

■ ORIGINAL ARTICLE

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The Validity and Reliability of Characterizing Epilepsy Based on an External Review of Medical Records

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OBJECTIVES: Our goal is to validate diagnosing and characterizing epilepsy based on a medical record survey by external reviewers.

METHODS: We reviewed medical records from 80 patients who received antiepileptic drugs in 2009 at two hospitals. The study consisted of two steps; data abstraction by certified health record administrators and then verification by the investigators. The gold standard was the results of the survey performed by the epileptologists from their own hospital.

RESULTS: The specificity was more than 90.0% for diagnosis and activity, and for new-onset seizures. The sensitivity was 97.0% or more for diagnosis and activity and 66.7-75.0% for new-onset epilepsy. This method accurately classified epileptic syndromes in 90.2-92.9% of patients, causes in 85.4-92.7%, and age of onset in 78.0-81.0%. Kappa statistics for inter-rater reliability and test-retest reliability ranged from 0.641-0.975, which means substantial to near-perfect agreement in all items.

CONCLUSIONS: Our data suggest that epilepsy can be well identified by external review of medical records. This method may be useful as a basis for large-scale epidemiological research.

KEY WORDS: Validity, Epilepsy, Epidemiology, Sensitivity, Specificity, Reliability

INTRODUCTION

The Korean National Health Insurance (NHI) has provided health care for the entire Korean population as well as all medical facilities since 1989 and its database is a useful source of data for epidemiological research. Our previous study demon-

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strated its value in estimating the national prevalence of epilepsy based on antiepileptic drugs (AEDs) prescribed and diagnostic codes for claims [1]. However, NHI data should be validated for epidemiological research [2,3]. In addition, the NHI data do not provide detailed clinical information. Therefore, we launched the Epidemiological Study of Seizure and Epilepsy using Nationwide database for Corean Epilepsy patients (ESSENCE) project to estimate the prevalence of epilepsy from NHI data, which were validated and supplemented by a review of medical records.

Surveys reviewing medical records hold an advantage over door-to-door surveys, as they prevent recall errors, and clinical details as well as laboratory results are readily available [4]. When easy access to care providers is guaranteed in a national health care system, a review of medical records can be utilized in understanding the epidemiology of certain disorders. To ensure efficiency and consistency of the overall study, the task of review-

ing medical records was carried out by trained external reviewers. The goal of this study was to develop a protocol for and evaluate the validity and reliability of medical record survey for epilepsy by external reviewers, to support our future epidemiological study.

MATERIALS AND METHODS

Subjects

The two study hospitals, Korea University Hospital (K hospital located in Seoul) and Eulji University Hospital (E hospital located in a suburban area), are both tertiary centers. K hospital has an electronic medical record system, whereas E hospital does not.

Among those who were prescribed AEDs during the year 2009, 80 patients were randomly selected from the NHI claims data from both hospitals. To guarantee an adequate representation of various conditions, for each hospital, we sampled 18 patients coded as having epilepsy or seizure, 12 as having central nervous system (CNS) illness other than epilepsy or seizure, and 10 without any diagnostic codes related to CNS disease. AEDs included carbamazepine, clobazam, ethosuximide, gabapentin, lamotrigine, levetiracetam, oxcarbazepine, phenobarbital, phenytoin, pregabalin, topiramate, vigabatrin, valproate, and zonisamide. Clonazepam was excluded because it is rarely used as monotherapy for epilepsy and is more frequently used for non-epileptic purposes. Other anticonvulsants, including primidone, felbamate and tiagabin were not available in 2009 in Korea. The diagnostic codes indicating epilepsy or seizure included G40* (epilepsy), G41* (status epilepticus), F803 (Landau-Kleffner syndrome), and R56.8 (convulsion), based on the 10th version of the International Classification of Diseases (ICD-10) and related health problems [5]. This study was approved by the Institutional Review Board of Korea University Hospital (AN10221-001).

Procedures

The investigators developed a case recording form (CRF) and common diagnostic algorithm, which was tested for consistency. The CRF consisted of two parts: the first part was a preliminary form for chart abstraction, written in layman terms and included guidelines for surveyors; the second part was the verification form, which included the diagnostic algorithm for epileptologists (Appendix).

Part one documented demographics, ICD-10 codes, department of primary physician, diagnosis, antiepileptic drugs prescribed, history of seizures, recurrence of seizures, age of onset, new-onset seizure or presence of any seizure during 2009, description of seizure type, cause of epilepsy, electroencephalog-

raphy (EEG) and brain imaging results. Age of onset was classified as <12 months, 12 months-6 years, 6 years-12 years, 12 years-18 years, 18 years-30 years, 30 years-60 years, and >60 years. EEG findings were categorized as normal, abnormal with focal epileptiform discharges, abnormal with generalized epileptiform discharges, and abnormal with non-epileptiform discharges.

Part two consisted of diagnosis, activity of epilepsy, cause, and classification of epilepsy. Diagnoses were categorized as: 1) epilepsy; 2) single seizure; 3) either epilepsy or seizure, unclear; 4) non-epileptic; and 5) either epileptic or non-epileptic, unclear. Epilepsy was defined as having two or more seizures during the patient's lifetime. In cases where it was uncertain whether he or she had single seizure or recurrent seizures, category 3 was assigned. Acute symptomatic seizures were categorized as 3, even if they were recurrent. If the AED was being used for other identifiable reasons such as pain, the patients were classified as being category 4. If the reason for prescribing an AED could not be determined, category 5 was assigned. Active epilepsy was defined as one or more seizures during 2009. The etiology was determined based on the clinical history, findings, brain imaging results, and EEG. If there were conflicting data, the etiology was determined by the clarity of the records and additional explanation from the treating physician. Non-specific imaging findings, such as small vessel disease, arachnoid cysts, venous anomalies, or diffuse atrophy were not considered as causes of epilepsy. Epilepsy was classified as: 1) generalized; 2) localization-related; 3) undetermined as to whether focal or generalized; 4) special syndrome, according to International League Against Epilepsy classification [6]; 5) and a lack of information for classification, based on the seizure type, syndrome diagnosis documented by the clinician, brain imaging, and EEG in the order of priority. Patients who had only generalized tonic-clonic seizures (GTCSs) with normal EEG and brain imaging were classified as 3. Patients who had only GTCSs with normal EEG but without any brain imaging results were classified as 5.

For chart abstraction, we recruited certified health record administrators (HRAs) who were experienced in reviewing medical records for epidemiological studies and health registry. These were coders certified by the Department of Ministry and Health Care of Korea for abstracting and managing data from medical records. The HRAs were intensively trained to review medical records and extract data related to epilepsy for 8 hours. The didactic portion included an overall introduction, a general overview on epilepsy, medical terminology and abbreviations commonly used in physicians' notes, how to find test results, and other conditions in the differential diagnosis or that are treated with AEDs. The HRAs then received hands-on training in completing the CRFs while receiving feedback from the epileptologists, until they achieved a high level of concordance with the

epileptologists. Training was provided at a third-party hospital.

In this study, we assessed the validity and reliability of reviews performed by two HRAs (HRA-A and B), followed by verification by an external epileptologist (included SY Lee). HRA-A repeated the review at a 1-month interval to determine test-retest reliability. To establish a gold standard, each epileptologist performed both steps of chart abstraction and verification at his or her own hospital (E hospital, K hospital). In addition, alternative sources, such as the individual hospital data for patients with epilepsy or physician opinions were incorporated into the gold standard. The design of the study is summarized in Figure 1.

We analyzed the validity and reliability of the six items: diagnosis, activity of epilepsy, cause, classification (all verified by the epileptologist), new-onset epilepsy, and age of onset (obtained by the HRAs without verification by the epileptologist). The validity of the survey was estimated by measuring sensitivity and specificity. For multiple-choice items, we estimated the rate of the correct diagnosis. The level of reliability was estimated by kappa value, and graded to almost perfect (κ =0.81-1.0), substantial (κ =0.61-0.80), moderate (κ =0.41-0.60), fair (κ =0.21-0.40), or slight (κ =0.0-0.2) agreement, according to the classifi-

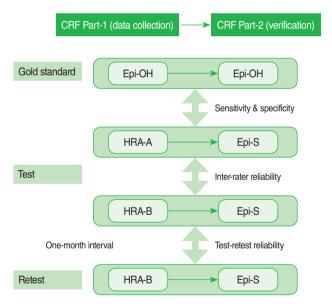


Figure 1. Study design for validation of medical record survey. The survey consisted of two-step data collection by certified health record administrators (HRAs) and then verification by the study epileptologist (Epi-S). For validation purposes, the gold standard was the conclusion each epileptologist made for his own hospital (Epi-OH), E or K hospital. In order to determine inter-rater reliability, two HRAs (HRA-A and HRA-B) reviewed medical records of the same patient while being blinded to each other. HRA-A repeated the reviews at a 1-month interval to determine test-retest reliability. CRF, case record form; HRA-A or B, health record administrator A or B; Epi-OH, epileptologist from the hospital; Epi-S, study epileptologist.

cation system suggested by Landis and Koch [7]. Statistical analysis was performed using SPSS version 18.0 (SPSS Inc., Chicago, IL, USA).

RESULTS

Baseline characteristics

Of the total 80 subjects, 46 (57.5%) were men and the mean age of subjects was 48.1 years old (range 9-88). Thirty-nine subjects had epilepsy, one had a single seizure, and two had seizure but it was unclear whether this recurred or not. Thirty-seven subjects received AEDs for non-epileptic causes; among them, 29 received AEDs for neuropathic pain, 4 for prophylaxis of seizure after brain insult or surgery, and the others for hemifacial spasm, facial nerve injury, oromandibular dyskinesia, or cramps. There was one case where the diagnosis was unclear (Table 1).

Validity

The sensitivity, specificity, and reliability of each surveyor are summarized in Table 2. For the diagnosis of epilepsy, the sensitivity was 97.6% for HRA-A and 100% for HRA-B, and specificity was 94.9% for HRA-A and 97.4% for HRA-B. For the activity of epilepsy, sensitivity was 100.0% for HRA-A and 97.0% for HRA-B, and specificity was 100.0% for both. For new-onset epilepsy, specificity was 90.9% for HRA-A and 100.0% for HRA-B, whereas sensitivity was 75.0% for HRA-A and 66.7% for HRA-B. The age of onset was correctly identified in 78.0% by HRA-A and 81.0% by HRA-B. The cause and classification of epilepsy were correctly identified and classified in 85.4%

Table 1. Patient demographics (n=80)

Clinical characteristics of study patients	n
Age, mean (range)	48.1 (9-88)
Gender Male Female	46 34
Diagnostic code 1. Epilepsy or seizure 2. CNS diseases other than epilepsy or seizure 3. Other than CNS diseases	36 24 20
Final diagnosis 1. Epilepsy 2. Single seizure 3. Either epilepsy or seizure, unclear 4. Non-epileptic Prophylaxis for seizure Pain Other (hemifacial spasm, facial nerve injury, oromandibular dyskinesia, and cramps)	39 1 2 37 4 29 4
Either epileptic or non-epileptic, unclear	1

CNS, central nervous system.

Table 2. Validity and reliability of the survey

	Sensitivity (%)		Specificity (%)		Correct diagnosis (%)		Reliability: kappa [SE]	
	А	В	A	В	А	В	Inter-rater (A-B)	Test-retest (A)
Diagnosis	97.6	100.0	94.9	97.4			0.907 [0.806-1.008]	0.975 [0.950-1.000]
Activity	100.0	97.0	100.0	100.0			0.932 [0.865-0.999]	0.796 [0.684-0.908]
New onset	75.0	66.7	90.9	100.0			0.728 [0.613-0.843]	0.641 [0.501-0.781]
Age of onset					78.0	81.0	0.753 [0.674-0.832]	0.697 [0.616-0.778]
Cause					85.4	92.7	0.792 [0.721-0.863]	0.693 [0.613-0.773]
Classification					90.2	92.9	0.864 [0.771-0.957]	0.787 [0.670-0.904]

A, Health record administrator (HRA)-A; B, HRA-B; SE, standard error.

and 90.2% of cases, respectively for HRA-A, and 92.7% and 92.9%, respectively for HRA-B.

Inter-rater reliability between HRA-A and B was almost perfect for the diagnosis (κ =0.907), disease activity (κ =0.932), and classification of epilepsy (κ =0.864). For new-onset epilepsy, age of onset, and cause of epilepsy, the reliability was substantial (κ =0.728, κ =0.753, and κ =0.792, respectively).

The reliability of repeated examination was almost perfect for the diagnosis of epilepsy (κ =0.975) and substantial for disease activity, new-onset epilepsy, age of onset, cause, and classification of epilepsy (κ =0.796, κ =0.641, κ =0.697, κ =0.693, and κ =0.787, respectively).

DISCUSSION

Our medical record review method demonstrated high levels of validity and consistency for the assessment of diagnosis, activity, and classification of epilepsy. The validity and reliability with regard to new-onset epilepsy, age of onset, and cause were acceptable.

The source of data from epidemiological studies may originate from direct population surveys, information or registries from physicians, medical records, or administrative data. Direct population surveys usually also involve interviews by non-physician surveyors or self-recorded questionnaires [8,9]. Some studies have validated questionnaires as a method to diagnose patients with epilepsy [8,9].

Reviewing medical records is highly useful to validate and supplement information from administrative data [8]. Reviewing of medical records is often performed by non-physician reviewers such as nurses or medical students, with or without a specialist's verification in epidemiological studies for epilepsy [9-11]. It would be ideal for the treating physicians to survey their own patients. However, not all of them are epileptologists and differences in experience would affect the consistency of the overall data. Although a standard protocol to confirm the diagnosis of epilepsy via medical records for epidemiological studies is not available, we are unaware of any other studies

that have validated their tools. We showed that our non-physician reviewers could collect data that were sufficient for the epileptologists to diagnose epilepsy.

It is one of the limitations of our study that the gold standard was derived from medical records, lacking a face-to-face interview. We could not conclude which factors affected the validity, such as the type of medical record system or institution, specialties of physicians prescribing AEDs, or diagnostic codes, due to the small sample size.

Our results suggest that trained health care workers' review of medical records followed by verification by an epileptologist is a valid and consistent way to identify and characterize epilepsy patients. This allows large-scale epidemiological studies involving multiple distant locations to be performed at relatively low costs.

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CONFLICT OF INTEREST

The authors have no conflicts of interest to declare for this study.

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Appendix

Epilepsy Case Recording Form (CRF	Epilepsy	Case	Recording	Form ((CRF
--	-----------------	------	-----------	--------	------

Date of Survey yr m d		Institution code						
DOB	nder	der Home address (City/ Gu)						
yr m d ∘ m		n o f						
	1							
Medical insurance clair Diagnostic codes	ns data	Drimor	y diagnos	tio ando		Secondary of	diaanaa	tia aada
		° G40			0		O	
Ephepsy of scizure		040		041	0	G40*		G41*
Other		1.90.		KJO		F803*		R56*
If there was no codes for epilepsy Antiepileptic medication			coaes given.					
	o Lai	-	0	Pregabalin		Pheny	toin	
-		etiracetam	0	o Topiramate		 Zonisamide 		
EthosuximideOxea		carbazepine	0	o Vigabatrin				
GabapentinPher		enobarbital	0	 Valproate 				
vienicai Recorus (ciinica		1)						
Medical Records (clinica	-			2)				
. 1)								
: 1)		· 						
1) 3) n chronological order Identification of seizure	e It can be des	cribed as seizure	. sz, fit, GTC	4) S, aura, or a spe	cific sym	ptom.		
1) 3) n chronological order Identification of seizure or example: clonus, head drop, los	e It can be des	cribed as seizure, ess, altered ment	. sz, fit, GTC al status, abi	4) S, aura, or a spec normal behavior,	cific sym	ptom.		
1) 3) n chronological order Identification of seizure or example: clonus, head drop, los. Any history of seizure	t can be des s of consciousn	cribed as seizure	. sz, fit, GTC al status, abr O Unclear	4) S, aura, or a spec normal behavior,	cific sym	ptom.		
1) 3) n chronological order Identification of seizure or example: clonus, head drop, los	t can be des s of consciousn	cribed as seizure, ess, altered ment • Yes • No • Yes • No	sz, fit, GTC. al status, abi • Unclear • Unclear	4) S, aura, or a spectormal behavior,	cific sym falls, et	ptom. c.		
1) 3) n chronological order Identification of seizure or example: clonus, head drop, los Any history of seizure History of repetitive seizu	e It can be des s of consciousn ares for prescrib on, paresthesia	cribed as seizure, ess, altered ment • Yes • No • Yes • No ing antiepile; s; headache, h	sz, fit, GTC al status, abr • Unclear • Unclear otic medic erpes	4) S, aura, or a spectormal behavior,	cific sym falls, et patient zure medica	ptom. c. did not hav tions were u	∕e a seiz	zure?
1)	e It can be des s of consciousn ares for prescrib on, paresthesia	cribed as seizure, ess, altered ment • Yes • No • Yes • No ing antiepile; s; headache, h	sz, fit, GTC al status, abr • Unclear • Unclear otic medic erpes	4) S, aura, or a spectormal behavior, ation if the prossible seing antiepileptic objective evidence.	cific sym falls, et patient zure medica lence as	ptom. c. did not hav tions were u	v e a seiz used des	zure?
1) 3) n chronological order Identification of seizure or example: clonus, head drop, los. Any history of seizure History of repetitive seizur What was the indication of Pain: abnormal sensation zoster, diabetes, polynomete. Hemifacial spasm Obesity	e It can be des s of consciousn ares for prescrib on, paresthesia europathy, t	cribed as seizure. ess, altered ment • Yes • No • Yes • No ing antiepile; as; headache, h	o Sz, fit, GTC, al status, abr	S, aura, or a spenormal behavior, ation if the prossible seing antiepileptic objective evid	cific sym falls, etc patient zure medica ence as `conscie al bel	ptom. c. did not hav tions were u follows:	v e a seiz used des	zure? pite lack of
1) 3) n chronological order Identification of seizure or example: clonus, head drop, los Any history of seizure History of repetitive seizu What was the indication of Pain: abnormal sensation zoster, diabetes, polynomete. Hemifacial spasm	e It can be des s of consciousn ares for prescrib on, paresthesia europathy, t	cribed as seizure. ess, altered ment • Yes • No • Yes • No ing antiepile; as; headache, h	o Sz, fit, GTC, al status, abr	4) S, aura, or a spectormal behavior, action if the prossible seing antiepileptic objective evidence of Unusu	cific sym falls, etc patient zure medica ence as `conscie al bel	ousness, LOC	v e a seiz used des	zure? pite lack of
1)	e It can be des s of consciousn ares for prescrib on, paresthesia europathy, t	eribed as seizure, ess, altered ment • Yes • No • Yes • No ing antiepile; as; headache, h rigeminal neur	sz, fit, GTC. al status, abr Unclear Unclear totic medic erpes algia,	4) S, aura, or a spectormal behavior, action if the prossible seing antiepileptic objective evides \(\text{Loss of } \) Unusuagitation	patient zure medica ence as conscie al belon	did not hav tions were u follows: pusness, LOC navior- am	v e a seiz used des	zure? pite lack of

	ould be considered a seizure)		
. Did t	the seizures start in 2009?		o Yes o No o Undetermined
. When	n did the seizures start?		
0	<12months (infant)	0	18~<30 years
0	12months~<6 years (toddler, preschool)	0	30~<60 years
0	6~<12 years (elementary school)	0	>60 years
0	12~<18 years (middle or high school age)	0	Undetermined
	the patient have auras? • Yes • No • Undetermined be multiple		
0	Epigastric rising sensation	0	Memory flashbacks
0	Nausea, vomiting	0	(Un-)familiarity, jamais-vu, deja-vu
0	Visual	0	Paresthesias
0	Auditory	0	Unexplainable feelings, cephalic aura
0	Dizziness (should be differentiated from adverse effect of drug or nonspecific symptoms)	0	Other
3. Type	e of seizure? can be multiple		
0	Generalized seizure (GS)		o Absence or petit mal
0	Generalized tonic clonic, grand mal or GTCS		o Atonic (drop attacks)
0	Secondary generalized or secondary GTCS		o Spasms
0	Partial seizure (PS), simple partial seizure (SPS), or complex partial seizure (CPS)		o Other
0	Myoclonus		o Undetermined
hem CNS	se of epilepsy? based on past medical history and doctor umatic brain injury such as subdural hemorrhage (SDH norrhage (tSAH), or contusion S infection	(), ep	idural hemorrhage (EDH), traumatic subarachnoi
	oke, cerebral infarction, intracerebral hemorrhage (ICH), su		
	cular malformation, arteriovenous malformation (AVM), c	avern	ous angioma (CA)
	in tumor- oma, DNT, DNET	C	(1.000)
	generative disorders: dementia such as Alzheimer's (AD) of	r fron	totemporal dementia (FTD)
Con	inatal injury or perinatal ischemia, cerebral palsy ngenital malformations of brain: malformation of co izencephaly, pachygyria (lissencephaly), polymicrogyria, o		
	pocampal sclerosis, HS, hippocampal atrophy		•
	er		
	identifiable cause (idiopathic or cryptogenic)		

○ Yes ○ No	I . Partial or focal epilepsy						
	o Localization-related epilepsy (LRE)	Occipital lobe epilepsy (OLE)					
	o Temporal lobe epilepsy (TLE)	o Parietal lobe epilepsy (PLE)					
	o Frontal lobe epilepsy (FLE)	o Benign rolandic epilepsy (BRE)					
	o Childhood epilepsy with occipital paroxysms (CEOP)					
	o Panayiotopoulos syndrome						
	 Gastaut type 						
	Other (anterior, posterior, left, right, central, ins	ula etc)					
∘ Yes ∘ No	II. Generalized epilepsy						
	Childhood absence epilepsy (CAE)						
	o Juvenile absence epilepsy (JAE)						
	o Juvenile myoclonic epilepsy (JME)						
	o Idiopathic generalized epilepsy (IGE)						
	 Epilepsy with generalized tonic-clonic seizures (GTCS) on awakening 						
	o Lennox-Gastaut syndrome (LGS)						
	Infantile spasms or West syndrome						
	o Epilepsy with myoclonic-astatic seizures (Doose syndrome)						
	o Epilepsy with myoclonic absences (MAE)						
	Early myoclonic encephalopathy (EME)						
	o Early infantile epileptic encephalopathy (EIEE) (Ohtahara syndrome)						
	Benign neonatal convulsions						
	o Benign myoclonic epilepsy in infancy						
∘ Yes ∘ No	Ⅲ. Undetermined whether partial or general	ized					
	• Severe myoclonic epilepsy in infancy (SMEI) (Dravet syndrome)					
	o Generalized epilepsy with febrile seizures plus	(GEFS plus)					
	o Landau-Kleffner syndrome (LKS)						
	o Continuous spikes and waves during slow sleep	(CSWS)					
∘ Yes ∘ No	IV. Special syndrome						
	o Febrile convulsion (febrile seizure, FC)						
	 Seizures occurring only when there is an acute of alcohol, drugs, eclampsia, or nonketotic hyperg 						
∘ Yes ∘ No	V. No documentation of an epileptic syndrome						

■ Diagnostic tests ➤ Search the interpretation rest	ults in order communication system or electric medical record first, then in the clinician's note.
11. Has the patient had an I	EEG? ○ Yes ○ No
11-1. What were the EEG results?	○ Normal ○ Abnormal If an EEG was reported abnormal even once choose 'abnormal'.
○ Yes ○ No	spikes, sharp waves, epileptiform discharges, rhythmic, ictal or epilepsy (do not include arrhythmic slowing)
	o Generalized or diffuse (spike distribution)
Other abnormality	Localized or focal (suggestive of seizure focus)
12. Has the patient had a B	rain MRI or CT?
$\circ \ Yes \circ \ No$	MRI (dateyrm)
$\circ \ Yes \circ \ No$	CT (dateyrm)
12-1. What were the biimaging results?	rain o Normal o Abnormal
	 If the report is too long, please attach the copy. Document only the results obtained prior to seizure onset; for example, traumatic brain injury after having a seizure would not be applicable.
Can be multiple	naving a seizare woma not be apprecible.
 Localized abnormality i 	in cerebral hemisphere, cortex, or lobe
 Localized abnormality matter 	in deep graymatter-basal ganglia, thalamus; brainstem-midbrain, pons, medulla; white
o Diffuse abnormalities: o	diffuse atrophy, hydrocephalus
Nonspecific: small vess	sel disease (SVD), unspecified bright opacities (UBO)
O Trauma: subdural hema	toma (SDH), epidural hematoma (EDH), traumatic SAH, contusion
 Encephalitis, CNS infection 	ction
 Stroke, cerebral infarcti 	on, cerebral hemorrhage, ICH, SAH, Moyamoya disease
Arteriovenous malforma	ation (AVM), cavernous angioma (CA)
 Brain tumor- oma, DNT 	
	lementia such as Alzheimer's (AD) or frontotemporal dementia (FTD)
č	natal ischemia, cerebral palsy
Congenital malformation	ons of brain: malformation of cortical development (MCD), cortical dysplasia (CD) yria (lissencephaly), polymicrogyria, heterotopia
 Hippocampal sclerosis 	or atrophy
o Trippocampai scierosis (
 Tuberous sclerosis or to 	ubers

Epileptologist's diagnosis

Date of Survey	yr m d
Institution code	



■ Diagnosis

O Epilepsy Both 1& 2: Yes

o Single seizure 1: Yes, & 2: No

Seizure or Epilepsy, unclear 1: Yes, & 2: Undetermined

Other (nonseizure/nonepileptic) 1: No or Undetermined, & 3: Other cause

Epileptic or nonepileptic, unclear 1 Undetermined, & 3 Undetermined

■ Active epilepsy

○ Yes ○ No If yes in item 4, yes

■ Cause of epilepsy (can be multiple)

Choose based on items 9 or 12. If there is conflicting data, 12 would hold priority, however, this would depend on the accuracy of the records and probability.

- ► Cases marked as stroke, vascular malformation, tumor, congenital malformation on 9, but normal on 12 would be defined as undetermined
- Cases marked as trauma on 9, but normal on 12 would be determined based on the accuracy of clinical information
- Cases marked as CNS infection or degenerative disease on 9, but normal on 12 will be determined as 9
- Cases marked as no specific cause on 9 and normal on 12 will be considered as idiopathic or cryptogenic
 - Traumatic brain injury (mild head injuries are not to be considered a cause), SDH, EDH, traumatic SAH, contusion
 - o CNS infection
 - Stroke, cerebral infarction, cerebral hemorrhage, ICH, SAH
 - o Arteriovenous malformation AVM, cavernous angioma CA
 - o Brain tumors
 - O Degenerative disorders: dementia such as Alzheimer's (AD) or frontotemporal dementia (FTD)
 - Perinatal injury or perinatal ischemia, cerebral palsy
 - Congenital malformations of brain: malformation of cortical development (MCD), cortical dysplasia (CD), schizencephaly, pachygyria (lissencephaly), polymicrogyria, heterotopia
 - Hippocampal sclerosis or atrophy
 - Other ______(lesion of unknown pathology cerebromalacia (trauma or stroke), cortical thickening (cortical dysplasia or tumor))
 - No identifiable cause (idiopathic or cryptogenic)
 - Missing information on cause

■ Classification of Epilepsy

- ► Classification is based on the seizure type (7-8), diagnosed syndrome (10) clinical information, brain imaging (12), and EEG (11) (in the order of priority)
- ▶ Seizure, or GTCS without any specific description -> undetermined
- 1) Localization-related epilepsy: the presence of one or more of the findings below without any findings to suggest generalized epilepsy
- o Partial seizures
 - o Aura
 - o Simple partial seizure, or complex partial seizure
 - Secondary generalized or secondary GTCS
- o Localization-related epilepsy (LRE), documented by physician
- Temporal lobe epilepsy (TLE), documented by physician
- Frontal lobe epilepsy (FLE), documented by physician
- Occipital lobe epilepsy (OLE), documented by physician
- o Parietal lobe epilepsy (PLE), documented by physician
- o Benign rolandic epilepsy (BRE), documented by physician
- o Childhood epilepsy with occipital paroxysm (CEOP), documented by physician
 - o Panayiotopoulos syndrome, documented by physician
 - Gastaut type, documented by physician
- CT/MRI: localized abnormality in hemisphere cf. mild small vessel disease or unspecified bright opacity (UBO) is not considered as cause
- o EEG: localized spikes
- Cause (history)
- Traumatic brain injury (trivial head trauma is not considered as cause) SDH, EDH, traumatic SAH, contusion
- CNS infection
- o Stroke, cerebral infarction, cerebral hemorrhage, ICH, SAH
- Arteriovenous malformation AVM, cavernous angioma CA
- Brain tumor
- O Degenerative disorders: dementia such as Alzheimer's (AD) or fontotemporal dementia (FTD)
- Perinatal injury or perinatal ischemia, cerebral palsy
- Congenital malformations of brain: malformation of cortical development (MCD), cortical dysplasia (CD), schizencephaly, pachygyria (lissencephaly), polymicrogyria, heterotopia
- Hippocampal sclerosis or atrophy
- o Tuberous sclerosis or tubers
- Other (lesion of unknown pathology cerebromalacia (trauma or stroke), cortical thickening (cortical dysplasia or tumor))

)	Generalized seizure					
	o Absence					
	 Myoclonus Atonic seizure 					
	o Spasm					
	Childhood absence epilepsy (CAE), documented by physician					
	Juvenile absence epilepsy (JAE), documented by physician					
	Juvenile myoclonic epilepsy (JME), documented by physician					
	Idiopathic generalized epilepsy (IGE), documented by physician					
)	Epilepsy with generalized tonic -clonic seizures (GTCS) on awakening, documented by physician					
	Lennox-Gastaut syndrome (LGS), documented by physician					
	Infantile spasms (IS) or West syndrome, documented by physician					
	Epilepsy with myoclonic-astatic seizures (Doose syndrome), documented by physician					
	Epilepsy with myoclonic absences (MAE), documented by physician					
	Early myoclonic encephalopathy (EME), documented by physician					
	Early infantile epileptic encephalopathy (EIEE) (Ohtahara syndrome), documented by physician					
	Benign neonatal convulsions, documented by physician					
	Benign myoclonic epilepsy in infancy, documented by physician					
	EEG: generalized spike					
	3) Undetermined whether partial or generalized					
	Severe myoclonic epilepsy in infancy (SMEI) (Dravet syndrome), documented by physician					
	Generalized epilepsy with febrile seizures plus (GEFS plus), documented by physician					
	Landau-Kleffner syndrome (LKS), documented by physician					
	Continuous spikes and waves during slow sleep (CSWS), documented by physician					
	Seizures without unequivocal generalized or focal features (including cases with only GTCS)					
	4) Special syndrome					
	Febrile convulsion (febrile seizure, FC)					
	Seizures occurring only when there is an acute metabolic or toxic event due to factors (such as alcohol , drugs, eclampsia, nonketotic hyperglycemia)					
	Other					
	5) Lack of information Signature :					