

NCI Formative Research with Rural and Uninsured Consumers Perspectives on Cancer and Related Communications: A Focus Group Study

Attachment B: Moderator's Guide

Participants with No Cancer Experience

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I. OPENING REMARKS AND INTRODUCTIONS (10 minutes)

- A. **Hello and welcome.** My name is _____ and I work for the Academy for Educational Development, or AED. We're working with the National Institutes of Health (NIH) on a project, and talking to people in several locations across the country about cancer.
- B. **Purpose.** During the next two hours, we will ask you to discuss some of your thoughts and experiences related to cancer prevention, diagnosis, and treatment, as well as communications on these topics. Your input and ideas will help inform NIH about how to provide cancer-related information materials and educational resources to the public.
- C. **Thanks.** We appreciate you taking the time to share your thoughts and opinions with us. Thank you for being here.
- D. **Disclosure and Process.** Before we get started, I'd like to tell you how groups like this usually work.
 - 1. First, you'll notice that we're taking notes as well as tape recording our conversation. The recording is to help us remember what you said, and the note taking is a backup in case the recorders break.
 - 2. None of the information that is written down and recorded during this session will be connected to you in any way. Your confidentiality will be maintained.

3. After we have written a report about all the opinions we have heard here and in other locations, the tapes and notes will be destroyed. Your name or any other personal information will not appear in the report.
4. When we have groups like this, we usually set ground rules that we can all agree on. Here is a list of ground rules we have used. Let me know if you have others to add. [POST LIST]
5. Can we agree on these ground rules? Are there any others you would like to add? [IF THERE IS CONSENSUS, ADD TO LIST.]

GROUND RULES

- There are no right or wrong answers
- It's okay to disagree
- Each person's comments are important and valued
- No judging or criticizing others or what they say
- One person speaks at a time
- Speak loudly and clearly
- Don't have to answer every question
- Please be honest and tell us how you really feel.

E. *Participant Introduction.* Let's get started. Please tell everyone:

- Your name
- Where you are from (what town/city/county you live in now)
- Who lives in your household

II. PERSONAL INSURANCE STORY (25 minutes)

Let's get started. First, I would like to know more about you. Each of you has unique personal circumstances related to some of the topics we will be discussing today, such as your health insurance status/coverage and your healthcare experiences. Based on the ground rules that we all agreed upon, you can be assured that you will not be judged in this group. But just so you know, everyone in this group does/does not have health insurance, is/is not currently working, and have not had to confront cancer personally, in their immediate family, or in their circle of close friends.

A. *Uninsured groups* [INSURED GROUPS, SKIP TO II.B.]

Please tell us how you came to not have health insurance. Also, please share whether your family members have health coverage and how they came to have it or not have it. Let's go around the table.

We are interested in how not having insurance coverage affects your decisions and experiences related to health.

1. When do you seek professional healthcare? In what circumstances? What health services do you get?
 - Which healthcare services do you put-off or forego altogether, if any? [Probe: What effect does your insurance status have on this?]
 - What other factors affect whether or not you seek healthcare? (e.g., access to transportation, schedules, geographic location, child care)

2. Where do you go to get healthcare? (e.g., clinic, ER, private physician) [Probe: Usual source of care or inconsistent sources of care? General medicine only or specialized care? Alternative sources?]
 - How does your lack of health insurance impact these choices?
 - What other factors influence where you go for services? (e.g., wait times, physicians/staff, geographic location, transportation, child care)

3. How does where you live [in an urban/suburban/rural area] affect how, when, and where you get healthcare?

4. We have already talked about several issues, but what other problems have you faced because you don't have health insurance?
 - How do you deal with these challenges? Share some example of how you are able to work around them.
 - What are some problems that have you not been able to overcome? [Probe: Sacrifices to health, sacrifices in other areas?]
 - How would having health insurance address these issues?

B. *Insured groups*

Please tell us how you came to have health insurance. Also, please share whether your family members have health coverage and how they came to have it or not have it.

We are interested in how your health insurance coverage affects your decisions and experiences related to receiving health care.

1. When do you go get professional healthcare? In what circumstances? What health services do you get?
 - Which healthcare services do you put-off or forego altogether, if any? [Probe: What effect does your insurance coverage have on this?]
 - What other factors affect whether or not you get healthcare? (e.g., access to transportation, schedules, geographic location, child care)

2. Where do you go to get healthcare? (e.g., clinic, ER, private physician)

- How does your health insurance coverage impact this?
 - What other factors affect where you go for health services? (e.g., wait times, physicians/staff, geographic location, transportation, child care)
3. How does where you live [in an urban/suburban/rural area] affect how, when, and where you get healthcare?
4. Today, most households in this country struggle with getting and paying for healthcare, even those that have health insurance coverage.
- What are some issues that you face related to paying for healthcare?
 - How would you describe the burden of paying your portion of insurance premiums, deductibles, and co-pays in your household?
[IN INSURED GROUPS, ASK:] Who pays premiums? What portion?
 - How do you deal with these challenges?

III. CANCER PREVENTION, SCREENING, DIAGNOSIS, AND TREATMENT (65 minutes)

It is my understanding that none of you have had cancer and don't have an immediate family member or close friend who has had cancer. But probably most of you have known a neighbor, coworker, or friend who has, so this may be a topic that brings up emotions and might be difficult to talk about. Mostly, we are going to talk about cancer prevention and screening, including your personal experiences and behaviors. Please share only what you feel comfortable discussing with the group.

A. *Feelings about Cancer and Types of Cancer* (10 minutes)

1. What thoughts and feelings do you have about cancer? Please describe them.
[Probe: How much do you worry that you or your loved ones will get cancer?]
2. What are some types of cancer that come to mind?
[WRITE CANCERS PARTICIPANTS MENTION ON A FLIPCHART]

We will talk more about this list later.

B. *Cancer Prevention* (20 minutes)

1. What are some things that affect a person's chances of getting cancer?
[Probe: Do you believe cancer can be prevented? To what extent?]

2. What can people do to prevent or reduce the chances that they will get cancer? [Probe: quit smoking, improve diet/nutrition, exercise regularly]
3. Thinking about how you live and your healthcare, what actions have you taken or encouraged others to take in order to prevent cancer?
 - How do these things help prevent cancer? [Probe: Which cancers?]
 - What motivated you to take action? Did something happen?
 - How hard is it to actually take these steps in order to prevent cancer? [Probe: What makes it easier for you? What makes it more challenging?]
4. What influence does your lack of health insurance/insurance coverage have over what you do or do not do to prevent cancer? [Probe: Effect on access to preventive care, tobacco cessation support, and information]
 - [IN INSURED GROUPS, ASK:] What information about cancer prevention have you gotten from your insurance plan? In what context? How useful was it?
 - [IN WORKING GROUPS: ASK:] What about from your employer?
5. How does where you live [in an urban/suburban/rural area] affect what actions you take in order to prevent cancer? [Probe: Effect on access to preventive care, tobacco cessation support, food/physical activity environment, and information]
6. What other factors impact your efforts to prevent cancer? How so?
7. Tell me a little about how you go about getting information about preventing cancer. [Probe: What information do you look for? What resources do you use? Where do you look? Who do you ask?]
 - How easy or difficult was it to find the information that you were looking for? [Probe: Was there any information that you wanted to have but had difficulty finding? What was it?]
 - What or who are the most helpful resources for information on cancer prevention that you have used? [Probe: Which materials/resources, media/channels/sources, people/ intermediaries, and/or organizations? Who do you think should be providing this information?]
 - What kinds of formats, materials, resources, and services do you find to be the most useful way of getting cancer prevention information? (e.g., print materials, Web site, e-newsletters, hotlines, videos, podcasts)
 - What are some good ways to offer cancer prevention information to make it available to adults like you? [Probe: Through which dissemination channels? (e.g., doctors/nurses, advocacy/community groups, TV/radio programs, online communities)]

- [IF INTERNET IS MENTIONED, ASK:] How have you found information on cancer prevention online? [Probe: Use of search tools and terms? Which sites?]
- What additional information about cancer prevention do you need?

C. Cancer Screening (25 minutes)

1. What does the phrase ‘cancer screening’ mean to you? [Probe: perceived benefits, negative associations, feelings/emotions]
2. Tell me some of the cancer screenings tests you have heard of.

[FOR EACH SCREENING TEST MENTIONED, ASK:]
 - What do you know about this screening test? What is involved?
 - What is the recommendation for this test – who should get it, how often?
 - How do you feel about this screening test?
4. Which of these cancer screening tests have you gotten in your life? [Probe: How often? Where? For what reasons?]
 - What makes it easier for you to get this test?
 - What makes it challenging? How have you overcome these challenges?
5. Now let’s talk about screening tests that you have not gotten. What are some reasons that you/they have not gotten these tests?
6. What issues have you faced when trying to get cancer screening tests?
 - What impact does your lack of health insurance/health coverage or plan have over whether, how, when, and where you or they get screening tests? [Probe: Effect on access to screening and information]
 - How convenient are the places where you/they can go to get screening tests? [Probe: What affect does where you live (in an urban/suburban/rural area) have? Do barriers like geographic location or distance from home and transportation prevent you or they get screened for cancer?]
 - What other factors affect this? [Probe: facilitators and barriers]
 - How do you deal with these issues?
7. Describe how you go about getting information about cancer screening tests. [Probe: What information do you look for? What resources do you use? Where do you look? Who do you ask?]

- How easy or difficult was it to find the information that you were looking for? [Probe: Was there any information that you wanted to have but had difficulty finding? What was it?]
- What or who are the most helpful resources for information on cancer screening tests? [Probe: Which materials/resources, media/channels/sources, people/ intermediaries, and/or organizations? Who do you think should be providing this information?]
- [IN INSURED GROUPS, ASK:] What information about cancer screening have you gotten from your insurance plan? In what context? How useful was it?
- [IN WORKING GROUPS: ASK:] What about from your employer?
- What kinds of formats, materials, resources, and services do you find to be the most useful for getting information on cancer screening? (e.g., print materials, Web site, e-newsletters, hotlines, videos, podcasts)
- What are some good ways to offer cancer screening-related information to make it available to adults like you? [Probe: Through which dissemination channels? (e.g., doctors/nurses, advocacy/community groups, TV/radio programs, online communities)]
- [IF INTERNET IS MENTIONED, ASK:] How have you found information on cancer prevention online?
- What additional information about cancer screening tests do you need?

D. Cancer Diagnosis and Treatment (10 minutes)

1. What role do you think screening tests have in diagnosing cancer?
2. What impact does early detection or diagnosis of cancer have?
[Probe: disease stage, treatment options, prognosis, and surviving/dying]
3. What issues do you think people in your community face getting cancer treatment once they have been diagnosed with the disease?
 - How easy or hard do you think it is for them to get needed treatment?
 - Where do people in your community go for cancer treatment? [Probe: Barriers - distance from home, transportation, schedules]
 - What impact does having health insurance/health coverage or plan have over whether, how, when, and where you get screening tests?
4. If you or a loved one were diagnosed with cancer, how do you think you would go about getting information about the disease and treatment options? [Probe: What resources would you use? Where would you look? Who would you ask?]
 - What cancer information materials and/or educational resources would you want to have available to you? [Probe: In what format(s)?]

- What topics would you want to learn more about if you, an immediate family member, or close friend were diagnosed with cancer?
 - What or who do you think would provide this information for you and your loved ones if you or they had cancer? [Probe: Which materials/resources, media/channels/sources, people/ intermediaries, and/or organizations? Through which dissemination channels?]
 - IN INSURED GROUPS, ASK: Would you go to your insurance company for information? What would you expect them to provide?
5. How familiar are you with clinical trials for cancer prevention and treatment?
- What have you heard about them?
 - Where would you go for information about clinical trials? From whom?
 - What else would you like to know about clinical trials?

IV. AWARENESS OF NCI AND REACTION TO NCI RESOURCES (15 minutes)

A. *Awareness of NCI.* How familiar are you with the National Cancer Institute (also known as NCI), which is part of the National Institutes of Health?

1. Where have you seen or heard of it? (e.g., newspaper, TV programs, Internet, from other people, etc.)
2. What is your impression of this organization? [Probe: Is it part of the Federal government? What does it do? Is NCI trustworthy?]
3. What about NCI as a source for cancer information? Have you gone to them for information in the past? Do you think you would in the future?
4. What NCI information materials, educational resources, or services have you seen or heard of? [Probe: Where have you come across them? What did you think of them?]
 - [IF INTERNET IS MENTIONED, ASK:] Have you visited cancer.gov?

B. *Reactions to NCI Resources.* Next, I would like to show you several resources that NCI offers and get your feedback. (This array may include a brochure or booklet, examples of www.cancer.gov Web pages, and a poster or a postcard.)

[READ NAME AND PREPARED SHORT DESCRIPTION OF EACH RESOURCE OUT LOUD. DISTRIBUTE COPIES TO PARTICIPANTS.]

Please take a few minutes to look over these examples of the information materials, educational resources, and services offered by NCI; then we will discuss them overall.

1. What's your general reaction to these resources?
2. What do you think about how they look?
3. Based on your quick review, what do you think of the information provided within these resources?
4. What suggestions do you have for NCI regarding these resources? [Probe: Recommended changes? Anything confusing? What's missing?]
5. Who do you think these NCI resources are meant for? [Probe: Who are the intended audiences? How relevant are they to you and the people you know?]
6. What are some ways that NCI could get the word out and get these resources into the hands of those that need them? [Probe: channels, intermediaries]

V. CONCLUSION (5 minutes)

- Is there anything else you would like to add to this discussion before we conclude?
- Do you have any questions for me?
- Here is some information from NCI for you take home with you today. Please take one or more copies. [DISTRIBUTE PRINT MATERIAL(S) TO PARTICIPANTS].
- We very much appreciate you taking the time to be a part of this discussion, and especially for sharing your experiences, insights, and feedback. NCI will certainly make use of the valuable information that you provided today.