# Epilepsy12 2020 National Report - draft reporting and analysis plan

## Introduction

This document provides a summary of the proposed reporting and analysis plan for the Epilepsy12 2020 National Report which will include the results of the analysis of both clinical and organisational audit data from participating Health Boards and Trusts in England and Wales.

The report will follow a similar structure to the national reports of rounds 1 and 2 of Epilepsy, published in 2012 and 2014 respectively. We are proposing to expand the report content to include case studies as well as sections covering CYP engagement, QI activity and an OPEN UK update. It has not yet been decided if these items will be in the national report or if they will be reported separately, either on the RCPCH website or as standalone reports (for completeness, they have been included in the proposed structure below). There will be no Patient Reported Experience Measures (PREM) element to the report as the project scope for the current round includes developing a PREM methodology for a potential round 4 rather than delivering a PREM during this round.

## Structure of the report

* Forward
* Summary (1 page summary of key findings and recommendations)
* Key findings and recommendations
* Introduction (Background to the audit, audit aims)
* Methodology (TBC whether to include in core report or website) covering descriptions of the following
  + Audit Domains
  + Description of the clinical cohort
  + Recruitment
  + Data Collection
  + Key Clinical Performance Indicators
  + Data quality and analysis
* CYP engagement (e.g. a supporting summary guide for young people and parents)
* The RCPCH Epilepsy Quality Improvement Programme (EQIP)
* Organisational of Paediatrics Epilepsy Networks in the UK (OPEN UK) Update
* Case studies (around organisational structure and clinical improvement activities)
* Results
  + Organisational audit domain results
  + Clinical audit domain results
  + Key Clinical Performance indicators
  + Combined clinical/organisational audit mapping results (tbc)
* Seizure freedom outcome data
* Key Recommendations line of sight table
* References
* Appendix 1: Glossary and definitions
* Other appendices TBC

The next section of this document provides an overview of what will likely be reported in the organisational audit, clinical audit and performance indicator chapters.

## Results sections

The tables in this section include a description of the data items, how they will be reported and where comparable data, from previously published Epilepsy12 reports, can be found. The data items that relate to “NICE Quality Standards” and the proposed data items to be used in outlier analysis are also highlighted.

#### Comparable data from previously published Epilepsy12 reports

In Rounds 1 and 2, data was collected at a paediatric epilepsy service “unit”, or individual hospital level rather than at a Health Board/Trust level. As such, it will not be possible to do a full comparative analysis of clinical audit data with the findings of previous audit rounds. If comparable data is available, reporting will be limited to national findings only (England and Wales separately, England and Wales combined). Similarly, it will only be possible to compare Health Board/Trust level results with previous rounds for a small number of data items, however, it will be possible to do a comparative analysis against the findings of the 2018 Organisational Audit (OA) report.

#### Levels of reporting

The levels of reporting have not yet been defined for each data item yet. All data included in the report will be reported for England and Wales combined and, where appropriate, results will also be reported for England and Wales separately, and by OPEN UK regional network.

All data will be published in some format (e.g. bespoke reporting tools, summary data files published online) for England and Wales combined, England and Wales, OPEN UK network level, HB/T level, CCG and STP level.

#### Outlier analysis

The three Epilepsy12 performance indicator metrics that are currently proposed to be subject to outlier analysis are as set out below and as agreed by the Epilepsy12 Methodology & Dataset Group and Project Board in September 2017 as set out on page 21 of the [round 3 methodology document](https://www.rcpch.ac.uk/sites/default/files/2018-07/epilepsy12_round_3_methodology_overview_july_2018_0.pdf);

1. Children receiving input from a Paediatrician with expertise in epilepsies within 12 months of first paediatric assessment 2)

2. Children receiving input from an Epilepsy Specialist Nurse within 12 months of first paediatric assessment

3. Children receiving Tertiary input within 12 months of first paediatric assessment

Once the initial data download has been analysed, a final decision will be made as to whether or not they will definitively be used for outlier analysis.

Again, once initial data is available, further analysis will be undertaken to assess if there are any additional metrics that are clinically and statistically appropriate that could be included in outlier analysis with Care Planning having been considered so far in particular.

The report will not include a dedicated outlier analysis section however some selected outlier analysis results may be included within key findings if anything of particular note is identified and these could be supported by related funnel plot images to show the distribution of outliers. We would then have the full outlier analysis results available in the proposed “Epilepsy12 Online” public facing reporting tool akin to [NNAP Online](https://nnap.rcpch.ac.uk/outlier-data.aspx)/[NPDA Reports Online](http://npda-results.rcpch.ac.uk/outlier-data.aspx).

#### Analysis of clinical audit results against organisational factors

If appropriate, clinical audit data and organisational audit data will be linked to examine if there is an association between the organisation of epilepsy services and how children and young people with epilepsy are assessed, supported and managed during their first year of care. For example, we might want to consider comparing:

* PI results for: tertiary vs non-tertiary services; those with ESN provision vs those without; having BPC clinics vs not having one; availability of paediatric neurologist input vs not having the availability of this input
* Mental health service provision vs actual mental health input
* Neurodisability service provision vs actual input

The project team will also explore whether the national level (England & Wales combined and England and Wales separately) 12 clinical key performance indicator results can be mapped to the organisational audit key findings measures.

#### NICE Quality Standards

The data items that relate to NICE Quality Standards are highlighted in the tables.

### Organisational audit domain results

Organisational audit domain results will be calculated using the results of the 2019 organisational audit (OA).

The listed key findings are those that were included in the 2018 organisation report based on a description of paediatric epilepsy services within Health Boards and Trusts as at April. They are therefore not set in stone and may change following analysis of the 2019 organisational audit data where Health Boards and Trusts will describe the organisation and structure of their paediatric epilepsy services as at November 2019. The Organisational audit dataset may be amended slightly with some additionally proposed measures subject to agreement and sign off by the Methodology & Dataset Group and Project Board.

|  | **Description** | **Summary of how data will be reported or analysed** | **Notes**  **(i.e. comparable data, NICE QS, outlier metric?)** |
| --- | --- | --- | --- |
| **1** | **2018 Key findings** |  |  |
| **1.1** | **Workforce** |  | Comparable data: organisational audit 2018 (all items apart from any newly added data items for the 2019 audit) |
| 1.1.1 | HB/Ts with at least some level of input from a general paediatric consultant with 'expertise in epilepsy' | % (n) of HB/Ts |
| 1.1.2 | HB/Ts with a defined epilepsy clinical lead | % (n) of HB/Ts |
| 1.1.3 | HB/Ts with at least some level of input from an epilepsy specialist nurse | % (n) of HB/Ts |
| 1.1.4 | HB/Ts that were able to support epilepsy specialist nurse rescue medication training for parents | % (n) of HB/Ts |
| **1.2** | **Epilepsy clinic configuration** |  |
| 1.2.1 | HB/Ts that had defined consultant or associate specialist led epilepsy clinic seeing patients at secondary level | % (n) of HB/Ts |
| 1.2.2 | HB/Ts that had a TFC 223 Epilepsy Best Practice Criteria (BPC) clinics  - Yes, no, in development | % (n) of Trusts |
| **1.3** | **Tertiary provision** |  |
| 1.3.1 | HB/Ts with agreed referral pathways to tertiary paediatric neurology services | % (n) of HB/Ts |
| 1.3.2 | HB/Ts that could provide vagus nerve stimulator review | % (n) of HB/Ts |
| **1.4** | **Mental health** |  |
| 1.4.1 | HB/Ts that were able to facilitate mental health provision within epilepsy clinics  Or  - had an action plan describing steps towards achieving it | % (n) of HB/Ts |
| **1.5** | **Service contact** |  |
| 1.5.1 | HB/Ts where specialist advice was available all year round on all weekdays | % (n) of HB/Ts |
| **1.6** | **Transition** |  |
| 1.6.1 | HB/Ts that had an agreed referral pathway to adult services |  |
| 1.6.2 | HB/Ts that had an outpatient clinic specifically for young people with epilepsies |  |
| **2** | **Full Epilepsy12 Round 3 organisational audit results** |  |  |
| **2.1** | **Workforce** |  | Comparable data: organisational audit 2018 (all items apart from any newly added data items) |
| 2.1.1 | WTE paediatric consultants with ‘expertise in epilepsy’ | Total, mean, median (mid-range percentile) |
| 2.1.2 | WTE epilepsy specialist nurses | As above |
| 2.1.3 | Functions supported by epilepsy specialist nurses  - Rescue medication training parents, nurse prescribing, emergency department visits, nurse led clinics, home visits, rescue medication training schools, ward visits, individual healthcare plan facilitation, school meetings, all nine functions | % (n) of HB/Ts |
| **2.2** | **Epilepsy clinic configuration** |  |
| 2.2.1 | Number of consultant or associate specialist led secondary level epilepsy clinics taking place each week  - Total, mean, median (mid-range percentile) | Total, mean, median (mid-range percentile) |
| 2.2.2 | HBT that held defined epilepsy clinics that allowed at least 20 minutes with a consultant with ‘expertise in epilepsy’ and/or an epilepsy specialist nurse | % (n) of HB/Ts |
| **2.3** | **Tertiary provision** |  |
| 2.3.1 | WTE consultant paediatric neurologists responsible for managing the care of children and young people with epilepsy, both acutely and non-acutely | Total, mean, median (mid-range percentile) |
| 2.3.2 | HBTs with at least some level of input from a consultant paediatric neurologist | % (n) of HB/Ts |
| 2.3.3 | HBTs where paediatric neurologists could receive direct referrals from general practice or emergency services to assess children with possible epilepsy | % (n) of HB/Ts |
| 2.3.4 | HBTs hosting satellite paediatric neurology clinics | % (n) of HB/Ts |
| 2.3.5 | HBTS that could:  - facilitate the commencement of a ketogenic diet  - undertake ongoing review of a ketogenic diet | % (n) of HB/Ts |
| 2.3.6 | HBTS that could provide:  - vagus nerve stimulator insertion  - vagus nerve stimulator review | % (n) of HB/Ts |
| **2.4** | **Investigations** |  |
| 2.4.1 | HBTs that could provide  - 12-lead ECG  - Awake MRI  - MRI with sedation  - MRI with general anaesthetic  - EEG standard  - EEG sleep deprived  - EEG Melatonin induced  - EEG Portable on ward area  - EEG 24-48h ambulatory  - EEG Sedated  - Video telemetry inpatient  - Video telemetry outpatient  - Video telemetry home | % (n) of HB/Ts |
| 2.5 | **Mental health** |  |
| 2.5.1 | HBT that routinely, formally screen for diagnoses related to epilepsy  - ADHD, ASD, Mental Health disorders, none | % (n) of HB/Ts |
| 2.5.2 | HBTs that could use particular mental health screening questionnaires   * BDI – Beck Depression Inventory * Connor’s Questionnaire * Emotional Thermometers Tool * GAD – Generalised Anxiety Disorder * GAD 2 – Generalised Anxiety Disorder 2 * GAD 7 – Generalised Anxiety Disorder GAD 7 * HADS – Hospital Anxiety and Depression Scale * MFQ – Mood and Feelings Questionnaire (Child, Parent, adult versions * NDDI -E Neurological Disorders Depression Inventory for Epilepsy * PHQ – Patient Health Questionnaire, PHQ 2, PHQ 9 * SDQ (Strength and Difficulties Questionnaire) | % (n) of HB/Ts |
| 2.5.3 | HBT with agreed referral pathways for children and young people with mental health concerns | % (n) of HB/Ts |
| 2.5.3 | HBTs that could provide agreed referral pathways for children and young people with mental health concerns;  -Anxiety  -Depression  -Mood Disorders  -Non-epileptic attack disorder  -Other  -No, not for any of the above | % (n) of HB/Ts |
| 2.5.4 | Composition of mental health provision in HBTs that were facilitating mental health provision within epilepsy clinics  - mental health professionals provide direct co-located clinical care  - MDT meetings where epilepsy and mental health professionals discuss individual patients  - Other | % (n) of HB/Ts |
| 2.5.5 | HBTs could refer to mental health assessment service  - clinical psychology, psychiatric, educational psychology, formal developmental, none | % (n) of HB/Ts |
| **2.6** | **Service contact** |  |
| 2.6.1 | HB/Ts where specialist advice was available all year round/part of the year:  - on some weekdays, all weekdays or all weekdays and out of hours | % (n) of HB/Ts |
| 2.6.2 | HBT providing specialist advice between scheduled reviews | % (n) of HB/Ts |
| 2.6.3 | Typical response time to requests for specialist epilepsy advice between scheduled reviews  - same weekday, next week day, 3-4 weekdays, within working week | % (n) of HB/Ts |
| 2.6.4 | Professional who ‘typically’ provides the initial specialist epilepsy advice  - ESN, consultant, paediatric neurologist, other | % (n) of HB/Ts |
| **2.6.5** | HB/Ts with a clear point of contact for non-paediatric professionals seeking paediatric epilepsy support | % (n) of HB/Ts |
| **2.7** | **Transition** |  |
| 2.7.1 | Age at which the outpatient clinic typically accepted young people with epilepsies | % (n) of HB/Ts |
| 2.7.2 | HBTs that have an outpatient service for epilepsy where there is a presence of both adult and paediatric professionals | % (n) of HB/Ts |
| 2.7.3 | Structure of outpatient clinic service for epilepsy where there is a presence of both adult and paediatric professionals  - Several joint appointments, single joint appointment, mix of joint & individual appointments, other | % (n) of HB/Ts |
| 2.7.4 | Estimated percentage of young people transferred to adult services through a joint professional process  - mean, median (mid-range) | % (n) of HB/Ts |
| 2.7.5 | HBTs using structured resources to support transition | % (n) of HB/Ts |
| 2.7.6 | Adult professionals indicated as routinely involved in the transition or transfer of paediatric patients to adult services  - adult ESN, adult learning difficulty, adult neurologist, youth worker, other | % (n) of HB/Ts |
| **2.8** | **Neurodevelopmental support** |  |
| 2.8.1 | HBTs had agreed referral criteria for children and young people with neurodevelopmental problems e.g. ASD and ADHD | % (n) of HB/Ts |
| 2.8.1 | HBTs had agreed referral criteria for children and young people with neurodevelopmental problems  -ADHD  -ASD  -Behaviour difficulties  -Developmental Coordination disorder  -Intellectual disability  -Other  -None of the above | % (n) of HB/Ts |
| **2.9** | **Care planning** |  |
| 2.9.1 | HBTs that routinely undertake comprehensive care planning for children and young people with epilepsy | % (n) of HB/Ts |
| **2.10** | **Patient database or registry** |  |
| 2.10.1 | HBT maintaining a database or register of children and young people with epilepsies, other than as part of Epilepsy12  - Yes, for all CYP; Yes, for dome CYP; No | % (n) of HB/Ts |

### Clinical audit domain results

This section of the report will include information on:

* Participation and case ascertainment
* Description of the cohort (demographics and diagnostic status)
* Initial referral and examination
* Description of episodes (seizure type, electroclinical syndrome, seizure cause, convulsive seizures)
* Neurodisability/neurodevelopmental problem(s)
* Mental health
* Investigations
* Treatment
* Care planning
* Professionals and services involved in care

|  | **Description of data item** | **Summary of how data will be reported or analysed** | **Notes**  **(i.e. comparable data, NICE QS, outlier metric?)** |
| --- | --- | --- | --- |
| 3 | **Participation and case ascertainment** |  |  |
| **3.1** | **Participation** |  |  |
| 3.1.1 | No. registered HBTs | % (n) of HB/Ts |  |
| 3.1.2 | No. HBTs that submitted data to the organisational audit | % (n) of HB/Ts |  |
| 3.1.3 | No. HBTs that submitted clinical data | % (n) of HB/Ts |  |
| **3.2** | **Case ascertainment** |  |  |
| 3.2.1 | Process map showing the flow of children and young people through the data capture system i.e. from entry via EEG or HB/T through to inclusion in Cohort 1 and diagnosis of epilepsy  - no. registered at EEG  - no registered at HB/T  - no verified by HB/T  - no. excl. (i.e. those who were excluded at the verification stage) | Process map | Comparable data: Round 2 report pg. 23 |
| **4** | **Description of cohort** |  |  |
| **4.1** | **Demographics** |  |  |
| 4.1.1 | - Year of age by gender 0-24 years  - Month of age by gender 0-2 years  - Deprivation quintile | % (n) by gender and age  % (n) in each quintile | Comparable data: Round 2 report pg. 26/27 |
| **5** | **Diagnostic status** |  |  |
| 5.1 | Prior experience of neonatal seizures, febrile seizures or acute symptomatic seizure | % (n) of cohort |  |
| 5.2 | Diagnostic status  - 1+ episode considered epileptic  - non-epileptic only  - uncertain episodes | % (n) of cohort | Comparable data: Round 2 report pg. 29 |
| 5.3 | Description of epileptic episode  - single episode  - cluster within 24 hours  - 2+ episode >24 hours apart  - diagnosed for another reason | % (n) of cohort  % (n) of cohort with 1+ epileptic episode |
| 5.4 | Description of non-epileptic episode  - Syncope and anoxic seizures  - Behavioural, psychological and psychiatric disorders  - Sleep related conditions  - Paroxysmal movement disorders  - Migraine associated disorders  - Miscellaneous events  - Other | % (n) of cohort  % (n) of cohort with non-epileptic episode |  |
| 5.5 | Variation in diagnostic status across HB/Ts (e.g. association between diagnostic status and the presence of an EEG) | TBC |  |
| **6** | **Initial referral and examination** |  |  |
| 6.1 | Service from which referral to first paediatric assessment was made  - ED, GP, Health visitor, outpatient, inpatient, PICU, Neonatal, Other | % (n) of cohort with a diagnosis of epilepsy by referral service | Comparable data: Round 2 report pg. 28 |
| 6.2 | Time since first referral  Age at first referral | TBC |  |
| 6.3 | First paediatric assessment in an acute or non-acute | % (n) of cohort with a diagnosis of epilepsy |  |
| 6.4 | Appropriate first assessment |  | Performance indicator 3  Performance indicator 4 |
| **7** | **Description of episodes** |  |  |
| **7.1** | **Seizure type** |  |  |
| 7.1.1 | No. of episodes:  - epileptic  - non-epileptic  - uncertain | mean (range) per CYP with a diagnosis of epilepsy(s)  num of seizures-national  % (n) of cohort with a diagnosis of epilepsy(s) | NICE Quality statement 6 (could be derived) |
| **7.2** | **Epileptic seizure type** |  | Comparable data: Round 2 report pg. 30/31 |
| 7.2.1 | - Focal onset  - Generalised onset  - Unknown onset  - Unclassified | Mean (range) per CYP with a diagnosis of epilepsy(s)  num of seizures-national  % (n) of cohort with a diagnosis of epilepsy(s) |
| 7.2.2 | Focal onset  - Impaired awareness, Automatisms, Atonic, Clonic, Left, Right, Epileptic spasms, Hyperkinetic, Myoclonic, Tonic, Autonomic, Behaviour arrest, Cognitive, Emotional, Sensory, Centro-temporal, Temporal, Frontal, Parietal, Occipital, Gelastic, Focal to bilateral tonic-clonic, Other | % (n) of cohort with a diagnosis of epilepsy(s)  % (n) of cohort with a diagnosis of epilepsy(s) **that had a focal onset seizure** |
| 7.2.3 | Generalised onset  - Tonic-clonic, Clonic, Tonic, Myoclonic, Myoclonic-tonic-clonic, Myoclonic-atonic, Atonic, Epileptic spasms, Typical absence, Atypical absence, Myoclonic absence, Absence with eyelid myoclonia, Other | % (n) of cohort with a diagnosis of epilepsy(s)  % (n) of cohort with a diagnosis of epilepsy(s) **that had a generalised onset seizure** |
| 7.2.4 | Unknown onset  - Tonic-clonic, Epileptic spasms, Behaviour arrest, Other | % (n) of cohort with a diagnosis of epilepsy(s)  % (n) of cohort with a diagnosis of epilepsy(s) **that had an unknown onset seizure** |
| **7.3** | **Non-epileptic seizure type** |  |  |
| 7.3.1 | - **Syncope and anoxic seizures**  (Vasovagal syncope, Reflex anoxic seizures, Breath-holding attacks, Hyperventilation syncope, Compulsive valsalva, Neurological syncope, Imposed upper airways obstruction, Orthostatic intolerance, Long QT and cardiac syncope, Hyper-cyanotic spells)  - **Behavioural, psychological and psychiatric disorders** (Daydreaming /inattention, Infantile gratification, eidetic imagery, tantrums and rage reactions, out of body experiences, panic attacks, dissociative states, non-epileptic seizures, hallucinations in psychiatric disorders, fabricated / factitious illness)  - **Sleep related conditions**  (Sleep related rhythmic movement disorders, Hypnogogic jerks, Parasomnias, REM sleep disorders, Benign neonatal sleep myoclonus, Periodic leg movements, Narcolepsy-cataplexy)  - **Paroxysmal movement disorders**  (Tics, Stereotypies, Paroxysmal kinesigenic dyskinesia, Paroxysmal nonkinesigenic dyskinesia, Paroxysmal exercise induced dyskinesia, Benign paroxysmal tonic upgaze, Episodic ataxias, Alternating hemiplegia, Hyperekplexia, Opsoclonus-myoclonus syndrome)  - **Migraine associated disorders**  (Migraine with visual aura, Familial hemiplegic migraine, Benign paroxysmal torticollis, Benign paroxysmal vertigo, Cyclical vomiting)  - **Miscellaneous events**  (Benign myoclonus of infancy and shuddering attacks, Jitteriness, Sandifer syndrome, Non-epileptic head drops, Spasmus nutans, Raised intracranial pressure, Paroxysmal extreme pain disorder, Spinal myoclonus)  - Other | % (n) of cohort with a diagnosis of epilepsy(s)  % (n) of cohort with a diagnosis of epilepsy(s) **that had a non-epileptic seizure** | At analysis – keep an eye out for patients with epilepsy without an ‘epileptic seizure type’ |
| **7.4** | **Electroclinical syndrome** |  |  |
| 7.4.1 | ILAE syndrome classification | % (n) of cohort with a diagnosis of epilepsy(s) | Performance indicator 5 |
| **7.5** | **Seizure cause** |  |  |
| 7.5.1 | - **Structural**  (Tuberous Sclerosis, Sturge Weber, Focal cortical dysplasia, Hypothalamic Hamartoma, Low grade tumour, Tumour (other), Malformations of Cortical Development, Vascular (e.g. arterial ischaemic stroke, venous ischaemia, cerebral haemorrhage), Traumatic brain injury, Not required)  - **Genetic**  (Dravet syndrome, Glucose Transporter Defect, Angelman Syndrome, Rett Syndrome, Chromosomal abnormality, Gene abnormality (further options))  - **Infectious**  - **Metabolic**  (Mitochondrial disorder, Neuronal Ceroid Lipofuscinosis (Batten Disease), Disorder of pyridoxine/pyridoxal phosphate metabolism, Disorder of biotin metabolism, Disorder of creatine metabolism, Disorder of amino acid  Disorder of urea cycle, Disorder of pyrimidine and purine, Disorder of cholesterol, Other neurometabolic disorder)  - **Immune**  (Rasmussen Encephalitis, Antibody mediated)  - **Not known** | % (n) of cohort with a diagnosis of epilepsy(s)  % (n) of cohort with a diagnosis of epilepsy(s) **with a recorded seizure cause** |  |
| **7.6** | **Convulsive seizures** |  |  |
| 7.6.1 | Convulsive epileptic seizures | % (n) of cohort with a diagnosis of epilepsy(s) |  |
| 7.6.2 | Prolonged generalised convulsive seizures > 5 min duration (or successive continuing > 5min) | % (n) of cohort with a diagnosis of epilepsy(s) |  |
| 7.6.3 | Prolonged focal seizures > 5 min duration (or successive continuing > 5min) | % (n) of cohort with a diagnosis of epilepsy(s) |  |
| 7.6.4 | Family history of epilepsy | % (n) of cohort with a diagnosis of epilepsy(s) |  |
| **8** | **Neurodisability/neurodevelopmental problem(s)** |  |  |
| 8.1 | 1. Autistic spectrum disorder  2. Cerebral palsy  3. Neurodegenerative disease or condition  4. An identified chromosomal disorder with a neurological or developmental component  5. Attention deficit hyperactivity disorder  6. Intellectual disability/global development delay/’learning disability’  7. Dyspraxia  8. Dyslexia  9. Speech disorder  10. Other learning difficulty | % (n) of cohort with a diagnosis of epilepsy(s)  For 6., include reporting on severity | Comparable data: Round 2 report pg. 27/28 |
| **9** | **Mental health problem(s)** |  |  |
| 9.1 | Mood Disorder  Anxiety Disorder  Emotional/behaviour  Self-harm  Other | % (n) of cohort with a diagnosis of epilepsy(s)  N.B. remember to include breakdown for whether Conduct Disorder or Oppositional Defiant Disorder (ODD) if Emotional/behavioural chosen |  |
| **10** | **Investigations** |  |  |
| 10.1 | First EEG  12 lead ECG  CT head scan  MRI brain | % of cohort with a diagnosis of epilepsy(s) that obtained each investigation | First EEG: Quality statement 2 (partly)  12 lead ECG: Performance indicator 6  MRI: Performance Indicator 7; NICE Quality statement 3 |
| **11** | **Treatment** |  |  |
| 11.1 | No. of AEDs provided  Name of AED | Mean (range) no. of AEDs per CYP with a diagnosis of epilepsy(s)  % of cohort with a diagnosis of epilepsy(s) on each AED  % of cohort with a diagnosis of epilepsy(s) by no. of AEDs and diagnostic status  Breakdown of type and length of treatments for different seizure types | Comparable data: Round 2 report pg. 30 |
| 11.2 | Use of sodium valproate and provision of information relating to risk in pregnancy for females (obvs) |  | Performance indicator 9 and 9b |
| 11.3 | Rescue medication provided | % of cohort with a diagnosis of epilepsy(s) |  |
| 11.4 | Met any of the CESS referral criteria | % of cohort with a diagnosis of epilepsy(s) |  |
| **12** | **Care planning** |  |  |
| 12.1 | Appropriate care planning |  | Performance indicators 10-10c, 11-11e; NICE Quality statement 4 |
| 12.2 | SUDEP |  |  |
| **13** | **Professionals / Services involved** |  |  |
| 13.1 | Professionals  - Consultant Paediatrician with expertise in epilepsies  - ESN  - Paediatric neurologist  - CESS  - Ketogenic dietician  - VNS service  - Genetic service  - Clinical psychologist  - Educational psychologist  - Psychiatrist  - Neuropyschologist  - Counselling service  - Other mental health professional  - Youth worker  - Other | % of cohort with a diagnosis of epilepsy(s) with input from various professionals  Compare no. of CYP with co-morbidities and whether or not they had input from relevant HCPs | Consultant with expertise in epilepsies: Performance indicator 1  ESN: Performance indicator 2; NICE Quality statement 5 |
| 13.2 | Ongoing investigations  - formal developmental assessment  - formal cognitive assessment  - clinical review by a paediatrician with expertise in epilepsy or paediatric neurologist in the past 12 months | % of cohort with a diagnosis of epilepsy(s)  Compare no. of CYP with co-morbidities and whether or not they had relevant ongoing investigation |  |

**Performance indicator reporting**

This section of the report will provide a summary of the 12 key performance measures. All PIs will be reported for England and Wales combined, England and Wales separately, regional paediatric epilepsy network and at Health Board/Trust level. We will also analyse the data to examine if there is variation across OPEN UK networks or by key patient demographics and include accordingly.

Description of performance indicator, and numerator and denominator to be used to calculate PIs

| **No.** | **Performance indicator** | **Calculation of performance indicator (numerator and denominator)** | **Notes**  **(i.e. comparable data, NICE QS, outlier metric?)** |
| --- | --- | --- | --- |
|  | Involvement of appropriate professionals |  |  |
| 1 | **Paediatrician with expertise in epilepsies**  % of children and young people with epilepsy, with input by a ‘consultant paediatrician with expertise in epilepsies’ within the first year of care | Numerator = Number of children and young people diagnosed with epilepsy at first year **AND** who had input from a paediatrician with expertise in epilepsy **OR** a paediatric neurologist within the first year of care  Denominator = Number of children and young people diagnosed with epilepsy at first year | Proposed outlier metric |
| 2 | **Epilepsy Specialist Nurse**  % of children and young people with epilepsy, with input by epilepsy specialist nurse within the first year of care | Numerator = Number of children and young people diagnosed with epilepsy at first year **AND** who had input from by an epilepsy specialist nurse within the first year of care  Denominator = Number of children and young people diagnosed with epilepsy within the first year of care | Proposed outlier metric  NICE Quality statement 5 |
| 3 | **Tertiary input**  % of children and young people meeting defined criteria for paediatric neurology referral, with input of tertiary care and/or CESS referral within the first year of care | Numerator = Number of children less than 2 years old at first assessment with epilepsy **OR**  (number of children and young people diagnosed with epilepsy *AND* who had 3 or more maintenance AEDS at first year)  **OR** (number of children and young people diagnosed with epilepsy *AND* met CESS criteria)  **AND** (had input of a paediatric neurologist **AND/OR** referral to CESS)  Denominator = Number of children less than 2 years old at first assessment with epilepsy **OR**  number of children and young people diagnosed with epilepsy *AND* who had 3 or more maintenance AEDS at first year  **OR** number of children and young people diagnosed with epilepsy *AND* met CESS criteria | Proposed outlier metric  NICE Quality statement 7 (partly) |
| 3b | **Epilepsy surgery referral**  % of ongoing children and young people meeting defined epilepsy surgery referral criteria with evidence of epilepsy surgery referral | Numerator = Number of children and young people diagnosed with epilepsy *AND* met CESS criteria  At first year **AND** had evidence of referral or involvement of epilepsy surgery service  Denominator = Number of children and young people diagnosed with epilepsy *AND* met CESS criteria  At first year |  |
|  | Evidence of appropriate assessment and classification |  |  |
| 4 | **Appropriate first paediatric assessment**  % of all children and young people with evidence of appropriate first paediatric clinical assessment | Numerator = Number of children and young people diagnosed with epilepsy within the first year of care (**4a)** with evidence of descriptions of episode **(4b)** timing of the first episode **(4c)**frequency **(4d)** general examination **(4e)** neurological examination **(4f)** the presence or absence of developmental, learning or schooling problems  Denominator = Number of children and young people diagnosed with epilepsy within the first year of care |  |
| 4a | % children and young people with evidence of descriptions of episode | Numerator = Number of children and young people diagnosed with epilepsy at first year **AND** with evidence of descriptions of episode  Denominator = Number of children and young people diagnosed with epilepsy at first year |  |
| 4b | % children and young people with evidence of descriptions of age of child/timing of the first episode | Numerator = Number of children and young people diagnosed with epilepsy at first year **AND** evidence of description of age of child/timing of the first episode  Denominator = Number of children and young people diagnosed with epilepsy at first year |  |
| 4c | % children and young people with evidence of descriptions of frequency | Numerator = Number of children and young people diagnosed with epilepsy at first year **AND** evidence of description of frequency  Denominator = Number of children and young people diagnosed with epilepsy at first year |  |
| 4d | % children and young people with evidence of descriptions of general examination | Numerator = Number of children and young people diagnosed with epilepsy at first year **AND** evidence of description of general examination  Denominator = Number of children and young people diagnosed with epilepsy at first year |  |
| 4e | % children and young people with evidence of descriptions of neurological examination | Numerator = Number of children and young people diagnosed with epilepsy at first year **AND** evidence of description of neurological examination  Denominator = Number of children and young people diagnosed with epilepsy at first year |  |
| 4f | % children and young people with evidence of description of developmental, learning or schooling progress | Numerator = Number of children and young people diagnosed with epilepsy at first year **AND** evidence of the presence or absence of developmental, learning or schooling problems  Denominator = Number of children and young people diagnosed with epilepsy at first year |  |
| 4g | % children aged 3 years and over with evidence of consideration of emotional or behavioural problems | Numerator = Number of children and young people diagnosed with epilepsy at first year **AND** evidence of description of the presence or absence of emotional or behavioural problems  Denominator = Number of children and young people diagnosed with epilepsy at first year |  |
| 5 | **Seizure formulation**  % of children and young people with epilepsy with appropriate seizure classification at first year | Numerator = Number of children and young people with diagnosis of epilepsy at first year **AND** who had ILAE seizure classification (all ILAE seizure types including ‘unclassified’ )  Denominator = Number of children and young people diagnosed with epilepsy at first year |  |
|  | Evidence of appropriate investigation |  |  |
| 6 | ECG  % of children and young people with convulsive seizures and epilepsy, with an ECG at first year | Numerator = Number of children and young people diagnosed with epilepsy at first year **AND** with convulsive episodes at first year **AND** who obtained 12 lead ECG  Denominator = Number of children and young people diagnosed with epilepsy at first year **AND** with convulsive episodes at first year |  |
| 7 | MRI  % of children and young people with defined indications for an MRI, who had MRI by at first year | Numerator = Number of children and young people diagnosed with epilepsy at first year ***AND*** who are NOT JME or JAE or CAE or CECTS/Rolandic **OR** number of children aged 2 years and under at first assessment with a diagnosis of epilepsy at first year **AND** who had an MRI  Denominator = Number of children and young people diagnosed with epilepsy at first year ***AND*** who are NOT JME or JAE or CAE or CECTS/Rolandic **OR** number of children aged 2 years and under at first assessment with a diagnosis of epilepsy at first year | NICE Quality statement 3 |
|  | Management and outcome |  |  |
| 8 | **Accuracy of diagnosis**  % of children diagnosed with epilepsy, who still had that diagnosis at 1 year | Numerator = Number of children and young people diagnosed with epilepsy at first year **AND** who have not had their diagnosis withdrawn  Denominator = Number of children and young people diagnosed with epilepsy at first year **OR** Number of children and young people who had their diagnosis withdrawn |  |
| 9 | **Sodium Valproate**  % of all females >9 years currently on valproate treatment with evidence of discussion of foetal risk | Numerator = Number of females aged 9 and above diagnosed with epilepsy at first year **AND** on valproate **AND** evidence of previous discussion of risk regarding birth defects and/or neurodevelopmental outcomes.  Denominator = Number of females aged 9 and above diagnosed with epilepsy at first year **AND** on valproate |  |
| 9b | % of all females currently on valproate treatment with evidence of discussion of foetal risk | Numerator = Number of females diagnosed with epilepsy at first year **AND** on valproate **AND** evidence of previous discussion of risk regarding birth defects and/or neurodevelopmental outcomes.  Denominator = Number of females diagnosed with epilepsy at first year **AND** on valproate |  |
| 10 *new* | **Comprehensive Care Planning agreement**  % of children and young people with epilepsy after 12 months where there is 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 | Numerator = Number of children and young people diagnosed with epilepsy at first year **AND(** with an individualised epilepsy document *or* copy clinic letter that includes care planning information )**AND** evidence of agreement **AND** care plan is up to date including elements where appropriate as below  Denominator = Number of children and young people diagnosed with epilepsy at first year | NICE Quality statement 4 |
| 10a *new* | % of children and young people with epilepsy after 12 months that had an individualised epilepsy document with individualised epilepsy document or a copy clinic letter that includes care planning information | Numerator = Number of children and young people diagnosed with epilepsy at first year **AND(** with individualised epilepsy document *or* copy clinic letter that includes care planning information )  Denominator = Number of children and young people diagnosed with epilepsy at first year |  |
| 10b *new* | % of children and young people with epilepsy after 12 months where there was evidence of agreement between the person, their family and/or carers as appropriate | Numerator = Number of children and young people diagnosed with epilepsy at first year **AND** with evidence of agreement  Denominator = Number of children and young people diagnosed with epilepsy at first year |  |
| 10c *new* | % of children and young people with epilepsy after 12 months where there is evidence that the care plan has been updated where necessary | Numerator = Number of children and young people diagnosed with epilepsy at first year **AND** with care plan which is updated where necessary  Denominator = Number of children and young people diagnosed with epilepsy at first year |  |
| 11 *new* | **Comprehensive Care Planning content**  % of children diagnosed with epilepsy with documented evidence of communication regarding core elements of care planning | Numerator= Number of children and young people diagnosed with epilepsy at first year **AND** evidence of written prolonged seizures plan if prescribed rescue medication **AND** evidence of discussion regarding water safety **AND** first aid **AND** participation and risk **AND** service contact details  Denominator= Number of children and young people diagnosed with epilepsy at first year | NICE Quality statement 4 or 6? Or both?? |
| 11a *new* | Parental prolonged seizures care plan | Numerator = Number of children and young people diagnosed with epilepsy at first year **AND** prescribed rescue medication **AND** evidence of a written prolonged seizures plan  Denominator = Number of children and young people diagnosed with epilepsy at first year **AND** prescribed rescue medication |  |
| 11b *new* | Water safety | Numerator = Number of children and young people diagnosed with epilepsy at first year **AND** with evidence of discussion regarding water safety  Denominator = Number of children and young people diagnosed with epilepsy at first year |  |
| 11c *new* | First aid | Numerator = Number of children and young people diagnosed with epilepsy at first year **AND** with evidence of discussion regarding first aid  Denominator = Number of children and young people diagnosed with epilepsy at first year |  |
| 11d *new* | General participation and risk | Numerator = Number of children and young people diagnosed with epilepsy at first year **AND** with evidence of discussion regarding general participation and risk  Denominator = Number of children and young people diagnosed with epilepsy at first year |  |
| 11e *new* | Service contact details | Numerator = Number of children and young people diagnosed with epilepsy at first year **AND** with evidence of discussion of been given service contact details  Denominator = Number of children and young people diagnosed with epilepsy at first year |  |
| 12 | School Individual Healthcare Plan  % of children and young people with  epilepsy aged 4 years and  above with evidence of a school individual healthcare plan by 1 year after first paediatric assessment. | Numerator = Number of children and young people aged 5 years and above diagnosed with epilepsy at first year **AND** with evidence of IHP  Denominator = Number of children and young people aged 5 years and above diagnosed with epilepsy at first year |  |

#### Analysis of clinical audit results against organisational factors

Below 2018 service factors associated with quality of care will be correlated

* Tertiary provision
* ESN provision
* BPC
* Mental health
* Neurodisability or neurodevelopment problems

|  |  |  |  |
| --- | --- | --- | --- |
| **2018 Organisational audit service factor** | **Comparative analysis criteria** | **Performance Indicators** | **Nice Quality Statements** |
| **Tertiary provision** - How many whole time equivalent (WTE) paediatric neurologists who manage children with epilepsy (acutely and/or non-acutely) are there employed within the Health Board/Trust? | % HB/T **with greater than 0 WTE** vs those **with 0 WTE** | Numbers 1-12 | **QS1 Referral to a specialist**: Children and young people presenting with a suspected seizure are seen by a specialist in the diagnosis and management of the epilepsies within 2 weeks of presentation  **QS5 ESN**: Children and young people with epilepsy are seen by an epilepsy specialist nurse who they can contact between scheduled reviews.  **QS7 Referral to tertiary care**: Children and young people who meet the criteria for referral to a tertiary care specialist are seen within 4 weeks of referral. |
| **ESN provision** - How many whole time equivalent (WTE) paediatric epilepsy specialist nurses (ESNs) are there employed within the Health Board/Trust? | % HB/T **with greater than 0 WTE** vs those **with 0 WTE** | Numbers 1-12 | **QS1 Referral to a specialist**: Children and young people presenting with a suspected seizure are seen by a specialist in the diagnosis and management of the epilepsies within 2 weeks of presentation  **QS5 ESN**: Children and young people with epilepsy are seen by an epilepsy specialist nurse who they can contact between scheduled reviews.  **QS7 Referral to tertiary care**: Children and young people who meet the criteria for referral to a tertiary care specialist are seen within 4 weeks of referral. |
| **BPC-** Does the Trust\* currently run TFC 223 Epilepsy Best Practice Criteria (BPC) clinics?   * Trusts in England only | % HB/T **Yes** vs those with **No in development, No not at all and Not applicable** | Numbers 1-12 | **QS1 Referral to a specialist**: Children and young people presenting with a suspected seizure are seen by a specialist in the diagnosis and management of the epilepsies within 2 weeks of presentation  **QS5 ESN**: Children and young people with epilepsy are seen by an epilepsy specialist nurse who they can contact between scheduled reviews.  **QS7 Referral to tertiary care**: Children and young people who meet the criteria for referral to a tertiary care specialist are seen within 4 weeks of referral. |

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| --- | --- | --- | --- |
| **2018 Organisational Audit Mental Health Provision Measure** | **Comparative analysis criteria** | **Clinical audit Mental Health diagnosis** | **Clinical audit input from a mental Health Professional** |
| Does your Health Board/Trust facilitate mental health provision within epilepsy clinics?  N.B.  Is this to be broken down into three sub-set groups of:   1. Epilepsy Clinics where mental health professionals can provide direct co-located clinical care 2. MDT meetings where epilepsy and mental health professionals discuss individual patients 3. Other | **Yes vs No** | **Section 5 Description of episodes**  **Q5.5**: Add or edit details of any known mental health problem(s)  Mood disorder  Anxiety disorder  Emotional/behavioural  Self harm  Other | **Section 10: Professionals / Services involved**  **Qs 1.8 to 10.13:** Is there evidence the child has current or previous evidence of input from any of:  -Clinical psychologist  - Educational psychologist  - Psychiatrist  - Neuropsychologist  - Counselling service  - Other mental health professional |

|  |  |  |  |
| --- | --- | --- | --- |
| **2018 Organisational Audit Neurodisability Provision Measure** | **Comparative analysis criteria** | **Clinical audit neurodisability diagnosis** | **Clinical audit ongoing investigations** |
| Does the trust have agreed referral criteria for children with neurodevelopmental problems (for example ASD and ADHD)? | **Yes vs No** | **Section 5 Description of episodes**  **Q5.4**: Add or edit details of any known neurodisability or neurodevelopmental problem(s)   |  | | --- | | Autistic spectrum disorder | | Cerebral palsy | | Neurodegenerative disease | | Identified chromosomal disorder | | Attention deficit hyperactivity | | Intellectual disability | | Dyspraxia | | Dyslexia | | Speech disorder | | Other learning difficulty | | **Section 10: Professionals / Services involved**  **Qs 10.16 to 10.18:** ongoing investigations:  -formal developmental assessment  - formal cognitive assessment  - review by a paediatrician with expertise in epilepsy or paediatric neurologist |