

QUESTIONNAIRE FOR INVESTIGATION OF EPILEPSY IN TROPICAL COUNTRIES

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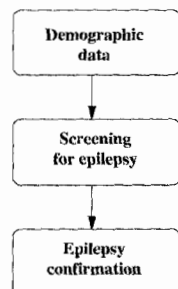
I - Introduction

The purpose of this questionnaire is to standardize information on the epilepsy studies. It was developed through collaborative work involving the Institute of Neurological Epidemiology and Tropical Neurology of Limoges (France), the Pan-African Association of Neurological Sciences and the International League Against Epilepsy (Commission on Tropical Diseases, 1993-1997).

II - Objectives

This questionnaire will be widely used in various tropical and subtropical regions. It was developed in a modular structure and comprises nine sections : demographic data, screening, confirmation of diagnosis, natural history of the seizure disorder, past medical history, clinical examination, paraclinical examinations, etiology, treatment. It investigates 4 different objectives:

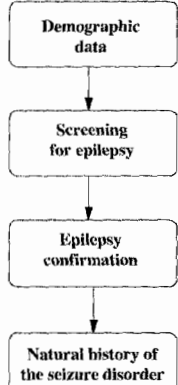
Appendix 1 : SCREENING



II - 1 - Screening (appendix 1) : using the sections "Demographic data, Screening, Epilepsy confirmation". This could help to estimate the prevalence in an area if the sampling is suitable for this.

II - 2 - Clinical forms of epilepsy (appendix 2) : using the sections "Demographic data, Screening, Epilepsy confirmation, Natural history of the seizure disorder".

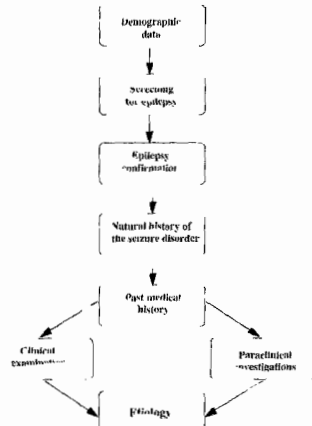
Appendix 2 : CLINICAL FORMS OF EPILEPSY



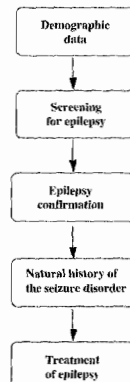
II - 3 - Etiology (appendix 3) : using the sections "Demographic data, Screening, Epilepsy confirmation, Natural history of the seizure disorder, Past medical history, Clinical examination, Paraclinical investigations, Etiology".

II - 4 - Treatment (appendix 4) : using the sections "Demographic data, Screening, Epilepsy confirmation, Natural history of the seizure disorder, Treatment".

Appendix 3 : ETIOLOGY



Annexe 4 : TREATMENT



III - How to use the questionnaire

The open brackets must be filled with the codes indicated in the questionnaire. The other questions must be answered in text language and will be coded later in the right column. This method allows to investigate with more freedom and greater accuracy. When the asked question needs a quantitative answer and this answer is not known, then the investigator should let the brackets empty.

The code of each individual is at the top of each page. The first 3 spaces are meant for the code of the country. To keep the study homogeneous, the codes could be given to the main investigator of the particular study, by the Institute of Tropical Neurology of Limoges; the next 2 spaces are meant for the year of the study, the 2 following spaces for the region and the last 4 spaces for the identification of each subject. Through this system, various studies can be carried out in the same country or in different countries (up to 9999 subjects), and remain confidential as the identification section can be separated from other sections.

For example, the code of the first subject of a study carried out in 1996 in the Atacora region in Benin could be BEN-96-AT-0001.

III - 1 - Demographic data

This provides the means to localize a specific subject (the address should be quoted very precisely), the professional activity and the period of stay in the study region. For the question D17, the definition of the rural-urban environment may change depending on the region of the study: the usual definition in France takes the threshold at 2 000 inhabitants. Although this may not perfectly apply, we propose to use this definition. Depending on the situation this definition may however be modified.

The data storage system used follows the ethical requirements of confidentiality and is quite safe. The questions concerning ethnic groups and religion are not compulsory.

III - 2 - Screening

This can be filled by a non medical investigator. However, it is important that all field-investigators should be trained and have a working knowledge of the different seizure types. If one of the answers is positive, the investigator must go on filling in the questionnaire and the subject must be examined by a physician to confirm the epileptic nature of the attack(s).

III - 3 - Confirmation

This section must be filled in by a physician to confirm the diagnosis of epilepsy. The clinical description of the attack(s) should be precised (foaming at the mouth, loss of bladder control, movements ...). If not, the physician can state if the attack(s) occurred in a particular situation, as part of an on-going disease, or if the attack was an isolated seizure. If epilepsy is confirmed, the questionnaire must be continued.

III - 4 - Natural history of the seizure disorder

This section should allow the possibility to describe the variety and the age of the epileptic seizures of the study subject. The question N1 looks for active epilepsy i.e. a subject who has had at least one seizure within the last 5 years, whatever treatment he may have had. The official document of the International League Against Epilepsy which classifies the definition of active epilepsy, the different classifications of seizures, as well as the guidelines for epidemiological studies is to be found in the appendix.

III - 5 - Past medical history

The questions concern the family history of epilepsy, and the personal history with an emphasis on the pregnancy history of the subject's mother, birth and psychomotor development, infantile diseases and neurological sequaelae due to these diseases and the period before the appearance of this sequaelae.

The siblings are defined as brothers and sisters of the same mother to the subject. The consanguinity relations and past family histories should strictly be looked for in the same family.

A pregnancy should be considered abnormal if the mother had haemorrhages, hypertensive attacks, premature uterine contractions, threatened abortion. Labour should be considered as prolonged if its goes beyond 12 hours for a primigravida and 6 hours for a multigravida.

An infant is considered as premature in this questionnaire if the mother gave birth before the 35th week of amenorrhoea. The psychomotor development should be assessed against the age of acquiring different milestones e.g. sitting, walking, language etc.

Measles is considered as severe if the subject developed neurological or pulmonary complications. Encephalitis is diagnosed if there is impairment of consciousness, presence of local neurological signs and fever. Encephalopathy presents with alterations of consciousness and neurological abnormalities. Meningitis is characterized by meningeal syndrome associated with fever. Coma beyond 24 hours is considered prolonged.

For the questions P47 to P49, one needs to find out if the subject works with animals, professionally or in his daily life, or if the animals live in his house. Excessive alcohol consumption is defined as daily ingestion of 300 ml or more of pure alcohol in females and 400 ml or more in males. All persons who use illegal toxic materials, natural or synthetic chemicals that may cause physical and / or psychological dependency are considered as drug addicts.

III - 6 - Clinical examination

The general state of health of the subject must be assessed by investigator and is defined as: poor if there is a loss of weight with asthenia, and difficulties in daily activities, average if there is asthenia or loss of weight but no problem in daily activities, good if there is no weight loss and no asthenia.

Intelligence Quotient is used to judge mental retardation of subjects. The following is the exact definition; mild mental retardation when the IQ is between 70 and 90, moderate mental retardation when IQ is between 50 and 70 and severe mental retardation when IQ is below 50. The IQ system is not however indispensable and the doctor should do a global evaluation of retardation.

III - 7 - Paraclinical examinations

is relatively complex and optional: it should not restrict the use of the questionnaire. This section has 5 parts: blood investigations, neuro-imaging techniques, electroencephalography, serologies and microbiology.

All paraclinical examinations that are possible to do, should be given a code as they may shed more light on the search of the etiology.

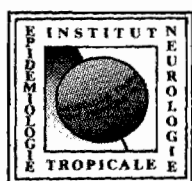
III - 8 - Etiology

This section searches the cause of the epilepsy and classify the seizure disorder in :

- Idiopathic (which corresponds to a classical syndrome, identified by an electrophysiological and clinical arguments, with often a strong genetic component),
- Symptomatic (of a previous disease, old lesions with no evolution; of an on-going disease),
- Cryptogenic (epilepsy which can not be classified as symptomatic or idiopathic and does not belong to the syndromes which have a strong genetic component).

III - 9 - Treatment

Classical or traditional medical treatment used by the patient is recorded. An evaluation of the efficacy of the treatment is carried out.



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des Sciences Neurologiques

Pan African Association
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DEMOGRAPHIC DATA

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D1) Can the subject answer for himself. (Yes = 1; No = 2)

D2) If not, who will ?

D3) Has a translator been necessary ? (Yes = 1; No = 2)

Personal Status of the subject:

D4) Surname (In capital letters):

D5) First Name:

D6) Address (Any information allowing to locate the subject):

D7) Town:

D8) Country:

D9) Age:

D10) Date of birth: (DD/MM/YYYY)

D11) Place of birth:

D12) Sex: (Male = 1; Female = 2)

D13) Marital status of the subject ?

(Married = 1; Living with a partner = 2; Living with parents = 3; Living alone = 4; Other = 5; Unknown = 9)

D14) How long has the subject been living in the study area ?

(Transiently = 1; For one year = 2; Between 1 and 5 years = 3; Between 5 and 10 years = 4; For more than 10 years = 5; Since birth = 6; Unknown = 9)

D15) Employment or trade ?

(Wage earner or civil servant = 1; Craftsman or tradesman = 2; Farmer = 3; Student = 4; Herdsman = 5; Works from home = 6; Unemployed = 7; Labourer = 8; Other = 9)

Date (DD/MM/YYYY) / /

Code

Name of investigator

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D16) If other, specify:

D17) Living area ?

(In an urban area = 1; In a rural area = 2; Unknown = 9)

D18) Sanitation ?

(In toilets situated in a house = 1; In latrines near the house = 2; In the countryside = 3; Unknown = 9)

(Optional answers):

D19) Ethnic group (specify):

D20) Religion ?

(Christian = 1; Muslim = 2; Animist = 3; Buddhism = 4; Hinduism = 5; Other = 6; Unknown = 9)

D21) If other, specify:

Date (DD/MM/YYYY) / / : : : : :
Name of investigator

Code

SCREENING

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For the questions: S1 to S5 (Yes = 1; No = 2; Unknown = 9)

Does the subject have a history of:

- S1) Loss of consciousness and / or loss of bladder control and / or foam at the mouth ?
- S2) Absence(s) or sudden lapse(s) of consciousness during a short time ?
- S3) Involuntary clonic movements or muscular jerks of arm(s) and / or leg(s) (convulsions) that start suddenly and stop within minutes ?
- S4) Does the subject sometimes experience sudden and brief bodily sensations, see or hear things that are not there, or smell strange odours ?
- S5) Did someone tell the subject that he / she had epilepsy or that he / she already had epileptic fits ?
- S6) To conclude, should the subject be examined by the medical team ?
(Yes = 1; No = 2)

If at least one answer is yes, the subject must
be examined by the medical team

Date (DD/MM/YYYY) / / : : : : :
Name of investigator

Code

EPILEPSY CONFIRMATION

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EC1) Description of the attack(s) (symptoms), which could be an epileptic seizure:

.....
.....
.....
.....
.....

EC2) Could the attack(s) be related to a particular situation or a medical condition * ?
(Yes = 1; No = 2; Unknown = 9)

EC3) If yes, specify:

EC4) Was at least one of these attacks an epileptic seizure ?
(Yes = 1; No = 2; Unknown = 9)

EC5) If not, what was the probable diagnosis ?

EC6) If yes, has only one epileptic seizure occurred ?
(Yes = 1; No = 2)

* Examples of particular situations or medical conditions:

Febrile convulsions; seizures occurring only during a metabolic or a toxic condition;
caused by alcohol; anti-malaria drugs; eclampsia ...

Date (DD/MM/YYYY) _____
 Name of investigator

Code

NATURAL HISTORY OF THE SEIZURE DISORDER

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- N1) Has the subject had any seizure in the last 5 years ?
 (Yes = 1; No = 2; Unknown = 9) /___/
- N2) Age at the first seizure ?
 (During the first 10 days of life = 1; Between 10 days and 6 months = 2;
 Between 6 months and 2 years = 3; Between 2 years and 6 years = 4;
 Between 6 years and 12 years = 5; Between 12 years and 20 years = 6;
 Between 20 years and 40 years = 7; Over 40 years = 8; unknown = 9) /___/
- For the questions N3 to N14: (Yes = 1; No = 2; Unknown = 9)**
- Does the subject have a history of:**
- N3) Generalized tonic and clonic seizures ? /___/
- N4) Generalized myoclonic seizures ? /___/
- N5) Generalized atonic seizures ? /___/
- N6) Absences ? /___/
- N7) Other generalized seizures ? /___/
- N8) If yes, specify : /___/
- N9) Simple partial seizures ? /___/
- N10) Complex partial seizures ? /___/
- N11) Partial seizures with a secondary generalization ? /___/
- N12) Another type of seizure (difficult to classify) ? /___/
- N13) Status epilepticus ? /___/
- N14) Several types of seizures ? /___/

5

Date (DD/MM/YYYY) _____
 Name of investigator

Code

If several types of seizures: (questions N15 to N17)

(Generalized tonic or clonic seizures = 1; Generalized myoclonic seizures = 2;
 Generalized atonic seizures = 3; Absences = 4; Simple partial seizures = 5;
 Complex partial seizures = 6; Seizures with a secondary generalization = 7; Other = 9)

- N15) Type of the first seizure ? /___/
- N16) Type of the most recent seizures ? /___/
- N17) Type of the most frequent seizures ? /___/
- N18) Age at the beginning of the second type of seizures ?
 (During the first 10 days of life = 1; Between 10 days and 6 months = 2;
 Between 6 months and 2 years = 3; Between 2 years and 6 years = 4;
 Between 6 years and 12 years = 5; Between 12 years and 20 years = 6;
 Between 20 years and 40 years = 7; Over 40 years = 8; unknown = 9) /___/

Precipitating Factors: (Yes = 1; No = 2; Unknown = 9)

- N19) Emotion ? /___/
- N20) Alcohol ? /___/
- N21) Sleep ? /___/
- N22) Lack of sleep ? /___/
- N23) Flashing lights (sun on water or through foliage, television screen or disco) ? /___/
- N24) Hyperventilation ? /___/
- N25) Menstruation ? /___/
- N26) Stopping the anti-epileptic drugs ? /___/
- N27) Other drugs or toxic agents ? /___/
- N28) If yes, specify : /___/
- N29) Do the seizures occur within one hour of awakening ? /___/
- N30) If one or several other precipitating factor(s) exist(s), specify:
 /___/

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Date (DD/MM/YYYY) / /

Code

Name of investigator

PAST MEDICAL HISTORY

What is the subject's order among his siblings ?

P2) Does the patient have a twin brother or a twin sister ?

P3) Consanguinity between parents ?

P4) If yes, specify:

P5) Does the patient have a family history of epilepsy (parents, grandparents, brothers, sisters, children, uncles, aunts, cousins) ?

P6) If yes, specify the family member(s):

P7) Family history of other neurological disorders ?

P8) If yes, specify the disorder(s) and the member(s) affected:

P9) Was the pregnancy of the subject's mother normal ?

P10) If not, specify:

P11) Did the subject's mother take any drug(s) during her pregnancy ?

P12) If yes, specify what drug(s):

Delivery (birth of the subject):

P13) Place of birth of the subject ?

For the questions P14 to P17: (Yes = 1; No = 2; Unknown = 9)

P14) Was it long and / or difficult ?

P15) Was it done under epidural or general anesthesia ?

P16) Was it done by caesarean section ?

P17) Were forceps, suction or other mechanical methods used ?

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Date (DD/MM/YYYY) / /

Code

Name of investigator

Birth:

For the questions P18 to P19: (Yes = 1; No = 2; Unknown = 9)

P18) Was the subject a premature delivery ?

P19) Did the subject cry immediately after birth ?

P20) Birth weight ? (in grams)

Feeding:

P21) What was the method of feeding used when the subject was a baby ?

Psychomotor development in childhood:

P22) Was psychomotor development in childhood ?

P23) If abnormal, specify:

Past medical history:

For the questions P24, 25, 27, 30, 32, 35, 36, 39, 42, 44.

P24) Severe measles ?

P25) Encephalitis or encephalopathy ?

P26) If yes, specify:

P27) Meningitis ?

P28) If yes, specify:

P29) If other important disease(s), specify:

P30) Is the subject currently in hospital for one or several other causes ?

P31) If yes, specify:

P32) Head injury with a loss of consciousness before the onset of seizures ?

P33) If yes, specify the type of the trauma:

P34) If yes, how long was it between the trauma and the onset of seizures ?

Date (DD/MM/YYYY) / /
Name of investigator

Code

P35) Prolonged post-traumatic coma ?

P36) Did his epilepsy start after another illness ?

P37) If yes, specify:

P38) If yes, how long after this illness ?

(Less than 2 years = 1; More than 2 years = 2; Unknown = 9)

P39) Does the patient have neurological sequelae of some disease(s) ?

P40) If yes, what sequelae:

P41) If yes, what disease(s):

Intoxication:

P42) Does the patient, or did he in the past, consume alcohol excessively ?

P43) If yes, specify the duration (in years):

P44) Does the patient abuse drugs ?

P45) If yes, specify the type of drug:

P46) If yes, specify the mode of administration:

Repeated contact with the following animals:

(Yes = 1; No = 2; Unknown = 9)

P47) Dogs or cats ?

P48) Pigs ?

P49) If other, specify:

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Date (DD/MM/YYYY) / /
Name of investigator

Code

CLINICAL EXAMINATION

CE1) Besides seizures, did the patient experience other health problem(s) ?
(Yes = 1; No = 2; Unknown = 9)

CE2) If yes, specify:

General examination:

CE3) What is the general state of health of the subject ?
(Good = 1; Average = 2; Poor = 3; Unknown = 9)

CE4) Weight (in kilograms) ?

CE5) Height (in centimeters) ?

Neurological examination:

(Yes = 1; No = 2; Unknown = 9)

CE6) Normal neurological exam ?

CE7) If the neurological exam is **abnormal**, what is the exact diagnosis:

CE8) Does the patient have mental retardation ?
(Yes = 1; No = 2; Unknown = 9)

CE9) If yes, is this mental retardation ?
(Slight = 1; Moderate = 2; Severe = 3; Unknown = 9)

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Date (DD/MM/YYYY) / /

Code

Name of investigator

Examination of other systems:

For the questions: CE10 à CE18

(Normal = 1; Abnormal = 2; Not done = 3; Unknown = 9)

CE10) Cardiovascular ?

CE11) Respiratory ?

CE12) Digestive ?

CE13) Endocrine ?

CE14) Genital ?

CE15) Urinary ?

CE16) Ear, nose and throat ?

CE17) Ophthalmological ?

CE18) Dermatological (including burns) ?

CE19) If abnormal exam. specify:

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Date (DD/MM/YYYY) / /

Code

Name of investigator

PARACLINICAL INVESTIGATIONS

Blood investigations: (Normal = 1; Abnormal = 2; Not done = 3; Unknown = 9)

PI1) Full blood count / /
PI2) If abnormal, specify:

EI3) Erythrocyte sedimentation rate / /

PI4) If abnormal, specify:

PI5) Urea / /

PI6) If abnormal, specify:

PI7) Creatinine / /

PI8) If abnormal, specify:

PI9) Fasting blood glucose / /

PI10) If abnormal, specify:

PI11) Hemoglobin electrophoresis / /

PI12) If abnormal, specify:

PI13) If other blood investigations were done, specify which:

PI14) If other blood investigations were done, specify their results:

Neuro-imaging techniques: (Normal = 1; Abnormal = 2; Not done = 3; Unknown = 9)

PI15) Skull X-rays ? / /

PI16) Brain computerized tomography scan ? / /

PI17) Magnetic Resonance Imaging ? / /

PI18) If something was abnormal, specify the localization and the type of the abnormality:

PI19) If other radiological exams were done, specify which:

PI20) If other radiological exams were done, specify their results:

Date (DD/MM/YYYY) _____
 Name of investigator

Code

Electroencephalography (EEG):

PI21) Was an electroencephalogram done ?
 (Done = 1; Not done = 2; Unknown = 9)

PI22) Was the EEG done ?
 (During a seizure = 1; Between seizures = 2; Unknown = 9)

PI23) Was one of these EEGs results abnormal ?
 (Yes = 1; No = 2; Unknown = 9)

If at least one EEG was abnormal, describe the most significant:
 (Yes = 1; No = 2; Unknown = 9)

PI24) Spikes and wave discharges ?

PI25) Generalized 3 per second (or more) spike and wave discharges ?

PI26) Photosensitivity ?

PI27) Focal spikes ?

PI28) Focal slow waves ?

PI29) Generalized spikes and polyspikes ?

PI30) Generalized slow waves ?

PI31) Generalized slowing of background ?

PI32) If something else was abnormal on the EEG, specify what:

PI33) If something else was abnormal on the EEG, specify where:

PI34) Is there a correlation between clinical symptoms and EEG ?

PI35) Specify the most pertinent EEG features that may determine the nature of the epilepsy ?

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Date (DD/MM/YYYY) _____
 Name of investigator

Code

Serology:

1st brackets (Normal = 1; Abnormal = 2; Not done = 3; Unknown = 9)
 2nd brackets (Serum = S; Cerebrospinal fluid = L; Both = B)

PI36) HIV ? 1 : 2 :

PI37) Syphilis ? 1 : 2 :

PI38) Toxoplasmosis ? 1 : 2 :

PI39) Cysticercosis ? 1 : 2 :

PI40) Shistosomiasis ? 1 : 2 :

PI41) If other serologies were done, specify which:

PI42) If other serologies were done, specify their results:

Microbiology:
 (bacteria, viruses, parasites)

PI43) Were microbiological samples taken ?
 (Yes = 1; No = 2; Unknown = 9)

PI44) If yes, specify:

PI45) If abnormal results, specify:

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Date (DD/MM/YYYY) / /
Name of investigator

Code

ETIOLOGY

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E1) Is the cause of epilepsy ?
(Definite = 1; Suspected = 2; Impossible to say = 9)

E2) If the cause of epilepsy is definite or suspected, can you classify
this seizure disorder (epilepsy) ?

Idiopathic (which corresponds to a classical syndrome, identified by electro-clinical
arguments, with often a strong genetic component) = 1

Symptomatic (of a past disease ; old lesions with no evolution) = 2

Symptomatic (of an on-going disease) = 3

Cryptogenic (epilepsy which can not be classified as symptomatic or idiopathic and
does not belong to the syndromes which have a strong genetic component) = 4

E3) If symptomatic epilepsy, specify:

E4) Give the conclusion of the probable etiology of this epilepsy:

Date (DD/MM/YYYY) / /
Name of investigator

Code

TREATMENT

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T1) What is or was the type of anti-epileptic treatment taken by the patient ?
(Traditional = 1; Drugs = 2; Both (1 and 2) = 3; Traditional then drugs (1 then 2) = 4;
Drugs then traditional (2 then 1) = 5; None = 6; Unknown = 9)

T2) If the answer to the question 1 is 4 or 5, specify the interval between the two types of
treatment (in months):

If traditional treatment:

T3) Who prescribed the anti-epileptic treatment ?
(Prescription by the subject or his family = 1; Sorcerer = 2; Traditional healer = 3;
Others = 4; Unknown = 9)

T4) What is or was the nature of the products used ?
(Herbal = 1; Animal = 2; Mineral = 3; Mixed = 4; No product used = 5; Unknown = 9)

T5) What is or was the mode of administration ?
(Oral = 1; Percutaneous = 2; Scarifications = 3; Amulets = 4; Inhalations = 5; Baths = 6;
Prayers or Incantations = 7; Others = 8; Unknown = 9)

T6) Is or was the treatment taken regularly ?
(Yes = 1; No = 2; Unknown = 9)

T7) If not, why ?
(Personal reasons = 1; Drugs not always available = 2; No money to buy drugs = 3;
Others = 4; Unknown = 9)

T8) If other, specify:

T9) Treatment efficacy (subject's view) ?
(Good = 1; Moderate = 2; Bad = 3; None = 4; Unknown = 9)

T10) Treatment efficacy (family's view) ?
(Good = 1; Moderate = 2; Bad = 3; None = 4; Unknown = 9)

T11) Treatment efficacy (Physician's view) ?
(Good = 1; Moderate = 2; Bad = 3; None = 4; Unknown = 9)

Date (DD/MM/YYYY) / / Name of investigator

Date (DD/MM/YYYY) / / Name of investigator

Code

Code

INVESTIGATOR COMMENTS

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If drug treatment:

For the questions: T12 à T21 (Yes = 1; No = 2; Unknown = 9)

- T12) Barbiturates ?
- T13) Diazepines ?
- T14) Phenytoin ?
- T15) Carbamazepine ?
- T16) Ethosuximide ?
- T17) Valproate ?
- T18) Vigabatrin ?
- T19) Gabapentin ?
- T20) Lamotrigine ?
- T21) Felbamate ?
- T22) Other, specify:
- T23) Is or was the treatment taken regularly ?
(Yes = 1; No = 2; Unknown = 9)
- T24) If not, why ?
(Personal reasons = 1; Drugs not always available = 2; No money to buy drugs = 3; Others = 4; Unknown = 9)
- T25) If other, specify:
- T26) Treatment efficacy (subject's view) ?
(Good = 1; Moderate = 2; Bad = 3; None = 4; Unknown = 9)
- T27) Treatment efficacy (family's view) ?
(Good = 1; Moderate = 2; Bad = 3; None = 4; Unknown = 9)
- T28) Treatment efficacy (Physician's view) ?
(Good = 1; Moderate = 2; Bad = 3; None = 4; Unknown = 9)
- T29) Any symptoms experienced since starting anticonvulsant drug treatment ?
(Not any = 1; Lethargy, drowsiness, somnolence = 2; Ataxia, gait difficulty = 3; Gait hypertrophy = 4; Learning difficulties = 5; Hyperactivity = 6; Skin rash = 7; Others = 8; Unknown = 9)
- T30) Serum anti-epileptic drugs levels ?
(Done = 1; Not done = 2; Unknown = 9)
- T31) If done, specify: