

Discussion Guide for Use in Focus Groups with Women or Interviews with Men

Focus Groups with Women

Public reporting burden of this collection of information is estimated to average 2 hours per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to CDC/ATSDR Reports Clearance Officer; 1600 Clifton Road NE, MS D-74, Atlanta, Georgia 30333; ATTN: PRA (0920-16C0)

Interviews with Men

Public reporting burden of this collection of information is estimated to average 45 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to CDC/ATSDR Reports Clearance Officer; 1600 Clifton Road NE, MS D-74, Atlanta, Georgia 30333; ATTN: PRA (0920-16C0)

Introduction (5 minutes; 2 minutes)

Describe Group purpose

People with chronic diseases often need help with various aspects of managing their condition. Self-management is the term we are going to use for those things you can do on a day-to-day basis to manage your condition and pursue the activities that are important to you.

Today we'd like to:

- learn what aspects of managing your lupus are most important to you and with which aspects you would like to receive help
- get your opinion on a resource for helping people manage lupus that was developed with input from other people living with lupus
- find out where you go for that kind of information

Review Participant Information Sheet

Q/A

Warm-up (10 minutes; 2 minutes)

How/when did you first learn that you had SLE?

Is the idea of SLE self-management a new idea, or something that you've heard before?

Self-Management Challenges

What is most the most important thing you do to manage your lupus?

What do you find most difficult about managing your lupus?

Probe:

What barriers have you encountered in attempting to manage your lupus?

What do you need the most help with in managing your lupus?

How have your self-management needs varied over time?

Probes:

How did your needs differ?

When was more help needed?

Attitudes toward Self-management (10 minutes; 3 minutes)

How important is it for you to take action to manage your lupus?

How confident are you that you can do what is necessary to keep your lupus under reasonable control?

If you saw or heard about a tool for helping you to manage your SLE, would it get your attention? Would you investigate it? Why or why not?

Reactions to Self-management Resource (55 minutes; 20 minutes)

Now we'd like to get your opinion on the *TOOL* developed by the CDC for helping people manage lupus.

First Impressions

How would you sum up in just a few words your first impression of the *TOOL*?

Probes:

Do you like it? Not like it? What makes you say that?

How similar is this tool to things you have seen/used before?

Probes:

How is it similar?

How is it different?

Comprehension

What do you think is the purpose of the *TOOL*?

Probes:

Is the *TOOL* trying to help people understand something or learn something?

Is the *TOOL* trying to get people to do something?

Is there anything in the *TOOL* that is confusing, unclear, or hard to understand?

Tool Content

Utility/Features

Which of the specific features are/were the most useful? Why?

In what ways would those features help you? Why is that?

Moderator Note: If participants are having difficulty understanding the question or articulating an answer please use some of prompts below. Do not go through entire list one by one for probes.

Would it help you with:

1. Physical challenges?
2. Emotional challenges
3. Mental challenges?
4. Medication-related challenges?
5. Relational/social challenges?
6. Communication challenges?
7. Challenges at work?
8. Challenges with your health care provider?
9. Challenges at home?

Would you add any features? Why?

Are there any features you would not include? Why not?

How easy or difficult would it be to use the tool? Why?

How likely would you be to use a tool like this?

Probes:

When would you use it?

How often would you use it?

What would keep you from using a tool like this?

Probes:

Time?

Access to technology?

Other?

How “do-able” are the suggestions for managing your lupus provided by the tool?

Organization

What do you think about the way the content is organized?

How easy is (was) it to find what you were looking for in the TOOL?

Would you re-arrange the content in any way?

Format/medium

Would you choose, or add another format?

Images, Graphics and Colors

How do you feel about the colors and graphics?

Persuasiveness

Does/did (using) the *TOOL* make you more or less likely to try to manage your SLE? Why is that?

What actions do you think you might take?

Is there anything that could be changed in the tool to increase your motivation to manage your SLE?

Other Improvements

What other changes would you make to the *TOOL*?

Reactions to Taglines (10 minutes; 5 minutes)

Now we would like to show you a list of potential phrases that might be used to advertise a *TOOL* or resource like we've been talking about. The idea is to get people interested in taking a look at the *TOOL*.

(For Focus Groups: Hand out tagline work sheet. Please read the instructions at the top of the worksheet to the group.)

(For Individual Interviews: Introduce list of taglines. Please read the instructions at the top of the worksheet to the participant and record their answers on a separate worksheet.)

By a show of hands, how many of you circled tagline number 1?

(For Focus Groups: Repeat with remaining taglines numbers until all participants have indicated their selection. Use the following set of questions to gather more information about the top 2 or 3 taglines [depending on time].)

(For Individual Interviews: Ask participant about their top 2 or 3 taglines [depending on time].)

Comprehension

What is the main idea that this tagline is trying to get across, in your own words?

What action(s) would the tagline prompt you to take?

What if anything, is confusing or difficult to understand in the tagline?

Affect

What makes the message appealing?

Are there any taglines that you rated as "strongly dislike?" Why?

Other improvements

What changes would you make to the taglines?

Reactions to Cues to Action (10 minutes; 5 minutes)

Here is another list of potential phrases that might be used to advertise a *TOOL* or resource like we've been talking about. The idea is to get people interested in taking a look at the *TOOL*.

(For Focus Groups: Hand out cues to action work sheet. Please read the instructions at the top of the worksheet to the group.)

(For Individual Interviews: Introduce list of cues to action. Please read the instructions at the top of the worksheet to the participant and record their answers on a separate worksheet.)

By a show of hands, how many of you circled cue to action number 1?

(For Focus Groups: Repeat with remaining cue to action numbers until all participants have indicated their selection. Use the following set of questions to gather more information about the top 2 or 3 taglines [depending on time].)

(For Individual Interviews: Ask participant about their top 2 or 3 cues to action [depending on time].)

Comprehension

What is the main idea that this message is trying to get across, in your own words?

What action(s) would it prompt you to take?

Is there anything confusing, unclear, or hard to understand? If so, what words or phrases could be used in their place?

Affect

What makes the message appealing?

Are there any cues to action that you rated as "strongly dislike?" Why?

Persuasiveness

Is there anything in the message that could be changed to make you more motivated to explore the self-management tool?

Channels and Sources of Information (15 minutes; 3 minutes)

Sources

When it comes to managing SLE, are there any organizations that you would really trust as a reliable source of information?

What makes them a trusted source of SLE information?

What has been your past experience in receiving information from the organization?

Through what channels would you expect to be introduced to this *TOOL*?

Where would you expect to see these kinds of messages (taglines and cues to action)?

Perceptions of CDC

Does having the CDC brand on this *TOOL* make you more or less likely to use it?

Moderator Note: If time allows please ask the following questions about perceptions of CDC.

How do you feel about CDC as the source of this information?

When you think about finding self-management information for SLE, do you think of the CDC?

Would you use a SLE tool presented by the CDC? If not why?

Closing (5 minutes)

Is there anything about self-management of SLE or this *TOOL* you think is important that we did not discuss today?

Thank you for your time and participation today.

Tagline Worksheet

For Focus Groups:

We are interested in your opinion of the following taglines for advertising the tool. For the following items, please rate them on a scale of 1 to 5; 1 being “really dislike” and 5 being “really like.” Please circle the tagline that you like the best. Please underline any words or phrases that are confusing or unclear.

For Individual Interviews

We are interested in your opinion of the following taglines for advertising the tool. I'm going to read out loud to you a list of items, please rate them on a scale of 1 to 5; 1 being “really dislike” and 5 being “really like.” When we've gone through all six items, I'm going to ask you to tell me which you liked the best. As I am reading these to you, please let me know if there are any words or phrases that are confusing or unclear.

Tagline	Really Dislike					Really Like
1. <i>Taking care of my lupus is taking care of me</i>	1	2	3	4	5	
2. <i>My lupus, my life, my choice</i>	1	2	3	4	5	
3. <i>Stop worrying, start managing</i>	1	2	3	4	5	
4. <i>Take back your life; take control of lupus</i>	1	2	3	4	5	
5. <i>You're the boss, not your lupus</i>	1	2	3	4	5	
6. <i>Managing lupus: for myself, for my family</i>	1	2	3	4	5	

Cues to Action Worksheet

For Focus Groups:

We are interested in your opinion of the following cues to action for advertising the tool. For the following items, please rate them on a scale of 1 to 5; 1 being “really dislike” and 5 being “really like.” Please circle the cue to action that you like the best. Please underline any words or phrases that are confusing or unclear.

For Individual Interviews:

We are interested in your opinion of the following cues to action for advertising the tool. I’m going to read out loud to you a list of items, please rate them on a scale of 1 to 5; 1 being “really dislike” and 5 being “really like.” When we’ve gone through all six items, I’m going to ask you to tell me which you liked the best. As I am reading these to you, please let me know if there are any words or phrases that are confusing or unclear.

Cues to Action	Really Dislike				Really Like
1. <i>Living a full life doesn't end with a lupus diagnosis. Take control of your disease with CDC's Lupus Self-management TOOL.</i>	1	2	3	4	5
2. <i>It's your life and your lupus. Learn how to be in charge of your disease with CDC's Lupus Self-management TOOL.</i>	1	2	3	4	5
3. <i>Lupus self-management - made simple. Learn more about how to take a proactive role in managing your illness with CDC's Lupus Self-management TOOL.</i>	1	2	3	4	5
4. <i>Your life is about more than your lupus. Learn steps to help manage your disease and get back to doing what you enjoy with CDC's Lupus Self-management TOOL.</i>	1	2	3	4	5
5. <i>Don't let lupus be the boss. Be in charge of your illness with help from CDC's Lupus Self-management TOOL.</i>	1	2	3	4	5
6. <i>Spend more time with your family and less time with your lupus. Learn how with CDC's Lupus Self-management TOOL.</i>	1	2	3	4	5