Patient Survey

Directions: Survey will be administered by a Bhutan trained evaluator and questions will be read to the patient in the patient's preferred language. The evaluator administering the survey will write in the response.

Patient #: _____ **Participated previously?** Yes No If yes, previous participant ID: _____

Name of participant:_____

If proxy respondent is required, name and relationship to patient:

Date of Evaluation: _____/_____/_____ (day/month/year) **Name of Evaluator: _____**

Village: _____ **Gewog: _____**

District: _____ **Tel/mobile: _____**

Date of birth: _____/_____/_____ (day/month/year) **Age (years): _____**

Gender (circle one): Male Female

Highest education level completed (circle one):
no school primary school secondary school high school college

Religion of child/family (circle all that apply):
Buddhist Hindu Muslim Christian Other [specify]: _____

Current Occupation: _____ □ Not working

How old were you when you had your first seizure (years)?: _____

Have you been diagnosed with epilepsy? Yes No

- **If yes, how old were you when diagnosed (years): _____**
- **If yes, who diagnosed you? (circle all that apply)**

medical doctor (western/modern) traditional healer both other: _____

How would you characterize your seizures? (Check all that apply)

□ loss of consciousness
□ falling to ground with stiffening and shaking of body
□ falling to ground, no shaking
□ uncontrollable shaking of one part of the body
□ staring spells
□ unusual behavior or acting strangely
□ unusual sensory events (vision hearing touch smell taste)
□ other: _____

Describe your seizures:

How many seizures have you had in your lifetime?: _____

How many seizures have you had in the past month?: _____

How many seizures have you had in the past year?: _____

What was the date of your last seizure?: _____

What was the date of your second last seizure?: _____

When was your last seizure? (check one)

□ within the last week □ within the last month
□ within the last year □ longer than one year ago

Do any of the following trigger your seizures? (check all that apply)

□ infections or fever □ lack of sleep □ flashing lights □ stress □ alcohol
□ forgetting to take medications □ other: _____

Seizure Treatment

Have you ever taken medication or had treatments for epilepsy? Yes No
If yes, please answer the following bulleted questions. If no, skip to below the bulleted questions.

- **When did you start medications for seizures?** (Age, in years): _____

- **Which medications or treatments? (check all that apply and complete questions)**

□ Phenobarbital Dose: _____ □ Currently taking □ Not anymore
□ Phenytoin Dose: _____ □ Currently taking □ Not anymore
□ Carbamazepine Dose: _____ □ Currently taking □ Not anymore
□ Sodium valproate Dose: _____ □ Currently taking □ Not anymore
□ Levetiracetam Dose: _____ □ Currently taking □ Not anymore
□ Clonazepam Dose: _____ □ Currently taking □ Not anymore

□ Clobazam Dose: _____ □ Currently taking □ Not anymore

□ Diazepam Dose: _____ □ Currently taking □ Not anymore

□ Herbal/traditional Dose: _____ □ Currently taking □ Not anymore

□ Special diet: _____ □ Current □ Not anymore

□ Other: _____ □ Current □ Not anymore

- **List any side effects you believe are due to your antiepileptic medications:**
  _____

  _____

Do you take your medications consistently? Yes No

If yes, how often do you miss doses of your medications?

□ Never/Rarely
□ Once in a while
□ Sometimes
□ Usually
□ All the time

Why do you not take your medications? (Check all that apply)

□ Forget to take it
□ Side effects of medications
□ Feel better not taking it
□ Symptoms are under control
□ Inconvenient to take medications

Family & Past Medical History

Does anyone else in the family (primary blood relatives i.e. parents/siblings/children) have seizures? Yes No

If yes, does *more than one* family member have seizures? Yes No

Have you ever had a head injury with loss of consciousness? Yes No

Have you ever suffered from a stroke? Yes No

Have you ever had an infection of the brain or nervous system, i.e. meningitis? Yes No

Have you ever been diagnosed with neurocysticercosis? Yes No

Do you drink alcohol? Yes No

If yes, much do you drink per week? _____

How much do you drink per day? _____

How many drinks do you have at one time? _____

Have you ever had a seizure after stopping drinking alcohol? Yes No

Do you chew doma (betel nut, quid, paan)? Yes No

If yes, how often do you chew?: _____

If yes, how much do you chew each time?: _____

Did you experience febrile seizures as a child? Yes No

Have you ever had a seizure that lasted longer than 5 minutes? Yes No

Do you struggle with your cognitive performance or have developmental delay?

Yes No

What other medical problems do you have? _____

_____

Are you on any other medications or medical treatments? _____

_____

Have you ever had any injuries related to seizures? (check all that apply)

□ Burns
□ Breaking bones/fractures or bone dislocation
□ Head injury
□ Car accidents
□ Other: _____

Please describe all injuries:

Do you drive a car/motorcycle/truck? Yes No

Have you ever had an MRI brain? Yes No

If yes, what did it show? _____

Have you ever had an EEG? Yes No

If yes, what did it show? _____

For women: have you ever been pregnant? Yes No

For women: have you ever had a seizure during pregnancy? Yes No

For women: did you take antiepileptic medications while you were pregnant? Yes No

If yes, which medications? _____

Social networks and depression

Over the last 2 weeks, how often have you been bothered by any of the following problems

Not at all Several days More than half of days Nearly every day

1.	Little interest or pleasure in doing things	0	1	2	3
2.	Feeling down, depressed, or hopeless	0	1	2	3
3.	Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4.	Feeling tired or having little energy	0	1	2	3
5.	Poor appetite or overeating	0	1	2	3
6.	Feeling bad about yourself or that you are a failure or have let yourself or your family down	0	1	2	3
7.	Trouble concentrating on things, such as reading the newspaper of watching television	0	1	2	3
8.	Moving or speaking so slowly that other people could have noticed. Or the opposite- being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9.	Thoughts that you would be better off dead or of hurting yourself in someway	0	1	2	3

If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

□ Not difficult at all □ Somewhat difficult □ Very difficult □ Extremely difficult

Marital status: Married Not married

How many *close friends* do you have, people that you feel at ease with, can talk to about private matters?

□ None
□ 1 or 2
□ 3 to 5
□ 6 to 9
□ 10 or more
□ Unknown

How many of these *close friends* do you see at least once a month?

□ None
□ 1 or 2
□ 3 to 5
□ 6 to 9
□ 10 or more
□ Unknown

How many *relatives* do you have, people that you feel at ease with, can talk to about private matters?

□ None
□ 1 or 2
□ 3 to 5
□ 6 to 9
□ 10 or more
□ Unknown

How many of these *relatives* do you see at least once a month?

□ None
□ 1 or 2
□ 3 to 5
□ 6 to 9
□ 10 or more
□ Unknown

Do you participate in any groups, such as a community center, social or work group, religious-connected group, self-help group, or charity, public service, or community group?

□ No
□ Yes
□ Unknown

About how often do you go to religious meetings or services

□ Never or almost never
□ Once or twice a year
□ Every few months
□ Once or twice a month
□ Once a week
□ More than once a week
□ Unknown

Is there someone available to you whom you can count on to listen to you when you need to talk?

□ None
□ 1 or 2
□ 3 to 5
□ 6 to 9
□ 10 or more
□ Unknown

Is there someone available to give you good advice about a problem?

□ None
□ 1 or 2
□ 3 to 5
□ 6 to 9
□ 10 or more
□ Unknown

Is there someone available to you who shows you love and affection?

□ None
□ 1 or 2
□ 3 to 5
□ 6 to 9
□ 10 or more
□ Unknown

Can you count on anyone to provide you with emotional support (talking over problems or helping you made a difficult decision)?

□ None
□ 1 or 2
□ 3 to 5
□ 6 to 9
□ 10 or more
□ Unknown

11. Do you have as much contact as you would like with someone you feel close to, someone in whom you can trust and confide?

□ None
□ 1 or 2
□ 3 to 5
□ 6 to 9
□ 10 or more
□ Unknown

Sleep Quality

How often during the past four weeks did you get enough sleep to feel rested upon waking up?

Never 1 2 3 4 5 **Very often**

If you have any comments, please write them here: _____

_____

_____

Thank you for completing the survey! If you have any questions about the survey, please ask the administrator, or other study personnel.

We may need to contact you to follow up or clarify your survey responses as we carry on with the study.

Version: 2, November 29, 2017

Parent of Patient Survey

Directions: Survey will be administered by a trained evaluator and questions will be read to the patient in the patient's preferred language. The evaluator administering the survey will written in the response. This survey is intended to be answered by the parents of patients who are too young to answer themselves. **All questions are in relation to the child.**

Patient #: _____ Participated previously? Yes No If yes, previous participant ID:_____

Date of Evaluation: _____/_____/_____ (day/month/year) **Name of Evaluator: _____**

Name of patient: _____

Parent Name: _____ Relation to patient: _____

Village: _____ Gewog: _____

District: _____ Tel/mobile: _____

Age (years): _____ Date of birth: _____/_____/_____ (day/month/year)

Gender (circle one): Male Female

Highest education level completed (circle one):
no school primary school secondary school

Religion of child/family (circle all that apply):
Buddhist Hindu Muslim Christian Other: _____

Occupation: _____

Was your child born preterm (early)? Yes No

Was your child born in a healthcare facility? Yes No

Was your child born as a twin? Yes No

Was your child delivered vaginally? Yes No

Was your child admitted to the ICU after birth? Yes No

Age at crawling (months): _____

Age at walking (months): _____

Age at first words (months): _____

How old was your child at the first seizure (years): _____

Was your child diagnosed with epilepsy? Yes No

- **If yes, how old was your child when diagnosed (years): _____**

- **If yes, who diagnosed your child with epilepsy? (circle all that apply)**

medical doctor (western/modern) traditional healer other: _____

Which of the following characterizes your child's seizures? (check all that apply)

□ loss of consciousness
□ falling to ground with stiffening and shaking of body
□ falling to ground, no shaking
□ uncontrollable shaking of one part of the body
□ staring spells
□ unusual behavior or acting strangely
□ communicating with spirits
□ unusual sensory events (vision hearing touch smell taste)
□ other: _____

How many seizures has your child had total: _____

How many seizures has your child had in the past month: _____

When was your child's last seizure? (check one)

□ within the last week □ within the last month
□ within the last year □ longer than one year ago

Do any of the following trigger your child's seizures? (check all that apply)

□ infections/fever □ lack of sleep □ flashing lights □ stress
□ forgetting to take medications □ other: _____

Seizure Treatment

Has your child has ever taken medication or had treatments for epilepsy? Yes No
If yes, please answer the following bulleted questions. If no, skip to below the bulleted questions.

- **When did your child start treatment for seizures?** (Age, in years): _____
- **Does your child take his or her medications regularly?** Yes No

  If no, explain: _____

- **Which medications or treatments? (check all that apply and complete questions)**

□ Phenobarbital Dose: _____ □ Currently taking □ Not anymore
□ Phenytoin Dose: _____ □ Currently taking □ Not anymore
□ Carbamazepine Dose: _____ □ Currently taking □ Not anymore
□ Sodium Valproate Dose: _____ □ Currently taking □ Not anymore
□ Levetiracetam Dose: _____ □ Currently taking □ Not anymore
□ Clonazepam Dose: _____ □ Currently taking □ Not anymore
□ Clobazam Dose: _____ □ Currently taking □ Not anymore
□ Diazepam Dose: _____ □ Currently taking □ Not anymore
□ Herbal/traditional Dose: _____ □ Currently taking □ Not anymore

□ Prayer or spiritual healer

□ Special diet: _____ □ Current □ Not anymore

□ Other: _____ □ Current □ Not anymore

- **List any side effects from medications: _____**

_____

Family & Past Medical History

Does anyone else in the family (blood relatives) have seizures? Yes No

If yes, does *more than one* family member have seizures? Yes No

Has your child ever had a head injury with loss of consciousness? Yes No

Has your child ever had a stroke? Yes No

Has your child ever had a brain infection? Yes No

Has your child ever been diagnosed with neurocysticercosis*?* Yes No

What other medical problems does your child have? _____

_____

Is your child on any other medications or treatments? _____

_____

Has your child ever had any injuries related to seizures? (check all that apply)

□ Burns
□ Breaking bones/fractures or bone dislocation
□ Head injury
□ Car accidents
□ Other: _____

Has your child ever had an MRI brain?

If yes, what did it show? _____

Has your child ever had an EEG?

If yes, what did it show? _____

Sleep Quality

How often during the past four weeks did your child get enough sleep to feel rested upon waking up? (If old enough to answer on their own)

Never 1 2 3 4 5 **Very often**

If you have any comments, please write them here: _____

Thank you for completing the survey! If you have any questions about the survey, please ask the administrator, or other study personnel.

Version 2: November 29, 2017