



Child Health and
Wellbeing Network
North East and North Cumbria

Epilepsy Project 1:

Scope and explore current
epilepsy services for Children
and Young People across North
East and North Cumbria

Executive Summary

September 2022

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Background

The Child Health and Wellbeing Network (CHWN) supports the delivery of the Children and Young Person's (CYP) Transformation Agenda and Improvement for services for CYP with long term conditions, including epilepsy. This report baselines current services to identify good practice and inequity in our region.

This improvement programme of work runs simultaneously with Epilepsy Project 2, which focusses on the availability of mental health and psychology support for CYP.

The project was undertaken between October 21 and April 22 and represents example of close collaboration between primary, secondary and tertiary care and also the inclusion and involvement of wider stakeholders including education partners.

Findings and Recommendations

There is recognition of the value and importance of good paediatric epilepsy care across our region, and the report has identified pockets of excellent practice with clear willingness amongst professionals working with CYP across the system to improve the quality of care they provide to CYP with epilepsy. Key positive findings are:

- **All epilepsy services in the region have a consultant who has taken responsibility** for leading the services and all services offer defined epilepsy clinics
- **Accuracy of diagnosis in the PENNEC/NENC ICS region is high at 97%** and 88% of CYP in the region are diagnosed with the appropriate seizure category after 1 year.
- **All services offer the 12-lead Electrocardiogram (ECG)** diagnostic test and all services have access to Electroencephalogram (EEG) locally or via inter-trust referral.
- **All epilepsy services offer a system or process to provide specialist advice to patients**, families and other professionals between Monday and Friday.
- **Most secondary epilepsy services have an agreed referral pathway** to tertiary paediatric neurology services for advice in relation to complex patients and need for epilepsy surgery

However, critical gaps and variation identified are in relation to primary care referral pathways, clinical leadership and recognition of roles, inequity of access to Epilepsy Specialist Nurse (ESN) support and diagnostic and treatment provision. These are detailed below:

- There is a **need for improved consistency** in the time allocation for clinical leads within the services as currently it is not always reflective of the need, or the actual time spent by clinicians in improving the epilepsy services.
- **Less than half of the defined epilepsy clinics meet the requirements** of national Treatment Function Code 223 (TFC223) best practice tariff.
- **Significant variation exists in relation to the model of delivery and ESN input.** At the point at which information was gathered, two services did not employ ESNs as part of the epilepsy workforce. ESNs are integral part of epilepsy services and at present, none of the services provide dedicated administration time/support within the ESN role.
- **Only 26% of CYP are seen by a paediatrician with specific expertise in epilepsy** within 2 weeks in our local region which is an area for improvement.

This report identifies a series of recommendations for the improvement in paediatric epilepsy services and care which include development to multi-agency systems and processes to remove or reduce variation and to improve experience and outcomes for CYP and their families.

The areas for improvement fall broadly into the following categories which are the areas of focus that have been identified nationally.

- 1) Mental health screening and access to psychosocial support
- 2) Referral pathways, care management/access to neurology and tertiary services (including surgery)
- 3) Transition from paediatric to adult epilepsy services
- 4) Variation and inequality of epilepsy care

The main vehicle to progress this work will be through the development and establishment of the strategic relationship between the Paediatric Epilepsy Network, North East and Cumbria (PENNEC) and CHWN. A key part of this will be to ensure that PENNEC has the necessary representation and lines of influence, as well as prioritising the recommendations of the report through this forum.

Following the further development to accountability and governance arrangements within PENNEC their role will be to support to develop service improvement plans and operationalise relevant recommendations. This work is planned and underway with the support of the Chair of PENNEC

For more information and to read the full report click [here](#).

To become involved in the continuation of this work or for further information please contact the team at england.northernchildnetwork@nhs.net