

Facilitator's Guide – Exploring patient and provider perspectives of sickle cell trait patient needs

Focus Group Facilitator's Guide

The purpose of this guide is to assist the focus group session facilitator in conducting guided open discussions on the needs of patients with sickle cell trait when interacting with their providers. The guide is meant to provide structure for the sessions. Facilitators should encourage participants to explore topics in depth.

1. Prior to the Focus Group

Running an effective focus group is a skill and requires planning. Prior to the session, please review the entire guide, all questions and questionnaires.

Tips for facilitating the sessions:

- a. Facilitator's key responsibilities
 - i. Keep participants engaged
 - ii. Monitor time
- b. How to be an effective facilitator
 - i. Active listener
 - ii. Ask open-ended questions to allow community members the opportunity to communicate effectively.
 - iii. Encourage one speaker at a time
 - iv. Encourage participants to share their thoughts and opinions and to feel comfortable doing so even if contradictory to popular belief.
 - v. Introduce and make the participants comfortable with the discussion topics.
 - vi. Emphasize that all participants have something valuable to offer.

2. Conducting the Focus Group

Facilitator's welcome. Welcome and thank you for volunteering to take part in this focus group. You have been asked to participate as your point of view is important. I realize you are busy and I appreciate your time.

Consent form. Each person must complete a consent form to participate in the focus group. *Ask if there are any questions regarding the consent form.* If you have not already completed your consent form, please do so now.

Survey. Before we begin the focus group, please take a few minutes to complete the survey (that is on the table in front of you). This survey tells us a little about you and there are some questions regarding your thoughts about research. I will give you a few minutes to complete. Please let me know if you have questions or need assistance. *Collect surveys* after participants have completed them.

Reminder about audiotaping. As noted in the consent form, these sessions are being audiotaped. Despite being taped, I would like to assure you that the discussion will be confidential. The tapes will be kept safely in a locked facility until they are transcribed, then they will be destroyed. Once the audio is transcribed, there will not be any information to link individuals back to statements made during the session. If there are

any questions or discussions that you do not wish to answer or participate in, you do not have to do so; however, I encourage you to be as involved as possible.

Purpose. The purpose of this interview is to improve researchers' understanding of the perceptions about their needs of sickle cell trait patients when interacting with their providers. Through our discussions I can learn more about how to improve communication between providers and their patients, as well as how to meet to the need for patient-centered care among patients with sickle cell trait.

Ground rules.

If you haven't already done so, please read through the consent letter. Print your name and age at the top of the consent document and then sign your name at the end if you agree to participate. If you do not wish to take part in this group, you are free to leave now. Please also fill out the short questionnaire you have in front of you.

Before we begin I would like to go over a few basic ground rules for our discussion.

- This session is being audiotaped. This allows me, as the moderator, to focus on you, instead of trying to jot down specific details about the discussion. Please speak in a voice as loud as mine, so the microphone can pick it up.
- I will write a report using the tapes. Our report will not mention any of your names. By assuring your anonymity, I hope that you will speak openly and honestly about today's topic.
- We want you to share your opinions with the group, but please don't have side conversations while other participants are speaking.

And remember, there aren't any right or wrong answers, so you can give both positive and negative viewpoints.

Introductions.

- *Let's begin with introductions. We will go around the room and have everyone tell us their names. Again, my name is...* Introduce the staff who are taking notes, keeping time, operating the recorder, etc.
- I would like to quickly go around the group and give each person a moment to introduce him or herself...We will go by first names only.

Patient Focus Groups:

- 1) What do know about sickle cell trait?
 - How did you find out you had sickle cell trait?
 - Did a relative tell you?
 - Did you read it on the internet?
 - How satisfied were you with the way you were told about your diagnosis?
 - What could have been better?
 - What was good/bad about it?
 - What do you wish would have happened?
- 2) How do you find information about sickle cell trait?
 - How do you use this information?
 - What information would like to receive?

- 3) How is life different after learning you have sickle cell trait?
 - Has your diet changed?
 - Have you change your lifestyle activities?
 - How does it affect your health?
 - Are you struggling with day to day issues?
- 4) Tell me about your interaction with your healthcare providers when you bring up your sickle cell trait status.
 - Do they seem concerned with your health?
 - Do they provider offer resources about your condition?
 - Do they provider answer your questions, if any?
 - Do you sometimes feel like you know more about sickle cell trait than they do?
- 5) Is there anything else we haven't discussed that you would like to share or suggest?

Conclusion

- Thank you for participating. This has been a very helpful discussion.
- Your comments are valuable and we sincerely appreciate your time.
- If you have any comments or concerns, please speak to me after we close.
- Just to remind you, all comments in this report will be anonymous.
- Before you leave, please be sure to give your completed forms to me.

3. Following the sessions

Collect all consent forms, demographic forms, questionnaires, and audiotapes and place them in the portable lock box provider. Lock the box and immediately store it in a locked office. All confidential information and participant identifiers must be kept secure at all times. Confidentiality must be strictly preserved.