

Appendix I. Structured survey about Patient-Reported Outcomes

1. Does your centre involve people with epilepsy and, when appropriate, family members/caregivers, in the decision-making process on the management of their condition?

- YES, always
- YES, often
- YES, sometimes
- NO, never

2. Does your centre inform people with epilepsy and, when appropriate, family members/caregivers, about the possibility and the importance of their involvement in the decision-making process?

- YES
- NO (Why? _____)

3. Does your centre involve people with epilepsy and, when appropriate family members, in the following clinical decision: *(Please, indicate YES / NO for each item)*

- Diagnostic exams (e.g., neuroimaging, genetic exams, EEG monitoring):
 YES NO
- Choice of the first antiseizure medication:
 YES NO
- Understanding of the risk of non-treatment / poor adherence to treatment:
 YES NO
- Addition of new drug/s:
 YES NO
- Changing doses of drug/s:
 YES NO
- Withdrawal of drug/s:
 YES NO
- Epilepsy surgery:
 YES NO
- Non-pharmacological treatment (e.g., VNS, ketogenic diet):
 YES NO
- Social aspects of epilepsy:
 YES NO

4. From a managerial/organisational standpoint does your centre assess patient satisfaction with their care path and treatment process?

- YES, always
- YES, often
- YES, sometimes
- NO, never (Why? _____)

5. How does your centre assess patient satisfaction with their care path and treatment process? *[Please, select all that apply]*

- We do with specific questionnaires
- We do by questioning during visits
- Another professional (e.g., a nurse) is responsible for it with specific questionnaires
- Another professional (e.g., a nurse) is responsible for it by questioning it
- We don't assess it (Why? _____)
- Other way (specify: _____)

If your centre assesses patient satisfaction, please specify the amount of time (minutes or hours) dedicated to each patient:

Please, specify the person in charge for the above-mentioned activity:

6. Does your centre evaluate outpatients with epilepsy for the following aspects? *[YES/NO for each item listed]*

- Impairment of vitality:
 - YES NO
- Emotional-behavioural control:
 - YES NO
- Subjective assessment of their well-being:
 - YES NO
- Assessment of emotional state in terms of limitations at work or for other activities:
 - YES NO
- Dysphoria together with nervous tension, anxiety, and depressed mood:
 - YES NO
- Denial of emotional problems with increased irritability in the interpersonal sphere:
 - YES NO
- Other (*specify*: _____)

7. What tools does your centre use to measure the Quality of Life of the people with epilepsy? *[Please, select all that apply]*

- Paper-based questionnaires

- Electronic questionnaires
- Face-to-face interviews
- Other (*specify:* _____)

8. Which recognised assessment scales does your centre use to identify the Patient Reported Outcomes (PRO) for psychopathological and emotional aspects of the disease? (Please, select all that apply)

- ESI-55 (Epilepsy Surgery Inventory)
- Liverpool QoL Battery
- NEWQOL (Newly Diagnosed Epilepsy Quality-of-Life)
- QOLIE-89 (Quality of Life in Epilepsy Inventory)
- QOLIE-31
- QOLIE-10
- QOLIE-AD-48
- IEQoL (Impact of the Epilepsy on the Quality of Life)
- Epi-QoL
- AEP (Adverse Event Profile)
- NDDI-E (Neurological Disorders Depression Inventory for Epilepsy)
- BDI (Beck Depression Inventory)
- GAD-7 (Generalized Anxiety Disorder)
- CGI-C (Clinical Global Impression – Clinical)
- PGI-C (Patient Global Impression – Clinical)
- STAI (State-Trait Anxiety Inventory)
- Other (*specify:* _____)

9. How frequently does your centre use recognised assessment scales to identify the PRO for psychopathological and emotional aspects of the disease?

- Always
- Often
- Sometimes
- Never (Why? _____)

10. When does your centre use recognised assessment scales to identify the PRO for psychopathological and emotional aspects of the disease? [Please, select all that apply]

- In profit studies (e.g., trials sponsored by pharmaceutical companies)
- In no-profit studies (e.g., academic/hospital observational studies, research projects at my centre)
- In routine clinical practice
- Other (*specify:* _____)

11. For what purposes does your centre use the PRO collected by the recognised assessment scales? [Please, select all that apply]

- To monitor therapy efficacy
- To monitor therapy tolerability/side effects
- To evaluate the impact of the treatment on the quality of life of the patient
- To evaluate the impact of the treatment on the quality of life of the caregiver
- To evaluate the impact of the treatment on the social domains of the patient (e.g., social functioning, productivity loss, work, school, etc.)
- To guide/inform decisions on the treatment (e.g., to add/discontinue a treatment)
- To provide more details to the patient/caregiver about health status
- For sharing information / therapeutic path with the patient/caregiver
- To define the timing of follow-up visits
- To guide the prescription of specific visits / exams
- To justify access/use of a new drug/technology
- To assess the quality of life of the patient
- To assess the quality of life of the caregiver
- To assess the social impact of the epilepsy or the treatment (e.g., social functioning, work productivity, school, etc.)
- To assess the impact of the epilepsy or the treatment on the mental health (e.g., cognition, anxiety, depression, etc.)
- To evaluate the expectations of the patient/caregiver from the treatment
- Other (*specify:* _____)

12. In your centre, who takes care of administering the questionnaires to the people with epilepsy?

- Clinicians
- Nurses
- Other (*specify:* _____)

13. How much time does your centre spend to collect PRO during the visit with the people with epilepsy/caregivers?

- Less than 5 minutes
- Between 5 and 10 minutes
- Between 10 and 20 minutes
- Between 20 and 30 minutes
- More than 30 minutes
- We do not collect patient-reported outcomes

Please, specify the person in charge for the collection and analysis of PRO: _____

14. Does your centre think that PRO can be beneficial in terms of: *[Please, select all that apply]*

- Patient management
- Disease management
- Access to care (in terms of timing)
- Access to care (in terms of facilitation)
- Healthcare resource utilization improvement
- Assessment of the value of a treatment
- Measurement of the success of a treatment

15. Does your centre consider the PRO as important as other main indicators like the efficacy and tolerability of the treatment?

- YES
- NO (Why? _____)

16. Which are the barriers on the use of PRO in clinical practice at your centre?

- Lack of time
- Lack of personnel
- Lack of economic resources
- Lack of knowledge/expertise in patient-reported outcomes
- Do not believe patient-reported outcomes are useful in clinical practice
- Other (*specify:* _____)

17. Does your centre think PRO could impact reducing or increasing the following activities: *[Please, indicate for each one the estimated amount as per percentage]*

- The number of visits:
 - Reduce _____%; Increase _____%; No impact
- The number of exams:
 - Reduce _____%; Increase _____%; No impact
- The time spent on each patient:
 - Reduce _____%; Increase _____%; No impact
- The number of neuropsychological services:
 - Reduce _____%; Increase _____%; No impact
- The number of psychological services:
 - Reduce _____%; Increase _____%; No impact
- The number of rehabilitation services:
 - Reduce _____%; Increase _____%; No impact
- The number of other services (*specify:* _____):

- Reduce _____%; Increase _____%; No impact
- The number of treatments (ASM):
- Reduce _____%; Increase _____%; No impact
- The number of other treatments (*specify*: _____):
- Reduce _____%; Increase _____%; No impact

18. Would your centre consider it useful to implement the standardized use of PRO in your centre?

- YES
- NO (Why? _____)

19. What method would you adopt to collect PRO in your centre:

- Capturing outcome data in-person (paper form questionnaire)
- Remotely (online survey platform)
- A combination of both

20. In your opinion, what kind of resources should be deployed in your centre to:

- Implement PRO process: *[please, indicate]* _____
- Collect and manage PRO: *[please, indicate]* _____
- Perform analysis and assessment of PRO: *[please, indicate]* _____