Epilepsy Project 1:

Scope and Explore Epilepsy 12 National Audit data and current epilepsy services for Children and Young People across North East and North Cumbria

North East and North Cumbria

Child Health and Wellbeing Network

Findings and Recommendations Paper

August 2022

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Foreword

Dear Network Member

It gives us great delight to share this in-depth baselining report that has been developed by the Epilepsy Clinical Lead in partnership with the Child Health and Wellbeing Network. We are proud that this work represents an example of close collaboration between primary, secondary and tertiary care and also the inclusion and involvement of wider stakeholders including education partners.

This provides us with a clear baseline about the delivery of epilepsy care to CYP in the North East and North Cumbria ICS region, focussing on diagnosis, referral pathways, care and treatment, medication, support in schools, staffing resource and transition from paediatric to adult epilepsy services. The report findings and recommendations enable us to identify areas of challenge and provisions to make service improvement.

It will be helpful to have this resource as a baseline to enable future review and an ability to monitor our progress and the impact of the ICS wide service improvement programme that will be the result of this evaluation and scoping work.

This repot will be widely available to systemwide colleagues and partners and will be of particular interest to ICB commissioners and NHS Foundation Trust Chief Executive Officers and Specialist Clinical Leads as we seek to make necessary improvements.

The CHWN has developed its strategic relationship with the Paediatric Epilepsy Network North East and Cumbria (PENNEC) and will continue to work in partnership and support to operationalise and resource broader system improvement.

We hope that the incidence and prevalence modelling information contained within will help us to identify and target our limited resources to improve health outcomes for those CYP who are more likely to suffer challenge due to socioeconomic factors and other health inequalities.

The analysis of information is available at granular level and is rich and allows us to pinpoint areas of particular concern. Within the PENNEC/NENC ICS localities, acute Trusts in South Tees, Newcastle, South Tyneside and Sunderland and North Tees & Hartlepool are seeing CYP from the most deprived areas.

This report presents us with a golden opportunity to identify and share good practice and to provide clarity on how to make the biggest impact on the experiences, outcomes and ultimately the lives of CYP with epilepsy, and their families, in the NENC ICS region.

We hope this report is a helpful resource to highlight our areas for improvement and we look forward to working alongside you to achieve some longer-term Children and Young People Transformation Programme goals.

We must also acknowledge not only the Epilepsy Clinical Lead for producing this fabulous resource with the support of our network Delivery Manager, but also our wider network membership that helps deliver a system perspective and in particular our Primary Care Advisor Dr Vaishali Nanda and our Education Advisor Mrs Kate Swaddle for their review and contribution to its development.

Best wishes

Dr Mike McKean

Heather Corlett

Clinical and Programme Leads of the NENC ICS's Child Health and Wellbeing Network (respectively) **Senior Responsible Officers** for the NENC CYP Transformation Programme

Executive Summary

This piece of work is the first of its kind in England and Wales and as such represents a positive step forward in relation to improvements to paediatric epilepsy care in the North East and North Cumbria (NENC). This programme has only been possible in the first instance due to the resource commitment of the NENC Integrated Care System (ICS) Child Health and Wellbeing Network (CHWN). There continues to be investment in local clinical leadership and oversight. This improvement programme of work runs simultaneously with another project, which focusses specifically on the availability of mental health and psychology support for Children and Young People (CYP) with epilepsy which is identified as an area for improvement nationally, led by Dr Anita Devlin, Consultant Paediatric Neurologist.

The benefits of this work are numerous and help to provide a baseline for improvement locally and a clear guide about how to target resources and also from a regional or national perspective provides a blueprint for similar programmes of engagement.

This work represents an example of close collaboration between primary, secondary and tertiary care and also the inclusion and involvement of wider stakeholders including education partners. This report brings together information from the stakeholders, collected in a multitude of ways as well as data from various sources, primarily the Epilepsy 12 Round 3 Cohort 2 dataset which forms an integral part of this programme of work.

Epilepsy 12 Round 3 Cohort 2 data captures information on CYP who had a first paediatric assessment for a suspected seizure between 1 December 2018 and 30 November 2019. The audit provides information about the follow up of the registered patients for 12 months care. For many CYP in cohort 2, this includes care provided during the COVID-19 pandemic in 2020. Since the finalisation of this work updated Epilepsy 12 data has been published by RCPCH (in July 22) which captures data and focusses on Cohort 3, which includes CYP who had a first paediatric assessment for a suspected seizure between 1 December 2019 and 30 November 2020. Where Epilepsy 12 data is referred to in this report, it specifically relates to Clinical Audit Data for Round 3 Cohort 2.

The progression of this work has enabled the CHWN to develop the strategic relationship with Paediatric Epilepsy Network of North East and Cumbria (PENNEC) and continues to forge forward with the finalisation of a partnership working and governance agreement to facilitate and operationalise a programme of service improvement across the NENC ICS region.

The NENC ICS region fortuitously maps directly across a local paediatric epilepsy network and as such is able to work more closely and coherently together as there is one single group of stakeholders to engage with and seek influence of. Each of the NHS Foundation Trusts providing epilepsy services in the NENC region are members of and represented within PENNEC which makes governance and decision making less challenging.

Statistical evaluation and analysis have been undertaken which has resulted in the incidence and prevalence being modelled on demography and population estimates. Further work has been done to consider this in relation to local levels of deprivation and health inequalities and information has been drawn from a variety of sources to be able to build a demographic and socioeconomic profile of our local area.

Data from the Facts of Life Report (based on Public Health Fingertips information) demonstrates that Emergency Department (ED) admission rates for epilepsy related needs in NENC were higher than they are nationally in 2018/19. Anecdotally, in more recent years ED are seeing fewer emergency admissions due to epilepsy related needs which indicates that work is being undertaken to streamline and promote effective referral pathways and refine processes to better manage needs in the community.

Although there are NICE national standards about epilepsy services however primary care colleagues report that there are challenges with understanding criteria for referral and there is a need for a clear referral pathway and there is a need to understand how soon patients need to be seen and how to establish urgency. Telephone triage service has been appreciated by primary care practitioners however this service is not universally available across the region.

All epilepsy services in the region have a consultant who has taken responsibility for leading the service, some services have renumerated this leadership role and some have not. There is a need for improved consistency in the time allocation across the services as currently it is not always reflective of the need, or the actual time spent by clinicians in improving the epilepsy services. All services also offer defined epilepsy clinics but less than half meet the requirements of national Treatment Function Code 223 (TFC223) best practice tariff.

The report has identified that significant variation exists in relation to the model of delivery and Epilepsy Specialist Nurse (ESN) input and support into epilepsy care for CYP across the services in the region. At the point at which information was gathered, two services did not employ ESNs as part of the epilepsy workforce however since this it is understood that one of these services has recruited an ESN and other services are currently in discussion with management. ESNs are integral part of epilepsy services and at present, none of the services provide dedicated administration time within the ESN role or alternatively any administrative support.

Only 26% of CYP are seen by a paediatrician with expertise in epilepsy within 2 weeks in our local region which is an area for improvement. 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, less than half of the services provide in-house Electroencephalogram (EEG) but all services have access to EEG via inter-trust referral. 74% of those who meet the criteria for Magnetic Resonance Imaging (MRI) receive this investigation. There are long waits for specialised diagnostic tests such as neurometabolic and genetics for various reasons.

All services confirmed that patients and their parents can access the epilepsy service for specialist advice although there are gaps and significant variation that exist in relation to ESN availability.

Nearly all services 7/9 have an agreed referral pathway into tertiary paediatric neurology and positive working relationships exist, with a variability in referral rate.

Variation within the region exists in relation to a range of areas including rate of prescription of sodium valproate to young girls of childbearing age, referral rate for epilepsy surgery, access to paediatric psychology services, approach and uptake of care planning and care plan agreement as well as input into school individual healthcare plans. In addition, there is variation in relation to the transition process and only 63% of services have an agreed transitional pathway.

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.

Project Delivery Team:

Clinical Lead: Dr Ramesh Kumar, Consultant Paediatrician with expertise in epilepsy

Project Manager: Louise Dauncey, Delivery Manager CYP Transformation Programme.

Acknowledgements

This project has been able to take advice, guidance and learning from other system wide colleagues and professionals. Part of this work has been to collaborate with others to understand and baseline the current position.

We thank the following individuals for their expertise and assistance throughout all aspects of our project and for their contribution to the drafting and finalisation of this findings and recommendations paper.

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Aims and Objectives

The purpose of the project was ultimately to facilitate improvements to the care for CYP with epilepsy especially in the areas of inequality, transition, psychological and mental health support, and to reduce incidence of epilepsy related death.

The Project aimed to review and scope the current epilepsy services in PENNEC/NENC ICS footprint and identifying areas for improvements will support with plans to target resources which would improve:

- experience for CYP with epilepsy and their families experience
- education health and social care outcomes of CYP
- navigation through care pathways for CYP and families
- consistency within the care system
- communication and working between primary, secondary and tertiary services

The project has included a detailed review of Epilepsy 12 data to understand variation in service delivery and pathways of care for CYP with epilepsy in relation to

- commissioning arrangements;
- availability of mental health support;
- referral pathways into paediatric neurology and tertiary services; and
- transition into adult epilepsy services.

Following the scoping exercise and initial report the intention is for planning to commence to improve epilepsy care and outcomes for CYP at a system/regional level (including evidence of co-production with CYP) in relation to:

- planning the restoration and recovery of paediatric epilepsy services, including access to necessary epilepsy investigations;
- a focus on reducing any health inequalities;
- identifying regional variations and examples of good practice

Review and evaluation focussed around the availability and provision of psychological and mental health support has been addressed separately under another specific programme of work led by a tertiary specialist paediatric neurologist.
The aims of the programme are multi-faceted, but all align with the priorities of the CHWN and the NHS Long Term Plan (CYP Transformation Programme).

- To agree with common vision based on NHS long term plan
- To review and consolidate the pathways of care across primary, secondary and tertiary care following stakeholder engagement.
- Identify the areas of good practice across the ICS
- Identify the key areas of regional variation and Health Inequalities or improvement by scoping/gap analysis

Key deliverables for the project are described below

- Steering Group Terms of Reference

- High level Logic Model Action Plan
- Governance reporting and approvals
- Findings and Recommendations Paper which will make recommendations in relation to:
  - Referral pathways in primary, secondary and tertiary care
  - Pathways of investigations
  - Pathways for ongoing annual reviews
  - Local arrangements for transition
  - Local arrangements for referrals to tertiary care
  - Regional arrangements for governance and oversight
- Evaluation paper and project closure

Background

National Context

The Long-Term NHS plan includes proposals to create ‘clinical networks’ to improve the quality of care for children with epilepsy. There is, however, little mention of how the proposed clinical networks will work. The plan mentions “sharing best clinical practice, supporting the integration of paediatric skills across services and bespoke quality improvement projects”. Long-term plan also includes reducing emergency department attendance from children with epilepsy by improving children's health services and making sure children with epilepsy get the support they need to stay well.

Epilepsy is a common chronic neurological disorder characterised by recurring seizures. Accurate estimates of incidence and prevalence of the childhood epilepsy in the UK is difficult to achieve because identifying children who may have epilepsy is difficult and there is a lack of national data base. It can be difficult to diagnose due to the lack of a specific diagnostic test and so under and over diagnosis is not uncommon. However estimated incidence is 50 per 100,000 per year and the prevalence of active epilepsy in the UK is estimated to be 5–10 cases per 1000. Two-thirds of people with active epilepsy have their epilepsy controlled satisfactorily with anti-epileptic drugs. Optimal management improves health outcomes and can also help to minimise other, often detrimental, impacts on social, educational and employment activity. Even among those who have a diagnosis of epilepsy, up to a third continue to have seizures despite treatment. Epilepsy is associated with a higher risk of mental health problems. Published research suggests that 37% of children with epilepsy have a co-existing mental health disorder, a higher prevalence than found in other long-term childhood conditions.

NICE in 2004 produced quality standards covering diagnosing, treating and managing epilepsy and seizures in CYP (under 18), which have been updated in 2012 and again in 2022. It describes high-quality care in priority areas for improvement. The quality standard for the epilepsies in CYP specifies that services should be commissioned from and coordinated across all relevant agencies encompassing the whole epilepsy care pathway. An integrated approach to the provision of services is fundamental to the delivery of high-quality care to children and young people with epilepsy, and the quality standard should be delivered by multidisciplinary teams through a local epilepsy clinical network.

Epilepsy 12 is a national audit programme that was established in 2009 and has the continued aim of helping epilepsy services, and those who commission health services, to measure and improve the quality of care for children and young people with seizures and epilepsies. The audit is commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP) and is delivered by the Royal College of Paediatrics and Child Health (RCPCH).

RCPCH have been conducting national organisational and clinical audit since 2012 against 12 performance indicators. The audit aims to enable improvement in the quality of and outcomes from care provision for children and young people with epilepsy or suspected epileptic seizures. The latest report published in July 2021 presents data and evidence from cohort 2 from the three main domains of ‘Epilepsy 12’, a clinical audit describing patient care, an organisational audit describing service structures, and related quality improvement activities. The clinical audit data describes patient care of children and young people who had a first paediatric assessment for a paroxysmal episode (or episodes) between 1 December 2018 and 30 November 2019. The latest results highlighted nationally the need to provide more mental health screening and care for those CYP with epilepsy. Other identified concerns included long waiting times for crucial investigations such as EEG or ECG and opportunities to improve rates of referral to tertiary neurology services.

The performance indicators align with NICE Guidelines and Quality Standards and cover the following areas:
- input from a paediatrician with expertise in epilepsies
- input from an epilepsy specialist nurse
- tertiary input
- epilepsy surgery referral
- appropriate first paediatric assessment
- seizure formulation
- access to electrocardiogram (ECG)
- access to magnetic resonance imaging (MRI)
- accuracy of diagnosis
- discussion of the risks of treatment with sodium valproate
- comprehensive care planning agreement and content
- school individual healthcare plans.

In June 2019 the RCPCH launched the first paediatric collaborative epilepsy quality improvement pilot in England and Wales, called RCPCH EQIP, supporting epilepsy services teams to identify sustainable improvements within their services for children and young people with epilepsy.

The RCPCH Epilepsy 12 audit project team, in collaboration with the Organisation of Paediatric Epilepsy Networks in the UK (OPEN UK), developed a model for a comprehensive Quality Improvement (QI) programme. It was tailored to support paediatric epilepsy teams to work together to define their shared aims and develop practical interventions matching their capacity and resources. The six-month programme had been developed in consultation with epilepsy practitioners, ensuring that it best suits the needs of teams providing epilepsy care while also borrowing from a similar model delivered with success in paediatric diabetes in the UK.

Each participating team:
- completes a comprehensive, multi-skill development training programme, delivered free of charge by a professional team from the RCPCH
- receives support in developing a transformative change for their team and care processes, towards lasting improvement
- has an opportunity to work with other teams from across England and Wales, learning from their experiences

- shares their improvement projects via the RCPCHQI Central website and other communication channels
- receives a CPD certificate for all individual team members for every learning event attended.

There were 12 teams, and a total of 85 team members, in the pilot, there was one team from the NENC ICS footprint area, South Tees Hospitals Foundation Trust (STHFT) whose project focussed on asking young people how their epilepsy service can support their wellbeing.

The aim of the programme was to engage with half of the children aged 12-16 years with a diagnosis of epilepsy (without a learning disability) and their parents/carers attending a paediatric epilepsy review to ask them specifically how the epilepsy service could better support their wellbeing. It is well documented that epilepsy has an impact on children and young people’s emotional wellbeing and mental health although the extent of this had been difficult to quantify as information was not routinely captured in a standardised way. Trusts are aware of many different services available to support children and young people with their emotional wellbeing and mental health but acknowledge that there is an overall lack of knowledge about how to identify and assess patients that may require more support in relation to their mental health and emotional wellbeing needs.

Information was collected from families in relation to this project and some suggestions were made about how services might be able to better support these needs. The success of this programme was impacted due to the COVID pandemic which restricted the opportunities to progress these conversations.

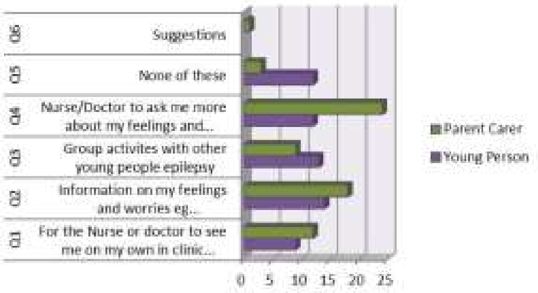
Feedback from Young People and Families that took part included the following

“make it more clear that the nurse/doctor will see you on your own for a small period during the consultation, not the entire time”

“kids are protective of parents and might not discuss issues in front of parents so as not to worry them”

“leaflet is a really good idea and we need copies in clinic rooms”

Figure 1. *Outcome data RCPCH EQIP; STHFT*



Other projects from other areas included a range of quality improvements, more information can be found at [RCPCH EQIP - Epilepsy Quality Improvement Programme | RCPCH]

Local Context

The NENC region covers a population of children 0-18 years providing secondary epilepsy care across 8 Trusts working very closely with primary care and also with the tertiary unit for complex patients.

The population of CYP aged under 18 in North East North Cumbria ICS area is c600,000. The incidence of epilepsy in this population is 40/100,000 and the prevalence is approximately 5,000. Published rates of psychiatric disorder for those with epilepsy (37%) indicate that approximately 1,850 CYP with epilepsy in the NENC ICS footprint have mental health needs.

Work has been undertaken as part of this programme to consider the identification, diagnosis, prevalence, incidence and reporting rates across the ICS footprint in relation to each of the locality areas as well as in respect of regional and national data. This analysis has also taken into consideration comparator regions in relation to population demographic and geography.

The Paediatric Epilepsy Network for the North East and North Cumbria (PENNEC) helpfully operates across the same footprint as the NENC ICS boundary areas and as such oversees and influences the paediatric epilepsy services delivered by the following NHS Acute Provider Trusts. In this case, all Trusts and boundary locality services are affiliated to PENNEC and participate in Epilepsy 12 Audit, to varying degrees depending on the available resources.

- South Tyneside and Sunderland NHS Foundation Trust
- North Cumbria integrated care NHS foundation Trust
- The Newcastle Upon Tyne Hospitals NHS Foundation Trust
- Northumbria Healthcare NHS Foundation Trust
- South Tees Hospitals NHS Foundation Trust

- North Tees and Hartlepool NHS Foundation Trust
- County Durham and Darlington NHS Foundation Trust

Since April 2022, Dr Ramesh Kumar has been appointed the Clinical Advisor to the CHWN in relation to the Epilepsy Programme of work. Strategic relationships between the CHWN and PENNEC have been developed and will be underpinned by a Partnership Working Agreement and Memorandum of Understanding. As such there is a role for PENNEC to operationalise and progress the recommendations that have been drawn from this scoping and mapping exercise. In addition to this, PENNEC can support with operationalising recommendations of the Exploring Mental Health and Psychology Support report, which has been developed as a simultaneous but distinct programme of work. Dr Kumar plays a key role within PENNEC and also participates at RCPCH OPEN UK as the NENC ICS representative.

North East and Yorkshire has the highest rate of epilepsy diagnosis across all the Health Authorities as evidenced by Epilepsy 12 Audit data.

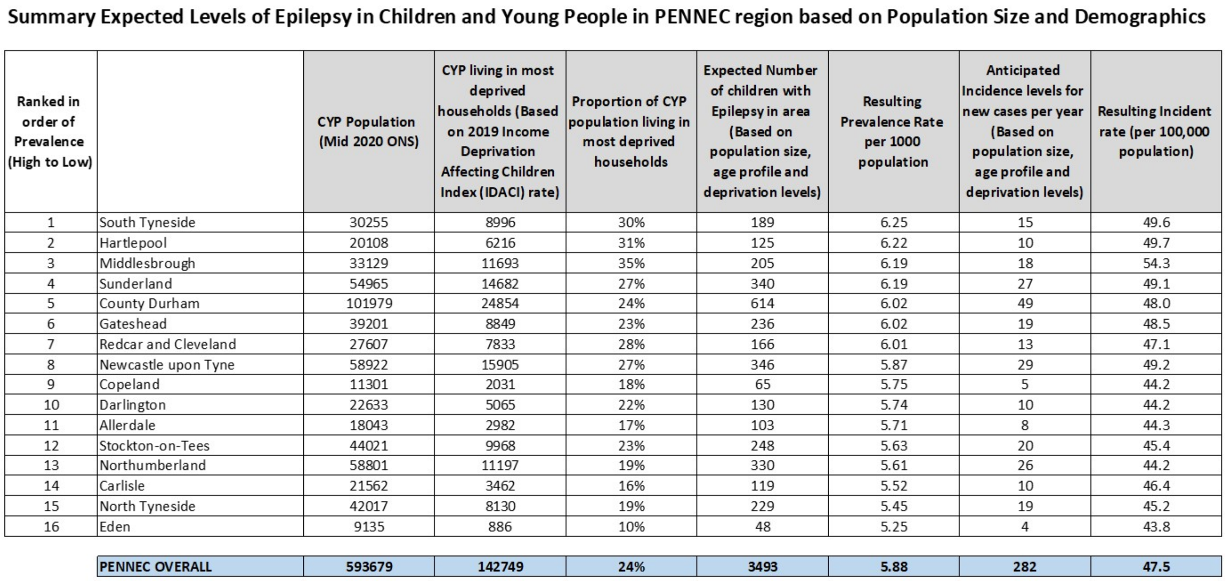
The age profile of the CYP assigned to Round 3 Cohort 2 (Epilepsy 12 2020 National Clinical Audit Results) within the PENNEC/NENC ICS region are consistent with the England and Wales national averages.

Further analysis of population demographics and modelled estimates of epilepsy incidence and prevalence rates in PENNEC/NENC ICS region and across other regions/networks (based on population size, age profile and deprivation levels) indicates that NENC ranks third highest nationally in terms of prevalence of CYP with epilepsy at 5.88 children per 1000 population (England average is 5.45).

PENNEC/NENC ICS region has the highest reported number of diagnosed epilepsy cases in the latest round of Epilepsy 12 data (Round3, Cohort2), and has the third highest conversion rate (37%) of referrals to diagnosed epilepsy cases across the Epilepsy regional networks. However, this may not be representative, as referral rates into the Epilepsy 12 study cohort relative to local population sizes of the participating Trusts and their associated networks varies significantly, ranging from 40 referrals per 1000 local CYP population up to 170 referrals per 1000 population. This variation is most likely a reflection of incomplete data submissions to Epilepsy 12. Also, there must be recognition that the participating Trusts in England represent around 72% of the overall CYP population in England and approximately 24% of acute Trusts (non-specialised) in England who are delivering epilepsy care to children and are not affiliated to an epilepsy network.

For the PENNEC/NENC ICS region, modelled estimations anticipated incidence levels for new cases per year (based on population size, age profile and deprivation levels) is 282 which looks to be consistent with the Epilepsy 12 diagnostics data from Epilepsy 12 2020 data (Round 3 Cohort 2) which identifies that 245 cases were diagnosed over the same timeframe. This number may also have increased as patients on ‘watch and wait’ may have been subsequently diagnosed with epilepsy. This indicates that the secondary services are identifying and diagnosing epilepsy in line with expected rates of incidence and this is a helpful indicator of success in relation to ensuring that families are able to receive accurate diagnosis giving greater chance of accessing services to meet their needs.

Table 1 Summary expected levels of epilepsy in CYP in PENNEC/NENC ICS region based on population size and demographics



Summary Expected Levels of Epilepsy in Children and Young People in PENNEC region based on Population Size and Demographics

Ranked in order of Prevalence (High to Low)		CYP Population (Mid 2020 ONS)	CYP living in most deprived households (Based on 2019 Income Deprivation Affecting Children Index (IDACI) rate)	Proportion of CYP population living in most deprived households	Expected Number of children with Epilepsy in area (Based on population size, age profile and deprivation levels)	Resulting Prevalence Rate per 1000 population	Anticipated Incidence levels for new cases per year (Based on population size, age profile and deprivation levels)	Resulting Incident rate (per 100,000 population)
1	South Tyneside	30255	8996	30%	189	6.25	15	49.6
2	Hartlepool	20108	6216	31%	125	6.22	10	49.7
3	Middlesbrough	33129	11693	35%	205	6.19	18	54.3
4	Sunderland	54965	14682	27%	340	6.19	27	49.1
5	County Durham	101979	24854	24%	614	6.02	49	48.0
6	Gateshead	39201	8849	23%	236	6.02	19	48.5
7	Redcar and Cleveland	27607	7833	28%	166	6.01	13	47.1
8	Newcastle upon Tyne	58922	15905	27%	346	5.87	29	49.2
9	Copeland	11301	2031	18%	65	5.75	5	44.2
10	Darlington	22633	5065	22%	130	5.74	10	44.2
11	Allerdale	18043	2982	17%	103	5.71	8	44.3
12	Stockton-on-Tees	44021	9968	23%	248	5.63	20	45.4
13	Northumberland	58801	11197	19%	330	5.61	26	44.2
14	Carlisle	21562	3462	16%	119	5.52	10	46.4
15	North Tyneside	42017	8130	19%	229	5.45	19	45.2
16	Eden	9135	886	10%	48	5.25	4	43.8
	PENNEC OVERALL	**593679**	**142749**	**24%**	**3493**	**5.88**	**282**	**47.5**

CYP population estimates were taken from the ONS Mid 2020 population statistics and deprivation levels were taken from the English Indices of Deprivation 2019 (Index of Multiple Deprivation IMD 2019) and the Income Deprivation Affecting Children Index (IDACI) Score to assess the number of CYP living in the most deprived areas. Estimates of CYP epilepsy rates were then calculated based on childhood epilepsy incidence and prevalence rates (Aaberg et al, 2017) and deprivation levels also accounted for on the understanding that epilepsy prevalence and incidence are strongly associated with deprivation. A recent study (Pickrell et al, 2015) indicates that epilepsy incidence and prevalence rates are twice as likely in the most deprived deciles compared to the least deprived deciles and this was factored into the calculations.

Data sources:

Table SAPE23DT2: Mid-2020 Population Estimates for Lower Layer Super Output Areas in England and Wales by Single Year of Age and Sex,

www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/datasets/lowersuperoutputareamidyearpopulationestimates

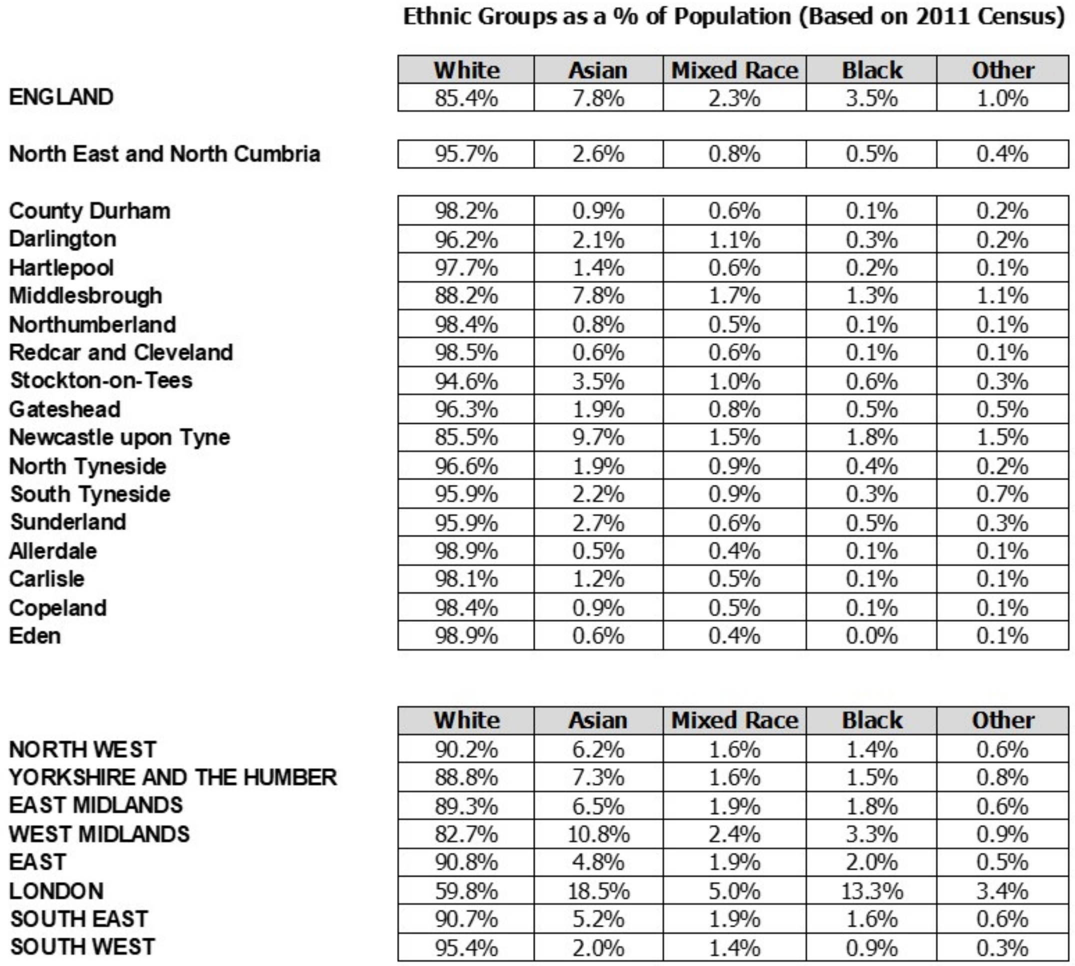
English Indices of Deprivation 2019 (Index of Multiple Deprivation IMD 2019), www.gov.uk/government/statistics/english-indices-of-deprivation-2019

Health inequalities

Social determinants, also known as wider determinants, are a diverse range of social, economic and environmental factors which impact on population health. These factors, influenced by local, national and international distribution of resources, shape the conditions of daily life and the extent to which individuals of all ages have the physical, social and personal resources to identify and achieve goals, meet their needs and respond to changes in their circumstances.

The Marmot review considered health inequality and health outcomes was published in 2010 it emphasised the strong and persistent link between social inequality and disparities in health outcomes and the importance of tackling the wider determinants of health to improve health outcomes and reduce health inequalities. Evidence suggests that these 'wider determinants of health' are more important than health care in ensuring a healthy population and reducing health inequality.

Table 2: Population Split by Ethnic Groups (based on 2011 census)



Ethnic Groups as a % of Population (Based on 2011 Census)

	White	Asian	Mixed Race	Black	Other
ENGLAND	85.4%	7.8%	2.3%	3.5%	1.0%
North East and North Cumbria	95.7%	2.6%	0.8%	0.5%	0.4%
County Durham	98.2%	0.9%	0.6%	0.1%	0.2%
Darlington	96.2%	2.1%	1.1%	0.3%	0.2%
Hartlepool	97.7%	1.4%	0.6%	0.2%	0.1%
Middlesbrough	88.2%	7.8%	1.7%	1.3%	1.1%
Northumberland	98.4%	0.8%	0.5%	0.1%	0.1%
Redcar and Cleveland	98.5%	0.6%	0.6%	0.1%	0.1%
Stockton-on-Tees	94.6%	3.5%	1.0%	0.6%	0.3%
Gateshead	96.3%	1.9%	0.8%	0.5%	0.5%
Newcastle upon Tyne	85.5%	9.7%	1.5%	1.8%	1.5%
North Tyneside	96.6%	1.9%	0.9%	0.4%	0.2%
South Tyneside	95.9%	2.2%	0.9%	0.3%	0.7%
Sunderland	95.9%	2.7%	0.6%	0.5%	0.3%
Allerdale	98.9%	0.5%	0.4%	0.1%	0.1%
Carlisle	98.1%	1.2%	0.5%	0.1%	0.1%
Copeland	98.4%	0.9%	0.5%	0.1%	0.1%
Eden	98.9%	0.6%	0.4%	0.0%	0.1%

	White	Asian	Mixed Race	Black	Other
NORTH WEST	90.2%	6.2%	1.6%	1.4%	0.6%
YORKSHIRE AND THE HUMBER	88.8%	7.3%	1.6%	1.5%	0.8%
EAST MIDLANDS	89.3%	6.5%	1.9%	1.8%	0.6%
WEST MIDLANDS	82.7%	10.8%	2.4%	3.3%	0.9%
EAST	90.8%	4.8%	1.9%	2.0%	0.5%
LONDON	59.8%	18.5%	5.0%	13.3%	3.4%
SOUTH EAST	90.7%	5.2%	1.9%	1.6%	0.6%
SOUTH WEST	95.4%	2.0%	1.4%	0.9%	0.3%

The NENC region as a whole has one of the highest proportions of CYP population (24%) living in the most deprived households in England (based on the Income Deprivation

Affecting Children Index population estimates). The national average for England is 19%. This is also reflected in the Epilepsy 12 data (assigned to Round 3, Cohort 2) which shows that localities in the PENNEC/NENC ICS footprint have the highest proportion of CYP that are under review for Epilepsy and live in the most deprived quintile across all the localities within the regional networks.

Within the PENNEC/NENC ICS localities, acute Trusts in South Tees, Newcastle, South Tyneside / Sunderland and North Tees & Hartlepool are seeing CYP from the most deprived areas, and again, this is shown in both the Epilepsy 12 data and ONS population and Index of Multiple Deprivation IMD data. The highest level of deprivation is seen in the Middlesbrough area with 35% of the local CYP population living in the most deprived households; with Hartlepool (31%) and South Tyneside (30%) not too far behind. County Durham is the largest area in the NENC ICS footprint and has the largest CYP population to manage (c102,000), it also has the largest number of CYP population living in deprived households (c24,850).

Recent ONS and other population profiling data demonstrates that our region houses a large and expanding number of young people and families facing multiple disadvantages, including poverty, poor mental health and family breakdown.

Long term conditions

The Kings Fund has defined long-term conditions as ‘conditions or chronic diseases are conditions for which there is currently no cure, and which are managed with drugs and other treatment’

Three conditions - asthma, diabetes and epilepsy - account for 94% of emergency admissions for children under 19 years with long term conditions.

Emergency hospital care is only one part of a complex health and social care system serving children and families. It is affected by supply (availability and quality of services) and demand (the need or desire for services) factors. Whilst access to primary care has been shown to have an impact on the number of A&E attendances, broader environmental and socioeconomic factors also shape health-seeking behaviours as well as admission behaviour e.g. higher neighbourhood deprivation has been associated with increased A&E attendances in both adults and children.

The current level of A&E use and emergency admissions usually from our more disadvantaged communities is unsustainable. We need to think about paediatric services and their networks and primary care networks collaborating to develop triage pathways and manage childhood illness in community settings.

The number of children and young people admitted to hospital is rising across the UK but there is a lack of evidence to recommend the best way to manage paediatric acute care and reduce avoidable admissions. Hospital admissions are costly but also carry multiple personal costs to children, young people and their families e.g. disruption to family and educational life, increased emotional distress and exposure to infections.

Preventive primary care can also play a key role in improving child health and reducing avoidable emergency hospital admissions for both acute and chronic conditions.

Children and young people account for 25% of emergency department attendances and are the most likely age group to attend A&E where it could otherwise have been avoidable. Children and young people from the most deprived areas are consistently more likely both to go to A&E and to need emergency hospital treatment than children from the least deprived areas. Many of these attendances could be managed effectively in primary care or community settings.

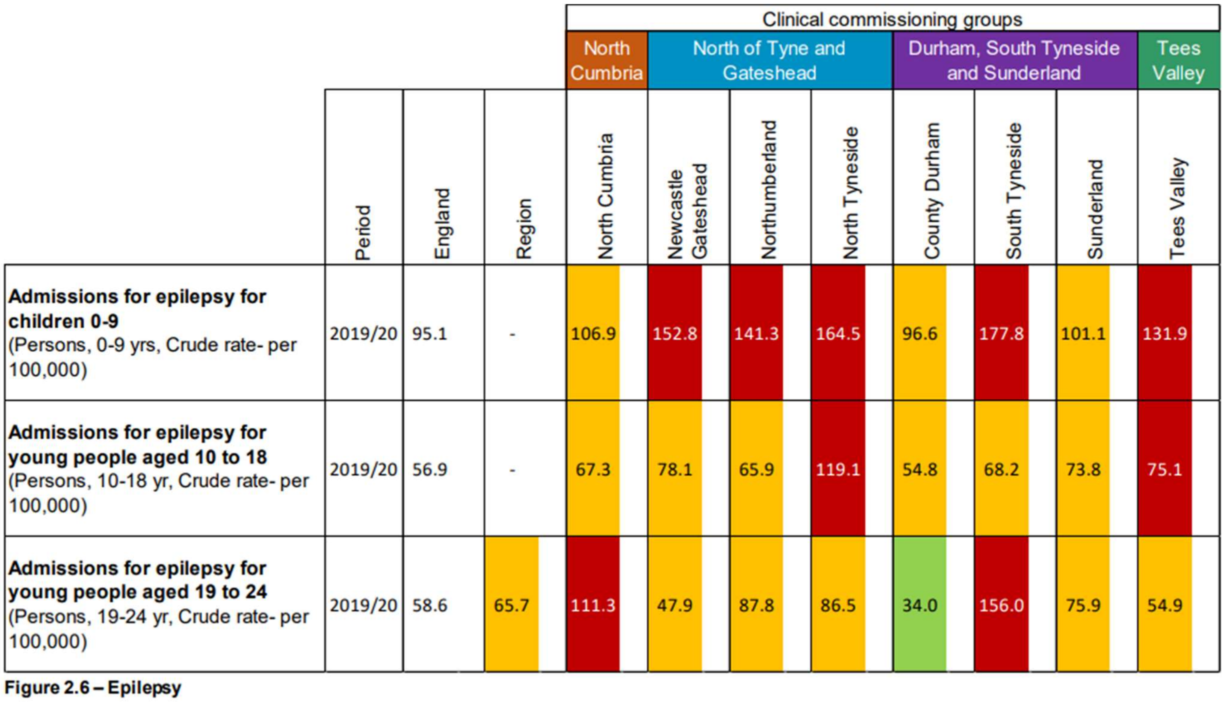
Emergency admissions and A&E attendances are included as a measure of healthcare need in an area, giving a picture of hospital activity across the life course of children and young people. This can be used to prompt further investigation into the causes of admissions and attendances.

Not all emergency admissions to hospital for epilepsy or seizures are avoidable. However, there is evidence that education, support with epilepsy medications and emergency seizure management plans can reduce emergency admissions. High-quality epilepsy care requires a holistic approach that includes psychological and practical support in addition to medical expertise, plus early recognition and support of additional needs (including mental health and special educational needs).

There is evidence to indicate that (where historic data is available) most NENC Clinical Commissioning Groups (CCGs) had significantly higher rates of A+E attendances across age ranges compared to the England average. In children aged 0-4 and 0-17 emergency admission rates were significantly higher than the England average in all NENC CCGs.

At a locality level, the data indicates that on average the majority of NENC CCGs had significantly higher rates of admissions for epilepsy for children aged 0 to 9 than the England average, with rates highest in the region in South Tyneside. For those aged 10 to 18 most NENC CCGs had rates similar to that of the England average. For 19 to 24-year olds there is more variation across the region.

Table 3 NEQOS Facts of Life Report data table showing admission rates for epilepsy for young people 19/20



				Clinical commissioning groups							
				North Cumbria	North of Tyne and Gateshead			Durham, South Tyneside and Sunderland			Tees Valley
	Period	England	Region	North Cumbria	Newcastle Gateshead	Northumberland	North Tyneside	County Durham	South Tyneside	Sunderland	Tees Valley
Admissions for epilepsy for children 0-9 (Persons, 0-9 yrs, Crude rate- per 100,000)	2019/20	95.1	-	106.9	152.8	141.3	164.5	96.6	177.8	101.1	131.9
Admissions for epilepsy for young people aged 10 to 18 (Persons, 10-18 yr, Crude rate- per 100,000)	2019/20	56.9	-	67.3	78.1	65.9	119.1	54.8	68.2	73.8	75.1
Admissions for epilepsy for young people aged 19 to 24 (Persons, 19-24 yr, Crude rate- per 100,000)	2019/20	58.6	65.7	111.3	47.9	87.8	86.5	34.0	156.0	75.9	54.9

Figure 2.6 – Epilepsy

Anecdotally however, there have been a reduced number of CYP presenting to A&E with seizures which reflects improvements in the provision of support to keep CYP out of the hospital and management within the community.

Methodology

The project was undertaken between October 2021 and March 2022. Stages of the work plan were as follows

1 – Establish core steering group and key roles and responsibilities, identify resources

The epilepsy workstream for NENC Child Health and Wellbeing Network has two distinct strands of work. PID and Logic Models were approved at OOG on 13th December 2021.

Project 1 (this project) aims improve the care for children in the NENC ICS footprint with epilepsy especially in the areas of inequality, transition and to reduce avoidable hospital admission and incidence of epilepsy related death. This project looked at the Epilepsy 12 review and focussed on wider service improvement issues e.g. clinic provision, training, emergency care plans, liaising about the medical care, drugs, drug titration, prescribing and transition. The second project focusses on mental health and psychology support for CYP with epilepsy seeking to ascertain availability, access and pathways of referral to mental health services and support for CYP with epilepsy and through analysis of gaps in provision and seeking consensus to develop recommendations for service improvement.

A Leadership Group for Project 1 was identified and set up with key roles (clinical leadership and project management and responsibilities articulated and Terms of Reference developed and agreed 25/11/21.

Additional capacity to support with mapping and data analysis was engaged.

Phil Archman, Data Analyst was appointed to support the programme for 0.2 whole time equivalent (WTE) for a 10-week period between January and March 2022.

Helen Gilpin, Epilepsy Specialist Nurse was appointed 0.3 WTE for a 10-week period between January and March 22. This added capacity to lead the programme of peer to peer interviews and to progress to the extent that was possible, stakeholder engagement.

In addition to this, the project received additional capacity and support from **Susan Lewis**, Epilepsy Specialist Nurse on a non-renumerated basis to extend our capacity to deliver the peer-to-peer interviews.

2 - Mapping Exercise to understand various regional pathways and map gaps (training needs analysis) across the system against the required standards.

This included targeted meetings with colleagues from Education, Primary Care, Secondary Care (Clinical Leads and Epilepsy Specialist Nurses) and Tertiary care. As well as findings and detail from Epilepsy Project 2 the programme of work also benefitted from input from information gathered as part of the NENC ICS Developmentally Appropriate Healthcare and Transitions Workstream.

An initial meeting was held with Mrs Kate Swaddle (Education Advisor to the Network) to gain perspective and current practices about the management of children with epilepsy in education settings across the NENC ICS footprint. An online survey developed using Microsoft (MS) Forms was distributed to an identified cohort of education settings. There was a delay to the commencement and distribution of this part of the work due to needing to align the two epilepsy projects.

A series of semi structured interviews took place between Dr Ramesh Kumar and the various Clinical Leads within each of the Paediatric Epilepsy Centres across the NENC ICS footprint. Darlington and Durham epilepsy services are part of the same Trust; however these services are at two sites with separate leads, hence it was beneficial to have separate discussions. These interviews took place between December 21 and March 22. Responses and interview feedback was recorded by the Interviewer on MS Forms in a way that enabled the capture of quantifiable and qualitative feedback. Results and detail from these semi structured interviews have been available since 17th March 2022.

A series of peer-to-peer semi structured interviews took place. Thirteen ESN's working within NENC ICS footprint and members of PENNEC were identified and given an overview of the project and requested mutual agreeable time to contact for interview. Discussion was to establish role of ESN, caseloads, varying practice and highlighting areas for possible improvement. Interviews were carried out over a period of 5 weeks in January and February 2022 via either face-to-face, phone or Microsoft Teams with peers (Susan Lewis – Paediatric Epilepsy Nurse for County Durham & Darlington NHS Foundation Trust or Helen Gilpin – Paediatric Epilepsy Nurse for South Tees NHS Foundation Trust). Interviews lasted approximately 1-2 hours and answers were uploaded to MS Forms. Results and detail from these semi-structured interviews have been available since 14th March 2022.

Further information that had been collated from Paediatric Epilepsy Clinical Leads and Adult Services speciality leads about transition that provided additional supporting information in relation to the transition and the approach to developmentally appropriate healthcare between paediatric epilepsy services to adult epilepsy services. Information included data about the following:

- Clinic availability resource and accommodation etc
- Involvement of other professionals (youth worker, psychologist, sexual health professionals)
- Documentation and care plan, validated tools, transition plan
- Review opportunities and CYP and family involvement in planning
- Programmes of support in place
- Accreditation
- Data capture / patient flagging
- Named worker/co-ordinator
- Training/knowledge
- Access to clinician for CYP and parent
- Opportunity to meet the adult team/visit ward before handover
- Levels of confidence in transitions processes

3 – Local engagement with CYP and Families to understand local need and aspirations

Work has been undertaken, led by Helen Gilpin (Epilepsy Specialist Nurse), supported by Susan Lewis (Epilepsy Specialist Nurse) to engage with a selection of CYP and families to hear their expectations and experiences of the service and their ideas for service improvement. This information was going to be pulled together into a series of anonymous case studies. The intention of this project was to engage with 4 families one from each of the four ICP areas, North Cumbria (Allerdale, Carlisle, Copeland, Eden) North (Northumberland, Newcastle Gateshead and North Tyneside), Central (Durham, Sunderland and South Tyneside) South (Tees Valley). This has been difficult to achieve. Work was undertaken to develop a process around consent seeking advice from YPAG North East, Children North East, NHSE/I CYP Programme Lead for Participation and CYP Mental Health Programme Lead. Agreed lines of enquiry for these discussions were as follows;

1) Services received? From which Trust?
2) Ease of access to the team? Experience of contact and response from the team? Who responds and how?
3) Experience of epilepsy clinics? Are they joint clinics? How could the process be better?
4) Involvement in writing Care Plans? What do you think of them? How could it be better?
5) Service Improvement: 3 good things, 3 bad things

The expectation was to triangulate the feedback in the resultant case studies against the input from other professional stakeholders and to support the validation of the responses about the services offered across the NENC regional footprint.

This work has not been able to be completed due to misalignment of projects, timescales, challenges with governance and NHS provider trust approval of processes.

4- Bring together findings of the mapping exercise together with the review of the Epilepsy 12 National Audit data and identify recommendations for local implementation

Work has been undertaken to bring together and analyse the information from the various sources alongside the Epilepsy 12 Audit Data to be able to look in detail at the delivery of services to the local population within the NENC ICS footprint.
Sources of information include:

- **NICE Quality Standards 2012–** in relation to the diagnosis, treatment and management of epilepsy and seizures in CYP (under 18) and managing epilepsy and seizures in CYP (under 18).
- **Epilepsy 12 –** local, regional and national data relating to the Epilepsy 12 Audit (Round 3 Cohort 2)
- **Best Practice Criteria Treatment Function Code 223**
- **NEQOS Facts of Life -** facts-of-life-report-final.pdf (northeastandnorthcumbriaics.nhs.uk) – Page 20 talks about epilepsy admission
- **Primary Care** – professional meeting 06/01/22 with Dr Nanda – information is in the form of meeting minutes

- **Schools feedback** (shared with Project 2) – professional meeting 30/11/21 with Mrs Kate Swaddle, meeting minutes available in addition to an online MS forms survey which went out 24/01/22 to approx. 123 settings, 28 responses were received
- **Clinical Leads** – MS forms dataset following structured interviews relating mainly to clinic provision, training, emergency care plans, liaising about the medical care, drugs, drug titration, prescribing, transition. 9 interviews were undertaken and captured
- **ESN** –MS forms dataset following structured interviews. 13 interviews undertaken and responses captured.
- **Stakeholder Feedback** – where available experiential information in the form of anonymous family case studies and CYP peer group story boards were anticipated although not available in time to be included within the report.
- **Clinical Leads Transitions: Developmentally Appropriate Healthcare Feedback**– feedback from paediatric clinical leads and adult services speciality leads in relation to transition and the provision of Developmentally Appropriate Healthcare within epilepsy services.
- **Tertiary Service Lead Interview –** Dr Ramesh Kumar met with Dr Innes Roncero on 17th March 2022 to undertake a semi structured interview to gather intelligence about tertiary service in the region including information about referrals to Epilepsy Surgery in the NENC ICS footprint.
- **NORCESS Data –** data provided by regional epilepsy surgery centre for NENC to demonstrate referral data over a 5-year period

There are several caveats that are to be applied in relation to the data used to support this report and analysis, mainly due to the incompleteness of the data sets and the inconsistency in completion. It has also been highlighted those certain data submissions have been omitted from the Epilepsy 12 data set (in relation to one of the areas: Northumberland) it is assumed however that the data omitted relates to a small number of individual cases and will not adversely impact the overall assumptions of the data. Gaps in data quality and accuracy mean that the data is not always representative.

This report provides an overview of the findings and a series of recommendations for improvement and review over the coming 12 months following April 2022.

5 - Develop a credible plan to respond to the recommendations

The findings from the peer-to-peer interviews and various discussions with professionals across the system have been brought together with local, regional and national data from a range of sources. The information has been triangulated to enable deepened understanding of local practice, engender positive relationships and partnership working and be able to identify some clear (and generally agreed by consensus) improvement areas.

The CHWN has developed its strategic relationship with PENNEC and is currently in the process of formalising this within a partnership working agreement to be able to progress a programme of service improvement across the NENC ICS footprint.

This report identifies some clear areas of deficit and areas for development which are more clearly articulated on page (Conclusions) of this report

A key aspect will be to use feedback from stakeholders to be able to prioritise the improvement areas and to develop the mechanisms for doing this and for ensuring the ongoing engagement feedback loops are well established as we begin to make endeavour to operationalise the strategic priorities of PENNEC and the CHWN.

The report itself will be taken to CHWN Operational Oversight Group in September 2022 as part of governance and approval for closure of the project. The report will also be tabled at CHWN Systems Engagement Group in August 2022 to ensure members are sighted on the programme of work. In addition, the report will be shared with Paediatric Epilepsy Services and PENNEC representatives in August 2022 and the paper will be tabled for further discussion at PENNEC in November 2022 to reflect on delivery.

Risks and Issues

A key role of the Epilepsy Leadership Group (Project 1) has been to manage, mitigate, respond to and resolve risks and issues that have been presented throughout the duration of the project and as such logs and actions have been captured and recorded as part of the risks and issues log which have been reviewed throughout the programme.

There were issues that could not be managed as risks including limitations to data and ability to quantify impact/measurable change, the COVID pandemic and systemwide focus on recovery impacted prioritisation of work. In addition, more practical issues like delay to the commencement of the data support resource due to financial/transactional issues, and the delay to the distribution of education questionnaire to align the requirements of a simultaneous project.

Gaps in data quality and accuracy, particularly Epilepy12 data was highlighted during the report development. This has been validated by the Epilepsy 12 data team at RCPCH, who provide data with caveats explaining why the data is not always representative for a multitude of reasons. Primarily, that submission of data is sometimes incomplete. All the national data audits have been impacted by the COVID pandemic.

Risks that have been identified, assessed, mitigated (to the best possible extent) and monitored are numerous, ranging from the limitations of the funding into future years to being able to deliver suggested recommendations on the back of the findings from this paper. Additionally, making sure there is efficient use of funds for the monies that had been made available in year 2021/2022.

Risks to project delivery due to resource (staff capacity and skillset) were identified due to the technical nature of some of these project tasks. Resources and support were obtained and engaged to ensure that necessary skills were available to secure delivery of the key requirements of the programme of work. Further to this, timescales were pressured due to sickness absence and also staff holidays as well as other unplanned leave of absence.

Another key risk that impacted the project was the need to place additional demands on an already pressurised system for example primary care, plans were put in place to be able to obtain a representative view and to be able to use the knowledge and experience of the Primary Care Advisor to the Network.

By far the biggest risk to this project was the requirement to align two epilepsy projects that had been running concurrently, this posed risks to timescales and delivery initially and became a challenge near the closure in relation to potential risks of duplication and participant fatigue. In each case mitigations were in place but remained pressing throughout the course of the project.

Education Settings

An initial meeting took place between Dr Ramesh Kumar, Kate Swaddle (Education Advisor to the Child Health and Wellbeing Network) and Louise Dauncey on 30th November 2021.

Purpose of meeting was to be able to gain perspective from education settings about effective management and competencies and support in relation to epilepsy in children.

Kate Swaddle explained her experience of epilepsy and identified that there are currently a small number of CYP on roll at her place of work and provided some information about management of their needs, training for colleagues in the setting and that medication was being reduced for one of the CYP who has not had seizures for a long time and how this was being managed/monitored.

The list below identifies the broad subject headings that were discussed at length at this meeting

- Training needs for the school staff
- Impact of epilepsy for CYP on access to education
- Prevalence of epilepsy in schools
- Management of healthcare needs in school settings
- Support from ESN
- 0-19 Universal Services involvement
- How to improve processes
- Wider engagement across the education system (best routes)

It was agreed that we would capture feedback from the education system to provide external input and credible experiential information by means of online questionnaire. We discussed and agreed an appropriate group of settings/mechanism for distribution.

The questionnaire was developed with the input of Kate Swaddle and the Epilepsy Project 1 Leadership Group and was then significantly enhanced and extended by the Epilepsy Project 2 Leadership Group to improve data capture for project 1 and provide feedback for Project 2.

An online survey (MS Forms) was sent to an identified cohort of education settings (109+14 = 123). It is assumed that larger settings (e.g. secondary schools) are likely to have more children on-roll with epilepsy compared with smaller local community primary schools. It is well-documented that specialist school settings, additionally resourced provision and pupil referral units have more children on-roll with a diagnosis of epilepsy than mainstream providers. The survey aimed to capture the views of staff working across these settings and as such the distribution list was tailored to enable representative feedback. The agreed distribution was to NENC CHWN's membership list: the survey was emailed to senior leaders e.g. headteachers, deputy/assistant headteachers, pastoral, mental health and inclusion leads and SENCOs. Fourteen additional settings were selected based on known local population and demographic and to ensure equitable spread of mainstream and special school provision. The survey was available and accessible/open for a three-week period in January/February 2022. There was a delay of approximately 5 weeks to the commencement and distribution of this part of the work due to needing to align the two epilepsy projects.

The questionnaire sought details of the Index of Multiple Deprivation (IMD) Index due to the increased prevalence of schools in deprived areas having an increased number of children with SEND (Education Endowment Fund, 2017). In addition, there is an increased prevalence of those from deprived backgrounds, also having epilepsy and less favourable outcomes as they reach adulthood (Camfield, Camfield and Smith, 2016).

Results have been available from this survey since 14th February 2022. This survey had a response rate of c23% with an average completion time of 36.5 minutes. Twenty-one of twenty eight respondents (75% of those surveyed) had worked with children and young people who had a diagnosis of epilepsy, in the last five years, and from those surveyed, most settings (n=22) had between 1-6 pupils on-roll, with epilepsy.

Primary Care

An initial meeting took place between Dr Ramesh Kumar (Consultant Paediatrician, Clinical Lead and Advisor to the Child Health and Wellbeing Network, Dr Vaishali Nanda (Primary Care Advisor to the Child Health and Wellbeing Network) and Louise Dauncey on 6th January 2022.

The purpose of the meeting was to gain primary care perspective in relation to epilepsy care for children and young people.

The list below identifies the broad subject headings that were discussed at length at this meeting:

- Background/vision and aim of Project 1 and an explanation of the different strands of the work
- Challenges within primary care and proposed solutions about what would be helpful
- Journey of the patient with suspected seizure/epilepsy
- Current pathways/expectations – role of primary care
- Access to medication/prescriptions by patients/carers
- Family and wider system impact
- Reviews / ongoing care
- Transition
- Changing face of primary care workforce
- Education and training about epilepsy in children in primary care workforce

- Primary Care Networks (PCN) platforms for engagement
- Future resources required by primary care from the Integrated Care System (ICS)

According to NICE guidance the following standards as described are expected and/or assumed for the care of children and young people with suspected seizures or epilepsy:

- Should be assessed by a healthcare professional.
- General Practitioners (GP) are generally the first point of contact.
- Carer may have been taken to the hospital emergency department.
- GP should refer the child with suspected seizures for specialist opinion in secondary care.
- CYP should be offered an urgent appointment within 2 weeks with a specialist (the specialist should be a doctor who treats and cares for children (a paediatrician) and who has also had special training in diagnosing and treating epilepsy).
- While CYP is waiting for an appointment with the specialist, the information about how to recognise a seizure and what to do if the CYP has another one, advice about first aid and contact details of a healthcare professional if they have another seizure before CYP have been seen by a specialist.
- Whilst CYP is diagnosed with epilepsy under specialist epilepsy team within secondary or tertiary care, GP's continues to have a crucial role including
    - ➢ Ensuring ongoing supply of antiepileptic medications.
    - ➢ Monitoring of complications related to underlying health issues.
    - ➢ Providing support to the CYP and the carer.
    - ➢ Helping to facilitate training if necessary.

Dr Nanda outlined her personal experience and an overview of areas for discussion:

- There is no change to the universal access to GP in primary care for CYP with presenting health needs in the community
- There are challenges with understanding criteria for referral and there is a need for a clear referral pathway.
- There is a need to understand how soon patients need to be seen and how to establish urgency, for example whether patients need to be seen today, 48 hours or whether routine appointment is acceptable. These should be described in a clear referral pathway.
- Telephone triage opportunity has been helpful and needs to be maintained due to current variation in practice in individual services across the region.
- Limited update from secondary care about what is the outcome of the referral into secondary care and GP is unaware of how soon patient will be seen. An assumption may be made by primary care colleagues that CYP have been managed well in secondary care. Improved communication would resolve this to understand when patients will be seen in secondary care.
- There is a need to understand whether patients have direct access to secondary care, a decision usually taken by secondary care clinical teams and services.
- It was felt that mental health and appropriate transition are areas for further discussion and could be improved with clear pathways.

- There is a need to use Healthier Together to communicate referral pathways once articulated clearly.

Findings and Interpretation

Education settings perspective in relation to epilepsy care in CYP

A range of information from education settings about the care, management and support for CYP with epilepsy was collated through the survey undertaken within education settings on behalf of NENC CHWN. This survey collated information for both of the epilepsy projects simultaneously, some information was relevant for both projects and some was unique to epilepsy project 2.

The survey was distributed to and gathered from the following local authority boundary areas: Allerdale and Copeland, Carlisle, County Durham, Darlington, Eden, Gateshead, Hartlepool, Middlesbrough, Newcastle-Upon-Tyne, North Tyneside, Northumberland, Redcar and Cleveland, South Tyneside, Stockton-on-Tees and Sunderland.

Whilst the survey captured the views of staff as defined by local authority boundary, it also gave an insight into Clinical Commissioning Group/Integrated Care Partnership support. This is useful when attempting to define the next steps to achieve an integrated approach to improving and optimising service delivery for CYP with epilepsy.

Responder characteristics

There were 28 responses from 15 local authority boundary areas**.** At least one school response was obtained from all local authority boundary areas within the NENC ICS footprint except Copeland (West Cumbria, based in Whitehaven).

Responses came from a mixture of school types including five Special Educational Needs (SEN) schools with the majority coming from nursery and primary schools (see Table 4 below).

Table 4 breakdown of setting type for responses to the education setting survey

Type of School	Number	As a proportion (%)
Mainstream nursery and primary school	18	64
Mainstream middle/secondary School	3	11
All-through provision school	1	4
SEN School	5	18
Other	1	4

The number of pupils at each school ranged from < 100 pupils to > 1000 pupils but 68% in this survey had between 100 to 399 pupils enrolled.

The independent sector was not represented in this survey and only 3 mainstream middle/secondary schools were represented.

Of the 28 responses that were received to the survey, 15 identified the IMD score for the school setting postcode area. Eleven of the fifteen who responded confirmed that their IMD score was five or under which demonstrates that there is a larger proportion of education settings that are in the more deprived localities.

Table 5: Overview of the roles of the colleagues who responded to the survey:

Role of person completing the questionnaire	Number	Comment
Headteacher	8	
Deputy/Assistant Headteacher	7	5 with (Special Educational Needs Co-ordinator) SENCO role
Senior leadership team member	2	Both with SENCO role
SENCO	6	
High Level Teaching Assistant	1	With SENCO role
Safeguarding lead and school health advisor	1	
Other	3	Emotional and Wellbeing Lead SEND Admin Manager Admin

The table shows that many deputy headteachers/assistant headteachers also fulfilled the SENCO role making them well-placed to respond to the survey's questions about delivery of care for CYP with epilepsy. It has been observed that there is a wide range of respondents to the survey who have provided information about the management and support for CYP with epilepsy in these settings.

Indices of deprivation

The survey asked respondents if they knew the Index of Multiple Deprivation (IMD) for their school. 54% of survey respondents knew their IMD. 15/28 respondents reported scores which ranged from 1 (most deprived) -10 (least deprived) with a median of 4. The information about IMD is pertinent for mainstream settings however IMD becomes more obscure for specialist settings because they are more likely to enrol pupils from across local authority boundaries, from a mixture of socioeconomic backgrounds.

Recording of epilepsy as a health condition by schools

21/28 schools (75%) reported that they had worked with CYP with epilepsy in the last five years and in the case of special schools, 4/5 have cared for 16 or more. 96% of schools confirmed that they recorded the presence of epilepsy as a diagnosis of main illness on the school's central information management system. At the time of the survey, 18 of the 28 settings reported that they currently had one or more CYP with epilepsy on-roll.

Information in relation to Individual Healthcare Plan

Of the 18 settings that had CYP with epilepsy on-roll at the time of the survey, all bar two of the settings had arrangements for the parents/carers to sign an Individual Health Care Plan declaration on the behalf of the CYP. 21 of the 28 respondents to this question indicated that Individual Health Care Plans, where they were in place, were updated at least annually.

Involvement/support from ESN

Of the 21 settings that have identified that they currently have (at the time of the survey) CYP with epilepsy on roll or that they have supported CYP with epilepsy in the last five years, 15 of them have confirmed involvement and support (to varying degrees) from the ESN. The remaining six reported that they have not received input from ESN for CYP with epilepsy either currently or historically.

Only 6/21 respondents confirmed that every CYP with epilepsy in the setting has an Individual Emergency Health Care Plan prescribed and issued by the hospital epilepsy team which is usually developed by ESNs. A further 7 respondents confirmed that some (not all) of the CYP with epilepsy had Individual Emergency Health Care Plans.

Of those that said yes to all or some CYP with epilepsy in their settings having Individual Emergency Health Care Plans, less than half (46%) did not have an annual review with the input and support from and ESN.

This survey has highlighted the variation in support received by education settings from ESNs across the NENC ICS footprint. This variation could be explained by agreed local practice of individual epilepsy services in place within the local authority boundary areas and availability of workforce and resources. However, the survey showed that there is input of ESNs in the formulation and review of Individual Health Care Plans in a significant number of cases. This is very important for continuity of epilepsy care in the education settings.

Staff training in education settings

75% of the respondents to the survey have indicated that some school staff have received specific epilepsy training, outside of paediatric first aid, or general first aid accredited courses. Only six respondents to this question estimated that more than half of the staff have received the training. 67% of the respondents indicated that less than a quarter of the staff team had received specific training. In most cases, this training was provided by the ESN, other sources of training included community nursing teams and internal learning disabilities nursing staff.

Only 3/28 respondents confirmed that they were aware of epilepsy training resources for teachers (e.g. PET (Paediatric Epilepsy Training) Level Zero delivered by the British Paediatric Neurology Association/Epilepsy Action - Course for Teaching Staff)

Only 6/28 respondents confirmed that there had been additional training needs (relating to epilepsy) identified for their workforce. 20/28 respondents either stated no additional training needs or don’t know. The remaining two survey participants did not respond to this question.

The survey has highlighted the significant variation in the perceived need for, availability and delivery of epilepsy awareness training for the staff in education settings who are involved (or who are likely to be involved) in the care of CYP with epilepsy. This area has potential to improve as there is strong evidence staff training in epilepsy care improves health outcomes for CYP with epilepsy.

SEND register and EHCP

Table 6 below demonstrates that the majority of mainstream schools that responded to the survey (92%) have relatively few CYP with epilepsy on their SEND register in comparison to special schools, where the majority of CYP are on the SEND register.

Table 6: Proportion (%) of CYP with epilepsy on school SEND Register

% of CYP with epilepsy currently on the SEND register	**0-19%**	**20-39%**	**40-59%**	**60-79%**	**80-100%**	**N/A**
Mainstream nursery and primary schools	11	0	0	0	1	6
Mainstream Middle / Secondary schools	3	0	0	0	0	0
All through provision school	0	0	1	0	0	0
Special educational needs schools	0	0	0	0	5	0
Other	0	0	0	0	1	0
	14	**0**	**1**	**0**	**7**	**6**
	64%	**0%**	**5%**	**0%**	**32%**	

Similarly, mainstream school respondents reported that a minority (2/16) of students with epilepsy have an EHCP (Education Health and Care Plan), whereas 4/5 special schools reported that all CYP with epilepsy had an EHCP.

Primary care perspective in relation to epilepsy care in CYP

The findings and interpretation in this section have originated from the discussion with Dr Vaishali Nanda and as such represent her opinion as a general practitioner in her capacity of the Primary Care Advisor to the Child Health and Wellbeing Network. The detail reflects her experience and understanding of practice in her local PCN, however her experiences can be extrapolated to reflect the local regional position.

The typical journey of a child and family is described below for the purpose of contextualising the following:

Acute seizures happen outside hospital settings including home, school and community which are usually witnessed by parents, teachers, or carers. In such acute situations, the child needs first-aid, access to acute care including admission to ED. In these circumstances primary care services are usually not required, however the CYP may need access to ambulance and/or emergency services. This is achieved by universal services and expected to have no variation.

The CYP with suspected seizures observed at home or at school have GP as a first point of contact (FPOC) via access to universal services, however there could be variation in relation to how primary care respond to each situation.

Dr Nanda identified the following areas of challenge and opportunities for development.

- Improve education, training and practical support for primary care in the form of study days that integrate newly developed pathways into the training package.
- Improve support to GPs to manage cases that have been discharged by epilepsy secondary care services.
- Enhance mechanisms to improve education and understanding for families of CYP with epilepsy.
- Improve parental relationship and confidence in primary care which has the potential to reduce dependency on secondary care services where it is not required.
- Need to develop an inter-speciality referral mechanism to address medical, educational (including SEND Needs) social, emotional needs of CYP with epilepsy.
- Develop transitional pathways across primary and secondary care, with the potential for GPs involvement in transition at an earlier stage.
- Review primary care contracting arrangements to ensure that there is provision for step-down patients and provision for CYP with epilepsy aged 16 or below to receive required intervention in primary care.
- Agree a process for shared care agreements for prescribing responsibility in primary care to provide continuity of care including ensuring medication is prescribed by staff with appropriate skills and authority to maintain prescription compliance to respond to CYP and family needs.
- Ensure primary care representation with Paediatric Epilepsy Network North East and Cumbria (PENNEC).

The variation in terms of primary care response could be explained due to the lack of clarity and inconsistency of the referral pathway into secondary care services.

GPs are generalists by nature and therefore cannot be expected to have specialism in various fields. Some GPs may have special interest in neurological conditions in CYP but this is not very common and can lead to variation in the level of skills and competency within primary care settings.

There is a need to consolidate and improve training and education across primary and secondary care.

The NICE guidance identifies the requirement for CYP to receive an appointment within secondary care within two weeks of referral; however, this rarely happens due to limited capacity and workforce in secondary care specialist services.

It was recognised through discussion with Dr Nanda that having access to a Rapid Access telephone triage is a beneficial service and conduit to support consistency and to improve confidence and competence to effectively manage needs in primary care settings. It is noted however that this is not a service that is universally accessible across the NENC region. This is an area of development for the Network to promote and support the availability.

It is highlighted that there is a significant gap in referral pathways and services to address wide ranging emotional wellbeing and mental health needs in CYP with epilepsy and their families.

It was appreciated that primary care should be represented in PENNEC and this would be helpful for cross fertilisation and for the improvement of coordination.

The interface between primary and secondary care can be improved by means of development of single digital platform to manage patient information to enhance communication and seamless service delivery.

Epilepsy 12 Indicators

Provision of a paediatrician with expertise in epilepsy care

NICE has published guidance to suggest that diagnosing epilepsy can be complex, and it has been estimated that misdiagnosis can occur in up to 30% of cases. It is crucial that specialists are involved early in the management of CYP with suspected epilepsy and establishing correct diagnosis of epilepsy which is a hallmark of epilepsy care.

NICE Quality Standard 27 (statement 1) states that CYP presenting with a suspected seizure are seen by a specialist in the diagnosis and management of the epilepsies within two weeks of presentation.

NICE Quality Standard 27 (Statement 8) states that children and young people with epilepsy have a structured review with a paediatric epilepsy specialist at least annually.

Regular structured reviews are important in ensuring that ongoing interventions are effective in meeting the needs of CYP with epilepsy and to identify if any other support measures are required to improve or maintain good quality of life. The reviews also ensure that epilepsy management care plans remain relevant and up to date.

Data from Epilepsy 12 2020 National Clinical Audit Results (Round 3, Cohort 2) identifies that services within PENNEC has similar levels (89%) of Paediatrician input (with expertise in epilepsy or neurologist) as England & Wales (87%).

Feedback from the clinical lead's interviews confirm that 100% (n=8) services have a consultant who is an unofficial lead and services have dedicated time in their job plan to lead the service. According to best practice tariff this should be 0.5 Programmed Activity (PA) allocated to the epilepsy lead in each service. The number of clinicians undertaking epilepsy related work in services across the NENC footprint was variable however services also had 1 or 2 consultants who provide expertise in epilepsy and who take epilepsy related work within their roles. Epilepsy 12 data indicates that there is anywhere between 1 to 9 Whole Time Equivalent (WTE) paediatric consultants with expertise in epilepsy but, clearly, only a small proportion of this time is dedicated to epilepsy work and, as such, this figure is misleading.

Soft intelligence from service leads confirmed that WTE consultant within epilepsy services was variable and was difficult to estimate however anecdotally ranged between 0.2 - 0.6 WTE spent working on epilepsy. Clinicians interviewed confirmed that in practicality the dedicated time for clinicians ranged between 0.25 to 0.5 PA per week. Three colleagues confirmed that they did not have any time allocated in their job plans. All participants interviewed felt that there should be dedicated time in their job plans for epilepsy lead role to improve the service.

Feedback from the service lead interviews and the ESN interviews confirm that all areas, with the exception South Tees and Newcastle, have a designated Epilepsy Clinical Lead; although anecdotal feedback indicates that someone is taking the lead in this area without the official recognition or job title.

The findings about the provision of consultant with epilepsy expertise across the region is variable within each of the services and there is need for more workforce to address this gap in the epilepsy service.

The findings also highlighted the need to ensure that there is adequate allocated time included within the job plans to recognise epilepsy related work and to formalise the expectation and manage capacity and resource.

There is a need for nominated clinical lead in each service across the PENNEC/NENC ICS footprint.

Epilepsy Clinic Provision in Services

The findings demonstrate that all services have defined epilepsy clinics at secondary level, the number of epilepsy clinics per week ranged between one and three per week in each service.

Some units monitor suspected epilepsy patients in general paediatric clinics. Five of the nine service leads interviewed confirmed that they do assess and monitor CYP in general paediatric clinics and confirmed that this was less often. However, very few of the clinicians interviewed were able to articulate how many children they saw in these clinics, although two of the five suggested that around 20% of children with epilepsy were seen in general paediatric clinics.

Service leads confirmed that most of the services were using hybrid epilepsy clinic templates, seven of nine responses have indicated that they hold a mixture of new and review clinic templates.

Feedback from service leads indicated that new patient appointments range between 30 and 45 minutes and that follow-up appointments range between 20 and 30 minutes

Five services provide joint clinics by clinician and nurse, this is corroborated by feedback from the ESNs. Four service leads have confirmed that their services provide joint clinics in the same room. One of the five services that provides a joint clinic does so but in a separate room however the feedback from the ESNs across the footprint confirm that in practicality this is delivered as a mixture of both. There was a range of responses from service leads relating to follow up appointment in joint clinics in terms of the length of appointment ranging between 20 and 30 minutes.

Four units were currently running TFC 223 epilepsy best practice criteria clinics whereas other units were in discussion with management about compliance.

All services have administration time associated with epilepsy clinics and this varied between 30 and 120 minutes, depending on the number of clinics held.

Feedback from service leads confirmed that no services provide specific administration time separately for epilepsy nurses within clinic time although feedback from the ESN interviews confirm there is some additional general administrative support that they can access for some but not all services.

Table 7 Feedback from Epilepsy Specialist Nurses about provision of administration support

	Admin support available	**Comments**	**Duties involve**
County Durham and Darlington FT (CDDFT)	No		Rely on support from an apprentice admin assistant, typing letters, filing notes and making appointments.
North Cumbria Integrated Care FT (NCIC)	Yes but minimal	Part of admin support team given to the community nursing teams	Answering phone and leaving messages
North Tees and Hartlepool FT (NTHFT)	Yes	Admin support provided by the Trust admin hub.	Taking phone calls and then tasking on SystmOne. Letters generated on SystmOne from consultations will then be printed by Admin Hub and sent out.
Northumbria Healthcare FT (NHCFT)	Yes	15 hrs per week	Types letters, care plans for new patients, rings patients week before clinic so good attendance, organises training sessions, keeps database up to date
South Tees Hospitals FT (STHFT)	Yes	9.5 hrs per week	Answering phone and take messages, keeping excel spreadsheet of patients up to date, printing & scanning of letters and care plans, ordering of information leaflets
South Tyneside and Sunderland FT (STSFT)	No	Rely on typing pool and consultant secretaries	

The findings have highlighted that most services are offering dedicated epilepsy clinics under supervision of epilepsy specialist and ESN. Over half of the services are using alternative methods such as seeing patients in general paediatric clinics or day units to endeavour to manage the demand.

The findings also highlighted the joint working between clinician and epilepsy nursing in outpatients setting to optimise the management of epilepsy.

Pattern of Referrals

Epilepsy 12 data for services in the PENNEC/NENC ICS region indicates that the majority of the referrals (45%) originate from the ED, and then from General Practice (32%). Other referrals come from outpatient and inpatient paediatric assessments and other services. Feedback from service leads interviews corroborates this.

NICE guidance states that CYP presenting with a suspected seizure should be seen by a specialist in the diagnosis and management of the epilepsies within two weeks of presentation. Epilepsy 12 data indicates that only 26% of CYP are seen by a paediatrician with expertise in epilepsy within 2 weeks within the PENNEC/NENC ICS footprint which is similar to the national average (25%). The service leads have expressed that they all struggle to provide this. The service lead's responses show that only two of the nine services have indicated that they are able to see new/suspected epilepsy patients within 2-4 weeks. There is the ambition from service leads to offer appointments within the 2 weeks and make best efforts to deliver this, however there are service limitations. Some services in PENNEC/NENC ICS region offer rapid access clinics and facilitate ward attendances to enable patients to be seen within 4 weeks and this may account for the proportion of CYP (c20%) seen in general paediatric clinics.

At the time of the contact with service leads the anecdotal average time to see new suspected epilepsy patients in various services range between 4 and 12 weeks which needs improvement

Access to the Services by Patients and their Parents

As per NICE guidance CYP with epilepsy should have an accessible point of contact with specialist services. [2004]

All services confirm that patients can access the epilepsy service for specialist advice, in all cases except one service, this access is available Monday to Friday. This is achieved by the availability of either a dedicated phone line or the ability to leave messages with the consultant's secretary, in most cases the follow up response and initial specialist advice is provided by the ESN, where available. Similarly, ESNs have confirmed that they generally are available Monday to Friday 9am until 5pm although one service has confirmed availability between 8am and 6pm. None of the services have weekend or bank holiday arrangements and one service, the largest, has no cover for annual leave or sickness absence. Service leads have commented on gaps and the deficiency and inequality in ESN support and consequently have articulated business cases and proposals to respond to this at Trust level. In terms of response times to patient contact, there is significant variation in the expectations. Five of the eight areas endeavour to respond by the next working day, the others respond accordingly in response to clinical need however this is impacted by staffing availability.

The findings suggest that access to services by patients and their parents is valuable to maintain the continuity of care and providing support to other health professionals. However, there is room to improve the availability and equity of this service across the NENC footprint. There is also the need to undertake an evaluation to understand the views and levels of satisfaction of the parents/professionals about the necessity and impact of this provision.

Provision of epilepsy specialist nurse in epilepsy services

NICE Guideline 1.8.3 suggests that Epilepsy Specialist Nurses (ESNs) are an integral part of the network of care for CYP with epilepsy. The key roles of the ESNs are to support both epilepsy specialists and generalists, to ensure the continuity of care and provide access to community and multi-agency services. Their role also involves providing information, training and support to the CYP, their families/carers and other professionals involved in the child's education, welfare and well-being.

NICE Guideline 1.8.4 identifies that healthcare professionals have a responsibility to educate others about epilepsy to reduce the stigma associated with it. They should also provide information about epilepsy to all people who come into contact with CYP with epilepsy, including school staff, social care professionals and others.

NICE Quality Standard 27 (statement 5) states that CYP with epilepsy are seen by an epilepsy specialist nurse who they can contact between scheduled reviews to provide appropriate support, information and guidance.

The recent NICE Guidance April 2022 states:
"Ensure that all children, young people and adults with epilepsy have access to an epilepsy specialist nurse who:

- has a central role in providing information, education and support;
- supports epilepsy specialists and healthcare professionals in primary and secondary care, and in educational, respite and social care settings;
- is a point of contact for, and facilitates access to, other community and multi-agency services".

The proposed 2022/23 National Tariff Payment System (NTPS) includes specific guidance and incorporates the existing provision of best practice tariffs (BPTs) for paediatric epilepsy. Clause 193 of the BPT for paediatric epilepsy states that "Trusts should develop services that include appropriate access to epilepsy specialist nurses (ESNs), mental health professionals and paediatricians with expertise in epilepsy. ESNs form a fundamental bridge between primary, secondary and tertiary care and epilepsy surgery care. They ensure that epilepsy is managed in the community and school settings when needed rather than just in the hospital ward or clinic".

Data from Epilepsy 12 2020 National Clinical Audit Results (Round 3, Cohort 2) indicates that the services within the PENNEC/NENC ICS region have lower levels (63%) of ESN input comparative to England & Wales (73%) and this reflects the reduced level of ESN input reported by Newcastle and Gateshead Epilepsy Services.

Services in the PENNEC/NENC ICS region provide below the national average in terms of reported ESN input at a Trust level, due principally to the lack of ESNs at Newcastle and Gateshead epilepsy services. This was confirmed by the feedback from service leads who explained that there are no ESNs within their service and that they were currently in discussion with management, in the meantime a proportion of the work that would be undertaken by the ESN is delivered by consultants.

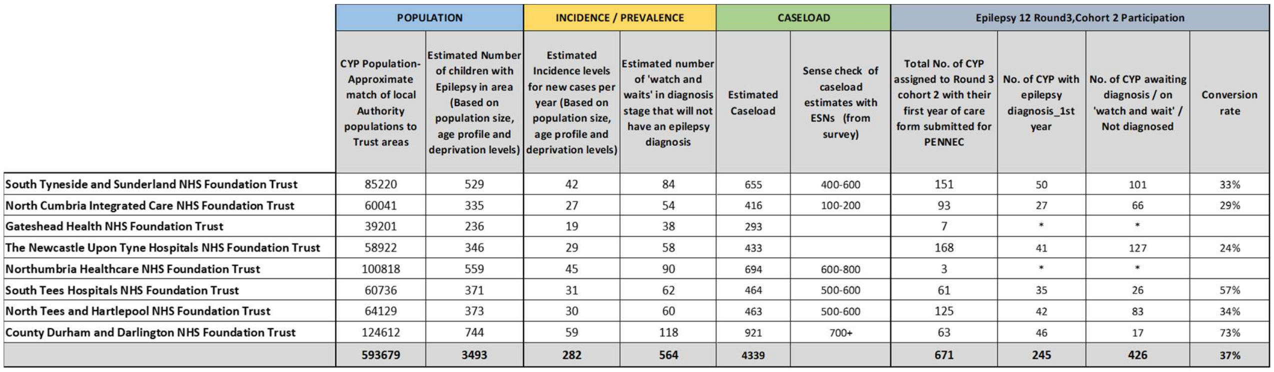
The national average ESN establishment is 1.7 WTEs per 100,000 CYP population. Across the epilepsy networks, this varies between 0.8 and 4.4 WTE ESNs per 100,000 CYP population. Services within the PENNEC/NENC ICS region has a totality of 9.6 WTE ESNs and serves a CYP population of circa (c) 600,000; equivalent to 1.5 WTE ESNs per 100,000, just below the national average.

The provision of ESNs varies between Trusts, ranging from Newcastle and Gateshead having no ESNs, to South Tees having the equivalent of 3.8 WTE ESNs per 100,000 CYP population catchment. This is supported by the feedback from the service leads and the ESNs however the South Tees locality is one of the most deprived with additional challenges that impact on health outcomes.

The Royal College of Nursing (RCN) and Epilepsy Action makes a general recommendation for Specialist Nurses in relation to caseload size and indicates that this should be in the region of 1.0 WTE ESN for every 250 cases. Based on a caseload of 4300 CYP with epilepsy in the PENNEC/NENC ICS region, there is a significant shortage of ESN support. There are currently 9.6 WTE ESNs, compared with the RCN recommended level of 17.5 WTE ESN for the overall caseload, which highlights a shortfall of 7.9 WTE ESNs.

There is also significant disparity between Trusts regarding the level of ESN support available. Gateshead and Newcastle do not have any ESNs; whilst South Tees has slightly more ESN resource than their estimated caseload would suggest is required. All other areas are under-resourced. In particular, County Durham and Darlington which covers the largest area in PENNEC/NENC ICS region and has the largest associated caseload, based on population modelled estimates.

Table 8 Population modelled estimates, incidence and caseload numbers and Epilepsy 12 Round 3, Cohort 2 participation by Trust



	POPULATION		INCIDENCE / PREVALENCE		CASELOAD		Epilepsy 12 Round3,Cohort 2 Participation			
	CYP Population- Approximate match of local Authority populations to Trust areas	Estimated Number of children with Epilepsy in area (Based on population size, age profile and deprivation levels)	Estimated Incidence levels for new cases per year (Based on population size, age profile and deprivation levels)	Estimated number of 'watch and waits' in diagnosis stage that will not have an epilepsy diagnosis	Estimated Caseload	Sense check of caseload estimates with ESNs (from survey)	Total No. of CYP assigned to Round 3 cohort 2 with their first year of care form submitted for PENNEC	No. of CYP with epilepsy diagnosis_1st year	No. of CYP awaiting diagnosis / on 'watch and wait' / Not diagnosed	Conversion rate
South Tyneside and Sunderland NHS Foundation Trust	85220	529	42	84	655	400-600	151	50	101	33%
North Cumbria Integrated Care NHS Foundation Trust	60041	335	27	54	416	100-200	93	27	66	29%
Gateshead Health NHS Foundation Trust	39201	236	19	38	293		7	*	*	
The Newcastle Upon Tyne Hospitals NHS Foundation Trust	58922	346	29	58	433		168	41	127	24%
Northumbria Healthcare NHS Foundation Trust	100818	559	45	90	694	600-800	3	*	*	
South Tees Hospitals NHS Foundation Trust	60736	371	31	62	464	500-600	61	35	26	57%
North Tees and Hartlepool NHS Foundation Trust	64129	373	30	60	463	500-600	125	42	83	34%
County Durham and Darlington NHS Foundation Trust	124612	744	59	118	921	700+	63	46	17	73%
	593679	**3493**	**282**	**564**	**4339**		**671**	**245**	**426**	**37%**

Table 9; Population modelled estimates, caseload numbers and staffing levels by Trust

	POPULATION		CASELOAD	STAFFING LEVELS				
	CYP Population- Approximate match of local Authority populations to Trust areas	Estimated Number of children with Epilepsy in area (Based on population size, age profile and deprivation levels)	Estimated Caseload	WTE general paediatric consultants	WTE general paediatric consultants with 'expertise in epilepsy'	Total WTE epilepsy specialist nurses	Recommended number of ESNs based on caseload (RCN recommend 250 pts per ESN)	Gap
South Tyneside and Sunderland NHS Foundation Trust	85220	529	655	16.7	3.2	1.5	2.6	1.1
North Cumbria Integrated Care NHS Foundation Trust	60041	335	416	16	1	1	1.7	0.7
Gateshead Health NHS Foundation Trust	39201	236	293	11.83	1.3		1.2	1.2
The Newcastle Upon Tyne Hospitals NHS Foundation Trust	58922	346	433	13.5	2.6		1.7	1.7
Northumbria Healthcare NHS Foundation Trust	100818	559	694	14	9	1.8	2.8	1
South Tees Hospitals NHS Foundation Trust	60736	371	464	23	4	2.3	1.9	-0.4
North Tees and Hartlepool NHS Foundation Trust	64129	373	463	22	2.5	1.5	1.9	0.4
County Durham and Darlington NHS Foundation Trust	124612	744	921	30	5	1.5	3.7	2.2
	593679	**3493**	**4339**	**147.0**	**28.6**	**9.6**	**17.5**	**7.9**

The level of ESN input / support across the PENNEC/NENC ICS region is similar to that in other regional networks across most of the ESN functions (for example home visits, ESN clinics, ED visits, ward visits, prescribing, school meetings, care plan facilitation, rescue medication training for parents), with the exceptions of ward visits (not provided In North Cumbria) and ESN prescribing (better than national average, but not provided at North Cumbria). This range of services provided by the ESNs was supported by the ESN peer to peer interview feedback who elaborated on the type of work. This includes in practicality, the following activities:

- *Clinical advice to patients*
- *School advice*
- *Social worker advice*
- *MDT meeting*
- *Nurse led clinics (independent)*
- *Joint clinics with clinicians*
- *New patient clinics*
- *Follow up clinics*
- *Home visits*
- *School visits*
- *Emergency Healthcare Plan*
- *Education Health and Care Plan*

In addition to these activities ESNs also need their own professional development opportunities.

Soft intelligence provided by the peer to peer ESN interviews highlighted that consultation in relation to Sudden Unexpected Death in Epilepsy Patients (SUDEP) with patient and families is a challenging scenario. Most nurses felt further education and training sessions would be valuable and can be arranged via PENNEC educational meetings.

All ESN's felt that a regular regional meeting of ESN's on a scheduled basis would benefit their services to enable sharing of good practice, strengthening relationships, peer support and ultimately improving care for CYP and their families.

When asked to state three areas for improvement to their services:

- 46% stated that administrative support or an increase in administrative support would improve their service, giving them more time to devote to CYP and families.
- 31% stated more nursing hours were needed
- 31% stated that an improvement in transition care e.g. a transition nurse, transition clinic, improved tool.
- Other areas included improvements in the mental health services for children with epilepsy (23%); more medical staff (23%); gaining the non-medical prescribing certification (15%); reducing waiting time for new patients (15%); and phone lines (15%).

When asked to state three positive points about their services;

- 54% stated a good working relationship with the consultants.
- 61% felt they gave patient centred care that adapted to the needs of the CYP and families.
- 23% stated that having some administrative support had improved their service.

The findings have highlighted that the variation in ESN provision across the PENNEC/NENC ICS footprint and there is appetite to make improvements to enable equity across the region in terms of access and support for CYP, parents and other professionals.

The results demonstrate that there are good working relationships between different members of the individual epilepsy services; however, it was felt that intercollegiate working would bring about wider improvements in the care for CYP with epilepsy.

Involvement of tertiary services in epilepsy care

NICE Clinical Guideline 137 (1.10) states that all CYP with epilepsy should have access via their specialist to a tertiary service when circumstances require.

Tertiary involvement can be vital for a number of reasons such as diagnostic uncertainty, specialised advice on drugs, surgery, epilepsy combined with other complicated medical conditions or psychological problems. Timely and appropriate access to tertiary services remains variable across the country.

If seizures are not controlled and/or there is diagnostic uncertainty or treatment failure, CYP should be referred to tertiary services soon (the Guideline Development Group considered that 'soon' meant being seen within 4 weeks) for further assessment and specialist advice on further management.

The proposed indication for referral should be considered when one or more of the following criteria are present:

- the epilepsy is not controlled with medication within 2 years
- management is unsuccessful after two drugs
- the child is aged under 2 years
- a child, young person or adult experiences, or is at risk of, unacceptable side effects from medication
- there is a unilateral structural lesion
- there is psychological and/or psychiatric co-morbidity
- there is diagnostic doubt as to the nature of the seizures and/or seizure syndrome.

NICE Quality Standard 27 (statement 7) states that CYP who meet the criteria for referral to a neurologist are seen within four weeks of referral.

The tertiary service should include a multidisciplinary team, experienced in the assessment of CYP with complex epilepsy, and have adequate access to investigations and treatment by both medical and surgical means.

Newcastle Hospitals NHS Foundation Trust provides the tertiary neurology services across the PENNEC/NENC ICS footprint. All the paediatric neurologists within the service provide expertise and advice in CYP with epilepsy in addition the service also provides specialist advice about ketogenic diet ongoing dietetic review, Vagal Nerve Stimulation (VNS) insertion and review, complex epilepsies management and cannabidiol (CBD) therapy. Ongoing dietetic review of ketogenic diet is undertaken by all the local epilepsy services in the PENNEC/NENC ICS region. The Service also runs a dedicated complex epilepsy clinic for the region. At the time of this project the service had six paediatric neurologists and four specialist neurology nurses.

The tertiary service does not accept direct referrals from General Practitioners and referral from secondary care are triaged for appropriate clinics. Only five of the nine secondary epilepsy services have provision of outreach clinic run by a paediatric neurologist. The remaining four services are limited due to workforce capacity although the services are looking into possible avenues to improve equity of access and service level. Local secondary services have found these clinics very useful for patient care and for building relationships between secondary and tertiary care services.

Epilepsy 12 data suggested that on average, 31% (77/245) of CYP in the PENNEC/NENC ICS region, diagnosed with epilepsy, meet the defined criteria for tertiary referral to paediatric neurology, which is higher than the national average for England & Wales (22%).

Only 48% of those meeting the criteria for a paediatric neurology referral with input from tertiary care receive it; again, this is similar to the national average (52%).

Epilepsy 12 data (limited due to small number pseudonymisation and overall accuracy and completion of data) identifies that only two of the Trusts have made referrals for CYP diagnosed with epilepsy who meet defined criteria for paediatric neurology referral with the input of tertiary care and/or CESS referral. However, in practice all the secondary services in the PENNEC/NENC ICS footprint have been referring patients to the tertiary service as per agreed pathways but the exact numbers are not accurately reflected in Epilepsy 12 data to the reasons already explained earlier in the report.

Feedback from the service leads confirms seven of nine services have an agreed referral pathway to tertiary paediatric neurology services. This is supported by data from Epilepsy 12 which indicates that CYP diagnosed with epilepsy have evidence of input from a paediatric neurologist suggesting that referral pathways within PENNEC/NENC ICS region are well established and this is in agreement with the feedback from the service leads. The pathway includes discussion with paediatric neurologist in outreach clinic (where they exist) or speaking to the neurology team for acute advice via the telephone. These clinics are very helpful and valuable; however, paediatricians feel that neurologists have significant workload as these clinics have patients with neurology and epilepsy background.

The findings suggest that there is a very good working relationship between secondary and tertiary services in the PENNEC/NENC ICS footprint and providing support in management of CYP with epilepsies. The result highlight that there is variation in provision of outreach clinics (which are very valuable and informative) and there is work underway to improve this service and equity of access across the region.

It has been noted that the referral rate to tertiary service is variable across the PENNEC/NENC ICS footprint, which could be explained by the expertise existing in local secondary services and population demographics, such as deprivation and poverty and incidence and prevalence of epilepsy

Epilepsy surgery referral

There are different kinds of epilepsy surgery. One kind of surgery involves removing a specific area of the brain which is thought to be causing the seizures. Another kind involves separating the part of the brain that is causing seizures from the rest of the brain.

Research has been conducted and published by Elsevier Ltd in the European Journal of Epilepsy to indicate that surgical procedures are increasingly used as a treatment option for paediatric patients with refractory epilepsy, as seizure control contributes positively to quality of life outcomes.

Information should be provided to children, young people and adults and families and/or carers as appropriate about the reasons for considering surgery. The benefits and risks of the surgical procedure under consideration should be fully explained before informed consent is obtained.

The tertiary service should include a multidisciplinary team, experienced in the assessment of CYP and adults with complex epilepsy, and have adequate access to investigations and treatment by both medical and surgical means. [2004]

The expertise of multidisciplinary teams involved in managing complex epilepsy should include psychology, psychiatry, social work, occupational therapy, counselling, neuroradiology, clinical nurse specialists, neurophysiology, neurology, neurosurgery and neuro-anaesthesia. Teams should have MRI and video telemetry facilities available to them. [2004]

The neurosurgeon in the multidisciplinary team should have specialist experience of and/or training in epilepsy surgery and have access to invasive EEG recording facilities. [2004]

There has been insufficient data submitted to the Epilepsy 12 data (Epilepsy 12 2020 National Clinical Audit Results (Round 3 Cohort 2) for meaningful analysis.

The number of CYP diagnosed with epilepsy who meet Children’s Epilepsy Surgery Service (CESS) criteria nationally is low. Epilepsy 12 data demonstrates that 105 CYP nationally were identified as meeting criteria, however less than ¼ across the Epilepsy Network were referred to one of the 4 national CESS centres. PENNEC locality identified 18 CYP who met the criteria but less than 5 CYP were referred. The referral rates in PENNEC/NENC ICS region are consistent with national rates of referral.

Table 10 – NORCESS Referral Data – showing referrals from Newcastle since November 2012

2022	3
2021	8
2020	13
2019	7
2018	8
2017	2
2016	3
2015	2
2014	3
2013	1

Neuropsychology services for CYP with epilepsy

CYP with epilepsy may develop learning difficulties and issues with cognition, memory and language which would require psychological assessment. There are also groups of children with epilepsy who have undergone epilepsy surgery and may need follow up neuropsychological assessment.

As per NICE Clinical Guideline 137 1.6.32, referral for a neuropsychological assessment is indicated:

- when a child, young person or adult with epilepsy is having educational or occupational difficulties
- when an MRI has identified abnormalities in cognitively important brain regions

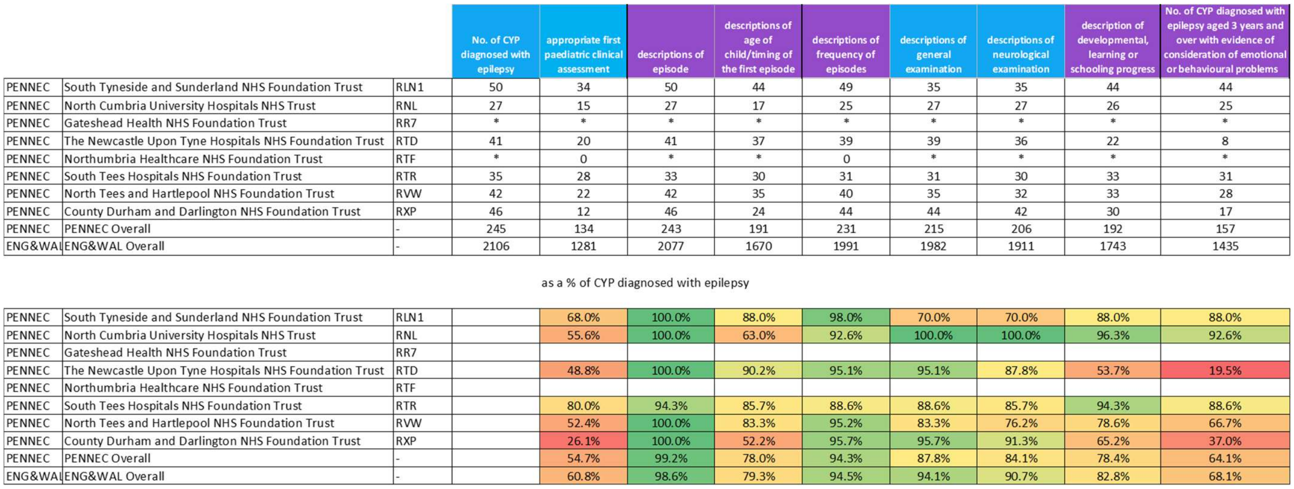
There is significant variation in provision of paediatric psychology services nationally as well as regionally. In our PENNEC/NENC ICS footprint, three services have access to health psychology services within their own Trust. For the services that don't have Trust based in-house psychology services the patient who needs psychology assessment are referred to other services such as CAMHS and community and school-based counselling services. However, the patients who need specific neuropsychology assessment related to epilepsy are referred to tertiary neurology services by the paediatric neurologist.

Appropriate first paediatric assessment

A first paediatric assessment is a 'face to face' assessment by a paediatrician in a secondary paediatric service occurring in any non-acute or acute setting. An assessment within emergency department (ED) counts if performed by a paediatric team rather than an emergency department team. Some paediatric neurologists see referrals direct from GP or ED and these would count as both a first paediatric assessment and tertiary input.

Epilepsy 12 Audit has collated and identified the detailed components of first paediatric assessment for services in the PENNEC/NENC ICS locality as described in the table below;

Table 11: Completed components of first paediatric assessment for Services in the PENNEC/NENC ICS footprint by Trust



			No. of CYP diagnosed with epilepsy	appropriate first paediatric clinical assessment	descriptions of episode	descriptions of age of child/timing of the first episode	descriptions of frequency of episodes	descriptions of general examination	descriptions of neurological examination	description of developmental, learning or schooling progress	No. of CYP diagnosed with epilepsy aged 3 years and over with evidence of consideration of emotional or behavioural problems
PENNEC	South Tyneside and Sunderland NHS Foundation Trust	RLN1	50	34	50	44	49	35	35	44	44
PENNEC	North Cumbria University Hospitals NHS Trust	RNL	27	15	27	17	25	27	27	26	25
PENNEC	Gateshead Health NHS Foundation Trust	RR7	*	*	*	*	*	*	*	*	*
PENNEC	The Newcastle Upon Tyne Hospitals NHS Foundation Trust	RTD	41	20	41	37	39	39	36	22	8
PENNEC	Northumbria Healthcare NHS Foundation Trust	RTF	*	0	*	*	0	*	*	*	*
PENNEC	South Tees Hospitals NHS Foundation Trust	RTR	35	28	33	30	31	31	30	33	31
PENNEC	North Tees and Hartlepool NHS Foundation Trust	RVW	42	22	42	35	40	35	32	33	28
PENNEC	County Durham and Darlington NHS Foundation Trust	RXP	46	12	46	24	44	44	42	30	17
PENNEC	PENNEC Overall	-	245	134	243	191	231	215	206	192	157
ENG&WAL	ENG&WAL Overall	-	2106	1281	2077	1670	1991	1982	1911	1743	1435

as a % of CYP diagnosed with epilepsy

PENNEC	South Tyneside and Sunderland NHS Foundation Trust	RLN1		68.0%	100.0%	88.0%	98.0%	70.0%	70.0%	88.0%	88.0%
PENNEC	North Cumbria University Hospitals NHS Trust	RNL		55.6%	100.0%	63.0%	92.6%	100.0%	100.0%	96.3%	92.6%
PENNEC	Gateshead Health NHS Foundation Trust	RR7									
PENNEC	The Newcastle Upon Tyne Hospitals NHS Foundation Trust	RTD		48.8%	100.0%	90.2%	95.1%	95.1%	87.8%	53.7%	19.5%
PENNEC	Northumbria Healthcare NHS Foundation Trust	RTF									
PENNEC	South Tees Hospitals NHS Foundation Trust	RTR		80.0%	94.3%	85.7%	88.6%	88.6%	85.7%	94.3%	88.6%
PENNEC	North Tees and Hartlepool NHS Foundation Trust	RVW		52.4%	100.0%	83.3%	95.2%	83.3%	76.2%	78.6%	66.7%
PENNEC	County Durham and Darlington NHS Foundation Trust	RXP		26.1%	100.0%	52.2%	95.7%	95.7%	91.3%	65.2%	37.0%
PENNEC	PENNEC Overall	-		54.7%	99.2%	78.0%	94.3%	87.8%	84.1%	78.4%	64.1%
ENG&WAL	ENG&WAL Overall	-		60.8%	98.6%	79.3%	94.5%	94.1%	90.7%	82.8%	68.1%

Data from Epilepsy 12 2020 Clinical Audit Results (Round 3 Cohort 2) demonstrate that PENNEC/NENC ICS regions perform at the lower end of the range, c55% of CYP diagnosed with epilepsy have evidence of appropriate first paediatric clinical assessment, compared with 61% across England and Wales.

In our region all the services have at least one paediatrician with expertise in epilepsy and, according to Epilepsy 12 data, 89% of services in the PENNEC/NENC ICS region provide input by a paediatrician with expertise in epilepsy which is slightly higher than national average (87%). However, the data indicates that only 26% of CYP with suspected epilepsy are seen by a paediatrician with expertise in epilepsy within two weeks which is similar to the national average (25%). This highlights the significant delay in offering first clinic appointments within 2 weeks by most services in the PENNEC/NENC ICS footprint despite alternative arrangements being made where possible.

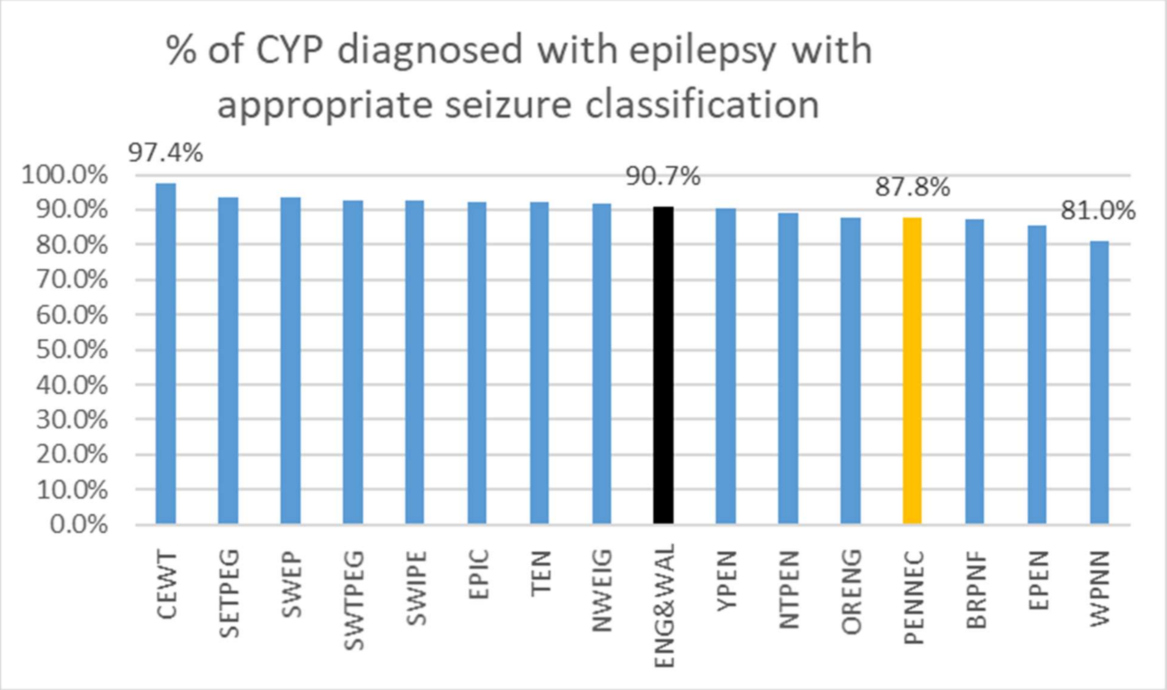
Seizure formulation

NICE Clinical Guideline 137 states that epileptic seizures and epilepsy syndromes in CYP should be classified using a multi axial diagnostic scheme. The axes that should be considered are: description of seizure (ictal phenomenology); seizure type; syndrome and aetiology.

Epilepsy 12 indicator evaluates this based on percentage of children with epilepsy, with appropriate seizure classification at the end of the first year of care.

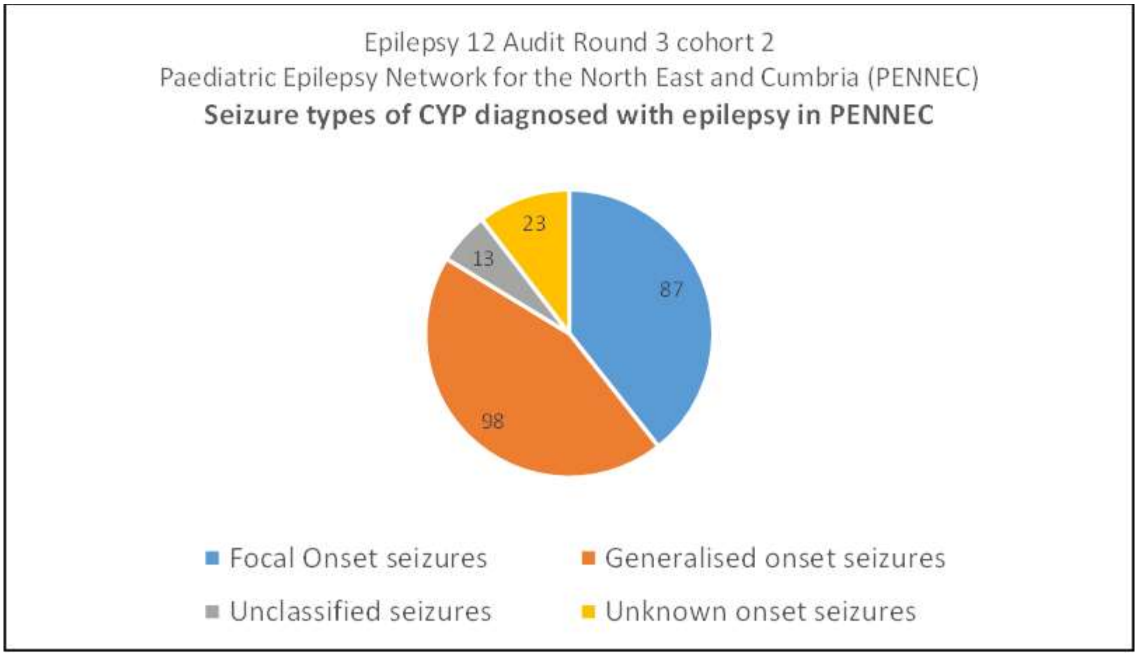
Epilepsy 12 data (Epilepsy 12 2020 National Clinical Audit Results Round 3 Cohort 2) demonstrates that 88% of CYP in the PENNEC/NENC ICS footprint are diagnosed with epilepsy with appropriate seizure classification compared with 91% for England and Wales as demonstrated in the figure below.

Figure 2: Proportion (%) of CYP diagnosed with epilepsy with appropriate seizure classification in PENNEC/NENC ICS region



The figure below demonstrates the breakdown of seizure types for CYP diagnosed with epilepsy in the PENNEC/NENC ICS footprint based on the Epilepsy 12 data (Epilepsy 12 2020 National Clinical Audit Results Round 3 Cohort 2).

Figure 3: No of CYP diagnosed with difference seizure types in PENNEC/NENC ICS region



Access to investigations

Following on from the initial assessment, the next NICE Standard considers the timeliness of the diagnostic tests. CYP with suspected epilepsy may need different types of investigations, as clinically indicated, such as electrocardiogram (ECG), electroencephalogram (EEG), Computed Tomography (CT) scan or Magnetic Resonance Imaging (MRI) Brain, genetic testing and neurometabolic testing.

NICE Quality Standard 27 (statement 2)2013 states that CYP having initial investigations including EEG and MRI for epilepsy undergo the tests within 4 weeks of them being requested.

Electrocardiogram (ECG)

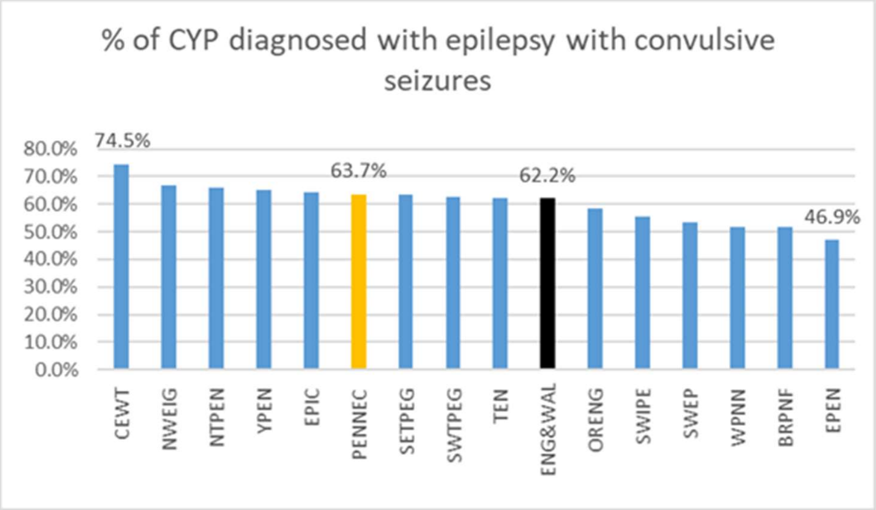
An electrocardiogram (ECG) checks heart rhythm and most of the services looking after CYP with suspected epilepsy routinely perform this simple test.

British Paediatric Neurology Association (BPNA) PET teaching curriculum, states that all children with a convulsive seizure should have a 12-lead ECG.

Epilepsy 12 data (Epilepsy 12 2020 National Clinical Audit Results (Round 3 Cohort 2) suggests that in the PENNEC region, 64% of CYP with epilepsy have convulsive seizures.

Similar levels are reported nationally. Of these, in PENNEC/NENC ICS regions, 55% have had a 12-lead ECG, compared to 65% nationally.

Figure 4: % of CYP diagnosed with epilepsy who have convulsive seizures in the PENNEC/NENC ICS region.



Feedback from the clinical lead's interviews confirm that all the services are offering the12-lead ECG test. It is not clear from the current data why only just over half of the patients with suspected epilepsy have had this test. It would be reasonable to explore the reason for this finding and prompts the need for a programme of quality improvement.

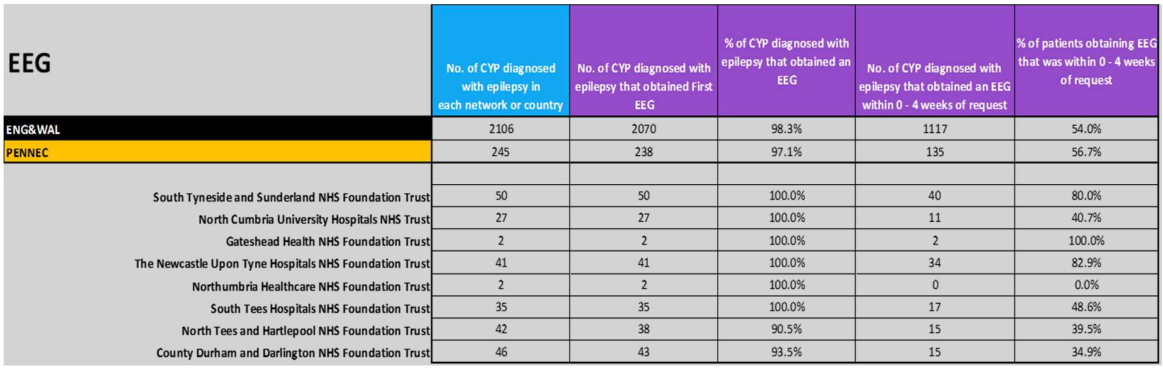
The availability of other investigations is variable amongst the provider Trusts

Electroencephalogram (EEG)

An electroencephalogram (EEG) is a recording of brain activity which is one of most common tests performed to support the diagnosis of epilepsy. In accordance with NICE guidance 2013 an appointment for EEG should be provided within four weeks of initial request.

Epilepsy 12 data (Epilepsy 12 2020 National Clinical Audit Results (Round 3 Cohort 2)) suggests that in the PENNEC/NENC ICS region 97% of CYP diagnosed with epilepsy obtained an EEG. Similar to national average levels of 98%. Of these, 57% obtained the EEG within four weeks of request again, similar to national average of 54%. According to Epilepsy 12 data, two services within the PENNEC/NENC ICS region had lower percentage of EEGs obtained within four weeks of request in comparison to other services in the footprint.

Table 12: EEG access by each of the different services in the PENNEC/NENC region.



EEG	No. of CYP diagnosed with epilepsy in each network or country	No. of CYP diagnosed with epilepsy that obtained First EEG	% of CYP diagnosed with epilepsy that obtained an EEG	No. of CYP diagnosed with epilepsy that obtained an EEG within 0 - 4 weeks of request	% of patients obtaining EEG that was within 0 - 4 weeks of request
ENG&WAL	2106	2070	98.3%	1117	54.0%
PENNEC	245	238	97.1%	135	56.7%
South Tyneside and Sunderland NHS Foundation Trust	50	50	100.0%	40	80.0%
North Cumbria University Hospitals NHS Trust	27	27	100.0%	11	40.7%
Gateshead Health NHS Foundation Trust	2	2	100.0%	2	100.0%
The Newcastle Upon Tyne Hospitals NHS Foundation Trust	41	41	100.0%	34	82.9%
Northumbria Healthcare NHS Foundation Trust	2	2	100.0%	0	0.0%
South Tees Hospitals NHS Foundation Trust	35	35	100.0%	17	48.6%
North Tees and Hartlepool NHS Foundation Trust	42	38	90.5%	15	39.5%
County Durham and Darlington NHS Foundation Trust	46	43	93.5%	15	34.9%

Feedback from service leads confirms that only four epilepsy services provide in-house EEG and other services send patients to nearest Trust as the locally agreed arrangements. The two services who demonstrate lower percentage of EEG within four weeks refer their patients to the nearest Trust for EEG.

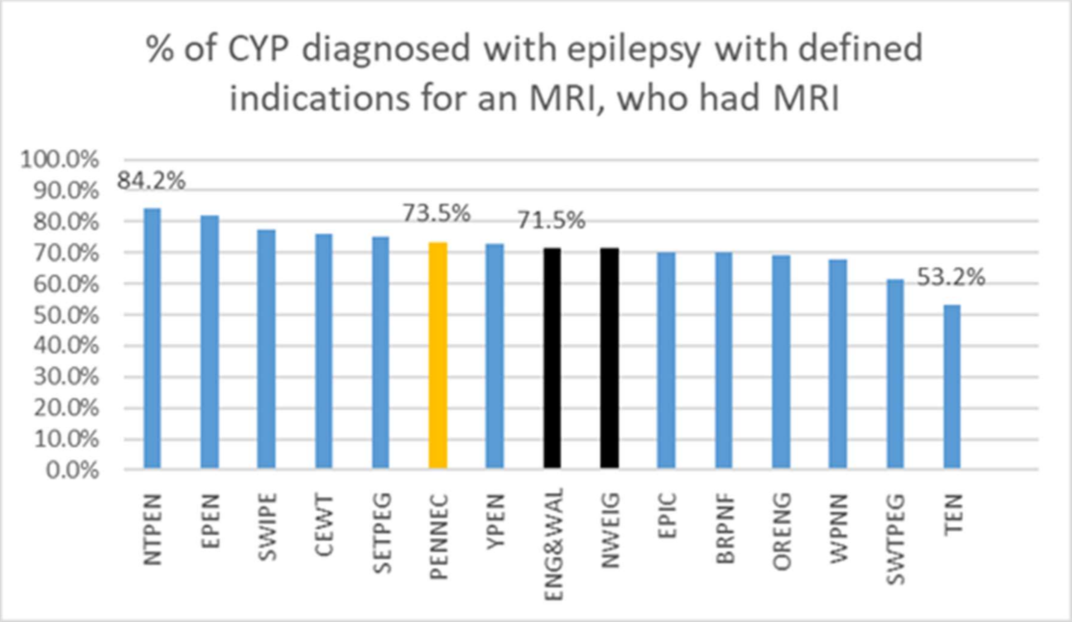
Magnetic Resonance Imaging (MRI)

Magnetic Resonance Imaging (MRI) is shown by evidence to be the most sensitive and specific neuroimaging option in terms of identifying structural abnormalities in the brain, but access to MRI scanning and reporting facilities varies across the country.

NICE Quality Standard 27 (Statement 3) 2013 states that CYP who meet the criteria for neuroimaging for epilepsy should have Magnetic Resonance Imaging (MRI) within four weeks.

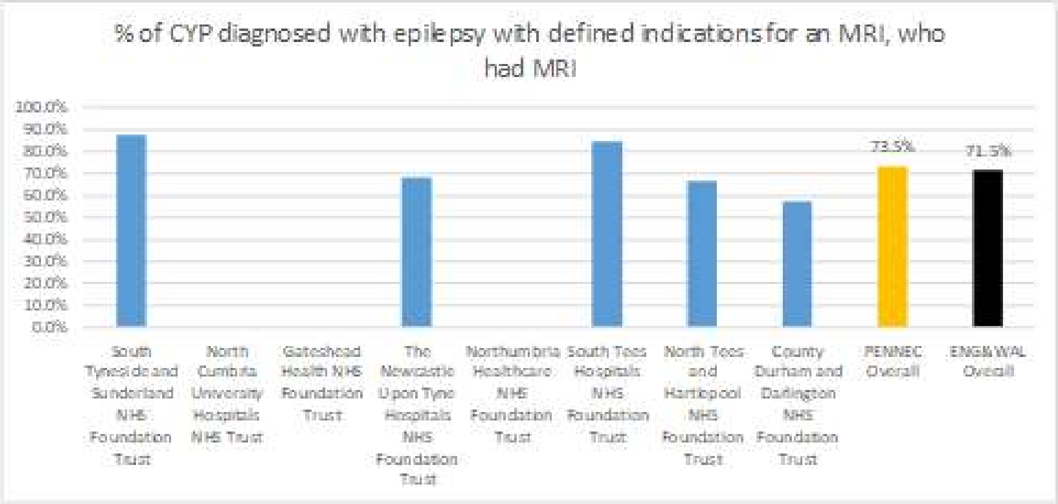
In PENNEC/NENC ICS region, 34% of CYP diagnosed with epilepsy meet the defined indications for an MRI similar to the national average of 33%. Of these 74% had the MRI brain. The figure below shows the Epilepsy 12 data about MRI indications.

Figure 5: Proportion (%) CYP diagnosed with epilepsy with defined indications for an MRI who had an MRI



The provision of MRI investigation is variable depending upon factors such as availability of MRI, paediatric radiology reporting, paediatric anaesthesia specialist service and resources. The services provide MRI for CYP who are awake, under sedation and general anaesthesia however the frequency and consistency of this is variable across the different services in the region.

Figure 6: Proportion (%) of CYP diagnosed with epilepsy with defined indications for an MRI who had an MRI in each Trust.



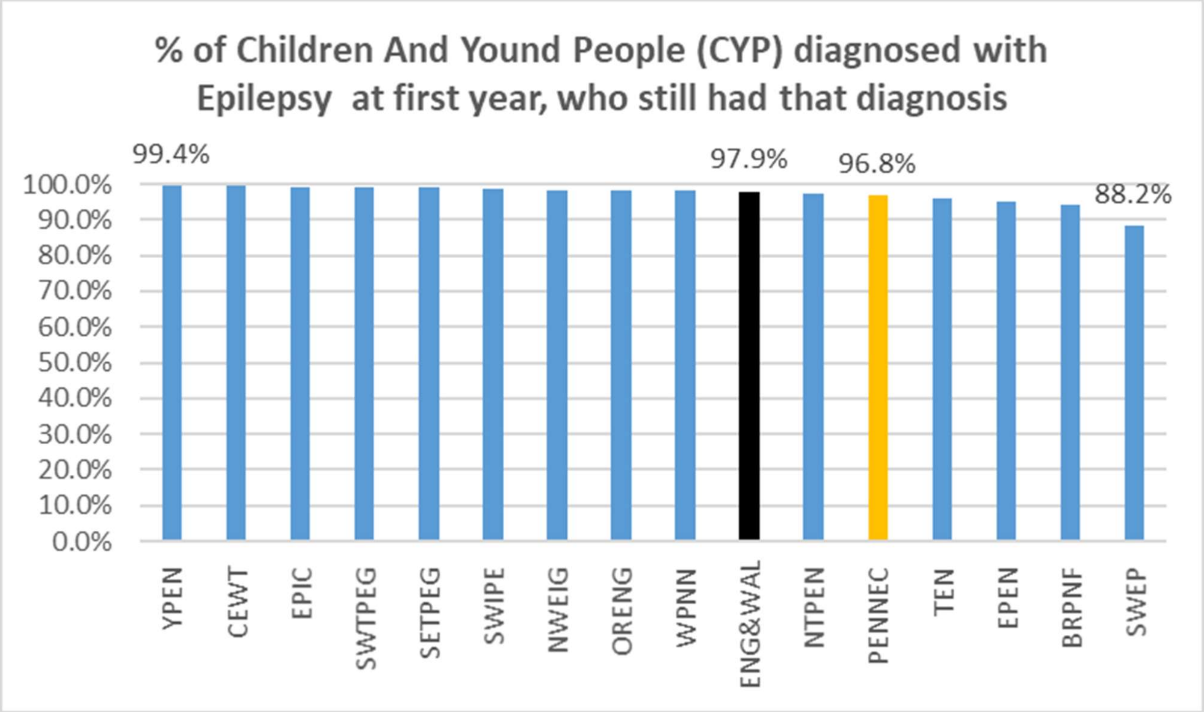
Service lead's interviews highlighted that most services offer provision of awake MRI but there is longer waiting times for MRI to happen under sedation or general anaesthesia. In addition, there is also variation in practice in relation to performing MRI under sedation within the region. Other confounding factors related to paediatric radiology are gaps in paediatric radiology workforce, inconsistency with MRI epilepsy protocols and inequitable access to paediatric neuroradiologist across the NENC footprint.

Accuracy of diagnosis

Epilepsy is a clinical diagnosis and sometime teaching an accurate diagnosis could be challenging. The literature has highlighted that misdiagnosis occurs in 5% to 30% of patients with suspected epilepsy across all age groups. It is therefore crucial that specialists are involved early in diagnosing epilepsy and that they take great care to establish an accurate diagnosis.

Epilepsy 12 data reports accurate diagnosis levels in the PENNEC/NENC ICS region is high at 97% which is similar to those found nationally (98%); within the region it varies between 91% and 100% amongst the services.

Figure 7: % CYP diagnosed with epilepsy at first year, who still had that diagnosis



As already stated, the accuracy of diagnosis in epilepsy care is paramount and it is clear from the epilepsy data the high accuracy rate in our area. Feedback from service leads confirms the Epilepsy 12 findings.

The accuracy of diagnosis in our ICS footprint is comparable to that nationally so this indicates that although CYP have often had to wait for their appointments and diagnostic investigations, such patients are seen by the appropriate team to reach an accurate diagnosis

Sodium valproate risk assessment

The sodium valproate is associated with a significant risk of birth defects and developmental disorders in children born to females who take valproate during pregnancy. As the risks to unborn children have been increasingly understood, the warnings have been strengthened.

NICE Clinical Guideline 137 strengthens warnings that valproate must not be used in girls of childbearing potential (including young girls who are likely to need treatment into their childbearing years), unless alternative treatments are not suitable. Girls of childbearing potential (and the parents of young girls) must be fully informed about the risks of taking valproate during pregnancy, and only take valproate if they have a pregnancy prevention programme in place, in line with the MHRA safety advice on valproate.

There is limited information included within the Epilepsy 12 data in relation to this, partially due to small number pseudonymisation. Nationally of the 121 females (aged 9 to 17) with epilepsy currently on sodium valproate treatment (at time of the data was collected), only half of these (60) had evidence of discussion about foetal risk. The PENNEC/NENC ICS region identified in the same audit, 20 females (same age group) on sodium valproate, of which, only 9 had evidence of discussion of foetal risk. Overall, it would appear that over half of the young girls on sodium valproate treatment were not made aware of the potential risks. This situation may be explained because the discussion may have happened but there was a lack of documentation made or available at the time of audit, or the young girls (and/or their parents) have not been made aware.

Based on Office of National Statistics population estimates and epilepsy prevalence rates for young girls (13 – 17 years of age), the PENNEC/NENC ICS region should expect around 6 live births per annum from this group of young girls with epilepsy.

Based on population modelling, the PENNEC/NENC ICS region has a 40% higher young teenage (13 - 17 years) conception rate compared to national average.

Epilepsy 12 data suggests that the PENNEC/NENC ICS region prescribe twice as much sodium valproate for young teenage girl population (13 – 17 years of age) compared to the national average.

However, it is not clear from the data the rationale as to why some young girls remain on sodium valproate and whether there have been historic or more recent discussions about this with them or their parents and carers. It is more likely that this cohort has complex, profound and multiple needs. In these cases, the expectation is that the epilepsy team has undertaken discussion and has documented the rationale for the continuation of such treatment.

Information related to care planning for CYP with epilepsy

This section has posed multiple challenges and confusion in relation to interpretation and understanding across the different sections of the health, education and social care systems.

Below we have set out the understanding and interpretation that has been taken in relation to this report, although it is not clear in all cases whether this is the understanding of other participants and contributors to this programme of work:

Emergency Healthcare Plan	This is a document primarily formulated by health care professionals after considering appropriate risk assessment, in conjunction with other stakeholders in the care of the CYP. This plan should set out the course of action to be taken in the event of an emergency situation, for example in the case of a prolonged seizure presenting risk to the CYP. This plan should be reviewed by health professionals and should be available to a range of settings, including school, home or other community setting for example sports club. This plan should be reviewed at regular intervals or when needs change by healthcare professionals with the input of others.
Individual Healthcare Plan	This is a document that is primarily drawn up by school, teaching and education colleagues that describes the care and monitoring needed on a day to day basis to effectively and safely manage the healthcare needs of the child in an education setting and may include additional provision for school trips, extracurricular activities or similar. This plan should be reviewed at regular intervals or when needs change by education colleagues with the input of other professionals such as ESNs
EHCP (Education Health and Care Plan)	This is a legal document which describes a child or young person's aged up to 25 special educational needs, the support they need, and the outcomes they would like to achieve. This is a document that is developed by a range of professionals across the education, health and social care system which is co-ordinated by the Local Education Authority. Healthcare professionals have a duty to contribute and provide information as follows: - the assessment of needs for the young person - the development of CYP health outcomes and plans to achieve these - the development and agreement of health interventions to meet the assessed needs and intended outcomes - the review and evaluation of these health outcomes on an annual basis

Care Plan	This is a document that may be maintained by a Local Authority or Social Care Provider and predominantly relates to the social care needs of a CYP and this would include day to day guidance about the management of needs, this would include a range of daily living needs and would include far more than healthcare needs. This is a document that would be developed by a Social Worker or Support Worker/Care Provider with the input and voice of the CYP and their parents/carers, as well as any other professional or agency involved in delivery of care and support to the CYP.

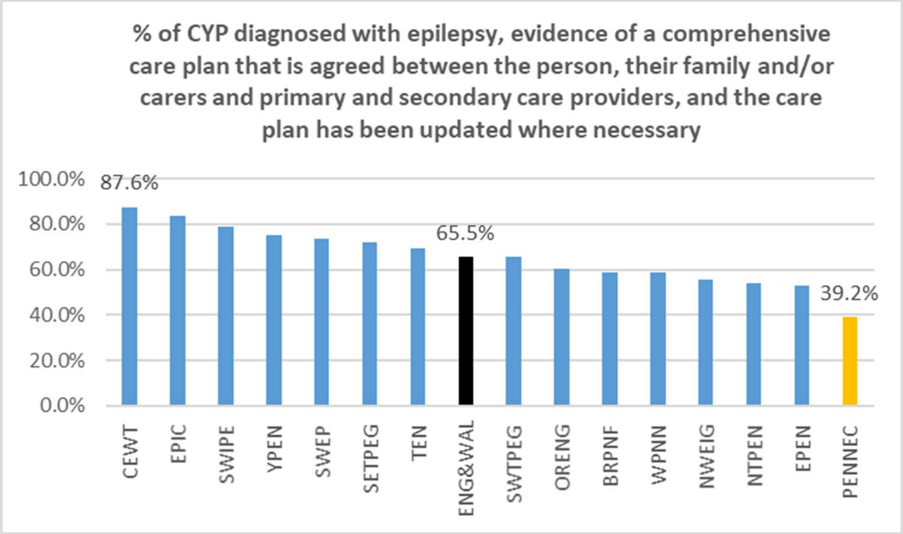
NICE Quality Standard 27 (statement 4) states that CYP with epilepsy have an agreed and comprehensive care plan.

NICE Quality Standard 27 (statement 6) states that CYP with a history of prolonged or repeated seizures have an agreed, written Emergency Healthcare Plan.
There are a number of potential lifestyle, health, education and wellbeing implications directly related to epilepsy in CYP. A care plan is an important tool in ensuring that these aspects of a CYP's life that could be affected by their epilepsy and the treatment they receive are considered and addressed. There are different types of care planning documents used to describe the needs of CYP and how to optimise their support in health, education and social care settings. As such the interpretation of ‘care plan’ varies across the system.

An Emergency Healthcare Plan is an important tool in improving and bringing consistency in emergency care provided to the CYP in different settings such as home, school and ambulance. It also provides guidance and training for family members or carers who may need to administer emergency treatment. Previous incidents and agreed treatment strategies are taken into account by healthcare professionals during the formulation of the emergency healthcare plan. Input from the CYP, parent/carer, school and others is also considered. The timely and appropriate management of a prolonged or repeated seizure may significantly reduce the risk of mortality and morbidity (long-term complications) known to be associated with prolonged or repeated seizures.

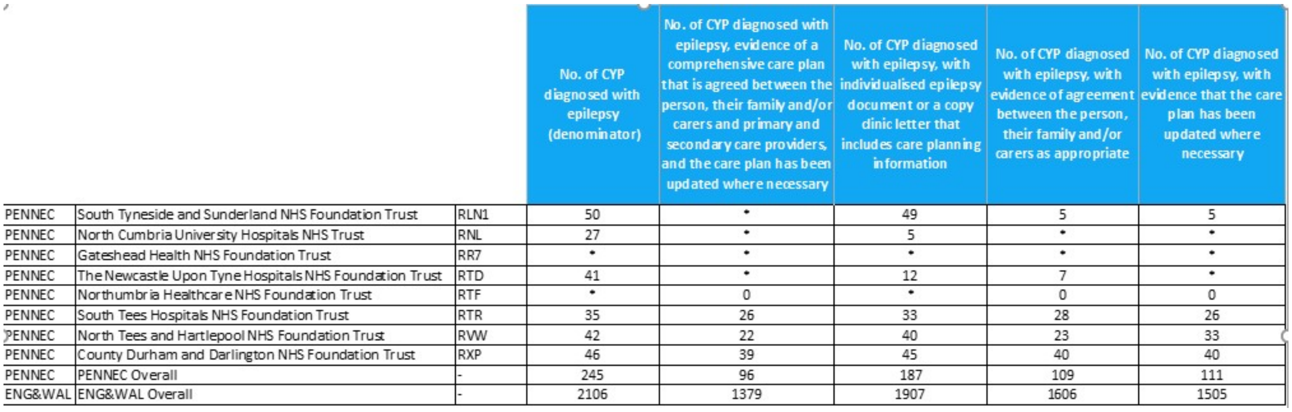
Epilepsy 12 2020 National Clinical Audit Results (Round 3 Cohort 2) data demonstrates that the PENNEC/NENC ICS regions have the second lowest reported level of evidence for comprehensive care planning agreement across all the epilepsy networks, 39% compared to the national average of 66%.

Figure 8: % of CYP diagnosed with epilepsy where there is evidence of a comprehensive care plan that is agreed between the CYP their family and/or carers and primary or secondary care providers and the plan has been updated where necessary



The supporting data shows that half of the Trusts in the PENNEC/NENC ICS region with a CYP diagnosed epilepsy caseload reported low numbers against one (or all) of the care plan content metrics in the Epilepsy 12 data. South Tyneside, County Durham and Darlington and South Tees Trusts reported higher than the national average, 90%, 89% and 86% respectively.

Table 13: No of CYP diagnosed with epilepsy where there is evidence of a comprehensive care plan that is agreed between the CYP their family and/or carers and primary or secondary care providers and the plan has been updated where necessary, presented in the table by Trust



			No. of CYP diagnosed with epilepsy (denominator)	No. of CYP diagnosed with epilepsy, evidence of a comprehensive care plan that is agreed between the person, their family and/or carers and primary and secondary care providers, and the care plan has been updated where necessary	No. of CYP diagnosed with epilepsy, with individualised epilepsy document or a copy clinic letter that includes care planning information	No. of CYP diagnosed with epilepsy, with evidence of agreement between the person, their family and/or carers as appropriate	No. of CYP diagnosed with epilepsy, with evidence that the care plan has been updated where necessary
PENNEC	South Tyneside and Sunderland NHS Foundation Trust	RLN1	50	•	49	5	5
PENNEC	North Cumbria University Hospitals NHS Trust	RNL	27	•	5	•	•
PENNEC	Gateshead Health NHS Foundation Trust	RR7	•	•	•	•	•
PENNEC	The Newcastle Upon Tyne Hospitals NHS Foundation Trust	RTD	41	•	12	7	•
PENNEC	Northumbria Healthcare NHS Foundation Trust	RTF	•	0	•	0	0
PENNEC	South Tees Hospitals NHS Foundation Trust	RTR	35	26	33	28	26
PENNEC	North Tees and Hartlepool NHS Foundation Trust	RVW	42	22	40	23	33
PENNEC	County Durham and Darlington NHS Foundation Trust	RXP	46	39	45	40	40
PENNEC	PENNEC Overall	-	245	96	187	109	111
ENG&WAL	ENG&WAL Overall	-	2106	1379	1907	1606	1505

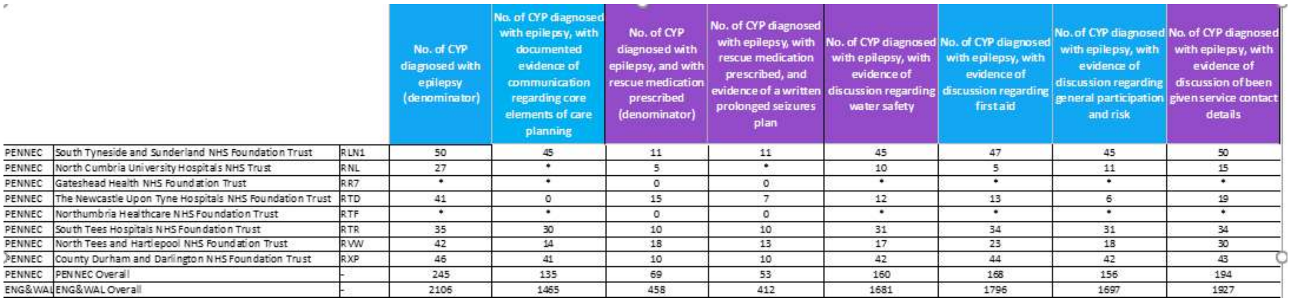
These numbers in the table above may reflect data submission quality however at face value this is representative of the PENNEC/NENC ICS region.

Feedback from service leads confirms that all 8 services felt that they undertake comprehensive care planning for CYP with epilepsy, anecdotal feedback explains that this focusses mainly on rescue medication and Emergency Health Care Plans, other intelligence indicates that these are not always regularly reviewed due to limitations of capacity, resource and clinical and nursing workforce within the setting.

Most of the Epilepsy Specialist Nurses (10/14) who took part in peer to peer interviews indicated that their services provide a written care plan for all CYP with a diagnosis of epilepsy, some provide care plans only when the child has a diagnosis of epilepsy and rescue medication is prescribed and occasionally for the CYP who have rescue medication prescribed for prolonged febrile convulsions.

Epilepsy 12 data demonstrates that the PENNEC/NENC ICS region has the second lowest reported level of evidence for comprehensive care planning content across all the epilepsy networks, an average of 55% compared to the national average of 70%

Table 14: No of CYP diagnosed with epilepsy with components of comprehensive care planning completed, presented in the table by Trust



			No. of CYP diagnosed with epilepsy (denominator)	No. of CYP diagnosed with epilepsy, with documented evidence of communication regarding core elements of care planning	No. of CYP diagnosed with epilepsy, and with rescue medication prescribed (denominator)	No. of CYP diagnosed with epilepsy, with rescue medication prescribed, and evidence of a written prolonged seizures plan	No. of CYP diagnosed with epilepsy, with evidence of discussion regarding water safety	No. of CYP diagnosed with epilepsy, with evidence of discussion regarding first aid	No. of CYP diagnosed with epilepsy, with evidence of discussion regarding general participation and risk	No. of CYP diagnosed with epilepsy, with evidence of discussion of been given service contact details
PENNEC	South Tyneside and Sunderland NHS Foundation Trust	RLN1	50	45	11	11	45	47	45	50
PENNEC	North Cumbria University Hospitals NHS Trust	RNL	27	*	5	*	10	5	11	15
PENNEC	Gateshead Health NHS Foundation Trust	RR7	*	*	0	0	*	*	*	*
PENNEC	The Newcastle Upon Tyne Hospitals NHS Foundation Trust	RTD	41	0	15	7	12	13	6	19
PENNEC	Northumbria Healthcare NHS Foundation Trust	RTF	*	*	0	0	*	*	*	*
PENNEC	South Tees Hospitals NHS Foundation Trust	RTR	35	30	10	10	31	34	31	34
PENNEC	North Tees and Hartlepool NHS Foundation Trust	RVW	42	14	18	13	17	23	18	30
PENNEC	County Durham and Darlington NHS Foundation Trust	RXP	46	41	10	10	42	44	42	43
PENNEC	PENNEC Overall	-	245	135	69	53	160	168	156	194
ENG&WAL	ENG&WAL Overall	-	2106	1465	458	412	1681	1796	1697	1927

The particular focus for the care plan document in epilepsy services of the PENNEC/NENC ICS region seems to be addressing general risk, first aid and where appropriate, rescue medication.

Only 6 of the 20 respondents to the education settings survey in the NENC footprint confirmed that every CYP with epilepsy in the setting has an individual Emergency Healthcare Plans prescribed and issued by the hospital epilepsy team. A further 7 respondents confirmed that some (not all) of the CYP with epilepsy had an Individual Emergency Healthcare Plan.

Of those that said yes to all (or some) CYP with epilepsy in their settings having individual Emergency Healthcare Plans, less than half of the respondents to the survey (46%) reported that Emergency Healthcare plans were reviewed annually with the input and support from and Epilepsy Specialist Nurse.

School Individual Healthcare Plans

This indicator has been difficult to effectively review and evaluate due to confusion around terminology.

Our understanding perhaps contradicts the Epilepsy 12 line of enquiry and have understood that an individual healthcare plan is a document that is primarily drawn up by school, teaching and education colleagues that describes the care and monitoring needed on a day to day basis to effectively and safely manage the healthcare needs of the child in an education setting.

Data from Epilepsy 12 2020 National Clinical Audit Results (Round 3 Cohort 2) demonstrates that the PENNEC/NENC ICS regions have a comparatively low reported level of evidence for a school individual healthcare plan across the epilepsy networks, 23% compared to national average of 33%.

Half the Trusts in the PENNEC/NENC ICS region reported very small numbers (>5) and only County Durham and Darlington NHS Foundation Trust reported higher than the national average, 68%.

Most ESNs who have participated in peer to peer interviews have indicated that they provide written Individual healthcare plans for CYP with epilepsy, one area indicated that they only provide care plans for CYP with epilepsy who have been prescribed emergency medication.

The feedback from the school settings online survey identified that at least 16 settings in the PENNEC/NENC ICS region currently have CYP on roll who have a diagnosis of epilepsy. Of these at least 13 of the settings confirmed that there were Individual Healthcare Plans in place. Most of these are/would be updated annually by school staff (with the input of an epilepsy nurse colleague as well as parent carers).

Sudden Unexpected Death in Epilepsy (SUDEP)

SUDEP is defined as the sudden, unexpected, witnessed or unwitnessed, non-traumatic, and non-drowning death in patients with epilepsy with or without evidence of a seizure, and excluding documented status epilepticus, in which post-mortem examination does not reveal a structural or toxicological cause for death.

SUDEP is a rare event in epilepsy management and risk in children with epilepsy is 0.22/1000 patient-years (American Academy of Neurology). The risk factors are uncontrolled epilepsy, multiple anti epilepsy medication, significant neurodisability. People with epilepsy and their families prefer to be informed of the individual's risk for a catastrophic event such as SUDEP, even when the probability of the event is low.

Feedback from the ESN peer to peer interviews suggested that newly diagnosed CYP receive epilepsy related information which includes risk management around water, sport and wellbeing safety, parents also receive information about SUDEP as appropriate. From this feedback ESNs have told us that they attempt to discuss this issue with families at the initial point of contact but that this largely depends on the presenting circumstances with the family and their levels of anxiety about the diagnosis of epilepsy. Some services re-address the issue of SUDEP with families, depending upon the clinical need of the CYP or change in circumstances such as developing more complex epilepsy or going through the transition process.

SUDEP is a difficult area in the management of epilepsy and communication around SUDEP could be challenging and ESNs shared their own anxieties in relation to addressing this issue in conversation with parents of CYP. Often ESNs use the available resources such as signposting to the SUDEP website (www.sudep.co.uk) and the epilepsy action website (www.epilepsyaction.co.uk) and provide information booklets to parents.

SUDEP was an area that most ESNs want additional training and support and further information to share with families.

Transition

The need for continuity of care during transition from paediatric to adult services is particularly important for young people managing the physical and mental transition from adolescence to adulthood. Good management of this transition period by healthcare professionals is vital to develop and maintain the self-esteem and confidence of the adolescent with epilepsy. It also provides an important opportunity to review the diagnosis, classification, cause and management of a young person's epilepsy before they enter adulthood.

NICE Quality Standard 27 (Statement 9) states that Young People with epilepsy have an agreed transition period during which their continuing epilepsy care is reviewed jointly by paediatric and adult services.

In the PENNEC/NENC ICS region, 5 of the 8 services have an agreed referral pathway into adult services. North Cumbria, Newcastle and CDDFT reported that they did not have an agreed transitional pathway between paediatric services and adult services.

Nationally, only 40% of Trusts offer epilepsy clinics specifically for young people. Typically, this is offered from around 14.5 years of age. At the time that information was gathered for this project and report, in the PENNEC/NENC ICS region, only Northumbria Healthcare NHS Foundation Trust offer this service.

Nationally, only 59% of Trusts offer joint clinics for transition of young epilepsy patients into adult epilepsy services. In the PENNEC/NENC ICS region, this is only offered in one Trust, South Tyneside and Sunderland NHS Foundation Trust, and this is limited to a single joint appointment.

In the PENNEC/NENC region, adult neurologists and ESNs are the predominant healthcare professionals that are involved in the transition process, although this is not universal across the Trusts. Notably, North Cumbria uses neither, but does involve the GP in the transition process.

Supplementary information available in relation to transitions processes and provision across the NENC ICS footprint is significantly variable. Most Trusts in the region provide some form of joint clinics for CYP who transition in to adult service however these joint clinics could be conducted by paediatric and adult specialist nurses and CYP may have limited opportunity to meet adult neurologists in the clinic prior to the actual transfer. The written or verbal information related to transition across the NENC region is variable and the timing of providing relevant information depends on the local processes and pathways.

The transition service is an area which is evolving rapidly in the last few years and there has been increased focus in bringing consistency in processes and pathways. There has been inadequate understanding amongst clinicians about the tools and information available within their own services. In the majority of transition pathways there is significantly more involvement of ESNs.

Feedback from the ESN peer to peer interviews confirmed the existence of transitions tool and that they provide specific written resources (epilepsy action sheets on a variety of topics driving, drugs and PIP, careers etc) and that this happens when the CYP are about 14 but demonstrated inconsistent application in one area and without a clinical pathway or consultant oversight in 5 of the 9 areas. The majority use Ready Steady Go (RSG) tool however some have remarked that it is not useful for the LD cohort. 5 of the 9 clinical leads interviewed understood that they did not have a specific tool or proforma, which suggests that the ESNs are trying to manage this transfer in the absence of clinical pathway. One of the PENNEC/NENC ICS areas has a lead transitions nurse role in place since April 22. ESNs suggest that they hold dedicated transitions clinic, adults ESN, specific transitions nurse.

Conclusions

This project is a positive and constructive step forward in relation to improvements to paediatric epilepsy care in the North East and North Cumbria.

The benefits of this work are numerous and help to provide useful and relevant information which will enable improvement to systems and processes locally. It also provides a clear guide about how to target resources and from a regional/national perspective provides a blueprint for similar programmes of engagement.

Positive Findings

- The CHWN has resourced this scoping exercise and commits to invest in clinical leadership and oversight in relation to epilepsy service improvement in line with CYP Transformation programme key deliverables and priorities.
- The CHWN has developed it's strategic relationship with PENNEC and is currently in the process of formalising this within a partnership working and governance agreement to be able to progress a programme of service improvement across the NENC ICS footprint.
- There are positive working relationships and collaboration between primary, secondary and tertiary care across the NENC ICS footprint.
- Access to telephone triage and advice from epilepsy specialist secondary services to primary care practitioners is appreciated, however this is not universally available across the region.
- All the acute Trusts in the NENC ICS footprint provide CYP epilepsy specialist services and are represented within the PENNEC.
- All the epilepsy specialist services in the NENC ICS footprint have defined epilepsy clinics delivered by paediatricians with expertise in epilepsy and in most cases, ESNs.
- ESNs are integral part of specialist epilepsy services however the input from ESNs are only available in 7 out of 9 epilepsy services. Epilepsy 12 data has shown that in the PENNEC/NENC ICS region only 63% CYP with epilepsy have had input from ESNs which is lower than the national average (73%).
- Specialist epilepsy services are identifying and diagnosing epilepsy in line with expected rates of incidence based on statistically modelled estimates and this indicates that the accuracy of epilepsy diagnosis in the PENNEC/NENC ICS region is high, at 97%.
- All the epilepsy services offer 12 lead ECG and awake MRI.
- 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

Areas for Improvement

- Although CHWN has resourced the programme of epilepsy service improvement across PENNEC/NENC ICS footprint however the funding at present is limited.
- Clear pathways of working between primary and secondary epilepsy services could overcome current challenges for primary care in understanding criteria for referral and on-going management of CYP with epilepsy
- Challenges exist in primary care in relation to patient’s management of treatment and prescriptions
- Regular education and training sessions in relation to epilepsy management in CYP for primary work force are lacking
- There is evidence of a lack of official recognition of clinical leadership in most CYP epilepsy services across the region
- Despite the delivery of unofficial leadership in most epilepsy services across the region, the clinicians are not appropriately remunerated in their job plans
- Only half the epilepsy services deliver TFC223 epilepsy best practice criteria clinics
- There is limitation in availability of clinical and nursing workforce across most epilepsy services across the region to deliver the care in line with national standards
- Epilepsy specialist services for CYP are currently not mandated to provide advice and support during out of hours but some services even struggle to provide staff cover for annual leave or sickness absence
- Services in PENNEC/NENC ICS area is below the national average in terms of reported ESN input for CYP with epilepsy, due principally to the lack of ESNs at Newcastle and Gateshead. In addition, there is variability in provision of ESNs at trust level
- Based on a modelled estimate caseload of 4,300 CYP with epilepsy in the PENNEC/NENC ICS region, there is a significant shortage of ESN support principally due to lack of ESN recruitment and foresight of the Trust
- There is significant variation in provision of administrative support to epilepsy specialist services
- Epilepsy specialist services in NENC ICS footprint are struggling to offer new epilepsy appointments within 2 weeks of referrals as recommended by NICE. In the NENC region only 26% of CYP are seen by a paediatrician with expertise in epilepsy within 2 weeks.
- There are significant waits to complete diagnostic tests, in relation to epilepsy management, across all services in the region
- The availability of diagnostic investigations is variable amongst the provider Trusts
- Epilepsy 12 audit data suggests that the young teenage girl population (13 – 17 years of age) in the PENNEC/NENC ICS region are more likely to be prescribed sodium valproate than the national average
- The PENNEC/NENC ICS region has the second lowest reported level of evidence for comprehensive care planning agreement across all the epilepsy networks
- Only 40% of Trusts in PENNEC/NENC ICS region offer epilepsy clinics specifically for young people and teenagers.
- Transition pathways for epilepsy patients are not established in some Trusts

- There are significant gaps in mental health provision for CYP with epilepsy across the NENC ICS footprint

In summary, the value and importance of good paediatric epilepsy care is recognised 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. This report identifies some clear areas of improvement and suggestions to respond in a collaborative manner.

Recommendations

Since the commencement of this project, NHS England has identified key areas of focus in relation to paediatric epilepsy care. To address the key areas identified by NHS England, strong and clear governance and leadership structures are required and as such, work has already started across our region. Clinical leadership and governance at system/regional level has already been established locally as well as the initiation of work with key stakeholders across the region to develop a plan for improving epilepsy care and outcomes for CYP with epilepsy.

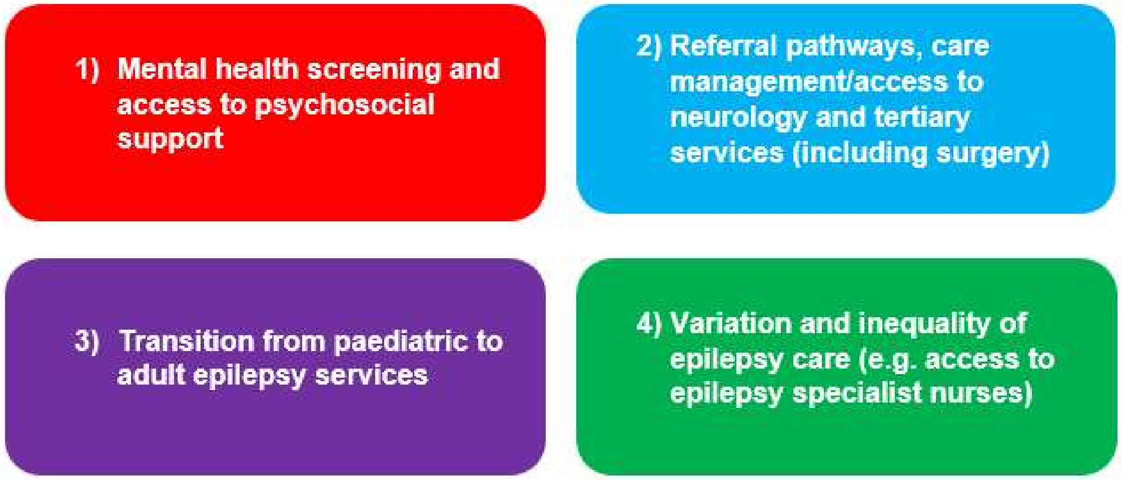
There is a region wide need for improvements in the quality and equity of epilepsy care for CYP with epilepsy in line with the outcome of the Epilepsy 12 National Audit. The report has identified that patients and families are offered variable support to meet their diverse and ever-changing needs and this one of the important areas of improvement for the region.

The work undertaken as part of this and the simultaneous epilepsy/mental health project seeks to scope and understand variation in service delivery and pathways of care for CYP with epilepsy.

Critical gaps identified are in relation to primary care referral pathways, clinical leadership and recognition of roles, inequity of access to ESN support and diagnostic and treatment provision. The programme of work has informed the development of a number of recommendations for NENC CHWN, PENNEC and ICS/ICB Commissioners.

There is also the need to develop and enhance engagement with CYP and their families to enable their voices to be influential within the planning and development of services, engaged in the ongoing service improvement processes and to support with service review and evaluation. Further work is required to engage more effectively with CYP and families and to gain an understanding of their experience, priorities, needs and expectations relating to epilepsy care.

The following are the areas of focus identified nationally which the recommendations below seek to support.



The first area of focus, access to mental health screening and psychological support, is addressed in more detail in a parallel piece of work led by Dr Anita Devlin, Consultant Paediatric Neurologist, Newcastle Upon Tyne Hospitals NHS Foundation Trust.

The colours of each of these areas of focus in the figure above are used within the lists of recommendations below to identify which key area each of the recommendation contributes to. Most of the recommendations contribute to more than one area of focus.

North East and North Cumbria Child Health and Wellbeing Network:

North East and North Cumbria CHWN should:

- Continue to support, resource and facilitate CYP epilepsy service improvement and clinical leadership via PENNEC. 🔵🟣🟢
- Continue to provide an engagement platform for colleagues and stakeholders from the wider system. 🔵🟣🟢
- Host an Epilepsy ‘Huddle’ (‘E-puddle’) with regards to project updates and provide opportunity to enhance collaborative work across the system. 🔵🟣🟢

Paediatric Epilepsy Network for North East and Cumbria:

PENNEC should:

- Review the findings and recommendations of this report from strategic and operational perspective and identify a tangible course of action to address required improvement. 🔵🟣🟢
- Encourage and facilitate full participation in data collation for Epilepsy 12 national audit. 🔵🟣🟢

- Develop and report on monitoring processes, using Epilepsy 12 data and other qualitative feedback to evaluate and measure service improvement in the PENNEC/NENC ICS region. 🔵🟣🟢
- Consider restructuring the model of governance and the terms of reference for PENNEC in line with the recent ICS reorganisation. 🔵🟣🟢
- Provide influence and guidance to local epilepsy services in respect of collaboratively developing or restructuring care pathways to provide equity and continuity of epilepsy care across primary, secondary, and tertiary services as well as in education settings. 🟢
- Communicate and promote the developed pathways across the system including use of Healthier Together as platform for dissemination. 🟢
- Develop and propose a model of epilepsy care (including workforce requirements) in line with proposed NICE service standards and work with Integrated Care Board (ICB) commissioners to facilitate the adoption and establishment of the model within services across the region. 🔵🟣🟢
- Evaluate the benefits of establishing and maintaining a sodium valproate regional risk register. 🔵🟣
- Develop and create a training programme to address the needs of ESN in relation to SUDEP risk assessment and management in clinical practice. 🔵
- Continue to deliver and extend the participation of wider heath, education and social care in current training and education programme. 🔵🟣🟢
- Supporting and facilitation of an ESN Community of Practice group. 🔵🟣🟢
- Identify good practice and develop communication resources about a range of issues including first seizure management, diagnostic investigation, risk assessment of sodium valproate and SUDEP. 🔵
- Promote and encourage services to work in partnership with Transitions: developmentally appropriate health care regional oversight group to improve services for young people in transition. 🟣
- To raise the profile of mental health needs in CYP with epilepsy and highlight the current gaps in service provision via study days, working with partner organisations and general communication across the system. 🔵
- Develop links and mechanisms for meaningful engagement with CYP and their families to sense check and evaluate the programme of improvement. 🔵

ICB commissioners:

ICB commissioners should

- Support and resource the accepted model of epilepsy care for CYP in NENC ICS footprint. 🔵
- Support the local epilepsy services develop an approach to service improvement to deliver and maintain services in line with national standards. 🔵

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References

Facts of Life Report Copyright © 2021 Cumbria, Northumberland Tyne and Wear and South Tees Hospitals NHS Foundation Trusts (On behalf of the North East Quality Observatory Service, (NEQOS)) Facts of life report | North East and North Cumbria NHS (northeastnorthcumbria.nhs.uk)

Davies, S., Heyman, I., & Goodman, R. (2003). A population survey of mental health problems in children with epilepsy. *Developmental Medicine & Child Neurology, 45*(5), 292-295. doi:10.1017/S0012162203000550., A population survey of mental health problems in children with epilepsy - PubMed (nih.gov)

NICE., 2012 Epilepsies in Children Young People and Adults., Epilepsies: diagnosis and management | Guidance | NICE

Best Practice Tariff Treatment Function Code 223., NHS England, 2021., Paediatric Epilepsy. *Annex DtC: Guidance on Best Practice Tariffs* 22-23NT_Annex-DtC-Best-practice-tariffs.pdf (england.nhs.uk)

Marmot Review Marmot M, Goldblatt P, Allen J et al. (2010) Strategic Review of Health Inequalities in England. *Fair Society, Healthy Lives*, fair-society-healthy-lives-full-report-pdf.pdf (instituteofhealthequity.org)

Sandeep B. Patil, Nilesh S. Kurwale, Sujit A. Jagtap, Aniruddha Joshi, Yogeshwari Deshmukh, Sujit Nilegaonkar, Deepa Bapat, Sonal Chitnis. (2022) Clinical profile and outcomes of epilepsy surgery in children from a tertiary epilepsy care center in India, *European Journal of Paediatric Neurology.* Volume 38, 13-19. https://doi.org/10.1016/j.ejpn.2022.03.006. (https://www.sciencedirect.com/science/article/pii/S1090379822000496)

Uldall P, Alving J, Hansen LK, Kibaek M, Buchholt J (2006). The misdiagnosis of epilepsy in children admitted to a tertiary epilepsy centre with paroxysmal events. Arch Dis Child. Mar;91(3):219-21. doi: 10.1136/adc.2004.064477. PMID: 16492886; PMCID: PMC2065931. The misdiagnosis of epilepsy in children admitted to a tertiary epilepsy centre with paroxysmal events | Archives of Disease in Childhood (bmj.com)