**Epi25 EE REDCap Database**

*Glossary*

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| Absence | See ILAE definition: <https://www.epilepsydiagnosis.org/seizure/absence-typical-overview.html> Additional comments about seizure semiology can be added through REDCap if desired. |
| Additional EEG abnormality 1 or 2 | Additional drop down options for patients with more than one EEG abnormality. Otherwise, ‘None’ can be selected. |
| Additional Neuroimaging abnormality 1 or 2 | Additional drop down options for patients with more than one neuroimaging abnormality. Otherwise, ‘None’ can be selected. |
| Age at first occurrence | Age of onset in months of that particular seizure type if known. Otherwise, ‘Unknown’ can be selected. If unknown, leave the field blank. |
| Age at first seizure (of any type) | Age of onset in months of any seizure type, including an unclassified seizure or seizure of unknown type, if known. If unknown, leave the field blank. |
| Age at last occurrence | Age at last occurrence in months of that particular seizure type if known. If unknown, leave the field blank. If seizure type is ongoing, enter age in months at last review. |
| Age at regression if known | Age in months at which there was a loss of skills or plateau in development if known. |
| Atonic | See ILAE definition: <https://www.epilepsydiagnosis.org/seizure/atonic-overview.html>  Additional comments about seizure semiology can be added through REDCap if desired. |
| Atypical absence | See ILAE definition: <https://www.epilepsydiagnosis.org/seizure/absence-atypical-overview.html> Additional comments about seizure semiology can be added through REDCap if desired. |
| Autism spectrum disorder | To be selected ‘Y’ where a clear diagnosis of Autistic Spectrum Disorder has been made. Otherwise, ‘Unknown’ can be selected. Additional comments about co-morbidities can be added through REDCap if required. |
| Bilateral clonic | Bilateral rhythmic jerking seizure without a tonic component. |
| Birth weight | To be answered if the specific weight at birth is ‘known’ or ‘unknown’. ‘Small for gestational age’ can be selected if the baby is known to be small but the exact weight is not known. |
| Birth weight (grams) if known | The birth weight in grams, to be completed if ‘known’. |
| Classical febrile seizures | Self-limited convulsive seizures with a documented fever of >38°C/100.4°F occurring between the age of 6 months and 6 years with no known history of afebrile seizures. |
| Clinician responsible for data | Clinician/Investigator who will be the contact person for the duration of the Epi25 study for any queries relating to the phenotypic data. |
| CNS infection | Documented infection of the central nervous system. |
| Comments for multiple syndromes | A free text field to be completed where more than one syndrome is selected. Please comment on the syndrome evolution. |
| Conventional karyotype | Answer to be selected from the list. Where ‘Abnormal, please specify’ is selected, please provide details in the ‘Conventional karyotype comments’. |
| Conventional karyotype comments | Free text field for comments about the conventional karyotype testing and any abnormal result. |
| Copy number analysis | Also referred to as Array CGH analysis, SNP Array analysis or Molecular Karyotype. Answer to be selected from the list. Where ‘Abnormal, please specify’ or ‘Finding of unknown significance, please specify’ is selected, please provide details in the ‘Copy number analysis comments’. |
| Copy number analysis comments | Free text field for comments about the copy number analysis and any finding of unknown significance or abnormal result. |
| Date of last data collection | Most recent date that information was collected that has been used to complete the form. Use 01 (Jan) as month or 01 as day for unknown. |
| Degree of intellectual disability | Degree of disability to be selected from list. Otherwise, ‘cannot classify’ can be selected. |
| Details of family history of epilepsy | Free text field for additional information about family history, other than that captured in the ‘First degree relative affected?’ section. |
| Developmental delay prior to seizure onset | ‘Y/N/Unknown’ to be selected as appropriate for any history of delayed development prior to seizure onset. If ‘Yes’ is selected, ‘Type of delay’ needs to be completed. Additional comments about co-morbidities can be added through REDCap if required. |
| Drug resistant | Failure of *adequate* trials of two tolerated and *appropriately* chosen and used AED schedules (whether as monotherapies or in combination) to achieve *sustained* (>12 months) seizure freedom (see *Epilepsia.* 2010 Jun;51(6):1069-77. doi: 10.1111/j.1528-1167.2009.02397.x. Epub 2009 Nov 3. Kwan P et al.). Patients who have had epilepsy surgery should be regarded as ‘Drug resistant’ and a comment about surgical outcome can be made through REDCap if desired. |
| Dysmorphic | ‘Y, please specify/N/Unknown’ to be selected as appropriate for any dysmorphic features. If ‘Y, please specify’ is selected, details can be provided in the ‘Dysmorphic features comments’. |
| Dysmorphic features comments | A free text field for additional information about any dysmorphic features. |
| EEG findings | Finding to be selected from list provided. Where ‘epileptiform’ is selected, ‘If epileptiform, type?’ will need to be completed. Where ‘Photo-paroxysmal response’ is selected, ‘Type of photo-paroxysmal response’ will need to be completed. Where multiple findings exist, please enter in chronological order. Additional information about EEG, including age at EEG if deemed important, can be added through REDCap. |
| Epilepsy syndrome | *Neonatal onset: Ohtahara syndrome:*  <https://www.epilepsydiagnosis.org/syndrome/ohtahara-overview.html>  *Neonatal onset: Early myoclonic encephalopathy (EME):*  <https://www.epilepsydiagnosis.org/syndrome/eme-overview.html>  *Early onset epileptic encephalopathy (<3 months):*  Epileptic encephalopathy with seizure onset of less than 3 months of age that does not meet the criteria for any other early onset epileptic encephalopathy.  *Infantile onset epileptic encephalopathy (not otherwise specified):*  Epileptic encephalopathy with seizure onset between 3 and 12 months of age that does not meet the criteria for any other infantile onset epileptic encephalopathy.  *Epilepsy of infancy with migrating focal seizures:*  <https://www.epilepsydiagnosis.org/syndrome/infancy-migrating-focal-overview.html>  *West syndrome/infantile spasms:*  <https://www.epilepsydiagnosis.org/syndrome/west-syndrome-overview.html>  *Late-onset epileptic spasms:*  Epileptic encephalopathy with epileptic spasms (<https://www.epilepsydiagnosis.org/seizure/epileptic-spasms-overview.html>) and seizure onset >1 year of age.  *Lennox-Gastaut syndrome:*  <https://www.epilepsydiagnosis.org/syndrome/lgs-overview.html>  *Epilepsy with myoclonic atonic seizures:*  <https://www.epilepsydiagnosis.org/syndrome/epilepsy-myoclonic-atonic-overview.html>  *Dravet syndrome:*  <https://www.epilepsydiagnosis.org/syndrome/dravet-overview.html>  *Landau-Kleffner syndrome (LKS):*  <https://www.epilepsydiagnosis.org/syndrome/lks-overview.html>  *Epileptic Encephalopathy with continuous spike-and-wave during sleep (CSWS):*  <https://www.epilepsydiagnosis.org/syndrome/ee-csws-overview.html>  *Febrile Infection Related Epilepsy Syndrome (FIRES):*  <https://www.epilepsydiagnosis.org/aetiology/febrile-infection-related-epilepsy-overview.html>  *Hemiconvulsion-Hemiplegia-Epilepsy:*  Epilepsy with hemispheric atrophy secondary to a prolonged focal motor seizure in infancy, usually during a febrile illness. Hemiplegia is also present (see *Neurology* 2012;79;e1-e4, Tenney et al, Child Neurology: Hemiconvulsion-hemiplegia-epilepsy syndrome).  *Nonsyndromic epileptic encephalopathy with focal seizures:*  Epileptic encephalopathy with predominantly focal seizures that does not meet the criteria for any epileptic encephalopathy syndrome.  *Nonsyndromic epileptic encephalopathy with generalized seizures:*  Epileptic encephalopathy with predominantly generalized seizures that does not meet the criteria for any epileptic encephalopathy syndrome.  *Nonsyndromic epileptic encephalopathy with mixed or unclassified seizures:*  Epileptic encephalopathy with mixed or unclassified seizure types that does not meet the criteria for any epileptic encephalopathy syndrome. |
| Epilepsy syndrome comments. | A free text field for additional information about epilepsy syndrome to be completed if desired. |
| Ethnicity | Ethnicity to be selected from list provided. The list of ethnicities contains the minimum acceptable categories as per the USA standards (<http://wonder.cdc.gov/wonder/help/populations/bridged-race/Directive15.html>). Select all relevant boxes for multiple ethnicities. |
| Ethnicity comments | A free text field for additional information about ethnicity. To be completed if ‘Caucasian other, please specify’ or ‘Other/mixed ethnicities, please specify’ is selected as the ethnicity. |
| Family history | ‘Y/N/Unknown’ to be selected as appropriate for a family history of any seizures (including febrile) regardless of reported aetiology. Family history refers to any biological relative of the proband, including their offspring. |
| Febrile seizures | Seizure of any type (or unknown type) provoked by a documented fever of >38°C/100.4°F |
| First-degree relative affected? | To be completed if ‘Family history’ is answered ‘Y’. First-degree relative is defined as the proband’s biological mother, father, brother, sister, son or daughter. The relative is regarded as ‘affected’ if they have any history of seizures (including febrile) regardless of reported aetiology. |
| Focal seizures of any type | Seizure type to be selected for focal seizures of any type. Additional comments about seizure semiology can be added through REDCap if desired. |
| Generalized Tonic-Clonic | See ILAE definition: <https://www.epilepsydiagnosis.org/seizure/convulsive-overview.html> Additional comments about seizure semiology can be added through REDCap if desired. |
| Genetic testing | Refers to both clinical or research based single gene tests. Answer to be selected from the list. Where ‘Abnormal, please specify’ or ‘Finding of unknown significance, please specify’ is selected, please provide details in the ‘Genetic testing comments’. |
| Genetic testing comments | Free text field to provide additional information about findings of unknown significance or abnormal single gene tests. Please provide the gene name and give details of the variant found. |
| Gestational age | To be answered if the gestation at birth is ‘known’ or ‘unknown’. |
| Gestational age at birth (weeks) if known | The gestational age at birth in weeks, to be completed if ‘known’. |
| GSW frequency | The frequency of generalized spike-and-wave activity to be selected from the list. |
| Head circumference at birth | To be answered if the head circumference at birth is ‘known’ or ‘unknown’. |
| Head circumference at birth (cm) if known | The head circumference at birth in centimetres, to be completed if ‘known’. |
| Head size | Most current head size to be selected from the list. Otherwise, ‘Unknown’ can be selected. |
| Head trauma with skull fracture, intracranial bleeding | ‘Y/N/Unknown’ to be selected as appropriate for any history of significant head trauma with skull fracture and intracranial bleeding. |
| Hemiclonic | See ILAE definition: <https://www.epilepsydiagnosis.org/seizure/motor-overview.html> (see elementary motor section). Additional comments about seizure semiology can be added through REDCap if desired. |
| If epileptiform, type? | To be selected from drop down list if ‘epileptiform’ is selected as an EEG abnormality. |
| Infantile/epileptic spasms | See ILAE definition: <https://www.epilepsydiagnosis.org/seizure/epileptic-spasms-overview.html> Additional comments about seizure semiology can be added through REDCap if desired. |
| Intellectual Disability | ‘Y/N/Unknown’ to be selected as appropriate for any history of intellectual disability. If ‘Yes’ is selected, ‘Degree of intellectual disability’ can be completed if possible. Additional comments, including specific IQ scores and comments about testing, can be added through REDCap if required. |
| Local identifier | Sample identifier as allocated by the group contributing the sample. |
| Location of focal epileptiform | To be completed if ‘Focal’ is selected as the epileptiform type. If localization is near the anatomical boundary of two lobes or could reflect one of two sites (e.g. F7, ‘fronto-temporal’) then both lobes should be selected. If there are two or more independent foci, then select ‘multifocal’ and the relevant lobes. |
| Metabolic testing | Answer to be selected from the list. Where ‘Abnormal, please specify’ or ‘Finding of unknown significance, please specify’ is selected, please provide details in the ‘Metabolic testing comments’. |
| Metabolic testing comments | Free text field to provide additional information about findings of unknown significance or abnormal metabolic tests. |
| Movement disorder | ‘Y, please specify/N/Unknown’ to be selected as appropriate for any history of a movement disorder. If ‘Y, please specify’ is selected, please provide further details in the ‘Movement disorder comments’ section. |
| Movement disorder comments | Free text field to provide additional information about movement disorder if ‘Y, please specify’ is selected. |
| Myoclonic | See ILAE definition:  <https://www.epilepsydiagnosis.org/seizure/myoclonic-overview.html>  Additional comments about seizure semiology can be added through REDCap if desired. |
| Neonatal period comments | Free text field to comment on any abnormalities present in the neonatal period. To be completed if neonatal period (other than seizures) was not normal. |
| Neonatal seizures | ‘Y/N/Unknown’ to be selected as appropriate for any history of neonatal seizures. |
| Neuroimaging performed | Type of imaging technology used to be selected from the list. Otherwise, ‘Not done’ can be selected. |
| Neuroimaging details | A free text field for additional information about neuroimaging findings. |
| Neuroimaging findings | Neuroimaging results to be selected from the list. If deemed to be important, details about findings can be provided in the ‘Neuroimaging details’ section. Where more than one abnormality exists, the Additional Neuroimaging Abnormality sections can be completed. |
| Neurological examination | Neurological examination results to be selected from the list. If ‘Abnormal, please specify’ is selected, information can be entered in the ‘Neurological examination comments’ section. |
| Neurological examination comments | A free text field for additional information about neurological examination findings. |
| Normal neonatal period (other than seizures) | ‘Y/N, please specify/Unknown’ to be selected as appropriate. When ‘N, please specify’ is selected, please provide more details in the ‘Neonatal period comments’ section. |
| Other abnormalities | Refers to any other abnormal features not captured in any other category. ‘Y, please specify/N/Unknown’ to be selected as appropriate. When ‘Y, please specify’ is selected, please provide more details in the ‘Other abnormalities comments’ section. |
| Other abnormalities comments | A free text field for additional information about other abnormalities. |
| Other epileptiform comments | A free text field for additional information about epileptiform if ‘Other, please specify’ is selected as an epileptiform type. |
| Other seizure types comments | Free text field for seizure semiology information when ‘Other seizure types’ selected. |
| Other seizure types, please specify | Seizure type category to be used for seizure types not included in the list of seizure types. If selected ‘Y’, please provide further details in the ‘Other seizure types comments’ section. |
| Other seizures provoked by fever | Any seizure provoked by a documented fever of >38°C/100.4°F that does not meet the criteria for a ‘Classical febrile seizure’. |
| Patient deceased | To be selected from list. If Yes, the cause is listed in brackets and includes ‘SUDEP’, ‘Other epilepsy related – status epilepticus, trauma’, ‘Death unrelated to epilepsy’ and ‘Unknown causes’. |
| Person completing form | Clinician or researcher completing the form. |
| Record ID | REDCap code for sample – country code, followed by person entering data’s initials and a six-digit numerical code. For example, a sample from Australia entered by Brigid Regan would be AUDBR100001. |
| Referral Centre | Source of sample and clinical data to be selected from list. |
| Regression/plateau | ‘Y/N/Unknown’ to be selected as appropriate for any history of developmental regression or plateau in development. If ‘Yes’ is selected, ‘Age at regression in months if known’ can be completed if possible. Additional comments about co-morbidities can be added through REDCap if required. |
| Reported family history of consanguinity | ‘Y/N/Unknown’ to be selected as appropriate for a family history of consanguinity. |
| Sex | Sex to be selected from the list. |
| Status Epilepticus: convulsive | Acute prolonged convulsive seizure >5 minutes in duration. Additional comments about seizure semiology can be added through REDCap if desired. |
| Status Epilepticus: non-convulsive | Acute prolonged non-convulsive seizure (generalized or focal) >5 minutes in duration. Additional comments about seizure semiology can be added through REDCap if desired. |
| Tone | Tone to be selected from the list provided. Otherwise, ‘Unknown’ can be selected. |
| Tonic | See ILAE definition: <https://www.epilepsydiagnosis.org/seizure/tonic-overview.html> Additional comments about seizure semiology can be added through REDCap if desired. |
| Type of delay | Type of delay prior to seizure onset to be selected from the list provided. Otherwise, ‘Unknown’ can be selected. Additional comments about co-morbidities can be added through REDCap if required. |
| Type of photo-paroxysmal response | Type to be selected from the list if ‘Photo-paroxysmal response’ is selected as an EEG abnormality. |
| Unclassified | Seizure type to be used when the seizure cannot be classified based on the information available. Additional comments about seizure semiology can be added through REDCap if desired. |
| Year of birth | Year of birth. USA PHI regulations allow YOB only (<http://cphs.berkeley.edu/hipaa/hipaa18.html>) |