Patient-Reported Outcomes – Epilepsy (PRO-EPI) version 4.0

All green: No follow-up required as yet.
One or more responses yellow: The nurse reads the case notes and contacts the user if required.
One of more responses red: The doctor must be informed.

1. INTRODUCTION

1.1 Who responds to this questionnaire?
I respond myself
Someone responds for me/with me
Name and relation to the person who has responded for you/with you: *Free text field*

1.2 How are you now, compared to last time you responded to this questionnaire?
This is the first time I respond to the questionnaire
I think I am worse
I think there is no change
I think I am better

2. SEIZURES

2.1 Have you had any seizures since the last time you responded to this questionnaire?
Yes, No, I don't know
If yes, proceed to secondary questions a-c:

a) Have you had generalized tonic-clonic (GTC) seizures?
Yes, No, I don't know

b) Have you had seizures at night/during sleep?
Yes, No, I don't know

c) Have you had other types of seizures?
Yes, No, I don't know

2.2 What is your seizure situation like now, compared to last time you responded to this questionnaire?
Better, Unchanged, Worse, I don't know
If worse, proceed to secondary question:

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What could be the reason to the worsening? *Chose one or more alternatives*

Psychological stress
Irregular sleep pattern/lack of sleep
Irregular meals
To much screen time
Alcohol
Other drugs
I have had an intercurrent illness, f.ex. respiratory tract infection
I have reduced the antiseizure medication
I have forgotten to take the antiseizure medication
I am trying out a new type of antiseizure medication
Other: *Free text field*
I don't know

3. MEDICATION

3.1 Do you take any antiseizure medication?

Yes, **No**

If yes, proceed to secondary questions a-e:

a) What type of antiseizure medication do you use now? *Chose one or more alternatives and fill in the daily dose*

Brivaracetam (Briviact)	*Dose (mg) per day*
Cenobamat (Ontozry)	*Dose (mg) per day*
Eslikarbazepin (Zebinix)	*Dose (mg) per day*
Etosuksimid (Zarondan, Zarontin, Petnidan)	*Dose (mg) per day*
Fenytoin (Epinat)	*Dose (mg) per day*
Karbamazepin (Tegretol, Trimonil)	*Dose (mg) per day*
Klobazam (Frisium)	*Dose (mg) per day*
Klonazepam (Rivotril)	*Dose (mg) per day*
Lacosamid (Vimpat)	*Dose (mg) per day*
Lamotrigin (Lamictal)	*Dose (mg) per day*
Levetiracetam (Keppra)	*Dose (mg) per day*
Okskarbazepin (Trileptal)	*Dose (mg) per day*
Perampanel (Fycompa)	*Dose (mg) per day*
Topiramat (Topimax)	*Dose (mg) per day*
Valproat (Orfiril)	*Dose (mg) per day*
Zonisamid (Zonegran)	*Dose (mg) per day*
Other: *Free text field*	*Dose (mg) per day*

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b) Does your antiseizure medication cause you unpleasant side effects?
Yes, No, I don't know

c) Since the last time you responded to this questionnaire, how much have you been troubled by

Headache
Not at all, A little, A lot, To a very large degree

Dizziness
Not at all, A little, A lot, To a very large degree

Trembling hands
Not at all, A little, A lot, To a very large degree

Double vision or other visual disturbances
Not at all, A little, A lot, To a very large degree

Poor appetite and/or weight loss
Not at all, A little, A lot, To a very large degree

Weight gain
Not at all, A little, A lot, To a very large degree

Difficulty concentrating
Not at all, A little, A lot, To a very large degree

Feeling easily irritated or impatient
Not at all, A little, A lot, To a very large degree

Tiredness and/or reduced sleep quality
Not at all, A little, A lot, To a very large degree

Sadness
Not at all, A little, A lot, To a very large degree

d) Do you ever forget to take your antiseizure medication?
Daily, Weekly, Monthly, Rarely/never

e) Do you ever take a different dose of the antiseizure medicatin than what was recommended?
Daily, Weekly, Monthly, Rarely/never

3.2 Has there been any changes to your antiseizure medication since the last time you responded to this questionnaire?
Yes, No
If yes, proceed to secondary question:
What kind of changes have been made? *Free text field*

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3.3 Did you start any new type of medication (not because of epilepsy) since the last time you responded to this questionnaire?

Yes, No

If yes, proceed to secondary question:

What is the name of the medicine you have started and what dose do you take? *Free text field*

4. LIVING WITH EPILEPSY

4.1 How is your quality of life?

Very good, Good, Fairly good, Poor

4.2 Are your family members worried about your epilepsy?

Never, Rarely, Sometimes, Often, I don't know

4.3 Do you live with someone?

Yes, No

4.4 Do you have any challenges at school or at work that you think are connected to your epilepsy?

No, I do not work/go to school,Yes

If yes, proceed to secondary questions a-b:

a) I am increasingly absent from school or work.

Yes, No

b) I don't think school or work have much understanding of my illness and situation

Yes, No

4.5 Are or your partner expecting a baby?

Yes, No

4.6 Are you or your partner planning a pregnancy within the next 12 months?

Yes, No

4.7 Do you have a valid driver's licence?

Yes, No

4.8 During the last month, how much have you been troubled by

a. Being afraid of having a seizure

Not at all, A little, A lot, To a very large degree

b. General anxiety (not just anxiety about a new seizure)

Not at all, A little, A lot, To a very large degree

c. Difficulty getting up in the morning
Not at all, A little, A lot, To a very large degree

d. Poor memory
Not at all, A little, A lot, To a very large degree

4.9 During the last month, how much have you been troubled by suicidal thoughts?
Not at all, A little, A lot, To a very large degree
If a little, a lot, or to a very large degree, proceed to secondary question:
Do you get help or follow-up for these thoughts? Explain in the free text field.
Free text field

4.10 Do you use
Oral snuff **Yes, No** Tobacco/cigarettes **Yes, No** Alcohol **Yes, No**
Other intoxicants **Yes, No**
If yes to other intoxicants, proceed to secondary question:
What other types of intoxincants do you use? *Free text field*

4.11 Roughly how often do you drink alcohol per week? *Free text field*

4.12 Do you feel secure and well looked-after regarding your diagnosis?
Yes, No, I don't know

5. APPOINTMENT

5.1 Would you like contact with the outpatient clinic of neurology now?
No, I don't need to be contacted right now
Yes, I would like to be contacted
I don't know

5.2 Are you waiting for feedback on an examination you were referred to by the department of neurology?
No, Yes, I don't know

5. 3 Do you get follow-up for epilepsy with your general practitioner (GP)?
Yes, No
If yes, proceed to secondary question:
Where do you get follow-up for epilepsy? *Chose one or more alternatives*
General practitioner (GP)
General practitioner, but just to measure the blood concentration of antiseizure medication
A specialized epilepsy clinic
A different hospital
A private practitioner
Other: *Free text field*

5.4 If any more information is needed, would you prefer us to call:

You
I would prefer you to call a family member
Name/relation/telephone number: *Free text field*

Comments, if any: *Free text field*