122) | 65% (79/122)  | 53% (65/122)                   | 7% (8/122) | 29% (35/122)      |
| <b>Wales (N=6)</b>                 | 33% (2/6)    | 33% (2/6)    | 33% (2/6)     | 17% (1/6)                      | 17% (1/6)  | 67% (4/6)         |
|                                    |              |              |               |                                |            |                   |
| <b>BRPNF (N=12)</b>                | 75% (9/12)   | 75% (9/12)   | 75% (9/12)    | 67% (8/12)                     | 0% (0/12)  | 17% (2/12)        |
| <b>CEWT (N=4)</b>                  | 75% (3/4)    | 75% (3/4)    | 75% (3/4)     | 75% (3/4)                      | 25% (1/4)  | 25% (1/4)         |
| <b>EPEN (N=13)</b>                 | 54% (7/13)   | 54% (7/13)   | 54% (7/13)    | 54% (7/13)                     | 0% (0/13)  | 31% (4/13)        |
| <b>EPIC (N=8)</b>                  | 63% (5/8)    | 63% (5/8)    | 63% (5/8)     | 50% (4/8)                      | 25% (2/8)  | 38% (3/8)         |
| <b>NTPEN (N=13)</b>                | 62% (8/13)   | 62% (8/13)   | 62% (8/13)    | 54% (7/13)                     | 15% (2/13) | 38% (5/13)        |
| <b>NWEIG (N=11)</b>                | 64% (7/11)   | 64% (7/11)   | 64% (7/11)    | 36% (4/11)                     | 0% (0/11)  | 36% (4/11)        |
| <b>ORENG (N=7)</b>                 | 43% (3/7)    | 43% (3/7)    | 43% (3/7)     | 29% (2/7)                      | 14% (1/7)  | 43% (3/7)         |
| <b>PENNEC (N=7)</b>                | 71% (5/7)    | 71% (5/7)    | 71% (5/7)     | 71% (5/7)                      | 29% (2/7)  | 14% (1/7)         |
| <b>SETPEG (N=9)</b>                | 78% (7/9)    | 78% (7/9)    | 78% (7/9)     | 67% (6/9)                      | 0% (0/9)   | 22% (2/9)         |
| <b>SWEP (N=5)</b>                  | 20% (1/5)    | 20% (1/5)    | 20% (1/5)     | 0% (0/5)                       | 0% (0/5)   | 80% (4/5)         |
| <b>SWIPE (N=9)</b>                 | 67% (6/9)    | 67% (6/9)    | 56% (5/9)     | 22% (2/9)                      | 0% (0/9)   | 33% (3/9)         |
| <b>SWTPEG (N=8)</b>                | 75% (6/8)    | 75% (6/8)    | 75% (6/8)     | 50% (4/8)                      | 13% (1/8)  | 13% (1/8)         |
| <b>TEN (N=6)</b>                   | 67% (4/6)    | 67% (4/6)    | 50% (3/6)     | 50% (3/6)                      | 0% (0/6)   | 33% (2/6)         |
| <b>WPNN (N=8)</b>                  | 75% (6/8)    | 75% (6/8)    | 75% (6/8)     | 75% (6/8)                      | 0% (0/8)   | 25% (2/8)         |
| <b>YPEN (N=8)</b>                  | 63% (5/8)    | 75% (6/8)    | 75% (6/8)     | 63% (5/8)                      | 0% (0/8)   | 25% (2/8)         |

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

| Country/network                    | Yes          | No            |
|------------------------------------|--------------|---------------|
| <b>England &amp; Wales (N=128)</b> | 19% (24/128) | 81% (104/128) |
| <b>England (N=122)</b>             | 20% (24/122) | 80% (98/122)  |
| <b>Wales (N=6)</b>                 | 0% (0/6)     | 100% (6/6)    |
|                                    |              |               |
| <b>BRPNF (N=12)</b>                | 0% (0/12)    | 100% (12/12)  |
| <b>CEWT (N=4)</b>                  | 0% (0/4)     | 100% (4/4)    |
| <b>EPEN (N=13)</b>                 | 38% (5/13)   | 62% (8/13)    |
| <b>EPIC (N=8)</b>                  | 38% (3/8)    | 63% (5/8)     |
| <b>NTPEN (N=13)</b>                | 23% (3/13)   | 77% (10/13)   |
| <b>NWEIG (N=11)</b>                | 9% (1/11)    | 91% (10/11)   |
| <b>ORENG (N=7)</b>                 | 0% (0/7)     | 100% (7/7)    |
| <b>PENNEC (N=7)</b>                | 14% (1/7)    | 86% (6/7)     |
| <b>SETPEG (N=9)</b>                | 22% (2/9)    | 78% (7/9)     |
| <b>SWEP (N=5)</b>                  | 0% (0/5)     | 100% (5/5)    |
| <b>SWIPE (N=9)</b>                 | 11% (1/9)    | 89% (8/9)     |
| <b>SWTPEG (N=8)</b>                | 25% (2/8)    | 75% (6/8)     |
| <b>TEN (N=6)</b>                   | 0% (0/6)     | 100% (6/6)    |
| <b>WPNN (N=8)</b>                  | 25% (2/8)    | 75% (6/8)     |
| <b>YPEN (N=8)</b>                  | 50% (4/8)    | 50% (4/8)     |

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

| Country/network                    | Epilepsy Clinics where mental health professionals can provide direct co-located clinical care | MDT meetings where epilepsy and mental health professionals discuss individual patients | Other       |
|------------------------------------|--|---|-------------|
| <b>England &amp; Wales (N=128)</b> | 9% (12/128)  | 13% (16/128)  | 9% (11/128) |
| <b>England (N=122)</b>             | 10% (12/122)   | 13% (16/122)  | 9% (11/122) |
| <b>Wales (N=6)</b>                 | 0% (0/6)   | 0% (0/6)  | 0% (0/6)    |
|                                    |  |   |             |
| <b>BRPNF (N=12)</b>                | 0% (0/12)  | 0% (0/12)   | 0% (0/12)   |
| <b>CEWT (N=4)</b>                  | 0% (0/4)   | 0% (0/4)  | 0% (0/4)    |
| <b>EPEN (N=13)</b>                 | 15% (2/13)   | 31% (4/13)  | 15% (2/13)  |
| <b>EPIC (N=8)</b>                  | 13% (1/8)  | 13% (1/8)   | 25% (2/8)   |
| <b>NTPEN (N=13)</b>                | 15% (2/13)   | 15% (2/13)  | 15% (2/13)  |
| <b>NWEIG (N=11)</b>                | 0% (0/11)  | 0% (0/11)   | 9% (1/11)   |
| <b>ORENG (N=7)</b>                 | 0% (0/7)   | 0% (0/7)  | 0% (0/7)    |
| <b>PENNEC (N=7)</b>                | 14% (1/7)  | 14% (1/7)   | 0% (0/7)    |
| <b>SETPEG (N=9)</b>                | 22% (2/9)  | 22% (2/9)   | 11% (1/9)   |
| <b>SWEP (N=5)</b>                  | 0% (0/5)   | 0% (0/5)  | 0% (0/5)    |
| <b>SWIPE (N=9)</b>                 | 0% (0/9)   | 11% (1/9)   | 0% (0/9)    |
| <b>SWTPEG (N=8)</b>                | 13% (1/8)  | 13% (1/8)   | 13% (1/8)   |
| <b>TEN (N=6)</b>                   | 0% (0/6)   | 0% (0/6)  | 0% (0/6)    |
| <b>WPNN (N=8)</b>                  | 13% (1/8)  | 13% (1/8)   | 13% (1/8)   |
| <b>YPEN (N=8)</b>                  | 25% (2/8)  | 38% (3/8)   | 13% (1/8)   |

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

| Country/network                    | Yes          | No           |
|------------------------------------|--------------|--------------|
| <b>England &amp; Wales (N=104)</b> | 15% (16/104) | 85% (88/104) |
| <b>England (N=98)</b>              | 13% (13/98)  | 87% (85/98)  |
| <b>Wales (N=6)</b>                 | 50% (3/6)    | 50% (3/6)    |
|                                    |              |              |
| <b>BRPNF (N=12)</b>                | 17% (2/12)   | 83% (10/12)  |
| <b>CEWT (N=4)</b>                  | 25% (1/4)    | 75% (3/4)    |
| <b>EPEN (N=8)</b>                  | 25% (2/8)    | 75% (6/8)    |
| <b>EPIC (N=5)</b>                  | 20% (1/5)    | 80% (4/5)    |
| <b>NTPEN (N=10)</b>                | 10% (1/10)   | 90% (9/10)   |
| <b>NWEIG (N=10)</b>                | 20% (2/10)   | 80% (8/10)   |
| <b>ORENG (N=7)</b>                 | 0% (0/7)     | 100% (7/7)   |
| <b>PENNEC (N=6)</b>                | 17% (1/6)    | 83% (5/6)    |
| <b>SETPEG (N=7)</b>                | 29% (2/7)    | 71% (5/7)    |
| <b>SWEP (N=5)</b>                  | 40% (2/5)    | 60% (3/5)    |
| <b>SWIPE (N=8)</b>                 | 0% (0/8)     | 100% (8/8)   |
| <b>SWTPEG (N=6)</b>                | 0% (0/6)     | 100% (6/6)   |
| <b>TEN (N=6)</b>                   | 17% (1/6)    | 83% (5/6)    |
| <b>WPNN (N=6)</b>                  | 17% (1/6)    | 83% (5/6)    |
| <b>YPEN (N=4)</b>                  | 0% (0/4)     | 100% (4/4)   |

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

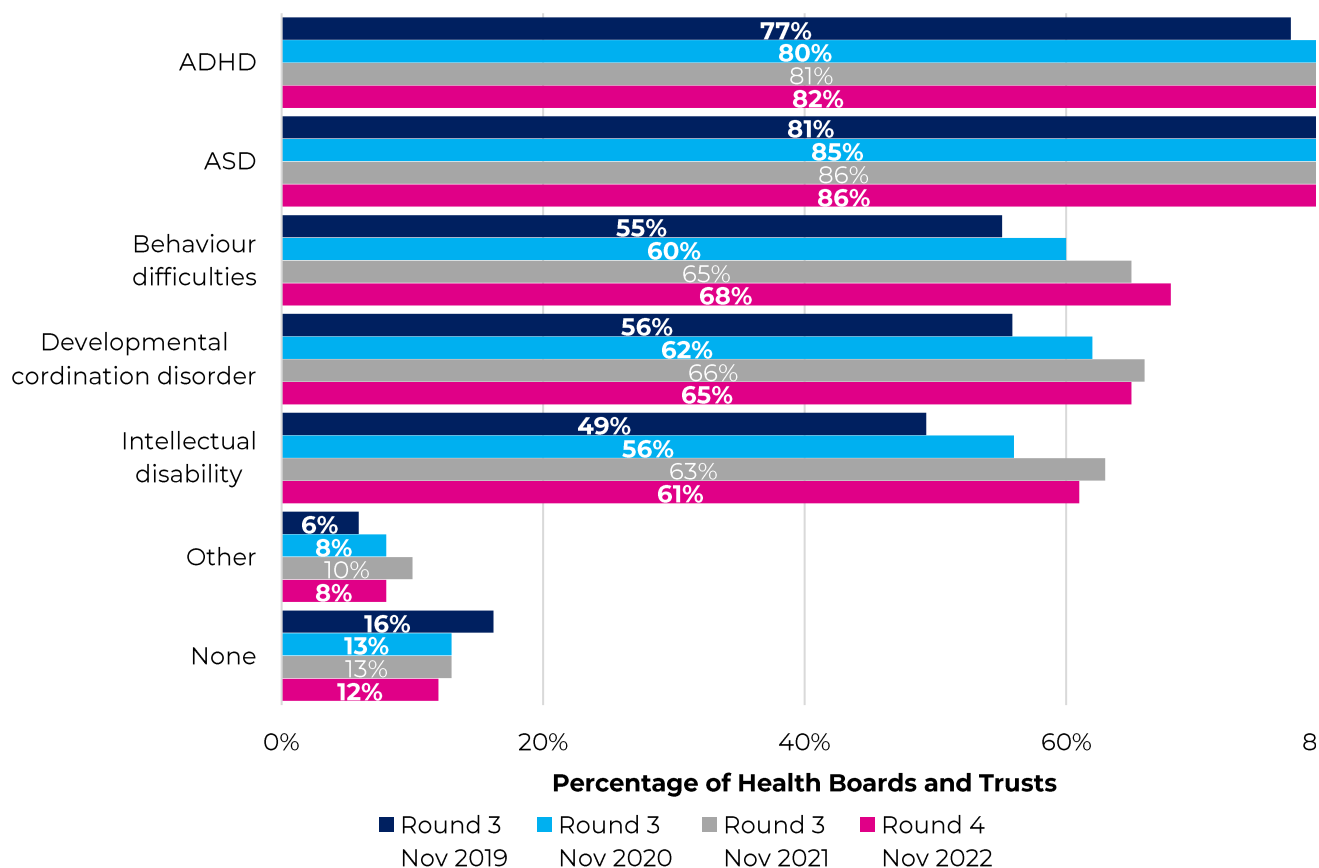
| Country/network                    | Clinical psychology | Psychiatric   | Educational psychology | Neuropsychology | Formal developmental | None       |
|------------------------------------|---------------------|---------------|------------------------|-----------------|----------------------|------------|
| <b>England &amp; Wales (N=128)</b> | 80% (103/128)       | 90% (115/128) | 45% (57/128)           | 50% (64/128)    | 87% (111/128)        | 5% (6/128) |
| <b>England (N=122)</b>             | 80% (98/122)        | 89% (109/122) | 43% (52/122)           | 52% (63/122)    | 86% (105/122)        | 5% (6/122) |
| <b>Wales (N=6)</b>                 | 83% (5/6)           | 100% (6/6)    | 83% (5/6)              | 17% (1/6)       | 100% (6/6)           | 0% (0/6)   |
|                                    |                     |               |                        |                 |                      |            |
| <b>BRPNF (N=12)</b>                | 83% (10/12)         | 100% (12/12)  | 58% (7/12)             | 33% (4/12)      | 100% (12/12)         | 0% (0/12)  |
| <b>CEWT (N=4)</b>                  | 75% (3/4)           | 75% (3/4)     | 0% (0/4)               | 75% (3/4)       | 75% (3/4)            | 25% (1/4)  |
| <b>EPEN (N=13)</b>                 | 85% (11/13)         | 92% (12/13)   | 46% (6/13)             | 38% (5/13)      | 85% (11/13)          | 8% (1/13)  |
| <b>EPIC (N=8)</b>                  | 63% (5/8)           | 88% (7/8)     | 25% (2/8)              | 75% (6/8)       | 100% (8/8)           | 0% (0/8)   |
| <b>NTPEN (N=13)</b>                | 92% (12/13)         | 100% (13/13)  | 46% (6/13)             | 62% (8/13)      | 100% (13/13)         | 0% (0/13)  |
| <b>NWEIG (N=11)</b>                | 91% (10/11)         | 91% (10/11)   | 45% (5/11)             | 64% (7/11)      | 55% (6/11)           | 0% (0/11)  |
| <b>ORENG (N=7)</b>                 | 86% (6/7)           | 86% (6/7)     | 57% (4/7)              | 71% (5/7)       | 86% (6/7)            | 0% (0/7)   |
| <b>PENNEC (N=7)</b>                | 100% (7/7)          | 86% (6/7)     | 71% (5/7)              | 71% (5/7)       | 86% (6/7)            | 0% (0/7)   |
| <b>SETPEG (N=9)</b>                | 100% (9/9)          | 100% (9/9)    | 44% (4/9)              | 56% (5/9)       | 100% (9/9)           | 0% (0/9)   |
| <b>SWEP (N=5)</b>                  | 80% (4/5)           | 100% (5/5)    | 80% (4/5)              | 0% (0/5)        | 100% (5/5)           | 0% (0/5)   |
| <b>SWIPE (N=9)</b>                 | 89% (8/9)           | 89% (8/9)     | 44% (4/9)              | 67% (6/9)       | 78% (7/9)            | 11% (1/9)  |
| <b>SWTPEG (N=8)</b>                | 50% (4/8)           | 75% (6/8)     | 13% (1/8)              | 25% (2/8)       | 75% (6/8)            | 13% (1/8)  |
| <b>TEN (N=6)</b>                   | 67% (4/6)           | 67% (4/6)     | 50% (3/6)              | 50% (3/6)       | 83% (5/6)            | 17% (1/6)  |
| <b>WPNN (N=8)</b>                  | 50% (4/8)           | 88% (7/8)     | 50% (4/8)              | 25% (2/8)       | 75% (6/8)            | 13% (1/8)  |
| <b>YPEN (N=8)</b>                  | 75% (6/8)           | 88% (7/8)     | 25% (2/8)              | 38% (3/8)       | 100% (8/8)           | 0% (0/8)   |

# Neurodevelopmental support

In **12% (15/128)** of Health Boards and Trusts, there was no agreed referral criteria for children and young people with neurodevelopmental conditions.

Other the responses included:

- Cerebral Palsy,
- Challenging behaviour associated with severe learning difficulties,
- Cerebral Palsy, development delay, neuromuscular,
- Referral to community paediatric service who will direct referral to appropriate pathway,
- Conditions details are not seen within our Health Board/Trust,
- Early Health Assessment pathway,
- Tics/Tourette's,
- Referral to the local services,
- Developmental delay.



**Figure 19: Percentage of Health Boards and Trusts that had agreed referral criteria for children and young people with neuro-developmental conditions services in Round 3 November 2019, November 2020, November 2021 and Round 4 November 2022.**

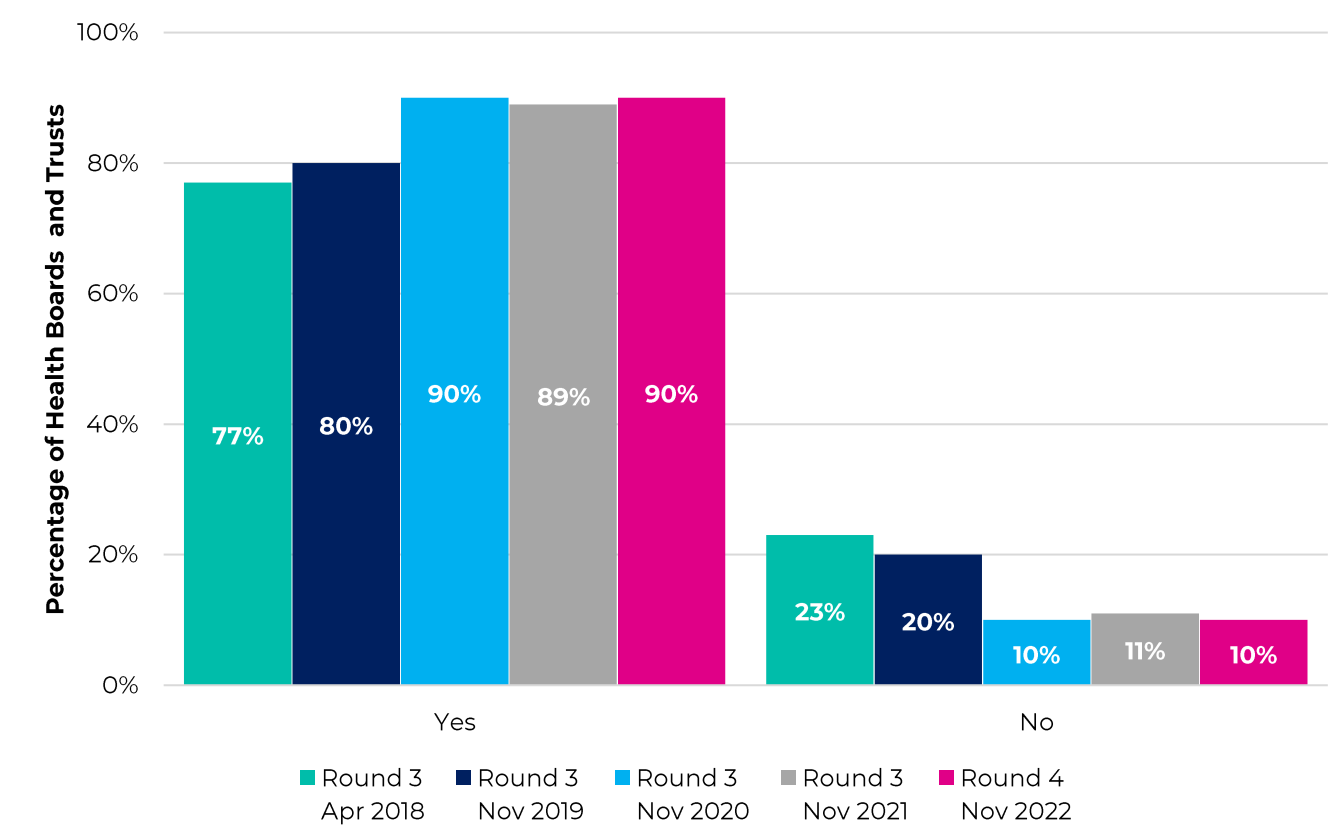
**Table 44: Health Boards and Trusts that had agreed referral criteria for children and young people with neuro-developmental conditions.**

| Country/network                    | ADHD          | ASD           | Behaviour difficulties | Developmental Coordination Disorder | Intellectual disability | Other       | None         |
|------------------------------------|---------------|---------------|------------------------|-------------------------------------|-------------------------|-------------|--------------|
| <b>England &amp; Wales (N=128)</b> | 82% (105/128) | 86% (110/128) | 68% (87/128)           | 65% (83/128)                        | 61% (78/128)            | 8% (10/128) | 12% (15/128) |
| <b>England (N=122)</b>             | 81% (99/122)  | 85% (104/122) | 68% (83/122)           | 64% (78/122)                        | 60% (73/122)            | 7% (9/122)  | 12% (15/122) |
| <b>Wales (N=6)</b>                 | 100% (6/6)    | 100% (6/6)    | 67% (4/6)              | 83% (5/6)                           | 83% (5/6)               | 17% (1/6)   | 0% (0/6)     |
|                                    |               |               |                        |                                     |                         |             |              |
| <b>BRPNF (N=12)</b>                | 92% (11/12)   | 100% (12/12)  | 92% (11/12)            | 100% (12/12)                        | 92% (11/12)             | 0% (0/12)   | 0% (0/12)    |
| <b>CEWT (N=4)</b>                  | 100% (4/4)    | 100% (4/4)    | 100% (4/4)             | 75% (3/4)                           | 100% (4/4)              | 50% (2/4)   | 0% (0/4)     |
| <b>EPEN (N=13)</b>                 | 62% (8/13)    | 77% (10/13)   | 69% (9/13)             | 54% (7/13)                          | 38% (5/13)              | 8% (1/13)   | 15% (2/13)   |
| <b>EPIC (N=8)</b>                  | 88% (7/8)     | 88% (7/8)     | 75% (6/8)              | 50% (4/8)                           | 63% (5/8)               | 13% (1/8)   | 13% (1/8)    |
| <b>NTPEN (N=13)</b>                | 62% (8/13)    | 69% (9/13)    | 62% (8/13)             | 46% (6/13)                          | 62% (8/13)              | 8% (1/13)   | 31% (4/13)   |
| <b>NWEIG (N=11)</b>                | 100% (11/11)  | 100% (11/11)  | 91% (10/11)            | 91% (10/11)                         | 73% (8/11)              | 0% (0/11)   | 0% (0/11)    |
| <b>ORENG (N=7)</b>                 | 71% (5/7)     | 71% (5/7)     | 43% (3/7)              | 43% (3/7)                           | 43% (3/7)               | 0% (0/7)    | 29% (2/7)    |
| <b>PENNEC (N=7)</b>                | 86% (6/7)     | 86% (6/7)     | 57% (4/7)              | 57% (4/7)                           | 57% (4/7)               | 0% (0/7)    | 14% (1/7)    |
| <b>SETPEG (N=9)</b>                | 67% (6/9)     | 78% (7/9)     | 67% (6/9)              | 78% (7/9)                           | 67% (6/9)               | 0% (0/9)    | 22% (2/9)    |
| <b>SWEP (N=5)</b>                  | 100% (5/5)    | 100% (5/5)    | 60% (3/5)              | 80% (4/5)                           | 80% (4/5)               | 20% (1/5)   | 0% (0/5)     |
| <b>SWIPE (N=9)</b>                 | 89% (8/9)     | 89% (8/9)     | 44% (4/9)              | 56% (5/9)                           | 56% (5/9)               | 22% (2/9)   | 0% (0/9)     |
| <b>SWTPEG (N=8)</b>                | 88% (7/8)     | 88% (7/8)     | 75% (6/8)              | 38% (3/8)                           | 50% (4/8)               | 0% (0/8)    | 13% (1/8)    |
| <b>TEN (N=6)</b>                   | 83% (5/6)     | 83% (5/6)     | 67% (4/6)              | 100% (6/6)                          | 67% (4/6)               | 0% (0/6)    | 0% (0/6)     |
| <b>WPNN (N=8)</b>                  | 75% (6/8)     | 75% (6/8)     | 63% (5/8)              | 38% (3/8)                           | 38% (3/8)               | 13% (1/8)   | 25% (2/8)    |
| <b>YPEN (N=8)</b>                  | 100% (8/8)    | 100% (8/8)    | 50% (4/8)              | 75% (6/8)                           | 50% (4/8)               | 13% (1/8)   | 0% (0/8)     |

# Care planning

Comprehensive care planning for children and young people with epilepsy was reported to routinely take place in **90% (115/128)** of Health Boards and Trusts, **(Table 45)**.

**Figure 20** shows the proportion of Health Boards and Trusts that routinely undertake/do not undertake comprehensive care planning for children and young people with epilepsy in Round 3 April 2018, November 2019, November 2020, November 2021 and Round 4 November 2022.



**Figure 20: Percentage Health Boards and Trusts that routinely undertake/do not undertake comprehensive care planning for children and young people with epilepsy in Round 3 April 2018, November 2019, November 2020, November 2021 and Round 4 November 2022.**

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

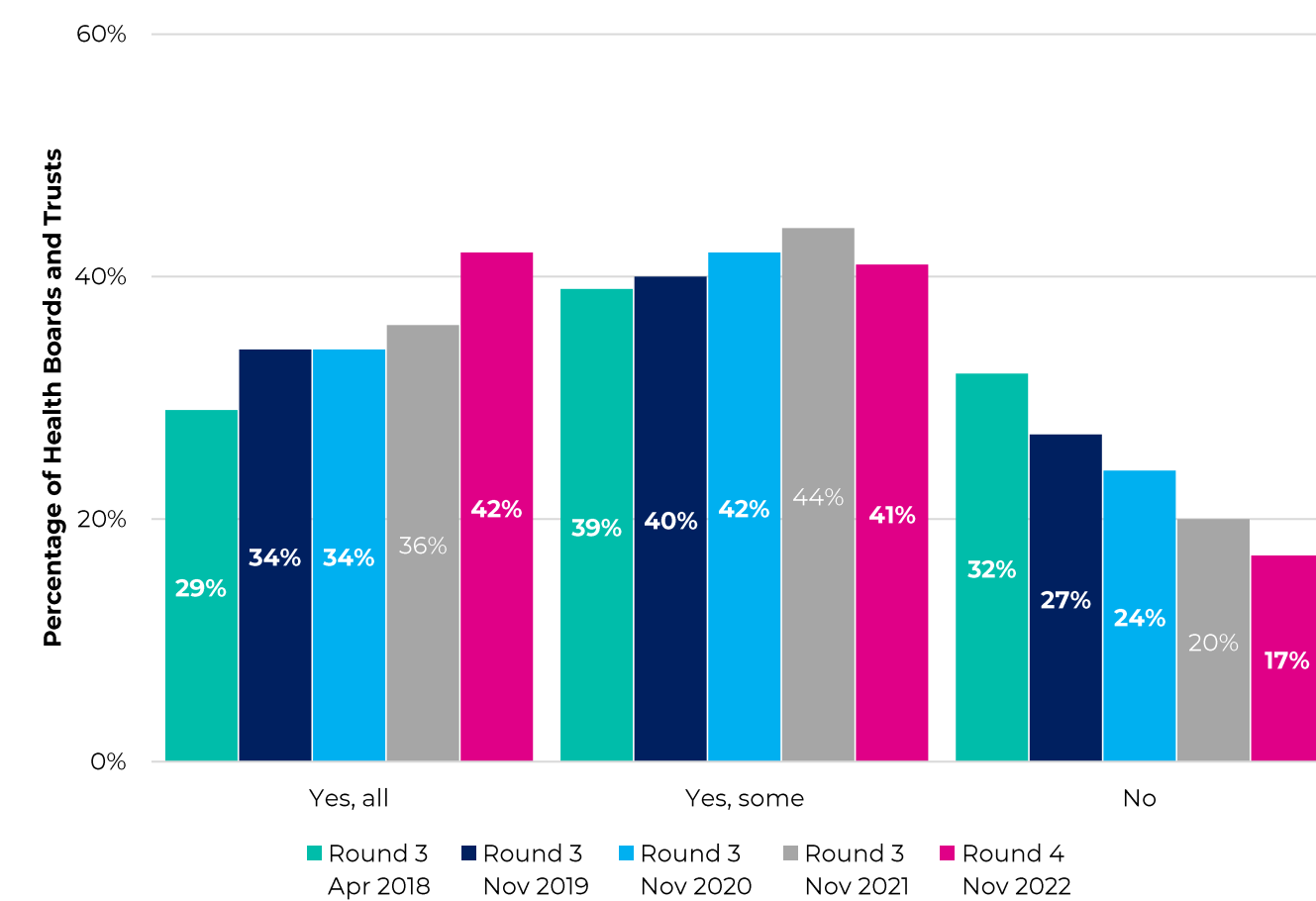
| Country/network                    | Yes           | No           |
|------------------------------------|---------------|--------------|
| <b>England &amp; Wales (N=128)</b> | 90% (115/128) | 10% (13/128) |
| <b>England (N=122)</b>             | 90% (110/122) | 10% (12/122) |
| <b>Wales (N=6)</b>                 | 83% (5/6)     | 17% (1/6)    |
|                                    |               |              |
| <b>BRPNF (N=12)</b>                | 75% (9/12)    | 25% (3/12)   |
| <b>CEWT (N=4)</b>                  | 100% (4/4)    | 0% (0/4)     |
| <b>EPEN (N=13)</b>                 | 77% (10/13)   | 23% (3/13)   |
| <b>EPIC (N=8)</b>                  | 88% (7/8)     | 13% (1/8)    |
| <b>NTPEN (N=13)</b>                | 92% (12/13)   | 8% (1/13)    |
| <b>NWEIG (N=11)</b>                | 100% (11/11)  | 0% (0/11)    |
| <b>ORENG (N=7)</b>                 | 86% (6/7)     | 14% (1/7)    |
| <b>PENNEC (N=7)</b>                | 86% (6/7)     | 14% (1/7)    |
| <b>SETPEG (N=9)</b>                | 100% (9/9)    | 0% (0/9)     |
| <b>SWEP (N=5)</b>                  | 80% (4/5)     | 20% (1/5)    |
| <b>SWIPE (N=9)</b>                 | 100% (9/9)    | 0% (0/9)     |
| <b>SWTPEG (N=8)</b>                | 100% (8/8)    | 0% (0/8)     |
| <b>TEN (N=6)</b>                   | 83% (5/6)     | 17% (1/6)    |
| <b>WPNN (N=8)</b>                  | 88% (7/8)     | 13% (1/8)    |
| <b>YPEN (N=8)</b>                  | 100% (8/8)    | 0% (0/8)     |



# Patient database or registry

**42% (54/128)** of Health Boards and Trusts reported that they maintain a database or register for all children and young people with epilepsies under their care (**Table 46**).

**Figure 21** shows the proportion of Health Boards and Trusts maintaining/not maintaining a database or register of children and young people with epilepsies, other than Epilepsy12, in Round 3 April 2018, November 2019, November 2020, November 2021 and Round 4 November 2022.



**Figure 21: Percentage of Health Boards and Trusts maintaining/not maintaining a database or register of children and young people with epilepsies, other than Epilepsy12, in Round 3 April 2018, November 2019, November 2020, November 2021 and Round 4 November 2022.**

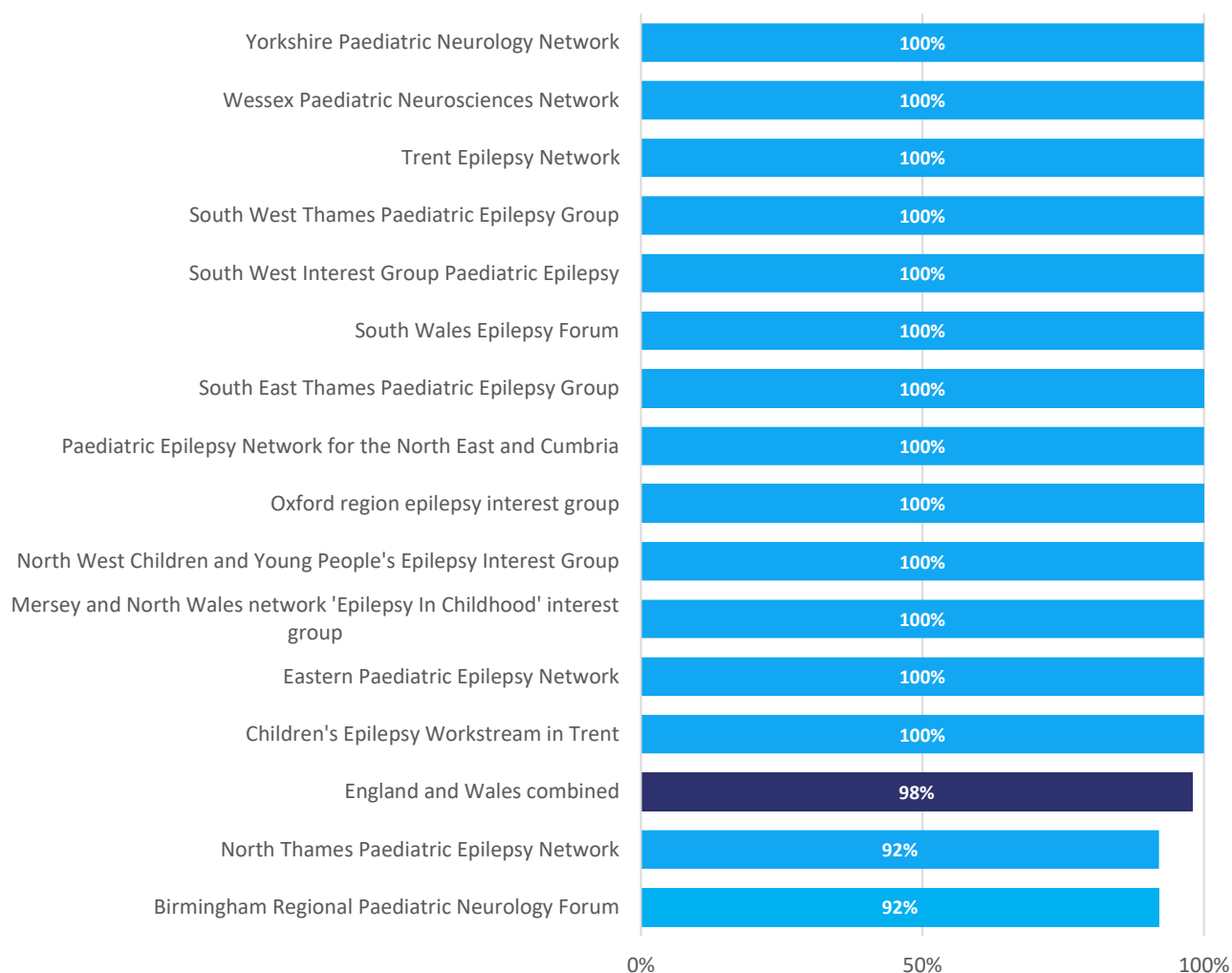
**Table 46: Health Boards and Trusts maintaining a database or register of children and young people with epilepsies, other than Epilepsy12.**

| Country/network                    | Yes, all     | Yes, some    | No           |
|------------------------------------|--------------|--------------|--------------|
| <b>England &amp; Wales (N=128)</b> | 42% (54/128) | 41% (52/128) | 17% (22/128) |
| <b>England (N=122)</b>             | 44% (54/122) | 39% (48/122) | 16% (20/122) |
| <b>Wales (N=6)</b>                 | 0% (0/6)     | 67% (4/6)    | 33% (2/6)    |
|                                    |              |              |              |
| <b>BRPNF (N=12)</b>                | 17% (2/12)   | 33% (4/12)   | 50% (6/12)   |
| <b>CEWT (N=4)</b>                  | 0% (0/4)     | 75% (3/4)    | 25% (1/4)    |
| <b>EPEN (N=13)</b>                 | 46% (6/13)   | 31% (4/13)   | 23% (3/13)   |
| <b>EPIC (N=8)</b>                  | 50% (4/8)    | 50% (4/8)    | 0% (0/8)     |
| <b>NTPEN (N=13)</b>                | 38% (5/13)   | 54% (7/13)   | 8% (1/13)    |
| <b>NWEIG (N=11)</b>                | 64% (7/11)   | 36% (4/11)   | 0% (0/11)    |
| <b>ORENG (N=7)</b>                 | 29% (2/7)    | 43% (3/7)    | 29% (2/7)    |
| <b>PENNEC (N=7)</b>                | 57% (4/7)    | 43% (3/7)    | 0% (0/7)     |
| <b>SETPEG (N=9)</b>                | 56% (5/9)    | 33% (3/9)    | 11% (1/9)    |
| <b>SWEP (N=5)</b>                  | 0% (0/5)     | 60% (3/5)    | 40% (2/5)    |
| <b>SWIPE (N=9)</b>                 | 33% (3/9)    | 33% (3/9)    | 33% (3/9)    |
| <b>SWTPEG (N=8)</b>                | 63% (5/8)    | 38% (3/8)    | 0% (0/8)     |
| <b>TEN (N=6)</b>                   | 50% (3/6)    | 33% (2/6)    | 17% (1/6)    |
| <b>WPNN (N=8)</b>                  | 50% (4/8)    | 38% (3/8)    | 13% (1/8)    |
| <b>YPEN (N=8)</b>                  | 50% (4/8)    | 38% (3/8)    | 13% (1/8)    |

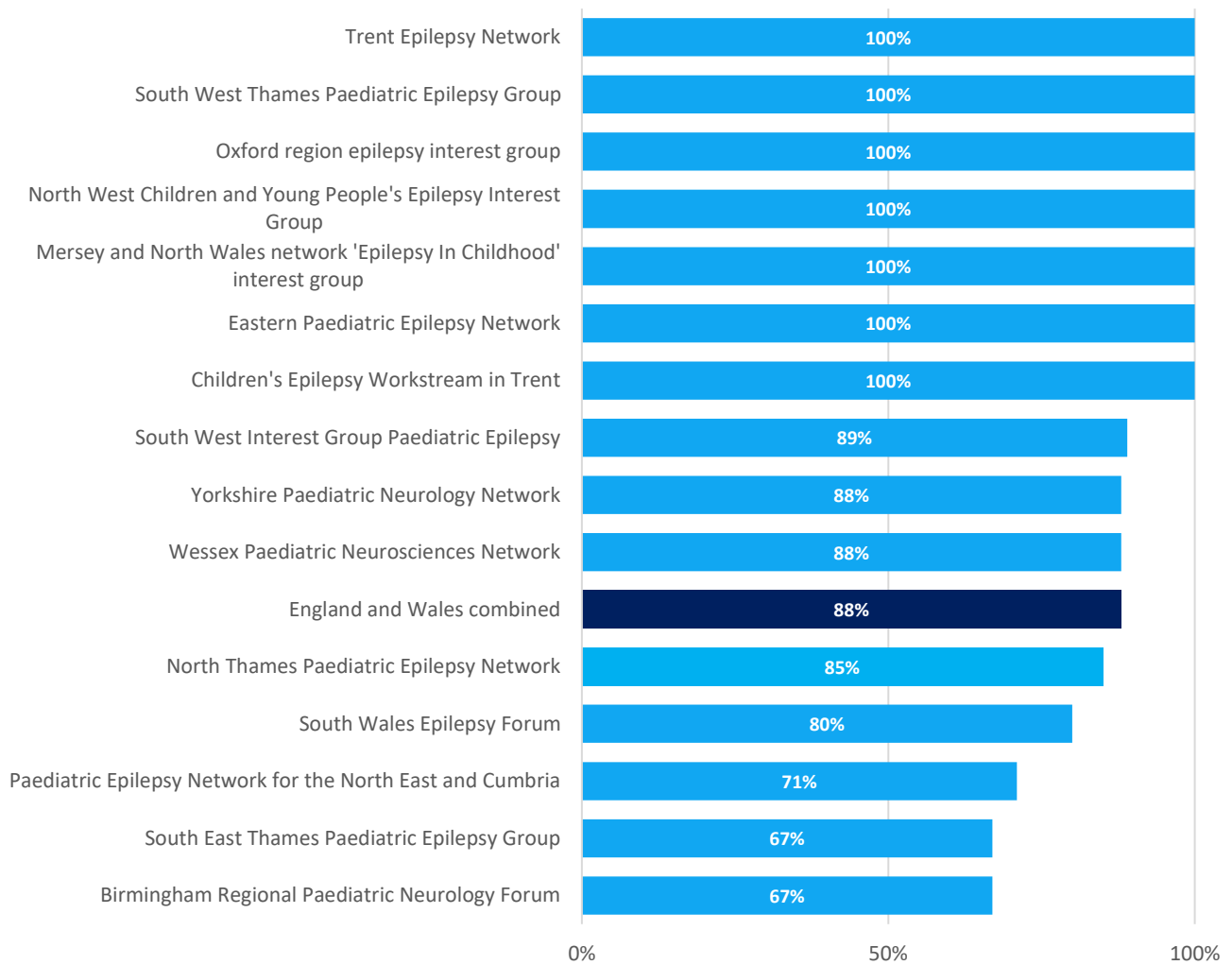
# Findings by OPEN UK regional networks

The figures in the following section show findings from the 2022 organisational data by OPEN UK regional network, compared to the England and Wales combined average, where data is displayed in descending order.

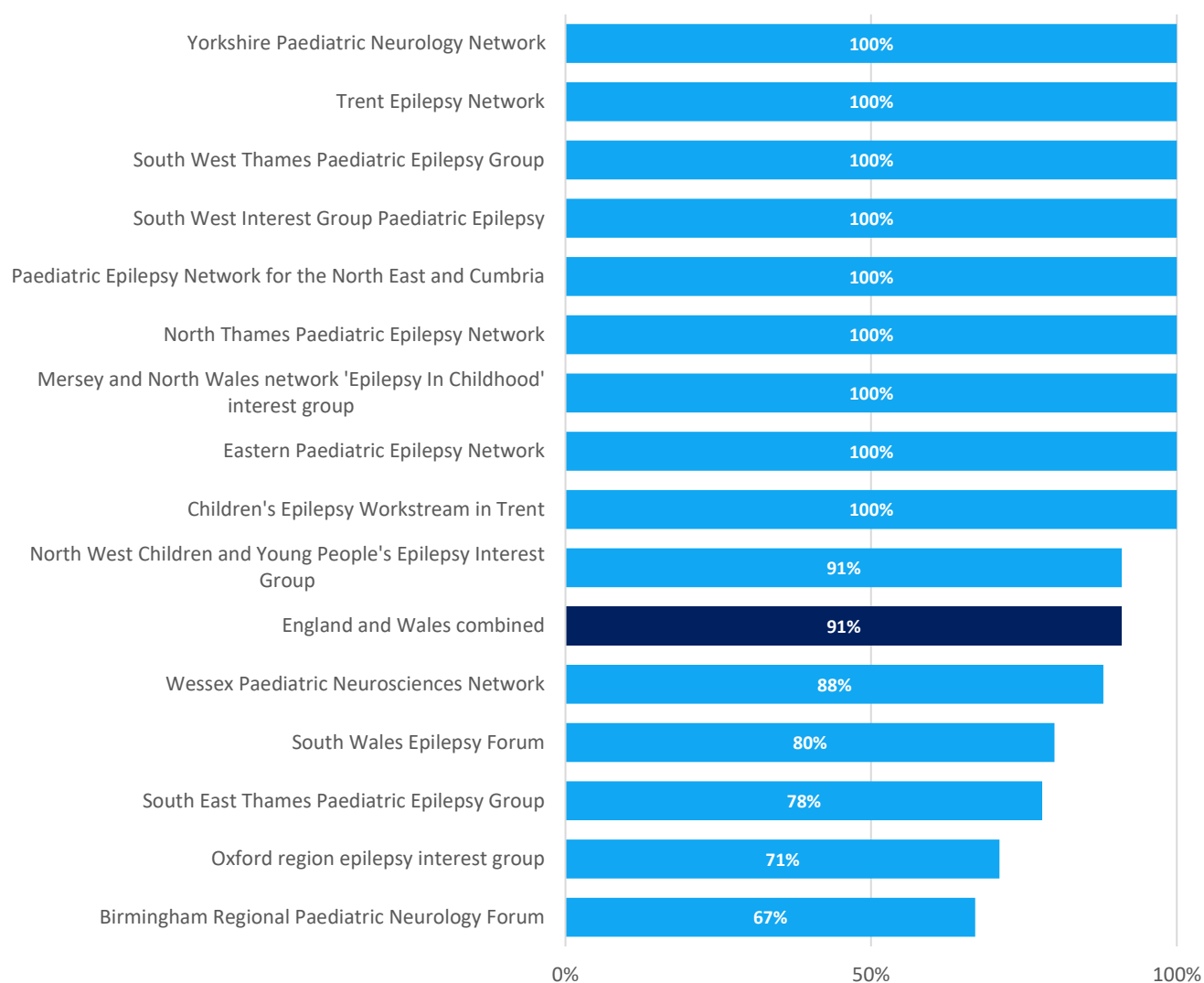
## Percentage of Health Boards and Trusts employing a consultant paediatrician with expertise in epilepsy



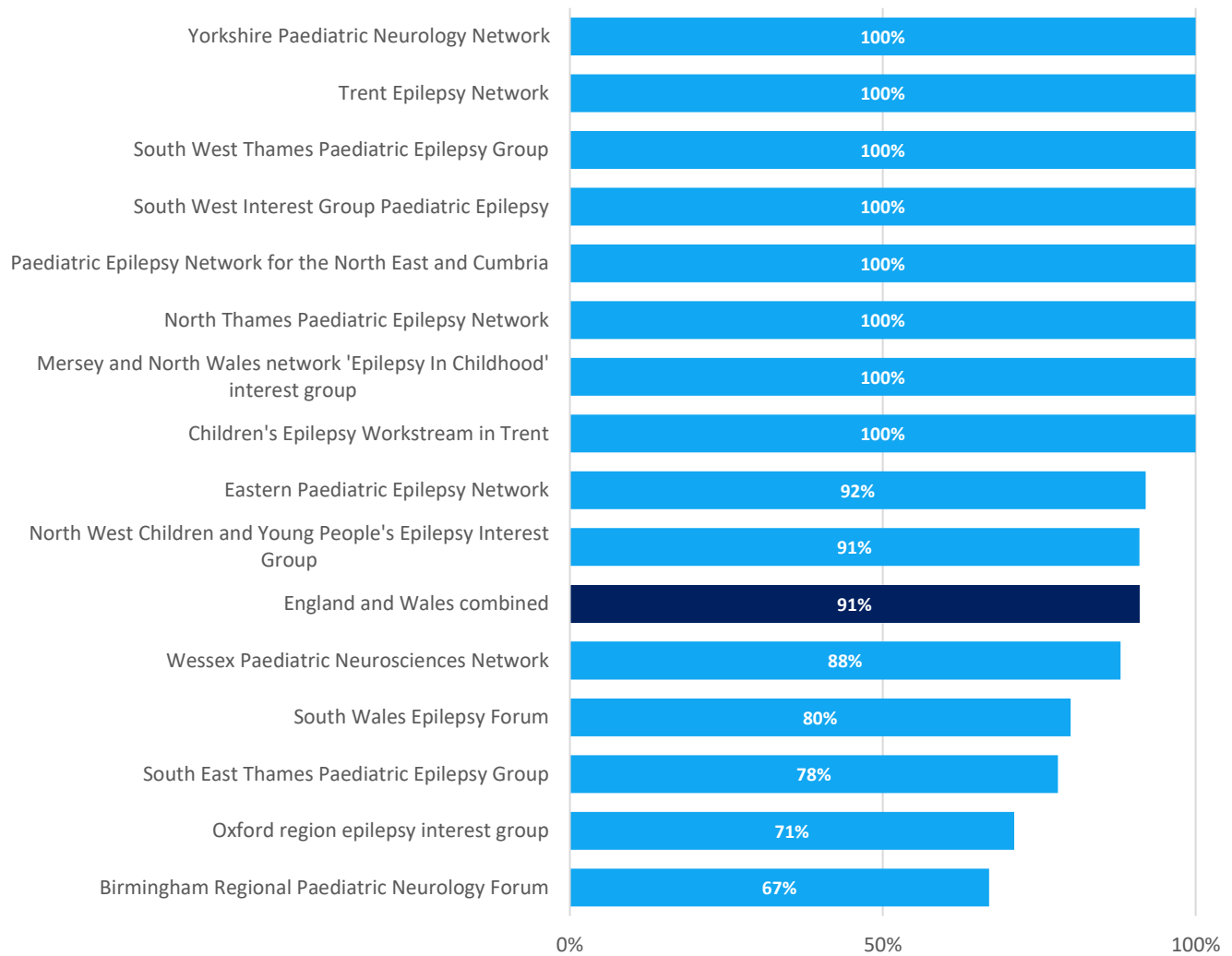
## Percentage of Health Boards and Trusts that had a defined paediatric epilepsy clinical lead



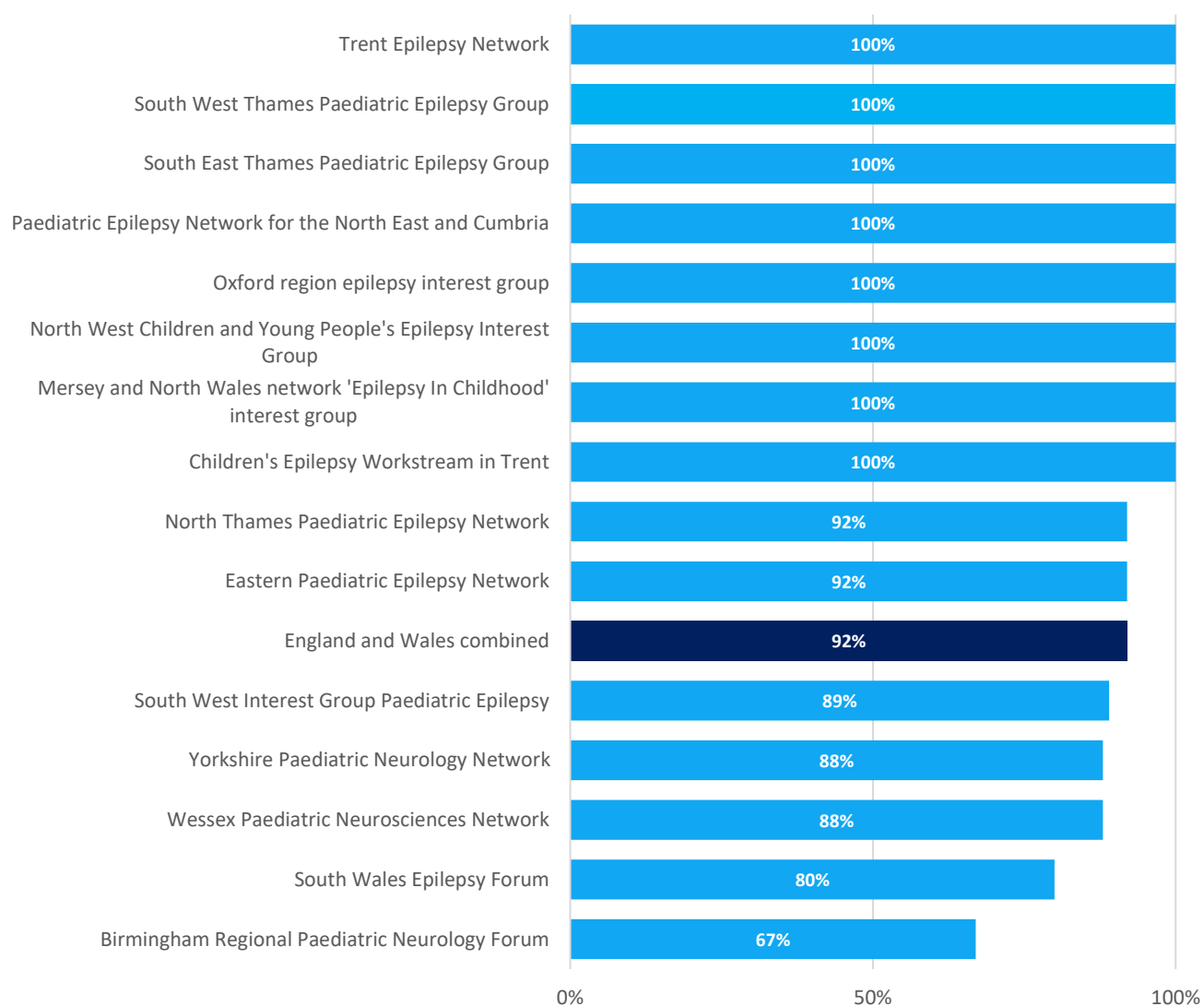
## Percentage of Health Boards and Trusts who had some epilepsy specialist nurse (ESN) provision within their paediatric service



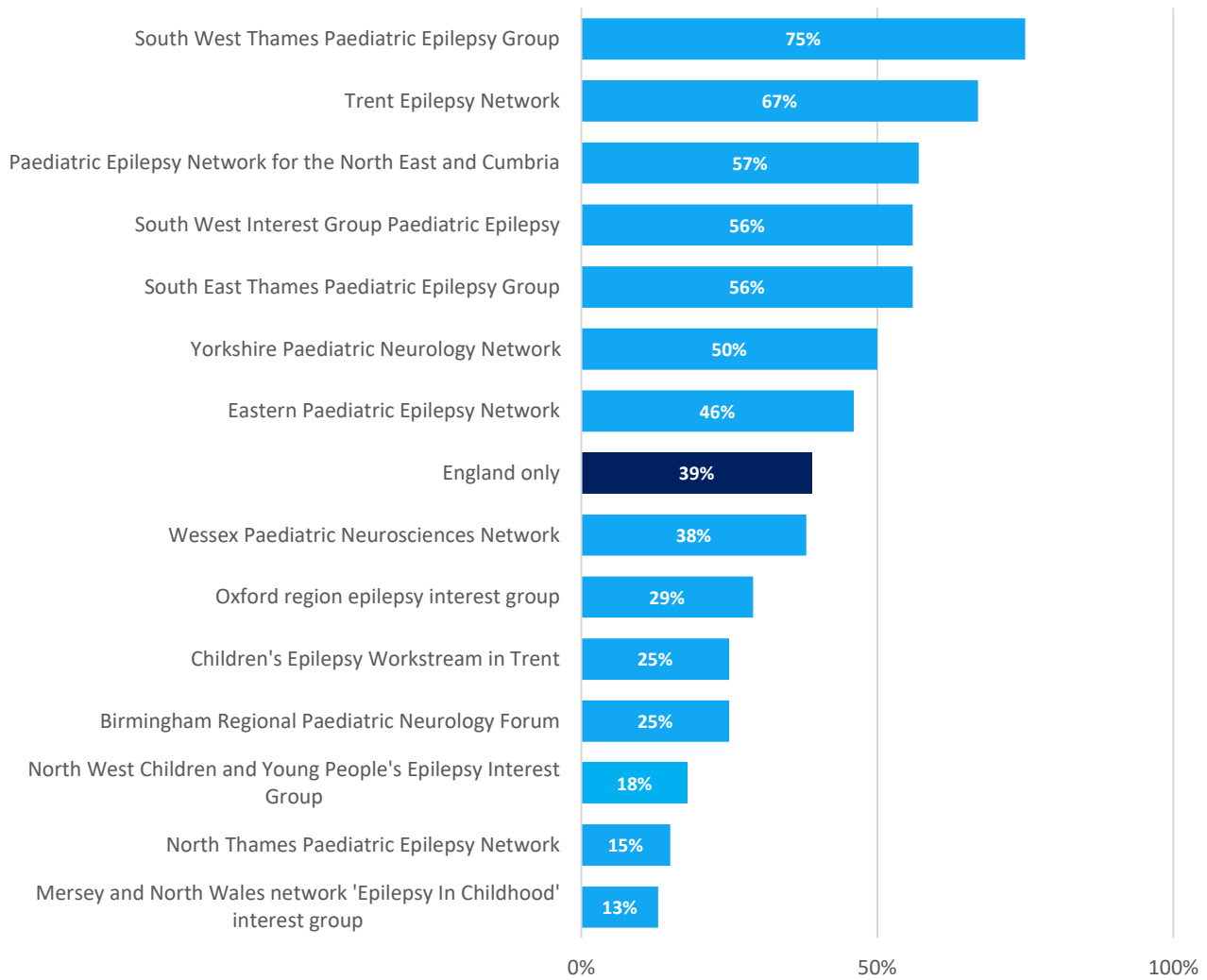
## Percentage of Health Boards Trusts that indicated that they could offer ESN support for rescue medication training for parents



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

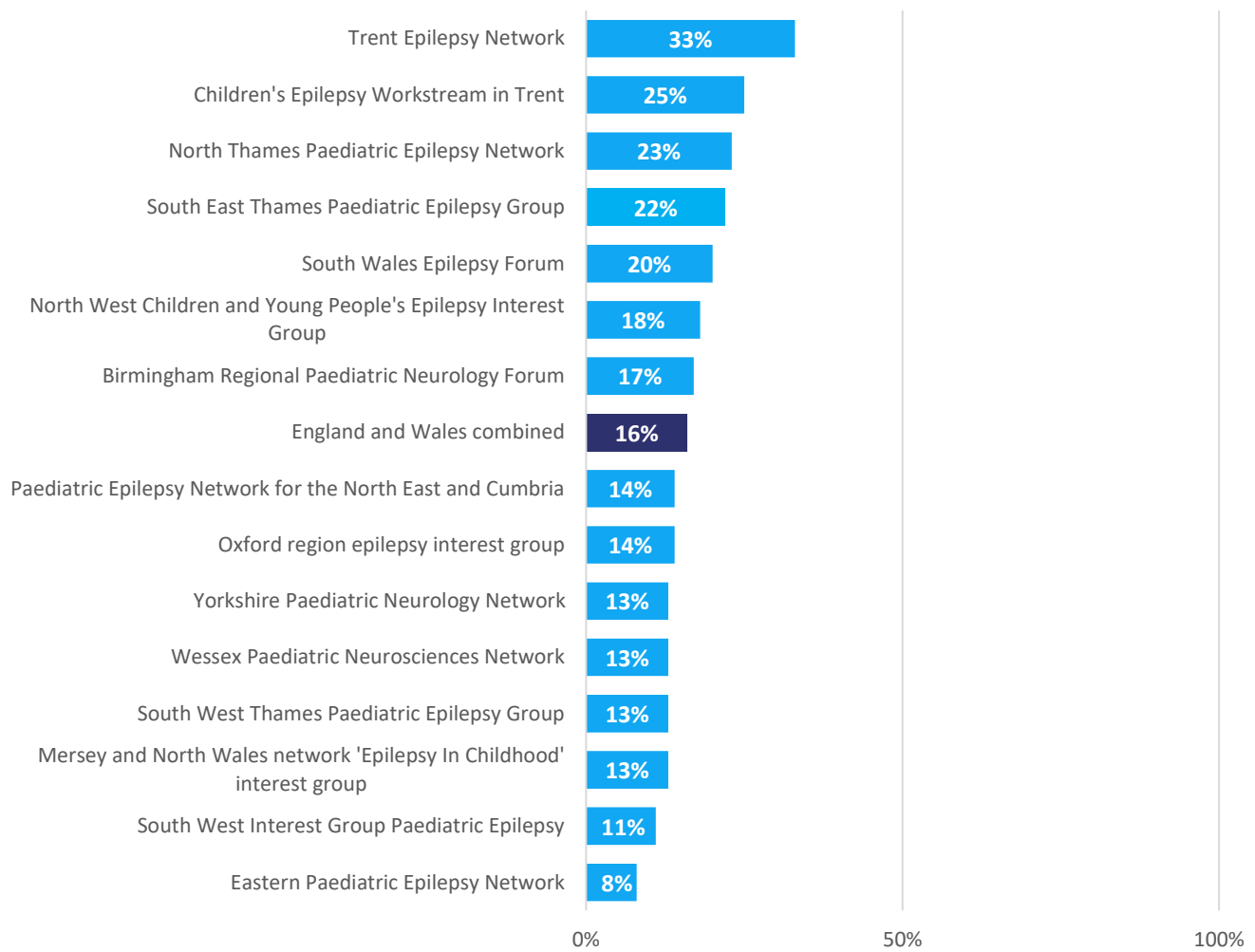


## Percentage of Trusts in England that currently run Epilepsy Best Practice Criteria (BPC) clinics

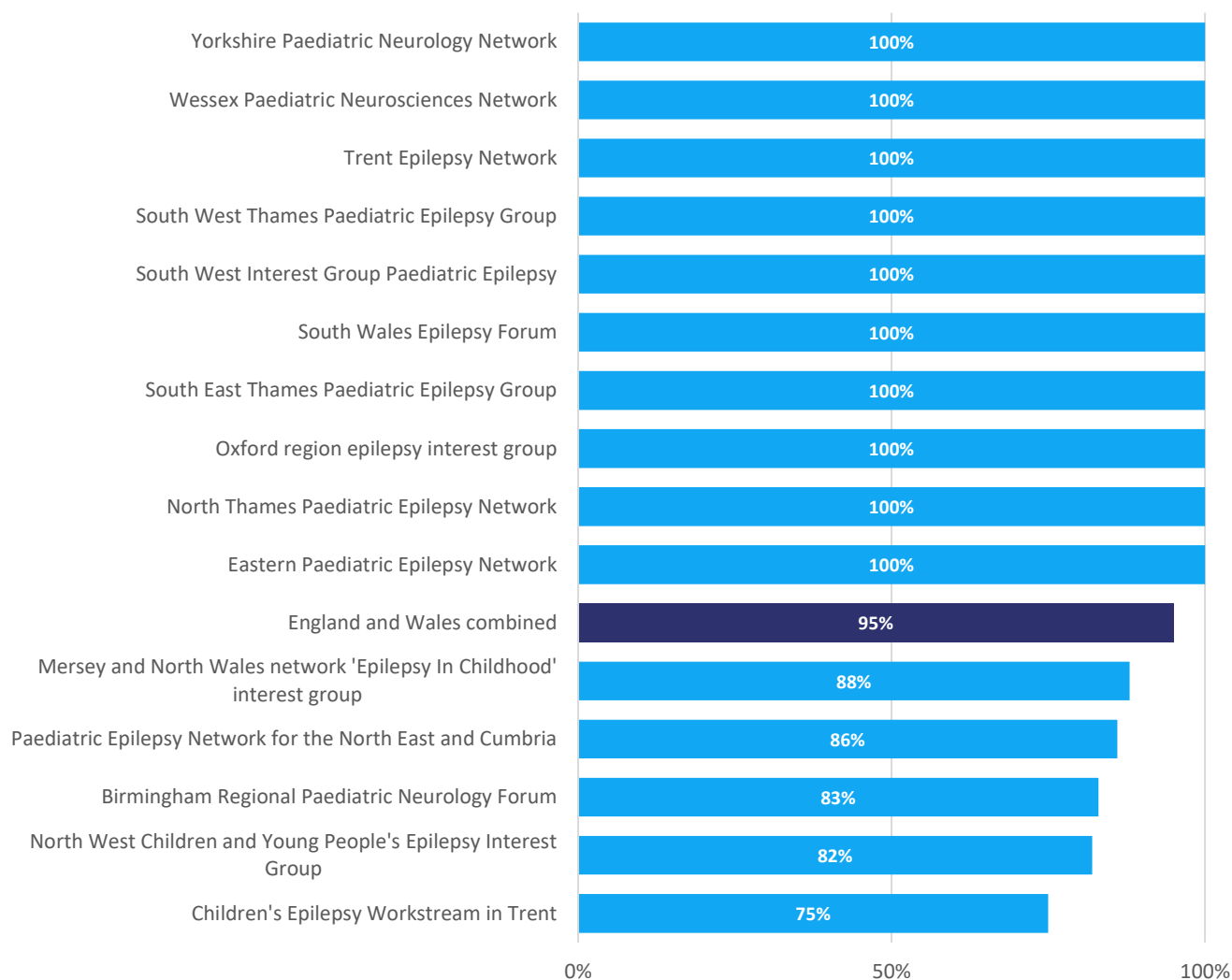




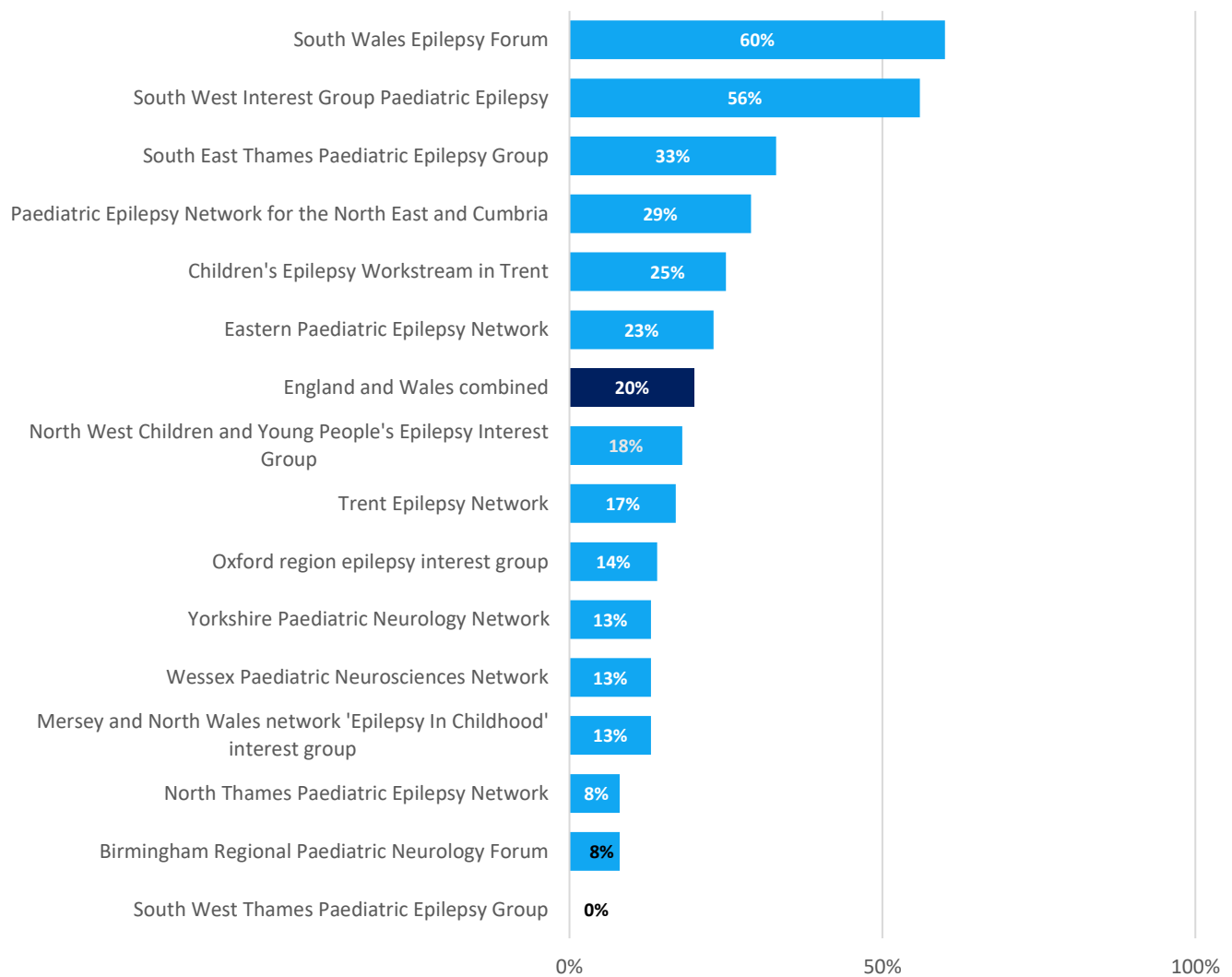
**Percentage of Health Boards and Trusts that have some tertiary provision within their paediatric service (paediatric neurologists who manage children with epilepsy (acutely and/or non-acutely))**



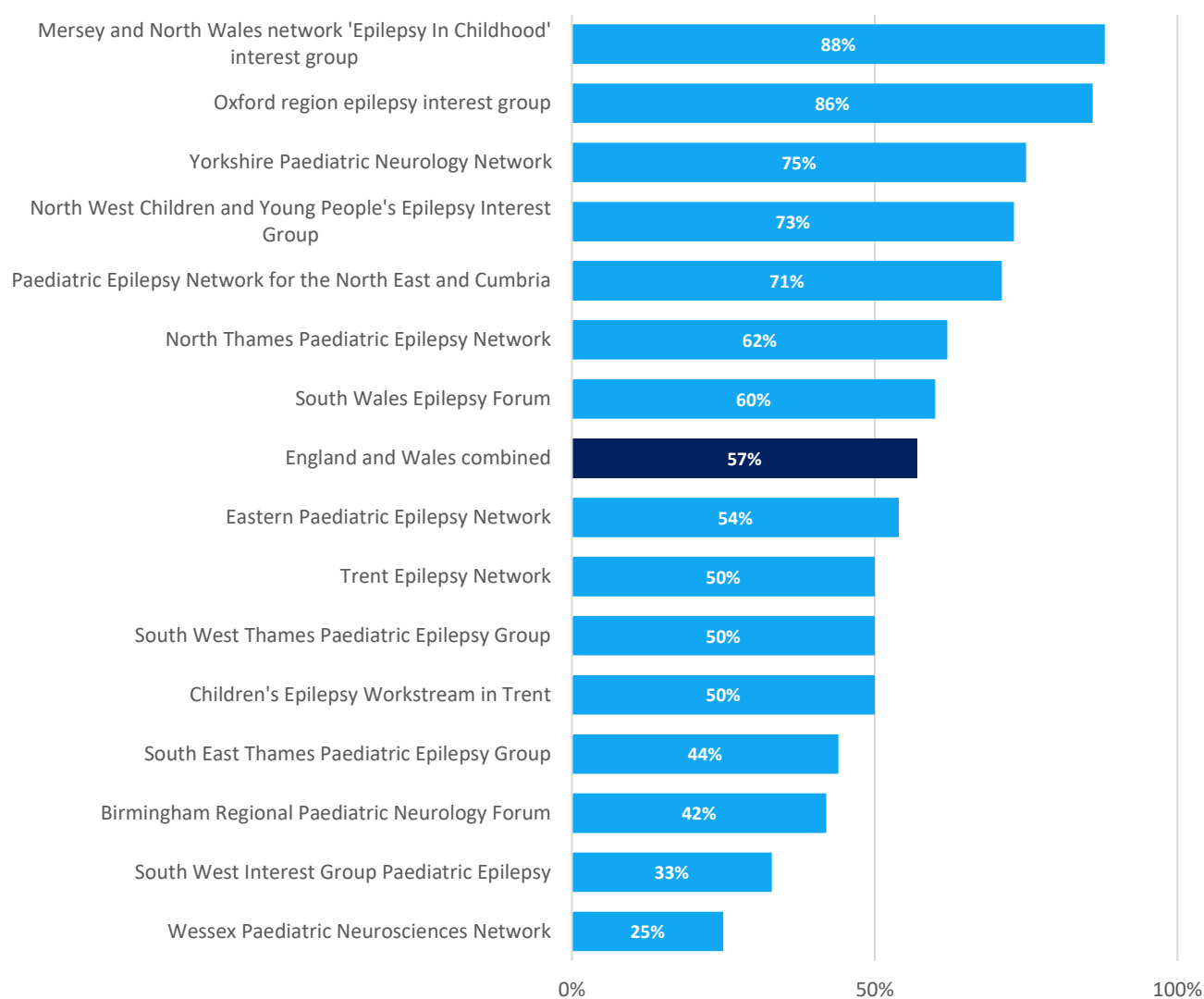
## Percentage of Health Boards and Trusts that had agreed referral pathways to tertiary paediatric neurology services



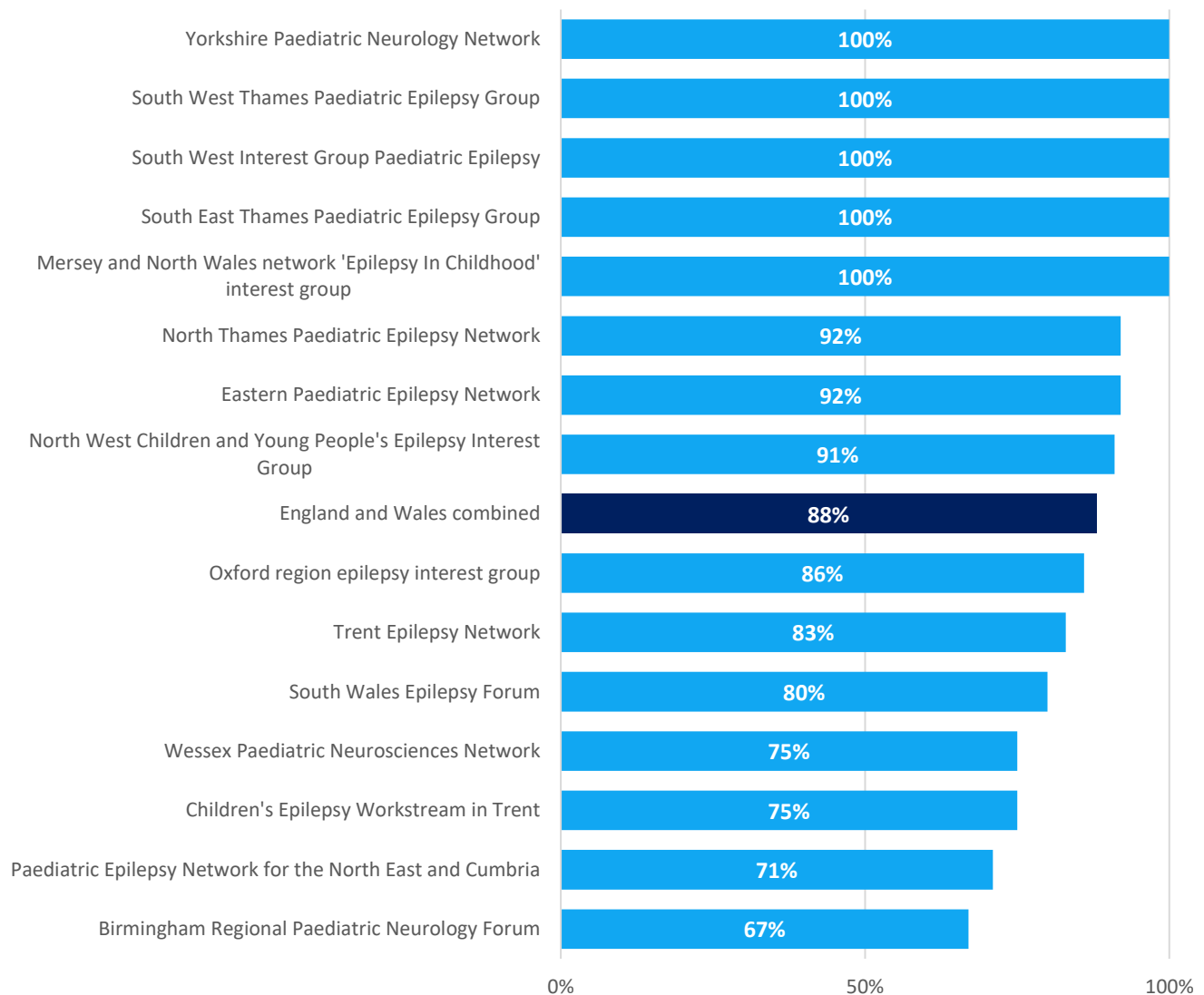
**Percentage of Health Boards and Trusts that were able to facilitate Vagal Nerve Stimulation (VNS) review at a location within the Health Board or Trust**



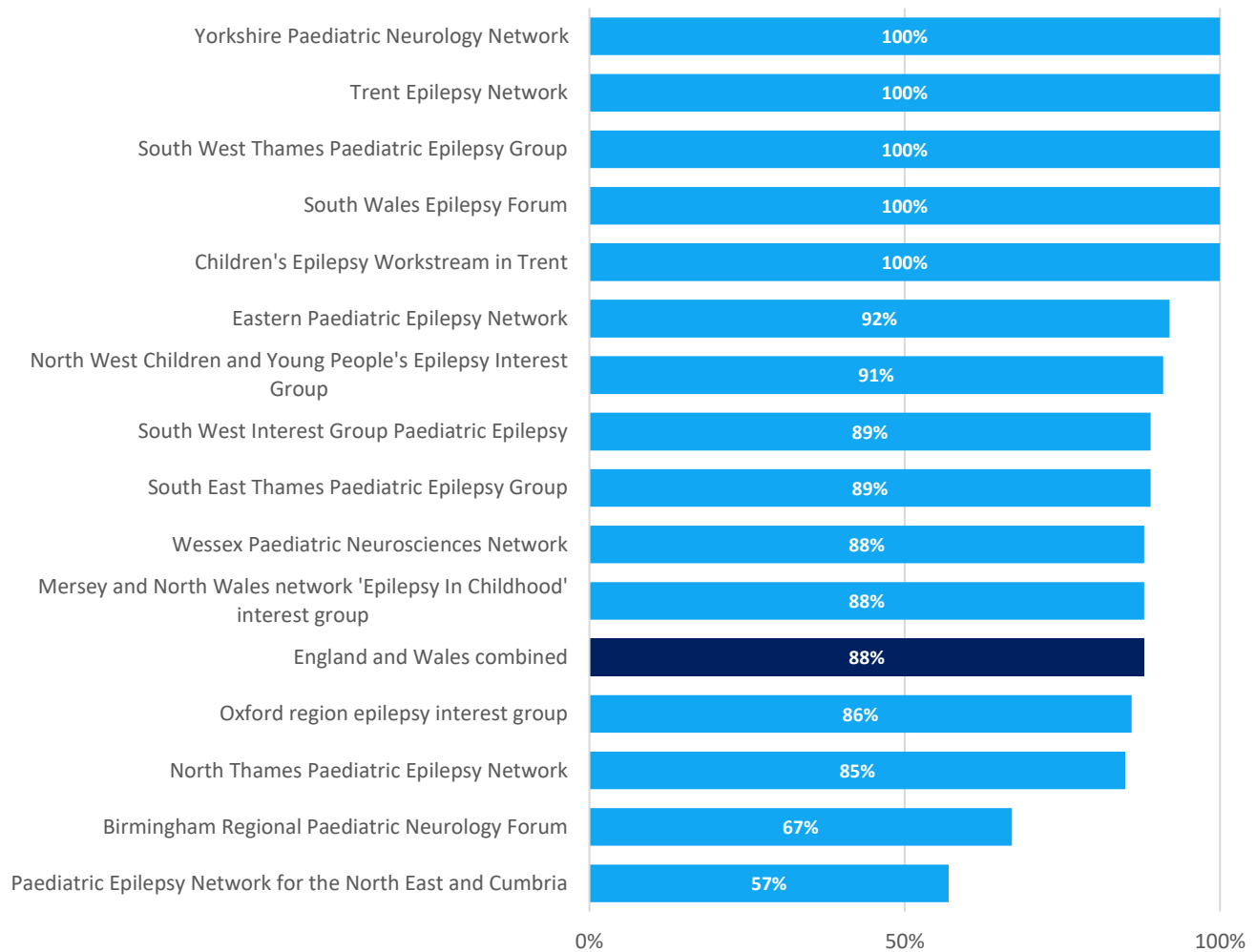
**Percentage of Health Boards and Trusts that could provide specialist advice between scheduled reviews every weekday for 52 weeks per year**



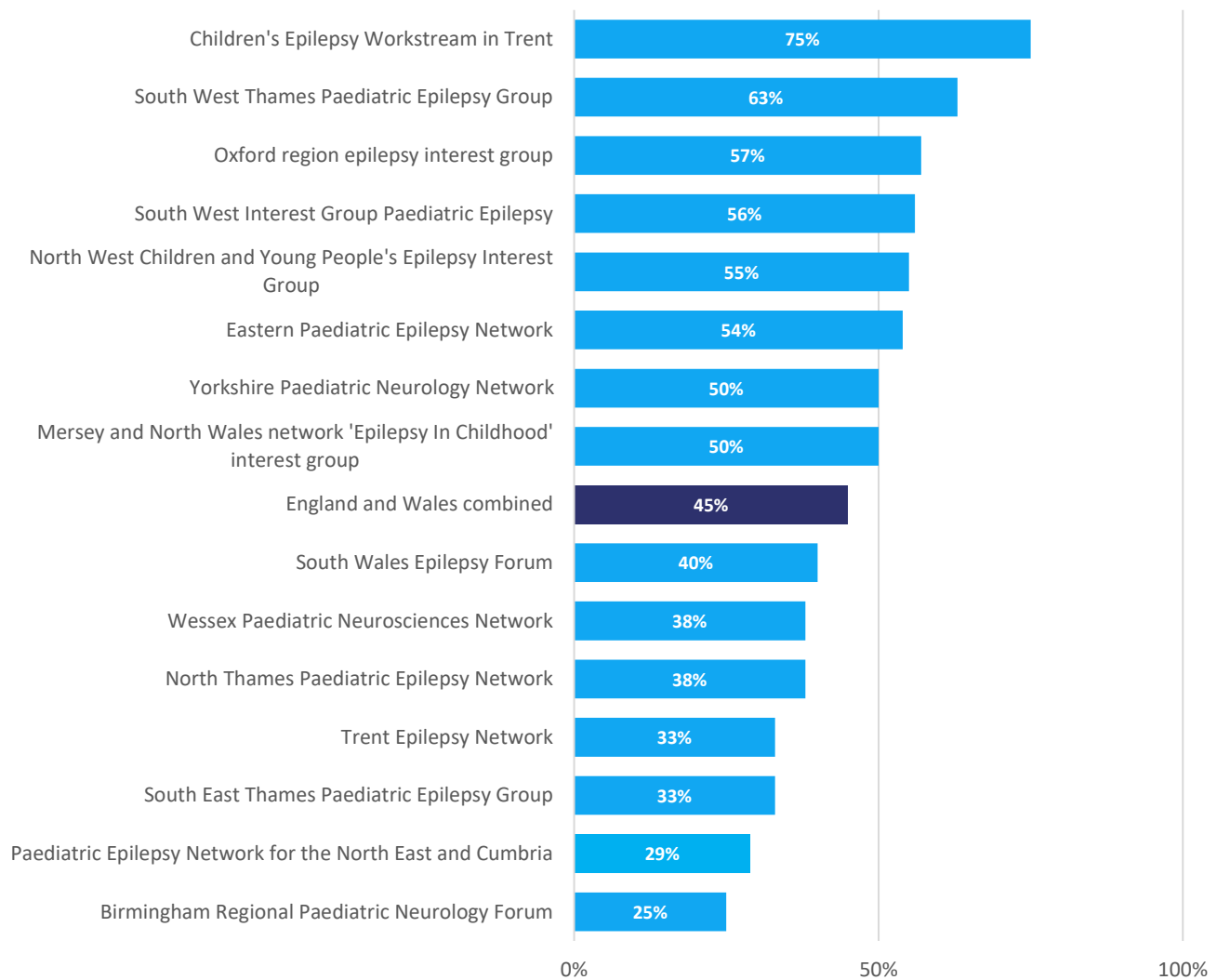
**Percentage of Health Boards and Trusts that have evidence of a clear point of contact for non-paediatric professionals seeking paediatric epilepsy support.**



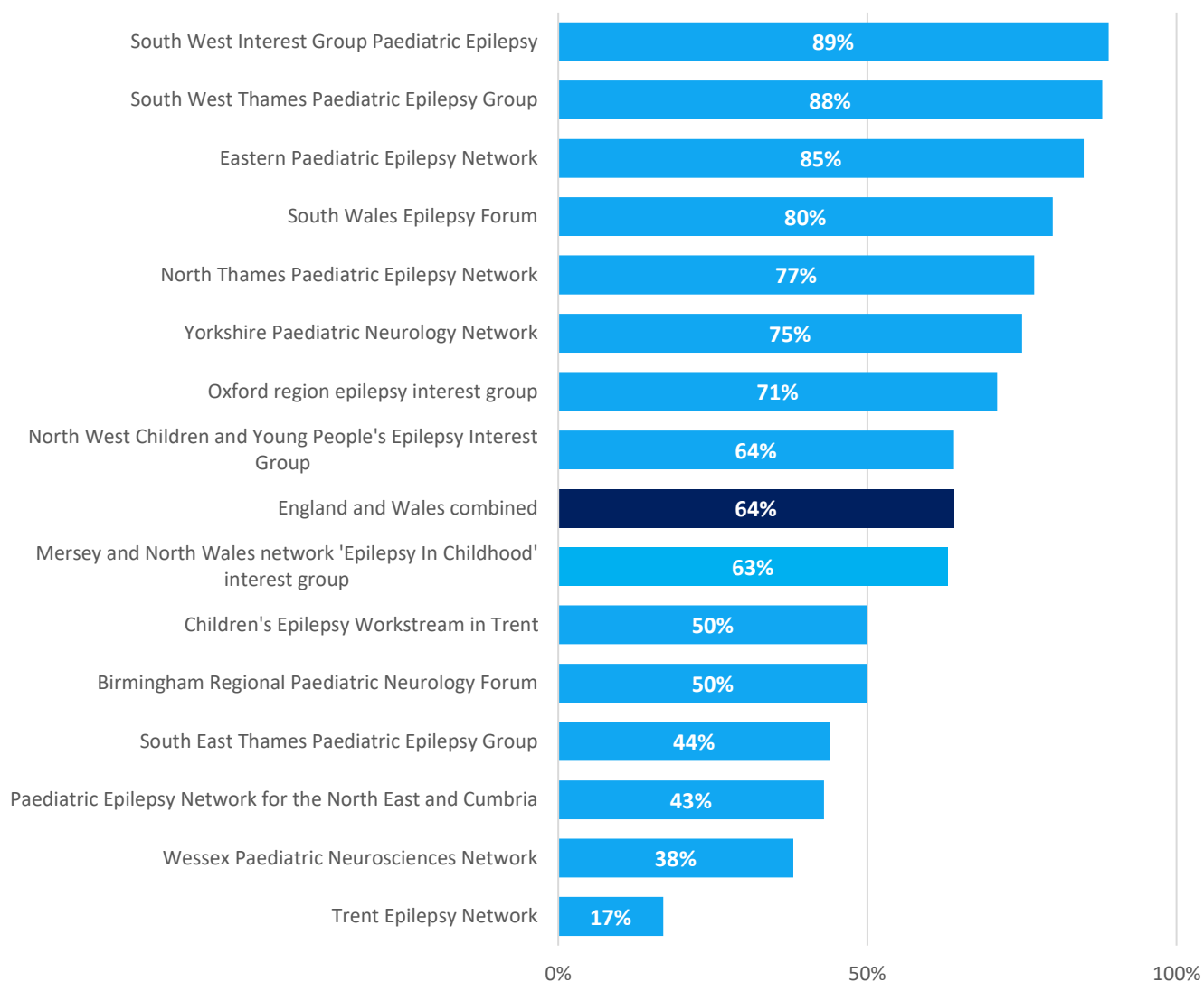
## Percentage of Health Boards and Trusts that have agreed referral pathway to adult services.



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

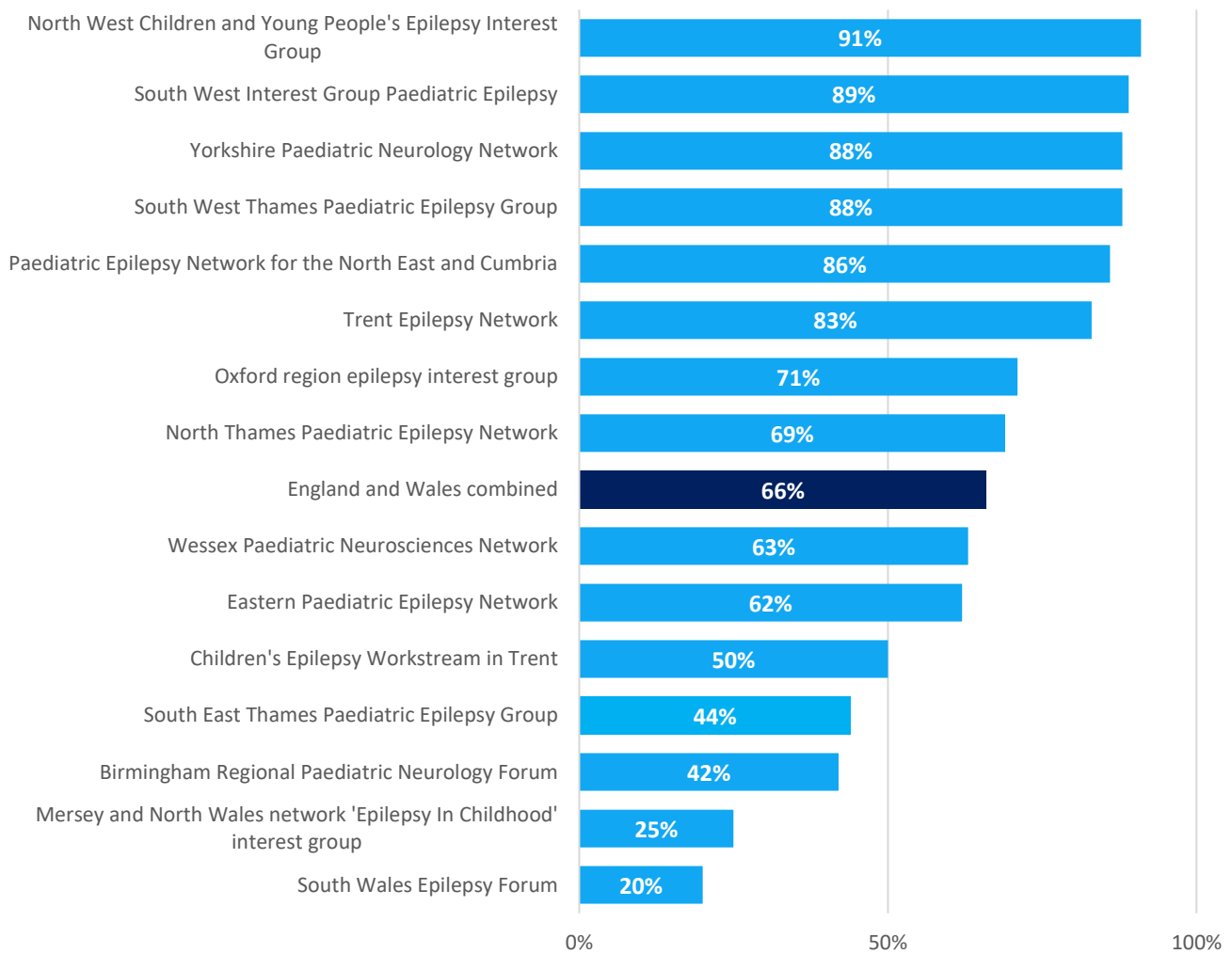


**Percentage of Health Boards and Trusts that have an outpatient epilepsy service involving adult and paediatric professionals.**

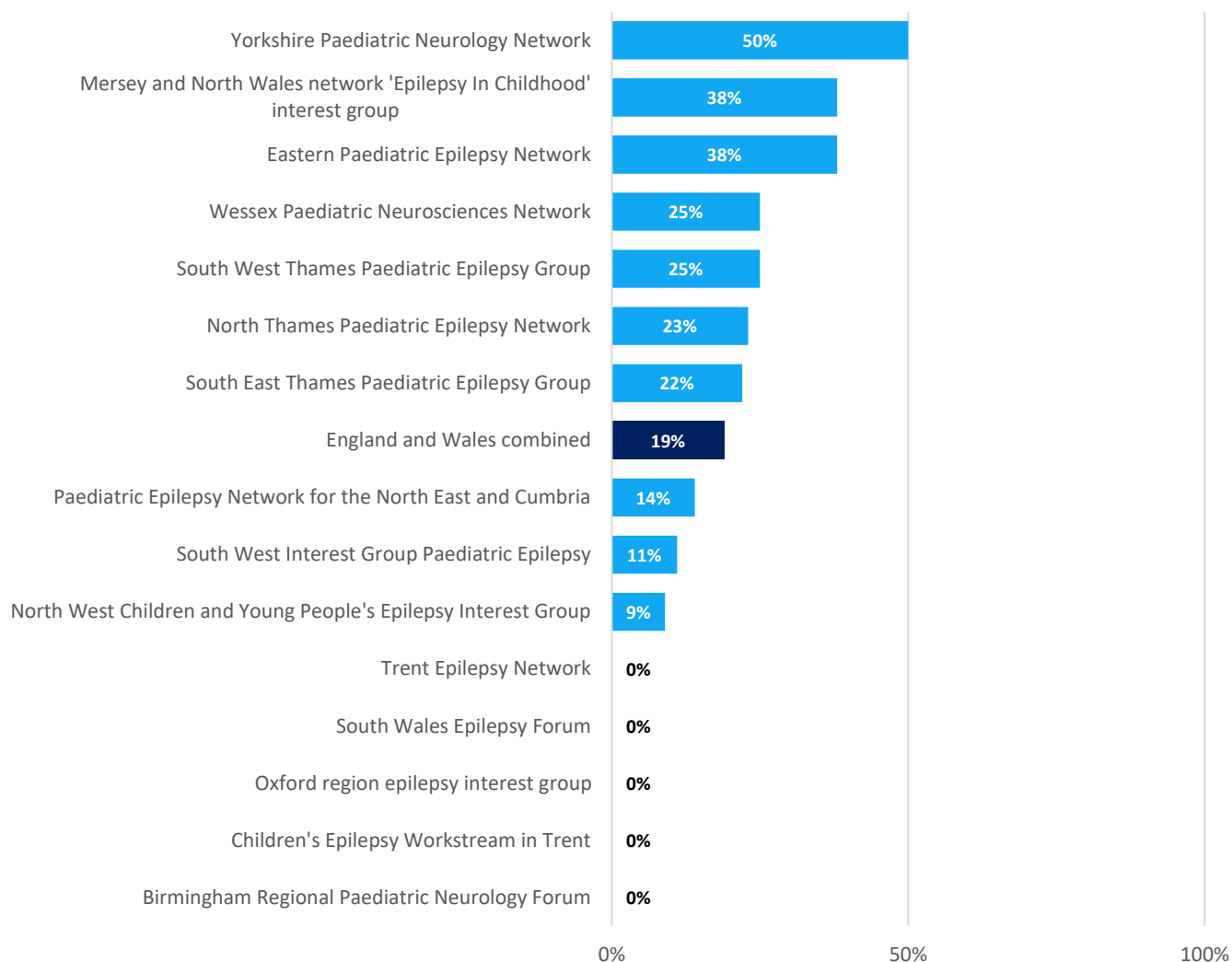




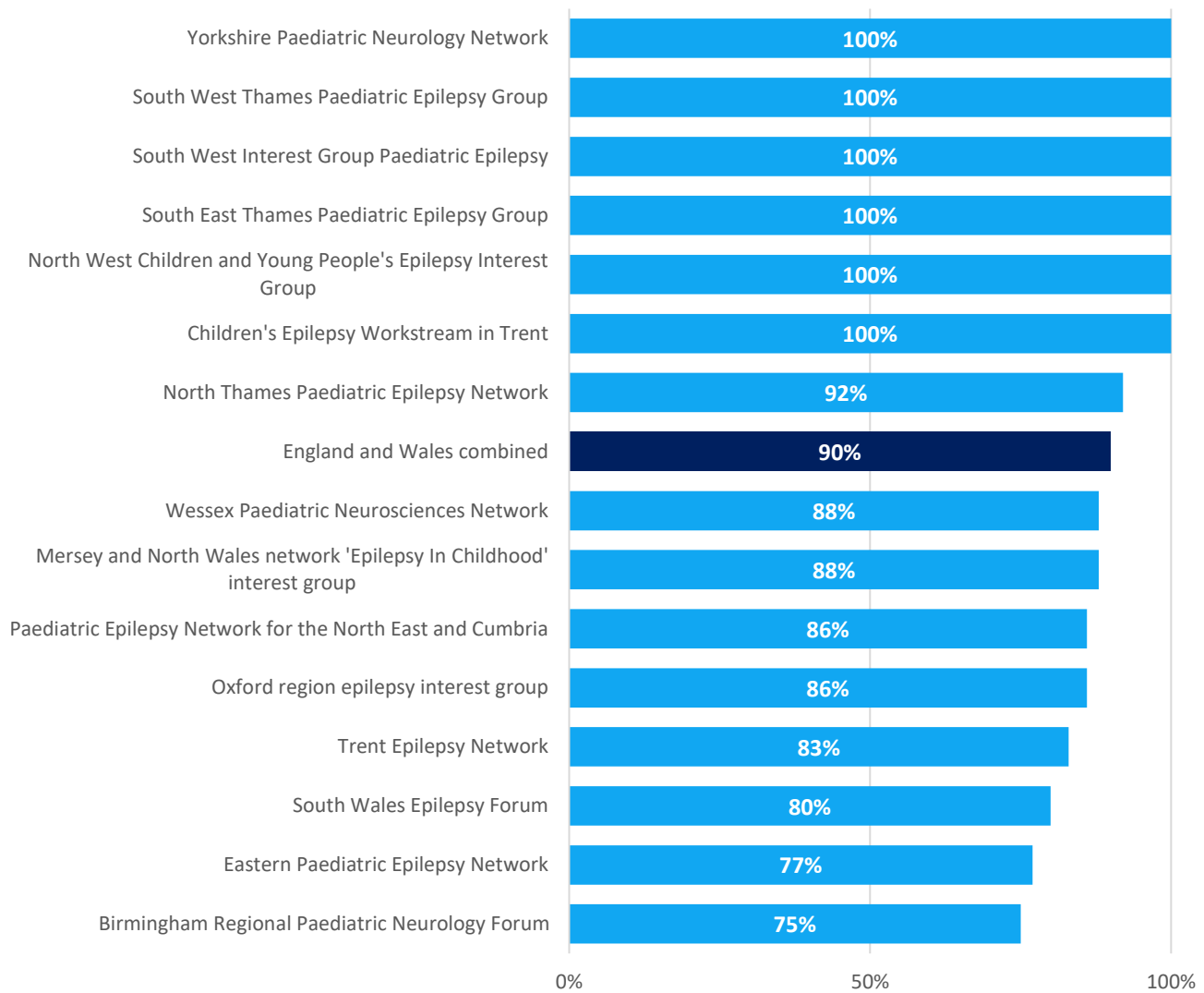
## Percentage of Health Boards and Trusts that have structured resources to support Young People transition



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



## Percentage of Health Boards and Trusts that routinely undertook comprehensive care planning for children with epilepsy



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

