EPILEPSY12

United Kingdom collaborative clinical audit of health care for children and young people with suspected epileptic seizures

National Report
September 2012

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

EPILEPSY12

United Kingdom collaborative clinical audit of
health care for children and young people
with suspected epileptic seizures

Epilepsy12 National Report

September 2012

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

Royal College of Nursing · epilepsy action · epilepsy scotland · BSCN · HQIP Healthcare Quality Improvement Partnership · BPNA · Healthcare Improvement Scotland · Young Epilepsy

Report prepared by

Dr Colin Dunkley, Project lead and Consultant Paediatrician
Rita Ranmal, Project Manager, RCPCH.
Carla Long, Data analyst, RCPCH.

Acknowledgements

We wish to thank all the health professionals and staff who have contributed data for all their hard work in helping to collect their data. A full list of unit's participation status can be found in Appendix 1.

We also wish to thank: Fiona Williams and Rishma Maini for developing the patient related experience measure questionnaire and the families who participated in the survey; Zaki Kramer, Emma Gilmore, Deanna Johnson, Melanie Simpson, Linda Haines, Yasir Musawar and Lubna Ansari from RCPCH for project support and advice at various stages of the project; Aimee Gee and Margaret Rawnsley from Epilepsy Action for project advice; and Anissa Tonberg from Epilepsy Scotland for comments on the draft report.

Project Board

Dr Helen Basu, Consultant Paediatric Neurologist, British Paediatric Neurology Association Representative
Ann Brown, Epilepsy Specialist Nurse, Royal College of Nursing Representative
Alan Cruickshank, Head of Strategy & Policy, Young Epilepsy
Dr Colin Dunkley, Consultant Paediatrician, Project lead
Dr Colin Ferrie, Consultant Paediatric Neurologist, Clinical lead
Jacqueline Fitzgerald, Director of Policy and Research, RCPCH representative
Dr Martin Kirkpatrick, Consultant Paediatric Neurologist, Scotland representative
Dr Lesley Notghi, Consultant Neurophysiologist, British Society for Clinical Neurophysiology Representative
Allana Parker, Public Affairs Officer, Epilepsy Scotland
Angie Pullen, Epilepsy Services Manager, Epilepsy Action
Grant Wright, Training, Epilepsy Scotland

Methodology Working Group

Katherine Bowyer, Neurophysiological scientist
Dr Richard Chin, Consultant Paediatric Neurologist
Dr Colin Dunkley, Consultant Paediatrician
Dr Colin Ferrie, Consultant Paediatric Neurologist
Dr Katherine Martin, Neurodisability Paediatric Consultant
Dr James Paton, Consultant Paediatrician, RCPCH Clinical Standards Committee lead for National Audit
Berni Waldron, Epilepsy Specialist Nurse

David Wells, Deputy Director, Children and Maternal Health Observatory
Dr William Whitehouse, Senior Lecturer in Paediatric Neurology

Audit Facilitators

Francesca Colaco, Researcher
Diane Flower, Epilepsy Specialist Nurse
Berni Waldron, Epilepsy Specialist Nurse

Stakeholder organisations

Association of British Neurologists
Association of Neurophysiological Scientists
British Association for Community Child Health
British Association of Childhood Disability
British Paediatric Neurology Association
British Psychological Society
British Society for Clinical Neurophysiology
British Society of Neuro-Radiologists
Centre for Maternal and Child Enquiries
College of Emergency Medicine
Contact a Family
Daisy Garland
David Lewis Centre
Epilepsy Action
Epilepsy Bereaved
Epilepsy Connections
Epilepsy Here
Epilepsy Nurses Association
Epilepsy Outlook
Epilepsy Research UK
Epilepsy Scotland
Epilepsy Wales
Gwent Epilepsy Group
Healthcare Improvement Scotland (formerly Quality Improvement Scotland)
Health Quality Improvement Partnership
Joint Epilepsy Council
Joint Neurological Council
Matthews Friends - Dietary Treatments of Epilepsy
National Clinical Guideline Centre Epilepsy Guideline Development Group
National Institute for Health and Clinical Excellence
National Society for Epilepsy
Young Epilepsy (formerly National Centre for Young People with Epilepsy)
Neonatal and Paediatric Pharmacists Group
Neurological Alliance
Roald Dahl's Marvellous Children's Charity
Royal College of General Practitioners

Royal College of Nursing
Royal College of Psychiatrists - Epilepsy Group
Royal College of Radiologists
Royal Pharmaceutical Society of Great Britain
Scottish Epilepsy Centre
Scottish Epilepsy Initiative
Scottish Intercollegiate Guidelines Network
Society of British Neurological Surgeons
Syncope Trust and Reflex anoxic Seizures

Forewords

Epilepsies are common neurological disorders of childhood, with a significant morbidity and mortality. Comprehensive national recommendations for childhood epilepsies were published by the National Institute for Clinical Excellence (NICE) in 2004 (recently updated in 2012) and the Scottish Intercollegiate Guidelines Network (SIGN) in 2005. Since these publications there has been little evidence of widespread implementation, and ongoing concern that service provision is variable across the UK.

This national audit, jointly funded by the Healthcare Quality Improvement Partnership (HQIP) and Health Improvement Scotland (HIS) is the first systematic approach to determining how effectively guidance is being implemented.

Over the 3 years of its lifetime, Epilepsy12 has harnessed considerable professional and stakeholder enthusiasm for bridging the gap between current practice and national recommendations, with a remarkably high engagement and return rate. This final report highlights where services are doing and well and where improvements are needed.

Regardless of differences in the way in which healthcare is structured and commissioned across the UK, there is a consistent emphasis on improving quality and outcomes, and reducing variability. The report's findings have much importance, not only for the improvement of the quality of care for children with suspected and diagnosed epilepsy and their families, but also as an example of how national co-operation in a quality improvement initiative could be emulated in other areas of paediatrics.

We strongly encourage you to share this report with colleagues.

Dr Hilary Cass
President, Royal College of Paediatrics and Child Health

Epilepsy is a common disease with an incidence in children and adolescents of 1/1000. 'Epilepsy 12' audit is the first ever UK wide national audit of epilepsy care for children and young people that has been commissioned by the Royal College of Paediatrics and Child Health.

It critically examines the provision of health care for children and young people (CYP) with suspected epileptic seizures, against 12 standard measures, in the first 12 months following presentation to district level health services. Its origins can be traced back to the National Sentinel Audit on Epilepsy-related Deaths published in 2002 and the enquiry in to epilepsy care of children and young people in Leicester performed by the British Paediatric Neurology Association and published in 2003. The findings of these led to widespread concern about the quality of epilepsy services for children with epilepsy and prompted a number of initiatives from the BPNA, including a proposal to audit the quality of epilepsy care for children in the UK.

For this audit, 186 units caring for CYP with suspected or confirmed diagnosis of epilepsy provided data regarding nearly 5000 children. This was analysed against 12 different measures of optimal

clinical care in suspected epilepsy, recommended by the National Institute for Clinical Excellence and (NICE) and Scottish Intercollegiate Guidelines Network (SIGN). Most importantly it included feedback from the children and young people themselves and their carers. 82% of CYP and 78% of carers gave positive feedback. Performance in audit measures is variable across centres and one particular area needing improvement is for greater involvement of specialist epilepsy nurses in clinical care. The audit is to be repeated in its present form in the next 24 months to seek consistency and assess improvements.

This is an excellent national initiative from the RCPCH on epilepsy care for children and young people and I recommend its findings to all clinicians as well as local and regional clinical commissioning boards for careful consideration.

Dr Venkateswaran Ramesh
President, British Paediatric Neurology Association

The audit findings reveal progress in the care of children and young people with epilepsy. It is however notable that there has been a considerable lack of progress in the availability of children's epilepsy specialist nurses to provide support and advice to children and their families. Forty-seven per cent of units audited had no epilepsy specialist nurse and overall the majority of children had received no input from an epilepsy specialist nurse within 12 months of assessment. This is extremely concerning particularly at this time of financial constraints. The importance of access to specialist nurses was first highlighted in the National Sentinel Audit on Epilepsy-related Deaths in 2002. Commissioners and service planners need to be reminded of the value added benefits access to specialists across primary and secondary care interfaces can have, along with long term efficiency enabling young people and families to effectively manage their own condition.

Fiona Smith
Adviser in Children and Young People's Nursing, Royal College of Nursing

The development of the NICE guidelines for the diagnosis and management of the epilepsies in primary and secondary care, initially published in 2004 (updated 2012), was a major step forward towards standardising services for care across England and Wales. Having previously experienced several national reports indicating that management of epilepsy overall was suboptimal at the time, the guidelines, although not rules, set a benchmark by which to strive toward best practice.

However it is important to determine whether such has been achieved. This audit as reported here, not only gives an overall view of achievement against some key standards, highlighting areas of variability, it also has acquired data on the overall problem in hand, obtaining key demographics about epilepsy in childhood in the UK not previously available. This has highlighted the issues in diagnosis, with almost half of children presenting ultimately diagnosed as having experienced non-epileptic seizures. The data so available will allow individual geographical regions to benchmark their practice, and strive for further improvement in services for children and young people with epilepsy.

Prof J Helen Cross
Clinical Advisor to the NICE update of the guidelines for the diagnosis and management of the epilepsies 2012.

When the large group of clinicians, social workers, psychologists, voluntary sector organisations and parents all assembled together to work on the production of the SIGN guideline on children's epilepsies we all wondered, at various stages of frustrating re-draft after re-draft, whether this would ever be more than a "shelf-state" guideline.

It is thus really gratifying to now see the publication of this audit with its Performance Indicators specifically referenced against SIGN and NICE guidance demonstrating the guidelines have not sat on a shelf after all. We are starting to be able to show that we are implementing national evidence-based guidelines and to prove it.

The astonishing recruitment rate to this audit is testament to the work that has been done in the assiduous preparation and then execution of this audit and indeed to the many clinicians who have, I know, sweated to various degrees to extract and upload this data. Finally and importantly, I think we should welcome the efforts that were made to carefully define a parent and child perspective on the service they were receiving. This, of course, is crucial in knowing whether we really are providing the quality service that children and their families want and deserve.

Dr Martin Kirkpatrick
Chair, SIGN Guideline Development Group – 'Diagnosis and Management of Epilepsies in Children and Young People'

As charities working on behalf of people with epilepsy we were delighted to be involved with this audit. We have all valued participating in the planning and delivery of Epilepsy12. We would like to thank Colin Dunkley and the project team – as well as the many health professionals involved across the UK - for their hard work.

The results support a number of the concerns we have expressed over the years about childhood epilepsy services. For example, the audit has provided further evidence of the lack of epilepsy specialist nurses and transition clinics which are key recommendations in the NICE and SIGN Clinical Guidelines. The information gathered in this audit must now be used to develop best practice and improve service provision for children and young people with epilepsy across the UK. Only then will all the efforts for Epilepsy12 prove worthwhile.

David Ford, Chief Executive, Young Epilepsy
Lesslie Young, Chief Executive, Epilepsy Scotland
Philip Lee, Chief Executive, Epilepsy Action

Contents

Executive Summary

The British Paediatric Neurology Association (BPNA) proposed a national audit of childhood epilepsies in 2007 in response to the continuing concern regarding the quality of care for children and young people with epilepsies. In 2009, the Healthcare Quality Improvement Partnership (HQIP) and Health Improvement Scotland (HIS) funded the Royal College of Paediatrics and Child Health (RCPCH) to establish Epilepsy12 - the United Kingdom collaborative clinical audit of health care for children and young people with suspected epileptic seizures. **The Epilepsy12 Glossary & Definitions (Appendix 1) contains definitions of all key terms used.**

The key aims of Epilepsy12 are:

- To facilitate health providers and commissioners to measure and improve quality of care for children and young people with seizures and epilepsies; and
- To contribute to the continuing improvement of outcomes for those children, young people and their families.

What is Epilepsy12?

Epilepsy12 is a UK-wide multicentre collaborative audit which measured systematically the quality of health care for childhood epilepsies. The '12' refers to the 12 measures of quality applied to the first 12 months of care after the initial paediatric assessment. Care was compared to National Institute of Clinical Excellence (NICE) and Scottish Intercollegiate Guidelines Network (SIGN) Epilepsies guideline recommendations.[1,2]

Who was involved?

All paediatric services that employ National Health Service (NHS) paediatricians for children and young people with seizures or epilepsies were invited to participate.

How was quality measured?

The Epilepsy12 National Audit described the care using three domains:

1. Service Descriptor: Paediatric services described the details of their service for a specific census day in 2011.
2. Clinical Audit: A retrospective case note analysis for all children meeting the project inclusion criteria, having their first paediatric assessment during a particular 6 month period before census day was undertaken.
3. Patient Related Experience Measure (PREM): Carers and young people with epilepsy were invited to describe their experiences of their health care.

What were the clinical audit measures of quality?

Quality of care was determined using 12 performance indicators derived from the NICE and SIGN Epilepsies guidelines.[1,2] Each performance indicator was the percentage of children within a defined group who had evidence of appropriate care. The performance indicators are listed in Figure 1.

Figure 1. Epilepsy12 Performance Indicators

Category		Title	Performance indicator
Professionals	1	**Paediatrician with expertise in epilepsies**	Percentage of children with **epilepsy**, with **input** by a '**consultant paediatrician with expertise in epilepsies'** by 1 year
	2	**Epilepsy Specialist Nurse**	Percentage of children with **epilepsy**, referred for **input** by an **epilepsy specialist nurse** by 1 year
	3	**Tertiary involvement**	Percentage of children meeting defined criteria for paediatric neurology referral, with input of tertiary care by 1 year
Assessment & Classification	4	**Appropriate first clinical assessment**	Percentage of all children, with evidence of **appropriate first paediatric clinical assessment**
	5	**Seizure classification**	Percentage of children with **epilepsy**, with **seizure** classification by **1 year**
	6	**Syndrome classification**	Percentage of children with **epilepsy**, with **epilepsy syndrome** by 1 year
Investigation	7	**ECG**	Percentage of children with **convulsive seizures**, with an ECG by 1 year
	8	**EEG**	Percentage of children who had an EEG in whom there were no defined contraindications
	9	**MRI**	Percentage of children with defined indications for an MRI, who had MRI by 1 year
Management & Outcome	10	**Carbamazepine**	Percentage of children given carbamazepine, in whom there were no defined contraindications
	11	**Accuracy of diagnosis**	Percentage of children diagnosed with **epilepsy**, who still had that diagnosis at 1 year
	12	**Information & advice**	Percentage of females over 12 years given anti-epileptic drugs, who had evidence of discussion of pregnancy or contraception

What are the Epilepsy12 results?

All 197 'audit units' identified through a UK mapping exercise were registered to take part in the audit. Each 'audit unit' comprised relevant acute and non-acute paediatric services including hospital and community care.

Service Descriptor

193 units completed the service descriptor questionnaire. Approximately 17% (347/2027) of whole time equivalent general paediatric consultants were reported as having defined 'expertise in epilepsy'. 47% (91/193) of audit units had no Epilepsy Specialist Nurse. 58% (112/193) of units had epilepsy clinics. 18% (35/193) had a specific clinic for 'young people' or ' teenagers' with epilepsies.

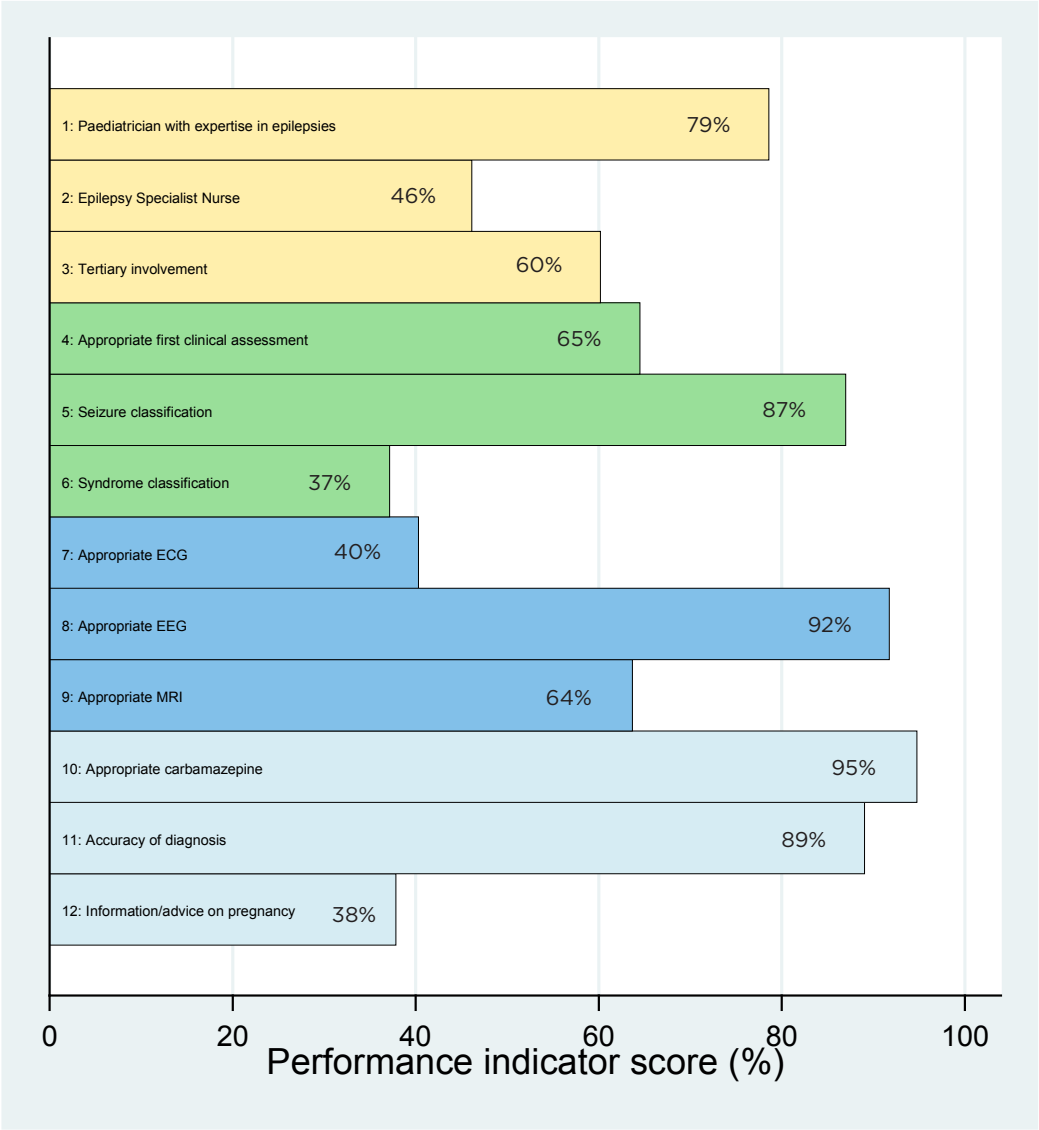
Clinical Audit

4945 eligible children were included in the audit from 186 participating audit units (See Appendix 2 for a list of participating units). Slightly more children had their initial paediatric assessment in non-acute settings (56%; 2790/4945) compared to acute settings (44%; 2154/4945). There was evidence of a neurodisability in 20% (966/4945) of the cohort.

Children were diagnosed as having non-epileptic episode(s), uncertain episode(s), single epileptic seizures and epilepsy and as would be expected some diagnoses changed over time. Approximately one third (36%; 1775/4945) had episodes diagnosed as epilepsy at 12 months.

Figure 2 shows the clinical audit domain results for all UK children.

Figure 2. Epilepsy 12 Performance Indicators results for all UK children



Patient Reported Experience Measure

178 audit units participated in the patient reported experience measure component of the audit. Units identified families where children were commenced on anti-epileptic drugs and these families were invited to participate. 319 parent/carers completed and returned paper or web-based questionnaires from 131 audit units. 158 children and young people completed their section of the questionnaire.

78% (249/319) of parent/carers and 82% (111/136) of children and young people who responded to the question, stated overall satisfaction with the care received from their epilepsy service. 8% (26/319) of parents/carers and 7% (9/136) of children and young people stated they were not satisfied.

70% (110/158) of children and young people reported that they had received enough information on seizures or epilepsy. 23% (36/154) felt that information given was hard to understand.

Areas where children and young people felt more information was needed included: the cause of epilepsy, guidance on participation, side effects of medication and what to tell others about the epilepsy. Children and young people suggested improvements which included: better information to schools; better age-appropriate activities in the waiting area and not being grouped together with younger children; reducing waiting times and better involvement and listening to children and young people.

Key Recommendations

The results show that improvements are needed for many aspects of service delivery and professional input including diagnosis, investigation, treatment and communication.

The key recommendations outline specific steps required to improve quality of care. Services with evidence of low performance in the 12 performance indicators should also consider the presence of wider deficiencies of their epilepsy services. Services should therefore not confine quality improvement to areas highlighted in this report but should take the opportunity to consider their epilepsy service as a whole. Good practice should also prompt services to share their experience. 'First seizure' clinics, epilepsy clinics, nurse-led clinics, 'satellite paediatric neurology' clinics, young people's epilepsy clinics and 'handover' clinics are all examples of service developments that some audit units have established.

The Epilepsy12 website (www.rcpch.ac.uk/epilepsy12) provides a quality improvement toolkit of useful resources to support audit units implement and share effective action plans.

Key Recommendations

Professionals	**1**	All services managing children with epilepsies should ensure that they include at least one consultant paediatrician with defined 'expertise in epilepsies'. One consultant should be formally defined as the epilepsy lead. Services should review consultant training, job planning and new appointments in order to achieve these roles and competences. Services where involvement of 'paediatricians with expertise' in children with epilepsy is low should also review care pathways to ensure that each child with epilepsy has evidence of input of a 'paediatrician with expertise'.
	2	Epilepsy Specialist Nurses are an essential component of paediatric services and all children diagnosed with epilepsy should have specialist nurse input offered as per NICE and SIGN guidance[1,2]. Epilepsy Specialist Nurse provision includes care planning, facilitating appropriate participation, risk assessment, school and respite care liaison, rescue medication training and telephone advice. All services without an Epilepsy Specialist Nurse should create new posts to ensure adequate care. Units where many children with epilepsy are not having input from an Epilepsy Specialist Nurse should improve their care pathways and Epilepsy Specialist Nurse provision.
	3	Services with low levels of Paediatric Neurology input should improve their referral strategies and shared care arrangements. Paediatric neurology provision should be improved where there is a shortfall.
Assessment & Classification	**4**	Services with low levels of appropriate first clinical assessment should explore underlying reasons for this and improve the quality and consistency of assessment. Training, documentation, first seizure guidelines and care pathways should be implemented as appropriate. Particular efforts should be made to ensure timely and ongoing assessments of development, educational, emotional and behavioural problems for all children with epilepsies.
	5	Rates of appropriate multi-axial epilepsy classification should be improved particularly in services where there is evidence of lower performance. Where the epileptic seizure cannot be classified there should be documentation to show that classification has been attempted. The ongoing diagnosis and classification of epilepsies should be undertaken by professionals with appropriate expertise.
	6	Children with epilepsies should have an appropriate electro-clinical syndrome classification recorded where possible.

Investigation	**7**	In services with low rates of appropriate 12 lead ECG, training, local guidelines and care pathways should be improved to ensure all children with a convulsive seizure have a 12 lead ECG with documentation to show that it has been assessed.
	8	Where services have high levels of use of EEG investigation in children with non-epileptic events the reasons behind this should be explored and rectified. EEG services should develop strategies with their referring colleagues to reduce levels of inappropriate EEG referrals.
	9	Services with low rates of appropriate neuroimaging should explore reasons behind this. Indications for MRI in children with epilepsies should be reviewed and neuroimaging rates improved. If necessary the availability of MRI should be improved.
Management & Outcome	**10**	Services where there is evidence of carbamazepine prescription in children with contraindications should ensure that the reasons behind this are addressed. Care pathways ensuring input from a 'paediatrician with expertise' should be established.
	11	Services where there is evidence of diagnoses of epilepsy being made that are subsequently withdrawn should investigate and respond to the reasons behind this. This is particularly the case if regular anti-epileptic medication has been initially prescribed as part of a 'trial of treatment' or where misdiagnosis is occurring. Care pathways ensuring input from a 'paediatrician with expertise' should be established.
	12	Services with inadequate services and transition arrangements for young people (e.g. 12 years and over) with epilepsies should improve provision. This may include increasing Epilepsy Specialist Nurse provision, developing clinics for young people with epilepsy, handover clinics, adult epilepsy services and referral pathways to adult services. Services should ensure that all relevant young people's health issues including pregnancy and contraception are reliably addressed.

1. Background

Epilepsies are a common and disabling chronic neurological disorder of childhood with a prevalence of approximately 1 in 200 children and an incidence of 50-80 per 100,000 per year.[1,2] Seizures account for an estimated 5% of 'medical' presentations to a children's emergency department and approximately 5% of new paediatric outpatient referrals.[3,4]

Epilepsies have a significant morbidity and mortality. Seizures place a substantial psychosocial impact on families due in part to the distressing nature of the condition and because of stigma and misunderstanding within the community. There is significant associated co-morbidity and disability with a resulting impact on the child at home and in community, educational and other residential and respite care settings. Many children with an epilepsy have learning difficulties and meet criteria for childhood mental health disorders.[5]

The annual direct and non-direct cost of epilepsies for adults and children in 1994 was £2 billion.[1] Estimates in 2002 demonstrated a 3-fold increase in drug costs alone over the preceding 10 years from £26 to £86 million.

'Epilepsies' refers to group of conditions characterised by recurrent epileptic seizures. The heterogeneous nature of the diagnosis and underlying causes explains the wide range of individualised management strategies needed for different children. Each child requires individualised assessment, investigation and management. Prognosis will vary and this means that the outcome aims will also vary. The majority of children present initially to primary care or acute services and are then diagnosed and managed in acute and non-acute secondary level paediatric services. Approximately one third require additional tertiary paediatric neurology involvement, some requiring evaluation for epilepsy surgery or other non-pharmacological therapies. Some children with an epilepsy do not require anti-epileptic drug treatment, although most do. Optimum care also involves good communication with the child and family and coordinated multi-agency work which may include mental health service input, educational plans, social care support and individualised care plans. At all stages of the diagnostic and treatment pathway, the child and family need to be enabled to make fully informed decisions.

A succession of national reports, the National Sentinel Clinical Audit of Epilepsy-related Deaths and the 'Leicester enquiry' have highlighted recurring concerns regarding misdiagnosis, and the quality of treatment and communication with a resulting significant health and economic impact.[6-12] Comprehensive national recommendations for childhood epilepsies were published by the National Institute for Clinical Excellence (NICE) and Scottish Intercollegiate Guidelines Network (SIGN) in 2004 and 2005 respectively.[1,2] In 2012, NICE published revised epilepsy guidelines (www.nice.org.uk). There has been little subsequent evidence of implementation of these guidelines and there was concern that service provision was variable across the UK. Although 2012 NICE guidelines were published after commencement of this audit, their recommendations remain entirely consistent with the quality measures within this audit.

Previous audits have measured some aspects of quality of care for children with epilepsies in small cohorts.[13,14] In 2007, the British Paediatric Neurology Association (BPNA) piloted a regional audit to assess the quality of care and service provision in Trent based on 12 key standards derived from NICE and SIGN guidance.[13,14] The pilot found significant variation in delivery and provision between NHS services and significant gaps between recommended and delivered care. In 2009, the Healthcare Quality Improvement Partnership (HQIP) and Health Improvement Scotland (HIS) funded the Royal College of Paediatrics and Child Health (RCPCH) to establish Epilepsy12 - the United Kingdom collaborative clinical audit of healthcare for children and young people with suspected epileptic seizures. The '12' refers to the design of 12 meaningful and pragmatic measures of quality applied to the first 12 months of care after first paediatric assessment.

The project is overseen by the RCPCH in partnership with the BPNA, British Society of Clinical Neurophysiology (BCSN), Epilepsy Action, Epilepsy Scotland, Young Epilepsy, and the Royal College of Nursing.

The Epilepsy12 Glossary and Definitions (Appendix 1) contains definitions of all key terms used.

1.1 Aims of the audit

The key aims of Epilepsy12 are:

- To facilitate health providers and commissioners to measure and improve quality of care for children and young people with seizures and epilepsies; and
- To contribute to the continuing improvement of outcomes for those children, young people and their families.

2. Method

The 'Epilepsy12 Full Methodology Document' summarises the audit methodology in detail (www.rcpch.ac.uk/epilepsy12)

2.1 Audit Domains

The Epilepsy12 National Audit involved 3 domains:

1. Service Descriptor: Paediatric services described the details of their service for a specific census day in 2011.
2. Clinical Audit: A retrospective case note analysis for all children meeting the project inclusion criteria, having their first paediatric assessment during a particular 6 month period before census day was undertaken.
3. Patient Reported Experience Measures (PREM): Carers and young people with epilepsy were invited to describe their experiences of their health care.

2.2 Recruitment

The audit covered England, Scotland, Wales and Northern Ireland. All paediatric services that employ NHS paediatricians that request EEGs and are involved with the care of children and young people with seizures or epilepsy were invited to participate.

An extensive mapping exercise was commenced in 2009/2010 in collaboration with providers to define 'Epilepsy12 audit units'. The UK was split into 21 pragmatic regions each consisting of at least one main tertiary unit and related Epilepsy12 audit units. Each 'Epilepsy12 audit unit' had defined: Consultant Paediatricians (one acting as audit lead); NHS trusts; Hospitals; Community Paediatric services and EEG services. In total, 197 audit units were defined and invited to register to participate. A tertiary paediatric neurologist agreed to act as the project lead per region. A list of participating units can be found in Appendix 2.

2.3 Data Collection

The data collection took place in two phases. Audit units in regions of 'North Scotland', 'Cambridge' and 'South East Wales' were invited to become 'Early adopter' units and begin data submission from February 1st 2011. All other audit units were invited to begin data submission from May 1st 2011.

Following registration, audit unit leads were sent an audit pack with joining instructions and guidance notes on using the web-tool.

Audit unit leads were first asked to complete the service questionnaire (Domain 1) regarding their service on the defined census day: February 1st 2011 for Early Adopter units and May 1st 2011 for all other audit units. The census days also determined the various dates that identified the target cohort for the audit unit. A copy of the service descriptor questionnaire can be found in Appendix 3.

For the clinical audit (Domain 2), all unit leads were asked to obtain from their EEG department(s) a list of all children referred for EEG over a defined 12 month period prior to their 'census day' via a standardised letter (Figure 3a and 3b). Unit leads were asked to then apply the inclusion/exclusion criteria (Table 1) to determine those children who should be entered into the audit web-tool. Inclusion dates were chosen such that each child submitted had completed 12 months of care after first paediatric assessment by the time of data entry. Data could be entered into a web tool using a secure login by the audit unit lead or nominated audit unit helpers. The web-tool was developed and hosted on a secure section of the RCPCH website to facilitate data collection. Data submission was open from the unit's census day until October 31st 2011.

A copy of the clinical audit questionnaire can be found in Appendix 4.

Figure 3a. Finding the clinical cohort for 'Early Adopters'

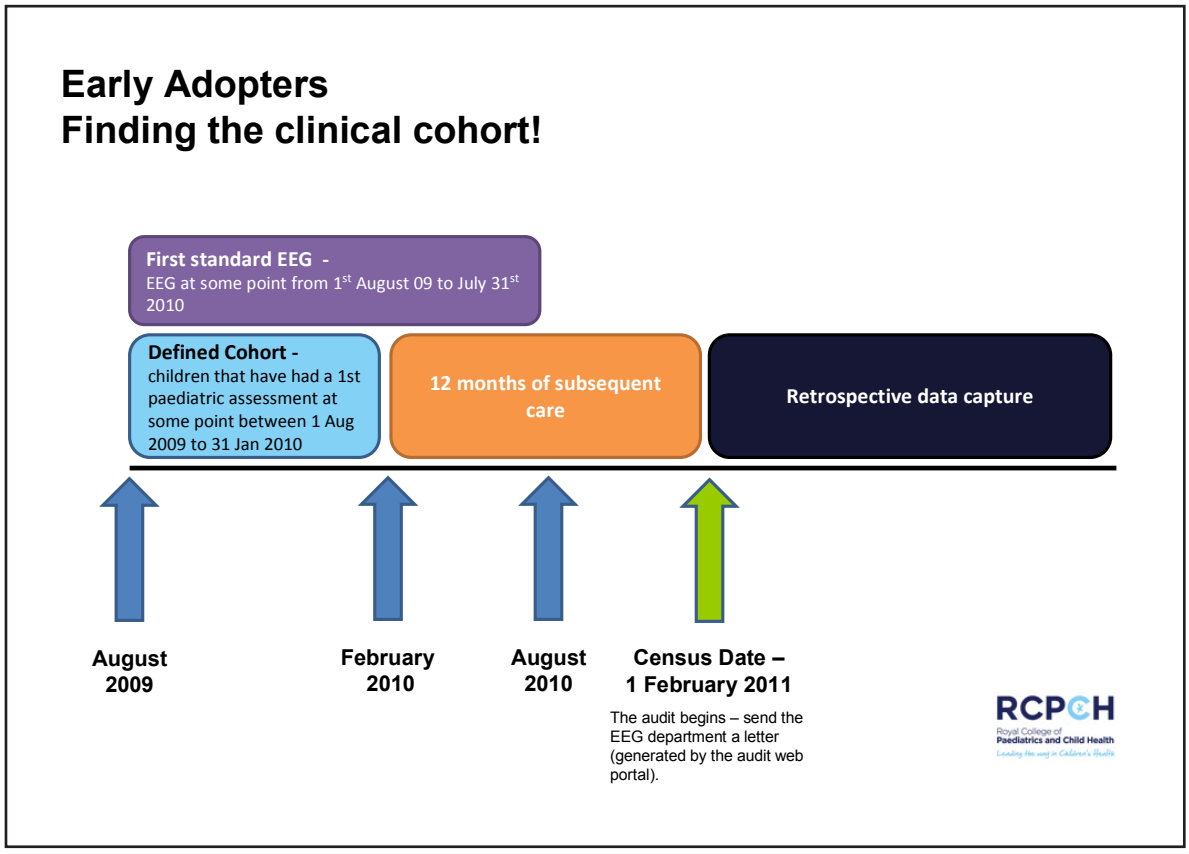


Figure 3b. Finding the clinical cohort for 'Regular Units'

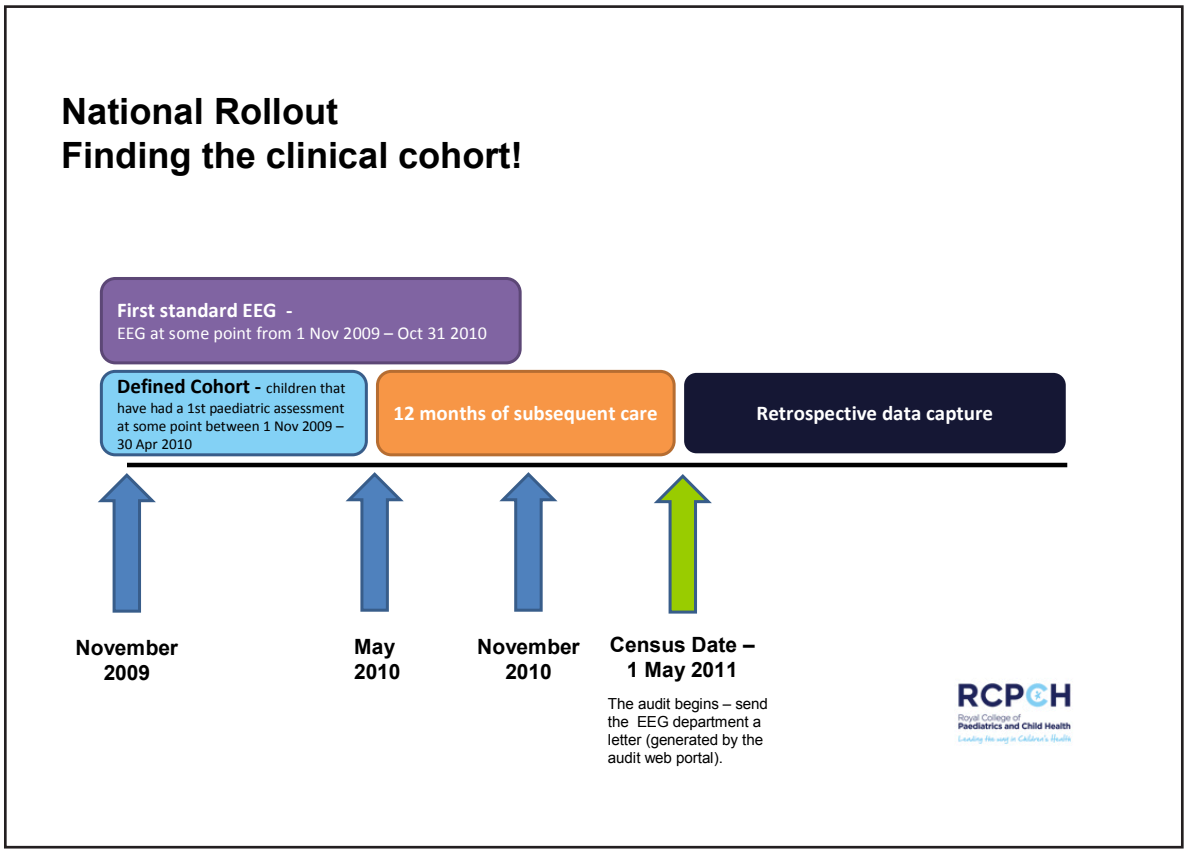


Table 1. Inclusion and Exclusion criteria

Inclusion criteria	Exclusion criteria
• First EEG during 12 month period during defined period prior to 'census day'. • The child has a 'first paediatric assessment' for the 'paroxysmal episode or episodes' during the defined 6 month time prior to 'census day' • Child is older than 1 month and younger than 16 years at 'first paediatric assessment' • The EEG was prompted by the patient having one or more afebrile paroxysmal episodes.	• All 'paroxysmal episodes' in question were diagnosed as 'febrile seizures'. (Children with a history of febrile seizures being assessed for different afebrile 'paroxysmal episodes' may be included). • The patient has had a paediatric assessment previously for similar episode or episodes or epilepsy prior to first paediatric assessment. • All the paroxysmal episodes that the patient had were acute symptomatic seizures or occurred within a week of a traumatic head injury. • The patient's care was permanently transferred to a secondary paediatric service outside the 'audit unit' boundaries or an adult service during the year after first paediatric assessment.

Upon completing the clinical audit, units were asked to 'close and lock' and complete two ascertainment-related questions.

Audit units were then asked to send PREM questionnaire packs (Domain 3) to eligible parent/carers of children with epilepsy. Patients defined as eligible for the PREM were those commenced on anti-epileptic drugs within 12 months of first paediatric assessment and who had not died. The pack included a cover letter, an information sheet explaining the project, questionnaires and explanations regarding questionnaire anonymity. Parent/carers were invited to complete Questionnaire Part A and to ask their child to complete Part B where appropriate. The questionnaire could be completed in paper form and posted back to RCPCH or completed online using an untraceable and unique login number.

Units were asked to send a reminder questionnaire pack to all parent/carers two weeks after initial mail-out. The closing date for accepting patient questionnaires was December 31st, 2011. A copy of the PREM questionnaire can be found in Appendix 5.

2.4 Performance Indicators

The clinical audit domain applied 12 broad measures of quality derived from NICE '*The epilepsies: diagnosis and management of the epilepsies in children and young people in primary and secondary care' (2004)*[1] *and SIGN 'Diagnosis and management of epilepsies in children and young people'* (2005)[2] guidelines. The 12 measures were developed and piloted by the Project Board and methodology group as pragmatic and meaningful measures of the quality of care. Each performance indicator was derived from specific NICE and SIGN recommendations. Each was designed to be applicable in the context of retrospective case note analysis. Figure 4 outlines the 12 performance indicators. The glossary (Appendix 1) contains further definitions of terms used (highlighted in bold). The 'Epilepsy12 Full Methodology Document' contains precise definitions of the numerator and denominator groups and the calculations applied. (www.rcpch.ac.uk/epilepsy12)

Figure 4. Epilepsy12 Performance Indicators

Category		Title	Performance indicator
Professionals	1	**Paediatrician with expertise in epilepsies**	Percentage of children with **epilepsy**, with **input** by a '**consultant Paediatrician with expertise in epilepsies'** by 1 year
	2	**Epilepsy Specialist Nurse**	Percentage of children with **epilepsy**, referred for input by an **epilepsy specialist nurse** by 1 year
	3	**Tertiary involvement**	Percentage of children meeting defined criteria for paediatric neurology referral, with input of tertiary care by 1 year
Assessment & Classification	4	**Appropriate first clinical assessment**	Percentage of all children, with evidence of **appropriate first paediatric clinical assessment**
	5	**Seizure classification**	Percentage of children with epilepsy, with **seizure** classification by 1 year
	6	**Syndrome classification**	Percentage of children with epilepsy, with **epilepsy syndrome** by 1 year
Investigation	7	**ECG**	Percentage of children with convulsive seizures, with an ECG by 1 year
	8	**EEG**	Percentage of children who had an EEG in whom there were no defined contraindications
	9	**MRI**	Percentage of children with defined indications for an MRI, who had MRI by 1 year
Management & Outcome	10	**Carbamazepine**	Percentage of children given carbamazepine, in whom there were no defined contraindications
	11	**Accuracy of diagnosis**	Percentage of children diagnosed with epilepsy, who still had that diagnosis at 1 year
	12	**Information & advice**	Percentage of females over 12 years given anti-epileptic drugs , who had evidence of discussion of pregnancy or contraception

Targets were not set for this audit. It is accepted that for some performance indicators the optimum score may not be 100%. However most performance indicators were defined such that scores should approach 100%. Performance indicator 6 is an exception as a proportion of children with epilepsy do not 'fit' into a defined electroclinical syndrome. Further work to evaluate and define targets is being undertaken.

2.5. Data quality and data analysis

2.5.1 Service and clinical data

There was automated checking of the data for missing data, inconsistencies, inaccuracies, outliers and any other discrepancies in the data entry. The data was analysed using StatTransfer (to convert the datasets from Excel format to STATA format) and STATA 11.2 (to undertake all aspects of data management and analysis).
The main summary statistic used in this report is that of the median percentage and the inter-quartile range parameters (25th and 75th percentile) for each performance indicator.

Data quality checks
Inter-rater reliability checks were carried out. Units within England, Scotland and Wales which submitted 20 or more cases were identified and 30 units were randomly selected from this group. Each of these units was approached and invited to take part in the re-analysis. Case notes of all submitted cases (where available) were re-reviewed and data entered into the web-tool by an independent audit facilitator. A total of 133 case notes were re-entered from 9 units and the data compared with the original entry on the following questions:

- Age
- *Gender
- *Question 4: Which statement best describes the number of paroxysmal episodes by the time of the first paediatric assessment?
- *Question 5: Which statement best describes the diagnosis made by the paediatric team by the end of the first paediatric assessment?
- *Question 8: Which statement best describes the total number of paroxysmal episodes occurring by 12 months after first paediatric assessment?
- *Question 9: Which statement best describes the diagnosis made by the paediatric team by the end of the 12 months after first paediatric assessment?
- *Question10: Was there any evidence that a diagnosis of epilepsy (two or more epileptic seizures) was made and then later withdrawn at any time during 12 months after first paediatric assessment?
- *Question 11: Were any afebrile episodes documented as convulsive?
- *Question 13: Which of the listed epilepsy syndromes were diagnosed?
- *Question 14: Were any of the listed epilepsy syndrome category identifiers used?
- *Question 15: Were any of the listed epilepsy syndrome categories identifiers used?
- *Question 22: By 12 months after first paediatric assessment, what number of different (maintenance) anti-epileptic drugs had been used?

Two tests of inter-rater reliability were employed: Intraclass Correlation Coefficient, and Kappa test.

Intra-class co-efficient

The Intraclass Correlation Coefficient (ICC) measured inter-rater reliability for numerical data such as 'Age' providing an estimate of the degree of absolute agreement or interchangeability of the two raters. The ICC can be interpreted as follows: Poor agreement: 0-0.2; Fair agreement: 0.3-0.4; Moderate agreement: 0.5-0.6; Strong agreement: 0.7-0.8; Almost perfect agreement: >0.8.

The intraclass correlation coefficient for age for the re-analysis sample of 133 children was 1.0. This indicates perfect agreement between the responses of the two raters for the age of the child at the first paediatric assessment.

Kappa test

The Kappa test measured inter-rater reliability for categorical data items asterixed above (*). This test provided a numerical evaluation of the agreement of the two raters (audit unit versus RCPCH audit facilitator). The un-weighted Kappa test was used for data items with two categories.

Table 2 shows there were high levels of observed agreement for the data items of gender and question 22 on AEDs. This is confirmed by Kappa values and their related confidence intervals which indicate substantial to almost perfect agreement beyond chance between the two raters.

There were discrepancies in the inter-rater reliability data for questions 10 on the withdrawal of the epilepsy diagnosis and questions 14 and 15 on epilepsy category identifiers with high levels of observed agreement between the raters but low Kappa values. These findings may be due to the high prevalence of negative cases in question 10 where the level of positive agreement is 29% and the negative agreement is 98% and the low sample size of 40 accompanied by multiple categories in questions 14 and 15.

Questions 4, 5, 8, 9, 11 and 13 show good levels of observed agreement between the two raters but Kappa values which point to moderate agreement beyond chance for these data items and wide confidence intervals for the Kappas. The latter findings would suggest that the sample sizes for re-analysis of these data items need to be larger to increase the precision and provide a reliable estimate for the Kappa values.

Table 2. Inter-rater reliability scores using un-weighted and weighted Kappa

Data item	Observed agreement	Expected agreement	Kappa	Bias corrected Kappa (95% C.I.)	P value
Gender	99%	50%	0.98	0.99 (0.96 - 1.00)	< 0.0005
Question 4‡	87%	64%	0.64	0.64 (0.45 - 0.78)	< 0.0005
Question 5‡	78%	59%	0.48	0.48 (0.36 - 0.65)	< 0.0005
Question 8‡	82%	69%	0.42	0.42 (0.24 - 0.58)	< 0.0005
Question 9‡	88%	73%	0.56	0.56 (0.43 - 0.69)	< 0.0005
Question 10	96%	95%	0.27	0.27 (0.00 - 0.56)	0.0003
Question 11	74%	53%	0.43	0.43 (0.22 - 0.55)	< 0.0005
Question 13‡	88%	79%	0.40	0.40 (0.17 - 0.70)	0.0003
Question 14‡	90%	87%	0.23	0.23 (0.09 - 0.35)	0.0025
Question 15‡	86%	81%	0.27	0.27 (0.00 - 0.60)	0.0338
Question 22‡	98%	91%	0.79	0.79 (0.60 - 0.93)	< 0.0005

‡ Weighted Kappa, bias corrected Kappa and 95% confidence intervals

2.5.2 Patient Reported Experience Measurement (PREM) questionnaire

Data from PREM questionnaires returned by post and data from questionnaires completed online were entered onto a Microsoft Excel spreadsheet. Descriptive statistics were used to summarise this data. For categorical variables, frequencies and percentages are presented and for continuous variables, the total n, median and range presented. The responses to the open ended questions were categorised into themes by a reviewer. The categorisation was checked by a second reviewer and any discrepancies resolved through discussion.

3. National Results

Explanatory notes

- Total percentages in the tables may not sum to 100% due to rounding up to nearest whole number.
- Only relevant categories are reported in tables summarising syndromes and seizures.
- The abbreviation (n/a) is used for the term 'not applicable' to indicate that the percentage for the given performance indicator has not been reported because there were no eligible children.
- Individual audit unit results are available online at: www.rcpch.ac.uk/epilepsy12
- The symbol  is used in this report to indicate the availability of additional online data found on the Epilepsy12 website: www.rcpch.ac.uk/epilepsy12. This includes supplementary information in the form of more detailed results for the individual audit units in addition to the information contained in this report.

3.1. Participation levels

All 197 units eligible to participate registered to take part in the audit (Table 3). 193/197 (98%) submitted service descriptors. 186/197 (94%) participated in the clinical audit. A list of the participation status of all audit units can be found in Appendix 2.

Table 3. Participation levels

Level of participation	UK	England	Wales	Scotland	Northern Ireland
Number of registered units	197	161	15	15	6
Service data submission	193 (98%)	159 (99%)	13 (87%)	15 (100%)	6 (100%)
Clinical data submission	186 (94%)	152 (94%)	13 (87%)	15 (100%)	6 (100%)
Clinical audit- number of submitted eligible children	4945	4085	225	471	164
Units- PREM printed*	178/186 (96%)	146/152 (96%)	13/13 (100%)	13/15 (87%)	6/6 (100%)
Units- PREM returned by patients*	131/186 (70%)	107/152 (70%)	7/13 (54%)	11/15 (73%)	6/6 (100%)
Patients eligible for PREM questionnaire	1531	1247	86	148	50
PREM respondents (response rate)	319/1531 (21%)	257/1247 (21%)	12/86 (14%)	41/148 (28%)	9/50 (18%)

*Denominator is the number of units which submitted clinical audit data

3.2 Service Descriptor results

193 units completed the service questionnaire (Domain 1). The responses are summarised below.

3.2.1 Staffing and clinic resources of the audit units

Unit leads reported a total of 2026.9 total WTE general paediatric consultants employed and 346.7 WTE (17%) general paediatric consultants with 'expertise in epilepsy' (Table 4). Just over a half (53%; 102/193) of units had at least one Epilepsy Specialist Nurse (ESN).

The total number of consultant (or associate specialist) led secondary level 'epilepsy clinics' per week for children or young people was 189.9. 58% (112/193) of units held at least one consultant-led 'epilepsy clinics' on average per week.

'Outpatient' adult services within units accept referrals from General Practitioners (GPs) for young people with a seizure or seizures with a median age of 16 years (range of 13 to 18 years). Therefore some young people would have not included within this audit because of referral to adult services.

Table 4. Staffing and clinic resources of the audit units

Staffing and clinic resources	UK N = 193	England n = 159	Wales n = 13	Scotland n = 15	Northern Ireland n = 6
Total WTE general paediatric consultants (or associate specialists) (community or hospital based)	2026.9	1701.5	105.9	165.4	54.1
Total WTE general paediatric consultants with 'expertise in epilepsy'	346.7	288.0	14.9	33.8	10.0
Total WTE epilepsy specialist nurses (ESNs)	100.9	71.4	10.4	12.1	7.0
Number of units with an ESN	102 (53%)	75 (47%)	10 (77%)	11 (73%)	6 (100%)
Total number of consultant (or associate specialist) led secondary level 'epilepsy clinics' within the audit unit per week	189.9	157.0	12.3	16.9	3.8
Number of units with at least 1 'epilepsy clinic' within the audit unit per week	112 (58%)	94 (59%)	7 (54%)	8 (53%)	3 (50%)
Age 'outpatient' adult services accepts referrals from GPs (Median, Range)	16 (13, 18)	16 (14, 16)	16 (16, 18)	16 (13, 16)	15 (14, 16)

WTE = whole time equivalent. e.g. One full time post is 1 WTE; Someone working 3 days a week = 0.6 WTE; 2 people both working 3 days a week = 1.2 WTE.

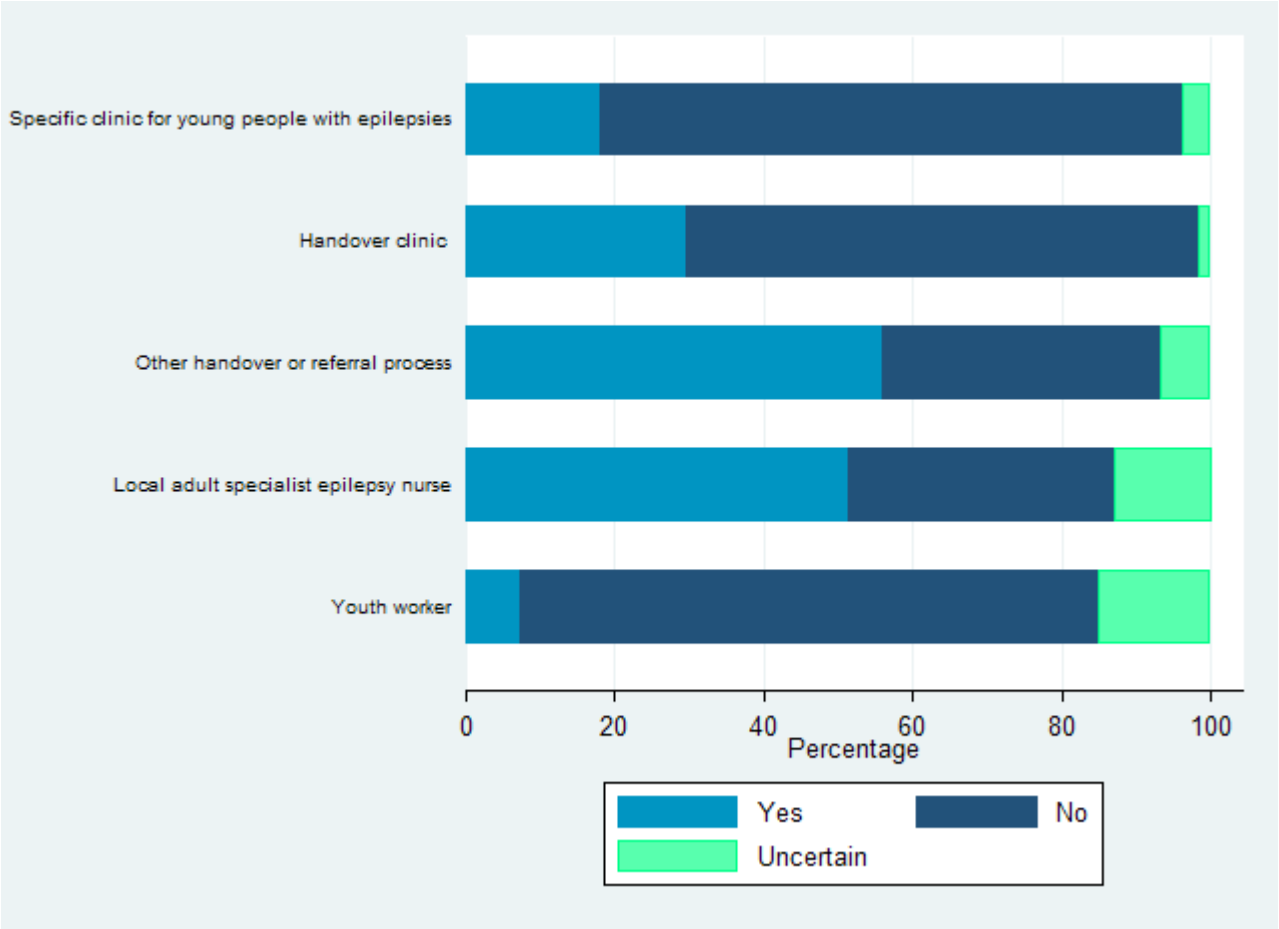
3.2.2 Services provided by the audit units

47% (90/193) reported a database or register of children with epilepsies. 85% (164/193) units hosted a paediatric neurology outpatient service (Table 5). The provision of 'Transition services' are shown in Figure 5.

Table 5. Services provided by the audit units

Services	**UK** N = 193
The 'audit unit' maintains a database or register of children with epilepsies	
No	103 (53%)
Yes for all children	26 (14%)
Yes for some children	64 (33%)
'Audit unit' host paediatric neurology clinics	
No	29 (15%)
Yes	164 (85%)
A specific clinic for 'young people' or' teenagers' with epilepsies	
No	151 (78%)
Yes	35 (18%)
Uncertain	7 (4%)
A 'Handover clinic'	
No	133 (69%)
Yes	57 (30%)
Uncertain	3 (2%)
Other defined handover or referral process	
No	72 (37%)
Yes	108 (56%)
Uncertain	13 (7%)
A local adult specialist epilepsy nurse	
No	69 (36%)
Yes	99 (51%)
Uncertain	25 (13%)
A youth worker	
No	150 (78%)
Yes	14 (7%)
Uncertain	29 (15%)

Figure 5. Percentage of different components of 'Transition services' available within UK audit units



Note that these components are not mutually exclusive.

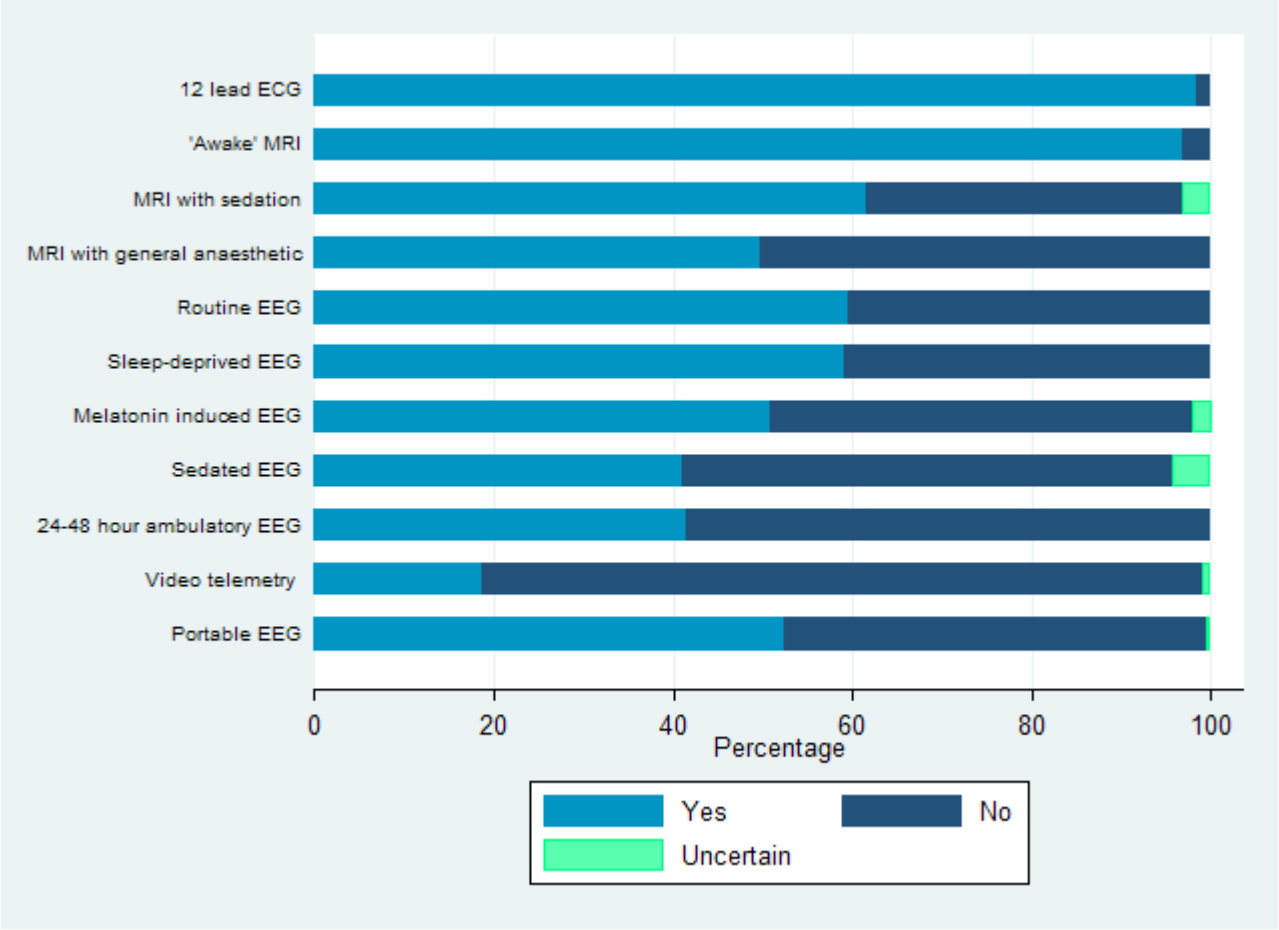
3.2.3 Investigations obtained by the audit units

Investigations were defined as being locally available if they could be achieved for patients without leaving services within the audit unit. Table 6 shows variations in the local availability of investigations. 98% (190/193) audit units had 12 lead ECG and 96% (186/193) 'Awake' MRI locally available (Figure 6).

Table 6. Investigations obtained by the audit units

Investigations	**UK** N = 193
12 lead ECG	
No	3 (2%)
Yes	190 (98%)
'awake' MRI	
No	6 (3%)
Yes	186 (97%)
MRI with sedation	
No	68 (35%)
Yes	119 (62%)
Uncertain	6 (3%)
MRI with general anaesthetic	
No	97 (50%)
Yes	96 (50%)
Routine EEG	
No	78 (40%)
Yes	115 (60%)
Sleep-deprived EEG	
No	79 (41%)
Yes	114 (59%)
Melatonin induced EEG	
No	91 (47%)
Yes	98 (51%)
Uncertain	4 (2%)
Sedated EEG	
No	106 (55%)
Yes	79 (41%)
Uncertain	8 (4%)
24-48 hour ambulatory EEG	
No	113 (59%)
Yes	80 (41%)
Video telemetry	
No	155 (80%)
Yes	36 (19%)
Uncertain	2 (1%)
Portable EEG on paediatric ward within audit unit	
No	91 (47%)
Yes	101 (52%)
Uncertain	1 (<1%)

Figure 6. Percentage of audit units where specified investigations were locally available.



3.3. Clinical Audit Results

3.3.1 Audit Sample Ascertainment

3.3.1.1 Sample

186 audit units submitted clinical patient data on 4991 cases. Following data cleaning, 46 were excluded from the analyses due to inaccuracy, inconsistency or missing data. The final eligible audit sample therefore comprised 4945 cases. A list of participating units can be found in Appendix 2.

3.3.1.2 Ascertainment

96% (178/186) units submitted 'close and lock' ascertainment information. 728 cases were declared by the 156 audit units as identified from EEG lists but without their inclusion/exclusion status ultimately determined. Therefore there were at least 728 children not entered into the web-tool who were not formally excluded. The ascertainment status of the remaining 8 out of 186 units is not known.

3.3.1.3 Demographics

The sample included 54% males and 46% females (2665 vs. 2280 respectively) (Table 7; Figure 7). Table 8 shows the distribution of ages at first paediatric assessment (Figure 8).

There was evidence of a neurodisability in 20%, (966/4945). Of these, 31% (298/966) had 'moderate, severe, or profound learning difficulty or global development delay' (Table 9 and Figure 8).

Table 7. Sex of the child

Sex	UK N = 4945	England n = 4085	Wales n = 225	Scotland n = 471	Northern Ireland n = 164
Female	2280 (46%)	1877 (46%)	111 (49%)	206 (44%)	86 (52%)
Male	2665 (54%)	2208 (54%)	114 (51%)	265 (56%)	78 (48%)

Table 8. Age at the first paediatric assessment

Age	UK N = 4945	England n = 4085	Wales n = 225	Scotland n = 471	Northern Ireland n = 164
Median (25th quartile, 75th quartile)	6.3 years (2.1, 10.8)	6.4 years (2.2, 10.7)	7.5 years (3.1, 12.1)	5.6 years (2.2, 10.8)	3.2 years (1.1, 8.7)
Age categories					
Infant (1 month < 2 years)	1170 (24%)	957 (23%)	41 (18%)	109 (23%)	63 (38%)
Preschool (2 - < 5 years)	984 (20%)	815 (20%)	39 (17%)	101 (21%)	29 (18%)
School (5 - < 12 years)	1841 (37%)	1525 (37%)	88 (39%)	179 (38%)	49 (30%)
Young people (12 - < 16 years)	950 (19%)	788 (19%)	57 (25%)	82 (17%)	23 (14%)

Figure 7. Age at the first paediatric assessment

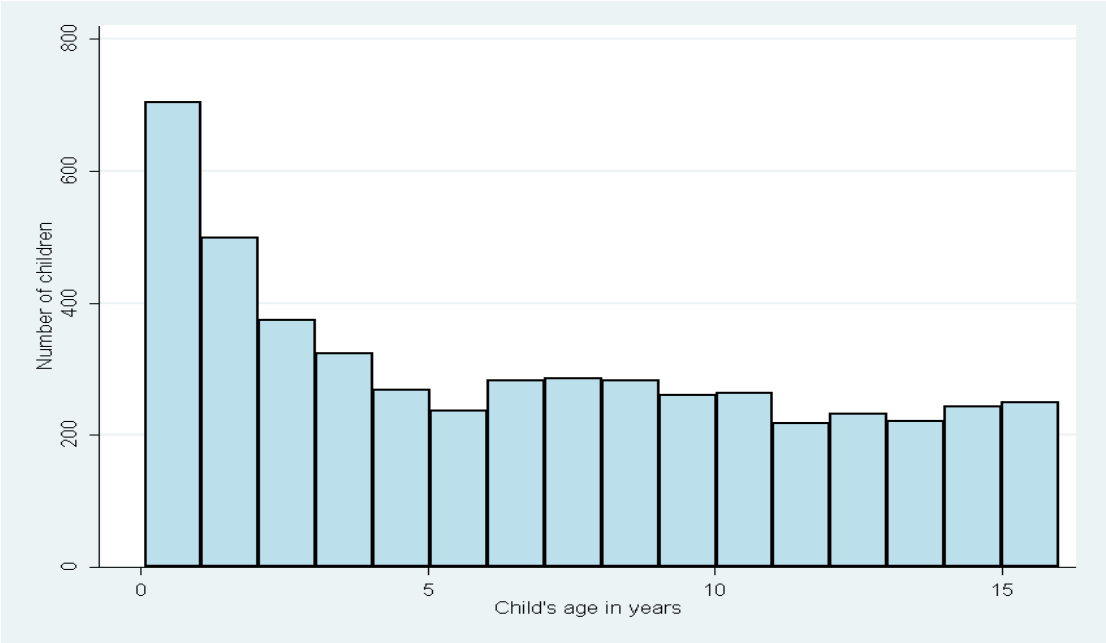
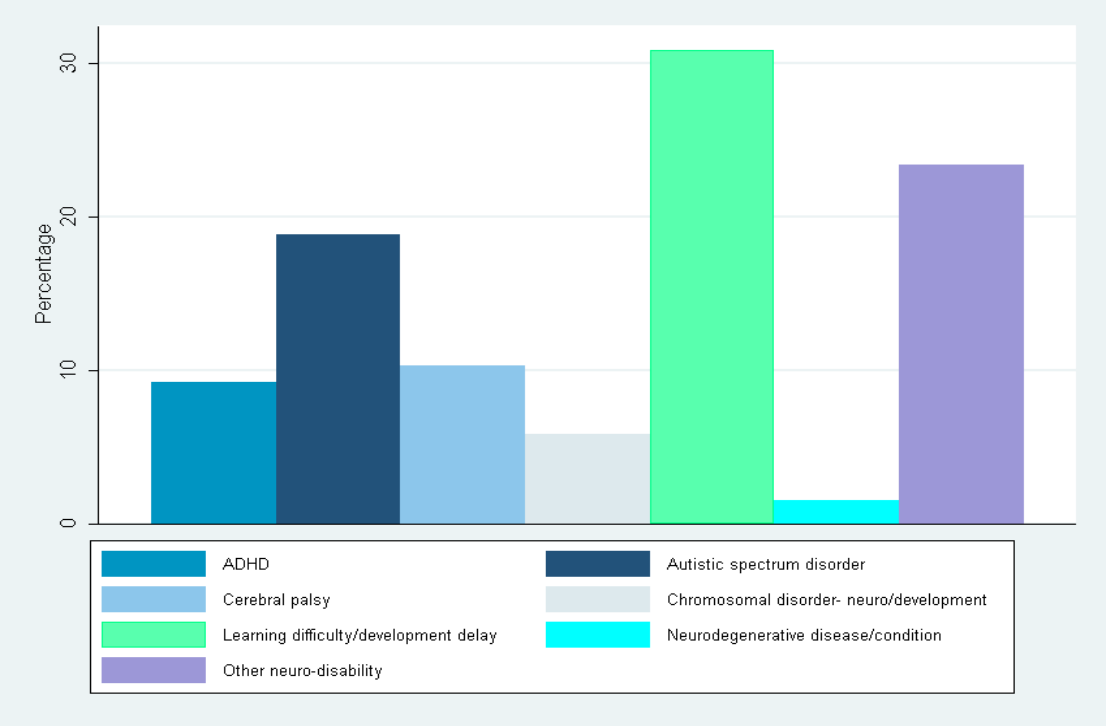


Table 9. Evidence of neurodisability and the types of neurodisability identified

Evidence of neurodisability	UK N = 4945
Evidence of neurodisability present	966/4945 (20%)
Types of neurodisability**	
Attention deficit hyperactivity disorder (ADHD)	89/966 (9%)
Autistic spectrum disorder	182/966 (19%)
Cerebral palsy	100/966 (10%)
An identified chromosomal disorder with a neurological or developmental component	57/966 (6%)
Moderate, severe (or profound) learning difficulty or global development delay	298/966 (31%)
Neurodegenerative disease or condition	15 /966 (2%)
Other	225 /966 (23%)

**Denominator for types of neurodisability is children with documentation of neurodisability present

Figure 8.Types of neurodisability identified.



Percentage refers to the percentage of specific types of neurodisability within those with neurodisability

3.3.1.4 Setting of first paediatric assessment

56% (2790/4945) had their first paediatric assessment in non-acute settings compared to 44% (2154/4945) in acute settings (Table 10).

Table 10. Setting of the first paediatric assessment

Setting	UK N = 4945	England n = 4085	Wales n = 225	Scotland n = 471	Northern Ireland n = 164
Acute	2154 (44%)	1766 (43%)	107 (48%)	184 (39%)	86 (52%)
Non-acute	2790 (56%)	2319 (57%)	118 (52%)	286 (61%)	78 (48%)
Not stated	1 (<1%)	0 (0%)	0 (0%)	1 (<1%)	0 (0%)

Acute = Inpatient review, or paediatric review in emergency department, or other clinical assessment in an acute paediatric setting. Non acute = Paediatric outpatients or clinic.

3.3.1.5 Diagnosis

'2 or more epileptic seizures' functioned as the operational definition of epilepsy within this audit. 30% (1488/4945) had episodes diagnosed as 2 or more epileptic seizures at first paediatric assessment rising to 36% (1775/4945) by 12 months. 18% (899/4945) had episodes diagnosed as non-epileptic seizures at first paediatric assessment rising to 45% (2202/4945) by 12 months. Approximately one third (36%; 1792/4945) of children's episodes were diagnosed as uncertain at first paediatric assessment falling to 14% (709/4945) at 12 months (Tables 11a, 11b, 12a, 12b and Figure 9). By 12 months after first paediatric assessment, 5% (259/4945) had a diagnosis of a single epileptic seizure.

Table 11a. Diagnosis at the first paediatric assessment

Diagnosis- First paediatric assessment	UK N = 4945
2 or more episodes of epileptic seizures	1488 (30%)
single epileptic seizure (or cluster)	766 (16%)
non-epileptic episode(s)	899 (18%)
uncertain or unclear episode(s)	1792 (36%)

Table 11b. Description of Diagnosis at the first paediatric assessment

Description of the no. of paroxysmal episodes	Description of diagnosis made by paediatric team by end of first assessment			
	Epileptic or probably epileptic episode	Non-epileptic episode	Uncertain or unclear episode	**Total**
2 or more episodes in more than 24 hrs	1488	699	1311	**3498**
A cluster of episodes in 24 hrs	265	42	155	**462**
A single episode	501	158	326	**985**
Total	**2254**	**899**	**1792**	**4945**

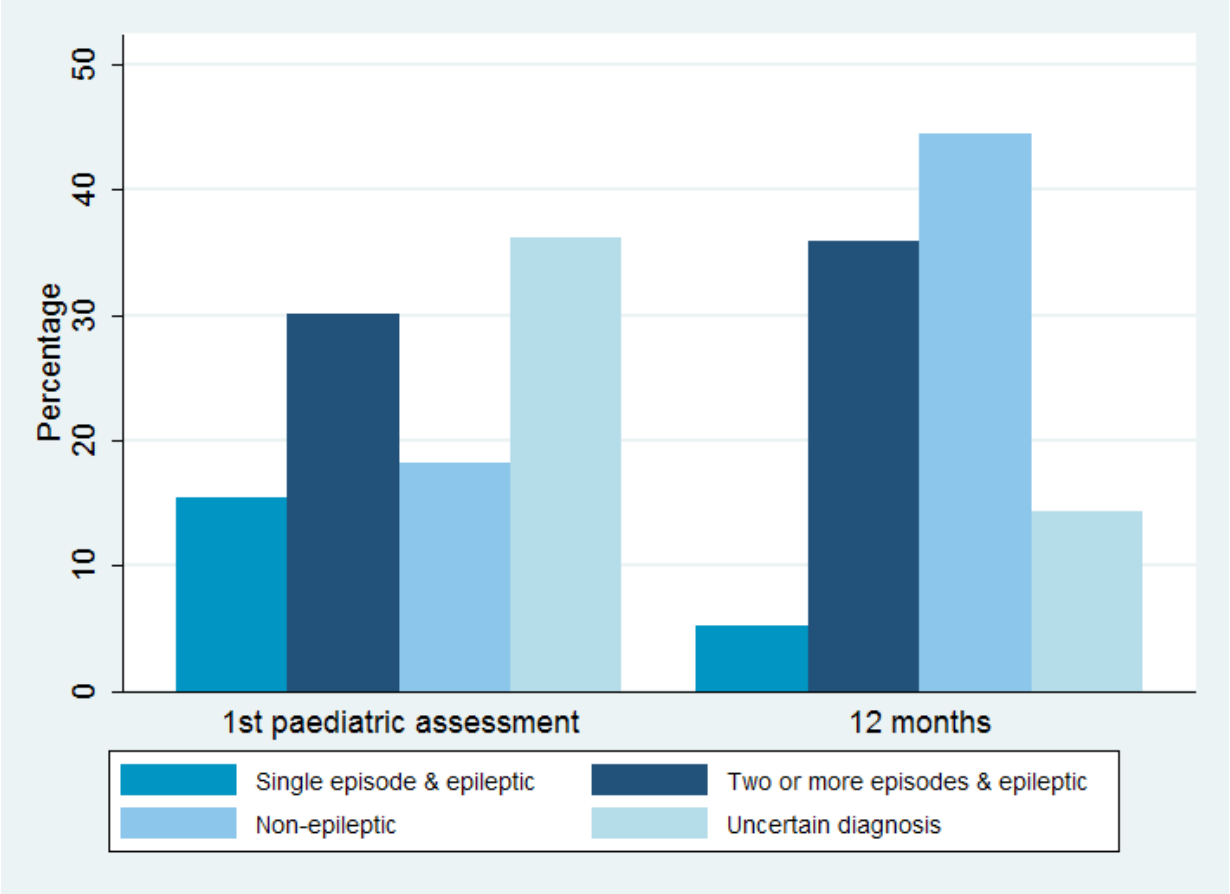
Table 12a. Diagnosis by 12 months after the first paediatric assessment

Diagnosis- by 12 months after the first paediatric assessment	UK N = 4945
2 or more episodes of epileptic seizures	1775 (36%)
single epileptic seizure (or cluster)	259 (5%)
non-epileptic episode(s)	2202 (45%)
uncertain or unclear episode(s)	709 (14%)

Table 12b. Description of Diagnosis by 12 months after the first paediatric assessment

Description of the no. of paroxysmal episodes	Description of diagnosis made by paediatric team by 12 months			
	Epileptic or probably epileptic episode	Non-epileptic episode	Uncertain or unclear episode	**Total**
2 or more episodes in more than 24 hrs	1775	1719	494	**3988**
A cluster of episodes in 24 hrs	79	111	46	**236**
A single episode	180	372	169	**721**
Total	**2086**	**2198**	**707**	**4945**

Figure 9. Diagnosis at the first paediatric assessment and by 12 months after the first assessment



3.3.1.6 Anti-epileptic drugs (AEDs)

Approximately one third of all children (31%; 1538/4945) were commenced on AEDs by 12 months after first paediatric assessment (Table 13a). Of those commenced on 1 or more AEDs, 91% (1406/1538) had a diagnosis of 2 or more episodes of epileptic seizures (Table 13b). There were 20 children who were commenced on 1 or more AEDs when the diagnosis was uncertain or unclear at 12 months after the first paediatric assessment.

Table 13a. Anti-epileptic drugs (AEDs) commenced in children by 1 year after the first paediatric assessment

AEDs	UK- All units N= 4945
Commenced on AEDs (1 or more)	1538 (31%)
Commenced on AEDs (3 or more)**	135 (3%)

** Not necessarily at the same time

Table 13b. Diagnosis and anti-epileptic drugs (AEDs) commenced in children by 1 year after the first paediatric assessment

Diagnosis- at 12 months after the first paediatric assessment	Commenced on AEDs	
	1 or more AEDs n = 1538	3 or more AEDs n = 135
2 or more episodes of epileptic seizures	1406 (91%)	129 (96%)
single epileptic seizure (or cluster)	68 (4%)	6 (4%)
non-epileptic episode(s)	44 (3%)	0 (0%)
uncertain or unclear episode(s)	20 (1%)	0 (0%)

3.3.1.7 Epilepsy Seizure types

This question could only be answered if the diagnosis was '2 or more episodes' (occurring over a time period greater than 24 hours) and episodes were defined as an 'epileptic or probably epileptic episode' by 12 months after the first paediatric assessment. This was a multi-response question and up to 5 seizure types could be selected from the drop down menu.

The drop down list of seizure types included both accepted International League Against Epilepsy (ILAE) seizure types (http://www.ilae.org/) and unofficial terms (highlighted in *italics*). Only seizure types which were selected at least once are shown. (Generalised) tonic-clonic seizures were the most frequent seizure type reported for 39% (692/1775) of children (Table 14).

Table 14. Seizure types (These are multi-response data)

Seizure types	**UK- All units** n = 1775
(Generalised) tonic-clonic seizures	692 (39%)
Absence seizures (typical or atypical)	543 (31%)
Focal seizures	290 (16%)
Myoclonic seizures	129 (7%)
No seizure type stated	114 (6%)
Secondarily generalized seizures	111 (6%)
Focal motor seizures	96 (5%)
Tonic seizures	66 (4%)
Infantile spasms	48 (3%)
Temporal seizure	35 (2%)
Atonic seizures	34 (2%)
Clonic seizures	33 (2%)
Grand mal seizures	24 (1%)
Frontal seizures	21 (1%)
Myoclonic absence seizures	19 (1%)
Focal sensory seizures	17 (1%)
Occipital seizures	17 (1%)
Spasms	16 (<1%)
Documented as 'unclassified' seizure	13 (<1%)
Myoclonic atonic seizures	10 (<1%)
Parietal seizures	9 (<1%)
Gelastic seizures	8 (<1%)
Petit mal seizures	6 (<1%)
Eyelid myoclonia	5 (<1%)
Reflex seizures	3 (<1%)
Hemiclonic seizures	1 (<1%)
Negative myoclonus	1 (<1%)

3.3.1.8 Epilepsy syndromes

This question could only be answered if the diagnosis was '2 or more episodes' (occurring over a time period greater than 24 hours) and episodes were defined as an 'epileptic or probably epileptic' by 12 months after the first paediatric assessment.

The most frequently used category identifier were 'other' (62%; 1102/1775) and 'Idiopathic (or primary) generalised' (22%; 391/1775) (Tables 15a and 15b). Syndromes in the 'other' category are listed in Appendix 4.

Table 15a. Syndrome category identifiers

Epilepsy syndrome identifiers	**Epilepsy syndrome identifiers**					
	Focal	Generalised	Multifocal	Uncertain	None of the above	**Total**
Genetic	12	13	1	9	0	**35**
Idiopathic (or primary)	77	391	2	27	0	**497**
Probably symptomatic	25	35	2	5	1	**68**
Symptomatic	62	17	9	9	3	**100**
Structural/metabolic	21	4	2	8	1	**36**
Unknown cause	48	34	4	35	1	**122**
None of the above	273	285	6	337	16	**917**
Total	**518**	**779**	**26**	**430**	**22**	**1775**

'Epilepsy syndrome identifiers' refer to question 14 on the questionnaire and 'epilepsy syndrome identifiers' to question 15.

Table 15b. Syndrome category identifiers

Syndrome category identifiers	**UK- All units** n = 1775
Genetic focal/multifocal	13 (<1%)
Genetic generalised	13 (<1%)
Idiopathic (or primary) focal/multifocal	79 (5%)
Idiopathic (or primary) generalised	391 (22%)
Symptomatic or probably symptomatic focal/multifocal	98 (6%)
Symptomatic or probably symptomatic generalised	52 (3%)
Structural/Metabolic focal/multifocal	23 (1%)
Structural/Metabolic generalised	4 (<1%)
Other*	1102 (62%)

* Remaining children not characterised by the above combinations of syndrome category identifiers

Epilepsy syndrome types are shown in Table 16. The list of responses reported for children with a diagnosis of '2 or more episodes' (occurring over a time period greater than 24 hours) and episodes defined as 'epileptic or probably epileptic' episode by 12 months after the first paediatric assessment include both accepted ILAE syndrome types, pragmatic epilepsy types (e.g. occipital lobe epilepsy) and 'non-acceptable' terms (highlighted in *italics*). 'Non-acceptable terms are those terms defined by the project team as not meeting the requirement for scoring within performance indicator 6. It is accepted that some children will have had epilepsy type attempted as evidenced by use of the syndrome category terms but will not have evidence of an electroclinical syndrome diagnosis. Also for a proportion of children with epilepsy, electroclinical syndrome diagnosis may not be possible or appropriate.

Table 16. Epilepsy Syndromes

Syndrome types	**UK- All units** n = 1775
BECTS (benign rolandic epilepsy)	160 (9%)
Childhood absence epilepsy (CAE)	128 (7%)
Defined as unclassified	65 (4%)
Juvenile absence epilepsy (JAE)	54 (3%)
Grand mal epilepsy	53 (3%)
Temporal lobe epilepsy	48 (3%)
Juvenile myoclonic epilepsy (JME)	41 (2%)
West syndrome (infantile spasms)	32 (2%)
Frontal lobe epilepsy	27 (2%)
Petit mal epilepsy	25 (1%)
Occipital lobe epilepsy	17 (1%)
Doose syndrome	16 (<1%)
Panayiotopoulos syndrome	10 (<1%)
Dravet syndrome	5 (<1%)
Parietal lobe epilepsy	1 (<1%)
No epilepsy syndrome stated	941 (53%)

3.4 Performance Indicators

3.4.1 Overview of Results for UK and by country

Figure 10 shows the percentage aggregate scores for the total UK cohort for each performance indicator. Figure 11 shows percentage aggregate scores for each country. Each performance indicator is examined in more detail in the subsequent sections.

The symbol is used in the rest of the report to indicate the availability of additional online data found on the Epilepsy12 website: www.rcpch.ac.uk/epilepsy12.

Figure 10. Epilepsy12 Performance Indicators - UK

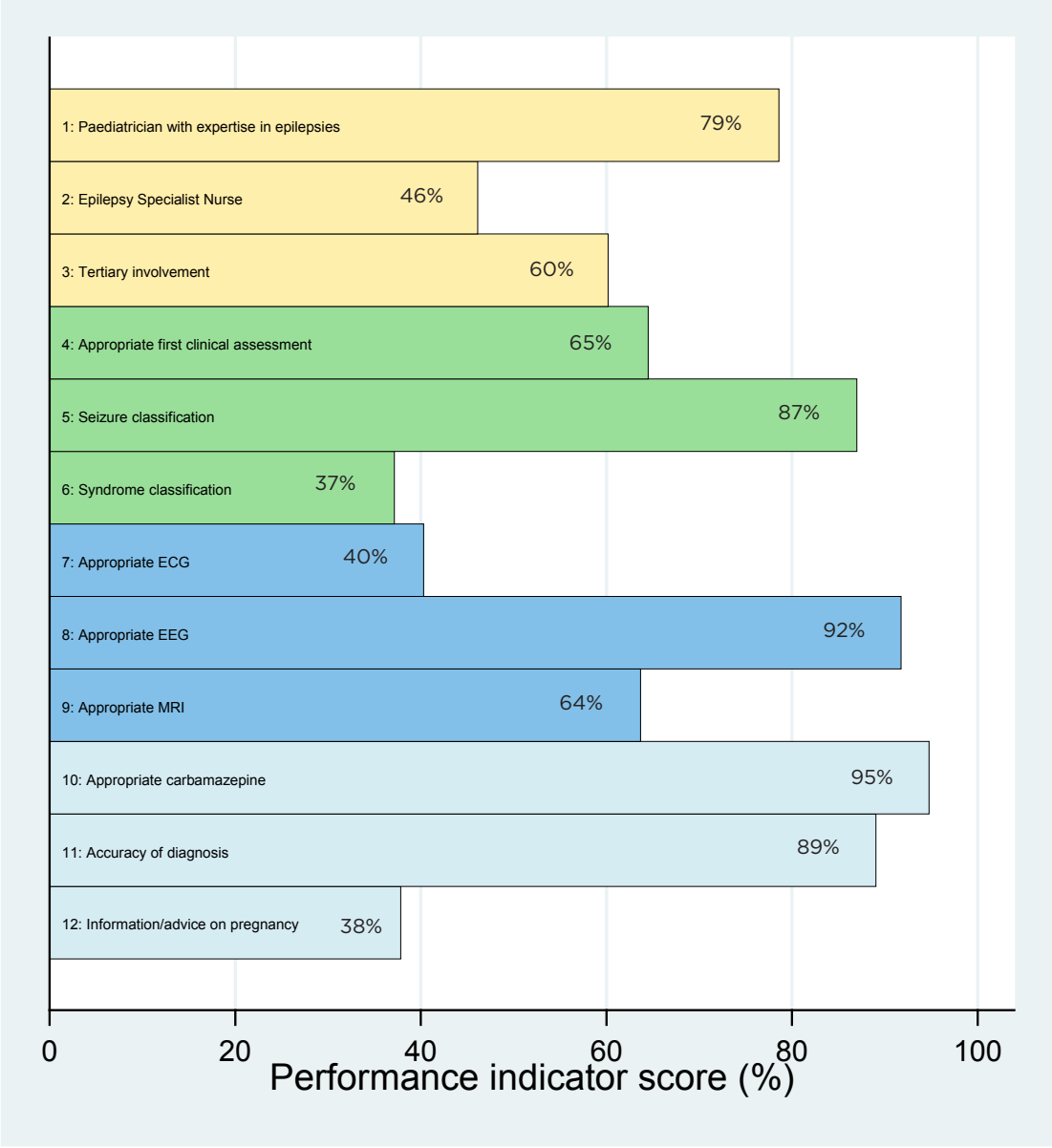
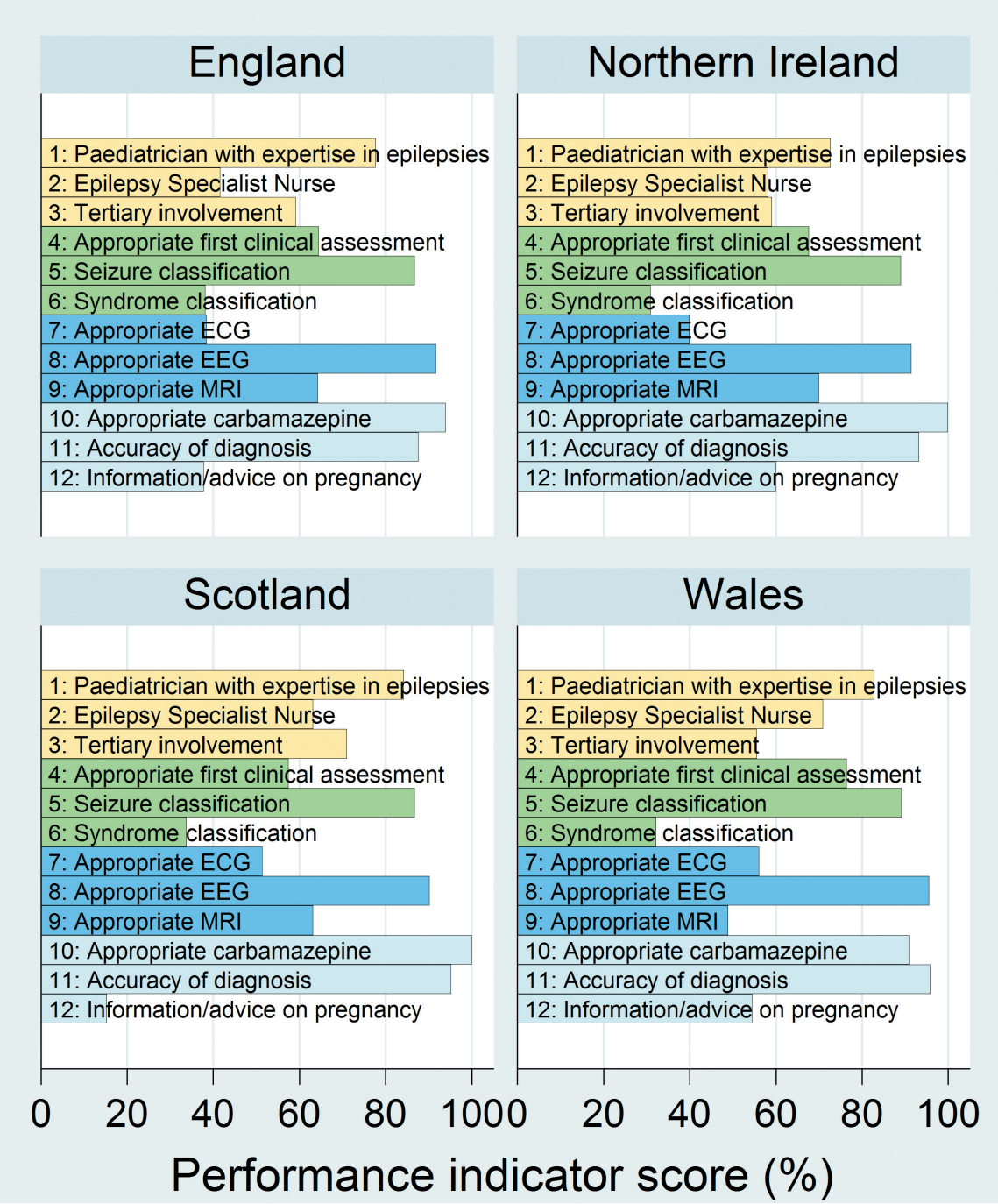


Figure 11. Epilepsy 12 Performance Indicators - England, Wales, Scotland and Northern Ireland



3.4.2 Professional input (Table 17)

Performance Indicator 1 (Table 17 and Figure 12)

NICE: The diagnosis of epilepsy in children should be established by a specialist paediatrician with training and expertise in epilepsy.

SIGN: The diagnosis of epilepsy should be made by a paediatric neurologist or paediatrician with expertise in childhood epilepsy.

Results:

- Of 1775 children with epilepsy, there were 1395 **(79%) children with input by a 'consultant paediatrician with expertise** in epilepsies' by 1 year. The median and related interquartile range (25th and 75th percentiles) for the performance indicator nationally were 83% (57%, 100%).
- For those commenced on AEDs, 81% (1144/1406) of children with epilepsy commenced on AEDs had input by a 'consultant paediatrician with expertise in epilepsies' by 1 year. The median and related interquartile range (25th and 75th percentiles) for the performance indicator nationally were 88% (64%, 100%).

Performance Indicator 2 (Table 17 and Figure 13)

NICE: Epilepsy Specialist Nurses (ESNs) should be an integral part of the network of care of individuals with epilepsy. The key roles of the ESNs are to support both epilepsy specialists and generalists, to ensure access to community and multi-agency services and to provide information, training and support to the individual, families, carers and, in the case of children, others involved in the child's education, welfare and well-being.

SIGN: Each epilepsy team should include paediatric epilepsy nurse specialists

Results:

- Of 1775 children with epilepsy, there were 819 **(46%) children referred for input by an epilepsy specialist nurse** by 1 year. The median and related interquartile range (25th and 75th percentiles) for the performance indicator nationally were 33% (0%, 77%).
- For those commenced on AEDs, 51% (710/1406) of children with epilepsy who were commenced on AEDs, were referred for input by an epilepsy specialist nurse by 1 year. The median and related interquartile range (25th and 75th percentiles) for the performance indicator nationally were 42% (0%, 87%).

Performance Indicator 3 (Table 17 and Figure 14)

NICE: Referral to a paediatric neurologist should be considered when 1 or more of the following criteria are present in a child with epilepsy: 3 or more maintenance AEDS by 12 months after first paediatric assessment or before 2nd birthday at first paediatric assessment.

SIGN: Referral to tertiary specialist care should be considered it a child fails to respond to two AEDs appropriate to the epilepsy in adequate dosages over a period of 6 months.

Note that the national recommendations state indications for neurologist referral other than this but the indicator is limited to those children where the indications for neurology referral were determinable using this retrospective methodology.

Results:

- Of 407 children meeting defined criteria for paediatric neurology referral, there were 245 **(60%) who had input of tertiary care** by 1 year. The median and related interquartile range (25th and 75th percentiles) for the performance indicator nationally were 50% (33%, 100%).

Table 17. Involvement of Appropriate professionals

No.	Performance indicators	UK (All units) Actual %	England Actual %	Wales Actual %	Scotland Actual %	Northern Ireland Actual %	UK (All units) Median % (25th & 75th percentiles)	Units submitting eligible children
Paediatrician with expertise in epilepsies								
1a.	% children with epilepsy, with input by a 'consultant paediatrician with expertise in epilepsies' by 1 year	1395/1775 79%	1106/1423 78%	77/93 83%	172/204 84%	40/55 73%	83% (57%, 100%)	184
1b.	% children with epilepsy who were commenced on AEDs, with input by a 'consultant paediatrician with expertise in epilepsies' by 1 year	1144/1406 81%	914/1138 80%	67/80 84%	126/142 89%	37/46 80%	88% (64%, 100%)	181
Epilepsy Specialist Nurse								
2a.	% children with epilepsy, referred for input by an epilepsy specialist nurse by 1 year	819/1775 46%	592/1423 42%	66/93 71%	129/204 63%	32/55 58%	33% (0%, 77%)	184
2b.	% children with epilepsy who were commenced on AEDs, referred for input by an epilepsy specialist nurse by 1 year	710/1406 51%	516/1138 45%	59/80 74%	105/142 74%	30/46 65%	42% (0%, 87%)	181
Tertiary Involvement								
3.	% children meeting defined criteria for paediatric neurology referral, with input of tertiary care by 1 year	245/407 60%	200/338 59%	5/9 56%	27/38 71%	13/22 59%	50% (33%, 100%)	137

The denominator varies due to sub group analyses.

Figure 12. Performance Indicator 1: Paediatrician with expertise in epilepsies (the percentage score for each of the individual audit units is shown)

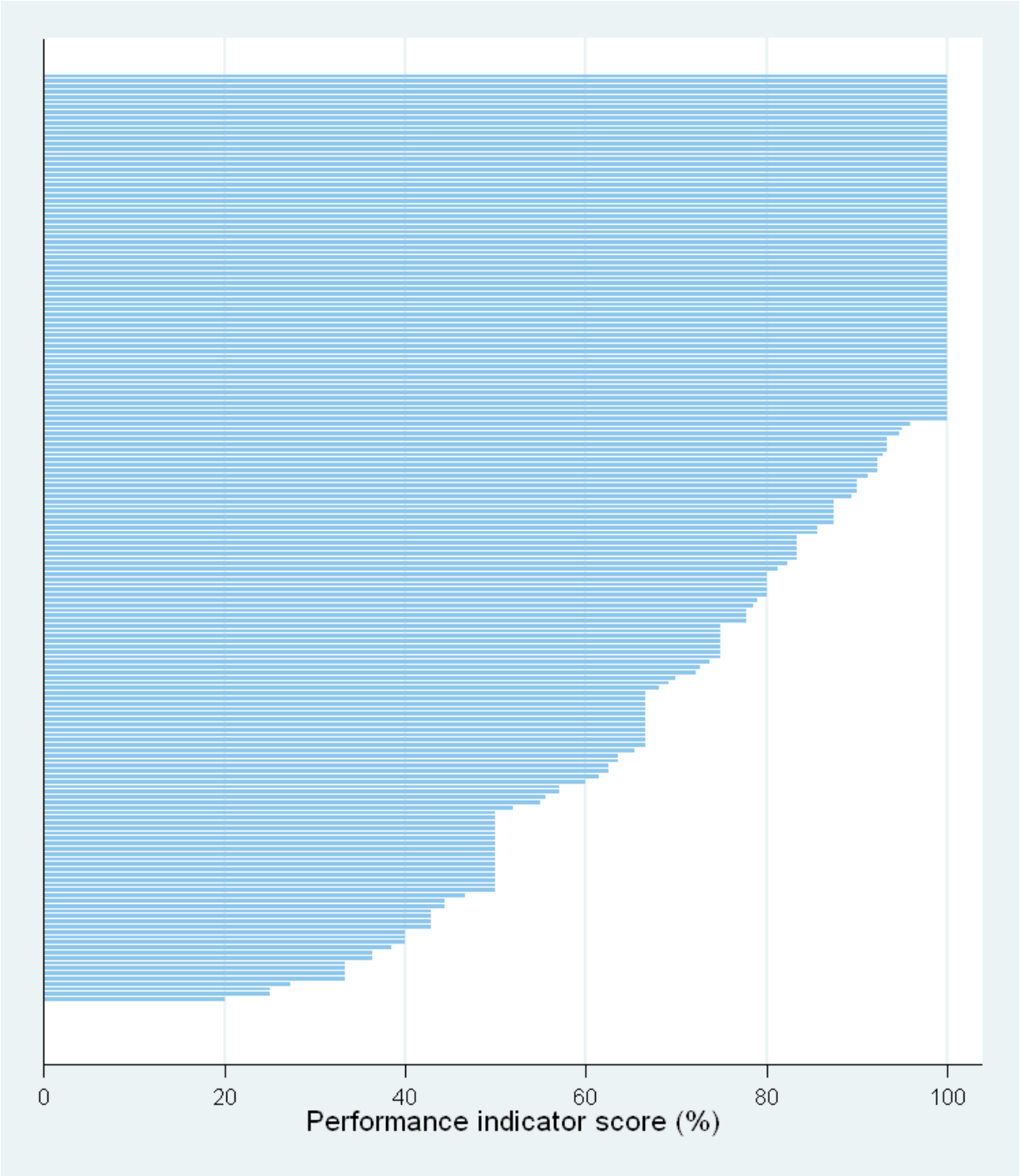


Figure 13. Performance Indicator 2: Epilepsy Specialist Nurse (the percentage score for each of the individual audit units is shown)

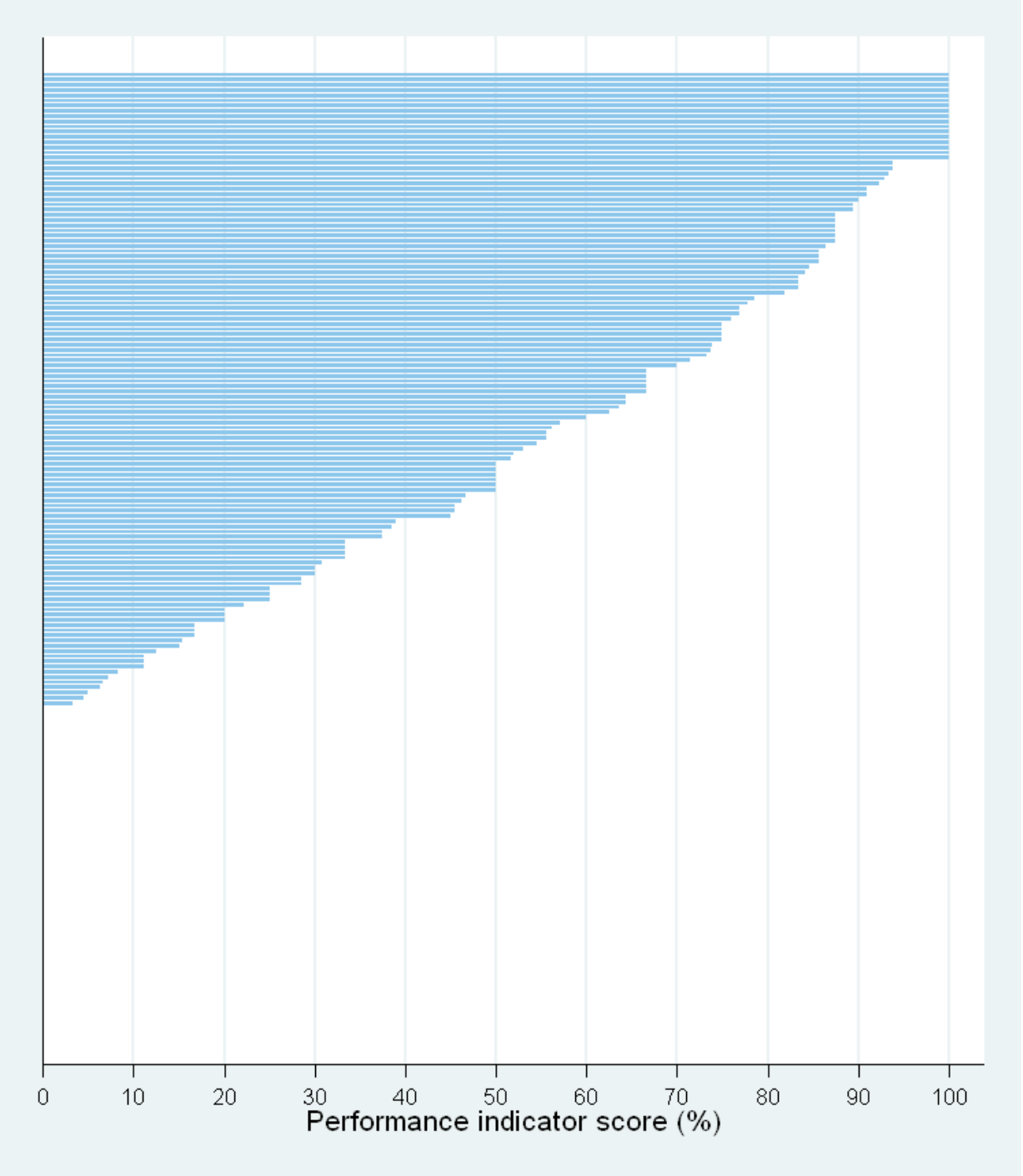
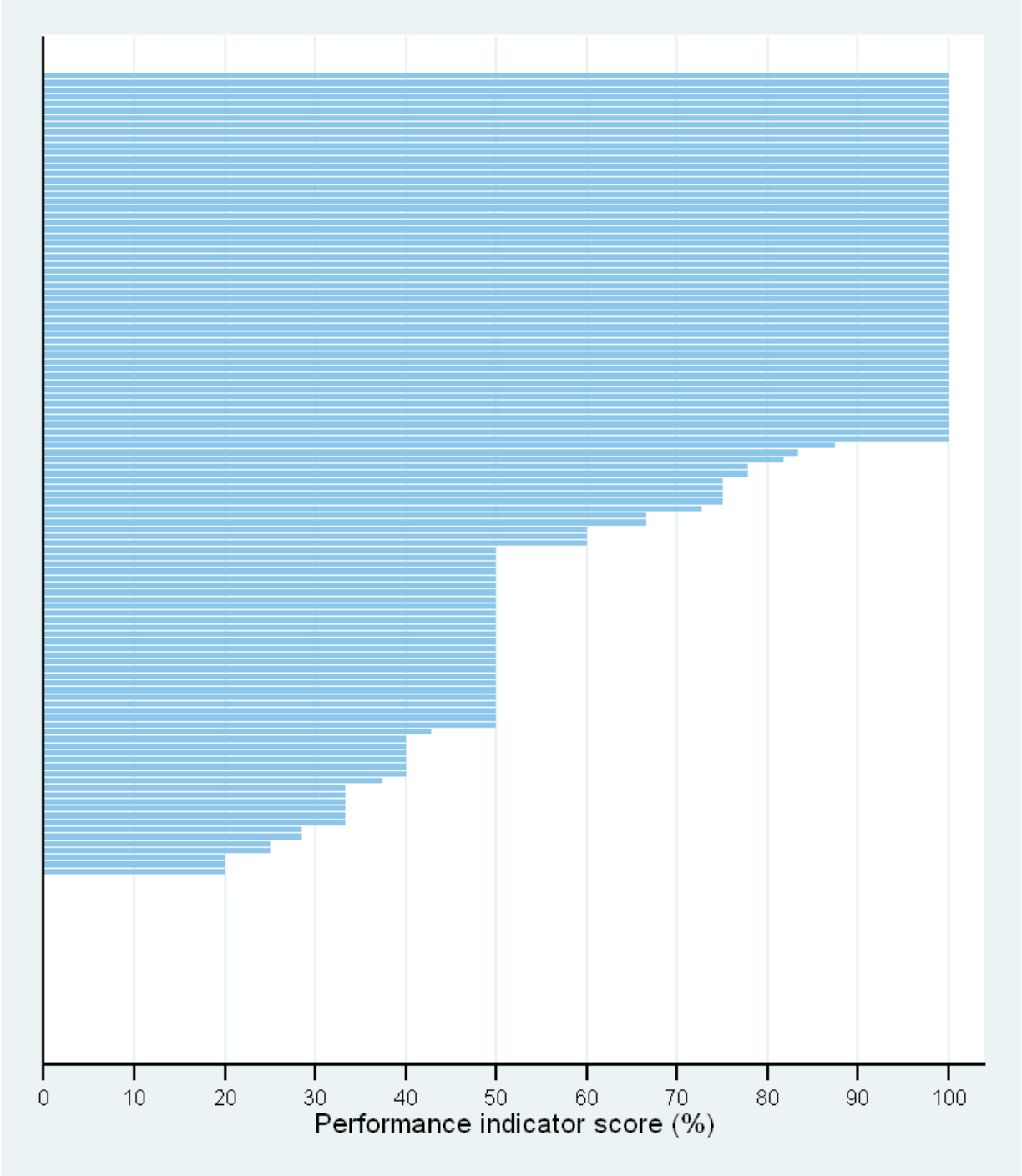


Figure 14. Performance Indicator 3: Tertiary involvement (the percentage score for each of the individual audit units is shown)



3.4.3 Assessment and Classification (Table 18)

Performance Indicator 4 (Table 18 and Figure 15)

NICE: In an individual presenting with an attack, a physical examination should be carried out. This should address the individual's cardiac, neurological and mental status, and should include a developmental assessment where appropriate.

SIGN: All children with epilepsy should have their behavioural and academic progress reviewed on a regular basis by the epilepsy team.

However national guidance does not define 'where appropriate' nor does it define the key components of clinical assessment. Epilepsy12 has defined these components in order to facilitate objective retrospective analysis of this recommendation.

Results:

- Of all 4945 children, there were 3189 **(65%) who had evidence of appropriate first paediatric clinical assessment**. The median and related interquartile range (25th and 75th percentiles) for the performance indicator nationally were 66% (50%, 79%).
- Evidence of descriptions of episode was the most well recorded for all children (98%; 4858/4945) and evidence of descriptions of emotional or behavioural problems for children 3 years and over, the least well recorded (55%, 1848/3389).

Figure 15 presents a graphical illustration showing the distribution of the Performance indicator 4 scores for professional input for the audit units. Results for each audit unit can be found on the Epilepsy12 website at: www.rcpch.ac.uk/epilepsy12.

Performance Indicator 5, 6 (Table 18 and Figures 16, 17)

NICE: Epileptic seizures and epilepsy syndromes in individuals should be classified using a multi-axial diagnostic scheme. The axes that should be considered are: description of seizure (ictal phenomenology), seizure type, syndrome and aetiology.

SIGN: The choice of first AED should be determined where possible by syndromic diagnosis and potential adverse effects.

Terminology for classification is difficult and is constantly evolving. International League Against Epilepsy (ILAE) terminology forms the best way of assessing appropriateness of terminology. Documentation stating that the seizure type was 'unclassified' was accepted. 'Petit mal and 'grand mal' or 'no seizure type stated' were not accepted as appropriate.

It is acknowledged that not all epilepsies can be appropriately classified within an epilepsy syndrome diagnostic category. For this audit if a child's epilepsy was documented as 'unclassified' then this was accepted as a legitimate attempt at syndrome classification.

Results:

- Of 1775 children with epilepsy, there were 1544 **(87%) children with seizure classification by 1 year**. The median and related interquartile range (25th and 75th percentiles) for the performance indicator nationally were 89% (78%, 100%).
- Of 1775 children with epilepsy, there were 660 **(37%) children with appropriate epilepsy syndrome classification**. The median and related interquartile range (25th and 75th percentiles) for the performance indicator nationally were 38% (20%, 50%).

Table 18. Assessment and Classification

No.	Performance indicators	UK (All units) Actual %	England Actual %	Wales Actual %	Scotland Actual %	Northern Ireland Actual %	UK (All units) Median % (25th & 75th percentiles)	Units submitting eligible children
Appropriate first clinical assessment								
4	% children with evidence of descriptions of episode & age of child/timing of the first episode & frequency & general and neurological examination & the presence or absence of developmental, learning or schooling problems	3189/4945 65%	2635/4085 65%	172/225 76%	271/471 58%	111/164 68%	66% (50%, 79%)	186
4a.	% children with evidence of descriptions of episode	4858/4945 98%	4013/4085 98%	224/225 99.6%	459/471 98%	162/164 99%	100% (98%, 100%)	186
4b.	% children with evidence of descriptions of age of child/timing of the first episode	4640/4945 94%	3830/4085 94%	213/225 95%	442/471 94%	155/164 95%	96% (91%, 100%)	186
4c.	% children with evidence of descriptions of frequency	4538/4945 92%	3735/4085 91%	212/225 94%	436/471 93%	155/164 95%	95% (88%, 100%)	186
4d.	% children with evidence of descriptions of general examination	4562/4945 92%	3781/4085 93%	213/225 95%	416/471 88%	152/164 93%	95% (89%, 100%)	186
4e.	% children with evidence of descriptions of neurological examination	4123/4945 83%	3402/4085 83%	203/225 90%	381/471 81%	137/164 84%	86% (77%, 93%)	186
4f.	% children with evidence of description of developmental history or educational progress	4069/4945 82%	3370/4085 83%	201/225 89%	364/471 77%	134/164 82%	84% (74%, 94%)	186
4g.	% children 3 years and over with evidence of descriptions of emotional or behavioural problems	1848/3389 55%	1536/2803 55%	109/171 64%	165/330 50%	38/85 45%	50% (38%, 67%)	185
Appropriate seizure classification								
5.	% children with epilepsy, with seizure classification by 1 year	1544/1775 87%	1235/1423 87%	83/93 89%	177/204 87%	49/55 89%	89% (78%, 100%)	184
Appropriate syndrome classification								
6.	% children with appropriate epilepsy syndrome classification	660/1775 37%	544/1423 38%	30/93 32%	69/204 34%	17/55 31%	38% (20%, 50%)	184

Figure 15. Performance Indicator 4: Appropriate first clinical assessment (the percentage score for each of the individual audit units is shown)

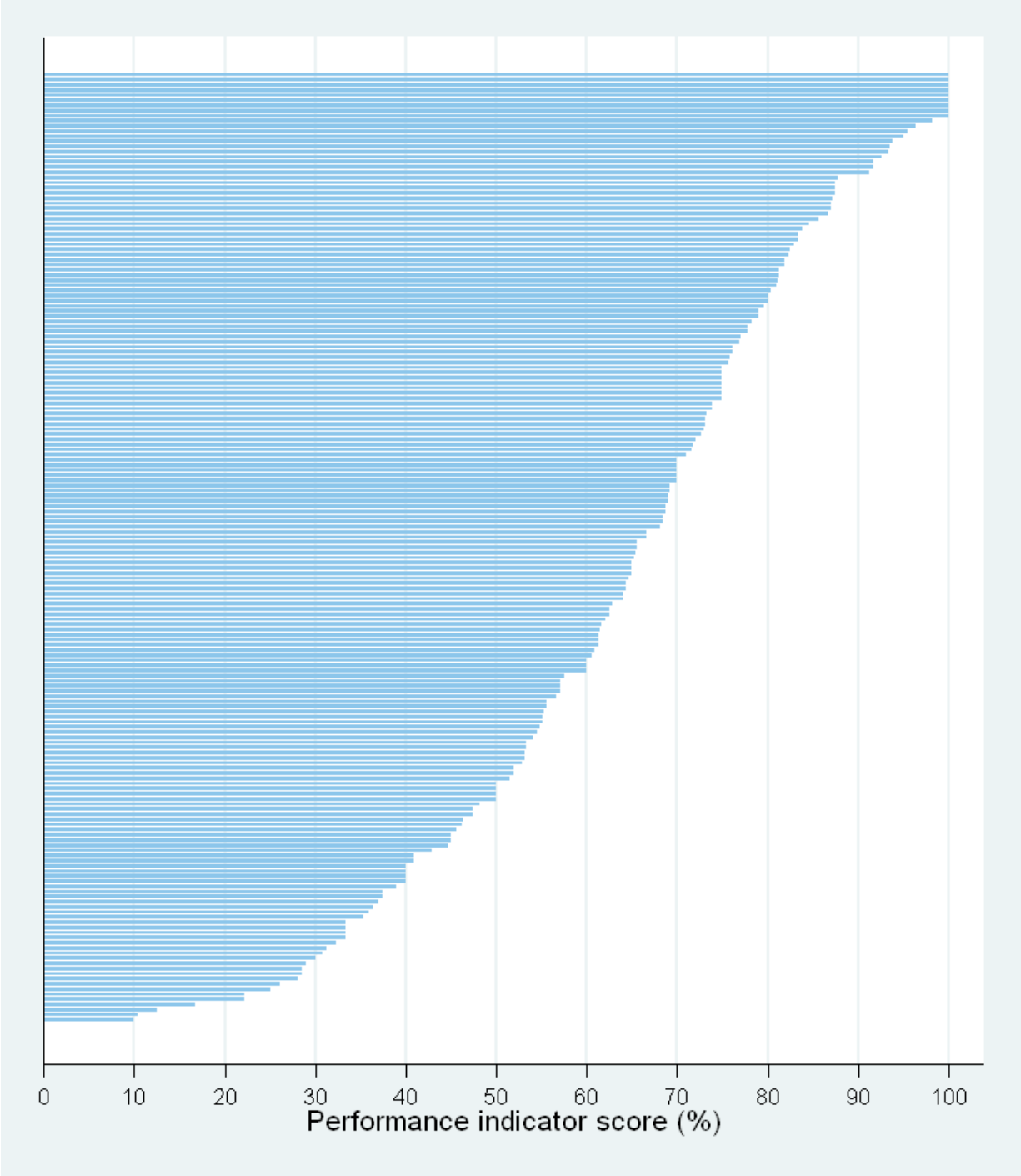


Figure 16. Performance Indicator 5: Appropriate seizure classification (the percentage score for each of the individual audit units is shown)

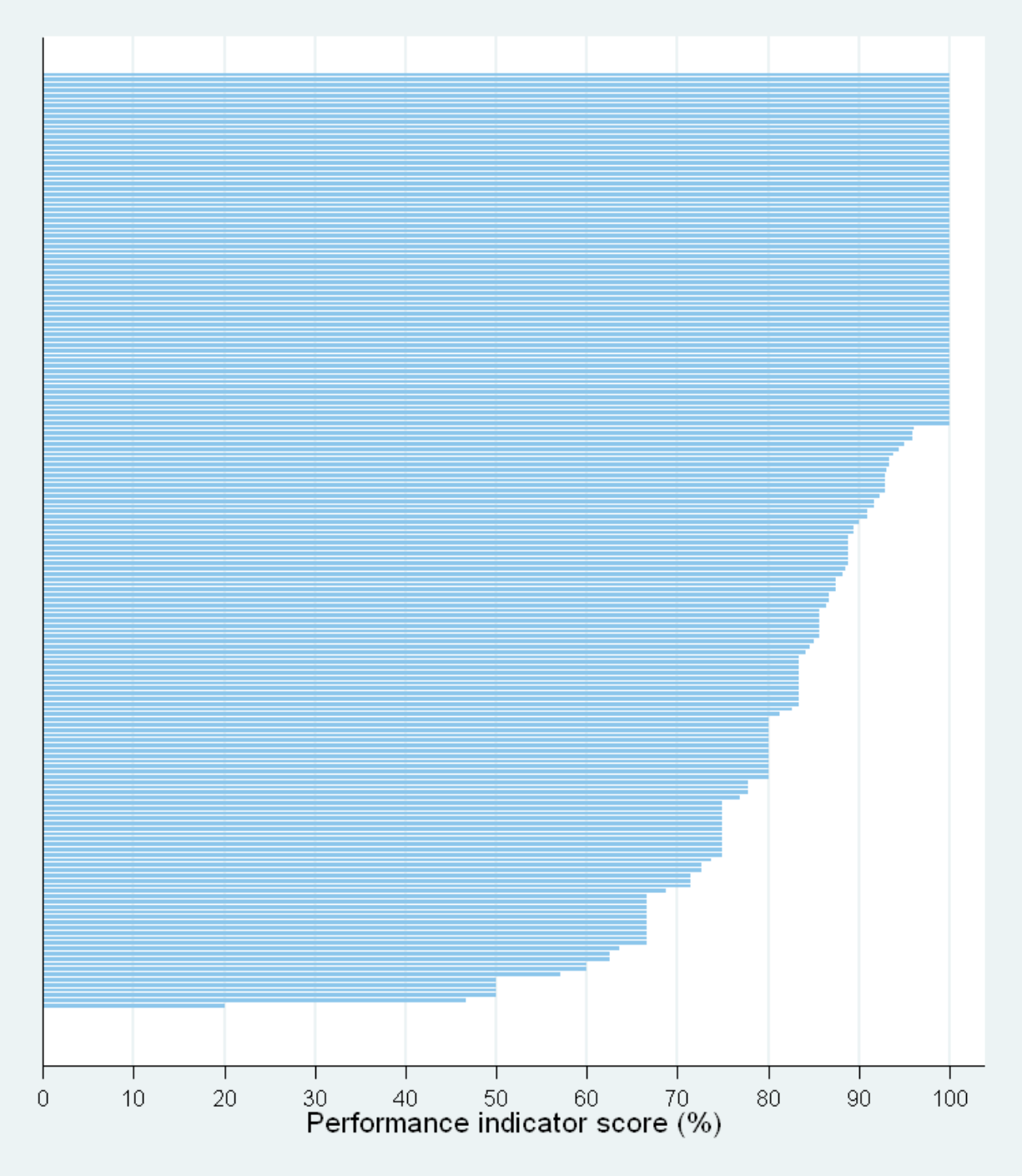
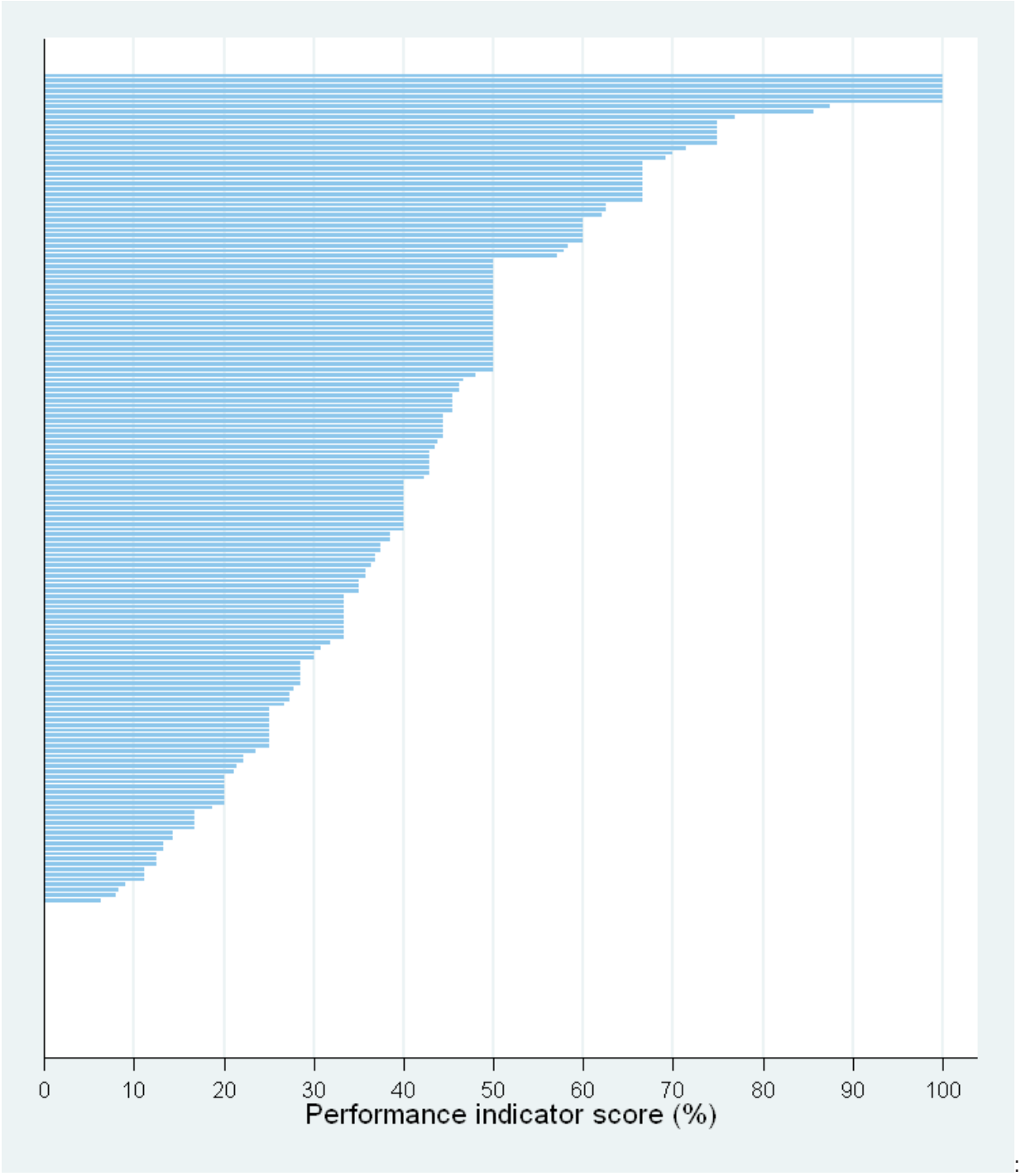


Figure 17. Performance Indicator 6: Appropriate syndrome classification (the percentage score for each of the individual audit units is shown)



:

3.4.4 Investigations (Table 19)

Performance Indicator 7 (Table 19 and Figure 18)

NICE: In children, a 12-lead ECG should be considered in cases of diagnostic uncertainty.
SIGN: All children presenting with convulsive seizures should have an ECG with a calculation of the QTc interval.
NICE and SIGN vary in their recommendations. SIGN recommendations were deemed easier to objectively audit and therefore selected for this Performance Indicator.

Results:

- Of 1745 children with convulsive seizures, there were 704 **(40%) children who had an ECG by 1 year**. The median and related interquartile range (25th and 75th percentiles) for the performance indicator nationally were 37% (22%, 53%).

Performance Indicator 8 (Table 19 and Figure 19)

NICE: The EEG should not be used to exclude a diagnosis of epilepsy in an individual in whom the clinical presentation supports a diagnosis of a non-epileptic event.

The purpose of the EEG is not always explicitly stated by the assessor. However if the child's episodes were diagnosed as certain non-epileptic episodes (syncope or tics at first paediatric assessment) and they have EEG then it was assumed that the EEG was inappropriate.

Results:

- Of all 4945 children who had an EEG, there were 4538 **(92%) children who had the EEG with no defined contraindications**. The median and related interquartile range (25th and 75th percentiles) for the performance indicator nationally were 94% (88%, 100%).

Performance Indicator 9 (Table 19 and Figure 20)

NICE: MRI should be the imaging investigation of choice in individuals with epilepsy.
SIGN: Children under 2 with epilepsy or with recurrent focal seizures (other than BECTS) should have an elective MRI brain scan.

National recommendations state MRI for children other than is appearing in this performance indicator. The performance indicator is limited to those children where the indications for MRI are determinable using a retrospective methodology.

Results:

- Of 1124 children with defined indications for an MRI, there were 716 **(64%) children who had MRI by 1 year**. The median and related interquartile range (25th and 75th percentiles) for the performance indicator nationally were 63% (50%, 80%).
- 70% (781/1124) of children with defined indications for an MRI, who had MRI or CT by 1 year. The median and related interquartile range (25th and 75th percentiles) for the performance indicator nationally were 69% (50%, 87%).

Table 19. Evidence of appropriate investigation

No.	Performance indicators	UK (All units) Actual %	England Actual %	Wales Actual %	Scotland Actual %	Northern Ireland Actual %	UK (All units) Median % (25th & 75th percentiles)	Units submitting eligible children
Appropriate ECG								
7.	% children with convulsive seizures, with an ECG by 1 year	704/1745 40%	568/1477 39%	46/82 56%	70/136 52%	20/50 40%	37% (22%, 53%)	176
Appropriate EEG								
8.	% children who had an EEG in whom there were no defined contraindications	4538/4945 92%	3748/4085 92%	215/225 96%	425/471 90%	150/164 92%	94% (88%, 100%)	186
Appropriate MRI								
9a.	% children with defined indications for an MRI, who had MRI by 1 year	716/1124 64%	578/899 64%	24/49 49%	86/136 63%	28/40 70%	63% (50%, 80%)	180
9b.	% children with defined indications for an MRI, who had MRI or CT by 1 year	781/1124 70%	631/899 70%	27/49 55%	92/136 68%	31/40 78%	69% (50%, 87%)	180

Figure 18. Performance Indicator 7: Appropriate ECG (the percentage score for each of the individual audit units is shown)

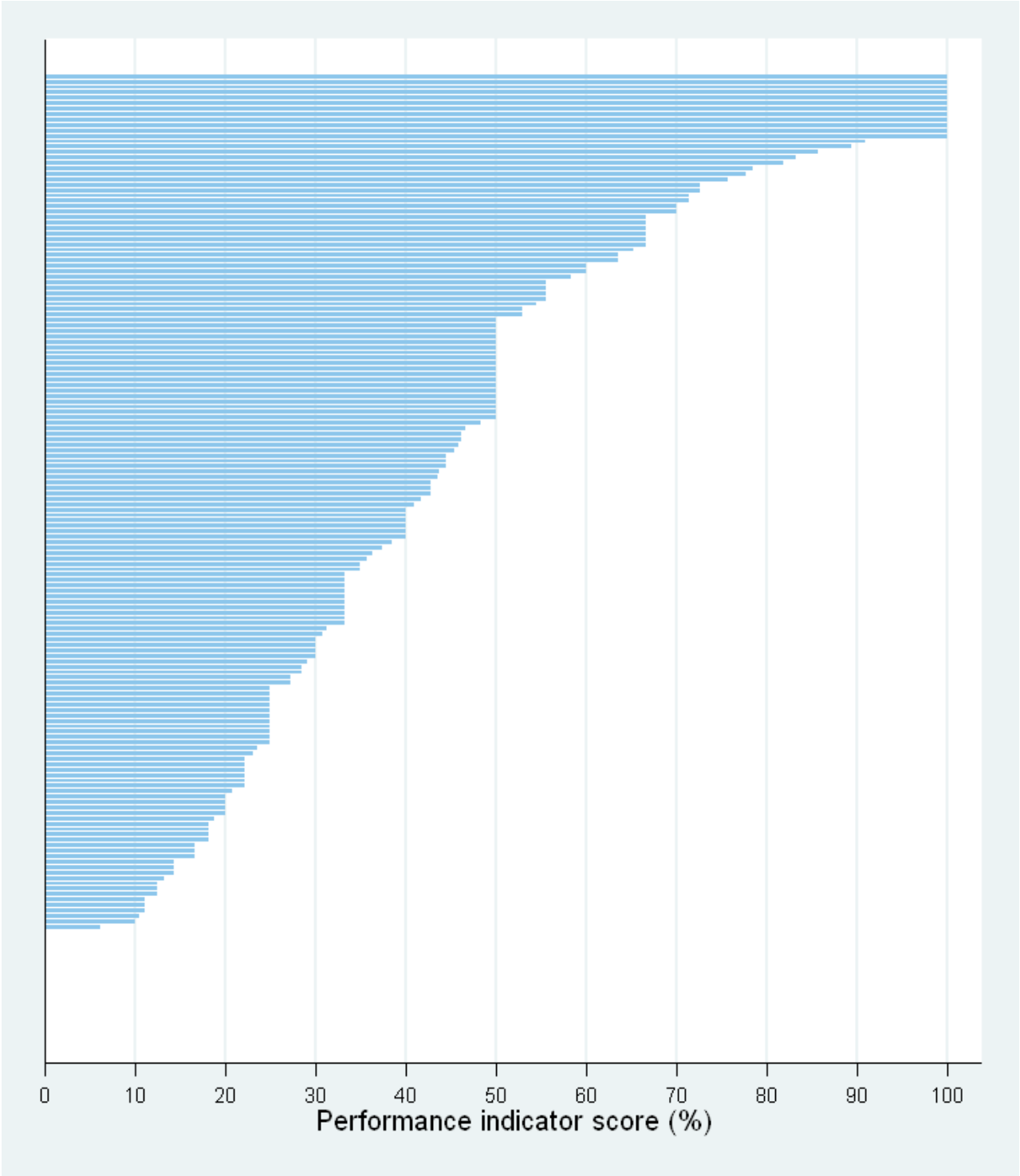


Figure 19. Performance Indicator 8: Appropriate EEG (the percentage score for each of the individual audit units is shown)

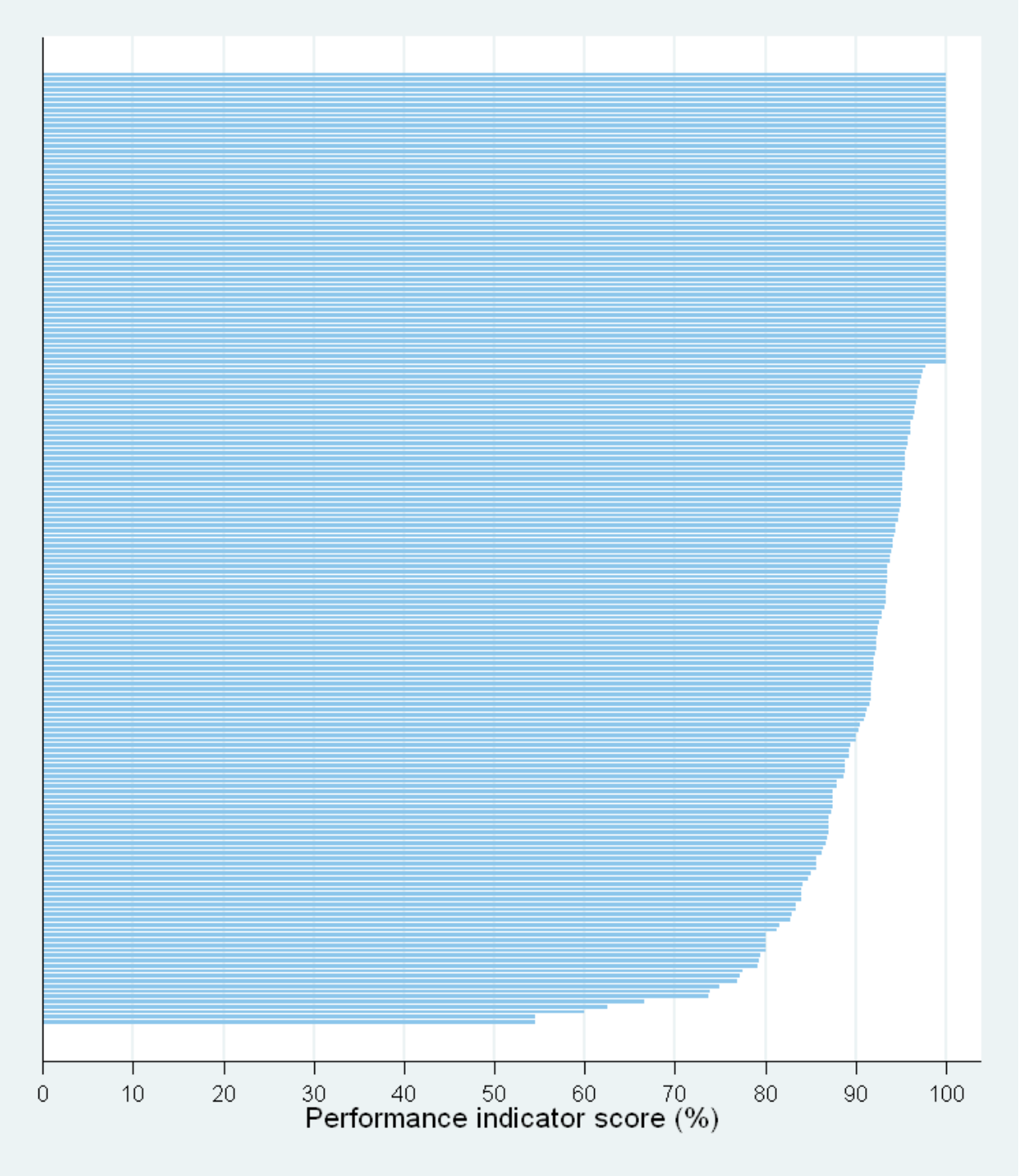
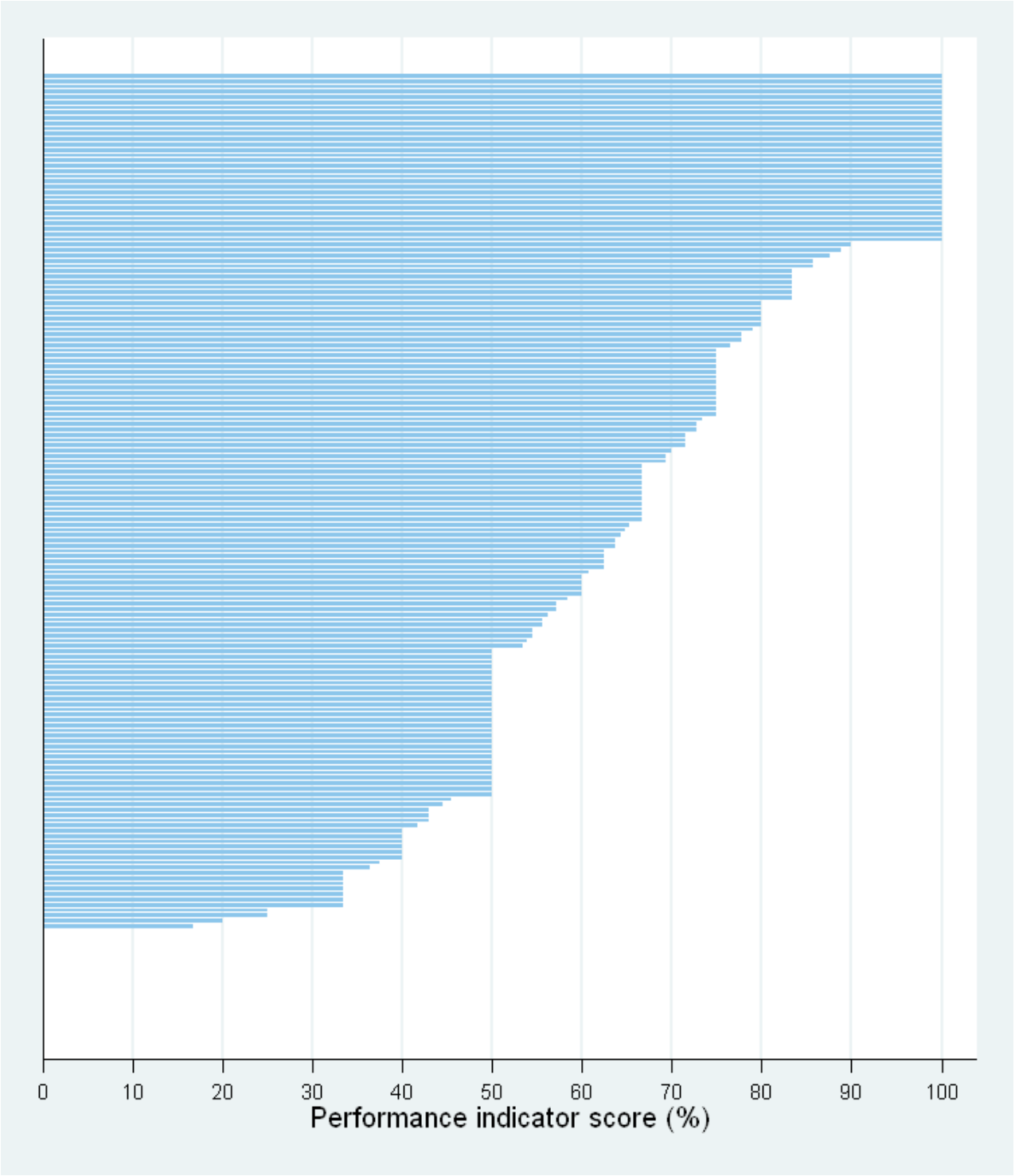


Figure 20. Performance Indicator 9: Appropriate MRI (the percentage score for each of the individual audit units is shown)



3.4.5 Management and outcome (Table 20)

Performance Indicator 10 (Table 20 and Figure 21)
NICE: See NICE Epilepsies Guideline Appendix G which outlines appropriate and inappropriate drug choices
SIGN: List of anti-epileptic drugs which may worsen specific syndromes or seizures

Carbamazepine is contraindicated in childhood absence epilepsy, juvenile absence epilepsy, juvenile myoclonic epilepsy and idiopathic generalised epilepsies. This has been selected as an achievable measure of appropriate drug choice using the methodology chosen.

Results:

- Of 403 children given carbamazepine, there were 382 **(95%) children given carbamazepine without defined contraindications**. The median and related interquartile range (25th and 75th percentiles) for the performance indicator nationally were 100% (100%, 100%).

Performance Indicator 11 (Table 20 and Figure 22)
NICE: AED therapy should only be started once the diagnosis of epilepsy is confirmed, except in exceptional circumstances that require discussion and agreement between the prescriber, the specialist and the individual and their family and/or carers as appropriate.

The performance indicator looks for incidence of children in whom a diagnosis of epilepsy was given and then later withdrawn and therefore there may have been a misdiagnosis of epilepsy. Children with an undetected misdiagnosis by 12 months after the first paediatric assessment are not determined by this audit.

Results:

- Of 1994 children diagnosed with epilepsy, there were 1775 **(89%) children who still had that diagnosis at 1 year**. The median and related interquartile range (25th and 75th percentiles) for the performance indicator nationally were 97% (82%, 100%).

Figure 22 presents a graphical illustration showing the distribution of the performance indicator 11 percentage scores for professional input for the audit units. Results for each audit unit can be found on the Epilepsy12 website at: www.rcpch.ac.uk/epilepsy12.

Performance Indicator 12 (Table 20 and Figure 23)

NICE: In girls of childbearing potential, including young girls who are likely to need treatment into their childbearing years, the risk of the drugs (see 1.8.13C) causing harm to an unborn child should be discussed with the child and/or her carer, and an assessment made as to the risks and benefits of treatment with individual drugs.

SIGN: Adolescent girls taking AEDs and their parents should be advised of the risks of fetal malformations and developmental delay.

Age of 12 years or over was defined as a pragmatic way of defining adolescence or 'childbearing' age.

Results:

- Of 148 females aged 12 years or over given regular anti-epileptic drugs, there were 56 **(38%) females who had documented discussion of pregnancy or contraception**. The median and related interquartile range (25th and 75th percentiles) for the performance indicator nationally were 0% (0%, 100%).

Table 20. Management and outcomes

No.	Performance indicators	UK (All units) Actual %	England Actual %	Wales Actual %	Scotland Actual %	Northern Ireland Actual %	UK (All units) Median % (25th & 75th percentiles)	Units submitting eligible children
Appropriate carbamazepine								
10.	% children given carbamazepine, in whom there were no defined contraindications	382/403 95%	311/331 94%	10/11 91%	48/48 100%	13/13 100%	100% (100%, 100%)	141
Accuracy of diagnosis								
11.	% children diagnosed with epilepsy, who still had that diagnosis at 1 year	1775/1994 89%	1423/1624 88%	93/97 96%	204/214 95%	55/59 93%	97% (82%, 100%)	184
Pregnancy or contraception discussion								
12.	% females over 12 years given epilepsy medication, who had evidence of discussion of pregnancy or contraception	56/148 38%	45/119 38%	6/11 55%	2/13 15%	3/5 60%	0% (0%, 100%)	106

Figure 21. Performance Indicator 10: Appropriate carbamazepine (the percentage score for each of the individual audit units is shown)

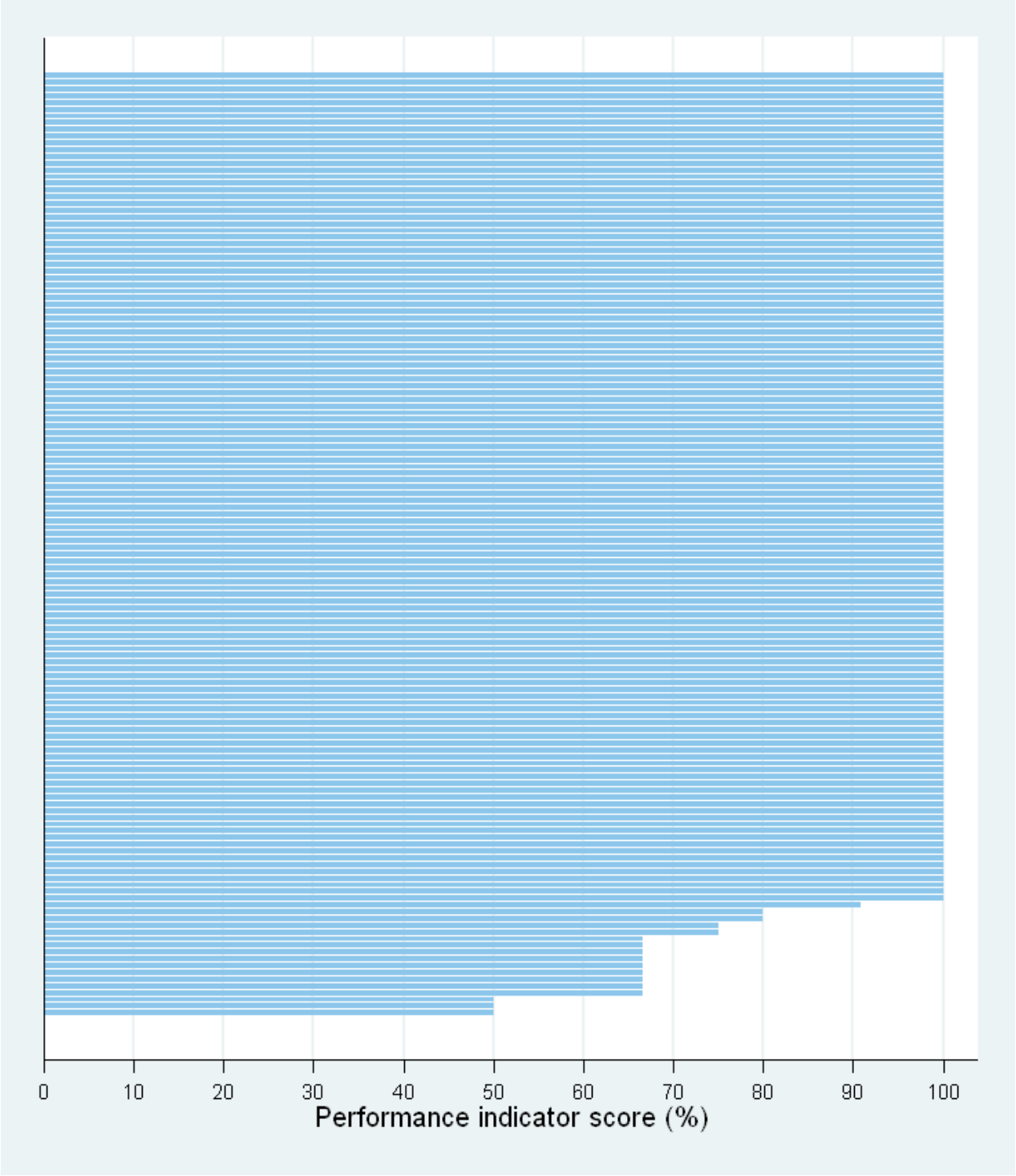


Figure 22. Performance Indicator 11: Accuracy of diagnosis (the percentage score for each of the individual audit units is shown)

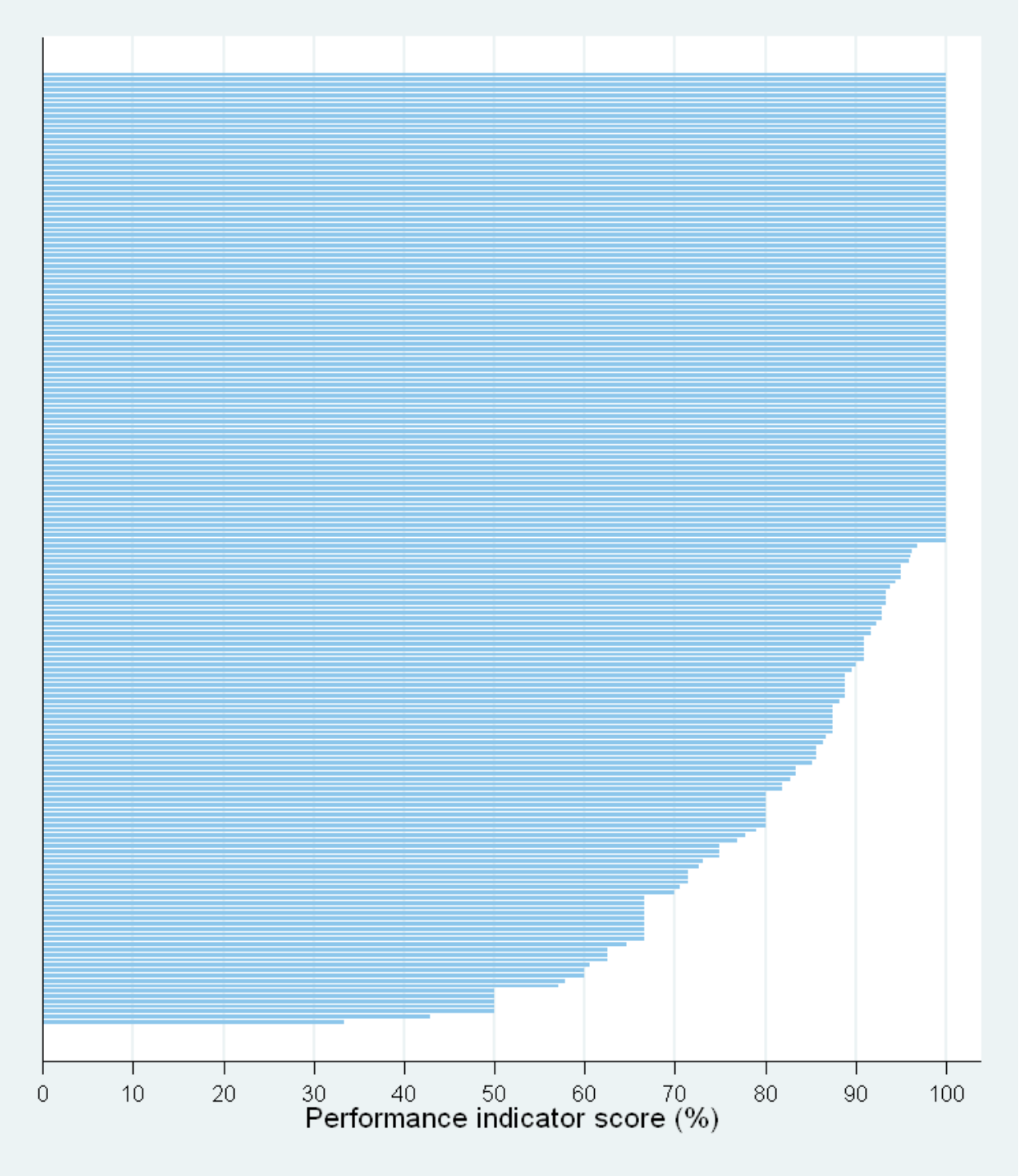
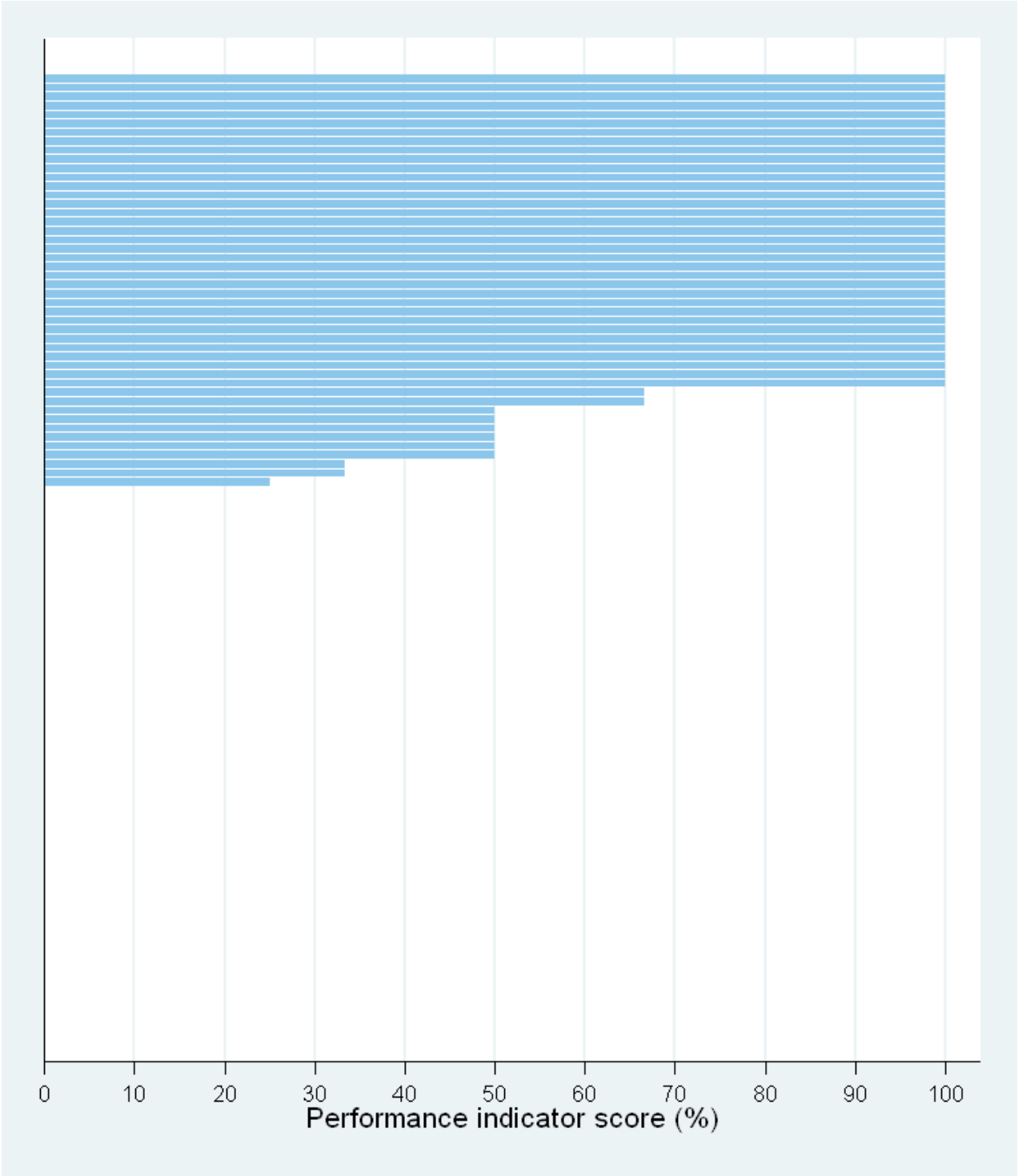


Figure 23. Performance Indicator 12: Pregnancy or contraception discussion (the percentage score for each of the individual audit units is shown)



3.4.6 Outlying data

Table 21 presents the number of units with outlying data (positive as well as negative) for each performance indicator. Outlying data is not reported for performance indicator 12 (Pregnancy or contraception discussion) as numbers were too small.

Outlying data was interpreted in the following way:

- Positive outlier- A unit performing above the upper limit of the 95% confidence interval of the median percentage for the relevant performance indicator
- Negative outlier- A unit performing below the lower limit of the 95% confidence interval of the median percentage for the relevant performance indicator
- Not an outlier- A unit performing at the same level as the median percentage. In other words the 95% confidence interval of the unit's performance indicator overlaps with the 95% confidence interval of the median.
- Not applicable - A unit where there are no eligible patients contributing to the relevant performance indicator.

The outlier status refers to a statistically significant deviation from the average; therefore a unit can have low performance that requires action without having outlying data. The outlier status for individual units for each performance indicator can be found on the Epilepsy12 website at: www.rcpch.ac.uk/epilepsy12. A copy of the Epilepsy12 Outlier data policy is also available from this webpage.

Table 21. Outlying data: Audit units: n = 186

Performance Indicators	**Median percent** (95% confidence interval)	**Positive Outliers**	**Negative Outliers**	**Not an outlier**	**Not applicable**
1: Paediatrician with expertise in epilepsies	83% (78%, 90%)	1 (0.5%)	28 (15%)	155 (83%)	2 (1%)
2. Epilepsy Specialist Nurse	33% (20%, 50%)	39 (21%)	2 (1%)	143 (77%)	2 (1%)
3: Tertiary involvement	50% (50%, 78%)	0 (0%)	0 (0%)	137 (74%)	49 (26%)
4: Appropriate first clinical assessment	66% (62%, 70%)	16 (9%)	31 (17%)	139 (75%)	0 (0%)
5: Appropriate seizure classification	89% (86%, 93%)	0 (0%)	11 (6%)	173 (93%)	2 (1%)
6. Appropriate syndrome classification	38% (33%, 42%)	7 (4%)	9 (5%)	168 (90%)	2 (1%)
7. Appropriate ECG	37% (33%, 44%)	16 (9%)	3 (2%)	157 (84%)	10 (5%)
8: Appropriate EEG	94% (93%, 95%)	0 (0%)	23 (12%)	163 (88%)	0 (0%)
9: Appropriate MRI	63% (56%, 67%)	2 (1%)	2 (1%)	176 (95%)	6 (3%)
10: Appropriate carbamazepine	100% (100%, 100%)	0 (0%)	18 (10%)	123 (66%)	45 (24%)
11: Accuracy of diagnosis	97% (93%, 100%)	0 (0%)	34 (18%)	150 (81%)	2 (1%)

3.4 Patient Reported Experience Measure

3.4.1 Response Rate

178 units participated in the patient reported experience measure (PREM) component of the audit and sent out questionnaires to 1531 eligible patients.

319 (21%; 319/1531) parent/carers completed part A of the PREM questionnaire covering 131 units. 15 units had 5 or more returns (range 1 - 11 returns). 158 children/young people completed part B of the questionnaire regarding their experiences.

The questions were not mandatory so there were varying levels of completeness for the forms returned by parents and children and young people.

The responses are reported at UK level due to small numbers and to preserve anonymity.

3.4.2 Demographics

The characteristics of children and young people with epilepsies as captured by the PREM questionnaire are presented in Table 22. Approximately one third experienced seizures less than once a month in frequency. 35% had learning difficulties/developmental delay. 52% had attended a general paediatric clinic, 20% a specific epilepsy clinic, 7% a community paediatric clinic and 25% a paediatric neurology clinic.

Table 22. Characteristics of children/young people

Characteristic	UK N=319
Child's Year of Birth	
1993-1997	66 (21%)
1998-2002	100 (31%)
2003-2007	86 (27%)
2008-2012	63 (20%)
Not answered	4 (1%)
Gender	
Females	141 (44%)
Males	177 (55%)
Not answered	1 (<1%)
Frequency of seizures on average over the past year	
Less than one per month	124 (39%)
1 or more a month but less than 1 a week	36 (11%)
1 or more a week but less than one a day	23 (7%)
1 or more per day	34 (11%)
None	11 (3%)
Unsure	16 (5%)
Other	69 (22%)
Not answered	6 (2%)
Other Conditions*	
Learning difficulties/developmental delay	112 (35%)
Cerebral palsy	17 (5%)
Autism or autistic spectrum disorder	16 (5%)
Attention Deficit Hyperactivity Disorder (ADHD)	8 (2.5%)
None of the above	197 (62%)
Other	51 (16%)
Type of clinic child attended*	
General paediatric clinic	166 (52%)
Community paediatric clinic	23 (7%)
Teenage epilepsy clinic	4 (1%)
Specific epilepsy clinic	63 (20%)
Paediatric Neurology clinic	82 (25%)
Don't know	20 (6%)
Other	21 (7%)

*Multiple responses possible

3.4.3 Parent/carer responses

3.4.3.1 Parent/carer experiences, information needs and overall level of satisfaction

67% (213/319) of parent/carers had been in contact with their health service 1 to 5 times; 14% (46/319) 6 to 10 times and 13% (41/319) more than 10 times over the past year. 82% (261/319) of respondents reported that they had found it easy to contact their health service looking after their child's seizures or epilepsy (Table 24).

Parent/carers reported particularly wanting more information about the cause of their child's epilepsy or seizures; possible side effects of medication, and guidance on what their child can or cannot do.

Overall, 78% (249/319) responded that they were satisfied with the care that their child received from the epilepsy service and 8% (26/319) were not satisfied.

Table 24. Parent/carer experiences, information needs and overall level of satisfaction

	UK N=319
Have you found it easy to contact the health service looking after your child's seizures or epilepsy?	
Yes	261 (82%)
No	34 (11%)
Unsure	19 (6%)
Not answered	5 (<2%)
Over the past year, including planned appointments, how many times have you been in contact with this health service (either by visiting the clinic, by telephone or by email)?	
None	17 (6%)
1 to 5 times	213 (67%)
6 to 10 times	46 (14%)
More than 10 times	41 (13%)
Not answered	2 (<1%)
Which areas, if any, would you like more information on?*	
Guidance on what my child can or can't do	110 (34%)
The cause of my child's epilepsy or seizures	165 (52%)
Possible side effects of medication	131 (51%)
Reasons for changing medication	35 (11%)
Reasons for, and results of, tests	68 (21%)
Support groups	69 (22%)
Contacting other families living with epilepsy	51 (16%)
What to tell other people about my child's seizures or epilepsy	95 (30%)
Other	17 (5%)
Overall, are you satisfied with the care your child receives from the epilepsy service?	
Yes	249 (78%)
No	26 (8%)
Unsure	31 (9%)
Not answered	13 (4%)

*Multiple responses possible

3.4.3.2 Parent/carers impression of services

Table 25 presents parent/carers views on the quality of service received. In summary:

- 68% (214/313) parent/carers felt that they had received enough information on seizures or epilepsy; 21% (66/313) did not feel that they received enough information on seizures or epilepsy.
- 75% (233/311) felt that the information they received was not hard to understand; 12% (37/311) felt that information was hard to understand.
- 76% (237/311) felt that their views were taken into account in the decision making process; 10% (31/311) did not feel that their views were taken into account in the decision making process.
- 10% (32/314) of parents/carers did not feel at times that they were allowed to ask questions; 84% (265/314) felt at times they were allowed to ask questions.
- 19% (60/314) of parents/carers felt that their child was not seen often enough by the service; 63% (197/314) felt their child was seen often enough.
- 21% (66/312) of parents/carers said that staff are not good at working together; 62% (192/312) said staff were good at working together.
- 41% (128/310) of parents/carers said that staff were good at working together with school or nursery; 17% (53/310) said they were not good at working together with school or nursery.
- 68% (210/311) said it was easy to contact someone in the epilepsy team; 14% (44/311) said the epilepsy team were not easily contactable.

Table 25. Parent/carers impression of services

	Number of responses	Strongly Agree/ Agree	Unsure	Strongly Disagree/ Disagree	Not Applicable
A9. Overall, I received enough information on seizures or epilepsy	313	214	31	66	2
A10. Staff listened to what I had to say	314	275	14	24	1
A11. The information I was given was hard to understand	311	37	30	233	11
A12. Staff did not take time to get to know me and my child	310	51	28	226	5
A13. Staff did not explain things in a way I could follow	311	26	18	262	5
A14. Staff took my views into account in making decisions	311	237	41	31	2
A15. I felt the staff respected our need for privacy during clinic visits	313	276	15	11	11
A16. Overall, staff seemed to know what they were doing	313	274	18	21	0
A17. At times I felt I was not allowed to ask questions	314	32	13	265	4
A18. It is easy to contact someone in the epilepsy team	311	210	51	44	6
A19. Staff make sure it is easy to attend the clinic e.g. when making appointments	311	242	32	36	1
A20. My child is not seen by the service often enough	314	60	49	197	8
A21. When attending the clinic staff tell me if the appointment is going to be delayed	312	137	36	105	34
A22. The waiting area does not have activities for my child	312	70	11	210	21
A23. Overall, the length of time spent with staff at the clinic is just about right	313	258	21	30	4
A24. Staff are not good at working together with others e.g. the GP when looking after my child	312	66	47	192	7
A25. Staff are good at working together with school or nursery	310	128	64	53	65
A26a. Overall, staff are friendly and polite? - Outpatient Clinic staff	308	293	5	7	3
A26b. Overall, staff are friendly and polite? - In-patient ward staff	288	221	10	15	42
A26c. Overall, staff are friendly and polite? - When going for tests staff e.g. EEG or MRI (if applicable)	301	275	5	12	9

Note that not all questions were answered or considered applicable, hence denominator changes.

3.4.3.3 Parent/carers perspective on what works well and areas for improvement

225 parent/carers commented on what they liked best about the service. The key themes from the comments were: service characteristics, staff characteristics and staff-patient/family interaction (Table 26). 17 made other comments.

Table 26. Parent/carers perspective on what works well

Repeating comments from parent/carers on the three best things about the service	**Themes and example comments**	**Number of parent/carers commenting on the theme (n=225)**
• Available, accessible and know who to contact and easy to do so • Appointments meet needs e.g. Easy to make appointments, frequent, on time, flexible • Enough consultation time and not rushed • Good information provided • Quick and efficient service • Continuity • Regular reviews • Specialist support • Communication and co-ordination with the school and with other services • Local • Waiting area	**Service characteristics** *"Ability to communicate without an appointment."* *"Being able to email epilepsy nurse."* *"Chance to speak to doctor directly over the phone."* *"If we have any worries or problems being able to see someone at short notice."* *"Good to have the same consultant and not someone different."* *"Speed of being seen initially and offered extensive tests."* *All tests performed quickly."* *"The EEG/MRI appointments were much quicker to make than expected and the staff brilliant."* *"Good atmosphere for child in waiting area."*	161 (72%)
• Knowledgeable and experienced • Friendly and polite • Approachable • Reassuring • Kind and helpful • Understanding • Informative • Caring and supportive • Thorough • Accommodating • Patient • Professional manner	**Staff characteristics** *"Consultant Dr (----) is brilliant. She explains in ways (----) understands."* *"Staff and nurses are caring and understanding in my child's condition."* *"Thorough in approach, dedicated practitioner. He is excellent!!! If he wasn't there, I don't know how we'd cope."* *"The paediatric epilepsy nurse has been very helpful."* *"When first admitted I was so scared for (----). Staff were amazing. Even Dr (----) saw us and made time to explain."* *"Children's ward staff were all amazing and EEG lady."*	154 (68%)

• Staff listen to concerns • Given time to ask questions • Good communication • Good explanations • Involve child as well as parent in the discussions • Taking views into account in making decisions	**Staff-patient/family interaction** *"Feeling the attention is personal and tailored to my child."* *"They listen to the worries about how I'm feeling."* *"My daughters new neurologist is understanding and listens to my opinions and thoughts on treatments."* *"Always answer questions and problems so I can understand."* *"They talk to my child, not just me."* *"The consultant is great at directing questions at the child"* *"Doctors talk to my child and explain in a way she understands."* *"They listen and respect what my daughter says."* *"Staff remember your name and history."*	63 (28%)

167 parent/carers commented on the worst things about the service. The key themes from the comments were: service characteristics, working together, building/travelling, waiting and delays, staff-patient/family interaction, staff characteristics and information and support (Table 27). 20 made other comments.

Table 27. Parent/carers perspective on what could be improved

Repeating comments from parent/carers on the three worst things about the service	**Themes and example comments**	**Number of parent/carers commenting on the theme (n=167)**
• Appointments not meeting needs e.g. long intervals between appointments, not regular, not enough. • Difficult to get hold of doctors • More time needed with staff • Under resourced services and lack of access to epilepsy nurses • Lack of follow up • Lack of continuity • Inadequate waiting area	**Service characteristics** *"Appointments are cancelled and I am not notified."* *"Sometimes we have to wait three months to see the doctor when things have gone wrong."* *"The staff there don't have enough time to devote to us because they are so busy and overstretched."* *"No epilepsy nurse at the time and different members of staff at each visit."* *"Not being able to get in touch with neuro or epilepsy nurse when need to. Not receiving a call back when they have said they would."* *"Difficult to contact outside of appointments."* *"The waiting area does not have reading material or activities for older children."*	97 (58%)

• Need for accessible information that is easy to understand • Lack of information on for example, role of nurse, service available, seizures, causes, what to look out for, side effects. • More information and support when first diagnosed • To be put in touch with others in a similar situation	**Information and support** *"More support when initially diagnosed would be helpful."* *"No support groups or leaflets given - we found out about a bed monitor to pick up seizures - It would have been helpful if we were told these were available by the staff in the hospital."* *"I think there should be leaflets about epilepsy at clinic – not only for diabetic people."* *"Having to ASK for information on epilepsy/ condition. …. Lack of information on equipment for epilepsy safety - Anti suffocation pillows, seizure alert bed alarms, etc."* *"Would like to have met others who had been through this too"*	48 (29%)
• Long wait for tests and results • Long wait for initial appointment with service • Long wait for initial diagnosis • Waiting times	**Waiting and delays** *"Initial appointment with specialist too long to wait."* *"Finding all this terrifying information on internet first before getting to see a consultant 3 months later."* *"Length of time to get tests done/results received."* *"Waiting times - child with behavioural problems - ADHD also makes it hard."*	28 (17%)
• Lack of communication and joined up working with GP and other services • Poor communication with schools • Lack of shared care arrangements	**Working together** *"No communication between service and school."* *"Communication between hospitals when sharing EEG scanner."* *"Do not feedback to GP."* *"Lack of join up with GP - have to go to reviews for medication even though we have quarterly reviews with hospital."*	23 (14%)
• Staff approach • Negative staff attitude • Lack of understanding	**Staff characteristics** *"Disappointing attitude from some staff at (--)."*	19 (11%)
• Poor communication • Not always listening	**Staff-patient/family interaction** *"Expect you to understand too much over telephone."* *"Having to explain things again and again."*	16 (10%)
• Long journey to clinic/ expensive to get to • Parking is expensive	**Building/Travelling** *"Parking at the hospital expensive, so costly to attend appointments."*	12 (7%)

3.4.4 Children and Young people responses

3.4.4.1 Children and young people's experiences, information needs and overall level of satisfaction

82% (111/136) children and young people were satisfied with the overall care that they received from the epilepsy service, 7% (9/136) were not satisfied (Table 28). More information was needed on the cause of epilepsy (55%); guidance on what he/she can and cannot do (47%); possible side effects of medication (37%) and what to tell others about their epilepsy.

Table 28. Children and young people's information needs and level of satisfaction

	UK
Which areas, if any, would you like more information on?*	
Guidance on what I can or can't do	69/148 (47%)
Contact with other young people with epilepsy	36/148 (24%)
What to tell other people about my epilepsy	54/148 (36%)
Possible side effects of medication	55/148 (37%)
Support groups	25/148 (17%)
Cause of my epilepsy	81/148 (55%)
Reasons for changing medication	24/148 (16%)
Reasons for, and results of, tests	44/148 (30%)
Overall, are you satisfied with the care you receive from the epilepsy service?	
Yes	111/136 (82%)
No	9/136 (7%)
Unsure	16/136 (12%)

*Multiple responses possible

3.4.4.2 Children and Young people's impression of services

Table 29 presents children and young people's views on the quality of service received. In summary:

- 70% (110/158) children and young people reported that they had received enough information on seizures or epilepsy; 16% (25/158) reported they did not receive enough information.
- 23% (36/154) reported that the information received was hard to understand; 50% (77/154) reported that it was not hard to understand.
- 72% (111/154) felt that staff took their views into account when making decisions; 11% (17/154) felt that staff did not take their views into account.
- 41% (61/149) felt that the waiting area did not have activities for their age; 42% (63/149) felt that it did have activities for their age.
- 21% (32/153) felt they were not seen by the service often enough; 58% (89/153) felt they were seen often enough.
- 21% (32/152) felt that staff were not good at working together; 53% (80/152) felt they were good at working together.

Table 29. Children and young people's impression of services

	Number responding	Strongly Agree/ Agree	Unsure	Strongly Disagree/ Disagree	Not Applicable
B1. Overall, I received enough information on seizures or epilepsy	158	110	19	25	4
B2. Staff listened to what I had to say	158	135	13	6	4
B3. The information I was given was hard to understand	154	36	30	77	11
B4. Staff did not take time to get to know me	157	19	12	119	7
B5. Staff did not explain things in a way I could follow	157	20	19	111	7
B6. Staff took my views into account in making decisions	154	111	20	17	6
B7. I felt the staff respected my need for privacy during clinic visits	155	136	11	1	7
B8. Overall, staff seemed to know what they were doing	155	140	7	3	5
B9. At times I felt I was not allowed to ask questions	154	20	13	114	7
B10. It is easy to contact someone in the epilepsy team	154	85	35	16	18
B11. Staff make sure it is easy to attend the clinic e.g. when making appointments	151	109	22	10	10
B12. I am not seen by the service often enough	153	32	24	89	8
B13. When attending the clinic staff tell me if the appointment is delayed	151	73	23	38	17
B14. The waiting area does not have activities for my age	149	61	13	63	12
B15. Overall, the length of time spent with staff at the clinic is just about right	153	119	10	19	5
B16. Staff are not good at working together with others e.g. the G.P., when looking after me	152	32	33	80	7
B17. Staff are good at working with school or nursery?	149	68	38	22	21
B18a: Overall, staff are friendly and polite? -Outpatient Clinic staff	151	141	5	2	4
B18b: Overall, staff are friendly and polite? -In-patient ward staff	138	107	10	3	18
B18c: Overall, staff are friendly and polite? -When going for tests staff e.g. EEG or MRI (if applicable)	143	129	7	3	4

Note that not all questions were answered or considered applicable, hence denominator changes.

3.4.4.3 Children and Young People's perspective on what works well and areas for improvement

71 children stated what they liked best about the service. The key themes from the comments were: service characteristics, staff-patient/family interaction, staff characteristics and medication/ investigations (Table 30). 11 made other comments.

Table 30. Children and young people's perspective on what works well

Repeating ideas from children and young people on the three best things about the service	**Themes**	**Number of children and young people commenting on the theme (n=71)**
• Kind, caring and understanding • Nice and Friendly • Helpful and supportive • Reliable • Welcoming • Respected • Polite • Reassuring • Knowledgeable	**Staff characteristics** *"Epilepsy nurses really care."* *"Staff at hospital are friendly."* *"The staff are excellent/polite."* *"The community epileptic nurse was brilliant"* *"Dr (----) is fantastic."* *"Staff and nurses are caring and understanding in my child's condition."* *"(----) and the team are brilliant."*	57 (80%)
• Appointments meet needs • Regular contact • Accessible and easily contactable • Seen quickly • Good service/ Support available • Quick and Efficient • Local • Activities in waiting area	**Service characteristics** *"Offered a good service."* *"Easy to see someone when I need to."* *"Appointments never delayed."* *"Results of tests come quickly."* *"Quick reply to urgent messages."* *"It's a lovely environment."* *"Fun activities."*	25 (35%)
• Staff answering and asking questions • Staff explaining well and helping to understand • Staff good with child • Staff listening • Staff take child's views into account	**Staff-patient/family interaction** *"They were able to answer questions when I had any queries."* *"They provided clear concise advice for when I needed it."* *"Consultant Dr (----) is brilliant. she explains in ways (----) understands."*	18 (25%)
• Medication • Having tests	**Medication/Investigations** *"The medication as it helps."*	7 (10%)

41 children commented on the worst things about the service. The key themes from the comments were: service characteristics, staff-patient/family interaction, medication/Investigations, waiting and delays, and information and support (Table 31). 11 made other comments.

Table 31. Children and young people's perspective on what could be improved

Repeating ideas from children and young people on the three worst things about the service	Themes	Number of children and young people commenting on the theme (n=41)
• Appointments not meeting needs • Lack of regular contact with the service • Lack of age appropriate activities/ toys in waiting area	**Service Characteristics** *"Sometimes the appointments were at inappropriate times."* *"If you cancel an appointment you wait ages for the next one.* *"Only 1 day per week you can visit the doctor."* *"Don't see epilepsy nurse enough."* *"Too many baby/toddler toys."* *"Don't like going with small children."*	15 (37%)
• Having to wait around to be seen or for results • Wait to diagnosis	**Waiting and delays** *"Sometimes a wait to see Dr."* *"Took ages to confirm seizures."*	9 (22%)
• Lack of information about epilepsy and side effects • Lack of information to school	**Information and support** *"Not knowing the side effects of my epilepsy."* *"Not enough written information given it's all on computer (not much access for me)."* *"I don't know what they are going to do."* *"My school does not understand enough."*	9 (22%)
• Staff not involving the child/young persons in discussions • Staff not listening • Staff not getting to know the child/ young person	**Staff-patient/family interaction** *"I didn't feel as if I could say much to the doctor when I didn't understand something."* *"Don't talk to me, they talk about me."*	7 (17%)
• Going for MRI or EEG scans • Taking the medication	**Medication/Investigations** *"EEG was horrible."* *"Giving the wrong medication."*	6 (15%)

3.5 Audit challenges

Some of the key challenges for this audit included:

- 11 units did not submit data to the clinical audit. Reasons included workload issues or resource issues.
- Some EEG departments struggled to produce an appropriate and timely EEG list due to database limitations, lack of understanding of what is required or workload issues.
- The mapping of providers was a complex process. However the pragmatic approach based on existing care pathways rather than Primary Care Trusts (PCTs) and Strategic Health Authorities (SHAs) was successful.
- The overall PREM response rate was low and prevented meaningful comparison of PREM data between individual audit units.

4. Summary and Key Recommendations

The audit attracted participation from the vast majority of UK paediatric services and their patient population.

There was considerable variation in resources available and service configuration. The audit found considerable variation between units in the extent to which care delivered met NICE and SIGN standards. There was evidence of significant gaps between recommended practice and delivered practice throughout the UK

Of particular concern, was that only just over a half of units had an Epilepsy Specialist Nurse and a majority of children with epilepsies had no evidence of Epilepsy Specialist Nurse input by 12 months after first paediatric assessment. Approximately a third of the cohort did not have evidence of an adequate first clinical assessment. This is particularly related to the absence of documented development assessment and neurological examination.

Feedback from parent/carers and children and young people about their experiences of their service was positive from most participants. However there was evidence of significant proportions of parent/carers, children and young people with negative experiences. This was particularly in the areas of achieving understanding, decision making, working together with schools and nursery and ease of contact.

Key Recommendations

Although the audit did not include targets, the results show that improvements are needed for many aspects of professional input, diagnosis, investigation, treatment and communication. The 12 key recommendations below outline specific steps that should be taken to improve quality of care. Services with evidence of low performance in the 12 performance indicators should also consider the presence of wider deficiencies of their epilepsy services. There are many aspects of epilepsy care that have not been captured by this audit. Services should therefore not confine quality improvement to areas highlighted in this report but should take the opportunity to consider their epilepsy service as a whole. 'First seizure' clinics, Epilepsy clinics, Nurse-led clinics, 'Satellite Paediatric Neurology' clinics, Young people's epilepsy clinics, 'handover' clinics are all examples of service developments that some audit units have established in order to implement national recommendations. The Epilepsy12 website provides a quality improvement toolkit of useful resources to support audit units implement an effective action plan.

Professionals	**1**	All services managing children with epilepsies should ensure that they include at least one consultant paediatrician with defined 'expertise in epilepsies'. One consultant should be formally defined as the epilepsy lead. Services should review consultant training, job planning and new appointments in order to achieve these roles and competences. Services where involvement of 'paediatricians with expertise' in children with epilepsy is low should also review care pathways to ensure that each child with epilepsy has evidence of input of a 'paediatrician with expertise'.
	2	Epilepsy Specialist Nurses are an essential component of paediatric services and all children diagnosed with epilepsy should have specialist nurse input offered as per NICE and SIGN guidance. Epilepsy Specialist Nurses provision includes care planning, facilitating appropriate participation, risk assessment, school and respite care liaison, rescue medication training and telephone advice. All services without an Epilepsy Specialist Nurse should create new posts to ensure adequate care. Units where many children with epilepsy are not having input from an Epilepsy Specialist Nurse should improve their care pathways and Epilepsy Specialist Nurse provision.
	3	Services with low levels of Paediatric Neurology input should improve their referral strategies and shared care arrangements. Paediatric neurology provision should be improved where there is a shortfall.
Assessment & Classification	**4**	Services with low levels of appropriate first clinical assessment should explore underlying reasons for this and improve the quality and consistency of assessment. Training, documentation, first seizure guidelines and care pathways should be implemented as appropriate. Particular efforts should be made to ensure timely and ongoing assessments of development, educational, emotional and behavioural problems for all children with epilepsies.
	5	Rates of appropriate multi-axial epilepsy classification should be improved particularly in services where there is evidence of lower performance. Where the epileptic seizure cannot be classified there should be documentation to show that classification has been attempted. The ongoing diagnosis and classification of epilepsies should be undertaken by professionals with appropriate expertise.
	6	Children with epilepsies should have an appropriate electro-clinical syndrome classification recorded where possible.

Investigation	**7**	In services with low rates of appropriate 12 lead ECG, training, local guidelines and care pathways should be improved to ensure all children with a convulsive seizure have a 12 lead ECG with documentation to show that it has been assessed.
	8	Where services have high levels of use of EEG investigation in children with non-epileptic events the reasons behind this should be explored and rectified. EEG services should develop strategies with their referring colleagues to reduce levels of inappropriate EEG referrals.
	9	Services with low rates of appropriate neuroimaging should explore reasons behind this. Indications for MRI in children with epilepsies should be reviewed and neuroimaging rates improved. If necessary the availability of MRI should be improved.
Management & Outcome	**10**	Services where there is evidence of carbamazepine prescription in children with contraindications should ensure that the reasons behind this are addressed. Care pathways ensuring input from a 'paediatrician with expertise' should be established.
	11	Services where there is evidence of diagnoses of epilepsy being made that are subsequently withdrawn should investigate and respond to the reasons behind this. This is particularly the case if regular anti-epileptic medication has been initially prescribed as part of a 'trial of treatment' or where misdiagnosis is occurring. Care pathways ensuring input from a 'paediatrician with expertise' should be established.
	12	Services with inadequate services and transition arrangements for young people (e.g. 12 years and over) with epilepsies should improve provision. This may include increasing Epilepsy Specialist Nurse provision, developing clinics for young people with epilepsy, handover clinics, adult epilepsy services and referral pathways to adult services. Services should ensure that all relevant young people's health issues including pregnancy and contraception are reliably addressed.

Epilepsy12 has established a firm foundation for continuing national audit and quality improvement for childhood epilepsies in the UK. The audit has welcomed considerable professional and stakeholder support for closing the gap between current practice and national recommendations. Collaborative audit has provided systematic evidence of significant shortfalls and variations in the quality of care delivered. Many of the key recommendations can be achieved without cost. Recommendations that imply increased costs must have these costs balanced against savings

that may be achieved by reduced misdiagnosis, appropriate drug treatment and improved case selection for surgical treatment. These findings should now prompt specific further actions for professionals, paediatric services, commissioners, clinical networks and those with national roles.

5. References

1. National Institute for Clinical Excellence (NICE). The epilepsies: diagnosis and management of the epilepsies in children and young people in primary and secondary care. 2004. National Institute for Clinical Excellence (NICE) Clinical Guideline.
2. Scottish Intercollegiate Guidelines Network (SIGN). Diagnosis and management of epilepsies in children and young people. 2005. Scottish Intercollegiate Guidelines Network (SIGN).
3. Armon K et al. The impact of presenting problem based guidelines for children with medical problems in an accident and emergency department. Arch Dis Child. 2004; 89(2):159–164.
4. Walton L et al. Audit of Referral Patterns for General Paediatric Outpatient Clinics (Nottingham), June 2005 (unpublished).
5. S Davies, I Heyman. A population survey of mental health problems in children with epilepsy. Developmental Medicine & Child Neurology. 2003; 45: 292-295.
6. CSAG (Clinical Standards Advisory Group). Services for patients with epilepsy. London: Department of Health, 2000.
7. Joint Epilepsy Council. National Statement of Good Practice and Care of People who have Epilepsy, Joint Epilepsy Council, 2002.
8. Hanna NJ et al. The National Sentinel Clinical Audit of Epilepsy-Related Deaths: Epilepsy—death in the shadows. The Stationery Office, 2002.
9. Consensus Conference on Better Care for Children and Adults with Epilepsy. Final Statement, Royal College of Physicians of Edinburgh, 2002. JRCPE 2003;33 (suppl 11).
10. Department of Health. Annual Report of the Chief Medical Officer. 2002. Department of Health Publications.
11. BPNA. A national approach to epilepsy management in children and adolescents. Submission by Royal College of Paediatrics and Child Health to Chief Medical Officer for England, July 2002. www.BPNA.org.uk
12. White C. Doctor referred to GMC after inquiry into epilepsy diagnoses. BMJ 2001;323:1323.
13. Dunkley C, Albert D, Morris N, Williams J, Whitehouse WP. A population audit of first clinic attendance with suspected epilepsy. *Seizure* 2005; 14: 606-610.
14. Appleton R, Besag F, Kennedy C et al**.** An audit of children referred with suspected epilepsy. *Seizure* 1998; 7(6):489-95.

Appendices

Appendix 1: Glossary and definitions
Appendix 2: Participating Units
Appendix 3: Service Descriptor questionnaire
Appendix 4: Clinical Audit questionnaire
Appendix 5: Patient Reported Experience Measure (PREM) Questionnaire

Appendix 1: Glossary and definitions

Acute	Inpatient review, or paediatric review in emergency department, or other clinical assessment in an acute paediatric setting
Acute Symptomatic Seizures	Seizures occurring at the time of a diagnosis of an acute disorder e.g. meningitis, encephalitis, electrolyte disturbance etc)
AED (Anti epileptic drug)	Regular daily drug treatment for reduction of risk of epileptic seizures in epilepsy. Not including drug treatment given for during a prolonged seizure (e.g. rectal diazepam/paraldehyde, buccal midazolam, IV lorazepam/phenytoin) or clusters of seizures (e.g. intermittent clobazam). Not including drugs where the purpose of treatment is for something other than epilepsy treatment (e.g. CBZ for behaviour, topiramate for migraine etc)
'Audit Unit'	One or more secondary tier paediatric services grouped together using pragmatic boundaries agreed by the paediatric audit unit link, the project team and the tertiary link
Cardiovascular Examination	Examination of the cardiovascular system to at least include cardiac auscultation
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 fulfill general paediatric roles.
Convulsive episode	An episode where there is symmetrical or asymmetrical limb motor involvement (tonic, clonic, tonic-clonic). Myoclonic seizures excluded.
Date of first paediatric assessment	Date of acute or non-acute assessment. For children admitted as part of first assessment then the date of admission is the date of first paediatric assessment
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/or hypersynchronous), usually self-limited activity of neurons in the brain. (ILAE)
Febrile seizure	An episode diagnosed by the assessing team as a 'febrile seizure' or 'febrile convulsion' or 'febrile fit''

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
First year	Time period from 'date of first paediatric assessment' to 12 months following that date
General examination	Any evidence of a multisystem examination of the child other then neurological examination
Handover clinic	A clinic where a young person '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
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
Non acute	Paediatric outpatients or clinic
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 • AND peer review of practice • AND regular audit of diagnosis (e.g. participation in Epilepsy12) (Consensus Conference on Better care for children and adults with epilepsy - Final Statement, Royal College of Physicians of Edinburgh, 2002) 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 origin.
'School age'	Child 5 years and older (past their 5th birthday)

Seizure	Paroxysmal disturbance of brain function that may be epileptic, syncopal (anoxic) or due to other mechanisms (SIGN 2004)
Single Cluster	A number of 'paroxysmal episodes' confined to a single 24 hour period (SIGN 2004)
Syncope	Synonymous with 'Faints' or 'vasovagal episodes'

Appendix 2: Participating Units

Units participating in clinical audit (and service questionnaire) (n=186)

Unit Name	Trusts listed at time of registration	Trust code
Aberdeen, Elgin & Grampian, Orkney and Shetland	• NHS Grampian • NHS Shetland	SNA20 SZ999
Abergavenny	Aneurin Bevan Local Health Board	7A6
Aberystwyth	Hywel Dda Local Health Board	7A2
Airedale	Airedale NHS Foundation Trust	RCF
Altnagelvin	Western Health and Social Care Trust	ZT005
Antrim	Northern Health and Social Care Trust	ZT002
Argyll & Bute	NHS Highland	SHA20
Ashford	Ashford and St Peter's Hospitals NHS Foundation Trust	RTK
Aylesbury and Wycombe	Bucks Healthcare NHS Trust	RXQ
Ayrshire	NHS Ayrshire & Arran	SAA20
Banbury	Oxford University Hospitals NHS Trust	RTH
Bangor	Betsi Cadwaladr University Health Board	7A1
Barnet and Chase Farm Hospital	Barnet and Chase Farm Hospitals NHS Trust	RVL
Barnsley	Barnsley Hospital NHS Foundation Trust	RFF
Basildon Hospital	Basildon and Thurrock University Hospitals NHS Foundation Trust	RDD
Basingstoke	Hampshire Hospitals NHS Foundation Trust	RN5
Bassetlaw	Doncaster and Bassetlaw Hospitals NHS Foundation Trust	RP5
Bath	Royal United Hospital Bath NHS Trust	RD1
Bedford	• Bedford Hospitals NHS Trust • South Essex Partnership University NHS Foundation Trust	RC1 RWN
Belfast	Belfast Health and Social Care Trust	ZT001
Berkshire	Royal Berkshire NHS Foundation Trust	RHW
Birmingham	Birmingham Children's Hospital NHS Foundation Trust	RQ3
Birmingham Heartlands	• Heart of England NHS Foundation Trust • Birmingham Community Healthcare NHS Trust	RR1 RYW
Blackburn	East Lancashire Hospitals NHS Trust	RXR
Blackpool	Blackpool Teaching Hospitals NHS Foundation Trust	RXL
Bolton	• Royal Bolton Hospitals NHS Trust • NHS Bolton - Community Clinics	RMC 5HQ
Boston	United Lincolnshire Hospitals NHS Trust	RWD
Bradford	Bradford Teaching Hospitals NHS Foundation Trust	RAE
Bridgend	Abertawe Bro Morgannwg University Local Health Board	7A3
Bristol	• North Bristol NHS Trust • University Hospitals Bristol NHS Foundation Trust	RVJ RA7
Burton	Burton Hospitals NHS Trust	RJF
Bury St Edmunds	West Suffolk NHS Foundation Trust	RGR
Cambridge	• Cambridge University Hospitals NHS Foundation Trust • Cambridgeshire PCT	RGT 5PP
Camden Paediatric Epilepsy Service	• Royal Free London NHS Foundation Trust • University College London Hospitals NHS Foundation Trust • Central And North West London NHS Foundation Trust	RAL RRV RV3
Cardiff	Cardiff & Vale University Health Board	7A4
Carlisle	North Cumbria University Hospitals NHS Trust	RNL

Carmarthen	Hywel Dda Local Health Board	7A2
Central Manchester	Central Manchester University Hospitals NHS Foundation Trust	RW3
Chelmsford	Mid Essex Hospital Services NHS Trust	RQ8
Chelsea & Westminster Hospital	Chelsea and Westminster Hospital NHS Foundation Trust	RQM
Chester	Countess of Chester Hospital NHS Foundation Trust	RJR
Chesterfield	Chesterfield Royal Hospital NHS Foundation Trust	RFS
Chichester	Western Sussex Hospitals NHS Trust	RYR
Colchester	Colchester Hospital University NHS Foundation Trust	RDE
Conquest Hospital	East Sussex Healthcare NHS Trust	RXC
Cornwall	Royal Cornwall Hospitals NHS Trust	REF
Craigavon	Southern Health and Social Care Trust	ZT003
Crewe	The Mid Cheshire Hospitals NHS Foundation Trust	RBT
Croydon	Croydon Health Services NHS Trust	RJ6
Darent Valley Hospital	Dartford and Gravesham NHS Trust	RN7
Darlington/Bishop Auckland	County Durham and Darlington NHS Foundation Trust	RXP
Derby	Derby Hospitals NHS Foundation Trust	RTG
Dewsbury	Mid Yorkshire Hospitals NHS Trust	RXF
Doncaster	Doncaster and Bassetlaw Hospitals NHS Foundation Trust	RP5
Dorset	Dorset County Hospital NHS Foundation Trust	RBD
Dudley	The Dudley Group NHS Foundation Trust	RNA
Dumfries and Galloway	NHS Dumfries & Galloway	SYA20
Durham	County Durham and Darlington NHS Foundation Trust	RXP
Ealing Hospital	Ealing Hospital NHS Trust	RC3
East Kent Hospitals	• East Kent Hospitals University NHS Foundation Trust • Eastern and Coastal Kent Primary Care Trust	RVV 5QA
Eastbourne District Hospital	• East Sussex Heathcare NHS Trust • Sussex Community NHS Trust	RXC RDR
Edinburgh	NHS Lothian	SSA20
Enniskillen	Western Health and Social Care Trust	ZT005
Exeter	Royal Devon and Exeter NHS Foundation Trust	RH8
Fairfield	Pennine Acute Hospitals NHS Trust	RW6
Frimley	Frimley Park Hospital NHS Foundation Trust	RDU
Furness	University Hospitals of Morecambe Bay NHS foundation Trust	RTX
Gateshead	Gateshead Health NHS Foundation Trust	RR7
Glan Clwyd & Colwyn Bay	Betsi Cadwaladr University Local Health Board	7A1
Glasgow	NHS Greater Glasgow & Clyde	SGA20
Gloucestershire	Gloucestershire Hospitals NHS Foundation Trust	RTE
Great Yarmouth	James Paget University Hospitals NHS Foundation Trust	RGP
Grimsby	Northern Lincolnshire & Goole Hospitals NHS Foundation Trust	RJL
Guildford	Royal Surrey County Hospital NHS Foundation Trust	RA2
Guy's and St Thomas	Guy's and St Thomas' NHS Foundation Trust	RJ1
Gwent	Aneurin Bevan Health Board	7A6
Harlow	The Princess Alexandra Hospital NHS Trust	RQW
Harrogate	Harrogate and District NHS Foundation Trust	RCD
Haverfordwest	Hywel Dda Local Health Board	7A2
Hereford	• Wye Valley NHS Trust • Herefordshire PCT	RLQ 5CN
Hillingdon Hospital	The Hillingdon Hospitals NHS Foundation Trust	RAS

Huddersfield, Calderdale & Halifax	Calderdale and Huddersfield NHS Foundation Trust	RWY
Hull	Hull and East Yorkshire Hospitals NHS Trust	RWA
Huntingdon	• Hinchingbrooke Health Care NHS Trust, • Cambridgeshire Community Services NHS Trust	RQQ RYV
Inverclyde	NHS Greater Glasgow & Clyde	SGA20
Inverness & Highland	NHS Highland	SHA20
Ipswich	Ipswich Hospital NHS Trust	RGQ
Isle of Wight	Isle of Wight NHS Trust	R1F
Kettering	Kettering General Hospital NHS Foundation Trust	RNQ
Kings Lynn	The Queen Elizabeth Hospital King's Lynn NHS Foundation Trust	RCX
Kingston Hospital	Kingston Hospital NHS Trust	RAX
Kirkcaldy	NHS Fife	SFA20
Leeds	• Leeds Teaching Hospitals NHS Trust • Leeds Community Healthcare NHS Trust	RR8 RY6
Leicester	University Hospitals of Leicester NHS Trust	RWE
Lewisham Hospital	Lewisham Healthcare NHS Trust	RJ2
Lincoln	United Lincolnshire Hospitals NHS Trust	RWD
Liverpool	Alder Hey Children's NHS Foundation Trust	RBS
Livingston	NHS Lothian	SSA20
Luton	Luton and Dunstable Hospital NHS Foundation Trust	RC9
Macclesfield	East Cheshire NHS Trust	RJN
Mansfield	Sherwood Forest Hospitals NHS Foundation Trust	RK5
Medway Maritime Hospital	Medway NHS Foundation Trust	RPA
Melrose	NHS Borders	SBA20
Merthyr Tydfil	Cwm Taf Local Health Board	7A5
Middlesbrough	South Tees Hospitals NHS Foundation Trust	RTR
Milton Keynes	Milton Keynes Hospital NHS Foundation Trust	RD8
Newcastle	The Newcastle Upon Tyne Hospitals NHS Foundation Trust	RTD
Newham General Hospital	• Newham PCT • Newham University Hospitals NHS Trust • East London Foundation Trust	5C5 R1H RWK
North Devon	Northern Devon Healthcare NHS Trust	RBZ
North Manchester	Pennine Acute Hospitals NHS Trust	RW6
North Middlesex Hospital	North Middlesex University Hospital NHS Trust	RAP
North Tees and Hartlepool NHS Foundation Trust	North Tees and Hartlepool NHS Foundation Trust	RVW
North Tyneside	Northumbria Healthcare NHS Foundation Trust	RTF
Northallerton	South Tees Hospitals NHS Foundation Trust	RTR
Northampton	Northampton General Hospital NHS Trust	RNS
Northwick Park Hospital	Northwest London Hospitals NHS Trust	RV8
Norwich	• Norfolk & Norwich University Hospital NHS Trust • Norfolk Community Health and Care NHS Trust	RM1 RY3
Nottingham	Nottingham University Hospitals NHS Trust	RX1
Nuneaton, Coventry & Rugby	• George Eliot Hospital NHS Trust • University Hospitals Coventry and Warwickshire NHS Trust • Coventry and Warwickshire Partnership Trust	RLT RKB RYG
Oldham	• Pennine Acute Hospitals NHS Trust • Pennine Care NHS Foundation Trust	RW6 RT2
Ormskirk	Southport and Ormskirk Hospital NHS Trust	RVY
Oxford	Oxford University Hospitals NHS Trust	RTH
Paisley & Vale of Leven	NHS Greater Glasgow & Clyde	SGA20

Pembury Hospital	Maidstone and Tunbridge Wells NHS Trust	RWF
Peterborough	• Peterborough and Stamford Hospitals NHS Foundation Trust • Cambridgeshire Community Services NHS Trust	RGN RYV
Plymouth	Plymouth Hospitals NHS Trust	RK9
Poole	Poole Hospital NHS Foundation Trust	RD3
Portsmouth	• Portsmouth Hospitals NHS Trust • Hampshire PCT • Solent NHS Trust	RHU 5QC R1C
Preston	Lancashire Teaching Hospitals NHS Foundation Trust	RXN
Princess Royal University Hospital	South London Healthcare NHS Trust	RYQ
Redditch	Worcestershire Acute Hospitals NHS Trust	RWP
Rochdale	Pennine Acute Hospitals NHS Trust	RW6
Rotherham	The Rotherham NHS Foundation Trust	RFR
Royal Alexandra Children's Hospital	• Brighton and Sussex University Hospitals NHS Trust • Sussex Community NHS Trust	RXH RDR
Royal London Hospital	Barts Health NHS Trust	R1H
Salford	Salford Royal NHS Foundation Trust	RM3
Salisbury	Salisbury NHS Foundation Trust	RNZ
Sandwell	Sandwell and West Birmingham Hospitals NHS Trust	RXK
Scarborough	Scarborough and NE Yorkshire Healthcare NHS Trust	RCC
Scunthorpe	• Doncaster and Bassetlaw Hospitals NHS Foundation Trust • Northern Lincolnshire & Goole Hospitals NHS Foundation Trust	RP5 RJL
Sheffield	Sheffield Childrens NHS Foundation Trust	RCU
Shrewsbury	Shrewsbury & Telford Hospitals NHS Trust	RXW
Sidcup and Woolwich	South London Healthcare NHS Trust	RYQ
South Tyneside	South Tyneside NHS Foundation Trust	RE9
Southampton	University Hospital Southampton NHS Foundation Trust	RHM
Southend Hospital	Southend University Hospitals NHS Foundation Trust	RAJ
St Georges Hospital	St George's Healthcare NHS Trust	RJ7
Stafford	Mid Staffordshire NHS Foundation Trust	RJD
Stevenage & Welwyn Garden City	East & North Hertfordshire NHS Trust	RWH
Stirling & Falkirk	NHS Forth Valley	SVA20
Stockport	Stockport NHS Foundation Trust	RWJ
Stoke	University Hospital of North Staffordshire NHS Trust	RJE
Sunderland	City Hospitals Sunderland NHS Foundation Trust	RLN
Surrey and Sussex Hospitals	• Surrey and Sussex Healthcare NHS Trust • Sussex Community NHS Trust	RTP RDR
Sutton Coldfield	• Heart of England NHS Foundation Trust • Birmingham Community Healthcare NHS Trust	RR1 RYW
Swansea	Abertawe Bro Morgannwg University Local Health Board	7A3
Swindon	Great Western Hospitals NHS Foundation Trust	RN3
Tameside	Tameside Hospital NHS Foundation Trust	RMP
Taunton	Taunton & Somerset NHS Trust	RBA
Tayside	NHS Tayside	STA20
Torbay	South Devon Healthcare NHS Foundation Trust	RA9
Trafford & South Manchester	• University Hospital of South Manchester NHS Foundation Trust • Central Manchester University Hospitals NHS Foundation Trust	RM2 RW3
Ulster	South Eastern Health and Social Care Trust	ZT004
Wakefield	Mid Yorkshire Hospitals NHS Trust	RXF
Walsall	Walsall Healthcare NHS Trust	RBK

Waltham Forest Epilepsy service -Whipps Cross Hospital	• Barts Health NHS Trust • North East London NHS Foundation Trust	R1H RAT
Warrington	Warrington and Halton Hospitals NHS Foundation Trust	RWW
Warwick	South Warwickshire NHS Foundation Trust	RJC
Watford General Hospital	• West Hertfordshire Hospitals NHS Trust • Hertfordshire Community NHS Trust	RWG RY4
West Kent	Kent Community Health NHS Trust	RYY
West Middlesex University Hospital	West Middlesex University Hospital NHS Trust	RFW
Weston	Weston Area Health NHS Trust	RA3
Wexham Park Hospital	Heatherwood and Wexham Park Hospitals NHS Trust	RD7
Whiston	St Helens and Knowsley Hospitals NHS Trust	RBN
Whitehaven	North Cumbria University Hospitals NHS Trust	RNL
Wigan	Wrightington, Wigan & Leigh NHS Foundation Trust	RRF
Winchester	Hampshire Hospitals NHS Foundation Trust	RN5
Wirral	Wirral University Teaching Hospital NHS Foundation Trust	RY7
Wishaw	NHS Lanarkshire	SLA20
Wolverhampton	The Royal Wolverhampton Hospitals NHS Trust	RL4
Worcester	• Worcestershire Acute Hospitals NHS Trust • Worcestershire PCT	RWP 5PL
Worthing Hospital	Western Sussex Hospitals NHS Trust	RYR
Wrexham	Betsi Cadwaladr University Health Board	7A1
Yeovil	Yeovil District Hospital NHS Foundation Trust	RA4
Ynys Maerdy	Cwm Taf Local Health Board	7A5
York	York Teaching Hospital NHS Foundation Trust	RCB

Units participating in service descriptor only (n=7)

Unit Name	Trusts	Trust code
Epsom Hospital	Epsom and St Helier University Hospital NHS Trust	RVR
Homerton Hospital	Homerton University Hospital NHS Foundation Trust	RQX
Kings College	• Kings College Hospital NHS Foundation Trust • Guy's And St Thomas' NHS Foundation Trust	RJZ RJ1
Pontefract & Castleford	Mid Yorkshire Hospitals NHS Trust	RXF
Queen Mary's Hospital	Epsom and St Helier University Hospital NHS Trust	RVR
St Mary's Hospital (Lon)	Imperial College Healthcare NHS Trust	RYJ
Whittington Hospital	The Whittington Hospital NHS Trust	RKE

Non participating units (n=4)

Unit Name	Trusts	Trust code
Lancaster	University Hospitals of Morecambe Bay NHS Foundation Trust	RTX
Neath & Port Talbot	Abertawe Bro Morgannwg University Local Health Board	7A6
Powys	Powys Teaching Local Health Board	7A7
Queen's Hospital & Havering	Barking, Havering and Redbridge University Hospitals NHS Trust	RF4

Appendix 3: Service Descriptor questionnaire

1. How many whole time equivalent (WTE) general paediatric consultants (community or hospital based) are there employed within the 'audit unit'?	• Decimal field	*Audit Unit - The audit unit is defined by your audit unit profile. Most audit units will include one or more secondary tier paediatric services grouped together using pragmatic boundaries agreed by the paediatric audit unit lead, the project team and the tertiary link.WTE = whole time equivalent. E.g. One full time post is 1 WTE; Someone working 3 days a week = 0.6 WTE; 2 people both working 3 days a week = 1.2 WTE.*
2. How many whole time equivalent (WTE) general paediatric consultants with 'expertise in epilepsy' are there employed within the 'audit unit'?	• Decimal field	*Paediatrician with expertise -Paediatric consultant (or associate specialist) defined by themselves, their employer and tertiary service/network as having: training and continuing education in epilepsies AND peer review of practice AND regular audit of diagnosis (e.g. participation in Epilepsy12).* *Paediatric neurologists should not be included in your response.*
3. What are the names of the consultant paediatricians defined by the audit unit as having 'expertise in epilepsy'?	• Free text	*This field is referred to in the clinical dataset when the user is asked whether evidence of input from a 'paediatrician with expertise'* *Paediatrician with expertise - Paediatric consultant (or associate specialist) defined by themselves, their employer and tertiary service/network as having: training and continuing education in epilepsies AND peer review of practice AND regular audit of diagnosis (e.g. participation in Epilepsy12).* *Paediatric neurologists should not be included in your response.*
4. How many whole time equivalent (WTE) epilepsy specialist nurses (ESNs) are there employed within the 'audit unit'?	• Decimal field	*ESN - A children's nurse with a defined role and specific qualification and/or training in children's epilepsies*

5. On average, how many consultant (or associate specialist) led secondary level 'epilepsy clinics' for children or young people take place within your audit unit per week?	• Decimal field	*A secondary level 'epilepsy clinic' is a clinic run just for children with seizures or epilepsy that takes referrals direct from GPs or emergency department (decimal answers are allowed).* *An 'Epilepsy Clinic' is defined as a paediatric clinic where all the children and young people attending have epilepsy or possible epileptic seizures.*
6. Do any of the paediatric services within the 'audit unit' maintain a database or register of children with epilepsies?	• Yes for all children • Yes for some children • No	
7. Which of the following investigations can be obtained at a location within the 'audit unit'? • 12 lead ECG • 'awake' MRI • MRI with sedation • MRI with general anaesthetic • Routine EEG • Sleep-deprived EEG • Melatonin induced EEG • Sedated EEG • 24-48h ambulatory EEG • Video telemetry • Portable EEG on paediatric ward within audit unit	• Yes/No/ Uncertain • Yes/No/ Uncertain • Yes/No/ Uncertain • Yes/No/ Uncertain • Yes/No/ Uncertain • Yes/No/ Uncertain • Yes/No/ Uncertain • Yes/No/ Uncertain • Yes/No/ Uncertain • Yes/No/ Uncertain • Yes/No/ Uncertain	
8. Does the 'audit unit' host paediatric neurology clinics? (e.g. a paediatric neurologist visits a site within the audit unit or is based within that 'audit unit')	• Yes • No	

9. Which of the following 'transition services' are available within the 'audit unit'? • A specific clinic for 'young people' or 'teenagers' with epilepsies • a 'Handover clinic' • Other defined handover or referral process • Local adult specialist epilepsy nurse • Youth worker • From what age do 'outpatient' adult services within your audit unit begin to accept referrals from General Practitioners (GPs) for young people with a seizure or seizures?	• Yes/No/ Uncertain • Yes/No/ Uncertain • Yes/No/ Uncertain • Yes/No/ Uncertain • Yes/No/ Uncertain • Number	*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*

Appendix 4: Clinical Audit questionnaire

SECTION A: OTHER INFORMATION		
Question	**Answer**	**Help/Validation Rules**
Has the UIN been noted on the ascertainment sheet?	Yes | No	*The UIN is the Unique Identifying Number that can be found on the top left hand corner of this page. The UIN should be recorded in the ascertainment sheet.*
1a. General Practice code	Number	*Each practice is identified by a unique code. The general practice code can be found on the hospital electronic record.*
1b. Which is the main trust that has been involved in managing this patient's seizure(s) during the 12 months after first paediatric assessment?	Drop down list	
1c. Which is the main hospital, if any, that has been involved in managing this patient's seizure(s) during the 12 months after first paediatric assessment?	Free text	
1d. Which is the main community paediatric service, if any, that has been involved in managing this patient's seizure(s) during the 12 months after first paediatric assessment.	Free text	
SECTION B: FIRST PAEDIATRIC ASSESSMENT		
2. Was the first paediatric assessment in an acute or non-acute setting?	- Acute - Non-acute - Don't know	*Acute - Inpatient review, or paediatric review in emergency department, or other clinical assessment in an acute paediatric setting. Non acute - Paediatric outpatients or clinic*
3. During the time period from the patient's first paroxysmal episode to the first paediatric assessment was there documentation of the following:		
a. A description of the episode or episodes	Yes | No	
b. Approximately when the first episode was, or how old the child was at that time?	Yes | No	

c. The approximate frequency or number of episodes since the first episode?	Yes | No	*If only one episode then as long as when this occurred is approximately defined then this can be answered yes*
d. A general examination?	Yes | No	*Any documentation accepted*
e. A neurological examination?	Yes | No	*Any documentation that suggests that part of the neurological system has been formally examined (e.g. mention of reflexes, tone, cranial nerves, fundoscopy or neuro ?) should be answered 'yes'; If neurological system is not specifically mentioned (e.g. examination normal) then answer 'no'.*
f. The presence or absence of developmental, learning or schooling problems	- Yes, this issue was assessed - No, this issue was not assessed	*Note that this question is determining whether this was assessed not whether there were problems.*
g. The presence or absence of behavioural or emotional problems?	- Yes, this issue was assessed - No, this issue was not assessed	***Only asked if child [age at first paediatric assessment] is 36 months or greater*** *This question is determining whether this was assessed not whether there were problems and is only asked if the child older than 3 years at first paediatric assessment.*
Comments		*Please add any comments you would like to be taken into account based on your response above*
SECTION C: DIAGNOSIS AT FIRST PAEDIATRIC ASSESSMENT		
4. Which statement best describes the number of paroxysmal episodes by the time of the first paediatric assessment?	- A single episode - A cluster of episodes within a 24 hour period - 2 or more episodes (occurring over a time period greater than 24 hours)	*For children with a mixture of different episodes some of which were clearly defined as epileptic just refer to those defined as epileptic. E.g. if the child was felt to have 1 epileptic seizures and 3 faints then this would be answered a single episode*
5. Which statement best describes the diagnosis made by the paediatric team by the end of the <u>first paediatric assessment?</u>	- Epileptic or probably epileptic episode(s) - Non-epileptic episode(s) - Uncertain or unclear episode(s)	*Diagnosis is that made by the child's health professional assessment as documented within the clinical records. Even if the user considers the diagnosis is wrong it is the health professionals diagnosis at the time that is counted.*
6. Was a diagnosis of probable syncope, faints, breath-holding episodes or reflex anoxic seizures made?	Yes | No	***Only for those where Q5 answered 'non-epileptic episode(s)' at first assessment***
7. Was a diagnosis of probable tics made?	Yes | No	**Only for those where Q5 answered 'non-epileptic episode(s)' at first assessment**
Comments		*Please add any comments you would like to be taken into account based on your response above*

SECTION D: DIAGNOSIS AT 12 MONTHS AFTER FIRST PAEDIATRIC ASSESSMENT		
8. Which statement best describes the **total** number of paroxysmal episodes occurring by 12 months after first paediatric assessment?	- A single episode - A cluster of episodes (confined to a 24 hour period) - 2 or more episodes (occurring over a time period greater than 24 hours)	*If no further episodes have occurred following the first assessment then this question will have the same answer as the number of episodes at first assessment*
9. Which statement best describes the diagnosis made by the paediatric team by the end of the 12 months after first paediatric assessment?	- Epileptic or probably epileptic episode(s) - Non-epileptic episode(s) - Uncertain or unclear episode(s)	*Diagnosis that is made by the child's health professional assessment as documented within the clinical records. Even if the user considers the diagnosis is wrong it is the health professionals diagnosis at the time that is counted*
10. Was there any evidence that a diagnosis of epilepsy (two or more epileptic seizures) was made and then later withdrawn at any time during 12 months after first paediatric assessment?	Yes | No	
11. Were any afebrile episodes documented as convulsive?	Yes | No	*Convulsive episode - An episode where there is symmetrical or asymmetrical limb motor involvement (tonic, clonic, tonic-clonic) Myoclonic seizures excluded.*
12. Which of the listed epileptic seizure type(s) were identified?	Drop down list of epilepsy seizures	***Only if 2 or more episodes (diagnosis at 12 months) answered for Q8 AND [Epileptic or probably epileptic episode(s)] at 12 months answered for Q9*** *Can select more than one option*
13. Which of the listed epilepsy syndromes were diagnosed?	Drop down list of epilepsy syndromes	***Only if 2 or more episodes (diagnosis at 12 months) answered for Q8 AND [Epileptic or probably epileptic episode(s)] at 12 months answered for Q9***
Other Epilepsy syndrome types	Drop down list of epilepsy syndromes See Appendix B	***'Other' dropdown menu only available if 'Common' drop down selected as 'Other'***

14. Were there any of the listed epilepsy syndrome category identifiers used?	- Idiopathic (or primary) - Symptomatic - Probably symptomatic (or cryptogenic) - Genetic - Structural/Metabolic - Unknown cause - None of above	***Only if 2 or more episodes (diagnosis at 12 months) answered for Q8*** ***AND*** ***[Epileptic or probably epileptic episode(s)] at 12 months answered for Q9***
15. Were there any of the listed epilepsy syndrome categories identifiers used?	- Focal (or partial) - Multifocal - Generalised - Uncertain - None of the above	***Only if 2 or more episodes (diagnosis at 12 months) answered for Q8*** ***AND*** ***[Epileptic or probably epileptic episode(s)] at 12 months answered for Q9***
16. Was there evidence of a neurodisability diagnosis recorded by professionals involved?	Yes | No	*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*
17. If yes, were any of the following diagnoses documented?	- 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) - other	***Only if answered yes to Q16***
Comments		*Please add any comments you would like to be taken into account based on your response above*

SECTION E: PROFESSIONAL INVOLVEMENT		
18. By 12 months after first paediatric assessment:		
a. Was there any evidence of input from a Consultant Paediatrician with expertise in epilepsy	Yes | No	***Only if 2 or more episodes (diagnosis at 12 months) answered for Q8 AND [Epileptic or probably epileptic episode(s)] at 12 months answered for Q9*** *Consultant Paediatrician with expertise in epilepsy-A paediatric consultant (or associate specialist) defined by themselves, their employer and tertiary service/network as having: training and continuing education in epilepsies AND peer review of practice AND regular audit of diagnosis (e.g. participation in Epilepsy12)*
b. Was there any evidence of input from a Consultant Paediatric Neurologist?	Yes | No	***Only if 2 or more episodes (diagnosis at 12 months) answered for Q8 AND [Epileptic or probably epileptic episode(s)] at 12 months answered for Q9*** *Input - Any form of documented clinical contact including face to face clinical, written, electronic or telephone contact*
c. Was there any evidence the child had a referral to or input from an epilepsy specialist nurse?	Yes | No	***Only if 2 or more episodes (diagnosis at 12 months) answered for Q8 AND [Epileptic or probably epileptic episode(s)] at 12 months answered for Q9*** *Epilepsy specialist nurse - A children's nurse with a defined role and specific qualification and/or training in children's epilepsies. Copy clinic letter to ESN or documented phone call would count as evidence*

Comments		*Please add any comments you would like to be taken into account based on your response above*
SECTION F: INVESTIGATIONS		
19. By 12 months after first paediatric assessment, is there an MRI head result documented?	Yes | No	
20. By 12 months after first paediatric assessment, is there a CT head scan result documented?	Yes | No	

21. By 12 months after first paediatric assessment, is there a12 lead ECG result documented or contained within notes?	Yes | No	
Comments		*Please add any comments you would like to be taken into account based on your response above*
SECTION G: TREATMENT		
22. By 12 months after first paediatric assessment, what number of different (maintenance) anti-epileptic drugs had been used?	Number	*Anti-epileptic drugs - Regular daily drug treatment for reduction of risk of epileptic seizures in epilepsy. Not including drug treatment given for during a prolonged seizure (e.g. rectal diazepam/paraldehyde, buccal midazolam, IV lorazepam/phenytoin) or clusters of seizures (e.g. intermittent clobazam). Not including drugs where the purpose of treatment is for something other than epilepsy treatment (e.g. CBZ for behaviour, topiramate for migraine etc). If no maintenance AED then answer 0.*
23. By 12 months after first paediatric assessment, was Carbamazepine prescribed at any time?	Yes | No	***Only asked if above 1 or more answered to Q22***
Comments		*Please add any comments you would like to be taken into account based on your response above*
SECTION H: COMMUNICATION		
24. By 12 months after first paediatric assessment was there any evidence of discussion with the parent and/or patient about issues relating to contraception, preconception or pregnancy?	Yes | No	***Only asked for females*** *Any documented evidence of discussion is acceptable. This discussion may not be indicated for many female individuals in this audit but a yes or no answer is still required. Indications for this discussion be taken into account during data analysis.*
Comments		*Please add any comments you would like to be taken into account based on your response above*

SECTION I: OUTCOME		
25. Was there documentation to suggest that seizures occurred between 6 months after first paediatric assessment to 12 months after first paediatric assessment?	- Documentation suggests no seizure occurred - Documentation suggests seizure(s) occurred - No documentation or documentation unclear	***Only if 2 or more episodes (diagnosis at 12 months) answered for Q8*** ***AND*** ***[Epileptic or probably epileptic episode(s)] at 12 months answered for Q9***
26. Was there documentation to suggest that seizures occurred between 9 months after first paediatric assessment to 12 months after first paediatric assessment?	Yes | No	***Only available if Q25 answered as Documentation suggests seizures occurred.***
27. Is there any evidence that the child has died?	- Died - Presumed alive	*Children who have died will be excluded from the user experience questionnaire*
Comments		*Please add any comments you would like to be taken into account based on your response above*

(Question 12) Epilepsy seizure types for matrix

- No seizure type stated
- Other seizure stated
- Documented as 'unclassified' seizure
- (Generalised) tonic-clonic seizures
- Clonic seizures
- Absence seizures (including typical or atypical)
- Myoclonic absence seizures
- Tonic seizures
- Atonic seizures
- Spasms
- Infantile spasms
- Myoclonic seizures
- Temporal seizures
- Parietal seizures
- Occipital seizures
- Focal seizures
- Focal motor seizures
- Focal sensory seizures

- Frontal seizures
- Secondarily generalized seizures
- Massive bilateral myoclonus
- Eyelid myoclonia
- Myoclonic atonic seizures
- Negative myoclonus
- Reflex seizures
- Gelastic seizures
- Hemiclonic seizures
- Reflex seizures
- Grand mal seizures
- Petit mal seizures

(Question 13) Common Epilepsy syndrome types – drop down menu

- No epilepsy syndrome stated
- (Benign) childhood epilepsy with centrotemporal spikes (BECTS) (benign rolandic epilepsy)
- Epilepsy with myoclonic astatic seizures (Doose syndrome) (Myoclonic astatic epilepsy)
- Panayiotopoulos syndrome (Early onset (benign) childhood occipital epilepsy)
- Grand mal epilepsy
- Petit mal epilepsy
- occipital lobe epilepsy
- parietal lobe epilepsy
- temporal lobe epilepsy
- frontal lobe epilepsy
- Juvenile myoclonic epilepsy (JME)
- Juvenile absence epilepsy (JAE)
- Childhood absence epilepsy(CAE)
- Dravet syndrome (severe myoclonic epilepsy of/in infancy or SMEI)
- West syndrome(of infantile spasms)
- Defined as ‘unclassified’
- Other epilepsy syndrome stated
    - See below

Other Epilepsy syndrome types – drop down menu

This drop down menu will only be available if ‘Other epilepsy syndrome stated’ is selected from the above **Common Epilepsy syndrome types** drop down menu.

- Benign familial neonatal seizures
- Idiopathic focal epilepsy of childhood
- Visual sensitive epilepsies
- Primary reading epilepsy
- Startle epilepsy
- Benign neonatal seizures Benign non-familial neonatal seizures
- Rasmussen’s encephalitis (chronic progressive epilepsia partialis continua) (Kozhevnikov

syndrome)
- Gelastic seizures due to hypothalamic hamartoma
- Eyelid myoclonia with absences
- Perioral myoclonia with absences
- Phantom absences
- Childhood epilepsy with occipital paroxysms
- Hemiconvulsion-hemiplegia syndrome
- Hot water epilepsy
- Bathing epilepsy
- Classical petit mal
- Reflex epilepsies
- Familial focal epilepsy with variable foci
- Generalized Epilepsies with Febrile seizures plus (FS+)
- Early myoclonic encephalopathy
- Ohtahara syndrome
- Migrating partial (focal) seizures of infancy
- (Benign) Myoclonic epilepsy in infancy
- Benign infantile seizures
- Myoclonic encephalopathy in nonprogressive disorders {myoclonic status in non-progressive encephalopathies}
- Late onset childhood occipital epilepsy (Gastaut type) (idiopathic childhood occipital epilepsy)
- Epilepsy with myoclonic absences
- Lennox-Gastaut syndrome
- Landau-Kleffner syndrome
- Epilepsy with generalized tonic-clonic seizures only (Epilepsy with generalised tonic clonic seizures on awakening)
- Progressive myoclonus (myoclonic) epilepsies (PME)
- Autosomal-dominant nocturnal frontal lobe epilepsy (ADNFLE)
- Familial temporal lobe epilepsies
- Autosomal dominant partial epilepsy with auditory features
- Other

Appendix 5: Patient Reported Experience Measure (PREM)

Epilepsy12 Experience Questionnaire

PART A: ***Parent/Carer Questionnaire:*** **Audit Unit Name:**

In this questionnaire, we ask you about your views of the health service that you and your child have been to for the care of seizures. Please answer the questions below by writing on the dotted lines or by putting a tick √ *in the appropriate box(es). Please return it in the envelope as soon as you can.*

A1. What is your child's year of birth? __ __ __ __

A2. Is your child: Male? ☐ Female? ☐

A3. On average over the past year, how often does your child have seizures?

- Less than one per month ☐
- 1 or more a month but less than 1 a week ☐
- 1 or more a week but less than one a day ☐
- 1 or more per day ☐
- Unsure ☐

Other, please specify.....

.....

A4. Has your child ever been diagnosed with any of the following conditions:

- Learning difficulties/developmental delay ☐
- Cerebral palsy ☐
- Autism or autistic spectrum disorder ☐
- Attention Deficit Hyperactivity Disorder (ADHD) ☐
- None of the above ☐

Other, please specify.....

.....

A5. What type of clinic does your child attend for their seizures or epilepsy? *Tick all that apply*

- General paediatric clinic ☐
- Community paediatric clinic ☐
- Teenage epilepsy clinic ☐
- Specific epilepsy clinic ☐
- Paediatric Neurology clinic ☐
- Don't know ☐

Other, please specify.....

A6a. Have you found it easy to contact the health service looking after your child's seizures or epilepsy?

Yes ☐ No ☐ Unsure ☐

A6b. Over the past year, including planned appointments, how many times have you been in contact with this health service (either by visiting the clinic, by telephone or by email)?

- None ☐
- 1 to 5 times ☐
- 6 to 10 times ☐
- More than 10 times ☐

A7. Which areas, if any, would you like more information on? *Tick all that apply*

- Guidance on what my child can or can't do ☐
- The cause of my child's epilepsy or seizures ☐
- Possible side effects of medication ☐
- Reasons for changing medication ☐
- Reasons for, and results of, tests ☐
- Support groups ☐
- Contacting other families living with epilepsy ☐
- What to tell other people about my child's seizures or epilepsy ☐

Other, please specify.....

A8. What is the levels of education that **you (not your child)** have completed? *Tick any that apply*

- Secondary school ☐
- College/apprenticeship ☐
- Undergraduate university ☐
- Postgraduate university ☐

Other, please specify:.....

*For questions A9-26, please indicate how strongly you agree or disagree with the statements given. We are interested in your **overall** impressions so please base your answers on your experiences over all of the last year.*

	Strongly Agree	Agree	Unsure	Disagree	Strongly Disagree	Not Applicable
A9. Overall, I received **enough** information on seizures or epilepsy	☐	☐	☐	☐	☐	☐
A10. Staff **listened** to what I had to say	☐	☐	☐	☐	☐	☐
A11. The information I was given was **hard** to understand	☐	☐	☐	☐	☐	☐
A12. Staff **did not** take time to get to know me and my child	☐	☐	☐	☐	☐	☐
A13. Staff **did not** explain things in a way I could follow	☐	☐	☐	☐	☐	☐
A14. Staff **took my views into account** in making decisions	☐	☐	☐	☐	☐	☐
A15. I felt the staff **respected** our need for privacy during clinic visits	☐	☐	☐	☐	☐	☐
A16. Overall, staff seemed to **know what they were doing**	☐	☐	☐	☐	☐	☐
A17. At times I felt **I was not allowed** to ask questions	☐	☐	☐	☐	☐	☐
A18. It is **easy to contact someone** in the epilepsy team	☐	☐	☐	☐	☐	☐
A19. Staff make sure **it is easy to attend** the clinic e.g. when making appointments	☐	☐	☐	☐	☐	☐
A20. My child is **not seen by the service often enough**	☐	☐	☐	☐	☐	☐
A21. When attending the clinic staff **tell me** if the appointment is going to be delayed	☐	☐	☐	☐	☐	☐
A22. The waiting area **does not have activities** for my child	☐	☐	☐	☐	☐	☐
A23. Overall, the length of time spent with staff at the clinic is **just about right**	☐	☐	☐	☐	☐	☐
A24. Staff are **not good at working together** with others e.g. the G.P., when looking after my child	☐	☐	☐	☐	☐	☐
A25. Staff are good at working together with school or nursery?	☐	☐	☐	☐	☐	☐
A26. Overall, staff are friendly and polite?						
Outpatient Clinic staff	☐	☐	☐	☐	☐	☐
In-patient ward staff	☐	☐	☐	☐	☐	☐
When going for tests staff e.g. EEG or MRI (if applicable)	☐	☐	☐	☐	☐	☐

A27. What are the 3 best things about the epilepsy service?	**A28.** What are the 3 worst things about the epilepsy service?
1	**1**
2	**2**
3	**3**

A29. Overall, are you satisfied with the care your child receives from the epilepsy service?

Yes ☐ No ☐ Unsure ☐

PART B: *This section is for the Child or Young Person*

In this questionnaire, we ask you about your views of the epilepsy service that you go to. Please answer the questions below by putting a tick ☑ *in the appropriate box(es).*

*For questions B1-18, please indicate how strongly you agree or disagree with the statements given. We are interested in your **overall** impressions so please base your answers on your experiences over all of the last year.*

	Strongly Agree	Agree	Unsure	Disagree	Strongly Disagree	Not Applicable
B1. Overall, I received **enough** information on seizures or epilepsy	☐	☐	☐	☐	☐	☐
B2. Staff **listened** to what I had to say	☐	☐	☐	☐	☐	☐
B3. The information I was given was **hard** to understand	☐	☐	☐	☐	☐	☐
B4. Staff **did not** take time to get to know me	☐	☐	☐	☐	☐	☐
B5. Staff **did not** explain things in a way I could follow	☐	☐	☐	☐	☐	☐
B6. Staff **took my views into account** in making decisions	☐	☐	☐	☐	☐	☐
B7. I felt the staff **respected** my need for privacy during clinic visits	☐	☐	☐	☐	☐	☐
B8. Overall, staff seemed to **know what they were doing**	☐	☐	☐	☐	☐	☐
B9. At times I felt **I was not allowed** to ask questions	☐	☐	☐	☐	☐	☐
B10. It is **easy to contact someone** in the epilepsy team	☐	☐	☐	☐	☐	☐
B11. Staff make sure **it is easy to attend** the clinic e.g. when making appointments.	☐	☐	☐	☐	☐	☐
B12. I am **not seen by the service often enough**	☐	☐	☐	☐	☐	☐
B13. When attending the clinic staff **tell me** if my appointment is delayed	☐	☐	☐	☐	☐	☐
B14. The waiting area **does not have activities** for my age	☐	☐	☐	☐	☐	☐
B15. Overall, the length of time spent with staff at the clinic is **just about right**	☐	☐	☐	☐	☐	☐
B16. Staff are **not good at working together** with others e.g. the GP, when looking after me	☐	☐	☐	☐	☐	☐
B17. Staff are good at working with school or nursery?	☐	☐	☐	☐	☐	☐
B18. Overall, staff are **friendly and polite**?						
Outpatient Clinic staff	☐	☐	☐	☐	☐	☐
Ward as inpatient staff	☐	☐	☐	☐	☐	☐
When going for tests staff e.g. EEG or MRI (if applicable)	☐	☐	☐	☐	☐	☐

B19. Which areas, if any, would you like more information on? *Tick all that apply*

Guidance on what I can or can't do	☐	Support groups	☐
Contact with other young people with epilepsy	☐	Cause of my epilepsy	☐
What to tell other people about my epilepsy	☐	Reasons for changing medication	☐
Possible side effects of medication	☐	Reasons for, and results of, tests	☐

B20. What are the 3 best things about the epilepsy service?	**B21.** What are the 3 worst things about the epilepsy service?
1.	1.
2.	2.
3.	3.

B22. Overall, are you satisfied with the care you receive from the epilepsy service?.

Yes ☐ No ☐ Unsure ☐

P.T.O

Your comments:
If you would like to let us know about anything else to do with your experiences of your health services please use this box.

Parent

Child/Young Person

Thank you very much for taking the time to complete this questionnaire

Appendix 6: Results by unit

See: www.rcpch.ac.uk/epilepsy12

Royal College of Paediatrics and Child Health
5-11 Theobalds Road, London, WC1X 8SH