

# EPILEPSY12

## National Report, Round 2 November 2014



**HQIP**

Healthcare Quality  
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**Paediatrics and Child Health**  
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# EPILEPSY12

National report of Round 2 of the United Kingdom collaborative clinical audit of healthcare for children and young people with suspected epileptic seizures

## Epilepsy12 National Report

November 2014



Commissioned by the Healthcare Quality Improvement Partnership



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The Healthcare Quality Improvement Partnership (HQIP) is led by a consortium of the Academy of Medical Royal Colleges, the Royal College of Nursing and National Voices. Its aim is to promote quality improvement, and in particular to increase the impact that clinical audit has on healthcare quality in England and Wales. HQIP holds the contract to manage and develop the National Clinical Audit Programme, comprising more than 30 clinical audits that cover care provided to people with a wide range of medical, surgical and mental health conditions. The programme is funded by NHS England, the Welsh Government and, with some individual audits, also funded by the Health Department of the Scottish Government, DHSSPS Northern Ireland and the Channel Islands.  
[www.hqip.org.uk](http://www.hqip.org.uk)

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The purpose of Healthcare Improvement Scotland (HIS) purpose to support healthcare providers in Scotland to deliver high-quality, evidence-based, safe, effective and person-centred care; and to scrutinise those services to provide public assurance about the quality and safety of that care.  
[www.healthcareimprovementscotland.org](http://www.healthcareimprovementscotland.org)

### **The Royal College of Paediatrics and Child Health**

The Royal College of Paediatrics and Child Health is responsible for training and examining paediatricians in the UK. The College has over 15,000 members in the UK and abroad and sets standards for professional and postgraduate medical education. [www.rcpch.ac.uk](http://www.rcpch.ac.uk)

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# Forewords

'Cheshire Puss,' she began, rather timidly..... 'Would you tell me, please, which way I ought to go from here?' 'That depends a good deal on where you want to get to,' said the Cat.

*Alice's Adventures in Wonderland*, Lewis Carroll

I am delighted to be able to write the Foreword for this second round of the Epilepsy12 National Audit, which reflects a collaborative effort between clinicians, voluntary sector organisations, RCPCH and most importantly the children and families whose insight and experience are so essential to all that we do.

The first Epilepsy12 audit report, published in September 2012<sup>1</sup>, gave us an insight into the state of play of our epilepsy services at that time, and identified key areas for improvement. However, two years down the line, this re-audit shows us very clearly that the direction of travel is positive. We are fortunate in having very good roadmaps provided through the NICE Epilepsy Guidance 2012<sup>2</sup>, SIGN Epilepsy Guidelines<sup>3</sup>, and NICE Quality Standards 2013<sup>4</sup>, as well as through the Epilepsy Best Practice Tariff, so that unlike Alice we know exactly where we want to get to from here.

The child in the back of the car may well be asking 'are we nearly there yet?' Whilst the honest answer is that we have a long way to go, it is a testimony to the creativity and commitment of those involved in providing services that such good progress has been made in a time of financial austerity.

Clinicians are passionate about improving the care they offer to their patients, and the fact that 98% of the original participating units contributed to this re-audit is strong evidence of that engagement and drive. This national audit of our services is an invaluable tool which enables us to encourage and motivate those who are doing well, highlight and share examples of good practice, and provide signposts to more secure pathways for those who are struggling in the rough ground along the way.

**Dr Hilary Cass**

**President, Royal College of Paediatrics and Child Health**

The publication of the second round of the Epilepsy12 audit provides a welcome opportunity to reflect on the improvements in services to children with epilepsies that have occurred over the past few decades. Epilepsy12 was initiated by the British Paediatric Neurology Association (BPNA) then led by RCPCH and commissioned by the Healthcare Quality Improvement Partnership (HQIP) and Healthcare Improvement Scotland (HIS). The need for the audit arose from concerns raised about the quality of care (diagnosis and management) for children with epilepsies within the UK. It has taken place alongside other important national initiatives including: the ongoing Paediatric Epilepsy Training (PET) courses, run by the BPNA, the epilepsy guidelines and quality standards produced by the National Institute for Health and Clinical Excellence (NICE), the Scottish Intercollegiate Guidelines Network (SIGN) epilepsy guidelines, the introduction of the RCPCH special interest in paediatric epilepsies (SPIN) modules and the introduction of the Epilepsy Best Practice Tariff in England and Wales.

This second round of Epilepsy12, which largely audited the same performance indicators as the first round, has allowed re-examination of the quality of care for children and young people with epilepsies

in the UK. The high level of engagement with the audit is impressive and the good news is that for most domains improvement has been demonstrated.

However, there is no room for complacency. One third of patients still do not have access to an epilepsy specialist nurse. Far more children, young people, parents and carers completed the Patient Reported Experience Measures (PREMs) questionnaires in this round. This constitutes one of the largest, if not the largest, surveys of what it is like for a child or young person to have epilepsy in the UK with regards to their contact with our services. It identified significant concerns about how professionals work together, the information that patients and families are given and the environments in which they are seen.

Round 2 demonstrates a small decrease in referrals for tertiary assessment by a paediatric neurologist (using national guideline referral criteria). This is not just an academic question as appropriate and timely specialist evaluation may provide early diagnosis for rare or complex disorders, access to new effective therapies, participation in clinical trials and selection of patients who may benefit from epilepsy surgery. There is work to be done with clinicians, hospital managers and Commissioning Groups to improve access to tertiary care.

Overall the audit presents both an encouraging picture and signposts for future improvements. I would recommend it to clinicians, managers and commissioners involved in the care of children and young people with the epilepsies.

**Dr John Livingston**  
**President, British Paediatric Neurology Association**

Epilepsy is a complex condition that can have a significant impact on children and young people and their families. They have a great deal to cope with and it is essential they receive the correct care and support from health professionals.

The Epilepsy12 audit shows improvements are being made to some aspects of patient care. It is encouraging that some areas are performing well, and this demonstrates that it is possible to provide a high standard of care for all those who need it. Overall patient satisfaction is reasonably high.

While we commend the improvements to date, further progress is still urgently needed across a wide range of areas to ensure NICE and SIGN guidelines and standards for epilepsy care are met. Commissioners, health boards, trusts and clinicians, many of whom are dedicated to providing excellent care, must now act on these results and work together to ensure a step change in improvements to services. Our charities will work with them to provide the care, information and support that is so clearly needed.

This audit is hugely important in providing organisations like ours with the evidence to assess whether children and young people are receiving the care that they have the right to expect. We take these findings extremely seriously and are working tirelessly to improve delivery of high-quality and consistent care and support for everyone.

**Carol Long, Chief Executive, Young Epilepsy**

**Philip Lee, Chief Executive, Epilepsy Action**

**Lesslie Young, Chief Executive, Epilepsy Scotland**

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## Executive summary

We wish to thank all of the people that have again given their time and effort in support of Epilepsy12. Round 2 is the second cycle of this audit which aimed to re-examine the quality of care for children and young people with epilepsies in the UK.

There continued to be high levels of engagement across England, Northern Ireland, Scotland, and Wales with 192 out of 196 units that registered for Round 1 registering to take part in Round 2. The results from the three audit domains allow us to examine systematically, for the first time, changes in the quality of care and provision of services from 2010 to 2014.

## Key findings

Key findings are highlighted using the following colour shading which categorises the findings in relation to differences across Rounds 1 and 2. There were no areas of significant deterioration across the Rounds.

Significant improvements across rounds/new positive findings for Round 2 are highlighted by a green box next to the key finding	
No evidence of significant change across rounds is highlighted by an amber box	
New concerns from Round 2 results are highlighted by a red box	

### Service descriptor key findings

The **service descriptor domain** captured data on the organisation and structure of paediatric epilepsy services at the census day of 1 January 2014. 186 audit units contributed data to this component (see tables 3 and 4, pages 24 and 25).

Key finding 1	Many more units report having a local children's Epilepsy Specialist Nurse (ESN).	Round 1, 53% (102/193) Round 2, 68% (127/186)	
Key finding 2	More units report availability of a weekly designated Epilepsy Clinic.	Round 1, 58% (112/193) Round 2, 66% (122/186)	
Key finding 3	More units report availability of a young person's Epilepsy Clinic.	Round 1, 18% (35/193) Round 2, 26% (48/186)	
Key finding 4	More units have a handover clinic for transition to adult services.	Round 1, 30% (57/193) Round 2, 38% (71/186)	
Key finding 5	Many more units have a local database or register for some or all children with epilepsies.	Round 1, 47% (90/193) Round 2, 65% (120/186)	
Key finding 6	The same number of audit units have Adult ESNs.	Round 1, 51% (99/193) Round 2, 54% (100/186)	
Key finding 7	The same number of audit units host local tertiary paediatric neurology clinics.	Round 1, 85% (164/193) Round 2, 85% (159/186)	

### Clinical audit key findings

In the **Clinical Audit Domain** 12 clinical performance indicators were applied to a cohort of 3,449 children for whom a 'first paediatric assessment' for a 'paroxysmal episode or episodes' was undertaken during the four months between 1 January and 30 April 2013. In Round 1 the cohort was identified similarly but across a six-month period from 1 August 2009 to 31 January 2010.

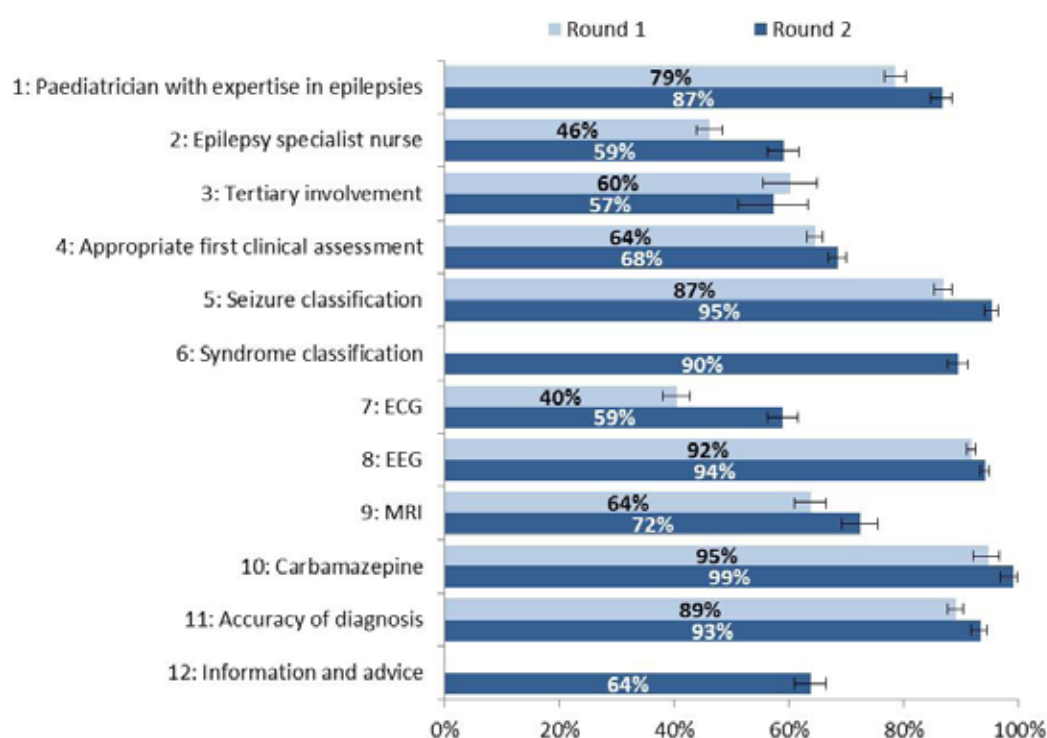
The performance indicators were derived from guidance from the National Institute for Health and Care Excellence (NICE) 'The epilepsies: the diagnosis and management of the epilepsies in children and young people in primary and secondary care' (2012)<sup>2</sup> and the Scottish Intercollegiate Guidelines Network (SIGN) 'Diagnosis and management of epilepsies in children and young people' (2005)<sup>3</sup>.

### Clinical audit cohort key findings

Key finding 8	The patient cohorts from Rounds 1 and 2 had very similar characteristics in terms of the setting of the first paediatric assessment, gender, age and evidence of the presence of a neurodisability.	Tables 5,6 and 7, pages 27 and 28	
Key finding 9	A similar percentage of children and young people within the cohorts had epilepsy diagnosed by 12 months after their first paediatric assessment.	Round 1, 36% Round 2, 35%	

### Clinical audit performance indicator key findings

10 of the 12 performance indicators were defined identically to those used in Round 1 and were applied to a similarly defined cohort of children in Round 2. Of the 10 clinical performance indicators where longitudinal comparison was possible across rounds, 9 indicators showed a statistically significant improvement across the UK (tertiary involvement being the exception - point 3 on the chart). The 12 performance indicators results for both rounds are summarised in the chart below:



Key finding 10	<p>In both rounds there were higher numbers of diagnoses of uncertain episodes at the first paediatric assessment compared to one year later. Whilst there were higher levels of uncertainty at the time of the first paediatric assessment in Round 2 compared to Round 1, these dropped to lower levels of uncertainty in Round 2 compared to Round 1 at one year.</p> <p>This is likely to represent an improvement in paediatricians avoiding premature diagnosis at initial assessment whilst improving certainty by one year.</p>	Figure 4, page 29	
Key finding 11	More children and young people received input from a 'paediatrician with expertise in epilepsies'.	Round 1, 79% (1395/1775) Round 2, 87% (1053/1215)	
Key finding 12	Many more children with epilepsies had evidence of referral to, or input from, a children's ESN.	Round 1, 46% (819/1775) Round 2, 59% (717/1215)	
Key finding 13	There has been a slight improvement in the percentage of children and young people undergoing an appropriate first paediatric assessment.	Round 1, 65% (3189/4945) Round 2, 68% (2361/3449)	
Key finding 14	More children and young people with epilepsy had seizure classification at 12 months.	Round 1, 87% (1544/1775) Round 2, 95% (1158/1215)	
Key Finding 15	Many more children and young people with convulsive seizures had 12 lead ECG obtained by one year post assessment.	Round 1, 40% (704/1745) Round 2, 59% (760/1291)	
Key finding 16	Almost no children or young people had Carbamazepine inappropriately prescribed in Round 2.	Round 1, 5% (21/403) Round 2, 1% (2/228)	
Key finding 17	There has been a clear reduction in withdrawal of diagnosis. In other words, there are fewer children and young people where a diagnosis of epilepsy appears to have been made and then removed.	Round 1, 11% (219/1994) Round 2, 7% (86/1286)	
Key finding 18	There remains a significant number of children and young people who did not receive input from tertiary care despite these children meeting the defined referral criteria.	Round 1, 60% (245/407) Round 2, 57% (145/253)	
Key finding 19	Although there is evidence of some improvement, there remain a significant number of children and young people with defined indications for an MRI who did not have MRI.	Round 1, 64% (716/1124) Round 2, 72% (544/751)	
Key finding 20	There was a clear improvement in females >12 years old given epilepsy medication with evidence of discussion regarding pregnancy or contraception.	Round 1, 38% (56/148) Round 2 54% (52/97)	

Key finding 21	Most children and young people with epilepsy had evidence of consideration of an epilepsy syndrome diagnosis or used terms describing the type of epilepsy.	Round 2, 90% (1088/1215) (longitudinal comparison not possible)	
Key finding 22	Over a third of children and young people with epilepsy had no documentation regarding discussion of safety around water, whether that be relating to swimming or bathing.	Round 2, 64% (774/1215) (longitudinal comparison not possible)	

### Patient Reported Experience Measures (PREMs) key findings

The **PREMs domain** questionnaire was extended in Round 2 to allow participation from all children and young people with epilepsy attending a paediatric outpatient service rather than just those newly presenting.

For Round 2 children and young people with epilepsy, and their parents and carers, were invited to complete a questionnaire on their experiences of the care that they have received from their local epilepsy service over the preceding 12-month period.

Audit units were asked to distribute the PREM questionnaires sequentially to all children or young people with epilepsy attending a range of paediatric clinics during the study period. This approach resulted in a substantial increase in the number of PREM respondents compared to Round 1 and represents possibly the largest ever user survey of paediatric patients with epilepsy and their parents/carers.

2,335 of the PREM questionnaires (from 145 separate Epilepsy12 units) in total were completed and returned anonymously in a sealed envelope to the project team, either by the unit or directly from the child, young person, parent or carer.

Key finding 23	Most of the respondents stated that they were satisfied with the care they receive from the epilepsy service.	Round 2, 88% (1897/2148)	
Key finding 24	A fifth of parents/carers think that staff are not good at working together.	Round 2, 20%, (264/1337)	
Key finding 25	A quarter of respondents did not think that staff were good at letting them know if an appointment was going to be late.	Round 2, 25% (503/1983)	
Key finding 26	There were differences in perspectives between the children/young people and parents/carers.  About two thirds of children and young people felt that the waiting area did not have activities that were appropriate for their age compared to about a quarter of parents/carers. A fifth of children and young people felt that information was hard to understand compared to about a tenth of parents/carers.	See table 24 on page 59	

## Key recommendations

Although there have been significant improvements in UK-level results there remains a continuing gap in many areas between recommended practice and what is actually being delivered. Furthermore, there is still substantial variation between units in both service provision and the delivery of many aspects of care.

Some units have been defined within their individual reports as outliers for a particular indicator. However, most units will require improvements in some areas and should be aiming to approach 100% for all indicators. Some of these shortfalls in care are likely to be due to the lack of availability of resources within that local service, whereas other differences in care will reflect the expertise or care delivered by the professionals. Standards have not been set within this audit; an ongoing study was commenced to agree appropriate standards for services using a Delphi Process and work regarding this is ongoing.

This report makes a series of recommendations to help address the issues identified within the results of the audit.

### Key recommendations by performance indicators

The Epilepsy12 Project Board believes that everyone should read the full list of recommendations but has also indicated where it feels that recommendations apply specifically to the certain areas of responsibility for the following key individuals or organisations:

- Commissioners (C)
- Healthcare Professionals (HP)
- Health Board/Trust managers (M)

Key recommendation number	Performance indicator and recommendation(s)	Aimed at one or more of: C, HP, M*		
1	<b>Paediatrician with expertise in epilepsies</b> About a half of services now appear to achieve input from a 'paediatrician with expertise' for all children and young people with epilepsy.			
	1a) All services managing children with epilepsies should ensure that they include at least one defined consultant paediatrician with 'expertise in epilepsies'.	C		M
	1b) A consultant should be formally defined as the service's epilepsy lead.		HP	M
	1c) Services should review consultant training, job planning and new appointments in order to achieve and maintain these roles and competences.		HP	M
	1d) Services where involvement of 'paediatricians with expertise' in children with epilepsy is low should review care pathways to ensure that each child and young person with epilepsy has prompt input from a 'paediatrician with expertise'.		HP	M

\* C = Commissioners; HP = Healthcare Professionals; M = Health Board/Trust managers

Key recommendation number	Performance indicator and recommendation(s)	Aimed at one or more of: C, HP, M*		
2	<b>Epilepsy Specialist Nurse (ESN)</b> Although there is evidence of improved numbers of, and access to, ESNs, there are still many units that do not have an ESN and even when they do, not all children and young people with epilepsy benefit from their input.			
	2a) Approximately a third of services do not have a Children's Epilepsy Specialist Nurse and these services should urgently create a new post as an integral part of patient care.	C		M
	2b) Some services will require more ESNs in order to ensure all children with epilepsy have adequate provision.	C		M
	2c) Units where many children with epilepsy are not having input from their ESN should improve their care pathways and referral strategies <sup>8</sup> .		HP	
3	<b>Tertiary involvement</b> Over half of units have shortfalls in referral rates to paediatric neurologists.			
	3) Access to, and availability of, paediatric neurologists needs to be addressed at both a local and regional level.	C		M
4	<b>Appropriate first clinical assessment</b> Many services have low levels of appropriate first clinical assessments.			
	4) Units 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.		HP	
	Particular efforts should be made to ensure timely and ongoing assessments of developmental, educational, emotional and behavioural problems for all children and young people with epilepsies.			
5 & 6	<b>Seizure and Syndrome classification</b>			
	5) Rates of appropriate multi-axial epilepsy classification should be improved in services where there is evidence of lower performance.		HP	
	6) 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.		HP	
7	<b>ECG</b> Most services should improve rates of appropriate 12 lead ECG in children and young people with convulsive seizures.			
	7) Training, local guidelines and care pathways should be improved to ensure all children and young people with a convulsive seizure have a 12 lead ECG with documentation to show that it has been reviewed.		HP	
8	<b>EEG</b> About a half of services are requesting some EEGs inappropriately.			

\* C = Commissioners; HP = Healthcare Professionals; M = Health Board/Trust managers

Key recommendation number	Performance indicator and recommendation(s)	Aimed at one or more of: C, HP, M*		
8 (continued)	8a) Where services are requesting EEG investigation in children and young people with non-epileptic events the reasons behind this should be explored and rectified.		HP	
	8b) EEG services should develop strategies with their referring colleagues to reduce levels of inappropriate EEG referrals.			M
9	<b>MRI</b> Many services have children and young people who are not having MRI where indicated.			
	9) Indications for MRI in children and young people with epilepsies should be reviewed and neuroimaging rates improved. If necessary, the availability of MRI should be improved.	HP		M
10	<b>Carbamazepine</b> This measure can be seen as a marker related to wider prescribing practice. Almost all services are scoring 100%.			
	10a) Services where there is evidence of Carbamazepine prescription in children and young people with contraindications should ensure that the reasons behind this are identified.		HP	
	10b) Where Carbamazepine is prescribed despite contraindications a wider examination of care should be considered. Incident reporting may be considered as a way of examining factors within individual cases where this occurs.		HP	M
11	<b>Accuracy of diagnosis</b> Withdrawal of epilepsy diagnosis is occurring in about a third of services.			
	11a) These services should investigate and respond to the reasons behind this. This is particularly the case where regular anti-epileptic medication has been initially prescribed as part of a 'trial of treatment' or where misdiagnosis is occurring.		HP	M
	11b) Care pathways ensuring input from a 'paediatrician with expertise' should be established.			M
12	<b>Information and advice</b> Water and bathing safety is just one of the risks for children and young people with epilepsies.			
	12a) Services should ensure that they have expertise and written material available to explain and discuss all relevant individual risks as part of initial and ongoing epilepsy care.		HP	
	12b) Services should ensure that risk management is accessible, communicated, individualised, documented, understood and reviewed.		HP	
	12c) All children and young people with epilepsies should have access to Epilepsy Specialist Nurses who have a key role in risk assessment and providing education and information to the person with epilepsy and their parent/carer.	C		M

\* C = Commissioners; HP = Healthcare Professionals; M = Health Board/Trust managers



**Key recommendations by PREMs**

All units should examine their local PREM data and develop local action plans tailored to improve the ongoing experience of parents, carers, children and young people. Many of these recommendations will apply to paediatric services in general for children and young people with other health problems and long-term conditions.

Key recommendation number	Patient Reported Experience Measures (PREMs) Recommendation(s)	Aimed at one or more of: C, HP, M*		
13	13) Services should review how their team works together with GPs, nurseries, schools and residential care settings. An Epilepsy Specialist Nurse is essential in order to support multi-agency working and appropriate care planning.	C	HP	M
14	14a) Services should encourage the participation of children, young people, parents and carers in the design of services and the review of information resources.		HP	M
	14b) Services should review the information they provide from a child and young person's perspective and take steps to improve ease of understanding.		HP	
	14c) Services should consider the activities available in waiting areas from the child and young person's perspective and ensure suitable age related activities.		HP	M
15	15) Services should review their processes for ensuring that patients are kept informed about appointment timings.		HP	M

\* C = Commissioners; HP = Healthcare Professionals; M = Health Board/Trust managers

**Key recommendations for further data analysis and continuation of Epilepsy12 audit**

Key recommendation 16	16) The results show for the first time data regarding seizure freedom rates by 12 months in different groups of children with epilepsy. This data should be analysed and validated further to explore whether pragmatic and meaningful clinical outcome measures can be developed for defined groups of children with epilepsy.
Key recommendation 17	17) Further analysis of Epilepsy12 data should be undertaken to understand which service configurations and components are associated with better performance indicators, patient experience and clinical outcomes.
Key recommendation 18	18) Analysis of Epilepsy12 data should be undertaken to understand the ongoing action plans of audit units and which interventions are associated with demonstrable improvement.
Key recommendation 19	19a) PREM data should be analysed further to explore themes amongst families open responses and also to examine particular subgroups relating to age bands and epilepsy type. 19b) Validation of the PREM questionnaire should be completed.
Key recommendation 20	20) Further rounds of Epilepsy12 should be undertaken to provide ongoing audit and quality improvement support for paediatric services throughout the UK.

## **Conclusion**

Epilepsies are amongst the most common significant long-term health conditions of childhood and pose significant challenges for the National Health Service. The Epilepsy12 audit has demonstrated significant improvement in care during its first five years.

As well as local action planning the audit has been undertaken alongside other important supporting national initiatives. These include the:

- introduction of the Epilepsy Best Practice Tariff in England and Wales<sup>5</sup>
- ongoing development of the British Paediatric Neurology Association (BPNA) Paediatric Epilepsy Training (PET) courses<sup>6</sup>
- recently updated NICE Epilepsy Guidance (2012)<sup>2</sup> and NICE Quality Standards (2013)<sup>4</sup>
- implementation of the RCPCH Framework of Competencies for a Special Interest Module in Paediatric Epilepsies (2014)<sup>7</sup>

It is reasonable given the results to conclude that Epilepsy12 and these other initiatives have contributed to these improvements in care. Epilepsy12 should continue to support ongoing action planning and evidence further improvements in care.

The high levels of engagement across the UK and the improvements identified through the audit demonstrate the continuing focus, dedication and commitment of volunteers, professionals, parents, carers, children and young people to improve the care, outcomes and outlook for all those living with seizures and epilepsies.

# 1. Background

The National Report of Round 1 of Epilepsy12 was published in September 2012<sup>1</sup>. Audit units were requested to complete action plans regarding their results for Round 1 as provided in their site-specific reports. 135/197 units submitted action plans. A thematic analysis of action plans demonstrated the following top five areas for improvement: access to a paediatrician with expertise; first clinical assessment; epilepsy classification; use of ECG; and access to specialist nurses.

A two-year extension was commissioned by the Healthcare Quality Improvement Partnership (HQIP) and Healthcare Improvement Scotland (HIS) to support re-audit, develop and improve the Epilepsy12 methodology and evidence and support further quality improvement. Round 2 commenced in October 2012 with the continued existing audit structures including the Project Board, Methodology Working Group and key stakeholders. The British Academy of Childhood Disability joined as an additional partner within the Project Board. The Round 2 methodology<sup>9</sup> was developed and agreed and, wherever possible, was kept identical to Round 1 in order to facilitate longitudinal analysis. Feedback and learning from Round 1 informed the following methodological changes:

- EEG services and audit units were able to ascertain their cohort prospectively if wished.
- A new performance indicator regarding water safety was introduced. This aimed to examine communication and management of risk and safety within a larger cohort than had been achieved with the pregnancy and contraception performance indicator used in Round 1.
- Performance indicator 6 was modified to allow syndromal category identifiers in order to permit as reasonable an attempt at epilepsy diagnosis where a specific electroclinical syndrome had not been identified.
- The Patient Reported Experience Measure (PREM) Domain methodology was extensively revised. This was influenced by the fact that in Round 1 the number of participants within the PREM domain was small and there was a low response rate, which, whilst producing useful information at UK level, did not allow for reporting at audit unit level.

In 2012 the National Institute for Health and Care Excellence (NICE) published updated Epilepsy Guidance<sup>2</sup>. The new recommendations did not necessitate any change in the Epilepsy12 performance indicators. NICE Quality Standards for Epilepsy were published February 2013<sup>4</sup>. These standards were informed by the Epilepsy12 results and experience and it was acknowledged that Epilepsy12 could provide a framework to support the future acquisition of these future Quality Standards for commissioners and providers. In April 2013, the Department of Health introduced an Epilepsy Best Practice Tariff for the follow up of children with epilepsies in England and Wales<sup>5</sup>. As well as fulfilling defined service criteria, units need to demonstrate that specific standards are met within each outpatient review and also be an active participant in the Epilepsy12 national audit.

The British Paediatric Neurology Association (BPNA) has had a lead role in championing and managing these and other national initiatives designed to improve care and outcomes for children with epilepsies<sup>6</sup>. Round 2 of Epilepsy12 provided an opportunity to support these ongoing activities but also captured metrics that for the first time might objectively demonstrate improvements in care.

## 2. Method

The Epilepsy12 Round 2 full methodology document can be found at:  
[www.rcpch.ac.uk/epilepsy12/methodology](http://www.rcpch.ac.uk/epilepsy12/methodology)

### 2.1 Audit domains

The Epilepsy12 audit is comprised of three domains:

1. **Service descriptor:** Units described their paediatric epilepsy service as at 1 January 2014.
2. **Clinical audit:** a retrospective case note analysis for all children having their first paediatric assessment for afebrile paroxysmal episode(s) between 1 January and 30 April 2013.
3. **Patient Reported Experience Measure (PREM):** Parents, carers and young people with epilepsy were invited to complete a questionnaire on their experiences of the care that they have received from their local epilepsy service over a 12-month period.

### 2.2 Recruitment

The audit covered England, Northern Ireland, Scotland and Wales. 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. During Round 1, the UK was split into pragmatic regions and 'audit units'. Each 'audit unit' had defined: Consultant Paediatricians (one of whom acting as the audit unit lead); NHS Health Boards, Trusts; Hospitals; Community Paediatric services and EEG services. Audit units invited to participate in Round 1 were also invited to participate in Round 2.

### 2.3 Data collection

Following registration for Round 2 in 2012, audit unit leads were sent an Epilepsy12 audit pack. Audit unit leads were asked to complete the service questionnaire (Domain 1) regarding their service on the defined census day of 1 January 2014. Census days also determined the various dates that identified the target cohort for the audit unit. For the clinical audit (Domain 2), all unit leads were sent reports from their EEG department(s) listing all children referred for EEG over a defined 10-month period from 1 January to 31 October 2014. Unit leads were asked to then apply the inclusion/exclusion criteria to determine those children from the EEG list who should be entered into the audit web tool. Inclusion dates were chosen such that each child entered into the audit would have completed 12 months of care after their first paediatric assessment during the data entry period. Data was 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 March 2013 to June 2014. For the Patient Reported Experience Measure (PREM) element (Domain 3) all units were sent a PREM Live pack in January 2014 containing instructions for audit unit teams, patient information leaflets, posters, PREM patient questionnaires and freepost return envelopes.

### 2.4 Performance indicators

The Epilepsy12 Clinical Audit domain applied 12 broad measures of quality derived from guidance from NICE 'The epilepsies: the diagnosis and management of the epilepsies in children and young

people in primary and secondary care' (2012)<sup>2</sup> and SIGN 'Diagnosis and management of epilepsies in children and young people' (2005)<sup>3</sup>. Each performance indicator was derived from specific NICE and SIGN recommendations and designed to be applicable in the context of retrospective case note analysis. In Round 2 performance indicator 6 was changed to also capture those epilepsy diagnoses where a syndrome category was identified even if an individual electroclinical syndrome was not documented. Performance indicator 12 was changed to a wider communication issue regarding water safety due to the low denominator numbers in Round 1 where pregnancy and contraception communication issues were in a subgroup of females >12 years on epilepsy treatment.

Figure 1 below summarises the 12 performance indicators. The glossary at Appendix 1 contains further definitions of terms used (highlighted in bold) in this report. Appendix 6 details the precise definitions of the numerator and denominator groups and the calculations that were applied to the performance indicators.

**Figure 1: Epilepsy12 performance indicators**

Professionals	<b>1</b>	<b>Paediatrician with expertise in epilepsies</b>	Percentage of children diagnosed with epilepsy, with input by a ' <b>consultant paediatrician with expertise in epilepsies</b> ' by one year
	<b>2</b>	<b>Epilepsy Specialist Nurse</b>	Percentage of children diagnosed with epilepsy, referred for input by an <b>epilepsy specialist nurse</b> by one year
	<b>3</b>	<b>Tertiary involvement</b>	Percentage of children with epilepsy meeting defined criteria for <b>paediatric neurology</b> referral, with input of tertiary care by one year
Assessment & Classification	<b>4</b>	<b>Appropriate first clinical assessment</b>	Percentage of all children, with evidence of <b>appropriate first paediatric clinical assessment</b>
	<b>5</b>	<b>Seizure classification</b>	Percentage of children diagnosed with epilepsy, with <b>seizure classification</b> by one year
	<b>6</b>	<b>Epilepsy classification</b>	Percentage of children diagnosed with epilepsy, with <b>epilepsy syndrome or Syndrome Category</b> by one year
Investigation	<b>7</b>	<b>ECG</b>	Percentage of children with convulsive seizures, with an <b>ECG</b> by one year
	<b>8</b>	<b>EEG</b>	Percentage of children who had an <b>EEG</b> in whom there were no defined contraindications
	<b>9</b>	<b>MRI</b>	Percentage of children diagnosed with epilepsy with defined indications for an <b>MRI</b> , who had MRI by one year
Management & Outcome	<b>10</b>	<b>Carbamazepine</b>	Percentage of children diagnosed with epilepsy given <b>Carbamazepine</b> , in whom there were no defined contraindications
	<b>11</b>	<b>Accuracy of diagnosis</b>	Percentage of children diagnosed with epilepsy, who still had that <b>diagnosis</b> at one year
	<b>12</b>	<b>Information &amp; advice</b>	Percentage of children diagnosed with epilepsy with evidence of <b>communication regarding water safety</b>

**As in Round 1 targets were not set for Round 2 of this audit.** It is accepted that for some performance indicators the optimum score may not be 100%. However, most performance indicators are defined so that scores should approach 100% and a higher percentage value is considered to be a better outcome. Performance indicator 6 (syndrome classification) is an exception as a proportion of children with epilepsy do not 'fit' into a defined electroclinical syndrome and may not have syndrome category identifiers appropriately applied.

## **2.5 Data quality and analysis**

The data collection system included validation rules to ensure that appropriate and internally consistent data was provided by the participating units. This meant that the overall data quality standard was high. Six records were removed from the dataset as the first paediatric assessment had taken place when the child was less than one month old or an implausible age at first paediatric assessment was recorded. Audit units were able to view provisional data and provide corrected data where appropriate.

The Epilepsy12 indicators are reported with 95% confidence intervals. The Wilson score method has been used to calculate confidence intervals. The confidence intervals can be used to assess whether there has been a statistically significant change in between Round 1 and Round 2 or between countries. If the 95% confidence intervals do not overlap the difference is statistically significant. Individual Audit Units are identified as a positive outlier (statistically significantly higher than the UK value) if the unit's upper 95% confidence interval is below the lower confidence interval for the UK. This is equivalent to being approximately two standard deviations above the UK value. Units are identified as a negative outlier (statistically significantly lower than the UK value) if the unit's lower 95% confidence interval is above the upper confidence interval for the UK. This is equivalent to being approximately two standard deviations below the UK value.

## **2.6 Patient Reported Experience Measure (PREM)**

All participating audit unit leads were sent a PREM Live pack in January 2014. The pack contained PREM instructions, 50 copies of the PREM questionnaire, patient information and return freepost envelopes. Audit unit leads were requested to facilitate the distribution of questionnaires to at least 25 sequential children and young people with epilepsy attending all secondary level paediatric clinics within that audit unit from 1 February 2014 through to 31 March 2014.

Units were instructed to ask the parent/carers and patient to complete the questionnaire prior to their clinical review. Part B of the questionnaire was to be completed by the young person with epilepsy or, if that were not possible, by the parent/carers. Within the questionnaire participants were requested to comment on their past 12 months of care only. After completion the questionnaire could either be returned anonymously within a supplied freepost envelope to the audit unit at the clinic itself or returned directly to the RCPCH using the same envelope. The questionnaires were collated by the central project team at the RCPCH and scanned to capture the data including any free text. The anonymity of the people completing the questionnaires was maintained throughout with questionnaires being attributed to a particular unit by an identifying unit code.

### 3. National results

#### 3.1 Participation and case ascertainment

The 197 'Epilepsy12 audit units' that had been invited to participate in Round 1 were invited to participate again in Epilepsy12 Round 2. 192 of the 197 units invited to participate registered for Round 2. Four of the 197 did not register and the remaining unit was incorporated into one of the other units taking part in Round 2. Details of unit participation can be viewed at Appendix 2.

- 186 out of 192 (97%) units that registered entered complete Service Descriptor data.
- 174 out of 192 (91%) units provided data on one or more children for the Clinical Audit.
- 2335 completed PREM questionnaires were received from across 145 units.

**Table 1a: Participation in Round 1 of Epilepsy12**

	UK	England	Wales	Scotland	Northern Ireland
Number of registered units	197	161	15	15	6
Number of units that submitted Service Descriptor data	193 (98%)	159 (99%)	13 (87%)	15 (100%)	6 (100%)
Number of units that submitted Clinical data	186 (94%)	152 (94%)	13 (87%)	15 (100%)	6 (100%)
Clinical audit – number of eligible children entered into the audit	4945	4085	225	471	164

**Table 1b: Participation in Round 2 of Epilepsy12**

	UK	England	Wales	Scotland	Northern Ireland
Number of registered units	192	158	14	15	5
Number of units that submitted Service Descriptor data	186	154	14	14	4
Number of units that submitted Clinical data	174	143	14	13	4
Clinical audit – number of eligible children entered into the audit	3449	2907	165	313	64

Table 2 overleaf provides details of the number of children assessed as eligible for the audit.

Case ascertainment and data completeness data were missing for 20 units. Across the UK 92% of children on lists received from EEG departments were assessed to see if they met the audit criteria. Of those children that did meet the audit criteria, 92% were correctly added to the audit web tool.

**Table 2: Case ascertainment**

	UK	England	Wales	Scotland	Northern Ireland
Children on list received from EEG department	14382	12391	582	1057	352
Children defined as 'excluded' (did not meet audit inclusion criteria)	9529	8479	353	467	230
Children where it was not possible to identify whether they met the audit inclusion criteria	907	787	32	33	55
Children entered into the audit	3449	2907	165	313	64
Children lost through data cleaning	6	6	0	0	0
Children excluded from the audit who moved units and therefore were excluded from the audit	29	28	0	1	0
Children who met the audit criteria but were not successfully entered on web tool	281	261	11	7	2
Case ascertainment	13294/14382 92%	11681/12391 94%	529/582 91%	788/1057 75%	296/352 84%
Data completeness	3449/3736 92%	2907/3174 92%	165/176 94%	313/320 98%	64/66 97%

## 3.2 Service descriptor domain results

### 3.2.1 Staffing and clinic resources

Table 3 overleaf provides a breakdown of staff provision across the audit units for Rounds 1 and 2. In Round 2 there were 325 Whole Time Equivalent (WTE) general paediatric consultants with 'expertise in epilepsy' in the UK and 124.3 WTE Epilepsy Specialist Nurses (ESNs). 68% of units had at least some ESN provision in Round 2. 66% of units have at least one epilepsy clinic per week.

There are 25 more audit units in Round 2 with an ESN. There are a greater number of designated epilepsy clinics. The results suggest a lowering in the total WTE numbers of secondary paediatricians with expertise in epilepsy across the UK (346.7 in Round 1 compared to 325 in Round 2). This may however be related to methodological issues rather than a true reduction. There is likely to be a change in who is understood to be a 'paediatrician with expertise' in Round 2 as efforts were made to clarify that paediatric neurologists should not be counted in this metric.



**Table 3: Staffing and clinic resources, Round 1 and Round 2** (England = E, Northern Ireland = NI, Scotland = S, Wales = W)

	Round 1					Round 2				
	UK n = 193	E n = 159	W n = 13	S n = 15	NI n = 6	UK n = 186	E n = 154	W n = 14	S n = 14	NI n = 4
Total WTE general paediatric consultants or associate specialists (community or hospital based)	2026.9	1701.5	105.9	165.4	54.1	19783.4	1677.1	110.5	153.0	42.8
Total WTE general paediatric consultants with 'expertise in epilepsies'	346.7	288.0	14.9	33.8	10.0	325	285.3	16.9	20.5	2.3
Total WTE paediatric epilepsy specialist nurses (ESN)	100.9	71.4	10.4	12.1	7.0	124.3	96.6	10.0	14.1	3.6
Number of units with an ESN	102 (53%)	75 (47%)	10 (77%)	11 (73%)	6 (100%)	127 (68%)	103 (67%)	12 (86%)	9 (64%)	3 (75%)
Total number of consultant or associate specialist led secondary level 'epilepsy clinics' taking place per week	189.9	157.0	12.3	16.9	3.8	215.8	182.2	9.5	21.3	2.8
Number of units with at least one epilepsy clinic taking place in the audit unit per week	112 (58%)	94 (59%)	7 (54%)	8 (53%)	3 (50%)	122 (66%)	108 (68%)	8 (73%)	5 (42%)	1 (25%)
Median age outpatient adult services accept referrals from GPs (range)	16 (13, 18)	16 (14, 16)	16 (16, 18)	16 (13, 16)	15 (14, 16)	16 (14-18)	16 (14-18)	16 (15-16)	16 (16-18)	15 (14-16)

### 3.2.2 Services provided by audit units

Table 4 below details services provided by units across Rounds 1 and 2. Round 2 results showed that more units (although they are still in the minority) maintain a register or database of all children with epilepsies, host a young person's epilepsy clinic and have transition elements. The majority of clinics (85%) continue to host a paediatric neurology clinic. Although there has been a rise in children's ESNs in Round 2, the number of adult ESNs is almost unchanged.

**Table 4: Services provided by units**

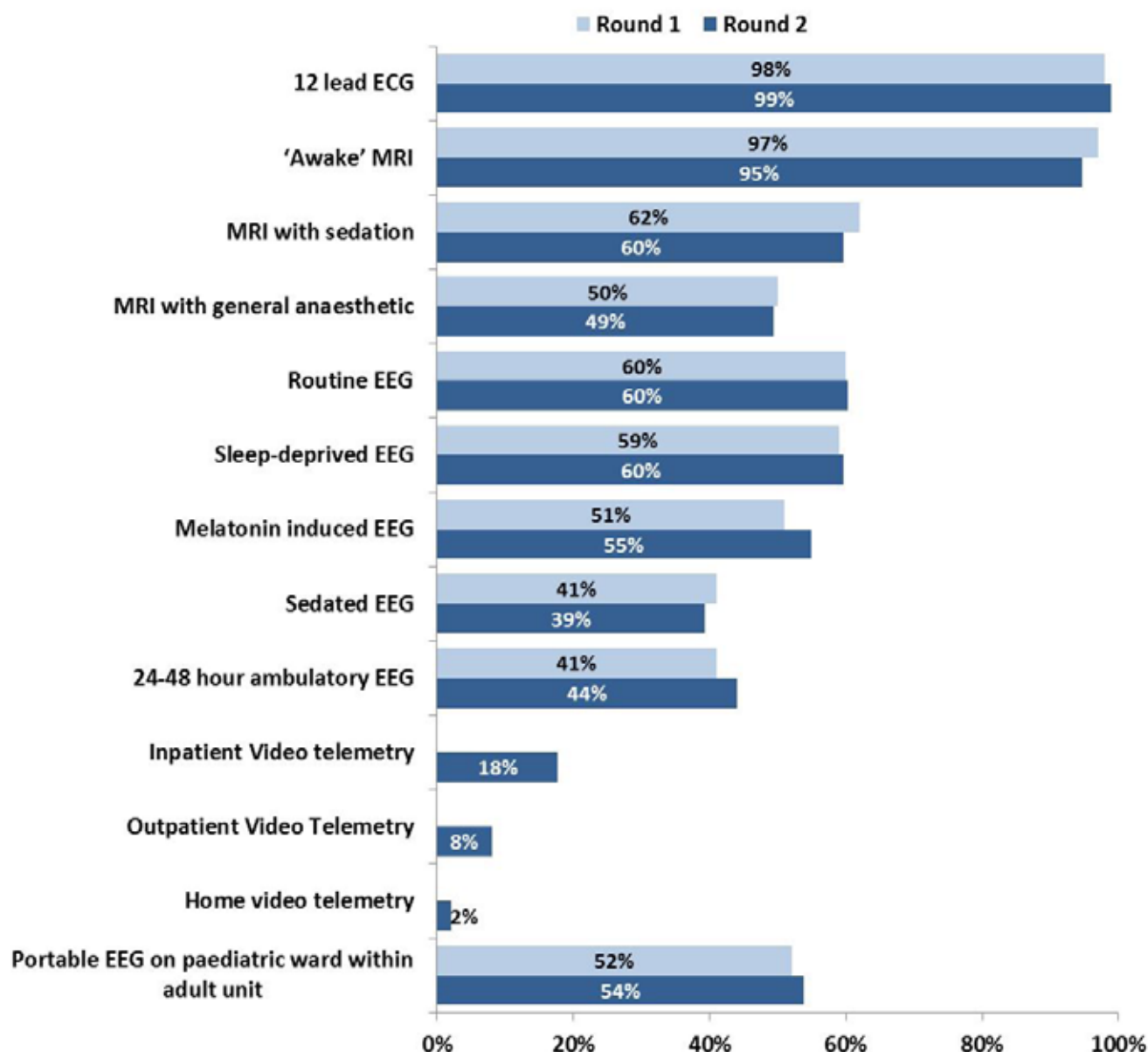
		UK Round 1 N = 193	UK Round 2 N = 186
Maintains database or register of children with epilepsies	Yes, for all children	26 (14%)	34 (18%)
	Yes, for some children	64 (33%)	86 (46%)
	No	103 (53%)	66 (35%)
Unit hosts a paediatric neurology clinic	Yes	164 (85%)	159 (85%)
	No	29 (15%)	27 (15%)
A specific clinic for young people or teenagers with epilepsies	Yes	35 (18%)	49 (26%)
	No	151 (78%)	134 (72%)
	Uncertain	7 (4%)	4 (2%)
Handover clinic	Yes	57 (30%)	71 (38%)
	No	133 (69%)	111 (60%)
	Uncertain	3 (2%)	4 (2%)
Other defined handover or referral process	Yes	108 (56%)	117 (63%)
	No	72 (37%)	56 (30%)
	Uncertain	13 (7%)	13 (7%)
A local adult ESN	Yes	99 (51%)	100 (54%)
	No	69 (36%)	63 (34%)
	Uncertain	25 (13%)	23 (12%)
A youth worker	Yes	14 (7%)	16 (%)
	No	150 (78%)	146 (78%)
	Uncertain	29 (15%)	24 (13%)

### 3.2.3 Investigations available at audit units

Figure 2 overleaf gives details of investigations available at units across Rounds 1 and 2. Investigations were defined as being available if they could be accessed by patients without leaving services within the audit unit.

Nearly all units could provide a 12 lead ECG (99%) and an 'awake' MRI (95%) in Round 2. 60% were able to provide a routine EEG but only 39% could provide a sedated EEG. Overall there has been little change in the availability of investigations between Round 1 and Round 2.

**Figure 2: Investigations available at units**



### 3.3 Clinical audit domain results

#### 3.3.1 Demographics of the children and young people included in the clinical audit

The median age of children included in the Round 2 of the audit was 5.2 years. 25% of the children were infants (aged between one month and two years), 24% were pre-school (two to four years old), 34% were aged between five and 11 years and the remaining 17% were aged between 12 and 15 years at first paediatric assessment. Overall there has been little change in the demographic characteristics of the children included in Round 1 and Round 2 and no clear differences by country.

**Table 5: Demographic characteristics of children included in Rounds 1 and 2 of Epilepsy12**  
(England = E, Northern Ireland = NI, Scotland = S, Wales = W)

	Round 1					Round 2				
	UK	E	W	S	NI	UK	E	W	S	NI
N	4945	4085	225	471	164	3449	2907	165	313	64
% female	46%	46%	49%	44%	52%	45%	45%	44%	44%	53%
Median age (years)	6.3	6.4	7.5	5.6	3.2	5.2	5.3	5.9	4.5	3.3
25th centile (years)	2.1	2.2	3.1	2.2	1.1	2.0	2.0	2.5	1.7	1.9
75th centile (years)	10.8	10.7	12.1	10.8	8.7	12.0	10.2	10.3	8.8	7.0
Infants (1 month to < 2 years)	24%	23%	18%	23%	38%	25%	25%	21%	29%	25%
Pre-school (2 - 4 years)	20%	20%	17%	21%	18%	24%	24%	21%	23%	36%
School (5 - 11 years)	37%	37%	39%	38%	30%	34%	34%	39%	35%	33%
Young people (12 - 15 years)	19%	19%	25%	17%	23%	17%	17%	19%	12%	6%

### 3.3.2 Evidence of neurodisability

Of the 3,449 children included in the audit 779 (22.6%) had evidence of a neurodisability present. This compares to 20% in Round 1 audit. Neurodisabilities and co-morbidities may, and often will, overlap and therefore some of the children in the table overleaf had two or more types of neurodisability present.

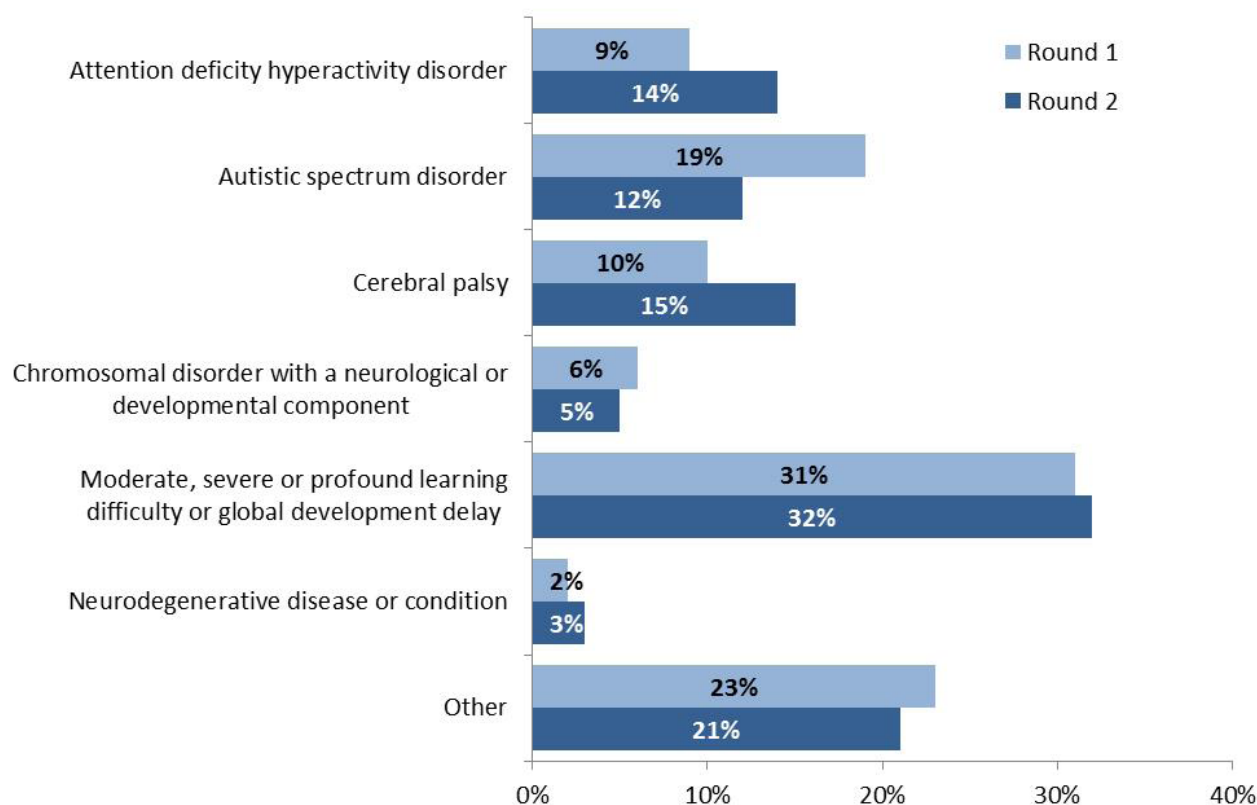
**Table 6: Evidence of neurodisability and types of neurodisability identified**

	UK Round 1	UK Round 2
Evidence of neurodisability present	966/4945 (20%)	779/3449 (23%)
<b>Types of neurodisability present*</b>		
Neurodegenerative disease or condition	15 (2%)	12 (2%)
Moderate, severe or profound learning difficulty or global development delay	298 (31%)	244 (31%)
Chromosomal disorder with a neurological or developmental component	57 (6%)	68 (9%)
Cerebral palsy	100 (10%)	99 (13%)
Autistic spectrum disorder	182 (19%)	283 (36%)
Attention deficit hyperactivity disorder (ADHD)	89 (9%)	82 (10%)
Other	225 (23%)	181 (23%)

*\*Denominator for types of neurodisability is children with documentation of neurodisability present = 966 and 779 for Rounds 1 and 2 respectively*

Figure 3 below provides a breakdown of the types of neurodisability reported. Round 1 and Round 2 results were similar.

**Figure 3: Types of neurodisability identified**



### 3.3.3 Setting of first paediatric assessment

The audit collected data on the setting of the child's first paediatric assessment. In Round 2, 1,553 out of 3,449 (45%) children had their first assessment in an acute setting (inpatient review, paediatric review in emergency department or other clinical assessment in an acute paediatric setting) and 1,897 (55%) had their first review in a paediatric outpatients or clinic (non-acute setting).

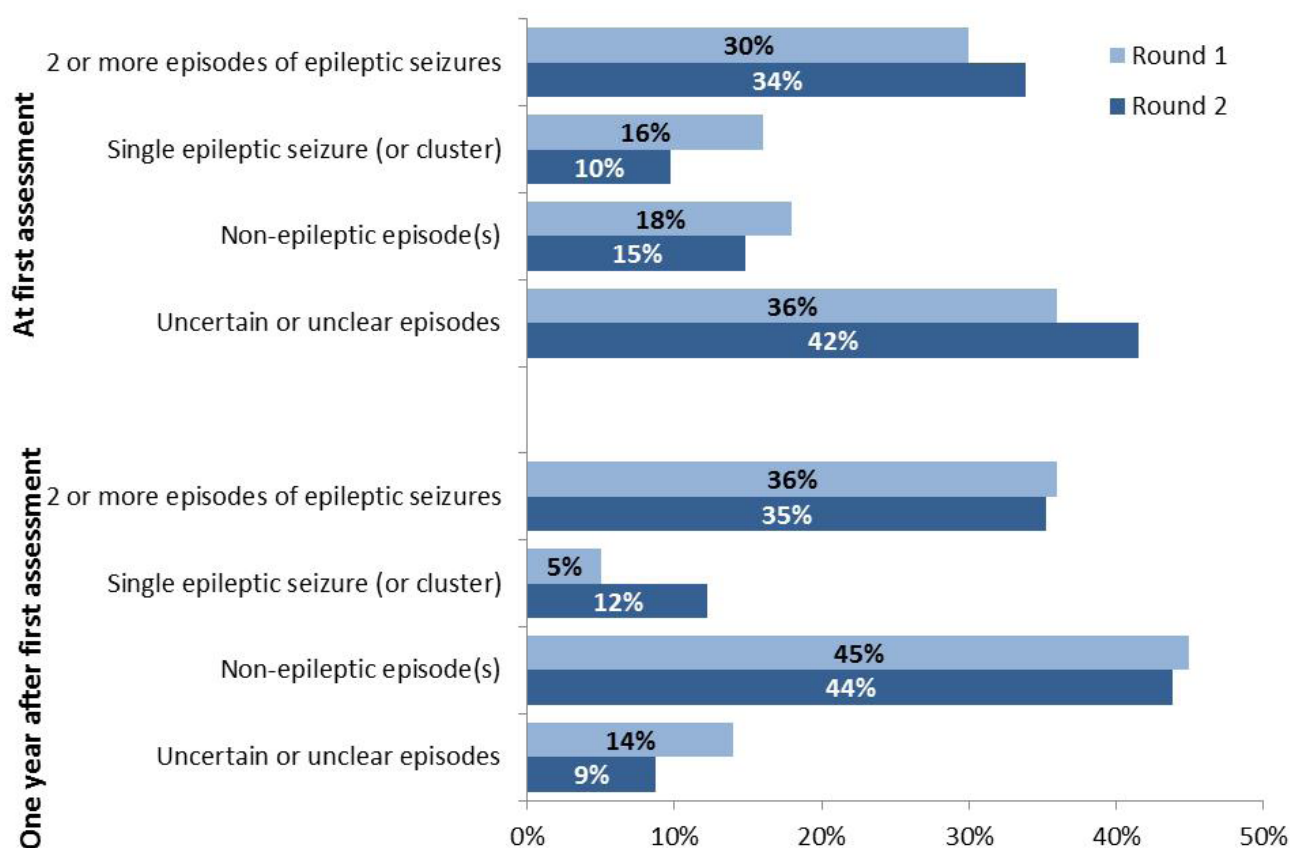
**Table 7: Setting of first paediatric assessment** (England = E, Northern Ireland = NI, Scotland = S, Wales = W)

	Round 1					Round 2				
	UK	E	W	S	NI	UK	E	W	S	NI
<b>Number</b>	4945	4085	225	471	164	3449	2907	165	313	64
<b>Acute</b>	44%	43%	48%	39%	52%	45%	46%	31%	43%	41%
<b>Non-acute</b>	56%	57%	52%	61%	48%	55%	54%	69%	57%	59%
<b>Not stated</b>	<1%	0%	0%	<1%	0%	<1%	1%	0%	<1%	0%

### 3.3.4 Diagnosis

Figure 4 provides details of the diagnosis of children at their first paediatric assessment and 12 months on from that assessment. In Round 2, at 12 months, 35% of children had a diagnosis of two or more episodes or epileptic seizures and 12% had a diagnosis of a single epileptic seizure (or cluster). Compared to Round 1 a greater proportion of children had a diagnosis of a single epileptic seizure (or cluster) at 12 months after first assessment and fewer children had a diagnosis of uncertain or unclear episodes.

**Figure 4: Diagnosis at first assessment and one year after first assessment**



At first assessment (in Round 2) a smaller proportion had diagnosed single epileptic seizure and a greater proportion had 'uncertain or unclear' episodes. In Round 2 there appeared to be less uncertainty by 12 months. This may reflect an appropriate caution in avoiding 'early certainty' and misdiagnosis of epilepsy.

### 3.3.5 Anti-Epileptic Drugs (AEDs)

In Round 2 1,059 children had been commenced on one or more AED whilst 84 had started taking three or more AEDs. The diagnosis of children on AEDs at 12 months is provided in the table overleaf.

**Table 8: Diagnosis and AEDs**

	Round 1		Round 2	
	1 or more AED N=1538	3 or more AEDs N=135	1 or more AED N=1059	3 or more AEDs* N=84
Two or more episodes of epileptic seizures	1406 (91%)	129 (96%)	976 (92%)	82 (98%)
Single epileptic seizure or cluster	68 (4%)	6 (4%)	9 (1%)	0 (0%)
Non-epileptic episode	44 (3%)	0 (0%)	20 (2%)	1 (1%)
Uncertain or unclear episode(s)	20 (1%)	0 (0%)	55 (5%)	1 (1%)

\*Not necessarily at the same time

### 3.3.6 Epilepsy seizure types

Tables 9 and 10 show the seizure type and syndrome type recorded within the medical documentation. It is worth noting that these classifications are not independently confirmed within the audit process. Some children have more than one seizure type. Only most common seizure types appear in table.

**Table 9: Seizure types**

	UK Round 1 N=1775	UK Round 2 N=1215
(Generalised) tonic-clonic seizures	39%	474 (39%)
Absence seizures (including typical or atypical)	31%	361 (30%)
Focal seizures	16%	253 (21%)
Secondarily generalized seizures	6%	111 (9%)
Myoclonic seizures	7%	89 (7%)
Focal motor seizures	5%	91 (7%)
Infantile spasms	3%	47 (4%)
No seizure type stated	6%	46 (4%)
Tonic seizures	4%	38 (3%)

**Table 10: Syndrome category identifiers and syndrome types**

		Round 1 N=1775	Round 2 N=1215
Syndrome category identifiers	Genetic focal/multifocal	<1%	43 (4%)
	Genetic generalised	<1%	27 (2%)
	Idiopathic (or primary) focal/multifocal	5%	339 (28%)
	Idiopathic (or primary) generalised	22%	108 (9%)
	Symptomatic or probably symptomatic focal/multifocal	6%	32 (3%)
	Symptomatic or probably symptomatic generalised	3%	32 (3%)
	Structural/metabolic focal/multifocal	1%	45 (4%)
	Structural/metabolic generalised	<1%	97 (8%)
	Other	62%	598 (49%)

		Round 1 N=1775	Round 2 N=1215
Syndrome types	BECTS (benign rolandic epilepsy)	160 (9%)	95 (8%)
	Other epilepsy syndrome stated	128 (7%)	229 (19%)
	Childhood absence epilepsy (CAE)	65 (4%)	116 (10%)
	Defined as unclassified	54 (3%)	75 (6%)
	Juvenile absence epilepsy	48 (3%)	39 (3%)
	Temporal lobe epilepsy	41 (2%)	37 (3%)
	Frontal lobe epilepsy	32 (2%)	23 (2%)
	Juvenile myoclonic epilepsy (JME)	27 (2%)	39 (3%)
	West syndrome (infantile spasms)	25 (1%)	31 (3%)
	Occipital lobe epilepsy	17 (1%)	9 (1%)
	Doose syndrome	16 (<1%)	16 (1%)
	Panayiotopoulos syndrome	10 (<1%)	11 (1%)
	Dravet syndrome	5 (<1%)	2 (0%)
	Parietal lobe epilepsy	1 (<1%)	0 (0%)
	No epilepsy syndrome stated	941 (53%)	502 (41%)

### 3.4 Performance indicator results

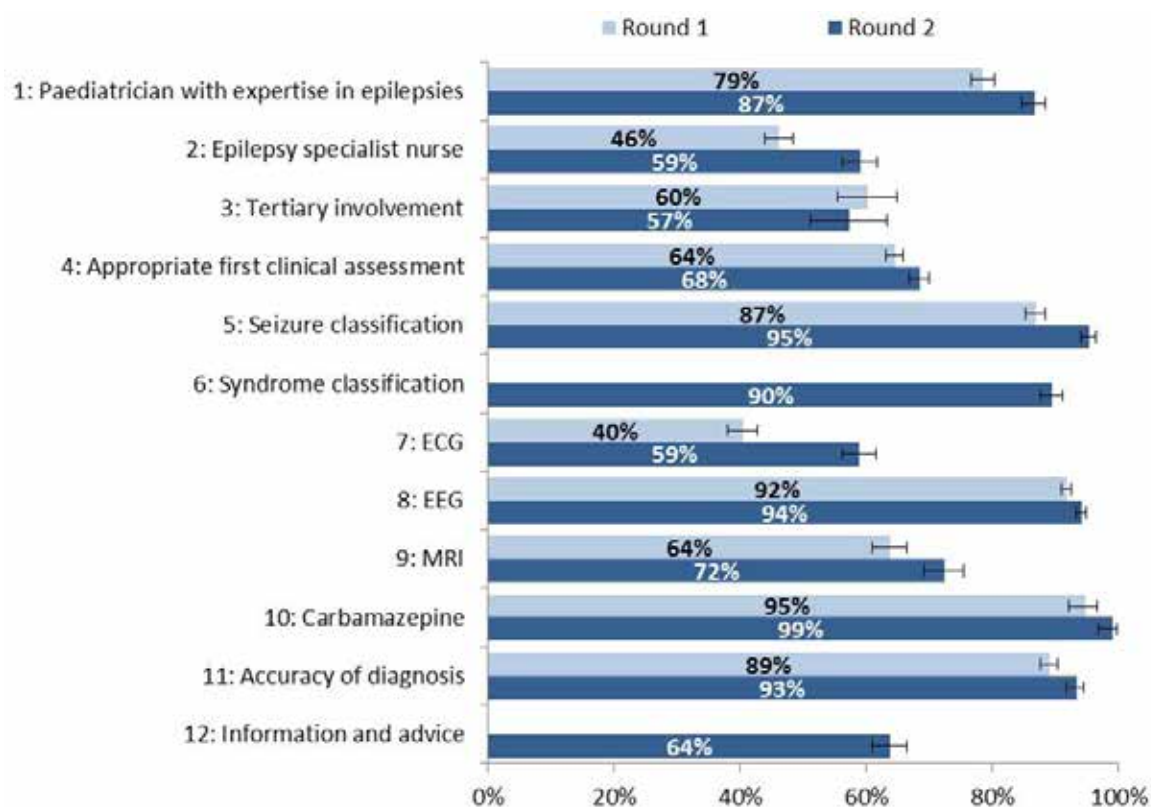
#### 3.4.1 Overview of performance indicator results for UK and by country

Overleaf, figure 5 sets out the performance indicators for Round 1 and Round 2 of Epilepsy12 for the whole of the UK. Figures 6 to 9 provide this information by country.

Between Round 1 and Round 2 there have been significant improvements in the achievement of indicators 1, 2, 4, 5, 7, 8, 9, 10 and 11. There was no significant deterioration in the achievement of any of the indicators although the percentage value for indicator 3 did decrease slightly. Indicators 6 and 12 changed between Rounds 1 and 2 and therefore longitudinal change is not displayed for these indicators.

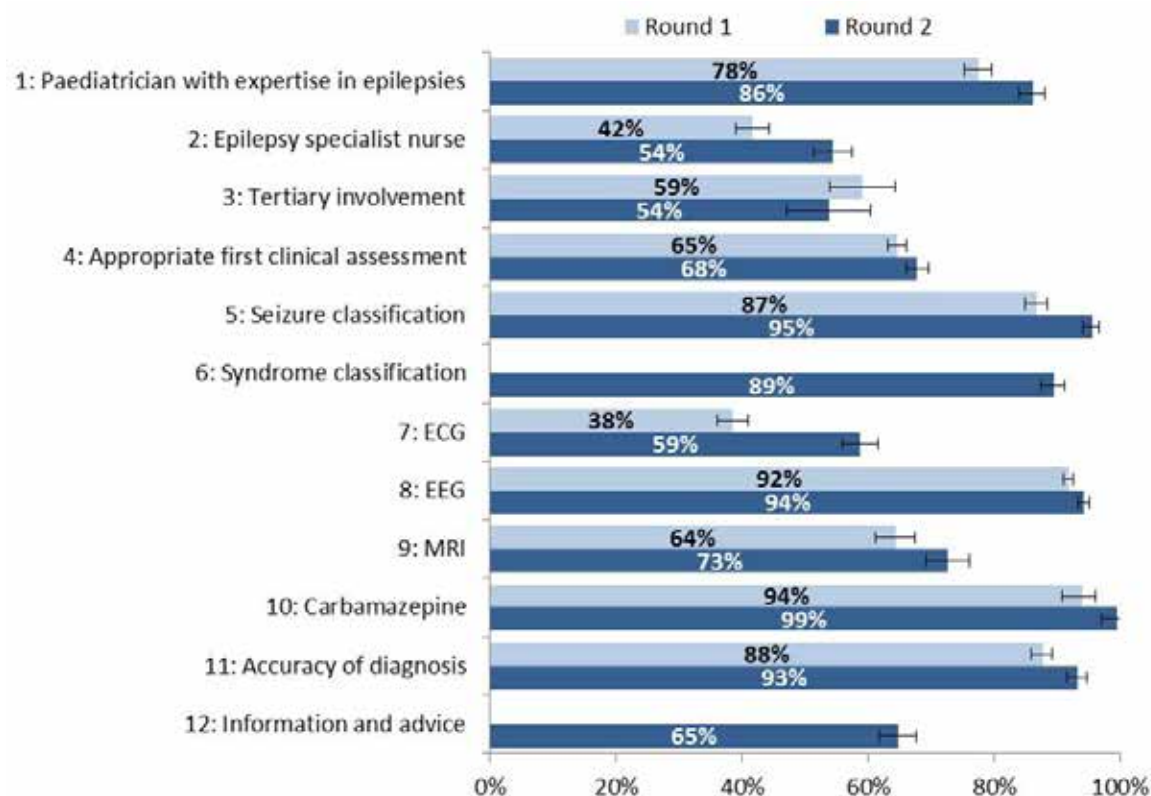


**Figure 5: Epilepsy12 performance indicators for the UK**

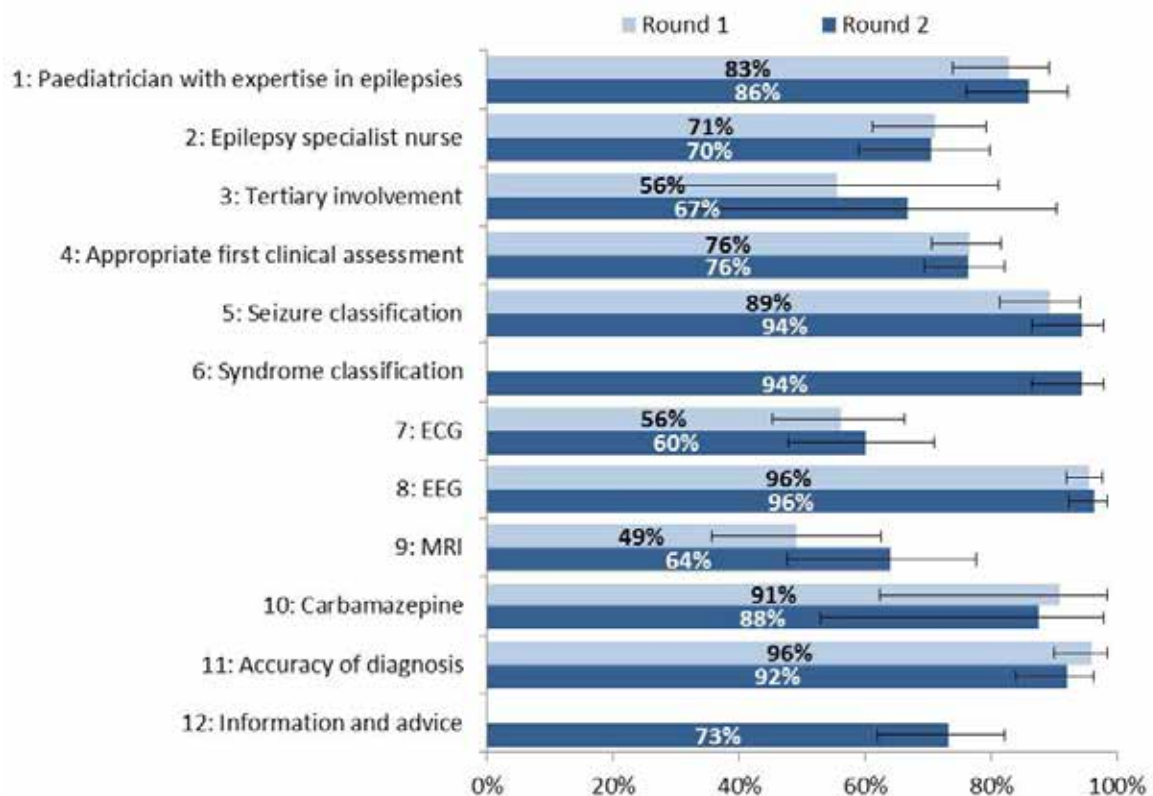


The 'whiskers' on the chart above represent 95% confidence intervals. If these whiskers do not overlap the difference is statistically significant.

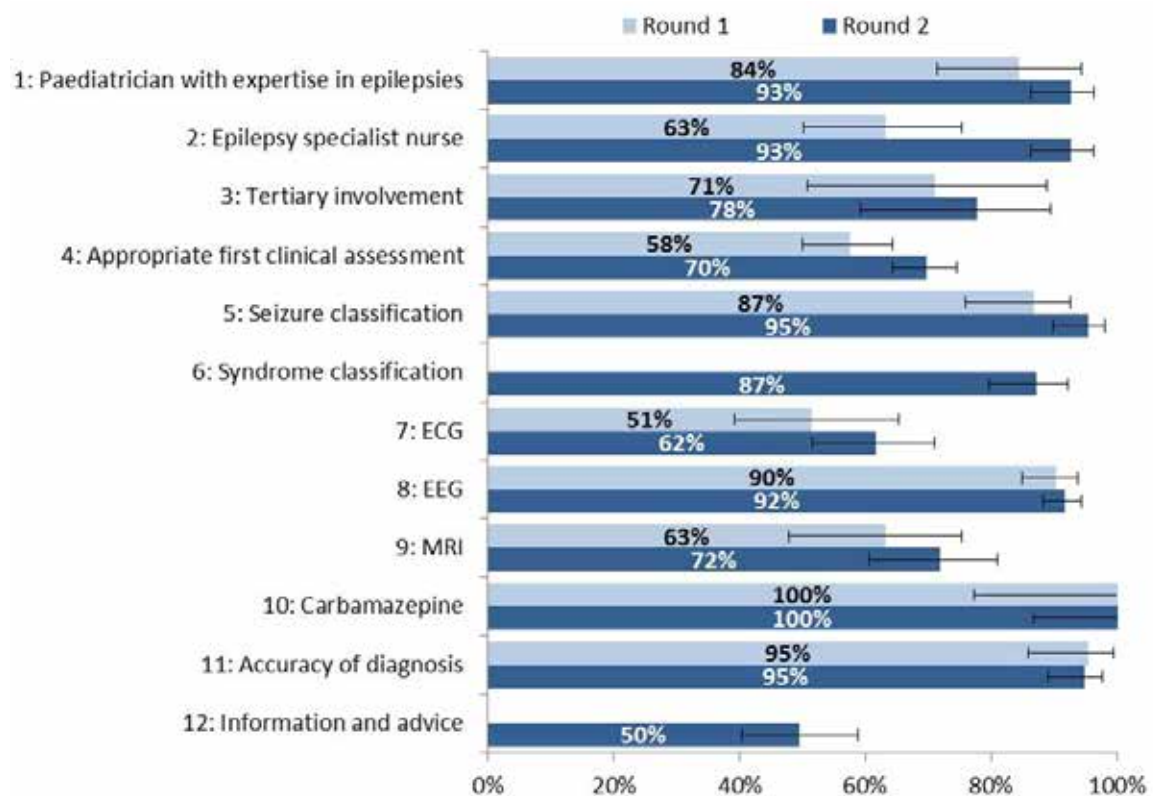
**Figure 6: Epilepsy12 performance indicators for England**



The 'whiskers' on the chart above represent 95% confidence intervals. If these whiskers overlap the difference in the achievement of the indicator is not statistically significant.

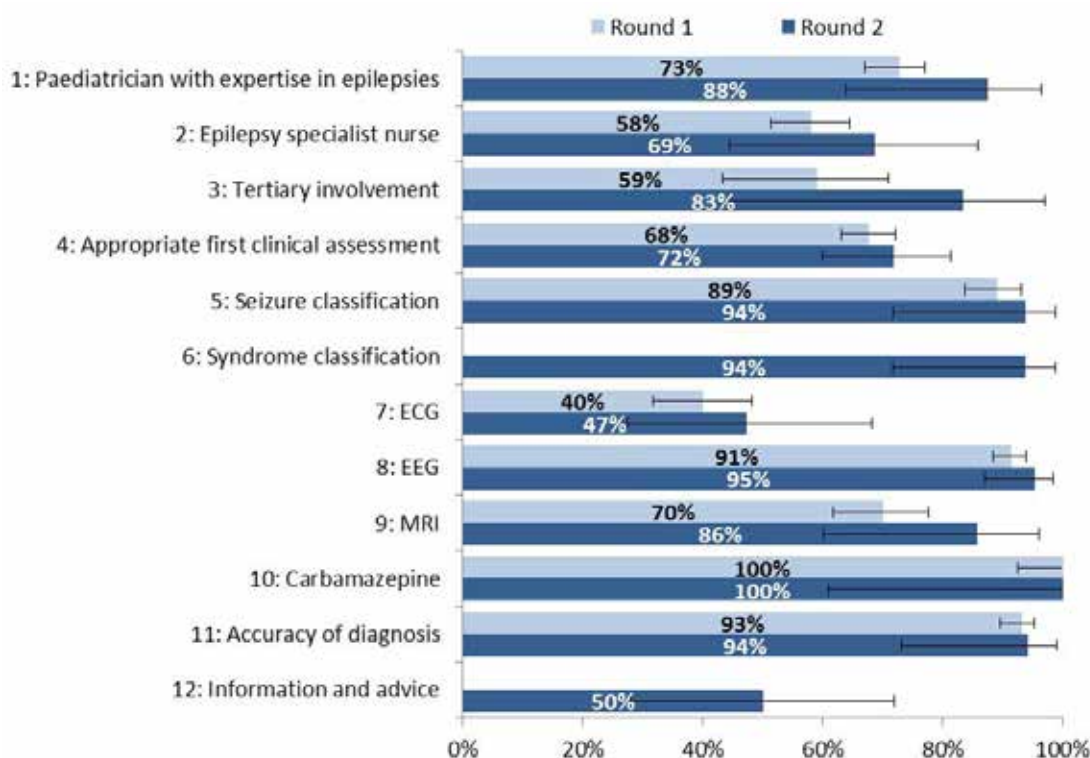
**Figure 7: Epilepsy12 performance indicators for Wales**

The 'whiskers' on the chart above represent 95% confidence intervals. If these whiskers do not overlap the difference is not statistically significant.

**Figure 8: Epilepsy12 performance indicators for Scotland**

The 'whiskers' on the chart above represent 95% confidence intervals. If these whiskers overlap the difference in the achievement of the indicator is not statistically significant.

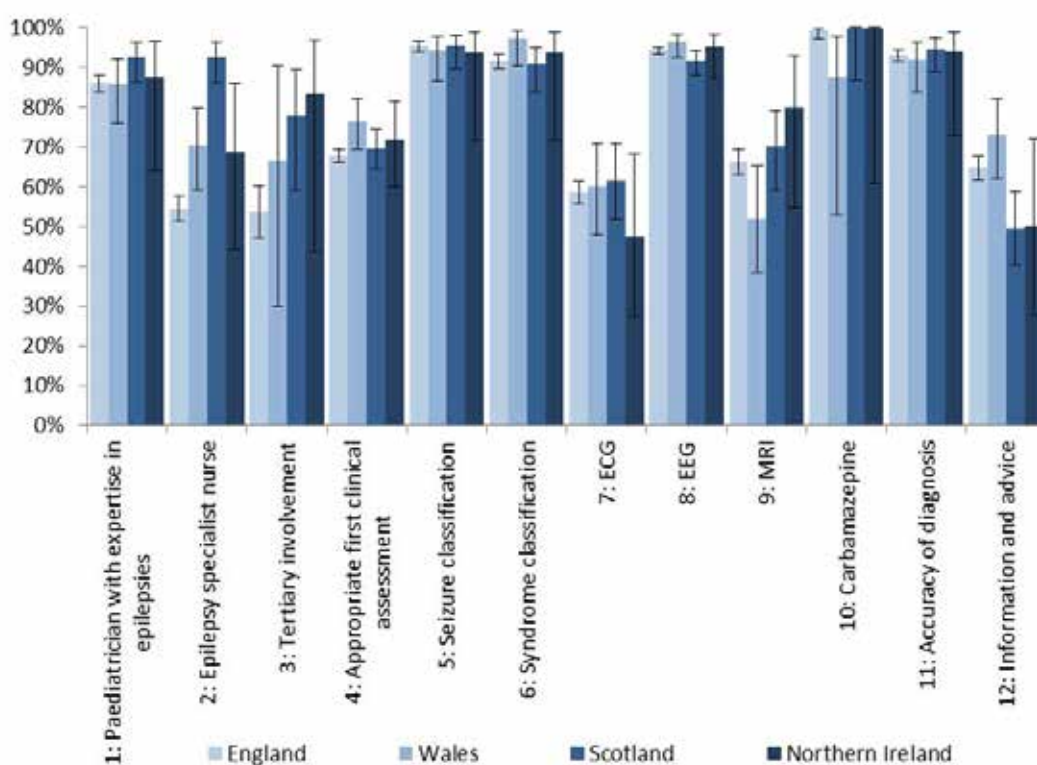
**Figure 9: Epilepsy12 performance indicators for Northern Ireland**



The 'whiskers' on the chart above represent 95% confidence intervals. If these whiskers overlap the difference in the achievement of the indicator is not statistically significant.

Figure 10 below shows the achievement of the Epilepsy12 indicators by country for Round 2. This shows that access to ESNs is significantly higher in Scotland.

**Figure 10: Epilepsy12 performance indicators by country, Round 2**



The 'whiskers' on the chart above represent 95% confidence intervals. If these whiskers overlap the difference in the achievement of the indicator is not statistically significant.

Table 11: Epilepsy12 Performance indicators by country across Rounds 1 and 2

			UK	England	Wales	Scotland	Northern Ireland
1	Paediatrician with expertise in epilepsies	Round 1	1395/1775 79%	1106/1423 78%	77/93 83%	172/204 84%	40/55 73%
		Round 2	1053/1215 87%	877/1019 86%	61/71 86%	101/109 93%	14/16 88%
2	Epilepsy Specialist Nurse	Round 1	819/1775 46%	592/1423 42%	66/93 71%	129/204 63%	32/55 58%
		Round 2	717/1215 59%	555/1019 54%	50/71 70%	101/109 93%	11/16 69%
3	Tertiary involvement	Round 1	245/407 60%	200/338 59%	5/9 56%	27/38 71%	13/22 59%
		Round 2	145/253 57%	115/214 54%	4/6 67%	21/27 78%	5/6 83%
4	Appropriate first clinical assessment	Round 1	3189/4945 65%	2635/4085 65%	172/225 76%	271/471 58%	111/164 68%
		Round 2	2361/3449 68%	1971/2907 68%	126/165 76%	218/313 70%	46/54 72%
5	Seizure classification	Round 1	1544/1775 87%	1235/1423 87%	83/93 89%	177/204 87%	49/55 89%
		Round 2	1158/1215 95%	973/1019 95%	67/71 94%	104/109 95%	15/16 94%
6	Epilepsy classification	Round 1	-	-	-	-	-
		Round 2	1088/1215 90%	911/1019 89%	67/71 94%	95/109 87%	15/16 94%
7	ECG	Round 1	704/1745 40%	568/1477 39%	46/82 56%	70/136 52%	20/50 40%
		Round 2	760/1291 59%	654/1113 59%	58/94 62%	58/94 62%	9/19 47%
8	EEG	Round 1	4538/4945 92%	3748/4085 92%	215/225 96%	425/471 90%	150/164 92%
		Round 2	3247/3449 94%	2740/2907 94%	159/165 96%	287/313 92%	61/64 95%
9	MRI	Round 1	716/1124 64%	578/899 64%	24/49 49%	86/136 63%	28/40 70%
		Round 2	544/751 72%	458/630 73%	23/36 64%	51/71 72%	12/14 86%
10	Carbamazepine	Round 1	382/403 95%	311/331 94%	10/11 94%	48/48 100%	13/13 100%
		Round 2	226/228 99%	188/189 99%	7/8 88%	25/25 100%	6/6 100%
11	Accuracy of diagnosis	Round 1	1775/1994 89%	1423/1624 88%	93/97 96%	204/214 95%	55/59 93%
		Round 2	1200/1286 93%	1007/1080 93%	70/76 92%	107/113 95%	16/17 94%
12	Information & advice	Round 1	-	-	-	-	-
		Round 2	774/1215 64%	660/1019 65%	52/71 73%	54/109 50%	8/16 50%

### 3.4.2 Professional input indicators

#### **Performance indicator 1: Paediatrician with expertise in epilepsies**

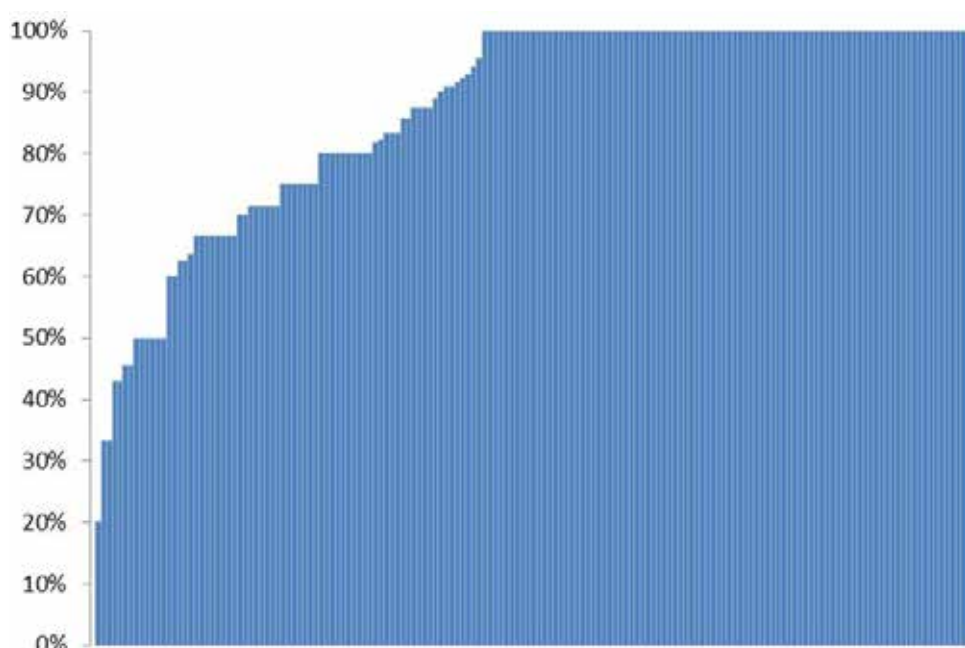
NICE guidelines state that the diagnosis of epilepsy in children should be established by a specialist paediatrician with training and expertise in epilepsies. SIGN guidelines say that the diagnosis of epilepsy should be made by a paediatric neurologist or a paediatrician with expertise in childhood epilepsy.

In Round 2, 87% (1,052/1,214) children with epilepsy had input from a paediatrician with expertise in epilepsies by one year. This is higher than for Round 1. There are no significant differences in achievement of this indicator by country. At unit level in Round 2 this indicator ranged from 0% to 100% (inter-quartile range 71% to 100%).

**Table 12: Input from a paediatrician with expertise in epilepsies**

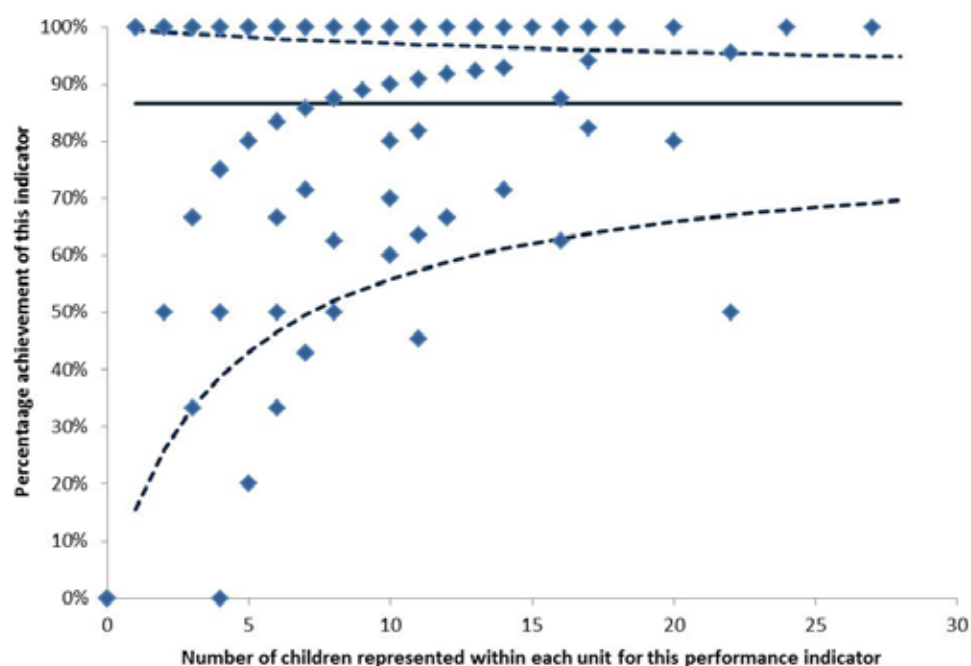
			UK	England	Wales	Scotland	Northern Ireland
<b>1a</b>	% of children with epilepsy with input by a consultant paediatrician with expertise in epilepsies by one year	Round 1	1395/1775 79%	1106/1423 78%	77/93 83%	172/204 84%	40/55 73%
		Round 2	1053/1215 87%	877/1019 86%	61/71 86%	101/109 93%	14/16 88%
<b>1b</b>	% of children with epilepsy who were commenced on AEDs with input by a consultant paediatrician with expertise in epilepsies by one year	Round 1	114/1406 81%	914/1138 80%	67/80 84%	126/142 89%	37/46 80%
		Round 2	875/976 90%	726/813 89%	53/60 88%	84/91 92%	12/12 100%

**Figure 11: Input from a paediatrician with expertise in epilepsies by unit, Round 2**



Each audit unit is represented by a vertical line in the above graph. All audit units are displayed in order of percentage score, including those scoring 0%



**Figure 12: Input from a paediatrician with expertise in epilepsies by unit, Round 2**

Dotted lines (funnels) show upper and lower 95% confidence intervals (approx. two standard deviations from the UK value). The solid line shows the UK achievement of this indicator.

### Performance indicator 2: ESN

NICE guidelines state that ESNs should be an integral part of the network of care of individuals with epilepsy. SIGN guidelines say that each epilepsy team should include paediatric epilepsy nurse specialists.

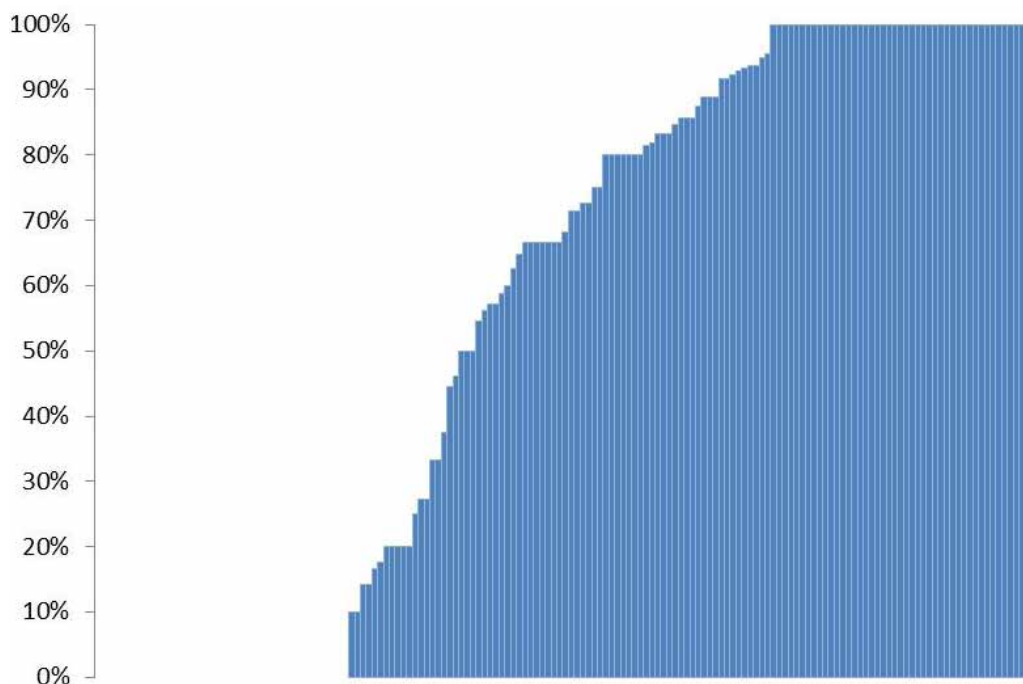
The key roles of the ESNs are to support both epilepsy specialists and generalists, to ensure access to community and multi-agency services and to provide information, training and support to the individual, families, carers and, in the case of children, others involved in the child's education, welfare and wellbeing.

In Round 2, 58% (709/1,214) of children with epilepsy had been referred to an epilepsy specialist nurse by one year. This is significantly higher than 46% of children in Round 1. Scotland scored significantly higher in this performance indicator compared to other countries. At unit level in Round 2 this indicator ranged from 0% to 100% (inter-quartile range 0% to 100%).

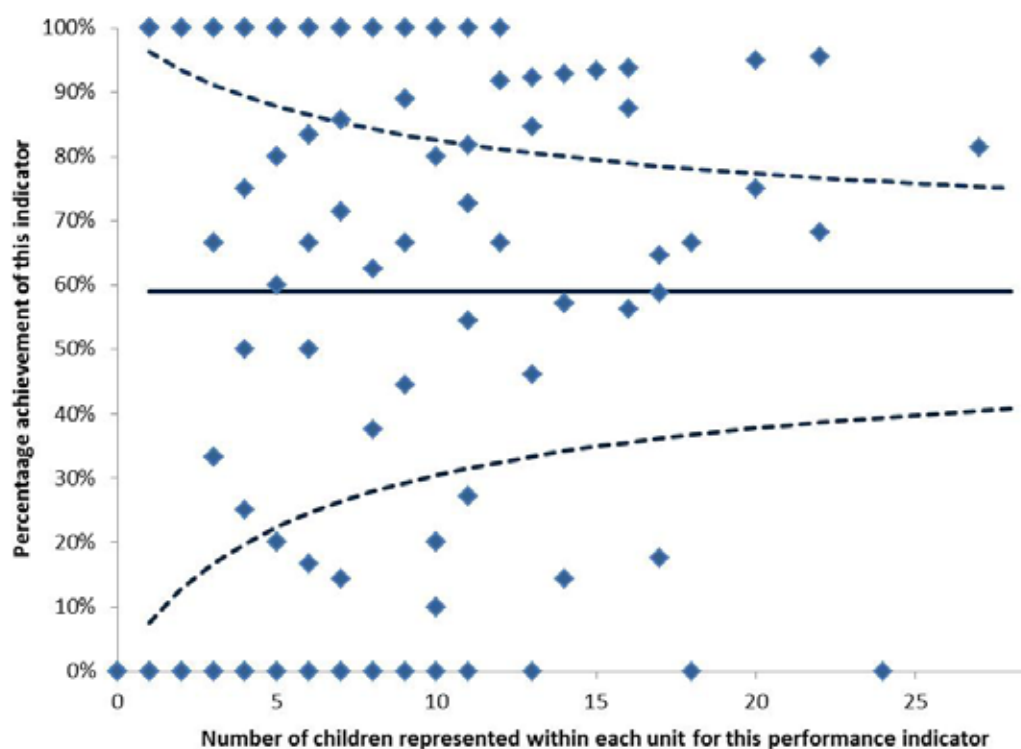
**Table 13: Input from an ESN**

			UK	England	Wales	Scotland	Northern Ireland
<b>2a</b>	% of children with epilepsy referred for input by an epilepsy specialist nurse by one year	Round 1	819/1775 46%	592/1423 42%	66/93 71%	129/204 63%	32/55 58%
		Round 2	717/1215 59%	555/1019 54%	50/71 70%	101/109 93%	11/16 69%
<b>2b</b>	% of children with epilepsy who were commenced on AEDs with referred for input by an epilepsy specialist nurse by one year	Round 1	710/1406 51%	516/1138 45%	59/80 74%	105/142 74%	30/46 65%
		Round 2	617/976 63%	474/813 59%	46/60 77%	87/91 96%	10/12 83%

**Figure 13: Input from an ESN by unit, Round 2**



**Figure 14: Input from an ESN by unit, Round 2**



Dotted lines (funnels) show upper and lower 95% confidence intervals (approx. two standard deviations from the UK value). The solid line shows the UK achievement of this indicator.

**Performance indicator 3: Tertiary involvement**

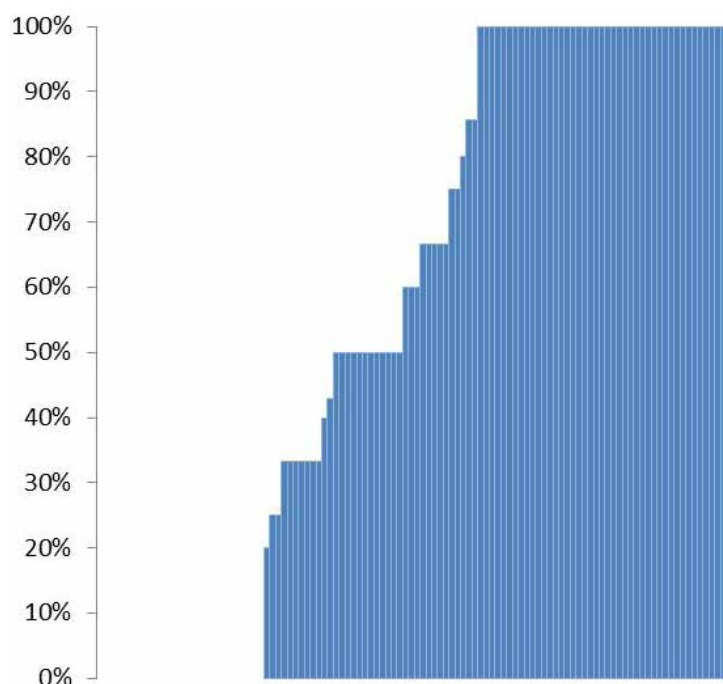
NICE guidance states that referral to a paediatric neurologist should be considered when a child with epilepsy is taking three or more maintenance AEDs by 12 months after the first paediatric assessment or aged under two years at the first paediatric assessment. SIGN guidelines say that referral to tertiary specialist care should be considered if a child fails to respond to two AEDs appropriate to the epilepsy in adequate doses over a period of six months.

In Epilepsy12, evidence of tertiary involvement was looked for in those children receiving three or more AEDs over time, or <2 years at first paediatric assessment.

In Round 2, 57% (145/253) children with epilepsy who met the criteria for tertiary referral had received input from tertiary care by one year. This is slightly lower than in Round 1 but this difference is not statistically significant. There are no significant differences in achievement of this indicator by country. At unit level in Round 2 this indicator ranged from 0% to 100% (inter-quartile range 0% to 99%).

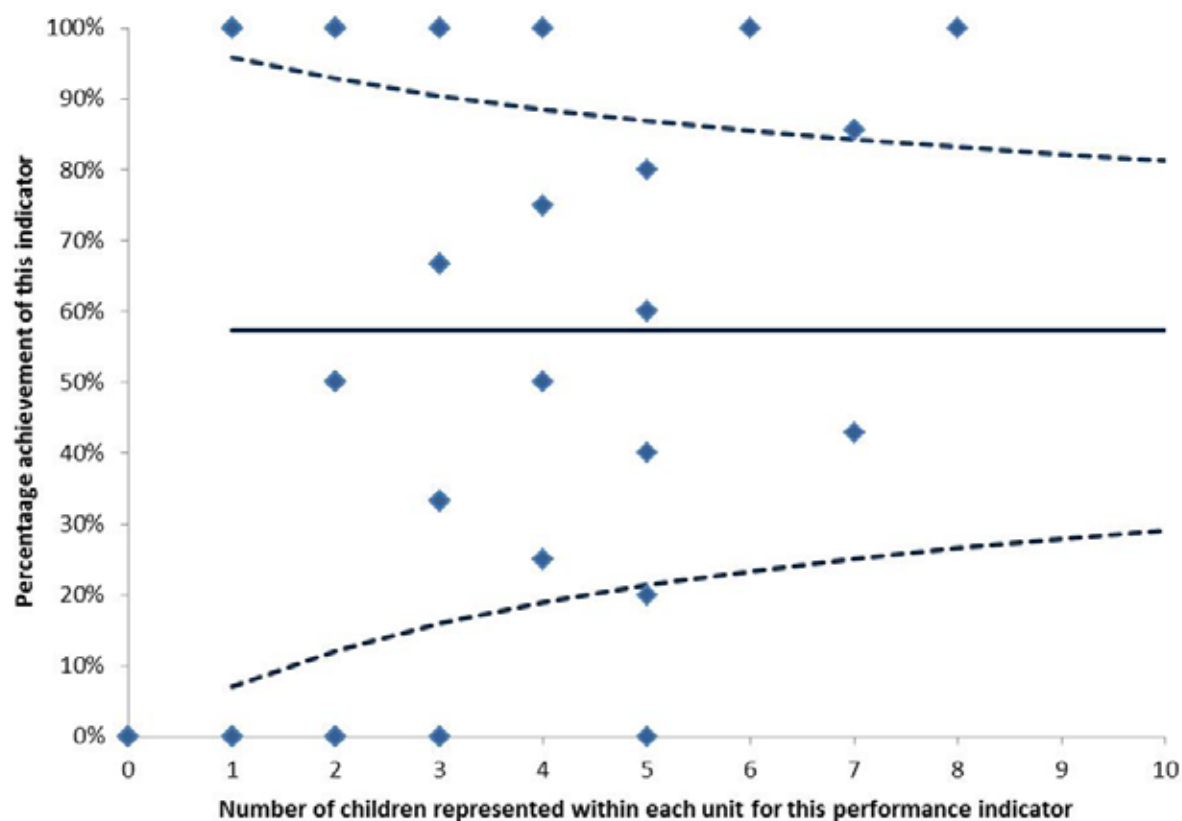
**Table 14: Tertiary involvement**

			UK	England	Wales	Scotland	Northern Ireland
<b>3</b>	% of children meeting defined criteria for paediatric neurology referral with input from tertiary care by one year	Round 1	245/407 60%	200/338 59%	5/9 56%	27/38 71%	13/22 59%
		Round 2	145/253 57%	115/214 54%	4/6 67%	21/27 78%	5/6 83%

**Figure 15: Referral to tertiary care by unit, Round 2**

Each audit unit is represented by a vertical line in the above graph. All audit units are displayed in order of percentage score, including those scoring 0%



**Figure 16: Referral to tertiary care by unit, Round 2**

Dotted lines (funnels) show upper and lower 95% confidence intervals (approx. two standard deviations from the UK value). The solid line shows the UK achievement of this indicator.

### 3.4.3 Assessment and classification indicators

#### **Performance indicator 4: Appropriate first clinical assessment**

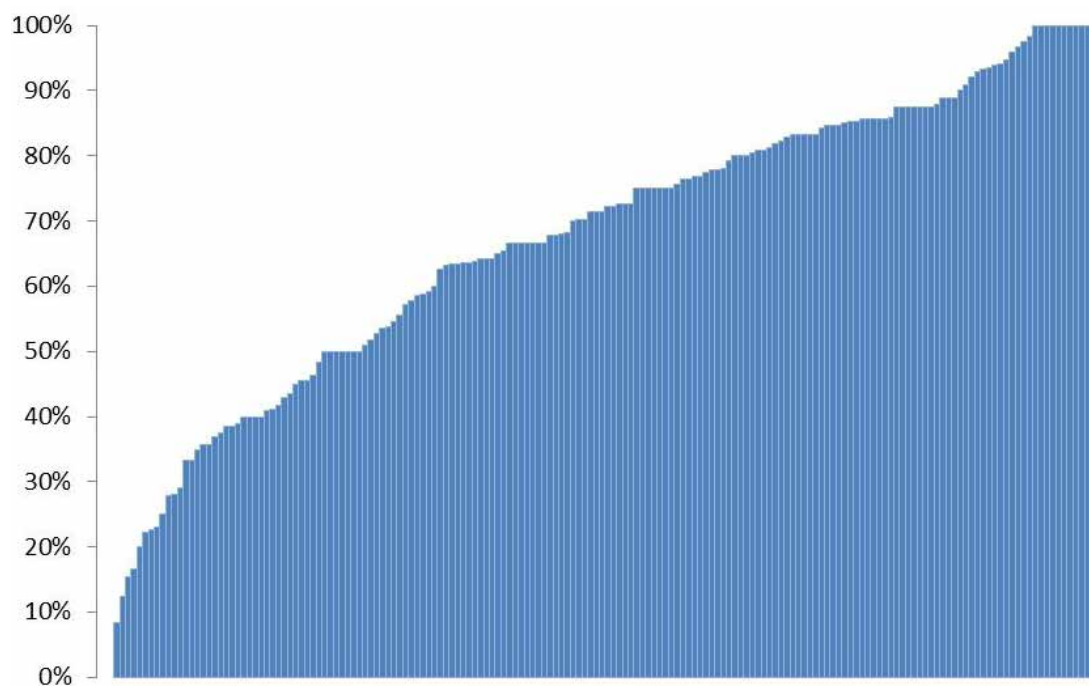
NICE guidance states that in an individual presenting with an attack a physical examination should be carried out. This should address the individual's cardiac, neurological and mental status and should include developmental assessment where appropriate. SIGN guidelines say that all children with epilepsy should have their behavioural and academic progress reviewed on a regular basis by the epilepsy team.

In Round 2, 68% (2,356/3,449) children had evidence that their first paediatric assessment was appropriate. This is slightly higher than in Round 1. There are no significant differences in the achievement of this indicator by country. At unit level in Round 2 this indicator ranged from 0% to 100% (inter-quartile range 50% to 85%).

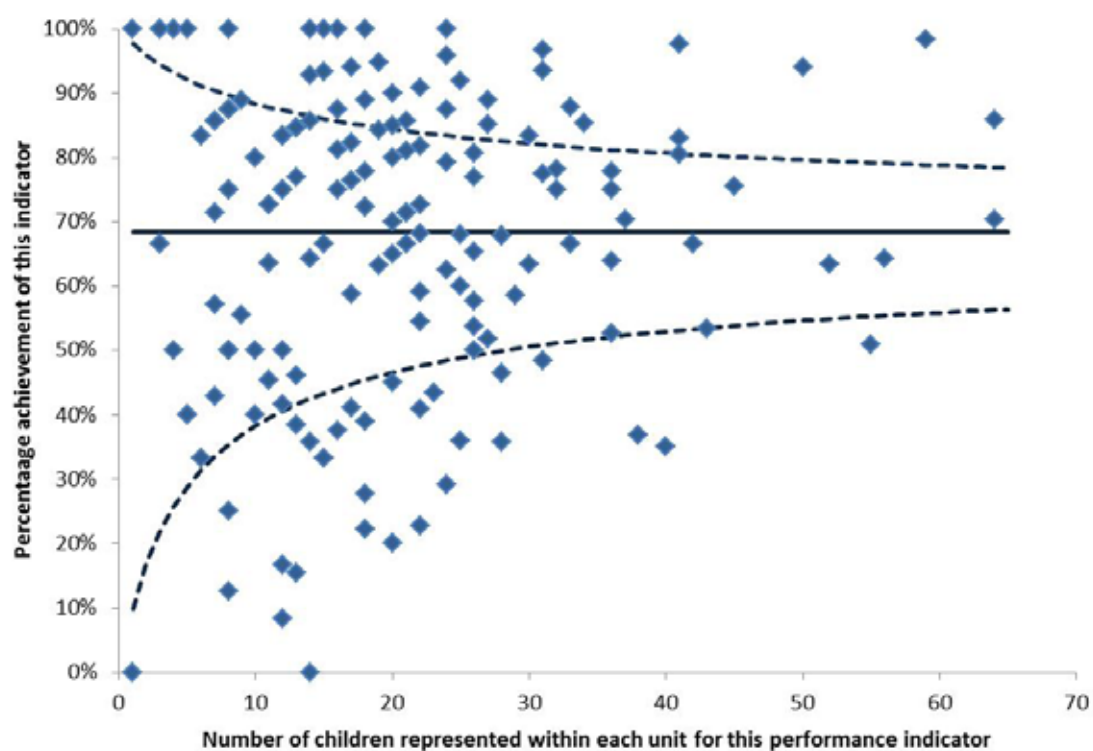
Table 15: Appropriate first clinical assessment

		UK		England	Wales	Scotland	Northern Ireland
<b>4</b>	% of children with descriptions of episode and age of child/timing of the first episode and frequency and general and neurological examination and the presence or absence of developmental, learning or schooling problems	Round 1	3189/4945 65%	2635/4085 65%	172/225 76%	271/471 58%	111/164 68%
		Round 2	2361/3449 68%	1971/2907 68%	126/165 76%	218/313 70%	46/64 72%
<b>4a</b>	% of children with descriptions of episode	Round 1	4858/4945 98%	4013/4085 98%	224/225 99.6%	459/471 98%	162/164 99%
		Round 2	3394/3449 98%	2863/2907 98%	161/165 98%	307/313 98%	63/64 98%
<b>4b</b>	% of children with descriptions of age of child/timing of first episode	Round 1	4640/4945 94%	3830/4085 94%	213/225 95%	442/471 94%	155/164 95%
		Round 2	3246/3449 94%	2739/2907 94%	156/165 95%	293/313 94%	58/64 91%
<b>4c</b>	% of children with descriptions of frequency	Round 1	4538/4945 92%	3775/4085 91%	212/225 94%	436/471 93%	155/164 95%
		Round 2	3205/3449 93%	2703/2907 93%	154/165 93%	292/313 93%	56/64 88%
<b>4d</b>	% of children with descriptions of general examination	Round 1	4562/4945 92%	3781/4085 93%	213/225 95%	416/471 88%	152/164 93%
		Round 2	3211/3449 93%	2704/2907 93%	157/165 95%	291/313 93%	59/64 92%
<b>4e</b>	% of children with description of neurological examination	Round 1	4123/4945 83%	3402/4085 83%	203/225 90%	381/471 81%	137/164 84%
		Round 2	2951/3449 86%	2471/2907 85%	148/165 90%	276/313 88%	56/64 88%
<b>4f</b>	% of children with description of developmental history or educational progress	Round 1	4069/4945 82%	3370/4085 83%	201/225 89%	364/471 77%	134/164 82%
		Round 2	2843/3449 82%	2376/2907 81%	152/165 92%	261/313 83%	54/64 84%
<b>4g</b>	% of children three years and over with descriptions of emotional or behavioural problems	Round 1	1848/3389 55%	1536/2803 55%	109/171 64%	165/330 50%	38/85 45%
		Round 2	1376/2280 60%	1160/1938 60%	77/116 66%	118/192 61%	21/34 62%

**Figure 17: Appropriate first clinical assessment by unit, Round 2**



**Figure 18: Appropriate first clinical assessment by unit, Round 2**



Dotted lines (funnels) show upper and lower 95% confidence intervals (approx. two standard deviations from the UK value). The solid line shows the UK achievement of this indicator.

**Performance indicators 5 and 6: Seizure and syndrome classification**

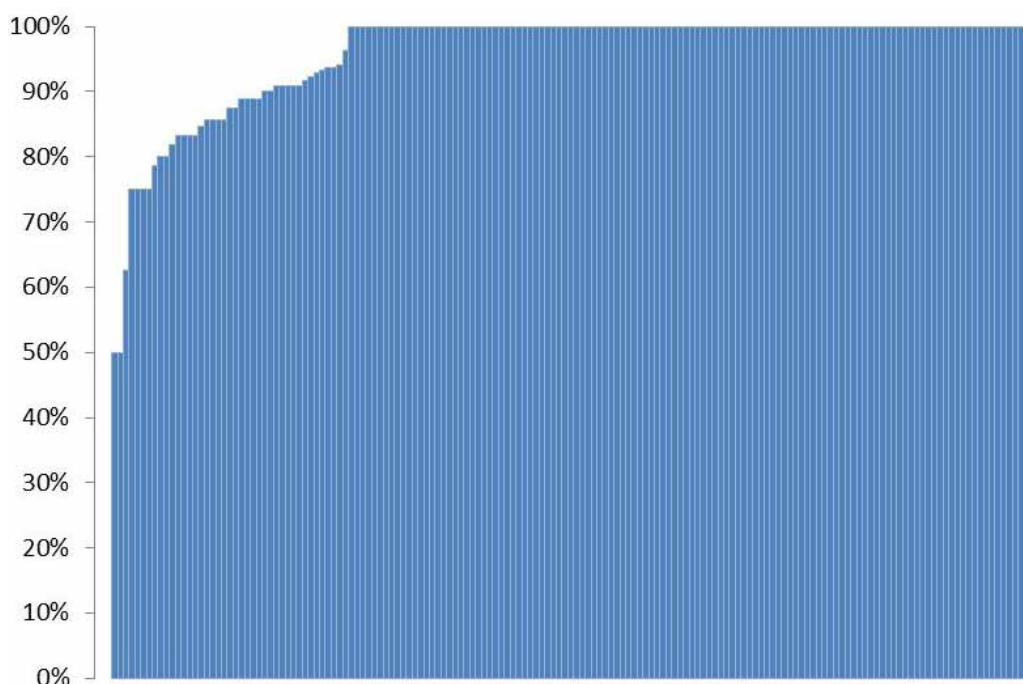
NICE guidance states that epileptic seizures and epilepsy syndromes in individuals should be classified using a multi-axial diagnostic scheme. The axes that should be considered are: description of seizure (ictal phenomenology), seizure type, syndrome and aetiology. SIGN guidelines say that the choice of first AED should be determined, where possible, by syndromic diagnosis and potential adverse effects.

In Round 2, 1,159 out of 1,215 (95%) children had a seizure classification and 1,088 out of 1,215 (90%) had an epilepsy syndrome or category identifiers. The percentage of children with a seizure classification has increased since Round 1. There are no significant differences in achievement of these indicators by country. At unit level in Round 2 Indicator 5 ranged from 0% to 100% (inter-quartile range 91% to 100%) and Indicator 6 ranged from 0% to 100% (inter-quartile range 80% to 100%).

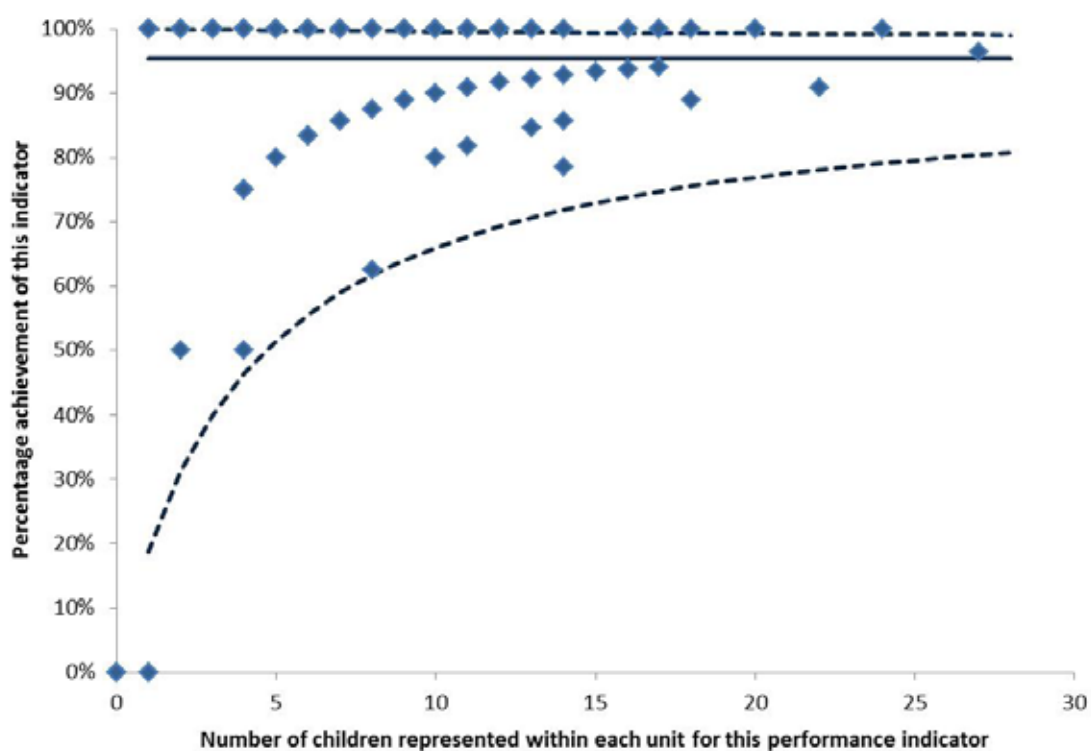
**Table 16: Seizure and syndrome classification**

			UK	England	Wales	Scotland	Northern Ireland
<b>5</b>	% children with epilepsy with seizure classification by one year	Round 1	1544/1775 87%	1235/1423 87%	83/93 89%	177/204 87%	49/55 89%
		Round 2	1159/1215 95%	973/1019 95%	67/77 94%	104/109 95%	15/16 94%
<b>6a</b>	% children with epilepsy syndrome classification by one year	Round 1	660/1775 37%	544/1423 38%	30/93 32%	69/204 34%	17/55 31%
		Round 2	678/1215 56%	556/1019 55%	45/71 63%	69/109 63%	8/16 50%
<b>6b</b>	% children with epilepsy syndrome or category identifiers by one year	Round 1	data not available				
		Round 2	1088/1215 90%	911/1019 89%	67/71 94%	95/109 87%	15/16 94%

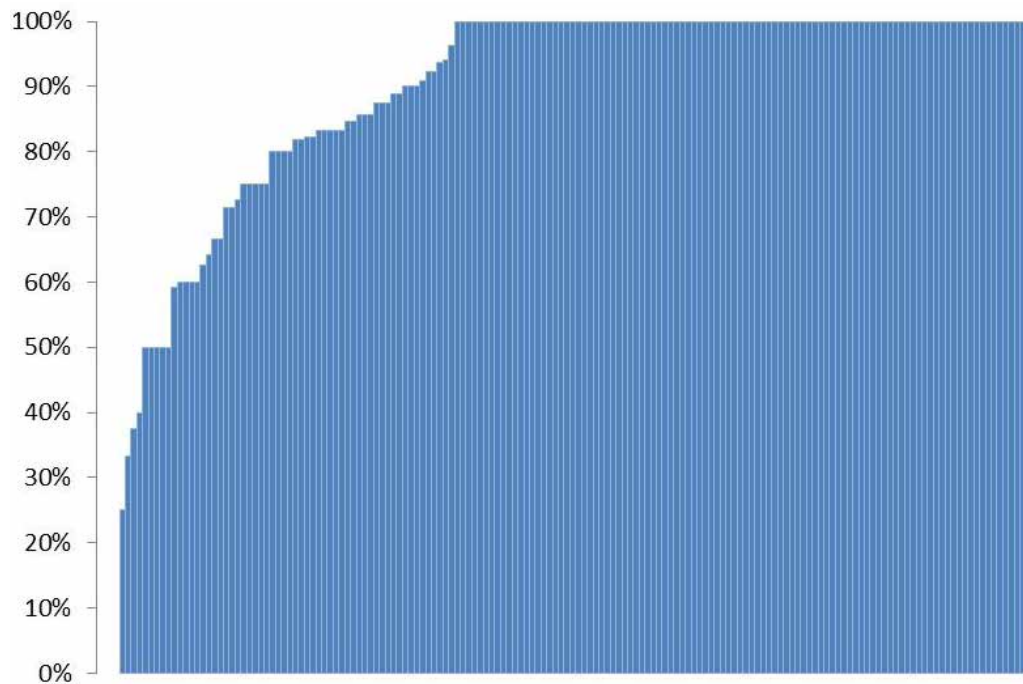
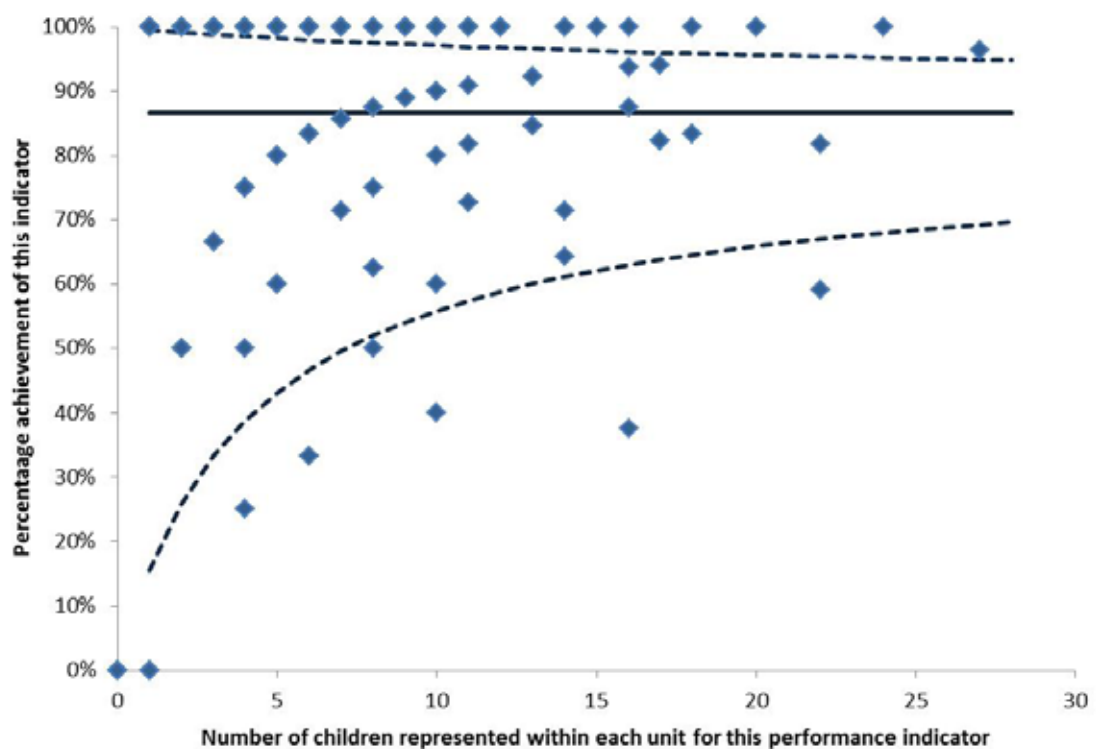
**Figure 19: Seizure classification by unit, Round 2**



**Figure 20: Seizure classification by unit, Round 2**



Dotted lines (funnels) show upper and lower 95% confidence intervals (approx. two standard deviations from the UK value). The solid line shows the UK achievement of this indicator.

**Figure 21: Syndrome classification by unit, Round 2****Figure 22: Appropriate syndrome classification by unit, Round 2**

Dotted lines (funnels) show upper and lower 95% confidence intervals (approx. two standard deviations from the UK value). The solid line shows the UK achievement of this indicator.

### 3.4.4 Investigation indicators

#### **Performance indicators 7, 8 and 9: Appropriate ECG, EEG and MRI**

NICE guidance states that in children a 12 lead ECG should be considered in cases of diagnostic uncertainty whilst the SIGN guidelines says that all children presenting with convulsive seizures should have an ECG with calculation of the QTc intervals. As the NICE and SIGN guidelines vary and the SIGN guidance was deemed easier to audit objectively this standard has been adopted for the performance indicator.

In Round 2, 759 out of 1,290 (59%) children who had a convulsive seizure had a 12 lead ECG by one year in comparison to 704/1,745 (40%) in Round 1. There are not significant differences in achievement of this indicator by country. At unit level in Round 2 this indicator ranged from 0% to 100% (inter-quartile range 27% to 78%).

NICE guidelines state that an 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 an EEG then it was assumed that the EEG was inappropriate.

In Round 2, 94% (3,247/3,449) children who had an EEG had no defined contraindications which is higher than in Round 1. There are no significant differences in achievement of this indicator by country. At unit level in Round 2 this indicator ranged from 60% to 100% (inter-quartile range 81% to 100%).

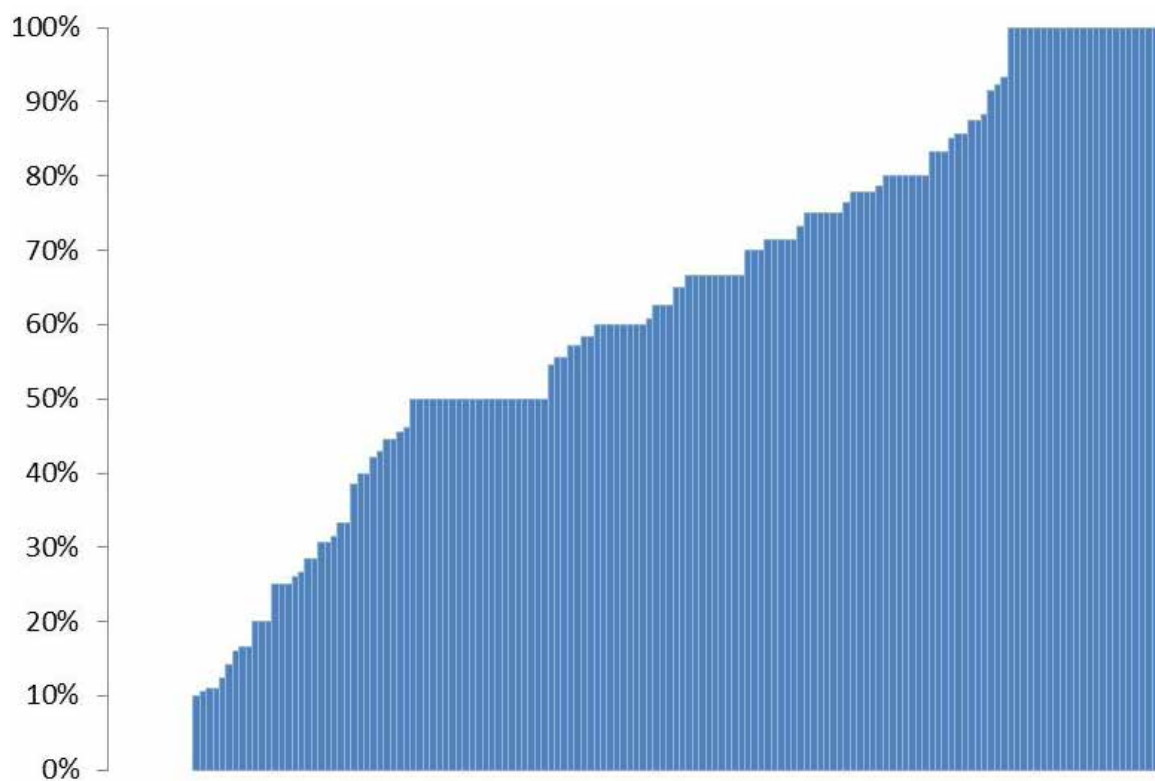
NICE guidelines state that an MRI should be the neuroimaging investigation of choice in those with epilepsy. SIGN guidelines state that children with epilepsy (other than BECTS or an 'idiopathic generalised epilepsy', e.g. Juvenile absence, childhood absence, juvenile myoclonic epilepsy) should have an MRI brain scan.

In Round 2, 72% (544/751) children with defined indications had an MRI which is a significant improvement from Round 1. There is no significant variation in achievement of this indicator by country. At unit level in Round 2 this indicator ranged from 0% to 100% (inter-quartile range 40% to 82%).

**Table 17: Appropriate investigations**

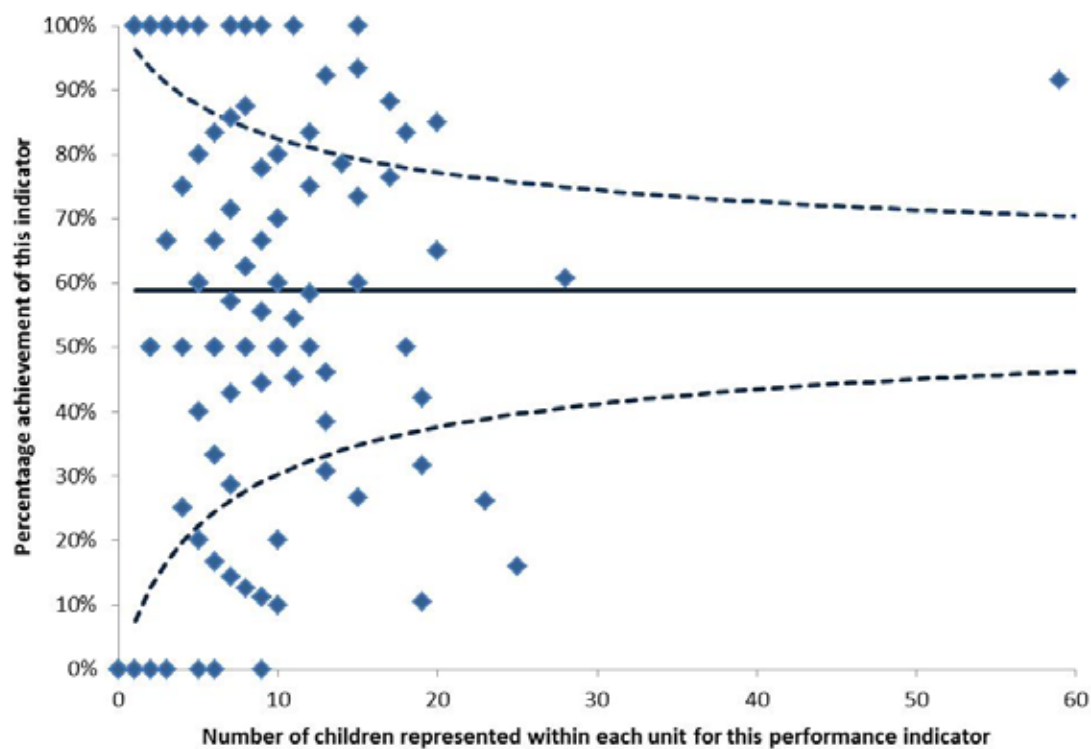
			UK	England	Wales	Scotland	Northern Ireland
<b>7</b>	% children with convulsive seizures with an ECG by one year	Round 1	704/1745 40%	568/1477 39%	46/82 56%	70/136 52%	20/50 40%
		Round 2	760/1291 59%	654/1113 59%	39/65 60%	58/94 62%	9/19 47%

			UK	England	Wales	Scotland	Northern Ireland
<b>8</b>	% of children who had an EEG in whom there were no defined contraindications	Round 1	4538/4945 92%	3748/4085 92%	215/225 96%	425/471 90%	150/164 92%
		Round 2	3247/3449 94%	2740/2907 94%	159/165 96%	287/313 92%	61/64 95%
<b>9a</b>	% children with defined indications for an MRI who had an MRI by one year	Round 1	716/1124 64%	578/899 64%	24/49 49%	86/136 63%	28/40 70%
		Round 2	544/751 72%	458/630 73%	23/36 64%	54/71 72%	12/14 86%
<b>9b</b>	% children with defined indications for an MRI who had an MRI or CT by one year	Round 1	781/1124 70%	631/899 70%	27/49 55%	92/136 68%	31/40 78%
		Round 2	583/751 78%	493/630 78%	24/36 67%	53/71 75%	13/14 93%

**Figure 23: Appropriate ECG by unit, Round 2**

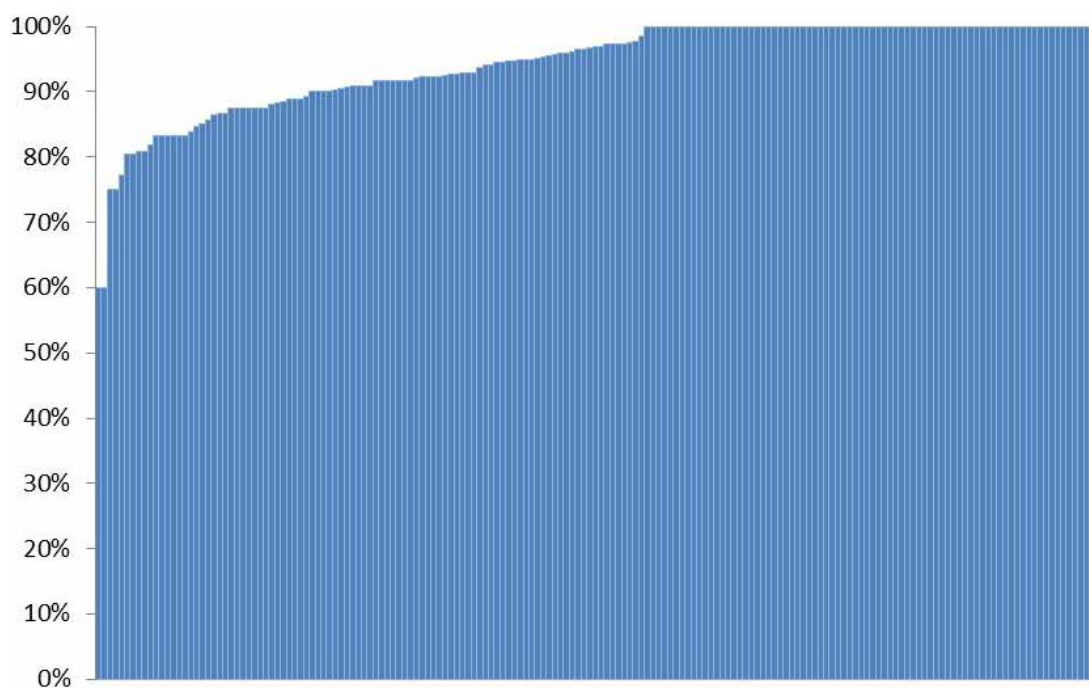


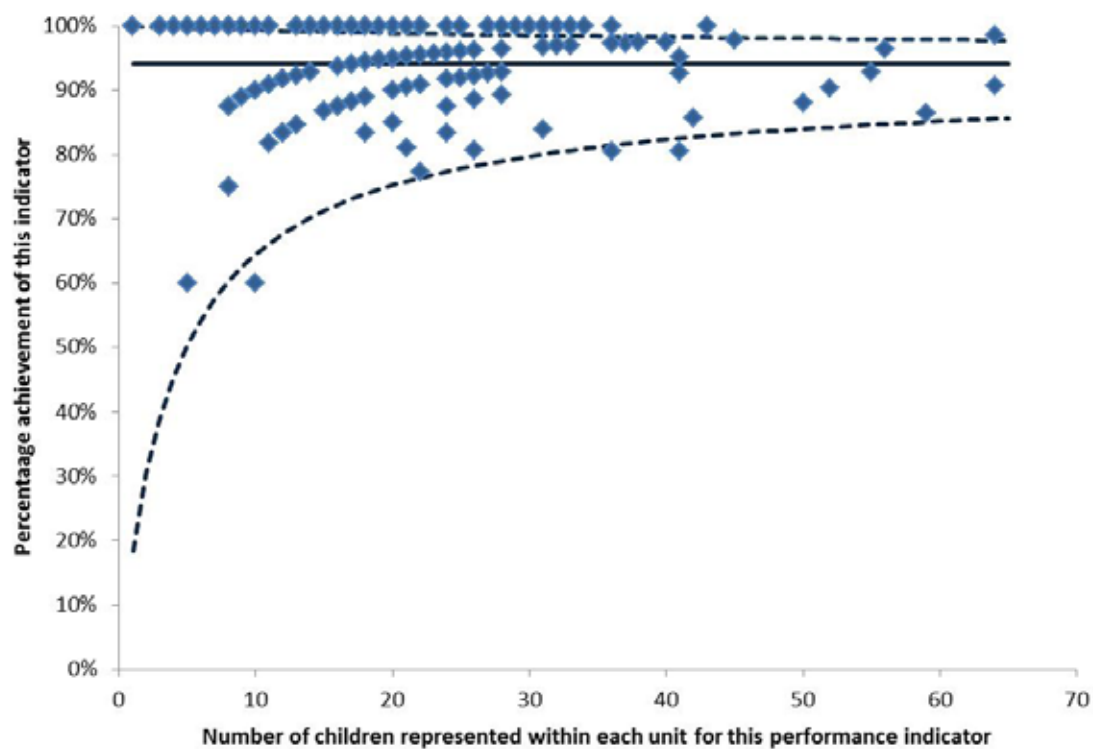
**Figure 24: Appropriate ECG by unit, Round 2**



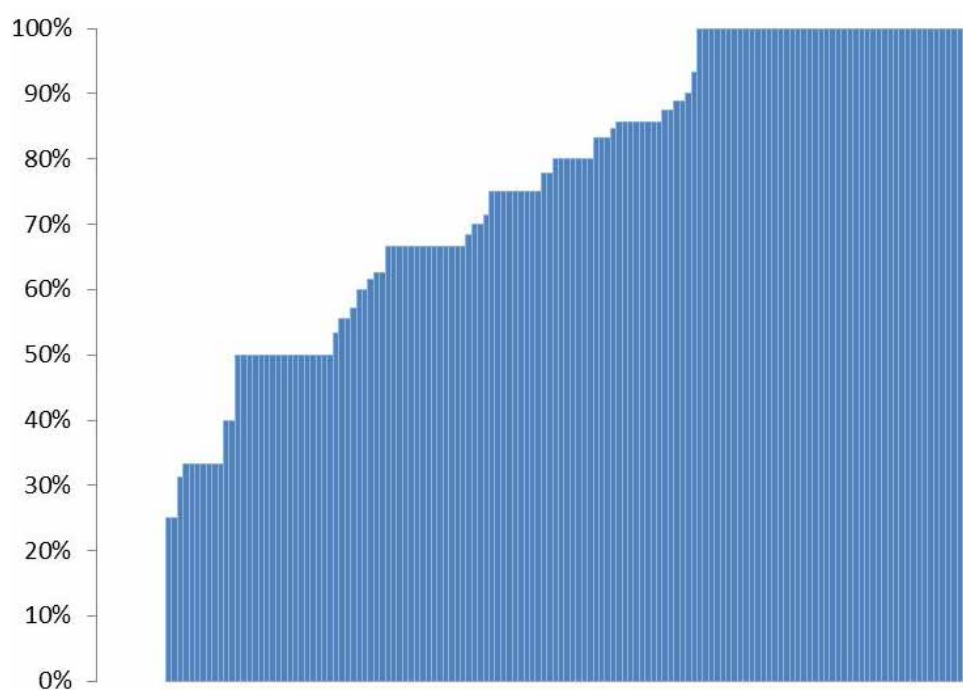
Dotted lines (funnels) show upper and lower 95% confidence intervals (approx. two standard deviations from the UK value). The solid line shows the UK achievement of this indicator.

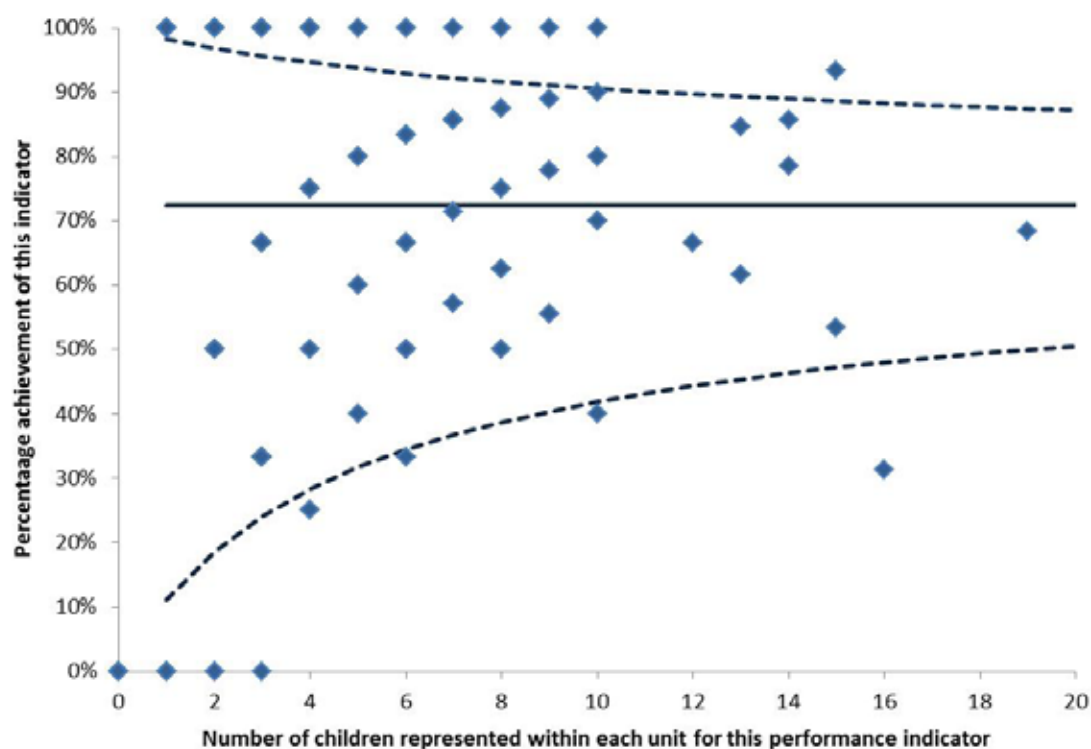
**Figure 25: Appropriate EEG by unit, Round 2**



**Figure 26: Appropriate EEG by unit, Round 2**

Dotted lines (funnels) show upper and lower 95% confidence intervals (approx. two standard deviations from the UK value). The solid line shows the UK achievement of this indicator.

**Figure 27: Appropriate MRI by unit, Round 2**

**Figure 28: Appropriate MRI by unit, Round 2**

Dotted lines (funnels) show upper and lower 95% confidence intervals (approx. two standard deviations from the UK value). The solid line shows the UK achievement of this indicator.

### 3.4.5 Management and outcome indicators

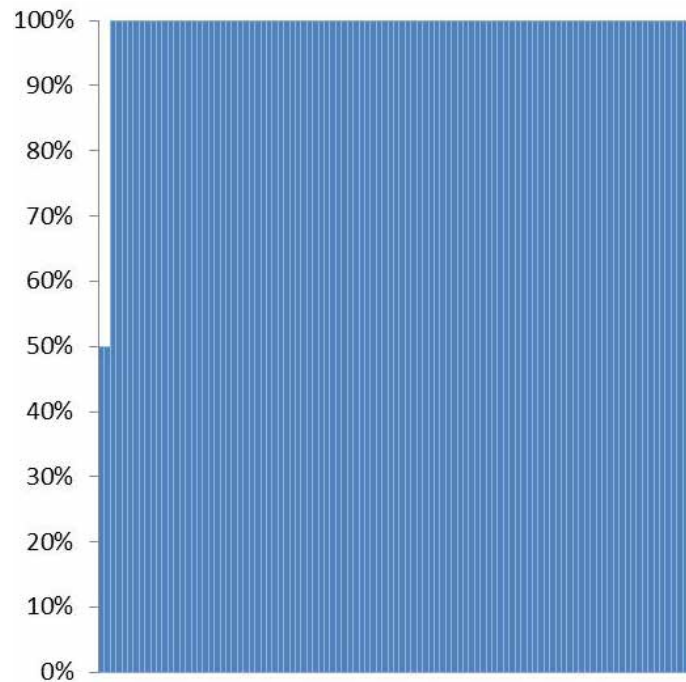
#### **Performance indicator 10: Appropriate Carbamazepine**

Carbamazepine is not indicated in childhood absence epilepsy, juvenile absence epilepsy, juvenile myoclonic epilepsy and idiopathic generalised epilepsies.

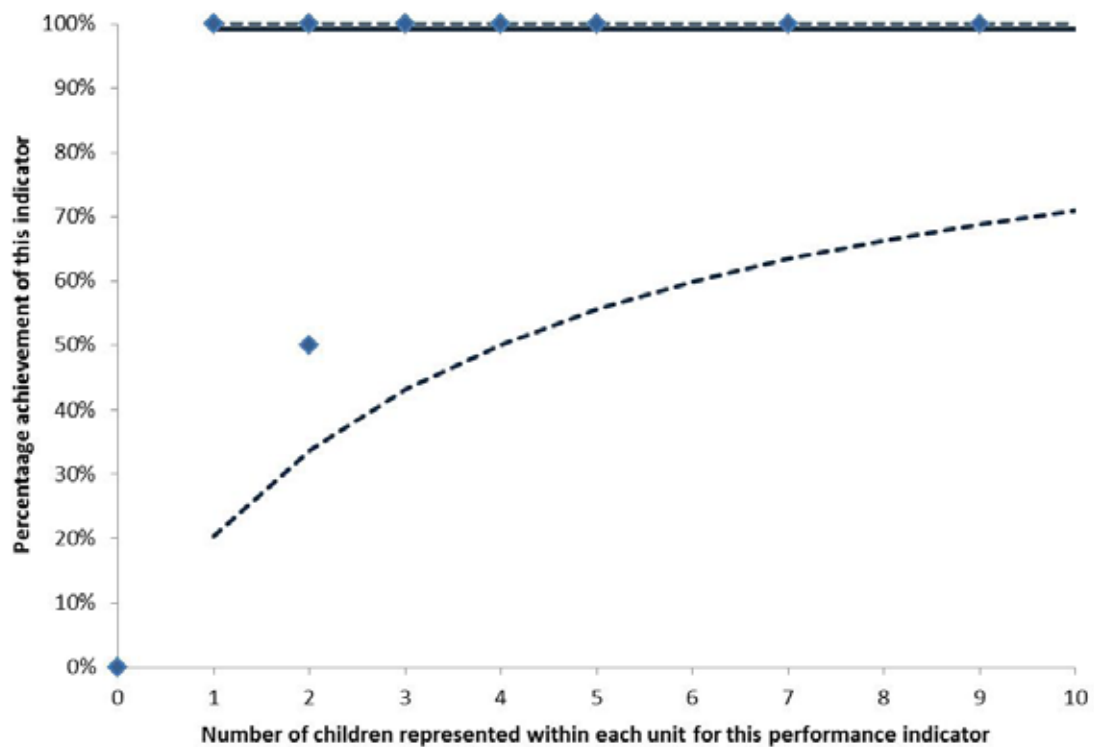
In Round 2, 99% (226/228) children in whom Carbamazepine was prescribed had no defined contraindications. There are no significant variations in achievement of this indicator by country. At unit level in Round 2 this indicator ranged from 0% to 100% (inter-quartile range 0% to 100%).

**Table 18: Appropriate Carbamazepine**

			UK	England	Wales	Scotland	Northern Ireland
<b>10</b>	% children given Carbamazepine in whom there are no defined contraindications	Round 1	382/403 95%	311/331 94%	10/11 91%	48/48 100%	13/13 100%
		Round 2	226/228 99%	188/189 99%	7/8 88%	25/25 100%	6/6 100%

**Figure 29: Appropriate Carbamazepine by unit, Round 2**

Each audit unit is represented by a vertical line in the above graph. All audit units are displayed in order of percentage score, including those scoring 0%.

**Figure 30: Appropriate Carbamazepine by unit, Round 2**

Dotted lines (funnels) show upper and lower 95% confidence intervals (approx. two standard deviations from the UK value). The solid line shows the UK achievement of this indicator.

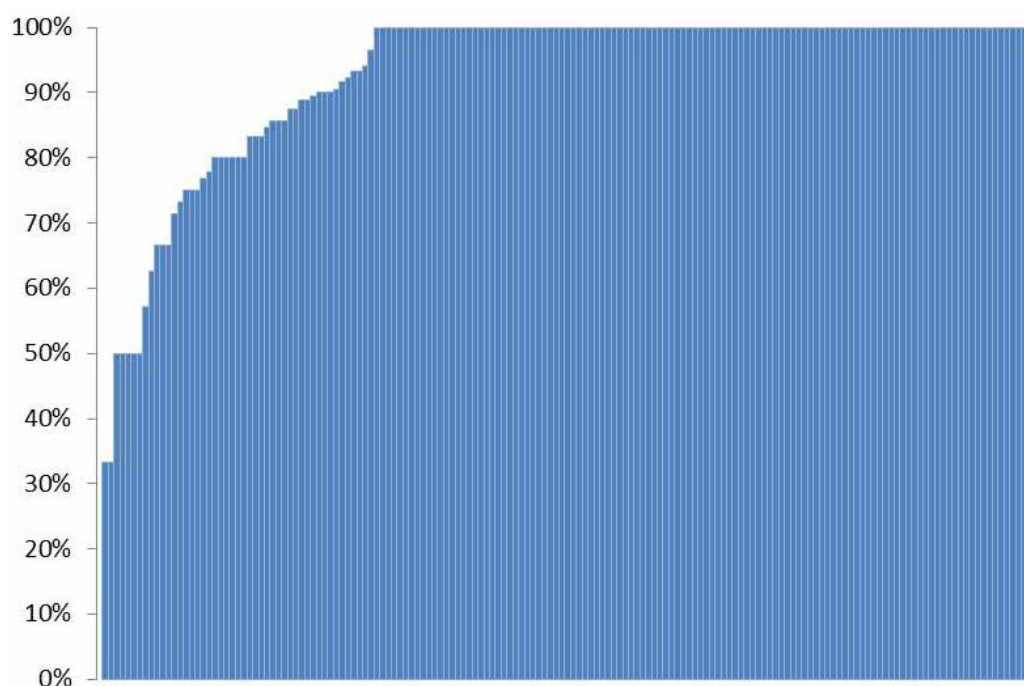
**Performance indicator 11: Accuracy of diagnosis**

NICE guidance states that AED therapy should only be started once the diagnosis of epilepsy is confirmed except in exceptional circumstance that require discussion and agreement between the prescriber, the specialist and the individual and their family/carers as appropriate.

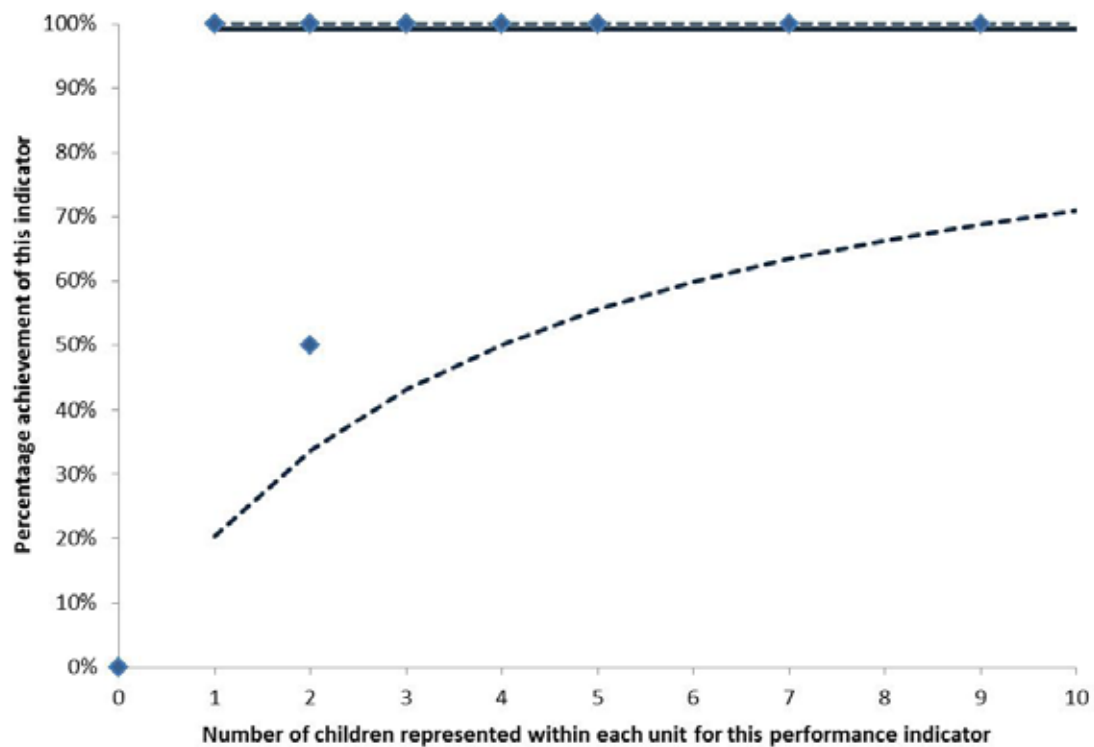
In Round 2, 93% (1,197/1,286 of children diagnosed with epilepsy still had that diagnosis at one year compared to 89% in Round 1. There are no significant differences in achievement of this indicator by country. At unit level in Round 2 this indicator ranged from 0% to 100% (inter-quartile range 86% to 100%).

**Table 19: Accuracy of diagnosis**

			UK	England	Wales	Scotland	Northern Ireland
<b>11</b>	% children diagnosed with epilepsy who still had that diagnosis at one year	Round 1	1775/1994 89%	1423/1624 88%	93/97 96%	204/214 95%	55/59 93%
		Round 2	1200/1286 93%	1007/1080 93%	70/76 92%	107/113 95%	16/17 94%

**Figure 31: Accuracy of diagnosis by unit, Round 2**

Each audit unit is represented by a vertical line in the above graph. All audit units are displayed in order of percentage score, including those scoring 0%.

**Figure 32: Accuracy of diagnosis by unit, Round 2**

Dotted lines (funnels) show upper and lower 95% confidence intervals (approx. two standard deviations from the UK value). The solid line shows the UK achievement of this indicator.

### **Performance indicator 12: Information and safety advice**

12b was a new performance indicator chosen for Round 2. NICE states that all children, young people and adults with epilepsy and learning disabilities should have a risk assessment including bathing and showering.

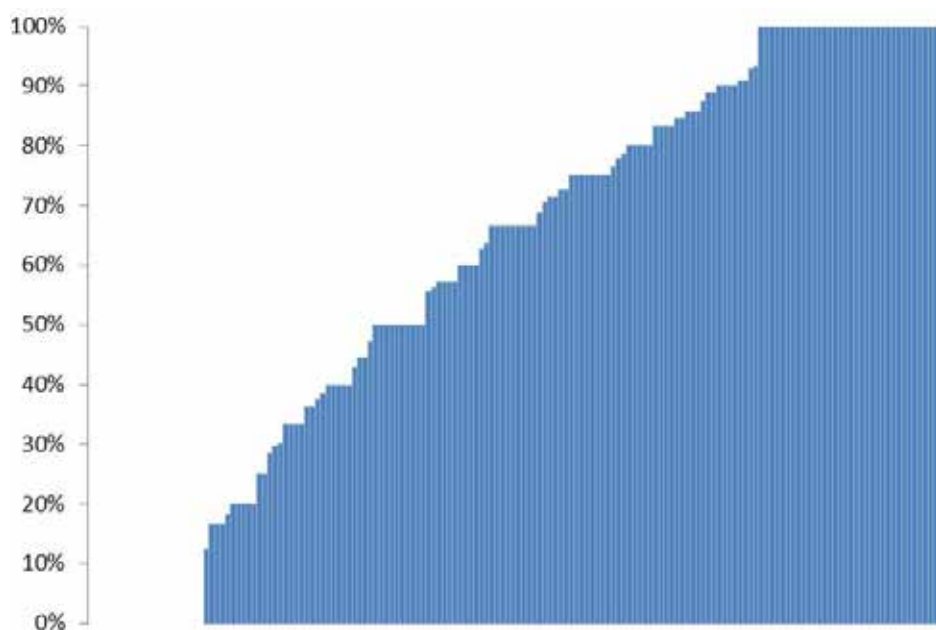
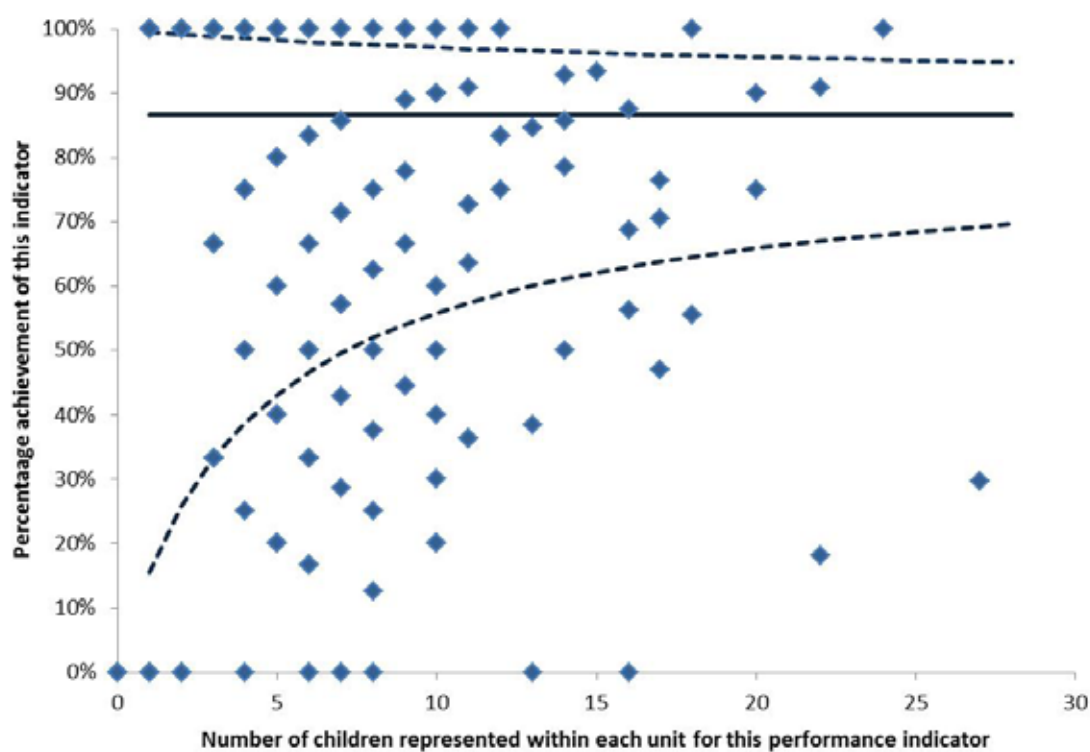
SIGN states that children with epilepsy should be encouraged to participate in normal activities with their peers. Supervision requirements should be individualised taking into account the type of activity and the seizure history.

In Round 2, 773 out of 1,214 (64%) children had documented evidence of communication relating to water safety. At unit level in Round 2 this indicator ranged from 0% to 100% (inter-quartile range 25% to 90%). Water safety and bathing is just one risk. Different children and young people with epilepsy have different risks at different times in their life. Other risks such as climbing heights, cycling, driving, Sudden Unexpected Death in Epilepsy (SUDEP) and burns/scalds may need discussing and balancing against the need to maximise inclusion and participation.

**Table 20: Information and advice**

			UK	England	Wales	Scotland	Northern Ireland
<b>12a</b>	% females over 12 years given epilepsy medication who had evidence of discussion of pregnancy or contraception	Round 1	56/148 38%	45/119 38%	6/11 55%	2/13 15%	3/5 60%
		Round 2	52/97 54%	48/86 56%	2/6 33%	2/4 50%	0/1 0%

			UK	England	Wales	Scotland	Northern Ireland
<b>12b</b>	% children diagnosed with epilepsy with documented evidence of communication regarding water safety	Round 1	Data not collected				
		Round 2	774/1215 64%	660/1019 65%	52/71 73%	54/109 50%	8/16 50%

**Figure 33: Information and advice on water safety by unit, Round 2****Figure 34: Information and advice on water safety by unit, Round 2**

Dotted lines (funnels) show upper and lower 95% confidence intervals (approx. two standard deviations from the UK value). The solid line shows the UK achievement of this indicator.

### 3.5 Seizure freedom outcome data

Table 21 below shows seizure free outcomes for children with a diagnosis of epilepsy at 12 months after first assessment. This data item was included in order to obtain baseline data to inform whether 'syndrome-specific seizure freedom rates by one year' for those children where seizure freedom might be expected, may be a potential clinical outcome measure in future audit rounds. Further analysis and validation of this data is intended. Overall 35% of children were known to be seizure free between six and 12 months after first assessment. If the outcome period is between nine and 12 months after first assessment the percentage of children who are known to be seizure free is 51%. A breakdown of seizure free outcomes by type of epilepsy is provided in table 22.

**Table 21: Seizure free outcome data by country** (England = E, Northern Ireland = NI, Scotland = S, Wales = W)

	Seizure free 6 to 12 months after assessment					Seizure free 9 to 12 months after assessment				
	UK	E	W	S	NI	UK	E	W	S	NI
Known to be seizure free	427 (35%)	374 (37%)	15 (21%)	35 (32%)	3 (19%)	614 (51%)	528 (52%)	22 (31%)	58 (53%)	6 (38%)
Not seizure free	709 (58%)	579 (57%)	49 (69%)	69 (63%)	12 (75%)	464 (38%)	379 (37%)	34 (48%)	43 (39%)	8 (50%)
Not recorded	79 (7%)	66 (6%)	7 (10%)	5 (5%)	1 (6%)	137 (11%)	112 (11%)	15 (21%)	8 (7%)	2 (13%)

**Table 22: Seizure free outcome data by epilepsy type**

	Known to be seizure free 6 to 12 months after assessment	Known to be seizure free 9 to 12 months after assessment
All epilepsy types	427/1415 (35%)	614/1415 (51%)
Benign Rolandic Epilepsy (BECTS)	42/95 (44%)	62/95 (65%)
Panayiotopoulos syndrome	5/11 (45%)	6/11 (55%)
Childhood absence epilepsy (CAE)	49/113 (38%)	65/113 (58%)
Juvenile absence epilepsy (JAE)	15/39 (37%)	21/39 (54%)
Juvenile myoclonic epilepsy (JME)	14/38 (30%)	20/38 (53%)
Temporal lobe epilepsy	11/37 (30%)	16/37 (43%)
West syndrome (infantile spasms)	15/31 (48%)	19/31 (61%)
Frontal lobe epilepsy	6/23 (26%)	11/23 (48%)
Occipital lobe epilepsy	3/9 (33%)	5/9 (56%)
Doose syndrome	3/16 (19%)	5/16 (31%)
Dravet syndrome	0/2 (0%)	0/2 (0%)
Parietal lobe epilepsy	0/2 (0%)	0/2 (0%)
Defined as 'unclassified'	3/10 (30%)	5/10 (50%)
No epilepsy syndrome stated	159/516 (31%)	234/516 (45%)



## 4. Patient Reported Experience Measure (PREM) domain results

A total of 2,335 patient reported experience measure questionnaires were received from 145 units. Information on the characteristics of the child or young person was provided by their parent or carer and these details are shown in table 23 below.

**Table 23: Characteristics of children, UK**

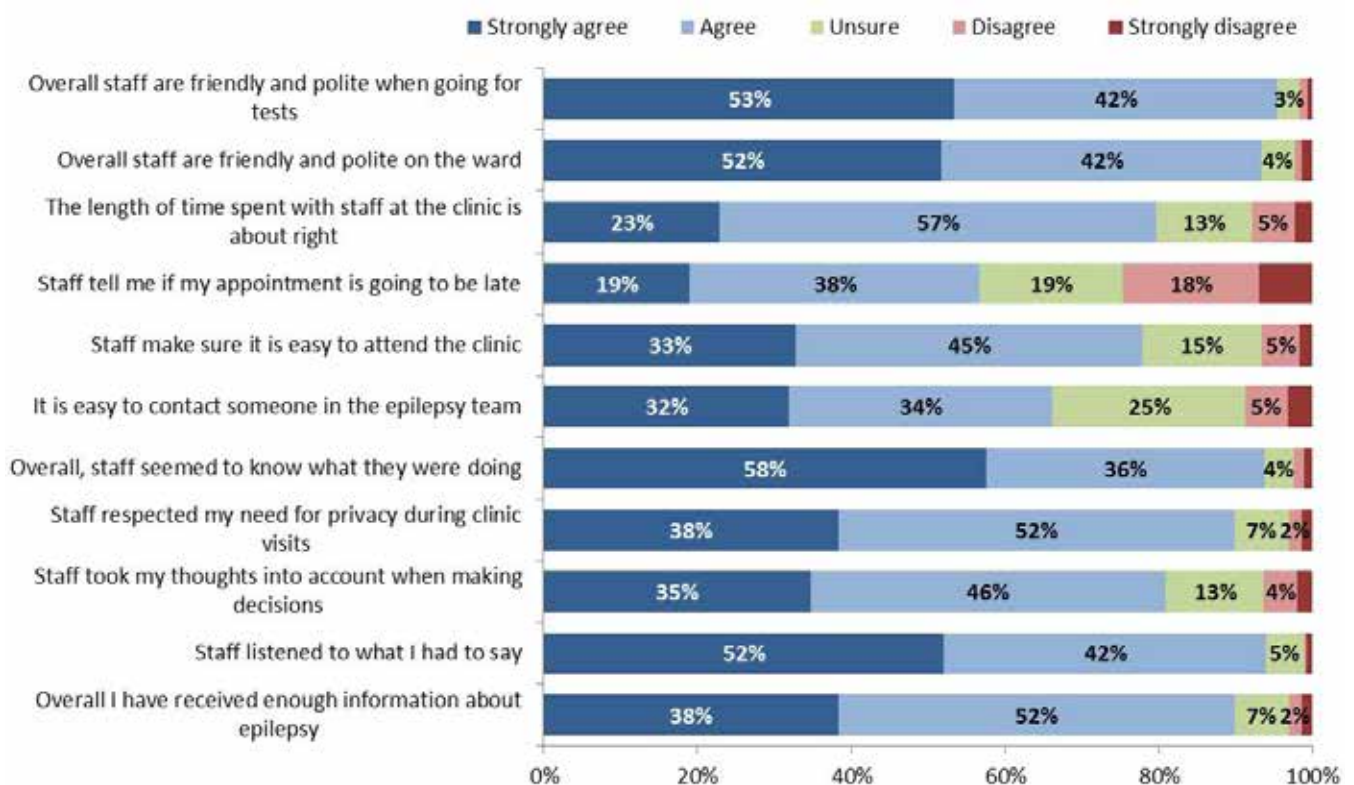
		Number N = 2335	Percentage
Year of birth	1994-1998	361	15.5%
	1999-2003	776	33.2%
	2004-2008	752	32.2%
	2009-2013	425	18.2%
	Not answered	21	0.9%
Gender	Female	1099	47.1%
	Male	1222	52.3%
	Not answered	14	0.6%
Diagnosis	Learning difficulties/developmental delay	1018	43.6%
	Cerebral palsy	220	9.4%
	Autism or autistic spectrum disorder	211	9.0%
	Attention deficit hyperactivity disorder (ADHD)	123	5.3%
	None of the above	947	40.6%
Timing of first assessment by paediatrician	Less than one year ago	456	19.5%
	Between one and two years ago	437	18.7%
	Two or more years ago	1338	57.3%
	Not answered	103	4.4%
Age at first assessment	Median (inter-quartile range)	4 years (1-8 years)	
	Infants (1 month to < 2 years)	550	23.6%
	Pre-school (2 - <5 years)	531	22.7%
	School (5 - < 12 years)	733	31.4%
	Young people (12 - <16 years)	221	9.5%
	Not answered	300	12.8%
Services attended	Hospital general paediatric clinic	296	12.7%
	Community paediatric clinic	296	12.7%
	Teenage epilepsy clinic	67	2.9%
	Specific epilepsy clinic	456	19.5%
	Paediatric neurology clinic	672	28.8%
	A&E	552	23.6%
	GP	506	21.7%
Drugs currently prescribed	Sodium Valproate	963	41.2%
	Carbamazepine	419	17.9%
	Lamotrigine	462	19.8%
	Levetiracetam	434	18.6%

The parent or carer completing the questionnaire was asked whether they found it easy to contact the health service looking after their child's epilepsy. 1,884 (84%) indicated that they did, 196 (9%) were unsure and 170 (8%) reported that they did not find it easy. 1,974 (88%) reported that they were satisfied with the care they receive from the epilepsy service and 154 (7%) indicated they were unsure. However, 130 (6%) stated that they were not satisfied.

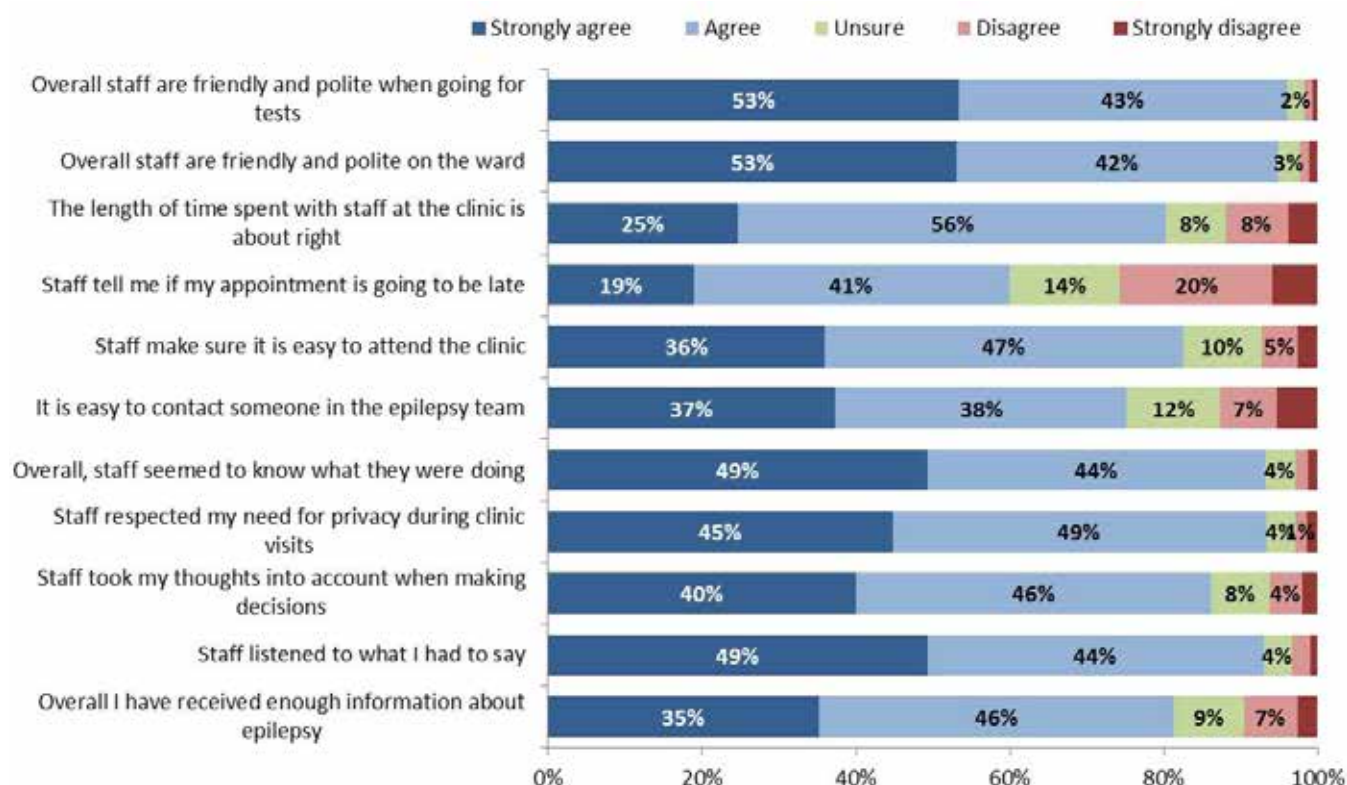
The following information was provided by the child or young person with epilepsy or their parent or carer if they were unable to respond. Out of the 2,335 completed questionnaires, 710 (30%) were completed by the child or young person, 1,550 (66%) by the parent or carer and it was not clear who had responded in 75 (3%). The respondent was also asked whether they completed the questionnaire before their clinic appointment (1,210 or 52%), after the appointment (774 or 33%) or a combination of before and after the appointment (209 or 9%).

Respondents were asked to indicate whether they agreed or disagreed with a number of statements about the epilepsy service. It is important to note that Figures 35 and 36 relate to levels of agreement about positive elements of the epilepsy service whereas figures 37 and 38 relate to negative statements.

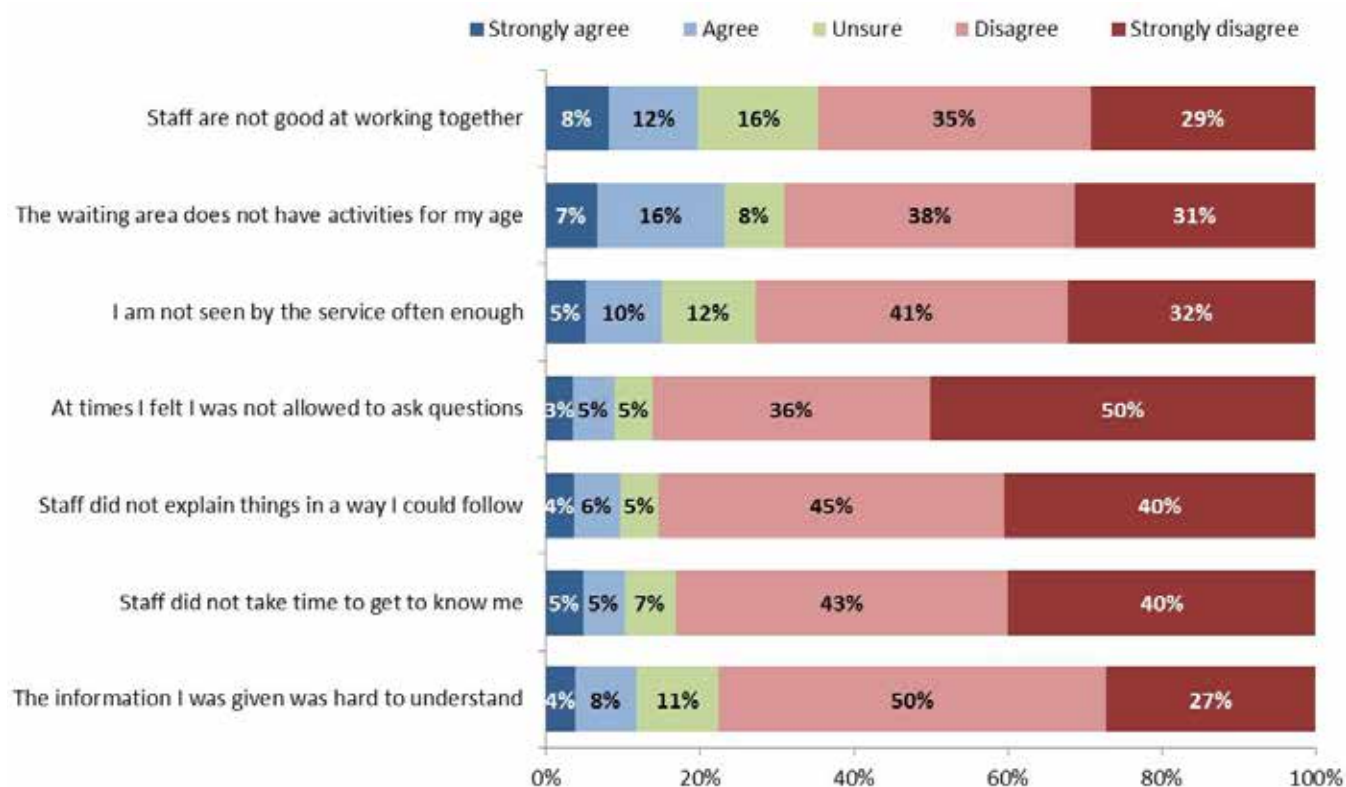
**Figure 35: Young peoples' responses to positive statements in questionnaire**

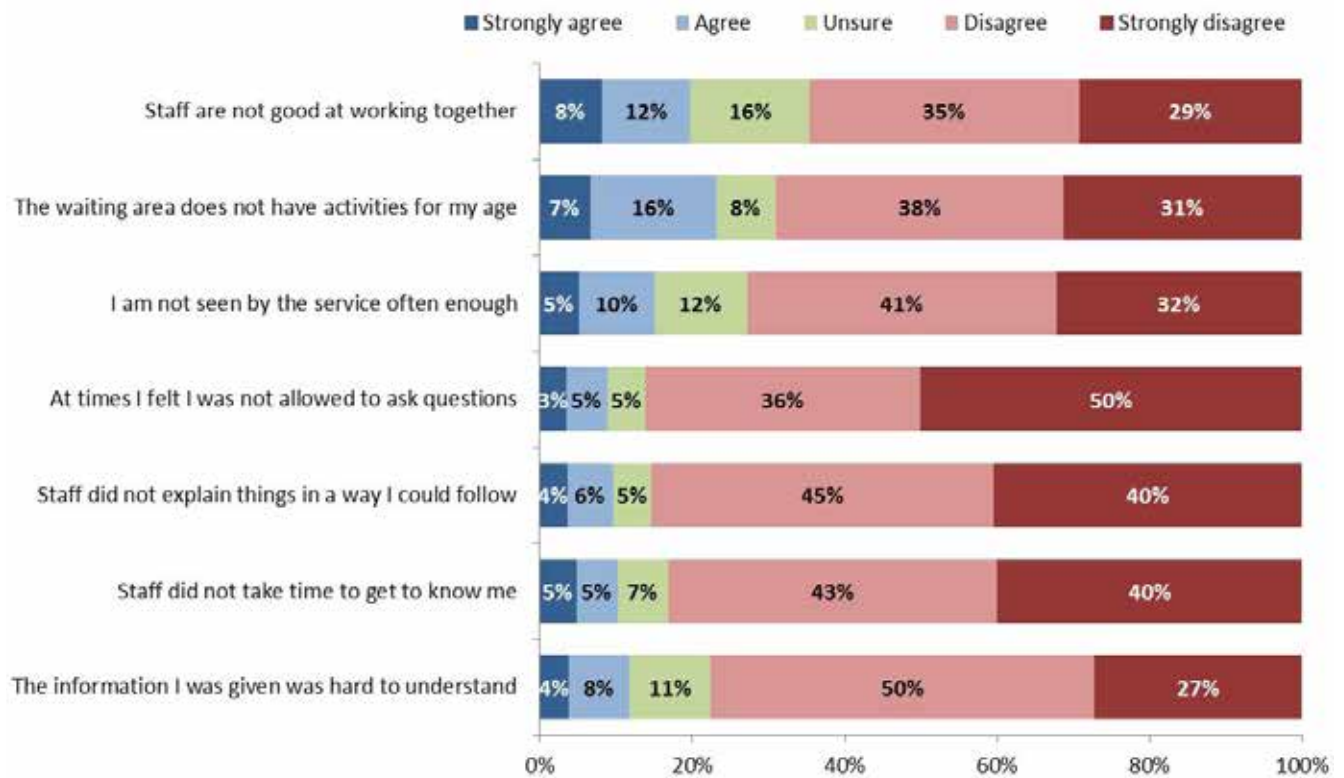


**Figure 36: Parent/carer responses to positive statements in questionnaire**



**Figure 37: Young peoples' responses to negative statements in questionnaire**



**Figure 38: Parent/carer responses to negative statements in questionnaire****Table 24: Impressions of the paediatric epilepsy service**

		Strongly agree	Agree	Unsure	Disagree	Strongly disagree
Levels of agreement with positive statements						
Overall I have received enough information about epilepsy	Young people	224	349	85	25	10
		32%	50%	12%	4%	1%
	Parent/carers	527	691	137	103	39
		35%	46%	9%	7%	3%
Staff listened to what I had to say	Young people	362	291	34	2	6
		52%	42%	5%	0%	1%
	Parent/carers	736	653	55	35	15
		49%	44%	4%	2%	1%
Staff took my thoughts into account when making decisions	Young people	237	315	88	29	14
		35%	46%	13%	4%	2%
	Parent/carers	575	661	111	61	28
		40%	46%	8%	4%	2%
Staff respected my need for privacy during clinic visits	Young people	258	348	47	12	9
		38%	52%	7%	2%	1%
	Parent/carers	632	686	54	21	20
		45%	49%	4%	1%	1%

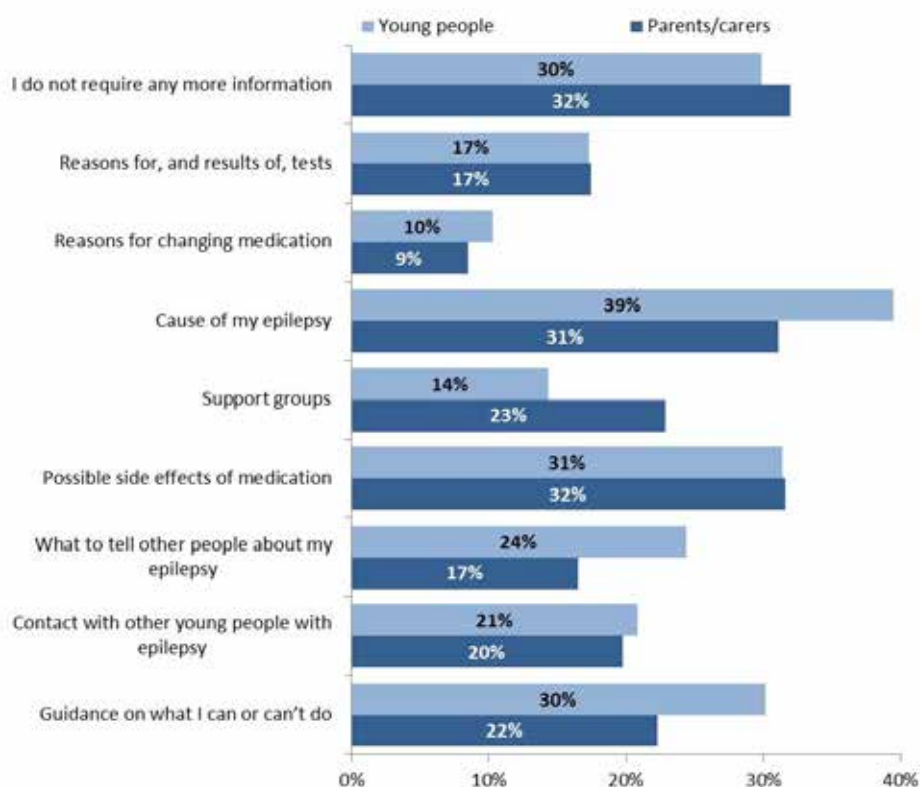
		Strongly agree	Agree	Unsure	Disagree	Strongly disagree
Overall, staff seemed to know what they were doing	Young people	398	251	26	9	8
		58%	36%	4%	1%	1%
	Parent/carers	720	640	56	25	18
		49%	44%	4%	2%	1%
It is easy to contact someone in the epilepsy team	Young people	205	220	161	35	21
		32%	34%	25%	5%	3%
	Parent/carers	535	543	174	106	75
		37%	38%	12%	7%	5%
Staff make sure it is easy to attend the clinic	Young people	221	303	104	34	11
		33%	45%	15%	5%	2%
	Parent/carers	524	680	150	67	38
		36%	47%	10%	5%	3%
Staff tell me if my appointment is going to be late	Young people	121	239	119	113	44
		19%	38%	19%	18%	7%
	Parent/carers	255	552	194	267	79
		19%	41%	14%	20%	6%
The length of time spent with staff at the clinic is about right	Young people	155	384	85	37	16
		23%	57%	13%	5%	2%
	Parent/carers	345	775	109	113	53
		25%	56%	8%	8%	4%
Overall staff are friendly and polite in the ward	Young people	265	213	22	5	7
		52%	42%	4%	1%	1%
	Parent/carers	658	518	36	15	13
		53%	42%	3%	1%	1%
Overall staff are friendly and polite when going for tests	Young people	342	269	18	7	4
		53%	42%	3%	1%	1%
	Parent/carers	702	560	29	15	8
		53%	43%	2%	1%	1%
Levels of agreement with negative statements						
The information I was given was hard to understand	Young people	22	108	142	281	122
		3%	16%	21%	42%	18%
	Parent/carers	53	113	150	710	384
		4%	8%	11%	50%	27%
Staff did not take time to get to know me	Young people	29	45	75	258	274
		4%	7%	11%	38%	40%
	Parent/carers	69	78	95	622	572
		5%	5%	7%	43%	40%
Staff did not explain things in a way I could follow	Young people	23	47	55	30	253
		6%	12%	13%	7%	62%
	Parent/carers	51	86	71	636	574
		4%	6%	5%	45%	40%



		Strongly agree	Agree	Unsure	Disagree	Strongly disagree
At times I felt I was not allowed to ask questions	Young people	22	35	54	259	314
		3%	5%	8%	38%	46%
	Parent/carers	49	76	72	510	711
		3%	5%	5%	36%	50%
I am not seen by the service often enough	Young people	16	48	121	275	211
		2%	7%	18%	41%	31%
	Parent/carers	72	140	173	575	456
		5%	10%	12%	41%	32%
The waiting area does not have activities for my age	Young people	161	237	54	125	69
		25%	37%	8%	19%	11%
	Parent/carers	91	224	107	514	426
		7%	16%	8%	38%	31%
Staff are not good at working together	Young people	35	60	113	223	205
		6%	9%	18%	35%	32%
	Parent/carers	108	156	209	473	391
		8%	12%	16%	35%	29%

The questionnaire included a question asking people what subjects they would like more information on. The results in figure 39 and table 25 below show that many respondents wanted further information on the causes of their epilepsy (particularly the young people), the possible side effects of medication and guidance on what they can or cannot do. 30% of young people and 32% of parents/carers indicated that they did not need any more information.

**Figure 39: Information needs**



**Table 25: Information needs**

	Young people N=710		Parents/carers N=1550	
I do not require any more information	212	30%	496	32%
Reasons for, and results of, tests	123	17%	270	17%
Reasons for changing medication	73	10%	132	9%
Cause of my epilepsy	280	39%	482	31%
Support groups	102	14%	355	23%
Possible side effects of medication	223	31%	489	32%
What to tell other people about my epilepsy	173	24%	256	17%
Contact with other young people with epilepsy	148	21%	306	30%
Guidance on what I can or can't do	214	30%	345	22%

Overall 1,897 out of 2,148 (88%) who answered the relevant question reported that they were satisfied with the care they received from the epilepsy service whilst 187 (9%) indicated that they were unsure whether they were satisfied. 64 (3%) stated that they were not satisfied with their overall care.

Overall satisfaction was similar for parents/carers completing the questionnaire (87%) and for the young people responding to the questionnaire (90%).

**Table 26: Overall satisfaction with the epilepsy service**

Overall, are you satisfied with the care you receive from the epilepsy service?	Parents/carers and young people combined who answered the question N=2148
Yes	88 % (1897/2148)
No	3% (64/2148)
Unsure	9% (187/2148)

## 5. References

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2. National Institute for Health Clinical Excellence. **The epilepsies: The diagnosis and management of the epilepsies in adults and children.** CG20. Department of Health, London; 2004 ([revised 2012])
3. Scottish Intercollegiate Guidelines Network. **Diagnosis and management of epilepsies in children and young people (SIGN 81).** SIGN, Edinburgh; 2005
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5. **Payment by Results (PbR) tariff for payment of healthcare providers over 2013 to 2014** (see paragraphs 490 to 500 at: [www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/214902/PbR-Guidance-2013-14.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/214902/PbR-Guidance-2013-14.pdf))
6. **British Paediatric Neurology Association (BPNA) Paediatric Epilepsy Training (PET) courses:** [www.bpna.org.uk/pet](http://www.bpna.org.uk/pet)
7. **RCPCH Framework of Competencies for a Special Interest Module in Paediatric Epilepsies,** 2013:  
[www.rcpch.ac.uk/system/files/protected/page/20130814%20RCPCH%20Spin%20in%20Epilepsy%20lara%20edit.pdf](http://www.rcpch.ac.uk/system/files/protected/page/20130814%20RCPCH%20Spin%20in%20Epilepsy%20lara%20edit.pdf)
8. **Specialist nursing of children and young people with epilepsy - RCN guidance for service planning and career development** August, 2013  
[www.rcn.org.uk/\\_\\_data/assets/pdf\\_file/0006/554226/004514.pdf](http://www.rcn.org.uk/__data/assets/pdf_file/0006/554226/004514.pdf)
9. **Epilepsy12 Round 2 Background and Methodology:** [www.rcpch.ac.uk/epilepsy12/methodology](http://www.rcpch.ac.uk/epilepsy12/methodology)



## **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 6:** Clinical Performance Indicators Definitions

## Appendix 1: Glossary and definitions

<b>Acute</b>	Inpatient review, or paediatric review in emergency department, or other clinical assessment in an acute paediatric setting
<b>Acute Symptomatic Seizures</b>	Seizures occurring at the time of a diagnosis of an acute disorder e.g. meningitis, encephalitis, electrolyte disturbance etc.)
<b>Anti Epileptic Drug (AED)</b>	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.)
<b>'Audit Unit'</b>	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
<b>Cardiovascular Examination</b>	Examination of the cardiovascular system to at least include cardiac auscultation
<b>Children's Epilepsy Specialist Nurse</b>	A children's nurse with a defined role and specific qualification and/or training in children's epilepsies
<b>Consultant General Paediatrician</b>	A paediatric consultant (or associate specialist) with a role that includes seeing children or young people in a general outpatient or community clinic setting. They may or may not have other specialty or acute roles. They are likely to receive referrals directly from primary care. Neonatologists would not be included in this definition unless they also fulfil general paediatric roles.
<b>Convulsive episode</b>	An episode where there is symmetrical or asymmetrical limb motor involvement (tonic, clonic, tonic-clonic). Myoclonic seizures excluded.
<b>Date of first paediatric assessment</b>	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
<b>Epilepsy</b>	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.
<b>Epilepsy Syndrome</b>	A complex of clinical features, signs and symptoms that together define a distinctive, recognizable clinical disorder (ILAE)
<b>'Epilepsy Syndrome Category'</b>	A group of epilepsies described using the terms idiopathic primary, symptomatic, probably symptomatic and cryptogenic and focal, partial, multifocal or generalized
<b>Epileptic seizure</b>	Clinical manifestation(s) of epileptic (excessive and/or hypersynchronous), usually self-limited activity of neurons in the brain. (ILAE)
<b>Febrile seizure</b>	An episode diagnosed by the assessing team as a 'febrile seizure' or 'febrile convulsion' or 'febrile fit'

<b>First paediatric assessment</b>	<p>A 'face to face' assessment by a secondary level/tier doctor in a paediatric service occurring in any non-acute or acute setting.</p> <p>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</p>
<b>First year</b>	Time period from 'date of first paediatric assessment' to 12 months following that date
<b>General examination</b>	Any evidence of a multisystem examination of the child other than neurological examination
<b>Handover clinic</b>	A clinic where a young people 'leaves the paediatric service and joins an adult service' and comprises both adult and paediatric health professionals
<b>Input</b>	Any form of documented clinical contact including face to face clinical, written, electronic or telephone contact
<b>Neurodisability</b>	<p>Documented diagnosis including any of the following phrases indicating the diagnosis made by the assessing team:</p> <ul style="list-style-type: none"> <li>• Autistic spectrum disorder</li> <li>• Moderate, severe (or profound) learning difficulty or global development delay</li> <li>• Cerebral palsy</li> <li>• Neurodegenerative disease or condition</li> <li>• An identified chromosomal disorder with a neurological or developmental component</li> <li>• Attention deficit hyperactivity disorder (ADHD)</li> <li>• Exclusions e.g. hypermobility, dyspraxia, specific learning difficulties e.g. (dyslexia, dyscalculia)</li> </ul>
<b>Neurological examination</b>	Any evidence of a neurological examination of the child
<b>Non acute</b>	Paediatric outpatients or clinic
<b>Paediatrician with expertise</b>	<p>A paediatric consultant (or associate specialist) defined by themselves, their employer and tertiary service/network as having:</p> <ul style="list-style-type: none"> <li>• training and continuing education in epilepsies</li> <li>• AND peer review of practice</li> <li>• AND regular audit of diagnosis (e.g. participation in Epilepsy12)</li> </ul> <p>(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'.</p>
<b>Paroxysmal episodes</b>	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.
<b>'School age'</b>	Child 5 years and older (past their 5th birthday)

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

## Appendix 2: Participating units

**Audit Units that entered both complete service descriptor data and at least one clinical audit case for Round 2 of Epilepsy12**

Epilepsy12 Audit Unit Name	Health Board/Trust Name
Aberdeen, Elgin & Grampian, Orkney and Shetland	<ul style="list-style-type: none"> <li>NHS Grampian</li> <li>NHS Shetland</li> </ul>
Aberystwyth	Hywel Dda University Health Board
Airedale General Hospital	Airedale NHS Foundation Trust
Altnagelvin	Western Health and Social Care Trust
Ashford	Ashford and St Peter's Hospitals NHS Foundation Trust
Ayrshire	NHS Ayrshire & Arran
Barnet and Chase Farm Hospital	Barnet and Chase Farm Hospitals NHS Trust
Barnsley	Barnsley Hospital NHS Foundation Trust
Basildon University Hospital	Basildon and Thurrock University Hospitals NHS Foundation Trust
Bath	Royal United Hospital Bath NHS Trust
Bedford	<ul style="list-style-type: none"> <li>Bedford Hospitals NHS Trust</li> <li>South Essex Partnership University NHS Foundation Trust</li> </ul>
Belfast	Belfast Health and Social Care Trust
Birmingham	<ul style="list-style-type: none"> <li>Birmingham Region Children's Hospital NHS Foundation Trust</li> <li>Birmingham Region Community Healthcare NHS Trust</li> </ul>
Birmingham Heartlands	Heart of England NHS Foundation Trust
Blackpool	Blackpool Teaching Hospitals NHS Foundation Trust
Bolton	Bolton NHS Foundation Trust
Bradford	Bradford Teaching Hospitals NHS Foundation Trust
Bristol	<ul style="list-style-type: none"> <li>North Bristol Region NHS Trust</li> <li>University Hospitals Bristol Region NHS Foundation Trust</li> </ul>
Buckshealth	Buckinghamshire Healthcare NHS Trust
Calderdale & Huddersfield	Calderdale and Huddersfield NHS Foundation Trust
Cambridge	Cambridge University Hospitals NHS Foundation Trust
Camden Paediatric Epilepsy Service	<ul style="list-style-type: none"> <li>Royal Free London NHS Foundation Trust</li> <li>University College London Hospitals NHS Foundation Trust</li> <li>Central and North West London NHS Foundation Trust</li> </ul>

<b>Epilepsy12 Audit Unit Name</b>	<b>Health Board/Trust Name</b>
Cardiff and Vale University Health Board	Cardiff & Vale University Health Board
Carmarthen	Hywel Dda University Health Board
Central Manchester	Central Manchester University Hospitals NHS Foundation Trust
Chelmsford	Mid Essex Hospital Services NHS Trust
Chelsea & Westminster Hospital	Chelsea and Westminster Hospital NHS Foundation Trust
Chester	Countess of Chester Hospital NHS Foundation Trust
Chesterfield	Chesterfield Royal Hospital NHS Foundation Trust
Child Health Business Unit: Northumbria Healthcare	Northumbria Healthcare NHS Foundation Trust
Colchester	Colchester Hospital University NHS Foundation Trust
Conquest Hospital	East Sussex Healthcare NHS Trust
Crewe	The Mid Cheshire Hospitals NHS Foundation Trust
Croydon	Croydon Health Services NHS Trust
Darent Valley Hospital	Dartford and Gravesham NHS Trust
Darlington & Bishop Auckland	County Durham and Darlington NHS Foundation Trust
Denbigh and Colwyn Bay	Betsi Cadwaladr University Health Board
Department of Paediatrics North Devon District Hospital Barnstaple	Northern Devon Healthcare NHS Trust
Derby	Derby Hospitals NHS Foundation Trust
Dewsbury	Mid Yorkshire Hospitals NHS Trust
Doncaster & Bassetlaw Hospital Foundation NHS Trust - Doncaster Royal Infirmary	Doncaster and Bassetlaw Hospitals NHS Foundation Trust
Dorset	Dorset County Hospital NHS Foundation Trust
Dudley	The Dudley Group NHS Foundation Trust
Durham	County Durham and Darlington NHS Foundation Trust
Ealing Hospital NHS Trust	Ealing Hospital NHS Trust
East and North Hertfordshire NHS Trust	East & North Hertfordshire NHS Trust
East Lancashire Hospitals Trust	East Lancashire Hospitals NHS Trust

Epilepsy12 Audit Unit Name	Health Board/Trust Name
Eastbourne District Hospital	East Sussex Healthcare NHS Trust; Sussex Community NHS Trust
Edinburgh	NHS Lothian
Epsom General Hospital	Epsom and St Helier University Hospitals NHS Trust
Exeter	Royal Devon and Exeter NHS Foundation Trust
Fairfield General Hospital	Pennine Acute Hospitals NHS Trust
Frimley Park Hospital	Frimley Park Hospital NHS Foundation Trust
Furness	University Hospitals of Morecambe Bay NHS Foundation Trust
Gateshead	Gateshead Health NHS Foundation Trust
Glasgow	NHS Greater Glasgow and Clyde
Gloucestershire Paediatric Epilepsy Service	Gloucestershire Hospitals NHS Foundation Trust
Good Hope Hospital: Sutton Coldfield	Heart of England NHS Foundation Trust
Great Yarmouth	James Paget University Hospitals NHS Foundation Trust
Grimsby	Northern Lincolnshire & Goole Hospitals NHS Foundation Trust
Guildford	Royal Surrey County Hospital NHS Foundation Trust
Hampshire Hospitals Foundation Trust - Royal Hampshire County Hospital	Hampshire Hospitals NHS Foundation Trust
Harlow	The Princess Alexandra Hospital NHS Trust
Harrogate	Harrogate and District NHS Foundation Trust
Haverfordwest	Hywel Dda University Health Board
Hereford	Wye Valley NHS Trust
Hillingdon Hospital	The Hillingdon Hospitals NHS Foundation Trust
Homerton Hospital	Homerton University Hospital NHS Foundation Trust
Hull and East Yorkshire NHS Trust	Hull and East Yorkshire Hospitals NHS Trust
Huntingdon	Hinchingbrooke Health Care NHS Trust
Inverclyde	NHS Greater Glasgow and Clyde
Ipswich	Ipswich Hospital NHS Trust

Epilepsy12 Audit Unit Name	Health Board/Trust Name
Isle of Wight	Isle of Wight NHS Trust
Kettering	Kettering General Hospital NHS Foundation Trust
King's College Hospital	<ul style="list-style-type: none"> <li>Kings College Hospital NHS Foundation Trust</li> <li>Guy's and St Thomas' NHS Foundation Trust</li> </ul>
King's Lynn	The Queen Elizabeth Hospital King's Lynn NHS Foundation Trust
Kingston Hospital	Kingston Hospital NHS Trust
Kirkcaldy	NHS Fife
Lancaster	University Hospitals of Morecambe Bay NHS Foundation Trust
Leeds	<ul style="list-style-type: none"> <li>Leeds Teaching Hospitals NHS Trust</li> <li>Leeds Community Healthcare NHS Trust</li> </ul>
Leicester	University Hospitals of Leicester NHS Trust
Lewisham Hospital	Lewisham and Greenwich NHS Trust
Lincoln	United Lincolnshire Hospitals NHS Trust
Liverpool	Alder Hey Children's NHS Foundation Trust
Livingston	NHS Lothian
Luton	Luton and Dunstable Hospital NHS Foundation Trust
Macclesfield	East Cheshire NHS Trust
Manor Hospital: Walsall	Walsall Healthcare NHS Trust
Mansfield	Sherwood Forest Hospitals NHS Foundation Trust
Medway Maritime Hospital	Medway NHS Foundation Trust
Melrose	NHS Borders
Middlesbrough	South Tees Hospitals NHS Foundation Trust
Milton Keynes	Milton Keynes Hospital NHS Foundation Trust
Neath & Port Talbot	Abertawe Bro Morgannwg University Health Board
Nevill Hall Hospital	Aneurin Bevan University Health Board
Newcastle	The Newcastle upon Tyne Hospitals NHS Foundation Trust
Newham General Hospital	<ul style="list-style-type: none"> <li>Barts Health NHS Trust</li> <li>East London NHS Foundation Trust</li> </ul>



Epilepsy12 Audit Unit Name	Health Board/Trust Name
NHS Highland	NHS Highland
Norfolk and Norwich University Hospital NHS Foundation Trust	<ul style="list-style-type: none"> <li>Norfolk &amp; Norwich University Hospitals NHS Foundation Trust</li> <li>Norfolk Community Health and Care NHS Trust</li> </ul>
North Manchester General Hospital	Pennine Acute Hospitals NHS Trust
Northallerton	South Tees Hospitals NHS Foundation Trust
Northampton	Northampton General Hospital NHS Trust
Northern Trust	Northern Health and Social Care Trust
Nottingham	Nottingham University Hospitals NHS Trust
Nuneaton, Coventry & Rugby	<ul style="list-style-type: none"> <li>George Eliot Hospital NHS Trust</li> <li>University Hospitals Coventry and Warwickshire NHS Trust</li> <li>Coventry and Warwickshire Partnership Trust</li> </ul>
Oldham	<ul style="list-style-type: none"> <li>Pennine Acute Hospitals NHS Trust</li> <li>Pennine Care NHS Foundation Trust</li> </ul>
Ormskirk	Southport and Ormskirk Hospital NHS Trust
Oxford	Oxford University Hospitals NHS Trust
Paisley & Vale of Leven	NHS Greater Glasgow and Clyde
Peterborough	<ul style="list-style-type: none"> <li>Peterborough and Stamford Hospitals NHS Foundation Trust</li> <li>Cambridgeshire Community Services NHS Trust</li> </ul>
Pilgrim Hospital: Boston	United Lincolnshire Hospitals NHS Trust
Pontefract & Castleford	Mid Yorkshire Hospitals NHS Trust
Poole Hospital Foundation NHS Trust	Poole Hospital NHS Foundation Trust
Portsmouth	<ul style="list-style-type: none"> <li>Portsmouth Hospitals NHS Trust</li> <li>Solent NHS Trust</li> </ul>
Powys	Powys Teaching Local Health Board
Preston	Lancashire Teaching Hospitals NHS Foundation Trust
Prince Charles Hospital: Merthyr Tydfil	Cwm Taf University Health Board
Princess Royal University Hospital	King's College Hospital NHS Foundation Trust
Queen Mary's Hospital for Children	Epsom and St Helier University Hospital NHS Trust
Queen's Hospital & Havering	Barking, Havering and Redbridge University Hospitals NHS Trust
Rochdale	Pennine Acute Hospitals NHS Trust
Rotherham	The Rotherham NHS Foundation Trust

Epilepsy12 Audit Unit Name	Health Board/Trust Name
Royal Alexandra Hospital for Sick Children: Brighton	<ul style="list-style-type: none"> <li>Brighton and Sussex University Hospitals NHS Trust</li> <li>Sussex Community NHS Trust</li> </ul>
Royal Berkshire	Royal Berkshire NHS Foundation Trust
Royal Cornwall Hospital	Royal Cornwall Hospitals NHS Trust
Royal Glamorgan Hospital - Ynysmaerdy	Cwm Taf University Health Board
Royal London Hospital	Barts Health NHS Trust
Royal Wolverhampton NHS Trust	The Royal Wolverhampton Hospitals NHS Trust
Salford	Salford Royal NHS Foundation Trust
Salisbury	Salisbury NHS Foundation Trust
Sandwell	Sandwell and West Birmingham Hospitals NHS Trust
Scunthorpe	<ul style="list-style-type: none"> <li>Doncaster and Bassetlaw Hospitals NHS Foundation Trust</li> <li>Northern Lincolnshire &amp; Goole Hospitals NHS Foundation Trust</li> </ul>
Sheffield	Sheffield Children's NHS Foundation Trust
Shrewsbury and Telford NHS Trust	Shrewsbury & Telford Hospitals NHS Trust
South Gwent	Aneurin Bevan University Health Board
South Manchester	<ul style="list-style-type: none"> <li>University Hospital of South Manchester Region NHS Foundation Trust</li> <li>Central Manchester University Hospitals NHS Foundation Trust</li> </ul>
South Tyneside NHS Foundation Trust	South Tyneside NHS Foundation Trust
Southampton	University Hospital Southampton NHS Foundation Trust
St George's Hospital	St George's Healthcare NHS Trust
St Mary's Hospital	Imperial College Healthcare NHS Trust
St Richard's Hospital: Chichester	Western Sussex Hospitals NHS Foundation Trust
Stafford	Mid Staffordshire NHS Foundation Trust
Stirling & Falkirk	NHS Forth Valley
Stockport	Stockport NHS Foundation Trust
Stoke-on-Trent	University Hospital of North Staffordshire NHS Trust
Sunderland	City Hospitals Sunderland NHS Foundation Trust
Swansea	Abertawe Bro Morgannwg University Health Board

Epilepsy12 Audit Unit Name	Health Board/Trust Name
Swindon	Great Western Hospitals NHS Foundation Trust
Tameside Hospital NHS Foundation Trust	Tameside Hospital NHS Foundation Trust
Taunton	Taunton & Somerset NHS Trust
Tayside	NHS Tayside
Torbay	South Devon Healthcare NHS Foundation Trust
Tunbridge Wells Hospital: Pembury	Maidstone and Tunbridge Wells NHS Trust
Ulster Hospital	South Eastern Health and Social Care Trust
University Hospital of North Tees and Hartlepool	North Tees and Hartlepool NHS Foundation Trust
Wakefield	Mid Yorkshire Hospitals NHS Trust
Waltham Forest Epilepsy Service -Whipps Cross Hospital	<ul style="list-style-type: none"> <li>• Barts Health NHS Trust</li> <li>• North East London NHS Foundation Trust</li> </ul>
Warrington Hospital	Warrington and Halton Hospitals NHS Foundation Trust
Warwick	South Warwickshire NHS Foundation Trust
Watford General Hospital	<ul style="list-style-type: none"> <li>• West Hertfordshire Hospitals NHS Trust</li> <li>• Hertfordshire Community NHS Trust</li> </ul>
West Middlesex University Hospital	West Middlesex University Hospital NHS Trust
West Suffolk Hospital	West Suffolk NHS Foundation Trust
Weston	Weston Area Health NHS Trust
Wexham Park Hospital	Heatherwood and Wexham Park Hospitals NHS Trust
Whiston	St Helens and Knowsley Hospitals NHS Trust
Whittington Hospital	Whittington Health
Wishaw	NHS Lanarkshire
Worcestershire Acute Hospitals Trust	Worcestershire Acute Hospitals NHS Trust
Worthing Hospital	Western Sussex Hospitals NHS Trust
Wrexham Maelor Hospital	Betsi Cadwaladr University Health Board
Yeovil District Hospital	Yeovil District Hospital NHS Foundation Trust
York	York Teaching Hospital NHS Foundation Trust
Ysbyty Gwynedd: Bangor	Betsi Cadwaladr University Health Board

**Audit Units that entered complete Service Descriptor data but did not enter any Clinical Audit cases for Round 2 of Epilepsy12**

Epilepsy12 Audit Unit Name	Health Board/Trust Name
Argyll and Bute Community Health Partnerships	NHS Highland
Burton Hospital NHS Foundation Trust	Burton Hospitals NHS Trust
Crawley and Horsham	<ul style="list-style-type: none"> <li>Surrey and Sussex Healthcare NHS Trust</li> <li>Sussex Community NHS Trust</li> </ul>
East Kent Hospitals University NHS Foundation Trust	East Kent Hospitals University NHS Foundation Trust
Guy's and St Thomas'	Guy's and St Thomas' NHS Foundation Trust
Hampshire Hospitals Foundation Trust - North Hampshire Hospital	Hampshire Hospitals NHS Foundation Trust
North West London Hospitals (Northwick Park and Central Middlesex Hospitals)	North West London Hospitals NHS Trust
Paediatric Department, Cumberland Infirmary	North Cumbria University Hospitals NHS Trust
Queen Elizabeth Hospital, Woolwich	Lewisham and Greenwich NHS Trust
West Kent	Kent Community Health NHS Trust
Whitehaven	North Cumbria University Hospitals NHS Trust
Wigan Infirmary	Wrightington, Wigan & Leigh NHS Foundation Trust
Wirral	Wirral University Teaching Hospital NHS Foundation Trust

**Audit Units that entered at least one Clinical Audit case but no Service Descriptor data for Round 2 of Epilepsy12**

Epilepsy12 Audit Unit Name	Health Board/Trust Name
Redditch	Worcestershire Acute Hospitals NHS Trust

## 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'?	<ul style="list-style-type: none"> <li>Response is numerical to two decimal points</li> </ul>	<p><i>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.</i></p> <p><i>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.</i></p>
2. How many whole time equivalent (WTE) general paediatric consultants with 'expertise in epilepsy' are there employed within the 'audit unit'? (Paediatric neurologists should not be included in your response.)	<ul style="list-style-type: none"> <li>Response is numerical to two decimal points</li> </ul>	<p><i>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).</i></p>
3. How many whole time equivalent (WTE) epilepsy specialist nurses (ESNs) are there employed within the 'audit unit'?	<ul style="list-style-type: none"> <li>Response is numerical to two decimal points</li> </ul>	<p><i>ESN (epilepsy specialist nurse) - A children's nurse with a defined role and specific qualification and/or training in children's epilepsies.</i></p>
4. 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?	<ul style="list-style-type: none"> <li>Response is numerical to two decimal points</li> </ul>	<p><i>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).</i></p> <p><i>An 'Epilepsy Clinic' is defined as a paediatric clinic where all the children and young people attending have epilepsy or possible epileptic seizures.</i></p>
5. Do any of the paediatric services within the 'audit unit' maintain a database or register of children with epilepsies?	<p>Select one from:</p> <ul style="list-style-type: none"> <li>Yes for all children</li> <li>Yes for some children</li> <li>No</li> </ul>	

<p>6. Which of the following investigations can be obtained at a location within the 'audit unit'?</p> <ul style="list-style-type: none"> <li>a. 12 lead ECG</li> <li>b. 'awake' MRI</li> <li>c. MRI with sedation</li> <li>d. MRI with general anaesthetic</li> <li>e. Routine EEG</li> <li>f. Sleep-deprived EEG</li> <li>g. Melatonin induced EEG</li> <li>h. Sedated EEG</li> <li>i. 24-48h ambulatory EEG</li> <li>j. Inpatient Video telemetry</li> <li>k. Outpatient Video Telemetry</li> <li>l. Home video telemetry</li> <li>m. Portable EEG on paediatric ward within audit unit</li> </ul>	<p>Select one from: Yes / No / Uncertain</p>	<p><i>For each of questions 6a) to 6m):</i></p> <p><i>If the child would have to travel to a location outside of the audit unit to have the investigation undertaken then answer 'No'.</i></p>
<p>7. 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')</p>	<p>Possible answer: Yes / No</p>	
<p>8. Which of the following 'transition services' are available within the 'audit unit'?</p> <ul style="list-style-type: none"> <li>a. A specific clinic for 'young people' or 'teenagers' with epilepsies</li> <li>b. a 'Handover clinic'</li> <li>c. Other defined handover or referral process</li> <li>d. Local adult specialist epilepsy nurse</li> <li>e. Youth worker</li> <li>f. 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?</li> </ul>	<p>Select one from: Yes / No / Uncertain</p> <p>Question 8f) Input a number</p>	

## Appendix 4: Clinical audit questionnaire

### Add a patient section

[illegible]

If the child has not been excluded this far into data entry when you click the “Next” icon on the web tool this particular patient will be granted a UIN and should be treated as part of the unit’s clinical audit cohort.

## Clinical Audit Questionnaire Part 1

Unique Identification Number (UIN):

Question	Please record your answer	Help
1. Has the UIN been noted on the ascertainment sheet?	Yes/No	<i>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.</i>
2. General Practice code		<i>This can be found on the hospital electronic record.</i>
3. Was the first paediatric assessment in an acute or non-acute setting?	Acute Non- acute Don't know	
4. 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  b. Approximately when the first episode was, or how old the child was at that time?  c. The approximate frequency or number of episodes since the first episode?  d. A general examination?  e. A neurological examination?  f. The presence or absence of developmental, learning or schooling problems  g. The presence or absence of behavioural or emotional problems?	Yes / No  Yes / No  Yes / No  Yes / No  Yes, this issue was assessed/ No, this issue was not assessed  Yes, this issue was assessed/ No, this issue was not assessed	<i>e. Any documentation that suggests that part of the neurological system has been formally examined should be answered 'yes'; If neurological system is not specifically mentioned (e.g. examination normal) then answer 'no'.  g. Only asked if child [age at first paediatric assessment] is 36 months or greater</i>



Question	Please record your answer	Help
5. Comments		<i>Please add any comments you would like to be taken into account based on your response above</i>
6. Which statement best describes the number of paroxysmal episodes by the time of the first paediatric assessment?	<ul style="list-style-type: none"> <li>- A single episode</li> <li>- A cluster of episodes within a 24 hour period</li> <li>- 2 or more episodes (occurring over a time period greater than 24 hours)</li> </ul>	
7. Which statement best describes the diagnosis made by the paediatric team by the end of the <u>first paediatric assessment</u> ?	<ul style="list-style-type: none"> <li>- Epileptic or probably epileptic episode(s)</li> <li>- Non-epileptic episode(s)</li> <li>- Uncertain or unclear episode(s)</li> </ul>	
8. Was a diagnosis of probable syncope, faints, breath-holding episodes or reflex anoxic seizures made?	Yes / No	<b>Only asked where Q7 answered 'non-epileptic episode(s)' at first assessment.</b>
9. Was a diagnosis of probable tics made?	Yes / No	<b>Only asked where Q7 answered 'non-epileptic episode(s)' at first assessment.</b>
10. Comments		<i>Optional</i> <i>Please add any comments you would like to be taken into account based on your response above</i>

## Clinical Audit Questionnaire: Part 2

To be completed once 12 months of care has been given from the date entered in the answer to question 4 of the Add a patient section. The UIN would have been allocated following completion of the "Add a patient section" on the Epilepsy12 web tool.

Unique Identification Number (UIN):

Question	Please record your answer	Help
11. Was the patient's care permanently transferred to a secondary paediatric service outside the 'audit unit' boundaries or to an adult service during the year after first paediatric assessment?	Possible answer: Yes/No  NB: "No" = eligible (proceed to question 12)  "Yes" = excluded*	<i>For example, the child has moved home address. If answer YES – the patients are then 'excluded' and no further questions are required. Referral for tertiary paediatric neurology care does not count as a transfer of secondary care.</i>

\*Please note if you have selected "Yes" as the answer for question 11 then the data entry webtool will exclude the patient from your sample cohort as the patient is no longer eligible for further data entry. You will not need to answer any further questions for this patient if you have answered Yes to question 11.

Question	Please record your answer	Help
12. Did the EEG referral request include the appropriate clinical information?	Possible answer: Yes / No / Not answered	<i>This question's answer is determined from the EEG list. If your EEG service have not taken part in this optional part of the audit select 'not answered'</i>
13. Was the EEG requested for appropriate reasons?  (PLEASE NOTE: question 14 will only be available if you answer "No" to this question.)	Possible answer: Yes / No / Not answered	<i>This question's answer is determined from the EEG list. If your EEG service have not taken part in this optional part of the audit select 'not answered'</i>
14. If "No", state the main reason why inappropriate request	One possible answer from: a) No paroxysmal episodes b) Single paroxysmal episode c) Episode(s) already diagnosed d) EEG requested to exclude epilepsy e) Other (please specify)	<i>This question's answer is determined from the EEG list</i>
15. Which statement best describes the total number of paroxysmal episodes occurring by 12 months after first paediatric assessment?  (PLEASE NOTE: questions 19, 20, 21, 22, 35, and 37 will only be available if option c) "2 or more episodes (occurring over a time period greater than 24 hours)" is answered for this question AND the question 16 answer is a) "Epileptic or probably epileptic episodes(s)".	One possible answer from: a) A single episode b) A cluster of episodes (confined to a 24 hour period) c) 2 or more episodes (occurring over a time period greater than 24 hours)	<i>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</i>
16. Which statement best describes the diagnosis made by the paediatric team by the end of the 12 months after first paediatric assessment?  (PLEASE NOTE: questions 19, 20, 21, 22, 35, and 37 will only be available if this question is answered as "a) Epileptic or probably epileptic episodes(s)" AND the answer to question 15 is c) "2 or more episodes (occurring over a time period greater than 24 hours)".	One possible answer from: a) Epileptic or probably epileptic episode(s) b) Non-epileptic episode(s) Uncertain or unclear episode(s)	<i>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</i>

Question	Please record your answer	Help
17. 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?	Possible answer: Yes / No	<i>This is an important question as it directly informs a performance indicator. If you are unsure about the answer, please discuss with your audit unit lead or the RCPCH team</i>
18. Were any afebrile episodes documented as convulsive*  *see Help text	Possible answer: Yes / No	<i>Convulsive episode - An episode where there is symmetrical or asymmetrical limb motor involvement (tonic, clonic, tonic-clonic) Myoclonic seizures excluded.</i>
19. Which of the listed epileptic seizure type(s) were identified? (Please select all that apply)	Multiple possible answer: choose from a drop down list of options (19.1 to 19.29) indicated at the end of this the proforma.	<i>Only available to answer if option c) 2 or more episodes (occurring over a time period greater than 24 hours)" was answered for Q15</i>  <i>AND</i>  <i>Option a) Epileptic or probably epileptic episode(s) was answered for Q16</i>
20. Which of the listed epilepsy syndromes were diagnosed? (Please select all that apply)	Multiple possible answer: choose from a drop down list of options (20.1 to 20.52) indicated at the end of the proforma.	<i>Only available to answer if option c) 2 or more episodes (occurring over a time period greater than 24 hours)" was answered for Q15</i>  <i>AND</i>  <i>Option a) Epileptic or probably epileptic episode(s) was answered for Q16</i>
21. Were there any of the listed epilepsy syndrome category identifiers used? (Please select all that apply)	Multiple possible answers from: a. Idiopathic (or primary) b. Symptomatic c. Probably symptomatic (or cryptogenic) d. Genetic e. Structural f. Metabolic g. Unknown cause h. Documented as 'Unclassified' i. None of above	<i>Only available to answer if option c) 2 or more episodes (occurring over a time period greater than 24 hours)" was answered for Q15</i>  <i>AND</i>  <i>Option a) Epileptic or probably epileptic episode(s) was answered for Q16</i>
22. Were there any of the listed epilepsy syndrome categories identifiers used? (Please select all that apply)	Multiple possible answers from: a) Focal (or partial or localisation-related) b) Multifocal c) Generalised d) Uncertain e) None of the above	<i>Only available to answer if option c) 2 or more episodes (occurring over a time period greater than 24 hours)" was answered for Q15</i>  <i>AND</i>  <i>Option a) Epileptic or probably epileptic episode(s) was answered for Q16</i>

Question	Please record your answer	Help
<p>23. Was there evidence of a neurodisability* diagnosis recorded by professionals involved?</p> <p>*See Help text</p> <p>(PLEASE NOTE: question 24 will only be available if you answer this question as "Yes".)</p>	<p>Possible answer: Yes / No</p>	<p><i>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</i></p>
<p>24. If yes to 23, were any of the following diagnoses documented? (Please select all that apply)</p>	<p>Multiple possible answers from:</p> <ul style="list-style-type: none"> <li>a) Autistic spectrum disorder</li> <li>b) Moderate, severe (or profound) learning difficulty or global development delay</li> <li>c) Cerebral palsy</li> <li>d) Neurodegenerative disease or condition</li> <li>e) An identified chromosomal disorder with a neurological or developmental component</li> <li>f) Attention deficit hyperactivity disorder (ADHD)</li> <li>g) Other (please enter further details - a free text box will be provided for this option.</li> </ul>	<p><i>Only if answered yes to Q23</i></p>
<p>25. Please add any comments you would like to be taken into account based on your responses to the questions in Section D</p>	<p>FREE FLOW TEXT BOX</p>	

Question	Please record your answer	Help
<b>SECTION E: PROFESSIONAL INVOLVEMENT</b>		
<p>26. By 12 months after first paediatric assessment:</p> <p>a. Was there any evidence of input from a Consultant Paediatrician with expertise in epilepsy</p> <p>b. Was there any evidence of input from a Consultant Paediatric Neurologist?</p> <p>c. Was there any evidence the child had a referral to or input from an epilepsy specialist nurse?</p>	<p>Possible answer: Yes / No</p>	<p><i>a. 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)</i></p> <p><i>b. Input - Any form of documented clinical contact including face to face clinical, written, electronic or telephone contact</i></p> <p><i>c. 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</i></p>
<p>27. Please add any comments you would like to be taken into account based on your responses to the questions in section E.</p>	FREE FLOW TEXT BOX	
<b>SECTION F: INVESTIGATIONS</b>		
<p>28. By 12 months after first paediatric assessment, is there an MRI head result documented?</p>	Yes   No	
<p>29. By 12 months after first paediatric assessment, is there a CT head scan result documented?</p>	Yes   No	
<p>30. By 12 months after first paediatric assessment, is there a 12 lead ECG result documented or contained within notes?</p>	Yes   No	
<p>31. Please add any comments you would like to be taken into account based on your responses to the questions in section F.</p>	FREE FLOW TEXT BOX	

Question	Please record your answer	Help
<b>SECTION G: TREATMENT</b>		
<p>32. By 12 months after first paediatric assessment, what number of different (maintenance) <u>anti-epileptic drugs</u>* had been used?</p> <p>*see help text</p>	Possible answer: free flow numerical value only	<p><i>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.</i></p>
<p>33. By 12 months after first paediatric assessment, was Carbamazepine prescribed at any time?</p>	Yes   No	<p><i>Only asked if 1 or more answered to Q32</i></p>
<p>33i. Please add any comments you would like to be taken into account based on your responses to the questions in section G.</p>	FREE FLOW TEXT BOX	
<b>SECTION H: COMMUNICATION</b>		
<p>34. 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?</p>	Possible answer: Yes / No	<p><i>Only asked for females &gt;12 commenced on AEDs</i></p> <p><i>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 will be taken into account during data analysis.</i></p>
<p>35. By 12 months after the first paediatric assessment was there any evidence of discussion regarding risks or safety issues of water (bathing or swimming)</p> <p>(Any documented evidence of discussion is acceptable.)</p>	Possible answer: Yes / No	<p><i>Only available to answer if option c) 2 or more episodes (occurring over a time period greater than 24 hours)" was answered for Q15</i></p> <p><b>AND</b></p> <p><i>Option a) Epileptic or probably epileptic episode(s) was answered for Q16</i></p>
<p>36. Please add any comments you would like to be taken into account based on your responses to the questions in section H.</p>	FREE FLOW TEXT BOX	

Question	Please record your answer	Help
<b>SECTION I: OUTCOME</b>		
37. Was there documentation to suggest that seizures occurred between 6 months after first paediatric assessment to 12 months after first paediatric assessment?  (PLEASE NOTE: question 38 will only be available if you answer this question as "b) Documentation suggests seizure(s) occurred".)	One possible answer from: a) Documentation suggests no seizure occurred b) Documentation suggests seizure(s) occurred c) No documentation or documentation unclear	<i>Only available to answer if option c) 2 or more episodes (occurring over a time period greater than 24 hours)" was answered for Q15</i>  AND  <i>Option a) Epileptic or probably epileptic episode(s) was answered for Q16</i>
38. Was there documentation to suggest that seizures occurred between 9 months after first paediatric assessment to 12 months after first paediatric assessment?	One possible answer from: a) Documentation suggests no seizure occurred b) Documentation suggests seizure(s) occurred No documentation or documentation unclear	<i>Only available if Q37 answered as Documentation suggests seizures occurred.</i>
39. Is there any evidence that the child has died?	One possible answer from: a) Died b) Presumed alive	
<b>SECTION J: OTHER INFORMATION AT 12 MONTHS</b>		
41. What is the name of the main Trust / Health Board that has been involved in managing this patient's seizure(s) during the 12 months after first paediatric assessment?	FREE FLOW TEXT BOX	
42. 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 FLOW TEXT BOX	
43. 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 FLOW TEXT BOX	

**Question 19 - Epilepsy seizure types - drop down list**

- 19.1 No seizure type stated
- 19.2 Other seizure stated
- 19.3 Documented as 'unclassified' seizure
- 19.4 (Generalised) tonic-clonic seizures
- 19.5 Clonic seizures
- 19.6 Absence seizures (including typical or atypical)
- 19.7 Myoclonic absence seizures
- 19.8 Tonic seizures
- 19.9 Atonic seizures
- 19.10 Spasms
- 19.11 Infantile spasms
- 19.12 Myoclonic seizures
- 19.13 Temporal seizure
- 19.14 Parietal seizures
- 19.15 Occipital seizures
- 19.16 Focal seizures
- 19.17 Focal motor seizures
- 19.18 Focal sensory seizures
- 19.19 Frontal seizures
- 19.20 Secondarily generalized seizures
- 19.21 Massive bilateral myoclonus
- 19.22 Eyelid myoclonia
- 19.23 Myoclonic atonic seizures
- 19.24 Negative myoclonus
- 19.25 Reflex seizures
- 19.26 Gelastic seizures
- 19.27 Hemiclonic seizures
- 19.28 Grand mal seizures
- 19.29 Petit mal seizures


**Question 20 - Epilepsy syndrome types - drop down list**

- 20.1 No epilepsy syndrome stated
- 20.2 Other
- 20.3 Documented as 'Unclassified'
- 20.4 (Benign) childhood epilepsy with centrottemporal spikes (BECTS) (benign rolandic epilepsy)
- 20.5 Epilepsy with myoclonic astatic seizures (Doose syndrome) (Myoclonic astatic epilepsy)
- 20.6 Panayiotopoulos syndrome (Early onset (benign) childhood occipital epilepsy)
- 20.7 Grand mal epilepsy
- 20.8 Petit mal epilepsy
- 20.9 occipital lobe epilepsy
- 20.10 parietal lobe epilepsy
- 20.11 temporal lobe epilepsy
- 20.12 frontal lobe epilepsy
- 20.13 Juvenile myoclonic epilepsy (JME)
- 20.14 Juvenile absence epilepsy (JAE)

- 20.15 Childhood absence epilepsy(CAE)
- 20.16 Dravet syndrome (severe myoclonic epilepsy of/in infancy or SMEI)
- 20.17 West syndrome(of infantile spasms)
- 20.18 Defined as 'unclassified'
- 20.19 Benign familial neonatal seizures
- 20.20 Idiopathic focal epilepsy of childhood
- 20.21 Visual sensitive epilepsies
- 20.22 Primary reading epilepsy
- 20.23 Startle epilepsy
- 20.24 Benign neonatal seizures Benign non-familial neonatal seizures
- 20.25 Rasmussen's encephalitis (chronic progressive epilepsy partialis continua) (Kozhevnikov syndrome)
- 20.26 Gelastic seizures due to hypothalamic hamartoma
- 20.27 Eyelid myoclonia with absences
- 20.28 Perioral myoclonia with absences
- 20.29 Phantom absences
- 20.30 Childhood epilepsy with occipital paroxysms
- 20.31 Hemiconvulsion-hemiplegia syndrome
- 20.32 Hot water epilepsy
- 20.33 Bathing epilepsy
- 20.34 Classical petit mal
- 20.35 Reflex epilepsies
- 20.36 Familial focal epilepsy with variable foci
- 20.37 Generalized Epilepsies with Febrile seizures plus (FS+)
- 20.38 Early myoclonic encephalopathy
- 20.39 Ohtahara syndrome
- 20.40 Migrating partial (focal) seizures of infancy
- 20.41 (Benign) Myoclonic epilepsy in infancy
- 20.42 Benign infantile seizures
- 20.43 Myoclonic encephalopathy in non-progressive disorders {myoclonic status in non-progressive encephalopathies}
- 20.44 Late onset childhood occipital epilepsy (Gastaut type) (idiopathic childhood occipital epilepsy)
- 20.45 Epilepsy with myoclonic absences
- 20.46 Lennox-Gastaut syndrome
- 20.47 Landau-Kleffner syndrome
- 20.48 Epilepsy with generalized tonic-clonic seizures only (Epilepsy with generalised tonic clonic seizures on awakening)
- 20.49 Progressive myoclonus (myoclonic) epilepsies (PME)
- 20.50 Autosomal-dominant nocturnal frontal lobe epilepsy (ADNFLE)
- 20.51 Familial temporal lobe epilepsies
- 20.52 Autosomal dominant partial epilepsy with auditory features



## Appendix 5: Patient Reported Experience Measure (PREM)

	Audit Unit Name	Form Number
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**Section A to be answered by parent/carer**

*Please give us your views of the health service that your child has been attending for their epilepsy care. This should only take you five minutes to complete.*

**1.** What is your child's year of birth?    \_\_\_\_    \_\_\_\_    \_\_\_\_    \_\_\_\_

**2.** Is your child                      Female? ☐                      Male? ☐

**3. On average** over the past 6 months, how often has your child had epileptic seizures? (*tick one option only*)

Less than 1 per month ☐

1 or more a month but not every week ☐

1 or more a week but not every day ☐

1 or more per day ☐

Blank spells only ☐

Other.....

**4.** Has your child been diagnosed with any of the following conditions? (*Tick all that apply*)

Learning difficulties/developmental delay ☐

Cerebral palsy ☐

Autism or autistic spectrum disorder ☐

Attention Deficit Hyperactivity Disorder (ADHD) ☐

None of the above ☐

Other .....

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**5.** When was your child's first assessment by a paediatrician for their epilepsy? (*tick one option only*)

Less than 1 year ago ☐

Between 1 and 2 years ago ☐

2 years ago or more ☐

**6.** What was the age of your child at their first assessment (years and months) .....

**7.** What clinics or services has your child attended for their epilepsy and how often have they attended in the last 12 months? (*Tick all that apply*)

Type of service	Number of visits in last 12 months
Hospital general paediatric clinic <input type="checkbox"/>	.....
Community paediatric clinic <input type="checkbox"/>	.....
Teenage epilepsy clinic <input type="checkbox"/>	.....
Specific epilepsy clinic <input type="checkbox"/>	.....
Paediatric neurology clinic <input type="checkbox"/>	.....
A&E <input type="checkbox"/>	.....
GP <input type="checkbox"/>	.....
Other..... <input type="checkbox"/>	.....

**8.** What drug(s) is your child currently prescribed for their epilepsy? (*Tick all that apply*)

Sodium Valproate (Epilim) ☐

Carbamazepine (Tegretol) ☐

Lamotrigine (Lamictal) ☐

Levetiracetam (Keppra) ☐

Other ☐

If other, state drug(s).....

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**9.** In the last 12 months, have you found it easy to contact the health service looking after your child's epilepsy?

Yes ☐

No ☐

Unsure ☐

**10.** In the last 12 months have you been satisfied with the care your child receives for their epilepsy from the service?

Yes ☐

No ☐

Unsure ☐

**11.** Over the last 12 months, what are the **three** best things about the epilepsy service?

1. ....

2. ....

3. ....

**12.** Over the last 12 months, what **three** things about the epilepsy service could be improved?

1. ....

2. ....

3. ....

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**Section B to be answered by child or young person, or if this is not possible, by parent/carer.**

If possible please now give this questionnaire to your child to complete. If your child does not or cannot answer the questionnaire themselves, **please answer the rest of the questionnaire yourself.**

**13.** Who is completing this section (questions 13-16)?

I am the child/young person ☐ ☐  
I am the parent or carer ☐ ☐

**14.** If you are a parent or carer completing this section, why is this? (*Tick all that apply*)

My child is too young ☐  
The questions are too difficult ☐  
My child is too unwell ☐

Other: .....

**15.** This questionnaire is being completed...

**before** the appointment today ☐  
**after** the appointment today ☐  
**before and after** the appointment today ☐

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**16.** Please let us know how strongly you agree or disagree with the statements given in this section. We are interested in your **overall** impressions **over the last year.**

	Strongly Agree	Agree	Unsure	Disagree	Strongly Disagree	Not Applicable
• Overall, I received <b>enough</b> information about epilepsy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Staff <b>listened</b> to what I had to say	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• The information I was given was <b>hard</b> to understand	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Staff <b>did not</b> take time to get to know me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Staff <b>did not</b> explain things in a way I could follow	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Staff <b>took my thoughts into account</b> when making decisions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• I felt the staff <b>respected</b> my need for privacy during clinic visits	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Overall, staff seemed to <b>know what they were doing</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• At times I felt <b>I was not allowed</b> to ask questions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• It is <b>easy to contact someone</b> in the epilepsy team	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Staff make sure <b>it is easy to attend</b> the clinic e.g. when making appointments	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• I am <b>not seen by the service often enough</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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	Strongly Agree	Agree	Unsure	Disagree	Strongly Disagree	Not Applicable
• Staff <b>tell me</b> if my appointment is going to be late	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• The waiting area <b>does not have activities</b> for my age	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Overall, the length of time spent with staff at the clinic is <b>about right</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Staff are <b>not good at working together</b> with others e.g. GP School or nursery, when looking after me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Overall, staff are friendly and polite						
○ In the ward as inpatient	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
○ When going for tests e.g. EEG or MRI (if applicable)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you would like to explain an answer or tell us about other concerns, please do so in this space:

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**17.** What would you like more information on? (Tick all that apply)

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





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

☐ Yes  
☐ No  
☐ Unsure

**Now please put your completed questionnaire in the envelope provided, seal it and return it to the clinic staff.**

**If you prefer, you can post the envelope directly to the Epilepsy12 Audit team. It is Freepost so does not require a stamp.**

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

Thanks to Chetna, Lisa, Catherine, Ravi, Sohail, Jane, Katie and Philip from the RCPCH Youth Advisory Panel, for their feedback when making this questionnaire

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## Appendix 6 - Clinical performance indicators definitions

Involvement of appropriate professionals				
Title	NICE	SIGN	Rationale	Calculation
<b>1a</b>	Percentage of children with epilepsy, with input by a 'consultant paediatrician with expertise in epilepsies' by 1 year	The diagnosis of epilepsy should be made by a paediatric neurologist or Paediatrician with expertise in childhood epilepsy.	Evidence of input important for children with epilepsies but even more important for those receiving AEDS hence supplemental PI.	Numerator = Number of patients diagnosed with epilepsy as defined who had input from a paediatrician with expertise in epilepsy or a paediatric neurologist Denominator = Number of children diagnosed with epilepsy as defined at one year (Children diagnosed with epilepsy as defined at 1 year [2 or more and epileptic or probably epileptic] AND with input by a Paediatrician with expertise in 1st year OR Paediatric Neurologist x 100  Children diagnosed with epilepsy as defined at 1 year [2 or more and Q9=epileptic or probably epileptic]
	Percentage of children with epilepsy who were commenced on AEDs, with input by a 'consultant paediatrician with expertise in epilepsies' by 1 year			Numerator = Number of patients diagnosed with epilepsy as defined who were commenced on AEDs who had input/referral from a paediatrician with expertise in epilepsy or a paediatric neurologist Denominator = Number of children with diagnosed epilepsy as defined who were commenced on AEDs at any time during first year (Children diagnosed epilepsy as defined at 1 year [Q8=2 or more and Q9=epileptic or probably epileptic] AND commenced on AEDs at any time during first year [1 or more AND with input by a Paediatrician with expertise in 1st year OR Paediatric Neurologist x 100  Children diagnosed with epilepsy as defined at 1 year [2 or more and epileptic or probably epileptic] AND commenced on AEDs at any time during first year [1 or more]
<b>1b</b>				

	Title	NICE	SIGN	Rationale	Calculation
2a	Percentage of children with epilepsy, referred for input by an epilepsy specialist nurse by 1 year	1.8.3 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 wellbeing	Each epilepsy team should include paediatric epilepsy nurse specialists	Evidence of input important for children with epilepsy but even more important for those receiving AEDs therefore split into 2 subgroups.	Yes= Number of patients diagnosed with epilepsy as defined who had input from or referral to an Epilepsy Specialist Nurse  Total = Number of children diagnosed with epilepsy as defined at one year  (Children diagnosed with diagnosed with epilepsy as defined at 1 year [2 or more and epileptic or probably epileptic with input from or referral to an Epilepsy Specialist Nurse] x 100  Children diagnosed with epilepsy as defined at 1 year [2 or more and epileptic or probably epileptic]
2b	Percentage of children with epilepsy who were commenced on AEDs, referred for input by an epilepsy specialist nurse by 1 year				Yes= Number of patients diagnosed with diagnosed with epilepsy as defined who were commenced on AEDs who had input from or referral to an Epilepsy Specialist Nurse  Total = Number of children diagnosed with diagnosed with epilepsy as defined who were commenced on AEDs at any time during first year  (Children diagnosed with epilepsy as defined at 1 year [2 or more and epileptic or probably epileptic AND commenced on AEDs at any time during first year [1 or more] with input from or referral to an Epilepsy Specialist Nurse] x 100  Children diagnosed with diagnosed with epilepsy as defined at 1 year [2 or more and Q9=epileptic or probably epileptic] AND commenced on AEDs at any time during first year [1 or more]

	Title	NICE	SIGN	Rationale	Calculation
<p><b>3</b></p> <p><b>Tertiary involvement</b></p>	<p>Percentage of children meeting defined criteria for paediatric neurology referral, with input of tertiary care by 1 year</p>	<p>Referral should be considered when 1 or more of the following criteria are present:</p>	<p>Referral to tertiary specialist care should be considered if a child fails to respond to two AEDs appropriate to the epilepsy in adequate dosages over a period of 6 months.</p>	<p>National recommendations state indications for neurologist referral other than is appearing in this PI. However the PI is limited to those children where the indications for neurology referral are determinable using this retrospective methodology</p>	<p>Yes = Number of children less than 2 years with epilepsy as defined OR number of children who had 3 or more maintenance AEDS by 12 months with epilepsy as defined who had evidence of referral or involvement of a paediatric neurologist by 1 year following first assessment</p> <p>Total = Number of children less than 2 years with epilepsy as defined OR number of children who had 3 or more maintenance AEDS by 12 months with epilepsy as defined</p> <p>(Children less than 2 years [Age &lt; 2.0] AND epileptic ([ 2 or more episodes] and [epileptic or probably epileptic]) OR 3 or more maintenance AEDS by 12 months [3 or more] AND input by a Paediatric Neurologist ) x 100</p> <p>(Children less than 2 years [Age &lt; 2.0] OR 3 or more maintenance AEDS by 12 months [3 or more] ) AND epileptic [2 or more episodes and epileptic or probably epileptic]</p>

Title		NICE	SIGN	Rationale	Calculation
Evidence of appropriate assessment and classification					
<b>4</b>	Percentage of all children, with evidence of appropriate first paediatric clinical assessment	1.4.6 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.	All children with epilepsy should have their behavioural and academic progress reviewed on a regular basis by the epilepsy team.	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	<p>Numerator = Number of patients with evidence of descriptions of episode and age of child/timing of the first episode and frequency and general examination and neurological examination and the presence or absence of developmental, learning or schooling problems</p> <p>Denominator = Number of children in the audit Children with evidence of description of episode AND age of child/timing of the first episode AND frequency AND general examination AND neurological examination AND the presence or absence of developmental, learning or schooling problems x 100</p> <p>All children in the audit (N)</p>
<b>4a</b>	Na % children with evidence of descriptions of episode recommendation				<p>Numerator = Number of patients with evidence of descriptions of episode</p> <p>Denominator = Number of children in the audit Children with evidence of description of episode x 100</p> <p>All children in the audit (N)</p>
<b>4b</b>	% children with evidence of descriptions of age of child/timing of the first episode				<p>Numerator = Number of patients with evidence of description of age of child/timing of the first episode</p> <p>Denominator = Number of children in the audit Children with evidence of description of age of child/timing of the first episode x 100</p> <p>All children in the audit (N)</p>
<b>4c</b>	% children with evidence of descriptions of frequency				<p>Numerator = Number of patients with evidence of frequency</p> <p>Progress</p> <p>Denominator = Number of children in the audit Children with evidence of description of frequency x 100</p> <p>All children in the audit (N)</p>



Title	NICE	SIGN	Rationale	Calculation
<b>4d</b>	% children with evidence of descriptions of general examination			<p>Numerator = Number of patients with evidence of description of general examination</p> <p>Denominator = Number of children in the audit</p> <p>Children with evidence of description of general examination x 100</p> <p>All children in the audit (N)</p>
<b>4e</b>	% children with evidence of descriptions of neurological examination			<p>Numerator = Number of patients with evidence of description of neurological examination</p> <p>Denominator = Number of children in the audit</p> <p>Children with evidence of description of neurological examination X100</p> <p>All children in the audit (N)</p>
<b>4f</b>	% children with evidence of description of developmental history or educational progress			<p>Numerator = Number of patients with evidence of the presence or absence of developmental, learning or schooling problems</p> <p>Denominator = Number of children in the audit</p> <p>Children with evidence of the presence or absence of developmental, learning or schooling problems X100</p> <p>All children in the audit (N)</p>
<b>4g</b>	% children 3 years and over with evidence of descriptions of emotional or behavioural problems			<p>Numerator = Number of patients 3 years and over with evidence of description of the presence or absence of emotional or behavioural problems</p> <p>Denominator = Number of children in the audit 3 years and over</p> <p>Children 3 and over [Age &gt;=3 years] with evidence of description of presence or absence of emotional and behavioural problems [Q3g= Yes] X100</p> <p>Number of children in the audit 3 years and over [Age &gt;=3 years]</p>

	Title		NICE	SIGN	Rationale	Calculation
<b>5</b>	<b>Tertiary involvement</b>	Percentage of children with epilepsy, with seizure classification by 1 year	1.7.1 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 phenomenonology); seizure type; syndrome and aetiology		NTerminology for classification is difficult as constantly evolving. ILAE terminology forms the best way of assessing appropriateness of terminology. Unclassified is accepted.	Yes= Number of children with diagnosis of epilepsy as defined at 1 year who had ILAE seizure classification (all seizure types excluding Grand mal seizures, petit mal seizures, other seizure stated, no seizure type stated and unanswered) Total = Number of children who had a diagnosis of epilepsy at 1 year mal seizures, petit mal seizures , other seizure stated, no seizure type stated and unanswered)] AND diagnosed with epilepsy at year [2 or more and epileptic or probably epileptic]) x 100  Children diagnosed with epilepsy at 1 year [Q8=2 or more and Q9=epileptic or probably epileptic]
<b>6a</b>	<b>Epilepsy classification</b>	Percentage of children with epilepsy, with epilepsy syndrome by 1 year	1.7.1 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 phenomenonology); seizure type; syndrome and aetiology.	The choice of first AED should be determined where possible by syndromic diagnosis and potential adverse effects	Terminology for classification is difficult as constantly evolving. ILAE terminology forms the best way of assessing appropriateness of terminology. Unclassified is accepted.	Yes= Number of children with diagnosis of two or more epileptic seizures at 1 year who had ILAE syndrome classification (all syndrome types except: Grand mal epilepsy, petit mal epilepsy, no epilepsy syndrome stated, other and unclassified) Total = Number of children who had a diagnosis of two or more epileptic seizures at 1 year  Children diagnosed 2 or more epileptic seizures at 1 year]
		Percentage of children with epilepsy, with epilepsy syndrome or category identifiers by 1 year				Yes = Number of children with diagnosis of two or more epileptic seizures at 1 year AND who had ILAE syndrome classification (all syndrome types except: Grand mal epilepsy, petit mal epilepsy, no epilepsy syndrome stated, other and unclassified) OR any use of category identifier terms  Children diagnosed 2 or more epileptic seizures at 1 year
<b>6b</b>						

Evidence of appropriate investigation				
Title	NICE	SIGN	Rationale	Calculation
<b>7</b> <b>ECG</b>	Percentage of children with convulsive seizures, with an ECG by 1 year	1.6.27C In children, a 12-lead ECG should be considered in cases of diagnostic uncertainty.	All children presenting with convulsive seizures should have an ECG with a calculation of the QTc interval.	<p>NICE and SIGN vary in their recommendations. SIGN recommendations are easier to objectively audit and therefore selected for this PI</p> <p>Yes= Children diagnosed with convulsive episodes who have 12 lead ECG obtained</p> <p>Total = Children diagnosed with convulsive episodes AND 12 lead ECG obtained) x 100</p> <p>Children diagnosed with convulsive episodes [Q11=Yes]</p>
<b>8</b> <b>EEG</b>	Percentage of children who had an EEG in whom there were no defined contraindications	1.6.6 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 are diagnosed as certain non-epileptic episodes and they have EEG then it will be assumed that the EEG was inappropriate.	<p>Yes= Number of children with diagnosis of epilepsy as defined at the first paediatric assessment + Number of children with unclear or uncertain episode at the first paediatric assessment + the Number of children with non-epileptic episode at the first paediatric assessment and no ticks or faints</p> <p>Total = Number of children in the audit</p> <p>Note that this calculation has an assumption attached i.e. that children with epilepsy or with unclear or uncertain episodes have had an appropriate EEG. This may not be an accurate assumption.</p> <p>Children with diagnosis of two or more epileptic seizures at the first paed assessment OR Children with unclear or uncertain episode at the first paed assessment OR (Children with non epileptic episodes with NO 'faints' or 'ticks') at first paediatric assessment x 100</p> <p>Number of children in the audit (N)</p>

	Title		NICE	SIGN	Rationale	Calculation
<b>9a</b>	Percentage of children with defined indications for an MRI, who had MRI by 1 year					Yes= Number of children under 2 years of age with a diagnosis of epilepsy as defined at 1 year OR children with a diagnosis of epilepsy as defined who are NOT Idiopathic & Generalised combined or JME or JAE or CAE or BECTS/Rolandic who had an MRI
	Total = Number of children under 2 years of age with a diagnosis of epilepsy as defined at 1 year AND children with epilepsy as defined who are NOT Idiopathic & Generalised combined or JME or JAE or CAE or BECTS/Rolandic		MRI should be the imaging investigation of choice in individuals with epilepsy	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 PI. The PI is limited to those children where the indications for MRI are determinable using a retrospective methodology	Yes= Number of children under 2 years of age with a diagnosis of epilepsy as defined at 1 year OR children with a diagnosis of epilepsy as defined who are NOT Idiopathic & Generalised combined or JME or JAE or CAE or BECTS/Rolandic who had an MRI or CT Total = Number of children under 2 years of age with a diagnosis of epilepsy as defined at 1 year AND children with epilepsy as defined who are NOT Idiopathic & Generalised combined or JME or JAE or CAE or BECTS/Rolandic Children with a diagnosis of epilepsy at 1 year [2 or more and epileptic or probably epileptic] AND {Under 2 years of age [Age <2.0 years] OR NOT ( {Idiopathic & Generalised} [Q14=Idiopathic AND Generalised] OR JME OR JAE OR CAE OR BECTS/Rolandic [JME OR JAE OR CAE OR BECTS])} AND (MRI or CT) Children with a diagnosis of epilepsy at 1 year [2 or more and epileptic or probably epileptic] AND {Under 2 years of age [Age <2.0 years] OR NOT ( {Idiopathic & Generalised} [Idiopathic AND Generalised] OR JME OR JAE OR CAE OR BECTS/Rolandic [JME OR JAE OR CAE OR BECTS])}
<b>9b</b>	<b>MRI</b>					

Title	NICE	SIGN	Rationale	Calculation
Management and outcome				
<p><b>10</b></p> <p><b>Carbamazepine</b></p>	<p>Percentage of children given carbamazepine, in whom there were no defined contraindications</p>	<p>NICE Appendix G</p>	<p>This has been selected as an achievable measure of appropriate drug choice using the methodology chosen</p>	<p>Yes = Number of children commenced on carbamazepine who do not have the contraindications for carbamazepine (NOT IGE or JME or CAE or CAE or Symptomatic and generalised or LGS)</p> <p>Total = Number of children commenced on carbamazepine</p> <p>Children commenced on carbamazepine who do not have the contraindications for carbamazepine (who are NOT ( {IGE} [Idiopathic AND Generalised] OR JME OR JAE OR CAE [JME OR JAE OR CAE] OR Symptomatic and generalised combined [Symptomatic AND Generalised] or LGS [Lennox Gastaut Syndrome])</p> <p>Children commenced on carbamazepine</p>
<p><b>11</b></p> <p><b>Accuracy of diagnosis</b></p>	<p>Percentage of children diagnosed with epilepsy, who still had that diagnosis at 1 year</p>	<p>1.8.15 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/or carers as appropriate.</p>	<p>Is looking for incidence of children in whom there may be a misdiagnosis of epilepsy or who may have received a 'trial of treatment'</p>	<p>Yes= Number of children with diagnosis of epilepsy as defined at 1 year who have not had their diagnosis withdrawn</p> <p>Total = Number of children who had a diagnosis of epilepsy as defined at 1 year or children had their diagnosis withdrawn</p> <p>Children with a diagnosis of epilepsy at 1 year [ 2 or more episodes and epileptic or probably epileptic] x 100</p> <p>Children with a diagnosis of epilepsy at 1 year [ 2 or more episodes AND epileptic or probably epileptic] OR Diagnosis withdrawn</p>

	Information and advice			
	Title	NICE	SIGN	Rationale
12a	Percentage of females over 12 years given anti-epileptic drugs, who had documented evidence of discussion of pregnancy or contraception	1.11.4C 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	Adolescent girls taking AEDs and their parents should be advised of the risks of fetal malformations and developmental delay.	National recommendations state MRI for children other than is appearing in this PI. The PI is limited to those children where the indications for MRI are determinable using a retrospective methodology
12b	Percentage of children diagnosed with epilepsy with documented evidence of communication regarding water safety	1.16.3.8 All children, young people and adults with epilepsy and learning disabilities should have a risk assessment including: • bathing and showering	Children with epilepsy should be encouraged to participate in normal activities with their peers. Supervision requirements should be individualised taking into account the type of activity and the seizure history.	Numerator = Female children 12 years and more who were commenced on AEDs who had evidence of discussion regarding pregnancy and/or contraception Denominator = Female children 12 years and more who were commenced on AEDs Females older than 12th birthday at first paediatric assessment [Age >=12.0] AND commenced AEDs during first year [1 or more] AND evidence of discussion regarding pregnancy and/or contraception [yes] X100 Females older than 12th birthday at first paediatric assessment [Age >=12.0] AND commenced AEDs during first year [≥1]  Yes = Number of children with diagnosis of epilepsy as defined at 1 year AND evidence of discussion regarding water safety Total = Number of children with diagnosis of epilepsy as defined at 1 year



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