RCPCH EQIP

Epilepsy quality improvement programme

Summary report 2023-2024

2023/2024 improvement case studies by paediatric epilepsy service teams

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Transition support case studies 2023-2024

Mapping a transition pathway and developing a personalised transition plan

Organisation

Hull University Teaching Hospitals NHS Foundation Trust (HUTH)

Project team

Fiona Lead, Children's Epilepsy Nurse
Dr Sandhya Jose, Consultant Paediatrician and Clinical Lead for Community Paediatrics
Emma Smith, Senior Improvement and Delivery Manager

Project aim

To develop and implement a personalised transition plan for children and young people with epilepsy for 40% of the caseload and map transition care pathways in line with the National Epilepsy Care Bundle, by May 2024.

Background/rationale

The combined hospitals of Hull University Teaching Hospitals NHS Foundation Trust and Northern Lincolnshire and Goole manage around 600 children with epilepsy, 70% of whom have additional learning needs. Both hospital Trusts are in socially deprived areas and work closely with tertiary centres, as well as with community health services, schools, and the wider multidisciplinary team (MDT). The area had been funded by the ICB to develop transition in epilepsy with the epilepsy nurse specialist leading on this project. The EQIP project formed part of these improvements, with some areas overlapping into the EQIP project.

Hull University Teaching Hospitals were reviewing their patient referral pathway prior to the EQIP from primary/tertiary care, focusing on the first clinic visit, consultant review, and diagnostic outcomes, including functional neurological disorder. A wellbeing questionnaire developed with CAMHS is now used in clinics. Hull has also created and implemented transition booklets for epilepsy.

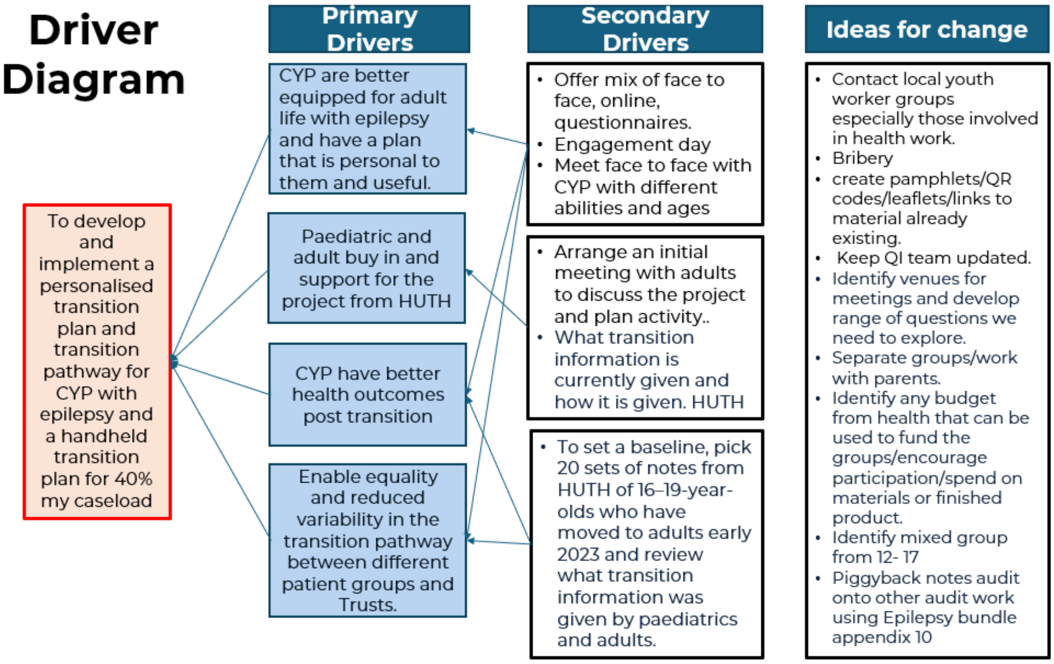
What was the problem?

All Trusts participate in the Epilepsy12 audit. Hull's epilepsy nurses offer hospital and outreach clinics in special schools and home visits. A specific epilepsy transition pathway with an easy-read version exists for those with learning disabilities.

The project had joint aims - to create a personalised transition plan for each young person aligned with National Confidential Enquiry into Patient Outcome and Death recommendations (covering epilepsy care and its impact on daily life); and, to map the current Hull epilepsy pathway into adult services. The Integrated Care System aims to share learning and undertake joint projects facilitated by the Integrated Care Board (ICB) lead. The team initially focused on transition care for children's epilepsy services across Hull, and improvements rolled out to Northern Lincolnshire subsequently.

The plan involved auditing current practices, information sharing, and identifying gaps to develop a personalised transition plan applicable across sites. The project initially targeted 40% of the specialist epilepsy nurse caseload (20-30 patients) with the aim to train the wider team and eventually cover 100% of caseloads incrementally.

Hull used the National Epilepsy Bundle of Care transition recommendations, mapping current services against it at a joint meeting with adult epilepsy services.



Driver Diagram

To develop and implement a personalised transition plan and transition pathway for CYP with epilepsy and a handheld transition plan for 40% my caseload

Primary Drivers

CYP are better equipped for adult life with epilepsy and have a plan that is personal to them and useful.

Paediatric and adult buy in and support for the project from HUTH

CYP have better health outcomes post transition

Enable equality and reduced variability in the transition pathway between different patient groups and Trusts.

Secondary Drivers

- Offer mix of face to face, online, questionnaires.
- Engagement day
- Meet face to face with CYP with different abilities and ages

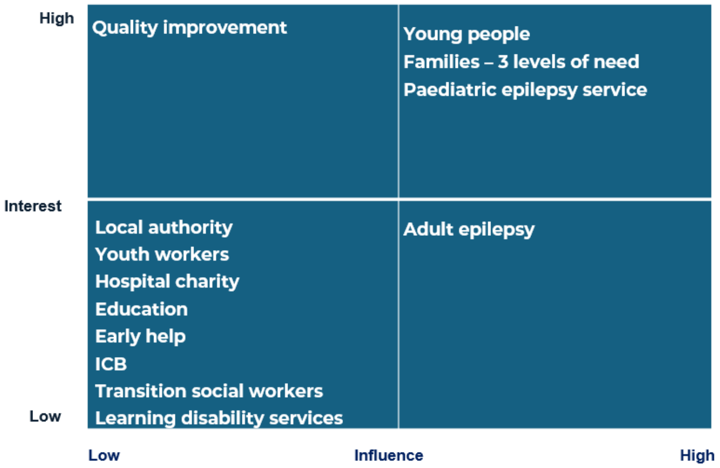
- Arrange an initial meeting with adults to discuss the project and plan activity..
- What transition information is currently given and how it is given. HUTH

- To set a baseline, pick 20 sets of notes from HUTH of 16–19-year-olds who have moved to adults early 2023 and review what transition information was given by paediatrics and adults.

Ideas for change

- Contact local youth worker groups especially those involved in health work.
- Bribery
- create pamphlets/QR codes/leaflets/links to material already existing.
- Keep QI team updated.
- Identify venues for meetings and develop range of questions we need to explore.
- Separate groups/work with parents.
- Identify any budget from health that can be used to fund the groups/encourage participation/spend on materials or finished product.
- Identify mixed group from 12- 17
- Piggyback notes audit onto other audit work using Epilepsy bundle appendix 10

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.



Interest \ Influence	Low	High
High	Quality improvement	Young people Families – 3 levels of need Paediatric epilepsy service
Low	Local authority Youth workers Hospital charity Education Early help ICB Transition social workers Learning disability services	Adult epilepsy

Figure 2: Shows the project stakeholder map, which provides analysis of stakeholders that are of influence/interest to the project. Stakeholders are plotted on the grid to guide the actions you should take for involving and communicating with them.

What was the solution?

Project scope adjustment: The project was delivered in phases across both organisations, starting with Hull University Teaching Hospitals NHS Foundation Trust and later involving Northern Lincolnshire and Goole NHS Foundation Trust (NLaG).

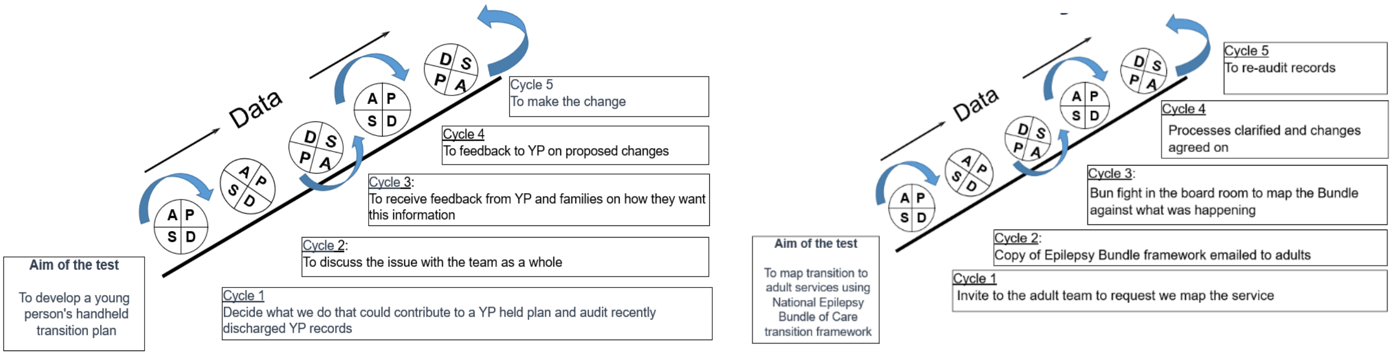
Information and support: The team recognised the need to develop developmentally appropriate information for young people transitioning between 13 and 25 years old. The pathway focused on helping young people understand and manage their condition, aiming for independence by breaking down steps and providing clear health information. Specific guidance included when and how to seek help during the transition, including contact details.

Secured funding and youth engagement: The team worked closely with local youth services to organise a youth engagement event for young people. The lead youth worker provided a central city location for the venue and funding was secured from the hospital charity for incentives to boost attendance such as gift vouchers and catering. This event offered valuable insights into the support needs of young people and the team's collaboration with the youth worker offered additional support for their engagement activities.

Family and young person engagement: The team created and developed short questionnaires, formed a small focus group, and held clinic discussions. They collected a total of 18 completed anonymised questionnaires from patients aged 13 and above in clinics and face-to-face meetings with young people. Families of children with autism and learning disabilities were also contacted through face-to-face meetings, phone calls, and home visits.

Transition pathway mapping: With support from the Trust's quality improvement manager, the team mapped the transition pathway, considering special educational needs, complex disabilities, Dravet syndrome, and other epilepsy specific transition needs. They identified issues such as inaccessibility of technology and low levels of education among some young people and their families. Regular meetings took place with the quality improvement manager and long-term conditions lead from the ICB.

Engagement with adult services: The team organised an MDT meeting with adult consultants, epilepsy nurses, and a business manager and agreed on developing a checklist of key care metrics for transition and a hospital passport for children with complex needs. They addressed referral acceptance for all patients with learning disabilities and improved tracking to prevent patients from being lost to follow-up. Continuous liaison with adult services continued to define and implement the new pathway details.



Aim of the test

To develop a young person's handheld transition plan

Cycle 1
Decide what we do that could contribute to a YP held plan and audit recently discharged YP records

Cycle 2:
To discuss the issue with the team as a whole

Cycle 3:
To receive feedback from YP and families on how they want this information

Cycle 4
To feedback to YP on proposed changes

Cycle 5
To make the change

Aim of the test

To map transition to adult services using National Epilepsy Bundle of Care transition framework

Cycle 1
Invite to the adult team to request we map the service

Cycle 2:
Copy of Epilepsy Bundle framework emailed to adults

Cycle 3:
Bun fight in the board room to map the Bundle against what was happening

Cycle 4
Processes clarified and changes agreed on

Cycle 5
To re-audit records

Figures 3 and 4: Show Plan, Do, Study, Act (PDSA) cycles of change ideas listed within the driver diagram being tested to develop a young person's handheld transition plan and mapping of transition pathways.

What were the challenges?

1. **Trust mergers:** Both Hull University Teaching Hospitals NHS Foundation Trust and Northern Lincolnshire and Goole are undergoing a reorganisation and merger. Therefore, more time is needed to allow for systems and processes to become embedded.
2. **Lack of patient groups:** The Trust does not have access to existing children and young people patient groups or forums to gather feedback on service improvements.
3. **Focus on transition plan vs pathway:** There were times of uncertainty concerning whether to focus on the transition plan or the pathway aspect of the project, as they seem quite separate outputs.
4. **Post-transition discharge issues:** The team identified that a quarter of patients were not seen by adult services after transition discharge.
5. **Mapping process:** The team initially conducted a mapping exercise to review processes and timing, leading to changes. However, the process mapping meeting was rescheduled and time allocated was adjusted to ensure engagement from adult services.
6. **Patient engagement:** Patient engagement exercises included questionnaires on information preferences, with options such as letters to parents/GP, transition

booklets, or simpler letters. The response rate was lower than anticipated, partly due to administrative issues, and there was uncertainty about whether responses came from parents and carers or the children themselves.

7. **Collaboration with adult and learning disability services:** Ongoing discussions and collaborations with adult and learning disability services involve changes to processes, referrals, and support. Further challenges include agreeing on pathway details, referral numbers, and ensuring effective communication and coordination between services.

What were the results?

- Patient questionnaire feedback (18 responses).

Patients were asked how they preferred to receive information, with options including:

  - A letter to parents with a copy to the GP.
  - A letter written solely to the young person.
  - A transition booklet.
  - A simpler letter to the GP.
  - A comment box was also included for additional feedback.

- Most children, young people and families were satisfied with the current method of receiving information, although some responses may have come from parents rather than the children themselves. 17% of questionnaire respondents wanted a transition plan written to the young person.
- Explored software for converting letters to an easy-read format for children and young people.
- Discussed tangible outcomes such as personalised patient letters and a short booklet with information on transition and personal goals.

Audit and focus group: A retrospective audit was conducted on 20 records of young people who had gone through the transition process in the past 6 to 18 months, including the outcomes from focus group sessions:

- 65% had a handheld transition plan in the form of a GP letter, but the plans were not SMART due to unclear outcomes and goals.
- 25% attended a first appointment with a member of the adult neurology team present, but there was no follow-up appointment.
- 0% had documented consent for sharing information.
- 0% of children and young people with learning disabilities or autism spectrum disorder had a completed hospital passport.
- 100% of focus group participants provided feedback on their need for a written transition plan specific to children and young people.

Changes to transition plans: The approach became more holistic and personalised to the needs of children, young people and their families. Transition plans were developed for different cohorts e.g. epilepsy, epilepsy and special educational needs and disabilities (SEND), epilepsy and complex disability, complex epilepsy. Young people were enthusiastic about being involved in the changes and expressed a desire for more frequent engagement.

Outcomes from collaboration with adult services: Continuous discussions with adult services with a focus on improving transition for patients with learning disabilities and epilepsy. Agreed to change some processes and include a checklist of topics based on the epilepsy bundle for patients with epilepsy, up to the age of 25 in adult neurology services. This includes regular reviews and appropriate support from GPs, covering topics such as employment and relationships.

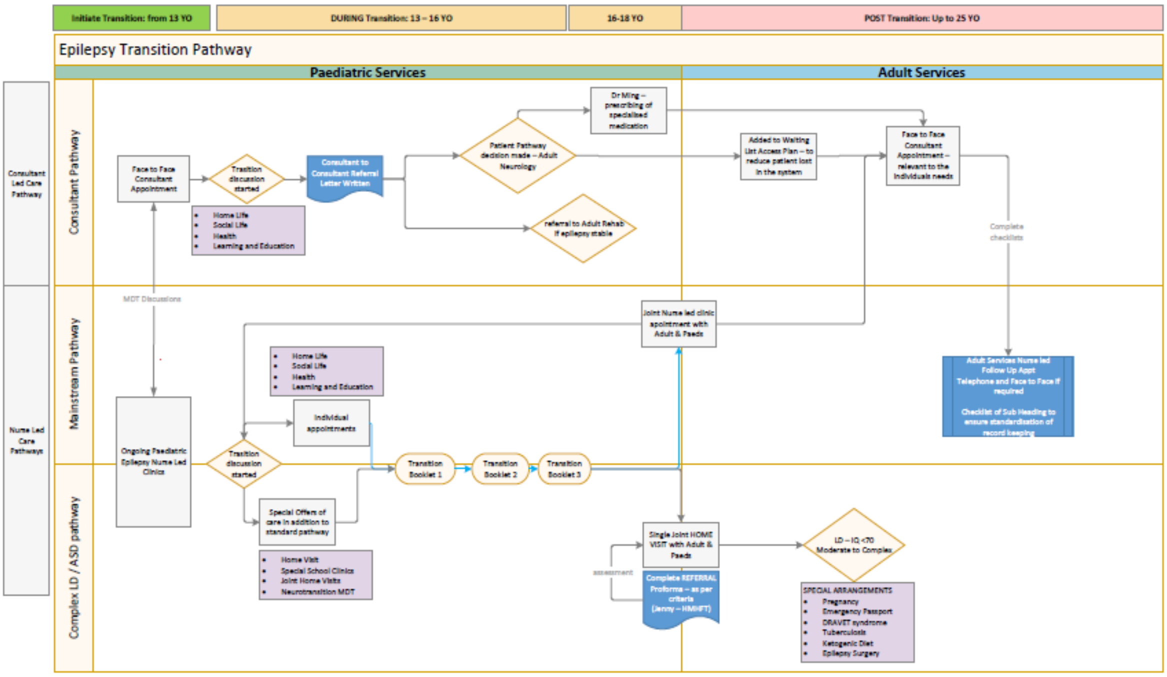
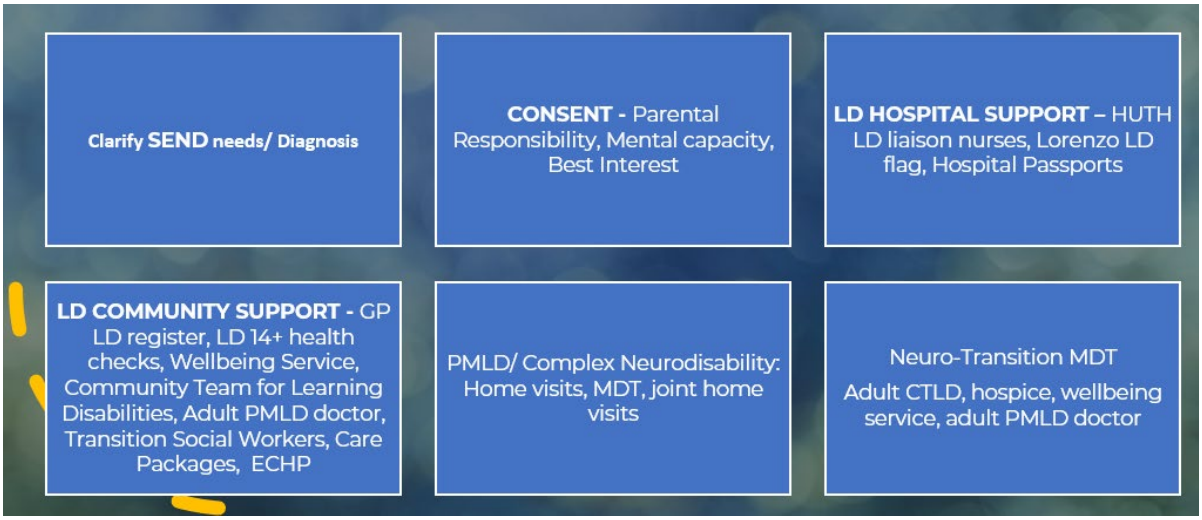


Figure 5: Shows mapping of transition pathways.



Clarify SEND needs/ Diagnosis

CONSENT - Parental Responsibility, Mental capacity, Best Interest

LD HOSPITAL SUPPORT – HUTH LD liaison nurses, Lorenzo LD flag, Hospital Passports

LD COMMUNITY SUPPORT - GP LD register, LD 14+ health checks, Wellbeing Service, Community Team for Learning Disabilities, Adult PMLD doctor, Transition Social Workers, Care Packages, ECHP

PMLD/ Complex Neurodisability: Home visits, MDT, joint home visits

Neuro-Transition MDT

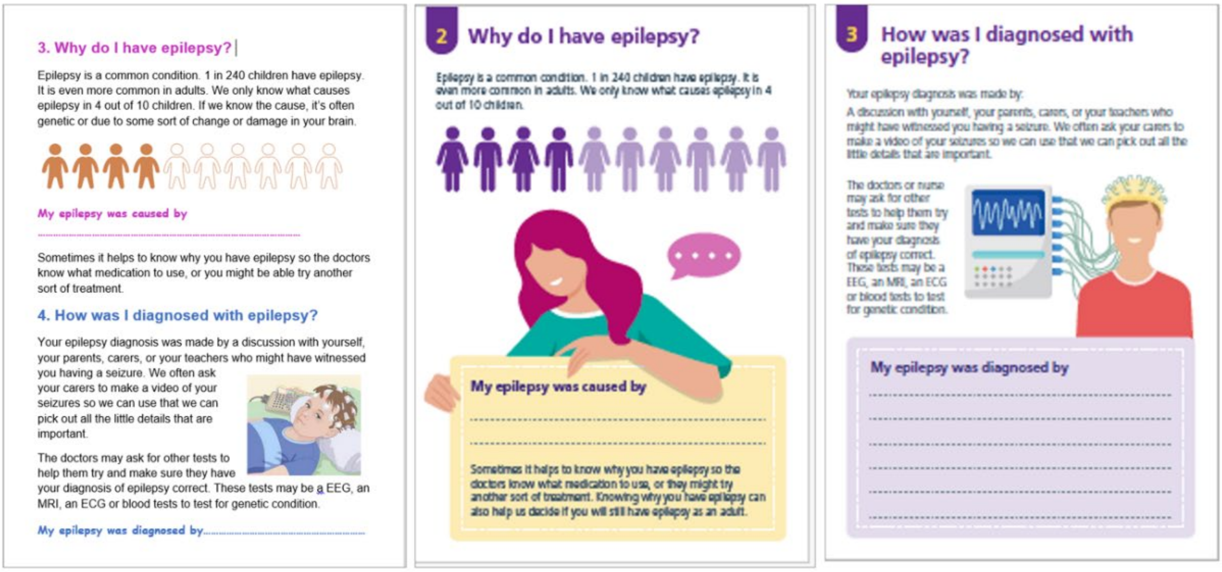
Adult CTLD, hospice, wellbeing service, adult PMLD doctor

Figure 6: Shows mapping of improving transition for people with a learning disability by engaging with Trust and local agencies, gaining a better understanding of when a patient is given a diagnosis of learning disability. This should provide access to improved primary care and social care support moving into adults.

1) Mum reads me letter,
letter doesn't make sense

2) difficult words in letter
needs bullet points, shorter simple sentences, spaced out paragraphs
shorter paragraphs
-I do understand some of the words like
my medication + diagnosis
layout - important bits in a box, or use bold.
• would like to know who I'm seeing

Figure 7: Images of interactive engagement and a questionnaire that was used at an organised young people's focus group. Feedback captured from the event included wanting short videos, information on epilepsy they could give to their friends, and to include information within appointment letters to say who they will be seen by.



3. Why do I have epilepsy?

Epilepsy is a common condition. 1 in 240 children have epilepsy. It is even more common in adults. We only know what causes epilepsy in 4 out of 10 children. If we know the cause, it's often genetic or due to some sort of change or damage in your brain.

My epilepsy was caused by

Sometimes it helps to know why you have epilepsy so the doctors know what medication to use, or you might be able try another sort of treatment.

4. How was I diagnosed with epilepsy?

Your epilepsy diagnosis was made by a discussion with yourself, your parents, carers, or your teachers who might have witnessed you having a seizure. We often ask your carers to make a video of your seizures so we can use that we can pick out all the little details that are important.

The doctors may ask for other tests to help them try and make sure they have your diagnosis of epilepsy correct. These tests may be a EEG, an MRI, an ECG or blood tests to test for genetic condition.

My epilepsy was diagnosed by……………………………

2 Why do I have epilepsy?

Epilepsy is a common condition. 1 in 240 children have epilepsy. It is even more common in adults. We only know what causes epilepsy in 4 out of 10 children.

My epilepsy was caused by

Sometimes it helps to know why you have epilepsy so the doctors know what medication to use, or they might try another sort of treatment. Knowing why you have epilepsy can also help us decide if you will still have epilepsy as an adult.

3 How was I diagnosed with epilepsy?

Your epilepsy diagnosis was made by:

A discussion with yourself, your parents, carers, or your teachers who might have witnessed you having a seizure. We often ask your carers to make a video of your seizures so we can use that we can pick out all the little details that are important.

The doctors or nurse may ask for other tests to help them try and make sure they have your diagnosis of epilepsy correct. These tests may be a EEG, an MRI, an ECG or blood tests to test for genetic condition.

My epilepsy was diagnosed by

Figure 8: Shows examples of the Trust's transition tool on the far left, and proposed improvements to the same documents when adopted by the National Epilepsy Bundle of Care.

What was the outcome?

- Enhanced capability to develop individual personalised transition plans with consistently SMART goals on transition clinic letters.
- Increased available resources for signposting children and young people with diverse needs, covering health, lifestyle, education, employment, and community inclusion. This includes the completion of a hospital passport and the addition of a reasonable adjustment data flag on the electronic patient record.
- Increased engagement with other healthcare professionals in collaboration to improve transition heightened the awareness of the wider support network available.
- Implemented changes to transition letters which are addressed directly to the young person and include domains from the National Epilepsy Bundle of Care.
- Amended letter templates to be both staff user-friendly and children and young people friendly.
- Gained a better understanding of adult service delivery and their specific requirements.
- Improved booking rules in adult services and revised adult clinic letter templates.
- Expanded the focus to include additional transition needs for young people with learning disabilities and complex disabilities within the epilepsy service across both paediatric and adult services.
- Mapped special arrangements for children and young people with Epilepsy, including those with Special Educational Needs and Disabilities (SEND), complex disabilities, and specific conditions such as Dravet syndrome, Tuberous Sclerosis, and those on the Ketogenic diet or epilepsy surgery pathways.

What were the learning points?

- Transition is much bigger and more complex than initially anticipated.
- Following an internal audit, the team realised they were not performing as well as they thought.
- Identified many underutilised community resources.
- Engaging more with the wider network and appreciating the challenges of coordination.
- Need to better prepare children young people and families for adult services.
- Increased focus on transition within the organisation.
- Importance of sharing learning within the ICB and regional network, YPEN.
- The team recognised the need for a structured approach.
- It is important to continuously monitor the implemented service improvements.
- Care must be personalised to children and young people and consider their aspirations.
- EQIP helped improve understanding of the need for closer collaboration with young people and for engaging individuals with diverse skill sets.

Communication with children and young people: feedback from youth group and parents

- Young people involved in the engagement activities appreciated receiving the gift voucher incentives.
- Remember to be friendly and make the young person feel at ease. Smile.
- Talk to the young person, even if they cannot answer back.
- Encourage the young person to join in the consultation.
- Use short, simple sentences. Do not rush; pause between sentences.
- Avoid “waffling” and give time for young people to think and consider their options.
- Do not expect quick answers.
- Provide longer appointments where possible and repeat important information on another day.
- Choose a quiet clinic room without distractions and avoid making families wait.
- Use information that the young person will understand.

Next steps and sustainability

- Establish clinics with specific focus on transition with longer appointments times.
- Plan a re-audit for the period 2024-2025.
- Maintain and continue to improve engagement with young people.

Want to know more?

If you wish to know more about this project, please contact:

- **Fiona Lead, Children’s and young people’s epilepsy nurse specialist, Hull University Teaching, Fiona.lead1@nhs.net**

Transition support case studies 2023-2024

Design and implementation of a transition package

Organisation

Northern Care Alliance NHS Trust (Oldham Care Organisation)

Project team

Dr Sri Nagesh Panasa, Paediatric Consultant with special interest in epilepsy
Dr Vandana Prasad, Paediatric Consultant with special interest in epilepsy
Joanne Holdaway, Children's Epilepsy Nurse Specialist
Lisa Fern, Children's Nursing Service Lead
Lucy Lees, ADNS Paediatrics
Evelyn Wild, Assistant Directorate Manger Paediatrics

Project aim

Design and implement a transition package for children and young people aged 16 years and over that enables them to understand and manage their epilepsy, by May 2024.

Background/rationale

The acute secondary care paediatric service, alongside the paediatric epilepsy service and the Integrated children's community nursing service, provides comprehensive care for children and young people with epilepsy. The team operates across two localities under two Integrated Care Boards (ICBs) and is currently awaiting the recruitment of one full-time equivalent (WTE) epilepsy specialist nurse and one WTE epilepsy youth worker. Their caseload comprises children primarily diagnosed with epilepsy, as well as those with complex medical needs and comorbidities.

The primary aim of the planned service improvement is to improve the support for children and young people transitioning into adulthood accessing epilepsy services. This initiative seeks to provide a comprehensive package of care that empowers young individuals to understand and manage their own health needs, promoting their active participation in their care and wellbeing within the broader context of their family and social lives. Transitioning to adult services is recognised as a national priority for all children with long-term conditions.

What was the problem?

Currently, there is significant variation across the service regarding the transition process and its timing. Communication between paediatric and adult services is minimal, leading to concerns among patients and families about the transition process. There are no adult epilepsy nurses covering the area, and only a small proportion of patients with complex needs are seen by adult epilepsy nurses from a tertiary centre. Most patients are transferred from paediatric to adult consultants via a letter at 16 years old, facing a 12 month waiting list, and receive no support from adult nursing staff until they turn 18 years old.

While the team is aware of the National Epilepsy Bundle of Care, they have not yet fully engaged with it from an ICB perspective. However, the Trust has successfully secured a 2 year fixed-term funding for epilepsy youth workers through epilepsy bundle of care funding opportunities. This funding has been beneficial for both acute and community settings in Oldham and for children and young people attending Rochdale Hospital.

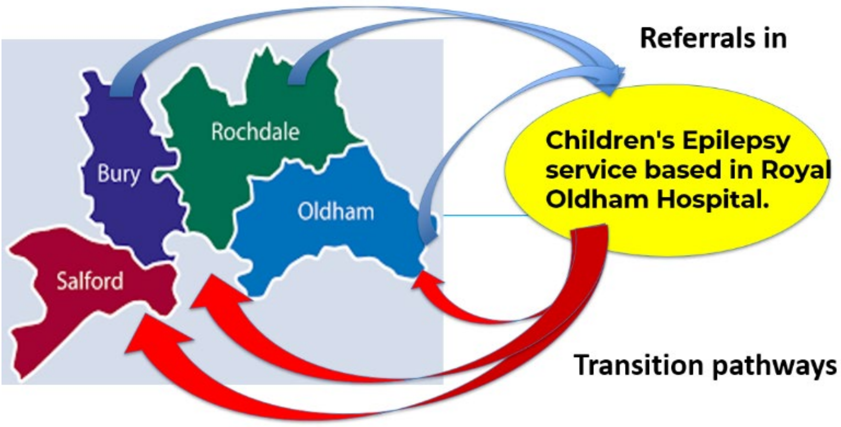
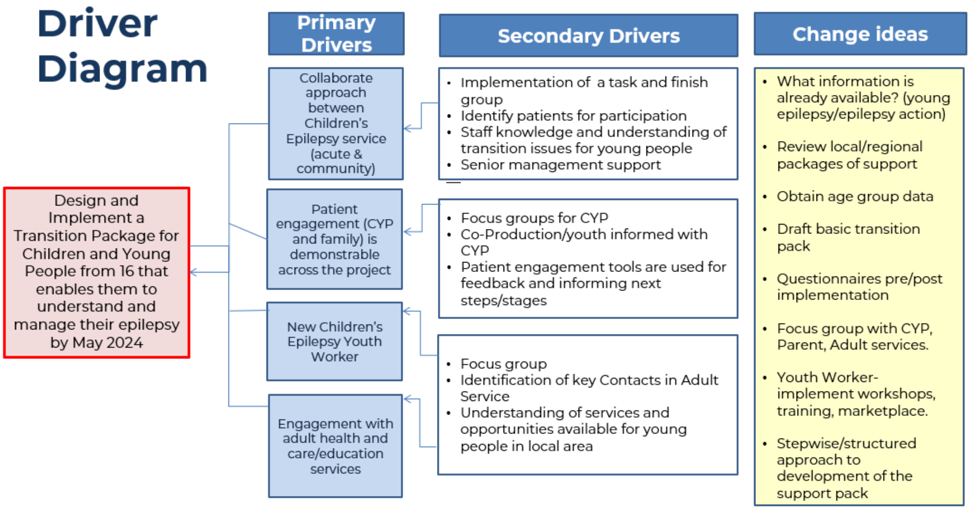


Figure 1: Example of transition pathways from hospitals within their region.



Driver Diagram

Design and Implement a Transition Package for Children and Young People from 16 that enables them to understand and manage their epilepsy by May 2024

Primary Drivers

- Collaborate approach between Children's Epilepsy service (acute & community)
- Patient engagement (CYP and family) is demonstrable across the project
- New Children's Epilepsy Youth Worker
- Engagement with adult health and care/education services

Secondary Drivers

- Implementation of a task and finish group
- Identify patients for participation
- Staff knowledge and understanding of transition issues for young people
- Senior management support

- Focus groups for CYP
- Co-Production/youth informed with CYP
- Patient engagement tools are used for feedback and informing next steps/stages

- Focus group
- Identification of key Contacts in Adult Service
- Understanding of services and opportunities available for young people in local area

Change ideas

- What information is already available? (young epilepsy/epilepsy action)
- Review local/regional packages of support
- Obtain age group data
- Draft basic transition pack
- Questionnaires pre/post implementation
- Focus group with CYP, Parent, Adult services.
- Youth Worker- implement workshops, training, marketplace.
- Stepwise/structured approach to development of the support pack

Figure 2: 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.

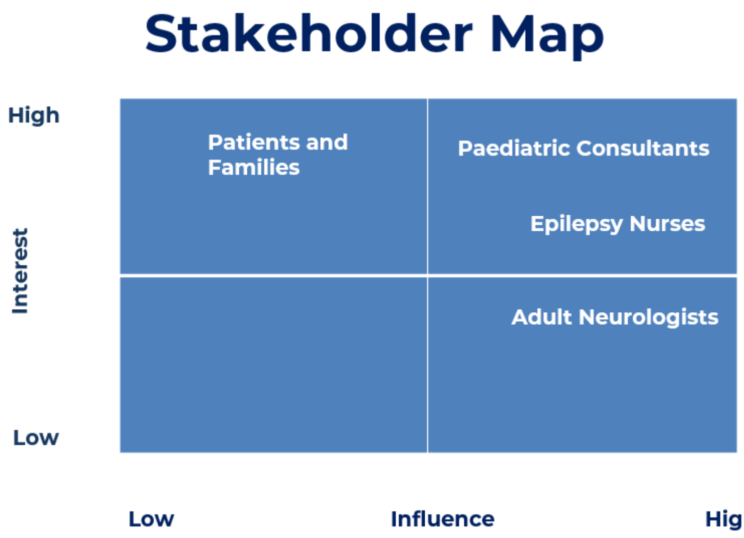
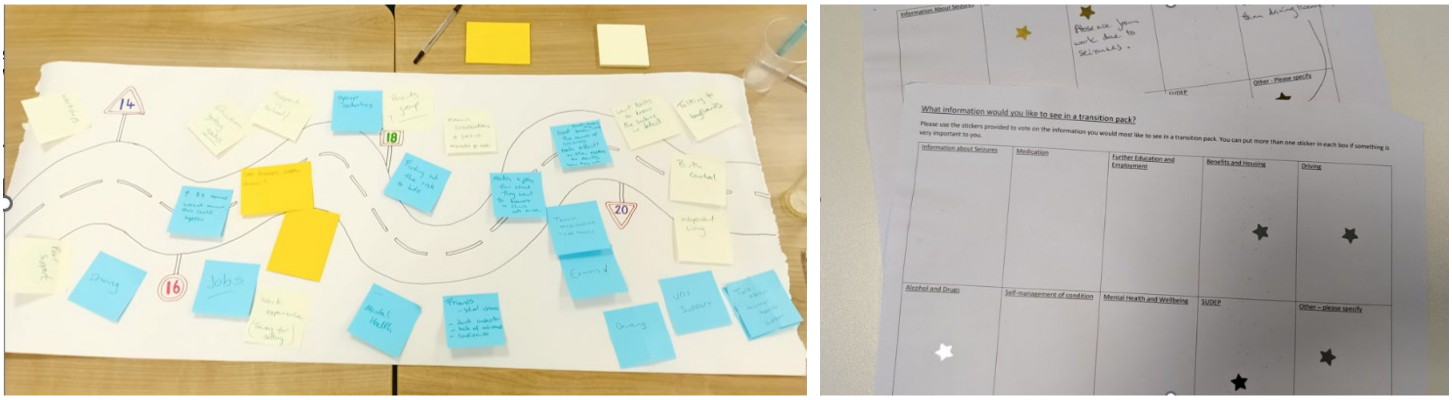


Figure 3: Shows the project stakeholder map, which provides analysis of stakeholders that are of influence/interest to the project. Stakeholders are plotted on the grid to guides the actions you should take for involving and communicating with them.

What was the solution?

To improve transition services, the team engaged with families and young people aged 15/16 years and upwards using various methods, including online questionnaires, face-to-face discussions, small focus groups, and “pasta voting”. Initially, engagement with children, young people, and adult service colleagues proved challenging. This led the team to change their approach – capturing feedback from young people in person, focusing on 10 areas, and asking patients to use stickers to highlight their priorities during home visits with older children which proved more effective than using the online form.



Figures 4 and 5: Show the process mapping of the patient journey through the referral pathways and feedback captured during the engagement activities.

The team researched various transition tools, including Ready, Steady, Go and those recommended in the National Epilepsy Bundle of Care. These tools aim to capture patient needs, identify accessible information sources, and determine what has already been used effectively.

Engagement with the adult neurologist was positive, which led to discussions in exploring two future key areas for improvement beyond the project. Firstly, the development of a standard referral template to ensure consistency and clarity when referring patients to the adult clinic. Secondly, it was recommended to have a paediatric clinician present in the adult clinic. This would improve the patient experience by providing continuity of care and familiarity during the transition period.

The team also explored developing a transition support package, determining its format, and then testing it with patients and families to capture feedback. The aim of this iterative process of testing and feedback was to refine and improve the support package to ensure it met the needs of transitioning young people and their families effectively.

What were the challenges?

The team has faced several challenges with their project.

- Most responses received initially were from parents or carers, highlighting the need for improved engagement with young people.
- Time constraints, especially during the festive period, led to limited capacity for engaging children and young people on a one-to-one basis, making this method time-consuming and resulting in minimal feedback.
- Running outpatient appointments across three or four clinics simultaneously hindered the exploration of alternative methods, such as setting up a voting display in waiting rooms.
- Additionally, the volume of information on transition can be overwhelming, making it difficult to determine the most effective approach for their cohort of patients.
- Designing the support pack involves navigating corporate branding requirements and the complexity of the service.
- Communication within the team has also been challenging due to members being located at separate sites.
- Creation of QR codes for information sheet to share during transition clinics.
- Despite hopes to hold the improved transition clinic before the end of the project, it could not be arranged to fit in with the adult service availability and timing coinciding with school GCSE and A-level exams.

What were the results?

Feedback was obtained from children and young people aged 16 and over regarding their views on the transition process and their support needs. Parents and families were also consulted to provide feedback on the following topics:

- If it was a parent or a young person was completing the survey.
- Do they understand what we mean by transition?

- Describe what they felt transition meant.
- How would they like to receive information on transition?
- If they would prefer their information in a language other than English (the service has quite a significant population of various ethnic minorities in their area).
- What kinds of things do they want to know about (e.g., driving, higher education, work benefits, sudden unexpected death in epilepsy [SUDEP]).

Feedback received from young people on their concerns:

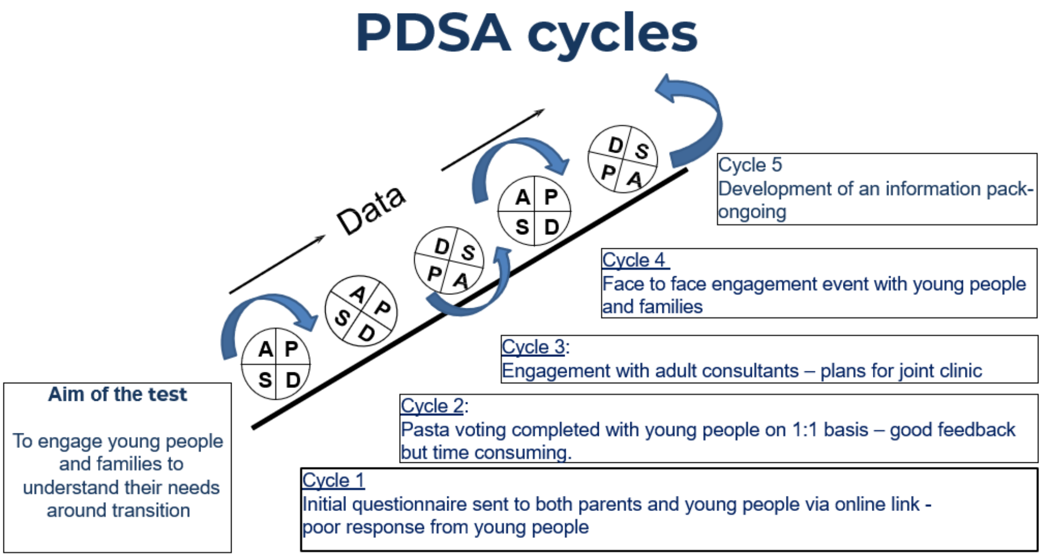
- How to talk to the adult team.
- Not understanding the terminology.
- Friends and relationships.
- Exams.
- Driving.
- Peer support.

Feedback received from parents and carers:

- Adult neurologists not understanding the history.
- No epilepsy specialist nurses.
- How to support their child in gaining independence.
- higher education and employment.
- SUDEP.

Feedback received in summary:

- Young people did not engage well with questionnaires.
- Both parents and young people felt isolated and wanted more peer support from other families.
- Parents and young people had different concerns.
- There was a preference for face-to-face appointments and information sharing.



Aim of the test

To engage young people and families to understand their needs around transition

Cycle 1
Initial questionnaire sent to both parents and young people via online link - poor response from young people

Cycle 2:
Pasta voting completed with young people on 1:1 basis – good feedback but time consuming.

Cycle 3:
Engagement with adult consultants – plans for joint clinic

Cycle 4
Face to face engagement event with young people and families

Cycle 5
Development of an information pack- ongoing

Figure 6: Plan, Do, Study, Act (PDSA) cycles of change ideas listed within the driver diagram being tested.

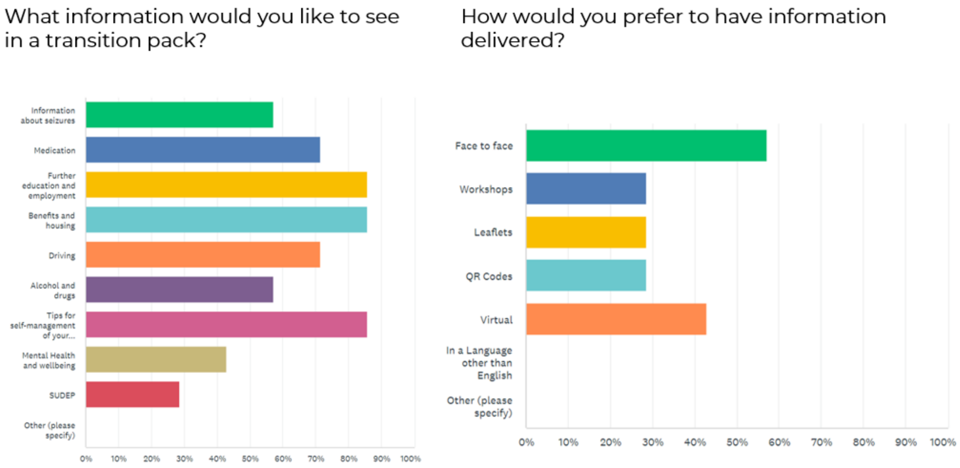


Figure 7: Shows feedback data collected from young people and families on the following questions “What information would you like to see in a transition pack?” and “How would you prefer to have information delivered?”.

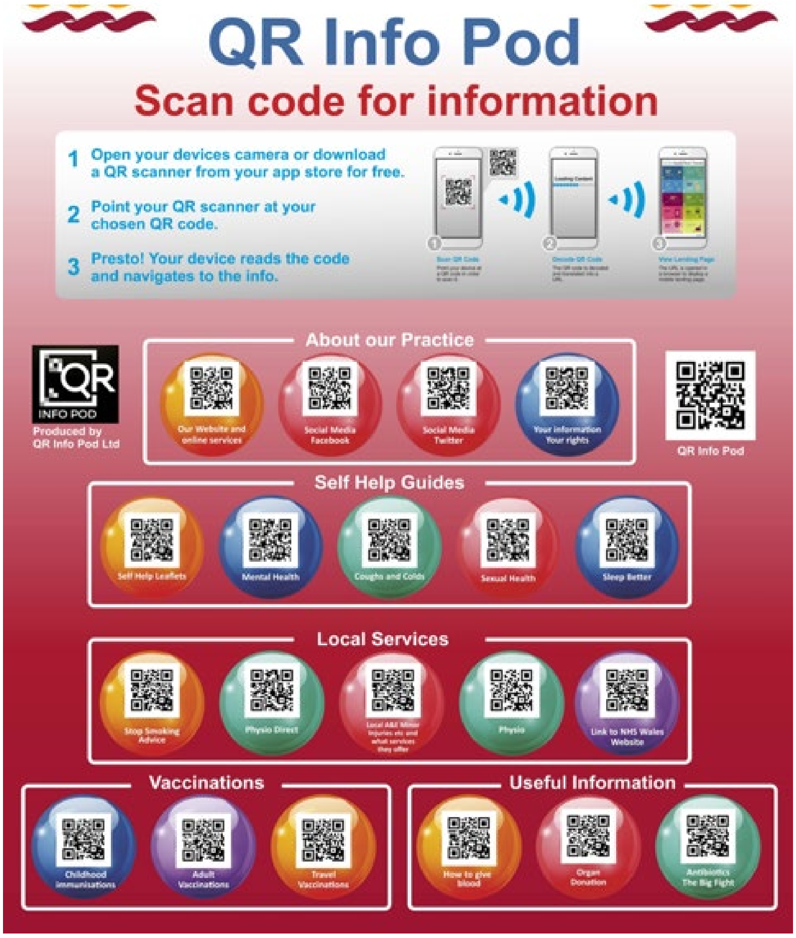
Figure 8: Shows a word cloud of patient feedback received.

What was the outcome?

- **Engagement**: The team had successfully engaged with families and young people, improving their understanding of their needs which will inform future service development.
- **Transition clinic**: A joint transition clinic has been established with a list of patients identified to transition via the new pathway. Two clinics are planned to run each year, involving an adult neurologist.
- **Youth worker**: A youth worker has been appointed to engage with the team to assist with current and future improvements.
- **Support and training**: The support and training from the EQIP has led to an improved understanding of quality improvement methodology.
- **Improved links**: Stronger connections with adult neurologists have been established, facilitating the start of a joint transition clinic. This improvement will

positively impact patients through better handover of care and a smoother transition process.

- Resource development: A QR code information sheet has been created, providing links to local, national, and service-related resources based on young people and family feedback.
- Referral improved process: A referral pro forma for adult services has been implemented, based on criteria set by the paediatric medical team to determine which patients will be transferred to the adult clinic.



QR Info Pod
Scan code for information

1 Open your devices camera or download a QR scanner from your app store for free.
2 Point your QR scanner at your chosen QR code.
3 Presto! Your device reads the code and navigates to the info.

Figure 9: Proposed layout of electronic epilepsy transition pack.

What were the learning points?

- The team adapted their approach to engaging with children and young people, recognising the need for more effective communication strategies.
- Integrating quality improvement into daily routines has become a standard practice.
- Starting small, focusing on one patient at a time, proved to be a practical and effective strategy.
- Employing different methods for data collection enhanced the feedback process.

- Avoiding assumptions was crucial in understanding the true needs and experiences of patients and families.
- Extensive feedback has been collected to shape the role of the new youth worker.
- A clear pathway for transitioning to adult services has been established, ensuring a smoother and more organised process.

Next steps and sustainability

- Finalise and publish the transition pack.
- Share the learning with local networks and other Northern Care Alliance services.
- Continue improving the joint transition clinic based on feedback from patients.
- Develop a nurse-led young person's clinic.
- Develop the youth worker role and establish peer support networks.
- Design a feedback mechanism for post-transition clinic evaluations to support ongoing improvement and identify areas that are working well or not working well.

Want to know more?

If you wish to know more about this project, please contact:

Dr Sri Nagesh Panasa, Paediatric Consultant with special interest in epilepsy, Northern Care Alliance (Oldham), srinagesh.panasa@nca.nhs.uk

Transition support case studies 2023-2024

Establishing a nurse-led transition clinic

Organisation

West Hertfordshire University NHS Trust

Project team

Dr Chaniyil Ramesh, Paediatric Consultant with epilepsy interest
Dr Vanita Rasiah, Paediatric Consultant with epilepsy interest
Daniel Kitchener, Epilepsy Nurse Specialist

Project aim

To create a structured pathway for 50% of children and young people (aged 14-16 years) to transition into adult services by June 2024.

Background/rationale

West Hertfordshire University Trust paediatric epilepsy service manages a caseload of 150-200 epilepsy patients, with current staffing comprising two paediatric consultants and one full-time epilepsy nurse specialist. The team care for children from birth to 16 years old with various types of epilepsy and collaborate closely with Great Ormond Street for complex and refractory cases. Many referrals come from community teams due to a lack of epilepsy expertise in the community, requiring the creation of epilepsy care plans and the management of these cases.

What was the aim/problem?

The paediatric epilepsy service faced challenges identified through national audit data, best practice indicators, and feedback. These included gaps in support during the transition from paediatric to adult services, particularly for young people with epilepsy and those with complex needs. A Trust-wide initiative has been launched to address these issues and improve the transition process.

Prior efforts to engage the adult team had been unsuccessful. The adult service has three consultants but lacks a dedicated epilepsy clinic and epilepsy nurse. Patients are seen once every 6 months, resulting in limited support between clinic appointments.

Additionally, not all patients attend the same clinic; therefore, running a shared adult clinic with the paediatric team was impractical. Recognising these significant barriers had reinforced the team's commitment to improving transitional care, which will benefit both services. Future service plans involve the epilepsy nurse conducting independent clinics and recruitment of another part-time epilepsy nurse.

The team planned to engage with patient and families using available feedback tools and methods from the Ready, Steady, Go model and develop a process for capturing young people's opinions before or during the transition to adult services. This will include feedback from adult services on what has worked well and areas for improvement.

For patients with complex needs, there are plans to test the new pathway with a small cohort of older children. While current conversations are often parent-led, the team have observed that some children and young people manage their own medication; therefore, the aim was to explore and test this area of engagement further.

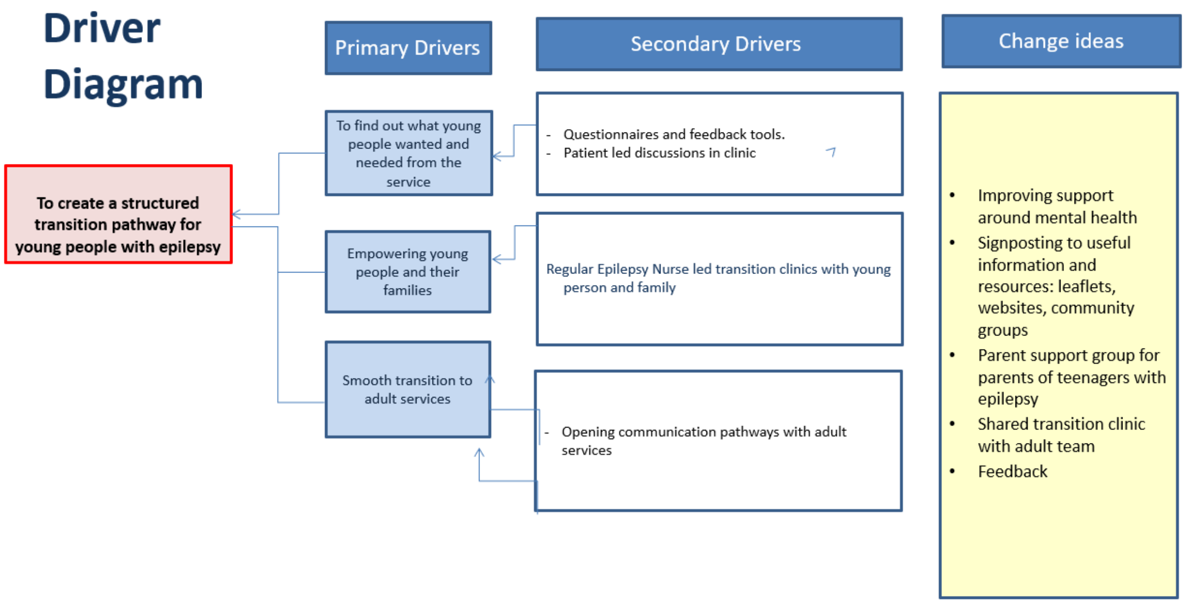


Figure 1: Team driver diagram that provides a clear statement of their project aim, with primary and secondary drivers that visually display the team's theory of what "drives", or contributes to, the achievement of a project aim.

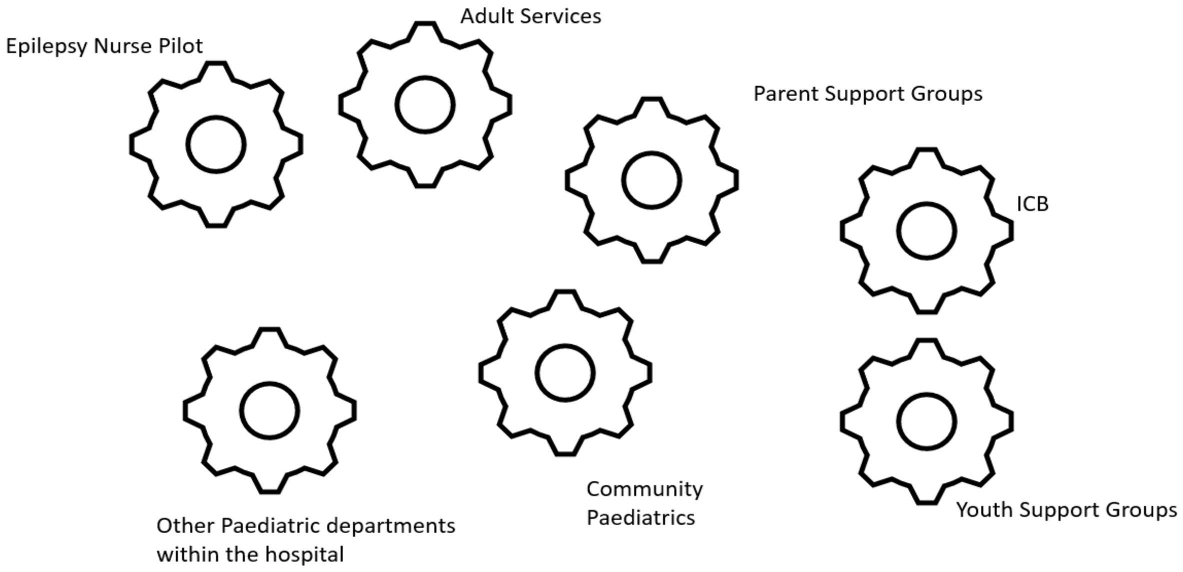


Figure 2: Stakeholder map of the groups that the team engaged to influence or inform with different levels of interest in the service improvements.

What was the solution?

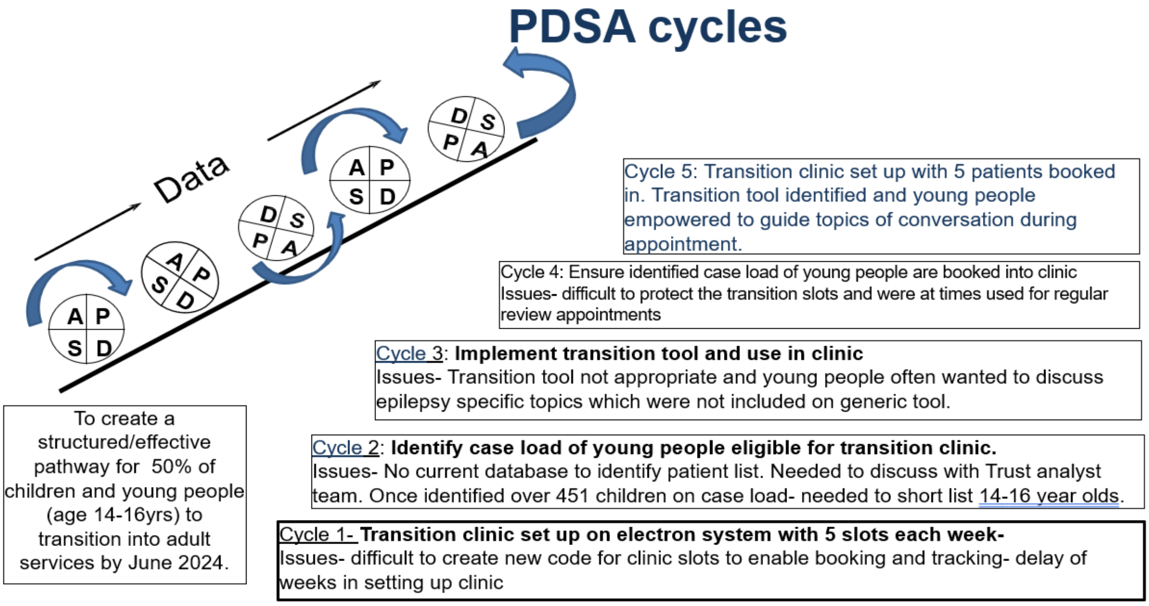
The team worked with their Trust paediatric data analyst to identify the eligible cohort of patients for transition. A proportion of patients and families were selected to begin testing the pathway.

Upon researching the Ready, Steady, Go questionnaire, the team found it was not epilepsy-specific after testing the tool with patients and families. This prompted the team to review what works and continue to explore different tools to develop a transition pathway. Additionally, the team recognised the need for a programme for children with complex needs, whose transition should start much sooner.

Prior EQIP team projects have provided learning opportunities on obtaining feedback from patients and their families. Some team members evidenced using QR codes for easy access, and presentation videos offered tips on involving parents and carers in the transition process, empowering them to step back and empower their child.

The team set up a nurse-led epilepsy clinic, which includes seeing young people aged 14 to 16 years. The team acknowledges the need for different pathways for cognitively able children with epilepsy, those with significant learning difficulties, and other disabilities. Additionally, within these groups, some patients have complex epilepsies requiring more clinic time. Therefore, designing the transition pathway may also vary in duration, with some children needing more extended support before moving to adult services. The need to engage with available community support was becoming crucial.

The team tested different ways in clinic to encourage patients to think about any questions or concerns they may have between appointments by writing them down in their diary and sharing them at their next appointment. This approach would help to ensure that all important topics were addressed and nothing was missed during the clinic sessions.



Cycle 5: Transition clinic set up with 5 patients booked in. Transition tool identified and young people empowered to guide topics of conversation during appointment.

Cycle 4: Ensure identified case load of young people are booked into clinic
Issues- difficult to protect the transition slots and were at times used for regular review appointments

Cycle 3: **Implement transition tool and use in clinic**
Issues- Transition tool not appropriate and young people often wanted to discuss epilepsy specific topics which were not included on generic tool.

Cycle 2: **Identify case load of young people eligible for transition clinic.**
Issues- No current database to identify patient list. Needed to discuss with Trust analyst team. Once identified over 451 children on case load- needed to short list 14-16 year olds.

Cycle 1- **Transition clinic set up on electron system with 5 slots each week-**
Issues- difficult to create new code for clinic slots to enable booking and tracking- delay of weeks in setting up clinic

To create a structured/effective pathway for 50% of children and young people (age 14-16yrs) to transition into adult services by June 2024.

Figure 3: Shows Plan, Do, Study, Act (PDSA) cycles of change ideas listed within the driver diagram being tested to implement a structured transition pathway and functioning clinic.

What were the challenges?

- Accessing the database to identify the caseload that met the project criteria became challenging, resulting in manually highlighting eligible patients.
- The team found that the high number of young people meeting the criteria for transitioning made it difficult to engage effectively.
- Many eligible patients did not have appointments to be seen in the clinic within the project time frame, complicating efforts to gather feedback on their needs and circulate clinic feedback appropriately.
- Upon transitioning to adult services at 16, there is no adult epilepsy nurse support until age 18, creating a critical gap. Due to this absence of an adult epilepsy nurse, the paediatric team needs to include complete care plans in the transition process that are updated and reviewed with patients, families, and schools. This approach will help to avoid or reduce young people missing school trips and other activities due to lack of a care plan.
- Changes in access to psychological services.
- The community paediatric epilepsy nurse does not support young people with learning disabilities until age 18, creating a 2 year gap in support. There are roughly 30 patients aged 16-17 and 12 patients aged 18-19 with complex needs who lack access to an adult epilepsy nurse. These patients remain under paediatric care due to the absence of appropriate adult support, posing patient safety concerns. Additionally, there is no access to a community youth worker.
- The Ready, Steady, Go questionnaire was found to be non-epilepsy specific, young people found it was “too long” based on feedback received and it did not help to open discussions between staff and young people during the clinic.

- Issues with IT and data storage impacted the effectiveness of using QR codes on feedback forms. Concerns about storing confidential data and the anonymity of responses further complicated feedback collection.
- The reduced consultant hours due to retirement resulted in many epilepsy follow-up patients being booked into the new clinic, making it difficult to protect slots specifically for transition use.

What were the results?

- The team successfully established a transition clinic, have begun seeing patients, and have booked 50 patients for the clinic. The clinic allows more time for patients and their parents to discuss important transition-related topics, addressing specific needs and providing necessary support and information.
- Increased engagement with young people and their families has been achieved by contacting them for consent to attend the new clinic and using a new transition pathway. This has led to young people co-producing a transition tool to guide discussions during the clinic.
- Each patient now has a care plan detailing seizure types and medication plans, ensuring a clear understanding of their condition and steps during the transition process. Parents and carers are also involved in the decision-making process and provided with resources and support.
- The team found open questions in the clinic, without parents/carers, to be more effective for some patients. They are also developing easy-to-read versions of care plans and other materials to make them more accessible.
- Young people responded positively to discussing a range of topics, leading the team to identify common themes. The team developed laminated or Velcro topic cards to guide discussions and empower young people. Approval for the Velcro board is pending, and the play therapist team were engaged to create the necessary resources.
- Parents and patients have provided positive feedback, highlighting common topics such as driving, jobs, and social activities. One parent involved in the project has agreed to help create easy-to-read materials and set up an epilepsy parent support group with a section for parents of older children, providing community support.
- Meetings with the head of children’s nursing and the children’s emergency team had been arranged to discuss training for patient-specific medications and streamline care through A&E.
- The team adapted to changes in psychological support systems throughout the project and updated care plans for patients attending the transition clinic. While the Epilepsy12 national audit data showed 100% of patients achieved completed care plans, the team are working to include more patients in the audit.
- The team has secured pilot funding for an additional epilepsy nurse to bridge the gap between community and acute hospital services, providing more support and improving the transition process.
- Collaboration with adult services has improved, ensuring a smoother transition for patients, especially complex children. Discussions with adult nurses and managers

are underway to develop pathways, upskill adult services, and ensure appropriate care for patients, reducing waiting times and improving the overall transition experience.
- The transition clinic has positively impacted the general waiting list by providing more support and information, allowing some appointments with consultants to be cancelled or rescheduled in agreement with families, increasing availability and flexibility.

Figure 4: Children and young people's feedback captured on the topics they would like to discuss during the transition clinic.

What was the outcome?

- An epilepsy nurse-led transition clinic has been established with five weekly slots, which did not exist prior to the EQIP, and 50% of eligible patients were booked into this clinic.
- Co-producing a transition Velcro board tool with young people, empowering them to guide discussions on important topics.
- Created a resource pack with leaflets and signposting to websites, including mental health resources, to support young people during the transition process.
- Identified increased community resources to support young people's mental health.
- Increased engagement with young people and their families, gaining better insight into the topics that matter most to them.
- Improved patient confidence in managing their epilepsy through taking small steps and established a parent-led support group.
- Improved communication with the adult team and supported their bid for an epilepsy nurse.
- Received funding for a part-time nurse to assist with complex patients.
- Fundamental elements of transition now underpin routine follow-up, creating a smoother transition process.

What were the learning points?

- Opening communication between the service team and young people, and empowering them to guide discussion topics, has led to improved engagement.
- Despite struggling with the workload, the team's persistence and wiliness to change enabled progress.
- Questionnaires were often unhelpful, as it was difficult to find the appropriate time to use them. Feedback from young people suggested they perceived them as long and boring, and they added to team administrative work.
- Seizing opportunities when they arise, such as replacing the prior access to CAMHS liaison service with a local mental health counselling service for referrals.
- EQIP demonstrated that service improvement can start with small steps and develop over time to create a positive impact.
- The team is now more open to change and willing to challenge current practices in all aspects of care.

Next steps and sustainability

- Further development of a Velcro board for use within transition clinics.
- Designing a feedback tool for service improvement.
- Maintaining engagement with young people and their families to enhance the service.
- Continuing open dialogue and collaboration with adult services to refine transition processes.
- Identifying additional community support areas.
- Regularly reviewing the transition clinic.
- Developing standardised transitional care across the region and collaborating with local colleagues to share experiences.

Want to know more?

If you wish to know more about this project, please contact:

- **Dr Vanita Rasiah, Paediatric Consultant with epilepsy interest, West Hertfordshire University Trust, vanita.rasiah1@nhs.net**

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
Dr Kamal, Consultant Paediatrician with special interest in epilepsy
Georgina Ward, Paediatric Epilepsy Specialist Nurse
Kari-Ann Croucher, Paediatric Epilepsy Specialist Nurse
Kerry Newall, Paediatric Epilepsy Specialist Nurse

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.

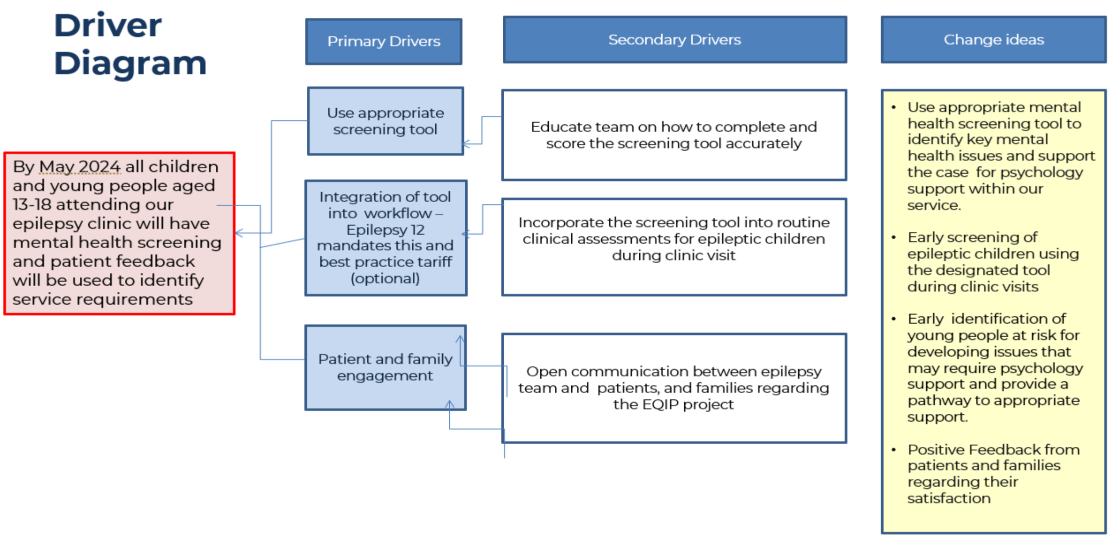
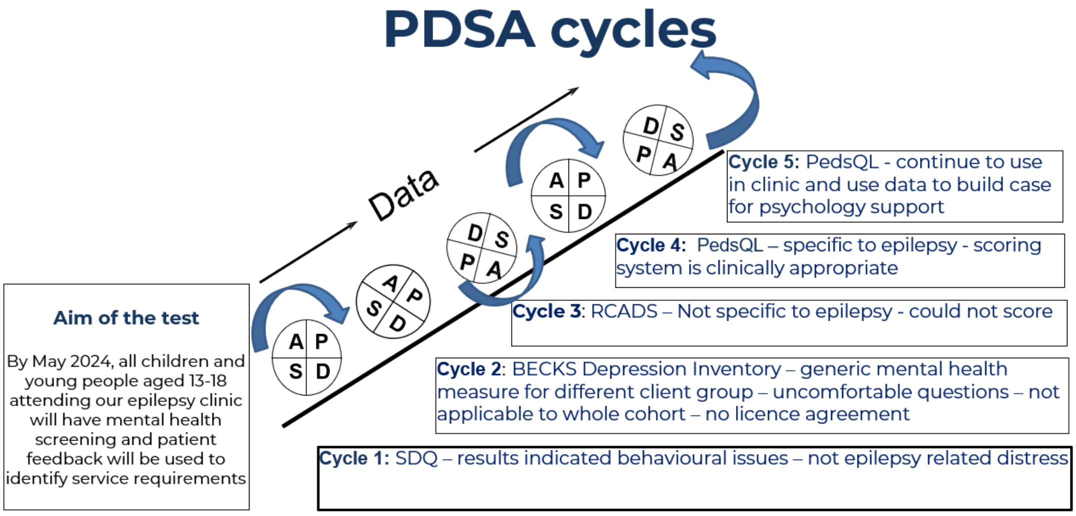


Figure 1: Team driver diagram that provides a clear statement of their project aim, with primary and secondary drivers that visually display the team's theory of what "drives", or contributes to, the achievement of a project aim.



Aim of the test

By May 2024, all children and young people aged 13-18 attending our epilepsy clinic will have mental health screening and patient feedback will be used to identify service requirements

Cycle 5: PedsQL - continue to use in clinic and use data to build case for psychology support

Cycle 4: PedsQL – specific to epilepsy - scoring system is clinically appropriate

Cycle 3: RCADS – Not specific to epilepsy - could not score

Cycle 2: BECKS Depression Inventory – generic mental health measure for different client group – uncomfortable questions – not applicable to whole cohort – no licence agreement

Cycle 1: SDQ – results indicated behavioural issues – not epilepsy related distress

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?

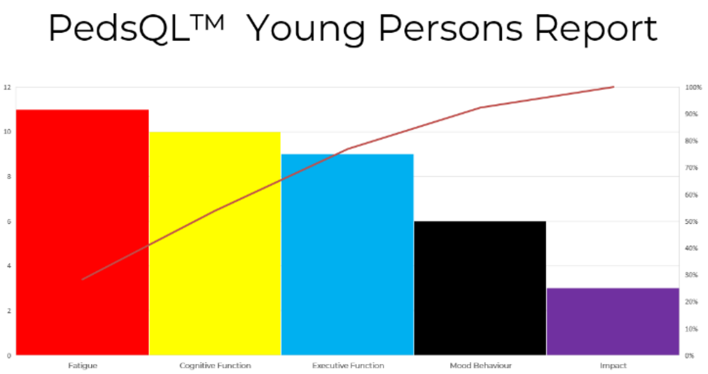
After testing several screening tools, the team identified the PedsQL as the most suitable to use and score for their epilepsy patients, because it includes the impact on more areas of daily life.

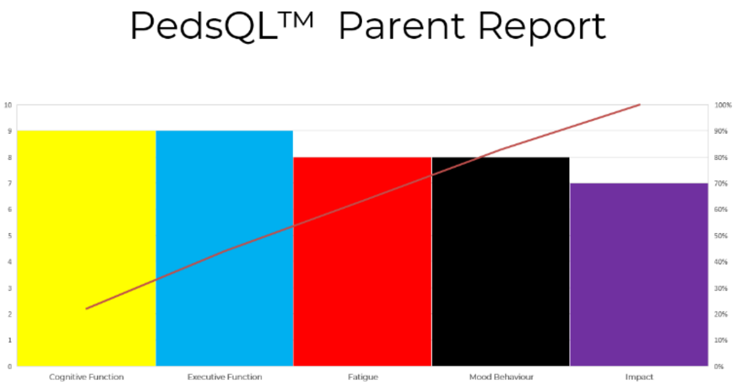
Using the PedsQL epilepsy module screening tool the scoring is divided into five sections:

- 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.



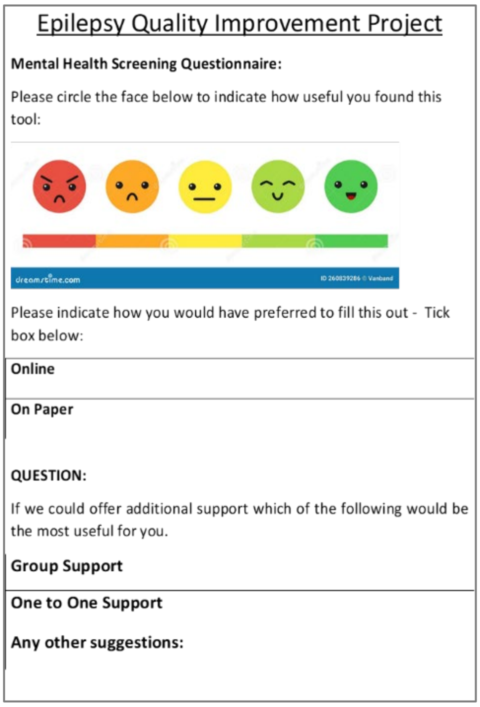


Figures 3 and 4: Show the scored results captured from young people and parents/carers using the PedsQL epilepsy module screening tool.

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:

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

Online

On Paper

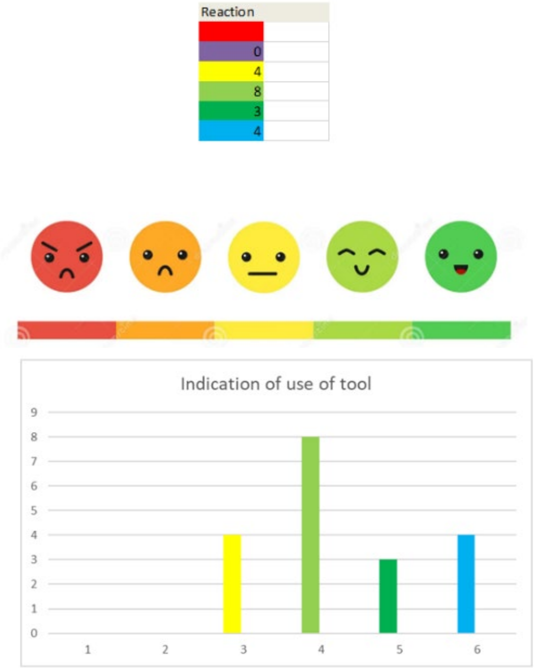
QUESTION:

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

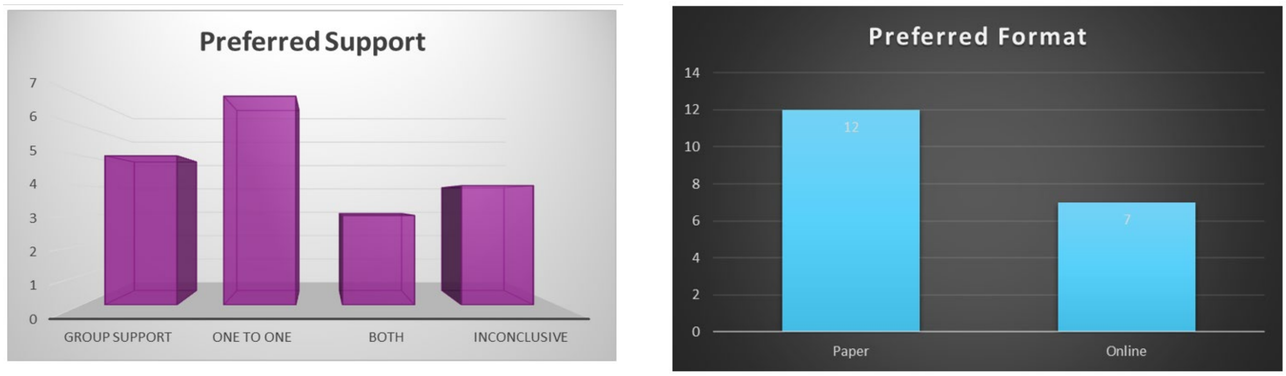
Group Support

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 areas of support 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 mental health concern 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:

Georgina Ward, Paediatric Epilepsy Specialist Nurse, East Sussex Healthcare NHS Trust (for direct access to the team contact the QI team at the RCPCH qips@rcpch.ac.uk)

Mental health support case studies 2023-2024

Improving mental health screening and signposting support pathways

Organisation

Isle of Wight NHS Trust

Project team:

Dr Ewa Szynaka, Consultant Paediatrician
Martyna Enser, Paediatric Registrar
Ruth Dubyk, Advanced Nurse Practitioner
Dr Laura Bohane, Clinical Psychologist

Project aim

To design, test and implement a mental health screening process and signpost children and young people to a variety of mental health resources by May 2024.

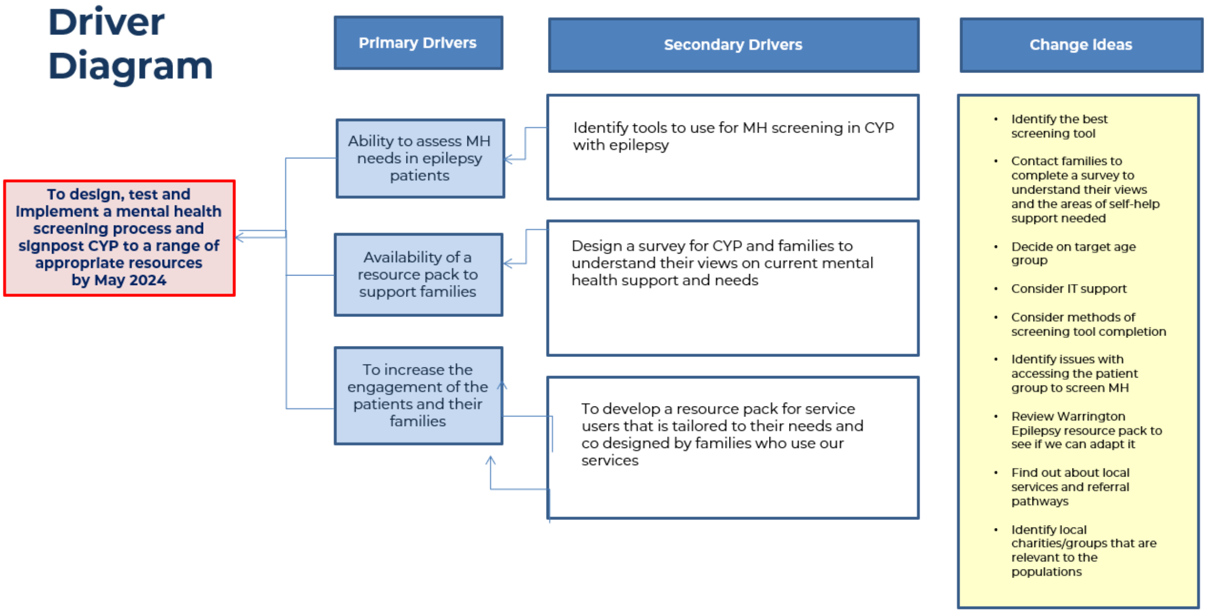
Background/rationale

The Isle of Wight NHS Trust paediatric service team works within a small District General Hospital. It is unique in its locality and currently cares for a caseload of approximately 100 children and young people diagnosed with epilepsy, who are seen in general paediatric clinics by eight general paediatric consultants. While some complex patients are managed jointly by secondary and tertiary services, who have access to an epilepsy nurse, most children and young people rely solely on the local paediatric consultants for their care.

The team aims to improve the identified gaps in routine screening for mental health, behavioural, and developmental conditions, including the lack of consistent access to a psychologist. At present, the team does not engage in quality improvement activities and lacks regular patient and family engagement activities due to resource constraints and the absence of a dedicated epilepsy clinic and epilepsy specialist nurse. Although there is a children's community nursing service within the paediatric department, there is no dedicated community outreach team.

What was the problem?

National audit results reported in Epilepsy12 highlighted these known gaps. The project's focus is on improving an area that is achievable and measurable, resulting in meaningful change, without any additional funding or resources. Epilepsy12 audit results identified mental health screening as a key area for service improvement. Additionally, many families had expressed a need for psychological support and were struggling to access this through community mental health services. Prior to joining EQIP, the team gained access to a small amount of paediatric clinical psychology time, which they plan to use effectively.



Driver Diagram

Primary Drivers

Secondary Drivers

Change Ideas

To design, test and implement a mental health screening process and signpost CYP to a range of appropriate resources by May 2024

Ability to assess MH needs in epilepsy patients

Availability of a resource pack to support families

To increase the engagement of the patients and their families

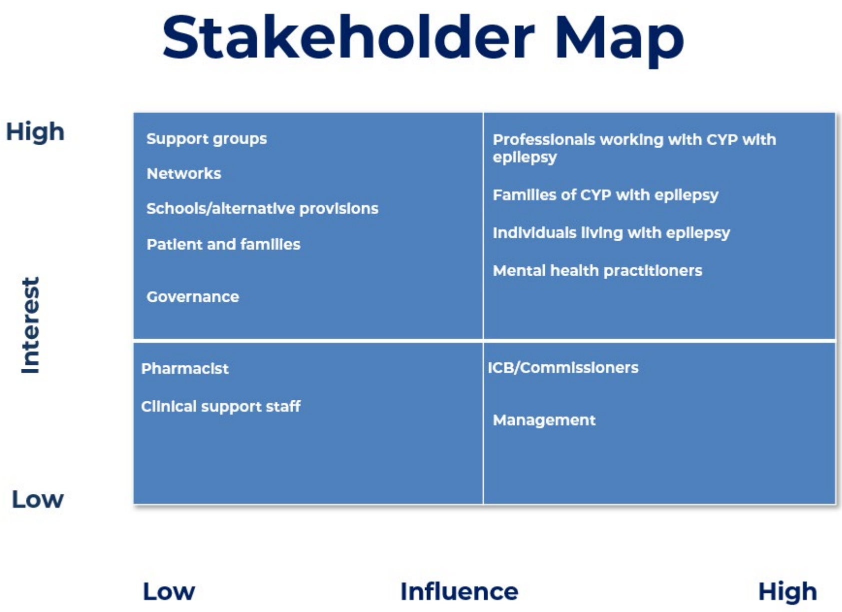
Identify tools to use for MH screening in CYP with epilepsy

Design a survey for CYP and families to understand their views on current mental health support and needs

To develop a resource pack for service users that is tailored to their needs and co designed by families who use our services

- Identify the best screening tool
- Contact families to complete a survey to understand their views and the areas of self-help support needed
- Decide on target age group
- Consider IT support
- Consider methods of screening tool completion
- Identify issues with accessing the patient group to screen MH
- Review Warrington Epilepsy resource pack to see if we can adapt it
- Find out about local services and referral pathways
- Identify local charities/groups that are relevant to the populations

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.



Stakeholder Map

Interest \ Influence	Low	High
High	Support groups Networks Schools/alternative provisions Patient and families Governance	Professionals working with CYP with epilepsy Families of CYP with epilepsy Individuals living with epilepsy Mental health practitioners
Low	Pharmacist Clinical support staff	ICB/Commissioners Management

Figure 2: Shows the project stakeholder map, which provides analysis of stakeholders that are of influence/interest to the project. Stakeholders are plotted on the grid to guides the actions you should take for involving and communicating with them.

What was the solution?

The team recognised the importance of providing comprehensive psychological and physical care for children and young people with epilepsy, adopting a combined approach to address both aspects. They emphasised the need for information and supportive resources for children, young people, and their families struggling with the diagnosis. The plan aimed to increase engagement with patients and families, involving them in designing resources that meet their needs.

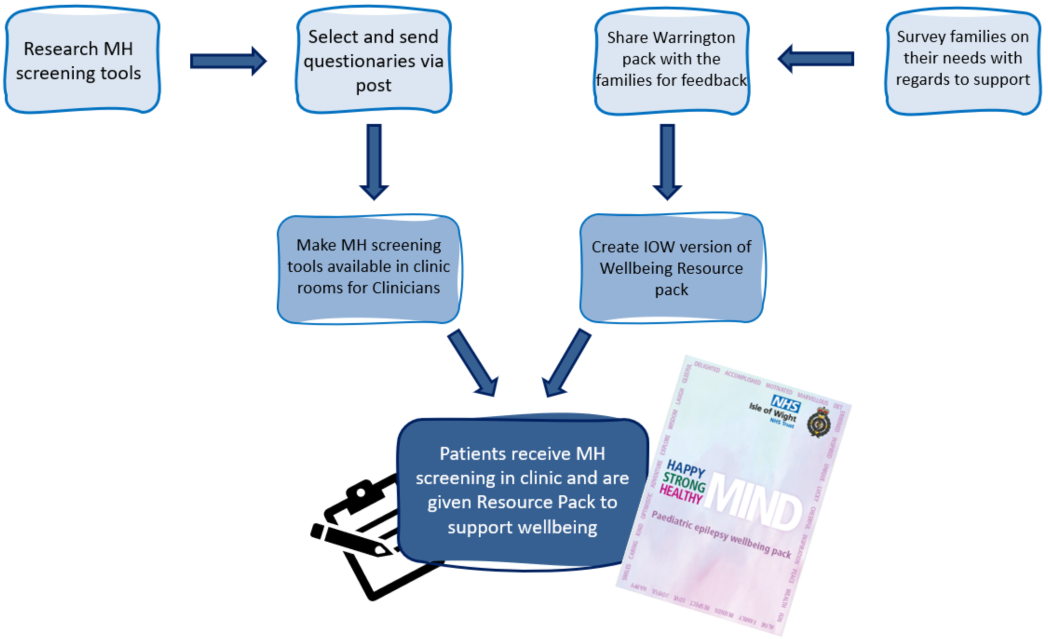


Figure 3: Shows the team's project process map of their journey for improvement.

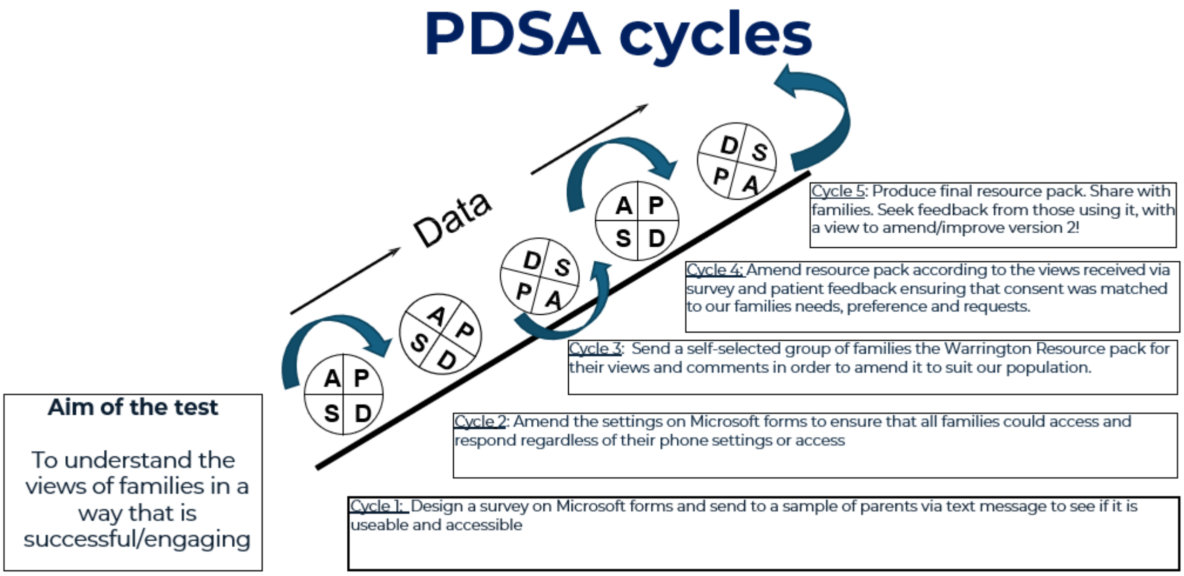
The following actions were taken:

1. **Identify a suitable screening tool**: The team tested several mental health screening questionnaires with children, young people, and their families, to gain their views on the current level of care provided by their service and the usefulness of the screening questionnaire. The following mental health screening tools were tested with families:
    a. PedsQL (Paediatric Quality of Life Inventory) screening tool. The PedsQL Measurement Model is a modular approach to measuring health-related quality of life in healthy children and adolescents and those with acute and chronic health conditions.
    b. Revised Child Anxiety and Depression Scale (RCADS) tool is a 47-item, youth self-report questionnaire with subscales including separation anxiety disorder, social phobia, generalized anxiety disorder, panic disorder, obsessive compulsive disorder, and low mood.

Selection: PedsQL was the preferred choice for its specificity to children and young people with epilepsy.

2. **Data collection**: The data collected from the mental health quality of life questionnaires were assessed and used for two purposes:
    a. Individual level: Surveys and questionnaires helped identify individuals needing specific interventions to address their mental health needs or improve their quality of life.
    b. Group level: The data provided an overall understanding of mental health needs and quality of life, identifying common trends or areas requiring further intervention.

3. **Testing and distribution**: Initial testing was conducted with a small group of children over the age of 8 years to refine the process prior to sharing the forms for wider distribution. In total, there were 66 families with children aged 8 years or over. Printed copies were available in outpatient clinics and distributed via the consultants.



PDSA cycles

Aim of the test

To understand the views of families in a way that is successful/engaging

Cycle 1: Design a survey on Microsoft forms and send to a sample of parents via text message to see if it is useable and accessible

Cycle 2: Amend the settings on Microsoft forms to ensure that all families could access and respond regardless of their phone settings or access

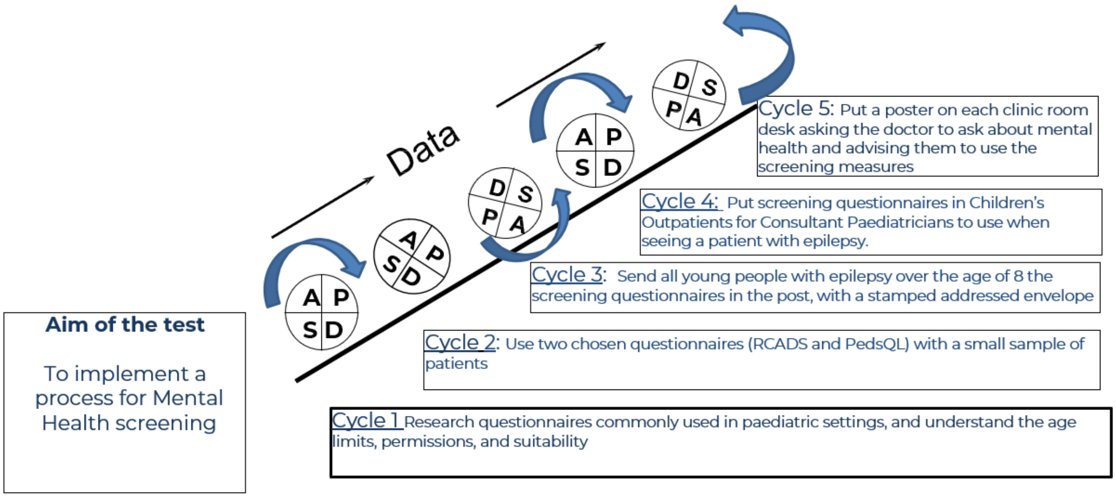
Cycle 3: Send a self-selected group of families the Warrington Resource pack for their views and comments in order to amend it to suit our population.

Cycle 4: Amend resource pack according to the views received via survey and patient feedback ensuring that consent was matched to our families needs, preference and requests.

Cycle 5: Produce final resource pack. Share with families. Seek feedback from those using it, with a view to amend/improve version 2!

Figure 4: Shows the Plan, Do, Study, Act (PDSA) cycles of change ideas to engage with young people and families within the driver diagram being tested.

PDSA cycles



Aim of the test

To implement a process for Mental Health screening

Cycle 1 Research questionnaires commonly used in paediatric settings, and understand the age limits, permissions, and suitability

Cycle 2: Use two chosen questionnaires (RCADS and PedsQL) with a small sample of patients

Cycle 3: Send all young people with epilepsy over the age of 8 the screening questionnaires in the post, with a stamped addressed envelope

Cycle 4: Put screening questionnaires in Children's Outpatients for Consultant Paediatricians to use when seeing a patient with epilepsy.

Cycle 5: Put a poster on each clinic room desk asking the doctor to ask about mental health and advising them to use the screening measures

Figure 5: Shows the PDSA cycles of change ideas for developing a mental health screening pathway within the driver diagram being tested.

4. **Patient engagement**: Feedback surveys were designed and sent via text message to all families and QR code posters of the survey were displayed in clinics to include the views of children, young people, parents and carers on the standard of care received and suggestions for service improvements. Notice boards were used in children's outpatient departments to communicate the project, provide access to resources, and gather feedback.
5. **Resource pack development**: The team planned to adopt and implement a mental health and wellbeing resource pack developed by the EQIP Warrington and Halton hospital paediatric service team, tailoring it to their patient population. Families were invited to join a small group to co-produce changes to the resource pack. Five families agreed to review and provide feedback on the resource pack content.
6. **Local resources**: The team undertook local research to identify available resources and services that could be signposted to support children, young people and families such as a locally run epilepsy support café, which was added to the wellbeing pack. Minor adjustments to the order of content were implemented based on survey responses.

What were the challenges?

The following challenges highlight the practical and logistical difficulties faced by the team in implementing their improvement project.

- **Age range decision**: The team initially planned to engage children and young people from the age of 10 years and over, which was changed to over the age of 8 years.
- **Technical issues**: The initial sample survey sent to three families had a non-functioning link, which required correcting.
- **Time constraints**: There was very limited time to work on the project.

- **Data management**: Gathering and analysing screening questionnaire data was time-consuming.
- **Physical space**: Lack of a dedicated epilepsy clinic and no dedicated epilepsy team made implementing changes to practice more difficult.
- **Consultant engagement**: The clinic is managed by eight consultants who treat children and young people with epilepsy but seven did not participate in the improvement programme. This complicated patient engagement due to infrequent appointments (every 4-6 months) which present challenges in securing their buy-in.
- **Lack of epilepsy specialist nurse**: No input from an epilepsy nurse creates a significant affect with patients' feeling unsupported and the effects on the standard of care delivered.
- **Infrequent appointments**: Insufficient time to capture feedback from patients and families due to the irregularity of clinic visits from patients that meet the criteria within the projects time frame.
- **Screening process**: Ideally, mental health screening tools would be administered in person to allow thorough exploration and generate conversation, but practical constraints resulted in sending them to families for self-completion.
- **Poor return rate**: Low return rate of screening questionnaires, which ideally should be completed in the clinic.
- **Scoring and action time**: Significant time is needed to score questionnaires and take action after completion.

What were the results?

The mental health screening questionnaires and feedback forms were sent to 66 families with children over the age of 8 years via post. In total 27 families responded to the survey, seven responded with screening questionnaires and four families agreed to help develop some resources.

Feedback results were captured from children, young people and their families on the following:

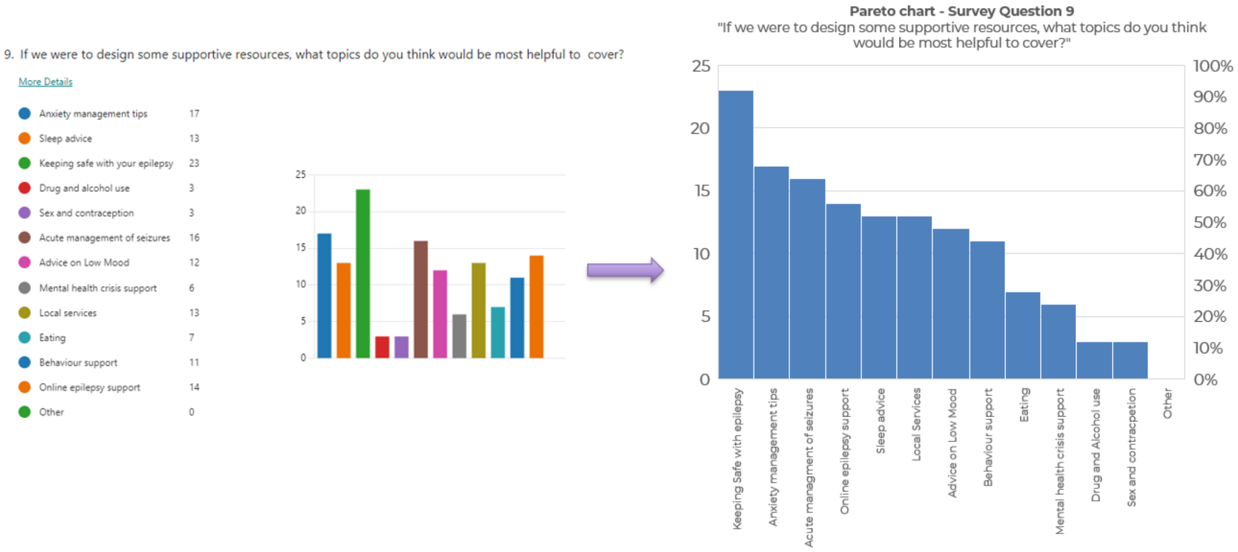
- **Service improvements:**
    - Many families highlighted a lack of support for staying safe with epilepsy.
    - There was a significant need for support from local services, online epilepsy resources, and general epilepsy management.
    - Mental health feedback identified the need for support with low mood and anxiety management.
    - Qualitative data revealed issues such as the absence of an epilepsy nurse, lack of a contact point, geographic barriers, and insufficient mental health support.
- **Routine enquiries and resource access:**
    - Families reported that children's mental health was not routinely addressed.

  - They also mentioned difficulties in finding resources to support their understanding of epilepsy and mental health.
  - Families expressed the need for more mental health support but struggled to access it.
  - Quick, accessible phone surveys were well received by families.

- **Patient and family needs:**
  - Patients and families were not regularly asked about their mental health and wellbeing.
  - There was uncertainty about where to find help and support.
  - Families preferred face-to-face contact methods.
  - There was significant interest in general epilepsy advice, with a particular focus on mental health, anxiety, and wellbeing.

- **Local context:**
  - The Isle of Wight has a high percentage of children and families living in poverty.
  - There is also a large proportion of children with special needs, autism, and ADHD.
  - Resource information will be made inclusive and accessible to all families.

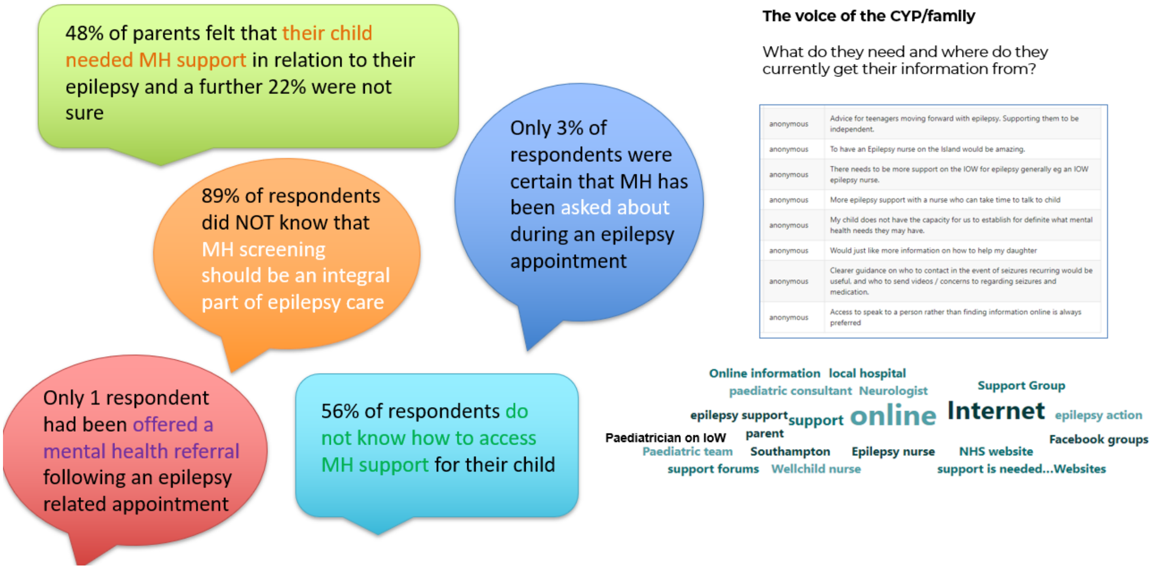
- **Resource pack feedback:**
  - Families indicated they were randomly searching for resources, risking access to inaccurate information.
  - A short survey asked families for their views on the resource pack, including what they liked, disliked, and what they would change about the content and layout.
  - Five families agreed to review and provide feedback on the Warrington and Halton “Happy, strong, healthy Mind” wellbeing pack.



9. If we were to design some supportive resources, what topics do you think would be most helpful to cover?

Anxiety management tips	17
Sleep advice	13
Keeping safe with your epilepsy	23
Drug and alcohol use	3
Sex and contraception	3
Acute management of seizures	16
Advice on Low Mood	12
Mental health crisis support	6
Local services	13
Eating	7
Behaviour support	11
Online epilepsy support	14
Other	0

Figure 6: Pareto chart of patient and familiy feedback from mental health quality of life questionnaire.



48% of parents felt that their child needed MH support in relation to their epilepsy and a further 22% were not sure

89% of respondents did NOT know that MH screening should be an integral part of epilepsy care

Only 3% of respondents were certain that MH has been asked about during an epilepsy appointment

Only 1 respondent had been offered a mental health referral following an epilepsy related appointment

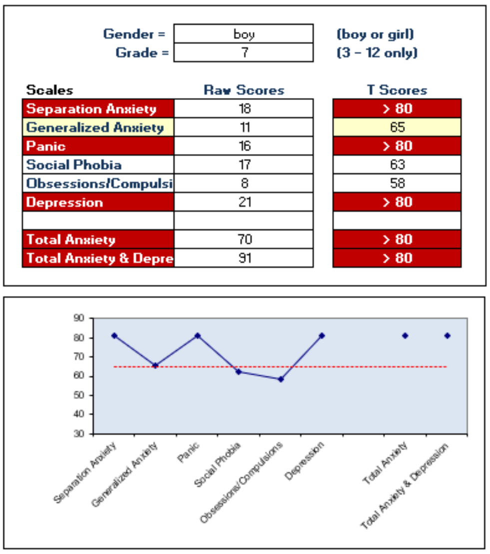
56% of respondents do not know how to access MH support for their child

The voice of the CYP/family

What do they need and where do they currently get their information from?

anonymous	Advice for teenagers moving forward with epilepsy. Supporting them to be independent.
anonymous	To have an Epilepsy nurse on the Island would be amazing.
anonymous	There needs to be more support on the IOW for epilepsy generally eg an IOW epilepsy nurse.
anonymous	More epilepsy support with a nurse who can take time to talk to child
anonymous	My child does not have the capacity for us to establish for definite what mental health needs they may have.
anonymous	Would just like more information on how to help my daughter
anonymous	Clearer guidance on who to contact in the event of seizures recurring would be useful. and who to send videos / concerns to regarding seizures and medication.
anonymous	Access to speak to a person rather than finding information online is always preferred

Figure 7: Patient and familiy feedback from mental health quality of life questionnaire.



Gender = boy (boy or girl)
Grade = 7 (3 – 12 only)

Scales	Raw Scores	T Scores
Separation Anxiety	18	> 80
Generalized Anxiety	11	65
Panic	16	> 80
Social Phobia	17	63
Obsessions/Compulsi	8	58
Depression	21	> 80
Total Anxiety	70	> 80
Total Anxiety & Depre	91	> 80

	IMPACT	COGN. F.	SLEEP	EXEC. F	MOOD
MAX SCORE	900	600	300	600	500
1	350	25	75	225	500
2	25	0	25	0	N/A
3	200	175	0	150	250
4	550	25	100	250	275
5	0	0	0	0	0
6	500	175	125	0	300
7	376	50	0	75	225
8	600	175	50	0	75

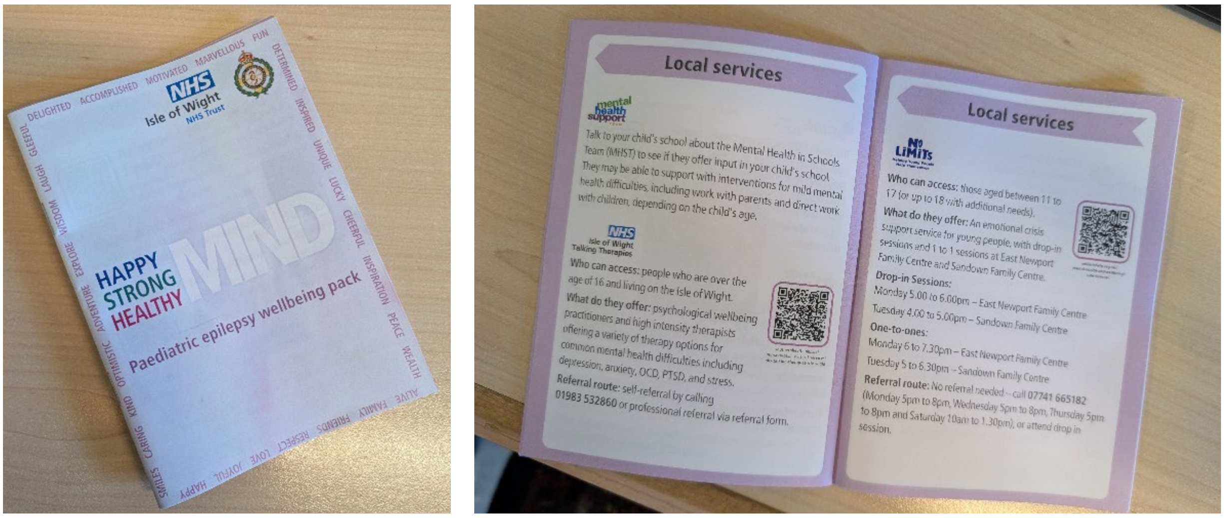
Figure 8 (left): RCADS is a 47-item youth self-report questionnaire with subscales. Posted to all children and young people with epilepsy over the age of 8 years. Seven responses, one of which was incomplete. Five of these met clinical threshold for self-reported anxiety disorder and/or low mood.

Figure 9 (right): PedsQL – Epilepsy Module: Scored results.

What was the outcome?

- **Resource pack for families**: All children and young people and their families now have access to a co-produced resource pack with high-quality self-help materials and local and national signposting information.

- **Team Cohesion**: The project fostered a dedicated and enthusiastic team, uniting members with a shared goal.
- **Understanding mental health needs**: There is now a better understanding of the mental health needs of children and young people who attend their service.
- **Patient involvement**: The project has incorporated the voice of patients and families within improvement processes to support ongoing service development initiatives.
- **Equity of care**: Efforts have been made to reduce variation in patient experience, ensuring equity of care for all.
- **Increased awareness**: The team is now more aware of the need to ask about and screen for mental health difficulties in patients with epilepsy.
- **Screening process**: Screening tools are now available for use within the clinic setting to effectively screen for mental health conditions in children and young people with epilepsy.
- **Future plans for an epilepsy specialist nurse**: The voice of patients and families, captured through surveys, will be used to demonstrate the need for an epilepsy specialist nurse (ESN). Access to an ESN will help to create an even better pathway.
- **Continuous feedback and improvement**: There are plans to gather feedback on the resource pack to make further changes if needed, ensuring it continues to meet the needs of children and young people and their families.



Local services

Talk to your child's school about the Mental Health in Schools Team (MHST) to see if they offer input in your child's school. They may be able to support with interventions for mild mental health difficulties, including work with parents and direct work with children, depending on the child's age.

Who can access: people who are over the age of 16 and living on the Isle of Wight.
What do they offer: psychological wellbeing practitioners and high intensity therapists offering a variety of therapy options for common mental health difficulties including depression, anxiety, OCD, PTSD, and stress.
Referral route: self-referral by calling 01983 532860 or professional referral via referral form.

Local services

Who can access: those aged between 11 to 17 (or up to 18 with additional needs).
What do they offer: An emotional crisis support service for young people, with drop-in sessions and 1 to 1 sessions at East Newport Family Centre and Sandown Family Centre.
Drop-in Sessions:
Monday 5.00 to 6.00pm – East Newport Family Centre
Tuesday 4.00 to 5.00pm – Sandown Family Centre
One-to-ones:
Monday 6 to 7.30pm – East Newport Family Centre
Tuesday 5 to 6.30pm – Sandown Family Centre
Referral route: No referral needed – call 07741 665182 (Monday 5pm to 8pm, Wednesday 5pm to 8pm, Thursday 5pm to 8pm and Saturday 10am to 1.30pm), or attend drop in session.

Figure 10: Images of Isle of Wight version of the Warrington and Halton "Happy, strong, healthy Mind" resource pack for families. The resource pack was reviewed and edited working with children and young people to ensure the content met with their needs.

What were the learning points?

- **Shared learning and preparation**: Being prepared to present findings at a clinical effectiveness meeting were crucial.
- **Ineffectiveness of postal method**: Sending the screening questionnaires by post to children, young people and their families proved ineffective due to postal costs and a very low return rate.

- **Engaging peers**: Clinicians need visual prompts incorporated into the process to remind them to use screening measures when seeing children and young people with epilepsy in clinic.
- **Importance of family voices**: Including the voice of children and young people and their families is vital for understanding their needs and involving them in the improvement process is crucial to service improvement.
- **Ineffectiveness of paper questionnaires**: Distributing paper questionnaires is not an effective engagement method and resulted in poor return rates.
- **Effective team collaboration**: The team worked extremely well together, using communication methods such as WhatsApp to keep all team members updated, because of the minimal opportunities to meet in person.
- **Optimising team skills**: Each team member's skill set was utilised to optimise productivity and move the project forward cohesively.
- **Engagement with key stakeholders**: Collaborating with the Integrated Care Board lead and Operational Delivery Network was essential for addressing the need for an epilepsy nurse and improving overall care.

Next steps and sustainability

- Encourage all consultant paediatricians to ask about mental health during patient consultations and use screening questionnaires in clinics.
- Share the resource pack with all families.
- Refer children and young people with the highest support needs to a paediatric clinical psychologist for one-to-one consultation.
- Encourage self-referrals and make referrals to mental health services or third sector organisations when indicated.
- Create a business case for an epilepsy nurse specialist, using the feedback from parents gathered in the project survey.
- Continue to gather further patient feedback on the resource pack to inform ongoing improvements.
- Plan discussions about expanding the psychology team, including the potential addition of an assistant psychologist.
- Present the resource pack at the Trust planned care board and clinical standards group.

Want to know more?

If you wish to know more about this project, please contact:

- **Dr Ewa Szynaka, Consultant Paediatrician, Isle of Wight NHS Trust, Ewa.szynaka@nhs.net**
- **Dr Laura Bohane, Psychologist, Isle of Wight NHS Trust, Laura.bohane@nhs.net**

Mental health support case studies 2023-2024

Improving mental health screening using SDQ tool

Organisation

Northern Care Alliance NHS Trust (Salford Royal)

Project team

Dr Amy Wilson, Community Paediatrician and Epilepsy Lead
Debbie Garner, Paediatric Epilepsy Nurse Specialist
Sarah Charlson, Epilepsy Nurse
Angela Gardiner, Advanced Nurse Practitioner
Tahmina Haque, ST Registrar
Angela Palmer, Medical Secretary
Lois Faux, Clinic Bookings Admin

Project aim

To utilise the Strengths and Difficulties (SDQ) screening tool in 50% of young people aged 14 years and above with a diagnosis of epilepsy on our caseload, by May 2024.

Background/rationale

The community-based team in Salford, closely linked with the paediatric neurology service at Royal Manchester Children's Hospital, serves a highly deprived population, with 70% of patients coming from the most deprived quintile. Despite regularly making changes to improve their service, the team has not undertaken formal quality improvement projects. With a caseload of approximately 280 children and young people, the team has recognised gaps in their service, particularly in mental health screening and support resources for patients with epilepsy. Their Epilepsy12 data showed 0% for mental health screening, highlighting the need for improvement.

What was the problem?

The team aims to implement a mental health screening tool for secondary school-aged patients and explore the correlation between mental health improvements and other health outcomes. This initiative is part of their broader commitment to addressing health disparities, as discussed in meetings with their commissioning team, focusing not only on epilepsy but also on other Core20PLUS5 areas.

What was the solution?

The Salford team explored several solutions to improve mental health screening for epilepsy patients, starting with the use of the SDQ. Testing the SDQ with one patient revealed its ease of use and effectiveness in generating insightful discussions during consultations. Positive feedback led to further testing with more patients, addressing initial concerns about the time-consuming nature of the scoring process. The team acknowledged the need to re-evaluate their clinic booking practices to ensure older patients, who are seen less frequently, receive timely appointments. They also plan to adopt resource packs developed by other EQIP teams – Warrington and Halton and Tameside and Glossop – to save development time and ensure resources are ratified within the Trust.

To address aspects of health inequalities, the team considered patients with communication difficulties and how best to engage them. They researched translated versions of the SDQ into different languages and extended clinic times to after school hours to increase attendance. In addition, by moving clinics to various locations, they aimed to make appointments more accessible for patients having difficulty travelling. The team utilised guidance from Core20PLUS5 and the Epilepsy12 audit data to support patients better in addressing health inequalities. The team presented on the progress of their project at regional conferences and attended a poverty proofing seminar to explore ways to address the needs of families in financial crisis.

What were the challenges?

The improvement project faced several challenges:

- The manual identification of the cohort of young people that met the criteria and ensuring the right age group attended the clinic within the programme's time frame was time-consuming. To address this, the team had to rebook appointments to ensure at least two patients from the cohort were seen per week.
- Among the 48 patients aged 14 years and above, 15 were identified as having significant learning difficulties. This group often includes patients who do not attend (DNA) appointments.
- The DNA rate posed a significant issue, compounded by an increase in new referral numbers.
- The large cohort of young people with additional needs and communication difficulties provided additional challenges to the project.
- Some patients had been seen for transition consultations shortly before the project started and therefore did not require an outpatient appointment (OPA) within the project's time frame.

- Trust restrictions on printing also hindered disseminating signposting and resources.
- Involving the admin team to help with the workload proved ineffective due to the clinics being held in different locations and improper patient assignment.
- Unexpected challenges included a reduction in patients seen in the clinic due to staff annual leave and changes in personnel at the beginning of the project.
- Positive feedback from the screening tool was acknowledged by the team, but some patients struggled to access the SDQ questionnaire, prompting the team to consider alternative approaches for those with learning disabilities.
- Currently, no resource packs are available for service users with mental health or emotional needs, highlighting a further area for improvement.

What were the results?

Project aim criteria and cohort selection results:

- 48 patients identified on the caseload aged 14+ years.
- Of these 48:
    - 15 did not have the capacity to complete the questionnaire.
    - 6 did not have a formal diagnosis of epilepsy (awaiting EEG results).
        - = 27 identified as being eligible to complete the questionnaire.
    - 8 patients completed the SDQ.

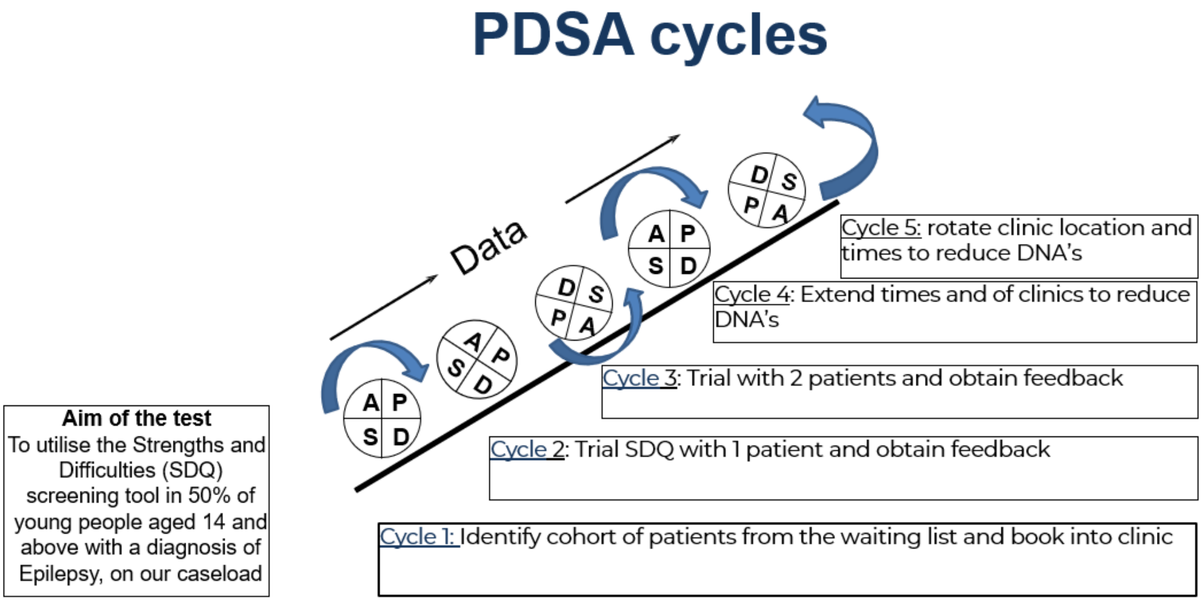
Results of DNA rates captured over the course of the project:

- DNA rates for 11-16 years of age from Nov 2023 to March 2024:
    - Nov 2023: 13%, Feb 2024: 20%.
- DNA rates for 16-19 years of age:
    - Dec 2023: 21.4%, March 2024: 25%.
- New referrals to the service from Nov 2023 to March 2024:
    - 72 required OPA within 2 weeks of referral to meet NICE guidance.
- Jan 2024 time slots for clinic changed.
- Feb 2024 location and time slots for clinics changed.

PDSA results:

- Cycle 1: process worked smoothly (although time consuming for clinicians). Difficulties: staffing numbers.
- Cycle 2: young person enjoyed completing the questionnaire and fostered conversations during consultation.
- Cycle 3: young people gave feedback that the tool is long and boring. Experienced a large number of DNAs for young people allocated to clinic.
- Cycle 4: movement of clinic locations and times in attempt to reduce DNAs. Some impact shown although too early to determine trend.
- Cycle 5: some improvement in DNA rates noted.

The team sought feedback from all young people aged 14 years and above attending clinic and screened using the SDQ. Most feedback received was positive, but some patients found the questionnaire “boring” and felt there were too many questions. In response, the team planned to explore developing their own version of the questions for use within the Trust, specifically for the cohort of patients for whom the SDQ is not suitable. (The team is aware that the SDQ is a licensed and validated tool, therefore the questions created by the team will not be associated with the SDQ.)



Aim of the test
To utilise the Strengths and Difficulties (SDQ) screening tool in 50% of young people aged 14 and above with a diagnosis of Epilepsy, on our caseload

Cycle 5: rotate clinic location and times to reduce DNA’s

Cycle 4: Extend times and of clinics to reduce DNA’s

Cycle 3: Trial with 2 patients and obtain feedback

Cycle 2: Trial SDQ with 1 patient and obtain feedback

Cycle 1: Identify cohort of patients from the waiting list and book into clinic

Figure 1: Shows the Plan, Do, Study, Act (PDSA) cycles of change ideas to engage with young people and families within the driver diagram being tested.

Months	DNAs 11-16
Oct-Dec	13%
Jan-Apr	10%

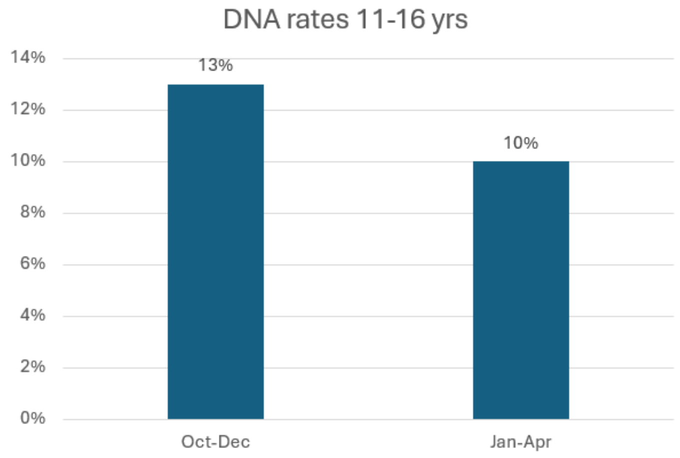


Figure 2: Shows the analysis of clinic DNA rates during the time frame of the project.

Months	Referral rates per month
Oct-Dec	11.3
Jan-Apr	19.5

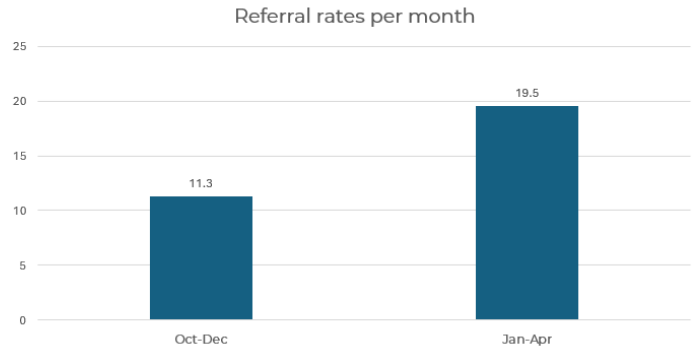


Figure 3: Shows the analysis of clinic referral rates during the time frame of the project.

What was the outcome?

The team achieved the following outcomes:

- **Implementation of SDQ screening tool**: Successfully integrated the SDQ into the clinic's process to gather patient feedback and guide conversations during consultations.
- **Reduction of DNA rates**: Achieved a significant reduction in DNA rates by extending clinic times to after school hours and reviewing clinic locations to provide more accessible options.
- **Increased screenings**: Screened eight patients using the SDQ tool, facilitating open conversations and identifying issues patients may not have shared otherwise.
- **Addressed health inequalities**: Held clinics at different locations closer to children's homes to address health inequalities and improve service engagement.
- **Future plans for SDQ**: Plan to roll out the SDQ tool to other services, expanding its use beyond the initial project scope.
- **Resource identification**: Identified necessary resources to signpost young people to appropriate support once the SDQ highlights high scores.
- **Engagement with Learning Disability Team**: Increased collaboration with the Learning Disability Team to support the development of visual aids and communication tools for better patient engagement.

What were the learning points?

- The SDQ is available in different languages, aiding accessibility.
- Manual identification of young people was time-consuming; future collaboration with the clinic's booking team could streamline this process.
- Identified gaps in service provision that need addressing.
- Reflected on the need to balance clinicians' agendas with young persons' needs during consultations.
- The SDQ itself was not problematic, but engagement was affected by DNAs, limited clinic capacity, and high referral rates.

- Recognised that the SDQ does not meet the needs of all young people, necessitating alternative methods or different question sets for some.
- The team is open to change and passionate about the project.
- The EQIP training taught the team that not all problems need to be solved at once, emphasising a step-by-step approach.

Next steps and sustainability

- Implement different communication aids in co-production with young people and the Learning Disabilities Team.
- Develop a business case for an epilepsy nurse specialist to join the team to support the mental health screening and improve service pathways.
- Co-produce resource packs with children and young people that support the mental health and wellbeing for children's services across epilepsy, diabetes and asthma conditions.
- Organise a summer event in Salford for young people with long-term conditions such as epilepsy, asthma and diabetes. This event aims to provide health education, involve professionals like dieticians and careers advisors, and foster interaction among the attendees to discuss common challenges and themes.

Want to know more?

If you wish to know more about this project, please contact:

- **Dr Amy Wilson, Epilepsy lead and Clinical Director Children's Services, Northern Care Alliance (Salford Royal), Amy.wilson@nca.nhs.uk**

Reducing variation case studies 2023-2024

Implementing anti-seizure medication weaning plans at discharge

Organisation

Great Ormond Street Hospital for Children

Project team

Dr Maria Gogou, Senior Clinical Fellow Paediatric Neurology
Dr Suresh Pujar, Consultant Paediatric Neurologist
Dr Noelle Enright, Consultant Paediatric Neurologist
Jahziel Darisan, Neurology
Husna Musa, Clinical Fellow in Paediatric Neurology and Clinical Trials

Project aim

To make sure that by May 2024, for all children (0-18 years) admitted to Great Ormond Street Hospital (GOSH) and started on antiseizure medications (ASM) after acute symptomatic seizures, there will be a plan in their discharge summaries to start weaning ASM or consider weaning within a period of 2-3 months, if this is clinically appropriate.

Background/rationale

The paediatric epilepsy service at GOSH is a busy service which provides specialised inpatient and outpatient tertiary care for children and adolescents with complex epilepsy, including ketogenic diet services, video-telemetry and epilepsy surgery service. Furthermore, there is provision of professional advice and guidance to the local paediatric teams as well as support for cases with diagnostic and management challenges through the refractory epilepsy specialist clinical advisory service.

Acute symptomatic seizures are seizures occurring in close temporal relationship with an acute central nervous system insult, (acute insults to the central nervous system represent some of the most common neurological disorders and often lead to long-term disability). Although treatment with ASM may be needed in the acute phase, they are usually not associated with future risk of epilepsy.

There is a dearth of literature and data showing that shorter vs longer duration of treatment may have a similar impact on recurring risk of seizure in some situations and that there are no differences in neurocognitive profile (having the ability to think and reason) at 24 months from early stop of medications in neonates with acute symptomatic seizures.

However, there are no established guidelines about the duration of treatment with ASM and there is currently considerable heterogeneity in daily practice, a fact which increases the risk of polypharmacy (when a person is taking many different medications at the same time) and any potential ASM-associated adverse events.

What was the problem?

The team's project aim was to address a real-life issue with direct clinical impact on patient care and help establish Trust guidelines on weaning ASM in infants, children and young people with acute symptomatic seizures and reduce variation in daily clinical practice, as well as unnecessary medication burden.

What was the solution?

The cohort criteria to implement ASM weaning plans within discharge papers for all children and young people from neonates up to 18 years old. Typically, at least one qualifying child or young person is seen weekly. The team provided educational training to colleagues at GOSH, including consultants and nurses in neurology, neurosurgery, inpatient wards, and intensive care units. This training involved creating and emailing PowerPoint slides to relevant staff and arranging one-to-one sessions, which proved particularly engaging and beneficial.

Reflecting on feedback, the team planned to increase one-to-one training sessions with additional hospital departments, incorporating necessary information into discharge summaries via electronic patient record systems. They aimed to ensure that discharge summaries included a medication weaning plans for all children with acute symptomatic seizures. Additionally, they checked if the weaning process began a few months post-discharge and compared treatment durations before and after the project.

To support sustainability, the team developed a "smart phrase" within their Trust's EPIC IT system to automatically pull text into clinical notes by typing in the smart phrase in the system. The weaning medication plan will then appear in the clinical notes.

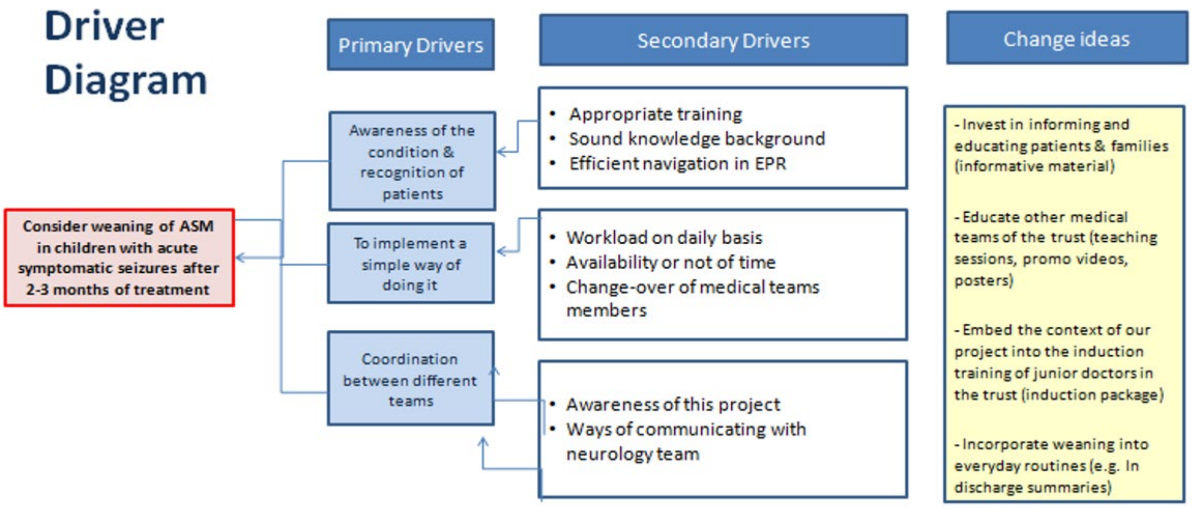
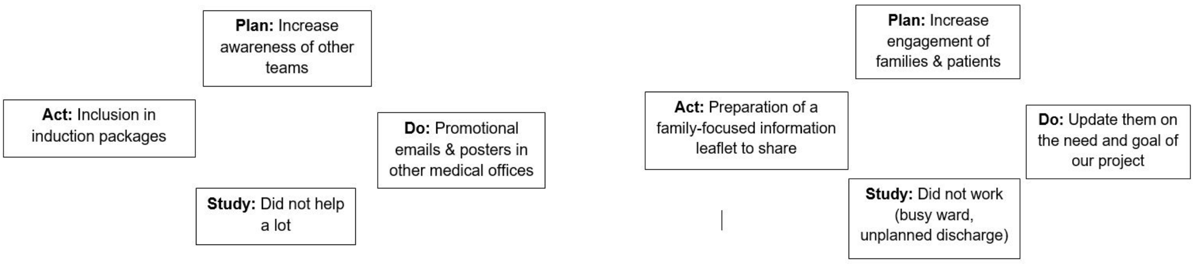


Figure 1: Team driver diagram that provides a clear statement of their project aim, with primary and secondary drivers that visually display the team's theory of what "drives", or contributes to, the achievement of a project aim.

Figures 2 and 3: Show small Plan, Do, Study, Act (PDSA) cycles of change ideas for implementation of weaning plans and methods to increase awareness of their improvement project amongst colleagues and Trust healthcare professionals.



Figures 4 and 5: Show small PDSA cycles of change ideas for patient engagement.

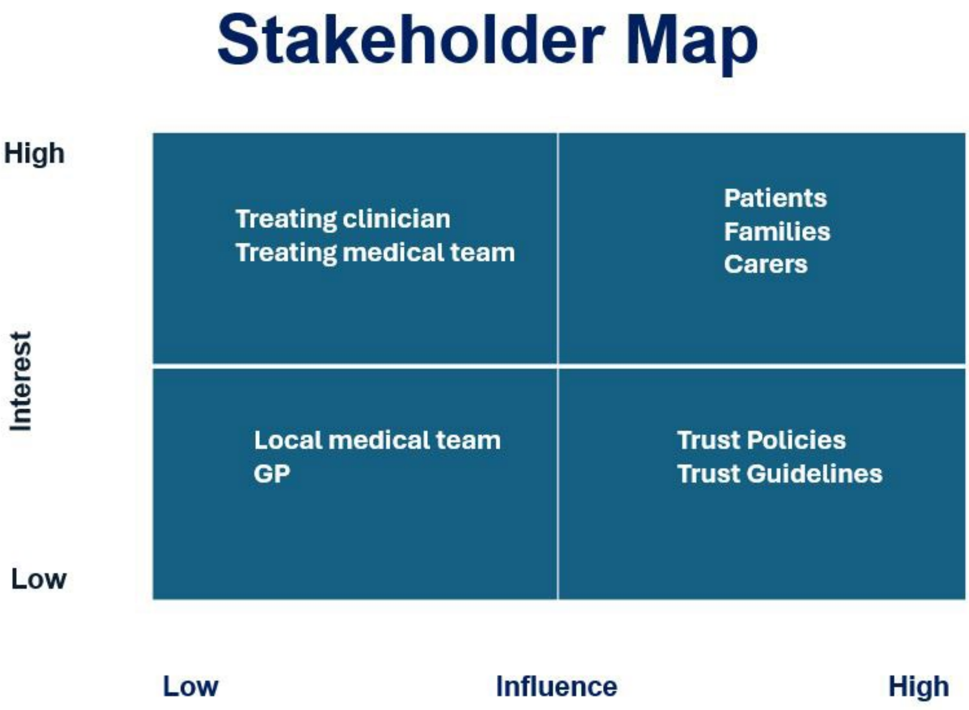


Figure 6: Shows the project stakeholder map, which provides analysis of stakeholders that are of influence/interest to the project. Stakeholders are plotted on the grid to guide the actions the team should take for involving and communicating with them.

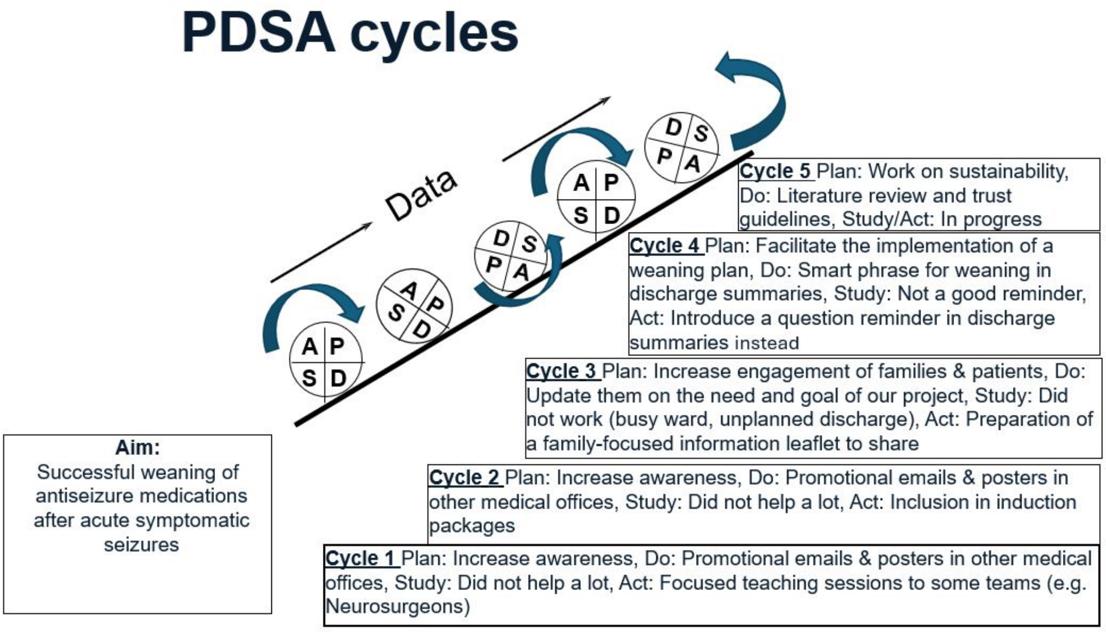
What were the challenges?

The project experienced the following challenges:

- Ensuring the intervention's success required substantial personal involvement from the team, prompting a review of their capacity.
- The team found engaging patients challenging as the team primarily interacted with medical and nursing staff within the Trust. Frequent doctor changes, unplanned discharges, and transfers to local hospitals hindered communication with families. Additionally, many patients who are referred for tertiary care are discharged once stable due to bed capacity issues.
- Patients with acute symptomatic seizures are often too unwell for the team to discuss the project with them and their families, as they are typically experiencing significant anxiety and concerns about the epilepsy condition, therefore complicating engagement with families.
- Initial plans to update families orally proved impractical due to busy schedules and unplanned discharges. Therefore, the team created a family-focused information leaflet and planned to collate feedback from families on the leaflet.
- The project lead changed jobs during the duration of the project but remained in contact with the team. A new team member joined the project and was tasked with familiarising themselves with the work undertaken and the current project activities. The team discussed the sustainability of the project and its continuity despite team changes.

What were the results?

- The project highlights the importance of collaborative care and structured weaning plans for patients with acute symptomatic seizures.
- Patient identification: 32 eligible patients identified.
- Weaning plans provided: 16 patients received weaning plans.
- Prompt and successful implementation of weaning plans is based on the engagement of patients, families, carers and liaison with local medical teams.
- The project achieved an increase in the number of cases with weaning plans included within discharge plans for children and young people seen by the neurosurgical and acute neurology teams without direct intervention from their teams.
- A training video has been created and shared with select staff members.
- There are plans to release the training video more broadly, along with guidelines on medication weaning, after further review.
- Posters were created to be displayed within clinics to raise the profile of the project.
- Further reviews and guidelines on medication weaning are being developed for broader dissemination.



Cycle 5 Plan: Work on sustainability, Do: Literature review and trust guidelines, Study/Act: In progress

Cycle 4 Plan: Facilitate the implementation of a weaning plan, Do: Smart phrase for weaning in discharge summaries, Study: Not a good reminder, Act: Introduce a question reminder in discharge summaries instead

Cycle 3 Plan: Increase engagement of families & patients, Do: Update them on the need and goal of our project, Study: Did not work (busy ward, unplanned discharge), Act: Preparation of a family-focused information leaflet to share

Cycle 2 Plan: Increase awareness, Do: Promotional emails & posters in other medical offices, Study: Did not help a lot, Act: Inclusion in induction packages

Cycle 1 Plan: Increase awareness, Do: Promotional emails & posters in other medical offices, Study: Did not help a lot, Act: Focused teaching sessions to some teams (e.g. Neurosurgeons)

Aim:
Successful weaning of antiseizure medications after acute symptomatic seizures

Figure 7: Plan, Do, Study, Act (PDSA) cycles of change ideas listed within the driver diagram were tested.

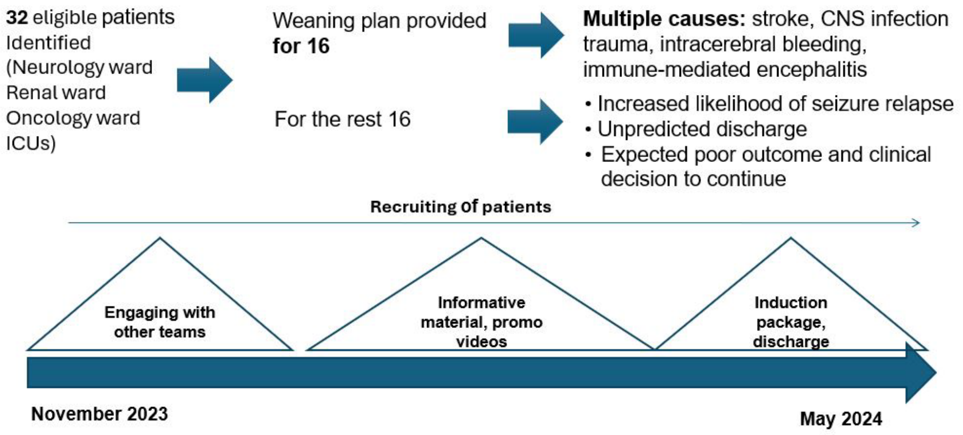
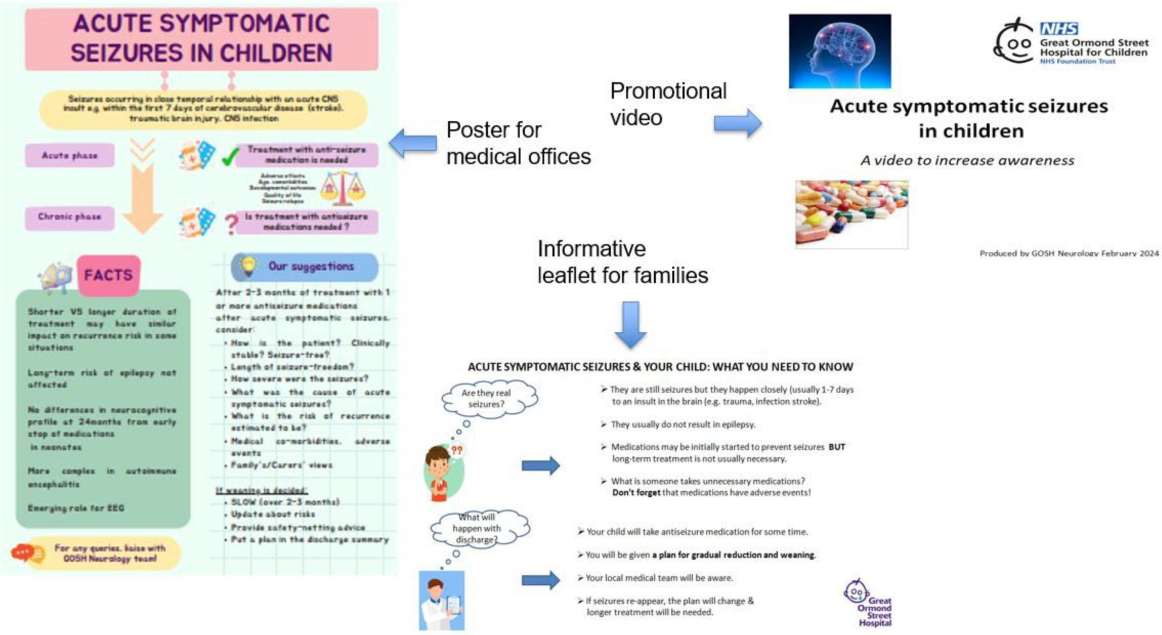


Figure 8: Data results on the number of children and young people who successfully had weaning plans included within discharge papers.

What was the outcome?

- Written weaning medication plans were successfully provided for 16 patients.
- Introduced a reminder smart phrase in discharge summaries to consider weaning ASM when appropriate.
- Launched a promotional educational video across the Trust to raise awareness about weaning ASM.
- Developed and distributed informative material for families and patients.
- Organised and delivered teaching sessions throughout the Trust.
- There are plans to submit a poster at future congresses.
- The team intend to write a paper on the quality improvement project itself, not a literature review.



ACUTE SYMPTOMATIC SEIZURES IN CHILDREN

Seizures occurring in close temporal relationship with an acute CNS insult e.g. within the first 7 days of cerebrovascular disease (stroke). traumatic brain injury. CNS infection

Acute phase

Treatment with anti-seizure medication is needed

Adverse effects
Age, comorbidities
Developmental outcomes
Quality of life
Seizure relapse

Chronic phase

Is treatment with antiseizure medications needed ?

FACTS

Shorter VS longer duration of treatment may have similar impact on recurrence risk in some situations

Long-term risk of epilepsy not affected

No differences in neurocognitive profile at 24months from early stop of medications in neonates

More complex in autoimmune encephalitis

Emerging role for EEG

Our suggestions

After 2-3 months of treatment with 1 or more antiseizure medications after acute symptomatic seizures. consider:

- How is the patient? Clinically stable? Seizure-free?
- Length of seizure-freedom?
- How severe were the seizures?
- What was the cause of acute symptomatic seizures?
- What is the risk of recurrence estimated to be?
- Medical co-morbidities. adverse events
- Family's/Carers' views

If weaning is decided:

- SLOW (over 2-3 months)
- Update about risks
- Provide safety-netting advice
- Put a plan in the discharge summary

For any queries. liaise with GOSH Neurology team!

ACUTE SYMPTOMATIC SEIZURES & YOUR CHILD: WHAT YOU NEED TO KNOW

- They are still seizures but they happen closely (usually 1-7 days to an insult in the brain (e.g. trauma, infection stroke).
- They usually do not result in epilepsy.
- Medications may be initially started to prevent seizures **BUT** long-term treatment is not usually necessary.
- What is someone takes unnecessary medications? **Don't forget** that medications have adverse events!

- Your child will take antiseizure medication for some time.
- You will be given **a plan for gradual reduction and weaning.**
- Your local medical team will be aware.
- If seizures re-appear, the plan will change & longer treatment will be needed.

Figure 9: Shows examples of project outcomes.

What were the learning points?

- The team have started to consider the practical benefits of their research projects.
- Projects build bonds among team members.
- The team have learned how to improve quality while working clinically.
- The team think in a sustainable way.
- Busy wards can generate valuable ideas!

I have to say that I enjoy these discussions we have because I have done quite a lot of research in the past, but I think this element of aiming for improvement, showing improvement and implementing improvement is something new for me. So, I'm happy that I'm trained in this area as well. So, I think it's a privilege.
Dr Maria Gogou, Senior Clinical Fellow Paediatric Neurology, GOSH

Next steps and sustainability

- The project will be included in the induction package for junior doctors.
- There are plans to conduct a systematic literature review to establish and write up a clinical guideline.
- The team will re-audit the practice in our trust after completion of this project.
- Their team aims to present our work in national and international meetings and publish a paper.

Want to know more?

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

Dr Noelle Enright, Consultant Paediatric Neurologist, Great Ormond Street Hospital, noelle.enright@gosh.nhs.uk

Reducing variation case studies 2023-2024

Improving SUDEP discussion with families

Organisation

Central North West London NHS Foundation Trust (Hillingdon Child Development Centre)

Project team

Dr Ahmed Ahmed, Consultant Paediatrician
Dr Chelvi Kukendra, Consultant Paediatrician
Vasileios Mouzias, Paediatric Epilepsy Nurse
Kate Barker, Team Lead (Operational Manager)

Project aim

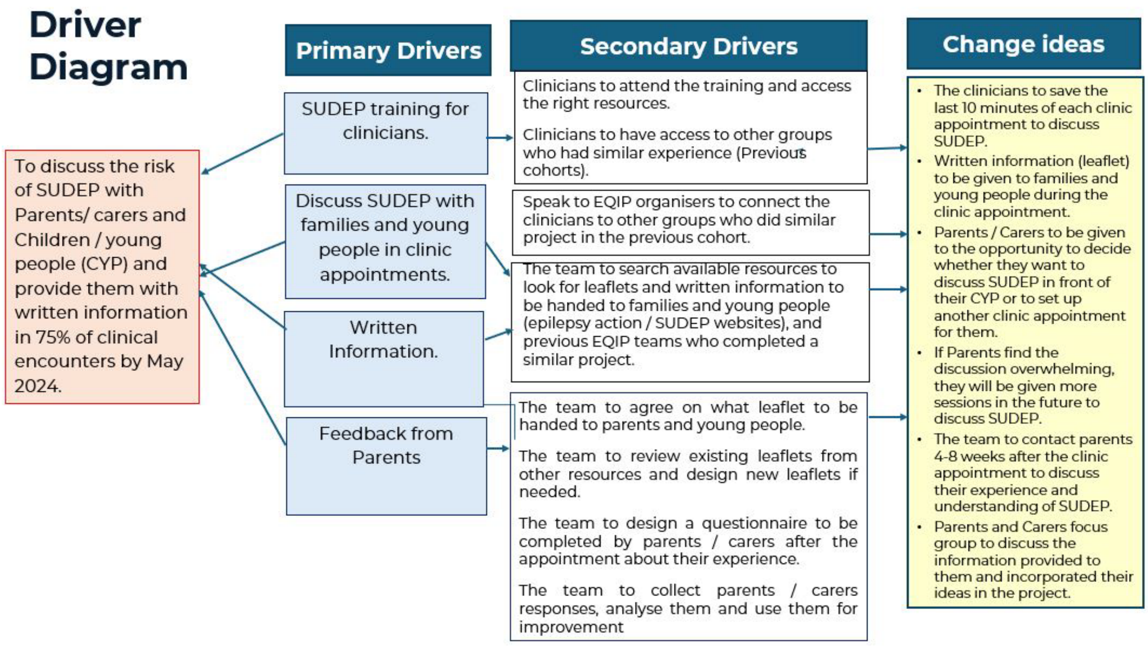
To discuss the risk of sudden death in epilepsy (SUDEP) with parents/carers and children/young people and provide them with written information in 75% of clinical encounters by May 2024.

Background/rationale

A total of four paediatricians provide care for children and young people with epilepsy in the community, aged 0-19 years with complex needs and most of them are attending special schools. All children and young people seen in clinic have associated special educational needs and disabilities. Clinics are also held on site in special schools, managing a caseload of 121 children, 98 of whom are over 13 years old and 21 over 16 years old. Our patients have access to acute care at Hillingdon Hospital for prolonged or uncontrolled seizures, and our medical team and epilepsy clinical nurse specialist review them in community based clinics. Support is received from the tertiary paediatric neurology teams at St Mary's and Great Ormond Street Hospital. The team work closely with the community nursing team to identify vulnerable children and families. Regular requests are made for a needs-based assessments for children with additional needs who require further funding for home-based care or hospice admission from NHS England and the Integrated Care Board (ICB).

What was the problem?

SUDEP is the leading cause of epilepsy-related mortality in children and young adults with epilepsy. Despite recommendations from consensus guidelines, many clinicians still do not follow practice in discussing with their patients and families about this risk. Risk factors for SUDEP include generalised tonic-clonic and nocturnal seizures, possible genetic predisposition, and non-adherence to medications. Developmental delay and intellectual disability are also potential risk factors for SUDEP in children and young people. Discussing SUDEP with parents and patients can be challenging, yet patients and their families want to be informed about this risk. Importantly, such discussions did not result in long-term anxiety or depression. The discussion of SUDEP with patients and families was inconsistent, as revealed by an internal audit. The audit reviewed the notes of 38 patients and found that SUDEP was mentioned in less than 10% of the cases.



Driver Diagram

To discuss the risk of SUDEP with Parents/ carers and Children / young people (CYP) and provide them with written information in 75% of clinical encounters by May 2024.

Primary Drivers

SUDEP training for clinicians.

Discuss SUDEP with families and young people in clinic appointments.

Written Information.

Feedback from Parents

Secondary Drivers

Clinicians to attend the training and access the right resources.

Clinicians to have access to other groups who had similar experience (Previous cohorts).

Speak to EQIP organisers to connect the clinicians to other groups who did similar project in the previous cohort.

The team to search available resources to look for leaflets and written information to be handed to families and young people (epilepsy action / SUDEP websites), and previous EQIP teams who completed a similar project.

The team to agree on what leaflet to be handed to parents and young people.

The team to review existing leaflets from other resources and design new leaflets if needed.

The team to design a questionnaire to be completed by parents / carers after the appointment about their experience.

The team to collect parents / carers responses, analyse them and use them for improvement

Change ideas

- The clinicians to save the last 10 minutes of each clinic appointment to discuss SUDEP.
- Written information (leaflet) to be given to families and young people during the clinic appointment.
- Parents / Carers to be given to the opportunity to decide whether they want to discuss SUDEP in front of their CYP or to set up another clinic appointment for them.
- If Parents find the discussion overwhelming, they will be given more sessions in the future to discuss SUDEP.
- The team to contact parents 4-8 weeks after the clinic appointment to discuss their experience and understanding of SUDEP.
- Parents and Carers focus group to discuss the information provided to them and incorporated their ideas in the project.

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.

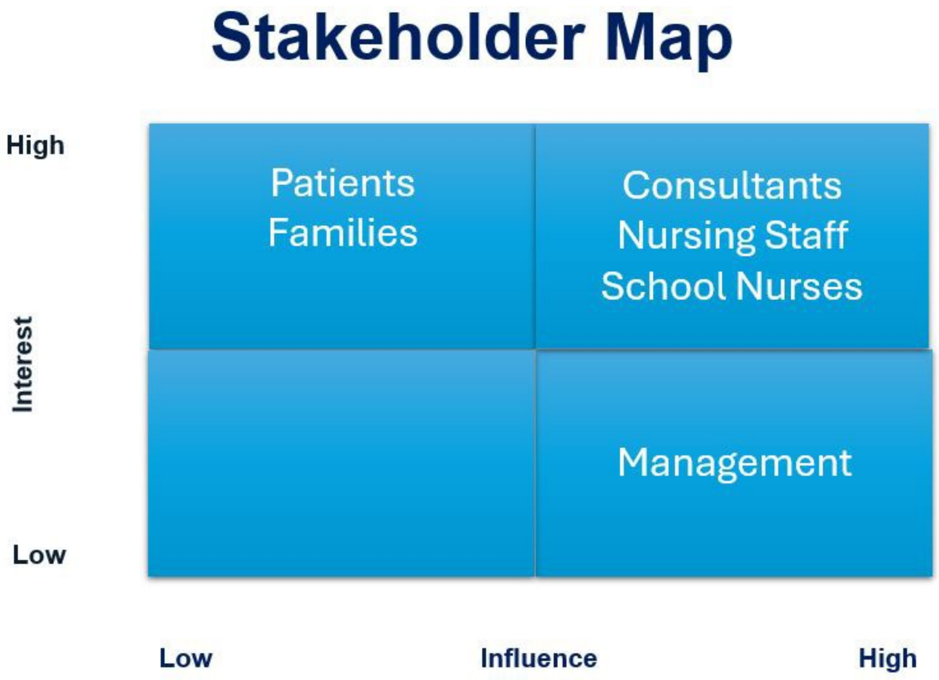


Figure 2: Shows the project stakeholder map, which provides analysis of stakeholders that are of influence/interest to the project. Stakeholders are plotted on the grid to guide the actions you should take for involving and communicating with them.

What was the solution?

To improve discussions of SUDEP with patients and families, the team explored the following:

- Collected feedback from families on the usefulness of SUDEP discussions held during clinic appointments and evaluated whether to include children in SUDEP discussions. Given that many patients have severe disabilities or learning difficulties, these children are typically not included in discussions. However, the team recognised the need to co-produce solutions with parents/carers on how to involve patients who might not understand the discussions.
- To address identified challenges, the team informed families about the SUDEP discussion prior to their clinic appointment. Families were contacted via a phone call and mentioned within appointment letters. This advance notice helped families prepare and provide consent regarding the presence of their child during the discussion.
- Feedback was collected via telephone conversations two weeks after the discussion, with more information or appointments provided if needed, and the team acted upon parents/carers' suggestions.
- The team began to address areas of health inequalities; they researched and sourced translated resources in a number of languages to test the usefulness with families according to their language spoken and arranged for translators to attend clinics to reduce language barriers.

- Initial consultations did not result in high levels of anxiety among parents/carers. In one case, an 18-year-old participated due to a parent's learning difficulties. The team planned to form a focus group of parents/carers to be involved in identifying and addressing gaps in the SUDEP discussion process. Six parents agreed to join this group.
- Responses from 15 parents/carers were analysed, revealing mixed feedback. While most parents and carers found the information useful and easy to understand. Some reported feeling anxious or found the discussion unnecessary. The team will continue to collect feedback to address any issues.
- Engagement with the Oxford University EQIP team resulted in discussions to develop a structured, individualised plan for SUDEP discussions, detailing what will be covered and informing families about risk areas and considering the needs and challenges of children with intellectual disabilities and autism.

What were the challenges?

- With a small caseload of 120-130 patients and their families, the team runs only two epilepsy clinics a month (one every fortnight), seeing a total of 10 patients and their families each month, once a year. This limited number of clinics restricts opportunities for regular SUDEP discussions.
- Follow-up calls revealed that many parents and carers did not read or engage with the written information provided during the clinic, potentially due to various reasons. A significant proportion of families (63%) were not accessing the information provided to them, which affected efforts to improve understanding and management of SUDEP risks.
- This indicated a need to explore other strategies to ensure that families understand and utilise the information.
- The initial difficulties included a lack of interest from families in participating in a focus group and challenges in engaging and co-designing processes with children who have intellectual disabilities and autism.
- Only 5% of patients attend public schools, 30% are verbal, and 70% are non-verbal, with the majority having autism. This highlighted the need for a careful approach in communication, requiring the team to engage with parents and carers first to avoid causing any stress or problems.
- There is still a lack of research on supporting families with children who have intellectual disabilities and autism, although there has been some increase in research over the last decade. This gap makes it challenging to develop evidence-based strategies for SUDEP discussions.
- The diverse population presents language issues, complicating effective communication. Some families felt uncomfortable discussing SUDEP in front of their children. These families require further follow-up phone consultations by the epilepsy nurse specialist to address their concerns.

What were the results?

- Total patients seen: 55.
- Patients excluded: 19 (mostly because the appointments happened over the phone).
- Patients who refused to have the conversation: 3.
- Total patients who participated in the project: 33 (91.6%)

Question: How did you feel about it?

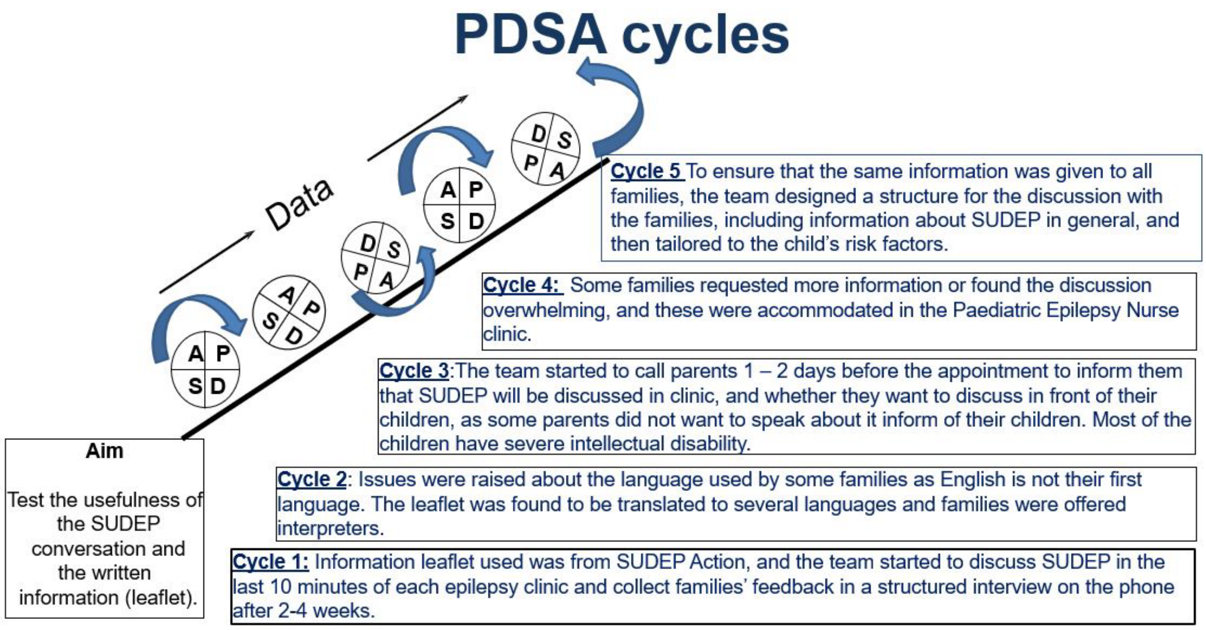
- Worried/stressed – came up in 9 interviews.
- Happy/ The discussion of SUDEP (Sudden Unexpected Death in Epilepsy) with patients and families was inconsistent, as revealed by an internal audit. The audit reviewed the notes of 38 patients and found that SUDEP was mentioned in less than 10% of the cases. Comfortable/content – came up in 17 interviews.
- Risk/aware – came up 12 times.
- More information needed – came up 3 times.
- Not relevant – came up 4 times.

Question: Was there anything not covered?

- They don't want any further conversation – came up 4 times.
- They would like more details – came up 2 times.

Other results

- It is possible to discuss SUDEP during routine epilepsy clinics.
- Although interpreters were provided, families could not access SUDEP Action resources, which were mainly available in English. This highlighted the need for translated resources.
- Some parents require further meetings for additional information, prefer not to discuss SUDEP in front of their children, or found the initial discussion overwhelming.
- Feedback from families was essential for improving the service. It helps the team understand the needs and preferences of parents and carers.
- Contacting parents and carers before the clinic appointment to confirm whether their children should be included in the discussion has proved successful. No issues were raised by parents about this pre-clinic contact.
- Two families requested to discuss SUDEP with the staff alone, without involving their children, demonstrating the importance of accommodating individual family preferences.



Cycle 5 To ensure that the same information was given to all families, the team designed a structure for the discussion with the families, including information about SUDEP in general, and then tailored to the child's risk factors.

Cycle 4: Some families requested more information or found the discussion overwhelming, and these were accommodated in the Paediatric Epilepsy Nurse clinic.

Cycle 3:The team started to call parents 1 – 2 days before the appointment to inform them that SUDEP will be discussed in clinic, and whether they want to discuss in front of their children, as some parents did not want to speak about it inform of their children. Most of the children have severe intellectual disability.

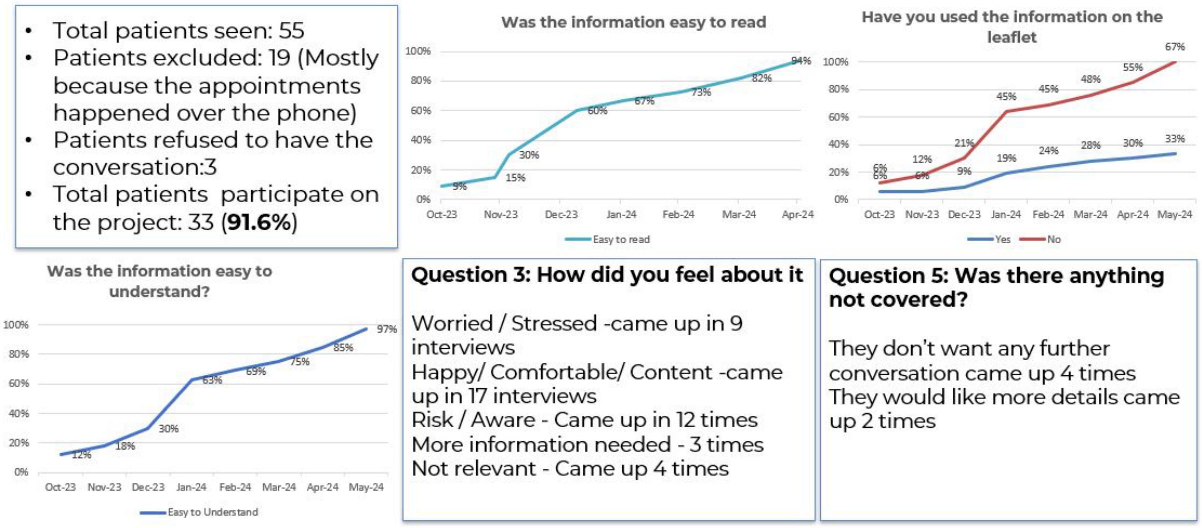
Cycle 2: Issues were raised about the language used by some families as English is not their first language. The leaflet was found to be translated to several languages and families were offered interpreters.

Cycle 1: Information leaflet used was from SUDEP Action, and the team started to discuss SUDEP in the last 10 minutes of each epilepsy clinic and collect families' feedback in a structured interview on the phone after 2-4 weeks.

Aim

Test the usefulness of the SUDEP conversation and the written information (leaflet).

Figure 3: Shows the Plan, Do, Study, Act (PDSA) cycles of change ideas to engage with young people and families within the driver diagram being tested.



- Total patients seen: 55
- Patients excluded: 19 (Mostly because the appointments happened over the phone)
- Patients refused to have the conversation:3
- Total patients participate on the project: 33 (**91.6%**)

Question 3: How did you feel about it

Worried / Stressed -came up in 9 interviews
Happy/ Comfortable/ Content -came up in 17 interviews
Risk / Aware - Came up in 12 times
More information needed - 3 times
Not relevant - Came up 4 times

Question 5: Was there anything not covered?

They don't want any further conversation came up 4 times
They would like more details came up 2 times

Figure 4: Shows examples of the data captured from patients and families the team engaged with and feedback received.

What was the outcome?

- The majority of families agreed to discuss SUDEP during their consultations.
- SUDEP was successfully discussed at every consultation, and feedback was collected from families.
- There has been a noticeable improvement in the frequency of SUDEP discussions during clinical encounters.

- The majority of families found the leaflets easy to read and understand.
- The entire team, including administrative staff, doctors, nurses, and managers, became involved in the project.
- The changes implemented are sustainable and have been integrated into day-to-day practice.
- Within 12 months, the team aims to complete SUDEP conversations with the vast majority of their clients.
- Interviews indicated that people are becoming more aware of the risks associated with SUDEP and revealed that some families would benefit from psychological support to cope with the stress related to SUDEP discussions.
- Efforts were made to improve the effectiveness of video and phone consultations.
- The project expanded to include counselling for parents, carers, children and young people on broader epilepsy-related issues beyond SUDEP.

What were the learning points?

- Even small changes require time to implement effectively.
- Gained knowledge of quality improvement principles, which has been instrumental in driving the project’s success.
- The project will be sustained within our day-to-day practice, ensuring ongoing improvements in SUDEP discussions.
- The project will be extended to include other aspects of epilepsy care, broadening its impact and enhancing overall patient and family support.
- The team planned to introduce additional clinics to discuss various topics, such as safety advice, alcohol, smoking, and medication, alongside SUDEP.

Next steps and sustainability

- Presenting the project and its outcomes in governance meetings to ensure continued oversight and support.
- Implementing a SUDEP checklist for each consultation to standardise discussions and ensure all relevant points are covered.
- Enhancing the use of electronic communication to update clinical encounters, improving efficiency and record-keeping.
- Applying the principles of this project to address various other aspects of epilepsy care, thereby broadening its impact.
- Organising social events to train families and provide them with opportunities to give feedback on our services, with the first event scheduled for July 2024.

Want to know more?

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

Dr Ahmed Ahmed, Consultant Paediatrician and Clinical Lead, Central and North West London NHS Trust (Hillingdon), Ahmed.Ahmed29@nhs.net

Reducing variation case studies 2023-2024

Developing a children and young people engagement strategy across the ICB/ICS

Organisation

York and Scarborough and Hull Integrated Care Board (ICB)

Project team

Dr R Gulati, Consultant Paediatrician, ICS Clinic Lead
Katie Ward, ICB Children and Young People's Long-Term Conditions Lead

Project aim

To develop a strategic framework for children and young people engagement across the Integrated Care Board (ICB) by May 2024.

Background/rationale

The Integrated Care System (ICS) encompasses York and Scarborough, Hull, Harrogate, and North Lincolnshire and Goole. Approximately 1,300 children and young people with epilepsy are under the care of paediatric epilepsy services within the ICS. Humber and North Yorkshire cover a vast area, with several regions facing deprivation, including limited access to psychological support and epilepsy specialist nurses.

In 2019, the York and Scarborough paediatric epilepsy team participated in an RCPCH EQIP pilot, collaborating to improve emergency plans and develop their Trust's version of an Epilepsy Passport. The ICB epilepsy network is currently investigating methods to include vulnerable and Core20PLUS5 children and young people in initiatives to address health inequalities.

What was the problem?

The National Epilepsy Bundle of Care outlines standards of care, including addressing care variation and transitioning to adult services. However, a key aspect of implementing these standards is co-production with children, young people and their families. National youth forums represent children and young people with epilepsy but do not always reflect the unique experiences of those living in Humber and North Yorkshire.

Currently, the ICS lacks a comprehensive engagement plan that includes the voices of children and young people in co-designing processes to inform service improvement. To address this, ICB leaders plan to develop a written strategy and engagement model to enable children and young people to contribute to service design, evaluation, and change. This model will aim to standardise engagement practices across service-level projects, forming a written engagement strategy for epilepsy.

What was the solution?

The initial aim of the project was to develop a clinical initiative across the ICB, focusing on creating a youth-informed pack for 12 to 16-year-olds to provide epilepsy signposting. However, as the project progressed, it became clear that implementing this across the entire ICB was challenging. Consequently, the plan evolved, as reflected in the Plan, Do, Study, Act (PDSA) cycles, to develop a strategic framework for children and young people engagement across the ICB by May 2024.

The project focused on improving patient engagement by prioritising the voices and involvement of children and young people with epilepsy. Recognising the importance of their engagement, the project aimed to support their input within the epilepsy service, involving various stakeholders in the care process. The primary drivers included co-production and clinical networks, aligned with national deliverables. The project identified existing engagement with children and young people across services and sought to utilise and enhance this. Efforts included engaging networks to ensure an ICB-level response, considering the national care bundle in relation to children and young people.

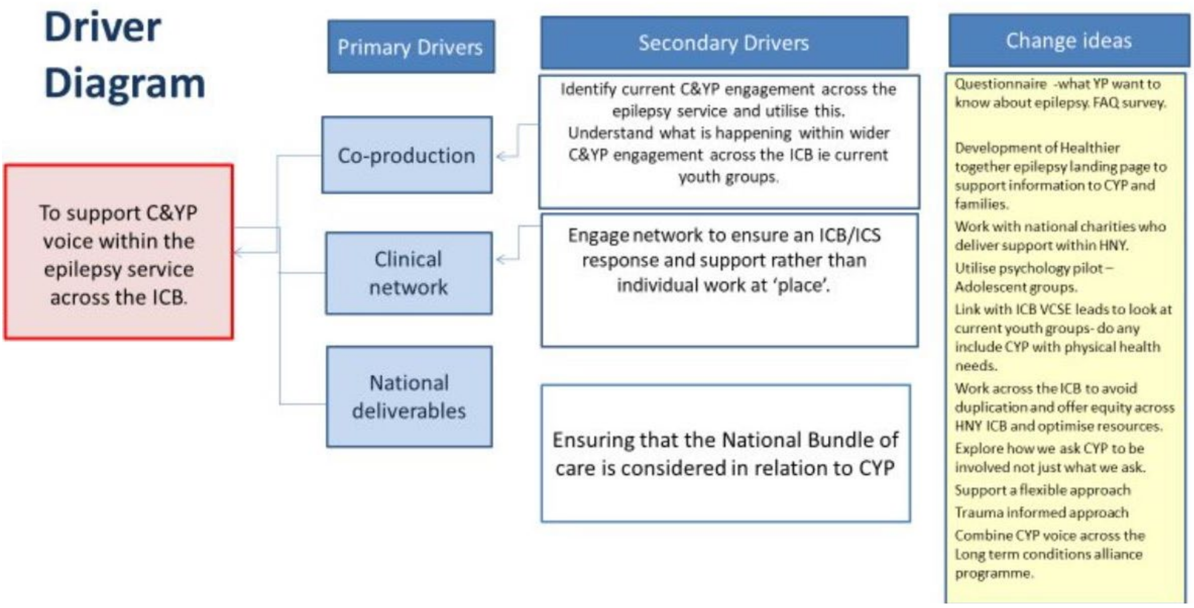
The PDSA cycles evolved over time. Initially, the project directly asked children and young people about their concerns and developed a frequently asked questions (FAQ) survey, although initial responses were limited. The survey was redesigned to encourage more responses. The project also investigated the work being done in different areas to engage children and young people and gathered data from an NHS England-funded psychology pilot.

To centralise information for children and young people, a landing page on the Healthier Together website was developed. This became a strategic development for children and young people engagement across Humber and North Yorkshire. The project engaged with patients and families, using survey feedback to understand children and young people concerns about epilepsy and leveraging information from the ongoing NHS England psychology pilot, which included youth and parent groups.

Activities and tests explored:

- Developing a landing page for epilepsy on their Healthy Together website.
- Researching a wellbeing pack for young people with epilepsy.
- Collecting feedback from patients through a pilot project.
- Starting to develop FAQ for the website.

- Engaging with young people and parents to gather their input and ideas.
- Exploring partnerships with organisations like Epilepsy Action for further engagement opportunities.



Identify current C&YP engagement across the epilepsy service and utilise this. Understand what is happening within wider C&YP engagement across the ICB ie current youth groups.

Engage network to ensure an ICB/ICS response and support rather than individual work at 'place'.

Ensuring that the National Bundle of care is considered in relation to CYP

Questionnaire -what YP want to know about epilepsy. FAQ survey.

Development of Healthier together epilepsy landing page to support information to CYP and families.

Work with national charities who deliver support within HNY.

Utilise psychology pilot – Adolescent groups.

Link with ICB VCSE leads to look at current youth groups- do any include CYP with physical health needs.

Work across the ICB to avoid duplication and offer equity across HNY ICB and optimise resources.

Explore how we ask CYP to be involved not just what we ask.

Support a flexible approach

Trauma informed approach

Combine CYP voice across the Long term conditions alliance programme.

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.

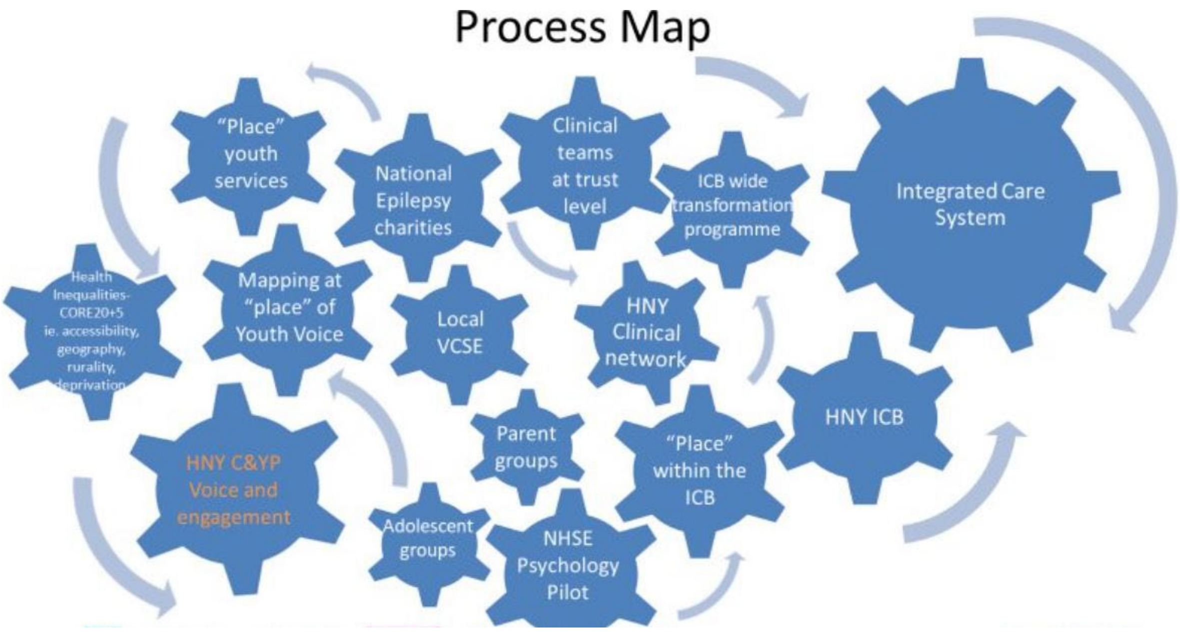


Figure 2: Shows the process mapping of pathways involved in implementing a patient engagement plan.

What were the challenges?

The project faced several challenges, primarily the difficulty of working across the ICB. The data received consisted of feedback captured from children and young people, requiring further work to understand the improvement work taking place within services and identify areas of excellence to engage across the ICB. Although the project had not yet directly changed clinical care as originally intended, it has shifted focus towards prioritising the voices of children and young people to co-design services as part of ICB engagement development. There is now consideration of how to incorporate their input, not only for epilepsy but also for long-term conditions like asthma and diabetes. The aim is to progress these efforts over time.

The ICB clinical lead faced challenges in engaging service teams within the ICB to participate in the project, resulting in limited success.

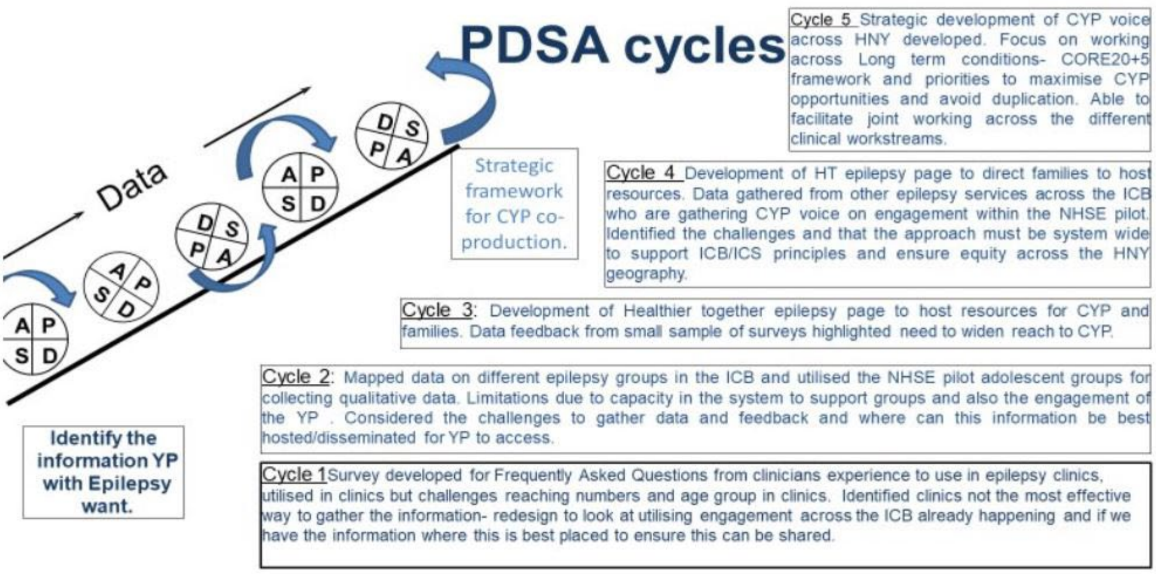
Capacity issues, lack of full service team engagement, and internal struggles within paediatric epilepsy services limited progress at times and the project became slightly abstract in achieving tangible results. Despite this, there was still motivation to advance the project, though there was uncertainty about how to effectively implement it within the ICB.

What were the results?

The project results revealed several insights into the concerns and preferences of children and young people with epilepsy. They are worried about driving, employment, mood changes, relationships, and sports. In response, adolescent groups were developed and are ongoing within the region. However, many adolescents expressed discomfort with group settings, citing nervousness, inconvenient timing, and a preference for online formats.

The testing highlighted the challenges of working across an ICB and the difficulty of getting the approach right. The project questioned whether it was engaging children and young people correctly and providing the appropriate opportunities and environments. It also considered the needs of those with comorbidities, such as learning disabilities or autism, and those facing access issues due to deprivation.

Overall, the findings indicated a need to strive for changes at a system level, rather than just an operational level.



Cycle 5 Strategic development of CYP voice across HNY developed. Focus on working across Long term conditions- CORE20+5 framework and priorities to maximise CYP opportunities and avoid duplication. Able to facilitate joint working across the different clinical workstreams.

Cycle 4 Development of HT epilepsy page to direct families to host resources. Data gathered from other epilepsy services across the ICB who are gathering CYP voice on engagement within the NHSE pilot. Identified the challenges and that the approach must be system wide to support ICB/ICS principles and ensure equity across the HNY geography.

Cycle 3: Development of Healthier together epilepsy page to host resources for CYP and families. Data feedback from small sample of surveys highlighted need to widen reach to CYP.

Cycle 2: Mapped data on different epilepsy groups in the ICB and utilised the NHSE pilot adolescent groups for collecting qualitative data. Limitations due to capacity in the system to support groups and also the engagement of the YP . Considered the challenges to gather data and feedback and where can this information be best hosted/disseminated for YP to access.

Cycle 1 Survey developed for Frequently Asked Questions from clinicians experience to use in epilepsy clinics, utilised in clinics but challenges reaching numbers and age group in clinics. Identified clinics not the most effective way to gather the information- redesign to look at utilising engagement across the ICB already happening and if we have the information where this is best placed to ensure this can be shared.

Figure 3: Shows the PDSA cycles of change ideas to engage with young people and families within the driver diagram being tested.

Figure 4: Shows examples of children and young people's feedback captured from the FAQ questionnaire.

What was the outcome?

The project aimed to broaden current practices and achieved several key outcomes:

- The collection of patient and family feedback was collected to further meet the project's needs and exploration goals.

- As part of a psychology pilot, children and young people's groups have been initiated, with parent groups also in the process of being implemented.
- Resources and support links collated across the Trust, including FAQ topics highlighted from feedback has been used as content on epilepsy on the Healthier Together Trust website landing page.

What were the learning points?

The project has provided several important lessons. From a wider ICB perspective, there is a desire to develop a support pathway for long-term conditions by integrating various work streams and involving children and young people groups across the ICB. These groups can provide insights into their struggles and challenges, working in co-production with healthcare professionals to improve services.

The ICB Children and Young People's Long-Term Conditions Lead aims to support services by engaging the children and young people's steering groups within the Trust to determine if they have access to engagement groups and leveraging the young people networks to facilitate co-production.

Connecting systems across the ICB through clinical networks has been instrumental to the project. The various work streams have provided valuable lessons and reflections on delivering national standards and engaging with children and young people. The project has highlighted the need to think strategically, rather than focusing solely on local implementation.

Next steps and sustainability

Sharing the work across the ICB at clinical networks. We plan to involve epilepsy charities, youth charities, and the Association of Young People's Health, building on previous co-production efforts in mental health projects. A proposal will be made to develop a platform for young people's voices, potentially forming a forum or board of young people.

In the future, they envision conducting a next quality improvement project with children and young people with epilepsy as leaders, collaborating with the multidisciplinary team within the wider system.

Want to know more?

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

Dr Ruchi Gulati, Consultant Paediatrician, ICS clinic Lead, York and Scarborough and Hull Teaching Hospital, ruchi.gulati@nhs.net

RCPCH EQIP

Epilepsy quality improvement programme

Summary report 2023-2024:
2023/2024 improvement case studies
by paediatric epilepsy service teams

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