

# Attachment D1: Discussion Guide for Focus Groups with American Indian/Alaska Native Young Women (With a Family History of Breast Cancer)

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# Discussion Guide: American Indian/Alaska Native 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 breast health and breast cancer. What we hear from you today will help CDC develop messages for young Native 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.*

## **Section 2: 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 Native American organizations? Do you regularly receive information online or from other media outlets (e.g. newspaper, TV) specifically for Native American 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 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?
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?
8. Have you heard of the *Bring Your Brave* campaign?
- If so, what have you heard/seen?
  - How, if at all, have you engaged with the campaign?

### **Section 3: Awareness of Risk Factors for Breast and Ovarian Cancer (30 minutes)**

9. 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?
10. 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?
11. 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?

12. Have you heard anything specifically about Native American women and breast cancer?

- What have you heard?

13. What are some signs or symptoms of breast cancer that you know of? What might cause a woman to suspect she has breast cancer?

14. 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?

15. 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? Do conversations include family members on both your mother's and father's side? Do conversations include family members across generations?
- Are there family members who choose not to participate? Why?
- When did you have those conversations? How frequently?
  - Early in diagnosis [*of family member*]
  - During treatment [*of family member*]
  - Post treatment [*of family member*]
- What types of information do you discuss?
  - Medical/clinical/research
  - Emotional/support
  - 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? If so, in what way?

16. 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?

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

Probe:

- If so, what have you heard? What have you heard about direct-to-consumer testing (like 23andMe)? What about genetic testing through a physician or genetic counselor?
- 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.
- 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?

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

- What have you heard?

- What might motivate someone to take action to reduce their risk of breast cancer?

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

#### **Section 4: Reactions to Campaign Messages and Materials (25 minutes)**

There are two 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 and messages.

##### What Every Young Woman Needs to Know Infographic

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

20. How does this information make you feel?

21. Who do you think this is for?

22. 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?

23. What did you underline as important?

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

24. 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?

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

- What makes this something to remove?

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

27. 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?

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

### Take Action Infographic

The moderator will give each participant a copy of an infographic about prevention/risk reduction measures for young women. Components of this infographic include information about family history, genetic counseling and testing, and lifestyle choices. 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 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.

29. How does this information make you feel?

30. Who do you think this is for?

31. 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?

32. What did you underline as important?

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

33. 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?

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

- What makes this something to remove?

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



36. 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?
37. What about the design—does it work for you? Is it eye-catching?

**Section 5: Wrap Up (5 Minutes)**

38. Since we started talking today, how have your feelings about breast cancer and young women changed from before this discussion?
39. Is there more information you would like to know?
40. 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.