RCPCH Epilepsy Quality Improvement Programme October 2022 – May 2023

Mental health support pathways

Great Western Hospital NHS Foundation Trust

RCPCH Epilepsy Quality Improvement Programme project team:

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Epilepsy12 national audit results are not yet included within this case study until the publication of cohort 5 in September 2024.

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Project aim

To optimise mental health support pathways for 10–16-year-olds with mental health difficulties and epilepsy by June 2023.
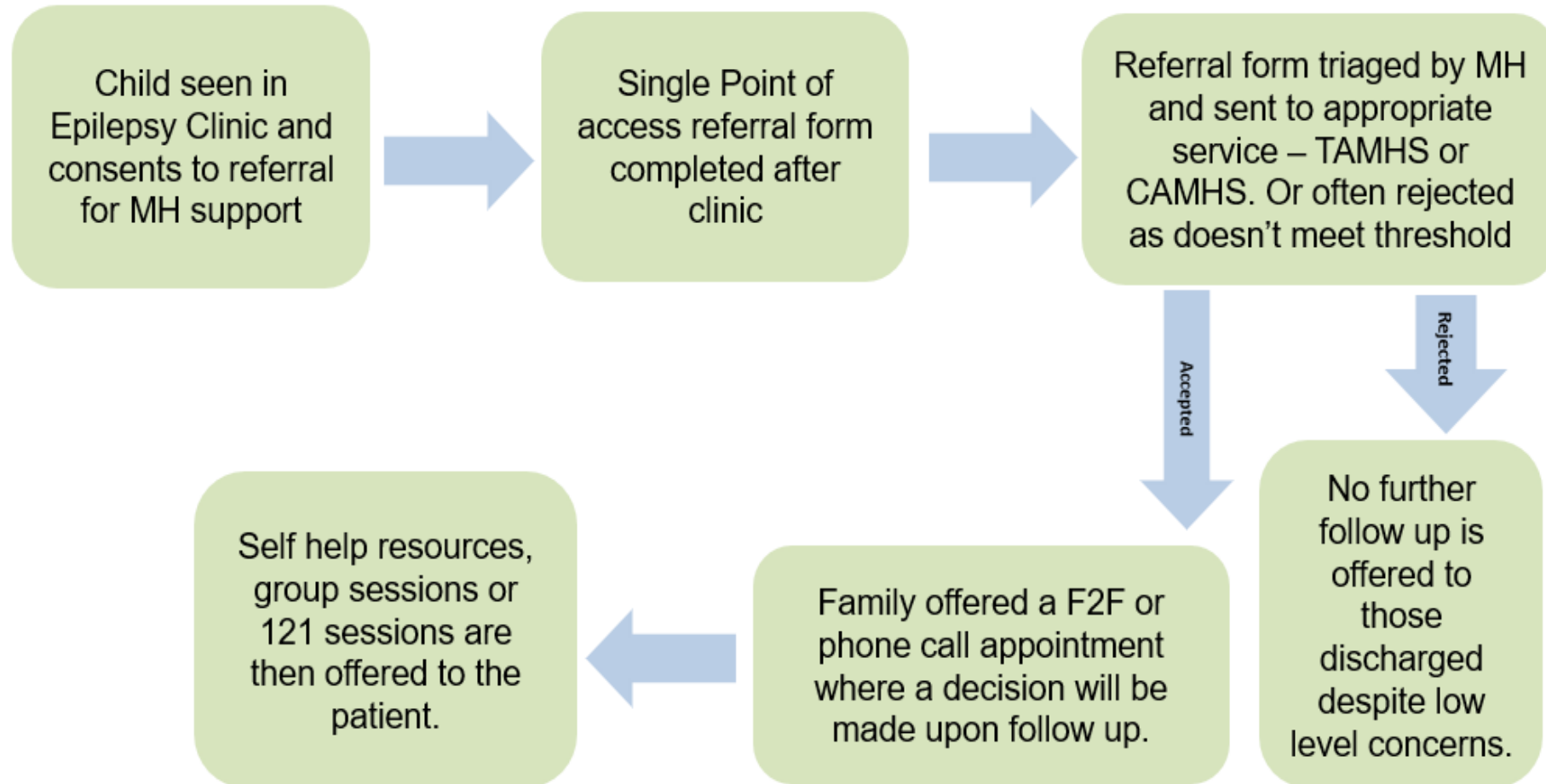
Background

A DGH paediatric epilepsy team with 1.5 WTE equivalent consultants, 0.5 staff grade, and 2 ENS. Mental health is a significant comorbidity with epilepsy. Mental health services are under significant pressure, resulting in long wait times for patients to access mental health support. Epilepsy12 audit results show local and national problems, and a large proportion of services, such as consultations and phone calls, are related to mental health issues and how patients do not have access to these services. Currently, referrals to CAMHS incur long waiting times, and their engagement with patients is very minimal. Patients and families who had been seen by CAMHS fed back that they had either been discharged without a sufficient reason or that they did not find the service useful enough to meet their needs. Therefore, the team would like to improve mental health referral pathways to CAMHS for only a select group of patients who need mental health support with the comorbidity of epilepsy.

Area of focus

- Improve mental health support pathways in adolescents with epilepsy by increasing engagement with patients and mental health services. To try and create a direct referral pathway to CAMHS for patients to receive mental health interventions in a timely manner. The team has thought about devising appropriate mental health questionnaires that implement a triage system for patients who need support from specialist teams and a separate self-help pathway that is supported by empowering patients, providing information to them and their families about mental health support, and creating a mental health wellbeing resource pack for patients.

- The team plans to engage CYP and families to obtain feedback on what information matters to them and explore the options of running late-evening clinics to increase engagement with teenagers and reduce the number of DNA appointments, resulting in providing the opportunity to be seen outside of school hours rather than miss school.
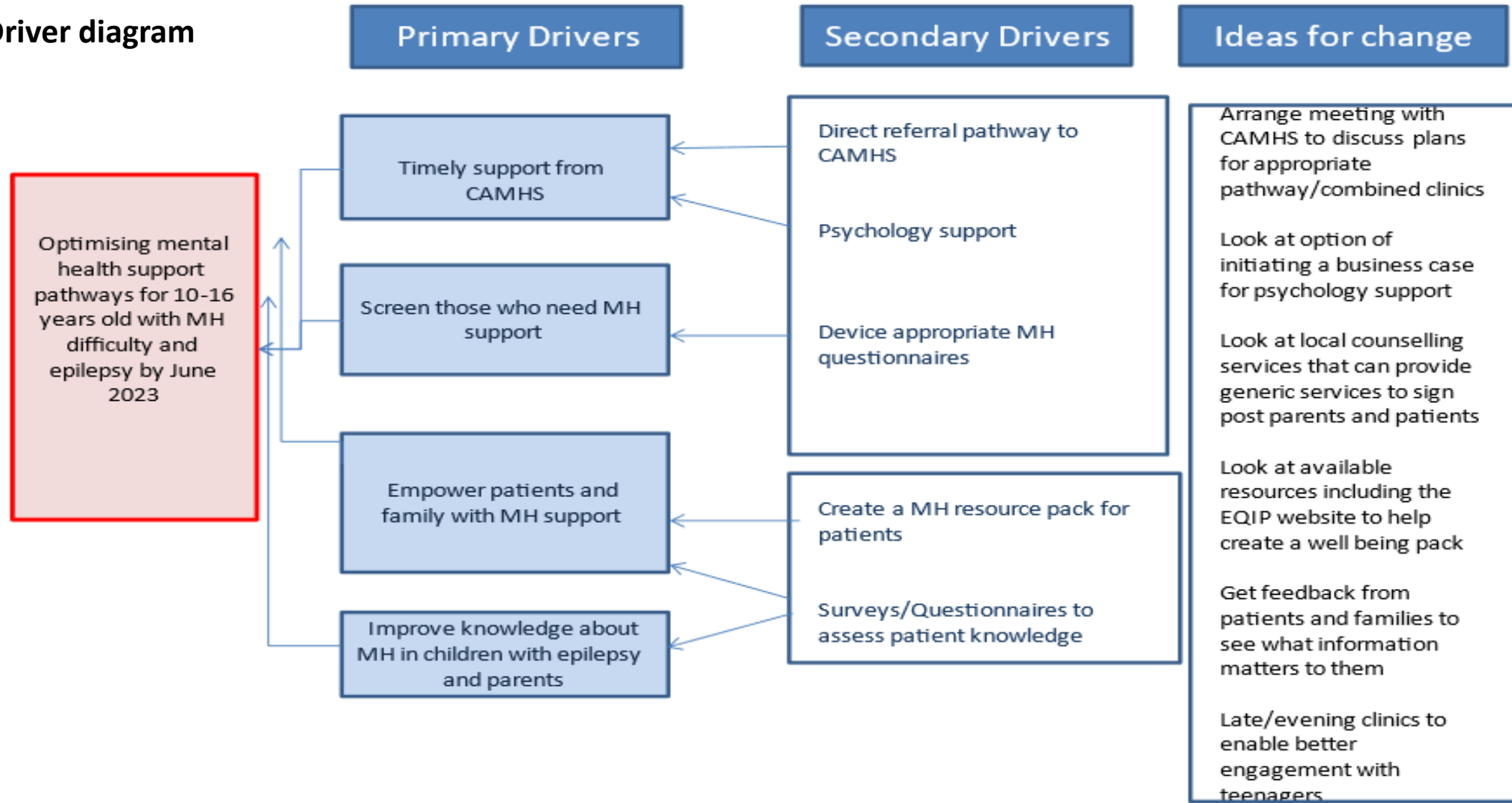
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Process Map for Current Mental Health Referral Pathway

Child seen in Epilepsy Clinic and consents to referral for MH support

→

Single Point of access referral form completed after clinic

→

Referral form triaged by MH and sent to appropriate service – TAMHS or CAMHS. Or often rejected as doesn't meet threshold

Accepted ↓

Rejected ↓

Family offered a F2F or phone call appointment where a decision will be made upon follow up.

No further follow up is offered to those discharged despite low level concerns.

←

Self help resources, group sessions or 121 sessions are then offered to the patient.

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Driver diagram

Primary Drivers

Optimising mental health support pathways for 10-16 years old with MH difficulty and epilepsy by June 2023

- Timely support from CAMHS
- Screen those who need MH support
- Empower patients and family with MH support
- Improve knowledge about MH in children with epilepsy and parents

Secondary Drivers

- Direct referral pathway to CAMHS
- Psychology support
- Device appropriate MH questionnaires
- Create a MH resource pack for patients
- Surveys/Questionnaires to assess patient knowledge

Ideas for change

- Arrange meeting with CAMHS to discuss plans for appropriate pathway/combined clinics
- Look at option of initiating a business case for psychology support
- Look at local counselling services that can provide generic services to sign post parents and patients
- Look at available resources including the EQIP website to help create a well being pack
- Get feedback from patients and families to see what information matters to them
- Late/evening clinics to enable better engagement with teenagers

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Changes

- The team changed their patient engagement from a questionnaire method to a more direct and interactive activity, using the skills and techniques learned from the Head of CYP Engagement, RCPCH&US. The team developed four questions that were asked of children and young people who attended two nurse-led clinics.

- Planned tests involve asking patients the four questions using an interactive display of sparkly jars and plastic shapes to capture feedback on each question anonymously. The age of the child was included on the jar, and patients could use cut-out shapes to go into the jar against each question.

- Met with the CAMHS team to provide feedback and discuss the need to develop a questionnaire or other means to screen epilepsy patients for mental health issues and develop a referral pathway.

- The team has begun engaging with local schools and GP surgeries, collating information in terms of the available support they can offer their patients, and exploring how they can ensure they receive the support that they need.

- Other referral pathways explored were the signposting of information on wellbeing support.

- The team had parallel activities take place, including exploring various local mental health support in school and local GP surgeries:

  - Primary school: ELSA for emotional support.

  - Secondary school: councillors and school nurses.

  - Primary care: nothing much; they direct patients to Kooth and LIFT.

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Results

- Initial patient engagement results using the questionnaire method had multiple questions, which made it difficult to delineate how children felt, and had a scoring system that they did not have access to.

- Included emoji questions, which one patient filled in and showed that they were not happy with the diagnosis of epilepsy. The other questionnaire results showed that patients were sometimes feeling sad about the epilepsy.

- Changed engagement methods to become more direct and interactive and reduced questions to capture feedback:
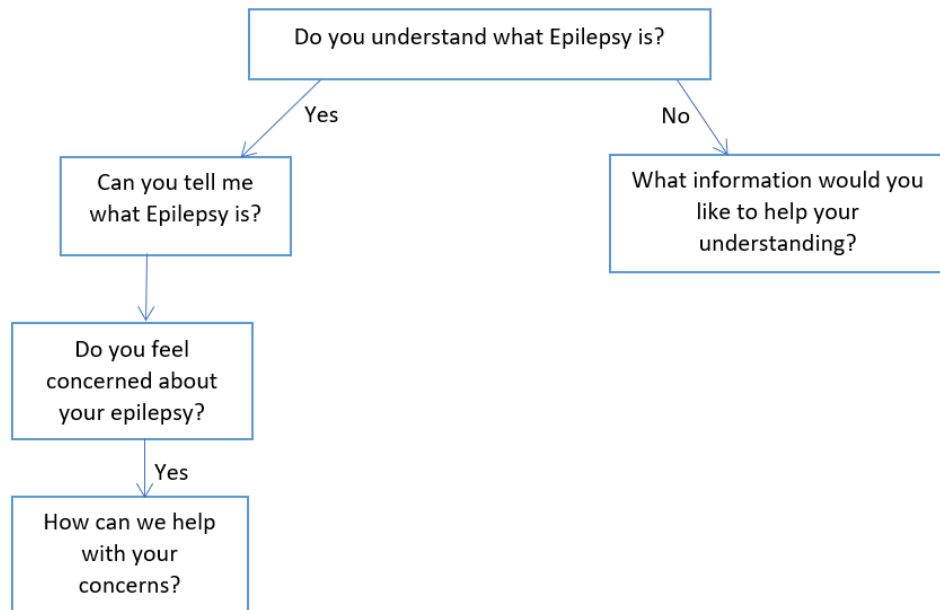
- The responses from patients were quite mixed in terms of whether some of the younger patients possibly enjoyed the experience more than some of the older patients.
- The team identified that the question display was aimed at a younger demographic of children and will make some changes to incorporate engaging older children.
- Feedback results reported that only 60% understood what they meant by epilepsy, which was surprising for the team because of the time taken to explain the condition to all patients and their families.
- Other findings reported that only a small percentage wanted support for their epilepsy.
- Overall, the team felt the actual process of doing the test was successful and was able to collate some results that they can work on to begin making service changes.
- Feedback from round 2 of testing with the incorporation of QR codes saw an increase in patients gaining a better understanding of their epilepsy condition.

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Round 1 data/results after change of engagement methods using jars and counters and reducing questions asked
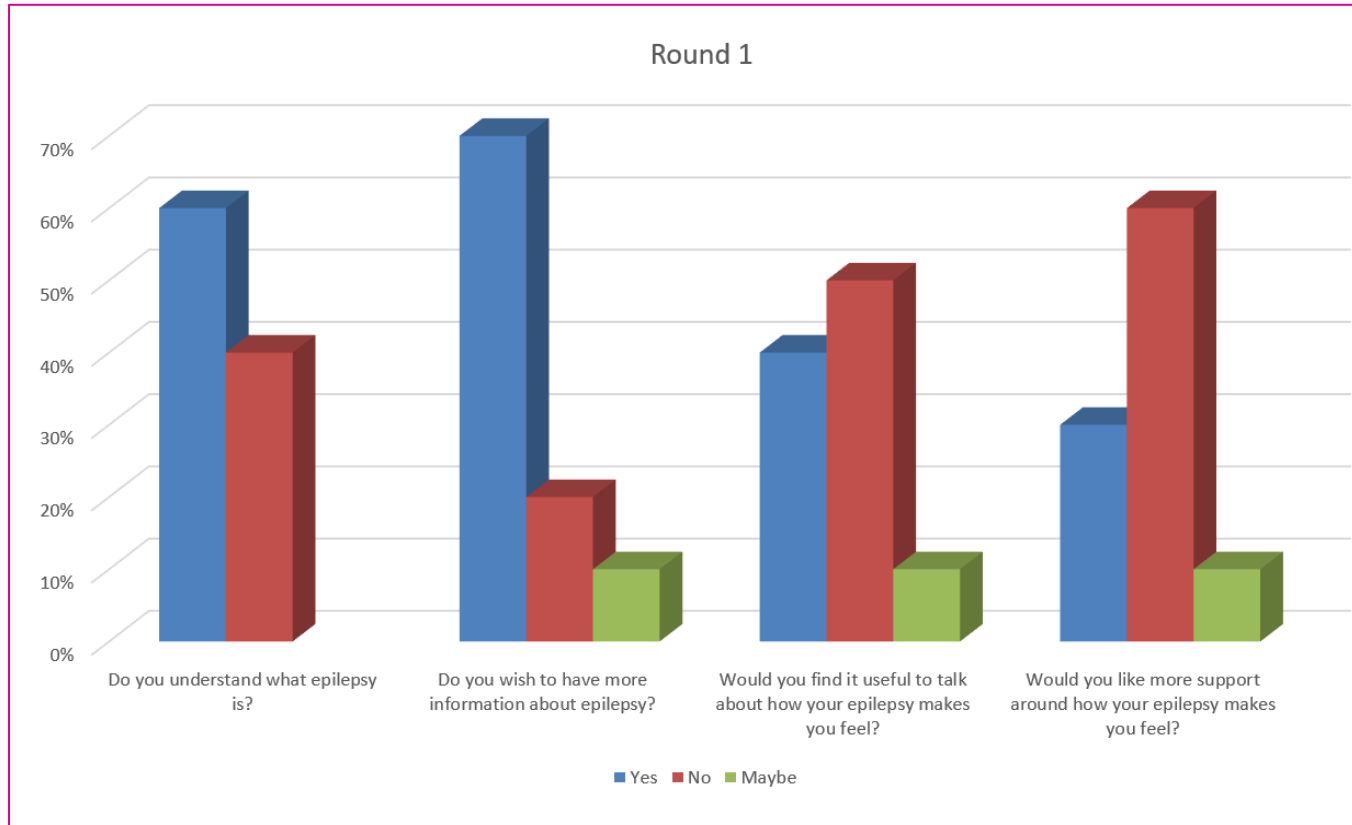
Round 1

	Do you understand what epilepsy is?	Do you wish to have more information about epilepsy?	Would you find it useful to talk about how your epilepsy makes you feel?	Would you like more support around how your epilepsy makes you feel?
Yes	6 (60%)	7 (70%)	4 (40%)	3 (30%)
No	4 (40%)	2 (20%)	5 (50%)	6 (60%)
Maybe		1 (10%)	1 (10%)	1 (10%)

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Patient engagement results after development of questions to increase engagement methods

- Involved patients (11-16 years) who attended outpatient clinics and their parents.
- Surprised to learn that the majority of patients weren't aware of what their epilepsy diagnosis meant.
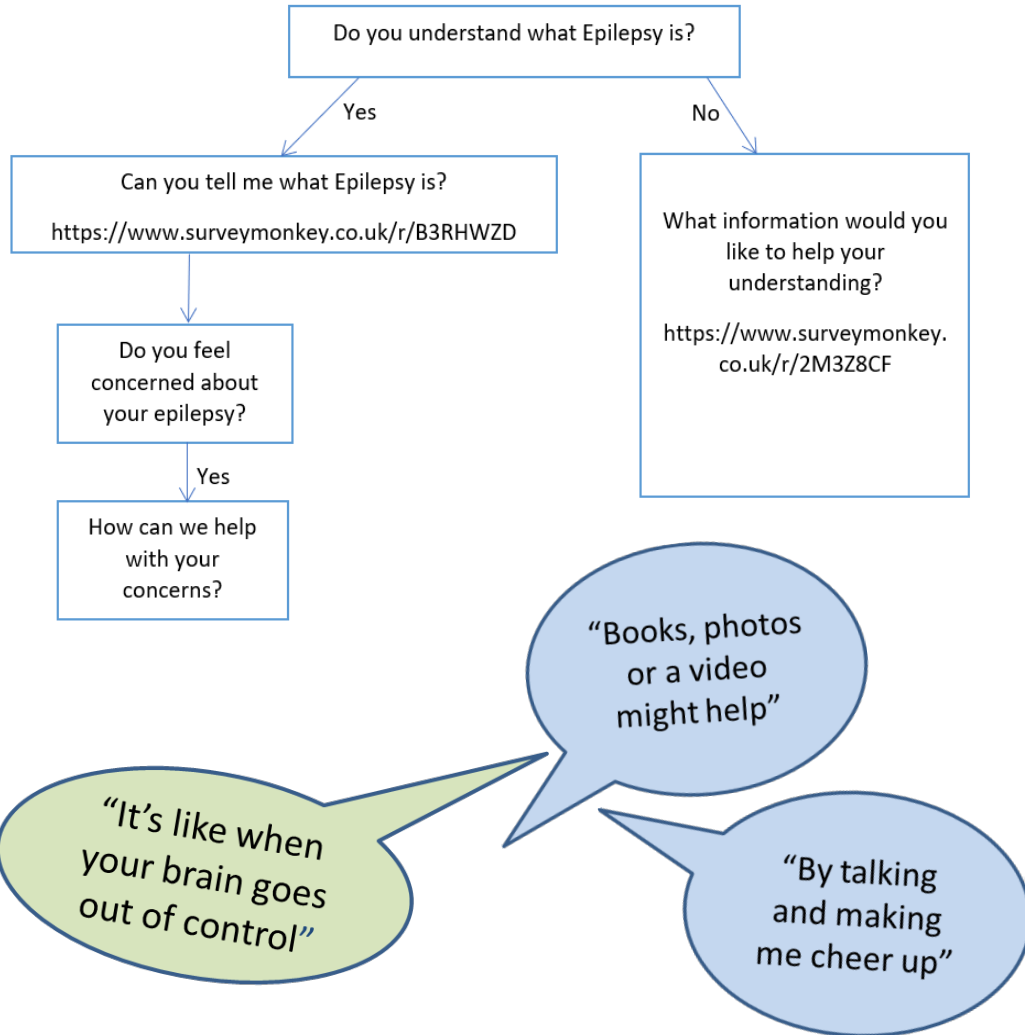- Stopped assuming things and focused the subsequent cycles on what patients needed.

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Round 2 data/results after development of questions to increase engagement methods
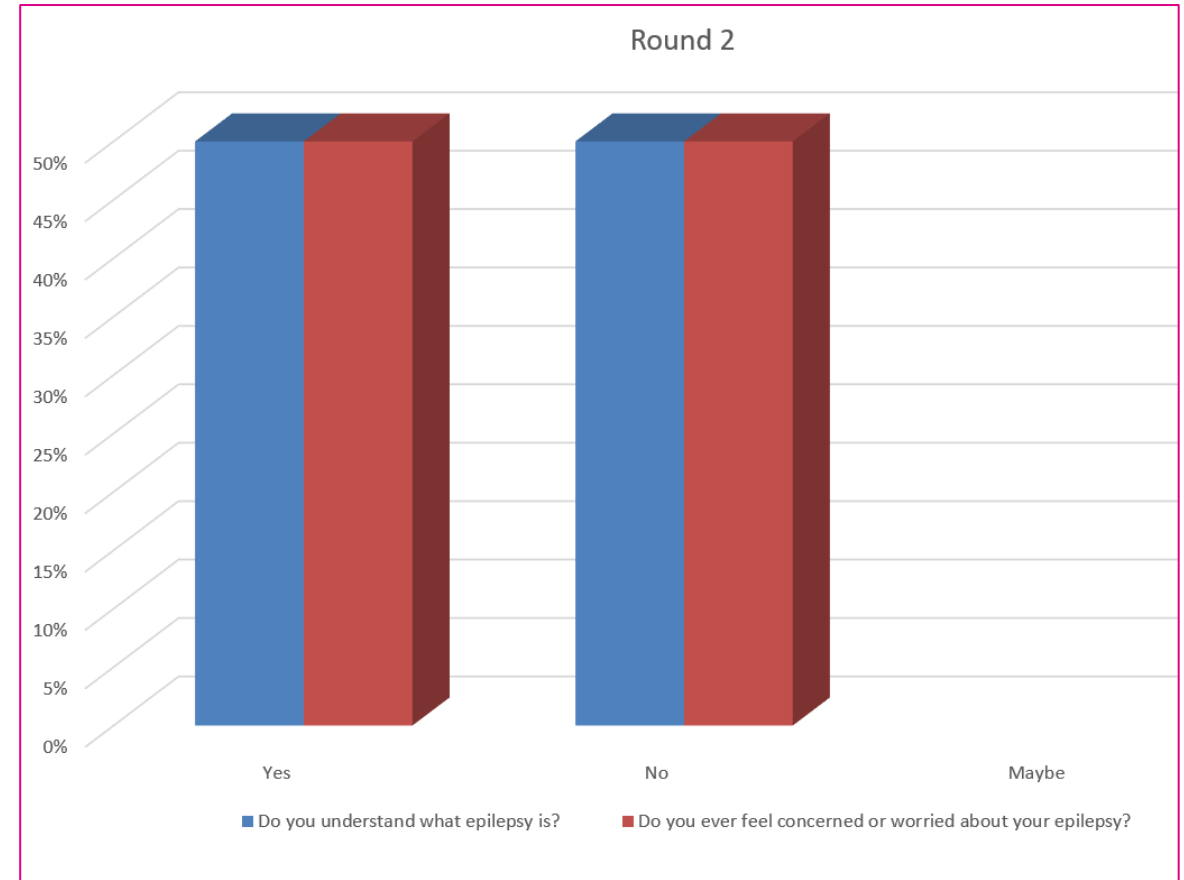
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Created a booklet on epilepsy with information around mental health support and links to supportive services

Stress - People with epilepsy often say that stress triggers their seizures. Epilepsy can be a cause of stress in itself. Stress is a normal physical and mental reaction. It happens when you feel you've lost control of what's going on around you. It usually only lasts a short time but can be harmful if it lasts for long periods. Stress may effect how you feel, think, behave and can even impact how your body works.

Self Help - There are a few things that you can try these include; talking to people you trust about how you feel, try to have regular good night's sleep, eat a balanced diet, make time to relax and exercise. Contact your epilepsy team, we have lots of information and links with organisations which may help you further.

Apps - There are a couple of apps which may help with relaxation techniques etc:

Anxiety and Stress - Chillpanda, Clear Fear, FearTools - Anxiety aid, Mindshift CBT and Molehill Mountain.

Mindfulness, Mood and Depression - Catch it, Cove, Headspace, Insight timer, Mood Tools - Depression Aid, Smiling Mind and Calm.

Sleep - Headspace, Sleepful and The Sleep Charity (website).

The Child and Adolescent Mental Health Services (CAMHS) also has lots of useful information and tools. This can be accessed via googling "CAMHs Swindon" (it is part of Oxford Mental Health Partnership).

Parents/Guardians

It is natural to have concerns when you are told your child has epilepsy. Finding out as much information as possible about your child's epilepsy and treatment, and sharing it with other people could be helpful. Your child's care plan will have specific information around your child's diagnosis, and their epilepsy team are more than happy to answer any questions you may have.

We are also looking at setting up a Parent Support Group run by parents for parents with support from the Paediatric Epilepsy Team at Great Western. This will be for families under Great Western Hospital Paediatric Epilepsy Team. The first session is due in May 2023!

Parents supporting their child with wellbeing

It is important as parents to support your child with their epilepsy and wellbeing as the two are closely interlinked. Further resources can be found on the Epilepsy Action QR codes below, from your Epilepsy Nurse Specialists or via the CAMHS website listed above.
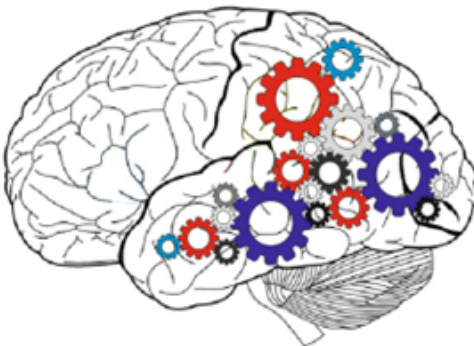
Epilepsy Websites

Epilepsy Nurse Specialists

Sue Mulhall & Natasha Thomas

Monday - Friday (09:00-17:00)
Not in an emergency!

01793604969

gwh.childrensepilepsy@nhs.net

NHS
Great Western Hospitals
NHS Foundation Trust

Epilepsy
Information Leaflet

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Challenges

- Improving the direct referral pathway to CAMHS was challenging and is ongoing.

- Acceptance of a business case for psychology support, which is similar to the support provided for their Trust's diabetes team.

- Initially, using the questionnaire method was difficult for interacting with patients and was as ineffective as expected.

- Had initial engagement from Oxford CAMHS, but communication lessened over time. Experienced barriers to changing the pathway for comorbidity patients, as this is primarily managed by mental health service teams.

- Having age and diagnosis-appropriate patients in the clinic to be involved in the project depended on follow-up time restrictions and bookings made by the Trust appointments team.

- Time!

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Outcomes

- Achieving the project aim is ongoing and the first steps were being able to increase the team's understanding of their patient needs and address their concerns by ensuring they understood their epilepsy condition, which more than likely had impacted on their mental health.

- Increased patient engagement skills, which captured feedback on concerns that the team were able to action and address.

- Able to create a booklet on epilepsy with information around mental health and links to supportive services which includes information on epilepsy and mental health support. The team hope to implement this in practice imminently and act as a first line of support for children who present with mental health comorbidities in clinic with links to apps and websites.

- Gained an understanding of what adolescents would find useful.

- Good integrated working with other epilepsy teams. Good interprofessional working with both CAMHS, TAMHS and School nursing team.

- Based on the feedback received, arranged the first parent support group for parents of children with epilepsy to provide peer support and expand this in the future to children with epilepsy.

- The parent support group will continue to provide feedback on the booklet which will be actioned to make appropriate improvements when required.

- Increased team working together.

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Lessons learnt

- The team learned the difference between a task and a test, for example:

    - A task is arranging a meeting with CAMHS.

    - A test is where the meeting led to a change, such as discussions resulting in agreeing on an appropriate referral pathway or discussions leading to a change in process or delivery.

- The team was surprised to learn that the majority of their patients were not aware of what their epilepsy diagnosis meant or wanted more information. The team felt that by addressing their concerns, they may also positively impact their mental health.

- There is limited to no immediate support for children who present with mental health concerns, unless in crisis. Research suggests that early intervention may prevent crises later on.

- The majority of adolescents reported they did not want face-to-face support for their mental health.

- The initial round of questions wasn't necessarily age-appropriate for all the children; therefore, the team defined an age group and created age-appropriate questions.

- Don't assume we know what children and young people want.

- Continue to access the EQIP web platform to plan future QI interventions.

https://eqip.rcpch.ac.uk

eqip@rcpch.ac.uk

@RCPCHEQIP