

Attachment D1: Discussion Guide for Focus Groups with African American Young Women (With a Family History of Breast Cancer)

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 (0920-0800)

Discussion Guide: African American Young Women with a Family History of Breast or Ovarian Cancer

Section One: Background (5 minutes)

Introduction and Informed Consent

Hello, my name is _____. Our discussion today is being sponsored by the United States Department of Health and Human Services (HHS), Centers for Disease Control and Prevention (CDC). Our purpose in talking with you today is to hear from you on your thoughts and opinions about messages CDC has developed for young women.

Before we begin, I would like to remind you that your participation in this discussion is voluntary and you may end it at any time or feel free to skip questions you feel uncomfortable answering. To ensure accuracy, our discussion today is being audio recorded. At no time will your name appear in any reports or presentations that result from this work.

Do you give your permission to be audio recorded today? (If participant says no, thank and terminate participation)

Also, some of my research team is observing our session to help me prepare my report. Ok? (If participant says no, thank and terminate the interview)

Thank you.

Let's start with a quick introduction. Please tell me your name and a little about yourself.

Section Two: Sources of Information/Communication (25 minutes)

1. Thinking about an average week, what are some of the websites you visit most often?
 - What content on those websites is most interesting or appealing to you?
 - How much time would you estimate you spend on those sites?
2. Thinking back, have you noticed any online ads or messages related to health recently? Please tell me about those ads.
 - What about that particular ad was interesting to you?

- Why do you think you noticed that particular ad (i.e., color, placement, content, image)?
 - Did you trust or believe the message? Did it prompt you to take any action?
 - Did you learn anything new?
3. What websites do you visit to get your health information?
- How frequently would you say you look for health information online each month?
 - What prompted the search? Were you looking up a particular symptom you were experiencing or were you looking for more general information?
 - Was it easy or difficult to find the health information you were looking for? What made it easy or difficult?

Thank you for sharing information about your online search habits and how you receive information. It's helpful for me to understand how you generally get your information. Now, I'd like to ask you specifically about health information related to breast or ovarian cancer.

4. Do you consume any media that is specifically intended for [*women interested in breast and ovarian health issues*]?
- If so, which ones?
 - What made you start following/reading that information?
 - What topics do they cover that most interest you?
 - Do you follow them on social media?
 - What do you like about them?
 - Have you seen any online media sources for [*women interested in breast and ovarian health issues*] that you do not like?
 - If so, what do you dislike about those sources?
5. At any point in the past, have you sought out any information on breast or ovarian cancer online?
- Where from? What did you find?
 - Were you satisfied with the information you found?
6. Do you have any affiliation with, regularly receive information from, or participate in any activities/fundraisers with organizations that are specifically intended for [*women interested in breast and ovarian health issues*]?
- If so, which ones?
 - What made you want to get involved with those organizations?
 - Do you follow them on social media?

Section Three: Awareness of Risk Factors for Breast and Ovarian Cancer
(30 minutes)

7. Have you heard of any risk factors for breast cancer? If so, what risks are you aware of?
- Where did you learn about this risk information?
8. When you think about breast or ovarian cancer, who do you think is most likely to get these cancers? Do you think of any groups as being at risk of getting these cancers?
- Why do you think those groups seem to be at risk?
9. Are you aware of things that might make some young women more likely to get breast cancer than others?

Probe:

- If so, what have you heard?
 - Where have you heard this information?
 - Do you consider this a trusted source? Explain.
 - Why do you think those groups seem to be at risk?
 - What would you like to know? What questions do you have?
10. What are some signs or symptoms of breast cancer that you know of? What might cause a woman to suspect she has breast cancer?

11. Have you ever talked with a doctor or provider about breast and ovarian cancer?

Probe:

- If yes,
 - o What type of doctor? (PCP, OB/GYN, other)
 - o Explain the circumstances – was this part of routine care, during a visit regarding another issue or specifically about your breast or ovarian cancer concerns?
 - o Did you initiate this conversation or did your doctor(s) ask if you [*had a family history of breast or ovarian cancer*]?
 - What kind of information did the doctor ask you for?
 - Do you think your provider tailors your care based on that information?
 - Do you think sharing that information impacted the conversations you had with your provider about your breast or ovarian cancer risk?
 - o In your opinion, what might have made the conversation more productive or

helpful for you?

o Did you take any actions after this conversation? Why or why not? What were they?

- If no,
 - o Did your provider ask about your family medical history?
 - o Did you want to talk to your doctor about breast and ovarian cancer? Why or why not?
 - o What might have helped you initiate this conversation with your doctor?

12. Within your family, have you had conversations about your family's cancer history?

- Who initiated the conversations and why?
- Who has been involved in those conversations? Are there family members who choose not to participate? Why?
- When did you have those conversations? How frequently?
 - o Early in diagnosis [*of family member*]
 - o During treatment [*of family member*]
 - o Post treatment [*of family member*]
- What types of information do you discuss?
 - o Medical/clinical/research
 - o Emotional/support
 - o Basic logistics of medical care/appointments
- How would you characterize the tone or feel of most of those conversations?
- Did these conversations influence how you think about your own risk for breast cancer?

13. Have you ever heard of the BRCA (**moderator note: say B-R-C-A and Bra-Ca the first time it's mentioned**) gene?

- If so, what have you heard?
- When did you first hear of the BRCA gene?
- Where have you heard this information? What is the source? Do you consider this a trusted source? Explain.
- What is significant about the BRCA gene?

14. Have you ever heard of genetic testing for breast and ovarian cancer?

Probe:

- If so, what have you heard?
- What are your thoughts about it?
- What would you like to know? What questions do you have?

- Where have you heard this information? What is the source? Do you consider this a trusted source? Explain.

15. Have you ever heard of anything women can do to reduce their risk of breast cancer?

16. Regarding genetic testing or breast cancer, what do you wish you knew more about? Do you have any questions or confusion?

**Section Four: Reactions to Campaign Messages and Materials
(55 minutes)**

There are five materials which will be tested during this section of the focus group. Approximately 10 minutes will be spent reviewing and discussing each item, including its content messages.

African-American women will provide feedback on the following materials (Attachment D2). Materials will be rotated across groups using the *Materials Rotation Matrix* below. As the moderator hands out each material, she will state the name and identifying code of the material out loud for documentation in the transcripts.

African American Young Women - Ad Rotation		
	With a family history of breast or ovarian cancer	
	Chicago, IL	Birmingham, AL
Age 18-29	1 group	1 group
Materials Testing Order	Factsheet E1, One-pager D1, Storyboards B1, A1, C3	One-pager D1, Storyboards A1,B1,C3, Factsheet E1
Age 30-44	1 group	1 group
Materials Testing Order	Storyboards A1,C3,B1, One-pager D1, Factsheet E1	Factsheet E1, Storyboards B1,C3,A1, One-pager D1,

[Fact Sheet](#)

The moderator will give each participant a copy of a fact sheet that presents general information about young women and breast cancer, determining risk, and prevention/risk reduction measures for young women. The moderator will provide participants the following instructions (which will also be written on a flip chart at the front of the room):

- **Underline** phrases or sentences you think are important
- **Circle** things that are not clear or you don't understand
- **X-out** things you think should be deleted or removed

The moderator will allow participants to read and mark the fact sheet before beginning a discussion about it. At the end of the discussion each marked up material will be collected and saved for the research team.

17. How does this information make you feel?

18. Who do you think this fact sheet is for?

19. Is it asking the reader to do anything? What action would you take after reading this?

- How likely would you be to take action after reading this fact sheet?
- What would make you more likely to take action after reading this fact sheet?

20. What did you underline as important?

- What makes this important?
- Is this part easy to understand?

21. What did you circle as unclear or confusing?

- What makes this area confusing or hard to understand?
- How could it be changed to be clearer?

22. What did you cross out as something to delete?

- What makes this something to remove?

23. Where should this be placed so you would receive it and read it?

24. What other changes or additions would you suggest to improve the fact sheet?

- Is there any information that is important for you to know that was not included on this fact sheet?

25. What about the design of the fact sheet—does it work for you? Is it eye-catching?

One-Pager

The moderator will give each participant a copy of a One-pager about breast cancer genetics that might be seen on a website or as a call-out box on a fact sheet or brochure. Components of this text-based piece include information about BRCA1 and BRCA2 gene mutations, as well as genetic counseling and testing. The moderator will provide participants the following instructions (which will also be written on a flip chart at the front of the room):

- **Underline** phrases or sentences you think are important
- **Circle** things that are not clear or you don't understand
- **X-out** things you think should be deleted or removed

The moderator will allow participants to read and mark the fact sheet before beginning a discussion about it. At the end of the discussion each marked up material will be collected and saved for the research team.

26. How does this information make you feel?

27. Who do you think this is for?

28. Is it asking the reader to do anything? What action would you take after reading this?

- How likely would you be to take action after reading this?
- What would make you more likely to take action after reading this?

29. What did you underline as important?

- What makes this important?
- Is this part easy to understand?

30. What did you circle as unclear or confusing?

- What makes this area confusing or hard to understand?
- How could it be changed to be clearer?

31. What did you cross out as something to delete?

- What makes this something to remove?

32. Where should this be placed so you would receive it and read it?

33. What other changes or additions would you suggest to improve the sidebar?

- Is there any information that is important for you to know that was not included?

34. What about the design—does it work for you? Is it eye-catching?

Storyboards

Each group of focus group participants will review a total of 3 storyboards. The storyboards feature real women's stories. Each storyboard includes still screens with stock photography relevant to the storyline, agreed upon messages, and a call to action. Each storyboard will be distributed, discussed, and assessed one at a time.

The following procedure will be repeated for each storyboard.

- The moderator will distribute to each focus group participant: one storyboard, and one response sheet for the storyboard (see example attached to this Guide).
- **The moderator will give participants a few minutes to look at the storyboard and gauge initial reactions on the response sheet prior to starting discussion**
- **The moderator will lead a discussion of each storyboard. Questions 35-43 (below) will be repeated for each storyboard.**
- At the end of the discussion response sheets will be collected and saved for the project team.

35. What do you believe is the main message of this ad?

36. Can you relate to the person in the ad?

37. How does this story make you feel?

38. Is there anything about the ad that is confusing, unclear, or hard to understand? If so, what?

39. Was there anything about the ad that you liked? If so, what?

40. Was there anything about the ad that you disliked? If so, what?

41. Does this ad make you want to take any action?

42. Does the ad make you want to encourage someone you know to take any action?

After all materials have been reviewed:

43. Which material was most appealing to you? Why?

Section 5: Wrap Up

(5 Minutes)

Example Response Sheet: *Storyboard B1*

After reviewing the story board, please check the box that most closely matches your opinions about the following statements.

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
A. This ad is convincing					
B. This ad grabbed my attention					
C. This ad was easy to understand					
D. I learned something new from this ad					
E. I trust the information in this ad					
F. This ad is believable					
G. I would talk to someone else about this ad					
H. This ad is annoying					
I. The people in this ad are believable					
J. This ad is worth remembering					
K. This ad is powerful					
L. This ad is informative					
M. This ad is meaningful					
N. I can identify with what the ad says					