

EPILEPSY12

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

National Report September 2012



RCPCH

Royal College of
Paediatrics and Child Health

Leading the way in Children's Health

EPILEPSY12

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

Epilepsy12 National Report - Executive Summary

September 2012



Royal College of
Paediatrics and Child Health

Leading the way in Children's Health



Report prepared by

Dr Colin Dunkley, Project lead and Consultant Paediatrician

Rita Ranmal, Project Manager, RCPCH.

Carla Long, Data analyst, RCPCH.

Acknowledgements

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

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

Project Board

Dr Helen Basu, Consultant Paediatric Neurologist, British Paediatric Neurology Association Representative

Ann Brown, Epilepsy Specialist Nurse, Royal College of Nursing Representative

Alan Cruickshank, Head of Strategy & Policy, Young Epilepsy

Dr Colin Dunkley, Consultant Paediatrician, Project lead

Dr Colin Ferrie, Consultant Paediatric Neurologist, Clinical lead

Jacqueline Fitzgerald, Director of Policy and Research, RCPCH representative

Dr Martin Kirkpatrick, Consultant Paediatric Neurologist, Scotland representative

Dr Lesley Notghi, Consultant Neurophysiologist, British Society for Clinical Neurophysiology Representative

Allana Parker, Public Affairs Officer, Epilepsy Scotland

Angie Pullen, Epilepsy Services Manager, Epilepsy Action

Grant Wright, Training, Epilepsy Scotland

Methodology Working Group

Katherine Bowyer, Neurophysiological scientist

Dr Richard Chin, Consultant Paediatric Neurologist

Dr Colin Dunkley, Consultant Paediatrician

Dr Colin Ferrie, Consultant Paediatric Neurologist

Dr Katherine Martin, Neurodisability Paediatric Consultant

Dr James Paton, Consultant Paediatrician, RCPCH Clinical Standards Committee lead for National Audit

Berni Waldron, Epilepsy Specialist Nurse

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

Audit Facilitators

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

Stakeholder organisations

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

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

Forewords

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

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

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

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

We strongly encourage you to share this report with colleagues.

Dr Hilary Cass

President, Royal College of Paediatrics and Child Health

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

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

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

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

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

Dr Venkateswaran Ramesh
President, British Paediatric Neurology Association

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

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

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

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

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

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

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

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

Dr Martin Kirkpatrick

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

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

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

David Ford, Chief Executive, Young Epilepsy

Lesslie Young, Chief Executive, Epilepsy Scotland

Philip Lee, Chief Executive, Epilepsy Action

Executive Summary

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

The key aims of Epilepsy12 are:

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

What is Epilepsy12?

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

Who was involved?

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

How was quality measured?

The Epilepsy12 National Audit described the care using three domains:

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

What were the clinical audit measures of quality?

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

Figure 1. Epilepsy12 Performance Indicators

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

What are the Epilepsy12 results?

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

Service Descriptor

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

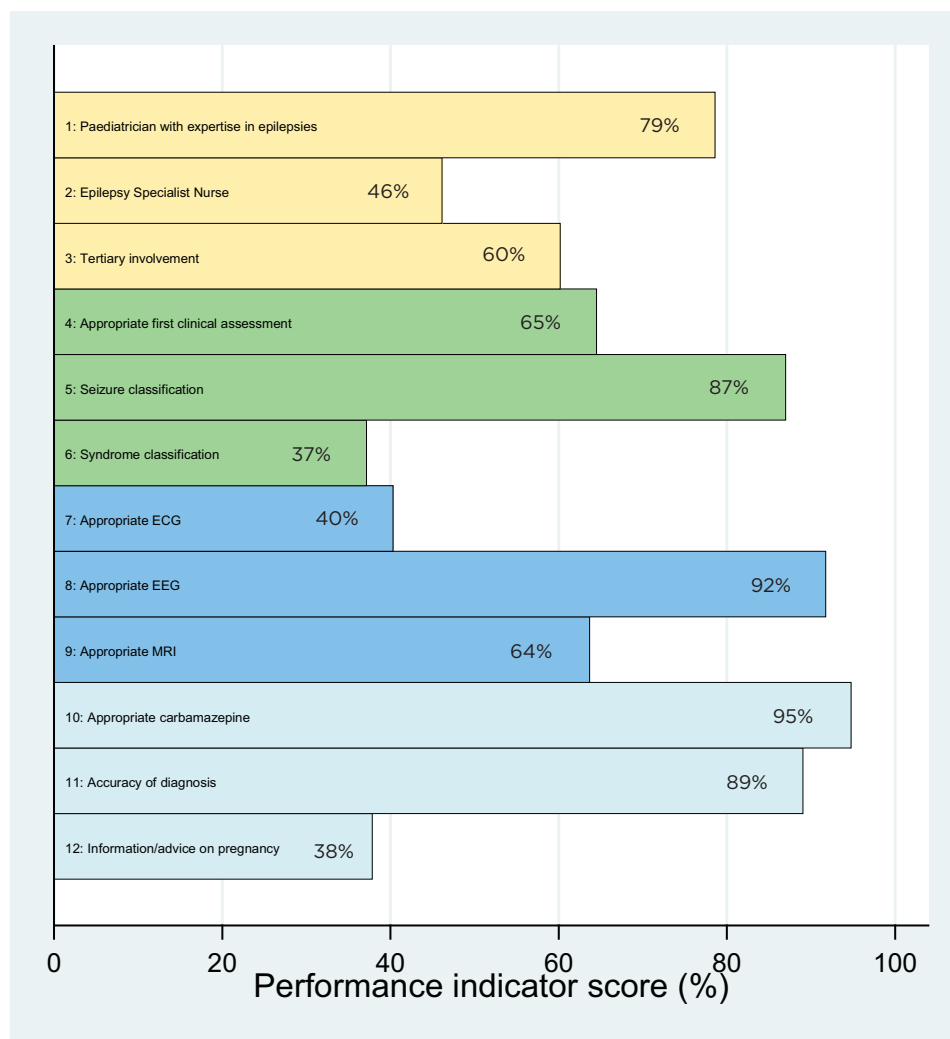
Clinical Audit

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

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

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

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



Patient Reported Experience Measure

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

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

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

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

Key Recommendations

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

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

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

Key Recommendations

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

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



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

The Royal College of Paediatrics and Child Health (RCPCH) is a registered charity in England and Wales (1057744) and in Scotland (SC038299).