



Y&H Children’s & Maternity (C&M) Clinical Network (SCN)

Y&H Children’s & Maternity (C&M) Strategic Clinical Network (SCN)

Long Term Conditions: Epilepsy

**Long Term Conditions Epilepsy**

Version number: 6.0

First published: May 2016

Prepared by: Emmerline Irving and Angie Pullen, May 2016

# Contents

[Contents 3](#_Toc429385936)

[1 Purpose 3](#_Toc429385937)

[2 Background 5](#_Toc429385938)

[2.1.1 Introduction 5](#_Toc429385939)

[2.1.2 The cost of Epilepsy 5](#_Toc429385940)

[2.1.3 5 Year Forward View 6](#_Toc429385941)

[2.1.4 NHS England’s Commitment and Mandate. 6](#_Toc429385942)

[2.1.5 Improving Children and Young People’s Health Outcomes: a system wide response (2013). 7](#_Toc429385943)

[3 Y&H Children’s & Maternity (C&M) Clinical Network (SCN) Epilepsy Scoping: 8](#_Toc429385944)

[4 Y&H C&M SCN Asthma Scoping Results: 9](#_Toc429385945)

[5 Key Recommendations and Conclusion 14](#_Toc429385946)

[6 Epilepsy Toolkit 14](#_Toc429385947)

[7 Epilepsy Action 14](#_Toc429385948)

[8 Key Documents 15](#_Toc429385949)

# Purpose

The purpose of this document is to share the insight and feedback provided by Yorkshire and the Humber (Y&H) CCG Commissioners and Providers.

To provide local and national evidence and priorities/ambitions in order to develop and define priorities and recommendations where working collaboratively across Y&H will assist in a system wide reduction in unplanned emergency admissions for children and young people (CYP) living with Epilepsy.

Support Y&H CCG Commissioner and Providers to:

* Develop and evidenced based approach to the care of CYP Epilepsy
* Identify best practice for the management of Epilepsy
* Implement revised service models.
* Identify and reduce system wide variation.
* Reduce emergency admissions across Y&H.
* Reduce attendances at A&E across Y&H
* Reduce variations in quality of care.
* Improve the quality and experience of care for CYP living with Epilepsy.

# Background

### Introduction

Reduction in unplanned emergency admissions for Children and Young People (CYP) living with long term conditions (Asthma, Epilepsy and Diabetes) was identified at the engagement event for the Children’s and Maternity Clinical Network (SCN) in September 2013 as a priority for stakeholders across Yorkshire and the Humber(Y&H). This priority was endorsed by all 24 CCG’s across Y&H and Long Term Conditions: Epilepsy has therefore been included on the Y&H Children’s and Maternity SCN’s work programme.

In September 2015 as part of the work programme Y&H Children’s SCN began to develop a focus on children and young people with long term conditions (LTCs), in particular for CYP living with Epilepsy. In order to develop a scope for this work and support commissioners and providers across the region, it is important that we have a clear understanding of the priorities and challenges in relation to Epilepsy.  Gathering this information will enable the SCN team to develop a project overview to identify key themes and how the SCN can provide valuable clinical expertise, knowledge and insight to inform commissioning and provision of services across Y&H.

### The cost of Epilepsy

Epilepsy affects a large number of Children and Young People. In 2011 the Joint Epilepsy Council calculated there were 63,400 children and young people under 18 with epilepsy in the UK, around one in every 220 children. There is a peak of incidence in very young children, falling in school age children and rising again in teenage years.

Children with epilepsy are at risk from seizures and may have a number of associated neurological, educational or psycho social problems and or co-morbidities. This population creates a significant demand on the resources of paediatric emergency departments, PICUs, paediatric wards, outpatient clinics, community paediatric services, neurodisability services and children’s learning disability teams.

The PICANet annual report 2012, indicated that 1,101 children and young people, aged 0-15 were admitted to paediatric intensive care units between January 2009 and December 2011 due to status epilepticus.

The 2013 Child health review (RCPCH) noted During 2008-10 the average annual number of registered deaths in the UK for children and young people (1-17 years inclusive) with epilepsy recorded as the underlying cause of death was 52. In addition, there were 107 registered deaths with a mention of epilepsy. While it is likely that most deaths directly attributable to epilepsy would be classified as such, there are some potential gaps. For example, there is no ICD-10 code for Sudden Unexpected Death in Epilepsy (SUDEP); some deaths might be attributed to epilepsy when, in fact, this was not the cause (e.g. a symptomatic seizure); and other deaths may be coded according to the final terminal event (e.g. a respiratory infection), even if the precipitating cause was epilepsy. Those deaths in children with epilepsies, where the epilepsy was not the primary cause of death may or may not include epilepsy on the death certificate, are likely to be underestimated in official statistics. In 2002 the national sentinel audit concluded that 59% of deaths were potentially avoidable. It has been suggested that delivering services in line with NICE guidance would reduce mortality and morbidity.

### 5 Year Forward View

This report sets out a clear direction for the NHS – showing why change is needed and what it will look like, how the health service needs to change, arguing for more engaged relationships with patients, carers and citizens to promote wellbeing and prevent ill-health, by empowering patients.

Over a quarter of the population in England has a long term condition (LTC) and an increasing proportion of people have multiple conditions. [The Five Year Forward View](http://www.england.nhs.uk/ourwork/futurenhs/) (5YFV) notes that ’long term conditions are now a central task of the NHS; caring for these needs requires a partnership with patients over the longer term rather than providing single, unconnected “episodes” of care’[[1]](#footnote-1).

### NHS England’s Commitment and Mandate

The Government’s Mandate to NHS England sets out clear priorities to improve the care and treatment for children and young people with Long Term Conditions including:

* Preventing people from dying prematurely.
* Enhancing quality of life for people with long-term conditions.
* Ensuring People have a positive experience of care.

### Improving Children and Young People’s Health Outcomes: a system wide response (2013)

This report highlights the need and presents evidence to prevent ill health for children and young people and improve their opportunities for better long-term health by supporting families to look after their children, when they need it, and helping children and young people and their families to prioritise healthy behaviour;

The NHS Outcomes Framework 2013–14 includes measurable outcomes to demonstrate improvement in critical areas including better support to children and young people with Epilepsy.

Findings and recommendations from national audits participated in by many services in the region should inform service improvement plans. Commissioners can support providers to achieve these improvements.

**Epilepsy 12** (*Round 2 National Report: November 2014* *audit of paediatric services in the UK against 12 indicators from NICE guideline CG20)*

*Epilepsy 12 is the National report of Round 2 of the United Kingdom collaborative clinical audit of healthcare for children and young people with suspected epileptic seizures[[2]](#footnote-2)* . The first Epilepsy 12 report was published in 2012 and highlighted the key areas for improvement and the current position of epilepsy services at that time. The second report in 2014 provides evidence of how services have developed and improved and on the whole things a moved forward in a positive direction.

The Epilepsy 12 audit provides the opportunity to identify improvement and challenges faced by service on a national level, share learning and promote best practice.

Some of the key findings from Epilepsy 12 for the services within the Yorkshire and Humber region are highlighted below:

1. **Access to Paediatricians with expertise in epilepsies** nationally about a half of services now appear to achieve input from a ‘paediatrician with expertise’ for all children and young people with epilepsy. It is recommended that all services managing children with epilepsies should ensure that they include at least one defined consultant paediatrician with ‘expertise in epilepsies’. Services where involvement of ‘paediatricians with expertise’ in children with epilepsy is low should review care pathways to ensure that each child and young person with epilepsy has prompt input from a ‘paediatrician with expertise’.

In Y&H most commissioners and providers report access to paediatrician expertise (exceptions being North Lincolnshire? and North Kirklees? and whilst Barnsley, Bassetlaw and Rotherham have not responded it is thought they access services via Sheffield? The position in East Yorkshire is unclear they may access the York service?)

1. **Access to Epilepsy Specialist Nurse (ESN)** Although there is evidence of improved numbers of, andaccess to, ESNs, there are still many units that do not havean ESN and even when they do, not all children and youngpeople with epilepsy benefit from their input.Approximately a third of services do not have aChildren’s Epilepsy Specialist Nurse It is recommended that these services should urgently create a new post as an integral part ofpatient care. Some services will require more ESNs in order to ensure all children with epilepsy have adequate provision. Units where many children with epilepsy are not having input from their ESN should improve their care pathways and referral strategies. In Y&H it is thought that there is an access issue being addressed in Airedale and Craven and some discussion about lack of access in North Kirklees and Scarborough, Leeds have limited access due to providing both secondary and tertiary services causing a strain on resource. There is inconsistency across Y&H due to difference in referral criteria, some families are given direct access, where are others only see the nurse if on a particular agreed pathway.
2. **Tertiary involvement** over half of units in UK were found to have shortfalls in referral rates to paediatric neurologists. Access to, and availability of, paediatric neurologists needs to be addressed at both a local and regional level. In Y&H nine CCGs report tertiary pathways are in place. Calderdale and Huddersfield FT has observed that there needs to be improved planning re access to tertiary service making referral criteria clearer as there are concerns that those needing the service may not get timely access due to inappropriate referral of those who don’t. Tertiary services involvement and advice without referral could be helpful. There are differences in opinion around referral pathways and protocols in to the tertiary centre at Leeds.
3. **Appropriate first clinical assessment** Many services have low levels of appropriate first clinical assessments. It is recommended that the underlying reasons for this should be explored and improvements in the quality and consistency of assessment implemented. Training, documentation, first seizure guidelines and care pathways should be implemented as appropriate. Particular efforts should be made to ensure timely and ongoing assessments of developmental, educational, emotional and behavioural problems for all children and young people with epilepsies.

**In Y&H** several providers don’t have formal pathways in place e.g. Airedale, Bradford, Calderdale, Chesterfield, Mid York’s has no pathway to psychological assessment. The scoping audit did not specifically ask about access to assessments of developmental, educational, emotional and behavioural problems for all children and young people with epilepsies. Some families have reported difficulty accessing these services to Epilepsy Action and the proposed survey of parents and young people could explore their perspective.

1. **Seizure and Syndrome classification** Rates of appropriate multi-axial epilepsy classificationshould be improved in services where there is evidence oflower performance. Where the epileptic seizure cannot be classified there should be documentation to show that classification has been attempted. The ongoing diagnosis and classification of epilepsies should be undertaken by professionals with appropriate expertise. In Y&H Calderdale and Huddersfield FT has explained that there is a significant lack of understanding of the process involved in making the diagnosis and there are difficulties due to of the number of similar presentations for other conditions and the lack of one definitive test.
2. **ECG** Most services should improve rates of appropriate 12 lead ECG in children and young people with convulsive seizures. Training, local guidelines and care pathways should be improved to ensure all children and young people with a convulsive seizure have a 12 lead ECG with documentation to show that it has been reviewed.
3. **EEG** About a half of services are requesting some EEGs inappropriately. Where services are requesting EEG investigation in children and young people with non-epileptic events the reasons behind this should be explored and rectified. EEG services should develop strategies with their referring colleagues to reduce levels of inappropriate EEG referrals. In Y&H Mid Yorkshire report delays in accessing EEG in Dewsbury.
4. **MRI** Many services have children and young people who are not having MRI where it is indicated. Indications for MRI in children and young people with epilepsies should be reviewed and neuroimaging rates improved. If necessary, the availability of MRI should be improved. In Y&H Mid Yorkshire report delays in accessing MRI in Dewsbury.
5. **Prescribing** Services where there is evidence of Carbamazepine prescription in children and young people with contraindications the reasons behind this should be identified. Where Carbamazepine is prescribing despite contraindications a wider examination of care should be considered. Incident reporting may be considered as a way of examining factors within individual cases where this occurs. The Y&H scoping audit did not address prescribing issues.
6. **Accuracy of diagnosis** Withdrawal of epilepsy diagnoses is occurring in about a third of services. These services should investigate and respond to the reasons behind this. This is particularly the case where regular anti-epileptic medication has been initially prescribed as part of a ‘trial of treatment’ or where misdiagnosis is occurring. Care pathways ensuring input from a ‘paediatrician with expertise’ should be established.

**In Y&H** Calderdale and Huddersfield FT has explained that there is a significant lack of understanding of the process involved in making the diagnosis and there are difficulties because of the number of similar presentations for other conditions and the lack of one definitive test. Leeds Teaching Hospitals describe close working with geneticists which aids diagnosis, prognosis and family management. The scoping audit did not seek information about withdrawal of diagnosis but this is something that could be monitored as a quality indicator in the implementation of integrated care pathways.

1. **Information and advice** Water and bathing safety is just one of the risks for children and young people with epilepsies. Services should ensure that they have expertise and written material available to explain and discuss all relevant individual risks as part of initial and ongoing epilepsy care. Services should ensure that risk management is accessible, communicated, individualised, documented, understood and reviewed. All children and young people with epilepsies should have access to Epilepsy Specialist Nurses who have a key role in risk assessment and providing education and information to the person with epilepsy and their parent/carer.

**In Y&H** Whilst all providers indicate that information is given to children and parents/carers how that happens, how understanding is checked and further communicated to schools, organisers of activities children participate in has not been discussed. There is scope for best practice sharing in this important area of safety.

1. **PREM findings** Services should review how their team works together with GPs, nurseries, schools and residential care settings. An Epilepsy Specialist Nurse is essential in order to support multi-agency working and appropriate care planning. Services should encourage the participation of children, young people, parents and carers in the design of services and the review of information resources. Services should review the information they provide from a child and young person’s perspective and take steps to improve ease of understanding.

**In Y&H** examples of MD team working feature in Leeds and Calderdale/Huddersfield. Education programmes for professionals and families are described in North East Lincolnshire. Mid York’s, Dewsbury describe regular patient experience audits many services mention the Friends and family test. Bradford and Doncaster express interest in gathering patient experience data.

**Coordinating Epilepsy Care: a UK-wide review of healthcare in cases of mortality and prolonged seizures in children and young people with epilepsies (RCPCH September 2013)** some of the key highlights form this report are below:

1. **Reviews**-Many children experienced repeated hospital admissions for prolonged seizures. This in addition to the multiple co-morbidities, a lack of forward planning and appropriate care plans being in place highlighted the potential danger of clinicians focusing on the management of individual acute episodes, and the failure of anyone to step back and consider the wider ongoing long term needs of the child. In such situations, it is vital to ensure each child receives regular coordinated reviews of their epilepsy management.
2. **Care plans-** The review highlighted the importance of clear and comprehensive care plans for parents, schools and others caring for children with epilepsies, and providing them with information on how to respond to prolonged seizures, including training in resuscitation and the use of rescue medication. This is important for all children with epilepsies, but particularly where the child is known to have suffered or be at high risk of prolonged seizures. The review findings showed that there were potentially modifiable factors leading to children’s deaths in relation to the communication with parents. This highlights the need for clear information and advice to parents and carers; in a manner they can understand, on the signs indicating when a child is unwell. Furthermore the clinician responsible for the care of the child should ensure there are clear and careful discussions around the risks of seizures and SUDEP, as set out in the recommendations in the NICE guidelines. This would help empower parents and carers to recognise and respond promptly in such situations.
3. **In Y&H fewer** providers and commissioners appear to be using review templates than the number reporting using healthcare plans. Care plans and IHPs are variably used. Epilepsy Action has spoken with families who have had a positive experience of participation in the production and appropriate sharing of plans with key people in the life and support of their child. Other families have struggled to provide something helpful to for example a provider of school transport or the leader of a Brownie pack because the care plan takes the form of letters shared between healthcare professionals and sometimes with social care or education professionals.
4. **Ambulance, A&E and PICU staff** - It is important to ensure all ambulance crews are trained and equipped to be able to administer buccal midazolam to children experiencing prolonged seizures. All emergency departments must ensure that their clinical staff are able to apply current NICE and APLS prolonged convulsion guidance, as well as ensuring availability and competency with buccal midazolam, IV lorazepam and IV phenytoin administration.

Admission to intensive or high dependency care provides an opportunity for reviewing the child’s overall care, and making appropriate adjustments to their management and follow up, as well as reflecting on the care provided and learning lessons locally.

Whenever a child is admitted to hospital with a prolonged seizure, the consultant responsible for the admission should notify the clinician in charge of the child’s overall care. The clinician with overall responsibility should then review the child’s epilepsy management in the light of that admission.

# Y&H Children’s & Maternity (C&M) Clinical Network (SCN) Epilepsy Scoping:

The aim of the Epilepsy scoping project was to understand and review:

* Commissioning of service across Y&H for CYP living with Epilepsy
* Provision of services for CYP across Y&H living with Epilepsy.
* Identify Best Practice for management of Epilepsy.
* Develop recommendations on how the SCN for Children can support and improve the commission and provision of Epilepsy services in Y&H

The scoping was undertaken by questionnaire circulated to CCGs and providers.

Responses were received from thirteen of twenty four CCGs and ten of fifteen providers. Epilepsy is a priority for 9 of the 10 providers and for 4 of the CCGs.

The following section provides the current position and results from the scoping.

# Y&H C&M SCN Epilepsy Scoping Results:

|  |  |
| --- | --- |
| **Epilepsy Common Themes** | |
| **Commissioning, Benefits, Outcomes & KPIs::** | |
| **Provider** | **CCGs** |
| **Current Position**   * Epilepsy has been identified as a priority in all provider Trusts that responded. * The majority of Trusts acknowledged that they do not fully understand the local population and have not conducted a needs assessment. * 5 Trusts have some kind of service specification in place for community nursing, specialised services or adult epilepsy nurse specialist service with a role in transition. 3 CCGs are working towards the development of a service specification. * Services reviews are not carried out across all trusts. Those that are conducting reviews vary from informal in-house reviews to compliance with BPT and Epilepsy 12 audit. * KPIs are only in place at two Trusts however they are being developed in others. | **Current Position**   * A number of CCGs have expressed an interest in support to develop service specification and the possibility of collaborative commissioning. * 3 CCGs identify epilepsy as a priority and have undertaken scoping exercises to understand the needs of the population including service user engagement. Epilepsy is not a priority for the remaining CCGs. * All CCGs who responded are confident they understand the needs of their population and some have expressed the need to ‘dig deeper’ into this data, this is direct contrast with providers who do not share the same confidence. * The majority of CCGs were not commissioning against best practice tariff (BPT) but would like to explore BPT implementation * Consider commissioning of nursing and psychology provision as part of specification * -5 CCGs have stated that they currently have service specification in place. * Only 2 CCGs are currently conducting service s reviews on a regular basis and 3 CCGs are under review. |
| **Commissioning, Benefits, Outcomes & KPIs::** | |
| **Provider Results** | **CCGs Results** |
| **Specifications in place:**   * Leeds Teaching Hospital FT (0-16) * Mid Yorkshire NHSFT - Pinderfields * North East Lincolnshire FT * North Lincolnshire & Goole FT (acute 0-16/Complex 0-19) * York Teaching Hospital FT (0-18) * Bradford working to develop a specification | **Specifications in place:**   * NHS Bassetlaw (nursing Service) * NHS Doncaster * NHS Hull * NHS Wakefield (nursing Service) * NHS North East Lincolnshire (nursing Service) |
| **Service Reviews:**   * Airedale NSHFT –under review * Bradford Teaching Hospital NHSFT–under review * Chesterfield Royal Hospital NHSFT * Leeds Teaching Hospital FT – August 2015 | **Service Reviews:**   * NHS Airedale, Wharfedale and Craven – Under review * NHS Bradford District – Under Review * NHS Bradford City – Under review * NHS Hull – will be reviewed 2015 * NHS Bassetlaw – Annually * NHS Doncaster |
| **KPIs in place:**   * Airedale NSHFT – To be developed * Bradford Teaching Hospital NHSFT – To be developed * Leeds Teaching Hospital FT * Mid Yorkshire NHSFT | **KPIs in place:**   * NHS Doncaster * NHS Airedale, Wharfedale and Craven * NHS Bradford District * NHS Bradford City |

|  |  |
| --- | --- |
| **Commissioning, Benefits, Outcomes & KPIs::** | |
| **Provider** | **CCGs** |
| **Adherence to best practice tariff:**   * Airedale NSHFT – begin delivering in 2016 * Bradford Teaching Hospital NSHFT - begin delivering in 2016 * Calderdale and Huddersfield NHSFT * Mid Yorkshire Hospitals NHSFT– Wakefield * Northern Lincolnshire and Goole Hospitals NHSFT – working towards * York Teaching Hospital NHSFT | **Adherence to best practice tariff:**   * NHS North East Lincolnshire – Working towards * NHS Bassetlaw |
| **Adherence to QA Standards i.e. NICE, Epilepsy 12**   * Airedale NSHFT – To be addressed * Bradford Teaching Hospital NSHFT – To be addressed * Calderdale and Huddersfield NHSFT * Chesterfield Royal Hospital NHSFT * Leeds Teaching Hospital NHSFT * Mid Yorkshire Hospitals NHSFT * Northern Lincolnshire and Goole Hospitals NHSFT – working towards * York Teaching Hospital NHSFT | **Adherence to QA Standards i.e. NICE, Epilepsy 12**   * NHS Hull – verbal assurance from provider that this is in place. * NHS North East Lincolnshire * NHS Bassetlaw * NHS Doncaster |
| **Current Position**  All services understand the training needs of the work force and are addressing these needs through a variety of ways including:   * Training audits, training updates, discussion of Epilepsy 12, RCN guidance for service planning and research. * Diploma and Postgraduate Qualification in Epilepsy particularly for specialist epilepsy nurses. * BPNA PET ‘Paediatric Epilepsy Training’ level 1 and level 2 * Local training in paediatric neurosciences including the management of epilepsy. * Joint clinics and radiology meetings. | **Current Position**  The majority of responding CCGs are not confident that the training needs of the workforce are known, understood and or being addressed. Training identified by the remaining CCGs focused primarily om the Epilepsy Specialist Nurse including the ESN undertaking prescribing training in 3 CCGs. There are a number of CCGs working with providers to improve training and workforce development, e.g.   * Undertaking assurance checks around training particularly in relation to private training organisations. * Including training in clinical pathway work |
| **Commissioning, Benefits, Outcomes & KPIs::** | |
| **Provider Results** | **CCGs Results** |
| **Are the Training needs of the workforce known, understood and being addressed?**  The following services report that training needs have been assessed and understood:   * Airedale NHSFT * Bradford Teaching Hospitals NHSFT * Calderdale and Huddersfield NHSFT * Chesterfield Royal Hospital NHS Foundation Trust * Leeds Teaching Hospitals NHS * Mid Yorkshire Hospitals NHSFT * Northern Lincolnshire and Goole Hospitals NHFT * Northern Lincolnshire and Goole Hospitals NHFT | **Are the Training needs of the workforce known and understood?**   * NHS North East Lincolnshire * NHS Bassetlaw * NHS Airedale, Wharfedale and Craven * NHS Bradford Districts * NHS Bradford City   **Are the training needs of the workforce being addressed?**   * NHS North East Lincolnshire * NHS Bassetlaw * NHS Airedale, Wharfedale and Craven * NHS Bradford Districts * NHS Bradford City * NHS Leeds CCGs – Undertaking statutory and mandatory training |

|  |  |
| --- | --- |
| **Documentation & Tools:** | |
| **Provider** | **CCGs** |
| **Current Position**   * Only 3 Trusts have a formal pathway in place (2 are integrated pathways) for epilepsy services. The remaining trusts report that informal pathways and a general understanding of services and referral exist. * 5 Trusts believe that all service providers understand their roles within the pathways formal or informal. * The types of tools vary across provider Trusts however all Trusts have a review template or a health plan in place for CYP. * The majority of provider trusts have information available for children young people and their families. * IT systems are not in place across all trusts. Those that are in place are not cleanly linked across services. * The main IT system in use is System 1. * Practice sharing * Pathways and protocols are in place in 3 Trusts * Age appropriate materials for children move to \* | **Current Position**   * 6 CCGs have identified that formal pathways are in place, however only one of these is an integrated pathway with some issues around adherence form secondary care. * Only 1 CCG is confident that providers understand their roles and responsibilities within the pathway.   \*There are some discrepancies between commissioners and provider around the implementation and use of health care plans**.** |
| **Provider Results** | **CCGs Results** |
| **Is there a pathway in place for epilepsy services?**  The following providers report pathways are in place:  Leeds Teaching Hospitals NHSFT  Mid Yorkshire Hospitals NHSFT  Northern Lincolnshire and Goole Hospitals NHSFT | **Is there a pathway in place for epilepsy services?**  NHS Hull  NHS North East Lincolnshire  NHS Bassetlaw  NHS Doncaster  NHS Leeds North, West and South & East  NHS Greater Huddersfield/NHS North Kirklees  It is interesting that some CCGs report pathways are in place but their providers do not report this |
| **Documentation and Tools:** | |
| **Provider** | **CCGs** |
| **Is it an integrated pathway?**  The following providers report pathways are integrated:  Leeds Teaching Hospitals NHSFT  Mid Yorkshire Hospitals NHSFT- Wakefield  Mid Yorkshire Hospitals NHSFT- Dewsbury | **Is it an integrated pathway?**  NHS Bassetlaw  NHS Doncaster |
| **Do all service providers understand their roles and responsibilities with in the pathway?**  Calderdale and Huddersfield NHSFT  Leeds Teaching Hospitals NHSFT  Mid Yorkshire Hospitals NHSFT- Wakefield  Mid Yorkshire Hospitals NHSFT- Dewsbury  Northern Lincolnshire and Goole Hospitals NHSFT | **Do all service providers understand their roles and responsibilities with in the pathway?**  NHS North East Lincolnshire  NHS Bassetlaw  NHS Doncaster  NHS Leeds North, West, South & East |
| **Health Review Templates:**  The following providers report templates are in use:  Bradford Teaching Hospitals NHSFT  Chesterfield Royal Hospital NHS Foundation Trust  Mid Yorkshire Hospitals NHSFT  Northern Lincolnshire and Goole Hospitals NHFT | **Health Review Templates:**  NHS Doncaster  NHS Hull  NHS Wakefield (nursing Service)  NHS Bradford Districts  NHS Bradford City |
| **Health Plans:**  Airedale NHSFT  Bradford Teaching Hospitals NHSFT  Calderdale and Huddersfield NHSFT  Chesterfield Royal Hospital NHS Foundation Trust  Leeds Teaching Hospitals NHS  Mid Yorkshire Hospitals NHSFT  Northern Lincolnshire and Goole Hospitals NHFT  York Teaching Hospital NHSFT | **Health Plans:**  NHS Doncaster  NHS Hull  NHS North East Lincolnshire  NHS Bassetlaw  NHS Airedale, Wharfedale and Craven  NHS Bradford Districts  NHS Bradford City |

|  |  |
| --- | --- |
| **Documentation and Tools:** | |
| **Provider** | **CCGs** |
| **Information for families:**  Bradford Teaching Hospitals NHSFT  Calderdale and Huddersfield NHSFT  Chesterfield Royal Hospital NHS Foundation Trust  Leeds Teaching Hospitals NHS  Mid Yorkshire Hospitals NHSFT  Northern Lincolnshire and Goole Hospitals NHFT  York Teaching Hospital NHSFT | **Information for families:**  NHS Doncaster  NHS Hull  NHS Wakefield  NHS North East Lincolnshire  NHS Bassetlaw  NHS Bradford Districts  NHS Bradford City |
| **Information for children and young people:**  Airedale NHSFT  Bradford Teaching Hospitals NHSFT  Calderdale and Huddersfield NHSFT  Chesterfield Royal Hospital NHS Foundation Trust  Leeds Teaching Hospitals NHS  Mid Yorkshire Hospitals NHSFT  Northern Lincolnshire and Goole Hospitals NHFT  York Teaching Hospital NHSFT | **Information for children and young people:**  NHS Doncaster  NHS Hull  NHS Wakefield  NHS North East Lincolnshire  NHS Bassetlaw  NHS Airedale, Wharfedale and Craven  NHS Bradford Districts  NHS Bradford City |
| **Information for professionals around epilepsy care and working CYP**  Airedale NHSFT  Bradford Teaching Hospitals NHSFT  Calderdale and Huddersfield NHSFT  Chesterfield Royal Hospital NHS Foundation Trust  Leeds Teaching Hospitals NHS  Mid Yorkshire Hospitals NHSFT  Northern Lincolnshire and Goole Hospitals NHFT | **Information for professionals** around **care and working CYP**  NHS Doncaster  NHS Hull  NHS North East Lincolnshire  NHS Bassetlaw  NHS Airedale, Wharfedale and Craven  NHS Bradford Districts  NHS Bradford City |

|  |  |
| --- | --- |
| **Documentation and Tools:** | |
| **Provider** | **CCGs** |
| **IT Systems: use of IT for patient records and sharing of information e.g. are IT systems fit for purpose, are they linked to other organisations.**  Airedale NHSFT  Calderdale and Huddersfield NHSFT  Mid Yorkshire Hospitals NHSFT - Wakefield  Northern Lincolnshire and Goole Hospitals NHFT | **IT Systems e.g. are IT systems fit for purpose, are they linked to other organisations.**  NHS Doncaster  NHS Hull  NHS North East Lincolnshire  NHS Bassetlaw  NHS Airedale, Wharfedale and Craven  NHS Bradford Districts  NHS Bradford City |

|  |  |
| --- | --- |
| **Prevention, Children Young People & Families:** | |
| **Provider** | **CCGs** |
| **Current Position**  **(Definition of prevention in this case is based on harm and seizure reduction)**  Services have a variety of things in place to meet the self-management needs of children young people and families, providing them with information and support.  Parents are being encouraged to use mobile phones to take videos of seizures.  Some trusts are using videos to increase parental awareness understanding or epileptic and non-epileptic events  The majority of information provided is carried out face to face or using leaflets, with some services signposting to Epilepsy Action.  Information technology is gradually being introduced with the use of Skype, email and text messages.  One trust stated that they are training parents in emergency management of prolonged seizures.  Another trust responded that training needs are met by the Epilepsy Nurse Specialist with the families in regard to rescue medication, their diagnosis and future. All information is shared with parents and families to create expert patients when it is age appropriate.  Social media use is very limited only one Trust stated that they used social media. | **Current Position**  CCGs have indicated that they are aware of approaches to self-management and providing information to children young people and their families, these include:   * One trust offers Parent support groups as part of transition, although limited attendance reported. * Aware of information and leaflets but unsure of usage locally * Exploring the use of epilepsy monitoring e.g. cameras and mat. * Pathway and development work to include a focus on self-management and information for CYP and Families * Social media use is very limited; it is being developed in some CCGS and other sign post to apps developed by charities. |
| **Prevention, Children Young People & Families:** | |
| **Provider Results** | **CCGs Results** |
| **Self-Management Information and Guidance:**  Airedale NHSFT  Bradford Teaching Hospitals NHSFT  Calderdale and Huddersfield NHSFT  Chesterfield Royal Hospital NHS Foundation Trust  Leeds Teaching Hospitals NHS  Mid Yorkshire Hospitals NHSFT  Northern Lincolnshire and Goole Hospitals NHFT  York Teaching Hospital NHSFT | **Self-Management Information and Guidance:**  NHS Doncaster  NHS Hull  NHS North East Lincolnshire  NHS Bassetlaw  NHS Airedale, Wharfedale and Craven  NHS Bradford Districts  NHS Bradford City |
| **Education and Training Programs:**  Airedale NHSFT  Calderdale and Huddersfield NHSFT  Chesterfield Royal Hospital NHS Foundation Trust  Mid Yorkshire Hospitals NHSFT  Northern Lincolnshire and Goole Hospitals NHFT | **Education and Training Programs:**  NHS Doncaster  NHS Hull  NHS North East Lincolnshire  NHS Bassetlaw  NHS Airedale, Wharfedale and Craven |
| **Expert Patients:**  Northern Lincolnshire and Goole Hospitals NHFT | **Expert Patients:**  NHS North East Lincolnshire |
| **Peer support groups/programmes:**  Airedale NHSFT  Bradford Teaching Hospitals NHSFT | **Peer support groups/programmes:**  NHS Hull  NHS Airedale, Wharfedale and Craven  NHS Bradford Districts  NHS Bradford City |

|  |  |
| --- | --- |
| **Prevention, Children Young People & Families:** | |
| **Use of technology for self-management:**  Airedale NHSFT  Bradford Teaching Hospitals NHSFT  Calderdale and Huddersfield NHSFT  Leeds Teaching Hospitals NHS  Mid Yorkshire Hospitals NHSFT | **Use of technology for self-management:**  NHS Doncaster  NHS Hull  NHS Airedale, Wharfedale and Craven  NHS Bradford Districts  NHS Greater Huddersfield and North Kirklees  NHS Bradford City |
| **Social Media:** | **Social Media:**  NHS Doncaster |
| **Data & Data Collection:**  Due to lack of a national or regional dataset comparison cannot be made on trust/CCG data this is an issue across the region. Therefore it is difficult to identify and compare prevalence in relation to admissions etc... and what may contribute to these | |
| **Provider** | **CCGs** |
| **Current Position**  **Data**: The majority of trusts collect all the data identified in the scoping and many trusts provided this data as part of their response.  **Prescribing Data**: Only one provider indicated that they collect data around prescribing and on stated that Specific data for prescribing could be explored.  Nationally there is not an agreed data set and the coding system limits what can be recorded, for this reason it is likely that diagnostic recording is incomplete. | **Current Position**  Data: Only one CCG stated that they do not have access/collect the data identified in the scoping. The remaining CCGs have access to the data with one CCG working towards improving data collection for elective admissions and readmissions.  **Prescribing Data**: One CCG stated that they are able to obtain some data due to the shared (secondary and primary care) arrangement, a second CCG currently has 230 patients that are prescribed to on the caseload. |

|  |  |
| --- | --- |
| **Data & Data Collection:** | |
| **Provider Results** | **CCGs Results** |
| **a) Non elective ED attendance and/or admissions**  Airedale NHSFT  Bradford Teaching Hospitals NHSFT  Calderdale and Huddersfield NHSFT  Leeds Teaching Hospitals NHS  Mid Yorkshire Hospitals NHSFT  Northern Lincolnshire and Goole Hospitals NHFT  Sheffield Children’s NHSFT  **b) Elective admissions**  Airedale NHSFT  Bradford Teaching Hospitals NHSFT  Calderdale and Huddersfield NHSFT  Leeds Teaching Hospitals NHS  Northern Lincolnshire and Goole Hospitals NHFT  Sheffield Children’s NHSFT  **c) Length of stay, both short and long**  Airedale NHSFT  Bradford Teaching Hospitals NHSFT  Calderdale and Huddersfield NHSFT  Leeds Teaching Hospitals NHS  Mid Yorkshire Hospitals NHSFT  Northern Lincolnshire and Goole Hospitals NHFT  Sheffield Children’s NHSFT | **a) Non elective ED attendance and/or admissions**  NHS Doncaster  NHS Airedale, Wharfedale and Craven  NHS Bradford Districts  NHS Bradford City  NHS North East Lincolnshire  NHS Leeds  NHS Wakefield  NHS Greater Huddersfield and North Kirklees  **b) Elective admissions**  NHS Doncaster  NHS Airedale, Wharfedale and Craven  NHS Bradford Districts  NHS Bradford City  NHS North East Lincolnshire  NHS Leeds  NHS Wakefield  **c) Length of stay, both short and long**  NHS Doncaster  NHS Airedale, Wharfedale and Craven  NHS Bradford Districts  NHS Bradford City  NHS North East Lincolnshire  NHS Leeds  NHS Wakefield  NHS Greater Huddersfield and North Kirklees |
| **Data & Data Collection:** | |
| **Provider Results** | **CCGs Results** |
| **d) Readmission rates**  Airedale NHSFT  Bradford Teaching Hospitals NHSFT  Calderdale and Huddersfield NHSFT  Leeds Teaching Hospitals NHS  Mid Yorkshire Hospitals NHSFT  Northern Lincolnshire and Goole Hospitals NHFT  Sheffield Children’s NHSFT  **Prescribing**  Mid Yorkshire Hospitals NHSFT | **d) Readmission rates**  NHS Doncaster  NHS Airedale, Wharfedale and Craven  NHS Bradford Districts  NHS Bradford City  NHS North East Lincolnshire  NHS Leeds  NHS Wakefield  **Prescribing**  NHS Doncaster  NHS Hull |
|  | |

|  |  |
| --- | --- |
| **Barriers:** | |
| **IT** | * Coding – Primary and Secondary Care * IT infrastructure, IT Systems * The unit requires a database for medical and surgical epilepsy in order to monitor performance and clinical outcomes. * Software; IT system major limitation. * There is inconsistent access to electronic records sharing systems for secondary care and community providers. The lack of integrated access is a key barrier to effective, efficient care processes. |
| **Finance** | * Finance supplement in BPT is inadequate to meet the needs of the service * Financial Service Envelope * Funding for psychology provision including neuro-psychology. |
| **Pathways** | * Lack of understanding in making the diagnosis * Diagnostic; Minor delay in Cranial MRI, waiting list for Video EEG * Need improved planning within Y&H with regards to the tertiary neurology level of service required as per NICE guidance * There could easily be agreed pathways and protocols that allow for tertiary neurology involvement without the paediatric neurologists actually having to see the patient. * Lack of integrated psychology services * Non specialist consultants not referring onto to specialist consultants and/ or the community nurse. |
| **Quality of Service** | * Inconsistency / equitability in services (Acute Care) * Time to develop quality of service further. * Access to psychological assessment and support * Liaison with school behaviour support etc. rarely mentioned as part of pathway like children with autism and ADHD these children frequently fail to achieve their potential a quality service would address developmental delay, short term memory problems etc. * The mind-set of a medical model is apparent in responses when a more holistic approach is called for |

|  |  |
| --- | --- |
| **Barriers:** | |
| **Staffing** | * There is no nationally agreed number of Epilepsy Nurses needed per number of CYP with epilepsy and so this does impact on the understanding of the resource required for an optimal service * We aim to deliver to the standards for BPT but this is not easy with existing epilepsy nursing resource * number of epilepsy specialist nurses for both tertiary and secondary epilepsy which are reported to be currently inadequate for the population catchment * Management; capacity issues at times (increasing number of referrals). Lack of Epilepsy nurse * Capacity (associated workload) - looking to increase clinics to weekly instead of fortnightly to meet the demand for the service * community epilepsy nurse is a single practitioner * Stakeholders reported a lack of training and exposure in relation to children and young people with epilepsy in primary care and for non-specialist hospital ward staff. This is reported to encourage a culture that perceives that epilepsy (in particular in children) can only be supported by specialist area, acute based staff. |
| **Patients** | * Growing number of patients. * No capacity for patient support groups but in the process of exploring how the voluntary sector can help with this. * Patients can remain in service post 16 if desirable and are supported through education but can't be referred in post age 16. These children have to access adult services that don't meet their needs. |
| **Commissioning** | * Not a priority however…... The intentions for a review of commissioning requirements for community paediatric services in 2016 provides further opportunities to review and understand the current service and requirements going forward. * The biggest challenge at the moment is that it isn't a priority area and as such will not get the level of focus and resource needed for service improvement. * Services are commissioned across many providers. * Barriers around commissioning of specific roles within epilepsy in relation to best practice tariff. |

|  |  |
| --- | --- |
| **Opportunities for Future Development:** | |
| **Transition** | * Transition to Adult Services -create dedicated clinics |
| **Finance** | * Implement paediatric best practice tariff. * The best practice tariff would help us to move this up the agenda without a big undertaking of resource. |
| **Self-Management & Support** | * Develop and implement community based patient Support groups. * Development of local Support Group (voluntary led), * Introduction of apps * Education for all etc... * Paediatric/Adult Information brochure on local support and services available |
| **Data & Performance** | * Data collection would give auditable measures of clinical outcomes and lead to service development, and support early identification of patients suitable for evaluation for epilepsy surgical evaluation. * Agreed standards for the outreach clinics across Yorkshire and Humber to improve patient experience and outcomes. |
| **Staffing** | * Nurse prescribing and nurse led clinics. Expansion of epilepsy nurse provision. * Epilepsy nurse and adequate??? * Introduction of support for nursing staff, * enhancing nursing support, psychology and school liaison |
| **IT** | * Electronic notes record. * E-consultation being developed for whole paediatric service which will facilitate advice to primary care regarding patients with possible fits or established patients. * IT system upgrade |

|  |  |
| --- | --- |
| **Opportunities for Future Development:** | |
| **Service & Pathways** | * Reducing mortality avoidable deaths? * Opportunities - Psychology provision. * Diagnostics; decreased waiting times, in-house cranial imaging in the under 5's with oral sedation * Psychology provision * Engagement with GPs and sharing pathways, * Strengthening working relationships with voluntary sector - Epilepsy Action/Young Epilepsy etc... * Developing an integrated pathway across all organisations to ensure service providers understand their roles, responsibilities and relationships. |
| **Commissioning** | * Newly commissioned service and so still in early stages of implementation. * Just commissioned care closer to home and this will be an essential element and engagement across the sectors. * reducing admissions and A&E attendances |

|  |  |
| --- | --- |
| **Examples of Good Practice:** | |
| **Staffing & Workforce Development** | * At CHFT we have redesigned the team so that the specialists have a more collaborative approach. For example, except when persons are on leave, consultants, the associate specialist and the Epilepsy Nurse are in clinic at the same time. * Epilepsy Nurse is a nurse prescriber which allows her to review patient's medications and suggest dose changes etc. * "TEACH" DCCNTT training team. * Teaching sessions for teachers, families and other staff. Junior doctor training * Regular teaching of trainees and staff. |
| **Service Provision & Commissioning** | * Functional Magnetic Resonance and Diffusion Tensor imaging are available in the Trust. * There is close liaison with geneticists which aid the diagnosis, define the prognosis and aids patient and family management. * Clinic proforma and pathway developed. * Clinical care; joint clinics with tertiary colleagues, * Regular discussion with tertiary care regarding epilepsy management for the under 2's and all complex epilepsy patients. * Cross cover by colleagues when one clinician is not around/ on leave * Hand held patient records for children presenting with status epilepticus. * Acute assessment proforma * Telephone clinics out of hours- to help resolve patient issues. * Community/acute model of care: - strong team with Consultant lead and Nurse lead * The ability to see patients at home is taking care closer to home. * Just commissioned care closer to home and this will be an essential element and engagement across the sectors. * Developing an integrated pathway across all organisations to ensure service providers understand their roles, responsibilities and relationships. * Avoiding a focus only on the medical there are significant neuro developmental and behavioural issues for children with epilepsy |

|  |  |
| --- | --- |
| **Examples of Good Practice:** | |
| **Data & Performance (including service evaluation)** | * All epilepsy related mortality data is reviewed in local clinical governance forum. * Regular audits including patient experience audit. * CQC feedback * The Trust has excellent clinical outcomes for reactive surgery for epilepsy paper published 2015 * The epilepsy community nurse has excellent feedback from patients, parents and carers and is undoubtedly helping to reduce emergency admissions for epilepsy. Last year we saw a reduction of 23% |
| **Patients & Self-Management** | * Patient and parent involvement. * Support system for families and good team working and communication. * Providing education programmes to support expert patients and self-management. * Supporting complex needs and management of long term conditions. * Recent survey highlighted that feedback from patients, parents and family members was resoundingly positive in a number of areas (see report) * The need for services to centre on patient care at a more holistic, family level, in particular when more than one child in any one family. |

# Emerging Themes for further discussion include:

Emerging themes for further discussion include:

1. Longer than average **inpatient stays** in some areas (Bradford) and for those with more complex needs especially life limiting conditions or where levels of deprivation reduce families ability to manage at home,
2. **Increasing admissions** (Kirklees),
3. **Zero day** admissions that could be managed in the community,
4. **Discharge delays** where community based support is not in place to give families the confidence to cope,
5. **Delays in** **investigations** and unclear pathways for more specialist referral,
6. Difficulty resourcing and organising **training for parents** and carers e.g. delivery of emergency medication,
7. **Transitions** 16 year olds sometimes remain in service but new patients go to adult services that may not meet needs or engage with family. Dedicated transition clinics not universal,
8. **Harm prevention practice sharing.**

# Key Recommendations and Areas for Further Support

|  |
| --- |
| **Commissioning, Benefits and KPIs** |
| 1. Support for a collaborative approach to the development of a service specification and identification of new models of care including: better access to nurses, support for best practice tariff and provision of psychology services. 2. Facilitate provider self-assessment against agreed standards / benchmark local services   Commissioners and providers sharing data and information about the needs of the population.   1. NHS England commissioners should review the availability of Epilepsy Clinical Nurse Specialist support for children in light of cases reviewed in the region by the CDOP in which there were modifiable factors. [[3]](#footnote-3) |
| **Workforce Development, Training and Education** |
| 1. Commissioners and providers use the competency frame work when considering the needs of the workforce and workforce development. 2. Scoping of the wider workforce is necessary e.g. training of A&E staff, GPs, practice nurses, school nurses and school staff. 3. Development of a regional framework for statutory and mandatory training, including the wider workforce and what is needed for different roles. 4. Education needs to be considered across all provider services to include new guidance around seizure classification and diagnosis (ILAE International League against Epilepsy) update 2016 from 2010. 5. Use the Nurse Audit tool within the epilepsy commissioning tool to identify and compare the role and activities of ESNs including case loading. 6. Regional scoping of evidence to support and advise the number of ESNs recommended per population. |

|  |
| --- |
| **Documentation and Tools:** Pathways and Services |
| CCGS and Providers to be aware of pathways that in are in place and to conduct joint reviews of pathways, including: identifying potential gaps with in what is included in the pathway, improvements and efficiencies. Clear and agreed roles and responsibilities identified within the pathways.   1. Clear definition of what is included in an integrated pathway e.g. only health? Social care? Community? CAMHs? 2. Clear and concise information is needed around pathways and protocols for referrals in to tertiary centres. 3. Access to psychological services/assessment needs to be reviewed and considered across providers in Y&H |
| 1. Commissioners to monitor and evaluate use of health plans and templates e.g. Integrated Health Care Plan, Education Health Care Plans, Epilepsy Passport. The type of plan used must be determined by the needs of the child, young person and their family and available with all agencies supporting the child, young person e.g. a section that should be added and updated.   Ensure age appropriate information is available for all young people and their families |

|  |
| --- |
| **Prevention, Children Young People and Families** |
| 1. Development of Children and Young People, Parent and Carers Surveys to include:    * quality and implementation of health plans    * self-management    * quality of and access to information, 2. Scope and understand national and regional best practice for self-care and management interventions and programmes. Including :    * Agreed definition of self-management support and interventions    * Continuum of self-management from minimum to maximum offer for CYP and families.    * Technology and voluntary sector. E.g. promote <http://www.thetea-room.com/>    * Learning from Adult based programmes    * Use of Social Media 3. Need to be a more holistic in the approach to provision of care and identifying the needs of CYP with epilepsy e.g. not just a medical approach looking at wider social determinants and need. 4. Trusts should make available emergency and first aid training for parents and professional (e.g. teachers) in contact with CYP with epilepsy e.g. consider promoting <http://learn.epilepsy.org.uk/courses/epilepsy-for-school-staff/>   And http://learn.epilepsy.org.uk/courses/epilepsy-for-teachers/ |
| **Education and Schools** |
| 1. Support for collaborative working between health and education to improve support for children within educational settings and ensure training is available for school nurses and school staff to support children with epilepsy 2. Put policies and plans in place to support pupils 3. A system should be developed whereby Trusts ensure notification to the School Nursing Service when a child or young person is diagnosed with epilepsy so that the school nurse can appropriately liaise with and support the school regarding the child or young person’s care[[4]](#footnote-4) |
| **Data and Data Collection** |
| 1. Share good practice of use of technology with a view to developing a consistent approach/system to enable electronic care records sharing between primary, community, secondary and tertiary care 2. Development of a regional dataset/dashboard for CYP epilepsy, addressing issues with coding with a view to compare and review prevalence particularly mortality and admissions data |
| **Provider Services** |
| 1. Undertake an exercise to define and agree the standards of care for the region including in outreach clinics and support the implementation of those standards 2. Keep records of seizure frequency and seizure freedom rates 3. Identify poorly controlled epilepsy patients that might benefit from evaluation for surgery across the region |

# Support and Resources from Epilepsy Action

* Example service specification http://www.epilepsytoolkit.org.uk/toolkit/service-specification/
* Promote online resources for school staff and pupils
* Nurse audit tools.
* Epilepsy Specialist Nurses
* Practice nurse and school staff training
* Consider adapting online programmes for children and co-produce with children if funding available
* Co-produce and circulate children, young people, parent and carer surveys.
* Parent support groups
* Epilepsy commissioning toolkit.
* Local data reports using CHiMat tools

# Epilepsy Commissioning Toolkit

Epilepsy Action and Epilepsy Society have worked with nine Clinical Commissioning Groups (CCGs) to create a single access point of resources to support effective commissioning for children and adults with epilepsy. The nine sections work through the whole commissioning process. Each section can be accessed individually to meet an organisations specific need.

Support for the following elements can be found in the toolkit:

* Scope – What needs to be done
* Data Analysis
* Map Current Provision
* Co-production
* Service Model
* Business Case
* Service Specification
* Contract Service
* Implementation

Click [here](http://www.epilepsytoolkit.org.uk/) to access the resource.

# Key Documents

| Title | Date | Author | Brief Description | Link |
| --- | --- | --- | --- | --- |
| The epilepsies in children and young  People – standard 27 | February  2013 | NICE | This quality standard covers the diagnosis and management of the epilepsies in children and young people (aged up to 18 years). For more information see the scope for this quality standard. | <http://www.nice.org.uk/guidance/QS27> |
| Joint Epilepsy council prevalence and incidence Dec 2011 | Dec 2011 | Joint Epilepsy council | Prevalence and incidence  You have this document again below | <http://www.epilepsyscotland.org.uk/pdf/Joint_Epilepsy_Council_Prevalence_and_Incidence_September_11_(3).pdf> |
| Operational Classification of Seizure Types by the International League Against Epilepsy | 2010 – 2016 Update | the International League Against Epilepsy | The purpose of such a revision is to recognize that some seizure types can have either a focal or generalized onset, to allow classification when the onset is unobserved, to include some missing seizure types and to adopt more transparent names. | <http://www.ilae.org/Visitors/Centre/documents/ClassificationSeizureILAE-2016.pdf> |
| Epilepsy 12 | 2009 | RCPCH | Epilepsy12 is a national clinical audit, established in 2009, with the 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  Epilepsy12 has now completed two rounds of national audit  The national report of round 2 of Epilepsy12 and a summary version for parents, carers, children and young people have been launched on 26 November 2014, and are now available to download.  [National report for professionals 2014](http://www.rcpch.ac.uk/system/files/protected/page/Epilepsy12%20report%202014%20for%20web.pdf) (PDF, 2.7MB)  [National report for parents, carers, children and young people 2014](http://www.rcpch.ac.uk/system/files/protected/page/parent%20Epilepsy12%20print%20version_0.pdf) (PDF, 1.8MB) | <http://www.rcpch.ac.uk/epilepsy12> |
| The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care CG137 | January 2012  Updates Feb 2016 | NICE | Clinical guideline based on best available evidence | [The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care CG137](http://www.rcpch.ac.uk/content/epilepsies-diagnosis-and-management-epilepsies-adults-and-children-primary-and-secondary-car) |
| The National Service Framework for Long-term (Neurological) Conditions | March 2005 | Department of Health | Sets out the government's quality standards for supporting people with long term conditions. | [The National Service Framework for Long-term (Neurological) Conditions](http://www.rcpch.ac.uk/content/national-service-framework-long-term-neurological-conditions) |
| Fundamentals of commissioning health services for children | March 2011 | CHIMAT – National Child and Maternal Health Intelligence Network | This paper uses information that is readily available to look at how some primary care trusts have not only reduced admissions but commissioned services which deliver better outcomes for children and young people. | [Fundamentals of commissioning health services for children](http://www.rcpch.ac.uk/content/fundamentals-commissioning-health-services-children) |
| Improving Young People’s Health and Wellbeing – A Framework for Public Health. | 2015 | Public Health England | This framework addresses the request by the chief medical officer in her 2012 Annual Report that PHE should consider the specific needs of this age group.  It has been produced with the Associations of Directors of Public Health, Directors of Children Services and the Local Government Association. It gives practical support to councillors, health and wellbeing boards, commissioners, and service providers. It sets out at a high level a way of thinking about young people’s health, taking an asset-based approach, and focusing on wellbeing and resilience. It sets out six core principles that will promote a more effective, integrated response to needs.  Later this year we will launch Rise Above, a national youth campaign that will focus on building young people’s resilience and help them make positive health decisions. | <https://www.gov.uk/government/publications/improving-young-peoples-health-and-wellbeing-a-framework-for-public-health> |
| Epilepsy Policy for Schools | January 2009 | Epilepsy Action | Printable Booklet – Information, guidance and support about Epilepsy in schools and what should make up a policy for schools. | [Epilepsy Policy for Schools](http://www.rcpch.ac.uk/content/epilepsy-policy-schools) |
| Epilepsy resource pack for general practitioners - Website | January 2005 | Epilepsy Action | This website has been developed to help you implement services for epilepsy patients in line with recently updated national guidance and the QOF.  There are three broad sections to the main website:   * [Section 1](https://www.epilepsy.org.uk/professionals/healthcare/primary-care-resource-pack/section-1/background-epilepsy-national-guidance) gives a background of epilepsy in the UK and reviews the latest guidance * [Section 2](https://www.epilepsy.org.uk/professionals/healthcare/primary-care-resource-pack/section-2/general-management/diagnosis) discusses general management of patients * [Section 3](https://www.epilepsy.org.uk/professionals/healthcare/primary-care-resource-pack/section-3/annual-review-rereferral) assists with annual review and quality outcomes reporting   [Complete an interactive action plan for your practice](https://www.epilepsy.org.uk/healthcare-tool/index.html)  In addition to the content of the three broad sections or the website, you will find relevant [tools and templates](https://www.epilepsy.org.uk/professionals/healthcare/primary-care-resource-pack/tools-templates) to assist you with annual reviews and quality outcomes reporting, as well as guidance on patient support information. For practices in your region, a downloadable booklet on commissioning epilepsy services has also been provided. You can use the navigation on the left of the page to move around the site and access topics of interest. | [Epilepsy resource pack for general practitioners](http://www.rcpch.ac.uk/content/epilepsy-resource-pack-general-practioners) |
| Epilepsy in England: time for change | January 2009 |  | Reports on the results of a survey of health trusts in England and a survey of people with epilepsy. The results show variation in the provision of epilepsy services, the collection of information and the quality of care. | [Epilepsy in England: time for change](http://www.rcpch.ac.uk/content/epilepsy-england-time-change) |
| Best care: The value of epilepsy specialist nurses | March 2010 |  | The report shows that among their many duties, ESNs:   * Review the control of seizures and adjust or change medication, * Provide essential advice and information, * Help patients understand the risks that come with epilepsy, * Provide a link, and first point of contact for a person trying to work their way through a complicated health system, and * Give time and support to help reduce the impact of this serious and often misunderstood condition * Deal with many of the more common problems, freeing neurologists to concentrate their time on more complex cases. This creates a better service for everyone, and saves money. | [Best care: The value of epilepsy specialist nurses](http://www.rcpch.ac.uk/content/best-care-value-epilepsy-specialist-nurses) |
| Guide to writing a business case for an epilepsy specialist nurse service | August 2011 | Epilepsy Action | This guide complements the ‘Commissioning Epilepsy Services Resource Pack for Commissioners’ which is one of the outcomes of ‘[Best Value, Better Care – Commissioning Epilepsy Services](https://www.epilepsy.org.uk/sites/epilepsy/files/primary-care-resource/epilepsyaction-primary-care-commissioning-book.pdf)’ conference held on 23 February 2010 in London.  The guide will be useful to anyone writing a business case for an epilepsy specialist nurse service, whether they are clinical practitioners or commissioning managers. It will help to identify the desired outcomes and the costs and benefits accrued in achieving them. | [Guide to writing a business case for an epilepsy specialist nurse service](http://www.rcpch.ac.uk/content/guide-writing-business-case-epilepsy-specialist-nurse-service) |
| Things to discuss with parents/young person with epilepsy | January 2015 | Epilepsy Society | How epilepsy is diagnosed and treated, how it can affect learning, and information for parents and teachers. | http://shop.epilepsysociety.org.uk/product/children-leaflet/44821/2/  [children (pdf)](http://www.epilepsysociety.org.uk/system/files/attachments/ChildrenJanuary2015_3.pdf) |
| Epilepsy Commissioning Toolkit | 2016 | Epilepsy Action/Epilepsy Society | Epilepsy Society has partnered with Epilepsy Action to design the new 'Epilepsy Commissioning Toolkit' to help commissioners provide better health services for people with epilepsy. | [Epilepsy Commissioning Toolkit](http://www.epilepsysociety.org.uk/epilepsy-commissioning-toolkit) |
| NICE commissioning guide for the diagnosis and management of the epilepsies in adults, children and young people. | 28 Feb 2013 | nice | NICE guide for commissioners focuses on improving the diagnosis of epilepsy and ensuring that diagnosis and treatment are both confirmed and reviewed as necessary. The guide focuses on tailoring treatment to individual circumstances and the needs of people with epilepsy so that they are offered the most suitable treatment. | [NICE commissioning guide for the diagnosis and management of the epilepsies in adults, children and young people.](http://www.epilepsysociety.org.uk/sites/default/files/diagnosis-and-management-of-the-epilepsies-in-adults-children-and-young-people-cmg47.pdf) |
| CG137 Epilepsy: baseline assessment | 2012 | nice | The baseline assessment is an Excel spreadsheet that can be used by organisations to identify if they are in line with practice recommended in NICE guidance and to help them plan activity that will help them meet the recommendations. | [CG137 Epilepsy: baseline assessment](http://www.epilepsysociety.org.uk/sites/default/files/Epilepsy%20-%20baseline%20assessment%20-%20implementing%20NICE%20guidance.xlsx) |
| CG137 Epilepsy: pharmacological treatment by seizure type | 2012 | nice | This form can be used to conduct a baseline assessment of a trust’s current activity in relation to the NICE guideline on epilepsy.  Current activity can be included along with actions needed to meet the recommendations and the trust lead. The document can help you identify which areas of practice may need more support, decide on clinical audit topics and prioritise implementation activities.  This document should be used in conjunction with the [NICE clinical guidance on Epilepsy](http://www.nice.org.uk/guidance/CG137). | [CG137 Epilepsy: pharmacological treatment by seizure type](http://www.epilepsysociety.org.uk/sites/default/files/Epilepsy-%20pharmacological%20treatment%20by%20seizure%20type.docx) |
| CG137 Epilepsy: pharmacological treatment by syndrome | 2012 | NICE | This clinical audit tool can be used to measure current practice in the pharmacological treatment of epilepsy against the recommendations in the NICE clinical guidance on Epilepsy. It contains criteria and a data collection tool. | [CG137 Epilepsy: pharmacological treatment by syndrome](http://www.epilepsysociety.org.uk/sites/default/files/Epilepsy%20pharmacological%20treatment%20by%20syndrome.docx) |
| childhood epilepsy  syndromes: factsheet 26 | Nov  2013 | Epilepsy Society | This factsheet gives a brief overview of what childhood epilepsy syndromes are and includes details of some specific syndromes. | <https://www.epilepsysociety.org.uk/childhood-epilepsy-syndromes#.VzGXqhtViko> |
| Children with epilepsy | Sep 2013 / review date 2016 | Epilepsy Action | This booklet is written by Epilepsy Action’s advice and information team, with guidance and input from people living with epilepsy, and medical experts.  This information will tell you about some of the issues that affect children with epilepsy, and where you can go for any help or support you need. | <https://www.epilepsy.org.uk/info/children/children-with-epilepsy> |
| The Epilepsy Passport | Sep  2015 | RCPCH | The Epilepsy Passport contains essential up-to-date information about a child or young person’s epilepsy, including their emergency care plan, medication history and key professional contacts.  This has been developed by the Royal College of Paediatrics and Child Health (RCPCH) with input from key epilepsy professionals, parents, children and young people and funded by the Healthcare Quality Improvement Partnership (HQIP). The aim is to help children and young people with epilepsy and their families communicate with healthcare and other professionals and to help healthcare professionals communicate with each other. | [Download the Epilepsy Passport (PDF, 680KB)](http://www.rcpch.ac.uk/system/files/protected/page/RCPCH%20Epilepsy%20Passport.pdf) |
| Coordinating Epilepsy Care: a UK-wide review of healthcare in cases of mortality and prolonged  Seizures in children and young people with epilepsies. Child Health Reviews–UK, | Sep  2013 | RCPCH | This report, from the Child Health Reviews - UK (CHR-UK) team, drills down into the detail of the epilepsies and highlights where services are doing well and where improvements are required. Because children with epilepsies can test every part of the healthcare system from diagnosis right through to end of life care, this report has implications for all professionals involved in the care of children, whether in hospitals, schools or other community settings. The ability to provide safe, equitable, integrated care for all children with epilepsies, in particular those with difficult to control epilepsies and multiple co-morbidities, is a true measure of the competence of our healthcare provision. This report sets out the essential improvements needed to move us towards that goal. Most importantly, it clearly shows the need for a partnership of care between those providing health services, and the children and families they serve. | [RCPCH Child Health Review into Epilepsy](http://www.rcpch.ac.uk/child-health-reviews-uk/programme-findings/programme-findings-chr-uk) |
| About epilepsy - information for young people | Dec  2014 /review date Dec 2017 | Epilepsy Action | If you’re a teenager with epilepsy, you probably have all sorts of questions about how epilepsy could affect your life. For example, will you be able to go on holiday with friends, go to concerts and clubs and drink alcohol? Or maybe you have a friend, brother or sister who has epilepsy and you just want to understand more about it. The aim of these webpages is to answer these questions. | <http://youngpeople.epilepsy.org.uk/> |

1. NHS England. 2015. Personalised care for long term conditions. [ONLINE] Available at: http://www.england.nhs.uk/resources/resources-for-ccgs/out-frwrk/dom-2/ltc-care/. [Accessed 10 March 15]. [↑](#footnote-ref-1)
2. **Epilepsy 12** (*Round 2 National Report: November 2014* *audit of paediatric services in the UK against 12 indicators from NICE guideline CG20)* [↑](#footnote-ref-2)
3. Leeds CDOP Report recommendation 6 [↑](#footnote-ref-3)
4. Leeds CDOP Report recommendation 7 [↑](#footnote-ref-4)