PARTICIPANT'S INFORMATION SHEETS

1. Purpose of the study

The purpose of this study is to create a Kinyarwanda translated version of different questionnaires, which have been created abroad for assessment of Quality of Life (QoL), disability, self-esteem, perceived stigma and self-esteem. The purpose in the future is to use these questionnaires in future research and clinical practice.

The translation of scales into Kinyarwanda is a multistep process which requires feedback from patients, healthy volunteers and physicians to ensure accurate translations. This project is an international collaboration between researchers from the University of Ghent (Belgium) and CARAES Neuropsychiatric Hospital, Ndera (Rwanda). Together with experts in epilepsy, linguistic experts and translators, we aim to provide highly accurate translated scales.

2. What will happen during the study and how the study will be conducted?

We recruit healthy volunteers, patients living with epilepsy and healthcare profession to participate in this study.

You participate as a: (tick which apply)

☐ Panel member with the role of patient or healthy volunteer: you are member of a panel with experts, forward translators and back translators, which convenes to reach consensus on the translation of scales and signs off on intermediate and final versions. You commit to complete the initial forward translation version of the questionnaires and answer questions for each item using a computer assisted self-interview. You commit to attend all panel meetings and participate actively to achieve an optimal translation.

☐ Panel member with the role of expert: you are member of a panel with experts, forward translators and back translators, which convenes to reach consensus on the translation of scales and signs off on intermediate and final versions. You commit to attend all panel meetings and participate actively to achieve an optimal translation.

☐ Panel member with the role of translator: as a translator, you are responsible for timely delivery of forward translation or backtranslation. You are member of a panel with experts, forward translators and back translators, which convenes to reach consensus on the translation of scales and signs off on intermediate and final versions. You commit to attend all panel meetings and participate actively to achieve an optimal translation.

☒ Validator of English backtranslation: you agree to participate in a survey on similarity/comparability of English version of the questionnaires, using an online questionnaire for each item, called computer assisted self-interview

☐ Patient or healthy volunteer for testing of the prefinal version: You agree to complete prefinal version of the Kinyarwanda translated questionnaires. Second, you also agree to an in-depth interview for each item which will be conducted, called computer assisted personal interview.

☐ as a healthcare professional for testing of the prefinal version: you agree to an online questionnaire, called computer assisted self-interview, which assesses the content validity for each scale and user preference questions.

3. Study participation.

Your participation in this study is voluntary and you may choose to withdraw from participation at any time.

You will not be penalized if you don't wish to participate in this study. Participation will have no effect on the medical care you receive.

4. Risks/Disadvantages.

The study doesn't require any invasive procedure. We do not anticipate any risks for patients participating in this study. If you have any health problem, please feel free to contact by phone the Principal Investigator Dr Fidèle SEBERA at (+250)788486102 or the president of ethic committee

5. Confidentiality.

Your data will be anonymised. Your data are analysed anonymously. An enrolment log will be kept at the study site of Ndera for 10 years, after which it will be destroyed.

The results of our research will be revealed as soon as they will be available.

6. Acceptation to participate

My questions about this study have been answered by …… (name of investigator).

I have read and I have understood my role in this study and I have heard that any time I want to withdraw I can do so without explanations and this has no impact to my health care.

Informed consent form

I…….. (name) confirm that I have read (has been read to me) and I understand the provided information about the current study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
I understand that my participation is voluntary, and I am free to withdraw at any time without my medical care or legal rights being affected.
I understand that relevant sections of my medical notes and data will be collected during the study. I give permission for relevant individuals to have access to my records.
I agree to take part in the above-mentioned study.

Name of Participant	Signature	Date

Name of the principal Investigator	Signature	Date