

# Epilepsy12 Quality Improvement Case Studies 2023

## Hampshire Hospitals NHS Foundation Trust

We developed the Child and young person Epilepsy Concerns Checklist (CHECC) to identify the wider needs of epilepsy patients. We aimed to facilitate information sharing between education and epilepsy services to identify concerns relating to epilepsy, neurodevelopment and mental health. It allowed us to confirm support that is in place, such as special educational needs provision.

CHECC also served to highlight areas that require further evaluation such as intellectual (learning) disability (LD), autism spectrum disorder (ASD), attention deficit hyperactivity disorder (ADHD) and developmental coordination disorder (DCD).

We developed the CHECC with input from parents, epilepsy charities and professionals including paediatric neurology, neuropsychiatry, psychology, epilepsy nursing, general paediatrics and neurodisability paediatrics. Three different versions of the checklist were created: one for parents/carers, one for education providers and one for the young person. Different questions were included in each version and all checklists had a specific space to set their top three goals.

CHECC was sent to certain families and education providers for CYP with epilepsy. These were reviewed in an epilepsy clinic supported by a neurodisability epilepsy paediatrician and epilepsy specialist nurse. Checklists were returned by education professionals for 41 patients. Below are the main areas of difficulty, identified by CHECC, in order of frequency:

- Attention and concentration,
- Learning and intellectual development,
- Communication and social interaction,
- Mood and behaviour.

### Outcomes

16 individuals had additional special educational needs support. In 22 cases, there were clear areas for evaluation, support and goal setting stated. Following or accompanying CHECC, more focused information gathering and evaluations were completed. These were associated with the following outcomes:

- Formal cognitive assessments confirming learning disability,
- ASD diagnoses,
- ADHD diagnoses,
- DCD diagnoses.

CHECC has proven to be an efficient and effective way of enabling education providers to highlight any broader concerns to the epilepsy team, without the need for multiple screening tools.

## **Next Steps**

We will collate further data to evaluate the checklist and we aim to develop the project further with online versions of each checklist. Young Epilepsy are supporting us in developing an app to facilitate feedback from young people.