

# EPILEPSY12

## RCPCH Epilepsy12 Case Study Form

Epilepsy12 is national audit with the continued aim of helping services, and those commissioning health services, to measure and improve the quality of care for children and young people. The Royal College of Paediatrics and Child Health (RCPCH) has been recommissioned to deliver Round 4 of Epilepsy12.

Epilepsy12 would love to hear from your teams about any quality improvement activities you have undertaken in the past year to improve the care provided to children and young people with epilepsies. Selected case studies will be published on our website.

Some examples of these may include (but are not limited to):

- How your team has ensured that patients and families are being informed of SUDEP.
- How your Trust/Health Board have supported young people transitioning to adult services.
- How your service has integrated mental health care and screening into your epilepsy clinics.
- How waiting times have reduced for assessments, treatments, investigations, etc.

For an example, you can [read last year's Quality Improvement Case Studies here](#).

Please complete this Quality Improvement case study form, where the prompts which may be of use when describing your trust's activities. The maximum word count for case studies is **500 words**. Please email the Epilepsy12 team at [epilepsy12@rcpch.ac.uk](mailto:epilepsy12@rcpch.ac.uk) with your case studies before the **28<sup>th</sup> March 2024**.

### EPILEPSY12 2024 QUALITY IMPROVEMENT CASE STUDY APPLICATION FORM

<b>Trust name</b>	<b>Sherwood Forest Hospitals NHS Trust (SFHFT)</b>
<b>Name of regional network</b>	<b>East Midlands</b>
<b>Name and Title of Primary Contact</b>	<b>Kirsten Johnson – Roald Dahl Sapphire Epilepsy Specialist Nurse</b>
<b>Email</b>	<b>kirsten.johnson4@nhs.net</b>
<b>Telephone</b>	<b>07973 193 840</b>

**Please describe any quality improvement activities you have undertaken this past year to improve the care provided to children and young people with epilepsies. You may wish to use the following prompts.**

**Maximum 500 words**

1. Briefly explain the aims and objectives of your quality improvement activity

As part of a Leadership Programme completed in July 2021 by Kirsten Johnson, ESN, we aimed to establish a standardised approach for the provision of essential information within the initial care plan for young people and their families who have a new diagnosis of epilepsy at Sherwood Forest Hospitals NHS Trust. This was to ensure that all families and young people are provided with essential written information at diagnosis and signposting to additional resources. This information includes service contact details, first aid for seizures, safety and participation information including water safety and night-time monitoring and information on SUDEP. Links to trusted websites that support and expand on this information for those who want to know more would form part of the bundle. As an epilepsy team we wanted to be able to easily evidence the information had been provided, ensure that it was available to view on an ongoing basis and be able to be added to and individualised.

2. Describe the steps taken to achieve those aims.

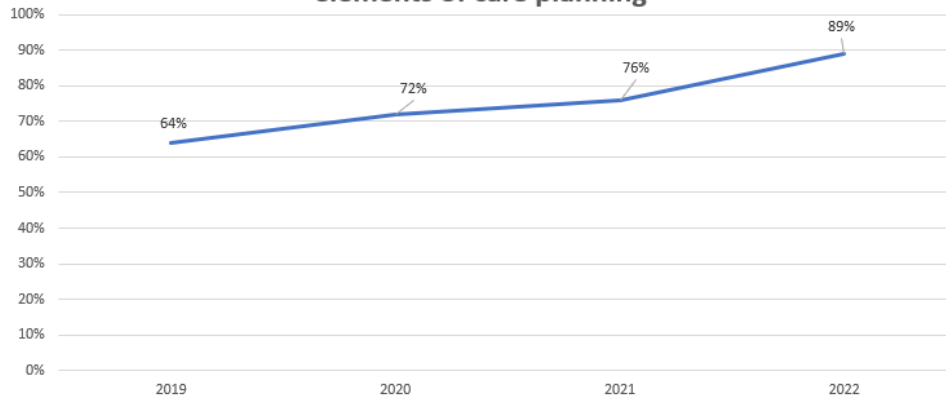
In March 2021 discussions had begun about using Patients Know Best, a digital platform linked to the NHS App, to connect young people and their families with the epilepsy team via a secure digital patient health record. Patients Know Best development was begun July 2021 and fully launched September 2021. The epilepsy module was created and tested in a test zone with stakeholders including a parent of a child with epilepsy. As well as helping solve care planning elements it allows secure messaging sharing, symptom diaries and trust clinic appointment diaries. This solution fully supported the aims outlined in the Leadership Programme and also aligned with those service improvements measured by Epilepsy12 care planning performance indicators. The patient health record was launched formally in September 2021 and has since been offered to children and young people with newly diagnosed epilepsy and to those with an existing diagnosis.

3. Outline the changes and improvement in epilepsy care which was observed by your work

This allowed the epilepsy team to work together to share key information on an individual or on a whole cohort basis. The platform is integrated with the NHS App for young people and is useful as a component of transition towards self-management.

Epilepsy12 results regarding care planning contents are shown in the following graph.

**% of SFHFT children diagnosed with epilepsy with documented evidence of communication regarding core elements of care planning**



Epilepsy12 2023 National Organisational Audit and Clinical Audit Results for SFHFT Showed a significant improvement with patient care planning for the 2022 results which aligned with the launch of this care planning approach.

4. Reflect on what you believe went well in your project and anything you would do differently

Collaborative working within the epilepsy team with agreed measurable goals. Learning and support from the Digital Notts team which allowed alignment with wider system benefits and consideration of interoperability and information governance.

5. Describe the next steps to your quality improvement

We have introduced a parallel project to support those with seizures who may or may not turn out to have epilepsy. We plan to introduce holistic care plan elements, results and clinic letter sharing, transition and mental health resources.

**Please continue on a separate sheet if you need more space.**

Please provide the names and roles of your team who were involved in the quality improvement activities	
Name	Current role
<i>Kirsten Johnson</i>	<i>Epilepsy Specialist Nurse</i>
<i>Colin Dunkley</i>	<i>Paediatric Consultant</i>
<i>Paula Thurman</i>	<i>Patient Pathway Coordinator</i>
<i>Martin Hogg</i>	<i>Project and Business Change Manager, Patient-Facing Digital Services Programme, Digital Notts</i>

**Please continue on a separate sheet if you need more space.**

<p><b>Please provide the name your Trust's Business Manager, Clinical Director or Service manager:</b></p> <p><b>Simon Rhodes, Service Director.</b></p>	
<p><b>Please ensure that the following confirm that they have read and fully support this application to submit a Quality Improvement case study for Epilepsy12</b></p>	
<p><b>Business Manager, Clinical Director or Service manager Signature</b></p>	<p><b>Simon Rhodes</b></p>
<p><b>Date</b></p>	<p><b>3/4/24</b></p>