

**Project Title:** CDC Bring Your Brave

**Attachment Title:** Focus Group Discussion Guide - English

**Attachment Number:** #5a

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## Session Overview: Total time—90 minutes

<p><b>SECTION A: Introduction and Icebreaker (5 minutes)</b></p> <p>The moderator will explain the purpose of the study, present the ground rules, and allow participants to ask questions.</p>
<p><b>SECTION B: Knowledge, Awareness, and Beliefs about Early Onset Breast Cancer (EOBC) and EOBC Risk (25 minutes)</b> This section will assess participant knowledge, awareness, and beliefs about EOBC and barriers to knowing one's personal risk.</p>
<p><b>SECTION C: Materials Testing (45 minutes)</b></p> <p>Participants will be asked to share reactions to four materials: i) social media graphics; ii) infographic; and iii) health care provider (HCP) provider guide. This section will assess initial reactions, message comprehension, relatability, believability, and how persuasive the material is. Participants will also be asked to discuss opinions about the imagery and their intentions following the exposure to the material.</p>
<p><b>SECTION D: Communications Preferences (10 minutes)</b></p> <p>Participants will be asked about where they would expect to see the three types of materials, where they would prefer to see them, and the likelihood that they would share the materials with friends or family members.</p>
<p><b>SECTION E: Conclusion (5 minutes)</b></p> <p>Moderator ensures that all questions are answered and all comments have been heard.</p>

## Section A. Introduction and Icebreaker (5 minutes)

Thank you for talking to me today, your time is greatly appreciated. My name is \_\_\_\_\_, and I work for Fors Marsh Group (or FMG), which is an independent research company. This means that I'm here to listen to you and what you have to tell me, and I have no stake in how you respond.

This study is sponsored by the Centers for Disease Control and Prevention (or CDC). Today, I am going to be asking you to share your thoughts, experiences, and opinions about breast cancer.

We will have about 90 minutes for our discussion. Before we get started, I want to go over a few general rules for our discussion today:

- Your participation is voluntary. You have the right to withdraw from the study at any time. You don't have to answer every question if you don't want to. If you need to go to the restroom during the discussion, please feel free to do so, just please let me know.
- Next, there are no wrong answers, and we are not here to evaluate or judge you. Our purpose for being here is to hear what you think, so please speak up, especially if what you have to say is different than what someone else is saying. You may have a thought that represents what a lot of other people think.
- With that, we are not here to come to a consensus, and we recognize that you all may have different perspectives on and experiences with the various topics we discuss today. That's OK! Please keep an open mind as we talk today and respect each other's opinions and experiences.
- Everything we talk about here is confidential; your individual responses will not be linked back to you in any way and your name will not be associated with anything you say in our reports. On that note, we ask that you (1) only use your first name during the group today and (2) refrain from discussing anything we talk about today outside of this group. Does anyone have any questions so far?
- There are some people from the research team observing and taking notes so I can be present in our discussion. Notetakers will be recording what is being said, not who is saying what. Even though people are observing, please speak openly about your opinions and experiences, since we are here to learn from you.
- We will also be audio and video recording this session. I will be speaking with a lot of people for this project, and it will be impossible for me to remember everything that is said in these conversations. Once the focus group is completed, we will refer to the recordings and notes when writing a final report. It will not identify you, and your information will not be used beyond the scope of this focus group.
- If you are in an area with background noise, please remember to mute yourself whenever you are not speaking to prevent any disruptions during the focus group. Please speak one at a time. You can raise your hand with the button at the bottom of your screen or you can

physically raise your hand if you have a thought while someone else is talking. I will see that you've raised your hand and I will get to you.

- I will be sharing some images and content throughout the focus group, so please make sure you can see your computer screen.
- Please turn your cell phone off or switch it to silent mode.

Do you have any questions before we begin?

Before we dive into our conversation, do you consent to taking part in this focus group? By consenting to be in the focus group, you are also consenting to being recorded. Please verbally respond yes or no. **[Moderator – be sure to receive a verbal yes or no from each participant prior to moving forward with the focus group]**

Great, thank you! Now, I'd like to kick us off with some introductions. As I call out your name, I ask that you introduce yourself and tell us your favorite thing to do in your spare time. **[Probe on their responses]**. We will begin recording this session after everyone has introduced themselves.

[Introductions and Icebreaker]

It's wonderful to meet you—let's get started. I am going to go ahead and start the recording now.

**[START RECORDING]**

**[Moderator – Questions in the guide are meant for all groups unless noted otherwise. For example [FOR PREVIVOR ONLY] will precede questions specific to that group only.]**

## SECTION B: Knowledge, Awareness, and Beliefs about EOBC and EOBC Risk (25 minutes)

To start off our discussion, I'd like to learn a little more about your experience seeing a health care provider.

1. What type of health care provider(s) do you typically see? **[Moderator: Probe on their response—is it a gynecologist, a breast specialist, primary care doctor, nurse, or nurse practitioner?]**
  - a. How often do you see this health care provider?
  - b. When did you last visit this health care provider?
  - c. **PROBE:** Do you go to a clinic where you see a different health care provider each time or do you have a regular health care provider that you see each time?
2. How did the COVID-19 pandemic impact the frequency with which you saw your health care provider(s)?
  - a. **PROBE:** What other factors, if any, affected your ability to see your health care provider more/less?
    - i. **PROBE:** Are those still factors today?
    - ii. **PROBE:** How did not going make you feel?



- b. **PROBE: [If genetic testing is mentioned]** What does that look like? How would you use that information?
- c. **PROBE: [If someone mentions breast exams]** How often do you check your breasts for lumps or changes?
  - i. **How often should you check your breasts for lumps or changes?**
- d. **PROBE: [if someone mentions MRIs or mammograms]** How often do you get those screenings?

Just for your awareness, CDC notes that you can learn about your personal risk for early onset breast cancer by learning your family history of cancer, from both your biological mother's and father's sides. Understanding your family history can help you learn whether you have a higher risk for getting hereditary breast or ovarian cancer at a young age. It can also help you better understand if you should talk to your doctor about your risk, and if genetic counseling and testing is right for you.

- 8. What is your reaction to learning your family history of cancer from your biological mother's and father's sides as a way to understand your own risk for breast cancer at a young age?
  - a. **PROBE:** To what extent were you already aware of this?
- 9. What barriers can you think of that would make knowing your own risk for breast cancer at a young age more difficult?
  - a. What makes you say that?
  - b. What would help you deal with this challenge?
  - c. **[FOR HISPANIC GROUP ONLY: IF LANGUAGE HAS NOT BEEN MENTIONED]** How does language—for example, having a health care provider speak Spanish or provide materials in Spanish—affect your decision to learn about your own risk for breast cancer at a young age?
- 10. Thinking about some of the ways to learn about your risk, how likely are you to take action to learn about your own risk for breast cancer?
  - a. What kind of support would make it easier for you to learn about your own risk for breast cancer? (**Probe on things that would make the process easier**)
  - b. What would make you less likely to learn more about your own risk for breast cancer? (**Probe on barriers, particularly cost, access to the right doctor**)

**[FOR PREVIVORS ONLY: Q10–Q13]**

- 11. How did you first learn about your risk for early onset breast cancer?
  - a. How old were you? What got you to start at this age?
  - b. What motivated you to learn about your risk for early onset breast cancer?
  - c. What prompted you/how did you make the decision to understand your own risk?
  - d. What did that process look like?
    - i. What challenges did you encounter?
    - ii. What helped you?
    - iii. What made you hesitate, if at all, to learning about your risk for early onset breast cancer?
  - e. What were your feelings around learning about your own risk for breast cancer at a young age?
    - i. How was your mental health impacted after learning your own risk for breast cancer at a young age?
    - ii. What support did you have, if any, after learning about your own risk for breast cancer at a young age?

- f. What other resources might help someone learn about their risk for early onset breast cancer?
12. What medical professionals have you interacted with throughout your experience with early onset breast cancer? (**Moderator:** If needed, ask if they have seen a breast specialist, oncologist, or primary care doctor.)
- What types and how often do you see these medical professionals?
  - What role did these medical professionals play in helping you manage your risk for early onset breast cancer?
  - Which medical professionals are you **actively** working with right now to manage your early onset breast cancer risk? (**Moderator:** Would like to hear the specific medical professionals they are working with—examples include gynecologist, general oncologist, gynecologic oncologist, breast oncologist, primary care physician, breast surgeon, plastic surgeon, general surgeon, other specialized surgeon.)
    - What is their role in helping you manage your early onset breast cancer?
    - What type of doctor were you first referred to once you were diagnosed as being high risk for breast cancer?
  - How was your experience interacting with these medical professionals?
    - PROBE:** What did you like about this experience? What did you dislike?
  - If you see more than one provider, how are your providers communicating with each other about your care?
    - PROBE:** Are the providers in the same hospital system and in communication? If your medical providers are in separate practices, then how are they communicating about your care, if at all?
13. When you were first told by a medical professional that you are at risk for early onset breast cancer, what options, if any at all, were presented to you to help manage your risk? (**Moderator:** If needed, probe on hormone therapies, increased screening, and preventive surgeries.)
- What was your initial reaction when hearing about those options (or the lack of options)?
  - What feelings did you have about the options?
14. What recommendations would you have for other women who may be unaware of their risk for early onset breast cancer?
- What would you tell them?
  - How would you motivate them to learn about their personal risk, if at all?
    - How would you do that?
    - [IF PARTICIPANT(S) NOTE THEY WOULD NOT WANT TO MOTIVATE OTHERS]** For what reasons would you not motivate others to learn about their personal risk?
  - What if, anything, would you warn women who may be unaware of their risk about?

## SECTION C: Materials Testing (45 minutes)

Material 1: Social Media Posts (2 social media posts per group) (~15 minutes)

Material 2: Infographic (~15 minutes)

Material 3: HCP Conversation Guide (~15 minutes)

Wonderful, thank you for sharing! Next, we are going to discuss four different materials related to early onset breast cancer communications. Of note, these materials are just drafts and not final. Your feedback and reactions today will help guide the development of the final materials.

Now I'm going to share my screen. **[Give brief context for the material you are about to show. Present material to group]** Please let me know if you cannot see my screen.

Can everyone see the material (material [x])? Great, I am going to give you a minute to read the material then we will discuss your initial reactions.

<p><b>Initial Reactions</b></p>	<ul style="list-style-type: none"> <li>• Where would you expect to see this material?</li> <li>• Where would you prefer to see it?</li> <li>• What about this material might make you stop and read it?</li> <li>• How would you sum up your first impression of this message in just a few words? <b>(7d)</b> <ul style="list-style-type: none"> <li>o Do you like it?</li> <li>o Not like it?</li> <li>o What makes you say that?</li> </ul> </li> <li>• <b>[If needed]</b> What feelings do you have in reaction to this material? Anything positive? Anything negative? <b>(8d)</b></li> </ul>
<p><b>Main message</b></p>	<ul style="list-style-type: none"> <li>• What is the main idea that this material is trying to get across, in your own words? <b>(1d)</b> <ul style="list-style-type: none"> <li>o How well do you think the main ideas come across? <b>(2d)</b></li> </ul> </li> <li>• Are there any words that are unusual or unfamiliar? <b>(4d)</b></li> <li>• <b>ALTERNATIVE:</b> Is there anything confusing, unclear, or hard to understand? <b>(6d)</b> <ul style="list-style-type: none"> <li>o What other words can be used in their place?</li> </ul> </li> </ul>
<p><b>Believable/ Compelling</b></p>	<ul style="list-style-type: none"> <li>• Is this message believable or not? <b>(15d)</b> <ul style="list-style-type: none"> <li>o For what reasons?</li> </ul> </li> <li>• What additional information would you need in order to more strongly believe this message? <b>(17d)</b></li> </ul>
<p><b>Resonate/Relatable</b></p>	<ul style="list-style-type: none"> <li>• <b>(Probe on segment specific imagery for relatability, e.g., Black, Hispanic, AI/AN, Cisgender LBQA)</b></li> <li>• Who would you say they are trying to reach? <b>(24d)</b></li> <li>• Does it seem like this message is talking to you and people like you? Or to someone else? <b>(24d)</b></li> </ul>



	<ul style="list-style-type: none"> <li>• What in the message suggests it is talking to you and people like you (or someone else)? <b>(24d)</b></li> <li>• Do you see yourself doing this or something like it? <b>(26d)</b> <ul style="list-style-type: none"> <li>• For what reasons?</li> </ul> </li> </ul>
<b>Intentions</b>	<ul style="list-style-type: none"> <li>• What action would the message prompt you to take? <b>(3d)</b></li> <li>• Which actions, if any, sound doable to you? <b>(38d)</b> <ul style="list-style-type: none"> <li>• Could you tell me more about that?</li> </ul> </li> <li>• How feasible is it that you would try to do this? <b>(39d)</b> <ul style="list-style-type: none"> <li>• For what reasons?</li> <li>• What other information would you need to do something?</li> </ul> </li> </ul>
<b>Imagery</b>	<ul style="list-style-type: none"> <li>• How do you feel about the images used in this concept? <b>(5e)</b></li> <li>• To what extent does the image fit with the message this material is trying to convey?</li> <li>• What, if anything, bothers you about the images, colors, or graphics? <ul style="list-style-type: none"> <li>• What specifically bothers you?</li> </ul> </li> <li>• What can we do to improve this image?</li> </ul>
<b>Red Flags/Unintended Consequences</b>	<ul style="list-style-type: none"> <li>• What, if anything, do you find potentially problematic or offensive about this?</li> </ul>
<b>Material Specific Probes</b>	<p><b>Social Media Graphics</b></p> <p><b>For Unaware Audience:</b></p> <ul style="list-style-type: none"> <li>• How comfortable do you feel talking about breast cancer with family members? <ul style="list-style-type: none"> <li>• <b>PROBE:</b> What would make you comfortable or hesitant to discuss breast cancer risk with family members?</li> </ul> </li> <li>• What steps would you take to figure out whether you have a family history of breast cancer? <ul style="list-style-type: none"> <li>• <b>PROBE:</b> How comfortable would you be talking to a health care provider about your breast cancer risk? [<b>Moderator: probe whether they have a provider, are they comfortable with their provider, etc.</b>]</li> </ul> </li> <li>• After viewing these three options, which phrasing do you prefer?</li> <li>• <b>[CISGENDER LBQA ONLY]</b> What has been your experience with finding a health care provider with whom you are comfortable discussing your breast cancer risk? <ul style="list-style-type: none"> <li>• <b>PROBE:</b> Are there certain qualities/characteristics you look for in a health care provider?</li> <li>• <b>PROBE:</b> How can a health care provider better meet your needs to discuss your breast cancer risk?</li> </ul> </li> </ul> <p><b>For Previvor Audience:</b></p>

- After viewing these three options, which phrasing do you prefer?
- **[FOR BLACK, OPTION 3]** What does the phrase “manage your risk” mean to you?
- **[FOR BLACK, OPTION 1]** You’ll notice this message talks about speaking up about your breast cancer risk. How comfortable do you feel talking about breast cancer with family members?
  - **PROBE:** What would make you comfortable or hesitant to discuss breast cancer risk with family members?
- **[FOR BLACK, OPTION 2]** What does the phrase “breast cancer story” mean to you?
  - o **PROBE:** How comfortable do you feel sharing your breast cancer story with family members and those around you?
  - **PROBE:** What would make you comfortable or hesitant to share your breast cancer story with others?
- **[FOR H/L, OPTION 1]** What does the phrase “talking about your breast cancer” mean to you?
  - **PROBE:** How comfortable do you feel talking about your breast cancer risk?
  - **PROBE:** What would make you comfortable or hesitant to share your breast cancer risk with others?
- **[FOR H/L, OPTION 2]** What does the phrase “don’t hold back with your health care provider” mean to you?
- **[FOR H/L, OPTION 3]** What does the phrase “share it with your family to help other generations” mean to you?
  - **PROBE:** In what ways can sharing what you know about your risk help other generations?
  - **PROBE:** How comfortable do you feel sharing your breast cancer risk with family members?
- **[FOR AII/AN, OPTION 2]** How comfortable do you feel talking about your breast cancer risk with others?
  - **PROBE:** What would make you comfortable or hesitant to share your breast cancer risk with others?
- **[FOR CISGENDER LBQA, OPTION 2]** How comfortable do you feel speaking up about your breast cancer risk with others?
  - **PROBE:** What would make you comfortable or hesitant to speak up about your breast cancer risk with others?
- **[FOR GEN POP, AII/AN, CISGENDER LBQA, Option 3]:** What is the difference between a “doctor” and a “health care provider,” if anything?
  - **PROBE:** Do you prefer one term over the other? How come?

#### **Infographic**

#### **For Unaware Audience:**

- Which of these risk factors were you aware of?
  - o **PROBE:** Which are new to you?
- Which of these steps for managing your breast cancer risk were you familiar with?
- Which of these steps have you taken, if at all?
- How comfortable are you scheduling regular doctor’s appointments or screenings?
  - o **PROBE:** What, if any, barriers are there making this difficult for you to do?

#### **For Previvor Audience:**

	<ul style="list-style-type: none"> <li>• Which of these options have you discussed with your health care provider? <ul style="list-style-type: none"> <li>o <b>PROBE:</b> What did your health care provider tell you? / What was that conversation like?</li> <li>o <b>PROBE:</b> How comfortable were you discussing those options with your health care provider?</li> </ul> </li> <li>• What important steps are missing from this list in terms of managing one's breast cancer risk?</li> <li>• What additional steps would make it easier to better manage one's personal risk?</li> </ul> <p><b>HCP Guide</b></p> <ul style="list-style-type: none"> <li>• How are these questions similar to or different than the questions you have discussed with your provider? <ul style="list-style-type: none"> <li>o <b>PROBE:</b> What, if any, questions or tips are missing from this guide?</li> <li>o <b>PROBE:</b> Would you use a guide like this?</li> <li>o <b>PROBE:</b> Do you think these are the right questions to address your concerns about early onset breast cancer?</li> </ul> </li> <li>• What would make it easier to discuss these questions with your provider?</li> <li>• <b>[FOR PREVIVORS ONLY]</b> How frequently are you having these conversations with your provider? <ul style="list-style-type: none"> <li>o <b>PROBE:</b> How comfortable are you discussing these questions with your health care provider?</li> </ul> </li> </ul>
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**(Moderator: Ask the questions below after showing all three materials.)**

1. **[FOR UNAWARE ONLY]** After seeing these materials, what is the likelihood that you will take action to learn your risk for early onset breast cancer?
2. **[FOR PREVIVOR ONLY]** To what extent do these materials motivate you to consider your options when managing your risk for early onset breast cancer?
  - a. To what extent do these materials motivate you to make sure you stay up to date on your screenings, care, and/or preventive surgeries?

## SECTION D: Communications Preferences (10 minutes)

I really appreciate you offering your opinions on this. Thank you for sharing. Now, I'd like us to discuss the best ways to communicate these types of materials with you.

1. How do you prefer to get health information?
  - a. For what reasons did you mention/not mention the Centers for Disease Control and Prevention (or CDC)?
  - b. What format do you prefer the information be in?
2. **[FOR HISPANIC GROUP ONLY]** In what language would you prefer to see these materials?

3. How likely are you to share any of this information with a family member?
  - a. How likely are you to share any this information with a friend?
4. How would you share this information? (e.g., word of mouth, social media, share print material, etc.)
  - a. **PROBE:** What information would you share?

## SECTION E: Conclusion (5 minutes)

This has been a very helpful session. Thank you so much for taking time out of your day to talk with me and share your perspectives and experiences. Before we wrap up, is there anything else that you would like to share or that we might have missed?

**[TIME PERMITTING]** If you don't mind, I am going to take just a moment to see if my team has any additional follow up questions for you. **[Ask any additional questions.]**

I'm going to share a link to a CDC website with information on early onset breast cancer in case you are interested in learning more about the topic. **[Insert link in the Zoom chat]**

[https://www.cdc.gov/cancer/breast/young\\_women/bringyourbrave/index.htm?utm\\_campaign=CDC\\_BYB\\_22&utm\\_source=Google&utm\\_medium=SEM&utm\\_content=cdcb](https://www.cdc.gov/cancer/breast/young_women/bringyourbrave/index.htm?utm_campaign=CDC_BYB_22&utm_source=Google&utm_medium=SEM&utm_content=cdcb)

Ok, thank you again for your time. Are there any final questions? If not, you are free to go. You will get an email with your incentive within a few weeks. Have a wonderful day!