

### Start-up Resource – NINDS Epilepsy CDE Recommendations

Each CDE or instrument could be classified according to the definitions below:

**General Core:** A data element that is required for all NINDS funded studies.

**Disease Core:** A data element that collects essential information applicable to any disease-specific study, including all therapeutic areas. The NINDS and its appointed working groups assign the disease “Core” classification based on the current clinical research best practices. In each case, the disease Core CDEs are a small subset of the available CDEs, where it is anticipated that investigators will need to collect the disease Core CDEs on any type of study. These are required for all disease-specific studies.

**Disease Supplemental - Highly Recommended:** A data element which is essential based on certain conditions or study types in clinical research studies. In most cases, these have been used and validated in the disease area. These data elements are strongly recommended for the specified disease condition, study type or design.

**Disease Supplemental:** A data element which is commonly collected in clinical research studies. Use depends upon the study design, protocol or type of research involved.

**Disease Exploratory:** A data element that requires further validation but may fill current gaps in the CDEs and/or substitute for an existing CDE once validation is complete. Such data elements show great promise but require further validation before they are ready for prime-time use in clinical research studies. They are reasonable to use with the understanding that it has limited validation in the target group.



## Summary of Core/Supplemental – Highly Recommended Recommendations: Epilepsy CDEs

<p><b>NIH Resources:</b> <i>The NINDS also strongly encourages researchers to use these NIH developed materials for NINDS-sponsored research, when appropriate. Utilization of these resources will enable greater consistency for NINDS-sponsored research studies. These tools are free of charge.</i></p>	<p><b>NIH Toolbox</b>  <b>Patient-Reported Outcomes Measurement Information System (PROMIS)</b>  <b>Quality of Life in Neurological Disorders (Neuro-QOL)</b></p>
--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	---------------------------------------------------------------------------------------------------------------------------------------------------------------------------

### Core CDEs for all NINDS Studies<sup>1</sup>:

Domain; Subdomain	CDE Name	CDE ID	Study Type
Participant Characteristics; Demographics	Birth date	C00007	All studies
Participant Characteristics; Demographics	Ethnicity USA category	C00020	All studies
Participant Characteristics; Demographics	Race USA category	C00030	All studies
Participant Characteristics; Demographics	Birth sex assigned type	C58676	All studies
Participant Characteristics; Demographics	Gender identity type	C58677	All studies
Participant History and Family History; General Health History	Medical history condition text	C00322	All studies
Participant History and Family History; General Health History	Medical history condition SNOMED CT code	C00313	All studies

### Core CDEs for Epilepsy Studies:

Domain; Subdomain	Data element	CDE ID
Disease/Injury Related Events; Classification	Seizure epilepsy classification type	C58581

<sup>1</sup> Note: Education year count C00015 is no longer a general Core CDE



## Summary of Core/Supplemental – Highly Recommended Recommendations: Epilepsy CDEs

Domain; Subdomain	Data element	CDE ID
Disease/Injury Related Events; Classification	Specific epilepsy etiology classification type	C58580

### General Core Instrument for all FDA-regulated epilepsy clinical trials:

Investigators should review the FDA’s ["Guidance for Industry: Suicidal Ideation and Behavior: Prospective Assessment of Occurrence in Clinical Trials"](#) for the most up-to-date information about suicidal ideation and behavior. One scale that FDA suggests is the Columbia Suicide Severity Rating Scale (C-SSRS) (available at [Columbia Suicide Severity Rating Scale Website](#)).

### Supplemental – Highly Recommended CDEs for Epilepsy Studies:

Domain; Subdomain	Data element	CDE ID
Participant/Subject Characteristics; Social Status	Education level USA type	C00012
Participant/Subject Characteristics; Social Status	Education level maternal USA type	C12607
Disease/Injury Related Events; Classification	Seizure epilepsy focal classification type	C58583
Disease/Injury Related Events; Classification	Seizure epilepsy generalized classification type	C58599
Disease/Injury Related Events; Classification	Seizure unclassified classification status	C58604
Disease/Injury Related Events; Classification	Genetic presumed genetic epilepsy etiology type	C58582
Disease/Injury Related Events; Classification	Data collected date and time	C06005
Disease/Injury Related Events; Classification	Data valid through date and time	C14134

## Summary of Core/Supplemental – Highly Recommended Recommendations: Epilepsy CDEs

Domain; Subdomain	Data element	CDE ID
Disease/Injury Related Events; Classification	Structural epilepsy etiology type	C58587
Disease/Injury Related Events; Classification	Metabolic toxic epilepsy etiology type	C58605
Disease/Injury Related Events; Classification	Epilepsy etiology specific present likelihood type	C14425
Disease/Injury Related Events; Classification	Epilepsy etiology primary type	C14426
Disease/Injury Related Events; Classification	Epilepsy etiology secondary type	C14427
Disease/Injury Related Events; Classification	Other epilepsy etiology type	C58606
Disease/Injury Related Events; Classification	Epilepsy syndrome age of onset type	C14472
Disease/Injury Related Events; Classification	Epilepsy syndrome likelihood type	C14470
Disease/Injury Related Events; Classification	Epilepsy syndrome neonatal type	C14471
Disease/Injury Related Events; Classification	Epilepsy syndrome infant type	C14473
Disease/Injury Related Events; Classification	Epilepsy syndrome childhood type	C14475
Disease/Injury Related Events; Classification	Epilepsy syndrome adolescence or adult type	C14477
Disease/Injury Related Events; Classification	Epilepsy syndrome less specific age relationship type	C14479
Disease/Injury Related Events; Classification	Epilepsy syndrome distinctive constellation type	C14481

## Summary of Core/Supplemental – Highly Recommended Recommendations: Epilepsy CDEs

Domain; Subdomain	Data element	CDE ID
Disease/Injury Related Events; Classification	Epilepsy syndromes distinct confidence level type	C14485
Disease/Injury Related Events; Classification	Data collected date and time	C06005
Disease/Injury Related Events; Classification	Data valid through date and time	C14134
Outcomes and Endpoints; Quality of Life/Patient Reported Outcomes	Seizure diary date and time	C10626
Outcomes and Endpoints; Quality of Life/Patient Reported Outcomes	Seizure daily diary seizure type	C10635
Outcomes and Endpoints; Quality of Life/Patient Reported Outcomes	Seizure daily diary no seizure indicator	C14136
Outcomes and Endpoints; Quality of Life/Patient Reported Outcomes	Seizure daily diary seizure type count	C14138
Outcomes and Endpoints; Quality of Life/Patient Reported Outcomes	Seizure diary completer type	C14139
Outcomes and Endpoints; Quality of Life/Patient Reported Outcomes	Seizure diary completer other text	C18904
Treatment/Intervention Data; Surgeries and Other Procedures	Surgical or therapeutic procedure start date and time	C05106

## Summary of Core/Supplemental – Highly Recommended Recommendations: Epilepsy CDEs

Domain; Subdomain	Data element	CDE ID
Treatment/Intervention Data; Surgeries and Other Procedures	Suspected pathology type	C59368
Treatment/Intervention Data; Surgeries and Other Procedures	Suspected pathology type other text	C59369
Treatment/Intervention Data; Surgeries and Other Procedures	Surgical or therapeutic procedure type	C05108
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode type	C14297
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode type other text	C59370
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode depth anatomic site	C59371
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode depth anatomic site other text	C59372
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode depth hippocampus laterality type	C59373
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode depth frontal laterality type	C59374

## Summary of Core/Supplemental – Highly Recommended Recommendations: Epilepsy CDEs

Domain; Subdomain	Data element	CDE ID
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode depth temporal laterality type	C59375
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode depth parietal laterality type	C59376
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode depth occipital laterality type	C59377
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode depth insula laterality type	C59378
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode depth amygdala laterality type	C59379
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode depth other laterality type	C59380
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode subdural anatomic site	C59381
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode subdural anatomic site other text	C59382
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode subdural hippocampus laterality type	C59383

## Summary of Core/Supplemental – Highly Recommended Recommendations: Epilepsy CDEs

Domain; Subdomain	Data element	CDE ID
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode subdural frontal laterality type	C59384
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode subdural temporal laterality type	C59385
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode subdural parietal laterality type	C59386
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode subdural occipital laterality type	C59387
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode subdural insula laterality type	C59388
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode subdural amygdala laterality type	C59389
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode subdural other laterality type	C59390
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode epidural anatomic site	C59391
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode epidural anatomic site other text	C59393



## Summary of Core/Supplemental – Highly Recommended Recommendations: Epilepsy CDEs

Domain; Subdomain	Data element	CDE ID
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode epidural hippocampus laterality type	C59394
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode epidural frontal laterality type	C59395
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode epidural temporal laterality type	C59410
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode epidural parietal laterality type	C59411
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode epidural occipital laterality type	C59412
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode epidural insula laterality type	C59414
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode epidural amygdala laterality type	C59416
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode epidural other laterality type	C59420
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode foramen ovale anatomic site	C59426

## Summary of Core/Supplemental – Highly Recommended Recommendations: Epilepsy CDEs

Domain; Subdomain	Data element	CDE ID
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode foramen ovale anatomic site other text	C59427
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode foramen ovale hippocampus laterality type	C59429
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode foramen ovale frontal laterality type	C59430
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode foramen ovale temporal laterality type	C59431
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode foramen ovale parietal laterality type	C59433
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode foramen ovale occipital laterality type	C59435
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode foramen ovale insula laterality type	C59438
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode foramen ovale amygdala laterality type	C59439
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode foramen ovale other laterality type	C59440

## Summary of Core/Supplemental – Highly Recommended Recommendations: Epilepsy CDEs

Domain; Subdomain	Data element	CDE ID
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode interhemispheric anatomic site	C59456
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode interhemispheric anatomic site other text	C59457
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode other location anatomic site	C59458
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode other location anatomic site other text	C59459
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode other type hippocampus laterality type	C59460
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode other type frontal laterality type	C59461
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode other type temporal laterality type	C59462
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode other type parietal laterality type	C59463
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode other type occipital laterality type	C59464

## Summary of Core/Supplemental – Highly Recommended Recommendations: Epilepsy CDEs

Domain; Subdomain	Data element	CDE ID
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode other type insula laterality type	C59465
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode other type amygdala laterality type	C59466
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery diagnostic electrode other type other laterality type	C59467
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery anterior temporal lobectomy laterality type	C59468
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery anterior temporal lobectomy resection size estimate type	C59469
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery anterior temporal lobectomy superior temporal gyrus resection estimated length value	C14299
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery anterior temporal lobectomy middle temporal gyrus resection estimated length value	C14300
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery anterior temporal lobectomy inferior temporal gyrus resection estimated length value	C14301
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery anterior temporal lobectomy parahippocampal gyrus resection estimated length value	C14302

## Summary of Core/Supplemental – Highly Recommended Recommendations: Epilepsy CDEs

Domain; Subdomain	Data element	CDE ID
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery anterior temporal lobectomy amygdala resection estimated percentage value	C14303
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery anterior temporal lobectomy hippocampus resection estimated length value	C14304
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery anterior temporal lobectomy plus adjacent resection indicator	C14305
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery anterior temporal lobectomy plus extended resection anatomic site	C14310
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery anterior temporal lobectomy plus extended resection lateral temporal laterality type	C59470
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery anterior temporal lobectomy plus extended resection occipital laterality type	C59471
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery anterior temporal lobectomy plus extended resection parietal laterality type	C59472
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery anterior temporal lobectomy plus extended resection orbitofrontal laterality type	C59473
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery anterior temporal lobectomy plus extended resection dorsolateral frontal laterality type	C59474

## Summary of Core/Supplemental – Highly Recommended Recommendations: Epilepsy CDEs

Domain; Subdomain	Data element	CDE ID
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery anterior temporal lobectomy plus extended resection medial frontal laterality type	C59475
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery anterior temporal lobectomy plus extended resection central cortex laterality type	C59476
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery anterior temporal lobectomy plus resection size estimate type	C59477
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery anterior temporal lobectomy plus largest anterior-posterior extent of resection estimated value	C14306
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery anterior temporal lobectomy plus largest lateral extent of resection estimated value	C14307
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery anterior temporal lobectomy plus largest depth of resection estimated value	C14308
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery anterior temporal lobectomy plus resected tissue estimated volume value	C14309
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery amygdalohippocampectomy laterality type	C59478
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery amygdalohippocampectomy approach anatomic site	C14314

## Summary of Core/Supplemental – Highly Recommended Recommendations: Epilepsy CDEs

Domain; Subdomain	Data element	CDE ID
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery amygdalohippocampectomy approach anatomic site other text	C59479
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery amygdalohippocampectomy resection size estimate type	C59480
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery amygdalohippocampectomy parahippocampal estimated length value	C14311
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery amygdalohippocampectomy amygdala estimated percentage value	C14312
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery amygdalohippocampectomy hippocampus estimated length value	C14313
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery lesionectomy suspect lesion anatomic site	C14316
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery lesionectomy suspect lesion anatomic site other text	C59481
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery lesionectomy suspect lesion lateral temporal laterality type	C59482
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery lesionectomy suspect lesion medial temporal laterality type	C59483

## Summary of Core/Supplemental – Highly Recommended Recommendations: Epilepsy CDEs

Domain; Subdomain	Data element	CDE ID
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery lesionectomy suspect lesion occipital laterality type	C59484
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery lesionectomy suspect lesion parietal laterality type	C59485
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery lesionectomy suspect lesion hypothalamus laterality type	C59486
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery lesionectomy suspect lesion orbitofrontal laterality type	C59487
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery lesionectomy suspect lesion dorsolateral frontal laterality type	C59488
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery lesionectomy suspect lesion medial frontal laterality type	C59489
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery lesionectomy suspect lesion central cortex laterality type	C59490
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery lesionectomy suspect lesion insula laterality type	C59491
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery lesionectomy suspect lesion multifocal laterality type	C59492



## Summary of Core/Supplemental – Highly Recommended Recommendations: Epilepsy CDEs

Domain; Subdomain	Data element	CDE ID
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery lesionectomy suspect lesion other anatomic site laterality type	C59493
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery lesionectomy resection extent type	C14317
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery lesionectomy resection extent other text	C18917
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery lesionectomy resection size estimate type	C59494
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery lesionectomy plus adjacent resection indicator	C14318
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery lesionectomy plus resection extent type	C59495
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery lesionectomy plus resection size estimate type	C59496
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery lesionectomy plus largest anterior-posterior extent of resection estimated value	C14319
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery lesionectomy plus largest lateral extent of resection estimated value	C14320

## Summary of Core/Supplemental – Highly Recommended Recommendations: Epilepsy CDEs

Domain; Subdomain	Data element	CDE ID
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery lesionectomy plus largest depth of resection estimated value	C14321
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery lesionectomy plus resected tissue estimated volume value	C14322
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery neocortical resection anatomic site	C59497
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery neocortical resection lateral temporal laterality type	C59498
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery neocortical resection occipital laterality type	C59499
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery neocortical resection parietal laterality type	C59500
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery neocortical resection orbitofrontal laterality type	C59501
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery neocortical resection dorsolateral frontal laterality type	C59502
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery neocortical resection medial frontal laterality type	C59503

## Summary of Core/Supplemental – Highly Recommended Recommendations: Epilepsy CDEs

Domain; Subdomain	Data element	CDE ID
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery neocortical resection central cortex laterality type	C59504
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery neocortical resection insula laterality type	C59505
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery neocortical resection size estimate type	C59506
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery neocortical resection largest anterior-posterior extent estimated value	C59507
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery neocortical resection largest lateral extent estimated value	C59508
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery neocortical resection largest depth estimated value	C59509
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery neocortical resection tissue estimated volume value	C59510
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery multi-lobar resection lesion indicator	C14329
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery multi-lobar resection lobe anatomic site	C14330

## Summary of Core/Supplemental – Highly Recommended Recommendations: Epilepsy CDEs

Domain; Subdomain	Data element	CDE ID
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery multi-lobar temporal lobe resection indicator	C59511
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery multi-lobar temporal lobe resection laterality type	C59512
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery multi-lobar temporal lobe resection percent estimate remove type	C59513
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery multi-lobar temporal lobe resection temporal percentage estimate remove range	C59514
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery multi-lobar occipital lobe resection indicator	C59515
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery multi-lobar occipital lobe resection laterality type	C59516
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery multi-lobar occipital lobe resection estimate type	C59517
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery multi-lobar percent estimate occipital lobe resection remove range	C59518
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery multi-lobar parietal lobe resection indicator	C59519

## Summary of Core/Supplemental – Highly Recommended Recommendations: Epilepsy CDEs

Domain; Subdomain	Data element	CDE ID
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery multi-lobar parietal lobe resection laterality type	C59520
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery multi-lobar percent estimate parietal lobe resection remove type	C59521
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery multi-lobar percentage estimate parietal lobe resection remove range	C59522
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery multi-lobar frontal lobe resection indicator	C59523
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery multi-lobar frontal lobe resection laterality type	C59524
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery multi-lobar percent estimate frontal lobe resection remove type	C59525
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery multi-lobar percent estimate frontal lobe resection remove range	C59526
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery multi-lobar insula resection indicator	C59527
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery multi-lobar insula resection laterality type	C59528

## Summary of Core/Supplemental – Highly Recommended Recommendations: Epilepsy CDEs

Domain; Subdomain	Data element	CDE ID
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery multi-lobar percent estimate insula resection remove type	C59529
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery multi-lobar percent estimate insula resection remove range	C59530
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery hemispherectomy type	C14335
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery hemispherectomy other text	C18918
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery hemispherectomy laterality type	C59531
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery vagus nerve stimulation laterality type	C59532
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery corpus callosotomy disconnection tissue type	C59533
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery corpus callosotomy disconnection extent type	C14338
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery multiple subpial transection anatomic site	C14341

## Summary of Core/Supplemental – Highly Recommended Recommendations: Epilepsy CDEs

Domain; Subdomain	Data element	CDE ID
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery multiple subpial transection lateral temporal laterality type	C59534
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery multiple subpial transection medial temporal laterality type	C59535
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery multiple subpial transection occipital laterality type	C59536
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery multiple subpial transection parietal laterality type	C59537
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery multiple subpial transection orbitofrontal laterality type	C59538
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery multiple subpial transection dorsolateral frontal laterality type	C59539
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery multiple subpial transection medial frontal laterality type	C59540
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery multiple subpial transection central cortex laterality type	C59541
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery multiple subpial transection estimate size type	C59542

## Summary of Core/Supplemental – Highly Recommended Recommendations: Epilepsy CDEs

Domain; Subdomain	Data element	CDE ID
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery multiple subpial transection largest anterior-posterior dimension estimated value	C14339
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery multiple subpial transection largest lateral dimension estimated value	C14340
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery multiple subpial transection with resection indicator	C14342
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery stereotactic lesion present MRI indicator	C59543
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery stereotactic lesion method type	C59544
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery radiosurgery marginal dose value	C14347
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery stereotactic lesion perform anatomic site	C59545
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery stereotactic lesion medial temporal laterality type	C59546
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery stereotactic lesion lateral temporal laterality type	C59547



## Summary of Core/Supplemental – Highly Recommended Recommendations: Epilepsy CDEs

Domain; Subdomain	Data element	CDE ID
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery stereotactic lesion occipital laterality type	C59548
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery stereotactic lesion parietal laterality type	C59549
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery stereotactic lesion orbitofrontal laterality type	C59550
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery stereotactic lesion dorsolateral frontal laterality type	C59551
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery stereotactic lesion medial frontal laterality type	C59552
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery stereotactic lesion central cortex laterality type	C59553
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery stereotactic lesion insula laterality type	C59554
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery stereotactic lesion periventricular laterality type	C59555
Treatment/Intervention Data; Surgeries and Other Procedures	Therapeutic brain stimulation procedure type	C59556

## Summary of Core/Supplemental – Highly Recommended Recommendations: Epilepsy CDEs

Domain; Subdomain	Data element	CDE ID
Treatment/Intervention Data; Surgeries and Other Procedures	Electrode brain count	C08039
Treatment/Intervention Data; Surgeries and Other Procedures	Therapeutic brain stimulation target anatomic site	C14349
Treatment/Intervention Data; Surgeries and Other Procedures	Therapeutic brain stimulation target anatomic other text	C18921
Treatment/Intervention Data; Surgeries and Other Procedures	Therapeutic brain stimulation cortical procedure anatomic site	C59557
Treatment/Intervention Data; Surgeries and Other Procedures	Therapeutic brain stimulation cortical hippocampus procedure laterality type	C59558
Treatment/Intervention Data; Surgeries and Other Procedures	Therapeutic brain stimulation cortical lateral temporal procedure laterality type	C59559
Treatment/Intervention Data; Surgeries and Other Procedures	Therapeutic brain stimulation cortical occipital procedure laterality type	C59560
Treatment/Intervention Data; Surgeries and Other Procedures	Therapeutic brain stimulation cortical parietal procedure laterality type	C59561
Treatment/Intervention Data; Surgeries and Other Procedures	Therapeutic brain stimulation cortical orbitofrontal laterality procedure type	C59562

## Summary of Core/Supplemental – Highly Recommended Recommendations: Epilepsy CDEs

Domain; Subdomain	Data element	CDE ID
Treatment/Intervention Data; Surgeries and Other Procedures	Therapeutic brain stimulation cortical dorsolateral frontal procedure laterality type	C59563
Treatment/Intervention Data; Surgeries and Other Procedures	Therapeutic brain stimulation cortical medial frontal procedure laterality type	C59564
Treatment/Intervention Data; Surgeries and Other Procedures	Therapeutic brain stimulation cortical central cortex procedure laterality type	C59565
Treatment/Intervention Data; Surgeries and Other Procedures	Therapeutic brain stimulation cortical insula procedure laterality type	C59566
Treatment/Intervention Data; Surgeries and Other Procedures	Therapeutic brain stimulation subcortical procedure anatomic site	C59567
Treatment/Intervention Data; Surgeries and Other Procedures	Therapeutic brain stimulation subcortical anterior thalamus procedure laterality type	C59568
Treatment/Intervention Data; Surgeries and Other Procedures	Therapeutic brain stimulation subcortical centromedian thalamus procedure laterality type	C59569
Treatment/Intervention Data; Surgeries and Other Procedures	Therapeutic brain stimulation subcortical cerebellum procedure laterality type	C59570
Treatment/Intervention Data; Surgeries and Other Procedures	Therapeutic brain stimulation subcortical subthalamic nucleus laterality type	C59571

## Summary of Core/Supplemental – Highly Recommended Recommendations: Epilepsy CDEs

Domain; Subdomain	Data element	CDE ID
Treatment/Intervention Data; Surgeries and Other Procedures	Therapeutic brain stimulation subcortical brainstem laterality procedure type	C59572
Treatment/Intervention Data; Surgeries and Other Procedures	Therapeutic brain stimulation anterior-posterior coordinates value	C14350
Treatment/Intervention Data; Surgeries and Other Procedures	Therapeutic brain stimulation lateral coordinates value	C14351
Treatment/Intervention Data; Surgeries and Other Procedures	Therapeutic brain stimulation depth coordinates value	C14352
Treatment/Intervention Data; Surgeries and Other Procedures	Therapeutic brain stimulation placement method type	C14353
Treatment/Intervention Data; Surgeries and Other Procedures	Therapeutic brain stimulation placement method other text	C18922
Treatment/Intervention Data; Surgeries and Other Procedures	Therapeutic brain stimulation placement verification type	C14354
Treatment/Intervention Data; Surgeries and Other Procedures	Therapeutic brain stimulation placement verification other text	C18923
Treatment/Intervention Data; Surgeries and Other Procedures	Therapeutic brain stimulation pulse frequency	C14355

## Summary of Core/Supplemental – Highly Recommended Recommendations: Epilepsy CDEs

Domain; Subdomain	Data element	CDE ID
Treatment/Intervention Data; Surgeries and Other Procedures	Therapeutic brain stimulation pulse voltage value	C14356
Treatment/Intervention Data; Surgeries and Other Procedures	Therapeutic brain stimulation pulse current value	C14357
Treatment/Intervention Data; Surgeries and Other Procedures	Therapeutic brain stimulation pulse polarity type	C14358
Treatment/Intervention Data; Surgeries and Other Procedures	Therapeutic brain stimulation pulse polarity type other text	C59573
Treatment/Intervention Data; Surgeries and Other Procedures	Therapeutic brain stimulation pulse width value	C14359
Treatment/Intervention Data; Surgeries and Other Procedures	Therapeutic brain stimulation pulse stimulus type	C14360
Treatment/Intervention Data; Surgeries and Other Procedures	Therapeutic brain stimulation intermittent pulse on duration	C14361
Treatment/Intervention Data; Surgeries and Other Procedures	Therapeutic brain stimulation intermittent pulse off duration	C14362
Treatment/Intervention Data; Surgeries and Other Procedures	Therapeutic brain stimulation postoperative MRI verification indicator	C14363

## Summary of Core/Supplemental – Highly Recommended Recommendations: Epilepsy CDEs

Domain; Subdomain	Data element	CDE ID
Treatment/Intervention Data; Surgeries and Other Procedures	Surgical or therapeutic procedure text	C17643
Treatment/Intervention Data; Surgeries and Other Procedures	Surgical language laterality type	C14365
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery intraoperative electrocorticogram type	C14366
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery intraoperative cortical stimulation mapping indicator	C14367
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery stereotaxis type	C14368
Treatment/Intervention Data; Surgeries and Other Procedures	Pathology temporal lobectomy hippocampus finding type	C14369
Treatment/Intervention Data; Surgeries and Other Procedures	Pathology temporal lobectomy temporal lobe finding text	C14364
Treatment/Intervention Data; Surgeries and Other Procedures	Pathology lesionectomy vascular finding type	C14370
Treatment/Intervention Data; Surgeries and Other Procedures	Pathology lesionectomy tumor finding type	C14371

## Summary of Core/Supplemental – Highly Recommended Recommendations: Epilepsy CDEs

Domain; Subdomain	Data element	CDE ID
Treatment/Intervention Data; Surgeries and Other Procedures	Pathology lesionectomy tumor finding other text	C18924
Treatment/Intervention Data; Surgeries and Other Procedures	Pathology lesionectomy tumor astrocytoma grade	C59574
Treatment/Intervention Data; Surgeries and Other Procedures	Pathology lesionectomy tumor mixed glioma grade	C59575
Treatment/Intervention Data; Surgeries and Other Procedures	Pathology lesionectomy tumor oligodendroglioma grade	C59576
Treatment/Intervention Data; Surgeries and Other Procedures	Pathology lesionectomy tumor other low grade developmental grade	C59577
Treatment/Intervention Data; Surgeries and Other Procedures	Pathology lesionectomy cortical dysplasia indicator	C14372
Treatment/Intervention Data; Surgeries and Other Procedures	Pathology lesionectomy infectious or inflammatory finding type	C14373
Treatment/Intervention Data; Surgeries and Other Procedures	Pathology lesionectomy infectious or inflammatory finding other text	C18925
Treatment/Intervention Data; Surgeries and Other Procedures	Pathology lesionectomy congenital malformation finding type	C14374

## Summary of Core/Supplemental – Highly Recommended Recommendations: Epilepsy CDEs

Domain; Subdomain	Data element	CDE ID
Treatment/Intervention Data; Surgeries and Other Procedures	Pathology lesionectomy trauma finding text	C14384
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery pathology hospital day count	C14375
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery post-operative seizure indicator	C14376
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery post-operative seizure count	C14377
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery post-operative neurologic complication type	C14378
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery post-operative aphasia complication text	C18585
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery post-operative neurologic visual field deficit type	C59578
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery post-operative memory deficit complication text	C18587
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery post-operative cranial nerve deficit complication text	C59579



## Summary of Core/Supplemental – Highly Recommended Recommendations: Epilepsy CDEs

Domain; Subdomain	Data element	CDE ID
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery post-operative altered state complication text	C18584
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery post-operative psychiatric complication text	C17638
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery post-operative medical complication type	C14379
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery post-operative medical complication other text	C18926
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery post-operative medical complication wound infection type	C59580
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery post-operative respiratory complication text	C17640
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery post-operative gastrointestinal complication text	C18586
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery post-operative readmission 30 days after surgery indicator	C14380
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery post-operative readmission 30 days after surgery reason	C17639

## Summary of Core/Supplemental – Highly Recommended Recommendations: Epilepsy CDEs

Domain; Subdomain	Data element	CDE ID
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery post-operative return to operating room indicator	C14381
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery post-operative return to operating room reason	C17641
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery post-operative complication text	C14382
Treatment/Intervention Data; Surgeries and Other Procedures	Surgery post-operative complication resolved date	C14383

### Supplemental – Highly Recommended Instruments:

1. [American National Adult Reading Test \(AmNART\)](#) (primary IQ estimation measure)
2. [Montreal Cognitive Assessment \(MoCA\)](#) (primary overall mental status measure)
3. [Hopkins Verbal Learning Test \(HVLN\)](#) (primary memory measure)
4. [Boston Naming Test \(BNT\)](#) (secondary cognitive measure for naming)
5. [Controlled Oral Word Association Test \(COWAT\)](#) (secondary cognitive measure for executive function)
6. [Continuous Performance Test-III \(CPT III\)](#) (secondary cognitive measure for attention)
7. [Seizure Diary](#) (primary patient reported outcome measure)
8. [Beck Depression Inventory-II \(BDI-II\)](#) (primary depression measure)
9. [Quality of Life Epilepsy Inventory-31 \(QOLIE-31\)](#)
10. [Quality of Life in Childhood Epilepsy \(QOLCE-55\)](#)
11. [Quality of Life in Neurological Disorders \(Neuro-QOL\) – Measurement System](#)

For the complete list of NINDS CDE recommendations for Epilepsy, please see the [NINDS CDE website](#).