

**\* Required fields**

**Early Termination Questionnaire (by phone if necessary)**

\* Name of Site: \_\_\_\_\_

\* Type of Visit: \_\_\_\_\_

e.g. Screening, Baseline, 6 months, 12 months, 18 months, 24 months, 30 months, 36 months, 42 months, 48 months, 54 months, 60 months.

\* Date of Visit: \_\_\_\_\_

\* GUID: \_\_\_\_\_

\* Age of Subject (years and months): \_\_\_\_\_

Subject ID: \_\_\_\_\_

Hello, my name is [NAME], I'm part of the research team at [PDBP SITE]. I am calling because you were a research participant or a study partner to a research participant at our Center. I'd like to ask you a few questions about your participation. You don't have to answer these questions if you do not wish to. The risk of this study is only the loss of your time. There are minimal benefits associated with this study, only that you will help us better understand why people who enroll in research do not always finish studies.

The purpose of the study is to understand why some people don't finish studies. If you agree to participate, we'll ask you some questions and also look back at the last available data from the study in which you were enrolled.

Your participation in this phone questionnaire is voluntary. You don't have to decide right now. If you'd like I could call back at another time that would be convenient for you. Would you be willing to discuss this with me now?

[If no, inquire if there is another time more convenient]

[If yes, continue]

Thank you. Your answers are confidential and will only be shared among the research team. Your answers will have no impact on your future care at [PDBP SITE] or your future research participation, should you choose to do so.

If you have any questions about this study you can contact [PDBP PI], who is the principal investigator for this study. Their phone number is xxx-xxx-xxxx.

**Questions**

1) I'd like you to try to remember why you initially chose to participate in the study. Please tell me if each of the following was part of why you originally chose to enroll?

My hope that participation would help me medically

My hope that my participation would help others

- My hope that your participation would advance science
  - The opinion of my doctor
  - My opinion of the institution
  - Compensation for my time
  - Other (please provide no more than one sentence describing another reason): \_\_\_\_\_
- 

2) If you had to choose only one answer as the most important thing that led to you to participate, what would it be?

- My hope that participation would help me medically
- My hope that my participation would help others
- My hope that your participation would advance science
- The opinion of my doctor
- My opinion of the institution
- Compensation for my time
- Other (please provide no more than one sentence describing another reason): \_\_\_\_\_

3) Please tell me if each of the following was part of why you chose to stop participating

- I didn't think being in the study was benefiting me
- I thought I was assigned to placebo
- I feared my health was in danger
- It didn't seem that important
- Being in the study was unpleasant, I didn't enjoy it
- Being in the study became too logistically challenging because of transportation
- Being in the study became too logistically challenging because of the frequency of visits
- I had other medical problems
- Being in the study became too expensive
- Being in the study wasn't worth the money
- I didn't have time/Being in the study wasn't worth my time
- Being in the study interfered with my job
- Other

4) Which of the following do you think best represents the reason you chose to stop participating? You can only choose one answer.

- I didn't think being in the study was benefiting me
- I feared my health was in danger
- It didn't seem that important
- Being in the study was unpleasant, I didn't enjoy it
- Being in the study became too logistically challenging because of transportation
- Being in the study became too logistically challenging because of the frequency of visits
- I had other medical problems

- Being in the study became too expensive
- Being in the study wasn't worth the money
- I didn't have time/Being in the study wasn't worth my time
- Being in the study interfered with my job
- Other

5) There was something specific I hoped to get out of participating and didn't.

- Strongly Disagree \_1
- Disagree \_2
- Somewhat Disagree \_3
- Neutral \_4
- Somewhat Agree \_5
- Agree \_6
- Strongly Agree \_7

6) The study did not live up to the expectations I had.

- Strongly Disagree \_1
- Disagree \_2
- Somewhat Disagree \_3
- Neutral \_4
- Somewhat Agree \_5
- Agree \_6
- Strongly Agree \_7