**Coding checklist**

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| --- | --- | --- |
| **Name of codelist** | *Epilepsy* | |
| **Definition of codelist** | All epileptic conditions | |
| **Databases searched** | | **Yes/No** |
| IMRD | | Y |
| CPRD Aurum | | Y |
| CPRD Gold | | Y |
| ICD-10 | | Y |
| CEGEDIM | | N |
| HES | | N |
| **Existing code lists searched:** | **Link** | **Yes/No** |
| Caliber code list | <https://caliberresearch.org/portal/codelists>   * <https://www.caliberresearch.org/portal/phenotypes/chronological-map> | Y |
| QoF/Digital | <https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/quality-and-outcomes-framework-qof/quality-and-outcome-framework-qof-business-rules/quality-and-outcomes-framework-qof-business-rules-v37-0> | Y |
| Manchester code list | <https://clinicalcodes.rss.mhs.man.ac.uk/medcodes/articles/>  <https://clinicalcodes.rss.mhs.man.ac.uk/medcodes/article/1/> | Y |
| Birmingham IMRD list | <https://dexter.bham.ac.uk:8181/> | Y |
| Cambridge code list | <https://www.phpc.cam.ac.uk/pcu/research/research-groups/crmh/cprd_cam/codelists/v11/> | Y |
| (NHS medication browser tool) | [https://applications.nhsbsa.nhs.uk/DMDBrowser/DMDBrowser.do#](https://applications.nhsbsa.nhs.uk/DMDBrowser/DMDBrowser.do) | Y |
| **Publications searched** | | |
| Evaluating the validity of clinical codes to identify cataract and glaucoma in the UK Clinical Practice Research Datalink  1. Gorton HC, Webb RT, Carr MJ, DelPozo-Banos M, John A, Ashcroft DM. Risk of Unnatural Mortality in People With Epilepsy. JAMA Neurol. 2018;75(8):929–938. doi:10.1001/jamaneurol.2018.0333   https://clinicalcodes.rss.mhs.man.ac.uk/medcodes/article/55/ | | |
| 2. | | |
| **Validation methods (if relevant)** | | **Yes/No** |
| Prevalence/ incidence | | No |
| Case note review | | No |
| Capture- Recapture method | | No |
| Double checked | | No |
| **List the search terms included (add rows as needed)**  ***(N.B. justification for inclusion/exclusion given in italics)*** | | |
| Epilep | | |
| Salaam attacks  Infantile spasms  Lightning attacks  Grand mal status  Lennox-Gastaut Syndrome  West Syndrome  Otohara Syndrome  Dravet Syndrome  Panayiotopoulos syndrome | | |
| Acquired aphasia **with epilepsy** [Landau – Kleffner] *(includes a diagnosis of epilepsy)* | | |
| Absences seizures (*implies the epileptic diagnosis rather than lone seizure)* | | |
| Epileptic fit, epileptic seizure (*implies epilepsy syndrome diagnosed)* | | |
| Epilepsy does/does not limit activities  Epilepsy impairs education  Epilepsy restricts employment  Epilepsy associated problems | | |
| Epilepsy monitoring default/NOS  Epilepsy monitoring in primary care/secondary | | |
| h/o epilepsy  history of epilepsy | | |
| **List the search terms excluded or filtered out (add rows as needed)** | |
| DNA  DNA - Did not attend epilepsy clinic | |
| Epilepsy screen invite  Epilepsy monitoring invite – likely to be coded as epilepsy and also may be misclassified | |
| Fit (in non-epileptic) | |
| Epilepsy monitoring call 1st letter/2nd letter/3rd letter  Epilepsy monitoring administration  Epilepsy care arrangement *(can be an admin code therefore excluded, not included in previously published lists)*  Epilepsy management plan given (*admin code, not included in other lists)* | |
| Epilepsy severity *(not specific)* | |
| FH  Family history | |
| Epilepsy society member | |
| Poisoning with antiepileptic medication | |
| Epilepsy drug side effects  No epilepsy drug side effects  Adverse reaction to Drugs Used In Status Epilepticus  Antiepileptics and antiparkinsonism drugs  Antiepileptic  Epilepsy medication review  Drugs used in control of epilepsy  Drugs used in status epilepticus *(Epilepsy medication can have other indications)* | |
| Epilepsy treatment started/stopped/changed/continued  Epilepsy treatment compliance/compliance poor  *(other indications for anti-epilepsy medications e.g. topiramate, also not included in previously published lists)* | |
| Initial epilepsy assessment  Follow-up epilepsy assessment  *(not diagnosis but assessment of ?suspected? epilepsy)* | |
| Referral to epilepsy clinic  Seen in epilepsy clinic  Suspected epilepsy | |
| Epilepsy leaflet given | |
| Assessment using NDDI-E (Neurological Disorders Depression Inventory in Epilepsy)  NDDI-E (Neurological Disorders Depression Inventory in Epilepsy) score | |
| No h/o epilepsy  No history of epilepsy | |
| epilepsy resolved  *(may include those who were wrongly diagnosed as epileptics)* | |
| Excepted from epilepsy quality indicators: Patient unsuitabl  Exception reporting: epilepsy quality indicators  Excepted from epilepsy quality indicators: Informed dissent | |
| Contraceptive advice for patients with epilepsy  Contraceptive advice for patients with epilepsy not indicated/declined  Pregnancy advice for patients with epilepsy  Pregnancy advice for patients with epilepsy not indicated/declined  Pre-conception advice for patients with epilepsy  Pre-conception advice for patients with epilepsy not indicated/declined  *(not specific for epilepsy, not included in previously published epilpesy lists)* | |
| Hypsarrthymia *(seen in epilepsy but needs symptoms to define epilepsy also)* | |
| Post-itcal state *(could be after one seizure only which is not defining of epilepsy)* | |
| O/E - salaam attack *(implies only one salaam attack cf epilepsy)* | |
| Grand mal seizure, Grand mal fit  Generalised seizure Partial complex seizure  (*implies only one attack cf epilepsy, only included if epilepsy explicitly specified)*  *(https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1363913/)* | |
| Landau-Kleffner syndrome  *(rare childhood epilepsy, characterised by auditory verbal agnosia, aphasia, and abnormal EEG and seizures in most but not all patients)* | |
| Seizure free >12 months  Fit frequency  Last fit  No seizure on treatment  2-4 seizures per month  1 to 7 seizures a week  Daily seizure  Many seizures a day *(these not specific for epilepsy)* | |
| Eye witness to epileptic seizure  Epileptic seizure witnessed by provider of history other than subject  *(even though it specifies epileptic seizure, an eye witness to single episode is not diagnostic and not included in other published epilepsy lists)* | |
| Non-epileptic attack | |
| 3D study – problems with epilepsy management *(not included in other published lists)* | |
| Sudden unexpected death in epilepsy  At risk of sudden unexpected death in epilepsy  (*Not a diagnostic code for epilepsy and also not included in previous lists*) | |
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| **Date completed** | 18th December 2020 |
| **Checked by** | *<name>* |