

# 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

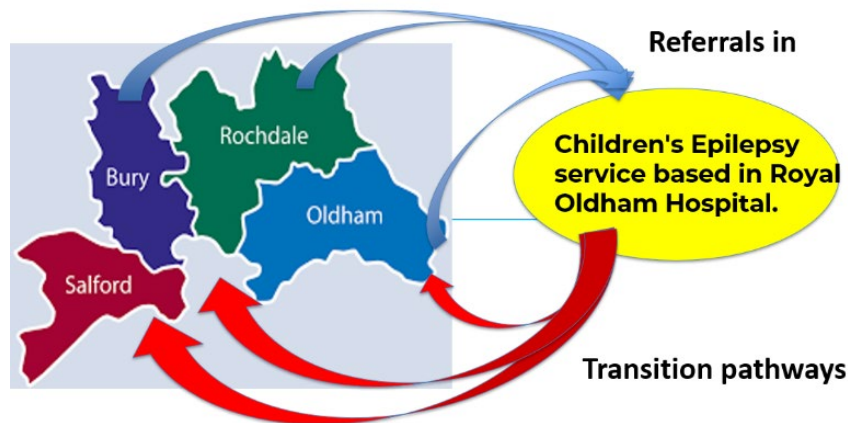
The acute secondary care paediatric service, alongside the paediatric epilepsy service and the Integrated children's community nursing service, provides comprehensive care for children and young people with epilepsy. The team operates across two localities under two Integrated Care Boards (ICBs) and 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.

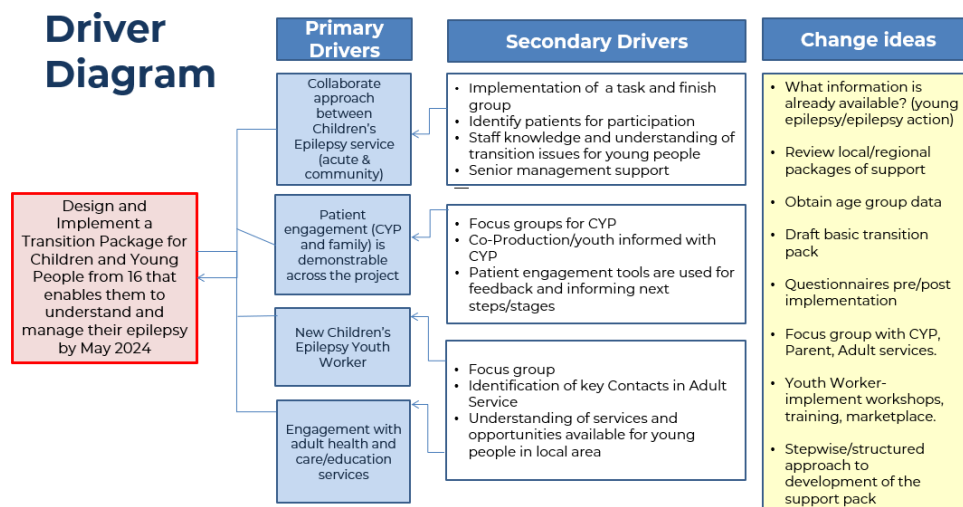
**What was the problem?**

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.

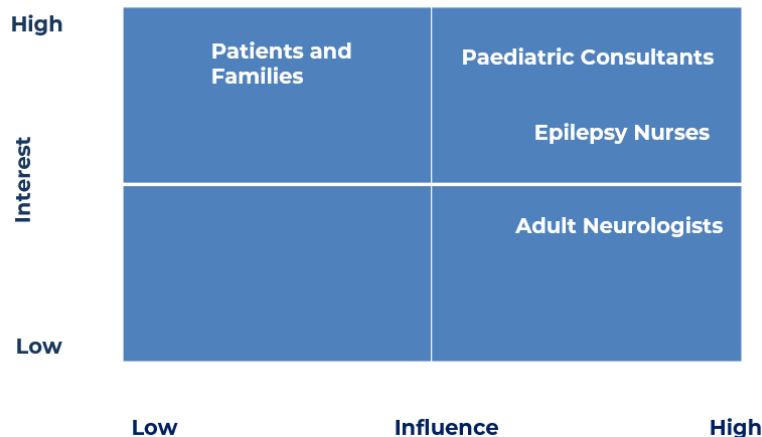


**Figure 1: Example of transition pathways from hospitals within their region.**



**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.**

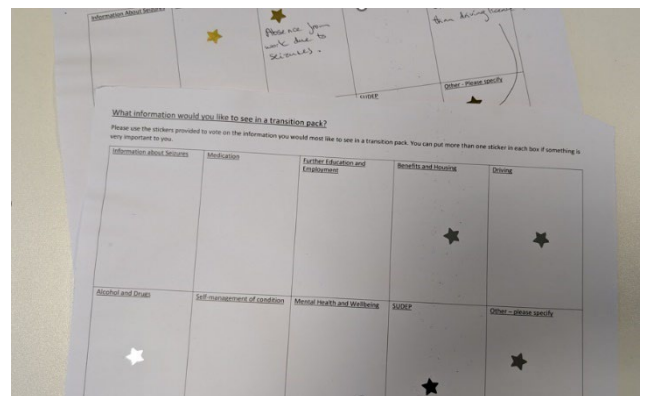
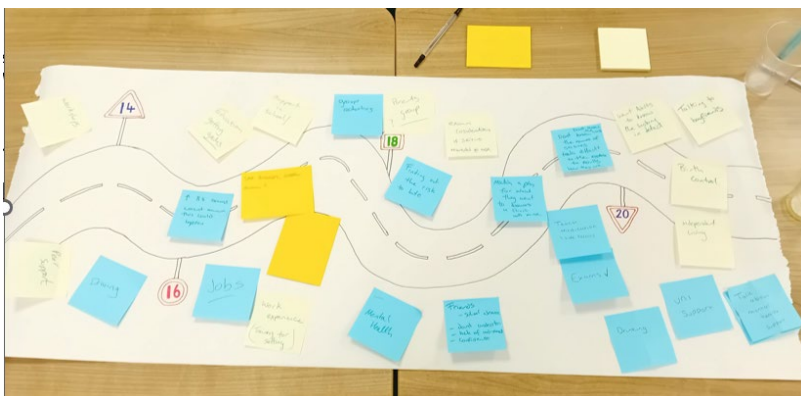
## Stakeholder Map



**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:

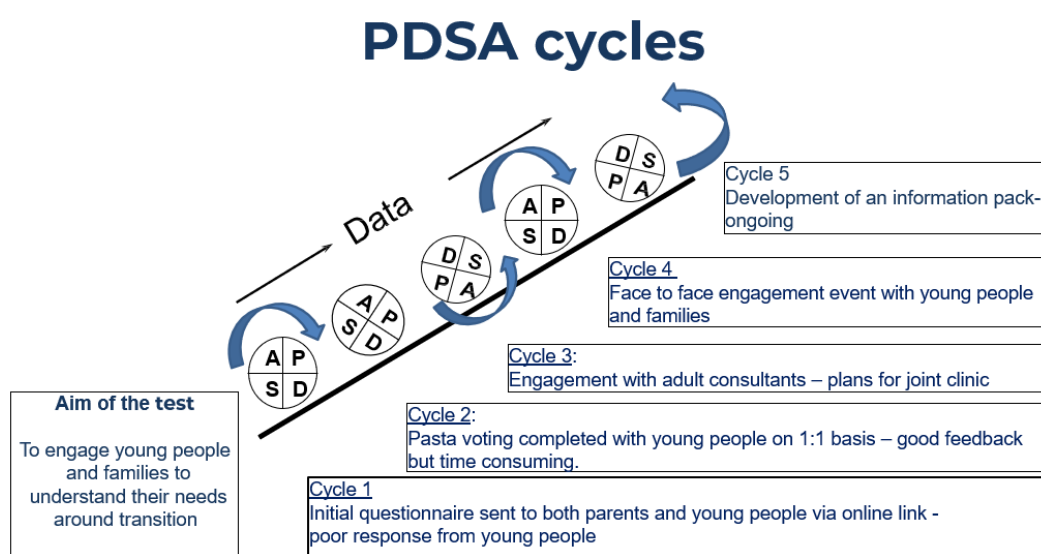
- How to talk to the adult team.
- Not understanding the terminology.
- Friends and relationships.
- Exams.
- Driving.
- Peer support.

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.

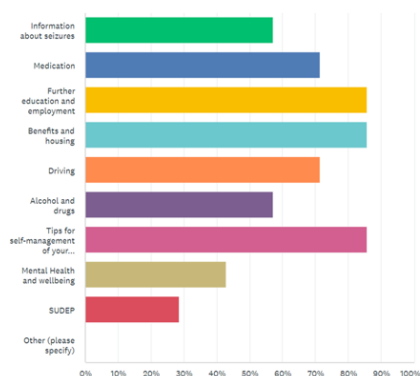
Feedback received in summary:

- 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.

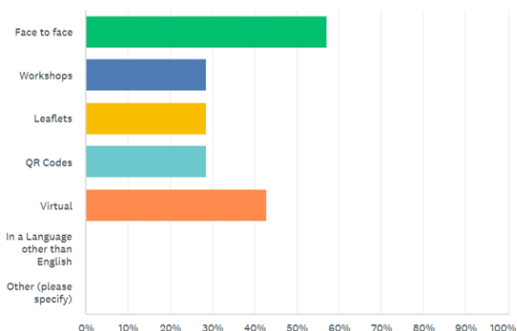


**Figure 6: Plan, Do, Study, Act (PDSA) cycles of change ideas listed within the driver diagram being tested.**

What information would you like to see in a transition pack?



How would you prefer to have information delivered?



**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.

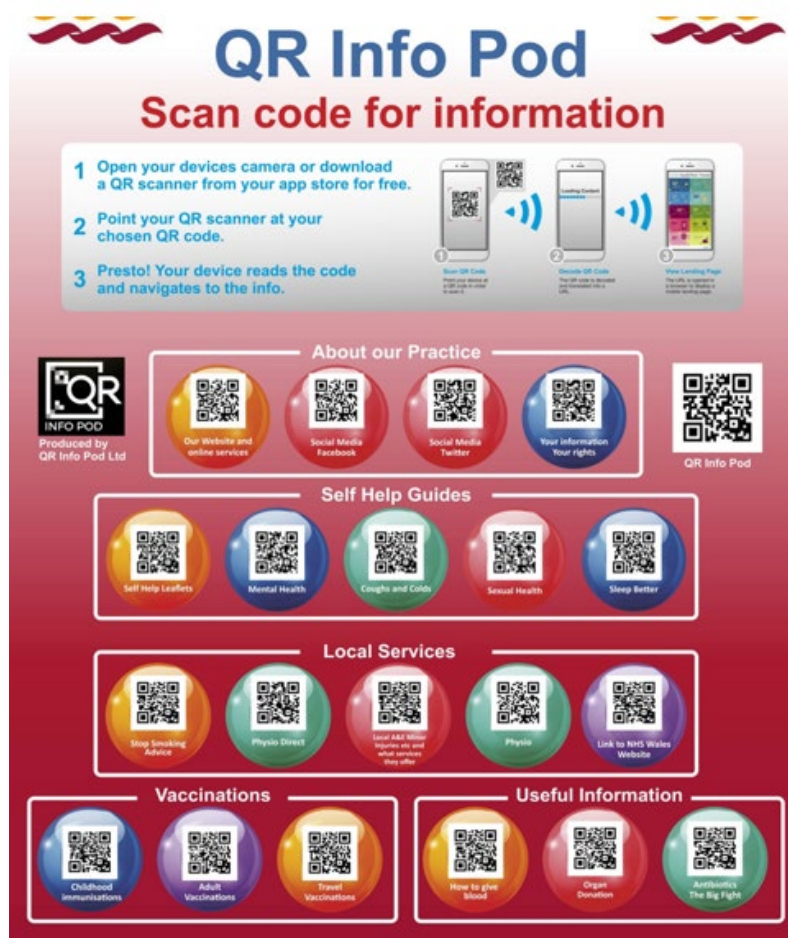


Figure 9: Proposed layout of electronic epilepsy transition pack.

### 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](mailto:srinagesh.panasa@nca.nhs.uk)**