2018 National Organisational Audit Report

RCPCH Audits

EPILEPSY12

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

HQIP
Healthcare Quality Improvement Partnership

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

Epilepsy12
National Clinical Audit of Seizures and Epilepsies for Children and Young People
National Organisational Report for England and Wales, 2018

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Table of contents

Forewords

The Royal College of Paediatrics and Child Health (RCPCH) has delivered Epilepsy12 since its inception in 2009 and I am pleased to introduce the **2018 Epilepsy12 National Organisational Audit Report for England and Wales.**

Some key developments have taken place within paediatric epilepsy care since the publication of the National Report of Round 2 of Epilepsy12 in 2014. The Organisation of Paediatric Epilepsy Networks in the UK (OPEN UK) has been established with the aim of joining up Health Boards and Trusts into functioning regional paediatric epilepsy networks to encourage and stimulate quality improvement. In addition, the UK Paediatric Epilepsy Programme Board was initiated by the RCPCH in 2016 to ensure alignment between Epilepsy12 and other national resources and strategies.

This report highlights some improvements in areas of paediatric epilepsy service provision. More, however, needs to be done to address the variation in care between regional paediatric epilepsy networks. A continued close collaboration between the Epilepsy12 Project Board, OPEN UK Working Group and the UK Paediatric Epilepsy Programme Board should help to understand and address this variation. The RCPCH State of Child Health report (2017) indicated that high-quality epilepsy care requires a holistic approach to improve the landscape of long term paediatric epilepsy care. The 2018 Epilepsy12 Organisational Audit report highlights where specific improvements are required.

I would like to thank all those involved in writing the report and developing its recommendations, including the Epilepsy12 Project Board, Methodology and Dataset Group, the Project Team, and Clinical Lead, Dr Colin Dunkley. Finally, I would like to thank the paediatric epilepsy teams across England and Wales who, by ensuring they provide good quality data to the audit, are able to use their results to strive to continuously improve the outcomes for this deserving group of children and young people.

Professor Anne Greenough,
Vice President, Science and Research, RCPCH and Chair of the Epilepsy12 Project Board

Epilepsy is a condition whereby individuals are prone to recurrent epileptic seizures – abnormal movement or behaviour the direct result of a change in the electrical activity of the brain. Epileptic seizures may be the presenting symptom of many different causes, and more accurately they should be referred to as the epilepsies. They affect 112,000 children and young people in the UK. Diagnosis may be complex – there is no single diagnostic test, and misdiagnosis rate has consequently remained high. Two thirds of patients will become controlled with antiepileptic drugs or enter spontaneous remission over time, but one third continue to have seizures, a figure that has remained constant over 30 years despite new antiepileptic agents[1]. There are high rates of cognitive and behaviour disorders, many of which remain unrecognised and consequently untreated, resulting in academic underachievement[2]. With real advances being made in our understanding of the underlying causes of the epilepsies, we have a real opportunity to improve outcomes in these children.

The key to improving epilepsy management is the optimisation of services and understanding of need. Several government reports and patient surveys documented variable and inadequate standards in epilepsy care by 2002. Several national initiatives have however since been developed to aim towards improving care and services, specifically for children with epilepsy e.g. the NICE guidelines for the diagnosis and management of adults and children with the epilepsies (2004, 2012) (**https://www.nice.org.uk/guidance/cg137**), and Paediatric Epilepsy Training courses developed by the British Paediatric Neurology Association(**https://www.bpna.org.uk/pet/**). The Epilepsy12 audit, initiated in 2009, has been a major initiative in England and Wales in both raising the awareness of need for service development, as well as in the tracking of its progress. Further, coordination has been enhanced through the development of Organisation of Paediatric Epilepsy Networks in the UK (OPEN UK), and the establishment of the UK Paediatric Epilepsy Programme Board, by the RCPCH. Epilepsy12 now reports on the initial phase of Round 3, and has demonstrated that key progress has been made, not least in organisation of services, although there remain deficiencies in some areas, particularly continued regional variation, and the absence of mental health provision.

As we move forward, Epilepsy12 remains an evolving tool from which we can gather useful information about epilepsy services, which will also enable prospective data collection reviewing outcomes and patient experiences, providing data that will prove vital as we continue to strive toward improved patient care.

Professor Helen Cross
Chair of the UK Epilepsy Programme Board, and The Prince of Wales's Chair of Childhood Epilepsy

Executive summary

Welcome to the Epilepsy12 2018 National Organisational Report for England and Wales.

Background

Epilepsy12 Round 3 began in April 2017, having previously published national reports of the results of Round 1 and Round 2 in 2012 and 2014 respectively. Round 2 of the audit showed statistically significant improvements from round 1 in paediatric epilepsy care provision. Round 3 commenced in 2017 when the audit was recommissioned as part of National Clinical Audit and Patient Outcomes Programme (NCAPOP). The key findings of the Nuffield Trust 2017 Report "**Admissions of inequality: emergency hospital use for children and young people**"[3] showed Epilepsy12 and other initiatives have coincided with its observation that "*Unplanned hospital admissions for epilepsy have reduced over time for all age groups and there has been most progress in reducing unplanned admissions for the most deprived groups*".

Williams et al, 2018 also reported findings derived from Epilepsy12 Round 2 data showing *"the most powerful factor affecting satisfaction related to how easy it was to contact the epilepsy service."*[4]

This report is the first formal output of Round 3 of the audit and includes the first 'yearly snapshot' of the organisation of paediatric epilepsy services for children and young people in England and Wales. The results detailed in the report reflect data submitted to the organisational audit by 148 Health Boards and Trusts with a paediatric epilepsy service across England and Wales. Data is reported at overall (England and Wales combined), England, Wales and regional network aggregate levels. Longitudinal organisational audit data across the three Rounds of Epilepsy12 is reported where possible.

Data entry for the first patient cohort of the clinical audit phase of Round 3 began in July 2018 and will be reported on in 2020. The time from onset of clinical cohort ascertainment to reporting is a function of both prospectively registering a reasonably sized cohort over several months and then ensuring that each child within that cohort has completed 12 months of care. The clinical audit report will focus on key clinical performance indicators and patient reported experience measures.

Epilepsy12 is also facilitating the development of the Organisation of Paediatric Epilepsy Network in the UK (OPEN UK) as a framework to join up Health Boards and Trusts into regional and national networksand an overarching UK Working Group. An associated quality improvement (QI) programme has been established to facilitate QI activities and initiatives at a local, regional and national level.

The UK Paediatric Epilepsy Programme Board was also initiated by the RCPCH in 2016 to develop an overarching strategy to inform paediatric epilepsy research, training and national quality improvement projects and to ensure alignment between national resources and strategies such as best practice tariff development, patient information resources and epilepsy courses for professionals. The participation of children and young people, parents and carers has been an increasingly important component of Epilepsy12. Young people were involved in the design of the Rounds 1 and 2 Patient Reported Experience Measure (PREM) domains and an engagement programme, led by children and young people, forms a key part of Round 3 as detailed within section 5, (page 26) of this report.

Results

It is encouraging that this report shows incremental improvements in some areas of paediatric epilepsy service provision, including:

- overall numbers of epilepsy nurse specialists
- overall numbers of paediatricians with expertise and
- the number of specific clinics for children and young people with epilepsies

However, there remains a considerable need for improvement in the following areas as highlighted in our recommendations within this report:

- sufficient provision of defined general paediatricians with expertise in epilepsies to correctly diagnose epilepsy and provide appropriate ongoing management for all children with epilepsy
- sufficient provision of epilepsy specialist nurses to ensure ongoing input to all children with epilepsies
- ensuring rescue medication training
- ensuring epilepsy clinic capacity
- fulfilling Best Practice Criteria
- defining paediatric neurology referral pathways
- facilitating local access to vagus nerve stimulation
- co-locating mental health provision
- improving 'service contactability'

There is marked variation between regional paediatric epilepsy networks in these listed areas. Further work must be undertaken to understand the levers and barriers behind this, particularly in the basic yet fundamental aspects of epilepsy care where there should not be any variation, such as the provision of epilepsy specialist nurses who are central to good patient care and safety. There are also significant improvements to be made in the pathways from paediatric to adult care and many services have no defined means for families to access specialist advice between scheduled reviews.

One of the key messages of the **RCPCH State of Child Health Report (2017)**[5] indicated that high-quality epilepsy care requires a holistic approach that includes psychological and practical support in addition to medical expertise, plus early recognition and support of additional needs (including mental health and special educational needs). This Epilepsy12 Report also shows that mental health support for children and young people with epilepsy is only present in a few services but that on the whole, it is not accessible, and certainly not integrated, within the vast majority of paediatric epilepsy services.

Doctors, nurses, managers, commissioners, regional networks and national strategic groups should be commended on improvements to date, but should now strive to focus on providing adequate levels of staff with expertise in epilepsies, transition services, 'service contactability' and support for mental health. There are some simple changes identified in our 12 recommendations that Health Boards, Trusts and commissioners should oversee that would radically improve the landscape of long term health care for this large and vulnerable group of children and young people.

Dr Colin Dunkley
Consultant Paediatrician, Sherwood Forest Hospital NHS Foundation Trust and Epilepsy12 Clinical Lead

1. Introduction

Epilepsy12 was established in 2009 and has the continued aim of helping epilepsy services, and those who commission health services, to measure and improve the quality of care for children and young people with seizures and epilepsies. The audit is commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England and the Welsh Government as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP) and is delivered by the Royal College of Paediatrics and Child Health (RCPCH).

The RCPCH delivered Rounds 1 and 2 of Epilepsy12 between 2009 and 2015, publishing related national reports for each Round in 2012 and 2014 respectively. The audit was inactive for two years at the end of Round 2, however, paediatric epilepsy was once again prioritised as a topic for the NCAPOP and the RCPCH was recommissioned by HQIP to deliver Round 3 of Epilepsy12 from 1 April 2017 to 31 March 2021.

Rounds 1 and 2 of the audit included Health Boards and Trusts across England, Northern Ireland, Scotland and Wales. This report covers the analysis of data collected by the audit on the organisation of paediatric epilepsy services within Health Boards and Trusts in England and Wales. It is hoped that in future, Health and Social Care Trusts in Northern Ireland and Health Boards in Scotland will also join Round 3 of the audit, subject to contractual and governance arrangements being put in place.

As per Rounds 1 and 2, the work of Round 3 of the audit is overseen by a Project Board which includes representatives of patient and professional organisations and a dedicated project team within the RCPCH.

1.1 Quality improvement

Facilitating quality improvement activities is a core element of Epilepsy12. The audit supports these activities in the following ways.

Identifying and sharing case studies

This report contains an example of the type of case studies relating to quality improvement activities which the audit seeks to collate from clinical teams at Health Board, Trust and regional network level and share with other audit participants. The audit encourages people to share such examples of their achievements with their peers and provides a platform for them to do so with a wide audience.

Joint Epilepsy12 and OPEN UK National Conference

The first joint Epilepsy12 and OPEN UK National Conference took place in London on 22 June 2018. The event was attended by over 160 people representing patient organisations, multidisciplinary clinical team members working in paediatric epilepsy services, commissioners and clinical governance staff.

The event provided an opportunity for attendees to receive updates on Epilepsy12 activities, hear the voice of children and young people and engage with OPEN UK-led quality improvement initiatives. A number of local clinical teams and regional networks were also given a platform at the event to showcase examples of their own quality improvement initiatives with their peers via verbal and poster presentations as part of the day.

An expert panel also discussed the topic of "Where next for the mental health of children with epilepsies?" and took related questions on the subject from the floor.

Copies of the presentations delivered on the day can be viewed via the project website: **www.rcpch.ac.uk/epilepsy12**

Supporting regional and national quality improvement activities

Epilepsy12 has supported the establishment of regional quality improvement (QI) facilitators within each of the paediatric epilepsy networks. The regional QI facilitators will work together as a group in conjunction with the Epilepsy12 project team to help promote Epilepsy12 communications and audit findings, identify opportunities for regional QI activities and share learning from within their respective regions across the whole OPEN UK national network.

1.2 Clinical audit phase

The clinical audit phase of Epilepsy12 began in July 2018 and focuses on performance indicators relating to the first paediatric assessments undertaken for children and young people who experience a paroxysmal episode (or episodes) and the first year of care that follows those initial assessments. The national report of the analysis of data from the first cohort of patients from the round 3 clinical audit phase will be published in the summer of 2020. The performance indicators align with NICE Guidelines and Quality Standards[6-7] and cover the following areas:

- Input from a paediatrician with expertise in epilepsies
- Input from an epilepsy specialist nurse
- Tertiary input
- Epilepsy surgery referral
- Appropriate first paediatric assessment
- Seizure formulation
- Access to electrocardiogram (ECG)
- Access to magnetic resonance imaging (MRI)
- Accuracy of diagnosis
- Discussion of the risks of treatment with sodium valproate
- Comprehensive care planning agreement and content
- School individual healthcare plan

The Epilepsy12 data platform allows participating Health Boards and Trusts to enter data on the care that they provide to children and young people for the clinical audit phase and view real time outputs including individual patient timeline and care planning reports and a performance indicator dashboard.

Full details of the Epilepsy12 Round 3 performance indicators can be viewed on the **Epilepsy12 website**

2. Key findings and recommendations

Epilepsy12 brings together a multidisciplinary group of representatives to highlight key findings and results and translate these into a set of recommendations that can be acted upon to improve paediatric epilepsy care. The Epilepsy12 audit of the Organisation of Paediatric Services in England and Wales covered the following areas:

- Workforce
- Epilepsy clinic configuration
- Tertiary provision
- Investigations
- Service contact
- Young people and transition
- Mental health provision
- Neurodevelopmental support
- Care planning
- Patient database/register

Key findings by OPEN UK paediatric epilepsy networks can be viewed in Appendix A from page 103. Key recommendations by audience can be viewed in Appendix B from page 115.

General and specific recommendations are made to support the existing goals and priorities of paediatric epilepsy services and regional networks, and are targeted at those with the ability to action the recommendation.

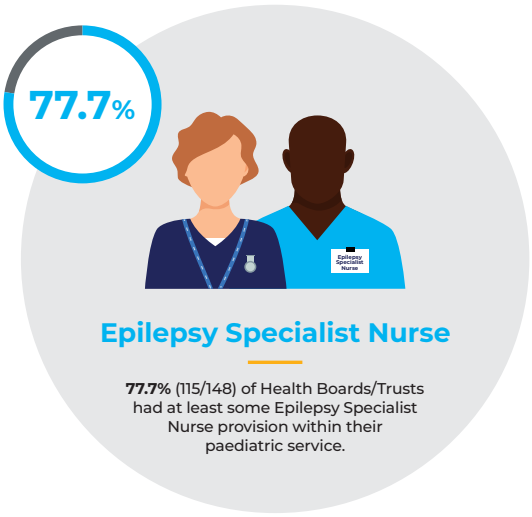
General recommendations

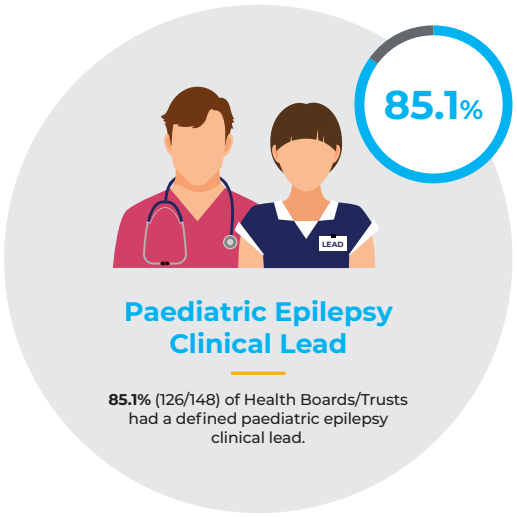
1. All **Health Boards and Trusts** should review Epilepsy12 local results and support action plans and actions to ensure that gaps in services for children with epilepsies are removed. They should risk assess any gaps and escalate via governance or performance routes.

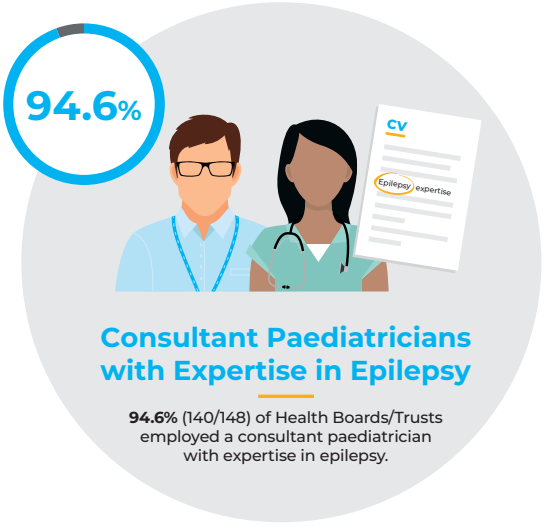
2. **Regional (OPEN UK) paediatric epilepsy networks and commissioners** should review Epilepsy12 results for their associated Health Boards and Trusts. They should develop benchmarking, quality improvement initiatives and interfaces between those with commissioning, clinical and provider roles.

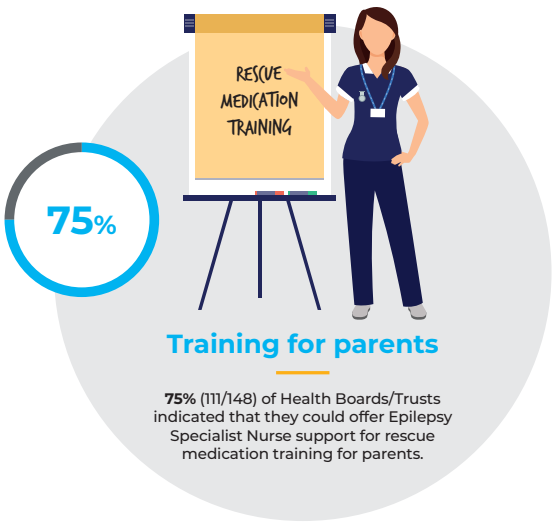
Full details of the 2018 Organisational Audit dataset are available on the **Epilepsy12 website**

2.1 Workforce









Key findings

- 94.6% (140/148) of Health Boards and Trusts employed a consultant paediatrician with expertise in epilepsy (Table 3, page 38). There has been an increase in the total number of whole time equivalent (WTE) consultant paediatricians with expertise in epilepsy employed across England and Wales, compared to Rounds 1 and 2 (Figure 1, page 35)

- 85.1% (126/148) of Health Boards and Trusts Health Boards and Trusts had a defined paediatric epilepsy clinical lead (Table 4, page 39)

- 77.7% (115/148) of Health Boards and Trusts had some epilepsy specialist nurse (ESN) provision within their paediatric service. 22.3% of Health Boards and Trusts still have no epilepsy specialist nurse provision (Table 6, Page 43). There has been an increase in the total number of WTE epilepsy specialist nurses employed across England and Wales, compared to Rounds 1 and 2 (Figure 2, page 40)

- 75% (111/148), of Health Boards and Trusts indicated that they could offer ESN support for rescue medication training for parents (Table 7, page 45)

Recommendations

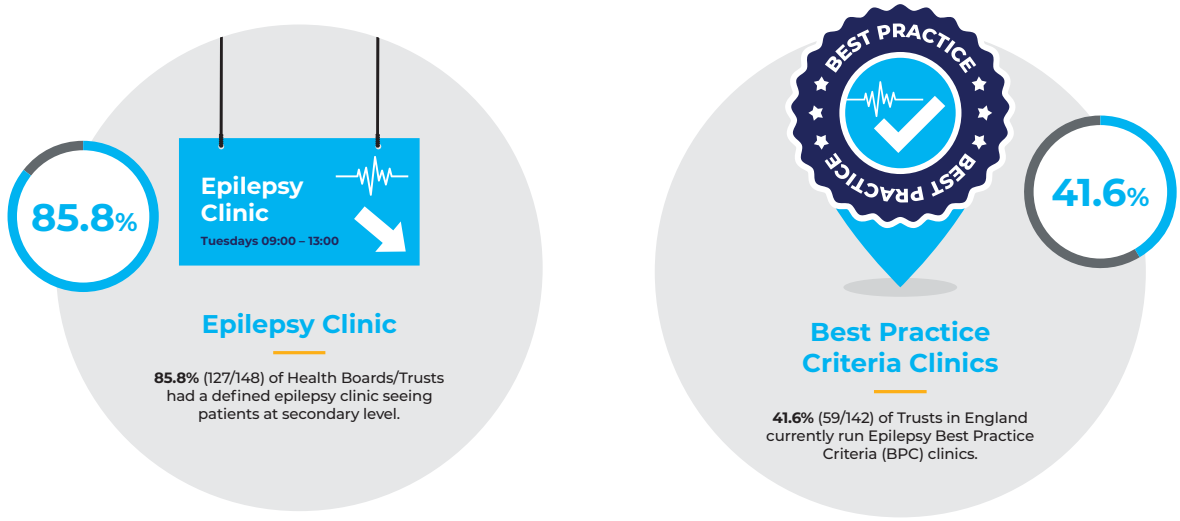
3. All **Health Boards and Trusts** should ensure they have sufficient defined general paediatricians with expertise in epilepsies to correctly diagnose epilepsy and provide appropriate ongoing management for all children with epilepsy. Children with 'complex epilepsy' should also have evidence of input from a paediatric neurologist.

4. All **Health Boards and Trusts** should ensure they have sufficient epilepsy specialist nurses to ensure ongoing input to all children with epilepsies.

5. All **Health Boards and Trusts** should ensure that when rescue medication is prescribed for use by parents and carers of children at risk of prolonged epileptic seizures that training and individualised emergency care plans are provided.

Full 2018 results for Workforce are found on page(s) 34-47.

2.2 Epilepsy clinic configuration



Key findings

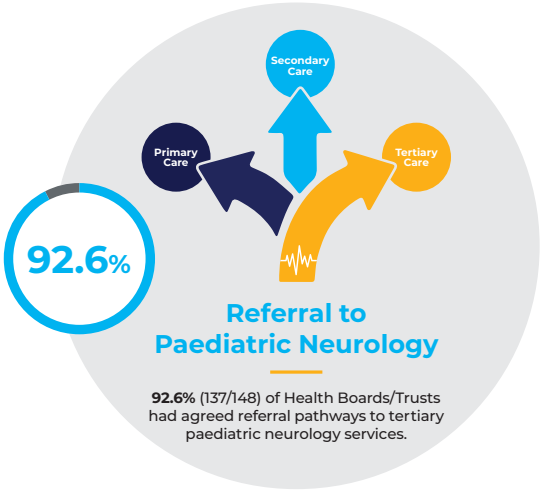
- 85.8% (127/148) of Health Boards and Trusts had a defined epilepsy clinic seeing patients at secondary level (Table 9, Page 49)
- 41.6% (59/142) of Trusts in England currently run Epilepsy Best Practice Criteria (BPC) clinics (Table 12, Page 53)

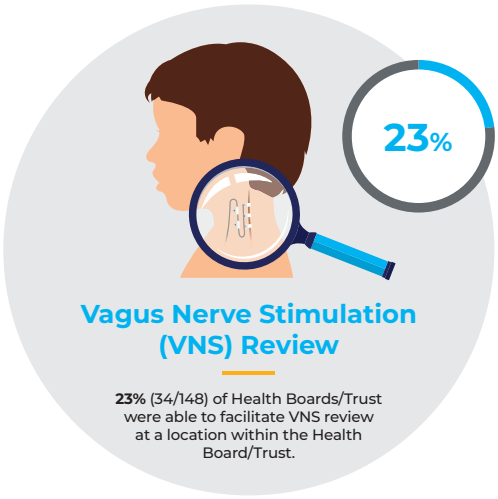
Recommendations

6. **Health Boards and Trusts** should ensure provision of sufficient follow up epilepsy clinic capacity. Where appropriate, children with epilepsy currently in a general paediatric clinic should be identified and streamed through designated epilepsy clinics.
7. **Health Boards and Trusts** should provide epilepsy services fulfilling Best Practice Criteria (BPC). **Health Boards and Trusts** with different funding mechanisms should still specify and embed Best Practice Criteria within secondary epilepsy clinics. Barriers to BPC implementation should be explored and overcome by **commissioners** working with Health Boards and Trusts.

Full 2018 results for Epilepsy clinic configuration are found on page(s) 48-53.

2.3 Tertiary provision





Key findings

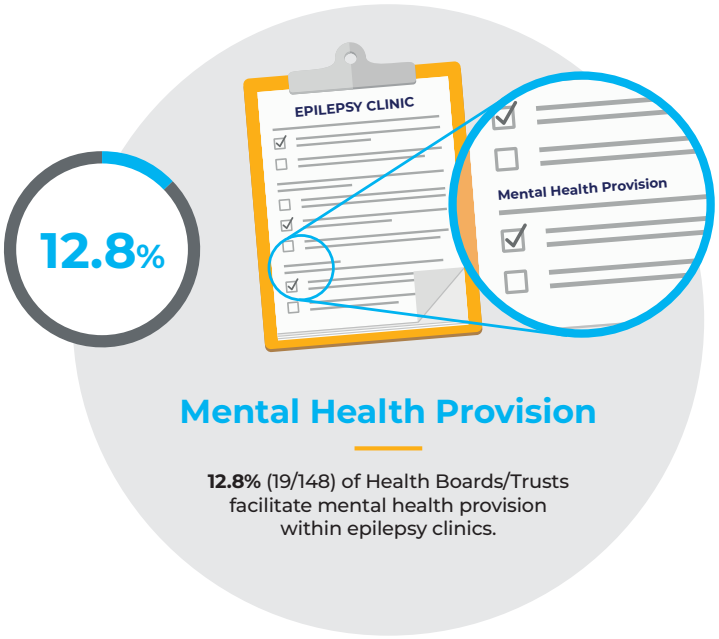
- 92.6% (137/148) of Health Boards and Trusts had agreed referral pathways to tertiary paediatric neurology services (Table 15, Page 57)
- 23.0% (34/148) of Health Boards and Trusts were able to facilitate Vagus Nerve Stimulation (VNS) review at a location within their Health Board or Trust (Table 21, Page 64)

Recommendations

8. **Health Boards and Trusts** should have agreed referral pathways to tertiary paediatric neurology services. Referral processes should ensure that after referral ongoing shared care is maintained. Referral pathways should also be clear to ensure appropriate timely referral for epilepsy surgery evaluation, ongoing complex epilepsy management or both.
9. **Health Boards and Trusts** should consider whether Vagus Nerve Stimulation (VNS) review and programming could be achieved more locally via satellite specialist neurology/epilepsy clinics.

Full 2018 results for Tertiary provision are found on page(s) 54-64.

2.4 Mental health



Key findings

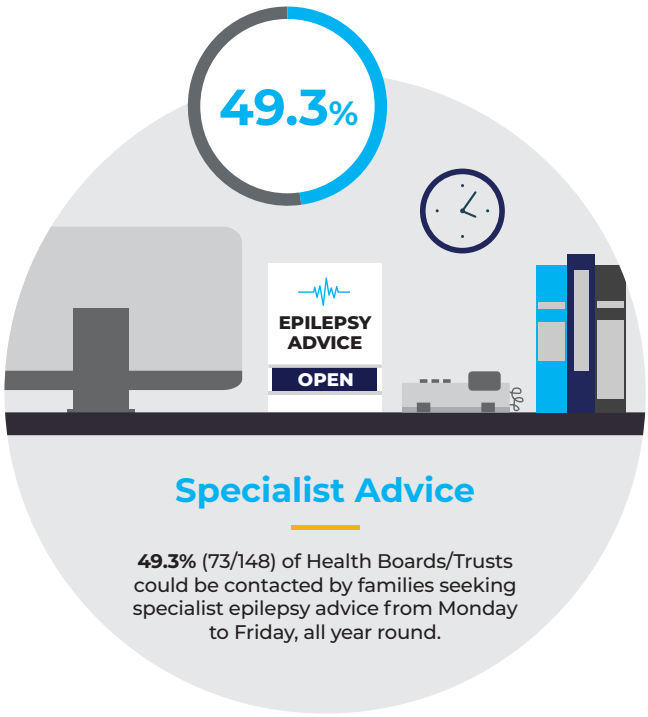
- 12.8% (19/148) of Health Boards and Trusts facilitate mental health provision within epilepsy clinics (Table 37, Page 95)
- Of the 129 Health Boards and Trusts that did not facilitate co-located mental health provision within epilepsy clinics, 6.2% (8/129) had a current Trust action plan describing steps towards achieving it (Table 39, Page 97)

Recommendations

10. **Commissioners, Health Boards and Trusts** should ensure that ongoing epilepsy care includes mental health assessment, diagnosis and treatment alongside management of seizures. If paediatric services do not have co-located mental health provision, Commissioners, Health Boards and Trusts should ensure they have action plans towards achieving co-located professionals with mental health competences within epilepsy clinics.

Full 2018 results for Mental Health are found on page(s) 91-99.

2.5 Service contact



Key findings

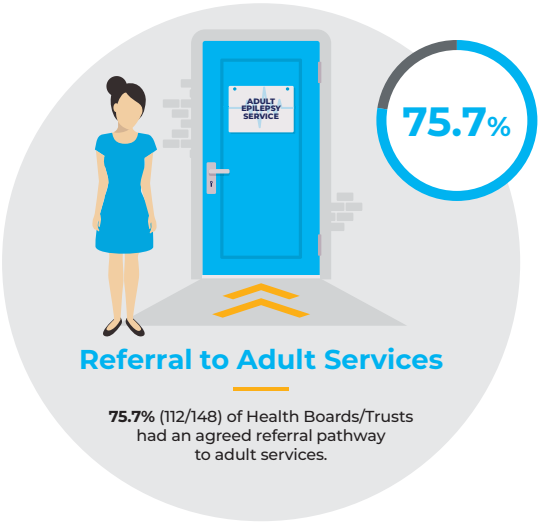
- Whilst nearly all (144/148) Health Boards and Trusts could provide some specialist epilepsy advice between scheduled reviews (Table 23, page 76), only 49.3% (73/148) were able to provide specialist epilepsy advice between scheduled reviews throughout Monday to Friday, all year round (Table 24, Page 77)

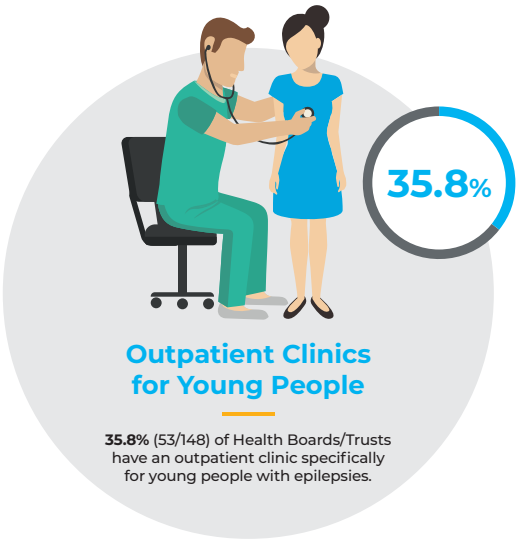
Recommendations

11. **Health Boards and Trusts** should review how 'service contactability' could be improved for their families.

Full 2018 results for Service contact are found on page(s) 75-79.

2.6 Transition





Key findings

- 75.7% (112/148) of Health Boards and Trusts had an agreed referral pathway to adult services. (Table 27, Page 83)
- 35.8% (53/148) of Health Boards and Trusts have an outpatient clinic specifically for young people with epilepsies (Table 28, Page 84)

Recommendations

12. **Health Boards and Trusts** should formally agree transition pathways from paediatric to adult services. Local arrangements should define how this is achieved for different young people with epilepsies with different associated problems, for example children and young people with an intellectual disability or neurodisability. In addition to providing epilepsy clinics for children, **Health Boards and Trusts** should also establish secondary tier clinics specifically for young people with epilepsies. This should support the evolving needs of the young person and their family throughout adolescence as well as during referral and handover to appropriate adult services.

Full 2018 results for Transition are found on pages 80-90.

3. Organisation of Paediatric Epilepsy Networks in the UK (OPEN UK)

Before 2015, there was a great deal of good work being done across the UK to improve the care of children with epilepsy. Notably, of course, there had been two iterations of the Epilepsy12 national audit, which gave each of the regional paediatric epilepsy networks some data into which they could sink their teeth.

The networks were busy producing processes and protocols, polishing leaflets and standards, delivering education and peer reviewing huge amounts of video footage of paroxysmal episodes to improve the quality of diagnosis. The British Paediatric Neurology Association (BPNA) was also continuing to deliver high quality education and meetings. There remained, however an evident need to join up the regional networks, so that clinicians could speak with a louder voice, gather regional and national data, and share best practice more readily.

The Organisation of Paediatric Epilepsy Networks in the UK (OPEN UK) came into existence in late 2015, as a confederation of the sixteen individual regional clinical paediatric epilepsy networks, with representation from the British Paediatric Neurology Association (BPNA) and British Academy of Childhood Disability (BACD). The OPEN UK Working Group is hosted by the RCPCH, and connects local Health Board and Trust and regional leads to the Epilepsy12 national audit. OPEN UK also represents clinicians on the UK Paediatric Epilepsy Programme Board alongside the BPNA.

The OPEN UK aims are to encourage the sharing of local, regional and national ideas, pilots and resources. This was well illustrated by the inaugural joint Epilepsy12/OPEN UK annual national conference which took place in June 2018, at which many fabulous projects and ideas were shared from across the UK.

OPEN UK has also become an established resource and professional UK body to which other organisations come to for support, information, data, and strategic or clinical input. Examples of this include a national survey, undertaken at the request of clinicians themselves, which examined the pathways to the Children's Epilepsy Surgery Service, and the dissemination via OPEN UK communication channels of a call for collaboration with the Changing Agendas on Sleep, Treatment & Learning in Epilepsy (CASTLE) research study.

OPEN UK can provide links between local, regional and national funding bodies and we have worked with the NHS England Best Practice Tariff pricing team to develop future iterations of the paediatric epilepsy tariff, so that it will acknowledge that co-located mental health care for children and young people with epilepsy is Best Practice.

OPEN UK is essentially an organ of quality improvement, and our main themes thus far have been improving routine access to mental health care for children with epilepsy, improving transition services, and improving equitable access to epilepsy specialist nursing. The establishment of OPEN UK regional network QI facilitators, who will work in conjunction with the regional clinical leads and receive support from Epilepsy12, should further increase the positive influence that OPEN UK can have for all children and young people with epilepsies across the UK.

Dr Richard Brown,
Consultant Paediatrician, Cambridge University Hospitals NHS Foundation Trust & Chair of the Organisation of Paediatric Epilepsy Networks in the United Kingdom (OPEN UK) Working Group

The sixteen OPEN UK regional paediatric epilepsy networks are named in the following table. The abbreviated regional network names appear in the regional network results tables in section 8, starting on page 34 of this report.

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

* This report covers the analysis of data collected by the audit on the organisation of paediatric epilepsy services within Boards and Trusts in England and Wales. It is hoped that in future Health Boards in Scotland will also join Round 3 of the audit, subject to contractual and governance arrangements being put in place.

4. Case Study

The following case study highlights an example of how paediatric epilepsy services have used their Epilepsy12 results as a basis for identifying and undertaking local quality improvement activities. This study was selected from posters submitted to the 2018 Epilepsy12/OPEN UK National Conference.

Rescue medication and Basic Life Support (BLS) workshops for parents and carers of children with epilepsy: Care above and beyond routine.

Presented by: Gandhi. V; Paul-Lockitt.L; Kaptonoglu.L; Archer.S; Stevens.L

Background:

Historically, Luton has a higher than national average for paediatric emergency admissions with seizures. To address this high incidence of seizure related emergency attendances we arranged rescue medication workshops for groups of parents and carers to enhance their understanding and enable them to receive clarification on concepts on prolonged seizure management, and also for them to network with other parents and carers.

At Luton and Dunstable hospital we see patients from several counties and have a multi-cultural, diverse ethnic population with a high prevalence of black minority ethnicity. The management of epilepsy in children and young people can vary in the community in our experience.

We have found that a significant number of our patients who are referred from outside of Luton and South Bedfordshire had no access to specialist epilepsy nursing support in the community and therefore had not received formal training in delivering rescue medication.

Aim:

As a team, we strive to improve upon the trust between our service and the patients and parents that we care for. Following the results of Round 1 of Epilepsy12, it was clear that we as a team could do more to improve on trust from families and carers.

More information on patient safety was one area in particular that was very important to us as a team and we decided that providing repeated refresher training on rescue medication would be an area that would support parents and carers.

What we did:

Over the last three and half years, we have been providing the parents and carers of children and young people under the care of the Luton and Dunstable Hospital who are prescribed rescue medication for prolonged seizures hospital with the opportunity to revise their skills in administering rescue medication and basic life support at dedicated workshops. This also allows parents and carers to have an opportunity to meet other families of children with seizures, outside of the outpatient clinical setting.

The service has been well received with approximately 20-30 adults and one young person in attendance at each workshop session. The sessions have been delivered over a two-hour period during evenings and at weekends and have been supported by healthcare assistants, student nurses and doctors, an advanced nurse practitioner, senior nursing staff, a paediatric epilepsy specialist nurse and a consultant paediatrician with a special interest in epilepsy.

The workshop feedback that has been received from families has demonstrated that parents and carers believe that we care for our epilepsy patients.

During the workshop, family members are offered childcare facilities for their children via our dedicated playroom staff. We found that our children's outpatients department was the perfect environment for running the workshop out of hours as it is a familiar environment and has separate rooms with soundproofing. Groups are split up into a maximum size of six adults per group and each workshop lasts 30 minutes in duration.

Each workshop is led by one or two nursing staff and at least one doctor and involves showing a video of how to administer rescue medication, and another demonstrating how to deliver basic life support to young adults, children and infants. Attendees are given the opportunity to practice/refresh their skills in a safe, friendly and non-judgemental environment. Each attendee is provided with a certificate of attendance and feedback is collated via a qualitative survey which is reviewed by the team. Reviewing the feedback received via the surveys helps to identify areas for improvement and form the structure of future workshops.

We present our unit's experience with workshop attendees through a feedback qualitative survey.

What we achieved

We have found that the presence of consultant paediatricians with special interest in epilepsy is vital to the success of these events as parents and carers will often want to ask specific questions relating to their child's seizures during the workshop and these can therefore, be addressed at the time rather than rescheduling follow-up appointments.

Recommendations for fellow peers

We care for over 350 children with epilepsy or prolonged seizures at Luton and Dunstable hospital and we would recommend the idea of delivering rescue medication and basic life support workshops as a powerful means of helping to provide support for parents and carers of children with prolonged seizures. In the future we hope to provide a full epilepsy fun day with several educational workshop elements to support children of all ages and their families.

Training packs are made up in advance and leaflets provided to families on the day are printed in the department and provided by the medication manufacturers. Playroom staff, trainers, and refreshments are provided as part of the workshop by our paediatric department. Carer parking charges are also covered by the department. Paediatric team members give up their own personal time in order to support the workshops.

We have found that the presence of consultant paediatricians with special interest in epilepsy is vital as carers will often want to ask specific questions relating to their child's seizures during the workshop and these can therefore be addressed at the time, rather than rescheduling follow-up appointments.

Acknowledgements

Paediatric Nursing Team, Luton and Dunstable NHS University Hospital.

Dr T Rao, Dr A Joshi, Paediatric Epilepsy Team, Luton and Dunstable NHS University Hospital.

Mrs Mary Hunt, Cambridge Community Specialist Nursing Team, Luton.

Mrs Tanith Ellis, General Manager Women and Childrens Services, Luton and Dunstable NHS University Hospital.

Paediatric Outpatient Clinic Staff, Luton and Dunstable NHS University Hospital.

Paediatric Playroom Staff, Luton and Dunstable NHS University Hospital.

Matron Marva Desir, Paediatric Matron, Luton and Dunstable NHS University Hospital.

Mrs Liz Stevens, Paediatric Epilepsy Specialist Nurse, Cambridgeshire Community Nursing Team. Luton CCG.

Mrs Carol Lander Paediatric Secretary and Workshop administrator. Luton and Dunstable NHS University Hospital

Luton and Dunstable University Hospital, Workshop flyer

5. Epilepsy12 Children and Young People's Engagement Plan

Children, young people and family engagement in Epilepsy12

The Royal College of Paediatrics and Child Health is committed to the safe, meaningful and ethical participation of children and young people. The Children and Young People's Engagement Team at the RCPCH works to ensure that their voice is making a difference in child health and healthcare for young patients.

Children, young people and families are recognised as key stakeholders by developing and improving epilepsy care across the country. Their involvement will be essential for the long term impact of the Epilepsy12 programme, by developing and supporting quality improvement outcomes that make a real difference to those living with epilepsy.

The engagement activities over the 3 years will concentrate on the involvement of children, young people and families in the audit design, quality improvement projects, social media campaigns, production of an annual children and young people led voice report and interactive sessions at the Epilepsy12/OPEN UK National Conferences in 2018 and 2019.

My wish for Epilepsy12 going forward is for practitioners to engage further with young people about their treatment, especially as patients start to grow up and come up to that transition period. This would make them more confident when speaking to practitioners and reduce the stresses relating to the transition to adult services. I believe the more patients know and understand, the more in control they feel, thus they become less worried and anxious about the changes ahead. By eliminating the unknown, you can remove anxieties and provide patients with hope and positivity about their future.

Rachael, RCPCH &Us member and Epilepsy12 youth advocate ”

I have read [from the clinic chat reports] examples of epilepsy specialist nurses being there for home visits when parents have needed to speak to them after a child has suffered, and this is always encouraging to see. I would strongly recommend children, young people, siblings, families, clinicians, specialist nurses and other paediatricians as well as other engagement groups should all come together and be made aware of what has been said. This way we can put forward an agenda and help shape the future of Epilepsy12 and other audits promoting children and young people, their rights and their wellness.

Owen, RCPCH &Us member and Epilepsy12 youth advocate

Engagement work

Between April and June 2018, over 130 children, young people and families took part in clinic chats run by the RCPCH Children and Young People's Engagement Team to collect views on 'service contactability' (identified as a result of the review of the last 2 audit cycles) and family mental health(an emerging area for consultation).

10 hospitals were visited as part of the clinic chats initiative. Two charity family days were also held in partnership with Epilepsy Action, with children as young as 3 contributing and the views of 75 parent/carers also captured. A near verbatim internal report of views shared was captured at each clinical chat setting. These reports were reviewed by a small group of Epilepsy12 youth advocates aged 15 - 20, who conducted a thematic analysis of them to identify themes. The themes identified to date were:

"**10** hospitals visited and **2** charity family days attended, with children as young as **3** contributing, and views captured from **75** parents/carers"

E12 youth advocates top priorities:

- **Schools** (support, good care plans, awareness, training, visits from nurses)
- **Support for worries and anxieties** (why me? transition, mental health, school support, messages of hope and coping strategies)
- **Face to face support** (value of group work / support groups, engagement sessions, parent/carer groups, young people groups, more time with health workers to have time to question)

Other regularly occurring themes:

- **Positive adult relationships** (school, with clinicians, specialist nurses, family, support workers)
- **More services** (mental health and wellbeing, weekends/evening non-emergency support, home visits, support groups)
- **Practical help** (lifestyle tips, family based training, coping mechanisms, products to use to explain it to children or others)
- **Emerging topics** (employment, sleep, independence)

Two of the Epilepsy12 youth advocates then created a 75-minute session on these themes and presented their findings at the Epilepsy12/OPEN UK Conference to 160 paediatric epilepsy specialists on 22 June 2018.

Of particular interest were responses from sibling carers aged 3 - 11, who created Epilepsy Superheroes that were on hand with super powers if someone had a seizure.

Super powers included having air coming out of hands (to support CPR), having rocket boots to be able to get the tablets in quick (rescue medication), knowing a language which can be "spoken" after a seizure by blinking, carrying pom poms to go next to the head (after seizure) and to be able to tell people to stand back or to tell the family what had happened.

Across the clinic chats, children, young people and families shared examples of great practice and identified gaps for improvement in the future. When asked about how, who and when families wanted contact with their specialist epilepsy services, there was a range of suggestions and comments.

Whilst online options were mentioned "*websites with forums or regular questions to look at would be good*" (children and young people) and "*we joined Facebook groups which help as social media is easier for contact but if you go online it gives you the worst case scenario*" (parent/carers), face to face contact was still the preferred approach.

There was also a recognition that a single approach doesn't work for everyone, all of the time, given that "*contact changes as time goes on. From the shock and isolation at the start, through to managing and needing help with things that are unusual, like knowing when to give the emergency meds*" (parent/carer).

Young people were also keen for professionals to remember that they needed to talk without their parents there, so that they could share their worries without thinking they are worrying their parents.

There was a lot of use of smartphones for photos/filming to update the child or young person on what happened or to show to GPs / epilepsy teams as well as one clinic using FaceTime for catch ups with young people meeting the face to face need, but using a method which sat within the comfort zone of patients.

Across the clinic chats, the role of the epilepsy specialist nurse was incredibly valued where they were in place, and missed where the role didn't exist locally. It added an extra level of reassurance for families and children and young people grew up with their nurses knowing about their lives. The training that they offered to extended families or schools was also invaluable. Where there was not a specialist nurse available, some families felt that they stored questions for their clinic appointments or that there was a lack of family/ school based training sessions available.

My epilepsy specialist nurse was fabulous throughout my care, putting on social events for patients and families. Sadly, it's not the same for everyone and now being in adult care, it's a completely scary journey.

RCPCH &Us Member

Mental health was a theme that was discussed across the sessions, with young patients and families noting the challenges of accessing services, the need for early intervention rather than waiting for a mental health crisis, and the need to further explore the link between changes in treatment plans with changes in mental health and behaviour.

Mental Health is equally as important as physical health. It is fundamental to epilepsy treatment. In the UK 1/5 people suffer from depression. For people living with epilepsy, this is 1/3.

RCPCH &Us Member

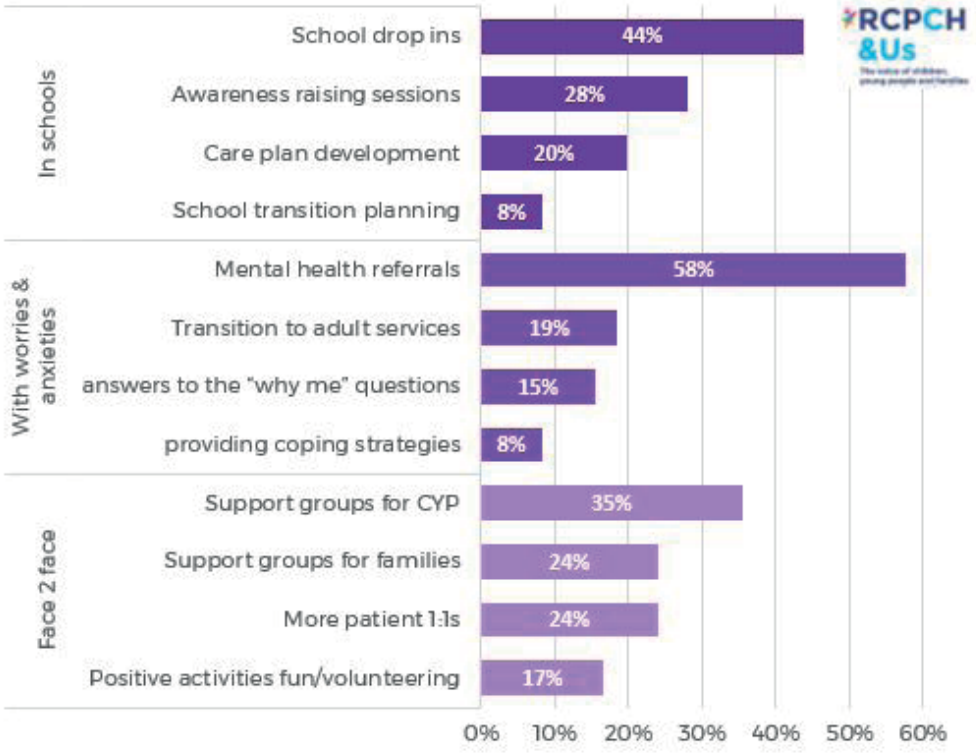
I believe referrals to mental health services during a new diagnosis would be very beneficial, as it would help patients identify and then deal with the many mental health issues as they arise, rather than waiting for them to become progressively and sometimes significantly worse, leaving patients desperate for the help as their condition continues. An added benefit could be that they spend less time in this service as both the patients and their families are supported from the start and have learnt to manage and live with the condition sooner. In addition, providing practical help such as information leaflets or websites giving support and advice on issues like exam stress or learning to drive would be beneficial.

Rachael, RCPCH &Us member and Epilepsy12 youth advocate

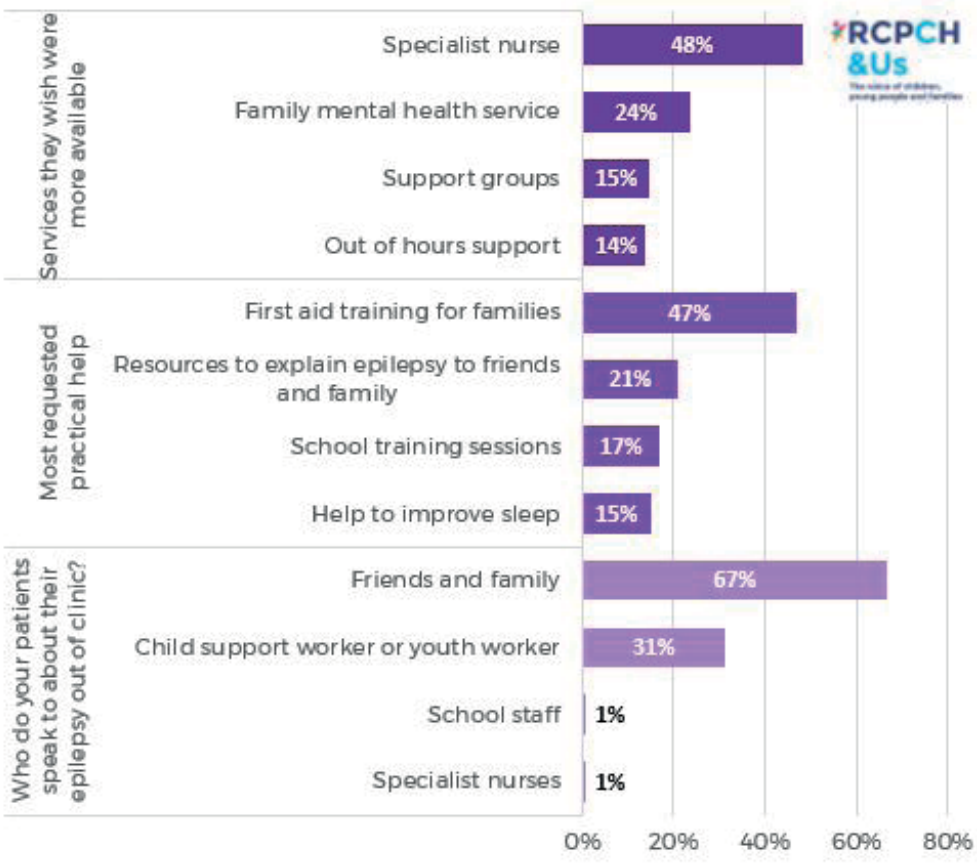
As part of the Epilepsy12/OPEN UK National Conference in June 2018, the Epilepsy12 Youth Advocates also explored the same themes of practical help, someone to talk to, local services, school support, face to face support, worries and anxieties to test out their thinking on solutions identified through the clinic chats.

The Epilepsy12 Youth Advocates used an online voting app – not everyone in the room took part, but the results are clear in that conference attendees identified the need for improvements in the same areas as those identified through the clinic chats. Results are shown on page 30.

We asked over 90 delegates what more they wish they could do to support CYP with epilepsy...



We asked 100 delegates what they thought about these topics...



Having been exposed to the views of the young people and their families in the clinic chats that occurred, it is clear that having systems in place to support them during the appointments, as well as forms of 24 hour care that families know are there, mean that there is a sense of reassurance for all involved with the condition.

Owen, RCPCH &Us member and Epilepsy12 youth advocate

Future engagement plans

The next phase of the engagement work (September 2018 to August 2019) will focus on developing the Epilepsy12 Youth Advocates to work within a small number of participating Epilepsy12 units. They will review audit data from a children and young people's perspective, receive training in children and young people's involvement in service design and identify their own quality improvement projects. An update on these activities will be shared at the 2019 Epilepsy12/OPEN UK National Conference.

My wish is that more can be focused on the children and young people – there are still countless families asking for more support and more research to be done in areas such as schooling, but it is more important that the patient gets their views heard. With Epilepsy12 now launched, I firmly believe that it can promote aspects such as confidence for the young people in question, and this can and will give more people independence as they try to overcome their condition.

Owen, RCPCH &Us member and Epilepsy12 youth advocate

After reviewing the information collected during clinic chats, mental health was identified as a prominent issue among patients. Patients believed that the side effects of their medication were not only making their mental health deteriorate, but was often the actual cause of that deterioration. Whilst there were fewer comments about depression, there was a notable increase in anxiety relating to growing up, particularly over key milestones like transitioning to adult services or going off to university and living independently. We also found that mental health issues were affecting close family members such as parents and siblings.

Rachael, RCPCH &Us member and Epilepsy12 youth advocate

For more information

Please contact the RCPCH Children and Young People's Engagement Team:

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6. Methods

6.1 Methodology & dataset development

The Epilepsy12 Methodology and Dataset Group was established in April 2017 and tasked with the development of the methodology and related datasets for both the clinical and organisational audit phases of Round 3 of Epilepsy12. The development of the methodology and datasets was broken down into separate work streams which covered different aspects of paediatric epilepsy care.

Audit measures were subsequently developed which aligned to:

- Epilepsies: diagnosis and management (2012) NICE guideline CG137
  and
- Epilepsy in children and young people (2013): NICE Quality Standard 27

Members of the Epilepsy12 project board reviewed and signed off the Epilepsy12 Round 3 methodology and datasets in September 2017.

6.2 Data entry

The Epilepsy12 Round 3 data platform was configured to allow the registered Health Board and Trust Epilepsy12 Designated Leads to complete the sections of the organisational audit and describe elements of their paediatric epilepsy service as at April 2018. Designated Leads were able to edit and update their data entry up until a defined deadline, by which time they had to formally submit and lock their data in order for it to be included in the final data download for analysis by the Epilepsy12 project team.

6.3 Data analysis and identification of key findings and recommendations

The Epilepsy12 project team downloaded all submitted and locked organisational audit data from participating Health Boards and Trusts at the end of June 2018. Members of the Epilepsy12 Project Board and Methodology and Dataset Group then met to review the analysis of submitted data and agree key findings and recommendations for the report.

7. Participation

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

Of the 163, one Health Board in Wales did not register and five acute Trusts in England were no longer eligible due to mergers, leaving 157 Health Boards and Trusts.

Nine of the remaining 157 were community Trusts which were excluded as non-eligible because they either had no paediatric services, or they defined their paediatric service as not assessing or managing children with seizures or epilepsies.

This left 148 registered Health Boards and Trusts, all of whom provided a full organisational audit submission for Round 3 of Epilepsy12 (including 100% of acute Trusts in England), a high level of participation given that the audit was inactive for a period of three years.

A full list of participating Health Boards and Trusts is shown in Appendix D on page 127.

8. Full Epilepsy12 Round 3 organisational audit results

In this section, we present the full tables of results and figures, attributed to England and Wales individually and combined, and by each OPEN UK regional network, for each of the Epilepsy12 Round 3 organisational audit measures. Cells that are highlighted in grey within the tables relate to results quoted within the key findings section of this report.

For individual Health Board or Trust level results, please go to the **Epilepsy12 website**.

Regional paediatric epilepsy network names are abbreviated in the following tables of results and figures. The full names of the networks can be seen on page 22 of this report.

8.1 Workforce

The key findings and recommendations for this audit measure are found on pages 14 and 15.

Consultant paediatrician with expertise in epilepsy

There was a total of 316.4 whole time equivalent (WTE) paediatric consultants with 'expertise in epilepsy' reported to be employed across England and Wales. This represents an increase compared to rounds 1 and 2 (**Figure 1**) and is equivalent to **14.8% (316.4/2143.7)** of the total reported WTE general paediatric consultant or associate specialist, workforce. Of the 140 out of 148 Health Boards and Trusts with a consultant paediatrician with expertise in epilepsy, the number employed within each Health Board and Trust ranged from **0.1 WTE** to **14 WTE**.

In **14.9% (22/148)** of Health Boards and Trusts, there was no defined paediatric epilepsy clinical lead.

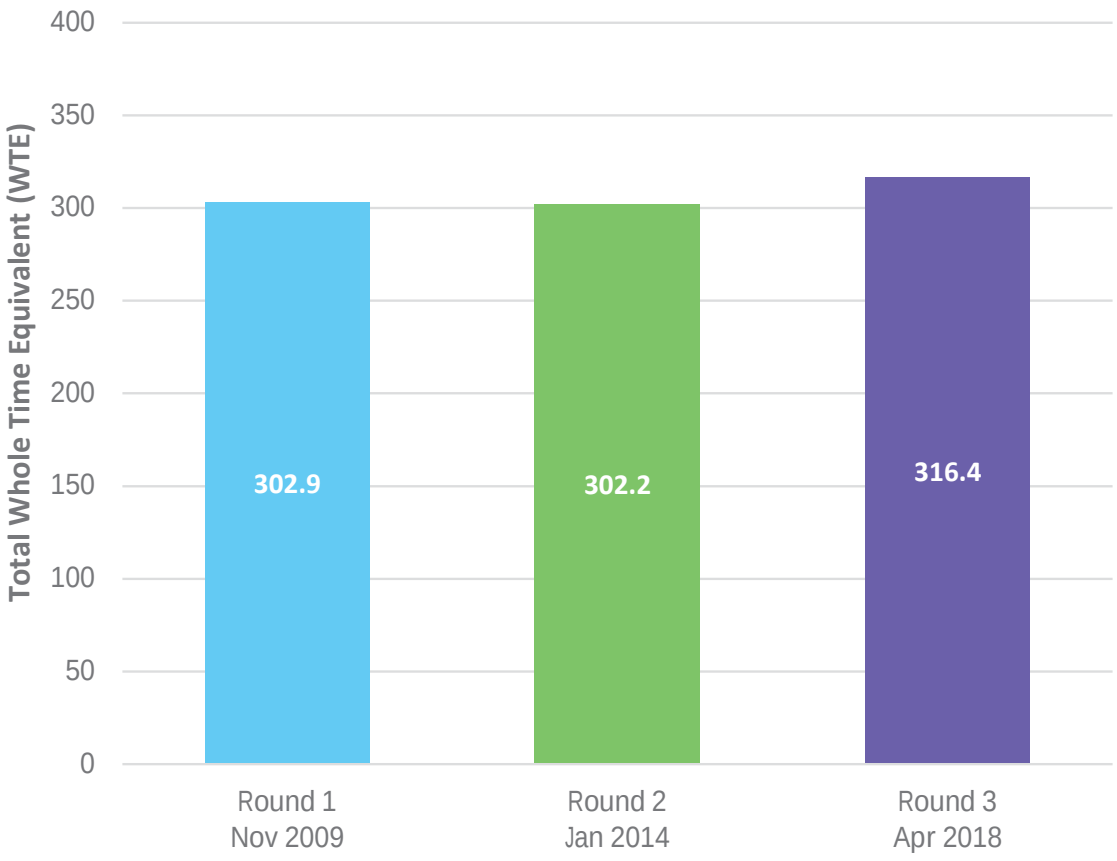


Figure 1: Total whole time equivalent paediatric consultants with 'expertise in epilepsy' employed in England and Wales in Rounds 1, 2 and 3

Table 1: Whole time equivalent (WTE) general paediatric consultants, community or hospital based, employed within Health Boards and Trusts

Country/network	Total WTE	Mean WTE
England and Wales (N = 148)	2143.7	14.5
England (N = 142)	2011.5	14.2
Wales (N = 6)	132.2	22.0
BRPNF (N = 14)	169.9	12.1
CEWT (N = 6)	110.4	18.4
EPEN (N = 15)	174.5	11.6
EPIC (N = 9)	117.6	13.1
NTPEN (N = 17)	259.3	15.3
NWEIG (N = 13)	214.0	16.5
ORENG (N = 7)	108.3	15.5
PENNEC (N = 9)	132.5	14.7
SETPEG (N = 10)	170.0	17.0
SWEP (N = 5)	98.7	19.7
SWIPE (N = 11)	142.5	13.0
SWTPEG (N = 8)	134.7	16.8
TEN (N = 6)	73.4	12.2
WPNN (N = 9)	105.5	11.7
YPEN (N = 9)	132.4	14.7

Table 2: Whole time equivalent (WTE) general paediatric consultants with 'expertise in epilepsy', excluding paediatric neurologists, employed within Health Boards and Trusts

Country/network	Total WTE	Mean WTE	Min WTE	Max WTE	% of general paediatric workforce with 'expertise in epilepsy'
England and Wales (N = 148)	316.4	2.1	0.0	14.0	14.8% (316.4/2143.7)
England (N = 142)	300.4	2.1	0.0	7.0	14.9% (300.4/2011.5)
Wales (N = 6)	16.0	2.7	0.0	14.0	12.1% (16.0/132.2)
BRPNF (N = 14)	25.6	1.8	0.0	4.5	15.1% (25.6/169.9)
CEWT (N = 6)	16.0	2.7	0.0	7.0	14.5% (16.0/110.4)
EPEN (N = 15)	24.3	1.6	0.6	4.0	13.9% (24.3/174.5)
EPIC (N = 9)	23.5	2.6	1.0	7.0	19.9% (23.5/117.6)
NTPEN (N = 17)	36.2	2.1	0.0	9.2	14.0% (36.2/259.3)
NWEIG (N = 13)	22.1	1.7	0.6	3.0	10.3% (22.1/214.0)
ORENG (N = 7)	22.5	3.2	1.0	14.0	20.8% (22.5/108.3)
PENNEC (N = 9)	28.0	3.1	1.0	9.0	21.1% (28.0/132.5)
SETPEG (N = 10)	22.9	2.3	1.0	3.9	13.5% (22.9/170.0)
SWEP (N = 5)	9.0	1.8	0.0	3.0	9.1% (9.0/98.7)
SWIPE (N = 11)	18.2	1.7	0.8	4.0	12.7% (18.2/142.5)
SWTPEG (N = 8)	14.3	1.8	0.0	4.7	10.6% (14.3/134.7)
TEN (N = 6)	12.8	2.1	1.0	3.0	17.4% (12.8/73.4)
WPNN (N = 9)	15.0	1.7	0.0	3.8	14.2% (15.0/105.5)
YPEN (N = 9)	26.1	2.9	1.0	12.0	19.7% (26.1/132.4)

Table 3: Health Boards and Trusts that employed at least some level of whole time equivalent (WTE) consultant paediatricians with 'expertise in epilepsy'

Country/network	% with some WTE	% with no WTE	WTE range in T/HBs with some WTE
England and Wales (N = 148)	94.6% (140/148)	5.4% (8/148)	0.1 - 14.0
England (N = 142)	95.1% (135/142)	4.9% (7/142)	2.0 - 7.0
Wales (N = 6)	83.3% (5/6)	16.7% (1/6)	0.1 - 14.0
BRPNF (N = 14)	92.9% (13/14)	7.1% (1/14)	0.7 - 4.5
CEWT (N = 6)	66.7% (4/6)	33.3% (2/6)	2.0 - 7.0
EPEN (N = 15)	100.0% (15/15)	0.0% (0/15)	0.6 - 4.0
EPIC (N = 9)	100.0% (9/9)	0.0% (0/9)	1.0 - 7.0
NTPEN (N = 17)	88.2% (15/17)	11.8% (2/17)	0.1 - 9.2
NWEIG (N = 13)	100.0% (13/13)	0.0% (0/13)	0.6 - 3.0
ORENG (N = 7)	100.0% (7/7)	0.0% (0/7)	1.0 - 14.0
PENNEC (N = 9)	100.0% (9/9)	0.0% (0/9)	1.0 - 9.0
SETPEG (N = 10)	100.0% (10/10)	0.0% (0/10)	1.0 - 3.9
SWEP (N = 5)	80.0% (4/5)	20.0% (1/5)	2.0 - 3.0
SWIPE (N = 11)	100.0% (11/11)	0.0% (0/11)	0.8 - 4.0
SWTPEG (N = 8)	87.5% (7/8)	12.5% (1/8)	1.0 - 4.7
TEN (N = 6)	100.0% (6/6)	0.0% (0/6)	1.0 - 3.0
WPNN (N = 9)	88.9% (8/9)	11.1% (1/9)	1.0 - 3.8
YPEN (N = 9)	100.0% (9/9)	0.0% (0/9)	1.0 - 12.0

Table 4: Health Boards and Trusts with a defined paediatric epilepsy clinical lead

Country/network	% with a defined lead	% without a defined lead
England and Wales (N = 148)	85.1% (126/148)	14.9% (22/148)
England (N = 142)	86.6% (123/142)	13.4% (19/142)
Wales (N = 6)	50.0% (3/6	50.0% (3/6)
BRPNF (N = 14)	85.7% (12/14)	14.3% (2/14)
CEWT (N = 6)	83.3% (5/6)	16.7% (1/6)
EPEN (N = 15)	86.7% (13/15)	13.3% (2/15)
EPIC (N = 9)	88.9% (8/9)	11.1% (1/9)
NTPEN (N = 17)	82.4% (14/17)	17.7% (3/17)
NWEIG (N = 13)	100.0% (13/13)	0.0% (0/13)
ORENG (N = 7)	100.0% (7/7)	0.0% (0/7)
PENNEC (N = 9)	88.9% (8/9)	11.1% (1/9)
SETPEG (N = 10)	60.0% (6/10)	40.0% (4/10)
SWEP (N = 5)	60.0% (3/5)	40.0% (2/5)
SWIPE (N = 11)	90.9% (10/11)	9.1% (1/11)
SWTPEG (N = 8)	75.0% (6/8)	25.0% (2/8)
TEN (N = 6)	100.0% (6/6)	0.0% (0/6)
WPNN (N = 9)	77.8% (7/9)	22.2% (2/9)
YPEN (N = 9)	88.9% (8/9)	11.1% (1/9

Epilepsy specialist nurse

There was a total of **147.3 WTE** epilepsy specialist nurses (ESN) reported to be employed across England and Wales. This represents an increase compared to Rounds 1 and 2 (**Figure 2**). Of the 115 out of 148 (**77.7%**) Health Boards and Trusts with some epilepsy specialist nurses (ESN) provision (i.e. greater than 0 WTE), the number employed within each Health Board and Trust ranged from **0.2 WTE** to **4.8 WTE**.

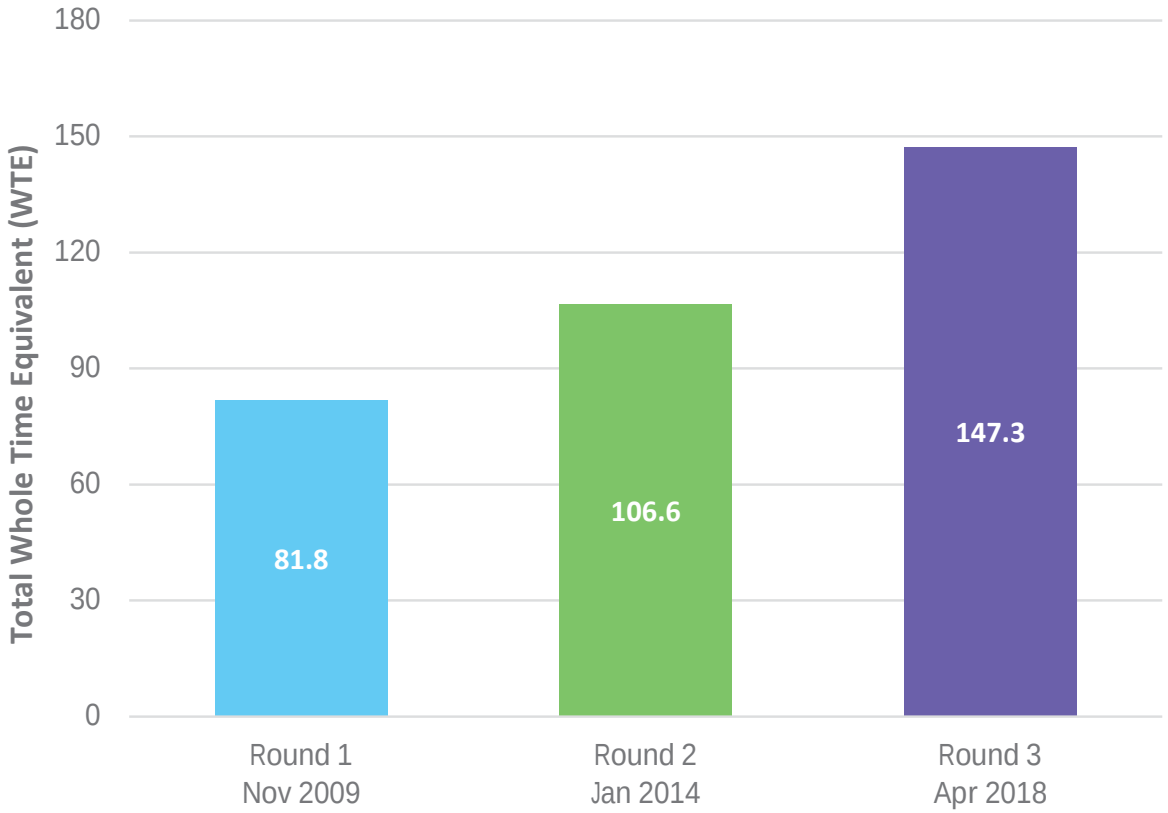


Figure 2: Total whole time equivalent epilepsy specialist nurses employed in England and Wales in Rounds 1, 2 and 3

Functions supported by epilepsy specialist nurses

Figure 3 shows, the percentage of Health Boards and Trusts that could support key ESN functions. More than **70%** of Health Boards/Trusts indicated that they could offer ESN support for; rescue medication training for parents (111/148), school meetings (106/148) and individual healthcare plan facilitation (105/148). In addition, **51.4% (76/148)** were able to support nurse led clinics and **31.8% (47/148)** were able to support nurse prescribing, while **37.2% (55/148)** were unable to support home visits. Health Boards and Trusts that reported they could support all nine functions was **14.2% (21/148)**. It is worth noting that services were asked whether it was possible and not whether it was achieved for all children where necessary.

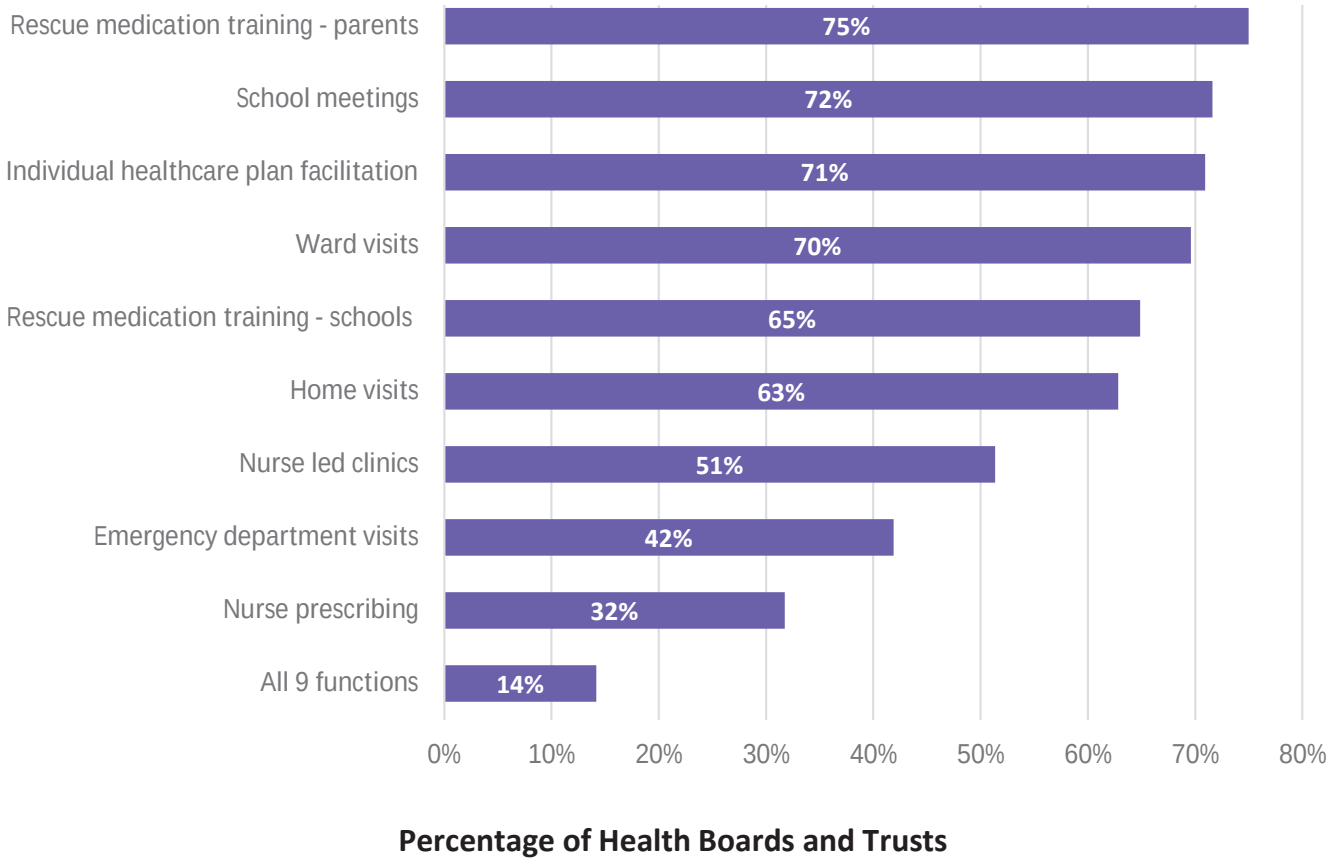


Figure 3: Percentage of Health Boards and Trusts that could support epilepsy specialist nurse functions

Table 5: Whole time equivalent (WTE) epilepsy specialist nurses employed within Health Boards and Trusts

Country/network	Total WTE	Mean WTE	Min WTE	Max WTE
England and Wales (N = 148)	147.3	1.0	0.0	4.8
England (N = 142)	137.1	1.0	0.0	4.8
Wales (N = 6)	10.2	1.7	0.0	3.0
BRPNF (N = 14)	7.9	0.6	0.0	2.0
CEWT (N = 6)	6.0	1.0	0.0	2.0
EPEN (N = 15)	13.9	0.9	0.0	2.0
EPIC (N = 9)	11.0	1.2	0.3	3.6
NTPEN (N = 17)	16.0	0.9	0.0	4.0
NWEIG (N = 13)	17.0	1.3	0.0	4.0
ORENG (N = 7)	4.2	0.6	0.0	1.0
PENNEC (N = 9)	7.5	0.8	0.0	2.0
SETPEG (N = 10)	9.8	1.0	0.0	2.5
SWEP (N = 5)	7.8	1.6	0.0	3.0
SWIPE (N = 11)	8.0	0.7	0.0	2.0
SWTPEG (N = 8)	7.2	0.9	0.0	1.6
TEN (N = 6)	11.0	1.8	0.0	4.0
WPNN (N = 9)	6.7	0.7	0.0	2.0
YPEN (N = 9)	13.2	1.5	0.0	4.8

Table 6: Health Boards and Trusts that employed at least some level of whole time equivalent (WTE epilepsy specialist nurse

Country/network	% with some WTE	% with no WTE	WTE range in T/HBs with some WTE
England and Wales (N = 148)	77.7% (115/148)	22.3% (33/148)	0.2 - 4.8
England (N = 142)	77.5% (110/142)	22.5% (32/142)	0.2 - 4.8
Wales (N = 6)	83.3% (5/6)	16.7% (1/6)	1.0 - 3.0
BRPNF (N = 14)	57.1% (8/14)	42.9% (6/14)	0.5 - 2.0
CEWT (N = 6)	83.3% (5/6)	16.7% (1/6)	0.6 - 2.0
EPEN (N = 15)	80.0% (12/15)	20.0% (3/15)	0.2 - 2.0
EPIC (N = 9)	100.0% (9/9)	0.0% (0/9)	0.3 - 3.6
NTPEN (N = 17)	76.5% (13/17)	23.5% (4/17)	0.4 - 4.0
NWEIG (N = 13)	92.3% (12/13)	7.7% (1/13)	0.6 - 4.0
ORENG (N = 7)	71.4% (5/7)	28.6% (2/7)	0.6 - 1.0
PENNEC (N = 9)	55.6% (5/9)	44.4% (4/9)	1.0 - 2.0
SETPEG (N = 10)	80.0% (8/10)	20.0% (2/10)	0.3 - 2.5
SWEP (N = 5)	80.0% (4/5)	20.0% (1/5)	1.0 - 3.0
SWIPE (N = 11)	63.6% (7/11)	36.4% (4/11)	0.3 - 2.0
SWTPEG (N = 8)	87.5% (7/8)	12.5% (1/8)	0.4 - 1.6
TEN (N = 6)	83.3% (5/6)	16.7% (1/6)	1.5 - 4.0
WPNN (N = 9)	77.8% (7/9)	22.2% (2/9)	0.2 - 2.0
YPEN (N = 9)	88.9% (8/9)	11.1% (1/9)	0.5 - 4.8

Table 7: 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
England and Wales (N = 148)	62.8% (93/148)	51.4% (76/148)	41.9% (62/148)	69.6% (103/148)	31.8% (47/148)	71.6% (106/148)
England (N = 142)	62.7% (89/142)	51.4% (73/142)	43.0% (61/142)	69.7% (99/142)	31.0% (44/142)	71.1% (101/142)
Wales (N = 6)	66.7% (4/6)	50.0% (3/6)	16.7% (1/6)	66.7% (4/6)	50.0% (3/6)	83.3% (5/6)
BRPNF (N = 14)	35.7% (5/14)	35.7% (5/14)	35.7% (5/14)	57.1% (8/14)	28.6% (4/14)	50.0% (7/14)
CEWT (N = 6)	33.3% (2/6)	83.3% (5/6)	66.7% (4/6)	66.7% (4/6)	33.3% (2/6)	66.7% (4/6)
EPEN (N = 15)	46.7% (7/15)	53.3% (8/15)	53.3% (8/15)	66.7% (10/15)	26.7% (4/15)	73.3% (11/15)
EPIC (N = 9)	100.0% (9/9)	33.3% (3/9)	44.4% (4/9)	100.0% (9/9)	66.7% (6/9)	100.0% (9/9)
NTPEN (N = 17)	58.8% (10/17)	47.1% (8/17)	41.2% (7/17)	76.5% (13/17)	23.5% (4/17)	64.7% (11/17)
NWEIG (N = 13)	92.3% (12/13)	61.5% (8/13)	23.1% (3/13)	84.6% (11/13)	38.5% (5/13)	92.3% (12/13)
ORENG (N = 7)	71.4% (5/7)	42.9% (3/7)	57.1% (4/7)	71.4% (5/7)	14.3% (1/7)	71.4% (5/7)
PENNEC (N = 9)	55.6% (5/9)	55.6% (5/9)	44.4% (4/9)	55.6% (5/9)	33.3% (3/9)	55.6% (5/9)
SETPEG (N = 10)	80.0% (8/10)	60.0% (6/10))	40.0% (4/10)	50.0% (5/10)	10.0% (1/10)	80.0% (8/10)
SWEP (N = 5)	60.0% (3/5)	40.0% (2/5)	20.0% (1/5)	60.0% (3/5)	40.0% (2/5)	80.0% (4/5)
SWIPE (N = 11)	45.5% (5/11)	45.5% (5/11)	45.5% (5/11)	63.6% (7/11)	36.4% (4/11)	54.5% (6/11)
SWTPEG (N = 8)	75.0% (6/8)	75.0% (6/8)	37.5% (3/8)	75.0% (6/8))	25.0% (2/8)	62.5% (5/8)
TEN (N = 6)	83.3% (5/6)	66.7% (4/6)	66.7% (4/6)	83.3% (5/6)	50.0% (3/6)	83.3% (5/6)
WPNN (N = 9)	44.4% (4/9)	33.3% (3/9)	33.3% (3/9)	66.7% (6/9)	22.2% (2/9)	66.7% (6/9)
YPEN (N = 9)	77.8% (7/9)	55.6% (5/9)	33.3% (3/9)	66.7% (6/9)	44.4% (4/9)	88.9% (8/9)

Table 7 (continued): Health Boards and Trusts that could support epilepsy nurse functions

Country/network	Individual health care plan (IHCP) facilitation	Rescue medication training parents	Rescue medication training schools	Supporting all 9 functions
England and Wales (N = 148)	70.9% (105/148)	75.0% (111/148)	64.9% (96/148)	14.2% (21/148)
England (N = 142)	70.4% (100/142)	74.6% (106/142)	64.1% (91/142)	14.1% (20/142)
Wales (N = 6)	83.3% (5/6)	83.3% (5/6)	83.3% (5/6)	16.7% (1/6)
BRPNF (N = 14)	50.0% (7/14)	57.1% (8/14)	42.9% (6/14)	14.3% (2/14)
CEWT (N = 6)	83.3% (5/6)	83.3% (5/6)	50.0% (3/6)	16.7% (1/6)
EPEN (N = 15)	73.3% (11/15)	80.0% (12/15)	53.3% (8/15)	20.0% (3/15)
EPIC (N = 9)	100.0% (9/9)	100.0% (9/9)	100.0% (9/9)	11.1% (1/9)
NTPEN (N = 17)	64.7% (11/17)	70.6% (12/17)	52.9% (9/17)	0.0% (0/17)
NWEIG (N = 13)	92.3% (12/13)	76.9% (10/13)	84.6% (11/13)	7.7% (1/13)
ORENG (N = 7)	71.4% (5/7)	71.4% (5/7)	57.1% (4/7)	0.0% (0/7)
PENNEC (N = 9)	55.6% (5/9)	55.6% (5/9)	55.6% (5/9)	22.2% (2/9)
SETPEG (N = 10)	80.0% (8/10)	80.0% (8/10)	80.0% (8/10)	10.0% (1/10)
SWEP (N = 5)	80.0% (4/5)	80.0% (4/5)	80.0% (4/5)	20.0% (1/5)
SWIPE (N = 11)	63.6% (7/11)	63.6% (7/11)	63.6% (7/11)	27.3% (3/11)
SWTPEG (N = 8)	75.0% (6/8)	87.5% (7/8)	75.0% (6/8)	25.0% (2/8)
TEN (N = 6)	66.7% (4/6)	83.3% (5/6)	83.3% (5/6)	33.3% (2/6)
WPNN (N = 9)	66.7% (6/9)	66.7% (6/9)	33.3% (3/9)	0.0% (0/9)
YPEN (N = 9)	55.6% (5/9)	88.9% (8/9)	88.9% (8/9)	22.2% (2/9)

Table 8: Health Boards and Trusts that could support epilepsy nurse functions
(For the 115 Health Boards and Trusts that have at least some epilepsy specialist nurse provision)

Country/ network	Home visits	Nurse led clinics	Emergency department visits	Ward visits	Nurse prescribing	School meetings
England and Wales (N = 115)	80.9% (93/115)	66.1% (76/115)	53.9% (62/115)	89.6% (103/115)	40.9% (47/115)	92.2% (106/115)
England (N = 110)	80.9% (89/110)	66.4% (73/110)	55.5% (61/110)	90.0% (99/110)	40.0% (44/110)	91.8% (101/110)
Wales (N = 5)	80.0% (4/5)	60.0% (3/5)	20.0% (1/5)	80.0% (4/5)	60.0% (3/5)	100.0% (5/5)
BRPNF (N = 8)	62.5% (5/8)	62.5% (5/8)	62.5% (5/8)	100.0% (8/8)	50.0% (4/8)	87.5% (7/8)
CEWT (N = 5)	40.0% (2/5)	100.0% (5/5)	80.0% (4/5)	80.0% (4/5)	40.0% (2/5)	80.0% (4/5)
EPEN (N = 12)	58.3% (7/12)	66.7% (8/12)	66.7% (8/12)	83.3% (10/12)	33.3% (4/12)	91.7% (11/12)
EPIC (N = 9)	100.0% (9/9)	33.3% (3/9)	44.4% (4/9)	100.0% (9/9)	66.7% (6/9)	100.0% (9/9)
NTPEN (N = 13)	76.9% (10/13)	61.5% (8/13)	53.8% (7/13)	100.0% (13/13)	30.8% (4/13)	84.6% (11/13)
NWEIG (N = 12)	100.0% (12/12)	66.7% (8/12)	25% (3/12)	91.7% (11/12)	41.7% (5/12)	100.0% (12/12)
ORENG (N = 5)	100.0% (5/5)	60.0% (3/5)	80.0% (4/5)	100.0% (5/5)	20.0% (1/5)	100.0% (5/5)
PENNEC (N = 5)	100.0% (5/5)	100.0% (5/5)	80.0% (4/5)	100.0% (5/5)	60.0% (3/5)	100.0% (5/5)
SETPEG (N = 8)	100.0% (8/8)	75.0% (6/8)	50.0% (4/8)	62.5% (5/8))	12.5% (1/8)	100.0% (8/8)
SWEP (N = 4)	75% (3/4)	50.0% (2/4)	25% (1/4)	75% (3/4)	50.0% (2/4)	100.0% (4/4)
SWIPE (N = 7)	71.4% (5/7)	71.4% (5/7)	71.4% (5/7)	100.0% (7/7)	57.1% (4/7)	85.7% (6/7)
SWTPEG (N = 7)	85.7% (6/7)	85.7% (6/7)	42.9% (3/7)	85.7% (6/7)	28.6% (2/7)	71.4% (5/7)
TEN (N = 5)	100.0% (5/5)	80.0% (4/5)	80.0% (4/5)	100.0% (5/5)	60.0% (3/5)	100.0% (5/5)
WPNN (N = 7)	57.1% (4/7)	42.9% (3/7)	42.9% (3/7)	85.7% (6/7)	28.6% (2/7)	85.7% (6/7)
YPEN (N = 8)	87.5% (7/8)	62.5% (5/8)	37.5% (3/8)	75% (6/8)	50.0% (4/8)	100.0% (8/8)

Table 8 (continued): Health Boards and Trusts that could support epilepsy nurse functions
(For the 115 Health Boards and Trusts that have at least some epilepsy specialist nurse provision)

Country/network	Individual health care plan (IHCP) facilitation	Rescue medication training parents	Rescue medication training schools	Supporting all 9 functions
England and Wales (N = 115)	91.3% (105/115)	96.5% (111/115)	83.5% (96/115)	18.3% (21/115)
England (N = 110)	90.9% (100/110)	96.4% (106/110)	82.7% (91/110)	18.2% (20/110)
Wales (N = 5)	100.0% (5/5)	100.0% (5/5)	100.0% (5/5)	20.0% (1/5)
BRPNF (N = 8)	87.5% (7/8)	100.0% (8/8)	75% (6/8)	25% (2/8)
CEWT (N = 5)	100.0% (5/5)	100.0% (5/5)	60.0% (3/5)	20.0% (1/5)
EPEN (N = 12)	91.7% (11/12)	100.0% (12/12)	66.7% (8/12)	25% (3/12)
EPIC (N = 9)	100.0% (9/9)	100.0% (9/9)	100.0% (9/9)	11.1% (1/9)
NTPEN (N = 13)	84.6% (11/13)	92.3% (12/13)	69.2% (9/13)	0.0% (0/13)
NWEIG (N = 12)	100.0% (12/12)	83.3% (10/12)	91.7% (11/12)	8.3% (1/12)
ORENG (N = 5)	100.0% (5/5)	100.0% (5/5)	80.0% (4/5)	0.0% (0/5)
PENNEC (N = 5)	100.0% (5/5)	100.0% (5/5)	100.0% (5/5)	40.0% (2/5)
SETPEG (N = 8)	100.0% (8/8)	100.0% (8/8)	100.0% (8/8)	12.5% (1/8)
SWEP (N = 4)	100.0% (4/4)	100.0% (4/4)	100.0% (4/4)	25% (1/4)
SWIPE (N = 7)	100.0% (7/7)	100.0% (7/7)	100.0% (7/7)	42.9% (3/7)
SWTPEG (N = 7)	85.7% (6/7)	100.0% (7/7)	85.7% (6/7)	28.6% (2/7)
TEN (N = 5)	80.0% (4/5)	100.0% (5/5)	100.0% (5/5)	40.0% (2/5)
WPNN (N = 7)	85.7% (6/7)	85.7% (6/7)	42.9% (3/7)	0.0% (0/7)
YPEN (N = 8)	62.5% (5/8)	100.0% (8/8)	100.0% (8/8)	25% (2/8)

8.2 Epilepsy clinic configuration

The key findings and recommendations for this audit measure are found on page 16.

Defined epilepsy clinic

There was a total of 242.5 consultant or associate specialist led secondary level 'epilepsy clinics' taking place each week across England and Wales. This represents an increase compared to the number reported in Rounds 1 and 2 (**Figure 4**). The mean number of consultant or associate specialist led clinics taking place per week was 1.9; this ranged from 0 to 6 per week.

There was a defined epilepsy clinic, seeing patients at secondary level, in **85.8% (127/148)** of Health Boards and Trusts. Of those, **84.3% (107/127)** 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.

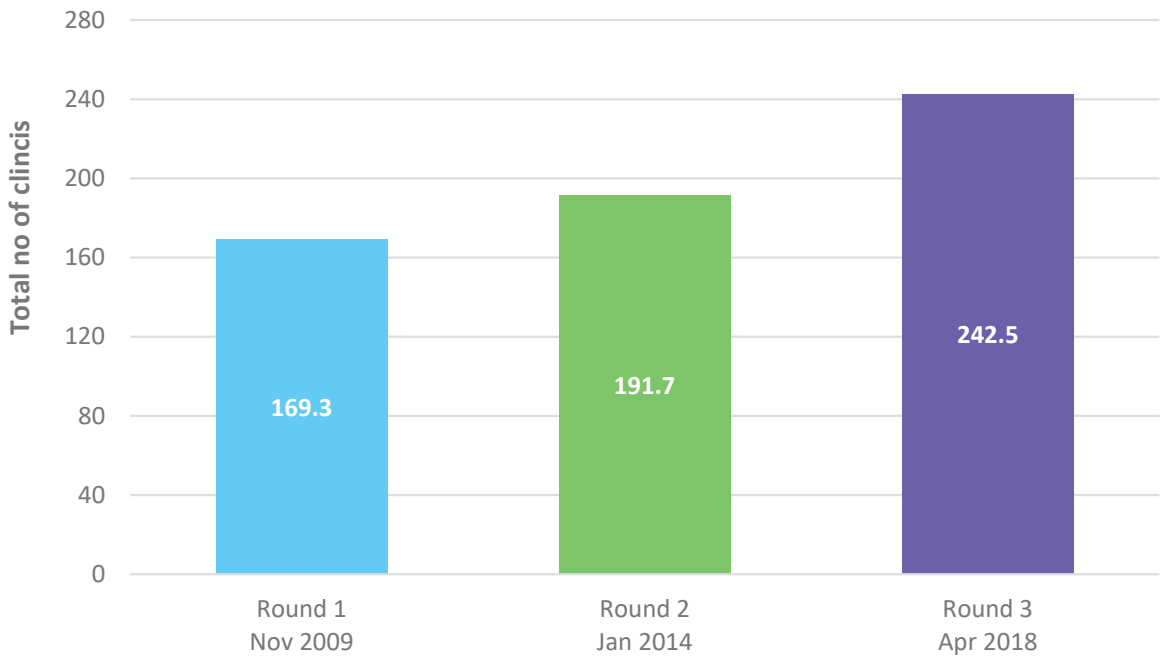


Figure 4: Total number of consultant or associate specialist led secondary level epilepsy clinics taking place each week in England and Wales, in Rounds 1, 2 and 3

Table 9: Health Boards and Trusts with a defined epilepsy clinic

Country/network	% with a defined epilepsy clinic	% without a defined epilepsy clinic
England and Wales (N = 148)	85.8% (127/148)	14.2% (21/148)
England (N = 142)	86.6% (123/142)	13.4% (19/142)
Wales (N = 6)	66.7% (4/6)	33.3% (2/6)
BRPNF (N = 14)	71.4% (10/14)	28.6% (4/14)
CEWT (N = 6)	100.0% (6/6)	0.0% (0/6)
EPEN (N = 15)	86.7% (13/15)	13.3% (2/15)
EPIC (N = 9)	100.0% (9/9)	0.0% (0/9)
NTPEN (N = 17)	76.5% (13/17)	23.5% (4/17)
NWEIG (N = 13)	100.0% (13/13)	0.0% (0/13)
ORENG (N = 7)	85.7% (6/7)	14.3% (1/7)
PENNEC (N = 9)	88.9% (8/9)	11.1% (1/9)
SETPEG (N = 10)	90.0% (9/10)	10.0% (1/10)
SWEP (N = 5)	60.0% (3/5)	40.0% (2/5)
SWIPE (N = 11)	81.8% (9/11)	18.2% (2/11)
SWTPEG (N = 8)	100.0% (8/8)	0.0% (0/8)
TEN (N = 6)	83.3% (5/6)	16.7% (1/6)
WPNN (N = 9)	88.9% (8/9)	11.1% (1/9)
YPEN (N = 9)	77.8% (7/9)	22.2% (2/9)

Table 10: Number of consultant or associate specialist led secondary level 'epilepsy clinics' taking place within Health Boards and Trusts per week

Country/network	Total no. clinics per week	Mean no. clinics per week	Min no. clinics per week	Max no. clinics per week
England and Wales (N = 127)	242.5	1.9	0.0	6.0
England (N = 123)	230.8	1.9	0.0	6.0
Wales (N = 4)	11.7	2.9	2.0	3.7
BRPNF (N = 10)	13.2	1.3	0.8	2.0
CEWT (N = 6)	11.0	1.8	1.0	4.0
EPEN (N = 13)	22.8	1.8	0.5	4.0
EPIC (N = 9)	16.3	1.8	0.3	3.7
NTPEN (N = 13)	23.6	1.8	0.5	4.0
NWEIG (N = 13)	22.5	1.7	1.0	4.0
ORENG (N = 6)	8.9	1.5	0.5	3.0
PENNEC (N = 8)	15.3	1.9	1.0	3.5
SETPEG (N = 9)	25.0	2.8	1.3	6.0
SWEP (N = 3)	8.0	2.7	2.0	3.0
SWIPE (N = 9)	14.5	1.6	0.0	4.0
SWTPEG (N = 8)	19.2	2.4	1.5	5.0
TEN (N = 5)	10.5	2.1	0.5	6.0
WPNN (N = 8)	16.0	2.0	0.5	4.0
YPEN (N = 7)	15.9	2.3	1.0	3.0

Table 11: Health Boards and Trusts that held a defined epilepsy clinics that allowed at least 20 minutes with a consultant with 'expertise in epilepsy' and/or an epilepsy specialist nurse

Country/network	% of clinics that allowed 20 minutes	% of clinics that did not allow 20 minutes
England and Wales (N = 127)	84.3% (107/127)	15.7% (20/127)
England (N = 123)	83.7% (103/123)	16.3% (20/123)
Wales (N = 4)	100.0% (4/4)	0.0% (0/4)
BRPNF (N = 10)	80.0% (8/10)	20.0% (2/10)
CEWT (N = 6)	100.0% (6/6)	0.0% (0/6)
EPEN (N = 13)	92.3% (12/13)	7.7% (1/13)
EPIC (N = 9)	100.0% (9/9)	0.0% (0/9)
NTPEN (N = 13)	61.5% (8/13)	38.5% (5/13)
NWEIG (N = 13)	100.0% (13/13)	0.0% (0/13)
ORENG (N = 6)	83.3% (5/6)	16.7% (1/6)
PENNEC (N = 8)	62.5% (5/8)	37.5% (3/8)
SETPEG (N = 9)	88.9% (8/9)	11.1% (1/9)
SWEP (N = 3)	100.0% (3/3)	0.0% (0/3)
SWIPE (N = 9)	77.8% (7/9)	22.2% (2/9)
SWTPEG (N = 8)	87.5% (7/8)	12.5% (1/8)
TEN (N = 5)	100.0% (5/5)	0.0% (0/5)
WPNN (N = 8)	75.0% (6/8)	25.0% (2/8)
YPEN (N = 7)	71.4% (5/7)	28.6% (2/7)

Epilepsy Best Practice Criteria (BPC) clinics – England only

At the time of the audit, **41.6% (59/142)** of Trusts in England were running Epilepsy Best Practice Criteria clinics. A further **27.5% (39/142**) were working towards Best Practice Criteria clinics and **23.2% (33/142)** were not running a Best Practice Criteria service. The remaining **7.8% (11/142)** of Trusts that selected 'not applicable,' presumably have a block contract type payment system in place (**Figure 5**).

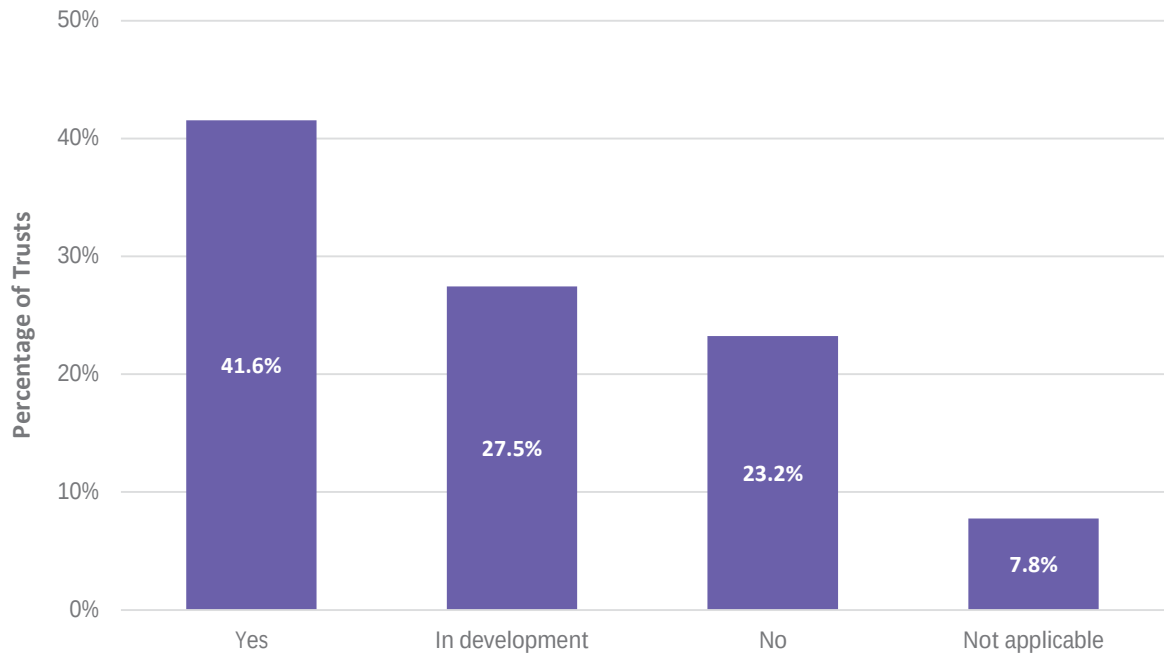


Figure 5: Percentage of Trusts receiving TFC 223 Epilepsy Best Practice Criteria (England only) (n=142)

Table 12: Trusts that were running TFC 223 Epilepsy Best Practice Criteria (BPC) clinics

Country/network	Yes	In development	No	N/A
England (N = 142)	41.6% (59/142)	27.5% (39/142)	23.2% (33/142)	7.8% (11/142)
BRPNF (N = 14)	35.7% (5/14)	35.7% (5/14)	28.6% (4/14)	0.0% (0/14)
CEWT (N = 6)	50.0% (3/6)	0.0% (0/6)	33.3% (2/6)	16.7% (1/6)
EPEN (N = 15)	40.0% (6/15)	20.0% (3/15)	20.0% (3/15)	20.0% (3/15)
EPIC* (N = 8)	62.5% (5/8)*	25.0% (2/8)	12.5% (1/8)	0.0% (0/8)
NTPEN (N = 17)	17.6% (3/17)	47.1% (8/17)	23.5% (4/17)	11.8% (2/17)
NWEIG (N = 13)	38.5% (5/13)	23.1% (3/13)	30.8% (4/13)	7.7% (1/13)
ORENG (N = 7)	28.6% (2/7)	28.6% (2/7)	42.9% (3/7)	0.0% (0/7)
PENNEC (N = 9)	44.4% (4/9)	33.3% (3/9)	22.2% (2/9)	0.0% (0/9)
SETPEG (N = 10)	40.0% (4/10)	10.0% (1/10)	40.0% (4/10)	10.0% (1/10)
SWIPE (N = 11)	54.5% (6/11)	18.2% (2/11)	27.3% (3/11)	0.0% (0/11)
SWTPEG (N =8)	50.0% (4/8)	25.0% (2/8)	25.0% (2/8)	0.0% (0/8)
TEN (N = 6)	50.0% (3/6)	33.3% (2/6)	16.7% (1/6)	0.0% (0/6)
WPNN (N = 9)	55.6% (5/9)	22.2% (2/9)	0.0% (0/9)	22.2% (2/9)
YPEN (N = 9)	44.4% (4/9)	44.4% (4/9)	0.0% (0/9)	11.1% (1/9)

* Does not include the data from Betsi Cadwaladr University UHB as it is a Welsh Health Board

8.3 Tertiary provision

The key findings and recommendations for this audit measure are found on page 17.

Paediatric neurology services

A total of **100.2 WTE** consultant paediatric neurologists responsible for managing the care of children and young people with epilepsy, both acutely and non-acutely, were employed in 26 of the 148 Health Boards and Trusts across England and Wales; this ranged from **0.02 WTE** to **10.30 WTE**.

92.6% (137/148) of Health Boards and Trusts had agreed referral pathways to tertiary paediatric neurology services leaving **7.4% (11/148)** that did not. **23.0% (34/148)** of Health Boards and Trusts indicated that paediatric neurologists could receive direct referrals from general practice or emergency services to assess children and young people with possible epilepsies.

Satellite paediatric neurology clinics were hosted in **77.0% (114/148)** of Health Boards and Trusts.

Other services

In relation to the provision of ketogenic diet services, **14.9% (22/148)** of Health Boards and Trusts reported they could facilitate commencement of the diet and **21.0% (31/148)** reported they could facilitate ongoing review of the diet. In relation to the provision of vagus nerve stimulator (VNS) services, **8.1% (12/148)** reported they could provide VNS insertion and **23.0% (34/148)** reported that they could facilitate VNS review **(Figure 6)**.

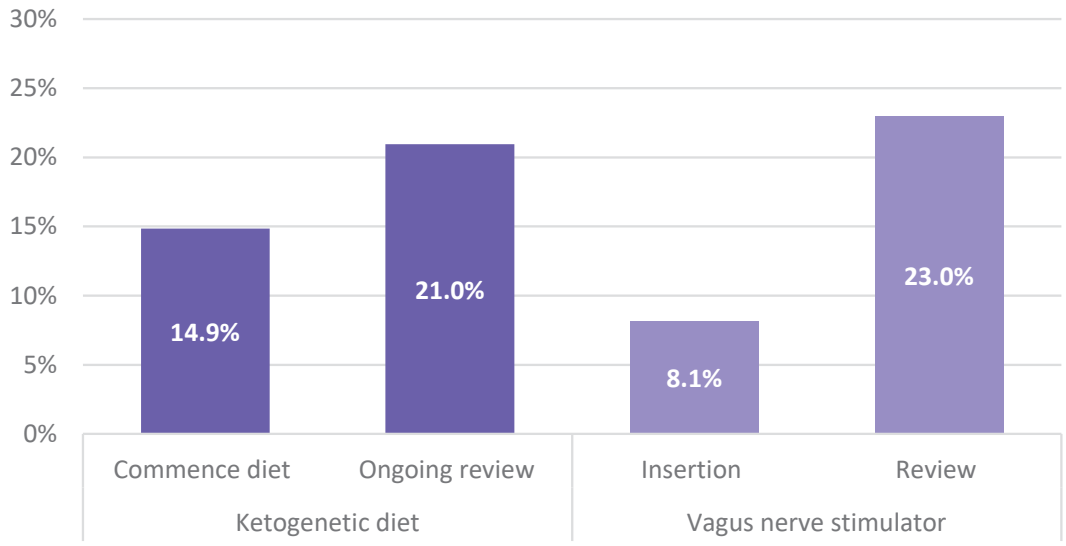


Figure 6: Percentage of Health Boards and Trusts that could provide ketogenetic diet and vagus nerve stimulator services (n=148)

Table 13: Whole time equivalent (WTE) paediatric neurologists, acutely and/or non-acutely, employed within Health Boards and Trusts

Country/network	Total WTE	Min WTE	Max WTE
England and Wales (N = 148)	100.2	0.0	10.3
England (N = 142)	96.4	0.0	10.3
Wales (N = 6)	3.8	0.0	2.8
BRPNF (N = 14)	5.0	0.0	5.0
CEWT (N = 6)	6.0	0.0	3.0
EPEN (N = 15)	5.0	0.0	4.0
EPIC (N = 9)	6.0	0.0	6.0
NTPEN (N = 17)	15.3	0.0	10.3
NWEIG (N = 13)	9.2	0.0	7.2
ORENG (N = 7)	5.7	0.0	5.7
PENNEC (N = 9)	5.7	0.0	4.7
SETPEG (N = 10)	3.6	0.0	2.6
SWEP (N = 5)	3.8	0.0	2.8
SWIPE (N = 11)	9.0	0.0	7.0
SWTPEG (N = 8)	3.0	0.0	3.0
TEN (N = 6)	10.0	0.0	5.0
WPNN (N = 9)	6.5	0.0	6.5
YPEN (N = 9)	6.4	0.0	6.4

Table 14: Health Boards and Trusts that employed at least some level of whole time equivalent (WTE) paediatric neurologists, acutely and/or non-acutely

Country/network	% with some WTE	% with no WTE	WTE range in T/HBs with some WTE
England and Wales (N = 148)	17.6% (26/148)	82.4% (122/148)	0.02 - 10.30
England (N = 142)	16.9% (24/142)	83.1% (118/142)	0.02 - 10.30
Wales (N = 6)	33.3% (2/6)	66.7% (4/6)	1.0 - 2.8
BRPNF (N = 14)	14.3% (2/14)	85.7% (12/14)	0.02 - 5.00
CEWT (N = 6)	33.3% (2/6)	66.7% (4/6)	3.0 - 3.0
EPEN (N = 15)	13.3% (2/15)	86.7% (13/15)	1.0 - 4.0
EPIC (N = 9)	11.1% (1/9)	88.9% (8/9)	6.0 - 6.0
NTPEN (N = 17)	17.6% (3/17)	82.4% (14/17)	2.0 - 10.3
NWEIG (N = 13)	15.4% (2/13)	84.6% (11/13)	2.0 - 7.2
ORENG (N = 7)	14.3% (1/7)	85.7% (6/7)	5.7 - 5.7
PENNEC (N = 9)	22.2% (2/9)	77.8% (7/9)	1.0 - 4.7
SETPEG (N = 10)	20.0% (2/10)	80.0% (8/10)	1.0 - 2.6
SWEP (N = 5)	40.0% (2/5)	60.0% (3/5)	1.0 - 2.8
SWIPE (N = 11)	18.2% (2/11)	81.8% (9/11)	2.0 - 7.0
SWTPEG (N = 8)	12.5% (1/8)	87.5% (7/8)	3.0 - 3.0
TEN (N = 6)	33.3% (2/6)	66.7% (4/6)	5.0 - 5.0
WPNN (N = 9)	11.1% (1/9)	88.9% (8/9)	6.5 - 6.5
YPEN (N = 9)	11.1% (1/9)	88.9% (8/9)	6.4 - 6.4

Table 15: Health Boards and Trusts with agreed referral pathways to tertiary paediatric neurology services

Country/network	Yes	No
England and Wales (N = 148)	92.6% (137/148)	7.4% (11/148)
England (N = 142)	93.0% (132/142)	7.0% (10/142)
Wales (N = 6)	83.3% (5/6)	16.7% (1/6)
BRPNF (N = 14)	85.7% (12/14)	14.3% (2/14)
CEWT (N = 6)	83.3% (5/6)	16.7% (1/6)
EPEN (N = 15)	100.0% (15/15)	0.0% (0/15)
EPIC (N = 9)	100.0% (9/9)	0.0% (0/9)
NTPEN (N = 17)	100.0% (17/17)	0.0% (0/17)
NWEIG (N = 13)	84.6% (11/13)	15.4% (2/13)
ORENG (N = 7)	85.7% (6/7)	14.3% (1/7)
PENNEC (N = 9)	77.8% (7/9)	22.2% (2/9)
SETPEG (N = 10)	100.0% (10/10)	0.0% (0/10)
SWEP (N = 5)	80.0% (4/5)	20.0% (1/5)
SWIPE (N = 11)	90.9% (10/11)	9.1% (1/11)
SWTPEG (N = 8)	100.0% (8/8)	0.0% (0/8)
TEN (N = 6)	100.0% (6/6)	0.0% (0/6)
WPNN (N = 9)	100.0% (9/9)	0.0% (0/9)
YPEN (N = 9)	88.9% (8/9)	11.1% (1/9)

Table 16a: Health Boards and Trusts where paediatric neurologists could receive direct referrals from general practice or emergency services to assess children with possible epilepsy

Country/network	Yes	No	N/A
England and Wales (N = 148)	23.0% (34/148	49.3% (73/148)	27.7% (41/148)
England (N = 142)	21.8% (31/142)	50.0% (71/142)	28.2% (40/142)
Wales (N = 6)	50.0% (3/6)	33.3% (2/6)	16.7% (1/6)
BRPNF (N = 14)	0.0% (0/4)	28.6% (4/14)	71.4% (10/14)
CEWT (N = 6)	16.7% (1/6)	16.7% (1/6)	66.7% (4/6)
EPEN (N = 15)	6.7% (1/15)	93.3% (14/15)	0.0% (0/15)
EPIC (N = 9)	0.0% (0/9)	55.6% (5/9)	44.4% (4/9)
NTPEN (N = 17)	17.6% (3/17)	64.7% (11/17)	17.6% (3/17)
NWEIG (N = 13)	38.5% (5/13)	61.5% (8/13)	0.0% (0/13)
ORENG (N = 7)	42.9% (3/7)	57.1% (4/7)	0.0% (0/7)
PENNEC (N = 9)	22.2% (2/9)	66.7% (6/9)	11.1% (1/9)
SETPEG (N = 10)	40.0% (4/10)	20.0% (2/10)	40.0% (4/10)
SWEP (N = 5)	60.0% (3/5)	20.0% (1/5)	20.0% (1/5)
SWIPE (N = 11)	27.3% (3/11)	36.4% (4/11)	36.4% (4/11)
SWTPEG (N = 8)	12.5% (1/8)	62.5% (5/8)	25.0% (2/8)
TEN (N = 6)	50.0% (3/6)	16.7% (1/6)	33.3% (2/6)
WPNN (N = 9)	11.1% (1/9)	44.4% (4/9)	44.4% (4/9)
YPEN (N = 9)	44.4% (4/9)	33.3% (3/9)	22.2% (2/9)

Table 16b: Health Boards and Trusts that could receive paediatric neurological direct referrals from general practice and emergency departments (excl. N/A)

Country/network	Yes	No
England and Wales (N = 107)	31.8% (34/107)	68.2% (73/107)
England (N = 102)	30.4% (31/102)	69.6% (71/102)
Wales (N = 5)	60.0% (3/5)	40.0% (2/5)
BRPNF (N = 4)	0.0% (0/4)	100.0% (4/4)
CEWT (N = 2)	50.0% (1/2)	50.0% (1/2)
EPEN (N = 15)	6.7% (1/15)	93.3% (14/15)
EPIC (N = 5)	0.0% (0/5)	100.0% (5/5)
NTPEN (N = 14)	21.4% (3/14)	78.6% (11/14)
NWEIG (N = 13)	38.5% (5/13)	61.5% (8/13)
ORENG (N = 7)	42.9% (3/7)	57.1% (4/7)
PENNEC (N = 8)	25.0% (2/8)	75.0% (6/8)
SETPEG (N =6)	66.7% (4/6)	33.3% (2/6)
SWEP (N = 4)	75.0% (3/4)	25.0% (1/4)
SWIPE (N = 7)	42.9% (3/7)	57.1% (4/7)
SWTPEG (N = 6)	16.7% (1/6)	83.3% (5/6)
TEN (N = 4)	75.0% (3/4)	25.0% (1/4)
WPNN (N = 9)	20.0% (1/5)	80.0% (4/5)
YPEN (N = 9)	57.1% (4/7)	42.9% (3/7)

Table 17: Health Boards and Trusts hosting satellite paediatric neurology clinics

Country/network	Yes	No	N/A
England and Wales (N = 148)	77.0% (114/148)	19.6% (29/148)	3.4% (5/148)
England (N = 142)	76.1% (108/142)	20.4% (29/142)	3.5% (5/142)
Wales (N = 6)	100.0% (6/6)	0.0% (0/6)	0.0% (0/6)
BRPNF (N = 14)	28.6% (4/14)	57.1% (8/14)	14.3% (2/14)
CEWT (N = 6)	66.7% (4/6)	16.7% (1/6)	16.7% (1/6)
EPEN (N = 15)	86.7% (13/15)	13.3% (2/15)	0.0% (0/15)
EPIC (N = 9)	100.0% (9/9)	0.0% (0/9)	0.0% (0/9)
NTPEN (N = 17)	29.4% (5/17)	70.6% (12/17)	0.0% (0/17)
NWEIG (N = 13)	84.6% (11/13)	7.7% (1/13)	7.7% (1/13)
ORENG (N = 7)	100.0% (7/7)	0.0% (0/7)	0.0% (0/7)
PENNEC (N = 9)	77.8% (7/9)	11.1% (1/9)	11.1% (1/9)
SETPEG (N = 10)	90.0% (9/10)	10.0% (1/10)	0.0% (0/10)
SWEP (N = 5)	100.0% (5/5)	0.0% (0/5)	0.0% (0/5)
SWIPE (N = 11)	90.9% (10/11)	9.1% (1/11)	0.0% (0/11)
SWTPEG (N = 8)	100.0% (8/8)	0.0% (0/8)	0.0% (0/8)
TEN (N = 6)	100.0% (6/6)	0.0% (0/6)	0.0% (0/6)
WPNN (N = 9)	88.9% (8/9)	11.1% (1/9)	0.0% (0/9)
YPEN (N = 9)	88.9% (8/9)	11.1% (1/9)	0.0% (0/9)

Table 18: Health Boards and Trusts that could facilitate the commencement of a ketogenic diet

Country/network	Yes	No	Uncertain
England and Wales (N = 148)	14.9% (22/148)	84.5% (125/148)	0.7% (1/148)
England (N = 142)	15.5% (22/142)	83.8% (119/142)	0.7% (1/142)
Wales (N = 6)	0.0% (0/6)	100.0% (6/6)	0.0% (0/6)
BRPNF (N = 14)	7.1% (1/14)	85.7% (12/14)	7.1% (1/14)
CEWT (N = 6)	50.0% (3/6)	50.0% (3/6)	0.0% (0/6)
EPEN (N = 15)	6.7% (1/15)	93.3% (14/15)	0.0% (0/15)
EPIC (N = 9)	11.1% (1/9)	88.9% (8/9)	0.0% (0/9)
NTPEN (N = 17)	5.9% (1/17)	94.1% (16/17)	0.0% (0/17)
NWEIG (N = 13)	15.4% (2/13)	84.6% (11/13)	0.0% (0/13)
ORENG (N = 7)	28.6% (2/7)	71.4% (5/7)	0.0% (0/7)
PENNEC (N = 9)	11.1% (1/9)	88.9% (8/9)	0.0% (0/9)
SETPEG (N = 10)	10.0% (1/10)	90.0% (9/10)	0.0% (0/10)
SWEP (N = 5)	0.0% (0/5)	100.0% (5/5)	0.0% (0/5)
SWIPE (N = 11)	36.4% (4/11)	63.6% (7/11)	0.0% (0/11)
SWTPEG (N = 8)	12.5% (1/8)	87.5% (7/8)	0.0% (0/8)
TEN (N = 6)	16.7% (1/6)	83.3% (5/6)	0.0% (0/6)
WPNN (N = 9)	11.1% (1/9)	88.9% (8/9)	0.0% (0/9)
YPEN (N = 9)	22.2% (2/9)	77.8% (7/9)	0.0% (0/9)

Table 19: Health Boards and Trusts that could undertake ongoing review of a ketogenic diet

Country/network	Yes	No	Uncertain
England and Wales (N = 148)	21.0% (31/148)	79.1% (117/148)	0.0% (0/148)
England (N = 142)	21.1% (30/142)	78.9% (112/142)	0.0% (0/142)
Wales (N = 6)	16.7% (1/6)	83.3% (5/6)	0.0% (0/6)
BRPNF (N = 14)	14.3% (2/14)	85.7% (12/14)	0.0% (0/14)
CEWT (N = 6)	50.0% (3/6)	50.0% (3/6)	0.0% (0/6)
EPEN (N = 15)	13.3% (2/15)	86.7% (13/15)	0.0% (0/15)
EPIC (N = 9)	11.1% (1/9)	88.9% (8/9)	0.0% (0/9)
NTPEN (N = 17)	11.8% (2/17)	88.2% (15/17)	0.0% (0/17)
NWEIG (N = 13)	15.4% (2/13)	84.6% (11/13)	0.0% (0/13)
ORENG (N = 7)	28.6% (2/7)	71.4% (5/7)	0.0% (0/7)
PENNEC (N = 9)	33.3% (3/9)	66.7% (6/9)	0.0% (0/9)
SETPEG (N = 10)	10.0% (1/10)	90.0% (9/10)	0.0% (0/10)
SWEP (N = 5)	20.0% (1/5)	80.0% (4/5)	0.0% (0/5)
SWIPE (N = 11)	54.5% (6/11)	45.5% (5/11)	0.0% (0/11)
SWTPEG (N = 8)	12.5% (1/8)	87.5% (7/8)	0.0% (0/8)
TEN (N = 6)	16.7% (1/6)	83.3% (5/6)	0.0% (0/6)
WPNN (N = 9)	22.2% (2/9)	77.8% (7/9)	0.0% (0/9)
YPEN (N = 9)	22.2% (2/9)	77.8% (7/9)	0.0% (0/9)

Table 20: Health Boards and Trusts that could provide vagus nerve stimulator insertion

Country/network	Yes	No	Uncertain
England and Wales (N = 148)	8.1% (12/148)	91.9% (136/148)	0.0% (0/148)
England (N = 142)	8.5% (12/142)	91.5% (130/142)	0.0% (0/142)
Wales (N = 6)	0.0% (0/6)	100.0% (6/6)	0.0% (0/6)
BRPNF (N = 14)	7.1% (1/14)	92.9% (13/14)	0.0% (0/14)
CEWT (N = 6)	0.0% (0/6)	100.0% (6/6)	0.0% (0/6)
EPEN (N = 15)	6.7% (1/15)	93.3% (14/15)	0.0% (0/15)
EPIC (N = 9)	11.1% (1/9)	88.9% (8/9)	0.0% (0/9)
NTPEN (N = 17)	5.9% (1/17)	94.1% (16/17)	0.0% (0/17)
NWEIG (N = 13)	7.7% (1/13)	92.3% (12/13)	0.0% (0/13)
ORENG (N = 7)	14.3% (1/7)	85.7% (6/7)	0.0% (0/7)
PENNEC (N = 9)	11.1% (1/9)	88.9% (8/9)	0.0% (0/9)
SETPEG (N = 10)	10.0% (1/10)	90.0% (9/10)	0.0% (0/10)
SWEP (N = 5)	0.0% (0/5)	100.0% (5/5)	0.0% (0/5)
SWIPE (N = 11)	9.1% (1/11)	90.9% (10/11)	0.0% (0/11)
SWTPEG (N = 8)	0.0% (0/8)	100.0% (8/8)	0.0% (0/8)
TEN (N = 6)	16.7% (1/6)	83.3% (5/6)	0.0% (0/6)
WPNN (N = 9)	11.1% (1/9)	88.9% (8/9)	0.0% (0/9)
YPEN (N = 9)	11.1% (1/9)	88.9% (8/9)	0.0% (0/9)

Table 21: Health Boards and Trusts that could provide vagus nerve stimulator review

Country/network	Yes	No	Uncertain
England and Wales (N = 148)	23.0% (34/148)	77% (114/148)	0.0% (0/148)
England (N = 142)	20.4% (29/142)	79.6% (113/142)	0.0% (0/142)
Wales (N = 6)	83.3% (5/6)	16.7% (1/6)	0.0% (0/6)
BRPNF (N = 14)	7.1% (1/14)	92.9% (13/14)	0.0% (0/14)
CEWT (N = 6)	50.0% (3/6)	50.0% (3/6)	0.0% (0/6)
EPEN (N = 15)	13.3% (2/15)	86.7% (13/15)	0.0% (0/15)
EPIC (N = 9)	11.1% (1/9)	88.9% (8/9)	0.0% (0/9)
NTPEN (N = 17)	5.9% (1/17)	94.1% (16/17)	0.0% (0/17)
NWEIG (N = 13)	23.1% (3/13)	76.9% (10/13)	0.0% (0/13)
ORENG (N = 7)	14.3% (1/7)	85.7% (6/7)	0.0% (0/7)
PENNEC (N = 9)	22.2% (2/9)	77.8% (7/9)	0.0% (0/9)
SETPEG (N = 10)	50.0% (5/10)	50.0% (5/10)	0.0% (0/10)
SWEP (N = 5)	100.0% (5/5)	0.0% (0/5)	0.0% (0/5)
SWIPE (N = 11)	45.5% (5/11)	54.5% (6/11)	0.0% (0/11)
SWTPEG (N = 8)	0.0% (0/8)	100.0% (8/8)	0.0% (0/8)
TEN (N = 6)	33.3% (2/6)	66.7% (4/6)	0.0% (0/6)
WPNN (N = 9)	11.1% (1/9)	88.9% (8/9)	0.0% (0/9)
YPEN (N = 9)	22.2% (2/9)	77.8% (7/9)	0.0% (0/9)

8.4 Investigations

Figure 7 shows the percentage of Health Boards and Trusts that reported that they could offer different epilepsy investigation services. Electrocardiogram (ECG) was not available in **4.7% (7/148)** of Health Boards and Trusts. Standard electroencephalogram (EEG) was not available in **39.2% (58/148)** of Health Boards and Trusts. Given the specialist nature of EEG services for children, this is not a surprising result as EEG services are often located within regional centres.

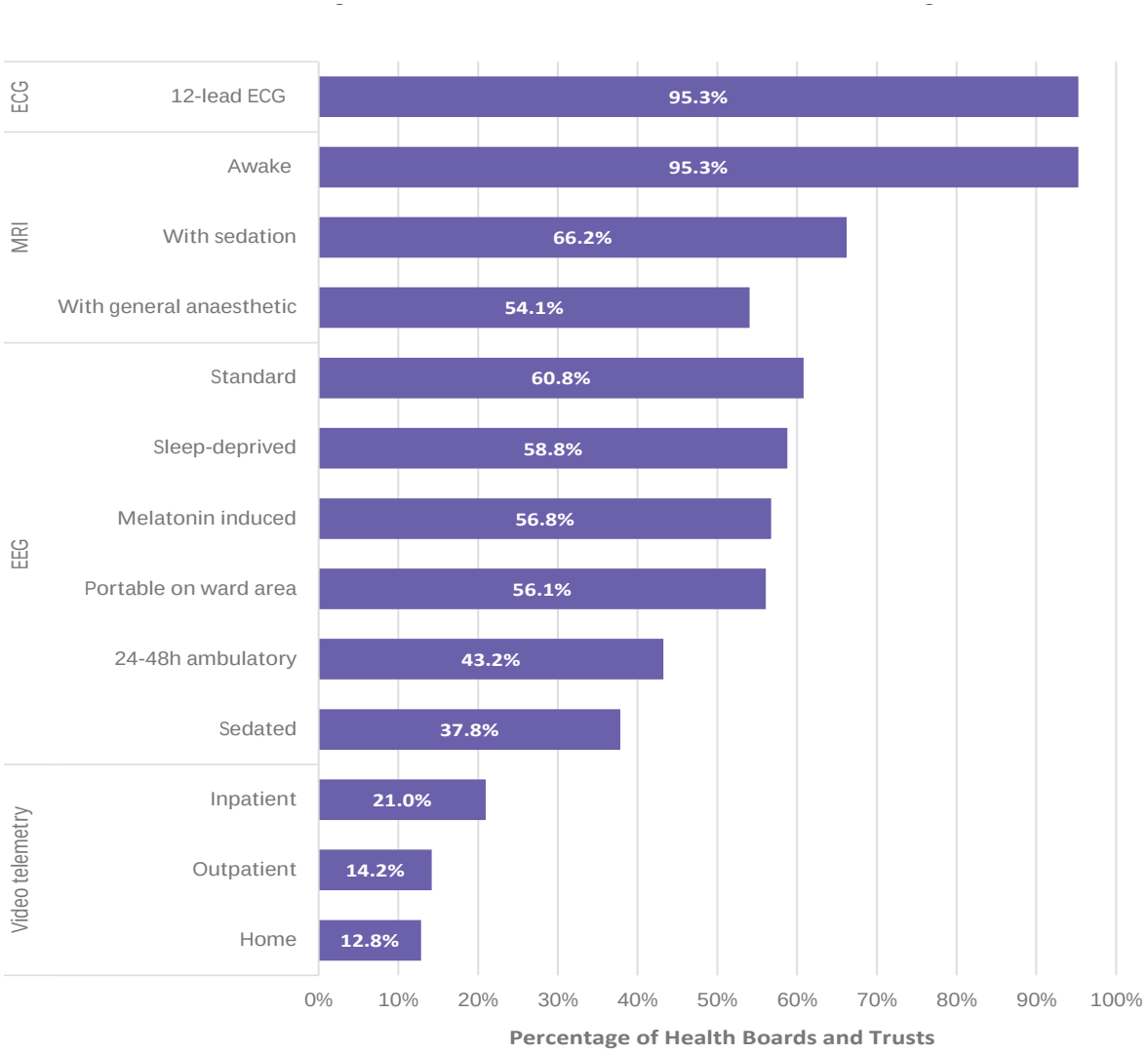


Figure 7: Percentage of Health Boards and Trusts that could provide investigation services (n=148)

Table 22: Health Boards and Trusts that could provide epilepsy investigation services

Country/network	12-lead ECG				
	Yes	No	Uncertain	Yes	
England and Wales (N = 148)	95.3% (141/148)	4.7% (7/148)	0.0% (0/148)	95.3% (141/148)	
England (N = 142)	95.1% (135/142)	4.9% (7/142)	0.0% (0/142)	95.1% (135/142)	
Wales (N = 6)	100.0% (6/6)	0.0% (0/6)	0.0% (0/6)	100.0% (6/6)	
BRPNF (N = 14)	85.7% (12/14)	14.3% (2/14)	0.0% (0/14)	92.9% (13/14)	
CEWT (N = 6)	100.0% (6/6)	0.0% (0/6)	0.0% (0/6)	100.0% (6/6)	
EPEN (N = 15)	93.3% (14/15)	6.7% (1/15)	0.0% (0/15)	93.3% (14/15)	
EPIC (N = 9)	100.0% (9/9)	0.0% (0/9)	0.0% (0/9)	100.0% (9/9)	
NTPEN (N = 17)	100.0% (17/17)	0.0% (0/17)	0.0% (0/17)	100.0% (17/17)	
NWEIG (N = 13)	100.0% (13/13)	0.0% (0/13)	0.0% (0/13)	84.6% (11/13)	
ORENG (N = 7)	100.0% (7/7)	0.0% (0/7)	0.0% (0/7)	100.0% (7/7)	
PENNEC (N = 9)	100.0% (9/9)	0.0% (0/9)	0.0% (0/9)	100.0% (9/9)	
SETPEG (N = 10)	80.0% (8/10)	20.0% (2/10)	0.0% (0/10)	90.0% (9/10)	
SWEP (N = 5)	100.0% (5/5)	0.0% (0/5)	0.0% (0/5)	100.0% (5/5)	
SWIPE (N = 11)	100.0% (11/11)	0.0% (0/11)	0.0% (0/11)	100.0% (11/11)	
SWTPEG (N = 8)	100.0% (8/8)	0.0% (0/8)	0.0% (0/8)	100.0% (8/8)	
TEN (N = 6)	83.3% (5/6)	16.7% (1/6)	0.0% (0/6)	100.0% (6/6)	
WPNN (N = 9)	88.9% (8/9)	11.1% (1/9)	0.0% (0/9)	88.9% (8/9)	
YPEN (N = 9)	100.0% (9/9)	0.0% (0/9)	0.0% (0/9)	88.9% (8/9)	

Table 22 (continued): Health Boards and Trusts that could provide epilepsy investigation services

'Awake' MRI		MRI with sedation		
No	**Uncertain**	**Yes**	**No**	**Uncertain**
4.7% (7/148)	0.0% (0/148)	66.2% (98/148)	33.1% (49/148)	0.7% (1/148)
4.9% (7/142)	0.0% (0/142)	66.2% (94/142)	33.1% (47/142)	0.7% (1/142)
0.0% (0/6)	0.0% (0/6)	66.7% (4/6)	33.3% (2/6)	0.0% (0/6)
7.1% (1/14)	0.0% (0/14)	71.4% (10/14)	28.6% (4/14)	0.0% (0/14)
0.0% (0/6)	0.0% (0/6)	100.0% (6/6)	0.0% (0/6)	0.0% (0/6)
6.7% (1/15)	0.0% (0/15)	86.7% (13/15)	13.3% (2/15)	0.0% (0/15)
0.0% (0/9)	0.0% (0/9)	55.6% (5/9)	44.4% (4/9)	0.0% (0/9)
0.0% (0/17)	0.0% (0/17)	88.2% (15/17)	11.8% (2/17)	0.0% (0/17)
15.4% (2/13)	0.0% (0/13)	53.8% (7/13)	46.2% (6/13)	0.0% (0/13)
0.0% (0/7)	0.0% (0/7)	57.1% (4/7)	42.9% (3/7)	0.0% (0/7)
0.0% (0/9)	0.0% (0/9)	55.6% (5/9)	44.4% (4/9)	0.0% (0/9)
10.0% (1/10)	0.0% (0/10)	80.0% (8/10)	20.0% (2/10)	0.0% (0/10)
0.0% (0/5)	0.0% (0/5)	60.0% (3/5)	40.0% (2/5)	0.0% (0/5)
0.0% (0/11)	0.0% (0/11)	63.6% (7/11)	36.4% (4/11)	0.0% (0/11)
0.0% (0/8)	0.0% (0/8)	25.0% (2/8)	75.0% (6/8)	0.0% (0/8)
0.0% (0/6)	0.0% (0/6)	50.0% (3/6)	50.0% (3/6)	0.0% (0/6)
11.1% (1/9)	0.0% (0/9)	55.6% (5/9)	33.3% (3/9)	11.1% (1/9)
11.1% (1/9)	0.0% (0/9)	55.6% (5/9)	44.4% (4/9)	0.0% (0/9)

Table 22 (continued): Health Boards and Trusts that could provide epilepsy investigation services

Country/network	MRI with general anaesthetic			Standard EEG
	Yes	No	Uncertain	Yes
England and Wales (N = 148)	54.1% (80/148)	45.9% (68/148)	0.0% (0/148)	60.8% (90/148)
England (N = 142)	52.1% (74/142)	47.9% (68/142)	0.0% (0/142)	59.2% (84/142)
Wales (N = 6)	100.0% (6/6)	0.0% (0/6)	0.0% (0/6)	100.0% (6/6)
BRPNF (N = 14)	28.6% (4/14)	71.4% (10/14)	0.0% (0/14)	57.1% (8/14)
CEWT (N = 6)	100.0% (6/6)	0.0% (0/6)	0.0% (0/6)	83.3% (5/6)
EPEN (N = 15)	66.7% (10/15)	33.3% (5/15)	0.0% (0/15)	53.3% (8/15)
EPIC (N = 9)	44.4% (4/9)	55.6% (5/9)	0.0% (0/9)	44.4% (4/9)
NTPEN (N = 17)	35.3% (6/17)	64.7% (11/17)	0.0% (0/17)	58.8% (10/17)
NWEIG (N = 13)	30.8% (4/13)	69.2% (9/13)	0.0% (0/13)	61.5% (8/13)
ORENG (N = 7)	71.4% (5/7)	28.6% (2/7)	0.0% (0/7)	42.9% (3/7)
PENNEC (N = 9)	44.4% (4/9)	55.6% (5/9)	0.0% (0/9)	44.4% (4/9)
SETPEG (N = 10)	60.0% (6/10)	40.0% (4/10)	0.0% (0/10)	40.0% (4/10)
SWEP (N = 5)	100.0% (5/5)	0.0% (0/5)	0.0% (0/5)	100.0% (5/5)
SWIPE (N = 11)	72.7% (8/11)	27.3% (3/11)	0.0% (0/11)	81.8% (9/11)
SWTPEG (N = 8)	50.0% (4/8)	50.0% (4/8)	0.0% (0/8)	87.5% (7/8)
TEN (N = 6)	50.0% (3/6)	50.0% (3/6)	0.0% (0/6)	33.3% (2/6)
WPNN (N = 9)	66.7% (6/9)	33.3% (3/9)	0.0% (0/9)	66.7% (6/9)
YPEN (N = 9)	55.6% (5/9)	44.4% (4/9)	0.0% (0/9)	77.8% (7/9)

Table 22 (continued): Health Boards and Trusts that could provide epilepsy investigation services

Standard EEG			Sleep deprived EEG		
	No	**Uncertain**	**Yes**	**No**	**Uncertain**
	39.2% (58/148)	0.0% (0/148)	58.8% (87/148)	41.2% (61/148)	0.0% (0/148)
	40.8% (58/142)	0.0% (0/142)	57% (81/142)	43% (61/142)	0.0% (0/142)
	0.0% (0/6)	0.0% (0/6)	100.0% (6/6)	0.0% (0/6)	0.0% (0/6)
	42.9% (6/14)	0.0% (0/14)	57.1% (8/14)	42.9% (6/14)	0.0% (0/14)
	16.7% (1/6)	0.0% (0/6)	83.3% (5/6)	16.7% (1/6)	0.0% (0/6)
	46.7% (7/15)	0.0% (0/15)	53.3% (8/15)	46.7% (7/15)	0.0% (0/15)
	55.6% (5/9)	0.0% (0/9)	44.4% (4/9)	55.6% (5/9)	0.0% (0/9)
	41.2% (7/17)	0.0% (0/17)	58.8% (10/17)	41.2% (7/17)	0.0% (0/17)
	38.5% (5/13)	0.0% (0/13)	61.5% (8/13)	38.5% (5/13)	0.0% (0/13)
	57.1% (4/7)	0.0% (0/7)	42.9% (3/7)	57.1% (4/7)	0.0% (0/7)
	55.6% (5/9)	0.0% (0/9)	44.4% (4/9)	55.6% (5/9)	0.0% (0/9)
	60.0% (6/10)	0.0% (0/10)	40.0% (4/10)	60.0% (6/10)	0.0% (0/10)
	0.0% (0/5)	0.0% (0/5)	100.0% (5/5)	0.0% (0/5)	0.0% (0/5)
	18.2% (2/11)	0.0% (0/11)	63.6% (7/11)	36.4% (4/11)	0.0% (0/11)
	12.5% (1/8)	0.0% (0/8)	75.0% (6/8)	25.0% (2/8)	0.0% (0/8)
	66.7% (4/6)	0.0% (0/6)	33.3% (2/6)	66.7% (4/6)	0.0% (0/6)
	33.3% (3/9)	0.0% (0/9)	66.7% (6/9)	33.3% (3/9)	0.0% (0/9)
	22.2% (2/9)	0.0% (0/9)	77.8% (7/9)	22.2% (2/9)	0.0% (0/9)

Table 22 (continued): Health Boards and Trusts that could provide epilepsy investigation services

Country/network	Melatonin EEG			
	Yes	No	Uncertain	Yes
England and Wales (N = 148)	56.8% (84/148)	41.9% (62/148)	1.4% (2/148)	37.8% (56/148)
England (N = 142)	55.6% (79/142)	43% (61/142)	1.4% (2/142)	36.6% (52/142)
Wales (N = 6)	83.3% (5/6)	16.7% (1/6)	0.0% (0/6)	66.7% (4/6)
BRPNF (N = 14)	57.1% (8/14)	42.9% (6/14)	0.0% (0/14)	28.6% (4/14)
CEWT (N = 6)	83.3% (5/6)	16.7% (1/6)	0.0% (0/6)	83.3% (5/6)
EPEN (N = 15)	40.0% (6/15)	53.3% (8/15)	6.7% (1/15)	6.7% (1/15)
EPIC (N = 9)	44.4% (4/9)	55.6% (5/9)	0.0% (0/9)	44.4% (4/9)
NTPEN (N = 17)	47.1% (8/17)	47.1% (8/17)	5.9% (1/17)	29.4% (5/17)
NWEIG (N = 13)	61.5% (8/13)	38.5% (5/13)	0.0% (0/13)	61.5% (8/13)
ORENG (N = 7)	42.9% (3/7)	57.1% (4/7)	0.0% (0/7)	42.9% (3/7)
PENNEC (N = 9)	44.4% (4/9)	55.6% (5/9)	0.0% (0/9)	33.3% (3/9)
SETPEG (N = 10)	40.0% (4/10)	60.0% (6/10)	0.0% (0/10)	30.0% (3/10)
SWEP (N = 5)	80.0% (4/5)	20.0% (1/5)	0.0% (0/5)	60.0% (3/5)
SWIPE (N = 11)	72.7% (8/11)	27.3% (3/11)	0.0% (0/11)	54.5% (6/11)
SWTPEG (N = 8)	87.5% (7/8)	12.5% (1/8)	0.0% (0/8)	12.5% (1/8)
TEN (N = 6)	33.3% (2/6)	66.7% (4/6)	0.0% (0/6)	33.3% (2/6)
WPNN (N = 9)	66.7% (6/9)	33.3% (3/9)	0.0% (0/9)	44.4% (4/9)
YPEN (N = 9)	77.8% (7/9)	22.2% (2/9)	0.0% (0/9)	44.4% (4/9)

Table 22 (continued): Health Boards and Trusts that could provide epilepsy investigation services

Sedated EEG		24-48h ambulatory EEG		
No	Uncertain	Yes	No	Uncertain
58.8% (87/148)	3.4% (5/148)	43.2% (64/148)	56.8% (84/148)	0.0% (0/148)
59.9% (85/142)	3.5% (5/142)	40.8% (58/142)	59.2% (84/142)	0.0% (0/142)
33.3% (2/6)	0.0% (0/6)	100.0% (6/6)	0.0% (0/6)	0.0% (0/6)
64.3% (9/14)	7.1% (1/14)	42.9% (6/14)	57.1% (8/14)	0.0% (0/14)
16.7% (1/6)	0.0% (0/6)	83.3% (5/6)	16.7% (1/6)	0.0% (0/6)
86.7% (13/15)	6.7% (1/15)	26.7% (4/15)	73.3% (11/15)	0.0% (0/15)
55.6% (5/9)	0.0% (0/9)	44.4% (4/9)	55.6% (5/9)	0.0% (0/9)
64.7% (11/17)	5.9% (1/17)	17.6% (3/17)	82.4% (14/17)	0.0% (0/17)
38.5% (5/13)	0.0% (0/13)	30.8% (4/13)	69.2% (9/13)	0.0% (0/13)
57.1% (4/7)	0.0% (0/7)	42.9% (3/7)	57.1% (4/7)	0.0% (0/7)
66.7% (6/9)	0.0% (0/9)	44.4% (4/9)	55.6% (5/9)	0.0% (0/9)
70.0% (7/10)	0.0% (0/10)	30.0% (3/10)	70.0% (7/10)	0.0% (0/10)
40.0% (2/5)	0.0% (0/5)	100.0% (5/5)	0.0% (0/5)	0.0% (0/5)
45.5% (5/11)	0.0% (0/11)	54.5% (6/11)	45.5% (5/11)	0.0% (0/11)
62.5% (5/8)	25.0% (2/8)	37.5% (3/8)	62.5% (5/8)	0.0% (0/8)
66.7% (4/6)	0.0% (0/6)	33.3% (2/6)	66.7% (4/6)	0.0% (0/6)
55.6% (5/9)	0.0% (0/9)	55.6% (5/9)	44.4% (4/9)	0.0% (0/9)
55.6% (5/9)	0.0% (0/9)	77.8% (7/9)	22.2% (2/9)	0.0% (0/9)

Table 22 (continued): Health Boards and Trusts that could provide epilepsy investigation services

Country/network	Inpatient video telemetry			
	Yes	No	Uncertain	Yes
England and Wales (N = 148)	21.0% (31/148)	79.1% (117/148)	0.0% (0/148)	14.2% (21/148)
England (N = 142)	20.4% (29/142)	79.6% (113/142)	0.0% (0/142)	14.1% (20/142)
Wales (N = 6)	33.3% (2/6)	66.7% (4/6)	0.0% (0/6)	16.7% (1/6)
BRPNF (N = 14)	14.3% (2/14)	85.7% (12/14)	0.0% (0/14)	14.3% (2/14)
CEWT (N = 6)	66.7% (4/6)	33.3% (2/6)	0.0% (0/6)	33.3% (2/6)
EPEN (N = 15)	13.3% (2/15)	86.7% (13/15)	0.0% (0/15)	0.0% (0/15)
EPIC (N = 9)	22.2% (2/9)	77.8% (7/9)	0.0% (0/9)	22.2% (2/9)
NTPEN (N = 17)	17.6% (3/17)	82.4% (14/17)	0.0% (0/17)	11.8% (2/17)
NWEIG (N = 13)	7.7% (1/13)	92.3% (12/13)	0.0% (0/13)	23.1% (3/13)
ORENG (N = 7)	28.6% (2/7)	71.4% (5/7)	0.0% (0/7)	28.6% (2/7)
PENNEC (N = 9)	22.2% (2/9)	77.8% (7/9)	0.0% (0/9)	11.1% (1/9)
SETPEG (N = 10)	20.0% (2/10)	80.0% (8/10)	0.0% (0/10)	20.0% (2/10)
SWEP (N = 5)	20.0% (1/5)	80.0% (4/5)	0.0% (0/5)	0.0% (0/5)
SWIPE (N = 11)	36.4% (4/11)	63.6% (7/11)	0.0% (0/11)	9.1% (1/11)
SWTPEG (N = 8)	12.5% (1/8)	87.5% (7/8)	0.0% (0/8)	0.0% (0/8)
TEN (N = 6)	16.7% (1/6)	83.3% (5/6)	0.0% (0/6)	16.7% (1/6)
WPNN (N = 9)	22.2% (2/9)	77.8% (7/9)	0.0% (0/9)	22.2% (2/9)
YPEN (N = 9)	22.2% (2/9)	77.8% (7/9)	0.0% (0/9)	11.1% (1/9)

Table 22 (continued): Health Boards and Trusts that could provide epilepsy investigation services

Outpatient video telemetry		Home video telemetry		
No	**Uncertain**	**Yes**	**No**	**Uncertain**
84.5% (125/148)	1.4% (2/148)	12.8% (19/148)	85.8% (127/148)	1.4% (2/148)
85.2% (121/142)	0.7% (1/142)	12% (17/142)	86.6% (123/142)	1.4% (2/142)
66.7% (4/6)	16.7% (1/6)	33.3% (2/6)	66.7% (4/6)	0.0% (0/6)
85.7% (12/14)	0.0% (0/14)	21.4% (3/14)	78.6% (11/14)	0.0% (0/14)
66.7% (4/6)	0.0% (0/6)	0.0% (0/6)	100.0% (6/6)	0.0% (0/6)
93.3% (14/15)	6.7% (1/15)	6.7% (1/15)	86.7% (13/15)	6.7% (1/15)
77.8% (7/9)	0.0% (0/9)	22.2% (2/9)	77.8% (7/9)	0.0% (0/9)
88.2% (15/17)	0.0% (0/17)	11.8% (2/17)	88.2% (15/17)	0.0% (0/17)
76.9% (10/13)	0.0% (0/13)	7.7% (1/13)	92.3% (12/13)	0.0% (0/13)
71.4% (5/7)	0.0% (0/7)	14.3% (1/7)	85.7% (6/7)	0.0% (0/7)
88.9% (8/9)	0.0% (0/9)	11.1% (1/9)	88.9% (8/9)	0.0% (0/9)
80.0% (8/10)	0.0% (0/10)	20.0% (2/10)	80.0% (8/10)	0.0% (0/10)
80.0% (4/5)	20.0% (1/5)	20.0% (1/5)	80.0% (4/5)	0.0% (0/5)
90.9% (10/11)	0.0% (0/11)	9.1% (1/11)	90.9% (10/11)	0.0% (0/11)
100.0% (8/8)	0.0% (0/8)	0.0% (0/8)	87.5% (7/8)	12.5% (1/8)
83.3% (5/6)	0.0% (0/6)	33.3% (2/6)	66.7% (4/6)	0.0% (0/6)
77.8% (7/9)	0.0% (0/9)	11.1% (1/9)	88.9% (8/9)	0.0% (0/9)
88.9% (8/9)	0.0% (0/9)	11.1% (1/9)	88.9% (8/9)	0.0% (0/9)

Table 22 (continued): Health Boards and Trusts that could provide epilepsy investigation services

Country/network	Portable EEG on ward		
	Yes	No	Uncertain
England and Wales (N = 148)	56.1% (83/148)	42.6% (63/148)	1.4% (2/148)
England (N = 142)	55.6% (79/142)	43% (61/142)	1.4% (2/142)
Wales (N = 6)	66.7% (4/6)	33.3% (2/6)	0.0% (0/6)
BRPNF (N = 14)	64.3% (9/14)	28.6% (4/14)	7.1% (1/14)
CEWT (N = 6)	100.0% (6/6)	0.0% (0/6)	0.0% (0/6)
EPEN (N = 15)	46.7% (7/15)	53.3% (8/15)	0.0% (0/15)
EPIC (N = 9)	33.3% (3/9)	66.7% (6/9)	0.0% (0/9)
NTPEN (N = 17)	41.2% (7/17)	58.8% (10/17)	0.0% (0/17)
NWEIG (N = 13)	61.5% (8/13)	38.5% (5/13)	0.0% (0/13)
ORENG (N = 7)	71.4% (5/7)	28.6% (2/7)	0.0% (0/7)
PENNEC (N = 9)	44.4% (4/9)	55.6% (5/9)	0.0% (0/9)
SETPEG (N = 10)	30.0% (3/10)	70.0% (7/10)	0.0% (0/10)
SWEP (N = 5)	60.0% (3/5)	40.0% (2/5)	0.0% (0/5)
SWIPE (N = 11)	72.7% (8/11)	27.3% (3/11)	0.0% (0/11)
SWTPE (N = 8)	75.0% (6/8)	25.0% (2/8)	0.0% (0/8)
TEN (N = 6)	50.0% (3/6)	33.3% (2/6)	16.7% (1/6)
WPNN (N = 9)	66.7% (6/9)	33.3% (3/9)	0.0% (0/9)
YPEN (N = 9)	55.6% (5/9)	44.4% (4/9)	0.0% (0/9)

8.5 Service contact

The key findings and recommendations for this audit measure are found on page 19.

Figure 8 shows the breakdown of the availability of specialist epilepsy advice between scheduled reviews that (144/148) Health Boards and Trusts indicated they could provide. It was reported that the service was available; some weekdays for 52 weeks of the year in (6/148) Health Boards and Trusts; every weekday for 52 weeks of the year in (73/148) Health Boards and Trusts; all weekdays and out of hours for 52 weeks of the year in (11/148) Health Boards and Trusts; some weekdays for part of the year in (15/148) Health Boards and Trusts; all weekdays for part of the year in (38/148) Health Boards and Trusts; or all weekdays and out of hours for part of the year in (1/148) Health Boards and Trusts.

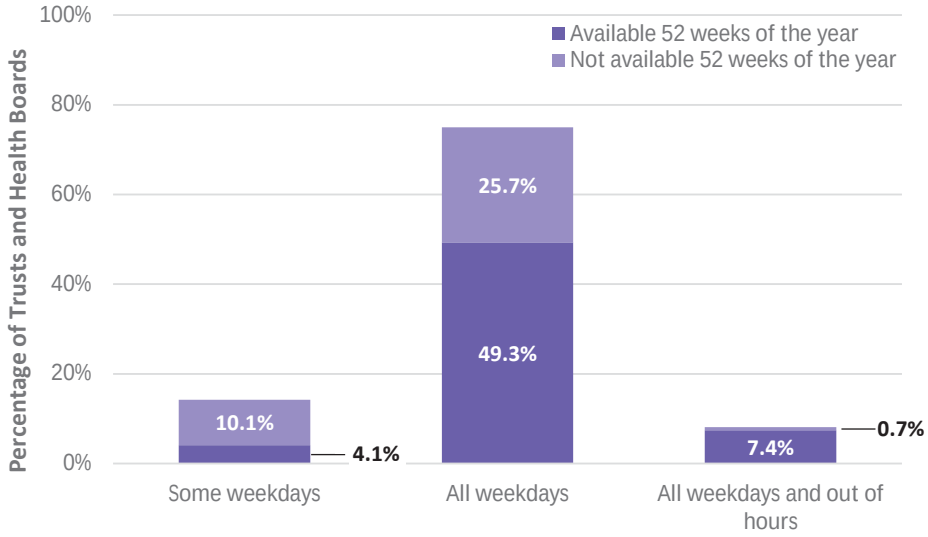


Figure 8: Availability of Health Boards and Trusts to provide specialist advice between scheduled reviews (n=144)

Just over half 52% (75/148) of Health Boards and Trusts described a typical response time of the same or next weekday. Initial specialist advice was 'typically' provided by a consultant paediatrician with expertise in epilepsy (63/144) or an epilepsy specialist nurse (62/144). In **2.1% (3/144)** of Health Boards and Trusts, specialist advice was provided by a paediatric neurologist, **(Figure 9)**.

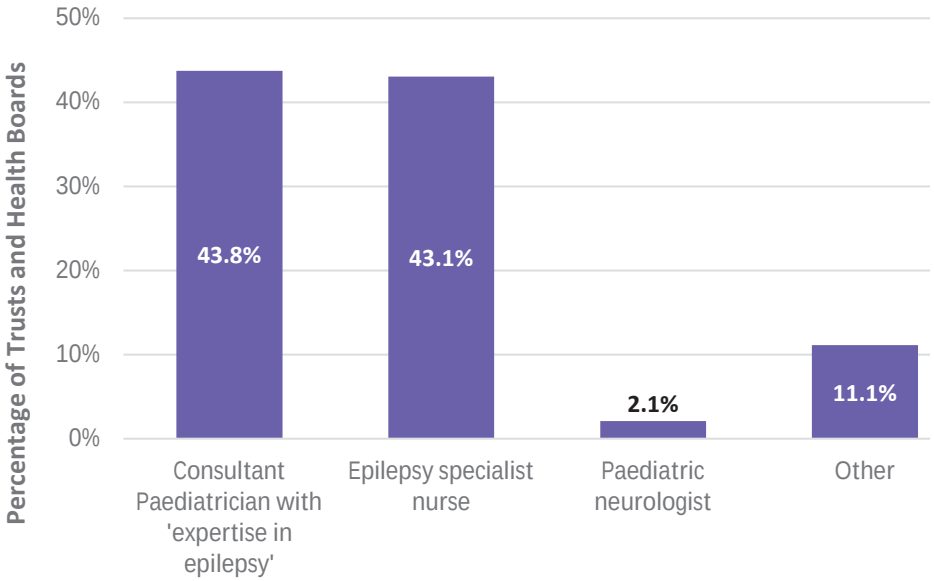


Figure 9: Professional who 'typically' provides initial specialist advice (n=144)

Of the **11.1%** (**16/144)** of Health Boards and Trusts who selected other, advice was typically provided by; both a consultant paediatrician with expertise in epilepsy and an epilepsy specialist nurse (11/144); a combination of all three (3/144); an 'on call' consultant paediatrician (1/144); or a named or on call paediatrician (1/144).

Table 23: Health Boards and Trusts providing specialist advice between scheduled reviews

Country/network	Yes	No
England and Wales (N = 148)	97.3% (144/148)	2.7% (4/148)
England (N = 142)	97.2% (138/142)	2.8% (4/142)
Wales (N = 6)	100.0% (6/6)	0.0% (0/6)
BRPNF (N = 14)	85.7% (12/14)	14.3% (2/14)
CEWT (N = 6)	83.3% (5/6)	16.7% (1/6)
EPEN (N = 15)	100.0% (15/15)	0.0% (0/15)
EPIC (N = 9)	100.0% (9/9)	0.0% (0/9)
NTPEN (N = 17)	100.0% (17/17)	0.0% (0/17)
NWEIG (N = 13)	100.0% (13/13)	0.0% (0/13)
ORENG (N = 7)	100.0% (7/7)	0.0% (0/7)
PENNEC (N = 9)	100.0% (9/9)	0.0% (0/9)
SETPEG (N = 10)	100.0% (10/10)	0.0% (0/10)
SWEP (N = 5)	100.0% (5/5)	0.0% (0/5)
SWIPE (N = 11)	100.0% (11/11)	0.0% (0/11)
SWTPEG (N = 8)	100.0% (8/8)	0.0% (0/8)
TEN (N = 6)	100.0% (6/6)	0.0% (0/6)
WPNN (N = 9)	88.9% (8/9)	11.1% (1/9)
YPEN (N = 9)	100.0% (9/9)	0.0% (0/9)

Table 24: Availability of specialist epilepsy advice in Health Boards and Trusts between scheduled reviews

	Available 52 weeks of the year			Not available 52 weeks of the year		
Country/ network	**Some weekdays**	**Every weekday**	**Every weekday and out of hours**	**Some weekdays**	**Every weekday**	**Every weekday and out of hours**
England and Wales (N = 148)	4.1% (6/148)	49.3% (73/148)	7.4% (11/148)	10.1% (15/148)	25.7% (38/148)	0.7% (1/148)
England (N = 142)	3.5% (5/142)	49.3% (70/142)	7.7% (11/142)	9.9% (14/142)	26.1% (37/142)	0.7% (1/142)
Wales (N = 6)	16.7% (1/6)	50.0% (3/6)	0.0% (0/6)	16.7% (1/6)	16.7% (1/6)	0.0% (0/6)
BRPNF (N = 14)	0.0% (0/14)	42.9% (6/14)	0.0% (0/14)	7.1% (1/14)	35.7% (5/14)	0.0% (0/14)
CEWT (N = 6)	0.0% (0/6)	83.3% (5/6)	0.0% (0/6)	0.0% (0/6)	0.0% (0/6)	0.0% (0/6)
EPEN (N = 15)	0.0% (0/15)	60.0% (9/15)	0.0% (0/15)	0.0% (0/15)	40.0% (6/15)	0.0% (0/15)
EPIC (N = 9)	0.0% (0/9)	66.7% (6/9)	0.0% (0/9)	11.1% (1/9)	22.2% (2/9)	0.0% (0/9)
NTPEN (N = 17)	0.0% (0/17)	35.3% (6/17)	17.6% (3/17)	23.5% (4/17)	23.5% (4/17)	0.0% (0/17)
NWEIG (N = 13)	0.0% (0/13)	69.2% (9/13)	15.4% (2/13)	7.7% (1/13)	7.7% (1/13)	0.0% (0/13)
ORENG (N = 7)	0.0% (0/7)	57.1% (4/7)	14.3% (1/7)	0.0% (0/7)	28.6% (2/7)	0.0% (0/7)
PENNEC (N = 9)	22.2% (2/9)	22.2% (2/9)	11.1% (1/9)	11.1% (1/9)	33.3% (3/9)	0.0% (0/9)
SETPEG (N = 10)	0.0% (0/10)	40.0% (4/10)	10.0% (1/10)	0.0% (0/10)	50.0% (5/10)	0.0% (0/10)
SWEP (N = 5)	20.0% (1/5)	60.0% (3/5)	0.0% (0/5)	20.0% (1/5)	0.0% (0/5)	0.0% (0/5)
SWIPE (N = 11)	9.1% (1/11)	36.4% (4/11)	9.1% (1/11)	45.5% (5/11)	0.0% (0/11)	0.0% (0/11)
SWTPEG (N = 8)	25.0% (2/8)	37.5% (3/8)	0.0% (0/8)	12.5% (1/8)	12.5% (1/8)	12.5% (1/8)
TEN (N = 6)	0.0% (0/6)	50.0% (3/6)	16.7% (1/6)	0.0% (0/6)	33.3% (2/6)	0.0% (0/6)
WPNN (N = 9)	0.0% (0/9)	44.4% (4/9)	11.1% (1/9)	0.0% (0/9)	33.3% (3/9)	0.0% (0/9)
YPEN (N = 9)	0.0% (0/9)	55.6% (5/9)	0.0% (0/9)	0.0% (0/9)	44.4% (4/9)	0.0% (0/9)

Table 25: Typical response time to requests for specialist epilepsy advice between scheduled reviews

Country/network	Same weekday	Next weekday	3-4 weekdays	Within the working week
England and Wales (N = 144)	12.5% (18/144)	39.6% (57/144)	36.1% (52/144)	11.8% (17/144)
England (N = 138)	13.0% (18/138)	40.6% (56/138)	34.8% (48/138)	11.6% (16/138)
Wales (N = 6)	0.0% (0/6)	16.7% (1/6)	66.7% (4/6)	16.7% (1/6)
BRPNF (N = 12)	0.0% (0/12)	41.7% (5/12)	41.7% (5/12)	16.7% (2/12)
CEWT (N = 5)	40.0% (2/5)	40.0% (2/5)	20.0% (1/5)	0.0% (0/5)
EPEN (N = 15)	6.7% (1/15)	46.7% (7/15)	40.0% (6/15)	6.7% (1/15)
EPIC (N = 9)	0.0% (0/9)	44.4% (4/9)	44.4% (4/9)	11.1% (1/9)
NTPEN (N = 17)	23.5% (4/17)	29.4% (5/17)	17.6% (3/17)	29.4% (5/17)
NWEIG (N = 13)	15.4% (2/13)	53.8% (7/13)	30.8% (4/13)	0.0% (0/13)
ORENG (N = 7)	28.6% (2/7)	42.9% (3/7)	14.3% (1/7)	14.3% (1/7)
PENNEC (N = 9)	11.1% (1/9)	33.3% (3/9)	33.3% (3/9)	22.2% (2/9)
SETPEG (N = 10)	10.0% (1/10)	40.0% (4/10)	40.0% (4/10)	10.0% (1/10)
SWEP (N = 5)	0.0% (0/5)	0.0% (0/5)	80.0% (4/5)	20.0% (1/5)
SWIPE (N = 11)	18.2% (2/11)	36.4% (4/11)	36.4% (4/11)	9.1% (1/11)
SWTPEG (N = 8)	12.5% (1/8)	50.0% (4/8)	25.0% (2/8)	12.5% (1/8)
TEN (N = 6)	0.0% (0/6)	16.7% (1/6)	83.3% (5/6)	0.0% (0/6)
WPNN (N = 9)	12.5% (1/8)	50.0% (4/8)	37.5% (3/8)	0.0% (0/8)
YPEN (N = 9)	11.1% (1/9)	44.4% (4/9)	33.3% (3/9)	11.1% (1/9)

Table 26: Professional who 'typically' provides the initial specialist epilepsy advice

Country/network	ESN	Consultant with 'expertise in epilepsy'	Paediatric neurologist	Other
England and Wales (N = 144)	43.1% (62/144)	43.8% (63/144)	2.1% (3/144)	11.1% (16/144)
England (N = 138)	42.8% (59/138)	43.5% (60/138)	2.2% (3/138)	11.6% (16/138)
Wales (N = 6)	50.0% (3/6)	50.0% (3/6)	0.0% (0/6)	0.0% (0/6)
BRPNF (N = 12)	16.7% (2/12)	58.3% (7/12)	0.0% (0/12)	25% (3/12)
CEWT (N = 5)	40.0% (2/5)	20.0% (1/5)	20.0% (1/5)	20.0% (1/5)
EPEN (N = 15)	60.0% (9/15)	40.0% (6/15)	0.0% (0/15)	0.0% (0/15)
EPIC (N = 9)	55.6% (5/9)	44.4% (4/9)	0.0% (0/9)	0.0% (0/9)
NTPEN (N = 17)	47.1% (8/17)	41.2% (7/17)	11.8% (2/17)	0.0% (0/17)
NWEIG (N = 13)	30.8% (4/13)	53.8% (7/13)	0.0% (0/13)	15.4% (2/13)
ORENG (N = 7)	57.1% (4/7)	28.6% (2/7)	0.0% (0/7)	14.3% (1/7)
PENNEC (N = 9)	22.2% (2/9)	66.7% (6/9)	0.0% (0/9)	11.1% (1/9)
SETPEG (N = 10)	50.0% (5/10)	30.0% (3/10)	0.0% (0/10)	20.0% (2/10)
SWEP (N = 5)	60.0% (3/5)	40.0% (2/5)	0.0% (0/5)	0.0% (0/5)
SWIPE (N = 11)	36.4% (4/11)	45.5% (5/11)	0.0% (0/11)	18.2% (2/11)
SWTPEG (N = 8)	50.0% (4/8)	37.5% (3/8)	0.0% (0/8)	12.5% (1/8)
TEN (N = 6)	50.0% (3/6)	50.0% (3/6)	0.0% (0/6)	0.0% (0/6)
WPNN (N = 9)	37.5% (3/8)	50.0% (4/8)	0.0% (0/8)	12.5% (1/8)
YPEN (N = 9)	44.4% (4/9)	33.3% (3/9)	0.0% (0/9)	22.2% (2/9)

8.6 Transition

The key findings and recommendations for this audit measure are found on page 20.

24.3% (36/148) of Health Boards and Trusts did not have agreed referral pathways to adult services.

An outpatient clinic specifically for young people with epilepsies was reported to be in place in **35.8%** (**53/148)** of Health Boards and Trusts. The median age of acceptance into these clinics was 15 years with a minimum acceptance age of 11 years and a maximum acceptance age of 17. **Figure 10** shows the proportion of outpatient clinics specifically for young people with epilepsies in Rounds 1, 2 and 3. It is important to note however that the results are not directly comparable because Round 1 and 2 results relate to epilepsy "units" whereas round 3 results relate to Health Boards and Trusts.

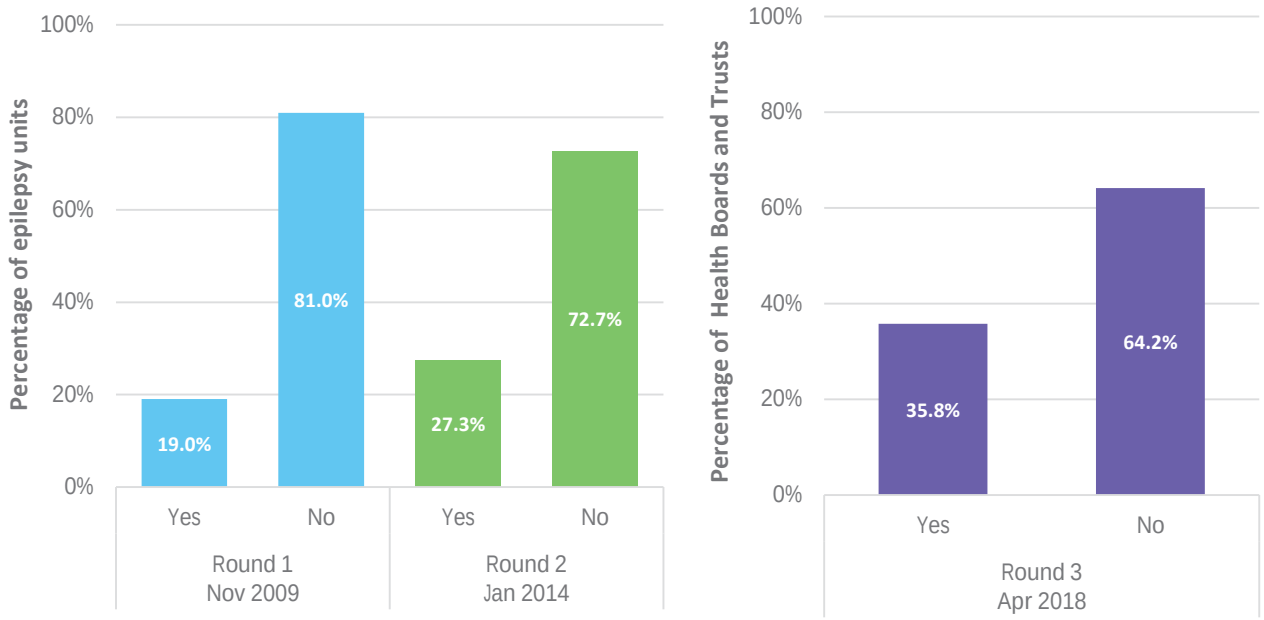


Figure 10: Outpatient clinics specifically for young people with epilepsies across Rounds 1, 2 and 3

Both adult and paediatric professionals were reported to be involved in outpatient services for epilepsy in **54.1% (80/148)** of Health Boards and Trusts. Of those 80 Health Boards and Trusts, a mean of 73.5% of young people were indicated as being transitioned through a joint professional process which comprised of either; a single joint appointment (49/80), several joint appointments (5/80), a mix of joint and individual appointments (19/80) or 'other' (7/80) **(Figure 11)**.

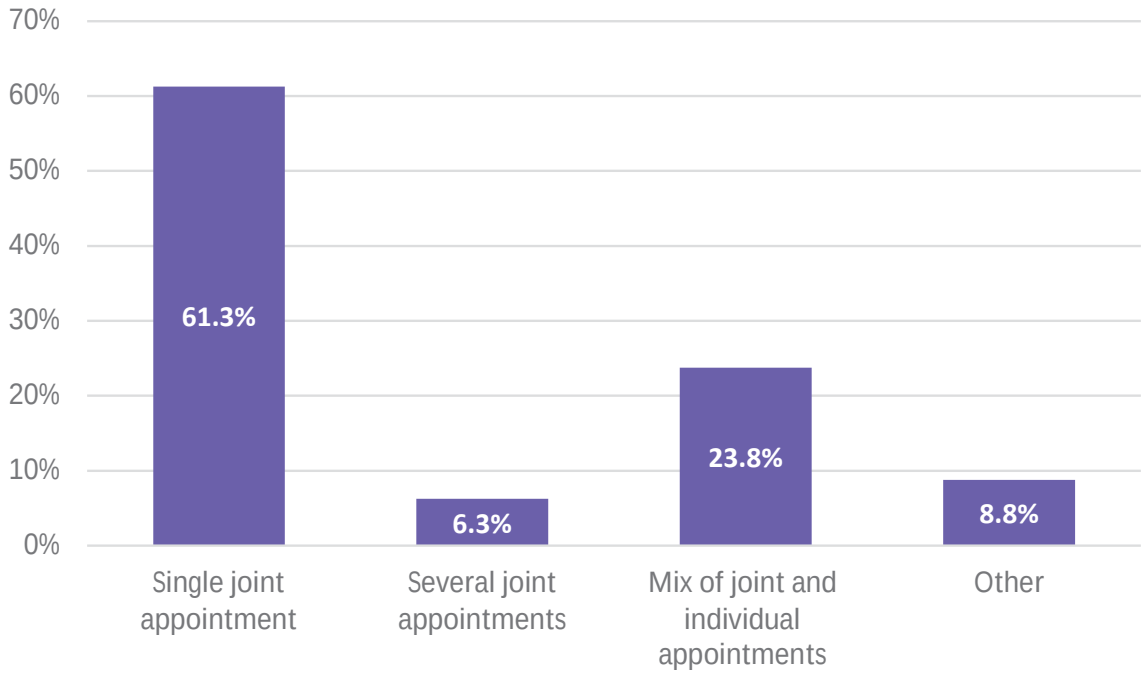


Figure 11: Composition of joint adult and paediatric transition process (n=80)

Structured resources, such as ready, steady, go, were used to support transition to adult services in **51.4% (76/148)** of Health Boards and Trusts.

Figure 12 shows the various professionals that were indicated as routinely involved in the transition or transfer of paediatric patients to adult services. Almost half (72/148) of all Health Boards and Trusts reported that they had no adult ESN supporting transition to adult services.

Other answers included:

- Adult Learning Disability Consultant or Psychiatrist
- Adult neurologist or neurophysiologist
- Consultant Paediatrician with interest in Epilepsy
- Education/social care
- GP alone or in conjunction with an adult neurologist
- Epilepsy midwife
- Run by a different trust
- None currently

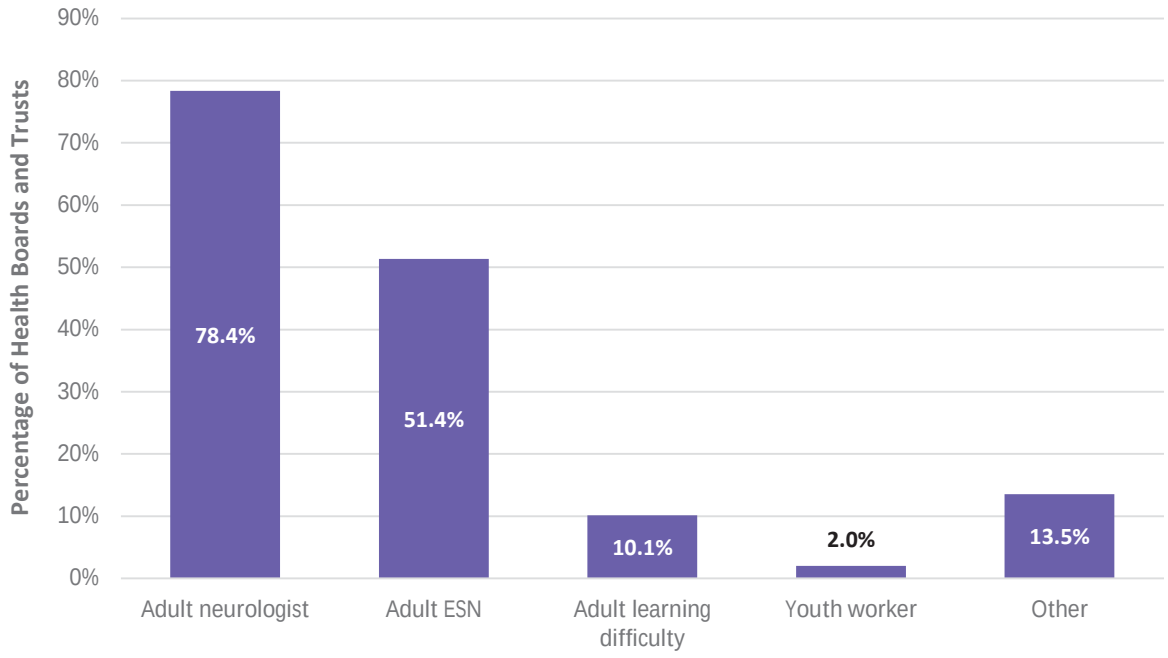


Figure 12: Adult professionals indicated as routinely involved in the transition or transfer of paediatric patients to adult services (N=148)

Table 27: Health Boards and Trusts that had an agreed referral pathway to adult services

Country/network	Yes	No
England and Wales (N = 148)	75.7% (112/148)	24.3% (36/148)
England (N = 142)	75.4% (107/142)	24.6% (35/142)
Wales (N = 6)	83.3% (5/6)	16.7% (1/6)
BRPNF (N = 14)	57.1% (8/14)	42.9% (6/14)
CEWT (N = 6)	83.3% (5/6)	16.7% (1/6)
EPEN (N = 15)	86.7% (13/15)	13.3% (2/15)
EPIC (N = 9)	88.9% (8/9)	11.1% (1/9)
NTPEN (N = 17)	70.6% (12/17)	29.4% (5/17)
NWEIG (N = 13)	69.2% (9/13)	30.8% (4/13)
ORENG (N = 7)	71.4% (5/7)	28.6% (2/7)
PENNEC (N = 9)	55.6% (5/9)	44.4% (4/9)
SETPEG (N = 10)	70.0% (7/10)	30.0% (3/10)
SWEP (N = 5)	80.0% (4/5)	20.0% (1/5)
SWIPE (N = 11)	63.6% (7/11)	36.4% (4/11)
SWTPEG (N = 8)	100.0% (8/8)	0.0% (0/8)
TEN (N = 6)	83.3% (5/6)	16.7% (1/6)
WPNN (N = 9)	88.9% (8/9)	11.1% (1/9)
YPEN (N = 9)	88.9% (8/9)	11.1% (1/9)

Table 28: Health Boards and Trusts that had an outpatient clinic specifically for young people with epilepsies

Country/network	Yes	No
England and Wales (N = 148)	35.8% (53/148)	64.2% (95/148)
England (N = 142)	35.9% (51/142)	64.1% (91/142)
Wales (N = 6)	33.3% (2/6)	66.7% (4/6)
BRPNF (N = 14)	35.7% (5/14)	64.3% (9/14)
CEWT (N = 6)	50.0% (3/6)	50.0% (3/6)
EPEN (N = 15)	60.0% (9/15)	40.0% (6/15)
EPIC (N = 9)	22.2% (2/9)	77.8% (7/9)
NTPEN (N = 17)	41.2% (7/17)	58.8% (10/17)
NWEIG (N = 13)	46.2% (6/13)	53.8% (7/13)
ORENG (N = 7)	42.9% (3/7)	57.1% (4/7)
PENNEC (N = 9)	11.1% (1/9)	88.9% (8/9)
SETPEG (N = 10)	30.0% (3/10)	70.0% (7/10)
SWEP (N = 5)	40.0% (2/5)	60.0% (3/5)
SWIPE (N = 11)	18.2% (2/11)	81.8% (9/11)
SWTPEG (N = 8)	37.5% (3/8)	62.5% (5/8)
TEN (N = 6)	16.7% (1/6)	83.3% (5/6)
WPNN (N = 9)	55.6% (5/9)	44.4% (4/9)
YPEN (N = 9)	11.1% (1/9)	88.9% (8/9)

Table 29: Age at which the outpatient clinic typically accepted young people with epilepsies

Country/network	Mean age	Median age	Minimum age	Maximum age
England and Wales (N = 53)	14.6	15	11	17
England (N = 51)	14.5	14	11	17
Wales (N = 2)	16.0	16	16	16
BRPNF (N = 5)	15.2	16	14	16
CEWT (N = 3)	13.0	13	12	14
EPEN (N = 9)	14.4	15	12	16
EPIC (N = 2)	14.0	14	14	14
NTPEN (N = 7)	14.7	15	12	17
NWEIG (N = 6)	13.5	13.5	12	16
ORENG (N = 3)	16.0	16	16	16
PENNEC (N = 1)	14.0	14	14	14
SETPEG (N = 3)	16.3	16	16	17
SWEP (N = 2)	16.0	16	16	16
SWIPE (N = 3)	15.0	15	14	16
SWTPEG (N = 2)	15.0	16	12	17
TEN (N = 6)	11.0	11	11	11
WPNN (N = 9)	11.0	11	11	11
YPEN (N = 9)	14.6	14	13	16

Table 30: Health Boards and Trusts that have an outpatient service for epilepsy where there is a presence of both adult and paediatric professionals

Country/network	Yes	No
England and Wales (N = 148)	54.1% (80/148)	45.9% (68/148)
England (N = 142)	52.8% (75/142)	47.2% (67/142)
Wales (N = 6)	83.3% (5/6)	16.7% (1/6)
BRPNF (N = 14)	57.1% (8/14)	42.9% (6/14)
CEWT (N = 6)	33.3% (2/6)	66.7% (4/6)
EPEN (N = 15)	60.0% (9/15)	40.0% (6/15)
EPIC (N = 9)	44.4% (4/9)	55.6% (5/9)
NTPEN (N = 17)	64.7% (11/17)	35.3% (6/17)
NWEIG (N = 13)	61.5% (8/13)	38.5% (5/13)
ORENG (N = 7)	71.4% (5/7)	28.6% (2/7)
PENNEC (N = 9)	11.1% (1/9)	88.9% (8/9)
SETPEG (N = 10)	50.0% (5/10)	50.0% (5/10)
SWEP (N = 5)	80.0% (4/5)	20.0% (1/5)
SWIPE (N = 11)	54.5% (6/11)	45.5% (5/11)
SWTPEG (N = 8)	75.0% (6/8)	25.0% (2/8)
TEN (N = 6)	16.7% (1/6)	83.3% (5/6)
WPNN (N = 9)	55.6% (5/9)	44.4% (4/9)
YPEN (N = 9)	55.6% (5/9)	44.4% (4/9)

Table 31: Structure of outpatient clinic service for epilepsy where there is a presence of both adult and paediatric professionals

Country/network	Several joint appointments	A single joint appointment	A mix of joint and individual appointments	Other
England and Wales (N = 80)	6.3% (5/80)	61.3% (49/80)	23.8% (19/80)	8.8% (7/80)
England (N = 75)	5.3% (4/75)	64% (48/75)	21.3% (16/75)	9.3% (7/75)
Wales (N = 5)	20.0% (1/5)	20.0% (1/5)	60.0% (3/5)	0.0% (0/5)
BRPNF (N = 8)	12.5% (1/8)	75% (6/8)	12.5% (1/8)	0.0% (0/8)
CEWT (N = 2)	50.0% (1/2)	0.0% (0/2)	0.0% (0/2)	50.0% (1/2)
EPEN (N = 9)	0.0% (0/9)	55.6% (5/9)	33.3% (3/9)	11.1% (1/9)
EPIC (N = 4)	0.0% (0/4)	75% (3/4)	25% (1/4)	0.0% (0/4)
NTPEN (N = 11)	9.1% (1/11)	72.7% (8/11)	9.1% (1/11)	9.1% (1/11)
NWEIG (N = 8)	0.0% (0/8)	87.5% (7/8)	12.5% (1/8)	0.0% (0/8)
ORENG (N = 5)	0.0% (0/5)	60.0% (3/5)	40.0% (2/5)	0.0% (0/5)
PENNEC (N = 1)	0.0% (0/1)	100.0% (1/1)	0.0% (0/1)	0.0% (0/1)
SETPEG (N = 5)	0.0% (0/5)	60.0% (3/5)	40.0% (2/5)	0.0% (0/5)
SWEP (N = 4)	25% (1/4)	25% (1/4)	50.0% (2/4)	0.0% (0/4)
SWIPE (N = 6)	0.0% (0/6)	16.7% (1/6)	66.7% (4/6)	16.7% (1/6)
SWTPEG (N = 6)	0.0% (0/6)	66.7% (4/6)	16.7% (1/6)	16.7% (1/6)
TEN (N = 1)	0.0% (0/1)	0.0% (0/1)	0.0% (0/1)	100.0% (1/1)
WPNN (N = 5)	20.0% (1/5)	40.0% (2/5)	20.0% (1/5)	20.0% (1/5)
YPEN (N = 5)	0.0% (0/5)	100.0% (5/5)	0.0% (0/5)	0.0% (0/5)

Table 32: Estimated percentage of young people transferred to adult services through a joint professional process

Country/network	Mean	Minimum	Maximum
England and Wales (N = 80)	73.5%	1.0%	100.0%
England (N = 75)	74.8%	1.0%	100.0%
Wales (N = 5)	55.0%	30.0%	80.0%
BRPNF (N = 8)	90.6%	70.0%	100.0%
CEWT (N = 2)	55.0%	40.0%	70.0%
EPEN (N = 9)	78.4%	1.0%	100.0%
EPIC (N = 4)	75.0%	20.0%	100.0%
NTPEN (N = 11)	56.5%	1.0%	90.0%
NWEIG (N = 8)	75.8%	50.0%	100.0%
ORENG (N = 5)	81.0%	40.0%	95.0%
PENNEC (N = 1)	100.0%	100.0%	100.0%
SETPEG (N = 5)	78.0%	50.0%	100.0%
SWEP (N = 4)	48.8%	30.0%	65.0%
SWIPE (N = 6)	76.5%	10.0%	99.0%
SWTPEG (N = 6)	85.0%	50.0%	100.0%
TEN (N = 1)	100.0%	100.0%	100.0%
WPNN (N = 5)	53.0%	5.0%	100.0%
YPEN (N = 5)	78.0%	30.0%	100.0%

Table 33: Health Boards and Trusts using structured resources to support transition

Country/network	Yes	No
England and Wales (N = 148)	51.4% (76/148)	48.6% (72/148)
England (N = 142)	52.8% (75/142)	47.2% (67/142)
Wales (N = 6)	16.7% (1/6)	83.3% (5/6)
BRPNF (N = 14)	35.7% (5/14)	64.3% (9/14)
CEWT (N = 6)	50.0% (3/6)	50.0% (3/6)
EPEN (N = 15)	60.0% (9/15)	40.0% (6/15)
EPIC (N = 9)	11.1% (1/9)	88.9% (8/9)
NTPEN (N = 17)	47.1% (8/17)	52.9% (9/17)
NWEIG (N = 13)	61.5% (8/13)	38.5% (5/13)
ORENG (N = 7)	42.9% (3/7)	57.1% (4/7)
PENNEC (N = 9)	33.3% (3/9)	66.7% (6/9)
SETPEG (N = 10)	30.0% (3/10)	70.0% (7/10)
SWEP (N = 5)	20.0% (1/5)	80.0% (4/5)
SWIPE (N = 11)	90.9% (10/11)	9.1% (1/11)
SWTPEG (N = 8)	75.0% (6/8)	25.0% (2/8)
TEN (N = 6)	66.7% (4/6)	33.3% (2/6)
WPNN (N = 9)	66.7% (6/9)	33.3% (3/9)
YPEN (N = 9)	77.8% (7/9)	22.2% (2/9)

Table 34: Adult professionals indicated as routinely involved in the transition or transfer of paediatric patients to adult services

Country/ network	Adult epilepsy specialist nurse	Adult learning difficulty	Adult neurologist	Youth worker	Other
England and Wales (N = 148)	51.4% (76/148)	10.1% (15/148)	78.4% (116/148)	2.0% (3/148)	13.5% (20/148)
England (N = 142)	50.0% (71/142)	9.9% (14/142)	77.5% (110/142)	2.1% (3/142)	13.4% (19/142)
Wales (N = 6)	83.3% (5/6)	16.7% (1/6)	100.0% (6/6)	0.0% (0/6)	16.7% (1/6)
BRPNF (N = 14)	42.9% (6/14)	7.1% (1/14)	92.9% (13/14)	0.0% (0/14)	14.3% (2/14)
CEWT (N = 6)	66.7% (4/6)	16.7% (1/6)	33.3% (2/6)	16.7% (1/6)	16.7% (1/6)
EPEN (N = 15)	53.3% (8/15)	20.0% (3/15)	80.0% (12/15)	6.7% (1/15)	13.3% (2/15)
EPIC (N = 9)	33.3% (3/9)	0.0% (0/9)	77.8% (7/9)	0.0% (0/9)	22.2% (2/9)
NTPEN (N = 17)	29.4% (5/17)	5.9% (1/17)	88.2% (15/17)	0.0% (0/17)	5.9% (1/17)
NWEIG (N = 13)	53.8% (7/13)	0.0% (0/13)	69.2% (9/13)	0.0% (0/13)	7.7% (1/13)
ORENG (N = 7)	71.4% (5/7)	28.6% (2/7)	100.0% (7/7)	0.0% (0/7)	14.3% (1/7)
PENNEC (N = 9)	22.2% (2/9)	0.0% (0/9)	55.6% (5/9)	0.0% (0/9)	22.2% (2/9)
SETPEG (N = 10)	70.0% (7/10)	10.0% (1/10)	100.0% (10/10)	0.0% (0/10)	0.0% (0/10)
SWEP (N = 5)	80.0% (4/5)	20.0% (1/5)	100.0% (5/5)	0.0% (0/5)	20.0% (1/5)
SWIPE (N = 11)	63.6% (7/11)	18.2% (2/11)	36.4% (4/11)	0.0% (0/11)	27.3% (3/11)
SWTPEG (N = 8)	50.0% (4/8	12.5% (1/8)	75.0% (6/8)	0.0% (0/8)	0.0% (0/8
TEN (N = 6)	66.7% (4/6)	0.0% (0/6)	83.3% (5/6)	0.0% (0/6)	0.0% (0/6)
WPNN (N = 9)	55.6% (5/9)	11.1% (1/9)	100.0% (9/9)	11.1% (1/9)	33.3% (3/9)
YPEN (N = 9)	55.6% (5/9)	11.1% (1/9)	77.8% (7/9)	0.0% (0/9)	11.1% (1/9)

8.7 Mental health

The key findings and recommendations for this audit measure are found on page 18.

In **12.8% (19/148)** of Health Boards and Trusts mental health provision is facilitated within epilepsy clinics. In nine of those nineteen Health Boards and Trusts this mental health provision involved direct co-located clinical care and in eight of the nineteen it comprised multi-disciplinary team meetings where epilepsy and mental health professionals discussed individual patients.

Of the 129 Health Boards and Trusts that were unable to facilitate mental health provision within epilepsy clinics only 6.2% (8/129) indicated they had an action plan describing steps towards co-located mental health provision.

Figure 13 shows the proportion of Health Boards and Trusts able to routinely provide formal screening services for diagnoses related to epilepsy. Almost three in every four (107/148) of Health Boards and Trusts indicated they had no formal screening services for Attention Deficit Hyperactivity Disorder (ADHD), Autistic Spectrum Disorder (ASD) and mental health disorders.

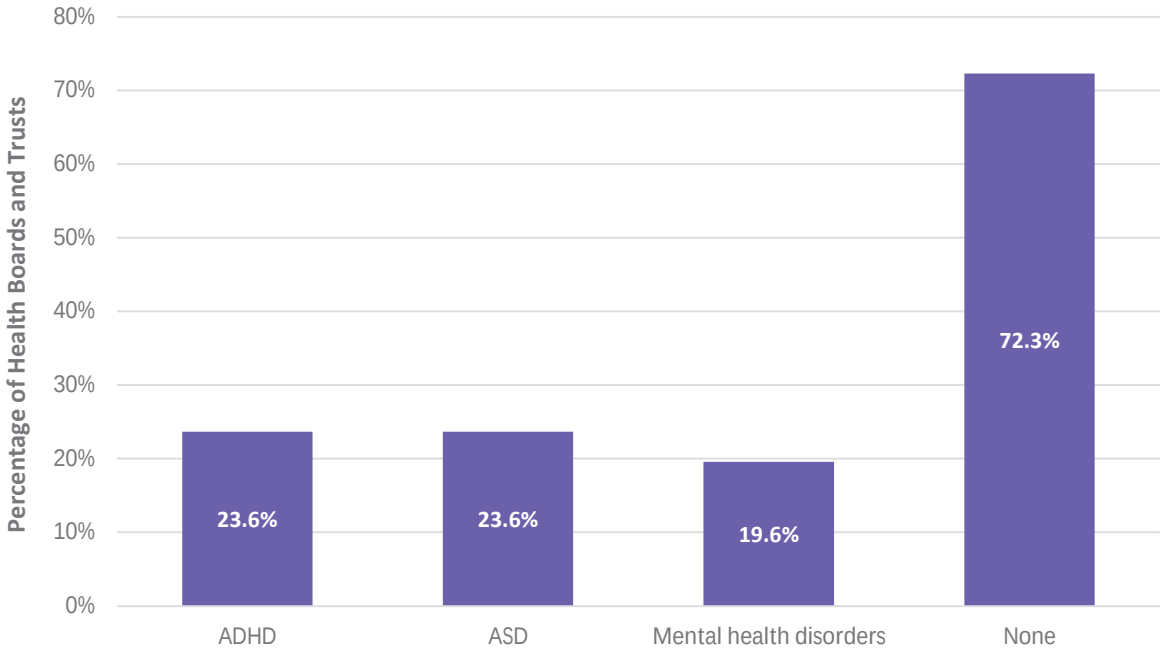


Figure 13: Percentage of Health Boards and Trusts routinely providing formal screening services (n=148)

Agreed referral pathways for children and young people with mental health concerns were reported to not be in place in **36.5%** (**54/148)** of Health Boards and Trusts.

Figure 14 shows the percentage of Health Boards and Trusts that could refer to mental health assessment services, either within or outside of their Health Board or Trust. Some were not able to refer patients for assessments by clinical psychology services (36/147) or psychiatric services (15/147), while a higher number were not able to refer to educational psychology (81/147) or neuropsychology services (76/147). Most could achieve formal developmental assessment (123/147) where required.

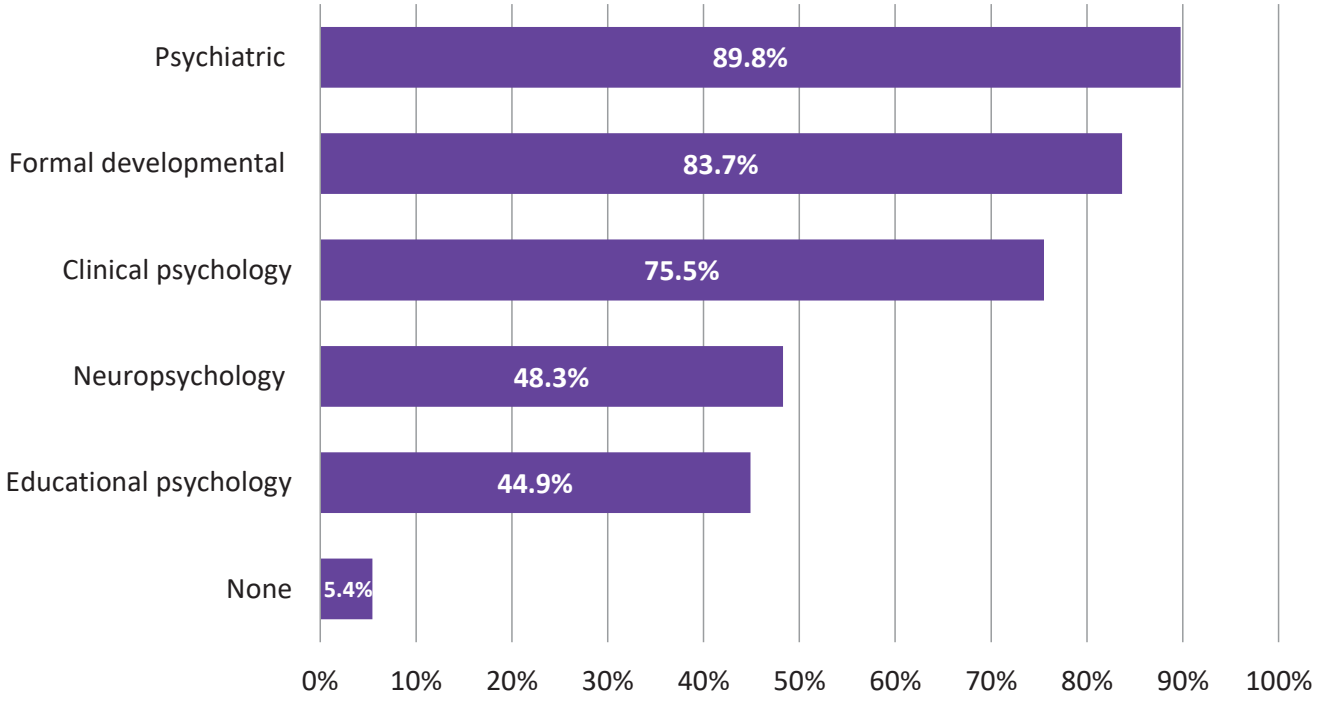


Figure 14:
Percentage of Health Boards and Trusts that could refer to mental health services (n=148)

Table 35: Health Boards and Trusts that routinely, formally screen for diagnoses related to epilepsy

Country/network	ADHD	ASD	Mental health disorders	None
England and Wales (N = 148)	23.6% (35/148)	23.6% (35/148)	19.6% (29/148)	72.3% (107/148)
England (N = 142)	23.9% (34/142)	23.9% (34/142)	19.7% (28/142)	71.8% (102/142)
Wales (N = 6)	16.7% (1/6)	16.7% (1/6)	16.7% (1/6)	83.3% (5/6)
BRPNF (N = 14)	14.3% (2/14)	14.3% (2/14)	14.3% (2/14)	85.7% (12/14)
CEWT (N = 6)	50.0% (3/6)	50.0% (3/6)	33.3% (2/6)	50.0% (3/6)
EPEN (N = 15)	13.3% (2/15)	13.3% (2/15)	6.7% (1/15)	86.7% (13/15)
EPIC (N = 9)	33.3% (3/9)	33.3% (3/9)	11.1% (1/9)	66.7% (6/9)
NTPEN (N = 17)	17.6% (3/17)	17.6% (3/17)	17.6% (3/17)	70.6% (12/17)
NWEIG (N = 13)	23.1% (3/13)	23.1% (3/13)	30.8% (4/13)	69.2% (9/13)
ORENG (N = 7)	42.9% (3/7)	42.9% (3/7)	28.6% (2/7)	57.1% (4/7)
PENNEC (N = 9)	55.6% (5/9)	55.6% (5/9)	55.6% (5/9)	44.4% (4/9)
SETPEG (N = 10)	30.0% (3/10)	30.0% (3/10)	30.0% (3/10)	70.0% (7/10)
SWEP (N = 5)	20.0% (1/5)	20.0% (1/5)	20.0% (1/5)	80.0% (4/5)
SWIPE (N = 11)	9.1% (1/11)	0.0% (0/11)	9.1% (1/11)	90.9% (10/11)
SWTPEG (N = 8)	37.5% (3/8)	37.5% (3/8)	25.0% (2/8)	50.0% (4/8)
TEN (N = 6)	16.7% (1/6)	33.3% (2/6)	0.0% (0/6)	66.7% (4/6)
WPNN (N = 9)	11.1% (1/9)	11.1% (1/9)	11.1% (1/9)	88.9% (8/9)
YPEN (N = 9)	11.1% (1/9)	11.1% (1/9)	11.1% (1/9)	77.8% (7/9)

Table 36: Health Boards and Trusts with agreed referral pathways for children and young people with mental health concerns

Country/network	Yes	No
England and Wales (N = 148)	63.5% (94/148)	36.5% (54/148)
England (N = 142)	64.8% (92/142)	35.2% (50/142)
Wales (N = 6)	33.3% (2/6)	66.7% (4/6)
BRPNF (N = 14)	64.3% (9/14)	35.7% (5/14)
CEWT (N = 6)	83.3% (5/6)	16.7% (1/6)
EPEN (N = 15)	60% (9/15)	40% (6/15)
EPIC (N = 9)	66.7% (6/9)	33.3% (3/9)
NTPEN (N = 17)	70.6% (12/17)	29.4% (5/17)
NWEIG (N = 13)	61.5% (8/13)	38.5% (5/13)
ORENG (N = 7)	42.9% (3/7)	57.1% (4/7)
PENNEC (N = 9)	66.7% (6/9)	33.3% (3/9)
SETPEG (N = 10)	70.0% (7/10)	30.0% (3/10)
SWEP (N = 5)	40% (2/5)	60% (3/5)
SWIPE (N = 11)	63.6% (7/11)	36.4% (4/11)
SWTPEG (N = 8)	75.0% (6/8)	25.0% (2/8)
TEN (N = 6)	33.3% (2/6)	66.7% (4/6)
WPNN (N = 9)	88.9% (8/9)	11.1% (1/9)
YPEN (N = 9)	44.4% (4/9)	55.6% (5/9)

Table 37: Health Boards and Trusts that were facilitating mental health provision within epilepsy clinics

Country/network	Yes	No
England and Wales (N = 148)	12.8% (19/148)	87.2% (129/148)
England (N = 142)	13.4% (19/142)	86.6% (123/142)
Wales (N = 6)	0.0% (0/6)	100.0% (6/6)
BRPNF (N = 14)	0.0% (0/14)	100.0% (14/14)
CEWT (N = 6)	0.0% (0/6)	100.0% (6/6)
EPEN (N = 15)	26.7% (4/15)	73.3% (11/15)
EPIC (N = 9)	11.1% (1/9)	88.9% (8/9)
NTPEN (N = 17)	23.5% (4/17)	76.5% (13/17)
NWEIG (N = 13)	15.4% (2/13)	84.6% (11/13)
ORENG (N = 7)	0.0% (0/7)	100.0% (7/7)
PENNEC (N = 9)	0.0% (0/9)	100.0% (9/9)
SETPEG (N = 10)	30.0% (3/10)	70.0% (7/10)
SWEP (N = 5)	0.0% (0/5)	100.0% (5/5)
SWIPE (N = 11)	0.0% (0/11)	100.0% (11/11)
SWTPEG (N = 8)	12.5% (1/8)	87.5% (7/8)
TEN (N = 6)	16.7% (1/6)	83.3% (5/6)
WPNN (N = 9)	22.2% (2/9)	77.8% (7/9)
YPEN (N = 9)	11.1% (1/9)	88.9% (8/9)

Table 38: Composition of mental health provision in Health Boards and Trusts that were facilitating mental health provision within epilepsy clinics

Country/network	Epilepsy Clinics where mental health professionals can provide direct co-located clinical care	MDT meetings where epilepsy and mental health professionals discuss individual patients	Other
England and Wales (N = 148)	5.4% (8/148)	6.1% (9/148)	5.4% (8/148)
England (N = 142)	5.6% (8/142)	6.3% (9/142)	5.6% (8/142)
Wales (N = 6)	0.0% (0/6)	0.0% (0/6)	0.0% (0/6)
BRPNF (N = 14)	0.0% (0/14)	0.0% (0/14)	0.0% (0/14)
CEWT (N = 6)	0.0% (0/6)	0.0% (0/6)	0.0% (0/6)
EPEN (N = 15)	13.3% (2/15)	6.7% (1/15)	6.7% (1/15)
EPIC (N = 9)	0.0% (0/9)	11.1% (1/9)	0.0% (0/9)
NTPEN (N = 17)	5.9% (1/17)	11.8% (2/17)	17.6% (3/17)
NWEIG (N = 13)	7.7% (1/13)	15.4% (2/13)	0.0% (0/13)
ORENG (N = 7)	0.0% (0/7)	0.0% (0/7)	0.0% (0/7)
PENNEC (N = 9)	0.0% (0/9)	0.0% (0/9)	0.0% (0/9)
SETPEG (N = 10)	30.0% (3/10)	20.0% (2/10)	10.0% (1/10)
SWEP (N = 5)	0.0% (0/5)	0.0% (0/5)	0.0% (0/5)
SWIPE (N = 11)	0.0% (0/11)	0.0% (0/11)	0.0% (0/11)
SWTPEG (N = 8)	12.5% (1/8)	12.5% (1/8)	0.0% (0/8)
TEN (N = 6)	0.0% (0/6)	0.0% (0/6)	16.7% (1/6)
WPNN (N = 9)	0.0% (0/9)	0.0% (0/9)	11.1% (1/9)
YPEN (N = 9)	0.0% (0/9)	0.0% (0/9)	11.1% (1/9)

Table 39: Health Boards and Trusts that had an action plan describing steps towards obtaining co-located mental health provision within epilepsy clinics

Country/network	Yes	No
England and Wales (N = 129)	6.2% (8/129)	93.8% (121/129)
England (N = 123)	6.5% (8/123)	93.5% (115/123)
Wales (N = 6)	0.0% (0/6)	100.0% (6/6)
BRPNF (N = 14)	0.0% (0/14)	100.0% (14/14)
CEWT (N = 6)	16.7% (1/6)	83.3% (5/6)
EPEN (N = 11)	0.0% (0/11)	100.0% (11/11)
EPIC (N = 8)	12.5% (1/8)	87.5% (7/8)
NTPEN (N = 13)	7.7% (1/13)	92.3% (12/13)
NWEIG (N = 11)	0.0% (0/11)	100.0% (11/11)
ORENG (N = 7)	0.0% (0/7)	100.0% (7/7)
PENNEC (N = 9)	11.1% (1/9)	88.9% (8/9)
SETPEG (N = 7)	0.0% (0/7)	100.0% (7/7)
SWEP (N = 5)	0.0% (0/5)	100.0% (5/5)
SWIPE (N = 11)	9.1% (1/11)	90.9% (10/11)
SWTPEG (N = 7)	0.0% (0/7)	100.0% (7/7)
TEN (N = 5)	20.0% (1/5)	80.0% (4/5)
WPNN (N = 7)	0.0% (0/7)	100.0% (7/7)
YPEN (N = 8)	25.0% (2/8)	75.0% (6/8)

Table 40: Health Boards and Trusts that could refer to mental health assessment services

Country/network	Clinical psychology	Psychiatric
England and Wales (N = 147)	75.5% (111/147)	89.8% (132/147)
England (N = 141)	76.6% (108/141)	90.1% (127/141)
Wales (N = 6)	50.0% (3/6)	83.3% (5/6)
BRPNF (N = 14)	85.7% (12/14)	85.7% (12/14)
CEWT (N = 6)	100.0% (6/6)	100.0% (6/6)
EPEN (N = 15)	60.0% (9/15)	80.0% (12/15)
EPIC (N = 9)	66.7% (6/9)	100.0% (9/9)
NTPEN (N = 17)	88.2% (15/17)	88.2% (15/17)
NWEIG (N = 13)	92.3% (12/13)	100.0% (13/13)
ORENG (N = 7)	71.4% (5/7)	100.0% (7/7)
PENNEC (N = 9)	77.8% (7/9)	100.0% (9/9)
SETPEG (N = 10)	90.0% (9/10)	100.0% (10/10)
SWEP (N = 5)	40.0% (2/5)	80.0% (4/5)
SWIPE (N = 10)	100.0% (10/10)	100.0% (10/10)
SWTPEG (N = 8)	37.5% (3/8)	62.5% (5/8)
TEN (N = 6)	33.3% (2/6)	50.0% (3/6)
WPNN (N = 9)	66.7% (6/9)	88.9% (8/9)
YPEN (N = 9)	77.8% (7/9)	100.0% (9/9)

Table 40 cont: Health Boards and Trusts that could refer to mental health assessment services

Educational psychology	Neuropsychology	Formal developmental	None
44.9% (66/147)	48.3% (71/147)	83.7% (123/147)	5.4% (8/147)
44.7% (63/141)	49.6% (70/141)	83.7% (118/141)	5.7% (8/141)
50.0% (3/6)	16.7% (1/6)	83.3% (5/6)	0.0% (0/6)
64.3% (9/14)	50.0% (7/14)	85.7% (12/14)	0.0% (0/14)
50.0% (3/6)	66.7% (4/6)	100.0% (6/6)	0.0% (0/6)
53.3% (8/15)	26.7% (4/15)	80.0% (12/15)	13.3% (2/15)
11.1% (1/9)	55.6% (5/9)	77.8% (7/9)	0.0% (0/9)
29.4% (5/17)	64.7% (11/17)	88.2% (15/17)	5.9% (1/17)
61.5% (8/13)	61.5% (8/13)	84.6% (11/13)	0.0% (0/13)
57.1% (4/7)	71.4% (5/7)	85.7% (6/7)	0.0% (0/7)
77.8% (7/9)	55.6% (5/9)	100.0% (9/9)	0.0% (0/9)
70.0% (7/10)	60.0% (6/10)	100.0% (10/10)	100.0% (10/10)
60.0% (3/5)	20.0% (1/5)	80.0% (4/5)	0.0% (0/5)
30.0% (3/10)	60.0% (6/10)	80.0% (8/10)	0.0% (0/10)
12.5% (1/8)	37.5% (3/8)	62.5% (5/8)	37.5% (3/8)
0.0% (0/6)	16.7% (1/6)	66.7% (4/6)	33.3% (2/6)
33.3% (3/9)	22.2% (2/9)	88.9% (8/9)	0.0% (0/9)
44.4% (4/9)	33.3% (3/9)	66.7% (6/9)	0.0% (0/9)

8.8 Neurodevelopmental support

In **85.1% (126/148)** of Health Boards and Trusts, there was agreed referral criteria for children and young people with neurodevelopmental problems (for example, ASD and ADHD).

Table 41: Health Boards and Trusts that had agreed referral criteria for children and young people with neurodevelopmental problems e.g. ASD and ADHD

Country/network	Yes	No
England and Wales (N = 148)	85.1% (126/148)	14.9% (22/148)
England (N = 142)	84.5% (120/142)	15.5% (22/142)
Wales (N = 6)	100.0% (6/6)	0.0% (0/6)
BRPNF (N = 14)	85.7% (12/14)	14.3% (2/14)
CEWT (N = 6)	100.0% (6/6)	0.0% (0/6)
EPEN (N = 15)	73.3% (11/15)	26.7% (4/15)
EPIC (N = 9)	77.8% (7/9)	22.2% (2/9)
NTPEN (N = 17)	88.2% (15/17)	11.8% (2/17)
NWEIG (N = 13)	84.6% (11/13)	15.4% (2/13)
ORENG (N = 7)	85.7% (6/7)	14.3% (1/7)
PENNEC (N = 9)	88.9% (8/9)	11.1% (1/9)
SETPEG (N = 10)	90.0% (9/10)	10.0% (1/10)
SWEP (N = 5)	100.0% (5/5)	0.0% (0/5)
SWIPE (N = 11)	90.9% (10/11)	9.1% (1/11)
SWTPEG (N = 8)	87.5% (7/8)	12.5% (1/8)
TEN (N = 6)	100.0% (6/6)	0.0% (0/6)
WPNN (N = 9)	66.7% (6/9)	33.3% (3/9)
YPEN (N = 9)	77.8% (7/9)	22.2% (2/9)

8.9 Care planning

Comprehensive care planning for children and young people with epilepsy was reported to routinely take place in **76.9% (113/147)** of Health Boards and Trusts.

Table 42: Health Boards and Trusts that routinely undertake comprehensive care planning for children and young people with epilepsy

Country/network	Yes	No
England and Wales (N = 147)	76.9% (113/147)	23.1% (34/147)
England (N = 141)	78.9% (110/141)	21.1% (31/141)
Wales (N = 6)	50.0% (3/6)	50.0% (3/6)
BRPNF (N = 14)	71.4% (10/14)	28.6% (4/14)
CEWT (N = 6)	100.0% (6/6)	0.0% (0/6)
EPEN (N = 15)	80.0% (12/15)	20.0% (3/15)
EPIC (N = 9)	77.8% (7/9)	22.2% (2/9)
NTPEN (N = 17)	76.5% (13/17)	23.5% (4/17)
NWEIG (N = 13)	92.3% (12/13)	7.7% (1/13)
ORENG (N = 7)	71.4% (5/7)	28.6% (2/7)
PENNEC (N = 9)	55.6% (5/9)	44.4% (4/9)
SETPEG (N = 10)	90.0% (9/10)	10.0% (1/10)
SWEP (N = 5)	60.0% (3/5)	40.0% (2/5)
SWIPE (N = 10)	60.0% (6/10)	40.0% (4/10)
SWTPEG (N = 8)	87.5% (7/8)	12.5% (1/8)
TEN (N = 6)	66.7% (4/6)	33.3% (2/6)
WPNN (N = 9)	66.7% (6/9)	33.3% (3/9)
YPEN (N = 9)	88.9% (8/9)	11.1% (1/9)

8.10 Patient database or registry

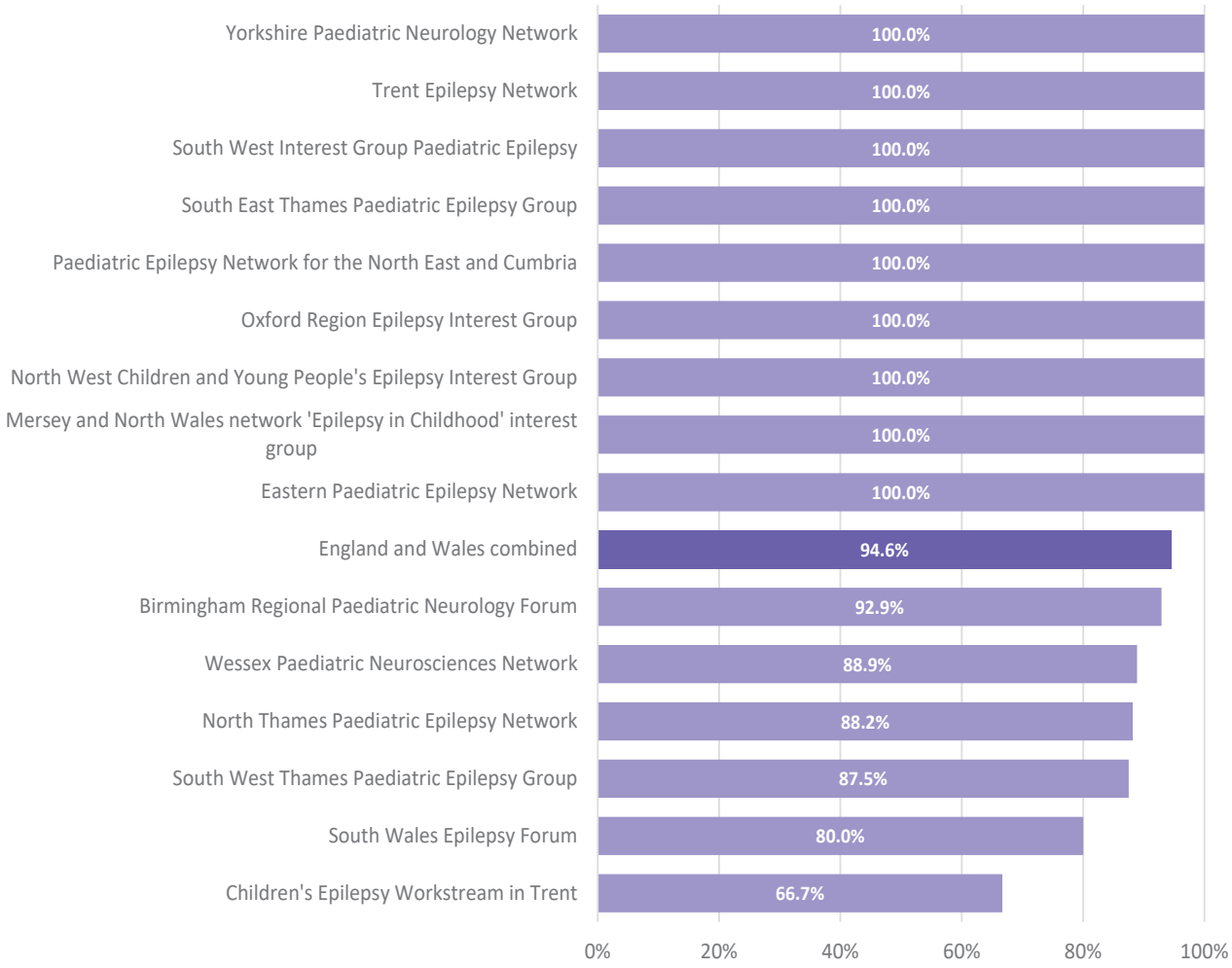
Over two-thirds of Health Boards and Trusts reported that they maintain a database or register for either all **(43/148)** or some **(58/148)** children and young people with epilepsies under their care.

Table 43: Health Boards and Trusts maintaining a database or register of children and young people with epilepsies, other than as part of Epilepsy12

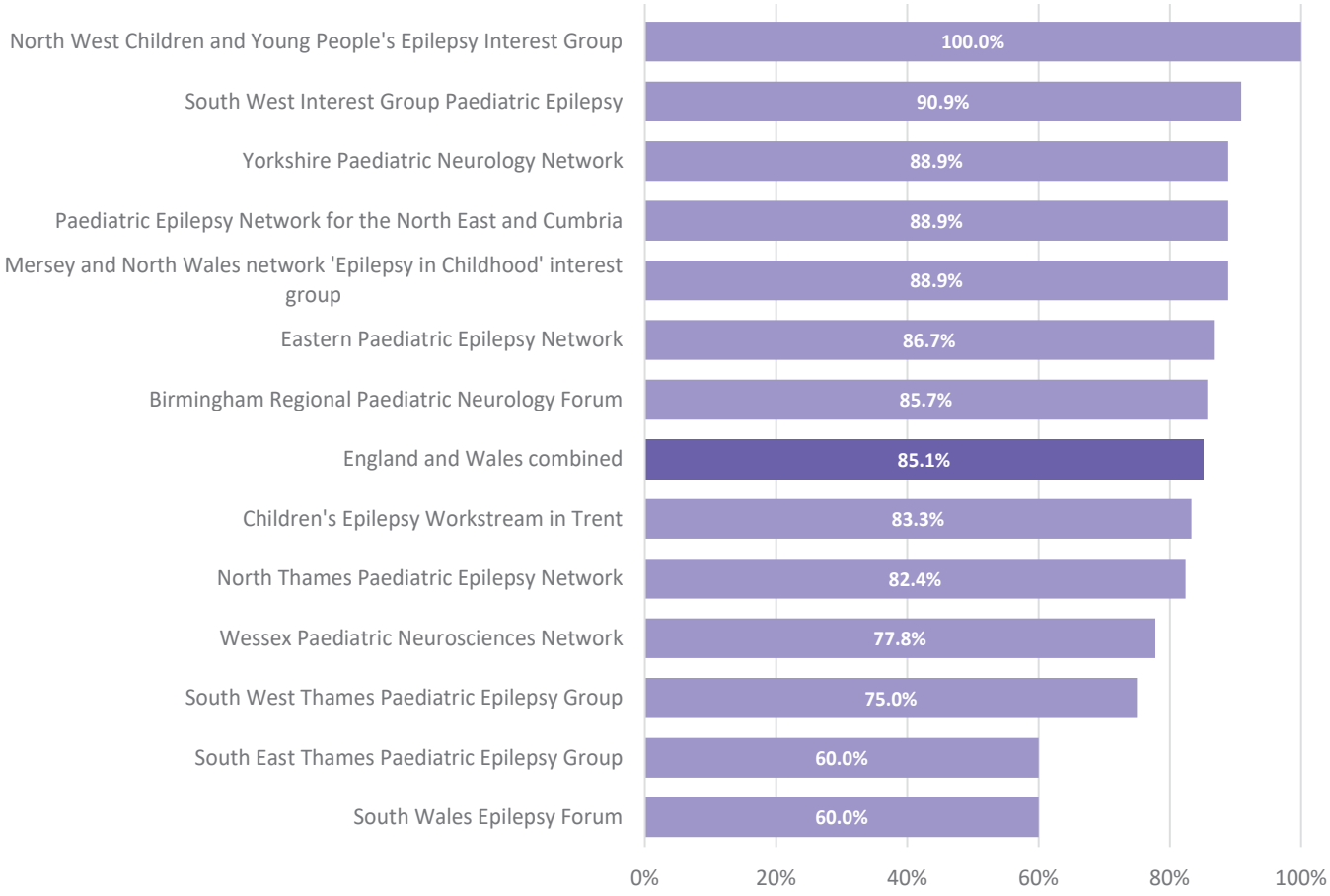
Country/network	Yes, for all children and young people	Yes, for some children and young people	No
England and Wales (N = 148)	29.1% (43/148)	39.2% (58/148)	31.8% (47/148)
England (N = 142)	30.3% (43/142)	38% (54/142)	31.7% (45/142)
Wales (N = 6)	0.0% (0/6)	66.7% (4/6)	33.3% (2/6)
BRPNF (N = 14)	7.1% (1/14)	35.7% (5/14)	57.1% (8/14)
CEWT (N = 6)	0.0% (0/6)	33.3% (2/6)	66.7% (4/6)
EPEN (N = 15)	33.3% (5/15)	33.3% (5/15)	33.3% (5/15)
EPIC (N = 9)	33.3% (3/9)	33.3% (3/9)	33.3% (3/9)
NTPEN (N = 17)	23.5% (4/17)	52.9% (9/17)	23.5% (4/17)
NWEIG (N = 13)	30.8% (4/13)	38.5% (5/13)	30.8% (4/13)
ORENG (N = 7)	14.3% (1/7)	57.1% (4/7)	28.6% (2/7)
PENNEC (N = 9)	44.4% (4/9)	33.3% (3/9)	22.2% (2/9)
SETPEG (N = 10)	30.0% (3/10)	40.0% (4/10)	30.0% (3/10)
SWEP (N = 5)	0.0% (0/5)	60.0% (3/5)	40.0% (2/5)
SWIPE (N = 11)	36.4% (4/11)	27.3% (3/11)	36.4% (4/11)
SWTPEG (N = 8)	75.0% (6/8)	12.5% (1/8)	12.5% (1/8)
TEN (N = 6)	33.3% (2/6)	33.3% (2/6)	33.3% (2/6)
WPNN (N = 9)	44.4% (4/9)	44.4% (4/9)	11.1% (1/9)
YPEN (N = 9)	22.2% (2/9)	55.6% (5/9)	22.2% (2/9)

Appendix A: 2018 key findings by OPEN UK regional networks

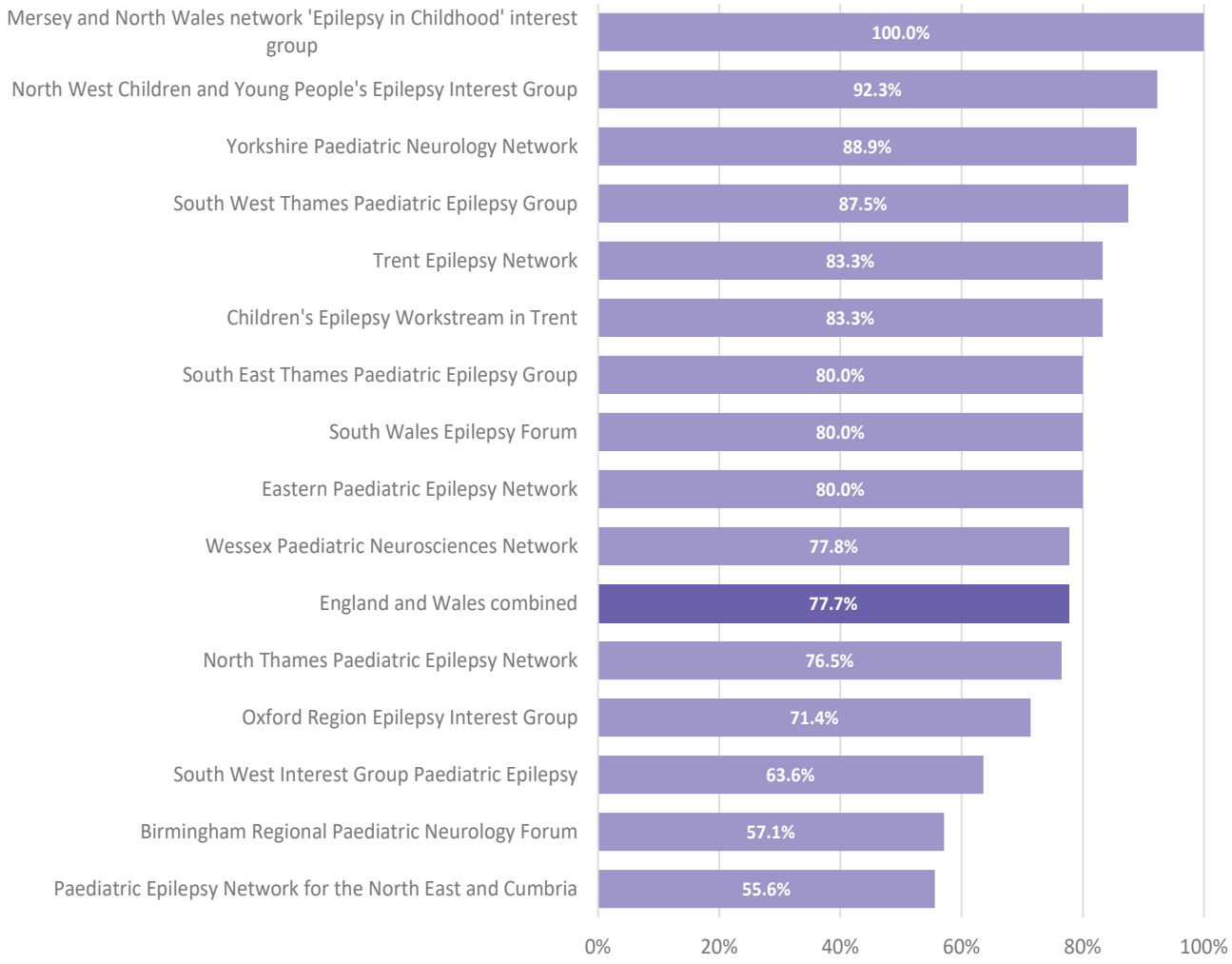
1. Percentage of Health Boards and Trusts employing a consultant paediatrician with expertise in epilepsy



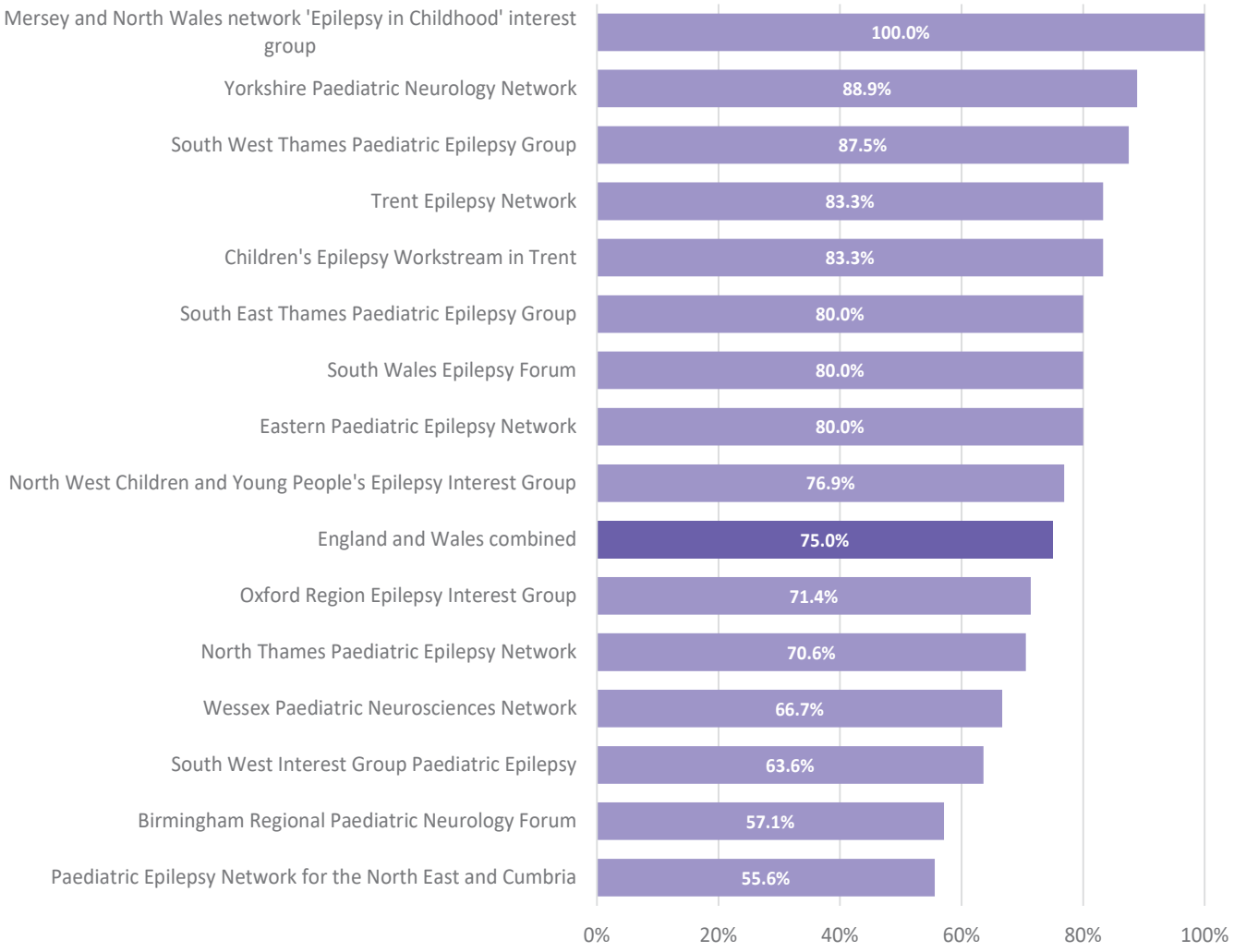
2. Percentage of Health Boards and Trusts that had a defined paediatric epilepsy clinical lead



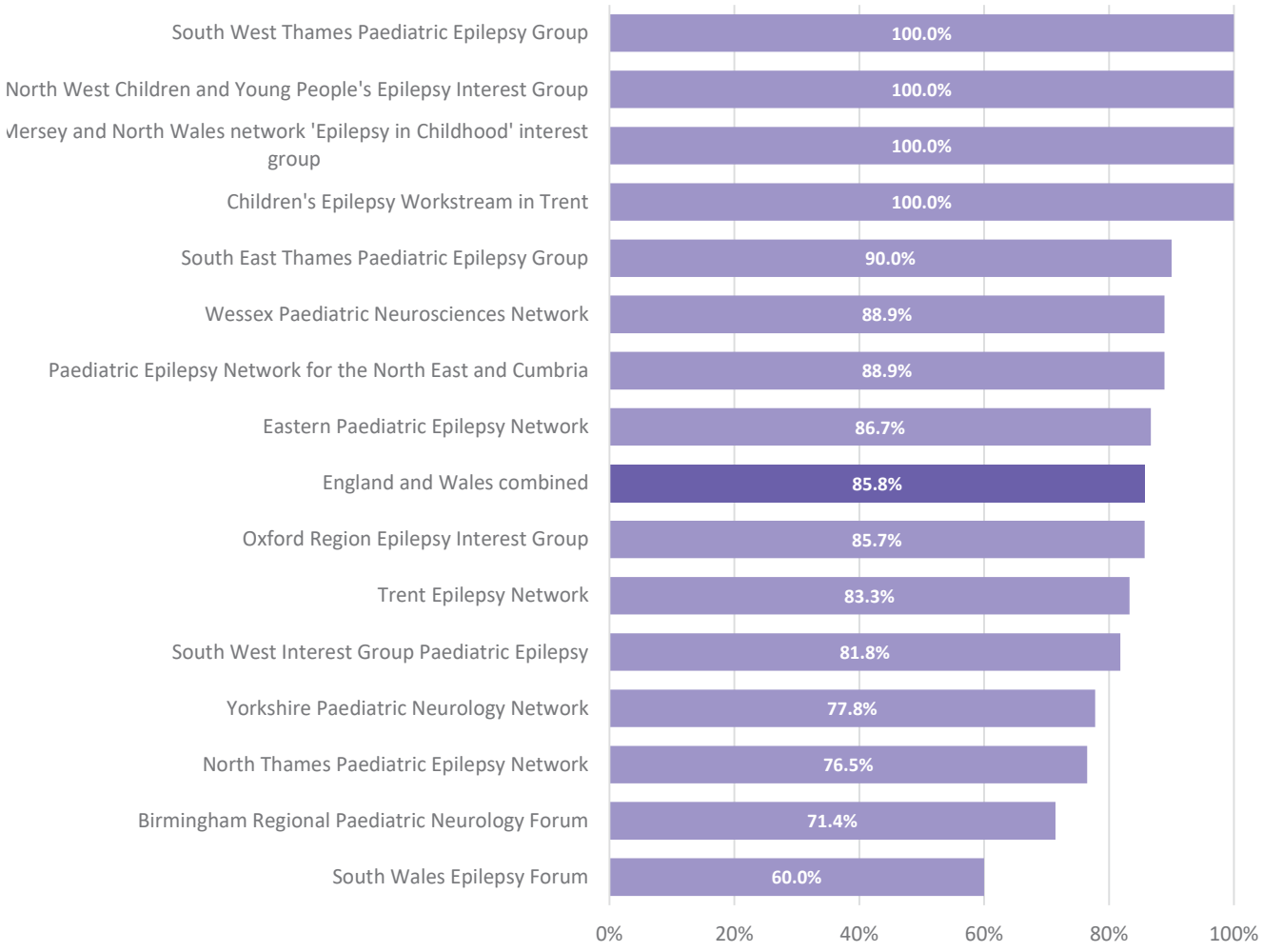
3. Percentage of Health Boards and Trusts who had some (greater than 0) epilepsy specialist nurse (ESN) provision within their paediatric service



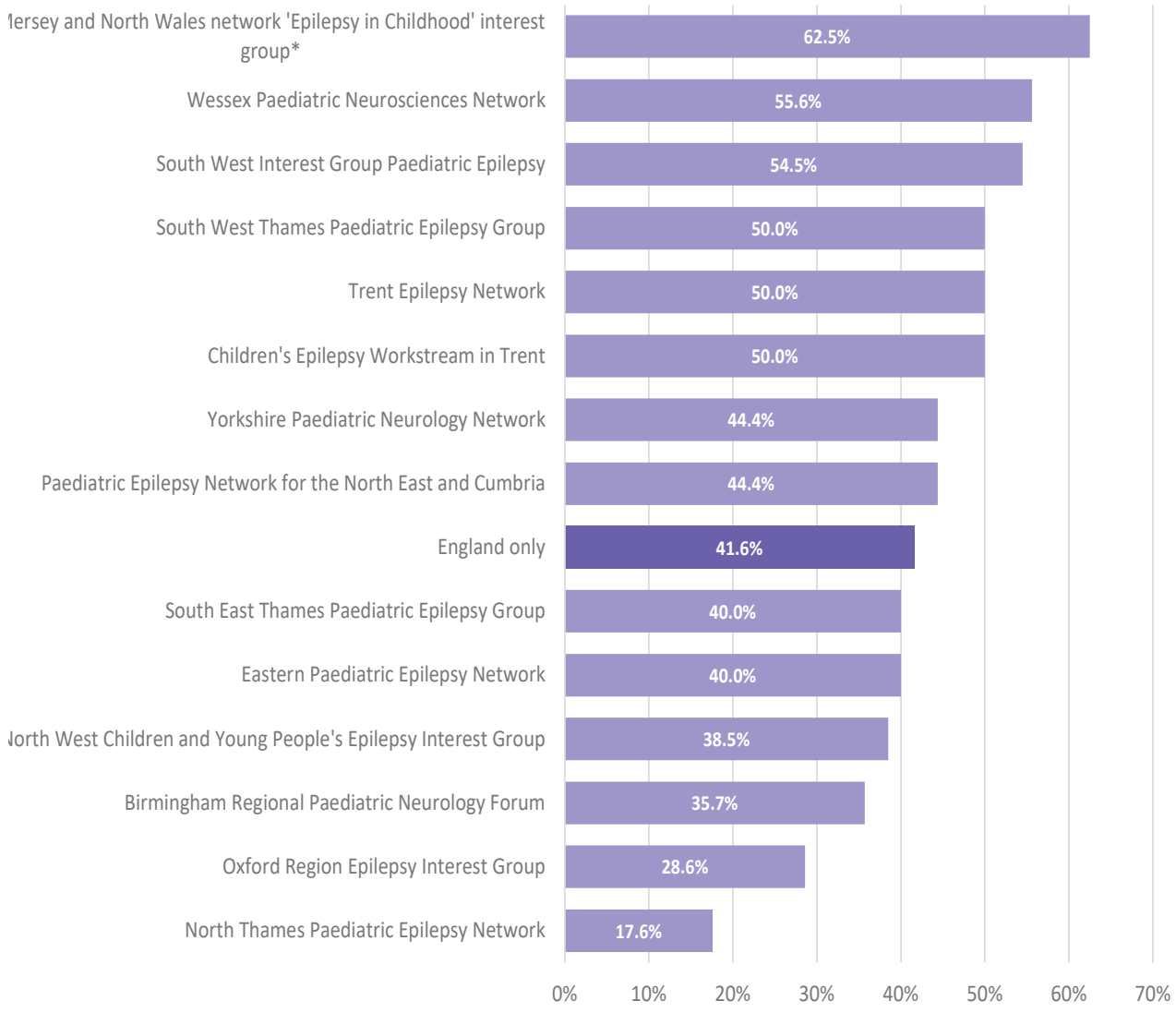
4. Percentage of Health Boards and Trusts that indicated that they could offer ESN support for rescue medication training for parents



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

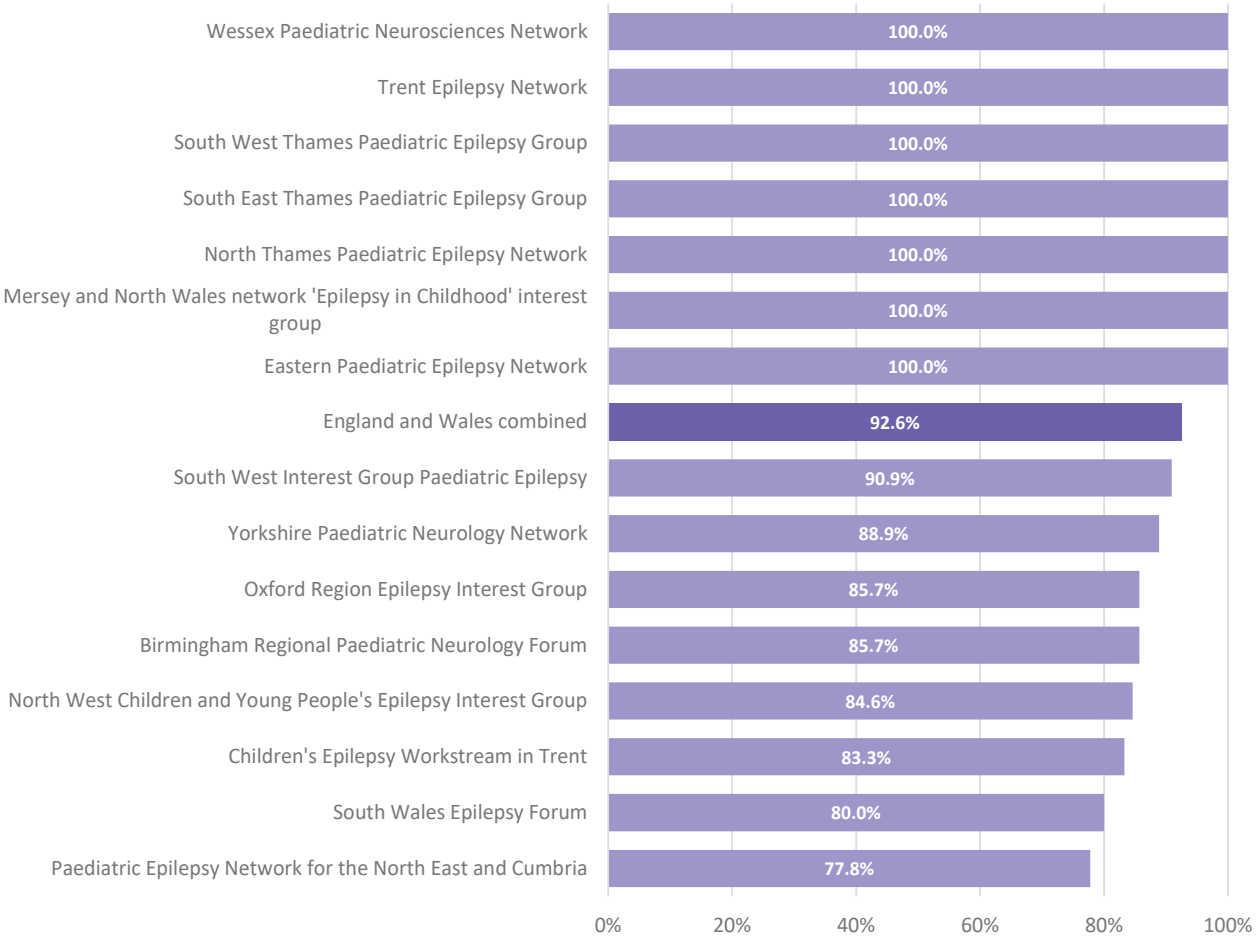


6. Percentage of Trusts in England that currently run Epilepsy Best Practice Criteria (BPC) clinics

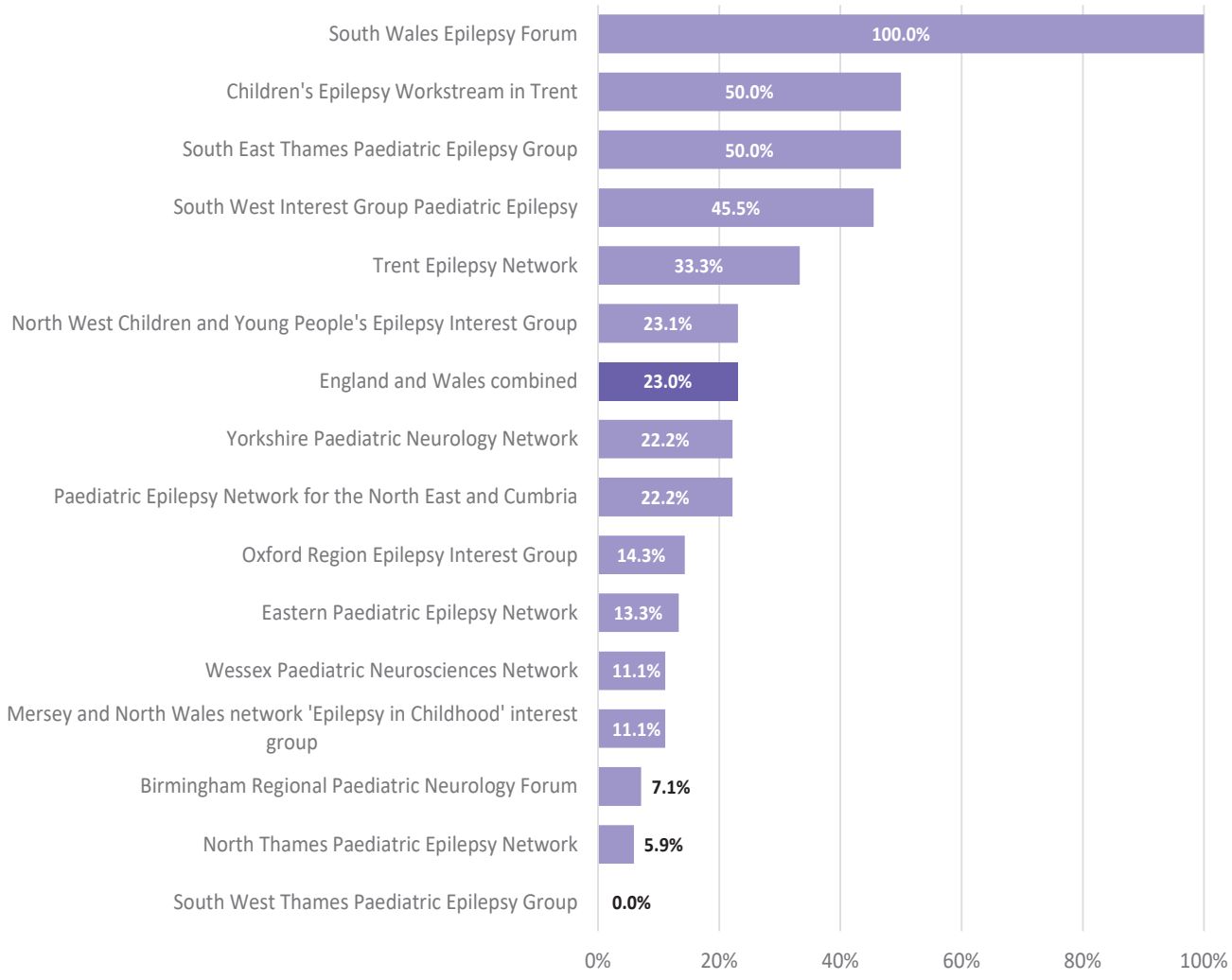


* Does not include the data from Betsi Cadwaladr University UHB as it is a Welsh Health Board

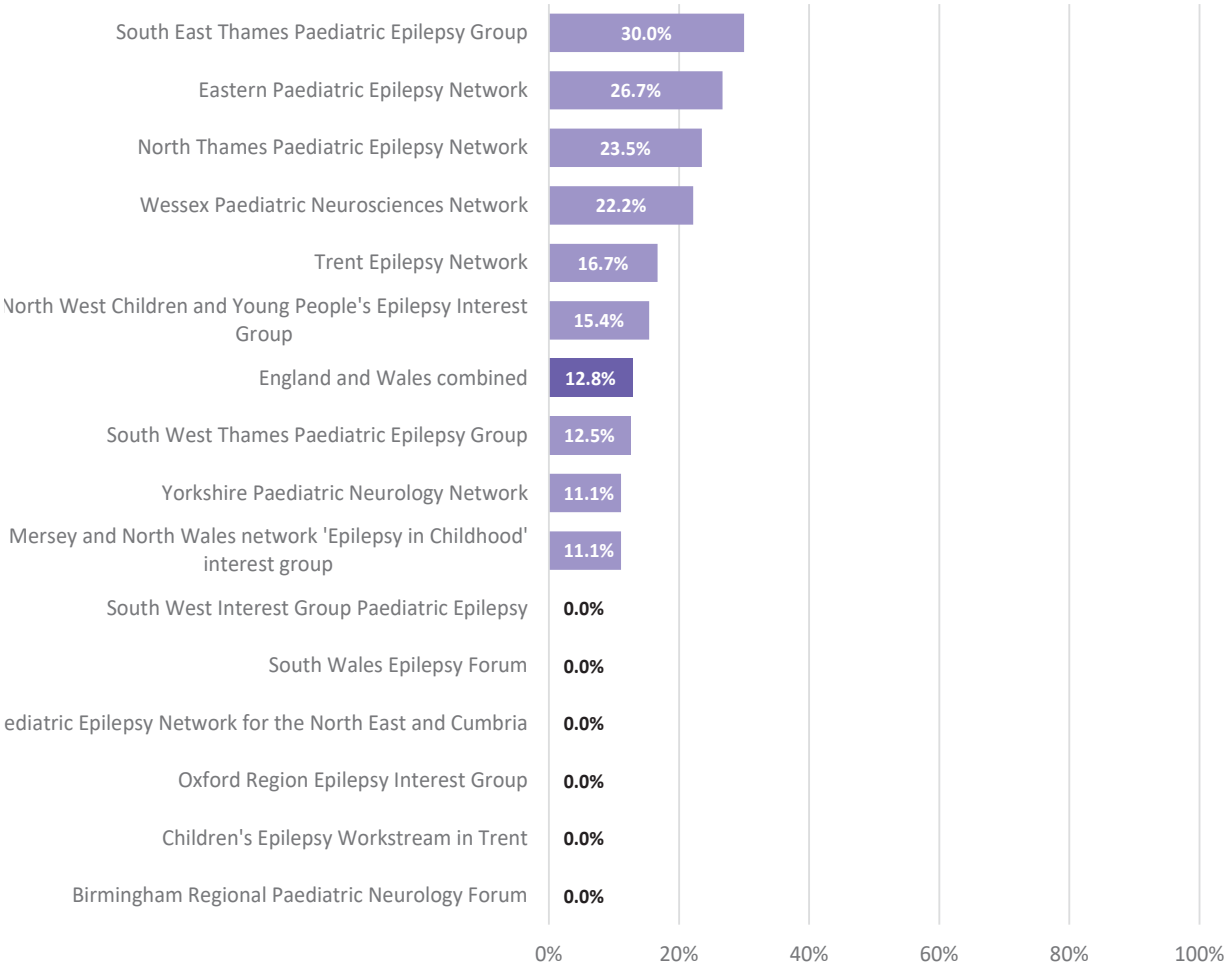
7. Percentage of Health Boards and Trusts that had agreed referral pathways to tertiary paediatric neurology services



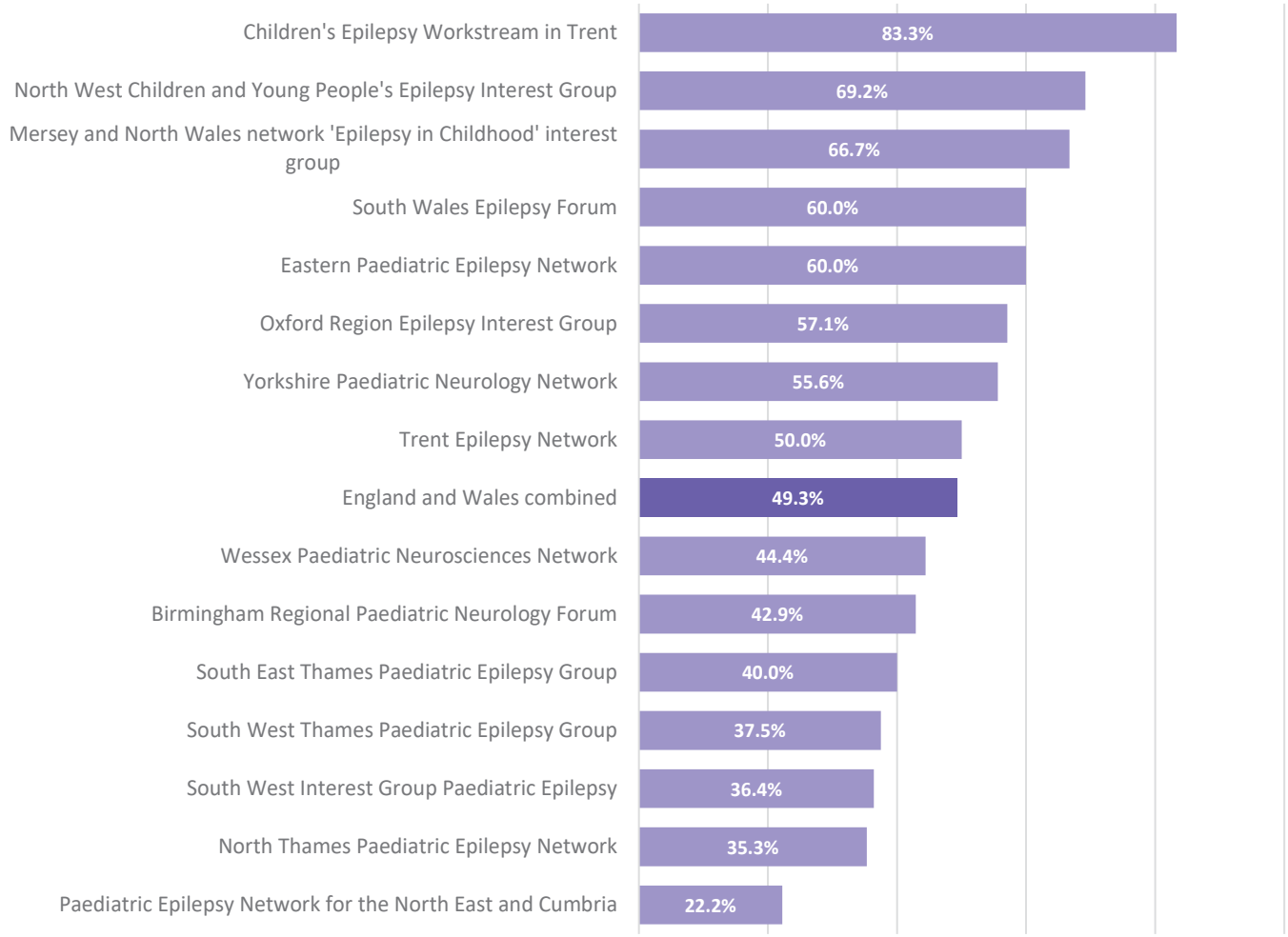
8. Percentage of Health Boards and Trusts that were able to facilitate Vagus Nerve Stimulation (VNS) review at a location within the Health Board or Trust



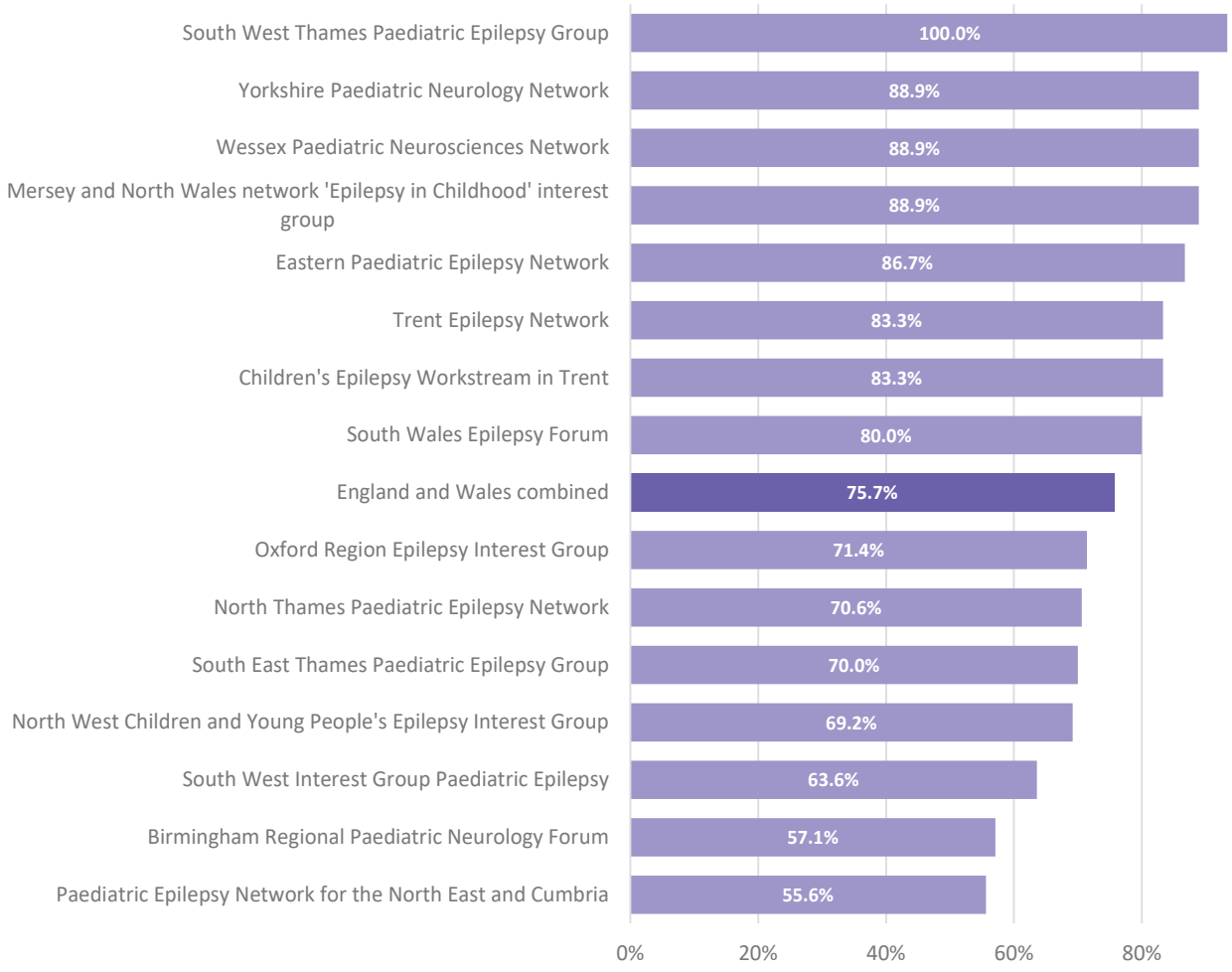
9. Percentage of Health Boards and Trusts that facilitate mental health provision within epilepsy clinics



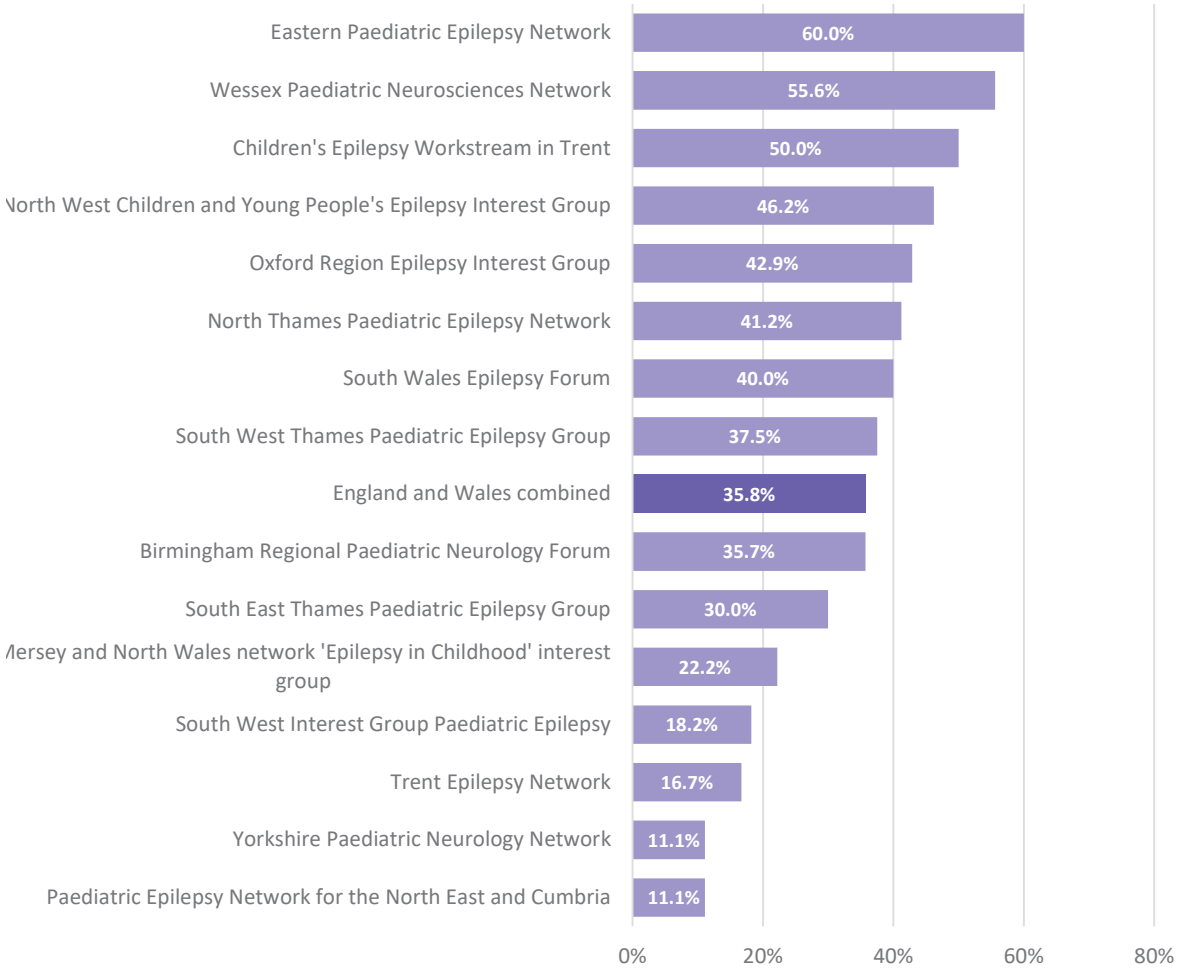
10. Percentage of Health Boards and Trusts that could provide specialist epilepsy advice between scheduled reviews every weekday for 52 weeks per year



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



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



Appendix B: Key recommendations by target audience

The Epilepsy12 2018 Organisational Audit Report makes a number of key recommendations of how to address the issues identified within the key findings and results of the audit. The tables below group the 2018 key recommendations by:

- Key recommendation number
- Recommendation source (i.e. the related guideline or standard)
- Details of the related 2018 key finding
- A comparison to previous audit round findings (where valid)
- The rationale for the recommendation
- The recommendation target audience
- Recommendation details

Title of Recommendation	Source	2018 Epilepsy12 Key finding(s)	Comparison to previous audit findings
General recommendation 1	Epilepsy12 local and national reports, 2018	n/a	n/a
General recommendation 2	Epilepsy12 local and national reports, 2018	n/a	n/a
Workforce recommendation 3	Epilepsies: diagnosis and management, NICE, Clinical guideline 137, 11 January 2012	94.6% (140/148) of Health Boards and Trusts employed a consultant paediatrician with expertise in epilepsy	The total number of whole time equivalent (WTE) consultant paediatricians with expertise in epilepsy employed across England and Wales has increased compared to rounds 1 and 2 The percentage of Health Boards and Trusts employing a consultant paediatrician with expertise in epilepsies cannot be directly compared across rounds due to changes in the configuration of participating units
Workforce recommendation 4	Epilepsies: diagnosis and management, NICE, Clinical guideline 137, 11 January 2012	77.7% (115/148) of Health Boards and Trusts had some epilepsy specialist nurse (ESN) provision within their paediatric service 22.3% of Health Boards and Trusts still have no epilepsy specialist nurse provision	The total number of whole time equivalent (WTE) epilepsy specialist nurses across England and Wales has increased compared to rounds 1 and 2 The percentage of Health Boards and Trusts employing an epilepsy nurse specialist cannot be directly compared across rounds due to changes in the configuration of participating units
Workforce recommendation 5	Epilepsies: diagnosis and management, NICE, Clinical guideline 137, 11 January 2012 Recommendation 1.14.1.4	75% (111/148), of Health Boards and Trusts indicated that they could offer ESN support for rescue medication training for parents	Not previously measured

Rationale for recommendation	Recommendation target audience	Recommendation
n/a	Health Boards and Trusts	All Health Boards and Trusts should review Epilepsy12 local results and support action plans and actions to ensure that gaps in services for children with epilepsies are removed. They should risk assess any gaps and escalate via governance or performance routes
n/a	Regional networks, commissioners and stakeholders	Regional epilepsy networks (OPEN UK) and Commissioners should review Epilepsy12 results for their associated Health Boards and Trusts. They should develop benchmarking, quality improvement initiatives and interfaces between those with commissioning, clinical and provider roles
n/a	Health Boards and Trusts	All Health Boards and Trusts should ensure they have sufficient defined general paediatricians with expertise in epilepsies to correctly diagnose epilepsy and provide appropriate ongoing management for all children with epilepsy. Children with 'complex epilepsy' should also have evidence of input from a paediatric neurologist
n/a	Health Boards and Trusts	All Health Boards and Trusts should ensure they have sufficient epilepsy specialist nurses to ensure ongoing input to all children with epilepsies
Rescue medication is kept by parents and carers of children at risk of prolonged epileptic seizure to allow earlier cessation. Prescription of rescue medication alone is not sufficient to ensure that it will be administered appropriately. 25% of Health Boards and Trusts could not provide this training via an epilepsy specialist nurse and they should urgently review how this provision is undertaken	Health Boards and Trusts	All Health Boards and Trusts should ensure that when rescue medication is prescribed for use by parents and carers of children at risk of prolonged epileptic seizures that training and individualised emergency care plans are provided

Title of Recommendation	Source	2018 Epilepsy12 Key finding	Comparison to previous audit findings
Epilepsy clinical configuration recommendation 6	2017/18 and 2018/19 National Tariff Payment System, NHS England and NHS improvement	85.8% (127/148) of Health Boards and Trusts had a defined epilepsy clinic seeing patients at secondary level	Not previously measured
Epilepsy clinical configuration recommendation 7	2017/18 and 2018/19 National Tariff Payment System, NHS England and NHS improvement	41.6% (59/142) of Trusts in England currently run Epilepsy Best Practice Criteria (BPC) clinics	Not previously measured
Tertiary provision recommendation 8	Epilepsies: diagnosis and management, NICE, Clinical guideline 137, 11 January 2012. 2017/18 and 2018/19 National Tariff Payment System, NHS England and NHS improvement	92.6% (137/148) of Health Boards and Trusts had agreed referral pathways to tertiary paediatric neurology services	Not previously measured

Rationale for recommendation	Recommendation target audience	Recommendation
A secondary level epilepsy clinic allows a pragmatic model for children with epilepsy to access ongoing input from a paediatrician with expertise in epilepsy, an epilepsy specialist nurse skilled in supporting families and other resources. It is difficult to provide expert led, joined up and comprehensive epilepsy care planning within general hospital or community paediatric clinics	Health Boards and Trusts	Health Boards and Trusts should ensure provision of sufficient follow up epilepsy clinic capacity. Where appropriate, children with an epilepsy currently in a general paediatric clinic should be identified and streamed through designated epilepsy clinics
Best Practice Tariffs have been developed via NHS England to support eligible trusts in England to fund essential components for a secondary level epilepsy service. Services meeting Best Practice Criteria (BPC) can code defined epilepsy clinics with the TFC 223 (Treatment Function Code) to facilitate additional payment to the trust over and above the TFC 420 code for general paediatric clinics	Commissioners, Health Boards and Trusts	Health Boards and Trusts should provide epilepsy services fulfilling best practice criteria. Health Boards and Trusts with different funding mechanisms should still specify and embed Best Practice Criteria within secondary epilepsy clinics. Barriers to BPC implementation should be explored and overcome by commissioners working with Health Boards and Trusts
	Health Boards and Trusts	Health Boards and Trusts should have agreed referral pathways to tertiary paediatric neurology services. Referral processes should ensure that after referral ongoing shared care is maintained. Referral pathways should also be clear to ensure appropriate timely referral for epilepsy surgery evaluation, ongoing complex epilepsy management or both

Title of Recommendation	Source	2018 Epilepsy12 Key finding	Comparison to previous audit findings
Tertiary provision recommendation 9	Epilepsies: diagnosis and management, NICE, Clinical guideline 137, 11 January 2012	23% (34/148) of Health Boards and Trusts were able to facilitate Vagus Nerve Stimulation (VNS) review at a location within the Health Board/Trust	Not previously measured
Mental health recommendation 10	Epilepsies: diagnosis and management, NICE, Clinical guideline 137, 11 January 2012	12.8% (19/148) of Health Boards/Trusts facilitate mental health provision within epilepsy clinics and of the 129 health boards/ trusts that did not facilitate co-located mental health provision within epilepsy clinics, 6.2% (8/129) had a current trust action plan describing steps towards achieving it	Not previously measured

Rationale for recommendation	Recommendation target audience	Recommendation
VNS is an effective evidence based intervention for some children with complex epilepsy Although VNS insertion requires a specialist neurosurgery service, ongoing monitoring is often provided at some distance from the family's home or local paediatric service	Health Boards and Trusts	Health Boards and Trusts should consider whether Vagus Nerve Stimulation (VNS) review and programming could be achieved more locally via satellite specialist neurology/ epilepsy clinics
Mental health co-morbidity is common in children and young people with epilepsy. Mental health often interacts with seizures, seizure control and treatment	Commissioners, Health Boards and Trusts	Commissioners, Health Boards and Trusts should ensure that ongoing epilepsy care should include mental health assessment, diagnosis and treatment alongside management of seizures. If paediatric services do not have co-located mental health provision, Commissioners, Health Boards and Trusts should ensure they have action plans towards achieving co-located professionals with mental health competences within epilepsy clinics

Title of Recommendation	Source	2018 Epilepsy12 Key finding	Comparison to previous audit findings
Service contact recommendation 11	Epilepsies: diagnosis and management, NICE, Clinical guideline 137, 11 January 2012. Recommendation1.3.8 A UK survey of the experience of service provision for children and young people with epilepsy, Williams et al. Seizure, 2018	Whilst nearly all (144/148) Health Boards and Trusts could provide some specialist epilepsy advice between scheduled reviews only 49.3% (73/148) were able to provide that specialist epilepsy advice between scheduled reviews throughout Monday to Friday, all year round	Not previously measured
Transition recommendation 12	Epilepsies: diagnosis and management, NICE, Clinical guideline 137, 11 January 2012	75.7% (112/148) of Health Boards and Trusts had an agreed referral pathway to adult services 35.8% (53/148) of Health Boards and Trusts have an outpatient clinic specifically for young people with epilepsies	Not previously measured Not directly comparable across rounds due to changes in unit configuration

Rationale for recommendation	Recommendation target audience	Recommendation
The ease with which a young person and their family can contact the epilepsy service for advice has been shown via the analysis of previous Epilepsy12 Patient Reported Experience Measures to be profoundly associated with service satisfaction6 The RCPCH Children and Young People Engagement Team is currently undertaking a thematic review of qualitative information derived from clinic chats to explore this further. The Epilepsy12 Project Board and OPEN UK Working Group plan to inform future recommendations regarding the ability to contact an epilepsy service ('service contactibility')]	Health Boards and Trusts	Health Boards and Trusts should review how 'service contactability' could be improved for their families
Clear referral pathways from paediatric to adult services form an important component of good transition. Young persons' epilepsy clinics with handover clinics, rather than just a single handover clinic, may provide improved transition to adult services	Health Boards and Trusts	Health Boards and Trusts should formally agree transition pathways from paediatric to adult services. Local arrangements should define how this is achieved for different young people with epilepsies with different associated problems, for example children and young people with an intellectual disability or neurodisability. In addition to providing epilepsy clinics for children Health Boards and Trusts should also establish secondary tier clinics specifically for young people with epilepsies. This should support the evolving needs of the young person and their family throughout adolescence as well as during referral and handover to appropriate adult services

Appendix C: List of figures & tables

Figures

Tables

Tables (continued)

Appendix D: Participating Health Boards and Trusts by OPEN UK region

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

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

The Princess Alexandra Hospital NHS Trust
The Queen Elizabeth Hospital, King's Lynn, NHS Foundation Trust
West Suffolk NHS Foundation Trust
EPIC (Mersey and North Wales network 'Epilepsy In Childhood' interest group)
Alder Hey Children's NHS Foundation Trust
Betsi Cadwaladr University UHB
Countess of Chester Hospital NHS Foundation Trust
Mid Cheshire Hospitals NHS Foundation Trust
Shrewsbury and Telford Hospital NHS Trust
Southport and Ormskirk Hospital NHS Trust
St Helens and Knowsley Hospitals NHS Trust
Warrington and Halton Hospitals NHS Foundation Trust
Wirral University Teaching Hospital NHS Foundation Trust
NTPEN (North Thames Paediatric Epilepsy Network)
Barking, Havering and Redbridge University Hospitals NHS Trust
Barts Health NHS Trust
Basildon and Thurrock University Hospitals NHS Foundation Trust
Central and North West London NHS Foundation Trust
Chelsea and Westminster Hospital NHS Foundation Trust
Great Ormond Street Hospital For Children NHS Foundation Trust
Homerton University Hospital NHS Foundation Trust
Imperial College Healthcare NHS Trust
London North West Healthcare NHS Trust
North East London NHS Foundation Trust
North Middlesex University Hospital NHS Trust
Royal Free London NHS Foundation Trust
Southend University Hospital NHS Foundation Trust
The Hillingdon Hospitals NHS Foundation Trust
The Whittington Hospital NHS Trust
University College London Hospitals NHS Foundation Trust
West Hertfordshire Hospitals NHS Trust
NWEIG (North West Children and Young People's Epilepsy Interest Group)
Blackpool Teaching Hospitals NHS Foundation Trust
Bolton NHS Foundation Trust
East Cheshire NHS Trust
East Lancashire Hospitals NHS Trust
Lancashire Teaching Hospitals NHS Foundation Trust
Manchester University NHS Foundation Trust
Northern Care Alliance NHS Group
Salford Royal NHS Foundation Trust

Stockport NHS Foundation Trust
Tameside and Glossop Integrated Care NHS Foundation Trust
University Hospitals of Morecambe Bay NHS Foundation Trust
University Hospitals of North Midlands NHS Trust
Wrightington, Wigan and Leigh NHS Foundation Trust
ORENG (Oxford region epilepsy interest group)
Buckinghamshire Healthcare NHS Trust
Great Western Hospitals NHS Foundation Trust
Kettering General Hospital NHS Foundation Trust
Milton Keynes University Hospital NHS Foundation Trust
Northampton General Hospital NHS Trust
Oxford University Hospitals NHS Foundation Trust
Royal Berkshire NHS Foundation Trust
PENNEC (Paediatric Epilepsy Network for the North East and Cumbria)
City Hospitals Sunderland NHS Foundation Trust
County Durham and Darlington NHS Foundation Trust
Gateshead Health NHS Foundation Trust
North Cumbria University Hospitals NHS Trust
North Tees and Hartlepool NHS Foundation Trust
Northumbria Healthcare NHS Foundation Trust
South Tees Hospitals NHS Foundation Trust
South Tyneside NHS Foundation Trust
The Newcastle Upon Tyne Hospitals NHS Foundation Trust
SETPEG (South East Thames Paediatric Epilepsy Group)
Brighton and Sussex University Hospitals NHS Trust
Dartford and Gravesham NHS Trust
East Kent : QEQM, Margate and WHM, Ashford, Kent
East Sussex Healthcare NHS Trust
Guy's and St Thomas' NHS Foundation Trust
King's College Hospital NHS Foundation Trust
Lewisham and Greenwich NHS Trust
Maidstone and Tunbridge Wells NHS Trust
Medway NHS Foundation Trust
Surrey and Sussex Healthcare NHS Trust
Sussex Community NHS Foundation Trust
SWEP (South Wales Epilepsy Forum)
Abertawe Bro Morgannwg University LHB
Aneurin Bevan LHB
Cardiff & Vale University LHB
Cwm Taf LHB
Hywel Dda LHB

SWIPE (South West Interest Group Paediatric Epilepsy)
Gloucestershire Hospitals NHS Foundation Trust
Northern Devon Healthcare NHS Trust
Plymouth Hospitals NHS Trust
Royal Cornwall Hospitals NHS Trust
Royal Devon and Exeter NHS Foundation Trust
Royal United Hospitals Bath NHS Foundation Trust
Taunton and Somerset NHS Foundation Trust
Torbay and South Devon NHS Foundation Trust
University Hospitals Bristol NHS Foundation Trust
Weston Area Health NHS Trust
Yeovil District Hospital NHS Foundation Trust
SWTPEG (South West Thames Paediatric Epilepsy Group)
Ashford and St Peter's Hospitals NHS Foundation Trust
Croydon Health Services NHS Trust
Epsom and St Helier University Hospitals NHS Trust
Frimley Health NHS Foundation Trust
Kingston Hospital NHS Foundation Trust
Royal Surrey County Hospital NHS Foundation Trust
St George's University Hospitals NHS Foundation Trust
TEN (Trent Epilepsy Network)
Barnsley Hospital NHS Foundation Trust
Chesterfield Royal Hospital NHS Foundation Trust
Doncaster and Bassetlaw Teaching Hospitals Foundation Trust
Northern Lincolnshire and Goole NHS Foundation Trust
Sheffield Children's NHS Foundation Trust
The Rotherham NHS Foundation Trust
WPNN (Wessex Paediatric Neurosciences Network)
Dorset County Hospital NHS Foundation Trust
Hampshire Hospitals NHS Foundation Trust
Isle of Wight NHS Trust
Poole Hospital NHS Foundation Trust
Portsmouth Hospitals NHS Trust
Salisbury NHS Foundation Trust
Solent NHS Trust
University Hospital Southampton NHS Foundation Trust
Western Sussex Hospitals NHS Foundation Trust

YPEN (Yorkshire Paediatric Neurology Network)
Airedale NHS Foundation Trust
Bradford Teaching Hospitals NHS Foundation Trust
Calderdale and Huddersfield NHS Foundation Trust
Harrogate and District NHS Foundation Trust
Hull and East Yorkshire Hospitals NHS Trust
Leeds Community Healthcare NHS Trust
Leeds Teaching Hospitals NHS Trust
Mid Yorkshire Hospitals NHS Trust
York Teaching Hospital NHS Foundation Trust

Appendix E: Glossary of terms and abbreviations

Acute	Inpatient review, or paediatric review in emergency department, or other clinical assessment in an acute paediatric setting
AED (Anti epileptic drug)	Anti-epileptic drugs (AEDs) are the main type of treatment for most people with epilepsy. AEDs are a type of medication that aims to stop seizures.
BPT/BPC	Best Practice Tariff/Best Practice Criteria
Children's Epilepsy Specialist Nurse	A children's nurse with a defined role and specific qualification and/or training in children's epilepsies
Consultant General Paediatrician	A paediatric consultant (or associate specialist) with a role that includes seeing children or young people in a general outpatient or community clinic setting. They may or may not have other specialty or acute roles. They are likely to receive referrals directly from primary care. Neonatologists would not be included in this definition unless they also fulfil general paediatric roles.
ECG	An electrocardiogram (ECG) is a simple test that can be used to check your heart's rhythm and electrical activity. Sensors attached to the skin are used to detect the electrical signals produced by your heart each time it beats.
ED	Emergency Department
EEG	An electroencephalogram (EEG) is a recording of brain activity. During the test, small sensors are attached to the scalp to pick up the electrical signals produced when brain cells send messages to each other. These signals are recorded by a machine and are looked at by a doctor later to see if they're unusual.
Epilepsy	A chronic neurological condition characterised by two or more epileptic seizures (International League Against Epilepsy, ILAE). A pragmatic definition for epilepsy in this audit is 2 or more epileptic seizures more than 24 hours apart that are not acute symptomatic seizures or febrile seizures.
Epilepsy Syndrome	A complex of clinical features, signs and symptoms that together define a distinctive, recognizable clinical disorder (ILAE)
'Epilepsy Syndrome Category'	A group of epilepsies described using the terms idiopathic primary, symptomatic, probably symptomatic and cryptogenic and focal, partial, multifocal or generalized
Epileptic seizure	Clinical manifestation(s) of epileptic (excessive and/orhypersynchronous), usually self-limited activity of neurons in the brain. (ILAE)

First paediatric assessment	A 'face to face' assessment by a secondary level/tier doctor in a paediatric service occurring in any non-acute or acute setting. Assessment within emergency department counts if performed by paediatric team rather than an emergency department team. Some paediatric neurologists see referrals direct from GP or ED and these would count as both a first paediatric assessment and tertiary input
General examination	Any evidence of a multisystem examination of the child other then neurological examination
GP	General Practitioner
Handover clinic	A clinic where a young people 'leaves the paediatric service and joins an adult service' and comprises both adult and paediatric health professionals
Input	Any form of documented clinical contact including face to face clinical, written, electronic or telephone contact
MRI	Magnetic resonance imaging (MRI) is a type of scan that uses strong magnetic fields and radio waves to produce detailed images of the inside of the body. An MRI scanner is a large tube that contains powerful magnets
Neurodisability	Documented diagnosis including any of the following phrases indicating the diagnosis made by the assessing team: • Autistic spectrum disorder • Moderate, severe (or profound) learning difficulty or global development delay • Cerebral palsy • Neurodegenerative disease or condition • An identified chromosomal disorder with a neurological or developmental component • Attention deficit hyperactivity disorder (ADHD) • Exclusions e.g. hypermobility, dyspraxia, specific learning difficulties e.g. (dyslexia, dyscalculia)
Neurological examination	Any evidence of a neurological examination of the child
Paediatrician with expertise	A paediatric consultant (or associate specialist) defined by themselves, their employer and tertiary service/network as having: • Training and continuing education in epilepsies • Peer review of practice • Regular audit of diagnosis (e.g. participation in Epilepsy12) • A paediatric neurologist is also defined as a 'paediatrician with expertise'
Paroxysmal episodes	This is the term chosen in this audit to represent the events causing concern. It includes all epileptic and non-epileptic seizures and also seizures of uncertain in origin.
'School age'	Child 5 years and older (past their 5th birthday)

Appendix F: Useful resources

The Royal College of Paediatrics and Child Health

The Royal College of Paediatrics and Child Health (RCPCH) was founded in 1996 and now has over 17,000 members across the world. We play a major role in postgraduate medical education, professional standards, research and policy.

The RCPCH has a number of useful resources, including:

- **Courses and online learning** www.rcpch.ac.uk/education/courses
  Progressing Paediatrics: Childhood epilepsies

- **Paediatric Care Online** http://pcouk.org/
  Paediatric Care Online (PCO UK) is an online decision support system designed for healthcare professionals who see children at the point of care. This innovative tool provides immediate access to clinically assured information to inform decisions at point of care, together with a repository of supporting reference material and patient information.

- **Continuing professional development** www.rcpch.ac.uk/education/continuing-professional-development If you are a career-grade paediatrician - whether a consultant or SAS doctor - or a child health professional we can help you develop your knowledge and skills.

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

- **MedsIQ** www.medsiq.org/
  Medication errors are a significant but preventable cause of harm to children and young people. Meds IQ aims to bring together tools and improvement projects that have been developed to address this problem.

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

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

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

Epilepsy12 Audit Key Stakeholder Organisations

The Association of Neurophysiological Scientists (https://www.ansuk.org/)
The ANS (formerly EPTA) is the professional body for clinical physiologists working in the field of Clinical Neurophysiology. It's principle aims are to represent its members at a national level, set standards of practice, promote career development, set education and training standards and award qualifications.

British Academy of Childhood Disability (www.bacdis.org.uk)
Membership is open to all professionals working in the field of childhood disability, including paediatrics, psychiatry, specialist nursing, speech and language therapy, physiotherapy, occupational therapy, psychology and education.

British Paediatric Neurology Association (www.bpna.org.uk)
The British Paediatric Neurology Association is the professional organisation for doctors who specialise in the care of children with neurological disorders. The BPNA delivers **Paediatric Epilepsy Training (PET)** courses which provide training for all health professionals diagnosing and managing children with an epilepsy or seizure disorder.

British Society for Clinical Neurophysiology (www.bscn.org.uk)
The BSCN is a medical charity whose aims, set out in its articles of association, are "to promote and encourage for the public benefit the science and practice of clinical neurophysiology and related sciences".

Epilepsy Action (www.epilepsy.org.uk)
Provides information about coping with epilepsy and seizures. It also provides free help and advice through the use of email and telephone helplines.

Epilepsy Scotland (www.epilepsyscotland.org.uk)
Epilepsy Scotland is Scotland's leading epilepsy charity campaigning for improved healthcare, better information provision and an end to stigma.

Epilepsy Specialist Nurses Association (ESNA) (https://www.esna-online.org.uk/)
ESNA is a professional organisation whose membership consists of nurses and other health professionals working to support people with epilepsy in the fields of adults, learning disabilities and paediatrics. ESNA works with its membership to raise the profile of epilepsy and to encourage a holistic and co-ordinated approach to care to enable our patients to reach the goal of self-management.

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

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

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