

EPILEPSY12



Epilepsy12 Round 2 National Audit Report: A Summary for Parents, Carers, Children and Young People

November 2014



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Introduction

Childhood epilepsy

Epilepsy affects around one in every 200 children and young people in the UK (aged 18 and under). The condition is one of the most common significant long-term health conditions of childhood.

Epilepsy can have a huge impact on children and families. Epileptic seizures can happen in any part of the brain and what happens next depends on where in the brain the seizure is happening. Seizures can be distressing but it's not just the seizures that are the problem. Children and young people may experience issues with learning, behaviour and emotions. That's why children and parents need support and guidance from healthcare professionals throughout the stages of diagnosis and treatment.

About Epilepsy12

Epilepsy12 is a national clinical audit set up to look at the quality of healthcare services for children and young people with epilepsy in the UK. It shows if children and young people get a consistently high level of care. It highlights gaps in the care provided and where improvements are needed.

Epilepsy12 is managed by the Royal College of Paediatrics and Child Health and is commissioned by the Healthcare Quality Improvement Partnership (HQIP) and Health Improvement Scotland (HIS).

The first Epilepsy12 audit (Round 1) results were published in 2012 and showed that:

- There was variation in the levels of care and available resources, such as specialist nurses and clinics, needed to provide this care across the UK.

- Some epilepsy services, based in hospitals and clinics, were not meeting guideline standards.
- Some services in some areas were doing a good job of supporting children and young people.

After the first audit (Round 1), units that took part were encouraged to use the information on their performance to develop action plans to improve standards of care.

The 2014 Epilepsy12 audit

The latest Epilepsy12 audit (Round 2) has gathered information from 187 units that look after children and young people with epilepsy.

- Information was gathered about the care of 3,449 children and young people from anonymised patient case notes.
- 2,335 children, young people and their parents/carers shared their experiences of their care over a 12-month period by completing questionnaires.

The audit looked at unit performance based on:

- **Patient experiences** – what children, young people, parents and carers said about the care that they (or their children) received.
- **Resources available** – the resources in each unit, for example the number of paediatricians, nurses and clinics patients can access.
- **Twelve quality measures** – based on national guidelines which set out the care children and young people with epilepsy should receive.

The results of the second audit (Round 2) suggest that improvements have been made to healthcare services for children and young people over the last two years but also highlight opportunities for further improvement.

An explanation of terms used throughout this report is provided on page 18.

2014 audit results

Summary

Overall care for children and young people with epilepsy appears to be getting better. Some areas are performing well, some are improving. This shows that it is possible to provide a high standard of care. Key findings include:

- Patient experiences were generally positive and the majority of children, young people and their parents and carers said they were satisfied with the care they had received.
- There have been improvements in the resources available in units, for instance more than two thirds (68%) now have a local children's Epilepsy Specialist Nurse (ESN) and more epilepsy clinics are being held, with two in every three units (66%) now reporting that they have a weekly epilepsy clinic just for children and young people.
- There have been improvements in the quality of care with more children (87%), newly diagnosed with epilepsy, having had care from a paediatrician with expertise in the condition and more children and young people (58%) having been referred to see an epilepsy specialist nurse.
- According to the data gathered no aspects of epilepsy care have been found to be getting worse.

However, despite the encouraging results of the audit the standard of care continues to vary across the UK and is still not up to guideline standards in many places. The audit makes a number of recommendations to healthcare professionals, hospital managers and healthcare commissioners about what they should do now to improve the care.

What children, young people and families had to say

Listening to what children and families say helps to develop and improvement healthcare services. Earlier this year, Epilepsy12 gathered questionnaires from over 2,300 children, young people and their parents/carers. We wanted to find out more about personal experiences of healthcare services and how people felt that the professionals involved in their care communicated with them.

Overall feedback from children, young people, parents and carers was good and the majority (88%) of respondents said that they were satisfied with the care they received. 93% said that hospital staff seemed to know what they were doing and 94% thought that hospital staff that were friendly and polite.

The care received by my son has been outstanding. We are very happy with every aspect of his care and the staff who have looked after us.

Consultants and epilepsy nurse are amazing and are a great comfort to my child and our family.

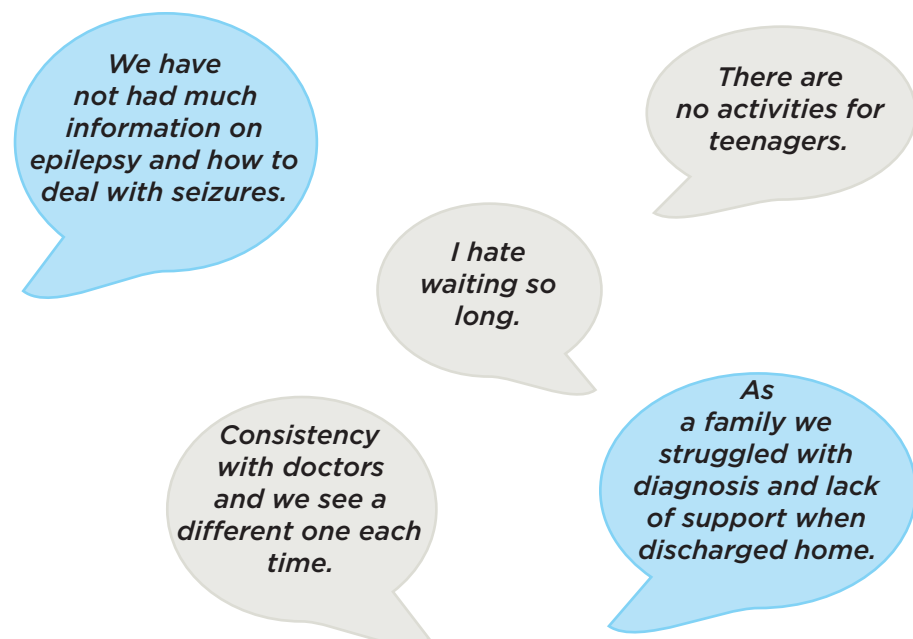
Experienced and knowledgeable staff make us feel safe.

Doctor has excellent knowledge and understanding and explained things thoroughly.

Responses from children and families also highlighted areas for further improvement:

- A fifth of parents/carers (20%) said that staff are not good at working together.
- A quarter of respondents (25%) did not say that staff were good at letting them know if an appointment is going to be late.
- Almost two thirds (62%) of children and young people felt that there weren't appropriate activities for their age in the waiting area.
- Over a third (37%) said the information they were given was hard to understand.

The questionnaire asked, 'Over the last 12 months, what three things about the epilepsy service could be improved', a selection of responses were as follows:



Each unit that took part in the audit will receive information about the feedback its patients gave.

Epilepsy12 recommends

Units should:

- Involve children, young people, parents and carers in the design of services and the review of information resources.
- Review the information provided from a child and young person's point of view and take steps to make it easier to understand.
- Consider the activities available in waiting areas from a child and young person's point of view and ensure that there are suitable age-appropriate activities.
- Review processes for ensuring that patients are kept informed about appointments.



Clinical guidelines and Epilepsy12 audit performance measures

Clinical guidelines are in place to support and guide healthcare professionals in their decisions. The aim of guidelines is to bring about improvements in health and social care for patients and set out standards of care. Each of the quality measures in Epilepsy12 links to guidance from NICE and/or SIGN.

Epilepsy12 measured the percentage of children:

1. With epilepsy, who had input from a paediatrician with a epilepsy expertise
2. With epilepsy, who had input offered by an epilepsy specialist nurse
3. Referred to a paediatric neurologist as needed
4. Where an appropriate first paediatric assessment was carried out
5. With epilepsy, who had their seizures classified
6. With epilepsy, who had their epilepsy type categorised
7. With convulsive seizures, who had undergone an ECG
8. Who had undergone an EEG as needed
9. Who had undergone a MRI as needed
10. Who were appropriately given the anti-epileptic drug carbamazepine
11. Diagnosed with epilepsy, who still had that diagnosis one year later
12. With epilepsy, who had been given safety information about bathing and/or swimming

The right healthcare professionals at the right time

It's vital that children and young people with epilepsy get access to the right healthcare professionals, at the right time, to ensure they get an accurate diagnosis and a high standard of ongoing care. Results from Epilepsy12 suggest that there have been improvements in patients' access to specialist healthcare professionals.

Key improvements are:

- 87% of children and young people with epilepsy had the input of a paediatrician with expertise in epilepsy in their care.
- Over half of children and young people (58%) with epilepsy in the audit had been referred to an epilepsy specialist nurse. In the first audit less than half (46%) had seen an epilepsy specialist nurse.

This suggests a significant step forward, but there is still a way to go to ensure that guidelines are more widely adopted by clinicians.

Epilepsy12 recommends

- All services working with children and young people with epilepsy should have at least one expert epilepsy paediatrician in their unit. If needed, processes should be changed to ensure that children and young people get better access to these specialists.
- In areas where there is no epilepsy specialist nurse, new roles should be urgently created to improve essential care for children and young people.
- Units that have an epilepsy specialist nurse, but where many children and young people with epilepsy are still not having input from them, should improve their care pathways and referral strategies to ensure that this input is always available.

Guidelines say that some children need further specialist input to their care from a paediatric neurologist. A significant number (57%) of children who should have been referred to one of these specialists were not. This highlights that more still needs to be done to improve this aspect of patient care.

Epilepsy12 recommends

- Access to, and the availability of, paediatric neurologists needs to be addressed at both a local level and at a national level within each of the four UK departments of health.



Getting the right medical assessments

An important part of diagnosis and ongoing care is making sure children and young people get the right assessments. These assessments help doctors to decide what further tests and investigations might be needed, how a child's condition might affect other aspects of life such as learning and behaviour, and what treatment may be required.

The Epilepsy12 audit suggests a slight improvement in the assessment stage of the care of children and young people. Around two thirds (68%) of first assessments met guideline standards. However, this means that a third of patients did not receive an adequate first assessment and the reasons for this need to be addressed.

Epilepsy12 also suggests improvements in classifying seizure types and syndromes. The majority of children and young people (95%) had their seizure type identified within a year of diagnosis.

Again, whilst there have been some improvements in assessment more work is needed to fully meet agreed national guidelines.

Epilepsy12 recommends

- Units should improve the quality and consistency of their assessments if they are not meeting guideline standards.
- Educational, behavioural and emotional problems should be assessed as these issues can have a huge impact on children, young people and their families.

Getting the right tests and investigations

Epilepsy is difficult to diagnose and there are a number of tests and investigations which help to make an accurate diagnosis of epilepsy. Guidelines set out which investigations should be carried out to help establish a diagnosis of epilepsy. The investigations the audit looked at are:

- ECG (electrocardiogram)
- EEG (electroencephalogram)
- MRI (magnetic resonance imaging)

The audit results showed that generally there was an improvement in the number of children and young people getting the correct tests and investigations that they needed. Many more children with convulsive seizures (59%) had an ECG. The improvement is a positive step forward but even more children and young people still need to undergo an ECG in order to record the electrical activity of the heart and help to rule out whether the seizure is being caused by the way that the heart is working.

Slightly more children (66%) who needed one had an MRI brain scan. However, there remains a significant number of children and young people who should have had a MRI but didn't. This may mean that an important cause of the epilepsy is missed.

The audit revealed that slightly fewer children who didn't need one had an EEG (6%); another step in the right direction.

Further improvements are still required to ensure that children and young people get the correct tests and investigations to diagnose epilepsy.

Epilepsy12 recommends

- Units should improve their rates of ECGs.
- In services where inappropriate EEGs are still being performed, staff and managers should work together to find out why this is happening and how it can be prevented.
- Certain children should be having MRIs and this option should be reviewed by units to improve rates of these tests where needed.



Diagnosis and treatment

Although epilepsy can be difficult to recognise it's vital that children and young people get an accurate diagnosis. Guidelines state that until a diagnosis is made patients cannot begin to start treatment with anti-epileptic drugs. The Epilepsy12 audit looked at whether accurate diagnoses were being made and whether children were being prescribed the correct medication.

The results showed an improvement with the majority of patients (93%) considered to have an accurate diagnosis. This means that 7% of children and young people included in the audit might have been initially told incorrectly that they have epilepsy.

The audit looked at the use of the anti-epileptic drug carbamazepine, which should only be used to treat certain seizure types. This was to check that it was not being inappropriately prescribed. Again there was an improvement and the results showed that almost no patients (1%) for who it was unsuitable had been given the medication.

These results are good news for children and young people with epilepsy. But there are still opportunities for improvements.

Epilepsy12 recommends

- Where diagnoses of epilepsy are being withdrawn, (not considered correct when reviewed at a later time), services should investigate and respond to the reasons behind this. These services should ensure that a paediatrician with expertise in epilepsy is involved in patients' care.
- If units know that carbamazepine is being incorrectly prescribed they should ensure that the reasons behind this are identified and rectified.

Communications with healthcare professionals

Good communication between healthcare professionals and families is vital in order to provide the best care possible. Guidelines say that healthcare professionals should provide families with information about epilepsy including the risks associated with the condition, such as water safety. Epilepsy12 looked at whether information about the importance of water safety was being communicated with families.

This might include information about appropriate supervision with swimming, taking a bath or suggesting showering as a safer alternative. It found that around two thirds (64%) of children and young people had received the information. This means that a third of patients hadn't had this potentially life-saving information communicated with them.

Obviously this is something that needs to be improved.

Epilepsy12 recommends

- Units have written material available and the expertise to explain and discuss all relevant individual risks associated with epilepsy care.
- They should ensure that risk management information is communicated and understood.
- All children and young people with epilepsies should have access to Epilepsy Specialist Nurses who play a key role in risk assessment and providing education and information to children and families.

What happens next?

How do I find out how my child's unit performed in the audit?

The audit results gathered during Epilepsy12 are available on the Epilepsy12 pages of the RCPCH. If you would like to find out more about what your local unit told us about the services they provide visit www.rcpch.ac.uk/epilepsy12

If after reading this report and the data in your local area you have questions or concerns about the care of your child please contact your paediatrician, specialist nurse or GP.

How will Epilepsy12 units know what to do?

The Epilepsy12 team has contacted all of the units that took part in the audit and provided them with unit-specific reports containing results and information on how they are performing against national guidelines in comparison to other services across the UK and within their region.

Epilepsy12 recommends

- Units should now review their local results and identify aspects of patient care and services that need to be improved.
- Units should develop action plans outlining how they intend to improve local patient care and make a case to hospital managers and commissioners for additional resources.
- Further analysis of the information gathered during the Epilepsy12 audit is now needed. This could help to highlight:
 - What is working well in high performing units that others could learn from.
 - The next action planning steps units should be taking to bring about improvements.
 - Themes in problems identified from the patient experience which may be relevant to certain patient groups.
 - Agreeing how the NHS can continue to monitor and improve local paediatric epilepsy care including future reviews of national clinical guidelines.

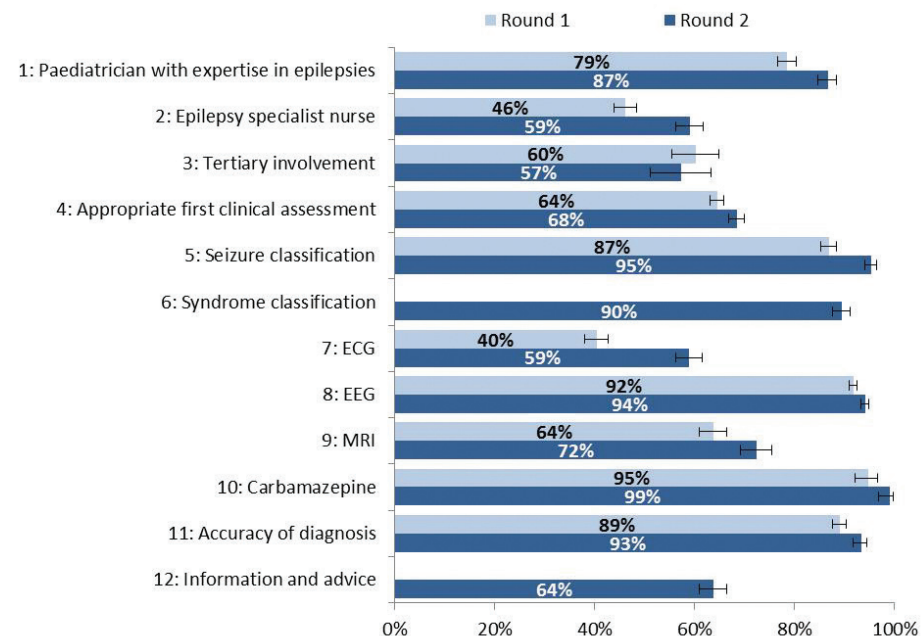
Terms used in this report

- **Units** – refers to those defined Epilepsy12 registered units which took part in the audit and includes hospital wards, outpatient clinics and other epilepsy clinics for children and young people.
- **Services** – the paediatric epilepsy services within the Epilepsy12 units.
- **NICE guidance** – This refers to guidance issued by the National Institute for Health and Care Excellence (NICE) named ‘The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care’. The guidance offers evidence-based advice on the care and treatment of children, young people and adults with epilepsy.
- **SIGN guidelines** - The Scottish Intercollegiate Guidelines Network (SIGN) develops evidence based clinical practice guidelines for the National Health Service (NHS) in Scotland.
- **Epilepsy Specialist Nurses (ESNs)** - are an expert and essential part of a multi-disciplinary team and the majority of their time is spent in patient-related activities. Their work is complex and varied and includes various clinical interventions, as well as providing psychological and social support to patients and their families.



Results at a glance

The chart below shows how the results for the 12 clinical audit performance indicators of Epilepsy12 have changed from Round 1 (2012) to Round 2 (2014):



Changes were made to performance indicators six (Syndrome classification) and twelve (Information and advice) between Rounds 1 and 2 of the audit. This means that the findings of indicators six and twelve cannot be directly compared. For this reason no results for Round 1 are shown for performance indicators six and twelve.

Nine out of those ten that could be compared across rounds showed statistically significant improvement. This is shown in the graph by the fact that the ‘whisker’ symbols on the Round 1 and Round 2 bars do not overlap.