

# Epilepsy12 Quality Improvement Case Studies 2023

## Royal Berkshire NHS Foundation Trust

We developed a patient engagement project, in line with the RCPCH&Us engagement pilot programme, to review the current epilepsy transition service and gain the view of young people and their families, including those with specialist education provisions.

We wanted to support young people transitioning into adult services to be as independent as possible in managing their health conditions, including comorbidities which can require more complex planning for transition and variable independence.

We aimed to review the following areas for the epilepsy transition service:

- Introduction and delivery of information about the transition to adult services and sharing risk information.
- Sharing information about things “outside” of the epilepsy, such as preparing for college, driving, pregnancy, drugs and alcohol.
- What the clinics should look like e.g., a teenager-specific clinic.

The project ran in four stages:

### **Stage 1 – Patient Engagement**

A series of events were planned to consider what the young people wanted from their services and how they would find it best to learn and develop their skills in self-management.

The feedback received from young people shows that young people were clearly provided information in clinic appointments and understood risks relating to water, heights, bikes, sports and sleep. Young people also felt that information was delivered in a sensitive way and they understood how to minimise the risks. Over half of young people felt they had been given sufficient information on their medication and medication management.

However, Young people wanted further information on their diagnosis and how to inform others of it, as well as information on potential side effects of their medication and how to tell if it is effective. Young people wanted information on how alcohol affects their epilepsy and felt that they should receive information on contraception at 13 years old and pregnancy at 15 years old.

Young people did not want teenage-specific epilepsy clinics but did want face-to-face group sessions without parents present to meet other young people with epilepsy and receive information on transition.

### **Stage 2 – Parent Engagement**

A series of events were planned to consider what parents needed from transition services, including families where the young person had a learning disability.

Parents of young people with epilepsy felt that risk and safety information was realistic, factual and informative. They also felt that there was a clear focus on what the young person could do after diagnosis. Parents felt safe in clinic to be able to open with difficult topics and understood that there was support outside of clinic appointments from consultants and epilepsy specialist nurses. Parents of young people with learning disabilities felt that individual transition summaries were important.

Parents felt that contraception, pregnancy, drug and alcohol risk information should be shared from 15 years old. They also felt that risk information and medication management support would be best held as a group session with other young people. Parents of children with learning disabilities wanted this information in a standardised format, so they could decide what to share with their child. Parents felt that a transition service was important for them to be informed of who will support them into adult services.

Parents of young people with epilepsy found it helpful to meet other parents, but this was not the case for parents of young people with epilepsy and learning disabilities.

### **Stage 3 – Clinician Engagement**

In stage 3, the paediatric epilepsy team will meet to discuss the results from stages 1 and 3 and to consider what might be possible within the existing workforce. Stage 3 has not yet taken place.

### **Stage 4 – Review of Resources**

A review will be held to consider what resources currently exist to support individual learning. Stage 4 has not yet taken place.

### **What went well?**

The face-to-face engagement for young people worked well as feedback from young people with epilepsy included that they enjoyed meeting other young people with epilepsy. Parents enjoyed the opportunity to meet other parents who have been through similar journeys.

### **What could have been done differently?**

It would have been beneficial to gain the views of those who have already been through the transition process. A bigger cohort of parents and young people with learning disabilities would have also provided a more representative sample and further feedback from their perspective.

