RCPCH Epilepsy Quality Improvement Programme November 2019 – July 2020

Improving patient engagement

Southport and Ormskirk Hospital NHS Trust

RCPCH Epilepsy Quality Improvement Programme project team:

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National audit results included within this case study acts as a guide only to performance standards. The service improvements made during the EQIP cannot be entirely attributed to the reported results in the Epilepsy12.

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Project aim

To develop feedback tool to obtain 50 pieces of feedback from children, young people and families by May 2020.

Background:

- The initial and overarching aim was to develop a valid feedback tool and offer a service that is person-centred. The implementation of an efficient ongoing feedback loop that incorporates a feedback forum would be ideal. What matters most is being able to deliver a continuously improving service that is guided by and responsive to children, young people, and their families. The team felt that the clinic needed to reflect the needs and expectations of patients and their families.

Area of focus

- The service team plans to reflect on the needs and expectations of their children and families by using effective engagement methods in collecting their feedback, reviewing responses, and acting upon what needs to be changed. There are a number of ideas to help improve the service, but it is important to first understand the needs of their patients.

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Changes

- Developed a questionnaire that was given to follow-up patients who would be attending clinic again.

- The following were excluded: New patients (not all of them had epilepsy), patients who were being discharged (and unlikely to be seen again).

- Patients and families that were offered follow-up appointments were asked if they were happy to take part in providing feedback. This was done on an individual basis after the clinic.

- The questionnaire was designed to be completed by parents/carers and young people over the age of 12 and was designed to look at the holistic aspects of the service and their experience attending clinics for patients and their families.

- Agenda setting sheets were given to patients and families prior to the clinic as an opportunity for them to highlight areas they would like to discuss for two weeks.

- The pandemic led to service changes such as staff using digital platforms such as 'Attend Anywhere' being installed and ready to use in all outpatient areas.

- Clinic appointments were offered either as a telephone appointment or using Attend Anywhere, giving patients and families a choice and flexibility.
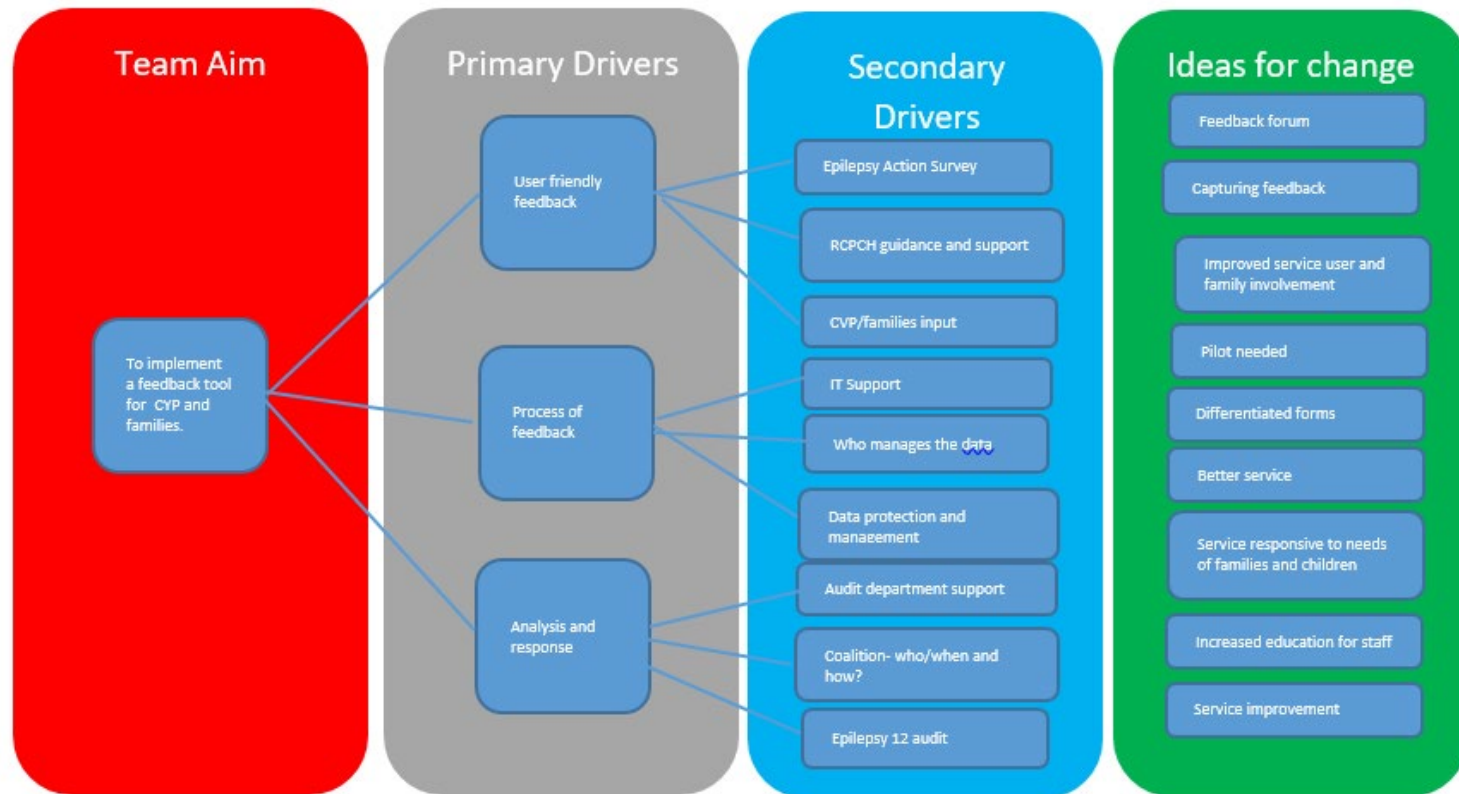
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Changes

- The team liaised with Emma Sparrow, Head of CYP Engagement, RCPCH&US, which led to a number of iterations before agreeing on a final version of the questionnaire.

- The team engaged with their IT department to set up a team email, which encouraged team communication and ensured that messages were seen and dealt with contemporaneously.

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Project Driver Diagram

Team Aim

To implement a feedback tool for CYP and families.

Primary Drivers

- User friendly feedback
- Process of feedback
- Analysis and response

Secondary Drivers

- Epilepsy Action Survey
- RCPCH guidance and support
- CVP/families input
- IT Support
- Who manages the data
- Data protection and management
- Audit department support
- Coalition- who/when and how?
- Epilepsy 12 audit

Ideas for change

- Feedback forum
- Capturing feedback
- Improved service user and family involvement
- Pilot needed
- Differentiated forms
- Better service
- Service responsive to needs of families and children
- Increased education for staff
- Service improvement

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Epilepsy Clinic day - Agenda setting

Please tick or underline anything which you would like to discuss at your appointment today. Thank you, Dr Mariguddi, Andrew, Fiona.
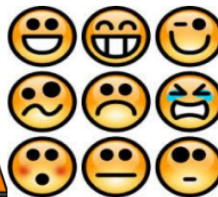
Prescriptions Medications Sleep Training Safety Emotional / mental health

Seizures Diary Videos behaviour Education Test/results Anything else ?

Agenda setting sheets were given to families as they arrived for their outpatient appointment to be complete prior to their appointment in order to lead the discussion.

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Results

- Distribution of questionnaires based on their caseload resulted in receiving 22 completed questionnaires by patients and families.

- A number of the teenage population were asked if they would be willing to join a young person's feedback group – response was good overall.

- Clinic 1 – 7 patients scheduled, 6 attended, 1 x DNA. Of these, 1 patient was excluded because they had been given a general paediatric appointment incorrectly.
  - 1 patient was excluded because they were under another hospital and was only seen by the team sporadically.
  - 1 patient was excluded because they were a new patient. This meant 3 forms given out and 3 completed.

- Clinic 2 – 8 patients scheduled,
  - 1 x DNA 1x cancelled due to illness, 1 x new patient and 5 x follow up patients.

- Clinic 3 – 8 patients scheduled,
  - 1 x DNA 1x cancelled due to illness, 1 x new patient and 5 x follow up patients. Of these, only 5 children were included, all 5 families completed the forms.

- Clinic 4 – 2 patients were booked, 2 patients attended both follow-up appointments. 2 x responses received.
  - 2 inpatients at the time who were asked the question and agreed to be part of the feedback exercise.

- Good results. Feedback over a 2-week period suggests that all families find the agenda setting sheet useful and feel that they are involved in the direction of discussion.

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Topics patients wanted to discuss
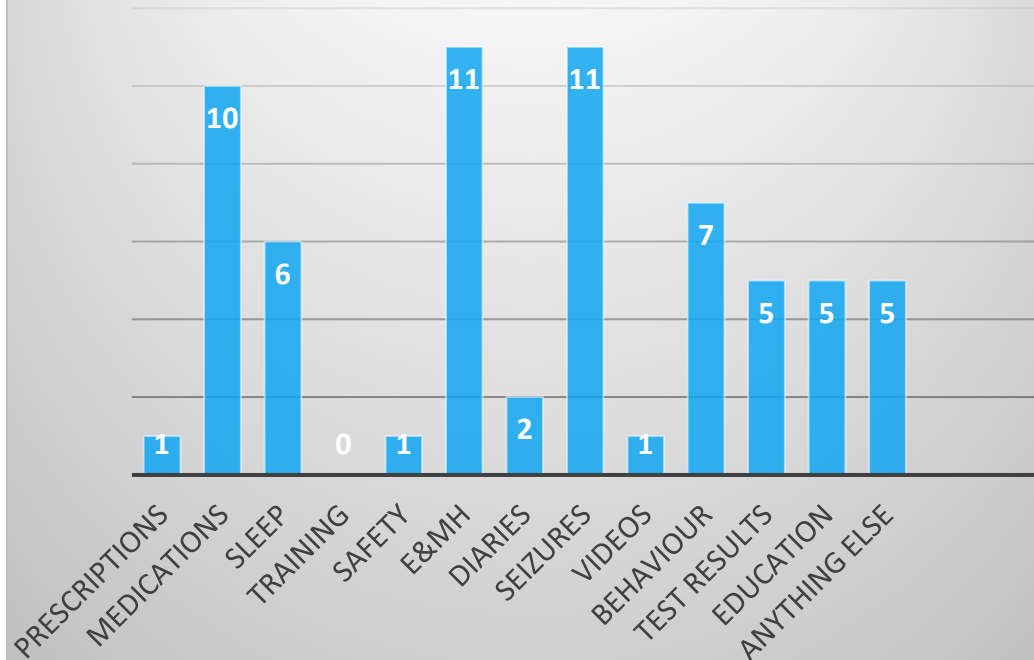
- Feedback over a 2-week period suggests that all families find the agenda setting sheet useful and feel that they are involved in the direction of discussion.

- Families accessing the agenda setting tool felt it acted as a prompt for them to remember things that they may have forgotten to ask previously. PDSA cycle completed.

- Verbal feedback from patients and families, revealed they were happy to use them and felt that it acted as a prompt in some cases to remind them of the questions they may have had.

- The older children and young people mostly helped their parents to fill them in.

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Results

The team learned that families perceive their clinic time slots to be just right, but they vary when it comes to preferred clinic times.

- Some families forgot to do the other side of the questionnaire – included 'PTO' at the bottom of the form.

- 2 families mentioned the fact that Sefton is not covered by the epilepsy nurse.

- 1 parent commented that they would like referrals for additional help to be made for them rather than asking school / GP.

- 1 family wanted general health information on viruses.

- 1 family mentioned that although they have always felt included and respected the team, they would like to see more consideration and communication to help them engage.

- Skype / video consultations were popular with 3 families and telephone consultations with 2 families.

- Good results.

- Distributed 11 questionnaires, all of which have been completed.

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Results

- In total 42 completed questionnaires received.

  - 20 were posted out with stamp addressed envelopes – only 3 were returned.

- The overall theme from the feedback received was that the clinic times are "just right" with 2 comments of "it depends what for."

  - 30 out of 42 people preferred morning time slots.

  - 7 preferred evening timeslots.

  - 2 people ticked all 3 time slots.

When asked about telephone and skype consultations.

  - 18 respondents wanted telephone consultations,

  - 4 wanted skype / video consultations

  - 4 said both 2 people were unsure.

  - The rest did not complete this question as they did not turn the page.

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Patient questionnaire

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Your epilepsy service needs your ideas!

We are looking at our service to make sure it meets your needs. We would be grateful if you could help us with your ideas and views.

We won't know who answered the questions so please be as honest as you can. We are not asking for your name so it is anonymous.

We would like all your answers by the 30th of April so that we can start looking at them in. We will put up a poster in Out Patients so you can see what people told us and what we plan to do next.

Are you a:

Parent/ carer ☐

Patient ☐

1. Do you think your appointment with the Epilepsy Doctor or Nurse is :
   a. Too long
   b. Too short
   c. Just right

We are looking at the times that our Epilepsy Doctor or Nurse sees patients. Which would be your first choice of when you wold like to come in?
   a. 0900-1300
   b. 1300-1700
   c. 1600-1900

Please could you give a reason for your choice
_____
_____
_____

Would you prefer to see your Epilepsy Doctor or Nurse (please tick your favourite choices)

At the weekend ☐

In a school holiday ☐

On a school day ☐

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2. What things would you like to be able to talk about or get advice on in your appointment?
Prescriptions   medications   Sleep   training   safety   emotional/mental
health   Seizures   diary   videos   behaviour   education   test/results

Anything else we have missed?
_____
_____
_____
_____
_____
_____
_____

3. Would you like the chance to have :
a. Telephone appointments   YES/NO/NOT SURE
b. Skype / video appointments   YES/NO/NOT SURE

4. Do you have any wishes for your epilepsy service that you would like to see?
_____
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For ages 12 and over..

5. Would you like a clinic just for young people?
   Yes
   No
   Not sure

6. What do you think a Young Person's clinic should look like/be like? please give your ideas / suggestions / drawings etc below

7. Would you   like to help us to make the Epilepsy service the best it can be?
   YES/NO/NOT SURE

8. If you said yes, would you like to share your ideas
   by text/WhatsApp
   by email
   in a workshop / activity session
   at a meeting / forum

Thank you for telling us what you think. We will get all of your ideas together and have a look and think about where we can make changes now or where we might need to do a project to make changes for the future.

If you want to get involved to help us, please tell your Doctor or Nurse or email
fiona.short1@nhs.net

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Challenges

- Developing and agreeing on suitable questions for the questionnaire was challenging.

- Staff annual leave and agreeing on a suitable date/time to meet as a team every week.

- It was difficult to obtain representation from families that were not due to attend clinic.

- Some families only filled out one side of the questionnaire until 'PTO' was added to the form.

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Outcomes

- Increased engagement with patients and families who have been happy to have received the support.

- Overall, based on the feedback received, patients were happy with the service.

- Created and tested questionnaires that can be disseminated either electronically or by post prior to clinics.

- Created and tested an Agenda Settings document that can be disseminated either electronically or by post prior to clinics.

- Collated all the evidence from the questionnaires to better understand what improvements or changes may be needed, what can be offered in the "new" way of working.

- Compiled feedback from parents and families and created a "you said, we did" board or poster.

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Lesson learnt

- The team has learned to employ a risk sensible approach to individual cases and has had to think about different approaches to working with children and their families.

- As a team, communication is a lot more efficient. The team is acutely aware of the benefits of having good lines of communication and the importance of regular meetings and catch-ups.

- There are multiple ways to communicate with children and their families.

- Be risk sensible not risk-averse.

- The team has come a long way despite the ongoing pressures of the pandemic and participation in the EQIP process. However, the team has strived to continue improving in order to offer patients and families the best possible service with the resources and restrictions available.

- QI does not have to be complicated and does not involve a large objective. Make sure the project objectives are SMART but also seemingly "small" or "simple" ideas.

- It is particularly humbling to work with families and support them rather than lead them. Once you have built a good relationship with your patients and families, it is good to encourage them to lead discussions and consultations.

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Lesson learnt

- Only try to offer what is "in your gift" to offer. And if it's not in "your gift," why not? Could it be? How will you know unless you test it?

- Learn from others.

- You do not need to reinvent things if they already exist.

- Drawing on the experiences and knowledge of others keeps you informed and helps grow your service.

- Using data in conjunction with patient, family, and carer feedback feeds into continuous improvement to help adapt and meet the needs of our patients and families.

Visual presentation of team project intervention

Video presentations

Team project poster

https://eqip.rcpch.ac.uk

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