

# Mental health support case studies

## 2023-2024

### Improving mental health screening pathways

#### Organisation

East Sussex Healthcare NHS Trust

#### Project team

Dr Lalani, Consultant Paediatrician with special interest in epilepsy  
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#### Project aim

By May 2024, every child and young person aged 13-18 years attending their epilepsy clinic will undergo mental health screening, with patient feedback being used to determine service needs.

#### Background/rationale

The East Sussex Healthcare NHS Trust provides acute paediatric care services at Conquest Hospital and Eastbourne District General Hospital. The team provides care for around 400 children and young people diagnosed with epilepsy, of whom over 30% have comorbidities such as ASD, ADHD, other neurodisabilities, and genetic conditions. Nearly 50% experience sleep regulation difficulties and behavioural conditions.

#### What was the problem?

In accordance with NICE standards of practice and the national audit Epilepsy12, all children should be screened for mental health conditions.

Mental health screening tools such as the [Strengths and Difficulties Questionnaire \(SDQ\)](#) and the [Beck Depression Inventory \(BDI\)](#) were used to assess the mental health support needs of children and young people. Following assessment, patients' scores can identify mild to moderate depression; however, these assessments did not always meet the referral criteria for CAMHS intervention. This raised ethical concerns for the team, as without a clear pathway for supporting patients once a mental health concern or condition was identified, they had no way to support patients and families. Consequently, this led to children and young people being untreated with no way for the team to determine what type of intervention was required.

## What was the solution?

Feedback provided by patients transitioning into adult services concerning service improvement during their time in paediatric care was gathered. Children and young people mentioned the need for:

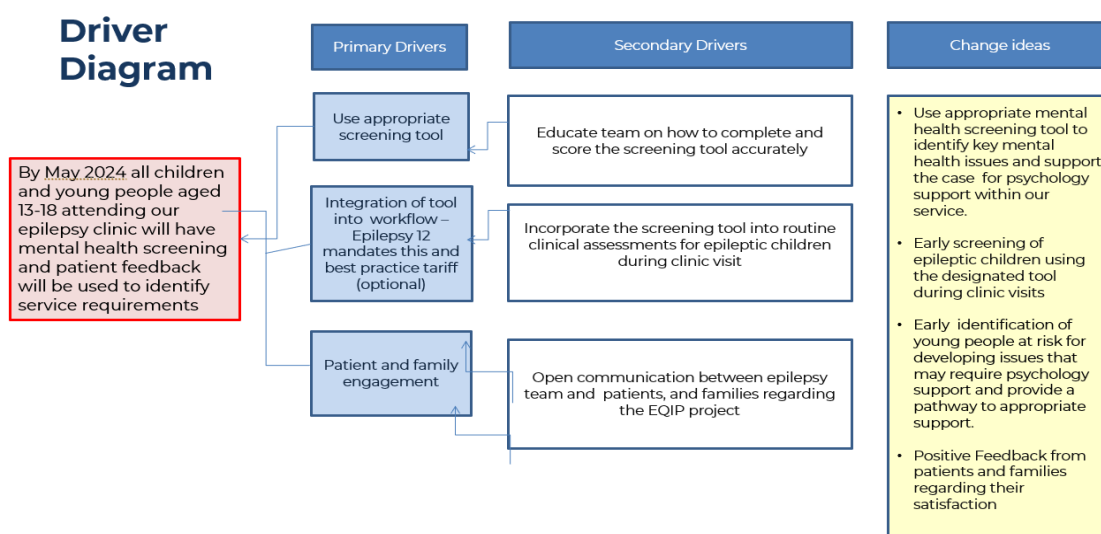
- Someone to talk to about their feelings and mental health and wellbeing.
- Someone at school who understands more about their epilepsy.

This feedback process prompted the team to focus on more specific questions and use this approach for gathering feedback on mental health screening tools.

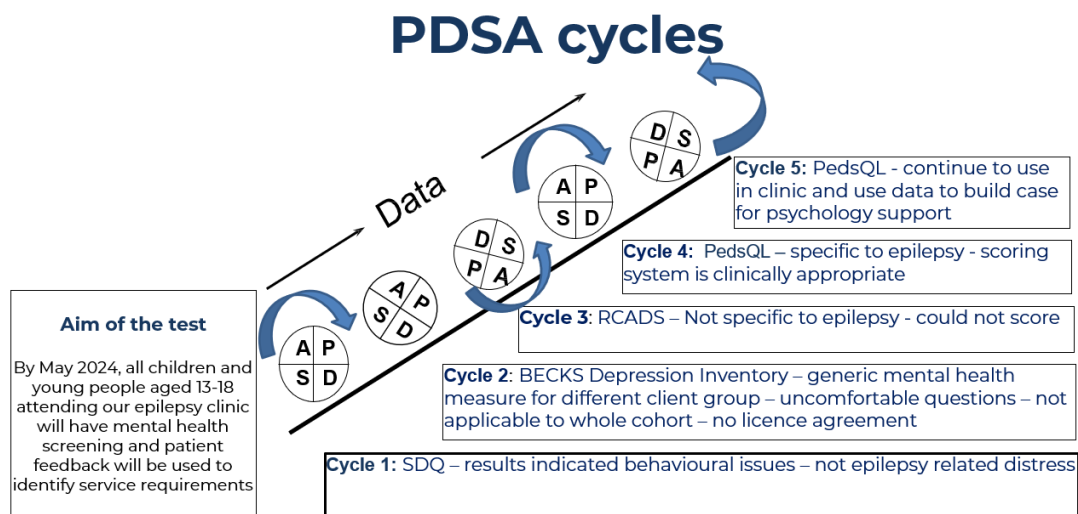
Other mental health screening tools were reviewed such as the [PedsQL, Paediatric Quality of Life Inventory](#) – epilepsy-specific measure of quality of life, which is applicable to all age groups. Following consent, the project aim was communicated to the children and young people that attended clinic and feedback was obtained. Children, young people aged 13-18 years and their families attending the clinic were asked to complete the PedsQL tool. Responses from 20 patients and their families was received.

The team compiled a list of applicable resources to help signpost children, young people, and their families to local organisations offering emotional and mental health support from not-for-profit organisations offering wellbeing services for children, young people, parents, and professionals.

Engagement with their Trust Deputy Head of Children’s Commissioning and the Integrated Care Board transformation regional leads confirmed that they will begin reviewing the recommendations set out in the National Epilepsy Bundle of Care. Additionally, the team engaged with the community Trust Clinical Psychologist, who expressed interest in their project, to better understand the teams support needs. The team developed a driver diagram to show the overall project aim and tests of change.



**Figure 1: Team driver diagram that provides a clear statement of their project aim, with primary and secondary drivers that visually display the team’s theory of what “drives”, or contributes to, the achievement of a project aim.**



**Figure 2: Plan, Do, Study, Act (PDSA) cycles of change ideas listed within the driver diagram being tested.**

### What were the challenges?

The team uncovered a number of challenges during their improvement journey.

- There was a lack of booked appointments for children and young people between the ages of 13 and 18 years during the time frame of the project. Mitigation plans involved mailing the forms to patients that met the criteria which would be completed and sent back to the team.
- Other issues identified with the screening tools were how the tools are scored, their ease of use for both staff and children and young people, and how efficient it was to interpret the result. A number of screening tools were tested with patients and families, which presented the following challenges:
  - Local research and through engaging with other teams, the team learned that there are many different mental health screening tools available. None of these was standardised and different services use different screening tools.
  - The [SDQ](#) psychological assessment tool for 2–17-year-olds performed better with younger children, but did not identify issues and concerns for older young people.
  - The [Beck Depression Inventory \(BDI\)](#) patient assessment tool for mental health screening, widely used to screen for depression and to measure behavioural manifestations and severity of depression in people aged 13 to 80 years, did not perform well when assessing children and young mental health conditions or support needs other than identifying them with depression.
  - The [Revised Child Anxiety and Depression Scale \(RCADS\)](#) tool is a 47-item youth self-report questionnaire with subscales. This tool is also based on an American system which incorporates questions on school grades in the

assessment, which made some questions inapplicable for the UK system.

Consequently, the team could not find a successful way to score this tool.

- Further feedback from families was obtained during the testing phase of the project. Patients and families attending clinic for the first time were asked to write on a lollipop stick their top wish regarding the support they felt was needed from the epilepsy team. However, this question was too broad and had to be posed in different ways.
- Insufficient time during clinic to explain and collect results, and limited time after clinic to gather data for project presentation.
- There was no dedicated time for the project.
- The small team has a large caseload.
- A clinical cut-off for scoring PedsQL has not yet been identified.
- The best practice tariff component for psychology is small, providing insufficient incentive.

### **What were the results?**

After testing several screening tools, the team identified the PedsQL as the most suitable to use and score for their epilepsy patients, because it includes the impact on more areas of daily life.

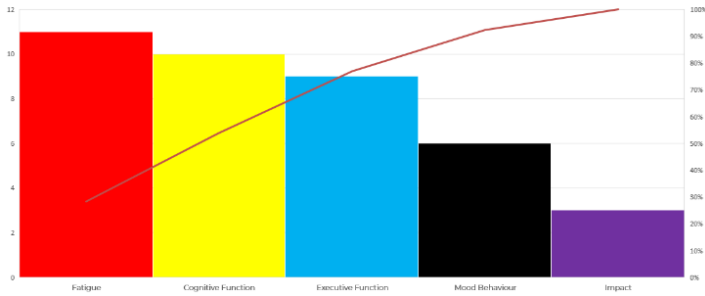
Using the PedsQL epilepsy module screening tool the scoring is divided into five sections:

- Cognitive function
- Executive Function
- Fatigue
- Mood and behaviour
- Impact

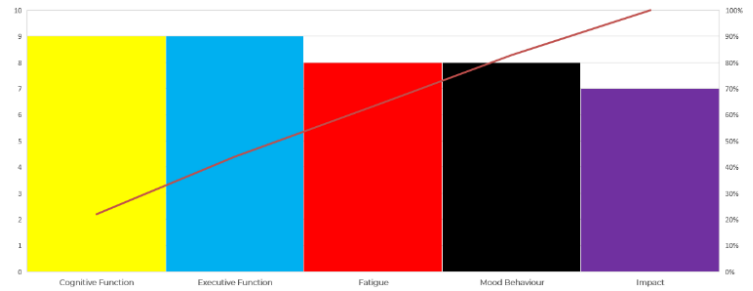
The results are stored in a database, with different colours indicating the severity of the identified mental health condition (e.g., higher scores indicate a higher health-related quality of life). If the total scores fall below a certain threshold, they are flagged in red, indicating a lower quality of life and suggesting that further discussions about support might be beneficial.

Results from children, young people and families that were screened using the PedsQL uncovered that cognitive function was identified as one of the main concerns. Impact was identified as the least important problem by children, young people and parents/carers. Fatigue and mood behaviour were also identified as being an issue.

## PedsQL™ Young Persons Report



## PedsQL™ Parent Report



**Figures 3 and 4: Show the scored results captured from young people and parents/carers using the PedsQL epilepsy module screening tool.**

Patients aged 13-18 years completing the PedsQL and attending epilepsy clinic were asked to complete a feedback questionnaire.


The questions asked were the following:


1. Please circle the face below to indicate how useful you found this tool.
2. Please indicate how you would prefer to fill out the mental health questionnaire.
  - a. Online
  - b. Paper
3. If we could offer mental health support which of the following would be the most useful for you
  - a. Group support
  - b. One to one support

**Epilepsy Quality Improvement Project**

**Mental Health Screening Questionnaire:**

Please circle the face below to indicate how useful you found this tool:





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Please indicate how you would have preferred to fill this out - Tick box below:

Online

On Paper

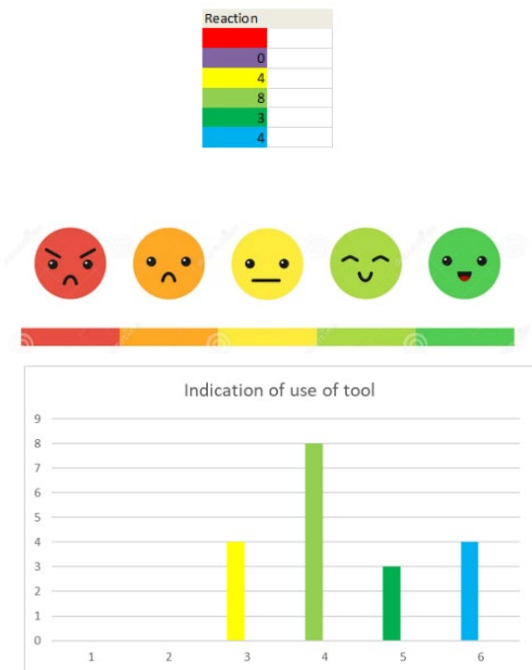
**QUESTION:**

If we could offer additional support which of the following would be the most useful for you.

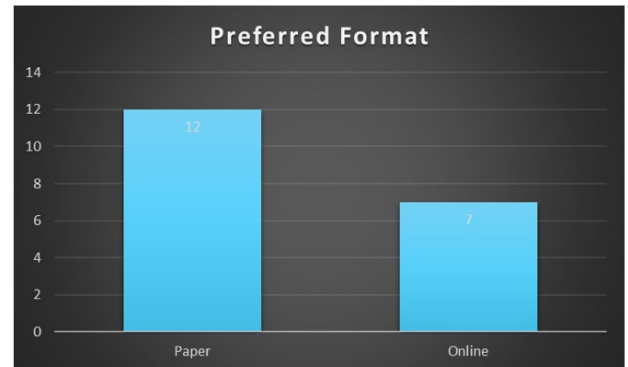
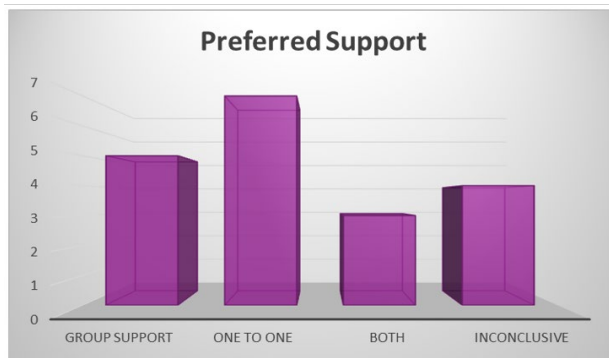
Group Support

One to One Support

Any other suggestions:



**Figures 5 and 6: Show an example of a feedback questionnaire shared with patients and families regarding how useful they found the PedsQL screening tool.**



**Figures 7 and 8: Show the responses collected and analysed from young people and their families regarding how useful they found the mental health screen tool.**

Patient feedback from the questionnaire revealed that the majority of children and young people using the PedsQL tool preferred to complete the tool in paper format. Members of the team also found the tool more convenient to use during consultations. Children and young people shared their preference of being offered one-to-one mental health support.

### What was the outcome?

- Implementation of PedsQL as the mental health screening tool.
- Extension of the tool's use to all age groups with the goal of early identification of problems or conditions.
- Continuous data collection to inform and direct service requirements.
- Planning regular meetings with psychologists within the Trust for case consultations when specific issues are identified in patients.
- Validation that PedsQL is clinically useful.
- Use of PedsQL before clinic appointments to guide questions during consultations.

### What were the learning points?

- The PedsQL screening tool can be used for a wider population, including younger age groups, for early identification and intervention.
- The small sample size of feedback will drive the continued use of PedsQL, involving the entire cohort and dividing it into epilepsy and neurodiversity and epilepsy-only groups.
- Initial assumptions about mood being the main issue were re-evaluated.
- The team is dedicated and has learned how to engage and gain support from other services.
- Understanding the broader impact of epilepsy is crucial.
- Various screening tools are available for use.

- Change requires time, dedication, and commitment.
- Implementing changes effectively requires careful planning.
- Developing and implementing ideas using available resources is essential.
- Engaging patients and their families is key to service improvement.
- There is satisfaction in making a positive change.
- Large goals can be achieved through small steps.

### **Next steps and sustainability**

Next steps for continuous improvement of the project include:

- Approaching senior Trust management to build a business case for psychology support for the paediatric epilepsy service.
- Inviting a community psychologist to join epilepsy meetings for case consultation – signposting ideas to other local support services or other specific suggestions.
- Developing a resource pack of researched services and signposting to mental health and wellbeing support.
- Presenting EQIP improvement project findings to audit and governance Trust meeting locally.
- Submitting a poster presentation to the Epilepsy12 Open UK annual conference.

### **Want to know more?**

**If you would like to know more information about this project, please contact:**

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