

Transition support case studies 2023-2024

Establishing a nurse-led transition clinic

Organisation

West Hertfordshire University NHS Trust

Project team

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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.

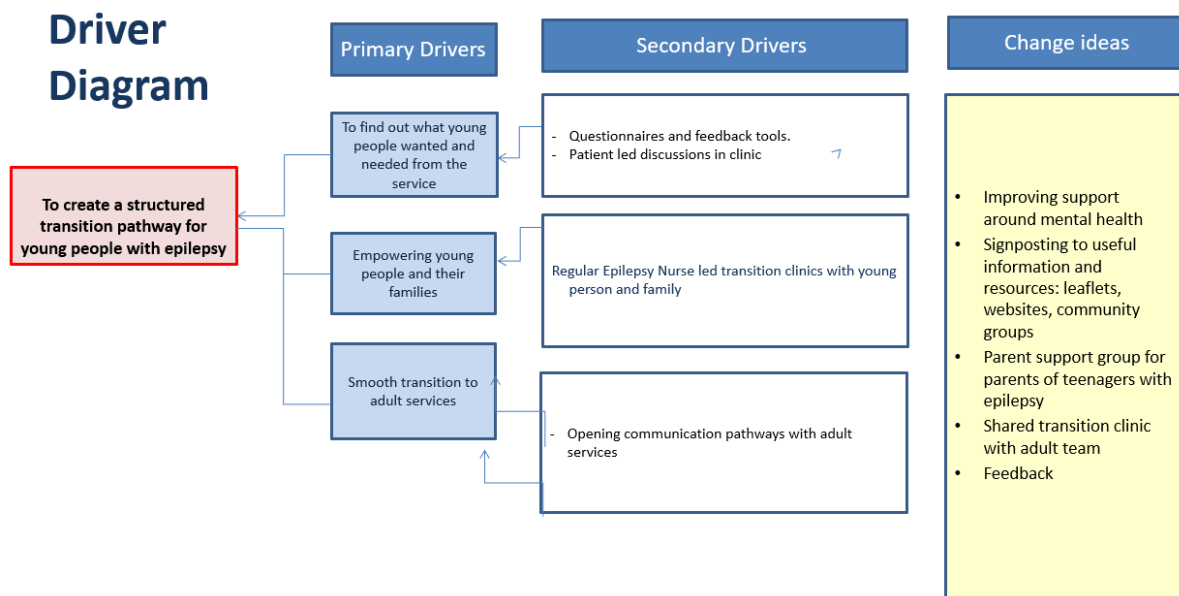


Figure 1: Team driver diagram that provides a clear statement of their project aim, with primary and secondary drivers that visually display the team’s theory of what “drives”, or contributes to, the achievement of a project aim.

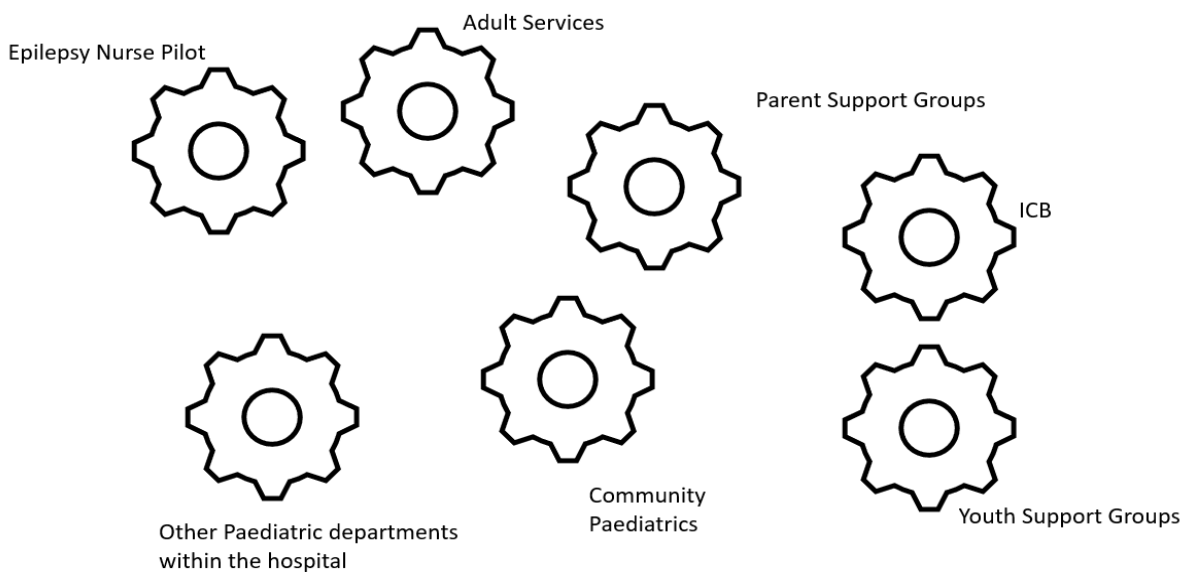


Figure 2: Stakeholder map of the groups that the team engaged to influence or inform with different levels of interest in the service improvements.

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.

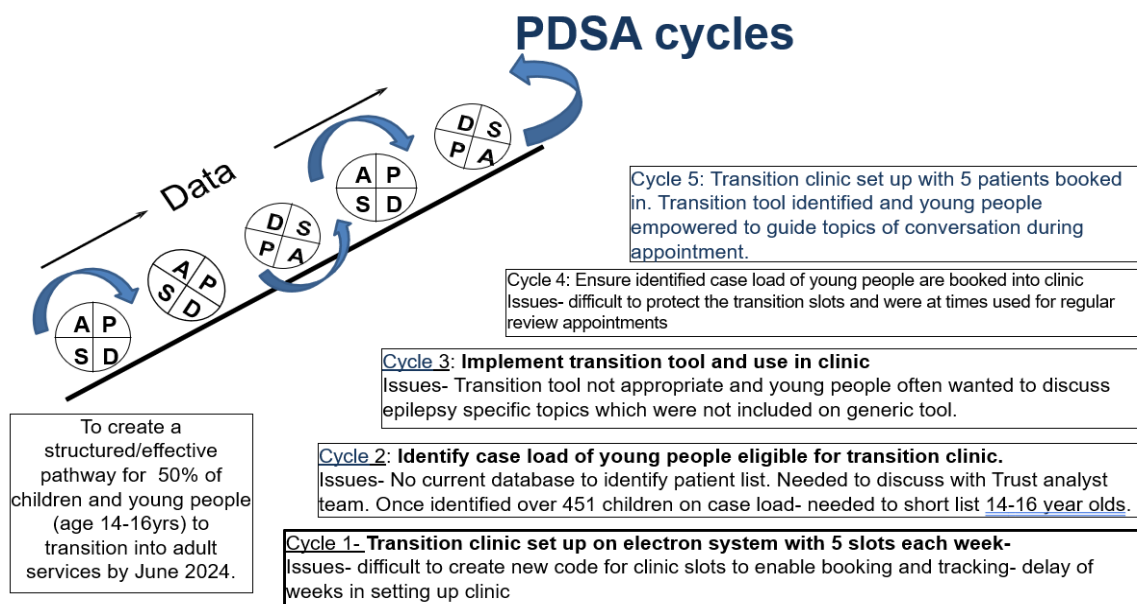


Figure 3: Shows Plan, Do, Study, Act (PDSA) cycles of change ideas listed within the driver diagram being tested to implement a structured transition pathway and functioning clinic.

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.

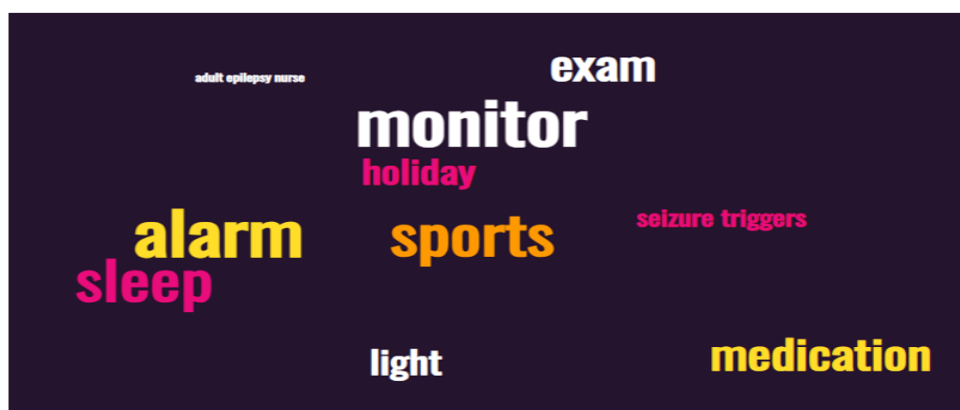


Figure 4: Children and young people's feedback captured on the topics they would like to discuss during the transition clinic.

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:

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