

## Development of wellbeing resource

### South Tees Hospitals NHS Foundation Trust

#### RCPCH Epilepsy Quality Improvement Programme project team:

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## Project aim

To capture the views of 50% of children aged 12-16 years with a diagnosis of epilepsy (without a learning difficulty) and their parents/carers on how the epilepsy service can support their mental wellbeing, by April 2020.

## Background:

- South Tees Foundation Trust covers two hospital sites managed by two different CCG's. One of these hospital sites does not have a paediatric epilepsy nurse service. It is well documented that epilepsy has an impact on children and young people's emotional and mental health; however, the significance of this is unknown for the young people seen in epilepsy clinics due to the lack of a standardised way to collect this information. The team is aware of the many different services available to support children and young people's emotional and mental health needs, but these differ between their local authorities. The team accepts there is an overall lack of knowledge about how to identify and assess patients, which may require more involvement in terms of their mental health.

## Area of focus

- Using patient engagement methods to obtain the views and needs of patients and families to provide support for their wellbeing, using an effective signposting pathway that includes the resources of efficient local and national organisations.

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## Changes

- The initial test of questions on 25/11/2019 were trialled on a child branch student nurse who provided feedback regarding the wording of the questions:
  - To change the wording to explain, 'the patient will be seen by the nurse or doctor on their own for a small period during the consultation, not the entire time'.
  - Nurse/doctor to ask me more questions about my feelings/worries during a one-to-one session.
  - *"Children are protective of parents and might not discuss issues in front of parents to avoid worrying them"*.
- Two young people and two parents used the board in clinic on 25/11/2019. It seemed easy to use, but it was noted that some of the questions required clarification. It was agreed that the nurse in clinic would clarify with the young person and parent/carer what each answer meant prior to them responding.
- The team felt it would be useful to separate emotion/mental health due to epilepsy from more general emotion/mental health because some children and young people may feel in control of their epilepsy but have other feelings or emotions they wanted to discuss.

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## PDSA cycle



1A – Test question format with Student Nurse

Question too wordy, could misinterpret “in clinic on own” – **Question reworded**



1B – Test with 1 parent and 1 child

Counters didn't fit in envelopes – **Changed counters and containers**

Nowhere to put counters when not applicable – **added “none of these”**



1C – Test with 20 patients 20 children

Not as many children/parents as we had anticipated – **Changed to 10 and 10 and then introduced new questions**

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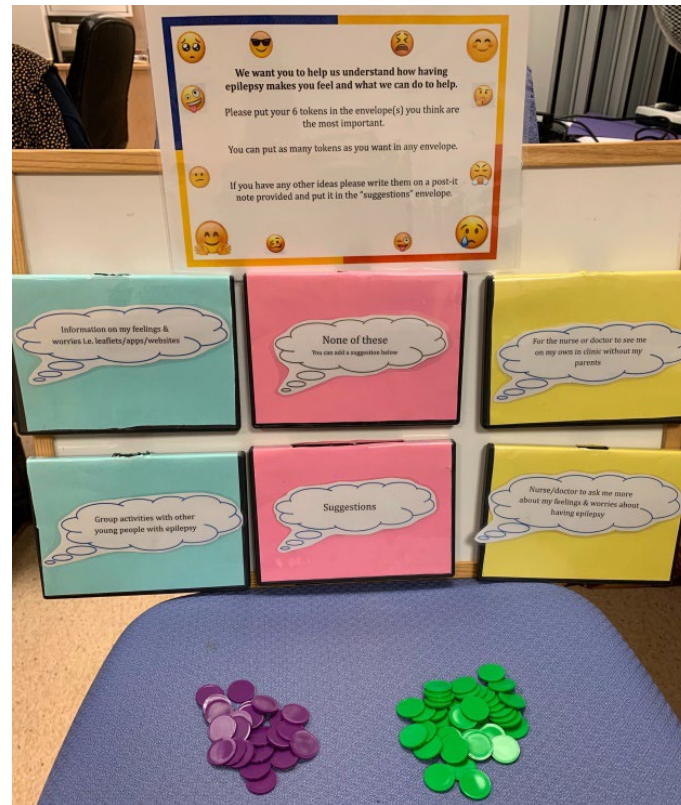
The first board had a simple question with six possible answers. *“What can we do to help your feelings and worries about having epilepsy?”*

Patients were given six purple tokens; parents were given six green tokens.

The optional answers were:

1. “For the nurse or doctor to see me on my own in clinic without my parents”,
2. “For the nurse or doctor to ask me about my feelings and worries about having epilepsy”,
3. “Information on my feelings and worries ie leaflets/apps/websites”,
4. “Group activities with other young people with epilepsy”,
5. “None of these – please add a suggestion below”.

The question was chosen to allow for better understanding of how young people wanted to address their feelings and emotions with the team.

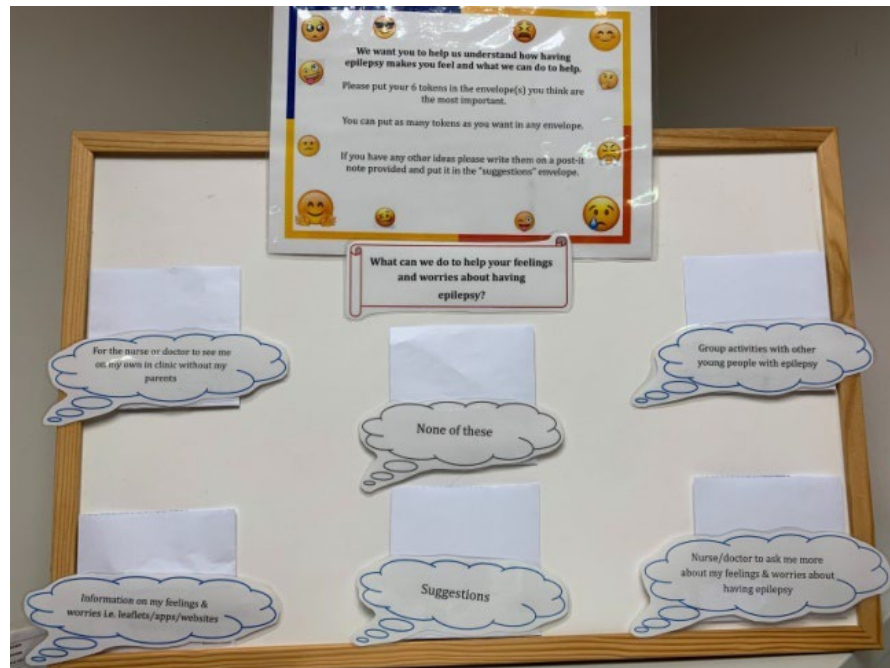


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The board was altered to make it more user friendly for patients, parents and staff.

Using old DVD cases meant the answers could easily be swapped into the case sleeve, the cases also hid the previous persons answers and held the tokens securely. This board worked really well.

A second board was not set up because only one patient was required to meet the criteria that was set from the 10 responses before reviewing the results.

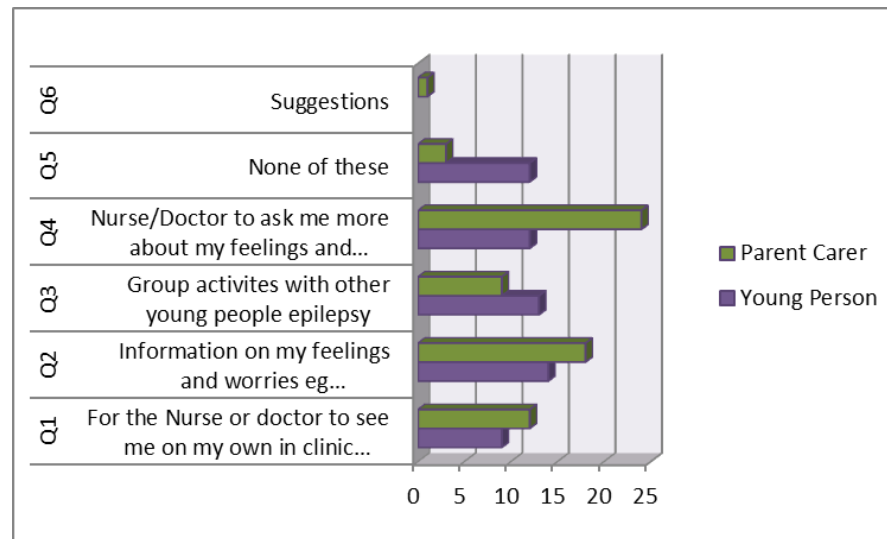


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Results showed that young people chose “Information on my feelings and worries” as their top choice with **14** tokens out of **60** possible.

Parents/carers chose “Nurse/Doctor to ask me more about my feelings and worries about having epilepsy” with **24** tokens out of a possible **66**.

It was decided to focus on the young people’s choice as the project was aimed at them, and look further into parent/carer choice at a later date.



## Responses received from patients and parents/carers were as follows:

		Young Person	Parent Carer
Q1	For the Nurse or doctor to see me on my own in clinic without my parents	9	12
Q2	Information on my feelings and worries eg leaflets/apps/webpages	14	18
Q3	Group activities with other young people epilepsy	13	9
Q4	Nurse/Doctor to ask me more about my feelings and worries about having epilepsy	12	24
Q5	None of these	12	3
Q6	Suggestions	0	1

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## Results

The boards were updated with the following question/statement:

- “We have been asking young people over the past 3 months what they feel is important to them for their care. The majority asked for more information to be given about managing their emotions and feelings. We would now like to find out the best way for us to give this information to you.”

The optional choices were:

- “Printed information about understanding your feelings & emotions about your epilepsy”,
  - “Pack that includes a list of websites & apps, leaflets to help you understand your feelings & emotions”,
  - “Printed information to help you understand your overall feelings & emotions”,
  - A paper list of helpful apps and websites”,
  - “None of these – suggestions below”.
- The response received from the children and young people and the parent/carer was “Printed information about understanding your feelings & emotions about your epilepsy”.
  - The team looked at what information was available regarding emotion/mental health for their patients from epilepsy charities and mental health charities. They discovered that information is available in different formats and varies greatly in how it is presented.



# Audit results for cohort 3 – Mental health - South Tees Hospitals NHS Foundation Trust

Since 2020, South Tees Hospitals NHS Foundation Trust has continued to screen children and young with epilepsy for mental health disorders. The service also established an agreed pathway for children with mental health concerns.

Mental health questions	2019	2020	2021
Does your paediatric service routinely, formally screen for any of the listed diagnoses related to epilepsy? <ul style="list-style-type: none"> <li>• Attention deficit hyperactivity disorder (ADHD)</li> </ul>	Yes	No	No
<ul style="list-style-type: none"> <li>• Autistic spectrum disorder (ASD)</li> </ul>	Yes	No	No
<ul style="list-style-type: none"> <li>• Mental health disorders</li> </ul>	Yes	Yes	Yes
<ul style="list-style-type: none"> <li>• None</li> </ul>	No	No	No
Does the trust have agreed referral pathways for children with mental health concerns? <ul style="list-style-type: none"> <li>• Anxiety</li> </ul>	Yes	No	No
<ul style="list-style-type: none"> <li>• Depression</li> </ul>	Yes	No	No
<ul style="list-style-type: none"> <li>• Mood Disorder</li> </ul>	Yes	No	No
<ul style="list-style-type: none"> <li>• Non-epileptic attack disorder</li> </ul>	Yes	No	No
<ul style="list-style-type: none"> <li>• Other</li> </ul>	No	Yes	Yes
<ul style="list-style-type: none"> <li>• None</li> </ul>	No	No	No

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## Challenges

- The team found difficulty in setting up the display boards to capture patient and family views and finding the most effective way to coordinate having the board taken safely to a different site and then transported back.
- The original board had questions that had to be laminated and stuck onto envelopes; however, having the time to laminate each question was time-consuming, and the envelopes were not practical as they did not hold the weight of the counters very well.
- Initially used connect 4 counters for responses, but these were heavy and large; they could be easily seen in the envelopes, meaning parents, carers, or other young people could see which options had been chosen by others. To mitigate against this, the team purchased new, smaller counters using charity funds.
- The team redesigned the board using old DVD cases, as these allowed them to change questions easily and did not need laminating. The DVD cases had a small cut-out area to insert the token.
- Staff sometimes forgot to take the board to and from the clinic because the board could not be stored securely in the Children's Outpatients.

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## Challenges

- Collecting responses separately from both the young person and the parent/carer to get reliable results without influence from either party.
- The team initially set out to obtain responses from 20 young people and 20 parents/carers, which proved difficult due to the pandemic; therefore, a team decision was made to reduce the number of initial respondents to 10. It took 2-3 weeks for the tenth patient to attend the clinic.
- The pandemic led to a lack of face-to-face contact, which impacted the opportunity to ask patients and their families questions about their support needs. Additionally, there was a lack of support networks for families such as school, family, and friends.
- The introduction of telephone consultations took place mainly with the parent alone and lacked the involvement of their child or young person.

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## Outcomes

- A5 leaflet was created with a list of 5 different organisations that can offer emotional support and mental health advice regarding epilepsy and in general.
- Once face-to-face clinics are up and running again, the team will meet to discuss continuing with this QI project, as there is still much to learn about what young people want from the service.
- Leaflet to be circulated among the epilepsy team for use and evaluation by young people.
- National audit results showed that the service has continued to screen children and young people with epilepsy for mental health disorders.
- Additionally, the epilepsy service has established an agreed-upon pathway for children with mental health concerns.

South Tees Hospitals **NHS**

NHS Foundation Trust

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<https://www.kooth.com/>

Free, safe and anonymous online support for young people



<https://www.mind.org.uk>

Twitter: [@MindCharity](https://twitter.com/MindCharity)

Facebook: [Mind](https://www.facebook.com/Mind)



<https://youngminds.org.uk/>

Twitter: [@YoungMindsUK](https://twitter.com/YoungMindsUK)

Facebook: [Young Minds](https://www.facebook.com/YoungMinds)

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



<https://www.epilepsy.org.uk/info/health-matters>

Twitter: [@epilepsyaction](https://twitter.com/epilepsyaction)

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

Facebook: [Epilepsy Action](https://www.facebook.com/EpilepsyAction)

Helpline: 0808 800 5050



<https://www.youngepilepsy.org.uk/>

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Facebook: [Young Epilepsy](https://www.facebook.com/YoungEpilepsy)

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## Lesson learnt

- During the pandemic, families have reported that they still felt supported and could contact the team as required.
- Many families were extremely anxious about their child having an epilepsy related problem and attending the hospital during the pandemic.
- Microsoft Teams has allowed more health professionals to attend meetings in a virtual capacity.
- Engaging with other agencies, such as social care, has been challenging due to their own regulations that are not in line with NHS guidance.
- Parents requested to spend more time talking to the team because they have received less support elsewhere.
- Additional time is required for telephone calls/consultations than initially thought. A usual 20-minute face-to-face appointment can take 30–40 minutes via telephone.
- In hindsight, the team felt they should have approached families to request that they also speak with the child or young person via speaker phone.

## Team poster

## Mental health screening tool

<https://eqip.rcpch.ac.uk>

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