

Attachment C1: Discussion Guide for Focus Groups with Ashkenazi Jewish Young Women (With No Family History of Breast Cancer)

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Discussion Guide: Ashkenazi Jewish Young Women with No 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?

4. Are you an active member of any Jewish organizations? Do you regularly receive information online or from other media outlets (e.g. newspaper, TV) specifically for Jewish audiences?

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.

5. Do you consume any media that is specifically about [women's 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?

6. 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?

7. 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)**

- 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?
- Can you think of anything you've heard that might make some young women more likely to get breast cancer than others?
 - 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? Have you heard of any risk factors for breast cancer?
 - What would you like to know? What questions do you have?
- Have you heard anything specifically about Jewish women and breast cancer?
- What are some signs or symptoms of breast cancer that you know of? What might cause a woman to suspect she has breast cancer?
- Can you think of any conversations you've had with friends, co-workers, or others about breast cancer in the past 6 months?
 - What prompted the conversation?
 - What was discussed or shared?
 - Did it influence your thoughts on your own risk?
 - Did it make you consider taking any actions?
- Have you ever talked with a doctor or other provider about breast and ovarian cancer? Probe:
 - If yes,
 - What type of doctor? (PCP, OB/GYN, other)
 - 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 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?
14. Within your family, have you had conversations about your family's medical history?
- Who started the conversations and why?
 - Who has been involved in those conversations? Are there family members who choose not to participate?
 - When did you have those conversations? How frequently?
 - How would you characterize the tone and content of most of those conversations?
15. 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?
16. Have you heard about genetic testing specifically to help a young woman find out if she is at high risk for breast and ovarian cancer?
- 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.
17. Have you ever heard of anything women can do to reduce their risk of breast cancer?
18. 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.

Ashkenazi Jewish women will provide feedback on the following materials (Attachment C2). 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.

Ashkenazi Jewish Women - Ad Rotation		
	With no family history of breast or ovarian cancer	
	New York City, NY	Chicago, IL
Age 18-29	-	1 group
Materials Testing Order		One-pager D2, Storyboards C2,B1,A2, Factsheet E1
Age 30-44	1 group	-
Materials Testing Order	Factsheet E1, One-pager D2, Storyboards C2, A2, B1	

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.

19. How does this information make you feel?

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

21. 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?

22. What did you underline as important?

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

23. 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?

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

- What makes this something to remove?

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

26. 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?
- **[If not addressed by participants in response to earlier questions] What do you think about the statistic or percentage used here?**

27. 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.

28. How does this information make you feel?

29. Who do you think this is for?

30. 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?

31. What did you underline as important?

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

32. 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?

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

- What makes this something to remove?

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

35. 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 on this sidebar?
- **[If not addressed by participants in response to earlier questions] What do you think about the statistic or percentage used here?**

36. 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 37-45 (below) will be repeated for each storyboard.**
- At the end of the discussion response sheets will be collected and saved for the project team.

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

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

39. How does this story make you feel?

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

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

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

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

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

After all materials have been reviewed:

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

Section 5: Wrap Up

(10 Minutes)

Example Response Sheet: *Storyboard C2*

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					