

Attachment B3: Discussion Guide for Ashkenazi Jewish Families (with a History of Breast Cancer)

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Discussion Guide: Ashkenazi Jewish Families (with a History of Breast 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 women ages 18-45.

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.

Ask primary recruit, “please introduce yourself and then tell me who you brought with you today and why you asked them to join you.” If introductions are very brief or unclear, the moderator can ask the group to tell a bit more about themselves by clarifying how they are related or describing an activity they enjoy as a family.

Section Two: Knowledge, Attitudes, and Beliefs – Breast and Ovarian Cancer in a Family Context (45 minutes)

1. Tell me a little bit about your family and how you communicate. How often do you see one another?
 - What are the most common ways you communicate? (i.e., phone, social media)?
 - What are some of the topics you talk most about?

- Do younger and older family members communicate about different things or in different ways?
2. Please tell me a little bit about your family's experience with breast and/or ovarian cancer.
- Who was diagnosed with breast or ovarian cancer?
 - Was everyone aware of the relatives' diagnosis or were there some family members who knew and others who didn't?
 - Where there reasons why the diagnosed relative did or did not share this information with all family members?
 - What information was shared about your relative(s) breast/ovarian cancer experience?
3. Within your family, have you had conversations about your family's cancer history?

If no:

- Is this something you think your family should discuss?

If so:

- What types of information should family members share with one another?
- Who should initiate the conversation?
- At what age is it appropriate to include family members in discussions on breast or ovarian cancer?
- Are there topics about breast or ovarian health that should not be discussed?
- Are there reasons why these topics should not be discussed?

If yes:

- Who initiated the conversations and why? How did they start the conversation?
- Who has been involved in those conversations? Are there family members who choose not to participate? Are there family members that were not included in conversations? Why?
- At what age is it appropriate to include family members in the discussion?
- When did you have those conversations? How frequently?
- What types of information do you or you and your family discuss? Are there any breast or ovarian health topics you do not want your family to discuss? Are there reasons why these topics should not be discussed?
- How would you characterize the tone or feel of most of those conversations?
- How do you handle it if some people in the family are uncomfortable with the topic?
- What terms exactly does your family use when referring to these diseases? ("cancer", "breast cancer", "ovarian cancer", "C", etc.)

4. What advice, if any, do family members provide to one another during these conversations?
 - What did you think about that advice (did you think it was trustworthy, accurate, supportive, helpful, etc.)? Why?
5. Did these conversations or experiences influence how you think about your own risk for breast cancer? Please describe.
6. Do you think any members of your family have taken action based on these conversations? These might be things like talking to their doctor, seeking out additional information on the topic, etc.
 - [As applicable] Why do you think some family members have taken action while others have not?
 - Any action you take to try and encourage others to take care of their breast health?
7. In your family, does everyone arrive at their own health choices independently or do you think some family members influence one another's choices?
 - How so? What characteristics seem to make certain family members influential?
8. Is there anything you can think of that might prevent family members from discussing their breast and/or ovarian cancer histories?
9. Do you think Ashkenazi Jewish families approach this topic or these discussions any differently than other types of families?
10. Can you think of anything that might help Ashkenazi Jewish families discuss their risk of breast or ovarian cancer with each other?
 - Information? Resources?
11. Can each of you describe the actions you personally take regarding your breast health? (self-breast exams, screenings, risk reduction behaviors [like maintaining a healthy weight, breast feeding your babies, provider discussions, seeking out health information from other sources, etc.])
12. Have any of 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 When was the first time you had this type of conversation? Did you initiate this conversation or did your doctor(s) ask if you [*had a family history of breast or ovarian cancer*]?
 - How long did this conversation last for?
 - What kind of information did the doctor ask you for?
 - Did the doctor provide you with any information to take home with you? If so what kind of information?
 - 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?

13. Can you think of anything that might help young women discuss their risk of breast or ovarian cancer with their doctors?

- Information? Resources?

14. 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?

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

16. Regarding breast cancer or any of the topics we have discussed today, what do you wish you knew more about? Do you have any questions or areas of confusion?

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

There are five materials which will be tested during this section of the focus group (See Attachment E). Five to ten minutes will be spent reviewing and discussing each item, including its content and layout.

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.

Focus Group - Material Rotation		
AJ Families	Miami	A1, B3, D3, C3, E1
	Miami	E1, A1, D3, B3, C3
	Dallas	C3, D3, B3, A1, E1
	Dallas	D3, B3, C3, E1, A1

A - Infographic (5 minutes)

The moderator will give each participant a copy of the infographic. 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

The moderator will allow participants to read the infographic 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 information is for?

- Is it relevant to the women in your family who are younger than 45?

19. What, if any, action would you take after seeing this?

- What would make you more likely to take action after looking at this?
- Is there anything else you would need to know before you could take action?
- Realistically, is this something you would share with other women? If so, who? (friends, co-workers, family members)

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 about the design and layout—does it work for you?

23. What other changes or additions would you suggest to improve the infographic?

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

B - Infographic (5 minutes)

The moderator will give each participant a copy of the infographic. 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

The moderator will allow participants to read the infographic 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.

24. How does this information make you feel?

25. Who do you think this information is for?

- Is it relevant to the women in your family who are younger than 45?

26. What, if any, action would you take after seeing this?

- What would make you more likely to take action after looking at this?
- Is there anything else you would need to know before you could take action?
- Realistically, is this something you would share with other women? If so, who? (friends, co-workers, family members)

27. What did you underline as important?

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

28. 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?
29. What about the design and layout—does it work for you?
30. What other changes or additions would you suggest to improve the infographic?
- Is there any information that is important for you to know that was not included?

C - Video (10 minutes)

- The moderator will distribute a brief response sheet to each respondent for capturing her emotional responses to the video
 - The moderator will show the group a brief video
 - Before any discussion ensues, the moderator will instruct participants to fill out the response sheet.
 - The moderator will then lead a discussion of the video.
 - At the end of the discussion response sheets will be collected and saved for the project team.
31. What do you believe is the main message of this video?
32. Who is this video for?
33. Can you relate to the person in the video?
34. How does this story make you feel?
35. Is there anything about the video that is confusing, unclear, or hard to understand? If so, what?
36. Was there anything about the video that you liked? If so, what?
37. Was there anything about the video that you disliked? If so, what?
38. Does this video make you want to take any action?
39. Realistically, is this the type of thing you would share with others online?

D - Fact sheet (10 minutes)

The moderator will give each participant a copy of the factsheet. 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

The moderator will allow participants to read and mark the factsheet 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.

40. How does this information make you feel?

41. Who do you think this is for?

42. Is this new information for you?

43. 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?

44. What did you underline as important?

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

45. 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?

46. What other changes or additions would you suggest to improve the webpage?

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

47. Are there any links or additional resources you'd like to see on this page?

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

E - Fact sheet (10 minutes)

The moderator will give each participant a copy of the factsheet. 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

The moderator will allow participants to read and mark the factsheet 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.

49. How does this information make you feel?
50. Who do you think this is for?
51. Is this new information for you?
52. 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?
53. What did you underline as important?
- What makes this important?
 - Is this part easy to understand?
54. 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?
55. What other changes or additions would you suggest to improve the webpage?
- Is there any information that is important for you to know that was not included?
56. Are there any links or additional resources you'd like to see on this page?
57. What about the design—does it work for you? Is it eye-catching?

Wrap Up

58. Thinking about the discussion we've just had, is there anything else you would want CDC to know about how families think about and discuss the issue of young women and breast/ovarian cancer?

Example Response Sheet: *Video*

After watching the video, please check the box that most closely matches your opinions about the following statements.

This video...	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
is convincing					
grabbed my attention					
was easy to understand					
taught me something new					
is trust-worthy					
is believable					
is annoying					
is believable					
is powerful					
is informative					
is hard to identify with					
would make me want to share it with someone else					