

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

### Attachment C: Moderator's Guide

#### **Participants with Cancer Experience**

Public reporting burden for this collection of information is estimated to vary from 2 to 2.5 hours per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. **An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number.** Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to: NIH, Project Clearance Branch, 6705 Rockledge Drive, MSC 7974, Bethesda, MD 20892-7974, ATTN: PRA (0925-0046-16). Do not return the completed form to this address.

#### 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 about 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 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 (35 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 experience with cancer. 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 has personally been touched by cancer (themselves or through a immediate family member or close friend).

### **A. *Types of Cancer***

1. Please briefly describe your experience with cancer. [*IF NECESSARY* Probe: Who had cancer? What type of cancer was it? What is the current status?]
2. Were you or the family member/friend who had cancer, covered by any type of health insurance at the time? Describe the type/level of coverage.

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

Please tell us how you came to not have health insurance now. 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 also interested to hear how not having insurance coverage affects your decisions and experiences related to you and your family's overall 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 multiple 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. We have 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 you have not been able to overcome? [Probe: Sacrifices to health, sacrifices in other areas?]
  - How would having health insurance address these issues?
4. How does where you live [in an urban/suburban/rural area] affect how, when, and where you get healthcare?

### **C. 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. Let's go around the table.

We are interested to hear how having insurance coverage affects your decisions and experiences related to you and your family's overall access and use of health care services.

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. 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?
  
4. How does where you live [in an urban/suburban/rural area] affect how, when, and where you receive health care services?

### **III. PERSONAL EXPERIENCE WITH CANCER (55 minutes)**

As we talked about earlier, all of you have had experience with cancer in your life. I want to hear more in-depth about your personal experience with cancer. I understand this may be a topic that brings up emotions and might be difficult to talk about. Please share only what you feel comfortable discussing with the group.

Some of you have had cancer yourselves, while others have had family members or close friends who have had cancer. In the following discussion, please talk about cancer diagnosis and treatment from your perspective as a patient, caregiver, family member, or friend.

**A. Cancer Diagnosis (20 minutes)**

1. How did you find out that you/family member/friend had cancer?  
[Probe: occurrence of symptoms, role of screening tests, scans, biopsy, and aspects of diagnosis]
2. How early was the cancer detected or diagnosed? [Probe: Stage at diagnosis and impact on disease stage, treatment plan, prognosis, and survival/death]
3. How was the process of diagnosing the cancer affected by your health insurance status?
  - How do you think your insurance status and/or employment situation influenced your access to needed information during cancer diagnosis?
  - [IN INSURED GROUPS, ASK:] What information about cancer screening or diagnosis have you gotten from your insurance plan? In what context? How useful was it?
  - [IN WORKING GROUPS: ASK:] What about from your employer?
4. How does where you lived [in an urban/suburban/rural area] affect when, where, and how you/they were diagnosed with cancer? [Probe: Effect on access to screening and information]
5. What other factors influenced your/their cancer care? [Probe: geographic location, source of care/provider issues, other facilitators/barriers]

6. When you or your loved one was diagnosed with cancer, what did you feel like you needed to learn more about?
  - What are some examples of information that a patient would want to know when they are being diagnosed with cancer?
  - What types of information does a patient's family members and friends want to have during this process?
  
7. Tell me a little about how you and your family and friends went about gathering the information that you needed, during the diagnosis stage. [Probe: What information did you look for? What resources did you use? Where did you look? Who did 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 was most helpful resource for information for you and your family members/caregivers/friends during this process? [Probe: Which materials/resources, media/channels/sources, people/ intermediaries, and/or organizations? Who should be providing this information?]
  - What kinds of formats, materials, resources, and services did you find to be the most useful during the cancer diagnosis process? (e.g., print materials, Web site, e-newsletters, hotlines, videos, podcasts)
  - How do you think people being diagnosed with cancer and their loved ones should receive information and education resources? [Probe: Through which dissemination channels? (e.g., doctors/nurses, support/ advocacy groups, TV/radio programs, online, community organizations)]
  - [IF INTERNET IS MENTIONED, ASK:] How did you find information on cancer online? [Probe: Use of search tools and terms? Which sites?]

**C. Cancer Treatment (25 minutes)**

1. Tell me about your experience with cancer treatment, when you or your family member or friend was battling cancer. [IF NECESSARY Probe: What was the course of treatment? How long/often was it? What was the outcome?]
  
2. How did you manage to get the needed treatment? Where did you go?
  - How easy or hard was it for was to find a cancer treatment provider? [Probe: Facilitators (e.g., information sources, referrals), What made it difficult? How did you overcome challenges?]
  - How does where you live affect your/their choice of where to go for cancer treatment? [Probe: Effect on access to information]

- How convenient was the place where you/ they went for cancer treatment? [Probe: Barriers – geographic location or distance from home, transportation, treatment schedule/hours]
3. How was your or your close friend or family members' treatment plan affected by your/their insurance status or the type of health or medical coverage used?
- How was the process of identifying and selecting a cancer treatment provider affected by you/their not having health insurance or their type of health insurance coverage?
  - How do you think your insurance status and/or employment situation impacted your access to needed information regarding cancer treatment?
  - [IN INSURED GROUPS, ASK:] What information about cancer treatment have you gotten from your insurance plan? How useful was it?
  - [IN WORKING GROUPS: ASK:] What about from your employer?
4. What other issues did you and your loved ones face over the course of the cancer treatment? [Probe: family life, provider issues, other facilitators and barriers] How did you address these issues?
5. When you or your loved one was receiving treatment for cancer, what did you want to know more about?
- What are some topics that a cancer patient needs more information on?
  - What kinds of information do a patient's family members and friends need to have over the course of cancer treatment?
6. Please describe how you, your family, and friends got the information that you and they wanted and needed, during the process of receiving cancer treatment. [Probe: What information did you look for? What resources did you use? Where did you look? Who did 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 was most helpful resource for information for you and your family members/caregivers/friends during cancer treatment? [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 did you find to be the most useful during the course of cancer treatment? (e.g., print materials, Web site, e-newsletters, hotlines, videos, podcasts)

- How do you think people being treated for cancer and their loved ones should receive information and education resources? [Probe: Through which dissemination channels? (e.g., doctors/nurses, support/ advocacy groups, TV/radio programs, online, community organizations)]
  - [IF INTERNET IS MENTIONED, ASK:] How did you find information on cancer treatment online? [Probe: Use of search tools and terms? Which sites did you frequent?]
7. How familiar are you with clinical trials research studies for cancer treatment? What have you heard about them?
- Where did/would you get information about these trials? From whom?
  - What else would you like to know about clinical trials?

**D. Cancer Prevention and Screening (10 minutes)**

1. What are some things that affect a person's chances of getting cancer? [Probe: individual behavior/lifestyle, medical care, other]
2. What actions have you taken or encouraged others to take in order to prevent cancer? [Probe: Before/during/after your personal experience with cancer?]
3. What things do you/family members/friends do to lower the chances of the cancer you/they have had coming back or of developing a different kind of cancer? [Probe: check-ups, screening, behavior/lifestyle changes]
4. Let's briefly talk about cancer screening. Tell me a little bit about what you know about cancer screening tests. (Examples, recommendations, impressions)
  - How did you learn this information? [Probe: Where? From whom? IN INSURED GROUPS: Have you gotten information from your insurance company? IN WORKING GROUPS: What about your employer?]
  - What aspects of screening tests do you want more information on?
5. What cancer prevention information do you look for? Where do you go?
  - What 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?]
  - Is there any information that you would like to have about cancer prevention that you have had difficulty finding? What is it?



6. What kinds of information do cancer survivors and their loved ones need after successful treatment? (e.g., related to preventing reoccurrence, check-ups, etc.) [Probe: In what format(s)? Who should provide this information? Through which dissemination channels?]

#### 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 (before/during/after cancer episode)? Would you?
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](http://cancer.gov)?

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

[READ NAME AND 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.