

Attachment E

EXAMPLE MODERATOR'S GUIDE

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Formative Research to Support the Development of Sickle Cell Disease (SCD) Educational Messages and Materials for the Division of Blood Disorders

Focus Group Moderator's Guide

This guide combines all of the questions that may be asked of participants in our four target audiences: adolescents (15-17), young adults (18-25), adults (26-35), and older adults (36+). The audiences for each question are indicated in gray shading and outline. Further, the process for implementing some of the activities included here will be modified to enable their completion during the telephone focus groups.

Purposes

- To obtain input from people with SCD about their experiences with SCD, and what they think is important for helping people with SCD to manage their disease.
- To obtain input from people with SCD about how they get information about SCD and other health self-management behaviors and how they would like to get such information in the future.

Outline

Part 1: Opening	5 minutes
Part 2: Self-management and prevention behaviors	30 minutes
Part 3: Message testing exercise	10 minutes
Part 4: Media preferences	10 minutes
Part 5: Closing	5 minutes

Logistics / Equipment

- Consent forms (2/participant)
- Incentives (in envelopes)
- Receipt forms
- Food (snacks plus appropriate beverages)
- Paper, flipchart, markers, pens, colored dots/stars (preferably a dark color)
- Audio recording equipment (recorder, tapes, batteries)
- Video recording equipment (recorder, tripod, tapes, charger)

- Tissues
- Small clock for moderator
- Blankets (if necessary)

Focus group guide: Protocol

Note: Spoken text is not underlined. Instructions to the moderator are underlined.

PART 1: OPENING

MODERATOR: As participants arrive, show them where to get refreshments and distribute consent forms. While they wait, ask them to review and sign the consent forms. Be sure to inform them that, if they have any questions about the consent form, they should ask you. Participants get to keep one copy and must turn in a signed copy before the discussion group can begin.

Start as close to the scheduled starting time as possible—do not wait for late arrivals.

If somebody appears ill during the group, take a 5 minute break and speak with this person on the side about their ability and willingness to continue.

IF GUESTS ARE PRESENT – INCLUDING CHILDREN: There is a no-guest policy at these discussion groups: only those people who are participating in the group today can be in the room. Outside of this room, [describe location], there is a space for visitors to wait. At this time, I'd like to ask all non-participants to please leave the room. We'll see you in about an hour! Thank you for understanding.

Introductions

Well, let's begin. My name is (YOUR NAME).

Notetaker: And, I'm (NAME). We've been asked by the Centers for Disease Control and Prevention to conduct this discussion group with you. The Centers for Disease Control and Prevention (sometimes called the CDC) is a government agency whose mission is to create the expertise, information, and tools that people and communities need to protect their health. They want to find out what sorts of information can really help people with SCD better manage their disease and prevent complications from this disease. They also want to come up with ways of sharing this information with other people with SCD. So, we'll also be asking how you learn about SCD and getting your opinions about some materials that have been developed to help people learn more about managing their SCD.

Ground rules

I'd like to begin by setting some ground rules for this session.

As you may have noticed, this session is being videotaped. This way, we won't miss anything you say.

Sometimes, we put together video clips for educational purposes. If, at the end of the meeting, there is something that you want us to erase from the tapes, we will do so. We will ask you about this at the end of the meeting.

Please set cell phones to "vibrate."

No side conversations please.

We'll need to move along – we have a lot to talk about and want to hear from everyone. There won't be enough time for long stories or full discussions of every topic. So please understand that when I ask that we move to a new topic or speaker, I don't mean to be rude.

Finally, a bit about my role: I am here to learn from you. You're the experts – you know what's important for managing your sickle cell and for avoiding complications. We want to learn from you.

Housekeeping

Finally, a couple of housekeeping items:

Our discussion will last from (TIME1 to TIME2). To make the most of this time, there will be no formal breaks.

If you need a quick break, the restrooms are [REDACTED].

Finally, be sure to let us know if you're not feeling well. If you're not feeling well, just signal (NAME OF PERSON), and they'll take care of things.

Does anybody have any questions?

Warm-up discussion

I'd like to ease into the topic by asking each of you to introduce yourself.

First, please share with us:

- (1) your first **name**,
- (2) the **city** in which you live, and
- (3) one thing you wish that people who didn't have SCD knew about it.

PART 2: SELF-MANAGEMENT AND PREVENTION BEHAVIORS

We are interested in finding out what it's like for you to live with sickle cell. So, I'd like to talk about your experiences with sickle cell.

1. [ALL] When I say the words "sickle cell" what do you think of?
2. [ALL] What are some things you do in your daily life that help you manage your sickle cell disease? By manage, I mean the things you do that help you take care of your sickle and reduce the risk of complications.

NOTE: Write "How to Manage SCD" on the flip chart. Write down responses.

3. [ALL] What is it like living with SCD?
4. [ALL] How do you deal with problems that come up with taking care of your SCD?
 - What do you do when the same problems come up over and over again?
 - What do you do when new problems come up?
 - What types of things help you handle problems with your SCD?
5. [ALL] Suppose someone with SCD said to you, "Having SCD really sucks. I wish there was some things I could do." What advice would you give them?
6. [ALL] What can people do to prevent complications from their sickle cell disease? By complications, I mean things someone with sickle cell can do to reduce the risk of stroke, gallstones, damage to your hip and other joints, leg ulcers, spleen damage, kidney disease, eye problems, drug dependence, and things like that.
7. [ALL] What are some things that people can do to help them get better health care for their sickle cell from doctors and other health care workers?
 - What do you do to keep your doctors and other health care workers on your side, fighting for your needs?
8. [ALL] How many of you have had to go to the Emergency Department due to complications from sickle cell? Please raise your hands. What are some things that someone with sickle cell can do to get better sickle cell health care from people in the Emergency Department?

NOTE: After list is complete, begin rating exercise (Item 7).

9. [ALL] I want to know which things on this list are the most important for taking care of a person's SCD and avoiding complications. First, I'd like to read through the list with you and answer any questions you have about any of these items. **READ LIST.**

I'd like you to "vote" for the most important items. But, you only have 6 votes. So, pick the six items that are most important to you -- the most important things for dealing with SCD and preventing complications. Here are 6 stars (stickers). One is

gold – and put that next to the item on the list that is most important. Then, use the other stickers to vote for the other things that are pretty important.

10. [ALL] I see that the items [] and [] have a lot of stars next to them. Can you tell me why you think this is?

11. [ALL] Not a lot of people picked the [] and [] items. Why do you think these were seen as less important?

12. [ALL] Choose several different responses. For each, ask:
When is the best time to get to get information like this? That is, when would it be most helpful or useful?

NOTE: Write “Advice for teenagers with SCD” on flip chart.

13A. [ADULTS 18+] We will also be preparing advice and messages for teenagers with SCD. What do you wish you had known about SCD when you were a teenager [FOR ADOLESCENTS: when you were first getting information about your SCD]? I'm interested in what would have helped you to take better care of your sickle cell and to reduce the risk of complications.

13B. [ADOLESCENTS] We will also be preparing advice and messages for teenagers with SCD. What do you wish you had known about SCD when you were first learning about the disease?

14A. [ADULTS 18+] What advice would you give to teenagers to help them take care of their SCD?

-How do you find providers that can help you as an adult with SCD?

14B. [ADOLESCENTS] What advice would you give to younger people with SCD to Help them take care of their SCD?

15. [ALL] What is important for teenagers to know and do when they are dealing with doctors, nurses, and other health professionals?

- IF NOT OBVIOUS: Why are these important?

NOTE: After list is complete, begin rating exercise (Item 14).

16. [ALL] Like we did before, I want to know which things on this list you think are the most important for teenagers to manage their SCD and avoid complications. Let's check this list and I'll answer any questions you have about these items. READ LIST.

Once again, I'd like you to “vote” for the most important items. But, this time, you only have 5 votes. Pick the five items that are most important -- the most important things for kids managing their SCD and preventing complications. Here are 5 stars

(stickers). The gold one is for the most important thing. Then, use the other stickers to vote for the other things that are pretty important.

17. [ALL] I see that the items [] and [] have a lot of stars next to them. Can you tell me why?

18. [ALL] Not many of you picked the [] and [] items. Why do you think these are not as important?

PART 3: MEDIA PREFERENCES

We want to develop materials that people will be able to understand and use. We want people to be able to easily find and use these materials when they want to or when they need to. So, I'd like to find out how you learn about SCD and what you think are the best ways to get information to help deal with health issues.

1A. [ADOLESCENTS] How did you learn about taking care of your SCD?

1B. [ADOLESCENTS] When did you first get information about SCD?

1C. [ALL] How did you learn about different ways to manage your SCD and to prevent complications or problems? How else?

2. [ALL] What has been particularly helpful for you in managing your SCD?

- How did you learn about this?

- Is this how most people get their information about SCD, or do they get their information in other ways?

3. [ALL] Who do you trust the most to give you information about SCD?

-SCD information can be very complicated and confusing. If you need to ask for clarification or help with understanding the information you receive, who do you ask?

4. [ALL] There are lots of different types of information and health messages – such as bits of advice for people with sickle cell. These are things like: Avoid altitude over one mile; drink plenty of fluids; and so on. What are the best ways of getting these kinds of messages to people like yourself – that is, people with years and years of experience with dealing with their SCD?

List responses on sheet of paper.

5. [ALL] Review list. For each item on list, ask:

How many of you think this is a good way to get this kind of information? Why?

6. [ALL] For people who did not raise their hands, ask:

Why don't you think this is a good way to get this information?

7. [ALL] There are other types of information and health messages. Some messages may be situation specific – like how to decide whether or not you need to go to a hospital. Can you think of any other situations when there would be an immediate need for information to help manage your sickle cell and avoid complications?

Write down responses on sheet of paper.

Now, let's think about this type of information – information that people would want to get and use when it is needed. How can one do this – that is, what are the best ways of providing access to situation specific messages like these? Point to list.

Write down responses (ways of providing information) on new sheet of paper.

8. [ALL] IF WEB SITES WERE NOT LISTED ABOVE: What kinds of web sites, if any, do you go to for health information?

I noticed that no one mentioned web sites. Why?

What do you think about using web sites to get information about SCD?

9. [ALL] IF SOCIAL MEDIA WAS NOT LISTED ABOVE: Do you ever go to social networking sites, like Facebook, to get health information or not?

- What do you think about using Facebook or other social networking web sites for getting information about SCD?

10. [ALL] IF CELL PHONE APPS WERE NOT LISTED ABOVE: Do you ever use your cell phone or cell phone apps to get health information?

- No one seemed to mention this either. Why?

PART 4: CLOSING

[ALL] Is there anything else that you'd like to say about what kinds of information we should provide for people with sickle cell disease or how we can provide and distribute this information? Anything else?

To thank you for sharing your experiences with us, we are giving each of you \$XX.. Please sign this receipt to acknowledge that you received the envelope. AFTER PARTICIPANT HANDS YOU A SIGNED RECEIPT FORM, GIVE THE PARTICIPANT THE ENVELOPE.

Finally, before we all leave, I wanted to check if anybody wants anything deleted from the tape. Is there anything that you said today that you want us to delete from the tape?

Thank you again for your help.