

Study ID _____

We think that it is important to understand patients' thoughts about research studies. This is especially important in the ESETT study that you were a part of. At the time you were included in this study, you were having a seizure so we were not able to talk to you about the study before including you. Now, we are asking everyone who was included in the ESETT study to answer a few questions about the study. You do not have to answer these questions, but we value any thoughts that you have about this study.

1. On a scale of 1 to 5 with 1 being strongly agree and 5 being strongly disagree, how do the following statements apply to you?

a. I am glad that I was included in the ESETT research study.

Strongly agree 1	2	3	4	Strongly disagree 5
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b. What is the major reason you chose this answer?

c. I think that it was ok for researchers to include me in the ESETT research study when I was having the seizure.

Strongly agree 1	2	3	4	Strongly disagree 5
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d. I think that it was ok to include me without asking for permission first.

Strongly agree 1	2	3	4	Strongly disagree 5
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2. Since you could not be asked about whether you wanted to be included in the ESETT study at the time you were having a seizure, you were told about it later and asked for permission to continue being part of the study. Thinking about when you were told about the study and asked whether you wanted to stay in it, can you tell me, on a scale of 1 to 5, how much you agree with the following statement?

a. I was told about the ESETT study at the appropriate time.

Strongly agree 1	2	3	4	Strongly disagree 5
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b. The research team treated me respectfully by asking for my permission to continue in the ESETT study.

Strongly agree 1	2	3	4	Strongly disagree 5
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c. Is there anything you would change about how you were told about the ESETT study or how we asked you for permission to continue in it?

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3a. Had you heard of the ESETT study before you were enrolled?

Yes

No

(If yes) 3b. How had you heard about this study?

4. When researchers do a study where people have to be included before being asked for permission, researchers have to talk to community members to get their thoughts and opinions about the study before it can be approved and started. This is in addition to having the study reviewed by the medical research review board that reviews all research studies.

a. In the ESETT study that you were included in, which groups of people do you think researchers should have talked to in order to get their thoughts about the study before the study started?

Members of the general public

Patients who have had seizures

Patients who may be likely to experience seizures (such as patients who have had a stroke or head injury)

Family members of patients who have had seizures

Religious leaders

Politicians

Other community leaders _____

Other specific groups _____

b. Of the people or groups of people that you chose above, which one do you think is most important for researchers to talk to in order to get their thoughts about the study before the study started?

Members of the general public

Patients who have had seizures

Patients who may be likely to experience seizures (such as patients who have had a stroke or head injury)

Family members of patients who have had seizures

Religious leaders

Politicians

Other community leaders _____

Other specific groups _____

Date ___ ___ / ___ ___ / ___ ___ ___ Time ___ : ___ ___ AM / PM