

Epilepsy12 &Us

Voices from the RCPCH &Us network



EPILEPSY12

OPEN UK

Organisation of Paediatric Epilepsy Networks in the United Kingdom

 **RCPCH &Us**
The voice of children,
young people and families

Epilepsy12 &Us

The Children and Young People's Engagement Team at the Royal College of Paediatrics and Child Health (RCPCH) works to ensure that the voices of children, young people and families is making a difference in child health and healthcare for young patients.

Through the RCPCH &Us network for children, young people, families, we actively seek and share their views to influence and shape policy and practice.

Acknowledgements:

The RCPCH &Us would like to thank all the children, young people and families who took part as well as the participants of the Epilepsy12 Youth Advocates Project.

Also thank you to the paediatricians, nurses, hospital staff who supported the engagement work and enabled us to carry out these clinic chats.



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 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

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What is Epilepsy12?

Epilepsy12 is a type of investigation across England and Wales. This is when the health care for children and young people with suspected epileptic seizure is being checked.

Epilepsy12 started in 2009, to help epilepsy services be the best they can be for children and young people. This now includes children and young people with a new diagnosis of epilepsy.

The RCPCH Children and Young People's Engagement Team have been championing a new project where children, young people and families have the chance to share what they think about epilepsy services. This project is called the Epilepsy 12 Youth Advocates Project.

What did we do?

Between April - June 2018, the team visited 10 epilepsy clinics. Ranging from Southampton, Luton, Nottingham to Manchester, families took part in 'clinic chats'. These were about "creating the best epilepsy service". In total, more than 130 children, young people and families took part.

Visits to charity 'Family Days' also took place in 2 locations. The Children and Young People's Engagement Team worked with children and young people through art-based activities, whilst parents shared their views and wishes in a forum meeting. Throughout the Epilepsy12 roadshows:

A total of...

23 children,
20 young people,
6 young adults
and 75
parent/carers...

...engaged in
the project, with
children as young
as 3 contributing.

At the end of these visits the team asked if any children or young people wanted to join our Epilepsy12 Youth Advocate Project, and be involved, with 14 interested in getting involved.

During the clinic chats, questions were asked both to children or young people and to the parent/carer about their experiences, ideas for improvements, their top tips and any additional comments they wanted to share. The questions asked were:

1. How children, young people and families want to get in touch with services
2. The kind of support they want to receive and from who
3. Their best experiences of epilepsy services support
4. Their ideas for future epilepsy services

But we found so much more!

Our Epilepsy12 Youth Advocates worked hard to review all the results of what people said. They were looking for things that were the same across all the settings, things that were different or that surprised them. They then shared these areas with each other. After, they agreed on common themes and what these meant for them.

What did we find?

Epilepsy12 hospital based clinic chats:

After our Epilepsy12 Youth Advocates looked at all the information, they chose three top priority areas;

- **Schools**
- **Support for worries and anxieties**
- **Face to face support**

The other topics that came up regularly were;

- **Having positive adult relationships**
- **More services to go to**
- **Practical Help and Tips**
- **Contacting your service**

On schools

Children and young people said that they wanted more help to: have good care plans, have more training in schools, support to prevent bullying about having epilepsy.

Children, young people and families really valued the support they have now like visits from their specialist nurses to their school to speak with students and staff.

Some children and young people with epilepsy told us that they felt labelled, bullied and picked on at school. So, they wanted to have more understanding and awareness about epilepsy for everyone in schools.

“
.....
My epilepsy specialist nurse has time to sit with us for as long as we need. Our specialist nurse has come to school as well and it feels like a relationship we can trust. The training on what to do has been really helpful.
Epilepsy12 Clinic Chat
.....
”

On support for worries and anxieties

Children and young people said that they wanted more support in helping to explain areas such as why me? When will it stop? as well as transition and establishing coping strategies.

Children and young people had lots of questions that they did not know how to answer. For example; **“How long will it last?” “What can I do or not do?” “Who jobs can I do?” “How dangerous is it?” “What injuries can you get?” “Can I drive?” “What happens if I have a seizure on a roller coaster?”**

They wanted support to help them deal with these questions. Parents/carers said that the whole family feels the impact. Other family members did not want to see the seizures, making them worry about what to do. Having access to mental health support services from when you first find out you have epilepsy is also important and having support for the whole family.

“
.....
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
.....
”

On face to face support:

Children, young people and their families felt there was a lack of both children's/young people and parent support groups/events. They also told us that there was a lack of specialist nurses in every area.

Children and young people said that events, activities or fundraising for charities made them feel more connected to other young people with epilepsy.

“
.....
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
.....
”

On having positive adult relationships:

Children and young people need a range of positive adults to help them feel supported and build resilience. They talked about role models who they trust and talk to including teachers, youth workers, support workers, extended family members.

Parents/carers valued having websites to look at and the opportunity to speak with a counsellor/support worker.



When I come into appointments I meet with the specialist nurse first and then mum would come in. It is better cos she gets to hear my point of view first and then she can hear my mum's side.

Epilepsy12 Clinic Chat



On more services to go to:

Children and young people said that they wanted more support with mental health and wellbeing, weekends or evenings non-emergency support, home visits and support groups, and getting ready for moving to adult services (transition).

Children, young people and families said that having access to these services in an easy way is important to them. They told us that they want to use their clinic time well and not have to repeat themselves.

Parent/carers said that there should be more services in the hospital to support patients with disabilities. For example, quiet clinics for children or young people with autism.



It would be good if we could see more people at the same time in one place, not come back again. Having more help at the beginning would be good, support groups to go to and someone to talk to.

Epilepsy12 Clinic Chat



On practical help and tips:

From our clinic chats, support for practical help was asked many times but in different ways. These included lifestyle tips on sleep management, family based training, coping mechanisms, products that could be used to explain it to children or others, first aid training and more.

Children and young people wanted help to think about the future. This was mainly about jobs, driving and going out with friends.

Parent/carers said that they wanted help to have coping methods that would help the whole family. Parents/carers also told us that they worried about their child not getting enough sleep and the impact that has at school.

Using print outs of scans and having drawings to explain to children and young people really helped understand epilepsy and diagnosis.



Don't be afraid to talk to us about the future. Don't speak to me just about my condition, but speak to me about my life.

RCPCH &Us Member



Contacting your service

There were many fantastic examples of top tips and innovative access as well as contact services.

Children and young people told us that Epilepsy is 7 days a week and affects the whole family. Sometimes, siblings and other families miss out on coming to important appointments. The main reason being the timing of the appointments.

Lots of children and young people and their families told us that being able to speak with their specialist nurse is important. This contact could be through email, text or exchanging mobile numbers. Amongst these, consistency is important and not having to repeat their story is key.

The top views of the children and young people were:

- They preferred to phone, text or even Face Time in one clinic
- They would like websites with a forum containing regular questions that they could look at

The top views of the parent/carers were:

- There were no clear views on the use of the internet but some parent/carers joined Facebook groups, which did help them as social media is easier for contact. However, some thought that google gives you the worst-case scenario
- Face to face is preferable
- Contact changes as time goes on. This could be from the shock and isolation to managing and requiring help with certain things that are unusual, like knowing when to give emergency medication

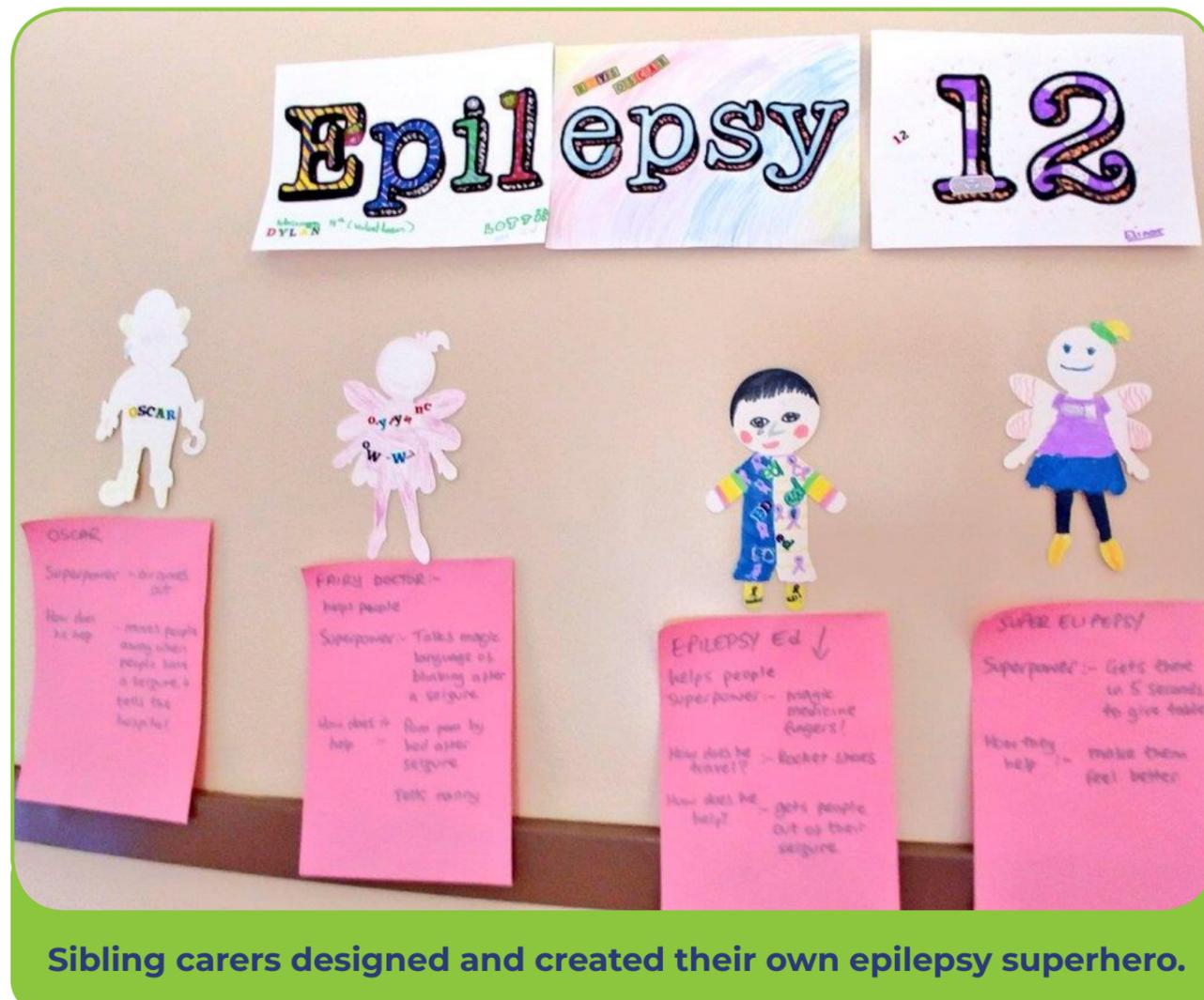
Family days

During the family day events, parents and carers told us about what is important to them in terms of living with epilepsy and their epilepsy services.

The team carried out different activities with the children and young people that took part.

What we heard – sibling carers:

Sibling carers designed and created their own epilepsy superhero. This helped them to express their views on what a superhero does to help someone having a seizure:



Oscar

His superpower is to have air coming out to assist with CPR. He helps move people away when people are having seizures and ensures the hospital is told (this sibling carer is 5 years old)



The Fairy Doctor

Her superpower is that she can talk in a magic language via blinking, since when mum has seizures she can't speak so they've worked out how to say yes/no in blinks, and helps by putting a pom pom by the bed after a seizure to protect the head and to make sure that nanny knows (this sibling carer is 7 years old)



Epilepsy Ed

His superpower is to have magic medicine fingers to get medicine to the person quickly, along with rocket shoes to ensure he gets there super-fast. He also helps people come out of their seizure (this sibling carer is 10 years old)



Super Epilepsy

Her superpower is to get to the person with epilepsy within 5 seconds to give the tablets straight away helping to make them feel better (this sibling carer is 7 years old)

What we heard – Epilepsy & me:

The other activity involved children and young people with epilepsy. They produced a 'My Health and Me' image board or created "Super Services" looking at what they needed to help them with their condition.

While looking at *My Health and Me*, they found magazines, pictures and images that represented how they feel as a young person with epilepsy. Throughout this activity there were lots of messages of hope. They wanted other young people with epilepsy, to know and realise, that having epilepsy was not the end of their dreams and to continue to dream big and achieve things.

In creating their 'Super Services' topics including school awareness, public campaigns to increase understanding, plans to support learning when school has been missed due to the condition, an epilepsy nurse for everyone and to increase information, maybe by having a "lifesaver" line to call for answers or advice.

There were also many ideas put forward by the young people to make them be included. One idea was to make something for their friends. So, they can have this in their bags/purses or a picture on their phones. This would've told them what to do if they walked off in an absence or they were having clonic seizures.



'My Health and Me' image board compiled by children and young people with epilepsy.

How we shared all the information:

On 22 June 2018 at the Epilepsy12/OPEN UK conference, two of our Epilepsy12 Youth Advocates delivered a 75-minute presentation in front of 160 epilepsy specialist. During their presentation, they shared the results on all the topics you have read about above.

They used Kahoot online voting and consulted with more than 100 clinicians present. Asking questions about their views on these topics and areas.

Results of online voting from Epilepsy12/OPEN UK conference

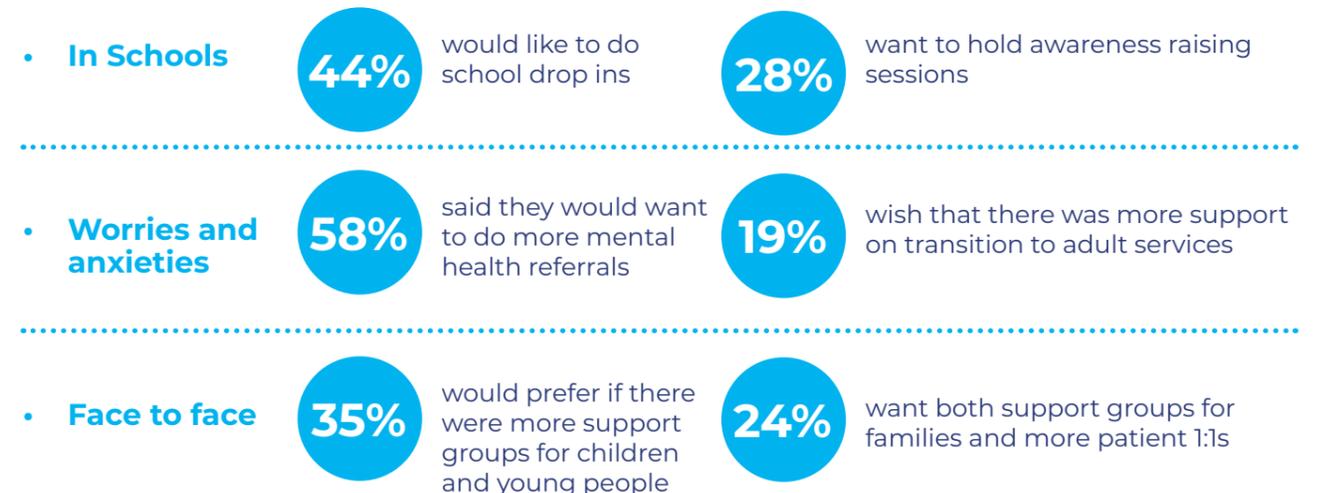
The first online vote asked 100 clinicians about their thoughts on three topics:

1. Services they (the clinicians) wish were more available
2. Most requested practical help
3. Who do they think their patients speak to about their epilepsy outside the clinic

The results were:



The second online vote asked over 90 clinicians, what they wished they could do to support children and young people with epilepsy in the following areas:



The third online vote asked 88 clinicians what “contactability” means to them.

We provided 4 different view/options to choose from. The results were:

- 59% Having a choice of people to speak with
- 20% Getting the answers to questions
- 14% Having more than one way to get in touch
- 7% How easy it is get in touch

In the fourth and final online vote, 87 clinicians were to choose one thing they plan to commit to do in their service that will benefit their patients and families, following the topics that were discussed.

Here were four options they had to choose from along with the results:

- 37% Share our slides with staff that are not here today
- 26% Find out what practical help is needed locally and tell &Us!
- 24% Set up a family event / drop in / session
- 13% Create a new epilepsy handout for patients and share with &Us

What are we going to do next?

The Epilepsy12 Youth Advocates will be working together over the next year to look at what the children, young people and families said, and the paediatricians vote results.

They will then look at creating their own solutions and seeing if these work, and being trained to visit units and give advice on engagement.

Want to get involved/ get in touch?

If you are interested to learn more about our Epilepsy12 project or our Children and Young People’s Engagement Team:

**Visit our website for
information and free resources:**

www.rcpch.ac.uk/and_us or

Email: and_us@rcpch.ac.uk

 **Follow us on our Twitter:**

[@RCPCH_and_Us](https://twitter.com/RCPCH_and_Us)

[@Epilepsy_12](https://twitter.com/Epilepsy_12)

 **We are also on Instagram:**

[@rcpch_and_us](https://www.instagram.com/rcpch_and_us)

Contact us:

Tel: 020 7092 6000 Fax: 020 7092 6001

Email: and_us@rcpch.ac.uk

www.rcpch.ac.uk/and_us



**Royal College of Paediatrics
and Child Health**

5-11 Theobalds Road,
London, WC1X 8SH

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