2012 Village Health Team (VHT) nodding syndrome case report form

Date: ………………………District: …………………………….. Sub-county: ……………………..
Parish: ………………………… Village: ……………………………………….
Name of LCI Chair: ……………………………………… Phone: …………………………..

Name of Household head: …………………………………………………
Phone number of Household head: ……………………………….  

Use one form per household. Start by listing the nodding syndrome and/ or epilepsy cases that are alive. Then inquire and list all household members who had either nodding syndrome and/ or epilepsy but are dead.
2017 survey: Household level questionnaire

NOTE: This questionnaire will be administered in a digitalized form on a tablet computer that will be used as a data collection tool during this survey. Within each household, all participants will be asked all the questions in sections 1.2 and 1.3 during one single interview sequence.

DATE: _____ / _____ / ________

FULL NAME OF INTERVIEWER: _______________________________________________

DISTRICT: ________________________________________________________________

PARISH: _________________________________________________________________

VILLAGE: ________________________________________________________________

1.1. HOUSEHOLD CHARACTERISTICS

UNIQUE HOUSEHOLD CODE: XX /XX /XX/XXXX (First 2 letters of: District/Parish/Village, followed by number (e.g.0001))

GPS coordinates of household:
LATITUDE __ __. __ __ __ __ __ LONGITUDE __ __. __ __ __ __ __ ALTITUDE __ __ __ __

Full name of household head:
_______________________________________________

Mobile phone number of household head:
_______________________________________________

Ethnic group of household head:
_______________________________________________

Total number of people in the household:
_______________________________________________

Livelihood generating activities of the family:
☐ Farmer ☐ Livestock ☐
☐ Fisherman ☐
☐ Business / trader ☐ Craftsman ☐
☐ Civil service ☐
☐ other, ☐

specify:____________________________

Has there been a family member that died from any form of epilepsy or nodding syndrome, lili or luc luc?
☐ YES ☐ NO ☐ DON’T KNOW
IF YES: When (year) ________ At what age: ________ years
IF MORE THAN ONE: When (year) ________ At what age: _____ years
When (year) ________ At what age: _____ years

Did the family or any family member(s) participate in the 2012 and / or 2013 survey on NS?
☐YES ☐NO ☐DON’T KNOW

1.2. INDIVIDUAL INTERVIEW WITH EACH HOUSEHOLD MEMBER

Person ID: ____________________________________________

Full Name: ____________________________________________

Age: ___________________________ years
Birth date: __/__/____
Sex: ☐Male ☐Female

Is the person present during the interview visit? ☐YES ☐NO
Who is answering to the questions? ☐self ☐mother ☐household head ☐other, specify

1.3. SCREENING FOR EPILEPSY AND NODDING SYNDROME CASES

If at least one of the 8 questions is answered with YES, the electronic questionnaire will automatically report the person for invitation to participate in the neurological survey for case verification.

QUESTION A.
Is the participant / are you suffering from luc luc (nodding syndrome)?
☐YES ☐NO ☐DON’T KNOW

QUESTION B.
Is the participant / are you suffering from Lili (epilepsy)?
☐YES ☐NO ☐DON’T KNOW

QUESTION C.
Is the person known to suffer from both, luc luc (nodding syndrome) and Lili (epilepsy)?
☐YES ☐NO ☐DON’T KNOW
QUESTION 1.
Have you ever suddenly fallen to the ground and experienced:
   a) Loss of consciousness ☐YES ☐NO ☐DON’T KNOW
   b) Loss of bladder control? ☐YES ☐NO ☐DON’T KNOW
   c) Foam at the mouth? ☐YES ☐NO ☐DON’T KNOW

QUESTION 2.
Have you ever experienced absence(s) or sudden loss(es) of contact with the surroundings, for a short duration of time?
☐YES ☐NO ☐DON’T KNOW

QUESTION 3.
Have you ever experienced sudden, uncontrollable twitching or shaking of your arms, legs or head, for a period of a few minutes?
☐YES ☐NO ☐DON’T KNOW

QUESTION 4.
Do you sometimes experience sudden and brief bodily sensations, see or hear things that are not there, or smell strange odours?
☐YES ☐NO ☐DON’T KNOW

QUESTION 5.
Have you ever been told that you are suffering from epilepsy or have you already experienced at least one episode of seizures?
☐YES ☐NO ☐DON’T KNOW

1.3. IVERMECTIN USE
Did you take ivermectin during the last distribution in 2016? ☐YES ☐NO ☐DON’T KNOW

Signature of Interviewer__________________________
2017 survey: Individual Neurology questionnaire

DATE: _____ / _____ / ________

FULL NAME OF THE INTERVIEWER: _______________________________________________

PARTICIPANT IDENTIFICATION

Participant ID: _________________________________________________

Last name (in capital letters): _________________________________________________

First name: _________________________________________________

The medical doctor/neurologist will first assess whether the person referred to him has epilepsy (Nodding syndrome or another form of epilepsy)

Diagnosis of Nodding syndrome or another form of epilepsy is confirmed

☐ YES ☐ NO

If NO: other diagnosis?

☐ Recurrent febrile convulsions
☐ Dizziness / syncope
☐ Paroxysmal vertigo
☐ Severe anaemia
☐ Mental retardation without epilepsy
☐ Psychiatric illness without epilepsy
☐ Classic migraine
☐ Other, specify______________________

If YES the following neurology questionnaire will be administered in a digitalized form using tablet computers. By indicating the individual Participant ID on paper forms, the neurologist can provide additional important notes of the anamnesis on paper.

PARTICIPANT IDENTIFICATION

Participant ID :_______________________________________________

Last name (in capital letters): ___________________________

First name: _________________________________________________

Town / Village:_______________________________________________

District:_______________________________________________

Phone number:_______________________________________________

Sex: Male ☐ Female ☐

Age: _______________

Date of birth: ___/___/_______
Place of birth: ____________________________________________

Country of birth: ____________________________________________

Ethnic group: ______________________________________________

Marital status: ____________________________

Married □ Living with parents □ In partnership
Living alone □ Other, specify ____________________________

Is the participant answering himself / herself? □ YES □ NO
If NO, who is answering and what is the relationship between the participant and respondent?

Full name: ________________________________________________

Relation to participant: □ Mother □ Father □ Sibling □ Other, specify _________

DEMographic data

Since how long is the participant lives in the village? ________YEARS
IF less than 1 year: how many MONTHS? ___ ___

Was the interviewed participant living in the village in 2011-12?
□ Yes □ No □ DON’T KNOW

IF NO, in which village has the participant lived before?
Village: ____________________________
Area: ____________________________
Health zone: ____________________________

IF in a foreign country: in which country has the participant lived before? ____________________________

Are you currently attending school? □ YES □ NO

School grade level completed: □ None
□ Primary □ P1 □ P2 □ P3 □ P4 □ P5 □ P6 □ P7
□ Secondary □ S1 □ S2 □ S3 □ S4 □ S5 □ S6
□ Tertiary □ University □ Vocational / college / Institute

IF NO: At which level did you stop school attendance: ____________________________

Reason: □ Due to epileptic seizures while in school
□ Fear to leave the epileptic child unattended
□ Due to epilepsy related stigma
□ Due to epilepsy related learning difficulties
□ Other reasons (financial, other illness than epilepsy, accessibility,)
□ DON’T KNOW

ADULT participant:
Occupation / livelihood activity: □ Domestic worker □ Farmer □ Livestock
breeder □ Fisherman □ Civil servant □ Craftsman
☐ Student  ☐ Business / trader  ☐ none  ☐ other, specify: _______________________

CHILD Participants:
Livelihood activity of family:  ☐ Domestic worker  ☐ Farmer  ☐ Livestock breeder
☐ Fisherman  ☐ Civil servant  ☐ Craftsman  ☐ Student  ☐ Business / trader  ☐ None
☐ other, specify: _______________________

HISTORY OF EPILEPSY AND HEAD NODDING

Nodding History
Does the participant have a history of head nodding (repetitive involuntary drops of the head towards the chest on 2 or more occasions):  ☐ YES  ☐ NO
IF YES: Year of onset __________
IF YES: Was the diagnosis of nodding syndrome made by a doctor? ☐ YES  ☐ NO  ☐ DON’T KNOW
What is the mental status during the head nodding?
☐ Awake and still able to respond
☐ Awake but not responding
☐ Decreased consciousness, not responding
☐ Unconscious

How old (years) was the child when the head nodding started? __________ years

What triggers the head nodding? (Tick which ever applies)
☐ Spontaneous (no obvious trigger)
☐ Food  ☐ Cold weather
☐ Nothing  ☐ DON’T KNOW
☐ Other, specify _______________________

Has head nodding continued until today?  ☐ Yes  ☐ No
IF YES:
What was the frequency of head nodding attacks in the last three months: (Tick highest appropriate frequency):
☐ less than 1 episode per week
☐ 1 or more episodes per week
☐ At least 1 episode per day
(Approximate number: _______/day)

Is the participant currently on treatment for nodding syndrome?  ☐ Yes  ☐ No
IF YES: specify treatment: _______________________
If yes, where does the participant go for treatment?
☐ Designated treatment center (Name______________)
☐ NS outreach post
☐ Other, specify _______________________

IF the nodding stopped:
At what age the nodding stopped? __________ Years

If the nodding stopped: does the patient now presents another form of epilepsy?
☐ YES  ☐ NO
If YES: complete the following questions
Other forms of seizures
Has the participant had a seizure in the last 5 years?
- [ ] YES
- [ ] NO
- [ ] DON’T KNOW

What is the number of seizures since onset?
- [ ] One attack
- [ ] Two or more seizures

If only two seizures, were they more than 24h apart?
- [ ] YES
- [ ] NO
- [ ] DON’T KNOW

Aura / sensation (hearing, seeing, tasting, smelling, feeling) before seizures:
- [ ] YES
- [ ] NO
- [ ] DON’T KNOW

Episodes of loss of consciousness
- [ ] YES
- [ ] NO
- [ ] DON’T KNOW

Seizures with passing urine or stool on self and/or foaming at the mouth
- [ ] YES
- [ ] NO
- [ ] DON’T KNOW

Has the participant had a seizure within the last 12 months?
- [ ] YES
- [ ] NO
- [ ] DON’T KNOW

IF YES, in which month has the last seizure been experienced?
- MONTH: __ __
- [ ] DON’T KNOW

What is the current frequency of the seizures?
- [ ] Yearly (if less than 1 per month)
- [ ] Monthly (if less than 4 per month)
- [ ] Weekly (if less than 7 per week)
- [ ] Daily (if more than 7 per week)

Specify number: ____________per ____________

How many seizures did you have LAST WEEK?
- Number __
- [ ] None
- [ ] DON’T KNOW

Was the onset of seizures within the first year of life?
- [ ] YES
- [ ] NO
- [ ] DON’T KNOW

IF the onset of the seizures was within the first year of life:
- [ ] During the first 10 days of life
- [ ] More than 10 days to 6 month
- [ ] More than 6 month to 1 year

If the onset of seizures was after the age of one, at what age?
- ___ years
- [ ] DON’T KNOW

Of what type are the most frequent seizures?
- [ ] Generalized seizures with loss of consciousness
Atonic seizures (drop attacks) □ Absences □ Simple partial (focal) seizures (consciousness not lost) □ Complex partial (focal) seizures (decreased consciousness) □ Secondarily generalized partial seizures □ Others, specify: _____________________________

MEDICAL HISTORY

Family history of nodding disease □ YES □ NO □ DON’T KNOW
IF YES: Number of affected siblings with nodding syndrome ______

Family history of seizures □ YES □ NO □ DON’T KNOW
IF YES, specify who these are (tick all that apply)
□ Siblings (brother/sister); No. of affected siblings ______
□ Father □ Mother □ Grandparent(s)

Family history of mental illness □ YES □ NO □ DON’T KNOW

Questions for the mother of the participant
Did the pregnancy of the mother of the participant proceed normally?
□ YES □ NO □ DON’T KNOW
If NO, specify: __________________________________________

Mode of delivery for the affected child:
□ Spontaneous Vaginal Delivery □ Assisted Vaginal Delivery □ Caesarean section

Was the interviewed participant born at term (pregnancy had completed 9 months)?
□ YES □ NO □ DON’T KNOW

Did the interviewed participant cry immediately?
□ YES □ NO □ DON’T KNOW

What was the birth weight? ___________________________GRAMS □ DON’T KNOW

Psychomotor Development during Childhood:

Prior to onset of seizures

Was the child growing normally prior to the onset of the seizures?
□ Yes □ No □ DON’T KNOW
IF NO, at what age did the abnormal growing appear? ______ Years

Did the child learn to do things like other children of his/her age prior to the onset of the seizures?
□ Yes □ No □ DON’T KNOW
IF NO, at what age did the learning difficulty start? ______ Year
Compared with other children of his/her age, did the child appear in any way mentally backward, dull or slow before the onset of the seizures?  
☐ Yes  ☐ No  ☐ DON’T KNOW
IF YES, at what age did it start? ______ Years

**Since the onset of seizures,**

Compared with other children of his/her age, did the child learned to do things like other children?

☐ Normal  ☐ Delayed  ☐ Abnormal
☐ Others, specify: ________________________________

Compared with other children of his/her age, did the child appeared in any way mentally backward, dull or slow?

☐ Normal  ☐ Delayed  ☐ Abnormal
☐ Others, specify: ________________________________

**Occurrence of severe disease in the past:**

Has the interviewed participant suffered from severe measles before the onset of epileptic seizures?  
☐ YES  ☐ NO  ☐ DON’T KNOW

Has the interviewed participant suffered from a severe form of malaria before the onset of epileptic seizures?  
☐ YES  ☐ NO  ☐ DON’T KNOW

Has the interviewed participant suffered from encephalitis/meningitis before the onset of epileptic seizures?  
☐ YES  ☐ NO  ☐ DON’T KNOW

Has the participant had a head injury with loss of consciousness before the onset of epileptic seizures?  
☐ YES  ☐ NO  ☐ DON’T KNOW

Has the participant had a prolonged post-traumatic coma before the onset of epileptic seizures?  
☐ YES  ☐ NO  ☐ DON’T KNOW

Has the patient presented febrile convulsions in the past?  ☐ YES  ☐ NO  ☐ DON’T KNOW

Was the onset of epilepsy following another illness?  
☐ YES  ☐ NO  ☐ DON’T KNOW

If YES, specify the illness:

______________________________________________________________

Has the participant a history of excessive alcohol consumption?  
☐ YES  ☐ NO  ☐ DON’T KNOW  ☐ Not applicable*
Has the participant a history of drugs abuse?  
☐ YES  ☐ NO  ☐ DON'T KNOW  ☐ Not applicable*

**GENERAL EXAMINATION**

**BODY WEIGHT** (kg):  
_________. ____kg

**HEIGHT** (cm):  
________________cm

How is the general condition of the interviewed participant?  
☐ GOOD  ☐ CORRECT  ☐ POOR

Thoracic abnormalities  
☐ YES  ☐ NO

If yes specify ________________________________________

Facial abnormalities  
☐ YES  ☐ NO

If yes specify ________________________________________

Does the adolescent (≥ 16 years old)/adult looks like a child?  
☐ YES  ☐ NO

If yes, external signs of sexual development conform to age:  
☐ YES  ☐ NO  ☐ EXAMINATION DECLINED

If NO, specify:  
- girls: ☐ breast not developed
- girls and boys: ☐ no pubic hear

**Ophthalmology**  
☐ NORMAL  ☐ ABNORMAL VISION  
☐ BLIND, BOTH EYES AFFECTED

**Dermatology**  
☐ NORMAL  ☐ ABNORMAL

Burn scars  
☐ YES  ☐ NO

Itching  
☐ YES  ☐ NO

Papular eruption  
☐ YES  ☐ NO

Depigmented lesions (leopard skin)  
☐ YES  ☐ NO

Suspected onchocerciasis nodules  
☐ YES  ☐ NO

**NEUROLOGICAL EXAMINATION**

Is the participant alert?  
☐ YES  ☐ NO

Fully oriented in place/time/person  
☐ YES  ☐ NO

Is the participant’s cognitive development comparable with peers?  
☐ YES  ☐ NO
Normal vision: YES  NO

Normal hearing: YES  NO

Normal eye movements? YES  NO

Generalised muscle wasting: YES  NO

Paresis: YES  NO
if YES specify__________________________________________

Contractures: YES  NO

Is the participant walking normally? YES  NO
IF NO, specify
- Ataxic (wide base) gait
- Waddling gait (like a duck)
- Spastic gait – with tip toe walking
- Hemiplegic – with one sided weakness
- Other, specify__________________

Psychiatric symptoms

Does the participant have hallucinations, i.e. sees, hears, smells, feels or tastes things that don’t exist? YES  NO

Does the participant have delusions, i.e. strongly held false belief by participant despite superior evidence against belief? YES  NO

Does the participant show aggressive episodes? YES  NO

Have you felt very sad (irritable) for a period of more than two weeks? YES  NO

Have you experienced loss of interest and pleasure in almost all activities for a period of more than two weeks? YES  NO

In the past month, have you been having strong memories / dreams of something bad that happened to you or your loved one? YES  NO

Does the participant suffer from another neuro-psychiatric / psychological problem? YES  NO  DON’T KNOW

IF YES for any of the questions about psychiatric symptoms, refer to neuro-psychiatrist:

**Diagnosis neuro-psychiatrist** (using the Acholi translated version of the MINI, a diagnostic tool for psychiatric disorders)
Major Depression
Post-traumatic Stress Syndrome
Generalized Anxiety
Pervasive Development Disorder

**Physical / Functional Indices**

*Modified Rankin Scale: Please mark the most accurate description of the current functional state of the child, as observed during the evaluation*

<table>
<thead>
<tr>
<th>Score</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>No symptoms at all</td>
</tr>
<tr>
<td>1</td>
<td>No significant disability despite symptoms; able to carry out all usual duties and activities</td>
</tr>
<tr>
<td>2</td>
<td>Slight disability; unable to carry out all previous activities, but able to look after own affairs without assistance</td>
</tr>
<tr>
<td>3</td>
<td>Moderate disability; requiring some help, but able to walk without assistance</td>
</tr>
<tr>
<td>4</td>
<td>Moderately severe disability; unable to walk without assistance and unable to attend to own bodily needs without assistance</td>
</tr>
<tr>
<td>5</td>
<td>Severe disability; bedridden, incontinent and requiring constant nursing care and attention</td>
</tr>
<tr>
<td>6</td>
<td>Dead</td>
</tr>
</tbody>
</table>

**SCORE (0-6): ________**

**CASE CLASSIFICATION**
- Head Nodding Syndrome
- Head Nodding Syndrome plus
- Other form of Epilepsy
- Other diagnosis

If other diagnosis:
- Recurrent febrile convulsions
- Dizziness / syncope
- Paroxysmal vertigo
- Severe anaemia
- Mental retardation without epilepsy
- Psychiatric illness without epilepsy
- Classic migraine
- Other, specify________

**TREATMENT**
What is or was the type of seizure medication taken by the participant?

- [ ] No treatment
- [ ] Traditional
- [ ] Anti-epileptic drug
- [ ] Mixed

If anti-epileptic drug treatment: Which substance is taken by the participant (additionally you may check patient’s treatment record)?

- [ ] Phenytoin
- [ ] Sodium valproate
- [ ] Phenobarbital
- [ ] Carbamazepin
- [ ] Diazepam
- [ ] Ethosuximide
- [ ] Other anti-epileptic treatment

If YES, specify: _____________________________________________

Compliance: Is the participant taking the anti-epileptic drug treatment regularly?

- [ ] YES
- [ ] NO

If NO, why?

- [ ] Side effects
- [ ] (Temporary) non-availability of medication
- [ ] Lack of financial means to access medication
- [ ] DON’T KNOW
- [ ] Other, specify ________________________________

If the person took anti-epileptic treatment what was the response to the treatment?

- [ ] No effect on the seizures
- [ ] Decrease of the frequency of seizures when the drug was taken
- [ ] No more seizures since drugs were taken
- [ ] DON’T KNOW

IVERMECTIN USE

Has the participant ever received ivermectin?  

- [ ] YES
- [ ] NO  
- [ ] DON’T KNOW

Not applicable (according to exclusion criteria, as follows):
1) age <5 years at the moment of CDTi; 2) pregnancy; 3) Breast feeding < 7 days; 4) acute severe disease:

- [ ] 1
- [ ] 2
- [ ] 3
- [ ] 4

IF YES: Has the participant taken ivermectin during the last CDTi in 2016?

- [ ] YES
- [ ] NO
- [ ] DON’T KNOW

How many times per year?

- [ ] How many times per year?
- [ ] TWICE
- [ ] DON’T KNOW

IF NOT taken in 2016, why?

- [ ] No distribution
- [ ] Absent during the CDTi
- [ ] Refused

- [ ] Afraid of secondary effects
- [ ] Pregnancy
- [ ] Breastfeeding an infant younger than 7 days
- [ ] Because I was asked to NOT take it
- [ ] Age <5 years at the time of CDTi
☐ severe acute disease at the time of CDTi
☐ other, specify _______________________________

IF TAKEN in 2016, why?
☐ It is recommended to be taken to prevent river blindness
☐ to decrease itching
☐ other, specify _______________________________

Was Ivermectin/Mectizan distributed in another way than orally?
☐ YES ☐ NO ☐ DON’T KNOW

Picture or video taken: ☐ YES ☐ NO

Action Taken by reporting officer: referred for treatment ☐ YES ☐ NO

If yes, where ______________________

Signature of the interviewer ________________________________