

A guide to the 2018  
**Epilepsy12 National  
Organisational Audit**  
report for parents and  
young people

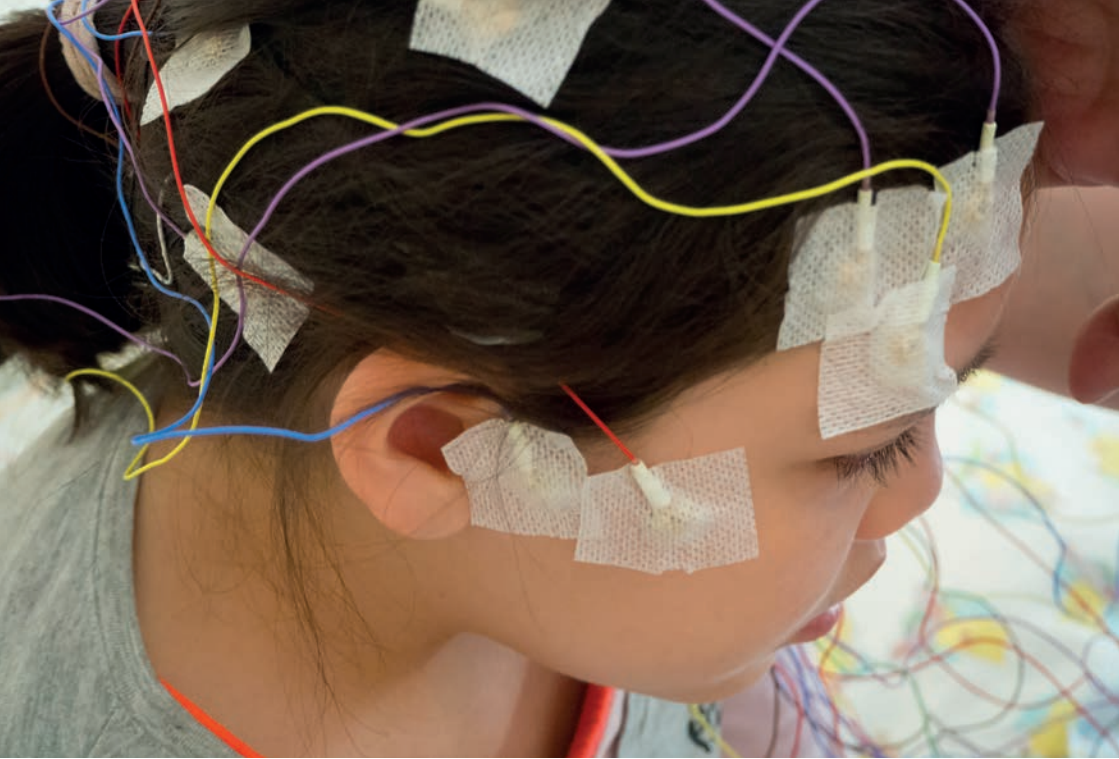
 **RCPCH Audits**

# EPILEPSY12

Improving the care of Children  
and Young People with Epilepsy



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



## What is the Epilepsy12 audit?

**Epilepsy12 is an important national healthcare project. It is managed by the Royal College of Paediatrics and Child Health (RCPCH). The project began in 2009 with the aim of improving the quality of care for children and young people with seizures and epilepsy.**

Epilepsy12 looks at whether paediatric epilepsy services provide consistent, high quality levels of care to children and young people with epilepsies that match the levels set out in national guidance and standards.

In April 2018 the Epilepsy12 audit asked all hospitals and clinics in England and Wales about their services for children and young people who could be having seizures. Epilepsy12 looked at their responses to see where things are going well, and where they need to get better.

## What is epilepsy?

**Epilepsy affects around one in every 200 children and young people in the UK (aged 18 and under). It is one of the most common significant long-term health conditions of childhood. This booklet describes the services received by children and young people with epilepsy in England and Wales in 2018.**

When someone has epilepsy, it means they have a tendency to have epileptic seizures. Epileptic seizures can happen in different parts of the brain and what happens depends on where in the brain the seizure occurs. The fact that seizures can keep happening is key, as a one-off seizure does not mean it is epilepsy. It can affect anyone, at any age, from any walk of life.

Diagnosis can be complex because there is no single diagnostic test. Some types of epilepsy last for a limited time where the individual stops having seizures. But for some people, epilepsy is a life-long condition.

## How does Epilepsy12 involve parents/carers, children and young people?

Epilepsy12 has teamed up with the RCPCH &Us (Children and Young People Engagement Team) to help ensure that engagement with children, young people and their families is included in all areas of its work. The experiences of children and young people are captured by a small group of Youth Advocates who help to identify areas that require improvement within epilepsy services. These areas requiring improvements are communicated to NHS staff, senior managers, government health departments and the general public through published reports, social media and the project website:

[www.rcpch.ac.uk/epilepsy12](http://www.rcpch.ac.uk/epilepsy12)

# What is the 2018 Epilepsy12 “organisational audit”?

**The 2018 Epilepsy12 National Organisational Audit Report was published in January 2019. It gives information on how hospitals and clinics organise their epilepsy services for children and young people. It also reports on whether the way those services are organised meets national quality guidelines and standards.**

The report highlights areas where epilepsy services should be improved. It also shows who should be responsible for making those improvements. Epilepsy12 gave hospitals and clinics their own local results, alongside regional and national results, so that they could compare themselves to other services and make plans to improve their own epilepsy services for children and young people.

The key findings and recommendations from the national report focused on six areas of paediatric epilepsy care, which are summarised on the following pages.

The full report can be viewed and downloaded from the Epilepsy12 website at: [www.rcpch.ac.uk/epilepsy12](http://www.rcpch.ac.uk/epilepsy12)

## General recommendations (1 and 2 in the main report) from the report indicated that:

- All Health Boards and Trusts should review their local Epilepsy12 results and take appropriate actions to address any gaps in their services for children and young people with epilepsies. They should risk assess any gaps and raise these through relevant channels within their health services.
- Regional paediatric epilepsy networks and healthcare commissioners should review the Epilepsy12 results for the Health Boards and Trusts within their regions. They should work with staff in the hospitals and clinics in their region to develop tools for improving the care provided by paediatric epilepsy services.

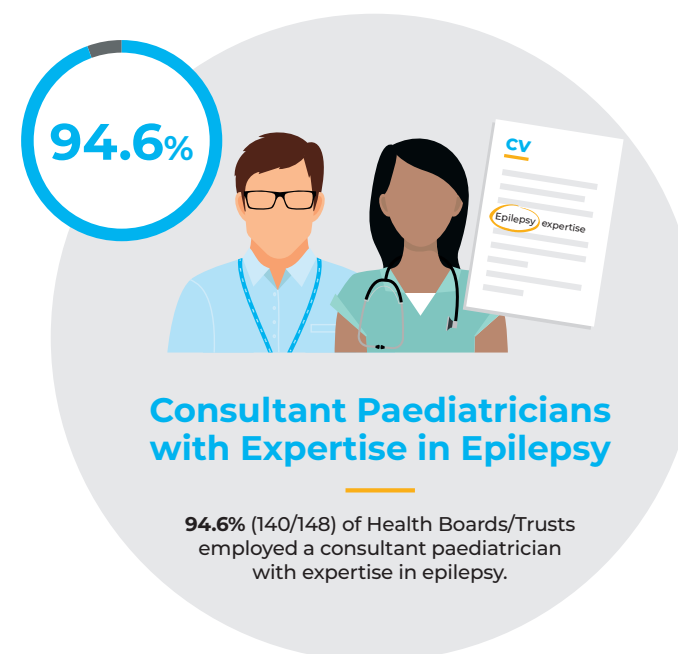
## Workforce

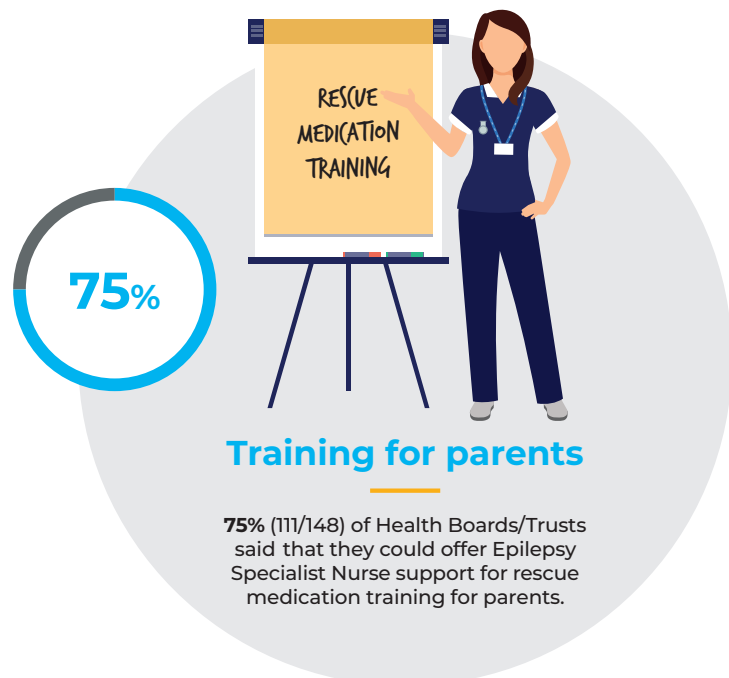
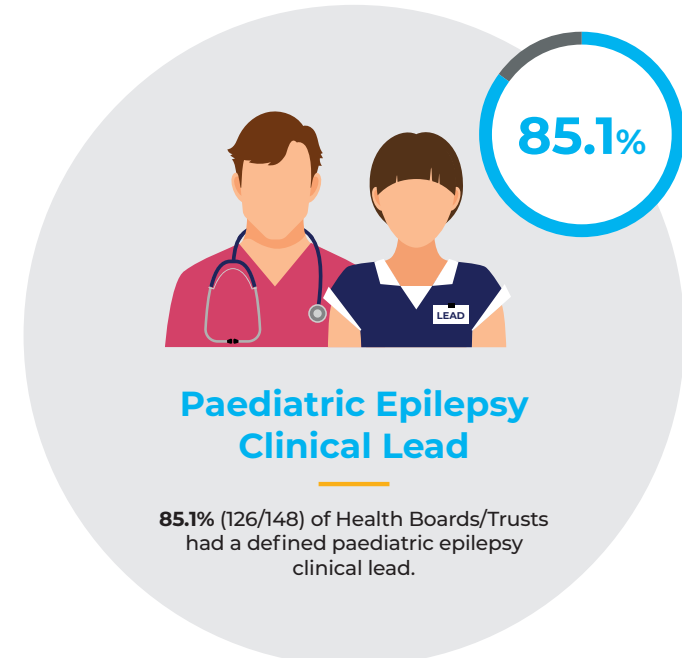
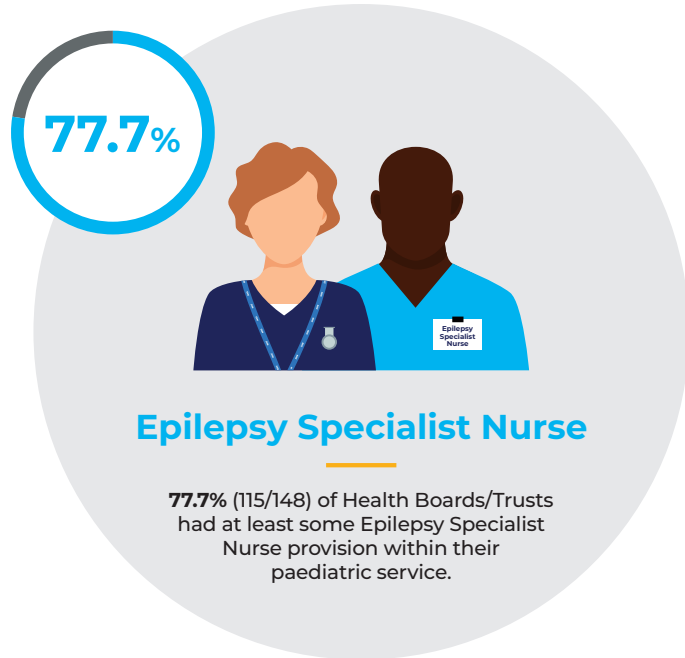
**Children and young people with epilepsy should get specialist support from hospitals and clinics. This also applies to those who have had a suspected epileptic seizure.**

For a child or young person, this specialist support should include:

- A doctor who treats and cares for children (a paediatrician) and who has also had special training in diagnosing and treating epilepsy.
- A named lead doctor for the paediatric epilepsy service.
- An epilepsy specialist nurse (ESN) who is trained in, and has experience of, caring for children and young people with epilepsy. They can also provide children, young people and family members with important information about epilepsy, such as rescue medication training for parents.

**The 2018 report showed the percentages of services with:**





### Workforce recommendations (3, 4 and 5 in main report):

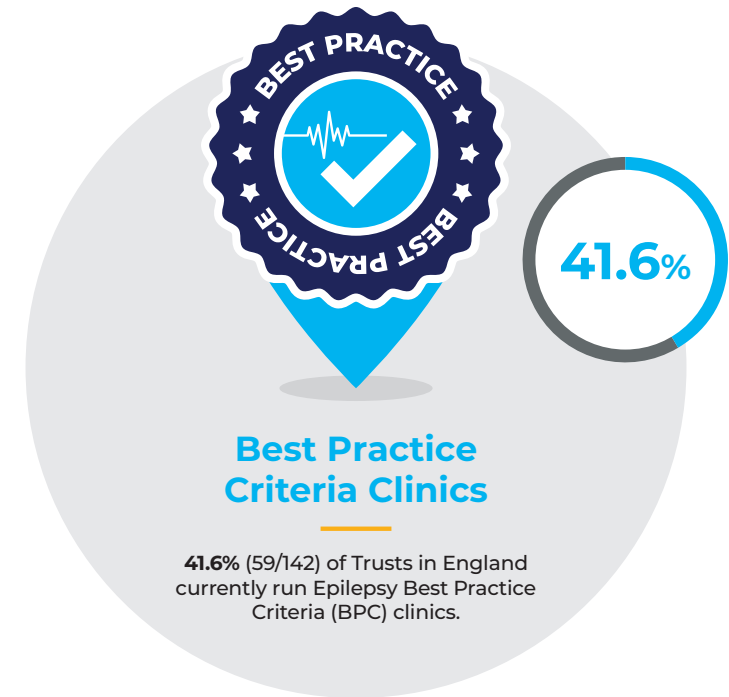
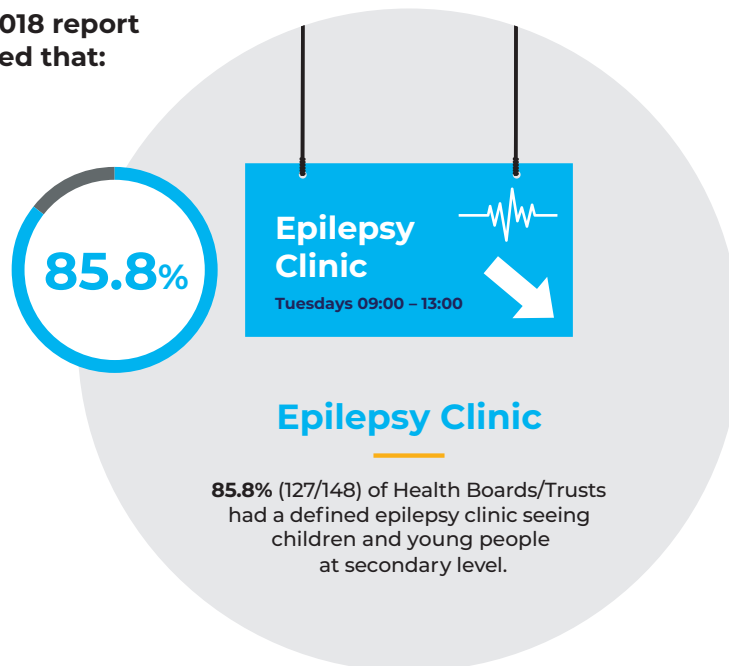
- All hospitals and clinics should ensure they have enough general paediatricians with expertise in epilepsies to correctly diagnose epilepsy and provide ongoing management for all children with epilepsy.
- All hospitals and clinics should ensure they have enough epilepsy specialist nurses to support all children with epilepsies.
- All hospitals and clinics should ensure that parents and carers of children at risk of prolonged epileptic seizures receive training. This should include information about using rescue medication if it is prescribed and personal emergency care plans.
- Children with 'complex epilepsy' should also have input from a paediatric neurologist.



## Epilepsy clinics

Where appropriate, children and young people with epilepsy should be seen by specialists within epilepsy clinics rather than general paediatric clinics.

The 2018 report showed that:



### Epilepsy clinic recommendations (6 and 7 in main report):

- Health Boards and Trusts should ensure children and young people can access follow-up epilepsy clinics. Where appropriate, children with epilepsy should be seen in designated epilepsy clinics, rather than general paediatric clinics.
- Health Boards and Trusts should provide epilepsy services that meet best practice criteria.

## Specialist advice (known as tertiary services)

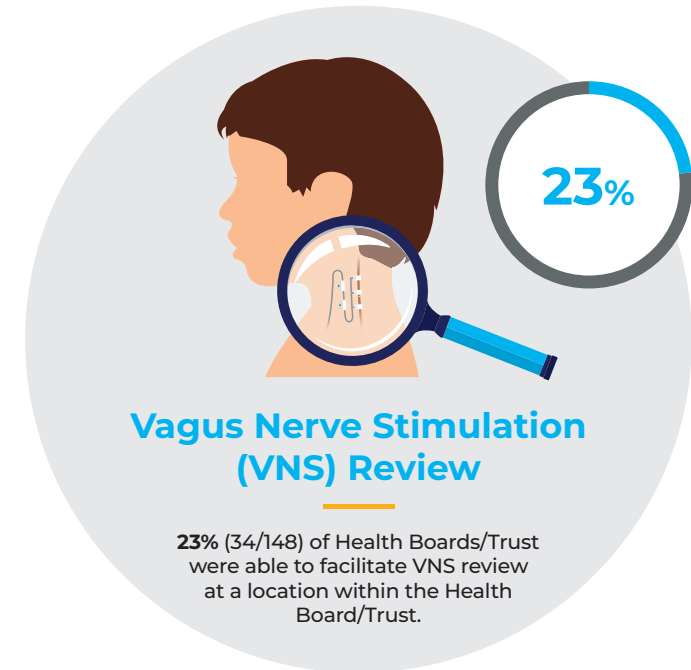
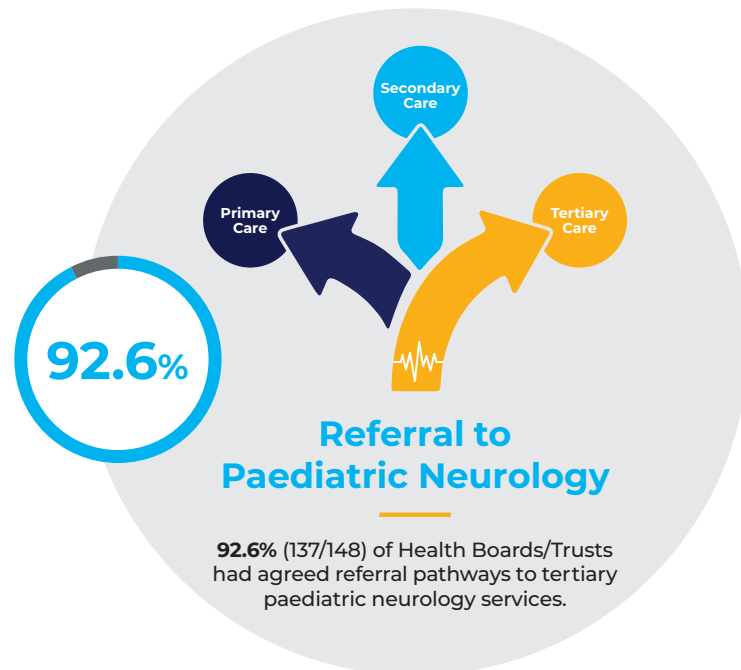
**Sometimes a paediatrician might ask for a child or young person to be seen by a paediatric neurologist. This is a consultant who specialises in neurological conditions in children, including epilepsy.**

The request, or referral, for this advice might be:

- Due to an uncertainty about a diagnosis.
- To seek advice on epilepsy combined with other complicated medical conditions or psychological problems.
- To seek specialist advice on drugs or surgery.

There should be clear agreed arrangements in place between hospitals, clinics and these tertiary paediatric neurology services. The NHS calls these arrangements referral pathways.

**The 2018 report showed that:**



### Specialist advice recommendations (8 and 9 in main report):

- Health Boards and Trusts should have clear referral pathways to specialist paediatric neurology services. This is to ensure timely referral for epilepsy surgery evaluation, complex epilepsy management or both.
- Health Boards and Trusts should look at whether vagus nerve stimulation (VNS) reviews and programming could be carried out by specialists in local neurology/epilepsy clinics.

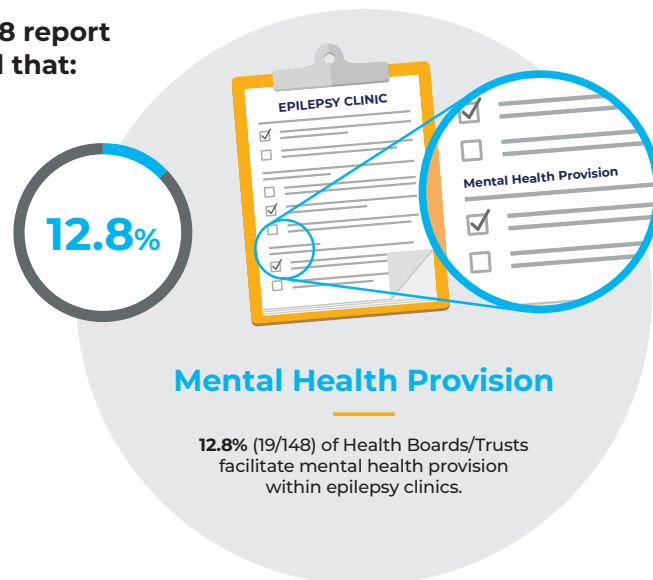
## Mental health provision

Epileptic seizures can be distressing, but it's not just the seizures themselves that are the problem. Children and young people may experience issues with learning, behaviour and emotions. That's why they, along with their parents, siblings and wider family members, need support and guidance. This support and guidance should be offered throughout the stages of diagnosis and treatment.

Epilepsy12 Youth Advocates listened to the views of children and young people. A top priority for them was support for worries and anxieties.

Ongoing epilepsy care should include mental health assessment, diagnosis and treatment. This support for mental health should be available within epilepsy clinics.

The 2018 report showed that:



### Mental health provision recommendation (10 in main report):

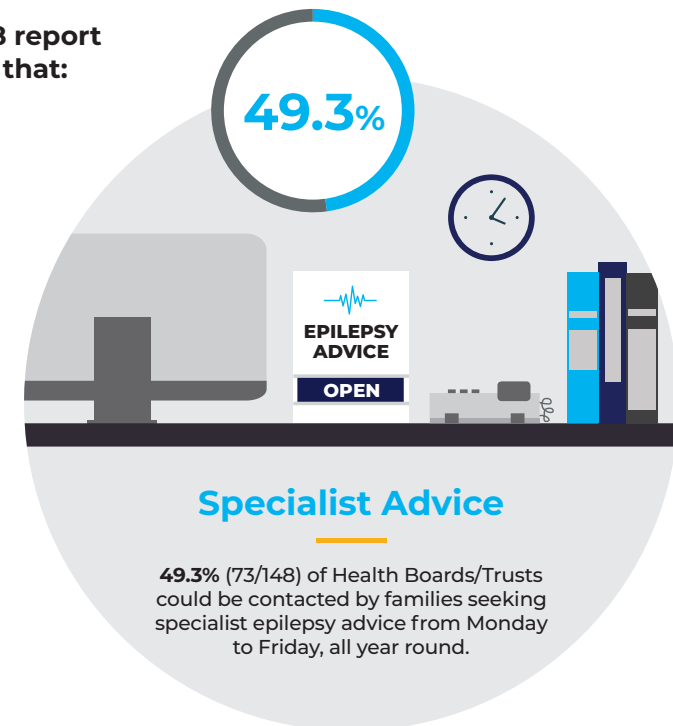
- Commissioners, Health Boards and Trusts should make sure that epilepsy care includes mental health assessment, diagnosis and treatment alongside seizure management.

## Service contact

It is important for children and young people to have a comprehensive review of their epilepsy care with a specialist, at least once a year. But, it is also crucial for them, and their family members, to know who they can contact for specialist advice whenever they might need it. This should include how best to contact those people and when they are available.

Hospitals and clinics should think about how they can improve access to specialist advice.

The 2018 report showed that:



### Service contact recommendation (11 in main report):

- Health Boards and Trusts should look at ways to improve access to specialist epilepsy advice for families between reviews.

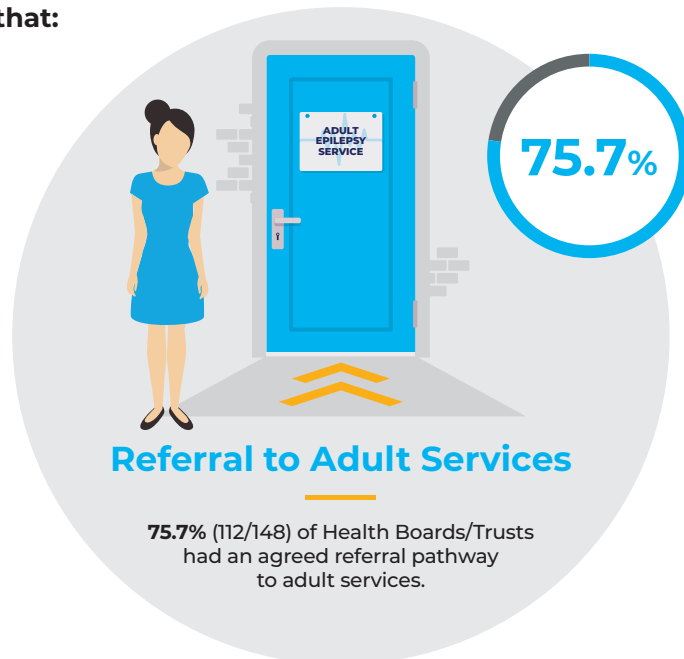
## Young people and transition

**Children and young people with epilepsy may have to deal with more issues than other people from their age group when making important future plans and decisions. They are also going through physical and mental changes as they move from adolescence to adulthood.**

For some, the move or transition from paediatric to adult hospital services can often be abrupt. In some cases, no transition arrangements are made at all.

Continuity of care can help young people with epilepsy have more self-esteem and confidence. It also gives an important chance to review a young person's epilepsy before they become an adult. This can include reviewing the diagnosis, the type and cause of epilepsy and treatment plans.

**The 2018 report showed that:**



### Young people and transition recommendation (12 from main report):

- Hospitals and clinics should formally agree the arrangements for moving from paediatric to adult services.

Local arrangements should also set out how this is done for young people with epilepsies with different associated problems, for example those with an intellectual disability or neurodisability.

As well as providing dedicated epilepsy clinics for all children, hospitals and clinics should also provide clinics that cater specifically for young people with epilepsies.

These dedicated clinics for young people can support the evolving needs of the young person and their family. They can be supported throughout adolescence as well as during the period of moving from paediatric to adult services.

# Involving children, young people and families

The RCPCH Children and Young People Engagement Team has started an Epilepsy12 engagement plan. This focuses on involving children, young people and families in Epilepsy12. It includes activities that capture their views and channel their voices via social media campaigns, and interactive sessions at local and national events.

## Engagement work so far

Between April and June 2018, the RCPCH Children and Young People Engagement Team ran a series of "clinic chats". They collected views on 'service contact' and family mental health (an emerging area for consultation). Over 130 children, young people and family members took part.

Ten hospitals were visited and two charity family days were held in partnership with Epilepsy Action, with children as young as 3 years old contributing, and the views of 75 parents/carers also captured. Epilepsy12 Youth Advocates reviewed the information captured during the clinic chats and identified the following top priorities:

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



Across the clinic chats, the role of the epilepsy specialist nurse was incredibly valued where they were in place, and greatly missed where they were not.

The epilepsy specialist nurses were reported as having added an extra level of reassurance for families and especially for the children and young people themselves who grew up with their nurses knowing about their lives. The training offered by these specialist nurses to extended families or schools was also said to be invaluable. Where there was not a specialist nurse available, some families felt that they stored questions up for their clinic appointments and others felt that there was a lack of availability of family or school-based training sessions.



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

**RCPCH &Us Member**



**Mental health was also a theme that was discussed across the sessions. Children, young people and families noted:**

- The challenges of accessing services.
- The need for early intervention rather than waiting for a mental health crisis.
- The need to further explore the link between changes in treatment plans with changes in mental health and behaviour.



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

**RCPCH &Us Member**



Two of the Epilepsy12 Youth Advocates created a 75-minute session on these themes and presented their findings at the first Epilepsy12/ OPEN UK National Conference. This was attended by over 160 paediatric epilepsy specialists in London on 22 June 2018. Highlights from the session can be viewed on the project website:

[www.rcpch.ac.uk/epilepsy12](http://www.rcpch.ac.uk/epilepsy12)

## Future engagement plans

From September 2018 to August 2019, the Epilepsy12 Youth Advocates will be focusing on developing their skills. The aim is that they can work with a small number of hospitals that take part in Epilepsy12.

They will review audit data from a children and young people's perspective. They will be involved in service design and identify their own quality improvement project. The results of this work will then be shared at the next Epilepsy12/OPEN UK National Conference in the summer of 2019.

# A guide to the 2018 **Epilepsy12 National Organisational Audit report for parents and young people**

## Would you like to know more?

To find out more about Epilepsy12 and how your information might be used to improve care within epilepsy services, please talk to a member of staff in your local paediatric epilepsy service.

You can also contact the project team at [epilepsy12@rcpch.ac.uk](mailto:epilepsy12@rcpch.ac.uk) or visit our website: [www.rcpch.ac.uk/epilepsy12](http://www.rcpch.ac.uk/epilepsy12)



The Epilepsy12 audit is commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP). 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 in patient outcomes, and in particular, to increase the impact that clinical audit, outcome review programmes and registries have on healthcare quality in England and Wales.

HQIP holds the contract to commission, manage and develop the National Clinical Audit and Patient Outcomes Programme (NCAPOP), comprising around 40 projects covering 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 projects, other devolved administrations and crown dependencies. [www.hqip.org.uk/national-programmes](http://www.hqip.org.uk/national-programmes)



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