

RCPCH Epilepsy Quality Improvement Programme

August 2021 – April 2022

Transition pathways

East Lancashire NHS Foundation Trust

RCPCH Epilepsy Quality Improvement Programme project team:

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

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Project aim

To offer transition as a staged approach equitably from 19% to 100% of our patients aged 16 years and over by March 2022.

Background

- East Lancashire Hospital Trust (ELHT) is passionate about providing a great service for our children, young people, and their families and carers. The team has recognised that transition is an area they would also like to improve by implementing a clinic with the children's epilepsy nurses and the adult epilepsy nurses, but there is no preparation for the young people ahead of this clinic. This is an area where it is vitally important to equip young people with the skills they require to manage their epilepsy well into adulthood. The children and young people that are cared for by ELHT were recognised by the Epilepsy12 audit as being among the most deprived in the country; therefore, in response, the service strives to ensure they support patients in a way that is accessible and equitable to all children and young people that attend clinic.

Area of focus

- Develop a clinic with the children's epilepsy nurses and the adult epilepsy nurses through effective patient engagement that will be used to develop information packs to support newly diagnosed patients to help educate and better prepare children, young people, and their families and carers transferring to adult services.

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Changes

- The team created a nursing pro forma because they do not have access to a secretary or run nurse-led clinics. It was agreed to run clinics for patients aged 16 years old and work backwards instead of patients aged 12 years in the first instance due to team capacity.
- Developed a five-question survey to capture feedback from young people and/or parents on their support needs.
- Reviewed the current patient transition journey and feedback from the questionnaire.
- Created a transition pathway, proforma, and leaflet, and reviewed the leaflet with young people and families.
- Tested with young people in two clinic sessions.
- The full transition pathway will be tested for one month.
- The service transition clinic had a high DNA rate, so in co-design with CYP, the team created a leaflet to help combat high DNA rates that explains more about the importance of the clinic.
- The leaflet was distributed with clinic letters to those patients who engaged and provided their feedback to obtain their opinions on what they thought and ideas on how the content could be improved before the final version was agreed.

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Results

- A nurse-led questionnaire included involvement from a junior doctor who contacted families to capture views via a questionnaire.
- February 2021: Questionnaires were asked at clinics and over the phone. **27** families engaged in the questionnaire.
- Questionnaire results mainly fell within the following topics:
 - Young people would like individual sessions.
 - Young people would like afternoon or evening clinics.
 - It was a split between virtual and face-to-face clinics.
 - Leaflets were preferred; a leaflet has been created.
- The nursing proforma for clinics was produced to contain the information young people want to know during clinic appointments.
- Analysed suggestions for clinic times, how to deliver clinics, and what to discuss.
- The nursing proforma for clinics was created from feedback.
- Information was gathered regarding topics requested to be discussed at clinics.

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Challenges

- Finding time as a team to work on the project.
- Time restraints
- Adult services are located within a different Trust, meaning it is difficult to share patient information easily.
- Motivation.
- Ensuring the improvements are sustainable.

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Questionnaire

We are looking at setting up a clinic aimed at young people, please answer these few questions about what you would like:

WHEN?

The clinic will be on a weekday, would you prefer the clinic to be in the:

Morning 9am- 12pm

Afternoon 1pm- 4pm

Evening 3pm- 6pm

HOW?

How would you like to be seen at clinic?

FACE TO FACE

VIDEO CALL

PHONECALL

WHO?

Would you prefer a group session with other young people with epilepsy or would you prefer to have a clinic session alone?

GROUP INDIVIDUAL OR BOTH

WHAT?

What information would you like to get whilst at clinic? Please only choose 4 options:

SAFETY

INDEPENDENCE

EDUCATION/EMPLOYMENT

HEALTH PROFESSIONALS

DRUGS & ALCOHOL

CONTRACEPTION/SEX

DRIVING

SUPPORT

OTHER

HOW?

How would you like information to be delivered/given?

SUPPORT GROUPS

VIDEOS

APPS

WEBSITES

LEAFLETS

SPOKEN

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Questionnaire results



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Questionnaire results



Transition as a staged process will be helpful

I was worried about transition, knowing there will be support makes me feel better

I am looking forward to learning how to manage my own epilepsy

The pre clinic leaflet is useful

Audit results cohort 3/4 - Professional input - East Lancashire NHS Foundation Trust

NICE guidelines (Quality statement5) state that children and young people with epilepsy are seen by an epilepsy specialist nurse who they can contact between scheduled reviews.

In 2021, 67% of CYP had input from an Epilepsy Specialist Nurse and 60% of CYP had input from an Epilepsy Specialist Nurse in 2022.

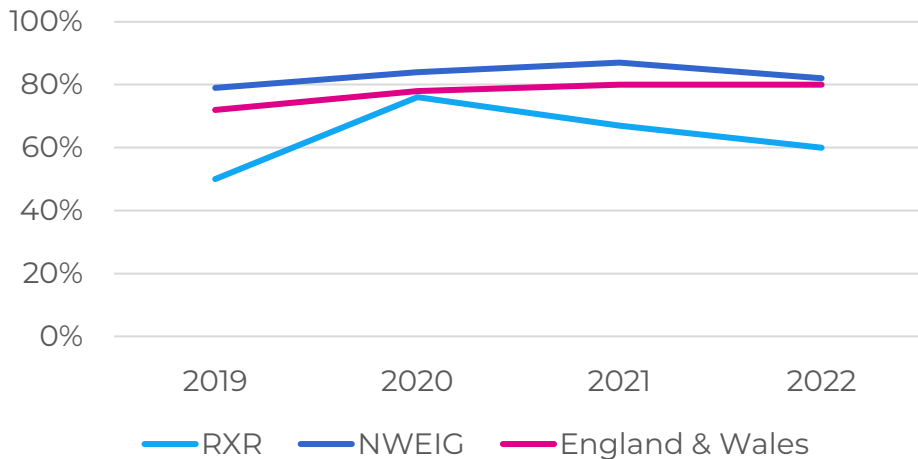
Percentage of CYP with input from:	2019	2020	2021	2022	2021 – NWEIG	2021 – England & Wales	2022 – NWEIG	2022 – England & Wales
Epilepsy Specialist Nurse	50%	76%	67%	60%	87%	80%	82%	80%
Paediatric neurologist	42%	31%	50%	40%	21%	25%	22%	20%
Paediatrician with expertise	42%	34%	100%	60%	95%	85%	92%	89%

Audit results cohort 3/4 - Professional input - East Lancashire NHS Foundation Trust

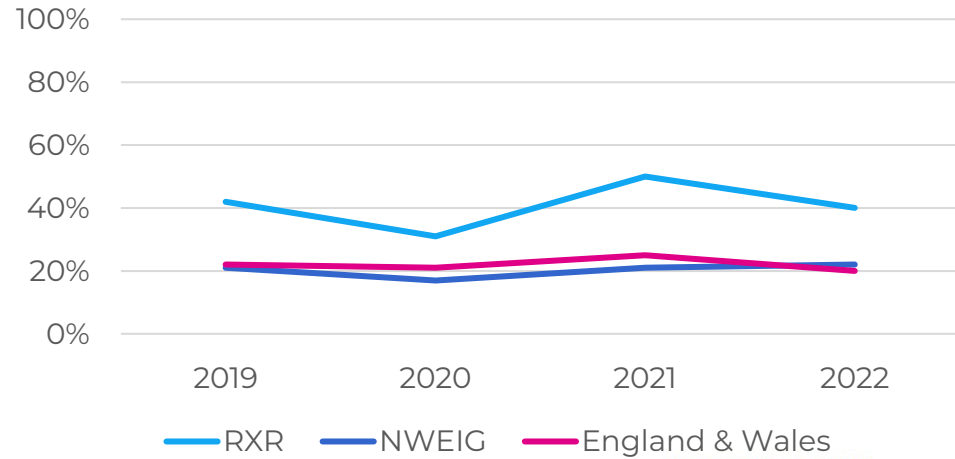
The percentage of CYP with input from an epilepsy specialist nurse in their first year of care has increased since 2019, but currently sits below the national and regional average.

The percentage of CYP with input from a paediatric neurologist in their first year of care has increased since 2019 and is consistently above the national and regional average. *RXR represents East Lancashire NHS Foundation Trust.

Percentage of CYP with input from an epilepsy specialist nurse in their first year of care



Percentage of CYP with input from a paediatric neurologist in their first year of care



Audit results cohort 3/4 - Structured transition resources - East Lancashire NHS Foundation Trust

NICE Quality Standard 140 (Statement 1) – Young people who will move from children’s to adults’ services start planning their transition with health and social care practitioners by school year 9 (aged 13 to 14 years), or immediately if they enter children’s services after school year 9.

From 2021, East Lancashire paediatric epilepsy service have continued to use structured resources to support CYP with transition.

	2018	2019	2020	2021	2022	2021 – NWEIG	2021 – England & Wales	2022 – NWEIG	2022 – England & Wales
Does your paediatric service use structured resources to support transition (e.g. Ready Steady Go)?	No	No	-	Yes	Yes	75%	63%	91%	66%

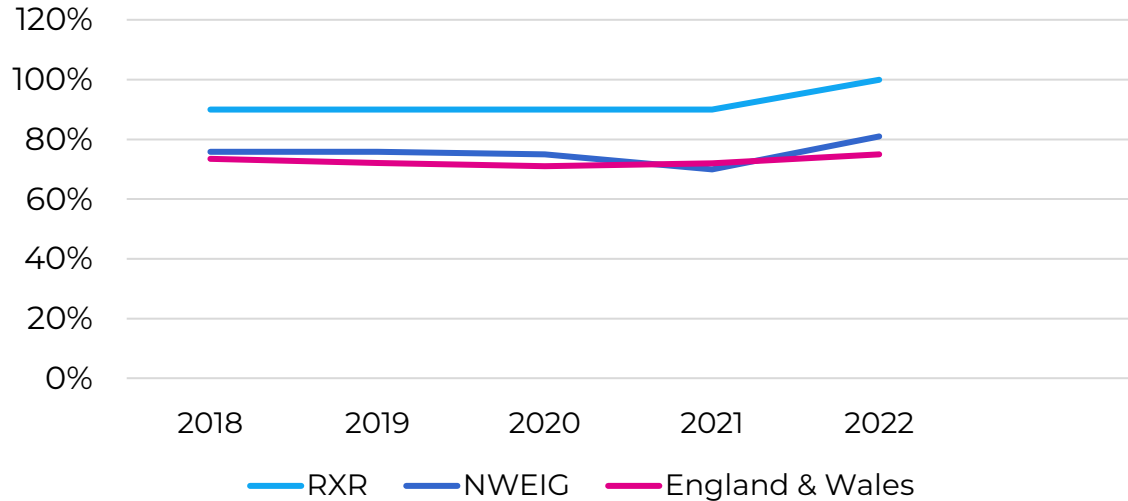
Audit results cohort 3/4 - Professionals involved - East Lancashire NHS Foundation Trust

From 2021, East Lancashire Hospitals NHS Trust began to routinely involve an adult epilepsy specialist nurse and adult neurologist in transition to adult services.

Which adult professionals are routinely involved in transition or transfer to adult services?	2018	2019	2020	2021	2022	2021 – NWEIG	2021 – England & Wales	2022 – NWEIG	2022 – England & Wales
Adult epilepsy specialist nurse	Yes	Yes	-	Yes	Yes	58%	61%	64%	66%
Adult learning difficulty	No	No	-	No	No	0%	17%	0%	20%
Adult neurologist	No	No	-	Yes	Yes	83%	86%	82%	88%
Youth worker	No	No	-	No	No	0%	4%	0%	3%
Other	No	No	-	No	No	0%	17%	0%	20%

Audit results cohort 3/4 - Joint clinics - East Lancashire NHS Foundation Trust

Estimated percentage of young people transitioned to adult services using a joint professional process



Graph showing Trust, regional and national results on Estimated percentage of young people transitioned to adult services using a joint professional process. *RXR represents East Lancashire NHS Foundation Trust.

East Lancashire Hospitals NHS Trust continues to provide CYP with an outpatient service for epilepsy where there is a presence of both adult and paediatric professionals via a single joint appointment. The estimated percentage of young people transitioned to adult services using a joint professional process has remained consistently high, achieving 100% in exceeding the national and regional average.

Audit results cohort 3/4 - Transition age - East Lancashire NHS Foundation Trust

In 2022, East Lancashire Hospitals Trust continues to provide an outpatient clinic specifically for 16 year old 'young people' with epilepsies.

	2018	2019	2020	2021	2022	2021 – NWEIG	2021 – England & Wales	2022 – NWEIG	2022 – England & Wales
Does your trust have an outpatient clinical specifically for 'young people' with epilepsies?	Yes	Yes	-	Yes	Yes	42%	40%	55%	45%
If yes, from what age does this young people's clinic typically accept young people?	16	16	-	16	16	Mean: 14 Median: 14	Mean: 15 Median: 14.5	Mean: 14.2 Median: 14.0	Mean: 14.7 Median: 15.0

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Outcomes

- Some patients received a good transition service; however, this was not the case for all young people who attended clinics.
- Young people, families, and carers are engaged in the thought process for improving transition and learning about independence. Increased engagement with young people, families, and carers, and have included their suggestions into the proforma content.
- Achieved by creating a pathway, proforma, and leaflets.
- Developed relationships with the adult epilepsy nursing team.
- Beyond the programme, continue with running young people and transition clinics, implementing what they have learned to improve transition, and reviewing them in a year on their effectiveness. Plans are in place to continue to learn about young people and transition from relevant training sessions and e-learning to fully equip staff to be able to deliver clinics.
- National audit results showed that from 2021, East Lancashire Hospitals NHS Trust began to routinely involve an adult epilepsy specialist nurse and an adult neurologist in transition to adult services.
 - The estimated percentage of young people transitioning to adult services using a joint professional process has remained consistently high, achieving 100% and exceeding the national and regional average.

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Lessons learnt

- Changing the project aim during the course of the programme was a process that helped the team focus on what was achievable.
- Creating this new pathway has created a lot more work, and the team found they would need to explore efficient ways of working.
- A new way of working is sometimes a challenge to approach; however, in spite of the challenges, the service worked well as a team.
- Connecting to young people, families, and carers to access their opinions and knowledge was a major change.
- Learning to take small steps results in a big change.
- Achieved engaging with a wider multidisciplinary team.
- The British Paediatric Neurology Association (BPNA) has information on moving away from using the word 'transition' because young people quite often think that's related to gender reassignment; therefore, they may look into calling the transition clinic a different name.

Visual presentation of team project intervention

[Video presentation](#)

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