

Appendix I: SEARCH HIV Cure Trials Decision Making Study

Participant Interview Guide: Retrospective (at Trial Conclusion)

Interview Guide Use Notes: This is a semi-structured interview guide. Each domain and question set should be included in each interview, but the order of questions, depth of probing, and addition of follow-up questions or probes depends on the specific interview context.

Introduction

Think back to before you started the clinical trial. What was the most challenging thing for you about having HIV?

What is the best thing that has come out of having HIV?

Before the trial started, how did you feel about your ART treatment?

Disclosure/Stigma

Have you told people close to you about your HIV?

If yes: How do you think they feel about you having HIV? Are there people you have chosen not to tell about your HIV? Have you ever worried about how they might treat you, if they knew?

If no: If they knew, how do you think they would feel about you having HIV? Have you ever worried about how they might treat you, if they knew?

Decision series

Think back to when you made the decision to be in the trial. What were the most important factors when you made your decision to participate in the trial?

Was it a difficult or an easy decision?

Who was involved in helping make the decision? What do people close to you think about your decision? How important were other people's opinions to you in making your decision?

Do you feel like you had all of the information you needed to make a decision?

Before you started the trial, do you feel that you understood the potential benefits or good things? What did you think the good things would be? How much did you expect [this good thing] would happen?

Before you started the trial, do you feel that you understood the potential risks or downsides? What did you think the potential downsides would be? How worried were you that [this downside] would happen?

Before the trial started, how did you feel about having to stop ART?

Trial experience

[Interviewer summarizes and checks in about trial status/participant outcome.]

Tell me about your experience of being in the trial?

What has it been like to stop your ART?

Were the day-to-day processes of the trial what you thought they would be, when you agreed to be in the trial? [Probe for impact of monitoring.]

Benefits, burden and harms

What was the best thing about being in the trial? [Continue to ask about other positive parts about having been in the trial.]

How did you judge whether you got any benefit from the trial? Do you think that the professionals at the study site think about benefit from the trial the same way that you do?

What was the most difficult part about the trial? Have you experienced negative effects? [Probe for emotional impact. Continue to ask about other downsides of having been in the trial.]

Expectations and hopes

Overall, did the trial meet your expectations? [Clarify: What you **thought would happen** before the trial started—did it actually happen?]

Thinking back to before the trial started, what did you expect would happen?

How did your expectations change from when you started the trial?

Overall, did you get what you hoped to get out of the trial? [Clarify: Did the trial meet your optimistic **hopes for what could happen**?]

Thinking back to before the trial started, what did you hope could happen?

How did your hopes change from when you started the trial?

Decisional regret

If you had to do it all over again, would you make the same choice about being in the trial? Why?

Would you go about making your decision in the same way or a different way?

Do you feel like you made an informed choice? What would have helped you make a more informed choice?

Did your experience in this trial make you more or less likely to participate in a future trial?

Advice

This is the last question. If you were giving advice to other people who were making decisions about whether they should enroll in a clinical trial similar to [name], what would you tell them?