

Attachment C1: 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 ninety 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 (0920-0800)

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

Section 1: Welcome and Introductions (5 minutes)

Introduction and Informed Consent

Welcome to our focus group discussion and thank you for coming. My name is _____, and I'm excited to be here to guide this discussion. 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 genetic counseling and testing for breast cancer risk. What we hear from you today will help CDC develop messages for young African American women.

Focus Group Process and General Rules

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.

This is meant to be an open discussion. We are taping the discussion, so I can write a report and get what you say exactly right, and this recording will be kept private and only be shared with my colleagues. At no time will your name appear in any reports or presentations that result from this work. Do you give permission to be audio recorded today?

My job is to keep us on the right track and moving along so that we're done in an hour and a half. I'd like to share a few ground rules before we get started:

- There are some interested colleagues observing our discussion.
- There are no right or wrong answers.
- All comments, positive and negative, what you know and don't know, are important.
- It is important to hear what everyone thinks, so please speak up and please let others do the same.
- Respect each other and personal opinions; you may not always agree, but we will be respectful of each other.
- Don't wait for me to call on you, but please speak one at a time.
- Respond to each other as well as to me.
- If I ask a question that you're not comfortable answering, feel free not to answer.

- If you need to go to the restroom or need a break, feel free to leave the room, but please come back as soon as possible because all opinions are important.
- Please turn off all of your mobile devices. You may put it on vibrate, but please do not disturb others during our discussion by checking your phone or leaving it on the table.

Do you have any questions before we get started?

Great! Let's start with a quick introduction. Please tell me your first name ONLY and your favorite family activity.

[Orienting question to get the group warmed up; moderator to spend only a few minutes here before moving to Section 2]

1. Today we're going to be talking about breast cancer risk. What are some signs or symptoms of breast cancer that you know of?

Section 2: Awareness and Understanding of Genetic Counseling and Testing (35 minutes)

2. 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?
3. Have you ever heard of genetic counseling for breast and ovarian cancer?

Probe:

 - How would you define genetic counseling?
 - *After answer, define for participants:* Genetic counseling is a process to evaluate and understand a family's risk of an inherited medical condition.
 - What have you heard about genetic counseling?
 - What happens during genetic counseling?
 - What is the role of a genetic counselor?
 - *After answer, define for participants:* A genetic counselor is a healthcare professional with specialized training in medical genetics and counseling. A genetic counselor can help you understand test results to help you make health decisions.

- How would you go about finding a genetic counselor?
 - When did you first hear of genetic counseling?
 - Where have you heard this information? What is the source? Do you consider this a trusted source? Explain.
4. Have you ever heard of genetic testing for breast and ovarian cancer?
- Probe:
- How would you define genetic testing?
 - *After answer, define for participants:* Genetic tests for cancer risk look for mutations, or errors, in specific genes that increase the chance that someone may get cancer.
 - What have you heard about genetic testing?
 - Are there different kinds of genetic tests?
 - Probe: direct-to-consumer vs. in-clinic; single-gene vs. panel
 - What happens during genetic testing?
 - What does it mean to get a positive result? Negative result?
 - When did you first hear of genetic testing?
 - Where have you heard this information? What is the source? Do you consider this a trusted source? Explain.
5. What is the difference between genetic counseling and genetic testing?
6. What have you heard about direct-to-consumer genetic testing (like 23andMe)?
- What is it?
 - *After answer, define for participants:* Direct-to-consumer genetic test kits are advertised and sold online and in stores. Consumers can take these genetic tests without the involvement of healthcare providers.
 - What are your thoughts about it? How do you feel 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.
 - Is direct-to-consumer genetic testing something you might be interested in trying? Why or why not?
7. What have you heard about genetic testing through a physician or genetic counselor?
- What is it?
 - What are your thoughts about it? How do you feel 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.
 - Is genetic testing through a physician or genetic counselor something you might be interested in trying? Why or why not?
8. Regarding genetic testing, what are the reasons you would choose to get tested?
- What might make it easier to get tested?
 - Probe: provider recommendation, insurance coverage, social support
 - What might make it harder to get tested?
 - Probe: cost, fear of results/not knowing what to do with positive results
 - Why would you choose not to get tested?
9. If you were to get genetic testing...
- What would you do if you found out you had positive results/changes in genes that put you at higher risk for breast cancer?
 - Who would you talk to?
 - Where would you go for information?
 - What do you think your doctor might say/recommend?
 - How would you feel if your doctor recommended medication to reduce risk? Lifestyle changes? Surgery? Taking a wait-and-see/monitoring approach?
 - What would you do if you found out you had negative results/no genetic risk factors?
 - Who would you talk to?
 - What do you think your doctor might say/recommend?

9a (alternative approach, in the case of limited response to Q9). Lisa is a 42-year-old African American woman who is unsure of her family health history. She decided to get genetic testing.

- What would she do if she found out she had positive results/changes in genes that put you at higher risk for breast cancer?
 - Who would she talk to?
 - Where would she go for information?
 - What do you think her doctor might say/recommend?
 - How would she feel if her doctor recommended medication to reduce risk? Lifestyle changes? Surgery? Taking a wait-and-see/monitoring approach?
- What would she do if she found out she had negative results/no genetic risk factors?
 - Who would she talk to?
 - What do you think her doctor might say/recommend?

10. For any of you that have had genetic testing before, what was your experience like?
- Why did you decide to get tested?
 - How did you get tested? Did you work with a genetic counselor? Did you use a direct-to-consumer product?
 - Do you know whether you were tested for BRCA1 and BRCA2 mutations or if you had multigene (panel) testing?
 - When making your decision to get genetic testing, did anyone talk to you about:
 - o Cost and insurance coverage?
 - o How your information would be used?
 - o What to do with your results once you had them?
 - o Who you could talk to about your results?
 - What were next steps like after getting your results? Did you meet with anyone to discuss your results? If so, how was that experience?
 - What actions did you consider taking as a result of your genetic testing results?
 - What actions did your doctor recommend after discussing your genetic testing results?

Section 3: Reactions to Messages and Materials (45 minutes)

There are three materials which will be tested during this section of the focus group. Approximately 10-20 minutes will be spent reviewing and discussing each batch of items.

The moderator will give each participant a copy of one handout at a time that present information about 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 each handout before beginning a discussion about each one. At the end of the discussion, each marked up material will be collected and saved for the research team.

BrightPink's ExploreYourGenetics.org Webpages (20 minutes)

11. How does this information make you feel?
12. Who do you think this is for?
13. 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?

14. How helpful is this information for you?
- What more would you want to know about genetic counseling and testing?
 - After reading this section, how likely would you be to take action? What kind of action would you take?
 - What might get in the way of you taking action? What might help you overcome those barriers?
15. What did you underline as important?
- What makes this important?
 - Is this part easy to understand?
16. 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?
17. What did you cross out as something to delete?
- What makes this something to remove?
18. Where should this be placed so you would receive it and read it?
19. What other changes or additions would you suggest to improve this resource?
- Is there any information that is important for you to know that was not included?
20. What about the design—does it work for you? Is it eye-catching?

FORCE Brochure: What you should know about genes and cancer (10 minutes)

21. How does this information make you feel?
22. Who do you think this is for?
23. 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?
24. How helpful is this information for you?
- What more would you want to know about genetic counseling and testing?
 - After reading this section, how likely would you be to take action? What kind of action would you take?
 - What might get in the way of you taking action? What might help you overcome those barriers?
25. What did you underline as important?

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

26. 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?

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

- What makes this something to remove?

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

29. What other changes or additions would you suggest to improve this resource?

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

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

23andMe Messages and Key Differences Table (15 minutes)

31. How does this information make you feel?

32. Who do you think this is for?

33. 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?

34. How helpful is this information for you?

- What more would you want to know about genetic counseling and testing?
- After reading this section, how likely would you be to take action? What kind of action would you take?
- What might get in the way of you taking action? What might help you overcome those barriers?

35. What did you underline as important?

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

36. 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?

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

- What makes this something to remove?

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

39. What other changes or additions would you suggest to improve this resource?

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

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

Section 5: Wrap Up (5 Minutes)

41. Since we started talking today, how have your feelings about breast cancer and young women changed from before this discussion?

42. Is there more information you would like to know?

43. That's all of my questions. Do you have any final comments on anything we've talked about?

Thank you so much; your help has been invaluable.